

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



Nakamanya, S; Siu, GE; Lassman, R; Seeley, J; Tann, CJ (2015) Maternal experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: a qualitative study. *Disability and Rehabilitation*, 37 (16). pp. 1470-1476. ISSN 0963-8288 DOI: <https://doi.org/10.3109/09638288.2014.972582>

Downloaded from: <http://researchonline.lshtm.ac.uk/2287441/>

DOI: [10.3109/09638288.2014.972582](https://doi.org/10.3109/09638288.2014.972582)

Usage Guidelines

Please refer to usage guidelines at <http://researchonline.lshtm.ac.uk/policies.html> or alternatively contact researchonline@lshtm.ac.uk.

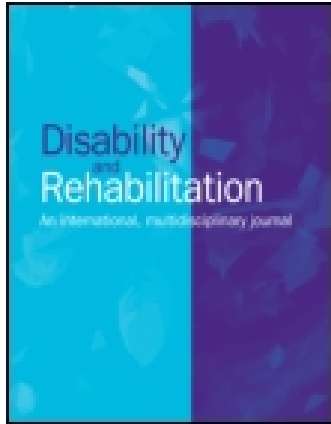
Available under license: <http://creativecommons.org/licenses/by/2.5/>

This article was downloaded by: [University of London]

On: 02 September 2015, At: 09:44

Publisher: Taylor & Francis

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: 5 Howick Place, London, SW1P 1WG



Disability and Rehabilitation

Publication details, including instructions for authors and subscription information:

<http://www.tandfonline.com/loi/idre20>

Maternal experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: a qualitative study

Sarah Nakamanya^a, Godfrey E. Siu^{ab}, Rachel Lassman^c, Janet Seeley^{ad} & Cally J. Tann^{acd}

^a MRC/UVRI Uganda Research Unit on AIDS, Entebbe, Uganda,

^b Child Health and Development Centre, Makerere University, Kampala, Uganda,

^c Institute for Women's Health, University College London, London, UK, and

^d London School of Hygiene and Tropical Medicine, London, UK

Published online: 17 Oct 2014.



[Click for updates](#)

To cite this article: Sarah Nakamanya, Godfrey E. Siu, Rachel Lassman, Janet Seeley & Cally J. Tann (2015) Maternal experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: a qualitative study, *Disability and Rehabilitation*, 37:16, 1470-1476, DOI: [10.3109/09638288.2014.972582](https://doi.org/10.3109/09638288.2014.972582)

To link to this article: <http://dx.doi.org/10.3109/09638288.2014.972582>

PLEASE SCROLL DOWN FOR ARTICLE

Taylor & Francis makes every effort to ensure the accuracy of all the information (the "Content") contained in the publications on our platform. Taylor & Francis, our agents, and our licensors make no representations or warranties whatsoever as to the accuracy, completeness, or suitability for any purpose of the Content. Versions of published Taylor & Francis and Routledge Open articles and Taylor & Francis and Routledge Open Select articles posted to institutional or subject repositories or any other third-party website are without warranty from Taylor & Francis of any kind, either expressed or implied, including, but not limited to, warranties of merchantability, fitness for a particular purpose, or non-infringement. Any opinions and views expressed in this article are the opinions and views of the authors, and are not the views of or endorsed by Taylor & Francis. The accuracy of the Content should not be relied upon and should be independently verified with primary sources of information. Taylor & Francis shall not be liable for any losses, actions, claims, proceedings, demands, costs, expenses, damages, and other liabilities whatsoever or howsoever caused arising directly or indirectly in connection with, in relation to or arising out of the use of the Content.

This article may be used for research, teaching, and private study purposes. Terms & Conditions of access and use can be found at <http://www.tandfonline.com/page/terms-and-conditions>

It is essential that you check the license status of any given Open and Open Select article to confirm conditions of access and use.

RESEARCH PAPER

Maternal experiences of caring for an infant with neurological impairment after neonatal encephalopathy in Uganda: a qualitative study

Sarah Nakamanya¹, Godfrey E. Siu^{1,2}, Rachel Lassman³, Janet Seeley^{1,4}, and Cally J. Tann^{1,3,4}

¹MRC/UVRI Uganda Research Unit on AIDS, Entebbe, Uganda, ²Child Health and Development Centre, Makerere University, Kampala, Uganda, ³Institute for Women's Health, University College London, London, UK, and ⁴London School of Hygiene and Tropical Medicine, London, UK

Abstract

Purpose: The study investigated maternal experiences of caring for a child affected by neurological impairment after neonatal encephalopathy (NE) ("birth asphyxia") in Uganda. **Methods:** Between September 2011 and October 2012 small group and one-on-one in-depths interviews were conducted with mothers recruited to the ABAaNA study examining outcomes from NE in Mulago hospital, Kampala. Data were analysed thematically with the aid of Nvivo 8 software. **Findings:** Mothers reported caring for an infant with impairment was often complicated by substantial social, emotional and financial difficulties and stigma. High levels of emotional distress, feelings of social isolation and fearfulness about the future were described. Maternal health-seeking ability was exacerbated by high transport costs, lack of paternal support and poor availability of rehabilitation and counselling services. Meeting and sharing experiences with similarly affected mothers was associated with more positive maternal caring experiences. **Conclusion:** Mothering a child with neurological impairment after NE is emotionally, physically and financially challenging but this may be partly mitigated by good social support and opportunities to share caring experiences with similarly affected mothers. A facilitated, participatory, community-based approach to rehabilitation training may have important impacts on maximising participation and improving the quality of life of affected mothers and infants.

Keywords

Birth asphyxia, health-seeking, impairment, infant, maternal experience, neonatal encephalopathy, Uganda

History

Received 12 April 2014
Revised 29 September 2014
Accepted 30 September 2014
Published online 17 October 2014

► Implications for Rehabilitation

- Caring for an infant with neurological impairment after NE in Uganda has substantial emotional, social and financial impacts on families and is associated with high levels of emotional stress, feelings of isolation and stigma amongst mothers.
- Improved social support and the opportunity to share experiences with other similarly affected mothers are associated with a more positive maternal caring experience. High transport costs, lack of paternal support and poor availability of counselling and support services were barriers to maternal healthcare seeking.
- Studies examining the feasibility, acceptability and impact of early intervention programmes are warranted to maximise participation and improve the quality of life for affected mothers and their infants.

Introduction

Complications occurring around the time of birth can have serious adverse effects on the unborn baby ("birth asphyxia"), and have been identified as the third leading causes of child mortality [1]. Each year such intrapartum complications are estimated to be responsible for more than 1 million new cases of neonatal encephalopathy (NE) and nearly half a million infant survivors with neurological impairment [2]. Retrospective cohort studies in

low-income settings provide estimates that 40–50% of cerebral palsy is secondary to perinatal asphyxia in this setting [3–5].

Infants exposed to a perinatal asphyxia typically present in the newborn period as encephalopathic which encompasses a clinical constellation of neurological dysfunction in the term infant including difficulty with initiating and maintaining respiration, depression of tone and reflexes, subnormal level of consciousness, and seizures [6]. Infant survivors of NE are at significantly

increased risk of neurodevelopmental delay, mobility and functional impairments, seizure disorders, cerebral palsy or impaired vision and hearing leading to reduced participation [7–11].

Studies suggest that care-giving practices serve an important role in influencing a child's development including cognitive, social and behavioural outcomes [12]; however, the experience of raising a child with an impairment/disability involves greater stress and additional care-giving challenges [12–16]. Parents/carers of impaired children often face difficulties in seeking appropriate health care due to increased costs of care giving and decreased earning possibilities [12]. Existing research, largely from high income settings, suggests that culture specific beliefs and norms surrounding disability also tend to influence attitudes and practices associated with management of the condition [11,17]. In many cultures, there is stigma attached to both physical and cognitive disability and it is possible that this may have a profound effect on the parenting practices and experience of mothers of children affected by impairment after NE [17–19]. Negative feelings may be increased in parents of impaired children resulting in parental depression. This has been shown to negatively impact on parenting practices [14,15,20]; however, social support is likely to reduce the negative effects of important stressors [16].

To improve the support to mothers and families of children affected by neurological impairment after NE, health-care providers and counsellors need to understand mother's experiences better [13]. However, most data on the experience of caring for a child after perinatal asphyxia are from high resource settings and may have limited application in resource constrained countries [7,21,22]. Further research is therefore needed, especially in resource limited settings [22,23].

The primary aim of this qualitative study was to explore maternal experiences of caring for a child affected by neurodevelopmental impairment after NE in an urban Ugandan setting.

Methods

Design and study participants

Study mothers and infants were identified from those recruited to a larger unmatched case control study examining risk factors for, and outcomes from, NE in Uganda (Associations between Birth Asphyxia and infection amongst newborns in Africa: Perinatal risk factors for NE in Uganda (the ABAaNA study). The ABAaNA study team recruited 210 infants term newborn with encephalopathy (defined as a Thompson score of >5 [24]) identified within 12 h of birth, and 409 unaffected term infants (controls) at Mulago Hospital, the National Referral Hospital in Uganda's capital Kampala. Mulago Hospital is the largest referral centre in Uganda for high-risk pregnancies with a delivery rate of more than 33 000 births per year. A special care unit for babies is available for sick newborns with facilities for intravenous fluids, antibiotics, oxygen and simple continuous positive pressure ventilation for those with significant respiratory distress. After discharge, infants are followed in the neonatal follow-up clinic. A weekly paediatric neurological clinic at Mulago outpatients department receives referrals for children identified as having neurological or neurodevelopmental problems. Infants affected by motor impairments may be seen on one or two occasions in a dedicated physiotherapy clinic for children with cerebral palsy and other neurodevelopmental impairments.

ABAaNA study infants were recruited between September 2011 and October 2012. Surviving infants were followed at between 12 and 15 months of age to ascertain early neurodevelopmental outcomes when the Griffiths Neurodevelopmental Scales for infants 0–2 years [25] and the Hammersmith Infant Neurological Examination (HINE) [26] were performed.

Significant impairment was defined as a developmental quotient of ≤ 70 on Griffiths assessments or ≤ 59 on the HINE scored assessment. Neurological examination was used to define the pattern of impairment seen categorised as spastic diplegia, spastic quadriplegia, hemiplegia, dystonic, choreo-athetoid or hypotonic. All ABAaNA study case infants found to have a significant level of impairment at the 12–15 months assessment were eligible to be included in the qualitative study. The qualitative study was conducted from February to May 2013. A list of 19 infants identified as severely or moderately impaired was generated during the 1-year follow-up and mothers of these babies were contacted by telephone and invited to take part. All infants requiring long-term follow-up were referred to Mulago Paediatric Neurodevelopmental clinic for on-going care. Recruitment into the qualitative study ended while the main study 12–15 months assessment was still ongoing and babies identified in the final months of the main study were not included.

Ethical considerations

The study was reviewed by the Science and Ethics Committees of the Uganda Virus Research Institute Science and Ethics Committee, Mulago Hospital, and University College London (UCL). The Uganda National Council for Science and Technology approved the study. All mothers gave written informed consent before participating. During the study, participants were offered light refreshments and a transport reimbursement of about US\$4. Mothers who had specific concerns or required extra support were referred back to the study nurse after the interview.

Data collection

Data were collected through group and individual in-depth interviews (IDI). In the initial stages of the study, six mothers of the affected children who had been identified as set out above, were contacted by the study nurse and invited to participate in small facilitated group interviews with similarly affected mothers. Dates for the group interviews were agreed upon and mothers were given a reminder call a day before the date of the group interview and asked to come to the study clinic in Mulago hospital. Following consent from individual mothers, two group interviews of three mothers per group were conducted on different days in a separate room from the study clinic in Mulago hospital. The group interviews were used to identify the social, emotional and economic implications of caring for a child with a disability. Through reading and re-reading of the group interview scripts, the authors identified emergent themes such as: experiences of stigma, stress, health-seeking, work, social support plus hopes and fears which formed the basis of topics for further investigation. The study team used the themes to develop an interview topic guide for individual in-depths interviews with the remaining mothers and one carer. The first author regularly sent completed interview scripts to co-authors who identified gaps that were explored further in subsequent interviews. The data reported in this article are, therefore, based on the information from the women who participated in the group interviews and the women interviewed individually.

Data analysis

The first author transcribed and translated audio interviews into English, and generated initial themes during her debriefing discussions with co-authors. More themes were identified through intensive reading and re-reading of interview transcripts and further discussion. The themes were developed in categories under which matching data were coded with the aid of Nvivo 8 (QSR International Pty Ltd., Doncaster, Victoria, Australia). Identified themes were further discussed and refined by the

authors during the drafting of the manuscript. Comparisons of inter-relationships between codes and categories were done throughout the analysis.

In the presentation of findings below, we use the following codes to denote involvement in either the group interviews (GI) or IDI. The participants in the group discussion were assigned a number according to their seat (GI 1, participant 2, for example denotes the women in Group interview 1 who sat in seat 1). The numbers of women participating in the IDIs are assigned according to the order of recruitment.

Results

Sample characteristics

Of the 19 women identified, 15 mothers and one care taker participated in the study, three were lost to follow-up. Participants' ages ranged from 16 to 39 years, with a mean age of 22.5 years. Over half were Baganda, the main ethnic group in the central region of Uganda. Half of the sample was first-time mothers, some living under the care of parents, grandparents or an elder sister. The number of children per mother ranged from one to five. Ten mothers reported cohabiting relationships while four reported desertion by partner because they had delivered an impaired child, as an 18-year-old mother during the IDI observed that: "He said in his family they do not bear lame children; that I should take my child away because even if I stayed, he would not waste a coin on the child."

The mothers' education levels were generally low, with only five having studied beyond primary level. Over half (seven) had stopped work due to the child's condition. Only three mothers reported earning a regular income, mostly from petty trade.

Care-giving experiences

Stigma, stress and worries

The mothers' narratives reflected overwhelming experiences of emotional distress arising from witnessing their child suffer with a strange condition. The failure to see the child grow and perform tasks like other children worried the mothers. Two mothers claimed that they had developed hypertension from worrying too much about the child. Fears of whether the child would get better were widespread among mothers and most broke into tears while narrating their painful experiences. The women reported areas of concern like the child's developmental delay reflected in failure to sit, crawl or stand, squinted eyes, stiff muscles, legs or arms, nasal congestion, drooling, soft spine and joints, head nodding and frequent seizures. A 32-year-old mother of five narrated:

Sometimes I doubt if my child will ever speak, walk or will he be lame! I reflect on the children I see seated with stretched legs and a bent back and wonder if he will be like them or will be able to sit properly. I sometimes see children with crooked legs; this leaves me thinking about mine. Most of the time, the abnormalities I see in other children make me feel fearful for mine. (IDI mother 3)

Such impairments attracted negative reactions from other people, causing stress to the mothers. Over half of the mothers (10/16) reported being stressed by negative actions, comments or isolation of the child. The 32-year-mother quoted above, who already had four older children, and who had had a child with a new partner described this feeling:

They do talk about him [the child] because sometimes you hear somebody saying eh, "imagine her first child with the man is mentally incapacitated". I hear such stories but I keep my child

away from them, most of the time I keep him indoors. When I am outdoors, I seat the child in a basin and support him with clothes so that he does not topple over; but I never let them carry my child and I cannot even let it happen because they speak ill about him. (IDI mother 3)

Another woman expressed similar experiences:

What I would personally say "musawo" [health worker] is that raising these children is not easy generally because of the fact that most people do not understand them. When they see that they (these children) are not behaving like other children, they start making funny comments which cause you to feel bad emotionally. The other thing is that these children require a lot of time and money, for they need special care and for that, you have to spend a lot of money, this plus the endless comments discourage you and you feel really bad. (22-year-old mother of one, Group interview [GI] participant 2)

While some mothers reported employing strategies like keeping the child in doors, others mentioned only taking the child out while accessing health care. One young mother said that her child was so thin that she felt shy exposing her as people used to laugh whenever they saw the child; she would always keep the child fully covered:

If you were to see this kid, the leg was like this [compares it to her finger]. I used to cover her with a towel for I did not want people to see. Whenever children would see [the child], they would start laughing at me [...] even in the village, they used to talk about this kid, others would laugh at how the kid is but me I don't care. One time there is a lady here in Kampala who said that, "if that kid was mine I would wait for floods to come then I would throw the baby to go with that water". (22-year-old first-time mother, IDI mother 1).

Mothers reported being cut off from social life as they could not easily attend any gathering with such a child. Caring for their children was intense work that required the constant presence of the mother herself. Although one could sometimes get assistance from other family members to mind the baby, this was often difficult as others shied away due to fear of the strange condition:

Yes, some people fear him, they fear him a lot now that he is very soft and fragile, some say ah ah (no), we fear your child and cannot touch him. For example, somebody finds him crying, you know we live in rental rooms, one may say your child is crying a lot but I am scared of him, he is very soft [flabby] and I fear holding him, everyone keeps telling you that they fear the child. (32-year-old mother of five, IDI mother 3)

"Mothers participating in one of the group interviews described how one often became stressed and sad when they attempted to go out, due to the tendency by others to gossip about the child. There is a place five houses away from my home where they play music but I cannot go there because of the child... moving with the child was only left to coming here [to the clinic] because even the people you find in the taxi eh, they stare a lot! ... They talk as if you committed a crime my dear!" (22-year-old mother of one, GI 2 participant 2).

Impact on work and income

Like other activities, work was also significantly affected by the child's condition. Mothers' narratives indicated that caring for a child with such a condition was a big challenge and took a lot of

time which undermined their ability to engage in work to make a living:

Before you give birth to a child like this one, you are absolutely free to do anything you want; you can do any job you are called upon for. Apparently [now] there is no one you can leave such a child even if you get a job, no one can take care of him [...] you always need to be with your child. In the end, you find that you cannot even set up a small business around where you stay. You continue suffering. (20-year-old mother of one GI 2, participant 3)

The majority of the women in this study had been involved previously in income generating work but gave it up and resorted to staying home and taking care of the child because either they were “always on hospital admission” or they could not access help, or they felt that their child could best be handled by the mother herself as illustrated below:

I used to own a bar. I used to go and sell alcohol then return home but that was before giving birth to this child, but now I cannot leave the child with anybody else, whoever you give the child says, “Ah [no], I cannot handle this child of yours”. (32-year-old, mother of five, IDI mother 3)

Other mothers lost their jobs for absenteeism from work due to the children’s illness or closed down their businesses because they used up all the business capital to support the child’s treatment. This undermined their ability to meet treatment expenses. A 36-year-old care taker who supported both mother and child described how she struggled:

All my working capital was used up and I accumulated debts which I am paying up to now. I no longer have working capital of my own but the wholesalers give me charcoal and after selling, I return their money and only keep the profit. In addition to that, I have to raise 6,000 shillings [roughly \$2.5] every day for the child’s food (36-year-old care taker, IDI participant 4)

All women expressed the desire to return to or find work to address the mounting financial challenge they were going through, although some felt that they could not resume work before the child’s condition improved.

Social support

Support was mainly from partners, although the wider family and society also sometimes helped. However, mothers described varying levels of support from partners. While four mothers reported partner abandonment or reduced support (one), nine reported supportive partners, who mainly provided money to meet care expenses. In exceptional circumstances, some partners (four men) also made an effort to seek treatment for the child. Mothers who reported receiving support from their partners reported less stress and were more positive about their experience of mothering a child with impairment compared to those without partner support. Similarly, single mothers with family support also expressed more positive views and had hope for the future compared to those without family support, as the following accounts illustrate. A single mother who had a non-supportive family said:

[...] the grandmother I live with tells her friends in the village that she told me not to take the child to hospital claiming that that’s the child’s nature (group laughs) [...]. Even when the

child is sick, she (the grandparent) cannot give you a single coin but just tells you to leave the child there, “where are you taking such!” [The grandparent asks]. (22-year-old first-time mother, GI 2, participant 2)

Another mother had better family support: “[my] grandmother is the one that is mostly involved because the father is still schooling, but even he [the father] brings support whenever he can” (17-year-old first-time mother, GI 1, participant 2).

In addition to family support, mothers also described the support from the wider society, which came mainly from neighbours and friends. This support largely took the form of advice on treatment, although some mothers were very sensitive about the kind of sympathy they received from those people, aware that someone may just be curious to find out what is wrong with the child.

[...] Someone could approach you wondering what’s wrong with the child and why the child is so flabby or why the child’s neck is like this! They then advise you to tie it with a cloth. (“25-year-old first-time mother, GI 1, participant 1)

Mothers’ response to their children’s condition

One of the most important aspects of care giving for children affected by NE is health-seeking, and our study showed that the mothers’ perceptions of their children’s condition tend to greatly influence health-seeking practices.

Perceptions of child’s condition

Mothers had a wide range of beliefs regarding their children’s condition. Most commonly, mothers described the condition as “the baby got tired at birth” and partly attributed it to the traumatic delivery process they went through:

[...] I came back early the next day and overstayed in the queue; I think the time [for delivery] passed [weeps]. I was still not experiencing labour pains. I was put on a drip and managed to push the baby [speaks while crying] but when I pushed, it [the baby] did not cry. I think that is the root of the problem. (39-year-old mother of five, IDI mother 10)

Some mothers however attributed the condition to traditional causes like to “**busobe**” (literally translated as to err. Among the Baganda the condition is believed to be caused by unfaithfulness of either partner), family disapproval of the choice of partner, failure to take the child to visit the ancestral home or the negative effect of having twins or malevolent ancestral/evil spirits. A 25-year-old mother whose other child had also suffered and died from complications around the time of birth commented: “We were told that it is the doing of ancestral spirits and my partner sought help at a traditional healer who asked for so many things and we have not yet raised the money” (IDI mother 7. Two other mothers were told the children were just slow progressors while others were told that the condition resulted from the things they had eaten during pregnancy; for example, too much ghee or bananas, herbs or contraceptives ingested. Others attributed it to the oxygen used during resuscitation or bad drugs used to treat child.

Mothers’ response to the condition

All mothers reported that they had taken some form of action regarding the child’s illness. Although all babies underwent resuscitation in the hospital during their first days of life, the

mothers did not have raised concerns at that time. However, they said that they had grown increasingly concerned when they noticed that their children had failed to attain certain expected physical and cognitive developmental milestones such as an inability to sit up on their own. One mother described how she had paid close attention to her child's development every month, and realised that it was not normal and they needed to "do something", saying:

When I gave birth, it [the baby] was very tired and did not cry but cried at one month. Three months went by and it started getting seizures, it was not like other children [...] people told me children start sitting at three months but mine was not sitting, it could neither see nor laugh. At four months a child should be able to sit firmly but mine could not, it reached six months and still no difference; that was when I realised that it had a problem. (18-year-old first-time mother, IDI mother 6)

Mothers reported attempting a range of remedies to help the children, including faith-based healing and prayer by Pentecostal pastors, traditional therapies, mainly involving use of herbs, and biomedical remedies. Among these options, the biomedical remedy was the most popular with 11 of the 16 women reporting that their children regularly underwent neurological examination and physiotherapy in Mulago hospital, as part of the follow-up service. There were mixed views on the effectiveness of the various therapy options but mothers were generally very positive about the physiotherapy.

Ever since they started him on exercises, I am seeing some improvement in him. If you lay him down to sleep, he can now turn in his sleep, for instance if he was lying on his belly, he can turn and lie on his side and vice versa. He can now play like children do. Before the therapy, he could not sit, crawl or stand. He would fold his legs when you tried to make him stand but he now straightens them and stands with support. (32-year-old, mother of two, IDI mother 4).

Although several mothers had tried other remedies such as prayer and traditional healing, they seemed to acknowledge that these were less effective compared to medical treatment. Some mothers therefore reported that they had become reluctant or had given up completely on such remedies:

When I apply it [herbal medicine] and see no change I stop using it and conclude that it is not effective (laughs) "I used it but when I saw that it wasn't working, I left it". (39-year-old mother of five, IDI mother 10)

Acknowledging the limits of prayer, another mother said:

All that [prayer] is necessary but you first seek medical treatment, because if not, how then will He [God] cure him! You have to ask for God's help while you also do your part, for even the care provider prays to God to cure the people that s/he treats yet s/he knows that the medicine works as a cure but s/he prays. So, you also have to seek medical treatment as you pray to God so that the treatment works. (26-year-old mother of two, IDI mother 9)

However, there seemed to be differences between different mothers treatment choices and their partners' preferences as mothers who reported partners' involvement in treatment seeking, reported frequent disagreements between them. Fathers appeared to have far more limited knowledge of the condition and either believed that the children were only slow progressors or tend to

believe the condition was too advanced for treatment. Others did not believe that the support the women said they got from the hospital was genuine. The men said that no medical facility could ever telephone a patient reminding them to seek treatment and questioned the women's actions when they responded to these calls. Such disagreements and variations in perceptions of options for remedies between mothers and their partners affected the health-seeking for the children and appeared to increase the stress experienced by the mothers.

Factors influencing health-seeking for biomedical therapies

Health-seeking regardless of the form proved very challenging to all mothers due to a range of factors. A lack of adequate money to cover the treatment bills, pay for transport costs or purchase other assistive equipment like sitting/standing devices as recommended by therapists, was one the most frequently cited factors. Although treatment is meant to be free in government facilities like Mulago hospital, mothers reported having to pay for services like X-rays, CT scans and even some drugs. Lack of funds caused some mothers to miss clinic appointments while others never sought proper treatment. A 25-year-old first-time mother said:

For instance, there are times when I have to come for appointments at the CP [cerebral palsy clinic] but I at times fail to come because of transport, I miss the CP appointments quite a lot [...]. (GI1, participant1)

Besides money, another challenge was the long waiting time to see the care providers and the frequent failure to find specialists at the health facilities:

The challenge we have faced in treating this child is that you come here when the child is sick but then spend a lot of time here. You may be lucky and see the doctor who prescribes drugs for you and you reach the top of the queue after lining up only for them to tell you the drugs are out of stock. (20-year-old first-time mother GI 2, participant 3)

Even in cases when they managed to see the doctors and got prescriptions, the drugs were always out of stock. Mothers also described the practical challenges arising from the physically demanding work that they had to perform while seeking care for an impaired child. They variously stated that often without anyone else to assist, minding and carrying the child on their backs and/or hands as they moved from one unit to another in the hospital, often for long hours, or as they helped the child through the prescribed physiotherapy exercises, was too physically exhausting for them:

When you come, you have to climb steps yet the child is heavy and you really get exhausted, I had personally gotten tired of those exercises. (25-year-old mother of three, GI 2 participant1)

Mothers were also concerned about the technical competence as well as the attitude of health workers. It was reported that in some cases, health care providers were rough and insensitive to the mothers, thus discouraging some from visiting the major health facility.

The health care providers treat us like we are a burden to them! "Haven't we seen people die before?" That also isn't right [speaks with a sad tone and look]. S/he has not given any treatment to your child but s/he asks if they haven't seen people die before! (20-year-old mother of one, GI 2 participant 2)

In other instances, the mothers held the perception that most people in their setting, including some health care providers, did not have adequate knowledge of how to deal with the condition affecting their children. Their narratives suggested that although health workers were competent in the medical treatment, the medical intervention was limited in scope and health systems lacked the capacity to provide counselling support and develop mothers' emotional/social skills that were required to cope.

All mothers regardless of experience reported experiencing challenges accessing treatment, although mothers without partner or family support appeared to express greater concerns. Nevertheless, they reported getting encouragement when they visited the health facility and shared experiences with other mothers or saw other children who were in an even worse state than their own.

[. . .] when you come to hospital, you gain heart and appreciate your challenge in comparison to others. For I once went to physiotherapy and saw children! I thanked God that mine does not reach that extent. Sincerely whenever you come to hospital, you are encouraged, that's what I appreciated and that's why every time I am called upon I try my level best and come. (26-year-old mother of three, GI 2 participant 1)

Furthermore, mothers were very positive about the physiotherapy given to the children and felt that if they continue with the therapy, the children might eventually walk.

Discussion

This qualitative study sought to investigate mothers' experiences caring for a child affected by neurological impairment after NE ('birth asphyxia'). We found overwhelming levels of emotional distress experienced by the mothers witnessing their child's experience of living with a condition they felt they understood poorly. The realisation of the child's disability created anxiety among mothers. This left them feeling fearful about their children's future, attracted negative feelings from other people and led to feelings of isolation and significant levels of stigma. Coupled with this were the economic and physical challenges faced in care giving and seeking a remedy. This study further showed that the burden of caring for an impaired child affected all mothers whatever their age and background and that social support was crucial in the process of coping.

Different explanations were put forward by the mothers to explain the NE that affected their children in the newborn period the majority referred to spiritual/cultural beliefs around misfortune and moral failure. This echoes findings of Etuk and Etuk [9], whereby spiritual beliefs led to increased unorthodox deliveries and the related risks. While some of the distress and physical difficulties may be shared across difference settings, understanding the social cultural manifestations of NE enables an appreciation of the complex context and challenges of health-seeking and support for this condition.

The issue of emotional distress among carers/families of children with neuropsychological impairments has been the subject of discussion in other studies [18,23]. Most recent research presents a more positive picture of caring for a child with disability and terms like 'adaptation' or 'resilience' are replacing earlier concepts of 'stress' [27], which partly agrees with our findings. However, we cannot ignore the high levels of stress and social isolation clearly manifested in these mothers' narratives. As other studies [12,28] have shown, we found that caring for children with disabilities carried greater stress and more care-giving challenges compared to unaffected children. However, in line with existing literature [29], results of our study revealed a

positive association between social support and care-giving experiences whereby mothers with both emotional and instrumental support seemed to cope better, as demonstrated by Belsky [30] in his model of the parenting process. Based on Belsky's notion that a positive marital relationship is a major support of competent parenting, results from our study strongly agreed with other studies showing the positive influence of husband's supportiveness on mothering. Social support has been identified as a critical aspect of positive coping for families of children with a disability [12,27].

Regarding treatment, a mother's acknowledgement of improvement in the child's condition after professional medical care such as physiotherapy is an indicator that biomedical support is seen as the most effective and popular form of care even in contexts where people have varied beliefs around neuropsychological impairment. This agrees with findings of a Nigerian study where unorthodox forms of treatment offered to babies with perinatal asphyxia, which included prayers and herbs/roots proved inappropriate and even dangerous [9].

Other studies have indicated the importance of early professional care among infants who suffer NE resulting from perinatal asphyxia [10,11]. It is important that mothers are made aware of the importance of seeking professional health care. However, efforts to seek proper health care were hampered by poverty. This agrees with findings of other studies which demonstrated that parenting of children with chronic health conditions proved more financially challenging due to increased costs of care giving and decreased income earning opportunities [12,18,28,31–34,27]. Authors have also highlighted the importance of service providers rethinking the health systems' organisation and the ways they relate to a person with a disability and their carers [35].

This study had some limitations. This was a small sample and may not be generalised to all mothers of children impaired as a result of NE. In addition, our urban study population had often had some level of access to specialist outpatient care at Mulago hospital and whose experiences could therefore be different from mothers who have even greater difficulty in accessing care. Furthermore, as these were mothers of very young infants this study was not able to report on the changing maternal experiences as the child gets older and faces major life transitions which come with increased needs like difficulties with toileting, schooling, and socialising. However, the IDI adopted for this study elicited valuable insights into mother's experiences thus contributing to the sparse data and help inform policy on improvement of care delivery and support to the affected mothers and families.

Conclusion

Mothering a child with neurological impairment after NE is emotionally, physically and financially challenging, but this may be partly mitigated by good social support and opportunities to share experiences with similarly affected women. Further research examining the feasibility, acceptability and impact of an early intervention programme to empower affected families are urgently needed to maximise participation and to improve the quality of life of affected mothers and infants.

Acknowledgements

We would like to acknowledge the mothers for their participation and Mulago hospital for their on-going support of the study. Special thanks to the ABAaNA study team for their support, particularly Margaret Sewegaba and Margaret Musoke for their invaluable assistance with mobilising study participants and also Sonia Kim for her inputs.

Declaration of interest

The study was funded by a Wellcome Trust training fellowship (Clinical PhD Programme in International Health Wellcome Trust/London School of Hygiene and Tropical Medicine) and an Innovative Research Grant awarded by the Research Foundation of Cerebral Palsy Alliance, Australia, both to CT. The time of SN, GS and JS was jointly funded by the UK Medical Research Council (MRC) and the UK Department for International Development (DFID) under the MRC/DFID Concordat agreement. The authors declare no conflict of interest.

References

1. You D, Bastian P, Wu J, Wardlaw T. Levels & trends in child mortality. In: UN Inter-agency Group for Child Mortality Estimation, ed. UNICEF, WHO, World Bank, UN-DESA Population Division; 2013.
2. Lee ACC, Kozuki K, Blencowe H, et al. Intrapartum-related neonatal encephalopathy incidence and impairment at the regional and global levels for 2010 with trends from 1990. *Pediatric Res* 2013;74:50–72.
3. Taha S, Mahdi A. Cerebral palsy in Saudi Arabia: a clinical study of 102 cases. *Ann Trop Paediatr* 1984;4:155–8.
4. Belonwu R, Gwarzo G, Adeleke S. Cerebral palsy in Kano, Nigeria – a review. *Niger J Med* 2009;18:186–9.
5. Singhi P, Ray M, Suri G. Clinical spectrum of cerebral palsy in north India – an analysis of 1000 cases. *J Trop Paediatr* 2002;49:162–6.
6. Nelson KB, Leviton A. How much of neonatal encephalopathy is due to birth asphyxia? *Am J Dis Child* 1991;145:1323–31.
7. Heringhaus A, Blom MD, Wigert H. Becoming a parent to a child with birth asphyxia – from a traumatic delivery to living with the experience at home. *Int J Qual Stud Health Well-Being* 2013;8:1–13.
8. Johnson SL, Hall DM. Post-traumatic tremor in head injured children. *Arch Dis Child* 1992;67:227–8.
9. Etuk SJ, Etuk IS. Relative risk of birth asphyxia in babies of booked women who deliver in unorthodox health facilities in Calabar, Nigeria. *Acta Trop* 2001;79:143–7.
10. Robertson NJ, Hagmann CF, Acolet D, et al. Pilot randomized trial of therapeutic hypothermia with serial cranial ultrasound and 18–22 month follow-up for neonatal encephalopathy in a low resource hospital setting in Uganda: study protocol. *Trials* 2011;12:138.
11. Wall SN, Lee AC, Carlo W, et al. Reducing intrapartum-related neonatal deaths in low- and middle-income countries-what works? *Semin Perinatol* 2010;34:395–407.
12. Arim RG, Garner RE, Brehaut JC, et al. Contextual influences of parenting behaviors for children with neurodevelopmental disorders: results from a Canadian national survey. *Disabil Rehabil* 2012;34:2222–33.
13. Tooten A, Hoffenkamp HN, Hall ASR, et al. Parental perceptions and experiences after childbirth: a comparison between mothers and fathers of term and preterm infants. *Birth* 2013;40:164–71.
14. Bailey Jr DB, Golden RN, Roberts J, Ford A. Maternal depression and developmental disability: research critique. *Ment Retard Dev Disabil Res Rev* 2007;13:321–9.
15. Gerstein ED, Crnic KA, Blacher J, Baker BL. Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *J Intellect Disabil Res* 2009;53:981–97.
16. Fondacaro MR, Moos RH. Life stressors and coping: a longitudinal analysis among depressed and nondepressed adults. *J Commun Psychol* 1989;17:330–40.
17. Munsaka E, Charnley H. 'We do not have chiefs who are disabled': disability, development and culture in a continuing complex emergency. *Disabil Soc* 2013;28:756–69.
18. Hartley S, Ojwang P, Baguwemu A, et al. How do carers of disabled children cope? The Ugandan perspective. *Child Care Health Dev* 2004;31:167–80.
19. Abberly P. The concept of oppression and the development of a social theory of disability. *Disabil Handicap Soc* 1987;2:5–19.
20. Lovejoy MC, Graczyk PA, O'Hare E, Neuman G. Maternal depression and parenting behavior: a meta-analytic review. *Clin Psychol Rev* 2000;20:561–92.
21. Lang R. Disability scoping study for DFID Uganda. London, UK: University College London; 2009.
22. WHO. World Report on Disability. Geneva: World Health Organisation; 2011.
23. Nassef SK, Blennow M, Jirwe M. Experiences of parents whose newborns undergo hypothermia treatment following perinatal asphyxia. *J Obstet Gynecol Neonatal Nurs* 2013;42:38–47.
24. Thompson CM, Puterman AS, Linley LL, et al. The value of a scoring system for hypoxic ischaemic encephalopathy in predicting neurodevelopmental outcome. *Acta Paediatr* 1997;86:757–61.
25. Huntley M. Griffiths mental development scales: from birth to 2 years. Association for Research in Infant and Child Development (ARICD). Oxford, UK: The Test Agency; 1996.
26. Haataja L, Mercuri E, Regev R, et al. Optimality score for the neurologic examination of the infant at 12 and 18 months of age. *J Pediatrics* 1999;135:140–2.
27. Hoogeveen J. Measuring welfare for small but vulnerable groups: poverty and disability in Uganda. *J Afr Econ* 2005;14:603–31.
28. Heiman T. Parents of children with disabilities: resilience, coping, and future expectations. *J Dev Phys Disabil* 2002;14:159–71.
29. Anaby D, Hand C, Bradley L, et al. The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disabil Rehabil* 2013;35:1589–98.
30. Belsky J. The determinants of parenting: a process model. *Child Dev* 1984;55:83–96.
31. Peterson S, Nsungwa-Sabiiti J, Were W, et al. Coping with paediatric referral – Ugandan parents' experience. *Lancet* 2004;363:1955–6.
32. Lawn JE, Cousens S, Zupan J. 4 million neonatal deaths: when? where? why? *Lancet* 2005;365:891–900.
33. Fisher KR, Shang X. Access to health and therapy services for families of children with disabilities in China. *Disabil Rehabil* 2013;35:2157–63.
34. Marvin RS, Pianta RC. Mother's reactions to their child's diagnosis: relations with security and attachment. *J Clin Child Adolesc Psychol* 1996;25:436–45.
35. Dew A, Bulkeley K, Veitch C, et al. Addressing the barriers to accessing therapy services in rural and remote areas. *Disabil Rehabil* 2013;35:1564–70.