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Socio-Cultural Representations and Therapeutic Itineraries of Parents of Autistic Children Followed in the INSP's Children's Mental Health Services

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Abstract

Pervasive developmental disorders (PDD) remain little known to populations in developing countries. In black Africa their social representations remain strongly influenced by local belief systems. The general objective of this study was to understand the perceptions and representations of Ivorian parents vis-à-vis PDD. This was a mixed (qualitative and quantitative) prospective cross-sectional study with a descriptive aim that involved a sample of 49 parents. The sampling was of the qualitative type by multiple cases with reasoned choice by saturation. Our results showed that male parents were mostly aged between 40 - 49 years (48.98%) with a higher level of education (67.34%) while mothers were mostly aged between 30 - 39 (61.22%) and a higher level (30.61%). Autistic children were negatively perceived by their parents: either as a source of psychological suffering (82.85%), or as mysterious children who sacrificed their parents (44.66%), or as "bobo" children (mute children in common Ivorian language) (16.66%) or like rude children (13.34%). The supposed origin of the disorder according to the parents was mystical-religious (60.94%); natural (25%); hereditary (6.25%). In 6.25% of cases, PDD were assumed to be of unknown or iatrogenic origin attributable to vaccination (1.56%). 75.51% of parents said that in addition to conventional medical therapies, they also used traditional therapies. The use of this therapeutic alternative would be linked to the perceptions and beliefs that feed the socio-cultural representations of our respondents.

Keywords

Pervasive Developmental Disorders, Socio-Cultural Representation, Parents, Therapeutic Itinerary

1. Introduction

Disorders of neurodevelopmental origin, pervasive developmental disorders (PDD) including autism are characterized by impaired social interactions, communication, associated with a repertoire of restricted, repetitive and stereotyped behaviors. The number and manifestation of symptoms varies from individual to individual depending on developmental stage and chronological age. According to the World Health Organization (WHO), one in 160 children in the world has a pervasive developmental disorder (PDD), although this prevalence varies according to each region [1]. In the United States of America (USA), an assessment carried out by the Centers for Disease Control and Prevention (CDC) in 2014 revealed an estimated prevalence of 2.4% [2]. In Africa, some work carried out in particular in Nigeria has made it possible to find 2.3% of new cases of autism [3].

Although widely publicized in recent decades and benefiting from the progress of research, autism on its etiological approaches has not yet acquired consensus among specialists. However, early detection associated with appropriate educational, pedagogical and therapeutic care can considerably improve the quality of life of the subject with autism and those around him. However, this quality of life often depends on the perception and representation that caregivers have of this disorder.

In Africa, the occurrence of a pathological condition always has a particular origin according to each people. Indeed, the representations that Africans have of a health phenomenon, the attitude and behavior of those around them vary according to cultures and traditions [4]. Pervasive developmental disorders in the African context are no exception to this reality. Autism is therefore also the victim of multiple interpretations ranging from pathology linked to the action of invisible or malefic powers or due to the transgression of social prohibitions, or even disagreement between family members. In order to ensure better parental guidance, it would therefore be appropriate to study the perception that families have of their children with ASD and their therapeutic itinerary. Based on these research questions, we undertook this study, the general objective of which was to understand the perception of Ivorian parents about PDDs.

2. Methodology

This was a mixed (qualitative and quantitative) prospective cross-sectional study with a descriptive aim. It took place from March 2019 to June 2020, *i.e.* 15 months. The sampling technique was of the qualitative type by multiple cases

with reasoned choice by saturation. Since we did not have comprehensive databases of the mother population in Côte d'Ivoire, we opted for this method. It reflects the purpose of our study since the parents surveyed gave similar information after a certain time. According to Pires (1997), empirical saturation then designates the phenomenon by which the researcher judges that the latest interviews or observations no longer provide sufficiently new information to justify an increase in the empirical material [5]; Mucchielli (1975: 245) asserts that in the field of research on attitudes, experience shows that after about thirty or forty interviews, there is enough evidence to stop data collection because the additional information not adding much in terms of diversity [6]. 49 families whose children diagnosed with autism and regularly monitored between 06 and 12 months by the multidisciplinary team of the mental and child health service of the INSP were included in this study based on the sampling technique and the criteria of 'inclusion. The inclusion criteria were: to be parents of children diagnosed with autism, followed at the Marguerite Té Bonlé center or at the INSP child guidance center; of black African descent; and having a complete exploitable file. The semi-structured interview was carried out mainly with mothers (n = 47) and fathers (n = 2). Data collection was carried out using individual and anonymous survey sheets, established for this purpose. The questionnaire was administered in the form of a semi-structured interview. The data collected related to socio-demographic characteristics (parents and children with autism), clinical characteristics, socio-cultural representations of the disorder and the therapeutic itinerary. Two methods of data analysis were used: the qualitative analysis method and the quantitative analysis using the method of analysis of the content of the participants' speeches (verbatim).

3. Results

3.1. Sociodemographic Characteristics of Parents

Still on the socio-demographic level, our results also showed that the majority of the parents surveyed (91.83%) came from a monogamous family system and the types of families were 83.67% two-parent, 14.28% single-parent and 2.05% reconstituted.

3.2. Characteristics Relating to Socio-Cultural Representations

Terms used by parents to talk about their children were: hypocoristic terms 83.67% and pejorative terms 16.33%. Regarding the perceptions of the parents and their entourage about an autistic child, our results showed on the one hand that the parents perceived the situation as a source of psychological suffering and additional burden for 82.85% of them and an ordinary perception as a normal child for 17.15%. At the level of the entourage, according to our respondents, the sick child was perceived as a strange/mysterious child and sacrificed by his parents (44.66%), as a dumb child "bobo in the common Ivorian language" (16.66%), as an impolite child (13.34%).

According to the participants in the study, the supposed etiologies of PDD were: mystical-religious causes (60.94%), natural causes (25%), hereditary causes (6.25%) and causes related to vaccination (1.56%).

Faced with the occurrence of PDD in children, the services of several stakeholders have been called upon in the search for a solution. These stakeholders can be classified into two categories:

- *conventional care or modern medicine providers*: Pediatrician (61.22%); ENT (57.14%); Child psychiatrist (57.14%); Special educator (46.93%); Neurologist (32.65%) and Speech therapist (16.32%).

- *non-conventional care providers*: Religious guides (53.06%); Traditional practitioners (42.85%) and Marabout (22.45%).

The solicitation of these providers by the parents in the care of the child, constitutes the essential elements of the therapeutic itinerary followed. In terms of recourse to care, 75.51% of the parents said that in addition to Western therapies, they also used traditional therapies.

4. Discussion

Addressing the perception of autism by parents, our work showed three main perceptions they have of their children: 57.14% source of psychological suffering; 25.71% additional burden; 17.14% like other children. We thus find here that autistic children are negatively perceived by their parents. This perception could be related to the daily difficulties encountered in their care. In this regard, Dénis who stated that: "*Most of them fear the gaze of others and their judgments because of the various disruptive behaviors that their child can adopt. Thus, some avoid going to public places or gatherings with their child, such as family gatherings, parties, etc. for fear of experiencing difficulties with their child and for fear of being judged.* [7]".

Regarding the perceptions that people have of children with ASD, parents stated that people around them considered these children to be mysterious/weird and sacrificed by parents for money; dumb; rude.

For example, during our survey, a mother stated that: "*my child's illness coincided with a professional promotion of his father and the beginning of my business, which is what made people around us say that we had sacrificed our child to have money*". This perception of those around us is the result of an idea that is generally widespread in African societies, as Ebwel *et al.* also pointed out in his study entitled: "Approach to the social representations of autism in Africa" [8]. Going in the same direction Ebwel, J. M. & Roeyers, H. also pointed out that "*in the majority of communities, people with autism not only do not receive this diagnosis, but some are furthermore equated with the social diagnosis of witchcraft*" [9]. This perception contributes to further stigmatization of these families and their descendants.

In terms of the supposed etiology of PDDs according to parents, the origin of the disorder mentioned by parents was in 60.94% of mystic-religious origin; 25% a natural disease; 6.25% of hereditary origin; 6.25% of unknown origin and

1.56% due to vaccination. The mystico-religious etiology is the main supposed cause of PDD according to parents. This mystical-religious origin is illustrated by several statements. Thus, during the survey, we recorded several expressions designating this origin, of which we give a few examples:

"*My parents-in-law did not want us to get married, so since they could not prevent our marriage, they attacked the fragile child that was in my belly*".

"*We consulted a marabout who told us that the child was possessed by a djinn and that we should wash him with nanssidji and make him wear white silver jewelry that will chase him away*".

"*My mother-in-law told me that in my husband's family, there is an allou spirit that has incarnated in the child, so this is what justifies his behavior of withdrawal and lack of contact with others. This spirit holds his throat and blocks his speech*".

"*A member of my family told me that my child was inhabited by a water spirit, to exorcise this spirit that took control of him, she recommended that I should wash him in the river of banco*".

In analyzing these speeches, we note that despite the parents' intellectual level, they always find an explanation for the origin of the disorder in their socio-cultural sphere. According to the socio-demographic data of our study, the fathers and mothers surveyed had a good level of education respectively by 65.34% and 30.61% (**Table 1**). On the question, several studies, including that carried out by Johada (1968), have concluded that adherence to the supernatural was independent from the university degree [10].

Table 1. Distribution of autistic parent according to socio-demographic characteristic.

Socio-demographic characteristics		Responded			
		Father	%	Mother	%
Age Class	20 - 29 years	0	0	04	8.16
	30 - 39 years	15	30.61	30	61.22
	40 - 49 years	24	48.98	14	28.57
	50 - 59 years	07	14.28	01	2.04
	60 years and older	03	6.12	0	0
Ethnic Group	Akan	24	48.98	21	4.86
	Krou	07	14.28	11	22.45
	Mandé	13	26.53	15	30.61
	Gour	02	4.08	0	0
	Others	03	6.12	02	4.08
Study level	Not in school	01	2.04	03	6.12
	Primary	02	4.08	08	16.32
	Secondary	13	26.53	08	16.32
	Higher education	33	67.34	30	30.61

Continued

Professional	Civil servant	13	26.53	05	10.20
	Private	26	53.06	23	46.94
	Informal sector	08	16.32	06	12.24
	Unemployed	01	2.04	13	26.53
	Other	01	2.04	02	4.08
Marital status	Married	25	51.02	25	51.02
	Cohabiting	24	48.98	24	48.98
Religious belief	Christian	29	59.18	31	63.26
	Muslim	13	26.53	12	24.49
	Animist	04	8.16	04	8.16
	Other	03	6.12	02	4.08

According to this cultural conception of the disorder, we note two main causes that would explain the occurrence of PDDs in the context of the parents who were interviewed. These two main etiologies are:

- spells cast on couples
- possessor spirits, which are called different names depending on the socio-cultural era (*djinn*[1], *allou*[2], *water spirit*[3]).

This etiology linked to a *spell or a djinn*, mentioned by our respondents, was also underlined in Sakoyan's study, which dealt with the anthropological approach to the representation of autism in a migratory situation [11]: mothers of Comorian origin faced with autism. In the same vein, Ebwel *et al.* also noted in their study that in the majority of Congolese cultures, the explanation given to the etiology of ASDs is generally based on the illusion of a mystic-religious origin [8].

Concerning the therapeutic itinerary followed by the parents, it appears that the pediatrician is the first intervener to be solicited, followed by the ENT and it is towards the end of the itinerary that the majority of the parents obtain a child psychiatric consultation. This preponderant solicitation of the pediatrician observed in our study could be explained on the one hand by the age of the children and on the other hand by the fact that they are more numerous and more accessible than the child psychiatrists in Ivory Coast. The intervention of ENTs in second place would be linked to the diagnostic approach of pediatricians who tend to eliminate an organic cause when faced with a communication disorder. In our Ivorian context, this intervention of the child psychiatrist in last position could be explained by the lack of specialists in this field of care. It should be noted, however, that during this trajectory an almost constant solicitation of religious guides

[1]Djinn: invisible supernatural creature, demon or evil spirit, capable of influencing and tormenting the human race spiritually and mentally when it takes possession of a body

[2]Allou: term designating a supernatural spirit or genie in Akan country that takes possession of the body of humans and acts on its own behalf. It is responsible for the behavior of the individual in certain situations or for solving difficult social problems.

[3]Water spirit: a kind of invisible force or spirit that resides naturally in the waterways, which at times leaves its initial habitat, reincarnating in the body of an individual.

and traditional practitioners is observed throughout the course of care.

In terms of use of health care, 75.51% of the parents said that in addition to Western therapies, they also used traditional therapies. **Table 2** lists some examples of traditional therapies used by our respondents (confer **Table 2**). This propensity to use traditional therapies is highlighted in the study by Ebwel et al [8]. This aspect of the study could be linked to the beliefs and religions of our respondents. Indeed, these traditional therapies vary according to the socio-cultural and religious parameters of the parents. Thus, it appears that the use of *nanssidji*, *incense*, *white silver jewelry*, *and Koranic recitation* are therapeutic rituals commonly used by respondents of Mande or Gour origin who are Muslim or animist. On the other hand, the use *of chicks to prick the child's mouth so that he or she can speak*; *making the child drink foutou water*; *purification baths in rivers*; *prayer for deliverance in prayer camps or at the pastor's house* are mainly the prerogative of Akan or Krou parents who are often of Christian or animist religion. This aspect of the study is highlighted in an article by Sakoyan where she stated that: "The type of tradithérapeutes is a function of the magico-religious practices used, some closer to witchcraft, others to divination, others to possession [12]". The high propensity to resort to traditional therapies reported in our study can be explained by Sakoyan's study, in which she argued that "But contrary to the classic division between biomedicine = quest for efficiency/traditional care = quest for meaning, with a disease like autism, where the improvements of the child, if they exist, are tenuous and visible only over time, the quest for efficiency also directs the child towards 'traditional' care [12]. Thus, when mothers consider that child psychiatric care does not bring any improvement, they start consulting a traditional therapist".

Table 2. Traditional therapies used according to cultural and religious background.

Examples of Traditional Therapies	Ethnic group/religious belief
"*Chick to prick the child's mouth to make him talk*". "*Make the child drink foutou water*[4]" "*Purification bath in the rivers* "*Prayer for deliverance in the camps or at the pastor's house*".	Akan and Krou/Christian or animist
"*Nassidji*[5] *used for the child's bath* "*Incense*[6] *to exorcise the place where the child sleeps* " *Wearing white silver jewelry to the child* "*Prayer and Koranic recitation at the marabout*[7] *or imam*	Mandé and Gour/muslim or animist

Source: survey.

[4]Foutou: A basic dish in black African countries, made from cassava roots, plantains or yams, cooked, mashed and shaped into loaves, served with a sauce.

[5]Nassidji: liquid used in the form of a beverage, bath or steam. It is obtained from Koranic verses written on tablets with ink made from a plant.

[6]Incense: Aromatic resinous substance, which burns spreading a penetrating odor, used to drive away malevolent spirits.

[7]Marabout: a person who is believed to have multiple powers, a kind of shaman or priest. Restoring health or social order with the help of talismans, Koranic recitation or animist rituals.

5. Conclusions

At the end of our work, it appears that children with PDD were mainly perceived by parents as a source of psychological suffering or an additional burden. Those around her children with autism perceived them as mysterious, bizarre children, children sacrificed by parents, mute or sometimes as children with a bad education. In general, children with PDD were negatively perceived.

A mystical-religious origin of the disorder was evoked in a majority way by the parents but one also found causes due to the natural disease, heredity and vaccination. This mystical-religious origin according to the parents was related to a spell or possessing spirit taking different names according to the socio-cultural and religious eras of the respondents.

The therapies used to treat this disorder were influenced by the representations made by these parents. Thus, despite a therapeutic syncretism by the concomitant use of modern medicine and traditional therapies, we have found a predominant use of unconventional care.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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