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CASE STUDY

Health-seeking by caregivers of children with a disability in two communities in the Ashanti Region, Ghana

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This case study comprises an exploratory qualitative study of health-seeking behaviour of caregivers of children with disabilities in Ghana. It reflects on the role that primary caregivers play in the first line of care, and the issues and concerns they face navigating the service system. Four individual cases of children with disabilities and a general description of the situation in two communities in the Ashanti Region are presented. The cases indicate that primary caregivers are the main actors in the health-seeking process because they can identify the child's disability and consequently play an active role in seeking health care. In the cases considered here, primary caregivers comprises an aunt and uncle, two sets of parents, and a grandmother. In three out of four cases, caregivers were engaged in a time-consuming and costly search for treatment, using spiritual, herbal and biomedical health services. In none of the cases did they receive adequate diagnosis and treatment. Extended family members, community members and different practitioners play an active role in giving advice to primary caregivers about which type of services to access. School attendance, and education more generally, were seen as beneficial for children with a disability for stimulating development of skills and fostering social inclusion in the absence of rehabilitation facilities and special education. However, primary caregivers often encounter financial and attitudinal barriers when trying to access education. To help address some of the issues highlighted here, tentative recommendations for policymakers and professionals working in the field of child disability in low resource settings are provided.

Keywords: health-seeking behaviour; children; disability; parents; caregivers; Ghana

Introduction

The United Nations Convention of the Rights of Persons with Disabilities (UNCRPD) elaborates the rights of person with disabilities and sets out a code of implementation in 166 countries that have ratified the agreement. The UNCRPD underlines that disability is not a health issue that needs to be treated, but persons with disabilities have the right to health services, including rehabilitation services required to manage disability-related health issues.

Early detection and adequate support and interventions can be of great importance to help prevent a minor disability from becoming more severe, especially during childhood (Figueiras et al., 2012; Scherzer et al., 2012). The World Health Organization (WHO) has advocated community-based rehabilitation (CBR) as the main strategy to achieve rehabilitation of persons with a disability in resource-poor settings. Biomedical rehabilitation services such as surgery, physiotherapy, provision of prosthesis, speech therapy, behavioural therapy and provision of pharmaceutical drugs and assistive devices used to be at the centre of this strategy. The current CBR Guidelines and Matrix endorse a larger focus on social inclusion, participation and anti-discrimination interventions (WHO, 2010). Some experts are now worried that this expanded focus and the associated shift away from a biomedical perspective to a rights-based approach to disability will threaten early identification, intervention and consequently prevention of severe disabilities in resource-poor settings (Cornielje, 2013; Cornielje & Veldman, 2011; Kuipers & Sabuni, 2016). Knowledge about health-seeking behaviour therefore remains important as a starting point for improving quality of life of children with a disability in these settings.

Ghana adopted a national Disability Act in 2006, and ratified the UNCRPD in July 2012 (Enable UN, 2006). This means that the Ghanaian government is obliged to offer quality rehabilitation services to children with a disability. Despite efforts to scale up these services to meet this obligation, the current capacity is insufficient (Buor, 2004; Kuyini et al., 2011; Tinney et al., 2007). Different estimations on the prevalence of child disability in Ghana are found. The 2010 Population and Housing Census of the Ghana Statistical Service (2013) reports an estimated one to two percent of young people in Ghana have a disability, while UNICEF and the University of Wisconsin (2008) report approximately 22% of all children aged 2-9 years screening positive for disability. Both reports show slightly higher prevalence rates amongst boys. According to the Ghana Statistical Service (2013), prevalence rates are highest in the Upper West and Volta Region, and visual impairments and emotional disabilities were most prevalent amongst both boys and girls. Against this background, it is also estimated that the prevalence of child disability will even increase in low- and middle income countries, such as Ghana, in the 2012-2022 period because of considerable reductions in under 5 child mortality with many survivors suffering developmental delays and other impairments which will not be adequately diagnosed and treated (Scherzer et al., 2012).

Despite considerable literature on health seeking behaviour of parents of children with malaria, fevers, and tuberculosis in sub-Saharan Africa, health seeking behaviour for disability is hardly investigated. However, recent studies on the accessibility of biomedical healthcare in the Kumasi Metropolis, Ghana, reveal that adults with a disability face significant barriers when accessing biomedical health care services. These barriers include financial barriers for 94% of the study population (despite membership of the National Health

Insurance Scheme), negative attitudes of health care personnel, and a lack of knowledge about treatment options and self-stigma by the adults themselves (Badu et al., 2015/ 2016; Mensah, 2015). Stigma and discrimination of persons with disability in Ghana is largely documented (Avoke, 2002; Baffoe, 2013; Slikker, 2009). Given the recognised dearth of biomedical rehabilitation services for children with disabilities, the constraints that adults with a disability face when accessing biomedical health care services and the current tendency of CBR to focus on social inclusion rather than rehabilitation, it is likely that caregivers of children with a disability rely more heavily on other types of services in these settings.

A qualitative study was conducted in the Ashanti region, Ghana, to examine health-seeking behaviour of primary caregivers of a child with a disability. This paper presents findings and tentative recommendations based on four individual cases that were produced as part of the broader qualitative study.

Methodology

The four cases presented are part of a larger qualitative study on health-seeking behaviour of caregivers of a child with a disability in Ghana. The study was conducted by the author in two neighbouring communities in the Barekese Sub-district of the Atwima Nwabiagya District in the Ashanti Region of Ghana, from March to June 2013.

During the month prior to data collection, the author invested time building relationships in the communities before moving there. This allowed the author to become familiar and accepted in the communities and enabled identification of children with a disability to participate in the study. Contacts with a Community Elder of one of the communities and a Health Promotion Assistant at the regional Health Centre in Barekese were established via a research unit of the Komfo Anokye Teaching Hospital (KATH) in Kumasi. The Community Elder introduced the author in both communities and the Health Promotion Assistant assisted and translated during the recruitment process and interviews.

Preliminary identification of all children with a disability by the author, was attempted by consulting the local chiefs and school teachers, taking community walks together with the Health Promotion Assistant and snowballing over a three week period. Disability was defined to exist when a child had ‘a condition that was seen as disabling by caregivers’ (Singal, 2010). In total, 24 children with a disability were identified and interviewed in the two communities. Caregivers (usually one) of 13 children were interviewed for the study described in this paper.

Semi-structured interviews were held with the parents or current caregivers of 13 children with a disability who participated in the study. Interview questions included: When did you first think that your child had a disability? What, if any, kind of advice did you receive? Who or what was the main influence in your decision to (or not) access a specific type of health care? Interviews were recorded and transcribed verbatim by the author. A digital logbook was kept with notes on observations and informal conversations during the stay (Green & Thorogood, 2009). Open coding (Verschuuren & Doorewaard, 2010) was used to identify themes which were then analysed.

Ethical approval was granted by the Committee on Human Research, Publications and Ethics of the School of Medical Sciences/KATH of the College of Health Sciences, Kwame Nkrumah University of Science and Technology, Kumasi, Ghana. General procedures for qualitative research were followed to ensure confidentiality of the gathered data. The author held an empathetic attitude, good rapport and enclosed personal information to enhance confidentiality, as was described by Corbin & Morse (2003).

Case studies of four children with disabilities

Out of the 13 interviews, four cases were purposively selected, based on the quality and depth of the interview, and variation in the stories regarding type of disability, primary caregiver, interventions pursued including results, and the role of other important people. A summary of each case is presented below. A description of daily family life in the sub-district of Barekese is presented first.

Everyday life and health care options in the sub-district of Barekese

The sub-district of Barekese is slightly hilly and consists of private farmlands and many communities. The two communities in this study had a population of approximately 4,000 and 2,500 inhabitants. The communities were connected to Kumasi, the capital of the Ashanti Region, by several public transport services. It took the author approximately 1.5 hours to reach the centre of Kumasi from the two communities by public transportation. Houses were mostly made from mud bricks and supplied with electricity. Water had to be fetched from a central water point or from one of the wells outside the communities. Family-houses or compounds often housed three or four generations. Few people living in the communities had official employment and most were involved in subsistence farming. Generally speaking, women were responsible for the care of children and preparation of food, besides working on the land or selling goods. Children were given household chores and helped with farming activities to the best of their ability. Most of them (irregularly) attended one of the local public primary or secondary schools. Religion and spirituality played an important role in daily life. Many community members were attending one of the Christian churches and a minority was Muslim. ‘Traditional natural’ or ‘animistic’ religion was also practiced.

Different levels of health care facilities were within reach, although biomedical rehabilitation facilities were not sufficiently available. There was a community-based health planning and services (CHPSs) facility located in one of the communities. This was the most basic health care facility that was part of Ghana's National Health Insurance Scheme. Here, a nurse provided biomedical health services once a week. A regional Health Centre was situated about 45 minutes away from the two communities by public transport. In Kumasi, a governmental, specialized teaching hospital and several special schools and private rehabilitation facilities were available.

A wide range of non-biomedical health care was also offered. Many herbalists lived in the communities and spiritual healing services were signposted along the roads. Ghanaian and Nigerian movies displaying instant healing of disease and disability by a spiritual healer were extremely popular. According to the Health Promotion Assistant, who acted as translator during the study, spiritual healing services were also offered by 'fetish priests' who applied so-called 'black magic', together with herbal remedies, although there was a taboo on these services. It is possible that participants did not fully disclose information about their use of these services.

Case 1: The story of Kwame

Kwame is a boy of 18 years old. His aunt took care of him after his mother died when Kwame was three months old. Kwame has the physical appearance of Down Syndrome, but this was neither confirmed nor diagnosed. He also has delayed motor development and trouble with speaking. The aunt of Kwame and her husband care for him and his five siblings, alongside their own six children. They took Kwame to the district hospital because he could not lift his head in his first year. Medication was prescribed, but did not improve his condition. At the funeral of Kwame's mother, a woman advised the aunt to go to a specific herbal doctor. Kwame's aunt was very worried about his condition so she went to this herbal doctor. Herbal medication was applied. In Ghana, it is common to apply specific herbs to prevent or cure a disease called *'asham'*. *Asham* is characterized by the widening of the head and weight loss of the child during early development. The herbal treatment was paid by the uncle of Kwame. At that time, there was no public transport so Kwame had to be carried on the back of his aunt. Advised by the aunt's daughter, Kwame also went to a prayer centre twice a week, until he was five years old and he was able to walk.

Through a television programme, Kwame's aunt also learnt about the existence of a school for deaf children. When she tried to enrol Kwame, he was not accepted because he did not fit the admission criteria. In a regular primary school, Kwame's motor and communication skills improved and he enjoyed his time there. However, teachers sent him home because of behavioural problems. Enrolment in another special school was impossible because the school fees were too high. Despite the troubles of getting Kwame into school, his aunt feels proud of herself because Kwame is in good health and can independently walk around the community.

Case 2: The story of Kofi

Kofi is a boy of 15 years old. He has a twin brother and they are both attending secondary school. The twins were born in the regional health centre. At birth, one of Kofi’s feet was in a twisted position. His parents thought this was caused by the older son lying on top of him during pregnancy. The health centre made a referral to the teaching hospital. There, Kofi was given an orthopaedic brace. The brace was too tight, so Kofi developed wounds. The orthopaedic brace was removed at the hospital, and the wounds were treated by Kofi's grandfather, a herbalist. The wounds healed but the position of the foot did not improve, so the parents went back for another orthopaedic brace. After some months, Kofi's parents removed the brace and applied hot water, as prescribed by the hospital. After finishing the treatment, no other services were consulted, because the prospect given at the hospital was that the remaining impairment would disappear over the years. In the years after, Kofi’s motor skills developed and he was even playing football. Kofi only experiences severe pains in the leg after heavy activities. The pain hampers Kofi’s attendance at school on those days. Kofi’s parents have not consulted anyone about the pain and do not know what to do about it. Kofi’s parents are worried about the future, because they think that Kofi will not be able to work on the farm. They try to save money so that Kofi can get better education and acquire a job that does not involve physical labour. Kofi is not worried about the future and hopes to become a doctor or a pastor.

Case 3: The story of Ama

Ama is an 18-year old girl. Her mother is around 50 years and has seven children, aged 8 to 23. Ama has epilepsy. It was a coincidence that a herbal doctor was bringing medication for her mother, when Ama had her first epileptic seizure. Ama’s mother and the herbal doctor took Ama outside and her mother screamed for help. Many neighbours came and said that Ama had epilepsy. At first, Ama’s father wanted to conceal the situation and prohibited her mother to take her to any prayer centre. Nevertheless, Ama’s mother decided to do so, because she believed the epilepsy had a spiritual cause. They visited four different centers, but the situation of Ama did not improve. Later on, an extended family member whose grandson also had epilepsy, advised Ama’s mother to use the same type of medication her grandson was taking, and to consult a biomedical doctor. Ama’s mother bought the medication but it did not have any effect. Although she wanted to consult a doctor, there were insufficient financial resources to do so. A couple of years later, an acquaintance advised them to visit a herbal doctor. Ama’s mother consulted this herbalist, applied herbs and followed his advice to avoid certain nutrients. It was again without a result. Once, an evangelical pastor visited the family. He did not know about Ama’s condition. After his prayer, Ama did not have any epileptic seizure for one year.

In secondary school, Ama was bullied because of her epilepsy so she decided to stop going. Since then, Ama helps her mother with household chores. She feels supported by a group of people in her own church that pray for her. In the future, Ama would like to become a pastor.

Case 4: the story of Akua

Akua is a girl of 14 years old who, since she was eleven, lives together with her grandmother. Akua has an intellectual disability: late motor development, and difficulty understanding other people or performing specific tasks. According to the grandmother, Akua's mother has a similar kind of condition, and is homeless in Kumasi. Out of fear for gossiping, the grandmother never sought help for her own daughter. Akua's father, who is living in the same community, does not acknowledge Akua, and ignores her grandmother every time they meet. The grandmother does not know how to support Akua, besides providing care for her. She took Akua to a prayer centre once, but was disappointed with the service: she had hoped to hear more information about a possible cause, referral to another place for treatment or advice on how to care for her. Akua has been going to school since she was seven. The main reason for her grandmother to send Akua to school is to avoid comments from community members.

Analysis of the cases

The health seeking process

The caregivers in these cases often recognized disability-related health issues by the 'strange' or 'different' appearance of the child, as compared to other children. They had sought treatment options from a range of herbal, spiritual and biomedical services, although they had not found diagnosis or successful treatments. Family members, neighbours, acquaintances and even strangers played an important role in suggesting diagnoses and treatment options, like the woman at the funeral of Kwame's mother.

A pattern could be identified in the type of intervention that was pursued, based on what caregivers believed was the cause of the disability: the hospital for clearly physical disabilities, prayer centres for what was perceived as spiritually-caused disabilities and herbalists for both causes. Different types of interventions were sometimes sought after failure of the initial consults. In the described cases, information and advice obtained from all kinds of practitioners was regarded with much respect and trust: caregivers reported to have followed most advice and referrals, varying from applying herbal or biomedical medication to performing prayers, and from applying hot water to dietary advice. The most common reason to *not* follow the advice was a lack of financial resources, or a lack of results in the short or long term.

Efforts made by caregivers to care for the child

Several scientific articles have described negative, discriminative and even violent attitudes of parents towards their own children with a disability in Ghana, leading to neglect, child abuse, abandoning or even murdering of a child (Avoke, 2002; Baffoe, 2013; Munyi, 2012; Slikker, 2009). In the cases presented here, primary caregivers were committed and tireless in their search to improve the quality of life of their child, often facing a taxing, worrisome and expensive health-seeking process. They spoke of the child in a loving way, expressing concern about the children's prospects and access to opportunities. Caregivers also felt proud of the care they provided for the children, and their successes in keeping the children as healthy as possible. Like the aunt of Kwame, who took him and his siblings in and supported them in addition to her own six children, or the ceaseless efforts of the mother of Ama, and the commitment of the father of Kofi to save extra money for his higher education. Only Akua's grandmother did not report many efforts to seek help. The reason for this appears to be a lack of knowledge about available options, and fear of stigmatisation by community members.

Searching for a cure

Except for the case of Ama, the specific diagnosis was not mentioned by the primary carer because an official diagnosis had not been provided. Two of the primary caregivers, namely Kwame's aunt and Ama's mother, were specifically looking for a *cure* for the disability. This could be partly explained by the information and advice or treatments given to them by several, mostly herbal or spiritual practitioners, as well as the popular West African movies showing instant healing of a disability through a spiritual intervention. The significance of local rites and spiritual care or support to many people is made clear in Ama's story. However, this becomes problematic when a particular intervention is harmful or ineffective and keeps caregivers away from effective interventions. Human Rights Watch (2012) and Buor (2004) have signalled the dangerous practices of many traditional and spiritual healers in prayer camps around Ghana. This issue may be compounded by the lack of rehabilitation facilities which incorporate effective diagnostics and interventions for children with disabilities, which leaves much space for possibly ineffective and harmful services to flourish. Furthermore, endless searching for cures can place an excessively high burden on children with disabilities and their caregivers.

Education as a means of rehabilitation

Although not part of the initial research question, school attendance and education more generally emerged from the cases as having the potential to foster rehabilitation of children with disabilities in low resource settings. Kwame, for example, developed his communication skills most when he was stimulated by his peers at school. Kofi's father anticipated the different abilities of his son by putting aside extra money for his study, so that he could prepare for a different job than working on the farm. These examples show some initial indications that access to education can be an important part of rehabilitation in a broader sense by fostering social inclusion and creating opportunities for children with disabilities in their communities, especially when formal rehabilitation services are absent.

Conclusions and recommendations

These case studies have tried to shed light on the health-seeking process. Caregivers' knowledge about, and recognition of child disability, form the starting point for the health-seeking process. Knowledge about child disability is often based on the caregivers' experience with raising other children, and local common knowledge or beliefs. Findings also suggest that perspectives of caregivers, and others in their network, on the cause of the disability, seem to have a large influence on the type of intervention that is accessed.

The study has some limitations because it is based on a small number of cases. More research is needed to substantiate these preliminary findings, possibly employing triangulation of data from key informants and other research methods. The role of practitioners and the quality of their interventions, including biomedical, herbal and spiritual practitioners, should also be explored. Based on these case studies, some tentative recommendations for CBR policymakers and professionals working in the field of child disability in low resource settings are made below.

First, the role of parents and other primary caregivers requires more recognition, partly because of the challenges they are facing but also because of their potential contribution to helping others deal with the same challenges. Primary caregivers could play a valuable role in advising other primary caregivers by involving them in parent groups or other support structures. Second, although most primary caregivers identified the disability of their child by themselves, there is a clear need for timely diagnostics and referral. Although it is important to recognise the limitations of the biomedical model of disability and current levels of knowledge, the case studies seem to indicate the existence of 'false' beliefs about child disability and harmful practices. Third, lack of sufficient rehabilitation services remains a barrier in ensuring early identification and treatment of child disability, and should be continuously addressed in policy making and programme planning. Lobbying and advocacy to local authorities for better rehabilitation facilities could be a valuable additional strategy. Fourth, access to education is a basic human right and a vital element within the development of any child, and could have an additional function within the rehabilitation process of children with a disability. Although inclusive or special education is preferred, this might be unrealistic in resource poor settings where even children without disabilities struggle to have access to school. In the absence of inclusive or special education, efforts should be made to ensure that children with disabilities are able to attend the standard school system.

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