

Experiences and needs of mothers of babies diagnosed with Hypoxic Ischaemic Encephalopathy due to birth asphyxia

By Mandy Naidoo

Student Number: 16375106



Research assignment presented in partial fulfilment of the requirements for
the degree of Master of Rehabilitation Studies
in the Faculty of Medicine and Health Sciences at Stellenbosch University

Supervisor: Ms Martha Geiger
Co-supervisor: Dr Surona Visagie

March 2016

Declaration

I, the undersigned, hereby declare that the work contained in this assignment is my original work and that I have not previously submitted it, in its entirety or in part, at any university for a degree.

Signature: Date:

Abstract

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Background: Observations during physiotherapy treatment of babies with Hypoxic Ischaemic Encephalopathy (HIE) due to birth asphyxia suggested that the mothers of these babies lacked emotional and psychological support. The focus of the health-care team is on managing the medical and physical manifestations of the baby's condition, and it appears as if the mother's needs are neglected.

Aim: to describe mothers' experiences and needs after diagnosis of HIE due to asphyxia at birth, in order to contribute to recommendations for the provision of support for these and other mothers in the future

Objectives: to explore the experiences, emotional responses and needs of participants after the diagnosis of HIE; to describe participants' perceptions of the type of support they needed at birth and after the diagnosis of HIE and to describe participants' perceptions of which sources and forms of support were available to them at birth and in the following months.

Method: A qualitative, exploratory study design was implemented. Semi-structured interviews were conducted with four participants; recorded data was transcribed, checked and verified by means of follow-up telephone calls to all participants and thematic content analysis was applied to identify themes.

Results: The findings indicated a need for emotional support, for information sharing and for improved communication between the health-care team and the mothers; as well as the importance of family and other support structures for these mothers.

Conclusion: The findings could assist individual health care professionals to be aware of mothers' needs and provide some of the required information and question opportunity during consultations. Furthermore, the findings could assist health-care teams in the neonatal units of hospitals to establish a support structure for mothers whose babies are diagnosed with HIE.

Introduction

In the South-African health-care context, we are often faced with shortages of personnel, large patient numbers and limited resources. As health professionals, we therefore tend to focus on the treatment of impairment and the management of the clinical manifestations of disease, and might neglect the surrounding environmental and personal issues that affect and/or are affected by the disease or condition. In my experience as a physiotherapist offering therapeutic management for babies with Hypoxic Ischemic Encephalopathy (HIE), I noted that the needs of the *mothers* in these situations are often neglected; an omission that was confirmed by the challenges in finding published evidence. Therefore, the aim of my study was to focus on the needs of the mothers of babies diagnosed with HIE caused by birth asphyxia and the support needed following diagnosis; in order to assist these and other mothers with support in the future.

Literature review

Birth asphyxia and Hypoxic Ischaemic Encephalopathy

Asphyxia at birth, or peripartum hypoxia, remains a common health issue both in local and international contexts. According to Itoo, Al-Hawsawi & Khan (2003), asphyxia usually refers to an insult or injury accompanied by decreased oxygen delivery to the foetal or neonatal brain. Birth asphyxia is the cause of 23% of all neonatal deaths worldwide (Zanelli, Stanley & Kaufman, 2012). The most frequent causes of birth asphyxia include prolonged labour, breech delivery in full-term infants, placental abruption, maternal sedation in premature infants, and unattended precipitate deliveries in immature infants (O'Brien, Usher & Maughan, 1966). According to Lawn, Shibuya and Stein (2005), most children who survive birth asphyxia present with problems such as cerebral palsy, intellectual disabilities, and/or other disabilities. More specifically, severe asphyxia has been linked to

cerebral palsy, intellectual disabilities, and epilepsy, while mild to moderate asphyxia has been associated with cognitive and behavioural alterations, such as hyperactivity, attention deficits, autism, schizophrenia and development of diverse psychiatric disorders in adulthood (Morales, Bustamante, Espina-Marchant, Neira-Pena, Gutiérrez-Hernandez, Allende-Castro & Rojas-Mancilla, 2011).

Hypoxia-ischemia in the perinatal period is one of the most frequent causes of cerebral palsy and associated disabilities in children (Fatemi, Wilson & Johnston, 2009). The most common form of hypoxic injury is intrauterine asphyxia, caused by circulatory problems, including clotting of placental arteries, placental abruption, or inflammatory processes. According to Fatemi et al. (2009), if an episode of hypoxic-ischemia is severe enough to damage the brain, within 12 to 36 hours it leads to a neonatal encephalopathy. This is known as Hypoxic Ischemic Encephalopathy (HIE), and is also called perinatal cerebral hypoxia-ischemia. Neonatal encephalopathy or HIE is a clinical syndrome of “disturbed neurological function in the earliest days of life in the term infant, manifested by difficulty with initiating and maintaining respiration, depression of tone and reflexes, subnormal level of consciousness, and often seizures” (Wachtel & Hendricks-Munoz, 2011; p.132). During the perinatal period, hypoxemia and/or ischemia occur because of asphyxia, impairment in the exchange of respiratory gases (Wachtel & Hendricks-Munoz, 2011). HIE is a key cause of permanent damage to central nervous system cells, which may result in neonatal death or manifest as cerebral palsy, intellectual deficiency and epilepsy (Ito, Al-Hawsawi & Khan, 2003; Vannucci & Perlman, 1997). This clinical syndrome also causes a depressed level of consciousness that could last from seven to 14 days, and some infants may require vigorous resuscitation to survive. According to Zanelli, Stanley & Kaufman (2012), HIE is characterised by clinical and laboratory evidence of acute or subacute brain injury due to asphyxia, and once HIE is suspected, neuroimaging techniques are performed to aid diagnosis. Otherwise, parents, doctors and caretakers take notice of visible signs, such as impaired motor

function, delayed developmental milestones, and delayed growth over time, as closely observed clinically. According to Lai & Yang (2011), perinatal hypoxic-ischemic encephalopathy occurs in one to three per 1000 live full-term births globally. Of the affected new-born babies, 15-20% will die in the postnatal period, and an additional 25% will develop severe and permanent neuropsychological sequelae, including mental retardation, visual motor or visual perceptible dysfunction, increased hyperactivity, cerebral palsy, and epilepsy (Vannucci & Perlman, 1997). Most deaths occur in the first week of life due to multiple organ failure or redirection of care, while some infants with severe neurological disabilities die in their infancy from aspiration pneumonia or systemic infections (Zanelli, Stanley & Kaufman 2012). Both clinical and experimental observations demonstrate that HIE is not a single “event” but is rather an evolving process (Fatemi et al. 2009).

Sarnat & Sarnat (1976) already described three clinical levels of severity; that is mild, moderate and severe encephalopathy, which may be helpful in determining the prognosis and could be indicative of the level of impairment or disability that the child might experience. The presence of seizures occurring within the first hours, predicts a poor outcome of HIE, and a statement of the level of severity can be provided once cognitive development can be accurately assessed. According to Zanelli, Stanley & Kaufman (2012), the incidence of long-term complications depends on the severity of the HIE. As many as 80% of infants who survive severe HIE develop serious complications, 10-20% develop moderately serious disabilities, while 10% are healthy. Among the infants who survive moderately severe HIE, 30-50% may have serious long-term complications, while 10-20% may have minor neurological morbidities (Zanelli, Stanley & Kaufman 2012). Even in the absence of obvious neurological deficits in the neonatal period, long-term functional impairments and resulting disabilities may be present. The outcomes of HIE are devastating and permanent, making it a major burden for the patient and the family (Lai & Yang 2011).

Dealing with disability diagnosis

Disability diagnosis has a considerable emotional and psychological impact on parents. For most parents, the birth of their child is a joyous time (Barnett, Clements, Kaplan-Estrin & Fialka 2003; Sengane 2013). As parents make preparations for the birth of their child, they may wonder not only about the gender of their child, their child's eye colour, or appearance, but they may hold expectations for who this child will become in the future (Orme 2005). During pregnancy, parents do not only expect a baby, but they also build up expectations of their child's future and their role as parents (Schuengel, Rentinck, Stolk, Voorman, Loots, Ketelaar, Gorter & Becher 2009). When a child is born with no complications or disabilities, this process seems to evolve naturally; but when there are prenatal or perinatal complications, or postnatal discoveries of developmental disabilities, the idealized picture of having a "normal" child is shattered (Orme, 2005). From the moment they first worry that something might be less than perfect with their child, they must manage new and often overwhelming emotions (Bingham, Correa & Huber 2012; Schuengel et al. 2009).

For most parents, the diagnosis of their child's disability is an initiation into a previously unknown world (Bingham, Correa & Huber 2012). According to Russell (2003), following the diagnosis of a child's disability, parents have to develop new expectations concerning their child, their role as a parent and the support services that are designed to meet their needs; and research shows that these needs frequently remain unmet. For parents of a child with a chronic medical condition, perhaps one of the most trying experiences is receiving their child's diagnosis, and the realization that their child might always be different from other children (Sheeran, Marvin & Pianta 1997; Schuengel et al. 2009). In addition to the typical stressors associated with having a new baby, these parents have to cope with many uncertainties about their child's health and prognosis, frequent medical

appointments and procedures, and the additional workload of caring for a child with special needs (Barnett et al. 2003). In the beginning, parents may face obstacles because they cannot easily access accurate information from professionals assisting with the diagnosis (Abery 2006). Professionals, therefore, need to understand these early experiences so that they can support parents as they learn to cope (Bingham, Correa & Huber 2012). This support should include empathy, listening, information sharing, and helping (Chokwe & Wright 2013).

The longer parents must wait for answers from professionals about what to expect related to the disability, the more stress they are likely to experience (Most, Fidler, Laforce-Booth & Kelly 2006). Oliver (1996) found that medical professionals treat the symptoms of disability rather than the needs, concerns and problems of the disabled child and the parents. According to Case (2000) parents often experience powerlessness in a professionally-controlled setting and this feeling is intensified if birth events do not meet their expectations and if medical concerns are not revealed. During the period immediately following disability diagnosis, parents experience a sense of meaninglessness and powerlessness owing to the loss of the future they anticipated for this child and themselves and their inability to envision what to do about creating a new future (Seligman & Darling 1997). Green (2002) states that raising a child with a disability is a profoundly transformative experience and that the child's diagnosis represents a unique form of interpersonal loss in which the object of the loss is still a commanding presence in the parents' lives. For parents, having a disabled child may increase stress; take a toll on mental and physical health; make it difficult to find appropriate and affordable child care; and affect decisions about work, education/training and having additional children. It may also trigger guilt, blame or reduced self-esteem (Reichman, Corman & Noonan 2008). Emotionally, many will need support to adjust to their new-found situation and the continued care of their child, and intellectually they need to learn and understand a new body of knowledge relating to their child's diagnosis and the systems designed

to support them (Russell 2003). Russell (2003) further states that parents can experience stress arising from their child's needs, their own practical and emotional needs and negative reactions to their child by others.

The official diagnosis of a disability in a child marks the occurrence of a family crisis and affects the family on many levels, as evidence over time has indicated (Fortier & Wanlass 1984; Watermeyer & McKenzie 2014). On a practical level, the family may need to provide immediate care for the disabled child, arrange transportation to treatment, alter previous systems of scheduling time and meet new financial needs (Fortier & Wanlass 1984). On the affective level, the family members, and mothers in particular, begin working through feelings of grief, anger, guilt, helplessness and isolation (Watermeyer & McKenzie 2014). On a physical or sensory level, somatic symptoms may arise as a result of the stress of the crisis experience. On an interpersonal level, the family may have to deal with labelling and stereotyping, a sense of isolation from others, handling 'helplessness' and advice from friends, and providing support for other family members. On a cognitive level, the family is called upon to assimilate technical information about the disability and to deal with the impact of the diagnosis on established values and expectations (Fortier & Wanlass 1984).

Parents of children with disabilities may experience a grief cycle that is similar to that at the time of the death of a loved one (Turnbull & Turnbull 2001). While this grief process includes similar stages of shock, denial, guilt, anger, shame and depression, it is important to note that the sequence of these processes may not be linear in nature or complete within each stage (Turnbull & Turnbull, 2001). These differences are due to individual and family members' coping mechanisms, cultural differences, the time of diagnosis, and the manner in which they were informed by professionals about their child's disability (Turnbull & Turnbull, 2001). Levine (2007) found that families with children with disabilities may experience unresolved grief,

caregiver burden, chronic sorrow and general family dysfunction. A number of people working with families in the period following diagnosis advocate counselling for some parents following their child's diagnosis as it can provide opportunities to support parents to reflect on and develop the expectations they have for their child and themselves as new information is gathered (Russell, 2003).

According to Reichman et al (2008) living with a disabled child can have profound effects on the entire family – parents, siblings, and extended family members. It is a unique shared experience for families and can affect all aspects of family functioning. On the positive side, it can broaden horizons, increase family members' awareness of their inner strength, enhance family cohesion, and encourage connections to community groups or religious institutions. On the negative side, the time and financial costs, physical and emotional demands, and logistical complexities associated with raising a disabled child can have far-reaching effects as described earlier. The impacts will depend on the type of condition and severity, as well as the physical, emotional, and financial means of the family and the resources that are available (Reichman et al, 2008).

Past research evidence as well as clinical observations in the study setting gave rise to the research question: *What are the experiences, emotional responses and needs of mothers after diagnosis of HIE due to asphyxia at birth?*

Methodology

Aims and objectives

In order to answer the research question, *the main aim* of the study was to describe mothers' experiences and needs after diagnosis of HIE due to asphyxia at birth, in order to contribute to recommendations for the provision of support for these and other mothers in the future.

The *objectives*, or steps to achieve the aim, were:

- to explore the experiences, emotional responses and needs of participants after the diagnosis of HIE
- to describe participants' perceptions of the type of support they needed at birth and after the diagnosis of HIE
- to describe participants' perceptions of which sources and forms of support were available to them at birth and in the following months.

The aspired *outcomes* of the study include the contribution of recommendations for the provision of support for these and other mothers of babies with HIE in the future.

Study design

This study was positioned within the interpretive paradigm, which focuses upon "the *whats* and the *hows* of social reality" (Gubrium & Holstein 2003: 215). A qualitative design was applied to explore the experiences, emotional responses and needs of mothers six to eight months after giving birth to babies with complications due to asphyxia, at a state hospital in the Western Cape.

Qualitative designs, focusing upon participants' views and experiences, are of growing importance in the rehabilitation literature (Carter, Lubinsky & Domholdt 2011; De Vos 2011). Moreover, a phenomenological approach was applied, which according to Carter, Lubinsky & Domholdt (2011; 161) "gives voice to the person being studied and requires that the researcher present the participant's view of his or her world".

Study setting

The study took place in the Western Cape Metropolitan area, in a government-funded district hospital, which provides a service to patients who live in the sub-districts of Bellville, Parow, Goodwood, Bothasig, Durbanville, Platteklouf, Kraaifontein and Kuils River. This site was chosen as the study setting, as I, the researcher, was employed at the facility during the time of the research, and had first-hand experience with the babies and their mothers. Part of the original motivation for the study was the personal interactions with mothers, and hearing about their emotions, experiences and needs while providing a physiotherapy service to their babies.

Study population, sampling and participants

The study population from which participants were recruited, comprised all mothers who gave birth at the hospital from 1 January 2014 to 31 March 2014 and whose babies presented with hypoxic ischaemic encephalopathy (HIE) due to birth asphyxia, as recorded in birth history notes in the hospital file. The total study population was seven (N = 7).

Inclusion criteria

- Mothers over the age of 18 (and therefore legally able to grant informed consent)
- Mothers who were physically, mentally and emotionally competent according to informal observation to give informed consent to participate in the study
- Mothers who gave birth at the hospital between 1 January and 31 March 2014 (i.e.: whose babies were 6-8 months old at the time of data collection).
- Mothers who were willing and able to be interviewed in English, Afrikaans or Xhosa.

(Arrangements were in place and an interpreter would have been used for interviewing Xhosa-speaking participants, as the researcher was only able to

communicate proficiently in English and Afrikaans. However, all the participants felt comfortable being interviewed in English, so there was no need for the interpreter.)

Exclusion criteria:

- Mothers who could not give informed consent
- Mothers whose babies died by the time of data collection

Qualitative researchers purposely select individuals who they believe will be able to lend insight to the research problem (Carter, Lubinsky & Domholdt, 2011). Purposive sampling was planned, but of the seven mothers identified three had to be excluded from the study; two of the mothers could not be reached, due to the unavailability of telephone numbers and one of the mothers was under the age of 18 years. The four remaining mothers were therefore invited to participate in the study telephonically (contact information was retrieved from patient folders). All four mothers agreed to participate, and were included in the study.

Description of participants

An overview of the demographic and other descriptions of the four women, who participated in this study, is summarised in Table 1.

Table 1: Demographic profile of participants:

	Race				Age category			Nationality		Birth no.		Baby's gender		Level of impairment			Birth type	
	W	B	C	I	18 - 24	25 - 34	35 +	South-African	Foreign	1	2	M	F	Mild	Moderate	Severe	Normal	Caesarean
P 1			√			√		√		√			√					√
P 2		√				√		√			√	√			√		√	
P 3		√			√			√		√		√			√		√	
P 4		√				√			√	√			√	√			√	

Pilot study

The value of a pilot study *in qualitative research* is increasingly supported (Kim, 2010). A pilot study was implemented before data collection started, and the purpose was to check the clarity and understanding of the proposed interview questions, and the logistical details of the interview set up and timing. The semi-structured interview was implemented with one mother, who met all the selection criteria. The proposed interview questions were found to be clear and easily understood by the participant. Logistics such as audio-recording, timing and the setting were evaluated and were found appropriate in order to proceed with the study interviews, without any changes needing to be made. As no changes were indicated after the pilot study, and as valuable information was gathered during the pilot, the data from this interview and follow up phone call was included in the study, as proposed in Visagie's study (2015:101).

Data collection

Data was collected through semi-structured interviews by the researcher in English. The interviews were carried out in a therapy room, with comfortable seating and privacy, at the physiotherapy department of the study hospital. Semi-structured interviews allowed the participants to speak freely about their experiences and emotions. Interviews were between 30-40 minutes long. The data collection tool was an interview guide consisting of 10 open-ended, as well as some closed-ended questions, namely;

1. How did you feel on the day that your baby was diagnosed with HIE?
2. What were the thoughts going through your head?
3. Did you experience any physical symptoms?
4. How were your daily activities at home and work affected?
5. Who supported you the most during this past six to eight months?
6. What type of support did they offer?
7. If you could choose, what type of support would you have liked to receive during this past six to eight months?
8. How do you feel now, compared to six months ago, and what has changed since the initial time of diagnosis?
9. If I can offer you any support right now, what do you think you need?
10. What advice would you give to mothers who go through the same situation in the future?

These questions were selected and adapted from three sources; the Emotional state questionnaire (EST-Q) (Aluoja, Shlik, Vasar, Luuk & Leinsalu 1999), the Hamilton Anxiety Rating Scale (HAM-A) (Hamilton 1959) and the Hamilton Depression Rating Scale (Hamilton, 1959). The interviews were audio-recorded, with the participants' consent.

Data analysis

Qualitative researchers, who apply an interpretive approach, describe their conclusions in narratives that provide a “thick description” of the phenomenon being studied (Carter, Lubinsky & Domholdt, 2011: 169). Three stages of qualitative data analysis, that is, data management, generating meaning and verification were followed (Carter, Lubinsky & Domholdt, 2011).

In terms of *data management*, I transcribed the recorded interviews verbatim and checked and coded them. The codes P1, P2, P3 and P4 were used to separate the data according to the source, yet keep the participants anonymous.

In terms of *generating meaning*, I immersed myself in the data, began the process of identifying themes and then, identified relationships between themes in line with thematic analysis which has been described as “a method for identifying, analysing and reporting patterns (themes) within data” (Braun & Clarke, 2006:79).

Verification was implemented by consulting a second researcher to audit the data analysis and to assist with the drawing of conclusions to determine whether findings from different sources were pointing in the same direction (Carter, Lubinsky & Domholdt, 2011). Member checking was done by means of a follow-up telephone call to all four participants to ensure that the data was interpreted as closely as possible to the participants’ meanings, and to ascertain whether they wanted to add or omit any information (Braun & Clarke, 2006).

Ethical considerations

Following approval from the Stellenbosch University Health Research Ethics Committee (Reference number: #S12/11/308), permission to proceed with the study was obtained from the Western Cape Provincial Health Research Committee,

followed by permission from the management of the hospital, where the study was done.

In terms of the ethics principles outlined by Carter, Lubinsky & Domholdt (2011:44), we ought to act in ways that do not cause harm or injury to others (non-maleficence) and which promote the welfare of other people (beneficence); moreover, we should act in such a way as to bring about the greatest benefit and the least harm (utility). Immediate beneficence to participants included having their fears and emotional stresses acknowledged through the explanation of the need for the study. I, as the researcher and interviewer, was aware throughout the study that I was investigating a sensitive topic, and that different emotional reactions could surface from different participants, which I needed to manage with care and respect and allowed participants time to express and deal with their emotions, as they arose. I provided immediate space and support in the instances where participants became emotional. Arrangements were in place for me to refer and escort participants to a social worker in the hospital who was on stand-by, if more professional counselling had been needed.

In terms of autonomy and self-determination, participants were contacted telephonically to inform them about and then invite them to participate in the study (Carter, Lubinsky and Domholdt, 2011). Strategies to ensure that consent to participate was well-informed, included an information sheet in the participant's language of choice (Appendix A); the opportunity to ask further questions before, during and after the interview and the completion of a consent form (Appendix B). Participants were also assured that they could choose to withdraw from the study at any time, even if they at first agreed to participate and that their further treatment at the hospital would not be affected in any way.

Participant confidentiality and privacy were ensured by assigning participant numbers (1-4) and only I had access to participants' personal details.

Trustworthiness

Lincoln and Guba's seminal trustworthiness criteria (1985, cited by Schwandt, 2001: 258) were applied as precautions to ensure the quality or soundness of the study.

Credibility refers to the fit between the respondents' views of the issues at hand and the researcher's reconstruction of these (Schwandt, 2001:258). With this in mind, member checking by follow up phone calls to the participants and peer debriefing by focused discussions with a clinical colleague and my research supervisor, were implemented.

Transferability was aspired by detailed descriptions of the cases in hand in order to enable others to establish the similarities between the cases studied and other cases to which the findings may be applied (Schwandt, 2001:258).

Dependability refers to the logic and traceability of the actual research processes (Schwandt, 2001:258). The interview guide, based on evidence based instruments and piloted before the main study, and the carefully planned and documented data collection and data analysis strategies contributed to dependability.

Confirmability (Schwandt, 2001:258) was ensured by an audit trail, to make sure that the participants' responses, the themes and the conclusions were linked in readily discernible ways.

Findings

The aim of the study was to describe mothers' experiences and needs after diagnosis of HIE due to asphyxia at birth, in order to contribute to recommendations for the provision of support for these and other mothers in the future. The findings indicated that there are common themes and similarities experienced by these mothers. A data-driven, inductive thematic content analysis led to the identification

of nine themes. These themes are presented here, supported by direct quotes from participants.

Theme 1: 'I was scared' - Fear

All the participants reported a sense of fear after the birth; fear of the unknown, fear of death and a fear of what the future would be for their child. They expressed their fear as follows:

I was scared that my baby's brain would be damaged permanently and that my baby would be disabled. P2

I was very scared. I was afraid that he was going to die right there. The doctors looked very concerned and I thought there is something they are not telling me. P3

I was scared that I would wake up and find my baby dead. P1

I was scared. P4

Theme 2: 'I didn't know what was happening' - Uncertainty and Isolation

The participants all experienced a sense of uncertainty and isolation at times during their hospital stays, and expressed it as follows:

They didn't tell me anything. Everybody carried on as if I wasn't there. P3

No-one spoke to me. I felt left out. P1

I didn't know what was happening. P4

I didn't know what was happening. I felt like they were hiding something from me. P2

Theme 3: 'I needed someone...' – The need for emotional support

Participants felt that they needed some form of emotional support during this difficult time. They shared their experiences by the following statements:

It was so tiring; I was physically and emotionally drained. I just needed someone to talk to during that difficult time. P2

I felt helpless. It was very difficult for me. If there was someone, like maybe a social worker. Just someone that I could talk to. It was tough. There was no time for me to show how I was feeling. P1

I needed someone to comfort me and tell me that everything will be okay and to explain to me the whole process of what happened. P4

I felt very sad. P3

Theme 4: 'I wanted to know what was wrong' - The need for information

All the participants spoke about the need to know what was happening to their babies during and immediately after the birth – they felt that all the medical professionals attended to the sick babies, and they, the mothers were ignored. They reported the following:

I wanted to know what was wrong. It seemed as if everyone was ignoring me ... No-one cared to tell me anything. P1

I didn't know that the baby had fits before that day, because no-one told me. I was hoping that someone would just sit me down and tell me exactly what was going on and what was really wrong with my child. I still don't know up until today whether this thing is permanent or if it will go away some time. P2

The doctors were speaking in language that I didn't understand. No-one cared to explain to me in simple language what they were talking about. P3

I needed someone to [...] and explain to me the whole process of what happened. P4

Theme 5: 'My ... was there' - Family support

The support of family members – from a mother, a grandmother, a sister or a husband respectively - was highly appreciated and kept all four of these women going during their difficult time. The participants shared the following:

My mother was always there to take care of my baby. When I was feeling down, she was there to pick me up again. She taught me to be strong and to care for my baby the best way I can. P1

My grandmother helped me to look after the baby. She was always there when I needed to talk (or cry). P2

My sister always popped in and helped where she can. P3

I felt comfort in the fact that my husband was also there to support me and the baby.

He was really there for me and the baby. P4

Theme 6: 'What did I do wrong?' - Self-blame

Two of the participants revealed a sense of self-blame for their child's condition. They felt that they did something wrong during the pregnancy to cause this condition. They stated the following:

What did I do wrong? P1

I don't know whether I was the problem or why it happened. P2

Theme 7: 'I did not leave him alone at any time' - Practical implications

Practical implications that came with the diagnosis, including the following:

I had to stay at the hospital for weeks. I had to feed my baby through a tube. I had to take care of my baby all the time. I didn't go out. I even forgot to eat sometimes. I was so scared that my baby would fit again. I was watching her all day long. In the night I hardly slept. P1

I did not want to leave my baby alone for one second. P2.

When I went to the bathroom, I took him with me. When I was in the kitchen, he was in the kitchen. I did not leave him alone at any time. P3.

My daily activities were not really affected so much. I was not working, so I could take care of the baby myself. P4.

Theme 8: 'all I wanted was for her to cry' - Expectations not met

One participant reported a feeling of her expectations that were not met. She expressed it as follows:

I expected my baby to be kicking and screaming, but all I found was a lifeless baby. While all the babies were crying, I never heard a sound. I so much wanted my baby to cry. The other mothers in the ward were getting irritated because their babies cried so much...and all I wanted was for her to cry. P1

Theme 9: 'It was God who got me through this thing' – Religion and faith

One participant felt strongly that it was her religion that helped her through this difficult time. She shared her experience as follows:

I was just praying that this baby would survive. I believed that God will make my baby healthy again. I was happy that God answered my prayers. It was God who got me through this thing. P4

In summary, the nine themes that emerged from the participants' responses were;

- Fear
- Uncertainty and isolation
- A need for emotional support
- A need for information
- Family support
- Self-blame
- Practical implications
- Expectations not met
- Religion and faith

Discussion

While most of the findings above, presented in the participants' own words, speak for themselves (Lipenga, 2014), some of the participant mothers' experiences and needs are here contextualised with existing evidence. An overview of how the nine themes related back to the data collection questions, the objectives and the overall study aim, is presented in Table 2 below.

Table 2: Overview of aim, objectives, data collection questions and themes

Aim	Objectives	Data collection questions	Themes
To describe mothers' experiences and needs after diagnosis of HIE due to asphyxia at birth, in order to contribute to recommendations for the provision of support for these and other mothers in the future.	1 - to explore the experiences, emotional responses and needs of participants after the diagnosis of HIE	<p>Q1 -How did you feel on the day that your baby was diagnosed with HIE?</p> <p>Q2 -What were the thoughts going through your mind?</p> <p>Q4 -How were your daily activities at home and work affected?</p> <p>Q8 -How do you feel now, compared to six months ago, and what has changed since the initial time of diagnosis?</p>	<p>Fear</p> <p>Uncertainty and isolation</p> <p>Self-blame</p> <p>Expectations not met</p> <p>Practical implications</p>
	2 - to describe participants' perceptions of the type of support they needed at birth and after the diagnosis of HIE	<p>Q7 -If you could choose, what type of support would you have liked to receive during the past six to eight months?</p> <p>Q9 -If I can offer you any support right now, what do you think you need?</p>	<p>A need for emotional support</p> <p>A need for information</p>
	3 - to describe participants' perceptions of which sources and forms of support were available to them at birth and in the following months.	<p>Q5 -Who supported you most during the past six to eight months and what type of support did they offer?</p> <p>Q6 -What type of support did they offer?</p>	<p>Family support</p> <p>Religion and faith</p>

According to Sheeran, Marvin and Pianta (1997) one of the most trying experiences for parents of a child with a chronic medical condition, is receiving the diagnosis, and the realization that their child might be different from other children. All four of the participants in the current study expressed their sense of fear – fear of the unknown, fear of death and fear of what the future might hold for their child. In addition to the normal stressors associated with the birth of a new baby, these parents also had to cope with many uncertainties about their child's health and prognosis as also described by (Barnett, Clements, Kaplan-Estrin & Fialka, 2003). The mothers in this study experienced a sense of uncertainty and isolation at times during their child's hospital stay after birth, because of a perceived lack of communication from the medical team.

The study findings indicated that when the normal expectations associated with having a new baby are not met, the mothers are often faced with overwhelming emotions and a sense of 'expectations not met'. As discussed in the literature review, parents make preparations for the birth of their child and they may not only wonder about the child's appearance, but may also hold expectations for who their child may become in the future. However, when there are complications at birth or discovery that there might be developmental disabilities, the idealized picture of having a normal child is shattered (Orme, 2005).

Some of the participants revealed a sense of self-blame for their child's condition. This concurs with Reichman, Corman & Noonan's findings (2008), which showed that having a disabled child may trigger guilt, blame or reduced self-esteem. The mothers in the current study felt responsible for their babies' condition, as indicated by their reflections on whether it could be due to something that they have done wrong.

The study identified a major need for emotional support. Disability diagnosis has a considerable emotional and psychological impact on parents, and from the time

parents first realise that something might be less than 'normal' with their child, they must manage and cope with new and often overwhelming emotions (Barnett et al. 2003; Bingham, Correa & Huber, 2012). Participants revealed that they needed someone to talk to, someone who could explain what was happening, and someone who would understand what they were going through. Parents of children with disabilities may experience a grief cycle that is similar to that at the time of death of a loved one; and coping mechanisms, cultural differences, time of diagnosis and the manner in which they were informed by professionals about their child's disability plays an important role (Turnbull & Turnbull, 2001). Fortier and Wanlass (1984) also described how the diagnosis of a disabled child affects the family in many ways, including having to deal with an isolation from others, handling 'helplessness', labelling and stereotyping.

According to Abery (2006) parents may face obstacles when they do not have easy access to accurate information from professionals. The longer mothers must wait for answers from professionals on what to expect related to the disability, the more stress they are likely to experience (Most, Fidler, Laforce-Booth & Kelly, 2006). The participant-mothers in the current study recounted that their need to be told what was happening to their babies, was not met. The mothers felt that the healthcare professionals only attended to the babies' medical needs, and that the mothers' need for information was not met. Earlier, Bingham et al (2012) concluded that health professionals need to understand such needs, so that they can support parents as they learn to cope. This is particularly important in view of the recognition that information-sharing by healthcare workers during the initial diagnostic period, is a vital element in accepting and dealing with a diagnosis of a possible disability (Abery, 2006; Most, Fidler et al. 2006).

The need for clearly communicated information during and after diagnosis of HIE in her baby – as expressed by all the participants in the current study - highlights the

importance of the health and allied professional's role of 'communicator'. Communicator is one of the seven interrelated roles (along with Healthcare Practitioner, Collaborator, Leader and Manager, Health Advocate, Scholar and Professional) adopted by the Health Professions Council of South Africa, for describing the required graduate attributes in the undergraduate training of all health and allied professions (Snyman, 2014).

The outcomes of HIE are devastating and permanent, making it a burden for the patient and the family (Lai & Yang, 2011). Fortier and Wanlass (1984) stated that the diagnosis of a disabled child affects the family in many ways, including having to deal with an isolation from others, handling 'helplessness', labelling and stereotyping. Participants here identified the support of family members as an important factor, which assisted these mothers in coping with a baby with HIE and dealing with the anticipation of raising their disabled child. Living with a disabled child is a unique shared experience for families, and may affect all aspects of family functioning (Reichman et al, 2008). Participants revealed that the support from family members (e.g. grandmothers, mothers, sisters, husbands/partners) made them strong and made it somewhat easier to cope. Religion and personal faith was also identified as a support in coping and dealing with the disability diagnosis.

Earlier, Fortier and Wanlass (1984) already concluded that having a disabled child affects the family on many levels; the family may need to provide immediate care for the disabled child, arrange transportation and accompany the child to treatment and appointments, alter previous time management schedules and meet new financial needs. According to Reichman et al (2008) the logistical complexities associated with raising a disabled child can have far-reaching effects, depending on the type of condition and severity, as well as the physical, emotional, and financial means of the family; and the resources that are available. Here, too, the disability diagnosis imposed practical implications on all the participants, which included an increase in

physical and emotional demands of caring for a disabled child, an increase in financial need, increased demands on time, frequent hospital visits and medical procedures, and decreased social participation for the mothers.

Conclusion

The findings of this study indicated that the participant-mothers of babies diagnosed with HIE, caused by birth asphyxia, experienced fear, uncertainty, helplessness, self-blame and isolation. The findings have confirmed and added specifics to earlier evidence about the need for improved communication between healthcare workers and the mothers of the affected babies at birth; at diagnosis of HIE as well as a need for continued support after diagnosis. The findings also indicated that the support of family members and in some instances the mother's religion or faith was highly valued and contributed towards coping with the newly diagnosed disability.

Limitations included the restricted scope and time frames of this study for degree purposes and comprised the following:

- as with all qualitative research, study findings are specific to a certain time and context and cannot be generalised. Thus recommendations are specific to the study setting. They are potentially useful for other settings since many secondary hospitals in South Africa face similar circumstances for instance regarding time pressure on staff, but exporting of recommendations to other settings should only be done after careful comparison of context and with constant monitoring.
- the study sample size was considered sufficient for a qualitative study of this nature, but a bigger study sample could have provided stronger confirmations of past evidence and richer, diverse findings to explore the experiences and needs of a bigger and more diverse population.

- only one interview was done with each participant, followed by a follow-up telephone call to each study participant to verify the data. More than one interview with each participant would have added more data.

Implications and recommendations: The need for improved communication between healthcare workers and the mothers, as well as a need for continued support was confirmed. It is thus recommended that:

- information on the diagnosis, its causes, the prognosis, the practical implications and the long-term effects that the condition may have on the child should be facilitated by the responsible healthcare practitioners: this may require direct provision of information or referral to relevant sources.
- immediate emotional support is available to mothers in the labour ward; while the prioritisation of medical care in a difficult labour and birth is a given, one of the team should be available to offer direct compassionate support which may be as simple as holding the mother's hand and letting her know that the doctors are worried, but that the team is doing its best for her and her baby.
- referral systems are implemented for seamless and appropriate information and emotional support as mothers go back to the ward and then are discharged into their communities.
- peer support systems are facilitated among inpatients or by mothers who have had babies with HIE to share experiences, support sources and coping strategies with new mothers.

Furthermore, future research could focus upon additional, related topics that can inform services and increase the support of mothers including:

- content and effective formats of information to support mothers in these situations;

- the focus of interprofessional training needed to equip health care professionals serving in maternity and neonatal wards to meet the needs of mothers
- the development of protocols to support mothers of babies diagnosed with HIE
- more focus on the experiences and needs of fathers within this context.

Through the multilevel dissemination of the results to future mothers of babies diagnosed with HIE, clinical staff and in academic forums, it is hoped that the findings of this study will benefit future patients at the study site, as well as at other institutions.

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Appendix A: Participant Information Leaflet

TITLE OF RESEARCH PROJECT: Experiences and needs of mothers of babies diagnosed with Hypoxic Ischaemic Encephalopathy due to birth asphyxia

RESEARCHER: Ms Mandy Naidoo

ADDRESS: Physiotherapy Department
Karl Bremer Hospital
Bellville

CONTACT DETAILS: (021) 918-1302
0732403851
Mandy.Naidoo@westerncape.gov.za

You are invited to take part in this research project. Please read carefully through this information leaflet, which explains the details of the study. You are welcome to ask any questions if anything seems unclear. You may also refuse to take part in this study. Your participation is voluntary and you may withdraw from the project at any point, if you so wish. Not taking part in the study, or withdrawing after starting, will not influence the help you get at this or any other facility. Participants will not be paid to participate in this study. You will be asked to sign a consent form, which allows the researcher to use your information in this study.

The purpose of the study is to learn about the feelings and needs mothers experience after birth when their babies suffered from birth asphyxia. The study will be carried out using mothers over the age of 18, who gave birth at Karl Bremer Hospital, whose new born babies suffered from birth asphyxia 6-8 months ago. A home visit will be given to the participants, where unstructured interviews will be held with each participant individually. The information collected will be treated as confidential. Your name and personal details will not be made available to anyone, except the researcher. The study aims to establish the support that was/is needed by you and to make recommendations on providing support for mothers in the same situation in the future.

You will receive a copy of this information, as well as the consent form, for your own records.

Thank you for your willingness to participate in this project.

Appendix B: Informed Consent Form

DECLARATION BY PARTICIPANT:

I,, agree to participate in the research study entitled: The emotional responses and needs of mothers in the six to eight months after diagnosis of HIE due to asphyxia while giving birth.

I fully understand the information that was provided and all my questions have been answered. I understand that my participation is voluntary and that I may withdraw from the study at any time. I understand that my information will be kept confidential and anonymous.

Signed at (place) On2013 (date)

.....
Signature or thumb print of participant

.....
Signature or thumb print of witness

DECLARATION BY INVESTIGATOR:

I,, declare that I explained all the information regarding the research project to the above-mentioned participant and I am satisfied that she understands all aspects of this study.

Signed at (place) On2013 (date)

.....
Signature of investigator

.....
Signature or thumb print of witness