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## RESEARCH ARTICLE

### THE PSYCHOLOGICAL AND SOCIAL EXPERIENCE OF THE SEQUELAES OF LEPROSY FOR A PATIENT TREATED AT THE RAYMOND POATY REFERENCE HOSPITAL IN BRAZZAVILLE

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#### ABSTRACT

This text presents a qualitative study which apprehends the psychological repercussions of leprosy for a patient who was cured, but living with the stigmata left by the disease, treated at the Raymond Poaty Reference Hospital in Brazzaville. It appears that these repercussions are mainly reflected in psychological affects, a deterioration of the socio-affective environment and a concern for professional life. They occur during treatment and after recovery, but also because of the pressure exerted by the social environment. The study highlights the need to integrate a qualitative approach to medical research and to take into account the psychological affects concerning the consequences linked to leprosy in the patient life. It refers to the examination and interpretation of observations not accessible to quantitative study which have enabled to discover the underlying explanations and the modes of interrelation between, on the one hand, the medical requirements linked to the consequences of leprosy and the psychological experience and, on the other hand, the socio-cultural requirements and constraints in the Congolese environment.

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## INTRODUCTION

The representation of the disease has gone through many interpretations during the history of humanity, due to the lack of knowledge on the etiology of the diseases. There are diseases that common people consider normal, from which everyone can catch and be cured. On the other hand, other diseases are considered to be abnormal, that is, supernatural and reserved for a category of people. This type of disease often led to the exclusion of victims within the community and among which leprosy disease. This disease caused a lot of literature and also sorrow, which can give rise to a social rupture between a person and his peers. This can result to a gap in attachment, a distance, therefore a deficiency or a decrease in effectiveness with the sick subject or vice versa with respect to his neighbours. We cannot talk about illness without talking about health, health and illness are linked to biological processes and interactions with the social and environmental layers. Generally, disease is defined as an entity opposed to health, whose negative effect is due to an alteration or disharmonization of a system at any level (molecular, bodily, mental, emotional, etc.) of the physiological or morphological state considered normal, balanced or harmonious. In the Republic of Congo, the disease remains in most cases an enigma, because of ancestral ethnic beliefs. Congolese society looks superstitious, while taking into account the existence of witchcraft, fetishism and taboos, which together constitute our cultural heritage. This is the reason why the disease remains mystified until today, whatever the level of education or the social rank of the social actors and the recourse to the hospital often comes in the background.

This mystification leads to multiple interpretations causing a delay in being consulted by a specialist in order to make a diagnosis. Thus, by letting time pass, the disease worsens and the case becomes more and more complicated. Faced with other views, the patient cannot do without the prejudices that are made about him. At this moment, his life will take another turn between the instinct to follow or abandoning himself to despair. In October 1980, the Raoul FOLLEREAU Association (from France) extended to the Republic of Congo to carry out its mission, that of caring for leprosy patients and contributing to their integration into social life. The kick-off ceremony of the foundation was under the supervision of the First lady of the Republic of Congo, Antoinette SASSOU NGUESSO, on October 05, 1980. Before the arrival of this association, the hospital only treated leprosy and burilli ulcer. It was in April 1992 that the foundation became a hospital in partnership with the government, hence the name of the Raymond POATY hospital, by adding preventive, curative and promotional actions. In the 1980s, the city of Brazzaville did not have a high population concentration as it does today. Recall that the leprosarium was located before on the avenue of the former national television; at that time, this place was considered a remote and less inhabited area, therefore a favorable place to house lepers. Under the influence of stigma and bad views, the center was moved to another, more remote location, a forest on the outskirts of what was then Brazzaville. It is located nowadays in Kinsoundi, a dam district, south of Brazzaville where the forest has given way to housing. Surprisingly, the dam district becomes as populated as one could imagine, the forest has given way to habitat. Faced with this situation, the State is faced with an impasse, because it can no longer move the center again.

So here is an opportunity to seize to fight against all forms of stigmatization towards lepers, and to demystify the disease. Thus, the opportunity Raoul Follereau to engage to work in partnership with the Congolese State, so that all together manage to take up the challenge in the fight against leprosy. The local populations have therefore become accustomed to living with lepers, although it has not been easy. According to the testimony of a citizen: *“At the time, when the leper colony was installed here. We took this route more, for fear of catching leprosy. Afterwards, we gradually began to familiarize ourselves with these patients without prejudices being definitively erased”*. We notice today that other patients suffering from various pathologies are hospitalized in the same rooms as the lepers and the sick guards also sleep there, the fear of leprosy disease is no longer visible. The hospital is now accessible to all without discrimination. Currently, the Raymond POATY hospital center has become the Raymond POATY Reference Hospital since August 14, 2018. Indeed, we conducted this study in this reference hospital Raymond POATY, by making observations within the leprosy department where we met former patients who are either under treatment or in a state of recovery. In fact, we asked the following questions: Do the morbid effects of leprosy affect the rehabilitation of the individual in society? Subsidiary question follows: Prolonged hospitalization, after the recovery of the patient victim of the sequelae of leprosy, can it be considered as a social project of others towards him or/and a social withdrawal that he makes himself to avoid those around him?

This study, which focuses on patients who are victims of leprosy, aims to understand the impact of the sequelae of this disease on the daily lives of patients. It takes into account the person, the health and the disease, by noting its psychological and social consequences on the mind and the body of the patient, in these interactions with the social environment. Thus, our study seeks to contribute to the development of former leprosy victims, by helping them to resume a normal life, in order to promote their social reintegration. I assume that the morbid effects of leprosy modify the way of life of the individual, making him dependent and limited to carrying out certain daily tasks without facing obstacles to his social reintegration. The fact of often keeping the leprosy patient in the hospital after his cure, for care and free care, is a facilitating factor in the process of his social reintegration.

**Clarification of key concepts:** The word "lived" can be considered as self-perception or self-image. It is therefore the situation experienced by a person in relation to his past, his present and the way he presents himself projects into the future. Psychosocial experience refers to an inseparable correlation between professional life and social reality. Man is considered in a social situation, facing a socio-cultural environment that he also helps to create. His personal experience thus materializes in collective life as underlined by BABIN (1971, p.5): *“Truly, man and society are not exclusive (...). Man is born within a social group (...) he is practically between the individual history of the subject and social reality to the point that it has been said that the social lives in each of us”*.

We note that the psychosocial experience is interested in the field of interaction, in particular that of people and groups in the context of daily life. By psychosocial experience, we mean the interaction between the person and the environment. *“The psychosocial experience represents actions that belong to the experience of life, which really happened, the real images are recorded, the imagination grave them in our memory”*

The experience is exacerbated by the unpredictability of the problems, the responsibilities and the demands inherent in caring for a being with a health problem (King, King & Rosenbaum, 1996; Pelchat, Ricard, Bouchard, Pereaault & Saucier, 1999). The experiences of relatives also focus on the organization of daily life with the patient suffering from leprosy disease, the special care he requires, the many appointments with specialists or hospitalization, research and the negotiation of services mobilizes the time and energy of close relatives. Considerable and specific adaptive strategies must then be implemented by each member of the family (Lazarus & Folkman,

1984, Pelchat, Lefebve & al. 2003; Schumacker & Maleis, 1995, Van Duüren, 1998). Several studies have also looked at the impact of a patient's health problem on individual and family functioning and on the way loved ones go about coping with this situation. According to Josse Evelyne (2007), even when it is anticipated, the announcement of a serious condition affecting a patient causes a significant emotional shock to the parents. Their distress is such that, very often, they find themselves intellectually inhibited, unable at first to hear and understand what is said to them. It is only gradually that they will be able to understand the different elements concerning the pathology of their loved one. Their distress is increased by the fact that the doctors cannot decide right away on the therapy depends on many factors (Wikipedia; 2003). Still by Josse Evelyne (2007) When the diagnosis of the disease (leprosy) is announced, the person is considered by his parents and the medical team to be seriously ill. In France, for example, research has shown that parents of patients with chronic illnesses such as cancer, diabetes and even leprosy attribute their stress to the following factors:

- Lack of information;
- The ineffectiveness of psychological support
- The non-existence of a program integrating both medical and psychosocial services;
- Empowerment failure;
- The weakness of coordinated and global services;
- Lack of health education

Thus in the Republic of Congo, these identifications are not excepted, they are very real. To better understand the experience, we must start from the idea that any living organism takes information from its environment, it is a vital function. Man perceives the outside world in an active way, this information is grouped, selected, structured and processed by him, it is an interaction represented by the concept *"Experienced"*. The experience also depends on the state in which the person who perceives finds himself, the interests, the search for a solution if it is a bad experience, the perceptual attitude that will guide the experience when stimulation takes place. From the psychosocial point of view, lived experience relates to the interaction between psychological and social facts, which come under psychology. Psychosocial lived experience contains psychosocial mechanisms, analyses, methods, realities, research, psychosocial theories, extended family or reduced family, the nuance of the family feeling is not without opening one day on certain aspects of the psychosocial balance (Mounier, Traitecaract, 1946, p.105).

According to Henri Dorvil (1998), the psychosocial experience helps the person to accept his situation with his qualities, his limits and his faults and to overcome his traumas while living in perfect harmony with himself and with others. Particular interest was given to this notion of lived experience, having been deeply developed in 1998, at the curie institute thanks to the creation of the psycho-oncology section, psychologists and psychiatrists offer support at all phases of illness whether in hospital or on an outpatient basis, they can also take care of the psychological problems of relatives (A, tradivon, EurRadiol, 2006). The limit is not only cancer, but this consideration can be extended to other diseases arousing fear and the involvement of several factors that can be considered as the cause of the disease, especially with regard to leprosy.

**Leprosy:** Chronic infectious disease caused by an acid-fast bacillus (*Mycocateriumleprea*, formerly Hansen's bacillus), transmitted by direct, prolonged and intimate contact. It begins with an insensitive or touching red spot and can evolve in various forms: red or depigmented spots, more or less infiltrated nodules with an ulcerative tendency, later complicated by mutilation (especially on the face and extremities), sensitivity disorder. Several types of leprosy are defined according to clinical symptoms, on a scale ranging from lepromatous leprosy to tuberculoid leprosy. Between the two extremities lie lepromatous borderline leprosy and tuberculoid leprosy borderline. Treatment with sulfones gradually lowers the disease index. (*Medical Dictionary*, 2004).

It should be remembered that leprosy is not a recent disease, it is as old as humanity. It affected all regions of the world. But today, thanks to scientific progress, the disease has been neutralized, without disappearing completely. Nowadays, the microbe that causes leprosy is known. And there is a specific treatment for this disease, that it is no longer incurable as it once was in antiquity. For, the leper no longer dies of leprosy. According to the ancient conception of the disease, leprosy was considered the result of a transgression of divine laws, a punishment from the gods, a disease of the accursed or an ordeal. Although the name of this disease (leprosy) is not common to all societies in the world, nevertheless the symptoms, the consequences, as well as the perception that we have of it, seem common to all societal ethnic groups. During the 19th century, the conception of the disease of leprosy will be seen from another angle. Actually, thanks to the work of certain scientists. Particularly, through research conducted by a Norwegian physician Gerhard Henrik Amauer Hansen, conclusions based on epidemiological studies that leprosy was a specific disease and was contagious rather than hereditary, as was widely believed at the time. His studies marked the scientific community, but did not influence or convince the population of this era. Therefore, the mystification of the disease of leprosy still remains present, even up to the present day. In Congo, the fight against leprosy took shape in the 1980s through the creation of a program to fight against this endemic, the signing of memorandum of understanding with partner-actors in the fight against leprosy, in particular the Raoul-Follereau, who works in partnership with the Raymond-Poaty hospital in Kisoundi.

In 2005, the prevalence rate was 0.67 per 10,000 inhabitants and the detection rate was 0.64 per 10,000. The proportion of multibacillary among new cases was 53.4% and that of children 6.23M. Disabled patients among the new cases represented 12.2%, of which 26.4% were women. For the whole country, 394 cases were detected in 2002, including 252 multibacillary, i.e. 63.5%. A total of 610 patients were taken into account, including 475 in regular treatment. Health and well-being a Brazza.com newspaper published on January 31, 2018 which was titled early detection of leprosy remains a challenge. The Ministry of Health and Population, Mrs. Jacqueline Lydia Mikolo, recently invited the Congolese people in Brazzaville to be screened very early for leprosy disease, to avoid disabilities resulting from it.

In her message delivered on the occasion of the celebration, on January 28, the World Leprosy Day, at the Leprosy Hospital of Kinsoundi, called Raymond-Poaty Hospital, in the first district of Brazzaville, Makélékélé, Minister Jacqueline Lydia Mikolo said that the government wishes to renew its commitments in the establishment and strengthening of national programs to combat neglected tropical diseases present in the countries. This is a real elimination and eradication as well as the social reintegration of the sick. To avoid the disabilities resulting from the disease, Mrs. Mikolo made available to the health structure a donation of medicines and food for the benefit of those who, for his part, the director of the reference hospital Raymond POATY, Mr. Gaston Ngoma Massala, indicated that this structure is the only specialized center still functional in the care of patients.

**Different types of leprosy:** I selected lepromatous leprosy further to the explanation of key concepts. For further clarification let us define different forms of leprosy. Schematically, there are two clinical forms: tuberculoid leprosy and lepromatous leprosy, linked by so-called intermediate forms. Since the 1960s, in order to better standardize and regulate therapy, the WHO has classified lepromatous and intermediate forms, with more than five skin lesions. The pauci bacillary forms, essentially corresponding to the tuberculoid form.

**Tuberculous leprosy:** This form of leprosy is the most common. It combines large depigmented spots on the skin which become insensitive to the touch, with sharp edges, single or in small numbers, containing few or no bacilli. Rashes, as in all forms of leprosy, are non-itchy; nervous disorders affecting the limbs, with sensitivity disorders and skin abnormalities: ulcers, perforating pain; mutilations, paralysis; and circular lymphocytes that recognize these patients are not contagious.

**Lepromatous leprosy:** Lepromatous leprosy is a general disease. It is a form where cutaneous and mucous membrane lesions predominate: Cutaneous involvement predominates, with discrete hypochronic macules (with or without anesthesia), with loose contours. There appears lesions of this form, lepromas, which are nodular shiny papules (infiltrated nodules) of normal sensitivity, located all over the body, but predominating on the face (with epistaxis and nasal congestion); nerve damage is less severe in this form; There is no immunity to these patients that are contagious; about half of patients with leprosy develop erythema nodosum leprosum (ENL) within the first few years of effective antibiotic therapy. This reaction can occur spontaneously before treatment, facilitating diagnosis, or it can occur up to 10 years after treatment.

**Impairments are associated with it:** Otorhinolaryngological (bloody rhinitis, perforation, nasal mutilation); ophthalmologic (very variable, possibly affecting the conjunctiva, the eyelid, the lacrimal apparatus, oculomotricity but with a preference for the anterior segment uveitis, scleritis and episcleritis, cataract, glaucoma); nervous; viscerable (dumb unless complicated): lymph node invasion, hepatosplenic, risk of sterility.

**Intermediate leprosy:** Between these two well-characterized forms, there is a real spectrum of so-called intermediate forms, for which the defense reactions are unstable and real. Skin lesions resemble those of tuberculoid leprosy, but are more numerous and irregular. Large spots can affect an entire limb, and peripheral nerves can eventually be affected causing weakness and loss of penalties. This type of leprosy is unstable and can progress to the symptoms of lepromatous leprosy or, conversely, to the tuberculoid form of leprosy. This spectrum is still poorly understood in the medical community. However, it is worth recalling that between the pauci bacillary leprosy (minor infection) and the multi bacillary leprosy (serious infection, the most dangerous is kind of leprosy is multibacillary leprosy. Because, the latter leaves indelible marks on the body. The patient finds himself lacking his limbs. This is what we allude to when we speak of the sequelae of leprosy in the psychosocial experience of the patient.

## METHODOLOGY

Faced with an increasingly technical approach to pathology and with the development of increasingly codified treatments, there is the person, with their history, their current experience of the disease, their assessment of their quality of life, and finally the meaning she gives to the experience she is experiencing. The life experience, the whole subjective side of the disease is a problem for research, because it evokes the bias, the relative, which cannot be validated. However, nursing researchers have often deplored the inadequacy of quantitative methods to address subjective phenomena (such as pain, suffering, bereavement or a patient's quality of life). Thus, for our research, we have chosen the qualitative method, which serves as an important contribution to the quality of our memory. We follow the methodological process: observation, documentary and biological research to situate the problem of study.

**Target population:** Within the Raymond POATY reference hospital, we found 15 patients hospitalized for leprosy disease, the majority of whom are cured former lepers, but living with certain lesions left by the disease. The consequences of leprosy is an obstacle for the resumption of an active life. Because, they are under the yoke of the aftermaths of the disease therefore condemned to the hospital to follow the daily care. This workforce is mixed, divided into six (6) women and nine (9) men, mostly an adult population.

**The sampling population:** For the choice of the sample, we sorted the patients, until reaching the choice of a single subject. So, we opted for a random sampling, the individual is chosen according to specific criteria guaranteeing randomness. Here, the type of random sample chosen is the quota sample. The individual is not chosen at random, but according to their ability to meet the criteria of the profile of the studied population.

**Among these criteria**

- The quality of reasoning;
- Cooperation ;
- Accessibility;

Unattractive somatic features: distorted face shape, narrowing of the fingers of the left hands, narrowing of the ears, and finally wounds.

**Data collection instruments:** The reliability of the results of any research work is based on an information collection system that permits to establish the facts in a rigorous and scientific manner. Several instruments are used in the social sciences. So, we adopted observation, documentary and biological research, finally in a semi-direct interview accompanied by an interview guide. While emphasizing that, our study being qualitative; we focus on the analysis of the speech, posture, attitude and perspective of the patient.

**Observation:** As a qualitative approach, our study attempts to understand the complexity of psychological phenomena and representations related to leprosy. For Borgès Da Silva (2001), Hudelson (2004) or even Casebeer and Verhoef (2000), this approach is the one that allows to grasp the complex phenomena of the behavior of actors in the health system, which escape the quantitative approach. Here, it mobilizes two theoretical perspectives. The first, the psychological approach, highlights psychological affects through the patient's discourse (Dantier, 2008). The second, the cultural approach based on social representation, identifies the contradictions between these requirements of medical follow-up. Indeed, the apprehension of the representations related to the disease of leprosy concerns a cultural approach, it is more and more accepted that the endemic of leprosy is not only a medical problem, but rather a complex phenomenon comprising societal and cultural aspects whose understanding requires a cultural approach (Unesco & UNAIDS, 2003). Thus, we chose semi-directive interview. It is a qualitative survey technique frequently used in research in the humanities and social sciences. It partly orients the discourse of the people interviewed around different themes defined beforehand by the interviewers and recorded in an interview group. This technique aims, while being centered on the questioned subject, to guarantee the study of all the questions that interest the interviewer. It also ensures the comparability of results.

**Conduct of the investigation:** We spent six (6) months of internship at the Raymond POATY reference hospital, we conducted our study survey for one month to better understand our subject of investigation. The interview took place in the medical department, room n°6, bed n°4.

**The patient's experience:** The patient tells us that they suffered from leprosy, 8 years ago between recovery and remission, living together and hospitalization. I remember they said "the first symptoms of the disease, which I considered banal as a stain, swelling, heat and the wound follows. At first I was consulted by righteous seers to find out who bewitched me. It's a pity that this process did not succeed. Forced by the pain, I was forced to go to the hospital, where I spent almost two (2) years for my first hospitalization. I was diagnosed cured so here is my return to the village. "At the slightest complication, I would come back to the hospital to be consulted again. Out of fear, I stayed in the hospital for a long time to see the improvement in my health state. I come from the interior of the country, so coming here all the time for the dressings is painful as a chore". The patient first admits that it was not easy for him to live with the disease. Also, they reassure that it was a moment of awareness, first of all about our being, then about the other and finally about the world, the meaning of life. During my treatment, I felt like I was not the same person, even those who knew me had difficulty identifying me. It is better when you only suffer from your disease, but when this is associated with the views and prejudices that others have on you, I reassure you that then we suffer twice. And I lived that for a long time. During my treatment phase, I suffered a lot.

The treatment, the cries, the pain, made me anxious. The only question was what will end all this? The only concern is that death alone will be my salvation?. After my recovery, few people could identify that I suffered from leprosy, at this stage no bad intentions. But, the misfortune occurred when I went to a medical service other than this one, close to my home there (...). When the nurse looked at my health card, I read in her eyes, actions and gestures, her attitude, her face really changed and that frustrated me a lot. Sometimes, I was hiked today tomorrow and so on. It is the nursing staff, in my opinion, who warns his close relatives and his friends, all of whom point the finger at me stating "*he has leprosy, so be careful*". This is where mistrust begins, avoidance, provocations and stigmatization. And yet in the beginning of my illness, when I suffered, the whole village assisted me closely. Maybe because they didn't know what I was suffering from before. I felt better in my environment with the ignorance of my illness rather than being cured of it in the knowledge of my illness. So, to avoid this whole cycle, I prefer hospitalization and wait until my wound ends. Although the hospital becomes the only safe place to regain one's health, there is little intimacy with the nursing staff, where one is far from any form of stigmatization. The post-healing phase is also difficult to ensure: look at how I have become? I could never fish like I used to. I have lost much of my tactile sensitivity, which leads to excessive attention condemned to chronic wounds. I hold the fire without feeling, I walk on spikes without feeling. In the end, these accidents hurt me. But as long as I live, I will always be condemned to be in contact with the environment, which amounts to saying that I remain until my death in the spiral of the sequelae of leprosy. On the other hand, the disease drilled my behavior. I think, he says, it's a trap that will make me look even more beautiful in my illness. For, the healing of the body should go with peace in the soul. The pain of injuries is very real and present. I'm scared in the morning when I think of dressing scissors, alcohol Betadine and cotton on my wounds. But, I have to continue my treatment if I want to heal even if it hurts. But over time some I overcame the prejudices against me, and life resumed as before. I feel good. Just a small regret that of certain members of my body who are no longer. But since these are not vital parts preventing me from existing, I continue to exercise my profession as a teacher. I am loved by my students and I regain a taste for life. Although it is not easy to have suffered from a disease like leprosy, a disease that scares many, my family has supported me throughout and I am very grateful to them.

**Element of psychological interview:** During our interview, Mr. O.B was very cooperative and very satisfied with our exchanges, which after him, talking with someone relieves him as well as the medicine, it is another form of treatment. When we talk to you, we pay attention to you, we dedicate time for you who are suffering so "to me" motivates, encourages and restores a taste for life, this rapprochement always shows our attachment to the world and that we are not discriminated against. Although he suffered from leprosy, he is happy, he reassures us. We were able to identify personality traits alluding to discouragement, stress, and depression. We could note a strong character, the combative hope of the patient and a strong self-esteem. Sometimes, the patient seemed sad when he was talking about his story, but this makes us understand that the pain came more from the disease (pathological pain) and not from what it could bring as a consequence on his body, and less from the looks of others. By carefully following the patient's speech, we were able to note important significant elements, those of the patient's combative hope and a strong self-esteem, it is as if the disease were coming to strengthen his self-confidence. Fear and complaints do not compromise his personality at all, the loss of certain members of his body does not prevent him from having a project for the future, he continues to exercise his profession. He is eager to leave the hospital to return to his duties. The denial of the disease keeps the patient in the dark, the subject will tend to become attached in the hallucinations to try to find consolation. On the other hand, if he accepts his sick condition, he follows his treatment and keeps his lucidity vis-à-vis the events, because that is what happened to Mr. O.B. In the relationship that we have been able to observe in relation to nurse-patient tandem, the notion of distances that are essential in human relationships

intervenes. They (distances) can be divided into two groups; the distances of relation and those of observation. Relationship distances are distances between 0 and 1.50m, they allow a genuine interpersonal exchange. Observation distances are the distances beyond 1.50m. Indeed, no real relationship can be established if the interpersonal gap is greater than this figure (1.50m).

**Data processing:** To systematize the general and specific information relating to the psychosocial experience of the sequelae of leprosy in a patient, we will treat qualitatively while taking into account the narrative of the subject. In relation to his testimony, we will proceed to see the hypotheses are affirmed or invalidated. We carried out a manual and qualitative processing of the data. This processing of information is essentially based on thematic and content analysis. This is a qualitative and indirect content analysis of the testimony collected in the sense defined by Aktouf (1987). In this analysis, the importance given to the words, terms and other expressions reported by the patient during the interview is not measured by their frequency, but rather by the particular interest and the semantic weight in relation to the context of the consequences of leprosy in his daily life. This analysis technique led us to establish significant categories from the testimonies by carrying out a series of steps aimed at distinguishing and naming different classes of elements presenting a certain homogeneity. It is under these categories that we then arranged the contents of the different expressions of the patient questioned, in the form of units of information corresponding to words, sentences or general ideas from the transcribed testimony. The stages of this content analysis were therefore successively:

- The repeated and careful literal reading of the testimony, which permits to detect the different expressions, tendencies, attitudes, opinions... expressed or implied;
- The definition of categories that enabled us to decide on the key themes;
- The determination of the units of information, which consisted in identifying from the testimony the words, expressions and sentences expressing an attitude, a position, or an opinion;
- The grouping of information units around themes according to their correspondence.

The dialectical method helped analyze the contradictions that arise in the life of the sick person (former leper). It is a heuristic approach that allows us to observe and understand contradictions, oppositions and ambivalences. On the one hand, the articulation of the medical requirements linked to leprosy and the Congolese socio-cultural realities, and, on the other hand, the articulation of these same requirements and the psychological realities linked to the disease raise contradictions specific to the dialectical analysis. A careful reading of the testimony made it possible to identify three major significant categories around which the grouping of the information units identified in them was made. These categories are: psychological affects in the interviewed patient, deterioration of the socio-affective environment of the interviewed patient and concern related to professional life. His testimony therefore leads us to remember that the experience of the sequelae of leprosy in the patient encountered is essentially determined by these three realities which are presented in the order mentioned above.

**Psychological effects in the patient:** After analyzing his experience, we identified various psychological affects ranging from fear to denial of the disease.

**Denial of disease:** The patient testifies to his attitude of refusal of the result during the diagnosis of leprosy: *"At the beginning, when I was declared leprosy, I refused to believe in the diagnosis and it was a year later when I refuted that I 'took it seriously; I didn't believe at first"*.

**Guilt and Persecution:** These affects are provoked by the diagnosis of leprosy; Mr. O.B feels both responsible and guilty for the disease, but also for the one he would have caused in others. Sometimes, he feels himself a victim of the imprudence and inattention of his actions

or of a previous sin caused by his parents of which he suffers the consequence and considers that the latter are responsible for his situation. *"I consider my infection to be the cause of bad luck."* These are the expressions borrowed by the patient met to express the feeling of guilt or persecution feeling. The most frequent and constant affects in the witness are anxiety, fear of tomorrow and mourning for future projects and dreams. Faced with the threat of death caused by the disease, as well as its chronicity, the patient encountered testimony of his anguish and fear. *"I'm anxious; I think a lot ; I cried. The first day of my hospitalization, I cried all day, I spent three days without sleeping, without eating."* We also note that the patient is anxious about the quantity of medicine to take and the uncertainty of recovery. *"The pills are quite big... if you still have to take such big pills, it's scary and it doesn't make me want to; Every morning and evening, when I think about taking medicine my heart beats; I did not believe in the treatment at first"*. Finally, it also emerges from the patient's comments that he has to grieve a lot: loss of body parts, social benefits and past health, loss of future plans, loss of affective relationships. *"Before my illness, I had double jobs, one as a teacher in a college in the private school square and a second one as a fisherman, I assure you that it brought me a lot of money. But today, I can no longer practice "My future is mortgaged, I have the impression that God has turned his back on me"*.

**Frustration, weakening and self-esteem and depreciation:** Attitudes of frustration, weakening of self-esteem and depreciation are among the psychological affects encountered in the patient. Faced with the effects of stigmata on the whole body, the patient not only loses hope, but also self-confidence. Mr. O.B thinks of attracting the attention of those around him because of the marks that leprosy leaves on his body: dermatological damage, pimples, weight loss. This subject experiences a situation that involves internal discomfort and feelings of frustration, guilt and shame, which weakens his self-esteem and creates a feeling of depreciation of his inferiority complex: *"When I hit on a girl , the problem comes to my mind and I feel a blockage, there was a time when I didn't go out because I had lots of pimples on my body"*. The feelings of frustration also come from the attitudes of the neighborhood: *"my girlfriend's sister is aware of my state of health, she is blackmailing about it ... she threatened until we separated"*.

**Depression, suicidal thoughts, desire and thoughts of death:** Psychological affects related to depression, suicide and thoughts of death are less intense in Mr. O.B. Indeed, the psychological stress linked to leprosy will always end up creating depression in the latter because we have noted this: *"I am anxious and that makes me sad, and when I find myself alone I think a lot..."* We did not find suicidal thoughts, but a little discouragement during his story. *"At the start, he says, that I was desperate for life"*.

#### ***The deterioration of the socio-emotional environment of the patient interviewed***

**Social isolation from the environment:** The degradation of the environment is sometimes determined by the attitude of those around you (family, friends, neighbours, medical staff, work colleagues, etc.). The patient noted several attitudes of stigmatization and rejection on the part of those around him: *"one of my aunts does not want to share the same plates and cups with her"; "friends have abandoned me [...] my cousin whom I was staying with has also left the house as if I'm going to contaminate her"; "Since I got sick and everyone knows I have leprosy... no one around me. They've all abandoned me."*

**Self-isolation:** Even when the patient is not the direct victim of ostracism on the part of those around him, the fear of being stigmatized can lead him to develop attitudes of avoidance or to remain in denial for a long time and to refuse the social support of associations or the treatment which could reveal it in broad daylight: *I was very afraid that people would discover that I was leprosy. In addition, the negative transformations of the body caused by leprosy and the side effects of drugs do not go unnoticed and attract the attention and curiosity of those around them.*

This can be embarrassing for him and contribute to developing attitudes of avoidance and isolation: "I don't go out because I look like my monster". Everyone in their experience may have already experienced this, when one is sick for a relatively long period of time, people, including relatives, often end up spacing out their visit, until they no longer come. Are they embarrassed to see you suffer? Boredom? Relationship change? It's hard to say, but it's an observation that sick people often make: over time, they often find themselves isolated. When, in addition, the disease you suffer from is rare, the risk of finding yourself alone is all the greater. Mr. OB emphasizes this fact, which only reinforces the feeling of abandonment they sometimes feel when no medical treatment is available to bring back their lost limbs. During my long hospitalizations, no one visits me anymore. It is a difficult situation to live in that the sick person feels alone because of the rarity of his illness. In the hospital, we all experience the same misery, so it is difficult to support and help each other. This could, however, precisely improve the daily lives of these patients. By sharing common concerns, giving each other tips for dealing with such and such a problem. There is also the lack of social recognition. The feeling of isolation also on the medical level, or very often, the doctors do not know much more than the patients about their disease. Similarly, it is sometimes difficult to make social organizations listen to reason, as well as the local health insurance fund, even if these pitfalls have really tended to ensure for a few years.

**Concern related to professional life:** With regard to professional life, the patient shows a lot of regrets and accuses the disease of being the cause of his lack of employment. "When I recovered, after my first discharge from hospital, I could not work. Everywhere I went, they pushed me away. The disease made me a handicap. Saying that, it was after 10 years that I was able to become independent again. Financially, I was dependent on my family. Because, I could no longer fish or teach."

**Testing of assumptions:** The results of our study show that psychological suffering is indeed present in this patient. It is expressed through guilt, feelings of persecution, anxiety, fear of tomorrow, mourning for projects, feelings of frustration, weakening of self-esteem, depreciation. The psychological disorders linked to the sequelae of leprosy derives from different emotional states. The mourning of inner health and the weight of medical follow-up, the uncertainty of healing, the fear of social rejection and the feeling of insecurity vis-à-vis the threat of death largely contribute to explaining these disorders. Denial in the sick subject can still be an attitude psychologically constructed to cushion the shock felt, therefore a defense mechanism. According to his testimony, one could still note that Mr. O.B was struggling with attitudes of stigmatization, discrimination and rejection on the part neighbors, sometimes in front of himself as well. These attitudes are most often fueled by stereotypes and other negative images associated with leprosy. These neighbour behaviors exert a pressure of rupture on the socioaffective relations. The subject thus feels abandoned, rejected, excluded because of his status as a leper; he therefore turns back on himself and feels humiliated, scorned in his pride. This social isolation sometimes becomes difficult to bear and this situation increases the psychological stress and degrades the latter's quality of life. It is important to point out that the testimony of Mr. O.B., and all these psychological affects here evoked his anterior, that is to say, in the first year of his illness when he was in a phase of guilt, denial, and despair. Currently, living with all these sequelae of leprosy, all feeling of fragmentation of guilt, death, abandonment are no more. His combative hope served him as a very important defense mechanism, while allowing him to overcome the slope that should drop him into a depression. The most important thing, according to him, is that the disease of leprosy has not destroyed him intellectually, "I am lucid, the focal point of all human relations," he says. But my vital senses were affected, such as the loss of sight, hearing, smell, taste, and voice. No doubt I could never have spoken to you, nor seen you, nor heard you. Without all these senses my pain, my sadness would be inside, and my psychological state would have deteriorated and I myself might pass away since a very long time.

The morbid effects of leprosy occur when the patient suffered from a severe type of leprosy such as lepromatous leprosy. This type of leprosy has quite a remarkable impact on the body of the one who has suffered from it, it is when the care has not been in time, that is to say, on time at the moment the consequences are enormous and the risk of prejudice stigma are high. Because, the earlier the disease is diagnosed, the more the chances of recovery are multiplied. In this kind of situation, the effects can be disastrous making the subject more vulnerable to even doing the easiest (simple) tasks. When the vital organs are not affected, the patient can resume a normal life, with time they will rehabilitate at this time our main hypothesis is affirmed therefore, the sequelae of leprosy do not prevent the patient from living in community and to be active there. However, when certain organs useful for everyday life are affected, the subject becomes inactive and therefore cannot participate in life in society at this time, the hypothesis is invalidated. Indeed, our hypotheses should be invalidated if we were limited only to the testimony of the phase before healing, that is to say, during the illness, and as our study extends to the phase after illness, That is to say, that the subject is therefore cured but will now live with the sequelae left by leprosy in this case, our hypotheses are affirmed. The patient is happy in his environment because he showed us his photo album eating from the same plate with three young girls, animated the parties he is at the heart of the actions of his community. So no stigma, I live like everyone else now. As soon as they knew it was leprosy, harmony returned to the way it was. And for the second hypothesis, it is also affirmed, that is to say that the long hospitalization is not due to the rejection that his environment has on him or a withdrawal that he makes himself, but rather because of the duration of treatment about a year and then move on to dressing the wounds. So, the subject prefers to stay in the hospital until seeing a complete recovery. The cost of transport and boarding are to be taken into account for the prolonged hospitalization of the subject.

## CONCLUSION

This qualitative study on a case study, allowed to see that Mr. O.B presents psychosocial difficulties of several orders. Psychosocial persecution results in behavioral problems, suicidal ideas and equivalents, mourning for projects, socio-affective isolation. These affects result from the announcement of the disease, the treatment and the pressure that the social environment exerts on a leprosy person. The study permits to meet two major challenges related to the Congolese context in the assessment of leprosy. The first is theoretical and methodological and concerns the approach. Indeed, leprosy includes a biomedical dimension which comes under quantitative epidemiological and etiological studies and a much more complex dimension linked to the experience of the disease and its representations, which comes under qualitative research. In the Republic of Congo, the experience linked to the consequences of leprosy presents a striking specificity because of the vital prognosis of this disease, the therapeutic problems (precariousness of the health system, shortage of drugs) and the strong social pressure (representation of leprosy, clichés negatives, place of the leper in professional life). The second is social. It is in terms of patient care and is justified by the double suffering (physical and psychological) linked to leprosy. Given the experience linked to leprosy, which is particularly lacking in Congo, psychological monitoring is to be prescribed in current therapeutic itineraries to achieve complete care for people affected and people living with leprosy and the sequelae of leprosy in this environment. Undertaking such a study on the sequelae of leprosy on the experience of the patient who is a victim of it in the Congolese environment involves difficulties of a theoretical order (documentary vacuum due to the poverty of the libraries, methodological and ethical (medical secrecy). First difficulty was circumvented thanks to the contribution of research on the Internet, the difficulties of an ethical nature were circumvented thanks to two approach techniques (informed consent and the guarantee of the anonymity of the respondents). In qualitative research, the quality of the sample matters more than its size. The choice of the qualitative approach in this paper is explained by the objective of our study

which is an attempt to understand the emotional states and the psychological variations in the patient victim of the consequences of leprosy, rather than to produce results quantifiable causal phenomena. It should be noted, however, that this approach did not allow to take into account certain aspects of moral suffering directly linked to the action of leprosy on treatment which fall under bioclinical methods. Other more in-depth studies taking into account all these aspects are to be encouraged. Thus, we seek to remove the ambiguity that persists in calling a former leper patient by leper and thereby, we open another door: how is leprosy perceived today? Our proposals are brought to the Ministry of Health and Population; to the Ministry of Social Affairs, Humanitarian Action and Solidarity, to the National Leprosy Control Program and the Raymond Poaty reference hospital in Kinsoundi:

**With regard to the Ministry of Health and Population, they should:**

- Create ambulatory and leprosy treatment centers especially in the most affected areas such as Likouala. And then in each center or hospital there is a specialist available and finally proceed to the vulgarization and awareness of the disease;
- Promote the profession of psychologist in the medical environment;
- Educate the population about leprosy;
- The Ministry of Social Affairs should:
- Create craft workshops adapted to lepers;
- Prepare an accompanying fund to support lepers wishing to exercise a profession favorable to their current condition;
- Contribute to the management of medicines, food infrastructure for patients.
- Regarding the National Program for the Fight against Leprosy:
- Provide training/Retraining of staff on leprosy and care;
- Intensify IEC activities in the communities by organizing focus groups.
- Regarding the Raymond Poaty referral hospital in Kinsoundi:
- Organize regular IEC sessions at the center level;
- Carry out bacteriological examinations before the start of treatments and before their expiry, as well as bacteriological examinations for control or monitoring after treatment;
- Organize home visits (VAD) for patients;

- Create production units at the level of the center for the sick;
- Carry out continuous advocacy.
- All of these activities will facilitate their reintegration into society while keeping them useful.

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