Research in Autism Spectrum Disorders 6 (2012) 589–601

Contents lists available at SciVerse ScienceDirect

Research in Autism Spectrum Disorders

Journal homepage: http://ees.elsevier.com/RASD/default.asp

Very early signs of autism reported by parents include many concerns not specific to autism criteria

Vincent Guinchat [a,c,*], Brigitte Chamak [b], Beatrice Bonniau [b], Nicolas Bodeau [a], Didier Perisse [a], David Cohen [a,c], Anne Danion [d]

[a] Department of Child Psychiatry, Pitié-Salpêtrière Universitary Hospital, APHP, Pierre and Marie Curie University, Paris, France
[b] CERMES3, Inserm, U 988, CNRS, UMR 8211, Paris Descartes University Paris, F-75006, France
[c] CNRS, UMR 7222, Institut des Systèmes Intelligents et Robotiques, Pierre and Marie Curie University, Paris, France
[d] Department of Child Psychiatry, Strasbourg Universitary Hospital, Strasbourg University, France

ARTICLE INFO

Article history:
Received 2 September 2011
Received in revised form 10 October 2011
Accepted 12 October 2011

Keywords:
Early diagnosis
Autism
Parents' first concerns
Questionnaire
France

ABSTRACT

This study assessed parents' first concerns about their autistic child. This information was categorized so that it could help healthcare professionals improve early detection of autism. We designed a questionnaire using an open-ended format, and 459 questionnaires were completed by parents to assess difficulties encountered in obtaining a diagnosis for their child. Answers about their first motive of concerns were categorized and compared with regards to age, gender, birth order, age of onset, delay in seeking professional advice, and delay in diagnosis. Concerns about social development or autistic behaviors were frequent, but not exclusive. Parents were divided into three clusters of concerns: (a) an "early awareness group": which included motor problems and passivity (14.6 months); (b) "intermediate awareness group": included emotional, hyperactivity, and sleep problems (15.3 months); and (c) a "later awareness group": which included communication problems, poor social interaction, and autistic-type behaviors (22.3 months). Parents who noticed general concerns not specific to autism were worried earlier, but received a later diagnosis. We suggest that motor problems, and/or emotional problems, and/or the level of a child's activity should encourage frontline professionals to seek autistic symptoms in infants.

1. Introduction

Despite evidence that some symptoms of autism spectrum disorder (ASD) are present early in life (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Goin-Kochel, Mackintosh, & Myers, 2006) diagnosis of autism is usually made between 3 and 5 years of age (Goin-Kochel et al., 2006; Latif & Williams, 2007; Mandell, Novak, & Zubritsky, 2005) and at around 11 years for Asperger's syndrome (Howlin & Asgharian, 1999). However, most parents describe concerns during the first 2 years of life (De Giacomo & Fombonne, 1998), but then wait almost 3 years to receive a diagnosis following their first visit to a professional (Siklos & Kerns, 2007). This long interval has a dramatic effect on parental stress (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Mansell & Morris, 2004; Osborne & Reed, 2008), on the therapeutic process, on the child's outcome

* Corresponding author at: Service de Psychiatrie de l'Enfant et de l'Adolescent, Groupe Hospitalier Pitié-Salpêtrière, APHP, Université Pierre et Marie Curie, 47 bd de l'Hôpital, 75013 Paris, France. Tel.: +33 1 42 16 23 51; fax: +33 1 42 16 23 53.
E-mail address: vincent.guinchat@psl.aphp.fr (V. Guinchat).

1750-9467/$ – see front matter
doi:10.1016/j.rasd.2011.10.005

(Mansell & Morris, 2004), and on parents' confidence in medical professionals (Harrington, Patrick, Edwards, & Brand, 2006). Delays in diagnosis are not only constrained by a shortage of specialist services, but by also clinical and developmental limitations regarding infant/toddler assessment itself.

Onset of at least 36 months is mandatory before a diagnosis of autism, but many behavior criteria are rare (i.e., stereotypes) or are not appropriate (i.e., language communication) under the age of 2 years. Therefore, timely diagnosis should start from parents identifying concerns regarding the development of their child, who may then need closer monitoring and surveillance. The extreme clinical heterogeneity of ASD requires us to define symptoms that are not necessarily included in the standard definitions of autism. These may vary through the life of the child but should be easy to screen for by first-line professionals.

Research, based on retrospective parental reports, family home movies, and prospective studies using high-risk samples, has aimed to identify specific early signs that predict early diagnosis of autism (Saint-Georges et al., 2010; Wetherby et al., 2004; Wetherby, Watt, Morgan, & Shumway, 2007; Zwaigenbaum et al., 2007, 2009). In a recent review of prospective studies using high-risk samples, Zwaigenbaum (2010) detailed changes in various domains, which could distinguish children with autism at an age of 18 months. These included social interaction (atypical eye gaze, orientation to name, imitation, social smiling, reactivity, social interest and affect, reduced expression of positive emotion), language, motor problems, play, and cognitive development (Zwaigenbaum, 2010). However, Rogers noted a lack of predictive symptoms at 6 months of age (Rogers, 2009). Although, family home movies tend to show subtle anomalies during the first year of life, most signs fail to distinguish intellectual disability from autism itself (Saint-Georges et al., 2010). These signs show moderate specificity and sensitivity, and are too subtle for current practice.

As a consequence, standardized screening methods for children are not yet sufficiently efficient to reduce the delay for clinical investigations, and pediatricians do not regularly use screening tools. Only trained clinicians are able to detect autistic children under the age of 2 (Klin, Lang, Cicchetti, & Volkmar, 2000). Clinicians base their clinical judgments on signs that have not been consistently recognized or documented, and also on spontaneous parental reports. Therefore, in spite of the methodological limitations to naturalistic appraisal of early-onset autism, studies based on parental reports can provide a good indication of the factors that may raise concerns and alert clinicians.

Glascoe, MacLean, and Stone (1991) showed that most child-developmental problems could be detected through clinical judgments based on parental concerns, and that clusters of parental concerns may be related to a child's performance in screening tests (Glascoe, Macias, Wegner, & Robertshaw, 2007). Parents can accurately appraise their child's development (Pulsifer, Hoon, Palmer, Gopalan, & Capute, 1994) and their concerns are often very accurate at predicting a disability (Rogers et al., 1992). The American Academy of Pediatrics recommends that parents should be asked about any developmental concerns at every well-child visit (Johnson, Myers, & The Council on Children with Disabilities, 2007).

With regard to autism, families frequently express an early sense that there is a problem (Baghdadli et al., 2003; Chamak et al., 2011; De Giacomo & Fombonne, 1998). Parental concerns have been recently correlated with later positive M-CHAT scores (Glascoe et al., 1991). Ozonoff et al. (2009) studied the relationship between parental concerns regarding the development of ASD in the first 18 months of life and later diagnosis of autism in a high-risk population (Ozonoff et al., 2009). Parents who had an older child with autism reported significantly more concerns about ASD-related areas than parents of children with a typical outcome, and also had more general concerns by the time their child was 12 months. However parental concerns at 6 months were not predictive of a diagnosis of autism. When data from the Parents' Evaluation of Developmental Status (PEDS) and M-CHAT were compared, PEDS missed the majority of children who screened positive for ASD (Pinto-Martin et al., 2008).

Among the most common and often first-noted concerns are delays in speech and language development (Coonrod & Stone, 2004; De Giacomo & Fombonne, 1998), some medical disorders (Young, Brewer, & Pattison, 2003), poor eye contact (Gillberg et al., 1990; Hoshino et al., 1987), abnormal social-responsiveness level, a lack of play and interaction (Gillberg et al., 1990; Hoshino et al., 1987; Rogers & DiLalla, 1990; Volkmar, Stier, & Cohen, 1985), extremes of temperament and behavior (Gillberg et al., 1990; Ohta, Nagai, Hara, & Sasaki, 1987), motor-control anomalies, non-specific difficulties related to sleeping, eating, and attention (Short & Schopler, 1988), and atypical development (i.e., apparent slowing of development or loss of previously acquired skills). However, these studies used forced-choice-response questionnaires or had tried to validate a checklist with various patterns of parental concerns (Lung, Shu, Chiang, & Lin, 2010).

In our opinion, most study designs may not necessarily reflect the parent's spontaneous cause for concern or detect their motives for seeking professional advice. An open-ended form of questioning may be a better way to be exhaustive and to collect the most spontaneous concerns. Moreover, most parents are not fluent in the physician's language and sometimes have difficulty describing what worries them regarding their child's development. For the process of appropriate referral, clinicians have to listen and scrutinize the parent's patterns of concerns in order to recognize the relevant clinical information and to actively seek more specific symptoms.

The aims of the current study were to (1) retrospectively address the warning signs and developmental abnormalities perceived by parents of children with ASD; (2) assess variables associated with a diagnostic delay (i.e., patterns of concern, mother vs. father, child's gender); and (3) establish whether some patterns of concern were prone to be taken more into account by primary-care physicians when identifying children in need of closer monitoring and surveillance regarding a possible diagnosis of autism.

2. Methods

2.1. Participants

A questionnaire was designed to assess the parents' experiences regarding the diagnostic process of autism (Chamak et al., 2011). Child psychiatrists and care units dedicated to ASD, from the different regions of France, were contacted to distribute the questionnaire. Local autistic societies and support groups cooperated in the survey by distributing the informative letter and the self-report questionnaires to their members or by indicating on their Internet site how to contact us to participate in the survey. We sent 700 questionnaires by post to the child psychiatrists and care units, and to 52 parents' associations. Questionnaires were also sent by email. The rate of returns, although impossible to estimate exactly, is less than 50%.

The participants were drawn from the population of mothers and fathers of children with ASD: 459 completed the questionnaires, which were obtained from all over France between 2005 and 2007 (Fig. 1A), from psychiatrists and care units ($n = 302$; 66%), from support groups ($n = 120$; 26%), and from the Internet ($n = 37$; 8%).

Of the 459 participants, 75% were mothers and 25% were fathers; 59% of the questionnaires were filled in by mothers only, whereas 10% were completed by fathers only. A majority of parents (87.5%) reported concerns about their child before they had been warned by professionals. The sample included 369 children and adults with ASD (male: $n = 294$; 79.6%). The mean age of the children was 12.6 years (SD = 3.86). The distribution of ages is shown in Fig. 1B.

According to the parents' reports, 142 (38.4%) children had received a first diagnosis of autism, 39 (10.5%) a diagnosis of pervasive developmental disorder – not otherwise specified, and 25 (6.7%) a diagnosis of Asperger's syndrome. Other children were reported to be psychotic ($n = 29$; 7.8%) or to have clinical features of autism ($n = 32$; 8.4%). One child had a childhood disintegrative disorder. The other children ($n = 101$; 27%) either had not received a diagnosis or had received an inadequate diagnosis from a medical doctor. Three families had two children with autism.

2.2. Questionnaire

The questionnaire was designed to assess the various experiences of the parents in obtaining a diagnosis of autism for their child, and to get quantitative and qualitative data. It included both forced-choice and open-ended questions. It covered the parents' demographic data, the child's age when the parents first became concerned, the reasons for their concerns,

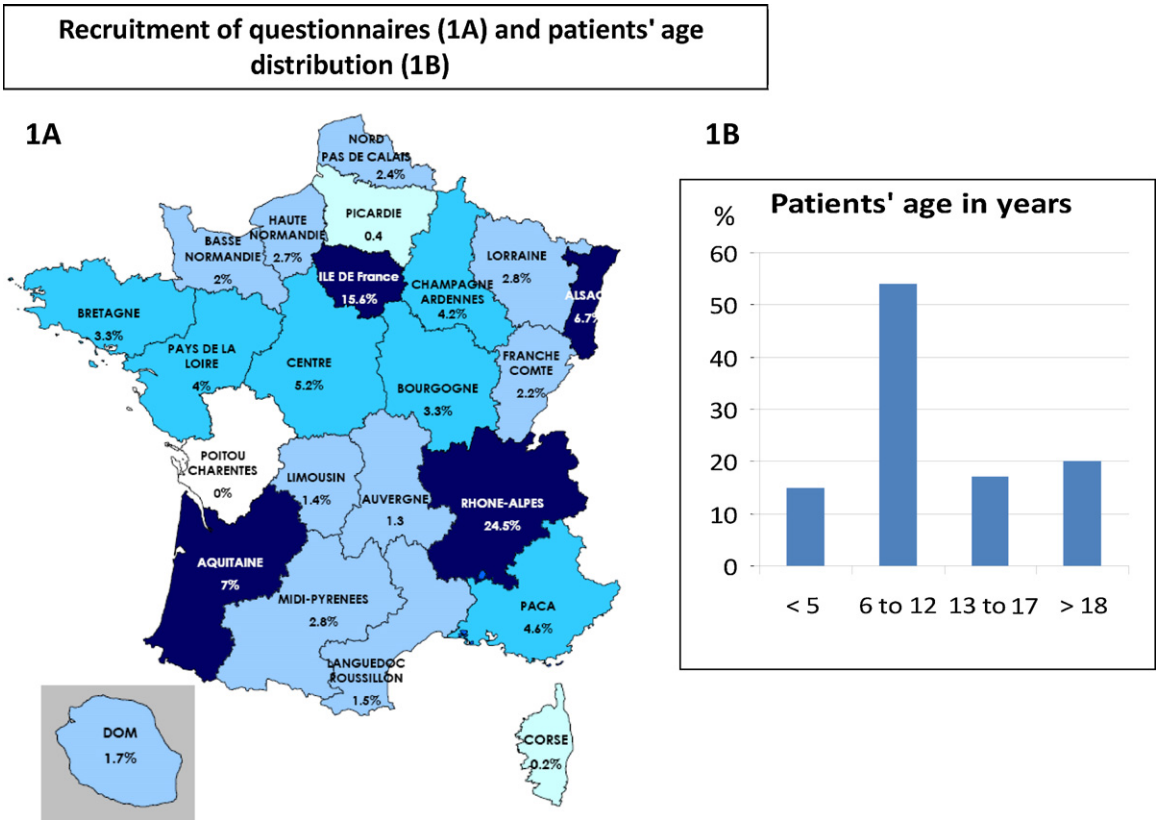

Fig. 1. Recruitment of questionnaires (A) and patient' age distribution (B).

which parent was first concerned, the child's age when help was sought, the professionals consulted, the different diagnoses obtained, and the precise terms used (Chamak et al., 2011).

Herein, we have focused on the first concerns described by parents in the open-ended questionnaire. This methodology required extensive coding (see below), but the open-ended questions enabled us to obtain more personal and spontaneous information than forced-choice questions. The general principle was to transform the responses into a set of categories that enabled both qualitative and quantitative analyses (Chamak et al., 2011).

The data from all the questionnaires were recorded using Modalisa software (see www.modalisa.com). We discarded five questionnaires that referred to adopted children and one questionnaire that did not contain any data regarding the parents' primary concerns. We also discarded 23 questionnaires because both parents of the same child completed the questionnaire with identical answers. Otherwise, even if the questionnaire was filled in separately by the two parents of the same child, both responses were taken into account. As two questionnaires could refer to the same child, some children had more weight within the analysis than those for whom only one questionnaire was completed. However, this methodology was justified because we focused on the parents' primary concerns. A discrepancy between the parents' answers provides valuable information about the various ways a single problem can be perceived and reported to clinician. This meant that, for a total of 369 subjects, 431 questionnaires were analyzed.

2.3. Coding procedure

The preliminary coding structure consisted of collapsing the parent's responses into 10 general (G) domains of symptoms: (1) abnormal socio-emotional development; (2) delayed/deviant language development; (3) autistic-type behaviors (i.e., stereotypes); (4) behavior difficulty not specific to autism; (5) abnormalities concerning major physiological functions (feeding problems, sleeping problems, incontinency); (6) anomalies in motor milestones; (7) perceptive abnormalities; (8) medical disorders (e.g., seizures); (9) loss of previously acquired skills; and (10) other concerns. Two authors (VG and BB) were independently in charge of the coding. Inter-observer agreement was superior to 0.9. Disagreements were resolved by consensus. In some cases, we had to interpret some ambiguous responses as our analysis was based on the parents' spontaneous discourse. We then decided if a single sentence could refer to several categories: e.g., "does not communicate" could be related to a deficit in verbal communication or a social skill, "does not react when we talk to him" could be related to social reactivity or language comprehension.

Within each domain, parental propositions were sorted, and we formed a detailed list of topics that included the parents' common concerns (see Table 1). The prominent topics were extracted and added to the previous categories for quantitative analysis. This enabled us to be more accurate in eliminating general assertions, such as "behavioral problem" not otherwise specified. Fig. 2 is an example of how patterns of concerns were classified into the 10 (G) domains, which included 31 subcategories of concerns.

2.4. Analyses

All statistical analyses were conducted using SAS software. We first performed a descriptive analysis of all the variables of interest: age at first concern, delay in seeking professional advice, delay in diagnosis, and domains and subcategories of first concerns. Using univariate analysis, we identified the explanatory variables related to parental concern and associated them with the following independent variables: child's age when parents fist became concerned, child's age when seeking professional advice, age at diagnosis, the delay between the age at first concern and the age when seeking professional advice, and the delay between the age at first concern and the age when the parent received a diagnosis of autism.

The following variables were extracted from the Modalisa database for statistical analyses and were listed within the following three groupings:

- *Global domains of concerns*: abnormal socio-emotional development, delayed/deviant language development, autistic-type behaviors, behavior difficulties not specific to autism, abnormalities concerning major physiological functions, anomalies in motor milestones, perceptive abnormalities, medical problems, loss of previously acquired skills, other concerns.
- *Subcategories of concerns*: gaze abnormalities, poor social interaction, lack of response to social stimuli, non-verbal communication, delayed language skills, no language, poor language comprehension, stereotyped movements, anxiety/crying, attention and interest deficits, tantrums/opposition, hyperactivity, passivity, sleeping problems, eating problems, delay in motor milestones, hypotonia/hypertonia.
- *Gender of child and reporting parent*.

Due to changes in medical practices during the last 20 years, analyses related to age at diagnosis was restricted to children aged < 12 years.

Given the number of concerns, we used a two-step analysis (R package "FactoMineR") to detect and represent the underlying structures in our data set. First, a multiple-correspondence analysis was conducted (function "MCA). This descriptive method allowed analysis of categorical data by calculating factorial axes. The first axis retained the maximum variance, the second axis the second most important variance, and so on. It was then possible to calculate the variables'

Table 1
First symptoms to arouse parental concern regarding autism spectrum disorder (ASD) ($n = 420$).

Subcategories: *n* (%)	Common pattern of content within each subcategory: *n*
Abnormal socio-emotional development (G) $n = 272$ (64.7%)	
Gaze abnormalities: 107 (25.4%)	Avoid eye contact: $n = 46$, no eye contact: $n = 22$; empty gaze: $n = 13$; no gaze $n = 12$; other $n = 17$
Poor social interaction: 141 (33.6%)	Social withdrawal or isolated $n = 89$; does not communicate $n = 49$, social avoidance (i.e., dislikes being cuddled, doesn't like to being approached) (17); poor social interest $n = 19$; lacks social engagement $n = 5$
Lack of response to social stimuli: 59 (14.0%)	No response to name $n = 29$; no reaction to social solicitation $n = 18$; no reaction to separation from family members $n = 4$; impression of deafness $n = 8$
Non-verbal communication: 32 (7.6%)	Pointing $n = 7$, poor emotional expression; $n = 19$; no joint attention $n = 5$; lack of gesture $n = 3$; imitation $n = 4$
Other social behaviors: 41 (9.8%)	Social reciprocity (i.e., Lack of shared enjoyment, interactivity, would not share games with peers) $n = 12$; integration problem noticed at school $n = 10$; other problems with sociability $n = 20$, i.e. relationship problems; does not differentiate between family members $n = 1$
Delayed/deviant language development (G) $n = 235$ (55.9%)	
Delayed language: $n = 76$ (18.1%)	Delayed language $n = 27$; language regression $n = 8$; language appeared later on $n = 4$; poor language $n = 6$; stagnation $n = 6$; difficulty in forming structural sentences or dialogue $n = 3$; cannot pronounce some words $n = 4$; rarely talks $n = 4$; language problems $n = 5$; problems with communication $n = 9$
No language $n = 122$ (29.0%)	Does not talk $n = 42$; no language $n = 66$; no babbling $n = 6$; did not communicate $n = 10$; total regression of language $n = 8$
Language comprehension $n = 40$ (9.5%)	No response to name $n = 29$; does not listen $n = 4$, no response to demands or questions $n = 4$; language comprehension $n = 3$
Other language anomalies $n = 11$(2.6%)	Lack of imaginative play $n = 3$; jargon $n = 2$; echolalia $n = 5$; stereotyped/repetitive language $n = 1$; imitation $n = 2$
Autistic-type behaviors (G) $n = 114$ (27.1%)	
Stereotyped movements $n = 62$ (14.8%)	Stereotypes $n = 33$, swinging $n = 15$; hand-flapping $n = 9$; ticks $n = 2$; jumping $n = 3$; running $n = 3$; lecking $n = 1$; strange gestures $n = 2$
Need for routine/rituals $n = 19$ (4.5%)	Rituals $n = 7$; anxious when change occurs $n = 4$; angry at changes $n = 4$; resistant to change $n = 3$
Stereotyped/restricted interest $n = 20$ (4.7%)	Staring at light?? $n = 3$; fiddling?? with hands $n = 2$; head turning?? $n = 3$; only interested in specific objects $n = 7$; restricted interest $n = 3$; obsession $n = 1$
Persistent preoccupation with parts of objects $n = 22$ (5.2%)	Rotating car wheels $n = 4$; cords $n = 3$; napkin $n = 1$; pen $n = 1$; any object $n = 1$; playing with lights $n = 2$; making lines with objects ($n = 4$); opening/closing doors $n = 4$; banging an object $n = 3$; other $n = 6$
Behavior difficulties not specific to autism (G) $n = 224$ (53.3%)	
Attention and interest $n = 50$ (11.9%)	No interest in toys and games $n = 17$; not interested by his/her environment $n = 20$; attention deficit $n = 14$
Tantrums/opposition $n = 66$ (15.7%)	Screams $n = 19$; tantrums $n = 5$; opposition $n = 13$; aggressive $n = 10$; anger $n = 24$
Hyperactivity $n = 31$ (7.3%)	Hyperactivity $n = 15$; agitation $n = 11$; instability $n = 5$
Passivity $n = 48$ (11.4%)	Calm/quiet $n = 16$; apathetic $n = 11$; absent/"on the moon" $n = 9$; too good $n = 3$; no reaction $n = 9$
Anxiety/crying $n = 48$ (11.4%)	Crying, sadness $n = 31$, i.e., cries all the time; anxious and anxiety $n = 21$, i.e., unusual fears
Other $n = 35$ (8.3%)	General assertions about behaviors $n = 17$; laughing for no reason $n = 3$; strange games $n = 5$, auto-mutilation $n = 7$; other (11)
Abnormalities concerning major physiological functions (G) $n = 61$ (14.5%)	
Sleeping problems $n = 36$ (8.5%)	Sleeping disorder $n = 29$; insomnia $n = 3$; wakes up often $n = 2$; wakes up crying $n = 2$
Eating problems $n = 25$ (5.9%)	Feeding disorders $n = 8$; selectivity $n = 1$; difficulty in feeding $n = 5$; anorexia $n = 3$; mastication $n = 3$; inappropriate ingestion; vomiting $n = 2$; suction and weaning problems $n = 3$
Incontinency $n = 9$ (2.1%)	Not potty trained $n = 8$; fecal incontinence $n = 1$
Anomalies in motor milestones (G) $n = 97$ (23.0%)	
Delay $n = 53$ (12.5%)	Delayed walking $n = 19$; delayed sitting $n = 17$; no crawling on hands and knees $n = 3$; comprehension $n = 3$; cannot hold up own head $n = 4$; motor delay $n = 15$; motor imitation $n = ??$, no grasping $n = 1$
Hypotonia $n = 29$ (6.9%)	Hypotonia $n = 23$; difficulty in maintain postures $n = 7$; like a rag doll $n = 3$; head hypotonia $n = 5$
Hypertonia $n = 10$ (2.4%)	Walks on tiptoes $n = 5$; rigidity $n = 6$; cannot release objects
Other $n = 22$ (5.2%)	Strange gestures/posture $n = 8$, motor problems $n = 8$; balance $n = 3$; suction $n = 3$; not moving during pregnancy $n = 3$
Perceptive abnormalities (G) $N = 49$ (11.6%)	
Visual $n = 8$ (1.6%)	Fixation (light, hand) $n = 5$; does not react to visual stimuli $n = 3$; both visual and hearing insensitivity $n = 1$; hypersensitivity to all senses $n = 1$
Hearing problems $n = 23$ (5.5%)	Scared by certain noises (canalization 1) $n = 5$; lack of reaction to noises $n = 18$
Somatotropic problems $n = 23$ (5.5%)	Only happy in water $n = 1$; does not want to be touched, to be in a bath, or be dressed $n = 11$; insensitive to pain $n = 10$; warm/cold sensitivity $n = 2$
Medical disorders (G) $n = 22$ (5.2%)	

Table 1 (*Continued*)

Subcategories: *n* (%)	Common pattern of content within each subcategory: *n*
–	Epilepsy *n* = 7; visual disorders *n* = 2; hearing disorders *n* = 3; infections *n* = 3; digestive problems *n* = 5; nystagmus *n* = 1; growth delay
Loss of previously acquired skills (G) *n* = 38 (9%)	
Other concerns (G) *n* = 39 (9.2%)	
Idiosyncratic development *n* = 15 (3.6%)	Overall delay *n* = 12; regression to a baby *n* = 1; abnormal development *n* = 2
Oddness not otherwise specified *n* = 8 (1.9%)	Subjective feeling that the child is different from other children *n* = 7; bizarre behavior *n* = 1
Other *n* = 13 (3.1%)	No sense of danger *n* = 2 or reality *n* = 3; time or logic dysfunction *n* = 2; confused relationship with caregiver *n* = 2; hyper-ability in a specific skill *n* = 1; school problems *n* = 1; feeling invaded *n* = 1; problems with sexual identity *n* = 1; state of tension *n* = 2

contributions to the axes, to assess what they represent. Graphical plots were used to visualize the projections of the individuals and the variables on the first dimensions. The (adjusted) eigenvalues corresponding to each axis were also calculated to select the most explicative dimensions.

This exploratory method did not measure statistical significance, but highlighted the relationships between the variables that described the parents' concerns. It enabled us to calculate factorial axes (clinical dimensions) and to identify those parental groups that had common patterns of concern. Each individual was represented by a point, and it was then possible to calculate the distances between each individual and, thus, enable classification.

The second step was the hierarchical ascendant clustering (HAC) of coordinates calculated with the MCA (function "HCPC"). The aim was to find sub-profiles of individuals within a dataset, and to determine the relationships between the profiles and factors. The principle was to merge the closest clusters at each step of the algorithm, which meant choosing a metric (distance between pairs of observations) and a linkage criterion (distance between sets of observations).

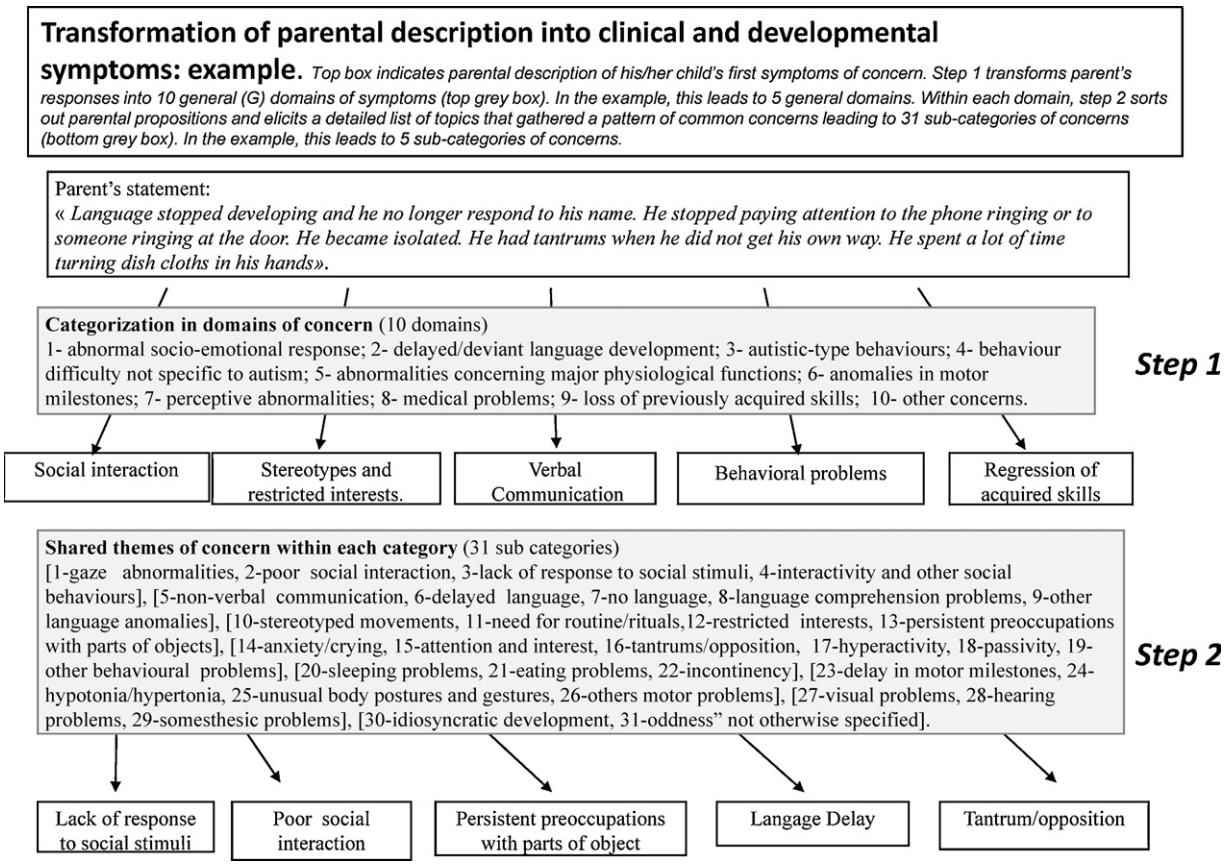

Fig. 2. Transformation of parental description into clinical and developmental symptoms: example. Top box indicates parental description of his/her child's first symptoms of concern. Step 1 transforms parent's responses into 10 general (G) domains of symptoms (top grey box). In the example, this leads to 5 general domains. Within each domain, step 2 sorts out parental propositions and elicits a detailed list of topics that gathered a pattern of common concerns leading to 31 sub-categories of concerns (bottom grey box). In the example, this leads to 5 sub-categories of concerns.

In our study, we calculated the matrix of distances using Euclidean distance (this is a natural choice as the axes calculated with MCA are perpendicular to each other) and Ward's criterion (this minimizes intra-cluster variance). An alternative to HAC is the *k*-means method, but its drawback is that the number of final clusters has to be selected. However, the *k*-means method is of particular interest when using HAC centroids as seeds for the algorithm. We actually applied this methodology as it included the "HCPC" function as a consolidation step.

3. Results

3.1. Symptoms and age at first parental concern, and age at diagnosis

The mean age of children was 19 months (SD = 11.7) when parents first reported warning signs, and 27 months (SD = 17.5; $n = 418/424$) when parents sought a first professional's advice. There was a wide range of ages when early characteristics were first noted, and 78% parents recognized a reason for concern before the child's second birthday. Parents described regressive events in no more than 10% of cases. The mean delay between the parents' first concern and receiving first professional advice was 5.2 months (SD = 11.7). Diagnosis was made by a professional after a mean time lag of 39.3 months (SD = 44.4) after the parents' first concerns. Children were, on average, 58.8 months (SD = 47.5) when they received a diagnosis from a medical doctor.

Table 1 shows the first symptoms that aroused parental concerns, listed according to the 10 major clinical domains (G), and divided into sub-categories. Examples of parental reporting are given in the far column to explain the coding procedure. We found that specific features of autism (abnormal socio-emotional development, delayed/deviant language development, autistic-type behaviors) and non-specific warning signs (behavior difficulties not specific to autism, abnormalities concerning major physiological functions, anomalies in motor milestones, perception abnormalities, medical disorders, other problems) were represented in equivalent proportions, respectively, at 78% ($n = 328$) and 72% ($n = 303$). In 56% questionnaires ($n = 236$) children exhibited both types of signs and in 18% questionnaires ($n = 78$) children exclusively exhibited non-specific warning signs.

The majority of parents (64.7%, $n = 272$) first noticed a set of problems directly related to abnormal socio-emotional development of their child (G). This category of concern included several subcategories. The most frequent subcategories were "poor social interaction" (33.7%; $n = 141$), when parents described their child as being "social withdrawn" ($n = 92$), "isolated", "in his/her own world" or "distant". A second sub-category was "gaze abnormalities" (25.4%; $n = 107$), where parents described avoidance of gaze, an absence of eye contact, or the feeling of an "empty stare" reflecting no expression. A "lack of response to social stimuli" was also frequently described ($n = 60$; 14%).

Delayed/deviant language development (G) was the second most significant domain within the warning signs, and was reported by 235 parents (55.9%). Parents were more worried by an absence of language or a delay in speech than by deviant features (e.g., echolalia) or problems related to language comprehension. Autistic-type behaviors (G) were described in only 114 questionnaires (27.1%).

Behavior difficulties not specific to autism (G) caused concern for half of the parents ($n = 224$; 53.3%). Among the most frequent problems (subcategories), we identified tantrum/opposition ($n = 66$; 15.7%), anxiety/crying ($n = 48$; 11.4%), passivity ($n = 48$; 11.4%), hyperactivity ($n = 31$; 7.3%), and lack of attention or interest (11.9%; $n = 50$), which was mainly reported by parents as "interested in nothing", "not interested in toys", or "lack of attention".

Among the other concerns, anomalies in motor milestones (G) were frequently noted ($n = 96$; 23.0%), including delay in motor milestones ($n = 53$; 12.5%), hypo- or hyper-tonicity ($n = 39$; 9.1%), and other abnormalities ($n = 22$; 5.2%) such as strange postures. Abnormalities concerning major physiological functions (G) (sleeping problems, eating problems, incontinency) were also reported by 59 (14.0%) parents. Perception abnormalities (G) (either lack of reaction or hyper-arousal) and various medical disorders aroused concerns in 49 (11.6%) and 23 (5.4%) parents, respectively. Global-developmental delay ($n = 18$, 4.2%) or the subjective feeling that their child was "strange" or "different" ($n = 18$, 4.2%) was rarely reported.

Univariate analysis showed that gender caused few significant differences except for poor social interaction, which was more common in boys (OR = 2.26 [95% CI: 1.17–4.53]; $p = 0.009$), and for several motor problems, which were more frequent in girls: i.e., anomalies in motor milestones (G) (OR = 0.42 [95% CI: 0.25–0.88]; $p = .001$), and motor delay (OR = 0.49 [95% CI: 0.25–0.88]; $p = 0.025$). The parents' gender did not cause a significant difference except for anxiety and crying, which were more frequently reported by mothers: (G) (OR = 0.26 [95% CI: 0.05–0.86]; $p = 0.022$).

3.2. Child's age, concerns, and time of diagnosis

Using univariate analysis, we first explored whether the 26 variables, including the 10 domains (G) and the 16 subcategories of parental concern (see Section 2), were significantly associated with age when the first worrying signs were observed, the age at first consultation, the age at diagnosis, the delay in consultation, and the delay in diagnosis. The significant results are presented in Table 2.

The age at first concern was significantly lower for children with anomalies in motor milestones (G), gaze abnormalities, lack of response to social stimuli, and eating and sleeping problems. As expected, the age of a child was higher

Table 2
Parental concerns significantly associated with age at first signs of autism spectral disorder (ASD), age at first consulting, age at diagnosis, delays in consultation and diagnosis (Mann–Whitney *U* test).

	Reported	Mean ± SD	Not reported	Mean ± SD	*U*	*p*
Age at first signs of ASD (months)						
No language	108	22 ± 9.9	270	17.6 ± 12.3	10,894	<.001
Tantrums/opposition	56	23.1 ± 10.6	324	18.1 ± 11.9	6424	0.001
Hypertonia	15	12.4 ± 8.6	365	19.1 ± 11.9	3626	0.028
Hypotonia	29	8.6 ± 8.4	349	19.7 ± 11.7	7924	<0.001
Gaze abnormalities	105	15.2 ± 9.9	268	20 ± 12.2	16,975	<0.001
Regression of acquired skills	34	23.2 ± 6.4	341	18.3 ± 12.2	3955	0.005
Lack of response to social stimuli	67	16.1 ± 8.8	313	19.4 ± 12.3	12,014	0.048
Language delay	75	24.7 ± 8.5	303	17.5 ± 12.1	6661	<0.001
Motor delay	54	13 ± 10.8	326	19.8 ± 11.7	11,879	<0.001
Restricted interests	116	22.5 ± 11.4	264	17.2 ± 11.7	11,276	<0.001
Verbal-communication problems	215	22 ± 9.9	160	14.3 ± 12.7	9540	<0.001
Eating problems	24	12.4 ± 10	352	19.1 ± 11.8	5286	0.012
Sleeping problems	39	13.4 ± 11.7	337	19.3 ± 11.7	8411	0.003
Other worries (G)	35	21.3 ± 16.3	341	13.4 ± 11.7	5224	0.02
Age at first consultation (months)						
Tantrums/opposition	57	32.3 ± 18.3	329	26 ± 13.4	7141	0.004
Hypotonia	28	14.8 ± 11	358	27.9 ± 14.2	7767	<0.001
Gaze abnormalities	108	23.2 ± 10.7	278	28.4 ± 15.4	17,967	0.002
Language delay	75	32.6 ± 15.9	309	25.6 ± 13.7	8073	<0.001
Motor delay	53	20.4 ± 13.5	333	28 ± 14.3	12,008	<0.001
Non-verbal communication	31	19.6 ± 11.6	355	27.6 ± 14.4	7364	0.002
Restricted interests	109	29.5 ± 14.4	277	25.9 ± 14.3	12,984	0.003
Verbal-communication problems	223	29.2 ± 14.2	163	23.8 ± 14.2	14,068	<0.001
Sleeping problems	39	21.6 ± 12.2	347	27.5 ± 14.5	8596	0.005
Motor problems	94	19.9 ± 13	292	29.2 ± 14.1	19,322	<0.001
Other worries (G)	37	32.8 ± 18	349	26.3 ± 13.8	5093	0.033
Age at first diagnosis (months)						
Hyperactivity	23	58.4 ± 27.2	214	45.3 ± 21.6	1718	0.017
Poor social interaction	87	49.3 ± 21.8	151	45 ± 22.7	5354	0.017
Other worries (G)	24	54 ± 24.2	214	45.7 ± 22.1	1871	0.029
Delay until consultation (months)						
Stereotypes	59	9.1 ± 8.4	307	8.2 ± 11.4	7605	0.046
No language	105	5.9 ± 8.3	261	9.3 ± 11.7	16,191	0.005
Verbal-communication problem (G)	212	7.2 ± 10.7	154	9.8 ± 11.1	18,734	0.027
Stereotypes/restricted behaviors (G)	104	9.6 ± 9.7	262	7.8 ± 11.4	11,108.5	0.005
Other worries (G)	34	11.5 ± 11.9	332	8 ± 10.8	4518	0.05
Reported by father	61	6.6 ± 10.5	268	8.8 ± 11.1	9658	0.024
Non-specific warning signs only	58	11.4 ± 12.6	303	7.7 ± 10.5	7414	0.036
Diagnosis delay (months)						
Verbal communication problem (G)	142	24.5 ± 22.1	83	30 ± 23.3	6880	0.036
Other worries (G)	21	34.2 ± 22.7	199	27.6 ± 24.7	1534	0.045
Reported by father	169	19 ± 19.6	33	27.5 ± 22.7	3554	0.012
Non-specific warning signs only	27	31.8 ± 20.6	198	25.8 ± 22.9	2023	0.04

(G), parents' concern; SD, standard deviation.

for delayed/deviant language development (G), tantrum/opposition behaviors, autistic-type behaviors (G), with these symptoms usually appearing later during development. The age when the parent received a diagnosis varied according to the presence or absence of three variables: poor social interaction, hyperactivity, and other warning signs (G), which included mainly non-specific developmental problems or worries about their child "being different". Finally, using an asymptotic Wilcoxon rank-sum test, the group of parents that noted warning signs that were not related to the clinical dimensions of autism ($n = 78$; 18%) reported concerns at an earlier age (14.35 ± 12 months) compared to parents whose children had at least one symptom related to clinical autism ($n = 343$; 81%; 19.52 ± 11.6 months). In addition, a diagnosis of autism was made after a longer delay (34.9 ± 22 months vs. 27.6 ± 24.7 months; p-value = 0.045) for parents who reported exclusively non-specific signs (data not shown in the tables).

3.3. Multivariate modeling

The MCA revealed three axes from which an ascending hierarchical classification was made (Fig. 3A). Table 3 summarizes the characteristics of each class in the model in terms of relative frequency: it shows parents' concerns that contributed most to each class. Cluster 1 was characterized by a higher frequency of children who aroused worries because of motor abnormalities (G) (48.1%), passivity (27%), medical disorders (G) (11.8%), attention problems (22.2%), and gaze abnormalities

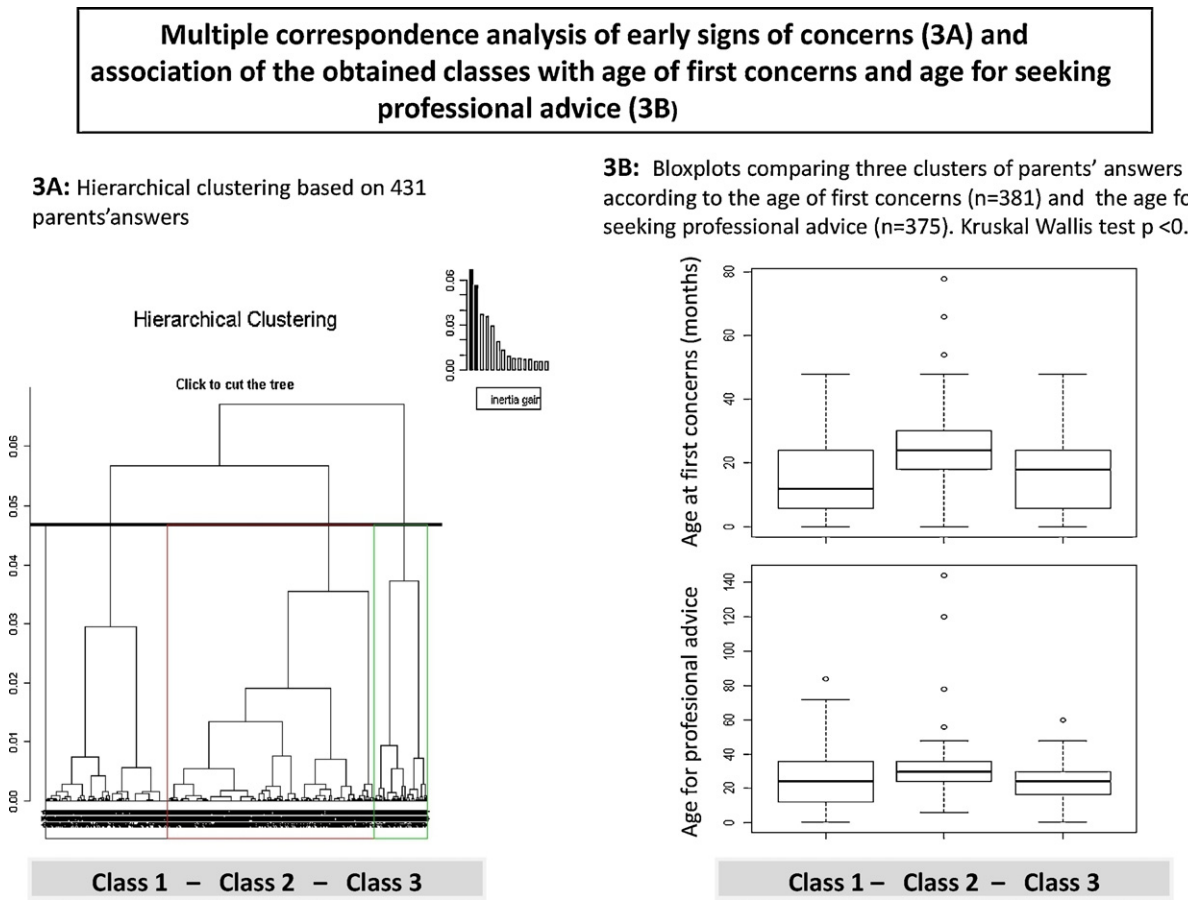

Fig. 3. Multiple correspondence analysis of early signs of concerns (A) and association of the obtained classes with age of first concerns and age for seeking professional advice (B). (A) Hierarchical clustering based on 431 parents'answers and (B) Bloxplots comparing three clusters of parents' answers according to the age of first concerns ($n = 381$) and the age for seeking professional advice ($n = 375$). Kruskal–Wallis test $p < 0.001$.

(37%). Frequency of other behavioral problems, autistic-type behaviors (G), poor social interaction, and verbal-communication abnormalities (G) were lower.

Cluster 2 included the children's profile that had a greater lack of response to social stimuli (25%), poor social interactions (42.6%), autistic-type behaviors (G, 34.8%), and verbal-communication abnormalities (G), (85.6%). In this class, concerns related to motor-developmental abnormalities (G), anxiety/crying, gaze abnormalities, hyperactivity, and sleeping and eating problems, did not exceed 10%.

In cluster 3, we found children who had a higher frequency of behavior difficulties not specific to autism, such as tantrums/opposition (30.7%), anxiety/crying (71.1%), hyperactivity (17.3%), sleeping disorders (61.5%), eating problems (30.7%), and perception abnormalities (34.6%). Problems related to poor social interactions were rarely reported.

The vast majority of children who aroused parental concerns because of non-specific signs only were included in cluster 1. Boys were more represented in cluster 2; girls were more represented in cluster 1. Finally, clusters 1 and 3 were the most potent predictors for a lower age of first-concern (Fig. 3B) and a lower age when parents sought professional advice.

4. Discussion

Despite the wide range of ages when parents first noticed worrisome signs, our study provides evidence that some features of a child's development can raise concerns during infancy, long before a diagnosis of autism. The majority of parental concerns were related to early socio-affective development, and repetitive interests and behaviors. Nevertheless, only gaze abnormalities, delayed language development, and the absence of a child being able to answer to their name, are clinical signs that are actively assessed by clinicians (Baranek, 1999; Oosterling et al., 2009), and are a common cause of parental concern when directly expressed in this way. Other manifestations were easily recognizable, but needed to be derived from the terms that parents used. Sometimes worries were too general (e.g., "does not communicate") and were not

Table 3
Parental concern according to the three classes obtained after multiple analyses were performed.

	Cla.Mod (%)	Mod.Cla (%)	Global (%)	*p*-Value	*v*-Test
CLUSTER 1: *"Passive/motor group"* (*n* = 135)					
Warning signs reported:					
Passivity	82.2	27.4	11.5	<0.001	6.85
Motor abnormalities (G)	68.4	48.1	24.2	<0.001	7.73
Medical disorders (G)	69.5	11.8	5.8	<0.001	3.32
Attention	50.8	22.2	15	0.007	2.66
Gaze abnormalities	45.8	37	27.8	0.005	2.78
Warning signs not reported:					
Verbal communication abnormalities (G)	67.6	83.7	42.7	<0.001	12.12
Stereotypic/restricted behaviors (G)	41.4	86.6	72.1	<0.001	4.71
Poor social interaction	39.7	79.2	68.7	0.001	3.18
Anger/tantrum	39.6	97.7	85.1	<0.001	5.52
Lack of response to social stimuli	39.6	94.8	82.6	<0.001	4.82
Anxiety/crying	38.6	94.8	84.6	<0.001	4.16
Perception abnormalities (G)	37.4	98.5	90.7	<0.001	4.06
Hyperactivity	37	99.2	92.5	<0.001	3.9
Sleeping problems	36.9	96.2	90	0.002	2.99
CLUSTER 2: "*autism- like group*" (*n* = 204)					
Warning signs reported:					
Verbal-communication abnormalities (G)	77.6	85.2	57.2	<0.001	11.97
Lack of response to social stimuli	75	25	17.3	<0.001	4.08
Poor social interactions	71.3	42.6	31.2	<0.001	5.05
Anger/tantrums	67.2	19.1	14.8	0.018	2.36
Stereotypic/restricted behaviors (G)	65.1	34.8	27.8	0.001	3.09
Warning signs not reported:					
Motor abnormalities (G)	64.1	93.1	75.7	<0.001	8.56
Sleeping problems	57.3	99	90	<0.001	6.48
Gaze abnormalities	57.2	97	88.4	<0.001	5.59
Passivity	56.7	78.4	72.1	0.005	2.79
Anxiety/crying	56.7	92.1	84.6	<0.001	4.2
Attention	55.4	90.1	84.9	0.003	2.92
Feeding problems	55.1	99	93.6	<0.001	4.61
Medical disorders (G)	54.6	98.5	94.1	<0.001	3.79
CLUSTER 3: "*non-specific behaviors group*" (*n* = 52)					
Warning signs reported:					
Sleeping problems	82	61.5	9.9	<0.001	10.6
Anxiety/crying	61.6	71.1	15.3	<0.001	10.06
Feeding problems	64	30.7	6.3	<0.001	6.02
Perception abnormalities (G)	50	34.6	9.2	<0.001	5.53
Hyperactivity	31	17.3	7.41	0.015	2.41
Anger/tantrum	27.5	30.7	14.8	0.002	3.02
Warning signs not reported:					
Poor social interactions	16.72	86.5	68.7	0.003	2.95

Cla.Mod, the proportion of individuals having the modality (in the whole dataset) who are in this cluster; Mod.Cla, the proportion of the individuals of this cluster having the modality; Global, the proportion of individuals having the modality in the whole dataset.

always referred to by the clinical targets recommended by evidence-based guidelines. For instance, within the social-communication dimension, parents would preferentially notice social withdrawal or qualify their child as being in "his/her own bubble", rather than evoking problems with emotional interactivity or pointing.

Concerns about social development or autistic behaviors are frequent but not exclusive. We found that the earliest warning signs were frequently not specific to autism. Most parents reported at least one general sign not related to features associated with a diagnosis of autism. Motor peculiarities, sensory reactivity, atypical regulation of emotions, a lack of attention, an abnormal level of activity, or sleeping problems were some of the common features evoked. These concerns occurred at varying ages and it is noteworthy that most of the concerns related to a diagnosis of autism were clearly not the earliest concerns evoked by parents (Bryson, Zwaigenbaum, & Roberts, 2004; Short & Schopler, 1988; Stone, McMahon, Yoder, & Walden, 2007). In contrast, many non-specific manifestations were described more prominently to occur earlier in infancy. Such manifestations accompany changes in other aspects of behavior that mark the emergence of autistic symptoms, which may be more difficult to pinpoint at an earlier stage (Bryson, Bradley, Thompson, & Wainwright, 2008; Garon et al., 2009; Ozonoff et al., 2009).

A good screening strategy should search for more complex inter-subjective impairments than the basic signs spotted during standard clinical observations. The description of the unique relationship between a child and its caregiver should

mirror more complex interpersonal relationships (Muratori & Maestro, 2007). Therefore, the value of a parent's spontaneous expression of concern about their child should be reconsidered as a practical clue that reflects more complex interactions, and should engage clinicians in further more specific investigations. In some cases, pediatricians and other health-care providers may dismiss a parent's concerns, considering that the public media have significantly increased awareness, or that parents are excessively anxious with regard to variations in normal development (Caronna, Augustyn, & Zuckerman, 2007).

Our results may encourage clinicians to consider parents as vigilant observers. Explicitly, investigations of parental concerns with appropriate questioning may enable us to identify children who need closer monitoring and surveillance for early signs of ASD. However, the specific signs of autism described in detail on the Internet tend to influence parents to adopt more stereotyped descriptions.

We found a bias in the usual screening of autism when we focused on features specific to autism. Parents who reported only general concerns about their child were alerted earlier, but had a longer delay until diagnosis. Therefore, we recommend pediatricians should keep a close watch on concerns involving motor development, temperament, and level of activity. Secondly, if any doubt persists, referral to a child psychiatrist may be warranted.

Universal screening procedures are impeded by the varying patterns of onset. On the basis of parental reports, we have identified three different clinical profiles that contain similarities in the patterns of concerns. These profiles may correspond to recognizable steps within a gradual emergence process, as has been reported in some prospective studies (Ozonoff, Heung, Byrd, Hansen, & Hertz-Picciotto, 2008). Some studies (Baghdadli et al., 2003; Hoshino et al., 1987; Short & Schopler, 1988), but not all (De Giacomo & Fombonne, 1998; Rogers & DiLalla, 1990; Volkmar et al., 1985) indicate a different prognosis depending on the age at recognition. This may provide evidence that some of these profiles account for distinct trajectories or clinical sub-groups.

The variety of parental concerns also mirrors individual differences in perceptions and descriptions among parents. Depending on the terms used by parents to express a concern, a clinician may not be oriented towards an anomaly in social development. A proposition, such as a "lack of interest" may encompass either social-attention problems or cognitive attention. Also, it is likely that "abnormal emotional response", frequently reported by parents, may refer to emotional reciprocity or to autistic behavior. Therefore, it is important to explore parents' worries and to help reformulate these worries to make them more specific.

Concerns also depend on the expectations that parents may have towards their child, which are determined by several parameters, including the social context. We found that concerns about social development are less likely to be raised for girls. These abnormalities fit the atypical clinical presentation of girls. They are also often misattributed to have a "shy temperament", which is a common pattern of copying conferred to young girls (Bumiller, 2008; Miller, 2003). Being a father or a mother may also influence these expectations, although there was no statistical difference in parent gender in our sample (although only a few fathers filled in the questionnaire compared to mothers). However, we did find that mothers were more sensitive to the abnormal emotional responses of their child. Such concerns may be linked to difficulties in emotional adjustment that mothers are more prone to notice because they often experience a closer proximity to their child during infancy.

No other study, with a similar design and such a large sample size, has focused on autistic children by analyzing parental reports. The large number of 459 questionnaires enabled us to scrutinize concerns in more detail and to include more categories in the analysis than previous studies with a similar design (Coonrod & Stone, 2004; Goin, 2004; Young et al., 2003). The open-ended form of the questionnaire enabled us to identify spontaneous concerns that have not been currently explored in structured questionnaires or in evidence-based checklists on clinical targets. However, despite these strengths, the current study suffers from a number of limitations related to the accuracy of the parents' reports.

Retrospective reports are prone to recall bias or a "telescoping effect" (Neter & Waksberg, 1964), which is a tendency of parents to report a later age of symptom recognition. This influences the perception of the timing when autism emerges. To evaluate this effect, we compared children, adolescents, and adults. Given that they did not exhibit major changes in early parental concerns, we kept all the subjects together in our analyses (data not shown). However, we found that children received a diagnosis more often and earlier than adults, which probably reflects changes to the French medical practice over the past 20 years (Chamak et al., 2011). The second limitation of this study was that diagnosis status was not validated by professionals. However, participants were recruited from specialized care units and parent associations.

In addition, our analysis could have included more factors that may have influenced the parents' reports, such as socio-economic data. Low-income parents are known to receive a later diagnosis of their child (Mandell et al., 2005). But it is also noteworthy that the French healthcare system is free and that a diagnosis is not a mandatory condition for initiating treatment. Finally, the influence of the initial risk-status of the child was not included in the analyses. All these factors may delay or precipitate a parent's concerns and, consequently, may affect the timing of appropriate assessment. These factors should be considered in future studies.

We conclude that asking parents open-ended questions about their child and appreciating their concerns may constitute a valid resource to identify young children in need of closer monitoring and surveillance with regard to ASD. Their experiences underline the necessity to improve the appraisal of non-specific warning signs, which should be integrated into the early-screening strategies for autism.

Acknowledgements

This research was supported by a grant from the Fondation de France. We would like to thank the psychiatrists, the care units and the associations of parents who agreed to distribute the questionnaire, and the parents who accepted to fill in the questionnaire.

References

Baghdadli, A., Picot, M. C., Pascal, C., Pry, R., & Aussilloux, C. (2003). Relationship between age of recognition of first disturbances and severity in young children with autism. *European Child and Adolescent Psychiatry, 12*, 122–127.

Baranek, G. T. (1999). Autism during infancy: A retrospective video analysis of sensory-motor and social behaviors at 9–12 months of age. *Journal of Autism and Developmental Disorders, 29*, 213–224.

Bryson, S. E., Zwaigenbaum, L., & Roberts, W. (2004). The early detection of autism in clinical practice. *Paediatrics and Child Health, 9*, 219–221.

Bryson, S. E., Bradley, E. A., Thompson, A., & Wainwright, A. (2008). Prevalence of autism among adolescents with intellectual disabilities. *Canadian Journal of Psychiatry, 53*, 449–459.

Bumiller, K. (2008). Quirky citizens: Autism, gender, and reimagining disability. *Signs: Journal of Women in Culture and Society, 33*, 967–991.

Caronna, E. B., Augustyn, M., & Zuckerman, B. (2007). Revisiting parental concerns in the age of autism spectrum disorders: The need to help parents in the face of uncertainty. *Archives of Pediatrics and Adolescent Medicine, 161*, 406–408.

Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism, 15*, 83–97.

Coonrod, E. E., & Stone, W. L. (2004). Early concerns of parents of children with autistic and nonautistic disorders. *Infants and Young Children, 17*, 258–268.

De Giacomo, A., & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *European Child and Adolescent Psychiatry, 7*, 131–136.

Garon, N., Bryson, S. E., Zwaigenbaum, L., Smith, I. M., Brian, J., Roberts, W., et al. (2009). Temperament and its relationship to autistic symptoms in a high-risk infant sib cohort. *Journal of Abnormal Child Psychology, 37*, 59–78.

Gillberg, C., Ehlers, S., Schaumann, H., Jakobsson, G., Dahlgren, S. O., Lindblom, R., et al. (1990). Autism under age 3 years: A clinical study of 28 cases referred for autistic symptoms in infancy. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 31*, 921–934.

Glascoe, F. P., MacLean, W. E., & Stone, W. L. (1991). The importance of parents' concerns about their child's behavior. *Clinical Pediatrics, 30*, 8–11.

Glascoe, F. P., Macias, M. M., Wegner, L. M., & Robertshaw, N. S. (2007). Can a broadband developmental-behavioral screening test identify children likely to have autism spectrum disorder? *Clinical Pediatrics, 46*, 801–805.

Goin, R. P. (2004). Parental reports of the development of autism in their children: The relevance of regression, comorbidity, and genetics in the detection of early characteristics. Dissertation Abstracts International, 64(7-B), 3558. Retrieved from PsychInfo database.

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism, 10*, 439–451.

Harrington, J. W., Patrick, P. A., Edwards, K. S., & Brand, D. A. (2006). Parental beliefs about autism. *Autism, 10*, 452–462.

Hoshino, Y., Kaneko, M., Yashima, Y., Kumashiro, H., Volkmar, F. R., & Cohen, D. J. (1987). Clinical features of autistic children with setback course in their infancy. *The Japanese Journal of Psychiatry and Neurology, 41*, 237–245.

Howlin, P., & Asgharian, A. (1999). The diagnosis of autism and Asperger syndrome: Findings from a survey of 770 families. *Developmental Medicine and Child Neurology, 41*, 834–839.

Johnson, C. P., Myers, S. M. & The Council on Children with Disabilities. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics, 120*, 1183–1215.

Klin, A., Lang, J., Cicchetti, D. V., & Volkmar, F. R. (2000). Brief report: Interrater reliability of clinical diagnosis and DSM-IV criteria for autistic disorder: Results of the DSM-IV autism field trial. *Journal of Autism and Developmental Disorders, 30*, 163–167.

Latif, A. H. A., & Williams, W. R. (2007). Diagnostic trends in autistic spectrum disorders in the South Wales valleys. *Autism, 11*, 479–487.

Lung, F. W., Shu, B. C., Chiang, T. L., & Lin, S. J. (2010). Parental concerns based general developmental screening tool and autism risk: The Taiwan National Birth cohort study. *Pediatric Research, 67*, 226–231.

Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116*, 1480–1486.

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service. *Autism, 8*, 387–407.

Miller, J. K. (2003). *Women from another planet? Our lives in the universe of autism* Bloomington: 1st Books Library.

Muratori, F., & Maestro, S. (2007). Autism as a downstream effect of primary difficulties in intersubjectivity interacting with abnormal development of brain connectivity. *International Journal for Dialogical Science, 2*, 93–118.

Neter, J., & Waksberg, J. (1964). A study of response errors in expenditures data from household interviews. *Journal of the American Statistical Association, 59*, 18–55.

Ohta, M., Nagai, Y., Hara, H., & Sasaki, M. (1987). Parental perception of behavioral symptoms in Japanese autistic children. *Journal of Autism and Developmental Disorders, 17*, 549–563.

Oosterling, I. J., Swinkels, S. H., Gaag, R. J., Visser, J. C., Dietz, C., & Buitelaar, J. K. (2009). Comparative analysis of three screening instruments for autism spectrum disorder in toddlers at high risk. *Journal of Autism and Developmental Disorders, 39*, 897–909.

Osborne, L. A., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism, 12*, 309–324.

Ozonoff, S., Heung, K., Byrd, R., Hansen, R., & Hertz-Picciotto, I. (2008). The onset of autism: Patterns of symptom emergence in the first years of life. *Autism research, 1*, 320–328.

Ozonoff, S., Young, G. S., Steinfeld, M. B., Hill, M. M., Cook, I., Hutman, T., et al. (2009). How early do parent concerns predict later autism diagnosis? *Journal of Developmental and Behavioral Pediatrics, 30*, 367–375.

Pinto-Martin, J. A., Young, L. M., Mandell, D. S., Poghosyan, L., Giarelli, E., & Levy, S. E. (2008). Screening strategies for autism spectrum disorders in pediatric primary care. *Journal of Developmental and Behavioral Pediatrics, 29*, 345–350.

Pulsifer, M. B., Hoon, A. H., Palmer, F. B., Gopalan, R., & Capute, A. J. (1994). Maternal estimates of developmental age in preschool children. *The Journal of Pediatrics, 125*, S18–S24.

Rogers, S. J., & DiLalla, D. L. (1990). Age of symptom onset in young children with pervasive developmental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 29*, 863–872.

Rogers, B. T., Booth, L. J., Duffy, L. C., Hassan, M. B., McCormick, P., Snitzer, J., et al. (1992). Parents' developmental perceptions and expectations for their high-risk infants. *Journal of Developmental and Behavioral Pediatrics, 13*, 102–107.

Rogers, S. J. (2009). What are infant siblings teaching us about autism in infancy? *Autism research, 2*, 125–137.

Saint-Georges, C., Cassel, R. S., Cohen, D., Chetouani, M., Laznik, M.-C., Maestro, S., et al. (2010). What studies of family home movies can teach us about autistic infants: A literature review. *Research in Autism Spectrum Disorders, 4*, 355–366.

Short, A. B., & Schopler, E. (1988). Factors relating to age of onset in autism. *Journal of Autism and Developmental Disorders, 18*, 207–216.

Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities, 28*, 9–22.

Stone, W. L., McMahon, C. R., Yoder, P. J., & Walden, T. A. (2007). Early social-communicative and cognitive development of younger siblings of children with autism spectrum disorders. *Archives of Pediatrics and Adolescent Medicine, 161*, 384–390.

Volkmar, F. R., Stier, D. M., & Cohen, D. J. (1985). Age of recognition of pervasive developmental disorder. *The American Journal of Psychiatry, 142*, 1450–1452.

Wetherby, A. M., Woods, J., Allen, L., Cleary, J., Dickinson, H., & Lord, C. (2004). Early indicators of autism spectrum disorders in the second year of life. *Journal of Autism and Developmental Disorders, 34*, 473–493.

Wetherby, A. M., Watt, N., Morgan, L., & Shumway, S. (2007). Social communication profiles of children with autism spectrum disorders late in the second year of life. *Journal of Autism and Developmental Disorders, 37*, 960–975.

Young, R. L., Brewer, N., & Pattison, C. (2003). Parental identification of early behavioural abnormalities in children with autistic disorder. *Autism, 7*, 125–143.

Zwaigenbaum, L., Thurm, A., Stone, W., Baranek, G., Bryson, S., Iverson, J., et al. (2007). Studying the emergence of autism spectrum disorders in high-risk infants: Methodological and practical issues. *Journal of Autism and Developmental Disorders, 37*, 466–480.

Zwaigenbaum, L., Bryson, S., Lord, C., Rogers, S., Carter, A., Carver, L., et al. (2009). Clinical assessment and management of toddlers with suspected autism spectrum disorder: Insights from studies of high-risk infants. *Pediatrics, 123*, 1383–1391.

Zwaigenbaum, Lo nn ie (2010). Advances in the early detection of autism. *Current Opinion in Neurology, 23*, 97–102.