

# STRUCTURAL BARRIERS TO COPING WITH TYPE 1 DIABETES MELLITUS IN GHANA: EXPERIENCES OF DIABETIC YOUTH AND THEIR FAMILIES

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## SUMMARY

**Objective:** To explore the structural barriers faced by families coping with type 1 diabetes mellitus (T1DM) in Ghana, and to provide insight for policy development.

**Methods:** Qualitative study conducted with families with a child with T1DM, receiving care in the greater Accra area. Total of 17 individuals were interviewed using individual and dyadic approaches: 7 youth with T1DM, 9 parents of children with T1DM, and one medical doctor.

**Findings:** 5 key barriers emerged from the data: primary care, schools, financial burden, lack of formal support, and access to information. Participants expressed concern over the misdiagnosis of T1DM at primary care facilities, resulting in some of the children going into a diabetic coma before receiving proper care. Children and parents noted discrimination and poor care at school. Financial burden was due to the high costs of medications and appliances needed for proper diabetes management. A lack of formal support was credited by participants to be the result of the lethargy of advocacy groups or resource centers. Finally, there was a lack of readily available and accessible information for children and parents on T1DM.

**Conclusion:** Awareness of T1DM needs to be increased, by incorporating lessons on recognition into already existing campaigns for type 2 diabetes mellitus (T2DM). Schools need to be more engaged with their responsibility for children with diabetes. Pressuring policy makers and pharmaceutical companies to make diabetes supplies more affordable and accessible could ease the financial burden. Social support networks need to be explored and strengthened. Study into the experiences of youth with T1DM in rural settings and other parts of Ghana, as well as, youth from low socioeconomic backgrounds is necessary.

**Keywords:** type 1 diabetes mellitus, children, families, Ghana, structural obstacles

## INTRODUCTION

Diabetes is becoming a world pandemic. Incidence and prevalence are increasing dramatically, with an estimated 171 million diabetics in 2000 and a projected increase to 366 million by 2030.<sup>1</sup> It has been estimated that in Africa for persons aged 35-64, diabetes claimed 7.1% of all deaths among males, and 7.9% among females.<sup>2</sup> These figures have been drawing increasing attention to diabetes in developing countries. Ghana has the challenging task of facing the 'double disease burden,' which means it must deal simultaneously with acute communicable diseases and chronic illness. In recent years steps have been taken to address the severity of diabetes in Ghana, and attention has been given to the prevention, diagnosis and care of type 2 diabetes mellitus (T2DM).<sup>3</sup> Type 1 diabetes mellitus (T1DM) diverges from T2DM in that it is not preventable, diagnosis in children is often missed, and in many cases it requires a different approach to care. Diabetics with either form face many of the same obstacles to obtaining adequate care such as under-resourced primary care facilities; financial burden; lack of formal support; access to information; and for children with diabetes, schooling presents an array of issues.

T1DM is unique from many other chronic illnesses in that it often develops during childhood and adolescence, entrenching itself in the lifestyles and routines of the diagnosed child and surrounding family members. A new responsibility is placed upon children and their key caregivers, with a life or death consequence. Experiences of families coping with T1DM have been documented in many developed countries, however, there is a void in the literature for families living in Ghana. The reported research explores the structural obstacles that are present in Ghana, and hinder families from managing this disease in their fullest capacity. This article aims to provide a starting point for more research and development. By outlining the structural obstacles that families face we can begin an informed dialogue on how to improve care.

## METHODS

Participants were recruited in two ways. A list of youth with T1DM was compiled with permission from a private practice in Accra that treats diabetic children. From that point others were opportunistically recruited through a snowball process, which gathered families with children with T1DM from Accra, Tema and Akosombo. T1DM is often misdiagnosed in Ghana (personal communication, expert informant, March 2009) and therefore the list of those afflicted is limited. A complete list of persons in Ghana with T1DM was unavailable. In addition to the children, their mothers were interviewed, and on some occasions, their fathers. Finally, an interview was conducted with an expert informant, a medical doctor dealing with pediatric chronic illness in Ghana.

Data collection and analysis were part of a larger, theory-driven study, that focuses on the psychosocial abilities of youth and their parents to cope with T1DM, using the theoretical constructs of biographical disruption and social representations theory. Criteria for sampling and analysis paid attention to age, but allowed for a spectrum of educational backgrounds, socioeconomic status and time living with the disease to provide a more representative picture.

Two methods were used to gather information: individual interviews and a diabetes quiz. Individual interviews were conducted with all 17 participants to gather biographical information, and a subjective interpretation of living with diabetes in Ghana. Illness can be an emotional and private part of someone's life, so individual interviews were chosen over focus groups to respect the privacy of respondents and to capture their interpretation of diabetes in Ghana with a relaxed rapport.<sup>4</sup> Interviews with diabetic youth sought to draw out the impact of chronic illness on the individual and the perceived effect of their illness on family members and friends. Interviews with parents contributed to the biography of the children, and provided more depth to the understanding of how T1DM impacts families and how they cope with it. The interview with the expert informant sought to provide an understanding of diabetes care in Ghana, how it is provided, and where it can be improved. By triangulating the study with the participation of three different types of informants, the study aimed to provide a more comprehensive view of the role of T1DM in Ghanaian families.

The initial interview guides were informed by literature on the psychology of chronic illness, namely Michael Bury's theory of biographical disruption<sup>5</sup> and current discussions on the state of diabetes in Ghana.<sup>6,7,8,9</sup> Interviews were carried out in a semi-structured manner, and the topic guide was refined throughout the process.

All interviews were conducted in English, however, one participant chose to respond largely in Twi, so as to explain herself more articulately. Her daughter provided translation into English throughout the interview. Taped interviews lasted between 20 and 60 minutes, and it was found that often pertinent information was disclosed before and after the recording. These conversations yielded many insights into life in Ghana with diabetes, and were also used to inform the research. Notes from all interactions with participants were logged in a field journal which has been analyzed by hand. 15 interviews were conducted in person, while two were performed over the phone. Permission was granted to record each interview, and all participants were made clear of their rights to end the interview at anytime, or ask for pieces of information not to be included in any subsequent reports. When interviews were conducted in person, participants were given a consent form outlining their rights, and were asked to sign it before the interview commenced. For the phone interview the consent form was read aloud to the participants and they provided verbal consent. Following the formal interview, youth participants were asked to take a verbal 3-question quiz, which tested their biomedical knowledge of diabetes. Each youth participant was offered a gift in thanks for their contribution of knowledge, experience and time, at the end of their interview session.

Each interview was transcribed verbatim, excluding only one specific portion of one interview, on request of the participant. Transcripts were coded using the qualitative analysis software, NVivo. Using de-Graft Aikins' framework of 'consensus, conflict and absence,'<sup>9</sup> analysis aimed to examine nuanced themes from the text. Three global themes emerged: access to health, social relationships and roles of the lay carer. This article reports on access to health, in particular the sub-theme of structural obstacles to coping with T1DM in Ghana, as reported by participants. Analysis for this report focuses upon the experiences and perceptions of families navigating within specific social and institutional constructs, while dealing with this particular chronic illness.

## FINDINGS

Analysis of the data revealed five key barriers to families coping with T1DM in Ghana: primary care facilities, schools, the financial burden, lack of formal support and access to information. Findings are discussed through these over-arching themes.

### Primary Care Facilities

Misdiagnosis is an obstacle commonly incurred by families with children with diabetes. The International Diabetes Federation (IDF), estimates that undiagnosed

cases of diabetes (type 1 and type 2) account for 70% of those suffering from the disease in Ghana.<sup>10</sup> Many families interviewed reported taking their child to multiple clinics and hospitals before being correctly diagnosed. Diabetes presents with a number of symptoms that are also attributed to several other illnesses commonly found in Ghana, and many children were initially diagnosed with malaria or typhoid. The trips to several care facilities did not only pose a financial obstacle, but more seriously, delayed treatment. As a result, several participants went into a diabetic coma before being properly diagnosed, even though they had already seen multiple medical professionals. Some of the mothers interviewed reported that they had researched their child's symptoms and had to request that their child be tested for diabetes. Both parents and children commented on the misconception that diabetes is only an affliction of adults and the obese. This belief clearly contributes to the misdiagnosis of diabetes when an under-weight child is presented.

In addition to delays and misdiagnosis, families also reported a frustration in the lack of urgency expressed by primary care facility staff when their child was properly diagnosed. One child was referred to Korle Bu Teaching Hospital for treatment, however, the parents, unaware of the seriousness of the diagnosis, waited until the following day to take their child in. When they were told that their child immediately needed to be admitted for up to a week, they were extremely frustrated and concerned that they had waited an extra night, putting their child at greater risk of slipping into a coma.

Many of the families interviewed preferred to use private hospitals and clinics when their children fell ill. One family explained that this devoured any funds for the rest of the family, but that it was simply a matter of life and death in their minds.

“But, we realized that...that...that care at the general hospital, because it was the public hospital....there was not enough care. So we decided to take her to a private so that we can save her life.” (Mother of a teenage girl)

### **School**

School presented itself as a significant challenge as it became a point of stress and vexation for many parents. Parents interviewed were very involved in the management of their child's illness, however, when children were at school, practical aspects of management were conceded to teachers, librarians, friends and the children themselves. Certain insulin regimens require snacks and meals to be taken at specific times in meas-

ured quantities. Parents worried that teachers wouldn't remember to give their child a snack break at the appropriate times. For one family this was not an uncommon experience and the parents became increasingly frustrated when their child came home, having had unnecessarily high or low blood sugar levels during the school day. Improperly managed sugar levels were also noted to have an affect on the child's ability to participate in school duties. Another parent expressed concern over allowing her son to go to boarding school. While she acknowledged that this was a socially important developmental experience to him, she believed that his diabetes would not be properly managed if he lived away from home.

Another participant recalled limitations imposed upon her at school. She had been a physically active individual prior to her diagnosis, and wished to continue participating in athletic activities at school. While the participant felt that she was capable of participating - physical activity is a recommended component of properly managing diabetes<sup>10</sup> - teachers restricted her from athletic activities enjoyed by the rest of the class. The participant recalled that teachers expressed concern that she was more likely to become injured or go into a coma, and they did not know how to deal with these events. The participant reported that teachers were afraid that they would get into trouble if anything happened to her.

### **Financial Burden**

The financial burden brought on by diabetes is substantial and often crippling to a family. Insulin is covered by the National Health Insurance Scheme (NHIS) in Ghana. However, according to the 2008 NHIS Progress Report, total registered membership covered 55% of the population at the end of 2007.<sup>12</sup> While this is a substantial increase from 2005, when less than half as many people were covered, many of the participants interviewed did not have insurance to cover insulin. Participants recounted various personal experiences of being unable to properly care for their children as a result of not being able to obtain insulin. One mother disclosed that the month before the interview they had run out of insulin, and had no money to afford anymore until her next paycheck. As a result, her daughter went a week without any insulin injections. There was an obvious toll on the child; sickness, fatigue, and knowing that each meal brought her closer to a diabetic coma. In addition, there was the worry felt by parents, who sat by and watched their child become increasingly ill. Another mother discussed how she regularly was unable to purchase the prescribed insulin for her daughter from the pharmacist. Out of necessity she became very resourceful and acquired insulin from adult friends with T2DM. She then made the trip into

Accra to check with her daughter's physician about the appropriateness of the insulin and doses to administer.

Managing diabetes not only requires great financial output, but it also requires time. Many of the participants were on an insulin regimen requiring two types of insulin (typically a rapid acting and a basal), and reported great angst in obtaining both types. Pharmacists generally do not stock both: this forced parents to travel around, looking for the correct insulin. This was a costly process (depending on the types of transportation people had available to them), and time consuming, which often took time away from work. This lack of availability of supplies has been noted as an obstacle in other research on diabetes in Ghana.<sup>3</sup>

While insulin is the most necessary tool in managing T1DM, it is not the most expensive. Blood glucose testing devices (glucometers and test strips), which are not covered by NHIS and are necessary to monitor sugar levels and typically used to calculate insulin injections, can cost anywhere between 2-5 Ghana Cedis per day. Given the average Ghanaian income, proper treatment of this disease is an absolute impossibility for the majority of citizens. The expert informant reported that many of her patients were unable to afford any testing of their blood sugar -not daily tests, and not glycosylated hemoglobin A1c tests (HbA1c) at doctors visits- resulting in poorly managed diabetes, and the incurrence of subsequent illnesses. Participants in this study tended to be in higher socioeconomic classes, indicated by their ability to afford treatment for their children, however, the financial burden was still a salient theme.

#### **Lack of Formal Support**

Many of the participants reported feeling a lack of support from any type of formal organization. It needs to be noted that informal networks of support were developed with doctors and family members, and were highly appreciated. Participants described the important role played by extended family in supporting and caring for the child, as well as, contributing to the financial burden. In addition, a few families highlighted the assistance they received from their physician. Doctors treating the diabetic children were reported to be very accessible, understanding, and in some cases offered an informal payment scheme to make insulin affordable.

The Ghana Diabetes Association (GDA) is a full member of the International Diabetes Federation (IDF), and is a national association concerned with diabetes or diabetes related conditions in Ghana. Few participants reported having any knowledge of the GDA. Those who did were unsure of its services for children, believing that it was largely concerned with adults. Children and parents expressed a need for a regular support group, or "diabetes club" specifically for youth.

The doctor attending to many of the children interviewed held a informational group session, which educated patients on diabetes care, and offered an opportunity for children and parents to share and compare experiences. This session was valued by families, and proved to be an effective way to dispel misconceptions and disseminate information. One family interviewed started a juvenile diabetes club. Both the diabetic youth and her parents reported that this club has been a beneficial and enjoyable venture. However, they also noted the time, energy and financial costs they personally incurred, and the need for more formal juvenile diabetes organizations.

#### **Access to Information**

A quiz was given to each youth participant, asking them to answer in their own words the following three questions: What is diabetes? How do you get type 1 diabetes? How do you stay healthy if you have diabetes? Table 1 shows the responses to the latter two questions. Responses to the first question were accurate and biomedical in nature, with 4 of the participants referencing the pancreas. Participants displayed a confident understanding of the illness. However, when asked how T1DM developed, the majority of youth responded that the over-consumption of sugar triggered the onset. Many believed that it was their own sugary diet which made them ill, thus placing the blame on the shoulders of themselves and their parents.

Many participants did not feel that information on T1DM was readily available to them. Some reported borrowing books from the doctor's office, and receiving a small pamphlet upon diagnosis. Several youths and parents referenced internet access, and friends abroad as key points of access to information on the management of diabetes and recent medical developments. Literature on the medical aspects of T1DM seemed to be available, however, little was provided on the psychosocial implications of the illness in Ghana.

**Table 1** Results of the diabetes quiz with child and youth participants

<b>DIABETES QUIZ</b>	<b>How do you get type 1 diabetes?</b>	<b>How do you stay healthy if you have diabetes?</b>
Sandy (age 11)	When the person is...when the person eats a lot of sugar.	Mmm. to become when you don't go...to anywhere...you stay at your home. You, you don't go...like, you go to parties, and running, there and here.
Princess Peach (age 8)	Type 1 diabetes...if you gets...like sick from something that you didn't cause yourself. You go to a hospital and then they'll tell you what you have. Hmm...maybe because...they went near someone that has diabetes...they spit on the person or something?	Umm...like I have to eat enough food that I know that it will make me stay in range.
V (age 9)	When, when, when...you catch the diabetes...because you eat too much...too sweet.	You eat sweet things if it is low...and then, um, when your sugar is low...and you take insulin when your sugar is high.
Cheex (age 21)	Uh, umm...sometimes through heredi...heredity. And then um....I think lifestyles should be included.	Exercise...which I hardly do. And then um, my insulin. I make sure that I always have it with me. Yeah, my insulin, and then what I eat.
Twetty (age 16)	Type 1...from eating too much sugar. Not from too much sugar, but too much carbohydrates, too much fat, and sugar. Researcher: So is it their fault? Yeah. And it's because most people don't know about diabetes. So, when you are doing these things, they don't think of anything that's going to come...the side effects of it. They just eat it. They only think of eating too much fat, would give me cholesterol and everything. But they don't know that...most people don't know that sugar comes with...eating too much sugar causes diabetes.	Eat...like, make researches, and...apply them to your life. Have everything...in the right proportions. Have a check up once in a while. A general check up.
Bob (age 14)	Um..having an...an irregular diet. Yeah, by um...not exercising too much. Um...yeah. Eating a lot of sweets and junk and stuff. Like a pudding and stuff...yeah, and..yeah. And, and um...through heredity.	Um..get exercise. Um, maybe not dieting, but a balanced diet. Um...and umm, maybe injections...and by doing what a doctor says.
Huxtible (age 10)	Umm people get it when they eat a lot of sugar. Then, um...I's say... my body can't develop sugar, but not everybody does that. Not everybody's body does that. If you eat sugar, then it goes inside, and that means that, the...those are the symptoms, that you're having diabetes. Like, all the time you want to go to the washroom, and you...you are feeling dizzy and a very short temper.	Um, I stay healthy by following what the dietician told us. About what food that I should be eating. Um, sometimes I follow...I do what the doctor also tells me.

## DISCUSSION

Parents of children with T1DM are willing to do whatever is necessary to care for their children, but are faced with insurmountable obstacles. Accurate diagnosis at the primary care level could prevent many children from falling into a coma, or dying. Several of the youth interviewed in this study fell into a coma after being incorrectly diagnosed at hospitals and clinics. The emotional trauma this causes families is long lasting.

In 1999 a three year project was embarked upon to develop and implement a Ghanaian model of a national diabetes care and education programme.<sup>13</sup> The purpose of this project was to improve diabetes care at the primary level. The project has been successful in making people aware of type 2 diabetes. However, in doing so, it may have posed an obstacle for children with T1DM. Bringing (needed) attention to Ghanaians dealing with type 2 may have resulted in primary care professionals

and the general public associating diabetes only with overweight adults and therefore assigning known diabetic symptoms in youth to other illnesses. Increasing the recognition of T1DM, by integrating with current diabetes awareness campaigns could prove to be a cost effective mode of spreading information.

Diabetes can be a complicated illness, and teachers need to be made comfortable in dealing with it. Parental involvement and administrative support are integral in providing teachers with the necessary knowledge and confidence. As was described by one of the participants, teachers may be “afraid” of the responsibility attached to having a diabetic student, and may restrain them from participating in certain regular class activities. However, this does not benefit the child, but rather acts as a hindrance to normal social experiences. Children with chronic illness typically strive towards normalcy<sup>14</sup>, and segregating them from peers only adds to this challenge. Clear communication between parents and teachers is important but not always sufficient.

Future policy should aim to provide a protocol for diabetic children in schools, which informs all teachers and administrators. A protocol would need to cover not only basic information about diabetes, but also designated options for when students’ sugars are too high or too low. This study reinforced the conviction that medical professionals are held in high regard in Ghana.<sup>9</sup> Information provided by doctors and nurses to schools, has the potential to be persuasive and effective. Community nursing staff, and medical students are two options for informing schools on diabetes.

The financial burden of diabetes in Ghana impacts families on a multitude of levels. It devours incomes, and takes away funds from other family members. It consumes time, energy and opportunities for income generation. It heightens distress levels and it limits the manageability of diabetes. The extensive financial costs result in many Ghanaians not receiving adequate treatment, if any treatment at all. It is well established that the secondary illnesses brought on by poor diabetes management, while often covered by insurance, are much more costly. Proper diabetes care from the outset is not only humane, but a financially sensible policy for governments.

Policy change, reducing the costs of diabetes care in Ghana, for example eliminating import taxes, are not yet feasible<sup>3</sup>, however, that does not mean that families are helpless. One relatively simple change that can reduce the time and transportation costs of families would be for pharmacists to provide a selection of insulin brands.

Participants generally agreed upon an increase in support from the GDA for youth with diabetes. Information and events geared at youth with T1DM would require significant volunteer efforts, and if families are short on time, this might not be an immediately feasible goal. The development of informal support groups, as was created by the expert informant and one of the families interviewed, integrated with community health workers would provide accessible and legitimized social care for families. Local support groups for adults have been increasing in the past few years, and have reportedly been beneficial.<sup>15</sup>

Access to information poses a challenging task. Table 1 illustrates misconceptions held by youth interviewed on how T1DM is developed. Many participants believed that it was their own poor diet which brought on their illness. Placing the blame of the child or parents is dangerous to family well-being, and contributes to feelings of guilt and stress. Greater access to accurate information would alleviate these unnecessary burdens, could improve care, and provides a greater body of knowledge for families to draw from. While some families found internet sources very useful, most families in Ghana do not have regular access to the internet, and require other forms of information transmission. Assisting families with access to appropriate diet plans, carbohydrate counting lists, and the experiences of other families with diabetes is highly recommended for diabetes care in Ghana.

## CONCLUSION

Families coping with diabetes in Ghana have a myriad of challenges. The structural obstacles to manageable diabetes are formidable, but not unassailable. The findings reported here aimed to shed light on the structural challenges faced by families with T1DM. It is important to note that participants for this study were all from a relatively high socioeconomic circumstance, all lived in urban areas in and around the capital, consulted with highly trained physicians, and were able to afford medical attention and diabetes supplies. The experiences of people with T1DM living in rural settings or other parts of Ghana with less monetary resources could be quite different. It is strongly emphasized that further study on this topic is urgently needed. In particular there must be inquiry into the challenges faced in rural areas and by youth from low socioeconomic backgrounds.

The present study had the twofold goal of bringing more attention to the illness, and to better understand its impact on those diagnosed and their families. Many Ghanaians meet issues with primary care facilities, finances, schools, formal support and access to information. However, these problems are exacerbated by

diabetes, adding an extra factor to the struggle. By gaining a greater understanding of the illness and the structural obstacles to adequate treatment, these impediments can be addressed. Becoming aware of the factors that hinder care is the first step in removing them. The parents interviewed were striving to provide the best level of care possible for their children, and youth acted responsibly in looking after themselves. They were not asking for handouts, merely for the opportunity of a healthy life. Ghana is a rapidly growing economy, and diabetes needs to garner a larger portion of the health agenda if people are going to be able to live with it in a manageable fashion.

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