

# Therapeutic non-compliance among people with beta thalassemia in Côte d'Ivoire

Lhaur-Yaigaiba Annette OUATTARA<sup>1,2</sup>

<sup>1</sup>Nangui ABROGOUA University, Côte d'Ivoire.

<sup>2</sup>Swiss Center for Scientific Research, Cote d'Ivoire.

Accepted 27 July, 2023

---

## ABSTRACT

Thalassemias are genetic diseases, an inherited blood disorder which is characterized by a defect in the production of hemoglobin. These diseases result in a decrease in the quantity or size of red cells. There are two types: alpha and beta-thalassemia. The most severe forms are manifested by chronic anemia which can lead to death without proper treatment. Many research works recognize that therapeutic compliance, especially among people with chronic disease, is mandatory for better management of the disease. However, very few studies shed light on the impact of the latter on hemoglobinopathies. This article is a preliminary study which aims to identify the factors observed in patients with beta-thalassemia. Starting from a qualitative approach, nine people were subjected to semi-structured interviews on their experience and perception of the management of beta-thalassemia by the nursing staff. The results obtained made it possible to identify on the one hand three factors of non-compliance which are: the quality of the doctor-patient relationship, the chronicity of the disease and the reliability of care, and the interactions between these factors and the efficient management of their health.

**Keywords:** Beta-thalassemia, therapeutic noncompliance, therapeutic alliance, Côte d'Ivoire.

---

E-mail: [annetteouattara@yahoo.fr](mailto:annetteouattara@yahoo.fr).

---

## INTRODUCTION

Beta-thalassemia (or beta thalassemia) is a genetic disorder of hemoglobin<sup>1</sup> hereditary transmission. It exists in three forms of varying severity: beta thalassemia major (Cooley anemia), beta thalassemia intermediate, and beta thalassemia minor (Cao and Galanello, 2010; Ali et al., 2021). Some shapes lead to minor symptoms, including beta thalassemia minor (Galanello and Origa, 2010; Bonello-Palota et al., 2016; Barouni et al., 2017), while others, on the other hand (beta-thalassemia major and intermediate), can be a source of handicap that is most often invisible<sup>2</sup> or endanger the lives of those affected. According to the Federation of Sickle Cell and Thalassemia Disease<sup>3</sup>, the symptomatic manifestations of beta-thalassemia are characterized by anemia<sup>4</sup>, which leads to pallor, profound fatigue, occasional dizziness,

and shortness of breath. This chronic disease is accompanied by various complications, such as growth problems, bone deformities, hepatomegaly, splenomegaly, cholecystitis, and heart problems (Galanello and Origa, 2010). These complications lead to social repercussions structured around the disease's manifestations.

In people with beta-thalassemia, one of the findings is that the constraints related to blood transfusions, the tendency to get tired more quickly than others and/or the feeling of recurrent weakness requires planning in schooling or professional life since these symptoms impact the existential daily life of patients. The chronicity of the disease and its various complications require long-term multidisciplinary care and permanent medical monitoring. Unfortunately, patients often fail to adhere to this regimen for reasons this article will attempt to shed light on.

Thus, individuals with beta-thalassemia must cope with the demands of managing their health while continuing to engage in social activities inherent to normal life (Lubkin

---

<sup>1</sup>Substance in red blood cells that helps carry oxygen through the body.

<sup>2</sup>Orphanet General Public Encyclopedia:

<http://www.orpha.net/data/patho/Pub/fr/BetaThalassemie-FRfrPub51v01.pdf>

<sup>3</sup>SOS GLOBI-Federation of sickle cell and thalassemia diseases,

<https://sosglobi.fr/thalassemie/>

<sup>4</sup>Lack of red blood cells and hemoglobin.

and Parsen, 1990; Loisselle and Michaud, 2008). The individual with beta-thalassemia is obligated to scrupulously adhere to their treatment. This commitment should guide them in making decisions and taking actions related to their diet, medication, social and family activities, and most importantly, monitoring their state of health (Bodenheimer et al., 2002). To date, hematopoietic stem cell transplantation is the only treatment that offers a complete cure for beta-thalassemia, but it is not feasible for all affected patients. Faced with this observation, several initiatives and research have been undertaken to improve the quality of care and management of these diseases. Among them is the establishment of international associations and federations dedicated to fighting against thalassemia. So, the importance of therapeutic adherence within the framework of this chronic disease becomes evident. Following this logic, Dr. Derek Yach<sup>5</sup> asserts that “poor compliance is the main reason why patients do not receive the full benefits they might expect from their medications. It leads to medical and psychosocial complications, reduces the patients' quality of life, increases the likelihood of developing drug resistance, and wastes resources. All in all, these direct consequences hinder health systems around the world from achieving their health goals”.

In Ivory Coast, according to available data and references cited in recent research on beta-thalassemia, its frequency varies between 2.3 to 11% depending on the region (Cabannes et al. 1971, 1977; Cabannes, 1987). Additionally, beta thalassemia represents approximately 3.26% of hemoglobinopathies in children in Côte d'Ivoire (Bassimbié et al. 1988). Given the age of the data, which are still used as references (1971, 1977, 1987, 1988), it is important to note that beta thalassemia is not frequently studied, unlike sickle cell disease (which is also a hemoglobinopathy). As an example of more recent studies on beta-thalassemia using the references cited above, we can mention the study by Segbena et al. (1997), Tolo et al. (2012), and Bassimbié et al. (2020), among others. This reality leads us to question the quality of care, both from the patient and the health professionals. This article registers as part of a pilot study that has a dual objective: firstly, to analyze the interactions between the patient and the doctor within the framework of medical follow-up and therapeutic treatment, and secondly, to make recommendations to improve the care. To achieve long-term success in sensitizing public authorities to the importance of a national program to fight against beta-thalassemia, as well as to establish a sustainable and effective care model, the field of social sciences, particularly sociology, can play a crucial role. Analyzing the patient's experience of this disease is essential in developing the underlying principles that promote patients' adherence to the care mechanisms recommended by health professionals.

<sup>5</sup>Executive Director, Noncommunicable Diseases and Mental Health (WHO).

## METHODOLOGY

Our work is a descriptive study of patients with beta-thalassemia who were monitored at the University Hospitals of Cocody and Treichville (Abidjan, Ivory Coast). The surveys were conducted from March 2022 to September 2022 with patients having beta-thalassemia.

Following this pilot study, a larger survey will be conducted among patients, parents, patient associations, and health professionals throughout Côte d'Ivoire.

### Study population

As part of this survey, the people questioned were patients diagnosed with beta-thalassemia who were attending one of the hospitals identified as part of this study.

### Inclusion criteria

- Patients with thalassemia syndrome
- Be 18 years of age or older
- Attending the University Hospital Center for more than a year
- Informed consent

### Data collection technique

Survey participants were identified during their consultation in the hematology department at various study sites. As a result, 9 patients voluntarily agreed to participate in the interview out of a total of 12 patients recorded during the duration of our survey. Semi-structured interviews were conducted with the encountered patients and an interview guide was developed (Table 1).

The interviews took place before and after their consultation to gather their emotions. Using their life stories, we sequenced the exchanges and conducted a thematic analysis.

The therapeutic compliance of people with beta-thalassemia was analyzed using the following indicators:

- 1- Patients' feelings about treatment.
- 2- Management of the therapeutic relationship (relationship of the patient to the doctor in terms of the history of perceptions related to previous consultations).
- 3- Relation to the disease in the face of its incurable nature.
- 4- Effectiveness of the prescribed treatment in durability.
- 5- Compliance with treatment (compliance with consultation appointments, compliance with medication intake).

**Table 1:** Interview guide.

Before consultation	After consultation	Goals
Reasons for consultation: Follow-up or state of illness	How did your medical consultation go?	Evaluate the level of satisfaction by the quality of the relationship between doctor and patient.
Therapeutic itinerary followed	Treatment protocol renewed or not	Identify the therapeutic itinerary of patients and the causes of this/these choice(s).
	Compliance with the prescribed protocol.	
	Motivation for following or not following the medical protocol.	Clarify the causes of patient adherence/non-adherence.

**Data processing**

The data collected for this study were presented and analyzed using MaxQda software. Thematic analysis was conducted based on the indicators of therapeutic observance identified within the framework of this work.

**Ethics**

The interviews were recorded after obtaining verbal consent from the patients. Anonymity was upheld in accordance with the wishes of the interviewees, who declined to have their photographs taken.

**Limits/Difficulties of the study**

This study did not take into account the data included in the medical records of the patients surveyed. The surveys were carried out over a two-month period, given the difficulty of meeting people with the disease. The

surveyed individuals did not adhere to their medical follow-up schedule, which made a second meeting with them impossible.

As part of a nationwide study resulting from this exploration, variables such as perceptions, quality of life, clinical/nosological characteristics, treatments received, clinical, biological, psychological, social response, evolution and complications will be analyzed. To better understand the implications of this chronic disease and improve its management.

**RESULTS**

**Characteristics of survey**

As part of this study, 9 patients (4 men (44.4%) and 5 women (55.6%)) with beta-thalassemia were interviewed, representing the majority at Treichville University Hospital. Regarding the typology of the disease, 55.6% had the intermediate form, and 60% of those with the intermediate form were female (Table 2).

**Table 2.** Breakdown of nine people with beta-thalassemia interviewed.

Gender	Beta-thalassemia type	Monitoring institution	Age range (yrs)
Female	Intermediate	University Hospital of Cocody	35-40
Male	Intermediate	University Hospital of Treichville	25-30
Male	Minor	University Hospital of Treichville	40-45
Female	Minor	University Hospital of Treichville	20-25
Male	Intermediate	University Hospital of Treichville	15-20
Female	Intermediate	University Hospital of Treichville	35-40
Female	Minor	University Hospital of Treichville	25-30
Female	Intermediate	University Hospital of Cocody	20-25
Male	Minor	University Hospital of Treichville	25-30

Source: Authors survey (2022).

**Factors of therapeutic non-compliance in beta-thalassemia**

The reasons for non-compliance with treatment vary from

one patient to another. The results of this study made it possible to identify mainly three main factors: the quality of the doctor-patient relationship, the effectiveness of the therapeutic prescription, and the chronicity of the diseases.

### Quality of doctor-patient relationship

The vulnerability of patients in pain has a lasting impact on their communication with caregivers. Indeed, confronted with this rare disease, caregivers are confronted, as reported by the respondents, with the difficulty of evaluating the pain they feel. Thus, based on the interviews carried out, two (02) homogeneous groups of patient-doctor couples were identified. They are the fusional alliance and the partial alliance. The first category is less frequent unlike the second which is the most mentioned. The main indicator used in this typology is trust, which according to the information collected, references to the following qualities: listening, observation, support, reception of the patient, and above all emotion in the face of this disease. Although the meetings with the caregivers are not regular, as the patients would have liked, the people surveyed linked the quality of the services and the regularity of the follow-up of the prescriptions.

**In the case of the fusional therapeutic alliance:** Of the 9 patients interviewed, only 2 claimed to be reassured more than 50% of the time during consultations with their doctor. In the case of ALY, for example, the patient surveyed was satisfied with:

*(...) I changed doctors three times due to dissatisfaction. Today, my new attending physician is sparing no effort to try to understand and relieve the pain felt by my child and me. We both have beta-thalassemia intermedia (...). He is considerate and attentive during the consultations, even though very often, I get the impression that he is a little powerless in the face of the explained situation. Nonetheless, I am reassured at each consultation with him. (...) We usually follow up with this doctor in the clinic, but since he is currently present for his consultations at the CHU and my child is currently suffering, as you have seen, I came to meet him there. His availability and the attention he gives us stimulate me to better monitor my health and especially that of my child (...).*

YYV is also part of this same logic. For her, counseling is:

*(...) blameless. Consultations with my doctor can last an hour. Before prescribing any medication, he recommends conducting thorough examinations to identify the underlying causes of the mentioned pain. While waiting for the results, he prescribed me maintenance medication. Frequent examinations and x-rays are expensive, but I prefer to have a proper diagnosis. I feel more reassured that way. The doctor manages to monitor the evolution of my*

*health condition, and, to tell the truth, I feel an improvement, and I am less absent at work. One thing that I especially appreciate is that he never doubts or neglects any of my feelings.*

It emerges from these remarks that the interactions between the doctor and his patient, within the framework of the medical follow-up, favor a balance to the therapeutic management of the disease, which itself is part of a psychotherapeutic process. This process takes place over time and has the advantage of creating a permanent and lasting communication dynamic between the doctor and his patient. Although not linear, this relationship of trust born within the framework of this alliance, to the analysis of the data collected, promotes better management of the patient and the disease by the doctor on the one hand, and on the other hand, to the management of the disease by the patient.

**In the case of the partial therapeutic alliance:** the data obtained revealed that the majority of respondents consider that neither the attending physicians nor the other health actors involved in the management of their health show empathy. As for this second category, the nursing staff has:

*(...) There seems to be better attention given to sickle cell patients than we receive during consultations. They are prioritized, even when they arrive after us for appointments. I noticed this pattern at the University Hospital of Yopougon. At times, I even questioned if I was being paranoid. Perhaps this behavior is because their students frequently consult here; I believe that's why they react in this manner. (...) This statement comes from ZSI, who was previously under the care of Yopougon University Hospital.*

This feeling is shared by the majority of respondents (7/9). As stated by IK, a young man aged 18:

*(...) the doctors do not know about this disease. When we try to explain the pain we feel to them, we have the feeling that they take us for liars. I even remember a doctor telling me that it was just rheumatism and that thalassemia could not be the cause of these pains.*

PU (male aged about 42) bounced back from the previous encounter by reaffirming his assertion. While expressing his desolation at this sudden situation, he mentioned the fact that:

*(...) the doctors we meet do not listen to us. They are always in a hurry to prescribe the same drugs without trying to understand what we*

*experience every day in our bodies (...). I wonder if they truly comprehend the disease. Let me give you an example: when I started my medical follow-up, the hematology card given to me listed sickle cell disease. How can I trust this when I am told that I have beta thalassemia? With each appointment, it's a new doctor who comes in. I am forced to explain the same thing repeatedly because they are not familiar with my case. It's discouraging, especially when it's medical students who attend the consultation. Everyone comes with their theories (...) Over time, I educated myself through social networks and other websites. I still have that card even though I stopped being followed there. If such a fundamental categorization is inconsistent, how can I trust their judgment? Pffff. I never receive satisfactory answers. I know that I will have to endure this disease throughout my life, but I believe the role of a doctor is not only to write long prescriptions but also to offer advice and explain the situation.*

The analysis of this information shows, on one side, a patient who is self-educated, and on the other side, the doctor who certainly has the information but does not manage to communicate with the patient to answer the various questions. This dissatisfaction creates in them both a feeling of insecurity and reliability. This feeling takes shape when the doctor or another member of the healthcare team fails to understand and/or manage the patient's feelings in the face of the suffering explained. The patient's refusal to cooperate then arises when one of these indicators is missing; which leads to doubt about the caregivers' abilities.

The nosological categorization of the disease raised as a problem by the respondents has an upstream impact on the primary knowledge of patients and their families. This situation becomes all the more difficult when patients expect to be seen by their GP, only to find that someone else is in charge. There is a systematic fracture in the relationship. This, in turn, results in a double challenge related to the perception of social stratification and the qualifications of healthcare staff. Regarding the double challenge mentioned, the first aspect is the automatic search for another doctor deemed "more competent", and the second refers to the immediate non-compliance with the prescription made by a professional other than the GP.

### **The combination of therapeutic prescription and medical follow-up of the patient and therapeutic non-compliance**

As part of our research, cross-checking the interviews conducted with the patients allowed us to identify two

types of non-compliance: 1) non-compliance with medication and 2) non-compliance with medical follow-up. The obtained results reveal that the causes of non-compliance in these patients are mainly linked to the duration of treatment, its effectiveness, and the chronicity of the disease. This chronicity generates personal, family, social, and professional difficulties for the surveyed patients due to its severity, seriousness, lasting nature, and the complications it induces. Furthermore, the results highlight the emotional fragility of patients who feel helpless in the face of this chronic condition. This vulnerability leads them to engage in a continuous search for new treatments that could improve their quality of life and overall health. Consequently, adhering to the treatment prescribed by the doctor becomes challenging, as they perceive it as ineffective.

**At the level of medication non-adherence:** 78% of respondents presented practices of medication non-compliance through their speech. This non-compliance leads to various issues, as indicated by the obtained results. These issues include irregular intake of prescribed drugs, taking other medications not prescribed by the attending physician (either alternately or simultaneously), failure to follow prescribed doses (posology) and medication-taking schedules, disregarding recommendations such as the timing of medication intake (before or after meals, for example), not following lifestyle and dietary rules, and even voluntarily interrupting and resuming treatment without seeking medical advice. For these surveyed patients:

*(...) the daily act of taking medication becomes tedious and merely a part of their routine, particularly since the prescribed drugs do not seem to have a curative effect! PU exclaims.*

For KBA, with recognized beta-thalassemia for almost 15 years:

*(...) it is not easy to take the same medications every day, especially when I don't feel any improvement. It's always the same tablets. It's too challenging. (...) I'm constantly tired, always out of breath, and my body still hurts. Nothing changes. Often, I take a break and seek treatment from traditional healers. At least they listen to me and provide natural healing. I've even received a food program offered to me, and I've noticed that the coagulopathy attacks have decreased. However, sincerely I still suffer. I wouldn't wish such suffering upon anyone. (...) Through prayers, I have faith that God will help me and my children too. We continue to pray to break these blood ties. The actions of our parents in the past seem to affect us today. How else can we understand such suffering within the*

*same family (tears)?*

This apparent feeling of "revolt" was mainly noted in patients who recorded more than three years of treatment. The chronicity of this disease, which requires the patient to take daily medication, becomes constraining over time and is perceived as ineffective by the latter. In search of a solution to recurring pain and discomfort, PU, like the other respondents, stated:

(...) I have been receiving folic acid for over five years, but without any apparent results.

This feeling, although shared by this cohort, is also felt by the remaining 22% who represent patients under treatment for less than three years. Indeed, for SM, a man over 35:

*(...) The first days, I was enthusiastic. I said to myself, at last, the end of my suffering. I even respected the hours taken. But as time went by my dreams faded away. I say to myself, what is the point since the pain persists? I take the drugs when I remember. I'm tired even when I come to the hospital a few times; I don't expect much. Only God will decide the end of my suffering. He is the doctor par excellence. He can do anything. I keep the faith.*

On reading the results, it becomes apparent that patients perceive the disease as a whole; poorly. The communication gap between patients and nursing staff regarding the potential consequences of beta-thalassemia on their well-being directly impacts their ability to recognize the necessity for regular follow-up with the practitioner. Additionally, it should be noted that the collected data indicate a variable pattern of medication non-compliance. Some patients exhibited partial non-compliance, leading to forgetting one or two tablets per month. On the other hand, a more frequent scenario involves patients deliberately discontinuing treatment due to perceived inefficiency, resulting in confirmed non-compliance.

**At the level of non-compliance with medical monitoring:** The information collected allowed us to assess the lack of adherence to medical follow-up, evidenced by the failure to adhere to the recommended consultation schedule and the requested assessments by the attending physician. Thus, 100% of the participants surveyed admitted that they only attended the consultations when experiencing pain, rather than following the physician's "quarterly follow-up" recommendation, as stated by KET. This follow-up, which aims to assess the general state of health of the beta-thalassemia, is perceived as:

(...) a formality to be completed because at the

end of the consultation, the doctor proceeds to a systematic renewal of the prescription with the addition or the change of the anti-inflammatory. YVY specifies.

This standardization noted by patients during consultations has caused them to develop new practices, thus compromising the interactional level on which their expectations of the doctor and the treatment are negotiated. Indeed, during the consultations, the patients meant to be:

*(...) generally, in search of answers to daily feelings. (...) but unfortunately, the consultation often ends the same way it started: Taking drugs for a lifetime without seeing any improvement. Even when I report it, the doctor seems not to believe me. KBA reports.*

Faced with the duration of treatment, patients must effectively manage this disease, which is considered disabling, throughout their lives. Unfortunately, this last element, which should be a trigger for efficient follow-up of the treatment, appears more like a factor of therapeutic non-compliance. Thus, in the hope of a total cure, the people surveyed hope to see the doctor operate a miracle, that is to say, to find definitive solutions to their physical suffering, but also and above all that they can understand what they feel. The inability of the doctor to permanently reduce this suffering creates in them a general dissatisfaction with the management of the disease, which leads to the practice of other forms of medication, such as religious practice (prayers of deliverance, healing, exorcism) and self-medication. This dissatisfaction encourages a new form of medical trajectory which is that of social networks. These spaces for exchange and virtual sharing are now succeeding in supplanting the services of doctors in pharmacies. They represent one of the most used sources in terms of health (search for treatments, dietary and hygienic advice, diagnosis, etc.). ALY states:

*I am a member of several groups on social networks. I will not deny that I often post on these groups asking for advice whenever I have a little discomfort. It has become a reflex. I do this long before I go to the hospital. Often, I don't go there. I am more satisfied by exchanging with his virtual friends. The opinions have helped me on several occasions, even if the last doctor who attends to me provides me with little satisfaction.*

KET, a person with beta thalassemia, while recounting his experience, emphasizes the static aspect of the evolution of his state of health:

*I have been under medical care for ten years,*

*and the doctor keeps prescribing the same drugs for me. Even when I mention new pains, he tells me they are not related to my condition. How can I fully trust him in such circumstances? Whenever I come across someone who claims to have a solution to my problem, I honestly try out their treatments to find relief. I even search for remedies on social networks. (...) when I hear about healing prayers or prayer camps, I wholeheartedly place my faith in God, without discriminating between religions. I'm seeking my miracle, as I believe that God did not create His children for suffering, and sickness does not come from God.*

These different actions are conducive to the creation of drug interactions, unfavorable to quality care by allopathic medicine and therefore susceptible to complications. This passiveness conferred by the caregiver on the patients results in a derogation from the indications of the doctors because they do not feel associated with the choice of their therapeutic route and even worse, doubt of the effectiveness of this one in the duration of the prescriptions. This conviction, shared by the respondents in the survey data, highlights the need for the patient to be an actor in his care. This immersion of the patient in the mechanism of management of the beta-thalassemia from which he suffers is part of a dynamic of guaranteed better health and quality of life with the direct consequence of therapeutic adherence<sup>6</sup> from them.

## DISCUSSION

The issue of therapeutic compliance is effective in the management of beta-thalassemia in Côte d'Ivoire. Although its measurement poses enormous problems, due firstly to the difficulty of obtaining recent data, for non-regular follow-up of patients (mainly due to the patient), the study successfully presented some indicators for its analysis. So, the results obtained within the framework of this pilot study highlight the quality of the doctor-patient relationship, by the level of knowledge of the disease by the various stakeholders and also by the level of patient involvement in the therapeutic choice. This last component has a negative impact on the long-term follow-up mechanism for the treatment prescribed by the healthcare professional. It can be likened to a momentary acceptance of the follow-up treatment prescribed by the nursing staff. The reasons for this non-adherence are also, with regard to our results, socio-cultural and religious. They interfere with the patient's perception of his treatment. Far from being inherent to beta-thalassemia, the work of Canas et al. (2013) on treatment non-compliance in schizophrenic patients also

noted that in addition to lack of awareness of the disease, socio-cultural parameters influence adherence to taking the drug.

Based on the preceding information, the role of doctors in the mechanism of therapeutic observance becomes crucial. It is right that Tarquinio and Tarquinio (2007) present the quality of the relationship that nurses-doctors maintain with patients as being a key determinant of therapeutic compliance. Data of this study highlighted an asymmetry in the relationship between caregivers and patients. As Parsons developed in 1939, the doctor positions himself as the only knowledgeable person and presents himself as the sole person responsible for the care process, which gives the patient a passive status. This model is mainly justified; by the patient's state of stress, who therefore relies on the doctor (Castel, 2005). The caregiver holds exclusive knowledge. Based on this reality, the patient does not intervene in the disease management process, which, according to our study, is criticized by patients who develop a feeling of dissatisfaction with this process. To respect or not the prescriptions seems to be a message to convey both to the patient himself and the health practitioner.

The model advocated by patients is that of participation, involving consideration of their feelings. Authors like Eliot Freidson (1984) have emphasized the importance of patient participation within the therapeutic relationship. Thus, as part of this interactionist perspective, the doctor should not have a dominant position. On the contrary, patients and their families should play an important role in the trajectory of the disease as proposed by Strauss (1992). Consequently, establishing a "compromise" of care between these two categories of actors is essential for improving therapeutic adherence. Patients must be actively involved in this therapeutic alliance alongside the medical teams, which requires well-informed information. However, according to the data collected, this is not always the case.

With respect to the impact of the chronicity of the disease on the level of compliance, our results differ from those obtained by Oudin-Doglioni et al., in 2019, in his study on sickle cell disease, where the perceived chronicity of the disease proved to be a primary determinant of therapeutic compliance. According to their results, the more aware patients are of the effectiveness of treatments and have knowledge of their disease as chronic, the more observant they become. However, our study revealed therapeutic non-compliance, primarily expressed by strong doubts regarding the prescriptions and the quality of the follow-up, particularly when painful crises linked to the complications. De Haes and Bensing (2009), had in their research, established that painful crises were the place of expression of the great vulnerability of the patient because the conditions in which painful crises are treated determine the confidence placed in the healthcare team, and adherence to follow-up. Thus, treating, which certainly means providing care to overcome the disease via a diagnosis made

<sup>6</sup>Therapeutic adherence translates effective and precise follow-up by the patient of medical prescriptions.

beforehand, takes on a double meaning by including the psychosocial management of the patient to improve his well-being and his state of health. This improvement in well-being must first go through the confidence of the patients by the caregivers (caregiver, nurse, doctor, biologist). As Berquin (2010) suggests, the quality of the management of hemoglobinopathies requires a shift in therapeutic practice from a biomedical model to a holistic biopsychosocial model integrated into care.

A change in the practices of caregivers would therefore, have a positive impact on the level of medical follow-up, which according to the data from the study, is relatively low. Haldi (2006) also supports this logic by asserting that the quality of the doctor's relationship with their patient influences the best results regarding satisfaction and therapeutic adherence. Indeed, as recommended by Sheen and Diet (2010), a few simple tips can sometimes be sufficient to increase therapeutic compliance. The consultation's interaction must then be considered as a therapeutic tool, ensuring a good level of therapeutic compliance. This paradigm shift is necessary because these causes of therapeutic non-compliance weaken patients and induce significant consequences on their health and on society, as has already been demonstrated in various fields of medicine (Osterberg and Blaschke, 2005). The finding is consistent with Bouric et al. (2011). The acute disease care model is not suitable for chronic disease because the patients expend their resources on care without reaping the expected benefits. This immersion of beta-thalassemia in the disease management mechanism will allow it to be an actor in its management through self-care.

Faced with the major challenge of therapeutic compliance for patients with beta-thalassemia, this research presents some possible solutions to improve compliance in patients with this disease in Côte d'Ivoire. These are:

1. Education and awareness to ensure that patients understand the nature of beta-thalassemia, its complications and the benefits of adequate adherence to treatment.
2. Strengthening the patient-physician bond with the aim of fostering a relationship of trust between the patient and the doctor. Good emotional support and effective communication can motivate patients to adhere better to their treatment plans. Sending reminders can be organized for medical appointments as initiated within private clinics.
3. Ease of access to drugs by setting up a mechanism to make them available and at an affordable cost for patients is necessary for treatment of beta-thalassemia. A consultation grant could be allocated depending on the recurrence.
4. Patient empowerment by setting up mechanisms to encourage patient autonomy by providing them with the knowledge and tools necessary to manage their own

treatment.

## CONCLUSION

Therapeutic adherence, which means that patients follow medical prescriptions effectively and precisely, is essential in the management of genetic blood diseases, particularly beta-thalassemia. Identifying the determinants of therapeutic non-adherence observed in this exploratory study will help to integrate them into clinical practice to improve the quality of care in Côte d'Ivoire. To better map all the determinants of non-compliance and create an appropriate framework to place the patient at the heart of the therapeutic management of beta-thalassaemia, targeted actions and large-scale surveys must be conducted at national level. Although health service records in Côte d'Ivoire show very few cases, these figures certainly do not reflect the reality of patients, as systematic screening does not yet exist in Côte d'Ivoire. This exploratory study will lead to researching the challenges facing the social sciences in dealing with beta-thalassemia, and conducting regional surveys on the prevalence to draw up an up-to-date map, the last of which dates back 45 years.

## REFERENCES

- Ali, S., Mumtaz, S., Shakir, H. A., Khan, M., Tahir, H. M., Mumtaz, S., Mughal, T. A., Hassan, A., Kazmi, S. A. R., Saida, I. M., and Khan, M. A. (2021). Current status of betathalassemia and its treatment strategies. *Molecular Genetics and Genomic Medicine*, 9(12): e1788. <https://doi.org/10.1002/mgg3.1788>
- Barouni, M., Aroua, S., Mellouli, F., Bejaoui, M., and Abbes, S (2017). Les modèles explicatifs de causalité de la beta-thalassémie majeure : Piste didactique pour une meilleure éducation du patient. *Spirale-Revue de Recherches en Education*, 37-47. <https://doi.org/10.3917/spir.hs1.0037>
- Bassimbié, J., Fabritius, H., Sangaré, A., Abissey, S. A., Tea, D. N. (1988). Prevalence of abnormal hemoglobin in the infant population in Abidjan. *Geography*, 90: 23-26.
- Bassimbié, J., Timéré, Y. N., Koné, D., Akroma, M., Boka, A., and Diakité, L. (2020). Prevalence of Hemoglobinopathies at the Central Laboratory of Treichville Teaching Hospital In Abidjan. *Revue Internationale de Sciences Médicales d'Abidjan*, 22(3): 210-215.
- Berquin, A. (2010). The biopsychosocial model: much more than a supplement of empathy. *Revue de Médecine Suisse*, 9: 1511-1513.
- Bodenheimer, T., Wagner, E. H., and Grumbach, K. (2002). Innovations in primary care. Improving primary care for patients with chronic illness. *Journal of the American Medical Association*, 288: 1775-1779.
- Bonello-Palota, N., Cerinoa, M., Jolyb, P., and Badens, C. (2016). Thalassemia in 2016. *Francophone Review of Laboratories*, 481: 67-75.
- Bouric, G., Beaumont, M., and Delplanque, D. (2015). Therapeutic education and physiotherapy. *EMC - Kinesitherapy-Physical Medicine-Rehabilitation*, 36(2): 1-12. [https://doi.org/10.1016/S1293-2965\(15\)70761-9](https://doi.org/10.1016/S1293-2965(15)70761-9)
- Cabannes, R., Bonhomme, J., Muran, A. (1971). Hemoglobinopathies in West Africa. *Annales de l'Université d'Abidjan*, 5: 23-58.
- Cabannes, R., Levy, G., Sangaré, A., Sombó, M. F., Kouadio, K., and Arne, D. (1977). African beta thalassemia. *Annales de l'Université d'Abidjan Série B*, 11 : 23-43.
- Cabannes, R. (1987). African beta thalassemia. *Annales de l'Université*



- d'Abidjan Série B (Med), tome XI .
- Cañas, F., Alptekin, K., Azorin, J. M., Dubois, V., Emsley, R., García, A. G., Gorwood, P., Haddad, P. M., Naber, D., Olivares, J. M., Papageorgiou, G., and Roca, M. (2013).** Improving treatment adherence for your patients with schizophrenia: the STAY initiative. *Clinical Drug Investigation*, 33(2): 97–107.
- Cao, A., and Galanello, R. (2010).** Beta-thalassemia. *Genetics in Medicine*, 12: 61–76. <https://doi.org/10.1097/GIM.0b013e3181cd68ed>
- Castel, P. (2005).** The doctor, his patient and his peers: A new approach to the therapeutic relationship. *Revue française de Sociologie*, 46 : 443-467. <https://doi.org/10.3917/rfs.463.0443>
- De Haes, H. and Bensing, J (2009).** Endpoints in medical communication research, proposing a framework of functions and outcomes. *Patient education and counseling*, 74(3), 287-294.
- Duverger, P., Malka, J., and Ninus, A. (2004).** Prescription and compliance. Reflections of a child psychiatry team. *Enfances and Psy*, 1(25): 31-41. DOI: 10.3917/ep.025.0031. URL: <https://www.cairn.info/revue-enfances-et-psy-2004-1-page-31.htm>
- Freidson, E. (1984).** The changing nature of professional control. *Annual Review of Sociology*, 10: 1-20.
- Galanello, R., and Origa, R. (2010).** Beta-thalassemia. *Orphanet Journal of Rare Diseases*, 5: 1-15. doi: 10.1186/1750-1172-5-11
- Loiselle, M. C., And Michaud, C. (2008).** Self-management of health and humanism in nursing sciences. *Journal of the University of Moncton*, 39(1-2): 41–67. <https://doi.org/10.7202/039842ar>
- Lubkin, M. I., and Parsen, P. D. (1990).** *Chronic illness impact and intervention.* (2e éd.). Boston: Jones and Bartlett.
- Orphanet General Public Encyclopedia (2008).** Beta-thalassemia. *Rare Diseases.* <http://www.orpha.net/data/patho/Pub/fr/BetaThalassemie-FRfrPub51v01.pdf>
- Osterberg, L., and Blaschke, T. (2005).** Adherence to medication. *New England Journal of Medicine*, 353(5): 487-497. doi: 10.1056/NEJMra050100
- Oudin-Dogliani, D., Gay, M. C., Lehougre, M. P., Arlet, J. B., and Galactéros, F. (2019).** Representations of sickle cell disease as determinants of therapeutic compliance. *Annales Médico-Psychologiques, Psychiatric Review*, 177(6): 517-525. <https://doi.org/10.1016/j.amp.2017.10.024>
- Parsons, T. (1939).** The professions and social structure. *Social Forces*, 17(4): 457-467.
- Segbena, A. Y., Kueviakoe, I., Mossiyamba, S., Messie, A.K., and Vovor, A. (1997).** Apport du test de Kleihauer dans le diagnostic des anomalies quantitatives de l'hémoglobine . *Médecine d'Afrique Noire*, 44(10): 501-505.
- Strauss, A. (1992).** *The frame of the negotiation. Qualitative sociology and interactionism.* Paris, L'Harmattan. 5-7.
- Tarquinio, C., and Tarquinio, M. P. (2007).** Therapeutic compliance: determinants and theoretical models. *Psychological Practices*, 13(1): 1-19.

---

**Citation:** Ouattara, L-Y. A. (2023). Therapeutic non-compliance among people with beta thalassemia in Cote d'ivoire. *Net Journal of Social Sciences*, 11(3): 89-97.

---