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Exploring a massage intervention for parents and their children with autism: the implications for bonding and attachment

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Abstract

This exploratory study aimed to address two questions: (1) What does touch mean between parents and their children with autism on completion of a massage intervention? (2) Do parents feel that their relationship with their children has changed on completion of a massage intervention? Fourteen parents agreed to be interviewed. Data were collected before the massage intervention (baseline), immediately after the massage intervention and 16 weeks from baseline and were analysed using interpretative phenomenological analysis. At baseline, parents felt distressed that they felt unable to get 'close' to their children. After the intervention, parents reported feeling physically and emotionally closer to their children. Children expressed a range of cues to initiate massage at home. These benefits were maintained at follow-up for parents who continued to use massage at home. In conclusion, giving massage to children with autism may help to enhance the emotional bond between parent and child.

Keywords autism • bonding • children • massage • parents

Introduction

Tactile stimulation including touch has been shown to be essential in children's growth and development (Eliot, 1999). Touch is a baby's first language and its

first encounter with another human being (Montagu, 1986). In addition, touch is one element of the bonding and attachment process between mother and child and, although it has been widely researched, the majority of studies have focused on parents and their healthy newborn babies and young children and attachment disorders in adults. There is less research on the bonding and attachment process between parents and children with autistic spectrum disorder. This may be because autism is rarely diagnosed before the age of three years.

Vanmeter (1996) found that, compared to children with learning difficulties, children with autism displayed a number of deficits in attachment behaviours including imitation, joint attention, recognizing others emotions, and peer play. In contrast, Ozonoff and South (2001) report no impairment in attachment in children with autism when compared to children with typical development. Earlier studies (Dissanayake and Crossley, 1997; Sigman et al., 1986) also found no differences in behavioural responses at either separation or reunion among children with autism, compared to children with typical development. Thus, the findings are somewhat mixed and are based on small sample sizes. However, these studies do demonstrate the complexity of the bonding and attachment process in this group of parents and children.

Anecdotally, children with autism avoid physical contact and appear to show no desire for affection. Consequently, the very nature of autism many hinder or prevent the reciprocation of cues and responses between mother and baby which are necessary for the bonding process to take place. Children may arch their backs away from parents to avoid being touched and may become floppy or rigid to avoid being picked up. Some children may cling uncontrollably to the parent. In this sense, touch becomes instrumental. For example, the parent provides a safe haven for the child rather than a source of affection. Thus, the familiarity of the parent may be less arousing than, for example, a stranger. Tactile defensiveness or the avoidance of physical contact may be a coping strategy used by children with autism to control the amount of stimulation that they receive. There is scant literature exploring the experience of touch for people with autism. However, autobiographical accounts about the experience of touch suggest that it can be a painful, overwhelming experience (Grandin and Scariano, 1986). Whatever the scenario, the parents of children with autism are faced with a unique challenge in their attempts to initiate physical closeness with their children. The bonding and attachment process between the parent and child with autism may be impaired, absent or not follow the 'normal' or expected patterns of behaviour.

However, research shows that children with autism show little resistance to touch in the form of massage (e.g. Escalona et al., 2001; Field et al., 1996). Touch in the form of massage was shown to decrease touch aversion, increase attentiveness in a classroom situation and reduce stereotypic behaviours such as rocking. In addition, the children initiated positive touch more frequently when playing with their peers and showed lower fussing, crying and self-stimulating behaviour.

It is suggested that, due to the predictable movements of massage, this type of touch may be more acceptable than the very unpredictable social stimulation that is frequently resisted. Interventions using massage have been shown to facilitate the bonding and attachment process and to enhance communication between parents and their newborn babies (Adamson, 1996; Scholz and Samuels, 1992). However, there is no documented evidence exploring the value of providing instruction for the parents of children with autism in positive touch in the form of massage and for use in the home environment. The majority of interventions for parents of children with autism focus on behaviour management, social skills training and communication development. This study aimed to examine two questions:

1 What does touch mean between parents and their children before and on completion of a massage intervention?
2 Do parents feel that their relationship with their children has changed on completion of a massage intervention?

Sample

The study reported here was part of a wider research and development project to determine the value of providing parents of children with disabilities with a practical skill (i.e. massage) that they could use on their children at home. Approval for the study reported here was received from the Ethics Committee, Coventry University.

Initially, parents were recruited from a variety of sources, including contact with organizations and health professionals working with and for parents of children with autism, to determine their interest in the massage intervention. These organizations in turn agreed to distribute to relevant parents a leaflet with a brief description of the massage intervention. Finally, the parents who had completed the massage intervention passed on information about it to other parents of children with autism. The entry criteria were: child with a diagnosis of autism spectrum disorder; and parent or main carer able to attend eight training sessions with the child.

The study used a sample of convenience. This method of sampling is commonly used within qualitative research and particularly for exploratory research (Bowling, 1997). Initially, 14 parents (one father and 13 mothers) with children (13 male and two female) within the autistic spectrum gave their consent to be interviewed and participate in the massage intervention. One parent brought both of her children to the massage intervention.

Of the parents, 13 were white/European and one was Asian. They had a median age of 37 years (range 28–48). Twelve parents were married, one parent was living with a partner and one parent was separated. All but one parent had a

formal educational qualification at GCSE level. Seven parents worked part-time and of these, five had reduced their working hours in order to care for their children; five remained at home; one was unable to work due to health reasons and one was unable to work due to the child's health. Four parents reported health problems including diabetes, asthma, myxedema and attention deficit disorder.

Five parents did not complete the full eight-week programme and nine parents completed all eight weeks. Reasons for withdrawal included: child's illness (2); personal reasons (2); parent's poor health (1). Two parents were unable to be contacted at the 16-week follow-up.

The children were aged between two and 13 years (median 6.5 years), with a median age at diagnosis of three years (range 1–9 years). Four children had co-morbidity (e.g. learning disability, attention deficit disorder and hyperactivity, hearing impairment, semantic pragmatic disorder and epilepsy).

Method

The study was exploratory, with data collected by semi-structured telephone interviews before the massage intervention (14 interviews), immediately after the massage intervention (10 interviews) and 16-week follow-up (eight interviews). Interviews lasted between 35 minutes and one hour. Questions included:

Pre-intervention:

- What do parents perceive to be the most difficult aspect of caring for children with autism?
- What is the current experience of touch between parents and children with autism and how does this make them feel?

Post-intervention:

- What are parents' experiences of the massage intervention?
- What does touch mean between parents and their children, and how does this make them feel?
- Do parents feel that their relationship with their children has changed?

The interviews at the 16-week follow-up allowed clarification of the issues reported at pre- and post-intervention and further exploration of the experiences and meaning of touch between parents and children.

Analyses of the transcripts followed the stages of analysis for interpretative phenomenological analysis (IPA) (Smith et al., 1999). IPA was chosen for two reasons. First, the theoretical underpinning, namely phenomenology and symbolic interactionism, accommodates the research aims. That is, phenomenology is concerned with an individual's perception of an event and symbolic interactionism is concerned with the meaning assigned to an event (Smith et al.,

1999). Second, IPA acknowledges the researcher's role in the research process as much as the participants'. That is, to ascertain people's feelings, thoughts and beliefs involves a dynamic research process (e.g. between participant and researcher) and the interpretive activity (e.g. between researcher and data).

Each transcript was transcribed verbatim by an independent person and read several times by the lead author to obtain thorough familiarity with the data. After the initial reading of the first interview transcript, any interesting or significant points were noted in the left margin. Following a second reading, emerging theme titles were noted in the right margin. The second stage of analysis involved grouping all emerging themes. Two transcripts were randomly selected and examined independently by a fellow researcher. Inter-rater agreement on transcript data was 85 percent. Finally, the themes were translated into a narrative summary.

As with all research, there were a number of ethical considerations. The sensitive topic (touch) and personal experiences are at risk of exposure. Thus all participants were informed about the purpose and format of the interview and their consent to be audiotaped was obtained. The quotes used in the results section have been selected to exemplify key points. All names have been changed to preserve anonymity.

The massage intervention

The massage intervention comprised eight one-hour weekly sessions of one-to-one instruction (i.e. therapist–parent with child) in simple massage techniques. The primary massage technique used was *effleurage*: a gentle stroking movement. In addition to the sessions, each parent received a training pack and a 50ml bottle of sweet almond oil. The training pack included:

- an introduction to the massage intervention;
- a list of contraindications and instructions on massage movements to accompany the instruction provided in each session;
- diagrams; and
- photographs of parents and their children to help illustrate specific massage movements.

Therapists already qualified in massage were trained in the delivery of the massage intervention.

Results

Interviews with parents before the massage intervention

Before attending the massage intervention, 14 parents were interviewed. It was evident that invariably the experience of touch between the parents and their

children was on the children's terms. That is, parents were unable to offer their child spontaneous affection or comfort even when they could see that their child was in pain. Rather, they had to wait until their child came to them for a hug or attention, as the following quote illustrates.

> If he is hurt, the natural instinct would be to comfort him and cuddle him and you can't touch him. No, if he hurts himself he explodes. He becomes very aggressive and you literally have to let him come out of it himself. Or the favourite is to hide under a blanket and shut the world out. Or he'll shove his fingers in his ears and block his ears and close his eyes tight. He won't let us cuddle him.

For four parents the experience of not being able to comfort their child had been a distressing experience. One parent was left feeling out of control of the whole situation, which in turn resulted in feelings of despair. One parent had grown to accept this situation over time:

> I suppose I have got used to it, I mean when he was three and four, it could be very very distressing, you know. I would give my other son a cuddle and I would go and give Casey a cuddle, but he would just turn his back on me. But again I have had this, well he was diagnosed at two years, so I have had this for 10 years.

The one overriding motivation to participate in massage intervention was the possibility that it could facilitate getting 'closer' to their children, both physically and emotionally.

Interviews with parents immediately after the massage intervention

Five parents withdrew from the massage intervention. One of these parents was ill but agreed to be interviewed. Therefore, interviews were conducted with 10 parents immediately on completion of a massage intervention. Overall, the parents were surprised at their children's positive response to receiving massage and at the children's requests for massage at home. In fact, one of these parents did not expect to get past the first session. Of interest were parents' perceptions of the children's reaction during and immediately after receiving massage. These were described as the children being more relaxed, lucid, talkative, happy and energetic. On the days after giving their children a massage, parents felt the children were happier and less frustrated. The consistency of the programme was considered a potential influence to children's positive adaptation to attending the massage intervention and receiving massage.

> It is something he knows, he has got used to it. It's not like – 'cos we have been through all sorts of behaviour management, you know, and I mean it changes all the time. Where this is, this has been constant for what, eight weeks? And he seems to be responding to it.

The parents were surprised at how much they enjoyed giving massage to their children and how much it had helped them also to feel relaxed. They felt

that they had gained an increased sense of closeness with their children. They described this sense of closeness in various ways, such as having quality, quiet time together, being able to sit with their children, being able to hold hands and to do something that is comforting and pleasurable for their children. One parent reported that the massage enabled her to maintain a physical closeness with her son (aged 11 years) in an age-appropriate manner.

> Well, it allows us to have quiet time together. It's opened up a different set of feelings towards each other. You know, my feelings towards Sam, because I mean, when you put this autistic child who doesn't even want to be held, to be able to hold his hand, to stroke his hand – it is wonderful.

Parents were asked to clarify what this 'enhanced closeness' meant. They felt acknowledged, happier and positive that they could offer a type of affection that was acceptable to their child, even during times of distress.

> Well, it makes me feel better, it makes me feel acknowledged where before I wasn't. It makes you feel a part of him. You know, we are that bit closer. That is very good. It is a very positive thing. Before I was just dad – you know, just a man. And now I feel like I am not quite just dad. I am dad who is quite nice. And he cuddles me a lot more than he ever did.

Thus, parents talked about feeling that they were 'a part' of their children and that they were now recognized as a parent as opposed to 'just another' person. They were feeling very positive about this development in the relationship with children.

Interviews with parents 16 weeks from baseline

Of the 10 parents interviewed on completion of the intervention, two parents were unable to be contacted at the 16-week follow-up, therefore interviews were conducted with eight parents. Parents liked the idea of being able to do something with their children that was enjoyable and made them feel closer. One mother who had been sceptical at the beginning of the massage intervention was delighted and amazed at her son's response to it. All the parents interviewed had continued with massage at home. However, the amount of massage undertaken was variable. One parent admitted that little massage was undertaken at home, but on occasion, her son would request it. One parent reported that school and other activities prevented a routine from being established, but massage was undertaken as often as possible. Three parents conducted massage at least once a week and three parents had continued with massage every day.

Four parents described the unusual cues for massage from children. One child would kneel on the floor with head bowed to indicate for massage to his back. One child would place a towel on the floor and lay on it, similar to the couch at the therapist's clinic, and another child would place his feet and legs on his parent's lap. One child, with no verbal communication, would fetch the

bottle of oil to her mother to indicate she wanted massage. One mother reported that her son liked his back and feet to be done, and preferred the gentler movements (e.g. *effleurage*). Although the parents perceived that their children responded positively to massage, it was difficult for some to ascertain their children's true feelings due to difficulties in verbal communication. However, the fact that children requested massage appears to indicate that they enjoyed receiving it.

All the parents reported that the enhanced relationship with children, in particular the feeling of being closer, had continued:

> It's our little closeness, you know. It makes him closer to me. He responds a little bit better to me. He'll cuddle me a bit more now, whereas before he wouldn't, you know.

Interestingly, one mother felt that her son had become more aware of himself and his body than previously:

> It is another way of making him feel nurtured and cared for, it helps him relax. It is a physical form of interaction and increases his awareness of himself and his body. It makes me feel confident, in that I can do something for him involving physical closeness and nurturing that he enjoys and has a positive attitude to. It also helps me to relax while I am doing it.

Discussion

On completion of the massage intervention, all the parents reported that they felt physically and emotionally closer to their children and subsequently that the relationship with their children had been enhanced. This 'emotional bonding' is consistent with the findings of other massage studies (e.g. Adamson, 1996; Scholz and Samuels, 1992) including children with a range of disabilities (e.g. Barlow and Cullen, 2000, 2002). However, whether these feeling of 'closeness' are linked to the process of bonding and attachment would require further exploration. The psychological aspects of bonding and attachment are more difficult to assess than observable behaviour patterns.

The key symptoms of autism include impairments in social interaction, communication and relationships (Wing, 1985). These symptoms are also important factors in the bonding and attachment process. Retrospectively, it has been reported that babies with autism may rarely cry or seek attention (Moreno and Donnellan, 1991). The typical behaviours (e.g. touch, crying, eye contact, smiling) that facilitate bonding and attachment may be absent in babies with autism. Therefore, the necessary 'bonding' cues and responses may be absent between a child with autism and their parent. However, the children in this study did display cues for touch to which the parents were able to respond by giving massage. Children were able to communicate their need for massage and in a way

that did not necessarily involve the use of speech and language: for example, kneeling on the floor with head bowed, placing a towel on the floor and laying on it, similar to the couch at the therapist's clinic, placing feet and legs onto the parent's lap, and taking the bottle of oil supplied in the training pack to the parent. These findings offer new perspectives to the cues and responses associated with bonding for parents of children with autism, and may generalize to parents of children with other disabilities. In addition, touch appeared to become a means of communication between parents and children other than speech and language, which for some children with autism is difficult to articulate and understand.

In addition, the processes of bonding and attachment are considered to occur at critical periods within a child's development. However, this study suggests that the processes of bonding and attachment can occur at a later stage of a child's development and challenges the critical stage theory within the attachment literature. Thus, these findings have the potential to take the concept of the bonding and attachment processes beyond the mother and early childhood stages of interaction.

The 16-week follow-up interviews with parents indicate that both parents and children continue to enjoy giving and receiving massage. Although all the parents had continued with some massage at home, the amount of massage was variable. Harris (1984) found that while many parents achieve a high level of skill as behaviour modifiers, they reduced their application of these skills during one year after acquisition. The author found that parents acknowledged that they were not doing what they were supposed to be doing. A 12-month follow-up interview may reveal the longer-term outcomes of giving massage.

Five parents withdrew from the massage intervention. This relatively high proportion of parental drop-out is in itself a potential problem in terms of sample size, validity and generalizability of findings. Although there were no differences on demographic variables (e.g. age, health status, marital status, children's age, co-morbidity) between the parents who completed the intervention and the parents that withdrew from it, the parents that withdrew were each experiencing the presence of additional 'stressors' such as divorce, ill-health and personal trauma. Weignor and Donders (2000) found that the presence of a significant stressor within the previous six months was a statistically significant predictor of parental distress. Similarly, Sharpley et al. (1997) found that parents with a major illness were more likely to experience higher levels of anxiety and depression. Hence, the timing of the massage intervention may be crucial for parents who periodically may need additional support mechanisms.

However, this study shows that giving massage to children with autism may help to enhance the emotional bond between parents and their children. Of interest is the range of cues used by children in this study to initiate massage from parents. Research based on larger samples and using a combination of qualitative and quantitative methods is required to help gain a deeper understanding of the

role of touch in the form of massage for this group of parents and children. Further, it is required to explore the role of massage in the facilitation of the bonding and attachment process: in particular, the sustainability of 'emotional bonding' and cues used by children with autism, as well as parental responses to the cues that are necessary for the bonding and attachment process to be successful.

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