

## Research Article

# The Influence of Social Meanings on Treatment Seeking Behaviours of Patients with Type 2 Diabetes Mellitus: A Qualitative Enquiry in a Ghanaian Hospital

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## Abstract

**Introduction:** It is noted that illnesses have both biomedical and experiential proportions as well as metaphorical inferences and meanings. Perceptions and beliefs that individuals and society hold regarding illness and health conditions seem to influence treatment and health seeking behaviour in general. In Ghana, most conditions including diabetes mellitus have various socially constructed meanings and connotations. Some of the meanings that are attributed to illnesses stigmatize patients and brand them.

**Aim:** The study sought to find out how social meanings attached to diabetes mellitus influence treatment seeking behaviours of patients with type 2 diabetes mellitus in a Ghanaian hospital.

**Methods:** Exploratory descriptive design to qualitative research was employed, in which 42 patients with type 2 diabetes were recruited through convenience sampling approach. In-depth audio recorded interviews were conducted. Analysis of the write out data was by content analysis.

**Results:** The main findings centred on lay representations of diabetes such as the causes, chronicity, familial nature, damaging effect of the condition, and the perception that the affected persons are cursed in society. These social meanings attached to diabetes informed participants' treatment choices.

**Conclusion:** It is argued that these lay perceptions held by diabetes patients are essentially important to be addressed through patient and public education by healthcare providers such as nurses to enhance diabetes outcomes.

**Keywords:** Patients; Diabetes mellitus; Social meanings; Treatment seeking behaviour

## Introduction

Social meanings attributable to diseases and illnesses are defined as the socially constructed connotations that are coined from diseases and attached to them [1]. Some illness situations or conditions are surrounded by specific cultural meanings. The meanings attached to these diseases are usually based on experiences of the person suffering the illness [2]. The social meanings attached to illnesses are also given by the society based on their perceptions regarding the condition. Additionally, social meanings that are assigned to diseases are constructed by "claim-makers and interested parties" [1].

In Ghana, most conditions including diabetes mellitus have various socially constructed meanings and connotations. Some of the meanings that are attributed to illnesses stigmatize patients and brand them [4]. For instance, the stigmatizing aspect of social meanings of diseases is not different from what happens in diabetes situation,

particularly in Ghana. Diabetes mellitus is given different names such as "Asikafo Yare" ("disease of the wealthy"), "Asikyire Yare" (sugary disease) [5] and "Yare bone" ("bad disease") as well as "Obonsam Yare" ("disease of the devil") [6]. These meanings of diabetes mellitus appear to indicate the source of diabetes and what the condition can do to the affected person. For instance, as a "devil's disease and bad disease" diabetes appears to originate from the devil and seen as a damaging and protracted illness respectively. Though not similar to diabetes mellitus, a social meaning attributed to patients with Sickle Cell Disease (SCD) in Ghana was "Ndwedwendwedwe" literally meaning "stunted growth" [7]. The perception over here is that individuals with SCD are associated with growth retardation, a form of stigma by association [8].

Cultural beliefs of every society to a large extent shape the local ideas about health and illness, as well as society's healthcare practices. Social meanings attributable to illness and health situations are derived based on the cultural beliefs and perceptions [9]. Even though, some diseases conditions have specific social and cultural meanings assigned to them, such meanings are often taken for granted and are unnoticed [10]. However, these meanings may lead to independent consequences on the patients and the overall healthcare system [10].

It is noted that illnesses have both biomedical and experiential proportions as well as metaphorical inferences and meanings [11]. For instance, [11] contended that the damaging metaphorical meanings attached to diseases such as cancer, as a malicious disease or cruel condition may significantly and expressively influence individuals distressed with the condition. In the same vein, [12] investigated the extent to which obesity representations including "obesity as sinful"

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(greediness) affects a person's backing for public policies intended to decrease obesity among the populace.

From the studies reviewed [9-12], it is observed that what is central regarding meanings assigned to illnesses is that they exist for socio-cultural rather than purely natural or biological reasons.

Perceptions and beliefs that individuals and society hold regarding illness and health conditions seem to influence treatment and health seeking behaviour in general [13]. It appears that issues on social meanings and how they influence diabetes patients in particular on treatment seeking have not been widely explored in Ghana. It is imperative that the subject is investigated using qualitative research approach [14].

### Purpose of the study

The study was to find out how social meanings that are attached to diabetes mellitus influence treatment seeking behaviours among patients with type 2 diabetes.

### Research objectives

1. To explore social meanings which are attached to diabetes mellitus.
2. To find out how social meanings inform diabetes patients to choose treatments for diabetes.
3. To explore the challenges social meanings attached to diabetes create for diabetes care among patients.
4. To find out how to improve the care among diabetes patients for better outcomes.

### Materials and Methods

Exploratory descriptive design of qualitative research was employed for this study, with the assumption that the researcher is part of the research participants. This assumption is built on the intention that "meanings are co-developed through shared humanness and life experiences" [15]. Thus, the researcher is inseparable from the studied object [16], who interact with each other and share common experiences in the same world. The spirit of exploratory descriptive design of qualitative research is about the examination of persons' experiences regarding a unique subject matter. Thus, the investigation of how social meanings attached to diabetes influence type 2 diabetes patients' treatment seeking behaviours.

### Sample and sampling approach

In this research, convenience sampling approach was used to recruit 42 research participants. All of them were type 2 diabetes patients. Convenience sampling method is used when the potential research participants are not known to the researcher, but placing notices around or through telephones call, the researcher is able to recruit them [17]. The names of the research participants and their telephone numbers were obtained from the attendance register at the diabetic clinic. The researcher was given permission by the hospital authorities to have access to their phone numbers and to interact with them. Seriously ill patients and patients with co-morbidities were excluded from the study on accounts of fragility of health. Additionally, the participants who could not speak the local language Twi or English were excluded. Inclusion was reserved for adult patients diagnosed with diabetes in the hospital.

### Data collection

Data were collected by using semi-structured interview

guide consisting of open-ended questions. The flexibility of the semi-structured interview questions allowed the emergence of other questions during the dialogue between the interviewer and interviewee [18]. It also allowed the researcher to seek clarification of certain responses from the participants which resulted in rich data [19]. Interviews were done in the local Twi language which the researcher speaks fluently and later translated into the English language by the researcher to ensure consistency. Back translation from English to Twi was done by a colleague researcher to ensure consistency and accuracy [19]. Questions such as "Tell me about the meanings that are attached to diabetes mellitus". "In what ways do these meanings inform you about the type of treatments you consider for diabetes?" were asked. Approximately, the researcher's interaction with each of the research participants during interview lasted between 45 minutes and 1 hour. Data collection and analysis occurred at the same time to find out if there was the need to adjust the interview guide [19].

### Data analysis

In this research conventional content analysis approach was employed for the data breakdown. This approach ensures that coding categories are derived in a straightforward fashion from the text data [20]. By reading through the raw data, phrases, sentences, statements, and words which depicted and described the specific issues under study were recognized [20]. The major findings centred on social meanings of diabetes around causative issues, chronicity of the condition, familial nature of the condition, damaging effect of the condition, perception that the affected are cursed individuals and influence of social meanings on treatment choices.

### Ethical considerations

In this research, some of the ethical concerns that were taken into account were anonymity, confidentiality, and informed consent among others. Pseudonyms were given to research participants to obscure their real identity. They were also given the chance to sign, or thumb print the consent form following the explanation of what the research was all about. In addition, relevant health authorities in Ghana gave cite endorsements to carry out this research. In this study, limited perils were predicted; hence participants were given 24 hours to take decision to participate in the research. The biographic data of the research participants was detached from the research data to circumvent any linkages between them.

### Results

The major findings centred on expressions of social meanings of diabetes around causative issues, chronicity of the condition, familial nature of the condition, damaging effect of the condition, perception that the affected are cursed individuals and influence of social meanings on treatment choices. Critical observation of the views of the Ghanaian diabetes patients show that the meanings attached to diabetes mellitus were related to social, cultural, and spiritual beliefs.

### Social meanings related to the perceived causes/sources of diabetes mellitus

The meanings attached to diabetes mellitus by the participants aligned with the perceived causes or sources of the condition hanged around phrases including "bayie yare" ("witchcraft disease"), "nto yare" ("bought disease") and "duabo yare" ("cursed disease"). In their narratives, the research participants described how they developed diabetes in various ways. Three participants had this to say:

- I know that a family member who has witchcraft powers gave this disease to me in a spiritual manner. Yeah, it was true mystical way that I got the condition (P23).
- In my case the condition was sold to me in the market. I went to the market to buy some food stuffs and it was through that the bad person gave it to me. You know diabetes is a bad disease and people who hate you can give it out when one is buying something in the market or somewhere in a spiritual buying (P36).
- Diabetes is a cursed disease. That is what I know. If the devil wants you to suffer in life, then one may be cursed with diabetes so that you can suffer every day because you can't get a cure for it and can kill at the end of it all (P5).

From the patient's stories it appears that diabetes is acquired through mystical ways in Ghanaian context. Thus, diabetes is derived from supernatural and evil forces, which defies cure and may ultimately takes the life of the affected person.

### Social meanings related to the chronicity of diabetes mellitus

The meaning assigned to the condition was also perceived by the participants as a chronic condition without cure. Social meaning such as "koankoro yare" ("chronic disease") was ascribed to diabetes mellitus which is strongly tied to the chronic nature of diabetes mellitus. As a nurse researcher and a Ghanaian, in my interactions with individuals in Ghana, I have also noted that chronic illnesses are perceived to be caused by spiritual powers. Two participants shared their stories that diabetes is a "koankoro yare" which literally means a chronic disease:

- As a chronic condition, diabetes patients have to take medicines every day, you either takes it by mouth or by injection. There is no cure for it and that is why it is chronic, and one has to take medication every day (P21).
- It is a condition which has no cure for it. Once it is developed, it has come to stay with the sufferer till the ultimate happens (P33).

The chronicity of diabetes as perceived by the patients was undoubtedly a matter of concern to the participants as patients have to take medications every day. When considered in Ghanaian context as a chronic condition and a condition perceived to be caused by evil spirits, it may be necessary to identify specific strategies for health education on accounts of the perceptions held by the patients.

### Social meanings related to the familial nature of the diabetes mellitus

The term "abusua yare" ("family disease") was used to denote diabetes mellitus as participants perceived that people in specific families get the condition. Thus, viewed diabetes as a "family property" because individuals in a particular family develop the condition through the generational line. Two participants stated why diabetes is a family disease:

- If your mother or father has the condition, you can also get it. It runs in families and that is why I got it. My father had the condition and I have it now, so you see that it is a family condition (P41).
- I am aware that if you have it in your family, other people in

that family may also get in the future. That is the main reason why people call diabetes a family disease, which is through genes (P10).

It appears that the condition in Ghanaian context as a "family disease" suggests that families with the condition are branded or labelled as having diabetes. The possibility is that the stigma associated with diabetes may be drawn-out to whole family. Furthermore, the patient who has the condition may be perceived as "carrying a family problem or load", diabetes as a "genetic or family condition".

It is obvious to note that each of the social meanings attached to the condition indicates the scope of the nature of diabetes, its origin, what the condition can do the affected person, the meaning of diabetes diagnosis to the patient, and how the social meanings brand the affected person. These factors appeared to prescribe or dictate treatment options for the affected patients in this study.

### Treatment options for diabetes patients based on the social meanings ascribed to the condition

The social meanings ascribed to diabetes informed the research participants' decisions regarding the choice of treatment for the condition. Their decisions to search for treatment or cure were established on their perceptions of how diabetes occurs, damaging effects of diabetes and chronicity of the disease. Three participants narrated their stories in this way:

- As for diabetes, if you need treatment, one has to rely on spiritualist. They have the powers to identify the cause of the condition and prescribe treatment as well. The faith healers and spiritualists have the powers to treat all chronic diseases including diabetes (P20).
- Diabetes is a harmful condition which can damage the body in many ways. At times, the hospital treatment alone cannot help diabetes patients. It is always important to combine hospital treatment and spiritual remedy, so that what the hospital medicines cannot do, the spiritual power can do it perfectly (P14).
- In most cases the spiritualist healer may identify the bad spirit which is causing the condition and deal with it in a spiritual way. Even if the one who has caused the condition comes from your family, they have the powers to deal with that devil. In some ways too, they can prepare some spiritual medications in a form of herbs or other substances for you to take to treat the condition (P6).

It is clearly noted from the participants narratives that, their treatment decisions are aligned with the perceptions they have regarding the origins, hurtful effects, and chronicity of diabetes. It is obvious that to assist diabetes patient's self-manage diabetes and to live productive lives, robust health education tailored to individual needs may be required for Ghanaian diabetes patients.

## Discussion

The research participants in this study ascribed diabetes mellitus to social meanings including "witchcraft disease", "bought disease", "cursed disease", "chronicity of diabetes" and "family disease". In Chinese illness groupings matched with the western categorization of diseases, [21] classified diabetes as a devil condition, which originates from the mystical realm. The mystical or the spiritual realm is perceived to be the dwelling place of devils and other spiritual beings

where their nefarious activities occur [22]. The findings in the current research appear to the same as those identified by [21] as all of them indicate that diabetes mellitus is caused by supernatural powers, or a human being alleged to be dwelling in the mystical domain. In Ghanaian context, beliefs and perceptions around illnesses, healing, unsuccessful healing, some circumstances, and even certain deaths are linked with despicable and evil activities of depraved spirits, family gods and ancestors, friends, and envious family members [6]. It is apparent that [21] did not report on additional social meanings as noted by this study, such as chronicity of diabetes, diabetes as a cursed disease, diabetes as a bought disease, diabetes as a witchcraft disease and diabetes as a family disease, these categorizations of diabetes are likewise identical to a devil disease recognized by [21]. The differences in contextual representation of social meanings in the two studies for diabetes may be due to the cultural orientation and background of the research participants [23]. Strengthened the knowledge on cultural representation of illness and health, and that social meanings of illness and health are determined by the individuals who experience the disease or the health situation, based on the person's cultural, social, educational, economic backgrounds as well as other psychosocial factors [23].

The results also appeared to suggest diabetic patients as sufferers or victims purported to have 'bought diabetes' from a sales shop or an open marketplace. Though different from diabetes mellitus, [7] identified six major lay representations of Sickle Cell Disease (SCD) denoted as "bought disease". Other lay and social meanings ascribed to SCD hovered around "a financial drain", "sickle cell disease as a social stigma", "SCD as a source of despair" and "a cause of recurrent illnesses" [7]. As a 'bought disease' hereditary factors or causes are barely considered as conceivable reason for the disease causation despite a family history of diabetes and sickle cell respectively. Genetic cause of diabetes therefore appears as a distant perception, and diabetes is recognized and depicted as a family curse. This categorization situates diabetes under a mystical or spiritual cause whereby supernatural powers including witches are alleged to have waged for the condition and wreaked it upon the one who suffers diabetes mellitus. By inflicting a disease such as diabetes on the victim, the spiritual power accountable for the disease causation derives a form of gratification for executing that mystical act [22]. In the traditional African setting, it is held believed that witches and other supernatural beings dwell in "unseen world" or "the spiritual world" where venomous activities are executed against persons. Similarly, it is perceived that, the supernatural bodies converge on big trees at night in remote areas where noxious activities are accomplished such as inflicting diseases on people [22]. In the African societies, the belief and credence in supernatural including witchcraft is pervasive regardless of individuals' background and orientation such as religion, ethnicity, and educational standing.

The outcomes of spiritual attacks on persons are manifested when identifiable diseases such as diabetes or a mysterious disease state sets in with signs and symptoms [24]. In such situations the afflicted individual chooses to search for cure from faith-based healer such as a diviner or herbalist and further sources [24].

Further, [25] epitomized diabetes as a 'frightened disease', 'diabetes as a nightmare', 'scary disease', 'silent killer', 'doing battle' and 'diabetes as a curse'. These connotations associated with diabetes are related to its destructive effects on the affected individuals. The findings by [25], are dissimilar from what were identified in this research with

the exception of the "diabetes as a cursed condition", they express how the person living with diabetes perceive it. As a researcher and a practicing nurse in Ghana, I have observed that a cursed condition in Ghanaian context denotes an illness devoid of cure and consequently has poor prognosis. In such illness situations, treatments in general are based on spiritual methods. The sense of meaning of a cursed disease in Ghanaian context appears to be shaped by cultural beliefs and insights. In addition, the meaning of a cursed condition goes beyond distressing or affecting the single individual of the family. As a cursed disease, the implication is that if a family member contracts it as a result of previous demeanors or sins for example it may have heaving or rippling consequences on other members of the whole family as a spell. The social connotation of diabetes as a "cursed disease" ("duabo yare") as noted in the Ghanaian Twi language was hence employed to represent a condition such as diabetes in Ghanaian sense. The social context of diabetes mellitus as a cursed disease is comparable to how [25] used it in the African American study, as it explicates how diabetes is viewed by people in relation to its devastating outcomes. The social and cultural meanings ascribed to diabetes such as "devils' disease" (Flaws and Sionneau, 2005), "bought disease" [7] and "curse" in addition to "demonic disease" and 'bought disease' [25] seem to be presenting similar perceptions around diabetes related to its source and nature in terms of contextual sense. Associated with contextual meanings of illnesses that [26] expressed the view that social meanings persons ascribe to illnesses are formed grounded on the magnitude of the problem experienced including debility and social cost aligned with the disease. However, [27] described diabetes as a "curse" wreaked on people as a way of retribution to institute order, and to dispense justice and equality in society. Thus, diabetes is noted as a manifestation of a spell of the affected person, and the whole family which the individual belongs to [22]. This appears to be similar to the findings of the current study and the results of [7] but [27] depicted diabetes as a form of castigation to ensure justice and order in society as a result of individuals' demeanors related to wrong doings. In most traditional African settings, one of the ways to promote social justice and order is to inflict curses by way of imposing diseases deter people from indulging in social evils including stealing, robbery to mention a few. However, [28] identified two forms of social connotations ascribed to diabetes by Iranian research participants. These were the negative and positive social meanings. Negative social connotations associated with diabetes were apparent in social context such as diabetes as "dreadful disease" which "disempowered and endangered" individuals' liberty. Similar, negative connotations ascribed to diabetes were "defect point" as well as "worse than cancer" [28], a condition which placed fear and apprehension in individuals as the condition could lead to the development of complications among sufferers [28]. Positive connotations of diabetes centred on perception that diabetes must viewed as a "high-risk baby" which needed extra and special care, an opportunity for optimistic and positive change if an individual had diabetes. The sense and contextual meanings assigned to diabetes by the appear to be similar to what [7,25,27] and what have been found in this study as all of them establish negative social meanings for diabetes with the exception of diabetes as a "high-risk baby" which required additional care [28]. In context, is prudent for persons living with diabetes to take thoughtful actions to manage diabetes as it is essential to give diabetes exclusive attention.

It is clearly observed that the misconceptions and beliefs regarding diabetes out of which some of the social meanings of diabetes were derived are social phenomenon which may thwart individual

and collective efforts in controlling and prevention of diabetes in Ghana. It is therefore essential to understand individuals' knowledge regarding the etiology of diabetes and cultural meanings attached to the condition in order to inform healthcare providers the kind of care to be rendered to the persons affected by the disease. Thus, the care needs of the affected individuals need to be tackled based on the socio-cultural beliefs, perceptions, attitudes, and insights prevalent in Ghanaian social settings.

The meanings attached to diabetes as noted above informed participants' decisions for particular treatment or cure. In other words, the participants' decisions around treatments were established on their perceptions regarding the causes, destructive effects, and long-lasting nature of diabetes. Related to the present findings [5], indicated that spiritual healing was sought for patients with Sickle Cell Disease (SCD) and epilepsy. These conditions are also perceived to be caused by bad spirits such as witches and demons in Ghanaian sense. However, according to [29], diabetes patients with poorer financial stand opted for spiritual treatment for the condition, with the aim that spiritual treatment was cheaper compared with the medical treatment. The participants from more affluent societies rather opted for medical care at the hospital. Participants in the current study perceived that as a chronic disease, diabetes is cured through supernatural means by faith healers, similar to what [29] noted that diabetes can be cured by the Supreme Being, God. Compared with the findings of the present study, the research participants in employed both spiritual and medical treatment to manage diabetes. Though it has been noted that combination therapy for spiritual and medical conditions is essential to treat chronic conditions as indicated by the current findings and posited that in African settings, chronic diseases do not exist due to the fact that faith healers have supernatural powers to cure all sorts of diseases together with the chronic diseases. If a chronic disease is perceived to have been healed and emerges again, the condition is considered as a "new bout" of the disease.

Persuasively, the assertions by are not poles apart from the result of the present study in addition to the findings from [29] about the capability of spiritual forces and Supreme Being to heal diverse forms of chronic diseases. The sense in what they are saying point belief and perception that spiritual forces, whichever God or lesser gods or spirits has the powers to cure diabetes in the African situation.

#### Limitation of the study

The limited number of 42 research participants employed for this study and the choice of only one research setting may not be adequate to generalize the findings. Generalization of findings in this study may be improved if multiple research settings are identified in future studies. In this research, the researchers did not bracket themselves from the research participants as health professionals which might have led to investigator biases. The researchers' professional background in health and their experiences through interactions with diabetes patients, and being native Ghanaians rather equipped them with needed knowledge to get extensive and rich data from the research participants.

#### Conclusion

The study was set off to explore social meanings attached to diabetes mellitus and how they influence treatment seeking behaviours of patients living with type 2 diabetes mellitus in a hospital in Ghana. The sense of what patients make of diabetes appeared to be socially constructed. In other words, social meanings attributed to diabetes

indicated that the condition emanates from spirits, has chronic sequel, perceived as a family and cursed disease and has damaging consequences on the affected persons. These perceptions held by the patients influenced their treatment options. It is suggested that the patients' sense of meanings attached to diabetes need to be addressed through patient and public education by healthcare providers including nurses to improve diabetes outcomes.

#### Nursing Implications

The findings may give us a better understanding of meanings that are attached to diabetes mellitus and how they influence patients' treatment options, and how that will help tailor patient education on their treatment options for diabetes mellitus. The social meanings may be used during health education and promotion for the general public since such terms are socially constructed which may convey simple but comprehensible health message to the public. Additionally, the findings may serve as a focal point on how to endow diabetes patients through health education to eschew negative social meanings, which may influence their treatment options in a negative manner.

#### Recommendations

The social meanings attached to diabetes and the treatment preferences perceived by diabetics as we have noted in this study appear to suggest that diabetes is misunderstood as a medical condition. As a medical condition, diabetes has defined pathophysiological progression and treatment.

1. There is the need for health care providers in Ghana including nurses to consider the social meanings attributable to diabetes mellitus and similar conditions to inform them about the content of health education to be offered to diabetes patients and the general public.
2. Similarly, the findings may be of help to the health care staff in other countries in their interactions with Ghanaian patients in the diaspora. The findings will offer them a better understanding of how to care for Ghanaian patients in the diaspora.

#### Institutional Review Board

Ethical and scientific authorization for this research was given by De Montfort University Research Committee in the UK, with reference Number (REF 347-08).

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