A Pilot Study on Autism Spectrum Disorders in Mali: Parental concerns about child developmental milestones and late diagnostic age

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Abstract

Background: In Mali, the health facility-based prevalence of autism spectrum disorders (ASD) in Mali was 4.5% (105/2,343) and the age of first medical visit for autistic children was around 7 years old in 2018. Parental recognition of developmental abnormalities initiates the early autism detection and diagnosis. In this pilot study, our aim was to investigate if parental concerns were associated with early first medical visits and subsequent ASD diagnostic in Mali.

Methods: We conducted a pilot study from November 2017 to July 2019. We surveyed 57 parents of autistic children aged 3-14 years old.

Results: Parents were concerned over verbal communication in 54.1% and reciprocal social interaction in 43.8%. Children with ASD had their first medical visit after 18 months old in 66.7%, $\geq$ two medical visits in 87.7%, and were identified after 36 months old in 76.8%.

Conclusion: Parental concerns were not significantly associated with early first medical visit and ASD identification. This pilot study will help in the design of larger studies on the same topic in Mali.

Background

Autism spectrum disorders (ASD) affect 1 in 59 children aged eight (8) years old in the United States of America (U.S) [1]. ASD is recognized as an emerging global public health concern. Its prevalence is not only increasing worldwide, but ASD awareness should be raised and the need for early diagnostic and lifelong care are real [2,3]. Almost everything we know about ASD comes mostly from developed countries. In sub-Saharan Africa, the stigma and unmet needs of children with ASD and their parents are considerable [4-6]. In Mali, the health facility-based prevalence of ASD was 4.5% (105/2,343) in 2018 [7].

Early ASD diagnosis is very important. It allows to offer appropriate services earlier in life with better outcomes [8,9]. Early ASD intervention requires early ASD risk screening. Various early autism screening tools have been developed in the U.S. to promote early autism risk detection [10]. In developed countries, the modified checklist for autism in toddlers-Revised/follow up (M-CHAT-R/F) and the social communication questionnaire (SCQ) are available online to parents who suspect their child at risk of ASD [11]. In Mali, we have validated in 2017-2018, the M-CHAT-R and SCQ for ASD screening. M-CHAT-R had a sensitivity of 50%, a specificity of 100%, a PPV of 100% and a NPV of 87% while SCQ had a sensitivity of 71%, a specificity of 72%, a PPV of 73% and a NPV of 70%. Only four out of 20 items on the M-CHAT-R were found to be culturally inappropriate in the Malian context [12]. Timely ASD diagnosis requires early detection, which depends on parental recognition of developmental abnormalities [13]. In the U.S, parental concerns of childhood developmental abnormalities have been shown to influence early or late ASD screening and diagnosis as well as the overall well-being of autistic children [14,15]. In general, the first concerns about the autistic child's development come from their parents in up to 80% [16]. Developmental motor delays during early childhood may represent an important predictor for ASD diagnosis [17,18]. In high risk children, parent-reported concerns can improve early recognition of ASD

[19]. However, research has demonstrated that socio-economic ranking of the parents correlate with the specific of the parental concerns in children suspected with ASD. For instance, parents with high socio-economic status were 8.5 times more concerned about the children being at risk of ASD as compared to those with low social economic status [20]. Parents with both high socio-economic status (S.E.S) and high education level tend to be more concerned about their child developmental than those with low S.E.S and education level. They may easily access healthcare for ASD screening, monitoring and surveillance [12, 13,18].

Mali is one of the poorest countries in the world. In Mali, women have a high unschooling rate and they struggle for their daily living more than men do [21]. The literacy rate is also one of the lowest in the world (33.1%) in people aged 15 years old and above [22]. In addition, early child visits and autism screening are neither mandatory nor systematic in the Malian health system. After the validation of the M-CHAT-R/F and SCQ in Mali, we wondered about the effectiveness of these tools in the early ASD screening and diagnosis in our socio-cultural setting. We hypothesized that parental concerns on childhood developmental abnormalities could guide our ASD awareness campaigns and promote the use of M-CHAT-R and SCQ for early screening of ASD risk in Mali. This original work was aimed to investigate the association between the child age at the first medical visit, as an indicator of the age of ASD diagnosis, and the parental concerns about their children's development abnormalities in Mali.

Methods

We conducted a descriptive cross-sectional pilot study from November 2017 to July 2019 in Bamako. In this study, we included 57 autistic children aged 3-14 years old who were already enrolled into our autism genetic family study in Bamako. Our study was conducted in three phases. In phase 1, potential study participants were screened using the social communication questionnaire (SCQ) at a private medical clinic "Kaidara" downtown Bamako, the capital city and the cutoff score of >15 was used as the main inclusion criterium. In phase 2, screened potential study participants underwent a thorough medical visit by a multidisciplinary team (a senior clinical psychologist, a senior child psychiatrist, a neuro-pediatrician, a neurologist, a resident in psychiatry and a resident in pediatrics). Those who did not have a brain CT scan at inclusion (n=40) underwent brain CT scan by an experienced neuroradiologist. All the potential study participants did eye and ear exams by a senior ear-nose-throat (ENT) specialist and a certified junior ophthalmologist to exclude any medical condition, which could explain the child's deficit in social interaction. In phase 3, study participants were selected based on presence of the signs and symptoms of autism spectrum disorders (dyad of ASD in DSM-V) and the normal brain CT Scan exam (or at least the absence of a structural cerebral lesion that can explain the child's condition). We interviewed parents of our study participants during home visits to administer our study questionnaire (see supplemental material). After informed consent, we collected information on the age of developmental milestones of their autistic children. We directed questions to the mothers of children with ASD to determine the age at which the child was able to do a specific task for the first time. We inquired about the reciprocal social interaction, verbal communication, motor skills, repetitive behaviors and the presence of other disorders such as epilepsy, strabismus, and absence of crying at birth. Autistic children and their parents were

compensated for their study participation at an approved rate by the Malian ethical committee at the Faculty of Medicine, Pharmacy and Odontostomatology (FMPOS), Bamako, Mali. Our study protocol, consent form and questionnaire were approved by the ethical committee at the FMPOS in July 2016. Completed questionnaires were coded without any identifiable personal information. In the database created, data were analyzed with SPSS version 25. We determined the median and mean age for each childhood developmental milestone with a standard deviation and the extreme ages (minimum and maximum). To diagnose ASD, we used the criteria of DSM-IV [23]. To determine the factors associated with a delayed first medical consultation for autistic children in our cohort, we used chi square or Fischer exact test to compare the proportions (before and after a cutoff age of 18 months old for early ASD risk screening and 36 months old for early ASD diagnosis) of the presence of a targeted factor (male gender, Bambara ethnicity, impaired reciprocal social interaction, impaired verbal communication, repetitive behaviors, other disorders). Other disorders represented the presence of epilepsy, presence of strabismus and the absence of crying at birth. p -value <0.05 was considered statistically significant.

Results

Among 57 surveyed autistic children aged 3-14 years old, the sex-ratio was 1.5 in favor of male. The first medical visit was done at 18 months old or older in 66.7%. The diagnosis of ASD was made at 36 months old or older in 76.8%. Autistic children had at least two medical visits before the ASD diagnosis in 87.7% (Table 1).

Table 1 Description of the study population

Characteristics		Frequency	%
Gender	Male	34	59.6
	Female	23	40.4
	Total	57	100
Ethnicity	Bambara	23	40.4
	Others	34	59.6
	Total	57	100
Age of first medical consultation	≤ 18 months	19	33,3
	>18 months	38	66,7
	Total	57	100
Age of ASD identification	≤ 36 months	13	23.2
	> 36 months	43	76.8
	Total	57	100
Health care provider	Conventional medical practitioner	23	40.3
	Traditional medical practitioner	7	12.3
	Both	27	47.4
	Total	57	100
Number of medical consultations before diagnosis	≤ 2 times per child	7	12.3
	>2 times per child	50	87.7
	Total	57	100

Parental concerns on their children's development were mostly about verbal communication (54.1%) and reciprocal social interaction (43.8%) (Table 2).

Table 2 Parental concerns by developmental domains of autistic children before and after age 36 months in Mali

Child's developmental domains	Frequency (N=57)	%
Verbal communication	32	54.1%
Reciprocal social interaction	25	43.8%
Repetitive behaviors	6	10.5%
Other disorders ¹	30	52.6%

The median age of imitation was 24 months old with the extremes of 4 and 168 months old (Table 3).

Table 3 Developmental age of key milestones acquisition for autistic Malian children

Child developmental milestones	Age of acquisition (months old)	
Reciprocal social interaction (being able)	Median	Mean $\pm$ SD [Min.-Max.]
To smile	4.00	7.66 $\pm$ 7.9 [2-36]
To applaude	24.00	36.17 $\pm$ 36.9 [5-132]
To imitate an adult	24.00	45.23 $\pm$ 44.8 [4-168]
To show body parts on request	36.00	52.55 $\pm$ 40.5 [9-156]
To participate in un/dressing	42.00	1. $\pm$ 44.2 [12-180]
Verbal communication	Median	Mean $\pm$ SD [Min.-Max.]
To utter high-pitched crying	7.00	16.10 $\pm$ 14.9 [3-144]
To say several syllables	21.00	31.74 $\pm$ 26.8 [5-84]
To tell a story	49.00	50.4 $\pm$ 21.5 [36-99]
Motor skill acquisition	Median	Mean $\pm$ SD [Min.- Max.]
To hold his/her head	6.00	8.9 $\pm$ 8.0 [3-36]
To reach for an object	7.00	16.1 $\pm$ 23.8 [3-144]
To move in bed by rotation	7.00	11.1 $\pm$ 10.7 [2-48]
To make pedaling movements	6.00	10.5 $\pm$ 9.6 [2-36]
To sit with support	6.00	12 $\pm$ 16.8 [2-108]
To turn around on his/her back	8.50	14.3 $\pm$ 14.6 [3-84]
To put his/her feet in his/her mouth	7.50	14.7 $\pm$ 16.3 [2-84]
To sit without support	7.00	11.7 $\pm$ 10.7 [3-48]
To know how to stretch his/her arms	7.00	13.6 $\pm$ 13.9 [3-72]
To sit from flat back position	9.00	17.5 $\pm$ 26.8 [4-84]
To crawl	10.00	16.8 $\pm$ 16.6 [4-96]
To stand with/out support	13.50	21.1 $\pm$ 13.6 [4-84]
To walk without support	14.50	19.5 $\pm$ 44.8 [7-72]
To eat alone	25.00	36.6 $\pm$ 32.3 [3-144]
To take off his/her shoes	48.00	57.1 $\pm$ 38.8 [13-180]
To jump with joined feet	30.00	37.2 $\pm$ 18.3 [17-96]
To button his/her cloth	60.00	64.8 $\pm$ 41.5 [15-180]

Gender, ethnicity, impaired verbal communication, impaired reciprocal social interaction, repetitive behaviors, epilepsy, strabismus, and absence of crying at birth were not significantly associated with a delayed age at the first medical visit at the following time points (18 months old or older (Table 4) and 36 months old or older (Table 5) $p>0.05$.

Table 4 Factors associated with delayed first medical consultation for autistic children before and after age 18 months

Factors		Age at first medical consultation			p-value
		≤ 18 months N (%)	> 18 months N (%)	Total N (%)	
Gender	Male	6 (26.1%)	17 (73.9%)	23 (100%)	0.628
	Female	12 (35.3%)	22 (64.7%)	34 (100%)	
	Total	18 (31.6%)	39 (68.4%)	57 (100%)	
Ethnicity	Bambara	9 (39.0%)	14 (61.0%)	23 (100%)	0.518
	Others	9 (26.5%)	25 (73.5%)	34 (100%)	
	Total	18 (31.6%)	39 (68.4%)	57 (100%)	
Impaired verbal communication	Yes	9 (39.0%)	22 (71.0%)	31 (100%)	0.805
	No	9 (34.6%)	17 (65.4%)	26 (100%)	
	Total	18 (31.6%)	39 (68.4%)	57 (100%)	
Impaired reciprocal social interaction	Yes	9 (36.0%)	16 (64.0%)	25 (100%)	0.695
	No	9 (28.1%)	23 (71.9%)	32 (100%)	
	Total	18 (31.6%)	39 (68.4%)	57 (100%)	
Repetitive behaviors	Yes	2 (33.3%)	4 (66.7%)	6 (100%)	1.000
	No	16 (31.4%)	35 (68.6%)	51 (100%)	
	Total	18 (31.6%)	39 (68.4%)	57 (100%)	
Other disorders ¹	Yes	9 (30.0%)	21 (70.0%)	30 (100%)	0.88
	No	9 (33.3%)	18 (66.7%)	27 (100%)	
	Total	18 (31.6%)	39 (68.4%)	57 (100%)	

¹Epilepsy, strabismus, and absence of crying at birth

Table 5 Factors associated with delayed first medical consultation for autistic children before and after age 36 months

Factors		Age at identification		Total N (%)	p-value
		≤ 36 months N (%)	> 36 months N (%)		
Gender	Male	3 (13.0%)	20 (87.0%)	23 (100%)	1.000
	Female	4 (11.8%)	30 (88.2%)	34 (100%)	
	Total	7 (12.3%)	50 (87.7%)	57 (100%)	
Ethnicity	Bambara	1 (4.3%)	22 (95.6%)	23 (100%)	0.4275
	Others	6 (17.6%)	28 (82.4%)	34 (100%)	
	Total	7 (12.3%)	50 (87.7%)	57 (100%)	
Impaired verbal communication	Yes	5 (15.6%)	27 (84.4%)	32 (100%)	0.7497
	No	2 (8.0%)	23 (92.0%)	25 (100%)	
	Total	7 (12.3%)	50 (87.7%)	57 (100%)	
Impaired reciprocal social interaction	Yes	3 (12.0%)	22 (88.0%)	25 (100%)	1.000
	No	4 (12.5%)	28 (87.5%)	32 (100%)	
	Total	7 (12.3%)	50 (87.7%)	57 (100%)	
Repetitive behaviors	Yes	0 (0.0%)	6 (100.0%)	6 (100%)	1.000
	No	7 (13.7%)	44 (86.3%)	51 (100%)	
	Total	7 (12.3%)	50 (87.7%)	57 (100%)	
Other disorders ¹	Yes	3 (10.0%)	27 (90.0%)	30 (100%)	1.0000
	No	4 (14.8%)	23 (85.2%)	27 (100%)	
	Total	7 (12.3%)	50 (87.7%)	57 (100%)	

¹Epilepsy, strabismus, and absence of crying at birth

Discussion

Children aged 18 to 24 months are screened for ASD to assist in early detection, consistent with current American Academy of Pediatrics' recommendations [24]. Despite the advances in ASD screening and evaluation, the mean age of diagnosis is still 4-5 years [25]. The age of ASD diagnosis depends on many factors and to label a child "autistic" may require a multidisciplinary team [26] or multiple medical visits (4-5 on average with the extremes of 1 and 29) [27]. While the high demand of services due to a recent increase in ASD prevalence delays its diagnosis in developed countries, the lack of trained health

professionals and the socio-cultural representation of the disorder may prevail in Mali. Similar to sub-Saharan Africa, in the Arab world, culture may significantly influence the age of noticing abnormality and the ways of investigating and treating autism [28].

The age of ASD identification was 36 months old or older in 76.8% (Table 1). In two separate U.S. national surveys, the 2011–2012 National Survey of Children's Health (n=95,677) and the 2009–2010 National Survey of Children with Special Health Care Needs (n=371,617), many parents of children with ASD reported identification after 3 years old with 1/3 to 1/2 of cases after 6 years old [28].

In our cohort, parental concerns on their children's development were mostly about verbal communication (54.1%) and reciprocal social interaction (43.8%) (Table 2). This result corroborates the findings of Richards et al. They reported that over 90% (n=532) of the parents brought up concerns during well child visits and 78.6% were about speech and verbal communication [29]. Children whose parents expressed concerns about their child's verbal communication experienced earlier ages for all outcomes when compared to children of parents who did not have verbal communication concerns [30]. Such finding highlights the evolution of parental concerns over time. In mid-2000s, parents of autistic children used to be concerned over either a delayed diagnosis of physical disabilities, such as hearing impairment, cerebral palsy [31], learning difficulty, being bullied, stress-coping, or achievement [32].

The median age of being able to smile (social and non-social) for the first time was 4 months old and the mean age was 7.7 months old $\pm$ 7.9 with the extremes of 2 and 36 months old (Table 3). Anticipatory smiling levels in the first year may predict ASD diagnosis or continuous ASD severity outcomes [33]. The median age of imitation was 24 months and the average age of 45.23 months $\pm$ 44.8 with the extremes of 4 and 168 months old (Table 3). Immediate and deferred imitations of adults by children with ASD were strongly associated with language ability at age 3-4 years and communication development from age 4 to 6.5 years [34], but the loss of social communication skills is highly variable (its rate, timing and severity) in ASD and it usually occurs in the period between 9 and 24 months [35,36].

The median age of storytelling in our cohort was 49 months and the mean age was 50.4 months $\pm$ 21.5 with the extremes of 36 and 99 months (Table 3). Difficulties in storytelling have been reported in children with ASD [37,38]. While the contribution of problematic use of subject pronoun has been demonstrated in the difficulties in storytelling in school-aged children with ASD [39], speculation has been on whether or not difficulties in orientation in time and space play an important role in the process [40].

Motor development is critical to the overall development of the child. In our cohort, the age of motor skill acquisition was very variable. For instance, the mean age of reaching out for an object was 16.1 months $\pm$ 23.8 with the extremes 3 and 144 months (Table 3). The gross and fine motor skills of young children with ASD are delayed and become progressively more delayed with age [41,42], but the great variability in motor skill acquisition makes it challenging the universality for health professionals [43]. The median age of walking (AOW) in our cohort was 14.50 months and the mean age was 19.5 months $\pm$ 44.8 with the extremes of 7 and 72 months (Table 3). Reindal et al. reported a mean AOW of 15.3 months $\pm$ 5.5 in

children with ASD versus 14.1 months $\pm$ 3.4. AOW is reported to be later in autism spectrum disorder (ASD) compared with typical normal development [44].

None of our targeted factors (male gender, Bambara ethnicity, impaired reciprocal social interaction, impaired verbal communication, repetitive behaviors, the presence of epilepsy, presence of strabismus, and the absence of crying at birth) was significantly associated with the age of first medical visit (the cutoff was 18 months) or the age of identification of autistic disorder (the cutoff was 36 months (Tables 4-5). This finding might have resulted from the small size of our sample. Otherwise, evidence from the literature are compelling for the association of some (if not all) of these studied factors with early detection and diagnosis of autism spectrum disorders.

Parental concerns are more pronounced in males and females with ASD. This may have many plausible explanations. First, even with higher ASD prevalence in both sexes, core ASD symptomology are easily presentable in males, and females are too good in camouflaging their symptoms, which may result in sex differences in parental concerns after age 5 years [45-50]. Second, females experienced less unusual stereotyped and repetitive behaviors than males due to genetic (Y chromosome) and hormonal factors (fetal testosterone) and they have an increased prevalence of internalizing problems [47,51]. Third, females were found to receive lower scores than males particularly on modules 2 and 3 of the Childhood Autism Rating Scale scores (CARS) [52]. Finally, Baron-Cohen's extreme male theory may induce a stronger examiner bias toward males than females with ASD [53].

Black parents reported significantly fewer autism concerns and fewer social and restricted and repetitive behavior concerns as compared to White parents [54]. The Bambara are the largest ethnic group in Mali with up to 36.5% of the total population. They also present in significant percentages in Guinea Conakry, Burkina Faso, Niger, Ivory Coast, and Mauritania [55]. In addition, the other disorders in Tables 3-5 (epilepsy, strabismus, and absence of crying at birth) are very frequent in autism [56-58]. The absence of crying at birth and seizure episode in childhood were highly associated with autism risk in Brazil (OR 5.75; 95%CI 3.37-9.81) [10]. Even though, strabismus has a low prevalence in Africa [59], it has a strong cultural representation in the West African society in general and in Mali in particular. It is referred to as "the hen is looking at the cloudy sky" in Mali and it is a distinctive and particular trait which, a child can be labeled with among his/her peer.

Which one of the impaired reciprocal social interaction, afflicted verbal communication and repetitive behaviors in children with ASD draws first the attention of parents? The answer to this question depends on multiple factors. Truly, ASD is a spectrum in the real sense of the word. When all domains of the child's development are affected moderately or severely at the same time, parents usually notice as early as possible, especially when they have another child with normal developmental for comparison [60]. When language skills lag far behind, parental concerns habitually raise between 18 and 24 months old of age [29,61].

Altogether, assessing parental concerns about children with ASD may be more challenging and more complex than one may initially think. Core symptoms of ASD alone may not explain at which extent

parents are concerned and stressed out their child development and well-being. A more comprehensive assessment should consider other aspects such as sleep and eating problems, parenting stress, the specific burden on mothers with subsequent poor marital relationship [53,60-63].

The main limitation of this study was the possibility of biased answers from some mothers to show that their child was less affected.

Conclusion

After this pilot study, we surveyed parents of 57 children with ASD aged 3-14 years. Parental concerns on their children's development were mostly about verbal communication (54.1%) and reciprocal social interaction (43.8%). The first medical visit was after the age of 18 months old in 66.7%; autistic children had at least two medical visits before the ASD diagnosis in 87.7%. The age of ASD identification was after 36 months old in 76.8%. No investigated factor was associated with the age of first medical visit and identification of ASD due to the small size of our sample. In the future, we will conceive an online version of our study questionnaire for a larger online survey across West Africa.

List Of Abbreviations

ASD: Autism Spectrum Disorders

AOW: Median age of walking

CARS: Childhood Autism Rating Scale scores

DSM-V: [Diagnostic and Statistical Manual of Mental Disorders-V](#)

ENT: Eye, nose & throat

FMPOS: Faculty of Medicine, Pharmacy and Odontostomatology

M-CHAT-R/F: Modified checklist for autism in toddlers-Revised/follow up

SCQ: Social communication questionnaire

OR: Odd ratio

Declarations

Ethics approval and consent to participate: Our study protocol, consent form and questionnaire were approved by the ethical committee at the FMPOS. "All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee (include name of committee + reference number) and with the 1964 Helsinki declaration and

its later amendments or comparable ethical standards.” Informed consent was obtained from all individual participants in the study.

Consent for publication: “Not applicable”

Availability of data and materials: The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests: None. The authors declare that they have no conflict of interest.

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Authors' contributions: All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by [Modibo SANGARE], [YA Diarra] and [Drissa TRAORE]. The first draft of the manuscript was written by [Modibo SANGARE] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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