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Faith and belief in autism in Cote d'Ivoire : about Judith, God's strange gift

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Abstract

Faced with autism, motherhood and parenthood are turned upside down in many ways? coping with stress and mental health problems, continuing to assume a rewarding parental role and finding suitable care are the trials and tribulations that mark out the journey of African parents. Faith and belief have been described as providing meaning and coping mechanisms in the frightening ordeal of disability. An encounter with a young girl and her parents provided an opportunity to analyse the mother's experience and the impact of beliefs and discourses on her commitment to care. Based on this clinical story, we discuss the place of other-actors (parents and carers) and the Other-God in relation to the psychopathological dynamics of the mother.

Keywords

Maternal-autism-belief-other-Cote d'Ivoire

1. Introduction

Autism is a disorder that confronts us with the limits of our understanding and our humanity, and the meeting with the parents of autistic children in Abidjan raises questions about knowledge, about the possible evolution and cure of autism. These questions expose the beliefs of the parents, especially those of the mother. Believing in a possible outcome for the child is also at the heart of parental guidance, to enable parents to get back on track. For many mothers, faith is a crutch. It enables them to face up to the long road they have to travel in the face of autism. This road begins with

the announcement of the diagnosis of autism and disability, which has a traumatic effect. By shattering the mirror and causing a narcissistic wound [1], disability alters the way we recognise others. It confronts us with the dread of the strangeness we carry with us. Indeed, these children who carry a difference are strange [2]. The silence of these strange children, who do not always speak, is heavy, as is the difficulty of meeting their gaze. In Côte d'Ivoire, many parents experience autistic symptoms as a refusal by their child to be with them.

Based on the story of a child we will call Judith, followed in child psychiatry at the INSP from 2015 to July 2023, we will examine the maternal experience and the psychopathological factors that influence it. Thus, the psychodynamic reading of Judith's clinical history and the idiographic approach will enable us to highlight the importance of the msyticoreligious dimension in the management of autism in Abidjan.

2. Observation: Judith, the strange child and her encounter with "others "

Judith was 2 years 6 months old when she was seen by a child psychiatrist for language delay with psychomotor regression. The youngest of nine siblings, her history was marked by an early refusal to suckle her mother's breast. The history revealed the first signs of autism at around 9 months, marked by a communication disorder (no speech, reactivity to his name, jargon) and instability. "I noticed that there was something wrong with her behaviour", says her mother, referring to the strangeness of her daughter. The team treating her diagnosed her as suffering from infantile psychosis, and an electroencephalogram revealed associated diffuse brain damage. Just as this mother was looking for a medical solution, she was given a diagnosis of psychosis. What does this mean? We don't think that this suggestion was linked to a genuine psychotic state in the child, but rather to the fact that until 2010, autism was still classified as a child psychosis in Cote d'Ivoire. Since then, the knowledge of professionals has greatly improved.

She was seen again at the age of 4 in 2017, at the request of the paediatrician, who wanted her to join the brand new child psychiatry department for children with autism that had just been set up at the INSP. Her treatment pathway had been chaotic, and she was attending mainstream school with speech therapy sessions, but despite the improvement in her autonomy, the signs of autism were severe. Judith was a late arrival, her mother was 45 and her father, a pensioner, had little interest in this umpteenth daughter and was hardly present. Along with her eldest daughter, the mother bore the burden of this child, who was rejected by the neighbourhood because of her quirks (tiptoeing, jargon, sign language, etc.). The parents have lots of questions: "They haven't told me exactly what's wrong with her. It was the speech therapist who asked me to attend International Autism Awareness Day to get a better understanding". At this consultation, the child psychiatrist explained the procedure for drawing

up the assessment, and urged the parents to get involved because "there are no miracle solutions, you need the parents to get involved!" An injunction that would later prove to be inappropriate.

An interview with the psychologist reports other elements of the mother's discourse: "My daughter used to talk, then everything stopped, I came here, then I interrupted the treatment before coming back. Until then, no one told me anything. It was very hard for me to see my child in this state and I said "why me? what did I not look after properly? It hurt, but the doctor's explanations helped a little. During the two years I was off work, I did some indigenous medicine (Traditional therapeutic practices based on ingur-giter decoctions or purges). With leaf baths given by an old Malian (Here, the mother recalls the Malian-born traditional therapist she consulted for traditional treatments). There were also prayer sessions, because the pastor said that people (enemies) had set their eyes on her out of jealousy and that he had to redeem her soul. He also recommended baths with olive oil and salt to put in her water. All these practices haven't worked. I'm waiting for the results of the assessment, I know that my child has autism even if I don't know much about it. My big problem is that she disturbs everything without tidying up and we have to sweep up after her 5 or 6 times. The maids refuse to stay with us. Even though she says that she has moved from pain to acceptance, there is a strong sense of ambivalence in her speech, between love and hatred for an unexpected and disturbing child.

The clinical and developmental assessment carried out at the CMTB confirmed a diagnosis of autism with severe cognitive impairment and language delay. Judith joined the day hospital in April 2018. She took part in Ateliers-Classe Préaut for two years, which led to a clear clinical improvement and the possibility of returning to school.

The parents are involved in the care and take part in the activities (regular consultations, parenting support, training, etc.). The mother's experience is difficult when faced with a child who is aggressive and violent towards her mother. "She's mean because she refuses to talk, she talks once and then she doesn't talk again", explains the mother, who hits her when she gets fed up.

The summary of progress made in March 2019 shows that the child's adaptive capacities are developing well. The father is satisfied, but the mother complains that she gets very dirty and refuses to brush her teeth. She points out that she can go and play with another child. She is gradually integrating socially, and distinguishes between the school and the church, which are on the same premises. She makes a lot of noise and sometimes isolates herself. Her mother's comments fluctuate between complaints and recriminations, but the progress she herself mentions has no positive effect on her. There is a strong ambivalence and rejection of what the child can be or do, as this is not what the mother expects.

The care team's assessment of the child's development is positive. The mother asked how she could help her at home. The interview revealed that the parents were more

tolerant of their child's autism, although the mother showed many signs of nervousness, whereas the father was more overprotective.

Six months after this interview, the mother felt that the child's progress had been limited and, once again, her discourse vacillated between evidence of progress and complaints that the child had not returned to normal. She complains about the little girl's crying, signs of autism, instability, imitative behaviour...

Everything is a cause for recrimination for this mother.

In April 2020, during the Covid-19 confinement period, the care team called the mother regularly, who reported that everything was going well and that Judith was adapting well. She was able to carry out the household tasks assigned to her. However, when care resumed after the health crisis, the mother announced that she had lost many of her skills. The parents are distraught because they can't get their child to obey them: a child who doesn't fall into line, who doesn't bend to parental will, as any "good" African child would. This child is a child who brings opprobrium on his parents.

Between 2018 and 2022, we have seen a significant clinical evolution. Language has appeared and his cognitive functioning has clearly improved, making mainstream schooling possible and productive. The child is autonomous and, paradoxically, the mother is asking for her autonomy to be improved. Interviews or informal exchanges with the mother always bring to light questions linked to dissatisfaction with the progress, and the search for the origin of the disorder: "I prayed too much for it to end, I made all sorts of prayers, I was told it was a spirit, we made all sorts of sacrifices... if the disorders were caused by a demon, she would have been freed a long time ago... I know it's autism, but where does it come from?"

Judith's strange behaviour has lessened.

The death of her father in 2023 breaks the evolutionary momentum. While Judith had become much more aware of herself and the people around her, her father's death seems to have plunged her into indescribable confusion. The mother recounts that shortly before his death, the father was quoted as saying, "My daughter is a gift from God, today she doesn't speak all the time, but there will come a time when she will, and I forbid you to tell her to shut up then. She will surprise you with her progress. Take care of her, she's precious"... " The mother hadn't understood what her husband was telling her. She recounts how Judith took care of her father, giving him his medication. She seemed to be the only one who knew that the inevitable hour had arrived. When her father died, she stopped trying to adapt and withdrew into her autism, as if she were turning in on herself. The work of mourning is not supported, the death is not named, the father is no more and his absence is there. Judith has lost her moorings and no one is thinking of working through the loss, neither the family nor the care team. Problem behaviours began to emerge: she self-harmed, stopped taking care of herself and undressed in public. She no longer washes herself, is careless and no

longer obeys... The achievements of recent years have collapsed with the disappearance of the father figure.

The father had gone from being indifferent to being present, a player in the care and management of the child. He had become a guardian and protector, the foundation of progress, committed to progress where the mother was running out of steam, suffocating herself with various preoccupations unrelated to the progress achieved.

This clinical story highlights several psychopathological elements that need to be taken into consideration: the strangeness of this different child, the belief in a mystico-religious cause, the pseudo-belief in possible care that life's ups and downs crumble, and the discursive construction of a possible being-mother/being-father/being-caregiver for a different child. Otherness is here the substratum of elaborations.

2.2. Discussion

2.1. Discourse, Belief and Otherness

The Ivorian is profoundly religious, as has already been written and demonstrated, but how does this manifest itself in care? The question of religion and belief arises essentially in the search for aetiology: Where does autism come from? What is the cause? Who is responsible for this state of affairs?

The search for a mystical or religious origin is the first parental quest. Indeed, African thought looks for a culprit to explain what is wrong [3]. African cosmogony is like that. In its existential approach and in its conception of life, the idea is that what goes wrong is always the fault of the evil eye and due to the shenanigans of the Other. The Other is all too often punishing, even malevolent. Nothing is ever simple. You can see this in care. Medical explanations often appear strange to parents, and negative counter-transference makes it clear that the medical discourse has no resonance. "You're the one who knows what you're saying, otherwise in our village, when a child doesn't speak, it's because the spirits are holding his throat". This is what one parent had to say when the diagnosis was announced. Whether during a child psychiatry consultation with the mother of a child with autism or during a psychosocial interview, the question of the origin of autistic disorders is omnipresent.

It is certainly less psychologically costly to look for someone to blame than to come to the conclusion that, as a parent, you are somehow responsible. In the West, developments in knowledge and attitudes have enabled parents to feel less guilty about autism. In Africa and Côte d'Ivoire, however, parents tend to blame themselves. Professionals explain that autism is a multifactorial disorder for which parents are in no way responsible, but unfortunately parents are consumed with blaming themselves in all sorts of ways or looking for someone to blame. On the one hand, this makes it difficult to establish a quality therapeutic relationship, and on the other, the parent becomes involved in the search for a miraculous solution. Many parents in Côte d'Ivoire look for answers in the many offers to cure autism by various means (chloride,

stem cells, dietary restrictions, prayers for deliverance, etc.).
In this way, disability creates a before and an after. It's like a tile falling on your head and knocking you out [4]. Aware of this, the care team needs to find the right switches to support the parent through this painful process, to give meaning back to the family. In Judith's story, the question of origin is central. Every interview leads to this question, which seeks to understand why her daughter has been struck with such a fate. Analysis of the mother's discourse shows that she has difficulty identifying with this strange child and perceiving him as her own. Oscillating between complaints and demands, this discourse confronts and questions the medical discourse. Indeed, when Judith and her strangeness arrive at the child psychiatric clinic, the medical discourse makes no sense and the maternal psyche is convinced of a supernatural cause attested by the pastor. What does medical discourse convey? Knowledge that does not know. If it is not the therapist's vocation to find the answer to every question, isn't not knowing the answer to autism a disavowal of his or her knowledge? Is not providing a clear answer to the parents' recurring quest for the truth proof that medicine does not know? In our socio-cultural context, faced with a lack of structures and professionals trained in autism, therapists can quickly feel overwhelmed and have difficulty constructing a discourse and a position that enable them to inhabit the place of the primordial Other [5]. And if professionals need to know, what do they know about autism in its African socio-cultural context? There is little written on this question.

Konan [6] has begun a reflection on this subject that needs to be pursued, because it seems to us that parental disbelief echoes the disbelief of the carer, who is himself caught up in his own representations of disability. Thus, at the frontiers of the human, of what is thinkable, of what can be symbolised and subjectivised, of what can be shared [7], carers sometimes fail to construct a coherent discourse and to convey it calmly and in a caring manner. This makes it even harder for parents to grasp the care on offer.

This is where the rise of traditional care practices in Africa comes in. Taken from the perspective of ethnopsychiatry, they provide a treatment response imbued with culture and mysticism. The traditional therapist speaks to the other person in a way that echoes his or her beliefs... in principle. Except in the case of autism. How do you get people to talk about a disorder that cannot be named, that is unnameable and unrepresented? How do you find the cultural switches that enable parents to understand the socio-cultural and mystical-religious meaning of this particular experience?
These questions raise the issues of strangeness and otherness. Otherness is the characteristic of that which is other, of that which is external to a 'self', to a reality of reference: the individual, and by extension the group, society, thing and place. Autism alters identification and immediately establishes the mother-daughter relationship as

one of strangeness. As Allouch [2] points out, there is a failure of the primary operation of erogenisation of the body, with a failure to establish the first affective bond (or primordial identification) with the Other. Otherness rhymes with strangeness in autism, and the autistic person takes no account of the will of the Other, as Allouch [2] points out. For the African, there is only a mystical cause that can explain what is happening. Faced with this belief, medical discourse stumbles.

Judith ignores her mother's wishes and goes her own way.

2.2. The mother: breakthroughs and identifications in the face of autism

The various protagonists in this clinical story are questioned by the mother and her suffering relatives in the face of infantile autism.

There is knowledge that is not imprinted in this mother, and she sees her daughter as a bad object, a persecutor. What is this knowledge? It is that of medical-psychological science, which has defined autism as a neurodevelopmental disorder, whereas African knowledge perceives it as a curse that strikes a child who, coming from elsewhere, is the bearer of a spell. Medical knowledge is contrasted with African beliefs [8]. Medical knowledge and African beliefs are contrasted with the hope born from faith. How does the mother manage to disentangle herself in the tangle of everything that assails her, in this collusion of knowledge and thoughts? It is certainly this collusion that sustains the mother's fear. The mother projects her own dread onto her child, turning her into a frightening being. She finds no pleasure in her daughter and is not happy about her progress. The mirror is broken, and Judith is a disturbing figure, a monstrous double who devours the maternal psyche, as described by Scelles and Korff-Sausse [7].

This absence of enjoyment on the horizon of autism, or its inconstancy, which exposes the mother to many moments of doubt or frustration, is an unspeakable pain for the mother. Many mothers wonder what they could have done to God to have such a child! As we can see, identifications are dehumanising and the mother suffers as a result. In fact, she has difficulty constructing a coherent and acceptable representation of being a mother for this strange child. While we need to think about 'normality' and 'abnormality' in terms of the links that exist between human beings, and between human beings and their environment, as recommended by Scelles and Korff-Sausse [7] and Rapp [9], we have to recognise that this is not easy for the person caught up in the spiral of disability, and Judith's mother has enormous difficulty thinking about her daughter in a different way. In fact, the increase in the child's adaptive capacities does not open up any prospects for her.

Autism is. Undeniable. Indubitable. Presently, we have must deal with the bitter harshness of its hermeticism and the audacity of its problematic behaviours. Faced with autism, mothers suffer, marked by setbacks and hopes, errors and educational wanderings. The support of care teams is important in supporting a parent who is

adrift.

The work of Korff-Sausse [2] shows the traumatic effect of disability on the family system: how do you accept the unacceptable? Does a child's disability feel like an earthquake or a bomb exploding?

This mother asks herself a lot of questions that cannot be resolved for lack of answer that would repair them. These questions have been found in other contexts [10].

Isn't autism the murder of a mother's pleasure? Mothers find it difficult to establish a valid, recognised and exercised maternal status. So how can we help mothers to re-write their kinship and define a new living space so that they can live together to their full potential? Albert Ciccone writes "Disability affirms otherness too early, too violently and too absolutely" [11]. Autism has a traumatic effect.

The maternal thinking of Judith's mother is, as Boublil [12] puts it, a "savage thinking" built on the myth of the child of the blessing who is beset by evil and turns out to be harmful to her family. Parental logic defies the reality of autism, and the lack of a place for conciliation produces great suffering.

In our context, as elsewhere, the discourse, thinking and actions around disability and vulnerability are not entirely free of the religious sphere [13]. African beliefs reinforce this state of affairs.

2.3. The father, between reparation and registration

In the early stages of the care process, the father was of little help, reproaching his wife for her maternal upbringing, but offering no respite or alternative. He was very tolerant of his daughter's attitudes. In an interview conducted in 2019 as part of a report on the CMTB, he said "I've tried everything, if it was an illness, she'd already been cured... we don't know where it comes from". You can hear in these paternal words, despair and resignation in the face of autism.

Gradually, he became more present and his support enabled Judith to be supported and given a place, but also to be included in the family history. The father's psychic work and his support enabled Judith to gradually become independent and to blossom. The father's reported discourse at the end of her life shows the symbolic place assigned by this father to his daughter, and the support that had gradually been built up over the years. In the father's mind, Judith had become a child, a living person, part of her social group. The death of her father, however, seems to have robbed her of the possibility of existing, and her achievements crumble. Judith's father was the one who accepted and welcomed her, without any injunction to be, and in the freedom to be what she was, Judith had become a child in her own right. He disappears, and with him dies the psychic tutor who had enabled Judith to grow. As Allouch [2] goes on to explain, the father seemed to Judith to be the 'helping other' who had enabled the body of this strange child to come to life and move its physicality in relation to the Other, to others and to herself.

2.4. The role of carers and the role of God

The Other is the carer, or even the care team, and first and foremost the therapist who makes the terrible announcement. The therapist wears the evil mask of the one who announces death. In the African context, the announcement of a diagnosis of autism is not far removed from a social death.

Abid [14] has shown that when mothers are told they have autistic children, they experience significant denial and rejection. To cope with this, they turn to religion to help them accept the diagnosis. In this context, what could be the effects of collusion between maternal beliefs and those of the 'professionals'? Does this not lead to a need to water down the announcement?

This clinical story provides food for thought about the appropriate medical discourse in the Ivorian context, not only for announcing the diagnosis but also for accompanying mothers who are lost in the midst of a flood of information from social networks, religious leaders, social workers and health professionals. Medical and societal responsibility is engaged here to build a discourse that carries meaning for mothers mired in existential nonsense.

This is why Meirsschaut [10] pointed out that maternal stress and depression have a major impact on maternal cognition, and that it is therefore important for practitioners to take account of parental experiences and become aware of the maternal feelings and cognitions that interfere, such as guilt or lack of parental self-efficacy.

The Other is also "God". It is also the place for God. Between a god who knows and a god who speaks [15], Judith's mother, in her quest for the saving Other, knocks at every door and attempts every kind of care. A quest for care coupled with a quest for God, God the saviour and rescuer. For Bousseyroux [16], "God is the function to which we assign the pleasure that escapes us". Is God, this God who seeks and questions himself about autism, still the God-Love of believers [17]? The question is: "Can we love autistic children? At what cost? Love should be given to the other who resembles us, driven by narcissism [18]. The Other we see in our neighbour is a reflection of who we are. Judith's battered image of her mother awakens a darker side in her, a source of uncontained aggression. And also anxiety, distress…

Judith gives rise to many questions: Is Judith raising the issue of belief?

Belief in healing. Belief in the mystical origin of disorders. Belief in medical knowledge. For Nominé [19], belief is founded on a belief in meaning and in the existence of a subject who holds that meaning. For this author, belief implies a saying, a writing and a being who is assumed to enjoy the meaning we lack. Drawing on Lacan, he argues that belief always implies meaning and a promised jouissance on the horizon. On the horizon of autism and Judith's disorders, enjoyment is nowhere to be seen. To compensate and make sense of it all, some mothers disinvest in their child, while others over-invest and love their child too much, as if the excess were compensating for the child's lack of love and rebalancing the balance of eros.

To love the other as oneself is to love the strangeness in the other and to accept our

own strangeness, the dark part of ourselves that we don't always want to see.

While Naomi [20] finds that a religious belief reduces mental health problems in mothers dealing with autism, in this monograph we see that the lack of solid support for Judith's mother's belief, as she is tossed around between several different types of knowledge that do not tie in with each other, is probably a factor influencing the distortions observed.

3. Conclusion

Ouattara[21], whose child was cared for at the CMTB for several years, has published a book entitled "La chance d'avoir un enfant autiste". In this autobiographical work, she evokes God, thanking him for her child's progress. In it, she bears witness to her belief in God and to the effects of discourse, whether that of her motivational inner voice, which sometimes rides the waves of despair, or the pitfalls of the pseudo-enlightened discourse of professionals.

Is it really an opportunity to have an autistic child? An opportunity for whom? For what?

It seems that the good fortune lies in the rearrangement of existential lines and in the possibility that autism offers of living with a family in a different way, in giving and surpassing oneself. Judith appears to be a skittle that restarts the drive of her family, but also of the care team, because the new signs that appeared with the death of her father force us to leave the comfort zone we had built up over the years, to go back to searching, working, understanding and returning to the position we had at the beginning of being caring others.

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