

THE MOTHER'S CARE-GIVING ROLE ON CHILDREN WITH INTELLECTUAL DISABILITY

Lloyd DN Tlale

ABSTRACT

The mother's role in stimulating the child's intelligence is pivotal since she carries the pregnancy and the child spends more time with her than with the father in the first few years of life. The early years are crucial because it is the time for the child's rapid brain development. This paper examines the mother's role of care giving on children with intellectual disability in the early years. Qualitative focus group discussions were employed to collect data. Four focus group interviews. Two groups consisted of six participants and another two consisted of seven participants in each interviews. The findings revealed that not leading a healthy life may lead to children being born with intellectual disability. The mothers from a low socio-economic context thought that the child with intellectual disability was an excessive burden and craved that the child would die rather than live. They were not willing to consider treatment options unless the child would become completely normal. This paper recommends that the mothers as the only participants in this study limit the findings but provided first hand experiences connected to care-giving and children with intellectual disability. In addition, there is an implication that mothers of children with intellectual disabilities are at an obviously bigger risk of suffering from social disorder and dispossession as well as emotional suffering which can progress to severe depression.

Keywords: Intellectual disability, cognitive development, brain, health and nutrition

INTRODUCTION

The strength of a child's intelligences is built while they are young (Piaget 1952; Guerin 2011). During the foetus stage the baby's life is vital because fundamentals of intelligence are constructed. Science tells us that a child's brain begins to form from the third week of conception but most of the vital links in the brain are made-up during infantile stage (Zero to Three 2011). When the baby uses any of his or her senses, a sensory link is created in his or her brain. In other words, the more the child's sense organs are put to use, the more the brain develops. Brotherson (2005) asserted that the connections in a child's brain are strengthened through repeated exercise. If a pathway is not used, it is eliminated. This implies that actions done only once are less likely to have an effect on brain development.

Intelligence is an attribute that any parent would want his child to have to succeed first in academic endeavours and then in career later in life. Fortunately, this attribute is not all about genetics. There are other factors which influence the degree of intelligence such as nutrition, health, early experiences and the environment to which the child is exposed (Herrnstein & Murray 1994; Block 2016). These are factors that are modifiable and not pre-determined by heredity. In other words, though the genes determine how far intelligence can grow, other factors within the control of man determine whether this height of intelligence is attained or not.

Considering the closeness as well as the amount of time spent interacting with the child, no other person is in the position of influencing the child's intelligence as the mother. She carries the child in her womb for about nine months, and after giving birth to the baby she is expected to breastfeed him for the first two years of his life (World Health Organization 2003; Shloim, Hugh-Jones, Rudolf, Feltbower, Lans & Hetherington 2015). Moreover, she bathes, feeds, clothes and interacts with the child more than any other member of the family. During the period when she carries the baby in her womb, the baby's survival depends on the mother. That is, by what she eats, drinks and her other habits, she determines whether or not the child will live, be born healthy, grow normally and live a normal life after birth.

This paper therefore examines the roles that a mother could play in ensuring that the child's brain develops well and that his or her intelligence reaches her or his full potential in the early years, thus paving a way for success in academics and thereby avoiding intellectual disability (Findet 2011). The research questions would, therefore, be as follows:

- i) What are mothers' views with regards to their role in caring for children with intellectual disability?
- ii) What can a mother do for the wellbeing of children with intellectual disability during early years of life?

STIMULATING THE CHILD'S BRAIN

The early years of life are critical for reasonable growth and development. It is during this period that neurological (brain and nervous system) and muscular growth and development occur most rapidly and these are all factors that will determine, to a large extent, the child's future intellectual growth or disability (Block 2016). The state of a child's health is determined by a variety of factors which interact with each other and this means that it is possible for an individual's health status to change continually for better or for worse. Mothers should be concerned about their health and the health of their children during prenatal and postnatal periods, since a healthy mother brings forth a healthy baby.

All the health-care precautions should be strictly adhered to in order to reduce maternal and child mortality rate and ultimately intellectual disability. From the time of conception, a number of factors may influence health at various times. Some of these earliest influences are the following (Women's Bureau 2000:9):

Prenatal factors (affecting the developing foetus from the time of conception until birth), which include genetic conditions, infections in pregnancy, poor nutrition of the pregnant mother, certain medication taken during pregnancy, alcohol consumption, drug abuse or smoking while pregnant, exposure to radioactivity, the age of the mother (very young or over 40 years) as well as prematurity of the baby.

Perinatal factors (around the time of birth), which include problems such as a lack of oxygen to the baby during the birth process, birth injuries, rhesus incompatibility or haemorrhage.

Postnatal factors (after birth), which could include damage to the central nervous system as a result of infections, injury, poisoning, lack of oxygen or metabolic disturbances.

THE MOTHER'S ROLE DURING PREGNANCY

Since the child's brain development starts a few weeks after conception, the mother's role in enhancing the child's intelligence starts during pregnancy. This continues during the early years when the mind is most ready to learn new things, and then into later years. During pregnancy, the mother can enhance or impede the child's intelligence by following a good diet, including iron and iodine (Johnson 2014).

Good diet: What the mother eats during pregnancy determines to a large extent how the baby develops. It also affects the quality of life that the baby will live after birth. For adequate foetal brain development, pregnant women should feed on foods rich in DHA (docosahexaenoic acid) – the most plentiful fatty acid in the brain, which is essential for brain health. It can be found in omega-3 rich foods like fatty fish (sardine, mackerel and salmon) and is available in omega-3 capsules as supplements (Jamis 2008).

Benefits of iron and iodine: Iron and iodine can be found in sea foods such as shrimp, fish, shellfish and sea weed. Iron is required to carry oxygen to the foetus for brain development and body growth. Iron can be found in beef, chicken, beans and liver, among other foods. Baldestamon (2011) reported that deficiency in iodine and iron leads to intellectual disability and lower IQ. Bacon and eggs could also boost the intelligence of the unborn child and is significant for the baby's brain for memory and recall.

RISKY ASPECTS THAT AFFECT THE BRAIN ADVERSELY

After birth, breastfeeding is the best food for a baby (Herrnstein & Murray 1994:15). As the child moves beyond the breastfeeding stage, it is important to give her a well-balanced, healthy diet. In addition to breast milk, the child is required to get half of her daily calorie requirement from good fats, which include yoghurt, cheese and whole milk (Probit Study Group 2008:65). A child's brain development and intelligence is greatly impacted by their early experiences in life.

Hard drugs (such as marijuana, cocaine and heroin): The use of such drugs by pregnant women could lead to damage of the baby's brain and intellectual disability. For instance, cocaine-exposed children were found to exhibit deficits of intelligence (Cuzone, Yeh, Yanagawa, Obata & Yeh 2008:28). At age six, children exposed to hard drugs show deficits in academic skills including poor sustained attention, intellectual disability and less abstract thinking (Cuzon et al 2008:29).

Influential Elements on the Brain: Evidence shows that neglect during infancy and the early years detrimentally affects the brain's chemical make-up and how it is organised. For instance, NICHD (2003) revealed that children who received more sensitive and stimulating care in the first three years exhibit higher cognitive ability, letter-word identification, applied problem solving, language comprehension and short-term memory. Since intelligence determines success first in school endeavours and then in career later in life, it is imperative that in the early years, the mother, who is closer to the child than any other person, should care for and stimulate him or her in the following ways to enhance his or her intelligence (NICHD, 2003):

Breastfeeding: Many studies (Probit Study Group 2008; Angelsen et al 2001; Jacobson, Chioso & Jacobson 1999) report that prolonged and exclusive breastfeeding increases the child's IQ. Therefore, the mother should breastfeed the baby for as long as possible. The World Health Organization (2003) suggests babies should be breastfed for up to two years. DHA which is good

for optimum brain development passes through breast milk to the baby. While baby formulas are now fortified with these fats, there are still other substances in breast milk that help the baby's development, such as antibodies, anti-viruses, anti-allergies and enzymes (Angelsen, Jacobsen & Bakketeig 2001:183).

Good diet: When the baby finally stops breastfeeding, he should be fed with food rich in protein and omega-3, which are needed for brain development.

Love and affection: Children ought to be shown love and affection especially by touching them as often as possible. This makes a child feel secure and boosts emotional intelligence. If a child feels threatened, the Amygdala, a component of the brain, creates a reaction which turns off the thinking component of the brain (Findet 2011).

Mental work-out: Providing work-outs such as puzzles, word games and Sudoku keeps the brain active by increasing its ability to process information and consequently leading to higher IQ.

Physical activities: Sports and outdoor games increase the flow of blood to the brain by bringing oxygen, which could lead to sound thinking, enhanced concentration and brain power boosting.

RESEARCH METHODOLOGY

This qualitative study used focus-group discussions on intellectual disability. The discussions were recorded, transcribed and analysed and then themes were developed (Miles, Huberman & Saldaña 2014). Qualitative research has made a significant contribution to the scientific body of knowledge regarding intellectual disability. This is an indication that there is increasing input in terms of children with intellectual disability in aspects of qualitative research. The qualitative approach plays a valuable role in informing us about the experiences and lives of people who have intellectual disability. We need to develop methods to enable increased participation of people who have intellectual disability in some aspects of research. The participatory paradigm is more established in qualitative approaches as it lends itself to participation in generating research questions, developing interview questions, conducting interviews and even stages of the analysis. Purposive sampling was employed to select participants based on their understanding of the study at hand (Cresswell 2014). The participants were chosen from four Special schools. At least a combination total amount of six teachers, psychologists and health experts were purposively chosen from each special school. Essentially, the researcher made sure that the participants chosen are knowledgeable regarding the phenomena being examined, namely the mother's role in children with intellectual disability.

i) Participants

The participants were mothers of children with intellectual disability, involving four rural special schools. The focus groups included mothers whose children have intellectual disability. Thirty-six mothers were sent invitation letters about this specific research by their school principals. The mothers were invited to participate in the study and a consent form was issued to all the mothers who responded and came for the four focus-group interviews. The participants were purposefully selected to offer their diverse views on the children with intellectual disability (Beail & Williams 2014).

ii) Ethical Considerations

Ethical considerations were an important aspect in this study. The researcher had an ethical responsibility to firmly consider it imperative to establish a sense of trust with the participants (Lahman 2008). The researcher stated the aim and purpose of the study, the type of interview and other data collection processes with the participants. The participants were further informed about all the steps that were to be taken in this research. Permission to conduct the study was obtained from the appropriate authorities. The participants' rights to confidentiality, anonymity, privacy and to withdraw from the study at any time were made clear through the consent form (Doyle 2007).

A member check was done, whereby the researcher gave feedback to the participants before the findings were published (Doyle 2007). The researcher needed to verify credibility of the findings with the participants, that the information at hand is consistent with the participants' experiences. The participants were also pleased that the data that they provided would help to improve the quality of care for children with intellectual disability (Creswell 2014).

FINDINGS AND DISCUSSIONS

Five major themes were identified, namely, perceptions about intellectual; description and causes of intellectual disability; managing of a child with intellectual disability; support from the family and the community; and spiritual principles in dealing with intellectual disability. The findings and discussion will be discussed now.

i) Perception about Intellectual Disability

Intellectual disability is the result of interactions between biological and environmental factors including the physical, economic, and social barriers imposed on an individual by society. Limited attention has been given to the situation of individuals with intellectual disabilities, who remain seriously neglected. Given the lack of resources available to address mental disorders, it is essential to examine the role of socioeconomic and socio-cultural factors in the lives of these individuals. The participants believed that intellectual disability was a challenge that was related to lack of sufficient stimulation by the parents.

“His mental ability is very little. He can possibly be okay with training” (Participant 17).

“His brain growth is slow and lazy. His brain may have had a better development if his mother had stimulated him to speak from the time he was a little boy” (Participant 09)

“She has late brain development. Perhaps she did not get enough stimulation” (Participant 12).

The teachers blamed the parents and held them responsible for the child's intellectual disability. The view that parents were not giving adequate support in the development of the child, they went to the extent of attributing the problem to bad character in the parents. They believed that the child's inability to do well at school was a bad trait inherited from parents rather than a skill deficit because of intellectual disability.

ii) *Description and Causes of Intellectual Disability*

Medical causes like poor pregnancy care, medical prescription treatment, infection and difficulties during delivery were recognised as likely sources of intellectual disability (Christensen, Baker & Blacher 2013). Participants expressed the view that numerous medications during pregnancy could have had an effect on the child. The participants stated psychological matters like persecution of the mother and strain encountered by the mother during pregnancy as contributing factors.

The mothers further reported that people in their community believed that witchcraft caused intellectual disability and therefore were not able to help the families with the intellectually disabled children (Ali, Hassiotis, Strydom & King 2012). The participants mostly stressed that emotional trauma encountered by mothers during pregnancy had a significant role as the source of the condition.

The participants strongly believed that the mother's risky mental health was a certain reason for intellectual disability. Absence of family support, shock experienced during the course of pregnancy and deprived adequate health care for the mother were deemed as harmful factors for intellectual disability. Others indicated that scarce medical monitoring at the time of delivery may cause intellectual disability. Some participants attributed the intellectual disability to not eating healthy food during the pre-birth period.

"At the time of my pregnancy I was in excellent physical shape and ate sufficiently and healthy. However, the clinic staff caused the disability" (Participant 15)

"Eating healthy food will prevent problems like brain underdevelopment" (Participant 18)

"Incorrect techniques and tools of giving birth when this is done at home are likely to cause brain damage" (Participant 13)

"Unsatisfactory care for the child may cause poor performance at school" (Participant 18)

"A husband who drinks too much alcohol may be the source of complications for the poor child with intellectual disability" (Participant 17)

"Women experience dreadful emotional tension during pregnancy" (Participant 07)

"The mother may have been downhearted and not had eaten sufficiently due to the torment from her husband" (Participant 21)

"When I was expecting my child, I watched as my neighbour was brutally beaten by thugs. I was shocked and traumatised. This may have caused what is happening now to my child" (Participant 02)

The participants further indicated that medical treatment can be able to bring about recovery, while others believed that the child would be completely fine as they grow up. The participants stated that they believed that with appropriate stimulation, a child with intellectual disability would be normal again (Elford, Beail & Clark 2010).

"It is possible for the child with intellectual disability to be normal, once appropriate training is afforded" (Participant 23)

"I have hoped that one day he will be fine as he grows up" (Participant 16).

"He will be all right if he eats nutritious food" (Participant 13).

"It is possible for the child to be better if he is given enough undivided care as well as devotion and showed compassion" (Participant 19).

iii) Knowledge of Managing a Child with Intellectual Disability

The mothers commented that the families in the community were not willing to seek help or advice. They specified that the greatest challenge in care-giving for children with intellectual disability was behaviour management. They believed that behaviour management skills were difficult to implement consistently due to a lot of intrusion of unqualified people in the community (Hatton, Emerson, Graham, Blacher & Llewellyn 2010).

“It will be so fulfilling if we are provided with helpful information on how to properly care for this child” (Participant 06)

“I am eager to get professional assistance and to see in what way other parents handle this kind of a child” (Participant 24)

“Even well-learned and informed parents do not seek support because they are afraid and somewhat ashamed that their child’s condition will be known by other people” (Participant 31)

The participants from a lower socio-economic background believed that the child with intellectual disability was an unnecessary load and wished that the child would die rather than live. They did not have the resources to care for the child and were not willing to consider treatment options unless the child would become completely normal. This highlights the fact that people with limited resources were not motivated to accept treatments wherein the cost of the ultimate outcome or benefits was exceeded by the process of managing the disability. The mothers from low-income background indicated that they do not get enough support to care for children with intellectual disability (Brown, Schalock & Brown 2009) and this created major stress and economic problems that placed the family in a very awkward position.

“There is no benefit in spending money on a disabled child. He will never be okay” (Participant 12)

“The future is bleak and gloomy for this child because if I try to have another child, she may also have this disability” (Participant 27)

“Let this child die because he is a financial load” (Participant 16)

“All that he does all day is eat, drink and watch television. He is not interested in attending school” (Participant 7).

“There is no hope; a person needs to allow the child to die instead of having deceitful expectations” (Participant 23).

iv) Support from the Family and the Community

In certain instances, the community have not been sympathetic towards the family of a child with intellectual or any other disability. People avoided such people or families.

“As mothers we are forced to take on the full accountability of caring for the child with a disability. Fathers do not care about what is happening. All that these men do is shift the blame to us and say that it is me who caused the child’s disability” (Participant 05)

“It is difficult to look after a child with intellectual disability because other family members expect only me to take care of all the child’s needs” (Participant 16)

“Other people in the family do not have an idea what the needs of this child really are” (Participant 07)

The participants also argued that the complexities of the family dynamics rendered the mothers helpless in managing the child with intellectual disability (Hassall & Rose 2005). They asserted that mother of a child with intellectual disability was regularly depressed, overwhelmed with guilt and were overwhelmed with more adverse emotions. The child's over reliance on the mother was also critical. Apprehensions and worries were highlighted over the future care of the child (Blacher & Bake, 2007).

"Fathers are indifferent" (Participant 13)

"The community laughs and gossips when they see me with my child" (Participant 17)

"They say that we have a child with a disability because my husband and I have sinned against God" (Participant 01).

"We cannot take him out to town, restaurants or the park because people look at the child strangely and unusually" (Participant 17)

"I feel so bad when people comment about my child's looks when we are in public places" (Participant 18)

"At the moment, I am overwhelmed. For life is full of difficulties or problems every single day" (Participant 13)

v) ***Spiritual Principles in Dealing with Intellectual Disability***

Spirituality was acknowledged as an influential individual, domestic and social means of coping (Carter 2013). The participants felt that religion helped them to overcome their unfortunate situations. They acknowledged the help offered by the church or the clerics (Townley, Kloos, Green & Franco 2011). The participants were of the view that faith in God would help the families with a disabled child to cope as well as see improvements in the child. The mothers asserted that faith helped them to cope. They turned to their respective subjective devotions as a basis of comfort and hope (Scior, Potts & Furnham 2013).

"God will give me knowledge and strength on how to raise this child" (Participant 15)

"She should go to a pastor and ask him to pray and possibly the child will finally be healed" (Participant 24)

"Initially I had faith in God but now I have lots of doubts. Why is this happening to me even when I pray" (Participant 18)

"Faith in God cannot cure everything. A person has to take initiative and be resourceful" (Participant 30)

CONCLUSION

In the light of this study, it can be concluded that mothers of children with intellectual disabilities are at danger of suffering from social disruption and deprivation as well as emotional anguish leading up to severe depression. Mothers as the only participants in this study limit the findings, but hinted into first-hand experiences related to care-giving and children with intellectual disability. There is definitely a need to understand intellectual disability from the maternal perspective.

Although qualitative research regarding children with intellectual disability is on the rise within noticeable journals, this area of research still inhabits a peripheral place in comparison

with other research studies. More research is required which investigates how children with intellectual disability cope with their disability, recognising that this is a potential stumbling block to their involvement in research studies. Participatory as well as emancipatory research is therefore suggested with children who have intellectual disabilities (Benton & Johnson 2014). This means that children with intellectual disabilities need to be more involved in the academic discussions and the research process itself. The challenge here is how the researchers are going to ensure that children with intellectual disability are actively involved in all phases of the research process. This dilemma remains to be seen.

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ABOUT THE AUTHOR

LLOYD DN TLALE

Department of Psychology of Education College of Education,
University of South Africa.

tlaleldn@unisa.ac.za