

## Psychosocial experience of diabetes by diabetics attending the Evangelical Medical Centre Nyankunde, Bunia Hospital centre, Ituri Province, Democratic Republic of Congo

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**ABSTRACT:** This study was conducted to explore the psychosocial experience of diabetes by diabetics attending the Evangelical Medical Centre Nyankunde, Bunia Hospital Centre. It was carried out using the phenomenological method supported by semi-structured interviews with 30 diabetics.

After analyzing and processing the data using content analysis, the study revealed that as soon as their diagnosis is announced, diabetics experience diabetes as a disappointment for some, as stressful for others, and as denial (non-acceptance of the disease 'diabetes'). In the daily lives of diabetics after the diagnosis, diabetes is experienced as stress for some, for several reasons: a life of dependence, bankruptcy, giving up work, encouraging the onset of other illnesses, eating badly (adherence to a diabetic diet), taking medication at all times, suffering at all times, loss of self-image and, finally, depression for others. Socially, diabetes has an impact on the relationship between diabetics and those around them. The family maintains a good relationship despite their member being affected by diabetes. At work, there is a change in professional life, and at the hospital, there is a great deal of support through the good relationship between the nursing staff and diabetics, which gives the latter hope for life. As for the church, it demonstrates a good relationship with diabetics and is of great importance in their lives, as it introduces them first and foremost to God, who is the solution to every human problem.

Although diabetics try to adapt to their condition with the support of members of their societies, diabetes remains a burden that requires awareness for its prevention and holistic support for its victims.

**KEYWORDS:** psychosocial, experiences, diabetes, diabetics.

### 1 INTRODUCTION

Diabetes is 'a disease characterized by a high level of sugar (glucose) in the blood, which makes it impossible for the body to use sugar and food containing sugar normally' (Martine 2006). Diabetes is 'a major public health problem worldwide, which has increased dramatically over the past two decades and is expected to affect 592 million adults by 2035' (Mandereau-Bruno, 2015). The WHO predicts 'a global increase in the prevalence of diabetes, which is expected to reach 300 million patients in 2025. This trend is most marked in developing countries, particularly in sub-Saharan Africa' (Thiam, Gring et al, 2007).

Faced with this chronic and incurable disease, people with diabetes perceive and experience it in different ways. The announcement of the diagnosis comes as a shock, and can even be a source of depression, as diabetics suffer more from depression and anxiety than the rest of the population. Once the shock of the diagnosis has passed, certain reactions occur, such as denial (refusal to accept the diagnosis), anger and depression (Martine, 2006).

As for the results provided by metabolic disease medicine among 300 diabetics, 50.5% mention only negative, mixed or only positive emotions in reaction to diabetes, 15% of diabetics feel negatively judged because of their diabetes and 16.7% of patients mention a great fear of hypoglycaemia (Consili, 2016).

In Cameroon, diabetes is perceived and experienced by patients as a consequence, a reward for a poor lifestyle and overeating. The idea of any genetic influence is almost always elided, and this experience of the disease generates a feeling of fatality or guilt in patients.

They perceive and experience it as a disease of food enjoyment, a diabolical disease, a hypocritical disease (without feeling bad anywhere), an incurable but curable disease, a disease that is not serious (diabetes leadership forum, 2010: 4 -7).

In the Democratic Republic of Congo, a study carried out by the association '*Vaincre le diabète au Congo*' in 2008 among people suffering from diabetes, by the medical team at the diabetes clinic in Kinshasa, showed that diabetes creates depression and anxiety as soon as the diagnosis is announced, and has an impact on their social life, particularly their professional life, which many patients have long wished they had a little book of advice adapted to their case (De Clerck, 2008).

During an internship at the Evangelical medical Centre, Bunia Hospital, in the internal medicine and intensive care wards, we observed depression and anxiety through depressed mood almost all day long: loss of pleasure or interest in normally pleasant activities, recurrent thoughts of death or suicidal thoughts, excessive worry or concern about events or activities of daily life, irritability, sleep disturbance in five out of eleven patients. When we approached them to address their concerns and make use of their records, we discovered that two out of five, or 40%, were diabetics. This study was conducted to explore psychosocial experiences of diabetes by diabetics at Bunia Hospital of Medical Evangelical Centre.

## 2 MATERIAL AND METHODS

This study, using qualitative design was carried out in the town of Bunia, specifically at the Bunia Hospital of the Medical Evangelical Centre, in the north-east of the Democratic Republic of Congo, in the province of Ituri. The phenomenological method described by Aubin-Augier et al (2008) was used. The study was conducted over a period of 22 days, from 30 May to 20 June 2022. The sample for this study consisted of 58 diabetics, as this was the level at which saturation was reached.

### 2.1 RESEARCH PARTICIPANTS' CHARACTERISTICS

N°	Gender	Age (years)	Education	Years with diabetes(years)
1	F	68	Primaire	10
2	F	49	Primaire	2
3	F	66	Secondaire	15
4	F	60	Secondaire	6
5	F	50	Universitaire	0.25
6	F	50	Secondaire	0.16
7	F	60	Analphabète	10
8	M	65	Universitaire	10
9	M	63	Secondaire	7
10	F	32	Secondaire	1
11	M	62	Secondaire	2
12	M	73	Secondaire	14
13	F	50	Analphabète	1
14	F	42	Secondaire	8
15	F	67	Primaire	11
16	F	62	Primaire	6
17	F	45	Analphabète	3
18	M	47	Secondaire	5
19	M	84	Secondaire	1
20	M	63	Secondaire	5
21	F	44	Secondaire	5
22	F	60	Secondaire	1
23	F	53	Primaire	10
24	F	38	Secondaire	6
25	F	66	Secondaire	14

26	F	61	Primaire	0.16
27	F	63	Secondaire	7
28	M	13	Analphabète	0.5
29	F	60	Primaire	1
30	F	63	Secondaire	5

Many diabetics were unemployed with secondary education, and more were women.

We used the occasional sampling to identify the research participants. We interviewed 58 diabetics who were accessible and available.

Semi-structured interviews were used to collect the data. As for data analysis, content analysis supported by the development of a thematic framework was used.

Before going into the field, we obtained a research certificate N°052/CS/SI/2021-2022, duly signed by the Head of the Nursing Sciences and approved by the Medical Director of the Bunia Hospital of Medical Evangelical Centre. It enabled us to make contact with the respondents in their wards. Naturally, anonymity and confidentiality were guaranteed during the interviews, after the respondents had given their informed consent.

### 3 RESULTS

#### 3.1 PSYCHOLOGICAL EXPERIENCES OF LIVING WITH DIABETES

##### EXPERIENCE OF THE DIAGNOSIS

Respondents reacted differently to the announcement of the diagnostic result. When the results were announced, some respondents were not bothered for various reasons

*'It didn't bother me because my wife had been suffering from this since 2004, I saw how we managed it and I wasn't bothered' (E08, Interview).*

*'Yes, it's still an illness like any other' (E01, Interview).*

On the other hand, some respondents were upset when the results of their diagnosis were announced.

*'I was very disturbed, especially physically, but also psychologically, trying to find out where this disease came from, and they say there's no cure. Taking medication every day...'. (E23, Interview).*

*'I was disturbed because I was the father of my children, the mother...'. (E02, Interview).*

*'When I was told I had diabetes, I was very worried and my health had deteriorated a lot like someone suffering from HIV/AIDS. I'd lost weight, I had a lot on my mind (E03, Interview).*

For another group, although they were initially shocked by the news, they resolved to accept it and live with the disease.

*'The children cried and were stressed when the diagnosis was announced. Afterwards, I said to myself, I need to know how to live with this' (E22, Interview).*

For one category, when the diagnosis was announced, the idea of death immediately came to mind.

*'I saw that I was at death's door, because you can't maintain the same health' (E09, Interview).*

##### DAILY LIFE AFTER THE DIAGNOSIS

In everyday life, despite the advice and explanations given by healthcare staff and other members of society, diabetes is experienced as stressful for various reasons.

After the results were announced, some respondents knew that this disease would lead to a life of dependence from now on

*'... if people don't help me, I do nothing...'. (E01, Interview).*

*'... Having to select food, seeing the recipe becomes difficult... lack of support...'. (E09, Interview).*

In a context of lack of financial means, some respondents mentioned that it would be difficult for them to live with this disease.

*'...I started the injections, but having the money is a problem, because the people who were helping me are now in the country where the war is going on. Because of that, I stopped the treatment' (E13, Interview).*

Some respondents even decided to give up their job/work to avoid being surprised by the complications of the disease.

*'I gave up work for fear of having attacks when I was travelling to sell' (E24, Interview).*

*'...It's stressful. I've even left my pupils without finishing the school year for fear that I'd fall down in front of them because of this illness. It really hurts' (E25, Interview).*

For the other respondents, diabetes has encouraged the onset of other illnesses

*'It awakens all the illnesses in the body' (E18, Interview).*

Diabetes has greatly affected the diet, to the extent that compliance with the new diet has posed many problems of adaptation.

*'The diet hurts me' (E06, Interview).*

*'Changing my eating habits... that's what has had a negative effect on my life...' (E11, Interview).*

Diabetes has been seen as a restrictive disease, as it requires you to take medication every day. On top of that, you suffer all the time, even to the point of losing your self-image.

*'...so you become someone who has to take medication all the time...' (E04, Interview).*

*'...think about your health every day and what the future will be like' (E25, Interview).*

*'I've lost a lot, because I used to be a hard-working woman... now here I don't even carry a can of water, even staying in the kitchen next to the fire...' (E24, Interview).*

Added to the stress are worries, depression and feelings of anger, but there is also an adaptation to a new life.

*'...Well! you have to follow the diet to go on living' (E22, Interview).*

*'...how I can't look after myself (work) when I'm ill, feeding myself is beyond me, looking after myself too, managing my family so...' (E19, Interview). (E19, Interview).*

*'...it's like an epidemic that's arrived, even the grandchildren have diabetes. It's the government that's incapable of identifying what's really threatening people' (E25, Interview).*

*'I've only respected the diet and treatment since... I'm at peace...' (E16, Interview).*

### 3.2 SOCIAL EXPERIENCES OF LIVING WITH DIABETES

When someone has diabetes, the society in which they live perceives the disease in different ways

#### IN THE FAMILY

Despite the fact that a person has diabetes, the family maintains the same relationship as before (good relationship) and considers this to be normal.

*'We still have a good relationship, I haven't heard them say anything yet' (E01, Interview).*

On the other hand, diabetes was perceived as an added burden.

*'Everyone contributes with what little they have (100Fc, 100Fc, 100Fc). 'Family members say: let's help our sister who is suffering; yes, they help me' (E17, Interview).*

For other respondents, the illness suffered by their family member was a source of stress and worry.

*'They were disturbed, my children until now when you prepare, my mother does not eat this food, you see they have stress' (E21, Interview).*

*'... they are worried about my health, they refuse to let me make long journeys on the road so that they don't lose me...'* (E09, Interview).

#### **AT WORK**

Despite an employee's condition, the employers and colleagues still maintain a good relationship, although diabetes sometimes changes the employee's way of working.

*'I ask permission because I've already told them that I have my check-up every month'* (E22, Interview).

*'The way I work has changed..., I take the trouble to work with the teachers' representative..., for example to draw up a report to present to the hierarchy...'* (E12, Interview).

For the others, diabetes was a disappointment to their colleagues and employers when one of them had the disease, especially when he or she gave up work.

*'They were also disappointed when I left because of this illness, but there was no choice'* (E25, Interview).

#### **AT THE HOSPITAL**

The hospital (CME) ensures a good relationship with diabetics by giving them advice and support that gives them hope of still living.

*'Aaah!!! They think well of us, their advice has really helped me a lot'* (E10, Interview).

*'Really, here because of my diabetes, the carers consider me more than a baby. They look after me really well, and I've known them for a long time. That's how I'm seen as the child of the house'* (E15, Interview).

#### **AT CHURCH OR MOSQUE**

Diabetes does not have much of an impact on the relationship between diabetics and others in church or in the mosque, but it does create stress for church members, due to the absence of their member or congregant following the service that the latter used to perform.

*'I pray, I am a deaconess, we know how I suffer, but am considered as someone who is not sick'* (E17, Interview).

*'I am also seen as someone who is not ill, because I am given a service and I do it, I am just as I was before'* (E12, Interview).

*'The illness disturbed my relationship, because I used to be a chorister, a mother of good news, but today there is no way of being with the mothers...even the mothers were disturbed, sometimes they come to take me home, to bring me to the duty office to pray for me, even when I arrive at the hospital, they visit me'* (E24, Interview).

## **4 DISCUSSION**

### **4.1 PSYCHOLOGICAL EXPERIENCES OF THE DIABETES**

#### **4.1.1 EXPERIENCE OF THE DIAGNOSIS OF DIABETES**

Diabetes is experienced in different ways by the respondents from the moment it is diagnosed, as evidenced by disappointment, stress and denial of the disease.

#### **DISAPPOINTMENT**

Diabetes is experienced as a disappointing phenomenon in life.

The results of this study are similar to those of Emilie and Geoffrey (2019), who reported that patients experienced the diagnosis of diabetes as an unpleasant surprise, with reactions of amazement, incomprehension, anger or tears, and despair comparable to the loss of a loved one.

Some people had said they had no particular reaction because of their many previous illnesses or because they didn't know much about the disease.

We discovered that being diagnosed with diabetes is interpreted as one of life's great disappointments. Once diagnosed with diabetes, patients often lose hope of leading an adequate life like other non-diabetics.

## **STRESS**

Diabetes is experienced as stressful from the moment of diagnosis by some of the respondents.

This result is also in line with that of Emilie and Geoffrey (2019), who found that for the majority of diabetics, the diagnosis had led to deterioration in quality of life. Some had experienced mood disorders and others had felt stressed or even traumatized.

Diabetes seems to be stressful from the moment it is diagnosed, because diabetics imagine the problems and difficulties they have to face in the world of diabetes of which they are already a part. It comes as a real shock.

## **NON-ACCEPTANCE OF THE DISEASE (DENIAL)**

Some respondents stated that they had not accepted the diagnosis of diabetes as soon as it was announced.

Martine (2006) states that the announcement of the diagnosis comes as a shock, and can even be a source of depression, as diabetics suffer more from depression and anxiety than the rest of the population. Once the shock of the diagnosis has passed, certain reactions occur, such as denial (refusal to accept the diagnosis), anger and depression.

People with diabetes do not readily accept the diagnosis of diabetes because of the sense of repression they feel as a result of their fear of the disease. For them, accepting the existence of the disease means accepting the difficult life that diabetics lead with complicated diets.

### **4.1.2 DAILY LIFE AFTER THE DIAGNOSIS OF DIABETES**

## **STRESS**

In everyday life, despite the advice and explanations given by healthcare staff and other members of society, the respondents say that they experience diabetes as stressful for various reasons: life as a dependent, lack of financial resources to enable strict adherence to diets, giving up work, encouraging the onset of other illnesses, eating badly (dieting), taking medication at all times, suffering at all times, loss of self-image.

Julien (2016) in his study reveals that the greatest daily difficulties experienced by diabetics relate to food and its restrictions. Many gave up or 'put the brakes' on what they considered to be 'pleasant' for fear of 'raising their blood sugar'.

One group of patients considered the onset or fear of hypoglycaemia to be the most difficult thing to cope with on a daily basis. The fear of symptoms was sometimes so great that some patients no longer dared to engage in certain activities for fear of lowering their blood sugar levels. Other patients deplored the difficulties of social isolation with diabetes, particularly in old age, and the moral distress it caused. The changes made in patients' daily lives logically concerned their diet, with the vast majority admitting that they had stopped or moderated their consumption of many products, and in some cases had completely changed their dietary range. The appearance of the wounds had also greatly altered patients' lifestyles in terms of their leisure and sporting activities, as well as their social and professional lives. Patients have changed the way they organize their active lives, depending on the constraints of the treatment, in particular with regard to dressings and the times when the nurses visit, the need to travel to dressing consultations at the hospital, the need to carry the treatment with them at all times, and the organization of their personal diaries or travel plans. The difficulty of getting around was also highlighted, with some patients unable to use a vehicle, often needing to be accompanied by a third party. Fear of 'minor discomfort' also prompted some patients to give up their various outings. Other patients pointed out the financial difficulties involved in following a diabetic diet.

This may lead us to say that, like other diseases with a high burden, diabetes is a stressful disease, because sufferers face a number of difficulties in their lives that previously did not

This can be explained by the fact that, once they have diabetes, people have to change their eating habits, they have to take part in certain physical activities to balance their blood sugar levels, they have to have the financial means to ensure

medical follow-up, and they need the support of those around them. And so, seeing all these difficulties, diabetics find themselves living with lifelong stress.

## **DEPRESSION**

The respondents in this study also revealed that they live in a permanent state of depression as a result of diabetes.

This finding is similar to that of De Clerck (2008), who showed that diabetes creates depression and anxiety as soon as the diagnosis is announced, and affects their social life, particularly their professional life, which many patients have long wished to have a little book of advice adapted to their case.

In other words, diabetics need to be supported and accompanied, both medically and psychologically, so that they don't feel abandoned.

Indeed, the lack of responsibility, support and accompaniment exposes them to a state of psychological depression. And many die too soon because diabetes has plunged them into a state of unacceptability.

## **4.2 SOCIAL EXPERIENCES OF LIVING WITH DIABETES**

From a social point of view, the respondents in this study report living or having different ways of life (relationships) in the societies where they find themselves because of diabetes.

### **4.2.1 IN THE FAMILY**

Despite their diabetic condition, the respondents report that they maintain good relations with their family members, who consider this to be normal and provide them with psychosocial support.

This result is in line with that of Emilie and Geoffrey (2019), who found that family and friends played an important role in the experience of diabetes and could condition the patient's attitude to his or her illness. For many, they were a source of support and motivation for self-management.

In the same way, Sinthu (2017) states that when people are asked what habits from their home country they miss, 7 out of 9 say it's the family. The persistence of family ties is striking. People keep in touch with their families; all those interviewed had families in their countries of origin and stayed there regularly.

The involvement of family and friends is an important part of the diabetic experience. In most cases, the role of caregiver is seen as a positive one, rather than a burden. In fact, 90% of family and friends adapt to changes in their loved one's lifestyle. They are generally aware of dietary changes, and report that 50% of patients are able to modify their diet. Only 30% of patients would start one (Julien, 2016).

The good relationship of the family (biological, extended, friends) allows diabetics to live the hope lost in society. On the other hand, if this good relationship is broken, these diabetics find themselves rejected and abandoned. This leads to depression, followed by suicidal ideation and death. Families are the only ones who can ensure that diabetics lead good, hopeful lives in society.

### **4.2.2 AT WORK**

It is clear from the comments made by the respondents to this study that, despite the good working relationship between diabetics, their colleagues and their employers, diabetes can change the way they work. They don't perform as well as they used to.

Gentilly (2021), in turn, notes that diabetes is a taboo disease with a mental burden that has heavy psychological effects. A large majority of diabetics (81%) confirm that the disease is restrictive. One in two patients reports that their illness has already affected their physical (57%) and psychological (50%) well-being.

Once a civil servant is diagnosed with diabetes, his or her way of working changes as the disease demands certain lifestyle measures, such as devoting more time to medical follow-up, respecting the diabetic diet and meal schedule, limiting long journeys without prior provision for service reasons, and so on. This is why support and assistance from the employer and colleagues is so important if the diabetic is to continue to perform his or her duties within the company or organization.

#### 4.2.3 A THE HOSPITAL

The respondents said that the hospital (CME) provided them with a good relationship, through advice and support, which gave them the hope of living even longer like people with other pathologies. This result is in line with that of Julien (2016), who states that diabetics as a whole are fairly satisfied with the way their doctor monitors their disease, particularly in terms of treatment, biological tests, and referral to various specialists as part of the prevention and management of complications, with a significant impact on their mood (46%) and sex life (41%). Many also deplore the negative impact on their social (38%), marital (33%), family (30%) and professional (32%) lives. Patients also report having experienced "intense periods of anxiety" as a result of their disease (44%, including 55% of "type 1" sufferers), or phases of depression (41%, including 48% of "type 1" sufferers).

In the same vein, Noémie (2017) reports that the work experience of people with diabetes is influenced by the disease and its constraints on co-ownership, sociality and their psychological instance. However, these multiple repercussions of diabetes on working life do not prevent those affected from considering themselves above all as "normal" workers. To cope with their situation as adequately as possible, diabetic workers do not remain positive, but develop a variety of strategies, personal meanings and seek solutions to best manage the difficulties they may encounter in the workplace.

Hospitals should therefore be seen as the best support for diabetics, through the various services they provide. In this way, diabetics can have full confidence in the hospital (nursing staff) to lead a life like other people, despite their illness.

#### 4.2.4 AT THE CHURCH OR THE MOSQUE

Respondents to this study stated that diabetes does not influence their relationship with others in church or mosque. According to Sinthu (2017), religion plays an important role, particularly the power of God in the development of the disease. Despite his diabetes, a Muslim believer continued to observe the Ramadan fast while following the advice of his GP. The church or mosque plays an important role in the lives of sick people in general, and diabetics in particular, because it presents God to diabetics as Master of all, capable of everything, even of curing their illness or giving them a life like other non-sick people. So they are called to obey and wait for His will to be done in their lives.

### 5 CONCLUSION

This study reveals that diabetics undergo diverse experiences once the problem is diagnosed. Although diabetics try to adapt to their condition with the support of members of their societies, diabetes remains a burden that requires awareness for its prevention and holistic support for its victims. It is important that community members are reached using a contextual approach so that they are well informed about diabetes.

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