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Music therapy for children with Autism Spectrum Disorder

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CHAPTER 7.

Conclusion and Discussion

Conclusion

The purpose of the studies presented here is to investigate whether by offering PMTP there is a visible improvement in the development of the social behavior of children and adolescents with ASD.

To accomplish this, in Chapter 2 a literature review was conducted to determine what goals and outcomes have been described to date regarding the use of music therapy with children and adolescents with ASD and what type of interventions are being used to achieve these goals. In addition, it was also clarified what therapy entails in practice by developing the Papageno Music Therapy Program, examining what elements might be responsible for a change in social behavior (see Chapter 3), and conducting a single case study to illustrate the process in therapy and the development a child shows during the program (see Chapter 4). Then, initial indications of effectiveness were explored through empirical research regarding the course of social behavior development before and during music therapy among ten children (see Chapter 5). Finally, a larger-scale study focused on the development of 40 children with ASD during therapy with the question of whether the changes we see in therapy can also be seen outside of therapy (see Chapter 6). This strategy fits well with Robey's (2004) model.

Robey's five-stage model for studying the effectiveness of an intervention begins with a "pre-trial" study. In the first phase, the intervention and its supposed effects are identified, this was done through the literature review (Step 1). In phase two the feasibility of a larger study is examined. This is done through the case study to see if any effects were found (Step 2). In phase three we start testing the effectiveness of the intervention, we did this by looking for the active elements (Step 2) and collecting the first indications of effectiveness (Step 3). This is a prelude to phases four and five in which the intervention is compared to another intervention, and it is determined whether the therapeutic effect is also achieved in daily clinical practice. A start was made by means of a large-scale study which also looked at the progress within and outside the therapy setting (step 4).

Music therapy already has a long history as an intervention with children and adolescents with ASD who experience severe social and community difficulties (Reschke-Hernandez, 2011). This treatment method uses the medium of music to create experiences that stimulate people's developmental process. The therapist is able to identify and interpret the human response to music, employing the musical elements of beat, rhythm, melody, harmony, and sound through the use of musical instruments, voice, musical game forms, improvisation, and existing repertoire (Kern & Humpal, 2012). The findings of this dissertation show a number of things.

Many studies lack a well-defined description of the target group and the intervention

The literature review in Chapter 2 on the status of the development and effectiveness of music therapy shows that although studies confirm positive effects of music therapy in children and adolescents with ASD, there are many critical comments to be made about the research conducted. In addition to the fact that the number of subjects in the studies is usually very small, another criticism is the wide variety of music therapeutic forms used. To properly study

the effects of an intervention such as music therapy, a well-bounded description of the target behavior is important. What is the focus of the treatment and what are the goals? It is also important that the intervention is well defined and that a clear manual is used so that the intervention can be offered in an unambiguous way. Effect studies of music therapies that focus on improving communication skills often lack clear definitions and operationalizations of these skills. In addition, in many studies the target group remains unclear, despite the importance of a clear identification of the cases included (Van Loon, Van der Meulen, & Minnaert, 2015). This is especially important in children and adolescents with ASD because this disorder is expressed in many different ways. As a result, it can be expected that in many studies the heterogeneity of the target group is very high. Once these elements are clearly defined, it is important to choose the right tools to measure the effects. This way we can transparently draw conclusions about the effectiveness of the treatment.

Music therapy can be well-characterized and described

In practice we see that music therapists often find it difficult to express and explain what they actually do. Nevertheless, in our experience, music therapy can be described quite well. The important thing here is not to try to describe music therapy in general, but to focus on a specific method that is offered to a specific target group.

Through qualitative practice research, an inventory was made of what methods and elements seem crucial within music therapy treatment for children with ASD (Chapter 3). Where music therapists initially indicated that they mainly worked intuitively, there were indeed major similarities in the working method with these children. They often used the same (improvisation) working methods, in which they initially sought to connect with the child.

During treatment with PMTP, the therapist uses an intervention guide (Pater, 2016). This manual describes the working methods that can be used. The techniques described in the intervention guide are consistent with Kenneth Bruscia's improvisational techniques (1987). Techniques used include: empathy techniques, structuring techniques, prompting techniques, techniques to take back the lead, techniques related to intimacy, procedural techniques, referral techniques, and techniques to explore emotions. In addition, structured methods are also offered that use musical parameters (sound, rhythm, melody, dynamics and form; Hegi, 1996) to facilitate change. Based on the needs of the child, the therapist can choose the most appropriate forms of work.

Subsequently, the presumed effective elements of PMTP were further investigated using video recordings. Videos of PMTP therapies with 14 children with ASD were analyzed. These analyses formed the input for an interview with the music therapists using the Stimulated Recall Method. These interviews were then developed so that they could be coded and analyzed. After data analysis, five categories of elements that stimulated change in social behavior in children and adolescents with ASD were presented: Setting, Communication, Musical Elements, Connecting, and Challenging, as described in Chapter 3.

These categories were then incorporated into an initial working model showing how changes in the social behavior of these children and adolescents occur during the music therapy process. The therapist's constant adaptation to the child appears to be an important element of this process. When the therapist, by adapting, connects with the child, he can then bring about change by initiating challenging activities. In order to illustrate and further concretize the method within the Papageno Music Therapy Program, a single case study, described in Chapter 4, was carried out first. This study report shows the added value of a music therapy treatment in an 8-year-old boy with ASD as an addition to the regular offerings in clinical practice.

Further research provides initial indications of effectiveness

***N*=10 repeated case study (Chapter 5)**

Indications of effectiveness of the Papageno Music Therapy Program were found when 10 children with ASD were observed for 23 weeks. The study shows that during 20 weeks of music therapy, a significant improvement is visible in the social behavior of children with ASD. All participants show significant change on 2 or more aspects of problematic social behavior compared to a pre-measurement ('baseline'). These changes are strongest in the areas of 'can handle change', 'behavior is adapted', 'can communicate verbally', 'can take into account another person' and 'takes initiative'. We also examined whether this improvement in behavior could be associated with the intervention phase. For the items "dealing with change" and "takes initiative" we see that this applies to eight children. For the item "is able to be considerate of others" this is true for seven children and for the item "behavior has changed" this is true for six children. This closer look at the data might imply that there is an acceleration of development during the intervention phase. This study confirmed previous studies indicating that during music therapy the social behavior of children with ASD improves compared to the developmental pace prior to therapy such as the one by Gattino et al. (2011), Lim (2010), Kim et al. (2008), Thompson (2012).

***N*=40 study (Chapter 6)**

A larger scale study of childrens' development when using the Papageno Music Therapy Program also shows improvement in social behavior. On the total VISK and SRS scores, all children show progress in social behavior. The Reliable Change Index, which captures individual-level outcomes, confirmed positive improvement in more than 32 participants ($RCI > 1.96$).

Since the RCI scores of the different groups of informants (music therapist, schoolteacher, parent and family member or babysitter) also show reliable progress, the observed improvement within music therapy sessions seems to generalize to situations outside of music therapy. This study, like the *N*=10 study, confirms previous research on the effects of music therapy on the social behavior of children with ASD: improvements in social behavior are apparent over the course of therapy. We see this improvement not only within, but also outside the therapeutic setting.

Discussion

The aim of this dissertation was to investigate whether by offering music therapy through the PMTP program there is an improvement in the social behavior of children and adolescents with ASD.

The positive results found in this study are not found in all other studies. For example, in a randomized controlled trial, Bieleninik et al. (2017) attempted to substantiate the effects of music therapy in children with ASD. 364 children aged 4-7 years were included. Based on the Autism Diagnostic Observation Schedule (ADOS) no significant difference was found between the experimental group, which was offered music therapy, and the control group, which received only standard care. The ADOS is a standardized observation tool for examining communication, social interaction, and (imaginative) play. It is administered to children and adolescents with suspected autism spectrum disorder. Broder-Fingert, Feinberg & Mischael (2017) responded critically to the findings of Bieleninik et al. (2017). The conflicting results between Bieleninik et al. (2017) RCT and Geretsegger et al.'s (2014) comprehensive meta-analysis suggests that the effects of music therapy in children with ASD should be examined with a more refined study design.

That the study by Bieleninik et al. (2017) does not confirm previously found effects in favor of music therapy could be explained by the fact that a large research group alone is not sufficient. This study also involved a very heterogeneous experimental and control group. There was also great diversity in the music therapy offered. To overcome this, studying one well-described type of music therapy in a more homogeneous group seems a more promising approach. In addition, it is important to use a stepwise research program that begins with finding an initial indication of the effect of a particular music therapy, followed by an experimental study with a carefully matched experimental and control group (Robey, 2004). We have performed the first step in this dissertation study, with additionally a clearly defined form of music therapy. In follow-up research a matched experimental study of the effects of this therapy could shed a light on the efficacy of the therapy.

In addition, we developed an initial working model that explains which elements might be responsible for the results. Therapists indicate that they mainly rely on their intuition while deploying musical working methods within the therapy, especially in the process of finding a connection with the child and challenging new behaviors. Nevertheless, in discussing the video recordings of the sessions, they were able to explain which techniques they use and why. This seems to indicate that the music therapist has internalized the therapeutic process to such an extent that treatment is performed at the level of 'unconscious competence' (Bijkerk & van der Heide, 2016). By making this more conscious through the discussions, it provides input for the description of the PMTP and the initial working model and offers an opportunity for research into the active elements in this delicate process.

When we look at why ‘The Papageno Music Therapy Program’ would work for children with ASD we see that it contains a number of essential components that are also found in other evidence-based treatment (Smith et al., 2015; Volkmar et al., 2014; NVvP, 2009; Knowledge Center KJP, 2017):

- Good psycho-education. In our case ‘good’ implies three things: parents should receive information about the ASD diagnosis, tools to deal with the diagnosis, and assistance in accepting of the diagnosis (Van Doorn and Verheij, 2002). In most cases, PMTP treatment is given in the familiar environment at home. As a result, there is close contact between the therapist and the parents. There is also a regular evaluation during which video footage can be reviewed. In this way, parents and caregivers obtain a lot of information about ASD and are given tools on how to deal with and accept the diagnosis.
- Integrated approach (home, school and leisure). Because of the use of music within the PMTP treatment, elements of the therapy can be easily integrated into daily practice. Practices that work well within therapy can be shared by the therapist with others parties that are involved. For example, short rhythmic exercises to trigger alertness. Because the PMTP is offered at home, it is easier to apply the skills in daily life (Smith et al., 2015; Volkmar et al., 2014)
- Actively involve the whole family. Because the PMTP therapy is often given in the home situation, there is already a great deal of involvement between the therapist and other family members and the child remains in his/her safe environment. The mere fact that the therapist literally walks around the house with a variety of instruments often stimulates interaction. In addition, other family members also directly see and/or hear what happens during the music therapy and experience the effects.
- Support tailored to the individual. Because the PMTP therapist uses music to connect with the child and continues to work from this connection, the support is always tailored to the child.
- Structured and understandable interventions. Children with ASD have the greatest developmental opportunities when support is provided in a structured environment with clear support (NVvP, 2009). PMTP has a clear format with a lot of predictability for the child. The sessions have a clear beginning and end point. It is also an approach that is accessible and understandable for the child because it uses music and musical instruments. Complicated items such as spoken language can be omitted, if necessary, or can be tailored to the child.
- Systematic approach to the intervention. The well-described program enables the therapists to offer the treatment in a more conscious way.
- But the PMTP adds another specific aspect to this: the non-verbal aspect of music. During this method the music therapist can, for example, play out verbal situations which are difficult, in the music non-verbally. If you cannot speak and cannot verbally express your emotions and feelings, then music could be the communication medium.

However, most of this is still theory. A further, careful evaluation of PMTP is important in substantiating a treatment method. The use of single case studies with repeated measures by multiple informants is then a more sophisticated technique to observe the changes, and what elements may cause these changes. The process of the therapy and the development of the

children can be monitored and evaluated in detail by multiple individuals, allowing for a broad evaluation. By using a multiple informant study design, we were able to get a sense of how outcomes became apparent not only within, but also outside the music therapy setting. We were able to see through this study design that progress was visible in different settings. However, more research will be needed to also determine which elements in particular trigger the outcomes and how permanent the improvement is.

The results of the Papageno Music Therapy Program look promising, yet music therapy by itself will not be sufficient to stimulate the development of children with ASD. There are three types of interventions described in the American Academy of Child & Adolescent Psychiatry guideline that have positive effects in children and adolescents with ASD: intensive behavioral therapy, educational programs, and social-communicative programs (Volkmar et al., 2014). In a 2009 advisory, the Health Council writes that in the treatment of people with ASD, there should be a focus not only on the specific, individual characteristics of the disorder and its impact on functioning, but also on the social and functional context. This therefore also requires the use of PMTP in a wider context of education and support of this particular group.

Strengths and limitations of this study

The present study shows promising results for the Papageno Music Therapy Program to improve the social behavior of children with ASD. However, there are a number of limitations that deserve more attention in follow-up research.

During the study, we wanted to reduce the burden with the number of measurement times for the observers. Nevertheless, we found that it was difficult to get responses from all observers. In this study, we chose to include only the data of those cases that had all measurements from at least three observers (including parents and music therapist). It was especially difficult for the teachers to provide all the data, as they often indicated that they were unable to complete the lists due to the high workload. To reduce missing data in the future, it would be beneficial to develop a shorter, validated questionnaire for measuring social behavior so that it takes less time to complete by observers.

In the $N=40$ study, we found that there was a high degree of agreement among observers. Based on these findings, we can conclude that the use of multiple informants provides a robust picture of behavior both inside and outside the therapeutic setting. In this study we divided the observers into an inner circle and an outer circle, if there was less missing data, we would not have had to merge these groups and would have a better picture of behavior in the different settings.

To analyze the results, we used SMA to see if the progress could be attributed to PMTP or if there was natural growth. When the values of slope 1 (the model that expects that, after a stable baseline phase, the development of social behavior accelerates during the intervention phase, indicating a therapeutic effect) are higher than those of slope 2 (the model that expects that the trend during the intervention phase is not different from the baseline phase, indicating more stable growth), this confirms that observed effects may be attributable to the intervention. In our study, no statement could be made because the values of slope 1 and slope 2 were very close

to each other. This allowed the data trend to be explained by both natural growth and a therapy effect. This may be due to the relatively short baseline phase in our study. Another explanation may be that the progression in values is not very large, which results in that the difference between the baseline and intervention phases is not large enough to observe a clear difference between slope 1 and slope 2 through the SMA. We performed simulations to determine whether these explanations were appropriate. We saw that even for data suggesting a large difference between baseline and intervention phase, the SMA analyses show values of the different slopes that remain close to each other. This may indicate that the SMA sometimes does not differentiate sufficiently. Additional analyses with other techniques allowed us to form a clearer picture of the differences in the baseline and intervention phases, which enable us to identify any intervention effects more sensitively. It is therefore recommended that future studies always combine SMA with such more sensitive analyses.

To see if the observed results are maintained, it is good to do a follow-up measurement. We were able to do this follow-up measurement only in the single case study. Here, we collected data again after six months to see if the progress remained stable once therapy was completed. In the $N=10$ and $N=40$ study, we did not include a follow-up measurement. To see if the observed results are lasting it would be advisable to also include a follow-up measurement in the design right from the start.

The $N=40$ study also included participants who participated in the $N=10$ study. Although this data was good to use together it might be stronger if these studies were performed strictly separate from each other. The strength of two separate studies may be that the second study would be more convincing in the replication if it includes all new cases. In our case, however, including the subjects from the first study did not lead to a unfavorable design. We compared the results from the $N=10$ with $N=30$ and this showed no significant differences. Moreover, in the $N=40$ study we also looked at the degree to which the results within the therapeutic setting were also visible outside this setting.

We can also look back on some strengths. In practice, music therapists indicate that they work primarily intuitively in tuning and adapting to the needs and abilities of the child. Putting into words what is really happening and how actions are taken during therapy often seems difficult (Pater, 2016). This makes it unclear exactly what music therapy entails, how it is used, and what causes that change in behavior. This study has resulted in an initial working model that describes that the elements of form, communication, musical elements, connecting and challenging seem to be responsible for an improvement in the social behavior of children and adolescents with ASD who are offered music therapy. It complements the previously conducted studies that provide insight into the effects of music therapy with this target group.

The use of an intervention guide allowed music therapists to provide therapy in a uniform manner. This made the results more measurable and comparable: the video analysis showed very clearly that intervention was made more comparable and that the therapists acted more purposefully. This gave us a better understanding of what happens during treatment, thus ensuring high treatment integrity.

During the study of the active elements of Chapter 3, it appeared that the music therapists viewed their treatment primarily as a process that takes place at the experiential level and which seems to be difficult to put into words. During music therapy, the therapist often responds to the child's experiences. He looks at what behavior the child is showing or what captures the child's interest. Here the therapist's empathic countertransference plays an important role. This means that the therapist looks closely at what he sees and experiences and adjusts his actions accordingly. Smeijsters (2006) argues that an external reviewer for this process would come to different observations because they do not experience the process themselves. To overcome this, the interview in this study was conducted using video recordings. This provided the opportunity to discuss interpretations of situations within the therapy with the therapists and to test the interpretation.

By first investigating and evaluating whether children with ASD developed more socially appropriate behaviors during a specific music therapy program (PMTP), we got a good indication of the progress that was visible. According to Robey's (2004) model, the use of multiple case study designs is well suited for this purpose. Good examples of similar approaches are the studies by Koegel, Singh, and Koegel (2010), Mucchetti (2013), and Schweitzer et al. (2020). This study design provides us with initial clues as to whether social behavior of children with ASD improves during PMTP, compared to a baseline condition. Moreover, it provided the opportunity to study individual cases in greater depth by collecting and analyzing detailed qualitative and quantitative information after which these results were verified in a larger group.

Recommendations for practice

In daily practice, music therapists indicate that they act primarily "intuitively" (Pater, 2016). As mentioned earlier, this seems to stem from the fact that the music therapist has internalized the therapeutic process to such an extent that treatment is performed at the level of 'unconscious competence' (Green, 2006). This means that the therapist's skills have become an integral part of his or her natural behavior. Since music therapy is an experiential form of therapy, there is a lot of acting in the 'here and now'. The music therapist continually connects to the child's experience and level of understanding. During this study, the therapist's actions were operationalized into an intervention manual, the Papageno Music Therapy Program. This manual is a guide to the working methods to be used during the intervention. For each treatment phase, various working methods are described for the various subgoals. The therapist can select the most appropriate working methods for each phase based on the child's needs. The choices made are noted in a journal kept by the music therapist. The intervention manual also has a decision-making tool on how to involve parents in music therapy. By working with the Papageno Music Therapy Program, the music therapist's work is more insightful and he/she can better articulate what is happening during treatment.

In order to further investigate music therapy for children with ASD, systematic practice using the PMTP protocol and proper reporting are recommended strongly. In doing so, it would be highly desirable if these reports could be designed in such a way that they could directly serve as data collection for research. In this way, data can be collected from daily practice over a longer period of time and from a larger population. This helps to make music therapy more evidence-based in the future practice.

In this study, the music therapist visited the children's homes in most cases. The goal was to involve parents as much as possible in music therapy. In practice, this was not always easy. Some parents did not feel free to actively make music themselves, sometimes it was very confusing for the child if for example the mother remained present, but there were also some parents who saw the therapy time as a "short break" to take some time for themselves. It would be desirable to take stock of how best to involve parents in music therapy. In this way, possibly psycho education for parents can be strengthened.

Recommendations for further research

For future studies, the following options may be considered to avoid the obstacles and limitations that were encountered during this study:

- It is important to have good baseline measurement when using the $N=1$ methodology. A baseline measurement of the child's functioning before the start of treatment is the reference point against which the child's development during treatment is compared (Delsing & Van Yperen, 2017). However, this is difficult with the target group with ASD. Because of the severity of the problems in these children, it is often ethically unjustified to take the time for a thorough baseline assessment. In this current study, the first three meetings were added to the baseline measurements before treatment, and this was used as the control condition. It is recommended that once a child comes into the picture for music therapy, parents are approached directly for a baseline measurement. For example, the time needed to arrange practical matters before starting music therapy can be used as a period for baseline measurement without having to wait an extended period of time for the therapy to begin.
- The heterogeneity and complexity of the characteristics and behaviors of the target population and the complexity of the experiential therapy form, make it difficult to create a robust RCT. Nevertheless, it is recommended that in the future such an RCT is set up to further test the effects found in this study. Given the complexity and diversity of the target group, it is recommended that a group of participants who are offered music therapy be followed for an extended period of time, and is matched with a control group. This involves looking for a case in the control group for each case in the experimental group that is as similar as possible on essential characteristics - such as age, gender, type of problem, IQ, level of communication and social skills at the beginning of treatment. If possible, this matching is done using appropriate techniques, such as Propensity Score Matching (Geurts, et al., 2010). In addition, when data from different, well-defined, therapies is collected over a longer period of time, a more complete picture of the different types of ASD and appropriate forms of treatment can be gathered. This data can then be statistically analyzed to produce more generalizable results. To achieve this, it is important that music therapy providers start working together to generate enough data.
- In analyzing $N=1$ data, even for data suggesting a large difference between baseline and intervention phase, the SMA analyses may sometimes be unable to differentiate clearly between natural growth and an accelerating development after baseline. It is therefore recommended that future studies always combine SMA with more sensitive analyses.
- No child satisfaction measurement was conducted in this study. Including these measurements in the future could contribute to the further development of the treatment

module. It provides insight into which elements are perceived as pleasant and which may need to be adjusted. These outcomes can also be used to test whether they correspond to the possible active elements that have emerged. It is likely that with the help of a child satisfaction survey, these can be further sharpened and used more effectively. We recommend using the measurements in dialogues with (groups of) adolescents and parents about which elements appeal to them and seem to be especially effective and what improvement suggestions there are (Van Yperen, Veerman & Bijl 2017).

Policy Recommendation

Within the municipalities and insurers, music therapy is a rather unknown form of treatment for children with ASD. Because of this, it is not self-evident that the care can be reimbursed. This ensures that music therapists together with parents of ASD children are often in conflict with health insurance companies, local teams, and aldermen to get (appropriate) reimbursement. Within the mental health care sector, insurers in collaboration with the National Health Care Institute, after reviewing whether or not therapies meet the state of science and practice, have determined that music therapy cannot suffice as monotherapy and must always be given in combination with another treatment.

Looking at this current study, the music therapy module PMTP shows good progress on the social behavior of children with ASD. There is initial evidence that this module can be used successfully to reduce social interaction problems. When the module is deployed, it is good that policy makers ask for outcome data so that they can see the results of the therapy and decide whether it should be considered the right help for children and adolescents with ASD.

In conclusion

This study has contributed in an innovative way to the further professionalization of music therapy for children and adolescents with ASD. A unified intervention manual was developed based on a literature review and practice research. This was then tested step by step to get indications of effectiveness and active elements. The evidence gathered provides insight into what is happening within music therapy and an initial working model was developed based on this. In addition, it provides clues to the effectiveness of the treatment and shows what the use of music therapy can do for an individual child. Most children show a favorable development in the area of social behavior when the PMTP is offered. Through the use of multiple informants, we saw a great involvement of the observers around the children. Therefore, the study serves as a good starting point to develop more parental involvement in a form of therapy such as music therapy. Because music therapy is an approachable form of treatment for parents, it can help them better understand their child. The PMTP is ready to be further applied in practice on the basis of which the module can be further substantiated and researched.