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Psychotraumatic Stress in Parents of Children with Autism Spectrum Disorders

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Abstract

This decade has produced many scientific works on Autism Spectrum Disorders (ASD) with a special focus on the various characteristics of the different types and how to support children who manifest specific symptoms. However, scholars have yet to produce sufficient work on the psychological effects of having children with ASD. The objective of this study is to investigate psychotraumatic stress in Congolese parents of children with ASD. The clinical method and the Posttraumatic Stress Disorder Checklist Scale (PCL-S) were used in this research. While the former offers the opportunity to explore the suffering related to psychotraumatic stress experienced by Congolese parents of children with ASD, the latter gives a quantitative description of the psychological details. The results of our investigations show the presence of psychotraumatic stress in Congolese parents who have children suffering from ASD. This study, therefore, concludes that Congolese parents who have children with ASD suffer from psychotraumatic stress disorder, and there is a need to give them the necessary attention.

Introduction

From the beginning, autism has been perceived as a mysterious condition. It should be noted that "the prevalence of autism is now estimated to be 1 in 200, but with the proviso that the diagnosis be extended to the entire autism spectrum and Pervasive Developmental Disorders "PDD" [19]. Studies around the world have shown that childhood autism is a "pervasive developmental disorder characterized by abnormal or impaired development before the age of three years and with characteristic disturbance of functioning in each of the following three psychopathological domains: reciprocal social interactions, communication, behaviour (restricted and repetitive)" (Romagnola, 2014).

There are eight categories of autism, namely: infantile autism, atypical autism, Rett syndrome, other childhood disintegrative disorder, hyperactivity associated with mental retardation and stereotyped movements, Asperger syndrome, other pervasive developmental disorders and pervasive developmental disorder, unspecified (ICD-10). According to Autistes Sans Frontières [5], the preference for "Autism Spectrum Disorder (ASD)" rather than a simple term such as "autism" is due to the diverse and complex nature of the definition of autism.

Many authors focus on the support of children with autism, but do not provide sufficient information on the psychological consequences of this condition on the child's family. This is why the present study proposes to examine psychotraumatic stress in parents of children with autism spectrum disorders. The psychological suffering experienced by the parents will depend on the attachment relationship they have with them. Some authors provide useful information on this psychological distress.

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According to Timmons et al [33]: "Having a sibling with autism can be difficult and complicated at times. Siblings of children with autism may feel neglected, embarrassed and confused". These authors emphasize the aspect of neglect which other siblings may suffer.

Parents of children with autism also suffer greatly from their child's illness. Isabelle [21] thinks that it is difficult to live with such heavy burden; you would want to talk about it. Thinking about the cost of treatment, the future of the autistic child and above all the dual demands of caring for one's child and performing well in the workplace, overburden and stress parents. Laws creating favourable conditions for the development of the child and the fulfillment of parents do not prevent parents from feeling guilty.

The lack of sufficient care for the suffering of parents of children with ASD is still an all too common reality. For most parents, it is a psychotraumatic stress experience. That is, the structures put in place to assure parents of a better future for their child do not measure the psychotraumatic stress of parents caring for their autistic child. Powers [29] writes: "Parents, when they first learn that their child has autism, typically have a shock reaction, feeling helpless, guilty, angry and resentful".

Having understood what autism is and that relatives of a patient (especially parents of a child with autism) might experience traumatic suffering, the general problem of this work is to examine the presence or not of psychotraumatic stress in parents of children with ASD.

Psychotraumatic Stress

Psychotraumatic stress is defined according to the theories that underlie it. Regardless of the orientation, psychotraumatic stress refers to the psyche. The different definitions of psychotraumatic stress complement each other. It is good to note that one normally moves from psychotraumatic stress to post-traumatic stress and not the other way around. Thus, Tarquino and Montel [32] define psychotraumatic stress as "a phenomenon of invasion of the psyche and overflow of its defenses by violent excitations related to the occurrence of an event that is aggressive or threatening to the life or integrity of an individual who is exposed to it".

To avoid confusion between stress and trauma, we define stress as a "bio-physiological reaction" [18]. This reaction is manifested in order to adapt to events as well as being an outdated (pathological) reaction. According to the same author, trauma is a "psychic and somatic disruption". The disruption can lead to what is called a psychological injury. It is worth noting that trauma can be experienced, perceived or felt, and the reaction in trauma can be immediate, post-immediate and delayed. For an individual to have trauma, "their integrity as a person must have been damaged" [34].

Post-traumatic stress disorder is "a disorder that results from unusual traumatic events" [30]. The event in question here may be the fact that one's child is diagnosed with autism. This is something exceptional in a family; the parents may manifest all the characteristics of someone who has experienced war, sexual violence, etc. Parents whose children have ASD may suffer from secondary stressors (such as lack of social and emotional support, loss of friends and social isolation), and when these are not well managed, parents will suffer from psychotraumatic stress.

Flavie [18] lists three different victims of trauma:

- **Direct victim** refers to all people exposed to a traumatic event. The person is more likely to be traumatized.
- **Indirect victim** refers to those close to a victim who have not experienced the trauma. They are less likely to be traumatized.
- **"Secondary" victim** refers to people such as rescuers, who take care of victims. This group of people is exposed to trauma and burn-out.

If the announcement to parents of their children's autism spectrum disorder is a traumatic moment for them, and these parents are called upon to take care of their children with autism, we believe that they could be among the indirect victims and/or secondary victims. A diagnosis must be made by a qualified physician (a family physician or psychiatrist) or a licensed psychologist; it must be based on a clinical examination, and the supporting documentation must be as complete as possible [3] (modifié en mars 2016).

The DSM-V criteria (2013 English version) that tell us about trauma are:

- *Criterion A = Traumatic experience:* It is a traumatic event that can cause serious psychological injury.
- *Criterion B = The event is constantly "relived"* (symptoms of intrusion or recall): This is the presence of one or more symptoms of intrusion that begin after the trauma has occurred (e.g. repetitive and involuntary memories of having brought an autistic child into the world).
- *Criterion C = Avoidance: 1 in 2 symptoms:* Avoidance or attempts to avoid thoughts, feelings, sensations, memories that are closely related to reality (e.g. having an autistic child).
- *Criterion D = Negative alteration of emotions and mood:* This is the persistent negative emotional state (fear, anger, shame, guilt).
- *Criterion E= Neurovegetative hyperactivity:* Self-destructive or risk-taking alteration or reaction such as exaggerated "startle"; concentration problems; sleep disturbance.

The treatment or management of a traumatized person or one who is in a state of post-traumatic stress can take several forms. These may include psychodynamic approach, cognitive behavioral therapy, systematic exposure/desensitization, Stress Management techniques, cognitive therapy, Eye Movement Desensitization (EMDR), interpersonal therapy, systemic approach and pharmacotherapy. Thus, in order to prove the presence of psycho-traumatic stress in parents of children with autism, we need to look at how the subject copes with stressful events, but also at the meaning he/she attributes to what he/she sees as a disability in his/her child.

Autism

Etymologically, the word is derived from the Greek "autos" meaning "self" [25]. Historically, the term "autism" was first borrowed from Eugen Bleuler. According to Georgieff [19] Eugen Bleuler used the term to describe the autistic person's isolation, withdrawal into the inner world and disconnection from reality. He made autism a secondary symptom of schizophrenia until the early 1940s when the American psychiatrist Leo Kan-

ner decided to place autism in a different category.

The Direction de l'Education Française [17] describes autism as, "a physical disorder of the brain causing permanent difficulties in development". In other words, when the brain is affected by this disease, the person will have difficulties in several aspects: mental development (cognition), language, communication, relationship. This can lead to some difficulties related to motor skills and adaptation. As for Leclerc & Charbonnier [25], "autism is a neurodevelopmental disorder of biological origin that manifests itself early in children". This author privileged the biological aspect of the cause or origin of this disease.

Bettelheim [12] promoted the theory of the "refrigerator mother". He, who lived for 10 months in the Nazi concentration camps, associated the life of an autistic child with the experience of the prisoners of these camps. In particular, he compared the mothers of these autistic children to Nazi guards. The etiology of Autism Spectrum Disorders is multifactorial. Bellusso et al, [10] assert a neurological basis.

Autism disorder was included in the DSM in 1980 under the term "childhood autism". The latter was considered in 1983 as "global developmental disorders" [25]. Autism was recognized as one of the developmental disorders and the term "PDD" used in the DSM-III R in 1992 was used in relation to socialization and communication disorders that "pervade" all aspects of children's lives.

In the DSM-IV "autistic disorder" was classified in a group of five with other Pervasive Developmental Disorders (PDD): "Rett syndrome", "childhood disintegrative disorder", "Asperger syndrome" and "pervasive developmental disorder not otherwise specified". The different categories of Pervasive Developmental Disorder are: childhood autism, Asperger's syndrome, Rett's syndrome, childhood disintegrative disorder and atypical autism.

According to Barthélémy et al, [7], autism disorder disrupts an individual's behaviour on three levels. Leclerc & Charbonnier [25] refer to these three levels as the "autistic triad". These are Socializing Behaviour, Communicative Behaviour and Coping Behaviour.

According to La Haute Autorité de Santé [20]: "ASDs bring together diverse clinical situations, resulting in heterogeneous disability situations". This means that the person with autism could suffer from one or more forms of disability. According to Aussilloux and Barthélémy [4] autism is a "handicap for the person, consequences on the family". In other words, the relatives of an autistic child suffer psychologically and can be traumatized.

Autism is considered a disability because it's most severe forms involve a lack of interpersonal relation, social interaction and verbal and non-verbal communication. Since the discovery of the seriousness of the handicap associated with autism, several laws have been enacted in Western countries (France, Germany, and Belgium) to support autistic people but also to reassure their parents of a good future and to lower the anxiety of parents.

In the Democratic Republic of Congo, there are a few centers to welcome and accompany autistic children and to ensure their future. This is the case of the Unité de soins et de recherche en psychiatrie infanto – juvénile, opened since 26 November 2017 within the Centre Neuro Psycho Pathologique de l'Université de Kinshasa (CNPP/UNIKIN). This unit offers adapted care to autistic children and other children disturbed by psychiatric conditions. Unfortunately, some parents still keep their autistic children at home.

The number of children affected by autism worldwide varies. According to the Direction de l'Education Française [17], "autism strikes four times more boys than girls". The Suisse Romande [31] report is worrisome. According to the report: "Globally, we could therefore say that 0.9% of children are affected by Autism Spectrum Disorders (ASD), which would give Switzerland a population of approximately 150,000 children aged 0 to 19 suffering from ASD". In this case, it is possible that many parents of such children are victims of post-traumatic stress.

What these studies have in common is the growing incidence of autism in today's society. Their results point to a high number of parents living with psychological trauma. The increase in cases of children with autism logically means an increase in the number of parents suffering psychologically from having a child with autism. In Africa, keeping children with autism at home, isolating children with autism makes it difficult to know the growth rate and number of children with autism.

Chamak [16] also argues that in Africa autistic people are sometimes seen as idiots, victims of mistakes made by their parents or other family members. Some equate the autistic "with those who have witchcraft or those who carry the curse of the family line" [16,23]. According to Wassa [24], Africans believe that the cause of autism is supernatural, i.e. either the child or its mother is under the influence of an evil spirit. Africans do not often think of brain, genetic or environmental causes. They find all the gestures and behaviours of an autistic child strange, they suspect him to communicate with spirits. Muadi-Mumba (2018-2019) would say that Africans used to consider autism as a punishment for a fault committed or a duty missed.

It is difficult to pinpoint the causes of autism to this day. However, the opinion of researchers is that "several factors play a role in its development. Genetic predispositions as well as, probably, biological processes occurring either before, during or after birth are likely to disrupt brain development" [31]. This is why Beaulne [8] argues that "the diagnostic accuracy of autism relies, to a large extent, on the etiological component and, in particular, on the ability to distinguish primary from secondary symptoms".

The diagnosis of autism is purely clinical [7] (Switzerland 2011). To date, a valid medical test for diagnosing autism has not been found. Since the treatment of autism is difficult, we talk of early diagnosis. Early diagnosis provides parents with information that enables them to take effective action, including finding appropriate care. It allows them to better understand the difficulties they encounter with their child. Early diagnosis thus enables parents to adapt their behaviour, education and stimulation to their child's specific needs [5].

Among the tools for diagnosis and functional evaluation of autism, the most effective would be clinical observation. The latter is multidisciplinary, i.e. a holistic approach is needed to understand the real problem. Baghdadli [6] offers essential tools in the diagnosis of autism: Parental observations, Clinical interview, Autism Diagnostic Interview Revised (ADI-R), The Autism Diagnostic Observation Schedule (ADOS-G), Childhood Autism Rating Scale (CARS). Functional assessment tools for autism include Observation with apparatus, psychological (or cognitive)

testing, Vineland Adaptive Behavior Scale: VABS (the Vineland scale), Autism Behavior Assessment-Revised (ABAR) scale.

Baghdadli [6] underlines the conditions to be fulfilled before the announcement of the result to the parents of a child with autism: 1) This information must be given in the department where the diagnosis and the evaluation were carried out, ensuring the conditions of reception of the families, respecting a delay which should not exceed 1 month; 2) The announcement of the diagnosis must be made in a framework allowing a discussion of sufficient duration with the parents, by giving them the possibility of asking questions and of exposing their point of view. The caregiver must take into account the particularities of each family and each child with autism. They should be aware that each family has its own unique patterns of interaction. In addition, the family situation in all its cultural, social and economic diversity counts a lot [20].

Afterwards, parents must in turn tell their child about the diagnosis. According to Timmons et al [33], "parents often wonder when is the best time to discuss autism with their child". In other words, there a specific time or age when a child with autism should be informed of their diagnosis. It is advisable for parents to bring up the subject of autism spectrum disorders before the child hears incorrect information from another person, or before the child has a negative experience, or when the child realizes that he or she is different, or when he or she starts asking questions.

To date, there is no drug treatment that can cure autism. The specific pharmacological treatment for autism that exists directly targets certain associated symptoms [7]. The Haute Autorité de Santé [20] is of the opinion that "psychotropic drugs can be considered as a second-line treatment (depression, anxiety, behavioral disorders)". In addition, there are several therapies that could be administered to a child with autism, the biological treatment, the pedagogical or educational treatment. But in Africa, the therapy consists in subjecting the parents and the child to exorcism sessions through prayers. Sometimes, certain medicinal herbs are given to the autistic child [16].

Parents of children with ASD

The phrase "parents of children with ASD" implies parents who have given birth to a child with ASD. They may be either their biological parents or adoptive parents. The suffering experienced by parents who have such children predisposes these parents to suffer from Psychotrauma [19]. Thus, the idea of parenthood is important to better understand the psychological suffering of parents of children with ASD.

Parents of children with ASD could show signs of some psychological grieving behaviours when they are told the diagnostic result of their child. Many of the parents would be shocked, they will report denial, guilt, detachment but also reorganization towards the announcement of the illness their child is suffering from [14]. The psychotraumatic stress of parents of children with ASD is still poorly understood. Firstly, it is not well known because it is believed that the relatives of a patient who provide support cannot suffer. Secondly, caregivers and the medical profession ignore psychological suffering and treat it as a mere emotion. We believe that the psychological attachment of parents to their children creates a strong commitment to get involved in various ways to help them.

Parents are involved in the diagnosis, screening and care processes because they know the patient's history (background, wishes). They have protective (advocate), facilitative (translation, explanation, interpretation) and supportive roles with the person with autism [22]. The Haute Autorité de Santé [20] emphasizes the responsibility of parents; it recommends the association of the person and their family in the evaluation of their situation, the co-elaboration of the project with their family, their support and accompaniment whatever their sector of activity.

It is the parents who provide all the information that can facilitate the diagnosis of autism. For this reason, Barthélémy et al [7] state that precise communication with families, who are particularly in demand of innovative treatments, is therefore desirable. Since parents are the closest to the child, they are often the ones who ask the first questions and express the first doubts [11]. Brelot [14] states that parents are usually the first to see abnormal behaviour in their child, as symptoms appear before the age of 3. Several warning signs can be noticed in early childhood, such as loss or regression of language or social skills as well as the absence of name calling at 12 months.

The involvement of parents of an autistic child in screening is not deep because many are not familiar with the scientific procedures to be followed. However, Barthélémy and his team is of the opinion that parents of autistic children are directly or indirectly involved in the care of their children. Doctors provide parents with information to follow. For example, they must respect the initial psychotropic prescription (neurologist or psychiatrist) because there is no argument in favour of combining psychotropic treatments. With regard to the responsibilities of parents towards an autistic child, parents in particular are neglected and suffer. Such neglect results in exacerbated psychotraumatic suffering of parents who experience the event of their child's disability.

Our concern in this work is to find out whether Congolese parents with autistic children also show signs of psychotraumatic stress. Specifically, we ask the following questions: What are the symptoms of vicarious psychotraumatic stress exhibited by parents who have a child with autism? What is the impact of the variables gender and level of education on the stress experienced by these parents?.

Objective and hypothesis

The general objective of this study is to investigate psychotraumatic stress in parents of children with ASD. As for the specific objective, it consists of 1) Identifying the clinical picture of vicarious psychotraumatic stress symptoms in parents with a child with autism; 2) Determining the impact of the variables gender and place of residence on the stress experienced by parents of children with autism.

Our study has a double interest: a scientific interest and a social interest. On the scientific level, this study contributes, in clinical psychology, to the diagnosis of psychotraumatic stress, to show health professionals the suffering endured by parents of children with ASD to the point of presenting psychotraumatic stress, and to arouse the desire of these health professionals to give much attention to the parents of children with autism before their stress becomes serious or pathological.

On a social level, this study will help the relatives of the parents being investigated to be aware of their psychological suffering and to be moved to give them the psychological support they need. Society underestimates the dangers of prejudice, negative comments, name-calling and caricatures to which par-

ents of children with autism are often exposed. Furthermore, the results of our study could also be used in awareness campaigns to change the mindset towards a more positive focus on parents of children with ASD.

The following hypotheses are formulated: Congolese parents with autistic children would present signs of psychotraumatic stress, the symptoms would be mainly reliving, avoidance and hyperactivity, the variables gender and environment would influence the stress experienced by these parents.

Presentation of the environment of study and methods

We conducted our study at the Centre Neuro Psycho Pathologique de l'Université de Kinshasa, specifically in the infant and juvenile psychiatry ward. It is a space commonly called POH (which means Pavilion for Men). In the past, the POH pavilion was reserved only for adult men who were ill. Since the creation of the unit dedicated to the care of children and adolescents, this pavilion is now a space for children and adolescents.

The Centre is in the commune of Lemba. Before being installed at Mont Amba, it was set up at Mont Ngaliema in 1926, but its activities began in 1928 as an asylum for various patients, notably the mentally ill, tuberculosis patients and lepers. In 1970, other missions were added to it: research, teaching and services to the community.

For reasons of insufficient experts, the Unité de Soins et de Recherches en Psychiatrie Infanto juvénile remained closed for a long time but its revival or start-up was made possible thanks to the efforts of Professor Dr. MAMPUZA MA MIEZI Samuel, Professor MBIYA MUADI Florence and Dr. MATONDA with supported from North-South cooperation through Professor Dominique Charlier, child psychiatrist of the Catholic University of Louvain in Belgium.

The Unité de Soins et de Recherches en Psychiatrie Infanto juvenile has a multidisciplinary team composed of the following specialties Child psychiatrists (doctor); child psychologist (specialized psychologist in childhood disorders); nurses; psychologists who provide individual, group and family psychotherapeutic follow-up; psychomotor therapist; educator who provides psycho-educational support; social worker who is a mediator between the institution and the family/school; speech therapist who deals with language re-education; painter (painting, drawing and storytelling workshops). These specialists provide services to the Congolese and other people from neighboring countries. The unit provides outpatient and inpatient services.

Until the publication of this work, the Unit had 29 active staff. From 2017 to date, and has received more than 544 patients in specialized consultations.

Population characteristics, sample and methods

In the archives of the Unité de Soins et de Recherches en Psychiatrie Infanto juvenile at the CNPP, which we accessed on 23/08/2020, there are a total of 544 children who are registered in this Unit because of different illnesses. The population of our research is composed of their parents. It is from this population that we selected the subjects who formed part of our research sample. In our case, the sample is 18 parents (male and female) whose children suffer ASD. We selected them on the basis of the selection criteria set for our study (being adults, being married, being a parent of a child with ASD, being a parent who benefits from the child unit service, having at least some knowledge of what their child is suffering from, having clear consent). We excluded from the sample subjects who: did not answer calls to confirm the appointment, excused themselves at the last minute, or were bereaved.

Considering that our interest is focused on parents of children with ASD, we were interested only in parents whose experiences are relevant to our problem. These are essentially parents who are regularly enrolled in this care unit and who have children with ASD. We asked permission from the head of the Pediatric Unit to allow us to interview this category of parents. We showed each parent the objective, the interview guide and the scale to be used in evaluation. Bearing in mind the parents' schedules, we agreed that we should conduct these interviews in their homes. We received a favourable response.

Twelve interviews were conducted from 06/09/2020 to 08/10/2020. It is worth noting that each interview took place in a calm, isolated atmosphere that encouraged parents to express their traumas which has to do with having a child with ASD. The following table presents our study population according to the gender variable.

Table 1: Distribution of the subjects according to their sex.

Sex	Effectives	Percentage
Masculine	4	33,3
Ferminine	8	66,7
Total	12	100

Table 1 shows that the majority of our study population is made up of female parents, who represent 66% of the population. Male parents are in the minority in our population and represent barely 33%.

In the context of our work, we have chosen the clinical method, opting in particular for the case study. The clinical method aims at a situation with a degree of constraint in order to collect information while giving the subject the opportunity to express himself. The choice of the clinical method is motivated by our desire to explore the suffering related to psychotraumatic stress experienced by parents of children with ASD. This method considers elements such as the singularity, the totality and the concrete dimension of an individual.

In addition to the clinical method, we used the psychometric method to test the hypotheses of our study. Indeed, the psychometric method covers all the procedures aimed at the quantitative description of psychological facts. This method was materialized by the use of the Posttraumatic Stress Disorder Checklist Scale (PCL-S).

The case study is relevant to our research work. It aims at obtaining comprehensive information about a specific situation of psychotraumatic stress in parents of children with ASD, to understand or grasp the individual in a singular and holistic way, to examine all the information related to the different aspects of the person's life for a deeper psychotraumatic analysis of his or her problem situation. In such as procedure, there is no "collection of data" as it is often said, but "production" or "co-production" of data [26].

For this study, we will use the following techniques to collect data: the clinical interview and the Posttraumatic Stress Disorder Checklist Scale (PCL-S). Note that the clinical interview will enable us to understand better the psychotraumatic stress. And the Posttraumatic Stress Disorder Checklist Scale (PCL-S) will allow us to assess how parents experience posttraumatic stress.

The semi-structured interview has certain advantages [9]. In relation to our research for example, the interview allowed us to obtain verbal responses but also to take into consideration the non-verbal communication that resulted. Our interview was facilitated by the Social Assistant of the "infant and juvenile" unit at the CNPP, who agreed to take us to the homes of the parents we had targeted. In developing the interview guide, we took into account the stated hypotheses in order to confirm or refute the hypothesis that parents of children with ASD may suffer from psychotraumatic stress. Our interview guide includes the following four themes:

- ✓ *Identification:* this concerns the socio-demographic aspects of the subjects, (gender, state, tribe and place of residence).
- ✓ *The announcement of the diagnosis of one's child:* this theme explores the way the news was announced, the feelings and emotions the subject experienced, the memories that came to him/her, etc.
- ✓ *Current feelings:* this theme explores whether the subject is still disturbed by the diagnosis. The aim is to highlight behaviour that shows that the subject is experiencing psychotraumatic stress.
- ✓ *Symptom Perspective:* This aspect explores the symptoms that the subject is experiencing, which actually show that they are traumatized.

Developed by Waethers and colleagues (1993), the PCL-S is a short and simple self-questionnaire. It consists of 17 items grouped into 3 subscales corresponding to the 3 sub-syndromes of PTSD: reliving (items 1-5) corresponding to DSM-IV criterion B, avoidance (items 6-12) corresponding to criterion C, and neurovegetative hyperactivity (items 13-17) corresponding to criterion D. The subject is asked to find below a list of common symptoms following the announcement of their child's autism diagnosis. They are then asked to circle a number between 1 and 5 for each symptom according to its intensity during the past month. The survey is short, lasting between 5 and 10 minutes. Thus, to be diagnosed with PTSD, the subject must score 3 or more on at least 1 item from criterion B (questions 1-5), 3 items from criterion C (question 6-12) and 2 items from criterion D (questions 13-17). The limit often used is 44.

After receiving permission to visit the homes of the target parents, and with the help of the social worker of the child welfare unit who knows the parents best, we explained to the parents the rationale for visiting their homes. Once they had agreed, we invited them to talk to us in French or Lingala. The social worker helped us to explain the reasons for our visit where circumstances required. We planned with our subjects (the parents) about the times to visit depending on their availability so as not to disturb their preoccupation or their work. The data collected through the interview and the PCL-S tests are processed through content analysis, in-depth case study and SPSS.

Presentation of results

The different symptoms of PTSD that we seek to ascertain in parents of children with ASD are: heart pounding, difficulty breathing, sweating (which we call reliving), difficulty remembering important parts of the stressful experience, loss of interest in activities, feeling cut off from others (which are symptoms of avoidance) and difficulty sleeping, angry outbursts, difficulty concentrating, and feeling irritated (are symptoms of hyperactivity).

Table 2: Distribution of symptoms of PTSD.

PCL-criteria	N	Mean
Reliving	12	15,4545
Avoidance	12	19,1818
Hyperactivity	12	15,8182
Total score	12	50,4545

Table 2 indicates that the subjects have high psychotraumatic stress. The means of all three criteria B, C and D are very high. This signifies that parents of children with autism suffer from PTSD. The variables gender and marital status are being examined in order to find out the level of PTSD.

Table 3: Distribution of symptoms by gender variable.

PCL-criteria	Gender	N	Mean
Reliving	Male	4	13,5
	Female	8	16,6
Avoidance	Male	4	13,0
	Female	8	22,7
Hyperactivity	Male	4	10,0
	Female	8	19,1
Total score	Male	4	36,5
	Female	8	58,4

Table 3 shows that women suffer more from EPST with an average of 16.6 reliving, 22.7 avoidance and 19.1 hyperactivity. And men show the following averages: 13.5 reliving, 13.0 avoidance and 10.0 hyperactivity.

We note that the presentation of the cases is based on the following aspects: Identification; the extract from the autobiographical narrative; the result of the PCL-S test; partial analysis. For ethical and deontological reasons, we use pseudonyms to refer to our subjects. It should be noted that the case presentation will follow the above aspects.

Asa case

Identification

Mr. Asa is 45 years old, married and has three children (two boys and one girl). Mr. Asa works and is originally from Congo Central and Yombe by tribe. He lives in Masina with his family. He is the father of an autistic child.

Extract from the psychotraumatic experience

I have an autistic child. I still hope that my son will be able to speak if the state puts in place a structure that could help him regain his speech. When they confirmed this to me, I was not happy. I was really discouraged by my son's diagnosis. The child was growing up like all normal children; he had acquired some speech before he lost it. So I can't say it's witchcraft.

Everyone at home has accepted the child's problem: us his parents, his sister, brother and uncle, even the neighbours. He is loved at home. I have no heartbeat problems; I sleep well except that I know I have to wake up several times in the night to help him "pee". I can't avoid conversations related to autism. I can participate in the discussion with other parents who have children with autism. What I also have to say is that the state

should provide structures to help parents. Medication is very expensive.

Test results

Mr Asa obtained a total score of 22 on the PCL-S scale, which means that he has a non-significant score (< 34). However, he needs information about post-traumatic psychological disorders that may appear later. He slightly meets criteria B and D. This information shows that Mr. Asa is somewhat disturbed, has difficulty sleeping and is defensive.

Partial analysis

Mr. Asa wanted his wife to be there to answer any questions we might have for him. We consider this behaviour to be an attempt to avoid. There is little chance that Mr. Asa will manifest the very high psychotraumatic stress because everyone accepts the health problem of the child. Mr. Asa is sometimes disturbed, avoids thinking about his son's problem, has a bit of a sleeping problem and is a bit defensive.

Basa case

Identification

Aged 50, Mrs Basa is married and has 3 children (2 boys and 1 girl). Mrs Basa works. She is originally from Equateur and the Ngala (Mongo) tribe. She lives with her family. She is the mother of an autistic child. Her daughter is 22 years old.

Extract from the psychotraumatic experience

I have a child with autism. I didn't want to conceive this child because I had a plan to travel abroad. I went through a soul-cure process. Then I tried to take care of her. I thought her problem was caused by a family member but after the diagnosis of the doctors who came from Germany, they said it was autism. His problem disturbed me a lot. I am still disturbed, especially when I think about his future. I don't avoid thinking about the episodes related to her problem anymore. I also get angry with her. She gets on my nerves.

Everyone at home has accepted the child's problem and empathizes with her. The neighbours are curious about her situation. No heartbeat and I sleep well at night I talk to other parents who have autistic children. Her schooling is expensive, but I would like her to be able to talk and resume life like other children.

Test results

Ms. Basa scored a non-significant (<34) 27 on the PCL-S. Her condition is not pathological, but does not rule out providing information about post-traumatic psychological disorders that may appear later. Ms. Basa slightly meets criteria B, C and D. She is somewhat disturbed, showing some signs of avoidance and hyperactivity.

Partial analysis

Concerns about her daughter's empowerment explain the presence of repeated reliving. The absence of psychotraumatic stress may be due to the fact that she has undergone the soul cure. According to Mubiayi [28], the soul is commonly the human heart. A soul cure is a cleansing, purifying session. The session is an absolute will to get out of one's situation.

Case casa

Identification

Aged 50, Mr Casa is married and has three children (one of whom is the only child from his first marriage and two other children from his second marriage). Mr Casa works. He is originally from Bukavu and the Bachi tribe. He lives in Kisenso with his family.

Extract from the guide of interview

I have an autistic child. I think his problem started at birth. I know the cause: scientifically it can be explained. I know the consequences of his problem: he will always be dependent for washing, for eating (sometimes), for other needs. This worries me (at this point I noticed that Mr Casa's eyes were full of tears). Now I am no longer disturbed by his problem. Avoidance is when he annoys me with his behaviour; like when he "pees", I get so angry that I hit him. He is loved by everyone except the neighbours who say I used my son to make money because I built a house. When he gets on my nerves, I go away for a while to calm down. Anyway, I get angry sometimes; especially when I think that he should learn to be independent.

I don't have any difficulty breathing or having a heartbeat. I also sleep very well. I can startle sometimes. I don't avoid conversations related to autism and by sharing with others I can get information that could help remedy his problem.

Test results

Mr Casa scored a non-significant (< 34) 24 on the PCL-S scale. This score means that he has a non-significant (< 34) score. He experiences flashes of anger at times; this meets criterion D for a diagnosis of psychotraumatic stress, there are some symptoms related to other criteria B and C. such as: reliving his son's episode, disruption and avoidance of certain activities.

Partial analysis

The concern to see the child grow up, satisfy needs like any man and get married is at the root of Mr Casa's reliving and anger.

Dasa case

Identification

Aged 50, Mrs Dasa is married and has only one child. Mrs Dasa works and is originally from Congo Central and the Yombe tribe. She lives in Ngaliema with her family. After asking some questions, hesitating to give any family information, we gained her trust by explaining that the interview and the information related to it will be confidential.

Extract from the guide of interview

Mrs. Dasa does not state that her son is autistic, yet her son have been diagnosed with autism. Here is her response to the interview questions "the child is ill": "I consulted Dr. Bueze who treated the problem my son was suffering from. I put a lot of effort into finding the solution to my son's problem. As an intellectual, I can't say it's witchcraft. I had not accepted the fact that my son is not like other children. When I think about what happened to him, I don't feel comfortable.

I was very upset by his problem. It was really difficult to sleep. I was really worried about his problem. In terms of avoidance, he is just a child. After the consultation, I accepted his illness

like any other illness that others might suffer. Even though it is difficult to accept. I get angry sometimes. His attitude of taking things from others irritates me. My heart beats sometimes I had so much trouble sleeping. I also sometimes startle when I sleep. I don't avoid conversations related to autism but there are places you shouldn't go with him.

Test results

The score obtained on the scale is 60. She has not accepted that her son has such an illness. Criterion C (avoidance) is very high. She also meets criterion D (hyperactivity).

Partial analysis

Mrs Dasa asked certain questions that we consider to be a search for a reason to avoid the interview. In addition, her refusal to state that her son had autism is a sign of avoidance. Mrs. Dasa's preoccupation with seeing her son speak is the cause of reliving and hyperactivity (startling). Mrs. Dasa shows very high psychotraumatic stress. The PCL-S result shows that she needs to be treated.

Esa case

Identification

Aged 65, Mrs Esa is a widow and grandmother of one child (1 boy). Mrs Esa no longer works. She is originally from Kasai Central and from the Luba tribe. She lives in Masina with her son.

Extract from the guide of interview

I have a little son who is autistic. He was growing up and saying certain words like "I want water". I had a hard time accepting the diagnosis. The memory I had of that day was not good - a child: why such an illness? I'm really disturbed by the diagnosis. Sometimes I avoid certain people. Family members are not bothered by his situation but they don't accept the fact that he is hyperactive, destroys their property and they get angry with him and they don't come anymore. I get very angry sometimes.

Really, my heart is beating all the time. His situation has made me to stop doing business; I don't have time to visit friends and family. You see. Even to go to church, I can't go. I have difficulty sleeping because of his disorder; I'm always confused by his problem. I also have difficulty concentrating - I mix things up, I forget some things. I'm always confused when I think about his future especially when I won't be there. Death is waiting for me, I am already old. I can be startled sometimes too. I choose the people I talk to about his problem. For parents who suffer because of the situation of their autistic children, I say: courage. But parents need to have a big heart and show a lot of love despite the difficulties.

Test results

Mrs Esa's response to the PCL-S test is too positive as the total score is 75. In relation to reliving (criterion B), the result shows that she is still disturbed, very upset and a pronounced physical reaction such as heartbeat. Avoidance (criterion C) is also very high: she avoids people who may remind her of her grandson's illness, she no longer participates in the activities she used to do and she thinks she has reached the end of her life. Criterion D (hyperactivity) looks like this: she has difficulty sleeping, is always angry, has difficulty concentrating, is defensive and feels irritated.

Partial analysis

Mrs Esa who is dealing with the problems associated with her grandson's illness (i.e., lack of autonomy) needs psychological care.

Faba case

Identification

Aged 49, Mr Faba is married and has 6 children (his who has problem is the 4th). Mr Faba works. He is originally from Lualaba and the Sukuili tribe. He lives in Camp Kokolo with his family.

Extract from the guide of interview

"I have an autistic child. It is not easy to digest the result of his diagnosis. I was angry; I had memories at the beginning of this problem with my son. When I sleep, I think about him. Other children love their brother, other family members come to visit the child. His problem had bothered me. I was worried about how and where to find the solution to his problem. I don't really have difficulty sleeping. You have to tie up his leg so that he can't get out of bed or destroy things. I don't have a problem concentrating. I can startle. I cannot avoid conversations related to him. I can talk to other parents.

Test results

Mr. Faba scored a significant (>34) 46 on the PCL-S. This requires referral for psychotherapy and/or EMDR. He responds positively to criterion B, which assesses reliving: he is still disturbed; he often has memories related to his son's problem and feels upset. Mr. Faba has a little problem with avoidance; however, he has lost interest in some of the activities he used to do. In relation to criterion D (hyperactivity), Mr. Faba startles and somewhat defensive.

Partial analysis

His son's problem disturbs him especially when he thinks about his autonomy - his son has not yet acquired the capacity to clean himself. This defect is the cause of Mr. Faba's reliving, avoidance and even some signs of hyperactivity. Mr Faba's attachment to his son explains why he shows many symptoms of reliving.

Gaba case

Identification elements

Aged 55, Mrs Gaba is the mother of 9 children, she no long works since the child was 3 years old (he is the son of her husband's first wife who died). She is originally from Equateur/ South Ubangi and from the Ngala (Nkundu) tribe. She lives in Kingabwa with her family.

Extract from the guide of interview

I have a problem child. The child is not my biological son, but I adopted him. After his mother died, I married his father and we had 9 children. I really took up the role of his mother to the extent that I gave up what I was doing - I was a shop assistant. I feel a lot of pain in my heart about his problem – 'mpasi moko boye ezo kanga ngai na motema'. The memories are a lot. I think a lot about how he can be independent.

I am no longer disturbed by his difficulties. I am a believer, and I know that nothing is impossible for God. I avoid situations that may result in someone talking badly about my son. I have

no feelings of irritation or anger. But his father is always angry. I would say to him, 'If you treat him like this, how do you expect others to treat him, even his brothers and sisters?' His situation doesn't cause my heart jump. I breathe well too. I sleep well now. But before, it was difficult.

Test results

Mrs. Gaba obtained a total score of 40 on the PCL-S scale. A subject with a score above 34 (>34) should be referred for psychotherapy. Ms. Gaba has a positive response to criteria C (avoidance) and D (hyperactivity). She avoids situations that may remind her of the traumatic event, she also has difficulty remembering important parts of the stressful experience, she has the problem of outbursts of anger and feels irritated too.

Partial analysis

Mrs. Gaba's biggest concern is this: her son's wedding. This concern is the basis of some physical reactions. The interview with Mrs. Gaba shows that she is defensive and that she is disturbed by memories. In the test result administered, her answers show that she has difficulty concentrating.

Haba case

Identifying

Aged 70, Mrs Haba is married and has several children (Jane is her granddaughter). Mrs Haba no longer works. She is originally from Kwilu and the Pende tribe. She lives in Mont-Ngafula with her family. The child is 14 years old.

Extract from the guide of interview

Mrs Haba does not clearly state and/or accept in direct words that she has an autistic child. However, when asked how she found out about the centre where her granddaughter is being treated she says: *"I was not happy with what the doctor said. At the beginning of her illness I was really upset, but I am not bothered by the result of her examination anymore. No, I don't avoid talking about episodes related to my little girl. People may say it's witchcraft but it's not like that. We went to the hospital and were told that this is a problem that needs to be followed up in hospital. Irritation, no; but anger, yes.*

Everyone at home has accepted the child's problem: me, his grandmother and his older sister (the one who gave you the chairs; they are only 2). The family who rented downstairs treats the child as ndoki (witch). They avoid the child. The others can talk about the child but they don't come and tell us to our faces. I don't have much of a heartbeat problem. I breathe normally, I am not agitated either. I sleep well. No, I don't avoid conversations related to his problem. But I don't have many places to go. I can participate in discussion with other parents whose children are suffering. At least we share the same problem. Every parent has to try to take care of their suffering child. Medication is very expensive.

Test results

Mrs. Haba got a score of 48. Since the score is higher than 34, she will need psychotherapy. She is disturbed by repeated dreams related to this event, she relives it and feels upset (criterion of reliving); she has lost interest in the activities she used to do (criterion C = avoidance); in addition, she experiences flashes of anger and gets upset easily (criterion D = hyperactivity).

Partial analysis

Mrs. Haba displayed avoidance behaviour, for example: She told us that the problem of her little girl is the first case she knows of without telling us what she was suffering from. The signs of her psychotraumatic stress could be due to the fact that she is advanced in age and that her daughter does not look after her child. The test administered reveals that the symptoms of criteria B, C and D are really strong.

Iba case

Identification

Mrs Iba is 25 years old. Mrs Iba is originally from Eqateur and from the Ngala tribe. She lives in Mont-Ngafula.

Extract from the guide of interview

The child has a language problem. When she was two and a half years old, she spoke, she said mummy, daddy, and called her big sister. But after a while she stopped talking. What I felt was just sadness. I was not happy. I was angry. When I remember how she was, it still hurts. Anyway, I am disturbed by his illness. Very often I avoid things that might remind me of her problem. For example, when I see a child with a problem. I used to feel angry, especially when she comes into my room and starts making a mess of it. I want to hit her but I hold back.

Yes, right! My heart beats a lot. But I breathe well. I only have a little difficulty sleeping. I also have difficulty concentrating. For example, I want to read - I have the notebook in front of me but I don't read. I can startle when I'm working. Well, I avoid any discussions related to his problem because when I talk about it, it's like exposing him. I will tell parents to take care of their children. It's a disease and I hope we'll find a solution soon. I'm waiting to see the miracle. It's not easy to buy medicines, to send the child to a special school in Kinshasa.

Test results

Madam Iba obtained a total score of 55 on the PCL-S scale. Considering that the score is above 34, she will need psychotherapy. Because she is disturbed by memories related to her child's illness, she is upset when something reminds her of symptoms corresponding to criterion B. The PCL-S test result shows that she avoids talking about the problem related to this episode, difficulty remembering, loss of interest in certain activities (these symptoms correspond to criterion C); she feels a flush of anger and startles (the symptoms mentioned correspond to criterion D).

Partial analysis

The different questions asked by Mrs Iba as answers refer to manifestations of reliving, of someone who is still disturbed. The interview with Mrs Iba shows that she is suffering from psychotraumatic stress. On seeing her, she looks as if she is carrying the weight of the world on her. Her voice seems to say that she is depressed. The test result administered confirms what we found from her voice and body language.

Jaba case

Identification

Ms Jaba is 34 years old. She is divorced and has 1 child. Therefore, her daughter is an only child. Mrs Jaba works. She is originally from Kwilu and from the Yanzi tribe. She lives in Ngaba Commune.

Extract from the guide of interview

As we speak, I don't know where she is. I have not been able to find my daughter for more than three weeks now. I can't rest until my daughter is home (at this point her eyes were full of tears). *When I think about this situation, I ask myself how am I going to die: may be I have to be hit by a car to die; or I have to die while I am sleeping. My heart is beating all the time* (she has tears in her eyes).

I find it very difficult to sleep. How do you expect me to sleep (she starts to cry). *I can't concentrate. It's difficult for me. I mix things up. Anyway, I am always distracted because of my daughter. Even the very little time I have, I can be startled and sleep will disappear. I do everything to get her to school.*

Test results

Ms Jaba has a total score of 84. In other words, she responded positively to the test administered. In relation to criterion B of psychotraumatic stress symptoms, she is disturbed, feels upset, and has physical reactions. In criterion C, she avoids feelings that are related to the stressful episode, has difficulty remembering important parts of the stressful experience, loss of interest, guilty, unable to have loving feelings. As for criterion D of psychotraumatic stress, she has difficulty sleeping, flushes of anger, difficulty concentrating and startles easily.

Partial analysis

She is really disturbed. Our interview with Mrs. Jaba shows that she is really suffering from psychotraumatic stress. When she talks and cries at the same time, she seems to show that she has really reached the end of her life. Her suicidal thoughts are a sign of someone who may pass into act. In all aspects of the assessment, the test confirms that Ms. Jaba has too much psychotraumatic stress, which requires psychological care and support.

Kaba case

Identification

A young couple received us. The man is 47 years old and the woman is 39 years old. This couple has two children (all boys). The Kaba couple is originally from Kwilu and from the Yanzi tribe. They live in Matete. This is the first time we have been received by a couple. Mr Kaba said: "When Madam told me that there is a team that will come to exchange with us, I was happy. And as it was Saturday, I cancelled other activities".

Extract from the guide of interview

(Mother) *I have a child with a language development problem. And the whole situation disturbed us a lot, especially his father. It was difficult to sleep, work activities were disrupted.* (Father) *I avoid certain people who can speak badly about the situation, I used to go out in the evening with friends to drink, but I stopped. I have palpitations, I don't have anger. Sweating, only a little. No, no, I don't startle; but I know that I am often in a state of alarm.*

Very often I avoid talking about this situation, even to family members. I can't say it's witchcraft or that it's someone's fault. Everyone at home has accepted the problem. (Mother) *some family members are pointing the finger at my husband saying that he used her child to get to do money ritual.* (Father) *this is not true, because before I got married I was working, I had the money.* (Mother adds): *If family members say such things, imagine what others will say.*

Test results

Mr. Kaba obtained a total score of 50. This is higher than 34 and requires a referral for psychotherapy. The symptoms of criteria B and C are very high compared to criterion D. Thus, Mr. Kaba is always disturbed by repeated dreams, acts abruptly as if the stressful episode is recurring, has a physical reaction like palpitation. He avoids feelings that are related to the stressful episode but also shows a high loss of interest. Finally, his result shows that he is in a super-alarm and defensive state.

Partial analysis

Mr Kaba's behaviour (i.e. cancelling all programmes to receive us) shows that he is in a super-alarm state. The interview with Mr Kaba reveals that he is still upset. When he spoke to us, his voice cracked and he slowed down the speed of his speech when talking about what might be the judgment of others towards him and the situation he was going through. In analyzing the test administered to Mr Kaba, the level of psychotraumatic stress is significant. His condition deserves to be treated by a psychologist.

Laba case

Identification

Aged 35, Mrs Laba is married and has three children (two boys and one girl). Mrs Laba is studying. She lives in Cité Maman Mobutu with her family. Mrs Laba was reluctant to receive us.

Extract from the guide of interview

At the beginning of our interview, she was reluctant to talk with us and to say what her child was suffering from. When asked how she came to know about the unit that takes care of her son, she said: *When I was watching TV, the information corresponded with the symptoms my son was manifesting. I was in a lot of pain. That's all I can say. I am often confused about my son's diagnosis. I don't know, I'm tired of his problem. I have done everything but there is no progress. I've done everything, I'm tired. Well, I avoid eh!* (She says and moves her head).

I have a lot of anger. No, no heartbeat (she also moved her head in negation). *I have a lot of trouble sleeping and a lot of trouble concentrating. I startle very often. To other parents I would say: "May they be able to bear it until a miracle happens". The brother and sister, members of the extended family, are supportive and sympathetic, except that the neighbours are unbearable.*

Test results

Mrs Laba scored 61. This is higher than 34 and indicates presence of post-traumatic stress disorder. She feels upset (this corresponds to criterion B of psychotraumatic stress symptoms). Mrs. Laba avoids talking about the stress episode she is experiencing and activities that may remind her of this episode but also a loss of high interest (these symptoms correspond to criterion B). Finally, high anger flush, difficulty concentrating, super-alarm and feeling nervous are other test results administered to Mrs. Laba.

Partial analysis

Mrs Laba's reticent behaviour before our interview is a sign of avoidance. During the interview she did not want to answer certain questions easily and once said that she preferred to

keep other things to herself. The test result administered confirms this aspect of avoidance and shows a very high level of hyperactivity: a flush of anger, difficulty concentrating, a state of super-alarm and easy startle.

Discussion of the results

According to the results obtained during the interviews, 100% of the parents of children with ASD had expressed their daily experience as stressful. Indeed, 15.45% had presented the signs of reliving, 19.18% presented the sign of avoidance and 15.82% presented the sign of hyperactivity. The administration of the PCL-S scale showed that 8 subjects showed post-traumatic stress and 4 subjects did not. Based on the cases examined, our overall analysis considers the following aspects.

Reliving

The quantitative aspect of our work shows that a large majority of our subjects still relive the experience of the diagnosis of their autistic child. Women are in the majority compared to men. The interpretation of the calibration of the PCL-S scale recommends the presence of 3 items in criterion B, which is a sign of psychotraumatic stress. Some subjects presented more than 3 items (e.g. the cases of Esa and Jaba). On the qualitative aspect, some subjects had cried during the interview, others had eyes full of tears and some subjects had difficulties to speak.

Avoidance

Overall, there were many cases of avoidance starting at the time we took the initiative to contact the target parents for the interview. There were a total of 6 subjects who had exhibited avoidance behaviour for various reasons. During the interview, some subjects were reluctant and others did not want to admit that their child had autism. We consider this behaviour as a sign of avoidance that is related to psychotraumatic stress. The PCL-S scale states that if a subject answers 3 of the criterion C items, it is a sign that the subject is suffering from psychotraumatic stress. Many of our subjects tested positive in more than 3 items (e.g. the cases of Esa and Jaba). The total average (19.1818) is very high; and women are in the majority compared to men.

Hyperactivity

On the quantitative side, the PCL-S scale states that having 2 items in criterion D is a sign of psychotraumatic stress. When we look at the scores of some subjects, we will see that most of them tested positive in 2 items (e.g. the cases of Esa, Jaba and Laba). As in the case of reliving and avoidance, women are always the majority to present signs of hyperactivity. On the qualitative aspect, our subjects had manifested various forms of hyperactivity: sweating, palpitation, nervousness. One of our subjects wanted to hit his son who had "peed" during the interview session.

We confirm here our general hypothesis that parents of children with ASD suffer from psychotraumatic stress.

Conclusion

Our study revealed the presence of psychotraumatic stress in Congolese parents whose children suffer ASD. The results of our research showed that the lack of sufficient care for the suffering of parents of children with Autism Spectrum Disorder (ASD) develops into a permanent stress. The neglect of such parents was raised in our problematic.

In accordance with the hypotheses, four (4) parents (33.33%) stated that the announcement of their child's diagnosis of autism was a traumatic event. These were Asa, Basa, Esa and Faba. In the scale we administered, five (5) parents, i.e. 41.46%, answered that they were very often disturbed by memories, thoughts or images related to their autistic child. This problem concerns the following cases: Esa, Faba, Gaba, Iba and Jaba.

Several questions can still be asked at the end of our research which can be used for future studies on the causes or sources of psychotraumatic stress: Does it come from the announcement of the diagnosis? Is it due to the fact that the child will always be dependent throughout his or her life? It should be noted that these questions may inspire further research in the direction of knowing that a child's disability status, as well as the choice of words used to announce the diagnosis, may cause psychotraumatic stress for parents of children with ASD.

Author declarations

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References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. 5th ed. Washington, DC: American Psychiatric Publishing. 2013.
2. American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-IV-TR. 4th ed. Washington, DC: American Psychiatric Publishing. 2000.
3. Anciens Combattants Canada. Lignes directrices sur l'admissibilité au droit à pension: état de stress post-traumatique. 2011 May, 2016.
4. Aussilloux C, Barthélémy L. Evolution des classifications de l'autisme: leur intérêt et leurs limites actuelles. Le Carnet Psy. 2002; 75: 21-23.
5. Autistes Sans Frontières. Autistes Sans Frontières. 2019.
6. Baghdadli A. Recommandations pour la pratique professionnelle du diagnostic de l'autisme. Paris: Haute Autorité de Santé. 2005.
7. Barthélémy C, Briffault X, Chamak B, Hérault M, Prado C, Fagot-Largeault A. Traitements pharmacologiques dans l'autisme: appréhender et communiquer. In: Rapport annuel 2013 de l'Agence de la Biomédecine. 2014.
8. Beaulne S. La conception de l'autisme depuis Kanner: où en sommes-nous? J Dev Disabil. 2012; 18: 43.
9. Belina A. Semi-structured interviewing as a tool for understanding informal civil society. Volunt Sect Rev. 2023; 14: 331-347.
10. Bellusso P, Haegelé M, Harnist K, Kathrein C, Massias-Zeder A. Autisme & sensorialité: guide pédagogique et technique pour l'aménagement de l'espace. 2017.
11. Benhaberou-Brun D. Les troubles du spectre autistique: comment mieux le connaître? Prat Clin. 2013; 10: 22-26.
12. Bettelheim B. La forteresse vide: l'autisme infantile et la naissance du Soi. Translated by Roland Humery. Revue d'Histoire et

de Philosophie Religieuses. 1968; 51: 407-408.

13. Bettelheim B. The Empty Fortress: Infantile Autism and the Birth of the Self. Glencoe: Free Press of Glencoe. 1967.

14. Brelot E. L'accompagnement des parents d'enfants autistes: en quoi la relation empathique apaise-t-elle la souffrance des parents? [Travail personnel de fin d'études]. Université de Lorraine, France. 2018.

15. Chamak B. L'autisme: surestimation des origines génétiques. Med Sci (Paris). 2010; 26: 659-662.

16. Chamak B. Modifications des représentations sociales de l'autisme et introduction du concept « autism-friendly ». Enfances Psy. 2018; 80: 63-73.

17. Direction de l'Education Française. Autisme. 1997.

18. Derynck F. Syndrome post traumatique: diagnostic, traitement, thérapie chimiques et non chimiques, place des TCC. Blogue de l'auteur. 2016.

19. Georgieff N. Qu'est-ce que l'autisme? Paris: Dunod. 2016.

20. Haute Autorité de Santé. Autisme et autres troubles envahissants du développement: interventions éducatives et thérapeutiques coordonnées chez l'enfant et l'adolescent. Paris: Haute Autorité de Santé. 2012.

21. Isabelle. Dur, dur d'être maman d'enfant malade! Blogue de l'auteur. 2009.

22. Jabre P. Place des proches lors des soins [Communication]. Le Congrès Médecins, Conférence d'Actualisation. 2014.

23. Ebwel JM, Roeyers H. Pour une approche diagnostique de l'autisme en République Démocratique du Congo. Rev Francoph Defic Intellect. 2016; 27: 88-100.

24. Le WASSA WASSA. Fondation SEMAFO. 2014; 1: 14.

25. Leclerc N, Charbonnier R. Autisme [Communication]. Cycle de conférences-Louhans. 2015.

26. Lejeune C. Manuel d'analyse qualitative. De Boeck Supérieur. 2019.

27. Mbiya-Muadi F. Cours de psychiatrie destinée aux étudiants de L1 Psychologie [Notes de cours]. Kinshasa: Université de Kinshasa. 2019.

28. Mubiayi Mamba A. Cure d'âme ou cure psychologique. Kinshasa: Editions MES. 2013.

29. Powers MD. Children with Autism: A Parent's Guide. 2nd ed. Bethesda, MD: Woodbine House. 2000.

30. Sindelar-Swiss P. Etat de stress post-traumatique: evidence based medicine et expertise [Communication]. Insurance Medecine. 2015.

31. Suisse Romande. Reconnaître et comprendre les troubles du spectre de l'autisme. 2nd ed. 2011.

32. Tarquinio C, Montel S. Du psychotraumatisme à l'état de stress post-traumatique. In: Tarquinio C, Montel S, editors. Les psychotraumatismes: histoire, concepts et applications. Paris: Dunod. 2014: 21-40.

33. Timmons V, Breitenbach M, MacIsaac M. Guide de ressources pour les parents d'enfants autistes: soutien de la pratique d'inclusion. Autism Society of America. 2004.

34. Virginie Q. L'état de stress post-traumatique (ESPT) après l'accouchement normal. Centre Hospitalier Universitaire de Nantes. 2018.

35. Weathers FW, Litz B, Herman D, Juska J, Keane T. PTSD Checklist—Civilian Version (PCL-C) [Database record]. APA PsycTests. 1993.