

Thesis

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"It was like discovering a whole new world" Experience of the video feedback method Marte Meo by parents of children with deafblindness

A qualitative interview study

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Abstract

The aim of this study was to explore parents' experience of the video feedback method Marte Meo as a tool to understand and develop communication with their children with deafblindness. Deafblindness is a severe and complex impairment leading to challenges and barriers in communication. Parents to children with deafblindness often have difficulties regarding communication with their children and express a need for support. In Sweden, support to persons with deafblindness, and their supportive network, is offered by multidisciplinary teams at deafblind departments operated by the public healthcare system. Marte Meo is a video feedback method recently introduced at a deafblind department in south of Sweden. The method is exercised by a speech and language pathologist to improve communication and social interaction between parents and their children. In a qualitative interview study, five parents of five children with deafblindness, 5-11 years old, participated. The families had received two to four Marte Meo-counselling sessions. Data was collected using semi structured interviews and analyzed with qualitative content analysis. The findings showed that parents to children with deafblindness experienced Marte Meo as a constructive and positive method to understand, develop and adjust communication with their children. The combination of the visual images in video recordings and the distinct feedback made new perspectives possible. The parents experienced the support in Marte Meo as affirming. Hence, Marte Meo seemed to establish a working alliance between parent and professional. The findings indicated that Marte Meo activated processes of increased reflection, new positive narratives, learning, self-efficacy and motivation. This promoted an enhanced attentiveness towards the child's signals, increased understanding of the parents' own vital role in communication and led to experiences of mutual exchange.

Keywords

Marte Meo, Deafblindness, Children, Parents' experiences, Communication, Interaction, Video feedback, Video interaction guidance

Background

Introduction

Depending on the complexity of deafblindness (DB), persons with DB may need varying kinds of rehabilitation, healthcare and social services support their whole life (Anderzen-Carlson, 2017). DB can have a large impact on a child's development and the whole family is affected (Correa-Torres & Bowen, 2016). In the three largest health care regions in Sweden, multidisciplinary teams at DB departments are available, operated by the public healthcare system (Anderzen-Carlsson, 2017). The teams give support, treatment and coaching to persons with different levels of combined vision- and hearing loss and to the supportive network of persons with DB, for example parents and professionals working with the patients. In the southernmost part of Sweden, Region Skåne, the DB department commonly consists of psychologist, optician, audiologist, occupational therapist, social worker and speech and language pathologist (SLP). The SLP in the deafblind team supports the patients and their network regarding e.g. communication. Recently, the SLP started to use a video feedback method, Marte Meo (Aarts, 2008), to support improvement of the communication between parents and their children with DB. Using video analysis is a known professional tool to give the supportive network a better understanding of communication with a person with DB (Nafstad & Rødbroe, 2013). Research within the area of DB is scarce and literature about evidence-based practices and research related to the needs of parents of children with DB is limited (Correa-Torres & Bowen, 2016). Research stressed that there is a need for more scientific knowledge about Marte Meo (Gill, Thorød & Vik, 2019).

Deafblindness

It is acknowledged that children born with DB belongs to a risk group due to the difficulties caused by their DB, as well as the difficulties experienced by their parents and other carers who meet them in daily interactions. Raising a child with DB often results in many challenges, uncertainty and stress factors that may affect the family emotionally (Preisler, 2005; Simcock, 2017). The scarce amount of research available on parents of children with DB addresses the lifelong need for searching information and fighting for access to service and care for their children (Kyzar & Summers, 2014).

DB is a severe and complex impairment, also known as dual sensory loss or dual sensory impairment (Dammeyer, 2014). The Nordic definition of DB is based on the impact of vision and hearing loss on everyday life activities: "Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate

for each other. Thus, deafblindness is a distinct disability" (Nordic Centre for Welfare and Social Issues, 2019). The deafblind population consists of three different groups, people with: 1) congenital DB (at birth or at an early stage), 2) acquired DB, 3) age-related DB. The term DB includes people with remaining hearing and/or vision (Dammeyer, 2014).

Many children with congenital DB also have additional intellectual and/or physical disabilities, due to genetic and chromosomal disorders. Common syndromes are CHARGE, Downs and Usher (Dammeyer, 2014). Regardless of the severity of DB, the disability often leads to challenges and barriers in communication; language; access to information; mobility and limited activities of daily life. This can in turn lead to various health related difficulties, lack of independence, invisibility in society and risk of social exclusion. There is a need of specific services, adaptations in public places and assistive technical solutions supporting the deafblind population in society (Dammeyer, 2014; Jaiswal, Aldersey, Wittich, Mirza & Finlayson, 2019).

World Federation of the Deafblind 2018 calculated DB to about 2% of the global population, although, this number is uncertain due to the many different definitions of DB. There is no exact number on individuals with DB in Sweden. The Swedish National Resource Centre for Deafblindness indicates that 6-8 persons are born with DB every year in Sweden and estimates around 2000 persons under 65 years old living with DB (NKCdb, n.d.).

Communication and deafblindness

The United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) states equality and non-discrimination for people with disabilities. The convention stresses that persons with disabilities have the right to express themselves with optional communication methods. In the deafblind community there are different communication methods, for example sign language, tactile sign language and alternative and augmentative communication (AAC) (Bruce, Luckner & Ferrell, 2018; Preisler, 2005).

Communication is a wide term which can include many aspects of social interaction and contact between people, as exchanging information and sharing of meaning with others (Preisler, 2005). Human beings are born with an innate motivation for interpersonal communication (Damen, Janssen, Ruijssenaars & Schuengel, 2015). Communication is a multimodal phenomenon and vision and hearing are important senses for interacting and learning (Bruce, Luckner & Ferrell, 2018; Correa-Torres & Bowen, 2016). Children develop skills through contact with parents or caregivers and learning takes place constantly in interaction with others in meaningful contexts.

When following six children with DB and their parents for two years, Preisler (2005) found that the development of communication followed the same path as those of children with no disabilities. When children with DB cannot imitate the actions they see or hear of others, they must rely on other senses and feel movement, touch and smell. Communication between a parent and a child with DB rely on the same basis as with any other child; the importance of the parent meeting the child's expression and emotions in a gentle rhythm and tempo, joint attention and turn-taking (Dammeyer, 2009). Yet, the DB affects early patterns of communication, and extensive difficulties regarding development of language has consequences for the entire development of the child (Preisler, 2005).

Marte Meo

Marte Meo is a video feedback method, also called video interaction guidance method (Vik & Rohde, 2014). The method was developed in the Netherlands in the 1980's to support parents, or professionals, to improve communication and relations in challenging relationships with children or students (Aarts, 2008). Marte Meo is today exercised worldwide in 36 countries and applied in numerous ways, for example in clinical settings with patients and with students in schools (Vik & Rohde, 2014; Wirtberg, Axberg & Petitt, 2014). The method is used to identify, activate and develop skills to enable and enhance social interaction (Aarts, 2008; Fukkink, 2008). Marte Meo can be described as a tutoring method, where interaction between individuals is being video recorded, analyzed and described by a Marte Meo consultant (MM-consultant) to the supportive network of a person. In the present study, the supporting network consists of mothers and fathers of children with DB.

In Marte Meo, focus is transferred from the child's responsibility in communication to that of the parents. The parents receive support to make necessary adjustments towards a functioning and satisfactory interaction. The parents get help to understand how they communicate with their child and on how their everyday environment can be designed to support communication. The parents also get support to increase their confidence and competence in their parental role regarding communication and to become better equipped to meet the needs of their children with DB in everyday interaction. One of the principles in Marte Meo is the child's needs to be approached in its own rhythm and tempo. In Marte Meo, focus is on both frequency and quality of interactions, on the atmosphere and on sharing of emotions and joy. The Marte Meo-counselling (MM-counselling) can be considered complete either when the parents experience that their request for help has been met, when the goals of the intervention have been met sufficiently or when the parents are showing developmentally

supportive behavior in communication with their child (Aarts, 2008; Fukkink, 2008; Gill, Thorød & Vik, 2019; Nafstad & Rødbroe, 2013).

During MM-counselling, the consultant shows the parents carefully selected video clips from everyday situations in the family. The videos are often recorded in the family's homes by the MM-consultant. It is also the consultant who edit the recordings using for example still pictures, slow motion and text to illustrate what is happening. The edited scenes show communication between the parent and the child step by step, sometimes second by second. The MM-consultant observes the parent-child communication with a focus to support the parents to see the need of their child. This is communicated to the parents, together with what the parents needs to take note of in order to support the next stage of development in communication. The MM-consultant tries to create a reflective dialogue with the parents, providing constructive and specific feedback. The MM-consultant's sensitivity to the parents' experience is important (Aarts, 2008; Gill, Thorød & Vik, 2019).

Marte Meo has similarities with other video feedback- and video interaction guidance methods, which are more scientifically documented. As in Marte Meo, these methods also focus on supporting interaction, parenting behavior, attitudes of parents and healthy child development (Balldin, Fisher & Wirtberg, 2018; Fukkink, 2008). None of these methods has been subject to research on individuals with DB, to the best of the author's knowledge this is also the case with Marte Meo and DB. However, there is a small amount of research showing positive effects and positive experiences of using Marte Meo in other contexts than DB. For instance, Marte Meo is exercised with vulnerable first-time mothers and their infants (Kristensen, Simonsen, Trillingsgaard & Kronborg, 2017) and also utilized with parents and their adopted children (Österman, Möller & Wirtberg, 2010). Other studies on Marte Meo focus on interaction between health care professionals and patients, for example patients with dementia (Alnes, Kirkevold & Skovdahl, 2011). In a recently published article, depressed parents' experience of Marte Meo with infants/toddlers is explored (Gill, Thorød & Vik, 2019). The findings indicate increased sensitivity, self-confidence, self-esteem and emotional availability among the parents and that Marte Meo facilitates development-supportive interaction.

The video feedback method Marte Meo was introduced at the DB department in Region Skåne in 2019 by the SLP in the multidisciplinary team at the department, who is a certified MM-consultant. Marte Meo can only be conducted by those who have certification. The SLP, who has been responsible for Marte Meo with the parents in the present study, has two Marte Meo certifications: Marte Meo Colleague Trainer and Marte Meo Supervisor

(Aarts, 2008; Wirtberg, Petitt & Axberg, 2014). The MM-consultant has a long experience of using Marte Meo with persons with different disabilities and their supportive network of relatives and professionals.

Aim

The aim of the present study is to explore how parents to children with deafblindness, experience the video feedback method Marte Meo as a tool to understand and develop communication with their children.

Methods

Study design

Qualitative research methodology with in-depth interviews and an inductive approach was applied in order to develop a deeper understanding of the parents' experience of Marte Meo. An inductive approach was chosen since there are not many previous studies dealing with this phenomenon and knowledge is fragmented. Further, the inductive approach was used to enable the author to be open to what the data would show without any preconceived theories (Elo & Kyngäs, 2008; Taylor, Bogdan & DeVault, 2016). A qualitative content analysis was adopted (Graneheim & Lundman, 2004).

Participants

The inclusion criteria for the participants were (1) parent of a child with congenital or acquired DB, (2) the parent had experienced two or more MM-counselling sessions with a SLP at the DB department in Region Skåne from 2019 and ongoing, (3) the child was between 0-17 years old. No exclusion criteria were used.

Due to the small possible sample given the inclusion criteria, a census sampling method was used. This means everyone in the specific population was asked to participate (Ejlertsson, 2019). The study was conducted according to a signed form with approval from the head of the department of Vision- Hearing- and Deafness in Region Skåne. The author acquired names from the SLP at the DB department of all the children to parents meeting the inclusion criteria, in total eight names. During ordinary consultation with parents of children with DB, the SLP briefly informed that the author would send them an information letter about the study. The author retrieved contact details to the eight children's parents from the medical record system used at the DB department.

The parents of the eight children received an information letter by post with an attached consent letter. The letter consisted of information about the study, voluntariness,

anonymity and that they were free to withdraw their participation at any time. One week after the letter was sent, the parents were contacted by telephone by the author. Six parents were interested of taking part in the study. If the child had two parents participating in Marte Meo, they freely could decide which parent that would participate in the study. The parents got to decide time and date for the interviews.

Finally, five parents participated in the interviews, since one parent had to cancel the interview due to personal circumstances. The four mothers and one father, of five different children, had received counselling between two to four times with a SLP at the Deafblind department in Region Skåne from 2019 and ongoing. Two out of five parents had Swedish as a mother tongue, the other three had various levels of language proficiency in Swedish. All the parents were approximately 40 years old. Their children were between 5-11 years old and had various degrees of hearing and vision. Four of the children had additional diagnoses or syndromes such as CHARGE syndrome.

Data collection

The data was collected through individual semi-structured, in-depth interviews. A semi-structured interview guide in Swedish was developed by the author to ensure all aspects relevant to the aim of the study were covered (see Appendix). The interview guide was based on the aim of this study and qualitative research methodology. It consisted of open-ended questions regarding the parents' experience of Marte Meo as a tool for developing communication with their child. The interview guide was tested in a pilot interview, with a parent to a child without DB. No changes were made in the interview guide after the pilot study. This interview was not added to the study. During the interviews, follow up questions, detail-oriented questions and rephrasing were used by the author to ensure that information was understood correctly. Questions were asked in different orders, to create smooth transitions. The semi-structured interview format invited the parents to expand their answers and talk freely (Kvale & Brinkman, 2015; Patton, 1990). Four interviews took place in the parents' home and one at the department of Logopedics, Phoniatrics and Audiology at Lund University. One of the interviews was performed with a translator who interpreted the interview to the parent's mother tongue. Before the interviews, the parents got written and oral information about the study and signed a consent letter. The interviews lasted between 45 to 120 minutes and was conducted from January to February 2020. The author audio-recorded and transcribed the interviews verbatim.

Analysis and interpretation process

The data was analyzed using qualitative content analysis following the steps described by Graneheim and Lundman (2004). In order to get familiar with the content, the transcribed interviews were reread several times by the author. Meaning units were selected, condensed and coded. The codes were grouped. Categories and subcategories emerged from the groups of codes and was thoroughly worked through, see table 1. When categorizing the codes into categories, the author aimed to stay as close as possible to the parents' own words, with no far-reaching interpretations (Graneheim & Lundman, 2004). To ensure the trustworthiness of the analysis, one of the supervisors independently coded a part of one of the transcribed interviews. The categories were discussed with the supervisor and a researcher at the Research and Development department of Psychiatry and habilitation, Region Skåne. Adjustments were made to enhance trustworthiness and to minimize author's bias. All the steps in the analysis process were made with caution in order not to lose the parent's original description of their experiences (Elo et al., 2014; Graneheim & Lundman, 2004). The author of this study is a SLP, employed by the department of Psychiatry and habilitation, Region Skåne, but has never worked with parents to children with DB or with the method Marte Meo.

For not to reveal parents' identities, quotes by the parents in the results are referred to with numbers (P1-P5) at the end of each quote. All the children are called "the child" and the MM-consultant is called "NN", also sometimes referred to as "she". Some quotes had grammatical errors; hence, the author edited the quotes for readability. The content in the square brackets provides clarity of the context.

Table 1. An example of the sequence from meaning unit to subcategory and category

Meaning unit	Condensed	Code	Subcategory	Category
	meaning unit			
NN says 'look what	Marte Meo	Marte Meo	Support by	Video
you did here'. I've	consultant sees,	consultant shows	"the	makes new
just looked at the	shows and	and explains	professional	perspectives
video clip, but she	explains that the	significant details	eye".	possible.
sees and emphasizes	small things the	in communication.		
that this little is in	parent is doing, in			
fact something big.	fact is something			
That what I do,	that matters.			
means this.				

Ethics

The study followed the ethical principles of the declaration of Helsinki (World Medical Association, 2001). An examiner of the Master in Medical Science, Lund University, informally approved the project plan of the study. This study is accomplished within Region Skåne and the study was conducted according to the Swedish Health and Medical Service Act (Hälso- och sjukvårdslag, 1982:763) and the Patient Data Act (Patientdatalag 2008:355). The study was conducted with approval from the head of the department of Vision- Hearing- and Deafness in Region Skåne as part of the organization's continuous quality assurance work.

Before the interviews started, written and oral information was given to the parents about the aim of the study, that participation was voluntary, that they were free to withdraw their participation at any time from the study and that recorded interviews would be pseudonymized and managed according to the General Data Protection Regulation (GDPR). Written informed consent was obtained from all individual parents included in the study.

The interviews could include a potential risk of arousing uncomfortable thoughts and feelings for the parents. Therefore, time was set aside after the interviews for post-talk to minimize the potential risk of leaving parents with discomfort. Taking part in the study could also bring positive effects for the parents, such as time for reflection and getting their voice heard (Malterud, 2014).

Considering the small group of persons with DB in Sweden, all the data has been handled with caution to protect parents from the risk of being identified (Roller, 2019). During the study all the data has been stored and locked where no unauthorized had access. The collected data will only be used in this study.

Results

The findings are organized in three categories with associated subcategories, presented in figure 1.

1. Video makes new perspectives possible

1. Support by "the professional eye"
1. Support by visual concretization
1. Feelings of both happiness and sadness
1. Difficulties regarding video as a tool

2. Both form and content are important in councelling

2. How information is mediated is important
2. Encouraged by constructive and affirming feedback

3. A tool to understand and develop communication
3. Everyday communication being developed

Figure 1. Categories and subcategories derived from the interviews

The parents described themselves as being open to all kind of intervention that could possibly support the family and they became expectant when first hearing about Marte Meo. Only one parent had earlier experience of video used by a professional health care worker, but not related to Marte Meo and the Deafblind department. Some of the parents reported earlier negative experiences of health care in general, such as experiences of been forgotten and of having asked for more support regarding communication. All parents shared feelings of gratitude regarding the support in Marte Meo.

1. Video makes new perspectives possible

Parents explained how video as a tool made new perspectives possible.

1.1 Support by "the professional eye".

All parents witnessed how the MM-consultant's professional interpretation of the video clips helped them. The MM-consultant's explanations supported the parents to reflect on new aspects. "It's good that someone from outside comes in and opens up a whole new

world to another kind of communication (...) if NN hadn't come, we would never had understood this." (P1)

The parents expressed how they, together with the MM-consultant, really was paying attention to the parent-child communication in the video clips. During the counselling sessions, they both had the time and possibility to see much more than they were able to identify in everyday life. The parents described that the MM-consultant was able to find a lot of interesting information, regarding communication, in very short, edited video clips. They emphasized how good it was that the MM-consultant discovered and explicated how the different actions in the videos had a purpose in communication. "If I had watched the video on my own, I wouldn't have seen even a tenth of what NN actually sees and retells and explains." (P1) "NN sees everything. She looks at all the small, small things in the video. And everything means something." (P4) When watching the videos during counselling, the situation was experienced as quiet with time for reflection together with the MM-consultant, without the child present. One parent described how the pace in everyday life goes so fast, without time for reflection. Another parent described not being mentally present with its child.

1.2 Support by visual concretization.

All parents emphasized the strength of the visual aspect of watching edited short video clips and that it is much more concrete than just talking about a situation. "When you get to see it in black and white, that it really is that way, it's pretty fantastic." (P1) Some parents compared Marte Meo to other earlier experiences of support regarding communication. They explained how the earlier communication support only had been presented orally, which made the support vague and that it had not led to any obvious progress. The parents appreciated the distinctness of Marte Meo, being able to have a joint focus on specific moments in the videos. "[Marte Meo] has been more concrete. We've had other [treatments], like with a speech and language pathologist (...) It has mostly been verbal advice and then you go home and try. Then you meet and talk about it. It's so vague, mostly chatter. But with these videos it's possible to very distinctly point at moments and see it. I like that." (P2) The parents underlined the positive aspects of several people watching the video clips at the same time, combined with feedback, discussions and that this way of getting support regarding communication was less subjective.

Parents described that the visual concretization supported them to make changes. "The best is that I can look at myself and change what I'm doing wrong. It's so hard if someone just explains to me, but it's easier when I see myself in the video." (P5) They explained that

they got to see "what things really are like" and how they through the videos could observe a progress. "In the video it looks like we're doing progress and it's a confirmation that we're on the right track." (P3)

1.3 Feelings of both happiness and sadness.

When the parents described their experience of watching the videos, different feelings were involved. They did, however, not specifically describe how the different feelings affected their experience of understanding and developing communication with their child.

Some of the parents experienced feelings of happiness and pleasure when recognizing that the child was happy in an everyday situation with the parent, or with a sibling. The child's actions, gestures or facial expressions, that was interpreted as happiness, was not as easy to discover in the moment of communication as when viewing the videos. The parents also expressed feelings of pride when watching the child in the video. They described enjoyment and excitement of looking at their child in the video. "I'm longing after looking at the child, especially when the child is not with me. It's exciting." (P4)

There was also one parent expressing feelings of sadness and stress when describing an awareness of its own deficiency. The feelings could arouse when getting aware of not being emotional available in everyday life, to that extent that the parent wished. The parent described how watching the video enabled awaited feelings and a longing after being more present in everyday situations and communication with its child. "When I see the videos, I feel that I can enjoy a little bit of being a parent. The way I feel while watching the video, maybe I should feel that way in that moment, when I do it. But these feelings are not that strong in the moment." (P1)

1.4 Difficulties regarding video as a tool.

In using video as a tool some difficulties were noted. One difficulty was to enable the recording of the videos that the method requires, and to record different kinds of everyday situations. Most of the videos were recorded in the families' homes by the MM-consultant. Some videos were recorded at the Child- and Youth Habilitation together with professionals working there, at the bathhouse or in the child's school. However, one parent expressed that the family also wanted to make videos in the school, but the school did not give them permission. "We've tried to ask school that NN should come to the school and record. But we didn't get permission, unfortunately (...) the school said that it's only the school making videos in the school (...) and I didn't have the strength to take that further." (P3) One parent

explained that they made a plan together with the MM-consultant, that the parents would record on their own at home. But the parents never had time or prioritized the video recording, even though they had intended to. Another parent explained how they tried a new way of recording at home, they put up a surveillance camera in their kitchen and the camera recorded every movement they did. This resulted in an extensive amount of video recordings. Nevertheless, the parents were still able to select some scenes from the large material and gave it to NN for editing.

The use of video was also perceived as inconvenient by some of the parents. Some of them described that they usually don't like being video recorded, that a stress about performing something particular often arises. "I tried not being in the video, I don't like being filmed. I don't feel free, someone is looking. I feel a little bit shy, [in the film] it's important to be as you always are." (P4) Yet, in this context of Marte Meo, most parents summarized the video recording situation as not being too problematic. Another aspect was if watching the video would be disturbed by the parent's own self-critical gaze. "Sometimes I could think, 'what do I look like' and things like that." (P3) However, most parents experienced watching themselves as mostly uncomplicated.

Another potential difficulty was the focus in Marte Meo of the video situations representing everyday life. The parents were told by the MM-consultant that they during the video recording should do things they do an ordinary day at home with their child. The videorecorded situations for example displayed the parent and the child playing, watching television, preparing food or eating. Most of the parents did not find it hard to do something ordinary while the MM-consultant was recording, they emphasized that it was enough just being together with the child. "NN video recorded when we really didn't do anything special; we just were, like we always are. It was nothing special, as if we would stage a special situation. It was just our everyday life, in the child's room, in front of the TV." (P1) However, one parent expressed that the video situations felt a little bit artificial. "It's not totally casual, it becomes a little bit staged, for the video." (P3) The parent further expressed a pressure of finding good situations where a lot of communication was present. However, in the end the parent did not only see negative aspects of the "staged" and unnatural video situation. A positive outcome was that the parent was positively confirmed by the MM-consultant when paying a lot of attention to its child and the parent got to understand that having this extra focus on communication with the child was beneficial. Yet, the parent did experience some stress in everyday life regarding performing as good as in the videos. "When NN comes [for video recording] we have to pick a communication situation, it's not enough that we just sit in the sofa having a cozy time with the mobile phone (...) it's a little bit like 'now we're gonna do something together', even if we maybe don't do that every day (...) play with clay, play with LEGO." (P3)

2. Both form and content are important in counselling

The parents expressed that it was important how information was mediated in the MM-counselling and described the affirmation and the constructive feedback as important.

2.1 How information is mediated is important.

The parents appreciated that the information, feedback and recommendations they received was mediated with distinctness. They experienced the MM-consultant as being committed and convincing and that it was easy to ask questions. "If there's a part in the video I don't understand, then NN re-runs the video and explains more until I understand. In the end, NN asks if I have questions, if I want to add something." (P5) The parents expressed that the MM-consultant presented the knowledge with respect and that they felt supported. They expressed thankfulness regarding the MM-consultant creating an organized and secure space during the counselling. One parent shared how the conversation with the MM-consultant helped when feelings of stress of not doing enough came up. The parent expressed that having a safe space where it was possible to express feelings of deficiency was soothing. "(...) but then we can also express these things with NN, and we can say that 'we're not doing what we should' - then we often get to hear that it's ok, if we try every now and then it is more than enough. You know, finding this good- enough level (...) so the conversation helps (...) I've cried so much during these conversations." (P3)

Some parents reflected on the impact that the MM-consultant had. They pondered about what parts of their experience that had to do with the actual Marte Meo method and what parts that was more dependent on the consultant with her professional and personal qualities. "I'm not sure how much it is NN as a person or how much it is Marte Meo as a method. But I get to see that NN knows better. That NN points out things we don't notice (...) and that's my aim, to learn something new." (P3)

Having a child with a disability often means that the parents, year after year, meet a lot of professionals in many various health care settings. One parent described being tired of hearing different people having opinions regarding the child and what the parents should do. But within Marte Meo, the parent did not express any concerns similar to this regarding the MM-consultant's support and recommendations.

All parents expressed that they trusted the information they got from the MM-consultant and that they appreciated that specific concepts and terms was used to explain communication. They experienced the way the MM-consultant was talking about communication as something new to them and that they got a deeper understanding regarding the actual method than they had in previous contacts with professionals in health care. "NN has talked about this [communication] in another way than I have earlier experienced (...) NN put things in concepts that I haven't heard before. I think it's interesting. I've been thinking that maybe NN puts words on what she's doing in another way than others have done. Maybe others have worked and been thinking of similar things, but they haven't expressed how they're working. Here it's clear, NN tells us what she's looking for and what she sees [in the videos]." (P2)

2.2 Encouraged by constructive and affirming feedback.

The parents expressed that the feedback and recommendations they got during MM-counselling was constructive and often focused on amplifying what they already did well. "NN stops the video and says, 'you did this thing very good' (...) and that feels great to hear." (P5) They appreciated that the MM-consultant did not focused on showing videos with missed opportunities in communication, "Instead of saying 'in these 30 seconds you didn't have any communication, you did nothing, your child did nothing, you should've done this instead'. NN doesn't choose that. It's this balance." (P3) The parents got constructive feedback on how they could make changes in communication with their child, but they never experienced the feedback as hard to listen to. One parent equated the positive and constructive focus, combined with the videos, as something like a shortcut to a better understanding of communication. "NN can guide us to something better, a gentle shortcut somehow." (P1)

The parents linked their progression in Marte Meo to the feedback and affirmation they received. Some parents explained how they, previously, felt more insecure about how to communicate with their child, that they did not want to do something "wrong". Now they started to bring the constructive feedback and affirmation from the MM counselling into everyday life. "Now when I know that it's good what I'm doing, I've been more secure keeping on doing it. And I remember it." (P4) They described how they got affirmed regarding actions they have always done, but never had thought of as something that had to do with communication, or as of something beneficial. "Oh my god, I lived believing that this [communication] doesn't work, that I didn't know what was needed, but in fact we've always known." (P1)

3. A tool to understand and develop communication

Marte Meo was considered a positive and constructive tool to help parents to understand and develop communication with their children. They expressed how they gained new knowledge about communication and discovered more signs of communication.

3.1 Discovering more signs of communication.

From the interviews it was evident that the parents came to a new understanding of communication due to the use of Marte Meo. They described how they became aware of new levels of communication that they were previously unaware of. "Then I got a shock, when NN showed the video clip. I believed I didn't do anything, but apparently I communicate a lot." (P1)

The parents described how they, with the support of Marte Meo, understood the importance of their own actions in the communication with their child. One parent expressed the new insight of that having a slower tempo in communication is important and that the slower tempo makes it possible to pay more attention to the child. "I do some things too fast, I do it automatically instead of communicating back (...) this [method] has made it so obvious now." (P1) All parents described a new understanding regarding the importance of the parents' attention to the child's actions, which enabled new insights. "In fact, the child communicates a lot, but not in the manner we're used to." (P1) They emphasized that they nowadays more carefully observe and listens to the child's actions, and that they can see more details and nuances in the child's communication. "This whole day the child was angry on me (...) I wouldn't have understood that if it wasn't for this method. I wouldn't have reflected over that." (P1) They mentioned several examples of how they, due to Marte Meo, started to perceive more of the child's communication and that they now were open to interpret different kind of actions as communication. Some children were using signs from the sign language that the parents did not know the children understood before. "These things the child does with its hands, there are signs in the movements, sometimes more than we think or more than we believe we can see. We've got that confirmed (...) sometimes we have to 'overinterpret'. (P3)

All parents described that they now understood how communication with their child can consist of much more than just talking or using sign language. "I was thinking, 'the child doesn't hear me', so I'm quiet. And the child doesn't look at me either. But with this method, I've understood that there are other ways to communicate." (P1) They expressed new

perspectives of how all the acts and body- and hand- movements they do are communication. "(...) there is communication, in the contact, the body language." (P5)

Marte Meo helped the parents to be able to perceive more and longer sequences of communication between the child and themselves. They mentioned a new awareness of that the children really do react on the parents' actions and of how the children reacts. One parent explained a video clip where they got to see the parent and child communicating for a long time and where the dialogue consisted of turn-taking. The parent had never observed that before. The parents emphasized their new understanding of how communication is built on many small steps and actions. Before Marte Meo the parents mainly saw the outcome of the communication, for instance that the child got what it wanted, or that the parent got the child to do what they wanted. With Marte Meo the parents got help to see more details in communication.

3.2 Everyday communication being developed.

The new understanding of communication was also manifested as a development of their communication in everyday life. The parents expressed that they had started to confirm, interpret and name the child's actions much more than before. "NN gave us that advice after the video in the kitchen (...) that we can communicate with sign language what we believe the child want to mediate. So we put signs on the child's actions, like questions." (P2) Some parents mentioned how they, due to Marte Meo, could see that communication had developed in specific everyday situations. One parent described an enhanced awareness of the importance of having the child's plate a bit to the right or left of the child during mealtime, since this supports the eye contact between the child and the parent when the parent is feeding the child. Eye contact was also mentioned by other parents, even though the children have reduced vision, some eye contact is possible and can support the communication. "There was this video clip we were watching and NN said that even if the child doesn't use sign language, the two of you have very good contact and then NN showed me how we got eye contact." (P2) One parent shared how they started to use more tactile signs and alternative and augmentative communication with the child in everyday routines. "(...) when the day is over, 'now we turn of the tv' which means the day is over. And then I sit with the child for a while and then I do 'good night' on the spine, tactile." (P1)

The parents experienced that their child's communication developed due to Marte Meo. They described how their increased attention towards the child, together with their changed behaviors in communication, helped the child in its own communication progress.

The parents explained that the child started to initiate more communication with the parent. "Now when I concentrate on the child (...) focus on the child, I experience that the child starts to turn to me more, that the child takes more contact with body language." (P5) One parent explained how the use of different objects in communication with the child had developed. The parent experienced that the child now, to a greater extend, can understand that an object can symbolize something that will happen, for example car keys as a symbol for a drive. "We've always used car keys [in communication with the child], but we haven't felt the child understand that before." (P1) The same parent continued describing how the child was now more present during interactions. "I also think, with this method, before the child hasn't watched, (...) [now] the child actually sees, is looking, is with us in another way. It's not like the child is living in its own world and looks away." (P1) Some parents shared their experience of how the child started to relate more to a sibling, that the child before mostly was playing on its own, but that they could see more interaction with the sibling. One parent expressed that the child was calmer and that the parent experienced the child as more secure.

Some parents mentioned that the progress they had seen in their children may not depend entirely on the Marte Meo training. Their children were also involved in other settings during the period of taking part in Marte Meo. Another important variable was their child's health condition, periods of hospitalization would inevitably prevent progress. "We've talked about that the child has developed a lot in communication the last six months. How much is connected to what we do? To NN's support within Marte Meo? And how much has to do with the sign language environment in school? But it doesn't matter, what is important is that the combination works." (P3) Altogether the parents described Marte Meo as an important part of the progress in communication that they had experienced.

All parents expressed that they got a new motivation to both communicate and develop communication, after taking part in the counselling. "I've got this little boost, that I should communicate (...) It feels like getting hope." (P1) "I feel encouraged and then I encourage myself that I should work more and more." (P5) They explained that they have reflected a lot since they started to receive Marte Meo counselling and that they have changed their behaviors in the communication with their child. "A conscious manner (...) that I'm just not doing. That my actions and my moves, that is my communication to my child." (P1)

Discussion

The parents' descriptions shed light on how Marte Meo is a useful tool for understanding and developing communication between the parents and their children with DB. Research on Marte Meo is scarce, but has now a growing and promising evidence of positive outcomes across various populations regarding parenting (DeGarmo, Jones & Rains, 2019; Gill, Thorød & Vik, 2019; Kristensen, Simonsen, Trillingsgaard & Kronborg, 2017; Vik & Rohde, 2014; Österman, Möller & Wirtberg, 2010). Marte Meo is the most used parenting intervention in Scandinavian countries when it comes to families with parent-child interactional problems during infancy (Høivik et al., 2015). There is a growing research base for the efficacy of different video feedback- and video interaction guidance methods used with parents and children (Fukkink, 2008; Taylor, 2016). Also, there is research showing positive outcomes of a video feedback program exercised with professional carers of children and adults with visual and intellectual disabilities (Damen, Kef, Worm, Janssen & Schuengel, 2011). Still, to the author's knowledge, there is no research on Marte Meo and parents to children with DB.

The parents' experiences of Marte Meo is described as a dynamical progress in figure 2. The model is an adaption of a model presented by Gill, Thorod and Vik (2019), here further processed and developed by the author according to this study's results and discussion. The model in figure 2 describes the process from the experience of the counselling session via processes that are activated inside the parent during and after consultation, to the progress and outcomes in communication. The arrows between and inside the windows show that the different factors in the model are catalysts for each other and that there is interaction between the factors. The arrow from Outcomes in Communication back to the first window represents the expected circularity in the process, that the parents in every session of counselling brings the new knowledge and experiences from previous counselling and that the process can be repeated.

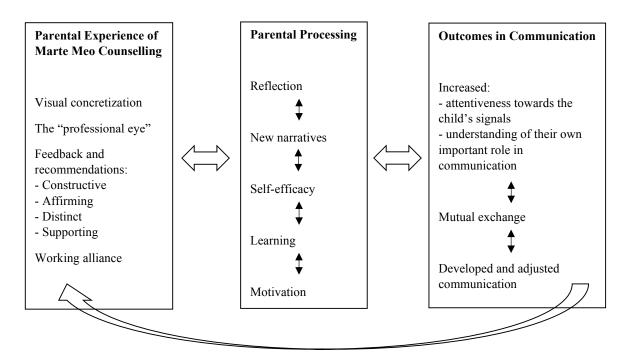


Figure 2. Model of parents' experience of Marte Meo - an adaption of Gill, Thorød & Vik's (2019) Dynamical explanatory model of parents experiences with Marte Meo

The arrangement of the MM-counselling is described in detail in the literature, both regarding actions and approach (Aarts, 2008). The parents' in the present study experienced the counselling sessions as constructive and supporting. Some parents reflected on the impact the MM-consultant had with her personality and strengths, compared to what was a part of the actual method. Vik and Rohde (2014) emphasizes that the counselling session is a complex interplay between human resources and technical devices.

Gill, Thorod and Vik (2019) discusses the balance in Marte Meo between challenging the parents in asking reflective questions, in relation to strengthening and supporting the parents' positive behavior. They underline that the balance can be crucial when supporting parents to new insights and empowerment and that it is important to contribute to the experience of being a competent parent. The MM-consultant often shows video clips with moments of shared joy between the parent and the child, this can have an emotional power and be important for the progress (Gill, Thorød & Vik, 2019). The parents in the present study were encouraged by the affirmation and the constructive feedback they got and experienced a balance regarding being challenged and being strengthen. Research on Marte Meo shows that parents enhance their self-esteem and self-confidence when taking part of the method (DeGarmo, Jones & Rains, 2019; Gill, Thorød & Vik, 2019; Vik & Rohde, 2014). The

positive circle of new emotions connected to self-esteem and self-confidence can lead to strength and hope, which in turn start processes leading to positive change (Vik & Hafting, 2009). In figure 2, the term self-efficacy (Bandura, 1982) represents both the concepts of self-confidence and self-esteem. In this context, self-efficacy stands for the parents' perception of their abilities regarding communication with their child with DB. The level of parent's self-efficacy can be decisive for whether new initiatives will be taken in everyday communication. The parents described the visual images in the videos helping them to get new positive memories of themselves being competent in communication situations with their child. They also expressed getting new motivation to communicate and develop communication. Gill, Thorød and Vik (2019) showed that the parents' increased sense of security and sense of achievement led to more room for joy and pleasure in the interaction with their child.

When watching videos in Marte Meo, parents often become emotional (Wirtberg, Axberg & Petitt, 2014). The combination of the videos and the verbal feedback can activate both positive and negative emotions and the parents become vulnerable in front of the MMconsultant (Gill, Thorød & Vik, 2019). During the counselling the parents are both seen, acknowledged and appreciated by someone else, which is one of the human beings' fundamental social needs (Nafstad & Rødbroe, 2013). Some of the parents in the present study described an already existing vulnerability, with feelings of stress in their everyday life and earlier experiences of a health care where their needs had not been listened to. But, the parents expressed that they felt secure during the MM-counselling. The MM-consultant has an important responsibility of creating a safe atmosphere for the parents. One foundation of the consultant's attitude towards the parents in Marte Meo is to 'start where they are and build with what they have' (Aarts, 2008), which requires an empathetic and flexible approach from the consultant. The consultant needs to be sensitive to the parent's reactions during the counselling (Vik & Rohde, 2014). The working alliance, and the relationship between the professional and the patient, has proven to be an important predictor of the treatment outcome in many different contexts. It is important for the professional to provide a secure base and environment for the parent to achieve positive and sustainable results of the intervention (Bowlby, 1998; Kåver, 2011). Still, there is a possible intrinsic asymmetry in the relation between patients and professionals in health care. The asymmetry is based on the inequality of that one part needs help and the other part has the requested competence to help (Thornquist, 2001). In the present study, the potential asymmetry seemed not to disturb the process. On the contrary, in a study where parents' experience of another video interaction guidance method was explored, Taylor (2016) found that the parents experienced the method involving

judgement of their parenting skills. The article highlights the importance for practitioners of video interaction guidance to be honest about their position and mindful of the feelings of the participants. However, Kennedy and Sked (2008) states that the intrinsic collaborative approach in video interaction guidance still enables a more equal power balance between the consultant and the participant, compared to traditional verbally based interventions.

The parents emphasized the importance of the visual aspects of using video and that they experienced the method as being concrete. One among other positive aspect of using video is that language barriers are easier to overcome. Some of the parents had Swedish as their second language, and the videos offered a distinct and joint platform for dialogues and information. To understand the role language plays in creating barriers in healthcare is crucial. Healthcare is experiencing an increasing amount of a culturally and linguistically diverse population (Meuter, Gallois, Segalowitz, Ryder & Hocking, 2015).

The concept of "video-confrontation" is presented by Cross and Kennedy (2011) as having an important role in video interaction guidance. Video confrontation in this study refers to the parents first having negative beliefs about the interaction and then getting to see successful interactions with their children in the video clips. This can create a cognitive dissonance (Festinger, 1985), which encourages the parents to change their beliefs and behavior to avoid dissonance. In the present study, the parents described that they initially did not know how much communication that was taking place with their children. One parent even told of a reaction of shock when the MM-consultant showed video clips.

Using video feedback can be described as a "behavioral microscope", where it is possible to analyze a sequence of communication in detail several times (Wirtberg, Petitt & Axberg, 2014). The parents experienced that they got to see "the way things really are" and that the videos represented a new reality in their life. The parents in both the present study and in Gill, Thorod and Vik's (2014) study emphasized that the visual impressions of the videos stayed longer in memory than verbal information and that the parents brought the memories of the videos into daily life. Through the videos, and feedback, the parents got new positive narratives and new ideas about themselves, the child and the interaction. Research (Vik & Hafting, 2009; Vik & Rohde, 2014) has shown that there is a specific power in the visual image, which can promote and increase reflection and growth. When parents see themselves and their child from the outside it enables them to really observe and to deal with the images of themselves and their actions. It also allows a needed distance and a new angle for reflection, which enables new perspective to arouse. Alnes, Kirkevold and Skovdahl (2011) describe how the visual aspects also helps to understand the progress. A learning takes place,

and in order to integrate the new knowledge into everyday life, both cognitive and emotional presence is required.

The parents described an enhanced understanding of their own important role in communication and an increased attentiveness towards the child's communicative signals. They started to more carefully observe and interpret their child and they could see more details and nuances in the child's communication. Vik and Hafting (2009) emphasizes that the video tool enables parents to see their child and themselves from another angle, this facilitates the ability to interpret their child's signals. Aarts (2008) states that, as a part of the Marte Meo method, the parent should "enter the child's world" and leave behind its own wishes and ideas. One example of increased attentiveness towards the child's signals was a parent who described a new insight of the importance of a slow pace in communication. The slower tempo made it possible to pay more attention to the child and to observe and wait for the child's various signals. This is supported in literature about Marte Meo, which also states that when parents adjust the pace and rhythm of interaction with their child, the child's ability to make contact increases (Österman, Möller & Wirtberg, 2010). Gill, Thorod and Vik (2014) emphasizes this mutual exchange between the parent and the child and the parents' experience of enhanced intersubjectivity. What the parents earlier experienced as coincidental or random actions from the child, now was interpreted as communicative signals. The parents experienced that their child's communication developed in different ways. One parent described that the child was not "living in its own world" as much as before. It is impossible to determine what parts of these experiences that has to do with the parents' increased attention to the child due to their new knowledge, compared to the child's actual communication development. Communication though, is a joint activity, where the parent and the child are intertwined in a dynamical interaction (Preisler, 2005). The parents' descriptions of a new awareness of their own significant role in communication with their child, corroborates with the findings in Vik and Hafting (2009). The focus on the parent's responsibility in communication with their child is one of the key concepts in Marte Meo. The MM-consultant supports the parents to integrate their new knowledge into their everyday life. However, in the end, the recommendations from the MM-consultant has to be possible to work with at home, and be at the action level of everyday communication, to be able to lead to a developed communication (Aarts, 2008).

Methodological considerations

An important part of qualitative studies is trustworthiness (Elo et al., 2014; Graneheim & Lundman, 2004), which have been considered during each phase of the study and is described below.

By using a distinct analysis method with explicit steps, the author tried to stay true to the parents' experiences (Graneheim & Lundman, 2004). A detailed methods description was written to increase the possibility of the current finding's transferability to other contexts and enhance the opportunity for replication of similar studies. The parents are not in detail described in this study; this is to ensure their anonymity since the sample group is small. When discussing transferability and credibility there is no established accepted general sample size for qualitative studies, the optimal sample depends on both the purpose of the study, the aim and the richness of the data (Elo et al., 2014). Even though the sample was small, the data in this study proved to be rich and the interviews gave voice to both similar and unique experiences within the group. The parents had two to four counselling sessions before the interviews. To experience progress after only two sessions is not self-evident, but the interviews indicate that progress was noticeable even with very few sessions. Only one SLP at the DB department in Region Skåne was conducting the MM-counselling, if different persons would have been responsible for the counselling the result may had varied.

Another important aspect connected to this study's credibility is the participant representation. The sample consisted of mostly mothers and only one father. This was mainly due to two reasons: 1. The mothers' telephone numbers was most often specified uppermost in the journal system and therefore the mothers were called firsthand, before the fathers. 2. Some fathers were not taking part in the MM-counselling as much as the mothers. The author investigated the possibilities of interviewing both parents in families where that could be possible, though this was not possible due to logistics. The method Marte Meo is not applied in any of the other two DB departments available in Sweden, and to the author's knowledge the method is not exercised anywhere else in Sweden with persons with DB.

According to Graneheim and Lundman (2004) a text always contains multiple meanings and provides possibility for different interpretations. How a researcher interprets their data also depends on their theoretical assumptions (Taylor, Bogdan & DeVault, 2016). To enhance credibility and confirmability, the author discussed the findings with both a supervisor and a researcher at Region Skåne (Graneheim, Lindgren & Lundman, 2017). The author also included a table with an example of the analysis process and quotes by the parents,

to show that the analysis is accurate in relation to the information provided by the parents. The author is aware of that this interpretation and analysis is one possible among others.

In data collection, when encouraging parents to share their experiences, the researcher is an instrument and a co-creator of data. It is important to constantly be aware of the possible pre-understanding of the author in both data collection, analysis and due to ethical aspects and aspects of bias (Roller, 2019). The author of this study is a SLP, but has never worked with parents to children with DB or with the method Marte Meo. The author has tried to ensure transparency and reflexivity and is aware of that the author's history, personality, sensibility and acts can influence the study (Eisner & Peshkin, 1990; Korstjens & Moser, 2018).

The time between MM-counselling and the interview date might have varied between the parents, this means a recapitulation bias might exist in some interviews. Moreover, in some of the interviews, it was obvious that difficulties regarding the Swedish language was present. In one of the interviews, a language interpreter was present. Altogether, this might have had an impact on the stability of the findings in the study; the study's dependability (Korstjens & Moser, 2018). The author tried to increase the dependability through follow-up questions during the interviews, to ensure a rich description of the parents' experiences (Elo et al., 2014). The time the interviews lasted varied, from 45 to 120 minutes, the author experienced that the quality and depth of the interviews varied.

Conclusion

The study shows that parents experience that the video feedback method Marte Meo helps them to understand, develop and adjust communication with their child with DB. The findings highlight how video is an appreciated tool and how the visual concretization, together with affirming and constructive feedback, makes new perspectives possible. Some difficulties regarding using video as a tool are described by the parents, but the many benefits outnumber the few difficulties. The study emphasizes the parents wish for, and their experience of a working alliance with the MM-consultant. Marte Meo seems to start processes inside the parents of increased reflection, new positive narratives, learning, self-efficacy and motivation. Also, parents discover more signs of communication and gain an increased attentiveness towards the child's communicative signals. Further, the study shows that the parents experience that Marte Meo leads to an increased understanding of their own important role in communication and that they start to experience a mutual exchange with their child.

Even though the sample size is small, many of the findings are consistent with those from prior Marte Meo research (DeGarmo, Jones & Rains, 2019; Gill, Thorød & Vik, 2019;

Kristensen, Simonsen, Trillingsgaard & Kronborg, 2017; Vik & Rohde, 2014; Österman, Möller & Wirtberg, 2010). This study adds to the existing body of Marte Meo research and is a contribution to the Marte Meo community, which contains not only research but also case studies (Aarts, 2008).

Clinical implications

This study provides information about parents' experience of Marte Meo as a useful tool to enhance communication development between them and their children with DB. The study supports use of Marte Meo in a DB department in Sweden, but many conclusions may be applied in other contexts and groups. The findings in this study supports professionals in their understanding of how parents experience Marte Meo, findings which may also be applied on other similar video feedback programs. The study illustrates both possibilities and challenges when supporting communication through a video feedback method. These findings can support professionals to further create a constructive and secure base for intervention when using video feedback methods. At last, this study can contribute to society's overall small knowledge about parents' experience of having children with DB and add knowledge of the parents' struggle and their longing to develop communication with their children.

Further research

More research in this field – especially longitudinal studies with larger sample, consisting of both parents and professional carers, combined with several MM-counselling sessions – may further explore the efficacy and experience of Marte Meo administered to the network of children with DB. Also using randomized controlled trials where Marte Meo is compared to no treatment or another treatment would provide evidence on whether Marte Meo has an actual effect on parent child communication. Further research could also explore if supporting parent-child communication in the DB field would be favored by combining the Marte Meo methodology with other specific methods. Most of the research available on Marte Meo is focused on mothers and very little research has examined Marte Meo exercised with fathers, which is also a field that could be further explored (DeGarmo, Jones & Rains, 2019).

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Appendix

Interview guide in Swedish

Inledning/kom ihåg

Går igenom informationsbrev, undertecknar samtycke. Ger info om: gott om tid, tid utveckla svar, får vara tyst, du få tänka. Inspelning, papper, penna. Paus.

Sociodemografiska aspekter

Berätta om dig själv, t.ex. vad du gör på dagarna (jobb, ålder, boende, relationer, utbildning, språk).

Att ha ett barn med dövblindhet

- 1. Berätta om den första tiden med ditt barn.
- 2. Var och när förstod du att ditt barn har en dövblindhet (stöd, verktyg, kunskap)?
- 3. Berätta om en vanlig vardag med ditt barn (konkret dag, kommunikationssätt, samspel, behov, styrkor).

Deltagande i Marte Meo

- 1. Berätta om hur du fick höra om Marte Meo (information, tacka ja, liknande metod).
- 2. Berätta om dina upplevelser av Marte Meo (innehåll, filmad, titta film, samarbete, dövblindpedagogen, känslor, rekommendera, förväntningar, förändring, behov av stöd, framtid).
- 3. Är det något mer ni vill berätta som jag inte frågat om, om Marte Meo (välkomna höra av sig efteråt om frågor uppstår/om de vill berätta ngt mer)?

Exempel på följdfrågor

Kan du berätta mer? Hur upplever du det?

Vill du beskriva mer detaljerat? Varför tror du att det är så?

Vill du ge ett exempel? Varför tror du att du upplevde det så?

Har du funderat mkt på det? Hur hanterar du det?

Vad lärde du dig av det? Hur har den erfarenheten påverkat dig?

Vad gör du då? När hände det senast?

Vad händer i dig då? Vad betyder det ordet för dig?