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## Investigation on children with acute non-communicable diseases and their caregivers in developing countries

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### ABSTRACT

**Objective:** To investigate children with acute non-communicable diseases (NCDs) and their caregivers in developing countries.

**Methods:** A cross-sectional survey was conducted in three out of the ten regions of Ghana. A total of 1540 caregivers/parents of children with NCDs were interviewed. Data was analysed with the aid of IBM SPSS version 20. Statistical techniques used in the analysis included frequencies, means, SD and factor analysis. Findings were analysed according to the major themes of the study.

**Results:** Caregivers indicated that the incidence of NCDs among children is on the increase. They also believed that enemies can cause diseases in children. Caregivers tend to seek treatment in hospitals/clinics rather than from traditional or herbal medicine. However, they complement biomedical treatment with prayers for healing/deliverance. It was also found that NCDs have a negative effect on the physical and mental development of children as well as their school performance; and caring for children with NCDs also poses material, emotional and financial burden to caregivers.

**Conclusions:** Serious attention needs to be given to the development and implementation of policies to better the lot of children with NCDs. Conscious efforts need to be made to encourage and assist the caregivers with necessary resources to cater for their children's educational and health needs in particular.

## 1. Introduction

The burden of non-communicable diseases (NCDs) is growing and has now become a major problem in the poorest countries. According to the World Health Organization (WHO),

in 2008 about 36 million deaths were due to NCDs, comprising mainly cardiovascular diseases (48%), cancers (21%), chronic respiratory diseases (12%) and diabetes (3.5%). This constituted 63% of the 57 million deaths globally in 2008. The WHO report also indicates that 80% of all deaths (29 million) from NCDs occurred in low- and middle-income countries. About 48% of the deaths in low- and middle-income countries are premature (under the age of 70 years) compared with 26% in high-income countries. WHO projects that annual deaths from NCDs will increase to 55 million by 2030, if serious measures are not put in place<sup>[1]</sup>.

In the late 2010s concerns were raised that children are at risk of being systematically excluded from the NCD discourse<sup>[1]</sup>. Even though in the past, children suffering from chronic illnesses never lived long to become adolescents, it is no longer so because of improvement in medical technology and treatment methods<sup>[2]</sup>. In spite of available treatments, however, the care of children with NCDs can pose a serious emotional and physical

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The study was approved by the Institutional Review Board of the Noguchi Memorial Institute for Medical Research of the University of Ghana (Study No. 014/12-13). All respondents were informed of the research objectives and were asked to take part in the study. Those who agreed were asked to sign a consent form.

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challenge for the individual or family<sup>[2–4]</sup>. According to Ellenwood and Jenkins<sup>[5]</sup>, it is not unusual for an individual's family members to feel anger, denial, self-blame, fear, shock, confusion, and helplessness once diagnosed with NCD.

Most of the NCDs that affect children and adolescents are usually characterized by an acute phase in relation to the diagnosis of the illness. This is usually followed by prolonged stress because of the extended treatment, recovery, and survivorship. Each phase of the NCD can present children and their families with enormous challenges and stressors<sup>[6]</sup>.

According to Boice<sup>[7]</sup>, NCDs can magnify issues of child development. It can also increase the desire to be socially accepted. Sometimes, NCDs cause children and adolescents to spend more time in isolation than with their peers. Also, children with NCDs are more likely to miss school often. Their intake of medications and the stress related to their illness may also cause them to experience difficulties in concentration and mental functioning. They may also experience more stress compared with their peers. These may manifest in many ways including feelings of incompetence and rejection due to their illness. They may also experience depressive symptoms. Pinquart<sup>[8]</sup> reported that young adults with chronic paediatric illness were less likely to complete higher education, find employment, leave the parental home, marry, and become parents than their healthy peers. A child with NCD may feel different from his peers, and may experience rejection by the peers, which could have detrimental effects on the child's self-concept<sup>[9]</sup>.

According to Millen and Walker<sup>[10]</sup>, society views individuals suffering from NCDs as a burden because of the incurable nature of NCDs. An individual diagnosed with NCDs needs to adapt to negative views of others, the loss of self-esteem which may be the result of social isolation, and sometimes loss of privacy if the individual has to depend on others because of dysfunction of a body part. Also, the individual needs to adjust to the symptoms of the disease, the stress of treatment, changes in structure of the family, financial burden due to the illness, as well as feelings of vulnerability and loss of control<sup>[10]</sup>. The authors thus view individuals with NCDs as experiencing a turning point in their lives since they have to make some adjustments in their emotional, social, physical, and perhaps their vocational lives<sup>[10]</sup>. Other studies indicate that living with NCDs is not just a concern for an individual but also a family affair<sup>[3,11–14]</sup>. Cousino and Hazen<sup>[3]</sup> found that caregivers of children with NCDs significantly reported greater parenting stress than those of healthy children.

Families and individuals may also be affected by the stigmas surrounding NCDs<sup>[15–19]</sup>. In many countries, chronic conditions such as diabetes, cancers, HIV/AIDS, epilepsy and mental illnesses like schizophrenia are stigmatized<sup>[20–25]</sup>. The different types of stigma and their consequences are documented. Actual stigma leads to discrimination or even ostracism of people with chronic conditions. Courtesy stigma leads to discrimination of caregivers and significant others of the chronically ill. Perceived stigma leads to self-imposed socially restricted lives for both the chronically ill and caregivers<sup>[26]</sup>. Murray *et al.*<sup>[4]</sup> highlight a paradox known as the spread phenomenon in which people does not only stigmatize a person's physical differences, but assume that along with the physical differences, there are also some cognitive disabilities<sup>[4]</sup>.

In spite of the availability of community services today, family members are often the primary caregivers for people suffering from NCDs<sup>[27]</sup>. There are however some challenges associated with this role including tension in family relations, struggles with time

management and high medical costs. Social networks may also be disconnected, family activities disrupted, and families may experience difficulties in interacting with the children's schools<sup>[4,28]</sup>. Several areas of family life may also be affected by NCDs including daily routines, careers, financial decisions, friendships, school performance, parenting strategies, sibling relationships and developmental transitions. If these stressors are viewed by the family as unmanageable, or they are unable to obtain supportive resources, the family relationships may be weakened which may further lead to accumulation of the negative effects of stress<sup>[4]</sup>. Murray *et al.*<sup>[4]</sup> also found that in order to cope with their child's NCDs, families often develop a set of rules. Family members who have poor cohesion tend to have higher distress levels, limited access to resources, and face additional crisis<sup>[29]</sup>. However, if families make use of resources available to cope with and negotiate a stressor which is perceived as manageable, they tend to become adaptive and confident.

Studies on asthma, cancer, diabetes, and sickle-cell anaemia in sub-Saharan Africa reveal that experiences are characterised by spiritual distress, depression, psychiatric disturbance, chronic unhappiness and suicidal ideation<sup>[21]</sup>. Even within the context of strong family support, psychological, emotional and spiritual disruptions can occur and often undermine social and medical relationships<sup>[30–34]</sup>. Williams *et al.*<sup>[29]</sup>, however, report that even though families caring for children with NCDs may experience more emotional and physical stress, they may develop resilience and advanced problem solving skills. Long and Marsland<sup>[35]</sup> also note that parents sometimes perceive deeper bonds with their children having NCDs and may even spoil or overprotect them.

In Ghana NCDs are also becoming a major problem, because the cases are increasing. For example, Ghana's leading tertiary health institution, the Korle Bu Teaching Hospital, has a ward named Burkitt's Ward where children with Burkitt's tumours and other types of cancers are treated<sup>[36]</sup>. Many children are now surviving during infancy and early childhood with congenital abnormalities due to the increasing availability of advanced modern diagnostic and treatment technologies<sup>[36]</sup>. However, taking care of them can pose a significant challenge to their parents.

In spite of the fact that the population of developing countries like Ghana are young<sup>[37]</sup>, there has not been any conscious policy direction towards the control of NCDs among the younger population. Until recently, public health policy has largely neglected NCDs in health planning<sup>[38]</sup>. Amoah *et al.*<sup>[39]</sup> indicate that prior to 2005 the health care policy in Ghana placed very little emphasis on the control and prevention of diabetes, mainly because of the dogma that such diseases are rare among Ghanaians. This apathy among policy makers makes the subject of NCDs less researched.

Meanwhile, the high cost of treatment of NCDs makes them a threat to the lives of those who suffer from NCDs as the average Ghanaian may not be able to pay the medical cost for treatment. The absence of coverage of NCDs under the Ghana national health insurance scheme also compounds the problems associated with their treatment. Even where health insurance schemes are available, treatment of some aspects of or all NCDs are excluded under the scheme.

Another major problem for the treatment of NCDs is that, though the biomedical approach to health care has been predominant for many health conditions, including NCDs, there has been evidence that Ghanaians are pluralistic in their health-seeking behaviour. Three main health systems exist and are accessed in the country. They include traditional, modern and

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