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The Effects of Cerebral Palsy on Early Attachment: Perceptions of Rural South African Mothers

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ABSTRACT The aim of the study was to explore the perceptions of mothers about the effect of cerebral palsy on early attachment behaviours of their children in a rural area of the Eastern Cape province of South Africa. The study explored the mother-child attachment relationship. Semi-structured interviews were used to assess mothers' perception of cerebral palsy and its effect on attachment behaviour of children. The interviews were recorded and then analysed using thematic content analysis. The study identified three recurrent themes that emerged in thematic content analysis. These were factors that facilitated bonding, hindered bonding and maternal response to the needs of the child. The findings of this study showed that children with cerebral palsy were reported to experience early attachment difficulties. The mothers reported that the emotional bond between mothers and children was affected by the severity of cerebral palsy. The results indicated that mothers of children with cerebral palsy needed both psychological and material support in order to strengthen early attachment behaviours of children and mothering practices. Directions for future studies could focus on educational interventions that assist mothers accept cerebral palsy diagnosis and the development of positive attitudes towards cerebral palsy in mothers who live in rural areas in South Africa.

INTRODUCTION

The relationship between the mother and her child facilitates the development of an emotional bond between the two. This emotional bond could be affected by the complexities of caring for children with cerebral palsy in rural areas in South Africa as each community could have various perceptions of cerebral palsy. When a diagnosis of cerebral palsy is made on a child, the family has to deal with the physical condition of their child. Cerebral palsy is first noticed by parents when a child shows impairment of movement and posture. Cerebral palsy was found to have a prevalence of 2 to 2.5 per 1000 live births in Northern Ireland (Dolk et al. 2006). In developing counties, the prevalence is much higher because of poor antenatal care, large numbers of children born at home, dehydration, malnutrition, and poor disease management (Baratt 2007). In South Africa, the estimated prevalence of cerebral palsy is between 1% and 8 % (Cooper 2002) with a higher prevalence in less developed communities and rural areas.

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Cerebral Palsy

Cerebral palsy is described as a non-progressive disorder which primarily causes motor disability (Kirby et al. 2011). Cerebral palsy may vary in severity, and may be present with other co-occurring developmental disabilities such as cognitive disorders, auditory impairment, visual impairment, speech and language impairment as well as conduct disorder (Kirby et al. 2011). A child with cerebral palsy may not be able to signal the need for physical proximity or closeness in a conventional way due to motor, sensory or cognitive deficits. This affects the mother' s attachment response to the child (Shah et al. 2011). Cerebral palsy disturbs sensation, perception, cognition, communication, behaviour and the child could have epilepsy and musculoskeletal disorders (Kirby et al. 2011). Children with cerebral palsy are usually put in special schools that have special facilities and a multi-disciplinary team of specialists who help them deal with emotional, physical, social, and learning difficulties. In early attachment, it is the home environment that is made up of the mother, father, caregiver and family members that first helps the child develop attachment behaviour before they go to school or interact with the outside community. In this study, the mother's interaction with her child with cerebral palsy was

considered to be essential in the development of attachment behaviour in early childhood.

Early Attachment

There are many factors that can affect the interaction between a child with a neurological disability and a parent. Cerebral palsy generally affects mobility, communication, cognition, feeding and interaction reciprocity which are essential in the formation of attachment behaviour in children (Berlin et al. 2011). The disability affects developmental milestones in children. There is paucity of information within the South African context that deals with effects of cerebral palsy on early attachment.

Attachment theories indicate that children develop and emotional bond with their parents and significant others (Bornstein et al. 2011). Researchers studying the social and emotional development of children argue that primary attachment relationships influence later attachment relationships between children and their parents. This study explored attachment behaviour of children with cerebral palsy and the behaviour of mothers towards children with cerebral palsy. The study was particularly interested in attachment perceptions of mothers of children with cerebral palsy in a rural context in South Africa as most of the studies on attachment are based on western middle-class families (Brown et al. 2008).

Attachment can be described as the bonding process between the infant and primary caregiver that satisfies the innate needs of the infant such as physical contact, closeness and safety. It is proposed that when these needs are fulfilled, usually by the mother caring consistently for the child, an enduring bond is created which provides the infant with a sense of safety and security (Brown et al. 2008). Attachment behaviour is observed when the infant initiates attention-seeking and proximity-seeking behaviours such as crying, smiling, babbling and gesturing. The adult in an attachment relationship responds with sensitivity and demonstrates behaviours such as holding, speaking to, feeding the child or performing an act the child the expected (Brown et al. 2008). The perceived security enables the infant to explore the world with confidence.

Language development influences attachment bond between the child and the mother (Cabrera et al. 2011). Children who can communicate properly using both verbal and non-verbal cues achieve tend to have better attachment than children who cannot effectively communicate their needs (de Falco et al. 2011). Children with cerebral palsy have speech and language use disorders that could impact negatively on attachment behaviour (Berlin et al. 2011). The mother and other caregivers have to understand the vocalisations and body language of children with cerebral palsy (Berlin et al. 2011).

Child attachment comes in four stages. These are the initial pre-attachment phase, the phase of attachment-in-the making, the phase of clear-cut-attachment and finally the phase of goal-corrected partnership (Ainsworth et al. 1978). These attachment phases might not develop fully or noticeable in the developmental milestones of a child with cerebral palsy (Ryll et al. 2011). These attachment phases could be affected by the cognitive and psycho-motor development of the child (Kirby et al. 2011). The pre attachment phase exists from birth and continues for a few weeks. In this phase the baby is more responsive and attuned to the stimuli that come from people but the child does not discriminate one person from another. They respond to different people in a similar way as they do to their mother. The infant at this stage is still equipped with a number of signalling behaviours which may be used to get attention such as crying. These behavioural signals attract attention and induce the caregiver to approach the child and pick them up (Ainsworth et al. 1978). This promotes contact with the mother or caregiver and hence an emotional bond develops (Sonkin 2005).

Phase two which is called " attachment in the making'' is characterised by behaviours such as being able to discriminate between familiar and unfamiliar figures (Ainsworth et al. 1978). The baby develops a larger repertoire of attachment behaviours, such as more co-ordinated reaching abilities, a wider range of vocalisations and smiling (Ainsworth et al. 1978). This comes with enhancement of proximity to the attachment figure (Ainsworth 1978).

The third phase of attachment is referred to as "clear-cut attachment" (Ainsworth et al. 1978). This occurs between 6-12 months but could be delayed in other children (Ainsworth et al. 1978). The child in this attachment stage is able to main-

tain proximity to the attachment figure through the use of locomotion and signals (Ainsworth et al. 1978). The child becomes more active in initiating and seeking proximity to the mother or caregiver. The child develops locomotive and language skills that enable them to move towards and communicate with the attachment figure. Object permanence develops at this stage and the child is able to search for the mother or caregiver even in their absence.

The last stage, "the stage of goal corrected partnership" is characterised by the lessening of egocentricity and the child can have the same perception of events and objects as the mother (Ainsworth et al. 1978). The child can set realistic goals that would influence the mother's behaviour (Sonkin 2005). The relationship becomes more reciprocal in nature as the child grows.

It is argued that some mothers or caregivers can show either positive or negative behaviour towards children with disabilities (Obladen 2011). These can be described within four categories, namely, sensitive versus insensitive to the baby's signals, co-operation versus interference with baby's ongoing behaviour, physical and psychological availability versus ignoring and neglecting, and acceptance versus rejection of the baby's needs (Mikulincer and Shaver 2007). If a mother is sensitive to the child's needs, she would respond to infant's signals. When a mother is co-operative, she respects the child's autonomy as apposed to imposing her wishes on the child. A mother who is physically and psychologically available to the child does not ignore and neglect the child. An accepting mother acknowledges her responsibility to childcare and shows a few signs of irritation towards her child with a disability (Mikulincer and Shaver 2007).

There are other external factors which affect early attachment between mothers and their children. These could be financial resources, living conditions, and psycho-social support. Mothers who are away or cannot be with their children due to financial constraints do not form strong attachment with their children (Cooper et al. 2002). It is argued that poor livings conditions can affect the emotional bond between the mother and the child (Cooper et al. 2002). Pycho-social support in the community helps develop stronger attachment behaviours between parents and their children (Obladen 2011). Mothers of children with disabilities and children with disabilities themselves could experience social, economic and political levels of inequality, discrimination and marginalisation, (Obladen 2011). There still exists a stigma around disability in South Africa. Families with a disabled child could be stigmatised and excluded from community social activities (Kakuma et al. 2010). This could be due to lack of understanding and knowledge about the disability or disabling conditions (Cooper et al. 2002). Others could attribute disability to religious beliefs or witchcraft (Penn et al. 2010).

Attachment behaviour is also related to sense of danger in children. The children show survival behaviours by being able to show an awareness of danger and protection-seeking behaviour (Howe 2006). In attachment theory, it is argued that children monitor their environment in order to determine whether or not signs of danger are present. If children feel frightened or distressed their attachment system is activated and this triggers attachment behaviours (Howe 2006). A child with cerebral palsy could have limited danger communication skills and their mothers could constantly look out for negative signs in the environment and checking on the child‘ s safety (Neely-Barnes et al. 2010). The child with cerebral palsy might show deficiencies in self-care, mobility, social function and expressions of fear or psychological distress (Smits et al. 2011). Low levels of maternal affect and emotional arousal in children could inhibit the development of attachment behaviour between the mother and the child.

Aim of the Study

This study explored the perceptions of mothers about the effects of cerebral palsy on attachment behaviour. The perceptions of mothers about cerebral palsy were investigated within the context of mother-child attachment dyad.

Research Question

What are rural mothers‘ perceptions of cerebral of cerebral palsy in early attachment in South Africa?

METHODOLOGY

Research Design

This was a qualitative study in a rural setting in the Eastern Cape of South Africa. The study was cross-sectional and it was based on one sample of mothers interviewed in one area at a defined time.

Participants

Mothers of children with cerebral palsy participated in the study. The mothers visited a hospital and clinics in the area for rehabilitation services. The study invited mothers with children under the age of six years to participate in the study. Seven mothers volunteered to participate in the study. Mothers who exhibited severe physical or cognitive disabilities were excluded from the study as it was considered that the mother‘ s disability could confound the results of the intended study.

Procedure

The study got ethics clearance from a University Ethics Committee. Permission to conduct the study was granted by the District Rehabilitation manager of Makana. Mothers attending a regular therapy programme for children with cerebral palsy consented to participate in the study after all the procedures of the study were explained fully to them. Informed consent was obtained and participants were informed that all proceedings were held confidential. The study interviewed mothers who agreed to participate in the study. They were asked about the effects of cerebral palsy on their children‘ s early attachment behaviours.

Instruments

A semi-structured questionnaire was used to obtain information on attachment between mothers and their children. The questionnaire asked for biographical information relating to age of mother, age of child, family size, marital status, education level and average monthly income. The questionnaire had a section that required information about the child‘ s medical profile. This was taken from the child‘ s medical record card or developmental file. The questionnaire asked for a brief diagnostic description of the child’s motor, cognitive, language and sensory impairments. The second section required information on attachment between the mother and the child. Mothers provided information on factors that enabled bonding, hindered bonding and maternal response to the needs of a child with cerebral palsy.

Data Analysis

The semi-structured interviews were taperecorded and then transcribed. The recorded information was analysed using thematic content analysis. The method involved identifying and analysing recurring themes about mothers‘ perceptions of cerebral palsy in early attachment. The accuracy of the information was validated by comparing information on tapes with transcribed information to ensure that key points raised by participants were included in the themes identified. In this study, key quotations from participants are included in the results section.

RESULTS

The diagnosis for cerebral palsy was complicated by the cormobidity of conditions such epilepsy, cognitive impairment, lower limb impairment, receptive and expressive language impairment, cortical blindness and low muscle tone or hypotonia in some cases. At first, the mothers of children with cerebral palsy were shocked by the diagnosis and some denied that their children were different. The study identified three major themes relating to early attachment. These were factors that enabled bonding between the child and the mother in early childhood, hindrances to early attachment and maternal reaction to the needs of a child with cerebral palsy in early childhood.

Factors That Were Perceived to Facilitate Early Attachment

All the mothers reported that they had a maternal duty to love their children. This is supported by the following statement: “I am the mother, I am the one who must take the care of her, no one else could do that job like the mother, I love her, I must try there is no one else, especially with a child like this when it is not

easy to understand her". They had consensus that they were expected to have a strong sense of responsibility towards their children even if the children had cerebral palsy or any other disability. The mothers reported that they were expected by society to promote a warm relationship with their children. African cultures teach mothers to look after their children as a gender-specific role. The mothers upheld the notion of same treatment of children by mothers; with cerebral palsy or without. All the mothers reported that they tried hard to maintain a healthy bond with their children despite the disability.

Factors That Were Perceived to Hinder Early Attachment

Although the mothers reported that they loved their children it was indicated that a child with cerebral palsy was more demanding emotionally and physically. The following statement corroborates this point: "The biggest difficulty is that I don't know what is going on with him, sometimes it is like he is sick, even when he is not crying without the tears, you know that there is something very wrong so not being able to tell I find that very hard and I feel hurt because I can't tell and he can't tell me."

Children with cerebral palsy were reported to be less independent and some of the children in this study did not have adequate activities of daily living skills. Most of the children with cerebral palsy did not indicate what they needed or initiate contact with the mother. They were not active in building a strong attachment with the mother. In a normal attachment relationship, the reciprocal interaction between the mother and the child builds a lasting attachment that can persist into adulthood. The mothers felt that the children were behaving in a manner that placed responsibility on the mother and the children lagged behind in developmental milestones. Language development was generally slow and locomotion skills were impaired. At times the mothers reported that they had to be with the child most of the time because they did not trust people around them. Some of the mothers felt that their neighbours did not love their children and that society was not protective enough of children with cerebral palsy. They had feelings of insecurity and were more protective of the children. The attachment was one-sided, with the mother protecting the child from actual and perceived hostility.

Maternal Response to the Child's Needs

The mothers reported that they attended to the children's needs but at times that tended to disrupt their other roles as housewives and income earners. This is supported by the following statement: "I have to carry her everywhere or otherwise she will just stay in the place that I left her, but she is getting so heavy now so she must just stay in the same place for some time, but that is difficult because she will cry." The mothers reported that they realised that their children were striving to improve the relationship but severity of disability interfered with the development of attachment behaviour between the mother and the child. The children in this study were reported to have poor health and some had been hospitalised more than once. In times of illness, the mothers struggled to understand the child` s illness because children with cerebral palsy have communication difficulties. The children in this study could not precisely tell their mothers what they wanted or felt. The speech was largely slurred and inarticulate. The mother would guess from tears, facial contortions, and generalised body language. In all cases, the mothers reported that they were sensitive, co-operative, physically and psychologically present for their children and that they accepted their children as they were. Sometimes the mothers reported that they ran out of ideas and were frightened by the child` s sickness. Most of the children with cerebral palsy in this study were reported to experience episodes of epileptic seizures. The mothers reported that when the child was able to smile that drew them closer to the child but when the child cried without expressing what they needed, the mothers experienced great emotional pain that still drew them closer to the child. They did not reject or abandon their children.

DISCUSSION

The findings of this study indicated that rural mothers had the perception that cerebral palsy affected the development of early attachment in their children. They reported that their children were different from other children and were slow in developing attachment with their mothers.

This study discusses mothers' perceptions of facilitators of attachment, hindrances to attachment and maternal response in the promotion of the mother-child bond in early childhood.

The mothers felt that they had to develop attachment behaviours in their children as a maternal duty. They felt that women were responsible for the welfare of their children in an African setting (Barrat 2007). They had to love their children because society expected them to look after children (Cooper 2002). The bond between the mother and their children with cerebral palsy was facilitated by the norms and values of society (Neely-Barnes et al. 2010). In an African setting mothers are not expected to abandon their children or give them up to other people even if they were severely handicapped (Penn et al. 2010). Children are deemed to belong to the parents, community and country. There is a belief among Africans that if an individual offends children they are going against the wishes of the society. In this study, mothers of children with cerebral palsy could have been working hard to maintain early attachment with their children more so as a social obligation than the reciprocal relationship that naturally develops between the mother and her child (Neely-Barnes et al. 2010). The mothers' perception of cerebral palsy was that it was caused by supernatural forces (Penn et al. 2010). All the mothers except one in this study reported that the fathers of their children did not want to be associated with the children (Kakuma et al. 2010). The fathers did not support the children either. The mothers' attachment to their children was considered to be part of predestination in which they had limited control over events affecting their children (Cooper et al. 2002). The mothers felt that they were fulfilling a predetermined role by maintaining an emotional bond with their children with cerebral palsy (Obladen 2011).

Cerebral palsy was perceived by participants in this study to retard attachment behaviour between mothers and their children. When considering the phases of attachment, it was apparent that a large number of the children in this study had not developed the cognitive, language and motor skills that matched other children of their age as judged by their mothers. They had delayed developmental milestones and this is common among children with cerebral palsy (Kirby et al. 2011). Most of the children in this study showed developmental characteristics that were at the pre attachment phase and attachment in the making stage. The children showed deficiencies in activities of daily life. They were not independent to initiate attachment relationships with parents. Lack of independence was perceived by mothers in this study as hampering attachment development in children with cerebral palsy.

The mothers felt that they promoted attachment behaviours in their children with cerebral palsy because it was evident that most of the children were able to respond to their mothers though slowly. It was reported by the mothers in this study that their children could identify their mothers, distinguish their mothers' voices from the voices of other people, smile at their mothers, and laugh with the mothers. It was evident in this study that maternal effort resulted in the development of early attachment in the mother-child dyad although the bond was perceived to be weak by the mothers. It could be argued that although the maternal response of mothers in this study could be described as sensitive, co-operative, physically and psychologically present and accepting of their children with cerebral palsy, the behaviour of the mothers showed more protective behaviours than attachment-building behaviours (Neely-Barnes et al. 2010). They perceived their children as generally helpless and dependent (Smits et al. 2010). They felt that the children had a limited sense of danger; hence they needed maternal protection (Smits et al. 2011). In a sense, maternal over-identification and over-protectiveness could have resulted in mothers dominating children with cerebral palsy in the mother-child dyad.

LIMITATIONS OF THE STUDY

The mothers' perception of cerebral palsy in rural areas was based on a small sample of women with limited financial resources. The study could yield different results among middle-class mothers. The perceptions of the mothers could have been influenced by their level of education and the availability of psycho-social support structures to mitigate the negative effects of cerebral palsy on mothers and their children.

CONCLUSION

The findings of this study indicated that mothers of children with cerebral palsy had the

perception that their children had limited attachment behaviours. The severity of cerebral palsy was reported to determine the strength of attachment behaviour between the mother and the child. The mothers in rural areas needed psychological and material support to accept the diagnosis of cerebral palsy in their children. The findings of this study suggest that future studies on cerebral palsy and early attachment could focus on education programmes for parents of children with cerebral palsy in rural areas of South Africa.

IMPLICATIONS OF THE STUDY

The findings of this study could be used in the development of training programmes for parents who have children with cerebral palsy. Parenting programmes on cerebral palsy could be held at primary health centres and primary schools in urban and rural areas in South Africa. Such programmes could sensitise government, non-governmental organisations and the private sector to work towards the promotion of cerebral palsy awareness in the general public and how to help children with cerebral palsy become independent and live their lives fully.

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