

Social impact of diabetes among young in Republic of Congo: Case series

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Abstract

Background: Diabetes has social implications for young people, their families and society, but has poorly documented mostly in Africa. So, we want to determine the social consequences of diabetes among young in the Democratic Republic of Congo (DRC), in 2020.

Case presentation: This study had a descriptive, case series, design. The 50 young living with diabetes followed in the Change Diabetes in Child (CDiC) project and present at the time of the study were included in the study. Data were collected from medical records and by interview based on a questionnaire. The interview was carried out on the day of the consultation with all the young or with their parents (if the child was accompanied by a parent). The median with its interquartile range and the proportions were used to describe data.

Discussion: The young people were all single, the male sex more numerous, the majority had reached the secondary level, but 17 were no longer in school at the time of the survey. Many came from the surrounding area. The age limit were 10 to 26 years. Few had balanced glycemia. Most received two insulins and 44 young people presented four social problems at the same time. The total number of social problems among young people was 138 because many had several problems at the same time. Distress was the most cited and very often discouragement at the announcement of the diagnosis.

Conclusion: Young people living with diabetes present social problems that we do not take into account in our routine consultations.

Keywords: Diabetes; Youth; Social problems; Distress; Discouragement.

Introduction

Worldwide, childhood diabetes is a public health problem. The 2019 report from the International Diabetes Federation estimated the annual growth of cases at around 3% with a greater incidence especially in Finland and Sweden [1].

Diabetes has social implications for children, their families and society, poorly documented, especially among young people. In the 2013 Diabetes Attitudes Wishes and Needs (DAWN2) study, which involved only adults in 17 countries, the social problems in diabetetic people were: Distress (40%), discrimination (19%) and depression (14%) [2]; also diabetes affected their financial situation (44%), hobbies (38%), work or school (35%), family, friends and peers relationships (21%) [2].

For young people, diabetes is also a problem for their family, creating stress because of the budget and the insulin injections [3]. Many children and adolescents manage with difficulty emotions with their illness. They are often exposed to discrimination and their family relationships are reduced [4]. Psychological risks includes stress, guilt, fear of losing control, helplessness, lack of self-confidence, frustration, renunciation of personal life, anxiety, fear and depression [5]. Families experience high levels of stress due to complications and or conflicts related to the management of type 1 diabetes (T1D)) such as, diet feeding, poor adherence to treatment, and patient resistance to the pain of injection [6]. Diabetes negatively affects children's final grades, and those who had diabetes as children were less likely to be gainfully employed by age 29 [2].

In sub-Saharan Africa the problem is acute because of poverty, lack of food and other basic needs. All this leads to anxiety, stress and depression, rarely documented. The young most concerned live either with an uncle, an aunt, a cousin, an older brother, etc. They are often called sorcerers because of their disease [7,8], for example because to drink water at night while others are sleeping. These young people were characterized by a higher frequency of divorced parents (8.5%) than in the general population (6.4%) [9]. On the other hand, frequent medical visits lead to absenteeism and a drop in school performance. Misunderstandings due to the difficulty of managing the disease can lead to suicide.

Some strategies fight against this problem, the peer educators and the integration of schools in the diabetes care, this latest is not yet integrated in the Democratic Republic of Congo (DRC). In the DRC there is no study on the subject. Often this problem is ignored by healthcare providers. And yet The DAWN studies [2] have sent a strong message that addressing the psychosocial and behavioral needs of people with diabetes is an essential component of diabetes care. In many countries efforts are being made in this direction.

That is why, the objective of this study was to determine the social consequences of diabetes in young at the Hospital Center of Mont-Amba (HCMA) in Kinshasa in 2020. Thus knowing the importance of the subject will make it possible to integrate this notion into the care of young patients with diabetes and to guide strategies for better social integration of these children.

Case Presentation

This study had a descriptive, case series design of diabetic children followed in the HCMA, located at the Kinshasa University, in the commune of Lemba. It organizes 23 services, including a diabetic clinic with a diabetic children's clinic created in 2012 by the «Changing Diabetes in Children» (CDiC) project of the Novo Nordisk firm. The clinic has three doctors, six nurses and an educator trained in the diabetes management. The service operates 24 hours every day. There is one day for the children medical visit, apart emergencies. The consultation for children is free as well as insulin, syringes and strips. Psychological aspects are not associated with medical visits. Participants were 50 young people with diabetes of the HCMA. Our statistical unit was a young diabetic or a parent of a diabetic child unable to answer the questions.

Age was the date of the survey minus the date of birth. Social issues were defined as follows: discrimination: being left out, experiencing a difference in consideration. Distress: having a deep concern, stress: having anxiety, difficult employment: the fact that people refuse to hire because for them the sick person is an expense or a burden, frustration: being frightened or afraid. Depression: feeling sad, down, and losing all motivation for life. Being called a wizard: people saying I'm a wizard. Reduced academic performance: measured from schooling, Parental separation: Parents no longer live together. Rejection by friends: friends are afraid to walk around with me because of illness for fear that I will have a seizure. Rejection by family: Family doesn't want me because I'm a burden. Stopping studies because of diabetes: He no longer studies because of the cost of hospital appointments. I become a burden for the family: A burden caused by the number of meals required by insulin injections and the cost of illness. The parents refuse that I travel because of the diabetes: the parents think that I am a load for the others. Men run away from me because I have diabetes: Being diabetic is a burden, in addition to the fear of death during childbirth.

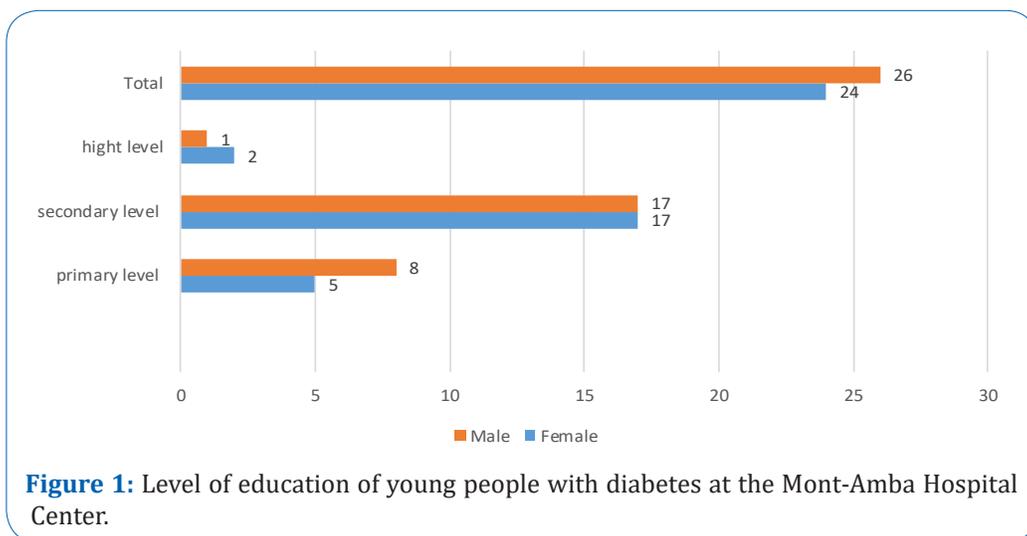
Data were collected from medical record and by the interview using a questionnaire. Before starting we obtained permission from the head of the hospital and the diabetic clinic, the children or their parents. The principal investigator, a qualified nurse collected the data. The interview was carried out at the hospital on the day of the consultation with all the children present that day or with their parents (if the child was accompanied by a parent). Some information was obtained from parents by phone call.

Some data have been categorized: blood sugar in 0-110 mg/dl, 111-200 mg/dl and more than 200 mg/dl; treatment in mixtard alone, mixtard with actrapid insulin and insulatard with actrapid; profession in pupil, student, unemployed and others (domestic); the duration of diabetes in <1 year, 1 to 5 years and >5 years. Data were entered and analyzed using Excel 2013 and SPSS22 software. Descriptive analyzes used the median with its interquartile range. The proportions were used for the qualitative variables.

The study received approval from the Ethics Committee of the School of Public Health, number : ESP/CE/89/2020. Respect for the human person was achieved by the confidentiality. The investigator had sole access to the data.

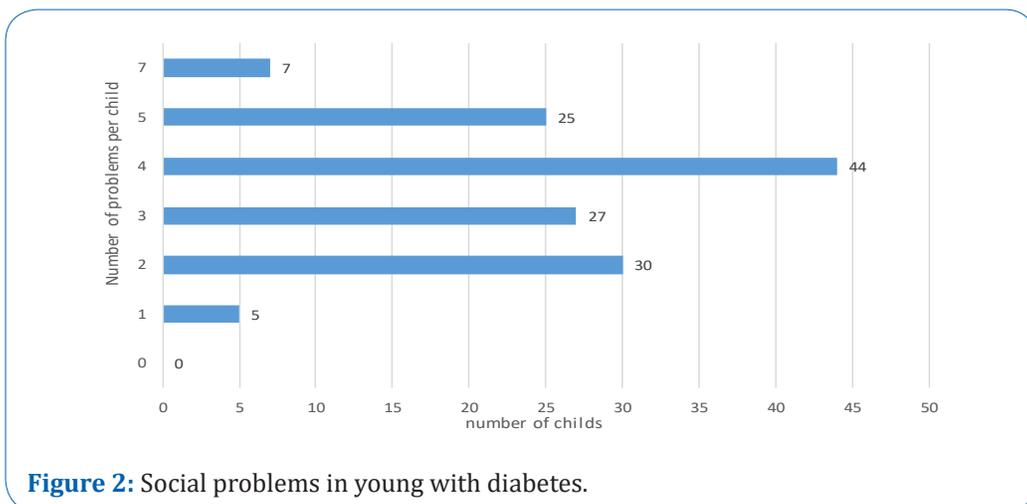
Discussion/Conclusion

Of the 70 young followed at the diabetic clinic, 50 took part in the study. The majority were boys, 52% (n=26). There was no children under the age of 10. The majority were over 15 years old. The majority come from our health zone and its surroundings. All were single. There were no notion of alcohol consumption and smoking. All the children had to attend school, the majority up to secondary level (68%, n=34), but 17 were no longer in school at the time of the survey. The education of young people is represented in Figure 1. Of all, 30 (60%) were pupils, three students, 13 (26%) unemployed and four working (domestic). The median glycemia was 210 mg/dl and the interquartile range 153.5 mg/dl. The glycemia was 66 to 600 mg/dl. Less than a fifth of patients had balanced glycemia levels. The majority had a glycemia above 200 mg/dl. The duration of diabetes was 2 months to 16 years. The majority received two insulins, more long-acting insulin.



Social problems in young with diabetes

The number of social problems is shown in Figure 2. The total number of social problems was 138, absent in four children. Five presented only one social problem, while 44 presented four social problems at the same time. Note that most of the children lived in a context of poverty.



The frequency of social problems

In total, the social problems was 20, shown in Table 1. The totals do not add up to 50, as some young people gave more than one answer. The main problems encountered were distress, stress and difficulty in obtaining a job.

Reactions upon discovery of diabetes

These reactions were discouragement (n=27) the major problem cited in this study, regret (n=18), disappointment (n=18), I didn't understand anything (n=11), to be worry (n=10), hard to accept (n=4), I found normal (n=4), waz in coma (n=3), desire to suicide (n=1), ideas disruption (n=1), I have become hard of character (n=1), it was a bad luck (n=1). The totals do not add up to 50, as some young people gave more than one answer.

Table 1: The social problems in young with diabetes.

Social problems	Frequencies	
	n	%
Discrimination	13	9,4
Distress	27	19,6
Stress	22	15,9
Difficult job	20	14,5
Frustration	18	13,2
Depression	15	10,9
Called a sorcerer	5	3,7
Reduced school performance	6	4,4
Stopping studies because of diabete	1	0,7
Having separated parents	1	0,7
Being a burden on the family	1	0,7
Men run away from me	1	0,7
Discontinued study due to diabetes	1	0,7
Divorced parent because of my diabetes	1	0,7
My parents refuse that I go on vacation	1	0,7
Rejection by friends	1	0,7
Disregard by familys	1	0,7
A blockage in my plans	1	0,7
Rejected or ashamed or unloved because of diabetes	1	0,7
TOTAL	138	100

The objective of the CDiC project was achieved in our clinic, the geographical accessibility. All the children were single at the time of the study. After the study 5 girls had a common-law pregnancy. One died after childbirth, four had an abortion and among them one died from anemia. One was absent for four months out of shame, knowing she was pregnant, every time she came to the appointment at the start of her pregnancy, she would tell the nurses that she had broken her insulin. By changing nurses, she has toaled a good number of vials that have served her during these four months. All the children have had to

go to school, but some have stopped, because of a financial problem. These children lived with their aunt, their uncle and their cousin. In their neighborhood, most of the children study. In the family of the diabetic children, many of their siblings do not study either. Over there, many young people have come from the village where diabetes care does not exist, and they have no inputs (glucometer, insulin, strip, urine strip, etc.). On the other hand there is a great distance to reach the health center. We measured glycemia, but the HBA1c would be better. At that time, the project had no inputs for this. The glycemia for many young was not balanced suggesting the occurrence of complications. Young people who received two insulins had a meal at noon, while those who had only one insulin had none.

Social issues

The young people present social problems not taken into account in our routine consultations. Studies [2, 10] have shown that people with diabetes show higher levels of distress, worry, fear, and negative quality of life than those without the condition. DAWN2 [2] showed that distress occupies an important place (nearly 45%) after anxiety in relation to episodes of hypoglycemia (nearly 55%). For Murillo et al 26.1% of children and adolescents had anxiety or depression [11]. Ellis et al. Reported that «adolescents present anxiety, mainly about the blood testing or administering insulin in public or at school and about long term complications of the condition» and also «Iranian adolescent girls have expressed significant concerns about finding a partner, pregnancy and possible discrimination in their future career». In another way «the fear of being isolated or rejected, lead adolescents to keep their disease secret» [12]. Guillot et al. found that discrimination in the professional world was felt in 11.8% of cases, but it rises to 23.1% for type 1 diabetes people [13]. Ellis said that «residential segregation is contributing to health inequity for United State children with diabetes» [13].

The acute and chronic complications of people with diabetes are generally seen as a burden on society. Ouzouni et al. noticed that «diagnosis of the disease causes shock to both parents and children, leading to anxiety. Adaptation to the diagnosis of diabetes lasts about 6-9 months for children» [14]. They report also that diabetic child were ashamed and suffocated by the overprotection of the parents. Over one third of diabetic children will develop in the first decade of the disease, depression and anxiety. They found an excessive consumption of alcohol (39%), smoking (34%), drugs (10%) contrarily to our study and a 10-fold increase in suicide higher with longer duration of diabetes, noncompliance, coexisting psychiatric disorders and single parent families [14]. Dybdal et al ([5] observed in 5,000 Danish type 1 diabetic children and adolescents, before their 18th birthday, highest risks of anxiety, stress and psychiatric disorders more in five years after diabetes onset. Jefferson et al report that 85.7% of the studies identified occurrence of victimization in diabetic people. An association between bullying and worse glycemic control was also observed, so type 1 diabetes is a limiting factor for socialization related to diabetes ([6]. In Egypt emotional problem of children and adolescents with type 1 diabetes were associated with a duration of diabetes ≥ 5 years, older child, male sex and low education of the mother [17].

In many countries, management of psychosocial issues is now part of the diabetes care [2]. In the DAWN2 [2] study, 63% of health professionals recognized the importance of increasing psychosocial support, 59% of them answered that they would like to receive more extensive training that would help them

to manage the psychosocial aspects of diabetes. Only 20% of them had received training in managing the psychological aspects of diabetes. It would be interesting for the project to organize at least once a year a consultation with the psychologist. Delamater et al, as well as Deborah Ellis et al, highlighted the fact to include psychologists and social workers, in the team [18,19].

The problems encountered in young people are factors that do not favor the equilibration of diabetes. Also, «children and young people with chronic poor metabolic control including recurrent diabetic ketoacidosis are more to have underlying psychosocial problem» [18]. Feldman et al. [20] find that the integration of psychological services into diabetes management can improve health outcomes, such as HbA1c, health-related quality of life and decrease health care expenditures. Young-Hyman et al. [21], report that «psychosocial care should be integrated with collaborative, patient-centered medical care and provided to all people with diabetes, with the goals of optimizing health outcomes and health-related quality of life». If our young people find it difficult to find jobs because of their disease, it is necessary to consider creating mini-companies for these patients who live with diabetes to give them jobs in these companies or to work independently. The most common reaction to the announcement of the diagnosis is discouragement, this can demotivate young people to properly take care of themselves and to consider plans for the future.

Conclusion

Young living with diabetes present social problems not taken into account in routine consultations. The total number of social problems among young people was 138 because many had several problems at the same time. So 44 young people presented four social problems at the same time. Distress was the most cited and very often discouragement at the announcement of the diagnosis.

Implications of this study is the necessity to include the psychological aspect in the medical visit, and to create revenue generating activities for young people.

The strength of this study is that this is the first in DR Congo and the rare in Africa to explore the social impact of diabetes in young.

The importance of this study for the research is to lead others studies in the family and the school.

The limitations of this study are the small size of the population and the absence of HbA1c.

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