PARENT PERCEPTION ON ACTIVE MUSIC EXPERIENCE: FAMILY-CENTERED MUSIC THERAPY & CHILDREN WITH AUTISM SPECTRUM DISORDER

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I describe the parents' perception of active music experience with their child who has Autism Spectrum Disorder, and the role active music experience plays on the level of parenting stress. The Parenting Stress Index Japanese Edition was conducted pre- and post music therapy phase to see the difference in the parenting stress between this period. A semi-structured interview was conducted to better understand parents' stress behind the child's characteristics and the parent's characteristics, and to further explore their active music therapy experience to make conclusions about the family practice. I completed data collection and Music Therapy Intervention with a total of four families in Japan. Family A includes a father, a mother and an 8 year old boy with Autism Spectrum Disorder; family B includes a father, a mother and a 4 year old boy with Autism Spectrum Disorder; family C includes a mother and an 11 year old boy with Autism Spectrum Disorder; and family D includes a mother and an 8 year old boy with Autism Spectrum Disorder (PDD-NOS). The findings revealed that the use of active music experience decreased the stress level of parents whose children had Autism Spectrum Disorder. Parents perception on parenting stress, however, in terms of what areas parents' perceived stress and how they identified stress varied. The findings of this study gives insight into the uniqueness of each parent's cause of stress, the parents' trauma, and the significant musical moment that triggers parents to change their way of perceiving their parenting stress. Recognizing parenting stress as a negative factor impacting family dynamics and offering support may better guide music therapists in the family practice to meet the needs of parents and children with Autism Spectrum Disorder. Asiasanat – Keywords					
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1 INTRODUCTION

If child rearing continues until a child becomes independent, the parenting journey is long, filled with mental, physical, and economic burdens. Parents are expected to cope with all kinds of challenges which arise during child rearing. This thesis explores the issues and stress parents of children with Autism Spectrum Disorder experience in their lives, as well as examines whether active music therapy experiences could positively affect parenting stress levels in a family context. In this course of therapy, father, mother, and the child equally participated in the therapy process. The Parenting Stress Index, Japanese second edition, (Kanenatsu, Asano, Araki, Arayasiki, Ohashi, Narama, & Maru, 2015) was used quantitatively to examine the changes in parent stress levels pre- and post music therapy interventions. In this study, the researcher also acted as a therapist for four families. To increase the readers' understanding of the music therapy sessions, and to relate to their own experiences, I have included detailed information about the researcher, the participants, the music therapy context, and the interaction that occurred among the members of the music therapy session (Aigen, 1996).

The primary data sources include the results of the Parenting Stress Index (PSI), recorded sessions, transcripts of interviews with the parents, and therapist notes. In order to investigate the topic, I compared each family's pre- and post- PSI results, then analyzed videos of the parenting interview in which parents expressed feelings about their cause of stress and changes within it over the course of therapy. I then utilized thematic analysis of the music therapy videoed sessions to find the relevant theme in their active music therapy making to understand the relationship between the parents' perception of stress and their active music experience. When I analyzed those videos, I looked at the quantitative results of each parent's parenting stress index to have a clear sense of when there was a decrease in parenting stress. The study was conducted with deep respect and appreciation for the families as they were observed and assessed during their family interactions.

1.1 Research aims

The section below describes the aim of conducting this research. My interest in this topic extends from my experience working with children who have neurodevelopmental disorders and their families in a music therapy clinic. In my work with the clients there, I mainly used the active music therapy method to build a relationship with the clients during our sessions. As many clinicians reported that active music experience is a successful way to reach an autistic child. I came to understand their reasoning through my practice and feel it is the right way to reach a child with autism in a non-verbal manner. Although there is no verbal communication, there is a sense of mutuality and relatableness experienced through active music making. I first began using the active music therapy methods of improvisation, recreating, and composing during my clinical fieldwork from 2013 at a music therapy clinic in Long Island, NY. Coming from a classically trained background, I first felt it impossible to communicate with a child through improvisation due to my lack of flexibility and knowledge of improvisational techniques. For me, using the pre-composed songs made me feel mentally available to my clients in the session. However, throughout our therapy process, our therapeutic relationship developed mainly through progress in vocal improvisation. My experience with the clients I worked with there changed my view of using active music experience, and I saw the importance of authenticity and playfulness in music therapy.

In 2014, I began working with children in the childcare support center where children have a variety of cultural backgrounds and different needs. As I kept working with the children and families there, I began to see each child's surrounding condition: the family environment. I spent my time there gaining knowledge to better understand the issues of families with a child who has a neurodevelopmental disorder. However, I did not have a chance to realistically address the parenting stress in music therapy until I was introduced to the work of Varvala Pasiali in Music Therapy with Families -Therapeutic Approaches and Theoretical Perspectives (Jacobsen & Thompsen, 2017). In this book, while 14 different authors share their work with families in a variety of settings, overlapping with other chapters, Pasiali talks about the concept of resilience, as well as the importance of preventive work in family music therapy settings. This reading inspired me to see the possibility of working with families, focusing on the child's closest caregivers who create the environment for the child, the parents.

Although the work with families is complicated with many layers of issues to address, I decided on the topic of this study to continue my work understanding the issues that families experience, and the value of using active music experience in the field of family care.

1.2 Definition of Terms

1.2.1 Autism Spectrum Disorders

Autism Spectrum Disorder refers to a group of conditions including challenges with social interaction and communication, and limited interest in activities. In most cases, ASD appears before the age of five. Individuals with ASD tend to present co-occurring conditions such as epilepsy, depression, anxiety, and attention deficits hyperactivity disorder (ADHD) (World Health Organization, 2013; American Psychiatric Association, 2013). A cure for ASD is not available. However, evidence-based psychological interventions for individuals with ASD and their caregivers can decrease difficulties in communication and social interaction, as well as enhance the quality of their life (WHO, 2013). The families of individuals with ASD can be placed under a lot of stress, especially in areas where there is inadequate services and support (WHO, 2013).

1.2.2 Parenting Stress

Parenting Stress is a series of processes that the parents experience through psychological and physiological reactions arising from attempts to adapt to the demands of parenthood (Kanenatsu, Asano, Araki, Arayasiki, Ohashi, Narama, & Maru, 2015, p.7)" This could be experienced as negative thoughts and feelings towards the parents themselves or their child (Deater-Deckard, 2004; Kanematsu et al., 2015).

2 LITERATURE REVIEW

2.1 Family Studies

The family is the most fundamental community where individuals belong. Families are the core source of love and support in various cultures and throughout human history. Families can protect and nurture individuals or empower them; however, we all know that families can experience hardship and frustration as well (Jacobsen & Thompson, 2017). The concept of family can be approached from multiple perspectives such as laws/legal agreements, economic aspects, cultural aspects, and subjective experiences, yet that makes studying family special. The challenge of defining family relies on several ideas: the multiplicity and diversity of households, the ambivalent and sensitive nature of family, and the changing nature of family due to societal influence (Rönka & Sevön, 2017). The family is a commonly used notion in our lives, and yet it is difficult to define it precisely. Because of the diversity of perspectives on the concept of family, the definition of family remains flexible. Similarly to other groups or units, families can find themselves "being at risk" for several reasons.

Violence, illness of family members, poverty, and children's developmental issues are a few factors that directly impact a family's life (Flower & Oldfield, 2008; Jacobsen & Thompson, 2016).

Feelings of attachment within a family can be constructed by the cycle of interaction between both caregivers and the child (Wilson, 2014). This cycle includes the child's need of caregivers, the caregiver's acknowledgment of being needed by the child and responding to the child, and meeting the child's needs (Dickstein, Seifer, & Albus, 2009; Raicar, 2008; Wilson, 2014). By repeating this interaction multiple times, trust is developed, and a bond fostered. If the caregiver is preoccupied with their issues and becomes unavailable to the child, the cycle mentioned above is interrupted (Wilson, 2014). In a typical family, it is expected that the attachment between the primary caregivers and the child develops naturally through their interaction in daily life. However, quite a lot of caregivers feel it is challenging to develop a healthy attachment with their child when additional problems exist in their household (Flower & Oldfield, 2008).

2.2 Family Therapy

The use of family therapy started during the 1950s as one of several new approaches to therapy. During the Second World War and up to the 1960s, the traditional psychoanalytic work by Sigmund Freud was highly valued, and it was the primary approach for many practitioners. In contrast to these trends, family therapy had the revolutionary idea of focusing on the "here and now" to work on the challenges of family operation (Barker & Chang 2013). In the 1960s, family therapy was described as "uncommon therapy" by Jay Haley, who brought directive work into family therapy sessions. Hayley saw family problems often came from the confusion and dysfunctional hierarchies within the family (Barker & Chang 2013). The practice of family therapy expanded as the American Association for Marriage and Family Therapy developed their family therapy training program in the 1970s. Since family therapy appeared first in the 1950s, the field has grown rapidly.

The modern family is experiencing societal changes including globalization, work, and family policies, and seeks available services for individuals in need (Rönkä & Sevón 2017). Creative Arts Therapy offers an alternative to the traditional verbal therapy. Clients are usually less stressed when they use the art mediums such as music, arts, and dance to express themselves compared to verbal expression. Therefore, using arts in a sensitive and complex family system is beneficial as the arts could naturally help clients to express themselves without the fear of being verbally too directive. Engaging clients in arts activities let them feel productive and defuse themselves from their problems and circulating thoughts. Moreover, the flexible nature of arts allows family members of every age and with different abilities to participate in creative arts (Jacobsen & McKinney 2015). Studies suggest that the use of expressive arts in family therapy is useful because it translates neuroscience knowledge into intervention and techniques. However, while the tools for assessments and interventions are currently developed and integrated into the family therapy contexts, music in those places is somewhat limited due to the therapists' lack of musical skills and confidence delivering the musical intervention (Kerr, Hoshini, Sutherland, Parashak, & McCarley, 2008; Nemesh, 2017).

2.3 Parents of Children with Disabilities

Studies have shown that the parents of children with disabilities experience high levels of parenting stress (Dyson, 1997; Lessenberry & Rehfeldt, 2004). Particularly, parents of children with Autism Spectrum Disorder and behavior disorder seem to report higher levels of stress than other disabilities (Baker-Ericzen, Brookman-Frazee & Stahmer, 2005). The parenting stress levels of Autism Spectrum Disorder groups was four times that of the typical group and double that of the developmental delay group (Silva & Schalock, 2012). Due to the high amount of stress levels, parents are more likely to experience depression and struggle with their child's condition (Lessenberry & Rehfeldt, 2004).

Parenting stress levels of 880 parents of children with disabilities were evaluated to see in what degree the stress is related to family functioning variables, such as social support, financial resources, and the severity of the child's disability (Smith, Oliver & Innocenti, 2001). The Parenting Stress Index/Short Form (PSI/SF) was used to see the parents' stress levels in the areas of Parental Distress, Parent-Child Dysfunctional Relationship, and Difficult Child. A child's functioning was measured by the five Battelle Developmental Inventory (BDI): personal/social, adaptive behavior, motor, communication, and cognitive development. The study revealed that the severity of the child's disability had a small impact on the overall parenting stress level, but had a notable impact on specific stress related to the parent-child relationship. Moreover, the child's social skills had a stronger influence on parenting stress than other domains, such as motor, communicative, adaptive behavior, or cognitive abilities (Smith, Oliver & Innocenti, 2001).

Parents of children with disabilities experience anger and frustration, which could be overwhelming without proper care of these negative emotions. When these emotions keep growing and parents become unable to control themselves, they channel these negative emotions into destructive outlets. With the cooperation of 10 special needs schools in Tokyo, 499 parents who have children with and without developmental disabilities were asked about their experience of physically punishing their children. The study showed that the children

with developmental disabilities were four times as likely to experience physical punishment compared to those without disabilities, and the parents' poor mental health was associated with physical punishment (Kimura & Yamazaki, 2016). The authors suggested the need of mental health programs for the parents, such as encouraging the exploration of the parents' perception of their child's disability, problem-solving skills, and relaxation skills (Jones et al, 2012; Kimura & Yamazaki, 2016). Parenting training is known as a support for parents who experience difficulties in parenting in Japan. However, it is often offered as a class with approximately ten other parents instead of being offered on an individual bases.

Although the number of children with neurodevelopmental disorders increases every year, there is no other specific support program for parents and children with neurodevelopmental disorders in Japan (Matsuo, Inoue, & Maegaki, 2015). 10 % of mothers who have children with pervasive developmental disorders experience severe depression compared to the 1 % of mothers with "typical" children. Therefore, there is a need to develop programs in Japan to support parents and children with developmental disabilities in all age groups (Nomura, Kaneko, Honjo, Yoshikawa, Ishikawa, Matsuoka, & Tsujii, 2010).

2.4 Active Music Therapy

Whether it is in a music therapy setting or not, music work is a medium to communicate with, relate to, soothe and motivate ones in need. Music and musical activity affect our bodies and minds, and music influences us both in a healthy or an unhealthy way (Thompson, 2012). When music therapists offer clients appropriate music, it provides a great medium to reach the client and offer avenues for assessed needs. Active Music Therapy requires active participation from the clients. Composing, re-creating and improvising music is considered active music therapy (Bruscia, 1998; Maratos, Gold, Wang, & Crawford, 2008). Improvisational-based active music experience involves instrumental or vocal exchange between the therapist and the client or among the group of clients. Re-creative experience includes singing or playing pre-composed music. Composing experience refers to writing songs (Brucisa, 1998). In these experiences, the relationship is built within the shared musical space while clients engage in creating music, learning or performing in any musical form (Bruscia, 1998; Wigram, Bonde, & Ole, 2002).

Creative Music Therapy was developed by Paul Nordoff and Clive Robbins, and further developed by Clive Robbins and Carol Robbins. In this model, the primary music therapist and co-therapist work in pairs. The primary therapist establishes a musical relationship, while the other works closely with the client to facilitate their responses. The therapy is to be a musical experience from the moment one enters to the moment one leaves the room (Wigram, Bonde, & Ole, 2002).

Since active musical experience offers the client nonverbal capacity of communication, expressive freedom, and flexible structure in therapy, many populations are benefitted: from children to adults; from handicapped to free of handicaps, from children with impulsive behaviors to depressed adults (Bruscia, 1998). For those who do not benefit from verbal communication, the musical interaction itself creates a social closeness (Perry, 2003). Although some participants cannot express their feelings in speech, they find something meaningful between the therapist and themselves within the context of active music experience. Evidence for this claim is shown through their nonverbal communications, such as their physical movements, vocalizations, and facial expressions (Perry, 2003).

Additionally, music experiences provide non-verbal clients chances to engage in mutual interaction (Carpente, 2011; Jacobsen, & McKinney, 2015; Jacobsen, McKinney, & Holck, 2014). These musical moments with the parents are helpful for both children and their family members as precious memories and connections are made. When the parents are struggling to verbally communicate with their child due to their child's developmental capacity, they often feel lost (Schwarts, 2011). Active music experience could act as a bridge between the children with limited communication skills and their parents. Active music experience has often used in the family settings in order to bring meaningful moments. Music functions as a non-threatening way of relating to their child, and also motivates parents to reach their child through alternative manners (Carpente, 2011). Allgood (2005) investigated the parents' perception of family-based group music therapy for young children with autism. The researcher utilized singing, improvisational music, and movements in a structured music therapy environment. The music activities were specifically chosen to increase join attention, interaction among the group members, self-expression and cooperative group experiences

(Allgood, 2005). The researcher observed the use of active music yielded parents to take a risk to learn new about their child and themselves. The result supported the benefits of using active music based interventions within a family-centered music therapy practice (Allgood, 2005).

2.5 Ecological Practice

An ecological thinking is inevitable to plan and conduct a family study; particularly to have a better understanding of the parent's role in family centered practice. In the field of music therapy, many authors have discussed *ecologies* to which health issues are related to. The ecological practice has its roots in Bronfenbrenner's ecological theory (1979), which explains that everything in an individual's environment influences on his or her growth process (Bruscia, 1998). He named the closest ecological context a child's development occurs in as the "microsystems." These contexts include families, schools, and nurseries. (Bronfenbrenner, 1979). He described the impact of each member's involvement with positive interactions in the same system would create a balance for the group member's growth and learning (Bronfenbrenner, 1979). This idea could be implemented in the family-centered music therapy practice as parents, a child, and a therapist communicate directly and work towards the shared goals. Each of the individual can rely on the balance they created and feel more secured. By treating a child as an integral member in this system gives rich results to the family (Allgood, 2005; Bronfenbrenner, 1979; Brusica, 1998). When parents have children with limited capacity in communication, the music might act to glue people in the micro system. Because of the flexible nature of music, it is easily shared within the ecological contexts (Allgood, 2005; Brusica, 1998). The ecological practice in music therapy includes all works of music and music therapy where the primary focus is on promoting health and wellbeing within socio-cultural communities (Bruscia, 1998). In this area of practice, the client(s) may be individual or grouped in various contexts or in their usual environments. Clients might be the context themselves, with their families, workplaces, and communities (Bruscia, 1998, 2014). In the ecological context, the changes in an individual will eventually lead to changes in other members. Bruscia (1998) described this to be:

Helping any ecological context to become healthier is not a separate enterprise from improving the health of its members; and helping individual and ecology to relate to one another harmoniously makes both healthier. (p.229)

When a music therapist implements the concept of ecological practice in music therapy, the approach and intervention might not directly address the client's behavior (Bruscia, 1998). In the work with parents and their child with autism, the music therapist might address the child's needs in front of the parents. Parents could gain new insights through experiencing the process of child's intervention together. In other words, the parents' active participation in the music therapy stimulates the child to the positive outcomes. In normal group therapy, the clients are selected according to their developmental stages, or common needs among clients; therefore, it is not a context in which individuals work or live (Bruscia, 1998). In contrast, the ecological model tells us, individuals best learn when they are in the natural ecological unit, which already exists for them, with defined roles of who lives and works within it, such as family members (Allgood, 2005; Bruscia, 1998; Bronfenbrenner, 1979).

2.6 Use of Music in Family Therapy

Musical interventions offer great therapeutic outcomes to the family. They offer new opportunities for the family to gain insight and promote changes in family dynamics (Pasiali 2013; Nemesh, 2017; Thompson & McFerran, 2015). Therapists who work with families encounter the situations to employ new experiences for their clients: practice through creative arts, body movement and not just listening and talking. Family therapy with the use of music, which acts as a different form of a trigger than talking, introduces authentic communication patterns among each family member and enhances the family dynamics. Pasiali (2013) described this to be:

Finding ways to enhance communication skills of adult partners during music therapy may indirectly affect the quality of relationships within the whole family ecosystem, thus becoming a fourth pathway of fostering attachment. (p.210).

When the clients are referred to music therapy treatment, they often have health-related and wellbeing issues. Quite a few clients live their lives depending on their families, relatives, and caregivers (Jacobsen & Thompson, 2016). No matter how often family members are active in the lives of their family members who need them, they are an important part of music therapy

in many different ways. In music therapy palliative care, family members are often invited to be part of the session to have a memorable moment before the client's passing. In the past, typically music therapy for children with developmental disorders did not involve the parents in the music therapy room, although the parents were the ones who were interested in music therapy for their child and brought their child for treatment. The opportunities for parents were limited to parent conferences and progress reports. However, the idea of including family members in the music therapy process is becoming common. Their involvement is incredibly valuable when the client needs to focus on their relationship with family members; moreover, there is the concept of seeing the family as a whole as in ecological practice instead of focusing on individual clients or groups of clients (Jacobsen & Thompson, 2016).

Lipponen has conducted a case study to explore early interaction music therapy work in the family therapy setting. The study consisted of two music therapy processes: parent and infant dyad and the parent's music therapy (Lipponen, 2014). The interaction was quantitatively assessed with the Early Intervention Video Assessment Method, Care Index, and qualitatively explored to gain therapeutically valuable insights. Her study supported the importance of providing a caregiver individual sessions for processing her crises in the past; it allowed the parent-child dyad to go on the appropriate therapeutic path (Lipponen, 2014). In contrast, Pasiali conducted a qualitative study with four families of low income and histories of maternal depression to investigate mutually responsive orientation behaviors of children aged three-to-five years old (2012). Grounded theory methodology was used to understand the phenomenon of their interaction during the music therapy work. Music therapy sessions were conducted at home for three families, and one family received their music therapy session at a university-affiliated clinic given the family's living circumstances (Pasiali, 2012). In Pasiali's study, therapeutic work varied for each family according to their needs and preferences, with the session length from 30 to 60 minutes. The results showed that the children were more engaged in the structured music activities, a task both verbally and physically directed by the therapist. The therapist's role of modeling interaction among the group supported parent-child interaction over time (Pasiali, 2013). Information regarding the participants' behavioral reactions and playful events were recorded, and participants' behavior was assessed in a nonmusical manner. While not addressed in this thesis, it would be an interesting study to know what happened in musical terms during these sessions. What were the musical components,

such as timbre, harmony, tempo, duration, dynamics, and rhythm? Descriptions of participants' presented music in the music therapy sessions could be valuable data because music can reflect who they are and how they are (Saarikallio, 2016).

2.7 Music Therapy for Parents Who Have Children with Disabilities

Music therapy intervention has been used in the clinical setting for children and their families due to the nature of how children respond to music (Schwartz, 2008). A study was conducted to see the effectiveness of short-term group music therapy intervention for parents of children with disabilities. Participants were 201 mother-child dyads who participated in an Australian national early parenting intervention music therapy program called, "Sing & Grow." Pre- and post- questionnaires and clinical observations were used to examine the changes in parenting wellbeing, parenting behaviors, and child development (Williams, Berthelsen, Nicholson, Walker & Abad, 2012). The 10-week group music therapy session was designed for the weekly (1 hour/week) participation of 8-10 parent-child pairs, 22 music therapists who had received training and continuous education led the program. The t-test results revealed that there was a significant reduction in parents' self-reported negative mental health symptoms from pre to post music therapy phase (Williams et al, 2012). Moreover, clinical observation showed significant improvements in the area of parenting behaviors: sensitivity to child, effective engagement of the child, and acceptance of the child (Williams et al, 2012). Although the author described the use of quantitative research method precisely, the study gave us qualitative insights as well. The study samples included only mothers, and makes one want to know the experience of fathers or other caregivers.

When the child's communication capacity is limited due to the symptoms of his/her diagnosis of a developmental disorder such as Autism Spectrum Disorder, the symptoms could get in the way of repeating the cycle of interaction. The healthy attachment between the primary caregiver and the child in their early life stage is particularly important to prevent the child from developing inappropriate behaviors and psychopathological symptoms later in their life (Pasiali, 2013). The parents' involvement in the child's therapy process is becoming more common in the field of music therapy, and the advantages of having parents in the session are not only for the children but also for the parents to have a better understanding of self and

his/her child (Oldfield, 2006; Flower & Oldfield, 2008; Jacobsen & Thompson, 2016). Short-term music therapy is effective to promote parental mental health for the mothers of children with disabilities (Williams, Berthelsen, Nicholson, Walker, & Abad, 2012; Thompson 2012). However, the information about other caregivers' experiences, particularly the father's experience, is often missing in the existing literature.

Music therapists can tailor active music therapy method along with the ecological practice model to directly engage parents concerning their high level of parenting stress. Although studies have shown that parents of children with disabilities receiving music therapy had reduced negative mental health symptoms and increased positive parenting behaviors, there is a lack of exploring the parents' experience (Nemesh, 2017; Pasiali 2013; Thompson & McFerran, 2015; Williams et al, 2012). The parents of children with Autism Spectrum Disorder are in a difficult situation because of the high level of parenting stress. It may cause further mental health issues, which affect the whole family dynamics. It is necessary to listen to parents so that the music therapists understand parents' stress as an important factor impacting family dynamics. Therefore, the purpose of this study is not only to examine the changes in the parenting stress, but also to capture parents' perception about their active music therapy experience.

3 RESEARCH QUESTIONS

I kept my questions and sub-questions open to expanding as my research was creative and ongoing (Sorel, 2010). The research question that guided my study was:

How does the experience of active music therapy change the perception of a caregiver's parenting stress, specifically parents of children with Autism Spectrum Disorder?

Sub-questions related to the main focus were:

- 1. What are the parents' struggles when they have children with Autism Spectrum Disorder?
- 2. What are the changes in the results of the Parenting Stress Index pre- and post- music therapy phase?
- 3. What were the parents' experiences with their child through music?

The goal of this study was to observe, describe, and analyze the use of musical experience in families. The study examined the issues that parents and a child with disabilities experienced in their lives, the parents' experience in music therapy, and the influence of active music therapy on the level of parenting stress.

4 METHOD

4.1 Research Design

Instead of making standardized comparisons or generalizations, I wanted to study a particular phenomenon: the influence of active music therapy experience on the perceptions of six parent's parenting stress who have children with Autism Spectrum Disorder. In order to examine the changes in the parenting stress level, a pretest and posttest study design was utilized with a sample of four mothers and two fathers of children with Autism Spectrum Disorder. This single group pre- and post- design is not unlike a case-study design (Ansdell & Pavlicevic, 2001, p125). The study also utilized a qualitative approach to explore how active music experience influenced on the parenting stress level. Qualitative research is used as a research method to study the concepts and behaviors of people in social science, and the issues or cases can be examined in depth. (Ansdell & Pavlicevic, 2001; Murphy, 2016; Short, 2008; Yin, 2014). It is appropriate to use a qualitative approach to take a look at the lives of this small group of people (Erkkilä, 2016). The findings cannot be generalized; however, it can be transferable to another setting. Yin furthermore described that the "case" is not simply a form of the qualitative research, saying (Yin, 2014)

The use of mix quantitative and qualitative evidence, along with the necessary for defining a "case," are but two of the ways that case study research goes beyond being a type of qualitative research. (p.19)

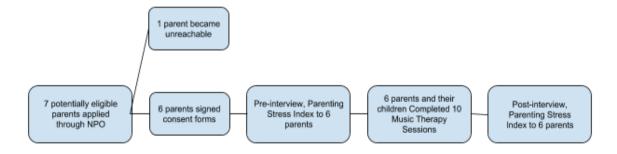


FIGURE 1. Study Flow Chart

4.2 Dual roles as therapist and researcher

Having multiple roles is complicated, yet this dual relationship as a researcher and a therapist often exists in music therapy research. As a researcher, the position is to gather data, analyze and understand the music therapy (Ansdell & Pavlicevic, 2001), as a therapist, the emphasis is on the client's well-being. The client also has this dual role as being a participant in the study and being a client in the therapy. I was aware of the need to balance my feelings between therapist and researcher, anxious I might interfere with the therapeutic relationship building by collecting the data I needed. Ansdell & Pavlicevic described the dual relationship as:

You are both the observer of the research process and the participant within it. You take full responsibility for the clinical relationship with clients, as well as for the quality, accuracy, and trustworthiness of the research materials. (p.104).

4.3 Participants

With the support from the local government and a non-profit organization in the Kyushu Region of Japan, five families were recruited. However, one family became unreachable for unknown reasons approximately one week before our first clinical work. Further investigation of this family was unable to be conducted since the contact person for this family cut off all communication from the researcher before starting the clinical process. When I recruited the participants, the following criteria was given to them:

- a. Family with a child diagnosed with Autism Spectrum Disorder under 11 years of age
- b. Parents who can participate in the music therapy session once a week totaling ten times
- c. Parents who are aware of their high level of parenting stress

Because of the nature of limited amounts of clinical sessions, I indicated "parents who are aware of their high level of parenting stress" under the criteria to match the client population to my study. When I received emails from the participants who enquired about the details of the study, I explained that the sessions would be 45 minutes, once a week, from June to August, 2017. I also explained that there would be active music making such as improvisation, re-creating experiences, and composing experiences during the music therapy session. By

having the four different families with their children of different ages, I was able to observe and obtain unique stories in different families. Recruited participants are displayed in Table 1.

TABLE 1. Participants

	Parents Interviewed	Parent's Age	Parent's Occupation	Child's Gender	Child's Age
Family A	Father	51	Full time worker	Boy	8
	Mother	44	Unemployed		
Family B	Father	33	Full time worker	Boy	4
	Mother	38	Unemployed		
Family C	Mother	50	Part Time Worker	Boy	11
Family D	Mother	44	Full time worker	Boy	8

Before beginning the course of clinical work, I obtained an informed consent to participate in the research study, as well as to film all of the music therapy sessions and interviews. I went over the document verbally with the participants and answered any questions they asked. Parents signed informed consent and children gave verbal consent. Throughout the work, I established a rapport with participants by respecting their thoughts and interests, and by providing a calm and comfortable environment (Ansdell & Pavlicevic, 2001).

4.3.1 Family A

Family A consisted of the father (51), the mother (44) and the boy (8). The family members walked into the therapy room with curiosity on their faces. Their application email was as simple as I ever saw. The father presented a calm and quiet attitude throughout the process. During the first few sessions, he often showed himself as a translator for his son. Whenever his son vocally or physically expressed something, the father interpreted it for me. He is usually the closest caregiver to his son. Boy A seemed to be severely impaired in both verbal-and nonverbal communication. He would stay in one position and look in the air with humming or vocalizing lines which were not understandable without his father's explanation. He was able to say simple greetings and phrases such as, "Hello" and "Thank you" with the encouragement of his parents saying, "say it" with a physical prompt of the mother tapping

Boy A's shoulder. The mother did not know if the music therapy was the right thing for the family. She knew that Boy A liked music because he would hum when he listened to music, and he would touch the instruments and make small sounds occasionally. Since Boy A was born, the mother said she let him listen to calm classical music, especially the ones with classical guitar. She thought that Boy A also liked soft classical music because he did not refuse to listen to it. During the music making, the father was the one who initiated the musical ideas followed by the therapist. He was initially excited about being in the music therapy session. He certainly made comments at every action his son made during and after the music making, trying to tell his son, "I am acknowledging you." The mother often arrived at the session looking tired. She participated in activities with minimal movement and energy in a rigid manner. The first sentence she verbalized during the interview, "My son does not like me," left a strong impact on me. Boy A was a calm and gentle boy. Ever since he walked into the session room on the first day and sat on the white couch in the room, the seat became his favorite spot. When he was regulated, he sat down on the couch and gazed at the fan on the ceiling while he hummed and softly vocalized. At other times, he could be sensitive to the sounds and communicate his likes and dislikes through vocal expression. When he liked the sounds, he would nod his head with a slight smile on his face. When he disliked the sounds, he would say, "片付け! Katazuke! (Clean-Up)." His expressive communication skills seemed to be quite limited, and he had only a few words he exhibited during music therapy. Although the parents did not see Boy A's singing ability before coming to the music therapy, Boy A sang and recorded a whole song by using the Garageband app during our recording project over sessions 5-8. He was usually withdrawn from socialization, although he could be responsive to others during the active music making.

4.3.2 Family B

Family B consisted of the father (33), the mother (38), and the boy (4). In the application email, the mother expressed that their son was newly diagnosed with ASD a few months prior and the parents were having a difficult time understanding him. Music was one of Boy B's interests, and the parents were expecting to bring changes to his life and explore alternative ways of relating to him. The father did not seem to fully grasp the role of his participation as a group member, although the mother took initiative to take part in the study. In this family, the

mother seemed to have a substantial responsibility to decide matters for the child. She often strived to obtain new sources for her son and expressed her admiration to the therapist's way of communicating with her son. Boy B presented himself as a creative and active boy with a wonderful sense of humor. Upon entering the session room, Boy B often took a walk along with his parents while the therapist was welcoming him with the greeting song. In these moments, Boy B and his parents vocalized along with the greeting song. From the very beginning of the session, the mother was actively singing and playing with him while the father seemed to observe how the mother and Boy B interacted with music. Although Boy B showed struggles to increase capacities, such as shifting his attention to the music, he consistently demonstrated an interest in playing the guitar and small percussion instruments within a musical environment. It seemed as if Boy B preferred to play the short musical theme along with the therapist and the parents' singing. The parents seemed to be exhausted at Boy B's hyperactivity at times. However, the parents showed their desire to understand Boy B within music and were being flexible to engage in musical play with their child. Also, he often enjoyed counting and jumping along with the song. However, movement requiring his grossmotor skills, which he liked, would also sometimes cause him to feel overwhelmed, so we had to monitor him and give tactile input sensitively.

4.3.3 Family C

The family consisted of the mother (50) and the boy (11). Boy C responded to music in various ways. Our meeting began with explaining to him the safety of the therapy room. According to the mother, he had a history of receiving lessons when he was between 3 and 6 years of age. He then became unable to continue his lessons after the piano teacher reported to his parents his inappropriate behaviors during the lessons several times. This incident was one of the traumatic events for his parents as it left them with a huge sense of rejection by someone whom they were looking to for the most support. Bringing her son back to the musical environment was a momentous decision for her. When he entered the therapy room, he noticed the clock hanging on the wall. He covered his ears immediately and asked me to bring the clock to the other room where he could not hear the sound it made. I accepted his request and invited him to move the clock to the storage next to the therapy room with me. Although we spent most of the time checking if there was another clock which made sounds,

it was a necessary process for him to make a safe place and be regulated to attend the therapy. During this time, the mother apologized to me several times saying,

「すみません。先生がかわいそうです」

"I am so sorry, I feel so bad he is doing this to you."

Her expression and the sentence were powerful as I still remember her face full of regrets. When he listened to the piano during our first meeting, he reacted to the sound quickly and came to the piano. From the very beginning of the music therapy session, Boy C developed an interest in a melodic activity, adding new melodies on top of the therapist's playing of a precomposed waltz on the piano. At the same time, I noticed his sensitivity to sounds as he could match the tone of his voice to the range of the piano I played. He was a talented improviser on the piano. However, he could be easily frustrated with the group member's unmatched musical playing. His mother usually played music with fixed tempo and tone with a commitment to each sound she made. The mother and Boy C were polar opposites in their way of playing. When the mother made what Boy C called an "error" while engaging in the drum playing, he was prone to exhibit rage and threatening behavior to the mother. At the end of session # 2, the mother shared that Boy C was happy about starting a music therapy session as he demonstrated his joy through talking, "I can start the piano again!" and hopping on their way home after the first session. As sessions progressed, our playing waltz on the piano extended to include movement and dance with the mother in the room. We would start playing the piano and gradually begin to move our bodies to the music and start to sing the melodies. Boy C watched me and anticipated sometime to start dancing. He was able to initiate movement as well as invite the mother to dance to the waltz together. During our third session, nearly the end of the session, I was playing C chord on the 1st beat with low C, C/6 on the third beat with low C, with a smooth attach on top of the mother's playing G - C ostinato on the resonator bells. Boy C joined playing G - C ostinato imitating the mother's playing. I began to sing, "Good Bye, Good Bye" according to the line we had and the boy continued "Thank you." Since then, this became our Goodbye song.

4.3.4 Family D

The family D consisted of the mother (48) and the boy (8). The mother was informative and did not hesitate to share about her child's history from the beginning of the parent interview. I was aware of my feeling of being intimidated by her in the pre-interview. When she was with her child, the group dynamics changed as she was much more relaxed and there seemed to be relatively mild discipline in the family. She spoke things in a roundabout way. Sometimes, she included phrases from movies to answer my questions. When that occurred, her meaning was often unclear to me and it required me to ask more questions to confirm if we had similar understanding of the matter. Boy D was a playful boy who liked to sing superhero songs, along with dynamic physical movement including jumping and skipping. He could express with simple language, however, stuttering and unique articulation were present. He would say "Kyukyo" instead of "Kuko" which means an airport in Japanese. His way of speaking contributed to his surroundings with people listening carefully while gazing at him and requesting him to repeat the phrases again and again, which possibly made it more difficult for him to initiate communication with people. Also, speaking in general seemed to be energy consuming for him. There were times I asked him, "What did you do at school today?" and he would say, "Mom, talk to her for me, please." The mother expressed music was the way she communicated with her son since he was born. She sang to him a lot when he was a baby. Nowadays, they listen to their favorite songs in the car on their way to school every morning. The mother particularly enjoyed playing the drum in the beginning, as she described, "I liked the tactile input from the drum when I beat it."

4.4 Music Therapy Procedure

From the beginning of the study, I was aware of the culture-related challenges. I was called "sensei," which is used to address school teachers and anyone knowledgeable or in a high position in their field. I was uncomfortable when I was first called "sensei," as it made me feel there was an expectation to build a teacher-student relationship in an Asian manner. Generally, children in Japan are trained to follow every direction from the teachers with a high amount of respect, modesty and decency. I also found similar manners shown by the parents. In the beginning of the music therapy phase, anything I would ask the children to do, the parents

would try convincing their child to follow my directions. Anything I would suggest to the parents, they would try to do their best to follow the task. I then considered the need of culturally appropriate intervention and a working style for the Japanese family. The following section will discuss more about the music therapy intervention and works with parents.

4.4.1 Timetable of Music Therapy Phase

The music therapy timeline was comprised of ten sessions lasting 45 minutes each, conducted once a week for three months. Since this study's aim was to see the pre- and post therapy effects in a short period, the therapist introduced the here and now aspects of their issues. Each session began with a Hello Song and closed with a Goodbye Song whether it was a pre-composed song or improvised song by the therapist. In the beginning phase, each session was structured with plans and the therapist took an active role to give group members directions.

Before starting the music therapy sessions, the room environment was arranged according to each child's needs. For example, Boy B was overwhelmed by the lighting of the room. During our first session, we had eight fluorescent lamps on the ceiling in the room. We noticed that the lighting of the room was beyond his tolerance as he screamed and did not stop spinning with his full strength. Upon discussing with his parents, we noticed that the fluorescent lamps might be bothering him. From the next session, we started to use floor lamps instead that provided tolerable brightness for him.

Sessions 1-3 were comprised of assessment sessions, with the use of different instruments and sounds. During sessions 1-3, the goals and objectives were discussed within the group members so that the group members could develop a realistic and rational attitude towards the choices they made. Sessions 4-8 were the working phase. In addition to the improvising experience, composing (song parodies) and re-creating experiences were introduced during this time. In this phase, the music therapy sessions were more structured than the sessions 1-3. In the sessions 9-10, group members had a chance to reflect on their experience and express their thoughts throughout the sessions.

4.4.2 Music Therapy Method & Intervention

During sessions 1- 3, improvising experiences on various instruments, both pitched and unpitched, were introduced to the groups. When a therapist meets clients for the first time, things might be unclear. Having too much structure limits the therapist's ability to authentically see the clients' needs. I decided to introduce the improvisational experience in the beginning phase of music therapy because it gives the clients and the therapist a more flexible and spontaneous manner in which to know each other by following the child's lead, and building a rapport through music. During this time, the empathy technique and structuring technique from the Bruscia's 64 clinical technique (1987) was mainly used. Bruscia described Techniques of empathy as:

One of the most powerful aspects of improvisational therapy is that the therapist has myriad ways of conveying empathy directly. This is accomplished by nonverbally matching or mirroring what the clients are doing. Matching the client serves to not only convey empathy but also to establish rapport and elicit an interactive response. (p.538).

Bruscia described Structuring Techniques as:

Grounding is used to help the client organize his/her improvising according to an underlying pulse, to stabilize the client's tempo, to help the client control his/her impulses, and to promote feelings of safety and stability. (p.539).

The therapist planned structured music activities and games according to each family's needs, and also directly encouraged each member to perform specific roles (Bruscia, 1998). The choice of music was made according to the family's preference and the child's needs. The recreative and composing experience was used to address communicating and exchanging ideas through music, exploring their specific roles in the family, and improving the interaction and group skills in the family (Bruscia, 1998).

Active Music Therapy Method was mainly utilized throughout the music therapy phase. As described in the literature review section, the active music therapy method includes composing, re-creating, and improvising music. Music Therapy Interventions include a demonstration of role-playing, a discussion focused on building self-esteem, decreasing anxiety, and developing a relationship with the child with autism. There are negative aspects to the role-playing as its purpose is strictly tied to the educational model and not the therapy level (Bruscia, 1998). In our case, however, the outcome of demonstrating role-playing and

allowing the parents to question the therapist was, as observed in later sessions, the parents beginning to act on their own initiative and changing their behavior to communicate with their child through music. Moreover, the parents expressed how observing the therapist's interaction with their child, and seeing the child find a unique way to relate to the therapist within music was one the most therapeutic experiences for them.

一番大きかったのは息子のここでの様子なんですよね。もちろん歌ったりとか一緒に過ごしたりしている様子見て、先生と和やかな感じで打ち解ける様子を見たりして、そしてそこから学べることもあったり、親としての嬉しさもあり、それを見て癒される

The most therapeutic experience for me was seeing my son here in the music therapy room, singing with him, watching him interact with the therapist harmoniously, leading us to learn. It was simply a joy for us. All of these things were healing for us.

Role-play and demonstrations within active musical interventions helps parents to develop a new capacity to communicate with their child via music, with less stress than verbal communication. At the beginning of a new activity, for example, I sang the welcoming song to the group members, and later sang to the parent, and then we had a discussion about it: What was the target of the song in the beginning? Why did the music therapist do something in a special way? What did the parents think would be best for their child? Finally, what did the parents think they could relay to their child through the song and so on? These types of questions were especially helpful in the beginning of the whole process, when the parents might have felt a bit uncertain of their roles in the group. Through discussion, the parents gained resources from music therapy.

Music Therapy offers new and different ways for parents of children with autism to think about their tasks or problems they face in life. Introducing to them that there is not "one" solution to a problem is invaluable; there could be several options to communicate with and reach their child. By introducing them to musical communication and explaining about it, letting them do the same thing differently, and encouraging them to do different things, the parents gain flexibility.

4.5 Research Instruments

4.5.1 Parenting Stress Index

When researchers conduct a study in a specific culture, they must notice the cultural difference before applying the results to other cultural contexts (Saarikallio, 2012). While there are many instruments available to measure parenting stress, I decided to use the Parenting Stress index Japanese second edition. The Parenting Stress Index (PSI) developed by Richard R.Abidin has been translated into more than 25 languages as it is the most effective tool for measuring the parenting stress related to child rearing, and it has been utilized in various scenes of research and clinical use. The Japanese version of Parenting Stress Index, Second Edition is a 78-item measure used to explore parental stress levels of a parent who has a relationship with his/her child between the ages of 3 months to 12 years (Kanematsu et al., 2015). This Japanese version of the Parenting Stress Index, Second Edition was re-developed for the particular use of Japanese parents, not just a literal translation into Japanese.

It is a highly accurate childcare stress scale conforming to Japanese culture, reliability and validity (Kanematsu et al., 2015). PSI can help parents to assess parenting stress, parents' and family problems, aid early discovery of cases requiring assistance and help parents to understand the effects of assistance and programs such as parenting counseling, as well as research tools (Kanematsu et al., 2015). Also, PSI gives parents a chance to observe themselves in the child-rearing period. It is essential for effective intervention in crisis situations, as it focuses on preventative intervention by allowing detailed assessment of not only the stress level but also which area the stress is derived from. It is used not only for healthy children, but for children with chronic diseases and developmental disorders, and it is possible to know their characteristics. The author of the Japanese version of PSI incorporated two domains to explore the stressors in parenting: a) child characteristics, and b) parent characteristics.

Scoring System

PSI is to explore the parenting stress levels of parents who have a relationship with their child aged 3 months to 12 years, and the index is to be answered by the parents themselves. 78 of

the items on the total stress scale are in Likert type scale from strongly disagree to strongly agree. The approximate time to complete the index is 20 minutes, and it requires elementary school grade 4 to 5 reading skills to answer the questions. Raw scores of each item are calculated, and they are added together to the two primary domains, Child or Parent. Finally, the scores from the two domains are summed to show the total stress score. Numbered scores are transferred from the scoring sheet to percentile scores based on a normed sample in Japan. Percentiles are derived from the frequency distribution of standard samples of 1109 parents in Japan. The average total score varies from 15 % to 80 %. The total scores 85 % to 89% are interpreted as high, and 90% or above are considered clinically significant (Kanematsu et al., 2015).

Child domain

In the child domain, it is possible to predict the level of psychological adaptation of the child at that time. The child domain includes seven subscales (C1 to C7); Reinforces parents; Mood; Acceptability; Distractibility/Hyperactivity; Hangs around parents; More problems/worries; Sensitive to stimuli. These categories suggest a type of problem behavior the child might show (Kanematsu et al., 2015). If the score in the child domain is higher than the parent domain, it can be interpreted that the child's characteristics are the main cause of contributing to the overall stress in the parent-child system. In such a case, intervention is necessary to focus on the problematic aspect of the child in order to decrease parenting stress (Kanematsu et al., 2015).

Example questions for the child domain are:

I think my child does not seem to smile as much as other children.

My child turned out to be more of a problem than I had expected.

Parent domain

The parent domain indicates whether the cause of the loss or the potential malfunction of the parent-child system is related to the parents themselves. The parent domain includes eight subscales (P1 to P8); Role restriction; Isolation; Spouse; Competence; Depression; Sad/uneasy feeling after leaving hospital support; Attachment; Health. Young parents and

parents who feel limited in their ability to build a relationship with their children tend to show a high score on the parent domain. Such parents often have experienced setbacks as parents, with a lack of confidence as parents. When the therapists work with parents, it is necessary to provide an environment for them to feel better about themselves, simultaneously supporting parents to build self-esteem before addressing the child's issues.

Example questions for the parent domain are:

I find myself giving up more of my life to meet my children's needs than I ever expected.

I feel alone and without friends.

4.5.2 Parents Interview

I conducted interviews with the parents pre- and post- the music therapy clinical phase. The primary purpose of having the pre- music therapy parents interview was to gather background information, to become familiar with the parents' current struggles with their child, and to have them fill out the Parenting Stress Index form. After the interview, I gave the parents a consent form that information shared during a clinical period would be included as data for my thesis study. Upon reading through the consent form with the parents, I received their signed consent and the verbal agreement of further participating in this study. I of course reminded them that they had the right to withdraw from the study at any time. At the end of the music therapy clinical phase, parents were invited to the post experience interview. This time, the parents were asked to share their overall experience in music therapy, notice changes in their parenting stress, and share what they felt were the significant moments in the music therapy sessions. They were asked to complete the Parenting Stress Index form again to assess the levels of parenting stress after the music therapy phase.

The interviewer used a semi-structured interview method, employed to encourage the participants to share their stories freely (Croucher, 2015). A semi-structured interview was a flexible tool with open-ended questions. The interview covered three key areas: (a) parents' perception of their child's capacity in music; (b) causes of parenting stress; and (c) their thoughts and reflections on the music therapy experience (Ansdell & Pavlicevic, 2001; Croucher, 2015). I developed a series of interview questions, which helped me to guide clients

to provide feedback. During the interview, the interviewer brought up the topic by saying, "Let's talk about ..." then moved into specific questions. When the client was distracted and ended up talking about an off-topic matter, the interviewer guided the participants to stay on topic by verbally saying, "Tell me more about....". Each interview lasted about an hour to an hour and a half. At the end of the interview sessions, parents were asked to fill out the Parenting Stress Index III. The child was not interviewed for this study as the theme was focused on the parents' experience in the music therapy.

4.5.3 Observation and Video Recording

The music therapy sessions and interviews were video recorded as data. In addition to the video recordings, I observed the participants inside and outside of the music therapy sessions. Observations began as they entered the music therapy room and ended as they exited the room. Casual talk outside of the clinic was also considered as data in this study. When this type of communication happened, I did not take out my phone to recorder and risk breaking the natural conversation flow. Instead, I took notes after the conversation. By looking back at the session videos and interviews, I was able to find the meaningful moments in the clinical process, and think about what was created in those moments. I value the qualitative data as importantly as the numerical data to have a better sense of each family's experience in music therapy (Bradt, Burns, & Creswell, 2013).

5 ANALYSIS

After collecting and scoring the Parenting Stress Index results and analyzing the quantitative data, the Wilcoxon signed rank test was conducted to see if there was a significant change between the pre- and post- therapy test results by using the SPSS. I was aware that the PSI was a self-report questionnaire, and as such the stress levels might deteriorate depending on the therapy process, with the changes of relationships within the family and the gaining of self-awareness. I paid attention to look at the meaning of changes based on the context of each person, each dyad, and each family. I also paid attention to each domain, child and parent, with subordinate concepts, which allowed analyzing in detail where the changes occurred.

All of the parent interviews were transcribed by myself. I watched the interview films multiple times to check the accuracy of the transcripts and to catch the nonverbal behaviors such as facial expressions, physical postures, and pauses. When I analyzed the qualitative data, thematic analysis was employed to identify significant statements, name the appropriate codes, and group them into either child domain or parent domain. After transcribing the pre- and post-therapy interviews, I followed this six-phase framework for reaching and reporting the major themes:

- 1. Familiarizing yourself with your data
- 2. Generating initial codes
- 3. Searching for themes
- 4. Reviewing themes
- 5. Defining and naming themes
- 6. Producing the scholarly report (Braun & Clarke, 2006, p. 87)

I then watched videos of the music therapy sessions to find the relevant moments in the active music experience that would help me to understand the relationship between the changes in their parenting stress level and their music. By watching the significant moments in session

videos and reading the transcribed interviews multiple times, several themes were identified. I returned to the data and repeated the process. As I conducted my study to examine the perception of the parents, the most important requirement was to listen to what the parents were saying, understand them without misinterpretation and avoid bias as much as possible. When translating the Japanese text to English text, it required sensitivity to consider individual differences in their expressive communication (Kim & Elefant, 2016). In many situations, it is common to use an in-directive way of communication in Japan. For example, Mother D would use metaphor to describe her feelings and events in the music therapy. She would use scenes of movies to describe the musical communication. When I look back at the script of her explaining one musical communication with her son, I found no musical words. Other researchers might find a completely different interpretation without the experiences of interacting with her. For Mother D, looking back to the therapist self-reflection was extremely important to confirm the validity of the study (Kim & Elefant, 2016). These analytical procedures and the results obtained from them are described in the next chapter.

6 RESULTS

6.1 Parenting Stress Index score

Total score

A Wilcoxon signed rank test revealed a statistically significant reduction in total score of statistics following participant in the active music therapy experience, z= -2.023, p <.05, with a large effect size (0.825). The median score on the child domain decreased from pre-program (Md =218.000) to post-program (Md = 210.000). Figure 1 shows the changes of total scores pre-music therapy phase and post-music therapy phase. The data indicates all participants, except Mother C, had their parenting stress decreased in this period. The largest change was in Mother D, where the total score decreased from 63 % to 15 %, whereas the smallest change was Mother C, with no change from 93 % to 93 %. Father A and Father B also had a large decrease. For Mother B, the decrease in stress was subtle from 85 % to 75 % whereas Father B had a large decrease from 40 % to 10 %. Four participants' experienced more stress than the average, and scored 85 % or more.

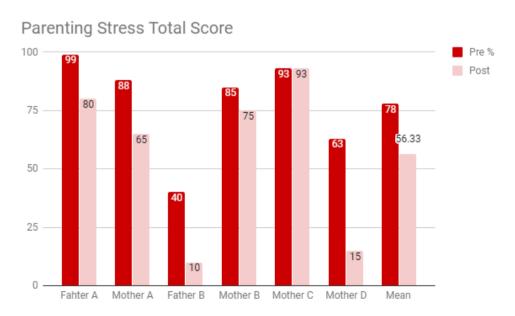


FIGURE 2. Changes in the total score according to the Parenting Stress Index results.

Child Domain

A Wilcoxon signed rank test revealed a statistically significant reduction in the child domain of statistics following participation in the active music therapy experience, z= -1.992, p <.05, with a large effect size (.813). The median score on the child domain decreased from preprogram (Md =112.000) to post-program (Md =94.500). Figure 2 shows the changes of the child domain score pre-music therapy phase and post-music therapy phase. Four participants experienced significant decreases after the music therapy phase. For Mother B and Mother C, their stress levels in the child domain remained from the pre-program 95 % to the post-program 95 %. The largest change was in Mother D, where the total score decreased from 95 % to 40 %. The decreased amount of four participants was larger compared to that of the parent domain.

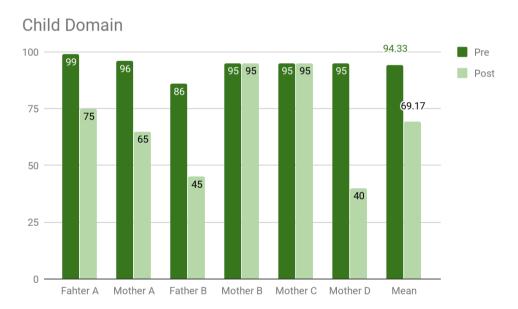


FIGURE 3. Changes in the child domain score according to the Parenting Stress Index results.

Parent Domain

A Wilcoxon signed rank test revealed a statistically insignificant reduction in the parent domain of statistics following participation in the active music therapy experience, z=-1,897, p >.05. The median score of the parent domain increased from pre-program (Md=106.000) to post-program (Md= 107.000). The difference between the variables after receiving the music therapy was small.

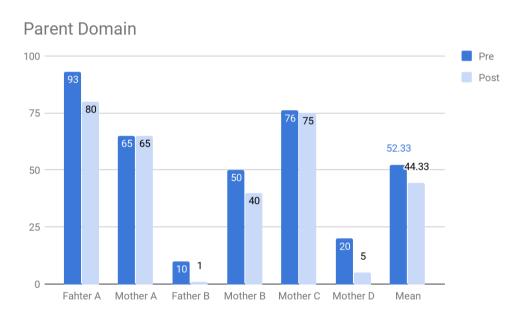


FIGURE 4. Changes in the parent domain score according to the Parenting Stress Index results

6.2 Interview Results

The results of the interview revealed (a) causes of parenting stress; and (b) their thoughts and reflections on the music therapy experience. Pre-interview data supports the results of the Parenting Stress Index, and this perception was further described by categorizing interview data into themes. The pre-therapy interviews revealed that the parents perceived stress sources in various ways, such as communication with their child, their child's acceptance of them, their child's adaptability to new environments, and role restriction as a parent of a child with autism. For example, five parents made commentary on communication with their child. Mother C stated,

「ほぼ、何を考えているのかもよくわからないし。」

"Well, most of the time, I have no idea what he is thinking."

and Mother B stated.

「私が息子が何を伝えようとしているのかがよくわからなくて、彼も彼なりに頑張って発信するんだけど、わからなくて疲れる。結局最後には喧嘩みたいになって、 泣きつかれて。」

".... It is because of me, I am not able to understand what he is trying to convey, he tries his best to tell me, but I get tired of not being able to understand him. In the end, it is like a fight, and we are both tired from crying."

When mother B stated this, she expressed her guilt through her facial expression and increased voice volume. Father A spoke on communication with feelings of disappointment by saying,

「言葉でのコミュニケーションは難しいですね。親とのコミュニケーションもお父 さん、お母さんって呼ばれた事もないですし」

"It is difficult to communicate with him. Even the communication between us, a father and a son, we have never been called, 'dad' or 'mom' for example..."

These statements informed me that their dominant way of communicating with their child had been limited to verbal communication throughout their lives, which if continued, might lead to neglect of the child who is limited in verbal communication. However, the music therapist observed the contrary situation in the music therapy sessions. Parents, who were usually comfortable, had a chance to experience struggles in communication like their child, who was finally flourishing in their capacity to express himself in music. Their hierarchy in verbal communication was easily reversed in the active music making.

All six parents noticed and made comments on the child's adaptability to the new environment. The first words Mother A stated in the first session were,

「先生や新しい環境に対しては結構敏感で、今日もドキドキしながら来たんですが、 部屋に入れて一安心です」

"He is very sensitive to people he meets for the first time and new environments, so I was nervous if he could enter the room. I am relieved since he was able to come into the room today."

She stated this comment without being asked a question by the interviewer. It seemed as though she naturally needed to share her feelings of relief. This communicated to me that her maladaptive thinking occupied her mind in everyday life, having a frightening and powerful impact on her mood. There were similarities regarding "entering the room" in what Mother C said too,

「音楽の授業でも音楽室に入れなかったりするんですよね。子供の泣き声とかで。 音楽とかすごい好きで、音程も取れるし、正確に歌ってるし。音に敏感というとこ るで。。。」

"He, for example, cannot enter into or participate in the music class because he is sensitive to his classmates' crying. He likes music, he sang a song in tune correctly, but because of his sensitiveness to the sound, he has to suffer."

Through the analysis of the pre-therapy interviews, feelings of shame experienced as a result of the child's lack of adaptability was made clear by three parents. Father B stated,

「はじめての場所なんかに行くと、すごくうろうろするし、人の目が気になる」

"Whenever we go to a new environment, he wanders aimlessly around, and I feel like people are looking at us,"

「自分も慣れていない環境に息子と二人でいるとき、泣き出したり癇癪を起される と、ちょっと困ります」 "I get in trouble when my son starts to cry or have a tantrum when I am alone with him in an unfamiliar environment."

There was a difference between the mother's and father's perception on the child's lack of adaptability. In contrast to Father B, Mother B commented,

「私は逆にかかわりのある人とか、そういう人の中のほうが気を遣う」

"I, on the other hand, I can be nerve-wrecked in a group of people I know."

Mother B further continued,

「関わり方が違うもんね。平日の公園でママたちととか。」

"Well, because we have a different way of interacting with him, you do not know what it is like to be in the park with him weekday afternoons with other moms."

Throughout the interview, parents would make statements that gave me an idea about their role restrictions. One can have different roles as a parent of a child. The comments parents stated could apply to any parents. Mother A made this statement,

「この子の自閉症が分かって、私が思ったのは、この子のせいで自分のしたいことを諦めるのはやめようと思っています。この子のせいで私が何かをできない、っているのは違うと思うし。」

"After I received his diagnoses, what I thought was, I should not give up things I want to do because of him. I don't think it is right that I cannot do things because of him."

Mother D made a statement about herself,

「自分の中に入りたい時があるんですが、その時間が持てない時間が続くと、ちょっと、ストレス。」

"I want to have time for myself sometimes. If I cannot have that time... I would be stressed out."

These statements helped me to identify their dilemma of balancing their lives as parents and their personal lives. However, in terms of the role restrictions, only Mother D made a positive comment on her specific role as a parent of a child with autism.

「息子が障害があることで今まで知らなかった世界が広がりました。」

"Because of his disabilities, I got to know a world I did not know before."

She further continued,

「できないことが明確に凹んでいることで、逆にできることはものすごく顕著に現れる。親としては、この子のできることをもっとサポートしてあげたい。」

"The difference between what he can do and what he cannot do is obvious. Because of his challenges, his ability is remarkably highlighted. I would like to give him more support to develop his skills, focusing on what he can do rather than focusing on what he cannot do."

She expressed her desire of wanting to focus on her child's strengths instead of weaknesses, whereas the other parents stated their desire of focusing on their child's weaknesses to be changed and developed.

It was clear that every parent had an expectation or hope for their child's development. Particularly, they wanted their children to have more opportunities to share, relate and communicate with others. Father A said,

「私は彼はもっと喋れると思うし、簡単なことは言えると思うんです。音楽で気持ちを開いてくれればと思うんですよ」

"I think he can speak more, and communicate more through easy phrases. I want him to open up through music."

Mother A continued,

「表現する機会を設けたいと思っています。それが音楽なのか、芸術か、彼がが表現できるものが何か一つあれば」

"We want to have opportunities for our son to express himself. Not sure if it is through music or art, but it would be good if he has one which he can use to express himself."

Through these statements, the parents showed the expectation that their child could come to express himself more verbally and nonverbally, and thought that having multiple ways of expressing himself is beneficial for their child.

During the post-therapy interview, parents' experiences in the music therapy sessions were highlighted. All participants stated that the active music therapy experience addressed their parenting stress in the child domain. They noticed positive changes in communication, and found similarities and positive emotions within the family. Parents agreed that the parenting stress for parents of children with Autism Spectrum Disorder should be addressed in child rearing. All participants stated the positive effects of using music in therapy as a form of alternative communication to build a relationship with their child.

Six parents stated positive effects of using active music experience in the therapy. They revealed they felt the music was an alternative form of communication that could help them to build a relationship with their child. For example, after the activity that involved call-and-response drumming play (giving and asking), Father B stated,

「最初は彼が本当に宇宙人みたいだったのが、段々とコミュニケーションとれて、 音楽でやりとりが出来るようになった。」

"In the beginning, he was like an alien to me. Eventually, we came to communicate with each other. We could communicate through music."

He noticed changes in communication throughout time spent in the music therapy sessions, and the way he described his son as an alien expressed the distance he felt towards his son.

Until his eighth session with his son, he was wondering why the music-involved communication was not such struggle for him. He then described that he saw his son's purposefulness while he was engaging in turn-taking, call and response, and exchange instruments, which he did not experience in a verbal forms of communication with his son. He concluded that the use of music was definitely a plus for their family in terms of smoother communication and less stress. Furthermore, Mother B continued after Father B by saying,

「例えば言葉とかだったら、私には分かって他の方には分からないのがあるけど、 音楽だったら共通の言語っていうか、子供とイコールになれる。」

"For example, if we have only verbal language, there can be situations that I understand and do not understand, however, music is like a common language for us, and I can feel on an equal level with my son."

Here, the statements from the parents express they are flexible and are open to modify their ways of communication with their child, from verbal to musical. The parents were able to feel contentment in communicating with their child.

Another participant discussed the benefit, not only from the parent's perspective, but also from the child's perspective, comparing their experience of seeing their child in another form of therapy. Mother A said,

「言語をメインにしたセラピーと比べると、音楽だと言葉に比べて本人からのアプローチがしやすいのかなって思いました。音楽を媒体して、そこに言葉足らずな部分があって本人もアプローチしやすい部分があって気が楽だったかなと思いますね。」

"I think it was more accessible for him to communicate through music as compared to verbal language-based therapy. Although he is insufficient in words, music could be the medium for him to approach us easily."

Mother D described her thoughts by using a scene from a movie she watched recently. She mentioned there was something transferable when each member shared a same style of communication or context with her son. She expressed it by saying,

「戦争で敵同士だった国が共通点を見つけて和解するっていうんですかね。」

"It was like a reconciliation between the countries that were enemies in the war after finding common ground."

The interviewer needed to confirm her understanding the meaning of "enemies" in this statement. Mother D revealed that there was a hidden conflict between her and her son which could not be verbalized well by either party because of his limited capacities in expressive communication and her assumption of his inability to receive communication. She continued,

「もし音楽じゃなくて普通に会話をしていたら一触触発だったんじゃないかと思う んですね。」

"If we continued to speak normally instead of with music, our relationship would be strained to the breaking point."

Here, Mother D described her experience of restoring the balance between her son and her family unit. She continued by expanding her capacity and changing her perception of music from a learning experience to a feeling experience.

「この歌知ってるってなった時に同じ人間だったから伝わったんじゃないかって思うんですね。今まで音楽を習い事とか自己研鑽の一つに考えていたんですけど、本当はもっと「感じるもの」というか。」

"When we thought we knew the song, we were able to convey ourselves because we are the same human being. I was thinking the music is a learning experience until recently, but there are actually more feelings involved in the activity."

Three parents made comments on positive emotions during and after the music therapy sessions, and two parents thought that they gained confidence as a parent of a child with autism. Mother B mentioned her motivation to come to the therapy was to seek out information and resources that would allow her to master new skills to solve problems. She further commented on the changes in her feelings,

「息子が何かに取り組んでいるのを一緒に見て、過程を経験するっていうのは、私 たちにとってとてもプラスになる。今後の自信に繋がる」

"Experiencing the process together with him was a positive experience for us. It lead us to gain confidence for the future."

Mother C revealed that the music therapy was overall effective, however, finding out her son was very sensitive to stimuli had a negative impact on her stress levels at one point. During her music therapy phase, she shared that she always had the emotions of worry and anxiety because of her son's reaction to auditory stimuli. During the post-therapy interview, she shared her experience of identifying her anxiety and worry about her son's reactions, which contributed to her parenting stress. She became more aware of controlling those emotions. She commented during the seventh session,

「この環境だけ、「不安」とか「心配」がやっと減ってきた。」

"Finally, my feelings of worry and anxiety are decreased, only during the music therapy sessions."

In contrast to Mother B's comment, Mother C thought the positive changes could be experienced only during the music therapy sessions, and would not contribute to her future state. Her words made the interviewer feel she did not have plans to continue alternative ways of communicating with her son in the future.

7 DISCUSSION

I compared the parents' responses to their parenting stress index and the semi-structured interviews about their experiences in music therapy. The results were congruent with the existing research as the parents of children with ASD experienced high-stress levels from their child's characteristics. Additionally, the use of music in the family-centered therapy brought positive outcomes to the families. However, the Williams et al. investigated the effects of music therapy for the mother-child dyad in a group setting, while I conducted music therapy sessions for two mother-child dyads, and two mother- father- child triads to examine the difference between the parenting stress pre- and post- music therapy sessions. I explored their changes in perception regarding their levels of parenting stress, and most importantly, gave a chance for them to let their voices be heard. Some parents compared their experience in the music therapy to other therapies they had received before.

The findings suggest that all of the parents who participated experienced high levels of parenting stress in daily life, with their score decreasing after the 10 music therapy sessions. Music therapy is helpful for the parents to work on nonverbal communication in a more efficient way than traditional treatment. Parents were happy about experiencing the process together with their child, to gain new capacities of interacting with their child, which cleared their uncertainty regarding the communication. The demonstration of role-playing and a directive attitude were frequently made available by the therapist.

In addition to the positive experience, parents' stories highlighted their past negative experiences and the need to address those in the therapy process. Interview results showed that parents of children with Autism Spectrum Disorder often experienced some sort of trauma. Those experiences include their child being mistreated, their inability to provide proper care they believe their child needs, and so on. Parents in general want to give their child every opportunity to have a community to support them, and the world around them to maximize their child's possibilities. Yet, due to their child's pathology, their difficulties in social interaction and communication, their children are often denied emotionally and socially from the community. Every time parents encounter this situation, they get hurt; however, not

many parents take care of to address these traumatic events. Instead, they ignore them, and as Mother C expressed about her experience with trauma, "I got used to it." Though this traumatic experience was pushed away from her conscious mind, its presence was always active and came back into her life from time to time. The music therapy session might have also triggered her to experience another phase of pain.

「私はいつも彼の音に対する反応が心配でした。 彼の耳が聴こえなかったらこんなに音に対して苦しむことはないのにな、と思うことがあります。そうすれば、彼が父親のくしゃみに反応したり、パニックになったりするのを見る必要が無くなります。彼の音に対する反応がなくなったときに、わたしの育児ストレスはなくなるのではないかなと思います。ここで、彼は音に対して普段とは全く違った行動をしていて、私は混乱さえします。なぜ父親の咳には酷く反応してピアノの音は大丈夫だったの?」

"I was always worried about his reactions to sound. Guess how many times I wished that he would be deaf so that he no longer suffered from the sound stimulus anymore. My stress will be gone when he becomes numb to sounds, so that I don't have to see him reacting to his father's sneezing, or getting panicked in public. Here, he acts totally different, and even that makes me confused. Why is he ok with the sound of the piano? Why can't he tolerate people coughing? He reacts to them like crazy."

I noticed my own feelings of alarm when I heard the mother's desperate prayer of wishing her son "would be deaf" in that situation. I knew that she was unable to accept her son's smile and enjoy the music in the session's room because of the past traumatic experience of him reacting to sound stimuli and becoming panicked. As a therapist, however, from the very beginning of the music therapy session, I noticed his wonderful sense of musicality and talents in improvisation. Boy C was engaged and responsive to the music from our first meeting. Music was his medium to relate to others and it was a meaningful moment for everyone who was present in the group. For Boy C, he was able to unleash his ability to relate to others nonverbally. In contrast, Mother C's musical behavior tended to be in certain manners isolated and rigid. The more and more the child engaged in the music, the more Mother C dissociated herself from the group. During the first several sessions, it was unclear to me that the mother hesitated to see her son's music in the music therapy session. I was frustrated with the mother for missing her son's remarkable musicality and not being able to celebrate these experiences in the group. Gradually, I came to notice how deep her trauma was towards her son's reactions to sounds, and how her mind was occupied by the thoughts of worry and anxiety whenever she was with her son. Her parenting stress might reflect her fears

concerning the child's behavior in social settings and parent's frustration of their child's betraying their expectation.

Family B expressed that they felt they were not able to get the support they believed necessary for their child. All of the parents who participated in this study experienced battles with care providers, such as schools, hospitals, and welfare departments, in order to get the support for their child. After being rejected by the care system, and not receiving adequate therapy information, parents became irritable enough to cause interruption to trust care providers. They described:

「助けを求めて行ったつもりが、余計に疲れてしまうんですよね。例えば、半年に一回市役所から手紙が届いて、面接に行かないといけないんですけど、行くと、育児書に書いてあるようなアドバイスを受けるんです。診断されているような、息子が普通の子か普通の子じゃないかを調べられているような気になります。この様な経験が積み重なると、人の事が信じられなくなるんですよね。人とのコミュニケーションに対してとても敏感になって、子どものケアに関わる人、全ての人がそうなんじゃないかって、怖くなるんですよね。実際に関わってもみないで、何が分かるのかって。」

"We go there to get help to ease our lives, but sometimes, it makes us more tired. For example, we receive a letter from the city municipals once in six months to come for a parents consultation. We have to go there and receive guidance. The officer usually gives us ordinal advises which we can find in the parenting books, you know. We felt like we were examined, like our child was examined to see if he was normal or abnormal. When I felt that my words were not appreciated, I invisibly shut my ears. Having these experiences makes us reluctant to trust people. We became very sensitive. We are afraid that any care providers are going to examine our child and tell us what to do. Without actually working with us, nothing is really helpful."

Parents of children with disabilities receive help in the child-rearing process in Japan. Though they clearly receive technological help from the social welfare from the municipals, the statement above gives feedback that is almost overwhelming. Here, I needed to confirm about the meaning of 助け "help" they were looking for in the Japanese context. The word he used in his interview was "help," however, the use of the alternative word he gave after the follow-up question in reference to "help" was "care," more specifically, "to treat with empathy." In such a sensitive situation, Father B described language might not be helpful.

I found the current therapy model was limited, unable to address those parents' negative experiences and trauma. Parents naturally prioritize their child, and the therapy is more child-centered when the child is present in the session. It is necessary to consider that the therapy setting with their child might have made it difficult for them to express their trauma related to the child's care since they were with their child there. This was problematic because the parents were not able to have an environment to explore their past experiences which should be done in the individual music therapy setting, and the music therapist could not provide it when the child was present. The model which was used in the study conducted by Lipponen (2014) seems to be the ideal solution to this as she supported the importance of a caregiver individual sessions for processing his or her crises in the past.

It was equally necessary to consider what I can do to address the parents' negative experiences and heal their trauma in the current model. Creating meaningful activities was one of the important goals during the music therapy clinical phase; in fact, music is an excellent medium to bring about meaningful moments. Music also provides time to heal traumatic experiences for the parents, and can eventually empower the parents (Aigen, 1996). Music provides a group a common flow by bringing them to experience the same rhythm, melody, and tonality (Bruscia, 1998). It should be noted that the meaningful moments experienced perceived by parents might be different than observed by the therapist. In the case of Family A, both the father and mother's levels of stress was significantly high (total stress score: Father=255/99 %; Mother= 225/88 %). After the music therapy phase, their results had significantly decreased, in both the parenting stress for the child domain sub scale and for the total score. The father A perceived that their lower parenting stress was linked to their perception of their child in music, as he felt he was more able to connect with his son through music, and it was a healing and meaningful experience for him.

「ただここでの様子なんです。本当に、息子がこのように音楽を通して人と触れ合う様子っていうのはここ以外の場所ではないんです。」

"It was just the scene in the music therapy room. Believe me, we won't be able to see how he interacts with others and sing or play as he does with you and us here in the music."

「彼が何を考えているのか大体わかった。彼の気持ちや嬉しさを感じているのを見たときに、 安心して癒されました。別れのときに見せた涙や悲しい表情さえも。表情を見るっていうこ とは私たちにとってとても貴重な瞬間なんです。」 "I was able to tell what he was thinking. I was relieved and healed when I saw his emotions such as his joy on his face, even his sadness and tears when he said goodbye. Seeing his emotions out on his face is rare."

What the father said in the interview reflected on the score of the "Reinforces parents" and "Mood" on the Parenting Stress Index. Seeing their child interested in the musical activity and being able to engage in the music together was an extraordinary moment for the family. For the parents, seeing their child singing with them and playing the instruments with them to the music brought joy and a sense of mutuality as a parents- child triad, which they had not experienced often in their lives. This was a meaningful moment for them; experiencing these moments eased their parenting stress levels. At the same time, meaningful moments empowered the parents to become more active in relating to their son in the music and increased mutual involvement.

Some stories from the parents during the pre-therapy interview revealed that the parents did not have intimate feelings with their children due to the difficulty to observe and understand their child's emotions, and two parents felt like they were rejected by their child. Without having an affirmative feeling towards their child, building an attachment was tough. The post-therapy interview suggested that the above described two parents displayed a potential change of their perception towards their child and began to feel a connection. It was a positive sign of their using music to build an attachment, which they had not been able to initiate earlier due to the feelings of being rejected by their son. Moreover, one of the parent's behavior towards the child changed significantly from giving negative feedback to positive feedback. Mother A stated in the pre-therapy interview,

「まあ、この子は私にはあまりなつかないので、主人の方がよくわかっています。私より主 人の方が大好きなんですよ」

"Well, my son does not really hang around me. My husband knows him better than me. He likes my husband better."

And Mother A stated in the post-therapy interview,

「あの、一緒に歌った時あったじゃないですか。息子が率先してマイクを握って歌った時あったじゃないですか。あのあたりからなんか変わったんですよね。『歌うよ、僕!」みたいな感じで歌ったんで、あれで、嬉しいなって思ったし。家で、家族で一緒にレコーディング

を聞いたんですけど、それを聞いている姿もなんだか嬉しそうで、それを見て、嬉しくて、 こういうのが好きなんだなって確認できた。」

"Well, you remember the time we sang together, the session he (son) grabbed the microphone and initiated singing. Since around that time, something has changed. Because he seemed to like telling me, "I am gonna sing!" that moment, I felt happy. We also listened to the recordings at home, and the way he was listening looked happy too, and we were happy, and, we were able to make sure that he likes it.

The mother mentioned that sense of mutuality several times in her statement. She had a positive feeling about making music with her son after seeing her son initiated singing. She thought her son was feeling the same when she was happy. Mother A noticed her perspective changed towards her child more positively from that moment in one session, and she thought that significant musical moment influenced her to change her way of viewing her son in the music therapy session.

As I conducted my study to examine the perception of parents, the most important requirement was to listen to what the parents were saying, understand them without misinterpretation and avoid bias as much as possible. When translating the Japanese text to English text, it required sensitivity to consider individual differences in their expressive communication (Kim & Elefant, 2016). In many situations, it is common to use in-directive ways of communication in Japan. For example, the mother D would use metaphor to describe her feelings and events in the music therapy. She would use the scene of the movie to describe the musical communication. When I look back her script of her explaining one musical communication with her son, I found no musical words. Other researchers might find completely different interpretation without the experiences of interacting with her. For Mother D, looking back to the therapist self-reflection was extremely important to make sure of the validity of the study (Kim & Elefant, 2016). A positive aspect of this working model is that it creates the collaboration of a music therapist and the parents, combining our individual areas of expertise into the therapy. Parents are active team members in this music therapy session. This requires that the parents, child, and the therapist share time, creativity, and the responsibility of setting and meeting goals in the therapy session (Bruscia, 1997). There was a positive effect for the parents in having a team approach to work with their child rather than one-on-one (the mother/father and the child) as discussed earlier. Whereas a parent feels too

challenged by the need to interact with their child one-on-one in everyday situations, parents can feel certain amount of security and nonverbal support from the team members who work with them during the therapy. The stress each member experience during/outside the therapy would be divided in a certain manner upon building a sense of *trust* and *mutuality* with other members, and that may be conveyed by other members although they are not very active in the moment.

"息子の行動に対して自分だけだったら諦めちゃいそうなところを、3人だったらできる事があった。普段1対1で接していると、どうしてもあきらめてしまうことがたくさんある。そして、疲れる。音楽療法のセッションでは違った。とてもいいちいさなことでも、夫と音楽療法士と一緒に真剣に話しあって解決した。夫と私と音楽療法士の3人で彼と同じ目線に立って一緒にやってみたりしたら、普段、母と息子ではできないことができた。 まるでストレスが3人で分割された感じで、それまで抱えていたストレスをもう抱えなくていいんんだなって"

"There was something we could do for him because we are three people in the team. If I am alone interacting with him, I would just give up so many things. I get tired, I get exhausted. During the music therapy session, it was different. Even a very little thing, we all sincerely thought about it. When I worked with my husband and Aiko, I was able to do things I normally cannot do in the 1 on 1 situation (mother and son). I was much more available to him. It is a feeling that the stress got divided up among two or more other people and I do not have to carry it all as much as I used to do."

Throughout the study, the parents demonstrated changes in their level of parenting stress and noticed their way of interaction with their child through active music experience. The time I spent with these four families raised challenges related to the family practice with children with Autism Spectrum Disorder. This experience brought up a question for future study: what are the differences in stress triggers of parents in other cultures, and what are the differences of addressing it through music therapy in other cultures? While I was working with these four families, they brought up issues that I believe they experienced only as families in a Japanese society. Such issues experienced within a certain culture were among things to consider when I decide the working style. It was important to understand the causes of struggles in their lives as parents of children with ASD in Japanese culture. This might be a unique experience for me, which native Japanese music therapists might not experience, because I was trained in other countries. What I experienced in my study does not necessary apply to similar client populations and models in other cultures. In the future, I would like to compare the perception of more parents of children with Autism Spectrum Disorder, and see if there are differences in causes of their stress and the ways of addressing it according to different cultures.

8 CONCLUSION

The purpose of this study was to explore the changes in parents' perception of parenting stress levels before and after music therapy sessions. The findings revealed that parents think the use of active music experience decreases the stress levels of parents whose children have Autism Spectrum Disorder. The findings of this study gives insight into the uniqueness of each parent's cause of stress, the parents' trauma, and the significant musical moments which triggered the parents to change their way of perceiving their parenting stress. The results from this study should be interpreted with caution due to the small size of participants. The sample size for this study was four families. Their participation results do not represent the whole of people who use family therapy and the results should not be generalized. I used active music experience differently for each of my participants' in accordance with their individual/ family needs. However, concerning the parents' voices, the qualitative results were significant. Increasing support and recognizing parenting stress as an important contributor in family dynamics may inform music therapists in the family practice to meet the needs of parents and children with Autism Spectrum Disorder. It is incredibly important that possible treatments and care be discussed and made available for those parents of children with disabilities (Smith & Innocenti, 2001). While many studies concerning children with Autism Spectrum Disorder exist in music therapy literature, the child's developmental behavior and manners tend to be the focus of the studies. By contrast, this study focused on the influence of an active music experience on parenting stress levels within the family. The therapeutic process might begin with a focus on the child's challenging behavior, then extend to other members in the family until the whole unit is included (Bruscia, 1998). The results of this research will help music therapists who work with children of neurodevelopmental disorders to realize the issues parents experience at home, and to expand the music therapy practice from individuals to the multiple members involved in a family context. The author hopes that music therapy with families becomes an established model and more accessible for the families in Japan. The goal is to resolve detrimental family conflicts and prevent negative secondary symptoms from arising in the children.

REFERENCES

- Aigen, K. (1996). The role of values in qualitative music therapy research. In M. Langenberg, K. Aigen, & J. Frommer (Eds.), *Qualitative music therapy research: Beginning dialogues* (pp. 9–33). Phoenixville, PA: Barcelona.
- Allgood, N. (2005). Parents' perceptions of family-based group music therapy for children with autism spectrum disorders. *Music Therapy Perspectives*, *23*(2), 92-99. Retrieved from http://search.proquest.com/docview/726950
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Ansdell, G., & Pavlicevic, M. (2001). *Beginning Research in the Arts Therapies: A Practical Guide*. London: Jessica Kingsley Publishers.
- Baker-Ericzén, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, *30*(4), 194-204.

 10.2511/rpsd.30.4.194 Retrieved from http://journals.sagepub.com.ezproxy.jyu.fi/doi/abs/10.2511/rpsd.30.4.194
- Barker, P., & Chang, J. (2013). The Development of Family Therapy. In Barker, P., & Chang, J. (Eds.), *Basic family therapy*, 6th *Edition*. (pp. 1-18). Hoboken, NJ: John Wiley & Sons.
- Bradt, J., Burns, D. S., & Creswell, J. W. (2013). Mixed methods research in music therapy research. *Journal of Music Therapy*, *50*(2), 123-148. Retrieved from https://search-proquest-com.ezproxy.jyu.fi/docview/1426029119?accountid=11774
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. doi:http://dx.doi.org.ezproxy.jyu.fi/10.1191/1478088706qp063oa
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.

- Carpente, J. (2011). Addressing Core Features of Autism: Integrating Nordoff-Robbins Music Therapy Within The Developmental, Individual Difference, Relationship-Based DIR ®/FloortimeTM Model. In Meadows, A. N. (Ed.), *Developments in music therapy practice: Case study perspectives.* (pp. 134- 149) Gilsum, NH: Barcelona Publishers.
- Croucher, S. M. (2015). Understanding communication research methods: A theoretical and practical approach. New York; Oxfordshire, England: Routledge.
- Deater-Deckard, K. (2004). *Parenting stress*. Retrieved from https://ebookcentral.proquest.com
- Dickstein, S., Seifer, R., & Albus, K. E. (2009). Maternal adult attachment representations across relationship domains and infant outcomes: The importance of family and couple functioning. *Attachment & Human Development, 11*(1), 5-27. doi:10.1080/14616730802500164
- Dyson, L. L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning, and social support. *American Journal of Mental Retardation : AJMR*, 102(3), 267. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/9394135
- Erkkilä, J. (2016). Mixed methods research in music therapy. *The oxford handbook of music therapy*. Oxford University Press. doi:10.1093/oxfordhb/9780199639755.013.12
- Flower, C., & Oldfield, A. (2008). *Music therapy with children and their families*. London: Jessica Kingsley Publishers.
- Jacobsen, S. L., McKinney, C. H., & Holck, U. (2014). Effects of a dyadic music therapy intervention on parent-child interaction, parent stress, and parent-child relationship in families with emotionally neglected children: A randomized controlled trial. *Journal of Music Therapy*, *51*(4), 310-332. doi:http://dx.doi.org.ezproxy.jyu.fi/10.1093/jmt/thu028
- Jacobsen, S., & McKinney, C. (2015). A music therapy tool for assessing Parent–Child interaction in cases of emotional neglect. *Journal of Child and Family Studies*, *24*(7), 2164-2173. doi:10.1007/s10826-014-0019-0

- Jacobsen, S. L., & Thompson, G. (Eds.). (2016). *Music therapy with families: therapeutic approaches and theoretical perspectives*. Retrieved from https://ebookcentral.proquest.com
- Jones, L., Bellis, M. A., Wood, S., Hughes, K., McCoy, E., Eckley, L., . . . Officer, A. (2012). Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies//doi-org.ezproxy.jyu.fi/10.1016/S0140-6736(12)60692-8 Retrieved from http://www.sciencedirect.com.ezproxy.jyu.fi/science/article/pii/S0140673612606928
- Kerr, C., Hoshini, J., Sutherland, J., Parashak, S., & McCarley, L. (2007). *Family art therapy: Foundations of theory and practice*. New York, NY: Taylor & Francis.
- Kim, S., & Elefant, C. (2016). Multicultural Considerations in Music Therapy Research. In Murphy, K., & Wheeler, B. (Eds.), *Music therapy research : Third edition* (pp. 277-305) Dallas, TX: Barcelona Publishers.
- Kimura, M., & Yamazaki, Y. (2016). Physical punishment, mental health and sense of coherence among parents of children with intellectual disability in japan. *Journal of Applied Research in Intellectual Disabilities*, 29(5), 455-467. doi:10.1111/jar.12198
- Lessenberry, B. M., & Rehfeldt, R. A. (2004). Evaluating stress levels of parents of children with disabilities. *Exceptional Children*, 70(2), 231-244. Retrieved from https://search.proquest.com/docview/201221028?accountid=11774
- Maratos, A. S., Gold, C., Wang, X., & Crawford, M. J. (2008). Music therapy for depression. *The Cochrane Database of Systematic Reviews,* (1), CD004517. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/18254052
- Matsuo, R., Inoue, M., & Maegaki, Y. (2015). A comparative evaluation of parent training for parents of adolescents with developmental disorders. *Yonago Acta Medica*, *58*(3), 109. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/26537096
- Nemesh (2017) Family Therapists' Perspectives on Implementing Musical Interventions in Family Therapy: A Mixed-Methods Study, *Journal of Family Psychotherapy*, 28(2), 118-133, DOI: 10.1080/08975353.2017.1285655

- Nomura K, Kaneko K, Honjo H, Yoshikawa T, Ishikawa M, Matsuoka M, Tsujii M. Kōkinōkōhanseihattatsushōgai-ji no hahaoya no yokuutsu ni tsuite (2010). [Depression in mothers of children with high-functioning pervasive developmental disorders]. *Psychiatria et neurologia paediatrica japonica*, 50, 259-67.
- Oldfield, A. (2006). *Interactive music therapy-A positive approach: Music therapy at a child development centre*. Retrieved from https://ebookcentral.proquest.com
- Pasiali, V. (2013) Music therapy and attachment relationships across the life span. *Nordic Journal of Music Therapy*, 23(3), 202-223. DOI: 10.1080/08098131.2013.829863
- Perry, M. M. R. (2003). Relating improvisational music therapy with severely and multiply disabled children to communication development. *Journal of Music Therapy*, 40(3), 227-246. doi:10.1093/jmt/40.3.227
- Rönkä, A., Sevön, E. (2017). Lecture 2: How we study and approach families Macro and micro perspectives [PowerPoint slides]. Retrieved from University of Jvväskylä KOPPA: https://koppa.jyu.fi/
- Saarikallio, S. (2012). Cross-cultural approaches to music and health. In MacDonald, R.A.R., Kreutz, G. & Mitchell, L (*Eds.*), *Music, health, and wellbeing*, (pp. 477-490). Oxford: Oxford University Press.
- Schwartz, E. (2008). Music, therapy, and early childhood. Gilsum, NH: Barcelona Publ.
- Short, C. A. (2008). 'What is architectural design research?' *Building Research & Information*, *36*(2), 195-199. doi:10.1080/09613210701811015
- Silva, L., & Schalock, M. (2012). Autism parenting stress index: Initial psychometric evidence. *Journal of Autism and Developmental Disorders*, *42*(4), 566-574. doi:10.1007/s10803-011-1274-1
- Smith, T. B., Oliver, M. N. I., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry*, 71(2), 257-261. doi:10.1037/0002-9432.71.2.257
- Sorel, S. (2010). Presenting Carly And Elliot: Exploring Roles And Relationships In A Mother-son Dyad In Nordoff-robbins Music Therapy. Gilsum: Barcelona Publishers.

- Retrieved from https://search-proquest-com.ezproxy.jyu.fi/docview/1170851233?accountid=11774
- Thompson, G. (2012). Family-centered music therapy in the home environment: Promoting interpersonal engagement between children with autism spectrum disorder and their parents. *Music Therapy Perspectives*, 30(2), 109-116. Retrieved from https://search proquest-com.ezproxy.jyu.fi/docview/1348605261?accountid=11774
- Thompson, G., & McFerran, K. S. (2015). "We've got a special connection": Qualitative analysis of descriptions of change in the parent–child relationship by mothers of young children with autism spectrum disorder. *Nordic Journal of Music Therapy*, 24(1), 3-26. doi:10.1080/08098131.2013.858762
- Yin, RK (2014). Case Study Research: Design and Methods (5th edition.). Los Angeles: SAGE.
- Williams, K. E., Berthelsen, D., Nicholson, J. M., Walker, S., & Abad, V. (2012). The effectiveness of a short-term group music therapy intervention for parents who have a child with a disability. *Journal of Music Therapy*, 49(1), 23-44. doi:10.1093/jmt/49.1.23
- World Health Organization. (2013) Autism spectrum disorders & other developmental disorders From raising awareness to building capacity. Geneva: World Health Organization.
- Kanematsu, Y., Asano, M., Araki, S., Arayasiki, R., Ohashi, Y., Narama, M., Maru, M. (2015). PSI Ikuji sutoresu indekkusu 2 tei-ban [Parenting Stress Index second edition]. Tokyo: Koyou Mondai Kenkyukai.