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Background

Mental disorders account for an enormous global burden of disease that is largely underestimated and underappreciated. In a given year, about 30% of the population worldwide is affected by a mental disorder and over two thirds of those affected do not receive the care they need (Chisholm et al., 2007; Kessler et al., 2005b; Wittchen, Jonsson, & Olesen, 2005). About 14% of the global disease burden is attributed to neuropsychiatric disorders, mostly depression, alcohol-substance abuse and psychoses (Murray & Lopez, 1996; Prince et al., 2001).

People suffering from mental health problems very often delay seeking professional help, or avoid it altogether, which in turn significantly compromises appropriate care and treatment (Okello, 2007). Seeking help also appears to be related to the individual's perception of the severity of the illness, with individuals who perceive the illness to be severe feeling more compelled to seek help (Bebbington, 2007). Furthermore, the choice of where to seek help is said to depend on what is believed to be the causal factor of the illness (Okello, 2007).

Mental illness is often believed to be caused by supernatural forces, a significant number of people with mental health problems tend to initially seek and to continue seeking traditional healers' services over western medical help (Abbo C., 2003). As a result alternative practitioners like traditional healers find themselves shouldering a large burden of care of patients with mental health problems.

For these health conditions, the decision to consult a health professional is less influenced by the nature of the illness itself than by a voluntary help-seeking process that often start-off from a traditional medium (Rosenstock, 1979). These health seeking behaviors are deemed to be about communicating with others to obtain assistance in terms of gathering understanding, advice, information, treatment, and general support in response to a problem or distressing experience.

Study Context

The study was conducted in post-war Northern Uganda primarily focusing on Gulu Regional Referral Hospital (GRRH) Mental Health Department clients with neurodevelopmental disorders including autism, Attention Deficit Hyperactive Disorder (ADHD) and learning disabilities. Northern Uganda is recovering from the LRA war and conflict that devastated the region and led to untold suffering to the masses. The study focused on participants from across the region who accessed health support in Gulu Regional Referral Hospital and followed them to their families. Children with neuro-developmental disorders (autism, ADHD and learning disabilities) fifteen (15) years and older were identified and their parents were interviewed. Parents and children were reached at their homesteads and (their parents) were interviewed in a safe and confidential environment.

Methodology

The study utilized an explorative design with an integration of the Health Belief Model. Data was collected through key informant interviews conducted with health professionals and parents of the children aged (6-15 years) with neuro-developmental disorders were recruited from the hospital to participate in focus group discussion, participant observation and individual in-depth interviews.

Study participants were drawn from all parts of Northern, they were randomly selected prior to their visit to access help at Gulu Regional Referral Hospital (GRRH).

Analysis

This pertains to how raw data were chosen, evaluated, and interpreted into meaningful and significant conclusions that other researchers and the public could understand and use. Every interview transcript was filed and analyzed. Manual analysis was used in analyzing the themes of the data generated from Key Informant Interviews (KIIs), Focus Group Discussion (FGD) and In-depth Interview (IDI). The findings of the data analysis were necessary in finding a common ground of discussion. Analyzing involved re-reading the interview transcripts to identify themes that emerged from the respondents' answers during the FGD, KIIs and IDIs. The researcher used the topics and questions in the interviews to organize the analysis, in essence synthesizing the answers to the questions proposed. If the interviews raised more questions than they answered, then more interviews were necessary to properly examine the issue at hand. Verifying involved checking the credibility of the information gathered and a method called triangulation was used to achieve this purpose. Triangulation involved using multiple perspectives to interpret a single set of information. The study used triangulation to examine the sociocultural perspectives of childhood neurodevelopmental disorders and its implications on health seeking behavior and it required the researcher to interview at least three groups of participants: parents of children, health workers and other community members. A simpler way to use triangulation in this study involved two colleagues read and analyze the same set of transcripts, and then notes were compared. The transcripts from interviews were sorted and analyzed into themes and emerging themes were considered in writing the report.

Results

The study found out that stigma extended from children to parents and caregivers who were also shunned by community members. The participants interviewed described their children as "a gift from God" others described them as "a test from God". The communities perceive the disorders as a spiritual infliction and always insisted that the children be taken for Acholi cultural and traditional rituals to cleanse children and they believed that mental illness has spiritual linkages.

While many of the respondents could not explicitly confirm the effectiveness of traditional or cultural remedies, a few respondents who were interviewed mentioned that the traditional remedies worked for them. Nonetheless, it was found out that the reason why many respondents went to traditional healers instead of going to the hospital was due to the complexity and difficulty involved in understanding neurodevelopmental disorders; children were utterly ignored when all remedies failed. Community's perception showed how ridicule, stigma and ostracism that affect the social life of both the parents and the children themselves since parents failed to ascertain the causalities of the mental disorders.

Health workers mainly preferred to offer explanations from a scientific point of view when explaining and articulating the signs and symptoms associated with the disorders; community members on the other hand articulated the disorders from the points of view commonly based on their lay understanding of the disorders including attribution to spiritual entities (goods).

The health workers also emphasized the fact that they have to continuously rely on the parents and caregivers when it comes to treating children with neurodevelopmental disorders, because the children themselves are often not aware of their situations. *"These children do not know the challenges they are going through. And to some of the parents, it takes them a long time to assess what is wrong with the child. In most cases, the children are brought to this hospital in critical conditions when the stages of their sicknesses have gone up. It has not been easy to manage such critical cases"* (Interview with a female Community Health Worker).

They described their children as "a gift from God", others as "a test from God" and others as their responsibility to look after.

Parents admitted that tensions often arose as a result of the children destroying property of neighbors or beating up their children. This places an extra burden on parents to confine their children. Community members were sometimes kind and even sympathetic to the children especially in cases where they (children) were not violent.

"If I had money, I would construct a wall fence around my home and lock him inside the gate so that he would remain inside at all times. I would not allow any other child to come inside" (FGD with parents of children with neurodevelopmental disorders). There is always some level of stigmatization and name calling.

"Ideally nobody would like to have any mental illness in the family, it stigmatizes, it discriminates, so even if there is such a child; they do not come up openly to mention, 'I have a child with this and this', you never hear that because of stigma" (Interview with a Mental Health Officer).

The parents and caregivers noted that the stigmatization unfortunately also extends to the parents and caregivers, who are sometimes shunned by other members of the community.

"I am sometimes mocked by people saying, 'the mother of Ocira is surprisingly beautiful. We thought she was an ugly lady'. People think that when you produce a sick child, you must be ugly. Some say, 'the mother has good manners but has produced a child who is worthless'. So people say all sorts of things (FGD with parents of children with neurodevelopmental disorders).

As a result of the stigma attached to mental health, people have developed the perception that it is contagious, and as a result do not associate with children suffering from mental illnesses. This affects the social relation of the children in terms of play, association and physical development. The communities perceive the disorders as a spiritual infliction and always insisted that the children be taken for Acholi cultural and traditional rituals to cleanse the child. Meanwhile, some of the parents affirmed that they often prayed and held firm their religious belief so as to help support the children. These illnesses are also linked to the spiritual world

"Culturally, they believe these children are cursed by God and only 'jok' can save them. They believe it is due to witchcraft or it is due to evil spirits or Satan and that is why they would persuade the family (...) They would also opt for witch doctors that hold some rituals to 'drive' away the evil spirits. Some people say it is the clan leaders and sects to perform some cleansing; failure of which causes a deformity in the brain of a child" (Interview with a Psychiatric Clinical Officer).

Another perception is to blame the mental illness on somebody who may have ill-will towards the family such as a step mother of a child or a jealous relative.

"We have a strong belief system and we commonly blame either the connotations that some body is cursed, some body is bewitched, some body is possessed - things of the nature. The first inclination is that my child is bewitched; then they first resort to the traditional healers and when they are defeated, they normally come to seek medicine here" (Interview with a Mental Health Officer).

There is lack of a clear referral mechanism in communities. Some were referred by relatives, caregivers (matrons in schools) or local officials such as LC chairpersons, and village health teams. Parents and caregivers who were disappointed with the results at the hospital then turned either to traditional healers or to religious mechanisms offered predominantly by born again churches. Interestingly, while some respondents could not explicitly confirm the effectiveness of traditional or cultural remedies, a few respondents mentioned that the traditional remedies they had sought worked (were efficacious) for them.

Discussion & Implications

Parents described their children as a 'gift from God' while others described them as a 'test from God'. The description of the children as a test further clarifies the burden of care that the parents and caregivers undergo in supporting their children. It is quite differential in the ways a 'gift' and a 'test' are understood because it further shows how decisions to seek health can be determined by these underlying perceptions from the parents and caregivers.

It was found out that stigma to the children suffering from the disorders often extend to their parents and caregivers. Kohrt & Harper (2008) similarly found that cultural beliefs, myths, and misconceptions about mental disorders develop negative attitudes toward mental disorders and those who suffer from it. The communities also resorted to traditional healers instead of going to the hospital due to the complexity and difficulty involved in understanding neurodevelopmental disorders. Wong et al. (2004) confirmed the strong positive relationship between family burdens and distress among caregivers and suggested that culturally specific health beliefs influence the way caregivers experience the family burden of care and that this is related to health-seeking behaviour.

Health seeking trend depended on convulsions onto the children; some depended on the distance to the supportive health unit. Nguyen (2003) and Wagner et al. (2006) postulated in the same way that people prefer to take care of persons with a mental illness in the family, but will bring the patient to a psychiatric hospital if the condition is very severe. Consent and decision making by parents and caregivers are key factors to be considered in the treatment of children. Kleinman (1988:5) as cited in Andrea S. Wiley, John S. Allen (2009) noted that illness complaints are what patients and their families bring to the practitioner. For minors or children, parents or caregivers take the central role in supporting them in deciding where, how and when to seek health support. The families associated mental illness with demons, evil spirits or spiritual haunting. Bussing, Koro-Ljungberg, Gary, Mason, & Garvan (2005), noted that parents interpret their observations of children's behavior based on their own sociocultural and ethnic experience, in combination with what they have been exposed to or taught overtime.

The study recommends demystification of these perspectives to support in ensuring resilience and decision making so as to amplify the needs to address mental health concerns of children and their families affected by neuro-developmental disorders in Northern Uganda and beyond. While some of the participants highly recommended biomedical approaches to prevention, management and control of the disorders, a significant group of respondents mentioned that socio-cultural measures are important in controlling the adverse situations presented by the disorders.

Acknowledgement

The study was also financially backed within the framework of the APPEAR project of the Austrian Development Cooperation. The AfriChild Centre is acknowledged for providing an opportunity to share this piece to a larger audience.