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Barriers to diabetes self-care: a qualitative study of patients' and health care providers' perspectives

Short title: Barriers to diabetes self-care

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Conflict of interest

None

Authorship

VM made substantial contributions to conception and design, acquisition of data, analysis and interpretation of data, and drafted the manuscript. NAJ, FT and CP contributed to conception and design, analysis and interpretation of data, and critically revised the manuscript. All authors gave final approval of the current version of the manuscript to be published and also agreed to be accountable for all aspects of the work.

Barriers to diabetes self-care: a qualitative study of patients' and health care providers' perspectives

Abstract

Aims and Objectives: We explored patient and health care provider (HCP) perspectives about patients' barriers to the performance of diabetes self-care behaviours in Ghana.

Background: Sub-Saharan African urban populations are increasingly affected by type 2 diabetes due to nutrition transition, sedentary lifestyles, and ageing. Diabetes self-care is critical to improving clinical outcomes. However, little is known about barriers to diabetes self-care (diet, exercise, medication taking, self-monitoring of blood glucose and foot care) in sub-Saharan Africa.

Design: Qualitative study that followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.

Methods: Semi-structured interviews were conducted among 23 people living with type 2 diabetes and 14 HCPs recruited from the diabetes clinics of three hospitals in Tamale, Ghana. Interviews were audiotaped and transcribed verbatim. The constant comparative method of data analysis was used and identified themes classified according to constructs of the theory of planned behaviour (TPB): attitudes/behavioural beliefs, subjective norms and perceived behavioural control.

Results: Barriers relating to attitudes included misconceptions that diabetes was caused by spiritual forces or curses, use of herbal medicines, intentional non-adherence, difficulty changing old habits, and feeling or lacking motivation to exercise. Barriers relating to subjective norms were inadequate family support, social stigma (usually by spouses and other members of the community) and cultural beliefs. Perceived behavioural control barriers were poor income levels, lack of glucometers, busy work schedules, long distance to the hospital, and inadequate access to variety of foods due to erratic supply of foods or seasonality.

Conclusions: Both patients and HCPs discussed similar barriers and those relating to attitude and behavioural control were commonly discussed.

Relevance to clinical practice: Interventions to improve adherence to diabetes self-care should focus on helping persons with diabetes develop favourable attitudes and how to overcome control barriers. Such interventions should have both individualised and community wide approaches.

What does this paper contribute to the wider global clinical community?

- The findings increases our understanding barriers to diabetes self-care in resource constrained setting, thereby providing important insights relevant for diabetes care in other low-and middle-income countries having health system challenges similar to Ghana.
- It brings to bear that both patients and HCPs comprehend similar challenges to diabetes self-care, providing an opportunity for improved patient-provider collaboration for diabetes care.

Keywords: Barriers, self-care, diabetes patients, qualitative, sub-Saharan Africa, Ghana

Introduction

Diabetes was responsible for five million deaths in 2015, and has become a disease of global importance affecting 1 in 11 adults (International Diabetes Federation 2015, WHO 2016). The prevalence of type 2 diabetes is rising rapidly in lower-and middle income countries. In 2015, 3.2% of adults aged 20-79 years were diagnosed with diabetes in sub-Saharan Africa (International Diabetes Federation 2015) and it has been estimated that by 2030, non-communicable diseases (NCDs) will surpass infectious diseases, maternal, perinatal and nutritional diseases in the sub-region (International Diabetes Federation 2015, WHO 2016). Sub-Saharan African urban populations are the most affected due to nutrition transition, sedentary lifestyles, and ageing (Aikins *et al.* 2010, Patel & Burke 2009, WHO 2016). Type 2 diabetes is the most frequently occurring type of diabetes in Sub-Saharan Africa and worldwide (International Diabetes Federation 2015, WHO 2016). However, access to recommended diabetes care in Sub-Saharan Africa is limited by a shortage of adequately trained HCPs, inadequate diagnostic tools and lack of medications for the treatment of diabetes (Mbanya *et al.* 2010, Motala & Ramaiya 2010). Diabetes care requires patients to navigate an interactive model of HCPs, healthcare systems, families and communities

(Goderis *et al.* 2009a). With the support of the provider the patient is expected to follow recommended self-care behaviours such as self-monitoring of blood glucose (SMBG), dietary change, exercise, foot care, and medication. Adherence to these self-care behaviours has been shown to improve glycaemic control, lower long-term morbidity, mortality, and increased insulin sensitivity (Balducci *et al.* 2012, Umpierre *et al.* 2011) as well as decreased risk of foot ulcers (Apelqvist *et al.* 2000, Bell *et al.* 2005).

Background

Most studies investigating patient barriers to self-care are from developed countries such as the United States, Canada and the United Kingdom (Bhattacharyya *et al.* 2011, Booth *et al.* 2013, Nagelkerk *et al.* 2006, Raaijmakers *et al.* 2013). These studies have found that potential barriers to self-care behaviours among patients with type 2 diabetes include poor patient-provider communication, lack of support from family, inadequate understanding or knowledge of the disease, lack of motivation to change (Brown *et al.* 2002, Goderis *et al.* 2009b), a need for education (Brown *et al.* 2002), cultural and psychological factors (Glasgow *et al.* 2001, Zeh *et al.* 2014). Given these settings generally have well established health care systems for diabetes care, the generalizability of these findings to sub-Saharan Africa, where the health systems are limited, is questionable. The few studies conducted in sub-Saharan Africa have largely adopted quantitative approaches (Adeniyi *et al.* 2009, Desalu *et al.* 2011, Doherty *et al.* 2014, Korkor 2015, Ojoawo & Ogunbeku 2012, Oyewole *et al.* 2014b), which provides limited insight into how to develop interventions which account for local or cultural beliefs (Thompson *et al.* 1998). Furthermore, the limited studies from sub-Saharan Africa, explored a single self-care behaviour (i.e. either diet only, diabetic foot care only or physical activity only) (Adeniyi *et al.* 2009, Desalu *et al.* 2011, Doherty *et al.* 2014, Ojoawo & Ogunbeku 2012, Oyewole *et al.* 2014a). A more comprehensive approach to understanding barriers to adherence is essential to the development of interventions which are effective for the full-suite of diabetes self-care behaviours.

Both patient and provider perspectives are relevant when exploring barriers to self-care. Increased participation of patients in treatment decisions and satisfaction with provider communication have been reported to result in improved adherence to self-care behaviours (van Dam *et al.* 2003, Williams *et al.* 2005) and better health outcomes in patients (Alazri & Neal 2003, Piette *et al.* 2003). Conversely, patients' and HCPs' discordance in health goals, targets, and barriers may result in poor health outcomes (Peyrot *et al.* 2005). There is evidence that patients and HCPs can differ in their perception of barriers to adherence to self-care behaviours (Nam *et al.* 2011, Peyrot *et al.* 2005). HCPs may be able to identify barriers that are not apparent to patients. A number of studies have investigated patient only and provider only barriers to self-care (Nam *et al.* 2011, Pun *et al.* 2009). Other than one study from the United Kingdom which concurrently investigated HCP and patient perceptions of barriers to diet and physical activity self-care behaviours (Booth *et al.* 2013); no study has concurrently explored patient and provider perceptions of barriers to adhering to self-care behaviours. A better understanding of patient and HCP barriers to self-care behaviour is needed to guide the design of interventions to improve self-management and quality of diabetes care. This study qualitatively explored provider and patient perceptions of barriers to the performance of five diabetes self-care behaviours (diet, exercise, SMBG, medication taking and foot care).

Methods

Design: Semi-structured in-depth individual interviews, informed by the Theory of Planned Behaviour (TPB) (Ajzen 1991) were conducted with Ghanaian type 2 diabetes patients and their HCPs. We followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (See Supplementary File 1).

Theoretical framework

TPB conceptualises that behaviour is determined by *intention* to act and perceived behavioural control (PBC) (Ajzen 1991). According to the TPB, intention to perform a self-care behaviour is determined by three components: the individual's attitudes (one's evaluation of the potential or expected outcome of performing a self-care behaviour); subjective norms (one's perception of social pressure to perform or not perform a self-care behaviour); and PBC (one's perception of the ease or difficulty in performing a self-care behaviour) (Ajzen 1991, Ajzen 2006). Latent to attitudes, social norms and PBC are beliefs that are useful targets for interventions to help change behaviour (Hardeman *et al.* 2002). These beliefs include behavioural beliefs, normative beliefs and control beliefs.

Setting and sample

Patients: Patients were recruited from the diabetes clinics of the Tamale Teaching Hospital, Tamale West and Central Hospitals located in the Tamale Metropolis of Ghana. Patients attending these hospitals are primarily from urban and semi-urban areas. These hospitals have weekly diabetes clinics to provide care to diabetes patients. Patients were eligible to participate if they: were older than 18 years; self-reported a healthcare professional diagnosis of type 2 diabetes; sought care from the diabetes clinic at least twice during the last 12 months and were registered with the hospital. Patients were excluded if they: had type 1 diabetes or were diagnosed with diabetes before the age of 30 years.

HCPs: HCPs were recruited from the diabetes clinics of the three hospitals where doctors, nurses, nutritionists and dietitians provided diabetes care. Eligible HCPs were those having a primary role in diabetes care and who had worked in the diabetes clinic for at least three months.

Procedures

Patients: All recruitment and data collection procedures were completed by a trained research assistant (RA). Patients waiting for their consultation with their provider were approached by the RA and invited to participate. After signing a consent form, an appointment for the study interview was made with the patient at a convenient time and venue. Noting that patients may feel vulnerable while in the waiting area we adopted a number of strategies to prevent coercion. Patients were assured that their participation was voluntary and they were at liberty to withdraw at any time during the interview without any consequences. In addition, patients were also assured that their decision whether or not to participate was not going to affect the availability of care to them. Finally, the research assistant who collected the data was not involved in the provision of care to the patients, thereby reducing the likelihood of coercion. Most interviews were conducted face-to-face at the patients' homes and all were audio-recorded. Interviews with patients were conducted in English or in a local dialect (i.e. Dagbani) if patients were unable to speak English. Interviews that were conducted in the local dialect were translated to English by the interviewer. Forward-and back-translations were adopted. All interviews with patients had a duration of 20-30 minutes. Interviews were conducted till the point of saturation.

HCPs: Participants were recruited using a combination of purposive sampling and snowballing techniques. All recruitment procedures and interviews were conducted by VM. Potential participants were approached on diabetes clinic days. Those who agreed to participate were interviewed in the hospital at a mutually agreed time. All interviews with HCPs were conducted face-to-face in English, audio-recorded and lasted for a duration of 15-30 minutes. All recruitment and data collection procedures was approved by two Institutional Human Research Ethics Committees, one each from Australia and Ghana.

Measures

The interview discussion guide included open-ended questions and covered all components of the TPB. Specifically for patients, topics relating to the diabetes patients' barriers to self-care were considered (Appendix 1). For the HCPs, the discussion guide covered topics, based on a literature review (Bhattacharyya *et al.* 2011, Booth *et al.* 2013) relating to general diabetes care and barriers they perceived hindered patients' adherence to diabetes self-care behaviours (Appendix 2).

Data analysis

All interviews were transcribed verbatim into English. Transcripts were checked for errors in conjunction with the digital audio recordings by VM. The coding procedures and constant comparative method of qualitative data analysis developed by Strauss (Strauss 1987) was used to analyse the interview transcripts. Following an inductive, bottom up approach, this method has been widely used for analysing qualitative data (Denzin & Lincoln 1994). Transcripts of the individual interviews were read and re-read and assigned a series of codes by the principal investigator. VM and a colleague, who has experience in qualitative research coded a sample (i.e. 25%) of interview transcripts independently. These were compared and differences resolved through discussion between the coders, and with other members of the research team if required. The codes were grouped into similar themes/concepts. Themes/concepts were presented according to the constructs of TPB and augmented with illustrative quotes. Nvivo software version 12.0 was used for processing, ordering and comparing the codes.

Results

Demographic characteristics

From the three diabetes clinics, 26 type 2 diabetes patients were approached in which 23 agreed to participate and were interviewed. Most patients were female (17/23) with a mean (SD) age of 60.9(12.6) years. Duration of diabetes ranged from one year to 20 years and most (18/23) had lived with the condition for less than ten years. Eighteen of the 23 patients either had no formal education or had attained low levels of education. Out of the 17 HCPs approached 14 agreed to participate and were interviewed. Nine of the 14 HCPs were male. The HCPs were nurses (n=8), physician assistants or prescribers (n=2), nutrition officers (n=2) and dietitians (n=2). The HCPs had been working in the diabetes clinic for an average of 3 years.

Barriers to self-care

Both patients and HCPs identified a number of perceived barriers to patients' adherence to self-care behaviours as described in full below. These barriers are summarised in Table 1.

=Insert Table 1 about here=

Attitudes/behavioural beliefs

Misconceptions and use of herbal medicines: According to the HCPS, diabetes patients had misconceptions regarding diabetes and its care. These misconceptions related to the causes of diabetes and dietary care. HCPs suggested that most diabetes patients misconstrued that diabetes was caused by the consumption of high carbohydrate diets and as a result should avoid such foods.

...most of them think it is sugar ... that causes diabetes, a lot of them have that misconception. Which is not true. – Participant 10, Nutrition Officer.

Some HCPs also noted some of these misconceptions as they usually advised diabetes patients not to take high carbohydrate diets making it difficult for some patients to make the right choice of meals.

Some do come here saying some nurses told them not to eat protein foods. ... I'll tell them that you're not supposed to avoid anything, even sugar, if you get a dietician involved. We call it carbohydrate counting....– Participant 5, Dietician.

HCPs perceived that some patients have the misperception that diabetes was caused by spiritual forces. This misperception usually resulted in such diabetes patients seeking care from other places such as prayer camps and/or from herbalists instead of visiting the hospital. Those that visit the hospital may not trust the diabetes self-care recommendations provided to them by their HCPs, may not adhere to them and only come to the hospital when they develop complications.

Those people that I was talking about were those who were reporting of local medications and spiritual healings. Majority of them were those who claim it was related to the culture. That some spiritual things or certain things and even up to now some people were even changing their medications. I think we even investigated, that was when we were told that they were having the mentality that it is due to some spiritual happenings. Because of that they were not also taking the drugs. Once they have that mentality that it is spiritual, somebody somewhere is working on them, they will not take our medications. Later they will come to the hospital worse. – Participant 12, Prescriber.

... Some of them will tell you that - they say with local medication it can be cured. With herbs, they can be cured. That is cure - which is one of their misconceptions. Sometimes, because they hear the condition is curable with herbs, they stop and they go in to buy those medications that is perceived to cure the condition. – Participant 3, Nurse.

HCPs further intimated that some patients misperceived that diabetes is a curse and once you are cursed with the condition there is nothing one can do about it and as result they do not follow recommended self-care behaviours.

They say its 'baari' as in it's a cursed sickness. So once it has affected the family, it means that it will affect everybody [in the family]. There's nothing you can do. –

Participant 6, Nutrition Officer.

HCPs thought that misconceptions that the use of herbal medicines could cure diabetes was rampant among patients. This misconception originated from patients' misconception that diabetes can be cured. Generally this misconception usually hindered patients' adherence to their diabetes medications as well as their dietary recommendations.

Yes. Some of them will tell you that - they say with local medication it can be cured. With herbs, they can be cured. That is cure - which is one of their misconceptions. Because diabetes is not curable. Sometimes, because they hear the condition is curable with herbs, they stop and they go in to buy those medications that is perceived to cure the condition. -Participant 3, Nurse.

A lot. Someone even came and said he met an herbalist who gave them some medicine which should be taken with alcohol. Meanwhile it is not advisable for diabetics to take alcohol and that is what they were doing. -Participant 5, Dietician.

Difficulty changing habits: HCPs were concerned that some patients usually found it difficult to change certain habits. Most of these habits were dietary related. Confirming the perceptions of the HCPs, some patients said they have been eating some foods for almost all of their lives and have developed a taste for such foods. As a result they found it difficult to follow recommendations that required them to either avoid such foods altogether or reduce the quantity or frequency of consuming such foods.

There are some particular food that you tell the patient not to take and the patient will be telling you that for this one, I'm used to it. I can't stop taking it- Participant 4, Enrolled Nurse.

My morning breakfast like this. I can't seem to be able to take it without sugar. It's very difficult. Participant 11, Patient.

Intentional non-adherence to self-care and fatalism: HCPs noted that while most patients were cooperative and eager to do something about their condition, some seemed not to care about their condition. These patients have poor attitudes towards self-care in general and some have a fatalistic belief that they will die whether they adhered to their diabetes self-care behaviours or not. HCPs suggested that some patients even prefer to die with the condition instead of making changes to their lifestyle.

It's also a misconception. Or is it - I might put it - self-endured something. Some of them will tell you, if you eat whatever you like and die, it's still the same death. Whether you eat good diet and die, its death. And if you eat what you are supposed to eat and you die - yes, they will tell you that slogan, "all die be die". So no matter what you tell the person, the person will still go back and do what she feels like doing. -Participant 3, Nurse.

Worrying about the continuous taking of medication: Some patients found it difficult to follow the new routine of taking diabetes medications every day for the rest of their lives. Those patients said they found it worrying and felt concerned about the chronic nature of diabetes and the continuous intake of diabetes medications for the rest of their lives. This

barrier was also shared by the HCPs.

*Am often worried about the chronic nature of the disease. Because how long can one continue to take these drugs. I sit down and I reflect, at my age can I continue taking these medications till thy Kingdom come. It is also a challenge. I know one guy, a colleague, the last two weeks we met, he said he had thrown away his drugs. He said we are too young to be taking these drugs. He wants to wait and see the reactions before he starts taking them. **Participant 10, Patient.***

*The problem is when you take it. You are always swallowing medicine. In the morning you take, afternoon you take and evening you take. **Participant 6, Patient.***

*It's because sometimes the person has taken their medication for quite too long. And because of that, she can't - she just ignores or stops taking the medication. – **Participant 3, Nurse.***

Feeling lazy to perform exercise: HCPs discussed that some patients were unable to exercise as required because they felt lazy to do so.

*The exercises too has to do with attitude, some of them their barriers could be laziness. **-Participant 14, Nurse.***

*Some too are just lazy or they don't see the importance of exercise. **-Participant 10, Nutrition Officer.***

*I don't do any physical activity or work I am just lying down. **Participant 21, Patient***

Side effects of medications: Both patients and HCPs alike explained that the medications have side effects that usually prevented them from adhering to the recommendations. Some of these side effects as identified by the patients included hunger, nausea, dizziness, shivers, and among others.

*Yes, it causes a lot of hunger and when you take it in the morning and evening, you become very hungry and your body starts shaking. So that is why I take it only in the morning. **Participant 18, Patient.***

*There are some they will give you to take and you will not feel your head. When you take the B.P medication plus the diabetes one, your head will be aching. So I find it difficult. **Participant 5, Patient.***

*Some of them especially the men; they do the defaulting. They believe that when you are taking the medications one of its bad effects is slowed libido. So when they take it for some time they complain that they are not able to “perform” the way they used to. So they start defaulting and won't come for the drugs. **-Participant 4, Enrolled Nurse.***

The fear of pricking the finger: Both patients and HCPs opined that some patients have glucometers and can also afford glucose strips to self-test but are unable to perform SMBG because of the pain of pricking themselves.

The difficulty is just the pricking part of it. **Participant 22, Patient.**

Some patients find it difficult to prick themselves. **-Participant 5, Dietician.**

Subjective norms/normative beliefs

Inadequate family support: HCPs and patients recognised that family support was key to successful diabetes self-care. They thought that family support was especially important for diet self-care behaviours and patients may not be able to adhere to their dietary recommendations at all if family support is inadequate.

They don't give me any support. It is 'cry your own cry'. **Participant 11, Patient.**

The barriers to receipt of adequate family support were generally gender specific as expressed by HCPs. Male patients visited the dietician or nutritionist without their spouses or those responsible for preparing their dishes. HCPs thought that this may have resulted in male patients' inability to adhere to any dietary advice because they may forget some of the advice or may not relay it to those responsible for their diets. HCPs also opined that female patients who found themselves in polygamous marriages found it difficult to adhere to some of the self-care behaviours such as diet and medication as they competed with the other wives to meet the needs of the husband.

During consultation, when a man who is living with the wife comes alone but he is not the one who cooks the food at home. So that is one of the barriers, so normally when it comes to consulting it is better for them to come with the person who prepares the meals for you. If the person comes alone, the question is what they tell their wives when they get home or do tell them what you instructed at all. **-Participant 8, Dietician.**

Some of them come with a lot of family issues. Because many of them, their husbands have many wives. So they are rather competing to please the husband instead of caring for themselves. So when you tell them to eat well, they get home and rather concentrate on taking care of their children and their husbands to the neglect of their own diabetes. **- Participant 6, Nutrition Officer.**

In most households of northern Ghana the entire family (which sometimes can be more than 10 members) eat meals cooked by one person or from a common pot. This arrangement sometimes makes it difficult for those who prepare the meals as they may not have time to prepare special meals for the diabetic patient or take into account the needs of the diabetic patient in the preparation of the family meal.

As for the diet and exercise; when you ask most of them, they either tell you their children are not around or their daughter in-laws won't help. Their daughter in-laws cook the family meal and the patients are usually old women or old men and can't cook for themselves. Their daughter-in-law worries about cooking for the entire family to eat and seldom has time for their special needs. **Participant 11, Nurse.**

Culture and beliefs: Given that the Ghanaian society generally associates being plump with a sense of a good living and wealth, plump patients who began to lose weight as a result of adhering to their self-care behaviours usually complained of their friends, family and significant others perceiving them to be sick. This perception usually resulted in these

patients defaulting on the recommendations. In addition, culture influences their adherence to dietary advice as it influences the kind of foods they eat.

Yes, culture might have an influence. There was this woman who came and she was morbidly obese and we were trying to bring her weight down. We started and she was doing very well. At a point she said a lot of people see her and question her why she was losing weight like that. So she came to tell us that we should add to her food. She didn't want to lose weight any longer. Because people are complaining that her weight is getting down and down and down. You know this part of the country, they always believe that if you are fat and plumpy it's a sign of good living. So once your weight is getting down, they think you have a problem. – Participant 5, Dietician.

Culture is the way we dress, the food we eat, ... So, like I said, the food we eat in my area if, basically, we farm only cassava, definitely affects how we adhere because that's what I have been eating from childhood.- Participant 7, Senior Nursing Officer.

Culturally, others perceived that exercise is for the rich or it's a western culture and hence will not participate in it if they think they are poor.

"The practice of exercising in the Northern culture is low or non-existent if I should put it bluntly. So if someone sees you exercising (e.g. jogging), it appears strange."- Participant 13, Nurse.

Social stigma: Due to patients' perception that they may be stigmatised as a result of their condition they usually do not want friends, family members, spouses and other close relations to know about their condition. Women in polygamous marriages dreaded being abandoned by their spouses if they were found to have diabetes. This perception usually affected their adherence to self-care behaviours and attendance to the diabetes clinic for regular checks and consultations.

There was an instance a lady was diagnosed and we asked her to assist us to call the husband and inform him to be supporting her among other things; she said "no" she won't allow that. After being told it was a part of hospital protocols to get guardians informed she still refused. So some don't even want relatives and friends to know about it; when they get diagnosed diabetic. Participant 3, Nurse.

I think stigmatization too; you come and then....some people don't even want to come for consultation. They don't want people to know that they are diabetic. They rather rely on over the counter medication.-Participant 8, Dietician.

Perceived behavioural control/control beliefs

Non-receipt of self-care support to perform SMBG: Some patients said they were not told to self-test their blood glucose and did not know the recommended blood glucose level.

They have never told me anything like that but the lowest I have ever had is 5.6. I have never had lower than 5. Participant 5, Patient.

Inadequate knowledge and skills to operate a glucometer: HCPs also thought that patients who are able to afford a glucometer found it difficult to either operate it or had challenges

doing the unit conversion as some of the machines are calibrated in different units. Patients shared similar difficulties.

And besides that, some are finding it difficult to operate it themselves. –Participant 5, Dietician.

Others too, they have the money, but when they buy the machine, the one to check it for them will be the problem. -Participant 4, Enrolled Nurse.

And when the children are not there I can't check because when I check I can't record the number. Participant 16, Patient.

Patients having comorbid conditions: According to the HCPs, some patients were unable to exercise due to the presence of other chronic conditions such as hypertension and other cardiovascular diseases.

The exercise, there are a few who come with an arthritis and they will tell you any time they try walking they feel pain, and some of them don't do. Those who come with multiple conditions, some of them it's not only diabetes, they're all age-related conditions.-Participant 5, Dietician.

Old age and body pains during exercise: Old age also prevented some patients from participating in exercise. Both patients and HCPs explained that due to their advanced age anytime they participated in any form of exercise they usually felt pains.

Sometimes with my age, the exercise is not easy. Participant 11, Patient.

Most of them are unable to exercise as a result of old age.-Participant 6, Nutrition Officer.

Yes how to bend down, the waist. To bend down, I have been struggling. When you want to flex and touch the ground, you will see that my waist will be in severe pains. Participant 5, Patient.

Poor income levels: HCPs opined that they frequently came across patients who did not have enough finances to cover the cost related to self-care. This barrier was more pronounced when patients had to buy drugs that may not be covered by health insurance. Other self-care behaviours affected by this barrier were diet and SMBG.

Another thing is financial barriers. The patient wants to comply but she/he tells you "look, I don't even get food to eat and much less the type of food you warn me not to eat?" "So if I get anything I eat". So all those things are barrier. – Participant 14, Nurse.

If not because of the price I would be checking everyday but the test strips are expensive for one to be self-testing every day. Participant 15, Patient.

At home, one has to check but if you don't have the machine how do you check. Participant 17, Patient.

Inadequate access to a variety of foods: HCPs were concerned that some patients do not have access to a variety of foods that will aid in their adherence to self-care behaviours. As a result, patients ate what was available to them. Furthermore, access to a variety of foods for patients to choose from was also related to seasonality. Some foods were available during the wet/rainy season but non-existent during the dry season. Also, some patients agreed with the HCPs that the foods recommended to them by their HCPs may not always be available. They said the supply of such foods is usually erratic in that they may get it at some times but not other times.

It's the setting that they are coming from. Some of them, where they are coming from will affect - will be a barrier. For example, you go from the Konkonba site. They mostly farm Konkonte. That is their stable. It's just there. So such a person when you advise him don't eat this don't eat that but when they go back that is what is just available. So it makes it difficult for them to resist. But that is what they see every day to eat. So the setting affects then. – Participant 7, Senior Nursing Officer.

Diet recommendations are too restrictive: Some patients rather felt that the limited variety of foods for them to choose from resulted from HCPs' recommendations being restrictive. They indicated that the recommendations limited them to only certain types of food. The regular consumption of such foods makes them become fed up and subsequently lose their appetite for such foods.

Yes, it's not easy. Some of the foods they advise us to eat I become fed up with it and I don't have taste for it. For instance they advised us to take porridge but as I speak I don't have taste for the porridge again because I've taken it for long time. And even bread, am not supposed to take because it is heavy. So if you want to eat bread you have to toast it. Participant 18, Patient.

Busy work schedules: Both patients and HCPs explained that some of the participants reportedly said their work schedule made it difficult for them to adhere to some of the self-care activities such as exercise and diet.

I think most of those we interact with are able to exercise. It is just a few. What they complain of is lack of time. They rise up early to go to work and come back late. We try to tell them to make time, it starts slowly. For exercising you can start with 5 minutes and progress from there. – Participant 10, Nutrition Officer.

The soup they want me to eat sometimes I don't get to eat it because by the time I would leave here for the house it is late and I just have to eat what they have prepared. Participant 24, Patient.

Discussion

The current study explored patients' and HCPs perspectives on the performance of diabetes self-care behaviours in which varied barriers were identified and conceptualised into the TPB constructs of attitudes/behavioural beliefs, subjective norms and perceived behavioural control. The TPB served as a framework to understanding the reasons why patients do not adhere to their recommended diabetes self-care behaviours.

Attitudes/behavioural beliefs

Misconceptions relating to the causes of diabetes and its care were commonly expressed by the participants. These misconceptions hindered a number of self-care behaviours including diet (in which patients' avoided carbohydrate rich foods because they felt diabetes was caused by high sugar intake), adherence to diabetes medications (seeking care from prayer camps or herbalists because they believed diabetes was caused by spiritual forces or it's as a result of curses), and diabetes self-care in general (as they believed the disease can be cured). The misconceptions reported in this study regarding the causes and treatment of diabetes differ from the poor understanding of diabetes and its treatment that is usually reported as a barrier to self-care among studies from high income countries (Bhattacharyya *et al.* 2011, Booth *et al.* 2013, Brown *et al.* 2002, Goderis *et al.* 2009b, Nagelkerk *et al.* 2006, Raaijmakers *et al.* 2013). The misconceptions found in this study are consistent with previous studies from Ghana (Aikins *et al.* 2010, de-Graft Aikins *et al.* 2015) and other parts of Africa that have identified such barriers to diabetes care including self-care (Abdulrehman 2015, Awah *et al.* 2008, Hjelm & Nambozi 2008, Mufunda *et al.* 2012). Self-care support and counselling sessions should thus focus on assisting patients to overcome these misperceptions regarding the causes and management of diabetes. Community-based interventions should also be implemented to help improve attitudes towards the disease at the community level.

Patients reported finding it difficult to modify entrenched dietary habits. This barrier was reported by both patients and HCPs. Our finding is similar to those reported by Booth *et al.* (Booth *et al.* 2013) among newly diagnosed diabetes patients from a hospital in the UK; the qualitative report by Ebrahim (2014) among diabetes patients from South Africa; and the qualitative report by Abioye-Akanji (2013) about West African Immigrant diabetes patients having challenges modifying their traditional West African diets. It is imperative that HCPs should endeavour to make dietary modifications more appealing, manageable, less daunting and achievable for patients (Booth *et al.* 2013). This may mean suggesting locally-relevant and successive small improvements to diet rather than abrupt major changes. These should be incorporated during individualised counselling and group diabetes self-management education.

In addition, we found that intentional non-adherence and fatalism affected patients adherence to self-care behaviours. Intentional non-adherence related to patients refusing to follow any recommendations given to them to cater for their condition. This may be due to a number of factors including denial or non-acceptance of being diagnosed with diabetes or the seriousness of the condition, feeling of wellness, worrying about the continuous intake of drugs, misconceptions and lack of trust in the effectiveness of the recommended treatment (Brundisini *et al.* 2015, Elwyn *et al.* 2003). Other factors may include the lack of motivation to adhere to the recommendation, cultural motives, and side effects of drugs (Vermeire *et al.* 2001). In a qualitative study of diabetes patients from Southern Ghana, Aikins (2005) identified chronic suffering characterised by financial difficulties, increasing complications, and inadequate family and social support as major contributing factors to intentional non-adherence (i.e. passive withdrawal from drug and dietary management) reported by patients. Aikins (2005) added that patients desired death as an alternative to chronic suffering from

diabetes. HCPs should continuously counsel patients to note that diabetes is a manageable disease and not a life sentence.

Fear of pricking the finger hindered patients' adherence to SMBG similar to the findings of Abioye-Akanji et al in a qualitative exploration of barriers to diabetes management among West African immigrants in the United States of America (Abioye-Akanji 2013) and those of Ong et al among type 2 diabetes patients from a primary care clinic of a teaching hospital in Malaysia (Ong *et al.* 2014). HCPs should provide information and support to people with diabetes regarding appropriate procedures of pricking the finger less painfully such as using the lateral side of the finger, limiting the use of the thumbs and index fingers, using needles that have shallower depths, and using alternative site of testing (e.g. the arm, abdomen and thigh) (Heinemann & Koschinsky 2008, Ong *et al.* 2014).

Lack of motivation or feeling lazy to exercise is consistent with other studies reported from developed countries (Dye *et al.* 2003, Korciakangas *et al.* 2009) but has not been identified in other studies originating from Sub-Saharan Africa. HCPs may be able to reinforce patients' motivation and commitment by educating them on the benefits and need for regular performance of exercise and also supporting them to adopt exercise strategies that are easy, low cost and able to be performed at home.

Subjective norms/normative beliefs

Family members are the significant sources of both instrumental (e.g. assisting patients to self-test) and emotional support (e.g. encouraging diabetes patients) for people with diabetes (Miller & DiMatteo 2013, Pamungkas *et al.* 2017). Family support has also been shown to improve adherence to diabetes self-care (Miller & DiMatteo 2013). Both patients and HCPs perceived a lack of family support required for diabetes self-care. For instance, we found that women in polygamous marriages struggled to adhere to their diabetes self-care due to competing interests to meet the needs of the husband. Inadequate family support hindered adherence to dietary recommendations and medication taking. Poor understanding of the causes of diabetes and its care at the family and community level were discussed as the reasons for the inadequate family support. This finding suggests that where possible, diabetes patients should be actively encouraged to involve family members in diabetes education programs and family support should be incorporated as part of the diabetes care plan as has been recommended by a number of care guidelines (Pamungkas *et al.* 2017).

Contrary to studies from high income countries but consistent with previous studies from Ghana and other parts of sub-Saharan Africa (Aikins 2003, Awah *et al.* 2008) we identified social stigma as a barrier to diabetes self-care. We found that some diabetes patients did not want family members to know they have diabetes and may not seek support to self-test their blood glucose for fear of being stigmatised. In addition, we found that women in polygamous marriages did not want their spouses to know they have diabetes for the fear of being stigmatised or deserted, particularly if they are seen to be taking medication. Another aspect of social stigma was the fear of losing weight as family members or friends may believe their health condition to be very serious. In the Ghanaian setting as well as in several African countries, being plump is generally considered as a sign of wellness and prosperity although

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this notion may be changing as more people are becoming aware of the health consequences of being overweight (Aryeetey 2016, Mogre *et al.* 2014). To the best of our knowledge, the perceived lack of family support and social stigma reported in this study have not been previously identified in other diabetes populations. These findings suggest the need to include family members in diabetes self-management education. It is also likely that culturally-relevant community-level interventions are required to address these social and cultural issues.

Perceived behavioural control

As per previous qualitative reports of studies from sub-Saharan Africa; barriers to SMBG included non-receipt of self-care support to perform SMBG and inadequate knowledge and skills to operate the glucometer (Abdulrehman 2015, de-Graft Aikins *et al.* 2015, Schmitt *et al.* 2013, Tewahido & Berhane 2017). There is the need for HCPs to continuously provide information and support regarding SMBG to persons with diabetes for them to be empowered (Hortensius *et al.* 2012, Nagelkerk *et al.* 2006). Empowerment based diabetes self-management education interventions have previously been shown to improve adherence to SMBG (Tang *et al.* 2012). HCPs should also implement individualised training regarding the use of a glucometer, continuous guidance and regular follow-up evaluations of the SMBG technique to improve patients' knowledge and skills in operating the glucometer.

Both patients and HCPs identified inadequate income levels as a common barrier to diabetes self-care. Our findings support those of previous studies from other parts of sub-Saharan Africa that report patients' inability to perform SMBG due to the high cost of glucose strips and the unaffordability of personal glucometers (Abdulrehman 2015, Hjelm & Beebwa 2013). In agreement with previous studies from Ghana (Aikins 2003, 2005) and elsewhere in Africa (Abdulrehman 2015, Muchiri *et al.* 2012), inadequate income levels made it difficult for diabetes patients to purchase medicines and to buy appropriate foods such as fruits and vegetables. Expanding the current national health insurance to increase the quantities of drugs given to patients and to cover more effective drugs as well as the introduction of subsidies for glucose test strips and needles may help reduce the financial burden for persons living with diabetes which may subsequently result in improved adherence to self-care.

Another barrier within the perceived behavioural control construct was patients' inadequate access to a variety of foods. Patients discussed that they did not have regular access to a variety of foods that they are required to eat to meet their dietary recommendations. Similar to our findings two studies (Lekoubou *et al.* 2010, Tewahido & Berhane 2017) reported limited availability of a variety of food items in the local market as a barrier that hindered dietary self-care practices among diabetes patients from Ethiopia.

Both patients and HCPs alike discussed that busy work schedules hindered patients' adherence to their diet, medication taking and regular participation in exercise. These findings are similar to those of Abioye-Akanji *et al.* (2013) in which West African immigrants reportedly found it difficult integrating their exercise recommendations to their daily work schedule and child care. Similarly, a study among African-Americans reported that participants found it difficult to integrate complex diabetes management regimen into their

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day-to-day activities (Utz *et al.* 2006). People with diabetes should be educated on suitable strategies, areas and times for performing self-care behaviours during work hours. The benefits of regular adherence to self-care behaviours should be emphasized.

Consistent with reports of previous studies from sub-Saharan Africa, barriers such as old age, body pains and having comorbid conditions hindered patients' adherence to exercise (Abdulrehman 2015, Tewahido & Berhane 2017). Walking is a common form of transport (relative to diabetes patients in HICs), but the presence of other conditions and old age may significantly decrease patients' ability to exercise. Participation in daily exercise regimens such as going to the gym may be unfeasible due to cost and other barriers. Patients should thus be given appropriate guidance and support to adopt exercise regimens that can easily be done in the home.

Limitations

The study may not represent the perspectives of those who do not seek biomedical care. The use of face-to-face semi structured interviews with an independent interviewer may result in limited social-desirability bias. The use of a convenience non-probability sample might have led to the selection of patients who were interested in improving diabetes self-care.

Conclusion

A wide range of barriers that hindered diabetes self-care were identified by both patients and HCPs. Barriers relating to attitudes and perceived behavioural control were more prominent than those relating to subjective norms. This is the first study to qualitatively explore diabetes self-care and its barriers in Ghana thereby increasing our understanding of diabetes self-care and its barriers within the context of a resource poor environment. The findings of this study highlight important areas that have not been previously reported which can inform the design of interventions in low and middle income countries to help improve adherence to diabetes self-care behaviours.

Implications for future research

This study is a contribution to the holistic perspective of self-care and serves as a foundation for future research. Our use of a theory-driven approach and literature search to derive the items in the discussion guide is worth noting as such an approach provides a conceptual framework to align the findings of the study. Future research could adopt similar approaches. Future research should also explore further the influence of polygamy on diabetes self-care and also how diabetes patients from large households adhere to diabetes self-care recommendations especially those relating to diet.

Relevance to clinical practice

Interventions should focus on assisting patients develop favourable attitudes towards self-care, and support their ability to perform priority self-care health behaviours. Such interventions will need to take careful account of the cultural context of patients' existing belief systems and therefore, may need to have a community-wide approach rather than solely focussing on the education of individual patients. Furthermore, HCPs should

encourage and support diabetes patients through targeted counselling to motivate and empower them to overcome barriers they perceive to be beyond their control.

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Table 1: Barriers to diabetes self-care categorised according to the constructs of the Theory of Planned Behaviour

TPB Construct	Barrier
Attitudes/behavioural beliefs	Misconception and use of herbal medicines
	Difficulty changing old habits
	Intentional non-adherence and fatalism
	Worrying about the continuous taking of medication
	Feeling lazy to perform exercise
	Side effects of medication
	Fear of pricking the finger
Subjective norms/normative beliefs	Inadequate family support

Perceived behavioural control/control beliefs

Culture and beliefs

Social stigma

Non-receipt of self-care support to perform SMBG

Inadequate knowledge and skills to operate the glucometer

Patients' having comorbid conditions

Old age and body pains

Poor income levels

Inadequate access to a variety of foods

Diet recommendations are too restrictive

Busy work schedules
