

Creating bridges

Music-Oriented Counseling for Parents of children with Autism Spectrum Disorder

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**CREATING BRIDGES: MUSIC-ORIENTED
COUNSELING FOR PARENTS OF CHILDREN
WITH AUTISM SPECTRUM DISORDER**

**BY
TALI KARPMAN GOTTFRIED**

DISSERTATION SUBMITTED 2016



AALBORG UNIVERSITY
DENMARK

**CREATING BRIDGES: MUSIC-
ORIENTED COUNSELING FOR
PARENTS OF CHILDREN WITH
AUTISM SPECTRUM DISORDER**

A MIXED-METHODS STUDY

BY

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CV

Tali Gottfried studied Singing and Performing Arts at 'Rimon, School for Jazz and Contemporary Music' in Ramat-Hasharon, Israel. In 1998, she gained her Bachelor degree in Music and Movement Therapy at Levinsky Colledge in Tel-Aviv. Tali has been working with children with special needs since 1999, and was case manager for children with autism spectrum disorder since 2001. Her clinical work focuses on children with neurodevelopmental challenges and working collaboratively with the parents of the children within a music therapy perspective. In 2010, she gained her Master in Music Therapy at Bar-Ilan University, Israel; her Master thesis investigated the musical language of children with high-functioning autism. In November 2011, she was awarded with a scholarship by Aalborg University for doctoral research. She so far presented different aspects of her clinical and research work in Austria, Denmark, Germany, Israel, Norway, and Spain.

Tali is the owner of a private music therapy clinic for children and their families. She is a lecturer at the M.A.A.T program at David-Yelin College, Jerusalem, Israel, and at the MA for music therapy program at Bar-Ilan University, the Jerusalem branch, Israel.

Since 2014, Tali is the elected Israeli delegate to the European Music Therapy Confederation (EMTC).

DECLARATION

I hereby declare that neither this thesis nor part of the thesis have previously been submitted for a higher degree to any other university or institute in Denmark or abroad.

Tali Gottfried

Tali Gottfried

___June, 1st, 2016___
Date

ENGLISH ABSTRACT

This study set out to further develop, strengthen, and test a parent counseling approach in music therapy. Studies show that parents of children with autism spectrum disorder (ASD) endure a significant amount of stress - not only compared to parents of typically developed children, but also compared to parents of children with other developmental disabilities. One source of increased stress for these parents includes difficulties in communicating with their child; as impairments in communication and social skills are at the core of ASD. Another source for increased stress is the insufficient access to professional help that could provide support to both the child and the parents. This limited access points out the need for a professional mechanism to support the parents with knowledge and strategies to foster better communication between them and their children and help in reducing parental stress level.

The use of music therapy with children with autism has been described in the literature since the 1960s. Only a few approaches in music therapy incorporate parents within music therapy sessions, or offer parent counseling within music therapy perspective. Little has been written about the parents' experience in using music with their children with ASD and in participating in consultation in music therapy.

This mixed-methods study aimed to investigate whether Music-Oriented Parent Counseling (MOPC) positively influenced levels of parental stress, quality of life perception, and use of music in everyday life by parents of children with ASD. In a 2x2 factorial design, thirteen pairs of parents and their children between the ages of four and seven years old were randomized for a five-month intervention to either the minimal form (3 sessions) or the maximal form of MOPC (10 sessions), and their children to either music therapy or control (standard care). All the sessions took place in the researcher's private music therapy practice. A variety of data was collected, including two standardized measures: Questionnaire for Resources and Stress (*QRS*) and Quality of Life Visual Analogic Scale (*QoL VAS*), a questionnaire of the daily use of music by parents with their children that was developed and confirmed as assessment within the study: Music in Everyday Life (*MEL*); these were conducted at baseline and at the end of the intervention. Semi-structured interviews with the participating parents were conducted at the end of the intervention.

The quantitative analyses included repeated measures in the two time points, descriptive statistics, and inferential non-parametric statistics. The descriptive analysis for the *QRS* showed a relatively better mean difference for the minimal MOPC with a small effect size of 0.82, and the inferential statistics missed significance ($p = .39$).

There was a significant positive effect ($p = .01$) in the child's *QoL* with a strong correlation ($r = .69$) between this change and the child's participation in music therapy. All the participating parents reportedly extended their use of music with their children. There was a significant positive effect ($p = .02$) in the daily use of music in routine activities, with a strong correlation ($r = .68$) between this change and the parents' participation in maximal MOPC.

Findings from the qualitative analysis of the semi-structured interviews' described a variety of improvements in the level of stress, *QoL*, and the use of music; as well as improvements in the parents' understanding of their child's needs and in feeling contained and supported. Furthermore, parents were able to adapt and implement musical tools to support their child in various daily activities, which improved their parental perception. The changes described by the parents were sorted into three themes that are mutually connected: *Learning Experience*, *Enabling Space*, and *Music in everyday life*.

These outcomes provide preliminary support for MOPC's effectiveness in reducing parental stress level, increasing quality of life perception, and extending the use of music in everyday life.

DANSK RESUME

Formålet med denne undersøgelse har været at videreudvikle, styrke og afprøve en musikterapeutisk tilgang, der har fokus på forældre rådgivning. Forskningsstudier viser, at forældre til børn med autisme spektrum forstyrrelser (ASF) oplever en betydelig mængde af stress - ikke kun i sammenligning med forældre til normaludviklede børn, men også i sammenligning med forældre til børn med andre typer udviklingsforstyrrelser. En af årsagerne til forøget stress hos disse forældre indbefatter problemer med at kommunikere med barnet, da kommunikationsvanskeligheder og udfordret sociale færdigheder er kernen i ASD. En anden årsag til øget stress er utilstrækkelig adgang til professionel hjælp, der kan støtte både barnet og forældrene. Denne begrænsede adgang peger på et behov for en professionel mekanisme, der kan støtte forældre med viden og strategier til at forbedre kommunikationen mellem dem og deres børn samt hjælp til at reducere forældrenes stressniveau.

Brugen af musikterapi med børn med autisme har været beskrevet i litteraturen siden 1960'erne. Kun ganske få tilgange i musikterapi inkluderer forældrene i musikterapisessionerne, eller tilbyder forældrene rådgivning indenfor et musikterapeutisk perspektiv. Der er beskrevet ganske lidt om forældrenes erfaring med at bruge musik med deres børn med ASF samt om deres erfaring med at deltage i musikterapeutisk konsultation.

Denne mixed-method undersøgelse havde til formål at undersøge, om Music-Oriented Parent Counselling (MOPC) positivt påvirker forældrenes stressniveau, opfattelse af livskvalitet samt brugen af musik i hverdagen hos forældre til børn med ASF. I et 2x2 "factor design" blev tretten par af forældre og børn i alderen fire og syv år randomiseret til en fem-måneders intervention enten i den minimale (3 sessioner) eller den maksimale form for MOPC (10 sessioner), og samtidigt blev deres børn randomiseret til enten musikterapeutisk behandling eller kontrol (standardbehandling). Alle sessioner fandt sted i forskerens private musikterapipraksis. En række data blev indsamlet herunder to standardiserede måleredskaber: Questionnaire for Resources and Stress (QRS) and Quality of Life Visual Analogic Scale (QoL VAS), samt et spørgeskema for den daglige brug af musik hos forældre med deres børn, som blev udviklet og valideret som del af studiet: Music in Everyday Life (MEL). Disse målinger blev gennemført ved baseline og ved afslutningen af forløbet. Semi-strukturerede interviews med de deltagende forældre blev gennemført i slutningen af forløbet. De kvantitative analyser omfattede "repeated measures" med to måletidspunkter, deskriptiv statistik og inferential non-parametrisk statistik. Den deskriptive analyse af QRS viste en relativt bedre "mean difference" for den minimale MOPC med en lille

effekt size på 0,82, og den inferentielle statistik viste ingen signifikans ($p = 0,39$). Der var en signifikant positiv forandring ($p = 0,01$) i barnets QoL med en signifikant positiv korrelation ($r = 0,60$) mellem denne ændring og barnets deltagelse i musikterapi. Alle de deltagende forældre rapporterede en udvidet brug af musik med deres børn. Der var en signifikant positiv forandring ($p = 0,02$) i den daglige brug af musik i rutinemæssige aktiviteter, med en signifikant positiv korrelation ($r = 0,68$) mellem denne ændring og forældrenes deltagelse i maksimal MOPC.

Resultaterne fra den kvalitative analyse af de semistrukturerede interviews beskrev en række forbedringer i niveauet af stress, QoL, brugen af musik såvel som forbedringer i forældrenes forståelse af deres barns behov samt følelsen af at blive rummet og støttet. Desuden var forældre i stand til at implementere og bruge musikalske værktøjer til at støtte deres barn i forskellige daglige aktiviteter, hvilket forbedrede deres opfattelse som forældre. Forandringerne beskrevet af forældrene blev inddelt i tre temaer, der opfattes som gensidigt forbundne: Oplevelse af læring, at skabe rum samt musik i hverdagen.

Disse indledende resultater støtter op om MOPCs effektivitet i forhold til at reducere forældrenes stress-niveau, at øge opfattelse af livskvalitet samt at udvide brugen af musik i hverdagen.

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1 INTRODUCTION

"Infants are responsive to the musicality of maternal expression as part of their adaptations to co-operate with and benefit from the strong message of care, concern and love that a mother intuitively presents" (Trevarthen, 2002)¹

This introduction focuses on the context of the study, the terminology in use, gives a description of the personal motivation, and the purpose of the study. This is the entrance to the 'study's path', which was paved over the last four and a half years, through an imaginary tangled forest of insights, un-certainty, beliefs, despair, and relief. In order to guide the reader through this forest and remain on the right path, each part will begin with a short section, describing the content of the chapter.

This study intended to examine the efficacy of a unique and innovative model of work in the field of music therapy and families with children with autism spectrum disorder (ASD), combining music therapy techniques within parent counseling sessions. The model was tailored to the special needs of parents of children with ASD, and based on the strong connection that is formed by these children with music, as revealed in a latest Cochrane review (Geretsegger et al., 2014). Cooperating with parents in music therapy treatment sessions has expanded over the last two decades, and certain approaches are being practiced (Larsen, 2011; Oldfield, 2008, 2011; Thompson, 2012). However, generalization in knowledge about effects and experience, and describing specific working mechanisms of parent counseling in music therapy for ASD, are still limited.

1.1 THE CONTEXT OF THE STUDY

This PhD study is linked to the international multi-center Randomized Controlled Trial "TIME-A" (principal investigator: Christian Gold, who is also one of the two

1. Trevarthen, C. (2002). Forward. In T. Wigram & J. De Backer (Eds.) *Clinical Applications of Music Therapy in Developmental Disability, Pediatrics and Neurology*, pp. 7-10, London, JKP

supervisors of this PhD study), conducted as the first Israeli site to participate within the large study, held at my music therapy private practice in Kfar-Saba, Israel. By the time that this PhD is complete, the international "TIME-A" RCT study will be still ongoing, with a second Israeli site in Jerusalem participating (site manager: Cochavit Elefant, who is the second supervisor of this PhD study).

In Israel, children diagnosed with ASD are referred to special kindergartens, where they receive music therapy sessions three times a week. In addition, their parents receive parent-counseling sessions twice a month by the same music therapist who treats their child. In this way, the music therapist works parallel with both the child and his/her parents, in a long-term treatment process. Over the years, I have used more and more music therapy techniques (like music improvisations and music listening) within the parents' sessions, both to facilitate parents' reflection on certain dilemmas and as guidance on how to use music within parent-child interactions. Gradually, this became the essence of my work with parents of children with autism. With this clinical orientation as my frame of work, I entered the TIME-A project, looking to find a niche that will enable me to investigate the music-oriented parent counseling aspects more deeply and thoroughly.

The current study offers a different perspective concerning the work with parents of children with ASD in music therapy. While the TIME-A focuses on the children and offers only three parent counseling sessions throughout the intervention period, the current study added another trial condition, where parents can participate in ten parent counseling sessions within the five month intervention period, reflecting the clinical model in which I work. In order to simplify the understanding of the relationship between this study and the TIME-A research, I figuratively imagine it as two 'bodies' with a clear size difference sharing some mutual aspects but also maintaining separate parts (see figure 1).

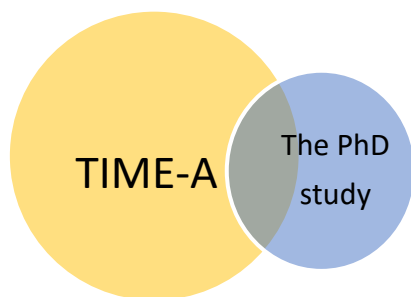


Figure 1 Graphic overview of the relationship between the PhD study and the TIME-A multi-site RCT

1.2 TERMINOLOGY

Parents of children with ASD

It is important to note, that the use of the term *parents of children with ASD* in this study is based on the wide use of this term within professional literature. It is not to say, however, that all parents of children with ASD are having the same personality characteristics or are identical in their needs and their expression abilities. I consider each human being as a unique individual, owning a complete set of beliefs, thoughts, and ideas. I am aware of the fact that for clinical and research purposes, grouping these individuals into one identifying group is essential, and facilitates an understandable discussion among professionals. Nevertheless, it is important to note and remember that having a child with autism is not the only factor that defines a person. Each parent that participated in this study presented an independent personality, which they shared generously with me.

Moreover, it is important to state that as a clinician, I strive to maintain an ability to follow the parent's lead, respectively to the basic concept in music therapy with children - following the child's lead (e.g. Gold, Wigram & Elefant, 2006; Holck, 2004). Having said that, the intentions were not to unify all parents into one *box*, using the same methods and techniques for all parents, but rather explore with each parent what is right for them and their family system, and establish a collaborative relationship between us, serving as a platform for our mutual journey. In addition, as a researcher, it is important to use language that is both acceptable within professional environment and respectful towards the participants.

Autism Spectrum Disorder

This term is used throughout this thesis, corresponding with the wide use of it within professional literature. I am aware of the negative connotation of the word *disorder* that might lead towards a thinking directed to *repairing, correcting, and reforming*, as means of handling or treating something which is *broken or damaged*. Perceiving autism as a neurodevelopment condition seems much appropriate in order to grasp the meaning of this condition fully. However, with this thesis referring to the paradigm of evidence-based practice and to health care context, it seems respectively suitable to use this term, which is presented by accepted classification systems (e.g., American Psychiatric Association, 2013).

I refer to the children in this study as *children with autism* rather than *autistic children*. It seems that this term captures both the childlike and the autistic characteristics, and affords the non-autistic representations of the children be expressed.

Music-Oriented Parent Counseling

Many considerations were made to find the right term to describe the clinical method used within this study. Clinical reality in Israel shows that most of the time music therapy for children with autism spreads over a long period, as a long-term treatment approach. In that case, considering the parents as active participants inside the therapy room for the whole treatment period is usually not feasible. Yet, it is essential to combine a working alliance with parents alongside the child's therapy process: both for getting familiar with the immediate environment of the child, and for exploring with the parents ways that suit them for coping and receiving relief from everyday challenges, which are a direct result of the child's diagnosis. Based on the wide history of music therapy with children with autism (Geretsegger et al., 2014) and on my own extensive clinical experience, it is realized that music has a powerful effect on communication and interaction skills of children with autism. There for, it seems natural to share this knowledge with the parents, parallel to treating the child. This setting enables a long and an on-going relationship between the therapist and the parents for the benefit of the whole family.

The definition of the term 'Music-Oriented Parent Counseling' draws from the above:

“Music-Oriented Parent Counseling is a developmental process that focuses on the needs and goals of a child and his/her parents, combining music and music-therapy techniques in a continuous dialogue between the music therapist-counselor and the parents.”

1.3 PERSONAL MOTIVATION

My personal background within the field of ASD started seventeen years ago, when I accepted a position working with a 7-year old boy with autism in a special classroom. Previously, I had an impression that children with autism were not able to engage in communication, and since receiving feedback from my patients was fairly important for me, I thought I would find it difficult to connect and understand children with ASD. Soon it became clear that connections were made, only in different ways. This boy might have not made contact directly with me, but he was responding to the music we made. There were moments of synchronicity between us through music-making (Gold, Wigram & Elefant, 2006; Holck, 2004; Kim et al., 2009; Schumacher, 1999), and a feeling that he expressed himself more freely using the language of music than the common verbal language. In time, he responded with joy and happiness to my singing, until one day he approached me and held my face with his two small hands, smiling at me and making a long meaningful eye contact. This was a memorable moment of acknowledgment.

This first experience with one child led to the expansion of work with children with ASD in various kindergartens and centers in the public sector as well as in my private practice. A special interest in the musical expression of these children met with the clinical experience with high-functioning children with autism led me to conduct a phenomenological research study for my Master degree. The research included analyzing of 42 musical improvisations of high-functioning children with ASD using the Forinash and Gonzales (1989) approach, resulting with a continuum of seven levels (Lost; Anxiously alone; Comfortably alone; Holding-back contact; Indulging contact; Initiating contact; reciprocity), which expressed the child's ability to connect (Gottfried, 2009).

As a part of my clinical experience, I have conducted series of parent counseling sessions as a part of the treatment plan for each child with ASD. This is a common way of working in special kindergartens in Israel, where music therapists conduct an on-going counseling process parallel to the child's music therapy process. This way of working derives from the developmental approaches of Winnicott (1957, 1960, 1964) and Stern (1985, 2004), perceiving the child and his/her parents as one functioning unit, rather than seeing the child as a separate individual. The benefits of working with parents became clearer to me, while seeing the influence of a broader parental understanding of the child's needs, both on the child's responsiveness to his parents, and on the parents' perception of their parental competency, as most of them have expressed verbally during counseling. Over the years, I have established a music-oriented parent counseling, using music improvisations and/or music listening during parent counseling sessions. I have worked with different parents in different stages of

copied with their child's diagnosis. I have learned to know, that even with the most 'difficult parents' (as were described by the kindergarten team), the connection being weaved between me and them had a crucial effect on the parents' ability to rely on and build trust with the care team of their child. The feedback from parents was that the language of music, which was live and present during our sessions, became the mutual language between them and their children, enabling a new way of connection.

Music therapists in Israel conduct parent counseling sessions as a part of their jobs' demands, but research-based guidelines on how to work with parents in music therapy are missing to follow. In addition, music therapists in Israel receive supervision for parent counseling by psychologists, based mostly on psychological theories, with limited knowledge and reference to music therapy. Therefore, there is limited access for music therapists to supervision on parent counseling which is oriented to music therapy. The research enabled the formulation of a music-oriented counseling guide that can be used by music therapists working with parents.

It is within this interest, that this study was kept as close as possible to everyday 'clinical reality' and still maintains good accuracy in research methodology. The aim was not only to acquire solid research skills, but also to maintain contact with practice-based research to clinical work. In other words, this project may be viewed as an opportunity to address my primary interests and practical needs:

- To fully understand the process of creating a containing, confident and trustworthy working alliance with parents of children with ASD.
- To understand the fundamental elements of communication among people in general and communication through music in particular.
- To investigate the use of music during parent counseling sessions.
- To let the parents' voices be heard.

During the beginning of conducting this study, the expectations were that more layers of meaning of my clinical work would reveal themselves, as well as new aspects of conducting research. It was also expected that not every aspect could be covered in this study's timeframe, and some may serve as perspectives in a broader view. These expectations were fully achieved, and the aspects, which were left un-investigated, would stand as inspirations for future studies.

1.4 THE PURPOSE OF THE STUDY

The purpose of this study was to learn about the influence of Music-Oriented Parent Counseling (MOPC) on the level of parental stress, quality of life perception, and the daily use of music, by parents of young children diagnosed with ASD.

The purpose of this triangulation mixed methods study was to converge both quantitative (numeric) and qualitative (texts form interviews) data. In this approach, measurements were used to test the theory of family-centered music therapy (described in section 2.4), that predicts that professional counseling in music therapy decrease the level of parental stress and increase the Quality of Life (QoL) perception of parents of children diagnosed with ASD. A Music in Everyday Life (MEL) questionnaire was used to test the theory of music as an engagement facilitator (chapter 5), that predicts that the use of music by parents with their young children positively influence parent-child interaction, which also contribute to improvement in level of parental stress and QoL perception. Concurrent with this data collection, qualitative interviews explored the experience of the participants in MOPC sessions. The reason for collecting both quantitative and qualitative data was to bring together the strengths of both forms of research and compare the results from two different perspectives.

2 LITERATURE REVIEW

This chapter presents literature that is relevant for the core topic of this study, which is counseling in music therapy for parents of children with Autism Spectrum Disorder (ASD). First, literature will cover the unique challenges that parents of children with ASD are coping with, because of their children's diagnosis. Characteristics of ASD, as a source for high level of stress among the parents (especially the mothers), are presented in section 2.1. In section 2.2, the importance of parent-child relationship in families with children with ASD is outlined. Section 2.3 presents literature concerning approaches to working with parents, first within the psychoanalytical and developmental theories, followed by review of literature in therapeutic and counseling processes for parents, and concluding with describing parent-mediated interventions and parent counseling approaches. Literature focusing on family-centered music therapy is presented in section 2.4, narrowing the review to the specific field of music therapy and families. Reviewing approaches in music therapy for children with ASD and their families, outlines the theoretical and clinical frame in which the music therapy and the counseling approach were developed in this study.

2.1 PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

Understanding parents of children with ASD is a complex task, as what unites them as members of the same group is connected with their *children's diagnosis* and not with specific characteristics of *their* personality or behavior. In addition, autism can affect individuals from all racial groups, socio-economic backgrounds, and levels of intelligence (APA, 2013), disqualifying any distribution of this population according to demographic characteristics. Never the less, literature in the field of social work and psychology argue, that the diagnosis of the child within the autism spectrum has a powerful effect on the stress level of parents. There are similar challenges that these parents need to cope with, which can be observed as unifying factors (Bake ´r-Ericzen et al. 2005; Holroyd & McArthur 1976; Pisula 2007; Schieve et al. 2007; Yamada et al. 2007).

The American Psychiatric Association (2013) defines Autism Spectrum Disorder in the DSM-5 as a set of neurodevelopment disorders that are diagnosed behaviorally and usually appear in early childhood and persists throughout life. The general characteristics of ASD are impairments in social interaction and communication skills, integrated with restrictive repetitive or stereotyped patterns of behavior. Within the autism spectrum, a term imprinted by Lorna Wing (1995), a large variety of levels of

individual abilities and wide clinical presentations is covered. This diversity and large variety of presentations within individuals affected with autism put a big challenge for clinical diagnosis as well as for therapeutic intervention.

The early relationship between parents and their baby show reciprocal non-verbal communication, where the baby absorbs his/her parents' message of care and concern, and responds adequately (Stern, 1985; Trevarthen, 1979, 1987; Winnicott, 1957, 1960). In autism, this ability is interrupted by organic impairments and influence significantly on the relationship between parents and their child with ASD. Research show, that raising a child with ASD is typically a challenging experience for parents and begins early in the child's life, is long lasting, and associated with a host of personal, familial, and vocational problems (Whitman, 2004). These challenges include, but are not limited to, obtaining the initial diagnosis, finding appropriate treatment and intervention services, establishing appropriate parenting practices, and coping with substantial financial burden of paying for services. Many of these challenges are unique to the disability and are likely a consequence of attempting to cope with the communication deficits and distinct behaviors associated with the autism spectrum (Jarbrink et al., 2003).

Psychological and emotional challenges of parents of children with autism

Parents who have children with autism endure a significant amount of stress (Abbeduto et al. 2004; Duarte et al. 2005; Konstantareas and Papageorggiou 2006; Montes and Halterman 2007). Studies show that they experience more stress not only compared to parents of typically developed children, but also compared to parents of children with other developmental disabilities (Schieve et al. 2007). In addition, mothers of children with autism report less parenting competence, less marital satisfaction, and less family adaptability than mothers of children with Down's syndrome or mothers with typically developing children (Bauma & Schweitzer, 1990; Holroyd & McArthur, 1976). Mothers of children with autism were less involved with people and activities outside the home (Bristol, 1984), and it was found that part of the stress stems from the amount of time needed to care for the child, and the reduced freedom family members have in their schedules (Johnson, 1985). Very few studies have explored the relationship between stress and the way parents of children with autism cope with the disability of their child. In a study by Vidyasagar and Koshy (2010), stress level and coping strategies were examined in 25 mothers of children with autism vs. 30 mothers of children who were typically developed. The study revealed that a significant positive correlation existed between stress and confrontation behaviors in mothers of children with autism. As the stress level increased in these mothers' experience, they adopted a more confrontational coping approach. In other words, with more stress experienced, mothers used more aggressive efforts to alter the

situation and were willing to engage in risk taking and hostile behaviors. No significant relationships were found between stress and other coping strategies (Vidyasagar & Koshy, 2010).

Three central issues have been found to be stressors for parents of children with autism: (a) the fear for their children's future, as their disorder significantly influence their chances to develop independency; (b) disapproval of others, usually family members, of the child's behavior; and (c) very limited social support (Sharpley et al., 1997). Other sources of increased stress for parents include difficulties in communicating with their child (Goin-Kochel and Mayers, 2005) and behavioral problems seen in most children with autism (Bishop et al., 2007; Hastings, 2003; Herring et al., 2006, Tomanik et al., 2004). The insufficient access to professional help is also a harming factor for the parents (Sakaguchi and Beppu, 2007), which obligates them to be responsible for coordinating, advocating, and making decisions about treatment (Wachtel and Carter, 2008).

In the late 60's, Leighton (1969) reported her experiences in working with parents of children with autism. Her clinical experiences as a social worker, working at a residential unit for children with autism at a psychiatric hospital, led her to the understanding of the importance of consultation for the parents. In this clinical article, she stated five main issues in which consultation is needed for the parents: 1) issues of high parental expectations for their child; 2) guilt associated with keeping a child with autism, perhaps even blame-shifting concerns; 3) appropriate placement for their children; 4) family assistance and practical solutions; 5) reducing their emotional stress. This early article, although was not developed into clear counseling guidelines for professionals who work with parents of children with autism, paved the way to professional understanding and clinical implications concerning counseling for these parents.

With the aim to learn about specific parental behaviors during interactions with their children with autism, several studies were conducted. In a 2002 study, Siller & Sigman examined the extent to which the caregiver's behavior synchronizes with the child's focus of attention during play interaction. The study had two major findings. First, caregivers of children with autism synchronized their behaviors to the children's attention and activities as much as did caregivers of children with a developmental delay and caregivers of typically developing children, matched on language capabilities. Second, caregivers of children with autism who showed higher levels of synchronization during initial play interactions had children who developed superior joint attention and language over a period of 1, 10 and 16 years than did children of caregivers who showed lower levels of synchronicity initially. Therefore, these findings suggest a developmental link between parental sensitivity and the child's subsequent

development of communication skills of children with autism. The findings of Siller and Sigman's study are surprising and striking. First, the fact that parents of children with autism achieved an equal level of synchronization, given on how difficult it often is to identify and interpret the interests of children with autism, is quite remarkable. Second, from a research perspective, this study contradicts earlier studies that point out, that parents of children with autism tend to be more controlling and directive (Arbelle et al., 1994; Kasari et al., 1988; Watson, 1998). These latter authors argue, that this happens due to the parents' attempts to compensate for their child's low level of development, or maybe influenced by parent-training programs, which instruct parents to structure their interactions as if they can predict their child's desires and way of behavior (e.g. The Applied Behavioral Approach, Lovaas, 1987). Arbelle and colleagues (2004) emphasized, that there is little evidence regarding the effectiveness of those approaches on the children's social responsiveness or language development. When confronted with interpersonal demands, children with autism tend to display less compliant behaviors, such as gaze and negative affect patterns. The evidences of these experimental studies and the study by Siller and Sigman (2002) stand in line with the early mother-infant interaction theories (Stern, 1985, 2010; Winnicott, 1957, 1960), which advocate for a more 'emotionally-based' interaction, encouraging parents to 'follow the child's lead'. Parental sensitivity to the attention of their child with autism is linked to gains of joint attention skills, communication abilities, and language development, as shown in several studies (Arbelle et al. 1994; Gold, Wigram & Elefant, 2006; Kim et al., 2009; Oldfield 2006a, b).

The uniqueness of Autism Spectrum Disorder as a source of stress for parents

Research suggests that there are some unique characteristics in autism, which produce elevated levels of distress for parents. In a study by Tomanik, Harris, and Hawkins (2004), the relationship between the child's characteristics and the maternal functioning was examined, in order to isolate the specific factors, which produce stress. Irritability, lethargy, hyperactivity, and deficiencies in self-care, communication, and social interaction were found as elevators of stress among the mothers. Additionally, Davis and Carter (2008) found that the children's deficits in social skills were predictive of parenting stress among mothers of toddlers with ASD. In addition, repetitive behaviors and mal-adaptive behaviors were connected to mothers perceiving themselves as incompetent in parenting skills (Bishop et al., 2007). Mothers' negative psychological outcomes are also influenced by the frequency with which children display ASD symptoms (Benson, 2006; Ekas et al., 2010). One more connection was found between high level of parenting stress to behavior problems that children with ASD might present, such as problems to self-regulate and externalizing behaviors (Davis and Carter, 2008; Estes et al., 2009; Lecavalier, Leone and Wiltz, 2006). Ekas and colleagues (2010) found that the frequency of behavioral problems was a better

predictor of maternal well-being than the frequency and levels of other ASD symptoms.

In a study by Dabrowska (2010), 162 parents of preschool children with autism completed the Questionnaire for Resources and Stress (*QRS*; the same questionnaire used in this current study). The results supported her hypothesis that the level of stress in this population would be higher than the level of stress among parents of children with Down's syndrome or parents of typically developing children. In addition, an interaction effect was revealed between child diagnostic group and parent's gender for two scales of parenting stress: dependency and management, and limits of family opportunities. It is interesting to see also that mothers of children with autism scored higher level of parental stress compared to fathers, and no such differences were found in the groups of parents of children with Down's syndrome or parents of typically developing children. Emotional-oriented coping strategies were the predictor for parental stress in this population's sample, and a difference was shown in the social diversion coping in parents of children with autism those in parents of typically developing children.

Feelings of parents and caregivers for children with autism were examined through surveys and published in 2003 by the National Survey of Children's Health (NSCH). The surveys revealed the parents' life sacrifices to care for their child, their difficulty in caring for their child, their frustration with their child's situation, and their anger towards their child. Schieve and colleagues (2007) examined this report using the Aggravation in Parenting scale, comparing parents of children with autism with parents of children with special health-care needs with other developmental problems, children with special health-care needs without developmental problems, and typically developed children. Parents of children with autism were significantly more likely to score in the "high aggravation" range than any other parent sample.

The next sections outline the importance of parent-child relationship to promote emotional-social development in children with ASD (2.2), and present different approaches to parent counseling in general, and with parents of children with ASD in particular (2.3).

2.2 THE IMPORTANCE OF PARENT-CHILD RELATIONSHIP IN FAMILIES WITH CHILDREN WITH AUTISM SPECTRUM DISORDER

There is an increased awareness of the importance of a *good* parent-child relationship in the development of communication skills in both children with typical development (Edwards, 2011) and children with ASD (Moore, 2000). A trusting and secure relationship is the fundamental element and is the result of success in communication with others (Prizant et al., 2000, p. 218). The goal in working with young children with ASD has been underlined by Prizant and colleagues (2000) as giving the children the opportunity to experience ongoing social interactions with family members and friends as successful and emotionally fulfilling. Through social interaction, the children experience the influence that their communication has on their environment. Therefore, social, cognitive, and communication development is pinned in trusting relationships with others who are emotionally attuned (Bruner, 1995; Pizant et al., 2000; Solomon et al., 2011). This ecological framework perceives the child's development in relation to the family's system of relationships (Bronfenbrenner, 1975; Winnicott, 1952).

The challenges of social-emotional interactions, which are at the core of the autism disorder, stand as a challenge to provide the adequate developmental support and therapeutic interventions. Social-emotional skills are very hard to teach, partly because they are abstract and can be seen differently within different people (Schertz & Odom, 2007). Therefore, supporting and influencing the child's motivation to stay in connection and be excited about relationships is crucial for successful social development (Campbell, Milbourne, & Wilcox, 2008; Poulsen, Rodger, & Ziviani, 2006). It is clear that the partners for interaction, whether parents, family members or friends, should be a part of this support system (Schertz & Odom, 2007; Wetherby et al., 2000).

One of the challenges that parents and therapists of children with ASD find are how to create an environment that enables and supports the child's engagement. When Maslow presented Motivation Theory in 1943, he described a hierarchy of five needs of a human being. He ordered the needs in the shape of a pyramid, with these levels starting at the bottom and going up: physiological, safety, belonging, self-esteem, and self-actualization. From Maslow's perspective, it is clear that an attuned environment is essential for children with ASD, in order for them to fulfill these needs. An attuned environment for children with ASD provides physiological pleasure, creates a sense of safety, develops the feeling of belonging, and strengthens the child's self-esteem as an individual who succeeds in making connections (Siller & Sigman, 2007). This is especially relevant to music therapy techniques with children with ASD, described in

the latest Cochrane review (Geretsegger et al., 2015), which form the core of the Music-Oriented Parent Counseling (MOPC) presented in this study.

2.3 APPROACHES TO PARENT COUNSELING

The challenges of working therapeutically with parents have been described since the development of psychoanalytical theories by usually addressing it as a marginal supplement to the treatment process of children (Oren, 2012). Within developmental theories (Stern, 1985; Winnicott, 1964, 1971) and the attachment theory (Bowlby, 1988), working with parents takes a central role, as the parent-child dyad is seen as the core of the intact emotional development of the child. A full review of the history and different programs available for working with parents is beyond the scope of this thesis; however, the range of programs available for working with parents of children with typical development will be outlined briefly. A broader review is given to different approaches of working with parents with children with ASD, both within psychology and music therapy fields.

2.3.1 A BRIEF SUMMARY OF THE DEVELOPMENT OF PARENT COUNSELING APPROACHES

At the outset of the psychoanalytical treatment in children, there was a complete separation between children and their parents. The focus was mainly on interpretation of unconscious conflicts and needs, and strengthen the *self* (Freud, 1965), or on the child's unconscious fantasies (Klein, 1932). The cooperation with parents in order to contribute to the therapeutic process of the child was usually overlooked. The Object Relations Theory, developed in the 1960's, presented the child's psychological development as connected with his parents and people around him. This theory perceives the primary relationship of the infant with his care figure (usually the mother) as the basis of his personality development as an adult (Mahler, 1965; Winnicott, 1971). Winnicott (1964) observed and understood infants from the perspective of infant-mother dyad, and interpreted the infants' behaviors and expressions within the context of early interaction between them and their mothers. He was an advocate of working closely with parents, consulting and supporting them, emphasizing the idea of the relationship within infant-mother dyad as significantly influencing the emotional-psychological development of the child. Winnicott coined the term 'holding environment', referring to the mother as the first and immediate environment for the infant. A central idea of his work was to empower mothers to provide a good mental holding and physical handling, and become 'good-enough' mothers to their children (ibid). Mahler (1965), who followed Winnicott's theory, and Kohut (1971) assume, that the main developmental process occurs from the stage where the infant is very dependent on his mother, including a lack of self-awareness,

up until a growing awareness of his separate physical and psychological being from the mother. The mother's role is to regulate the stimulations and act as the ego representation. Within an intact developmental process, clear boundaries are built between the *self* and the *other*, which enable the development of the child's ability of *intersubjectivity* (Trevarthen & Aitken, 2001).

Attachment Theory (Bowlby, 1988), emphasized the influence of the attachment in infancy on the future development of the child. Bowlby assumed that a baby is born with the ability to connect and with a congenital nature to seek connections. Infants need feedback of warmth, caring and closeness from their primary caregiver, in addition to their primary needs to be fed and sleep. Both Bowlby (1988) and Winnicott (1967, 1971) hold the idea that an infant is not a separate entity, but maintains a constant connection with his caregiver (usually the mother). In a 1979 study focusing on mother-infant dyads, Bowlby stated that by the emotional connections that an infant develops with his parents, internal working models are built within him. These internal models represent primary patterns or internalized representations of the *self* and the *other*, which is created between the infant and the parent. Grossman and Grossman (2009) expanded Bowlby's work and investigated the contact patterns of infants with each of their parents. They found that infants develop independent internal models of relationships with each parent separately. Stern (2004), following Mahler and Bowlby, focused on the development of the structure of the 'self'. According to Stern, the primary central sense of the self is congenital and appears soon after the first months of life. The development of the infant is based on the primary healthy relationship between the infant and the mother. Stern describes normal development as a development based on the essential *self*, meaning the development of self-identity in infancy (Stern, 2004). Like Winnicott, Stern emphasized the importance of mirroring as capturing the idea of the infant being understood by his parent, and his expressions are meaningful to them. These experiences accumulate until the point when the infant can attribute these experiences to himself. When the parent thinks of his child as one with complex inner states, even if the child has not yet obtained the skills to express this, he paves the path to mental development and gives the child the opportunity to perceive himself as having intentions. Therefore, according to Stern, the effect of the quality of parental attachment on the child's functioning, the ability to develop a sense of self, and belief in his abilities are crucial and important. Similarly, the inter-subjective model (Benjamin, 2005) opines that the substantial relationships of the child with his parents are meaningful factors and significantly influence the development of representations within his inner world. This model expands Stern's theory and emphasizes the way mental processes are affected by reciprocal processes. The development of the self derives from the need to be recognized by the other.

At the core of ASD are impairments in social and interaction skills (American Psychiatry Association, 2000, 2013), which have a significant effect on the primary relationship between the infant and the parents. Difficulty in understanding other's minds is a core cognitive feature of ASD. A review by Baron-Cohen (2013) of 'theory of mind' studies from 1985 until 2001 revealed that the mechanism of mindreading in the brains of individuals with autism is impaired. Yet, further research is needed to refine both the techniques for studying the skills of mindreading, and to better understand the underlying mechanism essential for mindreading. However, these studies have clinical implications for interventions and early diagnosis. As a difficulty in understanding the expressions of others is central to the autism disorder, it is likely to assume that it significantly affects the primary relationships between parents and their baby with autism.

Most of the theories presented above, emphasize the influence of the parent on the child's healthy and intact psychological-emotional development. However, most of the studies over the years (which some were presented here), investigated the mother-child relationship, while father-child relationships were rarely investigated. Within the last two decades, literature began to cover the fatherhood experience as well (Barrows, 1999, 2004; Liebman & Abell, 2000). Barrows (2004) reflected on the father's family role and pointed out three main functions: 1) the father as a symbolic figures that enables the separation between the infant and the mother, 2) the father gives a new expression to the father's role and enables the child to perceive the different roles of his parents, and by that, enables the child to come out of the tangled relationship with the mother, and 3) the substantial father, which helps with developing autonomy and individuation. Perceiving the father's role as essential for the development of the child, gives a more balanced perspective of the whole family unit. Different studies (e.g.: Kochanska at al., 2007; Puett & Litzenberger, 1992; Trowell & Etchegoyen, 2007) show that as much as the father is involved within the growing and developing process of the infant, the child would become friendlier, more active, would cope better with stress, and would be less anxious. In recent years, research is becoming more involved in the area of father-child relationship, including some studies conducted in Israel (Aluf, 2009; Barnet et al., 2008; Bogels & Phares, 2008; Diamant, 2007; Zukerman, 2010). In the light of the understanding concerning the significant role of the father within the development of the child, it was considered that both mothers and fathers would participate in counseling sessions within the current study.

2.3.2 PARENT COUNSELING

Parent counseling can be observed as a general term, including forms of parent-training and parent-mediated interventions (described below). As a first step in addressing this term, it is important to get familiar with the wide context of *counseling*.

A general overview is given as for the term *counseling*, and then a review of parent counseling approaches follows.

What is 'counseling'?

When challenged to provide a crisp and comprehensive definition of 'counseling', one may find more than only one. The British Association for Counseling (BAC), now the BACP, may have been the first professional association to adopt a definition of professional counseling. In 1986, it published the following definition:

"Counseling is the skilled and principled use of relationship to facilitate self- knowledge, emotional acceptance and growth and the optimal development of personal resources...The counselor's role is to facilitate the clients work in ways that respect the client's values, personal resources and capacity for self-determination" (BAC, 1986).

In 1993, Feitharn and Dryden included the following definition of counseling in their specialized Dictionary of Counseling:

"Counseling is a principled relationship characterized by the application of one or more psychological theories and a recognized set of communication skills, modified by experience, intuition and other interpersonal factors, to clients' intimate concerns, problems or aspirations... It is a service sought by people in distress or in some degree of confusion who wish to discuss and resolve these in a relationship which is more disciplined and confidential than friendship, and perhaps less stigmatizing than helping relationships offered in traditional medical or psychiatric settings" (Feitham and Dryden, 1993).

In 2014 the Governing Council of the American Counseling Association (ACA, 2014) accepted the ethical codes of professional counseling (<http://www.counseling.org/knowledge-center/20-20-a-vision-for-the-future-of-counseling/consensus-definition-of-counseling>):

"Counseling is a professional relationship that empowers diverse individuals, families, and groups to accomplish mental health, wellness, education, and career goals."

Professional values are an important way of living out an ethical commitment. The following are core professional values of counseling, as outlined by the ACA, 2014:

- 1) enhancing human development throughout the life span;
- 2) honoring diversity and embracing a multicultural approach in support of the worth, dignity, potential, and uniqueness of people within their social and cultural contexts;
- 3) promoting social justice;
- 4) safeguarding the integrity of the counselor-client relationship, and
- 5) Practicing in a competent and ethical manner.

In addition to these professional values, the ACA specifies also the fundamental principles of professional ethical behavior:

- *autonomy*, or fostering the right to control the direction of one's life;

- *no maleficence*, or avoiding actions that cause harm;
- *beneficence*, or working for the good of the individual and society by promoting mental health and well-being;
- *justice*, or treating individuals equitably and fostering fairness and equality;
- *fidelity*, or honoring commitments and keeping promises, including fulfilling one's responsibilities of trust in professional relationships, and
- *Veracity* or dealing truthfully with individuals with whom counselors come into professional contact.

Parent Counseling

The broad definition of parent counseling refers to any consultation between a professional and a parent (Guli, 2005). However, it has also been more narrowly defined as a structured, problem solving collaborative relationship between a consultant (e.g., counselor, psychologist, therapist) and one or more parent (Holcomb-McCoy, 2009). Studies from 2000 to present describe three main models of parent consultations: conjoint behavioral consultation, Adlerian consultation, and value-based consultation.

Conjoint behavioral consultation (CBC) is an extension of behavioral consultation that was popular during the 1970's. This type of parent counseling combines the resources of home and school to create change in a child's behavior. It is an indirect model of service delivery in which parents, teachers, and a consultant work together to address the needs of a child (Colton & Sheridan, 1998; Holcomb-McCoy, 2009).

The Adlerian approach to parent consultation posits that individuals want to belong to a group, and the sense of belonging is the motivation factor for their behaviors. When children believe that they are an accepted member of the family (or their class), they will contribute to the well-being of this group. Dinkmeyer & Carlson (2006) describe the foundations of the Adlerian approach to parent counseling as follows: a) behavior is goal-directed and purposive, b) effective change occurs when the individual perceives himself as capable of change and can identify this ability as strength, and c) the consultant considers the family-system while working with the parents.

Nelson and colleagues presented the *values-based parent counseling* approach in 2000. This approach includes a partnership with community members for implementing prevention programs in schools. They argue that a consultant should abandon the role of the expert and value the knowledge that parents and community members bring to counseling sessions. The three circles around the child - the parents, the broader family, and the community, form the immediate environment of the child, and their worldviews need to be expressed and acknowledged during counseling sessions. The counselor needs to consider these values, and include them within his own

professional views (Nelson et al., 2000). Davis (2002) refers to this approach as a *partnership model*, which advocates the importance of establishing a trustworthy collaborative relationship between the consultant and the parents, in order to provide effective help. According to Davis (2002), an ideal partnership includes the following elements: working closely; agreeing on common aims; integrating the expertise of the partners – counselor and parents; mutual respect; negotiating ideas and views; exchanging information within a safe communication atmosphere; honesty in expressing ideas; and flexibility in addressing change in needs or plans.

Within these three main parent-counseling models, different strategies are used, with different perspectives regarding the change factor. These strategies can be roughly divided into two types: The first strategy type puts the presentation of new information or ideas as the main change factor. Consultants who work within this strategy perceive the parent-consultant relationship as a source for delivering information and knowledge regarding appropriate parenting practices and family functioning (Holcomb-McCoy, 2009), and is used mainly within the *conjoint behavioral consultation* and the *Adlerian* models. This strategy of delivering information can create several problems when presenting certain parenting techniques without taking the unique needs of each family into an account (Wayman et al., 1991). The consultant who delivers information may also fail to consider the importance of psychosocial influences such as family structure, cultural value system, interactional patterns, and adoptive coping strategies on behavior and functioning in families who are dealing with the lifelong condition of their child. In addition to differences in family structure, parent consultation may be influenced by the adaptive coping strategies of certain groups (Holcomb-McCoy, 2009).

The second strategy type puts the relationship between the parent and the consultant as the source of change (Holcomb-McCoy, 2009). Consultants who impinge upon *relationship focused* parent counseling are likely to work within the *Value-based parent counseling* approach. Within this relationship-based approach, conscious and unconscious preconceptions, which are advised to be acknowledged, might influence both consultants and parents. In discussing the role of the consultant in establishing a good and trustworthy relationship with the parents, Holcomb-McCoy (2009) points out three attitudes that were found as damaging this process. Consultants who express lack of respect for parents and failure to trust them were cited as significant barriers to fostering a collaborative relationship. In addition, consultants who focused on the children's deficits while ignoring their strengths undermined a safe and beneficial relationship with the parents. Finally, consultants who expressed lack of appreciation for the mother's parenting style by blaming her for the child's behavior problems failed to achieve the goal of forming a good relationship with the parents. This undermined the change factor.

2.3.3 THE IMPORTANCE OF COOPERATING WITH PARENTS THROUGH THE THERAPEUTIC AND COUNSELING PROCESS

Because of a growing awareness concerning the importance of the child's connection with both of his parents, there is an expanding tendency to cooperate with parents during a therapeutic process. The parents' perception of their own parenthood stands as a basis for their representation as meaningful figures in their children's lives, and is influenced by past experiences as well as current ones. When a child is being diagnosed with a lifelong disorder, the alignment of the parents' expectation is shattered, and their parenthood is being challenged. The need for guidance is therefore rising, and the need to include the parents within the treatment process of the child is required. Literature in psychology reveals that cooperation with parents within a therapeutic and counseling process is described as a supplement to the child's therapeutic process (Oren, 2012). Most therapists who work with children nowadays agree that a good therapeutic process with children requires a change in the home environment through cooperation with the parents (Hunsley & Lee, 2007; Shechtman, 2002).

Alongside with the development in treatment approaches for children, the need to establish a therapeutic relationship with the parents became clear, in order to support and to empower the therapeutic process of the child (Creswell & Cartwright-Hatton, 2007; Feldman, 2007). Studies in recent years (e.g. Friedberg & McClure, 2002; Heutmann, 2010) point to the benefits of parent counseling to support their children's therapeutic process, and show that counseling and therapeutic interventions with parents, including parent guidance programs (Maughan et al., 2005), behavioral counseling (Gardner & Ward, 2002) and incorporate parents in treatment sessions (Harrison, 2005) improve the efficiency of the child's treatment. Comparative studies found that the parents' active participation significantly contributed to the success of the treatment (Fishel & Ramirez, 2005; Heutman, 2010; Karver et al., 2006; Maughan et al., 2005). Several meta-analysis studies (e.g. Adwell, 2005; Wyatt et al., 2008) investigated parent training programs in certain areas: the efficacy of behavioral parent training on their children's behavior problems (Maughan et al., 2005), the effect of parent counseling on the self-esteem of their children (Cedar & Levant, 1990), and the effect of parent counseling on the academic level of their children (Fishel & Ramirez, 2005). The findings of these studies support the hypothesis that parent counseling is an effective mean in improving children's varied difficulties and problems.

Following the growing understanding of the role of parents in their child's emotional development, several therapeutic and counseling models have emerged over the years that focus on both the needs of the child and the parents. This form of working with parents can be practiced either within a simultaneous model (Chazan, 2003), where the

child and the parents are treated within separate sessions by the same therapist, or within a dyadic approach of treating the child and parent together (Lieberman, 2004; McDonough, 2000). These models refer, among other things, to an inner interpersonal layer that represents inner processes of the ability to create change and develop as a parent. Working with parents at this level include clarification regarding their expectations, needs, belief, ways of thinking, their ability to reflect and interpret, and their emotional regulation (Cohen, 2007).

2.3.4 PARENT-MEDIATED INTERVENTIONS FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

The understandings described above shed a light on parent-mediated and training approaches. One field of the parent-mediated approach is Parent Training or Parental Therapy (PT). PT is a wide field, which includes different therapeutic interventions and counseling. This type of treatment focuses on an adult, who is interested in his/her parental identity, or that their parenting create some kind of distress, which then becomes the focus of the treatment. This is a process which evolves on a continuum, starting with a simple delivery of information or education in a certain area, giving advice, making clarifications, to treatment and guidance to help parents process experiences from their past, which they project onto their relationship with their children. Educating in a certain area includes usually a psycho-educational intervention, including a developmental understanding of the child's needs and giving advice for efficient parenting, using cognitive and dynamic elements. Parenting treatment usually starts because of a certain distress in the present, and will develop to a deep observing of the parenting patterns (Oren, 2012).

PT for parents of children with ASD is not new, and was developed in order to cope with disruptive behaviors often presented by these children. PT has also been applied to children with ASD who present disruptive behaviors (Baker, 2006; Baker & Brightman, 2004; Wade et al., 2008). Disruptive behaviors in children with ASD include tantrums, aggression, and noncompliance with routine demands, self-injury, property destruction, recklessness, and hyperactivity. These behaviors interfere with daily functioning levels and prevent their full ability to adjust and regulate (Wade et al., 2008).

The biggest study of PT with parents of children with ASD was conducted by the Research Units on Pediatric Psychopharmacology (RUPP) Autism Network, which developed and tested a structured PT program in combination with medication in 124 children ages 4–13 with ASD and serious behavioral problems (Aman et al. 2009; Johnson et al. 2007; Scahill et al. 2009). This program consisted of 11 individually

administered sessions based on a behavior analytic orientation. Sessions presented strategies for antecedent management (e.g., visual schedules), reinforcement, planned ignoring, and compliance training. This PT program, in combination with medication (Risperidone) produced larger reductions in problem behavior and greater gains in some domains of adaptive functioning than Risperidone alone in a randomized clinical trial (Aman et al. 2009; Scahill et al. 2012).

Researchers and theorists have discussed the general goals of parent training (Nixon, 2002; Wyatt et al., 2008), and stated that it is a process that provides emotional and practical support for the daily care of the child. According to these researchers, the essence of parent training is supporting the self-esteem of the parent (along the continuum that was described earlier), based on the assumption, that a child cannot prosper in treatment without his parents' support and encouragement (Chetik, 2004). Rigorous evaluations over the last 30 years support the efficacy of PT among children who are typically developing (Barkley 1997; Kazdin 2005; Lundahl et al. 2006; Reyno and McGrath 2006; Webster-Stratton and Reid 2010; Zisser and Eyberg 2010).

While there is certainly a need for PT to address disruptive behaviors in children with ASD, most research on parent-mediated interventions with this population focus on helping parents address core features of autism, such as socialization and communication (Aldred et al. 2004; Carter et al. 2011; Dawson et al. 2010; Drew et al. 2002; Green et al. 2010; Kasari et al. 2010; Oosterling et al. 2010). Parents were included in treatment sessions, and therapists taught the parents ways to enhance their child's eye contact, joint attention and play skills. For example, in a study by Kasari and colleagues (2010), 24 parent-mediated sessions were carried out over 8 weeks, focusing on increasing joint engagement between the parents and the children with autism. Large scale randomized clinical trials showed the effectiveness of parent training as adjunct to medication and school-based programs for children with ASD (Aman et al., 2009; Dawson et al., 2010; Landa et al., 2011). In Dawson and colleagues' (2010), trial therapists conducted parent-training sessions twice a month to expend an intensive child-focused intervention.

Another focus in treatment and guidance for parents is the development of *reflexivity* within the parent and the child. Fonagy & Target (1998) described the reflexivity function in treatment as the therapist's willingness to contain and name intensive emotional processes that develop in the therapy room. The development of the parent's reflexive ability enables them to perceive the child as a separate being with his own set of needs and desires; parallel, it enables the child to arrange his feelings in a more effective and coherent way, and grow and develop in an intact way (Fonagy, Gergely & Target, 2007).

Putting the cooperation with parents and caregivers at the center of support and guidance process, two established programs are in use within the population of children with autism. The first program is the Developmental Individual-differences and Relationship-based model (DIR[®]), known also as the floor time model. Developed by Dr. Stanley Greenspan (1979), the DIR[®] model is a comprehensive framework, which enables parents and clinicians to construct a program tailored to the child's unique challenges and strengths. Central to the DIR[®] model is the role of the child's natural emotions and interests which has been shown to be essential for learning interactions that enable different parts of the mind and brain to work together and built successively higher levels of social, emotional, and intellectual capacities. It includes floor time techniques to follow the child's lead and at the same time challenge the child towards greater mastery of social, emotional, and intellectual capacities. In addition to floor time, the model includes various problem-solving exercises and typically involves a team approach with speech therapy, occupational therapy, educational programs, and mental health intervention. This model follows a six levels scale of Functional Emotional Developmental Levels, with specific techniques to follow for each level. Four randomized controlled studies were published since 2011 identifying statistically significant improvement in children with autism who used floor time versus traditional behavioral approaches (Casenheiser, Shanker & Steiben, 2011; Lal & Chhbria, 2013; Pajareya & Kopmancejumsruslers, 2011; Solomon et al., 2014). These studies also showed the effectiveness of addressing the caregiver (Casenheiser et al., 2011; Solomon et al., 2014). In Solomon and colleagues' study (2014), 128 children diagnosed with autism and their parents were recruited for a one-year PLAY Project Home Consultation intervention, based on the DIR[®] model. Parents were given a monthly counseling session within the PLAY model, aiming to improve parent-child interaction and symptoms of autism in the children. Results showed large treatment effects for parent and child interactional behaviors on the Maternal and Child Behavior Rating Scales. PLAY children improved in diagnostic categories on the Autism Diagnostic Observation Schedule (*ADOS*), the stress level in PLAY caregivers did not increase, and the symptoms for depression decreased. These results support the effectiveness of a counseling intervention for parents and care givers on their ability to handle stress, to reduce depressions symptoms and to improve their well-being.

The second established program is the Relationship Developmental Intervention (RDI), which is a family-based behavioral treatment, designed to assess autism's core symptoms. It is built on the theory that *dynamic intelligence* is key to improving quality of life for individuals with autism. Dynamic intelligence is defined as the ability to think flexibly. This includes appreciating different perspectives, coping with change and integrating information from multiple sources (e.g. sights and sounds). In a small pre-post study of children receiving Relationship Developmental Intervention (RDI), Gutstein and colleagues (2007) found evidence of improvement in autism severity

following 30 months of treatment. A RDI consultant trains the parents to use the principles in the home environment, and educators can learn and use it in the classroom. The consultant assesses the child and his interactions with parents. Based on this information, the consultant designs a personalized teaching plan. It includes developing communications styles that best suit the child.

Parent-mediated treatment programs and Parent Training programs were developed to answer the need for practical and understandable ways of coping for the parents. The child's diagnosis with a chronic or lifelong disorder is a major crisis challenging for the parents and the whole family. Parents are forced into immediate change of their daily lives with no return. Their views of the world, their values, their aspirations, and their philosophy of life are turned upside down, as they receive their child's diagnosis (Davis & Bidmead, 2002). Professional counseling is one of the main resources parents usually look for, in an attempt to find some relief.

2.4 FAMILY-CENTERED MUSIC THERAPY

Literature in the field of *family-centered music therapy* show two main areas in which music therapy provides treatment: music therapy with families of children with special needs, and music therapy with families at risk, including traumatized children, families dealing with alcohol or drug addictions, and families with neglected children (Horvat & O'Neill, 2008; Jonsdottir, 2008; Lindhal-Jacobsen, 2012, Oldfield, 1993; Pasiali, 2004; Thompson, 2012). In working with families of children with special needs, the focus of the treatment is often directed at the child's progress and his/her ability to communicate. Parents may be directed to play a more active role in the interaction (Horvat & O'Neill, 2008; Oldfield, 2006). When working with families at risk, the focus might be directed more to the parents' ways of interacting with their child and how parents and children relate to each other (Lindahl-Jacobsen, 2015). Nevertheless, in both areas communication difficulties affecting interaction between parents and their children, and aspects of parenting competencies are considered in counseling. There are reports of family-centered interventions that are clinically or theoretically based in music therapy, but only few if any publications about parent counseling in music therapy.

In the following sections, I will refer to the area of families with children with special needs and ASD, and not to the area of families at risk, in order to remain inside the frame and scope of this study.

2.4.1 MUSIC THERAPY AND PARENTS OF CHILDREN WITH SPECIAL NEEDS

Some clinical descriptions and basic theories are presented in music therapy literature in the field of working with families of children with special needs such as: autism, developmental delays, physical impairments, to life threatening diseases and cancer. Several of the case studies that have been published show positive experiences and beneficial outcomes for both children and parents (Alvin, 1981; Flower, 2008; Horvat & O'Neill, 2008; Oldfield, 1993, 2006a; Oldfield & Nudds, 2002).

Approaches and aims

According to Horvat and O'Neil (2008), parents are taking a more active role in music therapy with their children with special needs due to two main reasons. First, the attempt to provide emotional and/or physical support to their child and secondly due to difficulties they are having in relating to their child. Oldfield's approach (2006a) focuses on the child's positive experience during music therapy sessions, emphasizing that positive experience is the key for the child's motivation to continue being in interaction with another person. She calls her approach *Interactive Music Therapy*, as the focus is on establishing a basic interaction with the child through positive events during therapy sessions. Whenever difficult emotions are being expressed within the trustfully relationship between the child and therapist, the overall experience remains positive for the parents. What motivates parents the most during music therapy with their children with special needs is the fact, that in opposed to other professions, music therapy focuses more on the achievements of the child rather than on his/her weaknesses (Flower, 2008; Loth, 2008; Oldfield, 2006a). Parents can have a better observing role being supportive and enjoy the child's newly gained freedom and interaction with the music therapist, depending on the special needs of the child (Flower, 2008).

Bull (2008) and Oldfield (2006a) described groups of mothers and young children as an opportunity for the mothers to interact with their children in a more spontaneous and positive way, through music therapy. Often, insights and recognitions rise up only during discussion between the group and the music therapists, allowing the mothers to both express and hear other experiences of other mothers in the group. This discussion provides mothers with an opportunity to receive recognition from other members of the group as well as from the music therapist. It might raise their hopes and confidence and may bring them out of isolation (Bull, 2008; Oldfield, 2006a). The advantages of working in groups include also an increase in the parents' sense of confidence and renew their resources by helping and giving support to other parents (Bull, 2008; Loth, 2008). In parents' reports after working in groups, the parents

described a development in their communication and social skills and improved their listening skills and self-expression (Loth, 2008).

In an article from 2011, Oldfield and colleagues describe the work of three different music therapists with three different families with children with special needs, in a short-term family-centered music therapy. They observed two common features in all three cases: 1) The primer focus of the therapists is the child's difficulties, later changes to family relationships and the parent's difficulties, and 2) In many cases involving music therapy work with families, nonverbal, improvised music-making and playful musical exchanges seem to be key components in facilitating family interactions (Oldfield et al., 2011).

2.4.2 MUSIC THERAPY WITH PARENTS OF CHILDREN WITH ASD

Children on the autism spectrum have certain difficulties in communicating, which needs to be addressed especially in cooperation with the parents. Two strong trends are revealed in an overview of contemporary literature (Edwards, 2011). The first is the international breadth of the developing work by music therapists within a family-centered context of practice, especially work with infants and their parents in the early years. Alongside with the trend of family-centered music therapy, the second trend is based on the theoretical principles of communicative musicality (described by Malloch & Trevarthen, 2009), and on knowledge of early musical skills and development (Briggs, 1991; Trehub, 2003). The second trend aims to understand how and why musical interaction with a qualified music therapist can offer a potential pathway to help repair difficulties that are currently occurring in, or are a result of, the first relationship. Both of these areas demonstrate increasing awareness within the music therapy field of the importance of successful attachment, and the rich possibilities of remediating unsuccessful attachment experiences through musical means within music therapy practice (Edwards, 2011).

Benenzon (1976) described an approach of teaching parents how to interact with their child with ASD, through music therapy sessions, using imitation, call, and response and echo clapping. Oldfield (2006b) described an approach of modeling for parents, where the music therapist interacts with the child, in the presence of the parent, in a more effective pattern of interaction, and provides the parents with verbal support and encouragement. A discussion between the parent and the music therapist may develop after the session, evaluating the child's progress and his/her strengths. Oldfield (2006b) stresses, that after the parent has acquired more effective patterns of interaction and has gained more confidence, the music therapist can verbally address issues of parenting skills.

Research in music therapy with parents

Most of the research publications in the field of music therapy with parents of children with ASD portray the style of working together with the child and his parents – sometimes even in the home environment with the whole family (for example: Thompson, 2012). In a series of single-case experimental design, Oldfield (2006b) examined 10 pre-school children with ASD and their parents; changes over time were detected at the children's behaviors because of mutual MT sessions with their parents, as well as parents' reports through interviews of the benefits from these sessions. Interpreting all the data and comparing the subjects showed positive results in general. Each of the 10 dyads showed positive changes in increased engagement and the amount of time playing instruments. Eight out of ten parents showed some significant changes in their attitude during music therapy sessions including engagement with their children (the exact numeral results were not provided by the author). Results from interviews and questionnaires showed that nine out of ten parents expressed a positive attitude towards music therapy treatment; two of the parents demonstrated considerable reduction in their level of stress post treatment (from 95 to 85 and from 90 to 50; Oldfield, 2006b, p. 186).

Several studies examined parent-child interaction in music therapy (for example: Muller & Warwick, 1993; Nicholson et al., 2008; Oldfield & Bunce, 2001; Oldfield, Bunce, & Adams, 2003; Pasiali, 2004, Thompson, 2012;). The goal of these music therapy studies with a family-based setting was to address challenging behaviors, promote interactional patterns, and improve parent child relationship. Four studies describe a setting where the music therapist provides the intervention in home environment (Muller & Warwick, 1993; Pasiali, 2004, 2010; Thompson, 2012). Muller and Warwick (1993) compared a group of mothers of children with autism participating in MT sessions with a group of mothers of children with autism without MT. The study showed, that during musical group activities, the level of the children's participation increased, including turn taking. Similarly, there was a decrease in the children's stereotypical behavior in music therapy. Regarding the development in parent-child interactions, the study showed a significant decrease in the mothers' demanding behavior, which was crucial for an equally significant decrease in the child's evasive behavior. The qualitative interviews with the mothers before, during, and after sessions reflected a better ability to look at their child's abilities more realistically. The mothers were also more aware of the positive and active sides of their child. Interviews during treatment showed that this trend could be seen, whether mothers were participating in group one or group two. This suggests that the mothers have experienced a change in the child outside of the music therapy setting. The most interesting result was that mothers more easily could read the emotional state of the child due to music therapy (Muller &

Warwick, 1993). In a study from 2004, Pasiali examined the use of a song-singing intervention with parents of three children with autism. The parents reported of a reduced challenging behaviors of their children, as they were expecting the familiar lyrics of the songs to appear. This expectation was understood as socially appropriate, and kept the children engaged with the parents. In a study from 2010, Pasiali examined music therapy as a family-based intervention with four families, providing eight home-based sessions. The findings from the inductive analysis of the qualitative data identified clinical themes, which focused on music therapy as a way to increase cooperation, mutuality, and connectedness between the children and their parents. In the remaining studies, families were invited for music therapy sessions in clinics or community settings.

In a recent study by Thompson (2012), sixteen family-centered music therapy sessions were conducted in the homes of 11 families. The study investigated whether family-centered music therapy positively influenced the social communication development of pre-school children with autism. In addition, parents' perceptions of their relationships with their children were expressed through self-report questionnaire and structured interviews. Thompson identified that the parents' descriptions of their relationship with their children with autism when the study took place, may be viewed along a continuum of the nature of intimacy, starting with the most distant position up to the closest one. Over this continuum, Thompson identified three phases. Interacting refers to the parents' experience of understanding their child during musical communication. Attuned refers to parents experiencing their interaction with their child as being synchronized. Interconnected refers to parents experiencing reciprocity and emotional closeness with their children. Overall, there were positive changes in shared activities, negotiation between the parent and the child, initiation of the child for musical communication, matching of the parent's behavior to the child's needs and increased engagement between parents and their children with autism (Thompson, 2010).

Generally, it seems that music therapists build strong working alliances with parents and offer much support and encouragement (Bull, 2008; Horvat & O'Neill, 2008; Oldfield, 2006b; Thompson, 2012). With some parents, talking about roles, aims, and approaches after each session can be very beneficial (Horvat & O'Neill, 2008; Oldfield, 2008). Larsen (2011) did one study that supports the importance of musical counseling to parents. The researcher used counseling for parents and caregivers of children with severe developmental delays throughout music therapy sessions. Two caregivers accompanied two children in music therapy took part in a phenomenological and hermeneutic study. The research method consisted of interviews with the caregivers and music therapist and of member-checking the music therapist's utterances. The results stressed the importance of observational counseling,

emphasizing the music therapist's role as a verbal and non-verbal supporter for the caregiver. According to Larsen, through musical counseling, a better understanding of the child was possible and it was crucial for the music therapist to assess the caregiver's ability to translate observational or musical experiences.

To sum up, music therapy takes a significant role in the treatment of children with ASD, using music as a communicative instrument to help in overcoming language and emotional boundaries (Gold, Wigram & Elefant, 2006; Holck, 2004; Kim et al., 2009). The need to cooperate with parents in music therapy has grown over the years, and certain approaches are being practiced (Larsen, 2011; Oldfield, 2008, 2011; Thompson, 2012). However, generalization in knowledge about effects and experience, and about specific working mechanisms of parent counseling in music therapy for ASD is still limited.

3 RESEARCH QUESTIONS

The main objective of this study is to investigate both the *effect* and the *experience* of a clinical approach of Music-Oriented Parent Counseling (MOPC), for parents of children with autism spectrum disorder. The aim is to investigate whether MOPC positively influences level of parental stress, quality of life perception and the use of music in everyday life by the participants, using self-report measurements. It also aimed to investigate the participants' experience of this clinical approach, using semi-structured interviews. Therefore, the research questions are as follow:

1. *What is the influence of Music-Oriented Parent Counseling (MOPC) on the level of stress and quality of life perception of parents of children with ASD?*

In order to focus on the main targets of this overall question, the following sub-questions guided this study:

- 1.1 *Does Music Oriented Parent Counseling (MOPC) decrease the participants' level of stress?*
- 1.2 *Does MOPC improve the participants' perception of quality of life (QoL)?*
- 1.3 *Is high-intensity MOPC superior to low-intensity MOPC in improving level of stress and QoL perception?*
- 1.4 *Is MOPC with MT for the children superior to MOPC without MT for the children in improving level of stress and QoL perception, as seen in parents' questionnaires?*

Complementing these questions on effect of MOPC, a question regarding the experience of the participants with MOPC, concerning level of stress and quality of life perception, was included:

- 1.5 *What is the participants' experience of MOPC and its' influence on their level of stress and quality of life perception?*

In order to investigate the influence of MOPC on daily use of music, the following question was formulated:

2. *What is the influence of MOPC on the use of music in everyday life by the participants with their children?*

In order to focus on specific areas of the daily use of music, three sub-questions of effect were stated, guiding the study:

- 2.1 Is there a wider use of music in everyday life by the participants with their children because of MOPC?*
- 2.2 Is high-intensity MOPC superior to low-intensity MOPC concerning a wider use of music in everyday life by the participants with their children?*
- 2.3 Is MOPC with MT for the children superior to MOPC without MT for the children concerning a wider use of music by the participants in everyday life with their children?*

Complementing these questions, a question concerning the experience of the participants with MOPC about daily use of music was added:

- 2.4 What is the participants' experience of MOPC in relation to their use of music with their children in everyday life?*

Based on the nature of the research questions, this study used multiple methods, with a fixed design (Creswell & Plano Clark, 2011; Robson, 2011). Both quantitative and qualitative methods were employed, and are described in sections 4.4.

3.1 EPISTEMOLOGICAL AND ONTOLOGICAL CONSIDERATIONS

The profession of music therapy has developed from empirical practice, theories, and knowledge generated both from itself and by investigating ideas from other disciplines (Wigram, 1999). Music therapy with children with autism is considered a beneficial approach for improving communication and interaction skills of the children within the profession itself (e.g., Geretsegger, Elefant, Mossler & Gold, 2014; Gold, Wigram & Elefant, 2006; Holck, 2004; Kim, 2009). From looking at the treatment reality around the world, including Israel, music therapy takes a significant role in treating these young children. In developmental psychology approaches (Stern, 1985; Trevarthen, 1979) the mother-child primary interaction is described with musical elements, such as pitch, melody, rhythm, and structure, presented by the mother with ultimate attention to her baby. These features stand at the basis of music therapy with children with ASD, and recapture pre-linguistic interaction, which corresponds well with early stages in development (Kim, 2009; Wigram & Elefant, 2009). Clinical practice of music therapists around the world who work regularly with children with autism shows that a child-centered focus has gradually transferred to family-centered focus. This comes out of the professional understanding of the enormous importance

of the parents' role in their children's well-being and the desire to share music therapy with parents in order to help them communicate better with their children. They receive relief from stress and feeling of incompetency (Oldfield, 1996, 2006a, 2006b, 2008; Thompson, 2011). Parent counseling is mentioned in the literature as a supplement to the parents' active participation in music therapy sessions (Oldfield et al., 2001). This study is the first to examine parent counseling with a musical orientation as a parallel process to MT for the children, given by the same music therapist. This way of working is based on the researcher's clinical practice.

With this in mind, it was important to develop this study as close as possible to clinical reality, examining music therapy as it is conducted in the field of ASD in everyday clinical practice (as opposed to studies with high experimentalism), emphasizing its' pragmatic orientation, as described in section 4.1.

This study is deeply rooted in clinical practice, aiming to investigate the effect and the experience of music-oriented parent counseling; thus, it clearly requires a mixed methods approach. Mixed methods have increased in popularity in different research milieus during the last decade. The concept of mixing different methods originated in 1959 when Campbell and Fisk used multi methods to study validity of psychological traits (Creswell, 2009). Others followed this research approach combining qualitative data (such as interviews and observations) with traditional surveys for quantitative data (Sieber, 1973). Triangulating data sources, – a means for seeking convergence across qualitative and quantitative methods – was first tested by Jick in 1979 (Creswell, 2009). The first handbook in mixed methods was published in 2003, aimed for the social and behavioral sciences (Tashakori & Teddlie, 2003).

The parents provided first-hand evidence regarding the effectiveness and influence of MOPC on the parents' level of stress and sense of competency through semi-structured interviews and self-report questionnaires. Research interviewing is a knowledge-producing activity, being seen as a journey that needs to be systematically planned in order to achieve the highest quality of knowledge (Kvale & Brinkmann, 2009). Music therapists who work in a family-centered focus with families of children with ASD (Larsen, 2011; Oldfield, 1994, 2006, 2008, 2011; Thompson, 2011) give a space for the parents' voice, and report their testimony regarding the beneficial process of cooperation during MT on their perception of their child. Up until now, no evidence was found in the literature regarding parents' testimony on participation in counseling as a parallel process to MT, conducted by a music therapist, well experienced in the field of ASD. This study highlights the position of parents, and gives an opportunity for their voice to be heard.

4 METHOD AND DESIGN

4.1 USING MULTIPLE METHODS

The present research focuses on parents of young children diagnosed with ASD. These parents cope with an extended stress level, which harms their quality of life (section 2.1). With a growing tendency of music therapists to work closely with parents of children with ASD (section 2.4.2), this study sets to examine a new and innovative approach, filling up a gap in research within this area. Several elements assembled to create the research design. Primarily, it was my wish to explore the role of parent counseling from a music therapy perspective as a beneficial factor in these parents' lives. It was interesting to explore the part musicality takes within the relations established between the parents and the researcher, and most important – the part musicality takes within the relation between the parents and their children with ASD. Secondly, to understand and update the professional perspective of the needs of parents of children with ASD; to expend my awareness and accurate my conception. Third, to let the parents' voices be heard, and let their personal experience be expressed. With an attempt to establish partnership and collaboration with the participants, and with an awareness of the complexity of the different roles I took in this study (Kvale & Brinkman, 2009), the participants were considered as essential partners in generating knowledge and shaping their stories.

My current conception of children with ASD and their parents is based on my clinical experience and theoretical reading. In this study, a parallel setting in music therapy, combining individual MT sessions for the child and counseling sessions for the parents, was investigated for the first time. In addition, the study's fixed design, framed by the study protocol of the TIME-A international study (Geretsegger, Holck & Gold, 2012), opened up the opportunity to investigate an unfamiliar condition for me - solely counseling sessions without MT sessions for the child, acquiring new knowledge of the phenomenon. Data was obtained using various techniques: collecting self-reports questionnaires from parents at two time points, conducting interviews with all the participants at the end of intervention period, and collect therapist notes after each counseling session. These goals and elements as well as my source for data were all leading towards a mixed methods design.

Mixed methods research employs the combination of quantitative and qualitative approaches by utilizing the strength of these two methods (Creswell & Plano Clark, 2011). When research questions are complex and require reference to different dimensions of the problem, like in the current study, mixed methods can meet these

challenges. Quantitative methodology using fixed design (research questions 1.1, 1.2, 1.3, 1.4, 2.1, 2.2, and 2.3) and qualitative methodology of a more observational nature, using analysis of interviews (research questions 1.5 and 2.4) were combined (Creswell & Plano Clark, 2011; Robson, 2011) in order to answer the overall questions (research questions 1 and 2). As the quantitative and qualitative methods in this study were predetermined and planned at the start of the research project, it may be called a fixed mixed methods design (Creswell & Plano Clark, 2011, p. 54).

Mixed methods converge and merge quantitative and qualitative data in order to provide a comprehensive analysis of the research questions. In this design, qualitative data may support the quantitative outcomes and vice versa (Creswell & Plano Clark, 2011). It may be defined as *"the collection or analysis of both quantitative and qualitative data in a single study in which the data are collected concurrently or sequentially, are given a priority, and involve the integration of the data at one or more stages in the process of research"* (Creswell, Plano Clark, Gutmann, & Hanson, 2003, p. 212). In addition, in this design, one smaller form of data may be embedded within another larger data collection, in order to analyze different types of questions while the quantitative addresses the outcomes and the qualitative addresses the process (Creswell & Plano Clark, 2007). In light of this, data in this study has been collected both numerically as well as through interviews, merging the two paradigms of quantitative and qualitative into triangulation mixed methods design.

Creswell and Plano Clark (2011) describe mixed methods within the context of quantitative and qualitative methodology:

"Quantitative research and qualitative research provide different pictures, or perspectives, and each has its limitations. When researchers study a few individuals qualitatively, the ability to generalize the results to many is lost. When researchers quantitatively examine many individuals, the understanding of any one individual is diminished. Hence, the limitations of one method can be offset by the strength of the other method, and the combination between the quantitative and qualitative data provide a more complete understanding of the research problem than either approach by itself" (p. 8).

With the aim to investigate both effect and experience of the phenomenon of parent counseling in music therapy, this description fit naturally.

The choice of mixed methods design is often driven by the nature of the research questions, or as Tashakkori and Teddlie (1998) expressed as a strong principle of "dictatorship of the research questions" (p.20). However, the nature of research questions does not stand alone in choosing to conduct a mixed methods study. A philosophical paradigm, or *worldview* as Creswell & Plano Clark (2011) name it, informs

the mixed method's practice of the researcher. Mixed methods research is often associated with *Pragmatism worldview*, which focuses on the consequences of research, on the primary importance of the questions asked rather than the methods, and on the use of multiple methods of data collection to inform the problems under study. Thus, "...it is pluralistic and oriented towards 'what works' and practice" (Creswell & Plano Clark, 2011, p.41). As pragmatism was a major factor in designing this study, with the ambition to investigate the clinical reality and the approach for Music-Oriented Parent Counseling (MOPC) as being conducted in *real life*, this worldview seems to fit naturally into my own professional values and stance. The precision provided by analyzing numbers within a quantitative approach, together with opportunity to present the individual's *voice* represented by the qualitative approach, seem to grasp the full picture of the phenomenon, and keep an ethical representation on behalf of the participants who share their concerns, experiences, and hopes within this study.

The three other worldviews that Creswell & Plano Clark (2011) mention, are: post positivism, constructivism, and participatory worldviews. Post-positivism worldview often associated with quantitative approaches includes determinism or cause-and-effect thinking, and focuses on select variables to interrelate as well as detailed observations and measures of variables. Constructivism is typically associated with qualitative approaches. This is the understanding of meaning of a phenomenon, formed by participants and their worldviews. In this form of inquiry, research is shaped from individual perspectives to broad patterns – "...from the bottom up." Participatory worldviews are influenced by political concerns and deal usually with marginal groups in society (p. 40-41).

Varied techniques were used to generate the data: parents' self-report questionnaires, parent interviews, researcher's notes of parent counseling sessions, and videos of random counseling sessions for a blind assessor of the music-oriented parent-counseling guide. Combining all should present rich information provided by the participants as well as from my own learning.

4.2 PARTICIPANTS

Fourteen participants² were recruited to this study; all of them had children diagnosed with autism spectrum disorder, and participated in the TIME-A research project. One couple dropped out after randomization did not fit their expectations, leaving the study with 13 participants. Table 1 describes basic demographic information of the participants.

Table 1 Basic demographic information on the 13 participants

Participant	Age	Education level	Job status	No. of children
A	Mother: 32 Father: 35	University degree University degree	Part Time Full Time	3
B	Mother: 29 Father: 30	12 years + University degree	Unemployed Full time	1
C	Mother: 34 Father: 35	University degree University degree	Full time Full time	2
D	Mother: 42 Father: 45	University degree University degree	Part Time Full time	4
E	Mother: 38 Father: 38	University degree University degree	Unemployed Full time	2
F	Mother: 28 Father: 30	12 years + 12 years +	Full time Full time	2
G	Mother: 36 Father: 37	12 years + 12 years +	Full time Full time	2
H	Mother: 32 Father: 36	Less than 12 years Less than 12 years	Unemployed Part time	3
I	Mother: 36 Father: 39	University degree University degree	Part time Full time	2
J	Mother: 40 Father: 40	University degree University degree	Part time Full time	3
K	Mother: 36 Father: 37	University degree University degree	Part time Full time	2
L	Mother: 38 Father: 45	12 years + University degree	Part time Full time	2

² Participants were pairs of parents or one parent solely. Both pairs of parents and single parents were considered parental unit for this study, corresponding with the *real life* situation, when sometimes counseling is conducted with pairs of parents and sometimes with single parent.

M	Mother:	36	University degree	Part time	2
	Father:	36	University degree	Full time	

Note: No. of children refers to all the children of the family, including the diagnosed child; All the couples were married.

The participants volunteered to participate through information sheets posted at care centers for children with autism in Kfar-Saba and surrounding area, an internet forum involving families of children with autism, and a Facebook group for parents of children with autism and professional therapists (Appendix A, *information sheet*). Nine of the participants came from small cities near Kfar-Saba (approx. 15 minutes' drive) and four came from more distanced cities (30-40 minutes' drive). Their mean age was 36 (median: 37) with a standard deviation of 4.36.

Inclusion criteria

Volunteers met the following inclusion criteria:

- Parents of children diagnosed on the Autism Spectrum between the ages 4-7
- No other sensory disorder of the children (i.e., blindness or deafness)
- No previous experience with music therapy or parent counseling by a music therapist

Participants who were dealing with children from the whole spectrum of cognitive and speech ability could be included. This decision was made in order to comply with the study's primary orientation towards research that is based on clinical practice and seeks clinical relevancy. Four families had children with IQ level below 70 (indicating intellectual disability), two families had children with IQ level 75 (indicating borderline intellectual ability), and seven families had children with IQ level of 90-109 (indicating an average intellectual ability).

In addition, there were no specific requirements concerning concomitant treatment for the parents, whether it is therapeutic intervention or medication. This stems from the perspective of providing a full range of variety within the population to be represented in the sample, enhancing the trial's primary orientation as a more *pragmatic* than *explanatory* study (cf. Thorpe et al., 2009). Furthermore, it would have been un-ethical to ask participants to avoid treatment, which might be beneficial for them. In cases where only one parent could attend the parent counseling sessions, the researcher evaluated the reasons and needs of the family, and made a decision whether to allow participation, following the MOPC Guide (Appendix F).

4.3 CLINICAL SETTINGS AND THERAPEUTIC PROCEDURE

Within this study, the parent counseling sessions and the music therapy sessions for the children were conducted by the same person (myself, the researcher). Parent counseling sessions were held according to the MOPC Guide, which was developed for this study (Appendix F) and music therapy sessions focused on improvisational music therapy, according to TIME-A's treatment guide (Geretsegger et al., 2012). Counseling took place over five months, with parents receiving either minimal MOPC (3 sessions) or maximal MOPC (10 sessions). Each parent counseling session lasted 60 minutes, and all sessions were video recorded by one steady video camera, in order to ensure a later fidelity assessment of the MOPC guide by a colleague. After each session, a short form addressing prominent aspects occurred during the session was completed (see Appendix J).

Participants were randomly assigned to one of the following groups:

- Group 1: Minimal MOPC + MT sessions for the children (three families)
- Group 2: Maximal MOPC + MT sessions for the children (three families)
- Group 3: Minimal MOPC + No MT sessions for the children (three families)
- Group 4: Maximal MOPC + No MT sessions for the children (four families)

Therapeutic procedure – music oriented parent counseling sessions

MOPC draws from the researcher's world-view, perceiving the relationship between her and the parents as collaborative, combining the parents' valuable knowledge of their child with her professional experience and knowledge. It stands in line with the *Values-based Parent counseling* (Nelson et al., 2000) and the *Partnership Model* (Davis, 2009) which encourages therapists to establish a secure and trustworthy environment with the parents, supporting them in achieving improvement in parenthood to their child with autism (section 2.3.2). The therapeutic procedure maintains the Parallel-Treatment approach (Chazan, 2003) in which one therapist conducts treatment for the child and the parents – separately but simultaneously (section 2.3.2). While Chazan, which is a psychotherapist, conduct parallel treatment for both the child and the parents, the MOPC consists also of parallel paths conducted by the same therapist, only here the parents receive counseling and not psychotherapeutic treatment. A central motive within the MOPC approach is the use of music and music-therapy techniques (such as improvisations and music listening) during parents' sessions and as a tool for parents to both further explore their feelings regarding their child's diagnosis and to use within interactions with their children.

MOPC comprises supportive conversations for parents regarding current difficulties and concerns arising from the child's diagnosis. An overarching principle of this model perceives the child's needs and capabilities *in combination* with the parents' strengths and weaknesses. This was sometimes perceived by the parents as an opportunity to look at reality in a new way, as parents tended to focus on their child's needs, overlooking their own. This meant that the therapist had the challenge of developing *parallel empathy*, with an attempt to avoid creating 'coalition' with one side of the equation (Nilsson, 2006).

MOPC emphasized the role of music in interaction with the child. Parents' testimonies regarding their child's responses to music (collected through self-reports using the MEL questionnaire) were seen in combination with insights from MT sessions conducted within this study according to allocation, and with the collected knowledge in the field of MT and autism for those who did not receive MT sessions within the study. The role of music in parent-child interactions was emphasized, and parents could reflect on using MT-like techniques in the home environment.

MOPC also provided information about ASD, child development and social communication relevant to the families' everyday life situations, incorporating terms widely used in the field of MT and autism (e.g. *attunement; communicative musicality; turn taking and turn giving* etc.), in order to offer a new point of view to the on-going routine in the home environment. Both parents were asked to participate in the sessions. For families for which this was not feasible, I evaluated the possibility of only one parent participating by considering the whole family's needs. Eventually, in two families only the mothers participated due to the complexity of the family's situation.

Parents' sessions were held in accordance with an MOPC guide created for this study (Appendix F) in order to specify the sessions' procedures. This guide outlines settings, general goals, and basic principles of the intervention. Although it is a systematic procedure, it was important that the guide is conducted maintaining flexibility according to the requirements of the respective situation and needs of the parents. It could only be applied in combination with and relying on the clinical expertise of the music therapist.

Therapeutic procedure – music therapy sessions for the participating children

The music therapy approach applied in this study is based on findings from previous music therapy research (e.g., Edgerton, 1994; Holck, 2004; Kim et al., 2008) developmental psychology (Stern, 2010), a psychodynamic approach, and improvisational techniques (Geretsegger et al., 2014). Generally, the music therapy

sessions included both structured activities and child-led parts consisted of active music making by the therapist and the child and verbal comments. In musical terms, this may involve matching, sustaining, or complementing *musical* features of the child's behavior (pulse, rhythmic pattern, dynamic or melodic contour, timbre), thus creating moments of synchronization and meeting (cf. Kim, 2006; Schumacher, 1999). Therapeutic principles fundamental to music therapy with children with autism, such as: fostering emotional expression, being emotionally involved in music, engaging the client in musical interaction, encouraging vocalization, etc, are also in use. All techniques and courses of action of the music therapy approach are specified in the study protocol of TIME-A (Geretsegger et al., 2011).

4.4 RESEARCH TOOLS

In order to achieve multidimensional observations for this study within a mixed methods design, I have used specific tools for each methodology:

The quantitative investigation

Within the quantitative part of the study, the purpose was to investigate the effect of a clinical approach of music-oriented parent counseling on level of parental stress, quality of life perception, and the daily use of music with their children.

The selection of test instruments was based on standardized tools, which are widely used in clinical trials with parents of children with autism (described in details below, under measurements tools):

- 1) Questionnaire for Resources and Stress – short Form (*QRS-F*)
- 2) Quality of Life Visual Analogical Scale (*QoL-VAS*)

For investigating the daily use of music by parents and their children with ASD, the researcher developed a self-report questionnaire for parents:

- 3) Music in Everyday Life (*MEL*)

The participants in two time points completed these three questionnaires at baseline and after five months (at the end of intervention period).

The researcher developed additional tools:

- 4) Fidelity Assessment of Music-Oriented Parent Counseling (full description of the purpose and procedure are given in section 4.4)

- 5) Session note-form, which was completed by the researcher after each parent counseling session.

In order to answer questions no. 1.1-1.4 and 2.1-2.3, the following hypotheses were produced:

- 1) *Participants will report reduction in stress level*
- 2) *Participants will report improvement in their quality of life perception*
- 3) *Participants participating in maximal MOPC will report more reduced stress and improved quality of life perception than participants participating in the minimal MOPC*
- 4) *Participants whose children received MT sessions will report more reduced stress and a higher improvement in quality of life perception than participants whose children did not receive MT sessions.*
- 5) *Participants will report a wider use of music in everyday life with their children*
- 6) *Participants participating in maximal MOPC will report a wider use of music in everyday life with children than participating attending minimal MOPC*
- 7) *Participants' children who received MT sessions within the study will report a wider use of music in everyday life than participants with children who did not receive MT sessions.*

Hypotheses 1, 3, and 4 were tested by the *QRS*. Hypotheses 2, 3, and 4 were tested by the *QoL-VAS*. Hypothesis 5, 6, and 7 were tested by the MEL.

Measurement tools

A short form of the Questionnaire on Resources and Stress (*QRS-F*; Friedrich et al., 1983) is a 52-item questionnaire assessing four subcomponents of parents perceptions: (a) parents and family problems (stressful aspects of the impact of the child with disability on parents and the wider family); (b) pessimism (parents' pessimistic beliefs about the child's future); (c) child characteristics (features of the child that are associated with increased demands on parents); and (d) physical incapacity (the extent to which the child is able to perform a range of typical activities). Hastings & Brown (2002) have used the *QRS-F*, excluding the subcomponents of physical incapacity (d) and child characteristics (c), as they thought of them as assessing the child's disabilities rather than measure the child's impact on the parents. This form of the *QRS-F* is used in the current study. It has 31 items, focusing on parent and family issues under the concept of parental wellbeing.

Despite the advantages of a shorter measure, some ambiguity as to the conceptual structure of the *QRS-F* remains. For example, Glidden and Floyd (1997) identified a further five item subscale within the *QRS-F* that seemed to be a robust measure of parental depression. The validity and reliability of the *QRS-F* 31-item scale with parents of young children with autism has been tested (Honey, Hastings &

McConachie, 2005). Reliability total score was established using the Kuder-Richardson coefficient (a measure of internal consistency similar to Cronbach's alpha, but for scales containing dichotomous items). Coefficients for mothers in one study (0.85), and for both mothers and fathers in another study (0.88) indicate that, the total score based on the 31 QSR-F items has a good level of internal consistency for parents of children with autism.

Analyses of the associations between severity measures and paternal stress found all of the relevant associations to be statistically significant. All of these associations were in the expected direction: those parents with children with more severe symptoms of autism reported more stress, and those whose children were more able reported less stress. These analyses lend preliminary support to the convergent validity of the scale. Overall, the data support the use of a total stress score from the 31-item version of the *QRS-F* in research with parents of young children with autism (See Appendix C).

The Quality of Life - Visual Analogue Scale (QoL-VAS) – This graph is adapted from EuroQoL Group (1990). Parents were asked to provide two numbers: one - the parents' perception of their child's quality of life, and two - the parents' perception of their family's quality of life. The participants were asked to mark a point on a 100mm line, which is transformed to a score from 0-100, where zero is the lowest possible and 100 is the highest possible QoL. These numbers, assessed pre and post intervention, provided information regarding any changes in the parents' perception of their and their child's quality of life (See Appendix D).

Music in Everyday Life (MEL) Questionnaire – This tool which was developed especially for the study, to measure the use of music in everyday life by parents with their child with autism (see chapter 5: *developing a scale to measure use of music in everyday life by parents of children with ASD*; see Appendix E, *Music in Everyday Life questionnaire*).

Fidelity Assessment of Music Oriented Parent Counseling (MOPC) Guide (See Appendix G) – Conducting randomized controlled trials of nonpharmacologic treatments raises certain challenges concerning trial reports. In an extension of the Consolidated Standards of Reporting Trials (CONSORT; Boutron et al., 2008) guidelines are presented for reporting trials of nonpharmacologic treatment, recommending that the results section of the report will include "*Details of the experimental treatment and comparator as they were implemented*" (Boutron et al., 2008, p. 63). In order to verify that the therapist followed the protocol guide in conducting the counseling sessions, an independent rater (a music therapist not involved in the study) completed a fidelity assessment at the end of intervention period (see Appendix G, *Fidelity Assessment of MOPC Guide*). The rater, using Likert-scale questions, assessed randomly selected videos of counseling sessions. When selecting the sessions for

assessment, the researcher avoided choosing the first or last session of each participant, as these were the starting point and closing point of the process. As for the participants who attended three counseling sessions, the researcher chose to assess the second session for fidelity. As for the participants who attended ten counseling sessions, the researcher took out the first and last sessions, numbered each of the remaining eight sessions on a note, and chose randomly by pulling one note from a box. The Fidelity Assessment followed the layout of the MOPC Guide, where the first part (items 1-9) describes WHAT needs to be done during parents' sessions in music therapy (i.e. goals and basic aspects), and the second part (items 10-17) describes HOW the music therapist should perform the sessions in order to achieve them. The items were analyzed separately, not combined as a scale, as the researcher wanted to keep the 'natural' aspects of the sessions, emphasizing the involvement of trust between the participants and the music therapist/counselor, and the adequate clinical judgment which the counselor had to perform with each family. Means and standard deviations were calculated and presented to assess adherence (Waltz et al., 1993). In addition to the Likert-scale items, the assessor gave an overall assessment of the session's quality as a *good* or *poor* MOPC session. This was analyzed and presented as a relative frequency. The ratings referring to adherence to the MOPC guide's principles should be above an average of 80% on the Likert-type scales in order to declare counseling fidelity as sufficient

Parents' session Note Form – (see Appendix J) – this form was developed in order to collect data relevant for assessing treatment fidelity and reviewing the counseling process from a clinical perspective. The researcher completed this form soon after each counseling session, and the collected forms served as *therapist journal*, addressing any difficult situation or conflicts that were expressed by the parents during sessions, and an overall impression regarding the level of stress and level of trust that the parents demonstrated in relation to the therapist. The data gathered in this form were used for in-depth reporting and comparison with parents' self-reports on the effectiveness of the counseling process.

As research sub-question 1.4 and 2.3 revolve around whether MT for the children made any difference for the participants' process, baseline data of the children was obtained. This was taken from the data gathered by the TIME-A project. These tools *were not analyzed* in the current study, but the information gathered by them helped to see fundamental characteristics of the children (e.g. the severity of autism, intelligence quotient and diagnosis), giving further information on what the participants were coping with. The tools were as follow:

The Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2001) - This is a widely used and validated scale. It is a standardized observation

instrument in which core features of ASD are assessed through play-based interactions between a child and a trained clinician. Although the *ADOS* was initially developed for the purpose of diagnosis, its' "Communication + Social Interaction Total" score has been used as outcome measure in previous RCTs investigating effects of interventions for ASD (e.g. Aldred, Green, & Adams, 2004; Green et al., 2010; Owley et al., 2001) and is the primary outcome in TIME-A (Geretsegger et al., 2012).

Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994) – This is a validated manual for conducting an interview for parents by a trained clinician, to acquire data not only on the behavior displayed during baseline assessment, but also on the history of development of each child and to avoid loss of specificity. Based on the *ADI-R* final score (above 8), children were assessed as eligible for the study. The combination of *ADOS* and *ADI-R* has been chosen for validating the clinical diagnosis of autism, as stated in the TIME-A study protocol, and as clinicians and psychologists in Israel to determine whether a child is affected by ASD administer these tools.

Social Responsiveness Scale (SRS; Constantino & Gruber, 2005) –

This is a parents' self-report questionnaire for evaluating the child's responsiveness in different situations. The *SRS* is a validated quantitative measure of autistic traits, feasible for use in clinical settings and for large-scale research studies of autism spectrum conditions. The *SRS* is a first-hand rating from parents who have observed the child in naturalistic social settings.

The qualitative investigation

In order to answer sub questions 1.5 and 2.4 and capture the participants' experience of MOPC, the researcher conducted semi-structure interviews with all 13 participants. The interviews took place at the last counseling session, at the end of the 5 months investigation period. The use of qualitative research interviews is appropriate when a study focuses on the meaning of particular phenomena, and qualitative data can provide clarity of the meaning of the findings (Creswell & Plano Clark, 2011). According to Robson (2011), qualitative research interviews "...lend themselves well to be used in combination with other methods, in a multi-strategy design or multi-method approach" (p. 279). Kvale and Brinkmann (2009) described the qualitative interview as "an attempt to understand the world from the subject's point of view..." to unfold the meaning of their experiences...and uncover their lived world prior to scientific explanations" (p. 1).

Semi-structured interviews

The interviews were held as a conversation between the researcher and the parents, but went beyond a simple exchange of views, as they were held as careful questioning and listening approach (Kvale & Brinkmann, 2009), with the purpose of exploring the phenomenon of participating in music-oriented parent counseling sessions. Semi-structured interviews allowed the researcher to prepare a list of questions, which were asked in a flexible way, adapted to suit the interviewee (Kvale & Brinkmann, 2009; Robson, 2002). The interviewer took a direct approach (Kvale & Brinkmann, 2009) by explaining to the participants about the purpose of the interview and posing direct questions. This direct approach was well suited for the purpose of collecting the desired information to answer research questions 1 and 2, and more specifically – research question no. 1.5 - *What is the experience of the participants of MOPC and its' influence on level of stress and quality of life?* In addition, research question no. 2.4 *what is the experience of the participants of MOPC in relation to changes in the use of music in everyday life.* (See Appendix H, *Questions for Semi-Structured Interviews*).

Interviews structure

The interviews were designed to cover the following topics linked to the research questions: (a) Level of parental stress, (b) Parents' perception of QoL of their child and their own, (c) the use of music in everyday life, and (d) the parents' experience of the Music-Oriented Parent Counseling (MOPC) process. The interview started with an open question on the parents' experience of the MOPC (d) functioned as a warm-up question. As a relationship between the researcher and the parents was established during counseling sessions, this question enabled the researcher to enter to the interviewer role, to set the interviewees at ease and to get used to the new format of the session. Occasionally, the interviewer encouraged the parents to think about how was it for them to participate in the counseling sessions did anything in particular help and did the sessions contributed anything for their parent-child interaction? The answers to these questions, wrapped into the open question, provided the parents' experience of the MOPC Guide's recommendations.

The question relating to parents' level of stress (a) helped in establishing if research participants perceived the MOPC process as contributing to reducing their level of parental stress, and in what way. The questions relating to QoL perception (b) concluded first with an invitation to define what QoL means for each of them (mother and father), and then to describe if MOPC contributed to an improved QoL perception. These questions were designed to answer Research Question no. 1: *What is the influence of Music Oriented Parent Counseling on level of stress and quality of life of parents of children with ASD?*

The questions concerning the use of music in everyday life with their child (c) gave valuable insight into the individual relationship of each participant with music, the daily situations in which they used music with their children, and its' contribution to the interaction between them and their children. These questions were designed to answer Research Question no. 2: *What is the influence of Collaborative Parents Counseling in Music Therapy on the use of music in everyday life by the participants with their children?*

All semi-structured interviews were video-recorded for a fidelity assessment of the MOPC Guide (see Section 5.2). A music therapist colleague, who assessed and rated whether the music therapist/counselor followed the counseling guide appropriately watched randomly selected videotaped sessions and evaluated counseling fidelity. The ratings referring to adherence to the counseling guide's principles should be above average of 80% on the Likert-type scales in order to declare counseling fidelity as sufficient. Thirteen semi-structured interviews were collected from 13 participants.

4.5 DATA ANALYSIS – THE QUANTITATIVE INVESTIGATION

Data include:

Twenty-six *QRS* (each of the 13 participants completed 2 questionnaires at two time points)

Fifty-two *QoL* graphs (each of the 13 participants completed four graphs at two time points)

Data was scored and analyzed according to the questionnaires manuals

Twenty-six *MEL* (each of the 13 participants completed 2 questionnaires at two time points)

The developmental of this scale and its' statistical properties are presented in Chapter 5 (*The developmental of a scale to measure the use of music in everyday life*).

Statistical analysis of the RCT

This study used repeated measures design with two time points (baseline and after 5 months) to explore the effect of minimal MOPC vs. maximal MOPC on level of stress, QoL perception and the use of music in everyday life.

Descriptive statistics were performed on the three self-report questionnaires. Inferential non-parametric statistics were used to test for differences between scores at the two data time points mentioned.

Means and standard deviations were conducted for the fidelity assessment of MOPC, representing the main aspects that were used by the researcher during counseling sessions, according to the MOPC Guide. The results are presented in section 6.3.

4.6 DATA ANALYSIS – THE QUALITATIVE INVESTIGATION

The data collected for analysis were 13 semi-structured interviews, videotaped and transcribed. The interviews were evaluated with respect to both dimensions: the *thematic* dimension, with regard to production of knowledge, and the *experience* dimension, with regard to phenomenological approach (Kvale, 2009). The interview questions were to address both dimensions, in relation to the research questions.

Selection Criteria

All interviews were selected for analysis, representing differing degrees of change in level of stress, QoL perception and the daily use of music while participating in MOPC. The participants' statements were seen in connection to their answers in *QRS-F*, *QoL-VAS* and MEL self-report questionnaires, identifying consistencies and inconsistencies. It was considered that selecting interviews representing differing degrees of change and outcomes could provide a rich and multilayered picture of the phenomenon and could enhance the discussion regarding similarities and differences between research participants. This could potentially give insight into optimal terms for conducting MOPC, considering the timing, length and structure of the process suitable for different types of parents.

Data preparation

All interviews were transcribed by two independent transcriptase: one MT student from University of Haifa, and one linguistic student from The Hebrew University of Jerusalem. All interviews were transcribed verbatim. Any names or details that could lead to identification of the participants were erased from the text to protect participant confidentiality. Later, the researcher compared the transcriptions to the video recordings, made certain corrections, and updated missing words. Paragraph numbering was inserted to facilitate tracing of text units back at the original context.

Multiple roles of the researcher

In this study, a complex position was taken by the researcher, serving also as the parents' counselor and the music therapist for the children. As such, not only did I have knowledge about the family in general, but also insight into the life situation and therapeutic process of the research participants. Since the counseling sessions with the parents were held on a regular basis, a relationship was established between the researcher and the parents, which may have helped communicating during the interviews. The dual role may have helped in receiving more data. An unknown interviewer might not have been able to form a trustworthy relationship with the parents within one interview session and communication might have been more hesitant and less open. Furthermore, this dual role corresponds with the ethnography tradition in social research. Ethnography may be understood as a scholarly approach to the learning of a group of people, where the relationship between insider (emic) perspective and outsider (etic) perspectives have been examined carefully in modern ethnography (Stige, 2002, p. 256-257).

Analysis

Driven by the researcher's theoretical and analytical interest in the area of music therapy with parents of children with ASD, this study took a semantic approach with a *theoretical thematic analysis* procedure, rather than an *inductive* one (Braun & Clarke, 2006). As such, coding was done according to specific research questions, identifying data connected directly to the desirable outcomes, and mapping the analysis to a more theoretical approach. Theoretical thematic analysis provides a more detailed analysis of some aspects of the data, even though it is a less rich description of the overall data (Braun & Clarke, 2006). The thematic analysis conducted in this study was within a semantic approach, in which the themes were identified within the explicit meanings of the data. It involved a progression from *description*, where the data has been organized and summarized to show patterns in semantic content, to *interpretation*, where there is an attempt to relate the significance of the patterns, their broader meanings, and implications to theory (Patton, 1990). Identification of ideologies and any other ideas going beyond the semantic meanings of the data, formulating a latent level of analysis, was not carried out in this study.

Focus of the thematic coding

The thematic coding focused specifically on the following areas:

- The influence of MOPC on level of parental stress
- The influence of MOPC on quality of life perception

- The influence of MOPC on daily use of music
- Overall experience of the participants within MOPC

The analysis procedure was conducted as follows:

Within participant analysis

The researcher first entered data illustrations, translated to English, in a chronological way with each interview, according to desirable outcomes. The researcher numbered the illustration sentences in order to be able to track them back in the text for further examination. Table 2 represents an example of data illustrations of one participant concerning the four desirable outcomes.

Table 2 Example of data illustration according to desirable outcomes of one participant

Participant	Level of stress	Quality of Life	Use of music in everyday life	Overall experience of MOPC
A Group 1	P7 mother: "When I understand the situation, it lowers my feelings of stress; I understood things during our sessions, and I felt less stressed"	P10 mother: "the sessions may have helped a little"	P11 father: "now I understand how he is more engaged while using music, so I join him more when he sings or plays his instruments"	P3 mother: "three sessions are not enough" Father: "even though there were only few sessions, I received certain understandings regarding his rigid behavior, and how music can help in these situations"

Note: Group 1 = with MT/minimal MOPC

The researcher then collated data illustrations of each desirable outcome with the respective rating of self-report questionnaire for each participant, in order to facilitate a later triangulation of data. In this way, four separate tables were made for each participant: for level of stress, for QoL, for daily use of music and for overall experience. The researcher entered descriptive codes into an additional column, representing the core idea of the selected illustrations. The codes were discussed

between the researcher and her supervisor. Tables 3-6 describe the four tables of participant E as examples for this procedure.

Table 3 *Example of data illustration of one participant of level of stress outcome with self-report rating*

Participant E (group 2)– Level of Stress			QRS-F	
Code	ID	Data illustration	pre	post
Stress is high due to the child's situation	E/2/8	"My stress is down a little, although still very high; with I. it's always high..."	20	14
Tools that helped the parents to feel less stress		"I'm a very practical person, so I need concrete tools; in our sessions I have received tools that help me feel less stressed when I interact with my son"		

Note: Group 2 = with MT/maximal MOPC; ID = upper case letter represents the participant, first number represents the paragraph in the transcription, second number represents the line number within the paragraph; *QRS-F* = high number represents high level of stress, low number represents low level of stress; green color represents improvement.

Table 4 *Example of data illustration of one participant of QoL outcome with self-report rating*

Participant E (group 2)– Quality of Life			QoL-VAS			
Code	ID	Data illustration	Child pre	post	Family pre	post
A safe place to talk and reflect	E/3/10	"My own QoL has improved, as I had a place here, where I could come and talk about things, reflect on them, and together we found good solutions for my family"	20	30	20	35

Note: *QoL-VAS* = high number represents high QoL perception, low number represents low QoL perception; green color represents improvement.

Table 5 *Example of data illustration of one participant of daily use of music outcome*

Participant E (group 2)– music in everyday life			MEL RAM		MEL JAM	
Code	ID	Data illustration	pre	post	pre	post
Music is the core of the process	E/1/1	"First of all – it's the music; this is the core of everything I got here"	6	14	1	5
Music = health and well-being; no music = despair and grief	E/4/3	"during our sessions I have realized how sad it was that music – that was so alive and present when I. was a baby, got lost since we got the diagnosis...through our conversations I realized that music – and mostly singing – relates in my mind to health and well-being, and how without being aware of it, I stopped singing to my son...it's a sign of my despair and grief over the child that I will never have..."				
Music is back	E/4/12	"Now, music is back to our home! I sing to him more, we dance together, and I can see how happy and engaged he is with me"				
Music at bed-time	E/4/15	"Every night we put soft music, and he just falls asleep smiling?"				
Music to calm down	E/4/18	"when he is agitated, I put classical music which he loves very much, and it helps him to calm down"				

Music as a tool	E/4/20	"Music is a tool!"		
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Note: MEL RAM = Music in Everyday Life Routine Activities using Music; MEL JAM = Music in Everyday Life Joint Activities using Music (see chapter 5 – development of a scale to measure the use of music in everyday life); green color represents more daily use of music

Table 6 *Example of data illustration of one participant of overall experience outcome*

Participant E (group 2)– Overall experience of MOPC		
Code	ID	Data illustration
surprisingly helpful	E/1/5	"The sessions were very helpful – more than I've expected. I could imagine the benefits of MT to my son, but couldn't imagine the contribution for me"
New insights; maximal MOPC	E/1/8	"It was really good to come here twice a month. Each time I felt I gained new insights"
Reciprocity between parent and counselor	E/2/4	"There was a lot of reciprocity going between us; it wasn't like I talked all the time and you nodded your head...or you lecturing me what I should do...it was quite equal"
New perspective	E/5/2	"You helped me to look at my son and myself through a new perspective"
Safe place	E/5/7	"You were very attentive and gentle to me; I could express myself without feeling judged; I felt every word you said resonated with me"

The researcher then collated the codes for each participant and ordered these according to a series of preliminary themes and sub-themes. Further discussions continued to take place between the researcher and her supervisor, and tables were revised reflecting new understandings.

Between participants analysis

The researcher grouped data illustrations of all participants according to desirable outcomes and group allocation rather than chronologically, resulting in four long tables (level of stress, QoL, use of music in everyday life, and overall experience). The researcher then entered coding according to the illustrations. Her coding was

descriptive. Table 7 represents grouping data illustration of all participants according to one desirable outcome – 'level of stress'.

Table 7 *Example of grouping data illustration of one outcome – level of stress*

Group	ID	Code	Data illustrations – level of stress
1	A	Minimal MOPC	"Not enough sessions to influence my stress"
	B	New understandings	"We understand now why he is behaving as he is, and that we can address that differently, so we feel less stressed with him"
	C	New understandings	"I achieved certain understandings here, so I'm less stressed with him"
2	D	Change at parental attitude; connect emotionally	"I feel less stressed now, as I try to emotionally connect to him; it's a change at my attitude"
	E	Gained practical tools that helped the parents to reduce stress	"I'm a very practical person, so I need concrete tools; in our sessions I have received tools that help me feel less stressed when I interact with my son"
	F	Practical tools help to reduce stress	"Overall I feel we are less stressed, because we got here tools that help us cope better with our son"
3	G	Change in parental attitude; more flexible	"During our sessions I changed my attitude; I'm more flexible now, and not insisting that he does things MY way. I can see that he's more flexible too...This makes me feel less stressed"
	H	No effect; Minimal MOPC	"Not enough sessions, so no change at the stress I feel"
	I	No effect; minimal MOPC	"The sessions here certainly open-up my awareness for the role of music in our lives, but there were too little sessions to influence

			my stress"
4	J	New understandings and new techniques help to reduce stress	"The sessions helped a lot; I felt that after each session I understand more and have new techniques to help me help my son. This certainly made me feel less stressed in situations that previously I had no idea what to do"
	K	Using music as a tool, reduces stress	"When we use music in situations of conflicts and rigidity, it helps him to calm down; when you have something that you can do – it makes you feel less stressed and helpless"
	L	Safe place	"The sessions gave me a place to talk about things, to reflect on situations; it's so good to have a place where you can talk on things as they are, and you will be understood. It certainly improved my feeling, and I'm less stressed now"
	M	A place to be heard; concrete tools to used	"The open discussions here made me feel heard – but also taught me things. I also received some concrete tools – like the morning song, that improved our lives dramatically. All that contributed to reduce my stress"

At the next stage, data illustrations from an individual participant's chart were extracted and reviewed in search for overarching themes common to some or all participants. New themes emerged and joined the previous ones, allowing for a fresh analysis of the data. The researcher then grouped codes and data illustrations according to the themes that emerged from the texts rather than according to desirable outcomes and group allocation, while using brief descriptive terms. The final themes represent common expressions to some or all participants, and are described in section 7.4. Further discussions between the researcher and her supervisor concerning the meaning of the themes took place, and the supervisor crosschecked the codes and themes. These measures were undertaken to guard against researcher-bias, and in order to strengthen the reliability and validity of the analysis as disagreements and discussions

could help refine coding frames (Barbour, 2001). Data illustrations concerning music were seen in various contexts within the themes, and were highlighted according to two foci, regarding *the use of music in everyday life* and *the meaning of music* to both the parents and their child.

A second researcher to analyze the interviews was not feasible for this study due to financial reasons and the time-consuming nature of the analysis.

Grouping the codes into major themes that emerged from the data illustrations, with no regard to group allocation or desirable outcomes, took the analysis process into a higher level. This gave interpretation to various aspects of the research topic (Boyatzis, 1998), highlighting shared experiences of different participants who participated in the same clinical setting but with different conditions (maximal vs. minimal). Themes represent some level of patterned response or meaning within the data set, and capture important aspects about the data in relation to the research questions (Braun & Clarke, 2006). Furthermore, as the meaning of *experiencing* a phenomenon was the focus of this study, the emerged themes highlighted shared experiences of different participants within the same intervention, might give a basis for generalization of the approach (Kvale, 2009). The themes are presented in Chapter 7 – *Findings of the qualitative investigation*.

4.7 ETHICS

This study was carried out according to ethical rules in Israel, and received approval by the Ethical committee, affiliated with University of Haifa, registered no. 031/13 (Appendix N).

Prior to study enrolment, an information sheet (Appendix A) was given to each parent who contacted the researcher, and informed consent forms (Appendix B) were obtained from every parent regarding their participation in counseling meetings and their children's participation in the study. Parents gave their consent by signing the information and consent form following an introductory discussion with the researcher informing them about all aspects of their and their child's participation in the study.

Ethical aspects in relation to the design and practical aspects of the study are explained as follow:

- Although the researcher carried out music therapy as well as parent counseling sessions with the participants once enrolled (see Clinical method, section 4.3), no dependent relationship between researcher and participants existed prior to their

consent to participate in the study. Potential participants' decisions on taking part in the study did not affect their treatment or any other services they wished to receive.

- Data protection: only the researcher and her co-workers (i.e., professional administering the assessments who were subject to confidentiality) had access to participants' personal data where participating children/families were mentioned by name. Participants were issued with an ID-code by the researcher, which was used in all data handling processes.
- Data disposal: This project will end in December 2015. All materials connected to data collected during the project (i.e. data files, video recordings, forms and questionnaires) will be deleted 4 years and 11 months after the end of the project.

There is an increasing awareness of the researcher's self-presentation in the field he/she studies, and his/her self-representation in the text he/she produces. Within qualitative music therapy research, the *researcher-as-instrument* aspect was seen as referring to *authenticity* and *integrity*. Within ethnography perspective, this also involves the need for *reflexivity* of the researcher on the different roles that he/she takes, talking about them, and reflecting upon them.

4.8 VALIDITY AND RELIABILITY

To ensure internal validity, the counseling protocol was documented, and only one music therapist (the researcher) conducted all the sessions (Mohr et al., 2009). The MOPC was documented (see section 4.3 for description of the therapeutic procedure) as well as goals and basic aspects concerning the music therapist-counselor activities were outlined (see Appendix F for the MOPC Guide). Although a working guide was developed to ensure validity, it was meant to be practiced with flexibility and adaptively to the needs of each family. As parents of children with autism demonstrate specific parenting patterns to answer their children's diverse needs (Arbelle et al., 1994; Kasari et al., 1988; Watson, 1998), flexibility in tailoring the sessions respectively to the parents needs is required.

External validity was threatened by the use of only one music therapist and the small sample size. However, external validity was strengthened by recruiting families from different parts of the center of Israel, and by that increasing the generalizability of results, despite the small sample size.

A recent consideration is also the ecological validity, meaning whether the research demonstrates "real-world" conditions (Robson, 2002). This study was design to be

close as possible to clinical reality, through conducting the sessions in typical setting and through typical reporting approaches using self-reports questionnaires from the participants together with researcher's notes.

This study includes the development of an assessment tool to assess the use of Music in Everyday Life (MEL) by parents with their young children with autism. Chapter 5 presents the development and reliability of this assessment scale.

Figure 2 provides a graphic overview of the mixed-methods and design of the study.

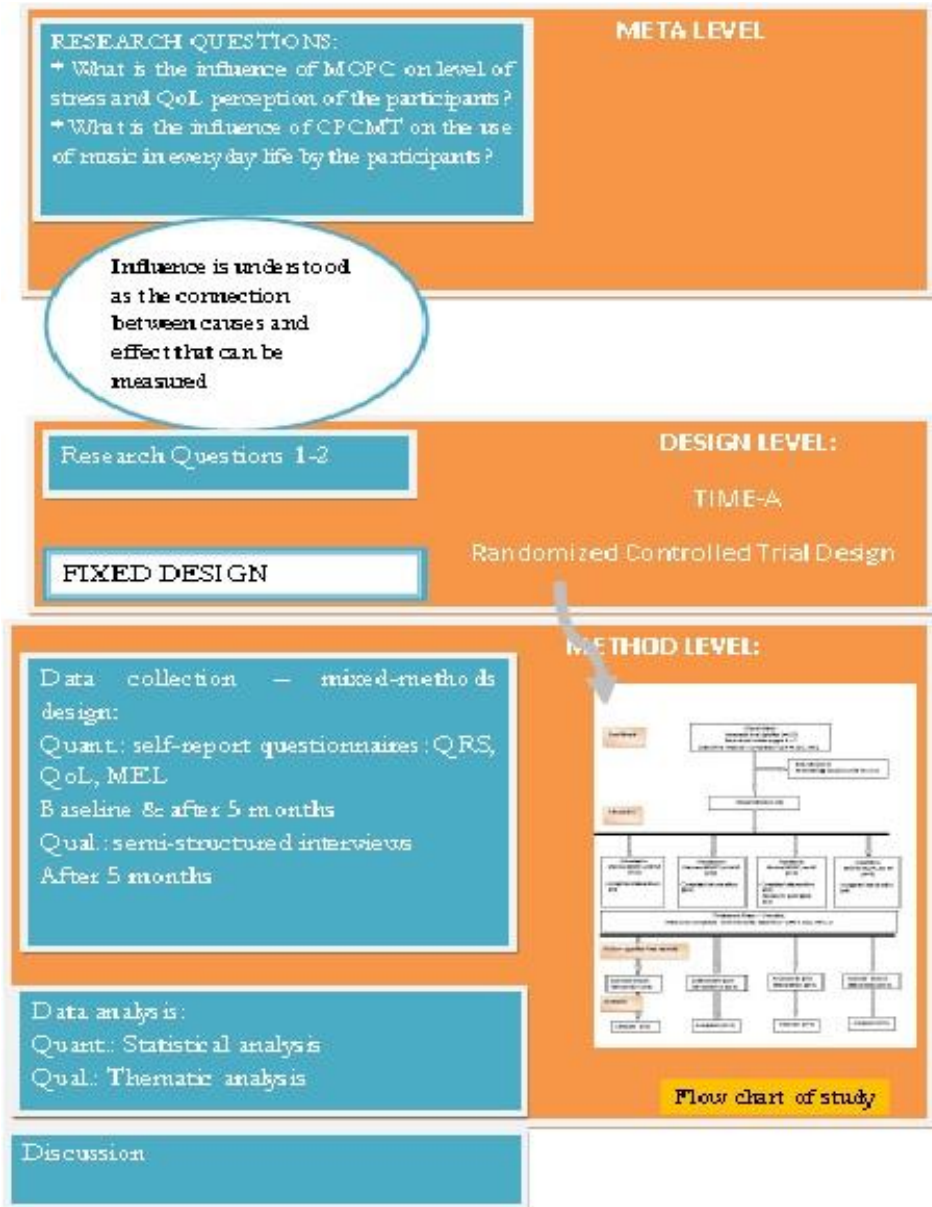


Figure 2 Graphic overview (simplified) of the mixed-methods and design (adopted from Bonde, 2014)

5 DEVELOPMENT OF A SCALE TO MEASURE USE OF MUSIC IN EVERYDAY LIFE BY PARENTS WITH THEIR CHILDREN WITH AUTISM SPECTRUM DISORDER

Introduction

Previous studies in music therapy with parents suggest the relevance of the use of music in everyday life by parents with their children (Chiang, 2008; Nicholson et al., 2008; Pasiali, 2004; Thompson, 2012), but there is a lack of standardized instrument for collecting data in this matter. Literature shows only one music therapy study (Thompson, 2012) that attempted to quantify or classify what parents do musically with their young children in the home environment on a daily basis or in between music therapy sessions. Therefore, we are not yet sure whether participating in music therapy sessions or parent counselling with a music therapist has impact on what happens musically in the home environment. As a first step in investigating whether parents incorporate methods from music therapy perspective into their everyday life, Thompson (2012) collected musical journals from 11 families participating in 14 weeks of weekly family-centered music therapy sessions. Parents recorded high frequencies of music activity in the home each week (53%), in which approximately one third of the time of musical engagement between parents and their children with ASD was by singing, another one third of the time was by listening to music with their child, and the rest of the time was by playing instruments and improvising with their child.

Outcome assessments in music therapy should be both relevant to the therapeutic approach and to the patient's process of change. A measure that is relevant only to the therapeutic approach, but is not of value to the client's life, is missing the main goal of therapeutic process of helping the patient make a change that will improve his quality of life, and empower his/her capabilities. The MEL questionnaire was intended to address both the approach's goal and the patient's personal process, by focusing on parents and children's engagement through music. Knowledge from previous qualitative studies (Ahmadi, 2011; Batt-Rawden et al., 2005) and from large-scale epidemiological studies (Cuyppers et al., 2011) emphasize that engagement through music in daily life can have important health implications. The MEL provides important information about spontaneous musical engagements, which already occur

naturally in home environment, as well as guide the therapeutic process toward what still needs to be improved (Appendix E).

The researcher of the current study cooperated with Dr. Grace Thompson, from Melbourne University in Australia, aiming to develop and test the reliability and validity of a self-report parents' questionnaire to measure the use of music in everyday life, as well as to collect information regarding the preferred genres of music, mutual activities, and personal experience. As one aim of the current study is to investigate whether on-going parents' sessions in music therapy influence the use of music in daily life within families with children with autism, the need to formulate such an instrument became clear, with a goal to use it both for research and for clinical purposes.

5.1 METHOD OF SCALE DEVELOPMENT

5.1.1 DEVELOPMENT OF ITEMS

Two music therapists with experience in working with children with ASD and their parents (the researcher and Grace Thompson) met in 2012 to discuss and develop items for the MEL scale, through the perspective of studies in the use of music in everyday life. Six Likert scaled questions, and two open questions assessing the spontaneous use of music by parents at home environment were originally developed in English and then translated to Hebrew, confirming the meaning was kept appropriately and not changed. This questionnaire was used within the current study as well as within the TIME-A Australian site, completed by parents' pre and post intervention. Changes in the use of music in everyday life were assessed.

In order to reflect the subjective experience of the participants with music in everyday life with their children, the questionnaire was formulated as a self-report questionnaire. In addition, in order to maintain the engagement aspect of using music, it was of high importance for us to focus on *mutual musical experiences* between parents and their children, and avoid asking about situations in which the children use music by themselves (i.e. "During the last week, how often have you listened to music *with* your child?").

The MEL assessment consists of the following questions: Questions no. 1-4 concern the frequency of different interactive uses of music during the last week (*singing together, listening to music together, playing musical instruments together, playing musical applications together*), each on a five-point scale (not at all – one day of the week – a couple of days of the week – almost every day of the week – every day of the week). In order to emphasize the mutual experience of parents and their child in each musical activity, questions 1-4

concern about the nature of the experience for both the child (on a 4 point scale: very positive - somewhat positive - neither positive nor negative - negative) and the parent (positive experience or negative experience). Formulating the content of questions 1-4 was based on previous studies suggesting the benefit of singing, listening to music and playing musical instruments on communication and interaction skills of children with ASD (Gold, Wigram & Elefant, 2006; Holck, 2002, 2004; Kim, Wigram & Gold, 2009).

Question no. 5 concerns first whether a member of the family plays a musical instrument; if the answer is yes, a second part of the question concern regarding the frequency in which the child with autism was exposed to this member's playing (on a 5-point scale from *not at all* to *everyday of the week*).

Question no. 6 concerns the frequency in which the family listened to each of eight genres of music (*music from your cultural heritage, classical music, Jazz music, children's songs, pop music, relaxation music, dance music and other*), again on a 5 point scale from *not at all* to *everyday of the week*.

Question no. 7 concerns the frequency of the use of music in each of nine daily routine activities (*calm down, at meal time, at bed time, to understand daily routine, have fun and experience enjoyment, exercise, transition smoothly between activities, learn new things, and travel calmly in the car or bus*), on a 5-point scale from *not at all* to *everyday of the week*. Formulating question 7 was based on statements repeatedly expressed by parents over the years during parents' sessions. These testimonies were gathered into question no. 7.

Question no. 8 is an open question, inviting the parents to comment on any other responses their child might have to music.

Overall, the questionnaire includes 23 items that are answered quantitatively on a 5-point scale (from *not at all* to *every day of the week*). In order to examine if there are significant differences between the pre and the post questionnaires, all responses were scored (e.g. not at all = 0, one day of the week = 1, a couple of days of the week = 2, almost every day of the week = 3, every day of the week = 4), and an overall score was computed, by summing those scores. Correlations between these items are of interest and were examined.

Table 8 describes the items of the MEL assessment in two languages: English and Hebrew.

Table 8 *Items of the Music in Everyday Life (MEL) assessment*

	English	Hebrew
Item 1	I sing with my child	אני שר עם ילדי
Item 2	I play musical instruments with my child	אני מנגן בכלי נגינה עם ילדי
Item 3	I listen to music with my child	אני מאזין למוסיקה עם ילדי
Item 4	I play musical applications with my child	אני משחק באפליקציות מוסיקליות עם ילדי
Item 5	A member of the family plays a musical instrument in the presence of my child	בן משפחה מנגן בכלי נגינה בנוכחות ילדי
Item 6a	We listen to music from our cultural heritage	אנו מאזינים למוסיקה מזרחית/ישראלית
Item 6b	We listen to classical music	אנו מאזינים למוסיקה קלאסית
Item 6c	We listen to Jazz music	אנו מאזינים לג'ז
Item 6d	We listen to children's songs	אנו מאזינים לשירי ילדים
Item 6e	We listen to pop music	אנו מאזינים למוסיקת פופ
Item 6f	We listen to relaxation music	אנו מאזינים למוסיקה מרגיעה
Item 6g	We listen to dance music	אנו מאזינים למוסיקת ריקודים
Item 6h	We listen to other genre of music	אנו מאזינים לסוג נוסף של מוסיקה
Item 7a	We use music in order to help our child calm down	אנו משתמשים במוסיקה על מנת לעזור לילדנו להירגע
Item 7b	We use music in order to help our child at meal time	אנו משתמשים במוסיקה על מנת לעזור לילדנו בזמן האוכל
Item 7c	We use music in order to help our child at bed time	אנו משתמשים במוסיקה על מנת לעזור לילדנו להירדם
Item 7d	We use music in order to help our child understand daily	אנו משתמשים במוסיקה על מנת

	routine	לעזור לילדנו להבין שגרת יומיום
Item 7e	We use music in order to help our child have fun and experience enjoyment	אנו משתמשים במוסיקה על מנת ליהנות ביחד
Item 7f	We use music in order to help our child exercise	
Item 7g	We use music in order to help our child make transitions smoothly between activities	אנו משתמשים במוסיקה על מנת לעזור לילדנו במעבים בין פעילויות
Item 7h	We use music in order to help our child learn new things	אנו משתמשים במוסיקה על מנת לעזור לילדנו ללמוד דברים חדשים
Item 7i	We use music in order to help our child travel calmly in the car or bus	אנו משתמשים במוסיקה על מנת לעזור לילדנו לנסוע בשלווה במכונית
Item 8	I have further comments regarding my child's response to music	יש לי מה להוסיף לגבי תגובותיו של ילדי למוסיקה

5.1.2 SCORING OF ITEMS

Part 1: Items 1-5 – joint³ activities using music

These questions consider musical activities conducted by the parents and the child together. The conditional a part of items 1-5 has response categories 0 to 4, where zero = *not at all*, and four = *every day of the week* (Appendix E). The conditional b part of items 1-5 has response categories -1, 0, 1 and 2, where -1 = *negative response* and two = *very positive response*.

Exception: item five has an additional part, represented by a*, which consists of a yes/no question. This part of the item has response categories 0 to 1, where zero = *no member of the family plays a musical instrument* and one = *there is a member of the family that plays a musical instrument*. At the stage of screening the data before analysis, it was clear that more than 50% of the families stated there was no member of the family who played a musical instrument; the number of participants answering the following parts

³ The term *joint activities* refers to musical activities conducted by the parent and the child **together**, the parent **with** the child, or **joint** musical activity.

of this question was reduced significantly. It was then decided to exclude item 5 from the analysis, leaving part 1 with **items 1-4**.

From the *a* and *b* parts of each question, we calculated overall item scores representing the frequency *weighted* by the experience. This was done by multiplying the 0 to 4 score for frequency with the -1 to 2 score for experience, so that the overall score for each item could range from -4 to 8.

Part 2: Items 7a to 7i – routine activities using music

These questions consider daily routine activities using music (i.e. ways of using music to facilitate routine daily situations). These items had response categories from zero to four, where zero = *not at all* and four = *every day of the week*.

Item 7f (*exercise*) was not included in the Hebrew questionnaire as it was not mentioned before in parents' testimonies as one of daily activities using music. Therefore, this item was excluded from the scale.

Part 3: items 6a to 6h – music genres

These questions consider different music genres used at home environment (i.e. classical music, music from cultural heritage, children's songs etc.). These items had response categories from zero to four, where zero = *not at all* and four = *every day of the week*.

Separate Item 8 – open question

This item was an open question concerning any other response that the child might have to music, and therefore was not scored.

5.1.3 ASSESSMENT OF RELIABILITY

Sample:

The scale was completed by 45 participants, in which 14 participants were from Israel and 31 were from Australia. One parent from each family (all mothers) completed each assessment. All were recruited for the project following the inclusion criteria (see section 4.2). Fourteen mothers (31.11%) and nine fathers (20%) had a University degree, while two mothers (4.44 %) and four fathers (8.88%) had less than 12 years of education. Fourteen of the fathers (31.11%) work full time, where only three of the mothers (6.66%) worked as much. Out of 45 children, 37 were boys (82.22%) and 8 of them (17.77%) girls, mean 22.5, SD 20.5. IQ scores were from 40 to 109, with a mean of 74.5, SD 48.8. Data was collected only from the baseline measurement point, between March 2013 and April 2014.

Given the strong emphasis on engagement during the use of music outlined above, the researcher was interested to see whether these might be related to the MEL scales: high quality of life and low level of stress may be positively related with an expanded use of music.

Statistical method:

The following analyses were conducted to examine reliability of this new measure: We first examined means and standard deviations for part one (items 1-4) and part 2 (items 7a-7i) at baseline. We then calculated inter item correlation and Chronbach's alpha if item deleted, in each part.

5.2 RESULTS OF SCALE RELIABILITY ASSESSMENT

MEL Part 1: Joint Activities using Music (JAM) – items 1-4

Cronbach's alpha was 0.63. The item means, standard deviations, item-total correlations, and the Cronbach's alpha if an item was deleted are shown in Table 9. Means were between 1.28 and 4.69, and standard deviations were between 2.43 to 3.18. All items show positive item-total correlation ranging from .23 to .62. For most items, Cronbach's alpha would not increase much if that item were deleted. Although item three (*listening to music together*) correlated poorly with the total scale (.24), and its' deletion would improve the scale's Cronbach's alpha to .70, it was decided not to exclude it, as it correlated well with the other items of the scale (1, 2 and 4; see Table 10).

Table 9 MEL part 1: Joint Activities using Music (JAM) – item statistics and reliability

	M (SD)	Item total correlation	Cronbach's alpha if item deleted
1. Singing together	3.50 (3.05)	.38	.58
2. Play musical instruments together	1.28 (2.43)	.62	.43
3. Listen to music together	4.69 (3.18)	.23	.70
4. Play music application together	1.80 (2.73)	.48	.52

Table 10 MEL part 1: Joint Activities using Music (JAM) - inter-item correlation matrix

	Singing together	Play musical instruments together	Listen to music together	Play music apps. together
Singing together	1.00	.40	.20	.30
Play musical instruments together		1.00	.23	.70
Listen to music together			1.00	.14
Play music applications together				1.00

MEL Part 2: Routine Activities using Music (RAM) - items 7a-7i

Cronbach's alpha of the whole scale was 0.75. The item means, standard deviations, item-total correlations, and the Cronbach's alpha if an item was deleted are shown in Table 11. Means were between .54 and 2.46, and standard deviations were from 1 to 1.69. Most items showed a satisfactory item-total correlation ranging from .30 to .67. For most items, Cronbach's alpha would not increase much if that item was deleted. One exception was item 7h (*travel calmly in the car*). This item correlated poorly with the total scale (.22), and its deletion would improve the scale's Cronbach alpha to .77. Furthermore, this item correlated poorly with several other items in the scale (7b, 7c, 7d... see Table 12). Therefore, this item was removed from the scale.

Table 11 *MEL part 2: Routine Activities using Music (RAM) – item statistics and reliability*

Item	M (SD)	Item-total correlation	Cronbach's alpha if item deleted
7a. Calm down	1.48 (1.57)	.48	.72
7b. Meal time	.54 (1.00)	.30	.75
7c. Bed time	1.37 (1.69)	.42	.74
7d. Understand routine	.67 (1.36)	.49	.72
7e. Fun/enjoyment	2.30 (1.24)	.52	.72
7g. Transitions	.54 (1.11)	.67	.69
7h. Learn new things	.70 (1.20)	.62	.70
7i. Travel calmly in car	2.46 (1.50)	.22	.77

Table 12 MEL part 2: Routine Activities using Music (RAM) – inter-item correlation matrix

	Calm down	Meal time	Bed time	Understand routine	Fun / enjoyment	Transitions	Learn new things	Drive calmly in car
Calm down	1.00	.21	.32	.27	.37	.38	.24	.27
Meal time		1.00	.26	.13	.15	.29	.27	.05
Bed time			1.00	.23	.24	.32	.46	-.02
Understand routine				1.00	.34	.62	.50	.01
Fun / enjoyment					1.00	.39	.36	.38
Transitions						1.00	.69	.19
Learn new things							1.00	.16
Drive calmly car								1.00

Items in part 3, *musical genres* (items 6a to 6h) were kept separately, as conceptually, this part did not fit into a scale, when each genre was equally scored. Furthermore, this part shows poor statistical result, with a Cronbach's alpha of $<.5$.

Based on these statistical results, it was concluded that the MEL should be organized into two scales. The first scale, labeled *Music in Everyday Life - Joint Activities using Music (MEL-JAM)* consisting of 4 items which describe different joint activities using music (singing together, listening to music together, playing musical instruments together and playing musical applications together), each with a possible range from -4 to 8 (overall item scores derived by multiplication of each a and b item). The second scale, labeled *Music in Everyday Life - Routine Activities using Music (MEL-RAM)* consists of 7 items which describe different goals of using music during routine activities (i.e. to help the child calm down, during meal time, during bed time, to better understand daily routine, to have fun together, to make a smooth transition from one activity to another, and to learn new things), each with a possible range from 0 to 4 (where 0 = *not at all* to 4 = *everyday of the week*).

In addition, both part three (*musical genres*) and item eight (*open question*) remain separate from the scales but provide additional information, mainly for clinical purposes.

In conclusion, the MEL was confirmed as a scale with reliability to assess the use of music in everyday life by parents with their children with autism.

6 RESULTS OF THE QUANTITATIVE INVESTIGATION

Introduction

The results from the analysis of the quantitative data are presented in the order of the desirable outcomes according to the research questions: *QRS-F* measured level of stress, *QoL-VAS* measured quality of life perception, and the MEL measured the use of music in everyday life. Fourteen participants were enrolled to the study, and one dropped out because of disappointment of the randomization (Figure 3). All remaining 13 participants completed all the sessions and filled out all the questionnaires. The main questions of the study were: *What is the influence of MOPC on level of stress and quality of life of the participants?* and *What is the influence of MOPC on the use of music in everyday life by the participants?* The seven hypotheses (generated from sub-questions 1.1, 1.2, 1.3, 1.4, 2.1, 2.2, 2.3) were tested in the following way: the *QRS-F* tested Hypothesis 1, 3, 4; the *QoL-VAS* tested Hypothesis 2, 3, 4; the MEL tested Hypothesis 5, 6, 7 (after having been confirmed as a validated scale; Chapter 5).

Following the CONSORT's recommendation (Boutron et al., 2008, p. 63), a flow chart of participants through each stage of the study is presented within the results Chapter.

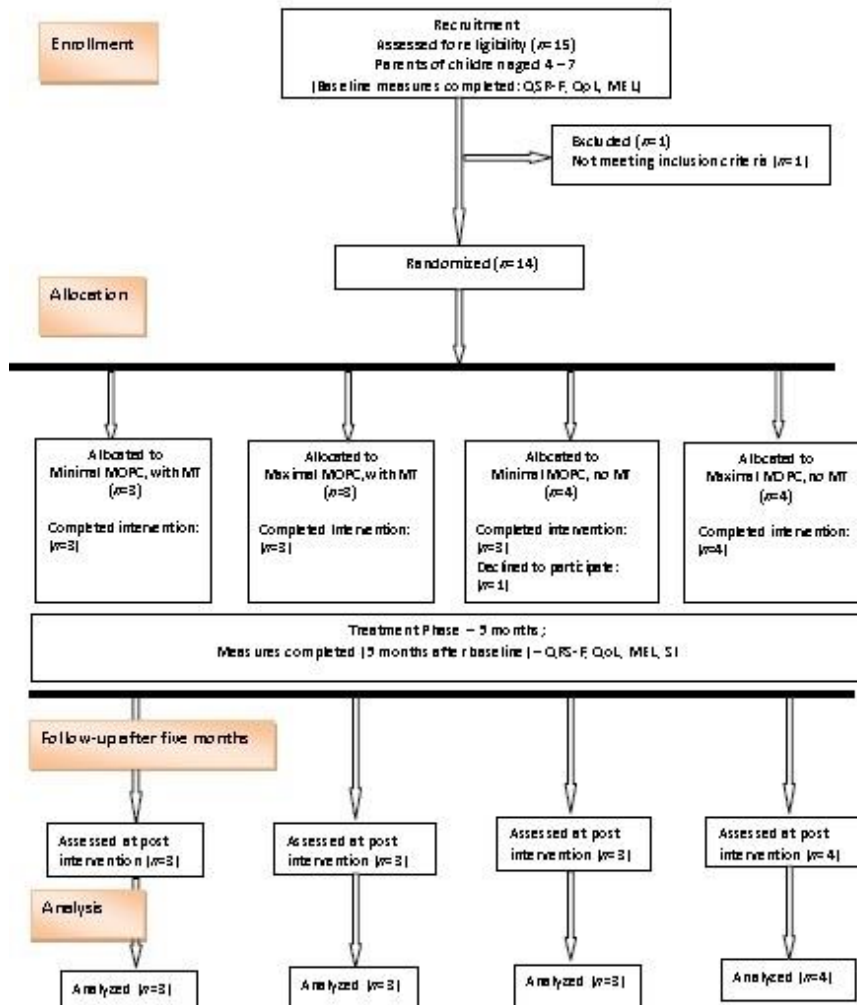


Figure 3 Flow-chart of participants

6.1 BASELINE CHARACTERISTICS

The following table gives relevant baseline characteristic information of the participants. The information for each baseline item is presented within groups, where three participants were allocated to groups 1, 2 and 4 participants were allocated to group 3 and 4. One participant from group 3 dropped out after allocation, and his data is not presented in the later statistical analysis. The baseline characteristics of the parents were collected through self-report questionnaires. Only the mothers completed the questionnaires each time, concluding with 14 questionnaires at baseline.

Group two consists of parents with the highest mean of level of stress (23.00) and the lowest mean of QoL (45.00). Group 4 consists of parents with the lowest mean of level of stress (12.75) and the highest mean of QoL (71.25). This might indicate something about the connection between these two variables, meaning that when level of stress is high, its' likely that QoL perception will be low, and vice versa.

The mean of the use of music in joint activities (MEL-JAM) are somewhat similar among groups (3.31-3.75) and the mean of the use of music in routine activities (MEL RAM) is high in-group 1 (14.66) and low in-group 4 (8.75). This may indicate that parents with a high level of stress tend to use music more in routine activities compared to parents with a lower level of stress. Nine mothers and eleven fathers out of 14 families have a university degree, 4 mothers and two fathers have more than 12 years of education, and only one family with both the mother and the father with less than 12 years of education (group 3). All men accept one work full-time, where most of the women (10 out of 13) are unemployed or work part-time. Only one women from each group – and none at group no. 4 work full-time.

Table 13 *Baseline characteristics of the parents across groups*

	GROUP 1 minimal MOPC/ With MT (n = 3)	GROUP 2 Maximal MOPC/ With MT (n = 3)	GROUP 3 Minimal MOPC/ No MT (n = 4)	GROUP 4 Maximal MOPC/ No MT (n = 4)	<i>p</i>
Continues variables					
	M (SD)	M (SD)	M (SD)	M (SD)	
<i>QRS-F</i>	15.00 (5.57)	23.00 (6.08)	18.75 (10.72)	12.75 (6.65)	.39
<i>QoL-VAS</i> family	63.33 (11.55)	45.00 (31.22)	50.00 (35.82)	71.25 (16.52)	.55
MEL JAM	3.75 (.90)	3.50 (3.07)	3.62 (2.95)	3.31 (2.19)	.99
MEL RAM	14.66 (6.35)	12.00 (6.55)	9.00 (3.74)	8.75 (2.22)	.37

Nominal variables	Mother n (%)	Father n (%)	Mother n (%)	Father n (%)	Mother n (%)	Father n (%)	Mother n (%)	Father n (%)	
Education:									
Less than 12 years	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (25%)	1 (25%)	0 (0%)	0 (0%)	
12 years + education	1 (33.3%)	0 (0%)	1 (33.3%)	1 (33.3%)	1 (25%)	1 (25%)	1 (25%)	0 (0%)	
University degree	2 (66.6%)	3 (100%)	2 (66.6%)	2 (66.6%)	2 (50%)	2 (50%)	3 (75%)	4 (100%)	
Employment :									
Unemployed or social support	1 (33.3%)	0 (0%)	1 (33.3%)	0 (0%)	2 (50%)	0 (0%)	0 (0%)	0 (0%)	
Working part-time	1 (33.3%)	0 (0%)	0 (0%)	0 (0%)	1 (25%)	1 (25%)	4 (100%)	0 (0%)	
Working full-time	1 (33.3%)	3 (100%)	1 (33.3%)	3 (100%)	1 (25%)	3 (75%)	0 (0%)	4 (100%)	
Other	0 (0%)	0 (0%)	1 (33.3%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	
Number of children in the family (in addition to the patient)									
0	1 (33.3%)		0 (0%)		0 (0%)		0 (0%)		
1	1 (33.3%)		2 (66.6%)		3 (75%)		3 (75%)		
2	1 (33.3%)		0 (0%)		1 (25%)		1 (25%)		
3	0 (0%)		1 (33.3%)		0 (0%)		0 (0%)		

Note: MEL JAM – Music in Everyday Life Joint Activities using Music; MEL RAM – Music in Everyday Life Routine Activities using Music; *QoL* – Quality of Life; *QRS-F* – Questionnaire for Resources and Stress.

In order to answer research sub-questions 1.4 *is MOPC with MT for the children superior to MOPC without MT for the children in improving level of stress and QoL perception, as seen in parents' questionnaires?* In addition, research sub-question 2.3 *is MOPC with MT for the*

children superior to MOPC without MT for the children concerning the use of music in everyday life by the participants? Data was collected for the children also.

Table 14 describes baseline characteristics of the children across groups. It shows that, although not significant, group 2 tended to include children with the lowest mean of IQ score (71.33), the highest mean for *ADOS* (17.67), and the highest mean for *SRS* (180.66). Both the *SRS* and the *ADOS* indicate a high level of autism's severity, meaning that the IQ for these children was in a low-normal range additionally to the most severe autism. Children with the highest mean IQ (90) are located at group 1. Group 4 includes children with the lowest severity level of autism, as indicated with the mean score of *ADOS* (13.25) and *SRS* (150.25).

All the children were males; eight children out of 14 were diagnosed with childhood autism, one child was diagnosed with atypical autism (in-group 4), and five children were diagnosed with PDD. Hebrew was the spoken language in most of their homes, with only one family (in-group 2) that spoke Russian.

Table 14 *Baseline characteristics of the children across groups*

	GROUP 1 minimal MOPC/ With MT (n = 3)	GROUP 2 Maximal MOPC/ With MT (n = 3)	GROUP 3 minimal MOPC/ No MT (n = 4)	GROUP 4 maximal MOPC/ No MT (n = 4)	<i>p</i>
Continues variables					
	M (SD)	M (SD)	M (SD)	M (SD)	
Age	4.67 (.58)	5.33 (1.15)	4.75 (.96)	5.25 (.96)	.73
IQ	90.00 (13.23)	71.33 (20.03)	83 (25.28)	87.25 (26.01)	.75
<i>ADOS</i>	15.00 (3.00)	17.67 (6.11)	13.5 (4.65)	13.25 (4.19)	.60
<i>SRS</i>	153.00 (20.07)	180.66 (8.14)	158.25 (30.48)	150.25 (52.85)	.69
<i>QoL-VAS</i> child	56.67 (7.64)	41.67 (25.66)	72.50 (28.72)	85.00 (7.07)	.08
Nominal variables					
	n (%)	n (%)	n (%)	n (%)	
Male	3 (100%)	3 (100%)	4 (100%)	4 (100%)	
First language:					.30

Hebrew	3 (100%)	2 (66.7%)	4 (100%)	4 (100%)	
Other	0 (0%)	1 (33.3%)	0 (0%)	0 (0%)	
Diagnosis:					
Childhood autism	2 (66.7%)	2 (66.7%)	2 (66.7%)	2 (50%)	.81
Atypical autism	0 (0%)	0 (0%)	0 (0%)	1 (25%)	.81
PDD-NOS	1 (33.3%)	1 (33.3%)	2 (66.7%)	1 (25%)	.91

Note: Pearson's Chi-Square has been done for non-numeric data. ADOS – Autism Diagnostic Observation Schedule; IQ – Intelligence Quotient; MT – Music Therapy; PS – Parents' Sessions; SRS – Social Responsiveness Scale.

6.2 EFFECT OF MOPC ON LEVEL OF STRESS, QUALITY OF LIFE AND THE USE OF MUSIC IN EVERYDAY LIFE

Statistical analysis of the changes over time was done regarding the three outcomes: level of stress (represented by the Questionnaire for Resources and Stress – *QRS*), parents' perception of their child's quality of life and their own (represented by the *QoL-VAS*), and the use of music in everyday life (represented by the MEL's two sub-scales – JAM and RAM). Normality was confirmed for all outcomes (example histograms are shown in Appendix M).

Change was significantly greater ($p = .011$) in the parents' perception of their child's QoL after participating in music therapy sessions, than in non-music therapy, indicating that music therapy has a good effect on the QoL for the children. In addition, change was significantly greater ($p = .020$) in the use of music in routine activities among parents who participated in MOPC, indicating that MOPC sessions contributed to expanding the use of music in daily routine activities by parents with their children with autism. Level of parental stress did not increase, yet the MOPC made no significant effect in any of the four study's groups. Although not significant, there is a tendency to a positive effect in the parents' perception of their own QoL among parents who participated in MOPC process, which might indicate that participating in parents' sessions improve QoL perception of the parents (Table 15). In addition, although not significant, there is a tendency to positive effect in the use of music in joint activities among families where the children participated in music therapy sessions, which might indicate that music therapy sessions contribute to expanding the use of music in joint activities among parents with their children with autism (Table 15).

Table 15 *Items statistics of change within groups of QRS-F, QoL-VAS, and MEL*

Source	F	Sig.	Mean difference (SD)				d
QRS-F CHANGE:							
MT	.474	.509	With MT		No MT		-0.98
			.333 (1.680)	1.917 (1.571)			
MOPC	.821	.389	Minimal MOPC		Maximal MOPC		-0.82
			2.16 (1.68)		0.83 (1.57)		
MT*MOPC	1.430	.262	Max/ with	Min/ with	Max no	Min/ no	
			.667 (2.37)	-9.99 (2.37)	-.500 (2.06)	4.33 (2.37)	
QoL child CHANGE:							
MT	10.20	.011 *	With MT		No MT		4.528
			15.833 (4.05)		-1.875 (3.79)		
MOPC	1.729	.221	maximal		minimal		1.864
			10.625 (3.79)		3.333 (4.05)		
MT*MOPC	.035	.855	With max	With min	No max	No min	
			20.00 (5.73)	11.67 (5.73)	1.25 (4.96)	-5.00 (5.73)	
QoL family CHANGE:							
MT	.078	.787	With MT		No MT		0.395
			5.000 (4.91)		3.125 (4.59)		
MOPC	2.904	.123	maximal		minimal		2.418
			9.792 (4.59)		-1.667 (4.91)		
MT*MOPC	.600	.458	With max	With min	No max	No min	
			13.33 (6.94)	-3.33 (6.94)	6.25 (6.01)	-1.776 (6.94)	

MEL – Joint Activities using Music CHANGE:							
MT	2.739	.123	With MT		No MT		2.347
			1.292 (.979)		-.927 (.916)		
MOPC	1.305	.283	maximal		minimal		1.619
			.948 (.916)		-.583 (.979)		
MT*MOPC	.002	.970	With max	With min	No max	No min	
			2.083 (1.38)	.500 (1.38)	-.188 (1.2)	- 1.67 (1.38)	
MEL – Routine Activities using Music CHANGE:							
MT	.048	.832	With MT		No MT		0.31
			.833 (2.23)		.167 (2.09)		
MOPC	8.032	.020*	maximal		minimal		4.02
			4.833 (2.09)		-3.833 (2.23)		
MT*MOPC	.107	.751	With max	With min	No max	No min	
			5.667 (3.16)	-4.00 (3.16)	4.00 (2.73)	-3.667 (3.16)	

Note: * $df = 1$. MT = Music Therapy; MOPC = Music-Oriented Parent Counseling; MEL = Music in Everyday Life

Using Pearson's Correlation, there is a strong correlation ($r = .68$) between the change that occurred in using music in routine activities (MEL-RAM) among participants who attended maximal MOPC, as described in table 16. This supports the hypothesis in which MOPC sessions contribute to expanding the use of music in daily routine activities by parents with their children with ASD.

Table 16 *Correlation between the change in using music for routine activities (MEL-RAM) and Music-Oriented Parent Counseling (MOPC)*

		MOPC	MEL-RAM
MOPC	Pearson Correlation	1	.68*
	Sig. (2-tailed)		.01
	N	13	13
MEL – RAM	Pearson Correlation	.68*	1
	Sig. (2-tailed)	.01	
	N	13	13

* Correlation is significant at the 0.05 level (2-tailed); *Note:* MOPC = Collaborative Parent Counseling in Music Therapy; MEL-RAM – Music in Everyday Life Routine Activities using Music

Using Pearson's Correlation, there is a strong correlation ($r = .69$) between the change in QoL of the child, as perceived by the parents, among participants who attended Music Therapy sessions (MT), as described in table 17.

Table 17 *Correlation between the change in Quality of Life (QoL) of the child and Music Therapy (MT) sessions*

		QoL child change	MT
QoL child change	Pearson Correlation	1	.69*
	Sig. (2-tailed)		.01
	N	13	13
MT	Pearson Correlation	.69*	1
	Sig. (2-tailed)	.01	
	N	13	13

** Correlation is significant at the 0.01 level (2-tailed); *Note:* QoL = Quality of Life; MT = Music Therapy

6.3 FIDELITY OF MUSIC-ORIENTED PARENT COUNSELING GUIDE

This section outlines the fidelity assessment of the clinical approach to parent counseling in music therapy applied in this study. Conducting randomized controlled trials of nonpharmacologic treatments raises certain challenges concerning trial reports. Following the CONSORT's (Boutron et al., 2008) guidelines for reporting trials of nonpharmacologic treatment, details of the experimental treatment were described within the MOPC Guide, and the assessment of its' implementations, assessed by an

independent rater, are presented within the results' chapter: "...details of the experimental treatment and comparator as they were implemented" (CONSORT; Boutron et al., 2008, p. 63).

An independent rater, a music therapist who had no connection to the research project, did a fidelity assessment of the MOPC Guide. The music therapist watched random videos of parents' sessions – one for each family, and completed the fidelity assessment, (the process of random selection of the videos was explained in the design, section 4.4).

It is natural to assume that not all items would appear in each session, and one should address it as a representative sampling. The fidelity assessment followed the layout of the MOPC Guide, where the first part (items 1-9) describes WHAT needs to be done during parents' sessions in music therapy (i.e. goals and basic aspects), and the second part (items 10-17) describes HOW the music therapist should perform the sessions in order to achieve them (Appendix G).

Results show that the items *creating a safe place* and *discussing topics raised by the parents* (items 1 & 2), and *the music therapist uses simple understandable language* (item 14) occurred in all sessions (mean 3.00; SD .00). The items *Providing information regarding ASD* (item 3), *Discussing parenting challenges in regard to children with ASD* (item 7), *parents' sessions focuses on the child's needs in combination with the parents' needs* (item 10), *the MTist uses professional judgment in deciding if and how to raise issues of conflicts and difficulties'*(item 11), *the MTist addresses each issue raised by the parents* (item 12), *the MTist uses his/her professional insights while addressing relevant issues* (item 13), and *the MTist offers solutions to a daily challenge in accordance with the parents abilities* (item 14) occurred highly in most sessions (mean between 2.46 to 2.92). The following items occurred the less: *providing information regarding normal development* (items four, mean .92), *providing information regarding techniques of music therapy as communication tool with children with ASD* (item five, mean 1.46), and *providing information regarding parent-child interaction in normal development, with particular attention to the role of the parent* (item six, mean 1.15). Table 18 sums the results of the fidelity assessment of MOPC Guide:

Table 18 Results of fidelity assessment of music-oriented parent counseling guide

	Items	M (SD)
	General aspects:	
1	Creating a safe place for parents to talk and reflect on stressful situations related to their child's diagnosis	3.00 (.00)
2	Discussing topics raised by the parents	3.00 (.00)
3	Providing information regarding ASD in various development fields	2.46 (.78)
4	Providing information regarding normal development	.92 (.68)
5	Providing information regarding techniques of music therapy as communication tool with children with ASD	1.46 (1.13)
6	Providing information regarding parent-child interaction in normal development, with particular attention to the role of the parent	1.15 (.80)
7	Discussing parenting challenges in regard to children with ASD	2.69 (.48)
8	Discussing the use of music in parent-child interaction	1.92 (.95)
9	Discussing structuring of activities in daily routine, with particular attention to possible uses of music	1.69 (.95)
	Basic principles:	
10	Parents' session focuses on the child's needs in combination with the parents' needs	2.85 (.38)
11	The MTist uses professional judgment in deciding if and how to	2.92

	raise issues of conflicts and difficulties	(.28)
12	The MTist addresses each issue raised by the parents	2.92 (.28)
13	The MTist uses his/her professional insights while addressing relevant issues	2.85 (.38)
14	The MTist uses simple understandable language	3.00 (.00)
15	The MTist offers solutions to a daily challenge in accordance with the parents abilities	2.77 (.44)
16	The MTist offers to use music in different ways to address certain challenges	1.92 (.86)
17	The MTist maintains the session structures, and explains the structure to the parents	1.77 (1.17)

Note: n = 13. Each item had a possible range of zero ('not at all') to three ('very much').

7 FINDINGS FROM THE QUALITATIVE INVESTIGATION

In this study, the influence of Music-Oriented Parent Counseling (MOPC) was investigated in relation with level of parental stress, QoL perception and developing and expanding the use of music in everyday life by the parents with their child. It was also an interest to investigate the personal experience of the participants within the parents' sessions process. To get an in-depth understanding on how participants perceived the MOPC process, answers from different parts of the interviews – and not only those answered to direct questions - were taken into account.

First, I will describe the findings for the three outcomes: level of stress, quality of life, and the use of music in everyday life. Then, three main themes that emerged from the qualitative analysis are described: Learning Experience, Enabling Space, and Music in everyday life.

7.1 LEVEL OF STRESS

In order to answer research question 1.5 – *What is the parents' experience of MOPC and its influence on their level of stress and quality of life perception*, two direct questions were asked during the interview. One question was regarding level of stress and is discussed in this section, and the other question was regarding QoL perception is discussed in section 7.2. Parents were familiar with the term *level of parental stress* from the Questionnaire for Resources and Stress (QRS-F), which they had completed before the interview (see section 4.4). Based on that, the question that was asked during the interview was: *Please describe your experience within the parents' sessions in relation to the stress level which you have experienced with your child during this period* (See Appendix H). Table 19 sums up the participants' answers to this interview's question, following the analysis *within* each participant, as described in section 4.4. Similar ideas were marked with the same color for a later analysis of codes and themes, following the analysis *between* participants, and are presented in section 4.6.

In all families, only the mothers completed the questionnaires at both time points; therefore, comparison of the scores (chapter 8) is done solely with the mothers' statements. However, the fathers' statements are addressed both within the emerging themes and are discussed later in the Discussion (Chapter 9).

Table 19 *Participants' perception of change in level of stress*

Group 1	Change in level of stress Data illustrating
Participant A	<i>Mother:</i> "I feel no change , because we didn't meet often and we had too little sessions " <i>Father:</i> "We actually had only one working session here; one can't expect this one session to lower my stress level "
Participant B	<i>Mother:</i> "When we understood WHY he's behaving as he is, and that we can address it differently, it lowered our stressed moments with him" <i>Father:</i> "This attitude helps us to feel more comfortable and less stressed "
Participant C	<i>Mother:</i> "Thanks to new understandings I have achieved here, I feel that I gone through the next step in my acceptance ability of his disorder. This had a major role in lowering my stress " <i>Father:</i> "When I understand the situation – it lowers my stress ; Here I understood certain things, even though, not enough "
Group 2	
Participant D	<i>Mother:</i> "Stress is still here, but less than before . Our sessions helped me to feel more calm " <i>Father:</i> "I am less stressed , as I try to emotionally connect with him – like we discussed here"
Participant E	<i>Mother:</i> "You gave me some practical tools which helped a lot. Stress level is a little lower , although still very high; with I. it's always high..."
Participant F	<i>Mother:</i> "I have learned here to trust him more, and now – he is more relaxed. This lowers my stress " <i>Father:</i> "Overall I feel less stressed , because we got good tools here, we use them with N., and they work!"
Group 3	
Participant G	<i>Mother:</i> "I had the opportunity to talk about things here without being judged , and it helped me release stress " <i>Father:</i> "I feel less stressed ; I learned here that I can be more flexible, and give him the feeling that we are on the same page, so he doesn't need to resist"
Participant H	<i>Mother:</i> " No change in my stress level, because we didn't have enough sessions "
Participant I	<i>Mother:</i> "The sessions here certainly opened my awareness to the role of music in our lives, but I can't say it had a powerful effect on my

	stress level, as we met for only a few sessions "
Group 4	
Participant J	<i>Mother:</i> "I still feel a high level of stress; it's a question of my personality..." <i>Father:</i> "The sessions helped a lot, because I came with zero answers, and got new insights and tools in only few sessions; if I do something new and it works - it lowers my stress "
Participant K	<i>Mother:</i> "When I receive new tools that help me – naturally the stress goes down " <i>Father:</i> "Especially in times when he is rigid and stubborn – when I use music it softens him, and it lowers my stress "
Participant L	<i>Mother:</i> "It's so important to have a place where you can talk about things as they are, without being judged . It certainly helped me to feel less stressed " <i>Father:</i> "I learned concrete strategies here, which makes my life easier, so I'm less stressed "
Participant M	<i>Mother:</i> "I have experienced more stress , as we focused on certain behaviors through a magnifying glass; I am a pessimist person, so this thing only makes me more stressed" <i>Father:</i> "The sessions kind of organized my understandings , so I trust him more now and am able to back off a little. It certainly lowered my stress "

Note: Group 1 = minimal MOPC/with MT; group 2 = maximal MOPC/with MT; group 3 = minimal MOPC/no MT; group 4 = maximal MOPC/no MT; Participants E and H – only the mothers attended the interviews. Participant G – only the father answered the question. Participant I – only the mother answered the question; **orange** – 'no change'; **red** – not enough sessions; **purple** – understand new things; **green** – less stress (improvement); **light blue** – enabling space; **pink** – tools; **brown** – learning; **yellow** – more stress (deterioration).

Participants who participated in the intensive process of MOPC (*maximal MOPC* - group two and group 4) show somewhat similar findings regarding the effect of MOPC on their level of parental stress. Overall, all seven of these participants talked about feeling less stressed, where *receiving new tools* (participants E, F and K), being able to *emotionally connect* to their child (participant D) and perceiving the parents' sessions as *a safe place to talk things over* (participant L) were the factors that made the difference. Out of these participants, for two parent couples the answers of the mothers and fathers did not correlate. The mother of participant J expressed *no change* and the mother of participant M expressed *more stress*. These will be examined further during the comparison with the numerical data of the *QRS-F* (Chapter 8). Based on the

findings of the qualitative analysis of participants who experienced the maximal process of MOPC, most described during the interviews feeling less stressed with their parenting of their child with autism.

As for participants who participated in *minimal MOPC* (group 1 and group 3), three participants out of six stated they felt less stressed, with *new understandings* (participants B and C) and *changing parental attitude* (participant G) as the factors that influenced the change. The remaining three participants (A, H, and I) stated during the interviews that they felt *no change* with their level of stress. Based on the findings of the qualitative analysis of the participants within the *minimal MOPC*, half of the participants expressed feeling less stressed, and the other half felt no change.

7.2 QUALITY OF LIFE

In order to answer the second part of research question 1.5, a two-part question was asked during the interview: *Please phrase your definition of Quality of Life* and *Please describe the parents' sessions process, which you have participated in, in relation to your perception of yours and your child's QoL*. Table 20 sums up the participants' answers to this interview question. Similar ideas were marked with the same color for a later analysis of themes.

Table 20 Participants' perception of Quality of Life (QoL)

Group 1	QoL definition Illustrating sentences	QoL Illustrating sentences
Participant A	Mother: "QoL is the ability to see the whole picture and address everyone's needs" Father: "QoL is about whether you enjoy life"	Both: "Due to the few sessions we had, we can't say it improved our QoL"
Participant B	Mother: "QoL is when the overall moments of happiness exceed the moments of anxiety" Father: "QoL is combined with routine and flowing with life"	Mother: "When you fight all the time with your child – you hate your life; when you create time for fun stuff to come – you gain a QoL" Father: "I learned here to change my attitude and address his needs better; when level of stress is going down – QoL goes up "
Participant C	Mother: "QoL is when you feel good about everything that you do – family, friends and work"	Mother: "We can see that the MT sessions improved Y.'s QoL, and when he is happy – we are happy.

	Father: "QoL for me is when we maintain our family routine"	The parents' sessions didn't make a difference for us"
Group 2		
Participant D	Mother: "Stress and QoL are linked together; QoL is when you don't have to limit yourself from doing things that you want to do"	Mother: "Not sure our sessions effected our QoL" Father: "G.'s QoL definitely improved as a result from MT sessions with you; our sessions were a place of calmness"
Participant E	Mother: "QoL is a functioning family, a family which interacts with society"	Mother: "My QoL improved a bit due to our sessions, as I can come here and talk about things, reflect on them and receive good insights"
Participant F	Mother: "QoL is to be able to go with him to public places without being afraid that he will fall apart" Father: "QoL for me is when we can be more spontaneous"	Mother: "You gave me some good advices which helped me change my attitude and improved my QoL" Father: "I got here a tool that helps me to connect better with my child – when I sing to him, he responds better; it certainly improved our QoL"
Group 3		
Participant G	Mother: "QoL is happiness and the ability to handle this thing called 'life'" Father: "QoL is the ability to do whatever you want whenever you want...no worries and no stress"	Mother: "For me, understanding that B. process singing better than spoken language made a dramatic change in the way that I interact with him, and improved a lot my QoL" Father: "No change for me; QoL depends in so many things, so overall – no change in my QoL"
Participant H	Mother: "QoL for me is to be able to go outdoors without having to chase after I., without apologizing for his behavior, without other people starring at us and feeling sorry for us"	Mother: "Not enough sessions to make a change"
Participant I	Mother: "QoL is to have a reason to wake up in the morning, to do things you	Mother: "The sessions gave us something, but I can't say it had a dramatic influence on our QoL;

	<p>believe in, and to go to sleep peacefully"</p> <p>Father: "QoL is quite, calmness, peaceful, to see the children develop, to have a family QoL"</p>	<p>there were only few sessions"</p> <p>Father: "It wasn't enough to have an impact; too little sessions"</p>
Group 4		
Participant J	<p>Mother: "QoL is quite in my head, without having to worry all the time about my son's future"</p> <p>Father: "QoL is good health of my family members, the time that you can spend for yourself and the time that you can spend with your family and friends"</p>	<p>Mother: "No effect on my QoL; it's a matter of my personality – I always find something to worry and be stressed about"</p> <p>Father: "No effect; not connected at all to my QoL"</p>
Participant K	<p>Mother: "QoL is about decreasing my worries, and to have more time alone with my husband"</p> <p>Father: "QoL is mental quite, calmness"</p>	<p>Mother: "I'm not sure the sessions improved my QoL; I worry a lot about his future, I don't have quite, my QoL is quite bad"</p> <p>Father: "Let's face it – when you have an autistic child – it damages your QoL. So if I use things that I have learned here and they help him feel more relaxed – than my QoL is better"</p>
Participant L	<p>Mother: "QoL is peaceful and calmness"</p> <p>Father: "Peaceful, calmness and money to support this"</p>	<p>Mother: "You gave me confidence that I know what is best for my child, which is a new feeling for me, and that improved my QoL"</p> <p>Father: "I got concrete tools here that improved my QoL"</p>
Participant M	<p>Mother: "QoL is quite, and to be able to do things that make you feel good"</p> <p>Father: "Whenever you have less things to worry and be anxious about, and you have quite"</p>	<p>Mother: "I'm not sure that the sessions effected my QoL"</p> <p>Father: "The sessions effected in specific parts of my life; the morning song changed completely our mornings for the best, and when the mornings are calm and</p>

		more fun – it effects your whole day"
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Note: Group 1 = minimal MOPC/with MT; group 2 = maximal MOPC/with MT; group 3 = minimal MOPC/no MT; group 4 = maximal MOPC/no MT; for participant C – only the mother answered the b part of the question; Participant D – only the mother gave a definition; Participants E and H – only the mothers attended the parents' sessions and the interviews; orange – 'no change'; red – not enough sessions; purple – understand new things; green – less stress (improvement); light blue – enabling space; pink – tools; brown – learning; yellow – more stress (deterioration).

Participants who participated in *maximal MOPC* (group two and group 4) show two main findings regarding the change in their QoL perception. While participants E, F, and L expressed an improvement in their QoL perception, participant J expressed *no change*. This dualism is evident in participants D, K, and M, where the mothers expressed *no change* and the fathers expressed an improvement in their QoL perception. For those who have expressed an improved perception of their QoL, finding the sessions *comforting and enabling* (participants D, E, L), receiving *concrete tools* (participants F, L, M), and *learning new things* (participant K) contributed to the change. Those who have expressed *no change* in their QoL perception connected it with being too worried or with having difficulty in pointing out what are it that can improve their QoL. This emphasizes the complex and multifaceted ways that parents describe their QoL; QoL perception is rich and uniquely experienced, and therefore challenging to report any changes.

Out of the six participants who participated in the *minimal MOPC* (group one and 3), five expressed *no change* in their QoL perception. Participants B and the father of participant G expressed that they have *learned new things* over the few sessions they had, which improved their perception of their QoL. Within these groups, the findings are quite unified.

It is interesting to look at the parents' definitions of QoL, which capture the complexity of this task. While some participants connected a good QoL to what they can or cannot do, others focused on the emotional aspects of feeling happy and less anxious. All the parents connected their definition of a good QoL with the ability of their child with autism to interact with the world, emphasizing the major effect of it on the overall perception. Putting together expressions that appear more than once, this definition appears to emerge:

"QoL is when happiness exceeds the worries, when quite is present, and when the whole family is safe and interacts with society".

7.3 MUSIC IN EVERYDAY LIFE

In order to answer research question 2.4 - *What is the participants' experience of MOPC in relation to their use of music with their child, in everyday life?* The following question was asked during the interview: *How have you used music during the last months? Please elaborate and give examples to the ways you have used music.* Table 21 sums up the participants' perception of any change they have experienced in their daily use of music:

Table 21 *Participants' perception of change in the use of music in everyday life*

Group 1	Music in Everyday Life Illustrating sentences
Participant A	Mother: "The sessions opened up our awareness to the role that music plays in C.'s life" Father: "we now understand that when he sings – he's actually communicating with us, so we are more attentive to it"
Participant B	Mother: "As a result of our sessions, I put more music at home during fun time with my child; I also sing instructions to him, and see that it helps him get organized" Father: "I join him when he sings a song, so we can enjoy together; it wasn't like that before the trial"
Participant C	Mother: "He loves playing the drums, and now I join him in playing, and it became our game" Father: "Because I started playing with him, he now initiates more interaction with me – especially a musical one; it's so exciting to see him initiating contact"
Group 2	
Participant D	Mother: "I use music in new ways now, for example – to help him calm down when he's agitated and it works!" Father: "Up until now, the possibility to use music in interaction with G. was blocked inside of me. Now, I join him when he plays the drums and I use music to help him calm down; these are moments of connection"
Participant E	Mother: "The music is the core of everything that I got here; music is back into our lives! I started singing to him again; I put more music now at home and in the car, and put soft music at bedtime. He

	responds so well to all of this"
Participant F	<p>Mother: "We didn't use to sing with him at all; now we sing a lot – with the CD but also when we call him to do daily activities, like shower, dinner or play together"</p> <p>Father: "Before the sessions, I could call him several times but he wouldn't come. Now, I call him by singing – and he comes immediately, and looks so happy"</p>
Group 3	
Participant G	<p>Mother: "I realize now, that music makes him more attentive and calm, so I put music at home. Music also helps him in transitions from one activity to another, so I use it more"</p> <p>Father: "I sing to him more now; it helps especially within activities which he refuses to do. I also sing funny words to familiar songs, and he loves it"</p>
Participant H	<p>Mother: "He can listen to same children song over and over again. Now I understand that I need to join him, so I sing together with the song – and he looks so happy about it"</p>
Participant I	<p>Mother: "I am more aware now that I can use singing during my communication with him. It still doesn't come naturally to me, but I'm more aware of that"</p> <p>Father: "Not much music making at our home"</p>
Group 4	
Participant J	<p>Mother: "No doubt that since we come here, we are much more aware of O.'s connection to music, and we use it as a tool. We put more music at home, and we sing with him – and we see how happy he is with it"</p> <p>Father: "Every morning I put the 'morning song' – and it's just brilliant! He gets organized so quickly and with so much enthusiasm! Also, we followed your recommendation and went with him to pick headphones for him; he uses them to listen to music whenever he's agitated, and it really helps him; we spoke also with his teacher, so he uses them also in class, whenever he feels flooded"</p>
Participant K	<p>Mother: "I've never thought of music as a tool; it's really an insight for me. I use music in order to help him calm down and during bedtime – and it works! Also, whenever I put a song at home, he wants me to dance with him"</p>

	Father: "Especially at times when he's rigid and stubborn – if I start to sing to him or put music that he loves – it helps him to calm down"
Participant L	<p>Mother: "I always used a lot of music. The new thing that I do now is change my intonation when I give him instructions; he responds to it better. Also, he tends to sing these tunes at me; now you have recommended that I'll join him, so I answer him back with tunes of my own; this kind of communication can last for long periods of time"</p> <p>Father: "I'm more aware of what I'm doing with music; I play with my voice more and change the words to familiar songs"</p>
Participant M	<p>Mother: "The main change is to pay attention to the role of music in our lives, and to the different ways we can use music"</p> <p>Father: "The most effective thing was the morning song, which completely transformed our mornings from 'hell' to 'heaven'; to say the truth, I doubted it at the beginning, but it's simply working!"</p>

Note: Group 1 = minimal MOPC/with MT; group 2 = maximal MOPC/with MT; group 3 = minimal MOPC/no MT; group 4 = maximal MOPC/no MT; **purple** = awareness of the role of music; **green** = implementations of music in home environment.

As shown in Table 21, all of the participants stated during the interview that because of the parents' sessions, they became more aware of the role of music in their children's lives, and use more music during the day. It was an exciting revelation for most participants to perceive music as a tool, which can help in certain daily situations, such as: calm down, get organized, and make transitions from one activity to another and to communicate. While participants D and G use music more during Joint Activities, participants F, H, and J use more music during Routine Activities. Participants C, E, K, L, and M use more music within both Joint Activities and Routine Activities.

In conclusion, all participants described a more extensive use of music with their children. Out of seven participants who attended the maximal process of MOPC (D, E, F, J, K, L and M), four developed their use of music in both Joint Activities and Routine activities. Overall, it is clear that the MOPC process had a major role in raising the awareness of the participants to the language of music, and to the role of music as a communicative and interactive tool, which they implemented in their lives.

After concentrating mainly on the findings that answer the research questions and whether the allocation to groups made any difference, it became evident that main themes have emerged from the analysis process, which crossed the boundaries of particular groups. I will now describe the three main themes: Learning Experience, Enabling Space, and Music in everyday life.

7.4 MAIN THEMES

As written at the beginning of this chapter, during analysis procedure it was clear that certain themes emerged from the participants' expressions that seem to reflect mutual experiences of the participants with MOPC. These three themes appeared across groups, and seem to reflect the basic characteristic of the MOPC process, with no regard to group allocation. Looking at these themes gives an aerial view of the process, and contributes to perceiving MOPC as a working model. In this section, the main qualitative research themes are described: Learning Experience, Enabling Space and Music in everyday life.

THEME ONE: LEARNING EXPERIENCE

Sub-themes:

- 1) *Gaining knowledge*
- 2) *New point of view*
- 3) *New ideas and tools to cope*
- 4) *Gaining a better understanding of the child's needs*
- 5) *A change in parental attitude*

For the first question of the interview (*Please share how was it for you to attend the counseling sessions*), participants D, E, F, J, K, L, and M stated that they gone through a learning experience during counseling sessions:

D/1/13⁴ "I enjoyed coming to the sessions; I felt we are going through a learning process here."⁵

⁴ UPPERCASE LETTER in blue = participant ID (A, B, C, D, E, F, G, H, I, J, K, L, M); 1 = paragraph number within the transcription; 13 = sentence number within the paragraph.

⁵ Quotes from the semi-structure interviews are representative rather than exhaustive and are given from illustrative purposes.

J/1/15 "We had a learning process here, as we have received new ideas and learned new techniques"

Opposite to these participants, which were included in the *maximal MOPC* groups, participants of the *minimal MOPC* groups (participants A, B, C and G, H and I) spoke about the *lack of process*.

A/1/12 "For me, three sessions are not enough to go through any process."

G/1/20 "I feel we have only just begun to touch certain issues. I guess that if we had more sessions, we could have gone through a much deeper process."

1) *Gaining knowledge*

All participants stated they had *gained knowledge about autism spectrum disorder*:

C/7/3 "I know now more about 'what is autism'; you have organized the chaotic information in a more understandable way for me."

G/5/7 "It's easier now to identify the characteristics of autism"

L/6/2 "We have received a lot of information about the autism spectrum disorder."

All participants stated they had *gained knowledge regarding their own specific child's characteristics*:

C/1/4 "We have received information regarding the causes of Y.'s behavior."

E/1/6 "It was the parents' sessions which gave me the most enlightening knowledge regarding my son's specific characteristics, and what is necessary for him."

J/1/8 "we have received explanations about what is right for our son, and why".

2) *New point of view*

All the participants spoke about receiving a *new point of view*, a new perspective, on their regular routine:

B/1/20 "It was a new point of view, a different perspective from what we are used to."

E/1/16 "I never thought of I.'s situation this way; you offered a new point of view that resonated with me."

I/1/18 "Even in the few sessions we had, it was interesting to look at things from a new perspective; it was refreshing."

L/1/28 "It was good for me to hear a new point of view on things, because I'm so used to see him through the same lance all the time".

3) *Ideas and tools*

All participants talked about specific *ideas and tools*, which they had received during sessions; some of the tools were musical while others were more attitude-related:

D/2/11 "I never thought of music as a communication tool; it is truly an exciting discovery."

F/6/3 "The sessions contributed to us by understanding how we can use music in order to get his attention and engagement."

L/1/6 "The sessions contributed to us especially in understanding the importance of musicality in our communication with him."

M/1/12 "The most effective thing we received here was the knowledge of how to use music to improve our lives"

B/1/21 "you gave us new ideas on how to cope with things."

B/2/25 "Because we are used to behavioral treatment, we played with him only by the table, and most of the time he refused to come. Now, we invite him to play all around the house by singing to him, and he just runs to us!"

D/3/15 "I realized that music can be like a tool to help him engage better."

F/1/10 "The sessions gave us tools on how to handle his tantrums as well as his willing to play".

I/1/3 "In each of the two sessions we had, I felt I received some tips to help me interact with him. One of the tips was regarding a piano application on the iPad, which he loves."

J/2/20 "I followed the tool you have recommended – to wait a bit after I'm asking him a question, giving him some time to gather his thoughts before he answers. And it worked!"

M/7/13 "The 'morning song' worked like magic; he gets organized quickly in the morning now, and the morning hours changed from struggle into fun family time."

4) *Better understanding of the child's needs*

All participants talked about *gaining a better understanding* of their child's needs, because of parents' sessions:

A/1/5 "I think we understand his world better now, realizing that when he sings to us his endless songs – it's actually his way to communicate."

B/2/18 "Now I understand what his behavior means, what is his need, so I'm less frustrated."

E/1/7 "Things have become clearer to me, and I understand his needs better now."

F/6/17 "Previously, I couldn't understand why he's behaving as he is; now I understand better what he needs from me."

5) *A change at parental attitude*

Participants in the *maximal MOPC* groups (D, E, F, J, K, L, and M) described a *change of their parental attitude*, because of the process:

D/2/13 "We have had certain fears and worries which prevented us from trying new things with G.; it blocked us. During our sessions, we were less afraid to do things differently, and our whole attitude towards G. is changed. We no longer see him as someone that needs to be treated, but rather as a child that has specific needs. Now I dear more and not so afraid to try new things; it's a big change at my attitude".

E/1/28 "There was an insight that I gained during our sessions; I could understand that he needs me. This changed my attitude towards his behavior, and I no longer get angry and frustrated. I'm able to be more empathic now, and it's different from what I did before."

L/2/8 "I no longer insist that he'll do everything I say; sometimes I see that all he needs is a hug from me, and I give it to him. I wasn't able to do it before."

M/3/19 "I used to worry a lot during his play-dates with friends, so I played together with them. Now I keep a certain distance and let him interact with his friends without me pushing him, and see how he is more relaxed and free. You gave me the courage to do so. I've changed my attitude completely after you helped me realize that I can trust him more."

Figure 4 describes the *ingredients*, which combine a learning process, as it emerged from the participants' expressions.

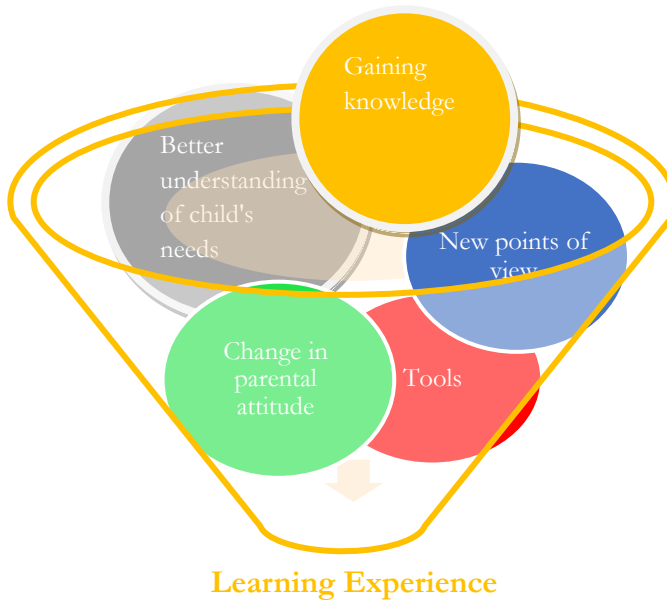


Figure 4 *Main components of the theme Learning experienc as expressed by the participants*

THEME TWO: ENABLING SPACE

Sub-themes:

- 1) *A safe, non-judgmental, containing, and honest place*
- 2) *Collaboration*
- 3) *A place to reflect and wonder*
- 4) *Openness*
- 5) *Empowerment*

- 1) *A safe, non-judgmental, containing, and honest place*

All participants stated they felt the sessions provided them with a sense of a *safe, non-judgmental, containing, and honest place*:

B/6/14 "The atmosphere was pleasant, non-judgmental, and very honorable; I felt I can say anything and won't be criticized"

F/9/3 "I felt that you are really listening to us – and not only to our son's needs"

- 2) *Collaboration*

Many participants talked about the sense of *collaboration*, which was built during sessions:

L/6/2 "I felt safe here, like we are on a mutual rode going towards the same direction"

- 3) *A place to reflect and wonder*

Some participants emphasize the importance of having *a place to reflect and wonder*.

E/1/9 "It was so good to have a place where you can reflect and wonder on stressful situations, and receive a helping point of view"

J/1/17 "It was good to come every other week, pour our hearts out and reflect together on our lives"

- 4) *Openness*

For some participants, the sessions helped *opening-up*:

M/7/15 "It was always hard for me to come here, but every time I felt I could really open-up and express my feelings; it helped me a lot"

J/1/18 "It was the first time that I could really open-up with a professional therapist; I always run away and hide..."

5) *Empowerment*

Many participants talked about feeling *empowered* by the process:

F/1/12 "I felt confident again with my parenthood"

K/1/8 "It was really empowering for me to discuss things with you; you always made me feel adequate"

Figure 5 sums-up the expressions of the participants regarding the characteristics of counseling sessions, which contributed to perceiving the sessions as an *Enabling Space*.

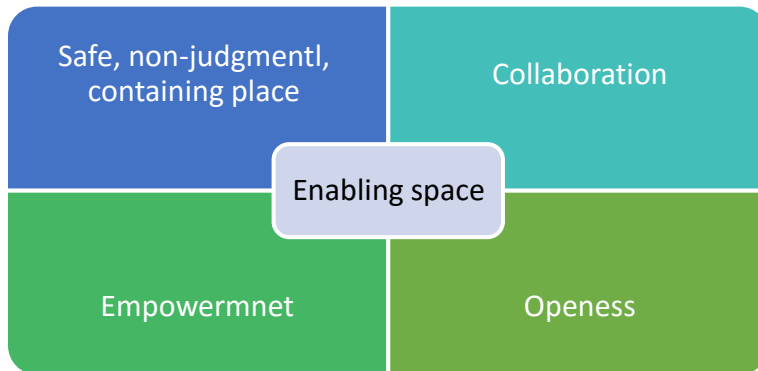


Figure 5 *Main components of the theme Enabling Space as expressed by the participants*

THEME THREE: MUSIC IN EVERYDAY LIFE⁶

Sub themes:

- 1) *The core of the counseling process*
- 2) *Awareness*
- 3) *Music helps to cope in daily situations*
- 4) *Music as an engagement facilitator*

- 1) *The core of the counseling process*

For most participants, the use of music in daily situations was the most prominent and powerful topic, with several participants who addressed it as *the core of the counseling process*

E/6/1 "The music is the core of everything that I received here; music is back into our lives"

- 2) *Awareness*

Many participants described how their *awareness* of the importance in using music had grown.

I/6/11 "I am more aware now that I can use singing during my communication with him"

J/5/7 "No doubt that since we come here, we are much more aware of O.'s connection to music, so we put more music at home"

- 3) *Music helps to cope in daily situations*

Some participants described how they used music to *cope within daily activities*:

⁶ In this section, *music in everyday life* refers to the parents' implementation of using music in the home environment, rather than the outcome measure named with the same name (the MEL assessment scales).

B/6/12 "I also sing instructions to him, and see that it helps him get organized"

F/6/2 "Now we sing a lot – with the CD but also when we call him to do daily activities, like shower, dinner or play together"

C/6/10 "I use music in new ways now, for example – to help him calm down when he's agitated, and it works"

K/6/8 "I use music in order to help him calm down and during bed time – and it works"

4) *Music as an engagement facilitator*

Most participants described how they used music *to help their child communicate and engage better:*

B/6/12 "I join him when he sings a song, so we can enjoy together; it wasn't like that before the trial"

C/6/5 "Because I started playing with him, he now initiates more interaction with me – especially a musical one; it's so exciting to see him initiating contact"

L/6/8 "He tends to sing these tunes at me; now you have recommended that I'll join him, so I answer him back with tunes of my own; this kind of communication can last for long periods of time"

Figure 6 sum-up the participants' expressions regarding the meaning of daily use of music to them:



Figure 6 *The meaning of the theme 'Music in everyday life' as expressed by the participants*

Summing up all of the above, it seems that the process of MOPC contributes greatly to develop awareness among the parents as for the role music plays in their children's lives – both as a communicative instrument as well as a helping source in different challenges during the day. It was made clear that this awareness led the parents to better understand their child's needs and created a change in parental attitudes; this led to a change with the child's behavior and engagement ability, which gradually improved daily life and reduced stress.

Figure 7 illustrates the MOPC as a form of work that combines components, which have emerged from the participants' expressions. When done properly, it creates an *Enabling Space*, which encourages a *Learning Experience* to occur, with the use of *Music in everyday life* as the core feature, folded at the center of the MOPC experience.

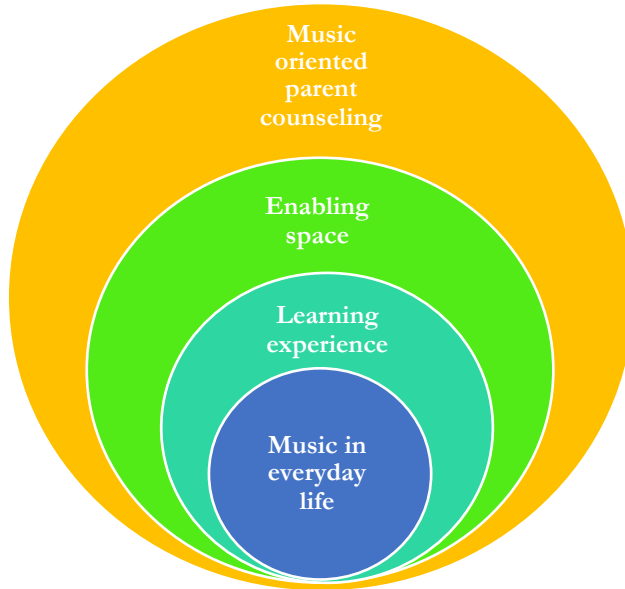


Figure 7 *Illustration of the overall experience of Music-Oriented Parent Counseling as emerged from the participants' expressions*

Conclusion

A qualitative analysis of 13 semi-structured interviews with parents who participated in music-oriented parent counseling sessions resulted in descriptions of a variety of improvements in the level of parental stress, the quality of life perception, and the daily use of music with their children with ASD. The changes described by the parents were sorted into three themes that are mutually connected: *Learning Experience*, *Enabling Space*, and *Music in everyday life*. Participating in MOPC was a platform for parents to reflect on their feelings, discuss daily situations and conflicts with their children, and learn substitute communication ways with their children. This improved their relationships in three key areas: the way they understood their child; the way they responded to their child; and their experience within their relationship with their child. For some parents, the change occurred mainly within the level of parental stress, and for some, the change occurred mainly within their quality of life perception. However, the change in the daily use of music with their child occurred for all the parents of the 13 young children with ASD, acknowledged by the parents as the essence of the process.

Chapter 8 will compare the qualitative analysis with the quantitative analysis related to Hypotheses 1-4. A side-by-side comparison for merged data analysis has been recommended by Creswell and Plano Clark (2011, p. 223) as a mean of comparing mixed results, and was used also in Thompson's (2012) PhD thesis. The comparison of these two sets of data will address the inconsistency shown between the quantitative and qualitative results of level of stress and QoL perception, as presented earlier. This will address question no. 1: *What is the influence of Music-Oriented Parent Counseling (MOPC) on the level of stress and quality of life perception of parents of children with ASD?*

8 COMPARISON OF MIXED DATA

Introduction

Chapter 3 outlined two questions and seven sub-questions guiding this study. The questions focused on two aspects – the *effect* and the *experience* of the intervention being investigated throughout the study. Both dimensions were included in order to thoroughly investigate the phenomena of interest (Teddlie & Tashakkori, 2010; 2011). The nature of the research questions led to using multiple methods (Creswell & Plano Clark, 2011) that were carried out simultaneously, both for the data collection and for the data analysis using a triangulation design. Chapter 6 presented the quantitative results of the RCT, looking at three outcomes: level of parental stress, quality of life perception, and the daily use of music in the home environment. Chapter 7 presented the qualitative findings from analyzing semi-structured interviews looking at these three outcomes, with an additional reference to the overall experience of counseling.

Standardized numerical measures were chosen to assess whether there had been any change in the participants' level of stress, quality of life perception, and the use of music in everyday life in order to contribute to the demand for empirical evidence of therapeutic interventions for parents of children with ASD. However, the collaborative principle of the counseling approach (which aimed to create a partnership between the parents and myself) could stand in contrast with an empirical research design that prefers blind assessors to determine whether outcomes were evidenced. This tension was answered in the study both by collecting self-report questionnaires from the participants and through semi-structured interviews that allowed verbatim quotation.

Sub-questions were outlined in order to investigate the *effect* of the intervention in specific desirable outcomes:

- 1.1 *Does Music Oriented Parent Counseling (MOPC) decrease the participants' level of stress?*
- 1.2 *Does MOPC improve the participants' perception of Quality of Life (QoL)?*
- 2.1 *Is there a wider use of music in everyday life by the participants with their child because of MOPC?*

Sub-question 1.1 was investigated using a parent-report standardized measure, the Questionnaire for Resources and Stress short Form (*QRS-F*; Freidrich et al., 1983). Sub-question 1.2 was investigated using a self-report graph, the Quality of Life Visual

Analogic Scale (*QoL-VAS*; The EuroQoL Group, 1990). Sub-question 2.1 was investigated using the Music in Everyday Life (MEL) questionnaire, whose development and psychometric properties are described in Chapter 5. The analysis of the *QRS-F*, *QoL-VAS*, and MEL numeric data was presented in Chapter 6.

Two sub-questions were outlined in order to investigate the *experience* of the intervention in these specific outcomes:

- 1.5 *What is the participants' experience of MOPC and its' influence on their level of stress and quality of life perception?*
- 2.4 *What is the participants' experience of MOPC in relation to their use of music with their child, in everyday life?*

These two sub-questions were investigated using descriptive data from the semi-structured interviews with the 13 parent couples (the participants) at the completion of the treatment. The analysis of this data was presented in Chapter 7.

Aiming to use the mixed methods to validate each type of data, a triangulation design was chosen (Plano Clark & Creswell, 2008). As described in Chapter 4, a concurrent triangulation design aims to provide a corroboration and correspondence of the results from the different methods (Creswell & Plano Clark, 2011, p. 62). One option to merge the results is a side-by-side comparison, presenting the quantitative results following by the qualitative results. Then, a comment follows, specifying how the qualitative results either confirm or disconfirm the quantitative results (Creswell & Plano Clark, 2011, p. 223). This chapter presents a comparison of the mixed methods – the numerical data from the *QRS-F*, *QoL-VAS*, and MEL and the descriptive data from the interviews – in order to address congruence and discrepancy in the outcomes.



Figure 8 *Visual presentation of procedures*

SOURCE: Steckler, McLeroy, Goodman, Bird, & McCormick (1992).

8.1 COMPARISON OF MIXED DATA ACCORDING TO OUTCOMES

Both the numerical and descriptive data were collected concurrently, with the interviews taking place in the same week that the parents completed the post measures (*QRS-F*, *QoL-VAS*, and MEL). My intentions for the concurrent triangulation design were to compare the results of the two data sets and analyze whether the findings of the mixed data were congruent. This stands in line with recent developments in mixed methods analysis models. Creswell and Plano Clark's (2011) proposed merging the mixed data in some way, so that the results of each data set of the concurrent design can be compared. One way to compare the mixed data is by considering the data from different angles: by looking at each type of data separately, and then by looking across the data types (Creswell & Plano Clark, 2011). So far, in this thesis, the results for each type of data were examined separately. I will now compare the quantitative and qualitative results concerning each outcome. For 11 out of 13 participants both parents participated in the semi-structured interviews, while for *all* the participants, only the mothers completed the questionnaires at the two time points. In order to keep *clean* data, I chose to conduct the comparison for the three outcome measures (level of stress, quality of life, and music in everyday life) using only the mothers' data, comparing their expressions within the interviews with their answers marked in the questionnaires. This choice might cause the loss of an additional perspective (the fathers' perspectives), but on the other hand will preserve consistency of the data.

8.1.1 OUTCOME 1: LEVEL OF STRESS

In Chapter 6, the quantitative results for the *QRS-F* were presented. In summary, the statistical results from the analysis of the *QRS-F* showed no significant change in level of stress as a result of MOPC ($p = .39$), the descriptive statistics were not strong as seen through the negative effect size ($d = -0.82$), and mean differences between the maximal and the minimal conditions were 0.83 and 2.12 respectively.

In Chapter 7, the qualitative findings of the analysis of the semi-structured interviews were presented. The interviews gave the participants the opportunity to describe changes in their level of parental stress that occurred during the 5 months of their participation in MOPC. As opposed to having to mark *agree* or *disagree* on the items of the *QRS-F*, which was basically a numerical rating, parents were encouraged to use their own words in describing any change that might have happened, deciding what they wanted to emphasize and highlight. The qualitative analysis of the mothers' expressions revealed that they described changes in their level of parental stress because of three factors: gaining new understandings, receiving new tools to coping, and feeling safe and contained within the sessions.

After completing the independent analysis of each type of data, Creswell and Plano Clark (2011) propose to first “specify the dimensions by which to compare the results from the two databases” (p. 215). Creswell and Plano Clark's (2011) steps were followed, as the aim was to compare two very different sets of data. In order to accomplish this, the descriptive data was examined again, looking for a way to quantify this data.

Converting the descriptive data

Within my qualitative thematic analysis of the parents' expressions addressing level of stress, I have identified that the change described by the mothers could be seen in terms of *what they have gained* during sessions. Alternatively, lack of change could be seen in terms of *what they have NOT gained* during sessions. The codes *gaining new understandings* and *receiving new tools* included descriptions of more concrete things that the participants felt they gained that helped them cope better at home. The code *feeling safe and contained* included more abstract descriptions of their feelings during the sessions, concerning the trustworthy relationship that was built between them and the researcher.

From these two aspects, I could compare the mixed methods through *concrete* and *abstract* dimensions. However, the findings from both the quantitative and the qualitative analyses were reported for the groups as a whole; *Items statistics of change within groups* (Table 15) for the *QRS-F* and *participants' perception of change in level of stress* (Table 19) for the descriptive analysis. Comparing the data for the groups as a whole may not be able to provide explanations for the inconsistency between the two data sets. While the quantitative results point no significant change in level of stress in parents participating in MOPC ($p = .39$), the qualitative findings do describe changes in level of stress among the participants. Furthermore, comparing the data for the groups may not provide any new understanding of the process of change (or lack of change) for each participant and might limit our knowledge about *what works* in working in music therapy with parents of children with autism.

In order to deepen the mixed methods comparison, I returned to the data for each participant. Since only the mothers completed the questionnaire, I have addressed only their answers in the interviews. I gathered the individual *QRS-F* change scores for the mothers, as well as their expressions during the interviews for *level of stress*, and examined any compatibility or gaps. For three mothers, the code from the qualitative

analysis was *new understandings*⁷ contributed to lower stress. The code *new understandings* was connected in the qualitative analysis with the theme *Learning Experience*. For three mothers, the code from the qualitative analysis was *feeling safe and contained* as contributing to lower stress. The code *feeling safe and contained* was connected eventually with theme *Enabling Space*. For two mothers, the code from qualitative analysis was *practical tools* as the factor to create change in level of stress. The code *practical tools* was connected eventually also with the theme *Learning Experience*. Four mothers stated no change in their level of stress, while three of them indicated that they did not have enough sessions to affect their stress level, and one connected it with her pessimistic personality. Only one mother reported a higher level of stress. I believe that comparing the individual results will provide a useful way to understand the relationship between the qualitative and quantitative findings.

A one-to-one comparison

The next step was to compare the rating order of the individual *QRS-F* change scores with each mother's codes and themes describing any change in level of stress. I have ordered the scores from the highest reduction, which indicates improvement (meaning that level of stress had decreased the most) to the highest increase, which indicates deterioration (meaning that level of stress had increased). Table 22 presents the one-to-one comparison of the mixed methods.

Table 22 Mothers' QRS-F rating order (highest reduction to highest increase) compared to codes

Participant (mothers only)	<i>QRS-F</i> change score	Type of MOPC (sessions received)	Codes	Theme	Comparison between quant. and qual.
I	-9 (23 to 12)	Minimal (3)	No change; not enough sessions	No change	Discrepant
E	-6 (20 to 14)	Maximal (10)	Received practical tools	Learning Experience	Congruent
F	-6 (20 to 14)	Maximal (10)	New understandings; I can trust him	Learning Experience	Congruent

⁷ Codes are written in italic with lowercase letters; themes are written in italics with capital first letters.

			more		
H	-3 (31 to 28)	Minimal (3)	No change; not enough sessions	No change	Discrepant
C	-2 (9 to 7)	Minimal (3)	New understandings	Learning Experience	Congruent
K	-2 (21 to 19)	Maximal (10)	Receiving practical tools	Learning Experience	Congruent
B	-1 (16 to 15)	Minimal (3)	New understandings of the reasons of his behaviors and how we can address them	Learning Experience	Congruent
M	0 (6 to 6)	Maximal (10)	More stress; too much focus on certain behaviors	More stress	Discrepant
G	+1 (6 to 7)	Minimal (3)	Safe and contained; no judgment	Enabling Space	Discrepant
J	+1 (15 to 16)	Maximal (10)	No change; pessimistic	No change	Discrepant
A	+3 (20 to 23)	Minimal (3)	No change;	No change	Discrepant
L	+3 (9 to 12)	Maximal (10)	Safe and contained; no judgment	Enabling Space	Discrepant
D	+4 (19 to 23)	Maximal (10)	Safe and contained, more calm	Enabling Space	Discrepant

Note. Levels of stress are represented in the *QRS-F* by scores between 1 to 31, where 1 is hardly stressed and 31 is highly stressed; Green *QRS-F* = improvement in level of stress (level of stress decreased); Red *QRS-F* = deterioration in level of stress (level of stress increased).

Table 22 reveals some interesting points of congruence and discrepancy across the two different data sources. The comparison of the five participants with the positive

change scores (participants E, F, C, K, and B) demonstrates congruence between the two data sets, where their scores of *QRS-F* showed improvement in their level of stress (scores decreased), and their expressions during interviews described feeling less stressed. It is interesting to see that all these five participants' expressions belong to the theme *Learning Experience*, which I have identified as dominant characteristic of MOPC. Looking at the codes that these mothers have expressed, three mothers described gaining *new understandings*, and two mothers described receiving *practical tools* as contributing to their low stress feelings. The comparison of both sets of data for these five mothers was therefore highly congruent.

The participant with the highest improvement in level of stress according to the numeric measurement is participant I, who expressed during the interview feeling no change at all in her level of stress, and connected it with the fact that she had participated in the minimal MOPC (three sessions only). This discrepancy is especially interesting given that this mother's initial score of the *QRS-F* was quite high (23, where 32 is the highest), and she showed a 9-point improvement by scoring 12 at the second *QRS-F*, which is below the middle range of stress level. A similarly opposite relation between the two data sets occurred with participant H, whom her *QRS-F* scores indicate a slight improvement in stress level, but had also expressed her feeling of having no change in her stress level. The *QRS-F* score of this participant was extremely high at baseline (31), and although she participated in the minimal MOPC, her score improved by 3 points, which is a good change regarding such a high level of stress. These two participants belong to group three, meaning they had participated in minimal MOPC and their children did not receive music therapy sessions within the study. It may be that one of these data sets was not completed authentic, or that the mothers interpreted the interview questions differently than the *QRS-F* items. It may also be observed as a surprising result, where the numerical data showed improvement in participants from group three, who participated in only three sessions. It might be that the participants themselves did not yet feel this change, as this setting offered only three sessions that ended before this change was discussed between the participants and the researcher, and therefore not expressed during the interviews.

At the bottom change scores rating order, representing deterioration in level of stress (meaning a higher level of stress at the end of intervention period), three mothers (participants G, L, and D) expressed during the interviews that they felt less stressed, and connected it with them feeling *safe and contained* during MOPC sessions. This code suggests that mothers who participated in MOPC felt that they could share their feelings without being judged and felt supported by the researcher. This code appeared with no regard to intensity of the MOPC. This comparison of the mixed data sets shows a discrepancy among these three participants, and the contrast between them might suggest that the way parents describe their level of parental stress may be

complex and multifaceted; parental stress is an evasive and unique experience and therefore, any change reported may be challenging to interpret. The other two mothers (participants J and A) have expressed no change at their parental stress level, where participant J, who deteriorated by one point, connected it with her pessimistic personality, and participant A, who deteriorated by three points, connected it with receiving minimal MOPC. This comparison of the mixed data also shows a discrepancy, but not an opposite one. Yet, it might emphasize again the complex task of describing parental stress level.

Participant M is the only participant who expressed in the interview feeling more stressed at the end of intervention period, while her score on the *QRS-F* had not changed. This mother marked quite low level of stress at baseline (6), and kept this score at the end of the study. Nevertheless, she expressed feeling more stressed, and explained that during the counseling sessions we have discussed certain characteristics of her child's behaviors, which made her more aware and worried. This discrepancy may suggest that alongside of new understandings and awareness that are gained through parent counseling sessions, new worries might arise.

Discrepancies between the two data sets that appeared in the comparison further highlight the difficulties with interpreting results. It may be, that parents tend to mark *more stress* when they are exposed to difficult questions about different aspects of their lives, as the items of *QRS-F* represent, as opposed to speaking about their stress with a professional, within a trustworthy non-judgmental relationship.

Conclusion

Research question no. 1 is: *What is the influence of Music-Oriented Parent Counseling (MOPC) on level of stress (and quality of life perception) of parents of children with ASD?* In order to answer these wide questions, sub-questions were outlined:

Sub-questions 1.1 and 1.3 addressed the quantitative data: *1.1 Does MOPC decrease the participants' level of stress? 1.3 Is high-intensity MOPC superior to low-intensity MOPC in improving level of stress (and QoL perception)?* Sub-question 1.5 addressed the qualitative data: *What is the participants' experience of MOPC and its' influence on their level of stress (and quality of life perception)?*

The comparison of the mixed data offers partial support for both the quantitative and the qualitative analyses, with the comparison of mixed methods revealing highly congruent data for 5 out of 13 mothers. Mothers with positive change scores on the *QRS-F* tended to describe the reasons for feeling less stressed as *gaining new understandings* and *receiving new tools* throughout the MOPC sessions. These codes compose the *Learning Experience* theme, representing a core feature of MOPC.

There were eight mothers with discrepancies when the data sets were compared; two mothers showed improvement in their *QRS-F* scores but expressed the feeling of *no change* (participants I and H). These two mothers' scores can be viewed as surprisingly improved, as both of them belong to group 3, where participants attended minimal MOPC and their children did not participate in music therapy sessions. This might suggest that in some cases, even minimal process of MOPC with no music therapy sessions for the children might have a beneficial effect on parental stress levels.

8.1.2 OUTCOME 2: QUALITY OF LIFE

In this study, parents' perception of their child's and their own quality of life (QoL) was investigated. In Chapter 6, the quantitative results for the *QoL-VAS* were presented. In summary, the statistical results from the analysis of the *QoL-VAS* showed a significant change ($p = .011$) in the parents' perception of their child's QoL after participating in music therapy sessions, indicating that music therapy had a good effect on the children's QoL. While the inferential statistics failed to reach significance after participating in MOPC ($p = .221$), the mean difference was in favor of maximal MOPC. A tendency to improvement ($p = .123$) is seen in the participants' perception of their own QoL among those who participated in MOPC process, indicating that participating in MOPC sessions tended to improve the parents' QoL perception.

In Chapter 7, the qualitative findings for the semi-structured interviews are presented. Within the interviews, parents were given the opportunity to describe their perception of quality of life, by first defining what quality of life was to them (presented in section 7.2), and then describing any change that might have occurred in their perception during the 5 months of their participation in MOPC. In contrast to having to numerically rate the scale of the *QoL-VAS*, parents were encouraged to use their own words to describe any change and emphasize the aspects they considered as important. Most mothers commented upon the fact that their QoL perception is connected with their stress level or with their child's QoL, and found this separation artificial. Nonetheless, a qualitative analysis revealed that mothers, who did feel a change in their QoL perception, described it in two different ways: by gaining *new understandings* and by feeling *contained and safe* within the sessions. Seven mothers stated they had no change in their QoL perception and related it to too few MOPC sessions.

In addition, here I decided to follow Creswell and Plano Clark's (2011) recommendations, by defining the dimensions the results of the two data sets would be

compared (p. 215) and examined the possibility of quantifying the descriptive data in some way.

Converting the descriptive data

Similarly to the codes found within my qualitative analysis for stress levels, I had identified that change in QoL perception described by the mothers could be seen in terms of *what they have gained* during sessions. Alternatively, a lack of change could be seen in terms of what *they have not gained* during sessions. The codes *received tailored advice*, *learned to make space for fun*, and *new understandings* included descriptions of more concrete things that the participants felt they gained that helped them cope better at home. The codes *confidence in parenting* and *felt safe to talk and reflect* included more abstract descriptions of their feelings during the sessions, concerning the trustworthy relationship that was built between them and the researcher.

From these two aspects, I could compare the mixed methods through *concrete* and *abstract* dimensions, as I did earlier in the comparison for stress levels. However, the findings from both the quantitative and the qualitative analyses were reported for the groups as a whole; *Items statistics of change within groups* (Table 15) for the *QoL-VAS* and *Participants' perception of change in quality of life* (Table 20) for the descriptive analysis. Also here, I have decided to compare the qualitative and quantitative findings for each individual (mothers only) in order to reach the possibility of explaining any inconsistency between the two sets of findings, and in order to achieve new understandings of the process of change (or lack of change) in each participant. These steps were taken to establish our knowledge about *what works* in working in music therapy with parents of children with autism.

In order to deepen the mixed methods comparison, I returned to the data for each mother. I gathered the individual mothers' *QoL-VAS* change scores, as well as their expressions during the interviews for quality of life, and examined any gaps or compatibility. For three mothers, the codes in the qualitative analysis: *received tailored advice*, *learned to make space for fun*, and *new understandings* contributed to a sense of improved QoL. These codes were connected in the qualitative analysis with the theme *Learning Experience*. For two mothers, the codes from the qualitative analysis were *feeling safe to talk and reflect on things* and *felt confidence in parenthood* contributed to improvement of QoL. These codes were connected eventually with the theme *Enabling Space*. Eight mothers stated no change in their QoL; three of them indicated that they did not have enough sessions to affect their QoL, two connected it with having too many worries, and three gave no specific reason for not going through any

change. I believe that comparing the individual results will provide a useful way of understanding the relationship between the qualitative and quantitative findings.

A one-to-one comparison

The next step was to compare the rating order of the individual change scores seen in *QoL-VAS* with each mother's codes and themes describing any change in quality of life. I have ordered the scores from the highest positive change, which indicates improvement (meaning that quality of life had improved the most) to the highest negative change, which indicates deterioration (meaning that quality of life had decreased). Table 23 presents the one-to-one comparison of the mixed methods.

Table 23 *Mothers' rating order of parents' QoL (from the highest positive change to the lowest negative change) compared to codes and themes*

Participants (only mothers)	Parents' <i>QoL</i> Change score	Type of MOPC (sessions received)	Code	Theme	Comparison between quant. and qual.
F	25 (from 35 to 60)	Maximal (10)	Received tailored advice	Learning Experience	Congruent
A	15 (from 50 to 65)	Minimal (3)	No change; not enough sessions	No change	Discrepant
E	15 (from 20 to 35)	Maximal (10)	Safe to talk about things	Enabling Space	Congruent
L	15 (from 70 to 85)	Maximal (10)	Gained confidence in parenting	Enabling Space	Congruent
I	10 (from 75 to 85)	Minimal (3)	No change; not enough sessions	No change	Discrepant

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K	10 (from 50 to 60)	Maximal (10)	No change; too much worries	No change	Discrepant
D	0 (from 80 to 80)	Maximal (10)	No change	No change	Congruent
H	0 (from 10 to 10)	Minimal (3)	No change; not enough sessions	No change	Congruent
J	0 (from 75 to 75)	Maximal (10)	No change; too much worries	No change	Congruent
M	0 (from 90 to 90)	Maximal (10)	No change	No change	Congruent
B	-5 (from 70 to 65)	Minimal (3)	Learned to make space for fun	Learning Experience	Discrepant
G	-10 (from 85 to 75)	Minimal (3)	New understan dings regarding the child's capability to process music better than spoken words	Learning Experience	Discrepant
C	-20 (from 70 to 50)	Minimal (3)	No change	No change	Discrepant

Note: Quality of Life is represented by scores between 0 to 100, where zero is the lowest *QoL* and 100 is the highest; **Green = improvement in Quality of Life perception; Red = deterioration in Quality of Life perception.**

Table 23 reveals some interesting points of congruence and discrepancy across the two different data sources. The participant with the highest improvement in quality of life according to the numerical measurement was participant F, who perceived her QoL as very low at baseline (35 out of 100), and improved significantly to 60. This participant showed compatibility with her expressions during the interview, that described her feeling of receiving adequate advice, tailored to her family's specific needs. This code relates to the *Learning Experience* theme. Six other participants showed congruence between the quantitative and qualitative findings, while two of them (participants E and L) improved their quality of life, and four (participants D, H, J, and M) had no change. Participants E and F, who started with a very low QoL perception (20 and 35 respectively) talked about the sessions as a safe place to talk, consult, and receive concrete tools, and improved to 35 and 60 respectively. Participant L talked about gaining confidence at their parenthood and receiving tools to help in daily situations, which improved their QoL perception; this participant started with 70 and improved to 85. Therefore, the comparison of seven participants out of 13 is highly congruent.

Six participants (A, B, C, G, I, and K) showed incompatibility between their answers to the interview question and their scores of *QoL-VAS*. Participants A, C, G, I, and K talked about no improvement in their QoL perception after participating in MOPC. While the graphs of participants A, I, and K showed better scores indicating there was an improvement (from 50 to 65, from 75 to 85, and from 50 to 60 respectively), participants C and G's data showed deterioration in their QoL perception (from 70 to 55 and from 85 to 75 respectively). Participant B talked about changing their parental attitude, which gave them a feeling of a better QoL, but their data shows a small decrease – from 70 to 65. The comparison of the data sets of these six participants shows incompatibility.

Another interesting finding is regarding the four participants who present zero change in the numerical measurement and showed compatibility with their expressions during the interviews. Participants D, J, and M showed a somewhat high quality of life at baseline, which remained unchanged (80, 75, and 90 respectively), while participant H marked very low quality of life, which also remained unchanged (10 out of 100). Participants D, J, and M were allocated to *maximal MOPC*, but showed no improvement in their QoL perception. This does not support the hypothesis that participants participating in maximal MOPC would report improvement in the QoL

perception (hypothesis 3). Participant H, who marked a very low QoL score (10), was allocated to *minimal MOPC* and showed no improvement in their QoL perception.

Conclusion

Research question no. 1 is: *What is the influence of Music-Oriented Parent Counseling (MOPC) on (level of stress and) quality of life perception of parents of children with ASD?* In order to answer these wide questions, sub-questions were outlined:

Sub-questions 1.2 and 1.3 addressed the quantitative data: *1.2 Does MOPC improve the participants' quality of life perception? 1.3 Is high-intensity MOPC superior to low-intensity MOPC in improving (level of stress and) QoL perception?* Sub-question 1.5 addressed the qualitative data: *What is the participants' experience of MOPC and its' influence on their (level of stress and) quality of life perception?*

The comparison of the mixed data offers partial support for both the quantitative and the qualitative analyses, with the comparison of mixed methods revealing highly congruent data for 7 out of 13 mothers. Mothers with positive change scores on the *QoL-VAS* tended to describe the reasons for feeling an improved quality of life as *gaining new understandings* and *feeling safe to talk and reflect* throughout the MOPC sessions. These codes combine the *Learning Experience* and the *Enabling Space* themes, representing a core feature of MOPC.

There were six mothers with discrepancies when the data sets were compared: three mothers showed improvement in their QoL scores but expressed the feeling of *no change* (participants A, I and K). The scores of participants A and I can be viewed as *surprisingly improved*, as both of them participated in minimal MOPC. This might suggest that in some cases, even minimal process of MOPC might have a beneficial effect on quality of life perception.

The discrepancies in the comparative analysis highlight the complexities of evaluating quality of life even when a variety of data is collected. Furthermore, the concept of quality of life is interpreted differently among different people, and it was hard to reach a concise definition to meet the variety of views. The researcher invited participants to define a personal definition of what quality of life is in his or her view, and only then asked them to address any change that might have occurred because of the intervention. This step might have helped the participants to acknowledge their own personal views of this term, but failed to form an acceptable definition for all the participants.

8.1.3 OUTCOME 3: MUSIC IN EVERYDAY LIFE

In this study, the parents' daily use of music with their children with autism was investigated. In Chapter 5, the Music in Everyday Life (MEL) measurement was confirmed as a scale with reliability to assess the use of music in everyday life by parents and their children with autism, resulting with two sub-scales: MEL-RAM and MEL-JAM. The MEL-RAM (Music in Everyday Life - Routine Activities using Music) includes the use of music in daily situations, such as – bedtime, mealtime, fun time, calm down, understand routine, transitions from one activity to another, learn new things, and drive calmly in the car. The MEL-JAM (Music in Everyday Life – Joint Activities using Music) includes the use of music in activities of mutual participation of both the parent and the child, such as – singing together, listening to music together, playing musical instruments together, and playing musical applications together.

In Chapter 6, the quantitative results for the MEL-RAM and MEL-JAM were presented. In summary, the statistical results from the analysis show a significant change ($p = .020$) in the parents' use of music in routine activities after participating in music-oriented counseling sessions, indicating that music-oriented parent counseling had a significant effect on the use of music parents do with their children with autism during routine daily situations. A significant correlation was found between the change occurred in using music in routine activities (MEL-RAM) and the participants in the maximal MOPC groups. This supports the hypothesis in which MOPC contributes to expanding the use of music in daily routine activities by parents with their children with autism. An improvement was seen in the parents' use of music in joint activities with their children among those who received music therapy sessions, even though not significant ($p = .123$). This might indicate that the children's participation in music therapy sessions enables opportunities for musical interaction between the parents and their children.

In Chapter 7, the qualitative findings for the semi-structured interviews were presented. Within the interviews, parents were given the opportunity to describe any change that might have occurred in their use of music during the 5 months of their participation in MOPC. In contrast to having to numerically rate the MEL scale, parents were encouraged to use their own words to describe any change and emphasize the aspects they considered as important. All the participants described a more extensive use of music attuned to their children. Overall, it is clear that the MOPC process had a major role in raising the awareness of the participants to the language of music, and to the role of music as a communicative and interactive tool, which they have implemented in their lives.

I will now proceed with Creswell and Plano Clark's (2011) recommendations, and examined the possibility of quantifying the descriptive data in some way.

Converting the descriptive data

In my qualitative analysis, I have identified that the parents' descriptions of the change in their daily use of music attuned to their children could be thought of in terms of *raising awareness* to the role of music and *implementing musical-techniques* in real life. The code *awareness* includes expressions concerning the importance of using music, the role music takes in their child's lives and in their own, and perceiving music as a communication tool. The code *implementation* includes descriptions of different techniques that the parents use with music to help cope with daily situations, such as singing instructions, putting music on to help the child calm down, and using music to help the child move from one activity to another. The parents also described music as an engagement facilitator, which improved the parent-child interaction.

From these aspects, I could compare the mixed methods through *awareness* and *implementation* dimensions. However, also here the findings from both the quantitative and the qualitative analyses were reported for the groups as a whole; *Items statistics of change within groups* (Table 15) for the MEL and *participants' perception of change in the use of music in everyday life* (Table 21) for the descriptive analysis. Comparing the data for the groups as wholes will not be able to provide any new understandings of the process of change in each participant, and will limit our knowledge regarding *what works* musically for parents with their children with autism.

In order to deepen the mixed methods comparison, I returned to the data for each mother. I gathered the individual MEL change scores of the mothers, as well as their expressions during the interviews for music in everyday life, and examined any gaps or compatibility. For 10 mothers, the code in the qualitative analysis was *implementation*, including descriptions of: more singing together, singing instructions, more listening to music together, joining the child in music-making, using music to help the child calm down, using soft music during bedtime, listening to music, dancing together, and speaking in a *melodic* intonation. This code was connected in the qualitative analysis with two themes: *Learning Experience* and *Music in Everyday Life*. As stated in Chapter 7, *Music in Everyday Life* as a theme refers to the parents' implementations of musical techniques in the home environment, rather than to the scales MEL-RAM and MEL-JAM. For seven mothers, the code in the qualitative analysis was *awareness*, including descriptions of: awareness of the role of music in the child's life, awareness of the importance of joining the child musically, awareness of the possibility of using music as a communication tool, and awareness of the role of music in the parents' lives. This code was also connected in the qualitative analysis to the themes *Learning Experience*

and *Music in Everyday Life*. For four mothers (participants G, H, J, and K) both codes were described as the signs of change. I believe that comparing the individual results will provide a useful way to understand the relationship between the qualitative and quantitative findings.

A one-to-one comparison

The next step was to compare the rating order of the individual change scores seen in MEL-RAM and MEL-JAM with each mothers' codes and themes describing any change in the use of music in everyday life. I have ordered the scores from the highest positive change to the highest negative change in MEL-RAM sub-scale, indicating an extensive use of music attuned to the child in routine activities using music. The change scores of MEL-JAM are also presented, although not in a certain order. Table 24 presents the one-to-one comparison of the mixed methods.

Table 24 *Mothers' rating order of MEL-RAM (from the highest positive change to the highest negative change) and MEL-JAM, compared to codes and themes*

Participant (mothers only)	MEL-RAM	MEL-JAM	Type of MOPC (sessions received)	Code	Theme	Comparison between quant. And qual.
F	11 (from 7 to 18)	2 (from 2 to 4)	Maximal (10)	Implementati on; more singing; singing instructions helps him organize	Learning Experience & Music in everyday life	Congruent
E	8 (from 6 to 14)	4 (from 1 to 5)	Maximal (10)	Implementati on; More singing and music listening in mutual enjoyment	Learning Experience & Music in everyday life	Congruent
H	7 (from 4 to 11)	-5 (from 8 to 3)	Minimal (3)	Awareness & Implementati on; Joins his singing in	Learning Experience & Music in everyday life	Congruent

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				mutual enjoyment		
L	4 (from 8 to 12)	1 (from 3 to 4)	Maximal (10)	Implementations; 'melodic' intonations when giving instructions helps him to organize, musical communication in mutual enjoyment	Learning Experience & Music in everyday life	Congruent
J	2 (from 7 to 9)	-4 (from 6 to 2)	Maximal (10)	Awareness & Implementations; use music as a tool for communication and engagement	Learning Experience & Music in everyday life	Congruent
K	2 (from 8 to 10)	1 (from 1 to 2)	Maximal (10)	Awareness & Implementation; Music as a tool is a revelation, music helps him calm down	Learning Experience & Music in everyday life	Congruent
C	1 (from 8 to 9)	2 From 3 to 5)	Minimal (3)	Implementation; Joins his playing in mutual enjoyment	Learning Experience & Music in everyday life	Discrepant
M	1 (from 7 to	1 (from 2 to	Maximal (10)	Awareness; new ways to use music	Learning Experience & Music in	Congruent

	8)	3)			everyday life	
A	-3 (from 8 to 5)	1 (from 3 to 4)	Minimal (3)	Awareness	Learning Experience & Music in everyday life	
B	-3 (from 18 to 15)	-1 (from 5 to 4)	Minimal (3)	Implementati ons	Learning Experience & Music in everyday life	Discrepant
D	-4 (from 16 to 12)	0 (from 7 to 7)	Maximal (10)	Implementati ons	Learning Experience & Music in everyday life	Discrepant
I	-5 (from 7 to 2)	-1 (from 2 to 1)	Minimal (3)	Awareness	Learning Experience & Music in everyday life	Discrepant
G	-7 (from 12 to 5)	2 (from 2 to 4)	Minimal (3)	Awareness & Implementati ons	Learning Experience & Music in everyday life	Discrepant

MEL-RAM = Music in Everyday Life - Routine Activities using Music; MEL-JAM = Music in Everyday Life - Joint Activities using Music; High score means more use of music, and low score means less use of music; green = improvement at the use of music ; red = deterioration at the use of music

There are some interesting points regarding congruence and discrepancies in table 24. The first eight participants in table 24 were of participants F, E, H, L, J, K, C, and M. These mothers show compatibility between their quantitative scores, which show a positive change in their use of music with their children and the qualitative findings, which also express extensive use of music with their children in the home environment. These mothers' interview responses were coded as awareness to the role of music and implementation of musical techniques during interaction with their children. These codes combine the themes *Learning Experience* and *Music in Everyday Life*, suggesting that participating in music-oriented parent counseling sessions offered new opportunities for parent-child interactions and improved their engagement.

While this comparison of the mixed data showed a good level of congruence, there were discrepancies in the results for five parents. Participants A, B, D, G, and I also

had the themes *Learning Experience* and *Music in Everyday Life*, but their scores suggested there was less use of music attuned to the child in the home environment. Participants A and G showed more use of music in joint activities, which resonates with their expressions during the interviews, and therefore are not completely discrepant. It was my decision to compare the data according to one sub-scale (the MEL-RAM), as comparing two sub-scales was not feasible or efficient, but looking at the scores of the other sub-scale (the MEL-JAM) might provide a wider perspective of this discrepancy. The discrepancies of participants B, D, and I's data might suggest a time difference between completing these two data sets, placing the scores of the MEL within one particular week, while the participants' responses in the interviews refer to a more general change. Future mixed methods design should consider asking the participants to comment on any discrepancy so that a better understanding of the splitting can be gained.

Conclusion

Research question no. 2 is: *What is the influence of Music-Oriented Parent Counseling (MOPC) on the use of music in everyday life by parents with their children with ASD?* In order to answer this wide questions, sub-questions were outlined: Sub-questions 2.1 – 2.3 addressed the quantitative data: 2.1 *Is there a wider use of music in everyday life by the participants with their child because of MOPC?*; 2.2 *Is high-intensity MOPC superior to low-intensity MOPC concerning a wider use of music in everyday life by the participants with their children?*; 2.3 *Is MOPC with MT for the children superior to MOPC without MT for the children concerning a wider use of music by the participants in everyday life with their children?* Sub-question 2.4 addressed the qualitative data: 2.4 *What is the participants' experience of MOPC in relation to their use of music with their child, in everyday life?*

The comparison of the mixed data offers partial support for both the quantitative and the qualitative analyses, with the comparison of mixed methods revealing highly congruent data for 8 out of 13 parents. Parents with positive change scores on the MEL-RAM sub-scale described an increased awareness of the role that music takes in their child's life and implemented musical techniques during interaction with their children; the categories in the qualitative analysis represent stages of the *Learning Experience*, as well as implementing *Music in Everyday Life*.

There were five parents with discrepancies when the data sets were compared. Although for participants A and G there was no compatibility between the answers in the interview with the sub-scale MEL-RAM, comparing to the change scores in the sub-scale MEL-JAM support their answers of using more music in everyday life. These discrepancies are therefore not complete.

9 DISCUSSION

Introduction

The aim of this study was to investigate whether Music-Oriented Parent Counseling (MOPC) positively influenced parents' perception of their stress and quality of life, and extended the daily use of music during parent-child interaction. Sources of increased stress for parents include difficulties in communicating with their child (Goin-Kochel & Mayers, 2005), and supporting the child's motivation to stay in connection and be excited about relationships is crucial for successful social development (Campbell, Milbourne, & Wilcox, 2008; Poulsen, Rodger, & Ziviani, 2006). A variety of data was collected including: numeric data of the *QRS-F* and the *QoL-VAS*, questionnaire of the use of music in everyday life, and interview data.

The intervention consisted of either three or 10 MOPC sessions, which took place in my private clinic. The counseling sessions involved the use of music from different perspectives – musical improvisations, as a means to express and engage in a non-verbal language; and listening to music, as a means to reflect and reattach to its' deep meaning and role in everyday life. Thus, music was used as a form of *space* for relief from stress and to gain wellness, as well as protecting and elevating from stressful everyday challenges and problems. DeNora (2013) addressed the representation of music as an asylum, within an ecological discussion about health and illness. She described the asylum as making room for creativity, expressivity, flow and flourishing, and at the same time, gaining distance from pathogenic factors that foster distress and pain (p. 136). In contrast to a familiar situation, where children with ASD (and typically developing children as well) often do not verbally express how music helps them in various aspects of their lives, the participating parents had continuously expressed how music helped them feel less stressed, more contained, and brought back hope and means of interaction with their children. Resonating with Ansdel's (2014) observation, that "*what is musically present and available has the potential to help*" (p. 88), I could see how using music within counseling sessions helped the parents feel safe and contained in our relationship, and enhanced their self-perception as competent parents.

Two counseling models influenced the way of conducting the counseling sessions in this study: The values-based parent counseling model (Nelson et al., 2000) and the partnership model (Davis, 2000). Starting from work in schools and addressing the whole system that surrounds the child, Nelson and colleagues (2000) based their model within a system oriented approach. They perceived the child and his needs within the context of the school and family, and emphasized the role of the family's life-views and values on the communication and social development of the child. In order to form a

helping system for the child, this model advocates for professional caregivers to abandon the 'expert' position that holds on to exclusively own the knowledge and solutions, and collaborate with the parents, incorporating their life-views and values. Similarly, the partnership model (Davis, 2000) advocates for professional caregivers to develop a working mechanism between them and the parents, and form a partnership. Davis points out that parents have their own expertise and knowledge that they can bring to the counseling sessions, and by forming a trustworthy relationship between them and the counselor, there is an opportunity to use the resources of all the partners to meet the desirable goals. Davis (2000) based his model on his extensive clinical experience in working with parents of children with neurodevelopmental disorders, without relying on a certain theory. The parents' values and attitude were centrally considered during the MOPC sessions, and guided the choices that were made as to when and how to offer solutions to certain situations within the home environment. The collaboration approach, which is a core feature of the MOPC, led to the development of partnership between the parents and me, respectively to the number of sessions of MOPC that were given.

The setting consisted also of either *with music therapy sessions* or *without music therapy sessions* for the children. For families for whom their children were allocated to receiving music therapy sessions, the setting was of parallel work with both the parents and the children (as described in section 4.3). The form of work where one-therapist conducts parallel sessions with both the child and his/her parents is known as parallel-treatment (Chazan, 2003) or simultaneous-treatment (Nilsson, 2006). Chazan and Nilsson are psychotherapists who conduct treatment for both the child and the parents, unlike Nelson who provides counseling that relies on their life values (and not treatment), to the parents. The parallel setting of my work includes treatment for the children and counseling within a musical orientation for the parents – conducted parallel to each other within the same period of time.

As a part of the TIME-A research project, the current study followed an RCT design, in response to the demand for evidence-based research. To my knowledge, an RCT design has not previously been used to research music-oriented parent counseling approach with parents of children with ASD.

There is a reciprocal relationship between collaborative approaches and those where the music therapy treatment focuses solely on the child. Similarly to the central perspective of *follow the child's lead*, which appears in several studies (Geretsegger et al., 2014; Holck, 2004; Kim, 2009), the MOPC being investigated here uses the idea of *follow the parents lead* as the first stage in building a trustworthy relationship with the parents. Nonetheless, as Randi Rolvsjord cohesively described in her book "Resource-Oriented Music Therapy in Health Care" (2010), in order to achieve collaboration,

both client and therapist should be active in the process of assessment, in deciding the goal of the process, and in finding a way to work towards problem-solving (p. 215). The therapeutic process, theoretical frame, and role of the therapist in this study were detailed, in order for the study's results to be replicable, and to enable future comparison between different therapy approaches. The counseling guide (counseling protocol) was designed to be as close as possible to my real-world approach to music therapy (Appendix F) by collaborating with parents to form a partnership. With the need to maintain a flexible frame work that allows adjusting the direction of counseling according to the capabilities and weaknesses or needs of each parent, a flexible counseling protocol was designed, instead of a fixed protocol. This was done in order to ensure "...acknowledgment of the participants' own competence and resources related to the process of change, and these should not be threatened by the details of pre-structured and standardized manuals" (Rolvjord, Gold & Stige, 2005, p, 28).

The choice of assessment measures contributed to the RCT design to be connected with the collaborative treatment model. The parents' perspectives were integral within collaborative practice, and therefore, standardized parent' self-report questionnaires of the three outcome measures were used and found as appropriate outcome measures in the context of this study.

Acting within a real-world research paradigm, this study aimed to investigate the effectiveness of MOPC for parents of children with autism. Therefore, descriptive statistics were combined with inferential statistics. In small sample size studies, statistical significance should not be used as a stand-alone measure of the effect of an intervention (Valentine & Cooper, 2003). Within the following discussion, a consideration is given to two ways of assessing the effect of the intervention: the statistical significance and the practical significance based on raw mean differences and effect size (Cohen's *d*).

The results are discussed in the following order: outcomes for level of stress; outcomes for quality of life; and outcomes for the use of music in everyday life. Qualitative findings are integrated with the quantitative results, and new understandings to music therapy practice and research are discussed. The implications of the findings relevant to parents, music therapists, and counselors are presented, and conclusions are made at the end of each section. The chapter ends with final remarks and recommendations for future music therapy research.

9.1 OUTCOME 1: LEVEL OF PARENTAL STRESS

There were three hypotheses related to change in levels of the parents' stress:

Hypothesis 1: *Participants will report improvement in their level of stress*

Hypothesis 3: *Participants participating in maximal MOPC will report more reduced stress (and improved quality of life perception) than participants participating in the minimal MOPC*

Hypothesis 4: *Participants whose children received MT sessions will report more reduced stress (and a higher improvement in quality of life perception) than participants whose children did not receive MT sessions.*

Investigating change in level of parental stress was relevant to this study, as stress is identified as directly connected to parenting a child with autism (Abbeduto et al. 2004; Duarte et al. 2005; Konstantareas & Papageorggiou 2006; Montes & Halterman 2007). One central aim of the MOPC approach was to influence the level of parental stress of those who participated in the process. Two data sets were used to address these hypotheses: numerical data from a standardized measure (the *QRS-F*) and descriptive data from an interview with the parents of 13 children with autism at the end of the intervention phase. The three hypotheses drew on both data sources in order to potentially validate and clarify each of the data. A comparison of the mixed methods was presented in Chapter 8.

The *QRS-F* is a standardized measure providing a quantified description of level of parental stress in parents of children with autism. This 31-item validated questionnaire is a shortened version of the original one, which originally focused on four areas of parents' perception regarding different aspects of their lives. The shorter version (Hastings & Brown, 2002) focuses on two areas directly connected with the impact of the child's diagnosis on the parents: a) parents and family problems (stressful aspects of the impact of the child with disability on parents and the wider family), and b) pessimism (parents' pessimistic beliefs about the child's future). The items on the measure assess the parents' attitude towards being a parent of a child with autism with agree/disagrees questions (e.g. "I worry about what will happen to my child when I can no longer take care of him/her"; "I have difficulty leaving the house because of my child.").

Both the minimal MOPC and the maximal MOPC groups recorded improvements in level of stress on the *QRS-F*, with mean change scores of 2.16 and 0.83 respectively (Table 15).

Out of the six participants in the minimal MOPC groups, three participants (participants B, C and G) reported a relatively low stress level at baseline (16, 9 and 6 respectively), and recorder improvement in two out of these three participants (Table 22). The other three participants (participants I, H and A) reported a relatively high stress level at baseline (23, 31, and 20 respectively) and two of these three participants recorded improvement (Table 22). It may be that these changes indicate that the minimal form of MOPC was quite appropriate to offer some relief from stress for participants with low stress level as well as the ones with high stress level. Examining the scores within the groups identified that the maximal MOPC with *no* music therapy group recorded improvements with mean change score of 4.33 (Table 15). Given the use of a standard care control for the children who were allocated to *no music therapy* within the study, it may be that this change indicates that children had received a quality standard care and that the maximal form of MOPC could offer some improvement in level of stress. While the results comparing groups was not significant, the gains made by the participants did not revert to baseline level at the end of the 5-month counseling period.

The outcomes captured by the numerical and descriptive data suggest ways that the MOPC approach was both beneficial and limited in supporting level of stress of parents of children with ASD. One way to understand the benefits of the intervention is to look at the effect sizes of the numerical data. The *QRS-F* effect size $d = 0.82$, suggests that 7 out of the 13 parents presented a reduced level of stress after MOPC. This might be connected with the severity of autistic characteristics of the children, which was recognized by Honney, Hastings and McConachie (2005) as affecting a high level of parental stress. In the current study, families with children with the lowest mean for IQ score (71.33), the highest mean for *ADOS* (17.67), and the highest mean for *SRS* (180.66; Table 14), which could be seen as the children with the most severe autistic symptoms in the study, were allocated to the group who participated in maximal MOPC and their children participated in music therapy sessions. Although these participants received the *full intervention* within the study, their results show no significant change, with a mean difference of .67. Therefore, these results do not support hypothesis 3 that anticipated that the participants in the maximal MOPC will report more reduced stress than participants in the minimal MOPC, and hypothesis 4 that participants whose their children received MT sessions will report more reduced stress than participants whose their children did not receive MT sessions. Not with standing, reviewing each of the participants within this group individually reveals an interesting point; both participants E and F scored a 6-point improvement of their level of stress, from 20 to 14 (Table 22). Even though these scores do not achieve statistical significance, they might indicate that the intervention positively affected these participants' stress level, and therefore do support hypothesis 3 and 4.

Another explanation regarding the small amount of parents, which presented improvement on the *QRS-F*, might be connected with the style of this questionnaire. Consisting of 31 statements, where some of them describe difficult life situations (e.g. "I am ashamed of my child's situation"; "my personal development is limited because of my child's situation"; "There is a lot of anger within our family"), parents in this study have described the *QRS-F* questionnaire as difficult and emotionally revealing to engage in. Moreover, the limited rating options within a 2-point Likert scale (agree or disagree) forced the parents to decide on critical matters in a *black or white* division, where reality is much more complicated to them. Referring to these specific characteristics of the questionnaire it can be assumed that *the way* the questions were asked, and the *narrow possibilities* to answer them, created a sense of stress in the parents, influencing their ability to calmly evaluate their attitude to each question. A stressful questionnaire that is targeted to measure stress is likely to influence its' target, and might miss authenticity.

Reducing stress level was a target of the counseling approach within this study. Across studies, there was no one strategy found to be successful for reducing parental stress (Richmond Mancil, Boyd & Bedesem, 2009). While in parents in the above studies reported experiencing decreased level of stress after relying on professional resources and programs outside the family (Donovan, 1988), others effectively coped with stress through parent support groups and social support (Luther et al., 2005). Also, several parents across studies noted that spousal support helped them cope with stress (Gray, 2003; Higgins et al., 2005); yet, spousal relationship problems were common stressors experienced by some parents (Baker-Ericzen et al., 2005; Dunn et al., 2001; Hutton & Caron, 2005). The above studies used various measurement tools, but not the *QRS-F*. Some researchers used instruments that have been previously developed and psychometrically validated, such as the COPE (Carver, Scheier, & Weintraub, 1989) and the Parental Self-Efficacy Scale (Sofronoff & Farbotko, 2002) while others solely relied on interviews developed for their particular studies (for example: Gray 1994, 2003).

Reflecting on research that address the use of the *QRS-F* to measure parental stress levels reveals that several of the researchers acknowledge the complexity of this task. For example, Honney, Hastings, and McConachie (2005) validated the use of a total stress score within the *QRS-F* used with parents of children with autism. They point to two important considerations: a) parents of children with the most severe autistic symptoms and fewer adaptive skills reported higher levels of stress; b) there were differences in the scores between families in higher socio-economic level, who could financially support multiple treatments for their children, compared to families on a

lower socio-economic level, with a higher level of stress for the latter; and c) cultural differences, which might affect the parents' ways of responding to this questionnaire.

The parents' responses in the semi-structured interviews in this study provided a different perspective on change in levels of parental stress. With the merging of these two sources of data, a richer response to hypothesis three was offered. The semi-structured interview offered an opportunity for the parents to describe any changes in their level of parental stress that occurred while they participated in music-oriented parent counseling. As opposed to numerically rating the items on the *QRS-F*, parents described any changes using their own words, emphasizing what they felt was important. The comparison of the mixed methods (presented in Chapter 8), which compared the *QRS-F* total change score and the *Learning Experience* and *Enabling Space* themes from the parents' interview, offered a partial validation of both the quantitative and the qualitative analyses. The comparison between the way parents described the changes in their level of stress in the interviews and their numeric scores on the *QRS-F* revealed highly congruent data for 5 out of 13 mothers (Table 22). Mothers with larger change scores on the *QRS-F* described their change as influenced by engaging in a *Learning Experience*, while mothers who scored the smallest change scores on the *QRS-F* described the music-oriented counseling sessions as *Enabling Space*. Among the four mothers who described *No change* in their level of stress, participant I presented the highest improvement of 9 points (from 23 to 12). Participant H, who expressed 'no change' in the interviews as well, had *QRS-F* score of 3-point improvement (from 31 to 28). These scores are quite unexpected, as these two participants were allocated to group 3, where minimal MOPC took place with no music therapy sessions for the children. Participants I and H connected their feelings of *no change* to the fact that they had too little counseling sessions, and yet – demonstrated good improvement at their level of stress as was measured by the *QRS-F*. Given that participant H reported the highest possible score for the *QRS-F* at baseline (31), any improvement would be considered valuable, especially a 3-point improvement.

Many studies agree that parents want to be treated with respect by professional helpers, to be listened to properly, and engaged in a collaborative relationship where the people helping them do not take over (e.g. Attride-Stirling et al, 2001; Family Policy Alliance, 2005). Participants I and H's results might indicate that in some cases, participating in relatively few counseling sessions within a collaborative nature, have a beneficial effect and level of parental stress decreases, as pointed out also by Davis and Spurr (1998).

There were eight mothers with discrepancies in the mixed data, highlighting the complexities of evaluating level of parental stress even when data is collected using various measures. The results from this comparison of mixed methods support the

belief that counseling for parents of children with ASD can offer information and tools for the parents that reduce their stress (Davis, 2008; Kuloglu-Aksaz, 1994), and that music therapy techniques can offer opportunities for parents to interact with enjoyment with their children (Oldfield, 2008). Inconsistency between the results of the *QRS-F* and the parents' statements in the interviews were described previously by Kolglu-Aksaz (1994), where parents of children with ASD in Turkey participated in what he named as 'informational counseling' sessions. Within this study, 28 pairs of parents of children with ASD were allocated to two groups. Fourteen pairs of parents attended the experimental group, which provided weekly group sessions of 2 hours over 8 weeks. The control group consisted of the other 14 pairs of parents, who had received no counseling meetings. The informational counseling meetings were conducted for the whole group and covered the following areas: the nature of autism and characteristics of autism, including motor, perceptual, mental, social, and language development. Holroyd's Questionnaire on Resources and Stress (*QRS*; 1974) was administered to all 28 parents at both the beginning and the end of the study. Results showed no significant difference in the level of stress as measured by the *QRS* between the two groups, between the mothers and the fathers in the experimental group, or between the pretest posttest scores of each group by itself. However, parents of the experimental group have expressed during a discussion at the end of the study that they have gained some important benefits from the process. They pointed out that they were more realistic about their children with autism and more accepting of their children just the way they were. They have pointed out also the support they have received by joining with other parents of children with autism and receiving helpful information (Kuloglu-Aksaz, 1994). The fact that *QRS* results did not reach significant change, and discrepancies were shown between these results and the statements that parents expressed verbally in both Kuloglu-Aksaz's study and the current study, might indicate the need of further investigation regarding the sensitivity of this scale. On the other hand, the test power of the current study was low, with a small sample size, which might have affected the lack of significant results. The considerations pointed out by Hasting and McConachie (2005) that the severity of the child's autism, the socio-economic level of the parents, and cultural differences influence the way parents of children with autism score the *QRS-F* questionnaire, further support the idea that the *QRS-F* might not be sensitive enough in order to assess such a complex issue as stress. Furthermore, it seems that when parents are asked to verbally describe the change in their level of stress after participating in counseling sessions using their own words and emphasizing what *they* consider as important, they *do* describe feeling less stressed, more knowledgeable, and more competent.

From a different perspective, it might be that the counseling sessions raised the parents' awareness of certain areas of conflicts around their child's situation. This

awareness might have led some parents to feel more stressed at the end of the intervention period, as reflected by the higher scores in the *QRS-F*.

When reflecting on the stressors that affect parental stress level, there is another important factor, which is overlooked. This factor is the degree to which their child suffers, as the old maxim, supported in an article by Fingerman and colleagues (2011), that "you're only as happy as your least happy child" (p. 184). Parents who see their child with autism hurt themselves in times of frustration, whether it is by banging their heads against the wall, chewing their fingers, or sinking in deep depression, are often overwhelmed with helplessness and worries and might be left solely with the need to accept the fact that their child suffers. Within the participants of this study, this issue was raised by several families, emphasizing the direct connection between the child's ability to manage himself and the level of calmness of the parents, in other words – the level of stress they endure. It is our obligation as a society to care for those in need, guiding us to deeply understand the nuances of the effects of autism, both on people with autism and on their families, and provide appropriate support. It is our professional obligation, as therapists who specialize in working with families of children with autism, to construct treatment models to answer the special needs they present, and strive to provide the essential help mechanism.

9.2 OUTCOME 2: QUALITY OF LIFE

There were three hypotheses related to the parents' perception of their quality of life:

Hypothesis 2: *Participants will report improvement in their quality of life perception*

Hypothesis 3: *Participants participating in maximal MOPC will report (reduced stress and) improved quality of life perception than participants participating in the minimal MOPC*

Hypothesis 4: *Participants whose their children received MT sessions will report (more reduced stress and) a higher improvement in quality of life perception than participants whose their children did not receive MT sessions.*

Investigating change in quality of life was relevant to this study, as autism is considered to be affecting the quality of life of the person and his family (Cooke, 2013; Pozo et al., 2014). In addition, investigating change in quality of life using the *QoL-VAS* was integrated within the design of the TIME-A study, meaning that parents were already asked to complete these graphs at two time points. It was not a burdening supplement to their required reports. Two data sets were used to address these hypotheses: numerical data from a standardized measure (*QoL-VAS*) and descriptive data from an interview with the parents of 13 children with autism at the end of the intervention

phase. The three hypotheses drew on both data sources in order to potentially validate and clarify each of the data. A comparison of the mixed methods was presented in Chapter 8.

The *QoL-VAS* was adapted from EuroQoL Group (1990). The parents were asked to mark two points on a line ranged from 0 to 100. The first point scored their perception of their child's QoL and the other point scored their perception of their own QoL. The scores were taken at two time points: at baseline and at the end of the intervention. These scores provided information regarding any changes in the parents' perception of their and their child's quality of life.

There were statistically significant effect ($p = .011$) in the *QoL-VAS* of the children that participated in music therapy sessions (Table 15). The child's *QoL-VAS* had the highest effect size ($d = 4.53$) and could be considered as a proximal measure to the counseling-treatment approach. In addition, there was a strong correlation ($r = .69$) between the changes in *QoL-VAS* of the children, as perceived by the parents, among families whom their children participated in music therapy sessions. These results are compatible with the findings of the most recent Cochrane review that emphasize the beneficial effect of music therapy on communication and social skills of young children with ASD (Geretsegger et al., 2014). It may be assumed that parents within the current study might have interpreted these improvements in their children's communication and social skills as a better QoL for them.

Parents' also recorded improvements in their own QoL after participating in MOPC as measured by the *QoL-VAS* of the parents, with mean change score of 9.79 (Table 15). An improvement close to 10-points on a scale from 0 to 100 that measures stress is an important difference, indicating that a positive change in the parents' perception of their quality of life was achieved. It also suggests that a positive change might be achieved in a period of 5-month MOPC. Examining the scores within the groups identifies that the maximal MOPC *with* music therapy group recorded improvements with mean change score of 13.33. Given the use of both MOPC for the parents and music therapy sessions for the child within this group, it may be that this change indicates that a quality counseling and music therapy was given. However, the results for the parents' *QoL-VAS* were not significant even though they did not revert to baseline levels at the end of the 5 months of counseling. One way to analyze the benefit of the intervention is to look at the effect sizes for the numerical data.

A large effect size ($d = 2.42$) was found for the *QoL-VAS* for the parents, assessing changes in their QoL perception after participating in MOPC. This means that 4 out of 7 of the parents that participated in maximal MOPC perceived their QoL as improved. Both the children's *QoL-VAS* and the parents' *QoL-VAS* could be considered as a

proximal measure of the counseling and the music therapy treatment approach. That is, the MOPC as an accompaniment to music therapy for the children targeted increased both the parents' and the children's QoL.

The complexity of evaluating quality of life was highlighted in this study even though a variety of data was collected. The concept of quality of life is interpreted differently among different people. Prior to asking the parents to describe any change that might have occurred in their QoL perception after participating in the study, I invited each participant to define what quality of life means to them using their own words. This might have helped the participants to acknowledge their own personal view of this term before answering the question about any changes they might have experienced.

The English Dictionary definition for Quality of life is: "The general well-being of a person or society, defined in terms of health and happiness, rather than wealth" (<http://www.collinsdictionary.com/dictionary/english/quality-of-life>)

Looking at the participants' personal definitions of the term *quality of life*, there was not one definition that stood out, but several perspectives were high lightened by the parents, which combined the *parents' definition for QoL*.

Four participants connected good quality of life with the whole perspective of life:

- Participant A (mother): "QoL is the ability to see the whole picture and address everyone's needs"
- Participant B (mother): "QoL is when the overall moments of happiness exceed the moments of anxiety"
- Participant G (mother): "QoL is happiness and the ability to handle this thing called 'life'
- Participant I (mother): "QoL is to have a reason to wake up in the morning, to do things you believe in, and to go to sleep peacefully"

Three participants talked about good health, good feeling, and enjoy life:

- Participant A (father): "QoL is about whether you enjoy life"
- Participant C (mother): "QoL is when you feel good about everything that you do – family, friends and work"
- Participant J (father): "QoL is good health of my family members, the time that you can spend for yourself and the time that you can spend with your family and friends"

These definitions can be seen as corresponding with the general definition, as they address health and happiness in a wide perspective.

The next participants' definitions focus on more specific aspects like maintaining routine, maintaining spontaneity, interacting with society, feeling less stressed, having less worries, having quiet, and feeling calm. These definitions seem to be connected with the specific needs of parents of children with ASD.

Two participants emphasized the connection between quality of life and maintaining daily routine:

Participant C (father): "QoL for me is when we maintain our family routine"

Participant B (father): "QoL is combined with routine and flowing with life"

Opposite to that, one participant emphasized the need for spontaneity:

Participant F (father): "QoL for me is when we can be more spontaneous"

The need to maintain a familiar routine is known as a means of creating a sense of stability and constancy and helping to manage anxiety in people with ASD. Therese Joliffe, who is an autistic person with a PhD for research into autism, wrote: *"Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights... Set routines, times, particular routes and rituals all help to get order into an unbearably chaotic life. Trying to keep everything the same reduces some of the terrible fear"* (Joliffe, 1992, p. 14). Parents of children with autism often need to respond to this need of maintaining an unchanged routine in order to provide their children with a safe and tension-free environment. This constant demand embeds a mark on the parents' lives, and these definitions of quality of life demonstrate the tension folded within this daily reality.

Three participants connected quality of life with the possibility of interacting with society:

Participant E (mother): "QoL is a functioning family, a family which interacts with society"

Participant F (mother): "QoL is to be able to go with him to public places without being afraid that he will fall apart"

Participant H (mother): "QoL for me is to be able to go outdoors without having to chase him, without apologizing for his behavior, without other people staring at us and feeling sorry for us"

Following the need for a constant environment and routine, going out to public places might be overwhelming and scary for children with ASD. When every other visit to the shopping mall, playground, supermarket, or any other public place might turn into fear and meltdown, followed by reactions from strangers, it is understandable that parents find this issue as harming their quality of life and wish to change that.

Four participants connected good quality of life with feeling less stressed, less worried, and freer to do things:

Participant D (mother): "Stress and QoL are linked together; QoL is when you don't have to limit yourself from doing things that you want to do"

Participant G (father): "QoL is the ability to do whatever you want whenever you want...no worries and no stress"

Participant K (mother): "QoL is about decreasing my worries, and to have more time alone with my husband"

Participant M (father): "Whenever you have fewer things to worry and be anxious about, and you have quiet"

Six participants talked about mental quiet and calmness as being connected with quality of life:

Participant I (father): "QoL is quiet, calmness, peaceful, to see the children develop, to have a family QoL"

Participant J (mother): "QoL is quiet in my head, without having to worry all the time about my son's future"

Participant K (father): "QoL is mental quiet, calmness"

Participant L (mother): "QoL is peaceful and calmness"

Participant L (father): "Peaceful, calmness and money to support this"

Participant M (mother): "QoL is quiet, and to be able to do things that make you feel good"

Summing up the parents' definitions to the term *quality of life* emphasize how the specific characteristics of the autism spectrum disorder color their daily life and the choices they need to make in different situations. Quality of life for parents of children with ASD is connected with level of stress, the degree of worry, and the functioning of the family as a whole. As described in Chapter 7, the participants' definition for QoL, as emerged from expressions that appear more than once, is:

"QoL is when happiness exceeds the worries, when quite is present, and when the whole family is safe and interacts with society".

The comparison of the mixed methods results (Chapter 8), which compared the *QoL-VAS* total change score and the themes from the parent interviews, *Learning Experience* and *Enabling Space*, offered partial support for both the quantitative and the qualitative analyses. The comparison of the mixed methods, which was done only for the mothers' responses (as explained in section 8.1) revealed highly congruent data for five out of thirteen mothers. Mothers with positive change scores on the *QoL-VAS* tended to describe the reasons for feeling an improved quality of life as a result of

gaining new understandings (*Learning Experience* theme) and - feeling safe to talk and reflect (*Enabling Space* theme) throughout the MOPC sessions.

Looking at the allocation of the groups, interesting points stand out. Four out of the 7 participants who attended maximal MOPC showed better scores at their *QoL-VAS* graphs, indicating improvement in their QoL perception. The interview statements of three of them support these scores, while discrepancy is shown for participant K, who stated in the interview that she experienced no change at her QoL perception.

Out of the six participants attending the minimal process of MOPC, five stated during the interviews that there was no change at their QoL perception as a result of participating in the sessions, while emphasizing that the low number of sessions prevented them from going into a deep process. One participant (B) described *changing parental attitude* as the outcome of their learning process through the sessions, and stated a feeling of a better QoL. The scores on their graphs, however, show a small deterioration – from 70 to 65.

According to these findings, it is appropriate to say that participants who attended minimal process of MOPC experienced no change in their QoL. Two of them show improvement at the *QoL-VAS* graphs, three of them show deterioration on their graphs, and only one remains with no change. The results from this comparison of the mixed methods offer support for the belief that quality of life of parents of children with ASD is influenced by the severity of the disorder, and that professional support and positive problem-focus, which for this group was minimal, contribute to coping strategies of parents of children with ASD (Pozo, Sarria & Brioso, 2013).

As for the QoL of the children, a significant correlation was seen between the change in *QoL-VAS* of children and their participation in music therapy sessions (Table 17). This stands in line with former studies in music therapy with children with autism, which show that improvisational music therapy contribute to improvement in communication skills (Brownell, 2002; Bunday, 1995; Farmer, 2003; Gold, Wigram & Elephant, 2006; Kim, 2009), expressing oneself (Gold, Wigram & Elephant, 2006), and engagement (Kim, 2009), which contribute to a better quality of life of children with ASD.

9.3 OUTCOME 3: MUSIC IN EVERYDAY LIFE

There were three hypotheses related to the change in the use of music in everyday life by the parents with their children:

- 5) *Participants will report a wider use of music in everyday life with their children*
- 6) *Participants participating in maximal MOPC will report a wider use of music in everyday life with children than participants attending minimal MOPC*
- 7) *Participants' children who received MT sessions within the study will report a wider use of music in everyday life than participants with children who did not receive MT sessions.*

Investigating the change in the daily use of music by the participants with their children with ASD was relevant to this study, as the use of music is a core feature of the MOPC. The main aims of the MOPC model were to develop awareness among the parents regarding the role that music takes in their children's lives, and to develop their use of music as a tool to facilitate communication and interaction with their children with ASD. In addition, previous studies pointed to the contribution of parents' daily use of music with their children to improving parent-child interaction (Chiang, 2008; Nicholson et al., 2008; Pasiali, 2004; Thompson, 2012). Two data sets were used to address these hypotheses: numerical data from a new measure (MEL) developed especially for this study and descriptive data from interviews with all the participating parents, at the end of the intervention phase. The three hypotheses drew on both data sources in order to potentially validate and clarify each of the data. A comparison of the mixed methods was presented in Chapter 8.

The MEL is an assessment tool developed especially for the current study, which its psychometric properties were confirmed with reliability to assess the use of music in everyday life by parents with their children with ASD in two scales: Music in Everyday Life-Joint Activities using Music (MEL-JAM) and Music in Everyday Life-Routine Activities using Music (MEL-RAM; Chapter 5). This 8-question self-report questionnaire was designed for clinical and research purposes. Clinically, this assessment provides information regarding the spontaneous use of music that parents do with their children. Aiming to work collaboratively with the parents, this information was highlighted during counseling sessions. It offered a space to raise the awareness of the impact of each of their musical activities on the child's engagement ability and on their interaction, and parents could reflect and share their experiences in using music with their children. The MEL data also provided information regarding what might still be missing in terms of musical interaction, allowing the parents to learn new musical techniques that might further improve their interaction with their children with ASD. This serves as a main goal of a therapeutic process of helping the

patient make a change that will improve his life and empower his capabilities. Research wise, this assessment provides two total scores indicating the level of joint musical activities and routine musical activities; these scores can be compared with later scores that result from a later assessment, indicating any change that might have happened because of the intervention.

The descriptive quantitative analysis showed significant change ($p = .02$) in the daily use of music in routine activities (MEL-RAM) by the participants with their children with the largest effect size of all the outcomes ($d = 4.02$; Table 15). This corresponds with hypothesis 5 that anticipated an extended use of music after participating in MOPC. In addition, there was a mean difference of 4.83 for the maximal MOPC group, and a strong correlation ($r = .68$) between the change in using music in routine activities (MEL-RAM) and the participation in maximal MOPC sessions (Table 16). This supports hypothesis 6, which anticipated the superiority of maximal MOPC compared with minimal MOPC on expanding the use of music in daily routine activities.

Parents of children within the experimental group (children who participated in music therapy sessions) recorded improvement in the use of music in joint activities (MEL-JAM), with mean change score of 1.29 (Table 15). For the participants of group 2, who received both the counseling and the music therapy sessions, the mean change score was 2.08. While the results were not significant, an increased use of music in joint activities was gained at the end of the five months of counseling and the treatment period. Furthermore, the MEL-JAM described a large effect size ($d = 2.35$) for families for whom their children participated in music therapy sessions within the study; this indicates that in families where the children participated in music therapy sessions, there was an increased use of music in joint activities, such as singing together and playing musical instruments together. These results are compatible with parents' reports in Thompson's study (2012), which stated they have used a variety of music activities independently during the week with their child, as a result of participating in her research. Singing was the most popular method, and also singing and instrument playing, improvising with the instruments, and listening to music together (Thompson, 2012, p. 191). However, data from the experimental group in the above study only was collected without a baseline, so a change in the use of music in everyday life could not be measured.

The parents' responses in the semi-structured interviews were unanimously in favor of the MOPC sessions as raising awareness and implementing music therapy-like techniques in daily life with their children. As opposed to numerically rating the items of the MEL, parents could describe any changes that might have occurred in their daily use of music, giving examples from daily situations and emphasizing aspects they

thought were relevant and important. The parents' statements regarding the change in their daily use of music appeared across the groups, and no difference was shown between the different allocations. This message was so homogeneous within the qualitative findings that it concluded as a central theme within the qualitative analysis. A further discussion of the theme *Music in Everyday Life* is given in section 9.3.

In the analysis of mixed data presented in Chapter 8, comparison was done between the qualitative data with the quantitative data of one sub-scale (the MEL-RAM), in order to simplify the investigation and reach a clear picture regarding the relationship between the two sets of data. This comparison revealed high congruent data for 8 out of 13 participants. In addition, two more participants (A and G) showed high congruency with the second sub-scale, as their increased use of music during joint activities (MEL-JAM) supports their statements in the interviews of using more music in the home environment. This points out that the majority of participants (10 out of the 13) were highly congruent between their statements of increasing the daily use of music and their scores on the sub-scales of the MEL. The results from this comparison of the mixed methods offer support for findings from previous studies in music therapy with children with ASD and their parents, which advocate the importance of sharing music therapy techniques with the parents, and supporting their learning process to implementing these techniques to foster parent-child interaction (Jonsdottir, 2008; Oldfield, 2006b; Thompson, 2012). Given that "musical experiences helpfully link music's world with the everyday world..." [and] "music helps by addressing our basic human needs – for recognition as persons, identity, and relationship..." (Ansdell, 2014, p. 295), the music-oriented parent counseling seems like an efficient form to foster interaction between parents and their children with autism.

The comparison also revealed discrepancies between the two sets of data for participants B, D, and I, which are quite confusing. During the interviews, these participants expressed that they had gained an awareness regarding the role of music and had implemented musical techniques during daily situations; yet their scores of the MEL's two sub-scales showed deterioration in their use of music. While the phrases *level of stress* and *quality of life* are abstract, and participants could interpret them in different ways, the phrase *music in everyday life* is more concrete in nature. It is either the participants used more singing, more playing musical instruments, listening more to music – or not. In this sense, it is difficult to explain these discrepancies as caused by the confusion of an abstract term. It could be, however, that the reason for these discrepancies lies in the fact that the MEL questionnaire asks the parents to score the use of music within the last week, while the interview asks of any change that might have occurred in their use of music after participating in the MOPC sessions.

9.4 IMPACT ON THE PARENTS' USE OF MUSIC IN EVERYDAY LIFE

One main aspect of this study was to examine any change that might occur in the parents' daily use of music after participating in MOPC process and parents were asked to address this aspect using the MEL assessment as well as during the interviews. Research question no. 2 focused on this aspect:

What is the influence of MOPC on the use of music in everyday life by the participants with their children?

Providing counseling for parents to benefit the therapeutic process of their child has been primarily described from two different viewpoints in the parent-counseling and parent-mediated intervention literature. First, supporting parents through counseling is seen as a means to empower the parents, so they could support their child through the complex disabilities they endure (Davis, 2000). Since a lifelong disorder, such as autism, colors the life of the child and the parents with different challenges and difficulties on a daily basis, it is agreed by most child-therapists that a good therapeutic process with the child requires a change in the home environment through cooperation with the parents (Hunsley & Lee, 2007; Shechtman, 2002). Second, parental mental health and child's improvement have been acknowledged as interrelated (Williams, 2010). In addition, it is acknowledged that impairments in the child's social communication skills negatively affect attachment (Rutgers et al., 2007) and the quality of the parent-child relationship (Rocha et al., 2007). When parent-child relationships fail to form attachment, it may constantly reawaken feelings of grief and loss for parents of children with disabilities (Barnett et al., 2003), and influence the parents' ability to respond sensitively to their children.

Parents in this study were encouraged to implement musical techniques to foster engagement and interaction with their children with ASD, and enhance their children's development. The outcomes suggest that MOPC inspired parents to change the way they responded to their children, not only in order to support their children in various daily situations, but also to receive relief from stress and gain a sense of competence. The qualitative data offered support not only for the *QRS-F*, but also for the QoL of the child and the parents and for the two MEL scales, which measured the expanding use of music by the parents with their children. The parents' descriptions of change in their level of stress and quality of life perception as caused by a *Learning Experience* within an *Enabling Space* are reflected in their judgment of their child's positive responses to their changed attitude which included music. Furthermore, the parents pointed out the direct connection between level of stress and quality of life, in which an improvement in one field leads to an improvement in the other. They stated that

experiencing the beneficial effect of implementing music-therapy-like techniques within parent-child interactions, developed a sense of capability, and positively influenced their level of stress and quality of life.

Musical activities used by parents in the home environment were previously reported, pointing out that many parents were singing with their young children (Custodero, Rebello Britto, & Brooks-Gunn, 2003). Some music therapy research describe a broad use of music in home environment by parents who participated in music therapy sessions with their children (Chiang, 2008; Nicholson et al., 2008; Pasiali, 2004, 2010). In a study by Thompson (2012), there was a first attempt to describe and quantify what parents do musically with their children, in between family-centered music therapy sessions. In this study, parents were asked to keep a record of the way they were using music with their children, and their reports showed they were using four methods: singing; singing and instrument playing; improvising with the instruments; and listening to music together. Out of these methods, singing and listening to music together were the most used activities during the treatment phase, averaging approximately 89 minutes per week. Of these, singing was the best maintained at the 8 week follow up, with a slight drop to 84 minutes per week on average. While the results indicate that parents used music actively with their children in the home environment during family-centered music therapy process, this study did not collect any data in baseline, as Thompson herself points out (2012; p. 192), meaning that it cannot be inferred whether parents used more music as a result of their participation in family-centered music therapy sessions.

Within the current study, the MEL assessment was developed especially for measuring any change that might have occurred in the parents' use of music in everyday life. It was validated as a scale (Chapter 5) with two sub-scales: MEL-JAM, which focuses on joint activities using music (e.g. singing together, listening to music together, playing musical instruments together), and MEL-RAM, which focuses on using music during routine activities with the child (e.g. during bed time, while driving in the car, during transitions from one routine activity to another). Data showed that most parents increased their daily use of music, even the ones who participated in minimal MOPC. Analysis showed a significant change ($p = .02$) in using music for routine activities among parents who participated in maximal MOPC process, as mentioned broadly in Chapter 6. Moreover, the MEL-RAM showed the second highest effect size ($d = 4.02$; Table 15), and could be seen as a proximal measure to the MOPC approach.

These impacts on the use of music in everyday life in the home environment were supported by the parents' interview data. Parents reported changes in their use of music, emphasizing the change in the ways they responded to their child. Most important was to see how parents commented on the active ways they had

implemented music techniques, after seeing how their children responded to them. Looking back at the parents' statements during the interviews, it is interesting to see the different ways parents used music with their children. Some of them picked up using music as a tool while others referred to use music to have fun with their children. Connecting this data with the quantitative data, using music as a tool seems to be connected more with the MEL-RAM subscale, where parents used music for routine specific purposes, such as: during bed time, helping the child calm down, or helping the child make transitions from one activity to another. On the other hand, using music for fun seems to be connected more with the MEL-JAM subscale. Within these musical activities (singing songs together, listening and dancing to music, or making up funny songs), parents used music during engagement with their children with no concrete purpose other than to enjoy being together.

Parents also commented on how central music was within the MOPC model of work strengthened by the MEL assessment. During the parents' sessions, the parents' answers to the MEL questionnaire were addressed, regarding the spontaneous and more *natural* ways that the parents used music in their daily lives. The qualitative data of the MEL helped me to understand the role of music in the parents' own lives and in their child's life. The parents were invited to expand on these issues and reflect on them. During the interviews, some parents described their strong connection to music, whether it was by listening to music during major periods of their lives, or by describing their love for singing by themselves or as a part of choirs. For some parents it was a painful reminder of how little they listened to music or sang since their child was diagnosed, and how emotional it was for them to return to using music and seeing their child respond so positively to them. There is support from the music therapy literature of the importance of providing activities that both the child with disabilities and their play partner enjoy (Allgood, 2005; Alvin, 1978; Chiang, 2008; Holck, 2004; Kern & Aldridge, 2006; Müller & Warwick, 1993).

The centrality of music within the model is reflected also by the amount of statements that parents stated during the interviews, assembled into a theme labeled with the same name as the assessment – *Music in Everyday Life*. The theme is combined with four different aspects, emphasizing the parents' perspectives on using music in everyday life (Figure 6). Most parents perceived the use of music as the core feature of the whole counseling experience, raising their awareness to the role of music in their child's life and to the different characteristics of music as a mean to help in daily situations, and as an engagement facilitator. The interviews data revealed that the parents applied what they felt was working for them and their child, rather than copying musical techniques that I described during parents' sessions. Working collaboratively with the parents meant that I did not teach specific techniques for the parents to use in the home environment, but rather encouraged them to experience what works for them in daily

situations. These outcomes indicate that a collaborative, respectful, and gentle approach well suits families of children with complex needs and can be successful.

One of the stronger themes that emerged from analyzing the interviews was how three sessions are not enough in order to experience learning and change. Some mutual elements appeared across groups: gaining new points of view, receiving specific tools, and gaining better understanding of the child's needs. However, only the parents of the Maximal MOPC process described a change at their parental attitude, which helped them to implement music techniques that affected a change at their child's engagement and communication ability. Interested in the mechanism of change, or in other words – finding out *what works* and how change is occurring in working collaboratively in music therapy with parents, it seems that the process of change taken place in the participants of this study is combined with five steps, described in Figure 9:

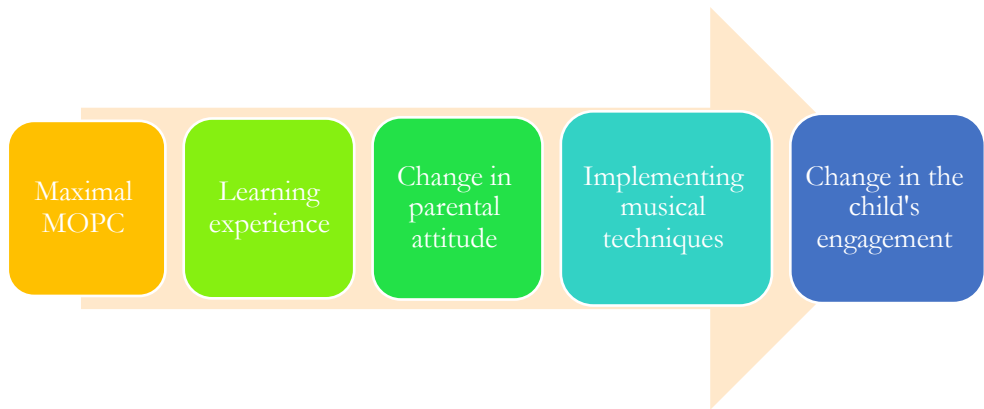


Figure 9 The mechanism of change in the use of music in everyday life by parents as a result of participating in Music-Oriented Parent Counseling

Looking at the MEL data and the descriptive data from the interviews shows that MOPC had a positive impact on the home environment. The assessment's data showed that parents did use more music in daily activities during the week, in a way that was attuned to their child. Following Stern's approach (1985), several processes might take place in order for affective attunement to occur. First, the parent should be able to read the child's behavior and interpret the child's feeling state. Second, the parent should perform some kind of behavior, which represents intention and not just imitation, to correspond with the child's behavior. Third, the child should be able to read this responding behavior of the parents as corresponding with his own original

feeling experience (1985; p. 139). The parents in the current study emphasized that they have used music in a way that corresponds with how they have understood their children's behavior, and continued to use music respectively with their children's responses and engagement. The descriptive data support this and provide evidence that the MOPC succeeded in promoting each parent to use music therapy-like techniques, as they felt suited and comfortable with. This data is an important step in reporting how parents use music methods in home environment without the music therapist's presence. The research design supported these outcomes, as baseline data were established by gathering information regarding the parents' use of music in everyday life before participating in the trial. The data gathered after 5 months provided the information regarding the increased use of music by parents with their children after participating in MOPC experience. The data gathered from the interviews emphasized that all the participants in the study increased their daily use of music with their children, especially after experiencing how motivating music was to their children. However, the participants who attended the maximal form of MOPC reported a deeper change process, which led to a change in their parental attitude that was followed by a change in their children's responsive ability (Figure 9).

One important aspect of the parents' ability to cope with the daily challenges is connected with the resolution with their child's diagnosis. Resolution with the diagnosis of one's child involves coming to terms with and accepting the diagnosis and its implications (Milshtein et al., 2010). In their study, Milshtein and colleagues investigated resolution rates of parents of 61 children with autism aged 2-17 years old. Nearly half of the parents were classified as being resolved with their child's diagnosis, meaning, among other things, that their expectations of their children were expressed respectively to their children's abilities, and they could cope better with daily challenges. Occasionally, I reflected on whether time is a factor for the parents' resolution process, and whether parents who live for many years with their child's diagnosis cope better than parents who only recently received the diagnosis. Therefore, it was interesting to see the finding within the above study, which suggests that resolution status is not associated with the duration of time that elapsed since the child was diagnosed. However, this does not inform us about whether parents' resolution status is stable throughout the years or not, and about possible mechanisms of change in resolution status. Milshtein and colleagues (2010) recommend that future studies explore the influence of different mechanisms of change on the resolution status of parents of children with autism. Although resolution level was not explored in the current study, reflecting on the mechanism of change described in Figure 9 suggests the influence of the MOPC on this aspect.

9.5 NEW UNDERSTANDINGS: MUSIC-ORIENTED PARENT COUNSELING

Working for 10 years in special kindergartens for children with autism in Israel that work collaboratively with families, enabled me to practice a parallel model of work, in which the music therapist works separately but simultaneously with the child and his/her parents. The view of these kindergarten teams was that the child's needs are seen in the perspective of the parent-child relationship, and parents are perceived as the most important figures within the child's development. Therefore, these teams advocated for supporting the parents through ongoing counseling sessions, held by the same music therapist who treats their child and knows him intimately. I continued to work within this setting in my private practice, developing and adjusting the parents' sessions to include and focus upon music and its special characteristics of communication and relationships. Conducting this research made me aware of the wide context and unique aspects of what I have practiced for years, mostly enabled me to reflect on what parallel treatment means, and what is the role of music, when working collaboratively with families of children with ASD.

A successful parallel treatment⁸ exists as an extension of the process of individual treatment, integrated with concepts formulated by learning theory, developmental psychology, and attachment theory (Chazan, 2003, p. 4). While arguing against the dyadic approach of treatment, where both the parent and the child participate as active partners within the same session, Chazan emphasizes that the focus of treatment within the parallel treatment model is on the internal representational world of each of the partners. Thus, transactions between partners emerge over time within individual sessions with the therapist (Chazan, 2003, p.5). Chazan continues by describing the therapist, as standing in the midpoint between parent and child, never loses contact with either member of the dyad, and empathically relates to their individual issues. She continues by saying: "...Reciprocally, each partner engages in treatment with the same therapist. The therapist thus provides both continuity and integration for the many qualitatively diverse experiences that make up the shared reality of the parent-child dyad" (2003; p. 5). Although I do not conduct psychoanalysis, but rather lean on developmental theories and attachment theories, my work focuses on the influences of the autism disorder on the child's internalized world, which significantly affects parent-child interaction (as described extensively in section 2.1). Being able to establish a parallel framework, maintaining the sensitive 'dance' between both the child's and the parents' needs, forms a good basis for a collaborative relationship with the parents.

⁸ In the context of this study, *parallel treatment* refers to parental counseling parallel to treatment for the child; the parents received counseling rather than treatment.

Within this study, I had the opportunity to investigate an unfamiliar condition, in which parent-counseling sessions were conducted with parents whose children I did not treat (parents whose children were allocated to *no music therapy sessions*). As a researcher, this condition raised much curiosity concerning the results of these two groups. The results of the quantitative analysis showed that the level of stress improved by nine points for participant I and by two points for participants K.. Participants I and K's QoL perception improved by 10 points. In addition, level of stress improved by three points for participant H and quality of life perception improved by 15 points for participant L. The descriptive data from the interviews described feelings of *no change*, mainly because parents felt they had received only a few sessions and could not experience a process of change. As for the use of music in everyday life, results showed that all parents, with no regard to group allocation, increased their use of music in everyday life. The use of music during the parents' sessions within the MOPC model is expressed in two main ways parallel to each other. In one way, music was used as an expressive way to experience feelings and thoughts during the parents' sessions, allowing the parents to explore those with a nonverbal language. The second and parallel one was sharing musical techniques with the parents, which have been used in music therapy sessions with their child, and showing effectiveness regarding the child's responsiveness. These two ways of experiencing music within the MOPC model complement each other, where the learning level complements the more emotional-experience level. The MEL was used for collecting information regarding the daily use of music in the home environment, and the parents' answers were addressed during counseling sessions, specifically adapted to each family. The study shows that in some cases, working only with the parents and not with the child can provide a certain degree of support and even change. Participating in MOPC sessions enabled the parents to increase awareness and knowledge, and empowered them. This is not to say that parent counseling within a musical orientation can replace music therapy process with the child, nor do I recommend working this way; however, it is shown that in certain circumstances this might work and provide a needed answer to some of the challenges that parents of children with autism cope with.

Although empowerment was not an outcome measure in this study, I will shortly address this term, as the participating parents have pointed out that they felt empowered by the MOPC experience. Within the context of this study, empowerment is perceived as a process of transition from a state of powerlessness to a state of relative control over one's life, destiny, and environment (Sadan, 1997, p. 20). Laschinger and colleagues (2010) identified components of Kanter's (1979) theory of empowerment within nurses and patients' behaviors (p. 9). Following their description, a similar identification might be used also within the current study, in the perspective

of the counseling process. Table 25 summarizes the behaviors of a professional to empower parents.

Table 25 Parents' empowering behaviors

<i>Component of Kanter's theory</i>	<i>Example of parent-empowering counselor behaviors</i>
Access to information	Share relevant information coupled in clear answers to parent questions. Share information regarding the physical and emotional effect of music. Share information regarding evidence-based practice in music therapy with children with ASD.
Access to support	Ascertain how parent beliefs, thoughts and feelings might affect their efforts. Ask what parents need to obtain from their interactions with health care providers. Describe your caregiver role and support parents'right to be the decision-maker. Respect parent choices. Provide a supportive environment by assuming a partnership approach.
Access to resources	Facilitate access to counseling resource. Help parents identify their own resources, self-care abilities and internal strengths.
Access to opportunities to learn and grow	Provide learning opportunities at an appropriate level (jargon free). Provide scenarios to create opportunities to practice new skills.
Informal power	Establish partnerships with families. Promote strong alliances between parents and the counselor. Work with parents to identify strategies for developing supportive alliances. View parents as important allies in the change producing process.
Formal power	Negotiate a mutually agreeable goals. Encourage parents to make decisions about care for their children.

Acknowledge that there is more than one way to accomplish mutually defined goals.

Note: adapted from Laschinger et al., (2010), p. 9.

Sharing certain insights and understandings that were gathered in therapy room with the parents are essential for the well-being of the child and the whole family. Furthermore, experiencing nonverbal musical communication with the children as overcoming barriers and creating an understandable frame of communication for the children encourages me to offer experiences like these to parents, making music, and reflecting upon music during parents' sessions. Through these musical experiences, parents are encouraged to learn and adopt different ways of using music in their daily interaction with their child with autism, as they see fit. By developing a dialogue with the parents, their spontaneous relation to music, as well as their different ways of using music tailors the framework with each family. Results from the two methods indicated that integrating music therapy techniques within counseling sessions promoted the child's treatment process, and enables the following: 1) a deeper understanding for parents of their child's musical therapeutic experience by active participation in musical activities during the parents' sessions; 2) improving the parents' ability to reflect upon their own feelings by experiencing their music together with the therapist; 3) reinforcing the parents' empathic abilities towards their child by using musical expressions, which overcome barriers and difficulties; and 4) learning new techniques to improve interaction with their child, especially in situations of frustration, stress, and lack of regulation, but also for fun and enjoyment.

To sum-up this perspective, the study emphasized the benefits of one music therapist working parallel with both the child and the parents. This setting resonates also with the DIR[®] model, where one therapist support parents to support their children with autism (Greenspan & Wieder, 1988). A recent study, which employed a DIR[®] based intervention, emphasized the benefits of providing counseling and modeling for parents to increase interactional behaviors for both the children and their mothers (Solomon et al., 2014). At the same time, it is important for therapists who work in a parallel setting to acknowledge the unique challenges hidden within this setting. Nilsson (2006) refers to the therapist's ability to relate to the child and the parents to ensure and establish a secure therapeutic alliance (p. 206). He supports the use of a parallel setting with families of children with autism, as it may provide tools for parents to better understand their children's emotional expressions, which are difficult to interpret (p. 215). However, Nilsson emphasizes the need for therapists to examine their motives. What are the actual reasons for working this way and with whom does the therapist identify: the child, the parents, or both? Nilsson (2006) encourages therapists who are working in parallel settings to discuss these cases with a colleague,

to ensure that no coalition is developing between them and one side of the equation. When a case depends solely on one therapist, it increases its vulnerability, and places great demands on the therapist's containing capability and competence. On the other hand, if done properly, it offers both the child and the parents an opportunity to experience themselves in a secure alliance with a therapist who is intimately familiar with the uniqueness of the family and responds to the different needs of the family members (Nilsson, 2006, p. 224). During the interviews, parents in the current study acknowledged the strength that dwells in the parallel setting of the MOPC, emphasizing their readiness to engage with a therapist that has an intimate acquaintance with their child. Furthermore, parents have stated that this setting enabled them to open up more easily, and enhanced their ability to trust the researcher.

An understanding of ecological family systems theory, which opines that events that affect the family will also affect the child, were expressed in Dunst and colleagues book (1988). Informed by the ecological system model of Bronfenbrenner (1975), these authors encouraged professionals working in the field of early child intervention to work collaboratively with families, and abandon the expert model. Similar to the family-centered music therapy model, as described in Thompson's study (2012), the MOPC model is concerned with *how* the therapy is delivered, rather than *what* is the aim of therapy (Moore, 2009). This study's messages are twofold: a) sharing with parents our knowledge about music as a beneficial tool in communicating with young children with ASD and encouraging a learning experience to foster interaction within home environment, and b) collaborating with the parents in a sensitive and attuned way, in order to enable a deep and adapted understanding and implementation. We should abandon the expert position, in which we hold the insights in our possession and give recommendations to the parents, but rather cooperate with each family and tailor the course action to their specific needs and capabilities. Undertaking this study enabled me to widely investigate the characteristics of the way of work, and reach the deep meaning of the basis of thinking, responding, and reacting. The counseling guide which was developed (Appendix F) specified the *why*, *how* and *when* aspects, giving a working frame, which needed to be implemented flexibly and respectively to each family.

Music-Oriented Counseling for Parents of children with ASD: Basic Concepts

Undertaking this study deepened and affected the understanding of the model of work, as specified in the MOPC Guide. The guide describes the settings, basic goals, and basic principles (Appendix F). I will now elaborate on some of the main characteristics:

The music therapist-counselor should:

1. Use music and music-therapy techniques during the parents' sessions respectively to the parents' wishes and capability to engage musically.
2. Develop a collaborative partnership with the parents.
3. Conduct the sessions with great sensitivity and respect for the parents' preferences, personal pace, strengths, and weaknesses.
4. Have experience in working with children with autism and their parents.
5. Use insights from therapy room in order to emphasize certain issues regarding the child's ways of experiencing in music and in relation to the therapist.
6. Be familiar with the main parents' coping needs resulting of their child's diagnosis.
7. Create a safe space for parents to reflect and contemplate on their child's situation as well as their own.
8. Encourage open discussions with the parents, allowing them an opportunity to engage in finding the right musical techniques for them.

9.6 NEW UNDERSTANDINGS: MUSIC THERAPY RESEARCH DESIGN

Over the course of conducting this study, I related to the words of many excellent researchers in music therapy and in the social sciences. The challenges in conducting mixed methods studies and reporting mixed results are enormous; yet, the conclusions might form and deepen an essential understanding of music therapy practice. Conducting a mixed methods study on a collaborative approach with parents adds more complexity, as the individually tailored music therapy and counseling practice and the emergent process of each participant by nature resist specifications. The mixed methods nature of this study was informed by the research questions that focused on both the effectiveness and the experience of a certain music therapy approach. In the words of Wigram, Pedersen, and Bonde (2002): "When determining the paradigm that is most appropriate, it is far more relevant to establish the focus of the research question first, before deciding on an appropriate research method" (p. 225). In addition, from a pragmatic point of view, mixed methods design provides the opportunity to combine descriptive statistics with phenomenological descriptions (Creswell & Plano Clark, 2011).

The quantitative part of this study was conducted as a Randomized Controlled Trial (RCT). While an RCT is accepted as the gold standard research design for evaluating the effectiveness of healthcare interventions, it has been criticized for not being able to capture the essence of the treatment process (Bradt, 2012). Being in an era that

encourages an evidence-based practice approach, especially for funding purposes and government support, RCT studies seem to answer this requirement. When trying to investigate *what works* for a specific population, RCTs can provide the answer. Yet, mixed reactions were expressed within the music therapy community for using RCTs; while some music therapists advocate for more effectiveness studies in order to protect and establish our profession, others have rejected it, trying to avoid our profession from being dominated by biomedical hierarchical model (Rolvstjord, Gold, & Stige, 2005). The results were presented in Chapter 6 for the parents as well as for the children, complimenting the parallel-treatment approach, observing the two parallel paths, and acknowledging the mutual influence on each other.

The qualitative part of this study was conducted as semi-structured interviews. In looking for an analyzing approach that focused on the research questions and desirable outcomes, thematic analysis seemed like the appropriate method to adopt. Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within data (Braun & Clarke, 2006, p. 79). The advantages of focusing on the research questions are clearly the possibility of receiving the answers that the researcher looks for, without being flooded with an enormous amount of data. On the other hand, the disadvantage of focusing on the research questions might be that I have prompted the parents and in a certain way, shifted their answers to address my specific goals. This was monitored by a reflexive approach, which enabled me to be aware of this danger and strive for authenticity and honesty.

One of the main challenges in conducting mixed methods studies is comparing quantitative findings with qualitative findings. Often the qualitative findings bring something different from what the researcher aimed for (L.O Bonde, personal communication, April 2015). In addition, a great challenge lies in reporting mixed methods studies; do you first present the quantitative results and then the qualitative findings? Moreover, how do they go together? Creswell and Plano Clark (2011) list three main strategies to compare quantitative and qualitative analyses and merge the results from the two sets of data. The authors pointed out a side-by-side comparison for merged data analysis as the most popular technique in today's mixed methods studies (p. 223). It involves presenting the quantitative results and the qualitative findings in a discussion or a separate chapter so they can be easily compared. The comparison then becomes the means for conveying the merged results. In Chapter 8, I have first presented the quantitative results, followed by the qualitative findings in the form of quotes. I then commented whether the qualitative quotes confirmed or contradicted the quantitative results, as recommended by Creswell and Plano Clark (2011, p. 223).

Mixed methods research design may provide varied perspectives on outcomes and experiences. Interviews provide an opportunity for an in-depth exploration on the meaning of a concept, while a questionnaire is often a de-contextualized form of dealing with a concept by ticking boxes (Meeto & Temple, 2003, p.8). Nevertheless, researchers are debating in regards to the philosophical validity of mixed methods, due to the tension inherent within the traditional quantitative and qualitative perspectives of research (Biesta, 2010). Johnson and Onwuegbuzie (2004) provided an innovative view on mixed methods, naming it "the third paradigm whose time has come" (p.15). They consider their philosophical view as *pragmatism*, a concept that provides a logical and practical alternative for the ongoing debate on paradigms. At the beginning of my study, I was concerned with whether the qualitative analysis could be combined with the results from the RCT design, and whether the quantitative results could strengthen the data regarding the experience of the participants. Now, I consider that the qualitative data provided a deeper understanding to the study, and the quantitative data shed a light on *what works* in music therapy with parents.

Implications of the findings

The findings from this study can be implemented by parents as well as by music therapists. The following sections describe the implications for each group, concluding with a conclusion part integrated by the discussions.

For the parents

MOPC was a feasible and applicable form of work for the parents. Parents indicated in the interviews that they valued participating in the sessions, and missed sessions only due to illness. Parents practiced methods of music therapy during the sessions, whether these were by listening to music and discussing its meaning, or whether by improvising with me and reflecting upon the emotional experience that followed it. Parents reported how they had experienced an increased awareness to the role of music in their lives and in the lives of their children and how they have adopted certain musical activities for everyday life in several daily situations. Parents emphasized that the use of music became a common practice for them as they witnessed how engaged and responsive their children were to them when they used music.

Parenting young children with ASD requires a considerable effort to understand the child's intentions, desires, and wills, especially among children who present delayed language. Many parents with whom I have worked with during the years, including the parents who participated in this study, have expressed their worries and frustration of

not being able to fully understand their children's message, and put much effort in supporting their verbal skills. However, parents in this study reported that after participating in MOPC they could identify and map their child's unique and specific musical expressions, which they could then understand and respond to in an attuned way. Furthermore, this study showed that going through a learning experience, adopting concrete musical tools, and implementing them in a home environment contributed to the parents feeling less stressed and more attuned to their children. The parents' growing awareness regarding non-verbal communication balanced their concern regarding any delays in verbal communication skills, and strengthened their confidence in their capabilities to interact with their children, understand, and be understood by them. For example: in the theme *Learning Experience* parents described the process of gaining knowledge and receiving a new point of view on their daily situation.

Participant E described, "It was the parents' sessions which gave me the most enlightening knowledge regarding my son's specific characteristics, and what is necessary for him." She continued by saying, "I never thought of L's situation this way; you offered a new point of view that resonated with me."

As parents put so much effort in supporting their children's communication, discovering ways to foster this is quite essential. This study showed that the MOPC offered concrete ideas and tools, some of which were musical and some related more to parental attitude, were extremely appreciated by the parents.

Participant D addressed the change she has experienced in her attitude towards music. "I never thought of music as a communication tool; it is truly an exciting discovery. I realized that music can be like a tool to help him engage better."

Participant F expressed it like this, "The sessions contributed to us by understanding how we can use music in order to get his attention and engagement. The sessions gave us tools on how to handle his tantrums as well as his willingness to play."

Participant M emphasized how the use of music improved their lives. "The most effective thing we received here was the knowledge of how to use music to improve our lives. The 'morning song' worked like magic; he gets organized quickly in the morning now, and the morning hours changed from struggle into fun family time."

Participant B described their child's responsiveness to their use of music as dramatic, changing completely their ways to interact with him. "Because we are used to behavioral treatment, we played with him only by the table, and most of the time he refused to come. Now, we invite him to play all around the house by singing to him, and he just runs to us!"

Summing up, there are several implications of MOPC for parents, such as: helping in organizing daily routine, interactive play, enhancement of attention and engagement, supportive learning experience, and fostering interaction.

Conclusions for parents

MOPC had a positive impact on the level of parental stress, quality of life perception and the use of music in everyday life. It was described by the parents as an approach that creates a safe, containing, non-judgmental place, and the process raised awareness and provided concrete musical tools, easily implemented during parent-child interactions. The literature emphasized that parents of children with ASD want to be able to work collaboratively with professional helpers that respect their parental views and form a trustworthy relationship with them (e.g. Attride-Stirling et al, 2001; Family Policy Alliance, 2005). In addition, it is emphasized in the literature that parent counseling approaches, which offer information and concrete tools for the parents, help in reducing parental stress (Davis, 2008; Kuloglu-Aksaz, 1994). Furthermore, literature show that music therapy techniques that are incorporated within parent-child interaction support the development of the children's communication skills and offer the parents an opportunity to engage through enjoyment and an attuned way (Oldfield, 2008; Thompson, 2012). This study showed that MOPC could provide a supporting learning experience for parents, and facilitate parent-child relationships using various music therapy techniques.

Within the last edition of the Diagnosis and Statistical Manual Disorders, Fifth Edition (*DSM5*; American Psychiatric Association, 2011) a new way of understanding the communication deficit among children with ASD is offered. The *DSM5* perceives the communication skills of children with ASD as a developmental process, rather than a separate existence. It encourages parents and caregivers to consider how they could foster the communicative behaviors of the children into creating a development in social interactions. This refers to capabilities of interacting on a non-verbal level, to maintain social-emotional reciprocity and interpersonal engagement. The outcomes from this study show that MOPC had a positive impact on parents' ability to engage and interact with their children with ASD. Using musical techniques that foster emotional attunement between the parent and child, the music therapist can respectfully work with families according to their strengths and interests.

For music therapists

Music therapy research in the field of families of children with autism continues to evolve, trying to provide answers to fundamental questions of *what works* and *how*. In

Israel, many music therapists conduct parent-counseling sessions as a part of a treatment program in special kindergartens for children with ASD. Often, the music therapists enter this challenge with limited training that is required for understanding the specific characteristics of parenting a child with autism, or a structured paradigm of how to work with parents within a music therapy perspective. While much focus in music therapy training programs is given to understand the child's needs and follow his lead in music therapy practice, little is invested in training the future music therapists on how to work with parents, even though they would certainly meet this need while working in the field.

The literature supports music therapists who treat children with ASD to incorporate parents and family members in the therapeutic process, whether it is by inviting parents to music therapy sessions with their child (Oldfield, 2008) or conducting music therapy sessions within the home environment (Thompson, 2012). The model presented in the current study is the first to describe and define a music-oriented counseling approach for parents of children with ASD.

The impacts that MOPC had on the parents' level of stress and their use of music during interaction with their children in this study might expand the ways we perceive music therapy for children with ASD and their parents. Rather than limiting our expectations to only supporting and developing the children's communication skills, it was emphasized that when parents undergo a learning experience, it led to a change in parental attitude. Furthermore, when parents experienced the children's positive response to their use of music, it lowered the parents' stress level and fostered attunement and engagement.

In contrast to research of parent-mediated models that focus on improving communication skills in children, this study focused on the parents' ways of understanding their children, and empowered the parents' active role in communicating with their children using music. MOPC sessions were perceived by the parents as motivating and collaborative, and offered a unique space for the parents to learn about themselves and about their child.

Methods in music therapy

The music therapy practice used in this study was combined of both improvisational and listening methods, implemented in an attuned way to each parent. Improvisational music therapy offers the opportunity to express feelings that are sometimes hidden or unconscious (Bruscia, 1987), and it is one of the most used techniques in working with children with ASD (Carpente, 2009; Kim et al., 2008, 2009; Oldfield, 2008). In this study, improvisational music therapy with the parents took place for two purposes: a)

to allow the parents to experience their feelings, and b) to practice improvisational techniques with me in order to implement them later in home environment. Not many parents agreed to act in active playing and musical improvisation, but those who were involved in improvising reported a deep emotional experience and practical learning process. Music listening is one of the most common music therapy coping strategies in several settings. While several authors describe music therapy listening as decreasing anxiety and pain in hospitalized children (e.g. Clark et al., 2006; Mitchell & MacDonald, 2006; Robb, 2000), others referred to listening to preferred music as increasing engagement and vitality in patients with dementia (Raglio et al., 2015). In this study, parents were invited to share musical materials that have a special meaning for them concerning their children with ASD. Some of the parents chose to share songs that they sing to their children, while others chose to listen to certain musical compositions that symbolized feelings and reflections they experienced. Using both methods enable the therapist and the client to share an emotional experience (Raglio, Traficante, & Oasi, 2011). This emotional experience reinforced intersubjectivity between the parents and the therapist and focused in the *here and now* (Stern, 2004).

Conclusions for music therapists

Many studies in music therapy for children with ASD evaluate changes in the child's behavior and skills during the music therapy process (For example: Geretsegger et al., 2014, Holck, 2004, Kim, 2009). In recent years, research in this field has expanded to evaluate these changes as affecting the parent-child interaction (Jonsdottir, 2008; Oldfield, 2008; Thompson, 2012), providing evidence to the role of the music therapist as a facilitator and a supportive figure. The current study contributes to this evolving approach. Yet, research in the field of ASD is focused on generalized outcomes and skills, where a lack of generalizability diminishes the value of the outcomes. Not many music therapy studies evaluated whether the participation in music therapy affects the general development of the child with ASD; this gap should become smaller when the results and conclusions of the TIME-A study are published.

This study contributes to our understanding of *what works* in music therapy with parents of children with ASD. Some of the understandings are similar to other interventions for parents of children with ASD, such as: helping parents to address core features of autism, such as socialization and communication (Aldred et al. 2004; Dawson et al. 2010; Green et al. 2010; Kasari et al. 2010; Oosterling et al. 2010); helping parents enhance their child's joint attention and play (Kasari et al., 2010); focusing on collaborating with parents within structured models (Greenspan, 1979; Gutstein et al., 2007) and a non-directive approach, allowing the parents to explore what is and is not helpful for their child (Aldred et al., 2004). Recognizing similarities of music therapy to other interventions is important, as it enables a discussion and

exchange of views within the broader research community. Therefore, findings from music therapy studies can assist the field of ASD research in general.

Alongside similarities between music therapy approaches to other interventions, certain aspects are unique to music therapy. Parents' and care-givers' statements within previous studies (Jonsdottir, 2008; Thompson, 2012) and within the current study point out the unique opportunity to engage in enjoyment through music therapy practice. Furthermore, the parents in this study emphasized the importance of going through a learning experience and adopting musical techniques as having a great impact on the way they have understood their children and interacted with them. Not only could they identify how well their children respond to music, they have also reported how well they felt when using music, and how they value the shared pleasure with their children with ASD. Music draws people together, enabling them to experience closeness and emotional attunement. The music therapist's craft is to respond sensitively and skillfully to the here-and-now situation, and to facilitate attunement with both the child and the parents, so they could experience it between themselves.

For clinical application, it is important to acknowledge that the working time frame of five months that was practiced in this study does not reflect real life. Regularly, whether within special kindergartens in Israel or in private practice, treatment occurs over a longer period, respectively to the families' needs. MOPC sessions continue parallel to the individual music therapy for the child, bridging between the child's treatment process and the parents' counseling process.

9.7 GENERALIZABILITY OF THE FINDINGS

Generalizability is concerned with the application of research results from a small number of people to a large number (Creswell, 2012, p. 14) and is often discussed in the light of opposite relations between internal and external validity, with improvement in one area often representing weaknesses in the other. Internal validity in this study was strengthened through the use of: a) development of a treatment guide (counseling guide); b) monitoring the parents not receiving music therapy services and counseling outside of the study; and c) the use of one music therapist to conduct all the sessions. However, while internal validity was strengthened by using only one music therapist, it also limited the generalizability of the findings.

External validity was strengthened through the recruitment of families from different cities around the center of the country. However, the small sample size limits the generalizability of the findings. No families of girls with ASD expressed an interest in the study, and therefore, only families of boys participated in the study. This does not

represent the 1 to 4 ratio of girls to boys expected in the general ASD population (Fombonne, 2009). In relation to ecological validity of the research design, or how this study reflected the real world (Robson, 2002), the outcomes of this study may be considered as highly generalized from this practical perspective. The MOPC sessions were designed to be conducted as close as possible to clinical reality, combining separate music therapy sessions for the children, and this, together with the standard care control, improved the applicability of the findings to counseling in music therapy practice. The ecological validity was strengthened further by using parent-report measures, as parents' opinions of the values of an intervention on their lives are essential in real-world contexts.

9.8 LIMITATIONS OF THE STUDY

Small sample size

During the initial stages of planning this study, there was an option of collaborating with a Youth Psychiatric Unit in one of the biggest hospitals, which confederates the diagnosis and treatment of children with autism in the south area of Israel. Unfortunately, the tremendous efforts made by the head of the unit and me to allow this collaboration were eventually not successful. Therefore, I had to locate and recruit families using advertisement in treatment centers in the area of my private practice, without having a list of eligible participants. This affected the possibility to recruit a large amount of participants.

In addition, during the course of the study it was decided that children who received music therapy three times a week within their kindergartens would be excluded from participating in the study. This was made in an effort to avoid their allocation to more music therapy sessions within the study in addition to the treatment they have been received already at the kindergarten. This clinical decision further narrowed the number of eligible participants.

Involvement in all stages of the study

This study received funding from the TIME-A international study, which investigated the effect of improvisational music therapy on the communication and interaction skills of young children with ASD (Geretsegger, 2012). The current study was designed as a niche within the TIME-A project, keeping a real-world study design. The funding covered mainly the psychologists' ADOS assessments that were highly relevant to the requirements of the TIME-A study, but less relevant to my own study,

which focused mainly on outcomes of the parents. This funding, together with the scholarship I received from Aalborg University, made this research possible. However, my involvement at all the different stages of the study raised the possibility for bias. As means to address this bias, I consulted regularly with my supervisors, as well as with fellow PhD candidates, the faculty in the Doctoral Program for Music Therapy at Aalborg University, other experienced researchers, and clinicians. These means, combined with a reflexive approach, helped me to stay focused on the parents and the children, just as I would do in clinical practice.

A real-world research

The wish to conduct the study as *real-world* research and keep it as close as possible to clinical reality, informed the choices I made in data collection. Empirical research on a collaborative style of work is challenging, mainly when standardized parents' reports are in use. From an empirical research design perspective, the parents were open to potential bias, as they were unable to be blind to the treatment condition of their children and of themselves. In order to address this limitation I used standardized parent-reports that had high test-retest reliability. Furthermore, I focused on the aspects I wanted to measure, without digressing from my initial plan, and without conducting repeated analysis of the results. In answering the intention to measure the daily use of music, with no standardized measure known for this purpose, a self-report for parents (MEL) was developed and approved as an assessment scale (Chapter 5).

The decision to conduct this study as a *real-world therapy process* put some limitations not only on the data collection, but also on the findings. It made good clinical sense that after a trustworthy relationship was established between the parents and me, it would be appropriate for me to conduct the interviews with the parents at the last counseling session. This should enable sharing information straight away, overcoming the need to form a comfortable and attuned relationship with a strange interviewer. This decision also freed the parents from having to tell their story multiple times. Before conducting the interviews, the four questions that combined the interview were defined (Appendix H), and the parents were told of the duration of the interview (1 hour). The clear guidelines, which can be seen as the administering protocol, reduced the potential for bias. In this way, the interviewer can apply the interviews with more consistency by following the protocol.

Conducting the interviews

From the perspective of human interaction, the limitations in the comparison of the results of the two data sets can be discussed also in the light of the relationship between the parents and the researcher. The interviews were held at the end of the

intervention period, after a relationship was formed between the parents and me during the counseling sessions, and trust was established between us. It was stated from the starting point, that I would interview parents at the last session, so by the time the interviews took place, I was no longer a stranger to them. Ethical issues in using interviews for research raise the asymmetrical power relations between the interviewer and respondents, where the researcher is usually positioned as the relatively more powerful side (Kvale & Brinkmann, 2009, p. 76). This can negatively influence the interviewees' ability to express their thoughts freely and openly. Given the collaborative nature of the counseling sessions, which was a core feature of the music-oriented parent-counseling model, this asymmetrical power relation might have been neutralized and parents seemed to feel contained and free to express their feelings in an honest way. This was seen also in the fidelity assessment of the MOPC Guide, which validates the collaborative nature of conducting the sessions, as described in section 6.3. Reviewing the inconsistency between the parents' scores on the *QRS-F* and their answers in the interviews in the light of the relationship between the parents and me, may raise a concern whether some parents' wished to satisfy me and provide me with the answers that they thought would please me, even if not reflecting accurately what they felt. Taking a reflexive position as a researcher (Stige, 2002), I was aware of the relationship between insider (emic) perspectives (as a partner of the collaborative sessions) and the outsider (etic) perspectives (as the researcher, investigating a phenomenon; Stige, 2002, p. 257). It is my belief that the relationship actually motivated the parents to speak openly and freely rather than speaking to a stranger. It is one ideal that researchers who conduct studies about human phenomenon – "...do not study people, but try to learn from them" (Stige, 2002, p. 259). This ideal communicates with the aspect of collaboration as a way to form and foster the relationship between the music therapist-counselor and the parents, which is a core feature of the MOPC.

In addition, an interview folds the factor of power, which exists between the interviewer and the interviewee. By definition of the setting, the interviewer seeks to collect the information that the interviewee holds (Nunkoosing, 2005). Power dynamics can affect interviewees that are asked to reveal private thoughts, exposing them to the danger of sharing under the pressure to please the interviewer. During the interviews in this study, parents were asked to reflect regarding sensitive daily situations that might have occurred between them and their child; this could have exposed their parenting attitude to criticism and judgment from me and from others. In order to neutralize the power factor in our relationships at the time that the interviews took place, parents were free to decide which information they choose to share and which information would not be shared, and by that owned the power (Nunkoosing, 2005). Working collaboratively with the parents, the interviews seemed

like a natural addition to our relationship. It was my impression that the parents did not face special difficulties in answering my questions, and were comfortable and relaxed, but there is always the risk that things were different from how I have perceived them.

Duration of the counseling and the music therapy

The counseling and the music therapy interventions lasted for 5 months, following the design of the TIME-A study. This duration does not represent what usually happens in clinical reality, where treatment and parallel parent counseling might last from 1 year to several years. Within a longer duration of collaboration with parents and treating the children, the therapeutic relationship and the established alliance usually enable more improvements to occur. Yet, when conducting an experimental RCT study, the duration of an intervention should be both sufficient to allow therapeutic process, but also not too long, in order to be feasible for the participants to complete their participation in the study.

Comparing mixed method data sets

The discrepancies in the comparative analysis of two outcome measures (level of stress and quality of life) highlight the complexities of evaluating fundamental and sensitive areas in people's lives, even when a variety of data is collected. Given that the perception of stress and quality of life is influenced by the subjective perception of each person, it might have affected the participants' answers to the standardized questionnaires. This could have been handled if I would have asked the participants to explain any discrepancy that was shown between their answers in the questionnaires and in the interviews. Their input might have shed a light into these mismatches, and provide the needed explanation for this issue.

9.9 EPILOGUE AND RECOMMENDATIONS FOR FUTURE RESEARCH

In trying to answer the question: *What is the influence of Music-Oriented Parent Counseling (MOPC) on the level of stress, quality of life perception, and the use of music in everyday life by parents of children with ASD*, the outcomes from this study point the positive influence on all three areas. Quality of life perception was found to be related to the level of stress, and the use of music in everyday life was found to be a source of reducing level of parental stress and increasing quality of life perception. Measures investigating

change in these three aspects provided evidences in favor of MOPC and music therapy. These outcomes will contribute to future understanding and defining the value of counseling within the frame of music therapy with parents.

MOPC was a feasible and applicable form of work for the parents. Local perspective was provided by the Israeli context, however future research is required. Mixed methods researchers have much to contribute to our understanding of the phenomenon of music therapy, combining RCTs investigating the effectiveness together with qualitative approaches inquiring the experience. Few studies focused exclusively on parents of children with ASD, and therefore little is known about their needs and the capacity for change. This study has shown that a reduction in parental stress level and an increase in quality of life perception can occur for parents of children with ASD, particularly through going through a learning process and adapting musical techniques to use in interaction with their children. Further research is required in order to evaluate whether parents' participation in various music therapy models impact their stress levels and ability to interact with their child with ASD.

Further research is needed to build knowledge on how to best support parents of children with ASD. While common characteristics in working with parents in music therapy can be identified in several studies worldwide, no succinct summary has been done yet. Future studies are needed to identify those common characteristics of music therapy with parents that are practiced internationally.

Given that most parents of children with autism, especially mothers, endure a significant amount of stress (Abbeduto et al. 2004; Duarte et al. 2005; Konstantareas & Papageorggiou 2006; Montes & Halterman 2007) and report of a poor quality of life (Bishop et al., 2007; Herring et al., 2006), further research investigating the impact of different interventions on reducing parental stress levels and improving quality of life would provide useful information to the professional community. Further studies with an intension to compare mixed data may be strengthened by using an explanatory design, where a further qualitative analysis could be used for explaining any discrepancies that might occur during comparison of the two data sets. Furthermore, it is highly recommended for future research that intend to compare mixed data in the way it has been done in this study to consider asking the participants to comment on any discrepancy, so that a better understanding of the divergence can be gained.

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דף מידע והסכמה למשתתפים במחקר קליני

ניסוי אקראי מבוקר (RCT)

**תרפיה במוסיקה והדרכת הורים
לילדים על הרצף האוטיסטי**



משתתפים יקרים,

אנו מזמינים אתכם ואת ילדכם/ילדתכם להשתתף במחקר הקליני שכותרתו מופיעה למעלה. תקבלו מידע מפורט לגבי המחקר והשתתפותכם האפשרית בדפים הבאים. **השתתפותכם במחקר זה הינה התנדבותית. אתם חופשיים להפסיק את השתתפותכם בכל זמן, ללא מתן הסבר. הפסקת השתתפותכם במחקר לא תהווה השפעה על התמיכה בכם ועל הטיפול שמקבל ילדכם/ילדתכם.**

הפרויקט המחקרי הוא בחסות המרכז למחקר בתרפיה במוסיקה, אקדמיית גריג, ברגן, נורווגיה (Grieg Academy Music Therapy Research Center, Bergen, Norway) עם פרופסור כריסטיאן גולד כמנהל המחקר. המחקר יתנהל בשבע מדינות: אוסטריה, אוסטרליה, ארצות הברית, ברזיל, נורבגיה, קוריאה וישראל.

(אתר המחקר - <http://helse.uni.no/default.aspx?site=48&lq=2>)

המחקר בישראל מנוהל ע"י דר' כוכבית אלפנט, ממרכז המחקר בבית הספר לטיפול באומנויות, אוניברסיטת חיפה. המחקר יתקיים בקליניקות רפואיות ובגני ילדים במרכז ובצפון הארץ, וביחידה לבריאות הנפש לילדים ונוער בבית החולים סורוקה בבאר שבע.

דר' כוכבית אלפנט הינה החוקרת האחראית הראשית. הגב' גוטפריד הינה מטפלת מוסמכת במוסיקה מאז שנת 1998, מוסמכת MA מאוניברסיטת בר-אילן (2009) והיא בעלת ניסיון רב שנים בטיפול בילדים על הרצף האוטיסטי ובהדרכה לבני משפחותיהם, הן בסקטור הציבורי והן בקליניקה הפרטית שלה. הגב' גוטפריד מרצה בתוכניות להתמחות באוטיזם באוניברסיטת בן-גוריון ובמכללת לוינסקי בנושא תרפיה במוסיקה ואוטיזם. מחקר

זה נעשה במסגרת לימודי הדוקטורט שלה בתוכנית לדוקטורט בתרפיה במוסיקה באוניברסיטת אולבורג בדנמרק. מחקרים קליניים הינם הכרחיים בשעה שמבקשים למצוא ממצאים מהימנים. נדרשת הסכמה בכתב של כל משתתף במחקר קליני שכזה. לצד הראיון שיערך עימכם, אנא קראו את המידע המופיע בדף זה ואל תהססו לשאול כל שאלה שמתעוררת בכם. אנא חתמו על טופס ההסכמה רק במידה ו:

- הבנתם במלואם את טבע המחקר וההליך שלו
- הינכם מסכימים להשתתף במחקר
- הינכם מודעים לזכויותיכם כמשתתפים במחקר קליני זה

מחקר זה ודף ההסבר וההסכמה הנ"ל אושרו ע"י ועדת האתיקה לניסויים בבני אדם, אוניברסיטת חיפה, מס' אישור – 13/031.

1. מהי מטרתו של מחקר קליני זה?

מטרת המחקר הקליני הנוכחי היא לבדוק את האפקטיביות של טיפול במוסיקה והדרכת הורים על שיפור ברמת מיומנויות התקשורת והאינטראקציה אצל הילדים, ובהפחתה של רמת המתח ההורי, שנגרם כתוצאה מהאבחנה של ילדם/ילדתם, והרחבת השימוש באמצעים מוסיקליים בחיי היומיום.

התפתחות מוקדמת של מיומנויות תקשורת יוצרת בסיס להתפתחות לשונית, ליכולת חברתית, וכן להתפתחות רגשית וקוגניטיבית. אצל ילדים על הרצף האוטיסטי נראים, לרוב, ליקויים במיומנויות אלה. קיימים מספר מחקרים ומאמרים קודמים, המבוססים על ניסיון קליני, המעידים כי אלתור בתרפיה במוסיקה עשוי לעזור לילדים על הרצף

האוטיסטי להביע רגשות ולחלוק אותם עם אחרים. למטרה זו, המטפל במוסיקה מגיב באופן מוסיקלי ומילולי להבעות מוסיקליות ו/או אחרות של הילד, ובכך יוצר סביבה מאפשרת לקיום אינטראקציות וחיבור בינאיש.

מטרה נוספת של המחקר היא להגדיר הנחיות מדויקות הן לתהליך הטיפולי בתרפיה במוסיקה והן לתהליך ההדרכה והתמיכה בהורים, מה שיכול לשפר את הנגישות של ילדים על הרצף האוטיסטי לשרותי תרפיה במוסיקה, ושל הוריהם לקבלת תמיכה ראויה. מכאן, שמסקנות המחקר הנוכחי יהיו בעלות ערך לא רק לגבי מחקרים עתידיים בתחום ההתערבות בטיפול בילדים על הרצף האוטיסטי, אלא גם למשפחות שלהם ילד עם בעיות תקשורת, המעוניינות בדרכים אפקטיביות ומעשיות לתמיכה בהתפתחות של ילדיהם.

2. מהם שלבי המחקר?

המחקר הקליני הנוכחי יתנהל בקליניקה לטיפול במוסיקה של טלי גוטפריד בכפר סבא, ובגני ילדים בירושלים, בהשתתפותם של כ-40 זוגות הורים ל-40 ילדים על

הרצף האוטיסטי. השתתפותכם במחקר קליני זה תימשך על פני חמישה חודשים. בנוסף, תיערך בדיקת מעקב שנה לאחר תחילת השתתפותכם בניסוי. ילדים בגילאי 4-7 המאובחנים על הרצף האוטיסטי יחולקו בצורה אקראית לאחת מתוך שלוש קבוצות. כל ההורים יקבלו פגישות הדרכת הורים. ההורים יחולקו בצורה אקראית לאחת מתוך שתי קבוצות – א) הורים שיקבלו שלוש פגישות הדרכת הורים במשך חמישה חודשים, ו- ב) הורים שיקבלו עשר פגישות של הדרכת הורים במשך חמישה חודשים. פגישת ההורים הראשונה תתקיים לפני תחילת המחקר (baseline) והאחרונה תתקיים בתום חמישה חודשים מרגע ההתחלה. פגישות ההדרכה ימשכו כשישים דקות. הפגישות יאפשרו הזדמנות לדון בנושאים שמעסיקים אתכם, קשיים ובעיות, הנובעים מהאתגרים, ההתנהגות וההתפתחות של ילדכם. הפגישות יספקו מידע לגבי אוטיזם, התפתחות של ילדים ונושאים רלוונטיים לחיי היומיום, האופייניים לכל משפחה, וכן תינתן אפשרות להביט בנושאים אלה מתוך ה"עיניים" הייחודיות של תרפיה במוסיקה.

בנוסף, ילדים שיחולקו באופן אקראי לאחת משתי קבוצות התרפיה במוסיקה, ישתתפו בטיפול פרטני במוסיקה למשך חמישה חודשים, אחת (תדירות נמוכה) או שלוש (תדירות גבוהה) פעמים בשבוע. תיעשה הכללה של ההשפעות של תרפיה במוסיקה ע"י מערך 'עיוור' (כלומר, שאינו יודע לאיזו קבוצה משויך הילד) בשימוש בכלי בקנה מידה סטנדרטי (ADOS = Autism Diagnostic Observation Schedule) וכן בשאלון הורים (SRS = Social Responsiveness Scale), בתחילת המחקר, אחרי חודשיים, חמישה חודשים ובתום 12 חודשים.

ילדים שיחולקו לקבוצת התרפיה במוסיקה ישתתפו בתהליך טיפולי פרטני. טיפול פרטני בתרפיה במוסיקה מאפשר לילד/ה להתנסות באינטראקציה מוסיקלית-משחקית עם המטפלת במוסיקה. התהליך מאפשר יצירה ספונטאנית של מוסיקה בין הילד/ה והמטפלת, כאשר המטפלת במוסיקה מאלתרת בכלי נגינה שונים עפ"י התגובות המשחקיות/מוסיקליות/רגשיות של הילד/ה. מכאן, שהמטפלת מאלתרת מוסיקה שיכולה לתמוך, ללוות ו/או להגביר את העשייה המוסיקלית של הילד/ה על מנת לעודד מערכת יחסים, אינטראקציה, תקשורת והדדיות. במהלך המפגשים צפוי כי הילד/ה יתנסה/תתנסה בכלים שונים, אף כי אין דרישה לידע קודם בנגינה. על בסיס המבנים המוסיקליים של הילד/ה תאלתר המטפלת במוסיקה בכלי נגינה שונים, על מנת להתאים, לתמוך, לדרבן, ולפתח את ההבעה המוסיקלית/רגשית של הילד/ה.

כל מפגשי התרפיה במוסיקה והדרכות ההורים יצולמו בווידיאו. הקלטות הווידיאו יישמשו למטרות המחקר בלבד, ויימחקו ארבע שנים ו-11 חודשים מתום המחקר. ילדכם/ילדתכם ישובץ/תשובץ באחת מהקבוצות הבאות – תרפיה במוסיקה בתדירות נמוכה; תרפיה במוסיקה בתדירות גבוהה; ללא תרפיה במוסיקה. אתם ההורים תשובצו באחת מהקבוצות הבאות – הדרכת הורים בתדירות נמוכה; הדרכת הורים בתדירות גבוהה.

מכאן, שאתם יכולים להיות שייכים לאחת מהקבוצות הבאות:

קבוצה 1 (תרפיה במוסיקה בתדירות נמוכה והדרכת הורים בתדירות נמוכה): כל ילד בקבוצה זו ישתתף במפגש תרפיה במוסיקה אחד בשבוע למשך 30 דק', והוריו ישתתפו בשלוש פגישות הדרכת הורים בנות 60 דק', למשך חמישה חודשים.

קבוצה 2 (תרפיה במוסיקה בתדירות נמוכה והדרכת הורים בתדירות גבוהה): כל ילד בקבוצה זו ישתתף במפגש תרפיה במוסיקה אחד בשבוע למשך 30 דק', והוריו ישתתפו בעשר פגישות הדרכת הורים (אחת לשבועיים) בנות 60 דק', למשך חמישה חודשים.

קבוצה 3 (תרפיה במוסיקה בתדירות גבוהה והדרכת הורים בתדירות נמוכה): כל ילד בקבוצה זו ישתתף בשלושה מפגשי תרפיה במוסיקה בשבוע, למשך 30 דק' כל מפגש, והוריו ישתתפו בשלוש פגישות הדרכת הורים בנות 60 דק', למשך חמישה חודשים.

קבוצה 4 (תרפיה במוסיקה בתדירות גבוהה והדרכת הורים בתדירות גבוהה): כל ילד בקבוצה זו ישתתף בשלוש מפגשי תרפיה במוסיקה בשבוע, בני 30 דק', והוריו ישתתפו בעשר פגישות הדרכת הורים בנות 60 דק', למשך חמישה חודשים.

קבוצה 5 (ללא תרפיה במוסיקה והדרכת הורים בתדירות נמוכה): ילדים בקבוצה זו לא יקבלו תרפיה במוסיקה; הוריהם ישתתפו בשלוש פגישות הדרכת הורים בנות 60 דק', למשך חמישה חודשים.

קבוצה 6 (ללא תרפיה במוסיקה והדרכת הורים בתדירות גבוהה): ילדים בקבוצה זו לא יקבלו תרפיה במוסיקה; הוריהם ישתתפו בעשר פגישות הדרכת הורים בנות 60 דק', למשך חמישה חודשים.

במהלך המחקר הקליני, יערכו ההערכות וההתערבויות הבאות:

בנקודת ההתחלה:

- **ADOS (Autistic Diagnostic Observation Schedule)** – זהו כלי תצפיתי, שבו הבודק מתקשר עם הילד באופן משחקי, תוך שהוא יוצר סיטואציות שונות של משחק ודיאלוג. כלי זה נותן מידע לגבי מיקומו/מיקומה של הילד/ה על גבי רצף האוטיזם.
- **ADI-R (Autism Diagnostic Interview-Revised)** – זהו ראיון מפורט, המיועד להורים של ילדים על הרצף האוטיסטי, לגבי תחומי התפתחות שונים של הילד/ה. הראיון יערך במועד החתימה על הסכם ההשתתפות במחקר.
- **SRS (Social Responsiveness Scale)** – זהו שאלון הורים, בו תתבקשו לענות על שאלות בתחומי החיים השונים של ילדכם/ילדתכם, התנהגות/ה ומיומנויות שונות שלו/שלה. תתבקשו למלא שאלון זה בביתכם, ולהחזירו לחוקרת תוך שבוע.
- **"שאלון מקורות תמיכה ודחק"** – זהו שאלון הורים, בו תתבקשו לענות על שאלות הנוגעות הן למקורות תמיכה והן למצבי לחץ איתם אתם מתמודדים בחיי היומיום. תתבקשו למלא שאלון זה בביתכם, ולהחזירו לחוקרת תוך שבועיים.

- **"שאלון מוסיקה בחיי היומיום"** – זהו שאלון שחובר ע"י החוקרת במיוחד למחקר זה, הבא לבדוק את השימוש היומיומי שאתם עושים במוסיקה במצבים שונים במהלך היום עם ילדכם/ילדתכם. תתבקשו למלא שאלון זה בביתכם, ולהחזירו לחוקרת תוך שבועיים.
- **גרף "איכות חיים"** – זהו גרף עליו תתבקשו לציין את רמת איכות החיים של ילדכם/ילדתכם ושל משפחתכם.

לאחר חודשיים:

- ADOS
- SRS

לאחר חמישה חודשים:

- ADOS
- SRS
- שאלון "מקורות תמיכה ודחק"
- גרף "איכות חיים"
- שאלון "מוסיקה בחיי היומיום"
- **ראיון הורים חצי-מובנה** – יועבר ע"י טלי גוטפריד, בפגישת ההורים האחרונה; הראיון יימשך כ- 90 דקות.

לאחר 12 חודשים:

- ADOS
- SRS

לשם קיום פגישות ההדרכה, פגישות התרפיה במוסיקה וההערכות תתבקשו להגיע לקליניקה לטיפול באמצעות מוסיקה של טלי גוטפריד ברח' העמק 8 בכפר סבא, בזמנים ידועים מראש. מספר הפעמים שתצטרכו להגיע יינתן לכם לאחר שיבוצכם בקבוצת המחקר. מפגשי התרפיה במוסיקה ופגישות הדרכת ההורים יינתנו ע"י טלי גוטפריד, שהינה בעלת ניסיון רב בטיפול במוסיקה בילדים על הרצף האוטיסטי ובליווי משפחותיהם, והינה החוקרת במחקר זה.

3. מהי התועלת הנגזרת מהשתתפות במחקר זה?

השתתפותכם במחקר קליני זה תאפשר לכם לקבל הערכות מקצועיות מקיפות לגבי רמת הלכות של הילד/ה ושלב הימצאותו/הימצאותה על הרצף האוטיסטי, וזאת ללא עלות כספית. ההערכות יינתנו ע"י אנשי צוות מיומנים ומוסמכים, בעלי ניסיון רב בתחום, אשר יעבירו לכם את תוצאות ההערכות בפגישה אישית. בפגישות הדרכת ההורים, אשר יינתנו אף הן ללא חיוב כספי, יתאפשר לכם לקבל מידע מפורט ועדכני לגבי לקויות שעל הרצף האוטיסטי וכן להתמקד בקשיים

הספציפיים בהם אתם נתקלים. בנוסף, יעלו הבנות מתוך חדר הטיפול במוסיקה ותיערך חשיבה לגבי שימוש בהן בחיי היומיום. במפגשי הטיפול במוסיקה, תינתן לילדכם/ילדתכם הזדמנות לעבוד על קשיים שנובעים מתוך ההפרעה האוטיסטית בסיוע פרטני, לדוגמה: הרחבת מיומנויות התקשורת של הילד/ה, פיתוח והעמקה בקשר בינאישי, פיתוח היצירתיות והגמישות המחשבתית שלו/שלה, ושיפור בביטחון העצמי שלו/שלה. במהלך ובתום השתתפותכם, נמסור לכם בפגישה אישית מידע מפורט לגבי תוצאות ההערכות של ילדכם, ויוגדר השלב ההתפתחותי העדכני שלו/שלה. כמו כן, אם תחפצו בכך, תקבלו מידע לגבי תוצאות המחקר כולו.

4. האם קיימים סיכונים, אי-נוחות או תופעות לוואי?

לא דווח במחקרים דומים קודמים על כל סכנה או תופעת לוואי בלתי רצויה בשימוש באלתור בתרפיה במוסיקה עם ילדים על הרצף האוטיסטי, וכן בשימוש בהדרכות הורים.

5. שימוש בטכניקות טיפוליות נוספות?

אין הגבלה על שימוש בטכניקות טיפוליות אחרות שאתם או ילדכם עשויים לקבל במהלך השתתפותכם במחקר, אך ילדכם לא יוכל לקבל טיפול במוסיקה נוסף אצל מטפל במוסיקה אחר, למשך כל תקופת המחקר הנוכחי (כולל תקופת המעקב). במקרים בהם הורים מקבלים הדרכת הורים מגורם אחר, תבדוק החוקרת את מהות ההדרכה והאם קיימות נקודות שעלולות ליצור קונפליקטים, ותחליט בהתאם לכך על השתתפותכם במחקר זה.

6. מה עליכם לעשות אם יתגלו סימפטומים נוספים, תופעות לוואי ו/או חבלות?

במידה ובמהלך ההשתתפות במחקר יתרחשו אצל הילד השפעות לא רצויות, סימפטומים נוספים או חבלות, אנא הודע לחוקרת האחראית.

7. באילו מקרים יופסק המחקר הקליני לפני שהושלם?

אתם חופשיים למשוך את הסכמתכם להשתתף ולהפסיק את השתתפותכם במחקר בכל זמן, מבלי לתת סיבות, ללא השלכות שליליות על הטיפול והתמיכה שאתם וילדכם מקבלים.

במקרים חריגים מאד, החוקרת יכולה להחליט להפסיק את השתתפותכם במחקר הקליני טרם השלמתו מבלי לקבל את הסכמתכם לכך. סיבות לכך יכולות להיות:

- אינכם יכולים לעמוד בדרישות המחקר
- החוקרת מתרשמת כי אינכם מעוניינים להמשיך להשתתף במחקר
- הקליניקה לטיפול באמצעות מוסיקה בילדים ונוער בכפר סבא מחליטה להפסיק את המחקר הקליני כולו, או רק את השתתפותכם בטרם הושלם זמן המחקר.

8. כיצד יאספו הנתונים במחקר?

רק לחוקרת האחראית, לחוקרת הדוקטורנטית, לעוזר המחקר ולמאבחנים תהיה גישה לנתונים חסויים בהם יוזכר שימכם. אנשים אלה מחויבים לשמירה על חיסיון. חשיפת מידע תתרחש למטרות סטטיסטיות בלבד, ושימכם ו/או תמונתכם לא יוזכרו כלל. כמו כן, שימכם ו/או תמונתכם לא יחשפו כלל בכל פרסום שהוא, שקשור למחקר.

9. האם נדרש מהמשתתפים במחקר תשלום כלשהו?

המשתתפים לא יידרשו לכל תשלום שהוא, הנוגע לשירותים הניתנים בזמן המחקר (טיפולים בתרפיה במוסיקה, פגישות הדרכת הורים והערכות שונות), בעת ההשתתפות במחקר זה.

10. שאלות נוספות

במידה ומתעוררות אצלכם שאלות נוספות הנוגעות למחקר הנוכחי, אתם מוזמנים ליצור קשר עם החוקרת הגב' טלי גוטפריד

2952438-052 taligott@bezeqint.net

או עם החוקרת האחראית ומנהלת המחקר בישראל – דר' כוכביית אלפנט

5944158-054 celefant@univ.haifa.ac.il

APPENDIX B. CONSENT FORM (HEBREW + ENGLISH VERSIONS)



1. טופס הסכמה מס' משתתף _____

שם האם: _____ תאריך לידה: _____

שם האב: _____ תאריך לידה: _____

אני מסכים/ה להשתתף במחקר הקליני "תרפיה במוסיקה והדרכת הורים לילדים על הרצף האוטיסטי" ביחד עם ילדי/תי _____, תאריך לידה _____

הוסבר לי באופן ברור ובצורה מפורטת לגבי השלכות אפשריות, וכן לגבי סוג המחקר, הרלוונטיות שלו, הדרישות המתאימות והיקפו. בנוסף, קראתי את דף המידע במלואו, הכולל 8 עמודים + טופס ההסכמה הנוכחי. שאלות שהתעוררו נענו כראוי ע"י החוקרת. ניתן לי זמן מספיק על מנת להגיע להחלטה, וכרגע אין לי שאלות נוספות. אני אענה לבקשות שיפנו כלפי מהחוקרת לשם עריכת המחקר, אך אשמור על זכותי להפסיק את השתתפותי ההתנדבותית בכל זמן, ללא השפעה על התמיכה שאני מקבל/ת או על הטיפול שמקבל/ת ילדי/תי.

אני מסכים/ה גם להקלטה וצילום של הפגישות לצורך איסוף נתונים למחקר. השימוש בנתונים הינו תחת שמירה על חיסיון ופרטיות המשתתפים, כפי שמפורט על שמירת נתונים למחקר – <http://openclinica.uni.no/>

קיבלתי עותק מטופס הסכמה זה. הטופס המקורי יישאר אצל החוקרת.

חתימת האם _____ תאריך _____

חתימת האב _____ תאריך _____

חתימת החוקרת _____ תאריך _____



1. Consent form **Participant Code:** _____

Mother's name: _____ Date of birth: _____

Father's name: _____ Date of birth: _____

I consent to participate in the clinical trial "Music Therapy and Parent Counseling for children with autism spectrum disorder and their parents" together with my child _____, date of birth _____ .

I received a clear explanations and detailed possible implications and risks as well as type, relevance, and scope of the clinical trial, and ensuing requirements. In addition, I have read the text of this information and consent form which includes 7 pages in total. Questions that have occurred have been answered by the principal researcher adequately and comprehensibly. I have had enough time to make my decision. I do not have further questions at the moment.

I will adhere to directions given by the principal researcher that are required for the conduct of the clinical trial, but reserve my right to terminate my voluntary participation at any time, without any adverse consequences on the care and support I receive or on the treatment of my child.

I also agree to the recording of my data within this clinical trial.

In handling the data, regulations of the Data Protection Act are adhered to.

I have received a copy of this information and consent form. The original is retained by the principal researcher.

.....
 (Date and participant's signature)

.....
 (Date and principal researcher's signature)

APPENDIX C. QUESTIONNAIRE FOR RESOURCES AND STRESS SHORT FORM (QRS-F; HEBREW + ENGLISH VERSIONS)

שאלון מקורות תמיכה ודחק (QRS-F)

Friedrich, W.N., Greenberg, M.I., & Crnic, K. (1983)

שם ממלא השאלון: _____ תאריך: _____

הורה נכבדה, לפניך שאלון העוסק ברגשות ומחשבות שיש להורים כלפי בנם/בתם עם צרכים מיוחדים, השאלון מורכב מ-32 שאלות-הצהרות. הנך מתבקשת לציין באם הנך מסכימה או לא מסכימה עם כל אחת מן ההצהרות. אם קשה לך להחליט באם הנך מסכימה או לא מסכימה, תחשבי על כך במונחים של מה אתה או בני משפחתך מרגישים או נוהגים לעשות ברוב המקרים.

לעתים תמצאי שאלות לבעיות שאינן קיימות במשפחתך, למרות זאת ניתן לענות עליהן במסכימה או לא מסכימה.

1) בני/בתי לא יוצרות קשר עם בני גילולה.

מסכימה לא מסכימה

2) בשל מצבו/ה של בני/בתי, בני משפחתנו צריכים לוותר על הרבה דברים.

מסכימה לא מסכימה

3) ישנה הסכמה במשפחתנו בנושאים מהותיים.

מסכימה לא מסכימה

4) אני חוששת ממה שעלול לקרות לבני/בתי כאשר לא אוכל יותר לטפל בו/בה.

מסכימה לא מסכימה

5) הדרישות המתמשכות לטיפול בבני/בתי מגבילות את קידומו.

מסכימה לא מסכימה

6) אני מקבלת את העובדה שבני/בתי יאלצו/אלץ להתגורר בעתיד במסגרת חוץ משפחתית (מוסד או הוסטל).

מסכימה לא מסכימה

7) כדי לטפל בבני/בתי ותרתי על דברים שמאוד רציתי לעשות בחיים.

מסכימה לא מסכימה

8) ביציאתי את הבית אני נמנעת לעתים מלקחת את בני/בתי.
מסכימה לא מסכימה

9) בשל האחריות הרבה שיש לנו כלפי בננו/בתנו, יפגעו בעתיד החיים החברתיים והכלכליים של משפחתנו.
מסכימה לא מסכימה

10) מטריד אותי שבני/בתי יהיה/תהיה תמיד כזה/כזו.
מסכימה לא מסכימה

11) אני מרגישה מתוחה כאשר עלי לצאת עם בני/בתי מחוץ לבית.
מסכימה לא מסכימה

12) אני יכולה לבקר את ידידי בכל עת.
מסכימה לא מסכימה

13) לקחת אתנו לחופש את בננו/בתנו עלול לפגום בהנאה של כולנו.
מסכימה לא מסכימה

14) משפחתנו עושה כיום את אותם דברים שעשינו בעבר.
מסכימה לא מסכימה

15) אני מתוסכלת מהדרך שבה מתנהלים חיי.
מסכימה לא מסכימה

16) בשל בני/בתי אני חשלה לעתים מאד נבוך/כה.
מסכימה לא מסכימה

17) קשה ליצור קשר עם בני/בתי בגלל הקושי שיש לו/לה בהבנת הנאמר.
מסכימה לא מסכימה

18) יש לנו מקומות רבים אליהם אנו יכולים לצאת וליהנות עם בננו/בתנו.
מסכימה לא מסכימה

19) אני מאוכזבת שבני/בתי איננה יכולה לחיות חיים נורמאליים.
מסכימה לא מסכימה

20) בדרך כלל קל לי להתרווח (לתפוס שלווה).

- | מסכימה | לא מסכימה |
|--|-----------|
| מסכימה | לא מסכימה |
| 21) אני מודאגת ממה שיקרה לבני/בתי כאשר הוא/יא יגדל/תגדל. | לא מסכימה |
| מסכימה | לא מסכימה |
| 22) אני בדרך כלל עייפה/ה מדי כדי ליהנות. | לא מסכימה |
| מסכימה | לא מסכימה |
| 23) במשפחתנו יש כעס רב מדי. | לא מסכימה |
| מסכימה | לא מסכימה |
| 24) הדרישות המתמשכות לטפל בבני/בתי הגבילו את התפתחותי האישית. | לא מסכימה |
| מסכימה | לא מסכימה |
| 25) אני מרגישה עצובה כאשר אני חושבת על בני/בתי. | לא מסכימה |
| מסכימה | לא מסכימה |
| 26) אני חוששת ממה שיקרה לבני/בתי כאשר לא אוכל לטפל בו/בה יותר. | לא מסכימה |
| מסכימה | לא מסכימה |
| 27) הטיפול בבני/בתי מעיק עלי מבחינה רגשית. | לא מסכימה |
| מסכימה | לא מסכימה |
| 28) בני משפחתנו עושים דברים דומים לאלה המקובלים במשפחות אחרות. | לא מסכימה |
| מסכימה | לא מסכימה |
| 29) בני/בתי יהיה/תהיה תמיד בעיה עברונו. | לא מסכימה |
| מסכימה | לא מסכימה |
| 30) אני נעשה/ת מדוכא/ת לעיתים רחוקות. | לא מסכימה |
| מסכימה | לא מסכימה |
| 31) אני מודאגת רוב הזמן. | לא מסכימה |
| מסכימה | לא מסכימה |

תודה על שיתוף הפעולה !

Questionnaire for Resources and Stress short Form (QRS-F)

Friedrich, W.N., Greenberg, M.I., & Crnic, K. (1983)

Name: _____ Date: _____

Dear parent, this questionnaire contains 32 questions/declarations of feelings and thoughts that parents have in regard to their children with Special needs and Autism.

Please mark if you agree or don't agree with each of these declarations. If you have difficulties deciding if you agree or don't agree, think of how you or your family think and do in most cases.

Sometimes you will find declarations of problems not existing in your family; still, you can answer if you agree or don't agree.

1. My child doesn't communicate with other children his/her age.

Agree

Don't agree

2. Due to my child's situation, our family needs to concede many things.

Agree

Don't agree

3. There is consent in our family on fundamental issues.

Agree

Don't agree

4. I'm worried about what will happen to my child whenever I won't be able to take care of him.

Agree

Don't agree

5. The on-going demands of treating our child limit our advancement.

Agree

Don't agree

6. I accept the fact that my child will need to reside in an out-family facility (an institution or a hostel).

Agree

Don't agree

7. In order to take care of my child, I have conceded things that I wanted to do in my life.

Agree

Don't agree

8. When I go out, I sometimes avoid taking my child with me.

Agree

Don't agree

9. Due to the responsibilities we have for our child, the social and financial situation of our family will be negatively affected.

Agree

Don't agree

10. It bothers me that my child will always be like this.

Agree

Don't agree

11. I feel tensed when I need to go out with my child.

Agree

Don't agree

12. I can visit my friends at any time.

Agree

Don't agree

13. Taking our child for a vacation with us might harm all of our pleasure.

Agree

Don't agree

14. Our family does presently the same things that we did before.

Agree

Don't agree

15. I'm frustrated with the way my life are.

Agree

Don't agree

16. I sometimes feel embarrassed because of my child.

Agree

Don't agree

17. It's hard to communicate with my child because of his difficulty in understanding what is said.

Agree

Don't agree

18. We have a lot of places where we can go and have fun with our child.

Agree

Don't agree

19. I'm frustrated that my child can't live a normal life.

Agree

Don't agree

20. Usually I find it easy to relax.

Agree

Don't agree

21. I'm worried about what will happen to my child when he/she grows up.

Agree

Don't agree

22. Usually I'm too tired to have fun.

Agree

Don't agree

23. In our family that is too much anger.

Agree

Don't agree

24. The on-going demands of treating our child limited my personal growth.

Agree

Don't agree

25. I feel sad when I think of my child.

Agree

Don't agree

26. I'm afraid of what will happen to my child whenever I can no longer take care of him/her.

Agree

Don't agree

27. Treating my child burden me emotionally.

Agree

Don't agree

28. Members of our family do things as customary in other families.

Agree

Don't agree

29. My child will always be a problem for us.

Agree

Don't agree

30. I seldom get depressed.

Agree

Don't agree

31. I worry most of the time.

Agree

Don't agree

APPENDIX D. QUALITY OF LIFE VISUAL ANALOGUE SCALE (HEBREW + ENGLISH VERSIONS)

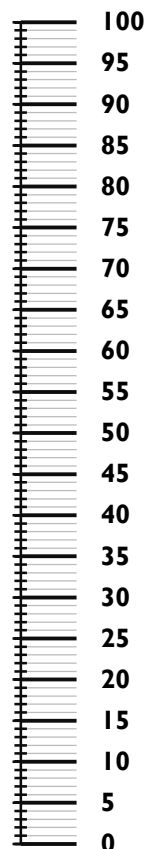
לפניך סולם (מעין סרגל) עליו תוכל לסמן עד כמה איכות החיים היא נמוכה או גבוהה – איכות החיים הגבוהה ביותר הניתנת לדמיון מצוינת במספר 100 והגרועה ביותר הניתנת לדמיון מצוינת במספר 0.

אנא ציין על פני הסולם עד כמה, לדעתך, נמוכה או גבוהה היא **איכות החיים של ילדך/ילדתך** כיום.

אנא מתח קו מהריבוע המושחר עד לנקודה על פני הסולם שמציינת את רמת איכות החיים של ילדך/ילדתך כיום.

איכות החיים הטובה ביותר הניתנת לדמיון

איכות החיים של
ילדך/ילדתך כיום



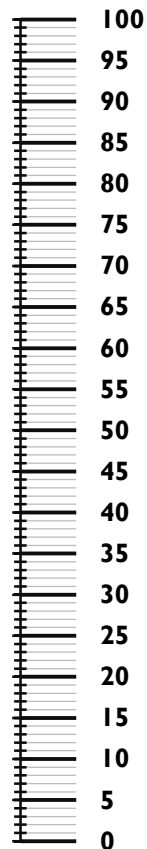
איכות החיים הגרועה ביותר הניתנת לדמיון

אנא ציין על פני הסולם עד כמה, לדעתך, נמוכה או גבוהה היא איכות החיים של משפחתך כיום.

אנא מתח קו מהריבוע המושחר עד לנקודה על פני הסולם שמציינת את רמת איכות החיים של משפחתך כיום.

איכות החיים הגבוהה ביותר הניתנת לדמיון

איכות החיים של משפחתך כיום



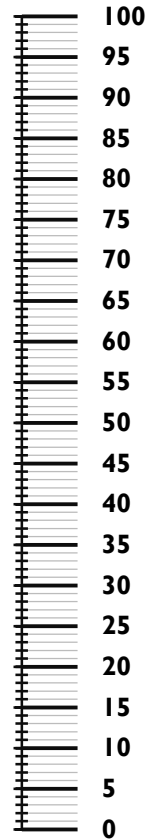
איכות החיים הנמוכה ביותר הניתנת לדמיון

Here you can see a scale (rather like a thermometer) on which you can state how high or low the quality of life is – the best quality of life you can imagine is marked 100 and the worst quality of life you can imagine is marked 0.

Please indicate on this scale how good or bad **your child's quality of life** is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your child's quality of life is today.

Best imaginable Quality of Life

Your child's quality
of life today

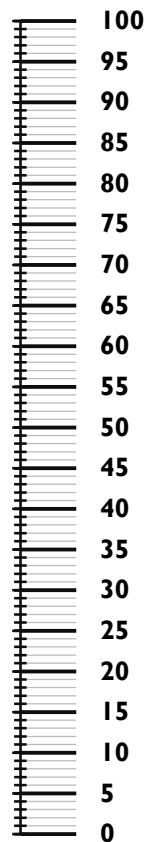


Worst imaginable Quality of Life

Please indicate on this scale here how good or bad **your family's quality of life** is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your family's quality of life is today.

Best imaginable Quality of Life

Your Family's
quality of life
today



Worst imaginable Quality of Life

APPENDIX E. MUSIC IN EVERYDAY LIFE (MEL) ASSESSMENT
(HEBREW + ENGLISH VERSIONS)

מוסיקה בחיי היומיום – שאלון להורים

שמו של ממלא השאלון: _____ תאריך: _____

זמן מילוי השאלון הוא בין 5-10 דקות. מטרת השאלון הן: להכיר את האופן בו את/ה משתמש/ת במוסיקה בחיי היומיום; לראות עד כמה ילדך/ילדתך נחשף/ת למוסיקה; וכיצד את/ה תופס/ת את תגובתו/ה לפעילויות מוסיקליות שונות.

בכל שאלה אנא סמן/י את האפשרות שמתארת בצורה הטובה ביותר את התנהגות ילדך/תך **בשבוע האחרון**. אנא שים/י לב כי המונח "ילדך/ילדתך" מתייחס לילד/ה שלוקח חלק במחקר הנוכחי.

שאלה 1

במהלך השבוע החולף, באיזו תדירות שרת עם ילדך/תך?

בכל יום מימות השבוע שרתי עם ילדי

כמעט בכל יום מימות השבוע שרתי עם ילדי

כשני ימים מימות השבוע שרתי עם ילדי

יום אחד השבוע שרתי עם ילדי

השבוע לא שרתי עם ילדי כלל

- כיצד את/ה חושב/ת ילדך/ילדתך הגיב/ה לשירה שלך?
(אנא סמן/י אפשרות אחת בלבד)

זו היתה חוויה חיובית מאד עבור ילדי/ילדתי

זו היתה חוויה די חיובית עבור ילדי/ילדתי

זו היתה חוויה לא שלילית ולא חיובית עבור ילדי/ילדתי (לדוגמא: הילד/ה המשיך/כה בעיסוקו/ה; קשה להבין את תגובתו/ה)

□ זו היתה חוויה שלילית עבור ילדי/ילדתי. אנא תאר/י:

- האם היתה זו חוויה חיובית או שלילית עבורך? אנא תאר/י:

שאלה 2

במהלך השבוע החולף, באיזו תדירות ניגנת ביחד עם ילדתי/ילדתך באמצעות כלי נגינה?
(אנא אל תכלולי/י צעצועים שמנגנים מוסיקה מוקלטת בלחיצת כפתור)

□ בכל יום מימות השבוע ניגנתי ביחד עם ילדי בכלי נגינה

□ כמעט בכל יום מימות השבוע ניגנתי עם ילדי בכלי נגינה

□ כשני ימים מימות השבוע ניגנתי עם ילדי בכלי נגינה

□ יום אחד השבוע ניגנתי עם ילדי בכלי נגינה

□ השבוע לא ניגנתי כלל עם ילדי בכלי נגינה

- כיצד את/ה חושבת/ת ילדך/ילדתך הגיב/ה לנגינתכם המשותפת? (אנא סמן/י
אפשרות אחת בלבד)

□ זו היתה חוויה חיובית מאד עבור ילדי/ילדתי

□ זו היתה חוויה די חיובית עבור ילדי/ילדתי

□ זו היתה חוויה לא חיובית ולא שלילית עבור ילדי/ילדתי (לדוגמא: הילד/ה המשיך/כה
בעיסוקו/ה; קשה להבין את תגובתו/ה)

□ זו היתה חוויה שלילית עבור ילדי/ילדתי. אנא תאר/י:

- האם היתה זו חוויה חיובית או שלילית עבורך? אנא תאר/י:

שאלה 3

במהלך השבוע החולף, באיזו תדירות האזנת בביתך למוסיקה עם ילדך/ילדתך?

בכל יום מימות השבוע האזנתי למוסיקה ביחד עם ילדי/ילדתי

כמעט בכל יום מימות השבוע האזנתי למוסיקה ביחד עם ילדי/ילדתי

כשני ימים מימות השבוע האזנתי למוסיקה ביחד עם ילדי/ילדתי

יום אחד השבוע האזנתי למוסיקה ביחד עם ילדי/ילדתי

השבוע לא האזנתי כלל למוסיקה ביחד עם ילדי/ילדתי

- כיצד את/ה חושבת/ילדך/ילדתך הגיב/ה להאזנה משותפת למוסיקה? (אנא סמן/י אפשרות אחת בלבד):

זו היתה חוויה חיובית מאד עבור ילדי/ילדתי

זו היתה חוויה די חיובית עבור ילדי/ילדתי

זו היתה חוויה לא חיובית ולא שלילית עבור ילדי/ילדתי (לדוגמא: הילד/ה המשיך/כה בעיסוקו/ה; קשה להבין את תגובתו/ה)

זו היתה חוויה שלילית עבור ילדי/ילדתי. אנא תאר/י:

- האם היתה זו חוויה חיובית או שלילית עבורך? אנא תארי:

שאלה 4

במהלך השבוע החולף, באיזו תדירות שיחקת עם ילדך/ילדתך באמצעות אפליקציות מוסיקליות בסמארטפון או כל מכשיר טאבלט אחר? (אנא התייחס לאפליקציות שמאפשרות נגינה או הלחנה של מוסיקה).

בכל יום מימות השבוע שיחקתי עם ילדי/ילדתי באפליקציות מוסיקליות

כמעט בכל יום מימות השבוע שיחקתי על ילדי/ילדתי באפליקציות מוסיקליות

כשני ימים מימות השבוע שיחקתי עם ילדי/ילדתי באפליקציות מוסיקליות

יום אחד השבוע שיחקתי עם ילדי/ילדתי באפליקציות מוסיקליות

השבוע לא שיחקתי עם ילדי/ילדתי כלל באפליקציות מוסיקליות

- כיצד אתה/חושבת/ילדך/ילדתך הגיב/ה למשחק באפליקציה מוסיקלית איתך?
(אנא סמני/י אפשרות אחת בלבד):

זו היתה חוויה חיובית מאד עבור ילדי/ילדתי

זו היתה חוויה די חיובית עבור ילדי/ילדתי

זו היתה חוויה לא חיובית ולא שלילית עבור ילדי/ילדתי (לדוגמא: הילד/ה המשיך/כה בעיסוקו/ה; קשה להבין את תגובתו/ה)

זו היתה חוויה שלילית עבור ילדי/ילדתי. אנא תארי:

- האם היתה זו חוויה חיובית או שלילית עבורך? אנא תאר/י:

שאלה 5

האם את/ה ו/או בן משפחה כלשהו מנגן בכלי נגינה כתחביב או כמקצוע? (התייחס לכל כלי הנגינה, מלבד צעצועי כלי נגינה):

כן

לא – נא המשך/כי לשאלה 6

- באילו כלי נגינה הם מנגנים?

אדם 1: _____

אדם 2: _____

אדם 3: _____

אדם 4: _____

אדם 5: _____

- במהלך השבוע החולף, באיזו תדירות את/ה ו/או בן משפחה אחר ניגן בכלי הנגינה שלו/ה בנוכחות ו/או ביחד עם ילדך/ילדתך?

בכל יום מימות השבוע כלי נגינה נוגנו בנוכחות או ביחד עם ילדי/ילדתי

כמעט בכל יום מימות השבוע כלי נגינה נוגנו בנוכחות או ביחד עם ילדי/ילדתי

כשני ימים מימות השבוע כלי נגינה נוגנו בנוכחות או עם ילדי/ילדתי

יום אחד השבוע כלי נגינה נוגנו בנוכחות או עם ילדי/ילדתי

השבוע לא נוגנו כלי נגינה כלל בנוכחות או עם ילדי/ילדתי

- כיצד אתה/חושבת/ילדך/ילדתך הגיב/ה לנגינתך ו/או נגינתם? (אנא סמן/י אפשרות אחת בלבד):

זו היתה חוויה חיובית מאד עבור ילדי/ילדתי

זו היתה חוויה די חיובית עבור ילדי/ילדתי

זו היתה חוויה לא חיובית ולא שלילית עבור ילדי/ילדתי (לדוגמא: הילד/ה המשיך/כה בעיסוקו/ה; קשה להבין את תגובתו/ה)

זו היתה חוויה שלילית עבור ילדי/ילדתי. אנא תאר/י:

שאלה 6:

במהלך השבוע החולף, לאיזה סגנון מוסיקה האזינה משפחתך? (אנא סמן/י כל מה שמתאים):

כלל לא	יום בשבוע	כיומיים בשבוע	כמעט בכל יום מהשבוע	בכל יום מימות השבוע	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	שירים ישראלים
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	מוסיקה מזרחית
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	מוסיקה קלאסית
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	ג'אז
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	שירי ילדים
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	מוסיקת פופ

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	מוסיקה "רכה" (ניו-אייג, צלילי מים וטבע וכד')
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	מוסיקה קצבית (תופים, אלקטרונית וכד')

- הערות (אם יש):

שאלה 7

אנו משתמשים במוסיקה (שרים, מנגנים, מאזינים) בדרכים שונות על מנת לעזור לילדי/ילדתי:

כלל לא	יום בשבוע	כיומיים בשבוע	כמעט בכל יום מהשבוע	בכל יום מימות השבוע	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	להירגע
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	בזמן האוכל
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	להירדם
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	להבין שגרת יומיום
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	ליהנות ביחד
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	במעברים בין פעילויות
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	ללמוד דברים חדשים
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	לנסוע בשלווה במכונית

- הערות (אם יש):

שאלה 8

אם יש לך משהו להוסיף לגבי התגובה של ילדך/ילדתך למוסיקה, אנא צייני זאת כאן:

תודה על זמנך ושיתוף הפעולה !

לשימוש משרדי:

מס' משתתף:

קבוצת שיוך הורים:	ליווי חלקי	ליווי מלא
קבוצת שיוך ילד:	עם תרפיה במוסיקה	ללא תרפיה במוסיקה

חתימה: _____

Music in Everyday Life – MEL Questionnaire

Name of person filling in this survey: _____ Date: _____

This survey should take between 5-10 minutes to complete. The aims of this questionnaire are: to become familiar with the way you are using music in everyday life; to see how much your child is being exposed to music; and how you perceive his/her responses to different musical activities.

In each question, please mark the option that best describes your child's behavior **over the past week**. You are also welcome to make additional comments in each section. Please note that the term “your child” refers to the child who is part of this research project.

Question 1

a) In the past week, how often have you sung with your child?

- Every day of the week I sang with my child
- Almost every day of the week I sang with my child
- A couple of the days of the week I sang with my child
- One day of the week I sang with my child
- Not at all

b) how do you think your child overall responded to your singing: (Please tick only one)

- It was a very positive experience for my child
 - It was a somewhat positive experience for my child
 - It was neither a positive nor a negative experience for my child (e.g. my child continued with his response was difficult to understand.)
 - It was a negative experience for my child. Please describe:
-
-

c) Was it a positive or a negative experience for you? Please describe:

Question 2

- a) In the past week, how often have you played musical instruments with your child?

(Please don't include toys that play recorded musical tunes.)

- Everyday of the week I played musical instruments with my child
- Almost every day of the week I played musical instruments with my child
- A couple of the days of the week I played musical instruments with my child
- One day of the week I played musical instruments with my child
- Not at all

- b) how do you think your child overall responded to playing with instruments with you: (Please tick only one)

- It was a very positive experience for my child
- It was somewhat a positive experience for my child
- It was neither a positive nor a negative experience for my child (e.g. my child continued with her/his Activities; his/her response was difficult to understand)
- It was a negative experience for my child. Please describe:

-
- c) was it a positive or a negative experience for you? Please describe:
-
-

Question 3

a) In the past week, how often have you listen to music with your child?

- Everyday of the week I listened to music with my child
- Almost every day of the week I listened to music with my child
- A couple of the days of the week I listened to music with my child
- One day of the week I listened to music with my child
- Not at all

b) how do you think your child overall responded to listening to music with you:
(Please tick only one)

- It was a very positive experience for my child
- It was somewhat a positive experience for my child
- It was neither a positive nor a negative experience for my child (e.g. my child continued with his/her Activities; his/her response was difficult to understand).
- It was a negative experience for my child. Pleases describe:

c) Was it a positive or a negative experience for you? Please describe:

Question 4

a) In the past week, how often have you played with music applications on a smart phone or tablet with your child? (Please consider applications for playing and composing original music)

- Everyday of the week I played music applications with my child
- Almost every day of the week I played music applications with my child
- A couple of the days of the week I played music applications with my child
- One day of the week I played music applications with my child
- Not at all

b) how do you think your child overall responded to playing a music application with you: (Please tick only one)

- It was a very positive experience for my child
- It was somewhat a positive experience for my child
- It was neither a positive nor a negative experience for my child (e.g. my child continued with his/her activities; his/her response was difficult to understand.)
- It was a negative experience for my child. Please describe:

c) was it a positive or a negative experience for you? Please describe :

Question 5

Do any family members currently play a musical instrument as a hobby or a profession?

(Please include all instruments apart from children's percussion instruments)

- a*) Yes
 No – please proceed to question 6

If yes, what musical instruments do they play?

Person 1: _____

Person 2: _____

Person 3: _____

Person 4: _____

Person 5: _____

- a) In the past week, how often have you and/or other family members played their instrument in front of, or with, your child?
- Everyday of the week musical instruments were played in front of or with my child
 - Almost every day of the week musical instruments were played in front of or with my child
 - A couple of the days of the week musical instruments were played in front of or with my child
 - One day of the week musical instruments were played in front of or with my child
 - Not at all
- b) how do you think your child overall responded to their playing: (Please tick only one)
- It was somewhat a positive experience for my child
 - It was neither a positive nor a negative experience for my child (e.g. my child continued with his/her activities; his/her response was difficult to understand.)
 - It was a negative experience for my child. Please describe:
-

Further comments (optional):

Question 6

In the past week, what type of music has your family listened to? (Please tick all that apply)

	Not at all	One day of the week	A couple of days of the week	Almost every day of the week	Every day of the week
--	------------	---------------------	------------------------------	------------------------------	-----------------------

Music from your cultural heritage

Classical music

Jazz music

Children's songs

Pop music

Relaxation music (e.g. new-age, nature sounds)

Dance music (e.g. electronic music, highly rhythmical music)

Other

Comments (optional):

Question 7

Our family uses music (singing, listening, playing) in different ways, in order to help my child:

	Not at all	One day of the week	A couple of days of the week	Almost every day of the week	Every day of the week
Calm down					
At meal time					
At bed time					
Understand daily routine					
Have fun and experience enjoyment					
Exercise					
Transition smoothly between activities					
Learn new things					
Traveling calmly in the car, bus, etc.					

Comments (optional):

Question 8

If you have any other comments regarding your child's response to music, please add them here:

Thank you for your cooperation !

For office use:

Low Intensity MT	High Intensity MT	No MT
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APPENDIX F. MUSIC-ORIENTED PARENT COUNSELING GUIDE

MUSIC-ORIENTED PARENT COUNSELING (MOPC) **for PARENTS of CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD) –** **PROTOCOL GUIDE**

The following descriptions and specifications are provided as guidelines for carrying out parent counselling sessions within the context of the present study. They are supposed to be applied flexibly according to the requirements of the respective situation and needs of the parents within the counselling session. The guidelines can only be applied in combination with and relying on the clinical expertise of a trained music therapist experienced in the field of ASD.

This guide contains information on (a) setting, (b) general goals, and (c) basic principles for the counseling situation. Specific examples are added when needed.

(a) Setting:

Music-Oriented Parent Counseling (MOPC) is carried out by a music therapist-counsellor with both parents. Both parents are to agree to attend all counseling sessions. In cases where only one parent solely responsible for the care of the child or only one parent can attend the counseling sessions, the music therapist-counselor will examine the reasons and causes for that, and evaluate the possibility to conduct the counseling with only one parent, putting the child's needs in priority. In that case, this parent's presence in all sessions is necessary.

The standard session time is 60 minutes, but some variation may occur due to specific requirements of the parent(s) or unexpected incidents.

(b) General goals:

Goals and contents of *Music-Oriented Parent Counseling* may be one or several of the following:

- Creating a safe place for parents to talk and reflect on stressful situations related to their child's diagnosis.
- Discussing the use of music in parent-child interaction.

- Providing information regarding techniques of music therapy as communication tool with children with ASD.
- Discussing structuring of activities in daily routine, with particular attention to possible uses of music.
- Discussing topics raised by the parents.
- Providing information regarding ASD in various developmental fields (motorist, social and language fields).
- Providing information regarding normal development.
- Providing information regarding parent-child interaction in normal development, with particular attention to the role of the parent.
- Discussing parenting challenges in regard to children with ASD.

(c) Basic principles:

- *Music-Oriented Parent Counseling (MOPC)* strives to construct a partnership form of work based on collaboration between the music therapist-counselor and the parents. This perspective offers an opportunity for non-hierarchy relationship between parents and the music therapist, looking at all partners as equally responsible for finding solutions to daily challenges along the way.
- *MOPC* sessions focus on the child's needs *in combination* with the parents' needs. Limitations observed in parental capability will be taken under consideration during discussions.
- First session – consists of presenting the parents with the main *aspects* of *MOPC* process, as well as the setting of the meetings. The music therapist should encourage the parents to express their expectations of the *music-oriented* counseling process.
- Following sessions – the music therapist-counselor should:
 - Strive to establish a working alliance with the parents, offering a safe place to reflect and discuss daily *situations with the child, and the ways they affect the* parents' perspective of their child's needs and of their parenthood.
 - Give updates regarding the music therapy process of the child, and share clinical insight with the parents.
 - Encourage the parents to reflect on these insights implement music therapy like-techniques everyday life.

- Discuss certain issues that are dominant in music therapy sessions with the child, and offer parents the opportunity to reflect on the update and share their understanding of the respective situation.
- Makes an appropriate connection between his/her clinical understandings of the child's needs, *as revealed in music therapy sessions* and daily challenges expressed by parents. These connections will take under consideration during mutual discussions of possible ways for parents to approach their child interactively.
- Encourage the parents to discuss certain issues and ask questions regarding matters in everyday life that are affected from their child's diagnosis.
- Use clinical judgment - if and when to make suggestions and provide solutions regarding difficulties raised by the parents, in order to meet the parents' strengths and weaknesses in the respected time; the music therapist-counselor must have the ability to decode the parents' capability to receive and use his/her suggestions, and work accordingly.
- Develop discussion on certain issues that rise up from the 'MEL' questionnaire and parents' self-reports in regard to the use of music in everyday life and the parents' perception of the counseling process, in order to stimulate music point of view in parents.
- Maintain a certain *structure of the sessions*.
- In cases where children do not receive music therapy (in the context of the current study), the music therapist-counselor should:
 - Use his/her clinical experience in working with children with ASD, and offer music therapy way of thinking as a helping strategy for parents.
- Last session – in the context of the current study, final interview took place at the last session.

APPENDIX G. FIDELITY ASSESSMENT OF MUSIC-ORIENTED PARENT COUNSELING GUIDE

**FIDELITY ASSESSMENT of
THE *MUSIC-ORIENTED PARENT COUNSELING GUIDE*
For parents of children with ASD**

This report is aimed to assess the proper implementation of the ‘*Music-Oriented Parent Counseling Guide*’. This report is to be filled up while watching the video of randomized counseling sessions. Although it is not expected that every goal will be addressed in each session, please make sure to follow every step in the treatment guide, and grade according to following index:

Very much: this application appears considerably during the session.

Much: this application appears plenty during the session.

A little: this application appears slightly during the session.

Not at all: this application doesn’t appear during session.

General Goals:

		Very much	Much	A little	Not at all
1	Creating a safe place for parents to talk and reflect on stressful situations related to their child’s diagnosis				
2	Discussing the use of music in parent-child interaction				
3	Discussing structuring of activities in daily routine, with particular attention to possible uses of music				
4	Discussing topics raised by the parents				
5	Providing information regarding ASD in various development fields				
6	Providing information regarding normal development				
7	Providing information regarding parent-child interaction in normal development, with particular attention to the role of the parent				
8	Discussing parenting challenges in regard to children with ASD				

Basic Principles:

Please complete this table using the index in accordance with your best judgment:

		Very much	Much	A little	Not at all
1	Counseling session focuses on the child's needs in combination with the parents' needs				
2	The counselor uses professional judgment in deciding if and how to raise issues of conflicts and difficulties				
3	The counselor offers to use music in different ways to address certain challenges				
4	The counselor addresses each issue raised by the parents				
5	The counselor uses his professional insights while addressing relevant issues				
6	The counselor uses simple understandable language				
7	The counselor offers solutions to a daily challenge in accordance with the parents abilities				
8	The counselor maintains the session structured				

In your best judgment, was this session a good counseling for parents of a child with ASD? YES / NO

APPENDIX H. QUESTIONS FOR THE SEMI-STRUCTURED INTERVIEW

Semi-structured interview

We have reached to the final stage of the study's five months intervention. During this period, we have met _____ times, and now, it is our last meeting, in which I ask to interview you.

I will ask you several questions; please answer them with your most sincerity and try to clearly express yourself. I might ask for examples to your descriptions.

1. What do you think of the counseling sessions you have participated in?
(How was it for you to participate in those sessions? Did anything help you? What particularly helped you? Do you think the sessions made any change? Did you experience a process? What do you feel that you gained from the sessions? Do you think the sessions helped understanding the child's needs more? Did they help understanding your personal strengths and weaknesses? Did they help understanding more of the Autism diagnosis? Did the sessions contribute to a change in parental attitude?)
2. Please describe the counseling process concerning level of stress you have experience as parents for your child with autism. (Did the counseling process helped to reduce parental level of stress? If yes – how?)
3. Please describe the counseling process in regard to your Quality of Life.
(How do you perceive the term "quality of life?")
4. How did you use music with your child at the last months? Please elaborate and give examples of the use of music. (Used MORE music, attuned to the child, in which situations, musical genre, parent-child interaction)
5. Was there anything that stood out for you in the way the sessions were guided? (For instance – was hearing descriptions of how I worked with your child helpful?)

Thank you so much for participating in this interview and in the study!

APPENDIX I. ADVERTISEMENT FOR RECRUITING FAMILIES TO THE STUDY



דרושים **הורים וילדים** המאובחנים על הרצף האוטיסטי (ASD) להשתתף במחקר הבודק השפעות של טיפול מוקדם בתרפיה במוסיקה בילדים עם אוטיזם.

השתתפות במחקר מעניקה הדרכת הורים, תרפיה במוסיקה והערכת מקצועיות לילדים ללא עלויות נצד המשתתפים.

מחקר זה הינו חלק ממחקר עולמי ראשון מסוגו בנושא תרפיה במוסיקה ואוטיזם, וממומן על ידי קרן מחקר אקדמית בינלאומית. המחקר אושר לביצוע בארץ על ידי ועדת האתיקה של אוניברסיטת חיפה. הטיפול יתקיים על ידי מטפלים מוסמכים במרכזים שונים ברחבי הארץ עם דגש על כפר סבא ואזור השרון וכן איזור הצפון.

מי מתאים:

- ילדים המאובחנים עם ASD, PDD, PDD-NOS
- בין הגילאים 4 – 7
- ללא ניסיון קודם בתרפיה במוסיקה (או ניסיון מועט ביותר)

אם אתם חושבים כי אתם וילדכם מתאימים להשתתפות במחקר ולאו אם יש לכם שאלות בנושא, אשמח אם תצרו קשר איתי - טל: גוטפריד, דוקטורנטית לתרפיה במוסיקה, אוניברסיטת אולבורג, דנמרק, חוקרת taligott@bezeqint.net ; טל. 052 – 2952438

או עם דר. כוכבית אלפנט, ראש התוכנית לתרפיה במוסיקה באוניברסיטת חיפה ומנהלת המחקר בישראל ; טל. 054 - 5944158 ; celefant@research.haifa.ac.il

בדקו באתר המחקר הבינלאומי: <http://helse.uni.no/default.aspx?site=48&lq=2>

APPENDIX J. PARENTS' SESSION NOTE FORM (HEBREW + ENGLISH VERSIONS)

טופס מטפל – לאחר פגישה ליווי הורים

מ.ס. משתתף _____
שם ההורים _____
פגישה מ.ס. _____
תאריך ושעת פגישה _____
מלווה הורים _____

נמוכה גבוהה

1. רמת המתח אצל ההורים

2. רמת שאלית שאלות בנושא האבחנה של ילד

3. רמת הבעת דאגה ע"י ההורים לעתידו של הילד

4. רמת השיתוף של ההורים ברגשותיהם

5. רמת תשומת הלב של ההורים למלווה

6. רמת הביקורת מצד ההורים למסגרות טיפול ציבוריות

7. רמת הביקורת מצד ההורים למלווה

8. רמת המוטיבציה של ההורים למצוא פתרונות מתאימים

לשימוש משרדי:

תדירות פגישות ליווי הורים: 3 פגישות / 10 פגישות
הילד מקבל טיפול במוסיקה . הילד אינו מקבל טיפול במוסיקה

COUNSELING SESSION NOTE FORM

Participant's ID:

Names of parents attending the sessions:

Session number:

Date and time of the session:

Counselor:

High Low

1. Level of tension of the parents

2. Level of asking questions regarding the diagnosis

3. Level of expressing concern regarding the future

4. Level of sharing their feelings

5. Level of the parents attention to the counselor

6. Level of criticism of public services

7. Level of criticism towards the counselor

8. Level of parent's motivation to find proper solutions

For office use:

Intensity of counseling: 3 PC / 10 PC

Child receiving MT / Child not receiving MT

APPENDIX K. MUSIC THERAPY NOTE FORM

טופס מטפל – לאחר פגישת תרפיה במוסיקה

מ.ס. משתתף _____
שם הילד _____
מ.ס. פגישה _____
תאריך ושעת פגישה _____
שם המטפל _____

הרבה לעתים מעט כלל לא

היענות של הילד לשירה של המטפל

היענות של הילד לנגינה של המטפל

היענות של הילד למשחק מוסיקלי

בקשה של הילד לשיר או פעילות מוסיקלית

יזמה של הילד לאינטראקציה עם המטפל

רמת מוסחות גבוהה של הילד

שימוש בכלים באופן קריאטיבי (ולא לגרייה)

תשומת לב משותפת בין הילד למטפל

התנגדות של הילד לקשר עם המטפל

2. האם הילד נראה מעוניין באינטראקציה ושיתף פעולה לאורך מרבית הפגישה? כן / לא
3. האם חשת את הילד כקשוב אליך? כן / לא
4. האם חשת את הילד כמנותק ממך? כן / לא
5. מה היתה רמת המובנות (structure) של הפגישה? גבוהה / נמוכה

Music Therapy Nore Form

Participants' ID _____

Name of the child _____

Session number _____

Date and time _____

Therapists' name _____

	Not at all	Little	Occasionally	A lot
Child's response to the therapist's singing				
Child's response to the therapist's playing				
Child's response to musical play				
Child initiates singing or playing				
Child initiates contact with the therapist				
Child's high level of destruction				
Child uses musical instruments creatively (and not for sensory stimulation)				
Joint attention between the child and the therapist				
Child resists contact with the therapist				

2. Does the child seem interested in interaction and was cooperative through the session? Yes/No
3. Was the child attentive to you? Yes/No
4. Was the child detached from you? Yes/No
5. What was the level of structure of the session? Low/High

APPENDIX L. CASE REPORT FORM

TIME-A | CASE REPORT FORM (CRF) **participant's ID:**

PARTICIPANT DATA:

Date of birth: . .20 **gender:** male female
first language: _____
previous music therapy: never not during last 12 months

ADI-R: sum A: sum B: sum C: sum D: ...
 nonverbal verbal
positive cut-offs: A B C D
 date: . .201

IQ score:

date: . .201

source: **K-ABC** SED/SEP: SGD/SIP: SIF/MPC:

FS/ACH:

other standardised scale:

.....

clinical judgment

ADOS module

ADOS SA + RRB Total score before intervention:

date: . .201

 (3's recoded to 2's, 7's and 8's recoded to 0)

SRS score before intervention: T-total: T-autism:

date: . .201

diagnosis:

assessor:

date of randomization = **baseline:** . .201

other clinical diagnoses:

number of adults in participant's home:

number of children in participant's home (excluding participant):

mother's level of education: less than 12 years education 12+ years education
 university degree unknown

father's level of education: less than 12 years education 12+ years education
 university degree unknown

mother's employment status:

unemployed or social support working part-time working full-time home maker other unknown

father's employment status:

unemployed or social support working part-time working full-time home maker other unknown

INTERVENTION DATA:

Allocated intervention:

- 3x p/week parent counseling + with music therapy
- 10x p/week + parent counseling + with music therapy
- 3x p/week parent counseling _ without music therapy
- 10x p/week + parent counseling + without music therapy

assessor:

ADOS SA + RRB Total score after 2 months:

date: . .201

(3's recoded to 2's, 7's and 8's recoded to 0)

SRS score after 2 months: T-total: T-autism:

date: □□. □□.201□

assessor:

ADOS SA + RRB Total score after 5 months:

date: □□. □□.201□

(3's recoded to 2's, 7's and 8's recoded to 0)

SRS score after 5 months: T-total: T-autism:

date: □□. □□.201□

number of parent counseling sessions conducted:

number of music therapy sessions conducted:

assessor:

ADOS SA + RRB Total score after 12 months:

date: □□. □□.201□

(3's recoded to 2's, 7's and 8's recoded to 0)

SRS score after 12 months: T-total: T-autism:

date: □□. □□.201□

Did the participant receive any music therapy or parent counseling OUTSIDE the study (since date of randomization)?

yes

no

If yes: how many sessions?

..... sessions of music therapy

..... Sessions of parent counseling

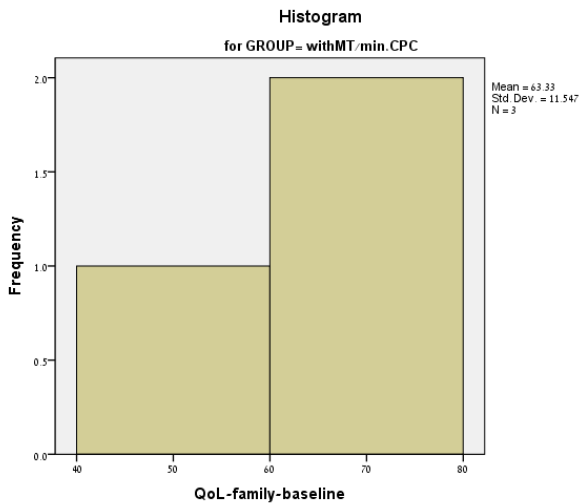
Comments:

Date, signature of site manager: _____

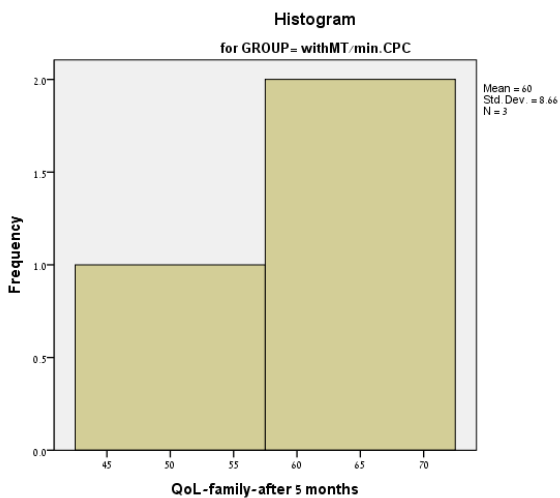
APPENDIX M. HISTOGRAMS

Group 1 (Minimal MOPC/with MT):

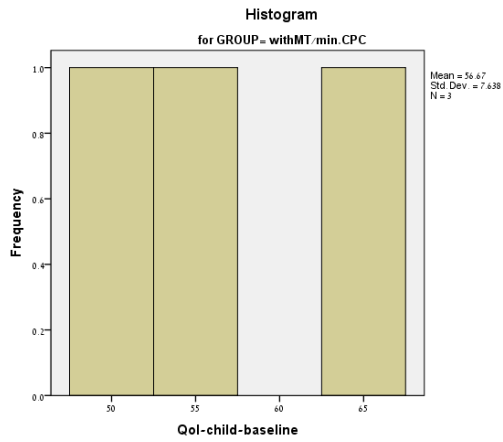
Parents' QoL baseline



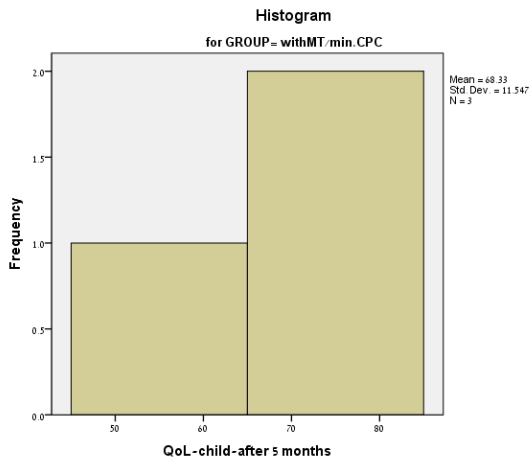
Parents' QoL after 5 months



Child's QoL baseline

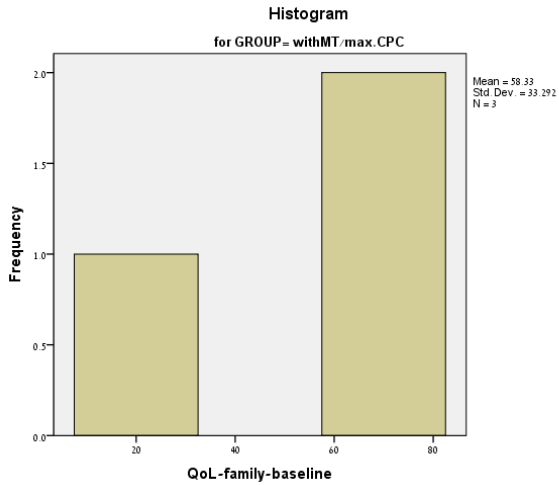


Child's QoL after 5 months

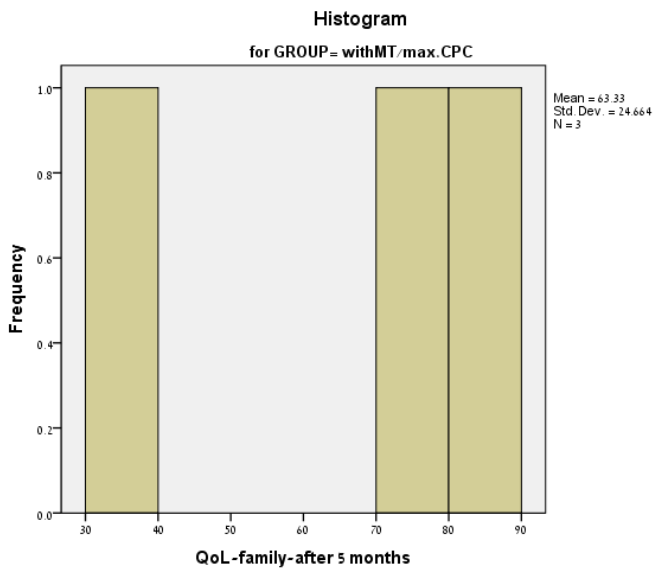


Group 2 (Maximal MOPC/with MT):

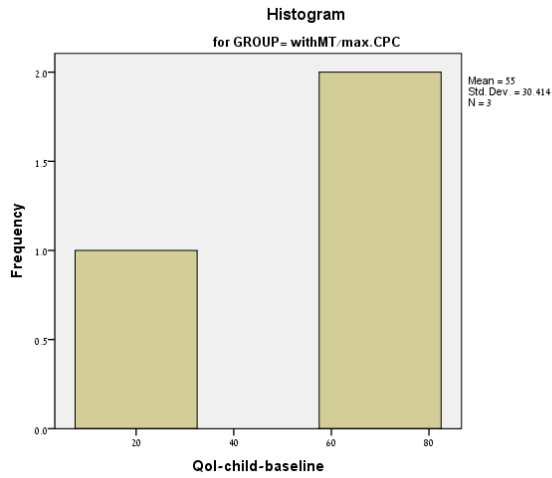
Parents' QoL baseline



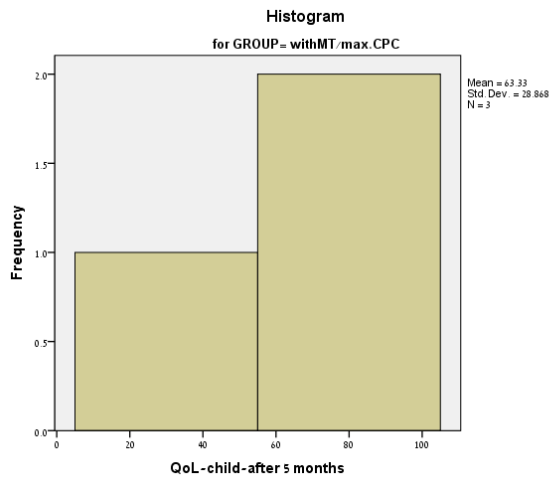
Parents' QoL after 5 months



Child's QoL baseline

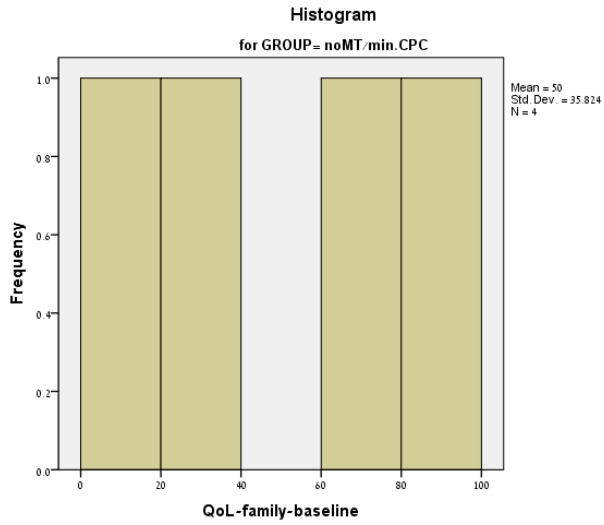


Child's QoL after 5 months

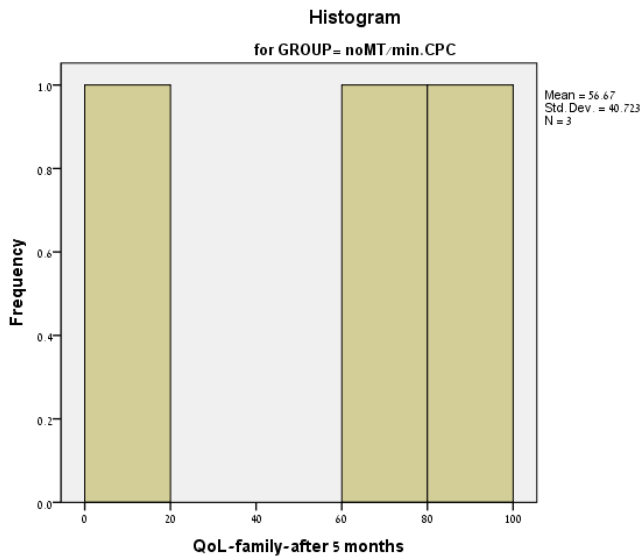


Group 3 (Minimal MOPC/no MT):

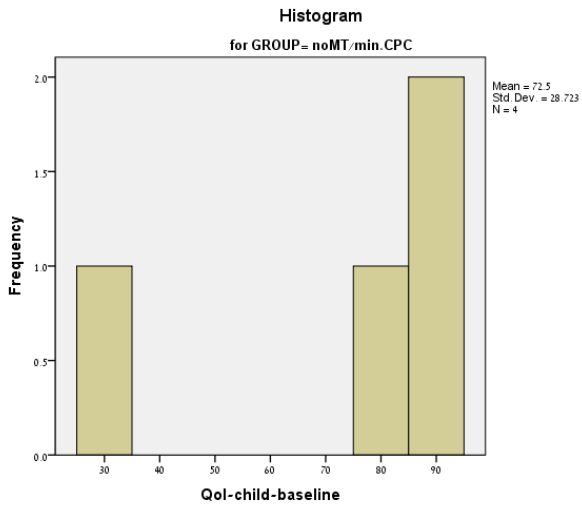
Parents' QoL baseline



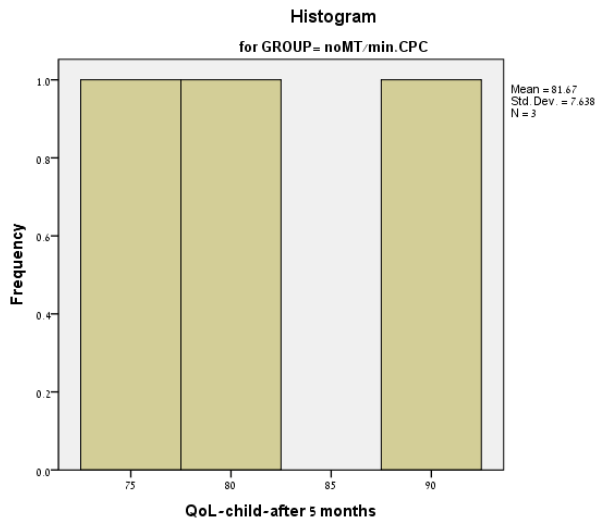
Parents' QoL after 5 months



Child's QoL baseline

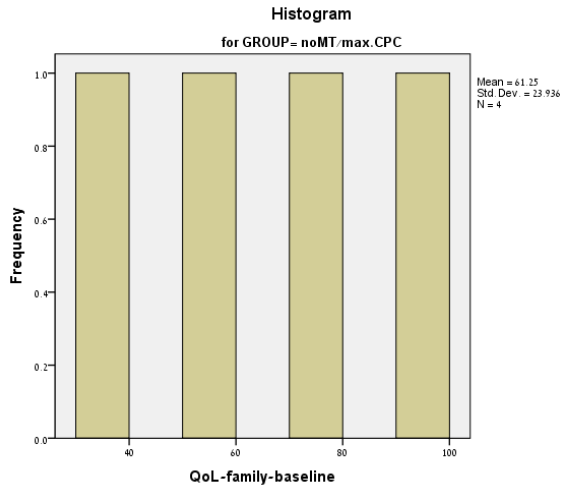


Child's QoL after 5 months

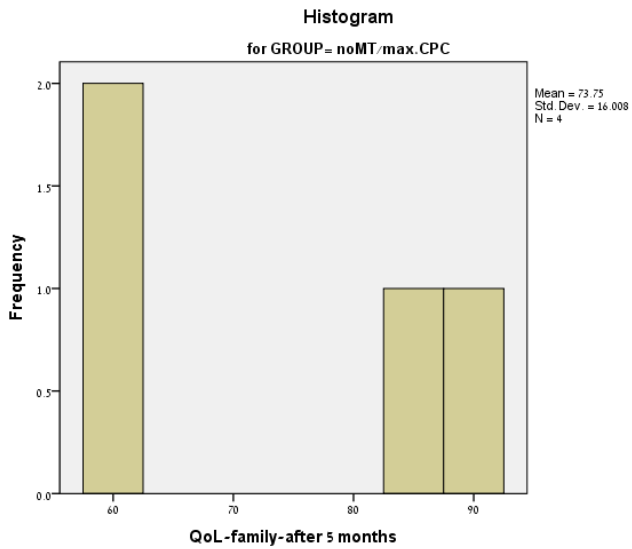


Group 4 (Maximal MOPC/no MT)

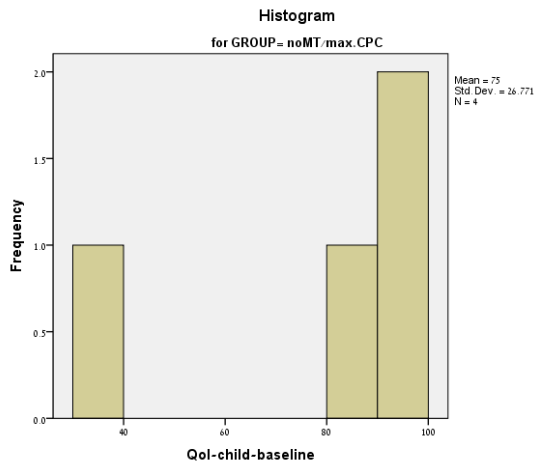
Parents' QoL baseline



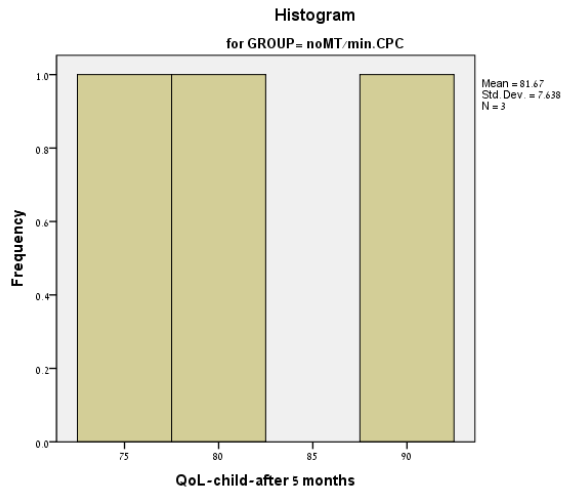
Parents' QoL after 5 months



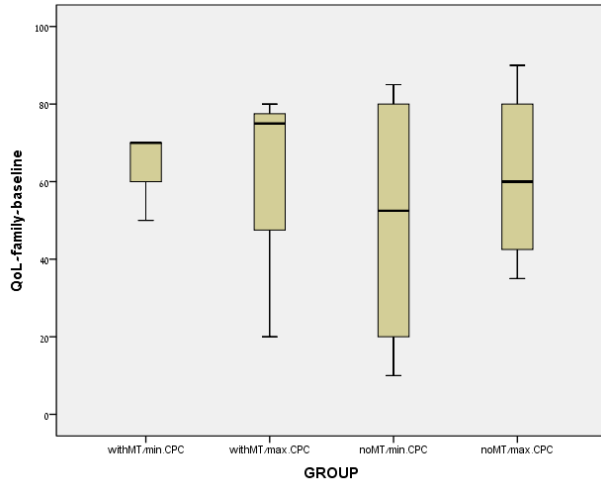
Child's QoL baseline



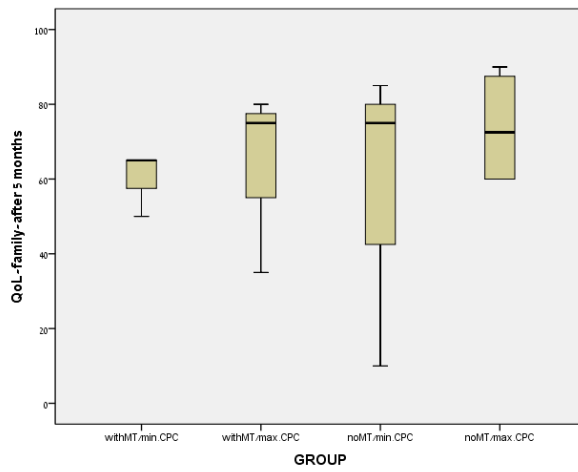
Child's QoL after 5 months



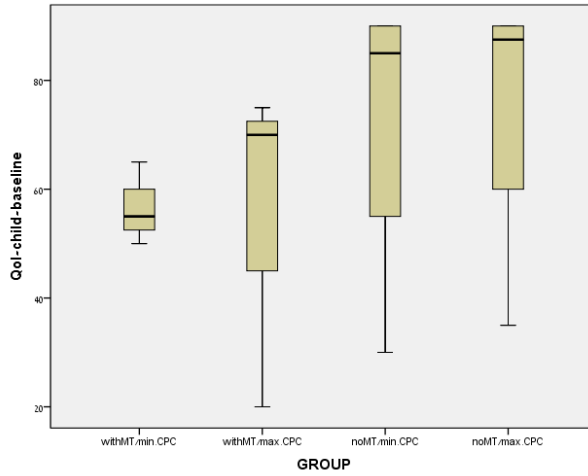
Parents' QoL baseline across groups



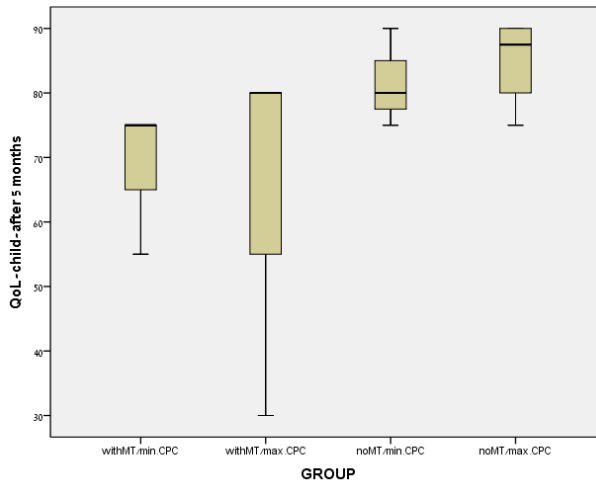
Parents QoL after 5 months across groups



Child's QoL baseline across groups



Child's QoL after 5 months across groups



APPENDIX N. ETHICAL APPROVAL UNIVERSITY OF HAIFA

אוניברסיטת חיפה
University of Haifa

הפקולטה למדעי הרווחה והבריאות
ועדת האתיקה לנסויים בבני אדם
Faculty of Social Welfare & Health Sciences
Faculty Ethics Committee

אוניברסיטת חיפה
חוגגת 40 שנה
ליזום השותפות
University of Haifa
Celebrates 40 Years
THE ISRAELI MOSAIC

30 בינואר 2013

לכבוד:

ד"ר כוכבית אלפנט, טלי גוטפריד

ביה"ס לטיפול באמצעות אמנויות

שלום רב,

הנדון: תרפיה במוסיקה והדרכת הורים לילדים על הרצף האוטיסטי
(אישור מס' 031/13)

הנני מתכבד להודיעכן שהוועדה הפקולטטית לבדיקת מחקרים בבני אדם עברה על הצעת המחקר והמסמכים הנלווים שהגשתן. הוועדה התרשמה שמדובר במחקר שעונה על הקריטריונים של מחקר אתי ומאשרת אותו ככזה.

מיותר לציין שהאחריות על ביצוע המחקר לפי הכללים של אתיקה מחקרית ומדעית נשארת אצל החוקר.

אנו מבקשים שתציינו את מס' הבקשה על כל הצעת מחקר, דו"חות, פרסומים וכדומה, לדוגמא: "מס' אישור ועדת אתיקה לנסויים בבני אדם, אוניברסיטת חיפה, מס' אישור _____".

אנו מאחלים לכן הצלחה בהמשך העבודה.

בברכה,

ד"ר גיא אנוש

יו"ר ועדת האתיקה הפקולטטית

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