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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

faith healing. In traditional Ghanaian societies, NCDs are largely perceived as afflictions by supernatural powers and could only be treated effectively by the traditional and faith healing health systems<sup>[40–42]</sup>. For these reasons some cases of NCDs may not be taken to modern health care facilities or may be taken there at advanced stages when there are already some complications with poor prognosis. Children, who depend on the health-seeking behaviour of their parents or caregivers may become victims of such situations.

Anthropological studies of the various ethnic groups in Ghana provide further insight on attitude to children with NCDs and congenital conditions and how such children may have access to or denied treatment. The studies indicate that among some traditional societies, children with some chronic diseases and congenital defects are considered as the embodiment of “mischievous spirits that masquerade as normal children”<sup>[43]</sup>. Another anthropological report<sup>[44]</sup> indicates that children with congenital deformities are considered as ancestors who are reincarnated. They must therefore be given special care to avoid any afflictions that may be sent by the ancestors as a result of the neglect of the child.

In contemporary Ghanaian society, attitude to NCDs among children and associated health-seeking behaviour by their parents also reflect some of these traditional practices and beliefs. A study by Badasu<sup>[36]</sup> on NCDs and congenital conditions in the Children's Ward at the Korle Bu Teaching Hospital shows that parental and/or caregivers' attitude to the NCDs and subsequent health-seeking behaviour was largely determined by several socio-cultural factors as well as financial affordability for the cost of treatment. The mothers who were mostly the caregivers (forming 95%) were working in the informal sector with no employment insurance, but contributing to their family budget. As the mothers are in the health facility to care for the sick child, they suffer loss of earnings from their economic activities. This is indicative of the possibility that some children may not be availed for treatment in such health facilities if the cost is too high for their parents. Thus, NCDs among children place a heavy burden on families, health care systems, and society at a large extent. Yet not much study has been done on NCDs among children.

A review of the literature reveals that studies on the effect of NCDs on children or their families/caregivers, especially in developing countries are lacking. This study therefore seeks to fill this gap by first developing a scale to assess caregivers' attitudes and health-seeking behaviour for children with NCDs in developing countries, followed by an analysis of the responses of caregivers based on the scale, using descriptive statistics.

## 2. Materials and methods

### 2.1. Study setting

The study was conducted in three out of the ten regions of Ghana: Greater Accra, Ashanti and Volta regions. The regions were selected by considering the major ethnic groups and the types of economic activities prevalent in the respective regions, so that the socio-economic factors influencing health-seeking behaviours of the various ethnic groups could be captured. Greater Accra region is the predominant settlement of the Ga-Adangme ethnic group. Being a coastal region, many of the indigenous people are fisher folk. However, by virtue of being the national capital, Accra also has a lot of people from various parts of Ghana, engaged in trading and industrial activities.

Ashanti region is the predominant settlement of the Akan ethnic group. The region is in the middle portion of Ghana and the indigenous people are engaged in farming cash crops such as cocoa and timber. Much of the minerals extracted in Ghana such as gold and bauxite is in the Ashanti region. However, Kumasi is the next cosmopolitan city in Ghana after Accra. Therefore many people from all over Ghana are engaged in commercial activities in Kumasi. The Greater Accra and Ashanti regions were selected because Ghana's leading tertiary hospitals, Korle Bu Teaching Hospital and Komfo Anokye Teaching Hospital, to which most cases of NCDs are referred, are located in these regions. Volta region is the predominant settlement of the Ewe ethnic group. Two communities were selected from each region, a rural and an urban community.

### 2.2. Ethics

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.

### 2.3. Study design

We conducted a cross-sectional survey on 1540 members of various communities in Greater Accra, Ashanti and Volta regions. We interviewed 600 individuals each from Greater Accra and Ashanti regions, and 340 people in the Volta region. The inclusion criteria were parents or caregivers 18 years old and above whose children/wards were having or ever had a NCD. Caregivers whose wards were suffering from communicable diseases were not included.

### 2.4. Sample size determination

The sample size was determined using OpenEpi Version 3, open source calculator-SSPropor. It was based on the following formula:

$$n = deff \times \frac{N\hat{p}\hat{q}}{1.96^2(N-1) + \hat{p}\hat{q}}$$

where,  $n$  = sample size,  $deff$  = design effect (used in cluster surveys),  $N$  = population size,  $\hat{p}$  = the estimated proportion,  $\hat{q} = 1 - \hat{p}$ ,  $d$  = the hypothesized % frequency of outcome factor in the population.

Since the respondents were community members, it was expedient to determine the sample size from the population of the communities interviewed in each of the three regions, but this was difficult to obtain. However, OpenEpi calculator permits a default population of 1000000 as the maximum population size to determine the largest sample size. The hypothesized % frequency of outcome factor in the population provides an educated guess of the percent of the population with the outcome of interest. In this study the outcome of interest was health-seeking behaviour of caregivers with children suffering from NCDs, represented by any response related to health-seeking behaviour. Since respondents were supposed to be contacted personally in the communities for interview, the study adopted 70% as the hypothesized frequency of responding to questionnaire on health-seeking behaviour. With the hypothesized frequency of 70% and confidence limits as  $\pm 5$ , the confidence interval would be 70%  $\pm$  5%, that is 65% and 80%.

Based on these specifications, the sample size generated by OpenEpi calculator for the study was 646. However, for convenience and the possibility of non-response, a sample size of 700 was used. We decided to interview 700 caregivers each in the Greater Accra and Ashanti regions where the teaching hospitals were located, and where many community members are expected to be aware of NCDs by virtue of proximity to the teaching hospitals. However, we decided to interview 350 caregivers in the Volta region where community awareness may be less. The total sample size determined was therefore 1 750 for the three regions. However, 600 caregivers each were interviewed in Greater Accra and Ashanti regions, and 340 were interviewed in the Volta region, giving an actual total sample size of 1 540, representing 88% response rate. The sample was divided equally between the rural and urban communities in each region.

### 2.5. Sampling method

We employed snowball sampling to select caregivers in the selected communities in the three regions whose children were suffering from various types of NCDs for interview. We relied on community members and caregivers that we have already interviewed to help us identify persons within the community whose children were suffering or ever suffered from NCDs.

### 2.6. Data collection

The questionnaire used in data collection was divided into two sections. Section one was on socio-demographic characteristics and section two was on attitudes and health-seeking behaviour of caregivers of children with NCDs. After a thorough training of field supervisors and research assistants, the questionnaire was pretested on 20 caregivers whose children were suffering from NCDs in one community in Accra. After the pretesting the questionnaire was further refined before the actual data collection. Data was collected from 12th to 30th January, 2013. On average, approximately 10–15 caregivers were interviewed per day in each community within a region. We interviewed the caregivers after they had given informed written consent. Interviews were conducted by field workers recruited and trained by the Regional Institute for Population Studies in the University of Ghana, Legon.

### 2.7. Data analysis

Data was analysed with the aid of IBM SPSS software, version 20. Descriptive statistics such as frequencies were used to describe the distribution of socio-demographic variables. The variables describing the effects of NCDs on children and caregivers were subjected to factor analysis to identify distinct components describing the various effects. The sub-items of the various components were then described using mean, SD and frequency distributions.

## 3. Results

### 3.1. Socio-demographic characteristics of respondents

Table 1 presents the results of the socio-demographic characteristics of respondents.

Table 1 shows that female respondents constituted 987 (64.1%) out of 1 540, while males constituted 553 (35.9%).

**Table 1**

Socio-demographic characteristics of respondents.

Variable	n (%)	
Gender	Male	553 (35.9)
	Female	987 (64.1)
	Total	1 540 (100.0)
Educational status	No education	220 (14.3)
	Primary	244 (15.8)
	Middle/junior high school	596 (38.7)
	Senior high/vocational/technical school	347 (22.5)
	Tertiary	133 (8.6)
Marital status	Total	1 540 (100.0)
	Never married	448 (29.1)
	Currently married	883 (57.3)
	Separated/divorced/widowed	209 (13.6)
Age of children	Total	1 540 (100.0)
	5 years and below	145 (18.4)
	6 to 10 years	226 (28.6)
	11 to 15 years	219 (27.8)
	16 to 18 years	199 (25.2)
Location of residence	Total	789 (100.0)
	Urban	761 (49.4)
	Rural	779 (50.6)
Region of residence	Total	1 540 (100.0)
	Greater Accra	559 (36.3)
	Volta	391 (25.4)
	Ashanti	590 (38.3)
Total	1 540 (100.0)	

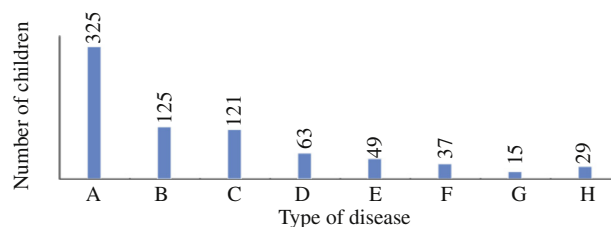
Respondents who had not been to school constituted 220 (14.3%), and almost two fifths of respondents (38.7%) attended school to middle school/junior high school level.

On marital status, 448 (29.1%) respondents never married, 883 (57.3%) were married, while those who were separated/divorced/widowed constituted 209 (13.6%). To the question on age there were 789 respondents. Caregivers with children aged 5 years and below were 145 (18.4%). Those with children aged between 6 to 10 years and 11–15 years were 226 (28.6%) and 219 (27.8%), respectively, while 199 (25.2%) had children being 16–18 years old.

A total of 761 (49.4%) respondents resident in urban areas; while those in rural areas were 779 (50.6%). Respondents in Greater Accra were 559 (36.3%), while 391 (25.4%) from Volta, and 590 (38.3%) from Ashanti region.

### 3.2. Type of NCDs suffered by child

Figure 1 presents a breakdown of the types of NCDs suffered by the children. There were only 764 respondents to this question.



**Figure 1.** Types of NCD suffered by children.

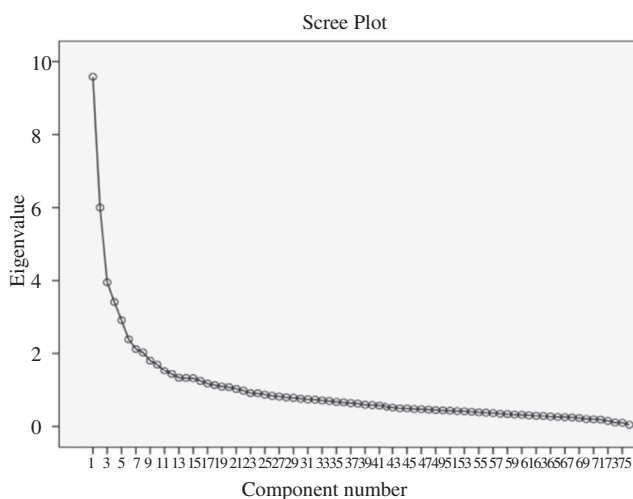
A: Asthma; B: Congenital deformities; C: Sickle cell disease; D: Epilepsy; E: Diabetes; F: Cardiovascular disease; G: Cancer; H: Others.

Figure 1 reveals that asthma was the leading NCD reported. A total of 325 (43%) were asthmatic. The rest were suffering from congenital deformities (16%), sickle cell disease (16%),

epilepsy (8%), diabetes (6%), cardiovascular diseases (5%), cancer (2%), and other diseases (4%). These other diseases were mainly mental illnesses, blindness, leprosy and ulcer.

### 3.3. Caregivers' attitudes and health-seeking behaviour for children with NCDs

Factor analysis based on principal component analysis was done to identify distinct variables with strong loadings in a rating scale describing caregivers' attitudes and health-seeking behaviour for children with NCDs. The principal component analysis revealed the presence of 21 components with eigenvalues exceeding 1. The variance explained ranged from high (12.6%) for component 1 to low (1.3%) for component 21. The 21 components explained a total of 65% of the variance. However, as shown in Figure 2, there was a clear break in Scree Plot at component 13, therefore the components were reduced to 13<sup>[45]</sup>. Pallant<sup>[45]</sup> proposed that components loading three or more items should be retained. Components with less than three items were therefore removed. Also, in view of the similarity of themes of some components, they were merged with others, thus reducing the number of components to six, with a total of 40 items. These components were then named according to the appropriate dimension which best describes the similar groups of items. The six dimensions include knowledge and beliefs about NCDs, effects of NCDs on children and caregivers, social stigma associated with childhood NCDs, health-seeking behaviour of caregivers for children with NCDs, coping mechanisms of caregivers of children with NCDs and policy concerns of caregivers of children with NCDs. Table 2 presents the results of the factor analysis.



**Figure 2.** Scree plot showing components of caregivers' attitude and health-seeking behaviour for children with NCDs.

### 3.4. Reliability analysis

Having adopted the scale on caregivers' attitudes and health-seeking behaviour for children with NCDs based on the factor analysis, the reliability of the scale was tested for internal consistency using Cronbach alpha. According to Nunnally<sup>[46]</sup>, a Cronbach alpha coefficient of 0.7 and above indicates a strong internal consistency. The Cronbach alpha coefficient of this scale was 0.89, indicating a strong internal consistency.

Table 3 shows the mean responses of caregivers on their children's NCDs.

The responses were based on a rating scale as follows: 1, strongly disagree; 2, disagree; 3, neutral/undecided; 4, agree; 5, strongly agree. For ease of interpretation, ratings from 1 to 3, that is, from strongly disagree to neutral/undecided, were described as a tendency to disagree, whereas ratings from 3.01 to 5 were described as a tendency to agree. Out of the 40 items constituting the rating scale, 16 (40%) were rated below 3, indicating a tendency to disagree, while 24 (60%) rated above 3, indicating a tendency to agree. In other words, 6 in ten respondents tended to agree with the questionnaire on attitudes and health-seeking behaviour of caregivers in respect of their children suffering from NCDs.

On the dimension of knowledge and beliefs about NCDs, respondents tended to agree that the incidence of NCDs among children is on the increase and that, by some supernatural means, enemies can cause diseases on children. However, they tended to disagree, among others, that the family/community views children with NCDs as problem children, or that children suffer from NCD because of the sins of their parents/ancestors, the gods or evil forces.

With regard to the effects of NCDs on children, respondents tended to agree that NCDs have negative effects on school attendance and performance. NCDs also negatively affect the physical growth and mental development of children. For the family, NCDs pose a burden financially as well as other forms of burden of care. However, respondents tended to disagree that children's NCDs result in family tensions and frictions. They also tended to disagree that families depend on other family members for financial support to manage the children's illness.

Concerning social stigma associated with childhood NCDs, respondents tended to disagree that their families were discriminated against by significant others because of their children's condition, that the conditions of their children were an embarrassment to the family, or that families found it difficult to go out in the company with their children to social gatherings. However, they tended to agree that the friends of their children may tease them about their conditions.

On the health-seeking behaviour of children with NCDs, respondents tended to agree that they attended hospitals/clinics for the treatment and regular checks of their children, as well as go to faith healers for prayers/deliverance. However, they tended to disagree that they treated their children with herbal medicines besides the doctor. They also tended to disagree that NCDs cannot be treated in a hospital.

Regarding coping mechanisms of caregivers of children with NCDs, respondents tended to agree that they receive emotional and spiritual support from significant others. However, they tended to disagree that the extended family or community members provide material, financial, or counselling support to their children.

Finally, with respect to policy concerns of caregivers of children with NCDs, all respondents tended to agree strongly that policy makers should provide education on regenerative health and nutrition practices in hospitals, clinics, churches, mosques, schools and health training institutions. They also recommended that the school curricula from basic to tertiary level should include the treatment and prevention of NCDs. Also, the national health insurance scheme should include all NCDs, especially of children, in its benefit package. They also recommended that a comprehensive policy on NCDs should be developed to include NCDs in children.

**Table 2**

Scale on caregivers' attitudes and health-seeking behaviour of children's NCDs.

Dimensions of attitudes and health-seeking behaviour		Components					
		1	2	3	4	5	6
Knowledge and beliefs about NCDs	Our enemies can cause the diseases on our children	0.815					
	The incidence of chronic diseases among children is on the increase	0.746					
	The family/community view my child with NCDs as a problem child	0.700					
	The family/community view my child's illness to be caused by environmental factors	0.687					
	Children suffer NCD because of the sins of their parents (ancestors)	0.573					
	I feel that this illness of my child has been caused by curse from the gods	0.504					
	The family/community view my child's illness to be caused by evil forces	0.468					
Effects of NCDs on caregivers/children	She/he cannot learn well like her/his colleagues in school		0.800				
	She/he cannot go to school regularly like other children		0.794				
	She/he cannot play like her/his colleagues in school or at home		0.781				
	The child will not feel as happy as her/his friends		0.641				
	My child's sickness has resulted in family tensions and frictions		0.870				
	The illness of children with NCDs is a burden/difficult responsibility		0.745				
	The ailment of children with NCDs will affect the family financially		0.743				
	I depend on other family members financially to manage my ward's condition		0.734				
	Life was on the whole much better until I found out my child's illness		0.731				
	It negatively affects her/his physical growth		0.744				
Social stigma associated with childhood NCDs	It negatively affects her/his mental development		0.643				
	It will make her/him look different from the colleagues		0.552				
	My family is discriminated against by others because of my child's condition			0.871			
	The condition of my child is an embarrassment to the family			0.803			
	We find it difficult to go out in the company with this child to social gatherings			0.545			
Health-seeking behaviour of caregivers of children with NCDs	Her/his friends may tease her/him about the condition			0.437			
	I take medicine from hospital/clinic for my ward				0.803		
	I ensure regular medical checks in hospital/clinic for my ward				0.742		
	I treat my child/children's illness with herbal medicines besides the doctor				0.709		
	I go for prayers/deliverance by faith healers				0.498		
Coping mechanisms of caregivers of children with NCDs	I believe this disease cannot be treated in a hospital				0.404		
	Extended family members will support my child/children					0.808	
	I do receive financial support from significant others					0.800	
	I receive support from members of the community in caring for my child					0.797	
	My family and I do receive counselling to deal with these challenges					0.589	
Policy concerns of children with NCDs	I do receive the emotional support from significant others					0.556	
	I do receive the spiritual support from significant others					0.496	
	Emphasize regenerative health and nutrition practices in healthcare institutions						0.783
Policy concerns of children with NCDs	Emphasize regenerative health and nutrition education in churches, mosques, etc.						0.757
	Emphasize regenerative health and nutrition in health training institutions						0.737
	Include the treatment and prevention of NCDs in school curricula						0.663
	Develop a comprehensive policy on NCDs in Ghana						0.619
	Include all NCDs in the national health insurance benefit package						0.592

**Table 3**

Mean responses of caregivers of children with NCDs.

Responses		N	Mean	SD	
Knowledge and beliefs about NCDs	Our enemies can cause the diseases on our children	1523	3.32	1.392	
	The incidence of chronic diseases among children is on the increase	1522	3.82	1.055	
	The family/community view my child with NCDs as a problem child	727	2.89	1.356	
	The family/community view my child's illness to be caused by environmental factors	727	2.87	1.211	
	Children suffer from NCD because of the sins of their parents (ancestors)	1518	2.59	1.322	
	I feel that this illness of my child has been caused by curse from the gods	726	2.19	1.223	
	The family/community view my child's illness to be caused by evil forces	726	2.62	1.317	

(continued on next page)

Table 3 (continued)

Responses	N	Mean	SD		
Effects of NCDs on caregivers/children	She/he cannot learn well like her/his colleagues in school	1176	3.53	1.203	
	She/he cannot go to school regularly like other children	1174	3.66	1.117	
	She/he cannot play like her/his colleagues in school or at home	1172	3.60	1.141	
	The child will not feel as happy as her/his friends	1177	3.62	1.127	
	My child's sickness has resulted in family tensions and frictions	729	2.28	1.257	
	The illness of children with NCDs is a burden/difficult responsibility	733	3.83	1.350	
	The ailment of children with NCDs will affect the family financially	733	3.86	1.182	
	I depend on other family members financially to manage my ward's condition	728	2.44	1.267	
	Life was on the whole much better until I found out my child's illness	730	3.41	1.228	
	It negatively affects her/his physical growth	1181	3.82	1.127	
	It negatively affects her/his mental development	1180	3.34	1.271	
	It will make her/him look different from the colleagues	1180	3.63	1.182	
	Social stigma associated with childhood NCDs	My family is discriminated against by others because of my child's condition	729	2.33	1.262
		The condition of my child is an embarrassment to the family	731	2.50	1.356
We find it difficult to go out in the company with this child to social gatherings		727	2.76	1.384	
Her/his friends may tease her/him about the condition		1180	3.01	1.325	
Health-seeking behaviour of caregivers of children with NCDs	I take medicine from hospital/clinic for my ward	1466	4.30	0.971	
	I ensure regular medical checks in hospital/clinic for my ward	1458	3.63	1.104	
	I treat my child/children's illness with herbal medicines besides the doctor	748	2.86	1.432	
	I go for prayers/deliverance by faith healers	1461	3.70	1.293	
	I believe this disease cannot be treated in a hospital	752	2.67	1.475	
Coping mechanisms of caregivers of children with NCDs	Extended family members will support my child/children	737	2.88	1.323	
	I do receive financial support from significant others	734	2.72	1.290	
	I receive support from members of the community in caring for my child	735	2.65	1.298	
	My family and I do receive counselling to deal with these challenges	733	2.89	1.293	
	I do receive the emotional support from significant others	735	3.42	1.182	
	I do receive the spiritual support from significant others	733	3.14	1.265	
Policy concerns of caregivers of children with NCDs	Emphasize regenerative health and nutrition practices in healthcare institutions	1522	4.37	0.582	
	Emphasize regenerative health and nutrition education in churches, mosques, etc.	1494	4.31	0.662	
	Emphasize regenerative health and nutrition in health training institutions	1518	4.36	0.580	
	Include the treatment and prevention of NCDs in school curricula	1525	4.50	0.601	
	Develop a comprehensive policy on NCDs in Ghana	1527	4.44	0.647	
	Include all NCDs in the national health insurance benefit package	1519	4.58	0.588	
Valid N (listwise)	638				

#### 4. Discussion

From factor analysis this study developed a scale for assessing caregivers' attitudes and health-seeking behaviour for children with NCDs in developing countries. The scale has a strong internal consistency, with a Cronbach alpha coefficient of 0.89. Further descriptive statistics indicate that caregivers tended to agree that the incidence of NCDs among children is on the increase. This is consistent with existing literature<sup>[36]</sup>. This finding provides further justification on the need for policy makers to turn their attention to childhood NCDs. The beliefs by respondents that their enemies can cause diseases on children are also consistent with literature on supernatural causes of diseases<sup>[40–42]</sup>. However, the tendency of respondents to disagree that children suffer from NCD because of the sins of their parents/ancestors, the gods or evil forces, is not only inconsistent with the literature, but seems to contradict the belief that enemies can cause diseases on children, since the *modus operandi* of the perceived enemies are expected to be supernatural, revolving around the gods or evil forces. However, the fact that respondents tended not to subscribe to the use of traditional or herbal medicine, seems to reinforce their tendency to disagree that NCDs could be caused by the gods or evil forces. Further study is needed to probe further the belief that enemies can cause diseases.

Respondents tended to agree that NCDs have an effect on their children in the following dimensions: they negatively affect the physical growth and mental development of children, they make children look different from their colleagues, children do not feel as happy as their friends, they do not go to school regularly like other children, they cannot learn well like their colleagues in school, and they cannot play like their colleagues in school or at home. These findings generally agree with previous studies<sup>[7,10,47]</sup>. Boice<sup>[7]</sup>, for example, found that children with NCDs may also miss school more often and experience difficulties with concentration and mental functioning due to certain medications and stress related to their illness. The nature of the NCDs reported (Figure 1) also confirms the associated effects. For example, conditions like asthma is known to be associated with difficulty in breathing when the child is under asthmatic attack, and this will affect the ability of the child to go to school or play. Sickle cell disease, depending on the type, also affects the growth of the child, while epilepsy is generally associated with social stigma. Considering that over 50% of respondents were from the rural area, where schools are usually far from home in most places in Ghana, and children have to walk to school, coupled with the socio-economic burden and social stigma expressed by caregivers, the finding that children with NCDs do not go to school regularly like other children could be a real and worrying situation. These are exacerbated by

their feelings of unhappiness, and their inability to play in school, among others.

Apart from the effect on children, the study also indicates that generally caregivers tend to agree that the illness of children with NCDs is a burden/difficult responsibility; that the ailment of children with NCDs will affect the family financially, and that life was on the whole would be much better if child had no NCD. These findings are generally consistent with literature<sup>[38,47]</sup>. Indeed, it is a truism that caring for a child with NCD which is usually prolonged and chronic, would pose a significant burden on the caregivers. The financial difficulty expressed by respondents is underscored by the fact that studies have also shown that chronic disease care in Ghana is expensive. The monthly cost of treating conditions like diabetes exceeds the average salary<sup>[38]</sup>. Regarding social stigma of NCDs, the tendency of respondents to disagree that their families were discriminated against by significant others because of their children's condition, that the conditions of their children were an embarrassment to the family, or that caregivers found it difficult to go out in the company with their children to social gatherings is inconsistent with the finding by Murray *et al.*<sup>[4]</sup>. It is rather consistent with Williams *et al.*<sup>[29]</sup> who found that families caring for chronically ill children may experience more strains and burdens in physical and emotional aspects. However, these families may become more resilient and have more advanced problem solving skills. It also finds support in study of Mcdaniel *et al.*<sup>[48]</sup>, who noted that in some cases, the child with the NCDs holds the family together and acts as a diversion for the family. Even though it is reasonable to expect some amount of tensions and frictions, as well as discriminations in some situations, anecdotal evidence in Ghana suggests that families generally cope with children with NCDs, and do not find a child with a NCD as an embarrassment to the family or have any difficulty going out in the company with their child to social gathering.

With respect to coping mechanisms by caregivers, the acknowledgement of emotional and spiritual support by respondents is also consistent with empirical and anecdotal evidence. Empirically, spiritual support and emotional support has been cited in several studies in Ghana<sup>[40–42]</sup>. Anecdotally, apart from prayers for the sick in churches and mosques, there are several 'prayer camps' in Ghana, some of which are sighted in forests with poor habitable conditions, yet people troop to these camps with various forms of ailments for 'deliverance' prayers. Also, faith-based, and even some government-owned health facilities organize devotional prayers before the start of daily duties, while some visitors to in-patients in hospitals also offer prayers for their healing. There is need for studies on the positive and negative effects of faith-healing in order to inform policy reforms for the benefit of patients.

The recommendations by respondents for policies to promote regenerative health and nutrition at various institutions, as well as the need for a comprehensive policy framework including NCDs of children are also consistent with literature<sup>[36,37]</sup>. The increasing trend of NCDs also makes this call imperative. The recommendation for the national health insurance scheme to cover all NCDs, especially for children, in the health insurance benefit package is necessary, in view of the protracted nature of NCDs and the acknowledgement of respondents that they face financial burden of caring for their children.

The paper sought to investigate the attitudes and health-seeking behaviour of caregivers of children suffering from

NCDs. First of all, a rating scale was developed, based on a review of literature on attitudes and health-seeking behaviour of caregivers, especially within the context of developing countries. The findings show that caregivers tend to agree that the incidence of NCDs among children is on the increase, and that enemies can cause diseases on children. However, they disagree that children suffer from NCDs because of the sins of their parents/ancestors, the gods or evil forces. Caregivers also tend to seek treatment in hospitals/clinics rather than from traditional or herbal medicine. They however complement biomedical treatment with prayers for healing/deliverance. While further research is required on the role of perceived enemies in inflicting diseases on their victims. It could be concluded that caregivers of children suffering from NCDs tend to rely more on biomedical approach rather than traditional or herbal treatment.

It is also found that NCDs have a negative effect on the physical and mental development of children, as well as their school performance. Caregivers also indicate that caring for children with NCDs poses material, emotional and financial burden on them. However, caregivers disagree that caring for children with NCDs is associated with social stigma. This is a positive attitude that could inspire policy makers in developing policies and programmes for the care of children with NCDs.

Caregivers strongly recommend that policy makers should develop a comprehensive policy including NCDs of children, as well as policies aimed at preventing NCDs, including the introduction of regenerative health and nutrition in healthcare institutions and public institutions of learning. Caregivers also strongly recommend that all NCDs should be included in the Ghana national health insurance benefit package in order to address the financial burden of caregivers in caring for their children with NCDs. While this may still be considered, the government needs to take concrete steps to provide financial assistance to caregivers of children with NCDs and also provide the necessary resources to cater for their children's educational needs.

Since respondents were caregivers of children suffering from NCDs and not the children themselves, it is possible that their judgements about the effect of NCDs on children might not have been entirely a true reflection of the reality. This point might be more important with respect to caregivers who are not biological parents of the children, who may be entrusted with the care of the child within a relatively shorter time prior to the study. Findings may therefore be interpreted with some caution. The same limitation applies to responses on effects of NCDs on caregivers.

Another limitation of the study is that the statistical analyses were mainly based on descriptive statistics and factor analysis. Findings are therefore not subjected to more advanced statistical analysis in order to test for significance. Notwithstanding this point, considering that the study is exploratory in nature, the development of a scale to assess NCDs in children in a developing country context is ground-breaking. Subsequent studies could therefore employ this tool for more advanced analysis.

### Conflict of interest statement

The authors report no conflict of interest.

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