

Musical behaviour and Sibling Quality of Life

*Exploring the role of Musical Behaviour as a Joint Activity for
Siblings of Children with Profound Intellectual and Multiple
Disabilities.*

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Abstract

Background: Research has shown that Sibling Quality of Life (SQoL) is influenced when a family member has Profound Intellectual and Multiple Disability (PIMD). Previous research stated that it is hard for siblings to find joint activities with their brother/sister with PIMD. A possible activity mentioned in previous research was musical behaviour. The positive effects of music on social bonding have already been acknowledged, but have never been a main topic in SQoL research. **Objective:** The objective of this research was to explore the role of musical behaviour as joint activity for siblings of children with PIMD. These insights could contribute to developing activities for siblings to enjoy with their brother or sister in order to influence the SQoL. **Methods:** In this study, six children aged three to nineteen were included. The group of siblings consisted of two boys and four girls. Firstly, three of the respondents visited a concert organized for families of children with PIMD. Here, non-participative observations, based on the sibling interaction scale, took place. After the concert, the three respondents participated in a focus group. With two of these respondents and three new respondents, participatory observations and semi-structured interviews by use of Photo Voice took place. Analysis of the qualitative results lead to four themes. **Results:** Musical behaviour as a joint activity plays a role in the SQoL in four different ways. First, it is considered a fun activity; second, it is considered a functional tool; third, it is considered an ageless activity and fourth it offers new possibilities for outdoor family activities. **Conclusion:** The results of this research shed a new light on SQoL - namely through the perceptions of siblings instead of primary caregivers – and can be used as a format to conduct further research regarding the possibilities of musical behaviour in improving the SQoL.

Keywords: Sibling, quality of life, Music, Joint activities,

Background

The percentage of children with a disability in the Netherlands has been rising from 2.0% (total of 68.000) in 2011 to 2.8% (total of 92.500) in 2015 according to Steketee, Mak & Tierolf (2017) (*figure 1*). Their research stated that, of all children with a disability in the Netherlands, approximately 10% has Profound Intellectual and Multiple Disability (PIMD).

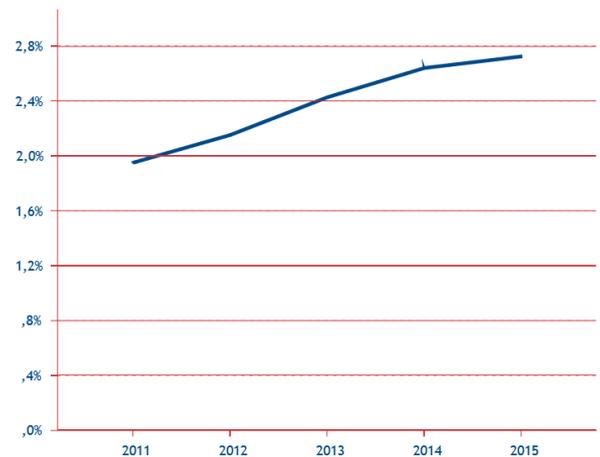


Figure 1: Percentage of children with Disability in the Netherlands.

They described PIMD as a disability that involves a combination of sensory-, mental- or physical disability. Children with PIMD have an IQ ≤ 25 , sensory impairments and severe motor disabilities that can cause inability to move independently.

The consequences of PIMD do not just affect the child itself, as most children with PIMD are raised at home surrounded by family (Hastings & Taunt, 2002). According to Moyson and Roeyers (2012), having a child with PIMD does not only require more care from the parents, it also has an effect on the other family members and, with that, influences the family system as a whole.

Family Quality of Life

Family is a child's most important environment and is often the factor that most significantly shapes its life and sense of belonging (Samuel, Tarraf & Marsack, 2018). Therefore, Family Quality of Life (FQoL) has become an increasingly relevant concept in developmental research during the last decade (Moyson & Roeyers, 2012; Luijkx, Van der Putten & Vlaskamp, 2016). It is all about having a life that is both good and meaningful for every member of a family. Therefore it is a concept that is best viewed from an individual's perspective.

On the one hand, FQoL is intended to describe the quality of life of all family members and on the other hand it is intended to describe the quality of life of the family system as a whole. It is, however, also intended to describe the way these two concepts influence each other, according to Brown & Brown (2003). Research has shown that FQoL is influenced both positively and negatively when a child in the family has PIMD (Turnbull, Brown & Turnbull, 2004).

Sibling Quality of Life

Apart from parents, siblings are a very important factor in the life of a child with PIMD because their relationship with their siblings is likely to last longer (Luijkx, Van der Putten & Vlaskamp (2016). Many siblings keep playing a role in the life of a child with PIMD, even after reaching adulthood. They often take over caring roles when parents are no longer able to do so (due to old age for instance) (Orsmond, & Seltzer, 2000). Also, individuals with PIMD interact more with their siblings than with their peers with PIMD. Interacting with siblings is more likely to be motivating and encouraging (Nijs, Vlaskamp & Maes, 2016). For these reasons, wellbeing of the sibling is an indispensable factor of FQoL.

Most of the FQoL research concerning children with PIMD has been conducted by interviewing the parents or main caregivers to provide information about the FQoL on behalf of themselves and other family members such as siblings (Moyson & Roeyers, 2012; Luijkx, Van der Putten & Vlaskamp, 2016). The results of FQoL researches may be biased, due to the fact that siblings and parents have a different view of the influence of a child with an intellectual disability (ID) on the FQoL, according to Guite et al (2004). They concluded that siblings are generally more positive in their views of the relationships with their PIMD sibling than their parents are about the relationship between their children. As a matter of fact, Cuskelly & Gunn (2003) have found that the relationships between siblings that include a child with a disability

may be more positive than the relationship between siblings without PIMD, because less unfriendly behaviour and more positive interaction was reported.

Moyson & Roeyers (2012), were the first to not only look at the FQoL, but to introduce a whole new field of research: the Sibling Quality of Life (SQoL). They stated that there are hardly any studies in which the researchers have investigated how (young) siblings experience being siblings of a child with a disability. They designed a more general concept to describe the SQoL: ‘the Nine Domains of Sibling Quality of Life’ (2012). These domains were defined as: joint activities, mutual understanding, private time, acceptance, forbearance, trust in wellbeing, exchanging experiences, social support, and dealing with the outside world.

PIMD and the Nine domains of Sibling Quality of Life

According to Luijkx, Van der Putten & Vlaskamp (2016) and Roper, Allred, Mandelco, Freeborn & Dyches (2014), children with a disability cannot be seen as one homogeneous group. Sibling relationships may differ, depending on the type of disability. It would therefore not be correct to interpret results of Moyson and Roeyers (2012) as valid for families with children with PIMD. For this reason, Luijkx, Van der Putten & Vlaskamp (2016) used the nine domains in their research that specifically concerned the SQoL for siblings of children with PIMD.

Although siblings were positive in describing personal experiences in almost all nine domains of sibling quality of life, the ‘joint activity’ domain was mentioned more often than the others. This domain describes how the siblings spend time together and how they experience the activities they do together. All siblings described negative aspects such as activities they were not able to do with their PIMD brother or sister, because of (physical) limitations. Some siblings described the ways in which they adapted some of these activities, so their brother or sister could join, but they also described some non-adapted activities such

as watching television and performing music behaviours (all activities that concern music, such as listening- and dancing to music and making music) that brought them a lot of joy.

Music and Sibling Quality of Life

The positive effects of music on social bonding have been acknowledged for a very long time (Boer & Abubakar, 2014) since music contributes to the development of collective identities (Tierney, Krizman, Skoe, Johnston & Kraus, 2013). Moreover, families benefit from music behaviour because it improves mental health and subjective well-being and it mobilizes social cohesion.

Recent studies by Boer & Abubakar (2014) stated that musical behaviour can help establish strong social and emotional bonds within a family, because in a home environment it contributes to

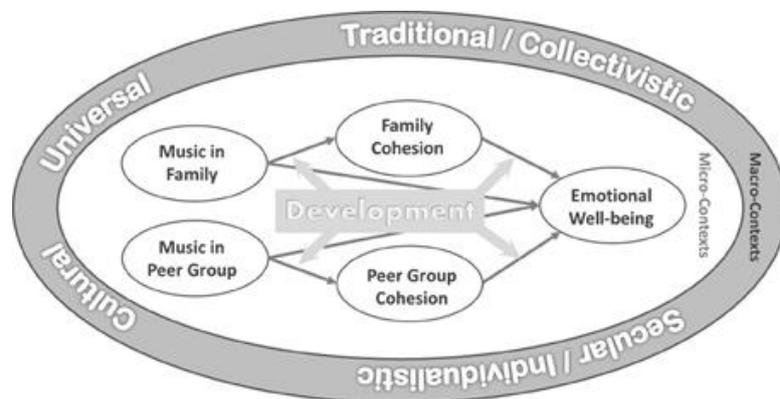


Figure 2: culture sensitive developmental model of music in families and peer groups and their effects on cohesion

triggering positive autobiographical memories. They found that musical behaviour does not only positively influence the family cohesion, but also the peer group cohesion. They established an overall research model on how music influences these two types of cohesion (figure 2).

No research has yet been conducted on the musical behaviour of siblings of children with PIMD in the Netherlands. Siblings have pointed out that they enjoy joined activities with their brother/sister with PIMD, but that it is hard to find such activities. Performing musical behaviour as a joint activity is expected to play a role in the SQoL. Therefore, the main objective of this research will be exploring the role of musical behaviour as a joint activity for

siblings of children with PIMD. These insights can contribute to developing useful activities for siblings to enjoy with their brother or sister in order to positively influence the SQoL.

Methods

In order to gain insight into the possibilities of the use of musical behaviour as joint activity to improve the SQoL for siblings with a brother or sister with PIMD, explorative qualitative research took place in the form of literature research, a focus group, several participative and non-participative observations and semi-structured interviews.

Participants

In this research, six children were included. The group of siblings consisted of two boys and four girls, aged between three and nineteen years. The characteristics of the group of participants can be found in *table 1*. All the respondents lived in the Netherlands with their parents and had one brother or sister with PIMD. Respondents were selected based on two criteria used and described by Luijkx, Van der Putten & Vlaskamp (2016).

The first was the age of the sibling (without PIMD). Luijkx, Van der Putten and Vlaskamp included children aged six to thirteen. For this research, the inclusion for age was based on the same age inclusion at first. This age group turned out to be too narrow and needed to be broadened because of two reasons: first of, it was more practical, because there was a set deadline for the research that served as a master's internship. The research had to be conducted within five months and therefore it was better to be able to approach more siblings for participation. Secondly: there was no research conducted among the very young siblings with regards to their SQoL. Their narratives have not been recorded yet, which leaves out crucial information.

<i>Respondent</i>	<i>Age</i>	<i>Residence</i>	<i>Gender</i>	<i>PIMD sibling is:</i>	<i>Concert/focus group</i>	<i>Observation</i>	<i>Interview</i>
1*	3	Amsterdam	F	Older (F)	Yes	Yes	Yes
2	4	Heemskerk	M	Older (F)	No	Yes	Yes
3	6	Veenendaal	M	Younger (M)	No	Yes	Yes
4*	7	Amsterdam	F	Older (F)	Yes	Yes	Yes
5	11	Rotterdam	F	Younger (M)	Yes	No	No
6	19	Winterswijk	F	Older (F)	No	Yes	Yes

*Respondents 1 and 4 are sisters.

Table 1: Respondents overview

There is a lot of supporting evidence that it is possible to conduct qualitative research among very young children by use of several techniques. Examples of these techniques are: Photo Elicitation (PE) where children are shown existing photographs or pictures to stimulate conversation and PhotoVoice (PV) where children are asked to take pictures or make drawings themselves, to indicate subjects they want to talk about (Zartler & Richter, 2014; La Rooy, Heydon, Korkman & Myklebust, 2016; Alaca, Rocca & Maggi, 2017; Dockett, Einarsdottir & Perry, 2017). For these reasons, the inclusion criteria on age for this research was set as: Siblings between the age of three and twenty one.

The second criterium that was set, was the type of disability of the brother or sister. In this research only siblings of children with PIMD as described by Nakken & Vlaskamp (2007) were included. In their research they speak of: “Individuals with PIMD have two key defining characteristics: (a) profound intellectual disability and (b) profound motor disability. They also have a number of additional severe or profound secondary disabilities or impairments. We can describe these individuals only in terms of ‘more or less’ belonging to the core group or related groups. Perhaps we should even talk about a profound intellectual and multiple disability *spectrum*.” (pg. 85).

Approaching the respondents.

At the start of the research, a concert was organised by “Stichting Omega” in Amsterdam (February 9th). This is a daytime facility for children with PIMD. The concert was organised by the parents of one of the children with PIMD that go to Omega, and was meant to offer a nice activity for the PIMD children and their families. They started the initiative because they felt a “lack of fun joint activities for families of PIMD children” from their own experience. The organisers of the concert offered an opportunity to perform a (non-participatory) observation during the concert and a focus group afterwards.

Before the concert took place, the organisers send out a questionnaire about some practical matters concerning the concert (music- and food preference for instance). The final question of the questionnaire was about the participant's willingness to join the research in the form of an observation and a focus group. Respondents of the questionnaire could answer this questions with: "Yes, my child would like to participate in this research", "no, my child will not participate in this research" or "I would like to receive more information and will decide at the concert". Two participants (respondents 1 and 4) joined the research this way. A third participant (respondent 5) joined the research at the start of the concert.

In order to approach and provide information to possible participants, a Dutch hand-out was developed (*see appendix*). This hand-out contained information about the research (the background paragraph) for parents of possible participants and information about the observations and interviews for both the parents as the siblings. In order to make the hand-out understandable for respondents of all ages, an easy read version of the description of the observations and interviews was included. Parents were encouraged to go through the hand-out with their children, to make sure they were all well informed. The final page of the hand-out contained a form to sign (the sibling) up for the research (this was not the informed consent) and contact details of the researcher with the encouragement to ask questions if needed.

In order to create a larger group of participants, the hand-out was also spread by means of the so called "snowball effect" through e-mail and social media, such as LinkedIn and Facebook. According to Barglowski, Bilecen & Amelina (2015), snowball effect sampling is useful when the research concerns a population that is harder to approach, such as families of children with PIMD. Three more participants (respondents two, three and six) joined the research this way.

Data collection

Data collection took place by means of different qualitative research methods: broad literature research, a focus group after the Omega concert, participative and non-participative observations (both during and after the Omega concert) and semi structured interviews.

Literature research.

In order to gain insight in the research that has already been conducted concerning PIMD, SQoL and music, extensive literature research was conducted. For this literature research, the online VU library and PubMed were used. The following terminology was used to find the right literature: Sibling quality of life, SQoL, Family quality of life, FQoL, children, PIMD, profound intellectual multiple disability, ID, sibling relationships, music, joint activity. After the initial literature research, field research started. Literature research is, however, an iterative process that took place during the entire research.

The omega concert.

During the Omega concert, a total of 60 people were present. These people came from 16 different families (all with one child with PIMD). Before the start of the concert, the hand-out was available at the “welcoming table” and families were asked once again to join in the research. When the concert began, three children took part in the non-participatory observation.

The non-participatory observation.

Right before, during and after the concert, non-participatory observations with three respondents (one, four & five) took place. The researcher was positioned behind the audience, but had clear vision of the participants. The observations started fifteen minutes prior to the concert (that lasted for one hour) and ended fifteen minutes after. This was done in order to

provide some insight in the difference in behaviour before, during and after the concert, because a change in behaviour was hypothesized.

In order to conduct the observation during the concert, the Sibling interaction scale was used like in the research conducted by Caro & Derevensky (1997). They recorded a set of observed behaviours on the Sibling Interaction Scale: Sibling body position, language, intensity of involvement, amount of sibling pleasure, sibling's choice of activity, attempts to engage, accuracy of reading behavioural cues, child's level of response and sibling's feedback.

Instead of using a scale, the observed behaviours were used to create a format for an observation list in order to offer structure to the observed behaviours at the concert. Behaviours of the three different participants were recorded using three different colours of pencils, in order to be able to make notes on only one observation list instead of three. Both the frequency of behaviours as a description of the behaviours was noted and later analysed. Furthermore, a form of member check took place during the focus group after the concert.

The focus group.

After the concert took place, the families were invited to have drinks and small bites and talk about their experiences during the concert. At this point, the three participants joined the researcher for the focus group, after their parents signed an informed consent as described by the Medical Ethical Board of the VU university in Amsterdam. Before the focus group took place, research by Gibson (2007) was used to tackle difficulties in performing focus groups with (young) children.

The location of the focus group was the library of Omega, where there were enough seats, but also enough room for the interactive parts of the focus group. This location was convenient, because the families were already at the concert and there was no need to arrange transportation. Also, it was a well-known environment for the participants and they felt

comfortable knowing their parents were close. Parents were not present during the focus group in order to avoid information bias due to socially accepted answers (Falkmer et al., 2016; Lyon, 2014; Hartung, 2017).

The focus group was conducted among young children (aged three, seven and eleven) and therefore it was important that the amount of participants was limited (Gibson, 2007). For children aged 6-11, Gibson (2007) set the ideal amount of participants in a focus group on four. During this focus group, the youngest participant was only three years old, so the amount of respondents was limited to three.

Gibson (2007) also states that focus groups concerning young children should not be too long, as they tend to lose focus after 45 minutes. However, people with good moderator skills, are presumed to hold the attention of young children for approximately 90 minutes. The moderator that lead the focus group, had experience in conducting a focus group with vulnerable participants (such as children). She had conducted focus groups before, regarding children and participants with Intellectual Disability (ID). Therefore, the focus group lasted up to 90 minutes.

At the start of the focus group, the moderator introduced herself and explained what was going to happen. Also, as a form of member checking, some of the findings during the observation were shared with the group. The participants got the opportunity to discuss and elaborate on these findings.

In research by Gibson (2007) it was strongly recommended to establish a relationship prior to the focus group. During this focus group, a relationship with (and among) the participants was established by performing an introduction game that was called “the spiders web”. During this game, a long piece of rope was used to make visual connections between the children. The moderator started the game by explaining how it works: The person who held the rope, got to tell something about him-/herself. If a member of the group heard something that

they recognized or had in common, he/she raised a hand and got passed the rest of the rope. This way, many connections were established between the participants. The participants not only felt comfortable, but they could also see that they had much in common. The introduction was ended by asking the participants to tell the group something they don't tell a lot of people. This to gain insight in the level of trust that was developed.

A variety of activities took place to start a conversation about the sibling's brothers/sisters with PIMD. The first activity was the drawing lab, where children were asked to make a drawing of the activities they liked most with their PIMD brother or sister. After drawing, they were asked to tell the other participants about their drawing. The final activity was called "the helping hand" where children were offered a phone to ask difficult questions about joint activities with their PIMD sibling to the other participants. There was a second phone on the table for the sibling that was able to give some advice.

The entire focus group was recorded both with a video camera and with a voice recorder, to serve as data for transcribing. All of the children were offered a disposable camera as a reward for joining the focus group.

The observations at home.

The observations at home with five out of the six respondents (all but respondent 5) prior to the semi-structured interviews, served a double purpose. Firstly, they were conducted to gain information about the joint activities the siblings enjoy at home. Secondly, they served as a way to establish a relationship with the participants and parents that did not join the Omega concert before the interviews took place. Both parents and the PIMD children were present at the time of observations, in order to create both a comfortable as representative environment, to make sure both the siblings and the parents got all the information they needed and the informed consent was signed for the observations and the interviews that took place afterwards.

Considering the age of the children, informed consent was signed by the parents, but children were present and provided with information about the research. Furthermore, children were asked if they joined the research voluntarily.

For the observations at home, the same observation list based on the observed behaviours of sibling interactions was used. After an hour of participatory observation, the child was asked to join in a semi-structured interview in absence of the parents.

The semi-structured interviews.

The five interviews took place right after the observation, after the siblings got a chance to get to know the researcher and were comfortable to speak openly. Parents were absent during the interviews for the same reason as the focus group: to avoid information bias.

The interviews started by asking the siblings about some of the findings during the observations, in order to establish a member-check. Afterwards the interviews preceded by means of the interview technique Photo Voice. At first, the plan was to make use of this interview technique by letting the participants take pictures with disposable cameras of joint activities they enjoyed with their PIMD brother/sister, like Luijckx, Van der Putten and Vlaskamp (2016) did. This turned out to be too time consuming. For practical reasons, the decision was made to let the children draw such moments during the interview, instead of showing pictures. The researcher then asked questions like: “why did you draw this?”, “what do you (dis)like about this drawing?” or “can you tell me what you are doing here?”.

The researcher used an interview list with certain topics that were supposed to come up, but no questions were written down. The questions that came up were open-ended questions, in order to gain as much information as possible. The interviews took 20 minutes on average and were all recorded by use of a voice recorder in order to be transcribed.

Data analyses

The collection and analysis of data was an iterative process during the whole research in which collecting and analysing data alternated.

All data was analysed separately by means of the “open analysing method” and afterwards, the results of the analysis of the focus group, the observations and the interviews were compared.

For practical reasons, the results of the focus group were not transcribed literally, but the voice recorder played the recordings while the researcher analysed the quotes of the children. Important quotes were written down on coloured pieces of paper (one for each theme) and got assigned a label.

After the focus group was performed, analysis of the observations during the Omega concert took place, in order to interpret certain behaviours according to the first three themes that were established: recreation, music and age & outdoor activity.

The interviews were all transcribed literally and the quotes were assigned to one of the themes. From the interviews, a fourth theme was established: function.

In order to enhance the validity of the research, the analysis of the research was discussed with fellow researchers and some of the labelling and coding was adjusted (triangulation). Peer debriefing took place at the 2019 International Association for the Scientific Study of Intellectual and Developmental Disability (IASSIDD) conference, where the research was presented to other researchers within the disability field. Here, three researchers (from Ireland, Sweden and Holland) showed interest in this study and asked to join in future research regarding music and SQoL.

Results

The research was conducted by use of a variety of methods for data collection. All the data was analysed by use of the same (analysis) and lead to four topics that will be discussed accordingly: ‘recreation’, ‘function’, ‘music and age’ and ‘outdoor family activity’.

Recreation

The first theme that came up during the analysis, was recreation. All results that were assigned to this topic, had something to do with musical behaviours that served the same purpose: enjoyment.

The Omega concert observation.

At the start of the observation, two of the three respondents (1 & 4) were already present at the venue. Their parents were the initiators of the concert, so they were present several hours before the other guests arrived and the concert started. Respondents 1 & 4 were running around, chasing each other and not paying much attention to their PIMD sister. They were laughing, giggling and shouting a lot and were told several times to keep it down by their parents that were setting up for the other guests to arrive. Respondent 4 was assigned some small tasks by her mother such as setting tables and poring drinks. Both respondent 1 and 4 were enjoying their time prior to the concert, but there was no interaction with their PIMD sister observed.

Fifteen minutes before the actual concert started, respondent 5 arrived with her mother and her PIMD brother. She stayed close to her mother at first and did not engage much with the other guests, until respondent 4 and her mother came up to them to engage in conversation. She engaged in conversation with respondent 4 and seemed to enjoy this. Shortly after, the concert started.

During the concert, respondents 1 and 4 were laughing, dancing and singing along with the music. They interacted with their sister from time to time by taking her hand, dancing and singing with/at her. Respondent 1, however, seemed to gravitate more towards her mother and seemed to enjoy her mother's attention a lot. Respondent 5, however, was very much engaged with her PIMD brother. She sat right next to him, held his hand, touched his cheek from time to time and looked into his eyes with a smile.

After the concert, all three respondents joined the researcher for the focus group.

The Omega concert focus group.

During the focus group, after playing the introduction game 'the spider's web', the respondents were asked to make two drawings: one of the activities they enjoyed without-, and one of the activities they enjoyed with their PIMD sibling. First, respondent 5 mentioned some of the activities she enjoyed, but her PIMD brother was not involved in. She mentioned the limits in their interactions:

"I really like to play outside and run around, play football and other games with my friends, but of course my brother does not join us. He cannot even talk! And he cannot walk! So what should I do with him?" ... "we do watch some television together, but sometimes mommy or daddy do not allow us to."

- Respondent 5

Respondent 4 mentioned that she did not always mind the fact that her sister could not always join in the activities she liked:

"I really like to listen to music, I sing in a children's choir, and take painting lessons. At night, before I go to bed, I like to read books. I really like to do some stuff with both of my sisters, but I also like that I go away for my singing- and painting lessons."

- Respondent 4

She did, however, mention some of the joint activities she enjoys with her PIMD sister:

“but with my sister I only listen to music. We dance to the songs we like. She also likes it when I read to her from the bible before we go to sleep. We sit on her bed together.”

- Respondent 4

Respondent 1 did not mention any limitations with regards to her interactions with her sister. She did mention one activity she played with her sister that morning:

*“I like to play a game with *name PIMD sister*. It is the balloon game”... “I take a balloon and throw it in the air. She laughs a lot when I do that.”*

- Respondent 1

The participatory observations.

All respondents were enjoying musical behaviour at one point during the observation.

Respondent 1 and 4 were dancing to a YouTube video with their PIMD sister. Respondent 2 was mostly playing outside on the trampoline. The second part of this observation took place on the playground, where the family went together. Here, the parents were more interacting with the PIMD child than respondent 2, who gravitated more towards peers. Sometimes, he would tell his PIMD sister that she was in the way. That was the only interaction that was observed. When they got back home, he started to interact more with his sister. They pulled out a box from which his PIMD sister chose an object that correlated with a song she wanted to sing. They would sing and perform hand signs together. Respondent 3 was also dancing with his PIMD brother. Respondent 6 was practicing trumpet as her PIMD sister listened and mumbled along.

The semi-structured interviews.

When asked to elaborate on the things the siblings enjoyed with their PIMD brothers/sisters, four out of five siblings spoke of music as a way of making fun:

“I love to read or listen to music with my sister, because that is something normal that we can do together.”

- Respondent 4

“I can always tell if my sister has fun or not. When we listen to ‘Kinderen voor Kinderen’ she is always laughing, singing and clapping her hands. If she doesn’t like the song, she gets pretty angry with me” ... “We also sing together. I let her choose the song, because I don’t want her to be upset. She picks the songs she likes from the song-box.”

- Respondent 2

Music was also mentioned as an activity that was available most of the time, unlike playing outside or watching television, because the parents did not allow that for too long:

“I like to play outside with my brother the most, we run around and I push him as fast as I can in his wheelchair, but sometimes it rains or we don’t feel like playing outside. Then we watch tv or a movie, but my mom won’t always let us. She says tv is bad for our eyes. So then we just play games or dance. If my brother is too tired, we just listen to music on the I-pad.”

- Respondent 3

Respondent 6 was the only respondent that mentioned that she felt obliged to make sure her sister was having a good time and enjoying herself from time to time. To her, music was an activity to have fun herself, but also to make sure her sister was enjoying herself:

“I love to play music myself and I know that my sister loves to listen. I don’t know if I would play for my sister if I didn’t like it so much myself. I probably would, because let’s face it: part of me feels obliged to make sure she is having fun and that she is not bored. but I think that that goes for all siblings, also the ones with ‘normal’ brothers or sisters.”

- Respondent 6

Function

The second theme that came up during analysis, was function. All the results of the participatory observations and semi-structured interviews at home that were assigned to this topic, had something to do with musical behaviours that served the same purpose: function.

Due to the fact that the theme ‘function’ was only established after analysing the participative observations and semi-structured interviews at home, no data was analysed regarding this theme during the observation and focus group held at the Omega concert.

The participatory observations.

During one of the five participatory observations, the function of music in the SQoL became very clear: respondent 2 and his PIMD sister communicate by use of music and hand signing to songs/nursery rhymes. Upon entering the room, respondent 2 introduced himself in a verbal way, but his PIMD sister approached the researcher by holding hands, mumbling and signing a song.

**To the researcher: “This song means she likes you and she wants to sing more songs with you. ”*

- Respondent 2

During the observations, respondent 2 communicated with his sister through songs. There were songs for expressing a desire for food or something to drink, songs for using the potty and for being tired. Though the music was a useful way of communicating, respondent 2 did not respond from time to time. He was playing rather rough with his sister on the trampoline and though she made it clear she was not in to it all the time, he ignored her non-verbal communication from time to time. Leading to some frustration from his PIMD sister.

The semi-structured interviews.

During the semi-structured interview, respondent 2 elaborated on the way he and his sister communicate:

“My sister cannot talk. She really can’t. I tried to teach her, but she does not listen to me. My mommy says she can talk, just not like me with her mouth and words. She talks by holding our hands and making a song with her hands.”

- Respondent 2

When asked whether he was always understanding what his sister was saying or what she wanted, he answered as follows:

“Not always, because sometimes she does not do it right. She forgets to use her hands for the songs and when I don’t understand, she can get a little bit angry. Sometimes, without the songs I can still tell if she is happy or angry.”

- Respondent 2

Three out of four respondents (3, 4 & 6) mentioned that music worked very relaxing for their PIMD brother or sister. Respondent 6 even mentioned that it made her feel more capable of taking care of her sister. She used music as a tool to help her sister relax. It made her feel less helpless.

*“Sometimes *name PIMD sister* muscles are very tensed. I know this hurts her, because it causes cramps and muscle aching. I know that music is a very good way to distract her and make her more relaxed. I believe this works positive on her muscle tension as well.”... “I know that this is a way for me to do something for her, so that makes me very happy. Having a sister that needs a lot of care makes you feel useless sometimes, because sometimes there is nothing I can do for her. This, I can do.”*

- Respondent 6

Music and age

The third theme that came up during the analysis, was music and age. All results that were assigned to this topic, had something to do with the relationship between music and age.

The Omega concert observation.

During the concert, a clear difference was observed between the two youngest respondents (1 & 4) and the oldest respondent (5). Respondents 1 and 4 were mainly having fun on their own and sometimes included their PIMD sister in their activities, but were more occupied with their own activities. Respondent 5, however, was very focussed on her PIMD brother. She was holding his hand, touching his face and making sure he was enjoying himself. Not once did she leave him. She was sat on a chair besides him and interacted with him throughout the entire concert.

Respondent 1 and 4 also differed in age, which resulted in some differences between them. Respondent 5 was paying slightly more attention to her sister, by dancing with her from time to time. She did not interact with her mother as much as respondent 1. Respondent 1 seemed to be more competing with her PIMD sister for their mothers attention: she was asking to sit on her mothers lap from time to time, most often while her mother was occupied with her PIMD sister.

4

The Omega concert focus group.

When the respondents were asked what they thought of the concert, they all agreed on the fact that they had a lot of fun, but for different reasons. The oldest respondent mentioned that she enjoyed the concert, because her brother did so:

*“I liked the music, but I liked it most that *name PIMD brother* liked it so much.” ...
 “I could see he had fun, because of the way he was looking and the sounds that he was
 making.”*

- Respondent 5

The younger respondents answered solely from their own perspectives:

“I loved to dance and to sing with mommy.”

- Respondent 1

*“I really liked the music they played and I danced with *name PIMD sister* and
 respondent 1. Also I liked to help my mommy and daddy and I like that we get to play
 games together right now.”*

- Respondent 4

The participatory observations.

There was a clear difference observed between the younger and the older respondents during the participatory observations at home. During the observation with respondents 1 and 4, respondent 1 was much more competing with her PIMD sister for her parent’s attention, other than engaging in fun activities with her. Her older sister, respondent 4, took more of a caregiver role over her two sisters.

The same was observed in the relationship between respondent 2 and his PIMD sister. In the activities they performed together, he took a more caring role, holding his sister’s hand and making sure she was both safe and having fun (as they were playing on a trampoline). This caring behaviour sometimes caused his PIMD sister to get frustrated. For instance, she got angry with her brother when he tried to constrain her when she was playing very rough.

Respondent 6 was also taking up more caring tasks rather than fun joined activities. She was practicing on her instrument while her PIMD sister listened, rather than playing with

her. Also, she wiped her sisters mouth from time to time and stopped her own activity when her sister made clear she wanted/needed some attention (by making a lot of sound).

The semi-structured interviews.

When the respondents were indirectly asked about their age perception in comparison with their PIMD sibling, respondents 2, 4 and 6 gave somewhat similar answers:

“I feel like more of a parent than a sister sometimes, because my sister needs a lot of care. I know she is supposed to be older than I am, but she has the mental capabilities of a one year old. It is all about what kind of age you count in, age in years or mental age.”

- Respondent 6

*“I like to take care of *name PIMD sister*. In a way, it is a lot like taking care of *respondent 1*. Only feeding her is harder than feeding *respondent 1*. She can do more things by herself.”*

- Respondent 4

*“I am confused sometimes when mommy says I am the little brother. I am the big brother, because I have to take care of *name PIMD sister* and teach her things.”... “She likes things I think are stupid. She likes childish things and I am a big boy.”*

- Respondent 2

Respondent 3 also mentioned that there is less fun joined activities to do with his PIMD brother now that he is getting older, but mentioned music as a good alternative for the things they used to do:

“I don’t like to watch Bumba anymore, because I am to old for that now. But even daddy still listens to music, so I am never going to be too big for that.”

- Respondent 3

Outdoor family activity

The fourth and final theme that came up during the analysis, was outdoor family activity. All results that were assigned to this topic, had something to do with the (in)ability to do outdoor family activities and the role music played or could play in these activities.

The Omega concert observation.

Though ability to go out on outdoor family activities (or mobility of the family) was not on the sibling interaction scale, some fieldnotes with regards to this factor were taken during the observations. The mobility of the families with PIMD children, is lower than the mobility in “regular” families because of the wheelchairs, for instance. The venue for the concert (the Omega day-care facility) was chosen for practical reasons: it was very accessible and a well known environment for the families. Also, special transportation was easily arranged, because parents already arranged (almost daily) special transportation to this venue, because it was their PIMD child’s day-care facility.

The Omega concert focus group.

During the focus group, some of the respondents mentioned some thresholds in going out on activities with the family:

*“We do some fun things with the family when my parents have time for that. Sometimes it is difficult, because we always have to make sure we go to a place where *name PIMD brother* can go as well. The wheelchair can be folded in and my brother has a special chair, so it is not difficult to take him in the car with us. Just... sometimes, it is hard to push the wheelchair on some terrains or when the road is very bad. I can see that it is hard for my parents sometimes and then I enjoy it less. I do help them by pushing.”*

- Respondent 5

*“We sometimes take the tram with *name PIMD sister* but I like it better if mommy takes me on the train without my sisters. It is more fun that way.”*

- Respondent 4

*“I only like to do things outside, if my mommy and daddy can play with me as well, and not only with *name PIMD sibling*.”*

- Respondent 1

The participatory observations.

One of the participative observations at home (respondent 2) took place partially on a playground. The family was able to go there, because they just bought a cargo bike and both kids could be transported in this. Respondent 2’s PIMD sister has relatively low muscular dystrophy, resulting in the fact that she is more mobile than the other PIMD brothers and sisters. This allows for a lower threshold to perform outdoor activities with the family.

Such activities were not observed during the participatory observations with the other respondents.

The semi-structured interviews.

During the interviews, respondent 3 did not mention a lot of limitations when it came to family outdoor activities:

“Me and my brother love to go to the zoo with mom and dad. We can put his wheelchair in the car. He loves to watch the animals with me. Sometimes, he does get a bit tired, but I think that that is just because he is still very little.”

- Respondent 3

The other siblings mentioned some more limitations with regards to outdoor activities they enjoyed with their family. They expressed different feelings:

“Sometimes I feel bad that my sister doesn’t go outside as much as I do, I mean, she has some regular activities, but I can go out whenever I want.”

- Respondent 6

*“We go to theatre sometimes. But never the long shows, because *name PIMD sister* gets very fuzzy and annoying when it takes too long. We tried that sometimes, but then we had to leave so early... or mommy leaves with her and I stay with daddy.”... “If we do things with the four of us, we go to a theatre or to a music show that does not take too long for my sister.”*

- Respondent 2

*“I am so happy *name PIMD sister* is not coming along on vacation this year! Because now we can swim! We are not allowed to swim when she comes with us, because mommy and daddy think it is too dangerous if they cannot pay any attention to us. I can swim very well, but *name respondent 1* can’t.”*

- Respondent 4

Conclusion & Discussion

The aim of this study was to explore the role of musical behaviour as a joint activity for siblings of children with PIMD. As hypothesized, results of the current research show that music plays a role in the joint activities of these siblings.

First, musical behaviour is considered a fun recreational activity. The respondents spoke of the limitations in finding joint activities with their PIMD siblings and, like mentioned in the study by Luijkx, Van der Putten & Vlaskamp (2016), music was considered to be an accessible and fun joint activity. Not all siblings seemed to mind that their PIMD brother or sister could not join every activity they enjoyed themselves. Some referred to moments where their PIMD brother or sister was not or could not be present, which lead to private time or quality time with the parents. This was also mentioned by the respondents in the research by Luijkx, Van der Putten & Vlaskamp (2016) and Moyson & Roeyers (2012).

Second, music is considered a functional tool. An important finding of the research, is the use of music as a way of non-verbal communication. For one of the respondents, respondent 2, music was the main communication tool that was used to interact with his PIMD sister. These findings also came up in research by Knapik-Szweda (2019). Moreover, Jentschke, Koelsch & Friederici (2005) found that the relationship between music and language perception, might be most important for the communication with language-impaired children. In the current study, music was also mentioned to have a calming effect on the PIMD siblings. This finding is supported in a variety of studies, such as research by Salehi et al (2016), who stated that music has a positive effect on people suffering from depression and anxiety. Furthermore, there is supporting evidence that states that music has a soothing effect on children with several disabilities such as migraine, Rett syndrome and autism (De Klerk, 2008; Yasuhara & Sugiyama, 2001; Broder-Fingert, Feinberg & Silverstein, 2017).

Third, music is considered an ageless activity. All the respondents that had an older brother or sister with PIMD, talked about how they felt like the roles were reversed in their sibling relationship. They felt like the older sibling due to a more caring role they played in the relationship. This concept was also recorded in adults with siblings with disability in the research by Hall and Rosetti (2018). They described this concept as ‘role reversal perception’: when the younger, non-disabled sibling’s mental level exceeds that of the disabled sibling. This offers a challenge in interactions, because their interests start to differ. Music offers an ageless activity when role reversal perception takes place.

Fourth, music offers opportunities for outdoor family activities. Most of the respondents mentioned the limitations of going on outdoor family activities with their PIMD brother or sister. These limitations were two-fold: firstly, there were physical limitations caused by the physical disabilities of the PIMD brother or sister. Secondly, there were limitations caused by behaviour of the PIMD brother or sister such as: a lack of patience and concentration. According to Serman, Naughton, Froude, Villeneuve, Beetham, Wyver & Bundy (2016), outdoor play and outdoor activities offer benefits for development and well-being for (families of) children with disabilities and are therefore an important aspect of family quality of life. During the interviews and the focus group, music was brought up as a way to enjoy an outdoor activity with the entire family, if the venue was carefully selected and the concert/show did not last for too long.

Strengths

An individual’s perception of quality of life is unique. For this reason, the research group existed from the siblings instead of their parents, as they are presumed to provide adequate answers themselves, if proper tools and techniques are used (Underwood, Chan, Koller, & Valeo, 2015; Luijkx, Van der Putten & Vlaskamp, 2016; Moyson & Roeyers,

2012). The tools that were used to allow the vulnerable participants (young children) to provide the researchers with adequate information in a comfortable and relaxed atmosphere, where as follows: In order to gain an insight in peer relationships (which Luijkx, Van der Putten and Vlaskamp did not encounter in their research in 2016) a focus group with three participants took place. During this focus group, that was moderated by a moderator with experiences with vulnerable respondents, a set of low threshold games was played.

Guidelines by Gibson (2007) were used to prepare and perform the focus group.

Moreover, during the focus group and the interviews, Photo Voice was used, which led to a deeper insight into the SQoL, because it offered the siblings a way to express their feelings and thoughts in a non-verbal way.

Use of strong theoretic frameworks, ‘the nine domains of family quality of life’ (Moysen & Roeyers, 2012) & ‘the sibling interaction scale’ (Caro & Derevensky, 1997), offered structure in analysing and interpreting the results of the research.

To ensure validity of the study, peer debriefing took place during the research and writing of the final report. Several researchers were asked to view the results and final report and changes were made accordingly. Furthermore, the research was presented during the 2019 IASSIDD world conference in Glasgow, Scotland. Three researchers showed interest in further research, one from Sweden, one from Ireland and one from the Netherlands.

Limitations

The biggest limitation of the current research, was the time frame. The entire research had to be conducted within five months, which turned out not to be enough to complete the entire research without practical compromises. The sample of participants was a convenience sample, rather than a randomized sample. This made the sample less representative, but turned out to be a necessity. Respondents were approached by means of the snowball effect

and the hand-out. Though the snowball effect turned out to be effective, the participants sample was still rather small. Furthermore, the hand-out contained the word ‘music’ which might have led to sampling bias.

Due to limited time, a combination of a lack of an extensive member-check and data robbery might have taken place. The participants gave the researchers their information, but did not ‘gain’ enough from their participation.

Researchers intended to perform an extended member-check and prevent data robbery by giving the respondents something to thank them for providing the information. The participants did receive a small gift, but the gifts were not related to the research.

Further research

The current research was the first in which the relation between SQoL of PIMD children and music was studied. It was an explorative study, which offers a foundation for much needed further research. The variety in research methods turned out to be very useful and is recommended for further research. Also, the opportunity to observe and perform a focus group after a concert, such as organized by Omega, is considered vital for future research.

First, researchers conducting further research should pay attention and plan enough time to randomly approach families with PIMD children and non-disabled siblings. An advice would be to approach day facilities for children with PIMD and work with them to approach the families.

In order to find more conclusive results on the difference between different ages, it is recommended to perform longitudinal studies, where siblings can be interviewed multiple times with several years in between.

To ensure proper member-check and prevent data robbery, an alternative way of member-checking could be conducted. Transcripts could be analysed with the participants. In future research, it is recommended to allow them to select words and sentences that are most important to them. These sentences and words could be made into a song with the participants. This song could be considered an alternative output/analysis of the research and the participants get something very special, their own song, in return for their participation.

Conclusion

This study explored the use of music as a joint activity on SQoL for siblings of children with PIMD. As hypothesized prior to the research, music can be used as a joint activity to enhance SQoL in different ways. For practice, this offers an insight into the different possibilities of music and the importance to consider music as an alternative tool to enhance the SQoL. Further research with a larger group of participants is necessary to gain more insight and empirical evidence to support this theory and convince the field of Quality of Life research of the importance of music as a joint activity in the family- and sibling quality of life.

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Appendix: hand-out



Dat klinkt als muziek in de oren!

Hoe kinderen de band met hun broertjes of zusjes met een meervoudige beperking kunnen versterken door samen te genieten van muziek.

Noëlle van den Heuvel

Gezondheidswetenschapper aan de Vrije Universiteit

&

Disability Studies in Nederland

Achtergrond (voor de pappa's en mamma's)

In Nederland zijn er ontzettend veel kinderen met een beperking, 92.500 maar liefst (in 2015). Van al deze kinderen is er bij ongeveer 10% sprake van een meervoudige beperking. Niet alleen voor het kind zelf brengt een dergelijke beperking uitdagingen met zich mee, ook de familie zal de nodige aanpassingen moeten maken. Waar ouders vaak de zorg voor het kind op jonge leeftijd dragen, zijn het de broertjes en zusjes (brussen) die waarschijnlijk in de toekomst de meeste zorg zullen dragen, daar de ouders steeds ouder worden.

Toch blijkt uit onderzoek dat het voor sommige brussen lastiger is om een optimale relatie met hun broertje of zusje met meervoudige beperking te hebben, omdat er een aantal gezamenlijke activiteiten wegvallen door de beperking. Wel geven de brussen aan erg te genieten van activiteiten die zij wél met hun broertje of zusje kunnen uitvoeren. Een activiteit die meermaals wordt genoemd is muziek luisteren of maken. De resultaten van deze onderzoeken zijn echter vaak gebaseerd op de verhalen en ervaringen van de ouders en niet van de brussen zelf.

Dit heeft er met name mee te maken dat niet alle onderzoekers jonge kinderen in staat achten om verlichtende antwoorden te geven over deze lastige kwestie. Neem bijvoorbeeld het begrip “kwaliteit van leven” wat is dat precies? Kunnen we deze lastige vraag wel bij kinderen neerleggen? Niet veel collega onderzoekers zullen deze vraag met “ja” beantwoorden, maar wij bij Disability Studies gaan uit van het principe “nothing about us, without us”. Dat zegt zoveel als: Je kunt geen onderzoek verrichten naar een groep, zonder deze groep actief bij het onderzoek te betrekken.

Om een beeld te krijgen van activiteiten die de band tussen tussen brussen kan versterken en hun relatie positief kunnen beïnvloeden, vragen wij uw goedkeuring voor deelname van uw zoon(s) of dochter(s) aan het onderzoek “Dat klinkt als muziek in de oren”, want hun ervaringen zijn van onschatbare waarde. De resultaten kunnen bijdragen aan het ontwikkelen van methodes om dergelijke activiteiten in te zetten ter verbetering van de kwaliteit van leven van de brussen in heel Nederland.

Bent u geïnteresseerd in deelname van uw zoon(s) of dochter(s) aan het onderzoek? Dan verzoeken wij u om deze brochure samen met uw kind(eren) door te lezen en contact met ons op te nemen door een e-mail te sturen naar het volgende e-mail adres:

Noelle.vandenheuvel@disabilitystudies.nl

Hier kunt u uiteraard ook terecht voor eventuele vragen of opmerkingen. Schroom ook zeker niet om mij in dat geval te bellen op het volgende telefoonnummer:

06-10173501

Noëlle van den Heuvel

Gezondheidswetenschapper aan de Vrije Universiteit te Amsterdam

Onderzoeker bij Disability Studies in Nederland te Amersfoort



Het onderzoek (voor de brussen)

Hallo! Wat fijn dat je mee doet aan ons onderzoek! Jij kunt een hele hoop andere kindjes in Nederland helpen om meer leuke dingen met hun broertje of zusje met een beperking te doen.

Stap 1

Als jij dat goed vindt, kom ik heel graag binnenkort bij jou thuis langs om even te kletsen met jouw pappa/mamma of andere verzorger. Ik kom dan even kennis met jullie maken en uitleggen hoe het onderzoek precies zal gaan. Ook zullen jouw pappa/mamma in overleg met jou een formuliertje tekenen waarop staat dat je mee mag doen.



Stap 2

Als ik al jouw vragen heb beantwoord over het onderzoekje, krijg je van mij een klein cadeautje: een echte camera! Let op, de camera is wel wat ouderwetser dan die op de telefoon: het is een wegwerpcamera. Dat betekent ook dat je maar ongeveer 20 foto's in totaal kan nemen. De foto's kun je niet wissen of bekijken!



Stap 3

Met dit foto toestel ga ik je vragen om de komende twee weken foto's te maken van alle dingen die jij samen met je zusje/broertje doet, leuk vindt, stom vindt of bijzonder vindt, kortom: alles wat jij belangrijk vindt om op de foto te zetten.



Stap 4

Als de foto's na twee weken op zijn, zal pappa of mamma het 'rolletje' dat in de camera zit, naar mij opsturen en zal ik de foto's laten printen.



Stap 5

Ik kom met de foto's nog een keer langs, maar dit keer heb ik alleen een gesprekje met jou. Pappa en/of mamma zijn wel in de buurt natuurlijk! We gaan dan samen kijken naar de foto's die je hebt gemaakt en ik zal je vragen om daar iets over te vertellen. Van ons gesprekje, neem ik ook het geluid op, zodat ik thuis alles nog eens rustig na kan lezen.



Aanmeldformulier (voor de pappa's en mamma's)

Indien zowel u als uw partner en het desbetreffende kind interesse hebben in deelname aan het onderzoek, verzoek ik u vriendelijk het onderstaande formulier in te vullen:

Graag neemt mijn zoon/dochter* (naam zoon/dochter) van jaar (leeftijd) deel aan het onderzoek naar de relatie tussen kinderen met een meervoudige beperking en hun brussen.

Mijn zoon/dochter* met een meervoudige beperking is jaar (leeftijd) en woont wel/niet* thuis, net als mijn andere zoon/dochter**.

U kunt mij bereiken op het e-mail adres.....

Of telefonisch op het nummer.....

Naam ouder.....

Handtekening***

Datum ondertekening.....

**Graag doorstrepen wat niet van toepassing is.*

***Voor het onderzoek is het belangrijk dat beide kinderen officieel thuis wonen.*

**** Let op: Dit is nog géén toestemmingsverklaring voor het onderzoek, dit is slechts een aanmeldformulier.*