

Social implications of Autism as a chronic disease and family coping strategies in Abidjan (Côte d'Ivoire)

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ABSTRACT: In our study we looked at the care of children with autistic syndrome. This modest contribution aims primarily to raise awareness of this pathology, and to present the reality of the care of a population with specific educational needs in an establishment for the mentally handicapped. The present study focuses on the social implications of autism and the forms of adaptation developed by the social entourage of patients. As part of the field of the sociology of chronic diseases, it is based on two observations. Firstly, a costly socialization of the sick and marginalization which contrasts with the integrative policy advocated by the care structures. Through direct observations and field interviews with institutional actors, it appears that despite the effort made, such as support and support for families, mobile consultations, communication with professionals and families and training days by these structures, the most striking observation is the inability of these children to develop any sociability or to establish communication with those around them.

KEYWORDS: *Autism, social involvement, coping strategy, Abidjan, Côte d'Ivoire*

I. INTRODUCTION

The reflections and debates conducted for more than 30 years in Western countries on the origin and treatments of autism have played a major role in the good quality of care for the autistic person. Furthermore, studies on child development conducted over the past thirty years by specialists in psychoanalysis, biology, neurology and genetics have contributed to the knowledge, understanding and improving interventions for childhood autism. This pathology which constitutes a serious developmental disorder; affects both personality development and cognitive development. All the more serious since it begins in the first years of life. And because this pathology begins with life, it is the whole of the developments which is altered in a considerable way. Moreover, according to Ridha Abdmouleh (2007) for Addressing the question of the social construction of this disease for a sociologist means analyzing all the social aspects that surround man. In short, given their intertwining in our lives, health and illness constitute for the sociologist of social facts a great revealing relevance of the fabric of society and culture. For others, autism is a set of early developmental disorders characterized by a deficit in social interactions and communication from which many children suffer.

In our study we looked at the care of children with autistic syndrome. This modest contribution aims primarily to raise awareness of this pathology, and to present the reality of the care of a population with specific educational needs in an establishment for the mentally handicapped. The present study focuses on the social implications of autism and the forms of adaptation developed by the social entourage of patients. As part of the field of the sociology of chronic diseases, it is based on two observations. Firstly, a costly socialization of the sick and marginalization which contrasts with the integrative policy advocated by the care structures. Through direct observations and field interviews with institutional actors, it appears that despite the effort made, such as support and support for families, mobile consultations, communication with professionals and families and training days by these structures, the most striking observation is the inability of these children to develop any sociability or to establish communication with those around them. There is a dysfunction in relationships with others and their social environment. Secondly, a multiplicity of community or even family alternatives despite official management. This results in The gap between advocated integration and displayed marginalization leads to “therapeutic navigation with various tactics of resilience despite official management. The opening of care centers in the management of autism in children, the different perceptions of this disease by parents direct them towards adaptation strategies other than the medical route. These findings pose the problem of the multiplicity of community or even family alternatives around the fight against the devaluing effects of the disease of autism despite the official management of care structures. On a sociological level, this question translates. A relationship between a form of activation of family sociability in the face of the social devaluation of autistic

people and associated formal mechanisms of care. What are the social implications of autism and coping strategies? In other words, how do the ideologies and social representations of this disease constitute strategic factors of adaptation? How do rituals and celebrations contribute to adaptation? how the quality of relational communication constitutes a cement of family adaptation around autistic people.

To position the added value of this study, it was necessary to go through the writings that review the state of the question in terms of the contribution of the sociology of health in the analysis of the disease with R. Abdmouleh (2007) and writings on perceptions of autism among different authors. It approaches the question of the social construction of the disease for a sociologist and returns to analyze the whole of the social aspects which surrounds the man. In short, given their intertwining in our lives, health and illness constitute for the sociologist of social facts a great revealing relevance of the fabric of society and culture. For J. Stoezel (1960), it is a way of being with oneself and with others that is taught to us by society. Indeed, it is our society that sets the standards for illness and health, directs our care practices, distributes roles and statuses between the patient, his entourage and the therapist. It is also what gives meaning to illness and determines our beliefs and representations about it. It is in this respect that illness and health constitute for the sociologist and the psychosociologist total social facts. AC. Bissouma (2018), considers autism as disorders of the neurological and psychological development of the child which are neuro-developmental disorders with a kind of continuum of disorder which goes from autistic disorders which combine with intellectual development disorders. We no longer speak of autism but rather of autism spectrum disorder. Autism is not a disease but a disability, a disorder. To this end, it becomes a social disease since it is a handicap which transforms the relationship of the patient to his social environment. This will influence families and their relationships with others. In the study by Mc. Gill and Cooper (2006), parents report a lack of help and listening from professionals. The help provided appears to be insufficient in view of the demand of these parents in distress. Family adaptation is the result of great cohesion between primary and secondary socialities.

The expression of the literature leads to analyze autism from the point of view of the theory of resilience of Marie Anaut (2005) which gives a scoop to solidarity, high expectation, active involvement, values mutual aid, social tolerances, diversities and social resources. Resilience is the capacity of a person or a group of people to develop well, to continue to project themselves into the future despite destabilizing events, difficult living conditions and sometimes severe trauma. This theory is consistent with family coping strategies when faced with the devaluing effects associated with autism. Insofar as the collective imagination apprehends autism as a socially degrading phenomenon, it follows a double social suffering both among the victims and in the families of the latter.

II. STUDY METHODOLOGY

The objectives of this study lead us to a qualitative approach carried out at the National Institute of Public Health (INSP) of Adjamé in Abidjan, precisely at the Center Marguerite Té Bonlé. This Center is one of the specialized centers for monitoring autistic children. This study is based on data collected first from practitioners who refer to all specialists on the question of autism. Then with the targets and witnesses who refer to the families of the patients. The families of the patients are those who are responsible for caring for their children with this disability at home. They identify themselves as an essential category of actors, indispensable in the process of resilience in the face of their children's handicap.

The survey also focused on the parents of autistic children who identify themselves as an essential category of actors, indispensable in the process of care and therapeutic follow-up of the patient. The families of the sick are those responsible for the daily follow-up of their sick children at home. To this end, they are likely to provide information for carrying out the study. 38 people were interviewed for this study, including 8 from services and support staff and 30 parents. The selection of the potentials investigated for the phenomenon was made on the basis of the medical results of the medical appointments, of their repeated absences at the medical appointment. Documentary research and observation reinforced the interviews and the analysis of the content made it possible to identify the different analytical categories of the corpus of discourse obtained.

III. STUDY RESULTS

The results present the social implications on the social environment of the occurrence or discovery of autism in children. These implications in this arise in terms of ideological dimension that underlies the social representations and perceptions that go towards adaptation strategies.

1. Ideological implications of autism: between perception of the diagnosis and social representations of the disease of the child

1.1. Perceptions of the diagnosis on the incurability of the disease

The diagnosis of this disease inscribes the parents of patients in perceptions relating to the idea of the "incurability" of the disease and the durability of the treatments. Illness is an ordeal of life that affects the state of mind and the hopes of parents and affected individuals with regard to a supposedly tragic or imminent social situation. This concern is felt among parents of autistic children. In this regard, CV, whose child is autistic affirms that: "...It must be said that it is an incurable disease..., malaria is not as small as cancer, but autism is

incurable...my child didn't make it, it's my way...". The idea that children will remain ill indefinitely affects the social environment, especially since the disease puts them in a situation of unproductivity and dependence vis-a-vis those around them. Thus, the risk of rejection and stigmatization because of children's illness is in the minds of parents of patients who make it a real concern. Thus, the outcome of the disease is a concern for people who know that their child's pathology may be "incurable". From then on, apprehensions of all kinds assail the minds in particular on the survival of the offspring, on the consequences which would occur after its disappearance. These apprehensions are legitimized by ideologies as to children's disease.

1.2. Social representations and perceptions of autism among actors

Sociological analysis can show how the social representations, that is to say the ideological productions of the parents are rooted in the social and historical reality of two entities (disease and childhood cancers), at the same time as they help to build them. It is therefore not a question of the physical illness in itself, but of the use that is made of it as a figure or metaphor by the parents.

- Ideology of the "curse" or the "transgression of the sacred"

The ideology of the "curse" or the "transgression of the sacred" is the one that dominates the social representations of the patient's parents. The perception of autism as a "mysterious" illness was evoked by most of the respondents. Indeed, if certain diseases offered a limited figurative use because they were not judged mysterious in themselves, but simply horrible, parents of sufferers think that the autistic disease is not only "horrible", but also mysterious. "I don't even know where this stuff comes from! It's a spell, it can't be explained" » From MG

- Ideology of "strange" disease and "dumb children"

Autism occupies a central place among the health concerns of parents of patients. Despite progress made in terms of care, it is still perceived today as the serious illness par excellence among parents. This idea emerged in the words of parents of patients during the present investigation.

The perceptions of autism still appear marked by a feeling of fatalism and resignation among the parents of patients. Almost all of the parents of patients here believe that no one is immune to the risk of an autistic child and they think that no one can avoid this pathology. This is why PN affirms that: "Autism, we can't do anything to avoid it... Autism strikes randomly, we can't do anything to avoid it".

While it is true that most surveys have given representations of cancers as devaluing, malevolent and other diseases, it is equally true that these images are not necessarily unanimous. Indeed, there are parents of patients who have different representations of this condition. The disease of autism as well as autistic people are socially devalued. According to the social imagination, those who suffer from this disease are stupid. That is to say social rejections, individuals without rationalities. They would act like animals. This is what emerges from the verbatim above: "He is rejected by his big brother with his remarks. My stupid little brother there". In fact, this discourse highlights a form of social dehumanization of children. It highlights a form of social disqualification that holds onto the social image of families whose members suffer from autism.

- Autism: the "dehumanizing evil and social death"

The chronicity of autism draws in some parents of patients a movement of rejection, which globally expresses that children with cancer are no longer men, are not considered as living. There is like a negation of a possible humanity in the affected subject (the child). Consequently, the perception of stigmatization or social relegation of affected people is present in the collective opinion. Disorders related to this disease in children are often synonymous with social exclusion and the associated shame participates in the revocation and stigmatization of the actors concerned and their parents, by proximity effect, to the relatives around them. It remains difficult to talk about it, to display and to live peacefully with children suffering from autism according to the parents. Related disorders therefore lead to situations of exclusion because of the taboo represented by these diseases and the symptoms that characterize them. Exclusion targets both sick people and their relatives. Shame, guilt and an extreme sense of duty often lock up and confine careers (parents) and cared-for (children) at home or in hospital

2. Autism Coping Strategies in Parents

2.1. The mobilization of spirituality as a ritual of making adaptation

It is the strategy that accompanies the spiritual perception of disease as a curse or a spell. Faced with the social stigmatization of child victims of autism as well as their families as an incurable disease and source of curse, families mobilize prayers. Spirituality appears as a source of inspiration for affective sociability within families. It constitutes a mechanism of activation of the divine to express the social pain linked to stigmatization. As a means of support, prayer and other beliefs used. This is seen through the following statements:

" Good for me it's a disease that tires the family and our child, the best thing is to pray not to have it. It's not easy given the rumors we hear, the autistic is as if the autistic is like that, you can't even see. When I first heard about it, they say there is a disease called autism if your child has it, it's for life and there's no cure for it. So

much that I was pissed off as the doctor reassured us, I understood. ". Mrs. Konan, mother of an autistic child

2.2. On the dedramatization of the disease of autism in parents as a source of adaptation

These surveys answer that one must normally fall ill. According to them, this is a normal event in the functioning of the human body. From this discourse, it can be argued that autistic disease is organic. In other words, it is a matter of organs, of a recognized medical specialty.

"When I discovered that my daughter suffered from this disability, I couldn't stand it at first. It was with the encouragement of my husband that I accepted and today I can say that it is a disease like someone who has diabetes. You can have an autistic child and live happily as a family. ". Mother KA, of a sick autistic child

2.3. On the mobilization of weak ties: associative participation as a strategy

Belonging to the association of parents of patients in Te Bonlé is a strategy for seeking therapy or taking charge of the disease by the parents. With the social resources that are offered there, this associative social space, by promoting acceptance of the disease of children by the parents, allows them to rebuild their identity and easy access to the biomedical sphere. At the structural level, as a resource, this association connects the parents of patients with the actors of the pediatric oncology department in the management of cases. Regarding symbolic resources, donations, for example, are forms of social mutual aid.

2.4. Improving the quality of intra-family communication

- Strengthening the emotional bonds between parents and children

Emotional ties develop through hugs and a lot through play. Parents use their child's interests to choose a game. Availability and listening with patience are values that guarantee adaptation to the situation.

"After all, you're playing for him, to make him happy!" By focusing on his interests, learning will be much easier; they won't have to put all their energy into getting him interested in the activity. So you can focus on the pleasure you get out of it. The parents place themselves at the height of their children, even if it means positioning themselves on their stomachs; you will clearly see his face and his facial expressions and will be able to more easily decode his emotions as well as his intentions".

- Organization of fun events

This is one of the most common and most developed activities of the association of parents of patients. In order to make life in the hospital as close as possible to the usual life of children or adolescents, the association organizes events to collect various entertainment objects such as toys, books for all the elderly. The presence of didactic and playful materials contributes to a reconstruction of the children's identity and their social adaptation to the chronic pathology from which they suffer.

IV. DISCUSSION OF RESULTS

The data of this study reveal that the forms of expression of the resilience of the parents of autistic children are explained by the mobilization of rituals and celebrations within the families of the autistic child, to the cultural and social beliefs of the family unit. . The mobilization of spirituality and the de-dramatization of the disease of children victims of autism in parents build family resilience. This result is shared by several authors. Thus AC Bissouma (2018), considers autism as disorders of the neurological and psychological development of the child which are neuro-developmental disorders with a kind of continuum of disorder which goes from autistic disorders which combine with developmental disorders intellectual. For him, we no longer speak of autism but rather of autism spectrum disorder. Thus Autism is not a disease but a handicap, a disorder. To this end, the author shows that autism becomes a social disease since it is a handicap that transforms the relationship of the patient to his social environment. This will influence families and their relationships with others. Cappe, bobet & Adrien (2009) through their recent data from the scientific literature provide an overview of personality traits, beliefs, social support, coping strategies that seem to have an effect on parents' quality of life. For them, the parents' quality of life is influenced by factors related to the characteristics of the autistic disorder and the special needs of the child. J.-C. Bensa (2001) goes in the same direction, noting that autism is a developmental disorder characterized by anomalies in social interactions and communication, by restricted interests and repetitive behaviors. This is an early disorder that can lead to severe disabilities and has significant repercussions on the family. The capacities of developing and maintaining a social network as a form of family resilience

Beyond social perceptions, there are abilities to develop and maintain a social network as a family resilience form of childhood autism that manifest social and economic support networks: family resilience factor, L relative autonomy of parents in the management of the disease of autism , patients and relatives and through a set of social realities linked to the experience of the child's handicap as a source of activation of the intra-family support networks of affected children of BMI. Indeed, social relations around the child's disability create a preservation of family solidarity because of the identity adjustment (preservation of strong ties): A renegotiation of the identity of the parents initiated by the pathology.

The results of this study agree with those of mc Gill, papa christoforou and cooper (2006) who show that parents report a lack of help and listening from professionals. The help provided appears to have been insufficient in the face of the request of these parents in distress. Thus in the same direction, Greeff & nolting (2013). Show that the various aids provided to parents and children must allow the reduction of the burden related to the child's disability and thus the improvement of the quality of family life. Thus for them, children with ASD manage to reconcile the requirements and particularities of the disability with the needs of the family and its members in their individuality as well as with the pressures of work and society, it is important to emphasize studies that have reported that a significant number of families of children with developmental disabilities are able to develop a healthy family life and a positive outlook on it through internal and external functioning.

V. CONCLUSION

The study on autistic children took place at the Center Marguerite TeBonlé at the INSP in Abidjan. The objective of the study is to analyze the resources or forms of expression of the ability to adapt mobilized by parents of autistic children and the justifications associated with their use at the CMTB in Abidjan. The use of several techniques appropriate to qualitative studies was necessary to collect data capable of giving answers to the questions raised by the study, in particular documentary research, direct observation, individual and in-depth interviews. The data collected were subject to a content analysis which shed light on the social implications and family strategies in the face of the disease in autistic children. This study shows that to see if the social perceptions of autism in children explain the forms of expression of family resilience by the ideological productions relating to social imaginaries, to identify the forms of intra-family social relations. Thus the analysis of the data made it possible to indicate the ideologies mobilized (perception on autism, belief on the therapeutic treatment of the child) to justify this behavior as observed in the actors. In addition, the analysis made it possible to describe the social relations (mutual aid relationship) between different actors and to identify the issues related to family resilience. In view of the foregoing, emphasis should be placed on the ideologies mobilized, on the preservation of links or relations with the environment and on the issues associated with this practice.

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