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Management of Diabetes in Adolescents at the Abidjan Diabetes Centre (CADA) : *Social Roles, Medical and Social Constraints, and Non-Adherence to Treatment*

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ABSTRACT : This research reveals a contradiction. Despite the existence of institutional mechanisms for diabetes care in Côte d'Ivoire (specialised centres, therapeutic education, relative accessibility of insulin), diabetic adolescents monitored at the Abidjan Diabetes Centre (CADA) remain unbalanced and frequently interrupt their therapeutic follow-up. From a sociological perspective, the study seeks to understand the social processes that account for non-compliance with prescribed social roles in the daily management of the disease. It is based on a qualitative analysis conducted in Abidjan among diabetic adolescents aged 10 to 21, their parents and health professionals, using observations, interviews and documentary analysis. The results show that non-adherence to treatment is not simply a matter of ignorance of the treatment or lack of personal initiative, but rather the intertwining of cognitive, economic, institutional, social and temporal constraints. These constraints undermine the coordination of those involved in care and make it a social construct, shaped by living conditions, interactions and the organisation of roles between adolescents, families and caregivers.

KEYWORDS : Non-adherence to treatment, therapeutic non-compliance, diabetic adolescents

1. INTRODUCTION

Diabetes is now considered a major public health problem, affecting 537 million adults, or 10.5% of the global population (IDF, 2021). In Africa, the increase is also significant: 24 million people are living with the disease and 55 million will be affected by 2045, according to forecasts (WHO, 2022). The situation is considered all the more significant given that over the last decade, the incidence of type 1 diabetes has increased significantly among children and adolescents, revealing a phenomenon that now affects young people. However, the transition to adolescence is precisely a time in life when individuals tend towards autonomy and assert themselves as normal in their relationships and bodies, while having to cope with regulated therapeutic prescriptions.

In Côte d'Ivoire, despite real progress since 2012, the emergence of competent centres, training for healthcare professionals and a reduction in the cost of insulin, diabetes has remained endemic, mainly type 2, with an estimated prevalence rate of between 4.9 and 10%. Nevertheless, for type 1 diabetes, although it is considered to be relatively rare, the daily care of younger generations by households with generally low purchasing power is particularly problematic due to the complexity of insulin therapy. The exploratory survey conducted at the Abidjan Anti-Diabetes Centre (CADA) highlights, on the one hand, persistent glycaemic imbalances and, on the other hand, frequent interruptions in treatment.

These findings invite us to shift our focus from the biomedical dimension alone to an understanding of situated practices, where diabetes management is not reduced to adherence or non-adherence to prescriptions, but is constructed in contexts of concrete actions, available resources and continuous adjustments between medical requirements and adolescent lifestyles.

The experience of adolescent diabetes thus plays out between several modes of action: the mode of medical discipline, with its requirement for blood sugar monitoring and regular injections; and the mode of maintaining a normal routine within the peer group, where the disease is expressed as a distancing from the adolescent social circle. It is therefore not simply a matter of managing diabetes through biomedical knowledge, but of organising the sharing of roles, the distribution of responsibilities and practical arrangements between adolescents, parents and carers, each trying to cope with inextricable situations of unequally shared constraints and demands.

In such a context, how can we understand that, despite the implementation of specialised diabetes care systems in Côte d'Ivoire, including dedicated centres, training for caregivers, and reduced insulin costs, and despite the transmission of biomedical knowledge to adolescents, we observe both persistent glycaemic imbalances and frequent interruptions in treatment at the CADA ?

The issue of diabetic adolescents' inability to fulfil their role in the division of medical labour is a continuation of analyses of the socialisation processes associated with chronic illness and requires an assessment of the available knowledge on the subject. In this regard, Jacquin (2017) shows that chronic illness conflicts with the developmental needs of adolescence, and that medical management at this stage of life is difficult. He also adds that insulin-dependent diabetes is a good example of the contradictions that exist between therapeutic constraints and what characterises adolescents : the need to feel normal, like others, the rejection of frustration and the importance of the present moment, the need to break free from the constraints of childhood, and the difficulty of thinking in terms of long-term prevention. Furthermore, Massol (2007) asserts that the family functions as a system governed by its own laws, which define each person's place and the interactions between members, in a spirit of mutual support. Illness disrupts this family system and upsets the balance. A new equilibrium must be found, which depends on each family's ability to adapt to change. When the family system is flexible and open, it is conducive to helping the patient and their loved ones adapt to the illness, in particular by allowing them to talk freely and share emotions that are often difficult and painful. On the subject of social roles, Sarradon (2002) asserts that the doctor-patient encounter is a place of social mediation. In the same vein, Fanny (2014) also emphasises the caregiver-patient relationship. The author discusses the caregiver-patient relationship in the education process, highlighting the characteristics of good collaboration between caregiver and patient. However, type 1 diabetes in adolescents is a demanding chronic disease that requires rigorous daily management. This management relies not only on medical discipline, but also on a social organisation based on the distribution of roles among the various actors involved. These actors include diabetic adolescents, their parents and health professionals. In principle, each actor in the process of managing diabetes in adolescents is assigned behaviours called roles, obligations or responsibilities in the management process. In view of this observation, it appears that despite the therapeutic education received and the autonomy acquired in managing their disease, diabetic adolescents do not adhere properly to their treatment.

In summary, type 1 diabetes in adolescence creates tension between therapeutic requirements (daily injections, blood sugar monitoring, dietary control, etc.) and the expectations of this formative period, namely autonomy, normality and integration among peers. Care is therefore not solely a medical issue, but involves a network of relationships between the adolescent, their family and their carers, each with specific responsibilities. Continuity of care depends on the joint ability to coordinate, adapt the family environment and use social and communication resources to facilitate the management of the disease.

This study therefore aims to understand how diabetic adolescents take ownership of their daily treatment, how responsibilities are shared between them, their families and healthcare professionals, and what dynamics promote or hinder therapeutic continuity.

In light of the literature, it appears that the management of diabetes in children and adolescents cannot be reduced to a strictly biomedical approach, but rather involves both relational and organisational issues involving several actors. The management of the disease takes place within a framework of coordination between adolescents, parents and caregivers, where each has a distinct role that determines adherence to treatment and the quality of follow-up. Analysing this social dynamic involves finding an analytical framework that can account for the place, expectations and responsibilities of each of the actors. It is in this sense that social role theory should be used.

Social role theory, articulated by Goffman from an interactionist perspective and Parsons from a functionalist perspective, is a conceptual reference that is well suited to this study. For Goffman (1973), everyday interactions take place in "roles" that individuals play according to the situation they are experiencing and the social rules to which they are subject. The chronic nature of a disease such as diabetes then appears as a new vector of social identity, that of a sick adolescent to be managed, a parent providing support, and a caregiver ensuring therapeutic follow-up. Goffman thus describes the ability of actors to modulate their behaviour and the effects of meaning by playing with the gaze of others, with the implicit norms and expectations that weigh on them. This reading thus allows us to finely identify the micro-dynamics of relationships within the care process.

In a complementary approach, Parsons (1951) defines role as a set of normative expectations assigned to the individual on a social level, based on the imperatives of social system equilibrium. In the situation explored, the role of the healthcare professional is focused on diagnosis and therapeutic education, while the parent must provide moral support and pay for daily expenses, and the adolescent must ensure self-management and adherence to treatment. The functionalist framework thus allows us to analyse how the coordination (or disjunction) of these roles is a source of success or fragility in the therapeutic process.

These two interrelated interpretations of social roles provide an overview :

- The interactionist approach allows us to understand the negotiations, tensions and strategies in real-life situations ;
- The functionalist approach helps to measure the organisation and complementarity of expected roles.

This dual theoretical perspective thus makes it possible to explore how diabetic adolescents and their parents construct their practices, position themselves with regard to medical and social obligations, and how healthcare professionals regulate these interactions during treatment.

2. METHODOLOGY

This research was conducted in the Autonomous District of Abidjan, which is not only the economic capital of the country, but also the main urban centre of Côte d'Ivoire. This district comprises thirteen (13) municipalities, including ten (10) urban municipalities and three (03) sub-prefectures, and is home to more than five million inhabitants (Diby, 2015). Indeed, the high population density and the presence of several anti-diabetes centres in the city, as well as the high rate of children and adolescents with diabetes receiving treatment, make it a suitable location for observing and analysing the phenomenon.

The target audience consists of 37 keys players involved in the management of paediatric diabetes, namely, a CADA manager at the INSP (1), paediatric doctors (2), nurses (2), nursing assistants (2), parents of diabetic children (15) and adolescents living with diabetes (15). Recruitment was carried out using purposive sampling (Quivy & Van Campenhoudt, 1995) in order to select participants with direct experience of the disease, thereby ensuring the quality and richness of the information to be collected.

Three data collection techniques were used in combination to ensure the richness of the information gathered :

- The first consisted of direct observation within healthcare centres based on the interaction situations set up ;
- The second is documentary research, drawing on medical documents (reports) as well as institutional texts and scientific and academic works ;
- The third is semi-structured interviews with identified stakeholders, allowing them to freely express their perceptions and experiences within the context being analysed.

The data is then analysed using thematic content analysis, including coding interview transcripts and identifying units of meaning, which are then grouped into thematic categories in line with the research objectives. A triangulation of information sources (interviews, observations, documents) is implemented to ensure the accuracy, consistency and credibility of the results. This methodological process led to three analytical categories: (1) social perceptions and beliefs of adolescents and their parents about diabetes, (2) experiences of the disease through social interactions and medico-social constraints that prevent social roles from being fulfilled in the management of the disease.

3. RESULTS

Analysis of the collected data shows that the "failure" of diabetic adolescents and their parents to fulfil the social roles expected of them in the management of the disease is not solely due to a lack of will or a total ignorance of medical prescriptions. Rather, it is part of a unique and complex combination of representations, interactional dynamics and medical and social constraints that make it difficult, even fragile, to fulfil the roles of patient, parent and caregiver. These results are presented in three areas in accordance with social role theory.

3.1. Social perceptions and beliefs of adolescents and their parents about diabetes

We observe that representations of diabetes have a major impact on decisions to adhere to prescribed medical behaviours. The adolescents in our survey present diabetes as much more than a biological condition, but as an activity in its own right, one that takes time, must be organised, requires energy and is the subject of almost constant self-management efforts. Treatment is not without reference to a kind of demanding daily "work", with injections following injections, repeated blood sugar tests, and diets that must be strictly adhered to. Curiously, the difficulty of the therapeutic protocol is highlighted by some participants in the survey:

"The doctor says to take three (3) injections, but at lunchtime I often skip it. (...) It's complicated, it's a lot of work that's asked of me. (...).", Olive, 15 years old

"Actually, getting the pen (insulin pen) to inject myself is a big problem. (...) I only do it when I feel my blood sugar has risen." Josiane, 14 years old

These comments suggest that the role of patient is anything but straightforward ; it requires a certain amount of self-organisation and mental and physical availability that adolescents find burdensome. For Goffman, this is referred to as the "work of the patient": it involves continuously playing a role in which the individual must comply with strict medical expectations at the risk of being labelled "non-compliant" or "negligent".

For parents, diabetes is seen as a material, physical and emotional burden on the family, with the disease being perceived as a "weight" to bear, particularly for mothers, who are often on the front line of care :

"Diabetes is a disease to be afraid of. It's a disease that's really not good at all, but what can we do ? It's tiring for parents, and it's me and his dad who take care of him, and it's become a burden for us, but what can we do ? He's our child, you have to watch him every day, if he has an episode you have to take care of him all the time, it's not easy." Parent of a sick child, stay-at-home mother (child Diaby, 19 years old)

In this situation, parents, who are supposed to play a key role in the care system to which the adolescent is subject (monitoring, supporting, supervising practices), often face fatigue, multiple burdens and reduced or limited resources. From a personal perspective, we can already see the tension between the prescribed role (the attentive, supportive parent) and the role actually played, which is either partially fulfilled or compromised.

Negative perceptions of treatment reinforce this tension. Adolescents report both the difficulty of care and undesirable side effects :

"(...) the insulin injections I was taking didn't suit me ; they gave me boils. Until now, my body has rejected insulin (...).", Nathalie, 16

"*Often, you don't feel like doing the injections because when you're done, the area where you pricked it either swells up or becomes hard and then itches. But when you scratch it, it becomes sore. (...)",* Alain, 17 years old

Although they are subject to constraints, some adolescents express a sense of responsibility that shows that they are becoming aware of and accepting of their role as patients, even if these processes are unevenly engaged. Responsibility is acquired through the management of emotions, the adoption of a healthy lifestyle (physical activity, stress management) and compliance with hygiene and dietary rules. The interview excerpts below illustrate this :

"Yes, yes, I manage it well because there are emotions, and if you can't control them, they can come back. That's why I don't like to get upset very often. There are conversations we have with friends that I don't like, so I avoid them." Diaby, 19
"I know that to manage diabetes better, you have to do physical activities, including sports, which help regulate your blood sugar levels. It's also important not to eat too little or not to be too hungry, to have a healthy lifestyle and to follow your treatment on time. That's all." Silué, 18 years old

Finally, diet is also a fundamental aspect of managing the disease. Medical prescriptions are often at odds with household eating habits or adolescents' preferences. Some adolescents even admit to eating large portions, as shown in the following interview excerpt :

"When they told me I had diabetes, it didn't affect me because I didn't know anything about the disease, but over time it started to hurt me. It's really not easy, especially when it comes to food, because I couldn't eat anything I wanted anymore." Béatrice, *19* years old

Overall, the data collected shows that adolescents' and parents' perceptions of diabetes oscillate between mastering the constraints of treatment and managing the difficulties of implementing it on a daily basis, both in terms of the system put in place to treat the disease and the treatment itself. These perceptions are central to how each individual organises themselves to cope with the treatment and partly determine what is respected in terms of therapeutic compliance.
However, these representations do not emerge independently. They are cultivated and mature in a relational context of transactions, trust, adaptations and, to some extent, disinvestment on the part of all stakeholders involved. This is what we aim to highlight in our analysis of the experience of the disease by focusing on social interactions around diabetes care in adolescents.

3.2. Experiencing the disease through social interactions

Analysis of the experiences of diabetic adolescents shows that the social interactions surrounding the disease are one of the key dimensions of how they "manage" or "invest" in their treatment. In principle, the organisation of care is based on coordinated interactions between several actors (the adolescent, their parents and caregivers), who are themselves, in principle, partners, each with a specific social role : the young person as the 'diligent patient', the parents as 'supervisors' and the professionals as 'experts who explain' the disease. However, the data collected indicate that these roles are often difficult for each of the partners to fulfil. One of the consequences of this mutual responsibility not being fully or partially assumed is that it affects the continuity of treatment. The first factor concerns family support, which several adolescents consider insufficient or non-existent, with some reporting that they feel they are solely responsible for tasks related to their care, excusing reminders, help and encouragement at home. This is reflected in the following excerpt from an interview with Leila :
"At home, everyone has their own problems and everyone goes about their business. So, to say that they're going to ask me if I took my injection in the morning or at noon or in the evening, I don't know if anyone cares. It's rare that anyone asks me if I still have insulin." Leila, 16 years old
Similarly, another teenager emphasises the independent management he has gradually adopted :

"For quite some time now, I've been taking care of my own health. I manage on my own, so I buy my own insulin and everything else. My parents aren't really involved in that." Patrice, 19 years old

A second aspect relates to diet and physical activity. In some households, meals are still eaten as a family and are not differentiated according to medical recommendations :

"It's a family meal, there's no diet in my house." Diane, 15 years old
Or :
"I eat like everyone else ; we have a normal meal for everyone," Béatrice, 19 years old

Similarly, physical activity is not always integrated as part of the treatment, as Ange, 18, points out :
"I can say that my parents aren't too interested in that. Whether I do it or not, in any case, it's not their problem." Ange 18 years old
These analyses indicate that the management of the disease takes place within the family environment, where daily practices, particularly in terms of diet, physical activity and organisation, do not always correspond to therapeutic prescriptions. In such a context, adolescents must adjust their behaviour, taking into account both the treatment recommendations and the habits of their social environment, a situation that influences the way in which they organise the management of their disease.
This configuration highlights the issue that diabetes management is determined both by the availability of resources in the adolescent's immediate environment and by the adjustments they must make on a daily basis. However, in addition to family and relationship factors, there are also material, organisational and informational factors that determine the degree of treatment adherence. Consequently, the analysis addresses the issue of medico-social pressures that specifically hinder adolescents from fulfilling the roles expected of them in managing their diabetes.

3.3. The various medical and social constraints that lead to non-compliance with social roles in disease management

Interpretation of the interview data reveals a significant gap between adolescents' stated knowledge of diabetes and their actual ability to rigorously manage their lifestyle and dietary treatment. Although some adolescents claim to be competent in managing their disease, most of them are unable to comply with therapeutic constraints in the long term. This is due to a lack of external (financial, material) and internal (practical skills, knowledge, self-management abilities) resources necessary to implement treatment.
The comments collected highlight the cost of the diet as a determining factor in non-compliance with treatment. The recommended diet, based on vegetables, cereals, fruit, sugar and diet oil, is expensive and difficult for adolescents and their families to afford. This economic constraint is evident in the comments made by those surveyed :

"When you're diabetic, you need at least £100 a day for breakfast," Fabrice, 17
"If you really want to stick to your diet, organic oil, diet sugar and other things can cost 60,000 or 70,000 francs a month," Paul, 21
"If you want to follow your diet properly, it's no less than 150,000-200,000 per month." Josiane, 15 years old

These figures reflect a mismatch between medical prescriptions and households' actual financial means, making diabetic adolescents vulnerable to treatment. As a result, non-compliance with dietary and lifestyle recommendations seems to be less a matter of individual choice than of structural medical and social constraints, which prevent these adolescents from fully exercising their social role as responsible patients in the management of their disease. Cheick, 17, says:

"Actually, when it comes to diet, it's a bit complicated. When I was first diagnosed, we went to the hospital there and they explained a little bit about how we should eat. They told us not to eat this, not to eat that. We understand, but in practice it's difficult to do because you have to eat breakfast, lunch and dinner, and often you have to eat snacks too. So they don't explain to us properly what we can eat from morning to night, for example, and how what we eat can raise or lower our blood sugar levels. We want to understand a little bit about how it works." Cheick, 17 years old

Through this verbatim quote, the study reveals that diabetes management in adolescents is compromised by a lack of knowledge about meal composition and how to adapt meals to different times of the day, which is crucial for blood sugar balance. Added to this are major socio-economic constraints, particularly the cost of blood glucose self-monitoring, which is difficult for families to bear. These financial and cognitive constraints impact the regularity of medical follow-up and therapeutic compliance. Thus, diabetes control seems less a matter of individual will than the result of medical and social constraints that compromise the continuity and effectiveness of care:

"It's often not easy because when you're diabetic, you take insulin at 7 or 6 a.m., and 15 or 30 minutes later you have to eat; you eat at 11 a.m., you eat at 4 p.m. (...). Well, often you have classes from 9 a.m. to 3 p.m., and you don't know how you're going to manage. So often, I don't take my insulin and then I leave," Alain, 17 years old
"In any case, I can't follow the treatment properly because my hospital appointments are on Mondays, and most Mondays we have homework. When I miss assignments like that, I get detention, and often the teacher won't let me skip it. That discourages me because when I want to justify myself, I have nothing to do it with, and then I don't make up for it. (...) So that means I don't keep my appointments." Nathalie, 16 years old

The data analysed in this section on the medical and social constraints of non-adherence to treatment among adolescents with diabetes show that these constraints affect all aspects of treatment adherence. The results first revealed a lack of control over the disease and its management by adolescents.

The analysis then identified the factors explaining this lack of control. According to the respondents, non-adherence to insulin treatment is due to a lack of knowledge about the treatment and the high cost of medication. Similarly, non-adherence to lifestyle and dietary measures is associated with a lack of knowledge about diet and the cost of the diet.

Thus, whether in terms of medication or lifestyle and dietary measures, non-adherence to treatment appears to be the result of cognitive and economic constraints that hinder the ability of adolescents with diabetes to manage their disease properly and sustainably.

4. DISCUSSION

The results of this research highlight a number of significant social factors, which can be discussed in detail on the basis of the theories used.

First, chronic glycaemic imbalances and interruptions in treatment, despite the existence of institutional care systems, reflect a breakdown in expected social roles. This result is consistent with Parsons' functionalist analysis (1951), according to which the proper functioning of a social system depends on the complementarity of roles. In adolescent diabetes, the inability of adolescents, parents and caregivers to assume their respective roles destabilises the therapeutic system and jeopardises the continuity of care.

Secondly, the study reveals that non-adherence to treatment is not a question of individual will, but of cognitive and economic constraints that hinder the appropriation of treatment. This finding is consistent with Goffman's (1973) approach, according to which chronic illness requires "work on the part of the patient" that demands skills, time and resources. When these conditions are not met, the role of patient becomes unbearable on a daily basis.

Thirdly, the results highlight the role of family and economic constraints in the management of the disease. This finding is consistent with the work of Massol (2007), who demonstrates that chronic illness destabilises family organisation and requires a reorganisation of roles, which is often undermined when resources are limited.

Finally, conflicts between medical imperatives and adolescent norms (school, relationships) corroborate Jacquin's (2017) analyses, according to which chronic illness is at odds with the developmental needs of adolescence. Thus, deviance appears to be a social construct, resulting from the interplay between structural constraints, family dynamics and identity negotiations.

Therapeutic non-compliance is therefore a social construct, the product of the interplay between structural constraints, family dynamics and everyday interactions. From a sociological perspective, this analytical reading invites us to move beyond approaches focused on the injunction to individual commitment in favour of care systems that are more sensitive to social contexts, the specific temporalities of adolescence and the actual material and relational capacities of families, which condition the sustainable and socially situated appropriation of treatment.

CONCLUSION

This sociological research helps us understand that non-compliance with social roles in diabetes management among adolescents cannot be attributed to isolated individual initiatives. The results highlight three key elements. On the one hand, the cognitive dimension seems to be predominant, as partial appropriation of practical knowledge hinders adolescents' ability to sustainably integrate therapeutic prescriptions into their daily lives. Furthermore, the study highlights the often fragile involvement of the family, with varying degrees of attention to treatment, limiting the support and regulation expected in the domestic organisation of the disease. Finally, institutional dysfunctions (dissatisfaction with the reception and waiting times in healthcare facilities) contribute to the distancing of the caregiver-patient relationship and the breakdown of medical follow-up.

Taken together, these factors reveal that diabetes management in adolescence occurs in a context of social tension, where the identities of patient, parent and caregiver are negotiated. The study thus shows that the social roles involved in diabetes management are the result of processes of stigma management, renegotiation of family balances and institutional accommodations, revealing adolescent diabetes management to be a socially constructed reality.

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