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Soft skin massage for children with severe developmental disabilities: caregivers' experiences

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The present study was designed to elucidate relational and behavioural effects of soft skin massage in children with severe developmental disability as observed by those administering the massage. Sixteen children aged 7–20 years with congenital brain injury or early acquired brain injury received soft skin massage during a 10-week period. After the intervention period structured interviews were conducted with the soft skin massage providers concerning how they experienced the outcomes of the intervention. The interviews were analysed with qualitative content analysis. Categories found in the interviews concerned closeness, social interaction, bodily responses, feelings and importance of preparation. Soft skin massage was found to contribute to more closeness and social interaction between children with severe developmental disabilities and their caregivers, as well as increased communication skills in the children. The children became more aware of their bodies and increased their bodily activities and a sense of well-being was created.

Keywords: soft skin massage; children; developmental disabilities; caregiver opinion

Introduction

Massage is an ancient medical intervention used for thousands of years in China, Egypt and India (Goldstone 2000). The American Massage Therapy Association defines massage as 'manual soft tissue manipulation that includes holding, causing movements and/or applying pressure to the body' (Moyer, Rounds, and Hannum 2004). Massage has been found to have a number of beneficial outcomes in adults, and it is used in different areas including pain alleviation (Field 1998), and has also been found to decrease sleep disturbances and crying behaviour, and increase mother-child interaction (Underdown et al. 2006). Massage given to children with developmental disabilities has also been reported to be beneficial to child-caregiver interaction (Cullen and Barlow 2004). Thus, massage seems to influence both body and mind in adults and in children with or without disability. Because children with

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severe developmental disabilities rarely can communicate their experience of receiving massage verbally, the focus in the present study is on the caregivers' opinions regarding the children's experiences of receiving massage. The present study was designed to elucidate the effects of soft skin massage in children with severe developmental disability as observed by those administering the massage. The research questions concern the relationship between the children and massage providers as well as the children's behaviour. It is also of interest to explore if the children express their experiences in some other way.

Background

In the massage literature, the types of massage used are frequently not specified. Some authors use the term Swedish massage, which is a deep tissue massage (Cambron, Dexheimer, and Coe 2006) or tactile massage (Agren and Berg 2006), which is a soft skin massage, or other terms such as aromatherapy massage (Furlan et al. 2008) or rhythmical massage (Hamre et al. 2007). Some studies in children used tactile stimulation or tactile massage, hereafter called soft skin massage (SSM).

Developmental disabilities are defined as a group of chronic conditions with cognitive, physical, speech or psychological impairment manifested at the developmental period, which contribute to substantial limitations in activity and participation (Van Naarden Braun, Yeargin-Allsopp, and Lollar 2008).

Massage has been shown to have effects on physiologic functioning such as pulmonary function in asthma and decreased glucose levels in diabetes, while other changes are common to all kinds of conditions including decreased depression and cortisol levels, enhanced sleep and increased serotonin and dopamine levels (Field, Diego, and Hernandez-Reif 2007). In a descriptive study of 108 children with low birth weight, the children who received SSM from their mothers showed better motor development than children who did not receive massage (Weiss, Wilson, and Morrison 2004). In a pilot study of 13 hypotonic children aged one–four years with developmental disabilities, SSM increased muscle activity and muscle tonus (Linkous and Stutts 1990). Reported effects of massage on children with developmental disability include decreased hypertonicity in the arms and legs of children with cerebral palsy and Down's syndrome (Field 1998).

Massage has also been shown to have effect on emotional and behavioural functioning such as primary depression, anorexia, bulimia, job stress and activity stress (Field et al. 2005). Of these clinical changes attributed to massage therapy, decreased depression, anxiety and cortisol levels have been found among children and adolescents with depression, bulimia, juvenile rheumatoid arthritis and asthma (Field et al. 2005). In a recent controlled study performed by von Knorring et al. (2008), massage in day care reduced aggression and improved social interaction among boys. Massage has also been found to enhance communication in nursing home residents (Sansone and Schmitt 2000). Furthermore, in a study of 14 autistic children and their parents, the parents experienced a closer relationship with their children after giving them massage. Both the parents and the children appreciated the massage (Cullen and Barlow 2004). Further, Field (1998) showed in a literature review that parents and grandparents who gave children massage experienced increased well-being.

Massage is an intervention applied to the body. The body could be experienced as object or as subject and it has been pointed out by Merleau-Ponty (1989) that

embodiment concerns how people experience the world through their bodies, through movement in space, time, language, sexuality, emotions and perception. Wilde (2003) interpreted the body as a silent partner and an informant of new processes after bodily changes. In the present study we focus on children with congenital disabilities, who do not know of any state without the disability. The massage could then be a means to experience the body and bodily changes.

The changes assumed to be achieved by massage could be due to more than one potential mechanism. Oxytocin levels are hypothesesized to increase and thereby induce calmness in individuals receiving SSM (Petersson and Uvnas-Moberg 2007). Furthermore, massage has been found to be beneficial to children, in that it increases serotonin levels (Field et al. 2005). Although a bodily sensation, massage influences social interaction since the body and mind are intertwined (Edwards 1998). Gadow (1980) stated that the essence of human existence is embodiment described as body and self as inseparable, thus massage could have a deeper influence on the human self. And also the massage is by definition an act of interaction, where the provider and the child are focused on each other in a friendly and comfortable situation.

In summary, massage is a perception of the world through the body and seems to affect physiologic functioning in children with disabilities, as well as the interaction and communication between children and care-givers and thereby has the potential to increase well-being in children with disabilities.

The objective of the original intervention project was to increase the well-being of children with severe developmental disabilities. Due to the children's inability to communicate their experiences verbally, the specific aim of the present evaluation study is to elucidate the effects of the SSM intervention based on the massage providers' experiences. The research questions were: What were the effects of the SSM on the relation between the children and the massage providers? What were the effects of the SSM on the children's behaviour and attitudes?

Methods

Participants

Sixteen children and young people with a median age of 13 years (range seven to 20) with congenital brain injury or early acquired bran injury resulting in various severe disabilities, including epilepsy, autism, linguistic and motor disabilities, swallowing difficulties and hypertonicity, were asked to participate in the study. None of the children or adolescents used verbal language, but some of them were able to use Bliss communication, which is a communication system consisting of easily understood pictures and symbols. Two of the children used communication through pointing either with fingers or eyes on letter tables. Some of the children could only communicate through bodily signs and sounds. Their mental capacity varied. All of the children were confined to a wheelchair and unable to perform activities of daily living by themselves. These children and adolescents attended an after-school centre or were residents of a home for developmental disabled youth in Göteborg.

The SSM was provided by 16 caregivers with three to 25 years experience of working with children with severe developmental disabilities. The caregivers regularly worked at the facilities where the study was conducted and were familiar to these specific children's manners of communication. Before the project began, the caregivers attended a 62-hour training course, focused on the SSM method described below.

Procedure

Soft skin massage

Soft skin massage (SSM) is a massage method increasingly used in healthcare for both adults (Agren and Berg 2006; Axelsson and Määttä 2007; Olsson, Rahm, and Högberg 2004) and children (Weiss, Wilson, and Morrison 2004). It uses slow longitudinal stroking to mark the length and transverse stroking to mark the breadth of the children's arms, hands, legs and feet in a predetermined pattern. Markings were also made at the end of fingers and toes as well as around joints. Vegetable oil was used to facilitate the massage. Particular attention was paid to the surroundings, special bath towels in uniform soft colours were used and the soft skin massage providers (hereafter referred to as SSMPs) wore uniform coloured t-shirts. Soft music or other music preferred by the child was played during the massage session. During each session the SSMP was calm and focused exclusively on the specific child.

Intervention

The project lasted for 10 weeks, during which the children received SSM twice a week. The massage sessions lasted for about 40 minutes, and were followed by a 10 minute pause and a 5–20 minute communication period using augmentative alternative communication (AAC) (Beukelman and Mirenda 1992) with symbols and pictures, to give the child opportunity to communicate his/her experiences. The SSMPs provided SSM to one, two or three children each and each child was provided with massage from one, two or three SSMPs. Each time the massage was given the SSMPs documented how it was performed.

Interviews

After conclusion of the intervention period, the third author conducted structured interviews with open-ended questions with the SSMPs. Two of the SSMPs were not available for interview due to parental leave and termination of employment for other reasons, respectively, and thus interviews were conducted with the remaining 14 SSMPs. The questions concerned the SSMPs' relation to the child, the child's behaviour and communication during treatment periods and at other occasions, the child's attitudes to massage, and the providers' own reactions of giving massage.

Data analysis

Notes were taken of all relevant material during the interviews, and these were transcribed afterwards and analyzed in its whole using qualitative content analysis (Krippendorf 2004). The interviews were read thoroughly and meaning units were extracted. Meaning units refer to words or statements relating to the same central meaning (Graneheim and Lundman 2004). These were then condensed to codes, which were then classified into subcategories and categories. The subcategories and categories were structured in a category table, which was revised until it was found mutually exclusive, i.e., each subcategory could only fit under one category, and exhaustive, i.e., all subcategories were classified under categories (Krippendorf 2004).

Ethical consideration

Ethical approval was obtained from the Regional Ethics Committee in Göteborg (no. 196-06). The children were given verbal information and in order to maintain the ethical principle of autonomy, they were shown how SSM is performed, to ensure that they knew to what they were consenting. Parents were given verbal and written information and gave informed consent. Due to their disability the children are 'more-than-ordinarily' vulnerable as expressed by Sellman (2005), a fact that was necessary to consider in the main massage project. The present study concerned the massage providers' experiences of the effect on the children, which could be considered as an evaluation of the massage project and it could be argued that it would be unethical not to provide any evaluation of interventions in vulnerable populations. On the other hand, to provide massage for the children was assumed to be beneficial to them and thereby ethical to give them the opportunity to receive the massage.

Results

The content analysis of the interviews resulted in five categories, with two–five subcategories each, and these are presented below with illustrative citations. The categories are Closeness, Social Interaction, Bodily Responses, Feelings and Importance of Preparation. The numbers in parentheses following the citations indicate the assigned number for each SSMP (1–14), and the letters indicate the assigned letter for each child (A–R). Most of the questions posed to the SSMPs concerned how the children reacted to the massage, but some focused on the providers' own reactions, i.e., the relation with the child, how the provider was influenced by giving massage, and the cooperation with other providers in the project. In the analysis, it was found that the answers to questions concerning the providers could be categorized into the same categories as the answers to the questions concerning the children. In order to distinguish the SSMPs' statements concerning the children from the statements concerning themselves the results relating to the children and the massage providers will be presented separately.

Closeness – hovering between confidence and vulnerability

Closeness indicated that the SSM resulted in a state of closeness between the SSMP and the child. The closeness appeared as confidence, but when coming close there is a risk of vulnerability. The closeness category includes two sub-categories, *the expression of closeness* and *the consequences of closeness. The expression of closeness* concerned what is characterizing the closeness, such as fellowship, attachment, togetherness, confidence, awareness and a close relationship. One child's confidence in the SSMP was expressed as:

> He's so careful about his right hand that you're hardly allowed to touch it. The first time everything worked well during the massage until the last part. The rest of the session he lay still with his arm extended and I could give it the full massage. (1/O)

The consequences of closeness concerned what happens when the closeness appear and these consequences were both positive and negative. The feeling of closeness was

described as something new, which goes beyond other feelings and their usual expressions:

> It gives you a fine sense of closeness with the child, and is another way, other than hugs, to achieve this. (8/H)

The closeness could also result in vulnerability. One child experienced SSM as painful, as she was very sensitive on her hands and feet which might be due to a difference in skin perception, originating from the brain damage. This girl took the hands of the SSMP and placed them on her face, indicating that she really wanted the SSM, but not where it hurt. One SSMP reported that another child could:

> enter an autistic bubble with stereotypical behaviour during the massage session. (9/J)

Even though this reaction appeared during the massage session, it is not obvious that it was a reaction due to the massage or due to the child's disability. Thus, the closeness could entail both physical and emotional vulnerability.

Social interaction – the courage to expose yourself and set limits

The social interaction category dealt with social interaction between the child and the SSMP that was evoked by the SSM. Social interaction concerned increased communication and that some children dared to open up, but also sometimes say no. This category had two subcategories, *means of obtaining social interaction,* which comprised different ways to do this, and *expressions of social interaction,* which comprised the characteristics of the social interaction. *Means of obtaining social interaction* included eye contact, signs, alternative communication, smiling, body contact and curiosity about the surroundings, expressed as:

> Communication has increased. She's talking longer and has become more curious. (9/J)

Some of the SSMPs reported that the children had more focused communication, and one of the providers experienced that the child showed enhanced empathy:

> He's become more empathetic, maybe because he's older, but the massage could have contributed. (7/P)

An expression of this empathy was seen when the child wanted to give SSM either to the provider or to other children:

> She wanted to give SSM to other children. I think she wants to do something good for others and it becomes a social interaction. (11/E)

The *expressions of social interaction* involved more clear communication, giving more distinct indication of their own borders, new sensitivity, respect, less whining, and confirmation, which were expressed as:

> Being seen and given time is probably the secret. (10/G)

The children expressed themselves in a more direct way, as described by one of the providers:

> I meet him in the morning at the Centre. During massage sessions I got clearer answers to yes or no questions. He made more eye contact after a while and he maintained that contact for a longer time. (9/H)

As the children began to express themselves more clearly, some of them became more direct in setting their limits, described as:

> She dared to refuse to do things with a girl friend, which she had never done before; it could be a maturity thing. (11/M)

The *expressions of social interaction* were described by some of the SSMPs. One boy, although not able to communicate verbally, expressed by Bliss communication an interest in more in-depth topics of conversation:

> He wants to talk with me, he knows he has a relation with me and dares to open up. He talks about death, about contacting the doctor to get his medical record about his diagnosis, about where he wants to live in the future, about high school. He dares to share this with me. We never interacted in this way before the massage sessions, we never had the time. Conversations about death, the doctor and the future came after the massage sessions. (10/G)

These quotations show that some of the children became aware of the SSM as a way to communicate and also to improve communication. They also elucidate that the children had a new courage to allow or reject interaction with others.

Bodily responses – a new awareness

The category bodily responses dealt with how the body was affected by the SSM; the massage influenced *movements, functions, activity and knowledge of the body. Movements* involved both an increase in spontaneous movements and changes in body position:

> I became affected when I saw that the child was able to lie still with outstretched legs and arms. (1/F)

Functions involved enhanced sleep, eating and defecating, but also increased concentration, alertness and relaxation, as described by one provider:

> The school has reported noticing an incredible difference in her with improved relaxation, concentration and alertness on days when she's received skin massage in the morning. (2/M)

Activity was related to an increased wish to train and an increased interest in activities of daily living.

The subcategory *knowledge of the body* concerned the fact that the children were sometimes not aware of their whole body but that during the massage sessions this awareness increased:

> His left arm always raised up when he lay down. I had to begin giving the massage when the arm was raised. After a while he could extend the arm on the mattress and the arm remained down when I worked with the other side. He doesn't use that arm so much, often hides it, stashes it away. By means of the massage I think he could really feel his whole arm and he thought it felt good. (4/L)

The bodily responses concerned changes in how the body worked and in the children's awareness of their bodies.

Feelings of calm and well-being

SSM results in different experiences, expressed as *mood improvements* and *sense of well-being*. Mood concerns being happy, calm, amazed and delighted, and were noted as changes during the massage sessions:

> Otherwise she was anxious when there were people outside the room, but during the massage sessions she was calm and didn't want to go out. (1/F)

Sense of well-being concerned experiences of delight and meaningfulness:

> I think the massage is meaningful to him, it's meant a whole lot to him. (10/G)

Sense of well-being could also be described as a feeling of security:

> I think he recognizes my steps when I coming, he becomes calm and I don't need to sing so he'll know who's coming. He connects in another way with me and the other provider. I think he feels secure in the relationship. (14/D)

SSM provided an opportunity to experience a nice cosy time:

> He's in his own world and often yells. He needs some time when he feels nice and cosy. (14/D)

The children sometimes had a wait-and-see attitude at the start of the massage project, which later changed to a positive attitude. The SSMP experienced that the SSM was a way to create calmness, security and well-being to the children.

Importance of preparation

Importance of preparation concerned the *practical* and *mental preparations* that were needed for the SSM sessions to have positive outcomes. *Practical preparations* involved the SSMPs' clothes, which were the same in order to signal to the children what was going on. Other preparations concerned the surroundings and the music and that the children also prepared themselves to receive massage:

> He looked at me a lot. His left hand often becomes spastic and closed. His hand must be open during the massage and he tried to open it with the other hand to be able to get the massage. I'd never seen him do that before. I think he wanted to have the massage so much. (6/A)

Mental preparations involved the children being mentally prepared and aware that the massage was about to begin, and also that both the providers and the children were observant.

The experience of providing massage

The following concern the SSMPs' reactions of giving the SSM. They described that they had closer relationships to the children that they provided massage for, which they assumed to be a mutual experience, which could be described as:

> I've become closer to him and I think he feels the same. (1/O)

The close relationship was expressed as taking special care of the specific child, which was reported by three of the providers:

> I feel closer to her. After the massage session I feel it's important to talk with her. When you connect with the child you're more concerned about her. (12–14/C)

The new closeness experienced by the SSMPs resulted in that they changed their way of treating the children, as expressed by one of the providers:

> I've become more aware of what massage involves. I think more about how I touch other children, how I touch them every day, I reflect about it more. I'm softer now. (7)

They also appreciated to have a task that resulted in a sense of well-being and they experienced it as positive and being able to do something positive for the child.

The SSMPs also experienced other feelings from the SSM project; first, they reported a new sense of togetherness with one another that they had not felt before the project. Although they had been working together for longer or shorter time when the project started, they acknowledged this sense of closeness as new. They also noted that others, such as school personnel and parents, appreciated the fact that the children were given massage. The SSMPs also reflected about their own bodily responses since they thought giving a massage was tiring.

Discussion

The present study presents the findings from an intervention with SSM given to children with severe developmental disabilities. The findings comprise the experiences expressed by the SSMPs providing SSM, and include closeness, social interaction, feelings, bodily responses and importance of preparation. Most of the SSMPs' own statements concerned closeness, social interaction and feelings, whereas statements about bodily changes and importance of preparation were fewer in number. This discussion is based on the categories obtained from the interview study.

In the present study increased relaxation and other bodily changes were expected as such changes in relation to massage have been reported in the literature (Field 1998; Linkous and Stutts 1990; Moyer, Rounds, and Hannum 2004; Richards 1998). Some studies have also reported increased social interaction (Cullen and Barlow 2004). However, in line with the theoretical background the main categories in the interview study involved closeness and social interaction. Although most of the SSMPs had been caring for severely disabled children for several years, they expressed surprise during the interviews regarding the closeness and the increased social interaction they experienced with the children. To a lay person the changes in the children's behaviour might not be remarkable, but to the SSMPs these changes were startling. Perception has been pointed out to be important to understand the embodied existence (Merleau-Ponty 1989) and therefore the perception of massage could be a facilitator of communication for these non-verbal communicating children. The massage is a mutual experience since the SSMP also perceives the contact with the child through her hands. Through giving the massage, the SSMP experienced closeness with the child that could be seen as a prerequisite for the social interaction that developed during communication following the SSM. Social interaction was expressed as an increased ability to communicate in different ways. Due to their disabilities these children have limited possibilities to communicate, but the massage gave them new opportunities. SSM provided some of the children with a new way of communicating, resulting in their giving SSM to the SSMPs or to other children. Other studies have also found a closer relationship between children receiving massage and those providing massage (Cullen and Barlow 2004; Field 1998), and one possible explanation for this is that the massage could be considered an instrument for communication. Some of the SSMPs also reported that the children dared to stake out their boundaries in order to open up or say no when they wanted. However, since these children are very vulnerable it is important to SSMPs to be vigilant on all signs of children feeling uncomfortable with the massage, as well as respect their limits for communication, in order not to intrude in their lives in an unethical way.

Preparation was both practical and mental. Practical preparation helped the children to understand what was going on. Both the SSMPs and the children prepared themselves mentally before the massage sessions. Henricson et al. (2006) described that preparation gave the SSMPs an inner balance, respect for the patients' integrity and a relationship with reciprocal trust. They also mentioned the importance of a supportive environment with limited disturbances, which is in accordance with the findings in the present study.

The SSMPs experienced closeness with the children and with the other SSMPs, but also that it was energy consuming to give a massage. It has been acknowledged by others that SSM is exhausting for those giving it, and that there is a need to maintain an inner balance, which could be done through an energy-controlling system (Andersson, Wandell, and Tornkvist 2007), comprised of energy takers, e.g., patient illness or therapist insecurity, energy returners, e.g., seeing positive effect on patients and on oneself, and energy controllers, e.g., creating routines, mobilizing energy and getting a massage. This energy-controlling system, especially the energy returners and energy controllers, could also be seen in the present study: the SSMPs noticed the positive effects on the children and they acknowledged the importance of preparation. Through the massage intervention the SSMPs were provided with a described method to interact with these severely disabled children, which could be seen as an energy controller as described by Andersson, Wandell and Tornkvist (2007).

There are several limitations to the present study. First, the described experiences are proxy experiences since the children were not able to communicate verbally. Another limitation is that the SSMPs were also the ones that evaluated the effects of massage. It would have been more credible if someone outside the project had evaluated it. Parents could have evaluated it since they know their children well and could have noticed subtle changes. In the present study, the parents are only represented indirectly, as the SSMPs reported that the parents appreciated that the children received SSM. Furthermore, we do not know the extent to which the massage alone contributed to the positive outcomes in the present study, or whether the fact that the children received extra attention and involvement, or the social interaction itself contributed to well-being. Nor have we distinguished the SSM effects and the effects of the communication period, but the SSM is a new way to communicate, which could have additional effects. One way to overcome these limitations could be to design a randomized controlled trial, although this would be difficult due to the nature of SSM as method to create a sense of security and pleasure.

However, to include children of different age and different kinds of disabilities would strengthen the findings. In this qualitative study it was important to capture the breadth of the expressions of experiences of the SSM. Also, to include several SSMPs in the study confirms the findings, since this is not only the opinion of one SSMP, but of most of the participants in the study.

Conclusion

Soft skin massage was found to contribute to both emotional and social well-being as demonstrated by more closeness and social interaction between children with severe developmental disabilities and their SSMPs, as well as increased communication skills in the children, with more in-depth dialogues. Furthermore, the children became more aware of their bodies and increased their bodily activities, and a sense

of well-being was created. Soft skin massage also affected the massage providers in a positive way, which might be one explanation to the positive outcomes in the present study.

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