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Music therapy for children with Autism Spectrum Disorder

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CHAPTER 1.

Introduction

Autism

An Autism Spectrum Disorder (ASD) is a developmental disorder characterized by deficits in social interaction and/or the presence of restricted, repetitive behaviors (American Psychiatric Association, 2013; Wing, 1997). ASD appears to be highly hereditary: in a cohort study in which 22,156 people were diagnosed with ASD, the heritability of Autism Spectrum Disorder was estimated to be about 80% (Bai et al., 2019). It does not appear that ASD is caused by one single gene. It is a combination of multiple genetic changes, influenced by social-environmental factors. It is suspected that this combination causes the brain to develop differently (Masi et al., 2017). An ASD diagnosis has substantial direct and indirect social consequences that span many different societal areas, including health care, education, social care, housing, employment, social services, and labor market (Buescher, 2014; Ganz, 2007).

The most recent estimates of the prevalence of ASD range from 1 in 59 to 1 in 77 children in the United States (Baio et al., 2018; Pinborough-Zimmerman et al., 2012). To date, no research has been conducted in the Netherlands regarding the number of registered diagnoses of ASD but in a 2018 health survey by the Central Bureau of Statistics (CBS), 3 percent (1 in 33) of parents with children aged 4 to 12 years indicated ASD, which amounts to approximately 43 thousand children.

As mentioned, problems in the area of social communication and exhibiting limited or repetitive behavior are the core problems of ASD. Social communication and interaction refer to language development, the quality of (non-)verbal communication, and the quality of and interest in social interaction (APA, 2013). Children with ASD often exhibit less than usual social and emotional reciprocity so that others often perceive interactions with them as one-way. The lack of reciprocity manifests itself, among other things, in problems with matching verbal and nonverbal behavior to the constantly changing social context (Murray et al., 2009). Restricted and repetitive behaviors include stereotypes in behavior or in language, rituals or routines, limited interests, and hypersensitivity to stimuli. The degree to which these behaviors manifest in this area depends on the cognitive level. In this dissertation we focus on problems in social interaction and communication of children and adolescents with ASD between the ages of four and eighteen. From here on whenever we speak of children with ASD we refer to children and adolescents with ASD.

ASD, social interaction and communication

The problem in social communication and interaction is often the most prominent feature in ASD. Children with ASD engage in significantly fewer social interactions with peers than children with "normal" development (Bauminger et al., 2003; Call et al., 2016; Humphrey & Symes, 2011). This has major implications for them when it comes to building and maintaining a relationship or when interaction is expected. Because children sometimes have difficulty empathizing with the feelings and thoughts of others or have difficulty dealing with information they receive, problems with reciprocity arise. As a result, they often develop fewer friendships (Kasari et al., 2011). When the child does manage to engage in social contact, there is often an increased level of stress and uncertainty. It seems that the amount of information to be processed creates busy traffic in the brain resulting in overstimulation. It is then no longer possible to respond

in a deliberate and conscious manner (Corbett et al., 2014; Lopata et al., 2008). One problem strongly associated with difficulty with social interaction is communication. This is not just about communication in the form of spoken words, it can also involve gestures or facial expressions. Without directing or recognizing signals associated with sending and receiving a message, there is limited communication. For children with ASD, this social communication is often difficult to understand which makes their ability to interact difficult. As a result, they sometimes lack the interest and motivation to socially interact with others (Adamson, Deckner, & Bakerman, 2010; Corbett et al., 2014).

Music Therapy

ASD is a lifelong disorder. However, with targeted treatment the children's skills can be improved so that the effects of the disorder become manageable. In the treatment of children and adolescents with ASD, a wide variety of behavioral and psychosocial interventions are used (Weitlauf et al., 2014). Some examples include Applied Behavioral Analysis (Bear, Wolf & Risley, 1968), Pivotal Response Treatment (Koegel & Koegel, 2006), FloorPlay (Dishoek, Dietz & Wiel, 2016), Theory of Mind training (Begeer et al. 2011) and psycho-education. A growing body of research on the effects of interventions suggests that positive outcomes for children with ASD are achieved when a behavioral intervention is used (Health Council, 2009). But there is still a need for studies that examine these interventions in different settings to discover which active elements are responsible for the effectiveness and whether the positive results are consistent. The use of nonverbal therapy such as music therapy can add value when social interaction and communication issues arise. This is because this type of therapy helps with expressing feelings and making contact in a more creative and/or active way, without necessarily having to talk.

Music therapy is used on a regular basis in the Netherlands for children and adolescents with ASD. This therapy is offered in an institutional context, within (special) education and in an outpatient form. Since communications skills are less developed and engaging in social interaction is less natural, it seems that music therapy can play an important role in the treatment of children with ASD. Music therapy can provide an additional means of communication that stimulates children with ASD to engage in social interaction to express their needs and emotions. Through music therapy, they can learn how to deal with social situations and be given skills to do so. In this way, it is expected that through music therapy, children and adolescents with ASD will experience fewer problems in social situations arising from their inadequate social behavior.

The rationale of music therapy is that nonverbal experiences can stimulate changes in mood and/or behavior. The therapist employs the musical elements of measure, rhythm, melody, harmony and sound through the use of musical instruments, voice, musical forms of play, improvisation and existing repertoire. The American Music Therapy Association (AMTA), describes music therapy as follows "*Music therapy is the clinical and evidence-based use of music interventions to meet individualized goals within a therapeutic relationship by a licensed professional who has completed approved music therapy training*" (AMTA, s.d.). However, in practice we see that many steps still need to be taken to fully endorse this definition. In the Netherlands, most music therapists are affiliated with the Netherlands Society for Music Therapy and the related Register for Professional Therapy (Register Vaktherapie). In order to be admitted to this association,

the music therapist must have completed training at one of the recognized programs of the Universities of Applied Sciences. The registry also requires active continuing education and training. However, working according to a substantiated evidence-based intervention program is often lacking.

There is not yet an inventory of which music therapy interventions are used for the treatment of children and adolescents with ASD and the possible results. As a consequence, there is still insufficient knowledge about what the therapy actually entails. This also makes it difficult to examine the effects of music therapy on children and adolescents with ASD.

Nevertheless, several studies have been carried out on effects of music therapy treatments of children and adolescents with ASD (see, among others, Accordino, Comer, & Heller, 2007; Geretsegger et. al., 2014; Hernández, 2011; Simpson & Keen, 2011; Wigram & Gold, 2006; Wipple, 2004). Based on these studies, it can be concluded that there is some evidence that music therapy has an effect on the social functioning of the children. But this evidence is still insufficient to say that music therapy is evidence-based. Strictly speaking, the idea that music therapy improves the social behavior of children with ASD is still an ill-substantiated hypothesis.

Purpose and structure of this thesis

The aim of this thesis is to investigate whether or not offering music therapy is associated with a positive improvement that is visible in the development of the social behavior of children with ASD. To achieve this goal, the steps as shown below in Figure 1 were followed.

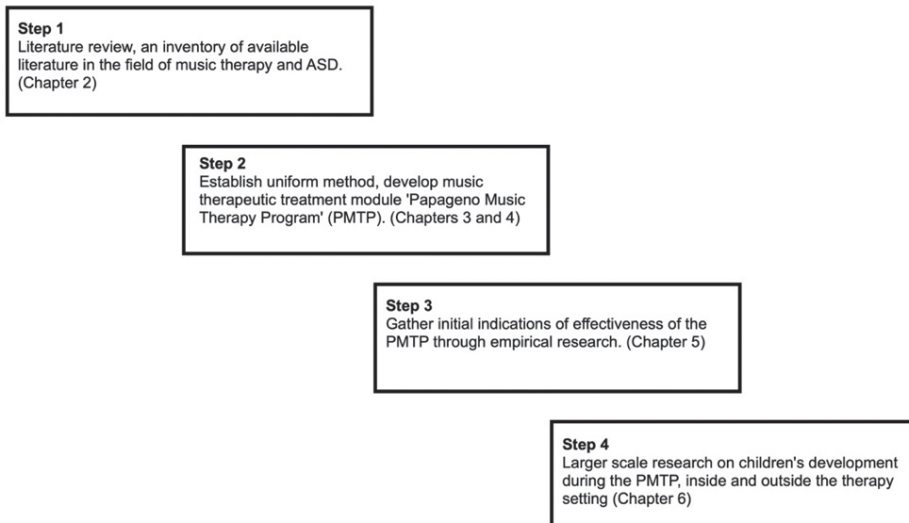


Figure 1

Step 1

The first step to achieve this goal is a literature review on music therapy in children and adolescents with ASD. The central question here is: what goals and results have been described so far about music therapy with children and adolescents with ASD, and what interventions are being used to achieve these goals? The result of this literature review is described in Chapter 2.

Step 2

In order to be able to examine the effects of music therapy in children and adolescents with ASD, it is important to establish a uniform intervention. For this purpose, the music therapeutic treatment module Papageno Music Therapy Program (PMTP) for children and adolescents with ASD was developed. The Papageno Foundation - owner of this program - always tries to offer therapy in the home situation so that the child does not have to leave his/her safe environment and there is a short, direct line with parents and other family members. The Papageno foundation was founded by Aaltje van Zweden-van Buuren and her husband, Dutch conductor Jaap van Zweden, and offers help to children and adolescents with ASD using music therapy (<https://www.papageno.nl/en/>).

A key element in the development of the PMTP is that it is developed through practice-based research in which expert input is gathered along with input from the literature review from Step 1. To this end, surveys were conducted, in-depth interviews were done, and videos were analyzed: three different data collection techniques to gain insight into knowledge from practice. The three techniques followed a pattern, going from general information to increasingly specific information.

To continue to clarify the method in PMTP post-development and to gain more insight into its presumed active elements, an intensive video analysis of sessions in which PMTP is offered was used. The analysis uses the stimulated recall method (Lyle, 2003) and aims to provide insight into the professional actions of the music therapist. It provides insight into the motivations behind the music therapist's actions. The stimulated recall method is an introspective method used to retrieve cognitive processes. Using a video recording of a person's actions, in this case the music therapist during music therapy, the therapist is asked afterwards to articulate his or her thoughts at the time of the recording (Glass & Mackey, 2000; Lyle, 2003). This provides information about the techniques and methods used during music therapy sessions, which serves as a starting point for further research. It also provides insight into the supposedly effective elements within music therapy for children and adolescents with ASD. The analyses were used to standardize the therapists' practices. The results of this study are described in Chapter 3.

Chapter 4 provides a case study that illustrates what the Papageno Music Therapy Program is, how it is used and what the associated effects are. PMTP was used to improve the social behavior of an eight-year-old boy with ASD. Contact with other children was very difficult for him which made him increasingly less self-confident. In addition, it was difficult for him to recognize emotions in himself and others which gave him a lot of anxiety. PMTP was offered for 20 weeks and developments within music therapy were tracked through a questionnaire that the mother completed weekly. This case study explores in detail what happens during the course of PMTP and what developments the child shows.

Step 3

A next step is to collect initial indications of the effectiveness through empirical research regarding the course of children's social behavior development before and during PMTP (Chapter 5). To answer the question of whether the social behavior of children with ASD improves when PMTP is offered, a repeated $N=1$ study design was used, including a baseline as a control condition, in which ten children were observed for 23 weeks. Their social behavior was scored weekly: 3 weeks prior to and 20 weeks during therapy. This design was chosen because it enables us to intensively observe the development of the children before and during PMTP.

Step 4

As a final step, in a larger-scale study, we studied children's development during therapy with the question of whether the changes we observe in therapy can also be observed in other social contexts. Chapter 6 describes the results found with a group of 40 participants. A non-experimental multiple-informant design was used to assess the development of the children's behavior in different situations: therapists and parents as informants that are directly involved and other family members and teachers for observation with a little more distance. In this way, the behavior could be evaluated in different settings and we could form a picture of the development of the children's functioning from different perspectives, inside and outside the therapy setting. The 40 children were observed over a 20-week period during which they were offered weekly music therapy according to PMTP.

The discussion (Chapter 7) elaborates on the significance of the results of the study and makes recommendations for further research, practice, and policy.

