

Women’s diabetes : Experiences and Challenges

مرض السكري لدى النساء: تجارب و معاناة

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Abstract:

Our study aims to understand the issues related to women's experiences, in the context of a chronic illness, in this case diabetes. It is essentially about showing all the complexity of the constraints they face and grasping from the inside, the representations and motivations that drive them. Adopting a comprehensive approach, our research posture attempted to question their social logics, through their discourse and their practices. To do this, we opted for the qualitative approach, through observation and semi-structured interviews. What emerges is the importance of the social dimension of diabetes, particularly through the social etiology of the "shock" as cause and consequence of the disease and the resulting impact, thus revealing the readjustments implemented in the face of vicissitudes of everyday.

Key-words: diabetes, women, experiences, challenges, social logics.

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Introduction :

Currently, chronic diseases are gaining increasing importance in societies where life expectancy continues to rise. They represent a crucial challenge not only from a scientific and medical standpoint but also from an economic and social perspective (Carricaburu, Ménoret, 2004).

Driven by socio-economic development and medical advancements, Algeria has been undergoing a health transition for nearly three decades. The decline in mortality rates has led to a dramatic decrease in fertility, resulting in a gradual aging of the population, accompanied by a significant reduction in infectious diseases and an increase in chronic pathologies (Ouchfoun et al., 1998).

These various diseases (cancer, cardiovascular diseases, diabetes, obesity), which cause 88% of deaths in industrialized countries, now reach 40% in emerging countries. The determinants of this type of pathology are identified. They are linked to individual lifestyles and behaviors, mainly related to changing dietary habits, including the transition from traditional to high saturated fat diets, and to sedentary lifestyles.

Among these chronic pathologies, diabetes emerges as one of the most significant causes of death worldwide. It is alarming and raises serious concerns among practitioners dealing with the disease. According to the latest global report on diabetes from the WHO, published in 2016, nearly 422 million people were already affected by this disease in 2014. This figure is all the more staggering given that it is expected to double by 2030. More than 63% of diabetics live in developing countries, where they were very rare just twenty years ago. 1.6 million deaths, 80% of them in low- and middle-income countries. The WHO estimates that the death rate from diabetes will rise by 50% over the next decade if urgent action is not taken. (WHO,2016).

Diabetes[†], a metabolic disorder, is characterized by chronic hyperglycemia (an increase in blood glucose levels). It results from a deficiency in insulin secretion (a hormone produced by the pancreas) or its action, or a combination of both abnormalities. It mainly presents in two forms:

1. Type 1 diabetes (or juvenile diabetes): It affects younger individuals and is characterized by insulin dependence. It has a higher frequency of comas and a faster onset of complications. Patients must adhere to a specific diet and undergo multiple daily insulin injections.

2. Type 2 diabetes (or Obesity and Type 2 Diabetes): It affects relatively elderly people and is non-insulin dependent, characterized by a generally slow progression of complications. A low-sugar diet and oral antidiabetic medications are recommended to balance blood glucose levels.

Diabetes is a global pandemic with serious consequences, including severe ophthalmological, cardiovascular and renal complications.

In Algeria, diabetes is the second most common morbid condition (8.78%) after hypertension (16.23%) (TAHINA, 2007). It is a real public health problem due to the financial impact related to its multiple expenses (insulin, test strips, examinations, etc.), its incurability, and the various challenges affecting both the affected child, his/her family, and potential complications (blindness, diabetic foot, renal complications, etc.).

Based on fieldwork conducted in Oran with diabetic women, we will focus here on the significance of diabetes as a social event that impacts the lives of the affected patients. To achieve this, we have adopted a qualitative approach. Our socio-anthropological standpoint,

[†] The term diabetes comes from the Greek diabêtês, which means "siphon", "to pass through", "because liquids do not remain in the body, but pass through it like a pipe through which they can flow" cited by A. Coussaert, health clothing, the case of insulin-dependent diabetes, medicine and anthropology, *Projections, Health in the future*, N°1, 1989/1990, 95-104.

rooted in alterity, aimed to convey the perspectives of the participants by exploring the quality of the discourses expressed during interviews. Indeed, working on the meaning people attribute to their actions, this form of empirical data collection allows us to understand the mechanisms and processes through which they find themselves in a given situation and how they strive to deal with it (Bertaux, 1997). It is based on individual, in-depth, repeated and long-term interviews (lasting between one and a half to two hours approximately) and careful observation of the various involved spaces. These two paired techniques seem most suitable to "capture the discourses and situations that provide access to the beliefs, representations, practices, and institutions that give meaning to a society" (Fassin, 1990).

The semi-directive interview technique, based on an interview guide, was most frequently used, although more directive interviews were also employed. Fieldwork is an ever-evolving experience, and no interview is the same as another. The constraints of the field require constant adaptation, while keeping the research objectives in mind.

We conducted interviews with a total corpus of about forty participants (women). This is by no means a representative sample, nonetheless, and as De Fainzang (1994) explains : "a given reality or situation does not need to be representative in the strict sense to be anthropologically relevant, and in this regard, the study of individual cases can teach us as much as that of multiple cases." Additionally, we aimed to diversify the ages and statuses of our interviewees to be closer to the richness and variety of social reality.

The analysis of the collected data revealed the extent of the emotion experienced upon receiving the diagnosis of diabetes, perceived as a disruption, a real tragedy. Our interviewees unanimously describe it as a shock, both at the announcement of the disease and regarding the presumed cause of its occurrence (loss of a loved one, family conflicts, concerns for children, etc.). Indeed, diabetes emerges as an unfortunate social event that irreversibly alters the lives of those affected and their surroundings. Furthermore, this phase

marking the diagnosis of the disease is only a prelude to a challenging and prolonged ordeal affecting the social life of the individual, marking an irreversible "biographical rupture" with what is commonly referred to as the "pre-diabetes" period.

Beyond the biological alterations (disease) of the pathology and the resulting psychological impacts (illness), diabetes becomes the principal point of a set of social interactions (sickness) that generate situations where it is difficult to ignore the preeminence of the social environment in which the sick person is immersed, primarily represented by the family network and neighborhood. It is interesting to note that, through the physical sufferings, very real in the biological sense, married diabetic women express this fear of losing their social status as mothers and caretakers (taking care of the husband, children, managing household chores, shopping outside, etc.). Some of them even referred to diabetes as a form of death, which could also be interpreted as the dread of losing certain social roles and therefore expressing a metaphorical social death.

On the other hand, among the younger individuals, we observed a form of self-stigmatization that sometimes transforms into a desire to isolate themselves, not wanting to see people, fearing being "unmasked" and thus "losing face." In fact, some of them told us that their reason for hiding their illnesses from others was not to seek "pity in the eyes of the people" and to avoid their malicious judgment.

1. The Onset of Diabetes: The Shock!!

Numerous sociological studies have delved into the consequences of chronic illnesses on both identity and biography (Carricaburu; Ménoret, 2004). The research of J. Corbin and A. Strauss (1987) is noteworthy for its contribution to sociological and anthropological analysis, moving away from psychological concepts such as adaptation or coping and

"unenclaving chronic illness from dominant medical interpretation" (Carricaburu; Ménoret, 2004). Their work, aligned with interactionist perspectives, provided critiques of Talcott Parsons' approach, demonstrating, among other things, that the patient's "role" is not simply to comply with medical prescriptions. The diagnosis announcement generates tensions and shapes the lives of those affected, requiring them to daily confront a long-term illness and adapt to it on an identity level and in various spheres of social life.

Despite the apparent simplification of diabetes treatment achieved through medical technological advancements (rapid glucose quantification, insulin type and dose selection, etc.), there are numerous considerations that the patient (and their family) must take into account and master: injection techniques, safety procedures in case of incidents, physical activity, dietary regimen, etc. Consequently, the diabetic individual is now primarily responsible for managing their illness. As Coussaert (1990) pointed out, they become "self-treating, decision-makers of a medicine they are not professionals in, managers of health they are no longer profane about." Through their extensive "career" with the disease, they acquire a skill set that can rival that of a general practitioner (Augé; Herzlich, 1994). Throughout his extensive ethnographic work based on in-situ observation of care activities, Strauss (1992) highlighted the patients' contribution to their care as an integral part of the division and organization of medical work. He also demonstrated that living with a chronic illness is not reducible to perceptions but involves actions taken by chronic patients to manage and shape their disease trajectory. He emphasized the need for the patient to engage in a "biographical work" to cope with the illness. His person-centered perspective addresses various dimensions of chronic illness management in daily life, including symptom control, time reorganization, dietary management, the role of the family, etc.

It is important to emphasize the social dimension of illness and its triple reality distinguished by Robinson (1986) through the concepts of illness, sickness, and disease. Beyond the organic imbalance and psychological experience, diabetes generates interactions

that create situations where it is challenging to ignore all the factors related to the social environment in which the patient is immersed. This environment is primarily represented by the family network and neighborhood, considered, as Janzen (1995) aptly put it, the "organizing group of therapy."

Our investigation has shown how diabetes is experienced as a disruption, a genuine tragedy. Our interviewees unanimously describe it as a shock, both at the announcement of the disease and regarding the presumed cause of its occurrence (loss of a loved one, family conflicts, concerns for children, etc.):

"It was a shock, learning the news, I thought my life was over; I believed diabetes only affected the elderly. But I knew about the complications related to the disease, especially the eyes and kidneys" (Amina, 25 years old, civil servant).

"After my sister's death, I didn't feel well until the day I fell into a coma. I couldn't see and hear. At the hospital, they did tests, and they told me that I had diabetes! Honestly, I didn't expect it; it was a shock! It's true that I was sick, but not to the point of having diabetes. My father had diabetes around the age of 50, and he died a few years later" (Saliha, 39 years old, homemaker).

Diabetes, which "will durably disrupt a person's adjustments" (Baszanger, 1995), forces the patient to forge a new identity. This is the case for Fatima, who decided, to the dismay of her parents, to interrupt her otherwise brilliant studies:

"I could no longer bear the fear of experiencing hypoglycemia outside. I wanted to escape people's gaze. I asked my father to dedicate a room just for me. That's where I spend the whole day reading, and it's also where I eat" (Fatima, 34 years old, single, housemaid).

It is interesting to see how Fatima expresses the sense of isolation she experiences. Her words strongly illustrate this "biographical disruption" (Carricaburu; Ménoret, 2004),

marking a rupture with the external social world of the patient but also within the family home itself.

The shock felt at the announcement of diabetes appears to be an expression of mourning for one's health, as diabetes, an incurable disease, signifies a loss of hope for potential cure. Moreover, the social representations of diabetic women clearly show that they do not think in terms of illness or chronicity; they assess their disease in relation to their social body and social environment, primarily constituted by the family network and neighborhood.

The interpretation that diabetic women make of their illness, expressing the need to assign non-organic causes to their "ailment," clearly demonstrates how the disease is apprehended as a "metaphor" and becomes a social construction. It also shows how the disease "becomes a bearer of meaning, a signifier whose meaning is the individual's relationship to the social order" (Augé; Herzlich, 1994). This autonomous conception of health and illness, independent and different from medical knowledge categories, explains the conflicts marking the doctor-patient relationship. While doctors are concerned with focusing on long-term prevention of the threat of complications, the diabetic patient "asks to live well in the present without constantly worrying about their health... (he/she) insist on the present, while the doctor is more concerned about the future" (Sinding, 2000). In this regard, it is crucial to move beyond the biological dimension of diabetes and delve into the social experience of those affected by it. Our study has revealed the extent of self-stigmatization among diabetic patients and how, in their daily lives, they develop tactics to shield themselves from the scrutiny of others.

2. Stigmatization and Social Status of Diabetes

The results of our research have shown how women with diabetes prefer to conceal their condition and ensure that it remains a secret that does not go beyond their immediate family circle: "When I was at school, I didn't want my friends to know I was sick. I would have

liked my teacher not to be informed, but my mother told her, and then my classmates found out. Even though they talked to me about the diet and what I shouldn't eat at the clinic and at home, I didn't take it seriously. As soon as I left school, I would go directly to buy sweets. When we're little, we love sweets, and prohibiting them like that is not easily accepted. Plus, I wanted to be like all the kids my age... It wasn't until around 19 years old that I really began to realize the gravity of my actions because I started to feel the complications..." (Zahia, 27 years old, unemployed).

Many studies on chronic illnesses have shown that it is the patients themselves who redefine the level of normality they want to achieve (Carricaburu; Ménoret, 2004):

"When I am invited to people's homes, I behave as normally as possible. I take a cake or two and increase the insulin dose. Even at work, no one knows. For my insulin, I inject myself in the bathroom, and it's better that way!" (Amina, 25 years old, university student).

This normality does not appear as a fixed state but is negotiated through social interactions and the various situations that diabetic women face (Carricaburu; Ménoret, 2004).

Saliha, 45 years old, has been diabetic for 5 years and has 5 children. During her daughter's wedding, she had to spend the night away from home. She refrained from taking her insulin injections and ate "like everyone else." Let's see what she says to justify her behavior:

"I went to the south for my daughter's wedding, and I stayed for 2 days without taking my insulin. Even though I had brought my insulin with me – my husband insisted that I take it and even checked my bag when we left – I didn't want to do it in front of people, you know how people are... Besides, I couldn't find a place to do it away from prying eyes. I didn't want people to feel sorry for me and hear them say, 'poor thing, she's sick.' So, I left it in my bag and came back with it, but I suffered afterward. You also know why I didn't want to take the

injection – well, because what if something happened now? I was also afraid of losing consciousness and disrupting the wedding. Moreover, who would take me to the hospital? How would I manage in that case? I won't hide from you that I also thought about my married daughter and my other daughters. Everyone knows now that diabetes is hereditary; I don't want anyone to insinuate anything to my newly-married daughter. I also don't want to jeopardize the marriage prospects of my other daughters; I prefer all of this to remain a secret" (Saliha, 39 years old, homemaker).

Saliha clearly expresses the "reasons" or social considerations she puts forward to justify her behavior. The discretion with which diabetics surround their illness also reveals how the onset of diabetes symbolizes a rupture with their social world. This fear of rupture forces Djamila to hide her disease to maximize her chances of finding a husband:

"Except for my family, meaning my sisters, no one knows that I have diabetes. I don't socialize with people; I don't visit neighbors. None of them is aware of my illness, not my cousins, nobody, just my sisters. I don't like to disclose my secrets. People talk too much. I don't want them to know; they will start saying, she has this, she has that, she did this, she did that. I want none of that. When I meet people, I talk to them as normally as possible, as if I have nothing. I tell them I'm fine, thank God, and that's it. I don't want people to be aware of my illness; I don't want to talk about it. Moreover, if someone comes to propose marriage, I don't want him to know that I have diabetes. If we get along and get married, I'll wait some time, then I'll tell him that the doctor just told me I have diabetes. I know very well that if people found out I have diabetes, no one will want to marry me. Who would take a sick woman as a wife? Anyway, it's my illness, and I'm the one affected by it; it concerns only me. I don't see why I should talk to others about it!" (Djamila, 51 years old, unmarried).

Djamila also mentions an episode where, invited to her cousins' house, she couldn't refuse freshly picked figs. Sensing her blood sugar rising, she preferred to go home, even though she had difficulty walking and recognizing the way: "I preferred to go home for fear

of my illness being discovered. When I left my cousins' house, I was lost; I had to ask people for directions because my blood sugar was high. When I got home, you know what I did? I added a tablet; I took one more tablet! In fact, I won't hide it from you, every time I eat things like that, I add an extra tablet. The doctor never told me, I add it on my own, and I never tell the doctor!" (Djamila).

The above examples clearly illustrate the performative work that diabetics engage in to shield themselves from the gaze of others and thus preserve their "face." This "face" represents a positive and sacred social value that diabetics claim through their conduct and ensures the respect they receive (Goffman, 1967). They also demonstrate how diabetics rely on "other criteria for evaluation, often far from expert knowledge, linked to daily life, their proximity to the object, their knowledge of the environment, and the more or less accurate assessment of their personal abilities" (Le Breton, 1995).

This staging work that diabetic patients carry out towards others clearly shows that "the main activity of chronic patients is not only to stay alive or control their symptoms," as advocated by the medical perspective, "but also to live as normally as possible, despite the symptoms and the disease" (Strauss et al., 1975). This leads us to the question of the double autonomy of sick individuals, the first being the autonomy "conquered over medicine" that transforms the patient into a "self-healer," considered by sociologists Herzlich and Pierret as the one who "through his conduct, asserts his right to speak specifically about his sick body and proclaims the effectiveness of autonomous management of his condition." The second autonomy opposes the first and relates to various dimensions of social life, such as relationships with others, work, leisure, etc. (Herzlich; Pierret, 1984). In this regard, the interviewed patients expressed their struggles with powerful words that vividly highlight the emotional dimension of their biographical impact.

3- Pain and Emotions

Diabetes, as an unfortunate event that irreversibly alters the individual lives of those affected, is strongly expressed in the statements of the interviewed women. Fatiha illustrates this well when she describes the insidious and profound transformations that have affected her body:

"This diabetes (had lehloua) touched my eyes, my knees, I walk, and I am tired, sometimes I fall..." And she adds: "Look at the state I'm in... Do you see what state!... The state of diabetes... Diabetes is an enemy, 'el hlewa âdouwa,' it's something we wish upon our enemies, those who don't utter the 'shahada,' who don't say 'la ilaha ila lah' (Fatiha, 60 years old, widow, retired).

As for Nacera, she describes the difference between her current state and when she didn't have diabetes. The changes emphasize social considerations related to her daily life. She particularly emphasizes the difficulties she faces when climbing stairs:

"Before having diabetes, I was fine, I didn't suffer from anything. I went out, I came back as normally as possible. Now it's different, when I go down the stairs leaving my house, I think, how will I manage to climb them back when I return. I have to stop to rest each time. I'm all soaked in sweat; it's as if someone poured cold water on me or as if I took a cold shower. I feel like I'm going to die ('el mout tegdabni'). Diabetes makes a person extremely tired ('ifechel besef'), it kills. Yet my blood sugar is only at 2 g; I wonder how I would be if my blood sugar reached 3, 4, 5 g like my mother." (Nacera, 43 years old, homemaker).

Conclusion

Our study aimed to decipher and unveil the logic of diabetic women, fundamentally influenced by the family and socio-cultural context. The interpretations they develop are based on their own representations of the situation. They take initiatives by making decisions based on the evaluation of the meaning they attribute to their illness and the possibilities offered to them. Thus, the social dimension of diabetes among affected women becomes evident through the disruptions that affect their daily lives following its diagnosis.

Their daily experiences reveal significant suffering and loneliness, sometimes leading them to social isolation to escape the scrutiny of others. The shock as a cause and/or reaction to its occurrence strongly expresses this challenging ordeal, to the extent that some of them do not hesitate to label their illness as an "enemy" or "death."

By exploring the experiences of these women with their illness, they have demonstrated undoubtedly unequal capacities for managing their condition. Nevertheless, they emerge as active participants, highlighting ways to distance themselves from the social situations they encounter. These diabetics allow themselves deviations from medical prescriptions. This "non-compliance," labeled as "irrational" behavior by the medical discourse, appears as a pursuit of autonomy. They prefer to be in a logic of symptom control rather than disease control, living their daily lives normally despite the symptoms that affect them.

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