

ORIGINAL ARTICLE

Caregivers' experiences in caring for children with Hydrocephalus at the University Teaching Hospitals, Lusaka Zambia

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ABSTRACT

Background: Hydrocephalus represents a serious public health problem and a major cause of disability as well as poor quality of life. Children who are born with hydrocephalus or acquire it later in life are often cared for in the home setting by a family caregiver, and in some cases by professional caregivers. Caregiving can often be stressful and can result in negative effects on the family caregiver.

Objective: The aim of this study was to explore caregivers' experiences in caring for children with hydrocephalus seen at the University Teaching Hospitals in Lusaka, Zambia.

Methods: A qualitative phenomenological study design was adopted. This study was conducted at the University Teaching Hospitals in Lusaka, Zambia, among a population of family caregivers for children with hydrocephalus. Purposeful sampling method was used to select ten (10) participants. Data were collected through face-to-face in-depth interviews using a semi-structured interview guide. Data obtained from the interviews was transcribed

verbatim and analyzed using thematic analysis. All ethical considerations were upheld accordingly.

Results: The findings of this study revealed that caregivers for children with hydrocephalus experience a great deal of psychological, social and socioeconomic challenges in caring for their children. These experiences range from emotional distress; sleep deprivation; deterioration of social support; to financial impoverishment associated with needs and expenses of caring for a child with hydrocephalus.

Conclusion: While most studies and interventions primarily focus on the restoration of function in children with hydrocephalus, it is important to develop and/or strengthen programmes that provide holistic support for caregivers of children with hydrocephalus because of the various experiences associated with caring for children with hydrocephalus.

INTRODUCTION

Hydrocephalus is defined as an active distension of the ventricular system due to mismatch between cerebrospinal fluid (CSF) production and its

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absorption, leading to abnormal growth of the head. Congenital hydrocephalus is attributed to genetic disorders or congenital malformations such as spina bifida, Dandy Walker malformations, or premature birth while acquired hydrocephalus is a consequence of central nervous system disorders including infections, brain tumours, head trauma, and intracranial haemorrhage. Smith *et al.*² emphasize that over 60% of hydrocephalus cases are caused by infection, typically meningitis.

The prevalence of hydrocephalus is estimated to be 88-175 per 100,000 live births, and is highest in Africa at 145 per 100,000 live births. In Zambia, the prevalence of congenital and infantile hydrocephalus has been estimated to be 0.48 to 0.81 per 1,000 live and still births. Due to the disproportionately enlarged head, the neck of a child with hydrocephalus will eventually not be able to support the head, making sitting and walking difficult. The child is also likely to become blind, deaf or mentally impaired, and may become more dependent in all spheres of life¹.

Management of children with hydrocephalus involves surgical procedure placement of a Ventriculoperitoneal shunt (VPS) which channels the flow of excess CSF away from the brain or spinal cord into the peritoneum, where the fluid can be absorbed and transported to the bloodstream. Caregiving for a child with hydrocephalus can be done by a family member or a designated healthcare provider. However, this can be very difficult, especially for family and unpaid caregivers who tend to experience high levels of emotional stress, depression, intense feelings of fear and guilt, poor health, and socioeconomic hardships.⁵

Despite documented clinical problems associated with hydrocephalus, there is scanty data on the experiences of caregivers for children with hydrocephalus. Therefore, this study set out to explore caregivers' experiences in caring for a child with hydrocephalus at the University Teaching Hospitals in Lusaka, Zambia.

METHODS

Study design:

This was a phenomenological study design using qualitative research methods.

Study site:

This study was conducted at the University Teaching Hospitals (UTH) in Zambia's capital, Lusaka. The UTH is a combination of specialist hospitals covering a catchment population of over 800,000 people. There are 56 wards at UTH, among which are the A-wards (Paediatrics) and D-wards (Neonatal) where children with hydrocephalus are seen. This site was selected because it is the largest referral hospital in the country and covers a large catchment population.

Study population:

The study population in this study included family caregivers of children with hydrocephalus.

Sample selection:

Purposive sampling was used to select study participants using ward registers as sampling frames.

Sample size:

Ten (10) caregivers were successfully recruited and interviewed. This sample size was consistent with the recommendations made by Thorogood and Green who proposed that 5-25 participants is ideal sample size for qualitative studies.

Data collection:

Eligible participants were identified and given adequate information about the study and its purpose. Those who agreed were asked to sign a consent form. The researchers and participants then agreed on an ideal time to conduct the interview in which privacy of the participant and the welfare of the child with hydrocephalus were prioritized.

Data collection was done through face-to-face in-depth interviews using a semi-structured interview guide. The tool included sections for gathering

demographic data of participants such as age, gender, place of residence, etc.; as well as a section for data on emotional, physical and socioeconomic challenges. Responses from participants were recorded using an audio recorder and transcribed verbatim. The researcher also a notepad to take down notes during the interviews. Each interview lasted on average 14 minutes.

Data management and analysis:

Data analysis was done using thematic analysis by coding the data collected; categorizing it; and eventually developing themes which were titled according to the findings. The first step involved familiarization of the data. Second step involved the generation of codes by organizing the data and putting it in an order that was meaningful and systematic. Third, the researcher generated themes after going through the codes created and recognized patterns among the codes. It is possible that one theme may encompass many codes. In the fourth step the researcher reviewed the themes which involved making certain that the themes generated during the third step were essential and represented the data correctly. This required the researcher to read through the data linked to each theme generated so as to compare and ensure that the data supported the themes. The fifth step involved the researcher naming and defining themes. The researcher listed each theme, named it and gave a definition of the themes. This step focused on identifying the meaning of each theme. This helped the researcher to understand the data and determine what each theme meant. In the sixth and final step the researcher did write-up the analysis of the data in a report or dissertation.

All results were presented in narrative form.

RESULTS

Sociodemographic characteristics of participants

Ten (10) caregivers were successfully recruited and interviewed. All participants were female, and in the age group 20 - 30 years. For the children with

hydrocephalus being cared for, six were male while 4 were female. Table 1 below summarizes the sociodemographic characteristics:

Table 1: Sociodemographic characteristics of participants

Participant	Participant's gender	Age (years)	Child's gender
1	Female	30	Male
2	Female	21	Male
3	Female	20	Female
4	Female	23	Male
5	Female	28	Male
6	Female	24	Female
7	Female	29	Female
8	Female	27	Female
9	Female	27	Female
10	Female	27	Female

Generation of themes and sub-themes

From the thematic analysis, the following themes were identified:

Themes	Codes
Psychological experiences in caring for a child with hydrocephalus	Psychological stress Levels of sadness Living with a child with hydrocephalus
Social experiences in caring for a child with hydrocephalus	Treatment by society Family views/utterances
Physical experiences in caring for a child with hydrocephalus	Child's dependence in activities of daily living Lack of adequate amount of rest for caregiver
Economic experiences in caring for a child with hydrocephalus	Necessities to buy Expenses to meet Occupation of caregiver

Psychological experiences in caring for a child with hydrocephalus

Participants reported experiencing stress as a result of caring for a child with hydrocephalus. One participant said:

“It is really hard to care for the child, there are times I start crying as a result of my child's endless crying. I feel the pain more when he cries especially that am the only one taking care of him and my husband rarely hardly helps me or even holding him” (Participant 3).

Another participant expressed sadness at the child's suffering:

“I feel like I made a mistake to have a child sometimes because it's like I've only brought this child on earth to suffer...I pray to God everything gets well sooner because the sadness keeps increasing day by day” (Participant 1)

Another Caregiver stated: it's really depressing and saddening to look at the child worse more caring for him and doing all the activities of daily living for him when at his age of 4 [years], he should be doing some stuff by himself” (Participant 10)

Social experiences in caring for a child with hydrocephalus

Most of the caregivers reported being socially stereotyped because of their child's condition:

“I pray to God My Daughter gets well because our social life at home hasn't been so fine, my husband shouts at me. He feels [I] am the problem, like I used to play around before we got married. Our marriage hasn't been stable” (Participant 9)

“I rarely go outside the house or socialize when am at home because people laugh at me and my child, I am mocked almost every time... it's painful” (Participant 10)

Physical experiences in caring for a child with hydrocephalus

Caring for a child with hydrocephalus posed several

physical challenges for the caregivers ranging from insufficient sleep to exhaustion. All the respondents agreed to having to wake up at least 3 times during the night to attend to the child with hydrocephalus. One of the caregivers stated that:

“I spend almost the whole time of the day taking care of him and I am worried about his outcome in the future...and sometimes I can't sleep before midnight...” (Participant 5)

Another responded added that: “No one touches the child at home so I do everything by myself; feeding the child, bathing the child, nursing him all by myself hence am usually tired and stressed every day” (Participant 3)

Economic experiences in caring for a child with hydrocephalus

One participant responded that:

“it is very costly to care for my daughter because she needs special attention, special food, a special chair, and going to the hospital by taxi twice a week. I am a single mother and it doesn't get any easier...” (Participant 7)

DISCUSSION

The aim of this study was to investigate the experiences of caregivers in caring for children with hydrocephalus at the University Teaching Hospitals. All of the participants were female in the age group 20-30 years. This finding reaffirms the observation that women are the primary providers of care for children. This female predominance in gender could present bias and not be representative of the views and experiences of male caregivers. It is the researchers' view that incorporating mothers or other female caregivers in the rehabilitation is likely to guarantee continuity of rehabilitation beyond the healthcare facility as women tend to spend more time at home.

In our study, participants reported having feelings anxiety, sadness, stress and depression as a result of caring for a child with hydrocephalus. A number of studies have found that having a child with

hydrocephalus can have detrimental psychological effects including low esteem, self-blame, negative perception and rejection by the spouse, as well as negative perception by the community. This stress could be attributed to a number of factors such as not knowing what will happen to the child; whether or not they are going to live a normal life; how long the shunt will stay in place, etc. In one of their recent reports, the Ministry of Health in Zambia has identified caregivers of children with disabilities to be at risk of clinical depression and emotional stress.⁴ The implication of this finding is that there is need to develop and strengthen systems that provide psychological support for caregivers of children with disabilities including hydrocephalus. This can be done through hospital-based or community-based counselling services. In the long run, the benefits of such support services will be three-fold: to minimize risk of clinical depression; to maximize caregiver well-being; and to increase the potential for more positive outcomes of the rehabilitation.

Participants in our study reported experiencing social stigma and discrimination on account of having a child with hydrocephalus. Furthermore, our study found that some caregivers did not receive adequate social support from their spouses and in fact were blamed by their spouses for the child's hydrocephalus. This is congruent with studies which found that caregivers for children with hydrocephalus experienced deteriorating social support from their partners, families, friends and society. The necessity to have great support from family, friends and society to care for children with hydrocephalus cannot be overemphasized. It would help to have support groups where caregivers can share experiences and draw encouragement from others as they care for children with hydrocephalus.

Our findings also show that some caregivers experienced cultural constraints and stigma arising from the misconception that children with hydrocephalus were curses in their families and in society. Similarly, a Ugandan study found that due to little knowledge of most society members and

mistreatment of parents of such children, they tend to take these children as curse, or a product of witchcraft. Therefore, they find these children to have no value in the family or society, and so do not see the need to take them for medical attention. This unfortunate finding is a wake-up call to healthcare providers that they need to do more to sensitize parents and communities about disability and the services that are available to assist children born with disabilities including hydrocephalus. In our settings, this can be done through awareness campaigns at antenatal visits; during under-five clinic visits; in schools; in mass and social media; and in other community engagement initiatives.

In terms of physical experiences, our study found that caregivers for children with hydrocephalus often experienced tiredness, fatigue, and weakness due to being awake for long hours without having adequate rest. Ogunleye *et al.*⁵ reported similar findings that caregivers tend to be often tired and stressed especially in most African settings. However, this finding is in contradiction to that of Oti-Boadi¹² who established that caregivers are usually helped and maximally assisted in caring for children with special needs, and so they get to have maximum rest and not always tired. The discrepancy in these findings could be attributed to differences in the settings in that in developed countries, children with special needs are cared for by hired caregivers whereas in poor countries most families cannot afford to pay for care giving services. In addition, most caregivers who also happen to be female end up losing spouse and family support. This means that the caregivers have to do a lot of extra work which may result in physical exhaustion. Extending support to caregivers through public, private or faith-based organizations during the day can be very helpful to help caregivers have enough rest even when they are disturbed in the night.

Our study found that caregivers experienced financial constraints in caring for children with hydrocephalus and this emanated from needs such as paying hospital bills, transport to and from the

hospital ,buying food and other items during their stay in the hospital, and other special needs. This in line with findings of previous studies which concluded that caring for a child with hydrocephalus comes with financial difficulties as these children tend to have complex care needs such as extra medical attention, equipment, technology, devices, medications, specialized therapy services, and in some cases modifications of the family home ^{10,16}. Furthermore, existing literature shows that having a child with a disability interferes with the caregivers ability to get employed, thus exerting a lot of pressure on finances. It is crucial that public- as well as private-financed social welfare programmes are implemented in order to empower caregivers of children with special needs and reduce the financial burden associated with caring for these children.

CONCLUSION

The findings of the study reveal that caregivers for children with hydrocephalus experience a great deal of psychological and socioeconomic challenges in caring for their patients. These experiences ranged from emotional distress; sleep deprivation; social alienation; to economic impoverishment associated with needs and expenses of caring for a child with hydrocephalus. The results also highlight the need for rehabilitation programmes that do not only focus on neuromusculoskeletal improvement of the child but also provide holistic support to caregivers.

What is already known on this topic:

- Functional, technical and quality of life challenges of living with hydrocephalus

What this study adds:

- This study highlights the need for a holistic support programme for caregivers owing to the various challenges they experience
- This study also adds to the body of knowledge on physiotherapy practitioners' perceptions and attitudes towards mental health

Study limitation

The study notes the following limitations:

- The study was conducted during the Coronavirus (COVID-19) quarantine period. Therefore, eligible participants were not readily available at the hospital unless for emergencies or critical conditions
- The female predominance in respondents could have resulted in the findings not being representative of the views and experiences of male caregivers
- Interviews lasted about 14 minutes on average. Longer interviews could have allowed for deeper insight into respondent's experiences

Recommendations

The study makes the following recommendations:

1. Development of and inclusion into holistic support services for caregivers of children with hydrocephalus such as financial empowerment opportunities to help alleviate the financial burdens associated with caregiving; social support groups in the communities or at health facilities for caregivers; and more sensitization and awareness campaigns to demystify hydrocephalus in communities
2. Further studies to explore differences in patient outcomes between those care for by family members and those cared for by hired caregivers
3. In future, wider studies with longer interviews could be done to help gain deeper insight into respondent's experiences beyond the context of our settings

DECLARATIONS

Ethics approval

Ethics approval for the study was granted by the Lusaka Apex Medical University Biomedical

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Conflicts of interest

Authors declared that they have no conflicts of interest

Competing interests

Authors declared that they have no competing interests

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Authors' contributions

Nancy Malekani – principal investigator, drafting of results section of manuscript

Matildah Mwape – research supervisor; drafting of methodology section of manuscript

Fair Banji Mwiinga – research supervisor, overall drafting and editing of manuscript

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