



## Research article

## Sufferings of its consequences; patients with Type 2 diabetes mellitus in North-East Ethiopia, A qualitative investigation

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## ABSTRACT

**Background:** The burden of diabetes in Ethiopia is exponentially increasing with more than 68% of people with it being undiagnosed and a death rate of 32%. It is a disease impacting patients with negative somatic, psychological, social, and economic consequences. Patients in Ethiopia have very low awareness about chronic complications, which is very worrying. The study aimed to explore the consequences of their disease experienced by type 2 diabetes patients in North-East Ethiopia.

**Methods:** The study employed a phenomenological approach informed by the consequences dimension of the *Common-Sense Model*. It was conducted from July 2019 to January 2020 using purposive sampling with face-to-face in-depth interviews, for about three weeks, until reaching theoretical saturation. The data were collected from twenty-four type 2 diabetes patients, who were selected to include various socio-demographic characteristics. The data were organized by QDA Miner Lite v2.0.8 and analyzed thematically using narrative strategies.

**Results:** Using *Common-Sense Model* as a framework, the diabetes consequences experienced by the participants were categorized as complications and impacts. While the most common complications were cardiovascular disorders (hypertension, erectile dysfunction, heart and kidney problems, hyperlipidemia, edema, stroke, and fatigue) and ocular problems; the most common impacts were psychosocial (dread in life, suffering, family disruption, hopelessness, dependency, and craving), and economic (incapability and loss of productivity) problems.

**Conclusion:** The patients here were bothered by diabetes complications as well as its psycho-social, economic and somatic consequences; being the psycho-social impacts the most common. As a result, the patients have been suffering in the dread of “what can come next?” This dictates that holistic care, based on *Common-Sense Model*, is needed in providing special emphasis to psycho-social issues.

## 1. Introduction

Diabetes affects people at any age with higher prevalence in middle and low-income countries (World Health Organization, 2018) at which 80% of adults are undiagnosed and 87% of diabetes-related deaths. The incidence has been increased in all continents. In Africa, it is expected to be increased to 143% by 2045. This is the highest in the world. In this continent, 60% of diabetes patients are undiagnosed and 75% of diabetes-related deaths occur below 60 years of age (International Diabetic Federation, 2019).

Coming to Ethiopia, more than 68% of people with diabetes are undiagnosed and have a death rate of 32% (International Diabetic Federation, 2019). Diabetes has been gradually increasing in this country; from

1% in 2000 (International Diabetic Federation, 2000) to 3.2% in 2019 (International Diabetic Federation, 2019) (Table 1).

Diabetes is a disease with major complications (Adam, 2012). Type 2 diabetes mellitus (T2DM) results in massive morbidity with metabolic complications, retinopathy, neuropathy, nephropathy, peripheral vascular disease, ulcerations and amputations, heart disease, stroke, digestive diseases, infection, oral complications, and depression (White et al., 2003). It is multifactorial with significant morbidity (Parry et al., 2006) and is epidemic (Brod et al., 2014). It reduces life expectancy by 5–10 years (White et al., 2003). Every minute, twelve people develop diabetes and half of them die from it and its co-morbidities or complications. Globally, it is the 4<sup>th</sup> leading cause of death (George and Thomas, 2010).

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**Table 1.** Prevalence of diabetes (20–79 years) in Ethiopia (2020).

Year	Diabetes prevalence (20–79 years)	Reference
2000	1%	(International Diabetic Federation, 2000)
2003	1.9%	(International Diabetic Federation, 2003)
2007	1.9%	(International Diabetic Federation, 2006)
2010	2% (estimated in 2009)	(International Diabetic Federation, 2009)
2011	3.45%	(International Diabetic Federation, 2011)
2013	4.36%	(International Diabetic Federation, 2013)
2015	2.9%	(International Diabetic Federation, 2015)
2017	5.2%	(International Diabetic Federation, 2017)
2019	3.2%	(International Diabetic Federation, 2019)

The economic burden of managing T2DM complications has substantially been high. Complications significantly intensified the costs of T2DM (Wu et al., 2018; Amon and Aikins, 2017). Diabetes patients are worried about the present and future (Penckofer et al., 2007). It has medical, personal (Barnard and Holt, 2016), social (Barnard and Holt, 2016; Kalra et al., 2018), physical and psychological consequences (Kalra et al., 2018).

Though Sub-Saharan Africa is currently enduring the heaviest global burden of diabetes, diabetes care is far below standards (Gudina et al., 2011). Despite a well-established health infrastructure for diabetic care (Feleke and Enqeselassie, 2005), the overall aspects of diabetes care at Ethiopian Hospitals are known to be far below any recommended standards (Gudina et al., 2011; Feleke and Enqeselassie, 2005). Moreover, due to a lack of diabetes education in public health institutions (Bayked et al., 2021), patients in Ethiopia have very low awareness about chronic complications, which is very worrying (Bahru and Abdulkadir, 1993). Thus, to help in planning holistic care, it was indispensable to investigate the comorbidities experienced by patients. To do so, this study aimed to explore the consequences of the disease experienced by T2DM patients in North-East Ethiopia.

## 2. Theoretical framework

“Qualitative research begins with assumptions and the use of interpretive/theoretical frameworks that inform the study of research problems addressing the meaning individuals or groups ascribe to a social or human problem” (Creswell, 2013). So, to conceptualize the study, we began with *Common Sense Model (CSM)*. This model focuses on ‘illness representation’ (personal model of health threat). The Model identified seven dimensions of illness representation: identity, timeline, causes, consequences, controllability, emotional representations, and illness coherence (Mora and McAndrew, 2013). For this study, we used the consequences dimension of CSM. CSM states that the consequences are the anticipated (abstract), perceived and experienced (concrete) outcomes of illness (Leventhal et al., 2001; Hagger et al., 2017; Mora and McAndrew, 2013), or the beliefs of the extent of the illness severity on how it will seriously affect life events (e.g. personal relationships, family, work) (Hagger et al., 2017), or the views concerning the impact of illness related to overall life quality, or how the illness may affect functional capacity; example: “*My illness prevents me doing certain things*” (Hagger and Orbell, 2003). According to CSM, such consequences are often expressed comparatively (Mora and McAndrew, 2013; Hagger and Orbell, 2003); for example: “*My life is worse than it was because of my illness*” (Hagger and Orbell, 2003). As to CSM, the consequences can be physical, social, economic, or financial (Leventhal et al., 1997, 2001, 2016; Mora and McAndrew, 2013), psychological (Mora and McAndrew, 2013), emotional (Leventhal et al., 2001), and functional (Leventhal et al., 2016; Hagger and Orbell, 2003) effects. Thus, the design of this study was framed by these key sensitizing concepts.

## 3. Material and methods

### 3.1. Study design and setting

The research employed a phenomenological approach, which creates opportunities to learn from the experiences of others (Neubauer et al., 2019), to explore the consequences of the disease experienced by T2DM patients. The study was conducted from July 2019 to January 2020, which was very time-consuming (Suter, 2012), at Dessie Comprehensive Specialized Hospital (DCSH) in Dessie City Administration (DCA), North-East Ethiopia, which is a multi-ethnic city (Table 2) and is the largest urban center in North-East Ethiopia (Dimon, 2018) at which the largest and highest level tertiary hospital (DCSH), with the widest catchment area, is located (Abejew et al., 2015).

### 3.2. Data collection tool and procedures

Bearing in mind that the sufficient sample size for the phenomenological study is 2 to 25 (Alase, 2017) or 5 to 25 (Creswell, 2013) or even fewer than 10 (Moser and Korstjens, 2018), the participants were twenty-four T2DM patients with insulin regimens, who were following their treatment at the DCSH. They were recruited purposively; the best sampling criterion in the phenomenological study (Pathak, 2017). They were selected to include various socio-demographic characteristics (age, sex, marriage, occupation, education, religion, and residence). They were over 18 years of age, lived with diabetes for at least a year, with no serious illness, interested to participate and able to communicate. All the recruited patients participated; no dropout. They were identified by the principal investigator (EMB) in advance from their registration cards at the diabetes clinic. No persons other than the data collector and the participants were present during the interviews.

The data collection was performed by EMB using a semi-structured interview guide prepared in the local language (Amharic) (Diefenbach, 2020; Broadbent et al., 2006; Weinman et al., 1996; Moss-Morris et al., 2002). The data collection techniques used were face-to-face in-depth interviews of three weeks; the only data collection techniques in phenomenology (Moser and Korstjens, 2018; Pathak, 2017). The interviews were conducted at the patients’ appointment time in quiet places (secured work areas of participants and their homes, at secured areas of the hospital compound, and separated areas of cafes), and recorded using an audio device. Memos (field notes) were being used along with the interviews. No repeat interviews were conducted. The interviews took 23 to 71 min (average of 46 min) and continued until theoretical saturation (the point at which no further themes were found), which is the most common concept to estimate sample sizes in qualitative research (Guest et al., 2020).

**Table 2.** Description of dessie city administration (DCA), 2020.

Significance	Largest urban center in North-East Ethiopia (Dimon, 2018)
Population	Town (209,226), Rural (35,903), Total (245,129) (Central Statistical Agency, 2013)
Ethnic groups	Amhara (94.89%), Tigre (3.79%); Others (0.67%) (Central Statistical Agency, 2007)
Religions	Islam (58.62%), Orthodox (39.92), Protestant (1.15%), and Others (0.31%) (Central Statistical Agency, 2007)
Language	Amharic (95%), Tigrigna (4%); Others (1%) (Central Statistical Agency, 2007)
Economy	Economically active (50.85%), Economically inactive (49.15%) (Central Statistical Agency, 2007)
Employment	Employed (88%), Unemployed (12%) (Central Statistical Agency, 2007)

### 3.3. Data processing and analysis

The interviews were being transcribed verbatim into MS Word by the principal investigator (EMB) and rechecked repeatedly by the whole research group (EMB and other native investigators, MHK and BDW) for better understanding. The transcripts were also translated to English and back to the local language (Amharic) for consistency by EMB, and rechecked by the whole team. Coding was started immediately at the first interview and performed simultaneously with data collection procedures; and conducted by the three researchers independently. They discussed each code at group meetings until consensus was reached on basic sub-themes and themes across the transcripts. The coding was done by moving back and forth repeatedly to find out further emerging themes and to gain a detailed description of the themes. Memos and notes were also included in the analysis to get rich findings. Lastly, each theme was merged to a conceptual model of the participants, their perceptions, and experiences of the consequences of T2DM. Generally, the data were organized thematically, a powerful yet flexible method for analyzing qualitative data (Kiger and Varpio, 2020), using QDA Miner Lite v2.0.8.

For data trustworthiness, the interview guide was pre-tested on two T2DM patients who were not included as actual participants and modified accordingly. The transcripts were returned to three participants before being translated to English and debriefed. The final findings were also given to the participants for feedback and checked. Moreover, the “Standards for Reporting Qualitative Research (SRQR) checklist” (O'Brien et al., 2014) was used to prepare the report.

### 3.4. Ethics approval statement

Permissions were obtained from the “Research, Community Service and Graduate Coordinating Office” of the Medicine and Health Science College of Wollo University (Ref. No. CMHS: 443/13/11). After the provision of sufficient information, written informed consent was signed by each participant. Illiterate participants affixed their fingerprints. The information gathered was kept confidential.

### 3.5. Reflexivity

EMB realizes that the finding of the study is the interaction of him and the participants. He has been a part of the community since his childhood and is very familiar with the local slang terms. This helped him to easily understand and interpret the experiences and perceptions of participants from lay perspectives. However, the participants perceived him as an influential individual. Therefore, his knowledge of the local jargon and diabetes, and perception might result in bias if he did not remain conscious in the research process.

## 4. Results

### 4.1. Socio-demographic description

Twenty-four patients (11 males and 13 females) were interviewed. The age range of the participants was 35–75 years, and the median age of 57 years. The average life of patients with diabetes was 12 years. The patients were in various socio-demographic characteristics. Most (n = 17) of them were married. One of them was single, and the rest were widowed. Regarding religion, the majority of them were Muslims (n = 12) and Orthodox Christians (n = 11). About education, most (n = 11) of them were illiterates. They were from various occupational areas. However, most (n = 5) were farmers. Most (n = 17) of them were rural residents. The result of this study showed that the consequences that

diabetes brought to patients were categorized as complications and impacts.

### 4.2. Complications

The most commonly expressed complications were cardiovascular disorders (Hypertension, erectile dysfunction-ED, heart and kidney problems, hyperlipidemia, edema, stroke, and fatigue), ocular problems, neurogenic problems (pain including toothache, backache and arthritis, and numbness), thyroid problems, and weight reduction.

The most common complication was hypertension followed by ED. However, the complication which was very pronouncedly expressed was ED.

*The problem (diabetes) got worse. I am not interested in sex right now. It has almost eliminated my desire for sex. (Male, 59 years, Master's degree holder)*

*I have something strange that ‘Siquar’ (diabetes) brings me. It killed my penis. I lost sexual intercourse. Right now, I am disabled. (Male, 46 years, Illiterate)*

*...But let me tell you. I have a problem. It forbade me from having sexual intercourse. I did not tell to my doctor. Help me? Tell the doctor to prescribe a medicine for me. (Male, 65 years, illiterate)*

*The ‘Siquar’ (diabetes) controlled my entire penis. I am incapable of having sexual intercourse. (Male, 58 years, illiterate)*

The next commonly mentioned complications were ocular problems followed by neurogenic pains including toothache, backache, arthritis, and numbness.

*My eyes appear to me like white cloth. They seemed misty and smoggy. It (the eye pain) is piercing me. It (diabetes) brought me hypertension too. My back is involuntary and very irritant. It (eye) is burning me like ‘Berbere’ (dried powdered red pepper). My back and legs are involuntary whenever I try to use a latrine. It gives me everything it wants, loading me like a lorry. (Female, 71 years, illiterate)*

*Another illness that I got due to it (diabetes) is a neurological disorder. It will also destroy your male interest, which is difficult. (Male, 73 years, Diploma holder)*

Thyroid problems and weight reduction were the least expressed complications of diabetes mellitus.

*Right now, the trouble with me is the thyroid problem what it (diabetes) awarded me. (Female, 42 years, Secondary school completed)*

### 4.3. Impacts

The most common diabetes impacts were psychosocial (dread in life, suffering, family disruption, hopelessness, dependency, and craving), economic (incapability and loss of productivity), and somatic disability.

The most common negative impacts were psychosocial from which dread in life (apprehension of what to come to them or family and how they live in coping it) was the most common followed by suffering and hopelessness.

*I am very afraid of ‘Siquar’ (diabetes). This is because it is difficult to live with it. My father died because of it. I always worry when I think that my final destination is something bad because of it. (Female, 42 years, Secondary school completed)*

*Many things are changed because of ‘Siquar’ (diabetes). It brings you a lot of bad changes. The children are worried in saying that she may annoy, it*

(blood sugar) will go up to her, she will become sick, etc. (Female, 51 years, Secondary school completed)

Patients expressed that the alarming increment of diabetes incidence has created fear (dread) in the family of the diseased and the community within the low socio-economic level.

*After I was caught, within a short duration; from time to time, a lot of my neighbors have got it (diabetes). So, we are worrying about our children and poor relatives. The poor families will not afford the treatment if being diseased. (Male, 63 years, illiterate)*

Patients were suffering from diabetes consequences. They experienced restless pain and losing natural vacation (sleep) as a consequence of the worst pain that it brings to them.

*It (the pain) burns, irritates, pierces my kidneys. I cannot be able to stand and sleep. Nighttime, the time that I am deprived of sleep is more than that I have it (sleep). I am suffering from restless pain and losing rest. (Male, 58 years, illiterate)*

Patients expressed that living with diabetes was meaningless. They perceived that it was lessening their life interest.

*'Siquar' (diabetes) just killed the whole thing of mine. I lost everything enjoyable as a result of it; no meaning to live if you think. (Male, 46 years, Illiterate)*

Patients perceived that they were experienced family instability as a result of diabetes. They perceived that diabetes keeps away them from their couples without real divorce and disrupting their families.

*It (diabetes) is finishing my teeth; it troubles my eyes too as far as no my age permits. Again, it diminishes my desire (libido); it has diminished my relationship with my wife. How can you manage your family with this evil condition? I lost my wife while she is with me. You see! How much it is evil. (Male, 63 years, illiterate)*

The second most commonly expressed impact of diabetes was economic deprivation due to incapability to do work or loss of productivity. They stated that diabetes could not allow them to do hard work to the extent of their need.

*It (diabetes) keeps you away from work; it does not allow you to work hard. Food is also needed. If you do not eat frequently, it will throw you; you will fall. So, what I can tell you? And the only thing is to live as long as 'Allah' permits; no work, just to live. (Male, 58 years, illiterate)*

*We crave what any healthy people do have like eating, closing, etc., but it (diabetes) hurts us economically. A diabetic should be careful, but economic conditions do not allow us to go accordingly. And you are hurt by that. For example, if you always eat 'Shiro' ('watt' usually prepared from pea, bean, chickpea, and grass pea), your body will not get blood. (Male, 72 years, Secondary school completed)*

The least common expressed impacts of diabetes were somatic disabilities. They lost their body as a result of diabetes. They stated that it hardly impacted their body.

*One foot of mine was operated. I cannot move freely. My legs hurt so much. My heel is very sore when I go. (Female, 36 years, Illiterate)*

## 5. Discussion

The study was framed by the consequences dimension of CSM of illness representation. As to this model, the consequences of illness impact the physical, social, economic or financial, psychological, emotional, and functional well beings of individuals. Bearing the model in mind as a framework, this study revealed that cardiovascular problems (hypertension followed by ED), ocular problems (visual disturbances), and neurogenic pains were the most common complications. Similarly, quantitative studies at DCSH (North-East Ethiopia) (Abejew et al., 2015),

Black Lion Specialized Hospital (Addis Ababa, Ethiopia) (Gizaw et al., 2015), and Nigist Ellen Mohamed Memorial Hospital (Hosanna, Southern-Ethiopia) (Tadesse et al., 2018) showed that hypertension was the most common complication of diabetes. However, the complication which was noticeably stated here was ED. It was reported to be an early indicator of endothelial relaxation dysfunction, and a marker of increased cardiovascular risk (Price, 2016), which are advanced and difficult to manage, and the most common complications reported in this study. Hence, it seems that the failure to be aware of and unable to launch early intervention to the initial risk factors might be the reasons that bring the worst complications. The prevalence of ED was also found to be very high in Africa as a whole (Shiferaw et al., 2020) and Northern Ethiopia, specifically, at which almost all patients had not been screened or treated for it (Seid et al., 2017).

The second most common complications were visual disturbances (ocular problems). Diminished or loss of eyesight was also reported to be a major complication of diabetes by studies in Butajjara and Addis Ababa (Ethiopia) (Habte et al., 2016), DCSH (North-East Ethiopia) (Abejew et al., 2015), Black Lion Specialized Hospitals (Addis Ababa, Ethiopia) (Gizaw et al., 2015); and Nigist Ellen Mohamed Memorial Hospital (Hosanna, Southern-Ethiopia) (Tadesse et al., 2018). This entails that diabetes patients should have a yearly dilated eye examination (Hopper, 2007).

The most common untoward impacts of diabetes were psycho-social (dread in life, suffering, family disruption, hopelessness, dependency, and craving), economic (incapability and loss of productivity), and somatic disabilities. In similar studies, psychosocial impacts were reported to be the most common in diabetes patients, which in turn often result in a serious negative impact on patient's well-being and social life (Kalra et al., 2018); dictates addressing such psychosocial aspects could be the ultimate goal of diabetes management (Kalra et al., 2018; Pascoe et al., 2017).

Patients feared what will be going to them because of diabetes. They were psycho-socially in dread of 'what can come next?' They were struggling with the changing health situation of diabetes, and worrying about the present and the future (Penckofer et al., 2007). While psychosocial support improves the wellbeing of patients, skipping it undermines the quality of life (Pascoe et al., 2017; Kalra et al., 2018; Guo et al., 2018). These patients were not only dreading the future but also suffering from restless pains and deprivation of their sleep. Unless properly managed, sleep disorders were common in T2DM patients and detrimental to their wellbeing (Khandelwal et al., 2017).

It also impacted their relationship with their spouses as a result of impotency (ED). They stated that it kept them away from their spouses. Consequently, patients have been faced family disruption and diminished hope to survive. Similarly, in Butajjara and Addis Ababa (Ethiopia), diabetes had been known to affect the social relationships of patients with their spouses secondary to impotency (Habte et al., 2016). They also felt to be a burden to their family with no contribution, and hence encountering challenges in relationships with self, family, and others (Penckofer et al., 2007).

Patients were craving what healthy family members eat. They perceived that if they craved, the family members would not enjoy their meals freely in thinking of them. The same report showed that abstaining from former culinary treats was indicated as a core experience, which was expressed as the feeling of giving up a previously enjoyable life forever (Buchmann et al., 2016).

The economic and somatic impacts were found to be inseparable. The physical impacts were secondary to the complications of diabetes, and the economic impacts were due to the negative somatic impacts. The patients expressed that they were incapable and lose productivity. Physical incapability like problems in eye vision, and fatigue due to cardiovascular complications were major reasons for the loss of productivity which in turn impacts economic capability. Fatigue was found to be negatively related to the quality of life and functional status (Singh et al., 2016). The patients were suffered from economic deprivation as a

result of physical disabilities. It was also reported that the economic consequences were due to diminished eyesight and body strength or limited mobility, which lead to the inability to carry out daily activities (Habte et al., 2016). Similar studies also showed that the considerable economic burden of T2DM management was aggravated by its complications (Amon and Aikins, 2017; Wu et al., 2018).

### 5.1. Practical and policy implications

The study revealed that the consequences of diabetes were various complications with psychosocial, economical, and physical hardships, which mandate a holistic approach including policies and activities across diverse settings (Levitt et al., 2016). The Chronic Care Model (CCM) which has demonstrated effectiveness in a wide variety of clinical settings (Mehta and Gabbay, 2016) with Integrated Care Model (ICM) (Satyrganova, 2016) should be followed. According to CSM, not only expert intervention but also self-control should be sought (advocated) (Mora and McAndrew, 2013; Leventhal et al., 2016).

### 5.2. Implications for future research

Action research which will direct an effective means, considering the local socio-cultural and socio-economic context, in implementing holistic care will be crucial.

### 5.3. Limitations

The interview data were collected from only those who were attending their treatment in DCSH. It did not include type 1 diabetes patients (T1DM). It did not also consider T2DM patients who were following their treatment at other governmental and private hospitals. Because of the qualitative nature of the study design, it could not be generalizable and should be interpreted contextually (applies ideas across contexts) (Suter, 2012).

## 6. Conclusion

Generally, the most common complication and impacts, respectively, were hypertension (followed by ED and visual disturbances) and psychosocial outcomes (followed by loss of productivity and somatic disturbances). The study was also found to satisfy the 4<sup>th</sup> dimension of CSM (the consequences domain).

## Declarations

### Author contribution statement

Ewunetie Mekashaw Bayked: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Birhanu Demeke Workneh and Mesfin Haile Kahissay: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data.

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### Data availability statement

Data included in article/supplementary material/referenced in article.

### Competing interest statement

The authors declare no conflict of interest.

### Additional information

No additional information is available for this paper.

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