BRIEF REPORTS

Differences in Malaria Prevention between Children with and without a Disability in the Upper East Region of Ghana

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ABSTRACT

Purpose: *Malaria is a common cause of death among children with a disability in Ghana. This research aimed to find out whether there are differences in malaria prevention measures given by caretakers to children with and without a disability – under 15 years of age – within one family, in the Upper East Region of Ghana.*

Methods: *Semi-structured interviews were conducted with 19 families who had both a child with and without a disability. Snowball sampling was used to locate the families living in both rural and urban areas. They were interviewed by using a non-validated topic list based on literature. Statements were processed through qualitative data analysis. A malaria professional working at the Bolgatanga Regional Hospital was interviewed for a nurse's perspective on the subject.*

Results: *Caretakers with some education knew more about malaria and malaria prevention measures than uneducated caretakers. None of the caretakers in rural areas had any education and they had limited knowledge about malaria. All the children in this study received some form of prevention from their caretakers, but it was not very effective. In the rural area there was a difference in the incidence of malaria among children with and without a disability. The malaria professional's perspective was that children with a disability are more vulnerable despite receiving the same prevention and treatment as other children.*

Conclusions: *Almost all the children within one family received the same malaria prevention measures from their caretakers, but it was not always as*

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effective as required, especially in the rural area where the incidence of malaria was higher among some of the children with a disability.

Limitations: *Some of the study limitations are the use of translators, the discussion of sensitive subjects and the possibility that socially desirable answers were given.*

Key words: *Developing countries, West Africa, disabilities, malaria, Plasmodium falciparum, treated mosquito net*

INTRODUCTION

According to the World Health Organisation (WHO, 2015a), malaria is one of the most common diseases worldwide and remains one of the biggest causes of death among infants, young children and pregnant women in developing countries. The disease is caused by parasites, which are transmitted by infected mosquitoes that most often bite at night. The malaria parasite enters the human bloodstream through the bite of an infected female Anopheles mosquito. Of the four malaria parasites that affect humans, Plasmodium falciparum is the most common in Africa – and the deadliest. Malaria typically results in flu-like symptoms that appear 9-14 days after an infectious mosquito bite. Initial symptoms can include headache, fatigue, aches in muscles and joints, fever, chills, vomiting and diarrhoea; they can quickly progress in severity and lead to death. Among children, fever is the most common symptom of malaria (Johansson, 2007).

The problem is worst in the African Region where an estimated 90% of all malaria deaths occur, and where children aged 5 years and younger account for 78% of all deaths (The World Bank Group, 2016). Malaria incidence and mortality are the highest among children. In malaria endemic areas and those with high malaria transmission, nearly 100 million children under 5 years of age face high risks of malaria morbidity and mortality (WHO, 2016). The importance of malaria is recognised in Goal 6 of the Millennium Development Goals (MDGs) and the Millennium Declaration of the United Nations. This statement forms the basis for the MDG's 8 international agreements to combat poverty and improve health and the environment. The deadline for the goals was 2015 (United Nations, 2015). MDG's sixth goal was Combat HIV/Aids, Malaria and other diseases. Goal 6 is divided into three parts: 'Target 6.C: have halted by 2015 and begun to reverse the incidence of malaria and other major diseases' (United Nations, 2016). There have been some changes thanks to the MDGs. Between 2000 and 2015 the substantial

expansion of malaria interventions led to a 58 % decline in malaria mortality rates globally. Since 2000, over 6.2 million deaths from malaria were averted, primarily among children younger than 5 years of age in Sub-Saharan Africa. Due to increased funding, more children are sleeping under insecticide-treated bed nets in sub-Saharan Africa (UN, 2016) The number of reported confirmed malaria cases in Ghana in 2013 was 1.639.451 (WHO, 2015), out of 25,9 million inhabitants (The World Bank Group, 2016). Ghana is in the top ten of most reported confirmed cases (WHO, 2015b).

Worldwide there are more than 600 million people who have a disability, of whom approximately 80% live in low-income countries (Ghana Federation of Disability Organisations, 2008). According to the World Health Organisation (WHO, 2011), 'Disability' is an overarching term and covers impairments, activity limitations, and participation restrictions. 'Disabilities' can be defined as a problem in the body function or structure that can be a constraints experience for an individual in carrying out tasks and actions. As a result an individual can experience negative involvement in life situations. The situation is complex, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers (WHO, 2011).

In most developing countries, including Ghana, people with a disability constitute an impoverished marginalised group, characterised by lack of access to public health, education, and other social services that would ideally support and protect such people. Economically, as well as in social terms, people with a disability in developing countries are classified among the poorest of the poor (ILO, 2004).

At present there is insufficient information about the relationship between malaria and children with disability. People with disability lack access to public health. It is not known whether children with a disability are more vulnerable to malaria due to lack of malaria prevention measures, in comparison to children without a disability in Ghana.

Objective

This study aims to provide information about differences in malaria prevention measures given by caretakers to children with and without a disability – under the age of 15 years – within one family, in the Upper East Region of Ghana. Based

on this, the local NGO Nurses on Tour can make adjustments in their Malaria Prevention Programmes to fulfil their mission to reduce the incidence of malaria in the area.

METHOD

Setting

The Upper East Region of Ghana had a total population of 1.046.545 in 2010, according to the Ghana Statistical Service (2010). Bolgatanga, the capital, is the largest city in the region. Within this urban area, a distinction can be made between central Bolgatanga and other parts of the city. The rural area of the Upper East Region is a large collection of little villages.

Study Design

This study was a peer-reviewed original research article, qualitative in its design.

Study Population

The study population comprised 19 caretakers of children (3–14 years old), with and without a disability, and 1 nurse who worked at the Regional Hospital of Bolgatanga, which serves both urban and rural areas in the Upper East Region.

Every family in this study had at least one child with and one child without a disability. The children with disability in this study were all under 15 years of age. The children without a disability lived in the same house/compound as their siblings with disability.

Data Collection

Some of the local employees of NOT, an NGO, and inhabitants of Bolgatanga knew families which had a child with a disability. A local employee took permission from the head of each family before the interviews. Through snowball sampling more families were located and interviewed. One of these families mentioned a school for children with a disability: the St. Charles Unit for Special Needs Children. The director of the school gave permission to approach the children's caretakers and a few of them were willing to be interviewed. In total, 11 interviews were held in the urban area of Bolgatanga.

By joining both a distribution and evaluation programme of NOT, it was possible for the study population to include 8 families who had a child with and without a disability, living in the rural areas of the Upper East Region. NOT asked the chief of the villages for permission to conduct the interviews and received oral consent. After the families were located, permission was taken from the heads of the families. All interviews are held in a private environment and conversations were recorded after the caretakers gave oral consent. A translator was only used in cases where the caretakers did not speak English. A non-validated topic list was used for semi-structured interviews. The topic list was based on literature, discussed with NOT, and it went through an iterative process during data collection. The interviewees were asked a number of closed-ended questions that focussed on obtaining background information, and open-ended questions that focussed on the kind of disability, knowledge about malaria, its incidence and prevention. Interviews lasted approximately 15 minutes. At the end of every interview, all prevention measures were observed and recorded in a memo. For greater reliability, all the interviews were translated a second time by another translator. The saturation point in the urban area was achieved with 11 interviews. In the rural area the data displayed a broad picture of variation.

To get a nurse's perspective, a professional nurse with a certificate in Paediatric Nursing, working at the Children's Ward of the Regional Hospital of Bolgatanga, was interviewed. She had worked among young clients with malaria for many years. Consent for the interview was given by the Research Committee of this hospital and by the nurse herself. The interview took place in the hospital. All the participants remain anonymous and permission from an Ethics Committee was not required.

Data Analysis

Recorded data was transcribed and encrypted by one researcher and was checked by a second researcher. The statements given by the interviewees were entered in Microsoft Excel and coded according to the main topic, using open coding.

RESULTS

Interview participants were caretakers of at least one child with a disability, under 15 years of age, and one child without a disability. Families from both rural and urban areas in the Upper East Region were included, as well as children of both sexes. Every kind of disability or health problem was accepted

in this research, as long as it matched the definition from the World Health Organisation (2011).

The average age of the children with a disability was 11 years (range from 3-14 years), with about the same number of male and female children (Male: 10, Female: 9). Eleven of the 19 interviews took place in the urban area, the remaining 8 in the rural area. Most of the children with a disability (12) were not going to school, 5 were school-going and 2 were attending Education for Special Needs. All the children without a disability in this study were school-going (Table 1).

Table 1: Demographics of Children with and without a Disability within one Family

Variable	Urban (N=11)	Rural (N=8)	Total (N=19)
Age in years			
Average (range)	8 (3-14)	8.5 (5-14)	11 (3-14)
School, child with disability			
Not going	5	7	12
Normal school	4	1	5
Education for Special Needs	2	0	2
School, child without disability			
Not going	0	0	0
Normal school	11	8	19
Malaria incidence, child with disability			
No malaria incidence	1	0	1
Less than five times	8	4	11
Between five and ten times	0	1	1
More than ten times	2	1	4
Unknown	0	2	2
Malaria incidence, child without disability*			
No malaria incidence	1	0	1
Less than five times	0	5	5
Between five and ten times	0	1	1
More than ten times	1	0	1
Unknown	9	2	11

*The child without a disability who contracted malaria most often, besides the child with the disability, within one family

Table 2: Demographics of Caretakers of Children with a Disability

Variable	Urban (N=11)	Rural (N=8)	Total (N=19)
Education of caretaker			
No education	7	8	15
Primary and/or secondary school	3	0	3
College	1	0	1
Work of caretaker			
Employed	6	4	10
Unemployed	5	4	9

Perspective of Caretakers in the Urban Area

Findings from the qualitative interviews showed that caretakers with education (Table 2) knew more about malaria and malaria prevention, compared to uneducated caretakers. All the caretakers knew that malaria is caused by a mosquito/mosquito bite. Other causes were mentioned, such as dirty environment, cold temperature, dirty water and God. Besides, some participants mentioned words like 'infection', 'malaria is bad', 'slow killing' and 'killer disease'.

Most of the caretakers mentioned that body warmth/heat or fever is a symptom of malaria. Almost half of them mentioned that body weakness, vomiting, headache, body pain and loss of appetite are symptoms as well. Some mentioned symptoms such as feeling cold, yellow urine, shivering, weakness in the veins, feeling sick, body stress and bitter taste of the mouth.

One educated caretaker, who went to college and is a Pastor, gave an extensive description of the symptoms: *"Actually, at times you'll find that your body is hot (...) you have a lack of appetite (...), you look very weak. You are just helpless. (...) At times you have dizziness and you'll get high blood sugar. And that can disturb your brains and you look as if you are almost insane."*

Malaria Prevention

All the children, both with and without a disability, received malaria prevention measures from their caretakers. Almost all of them used to sleep under a treated mosquito net (TMN). One participant explained that there were not enough TMNs available for everyone to sleep under every night. Another caretaker used incense and not the TMN because of the heat. Two of the participants had only

damaged TMNs. A small group of caretakers used to clean their surroundings, bathe their children well and/or use incense to prevent mosquitoes from biting. One of these groups did not let their children play near water, and one used to make the children wear long clothes in the evening.

Almost all children with a disability received the same prevention measures as their siblings; only one child used to get something different. This 14-year-old child, with a fuel addiction since he was four, did not sleep under the TMN. His caretaker explained: *"No, this guy is not sleeping under a net because he does not sleep in the night. So I give him the Medisoft Mosquito Cream."* Another child with a disability used to get special food as well as use the TMN to increase his protection against malaria, when the caretaker could afford it.

Malaria Incidence

Although all the children received malaria prevention measures, these were not always sufficient or as effective as needed. Caretakers mentioned that 2 children with a disability suffered from malaria too often to count, 3 got it more than once, and 6 suffered from malaria once or not at all. The reason why some of the children contracted malaria, according to the caretakers, was because there were no TMNs available at that time. They mentioned that ever since they got the TMNs, the children did not get malaria.

Those who continued to suffer from bouts of malaria were contracting it because they did not remain under the TMN, or were being bitten during the day (especially during the rainy season), and/or *"Everybody gets it, so does she"*, as a retired security man explained about his 11-year-old granddaughter. One of the participants said that it was not known why her grandchild, an 8-year-old girl with problems with her speech, left hand and leg, still gets malaria, and suggested, *"Maybe because of the disability?"*

Perspective of Caretakers in the Rural Area

None of the caretakers in the rural area of the Upper East Region had any education, and most of them had no knowledge about malaria, the causes and/or symptoms. A few did not know anything at all about malaria. Some caretakers knew that malaria is caused by a mosquito bite. One caretaker explained that he did not know what malaria was, but if one did not clean one's environment it could cause the mosquito to bite. Other reasons given were not sleeping under a

TMN and a dirty environment. Another caretaker said that besides the mosquito bite, *"stagnated water and eating food you are not supposed to eat"* could cause malaria. This caretaker had no knowledge about symptoms, but said that changes in urine and body weakness are signs. Two other participants mentioned that they did not know any of the symptoms of malaria. The remaining caretakers said that feeling cold, body warmth, body weakness, vomiting, headache, body pain and loss of appetite are symptoms.

Malaria Prevention

All the children with a disability were getting the same preventive measures as the other children in their families, but these were not always sufficient or as effective as required. Five caretakers explained that they did not know what precautions to take for themselves, but four of them mentioned that they were using a TMN every night. The reason for its use varied. One said that it was given by a hospital, another said it was given to prevent fever, and two used it to prevent mosquitoes from biting because, *"Mosquito bites will make you sick"*.

One participant, who used the TMN every night, only did so during the rainy season because it was too hot to sleep under it during the dry season. This caretaker did not mention prevention measures.

Drinking boiled leaves, cleaning the surroundings, drinking water that is kept well-covered and burning herbs or leaves to keep away the mosquitoes, were measures used by other caretakers to save themselves from contracting malaria. Those who were burning leaves/herbs explained that this was not effective as there is not enough smoke and the fire tends to die out.

Malaria Incidence

In the rural area there is a difference in the malaria incidence between children with and without a disability. Some caretakers did not know how many times their children had contracted malaria, some children with a disability suffered from it more often than children without a disability and vice versa, and sometimes there was no difference. Two of the caretakers who did not mention prevention measures for malaria, did not know whether their children had ever suffered from the disease. One participant explained that the child with a disability got malaria only once, while the sibling got it twice. Some caretakers mentioned that children with a disability had a higher malaria incidence compared to their siblings. One caretaker said that the child with a disability, the last-born, suffered from malaria

at least 7 times and the remaining six children without a disability only suffered from it once in a while. She could not think of any reason: *"I'm trying all that is possible by providing mosquito nets and making sure the surroundings are clean. But I cannot relate why he still got malaria."* Another last-born child with a disability contracted malaria more than 10 times, while the other seven siblings got it less than 10 times. According to the caretakers, the reasons for these findings were: burning of the leaves was not effective and powerful enough, the children were not under the TMN for the whole night, and there was the habit of sitting outside before going to bed. One of the participants said that it was not known why the child with a disability still gets malaria: *"Maybe because of the disability?"*

Perspective of Health Professional

According to the nurse, children with a disability are more vulnerable than their siblings. Depending on the kind of disability, they are more at risk of getting diseases and complications because of mobility problems, more exposure to danger and their system not being as strong as that of children without a disability. Besides, the nurse mentioned that these children are disadvantaged in comparison to children without disability. In the hospital, children with and without a disability get the same vaccinations and their caretakers get the same education about how to prevent malaria. They are told that the child must sleep under a TMN, that they must let them wear long clothes, clean their environment well, cover their water in the house and not get out of the TMN before 6 am. The Degree nurse felt that parents offered the same protection to all their children, whether with or without a disability. A large number of the caretakers made use of mosquito cream, wood incense and a TMN, but could still experience problems.

DISCUSSION

This qualitative research yielded valuable insights into the use of malaria prevention measures by caretakers of children with and without a disability. In Africa, malaria is one of the biggest causes of death among infants, young children and pregnant women (Fuso and Mwabu, 2007; The World Bank Group, 2016; WHO, 2016). In this research, most of the children with and without a disability had suffered from malaria at least once. Some had even contracted it several times every year. This shows that malaria continues to be a common disease in the Upper East Region of Ghana.

According to the Ghana Federation of Disability Organisations (2008), people with disability are a marginalised group characterised by lack of access to public health, education, and other social services. As this research showed, a majority of the children with a disability do not go to school, while their siblings usually do.

Results indicate a relationship between the education of the caretakers, the knowledge they have about malaria, malaria prevention measures, malaria incidence and the area they live in. Findings showed that almost all the caretakers were not educated; those who were educated knew more about malaria. Especially in the rural area, where there were no educated participants, knowledge about malaria was low. This may have resulted in the non-usage of prevention measures and could be the reason for children in the rural area contracting malaria more often than their peers in the urban area. Some of the participants in both urban and rural areas seemed to have knowledge about malaria, but some of the answers received, even from those with education, were incorrect when compared with symptoms mentioned by Johansson (2007), namely: headache, fatigue, aches in muscles and joints, fever, chills, vomiting and diarrhoea. Although all children but one received malaria prevention, most of them contracted malaria because of the ineffectiveness of the measures used. In the urban area, the use of more effective prevention measures resulted in lower malaria incidence among the children with a disability. In the rural area there was diversity in the malaria incidence among children with and without a disability. Half of the children with a disability, who were the last-born in their families, contracted malaria more often than their siblings even though the same preventive measures were followed. This could be because of the kind of disability they had.

To reduce socially desirable answers concerning this rather sensitive subject, every interview started with an introduction and closed-ended questions. Besides, the interviews took place in the interviewee's living area, which provided a safe environment. The most sensitive subjects were discussed by asking open-ended questions, by probing and by repeating questions during the interview.

To increase the reliability and the validity of this research, several interventions were employed. A second translator translated every interview to contribute to reliable data collection. To reduce mistakes during the data analysis, a second researcher tested and adjusted the analysis of the first researcher. Using memos and recording every interview minimises the bias of this research.

Limitations

This study had several limitations that could have influenced the results. A translator from Nurses on Tour translated the English questions into the spoken language of the participants. Three of the participants spoke English so no translator was required for their interviews. In hindsight, questions can be raised about the skills of the first translator who participated in a few of the interviews. Another independent translator, not connected to the NGO, listened to the recorded interviews and translated them once more to get reliable answers. For the other interviews, another translator was used. Most of the interviews took place out-of-doors; this may have influenced the quality of the recordings. The second translator was unable to hear some of the given answers and could not translate them. This data was not used for further data analysis.

A newly developed topic list, based on literature, was used as a measurement for the interviews. It went through an iterative process. The first interviews were conducted with a different topic list from the last ones. Although interventions were employed to reduce socially desirable answers from the participants, there is the possibility that these may have crept in.

Due to lack of time the saturation point has not been achieved in the rural area, though there is a great variation in data available. Literature studies showed no previous research done on the relationship between malaria and children with a disability, therefore a comparison could not be made.

CONCLUSION

This qualitative study aimed to provide knowledge about the differences in malaria prevention measures provided by caretakers, to children with and without a disability – under the age of 15 years – within one family, in the Upper East Region of Ghana. This study indicates that almost all children in one family, whether with or without a disability, received the same malaria prevention measures from their caretakers. The prevention they received was not always as effective as needed, especially in the rural area, which is reflected in higher malaria incidence according to the caretakers. Overall, participants with some education had more knowledge about malaria and malaria prevention in comparison to uneducated participants.

Implications

No reason was found for the frequent susceptibility to malaria among some of the children with a disability as compared to the children without a disability,

even though they received the same malaria prevention measures. However differences were seen in the malaria prevention measures followed in urban areas as compared to rural areas. Further research is recommended along both these lines.

To reduce the incidence of malaria in the Upper East Region, maybe even in Ghana, the NGOs and the government must spread more information about malaria and preventive measures. Findings of this study showed a lack of knowledge on the subject.

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