A Phenomenological Inquiry into an Autistic Adolescent's Experience in Relationship-based Music Therapy from the Perspectives of the Adolescent and Parent

Diana N. Abourafeh
dabourafeh@gmail.com

Follow this and additional works at: https://digitalcommons.molloy.edu/etd

Part of the Music Therapy Commons

This Thesis has All Rights Reserved. DigitalCommons@Molloy Feedback

Recommended Citation
https://digitalcommons.molloy.edu/etd/73

This Thesis is brought to you for free and open access by DigitalCommons@Molloy. It has been accepted for inclusion in Theses & Dissertations by an authorized administrator of DigitalCommons@Molloy. For more information, please contact tochter@molloy.edu,thasin@molloy.edu.
A PHENOMENOLOGICAL INQUIRY INTO AN AUTISTIC ADOLESCENT’S
EXPERIENCE IN RELATIONSHIP-BASED MUSIC THERAPY FROM THE
PERSPECTIVES OF THE ADOLESCENT AND PARENT

A THESIS

Submitted in partial fulfillment of the requirements
For the degree of Master of Science
In Music Therapy

by

Diana N. Abourafeh, MT-BC
Molloy College
Rockville Centre, NY
2018
MOLLOY COLLEGE

A Phenomenological Inquiry into an Autistic Adolescent’s Experience in Relationship-Based Music Therapy from the Perspectives of the Adolescent and Parent

by

Diana N. Abourafeh, MT-BC

A Master’s Thesis Submitted to the Faculty of Molloy College

In Partial Fulfillment of the Requirements For the Degree of Master of Science

August 2018

Thesis Committee:

Dr. Heather Wagner
Faculty Advisor

Dr. Suzanne Sorel
Committee Member

Dr. Suzanne Sorel
Director of Graduate Music Therapy

5/14/18
Date

5-15-18
Date

5-15-18
Date
ABSTRACT

This study explored the essence of relationship-based music therapy through the lens of an autistic adolescent and their parent. Though previous research examines this phenomenon through a parent’s perspective (Corcoran et al., 2015; Thompson & McFerran, 2015; Sorel, 2010, 2004; Warren & Nugent, 2010), the present study supports the neurodiversity paradigm shift through providing opportunities for an autistic participant to speak on his experience. The data sources included two interviews, adolescent and parent, as well as indexes of the music therapy session. A thematic analysis was conducted through collecting and analyzing all data sets. Themes were developed and musical descriptions were used to construct meaning and comprehensively explore the lived experience of the autistic individual in relationship-based music therapy. Themes were constructed for the adolescent, the parent, and then data was synthesized to create collective themes. The findings yielded themes for the adolescent: a) “I can be me!” b) a range of musical-emotional experiences, and c) significant relationships. Themes for the parent included: a) being himself, b) reciprocity and the relationship, and b) growth. The corroborated themes were a) freedom of self, relating to the themes, “I can be me!” and being himself; b) forging meaningful relationships; and c) pride. Relationship-based music therapy is supported by the findings through determining the significance of relationship-based strategies and philosophies to the autistic’s sense of self and experience.

Keywords: music therapy, neurodiversity, relationship-based music therapy, reciprocity, therapeutic relationship, phenomenology
ACKNOWLEDGMENTS

I’d like to express my deepest gratitude for all the people in my life who have made this research possible. Thank you to my thesis committee, Dr. Yasmine Iliya, Dr. Noah Potvin, Dr. Suzanne Sorel, and Dr. Heather Wagner for all of your support and guidance throughout this process. Yasmine, “shukran” for always being available and for your constant words of encouragement. I always felt at ease through this process because of you. Noah, you went above and beyond as an editor. Thank you for helping me to think more deeply about the work. Suzy, you helped me make connections that I did not make myself. I am grateful for your guidance. Heather, for helping me through this process at all hours of the day and reminding me to “breathe”, I thank you.

To the professors at Molloy College that constantly reminded me why I love this field, especially Evelyn Selesky and Dr. Seung-A Kim. Evelyn, you were a constant light that showed nothing but kindness to everyone you met. You were the first person I met at Molloy, and the reason I chose to be a part of the Molloy family. Thank you. Seung-A, you have been my academic advisor for 7 years. I cannot put into words how appreciative I am for you. Thank you for helping me grow.

Thank you to the Rebecca Center staff, Dr. John Carpenter, Jill Mulholland, Michael Muñoz, Stephanie Cestaro, and Dr. Audra Cerruto. You all inspire me to become the best music therapist and person I can be. I am lucky to be able to call my colleagues my work family.

To that end, family can be more than blood. To my forever friends, Liesel Gutierrez, Melissa Sandoval, and Jessica Knox. Your friendships have seen me through my best and worst days, and for that, I am forever grateful. To Inbar Kaplan, my friend. You have been invaluable to me. To Terry, Nicky, Kaity, Anthony, and Seamus, thank you for letting me in with open arms and sharing your love with me.

To my mother. Thank you for always believing in me, for your words of encouragement and for being resilient. I am privileged to have you as a mother, and honored to call you a friend.

Michael. It’s hard to find the words to describe how thankful and how lucky I feel. You motivate me and inspire me each and every day. Thank you for your unconditional love and the endless laughter.

Lastly, thank you to Charlie and Tim for sharing your experience and your love of music.
TABLE OF CONTENTS

ABSTRACT ................................................................................................................... iii
ACKNOWLEDGMENTS ................................................................................................. iv
TABLE OF CONTENTS ................................................................................................. v
LIST OF TABLES .......................................................................................................... vi
LIST OF FIGURES ....................................................................................................... vii
“WE ARE THE REAL VOICES” .................................................................................. 1
REVIEW OF THE LITERATURE ................................................................................ 8
  Music Therapy and ASD ......................................................................................... 8
  Relationship-based therapy .................................................................................... 10
  Lived Experiences ................................................................................................ 14
METHOD ..................................................................................................................... 19
RESULTS ..................................................................................................................... 26
  Charlie’s Lived Experience .................................................................................... 28
  Charlie’s Lived Experience – Parent Perspective ................................................... 35
  Essence of Music Therapy – Both perspectives ...................................................... 39
DISCUSSION ................................................................................................................ 42
  Limitations ............................................................................................................. 46
  Implications for Music Therapy Practice ............................................................. 47
  Recommendations for Future Research ............................................................... 47
CONCLUSION ............................................................................................................. 49
REFERENCES ............................................................................................................. 50
APPENDICES ............................................................................................................. 57
  Appendix A: IRB APPROVAL LETTER ................................................................. 57
  Appendix B: IRB APPROVAL LETTER, AMENDMENT ..................................... 58
  Appendix C: INVITATIONAL LETTER ................................................................. 59
  Appendix D: LETTER OF INFORMED CONSENT ............................................. 60
  Appendix E: ASSENT FORM ................................................................................. 62
  Appendix F: PERMISSION TO VIDEO RECORD ............................................... 63
  Appendix G: INTERVIEW QUESTIONS ............................................................... 64
  Appendix H: A LETTER OF PERMISSION FORM ............................................... 65
LIST OF TABLES

Table 1. Essence of the music therapy experience ................................................................. 39
LIST OF FIGURES

Figure 1. Autistic adolescent themes ................................................................. 28
Figure 2. Here we are in music improvisation ............................................... 30
Figure 3. Play a-long song improvisation ..................................................... 32
Figure 4. Who’s got a joke improvisation ...................................................... 33
Figure 5. Parent themes .............................................................................. 35
“We are the real voices”

Neurodiversity frames various neurological conditions as natural variations in the human genome (Aigen 2015; Jaarsma & Welin, 2012; Singer, 2016; Walker, 2012). The neurodiversity perspective describes the neurology and personhood of autistic people as human diversity, similar to diversities like ethnicity, nationality, gender, and socio-economic status (Robertson, 2009). The paradigm shift and movement emerged in the 1990s when autistic self-advocates recognized their needs were not being met and that they needed to have a say in the policies that directly affected them (Jaarsma & Welin, 2012; Singer, 2016). They declare, “we are the real voices” (Singer, 2016, p. 778). The lived experienced of autistic individuals has assumed greater importance as the neurodiversity movement has established a firmer foothold in the American cultural zeitgeist. To that end, this study sought to provide an autistic adolescent the opportunity to share his voice about his experience in music therapy, providing opportunity for the individual to express and actualize his autonomy. This study also provided opportunity for the autistic’s father to share his thoughts on his child’s experience to provide further exploration of the essence of the music therapy experience as well as to distinguish individualized themes between father and son.

Advocacy efforts towards neurodiversity preach autism acceptance as opposed to autism awareness. Awareness tends to have a deficit-focused view on autism while autism acceptance reflects a neurodiversity perspective and identifying the autistic as a person of abilities (Robertson, 2009). Josephine DeMarco (2018), an autistic young woman stated at a RED Talk, Respect Empathy Diversity: “Autistic thinking is the closest thing to magic there is…While autism may be noted as a developmental disability, there are far more abilities that these individuals have to offer.” Although acceptance is advocated for, advocates are aware that
autistics have certain challenges and weaknesses (Robertson, 2009). In fact, autistic self-advocates identify themselves as having “a blend of cognitive strengths and weaknesses in core domain areas: language, communication and social interaction, sensory processing and self-regulation, motor skill execution, goal-oriented and reflexive thinking, and planning” (Robertson, 2009, para. 5). Prior to autistic self-advocacy, standard care for neurologic conditions consisted of advocating for a cure. The emergence of the neurodiversity movement created a shift in conceptualization that encouraged healthcare professionals and educators to try to find ways to support and accommodate the needs of the autistics without vilifying the unique qualities of their neurological functioning (Jaarsma & Welin, 2012). The movement values individual differences and challenges the common conceptualization and stigmatization of disability (Jaarsma & Welin, 2012; Singer, 2016).

To that end, the term, “autistic” instead of “individual with autism” will be used throughout this study. Jim Sinclair (2012a), an autistic self-advocate, stated, “Autism is not an appendage. Autism is a way of being. It colors every experience, every sensation, perception, thought, emotion, and encounter, and every aspect of existence” (p. 16). Autism is accepted as a person’s identity because their entire experience of and relationship to the world is because of filtered through their neurological lens (Jaarsma & Welin, 2012; Sinclair, 2012a).

To autistic self-advocates, identifying as autistic is empowering. While this is the stance supported by the neurodiversity movement, it is significant to acknowledge that person-first language, or saying a person with autism, is still utilized and widely accepted amongst medical professionals, schools, and parents (Ratts & Pederson, 2014). Person-first language suggests that the person is separate from autism and that there is more to the person than just the diagnosis (Sinclair, 2012b). Aigen (2015) suggested that for years, parents have been taken advantage of
and told that their child can be cured so that the child can emerge and that their true self can be accessed through rigorous medical and behavioral services. The idea that their child can be normalized is attractive to parents as they often feel a sense of loss and grief upon knowing that their child is autistic (Fernández-Alcántara, 2016; Silberman, 2015; Sinclair, 2012a).

Although a feeling of grief over the loss of a typically developing child is experienced, Sinclair stated (2012a), “Grieve if you must, for your own lost dreams. But don’t mourn us. We are alive. We are real. And we’re here waiting for you…autism is not an impenetrable wall” (p. 17). Sinclair’s (2012a) words express that although it is challenging for autistics to engage in social experiences, this does not mean the child is incapable of relating at all. Caregivers and service providers can offer opportunities for growth by accommodating autistic needs and working with the individuals’ strengths so that they can simultaneously build bridges for communication.

**Professional Context of the Researcher**

The current neurodiversity paradigm led me, as a new clinician, into a state of self-reflection. My clinical work and underlying philosophies are heavily influenced by principles within the Nordoff-Robbins Music Therapy (NRMT) approach, DIRFloortime® (DIR), and existential and person-centered philosophies. Neurodiversity challenged my own values and beliefs. Person-first language was always instilled into my belief system because I learned in my early studies that this was respectful and socially acceptable. However, the neurodiversity paradigm shift altered what I considered to be respectful.

Since 2015, I have re-conceptualized one theory of NRMT: the music child, defined as “the individualized musicality inborn in every child” (Nordoff & Robbins, 2007, p. 3). The music child is the “entity in every child which responds to musical experience, finds it
meaningful and engaging, remembers music, and enjoys some form of musical expression, communication, and sharing” (Nordoff & Robbins, 2007, p. 3), creating a new self that bypasses pathology and develops apart and in addition to the old self (Bruscia, 1987).

From this new perspective, the music child still exists in that each individual has innate musicality that emerges in a therapeutic process. However, neurodiversity led me to reject the concept of the new self that bypasses pathology, instead embracing music therapy’s ability to access clients’ potentials. By abandoning the idea of bypassing pathology, there is a greater acceptance for neurodiversity and engaging in the creative process. As Nordoff and Robbins (2007) stated, music therapy provides opportunity for “purposeful connections [to] arise with the child that may become a harbinger to a process of therapeutic self-realization” (p. 3). Music therapy allows for self-realization and growth. Further, music therapy services provide opportunities for individuals to gain agency through a therapeutic relationship that values each person’s individual differences.

**Personal Context of the Researcher**

The neurodiversity movement not only resonated with my clinical work, but also with my personhood. From a social justice point of view, autistics may experience unfair treatment or exclusion due to engaging with the world in a way that may seem inappropriate for the social norms imposed on society today. In line with inclusion efforts, this study supports the neurodiversity movement and offers the option for autistics to speak to their experience.

My constructivist worldview helped to form this study. From this vantage point, truth is a subjective entity wherein individuals form their own meanings and truths, even towards the same objective phenomenon (Creswell & Creswell, 2017). Consequently, it is not only important to explore a parents’ perspective of their child in the context of music therapy, but just as essential
to know the child’s account of the same experience. This study sought to understand autistics’
lived experiences of a music therapy session from both the adolescents’ and parents’
perspectives.

**Need for Study**

My work with autistic clients as a board-certified music therapist at the Rebecca Center
for Music Therapy at Molloy College is informed by the ideals of DIRFloortime® (DIR). DIR
focuses on building healthy foundations for developmental, social, and emotional and capacities
in children (Greenspan & Weider, 2009). The model, DIR, is built on three concepts:
development, individual difference, and relationship. Development refers to six functional
emotional developmental stages:

1. Self-regulation and interest in the world
2. Engaging and relating
3. Purposeful two-way communication
4. Complex communication and problem-solving
5. Using symbols and creating emotional ideas
6. Logical thinking and building bridges between ideas

Individual difference refers to each individual’s unique biology and unique way of
experiencing the world based on personal differences in motor planning, auditory language
processing, visual/spatial processing, or sensory modulation (Greenspan & Weider, 2009).
Relationship describes the learning relationships with caregiver, educators, therapists and peers
who tailor their affect-based interactions to the individual’s differences and developmental
capacities (Greenspan & Weider, 2009). Floortime is the act of creating emotional and
meaningful interactions in order to support the individuals’ development (Greenspan & Weider,
Key features of DIR include interaction, following the child’s lead or interests, play, affect, capacities, abilities, respecting individual difference, and development (Casenhiser, 2015). Thus, in order to foster growth in various areas of development, social and emotional capacities, the therapist or caregiver must engage in interactive play within the context of relationship through following the child’s interest.

To that end, both neurodiversity and DIR, a relationship-based approach, support the idea that autistics are capable of interpersonal engaging and relating when their individual differences are understood and provided space for. Thus, it’s important to explore the phenomenon of an autistic’s experience in music therapy within this model that seeks to support individual differences as it may promote the research base for music therapy, DIRFloortime®, as well as for the neurodiversity movement by giving the autistic a voice. While there is considerable research examining the parents’ lived experience of their child with autism in the music therapy literature (Thompson & McFerran, 2015; Sorel, 2010, 2004; Warren & Nugent, 2010), absent from this body of work is the autistics’ articulated point of view. This research study will contribute to the research base that looks at the autistics’ lived experience, specifically the autistic adolescent. The adolescent population was examined considering the research is scant looking at this population (McFerran, 2010).

**Methodology and Research Questions**

This phenomenological study, informed by essential phenomenology, investigated the lived experiences of an autistic adolescent in a relationship-based music therapy session from the perspective of an autistic adolescent and their parent. An autistic adolescent who currently attends The Rebecca Center for Music Therapy at Molloy College and parent participated in the study. Both participants viewed an archived video of a music therapy session in which the
adolescent participates in, with the researcher, independent of one another. Data included individual interviews with the adolescent and parent and musical transcription, in an effort to investigate the experience of the music therapy session. A thematic analysis was conducted to make meaning of the data and the music served as supplemental data so as to comprehensively explore the lived experience of an autistic in music therapy. The following research questions were explored:

1. What is an autistic adolescent’s lived experience of relationship-based music therapy?

2. What is the parent’s perception on the autistic adolescent’s lived experience of relationship-based music therapy?

3. What is the essence of the lived experience of relationship-based music therapy from both perspectives?
Literature Review

This study explores the lived experience of a relationship-based music therapy session as experienced by an autistic adolescent and by his parent. Though there is an array of literature that examines parents’ lived experience of music therapy (Corcoran et al., 2015; Thompson & McFerran, 2015; Sorel, 2010, 2004; Warren & Nugent, 2010), research that collects data from autistic adolescents about their lived experience in music therapy is scant. This literature review will examine Autism Spectrum Disorder (ASD), music therapy with the autistic community, and lived experiences of autistics and their parents.

Music Therapy and ASD

Currently, 1 in 59 children across a range of ethnic, racial, or socioeconomic groups are diagnosed with autism in the US according to the Center for Disease Control and Prevention (Baio et al.). Music therapy is an evidence-based practice drawing from a diverse body of research, theory, and practice that has been extensively utilized for the autistic population. Four fundamental types of music experiences can be used in order to engage and promote client growth. These methods include improvisation, re-creation, composition, and receptive experiences (Bruscia, 2014). The methods used, clinical goals, and therapeutic processes are contingent on the music therapist’s working approach. Music therapy approaches include, but are not limited to, developmental (Schwartz, 2008), developmental individual difference, relationship-based approach (Carpente, 2012), interactive (Oldfield, 2006), creative music therapy (Nordoff & Robbins, 2007), family-centered (Thompson, 2012), applied behavioral analysis (Martin, 2012), improvisational (Kim, Wigram & Gold, 2008, 2009) and psychoanalytic (Lecourt, 1991). Each approach works towards different goals, but the essential common factor is working towards helping the autistic population reach their fullest potentials (Carpente &
LeGasse, 2015). Research shows that music therapy has been beneficial in addressing core features of autism, particularly the area of social communication (Carpente & LaGasse, 2015; Kim et al., 2009, 2008). Music therapy promotes engagement, communication, and relatedness, which are core deficits of autism (Geretsegger et al., 2015).

**Music therapy and autistic adolescents.** Music therapists have been describing their work with adolescents for more than five decades (McFerran, 2010). While the number continues to rise, there is significantly more research pertaining to autistic children than to autistic adolescents. In a systematic review drawing from the entirety of music therapy literature until 2008, 140 articles were determined to have a focus on adolescents (McFerran, 2010). Of those 140 articles, 31 of them targeted the disability population, which may have included autism (McFerran, 2010). McFerran (2010) discerns a lack of research in the neurotypical adolescent population and certainly in the autistic adolescent population. She inferred that the lack of research comes from the fact that although clinicians work with the autistic adolescent population, not all music therapists write about their clinical work. It is understood that the knowledge on adolescents is scant and is only compounded for autistic adolescents.

Qualitative studies, phenomenological inquiries specifically, provide clinicians, researchers, parents, and autistics with the opportunity to understand an adolescent’s experience of music therapy within a relationship-based model for him- or herself. Aigen (2008) conducted a comprehensive analysis of all of the qualitative research studies that were published in peer-reviewed music therapy and non-music therapy journals, peer-reviewed research monographs, and edited books between 1987 and 2006, ultimately finding 140 articles that fit criteria. Of these articles, 16 of them used phenomenology as a research method, while only three of them made note that it was an epistemological orientation. Aigen did not specify what populations these
articles examined or discussed. The research shows through a multitude of databases that there were no available published music therapy phenomenological inquiries that featured an autistic adolescent.

**Relationship-based therapy**

There are a variety of approaches used when working with autistics: behavioral, developmental, and naturalistic-behavioral. Behavioral approaches were once considered the gold standard of treatment modalities, yet this has been challenged due to significant limitations. Autistics’ gains in skills were not being generalized to new settings or maintained over time (Harris et al., 2015; Ingersoll et al., 2007; Schreibman & Koegel, 2005), and they lacked spontaneity, demonstrating an overdependence on prompts (Schreibman & Koegel, 2005; Schreibman et al., 2015). Autistic self-advocates consider behaviorally-based interventions not just limiting, but unethical (Aigen, 2015; Robertson, 2009; Singer 2012a). Self-advocates go so far as to argue that behavioral interventions, specifically Applied Behavioral Analysis (ABA), are a form of abuse to induce compliance (Aigen, 2015). Due to the limitations and the ethical considerations of behaviorally based treatments, more developmentally based and relationship-based strategies are being implemented. Developmental Social Pragmatic models focus on developing capacities towards social communication within the context of relationship, considering the individuals developmental level (Carpente, 2016; Casenhisier, 2013). DIRFloortime® is one such Developmental Social Pragmatic model.

Qualitative and quantitative evidence supports the use of developmental, relationship-based models of therapy. Two developmentally-based quantitative studies, Solomon et al. (2014) and Gutstein et al. (2007), supported the use of developmental and relationship-based strategies such as use of affect, scaffolding, co-regulation, and play. This was evidenced by results that
indicated improvements in children’s autism severity based on the Autism Diagnostic Observation Schedule, which is considered the gold standard assessment tool for autism diagnosis (Gutstein et al., 2007; Solomon et al., 2014). Autism severity in the area of social interaction showed a significant trend, indicating significant improvement of social interaction (Gutstein et al., 2007). Similarly, Casenhiser et al. (2013) utilized parent-mediated treatment informed by DIR, also resulting in improvements in social interaction.

A significant component of DIRFloortime® is respecting individual differences. To that end, certain individual differences can manifest in the autistic’s sensory system, which results in a state of dysregulation. Greenspan and Weider (2009) indicated that the sensory system helps an individual feel balanced and safe, allowing others to get close and allowing the self to protect themselves when they don’t feel safe. However, when an individual experiences regulatory issues, they have difficulty navigating their environment, thus leading to anxiety (Greenspan and Weider, 2009). This may result in withdrawal and being self-directed, leading to distancing from relationships (Durrani, 2014; Emery, 2004). Thus, the autistic child’s capacity to connect to others is challenged when they themselves are challenged by not being able to process their environment. Research shows that co-regulation, or adult use of his or her own arousal level to counterbalance that of the child’s is significant as an intervention strategy (Casenhiser et al., 2013). Research suggests there is an association between co-regulation and improvements in key social interaction skills or in engagement (Carpente, 2016; Casenhiser et al., 2013).

Individuals experiencing challenges in musical-play or engaging in relationship may be experiencing regulatory issues unrelated to music or to the interaction (Carpente, 2016). Therefore, in order to promote relationship and socialization with an autistic individual, it is
important to understand their individual differences and work with these differences within the context of relationship.

**Relationship-based music therapy.** Relationship-based music therapy provides opportunities for clients to grow while respecting individual differences and valuing the therapeutic relationship, and incorporate philosophies from Carl Rogers, Irvin Yalom, and Abraham Maslow (Bruscia, 1987; Corey, 2013; Yalom, 2005). Growth and self-expression will occur through the therapeutic relationship, with a therapist that is authentic, nonjudgmental, and warm (Corey, 2013). Similar to Rogers and Yalom, relationships are significant to the therapeutic process, specifically, the musical relationship. Improvisational music therapy is used in order to promote here-and-now reciprocal experiences (Bruscia, 1987).

Gattino et al. (2011) carried out a randomized controlled trial that utilized relational music therapy (RMT), a non-directive approach in which the therapist improvises an experience based on the client’s lead and helps develop their capacities through interaction in the therapeutic setting. RMT resulted in improvements in nonverbal communication (Gattino, et al., 2011), similar to improvisational music therapy with a DIRFloortime® informed approach that showed improvements in social communication (Carpente, 2016).

Family-centered music therapy involving autistic children and their families promoted changes to the parent-child relationship, the parents’ perception of the child, and in the parent’s response to the child (Thompson & McFerran, 2015). A program that utilizes relationship-based interventions yielded similar results (Warren & Nugent, 2010). The Music Connections Programme, developed in New Zealand helps parents become more responsive to their child through being an active member in music making. Understanding their child’s individual differences while understanding their child’s strengths helped parents view their child in a more
positive manner and more clearly perceive their child’s potentials (Thompson & McFerran, 2015; Warren & Nugent, 2010). Parents reported that being provided with opportunities to understand their child’s needs helped them understand how to best interact with them, thus, bridging the gap between parent and child, promoting bonding, and building the relationship (Thompson & McFerran, 2015; Warren & Nugent, 2010; Sorel, 2004, 2010). In addition, parents indicated that they began to interact with their children differently when provided with more opportunities for social interaction. Parent’s perceived their child as being more flexible and adaptive, improving in a variety of areas, and transferring the skills they learned in therapy to other settings, like home (Gutstein, 2007; Warren & Nugent, 2010). Thus, relationship-based music therapy not only provided autistics with opportunities to grow and communicate more expressively, but also allowed for parents to comprehend their child’s unique differences and connect more fully.

Sorel (2004, 2010) explored the parent-child relationship in family-based music therapy sessions. Meaning was constructed through a variety of data sources, including interview transcriptions from the mother, therapists’ session notes and reports, and analysis of videotaped sessions. Relating quotations from the interviews to indexes of the sessions allowed for the researcher to compare and contrast data sets and provided opportunities for a more comprehensive understanding of the family therapy. The musical analysis provided context for how the music was being used in the process and how it related to the findings of the study. Through naturalistic inquiry, Sorel (2010) explored how treating a child in the context of his or her family is significant to the success of that child and how music, “was relational, experiential, about being together in that moment” (p. 218).
Lived Experiences

The focus of phenomenological research is to understand the lived experience of the human experience (Hiller, 2016; Jackson, 2016). The lived experience is how individuals experience and make meaning of phenomena (Jackson, 2016). Meaning is constructed through data collection and analysis that often is composed of accounts of the phenomenon from the individuals who have experienced it (Jackson, 2016). The essence of the experience can be identified in a way that describes the quality and significance of the experience in a deep manner (Hiller, 2016).

Parent’s lived experience of having an autistic child. Research has shown that parents express negativity about their own experiences of having an autistic child (Woodgate et al., 2008; Hoogsteen & Woodgate, 2013). In a hermeneutic phenomenological exploration of the experiences of parents of autistic children, Woodgate et al. (2008) discovered themes of vigilant parenting or super-parenting, protecting their own sense of self and family, and fighting all the way. These themes suggest that parents of autistic children do not feel supported. In a similar phenomenological inquiry with parents of autistic children, Hoogsteen and Woodgate (2013) identified three themes: parents take on multiple roles, a majority of their energy is focused on their child’s needs, and parents seek balance. The essence of “making the invisibility of autism, visible” emerged as a clear indication that autism is not often supported in their communities and not all of their needs are being met (p. 136).

A meta-synthesis of 14 studies was conducted in effort to understand the qualitative research surrounding the lived experience of parents of autistic children in the United States (Corcoran et al., 2015). To be included in the meta-synthesis, studies had to employ qualitative methods, focus on the lived experience of parents, include participants that were parents of
children with ASD, and be conducted in the United States. Six main themes were identified as a result of the study: emotional stress and strain, adaptation, impact on the family, services, stigmatization, and appreciating the little things. Although struggles were evident in parents’ lived experiences, strengths, family resiliency, and adaptation were also significant components of the findings. These studies are relevant in showing that parents often do not feel supported and thus, services that work within a therapeutic relationship and promote use of client strengths are significant to not only the client’s process, but to the parent’s process as well.

Cascio (2012) explored the influence of the neurodiversity movement on parents of autistic children. A cross-sectional multi-method ethnographic approach was utilized, in which the researcher gathered data through participant observation in various support groups and conducted qualitative interviews. This data was then contextualized with supplementary data. The field observations suggested that parents navigate a variety of approaches, often picking and choosing various strategies that have been positioned as incompatible. Although parents seemed to use treatments that oppose neurodiverse concepts, several themes emerged during interviews that indicated that neurodiverse concepts influenced them in their process. Themes included accepting their child’s behaviors as cognitive variations as opposed to disorders, expressing positive ideas about autism, and resisting negative ideas about autism.

**Perception of the autistic experience.** While an extensive amount of research speaks to the parents’ experiences of having a child with autism or their perceptions of their autistic child, emerging research focuses on autistic perception of the self and their own experiences. Bauminger et al. (2004) examined the perception of friendships among 32 autistic children and teenagers, aged 8-17. The Friendship Picture Recognition Interview, Friendship Qualities Scale, and the Loneliness Rating Scale were conducted in effort to evaluate children’s perception of
friendship, perception of the self, and experience of loneliness. Autistics who identified as having a best friend scored lower in the areas of companionship, security, and help, experienced a higher sense of loneliness, and scored lower on the social acceptance and athletic competence scales. Significant findings demonstrated that perception of one’s scholastic competence positively correlated with a friendship characterized by companionship, helping, and closeness.

There seem to be differing perceptions of autistics experiences in research that includes a parent perspective and a child’s perspective. A quantitative examination of 42 children, adolescents, and their parents was conducted in effort to identify how autistics perceived their autism-related traits and behaviors compared to their parent (Johnson et al., 2009). Johnson et al.’s (2009) analysis indicated that there were significant discrepancies between parent perception and self-perception in the Autism Spectrum Quotient and Empathy Quotient questionnaires as autistics scored themselves higher in their capacities than their parents. Bauminger & Kasari (2000) similarly offered questionnaires to autistics, typically developing children, and parents using a loneliness rating scale and friendship scales. In contrast to Johnson and colleagues’ (2009) findings, however, parents rated their children higher than the autistics rated themselves in regard to loneliness. Results suggested that autistic children feel lonely and want to be involved in social relationships, but that the qualities of their friendships were reported to be poorer.

Exploring both the parent perspective and adolescents perspective of an autistic adolescent in music therapy may be significant to the field of music therapy and to the autistic community itself because it lends further insight into, not only the parent’s perception that is so often looked at, but at the adolescent’s perception. More so, it gives voice to adolescents, which supports the neurodiversity stance towards self-advocacy and agency.
Experiences of autistic individuals in music therapy. A quantitative study examined a pilot music therapy group program and collected data based on self-reports of adolescents and adults on the autism spectrum (Hilliard et al., 2011). The data indicated that these individuals reported a significantly higher level of self-esteem, a significantly lower level of anxiety, and a significantly improved attitude towards peers. Of note, Hilliard and colleagues provided opportunity for autistics to speak to their own experience through a quantitative method.

Hibben’s (1999) text provides readers with a collection of 33 narratives of experiences of music therapy. A variety of clinicians and researchers collected data of experiences of music therapy from a variety of perspectives. Music therapists invited their clients to describe their experience or write about being a client in music therapy themselves. The narratives sought out to provide insights into client experiences in music therapy through client depictions, therapist descriptions, or parent descriptions. Music therapists shared clinical experience and the dynamics of the therapeutic relationship to interpret how a client is interpreting music therapy. For clients who cannot necessarily describe the music therapy process themselves, this kind of research and data collection is significant to understanding the qualitative experience of a music therapy session. This is especially so when the therapist utilizes both his or her expertise as well as the expertise of an active parent or guardian. Although therapist interpretation and parent interpretation of a music therapy experience exists, there was no research found that explores the lived experience of an autistic adolescent in music therapy from their point of view. For those who can speak to their experience, allowing them opportunity to share their voice is significant.

Summary and Rationale for the Study

Research as inferred from the above-mentioned studies indicates the benefits of relationship-based music therapy in further developing skills, building upon strengths,
fostering growth in areas of difficulty. A relationship-based approach to music therapy utilizes individuals’ strengths to order to provide opportunities for growth in areas of need, which seems to align with the neurodiversity paradigm. Parents value relationship-based music therapy, primarily in regards to improving social relationships and strengthening bonds. While music therapists and parents have expressed their experiences and feelings towards music therapy, there is no published research, to the researcher’s knowledge, that explores an adolescent’s experience in music therapy from their point of view. Therefore, this phenomenological study sought to expand the body of literature and provide opportunity for both a parent and adolescent to share their experience of music therapy, drawing upon interviews and the music, similar to Sorel (2004, 2010), to construct meaning.
Method

This study explored an autistic adolescent’s lived experience of relationship-based music therapy through the lens of the autistic adolescent participant and the parent participant. A phenomenological research method was implemented, informed by essential phenomenology, in which individual interviews were conducted and meaning was constructed from the data sets.

Participants

This study included two participants: an autistic individual as defined by the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM–5*; American Psychiatric Association, 2013) and his parent. Inclusion criteria for the ASD individual included, (a) diagnosis of ASD, (b) between 10 and 25-years-old, (c) verbal, and (d) Autism Diagnostic Schedule module 3 or 4 which identifies the autistic as having a verbal fluency and expressivity language of at least a typically developing four-year-old. Inclusion criteria for the parent of the ASD person included, (a) parent of child diagnosed with ASD and (b) English-speaking. Participants were recruited through purposive sampling at The Rebecca Center for Music Therapy at Molloy College. Upon receiving approval from the Molloy College Institutional Review Board (IRB) (Appendices A and B), the recruitment process began. The researcher examined the demographics of the Rebecca Center’s clinical caseload and identified the clients that fit criteria. An invitational letter (Appendix C) was hand-delivered to potential participants and included information regarding the purpose of the research. Potential participants were given one week (7 days) to contact the researcher about interest in the study. Participants were selected based on who best met inclusion criteria, response rate, and availability.

The informed consent form, assent form, and permission to video record form (Appendices D, E, and F) were hand-delivered and personally read to the participants. The
informed consent form included information about the purpose of the study, as well as information about confidentiality and securing the data. Verbal assent was obtained from the adolescent participant and signature was acquired. An additional consent form for permission to view and video record both the music therapy session and interviews were obtained.

Data Collection

The study took place at The Rebecca Center for Music Therapy at Molloy College (TRC) located in Rockville Centre, NY. The autistic adolescent’s music therapist provided the researcher with one archived video of a 60-minute music therapy session after consent was obtained. The adolescent and the parent were each interviewed, individually. Data collection took place in these two 30-60 minute in-person interviews in which the participants watched the archived video and were asked open-ended questions (Appendix G). The interview location took place in a private room at TRC, where confidentiality was maintained. The interviews were video recorded and transcribed. The music therapy session was transcribed using the method of indexing (Nordoff & Robbins, 2007). When the participants referred to specific musical moments, such moments were used as supplemental data for the study to depict the music therapy scenario. Following data analysis, participants partook in a 15-30 minute follow-up meeting for the purposes of member checking. All video files and transcriptions were kept on a personal double password protected computer.

Procedures and Protocols

The clinical protocol follows Carpentee’s (2013) procedural phases, which are informed by DIR and NRMT. The music therapist greeted the participants in the waiting area and invited the autistic into a session room. The session room was set up to include the following instruments and any additional instruments: piano, guitar, floor tom, snare drum, tubano, cymbal,
xylimba, metallophone, buffalo drum, tambourine, and two horns. The phases with the corresponding procedure included:

1. Following the client’s musical emotional lead: The therapist observed, listened and created musical experiences based on the client’s reactions responses, and initiated behaviors. The music was responsive to client’s affect.

2. Two-way purposeful music making: The therapist improvised and initiated her own music that expressed a musical question or statement that sought client musical/verbal response.

3. Affect Synchrony in Musical Play: The therapist created musical experiences with a range of musical elements and contexts providing opportunities for the client to initiate, respond, and engage in a continuous flow of affective musical interactions.

Bruscia’s (1987) clinical improvisation techniques were implemented to facilitate the music therapy session. Music therapy provided opportunities for the participant to engage in active music making in a continuous flow of interactions.

After consent was obtained, the researcher interviewed the autistic participant. The interview consisted of watching the archived music therapy session together and asking open-ended questions. In the interest of time, only a portion of the music therapy video was shown.

After interviewing the autistic, the researcher interviewed the parent. The interviews lasted 30-60 minutes per participant and was video recorded in order to account for affective responses to questions. The following prompt was provided for the interview with the autistic participant:

*What is your experience of music therapy?* The following prompt was provided for the interview with the parent: *What do you think is Charlie’s experience in a music therapy session?*
Data Analysis

A phenomenological research method, informed by essential phenomenology was employed in order to explore the lived experience of an autistic adolescent in music therapy from the adolescent’s perspective and the parent’s perspective. Phenomenological inquiry seeks to explore the nature of a phenomenon and understand the essence of a person’s experience (Creswell & Creswell, 2017; Jackson, 2016; Moustakas, 1994). Essential phenomenology, specifically, constructs meaning through identifying patterns that are the same within individual experiences (Jackson, 2016).

The music therapy session was indexed with both musical and verbal interactions between the music therapist and participant. The interviews were then analyzed through a process of inductive thematic analysis (Braun & Clarke, 2006). This analysis consist of six phases:

1. Become familiar with the data
2. Generate initial codes
3. Search for themes
4. Review themes
5. Define and name themes
6. Produce the report

In phase one, the researcher became familiar with the data by first transcribing the interviews (Braun and Clarke, 2006). Considering the nature of the video interviews, the researcher included any facial or affective expressions. In phase two, initial codes were created based on what the researcher deems significant or interesting about the data (Braun & Clarke, 2006; Jackson, 2016). These codes were words or short phrases that changed as the analysis
continued. In stage three, the researcher searched for themes by sorting relevant codes into potential themes or patterns. Groupings were examined in a process of horizontalization in which the data was examined with all pieces given equal importance (Moustakas, 1994). The true nature of the phenomenon became clearer and essential structures of phenomenon began to be recognized through this process of horizontalization (Moustakas, 1994). In stage four, the researcher reviewed themes by refining them (Braun & Clarke, 2006). The process of culling occurred in order to remove parts of the data that were deemed irrelevant to the focus of the study (Jackson, 2016). Stage five included defining and refining themes, and writing a detailed analysis that captured the essence of the experience (Braun & Clarke, 2006; Moustakas, 1994). Stage six was the final write-up of the essence of the experience (Braun & Clarke, 2006). This stage consisted of choosing vivid examples from the interviews and music to create a more comprehensive analysis of the themes. This process was conducted for both participants as two separate data sets, and then the researcher interacted with both themes to construct meaning about the essence of relationship-based music therapy from both perspectives.

The researcher engaged in a process of triangulation between the two data sets: the themes from the interviews and the music. The researcher included the music as supplemental data to support the thematic analysis, including a musical description. A process of member checking was utilized in order to improve the accuracy, credibility, validity, and transferability of the qualitative analysis (Jackson, 2016). Member-checking was significant in validating the autistic adolescent and providing him with a constant voice throughout the study.

**Trustworthiness**

The researcher utilized three validity strategies in order to ensure trustworthiness of the study (Creswell & Creswell, 2017). The three strategies included triangulation, peer-debriefing,
and member-checking. Triangulation is a process by which the researcher examines and converges multiple data sources to build a more comprehensive thematic analysis (Creswell & Creswell, 2017). In this study, the researcher used data from the interviews and interactions within the music therapy session to create a comprehensive understanding of the adolescent’s experience of music therapy. Peer-debriefing was carried out by a music therapy colleague who has no connection to the participants. This colleague reviewed and questioned the results, in order to add validity to the proposed study. Member-checking was used to ensure the credibility of thematic analysis. Following transcription and thematic analysis, the researcher set up a 15-30 minute follow-up meeting with the participants to review results and comment on the findings (Creswell & Creswell, 2017).

**Epoché**

I engaged in the process of bracketing in order to identify and put aside preconceived beliefs, biases and preconceptions in an effort to more readily comprehend and analyze the data to be collected (Jackson, 2016). First, I conducted the study in my current place of work. I purposely did not choose a client from my clinical caseload in order to eliminate bias. While I was not the music therapist conducting the session, I did have a previous therapeutic relationship with the adolescent participant in previous years as the clinician and as a music therapy intern. I have not worked with the participant since 12 months prior to recruitment. I am aware that this may have made my participants feel uncomfortable sharing any negative moments with me during the interview and member-checking process. However, I encouraged the participants to share their thoughts and opinions without reservations, and emphasized that there would be no negative consequence to their experience in music therapy or elsewhere.
I acknowledged that my philosophies are heavily rooted in DIR and NRMT traditions, and in existential and person-centered philosophies. To that end, it is my belief that each individual possesses unique qualities that make them who they are. Through relationship-based music therapy, individuals may be able to grow and reach their full potentials. I believe that it is not up to a music therapist to fix anyone, but rather it is the music therapist’s job to provide opportunities for an individual to grow and attain a sense of agency through support, a musical relationship, and essentially the therapeutic relationship. Relationship is a key word for the researcher. There is meaning in relationship between the therapist, client, and music.

In an effort to avoid such biases and add trustworthiness to the study, I implemented the validation strategies that are aforementioned. These strategies include triangulation, peer debriefing, and member checking (Creswell & Creswell, 2017).
Results

This study examined the lived experience of an autistic adolescent in music therapy as described by an autistic adolescent and his parent. Furthermore, trends were examined between the two data sets. Findings of the study are presented in a qualitative thematic analysis that was revealed through transcriptions of the adolescent’s interview, parents’ interview, and the videotaped music therapy session.

Participants

Pseudonyms will be used throughout this study to protect the identities of the participants. The autistic adolescent, referred to as “Charlie,” is a 17-year-old male who has been a client at TRC since 2011. The second participant is his father, referred to as “Tim.” Since 2011, Charlie has participated in various programs at TRC, e.g., individual music therapy, group music therapy, school district music therapy, school district campus connections program. The researcher previously worked with Charlie as a music therapy intern along with her supervisor, with Charlie in his current group music therapy, as well as in a separate group as a board-certified music therapist in his school district music therapy group at TRC. She has not provided music therapy services for Charlie for 12 months prior to recruitment. For the purposes of this study, the researcher examined his lived experience as a group member. His peer, aged 15, is referred to as “Max,” the music therapy intern is referred to as the “MT intern,” and the music therapist is referred to as the “MT.” His dyad group meets once a week for 30-minutes for the clinical year.

Thematic Results

This study consisted of data from transcriptions of Charlie’s interview, Tim’s interview, and transcriptions of a video-recorded music therapy session from April 4, 2018. The
transcription of the video recorded music therapy session included verbal and musical interactions. The transcription of the music therapy session was utilized in support of the themes that were identified.

Thematic analysis captured the essence of Charlie’s music therapy experience from Charlie’s perspective and his father’s perspective. Three themes emerged from Charlie’s perspective: a) “I can be me!” b) range of musical-emotional experiences, and c) significant relationships. Three themes emerged from Tim’s perspective: a) being himself, b) reciprocity and the relationship, and c) growth.

The synthesized data established that two themes of each participant were interconnected while one theme from each was independent. The integrated themes were a) freedom of self, derived from, “I can be me!” and being himself; and b) forging meaningful relationships, relating to the themes reciprocity and the relationship and significant relationships. Individual themes were a) range of musical-emotional experiences and b) growth. An additional theme was extracted which was related to watching the recorded session: pride. These themes are presented in the following section, utilizing direct quotes from the transcriptions and musical and verbal interactions from the music therapy session to support the findings.
Charlie’s Lived Experience

Figure 1. Autistic adolescent themes

**Theme 1: “I can be me!”** Throughout the interview, Charlie presented as an animated young man who often shared jokes as a means of connecting with people. He shared that he feels that he can do what he loves to do in the music therapy context, which includes joking. He reflected on how he was the one to initiate this idea of sharing jokes in music. He expressed that the music therapy team follows his lead, as well as his peers’ ideas. When asked how he felt when his peer joined his idea in the video, Charlie exclaimed, “It was good!”

When asked what he would like people to know about his experience of music therapy, Charlie indicated, “I play music…I like music. I love music.” While initially the researcher viewed this as an emotional expression of his experience, Charlie indicated during member checking that he believed this was a part of who he is, and declaratively stated that he wanted to put the in vivo code, “I love music” under, “I can be me!” Music therapy provides him with the freedom to be himself.
Transcriptions of Charlie’s musical and non-musical expressions (e.g. affective responses) in the music therapy group session further support the theme, “I can be me.” These moments will be indicated in the following section.

**Excerpt 1.1 April Fools:** Charlie initiated the idea of telling April Fools jokes. He hid the children’s guitar beneath the chair and said he couldn’t find the guitar. Seconds later, Charlie picked up the guitar from under the chair where he hid it and said “April Fools!” He triumphantly strummed eighth notes in a downward manner at 108 bpm. The MT and MT intern exclaimed, “Oh!” in response. Soon after, Charlie independently asked Max if he pulled any April Fools tricks. Max, smiling, stated that he would do an April Fools joke. He approached the cabinet, got 12 egg shakers, and proceeded to put these egg shakers in the back of his shirt. He then stated he was a goose laying rainbow eggs and released all of the eggs. Both Charlie and Max responded affectively via smiling, and the MT team responded with a drum roll and cymbal crash. This was a clear example of Charlie bringing his creative ideas to music therapy in which his peer and music therapy team joined in his idea and contributed their own spontaneous ideas. This provided him with a platform to share his comedic self in an environment that accepts and expands upon his ideas, as evidenced by the musical interaction that transpired due to Charlie’s ideas. The MT intern facilitated an improvised experience on the guitar in the key of A minor, the MT supported on the djembe, Max played the floor tom and cymbal, and Charlie strummed the child sized guitar. The MT intern further expanded and related to Charlie’s idea by vocalizing, “We’re the April Fools band!” The transcription of the interaction is as follows in figure 2:
Theme 2: Range of musical-emotional experiences. Charlie shared that music therapy consists of “music, singing, and playing instruments.” He expressed taking pretend trips in music therapy, therefore, engaging in imaginative play experiences.

Charlie also expressed a variety of emotional experiences that occur in a music therapy session. In direct response to watching himself in the music therapy session, the therapist probed Charlie and asked how it feels when Max and the MT intern followed his lead by imitating the punch line of a joke. Charlie exclaimed, “Happy!” and later indicated that he felt “good” in the session when this happened.

During the interview, Charlie indicated that there were “a little, not a lot” of challenging moments in music therapy. Charlie did not delve deeper into this when speaking about the music therapy session presented during the interview; however, he independently began discussing various moments that were challenging for him in his other music therapy group when a peer
became dysregulated (e.g. crying, screaming, and hitting himself). He reflected on this moment in his other music therapy group setting when he felt “sad, very upset” about his peer. His mention of this incident indicates that Charlie explores a variety of emotion in the music therapy context, whether it is happy, good, challenged, sad, or upset, and continues to think about and process significant emotional moments in music therapy.

During music therapy, he also feels bittersweet when there’s change and nostalgia. For instance, he asked, “When will 2011 come back?” an expression of a desire to relive previous music therapy experiences and relationships that he had with his current MT in an individual setting. Though he later expressed contentment with his group setting, this demonstrates the complexity of Charlie’s emotions and how he often tries to navigate these feelings in music therapy, illustrated in excerpt 2.1.

Transcriptions of Charlie’s musical and non-musical expressions (e.g., affective responses) in the music therapy group session further support the theme, a range of musical and emotional experiences. The following descriptions of Charlie’s interaction in the music therapy session shed to light how these various emotions manifest.

**Excerpt 2.1 Feeling Bittersweet:** The MT facilitated the experience, entitled “The Play-A-long Song” by David Marcus and Alan Turry (Ritholz & Robbins, 2003) in the key of C on the piano, while the MT intern created a grounding beat on the djembe. Max was plucking notes on the electric guitar within the key while Charlie played on the C scale xylimba and sporadically vocalized with the MT. The MT provided opportunities for Charlie and Max to complete the phrase, “I think I’ll call this song, the ___ song”. The MT bridged Charlie and Max’s ideas together to facilitate the experience with the lyrics, “Well it’s almost summer
vacation, but it’s still spring.” The musical transcription of the new theme is as follows in figure 3:

![Musical transcription](image)

Figure 3. Play a-long song improvisation

Charlie responded, “Summer’s almost here…I can’t wait for summer vacation.” The MT provided Charlie with the opportunity to take a turn. While Charlie expressed excitement towards summer affectively in prosody, his play gradually became somber as evidenced by a shift in dynamic from forte to piano and a shift in body posture. The MT reflected this, musically, providing space for the emotional energy that was being expressed. She made the musical choice to shift from a mixolydian mode in the A section to an Ionian mode in the improvised B section by introducing a B♭. The following chords reflected a somber and longing feeling: Fmaj7, Cmaj7/E, dmin7, Cmaj7, dmin7, Gmaj7, Cmaj7. She played a walk down bass line, which provided movement through the improvisation. The Fmaj7 chord promoted a sense of longing, as the major 7 interval sought to reach the root of the chord. Meanwhile, the Cmaj7/E chord, as a first inversion I chord, has a minor 2 interval. This interval inherently wants to resolve, which propelled the music forward. The intervallic relationships promoted a sense of longing and thoughtfulness, reflective of Charlie’s play on the xylimba. When the Gmaj7 chord was introduced, this moment shifted. Charlie returned to forte play and began playing the melody of “Row, row, row your boat.” The MT followed his lead and provided him the avenue to move through his emotions. The experience continued as Charlie played in an improvisatory manner on the xylimba. It was almost 30 minutes later that Charlie independently said, “Our school year
will be over” in a low voice with eyebrows raised, and asked, “Why does the school year have to end?” Thus, Charlie explored and musically expressed what seemed to be a bittersweet emotion through musical play and later verbalized what seemed to be his thought process in the moment.

**Excerpt 2.2 Happy!**: During the interview, Charlie referenced the following musical interaction as him feeling happy and good in the music therapy session. The MT intern improvised an experience in the key of E major. The musical transcription of the theme is as follows in figure 4:

![Image of musical transcription]

*Figure 4. Who’s got a joke improvisation*

The MT intern facilitated the experience on the electric guitar, the MT played the floor tom and cymbal with brushes, Max plucked notes on another electric guitar, and Charlie played the temple blocks. The MT intern offered a turn to the two clients, to which Charlie indicated he had a joke. Charlie stated, “Excuse me waiter, there’s coffee in the mud” with high affect in prosody (vocally). At this moment, Max lifted his head from his self-directed play on the electric guitar, smiled slightly, and repeated the phrase in a monotone manner, and the MT intern repeated the phrase on the dominant seventh chord. At that moment, Charlie jumped the octave and sang “ex-cuse” sliding from an E pitch to the G♯ pitch, as he seemingly became excited, as evidenced by the upper half of his body collapsing while he smiled, laughed, and beat the temple block. He eagerly exclaimed, “ah” in a G#.

**Theme 3: Significant relationships.** Throughout the interview, Charlie explored various interpersonal relationships. He spent time reminiscing about the experiences he has had with his
current MT. He indicated that the moments that stood out to him were “in 2011 – the first year I come here.” He reflected on his music therapy experiences that were significant to him and expressed the following:

I used to take pretend trips with [the MT]… We went to the party store for my birthday. We bought balloons and they were all high up in the sky [extends hand to the ceiling]… I couldn’t reach them! We had my birthday – we celebrated my birthday here one time in that room [points to session room #1]… I remember that.

Charlie indicated that the nature of his relationships in music therapy is “telling jokes.” He verbalized that when he does this in music therapy, people may think he’s silly. He specifically indicated that he thinks the MT intern thinks he’s silly, responding with affect (i.e. smile). He then proceeded to speak about the previous MT intern from the 2016-2017 clinical year and plays out a joke that they used to do together. This recall and reminiscence of a previous clinician indicated that Charlie developed significant relationships in music therapy that he remembers.

Transcriptions of Charlie’s musical and non-musical expressions (e.g. affective responses) in the music therapy group session further support the theme, significant relationships. The following excerpt highlights the peer relationship.

**Excerpt 3.1 Peer Relationship:** Excerpt 2.2 depicts a moment in which Charlie is happy, as he stated in the interview. Following the moment highlighted above, Max asked the MT, “Is that a real joke?” The MT indicated that it was Charlie who told the joke, facilitating the opportunity for Max and Charlie to interact with one another as opposed to Max interacting solely with the MT. Max followed up by asking Charlie if that was a real joke. The two boys socially referenced one another and Charlie excitedly said, “It’s a dirty joke!” Max imitated this,
smiled, and triumphantly strummed his guitar on a whole note. This cued the MT intern to play the B7 chord with exaggeration, and the MT and MT intern exclaimed, “Oh!” Charlie responded via smiling, biting his collar in an effort to regulate himself through his excitement, and playing sixteenth notes. This moment emphasized the peer relationship, the musical relationship, and how the therapeutic relationship facilitated the social communication between the two adolescents.

Charlie’s Lived Experience – Parent Perspective

Figure 5. Parent themes

**Theme 1: Being himself.** Tim described Charlie as a creative entity, enjoying the arts within a variety of modalities through music, creative writing, artwork, photography, and videography. Considering he already “loves music so much, that increases his enjoyment of being here [in music therapy].” When reflecting on what happens to Charlie in music therapy, Tim stated, “I think he is just, you know, him.” There are no reservations when Charlie is in music therapy because he can be himself, different from other settings where he’s told it’s not appropriate for him to share jokes.
He is just a comedian, a joker. I think he loves it. Loves being here. The whole experience. Playing the music, playing the instruments, and getting to be himself where he can joke the way he does.

Tim made several comments as he described how Charlie’s personality comes through in music therapy. He reflected: “His arms are waving, he’s pounding on the [temple blocks] with the drumsticks. But that’s just him, that’s his personality. That’s what comes out of him when he’s here.”

While watching the music therapy session, Tim responded affectively to one of Charlie’s jokes when he stated, “See, that’s him! That’s his personality.” This moment is highlighted below in excerpt 1.1. The following transcription of Charlie’s musical and non-musical expressions (e.g. affective responses) supports the theme of being himself where he can “be himself where he can joke the way he does”.

**Excerpt 1.1 Something Smells:** During the “Who’s got a joke?” experience described above, the two adolescents take turns offering jokes. At that moment, the MT intern supported both clients to contribute their spontaneous ideas by offering a turn. Charlie immediately raised his hands above his head in excitement and stated that he had one. Charlie waited for the B7 chord after two measures of 4/4 and then introduced the joke on the I chord. He stated, “What did one eye say to the other eye? Between you and me, something smells!” Max vocally joined Charlie on, “Something smells,” to which the MT and MT intern say, “Oh!” At that moment, Charlie responded with affect via smiling and biting his collar in excitement.

**Theme 2: Reciprocity and the relationship.** The significance of reciprocity as it relates to the interpersonal and musical relationships was highlighted during the interview process. Tim reflected upon the various relationships Charlie has had in music therapy, such as with previous
co-therapists and music therapy interns, and how they have had impact on him, as evidenced by Charlie’s reminisce about these relationships. He noted that Charlie is “always looking for the humor in things” and that Charlie often brings up the previous MT intern because he would joke around with him. Tim shared that this ties into navigating different relationships and the current impact of those relationships on Charlie.

Reciprocity and the relationship was further supported when Tim shared that the client-therapist relationship is “a two way street…it goes both ways…you both have this experience together.” Tim reflected on the reciprocity and cohesion in the musical relationship, stating: “He really got into that. At one point he was really like, jamming on it. It went along with what [the MT] was playing. So it really kind of fit together…Even Max. Max really got into that session.” He reflected on how the following theme that will be discussed, growth, is a direct result of this kind of relationship: “He’s grown and to see how, with this relationship, it’s developed over these years.” This description will be further elaborated upon below in excerpt 2.1.

Transcriptions of Charlie’s musical and non-musical expressions (e.g. affective responses) in the music therapy group session further support the theme, reciprocity and the relationship. The following excerpt highlights the theme

Excerpt 2.1 We just want to say goodbye: The MT facilitated the experience, “We Just Want to Say…Goodbye”, by David Marcus and Alan Turry (Ritholz & Robbins, 2003) in the key of F major using a swing-like rhythm. The MT intern accompanied on the drum and cymbal, Max played on the tambourine, and Charlie joined the MT on the high register of the piano. He played the melody of song, which he learned by ear, and then began playing swung eighth notes, to which Max joined him on the tambourine. The group’s music was cohesive and Tim described
this moment as “jamming on it.” He responded affectively to this via nodding his head to the beat, tapping his foot, and smiling.

**Theme 3: Growth** The theme, growth, is derived from reflections about Charlie’s overall experience in music therapy. Tim made several comments about how Charlie has grown in various areas, socially, expressively, and relationally, through the process of music therapy. Tim concluded:

I’ve noticed with him over the years is...that he’s grown a lot. Especially socializing with people...For a long time he wouldn’t talk to anybody. Someone would say hello to him and he would ignore them. But I think this has brought out a lot of him being a socially active person.

Tim jokingly and lovingly said that Charlie communicates so much now that he can’t get him to stop. While watching Charlie in the music therapy session and seeing him sit next to his MT on the piano bench, he reflected on the “passage of time,” and how when he came to music therapy as a 10-year-old. He was so small compared to his MT and now, as a 17-year-old, he towers over her. He reminisced on Charlie as an infant in his arms to the teenager he is today, and how much Charlie has grown.

Tim described how this growth has generalized outside of the session room, specifically referring to navigating relationships and social interactions. He stated:

Even the way, after the session is over, he would come up, talk to you [the researcher]. He wouldn’t do that in the beginning. [Until] finally he started doing that… Just to see him now, standing there talking to you. That’s where he’s grown.
Essence of music therapy - both perspectives

Charlie and Tim spoke to the experience of the music therapy session and were provided opportunities to elaborate. Thematic results were corroborated, though each participant added to the essence of the music therapy experience through their own lenses. There are three collective themes: a) freedom of self, b) forging meaningful relationships, and c) pride. Individual themes include: a) range of musical-emotional experience, and b) growth. Table 1 represents the collective and individual themes.

Table 1. Essence of the music therapy experience

<table>
<thead>
<tr>
<th>Essence of the music therapy experience themes</th>
<th>Autistic Adolescent Theme</th>
<th>Parent Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collective Themes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Freedom of self</td>
<td>“I can be me”</td>
<td>Being himself</td>
</tr>
<tr>
<td>Forging meaningful relationships</td>
<td>Significant relationships</td>
<td>Reciprocity and the relationship</td>
</tr>
<tr>
<td>Pride</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual Themes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range of musical-emotional experiences</td>
<td>Range of musical-emotional experiences</td>
<td></td>
</tr>
<tr>
<td>Growth</td>
<td></td>
<td>Growth</td>
</tr>
</tbody>
</table>

Charlie’s theme, “I can be me!” relates to Tim’s theme, being himself. Both participants expressed how in the music therapy session(s), Charlie’s personality emerges and he is provided opportunities for autonomy and freedom of self. During which, his peer and music therapy team followed his lead and elaborated on his ideas in the music. In being himself and his group joining his ideas, he indicated that he feels good and excited.
Furthermore, both participants spoke to the concept of *forging meaningful relationships* in the music therapy context. The music therapy team creates reciprocal musical interactions that often utilize strategies of following the client’s lead. These musical and interpersonal interactions forge meaningful relationships that impact the autistic participant both inside the session room and outside of the session room, evidenced by Charlie’s reminiscence and Tim’s indication that these relationships are significant to Charlie.

Differences found in the interviews were the themes: *range of musical-emotional experiences,* and *growth.* Charlie focused on sharing a variety of musical and emotional experiences that occur, while Tim focused on sharing the idea of process and growth in the music therapy session(s).

The purpose of this study was to understand the essence of the music therapy in a relationship-based music therapy session. The themes discussed relate to this question, but there was another theme that emerged from both participants based on the experience of watching the recording of the music therapy session: *pride.* Tim supports this theme when he reflected on his growth in the session: “I’m proud of the kid. [Nods head.] You know, I’m proud to see how far he’s come.” Also, while watching the video, Tim often demonstrated with affect (e.g. smiling and laughing) and socially referencing the researcher. Charlie also seem to reflect this concept of pride while he was watching the video as he made comments like “That was a good joke!” He also beamed with excitement as he often laughed, put his palm to his head, and bit his collar. The researcher asked Charlie during member checking about this topic of pride. Charlie asked what pride is, and the researcher explained the definition to him. Charlie quickly exclaimed that he is proud. Thus, solidifying the idea that watching himself in the music therapy session gave him a sense of pride.
Summary

The themes extracted from the interviews revealed that Charlie seemed to feel free to be himself in the music therapy session, and felt supported in this through the music therapy team and peer following his lead, joining, and contributing their own ideas. Tim, too, identified that Charlie seemed to be free to be himself and that his personality could emerge in the music therapy context. The music therapy session featured reciprocal interactions that manifested through the therapeutic relationship.

As described by Charlie, the music therapy session(s) also provide opportunities for musical-emotional experiences such as the exploration of pretend play, and feelings of happiness, sadness, longing, and feeling bittersweet. Tim indicated that the music therapy session(s) provide opportunities for social, expressive, and relational growth. Another theme emerged as a result of Charlie and Tim watching the video of the music therapy session: pride.
Discussion

This phenomenological study examined an autistic adolescent’s experience of a relationship-based music therapy session through the lens of the adolescent and his parent. The participants included the adolescent, Charlie, and his father, Tim. The music therapy videotaped session examined originated from Charlie’s dyad group, with peer, Max, a MT intern, and the MT. Data was collected through interviews with Charlie and Tim regarding a music therapy session that occurred on April 4, 2018, through transcriptions of the interview, and musical and non-musical interactions in the session. The data was analyzed utilizing an inductive thematic analysis (Braun & Clarke, 2006). Themes for each participant were established and then were synthesized. The data offered collective themes and individual themes. Collective themes included: a) freedom of self, b) forging meaningful relationships, and c) pride. Individual themes included: a) range of musical-emotional experience, and b) growth.

The thematic analysis provided insight into the lived experience of an autistic adolescent in music therapy, from the point of view of the autistic adolescent. This supports the neurodiversity movement in providing opportunities for autistics to speak their own truths. Member checking also served as a means for Charlie to express and actualize his autonomy, consistent with the neurodiversity movement. Of note, Charlie decided to change the researcher’s original categorization of a code, “I love music...I like music” from range of musical-emotional experiences, into what he felt was better suited as the theme “I can be me!”

The results of the thematic analysis coincide with relationship-based ideals. The collective theme, freedom of self, is derived from the Charlie’s feelings towards being himself, with no constraint. His father, Tim, reflected on Charlie’s musical and non-musical expressions as Charlie excitedly played the temple blocks, bringing his hands over his head, and at various
times, bit his collar as he became over-excited and tried to regulate himself. Tim reflected how this is who Charlie is, his personality, and what comes out in music therapy. Charlie’s overexcited nature and manner of self-regulation are examples of Charlie’s individual differences. The theme, freedom of self, comes about because of the non-judgmental temperament of the therapeutic team as well as the music therapist’s tendency to follow his musical and emotional lead (Corey, 2013). Following client lead and respecting individual differences, as relationship-based strategies, that allow for the self to emerge, provide opportunities for individuals to develop their capacities (Carpente, 2016; Gattino et al., 2011).

Furthermore, providing opportunities for the self to emerge and be true is the path to forging meaningful reciprocal musical and interpersonal relationships (Carpente, 2016; Gattino, et al., 2011; Kim et al., 2008; Sorel, 2010). Charlie reflected on a variety of musical and interpersonal relationships, in which he reminisced about past and present musical experiences and therapeutic relationships, demonstrating the relevance and significance of the therapeutic relationship (Corey, 2013). Specifically, he conveyed a deep appreciation for pretend play experiences that he co-created with his music therapist. He also discussed how his current therapeutic relationship revolves around making jokes, which is something he prefers and loves to do. In these experientials, he, his peer, and therapeutic team engage in reciprocal play in which they take turns contributing their own spontaneous ideas. There is a consistent flow and give-and-take throughout the musical process. Shared music making, through pre-composed and improvised songs, promoted spontaneity, playful exchanges, and meaningful verbal and musical expressions (Guerrero & Turry, 2013). Sorel (2010) wrote about the function of music as a relational entity that provided opportunities for moment-to-moment interactions. These musical interactions facilitated the client’s deep involvement with the group members as well as in the
music being created, thus, forging meaningful relationships through the musical process. The study (Sorel, 2010) also speaks about a mother appreciating her child in a new way, discovering what she needed as a parent of an autistic child, and re-igniting her love for her son. While the current study does not involve a parent in the session like Sorel’s (2010) study, sharing the clinical video provided opportunities for Charlie’s father to appreciate his son and feel proud of who his son is and how far he has come in the music therapy process.

Interestingly, the theme range of musical-emotional experiences supports earlier findings recognizing the importance of emotional aspects of interpersonal engagement with autistics (Kim, Wigram, & Gold, 2009). This theme identified that improvising music together is an emotionally engaging process (Kim et al., 2009). Specifically, creating music with qualities that relate to the client’s expression or interest may evoke responses and relational music (Kim et al., 2009). Thus, forging reciprocal relationships and providing a range of musical-emotional experiences are interrelated. Kim and authors’ (2009) findings indicated that the use of musical attunement during improvisational music therapy promoted positive emotional expression. Similarly, Charlie expressed a variety of musical-emotional experiences, such as participating in pretend play experiences and joking that provided him with feelings of joy and excitement. While Kim and authors’ (2009) study only reflected musical attunement and positive emotional expression, this phenomenological study truly embodies the emotional spectrum, supporting the idea of exploring a range of emotional experiences and working through challenging emotional moments. Specifically in the excerpt 2.1 feeling bittersweet, the MT musically and emotionally attuned to Charlie (Guerrero & Turry, 2013). She reflected qualities of his expression by using the various musical elements, e.g., harmony, rhythm, phrasing, dynamic, and changing the mode in order to musically and emotionally attune to a longing, somber feeling (Guerrero & Turry,
This not only provided him with a range of musical experiences, but also afforded him the opportunity to interact with his emotions.

Tim described Charlie’s music therapy as a process by which he has grown in the areas of socialization and expression. He elaborated by recounting how in the past, Charlie would often not speak to people, but in time, has become a social person. He attributes this to music therapy stating, “I think this has brought out a lot of him being a socially active person.” It was evident that Charlie was a social being while viewing the music therapy session, as he often initiated musical ideas, socially referenced his peer, and asked questions to both his music therapy team and his peer. This study supports music therapy research that indicating that music therapy promotes social and expressive growth (Carpente, 2016; Carpente & LaGasse, 2015; Gattino et al., 2011; Geretsegger et al., 2015; Gutstein, et al., 2007; Warren & Nugent, 2010). Not only were these skills present in the music therapy session, but they have been observed outside of the music therapy session in the TRC waiting room as well as outside of the therapy context. This supports Warren and Nugent’s (2010) findings that the skills developed in the music therapy session were transferred to other settings.

Lastly, the theme of pride was not necessarily characteristic of the autistic adolescent’s experience in music therapy, but rather through individual viewing of the session by both participants. Tim stated that he was proud of Charlie and how far he has come while staying true to his personality. Charlie’s sense of pride was reflected through his verbal and non-verbal expressions while watching the video of the music therapy session. He stated, “Was that a good joke?” and soon after stated, “It was!” He later spontaneously stated, “That was a good joke!” The non-verbal expressions characteristic of his seeming excitement and pride were expressed as he initiated the ideas in the musical interaction, socially referenced the researcher, smiled, and bit
his collar in excitement, as well as his need to self-regulate. During member checking, the researcher asked Charlie what he thought about the theme, \textit{pride}. Charlie asked the researcher what pride is and she informally described being proud as feeling good about yourself for what you did. He immediately said, “Yes, I’m proud.” Thus, he confirmed the theme and then afterwards, wrote a sentence on the sheet saying, “I agreed with all the topics” discussed during member checking.

\textbf{Limitations}

Several limitations arose during the process of conducting this study. First, there were challenges during the recruitment process. There were few clients at TRC that fit the criteria for this study, specifically in the areas of age and functional language capacity. Once the participants consented to the study, there was a medical emergency for one of the participants that delayed the interview process.

The second limitation was that the researcher was a clinician in the adolescent’s school district group in a previous year. While the researcher currently does not conduct music therapy with the adolescent, the adolescent does approach the researcher as a clinician at TRC to dialogue weekly. This may have created bias in the study. The potential for bias was minimized through establishing trustworthiness utilizing strategies of triangulation, peer debriefing, and member checking. Establishing transparency through reflecting on the researcher’s personal, clinical, and philosophical stance, also, contributed toward ensuring trustworthiness.

The third limitation presented was the small sample size. It is recommended that phenomenological research studies include three to ten individuals (Creswell & Creswell, 2017). Therefore, this presented as a limitation towards this phenomenological inquiry.
Implications for Music Therapy Practice

The findings of this study afforded opportunities for an autistic adolescent and parent to speak to their experience about a relationship-based music therapy session. Collective themes and individual themes were established to describe the essence of the music therapy experience. This research is particularly significant because, while this study joins others in obtaining information from parent interviews, (e.g., Hibben, 1999; Sorel, 2010, 2004; Thompson & McFerran, 2015; Warren & Nugent, 2010;) this study, to the best of the researcher’s knowledge, is the first phenomenological inquiry of its kind in the field of music therapy that interviewed an autistic adolescent. This opens the door to future research with this population in giving autistics opportunities to speak for themselves, because as an autistic self-advocate once said, “We are the real voices” (Singer, 2016, p. 778). Many studies with a parent component often contain all or most of the parent participants as mothers (Gutstein, 2007; Sorel, 2010, 2004; Thompson & McFerran, 2015; Warren & Nugent, 2010). This study examined a father’s perspective of his son’s experience while also talking about his own experience of viewing the session and understanding the music therapy work, thus, offering more insight into a father’s experience.

The findings in this study support the use of relationship-based music therapy with autistic individuals because it provides opportunities for freedom of self and self-expression; a range of musical-emotional and relational experiences; and opportunities for growth.

Recommendations for Future Research

Future research is necessary in continuing to understand the phenomenon of relationship-based music therapy from the perspective of an autistic adolescent. Creswell & Creswell (2017) suggests three to ten participants in a phenomenological research study. Therefore, the researcher
recommends replicating the same study with a larger sample size to provide more insight into the phenomenon.

It is also recommended to do a similar study interviewing the adolescent and the whole parental system, e.g., mother and father, father and father, or mother and mother. This would give insight into the experience of music therapy from the entire family system, and could generate collective themes and individual themes.

The last recommendation leans towards the neurodiversity movement in conducting this same study, but solely interviewing autistic participants. Although this study supports the neurodiversity paradigm shift, a future study would further support the movement by solely interviewing autistics. If the participants were younger than 18 or if parents have legal rights over their child, than parents would have to be involved. However, if older than 18, legally emancipated, and capable of consenting to the study themselves, this would provide greater support for the neurodiversity movement.
Conclusion

Metaphorically in music therapy research in the autism community, the microphone is handed to a parent. This study handed the microphone to both the adolescent and parent, where they both “vocalize” and there is interplay. For the adolescent, the microphone is plugged in for the first time, with the volume dial on maximum. This phenomenological inquiry provided qualitative evidence about the lived experience of a relationship-based music therapy session from the perspective of the autistic adolescent and a parent, supporting the neurodiversity paradigm shift and disability rights movement through heeding the motto, “nothing about us without us” by providing opportunities for an autistic participant to speak on his experience (Cascio, 2012; Robertson, 2008). The study yielded results that indicated the adolescent’s experience of freedom regarding self-expression in that he could “be himself” in the music therapy session. The study supports relationship-based music therapy because strategies of following the child’s lead, joining, and elaborating, aided the participant in forging meaningful reciprocal relationships and exploring a variety of musical-emotional experiences (Carpente, 2016; Gattino, et al., 2011; Kim, Wigram, & Gold, 2009; Kim et al., 2008; Sorel, 2010, 2004). The participants shed light on the significance of the therapeutic relationship as they reflected on present and past interpersonal and musical relationships. Respecting individual differences in which individuals can express their true selves helps forge meaningful reciprocal relationships, through which there can be an exploration of musical-emotional processes that foster growth.
References


Carpente, J. (2012). DIR/Floortime model. Introduction and considerations for improvisational music therapy. In P. Kern & M. Humpal (Eds.), Early childhood music therapy and


DeMarco, J. (2018, March) RED Talk: Respect, empathy, diversity. Speech presented at Unity through Diversity: Celebrating all abilities in the arts, The Rebecca Center for Music Therapy at Molloy College, Rockville Centre, NY.


Appendix A
IRB APPROVAL LETTER

1000 Hempstead Avenue
Rockville Centre, NY 11571
www.molloy.edu
Tel. 516.323.3801
Tel. 516.323.3711

Date: December 19, 2017
To: Professor Yasmine Illya for Student Diana Abourafeh
From: Kathleen Maurer Smith, Ph.D.
       Co-Chair, Molloy College Institutional Review Board
       Patricia Eckardt, Ph.D., RN
       Co-Chair, Molloy College Institutional Review Board

SUBJECT: MOLLOY IRB REVIEW AND DETERMINATION OF EXPEDITED STATUS – MUS 551
Study Title: Exploring the Lived Experience of an Autistic Adolescent in a Relationship-Based Music Therapy Session from the Adolescent’s Perspective and Parent’s Perspective
Approved: December 19, 2017
Approval No.: 04010215-1219

Dear Professor Yasmine Illya:

The Institutional Review Board (IRB) of Molloy College has reviewed the above-mentioned research proposal and determined that this proposal is approved by the committee. It is considered an EXPEDITED review per the requirements of Department of Health and Human Services (DHHS) regulations for the protection of human subjects as defined in 45CFR46.101(b) and has met the conditions for conducting the research. Please note that as Principal Investigator (PI), it is your responsibility to be CITI Certified and submit the evidence in order to conduct your research.

You may proceed with your research. Please submit a report to the committee at the conclusion of your project.

Changes to the Research: It is the responsibility of the Principal Investigator to inform the Molloy College IRB of any changes to this research.

Sincerely,

Kathleen Maurer Smith
Kathleen Maurer Smith, Ph.D.

Patricia Eckardt, Ph.D., RN
Appendix B
IRB APPROVAL LETTER, AMENDMENT

Institutional Review Board
1000 Hempstead Avenue
Rockville Centre, NY 11571
www.molloy.edu
Tel. 516.323.3801
Tel. 516.323.3711

Date: March 5, 2018
To: Diana Abourafeh
From: Kathleen Maurer Smith, Ph.D.
Co-Chair, Molloy College Institutional Review Board
Patricia Eckardt, Ph.D., RN
Co-Chair, Molloy College Institutional Review Board

SUBJECT: MOLLOY IRB REVIEW OF AMENDMENT TO PREVIOUSLY APPROVED EXPEDITED STUDY
Study Title: Exploring the Lived Experience of an Autistic Adolescent in a Relationship-Based Music Therapy Session from the Adolescent’s Perspective and Parent’s Perspective
Approved: March 5, 2018
Approval No: 04010215-0305

Dear Diana:

The Institutional Review Board (IRB) of Molloy College approves the amendment to the above-mentioned study that was previously approved as an EXPEDITED review per the requirements of Department of Health and Human Services (DHHS) regulations for the protection of human subjects as defined in 45CFR46.101(b) and has met the conditions for conducting the research. Please note that as Principal Investigator (PI), it is your responsibility to be CITI Certified and submit the evidence in order to conduct your research.

The amendment involves a change in methodology whereby instead of watching a live music therapy session, participants will watch an archived session, and a change in faculty advisor. You may proceed with your research. Please submit a report to the committee at the conclusion of your project.

Changes to the Research: It is the responsibility of the Principal Investigator to inform the Molloy College IRB of any changes to this research.

Sincerely,

Kathleen Maurer Smith, Ph.D.

Patricia Eckardt, Ph.D., RN
Dear potential participant:

As a graduate student at Molloy College in New York, I am conducting a research study titled, *A Phenomenological Inquiry into an Autistic Adolescent’s Experience in Relationship-Based Music Therapy from the Perspectives of the Adolescent and Parent*. The purpose of the study is to examine an autistic adolescent’s experience of music therapy from his/her point of view as well as from the parent’s point of view.

You have been contacted and considered eligible for the study because your child meets the following criteria:

(A) Diagnosis of ASD  
(B) A verbal fluency and expressivity language of at least a typical four year old  
(C) Aged 10-25

Furthermore, you meet the following criteria:

(A) Parent of child diagnosed with ASD,  
(B) English speaking

Participation in the study will entail your child’s participation and your participation in independent interviews. Each interview will be 30-60 minutes long and will consist of viewing an archived video of your child’s music therapy session as well as open-ended questions asking your child about his/her experience in music therapy and asking you about your experience observing your child in music therapy. The two interviews will be video recorded. Participation in the study will entail a 15-30 minute follow-up meeting with the principal investigator to allow for member checking, which is a process in which the participants will be given the opportunity to give feedback on research results.

The interviews and data will remain anonymous and confidential. Pseudonyms will be used in the study to protect your identity. These pseudonyms will be used if the study is presented or if the results are published. Data will be stored and secured with access granted solely to the researcher.

Participation in this study is voluntary. You may withdraw at any time, with no negative consequence. If you would like to participate in the study, please confirm interest via phone, email, or in-person notification after one week (7 days) of receiving this invitation. You will receive a consent form once you confirm your interest in participating.

If you have any questions about this study, please feel free to contact me or my faculty advisor, Heather Wagner, at hwagner@molloy.edu.

Thank you for your consideration.

Diana N. Abourafeh, MT-BC  
The Rebecca Center for Music Therapy at Molloy College  
(516) 323-3333  
DAbourafeh1@molloy.edu

Heather Wagner, PhD, MT-BC  
Faculty Advisor, Molloy College  
HWagner@molloy.edu
Appendix D
LETTER OF INFORMED CONSENT

Title: A Phenomenological Inquiry into an Autistic Adolescent’s Experience in Relationship-Based Music Therapy from the Perspectives of the Adolescent and Parent

Student Researcher:
Diana N. Abourafeh, MT-BC
Music Therapist, The Rebecca Center for Music Therapy at Molloy College
1000 Hempstead Avenue
Rockville Centre, NY 11571
DAbourafeh1@molloy.edu

Faculty Advisor:
Heather Wagner, PhD, MT-BC
Adjunct Instructor, Music Therapy
Department of Music, Molloy College
1000 Hempstead Avenue
Rockville Centre, NY 11571
HWagner@molloy.edu

Dear potential participant:

As a requirement for the graduate music therapy program at Molloy College in New York, I am conducting a research study titled, A Phenomenological Inquiry into an Autistic Adolescent’s Experience in Relationship-Based Music Therapy from the Perspectives of the Adolescent and Parent. The purpose of the study is to examine an autistic adolescent’s experience of music therapy from his/her point of view as well as from the parent’s point of view. The data will be examined to see if there is a relationship between the parent and his/her child.

You have been contacted and considered eligible for the study because your child meets the following criteria:

(A) Diagnosis of ASD
(B) A verbal fluency and expressivity language of at least a typical four year old
(C) Aged 10-25

Furthermore, you meet the following criteria:

(A) Parent of child diagnosed with ASD,
(B) English speaking

Participation in the study will entail your child’s participation and your participation in independent interviews. Each interview will be 30-60 minutes long and will consist of viewing an archived video of your child’s music therapy session as well as open-ended questions asking your child about his/her experience in music therapy and asking you your experience of your child in music therapy. Participation in the study will entail a 15-30 minute follow-up meeting with the principal investigator to allow for member checking, which is a process by which the participants will be given the opportunity to give feedback on research results. A time commitment of, at most, 90 minutes per participant will be required.

The interviews and data will remain anonymous and confidential. Data will be stored and secured in a locked file cabinet at the Rebecca Center for Music Therapy with access granted solely to the researcher. All video recordings
and transcriptions of the interviews will be securely stored in a double password protected computer. The video recordings will be destroyed after the study is completed. The transcriptions of the interviews may be used for future publications or presentations, but your identity will remain anonymous.

This study may not necessarily provide any benefits to you or your child. You and your child’s participation in this study will provide opportunities for you and your child to share your experience of a relationship-based music therapy session. The researcher will seek to understand the relationship between your child’s experience and your experience of music therapy. The information may be beneficial to students, educators, and clinicians.

Should you experience any sense of discomfort during the interview process, emotional support will be provided. You may choose to end the interview process at any time, but you will have the option to reschedule the interview. You may also choose to withdraw from the study at any time with no negative consequences.

Please contact the primary investigator at dabourafeh1@molloy.edu for more information or with any concerns that may arise for you during the study. You may also contact the faculty advisor, Heather Wagner, at HWagner@molloy.edu, at any time. Questions about your rights as a study participant may be directed to the Molloy College Institutional Review Board at: irb@molloy.edu or 516-323-3000.

An explanation of the procedures to be employed in this study, in which I have voluntarily agreed to participate, has been offered to me. All my inquiries concerning the study have been answered to my satisfaction. I understand that the information collected will be held in confidence, and that my name will not in any way be identified. I understand that additional information about the study results will be provided at its conclusion upon my request. I know that I am free to withdraw from this study without negative consequences at any time. I understand I will receive a signed copy of this form.

Signing your name below indicates that you have read and understood the contents of this consent form and that you have voluntarily agreed to participate in this study. Please sign your name and deliver it back to the researcher by April 17, 2018 in person.

Check all statements you agree to:

____ I give permission to Diana N. Abourafeh to view my son’s/daughter’s archived music therapy session.

____ I give permission to Diana N. Abourafeh to video record her interview sessions with my son/daughter.

____ I give permission to Diana N. Abourafeh to video record my interview sessions.

____ I give permission to Diana N. Abourafeh to use transcriptions of the recordings for educational purposes related to this research study.

______________________________________________  ____________________________
Participant’s Signature                                    Date

______________________________________________  ____________________________
Researcher’s Signature                                    Date
Appendix E
ASSENT FORM

An explanation of the research study, *A Phenomenological Inquiry into an Autistic Adolescent’s Experience in Relationship-Based Music Therapy from the Perspectives of the Adolescent and Parent*, has been offered to me. I voluntarily agree to participate. All of my questions about the study have been answered to my satisfaction. If I have questions later, I can email or call the researcher or ask my parent to email or call the primary investigator or faculty advisor at any time. I understand that the information collected will be held in confidence. I understand that data will be stored and secured in a locked file cabinet at the Rebecca Center for Music Therapy with access granted solely to the researcher. All video recordings and transcriptions of the interviews will be securely stored in a double password protected computer. I understand that my name will not in any way be identified. I understand that additional information about the study results will be provided at its conclusion upon my request. I know that I am free to withdraw from this study without negative consequences at any time. I understand I will receive a signed copy of this form.

This form indicates that I have been asked permission to participate in this study.

Name of Child: ____________________________

Parental Permission on File: □ Yes □ No
*(If “No,” do not proceed with assent or research procedures.)*

Child’s Voluntary Response to Participation: □ Yes □ No

______________________________
Participant’s Signature (Optional)  Date

______________________________
Researcher’s Signature  Date
Appendix F
PERMISSION TO VIDEO RECORD

Student Researcher:
Diana N. Abourafeh, MT-BC
Music Therapist, The Rebecca Center for Music Therapy at Molloy College
1000 Hempstead Avenue
Rockville Centre, NY 11571
DAbourafeh1@molloy.edu

Faculty Advisor:
Heather Wagner, PhD, MT-BC
Adjunct Instructor, Music Therapy
Department of Music, Molloy College
1000 Hempstead Avenue
Rockville Centre, NY 11571
HWagner@molloy.edu

I, _________________________, give Diana N. Abourafeh permission to video record my interview session and my son/daughter’s interview session. This video recording will be used only for research purposes. I have already given written consent for our participation in this research project. At no time will my name, personal information, or contact information be used.

I understand that my son/daughter and I will be video recorded during our individually scheduled 30-60 minute interview session for purposes of transcription. I give permission for the recording to be used from December 2017 to May 2018.

I understand that I can withdraw my permission at any time. Upon my request, the video recordings will be erased and removed immediately.

If I want more information about the video recordings, or if I have questions or concerns at any time, I can contact the investigators at the top of this page.

I understand that my signature below indicates my voluntary consent to be videotaped. I understand that I will be given a copy of this signed form.

Please hand this form to the researcher by April 17, 2018 in person. Thank you for your participation.

____________________________________________  ____________________
Participant’s Signature                              Date
Appendix G
INTERVIEW QUESTIONS

Questions to Autistic Adolescent:

General Questions:
1. What is music therapy?
2. What is your experience of music therapy?
3. What usually happens in a music therapy session for you?
   a. Who is in your session?
   b. What are your thoughts about your relationship with your music therapist?
   c. What are your thoughts about your relationship with your peer?
4. Are there any moments in music therapy that stick out to you?

After watching music therapy session video:
1. Is there anything that you would like to say or that comes to mind after watching the video?
2. What was music like for you?
3. What part of music, if any, stuck out to you?
4. Was there any moment in music therapy that was difficult for you?
5. What was it like for your peer to join you?
6. If you had the chance to tell someone about your experience in music therapy, what would you tell them?

Questions to Parent:

General Questions:
1. What is music therapy?
2. What is your experience of music therapy?
3. What do you think is ____’s experience in a music therapy session?
   a. What do you think his relationship with his music therapist is?
   b. What do you think his relationship with his peer is?
4. Are there any moments in music therapy that stick out to you?

After watching music therapy session video:
5. Is there anything that you would like to say or that comes to mind after watching the video?
6. How do you feel watching your son/daughter in music therapy?
7. What part of the music therapy session, if any, stuck out to you? Please explain
8. How do you feel watching your son/daughter in music therapy?
Appendix H

A LETTER OF PERMISSION FORM

Title: A Phenomenological Inquiry into an Autistic Adolescent’s Experience in Relationship-Based Music Therapy from the Perspectives of the Adolescent and Parent

Student Researcher:
Diana N. Abourafeh, MT-BC
Music Therapist, The Rebecca Center for Music Therapy at Molloy College
1000 Hempstead Avenue
Rockville Centre, NY 11571
DAbourafeh1@molloy.edu

Faculty Advisor:
Heather Wagner, PhD, MT-BC
Adjunct Instructor, Music Therapy
Department of Music, Molloy College
1000 Hempstead Avenue
Rockville Centre, NY 11571
HWagner@molloy.edu

The following research project is part of the Molloy College Graduate Music Therapy Program: MUS 551/04 (Thesis: Music Therapy). My research involves exploring lived experience through a phenomenological inquiry. The researcher will explore the lived experience of an autistic adolescent in a relationship-based music therapy session from the perspective of the autistic adolescent and his/her parent. Both the adolescent participant and the parent participant will be interviewed, independently in a 30-60 minute open-ended interview whilst watching an archived video of the adolescent participants music therapy session.

This project will be conducted by Diana N. Abourafeh at The Rebecca Center for Music Therapy at Molloy College. This course is a requirement for graduation. Approval is contingent upon the Executive Director of the Rebecca Center for Music Therapy in accordance with the Molloy College Review Board procedures.

Executive Director Signature: ________________________________

Researcher Signature: ________________________________

Date: 11/28/17