



Illness and Treatment Experiences of Adult Patients with Type 2 Diabetes Mellitus in the Urban and Peri-Urban of Central Ethiopia – A Qualitative Study

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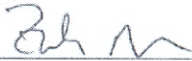
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Addis Ababa University
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Department of Pharmaceutics and Social Pharmacy

This is to certify that the dissertation prepared by Bruck Messele Habte, entitled: *Illness and treatment experiences of adult patients with type 2 diabetes mellitus in the urban and peri-urban of Central Ethiopia – a qualitative study* and submitted in partial fulfilment of the requirements for the Degree of Doctor of Philosophy (PhD) in Social and Administrative Pharmacy complies with the regulations of the University and meets the accepted standards with respect to the originality and quality.

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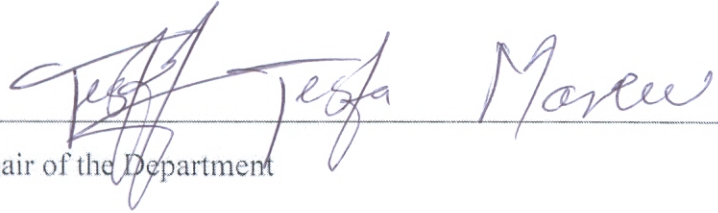
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Chair of the Department

Original Papers

This PhD dissertation is based on the five papers listed below.

- I. Habte, B.M., Kebede, T., Fenta, T.G., Boon, H. (2016). Explanatory models of adult patients with type 2 diabetes mellitus from urban centers of central Ethiopia. *BMC Res Notes*, 9:441.
- II. Habte, B.M., Kebede, T., Fenta, T.G., Boon, H. (2017). Ethiopian patients' perceptions of anti-diabetic medications: implications for diabetes education. *J Pharm Policy Pract.* 10: 14.
- III. Habte, B.M., Kebede, T., Fenta, T.G., Boon, H. Patient-healthcare provider communication – the perspectives of Ethiopian patients with type 2 diabetes (manuscript prepared).
- IV. Habte, B.M., Kebede, T., Fenta, T.G., Boon, H. (2017). Use of medicinal plants among Ethiopian patients with diabetes: A qualitative exploration. *Ethiop. J. Health Dev.*, 31(1):18-26.
- V. Habte, B.M., Kebede, T., Fenta, T.G., Boon, H. Barriers and facilitators to adherence to anti-diabetic medications – Ethiopian patient perspectives. *Afr J Prim Health Care Fam Med* (manuscript submitted).

Abstract

Illness and treatment experiences of adult patients with type 2 diabetes mellitus in the urban and peri-urban of Central Ethiopia – a qualitative study

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Introduction: Type 2 diabetes, which is increasingly becoming a public health problem in developing economies including Ethiopia, is associated with a high level of microvascular and macrovascular complications. Evidence from the Western world indicates that gaining an understanding of patient perceptions and experiences would serve as useful inputs in the design of effective strategies aimed at improving their care and health outcomes. This research project utilized different theoretical models, namely Kleinman’s explanatory model, Horne’s necessity-concerns framework as well as de Haes and Bensings’ medical communication model to explore the illness and treatment experiences of patients with type 2 diabetes in selected hospital settings in Addis Ababa and Butajira.

Methods: Qualitative interviews were held with 39 purposively sampled patients with type 2 diabetes who were selected to represent varied socio-demographic and a range of illness and treatment experiences. Interviews were conducted until saturation of key themes. The analysis and interpretation was carried out using a thematic analysis approach.

Findings: The findings from this study revealed that participants’ explanatory frameworks were influenced by the biomedical and traditional models (including cultural and religious influences). It was also apparent that participants’ biomedical knowledge was low which was expected given their low formal education status. Cultural influences were apparent for instance in the manner that participants labelled their illness as ‘sugar disease’ and their perception of suitable treatment strategies. Religion likewise exerted its own influence with respect to the perceptions of causation and the appropriateness of treatments. With regards to the anti-diabetes medication, findings indicated that participants’ perceptions revolved around their necessity and concerns which were also indicative of the utility of the Horne’s necessity-concerns framework. In this regard participants’ concerns about their

medications were not that much different to those of their Western counterparts in certain aspects (e.g., about the adverse effects and the number of medications) while they differed in others (e.g., associating diabetes-related complications such as eye problems to medication adverse effects) which seem to be influenced by their socio-cultural and low educational backgrounds. Perceptions about the necessity of their medications were however given less attention as compared to the concerns about safety issues. Though participants' concerns were mostly about adverse effects, inconveniences in handling and accessing their medications were also found to be sources of concern. It was also apparent that some of the participants' concerns were quite strong or not based on evidence but may nevertheless potentially affect adherence to prescribed medications. Findings with regards to participants' perception towards their healthcare providers were organized following de Haes and Bensing's communication model. Perceptions focused on fostering the relationship and the provision and gathering of information aspects. By and large, participants detailed their suboptimal experiences in the care provided by their healthcare providers that were below their expectations. Participants' adherence to prescribed anti-diabetes medications were negatively affected by a range of factors that included: perceptions about their illness especially related to symptoms and hope for a cure, perceptions about prescribed medications especially related to concerns, their relation to the healthcare providers and the health system factors such as the provision of diabetes education and availability of medications and religious healing practices especially use of holy water and religious duties. Factors that served as facilitators to adherence included the presence of diabetes complications and perceived health benefits that enhanced medication necessity perceptions, religious practices and social support. On the other hand, some of the participants reported using medicinal plants such as *Shiferaw* (*Moringa* spp.) and *Anamuro* (*Ajuga* spp) in a complementary manner to their biomedical regimens. While their use did not seem to negatively affect adherence, some participants reported adverse effects which led to discontinuation of these medicinal plants. Different factors influenced the use of medicinal plants including perceptions that bitter things were good for diabetes, claimed or experienced efficacies and mass media messages. Findings also revealed that the use of medicinal plants was occurring in the context of limited information which may further result in suboptimal health outcomes.

Conclusion: The perceptions held by the study participants towards their illness and its treatment were found to negatively influence their experience and adherence to prescribed anti-diabetes medications. The suboptimal care provision experienced by these participants appears to be another factor that contributes to the nonadherence issue. It is therefore recommended that a chronic care model be implemented that incorporates current care standards, strengthened and context specific diabetes education and adherence support programs.

Key words: Type 2 diabetes, Kleinman's model, Horne's Necessity-Concerns model, de Haes and Bensing Medical Communication model, Adherence to Anti-diabetes Medications, Qualitative research, Ethiopia, Addis Ababa, Butajira

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List of acronyms

AAU Addis Ababa University

NCDs Noncommunicable diseases

List of appendices

Appendix 1: Information sheet and consent form (English and Amharic versions)

Appendix 2: Interview guide for in-depth interview with patients with type 2 diabetes
(English and Amharic versions)

Appendix 3: Information card on socio-demographic and other information from patients
(English and Amharic versions)

Appendix 4: Institutional Review Board Ethical Approval

1. Introduction

This PhD dissertation details the qualitative work to explore the illness and treatment experiences of patients with type 2 diabetes who were attending treatment in three hospitals in central Ethiopia, two of which were in Addis Ababa and third one in Butajira. A qualitative design was followed for this study that used individual interviews.

This dissertation is organized into four chapters. The first one is this introductory chapter that contains background and problem statements, study rationale, review of relevant literature, introduction of the different conceptual frameworks used in the study and the research objectives. The second chapter describes the methods used in detail including the philosophical assumptions that guide the study and the ethical considerations. The third chapter presents an overview of the main findings of the study, a discussion of these main findings as well as their practice and policy implications. The final chapter presents the conclusions, recommendations and directions for further research.

1.1. Background

Non-communicable diseases (NCDs) have as of late drawn the attention of global leaders, international health organizations and health authorities in developing countries. Among these is diabetes mellitus that has been described by the International Diabetes Federation (2015, p 12) as “one of the largest global health emergencies of the 21st century”. Current estimates put the number of adults with diabetes at more than 415 million globally with this figure expected to increase to 642 million by the year 2040 (International Diabetes Federation 2015). The most prevalent form of diabetes is type 2 which is increasing due to cultural and societal changes. The International Diabetes Federation estimates that more than 193 million individuals with diabetes are undiagnosed and are therefore more likely to develop complications. In addition, one-in-15 of all adults is estimated to have impaired glucose tolerance with one-in-seven births being affected by gestational diabetes. Both of these can lead to an increased risk for the development of type 2 diabetes in later life (International Diabetes Federation 2015). Global reports also indicate that around 75% of individuals with diabetes live in low and middle income countries, with type 2 diabetes increasing across all countries (International Diabetes Federation 2015).

The number of adults with diabetes in the sub-Saharan Africa region and Ethiopia are estimated to be more than 14.2 million and 1.3 million people, respectively (International Diabetes Federation 2015). Studies from the African region including Ethiopia further indicate the prevalence of diabetes is much higher in the urban areas compared to the rural areas (Hall et al. 2011; Tesfaye 2008; Tran et al. 2011; Yemane et al. 2007). The rise in diabetes has been attributed to the rise in the economic development, urbanization, and life expectancy and as well decreased physical activity and less healthy diets (International Diabetes Federation 2015). In case of Ethiopia, the wide use of alcohol and tobacco have also been implicated as additional factors for the increase in the NCDs including diabetes (Tefsaye 2008).

Diabetes is estimated to have caused about 5 million deaths and cost between 673 million to 1.2 billion dollars in health spending in 2015 (International Diabetes Federation 2015). In this same year, over 321,000 people, most of whom were below the age of 60, are estimated to have died in the African region due to diabetes – the highest proportion of the world’s regions. In the case of Ethiopia, more than 23,145 deaths associated with diabetes were reported (International Diabetes Federation 2015). Diabetes places a substantial economic burden on countries and their health systems in addition to the large financial impact on individuals and their families. The large burden is related to the increased use of health services, productivity loss and the long-term support required to manage diabetes-related complications. The majority of countries are believed to spend between 5 and 20% of their total healthcare expenditure on diabetes and with such a high cost, this condition is bound to be a significant challenge for the health system and an impediment to sustainable economic development (International Diabetes Federation 2015).

The limited studies from Ethiopia in relation to diabetes care attest to the poor health outcomes of patients receiving treatment for diabetes at the public health facilities that serve the large majority of the population. For example, the patients had blood glucose and blood pressure above recommended levels and experienced high levels of micro- and macro-vascular diabetes-related complications (Feleke & Enquselassie 2005; Gudina et al. 2011; Wabe et al. 2011; Worku et al. 2010; Adem et al. 2011; Nigatu 2012). A review study also reported high levels of diabetic foot and other skin infections as well as high

levels of hypercholesterolemia and hypertriglyceridemia among diabetics in different parts of the country (Nigatu 2012). A study from Ethiopia reported that uncontrolled diabetes led to hospital admissions among a high proportion of patients (Feleke & Enquesselassie 2005). Another study indicated that direct hospital costs were significantly higher with substantial parts related to the management of diabetes-related complications (Feleke & Enquesselassie 2007).

A retrospective hospital-based study in Addis Ababa found out that the contribution of NCDs to the proportion of deaths was high and asserted that the healthcare system not geared towards the management of these group of diseases (Misganaw et al. 2012). This has actually been observed by facility-based studies from different parts of the country which have consistently described the services provided to NCDs including to diabetic patients as below standard. For example, a study by Feleke and Enquesselassie (2005) described diabetes care as below acceptable standards despite the presence of well-established material and human resource infrastructure especially in the surveyed public hospitals. Another report came from the southwestern part of the country indicated that the diabetes care in one of the prominent referral hospitals of the country was ‘far below any recommended standards’. In this study, around two-third of the patients with type 2 diabetes had blood glucose levels well above recommended levels. Despite having fasting blood sugar well above target level over the last three visits, no modification was done for glycemic management for 69.3% of these patients (Gudina et al. 2011). Similarly, the review study by Nigatu (2012) revealed that the recommended diabetes care components were actually provided only in a low proportion of diabetic cases and that a lower proportion of patients had adequate glycemic control. Study findings also depicted that a high proportion of patients exhibited inadequate knowledge on the biomedical management of diabetes (Feleke & Enquesselassie 2005; Gudina et al. 2011). The review paper by Nigatu (2012) similarly reported poor knowledge of chronic complications among both type 1 and 2 patients, with patients with type 2 diabetes exhibiting significantly lower overall knowledge compared to their type 1 counterparts.

A global strategy for the prevention and control of NCDs was endorsed by the World Health Assembly in 2000 which has since been followed by action plans with a particular

focus on low and middle income countries and vulnerable populations (World Health Organization 2011). African Ministers of Health have since expressed their commitment in their regional WHO meeting to develop integrated national action plans and strengthen institutional capacities for the prevention and control of NCDs (WHO Regional Office for Africa 2011). However such policy level decisions and plans may take time to bear tangible results as can also be discerned from a recent global assessment report (World Health Organization 2016). In the case of Ethiopia, it has followed up its global and regional commitments by publishing a strategic framework document and a national strategic action plan for the prevention and control of NCDs with diabetes among the four prioritized diseases. Among the objectives of the action plan was to ‘Strengthen and reorient health systems to address prevention and control of non-communicable diseases through people-centered primary care and universal health coverage’ (Federal Ministry of Health 2010; Federal Ministry of Health 2014). A national guideline for prevention, screening, treatment and care for NCDs including that for diabetes has recently come out as part of the government’s intervention efforts to reduce the diseases burden (Federal Ministry of Health 2016a). The situation on the ground in the Ethiopian case with regards to NCDs and diabetes is however still indicative of the enormous tasks ahead with a recent Federal Ministry of Health (2016b, p 59) report describing the situation as indicative of the “poor priority given to NCDs at all levels of the health system and in the community”. The initiatives that have been underway are indeed encouraging but need to be followed up with strong implementation and monitoring tools. Initiatives must also consider current global standards for diabetes care while also giving due consideration to the local contexts and cultures if they are to be successful and sustainable.

Current global practices suggest that healthcare for chronic conditions including diabetes requires patient-centered approaches that give due consideration to their preferences and concerns and requires their active involvement given that they are the ones responsible for the bulk of self-care activities such as medication-taking and lifestyle modifications (Capoccia et al. 2016; American Diabetes Association 2017). Study reports have revealed that adherence to recommended treatment regimens and patients’ active participation can be affected by their illness and treatment perceptions (Nam et al. 2011). Perceptions and adherence to treatment have also been demonstrated to be associated with patient outcomes

(Mc Sharry et al. 2011). Many of the studies have used conceptual models to guide their inquiry into illness perceptions that resulted in interventions including educational that were aimed at impacting illness perceptions so as to improve adherence to recommended regimens and also improve patient outcomes (Mc Sharry et al. 2011; Sapkota et al. 2015). Interventions that are available in the literature are mostly based on studies conducted in the Western countries setting or minorities living there and it may not be appropriate to apply them directly to the Ethiopian situation. Instead they likely need to be adapted considering local contexts and culture.

1.2. Rationale for the study

The increasing burden of diabetes and especially type 2 diabetes coupled with the low standard of care provided for these patients and consequent poor outcomes is indeed a cause for concern. Identifying some of these patients' illness and treatment experiences would serve as an input for further research works and interventions to improve patients' care delivery, their self-management activities and hence health outcomes. Interventions in a setting such as Ethiopia need to be informed by studies into the management of diabetes. Some of the relevant studies may include the assessment of the illness and treatment experiences of patients from the perspectives of the different actors including but not limited to the patients.

The present study is an attempt to assess the illness and treatment experiences of type 2 diabetes mainly from the perspective of the patient who is suffering from this condition. This research project utilized a qualitative study approach informed by different conceptual models including Kleinman et al's explanatory model, Horne's necessity-concerns framework and the six functions medical communications model that have been widely used elsewhere for exploring chronic diseases such as diabetes. The study settings selected were public hospitals in central Ethiopia; specifically two hospitals in Addis Ababa which mainly cater to urban patients and a referral hospital in Butajira town that serves peri-urban and rural communities.

Such a study could provide useful information about the prevailing situation and local contexts with respect to the management of this group of patients for policy makers,

practitioners, patients and other researchers who may want to follow it up with further studies. This is very important because in chronic conditions such as diabetes, the patient is an important decision maker and primarily responsible for the self-management of his/her condition including the self-administration of medication and other treatment regimens. This suggests that healthcare providers should be more open to sharing their power with the patient and be more patient-oriented as has been recommended by studies from the developed countries. At the same time, local culture and contexts should be considered in developing recommendations and thus the rationale of studies that depict patients' perspectives towards these diseases. Policy makers can use the information to plan interventions that can improve the situation while practitioners can use the findings to improve their care for their patients and improve outcomes. Training institutions may likewise use the findings as inputs in their curricula especially in relation to the communications aspect. The findings of this study can also help researchers in a number of ways including further studies to explore existing gaps and as well to investigate the findings of this qualitative study on a larger, representative sample. Furthermore, the findings may be useful for further intervention studies into addressing patients' illness and treatment experiences as well as their communication with their providers.

1.3. Review of the literature

1.3.1. Illness and treatment perceptions

Current standards for the biomedical management of diabetes recommend the active involvement of patients given their critical role for the management of diabetes including taking medications, self-monitoring, dietary and exercise modifications and foot care among other things (American Diabetes Association 2017). A number of studies have shown how adherence to recommended treatment regimens and other aspects of care have been affected by patient perceptions about diabetes and its treatment (Ashur et al. 2015; Alzubaidi et al. 2015; Broadbent et al. 2011; Nam et al. 2011; Martin et al. 2005; Lin et al. 2008). Perceptions about diabetes and adherence to recommended regimens have furthermore been associated with the degree of control established over glycated hemoglobin, fasting blood glucose, total cholesterol and blood pressure (Mc Sharry et al. 2011; Petriček et al. 2009; Broadbent et al. 2011). Negative illness perceptions were also

associated with emotions such as depression and anxiety which could further negatively affect adherence to recommended regimens (Hudson et al. 2014; Egede & Ellis 2010). The various study findings have been used to target interventions at illness perceptions and adherence in an effort to impact patient outcomes (Hornsten et al, 2008; Mc Sharry et al, 2011; Phillips et al, 2012). Majority of these studies however involve Western patients or minorities living in the West, some of which are discussed below.

There are a number of studies that have attempted to compare the perceptions of Western patients with diabetes with that of immigrants living in the Western countries. It was apparent that the rich findings depicting illness perceptions were from qualitative studies mainly using interview methods. The findings indicate that while there are some similarities, there were a number of peculiarities among the non-Western patients. According to some of these studies, Western patients in general reported better biomedical knowledge and overall understanding about diabetes. These groups of patients also exhibited more positive beliefs towards diabetes, had stronger beliefs in the both the ability of the prescribed treatment regimen as well as their own ability to control diabetes, suspected and related their symptoms to diabetes and sought help from the doctor, had better understanding of its chronicity, and tended to recognize and report depressive symptoms more openly. The Western patients also tended to internalize responsibility for their diabetes and commonly cited personal roles including lifestyle and dietary choices as being to blame for their diabetes (Alzubaidi et al. 2015; Hjelm et al. 2003; Barko et al. 2011; Lawton et al. 2007).

In general, non-Western study participants revealed limited biomedical knowledge about diabetes and what can be considered a different explanatory model. In a number of different cultures there is a tendency to label diabetes as ‘sugar disease’ and associate the condition to sugar (Awah et al. 2009; Yilmaz-Aslan et al. 2014; Suparee et al. 2015). Similarly, many patients described that their primary concern would be to decrease the sugar in their bodies and thus linked diet control to just controlling sugar intake (Choudhury et al. 2009; Suparee et al. 2015) and in some cultures to taking bitter things such as bitter melon, a medicinal plant (Choudhury et al. 2009). Some studies have reported about delays in visiting health facilities to get care for their diabetes because symptoms were not initially related to

diabetes and many individuals waited until the symptoms become severe. Or they may seek care for another condition which may lead to the chance diagnosis of diabetes (Hjelm et al. 2003; Hjelm & Mufunda 2010). There was a tendency to reported global, holistic and more physical symptoms related to their diabetes on the one hand (Barko et al. 2011) but also the tendency to associate their condition with the presence of physical symptoms and the lack of symptoms commonly referred to as 'mild' or 'invisible' (Yilmaz-Aslan et al. 2014). Participants in some study settings expressed strong negative beliefs about their illness, reporting more somatic complaints, and that their diabetes exerted significant burden on their lives (Alzubaidi et al. 2015). Diabetes was further considered to be a complex and unpredictable condition which requires one to constantly be on guard (Yilmaz-Aslan et al. 2014). Negative emotions such as feeling sad and stressed were expressed by some towards their condition (Suparee et al. 2015) where the depression was indicated in an indirect manner by describing other symptoms consistent with the condition in certain cultures (Barko et al. 2011). There were others however such as the Hispanic migrant workers living in the United States who openly expressed depression in relation to their diabetes (Heuer & Lausch 2006).

Participants of Indian and Pakistani origin for their part tended to externalize the responsibility for their diabetes and would instead ascribe it to life circumstances such as not being able to access appropriate diets and family responsibilities or experiences in moving to Britain (Lawton et al. 2007). Some have cited as causes for diabetes supernatural factors such as 'Allah's will' (Ashur et al. 2015), God in the context of 'divine trial' (Yilmaz-Aslan et al. 2014), punishment from God, fate and witchcraft (Hjelm & Mufunda 2010) and karma (Suparee et al. 2015). Social and emotional factors such as stress or negative emotions were also commonly believed to be causes among non-Western patients including Hispanics where they are traditionally known as *susto* (Concha et al. 2016; Yilmaz-Aslan et al. 2014; Hjelm et al. 2003; Hjelm & Mufunda 2010; Awah et al. 2008). While the supernatural and social causes appear to dominate, there were some who cited heredity and lifestyle factors (Hjelm & Mufunda 2010).

Diabetes was also thought to be an acute illness that would be cured in different cultures but also as one that was a lifelong condition requiring chronic medication-taking in others

(Suparee et al. 2015). Hope for a cure was widely expressed which was in tandem with the traditional and religious beliefs of the cause especially in participants from the African region but also following completion of the prescribed regimen in others (Heuer & Lausch 2006; de-Graft Aikins 2004; de-Graft Aikins 2005; Hjelm & Mufunda 2010; Awah et al. 2009). The different studies also report about the desire of participants for self-management so as to lead a normal life and not become dependent on others. However, most of the studies report about the very limited understanding that the participants had about their condition and their demonstrated passive role in their self-management (Choudhury et al. 2009).

With regards to studies that have assessed specifically medication-related beliefs, those that used qualitative, rich descriptions were very limited. The findings of quantitative studies revealed that patients' beliefs about medications such as about their necessity and concerns affected adherence to recommended treatment. The findings of a meta-analytic review for instance, indicated that patients may intentionally decide to not adhere to treatment if they have concerns about the potential or actual harms that could result from a prescribed medication especially if they feel they have no personal need for that medication. Alternatively, some patients may continue to take their medications they consider as necessary for their condition even if they have safety concerns. There could also be individuals who may forget to take their prescribed regimen if they have doubts about its necessity and thus unintentionally non-adhere (Horne et al. 2013). A systematic review study that assessed among other things the risk factors associated with nonadherence to anti-diabetic medications revealed that lower adherence was associated with concerns about the side effects and doubts about the necessity (Capoccia et al. 2016). It was also highlighted by this, and other studies, that variations among different cultures in medication beliefs may influence adherence. These findings are suggestive of the need to explore potential variations in medication beliefs and to follow patient-centered approaches that take into account patient preferences and address their specific concerns, be it about the necessity for or concerns about different treatments (Capoccia et al. 2016; Horne et al. 2013).

1.3.2. Patients' perceptions towards their healthcare providers

Studies into patient-provider communication from the perspective of patients with diabetes in Western settings have described different perceptions towards their relationship with their healthcare providers that influence adherence to recommended regimens (Matthews et al. 2009; Brundisini et al. 2015). Some of the factors that positively influence adherence include healthcare providers' support, collaboration and good communication strategies. Some of the factors that negatively influence adherence include relaying and explaining diagnosis in a less caring manner; providing instructions as warnings and in a threatening manner; deciding on topics to be discussed while also failing to address patients concerns; patients' perception of lack of support; barriers to communication; cultural insensitivity of some providers towards minorities; inaccessibility of healthcare providers such as short consultation times; and patients' desire to be perceived as individuals and not as illnesses. Another important factor was patients' hope for a collaborative relationship with their providers that was based on mutual trust and mutual agreement, that would allow open discussion about their challenges and the concerns of the healthcare providers. Patients also considered healthcare providers to be the major and reliable sources of information about their illness and its treatment although communication barriers may preclude collaborative relationships, preventing a shared understanding of appropriate treatment and thus hindering adherence to medication adherence (Brundisini et al. 2015; Matthews et al. 2009).

Among the studies from non-Western settings is one from Oman which focused on the perceptions of patients with type 2 diabetes regarding their clinical encounters with their primary healthcare providers. The patients largely expressed dissatisfaction with the care provided to them and cited weaknesses such as unfriendly welcoming, interrupted consultation privacy, poor attention and eye contact and lack of encouragement for the patients to ask questions by the providers. The participants in this study also noted their inability to participate in the dialogue with their providers or express concerns. Other issues cited by these patients from the Abdulhadi *et al* (2007) study include problems in being patient-centered, insufficient access to health education, professional incompetence and long waiting time (Abdulhadi et al. 2007). Studies from African settings that reported on

patient negative perceptions towards their healthcare providers have reported problems related to delays and lack of time by doctors to explain things and the array of restrictions and prohibitions imposed that were considered as barriers to compliance. In relation, the fact that patients' illness and treatment beliefs were not considered by their doctors was also among the issues that have led to conflicts (Hjelm & Mufunda 2010; Awah et al. 2008). One study involving Bangladeshi immigrants has reported their heavy reliance on doctors for most of their diabetes-related information (Choudhury et al. 2009) while another one involving Thai participants has reported that patients' self-management was influenced by their attempts to avoid the blame that may come from their healthcare providers when their blood sugar levels increased above the recommended levels (Suparee et al. 2015). Positive perceptions towards healthcare providers included their usefulness in providing medication and lifestyle related information and in terms of psychosocial aspects (Hjelm & Mufunda 2010; Hjelm & Nambozi 2008).

In the African setting, it was also apparent that one of the contentious issues that was the cause of disagreement and dissatisfaction with the health services and communication barriers was the different explanatory models held by study participants. This was another reason for using traditional medicines which has affected their anti-diabetes treatment (Awah et al. 2008). An Ethiopian study which determined that about a quarter of surveyed patients used traditional medicines, either concurrently or while interrupting prescribed medications, also revealed that patients were often reluctant to provide information to their doctors pertaining to the utilization of traditional treatment, fearing disapproval (Abdulkadir 1985). Such issues are illustrative of the importance of patients' perceptions towards their healthcare providers in influencing their self-management behavior including adherence to recommended treatment regimens. Given that there are no reported studies in this regard and its importance to inform interventions to improve diabetes care delivery, this study aims to explore patient perceptions of their expectations and their experiences towards their healthcare providers.

1.3.3. Illness and treatment experiences with diabetes

With regards to the studies dealing with the illness and treatment experiences of patients with diabetes, most of them are from the Western setting and are quantitative, although there are a few from other settings and of qualitative nature. These studies in general indicate that patients have low adherence to recommended biomedical regimens. Furthermore and especially in the non-Western settings, there was the tendency for the patients to use religious healing and traditional medicine complementary or alternative to the biomedical regimen.

Some of the studies involving Western patients that revealed low levels of adherence, also identified intentional nonadherence as a major concern. According to a study among patients living in England, many of the patients reported problems with their prescribed medications and had substantial unmet need for information. The major categories of these problems included experience of side effects and concerns about their medication such as skepticism in taking medicines and worries about taking new medicine including about potential interactions and allergies (Barber et al. 2004). Another study involving African-American and Latino patients of low socio-economic status also exhibited intentional nonadherence related to low necessity beliefs about their medications especially when sugar levels were considered in the normal range and concerns about side effects and addiction (Mann et al. 2009). A meta-analysis of studies on the utility of the necessity-concerns framework, most of which were from the Western settings revealed that higher adherence to prescribed medications was associated with stronger necessity perceptions and fewer concerns. This study concluded that interventions to improve adherence to appropriately prescribed medications may be more effective if they consider patients' beliefs about their treatment and how they perceive their personal need for the medicines vis-à-vis their concern about adverse effects of taking them (Horne et al. 2013).

Studies carried out among diabetes patients in the African region have reported different factors that have negatively affected their adherence to biomedically recommended treatment regimens. Some of these include their low biomedical knowledge, psychosocial burden of the treatment regimens themselves and stigma and discrimination (or fear thereof). A major factor that stood out is patients' explanatory model with regards to the

cause and the course of illness, i.e. hope for a cure that was influenced by traditional and religious beliefs. It was apparent from these studies that ethno-medical and religious healing were used by the study participants alongside the biomedical regimens. Some of the religious healing used included prayers and holy water. It was interesting that the hope for a cure was also expressed even among the more educated participants who hoped for a research breakthrough which might be further reasons to try out medicinal plants (Awah et al. 2008; de-Graft Aikins 2005; de-Graft Aikins 2004; Hjelm & Mufunda 2010; Hjelm & Nambozi 2008; Kolling et al. 2010; Awah et al. 2009). It may be worthwhile to note here that religious practices were reported as positive coping strategies not only by non-Western patients but also among the Westerners (Namageyo-funa et al. 2015; Hjelm et al. 2003).

Studies carried out among individuals with diabetes living as immigrants in Western countries have revealed a relatively higher use of medicinal plants compared to their nonimmigrant, Western counterparts (Barko et al. 2011; Hjelm et al. 2003). Some of the reported medicinal plants included bitter melon, neem, spices such as fenugreek and cumin and as well teas and walnuts (Porqueddu 2017; Choudhury et al. 2009; Hjelm et al. 2003). A study that assessed the use of herbal remedies among patients with diabetes in Trinidad and Tobago revealed that the use of herbal remedies was part of the shared culture in that region and that a large proportion reported using them at least once weekly for their condition. It was apparent that those who reported numbness or burning in the feet or feelings of weakness, tiredness, giddiness or dizziness used herbal medicines more frequently for their diabetes than those who reported other symptoms. Furthermore, participants who were on insulin less frequently used herbal medicines. Some of the commonly reported medicinal plants used as herbal medicines which have also been reported to demonstrate hypoglycemic activities included *Momordica charantia*, *Stachytarpheta jamaicensis*, *Aloe vera*, *Aloe barbadensis*, *Neurolaena lobata*, *Leonotis nepetifolia* and *Annona muricata* (Mahabir & Gulliford 1997).

A number of studies are available that have reported on the use of medicinal plants by patients with diabetes. Some of the studies that involved participants from African countries have reported a wide use of medicinal plants to manage their diabetes. Among those mentioned include *Moringa* powder, garlic, aloe, coconut, cinnamon, onion, ginger

and honey (Hjelm & Nambozi 2008; Hjelm & Mufunda 2010; Popoola 2005). In fact, the use of medicinal plants as part of traditional medical practice and as self-care tool are reported across the sub-Saharan Africa region with studies from the western Africa region corroborating this phenomenon (Dièye et al. 2008; Abo et al. 2008). In the study report from Senegal by Die`ye et al (2008), the majority (65%) of surveyed diabetic patients considered medicinal plants to be 'efficient' for the treatment of diabetes. Other reasons mentioned by these patients included the fact that they were traditional options and the lower cost. A minority of participants from the Senegalese study also mentioned side effects and lack of information on the doses of the medicinal plants. Given the fact that the disease is becoming of public health importance and the expected considerable use of medicinal plants by African diabetic patients either as home remedies or after recommendation by traditional healers, studying the use of this group of remedies will be important in the effort to identify their care practices and come up with appropriate recommendations.

Some of the studies from Ethiopia have also reported the use of medicinal by patients with diabetes in Addis Ababa (Abdulkadir 1985) and the southwestern part of the country (Wabe et al. 2011) which could have its own impact on the treatment of diabetes. The study by Abdulkadir (1985) had its main focus on the utilization of medicinal plants by diabetics attending the diabetes clinic at Black Lion Hospital. It reported that among the 729 patients registered and attending the clinic in 1982, 34.7% reported using traditional medicinal plants. Abdulkadir (1985) further reported that the treatment was taken concurrently with or during interruption of modern medicine. This practice of traditional medicine use could lead to nonadherence to recommended regimens and possible interactions with prescribed medicines. On the other hand, such studies could reveal medicinal plants used which actually have anti-diabetic activities such as the ones that have been reported by local pharmacological studies on the crude extracts of commonly used medicinal plants (Ghebreselassie et al. 2011).

1.3.4. Summary of the literature review

The literature review carried out on the illness and treatment perceptions and experiences of patients with diabetes revealed rich findings that also revealed differences based on the different contexts and cultures. Importantly, perceptions which have been observed to have considerable influence on patients' self-management of their diabetes are different among Western and non-Western patients and especially from that of the biomedical way of thinking which informs standard textbooks and authoritative recommendations on the treatment guidelines. Current global recommendations now recommend that individual and cultural contexts be considered so as to optimize the management of diabetes. Guidelines also are recommending patient-provider communications that are considerate of the different factors that may affect patients' self-management of diabetes but also aim for a collaborative relationship and recommendations not to blame patients for nonadherence when their health outcomes are not optimal (American Diabetes Association 2017). Of course such recommendations suggest the need for studies that illuminate some of the cultural and contextual factors that could be used to adapt them.

In light of the dearth of relevant literature in Ethiopia on these issues, and especially qualitative studies that provide rich information about the experiences and contexts that could guide further interventions, studies such as the present one are needed. This study will help to fill important gaps and could open the way for further exploration and wider recognition of patients' perspectives and experiences that can be used as inputs in the national effort to improve their care and health outcomes.

1.4. Conceptual frameworks

This study followed a critical realist perspective and used three theoretical models to better understand the illness and treatment experiences of type 2 diabetes patients (Cruickshank 2012). The models that informed this study were Kleinman's Explanatory Model, Horne's Necessity-Concerns Framework, and the Six Functions Communication Model. These three models helped to look at the data in a more detailed manner and from different perspectives. Each model is described in more detail below.

1.4.1. Kleinman's explanatory model

According to Kleinman, individuals have their personal explanatory models about their health and illness which could potentially influence their health seeking behavior, adherence to treatment and their health outcomes. It is therefore important that these explanatory models are understood so as to improve healthcare delivery. It appears that these explanatory models are informed by individual, family, social and cultural beliefs, religious affiliations, education and past illness and treatment experiences among other things. These social and cultural factors govern patients' perceptions, the manner in which they label, explain and value their discomforting experience including the symptoms and the complications as well as how they cope with their condition. Patients' perceptions and explanations about these generally include issues similarly described by healthcare providers' models which include: etiology; onset of symptoms; pathophysiology; course of illness (including type of sick role – acute, chronic, impaired – and severity of disorder); and treatment (Kleinman et al. 1978).

According to Kleinman's explanatory model, patients and healthcare providers have different versions or perspectives on sickness– the illness version for the patient and the disease version for the provider. Illness from the patients' perspective constitutes the entire condition including difficulties of living with and managing the condition. In contrast, providers usually disregard these illness problems and focus instead solely on the disease. The outlook difference is partly responsible for suboptimal clinical care, dissatisfaction with professional care and nonadherence to recommended treatment. Such differences may also serve at least partly as explanations for patients' resort to alternative treatments which may at times negatively affect the benefits of the biomedical regimen and lead to decreased health outcomes. It is therefore of high importance that providers try to understand the illness as well as the disease aspect and direct their care towards both aspects. This can be done by investigating patients' explanatory models so as to better understand the social and cultural influences on the disease and its management and thus incorporate their perceptions and concerns into the decision making process. The clinically relevant points of difference between the healthcare provider and patient perspectives can be focuses for

frank negotiation, clear explanation and patient education so as to improve the care process and clinical outcomes (Kleinman et al. 1978).

1.4.2. Horne's necessity-concerns framework

The necessity-concerns framework is among the widely used models to assess patients' medication-related perceptions. This conceptual model that focuses on beliefs about the necessity and concerns is deemed to play a major role in patients' decision-making process with regards to their medication-taking (Horne 2003; Horne et al. 2013). Patients' beliefs about their medications are likely to be different from their healthcare providers. These are expected to be based on their personal evaluations of evidence about the benefits and risks of different interventions (Horne et al. 2009).

The 'necessity' aspect of the Necessity-Concerns model deals with perceptions of personal need patients may have for their medications which may also be affected by their beliefs about efficacy of these medicines (Horne 2003; Horne et al. 2013). The 'concerns' aspect deals with both abstract and concrete concerns towards their medications. The concrete concerns are related to the unpleasant symptoms e.g. side-effects and disruptions of daily life, while the abstract concerns are related to the worries that regular use might lead to dependence or long-term effects (Horne 2003; Horne et al. 2013). Accordingly, patients tend to adhere when perceived necessity is strong and the concerns are weak. On the other hand, patients tend to intentionally nonadhere to their treatment when they have strong perceived concerns and weaker necessity beliefs. Furthermore, patients may tend to unintentionally nonadhere to their medication regimen and forget to take it if they have lower necessity beliefs, i.e. they consider it to be unimportant for their illness. Other factors that have been reported to intentional nonadherence include culture (Horne et al. 2013).

1.4.3. Six function model of medical communication

Haes and Bensing (de Haes & Bensing 2009) have suggested a communication model that can be utilized to investigate the encounter between patients and healthcare providers. This model has six functions that include (a) fostering the relationship; (b) gathering information;

(c) information provision; (d) decision making; (e) enabling disease and treatment-related behavior and; (f) responding to emotions. There is a dearth of literature that has used this model. One review paper has reported its usefulness in framing patient perceptions towards their expectations of doctors' behaviors during the clinical encounters. The findings of this review revealed patients' abilities to express their desired communication behavior of doctors which they were able to describe as 'basic and too much taken for granted, interpersonal abilities'. Additionally, findings revealed patients' desire for recognition and to be treated as individuals, along with other 'relational expectations'. These expectations were indicative of the importance of following flexible approaches on the healthcare providers' parts (Deledda et al. 2013).

Fostering the patient-practitioner relationship includes elements such as respect, trust and rapport which are considered to be critical components of a therapeutic relationship. Information gathering includes providers' activities to solicit information from patients about symptoms, experiences and expectations that would be used as inputs for establishing the diagnosis and treatment plan. Information provision involves the healthcare providers providing information to patients about their illness and its treatment that would help them in the decision making process and to better support their coping efforts. Decision making may involve an informed or shared decision making where communication between the healthcare provider and the patient plays a crucial role to reach an acceptable decision. A good decision making process has been determined to lead to improved adherence and health outcomes. Enabling disease and treatment-related behavior is related to the support or promotion of behavior related to the disease management that includes dietary and lifestyle related behavior changes and adherence to treatment among other things. Responding to emotions is another critical function which is important given that emotions are inherent in the illness condition where both the disease and treatment may make patients more vulnerable and consequently laden with negative emotions such as anxiety, sadness and even anger. And thus healthcare providers may naturally want to relieve this emotional distress. Such emotions may also interfere with the other goals of the clinical encounter and thus detection of such problems and appropriate referral may form part of the treatment plan (de Haes & Bensing 2009).

1.4.4. Summary of the discussions on conceptual frameworks

The three models facilitated exploration of different patient perspectives into their illness and treatment experiences. Kleinman's explanatory model opened the way to understanding individuals' outlook into their illness and treatment experiences mainly from the socio-cultural perspective. Horne's necessity-concerns framework for its part focused the attention of this research on the beliefs that the study participants had about their anti-diabetes medications. The medical communications model for its part turned the focus on the clinical encounters that the participants had with their healthcare providers. These models therefore allowed a more detailed and varied perspective of the illness and treatment experiences of the study participants. They were used in this study to guide three of the five objectives which in turn resulted in the respective original articles.

1.5. Objectives of the research

1.5.1. Research questions

The main question that this PhD research intended to answer was, 'What are the illness and treatment experiences of patients with type 2 diabetes attending their treatment in the outpatient settings of selected hospitals in Addis Ababa and Butajira?' and the specific research questions were:

- What are the perceptions of these patients with regards to their illness and its treatment?
- How do these patients perceive their communication with their healthcare providers?
- What are the experiences of these patients in managing their diabetes?
- What are the experiences of using medicinal plants by patients with diabetes alongside their prescribed medications?
- What are some of the reasons that hinder and facilitate the adherence to recommended anti-diabetic treatment of these patients?

1.5.2.Objectives

1.5.2.1. General objective

The general objective of this PhD research was to explore the illness and treatment experiences of adult type 2 diabetes patients receiving care in the outpatient settings of selected hospitals in Addis Ababa and Butajira, Central Ethiopia.

1.5.2.2. Specific objectives

The specific objectives were to:

1. Elicit patients' personal viewpoints or explanatory models with regards to type 2 diabetes
2. Elicit patients' beliefs towards their anti-diabetic medications
3. Elicit patients' perceptions of their expectations and experiences towards their healthcare providers.
4. Explore patients' experiences with medicinal plants
5. Explore the barriers and facilitators to anti-diabetic medications adherence inherent in Ethiopian patients' experiences with type 2 diabetes.

2. Methods

2.1. Choice of the qualitative study design

A qualitative research design was chosen for the present research to get a detailed understanding of the illness and treatment experiences including the contexts in which patients with diabetes live and manage their illness. This would be further justified in the context where there is a dearth of literature in the Ethiopian setting regarding the perceptions and experiences of patients with type 2 diabetes as almost all of the few studies available were quantitative surveys with limited attention to these important issues. The use of qualitative interviews for this research was appropriate as the purpose was to elicit the beliefs, perceptions and experiences of patients with diabetes in dealing with and managing their illness. Such an approach is further recommended to empower individuals who can share their stories (Creswell 2012; Miller & Crabtree 2005).

Qualitative research has been described as a method that utilizes an emerging approach for its inquiry; collecting data in a natural setting where study participants experience the study problem, and data analysis in a manner that is inductive, i.e. building patterns, categories and themes from the raw data in a bottom-up manner. The use of qualitative research in health has been argued to lead to an increased understanding of illness and disease by acknowledging and exploring it as a cultural construction. It can open up knowledge of a range of explanatory models and acknowledge the importance of spirituality in an individual's life. Furthermore, qualitative research can better illuminate that the therapeutic process especially for a chronic condition occurs in everyday life and is not limited to the clinic events. The presentation of qualitative research, be it in written form or oral, includes the voices of the study participants, a complex and rich description and interpretation of the findings and the reflexivity of the researcher (Creswell 2012; Miller & Crabtree 2005).

2.2. Philosophical assumptions

Researchers must ensure congruency between their philosophical assumptions and the research questions and objectives they intend to address. It is useful to understand how these philosophical assumptions influence not only the research process, but also the outcomes. In selecting the qualitative research approach for the present study, certain

philosophical assumptions were made about the ontology (the nature of reality), epistemology (the relationship of the researcher with the participants) and the axiology (the role of values in research) (Creswell 2012).

The ontological aspect deals with the nature of reality and that of human beings. In the present study, a critical realist philosophical position was selected (Bhaskar 2011). This position recognizes and in fact insists upon, the reality of events and discourses of the social world. Bhaskar (2011, p 2) however holds that “one will only be able to understand – and so change – the social world if the structures at work that generate those events and discourses can be identified...These structures are not spontaneously apparent in the observable pattern of events; they can only be identified through the practical and theoretical work of the social sciences”. The task of the scientist then would be to interpret how these structures operate in an open system for which theory can be used positively to inform policy or other recommendations emanating from the study (Cruickshank 2012). In line with this position, this research has strived to understand how patients with type 2 diabetes live with and manage their condition. In relation, different factors including individual, cultural and religious factors as well as healthcare providers and system factors that influenced their explanatory models and illness and treatment experiences including some that may have negatively affected their self-management and health outcomes were identified. This philosophical approach was amenable to qualitative research that has been described to be well suited in such studies that endeavor to understand individuals’ perceptions. The subjective realities of the different study participants can be evidenced in the multiple quotes that are based on the words of different patients with diabetes, reflecting their different perspectives (Creswell 2012; Cruickshank 2012).

With regards to the epistemological assumption, a critical realist approach was followed in this qualitative study. In line with this approach, the researcher tried to get as close as possible to the study participants with the intention of understanding the contexts in which patients with diabetes perceive their illness and its treatment, interact with their social world and how it influences how they manage their conditions (Bryman 2012). A basic assumption in this regard is the need to analyze individuals’ actions and exchanges which involves actively engaging them. For this purpose, in-depth interview was selected as

appropriate because it would allow the exploration of in-depth personal experiences that the study participants had with living with and managing their diabetes. In addition to the detailed information that was obtained, this interview method also allowed freedom to discuss personal topics in an inhibited manner. Furthermore, the study was conducted in the 'field', where the study participants attend their treatment, live, worship or recreate which are considered as important contexts to better understand the intended messages (Creswell 2012; Verhoef & Boon 2011).

While all researchers bring forth values to a particular study, qualitative researchers explicitly express those values which is the axiological assumption characterizing qualitative research (Creswell 2007). In this study, the values of the principal investigator are explicitly stated, considering that these values are bound to influence the conduct of the research including the design, data collection and analysis as well as its reportings. This has been presented in the 'researcher position and reflexivity' in the study.

2.3. Researcher's position and reflexivity

A qualitative researcher needs to be conscious of his relationship with the study participants. An important issue has to do with the positionality of the researcher which has been described as to how his various identities (e.g. age, race, gender and social class) may influence the interactions, processes and outcomes of the research (Hopkins 2007). The principal investigator therefore had to be conscious of his own positionality and how it may influence the manner in which the study is carried out and its results interpreted. The process of qualitative inquiry is too sensitive to the setting and the primary investigator had to be conscious about the manner of asking questions, the locations where the interviews were conducted and how the analysis and interpretation were carried out among other things.

With regards to the investigator's positionality there were three major considerations. First is the fact that the primary investigator is an academician and a PhD researcher and is bound to be considered as a 'scholar' among the study participants most of whom have limited education. This has been one issue requiring consideration as it might set him apart from the majority. Secondly and perhaps relevant to this study is the fact that the

investigator is a healthcare provider, a pharmacist, which he revealed to a few participants who asked. The majority of the participants were satisfied with the researcher's initial introduction as a 'researcher doing his PhD studies'. However a few of the better educated participants did question further and thus were informed that the person interviewing them was a pharmacist as well. The principal investigator had practiced for some years in a community pharmacy setting in Addis Ababa serving different kinds of patients including those with type 2 diabetes. This could have impacted the interaction with some participants. Although the researcher no longer involves in patient care activities, he cannot escape from his biomedical perspectives which is what the patients are encountering in the clinics and that may have affected the design, interview process, analysis and interpretation. In this regard, some of those who knew about the researcher's status as a healthcare provider may not have revealed some of their actual perceptions and experiences.

On the other hand, the fact that the principal investigator is from the health sciences and thus of a quantitative background may have its own impact in the design, conduct and analysis of the research. For instance, during the interview the investigator had used a preprepared set of questions for the interview guide as per the predetermined research themes. This interview guide was used in the early stages so as to cover all questions faithfully. Reflection following the interview and the preliminary analysis indicated that the participants had little interest with some of the questions. This is suggestive that researchers should enter the field and interview with an open mind so as to be able to explore the subject matter collaboratively with the participant. It is further testimony of the need to use the interview guide as a mere steppingstone and that qualitative researchers need to be willing to 'discard' their interview guide should it become overly restrictive for the interview (Hsiung 2008).

The third consideration had to do with the socio-demographics where the principal investigator is male, an Ethiopian, an Amharic speaker, a native of Addis Ababa and a follower of Orthodox Christianity. Such a background would bring commonalities with a number of the participants which may have helped in a better acceptability by the participants but also provided a situation where he had some understanding of the context in which the diabetes study participants live and struggle with their illness and its treatment.

In actual context, gaining access to the participants and their lived experiences was achieved with minimal restriction in Addis Ababa but also in Butajira. He also personally knows patients with diabetes in the course of his life some of whom have been close relatives. His experiences as a native as well as specific experiences with patients also gave him some idea about the use of religious healing especially among the followers of Orthodox Christians and also about the use of medicinal plants. That did not however prevent him from presenting himself as naïve to their experiences and doing his best to inquire for deeper and richer details of the participants' perceptions and experiences.

The principal investigator has tried his best to approach the patients as a 'researcher' with an interest in diabetes and diabetes patients and has not volunteered his profession lest they saw him as another healthcare provider. He has instead tried to be conscious of his position and attempted his best to document their perspectives and their experiences as 'any' social scientist will do. It is however very possible that the researcher's positionality as a PhD researcher, a healthcare professional and his socio-cultural background has influenced his relationship with the study participants and as well during the analysis and interpretation phase. Most of the participants seemed to be content to discuss their illness and treatment experiences. For one, it was an opportunity to discuss about their concerns about the healthcare delivery in the respective hospitals including about their healthcare providers, the different doctors each time they came to the hospital, low level of diabetes education provided, problems with medicines accessibility, delays in the start of the clinic services and cleanliness of the facilities among others. In revealing this, some were just airing their frustration while others may have assumed that the investigator had some authority or at least may relate their message to the responsible bodies. For others, it was an opportunity to discuss about their illness experiences including about the many challenges that they faced and many appeared to experience relief from an empathetic conversation. There were still others who had a need for information about their illness or its treatment and were seeking advice in that regard. This the primary investigator was able to address on issues that could be handled and offered advice to consult a relevant healthcare provider for the others. The consultation and referral were all done after the completion of the interviews. The principal investigator maintained a diary to note his reflections throughout the research

process so as to be able to assess his assumptions, to document any factors which may influence the research process and of course as a quality assurance means.

2.4. Selection of study settings

The settings for this study were three selected hospitals in Addis Ababa and Butajira, both of which are located in central part of Ethiopia. Amharic, the official language of Ethiopia, is widely spoken in both Addis Ababa and Butajira.

Addis Ababa city is the capital city of Ethiopia and the largest urban center hosting almost 25% of the urban population in the country. There are a total of 11 public hospitals in Addis Ababa including the one managed by Addis Ababa University (AAU), four managed by the Federal Ministry of Health designated as referral hospitals and six hospitals managed by the Addis Ababa City Administration. The city administration also operated 88 health centers and this number was expected to increase in the coming few years (Federal Ministry of Health 2015a). Six of these hospitals offer specialist diabetic services of which four general hospitals, namely Yekatit 12, Menelik II, Ras Desta Dantew and Zewditu Memorial Hospitals are managed by the city administration (Feleke & Enquesslassie 2005) and are expected to primarily serve the residents of Addis Ababa. Two of these hospitals, Tikur Anbessa Specialized Hospital run by AAU and Yekatit 12 General Hospital, that are serving a high number of patients with diabetes were selected as the study sites for the Addis Ababa study.

Tikur Anbessa Specialized Hospital, located in Lideta Sub City is the largest teaching and national referral hospital run by AAU. During the study period, the hospital had 850 beds for pediatric and adult patients to be treated as inpatients. The major operations of the hospital are to provide medical services, training to undergraduate and graduate programs in the College of Health Sciences and to medical residents and conducting research in the health sciences. The number of physicians employed directly by the hospital at the time of the study was 20. This number, however, does not include the resident and specialist physicians who were working in the School of Medicine. The number of nurses was 600 and there were 26 pharmacy professionals including 6 druggists. The hospital provides diagnostic and medical services in the outpatient, inpatient and emergency departments.

Other services in the outpatient department include the information service, referral clinics /units/ service, special diagnostic service, pharmaceutical service and minor surgery service. The inpatient medical service includes internal medicine, surgery, gynecology and obstetrics, pediatric, intensive care units for internal medicine and gynecology, radio therapy, anesthesia department service and infant recovery service. Endocrinology unit is one of the specialty units of the hospital, which provide service for diabetes patients. Patients with diabetes are managed in the Diabetes Center that was run during the study period by three endocrinologists and two internists attending the endocrinology subspecialty program who work as consultants on a rotating basis, five to six residents in the Internal Medicine program who during their month long attachments are assigned to take the primary role in managing patients, six nurses and one recently recruited pharmacist. Patients treated in Tikur Anbessa would be ‘randomly’ assigned to one of the doctors each time they come for their clinic appointment.

Yekatit 12 Hospital, located in Arada Sub City, is a hospital managed by the Addis Ababa City Administration. It was a 265 bed hospital that was undergoing a service and facility expansion at the time of the study. This hospital had recently become a teaching hospital for training medical doctors in the country and thus the formal change of its name to Yekatit 12 Hospital Medical College. The hospital had a total of 564 staff of which 351 were health personnel including 23 specialists, 30 general practitioners, 197 nurses, 13 pharmacy personnel, and 88 comprising the other medical personnel. The clinical services for patients with diabetes were predominantly offered in the general outpatient department that was run at the time by four general practitioners and four nurses. Similar to that of Tikur Anbessa, patients coming for their clinic appointment would be ‘randomly’ assigned to be seen by one of the doctors. Those cases that were deemed to need specialist care were referred to the medical clinic run by internists on a rotating basis.

This study aimed to explore the perspective of patients living not only in urban settings but also that of the peri-urban and rural part of central Ethiopia for which reason Butajira town was selected as an additional site for the study. Butajira town which is located 135 kms away from Addis Ababa has one publicly owned referral hospital and a public health center while another NGO run hospital exists about 10km away from the town. A growing number

of private clinics and dispensaries are also reported to exist. Butajira is home to the Butajira Rural Health Program, which is one of the very few demographic surveillance sites monitoring vital events in populations in the country that has been operational since 1987 (Shamebo 1994; Tesfaye 2008) . It has, therefore, a rich source of information about the health status of its population including a population-based study on cardiovascular risk factors that included populations from both the rural and urban part of Butajira (Teskaye 2008). The Butajira Rural Health Program is an AAU public health ‘laboratory’ managed by the School of Public Health, College of Health Sciences to which the investigator has better access. The staff working there were expectedly lower in number and expertise than those in the Addis Ababa hospitals. The care delivery for patients with diabetes at Butajira had been similar to that of the other two study hospitals described above. Butajira had however lately established a medical clinic run by a general practitioner and a nurse to separately serve patients with diabetes. At the time of this study, these patients had just started seeing the same doctor when they came for the monthly appointment.

2.5. Sampling and recruitment

Participants for this study were patients with type 2 diabetes who were purposively selected while attending treatment in the selected hospitals during the study period. The inclusion criteria for this study were: age of 18 years and older, being on anti-diabetic medications for at least a year and not exhibiting overt or known psychiatric conditions. The only exclusion criterion was being a healthcare professional. Furthermore, efforts were made to include participants with varying socio-demographic and socio-economic backgrounds such as sex, age, marital status, religion, educational level, employment status, place of residence (in case of Butajira) and a range of illness and treatment experiences. In this aspect, the principal investigator initially recruited every one who fulfilled the study criteria. After about three or four participants were recruited and interviewed in each site and the initial analysis of the interviews and of the participants’ background ensued, additional recruitment followed a more purposive approach. For example, all those recruited were initially females, and thus subsequent recruiting focused on the males. In this manner, age, religion, educational level, duration of illness and medications used were taken into consideration and some of those originally approached were not included if they did not

fulfill these additional criteria. Study participants' recruitment was facilitated by the respective clinic nurses whereby they identified eligible patients and introduced the study.

Once a preliminary selection was made, the principal investigator followed up by contacting each potential study participant to begin the recruitment process. In this a brief self-introduction was followed by additional information about the study such as the general purpose of the study and about further eligibility checks. These checks ensured that the individual was a resident of Addis Ababa/ Butajira or its environs, able to communicate fluently in Amharic and willing to complete in-depth interviews. Responses to the checklist was used to determine if an individual was eligible to participate in the study or not. If an individual was found to be eligible to participate in the study, he or she would be informed about it and further information provided that was available in the information and consent form (Appendix 1). When however an individual was found not to be eligible, an explanation was also provided as detailed in the information and consent form.

For those individuals who were found to be eligible, still further information about the study was given in the form of a verbatim reading of the study information including more detail about their required participation, short description of measures that would be taken to ensure privacy, anonymity and confidentiality (Appendix 1). Following this it was assessed whether each individual was still interested in the study or learning more about the study. In the end of this exercise, time was taken to respond to any inquiries that the individual may raise before they could move forward. Once participants who could potentially be involved in the study were identified and their eligibility was determined, they were asked to sign the informed consent form (Appendix 1). This was followed by arranging an initial meeting date at a location that was mutually acceptable to conduct the first in-depth interview.

In this manner, a total of 45 participants who fulfilled the study criteria were approached of which 39 were able to actually take part in the study. The other six were not included due to some refusing citing personal reasons or due to problems in telephone communication. Among the study participants, 24 were from Addis Ababa with Tikur Anbessa and Yekatit 12 Hospitals contributing 12 each. The remaining 15 were recruited from Butajira Hospital. Although a pre-determined sample size was not set when entering

the field, the final sample size was reached based on the concept of data saturation described as, ‘the point where you have identified the major themes and no new information can add to your list of themes or to the detail for existing themes’ (Creswell 2012). Data collection at each of the three study sites was stopped after conducting two additional interviews following a preliminary analysis that was indicative of data saturation.

2.6. Data collection instruments and procedure

Data collection for this study comprised of in-depth interviews with individual participants with field notes taken about each encounter. The in-depth interview guide was mostly framed on and adapted from Kleinman et al.’s (1978) explanatory model, Horne’s (2003) Necessity-Concerns framework and Abdulhadi et als’ (2007) paper on patient perceptions towards their healthcare providers. See Appendix 2 for the interview guide. These set of questions aimed to understand and capture study participants’ illness explanatory models including about the symptoms, illness course, problems encountered as a result of their diabetes, causation and treatment; medication-related perceptions about their necessity and concerns; and about their perceptions towards their healthcare providers including the doctors, nurses and pharmacy personnel. The interview guide which was initially prepared in English was translated to Amharic and back to English where the consistency was checked before the Amharic version was used in a pilot study prior to the conduct of the main study. In the pilot study, test interviews were conducted with three patients with diabetes attending their treatment in a hospital setting to ensure the comprehensibility of the interview guides. As this pilot test did not identify any major issue with comprehensibility, the interview guide prepared was largely used in its original form. Data that were obtained from the pilot test was not included in the analysis.

The in-depth interviews that were held from December 2013 until March 2014 by the principal investigator lasted from 30 to 120 minutes (median duration of 49 min). All the interviews (completed in Amharic) were audio-recorded with the consent of participants. The interviews were conducted in a conversation-like manner to facilitate the exchange of information focusing mainly on eliciting information and getting feedback from the study participants. During the interviews, standardized probes were not used although prompting

questions were used to gain deeper understanding on a particular topic or for the purposes of clarification or elaboration. Effort was also made not to discourage the participants to discuss issues that were of concern to them freely so long as they are within the broad framework of their illness and treatment experience of diabetes. The in-depth interviews were supplemented with field notes of the interview. The interviews were conducted in different places including quiet spots of restaurants and cafes, church compound, participant homes, academic office and vacant classroom in the School of Pharmacy (AAU) and secluded location in the hospital compound. Following each interview, basic information about the recruit was taken including about the socio-demographic and socio-economic backgrounds, illness duration and prescribed medications (see Appendix 3).

2.7. Data analysis

The data from the in-depth interviews which were all audio-recorded were transcribed by an experienced research assistant. The field notes taken during each interview were likewise transcribed by the principal investigator. Quality of the interview transcripts was checked by the principal investigator by listening to randomly selected audio-recordings. This check did not reveal major issues with the quality of the transcribing. The transcripts were repeatedly read that helped in the development of preliminary analytic ideas. This was followed by open coding that led to the identification of key content areas and then further grouping into separate subthemes and main themes depicting participants' illness and treatment perceptions and experiences. For this a thematic analysis approach was used which has been demonstrated to be a flexible tool while providing detailed and rich accounts of the results (Braun & Clarke 2006). Coding of data from each study site was continued until data saturation and no new information was emerging (Creswell 2012). Every effort was made to ensure that the analysis was grounded in the data rather than just reflecting the analytical frameworks that are used for this research. In this regard, an inductive style was followed with 'immersion' into the transcripts from the interviews and the field notes read and reread individually until they made sense. There was also a 'simultaneous immersion' into literature from the field that influenced the data analysis (Sandelowski 1995).

The initial stages of the data analysis were done in Amharic. The field notes were primarily used for the reflection on the experiences of the principal investigator and the participants and the clinic settings which also enabled him to focus his attention on any issues that needed further investigation in the subsequent interviews. The field notes were also analyzed for any emergent themes. Patterns and themes emerging from the transcripts of the initial interviews in each site were discussed with the research assistant and other PhD candidates in the group. Use was made of different and relevant conceptual models which provided a framework for both the 'interpretation and representation of the data' following preliminary analysis. The use of conceptual frameworks such as Kleinman et al.'s (1978) explanatory model and Horne's (2003) Necessity-Concerns framework has been found to increase confidence in the codes and themes that were generated, and in a manner served as a theoretical triangulation (Sandelowski 1993). This was followed by further interpretation that was conducted after translating key sections of the transcripts, i.e. those that are relevant to the emerging themes, to English. The principal investigator worked with one of his supervisors (Prof. Boon, who is a medical sociologist with a pharmacy background) to interpret key findings until they reached consensus. This was followed by further discussions with his other supervisors. The data management including storing, searching through the data for specific phrases or words, assigning codes and organizing into subthemes and themes was facilitated by NVivo version 10 qualitative data analysis software.

2.8. Quality of the research

2.8.1. Validity

The issue of quality of qualitative research has been a subject of attention by many researchers who reported different perspectives (Creswell 2007). In the present research, a range of strategies were used to ensure the quality of the research including clarifying the researcher's position and reflexivity, prolonged engagement in the field, as well as researcher and theory triangulation (Creswell 2007).

The principal investigator spent a total of more than four months in the study settings and engaging with the study participants. In this endeavor, he was able to interview a number

of participants, some of which he met more than once. Such extended stay and repeated encounters has helped to understand what is important and of concern to the participants and of relevance for the purpose of the study and of interest to focus (Creswell 2007).

The other issue is about clarifying the researcher's bias so that the readers will know his position and of any bias or issues that may influence the research (Creswell 2007). In this regard, this paper has dedicated a section clarifying the position and reflexivity of the principal investigator.

This research strived for multiple triangulations in order to gain a more thorough understanding of the phenomenon. One of these is the triangulation of data where the interviewer used interviews and field notes data from multiple individuals and at different sites which enabled for a varied spectra of perceptions and experiences (Creswell 2012). The other issue is the involvement of different researchers from different background. The design, conduct, analysis and interpretation and the write up of this dissertation was done with the close collaboration of his supervisors Prof. Boon (a senior medical sociologist with a pharmacy background) and Dr. Teferi a senior pharmacoepidemiologist with a pharmacy background) and his co-supervisor Dr. Tedla, an endocrinologist with an almost daily encounter with patients with type 2 diabetes. Furthermore, continual discussions were conducted with other PhD candidates in the team who were all involved in qualitative researches. Such discussions with senior researchers having different practice and research backgrounds helped to enrich the analytical and interpretation process and served as a further triangulation by virtue of the different investigators (Creswell 2007).

2.8.2. Reliability

Reliability in qualitative research can be addressed in different ways including the use of detailed field notes, audio recording the interview for subsequent transcription, the use of computer software in the analysis of the data and intercoder agreement use of multiple coders to analyze transcribed data (Creswell 2007). In the present study, reliability was maintained by taking detailed field notes which were transcribed. Furthermore, all the interviews were audio recorded, transcribed in MS Word and then analyzed with the support of a computer software for qualitative data analysis, NVivo version 10. The

primary investigator also worked on the data analysis and interpretation of the key findings with Prof. Boon (highly experienced in qualitative research methods) until consensus was reached.

2.9. Ethical considerations

This research was approved by the Institutional Review Board of the College of Health Sciences, Addis Ababa University (protocol number 036/13/PSP, see Appendix 4). Following this approval, all the hospitals where the study took place gave permission for the conduct of this study.

2.9.1. Informed Consent Process, Privacy and Confidentiality

All the participants recruited for this study were provided with adequate information about the study and their participation before they were requested to consent in written form. Those participants who were not able to write stamped on the signature page using their finger. An information and consent form was prepared in English which was translated into Amharic and used with the participants (see Appendix 1). They were further told that their involvement was voluntary, and that their identity would be held in the strictest confidence and that anonymity maintained in the research reports. Patients were informed that their decision to participate or their choice to decline would not in any way affect their care or any other services in the hospital. Audio-recording was done after informing participants who were told that they can request that it be stopped at any time or the interview for that matter. With regards to withdrawing from the study, the information sheet and consent form clearly specified the conditions including that the information collected prior to the withdrawal would be retained and that no further information would be collected after that.

All material identifying the participants in the study, including audio-recordings of interviews and interview transcripts, field notes and any others were stored in locked files at the investigator's office at the School of Pharmacy, Addis Ababa University and were accessible only to himself, and his graduate supervisors. Audios, reports based on this research and all paper files were anonymized – with no names attached, as all identifying information were removed, except a code number or pseudonym--prior to analysis of data

or storage of it. All computer files were password protected, and data collected is kept indefinitely in an appropriate database. No reports from this study have or will not identify any single individual. With regards to all written reports as well as other future forms of presentations where verbatim quotes will be used, it was noted in the information sheet and consent form that anonymity would be maintained in cases excerpts from the interview were or would be used.

2.9.2. Risks and Benefits

The study is assumed to have entailed minimal risk to the study participants. In the conduct of the study the principal investigator did not detect any major problems, physical or emotional. Some participants, may have in fact benefited from the opportunity of being listened to and the chance to reflect on their perspectives and experiences with some expressing their appreciation in this regard. Furthermore, patients and practitioners may benefit in the future if some changes are made to the health services to improve the situation as a result of the reports emanating from this study and further engagements by the research group. Participants were free to decline to have their interviews audio-recorded, to decline to discuss issues that they find uncomfortable, to request that components of their interviews not be audio-recorded; or to stop participating in the study at any time.

3. Key findings and discussion

3.1. Introduction

This study has contributed to an understanding of the illness and treatment perceptions, beliefs and experiences of patients with type 2 diabetes from Addis Ababa and Butajira and its environs. The findings have highlighted how cultural and religious factors coupled with low biomedical knowledge influences the practices of these patients which is further constrained by different resource levels and system factors which may have contributed to the suboptimal adherence among the study participants.

In this chapter, an overview of the main findings from the five papers that constitute this PhD study will be presented. This will be followed up by discussion that will further explore key issues raised by this study and their practice and policy implications. The chapter will end by stating the strengths and limitations of the study.

3.2. Overview of the main findings

The main findings from Paper I revealed participants' explanatory models that were influenced by both biomedical and traditional models. Participants' biomedical knowledge was limited, which was not unexpected given the low formal education status of the majority. The traditional influence was pervasive amongst participants which was informed by both cultural and religious factors. The cultural factors were clear, for example, in the naming of their condition as 'sugar disease' but also in their perceptions of appropriate treatment strategies. Religion had its own influence with respect to perceptions about the cause of the illness and also the appropriate treatment. For example, religious healing was quite popular, especially among the followers of Orthodox Christianity. Participants discussed treating diabetes with religious healing and medicinal plants alternatively or in a complementary manner to the prescribed biomedical regimen. Diabetes care for these patients should therefore consider local and individual contexts and strive for a patient-centered approach that also considers mental health aspects.

The main findings from Paper II revolved around the necessity and concerns that participants had in relation to their medications. It was apparent that their perceptions were

similar to those of Western patients in certain aspects but different in other aspects which seem to have been informed by socio-cultural contexts and the low educational status of the participants. Necessity perceptions were given less emphasis compared to the concerns about medication adverse effects. Concerns about medication adverse effects focused on those perceived at an abstract level and as well those that were actually experienced. Additionally concerns were expressed about inconvenience in handling medications especially insulin and about access issues. The findings indicate that some of the concerns were quite strong and with others based on unfounded evidence which in any case have the potential to negatively affect adherence to medications that were prescribed. Findings were also suggestive of the utility of the selected conceptual model, i.e. the necessity-concerns framework, in framing study participants medications-related perceptions. It can be surmised that the patients could benefit from diabetes education that is developed considering local and individual contexts and address their concerns and strengthen necessity beliefs so as to improve adherence to prescribed medications and health outcomes.

The analysis of the findings described in Paper III were guided by de Haes and Bensing's medical communication model . They revealed that participants of the study emphasized fostering the relationship with their healthcare providers and as well the provision and gathering of information. Participants expressed few expectations and experiences in decision making roles in relation to their care. Participants described suboptimal experiences and that were less than their expectations in relation to the care provided by their healthcare providers although there were some expressing positive experiences. Recommendations from this paper included changes in the care delivery for diabetes including adoption of a chronic care model, optimal use of nurse and pharmacist healthcare team members who can work collaboratively with the doctors and a communication skills training for the healthcare providers.

The findings from Paper IV revealed that a variety of medicinal plants including *Shiferaw* (*Moringa* spp.) and *Anamuro* (*Ajuga* spp) were used by the participants while also following their biomedical regimen. This paper also identified different factors that influenced the use of the medicinal plants. Perceptions of the usefulness of bitter things for diabetes, claimed and experienced benefits of some medicinal plants as well as the

information from mass media were some of the factors that positively influenced the use of medicinal plants. On the other hand, safety concerns were the primary reason that negatively influenced the use of medicinal plants. It was apparent that most of the use of medicinal plants occurred in contexts of very limited information held by the participants which may contribute to their suboptimal experiences. A recommendation that emanated from this study is of the need to give more attention to the medicinal plants commonly used by patients with diabetes and to provide evidence-based information so as to optimize their health benefits and outcomes.

The findings from Paper V revealed a number of factors that affected adherence to prescribed anti-diabetes medications. Factors that seem to negatively influence adherence included illness-related perceptions related to symptoms, perception of ‘minor’ consequences and hope for a cure, and medication-related perceptions especially safety concerns and to some extent doubts about their efficacy and as well perceived inconveniences with insulin. Furthermore religious duties and religious healing practices, healthcare provider factors and the low level of diabetes education and medicines availability also appeared to negatively influence adherence to their medications. On the other hand, factors such as diabetes-related complications and perceived health benefits of their medication as well as efficacy that contributed to necessity beliefs about their medications and religious practices that provided psychological benefits, perceived self-efficacy and social support have positively influenced adherence. These findings are indicative of the need to give due attention to diabetes care including development of care standards, strengthened contextual diabetes education and adherence monitoring and support programs.

Each of the key research findings from these papers will be discussed in additional detail below.

3.3. Illness and treatment perceptions

Findings related to participants illness and treatment perceptions are discussed.

3.3.1. Illness perceptions

The findings from Paper I indicate that participants had explanatory models about type 2 diabetes which were a mix of biomedical and traditional models. On the one hand, the model was indicative of the low biomedical knowledge that most participants had which was in tandem with their low educational status. On the other hand, their explanatory model was illustrative of the strong religious and cultural influences which was pervasive even amongst the better educated ones. Some of the issues discussed in relation to diabetes, locally labelled as ‘sugar disease’, were in relation to the symptoms, causation, course of illness, its control and associated negative emotions that participants perceived and experienced as part of their illness experiences similar to that described by Kleinman et al. (1978).

Symptoms seem to play important roles in the participants’ models where decisions about ill health and care seeking were made based on their appearance. It was apparent however that most of the participants were not able to identify initial symptoms as related to diabetes but had to be informed about it at the health facility. Such low biomedical knowledge regarding diabetes-related symptoms and diabetes in general and lack of discernible diabetes-related symptoms have been stated as reasons for lack of early detection and delays in care seeking as reported in local studies (Muluneh et al. 2012; Abebe et al. 2014). Similar issues with patient models that are indicative of low biomedical knowledge and different explanatory models have been reported by studies involving Turkish immigrants in Germany (Yilmaz-Aslan et al. 2014), Arabs and Ex-Yugoslavs immigrants in Sweden (Hjelm et al. 2003) and Zimbabweans (Hjelm & Mufunda 2010).

With regards to the cause of diabetes, a number of participants expressed uncertainty. Those who claimed certainty, suggested negative emotions or heredity as the cause. The uncertainty may be related to the low awareness about diabetes among the society similar to that reported in similar settings (Nguma 2010). The most commonly cited emotional causes in the present study had to do with rage which was in relation to social interactions while among the least cited is religious cause, namely evil spirit attack. Such psychosocial and supernatural causes seem to be commonly reported among non-Western study participants such as Libyans (Ashur et al. 2015), Hispanics (Concha et al. 2016; Poss &

Jezewski 2002; Jezewski & Poss 2002; Heuer & Lausch 2006), Turkish immigrants in Germany (Yilmaz-Aslan et al. 2014), Arab and Ex-Yugoslav immigrants in Sweden (Hjelm et al. 2003), Zimbabweans (Hjelm & Mufunda 2010), Ghanians (de-Graft Aikins 2005) and Cameroonians (Awah et al. 2009). Most of the causes given emphasis by the participants in the present study, as well as in the non-Western studies, were external factors that were considered beyond the control of individuals. Such perceptions may affect self care activities including adherence to recommended biomedical regimens and may further lead individuals to try out other healing systems such as traditional medicine and religious healing which may be considered as more appropriate than conventional biomedicine (Kassaye et al. 2006). Alternatively, studies that reported perceptions of primarily internal factors such as dietary and lifestyle as causes for diabetes revealed that individuals including the Swedes that were compared to the Arabs and Ex-Yugoslavs (Hjelm et al. 2003) and Nigerians (Omeje & Nebo 2011) tended to adhere better to prescribed treatment regimens (Theofilou & Saborit 2012).

Conflicting ideas were expressed by participants in this study about the chronicity and curability of diabetes. However, the regimen perceived for both the acute, curable or the chronic, controllable condition seem to be similar. They included the use of biomedicine but also traditional medicine and religious healing. A point that practitioners should note is that there may be some patients who may be expecting a cure and so are carefully adhering to their biomedical regimen. In due course however, they may be frustrated should their goal of a cure be not fulfilled which in turn could result in lower adherence to these regimens or the tendency to use other healing modalities such as traditional medicines including medicinal plants or religious healing or both (Kassaye et al. 2006; Levene et al. 2016). Other studies reporting from similar settings have detailed as to how such beliefs as hope for a cure may lead to patients to try out what they perceive to be more culturally appropriate approaches such as traditional medicines which have resulted in suboptimal outcomes (Awah et al. 2008; Kolling et al. 2010).

Diabetes was also portrayed by some participants in the study as a deadly or as an uncontrollable disease that would inevitably lead to severe physical and social consequences however one adheres to recommended treatment. Such issues as poor control

and severe complications were similarly described by an Israeli study involving immigrants of Ethiopian origin which led the authors to suggest that the participants had limited experiences of 'living with and controlling a chronic illness' and that disease management was not a common word in their vocabulary (Jaffe 2002).

Negative emotions are not unexpected among those with chronic illnesses. However strong emotional expressions that portray diabetes as deadly on the one hand and uncontrollable on the other may potentially be destructive for patients' adherence to their treatment regimen and related health outcomes (Cameron 2003; Jayne & Rankin 2001; Mc Sharry et al. 2011). The negative emotions may also lead some to try out other healing systems that promise better control or even cure but actually result in worse health outcomes (de-Graft Aikins 2005; Harvey & Lawson 2009).

Negative emotions have been reported by study participants as causes for their diabetes while emotional distress was also reported as an illness consequence. This is suggestive of the need to consider the possible influence of emotions in the illness and treatment for this group of patients. The possible relationship between type 2 diabetes and emotional distress and even depression has been reported previously. Diabetes has been associated with higher risk of depression and vice versa (Egede & Ellis 2010; Moulton et al. 2015). Although it is possible that some of the study participants in the present study may exhibit depression as also been reported by another local study (Teklay et al. 2013), the presence of diabetes-related emotional distress seems apparent. Such emotional distress and depression have been found to relate to suboptimal adherence and poor glycemic control (Moulton et al. 2015; Egede & Ellis 2010). Such findings are suggestive of the potential health benefits that patients with diabetes could get if some form of mental health support such as psychotherapy was to be instituted for their distress and depression if it is present. The World Health Organization's mental health gap action program that was also adopted by the Ethiopian government actually recommends for the integration of mental healthcare into all levels of the healthcare system and intends to utilize different arrays of health professionals and paraprofessionals following short-term training (Federal Ministry of Health 2012). Treatment for the mental health conditions include psychotherapy,

pharmacotherapy or a combination therapy that includes both psychotherapy and medications (Moulton et al. 2015; Egede & Ellis 2010).

3.3.2. Treatment perceptions

With regards to the treatment perceptions towards anti-diabetic medications, the findings from Paper II revealed that a number of the participants expressed necessity beliefs which were specifically about the efficacy of insulin compared to the oral agents. In general though, participants placed greater emphasis on the concerns about their medications compared to the necessity which could possibly affect adherence to the recommended biomedical regimens and to the initiation of insulin. This seems in line with the necessity-concerns framework which suggests that such perceptions can influence adherence potentially leading to intentional nonadherence should the concerns about medications much outweigh the necessity beliefs (Horne 2003).

Study participants raised a range of concerns related to the perceived potential harms from the oral agents. Some of these include adverse effects such as hypoglycemia and gastritis and to a lesser extent about the number of prescribed medicines similar to those raised by patients in other settings (Grant et al. 2011; Lawton et al. 2008). Perceived concerns which appear to be specific to the present study included concerns about adverse effects which actually are expected as diabetes-related complications such as impotence and eye problems. There were also concerns that related hypoglycemia to diabetes as a complication rather than identifying it as a medication-related adverse effect which has also been reported by another local study (Tassew 2015). Such findings are further indications of the need to assess patient perceptions and of the importance of being open to listen to their views so as to be able to offer appropriate diabetes education including about the medications. Such interventions could alleviate some of the safety concerns that can act as major barriers to medication adherence (Teklay et al. 2013; Wabe et al. 2011; Bizu & Habte 2016).

Hypoglycemia was among the major adverse effects reported by study participants who were on oral agents. Incidents reported that were likely related to hypoglycemia included falls which may lead to dose skipping or reluctance to accept additional agents or dose

increments. Hypoglycemia would not be unexpected given that most participants in the present study were on glibenclamide which has high hypoglycemic potential (Bolen et al. 2015; Davis 2006). A study report from Nigeria indicated that hypoglycemia was among the commonest side effects and a common reason for nonadherence for patients on glibenclamide (Yusuff et al. 2008). Another study has reported a more than two-fold rise in coronary artery disease risk when glibenclamide was used as the initial treatment with the risk declining with newer agents such as glimepiride (Sadikot & Mogensen 2008). These findings suggest that the government should consider alternative oral agents with comparable costs but better safety profile such as glimepiride which is also a member of the sulfonylureas (Davis 2006).

With respect to insulin initiation, the concerns reported in the present study such as perceived adverse effects and its indication of an increased level of illness severity, appear to be similar to the findings of other studies (Ng et al. 2015). Among concerns unique to the present study was the perceived need to maintain stricter adherence for insulin compared to the oral agents especially for those who make use of holy water as part of the religious healing practice (Kassaye et al. 2006). There are other studies that have reported that the use of holy water led to the discontinuation of treatment for other chronic conditions (Bezabhe et al. 2014; Kloos et al. 2013). This also suggests the need to assess patient perceptions and beliefs and provision of need-based education concerning the benefits of following the recommendations with the biomedical regimen and not to discontinue treatment even if one has plans to use holy water. The latter evidently requires support at higher levels and possible similar policy interventions to those which have been tried in the treatment of HIV/AIDS. In the management of HIV/AIDS treatment adherence, collaboration with religious leaders has led to the endorsement of the combined use of antiretroviral treatment and holy water as compatible and thus encouraging the complementary use of both forms of treatment contributing to increased adherence levels (Kloos et al. 2013).

3.4. Illness and treatment experiences

The illness and treatment experiences of patients with type 2 diabetes along with the different factors that influence them are hereby discussed. The major findings in this regard include the experiences with healthcare providers, experiences of taking anti-diabetic medications including the barriers and facilitators, the practice of religious rituals and use of religious healing and the use of medicinal plants, experiences with healthcare providers and certain aspects of health system. Some of the major factors identified by this study that affected adherence to prescribed medications include treatment perceptions about their necessity and concerns; illness perceptions such as about symptoms, consequences, curability and treatment; perceptions about healthcare providers and health system factors such as diabetes education program and medications availability. In addition, cultural and religious healing practices have affected adherence to biomedical regimen.

3.4.1. Experiences with the healthcare providers

Study participants experiences with healthcare providers reported from Paper III were analyzed based on the six functions model recommended by de Haes and Bensing (2009). More emphasis was given to ‘fostering the relationship’, ‘providing’ and ‘gathering information’ aspects of the healthcare providers with little attention given to patients’ decision making function. More of the experiences described by the participants can be described as negative with a few positive ones cited.

One of the functions given much attention by the participants was ‘fostering the relationship’. In this respect, high expectations were expressed by the participants to being shown respect and addressed in a caring manner which was often not fulfilled by their healthcare providers. Many participants also expressed their strong desire to be treated by the same doctors over time citing its importance to foster a good relationship. This was also not the case for the large majority of participants in this study who were seen by different doctors each time they came for their clinic visit. These findings were similar to others with regards to a desire for a respectful, caring and a friendly approach by the providers and to be seen by the same doctors to also ensure continuity of care (Deledda et al. 2013; Abdulhadi et al. 2007; Ridd et al. 2009; Mayston et al. 2017). The findings from

the local study that involved users of mental health services in Butajira town revealed that being treated with respect, associated with warmth, acceptance, courtesy and hopefulness, was identified as a foundation for a fruitful therapeutic relationship (Mayston et al. 2017). Ridd et al (2009) on the other hand have described care provision by the same doctor to enable both the patient and the healthcare provider to get to know one another personally. Furthermore, it would support relationship building and for patients' to gain trust and enable the doctor to further know the patient's medical history (Ridd et al. 2009). Developing caring, respectful and compassionate health professionals is actually one of the prominent targets of the five year Health Sector Transformation Plan of the Ethiopian government (Federal Ministry of Health 2016b) . Expectations involving Western patients additionally include expectations to be treated as a partner and for the healthcare provider to be open to discussion (Deledda et al. 2013; Ridd et al. 2009).

According to some participants in the present study, the problem of not being seen by the same doctor was further compounded when it appeared that some of the providers do not review the medical history and tests ordered previously and nor do they give feedback on the results of such tests which was a further source of frustration. It was also apparent that there was limited education provided to patients about diabetes and its management. These complaints are shared by patients in other studies reported from Ethiopia and other developing countries which identify substandard care provision even in cases where adequate human and material resources were available (Feleke & Enquselassie 2005; Gudina et al. 2011; Nigatu 2012; Abdulhadi et al. 2007; Rabkin et al. 2012; Workneh et al. 2016). Some of the local studies have reported about the 'poor attention' afforded to diabetes care and lack of clinical guidelines for patient management according to standards (Workneh et al. 2016; Rabkin et al. 2012). In addition, limited education as well as adherence support for patients with diabetes were other issues raised by local studies (Workneh et al. 2016; Feleke & Enquselassie 2005). Attempts were made by some of the local studies to compare the service delivery for diabetes with that for HIV and tuberculosis which are known to have much better services. They went further discussing how experiences from the care delivery for these conditions can be used to improve the suboptimal care for chronic diseases such as diabetes (Rabkin et al. 2012; Workneh et al. 2016). Experiences of managing diabetes in primary healthcare settings in high resources

contexts using the chronic care model has been demonstrated to improve the health outcomes (Stellefson et al. 2013) which could be considered for adaptation in resource-limited settings. There is an intention by the Ethiopian government to institute measures such as patient-centered care that considers the ‘preferences and aspirations of individual service users and the cultures of their communities’ in its drive to improve quality of the healthcare delivery (Federal Ministry of Health 2015b; Federal Ministry of Health 2016b).

Another major finding from this study was that the role of pharmacy personnel and nurses from the perspective of the patients appeared to be suboptimal in areas such as relationship building, responding to emotions and providing education and diabetes self-management. The role of nurses in the care of patients with diabetes according to a study from Oman was similarly limited to providing basic screenings such as weight and blood pressure measurements, minimal communication with patients and likewise limited in the provision of education (Abdulhadi et al. 2007). Some Western countries have identified the benefits to diabetes care of using diabetes educators who usually are practising nurses and pharmacists who are given additional training. These professionals work with the doctor and other relevant members of the healthcare team and meet the patients more frequently than the doctor to provide support with regards to behavior modification and improved self-management so as to address both their physical and psychosocial needs. Successes have been reported by such programs in different settings in improving clinical outcomes (Wang et al. 2014; Burke et al. 2014). Current global standards also recommend redefining the roles of the healthcare team members, including nurses and pharmacists, so that they can function in a collaborative manner in managing chronic conditions. These standards call for the empowerment of patients’ self-management which is considered critical for managing chronic conditions alongside the multidisciplinary healthcare team working in a collaborative manner (American Diabetes Association 2017).

3.4.2. Barriers and facilitators to medications adherence

The treatment related perceptions reported by Paper V were found to be similar to those reported by others who studied participants of Western cultures (Mcsharry et al. 2016; Ng et al. 2015). Some of the concerns identified as major barriers to medication adherence

were safety issues that led participants to refuse insulin initiation out of fear of adverse effects or decreasing of the doses and discontinuation of medications that they were taking upon experience of different adverse effects. These findings were largely similar to those from other studies from Ethiopia and as well from other countries (Kassahun et al. 2016; Teklay et al. 2013; Wabe et al. 2011; Ng et al. 2015; Odegard & Capoccia 2007; Capoccia et al. 2016; Mcsharry et al. 2016). Alternatively, illness perceptions especially about impending complications and chronicity of diabetes, mediated with strong necessity perceptions for the anti-diabetic medications were found to facilitate adherence similar to other studies that have reported positive associations between these factors and adherence to chronically taken medications including for diabetes (Horne et al. 2013; Kucukarslan 2012; Peeters et al. 2015).

As suggested by Kleinman, study participants' explanatory model seem to be responsible, at least partly, for the decisions and self-management related to their diabetes (Kleinman et al. 1978). Among the illness perceptions that seem to have influenced adherence to recommended treatment regimens were perceptions about diabetes symptoms – their absence led to delay in treatment initiation or to treatment discontinuation only to restart when symptoms reappeared. Such observations do not seem to be common among Western patients diagnosed with diabetes although there are similar reports among patients with hypertension (Ogedegbe et al. 2004). Perceptions about the symptoms however are reported among non-Western patients including immigrants in the West and from Thailand where study participants expressed belief that diabetes was a short term illness with the oral agents providing symptomatic relief which however were unneeded once they 'felt well' (Mcsharry et al. 2016; Lawton et al. 2005; Alcozer 2000; Heuer & Lausch 2006); they would be restarted once their illness was visible and symptomatic, and starting to affect daily routines (Naemiratch & Manderson 2008). These reports are similar to the quantitative studies done locally among Ethiopian patients with diabetes which reported 'feeling of being well without treatment' and 'disappearance of symptoms' as among reasons for the low adherence to prescribed anti-diabetic medications (Tsehay et al. 2016; Wabe et al. 2011). This result is similarly supported by other local studies where more emphasis is afforded to symptomatic and acute conditions and hope for a cure is also expressed (Reiff et al. 1999; Levene et al. 2016).

Hope for a cure in relation to religious healing was another major barrier to participants' adherence to their anti-diabetic medications. This involved going to holy water sites where they had to discontinue their anti-diabetic medications either for short or long durations which was the case among certain followers of Orthodox Christianity. This practice may be related to the wide-held belief among Orthodox Christians that supernatural forces (especially the devil) is cause of illnesses and God provides healing usually through the use of holy water. Holy water is commonly used by bathing in it or drinking it (Kassaye et al. 2006). Studies involving patients with HIV/AIDS have cited visiting holy water sites to be baptized as part of healing process as one of the common reasons for treatment discontinuation and being lost to follow up (Kloos et al. 2013; Bezabhe et al. 2014). Cases of treatment discontinuation among patients following chronic treatment in favor of alternative treatment systems are also reported from other places in Africa. Studies revealed that patients with diabetes from Ghana and Tanzania reported hope for a cure leading to use of faith healing (primarily prayers) and herbal medicines used on a complementary basis but also alternatively that led some to discontinue their biomedical treatment (Kolling et al. 2010; de-Graft Aikins 2005). The wide use of holy water for the healing practice however appears to be more common among the followers of Orthodox Christianity in Ethiopia.

Fasting which is one of the religious norms expected of the laity while taking hypoglycemic agents such as glibenclamide and insulin was observed to act as a barrier to adhering to recommended medication regimens that could lead to problems in the short or long term. Fasting is a common duty followed by religious adherents in Ethiopia that is also believed by certain individuals to have a curative power (Kloos et al. 2013). During the year, Orthodox Christians are recommended to fast for 250 days of which 180 days are obligatory for anyone older than 13 years. Fasting usually implies a single meal per day to be taken after 2:45 p.m. or in the evening and the total avoidance of animal products (e.g. meat, egg and dairy products (Ethiopian Orthodox Tewahdo Church 2003). Similarly, Muslims are to avoid foods or drinks starting from early dawn to after sunset during the holy month of Ramadan. Studies involving Ethiopian patients with HIV/AIDS have reported that the followers of Orthodox Christianity and Islam either discontinued their anti-retroviral treatment during their respective fasting seasons in order to fulfill their

religious duties but also to avoid stigma (Kloos et al. 2013) or modified their dosing regimens which mostly involved missing one of their medication doses during fasting (Bezabhe et al. 2014). The present study is among the first to report on the influence of fasting on anti-diabetic medication regimens among Orthodox Christians, although there is literature describing how Muslim patients reduce their medication doses during Ramadan (Mcsharry et al. 2016).

On the other hand, religious and religious healing practices such as going to church, praying and use of holy water at home were observed to provide some study participants with psychological benefits that can positively influence their illness experience and adherence to prescribed medications, albeit in an indirect manner. These psychological and mental benefits that participants may obtain from the religious healing and practices can mitigate possible diabetes-related distresses that may be present and may lower adherence among other things (Egede & Ellis 2010; Teklay et al. 2013; Birhanu et al. 2016). Such observations were made regarding patients with HIV in Ethiopia where use of holy water concurrently with medications led to gains from a holistic regimen that offered psychological, mental and spiritual health benefits (Kloos et al. 2013). This form of treatment is in line with the concept of health in Ethiopia where it is considered as holistic encompassing not only physical but spiritual, mental, social, and psychological aspects. Furthermore, health is considered a 'gift' or 'will of God' and thus the criticality of religion believed by many to help keep them in good health (Kassaye et al. 2006). The benefits of religion and religious practices among patients with diabetes are also reported from different cultures involving both non-Western and Western patients such as Iranians, African Americans, Swedes, Arabs and Ex-Yugoslavs. The participants reported prayers, 'turning things over to God', reading the holy scriptures and attending churches and mosques as coping strategies that led to feelings of hope, security, peace and strength and as well the alleviation of physical and spiritual distress (Namageyo-funa et al. 2015; Heidari et al. 2016; Hjelm et al. 2003).

The Iranian study where the study participants engaged in 'high levels' of religious practices, reported significant association with the self-care activities (Heidari et al. 2016). Religious practices such as prayers and performing *solat* (obligatory prayers of Islam),

described as ways of being close to God were likewise reported to have significant correlation with illness perceptions among patients with end-stage renal disease in Malaysia. Furthermore, these practices emerged as positive mediators between illness perceptions and health-related quality of life in. This led to the study recommendation to give due attention to illness perceptions and religious coping mechanisms in intervention programs to enhance patients' quality of life (Ibrahim et al. 2012).

3.4.3. Experiences with the use of medicinal plants

Findings from Paper IV, which was on the use of medicinal plants by some of the study participants, revealed that they did not pose a major barrier to their adherence to the prescribed treatment regimen. While cultural factors and hope for a cure from diabetes could be considered as major reasons for the use of medicinal plants, participants also cited additional ones. These include perceptions that bitter things are good for diabetes, beneficial effects either claimed or perceived and mass media influence. Safety concerns about harm that they personally experienced or with others were on the other hand reasons for deciding against using them.

Among the commonly cited reasons that influenced use of medicinal plants was the pervasive belief among the study participants that bitter things are good for diabetes and that they should be taken. While this belief may have a cultural root, it may be further boosted by the education given by some healthcare providers who may recommend patients to 'take bitter things and avoid sweets'. This was actually amongst the common reasons for using different medicinal plants such as the psychostimulant *Tchat* (*Catha* spp.), citing benefits for diabetes and whose fresh leaves were chewed. Studies however have reported that chronic *Tchat* chewing have led to an increase in blood glucose in patients with diabetes (Saif-Ali et al. 2003). Such beliefs about the value of bitter things do not seem to be unique to this study. Studies done involving Bangladeshi and Indian patients with diabetes have also reported on the perceived value of bitter herbs and diets for diabetes management (Chacko 2003; Choudhury et al. 2009; Khajuria & Thomas 1992).

The claimed benefits of medicinal plants, primarily to cure but also to control diabetes through their sole use were among the major factors for using them. The commonly cited

medicinal plants reported by study participants included *Shiferaw* (*Moringa* spp.) and *Anamuro* (*Ajuga* spp.), both of which were claimed to cure diabetes or at least reduce blood glucose levels. *Shiferaw* (*Moringa stenopetala*), which is a tree native to southern Ethiopia and widely used as a staple food is widely claimed as a remedy for various illnesses including diabetes (Seid 2013). Claims of the anti-diabetic activities of some of the other medicinal plants have also been reported previously (Abdulkadir 1985; Seid 2013). The anti-diabetic activities of these medicinal plants have also been demonstrated by local studies that have used animal models (Toma et al. 2015; Nardos et al. 2011; Assefa et al. 2017). One can therefore assume that at least some of these medicinal plants may indeed affect the diabetes symptoms if not the blood glucose levels. However, there is no reported evidence to date that these or any other medicinal plant may be as effective or more effective than the biomedicines that these participants are using or that they can offer a cure for diabetes.

A number of concerns about medicinal plants used for diabetes and traditional medicines in general were raised that were cited to negatively affect the use of medicinal plants by the study participants. The concerns about possible harm from traditional medicines and medicinal plants were related to the negative experiences that some of the participants had encountered personally or observed with an acquaintance or a close relative. The safety concerns were mostly related to the lack of dose standardization and unknown quantities recommended for these herbal medicines. The very limited regulatory activities in Ethiopia with regards to traditional medicine and medicinal plants could be cited as important sources for these concerns (Food Medicine and Healthcare Administration and Control Authority 2016; Ethiopian Public Health Institute 2015). Most participants in the present study who have used these medicinal plants for their diabetes uses reported different adverse effects including anemia, hypoglycemia and problems related to the abdomen, heart and kidney. Adverse effects related to the use of medicinal plants used for the management of diabetes have been reported elsewhere. These studies have suggested that the problems may be associated with patients' low knowledge regarding the doses, inherent toxicities of some of the remedies even at low doses and possible interactions with the prescribed allopathic medicines already being taken for their condition (Dièye et al. 2008; Chang et al. 2007; Ezuruike & Prieto 2014).

3.5. Implications of the study

The findings of this study have a number of practice and policy implications . Some of the major ones will be discussed.

3.5.1.Practice implications

A number of practice implications arise from the present study. One of the most important has to do with the strengthening and reorienting the healthcare system so that it can provide optimal care to patients with diabetes. In this regard, the chronic care model which has been demonstrated to enhance the health outcomes of patients with diabetes at different healthcare levels needs due consideration (Stellefson et al. 2013; Baptista et al. 2016). This model incorporates multifaceted interventions such as patient and provider education, decision support, health organization support, clinical information system, care delivery system redesign and community resources mobilization and is reported to be more effective than the use of isolated components (Baptista et al. 2016; Piatt et al. 2010). The government of Ethiopia should therefore give due consideration to this model in its endeavor to improve the quality of healthcare delivery for chronic diseases such as diabetes (Federal Ministry of Health 2010; Federal Ministry of Health 2014). In adapting this model, the government can make use of previous experiences with local chronic care models such as with the anti-retroviral treatment and tuberculosis programs which have systems for chronic diseases management. Some of the strategies that can be adapted to a chronic care program for diabetes include a minimum package of key services, the use of standard operating procedures, introduction of support tools such as pocket guides and desktop references, health information system tools, patient monitoring tools and adherence support programs and peer educator programs (Rabkin et al. 2012; Workneh et al. 2016).

A strong group diabetes education program should constitute one critical part of the care model cited above. In designing the group training programs, due consideration should be made to encourage the active participation of the patients in the discussions about their responsibilities in the care of diabetes (Adolfsson et al. 2008). This education program needs to address local concerns and scenarios such as the one that are identified by the present study. Some of the health education topics that may be considered include the role

and implications of diabetes symptoms and relations to other monitoring mechanisms such as blood glucose measurements, illness causes, its chronic and controllable nature, evidence-based management approaches, about different anti-diabetes medications including about their necessity and concerns, etc.

The group education programs should however not be a substitute for one to one education sessions with patients by appropriately trained healthcare providers. It was evident in the present study that participants differed in the level of biomedical knowledge, cultural and religious influences and with the level of emotional distress and thus further rationale for the individual sessions. Such one to one sessions would allow individual assessment of patients' knowledge and beliefs about their illness and its treatment, their motivation and psychosocial status, required self-management skills and other issues of relevance to the optimal management of diabetes. This can be used to facilitate more tailored and individualized education, adherence support programs and care approaches that make use of patient-centered principles. Such one to one sessions may also incorporate mental health components, either in the form of psychotherapy or other forms that are appropriate to be determined on a need basis. It is recommended that healthcare providers should regularly assess and monitor patients with diabetes for depression (Egede & Ellis 2010). These providers will need additional training in different areas including health communication (Kleinman et al. 1978) and the fundamentals of identification and management of depression (Egede & Ellis 2010) if they are to effectively care for their patients and offer meaningful advice.

Individual sessions are also useful to assess perceptions towards and the use of traditional medicines including medicinal plants and religious healing. With regards to medicinal plants use, healthcare providers may inquire about their identity and mode of use in a nonjudgemental manner. With information gathered in this manner, providers can explore the medicines in common use and strive to provide evidence-based information which in turn can be shared with the patients. Patient education should include the possibility of adverse effects and potential interactions with the prescribed medications and illness condition. While the concept of 'bitter things' may need additional study, education topics need to include the merits and demerits of related practices. In relation to religious healing

and religious practices, individual assessments should likewise be made so as to frankly discuss their benefits and possible challenges with respect to diabetes management. Such roles would evidently require that the concerned providers have training or orientation about common traditional and religious healing practices and medicinal plants used for diabetes.

The other important issue that needs consideration is task-shifting so as to optimally use nurses and pharmacists as part of the healthcare team in support of the care provision by the doctors. These providers, after undergoing additional training, have been used even in more resource rich settings to take more advanced roles of diabetes educators where they work collaboratively with the doctor. In this regard, they meet with the patients more frequently to provide support in behavioral modification and other self-management issues to address not only patients' physical needs but in the psychosocial areas as well. Such programs have been reported to result in improved health outcomes in different settings (Wang et al. 2014; Burke et al. 2014).

3.5.2. Policy implication

In dealing with the religious healing and practices of patients, one needs to recognize the challenges in bringing about behavioral changes in certain aspects while also recognizing the psychological and mental health benefits from such practices. These issues therefore may require discussions at higher levels from the side of the policy makers with leaders and healers of the different religious institutions so as to forge collaborations aimed at improving the self-management practices and health outcomes of patients with diabetes. One target area could be supporting patients' adherence to recommended medication regimens while still following religious practices and healing modalities in a complementary and compatible manner. There are reports of successful collaborations for the management of psychiatric conditions and HIV/AIDS with the Ethiopian Orthodox Christian Church in encouraging the use of both biomedicines and religious healing that have resulted in improved adherence to the prescribed medication regimens (Kloos et al. 2013; Birhanu 2014).

The issue of medicinal plants use among patients requires that the government implements recommended regulatory frameworks required to enhance the safety, efficacy and quality of at least those that are commonly in use. Measures in this regard include instituting measures to ensure that medicinal plants offered for sale are safe, fulfill required information for the appropriate use and are of appropriate quality. In addition, the existing pharmacovigilance system should be strengthened and adapted to include safety reports emanating from medicinal plants used by patients. The regulatory body should also work to avail evidence-based information to patients, healthcare providers and other relevant and concerned bodies (Ezuruike & Prieto 2014; World Health Organization 2004).

3.6. Strengths and limitations of the study

3.6.1. Limitations of the study

Like all studies, this one has some limitations which are described below.

Only study participants attending their treatment in hospitals were included in the study. This may not be representative of those who may be following treatment with limited interaction with the biomedical setting, have avoided the biomedical option and instead following religious healing or traditional medicine or using medicinal plants either on a self-medication basis or upon the recommendation of a traditional healer. In addition, the fact that the study participants were recruited from public hospitals which primarily serve populations from lower socio-economic section would indicate that those attending treatment in the private facilities and who have higher socio-economic status may be less represented in the present study. In addition, only those patients who had had diabetes for at least one year or more were included. This would limit the perspectives of newly diagnosed patients.

This study included only the perspective of the patients and not of the biomedical providers, the religious healers or the traditional healers who may routinely use medicinal plants having anti-diabetic activities. Future research should focus on gaining additional perspectives on this topic.

3.6.2. Strengths of the study

The qualitative nature of the study allowed for an in-depth exploration of the views and experiences of patients with type 2 diabetes, which makes this study one of the first in Ethiopia. This study used multiple in-depth interviews with purposively recruited individuals of diverse socio-demographic and a range of illness and treatment experiences. This has allowed for a richer understanding of the context and relevant socio-cultural and individual factors influencing the illness and treatment experience of patients with type 2 diabetes including about the barriers and facilitators to medications adherence, use of religious healing and use of medicinal plants.

Prolonged engagement in the field allowed for the research findings to be well-contextualized and allowing for a more holistic understanding of experiences in living with and managing their illness. As is appropriate for qualitative research, the principal investigator clarified his positionality at the outset which allows readers to understand how his perspective and previous experiences may have impacted the research. This research has made use of data, researcher and theory triangulation which are expected to further enhance the validity of the study.

4. Conclusions and recommendations

4.1. Conclusions

Findings from the present study have revealed that participants' explanatory models which included the labeling, symptoms, the course or timeline, impact, causation and treatment of diabetes were a mix of biomedical and traditional models. It was also apparent that participants expressed emotional distress in relation to their illness. This explanatory model was found useful to identify different issues that may affect patients' care of diabetes including their adherence to prescribed treatment regimens and their health outcomes.

The treatment perceptions of study participants was also found to be different in certain aspects compared to those commonly expressed by Western patients including very strong and at times unfounded concerns towards insulin and the oral anti-diabetic agents. Their perceptions towards the necessity of their medications were weaker especially towards the oral agents. Such perceptions were further reasons to potentially non-adhere. The necessity-concerns framework that was utilized to organize the medication-related perceptions was found to be a useful tool in the study settings of this study.

Study participants expressed a range of expectations in relation to their communication with their providers. The most common themes in this regard were fostering the relationship with and the gathering and information provision of their healthcare providers. The findings revealed that their communication expectations were largely not met by the healthcare providers.

Findings also revealed that different medicinal plants including the commonly cited ones of *Shiferaw* (*Moringa* spp.) and *Anamuro* (*Ajuga* spp.) were used by some of the study participants. It was apparent that the medicinal plants were used in a complementary manner alongside the prescribed medications. The use of these medicinal plants was reported to be used in the context where participants had very limited information about them and which have led to adverse effects and potentiation of the prescribed medications in certain participants.

According to participants' reports about their adherence to prescribed medications, they reported a number of cases where they did not adhere, often intentionally. Some of the

factors that were mentioned as barriers were illness related perceptions mainly about symptoms and curability of diabetes and in relation religious healing and practices, treatment perceptions especially concerns about the safety of the anti-diabetes medications. Among the factors that were mentioned as facilitators were social support and religious healing and practices that were reported to offer psychological benefits.

The main conclusion that can be drawn from this study is that illness and treatment perceptions held by the patients with diabetes were found to negatively influence adherence to the prescribed medications. Furthermore, the diabetes care provision by the healthcare providers was below the expectations of the patients and recommended standards. Such a context was at least in part responsible for the different types and levels of nonadherence, in many cases intentional ones and the complementary and alternative use of religious healing and medicinal plants that have led to suboptimal outcomes.

4.2. Recommendations

Based on the key findings and discussions, the following are recommended:

- There should be instituted a strong diabetes education program, individual and in groups, that is considerate of the local and individual contexts. It would be beneficial to incorporate mental health components into the individual sessions.
- Efforts should be made to make optimal use of other healthcare providers such as nurses and pharmacists who can work in close collaboration with the doctor and better address the needs of the patients.
- Further and continuing training needs to be given to healthcare providers in different areas that include but are not limited to health communication, relevant mental health issues and diabetes management.
- The need to consider use of chronic care model for chronic conditions such as diabetes. In this regard, the experience of HIV/AIDS and tuberculosis care can be used as a starting point.
- The need to forge collaborations with religious leaders and healers so as to encourage patients to adhere to the biomedical regimens while also following their desired religious healing in a complementary manner.

- The need to give more attention to medicinal plants commonly used for diabetes in terms of providers' education but also regulatory and safety issues.

4.3. Directions for further research

Further research is recommended in different areas including:

- Qualitative studies on the exploration of illness and treatment experiences in noninstitutional settings to get the perspective of patients who do not regularly follow treatment in these settings.
- Qualitative studies to explore the explanatory models of individuals without diabetes would also be an important area for further research so as to design appropriate interventions including health education and screening programs that could be used in the prevention, early detection and appropriate management of type 2 diabetes.
- Assessment of the illness and treatment perceptions on a large population sample, that could complement the findings from the present study and further strengthen recommendations for interventions to improve adherence to recommended treatment regimen.
- Further ethno-pharmacological research in different areas into the most commonly used medicinal plants so as to provide evidence-based information for patients, providers, policy makers and other relevant bodies. Such surveys on medicinal plants could come up with information about the common local names, their common benefits, expected adverse effects and likely interactions with prescribed medications and existing conditions. Furthermore, such surveys may potentially identify gaps for additional pharmacological studies. In relation, it would be worthwhile to include traditional healers and herbalists in the survey.

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Original Papers I - V

Paper I

RESEARCH ARTICLE

Open Access



Explanatory models of adult patients with type 2 diabetes mellitus from urban centers of central Ethiopia

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Abstract

Background: Type 2 diabetes, which is increasing as a public health problem in the low resource settings of Africa has been associated with the high prevalence of micro-vascular complications and increasing levels of macro-vascular complications. There is evidence from the developed world that understanding patient perceptions of chronic illness is important to design effective strategies for helping patients manage these conditions. This study utilized Kleinman's model to explore the illness perceptions of type 2 diabetes patients attending treatment in Addis Ababa and Butajira (Ethiopia) and better understand how they manage their illness.

Design: Qualitative interviews were conducted to elicit the explanatory models of purposively sampled type 2 diabetes patients attending treatment in three hospitals in central Ethiopia until saturation of key emerging themes was achieved. Analysis of interview transcripts was guided by Kleinman's model.

Results: A total of 39 participants, 24 from Addis Ababa and the rest from Butajira took part in the study. This study revealed that patients' explanatory models were informed by both the traditional and biomedical models with emotional distress evident in some of the participants. The traditional model seemed to reflect the strong religious and cultural influences for the majority of study participants. The findings also revealed that symptoms played significant roles in how patients viewed their illness including assessment of its severity. Most were uncertain about the cause of their illness, with those expressing certainty citing factors over which they believed they had little or no control. This may have contributed to the perceptions about the use of religious healing and traditional medicines in a complementary or alternative manner to the biomedical regimen which could affect their adherence to recommended regimens and their health outcomes.

Conclusion: This study suggests the need for a strong diabetes care program that is sensitive to patients' experiences of their illness including emotional distress. Individuals providing the diabetes care should consider local and individual contexts and strive to make their approach patient-centered and engage active participation of patients. There appears to be a need for better training of health providers in different areas including health communications and the fundamentals of mental healthcare.

Keywords: Type 2 diabetes, Explanatory models, Kleinman's model, Ethiopia, Qualitative research, Addis Ababa, Butajira

Background

Non-communicable diseases such as diabetes mellitus are increasingly becoming major public health problems

in low and middle income countries [1]. With regards to diabetes, estimates suggest that there are more than 415 million adults worldwide with diabetes, with this number expected to rise to 642 million by 2040 [2]. Approximately 4 out of 5 people with diabetes live in low- and middle-income countries with the number of people with type 2 diabetes mellitus increasing in every country.

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More than 321,000 deaths in the African region are estimated to be attributed to diabetes with 79 % of these deaths occurring in people below the age of 60, which is the highest proportion among the world's seven regions. In Ethiopia, there are an estimated 1.3 million adult diabetes cases with a prevalence estimate of 2.9 % for the year 2015 in which 23,145 diabetes-related deaths were also reported [2].

Non-communicable diseases such as diabetes, cancer and stroke are now the leading cause of premature death among adults in Addis Ababa (Ethiopia) while the focus of the healthcare system is still geared toward addressing communicable diseases [3]. Studies done among patients with diabetes in different parts of the country have reported poor health outcomes including unacceptably high levels of blood glucose and blood pressure levels, micro- and macro-vascular diabetes-related complications, diabetic foot and other skin infections as well as hypercholesterolemia and hypertriglyceridemia [4].

Healthcare for chronic conditions such as diabetes requires the active involvement of patients given that they are the ones responsible for the bulk of self-management activities, be it medication-taking or other relevant lifestyle modifications. Different studies have reported how adherence to the recommended biomedical regimens and involvement of patients are affected by their perceptions about diabetes and its treatment [5]. Illness perceptions and adherence have been shown to be associated with patient outcomes [6]. Many of these studies have used theoretical models to guide the inquiry to elicit patient perceptions towards their illness and resulted in interventions aimed at impacting illness perceptions to improve adherence to recommended treatment regimens and improve patient outcomes [6].

Recent reports from hospital-based studies on the medication-taking behavior of patients with diabetes in southwestern Ethiopia have reported low levels of adherence (nearing 50 % in one of the studies) to recommended regimens [7, 8]. One of these studies reported that 33 % of the 267 participants had depressive symptoms which in turn was significantly associated with non-adherence to medication regimens. This in turn was associated to diabetes-related hospitalizations [8]. Studies of quantitative design give limited emphasis to patients' perceptions, and there is dearth of literature that has explored patients' explanatory models of their illness that could serve as basis for further interventions that incorporated individual and local contexts. The aim of this study was to conduct a qualitative, exploratory study to elicit the personal viewpoints or explanatory models of patients with type 2 diabetes that are attending treatment in Addis Ababa and Butajira.

Theoretical model

Individuals have their own explanatory models about health and illness that could influence their health seeking behavior, adherence to treatment regimens and health outcomes. Understanding these explanatory models is therefore essential for the effective delivery of healthcare. These explanatory models appear to be informed by personal, family, social and cultural beliefs, occupation, religious affiliation, education and past experience with illness and healthcare among other things. Patients' perceptions and popular explanations generally include similar issues as described in healthcare providers' explanatory models which are: etiology; onset of symptoms; pathophysiology; course of illness (including type of sick role—acute, chronic, impaired—and severity of disorder); and treatment [9].

According to Kleinman's work on explanatory models, patients and healthcare providers have different versions of the sickness condition—the illness aspect for the patient and the disease version for the provider. The illness problems for patients constitute the entire disorder including the difficulties of living with the sickness condition. In contrast, providers often disregard the illness problems and focus on the disease as the disorder. This difference in outlook is in part responsible for inadequate clinical care, patient and family dissatisfaction with professional care and patient non-adherence to recommended treatment regimen. It is highly recommended therefore for providers to understand patients' explanatory models so as to be able to incorporate patients' perceptions and concerns into clinical decision making. The critical points of difference between provider and patient perspectives, especially those that are believed to affect appropriate care, can be the focus for clear explanation, patient education and frank negotiation [9].

Kleinman's model has been used as a framework in a variety of studies investigating patients' viewpoints towards their illness and its influence on how they manage it. Most of these studies are from Western countries. The few studies done among ethnic minorities or immigrants in Western countries [10, 11] and non-western countries [12] have reported perceptions that combined the biomedical and cultural (folk) models to varying degrees. For example, a study done among Mexican-American patients with diabetes living along the US-Mexican border reported that their explanatory model was a synthesis of both Western biomedicine and traditional Mexican beliefs. This was especially evident in their expressions of their beliefs about the cause of type 2 diabetes and its treatment. With regards to the cause, many of the study participants believed that 'susto' (a fright or scare) was the cause of their illness while also

citing that biomedical causes such as heredity, obesity, poor diet and lack of exercise may have played contributory roles [10].

A similar study to assess the perceptions towards diabetes of Hispanic migrant farm workers living in the US revealed combined biomedical and traditional belief systems. While some study participants did not know the cause of diabetes, others provided combined beliefs to describe the causes. With regards to the majority who were discussing biomedical factors as causes, most also reverted to a traditional belief model where life stressors were considered as precipitating factors to diabetes. The majority also upon diagnosis believed that diabetes was an acute illness that would be cured after completing the medication regimen. Another finding of this study was the self-report by the majority of developing depression following their diabetes diagnosis [11]. Such findings are indicative of the need to consider not only the biomedical model but also the traditional belief models and patient realities of living with diabetes to be able to effectively support them in its management. There is however dearth of similar literature dealing with such non-communicable diseases in African and especially in the Ethiopian setting that could better inform the management of patients with diabetes.

Methods

Qualitative methods were selected as the most appropriate for the initial exploration of these intricate issues and to gain deeper understanding of patients' explanatory models towards their illness. This study received ethical approval from the Institutional Review Board of the College of Health Sciences, Addis Ababa University (protocol number 036/13/PSP).

Study settings

The study sites were 3 public hospitals in central Ethiopia. Tikur Anbessa Specialized Hospital (hereafter referred to as Tikur Anbessa) and Yekatit 12 Hospital (hereafter referred to as Yekatit 12) serve a high number of patients with type 2 diabetes in Addis Ababa (the capital city

of Ethiopia). In contrast, Butajira Hospital (hereafter referred to as Butajira) is the only public hospital in Butajira and was included to investigate the perspectives of patients living in the peri-urban part of central Ethiopia. A brief description of the two urban settings is given in Table 1.

Tikur Anbessa is the highest referral university hospital in the country. Patients diagnosed with diabetes are seen in the Diabetes Center which during the study period was run by 3 endocrinologists and 2 endocrinology fellows who work as consultants on a rotating basis, up to 6 Internal Medicine residents assigned to take the primary role in managing the patients doing their month long attachments, 6 nurses and 1 recently recruited pharmacist.

Yekatit 12 is a general hospital which has recently started training medical doctors is managed by the city administration. The services provided for diabetic patients were primarily in the general outpatient department run by 4 general practitioners while problematic cases were referred to the medical referral clinic run by internists on a rotating basis. In both Tikur Anbessa and Yekatit 12, patients are 'randomly' assigned to a doctor each time they visit.

Butajira is a general hospital that serves diabetic patients at a separate medical clinic run by a general practitioner and a nurse. In this case, diabetic patients would meet the same doctor when they come every month for at least a 6 month period.

Study participants recruitment

The study participants were purposively selected patients with diabetes attending their treatment in the selected hospitals during the study period. The inclusion criteria included age of 18 years and older, being on anti-diabetic medications for minimum of 1 year and having no known or overt psychiatric problems while being a healthcare professional was an exclusion criterion. Apart from these criteria, patients were purposively selected to include a wide variation in terms of socio-demographics (sex, age, marital status, educational level, religious affiliations,

Table 1 Description of study settings

	Addis Ababa	Butajira
Significance	Largest urban center in Ethiopia	Home to the demographic surveillance site of AAU
Population [35]	3.2 million	63 thousand
Ethnic groups [36]	Amhara (47 %), Guragie (16.3 %), Oromo (19.5 %) and Tigrie (6.2 %)	Guragie (82 %)
Religions [36]	Orthodox Christianity (74.7 %), Islam (16.2 %) and Protestant Christianity (7.8 %)	Islam (51.3 %), Orthodox Christianity (39.6 %) and Protestant Christianity (8.7 %)
Literacy [36]	85.3 %	37.9 %

employment status, place of residence), income level and years since diagnosis.

Interview methods

Individual in-depth interviews (completed in Amharic) were conducted by the first author from December 2013 to March 2014. The interviews which had a median duration of 49 min (and ranged from 30 to 120 min) were audio recorded with participants' consent. The set of questions recommended by Kleinman et al. [9] were largely used to frame the interview guide (as shown in the "Appendix") with minor modifications made as per related literature [9]. Patients were asked to discuss their explanatory model including about symptoms, course of their illness, problems caused by their diabetes, cause and treatment. The interview guide was translated to Amharic and back to English to check the consistency before using the Amharic version.

Data analysis

The collected data were transcribed into MS Word by an experienced research assistant. The first author checked the quality of the transcripts by simultaneously listening to randomly selected audio recordings from each study site while reading the transcripts. The transcripts were then read repeatedly to ensure a good understanding before initially coding them according to the categories recommended by Kleinman's model [9]. For some of those which did not fit with the model, open coding was done to accommodate them into separate categories and sub-categories. The coding process in each site continued until all key themes were saturated, i.e. no new information was emerging [13]. While initial coding and categorization was done in Amharic, further analysis, and interpretation was carried out after translating key components of the transcripts relevant to the emerging themes into English. In this regard, BMH worked collaboratively with HB to analyze and interpret key findings until consensus was reached. NVivo 10 was utilized to manage the data.

Results

Forty-five patients who met the eligibility criteria were identified during the study period. Of those, 6 did not participate either due to personal reasons such as being too busy or because of problems with telephone communication. A total of 39 study participants participated in the in-depth interview, of whom 24 were residents of Addis Ababa following treatment at Tikur Anbessa and Yekatit 12 and the rest of Butajira town or its environs. Table 2 provides a summary of the demographic characteristics of the study participants.

Study participants' explanatory models of illness are presented below, organized into six themes: labeling

Table 2 Study participants' characteristics (n = 39)

Description	Number of patients
<i>Sex</i>	
Female	19
Male	20
<i>Age (years)</i>	
30–39	2
40–49	8
50–59	14
60–69	10
>70	5
<i>Religion</i>	
Orthodox Christian	29
Muslim	8
Protestant	2
<i>Marital status</i>	
Married	27
Widowed	8
Divorced/single	4
<i>Educational status</i>	
Illiterate	6
Basic literacy (read and/or write)	10
Elementary complete	8
Secondary school complete	8
Post-secondary school education	7
<i>Occupation</i>	
Clerical work	7
Rents house	4
Small business	5
Farming	5
Pensioner	9
Unemployed	5
Others	4
<i>Diabetes duration (years)</i>	
1–5	10
6–10	14
11–15	7
16–20	4
21–25	4

diabetes, symptoms, course of illness, impact of diabetes, cause and treatment. There were minimal differences in relation to the illness representations among the participants from the different study sites and thus the data were combined into a single set.

Labeling diabetes

The Amharic term for diabetes is '*ye sequar beshita*', literally translated as 'sugar disease'. '*Sequar*' (as it is called for short) has a negative and bitter connotation for many

of the participants as depicted by emotion-laden expressions. Diabetes is considered by many to be a disease of the rich because they believe that diabetes comes to those who indulge in extravagances in their lifestyle especially with regards to diet or that the care required for managing the disease can only be afforded by the rich.

They call it 'sequar' (literal translation is sugar) as if it were as nice; it is very bitter for those who tasted it (Female, 55 years, diploma graduate, 9 years with diabetes)

I thought that those who get diabetes were those who spend all their day eating fatty meat and drinking tej (a homemade wine made from honey). (Male, 70 years, diploma graduate, 25 years with diabetes)

Symptoms

The experience of symptoms was expressed in relation to learning of diabetes status and in assessing illness severity.

Learning of diabetes status: Participants described two primary routes to learning of their diabetes diagnosis: experience of different symptoms that ultimately led to their seeking care and chance diagnosis. Common symptoms such as increased thirst and urination frequency, weakness and loss of weight led most to seek healthcare. The vast majority (including those who had close family members with diabetes) did not relate the symptoms to diabetes. There were also a few who suspected that the symptoms could be indicative of HIV/AIDS, which was an important component of their reaction to the symptoms.

For my case it suddenly started this time last year. I was very sick.... they took me to the hospital... When it started, I was unable to talk, extremely thirsty, couldn't control my urine - the urge was constant and I couldn't hold off (till I reached the toilet). (Male, 45 years, high school, 2 years with diabetes)

Initially, I used to urinate a lot; also drank water a lot... When my condition further worsened and I continued to lose weight and couldn't even go to the toilet by myself, I wondered if I might have contracted AIDS. (Male, 57 years, elementary school, 15 years with diabetes)

Some were diagnosed when they sought care for other conditions and since they did not identify diabetes-related symptoms it made it more difficult for them to accept the diagnosis of diabetes:

When I went to be treated for another illness they

told me I had diabetes. And I inquired, "What is diabetes? How does it work?"; as I didn't know anything about it. ... But I didn't believe the laboratory technician and so went to a different place to get checked. (Male, 61 years, elementary school, 15 years with diabetes)

Strong emotions such as being startled, upset and hopelessness were expressed upon being informed of diabetes diagnosis:

I was very startled (when I was told of my diabetes). I didn't think I would walk. (Female, 73 years, low education, 20 years with diabetes)

Symptoms used to assess illness severity: Symptoms, or their absence thereof, and the carrying of sweets (to protect against hypoglycemia) were used to assess illness severity.

My type doesn't have any symptoms, none of the illness indication. But the other type has excessive urination; I think it also has low sugar levels. The medicines are the same but (those with) the other type also take sweets when it goes down. I think that one is worse. (Female, 50 years, diploma graduate, 14 years with diabetes)

Course of illness

Perceived onset: Participants often identified specific incidents they considered the starting point of the illness. Many linked the beginning of their illness to an episode of sudden rage or similar emotional moments. There were a few however who surmised that the illness may have been with them without being detected for a quite a while.

When it started it did so with anger. Incidentally I was on leave and they shifted me from my job position which my friends told me. Soon after, I had a burning feeling here on my side. I also started drinking ten bottles of water every day (Female, 54 years, elementary school, 2 years with diabetes)

When I went back to the hospital where I had the operation they asked, 'Where did the diabetes come from? It was not there when you had the operation. So did you get angry or get stressed? To which I responded, 'Yes I got angry'. (Female, 60 years, low education, 8 years with diabetes)

Understanding the chronic nature: Many participants expected diabetes to be an acute condition that was easily cured following treatment. In contrast others thought it was a deadly disease that would kill them after a short duration.

Most only came to understand and accept the chronic nature of diabetes after months or years of experience with the disease and explanations from healthcare providers. An emotional tinge was evident in some of the expressions.

When told that I had this illness I thought I would die the very next day. I didn't think that I would get to live for all these years because I had no knowledge about the disease. (Male, 45 years, high school, 22 years with diabetes)

This illness doesn't go away once you get it; it is for life time. I am experiencing it now. While being treated here in this diabetic center, I had once requested them to release me (as cured) because the levels used to go very low. But they told me that once you get diabetes it doesn't go away and that one cannot say I don't want it any more. (Female, 50 years, diploma graduate, 14 years with diabetes)

Impacts of diabetes

Diabetes was initially considered by some to be a condition that would not lead to serious consequences, but this often changed as the illness duration increased. The participants cited a number of diabetes-related consequences ranging from limited to severe physical and social problems.

Physical health problems: Some of the physical health problems cited include liver, kidney or heart complications, loss of eye sight, leg amputation, and paralysis of parts or the whole of the body that could also lead to loss of speech were mentioned. Most of these were considered to eventually lead one to become home-bound or even bed-ridden and thus a burden to family members and relatives. Expressions were filled with emotional terms such as being fearful, troubled, and hateful when discussing about these problems especially as they related to being a burden to family.

My father died after being paralyzed. He was not able to speak. I hate not being able to talk; I also hate losing my sight. It could completely blind you. I fear that a lot. (Male, 45 years, high school, 2 years with diabetes)

I worry a lot as to whether I die now or tomorrow. I wouldn't wish diabetes for anyone. I worry quite a lot if it would kill me today or tomorrow.... Diabetes usually takes you while sleeping, no will or anything like that. It could also make you fall while traveling. I don't go out without having my wife by my side. (Male, 55 years, low education, 25 years with diabetes)

Diabetes was further thought to be an uncontrollable illness by some who considered that severe

complications or debilitating sugar level fluctuations occur despite taking precautions or without any warning in turn leading to severe disability or even death. Participants' expressions had emotional components mostly related to fear.

The sugar may go up or down and go out of control which may lead to one becoming bed-ridden. This could cause disturbance in the family and is what I fear. You are not dead or you won't get well—this problem makes one fearful indeed. (Male, 50 years, diploma graduate, 7 years with diabetes)

I fear that my sugar level suddenly increases and kills me. There is also hypertension and it could be troublesome. Many people who followed treatment with us have died this year alone as a result of sudden increase in their sugar levels. (Male, 63 years, high school, 3 years with diabetes)

Social consequences: Diabetes was also seen to affect social interactions by making some to become short-tempered and in a few other cases affecting relationships with spouses secondary to physical consequences such as impotency, which was a problem especially among the younger male participants. Other physical diabetic-related problems described as having social and economic consequences included diminished eyesight and body strength, since these were considered essential for fulfilling daily activities such as simple household chores, other communal chores or going out to fulfill religious duties. Problems related to limited mobility and eyesight have led to an early retirement for some due to their inability to carry out duties at their former workplace.

In fact the disease makes you ill-tempered; you get irritated even for minor things. (Male, 50 years, diploma graduate, 7 years with diabetes)

My eye has also created problems for me. It is only when I bake injera [a flat spongy bread made from teff] that my eyes black out and so I no more bake injera. In my neighborhood I participate in idir [neighborhood/community association that provides support to households in times of death and funerals]. But because of my eye problem, to avoid dust and smoke I don't participate in that often. My body and my strength is not right. I do go out for example to the church. The maid does all the household chores and I help with some of the food and so it is like this. (Female, 58 years, low education, 8 years with diabetes)

There were also reports by a few of the participants in relation to social stigma which had implications on social life and possibly on diabetes care.

At my place of work, there was an individual who didn't tell us about his illness as if it were something wicked and we heard about his admission to a hospital. Even he did not reveal about his illness to his wife. Anyway, his new shoe led to toe amputation and his leg after that. After that he lost hope, got weak and then it was all over. (Female, 55 years, diploma graduate, 9 years with diabetes)

That time I had fear going out of the house as my weight was decreasing and fear of people talking about me. I myself had heard one individual telling his friend about me having "drawn" the joker (contracting AIDS). Thereafter I stopped mixing with people. (Male, 45 years, high school graduate, 22 years with diabetes)

Causation

Many participants expressed uncertainty about the cause of diabetes, but when causes were discussed, heredity and emotional causes were the most commonly expressed while dietary/lifestyle and attribution to the evil spirit/Satan attacks were less common ones mentioned.

I really don't know! I can't tell how I got it. Of course I have hereditary inheritance; almost all my family members are on insulin. (Male, 45 years, high school, 2 years with diabetes).

Negative emotions such as anger, rage and being upset related mostly to social interactions were the most common and widely mentioned as a sure cause for diabetes. Grieving for an extended time and being startled were also mentioned as probable causes believed to have immediately led to the diabetes condition. Such emotions were not only considered to be causes but also as exacerbating factors for those living with diabetes.

The cause for my diabetes and that of others may be different. As for me I had cattle and one day I had 2000 birr prepared in order to buy frushka (a semi-processed cattle feed). When a merchant who went around selling dried grass (another animal feed) came to the house, I put the money away and went out to buy that instead. When I came back for the money, it was nowhere to be found. I turned mad and was so enraged and didn't know where to go. People rebuked me for that but I was so furious and couldn't let go easily. It is my guess that is the cause of my diabetes. In fact my children now talk about my actions then that led to this illness and so that is what I and my children now believe as cause of my illness. (Female, 73 years, low education, 20 years

with diabetes).

It had gone down but last time I was in mourning and because of that reason it went back again. It doesn't like mourning. (Female, 59 years, elementary school, 9 years with diabetes).

Treatment

Biomedical treatment, religious healing and traditional medicines were described as being useful for the treatment of diabetes—be it control or cure.

Diabetes was believed by many participants to be a controllable illness if the biomedical treatment regimen is followed.

If one takes good care of it, one can live peacefully for many years... I think that diabetes is better compared to other diseases; the main thing is to take care of oneself. Had it not been for one's own negligence, it would be possible to control it. (Male, 56 years, bachelor's degree, 15 years with diabetes).

There were a few however, who perceived that the biomedical regimen could lead to cure from diabetes if the recommended regimens such as diet and medications are followed. Some would express cure via following the biomedical regimen while adding the importance of God's will for the success of the biomedical regimen to effect cure.

Yes I think that I will be cured. I believe that God will cure me. By improving my food, God will support me when I act. My preparation is needed and so I have great hope of being cured by correcting my food, exercising and taking my medicines properly. (Female, 48 years, low education, 18 years with diabetes).

Religious healing practices, especially holy water and prayers have been cited by Christians for their benefits in managing diabetes complementary to the biomedical regimen and also popularly described to cure diabetes. Muslims participants apparently did not subscribe to any healing practices other than praying which was described as not specific to diabetes. Holy water was the most popular among the majority Orthodox Christian participants, with prayers cited more commonly among Protestant Christians.

If I drink lots of it [holy water] continuously it has benefits; it decreases it (sugar levels) by 35, 40. (Female, 33 years, high school, 6 years with diabetes).

Some people claim that holy water cures. There

are even some who promote for people to go there. Now my friend's wife has been cured and examinations have confirmed it. (Male, 63 years, high school, 3 years with diabetes).

Traditional medicines, specifically medicinal plants were primarily mentioned for their benefits in controlling sugar levels. Among these *shiferaw* (*Moringa* spp), was described as the most popular for diabetes. Others mentioned included *anamuro* (*Ajuga* spp) and kosso areqi (traditionally made hard liquor prepared from *Hagenia abyssinica*).

Scientific breakthroughs were another hope for a cure that was cited. In this regard, 'recent' media reports that have apparently described scientific research about a cure for diabetes and that are 'nearing fruition' were mentioned. A lifestyle free from negative emotions such as enagement and mourning or where they are controlled were also considered as one of the ways to help mitigate the illness.

Discussion

This study is the first to report an in-depth exploration into the explanatory models of Ethiopian patients' with diabetes mellitus. The analysis of the explanatory models focused on a number of issues including the meanings these study participants attach to the label, the symptoms, causation, course of illness, social and physical impacts of illness and treatment as well as their associated negative emotions. It was apparent from the findings that participants had explanatory models that were a mix of the biomedical model and traditional models, with the latter reflecting strong cultural and religious influences. Even though the findings cannot be generalized, the explanatory models identified in this study will offer greater insight to the illness perceptions and experiences of Ethiopian patients with diabetes attending healthcare in similar contexts.

According to the findings, symptoms played important roles in patients' decisions about their ill health status and care-seeking although most did not identify the symptoms as related to diabetes and were informed of their diagnosis at the health facilities. Low knowledge about the symptoms, or for that matter about diabetes in general, and lack of discernible symptoms have also been identified in studies as a reason for the lack of early detection and the delays in healthcare seeking [14, 15].

With regards to illness causation, many expressed uncertainty while those who were certain primarily cited emotional causes or heredity for their diabetes. The uncertainty about the cause could be influenced among other things by the low public awareness about diabetes as has also been reported in other similar settings [16].

Most of the causes cited in the present study including the rage in relation to social interactions were either external factors or beyond individuals' control which could have negative implications for their decisions about adherence to recommended regimens and with potential to try out other healing practices such as religious healing and traditional medicine which are thought to be better suited to address illnesses in their cultural and religious contexts [17]. Other studies have reported that when the disease is perceived to have an internal cause, individuals take responsibility and have been associated with better adherence to treatment regimens [18, 19].

There were conflicting ideas with some believing or hoping that diabetes is an acute, curable condition and others maintaining that it was a chronic, controllable condition. It was however interesting to note that the regimen described for both the cure and control of diabetes were mostly similar and included the use of biomedical treatments, religious healing and traditional medicine. One reason for practitioners to understand if their patients were expecting a cure is that some may be carefully following the biomedical regime in hope of a cure which may over time lead to frustration if their goal is not fulfilled. This in turn could lead to lowering adherence to the recommended regimen or trying out different healing practices such as religious healing or traditional medicines which would have the potential to adversely affect the treatment regimen one way or another and affect health outcomes. Reports from other studies done in similar settings report how hope for a cure could actually lead patients try out traditional medicines which is a culturally appropriate approach, albeit with suboptimal health outcomes [20, 21].

Religious healing and traditional medicine were control approaches for diabetes that could be used on a complementary or sometimes alternative to the biomedical regimen in the present study. The use of religious healing such as holy water which is thought to cure diabetes, control sugar levels or otherwise manage related complications may prompt patients to reduce or even discontinue their medicines to observe the effects. On the other hand, use of traditional medicinal plants alongside the biomedical regime may lead to interactions with the possibility of lowering sugar levels and hypoglycemia if the herb indeed has hypoglycemic activity as has been reported for *shiferaw* (*Moringa*) [22]. It could also lead to discontinuation of the biomedical treatment in favor of traditional medicine, whose safety and efficacy have not been proved. Shifting to religious or traditional medicines were in fact among common reasons cited by psychiatric patients for not adhering to their medications according to a study reported from a hospital-based study in the southwestern part of the country [23]. Going to holy water sites

to be baptized was also among the frequently cited reasons for HIV patients being lost to follow up according to a study reported from the northwestern part of Ethiopia. Measures recommended by some priests of Orthodox Christianity to be cured of HIV/AIDS included taking holy water, praying to God and stopping medication taking [24]. Efforts to mitigate some of these challenges include the collaborations forged between biomedical practitioners and the Ethiopian Orthodox Tewahedo Church where encouraging results with regards to improved adherence were reported in the treatment of mental illness and HIV/AIDS [25, 26]. The perceptions of priests involved in the religious healing of these patients and possibility of collaborations could be one of the areas to be explored for the management of diabetes as the combined use of these treatments could also benefit spiritual and mental health, which are not well-addressed by the biomedical system [25].

A number of the study participants also portrayed diabetes as a deadly disease or as an uncontrollable condition which would inevitably lead to severe physical and social consequences despite following treatment recommendations. It is interesting to note that the poor control and high rate of complications widely described by our participants has also been reported by an Israeli study done among immigrants of Ethiopian origin there. The author surmised that the migrants have little experience of 'living with and controlling a chronic illness' and that management was not a common term in relation to disease [27]. While negative emotions are not unexpected, such strong emotional expressions which depict diabetes as a deadly disease, the fatalistic nature of the diabetes-related complications and its uncontrollable nature could potentially prove destructive for these participants' adherence to recommended treatment regimen and their health outcomes [6, 28, 29]. Negative emotions could also strengthen tendencies to try out healing systems promising cure or better control and further result in poor patient outcomes [30, 31].

The negative emotions that have been identified by participants of this study as possible causes for diabetes as well as the emotional distress reported by some study participants suggests the need for consideration of the influence of emotions in the patients' illness experience and its management. This is supported in the literature where others have identified a possible relationship between diabetes-related distress and depression with type 2 diabetes, whereby the diabetes is associated with an increased risk of incident depression and vice versa [32, 33]. While it is possible that depression may coexist in some of the study participants as has also been reported in another local study [8], the existence of unique diabetes-related distress seems to be evident as well. Depression and diabetes-related distress in turn have been related to suboptimal adherence

levels and poor glycemic control [32, 33]. This may hint of the possible benefit that patients with diabetes may get with regards to their illness should some form of mental health treatment such as psychotherapy be included for their distress and depression, if present. As there is currently no mental health service in the routine diabetes care, it is recommended that diabetes management should consider its incorporation in the consultations, be it individual patient-centered or group education sessions, in addition to the context-related diabetes education in order to improve patient outcomes with regards to mood but also those that are diabetes-related [32, 33].

Practice and research implications

The findings of this study have highlighted important issues for consideration in the care of patients with type 2 diabetes. One of these is study participants' perceptions that are strongly informed by religious and cultural influences and their low awareness about diabetes and its biomedical management. The other issue is the emotional distress that seems to exist among some of the study participants. These issues signify the need for a rigorous group diabetes education program that addresses local concerns and scenarios such as the ones identified in this study. Diabetes health education topics may include, but are not limited to, the role and implications of symptoms and other monitoring mechanisms such as blood glucose measurements, the chronic and controllable nature of diabetes and evidence-based approaches to management and expected outcomes, as well as causes. Incorporating mental health components, be it in the form of psychotherapy or others appropriate would be useful additions on a need basis. An important issue to consider is the use of innovative training programs such as group sessions that could entail active participation of patients both in the discussions and with regards to their responsibility in their care [34]. The use of diabetes patients who have good control of diabetes can also be considered to share their experiences and further serve as models about the controllable nature of diabetes.

The diabetes education program discussed above should complement but not substitute one-to-one consultation of patients with healthcare providers. It was apparent from the study that participants differed in their levels of biomedical knowledge and religious and cultural influences and as well with the levels of emotional distress expressed which would be indicative of the different management and education needs of these patients. With regards to the emotional issues, it is recommended that providers regularly assess and monitor patients for depression [33]. This would indicate the need for a more tailored and patient-centered approach to education that addresses patients' specific needs in understanding and managing

their diabetes. Healthcare providers may evidently need additional trainings on different areas including health communication [9], fundamentals of identification and management of depression [33] and as well about common traditional and religious healing practices if they are to effectively care for their patients and offer meaningful advice.

Further research is recommended to assess the explanatory models on a large population sample and design and assess specific interventions that include patient education and mental health treatment components aimed at improving adherence to recommended regimens and consequently health outcomes. Further ethno-pharmacological research is also recommended into the most common traditionally used medicinal plants and so that the findings can be used to provide evidence-based recommendations to patients. Studies to assess the explanatory models among individuals without diabetes in the Ethiopian and other low and middle income settings where diabetes is growing as a public health problem could also serve as useful inputs in the design of health education programs for the prevention and early detection of type 2 diabetes as well as its appropriate care.

Limitations

Among the limitations of this study is that study participants were recruited from among those following their biomedical treatment in hospitals and those that were not on follow up were not included. The findings expectedly would not represent those who may have avoided the biomedical option and instead chosen traditional, religious or other options. The hospitals where these participants were recruited were public hospitals which serve the relatively lower socio-economic group of population and these perceptions may not be applicable to those who would go to private health facilities and the relatively better-off. Furthermore, all study participants had had diabetes for at least a year when they were recruited and thus the perspectives of newly diagnosed patients would not be included. Finally, this study was limited to exploring the perceptions of patients and did not involve the perspectives of healthcare providers as well as the religious healers caring for these patients.

Conclusions

The findings of this study indicate that study participants' explanatory models were a mix of traditional and biomedical models to which emotional distress was an additional component. This model was useful in identifying the different issues that may influence patients' care for their diabetes which could affect their adherence to recommended regimens and health outcomes. It is therefore recommended that diabetes education sessions, both

group and one to one, need to be strengthened including the incorporation of some form of mental health components and be delivered in a manner that consider local contexts and be patient-centered.

Authors' contributions

BMH, TG and HB were involved in the conceptualization and the design of the study. BMH carried out the interviews. BMH and HB analyzed the interviews with TK and TG commenting on their analysis. BMH drafted the manuscript and HB, TG and TK revised it. All authors read and approved the final manuscript.

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Competing interests

The authors declare that they have no competing interest.

Availability of data and materials

Data which are audio recordings and transcripts of interviews will not be shared. The interviews were conducted in Amharic (the official and widely used language of Ethiopia) and they may be of limited use to international readers and there is the possibility of losing anonymity as some may contain identity revealing information.

Consent to publish

All the participants have given consent for the findings emanating from this study to be published.

Ethics, consent and permissions

All the participants in this study were provided with adequate information about the study and their participation before they gave their consent. The study received ethical approval from the Institutional Review Board of the College of Health Sciences, Addis Ababa University (protocol number 036/13/PSP). Furthermore, the study was approved by the heads of the respective hospitals.

Appendix

Interview guide

1. When did you find out you had diabetes? How did you feel when you were told you had it? Why do you think your diabetes started when it did?
2. What do you think has caused your diabetes?
 - Can you think of anything else that may cause diabetes?
3. What are the symptoms of your diabetes? Have you encountered any stigma or discrimination because of your diabetes or some of its symptoms?
4. What do you think your diabetes does to you?
 - How does it work?
 - What do you fear most about your sickness?

5. Will your illness have a short or long course?
 - How long does it take to get over this illness?
6. What are the chief problems this illness causes for a person?
 - What are some obstacles to your day-to-day management of diabetes?
7. How severe is your sickness? Does diabetes get better or worse the longer you have it?
8. What can people do to take care of this illness? What works and what doesn't?

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Paper II

RESEARCH

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Ethiopian patients' perceptions of anti-diabetic medications: implications for diabetes education

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Abstract

Background: The purpose of this study is to explore medication-related perceptions of adult patients with type 2 diabetes attending treatment in public hospitals of urban centers in central Ethiopia.

Methods: Qualitative in-depth interviews were held with 39 participants selected to represent a range of treatment experiences and socio-demographic characteristics who were attending their treatment in 3 public hospitals. Interviews continued until key themes were saturated. The interview and analysis was guided by Horne's necessity-concerns model.

Results: The findings revealed medication-related perceptions some of which were similar to those of Western patients and others that seem to be informed by local socio-cultural contexts. Participants' perceptions focused on the necessity of and concerns about their anti-diabetic medications, giving more emphasis to the latter. Concerns were expressed about both perceived and experienced adverse effects, inconveniences in handling the medications and access. It was evident that some of these concerns were exaggerated but could nevertheless negatively affect adherence to prescribed medications including resistance to initiate insulin with potential impact on health outcomes.

Conclusions: Understanding patients' perceptions of their medications is critical for developing a diabetes education program that considers local contexts and beliefs to enhance adherence. Education programs should consider patients' concerns about medication adverse effects and reasons for use so as to improve their adherence and health outcomes.

Keywords: Patients' perceptions, Anti-diabetic medications, Qualitative interview, Necessity-concerns model, Ethiopia

Background

Diabetes mellitus, especially type 2 (hereafter referred to as diabetes) is increasingly becoming an important public health problem in sub-Saharan Africa including Ethiopia with a prevalence estimate of 5.1%, and higher rates reported from the urban centers [1–4]. Ethiopian studies indicate that the majority of patients have poor health status including blood glucose levels well above recommended levels with a high proportion also having experienced micro- and macro-vascular diabetes-related complications [5–9]. One of the studies also reported uncontrolled diabetes leading to hospital admissions in a high proportion of surveyed patients [6]. A similar study reported that direct hospital costs for patients with

diabetes was significantly higher compared to controls and that substantial a part of the cost was related to treatment for diabetes-related complications [10].

Among the mainstay of diabetes therapy are the anti-diabetic agents which greatly contribute to the control of blood glucose levels and associated micro- and macrovascular complications. The success of these agents, and other components of the treatment regimen, depends among other things on patients' adherence to their recommended regimen so as to prevent acute complications and reduce long term complications [11]. However, adherence to medication regimens has been found to be a major challenge for patients with diabetes. Lower adherence to recommended medication regimens has been reported to have a negative impact on health outcomes and health services utilization such as emergency department visits, hospitalization and doctors' visits [12].

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The review paper by Capoccia et al. (2016) found that lower medication adherence was related to concerns about medication side effects and doubts about their necessity. This study also highlighted the influence of cultural variations in medication-related beliefs among different ethnic groups on adherence. These findings and others suggest the need for patient-centered approaches that consider patient preferences and address their specific medication-related concerns [12]. A number of approaches to improve adherence to anti-diabetic medications are reported including educational and pharmacy-driven interventions [11, 13, 14]. The most effective approaches appear to be those that provide proactive care, and where visits are coordinated among a team of healthcare providers, in either community or institutional settings. Furthermore, interventions should be based on the principles of patient-centered care that require patients' active involvement in their self-management [11, 15]. The different interventions are based on studies of medication adherence to diabetes and influencing factors that have mostly been conducted in Western nations or minority groups living in Western countries. There is a dearth of literature from developing countries like Ethiopia which are facing an increasing burden from diabetes.

Among the widely reported conceptual models to assess patients' medication related perceptions is the necessity-concerns framework which posits that patients' treatment perceptions, especially those with respect to beliefs about necessity and concerns, will play an influential role when patients come face to face with decisions to take medications [16, 17]. Patients' perceptions are likely different from that of their healthcare providers, and are thought to be based on their perceptions of the evidence about the benefits and risks [18].

The 'necessity' part of the Necessity-Concerns framework deals with the perceptions of personal need that patients may have for the medicines which may also be influenced by their beliefs about the efficacy of the medicines [16, 17]. The 'concerns' part deals with both concrete and abstract concerns related to medication-taking. The concrete experiences have to do with unpleasant symptoms such as side-effects and disruptions of daily life, while abstract concerns have to do with worries that regular use could lead to dependence or long term effects [16, 17]. In cases when the perceived necessity is strong and the perceived concerns are weak, patients tend to follow the recommendations to adhere while strong perceived concerns and weaker necessity may lead to them not to adhere to treatments. Treatment perceptions may also lead to unintentional non-adherence if, for instance, patients who consider their medicine to be unimportant for their condition forget to take it. Apart from necessity and concerns perceptions, culture has also been reported to influence adherence to medications. It is

also noteworthy that patients may not adhere due to reasons related to unintentional non-adherence (i.e., due to lack of resources) [17].

There are a limited number of articles focusing on adherence to anti-diabetic treatment in developing countries like Ethiopia. The few studies from Ethiopia report unacceptably low levels of adherence to recommended medications. The common factors cited for the low levels of adherence include: being on non-insulin drug regimen [19]; consulting traditional healers [19]; lack of financial resources [20]; perceived side effects [20]; experience of depressive symptoms [21]; complexity of medication regimens [21] and concerns about medications' safety [22]. All of these were reported in quantitative studies and provide limited insight into patients' perspectives of their medications which may be used to design patient-centered interventions to encourage adherence.

The aim of this study was to conduct a theory-guided, exploratory study using qualitative methods to elicit medication-related beliefs of type 2 diabetes patients who are following treatment in Addis Ababa (the largest urban center of Ethiopia) and Butajira (a town in Central Ethiopia that serves as center for the demographic surveillance site of Addis Ababa University) [23]. The Necessity-Concerns conceptual framework that has been widely used to study chronic patients was selected as the conceptual framework [17].

Methods

This study is part of a larger study that utilized qualitative interview methods to gain in-depth understanding of issues surrounding patients' medication-related perceptions in urban Ethiopia. In-depth interviews with individual participants were conducted from December 2013 to March 2014 in locations that were mutually agreed by individual participants and the first author (BMH, a licensed pharmacist and PhD student trained in qualitative research methods) such as a quiet place in the hospital compound, participants' homes, church compound, quiet spot in cafes, an academic office and a hospital office. Ethical approval (036/13/PSP) was obtained from the Institutional Review Board of the College of Health Sciences, Addis Ababa University.

Study setting

Participants were selected from three public hospitals in central Ethiopia. Two of these, Tikur Anbessa Specialized Hospital (hereafter referred to as Tikur Anbessa) and Yekatit 12 Medical College Hospital (hereafter referred to as Yekatit 12) are located in Addis Ababa and serve a high number of patients with type 2 diabetes. The third hospital, Butajira General Hospital (hereafter referred to as Butajira) located in Butajira town located 135 kms away from Addis Ababa is the only public hospital in this town

and was included to explore the perspectives of patients in a peri-urban area of central Ethiopia. Table 1 gives a brief description of the two settings.

Tikur Anbessa is currently the highest referral hospital in Ethiopia. During the study period, patients were seen in the Endocrinology Unit that was run by 3 endocrinologists and 2 endocrinology fellows working as consultants on a rotating basis, up to 6 Internal Medicine residents who were assigned to take primary roles in managing patients during their month-long attachments, 6 nurses and 1 recently recruited pharmacist.

Yekatit 12 is a general hospital that has recently started training doctors. The services provided for patients with diabetes were mostly in the general outpatient department (with no dedicated or separate diabetes care clinic) that was run by 4 general practitioners with complex cases referred to the medical referral clinic, run by internists on a rotating basis. In both of the above hospitals, patients would be 'randomly' assigned to a physician each time they come for their appointment.

Butajira, also a general hospital, serves patients with diabetes at a medical clinic separate from other outpatients. The clinic was run by a general practitioner and a nurse where patients meet the same physician and nurse each time they come for their monthly appointments for at least a 6-month period.

Study participants recruitment

Patients with diabetes who were attending treatment in the selected hospitals during the study period who were 18 years and older, had been prescribed anti-diabetic medications for minimum of one year and had no known or overt psychiatric problems were eligible to participate. Being a healthcare professional was the only exclusion criterion. Participants were purposively selected to include a wide variety of patients in terms of socio-demographic characteristics (age, sex, educational level, marital status, employment status, religious affiliations and place of residence), income level, medication regimen and years since diagnosis. Participant recruitment was facilitated by the clinic nurses who identified the patients and provided initial information about the study which was followed up by

the first author who provided further information and recruited eligible patients.

Interview methods

Interviews were conducted in the Amharic language which is the official and widely used language in the study settings. The first author conducted the interviews (audio recorded with participants' consent) that ranged from 30 to 120 min. Sets of questions recommended by Kleinman et al. (1978) [24] and those from the necessity-concerns framework [16] were used to frame the interview guide (Appendix). Study participants were asked to discuss their treatment perceptions including their views on the necessity and concerns about their medication regimen. The interview guide was translated to Amharic and back to English to check the consistency before using the Amharic version.

Data analysis

The interviews were transcribed verbatim into MS Word by an experienced assistant. The quality of the transcripts was checked by the first author by listening to randomly selected recordings from each study site while reading transcripts. Transcripts were read repeatedly to ensure good understanding before coding them to identify components of the necessity-concerns framework. Coding included looking for new themes emerging from the data that were unique. Interviews continued until all key themes were saturated (the point at which no new information was emerging) [25]. Analysis and interpretation was carried out by the first author in collaboration with the last author. Initial coding and categorization was done in Amharic followed by further analysis and interpretation which was done after translating key components relevant to the emerging themes into English. NVivo 10 was used to manage the data.

Results

Description of the study participants

Forty-five patients who met the eligibility criteria were identified during the study period of which 6 did not participate either due to personal reasons or because of

Table 1 Description of study settings

	Addis Ababa	Butajira
Significance	Largest urban center in Ethiopia	Home to the demographic surveillance site of AAU
Population [48]	3.2 million	63 thousand
Ethnic groups [49]	Amhara (47%), Gamo (1.7%), Guragie (16.3%), Oromo (19.5%), Silte (2.9%), Tigrie (6.2%), others (6.4%)	Guragie (82%), others (18%)
Religions [49]	Orthodox Christianity (74.7%), Islam (16.2%), Protestant Christianity (7.8%), others (1.3%)	Islam (51.3%), Orthodox Christianity (39.6%) and Protestant Christianity (8.7%), others (0.4%)
Literacy [49]	85.3%	37.9%

problems with telephone communication. Of the 39 patients with diabetes who participated in the study, 24 were residents of Addis Ababa following treatment at Tikur Anbessa and Yekatit 12 and the remaining of Butajira town or its environs. Table 2 summarizes demographic characteristics of the study participants. As

Table 2 Study participants' characteristics (n = 39)

Sex	
Female	19
Male	20
Age (years)	
30-39	2
40-49	8
50-59	14
60-69	10
>70	5
Educational status	
Low education (illiterate or basic literacy)	16
Elementary complete	8
Secondary school complete	8
Post-secondary school education	7
Occupation	
Clerical work	7
Rents house	4
Small business	5
Farming	5
Pensioner	9
Unemployed	5
Others	4
Payment for health services incl. medicines	
Out of pocket	13
Government	23
Employer	3
Diabetes duration (years)	
1-5	10
6-10	14
11-15	7
16-20	4
21-25	4
Treatment regimen	
Oral:	
Glibenclamide + metformin	22
Glimepiride + metformin	1
Glibenclamide	1
Insulin	14
Insulin plus metformin	1

notable differences were not observed in the perceptions of participants from the different sites, the data are presented as a single set.

Treatment perceptions

The findings revealed that most study participants didn't know the names of their anti-diabetes medicines and instead labeled them using the Amharic terms for pill (*kinin*) and injection (*merfe*). Among the pills glibenclamide (a sulfonylurea), was labelled as the small or the thin one, while metformin (a biguanide), was the bigger or fatter one. A few, with better education, used brand names such as Daonil (a popular trade name for glibenclamide even if most actually took the generic versions), or Metformin. Participants' treatment perceptions focused primarily on the necessity and concerns although it was apparent that increased emphasis was given to the concerns aspects of the medications and less to their necessity.

With regards to necessity perceptions towards anti-diabetic medications, they were mostly related to the health benefits and their efficacy. Generally, perceptions of necessity were stronger, with respect to insulin than for oral hypoglycemic agents:

Now, if you stop your medicines [the pills] it could bring problems, may make you lose your eye (sight), paralyzed. (Male, 61 years, elementary school complete)

And so when it wouldn't go down (with the tablets), they changed it to the injection And it's done well, I now started to feel good inside. There is no weakness that used to be there, none of that ... (Female, 60 years, high school complete)

Participants' concerns with regards to their anti-diabetic medications can be broadly categorized into: a) perceived concerns about the efficacy of the oral anti-diabetic agents; b) abstract concerns/worries of adverse effects; c) the actual experience of adverse effects; d) challenges with use and storage and; e) challenges with medicines availability or affordability.

Concerns about the efficacy of oral anti-diabetic agents

The efficacy of the generic oral anti-diabetic medications available through the hospital pharmacy either for free or at low prices were questioned mostly in relation to their perceived lesser efficacy compared to the western brand medicines.

The Indian ones (tablets) are useless and if the government tried to import the German ones, now that could be helpful for the patients; otherwise these are useless. But what other choice do we have? ... (Male, 54 years, high school complete)

Worries about potential adverse effects of the anti-diabetic medicines

Worries were expressed about possible adverse effects of anti-diabetic medicines with hypoglycemia and gastritis cited as common concerns and as well about 'too many' medicines to a lesser extent. There were cases however where certain diabetes complications such as impotence and eye damage were attributed to be adverse effects of the medications on the one hand and the hypoglycemia due to the medications was ascribed to diabetes on the other.

They say that it (diabetes) makes you fall and that you should always have candy or sugar on you. But how can I take sugar when I have been prohibited. My sugar has gone up and I have been told not to eat sweets and so how can I carry with me sugar? (Male, 61 years, elementary school complete)

I hear from professionals with whom I work that the medicine has many side-effects; the Daonil creates problems on the eye, metformin damages the stomach. ... Yes it (the medicine) has many side-effects. (Male, 46 years, Diploma holder)

Insulin was associated with a higher degree of severity because patients believed it was prescribed when the diabetes was not responding to other forms of treatment. This was perceived as evidence that one has perhaps neared the end of life and thus some patients became very emotional when discussing new insulin prescriptions:

The very idea of injection disturbs one emotionally. It is also disturbing when discussed by the community. (Male, 46 years, Diploma holder)

Different adverse effects have been associated with insulin such as falls, paralysis and weight gain. The expression of some had an emotional tinge to it revealing a strong feeling against insulin. On the other hand, a participant who earlier on had a serious concern which has since been replaced with strong expressions about the necessity of insulin was an interesting finding.

Injections need great care; if the (sugar) levels go down there is the possibility of falling down and that's what I think of. I don't think I will be able to get up again if I fall. I am hypertensive and such complications may make me paralyzed. (Female, 55 years, Diploma holder)

They said that I deserved injections after this (sugar levels wouldn't go down with the tablets)... I was very startled (when they told me to start on injections). I didn't think I would be able to stand and walk. I was

so fearful.... (But) it is only after the injections that I regained my identity and I became happy. (Female, 65 years, low education status)

The influence of others, be it positive or negative, on insulin initiation was also reported. The positive aspects which participants observed or heard seem to have allayed some of their concerns while the negative aspects such as observing the scars and suffering apparently have negative influences towards initiating insulin.

I hate it [insulin]. Even when I got diabetes I hoped not to become an insulin user. I don't know why. I sadden when I see her (my sister's) body. When I see her I don't feel as if I am ill. I just see her suffering. The places in her body which have been injected have scarred so much and created a pattern on its own.... and her body is like a sieve. (Male, 45 years, high school complete)

Experience of adverse effects

Study participants described their experiences of adverse effects they perceived as being associated with their oral anti-diabetic agents and insulin. The most common adverse effects associated with oral anti-diabetic agents were gastritis. In addition, some taking glibenclamide reported hypoglycemic feelings such as feeling dizzy and shivering.

Hypoglycemia was a major concern for those on insulin where shivering, dizziness, loss of consciousness and falls were reported. It was evident that the hypoglycemic incidents were puzzling, and led to emotional reactions for some of the study participants:

My problem now is my fainting, it disturbs me. I say what if it (the fainting) happens while travelling on the road. Who would pick me up? Then my mother would no more have a child and my daughter wouldn't have a mother. That possible scenario disturbs me a lot. (Female, 46 years, high school complete)

The hypoglycemic incidents above have led to life-threatening incidents and hospital emergency admissions for some study participants while it has led to extended treatment and absences from work for others.

Fear of pain associated with injections, which may directly impact adherence, was also identified by study participants as a concerning side effect.

The injection indeed is difficult. I used to shiver and in the process hurt my legs. I had started injections one time. And so it was very painful and I also told myself of its painfulness. I imagined not about the efficacy of the medicine but of the bruise marks that it will leave on my body. (Female, 37 years, high school complete)

Challenges with use and storage

Perceptions about the need for stricter adherence required of insulin were cited as reasons to resist recommendations to start this medication:

I didn't want the injection because they told me that you couldn't discontinue it from time to time (as is possible for the pills in case one has to go for holy water). (Male, 68 years, low education status)

I think the injection is a bit complicated as compared to ours especially with regards to time. Now we can take our medicines (pills) but can stay for 2 or even 3 h without eating but they would fall. If they say 8 o'clock, they have to take it exactly at 8 o'clock. (Male, 63 years, high school complete)

The inconvenience of handling insulin especially in relation to its cold storage requirement was mentioned to restrict mobility:

I find the injection to be very difficult because I am used to the tablet... It is more convenient (to transport and store even in rural areas). The injection needs a fridge and when you go out it is difficult (to use it) because if it is not placed in the fridge it will be damaged. And so if I go to my relatives who live far away, I could take my medicines in my pocket. (Male, 54 years, high school complete)

Challenges with the availability and affordability of the medicines

Concerns were expressed by some in relation to the availability and affordability of the prescribed medicines. For some, the concern is related to having to pay for the medicines as it was not affordable for them even to buy from the hospital pharmacy where generic medicines were available at low prices. For others it was the unavailability in the hospital pharmacy which might lead to paying even higher prices in the private outlets, or worse, having to buy low quality products from illegal sources.

There are some people who inject expired medicines after buying it from private sources... Now if the medicine is not available at the hospital you have to buy it from outside. One time a friend of mine was offered to buy such medicine by some people who just rolled it up in a plastic bag and he encountered a problem. Now many people face such problems. (Male, 57 years, elementary school complete)

Yes sometimes medicines are unavailable (at the hospital). Now last time they were unavailable and we had to buy at the pharmacy (private). When one is

available the other is not. There is a problem with medicines. (Male, 54 years, high school complete)

Discussion

This qualitative study of patient perceptions of anti-diabetic medications is a first from Ethiopia. Many participants perceived the medications' necessity, with stronger belief in the efficacy of insulin compared to the oral agents. Given the increased emphasis on concerns about medications compared to their necessity, it is quite likely that these perceptions impact adherence to prescribed regimens and recommendations to initiate insulin. This seems to be in line with the necessity-concerns framework proposed by Horne et al. (2003) where such perceptions about necessity and concerns can lead to intentional non-adherence [16].

A range of concerns about the potential adverse effects of the oral agents were raised. These include concerns which were similar to those raised by Western patients that were mainly about adverse effects (e.g. hypoglycemia and gastritis) and to a lesser extent the number of medicines being taken [26, 27]. Medications-related concerns which are specific to this study include perceived adverse effects which are actually expected as complications of diabetes itself (e.g., impotence and eye problems) or relating hypoglycemia to the illness itself as a complication and not to the medication as adverse effects as also reported by another local quantitative study [28]. This signifies about the need to be open in assessing patient perceptions so that appropriate education about the diabetes and the drugs used to treat it may be offered. Such measures could minimize safety concerns which is one of the major barriers reported by local studies that have been reported to affect adherence to medications [20–22].

This study revealed hypoglycemia to be a major concern among some study participants on oral agents. Hypoglycemic incidents which included falls that were encountered personally or among their social circles could expectedly make patients to skip doses or make them reluctant to accept dose increments or additional medication. As most study participants were taking glibenclamide, the reported hypoglycemia, is not unexpected given its high hypoglycemic potential [29, 30]. The findings from a study done in Nigeria similarly reported hypoglycemia as one of the most common side effects and common reasons for non-adherence for those patients on glibenclamide [31]. Glibenclamide has further been associated with cardiac risks where one study reported how the initial treatment with glibenclamide was associated with a more than two-fold increase in the risk of coronary artery disease which was however reduced with newer sulphonylureas such as glimepiride and gliclazide [32]. The findings of the present study and supporting literature further highlight about the need by the

government to consider alternative generic oral anti-diabetic agents available with comparable costs but less hypoglycemic potential such as glimepiride, another member of the sulfonylurea family [29].

There were others who expressed concern about perceived inefficacy of the generic oral anti-diabetic agents that were made available to patients for free or at low prices. Such type of concern about generic medicines is reported in another study conducted among patients attending treatment for diabetes in selected public and private health facilities in Addis Ababa. This study revealed that only 30% were comfortable taking any brand even if their physician recommended it and quality was one of their main concerns [33]. The concern towards generic medicines do not seem to be limited to the patients but also extends to the providers. For example a study reported that over one-third of community pharmacy clients and pharmacy personnel apparently had distrust on the approval system for generic medicines in Ethiopia [34]. This issue needs the attention of policy makers and healthcare providers to provide relevant education about generic medicines as such concerns may affect adherence [35].

On the other hand findings of a local study that evaluated the quality of different brands of amoxicillin capsules marketed in Ethiopia showed that most generic brands were not interchangeable with the innovator brand. A recommendation was made by that study for the reinforcement of the capacity of the drug regulatory body including strengthening of post marketing studies [36]. Another post marketing study done to assess quality of antibiotic, antimalarial and anti-tuberculosis medicines from selected sites in Asia, Africa (including Ethiopia) and South America reported that 848 (5.6%) of the total samples failed the quality test and furthermore 81 counterfeit medicines were reported, 13.6% of which were from Africa [37]. This highlights for the need to work to strengthen the regulatory system and ensure the quality of medicines at all levels of the supply chain so that efforts to increase access to affordable, generic medicines and improve the health outcomes of patients achieve intended outcomes.

With regards to insulin initiation, most of the concerns are similar to those reported elsewhere including insulin signifying an increased degree of illness severity and adverse effects mainly hypoglycemia [38]. Among the concerns that may be unique to this study is the perceived need for stricter adherence required with insulin compared to the oral agents which is perceived to be complicated by local religious healing practices such as use of holy water [39]. The use of holy water has been reported to lead to discontinuation of treatment according to studies done on other chronic illnesses [40, 41]. This issue needs to be assessed in a nonjudgmental

approach. Patients need to be educated about the benefits of following recommended regimens and not discontinuing their treatment even if they intend to use holy water. Such attempts actually may need the support of higher level policy interventions as has been tried for HIV/AIDS treatment. In this regard collaborative work with religious leaders has endorsed the combined use of anti-HIV medications and holy water as compatible, encouraging the use of both types of treatment and contributed to increase in adherence to recommended regimens [40].

The issue of perception that insulin needs to be refrigerated at all times appears to be another potential problem in relation to its initiation as many may not possess refrigerators. If they are living in the rural areas or are to travel outside urban centers, accessing cold storage may be even more difficult [42]. Such conditions could thus be considered as credible reasons to resist recommendations to initiate insulin regimen by the patients. Healthcare providers should take time to assess their patients' perceptions and contexts to discuss as needed about the importance of cold storage conditions for insulin, its utility for short and long term conditions and possible options to store especially for the spare insulin vials such as with relatives, friends or others who have a fridge. They should also stress the acceptability of storing insulin that is being used at room temperatures and that it should not impede acceptance of an insulin regimen [42–45].

It was also apparent from this study that some of those who expressed concerns about insulin were willing to accept an insulin regimen if it were recommended by their healthcare providers. This should be given due consideration in light of the reluctance to prescribe it by some providers citing strong patient resistance [38, 46].

Group diabetes education programs should be strengthened. Patients who have started on insulin and demonstrated improved health outcomes may have passed through the same anxiety as those patients who have concerns and so may play beneficial roles in such programs. The utility of other patients who are more experienced and 'further along the treatment trajectory' has been cited in reassuring patients who may be anxious about starting new treatments such as insulin [47]. It has to be stressed however that while group education may play a critical role in the care program of patients, they should not be a substitute for one to one education of patients by appropriately trained healthcare providers. Such individual-based educations would allow assessment of patients' knowledge, beliefs and requisite skills with respect to their medications and facilitate a more tailored and patient-centered approach in educating and discussion to alleviate their concerns and improve their medication-taking behavior.

This study explored the perceptions of limited groups of patients with diabetes – those following their treatment at

a public hospital in urban settings and consented to participate –and may not be representative of a larger and more diverse population. The findings may not be applicable to those who may have avoided biomedical treatment and also those attending treatment in the private health institutions who may be of higher socio-economic standing. This study however recruited patients of diverse socio-demographic backgrounds and having varied duration of illness which has allowed a rich and diverse information on their perceptions about anti-diabetic medicines which gave us a good insight. This study also gave the context for the majority of patients with diabetes who attend treatment in these urban centers which can be translated to other hospitals and patients with similar settings.

Conclusions

Findings of this study are suggestive of the utility of the necessity-concerns framework in organizing the medication-related perceptions in our setting. While some of the participants' anti-diabetic medications-related perceptions appeared to be similar to those expressed by Western patients, there were perceptions that were different including the exaggerated concerns towards oral agents and insulin which could potentially lead to intentional non-adherence and affect health outcomes. Diabetes education, be it individual or in groups, needs to consider local contexts such as patients' religious backgrounds and their socio-economic contexts in addressing about the use of holy water, medication adverse effects and insulin storage among other things.

Appendix

Interview guide

1. What treatment has been recommended to you by your healthcare provider(s)?
2. What are the most important results you hope to receive from this treatment?
3. What is your view regarding the necessity of the treatment regimen(s) recommended by your healthcare provider?
4. What are your concerns in relation to the anti-diabetic medications that are recommended by your healthcare provider?
5. If there is any other thing you would like to add in relation to our discussion on medications that have been recommended for your diabetes?

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Availability of data and materials

Data which are the audio recordings and transcripts of interviews will not be shared at this time. The interviews which were conducted in Amharic (the official and widely used language of Ethiopia) may be of limited use to international readers. Furthermore, there is the possibility of losing anonymity if interview transcripts were made available as some may contain identity revealing information. However these data sets may be available from the corresponding author upon reasonable request.

Competing interests

The authors declare that they have no competing interests.

Authors' contribution

BMH, TGF and HB author were involved in the conceptualization and the design of the study. BMH carried out the interviews. BMH and HB were involved in the analysis of the interviews with TK and TGF commenting on their analysis. BMH drafted the manuscript and all the others revised it. All authors read and approved the final manuscript.

Ethics approval and consent to participate

All the participants in this study were provided with adequate information about the study (including that some of their verbatim expressions may be published) and their participation before they gave their consent. The study received ethical approval from the Institutional Review Board of the College of Health Sciences, Addis Ababa University (protocol number 036/13/PSP). Furthermore, the study was approved by the heads of the respective hospitals.

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Paper III

Patient-healthcare provider communication – the perspectives of Ethiopian patients with type 2 diabetes

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Abstract

Introduction: Good patient-healthcare provider communication has been established as an important factor for achieving optimal patient outcomes. The aim of this study was to explore patients with diabetes' expectations about, and experiences of, communicating with healthcare providers.

Methods: Individual qualitative interviews were conducted with 39 patients with diabetes attending their care in three hospitals in central Ethiopia from December 2013 to March 2014. Coding of the data and interviewing continued until saturation of all key themes.

Results: Guided by Haes and Bensing's communication model, six themes were identified: fostering the relationship, gathering information, providing information, decision making, enabling disease and treatment-related behavior, and responding to emotions.

Conclusions: A number of participants' desired expectations in their communicating with their healthcare providers were not met. Participants' experiences suggest that changes in the healthcare is delivery for diabetes such as adoption of the chronic care model, taskshifting to make optimal use of healthcare providers such as nurses and pharmacists, and as well a communication skills training for all healthcare providers caring for patients with diabetes are recommended.

Key words: patients'-healthcare providers' communication, patients' perspectives, type 2 diabetes

Introduction

The role of anti-diabetic medications in the control of blood glucose levels and reduction in microvascular complications has been long established (1,2). However, optimal adherence to

treatment regimens is often not the case especially for chronic conditions such as diabetes (3,4). Studies with Ethiopian patients have reported on modifiable factors that negatively affected adherence to anti-diabetic medications such as experience with, or concerns about, medication adverse effects, perceived inefficacy, depressive symptoms, treatment regimen complexity, use of traditional medicines and dissatisfaction with the service provision (5–9). Except for the mention of service dissatisfaction in one of the studies, there has been little focus on the potential influence of patient-provider communication and relationship on adherence, although studies done elsewhere have described its critical role in predicting adherence to recommended treatment and health outcomes (3,10,11). In fact, current global standards recommend a good patient-provider relationship as a foundation for supporting optimal patient outcomes (12).

Studies exploring patient-provider communication from the perspective of the patients with diabetes in the western settings have described different perceptions towards their relationship with their healthcare providers that influence adherence to recommended regimens. Some of the factors found to positively influence adherence include healthcare providers' support, collaboration and good communication strategies. Some of the factors that appear to negatively influence adherence include relaying and explaining the diagnosis in a less caring manner; providing instructions such as warnings and in a threatening manner; deciding on topics to be discussed while also failing to address patients concerns; patients' perception of lack of support, barriers to communication, cultural insensitivity of some providers towards minorities; inaccessibility of healthcare providers such as short consultation times; and patients' desire to be perceived as individuals and not as illnesses. Previous research indicated that patients hope for a collaborative relationship with their providers that is based on mutual trust and mutual agreement, that would allow open discussion about their challenges is an important factor in patients' subsequent adherence to prescribed medications (13,14).

Studies from non-Western settings have identified some similar and some unique factors related to patient-professional communication. For example, patients in Oman largely expressed dissatisfaction with the care provided to them and cited weaknesses such as unfriendly welcoming, interrupted consultation privacy, poor attention and eye contact and lack of encouragement for the patients to ask questions by the providers. Other issues cited by these patients from the Omani study include problems in being patient-centered, insufficient access to health education, professional incompetence and long waiting time (15). Studies from African settings have reported a number of negative patient perceptions towards their healthcare providers such as lack of time to explain things to doctors, as well as the array of restrictions and prohibitions imposed as part of the treatment regimen that were considered as barriers to compliance (16,17). Some of the issues between patients and the healthcare providers in the African setting has to do with the different explanatory model that patients may have about disease cause and hence treatment which may involve use of traditional medicines (17–19).

Positive perceptions towards healthcare providers include their usefulness in providing medication and lifestyle related information and psychosocial aspects (16,20). Such issues are illustrative of the importance of patients' perceptions towards their healthcare providers in influencing their self-management behavior including adherence to recommended treatment regimen. This study aims to explore Ethiopian patients diagnosed with diabetes' expectations and their experiences interacting with their healthcare providers.

Haes and Bensing (21) have suggested a communication model that can be helpful in investigating the encounter between patients and healthcare providers. This model identifies six functions: (a) fostering the relationship, including elements such as respect, trust and rapport; (b) gathering information including activities to solicit information from patients about symptoms, experiences and expectations; (c) information provision, with a focus on providing information to patients about their illness and its treatment; (d) decision making; (e) enabling disease and treatment-related behavior and; (f) responding to emotions. This model has been used in framing patients' perceptions towards their clinical encounters by a review study which described its usefulness in linking the communication model of researchers with that of patients (22).

Methods

Qualitative interview methods were used for this initial exploration into patients' perceptions and experiences of their communication and relationships with their doctors and other healthcare providers. This study was approved by the Institutional Review Board of the College of Health Sciences, Addis Ababa University (protocol number 036/13/PSP).

Study settings

Study sites were three public hospitals in central Ethiopia. Two of these which are located in Addis Ababa (the capital city of Ethiopia) are Tikur Anbessa Specialized Hospital (hereafter referred to as Tikur Anbessa) and Yekatit 12 Hospital (hereafter referred to as Yekatit 12), which serve a large number of patients with type 2 diabetes. The third one is Butajira Hospital (hereafter referred to as Butajira) which is an only public hospital in Butajira which was included to explore the perceptions of patients living in the peri-urban part of the country. Tikur Anbessa is a teaching hospital which is also the highest referral hospital in Ethiopia. Patients who are diagnosed with diabetes are seen in the Diabetes Center which was run by 3 endocrinologists and 2 endocrinology fellows who work as consultants on a rotating basis during the study period, around 6 Internal Medicine residents assigned to take the primary role in managing the patients during their month long attachments, 6 nurses and 1 recently recruited pharmacist. Yekatit 12 is a general hospital which is managed by the city administration and has newly started training medical doctors. The clinical services for diabetic patients were primarily given in the general outpatient department that was run at the time by 4 general practitioners. Cases that were considered to be in need of specialist care were referred to the medical clinic run by internists on a rotating basis. Patients attending treatment

in Tikur Anbessa and Yekatit 12, are 'randomly' assigned to an attending doctor each time they came for their appointment. Butajira is a general hospital that managed the treatment of patients in a similar pattern as those of the other two hospitals. It however has lately established a separate medical clinic run by a general practitioner and a nurse that serves patients with diabetes. During the time of the study, these patients have started to meet the same doctor when they come for their monthly appointment for at least a 6 months period.

Study participants recruitment

Participants for this study were purposively selected patients with diabetes who were attending their treatment for the duration of the study in the selected hospitals. The inclusion criteria were: age of 18 years and above, being on anti-diabetic medications for at least a 1 year and having no known or overt psychiatric problems. The only exclusion criterion was being a healthcare professional. Apart from these, efforts were made to purposively select patients with a wide variation in terms of socio-demographic characteristics (such as sex, age, marital status, educational level, religious affiliation, employment status and place of residence), income level and illness duration.

Data collection methods

Individual in-depth interviews coupled with field notes were used for the data collection. The interviews which had a median duration of 49 min (range from 30 to 120 min), were conducted from December 2013 to March 2014 by the first author. The interviews (completed in Amharic) were audio recorded with the participants' consent. The interview questions focused on eliciting study participants' perceptions towards their healthcare providers, namely doctors, nurses and pharmacists. Specifically the questions sought to explore participants' general expectations towards their healthcare providers and describing their experiences during their clinical encounters. The interview guide, which was originally prepared in English, was translated to Amharic and back to English to check its consistency before the Amharic version was used.

Data analysis

The interview data were transcribed by an experienced research assistant. BMH checked the quality of interview transcripts by listening to randomly selected audios from each study site while reading the transcripts. Interview transcripts were then read repeatedly before coding them according to the categories by (21). Coding for data continued until all key themes were saturated and no new information was emerging (23). Initial coding and categorization was done in Amharic which was followed by further analysis and interpretation that was carried out after translating key components of the interview transcripts that were relevant to the emerging themes into English. BMH in this regard worked with HB to analyze and interpret key

findings until they reached consensus. NVivo 10 qualitative data analysis software was used to manage the data.

Results

Among the 45 patients who fulfilled the inclusion criteria and were invited to participate in the study, 39 were able to take part in this study. The rest did not participate citing personal reasons or due to difficulties in telephone communication. Among those who participated, 24 were from Addis Ababa, equally divided 12 each from Tikur Anbessa and Yekatit 12 Hospitals while the remaining 15 were from Butajira. A summary of participant characteristics is given in Table 1.

The perceptions of the study participants were categorized into six main themes based on Haes and Bensing's communication model: fostering the relationship, gathering information, providing information, decision making, enabling disease and treatment-related behavior and responding to symptoms. Notable differences were not observed in the perceptions of participants from different study sites and thus study findings are presented as one data set.

Fostering the relationship

Study participants expressed their expectations of their healthcare providers which include showing a welcoming face and greeting, listening attentively and speaking in a caring manner, providing an appropriate response that is considerate of age and sex and demonstrating respect. Descriptions of experiences with healthcare providers identified that some met these expectations while others did not. Example of those that did not meet expectations included not demonstrating respect toward patients and using what patients described as attempts to "scare" them into complying.

The doctors assigned to the clinic are new ones who have limited knowledge about medical care. They act very disrespectfully towards patients. This hurts one and especially the elderly. They cannot tolerate it as they want respect. Even if you don't give them any medicine the (good) psychological treatment suffices for them. They would leave happy (Male, diploma graduate, 8 years with diabetes).

When I had a problem with my leg, they had asked me if I didn't want it (my leg). Why wouldn't I? I was very frightened when they said that. I was very frightened (Female, low education, 7 years with diabetes).

Many study participants expressed their preference to be seen by a single doctor. Relationship building was difficult if the doctors changed each time patients come for their clinic appointment. There were also some patients who described the need to narrate their whole medical history each time they came for an appointment.

They are constantly changing. It would have been good if they assigned only one as he would have better knowledge and be able to best care for you (Female, elementary school complete, 3 years with diabetes).

Study participants mostly had no problems with their limited interactions with pharmacy personnel. With regards to the nurses, while there are some who reported good encounters, there were others who expressed dissatisfaction with the manner in which they were treated such as not being shown a welcoming face, not greeting patients who have been treated there for a long time, treating disrespectfully patients who may inquire about a lost medical history card or when one misses the appointment date and comes the following day.

Gathering information

Doctors were described to gather information from study participants in a number of different ways including: physical examination, laboratory tests, reviewing medical history cards and by interviewing them. The majority of the study participants expressed their desired expectation that there would be physical examination at each visit. In actual practice however, only a few reported that physical examination was conducted. Some study participants described good experiences with doctors who inquire in detail about any problems faced and changes observed as well as questioning about what led to increases in sugar levels and carefully reviewing the medical history as per their expectations. Others detail about the not so good experience whereby some doctors do not review past history with some even asking patients about the dose of the antidiabetic agent that will be prescribed or others omitting some medicines which need to be taken chronically such as aspirin or anti-cholesterol medicines.

He does a thorough physical examination, including my eyes and my feet. He makes me take off my shoes and examines everything including my nails bending down without being offended by my shoe odor. He talks to me gently and when everything is fine he sees me off saying things are very good. It is after that (I was seen by him) that I became hopeful that I could live... (Female, low education, 7 years with diabetes).

Some participants expressed frustration about not being heard which was mostly in relation to presenting their complaints related to encountered problems which they perceived was ignored by the doctors.

They don't listen when you tell them. I came here to get good hospitality. When you treat me well, I am sure that I will be healed even if you don't give me any medicine and leave a happy woman. The kids (young doctors) are not good... They should listen to what we have to say because the illness is with me. He is going to prescribe the medicines based on what I tell him. I have left the (hospital) many times feeling dejected ... (Female, low education, 18 years with diabetes)

Some study participants described good experiences with doctors who ordered laboratory and other relevant tests as per their expectations. Many however complained as to how the doctors don't order different tests they were expecting. There were also study participants who expressed their concern that they were mostly seen by young, inexperienced doctors when they should have been seen by the senior doctors.

Providing information

Participants expressed their desired expectations about doctors who provide hope and encouragement which was met for some of them. There were others, however, who expressed their disappointment that their concerns and distress related to their illness and its complications were not addressed and little or no information nor encouragement was provided.

The doctors don't talk that much. They just instruct you to increase (the dose) if there is an increase or decrease if there is a decrease (in sugar levels). Other than this, they don't discuss other things that much (Female, elementary school complete, 2 years with diabetes).

Another concern which was in relation to the lack of continuity of care, was about doctors who do not give feedback on previously ordered tests or regimens.

One time they ordered here around six types of tests; blood, urine (two types), heart and I did the tests. When I returned with the results I was assigned to another doctor who however didn't look at my results... I went in and out with the results in the plastic bag after doing so many tests which was not seen. No, they don't look at it. (Female, low education, 20 years with diabetes)

Decision making

There were no study participants who expressed expectations with regards to involvement in the decision making process. A few of the study participants described that the doctors had in some way involved them in the decision making which helped in acceptance of the forthcoming recommendation to start on insulin regimens. The expressions by the majority of the study participants indicates that they were given little or no information about, nor involvement in, the decision making process. This has apparently led to safety concerns and nonadherence in certain cases.

The manner that they order (treatment) sometimes seems to have a threatening component... For example I don't have hypertension but they tell me to take enalapril, and aspirin. When I ask why they tell me that it is good for my heart. I on the other hand

think that it will also bring problems to the kidney and don't want to take. But they try to invoke fear. (Male, bachelor degree graduate, 15 years with diabetes)

Enabling disease and treatment related behavior

Some participants expressed good experiences with the doctors in relation to their provision of education about diabetes and its management as well as explained options for their care.

The doctors are good. There are some who provide education. For example, when our sugar levels increases they tell us about the types of food that we should eat, and the types of exercise that we do. They provide us with such advices and see us off after prescribing our medicines (Female, high school complete, 12 years with diabetes)

Later on he told me that as I don't have that much income I would not be able to afford the treatment and advised me that I should enroll in the free (government care) program and get free treatment. I took his advice and enrolled for the free program (Female, low education, 20 years with diabetes).

A number of the study participants however have described the little or no education provided to them about diabetes and its management. Some also indicated that doctors do not inquire about their religious healing beliefs nor give education about the traditional medicines.

There is no one who discusses about these things (public education). You enter (the consultation room), a medicine is ordered; you go to the pharmacy where they instruct you how to take and that is it... They don't advice about things we shouldn't do or eat; nor about what we should do (Male, low education, 6 years with diabetes).

Now when you come here for the first time, they provide you a one-time general education but otherwise there is no other education. For example, they post about how to inject (insulin) there but how many understand that? If I were to show you my body you would be very surprised - it has turned dark (as a result of my injection practice). They don't tell us about this. They should have educated about this. We are illiterate people (Female, low education, 18 years with diabetes).

With regards to the role of pharmacy personnel and nurses, study participants reported that their role was minimal. Pharmacy personnel were reported to mainly provide information related to the dosage schedule of the medicine during dispensing which were provided orally and in certain instances in writing. Some participants however expressed their dissatisfaction that they don't counsel about the possible safety issues and schedule in relation to food and if milk is to be avoided.

The pharmacy people didn't educate me. And when I inquired of them as to how I take it (insulin) citing that I was a novice, they told me to go and ask my doctor. And when I went with my medicines to the doctor, he told me to go and get educated at the health center and it was not his concern. So in the middle of it I was not going to take the medicines and that was a problem. Should something happen I was the one to be hurt. Now that is indeed a concern when you see it professionally. It shouldn't have been like this; they should either have arranged a date to educate us or assign someone who could assist us. (Female, high school complete, 12 years with diabetes)

Nurses' role in providing education was reported to be limited.

The nurses do not provide education but previously they did. They also used to show us how to inject (Female, low education, 7 years with diabetes)

The nurses measure your weight, and send you to the doctor along with your card. That's it (Female, low education, 18 years with diabetes).

Responding to emotions

Some study participants expressed their desire to be seen by doctors who would listen to them well which they felt would relieve their emotional distress. Some described 'good' experiences they had with doctors who listened to them attentively, were compassionate and highly encouraged them to take responsibility for their care instead of scolding them. Such encounters were described as healing even without taking the medicines.

There are also some very good doctors. These ones encourage us by telling us that our conditions can improve, that we should make efforts in doing physical exercise and taking care of ourselves, and that we can take care of it by our own efforts. There are times when I came in sick but left much better. This is not because I took medicines but do to their encouragement. I have also encountered other patients who have praised the doctors that they have encountered (Female, low education, 18 years with diabetes).

Some study participants described about the not so good experience they had with the doctors who used scare tactics instead of encouraging them, did not provide them emotional support or demonstrate care which led some to feel dejected. Majority of the study participants were also not satisfied with the limited consultation time they had with the doctors except the very few assigned to the referral clinic at Yekatit 12. Some patients ascribed the limited time spent with doctors to the large number of patients seen in the clinics.

Some of them try to use scare tactics citing the possibility of leg amputation or the loss of vision which is not good. What they should do instead is to inquire as to what

happened, if the patient was somewhat enraged, if she did not do physical exercises or if it was related to the diet. When the doctor encourages me and appreciates the good things I have done, I get encouraged and will strive to do better. Why do you think AIDS patients are given counseling? Is it not to instill hope? Similarly we would have hope too (if similarly treated). One time I had a wound here on my leg and when I showed him [the doctor], he responded by telling me that my leg would get amputated as a result of my actions. This is however something that he shouldn't say. I wish they would correct it and instead encourage us by telling us that we are the doctors responsible for ourselves. Such expressions would make me leave the clinic healed (Female, low education, 18 years with diabetes).

Discussion

This qualitative study is among the first to have reported on the perspectives of Ethiopian patients regarding their communication with healthcare providers. The findings indicate that participants had certain expectations towards their health communication with regards to most of the six functions of Haes and Bensing's communication model. It was evident that among the six functions of this model, study participants' emphasized 'fostering the relationship', 'providing' and 'gathering information' while few expectations related to playing a role in decision making were expressed.

Fostering the relationship was one of the areas that was identified as very important by the study participants. In this regard, participants expressed the importance of being shown respect and spoken to in a caring manner by their healthcare providers. Many preferred to be seen by a single doctor which was not described to be common for the the large majority of participants. The findings of the present study revealed similarity to other studies with regards to the desire of patients for healthcare providers to be respectful, friendly and caring and to be followed by the same doctors, (i.e., to experience continuity of care) (15,22,24). The expectations from studies involving Western patients include additional expectations for the provider to be open to discussion and wanting to be treated as a partner which were not common expectations for the Ethiopian participants in this study (22,24).

Many of the patients expressed a strong desire to be cared for by the same doctors which they described as important in fostering a good relationship. This desire to be seen by the same doctor was similar to findings from other studies involving patients with diabetes and other chronic conditions (15,24). This however was generally not the case for the majority of the study participants which was one of their major concerns. Care provision by the same doctor has been described as enabling both the provider and the patient to know each other

personally and also in relationship building and patients' gaining trust and allowing the doctor to further know about the medical history of the patient (24).

Some of the issues raised by the study participants (e.g., care provision lacking continuity, a lack of caring approach and low quality of care) do not seem to be unique to the context of the present study. These issues have previously been reported by studies investigating care provision in Ethiopia and other developing country settings (15,25–27). Local studies have cited the 'poor attention' given to diabetes care and the lack of clinical guidelines to manage patients with diabetes according to set standards (26,27). Others have reported the limited education and adherence support for patients with diabetes (25,26). Some of these studies have attempted to compare and contrast the service delivery for diabetes with the much better services for HIV and tuberculosis care, identifying how experiences from these conditions can be used to leverage the suboptimal care for noncommunicable diseases such as diabetes (26,27).

It was also apparent from the present study that the role of nurses and pharmacy personnel were less than optimal in the areas of relationship building, responding to emotions or providing education and diabetes self-management. A study carried out in Oman has similarly reported that the role of diabetes nurses was limited to basic measurements such as weight and blood pressure with limited communication with the patients and in provision of diabetes education (15). A study from a Western setting offers a different model that could be applied in the participants (being treated for breast cancer) describe their emotional and coping needs addressed by the sessions described as 'comprehensive' mostly with nurses as different from the 'doctor talk' they had with their doctor which was primarily focused on the physical aspects of the disease (28).

Participants in the present study made little reference to any expectation to be included in decision making which contrasts with findings from studies in western settings (22,29). Given that in the ambulatory setting it is patients that have to make the daily decision to enact treatments, efforts to involve the patients in the decision making process appears especially important. Other studies indicate the importance of assessing patient preferences to determine the levels or desires for involvement in the decision making process (29). Such preferences may differ where patient backgrounds and culture differ. Global standards for diabetes care in any case recommend that patients be given appropriate self-management education and support that reinforce informed decision making and facilitate the 'knowledge, skills and abilities necessary for optimal diabetes self-care'. It should be noted that such programs need to consider patients' self-efficacy and social support among other things (12).

Practice and policy implications

The chronic care model has been shown to improve the health outcomes of patients with diabetes at different levels of healthcare in high resource settings (30,31). The multifaceted interventions of the chronic care model such as education of both the patient and the healthcare provider, health organization support, decision support, delivery system redesign, clinical information system and community resources mobilization were more effective than use of isolated components of the care model (31,32). In its effort to improve the quality of healthcare delivery and institute a patient-centered care, the Ethiopian government may consider use of this care model (33). In adapting a chronic care model, the government may not have to start from scratch as it already has experience with HIV and TB programs (26,27). Thus relevant components of these programs can be adapted along with other best practices in the chronic care model for diabetes and other diseases so as to come up with an appropriate model that can be used to improve patient outcomes.

As part of the healthcare reorganization of the chronic care model, task shifting may be considered so as to better utilize nurses and pharmacists to support the care by the physicians. Additional training for these providers has allowed them to take on the roles of diabetes educators able to work with the physician to meet with patients more frequently to support them in behavior modification and successful self-management in a manner that addresses not only their physical but also their psychosocial needs. Such programs have been found to be successful in improving clinical outcomes in different settings (34,35).

It was apparent that the healthcare providers in this study would benefit from communications skills training in the areas of gathering and providing information as well as responding to emotions which were among the issues raised by the study participants. This is one of the issues that the Ethiopian government aims to address in its plan to develop 'caring, respectful and compassionate' healthcare providers. One of the pillars in this plan is the need for healthcare providers to have effective communications with the patients (33). This is in line with current global standards where patient-centered communications are highly recommended so as to 'optimize patient health outcomes and health-related quality of life' (12).

Conclusion

This study has revealed that study participants had a range of desired expectations with regards to the communication of their healthcare providers. The most commonly expressed expectations fall under the themes of fostering the relationship, as well as gathering and providing information. While some of their expectations were met, a number of others were not met. It is the recommendation of this study that evidence-based chronic care approaches such as the chronic care model be adapted for diabetes care. Furthermore, it may be

worthwhile to consider task shifting to optimally utilize healthcare providers other than physicians to support optimal care provision. Finally, all providers caring for patients with diabetes should be given communication skills training to support them to further address the physical and psychosocial needs of their patients.

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Table

Table 1: Study participants' characteristics (n=39)

Sex	
Female	19
Male	20
Age (years)	
30-39	2
40-49	8
50-59	14
60-69	10
>70	5
Educational status	
Low education status (illiterate or basic literacy)	16
Elementary complete	8
Secondary school complete	8
Post-secondary school education	7
Diabetes duration (years)	
1-5	10
6-10	14
11-15	7
16-20	4
21-25	4
Treatment regimen	
Oral:	
Glibenclamide + metformin	22
Glimepiride + metformin	1
Glibenclamide	1
Insulin	14
Insulin plus metformin	1

Paper IV

Use of medicinal plants among Ethiopian patients with diabetes: A qualitative exploration

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Abstract

Background: Most studies on the use of medicinal plants reported from Africa (including Ethiopia) have focused on the clinical actions of medicinal plants with little attention given to patient experiences in using these plants and factors impacting patients' decisions about using them.

Objectives: The main objective of this study is to explore the experiences of patients with diabetes attending treatment in the biomedical setting regarding their use of medicinal plants.

Methods: Qualitative interviews were held with 39 purposively selected participants attending their treatment in 3 public hospitals in urban centers of central Ethiopia. Interviews continued until key themes were saturated.

Results: Medicinal plants were used alongside prescribed medicines with a range of factors impacting study participants decisions to trying out and continuing to use medicinal plants and also in recommending against their use or discontinuing them. Some of the main factors that encouraged use of medicinal plants include perceptions that bitter things were thought to be good for diabetes, their claimed and experienced benefits as well as the influence of others and the media while those that discouraged the use of medicinal plants primarily include safety concerns in relation to using the plants.

Conclusions: The findings highlight the use of medicinal plants by patients with diabetes in the context of limited information. This is suggestive of the need for the healthcare practitioners in the conventional healthcare system to give more attention to patients' interest in medicinal plants and for providing more evidence-based information about the plants used by these patients so as to improve health outcomes. [*Ethiop. J. Health Dev.* 2017;31(1):18-26]

Key words: medicinal plants, type 2 diabetes, Ethiopia, qualitative research

Introduction

Self-care practice using medicinal plants comprises one of the common forms of traditional medicine practices in Ethiopia. Limited quantitative surveys report that these practices are primarily used to treat acute conditions (1–3), although there are a few reports of its use in chronic conditions such as diabetes (4,5). It was also apparent from studies done elsewhere and in Ethiopia that sizeable proportions of patients with diabetes used medicinal plants alongside the biomedicines although there was little or no interaction in this regard with their healthcare providers. Few studies from Africa including Ethiopia have cited different reasons that patients reportedly gave for using medicinal plants. These include them being a traditional option, efficacy in managing their condition, less expensive, ease of access, less restriction in terms of diet as compared to biomedicines among other things (5–8). Furthermore, study participants had reported as to how they obtained information regarding these traditional medicines from lay individuals, mostly other patients, and that they had paucity of information about the recommended dosing (5,6,9). Some of the study participants had reported benefits from these medicinal plants including decrease in glycemc levels and resolution of diabetes-related symptoms but also experienced adverse effects including gastric disorders and hypoglycemic incidents (5,6).

Most of the studies reported from Africa, including the one from Ethiopia, focused on the clinical aspects of specific medicinal plants used, but little attention was given to the patient perceptions with regard to their experiences in using (or not using) these medicinal plants. With this in mind, this qualitative study aims to explore in an in-depth manner the experiences with medicinal plants of patients with diabetes who are attending treatment in the biomedical setting. This study intended to explore the perceptions of not only those participants who have used medicinal plants but also those who have not further aim to explore possible reasons for not using them.

Methods

A qualitative method was selected in order to focus on the views and experiences of the study participants(10). This study was approved by the Institutional Review Board of the College of Health Sciences, Addis Ababa University (protocol number 036/13/PSP). All the hospitals have been where the study took place and gave consent for the study which was part of a PhD thesis. All study participants have given their written consent for this study. Anonymity was maintained by storing all data and presenting findings in a way that they cannot be traced back to individuals.

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Study settings: Sites for this study were three public hospitals in central Ethiopia. Two, namely Tikur Anbessa Specialized Hospital and Yekatit 12 Hospital, are located in Addis Ababa (the political and commercial capital of Ethiopia). The third site, Butajira Hospital, which is the

only public hospital in Butajira town, was included to explore the perceptions of patients living in the peri-urban part of the country. A brief description of Addis Ababa and Butajira is given in Table 1.

Table 1: **Description of study settings**

	Addis Ababa	Butajira
Significance	Largest urban center in the country	Home to AAU's demographic surveillance site
Population(26)	3.2 million	63,000,000
Ethnic groups(27)	Amhara (47%), Guragie (16.3%), Oromo (19.5%) and Tigrie (6.2%)	Guragie (82%)
Religions (27)	Orthodox Christianity (74.7%), Islam (16.2%) and Protestant Christianity (7.8%)	Islam (51.3%), Orthodox Christianity (39.6%) and Protestant Christianity (8.7%)
Literacy (27)	85.3%	37.9%

Tikur Anbessa Hospital is the largest teaching and national referral hospital in Ethiopia which manages patients with diabetes in its Diabetes Center. This clinical center was managed by three endocrinologists and two internists attending the endocrinology subspecialty program who worked as consultants on a rotation basis during the study period, five to six Internal Medicine residents assigned to take the primary role in managing the patients during their month long attachments, six nurses and one recently recruited pharmacist. Yekatit 12 Hospital is a general hospital managed by the Addis Ababa City Administration which has recently become a training center for general practitioners (GP). Clinical services for patients with diabetes were primarily offered in the general outpatient department run during the study period by four general practitioners. Patients that were deemed to be in need of specialty care were referred to a medical clinic run by specialists who served on a rotation basis. Butajira is also a general hospital that has recently started serving patients with diabetes at a medical clinic along with other chronic conditions in the outpatient setting. This clinic was at the time run by a general practitioner and a nurse.

Study participants recruitment: Study participants were purposively selected patients with type 2 diabetes who were attending treatment during the study period in the selected hospitals. Criteria for inclusion in the study were: age 18 years and above, taking anti-diabetic medications for a minimum of one year and exhibiting no overt or known psychiatric problems. The sole exclusion criterion was being a healthcare provider. In addition, efforts were made to include patients with diverse socio-demographic and economic characteristics (e.g. age, sex, marital status, religious affiliation, educational and income level, employment status, place of residence) and illness duration. The recruitment of study participants was facilitated by the nurses working in the respective clinics. These providers identified the patients and introduced the study. The first author followed this up by

providing further information and recruiting eligible participants.

Interview methods: In-depth individual interviews with a median duration of 49 min (range from 30 to 120 min) were conducted starting from December 2013 until March 2014 by the first author. Interviews (completed in Amharic) were audio-recorded with the consent of participants. The interviews focused on the experiences that patients had with traditional medicinal plants including the types that they used, information sources about them, their reasons for trying out and using them, about any benefits obtained from them as well as concerns that they may have or experienced while using them. The interview guide was originally prepared in English and was translated to Amharic and then back to English to check its consistency, before the Amharic version was used for the study.

Data analysis: The interview data were transcribed by an experienced research assistant. The quality of the transcripts was checked by the first author by listening to randomly selected recordings from each site while reading the respective transcripts. These transcripts were repeatedly read which helped in the development of initial ideas which was followed by open coding to identify key content areas which were further classified into separate sub-themes and main themes using thematic analysis approach, which has been shown to be a flexible tool that can provide rich and detailed account of the findings (11). Coding of data obtained from each study site continued until key themes were saturated and no further information was emerging(10). Initial stages of the analysis were done in Amharic that was followed by further interpretation carried out after translating key parts of the transcripts, i.e. those relevant to the emerging themes, to English. The first and last author worked together in this regard to interpret the key findings until consensus was reached. The qualitative data analysis

software, N Vivo version 10, was used in data management.

Results

A total of 45 patients who fulfilled the inclusion criteria were invited of whom 39 actually took part in this study with the rest having been excluded due to refusal citing personal reasons or problems in telephone

communication. Among the participants, 12 each (a total of 24) were from Tikur Anbessa and Yekatit 12 hospitals with the remaining from Butajira. Table 2 presents a summary of the relevant participant characteristics. As there was apparent difference in experiences and perceptions between the groups from Addis Ababa and Butajira, the findings are presented as a single data set.

Table 2: **Study participants' characteristics (n=39)**

Socio-demographic Characteristics	Number
Sex	
Female	19
Male	20
Age (years)	
30-39	2
40-49	8
50-59	14
60-69	10
>70	5
Educational status	
Low education status (illiterate or basic literacy)	16
Elementary complete	8
Secondary school complete	8
Post-secondary school education	7
Diabetes duration (years)	
1-5	10
6-10	14
11-15	7
16-20	4
21-25	4
Treatment regimen	
Oral:	
Glibenclamide + metformin	22
Glimepiride + metformin	1
Glibenclamide	1
Insulin	14
Insulin plus metformin	1

The findings revealed that a little less than half of the study participants claimed to have used or briefly tried out medicinal plants for their diabetes, with all using it on a self-care basis except for one participant who made a visit to a traditional healer against his will by his family. The study participants identified 15 different medicinal

plants believed to have some use in managing their diabetes. The most commonly used medicinal plants included *Moringa* spp. (*Shiferas/ Haleko*) and *Ajuga* spp. Focuses on use, stopped using or decided not to use medicinal plants for their diabetes 'Mostly they advise to take bitter things'

Table 3: Traditional medicines used in the management of diabetes by study participants

Local name*	Scientific name	Preparation and use	Indication
<i>Shiferaw/Haleko</i>	<i>Moringa</i> spp.	Dried, powdered leaves brewed and drunk as tea; drink as juice after the brew cools; eaten as a vegetable or the dried, powdered leaves sprinkled on tea or food	Diabetes, hypertension
<i>Anamuro/ Armagusa</i>	<i>Ajuga</i> spp.	Fresh leaves washed with water and juice obtained from expressed leaves drunk	Diabetes, hypertension
<i>Kosso</i>	<i>Hagenia</i> spp.	The alcohol distilled from the dried and ground fruits and drunk either alone or after mixing with others such as lemon, <i>netchshinkurt</i> or garlic (<i>Allium</i> spp. and <i>feto</i> (<i>Lepidium</i> spp.))	Diabetes mellitus, hypertension
<i>Abish</i> (spice)	<i>Trigonella</i> spp.	Unspecified seed preparation taken orally	Bitter, diabetes mellitus
<i>Meqmeqo</i>	<i>Rumex</i> spp.	Dried, powdered root part brewed and drunk as tea	Hypertension
<i>Gibto</i>	<i>Lupinus</i> spp.	Seeds roasted a bit and soaked to reduce bitterness and then eaten	Bitter, hypertension
<i>Kerkedi</i>	Hibiscus spp.	Dried, unspecified parts drunk as tea	Diabetes mellitus
<i>Grawa</i>	<i>Vernonia</i> spp.	Expressed liquid from leaves drunk	Diabetes mellitus
<i>Qerefa</i> (spice)	<i>Cinnamon</i> spp.	Dried bark ground and brewed as tea and drunk	Diabetes mellitus
Mix of telba, papaya and beso	<i>Linum</i> spp., <i>Caricaspp</i> , barley respectively	Telba and beso ground together which are added to the flesh of papaya to which water is added, allowed to stay overnight and decant the supernatant and then orally taken	Mitigate burning feeling
<i>Damakesse</i>	<i>Ocimum</i> spp.	Fresh leaves rubbed and applied to the gums	Inflammation (mitch)
Lemon	<i>Citrus</i> spp.	Fresh fruit applied to the gums	Gum bleeding
Qey sir	<i>Beta</i> spp.	Boiled with water and water drunk	Diabetes mellitus
<i>Tchat</i>	<i>Catha</i> spp.	Fresh leaves chewed	Bitter

*All the local names for the medicinal plants are the Amharic versions except for *Haleko* (*Moringa*spp) which is term commonly used in South Ethiopia especially in Derashe and GamoGofa(18).

Among the factors that influenced participants' use of traditional medicines is the widely held belief that bitter things are good for diabetes which has led to the use of traditional medicines such as *Damakese (Ocimum spp.)*, *Anamuro (Ajuga spp.)*, *Abish (Trigonella spp.)*, *Meqmeqo (Rumex spp.)*, *Gibto (Lupinus spp.)*, *Tchat (Catha spp.)* and coffee. Such belief led some participants to try out and continue to take different traditional medicines, including the stimulant *Tchat (Catha spp.)*. Some study participants however expressed how the extreme bitterness was actually a reason to refrain from trying out some traditional medicines such as *Anamuro* and to discontinue others, namely *Grawa* and *Shiferaw*.

Bitter is also good for diabetes too. Mostly they advise to take bitter things (Female, low education, 8 years with diabetes).

Anamuro is good (for diabetes). I fear it and don't take it because it is very bitter (Female, low education, 7 years with diabetes).

Benefits of traditional medicines: A number of the study participants identified perceived benefits and expectations which induced them to try traditional medicines. The most commonly mentioned claimed benefits especially of *Shiferaw* include cure from diabetes, controlling diabetes using *Shiferaw* only, reduction of the doses of prescribed medications when used concurrently and expectation to act as 'additional vanguard' to the medications being taken. On the other hand, belief that there is no benefit from taking traditional medicines was cited as reason not to try them.

Many people say that they have been cured after taking it (Shiferaw) (Female, low education, 2 years with diabetes).

They are telling me about a traditional medicine known as Shiferaw. I just heard from a man whose sugar level has reached 90 while taking it. He told me that his dose has decreased from one and a half tablet to one. He plans to discontinue it (Shiferaw) and try it out with the (bio) medicine only; if the sugar level increases, he plans to abandon the medicine and take only Shiferaw (Female, elementary complete, 2 years with diabetes).

Now that I think about the reasons why I took these medicines was that they might act as additional vanguards against things which may come through food or other ways. I didn't expect total cure from diabetes but to lessen the impact from some of these things (Male, high school graduate, 22 years with diabetes).

I don't take traditional medicine. I have never taken. I don't believe that those who have taken obtained any benefit from it (Male, low education, 6 years with diabetes).

Beliefs that one had observed the benefits such as decrease in blood glucose levels, relieving burning feelings and wound healing have been reported as common reasons for continued use of traditional medicines. In contrast, some of those who tried traditional medicines such as *Shiferaw* discontinued them if they thought they did not get that much benefit.

The one called Shiferaw seems to be a good leaf. In fact I went for my appointment after having drunk it (for some time) and my levels have gone down to 142... I am sure that it is not the medicines only that reduced the (sugar) levels... I am sure the reduction was due to the leaf. I only started metformin later on (Female, diploma graduate, 9 years with diabetes).

There is a leaf known as Anamuro (Ajuga sp.) which is claimed to be medicine for diabetes. It highly reduces it. The fresh leaves are washed with water and then the juice expressed which is then drunk. This should be followed with 2 eggs or one cup of butter as antidote. I take it from time to time and it actually reduces it (Male, low education, 1½ years with diabetes).

It (Shiferaw) didn't reduce the sugar but reduced the tiredness. There were differences when you took it and when you didn't. But in general I didn't get that much benefit from it (explaining why he didn't persist with it) (Male, diploma holder, 8 years with diabetes).

Safety concerns about traditional medicines: A number of study participants were non-supportive of the use of traditional medicines, with many of them warning against its use. Common reasons for this include unpleasant experience with a traditional healer and traditional medicine given, concern about unspecified dose and quantity of traditional medicine, fear of traditional medicine, observation of people who have died after abandoning their prescribed medications, experience of death of a close family member due to traditional medicines given by a traditional healer and personal experience of adverse effect after taking traditional medicine.

Safety concerns, whether potential or observed in others, have been reasons for some study participants who have contemplated using traditional medicines but have refrained from using them to date. Some of these concerns include the uncertainty as to how it would interact with the biomedicine they are taking, fear that it may affect the liver and the heart, cause adverse effects especially if used regularly.

Now there is a leaf known as Shiferaw. For those who took the ground material, they claim that the sugar has gone down. But I have fear that it may affect the liver. Even though I wanted to take it I

was afraid. When you take it regularly, I feared that it may have side-effects... There are many people including in my neighborhood who use it and claim that it was good. I have bought it but have still not used it out of fear. (Male, high school graduate, 14 years with diabetes)

Some of the participants who reported to have started using traditional medicines have discontinued because of the experience of adverse effects which they attributed to *Shiferaw* such as increased heartbeat and blood pressure, burning feeling in the 'kidney', low blood pressure and blood glucose or out of concerns that the dosage is unknown. Others have also cited the fear it may exacerbate existing kidney and abdominal problems to discontinue *Kossoareqe* (a hard liquor made from *Kosso*), and as well as abdominal side effects as reasons to discontinue *Grawa*. Alternatively, the absence of 'problems' with the traditional medicine was a reason for one participant to continue using *Shiferaw* despite having not yet perceived any benefit from it.

But do you test them? The one called Shiferaw seems to be a good leaf. In fact I went for my appointment after having drunk it (for some time) and my levels have gone down to 142 but there seems to be a problem with my heart beat. Perhaps I drank too many glasses... The blood pressure however highly increased [to reach 180/120] and the doctor whom I saw that day tried to calm me and asked me to call family, which I did. He then examined me and ordered medicines. After a while and I have calmed down, he allowed me to go home. It worsened because I drank a lot from the leaves (as tea), which is my guess. After that I discontinued it. That time was very serious (Female, diploma graduate, 9 years with diabetes).

I have used Moringa. It had indeed lowered it (my sugar levels) when I drank it as tea every morning after brewing it as a tea. After a week I felt light headed. When I went for tests to Arsho (Laboratories), they told me that the hemoglobin had reached 8. I took this result to Zewditu (Hospital). They asked me as to how it could happen while I was on Vitamin B12. I told them that I was taking Shiferaw. They told me to stop it or to take it once every 15 days. I was okay for the next 15 days. I stopped it thereafter. Previously my levels wouldn't go lower than 200 but while taking it (Moringa) it reached 105, 107 (Female, high school graduate, 6 years with diabetes).

I don't agree with such kinds of things (referring to traditional herbal medicines). I am afraid of traditional medicines when a doctor is available. There are some for whom it does not agree with. For example, that individual may not know about it but the traditional medicine might damage his liver. If I tell you my experience, my sister was sick and

she went to that traditional healer and the medicine affected her liver and she passed away. Her belly swelled and when she went to the hospital they asked what it was she drank but she died soon after. So I don't like it, I am afraid (Female, low education status, 3 years with diabetes).

Influence of the media and significant others: Information obtained from the media such as broadcast media and the internet was among the reasons cited to influence taking medicinal plants. On the other hand, those who have contemplated using medicinal plants but refrained from using often cited safety concerns such as possible adverse effects. Moreover, those who have tried but were still concerned, articulated their desire to obtain credible and adequate information from their healthcare providers which unfortunately was not forthcoming.

I even heard on TV (a satellite-based TV channel broadcasting in Amharic) doctors in the United States urging Ethiopian doctors to give (Moringa) to diabetic patients as it brings very good results (Female, high school graduate, 6 years with diabetes).

Among factors that influenced study participants to try traditional medicines were recommendations from other patients or push from their families.

I have been made to go to a traditional healer with push from my family. After payment of close to 600 birr (significant sum at the time of his visit), I was made to take 'Altet', a medicine for buda (evil eye) sold in Merkato, which had a very repulsive odor. For a whole month I was made to drink a bitter thing with coffee on empty stomach. It looks like mud, I don't even know what it is prepared from. Even after it was completed, there is the thing known as Armagusa. It is extremely bitter. It was brewed and placed in the fridge for me to take. I couldn't take it and then quarrelled with my family and left home (Male, high school graduate, 22 years with diabetes).

Discussion

This study has revealed the experience of participants with diabetes using medicinal plants that were taken alongside prescribed biomedicines. The major factors in the decisions patients made regarding the use of traditional medicines included: the perceptions that bitter things were good for diabetes; the claimed and perceived benefits of the medicinal plants; safety concerns; and the influence of others including the media.

There seems to be a widely held belief among study participants that bitter things are good for diabetes and that one should take such things. This seems to be among the most common reasons for using medicinal plants including the psycho-stimulant *Tchat* (*Catha* spp.), whose fresh leaves were cited as beneficial for diabetes

although studies elsewhere have reported quite the reverse where chronic *Tchat* chewing led to increase in glucose levels in patients with diabetes (12). Perceptions that bitter things are thought to be good for the treatment of diabetes does not seem to be unique to Ethiopia. Studies involving participants of Indian and Bangladeshi origin have also reported traditional beliefs in the value of bitter foods and bitter herbs for the management of diabetes (13–15). While culture appears to influence these perceptions, recommendations by some healthcare providers to ‘take bitter things and avoid sweets’ seems to have a role in supporting these perceptions as observed in the present study.

Claimed benefits, namely cure and controlling diabetes, solely using medicinal plants such as *Shiferaw*, were an important impetus for trying them. Hope for a cure is a belief held by many Ethiopians and is arguably much more attractive than taking medications for the rest of one’s life, which would induce them to try out different traditional and religious healing options including medicinal plants (16,17). Among the medicinal plants frequently mentioned were *Shiferaw* (*Moringa* spp.) and *Anamuro* (*Ajuga* spp.), which the study participants claimed to lower their blood glucose levels. *Shiferaw* (*Moringa stenopetala*) is a tree that is native to the southern part of Ethiopia where it is a staple food providing a good source of balanced diet. In addition to its use as food, the plant is also used for water treatment and as medicine for various conditions, including diabetes (18). *Shiferaw* was not mentioned as a medicinal plant by a study of herbal medicine use among Ethiopian patients with diabetes in 1985 (5), when this plant had not yet become a popular folk medicine in Ethiopia. Claims of anti-diabetic activities of these plants have previously been reported by other local studies (5,18) and there is some support from pharmacological studies of *M. stenopetala* carried out in animal models (19,20). *M. oleifera* was one of two most frequently mentioned medicinal plants identified by a study carried out among patients with diabetes in Senegal which also reported about its effectiveness to reduce blood glucose levels in diabetic rat models (6). So it is possible that some of the traditional medicines may reduce diabetes symptoms; however, to date there is no evidence that they are as effective as or more effective than conventional pharmaceuticals or that they can ‘cure’ diabetes.

Study participants also reported a number of concerns about traditional medicines in general and specifically about those commonly used for diabetes. The general safety concerns have to do with negative experiences that some of these study participants have encountered either personally or with a close family member or acquaintance. The safety issues mostly had to do with lack of standardization about the doses and quantity of these medicines. Such concerns may emanate from the limited regulatory work in Ethiopia for traditional medicines despite the existence of a regulatory

framework (21–23). Study participants, most of whom used these medicinal plants on a self-care basis reported experiencing a number of adverse effects including hypoglycemia, anemia and kidney, heart and abdominal problems. Such adverse outcomes are also reported elsewhere and it has been suggested that they may be related to patients’ inadequate knowledge about the doses, inherent toxicities of these medicinal plants even at low doses as well as interactions with the biomedicines already taken for diabetes (6,9,24).

This study may be limited by the fact that only patients with diabetes who were attending their treatment in the hospitals were included and that those who have avoided biomedicine and perhaps were more successfully managing their condition with medicinal plants upon the recommendation of a traditional healer or on self-medication basis or were not included. The perspectives of traditional healers who routinely use and prescribe medicinal plants for the management of diabetes have not been included, which may be a further limitation. Nevertheless, great efforts have been made to include participants with diverse socio-demographic and economic backgrounds so as to be able to obtain a diverse outlook on the use of medicinal plants for the management of diabetes.

Practice and research implications: The findings of this study have different practice and research implications. With regards to practice implications, health providers need to regularly assess the use of medicinal plants with their patients, including their identity and mode of use. Based on the information obtained, they can make efforts to know further about those medicines so as to strive to provide evidence-based information. Patient education should be given about medicinal plants, including that they can have adverse effects and interaction with other medicines as is true with other biomedicines or existing illness. Patients’ perceptions related to ‘bitter diets’ need additional investigation and education should be provided that incorporates evidence-based information relevant to local contexts and cultures. Finally, sessions with patients should assess patient perceptions about diabetes including its incurability and provide need-based education in this regard.

Evidence-based information about medicinal plants commonly used for the treatment of type2 diabetes could help providers and patients make more informed decisions. It is recommended that a survey is done to compile information about medicinal plants commonly used including the common local names of the medicinal plants, uses, expected adverse effects, potential interactions with biomedicines as well as with existing illness conditions. Such a study may also identify gaps for further pharmacological studies to assess about efficacy, adverse effects and interactions among other things. In relation, the perspectives of patients with diabetes who do not follow treatment in a biomedical

setting as well as those of traditional healers and herbalists need to be included in the survey. Such information can be used by providers in their counseling of the patients and for the media, as well as for patients provided it is available in local languages.

Government needs to work to implement the regulatory frameworks stipulated to improve the safety, efficacy and quality of at least the commonly used medicinal plants as it has also been recommended by the World Health Organization. This may involve instituting measures to ensure that any medicinal plant approved for sale to the community is safe, fulfills minimal information required for the appropriate use by patients and is of suitable quality. Furthermore, the pharmacovigilance program currently in place in the country should be designed and promoted to include adverse effects as a result of medicinal plants that may be taken by patients. The national medicine regulatory body should also strive to provide evidence-based information to consumers, healthcare providers and traditional healers and others involved in the provision of these medicinal plants (24,25).

Conclusion:

The present study is indicative of the use of medicinal plants by patients with diabetes in the context of very limited information which can easily contribute to suboptimal health outcomes among these patients. This calls for more attention to the use of medicinal plants and for the provision of evidence-based information to these patients and their healthcare providers.

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Conflict of interests

The authors declare that they have no conflicts of interest related to this article.

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Paper V

Barriers and facilitators to adherence to anti-diabetic medications – Ethiopian patient perspectives

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Abstract

Background: Little is known about the experiences of Ethiopian patients with type 2 diabetes related to adherence to their anti-diabetic medications. This may limit attempts to develop and implement patient-centered approaches that consider Ethiopian contexts.

Objectives: To conduct an exploratory study with a focus of identifying barriers and facilitators to anti-diabetic medications adherence in Ethiopian patients with type 2 diabetes.

Methods: Qualitative methods were used to conduct semi-structured interviews with 39 purposively selected participants attending their treatment in three public hospitals in central Ethiopia. Open coding was used to analyze the data to identify key themes.

Results: A number of factors were identified as barriers and facilitators to participants' adherence to their anti-diabetes medications. The most common factors were perceptions related to their illness including symptoms, consequences and curability; perceptions of medications including safety concerns, convenience and their necessity; religious healing practices and beliefs; perceptions about and experiences with their healthcare providers and the healthcare system including the availability of medications and diabetes education; and finally perceived self-efficacy and social support.

Conclusions: The findings of this study provide guidance to strengthen diabetes education programs so that they reflect local patient contexts focusing among other things on the illness itself and the anti-diabetic medications.

Keywords: adherence, anti-diabetic medications, barriers, facilitators, Ethiopian patients

Introduction

Diabetes mellitus, described as 'one of the largest global health emergencies of the 21st century', is among the non-communicable diseases that continues to rapidly increase in numbers and significance especially in the developing world. The African region is home to around 14.2 million people with diabetes of which 1.3 million are in Ethiopia. These figures are expected to rapidly increase along with increases in urbanization and life expectancy.¹ Type 2, which is the most

common type of diabetes, has been associated with economic development, increasing urbanization, ageing populations, reduced physical activity and less healthy diets. Good self-management with non-pharmacological and pharmacological therapy along with appropriate healthcare provider support enables people with diabetes to live a long and health life. On the other hand, poorly managed diabetes leads to serious complications and a shortened life.¹ The positive impact of anti-diabetic medications in the blood glucose control of type 2 diabetes and the associated reduction of micro-vascular complications has long been established.^{2,3}

Nevertheless, adherence to recommended medication regimens is a challenge with poor adherence associated with increased blood glucose levels, suboptimal diabetes outcomes including diabetes-related complications, more hospital admissions and increased medical care costs.⁴⁻⁹ Common factors that have been cited for the suboptimal adherence levels among Ethiopians include: consulting traditional healers and being on non-insulin medication regimen;¹⁰ potential and experienced side effects and lack of financial resources;¹¹⁻¹³ complexity of medication regimens and experience of depressive symptoms¹⁴ and medium level of diabetic knowledge.¹⁵ These studies, however, all utilized quantitative methods and were unable to provide in-depth insight into patients' perceptions and experiences of adherence to their recommended medication regimens. They may therefore be of limited use in informing patient-centered approaches that could be used to improve adherence. The aim of this study was to conduct an exploratory study using qualitative methods to elicit the barriers and facilitators to adherence to recommended anti-diabetic regimens of patients with type 2 diabetes.

Methods

This qualitative interview study received ethics approval from the Institutional Review Board of the College of Health Sciences, Addis Ababa University (protocol number 036/13/PSP). All the respective health institutions also gave permission for the data collection. Furthermore, all the participants who took part in the study gave their informed consent while their anonymity was maintained.

Study settings

Study sites were three public hospitals in central Ethiopia. Two of these, Tikur Anbessa Specialized Hospital (hereafter referred to as Tikur Anbessa) and Yekatit 12 Hospital (hereafter referred to as Yekatit 12), are located in Addis Ababa (the capital and largest city of Ethiopia). The third study site was Butajira Hospital (hereafter referred to as Butajira) which is the only public hospital in Butajira which was included to explore the perceptions of patients living in the peri-urban part of the country. A brief description of Addis Ababa and Butajira is given in Table 1.

Tikur Anbessa is a teaching hospital which is also the highest referral hospital in Ethiopia. Patients who are diagnosed with diabetes are seen in the Diabetes Center which was run by 3 endocrinologists and 2 endocrinology fellows who work as consultants on a rotating basis during the study period, around 6 Internal Medicine residents assigned to take the primary role in managing the patients during their month long attachments, 6 nurses and 1 recently recruited pharmacist. Yekatit 12 is a general hospital which is managed by the city administration and has recently started training medical doctors. The clinical services for diabetic patients were primarily given in the general outpatient department that was run at the time by 4 general practitioners. Cases that were considered to be in need of specialist care were referred to the medical clinic run by internists on a rotating basis. Patients attending treatment in Tikur Anbessa and Yekatit 12, were 'randomly' assigned to an attending doctor each time they came for their appointment. Butajira is a general hospital that managed the treatment of patients in a similar pattern as those of the other two hospitals. However it has lately established a separate medical clinic run by a general practitioner and a nurse that serves patients with diabetes. During the time of the study, these patients had started to meet the same doctor when they come for their monthly appointment for at least a 6 months period.

Study participant recruitment

Participants for this study were purposively selected patients with type 2 diabetes who were attending their treatment for the duration of the study in the selected hospitals. The inclusion criteria were: age of 18 years and above, being on anti-diabetic medications for at least a 1 year and having no known or overt psychiatric problems. The only exclusion criterion was being a healthcare professional. Apart from these, efforts were made to purposively select patients with a wide variation in terms of socio-demographic characteristics (such as sex, age, marital status, educational level, religious affiliation, employment status and place of residence), income level and illness duration.

Interview methods

Individual in-depth interviews which had a median duration of 49 min (and ranged from 30 to 120 min), were conducted from December 2013 to March 2014 by the first author. The interviews (completed in Amharic) were audio recorded with the participants' consent. The interview questions focused on the anti-diabetic medication-taking experiences of study participants with special emphasis on the barriers and facilitators to participants' adherence to recommended regimens. The interview guide which was originally prepared in English was translated to Amharic and back to English to check its consistency before the Amharic version was used.

Data analysis

The interview data were transcribed in Amharic into MS Word by an experienced research assistant. The first author checked the quality of interview transcripts by listening to randomly selected audios from each study site while reading the transcripts. Interview transcripts were then read repeatedly before using open coding to identify key concepts and classify them into separate categories and sub-categories. Data collection and analysis continued in an iterative process until all key themes were saturated and no new information was emerging from the interviews.¹⁶ Initial coding and categorization was done in Amharic which was followed by further analysis and interpretation that was carried out after translating key components of the interview transcripts that were relevant to the emerging themes into English. In this regard the first and last author worked together to analyze and interpret key findings until they reached consensus. NVivo 10 qualitative data analysis software was used to manage the data.

Findings

Demographics of study participants

In total, 45 individuals were invited to participate in this study of which 39 participated. Reasons for not participating were most commonly described as personal reasons or problems with telephone communication. Of the study participants, 24 were from Addis Ababa attending treatment at Tikur Anbessa and Yekatit 12 (12 from each site) and the remaining were from Butajira town or its environs. Most of the study participants were on either a combination of glibenclamide (popularly referred to using the innovator brand name of Daonil) and metformin (22/39) or insulin (14/39). Close to two-third of participants were enrolled in a government care program that allowed free medical treatment and medications when available while 13 were paying patients. Table 2 summarizes relevant demographic and treatment characteristics of the study participants. Notable differences were not evident in the perceptions and experiences of the participants from the different sites and thus the findings are presented as a single set.

Factors affecting recommended medication-taking

Although the majority of the participants claimed to be adherent to the recommended medication regimen, almost all described at least some times when they were non-adherent and a few openly expressed their non-adherence, explaining that they take their medication only when 'required'.

A number of barriers and facilitators related to adherence were cited by the study participants. The most common factors related to adherence reported include: illness perceptions especially related to symptoms, consequences and the curability/controllability of diabetes; medication-related perceptions, including about the necessity of taking medication, concern about adverse effects and convenience; religious healing practices and beliefs; perception towards health care providers; healthcare system related perceptions such as the availability of medications and

presence of diabetes education; and finally self-efficacy of patients and social support from family and others close to participants. It was apparent that usually multiple factors impacted medication adherence for each participant.

Illness perceptions

Illness perceptions was a key factor that seemed to influence participants' decisions to adhere to recommended medications. Most notable among these were patient perceptions regarding the severe consequences and incurability of diabetes. Some cited experiences with close family members who have lived and died with diabetes or experienced complications as shaping their perceptions.

Diabetes leads to many different complications if one does not take precautions - it could paralyze and shut off the brain...The medicine would never be discontinued... I take the smaller medicine 30 minutes before eating my meal, I eat my meal and take the bigger one. It wouldn't be discontinued even if there is fasting. (Female, elementary school complete, 9 years with diabetes)

Appearance of severe diabetes-related symptoms led some participants who had abandoned treatment early on to restart it.

Had I been able to follow (my regimen) strictly, I think it (my illness) could have been in a better position even if it would not go away. But I abandoned it for 8 months (in favor of holy water) and my body became so horrible and myself so ugly-looking. I literally became a cloth on a wooden pole. I gave all my clothes to my relatives and I am now buying all over again now that my body has regained some of its old self (Female, high school graduate, 12 years with diabetes).

There were some participants who delayed initiation of their treatment for diabetes largely due to a lack of acceptance of their diagnosis. This may have been due to their being asymptomatic, having limited knowledge about diabetes and/or the fact that diabetes was sometimes diagnosed by chance while seeking treatment for another condition.

At the beginning I had hypertension and then I went to have treatment for my hemorrhoid. That was when they informed me that the tests showed diabetes - a diagnosis I had difficulty to accept. I thought I would die immediately. The doctors present at the time appeased me and urged me to start on medications. But I didn't start until after 2 years later (Female, diploma graduate, 9 years with diabetes).

Illness perceptions especially related to diabetes symptoms, hope for a cure and perceived minor consequences were among reasons cited by some study participants for not adhering to their recommended treatment regimen. Nonadherence included abandoning treatment in the early period as well as discontinuing it from time to time, as can be discerned in the following quote.

When I was tested, it had reached 400 (mg/dl). They then gave me these medicines. So when it goes down, I would discontinue it, and when it goes up I would restart on the medicine. When I noticed that the increase in the urine frequency and also in the hunger feelings, I would start on the follow up. My follow up fluctuates, it goes up and down and this is how I have been. Today it is 322, last month it was 240 but there is no symptom that I feel. I am taking Daonil... (Male, high school graduate, 3 years with diabetes).

Medication-related perceptions

Necessity of treatment

Some study participants stated their strong commitment to take their medications as per the recommended regimens citing necessity beliefs such as health benefits and the efficacy of their medications. The necessity beliefs were so strong that these participants claimed not to discontinue their medications even if they have to buy it from private sources when they are unavailable at the hospital pharmacy.

It (diabetes) is still tormenting me. My efforts to get free medical aid from the government were not successful. I am surviving by purchasing (medicines) with whatever means I have. After all it is (my) life...It will never be discontinued. I will take even if it means troubling my son for money to buy (Female, low education, 18 years with diabetes).

In contrast, a few participants did not strictly adhere to recommended regimens because of lack of perceived necessity of the medicine in reducing the blood glucose levels or to effect cure.

I started taking metformin later on. So it was 2 but what use does it do for me? There is nothing that goes down and I observe no change whatsoever. So ... I didn't take it (metformin) even though I brought it (from the hospital), I didn't give it a second thought (Female, Diploma holder, 9 years with diabetes).

It is no use taking medicines after the problem has come. Once you get the nerve problem, there can only be a pain killer but no cure for the disease. You have to take precautions beforehand (Male, Diploma holder, 8 years with diabetes).

Safety concerns about medications

Some study participants expressed concerns about the safety of their medications especially related to hypoglycemia and abdominal side effects. Such concerns led them to decrease in the dose or discontinue the medications they were taking. Other participants refused to accept recommendations to initiate insulin citing perceptions about the possible complications and adverse effects and associating it with advanced degree of illness severity.

I informed the doctor that it has been 15 days since I discontinued the second one (metformin) because it was disagreeable to me. It hurt my stomach (Female, high school graduate, 18 years with diabetes).

Now they are telling me to move to the injections. But I am resisting it... I fear the injections very much; even when I think about it. Injections need great care; if the levels go down there is the possibility of falling down and what I think of. I don't think I will be able to get up again if I fall. I am hypertensive and such complications may make me paralyzed (Female, Diploma holder, 9 years with diabetes).

Convenience

Convenience (or lack thereof) was another factor that participants cited as a reason to miss their medications. Some participants reported resisting recommendations to initiate insulin citing inconveniencies in handling insulin as compared to the oral agents. On the other hand, convenience also seems to contribute to one participant's decision to inject more than the recommended dose of insulin.

And if I have to go to the countryside for mourning I don't carry them (the oral anti-diabetic medicines) and would take them after a couple of days. This is my own fault. I don't take it because it is inconvenient and I don't have it with me, but this shouldn't have been the case. In any case I should take precautions whether it is convenient for me or not (to take my medicines) but still it wouldn't kill me at once (Male, Diploma holder, 7 years with diabetes).

The tablet you can put in your bag and take it wherever you go. But that one (insulin) is difficult (explaining why she resists doctors' recommendation to start (Female, Diploma holder, 9 years with diabetes).

I take Insulatard Denmark, the milky one. I take 20 in the morning and 15 in the evening. Sometimes if I will be staying late at the office, I take the whole dose in the morning. I take metformin 1000 (milli) gram in the evening. I have never encountered any lowering (of sugar levels) problems. As I take things easy, I have no pain whatsoever (Male, Diploma holder, 8 years with diabetes).

Religious healing

Some study participants described how they practiced their religious healing practices and duties in a manner that does not affect their adherence to recommended treatment regimen. This included going to Church and praying, using holy water while still maintaining recommended dosage schedule, going to church after taking their medicines and food and fasting from selected foods but not abandoning food altogether contrary to what is practiced

by strong adherents of the Orthodox Christianity. Such practices at the very least bring about psychological benefits to the study participants.

Now I fast by abstaining from meat and butter but otherwise eat other food and water. I have to eat at the specified times, it is mandatory (for the medication). But otherwise I fast like everybody else (Female, low education, 7 years with diabetes).

For other participants, religious healing practices were observed to affect the adherence to recommended medication regimens. Notable was the use of holy water instead of prescribed medicines among the followers of Orthodox Christianity especially those visiting holy water sites and for the refusal to initiate on insulin as it was not amenable to discontinuation ‘from time to time’ for religious reasons as are the oral agents. The other religious duty that affected adherence was fasting which was reported by participants who were Orthodox and Protestant Christians and Muslims. Fasting led to decrease in the frequency and dose for some while it led to modification of the time schedule for others. For those who continue taking their insulin without food, it may have led to hypoglycemic incidents.

I use holy water that people bring to me as I (now) cannot manage to go to the holy water site. I have discontinued the medicine that time when I went to a holy water site at Shenkora (Female, low education, 18 years with diabetes).

I fast. Previously I would unknowingly inject the medicine in the morning and spend the day without eating. I stopped this after having read some paper which says that if one does not eat within 30 minutes of insulin injection it would lead to kidney damage. Sometime I would spend the day without eating and injecting. If it is a mass prayer program I might fast until 3 pm, if it private I might stay until 6 pm. If I have to inject in the interim I might do so in less amount, say half the dose. If it is evening I only take the 40 only (Female, low education, 18 years with diabetes).

Healthcare providers

Healthcare providers, especially the relationship and availability of appropriate providers, were identified both as barriers and facilitators to medication adherence. Healthcare providers, especially doctors, were reported to have played a positive role in supporting the adherence, be it in the maintenance of prescribed regimens or initiation of insulin.

They prescribe the medicines for restoring health and I take them; I take them correctly at the specified times. They tell me not to stop taking it no matter what, and not to let the time pass. So I take the medicine at the specified times, I am healthy (Female, low education, 20 years with diabetes).

There were some study participants who expressed resistance to the recommendations by doctors to increase doses of anti-diabetic medications which were related to safety concerns but also apparently lacking trust in them and questioning their expertise.

Sometimes I feel sick when I take the medicine for my diabetes. I sometimes wonder if I should decrease the medicine (dose) but I am afraid (of the consequences). Because, when I (my sugar level) am at 70 (mg/dl), the doctors continue to prescribe the same dosage. I haven't received counseling from them and so I simply continue to take the 2 tablets as prescribed out of fear. But I plan to decrease it (the dose). If I am okay I would like to take just one while still controlling it. But there is no idea coming from them, even when the level reaches 70. I have never asked them about this because they are the ones that look at the results and should reduce it. But I really would like to reduce it. When it (sugar level) is 600 (mg/dl) I still take 2 (tablets). There is no change (in the doses) to go up or down. I have my sugar levels checked every 15 days even though I hardly afford it. It (the level) is okay, never goes beyond 100 (Male, high school graduate, 2 years with diabetes).

Healthcare system

The healthcare system, especially the provision of diabetes education and the availability of medications, was cited among the factors influencing adherence to medications.

Availability of medications

The availability of medicines at the hospital pharmacy was among key factors mentioned for patient adherence. There are few participants who have not encountered problems with the availability but reported concerns were more pronounced among those who get depend on free medications (or programs that allow them to purchase medications for reduced prices) as they couldn't afford to purchase their medications from sources outside these free or subsidized programs. This apparently had implications of decreasing medication doses, going by without the medicines and even having to buy expired medicines from illegal sources.

Now I get the medicines for free, previously I had to pay for it. No, the medicines are not always available. The smaller one was not available for 4 months. So during that time it has to be bought. Sometimes there are cases when out of fear that I wouldn't completely get the medicine I would decrease the dose from 4 to 2. So I make it 1 in the morning and evening. No problem with the bigger because it is available (Male, elementary school complete, 15 years with diabetes).

Diabetes education

Patients clearly valued education about diabetes from health care providers, but many expressed frustration and concern that they had not received sufficient information.

I know nothing about diabetes. Let alone the basics, there was no one who instructed me as to how I should inject insulin when I was started on it. ... The pharmacy people didn't educate me. And when I inquired of them as to how I take it citing that I was a novice, they told me to go and ask my doctor. And when I went with my medicines to the doctor, he told me to go and get educated at the health center and it was not his concern. So in the middle of it I was not going to take the medicines and that was a problem. Should something happen I was the one to be hurt... See here (showing the bruise marks on her thighs) what happened to me, all because I didn't know how to use insulin. (Female, high school graduate, 12 years with diabetes).

Yes, I agree on the necessity of the medicine. If I could get a good doctor, one that gives good counseling like the ones that used to be here that counseled. Now this (present) ones, they don't even have written materials. The previous ones (who used to be there) used to write about eye problems, about legs, about teeth; foods to be eaten separately and those to be avoided separately in great detail (Female, low education, 8 years with diabetes).

The diabetes education sessions especially offered by the Ethiopian Diabetes Association was commended by some participants who claim to have gained knowledge about the illness and the treatment that supported their adherence to recommended treatment regimen.

After attending educational sessions at the association (Ethiopian Diabetes Association) I knew what was beneficial and what was harmful. After that I wouldn't let 5 minutes pass for taking my medications; if I take my medicine at 8 in the morning, I will take it at 8 in the evening (Female, high school graduate, 25 years with diabetes).

Patients' self-efficacy

There were some participants who appear to be confident in modifying their insulin dose. While some decrease or increase based on the laboratory results of their blood glucose levels, there are others who may just decrease based on subjective feelings or when planning some activities which they believe may further decrease their glucose levels.

One should make his own modifications in addition to that of the doctor. I could decrease the medicine by 10 or 5 (units). When it goes up, one also needs to increase (the dose of the medicine). But myself, I take the prescribed dose (and do not increase) and it is only when it lowers that I modify. It is of course important to consider the doctor's advice. Now when I go to my farm or have to travel it goes down. So I take a lower dose and it doesn't create that much problem. But if I take as per their (doctors') recommendation I could fall (Male, low education, 8 years with diabetes).

There were a couple of study participants who seem to have lower self-efficacy and instead expressed their strict adherence to healthcare providers' recommendation.

I do as the doctor tells me; I don't deviate from his words and if I do the harm is on me. If I reduce it (the dose) I myself will be harmed, if increase it I will still be harmed. Why would I go to a doctor if I decide by myself? This is it (Female, high school complete, 25 years with diabetes).

Social support

Social support from among family members, colleagues at work and neighbors were stated as being beneficial for participants' adherence to recommended medication regimens. Support was in the form of moral support of adherent behavior, reminding to take medications, availing medications (in kind or providing funds), covering work to avoid falls due to hypoglycemia and preventing medication-taking when glucose levels are low.

Sometimes when there is a problem at home (such as mourning), neighbors check and remind if I have taken (my medications) or not... There are small children (in the house) who remind me of my breakfast and my medicines. They are constantly doing that. And so I don't delay the taking injection. And I am at peace now (Female, low education, 20 years with diabetes).

Discussion

Current evidence shows that a successful diabetes care model requires the active engagement of patients in managing their condition so as to achieve and maintain optimal health outcomes.¹⁷ Studies to date, most of which are from western cultures, report patient, treatment and health system related factors that serve as barriers and facilitators to the successful management of diabetes. However the few reports from developing countries including Ethiopia tend to focus solely on the barriers and do not give due attention to factors that may facilitate adherence to recommended regimens. This study is among the few from the Ethiopian setting and to our knowledge the only one to report in-depth on both the barriers and facilitators to adherence to anti-diabetic medications. The major factors that were identified in this study included participants' perceptions about their illness such as symptoms, consequences, curability and treatment using religious healing practices and perceptions of medications especially about its necessity and concerns about its safety.

It was apparent from this study that treatment related perceptions of participants were similar to those reported by other studies including those from western cultures.^{18,19} Safety concerns regarding medications similar to reports from other studies in Ethiopia as well as from other settings were identified as major barriers for medication adherence that led to refusal to initiate insulin out of concern of adverse effects or decreasing of doses and discontinuation of

medications upon experience of adverse effects.^{11,13,14,18-21} On the other hand, illness perceptions about the impending complications and the chronicity of diabetes that were mediated with strong perceptions about the necessity of medications were observed to facilitate adherence to anti-diabetic medications similar to other studies that reported positive association between these factors and adherence to medications for long term conditions including diabetes.²²⁻²⁴

With regards to illness perceptions especially those related to symptoms, (e.g., hoping for a cure and treatment) it was evident that study participants hold explanatory models that were different from the biomedical model and those reported among western cultures. These explanatory models seemed to be heavily influenced by participants' cultural and religious backgrounds and appeared to be responsible, at least in part, for decisions and practices in managing diabetes.²⁵ Among their illness perceptions which seem to affect adherence to recommended medication regimens were their perceptions about diabetes symptoms whose absence has led to delay in treatment or discontinuation of medications only to restart on them when symptoms reappear. Such observations are not common among Western patients diagnosed with diabetes although there are similar reports among immigrants in these countries and from Thailand where the study participants have expressed belief that diabetes was a short term condition with the oral anti-diabetic agents providing symptomatic relief but were unneeded once they 'felt well',^{18,26-28} only to restart on them when their illness was visible and possibly affecting their daily routines.²⁹ Such reports are similar to the reports from the quantitative studies done among Ethiopian patients with diabetes which also reported 'feeling of being well without treatment' and 'disappearance of symptoms' as reasons for low adherence to anti-diabetic medications.^{11,30} This finding is also supported by other studies from the Ethiopian context where more emphasis is given to symptomatic, acute conditions and where hope for a cure is expressed.^{31,32}

Hope for a cure especially in relation to religious healing was another factor that served as a barrier to anti-diabetic medication adherence among some study participants. In this case, the practice that involved going to holy water sites has led to the discontinuation of anti-diabetic medications for short or long durations among the followers of Orthodox Christianity. This may be related to the wide belief among the followers of Orthodox Christianity that supernatural forces (especially the devil) cause illnesses and that God provides healing for which holy water is a commonly used healing mechanism. Holy water is believed to provide cure when it is bathed in or drunk.³³ Going to holy water sites to be baptized and healed has been one of the commonly cited reasons to discontinue treatment and being lost to follow up in favor of holy water is not uncommon according to studies done among patients with HIV.^{34,35} Such cases of discontinuation of chronic treatment in favor of alternative treatments are not unique to Ethiopia and are also reported from other settings in Africa. Studies done among patients with

diabetes in Ghana and Tanzania had reported about hope for a cure that led to healer shopping that involved using faith healing (mainly prayers) and ethnomedicine which were used on a complementary basis but also as an alternative that led to discontinuation of the biomedical treatment.^{36,37} The alternative and wide use of holy water as religious healing practice however seems to be more common among the Orthodox Christians in Ethiopia.

In relation to religious healing, fasting while taking hypoglycemic medications such as insulin and glibenclamide was observed to be a barrier to follow recommended medication schedules that could lead to problems in the long or short term. Fasting is actually a common routine among religious adherents in Ethiopia that is also considered by some to have a curative power.³⁴ For the Orthodox Christians, 250 days of fasting are recommended of which 180 are obligatory for anyone above the age of 13. Fasting in general implies just one meal per day that is to be taken after 2:45 in the afternoon or in the evening and total avoidance from animal products such as meat, dairy products and eggs.³⁸ In a similar manner, Muslims avoid foods or drinks from early dawn to after sunset during the month-long Ramadan. Studies done among Ethiopian patients with HIV have reported how Orthodox Christians and Muslims either discontinued their antiretroviral treatment during the fasting seasons in their bid to fulfill religious duties but also to avoid stigma³⁴ or modified their dosing schedules which in most cases involved missing one of their doses of anti-retroviral medication during fasting.³⁵ This is among the first reports to report on the influence of fasting on anti-diabetes medication regimen among the followers of Orthodox Christianity although there exist literature that describe as to how Muslim patients would reduce their medication dose during the month of Ramadan.¹⁸

Conversely, religious and religious healing practices that included going to church, praying and even use of holy water at home were observed to provide some participants at the very least with psychological benefits which can positively influence the illness experience and adherence to medications albeit in an indirect manner. The psychological and mental benefits that these participants may have from the religious healing can minimize possible diabetes-related distress that may be present in some of the participants that in turn may lead to lower adherence among other things^{14,39,40} as also been practiced by patients with HIV elsewhere in Ethiopia where the use of holy water alongside to medications has been reported to lead to gains from a holistic treatment that may offer psychological, spiritual or mental health benefits.³⁴ This seems in line with the concept of health in Ethiopia which is considered a holistic concept encompassing physical but also spiritual, social, mental and psychological aspects and that health is a 'gift' or 'will' of God and thus the importance of religion which many believe helps to keep them in good health.³³ The use of religious practices among patients with diabetes are also reported from other settings such as among blacks in the United States and participants from Iran where prayers, 'turning things over to God', reading holy scriptures and attending to

churches and mosques have been reported as coping strategies.^{41,42} The finding from Iran, where participants have engaged in 'high levels' of religious practices, has reported significant association between religious practices and self-care activities among the study participants.⁴² Religious coping mechanisms such as prayers and performing *solat* (obligatory prayers of Islam) which were described as ways of being close to God were also reported to be significantly correlated with and were mediators between illness perceptions and health-related quality of life positively in a study which involved patients with end-stage renal disease from Malaysia. This led the authors of this study to recommend that due attention be given to illness perceptions and positive religious coping mechanisms in intervention programs to improve the quality of life of the patients.⁴³

The findings of this study could be limited by the fact that only the perceptions of a group of patients, i.e. those who were following treatment in public hospitals of urban centers and had had diabetes for at least 1 year, were included and thus may not represent a more diverse group. Thus the results may not be applicable to patients with diabetes who follow treatment in the health institutions outside the public arena as well as those who chose to avoid western treatment. Nevertheless, this study included patients with diverse backgrounds in terms of socio-demographic, illness and treatment characteristics which has enabled a rich and diverse view on their treatment experiences and perceptions about the facilitators and barriers to anti-diabetic medications.

Practice implications

This study has practice implications especially about the need to provide appropriate patient education, be it in groups or individually, with regards to diabetes and recommended medications. This education that should consider local and patient-specific contexts. This may include strengthening patients' understanding of the chronicity of diabetes and stressing the necessity of their medications in relation to its benefits in reducing and delaying diabetes complications and improving outcomes. Patient education can also focus on the controllability of diabetes and about the meaning of symptoms, the relationship with blood glucose levels and the need to continue taking medications even if 'symptoms' disappear. This should be coupled with appropriate medication-related education that should emphasize their necessity while giving due attention to the possible adverse effects and how they can be prevented and mitigated. Healthcare providers should also closely monitor their patients with regards to their medication-taking experiences and make concerted effort to explore patients' experiences of the medications including about any adverse effects with the objective of alleviating their concerns so as to support patients' decisions to adhere to them.

Issues in relation to religious healing and practice require the recognition that some patients may have strong feelings about their religious practices and the need to adhere to them. Such

issues require an open discussion about the pros and cons of religious healing and practices to be followed and the collaboration with religious healers and as well the religious leaders and teachings in order to support patients' adherence to recommended medications while still practicing religious healing and practices in a compatible manner. Attempts are reported of collaborative works in the areas of HIV/AIDS and psychiatric treatment with the Ethiopian Orthodox Church to encourage the use of both types of treatment citing compatibility and which have yielded encouraging results in terms of increased adherence to recommended medications.^{34,44} Similar attempts may also be beneficial for patients with diabetes as has also been hinted in the Malaysian study to improve patient outcomes.⁴³ The issue with determining the benefits of religious healing and practice in relation to alleviating diabetes-related distress and other issues such as fasting however are among areas that may need further research.

Conclusion

A number of factors that could serve as barriers and facilitators to anti-diabetic medications adherence were identified. The major perceptions include about diabetes including its symptoms and curability, which seem to be different from that reported from western culture, and concerns about the safety of recommended medications similar to those reported elsewhere. The findings are strongly suggestive of the need to institute strengthened education programs for the patients including about diabetes and the anti-diabetic medications considering local and patient contexts. Further studies are recommended to explore the benefits of religious healing practices and the effects of fasting and other rituals among religious adherents.

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Competing interest

The authors declare that they have no financial or personal relationship(s) that may have inappropriately influenced them in writing this article.

Authors' contribution

B.M.H. and T.G.F. (Addis Ababa University) and H.B. (University of Toronto) conceptualized and designed the study. B.M.H. and H.B. carried out the interviews and analysis with T.K. (Addis Ababa University) and T.G.F. commenting on the analysis. B.M.H. drafted the manuscript and H.B., T.G.F. and T.K. revised it. All of the authors read and approved the final manuscript.

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Tables

Table 1. Description of study settings

	Addis Ababa	Butajira
Significance	Largest urban center in the country	Home to AAU's demographic surveillance site
Population ⁴⁵	3.2 million	63,000,000
Ethnic groups ⁴⁶	Amhara (47%), Guragie (16.3%), Oromo (19.5%) and Tigrie (6.2%)	Guragie (82%)
Religions ⁴⁶	Orthodox Christianity (74.7%), Islam (16.2%) and Protestant Christianity (7.8%)	Islam (51.3%), Orthodox Christianity (39.6%) and Protestant Christianity (8.7%)
Literacy ⁴⁶	85.3%	37.9%

Table 2: Study participants' characteristics (n=39)

Sex	
Female	19
Male	20
Age (years)	
30-39	2
40-49	8
50-59	14
60-69	10
>70	5
Educational status	
Low education status (illiterate or basic literacy)	16
Elementary complete	8
Secondary school complete	8
Post-secondary school education	7
Diabetes duration (years)	
1-5	10
6-10	14
11-15	7
16-20	4
21-25	4
Payment for health services incl. medicines	
Out of pocket	13
Government	23
Employer	3
Treatment regimen	
Oral:	
glibenclamide+metformin	22
glimepiride+metformin	1
glibenclamide	1
Insulin	14
Insulin plus metformin	1

Appendices

Appendix 1: Information Sheet and Consent Form

Illness and treatment experiences of adult patients with type 2 diabetes mellitus in the urban and peri-urban of Central Ethiopia – a qualitative study Study

Information to be read to participant:

“My name is Bruck Messele and I am a PhD student at the Addis Ababa University.”

“The purpose of this study is to learn about the illness and treatment experiences of type 2 diabetes mellitus patients being treated in selected hospitals. I hope to use the information collected in this study to assist different healthcare professionals involved in the care of type 2 diabetes to better understand the perceptions and experiences of these patients in the course of managing their illness. In order to better communicate with their patients, healthcare professionals need to appreciate and better understand the different perceptions that patients may have towards their treatment and the challenges that they encounter in managing their illness. This might lead to better communication and care, improved health services for these patients at the health facilities and hence to better health outcomes. I would like to know more about the perceptions and experiences of T2DM patients including their clinical encounters with their HCPs and to improve services that these patients get at the health facilities.”

“If you are interested in finding out if you are eligible to participate in this study, I will ask you a few short questions to confirm your eligibility”

Eligibility Check:

“Thank you for your interest in my study. I will ask you a few questions to determine whether you are eligible to participate”

1. Are you a resident of Addis Ababa/Butajira or its environs? Yes or No
2. Can you fluently communicate in Amharic orally? Yes or No
3. Are you willing to complete one in-depth interview? **Yes or No**
4. Are you a healthcare professional? **Yes or No**

Eligible to Participate? Yes or No

If recruit responds `no` to any of questions 1-3 above, individual is NOT ELIGIBLE.

Explanation for each question if recruit asks why they are ineligible:

This study will specifically explore the perceptions and experiences of type 2 diabetes mellitus patients who are residents of Addis Ababa/Butajira or its environs.

Interviews and discussions will be held in Amharic and therefore participants must be able to orally communicate fluently in Amharic.

This study is based on one in-depth interview.

If recruit responds `yes` to question 4, individual is NOT ELIGIBLE.

This study will explore lay perspectives and experiences, and therefore healthcare professionals are excluded from this study.

Further information regarding the study

You are being invited to participate in this study because you are a type 2 diabetes mellitus patient (age of 18 or over) who is on diabetes medications for at least one year prior to the start of this study, and being Amharic fluent.

All participants will complete one face-to-face interview.

During the in-depth interviews, I will be asking you very general questions about your illness and treatment perceptions and experiences, and will want to know about your understanding of your illness and its treatment including the biomedical and traditional, your experiences in managing your illness including the challenges that you face in this regard.

If you agree to participate in the study, your first interview will be arranged to take place at a convenient location and will last from 45 minutes to one hour. Eventhough I will be taking notes during our interview, I may not be able to capture all that you are saying. I will therefore be audio-recording the interviews with your permission. In asking you about your experiences, I recognize that I am asking you to discuss private matters with me. However, your participation in this study is completely voluntary. You are free to withdraw or discontinue your participation in the study at any time, or to end any of the interviews at any time, and to decide not to participate in the later discussion. If you are uncomfortable with the questions I ask, you do not have to respond to them, and you may request that I stop tape recording at any time. If you find an interview too long or tiring, feel free to tell me, and we can take a break, or re-schedule the remainder of the interview for another time.

No risks to participants are foreseen by the researchers and there are no direct benefits to participating in the study, other than the chance for you to discuss your perceptions and experiences concerning your illness.

However, you should know that I respect your privacy, and that your name, identity and anything we discuss will be held in strict confidence. Confidentiality will be maintained in the following ways: your name and phone number will not be known to anyone except

for me and my graduate supervisors. Your name will not be used in the interview, or in any written reports (interview tapes and printed copies will identify participants with a code number or fictitious name).

Reports from this study may use excerpts from our interview; however any identifying information will not be used. What we discuss during the interview will not be reported in a way that others will be able to identify you. For instance, your views will be reported along the views of other participants taking part in this study.

Tapes of interviews, and interview transcripts will be stored indefinitely in secure files in my office at the Addis Ababa University, and will be accessible only to myself and my graduate supervisors (Tapes and all paper files are anonymized--no names attached, all identifying information removed, except a code number or name--prior to analysis of data or storage of it). A master list of names of all participants in the study will be stored in a separate location, but also in secure storage. All computer files will be password protected, and access to study files will be restricted.

A summary of the results of the study will be distributed to interested participants.

Do you have any questions?

Notes

If you have any questions, or if you require more information about this project, please contact me on my personal telephone line at (0911)626356. You may also obtain information about ethical considerations relating to this research by contacting the office of the institutional review board at ____.

Participant Consent Form

I have been given adequate information about the research on “Illness and treatment experiences of adult patients with type 2 diabetes mellitus in the urban and peri-urban of Central Ethiopia – a qualitative study”. All questions that I have asked have been answered to my satisfaction and I have agreed to participate. I understand that my interview will be tape-recorded. I also understand that there are no direct benefits in to my joining the study. I have been assured that the information I give will be kept confidential and that any reports published or presented will not disclose my identity.

I understand that my participation in this study is voluntary and that I have the right to withdraw at any time, even after signing this form. I understand that if I decide to withdraw from the study, the information collected during the study before I withdrew will be retained. No further information will be collected after a study participant has withdrawn from the study.

I understand that the researcher has a legal obligation to report information revealed by a participant with regard to physical, psychological or social harm or abuse. Confidentiality will be maintained to the limits of law. I understand that a disclosure of confidential information as required by law shall not be considered to be a breach of this agreement.

Name: _____

Phone #: _____

Signature: _____

Principal investigator's signature: _____

Date: _____

Appendix 1: Information Sheet and Consent Form (Amharic version)

ለህመማን ጥልቀት ላለው የቃለ-መጠይቅ ተሳታፊዎች ጥናቱን በተመለከተ መረጃና ስምምነት መግለጫ ቅጽ

የጥናቱ ርዕስ “የሁለተኛው አይነት ስኳር ህመምና ህክምና ተሞክሮ በዐዋቂ ህመማን፤ በመካከለኛው ኢትዮጵያ በሚገኙ ከተማና የገጠር ቀመስ ከተማ ሆስፒታሎች ላይ የሚሰራ ጥናት” የሚል ነው።

ጥናቱን በተመለከተ ለተሳታፊ የሚነበብ መረጃ፡

ጤና ይስጥልኝ!!

“የኔ ስም ብሩክ መሰለ ሲሆን በአዲስ አበባ ዩኒቨርሲቲ የፍልስፍና ዶክትሬት (ፒ.ኤች.ዲ) ተማሪ ነኝ።”

“የዚህ ጥናት ዋና ዓላማ በተመረጡ ሆስፒታሎች ውስጥ በሚታከሙ የሁለተኛው አይነት ስኳር ህመማን ስለ ህመማቸውና ህክምናው ያላቸውን አስተሳሰብና ተሞክሮ ለመረዳት ነው። ከዚህ ጥናት የማገኘው መረጃ የስኳር ህመማንን በማገልገል ላይ የሚገኙ የጤና ባለሙያዎች የህመማኑን አስተሳሰብና የበሽታቸውን የማስታመም ሂደትን ተሞክሮ የበለጠ እንዲረዱ ለማድረግ እጠቀምበታለሁ። የጤና ባለሙያዎቹ ከህመማን ጋር በሚያደርጉት ግንኙነት የስኳር ህመማኑ ስለ ህክምናቸው ያላቸውን አስተሳሰብና በሂደት ስለሚያጋጥሟቸው ችግሮች መረዳት ይኖርባቸዋል። ይህም ሁኔታ በጤና ባለሙያዎችና ህመማን በጎ ግንኙነትና እንክብካቤ፣ በጤና ድርጅቶች የሚሰጠውም አገልግሎት የተሻሻለ እንዲሆን ብሎም የህመማንን ጤና የተሻለ እንዲሆን ይረዳል ተብሎ ይታሰባል። የሁለተኛው ስኳር ህመማን አስተሳሰብና ልምድ፣ ከጤና ባለሙያቸው ጋር ያላቸውን ግንኙነትም ጭምር ማወቅ በጤና ተቋማት የሚሰጠውን ግልጋሎት ለማሻሻል ይረዳል።”

ጥናቱ ላይ ለመሳተፍ የሚያስፈልጉትን መስፈርቶች ማሟላት አለማሟላትም ለማወቅ ከፈለጉ አንዳንድ ጥያቄዎችን ከዚህ ቀጥሎ እጠይቃለሁ። በጥናቱ ላይ ላሳዩት ፍላጎትም ላመሰግኖት እወዳለሁ።

ከዚህ በመቀጠል በዚህ ጥናት ላይ ለመሳተፍ የሚያስፈልጉ መስፈርቶችን ማሟላት አለማሟላትም የሚመለከቱ የተወሰኑ ጥያቄዎችን እጠይቃለሁ።

1. የአዲስ አበባ/ቡታጂራ ወይም አካባቢው ነዋሪ ነዎት? አዎን ነኝ ወይም አይደለሁም
2. በአማርኛ ቋንቋ በደንብ መግባባት ይችላሉ? አዎን እችላለሁ ወይም አልችልም
3. አንድ ጥልቅ ቃለ-መጠይቅ እንዳደርግሎት ፈቃደኛ ነዎት? አዎን ነኝ ወይም አይደለሁም
4. የጤና ባለሙያ ነዎት? አዎን ነኝ ወይም አይደለሁም

በጥናቱ ላይ መሳተፍ ይችላሉ? አዎን ይችላሉ ወይም አይችሉም

ተጠያቂው ከጥያቄ ቁጥር 1-3 ካሉት ውስጥ ላንዱ እንኳ “አልችልም/አይደለሁም” ብለው ከመለሱ በጥናቱ ላይ ተሳታፊ መሆን አይችሉም።

ተጠያቂው ተሳታፊ የመሆን መስፈርቱን የማያሟሉ ከሆነ ተከታዮቹ ማብራሪያ ይሰጣቸዋል፤

- ይህ ጥናት በተለይ በአዲስ አበባ/ቡታጂራ ከተማ እና አካባቢዋ የሚኖሩ የሁለተኛው አይነት የስኳር አይነት ህመማን አስተሳሰብና ተሞክሮ ላይ ያተኩራል።
- ቃለ-መጠይቆቹና ውይይቶቹ የሚካሄዱት በአማርኛ ቋንቋ እንደመሆኑ መጠን የጥናቱ ተሳታፊዎች በዚህ ቋንቋ በደንብ መግባባት መቻል ይኖርባቸዋል።

- ይህ ጥናት በዋናነት አንድ ጥልቅ ቃለ-መጠይቅ ላይ የተመሰረተ ነው።

ተጠያቂው ለጥያቄ ቁጥር 4 “አዎን” ብለው ከመለሱ በጥናቱ ላይ መሳተፍ አይችሉም

- ይህ ጥናት የጤና ባለሙያ ያልሆነ ሰውን አስተሳሰብና ልምድን በማጥናት ያተኮረ እንደመሆኑ የጤና ባለሙያዎች በዚህ ጥናት ላይ አይሳተፉም።

ጥናቱን በተመለከተ ተጨማሪ መረጃዎች

በዚህ ጥናት ውስጥ እንዲሳተፉ የተጋበዙት የሁለተኛው አይነት የስኳር ህመም ያለባቸው በመሆኑ፣ ለዚህ ህመም የሚያስፈልገውን መድሃኒት ከአንድ አመት በላይ በመውሰድዎቻቸውም ከ18 አመት በላይ በመሆኑና በአማርኛ ቋንቋ መግባባት በመቻልዎ ነው።

ሁሉም የጥናቱ ተሳታፊዎች አንድ ቃለ መጠይቅ በመሳተፍ በጥናቱ እንዲሳተፉ ይጠበቃል።

በመጀመሪያው ቃለ መጠይቅ ህመምዎንና ህክምናዎን፣ የባህል ህክምናን በተመለከተ አንዲሁም እርስዎን ስለሚከታተሉ የጤና ባለሙያዎች ያለዎትን አስተሳሰብና ተሞክሮ ላይ አተኩራ እጠይቃለሁ።

በዚህ ጥናት ላይ ለመሳተፍ ፈቃደኛ ከሆኑ፣ ከ45 ደቂቃ እስከ 1 ሰዓት ሊፈጅ የሚችለውን ቃለ መጠይቅ አመቺ በሆነ ቦታ እናካሂዳለን። ከርስዎ የማገኘውን መረጃ ምንም እንኳን በማስታወሻ ወረቀት የምይዝ ቢሆንም በፍጥነት ሁሉንም ለመጻፍ የማይቻል ስለሆነና የሚሰጡኝን ሃሳብ ላለማጣት በቃለ መጠይቁ ጊዜ በርስዎ ፈቃድ መቅረጸ ድምጽ እጠቀማለሁ። አስተሳሰብዎትንና ተሞክሮዎን ስጠይቅ የግል ጉዳይዎን እየጠየቀሁ እንደሆነ እረዳለሁ። በመሆኑም በዚህ ጥናት ላይ መሳተፍዎ በርስዎ ፈቃደኝነት ላይ የተመሰረተ ነው። በጥናቱም መሳተፍ ከጀመሩም በኋላ በማናኛውም ጊዜ ማቋረጥ ይችላሉ። አንዳንድ ጥያቄዎች ካልተመችዎት የግድ መመለስ የለብዎትም፤ መቅረጸ ድምጹም እንዲጠፋ ከፈለጉ ይህንኑ መጠየቅ ይቻላል። ቃለ መጠይቁ ረጅምና አድካሚ ከሆነብዎት አባክዎ ይንገሩኝ፣ እረፍት መውሰድ ወይም ቀሪውን ለሌላ ጊዜ ማስተላለፍ እንችላለን።

በዚህ ጥናት በመሳተፍዎ በርስዎ ላይ ጉዳትም ሆነ ቀጥተኛ የሆነ ጥቅም ይገኛል ተብሎ አይጠበቅም፤ ስለ ህመምዎ የመወያየት እድል ከማግኘትዎ በስጠቀር።

ነገር ግን የርስዎን ማንኛውም የግል ጉዳይ እንደምጠብቅ፣ ስምዎ፣ ማንነትዎ እንዲሁም ማንኛውንም መረጃ በምስጢር እንደምይዝ እንዲያውቁ አፈልጋለሁ። የግል ጉዳይዎን ምስጢር በሚከተለው ሁኔታ ነው የምጠብቀው፤ በመጀመሪያ ስምዎን ከኔና ከምርምር አማካሪዎቼ በስተቀር ሌላ ሰው እንዲያውቀው አይደረግም። ስምዎን በምናደርጋቸው ቃለ መጠይቆች፣ ተከትለው በሚወጡ ጽሁፎች ላይ አንጠቀምም። ለዚህ ጥናት ስንል የፈጠራ ስም ወይም ሌላ ኮድ እንጠቀማለን።

ከዚህ ጥናት ተከትለው የሚወጡ የጽሁፍ ሪፖርቶች እርስዎ የተናገሩትን አባባሎችን ይዘው ሊወጡ ይችላሉ፣ ነገር ግን ስምዎን ወይንም ሌላ የርስዎን ማንነት የሚገልጹ መረጃዎች አብረው አይካተቱም። በሚወጡ ጽሁፎች ላይም ሌሎች የርስዎን ማንነት ሊያሳውቁ የሚችሉ መረጃዎችን አንጠቀምም። ለምሳሌ የርስዎ ሃሳብ የሚገለጠው ለብቻው ሳይሆን ከሌሎች የጥናቱ ተሳታፊዎች ሃሳብ ጋር አብሮ ነው።

የጠቀረጸው ድምጽዎ አንዲሁም ይህንን ተመስርቶ ወደ ወረቀት የሚገለበጠው መረጃ አዲስ አበባ ዩኒቨርሲቲ ውስጥ በሚገኘው ቢሮዬ ውስጥ በጥብቅ ፋይል ላልተወሰነ ጊዜ ይቀመጣል። ከኔም በስጠቀር የምርምር አማካሪዎቼ ብቻ ነው ይህንን ፋይል ማግኘት የሚችሉት። አሁንም ማስታወስ የምፈልገው ማንኛውም የርስዎን ማንነት የሚገልጽ መረጃ አይያያዝበትም። የሁሉንም የምርምሩ ተሳታፊዎች ስም የያዘ መረጃ በተለየ በቁልፍ ውስጥ ይቀመጣል። ሁሉም የኮምፒውተር ፋይሎች በምስጢር ኮድ ይዘጋሉ በዚህም ፋይሎቹንም ማየት የሚችሉት ከላይ የተጠቀሱት ውሳኔ ሰዎች ይሆናሉ።

የጥናቱ አጠቃላይ ውጤት ፍላጎት ላላቸው የጥናቱ ተሳታፊዎች ይሰጣል።

ጥያቄ አለዎት?

ማስታወሻ

ጥያቄ ካለዎት ወይም ስለዚህ የምርምር ስራ ተጨማሪ መረጃ ከፈለጉ በሞባይል ቁጥሩ (091) 1626356 ደውለው ይጠይቁኝ። አንዳንድ ይህንኑ ምርምር የስነ-ምግባር አካሄድ በተመለከተ ተጨማሪ ጥያቄዎች ካልዎት በጥቁር አንበሳ ስፔሻላይዥድ ሆስፒታል ግቢ ውስጥ ይህንኑ የሚከታተል አካልን በአካል በማግኘት ወይም በስልክ ቁጥር (011) 8961396 በመደወል ነው።



የጥናቱ ተሳታፊዎች የስምምነት ቅጽ

“የሁለተኛው አይነት ስጋር ህመምና ህክምና ተሞክሮ በዐዋቂ ህመማን፤ በመካከለኛው ኢትዮጵያ በሚገኙ ከተማና የገጠር ቀመስ ከተማ ሆስፒታሎች ላይ የሚሰራ ጥናት” በሚል ስለቀረበው ጥናት በቂ መረጃ ቀርቦልኛል፤ ያነሳሁቸውም ጥያቄዎች በሚገባ በመመለሳቸው በጥናቱ ላይ ለመሳተፍ ወስኛለሁ። ቃለ መጠይቁ በመቅረጻ ድምጽ እንደሚቀዳ አውቃለሁ። በዚህ ጥናት ላይም በመሳተፌ ቀጥተኛ የሆነ ጥቅም እንደማላገኝ እረዳለሁ። ማንኛውም የምስጢው መረጃ በምስጢር እንደሚጠበቅልኝ፤ ከጥናቱ የሚመነጨ ሪፖርቶችና ሌሎች መረጃዎችም የኔን ማንነት እንደማይግልጹ ማረጋገጫ ተሰጥቶኛል።

በዚህ ጥናት ላይ ያለኝ ተሳትፎ በፍላጎቴ መሆኑን፤ በማንኛውም ጊዜ ይህንንም ቅጽ ከሞላሁ በኋላ ተሳትፎዬን ማቋረጥ እንደምችል ተረድቻለሁ። ጥናቱ ላይ ካለኝ ተሳትፎ ለማቋረጥ ከወሰንኩኝ ቀደም ሲል የተሰበሰበው መረጃ ለጥናቱ ዓላማ ሊውል እንደሚችል እረዳለሁ። ተሳታፊው ከጥናቱ ከወጣ በኋላ ግን ምንም ተጨማሪ መረጃ አይወሰድም።

ተመራማሪው አንዳንድ የአካላዊ፣ የስነ-ልቦናዊ ወይም ማህበራዊ ጉዳዮችን ሊያስከትሉ የሚችሉ መረጃዎችን የማሳወቅ ህጋዊ ግዴታ እንዳለበት አውቃለሁ። ምስጢርም የሚጠበቀው ህግን በማይነካ መንገድ መልኩ ነው። በመሆኑም ህግ በሚፈቅደው መሰረት የሚወጣ ምስጢር ይህንን ስምምነታችንን የሚሸር አለመሆኑን እገነዘባለሁ።

የተሳታፊው ስም: _____

የስልክ ቁጥር: _____

ፊርማ: _____

የተመራማሪው ፊርማ: _____

ቀን: _____

የመለያ ኮድ ቁጥር: _____

Appendix 2: Interview guide for in-depth interview with patients with type 2 diabetes

Patient interview guide (adapted from Kleinman *et al*, 1978; Horne *et al*, 1999; Abdulhadi *et al*, 2007)

I want you to discuss on your opinions and views with regards to your illness and its treatment. It is an open discussion and I want you feel at ease and free to talk. I will ask you some basic information about your self before I start the interview.

Introductory remarks will be initially be made asking about the patient's general well-being.

Major questions and probing questions (bulleted)

1. When did you find out you had diabetes? How did you feel when you were told you had it? Why do you think your diabetes started when it did?
2. What do you think has caused your diabetes?
 - Can you think of anything else that may cause diabetes?
3. What are the symptoms of your diabetes? Have you encountered any stigma or discrimination because of your diabetes or some of its symptoms?
4. What do you think your diabetes does to you?
 - How does it work?
 - What do you fear most about your sickness?
5. Will your illness have a short or long course?
 - How long does it take to get over this illness?
6. What are the chief problems this illness causes for a person?
 - What are some obstacles to your day-to-day management of diabetes?
7. How severe is your sickness? Does diabetes get better or worse the longer you have it?
8. What treatment has been recommended to you by your healthcare provider(s)? What are the most important results you hope to receive from this treatment?
 - What is your view regarding the necessity of the treatment regimen(s) recommended by your healthcare provider? Do you have any concern in adhering to your regimen? How is your confidence in following this treatment regimen?
9. What can people do to take care of this illness? What works and what doesn't?
10. Have you ever used traditional medicinal plants? If so, please tell me about it.
 - What is the name of the plant, mode of preparation, specific indication, outcome of use, any problems faced in relation to its use.

I want you to discuss on your opinions and views with regards to your healthcare providers caring for you at this hospital and your clinical interaction. It is an open discussion and I want you feel at ease and free to talk. I will ask you some basic information about your self before I start the interview.

We will start with the doctor, and then follow with the nurse and the pharmacist.

1. Please tell me what you feel when you meet the doctor/nurse/pharmacist from the beginning of the consultation to the end of it, and what you like and what you don't like?
2. Please describe your interaction with the doctor/nurse/pharmacist? What did you like, what didn't you?
3. How was physical environment (comfort, privacy)? What did you like, what didn't you?
4. In your opinion, what are the characteristics of a 'good' doctor/nurse/pharmacist? What are the characteristics of a 'bad' doctor/nurse/pharmacist?
5. Can you describe your best experience with a doctor/nurse/pharmacist? Can you describe your worst experience with a doctor/nurse/pharmacist?
6. What do you discuss during your office visit with the physician? How do you see the consultation? Does your provider try to elicit your view on your illness condition and its treatment? Does he consult you on how to manage your condition? How well did the healthcare provider address your needs?
7. What are your suggestions to improve the quality of interaction with the health-care providers? What advice would you give to healthcare providers to help them better communicate with patients and manage diabetes more effectively?

Appendix 2: Interivew guide (Amharic version)

ከስኳር ህመምን ጋር ህመማቸውንና ህክምናውን በተመለከተ ለሚደረገው ቃለ-መጠይቅ የሚያገለግሉ ጥያቄዎች

ለህመማኑ ስለታዘዘው ህክምና፣ የጤናቸው ሁኔታ እንዲሁም ሌሎች ተያያዥ መረጃዎችን ከህክምና ካርዱ ላይ ይወስዳሉ።

የስኳር ህመምዎንና ህክምናውን በተመለከተ ያልዎትን አመለካከት በተመለከተ መወያየት እፈልጋለሁ። በውይይቱ ወቅት የመሰልዎትንና የሚሰማውትን ሃሳብ በግልጽ እንዲያነሱ እፈልጋለሁ።

ለቃለ-መጠይቁ መግቢያ እንዲሆን በመጀመሪያ ህመማኑን ስለ አጠቃላይ የጤና ሁኔታቸው ይጠየቃሉ።

የቃለ-መጠይቁ ጥያቄዎች የሚከተሉት ናቸው፤

1. የስኳር ህመም እንዳለብዎ ካወቁ ምን ያህል ጊዜ ሆኖት? የስኳር ህመም ምልክቶች ምን ምን ናቸው? ህመሙ በጀመረዎት ሰዓት/ሰዎን ምን ሁኔታ(ዎች) አስተዋጽዖ አደረጉ ይላሉ? ህመሙ እንዳለብዎ በተነገርዎ ጊዜ ምን ተሰማዎት?
2. የስኳር ህመም አይነቱ የተለያየ አለ ይባላል። እርስዎ ስለዚህ የሚያውቁት ካለ ቢነግሩኝ።
3. የስኳር ህመምዎ እንዴት ያዘኝ ወይም በምን ምክንያት ያዘኝ ይላሉ?
 - ሌላ ለስኳር ህመም መንስዔ ሊሆኑ የሚችሉ ነገሮች ብለው የሚያስቧቸው ነገሮች አሉን?
4. በህመምዎ ወይም በህመምዎ ምልክቶች ምክንያት የደረሱበዎት ማህበራዊ ችግር አለ/ነበር? ካለ ቢጠቅሱልኝ።
5. የስኳር ህመምዎ በጤናው ላይ ምን ጉዳት የሚያደርስ ይመስሎታል?
 - ከስኳር ጋር ተያይዞ የሚመጣ የጤና ችግር ካለ/ሉ ቢጠቅሱልኝ።
 - በምን መንገድስ ይህንን ጉዳት የሚያደርስ ይመስልዎታል?
 - የስኳር ህመምዎን በተመለከተ የሚፈሩት/የሚያሳስቡት ምንድን ነው?
 - የስኳር ህመም የመዳን ተስፋው ምን ይመስላል? ከዚህ ህመም ለመዳን ምን ያህል ጊዜ ይወስዳል ብለው ያስባሉ?
6. ህመምዎ ምን ያህል ከባድ ወይም የከፋ ነው ብለው ያስባሉ? የስኳር ህመም በጊዜ ሂደት እየተሻሻለ ነው ወይስ አየባሰበት ነው የሚሄደው?
7. ለህመምዎ ምን ዓይነት ህክምና በሃኪምዎ ታዘዙታል? ከዚህ ህክምና በዋነኛነት የሚጠብቁት ውጤት ምንድን ነው? ለህመምዎ ስለታዘዙት ህክምና መድሃኒት(ቶች)ን ጨምሮ ጠቃሚነትና አስፈላጊነት ምን አስተያየት አልዎት? ለህመምዎ የታዘዙለዎት ህክምና መድሃኒት(ቶች)ን ጨምሮ መከታተልን (መውሰድን) በተመለከተ እንደ ችግር የሚያነሱት ነገር አለ?
 - መድሃኒቶቹን ከሆስፒታሉ ሁሉ የመገኘቱ ነገር ምን ይመስላል? የመድሃኒት ዋጋውስ እንዴት ነው?

○ ይህንን የታዘዘልዎትን ህክምና በመከታተል በኩል ያልዎት በራስ መተማመን እንዴት ይገልጹታል?

8. ለህመሙ የሚጠቀሙበትን መድሃኒት(ቶች) ስምና መቼ መወሰድ እንዳለበት(ባቸው) ያውቃሉ? በመድሃኒቱ(ቶቹ) ምክንያት የሚመጣ(ጡ) የጎንዮሽ ጉዳቶች ምን እንደሆኑ ያውቃሉ? እርስዎስ ከመድሃኒቱ(ቶቹ) ብለው የሚገምቱት የጎንዮሽ ጉዳት የደረሰብዎት አለ? ስለ መድሃኒትዎ ምን ያስባሉ? ይጎዳል ወይስ አይጎዳም? መድሃኒትዎን በታዘዘልዎት መሰረት ሳያዘጋጁ ይወስዳሉ ወይስ አልፎ አልፎ የሚወስዱበትን ጊዜ ወይም መጠኑን ወይም ደግሞ ሁለቱንም ይቀይራሉ? በመርፌ መልክ ስለሚሰጠው የስኳር መድሃኒት ያለዎት አስተሳሰብ ምን ይመስላል?

9. ህመምዎን ማስታመም በተመለከተ ህሙማን ምን ማድረግ ይችላሉ? በርስዎ ተሞክሮ የትኛው ተግባር ውጤታማ ነው የትኛውስ አይደለም?

10. ስለ ህመምዎና ስለ ህክምናው ተጨማሪ መረጃ ከየት ያገኛሉ? ስለዚህ ቢነግሩኝ::

11. ከእጽዋት የተዘጋጁ ባህላዊ መድሃኒቶችን ተጠቅመው ያውቃሉ? እንደዚያ ከሆነ ስለተጠቀሟቸው መድሃኒቶች ይንገሩኝ::

○ የእጽዋቱ ስም ምንድን ነው፣ የመድሃኒቱ አዘገጃጀት፣ በተለይ ለየትኛው ችግር ጥቅም ላይ አንደዋለ፣ የህክምናው ውጤት እንዲሁም ከዚህ ህክምና አጠቃቀም ጋር ተያይዞ የተከሰተ ችግር ካለ ቢገልጹልኝ::

በዚህ ሆስፒታል ውስጥ በርስዎ ህክምና ውስጥ ስለሚሳተፉ የጤና ባለሙያዎችና ከነርሱ ጋር ስላሎትም ግንኙነት ያልዎትን አመለካከት በተመለከተ መወያየት እፈልጋለሁ:: በውይይቱ ወቅት የመሰልዎትንና የሚሰማውትን ሃሳብ በግልጽ እንዲያነሱ እፈልጋለሁ::

ቃለ-መጠይቃችንን ሃኪሙን በሚመለከቱ ጉዳዮች እንጀምርና ከዛ ወደ ነርስ ቀጥሎም ወደ ፋርማሲ ባለሙያው እንሄዳለን::

1. ሃኪም/ነርስ/ፋርማሲ ባለሙያዎን በተመለከተ ያልዎትን አጠቃላይ አመለካከት ምን ይመስላል?
2. ከሃኪም/ነርስ/ፋርማሲ ባለሙያ ጋር ከሚቀርቡበት ወቅት ተጀምሮ እስኪያልቅ ያሉት ቆይታ ምን ይመስላል? ምኑ እንደሚመኝት፣ ምኑ ደግሞ እንደሚይመኝት ቢገልጹልኝ::
3. ከሃኪም/ነርስ/ፋርማሲ ባለሙያ ጋር ያሉትን ውይይትና ግንኙነት ቢያብራሩልኝ? ምኑ እንደሚመኝት፣ ምኑ ደግሞ እንደሚይመኝት ቢገልጹልኝ::
4. የህክምናው ቦታ/ፋርማሲው ምኝትና ምስጢር አጠባበቅ ሁኔታ ምን ይመስላል? ምኑ እንደሚመኝት፣ ምኑ ደግሞ እንደሚይመኝት ቢገልጹልኝ::
5. በርስዎ አመለካከት የጥሩ ሃኪም/ነርስ/ፋርማሲ ባለሙያ መለያ ባህሪዎች የትኞቹ ናቸው? የ'መጥፎ' ሃኪም/ነርስ/ፋርማሲ ባለሙያ መለያ ባህሪዎችስ የትኞቹ ናቸው?
6. ከሃኪም/ነርስ/ፋርማሲ ባለሙያ ጋር የገጠሞትን ምርጥ የሚባል ተሞክሮ አብራርተው ቢገልጹልኝ:: እንዲሁም ከሃኪም/ነርስ/ፋርማሲ ባለሙያ ጋር የገጠሞትን ከሁሉ በጣም የከፋ የሚባል ተሞክሮ አብራርተው ቢገልጹልኝ::

7. ከሃኪም/ካርስ/ፋርማሲ ባለሙያ ጋር በሚኖረዎት ቆይታ በምን ጉዳዮች ላይ ነው ውይይቱ የሚያተኩረው? ይህንን ውይይት እንዴት ይመለከቱታል? ባለሙያው ስለ ህመምና ህክምናው ያለዎትን እሳቤ ለመረዳት ይሞክራል? ባለሙያው ህመምን እንዴት ማስታመም እናዳለበት ምክር ይሰጣል? የጤና ባለሙያው የርስዎን ፍላጎት ምን ያህል ያሟላል?
 - መድሃኒቶችን በተመለከተ ለምሳሌ የመድሃኒቱን አወሳሰድ መረዳትዎትን፣ ከመድሃኒቱ ጋር በተያያዘ ስለሚደርስበት አንዳንድ ችግር ከጤና ባለሙያው ጋር ያለው ውይይት ምን ይመስላል? ወይስ የተሰጥዎትን ትዕዛዝ ብቻ መከተል ነው?
 - አመጋገብ ሥርዓትን/የአካል ብቃት እንቅስቃሴንና ሌሎች የኑሮ ዘይቤዎችን በተመለከተ ውይይትና ምክክር ከጤና ባለሙያው ጋር ታደርጋላችሁ?
8. ህመማን ከጤና ባለሙያዎች ጋር የሚደረጉትን ግንኙነትን ጥራት ለማሻሻል ምን ምን ነገሮች ቢስተካከሉ ይላሉ? የጤና ባለሙያዎችንስ ከህመማኑ ጋር በተሻለ ሁኔታ ግንኙነት ማድረግ እንዲችሉና የስኳር ህመሙን በተሻለ ሁኔታ ማከም እንዲቻል ምን ምክር ይሰጧቸዋል?

Appendix 3: Information card on socio-demographic and other information from patients

To be collected after completion of the interview

- Name: _____
- Identity code: _____
- Address: City _____ Out of city: _____
- Sex: Male _____ Female _____
- Age: _____
- Educational level:
Illiterate ____ Read only ____ Can read and write ____ Completed elementary education ____ Completed secondary education ____ Diploma and above _____
- Religion: _____
- Marital status: _____
- Work status: Working _____ Not working/retired _____
- Profession/occupation: _____
- Monthly income: _____
- Illness duration: _____
- Duration since diagnosis: _____
- Medicines taken for diabetes (ask patient and see from prescription):

Appendix 3: Information card on patient information (Amharic version)

ከቃለ-መጠይቁ በኋላ የሚሰበሰብ የህመማን መረጃ፤

የጥናቱ ተሳታፊ ከሆኑ ህመማን መረጃ መሰብሰቢያ ቅጽ

- ስም: _____
- የመለያ ኮድ ቁጥር: _____
- አድራሻ: ከተማው ውስጥ _____ ከከተማ ውጭ _____
- ያታ: ወንድ _____ ፣ ሴት _____
- ዕድሜ: _____
- የትምህርት ደረጃ:
ማንበብና መጻፍ የማይችል _____ ማንበብ የሚችል _____
ማንበብና መጻፍ የሚችል _____ ነኝ ደረጃ ያጠናቀቀ _____ 2ኛ ደረጃ ያጠናቀቀ _____
ዲፕሎማና ከዚያ በላይ _____
- ሃይማኖት: _____
- የትዳር ሁኔታ: _____
- የስራ ሁኔታ፣ ባሁኑ ወቅት በስራ ላይ ነኝ _____ አይደለሁም _____
- ሙያ: _____
- ወርሃዊ የቤተሰብ ገቢ: _____
- በስኳር ህመም መያዝዎን ካወቁ ምን ያህል ጊዜ ሆኖት? _____
- በአሁኑ ሰዓት የሚወሰዱ መድሃኒቶች (መረጃውን በመጠየቅና የመድሃኒት ማዘዣ በመመልከት)
- የህክምናና የመድሃኒት ወጪ በማን ነው የሚሸፈነው? _____

