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ORIGINAL CONTRIBUTION

Parents' views and experiences of the autism spectrum disorder diagnosis of their young child: a longitudinal interview study

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Abstract

Parents are valuable stakeholders in research, clinical practice and policy development concerning autism spectrum disorder (ASD). Little is known, however, about how parents view and experience an ASD diagnosis. We investigated the evolution of parents' views and experiences of the ASD diagnosis before, right after and 12 months after their child was diagnosed. Seventeen Flemish parents waiting for their young child's diagnostic ASD assessment participated in a longitudinal study consisting of three in-depth interviews. They described their views and experiences concerning their child's ASD diagnosis at three separate moments: (T1) prior to a diagnostic ASD assessment; (T2) immediately after their final feedback session at the end of the assessment; and (T3) 12 months later. Interviews were digitally recorded, transcribed and analysed in Nvivo 11 according to the procedures of interpretative phenomenological analysis. We extracted three themes from the interview material throughout the parental journey: (T1) expecting certainty and exculpation; (T2) vulnerabilisation of the child; and (T3) pragmatic attitude and some disappointment. At T3, the parents overall had come to value the diagnosis because of two reasons: they were satisfied with their child's entitlement to ASD-related support at school, and with the diagnosis' impact on the child's relationships with parents and teachers. Many parents experienced their child with an ASD diagnosis as vulnerable, and themselves as acutely responsible for his development and future. Our findings may lead to a higher satisfaction with the clinical trajectory in both clinician and parents by inspiring a conversation between them about parents' evolving views, hopes and concerns related to their child's ASD diagnosis.

Keywords Autism spectrum disorder diagnosis · Parents · Longitudinal · Experiences · Blame · Vulnerability

Abbreviations

ADHD	Attention deficit and hyperactivity disorder
ASD	Autism spectrum disorder
DSM	Diagnostic and statistical manual of mental disorders
ID	Intellectual disability
IPA	Interpretative phenomenological analysis

Background

Autism spectrum disorder (ASD) is a neurodevelopmental condition diagnosed through the assessment of early-onset difficulties in social communication and repetitive behaviours and restricted interests, leading to dysfunctioning in at least two contexts [2, 33].

Parents are pivotal in the care of children with a (presumed) ASD diagnosis. Indeed, in understanding and supporting children with a diagnosis, parents occupy a central position [37, 45]. Moreover, it has been argued that understanding ASD begins with listening to, communicating with, and learning from autistic people and their families, and by understanding their experiences [5, 10].

Several studies investigated parents' experiences of their child getting an ASD diagnosis and having ASD. Previous research investigated diagnostic best practices for ASD, and made recommendations to improve the diagnostic assessment, the disclosure of a diagnosis, and parents' satisfaction after the feedback session. For example, studies have shown

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that a clinician's manner during the disclosure of the ASD diagnosis was important, and a follow-up appointment was advised to take place within weeks after the feedback session [1, 8, 11]. Also, parents' perspectives on and experiences of the impact of their child's ASD-related behaviours and needs on their lives were investigated. For example, studies have described the challenges associated with caring for a child with ASD, and the need of parents of a child with an ASD diagnosis (as well as adults with an ASD diagnosis) of post-diagnostic support [11, 14, 49].

However, several authors have claimed that few studies aimed at exploring parents' views and experiences of an ASD diagnosis per se [36, 53]. That is, few studies focussed on parents' understandings and experiences of an ASD diagnosis. In a review of the few empirical studies that investigated this topic (for example [58, 63], we found (1) a temporal shift in parents' understandings and experiences of an ASD diagnosis throughout their trajectory in clinical ASD care; (2) a preference for a collaborative relationship between clinician and parents over, e.g. a paternalistic relationship [18, 51]; and (3) that both clinicians and parents experienced important psycho-relational implications of an ASD diagnosis [29]. These findings inspired the research question and design of this study.

The aim of this study is to explore and gain an insight into how parents understand and experience the ASD diagnosis of their child. Because our literature review showed a temporal evolution in parents' understandings and experiences of ASD, we set up a longitudinal study investigating parents' views and experiences of an ASD diagnosis before and after the ASD diagnostic assessment of their child. We conducted three interviews: (1) before the start of the diagnostic assessment; (2) right after parents' feedback session at the end of the assessment; and (3) 12 months later. This longitudinal study with parents in turn is part of a broader research project also investigating doctors' views and clinical experiences of an ASD diagnosis of a young child [28, 31, 32].

Method

This method section is similar to the method section in the article concerning the pre-diagnosis interviews alone, conducted at T1 [30].

Sample

We included Flemish parents of young children (up to 6 years of age) without a previously diagnosed disability (intellectual disability (ID) or other disability) who applied for a diagnostic ASD assessment. In the Flemish Region of the federal state Belgium, health insurance is mandatory and covers the majority of all medically indicated procedures, such as an ASD assessment. Children need a categorical DSM diagnosis (Diagnostic and Statistical Manual of mental disorders) to be entitled to specialised support and treatment [2]. Half of the toddlers attend day care, mostly state-funded, and from 2.5 to 3 years on, more than 90% of the children go to a state-funded school in which extra support can be provided to children with special needs. In 2015, the school support organisation changed towards an inclusive system in which children's special needs are judged dimensionally. Thus, children would not need a categorical diagnosis anymore to qualify for extra school support [15] but, according to frequent articles in Flemish lay press (e.g. https://www.standaard.be/cnt/dmf20190611_04454183), this organisation is not put into practice (yet). We purposively sampled 17 parents [42, 52, 60] who asked for a diagnostic ASD assessment of their child in two specialised centres in Leuven: a child psychiatric and a paediatric centre. We chose these two centres, because young Flemish children are most often diagnosed in these two types of centres by multidisciplinary teams including a child psychiatrist or a paediatrician [55]. The two centres collaborate to some degree and there does not seem to be a difference between their respective patients up to 6 years of age whose parents ask for a diagnostic ASD assessment. Parents are either referred to such a centre by a child professional and/or they self-refer. One of the clinicians who would be conducting the child's assessment invited both parents, mother and father, to participate in this study. Information about the study was given orally and in written form, and all participants gave their informed consent to their inclusion in the study and to the publication of the study results. The Ethics Committee of the University Hospitals Leuven approved this study on 3 February 2017 (Belgian Registration Number B322201731147).

Data collection

Data were gathered by conducting one pre-diagnosis and two post-diagnosis phenomenological in-depth interviews. The first interviews took place after the parents had called to ask for a diagnostic assessment, and a couple of weeks before the first session of the child's diagnostic assessment (T1). The second interviews were conducted within 2 weeks after the parents' feedback session at the end of their child's assessment (T2). The third interviews took place 12 months after the feedback session (T3). The interviews were semi-structured by topic guides (Online Resource 1) that were based on the findings from our literature review on how parents conceptualise ASD [29, 64]. The interview guides consisted of open-ended questions. They were used flexibly to encourage participants to elaborate freely and reflectively on a theme—either mentioned by the interviewer or a closely related one they wanted to talk about. All interviews were conducted in Dutch by the first author (D. J.)

Table 1 Sample characteristics

Child	Age at first interview	Sex	Interviewed parent	Sibling with ASD diagnosis	Family structure
1	2y9m (2.75)	Male	Mother	/(first child)	Mother + father
2	2y10m (2.83)	Male	Mother + father	+	Mother + father
3	1y11m (1.92)	Male	Mother + father	/	Mother + father
4	2y3m (2.25)	Male	Mother + father	/(first child)	Mother + father
5	6y4m (6.33)	Male	Mother	/	Parents divorced, father absent
6	4y (4)	Male	Mother + father	+	Mother + father
7	3y7m (3.58)	Male	Mother + father	+	Mother + father
8	4y11m (4.92)	Male	Mother	+	Mother + father
9	4y2m (4.17)	Male	Mother	+	Mother + father
10	5y6m (5.5)	Male	Mother + father	/	Mother + father
11	1y11m (1.92)	Male	Mother	+	Mother + father
	Average age: 3y8m (3.65)	Male	Mother + father	Sibling with ASD diagnosis	Mother + father
	SD: 1y5m (1.42)	11/11 (100%)	6/11 (55%)	6/11 (55%)	10/11 (91%)

and audio-recorded. They took between 36 and 102 min, depending on parents' elaboration on the topic. Data were collected between July 2017 and February 2019.

Analysis

We inductively analysed the data by applying the procedures outlined for interpretative phenomenological analysis (IPA) [64]. D. J. transcribed each recorded interview verbatim. She systematically and inductively coded the transcripts line-by-line in NVivo 11 (QSR International 2017), identifying passages of text across the data of one interview that were loosely or closely related to the research question. Then, D. J. and K. H. combined the relevant codes across interviews to discern patterns (1) within one series of interviews (cross-sectional analysis, at respectively T1, T2 and T3); (2) between the three different interviews concerning one child (longitudinal analysis of case profiles, regarding one single child at T1, T2 and T3); and (3) between the successive series of interviews (cohort analysis, at T1, T2 and T3) [59, 65, 66]. Consequently, these primary emergent codes were clustered into recurrent subthemes and interpretively synthesised into themes. All four authors met regularly to discuss and govern this analytic process in an interdisciplinary collaboration. Finally, an overall narrative account was created by combining the themes which were created out of the three types of analysis. We translated representative quotations verbatim from Dutch to English to give an impression of the interviewees' original expressions. Square brackets indicate information added from the interview material before or after the quote to facilitate readers' understanding of the quote. Several strategies were employed to strengthen the trustworthiness of the findings [62]. For example, the analytic process was subjected to peer scrutiny by researchers from the local psychology and pedagogy faculties during several meetings and seminars; the data were triangulated by also interviewing physicians working with the same group of children—and their parents—with a similar research question [28, 31, 32]; and, by conducting several interviews, the study's credibility was increased because of its improved potential to generate data which fitted the views of the participants and properly represented the dynamic process [6, 9].

Results

We interviewed 17 parents after they applied for a diagnostic ASD assessment of their child in one of two university centres (Table 1): 11 mothers and 6 fathers of 11 children who were, at the moment of the first of 3 interviews, between 1 and 6 years of age (average age of the children at the first interviews: 3y08m, SD: 1y05m). Fifty percent of the invited parents did not accept the invitation to participate in the study. All 11 children were male. Ten children were living in a family consisting of a mother and a father. One child's parents had divorced and his father did not have any contact with him. The parents' education and employment were diverse. Six children were found to have an older sibling who already was diagnosed with ASD. We conducted three consecutive interviews with six couples of mother and father, one divorced mother, and four mothers without their partners. Therefore, four fathers chose not to participate in the interviews, although they had been explicitly invited. In the interviews, their partners, the four corresponding mothers,

were asked to say something about their views on their partners' experiences.

At the moment of inclusion, we did not know if the included children would get an ASD diagnosis at the end of the diagnostic assessment. Eventually, all but one child got an ASD diagnosis. One of the ten diagnosed children first got the diagnosis of a 'working hypothesis of ASD'; 1 year later, after a planned second diagnostic assessment, this child got the actual ASD diagnosis.

In the course of the second interview with the parents of the one child who did not get a diagnosis, the interview guide had to be slightly adapted to more conditional wordings once the parents told the interviewer that the child had not been diagnosed with ASD (e.g. "can you describe what 'getting an ASD diagnosis' for your child would have meant to you?"). These parents were clearly disappointed about their child not being diagnosed with ASD. They said that he was too young (3y07m) to be certain about the outcome of the assessment, and they were planning to have him reassessed in 2 years' time, although this was not advised to them by the diagnosing professionals. These parents chose not to participate in a third interview, because of lack of time.

Several themes were extracted from the interviews on parents' understandings and experiences of the ASD diagnosis of their child. We describe the three themes which were most prominent in the analytic coding process throughout the three series of interviews: (T1) expecting certainty and exculpation; (T2) vulnerabilisation of the child; and (T3) pragmatism and some disappointment. Where appropriate, we highlight the difference between the interviews of parents with an older child diagnosed with ASD (Sib +) and the interviews of parents without an older child diagnosed with ASD (Sib −). We do not mention parents' Sib + and Sib − status if we did not find any difference.

Before the assessment (T1): expecting certainty and exculpation

At T1, in the pre-diagnosis interviews, parents overall wished to understand and gain certainty about what was going on with their child and hoped for an exculpatory effect of the ASD diagnosis.

All parents said that their children behaved in some respect differently from their peers, and some parents said that their children were more difficult than their siblings and peers. They expected that the ASD diagnosis and the corresponding explanations by the ASD professionals would provide them with answers (*All people want answers, you know.*—Mother 3), and specifically for Sib − parents, to guide them in their education of the child. The following Sib − mother did not think about ASD until the school mentioned it. Once ASD was mentioned, she wanted certainty:

> I decided on my own [after the school had suggested to have my child tested, but left all initiative to my] to well: "I have him tested um I want to know now if he really has that [ASD], and what is going on."—Mother 5

However, parents who had an older son or daughter diagnosed with ASD (Sib +) already at T1 expressed quite some certainty about their child going to be diagnosed with ASD. These parents often did not expect an ASD diagnosis to have an impact on their child-rearing practices, like the following mother who also had a 2 year older child with an ASD diagnosis:

> Though I ask myself with [my child who is going to be assessed]: "What?" Because we already have home counselling [for the older brother with an ASD diagnosis] and we have a day line, we know how we have to handle everything, so that's playing inside of me like "Uh?".—Mother 4 (Sib +)

Many parents talked about blame, that is, whether they as parents or the child were to blame for the child's different or difficult behaviours. Both parents and others (relatives, friends, acquaintances) appeared to be worried in this regard. An ASD diagnosis was expected to dissolve these concerns. For example, the following mother—and father, not quoted here—had one 2-year-old child, and were very insecure about their own contribution to the child's challenging behaviours.

> Yes, [an ASD diagnosis will tell us whether] it is congenital, something that we have to learn to live with, or [whether] it is just our way of raising him that is no good?—Mother 4

Second, the diagnosis was also expected to lift blame from the child:

> I think for me it [an ASD diagnosis] will rather be a relief, because then I know: "Yes, you see, he can't help it, he's not naughty, it's, you know, it's just a kink in his brain and we have to accept that, you know, we have to learn to handle this".—Mother 8

Third, parents expected other people to be susceptible to an exculpatory effect of the ASD diagnosis towards both child and parents:

> If you can say to people: he has ASD, [I hope] that people will more easily say "Oh yes, he can't help it" you know. [I hope] that they won't judge him that easily, and also us, you know, that maybe they will also better understand us, you know.—Mother 10

After the diagnosis (T2): Vulnerabilisation by the ASD diagnosis

After their child was diagnosed with ASD, all parents were satisfied with the certainty they felt the diagnosis conveyed *(Now you finally effectively know that there really is something.*—Mother 5) but many parents also told that the diagnosis made them view the child as more vulnerable.

At T2, compared to T1, despite the interviewer's explicit prompts in this regard, all parents talked little about what exactly was ASD and what caused it, that is, about the exact nature of the certainty that the diagnosis had provided. Rather, all parents were satisfied with a broad understanding of ASD as a congenital condition caused by biological—neurological and/or genetic—mechanisms.

> Well, now apparently, it's genetically determined hum the daughter of my husband's brother also has it [ASD]. Hum but how it is caused…? Well, I, yes, no, it is 'in there' I suppose and then, you have it or you don't have it.—Mother 1

At T2, after the child was diagnosed with ASD, many parents said that their child was vulnerable or in need of protection, in a general sense—not related to specific problems. The ASD diagnosis, which was often sought for as an explanation for specific challenges the child was facing, also could bring along the conviction that there was something pervasively fragile about the child. This feeling had been only rarely and implicitly discerned in the parents' narratives at T1, but at T2, it had become explicit. The following mother said that she had always been protective of her only child because he was born after lengthy fertility treatment. Once he was diagnosed with ASD, she considered herself to have become even more protective:

> But it's not, you know, that I love him less because I know there is something wrong, actually, maybe quite the opposite [laughs]. I am, yes, I really became very protective. Because, you know, he's, yes, maybe he is more vulnerable than other children.—Mother 1

Many parents said that they were concerned about the child because they understood ASD to be a life-long impairment.

> For me it actually is, well, I would kind of say an impairment, a personality trait yes, because I won't be able to change it, you can't cure it. He is like that, he will have to learn to live with it, we too.—Mother 10

On the contrary, one mother was convinced that, at the university where she had been working, many professors were 'autistic'. Likewise, she believed that children with an ASD diagnosis would not encounter problems anymore once they would turn 18.

> So we will have to find a place for them [my child and his older sister with an ASD diagnosis] where they are not just weird but yes, they can do their own thing. I think that if we are able to guide them through secondary school, these [ASD-related issues] will not really annoy them anymore.—Mother 9

As a consequence the child's vulnerabilisation by the diagnosis, we found many parents to feel much weight put on their shoulders for helping the child thrive. Although they often viewed ASD as life-long, many parents were convinced that the evolution in the child's challenges and development was dependent on their personal efforts to do whatever was helpful to the child. The following mother had a university degree, and her mother worked as an auti-coach at a primary school. Mother and grandmother highly valued stimulating children's development, and helping them to attain an optimal educational level:

> I buy a lot of stimulating and educational material. These things are actually used in therapy [by a therapist] or in nursery school by a support teacher. Like for his birthday, he [my child who got an ASD diagnosis 1 year ago] got this peg-board that is meant for learning the pen grip.—Mother 11

Several parents worried about not doing enough to help their child, e.g. because of not providing every single available therapy to the child or because they felt not to have enough expertise on ASD.

After the diagnosis (T3): pragmatism and some disappointment

Twelve months after their child was diagnosed with ASD, all parents expressed a pragmatic attitude towards their child's diagnosis. They valued the corresponding entitlements and experienced the diagnosis' exculpatory effect, but also said to be disappointed about the post-diagnosis services and the extent of this exculpation. Despite the interviewer's explicit prompts in this regard, the parents did not venture anymore into what exactly was ASD and what was its cause. They were all satisfied with the diagnosis: several parents said that the diagnosis was "really useful" or "necessary" to obtain services. Especially support and adaptations at the children's school were wanted and valued.[1]

[1] Sib + parents often had already experienced these same pragmatic benefits of the diagnosis with their older child with an ASD diagnosis.

> For autism you get school guidance and not for ADHD. Really, the diagnosis [of ASD], we were like: we need it for school and for the rest we are actually doing what we, yes, think is best. We only need that [ASD diagnosis] for school, we don't use it outside of school.—Mother 9

Compared to the pre-assessment interviews at T1, all parents who had been worried about their causal role in the child's behaviours, at T2 accepted that they were *not* the cause of the behaviour, as ASD was the cause. The following mother had an older daughter with an ASD diagnosis, but she said concerning her recently diagnosed youngest child:

> Yes, that question would have continued to play [if my child hadn't been diagnosed with ASD]: what am I doing wrong here? Yes.—Mother 8

Importantly, all parents said, explicitly or implicitly, that they believed that the diagnosis exculpated the child. Accordingly, many parents spontaneously mentioned that the relationship between them and their child had become better. Also, several parents experienced the ASD diagnosis as providing an affirmation of the fact that they were *right* to adapt their interactions with the child, that is, to take the child's problems into account. Parents, both Sib + and Sib −, had often already been adapting their interactions with the child prior to the diagnosis according to what they had heard and read about ASD. These parents felt that their child's ASD diagnosis proved that they were not spoiling the child when adapting their child-rearing practices to him, like the following father:

> Because then [after the diagnostic assessment] you know for sure that he [has this condition] and you know that your aren't spoiling him because if you do this [interact with a child in this way] with other children, yes, then you are spoiling them rotten because they are allowed to do everything.—Father 3

However, already at T2 and more so at T3, many parents' hopes that also *other* people would view a diagnosis as exculpating parents and child did not come true to the extent they had hoped.[2] Several parents experienced that some others indeed were accepting the diagnosis as exonerating both parents and child. This was especially the case for most professionals such as teachers and therapists, who were taking the child's diagnosis into account in their interactions with the child.

> The advantage [of an ASD diagnosis] is that he is not seen as one of the annoying and bad children. He displays annoying behaviour but there is a reason: it's not because he is spoiled and irritating but there really is a reason.—Mother 9

Consequently, the child's relationships with most teachers had become better.

However, this was not always the case, since teachers regularly did not notice that the child dysfunctioned at school. The parents of these children—who did not seem to be challenged at school—were struggling to obtain extra care for their child at school, because they felt that the child had to put much effort into not dysfunctioning at school:

> At school, they don't want to come along. The teachers say that they don't see his autism in the classroom. Last week I went to see the school principal to slam my fist down on a table because they don't want to provide extra support.—Mother 6

Also, many parents said that several other people—some relatives, friends and acquaintances—did not 'accept' the diagnosis. These people did not 'believe' that there existed something like ASD. Some people in parents' vicinity thought that children were given the diagnosis too often and too easily. The following mother first talked about father's recent diagnosis of ADHD to consequently draw a parallel with the diagnoses of ADHD and ASD in children:

> That's a feeling that people often express: yes, yes, if nowadays children are a bit lively… [they quickly get an ADHD diagnosis]. And people also talk like this about autism: yes, yes, nowadays they [children] quickly get [an ASD diagnosis].—Mother 6

Accordingly, many parents told that, after the child was diagnosed with ASD, several people (such as some teachers and family members) continued to not adapt their interaction with the child according to the ASD diagnosis. Also, some people were still blaming the child and/or the parents. The following parents experienced that the child's stepgrandfather was blaming them as parents and their child-rearing practices:

> His [father's] stepfather doesn't believe and accept this [the ASD diagnosis of our child], and it [our child's problem] is entirely due to his education, and we suck as parents.—Mother 4

The second parental disappointment concerned the post-diagnostic services. Several parents, especially Sib − parents, felt that after the feedback session, they received right after the diagnosis, they were 'left on their own' by the diagnosing professionals to find out what should happen next.

[2] This was the case for both Sib + and Sib − parents because when Sib + parents talked about this evolution they conflated their experiences with both the concerned child and their older child(ren) with an ASD diagnosis.

> Yes, just the feeling that for them [the diagnosing professionals] it's all closed down. Because yes, she [the professional] gave us websites and phone numbers and it's like "Now handle it yourself".—Mother 1

Moreover, services did not always offer exactly what parents had hoped for, although all parents wanted to obtain whatever treatment and support might be helpful to their child. For example, ASD-specific services like home counselling had long waiting lists, and several parents talked vigorously about their unmet need to have one coordinating professional that would guide them throughout their clinical trajectory. Also, some parents noticed that professionals were not always able, based on the ASD diagnosis, to provide solutions to certain behavioural problems of the child. For example, the following mother's youngest child, diagnosed 1 year ago, had severe sleeping problems. She pointed out that her request for help regarding these problems was delegated from one professional to the other:

> And no one is able to, you know… the psychiatrist is saying "Maybe ask the psychologist", and the psychologist says "Maybe ask the home based counsellor", and the home based worker says "Maybe ask…", so no one actually has the answer to his [my child's] fears, to his sleeping problems.—Mother 6

Discussion

In this study, we interviewed parents before, right after and a year after their child underwent a diagnostic assessment for ASD. The interviews showed an evolution of parental views and experiences of the ASD diagnosis from before the start of their child's diagnostic ASD assessment until 12 months after their child was diagnosed with ASD. The certainty and exculpation that the ASD diagnosis was expected to offer at T1 rarely translated, at T3, into certainty regarding tailored solutions for the child's worrisome behaviours and into a generalised exculpation of child and parents. Parents' need for de-responsabilisation (exculpation) of both themselves and the child was replaced by parents feeling highly responsible for their child's vulnerable development. After 12 months, a pragmatic attitude towards the diagnosis prevailed as it was felt to be necessary to provide entitlements to extra services, especially at school, and thus to attend to the child's vulnerability.

Ten out of 11 children whose parents were interviewed got an ASD diagnosis. The high proportion of diagnoses might be partly due to the fact that parents were recruited in specialised diagnostic centres, so if parents did not (only) self-refer but had been referred to these centres, the referrer might already have highly suspected a developmental disorder. To our knowledge, the prevalence of ASD diagnoses among children (self-)referred for diagnostic ASD evaluations (i.e. not after a screening for ASD) has only been reported once as being 61% [47]. In a sociological analysis of diagnostic practices related to disability, Nettleton argued that in the clinic, diagnosing a disability[3] is preferred over non-diagnosis, because diagnosing the well would be better than to leave the unwell untreated, and because non-diagnosis would leave the patients with uncertainty and illegitimacy [56]. Hence, it is suggested that when parents request professional help, diagnosis may be considered an intrinsic part of the therapeutic trajectory because of the certainty it provides. Additionally, a need to understand and make sense of symptoms is critical as a coping mechanism [17, 43]—even if this understanding is only partial in the case of ASD, because ASD diagnostics, cause and mechanism are uncertain [12, 37]. Nevertheless, an interpretation in ASD terms might provide parents with a 'narrative account' of their concerns about the child's behaviours [3, 69]. Such an account is most often not really causal but the parents we interviewed welcomed it for providing a socially accepted (medical) 'story' or narrative [13, 19, 69].

Importantly, however, 1 year after the diagnosis, this hope for and, subsequently, satisfaction with certainty had given way to a pragmatic attitude in the parents towards the child's ASD diagnosis. That is, all parents prioritised obtaining whatever support and treatment might be helpful to their child, and they appreciated the usefulness of the diagnosis with regard to acquiring entitlements to school support and therapeutic services. In many Western countries, indeed, an ASD diagnosis entails that the child will receive support at school and in the community, which is not the case for other diagnoses [20]. Within this pragmatic stance though, parents expressed disappointment at T3 compared to T1 and T2, about the post-diagnostic support and treatment services. Previous research also has shown that a diagnosis per se is not helpful to parents [57], but instead, has emphasised parents' need for post-diagnostic support [1, 11, 22].

At T1, both parents and other people sometimes wondered whether the parents were to blame for the child's different behaviours. But significantly, their concerns also revolved around the blame that might be attributable to the child. Within policy and the disciplines of education and psychology, a long tradition exists of looking for causal relationships between parental practices and outcomes for children [16]. Like other authors, we found that also lay people (including parents themselves) may consider parents to have a causal influence on their child's different behaviours [7, 68]. And like in previous studies, the interviewed parents who had been worrying about their own causal role in the child's unusual behaviours, no longer had this concern after

[3] ASD is often viewed as a disability (Baron-Cohen 2002).

their child got an ASD diagnosis (e.g. [58]. This shift probably took place, because the dominant understanding of ASD as a purely biological disorder invalidates previous claims in the professional field about parental blame in ASD [23].

Significantly, however, at T2 and more so at T3, many parents were disappointed that several other people continued to blame them for the child's behaviours after the child was diagnosed with ASD. Accordingly, neurobiologically explained mental health diagnoses in adults have been found not to be linked to reduced blame [38]. Also, many parents told that several lay people—like parents' relatives and acquaintances—continued to not 'believe' in the 'existence' of the entity of ASD or to not 'believe' that the ASD diagnosis had been appropriately given to the child. No research exists on the topic of people believing versus not believing in the existence of ASD (for a short mention on the topic of 'believing' an ASD diagnosis, see [48]) or in its presence in a particular child. Therefore, it is not known how many people 'disbelieve' an ASD diagnosis and for what reasons. Anyway, these doubts are reminiscent of scholars questioning the validity of ASD—and other DSM diagnoses [25, 26, 40]. Such scholarly questions might be disseminated to the general public through various channels, and have some influence on their views.

Strikingly, many parents also anticipated an ASD diagnosis to provide exculpation of the child—both on behalf of the parents and of other people. Once the child was diagnosed with ASD, the diagnosis was indeed experienced as effective in this regard, but only partially. Many parents highly valued this potential benefit of the ASD diagnosis. They equally valued its correlate of an adaptation by parents and other people of their relationship and interaction with the child according to his ASD diagnosis and unique needs.

The child's diagnosis often led to the child being seen as vulnerable, and the parents as having an extra responsibility with regards to this vulnerability. At T2 and T3, when compared to T1, many parents expressed more concerns about their child's present fragility to function as expected, his future being compromised by a life-long condition, and his need for protection with regard to his relationships and well-being. This finding constitutes one possible reason why an ASD diagnosis has the potential to increase parental stress [4, 50, 68]. Indeed, studies have shown that parents thought that, after their child got a diagnosis, he would never be completely 'normal' anymore and that this created worries about his future [41]. For example, an ASD diagnosis might be viewed as implying that the person diagnosed has less self-control and is not fully able to independently participate in community life [21, 34]. Additionally, the labelling theory claims that a mental health diagnosis may lead to self-fulfilling prophecies and damaging preconceptions in others [58, 61]. Moreover, biomedical conceptualisations of psychopathological conditions, such as the notion of ASD as a neurodevelopmental disorder, are associated with prognostic pessimism [35]. Also, describing individuals as 'vulnerable' in itself may carry the risk of viewing them as worthy of pity [27]. Pity is a sentiment that might not be easy to cope with in the parent–child relationship. Early detection and diagnosis of ASD have been advocated by many experts, as it would make sure that parents do not have to search unnecessarily long for explanations for their child's challenges [70]. However, the potential risk that a diagnosis actually increases parental concerns has rarely been mentioned [46].

Additionally, at T2 and T3, many parents talked explicitly and implicitly about their acute sense of responsibility concerning the child's challenges, development and future. This ties in with the general evolution in views on parenthood, as described by Lareau: since several decades, parents "are no longer merely expected to give their children love, intimacy and security and to safeguard their physical health and development, but are expected to stimulate and take responsibility for the intellectual development of their children" (Lareau 1989 in [54], p. 197; [56]). Specifically in the context of autism, sociologist Jennifer Singh writes that "in a neo-liberal context, parents are expected to provide an environment that will enable their children to live 'meaningful' and 'productive' lives" (Singh [63], p. 12). Thus, at present, parents in general carry much responsibility towards their children's development and future, and we have demonstrated that parents of a child with an ASD diagnosis might experience this responsibility more acutely. This stressful experience of responsabilisation should be addressed by clinicians in their consultation with parents.

In sum, this study gives an indication about how parents understand an ASD diagnosis and why parents may value it. This is of relevance to clinicians, researchers and policy makers, and also to parents themselves and the general public. We found that the interviewed parents did not feel the need to exactly know what ASD is. A broad understanding of ASD as a genetic and neurological condition appeared to be sufficient for them. Their main concern was to obtain whatever could be helpful for their child. Significantly, we found that an ASD diagnosis might help adults to consider a child as not blameworthy for different or difficult behaviours. The child might not be seen as 'naughty' or 'bad' anymore once he is diagnosed with ASD. The interviewed parents valued that the diagnosis gave them as well as other people a reason to adapt their relationship with the child to his unique needs instead of wanting the child to fit in the 'normal' adult–child interactions. However, between the moment their child got an ASD diagnosis and 1 year later, parents' hopes for the

diagnosis' exculpating effect on other people—towards the child and also to themselves—were partially disappointed. Moreover, an ASD diagnosis often increased parents' worries about their child's vulnerability, which in itself gave them a new kind of responsibility[4] towards the child's behaviours—now seen by many parents as representing a life-long vulnerability in the context of ASD. This sense of responsibility arguably contributed to parents pragmatically valuing an ASD diagnosis for its administrative utility towards service entitlements in Flanders—as is the case in many other regions and countries.

These findings have clinical relevance. We argue that addressing parents' evolving views, hopes and concerns related to an ASD diagnosis during each clinical consultation may lead to a better patient–clinician alignment and a higher satisfaction with the clinical trajectory in both parties [24, 44, 51]. Hence, clinicians should not consider the diagnosis as a goal in itself, and the feedback session with parents as an end-point, but reassess and address parents' experiences related to the diagnosis during each consult, since they will probably be evolving. E.g. parents' relationships with the people around them may be tense because of people's doubts whether the child's ASD diagnosis is justified.

Specifically, we suggest that a clinician, in the beginning of a diagnostic ASD trajectory, transparently talks with parents about the reasons why parents feel that an ASD diagnosis might be useful to them and the child. The clinician may address the degree of certainty and exculpation an ASD diagnosis will actually be able to provide. By openly discussing the certainty, exculpation and pragmatic usefulness parents are looking for, she may help parents to adjust their expectations to their actual future experiences and pragmatic views in the post-diagnosis phase.

Importantly, she may—in collaboration with her colleagues—set up a clinical trajectory in which, first of all, she devises 'hands-on' answers to parents' requests for help. But she may also assist parents in coping with their worries and challenges concerning their child without attaining complete certainty about the child's behaviours and without attaining complete exculpation towards the child and themselves.

Later on in the clinical trajectory, a clinician may address potential feelings in the parents of the child's vulnerability and the parents' responsibility. In this regard, she may prefer to elaborate a 'profile' or 'clinical case formulation' of the child including both stronger and more vulnerable characteristics of the child and his context—in combination with or instead of a categorical diagnosis of ASD [32, 39]. Throughout this clinical trajectory, we argue against the partition of the diagnostic and the therapeutic phases, as is the case in Flanders—and in many other regions and countries. The coordinating clinician should try to be a care provider who is available in a continuous way and provides both the treatment-related and psycho-relational help that parents need. In this way, she may be a consistent partner to those parents who acutely feel responsible for their child's development and well-being after their child is diagnosed with ASD. Finally, parents should feel that the responsibility concerning the vulnerable child is really shared between the clinician and them.

Limitations

Since we purposively sampled parents who asked for a diagnostic ASD assessment of their child, we cannot exclude that there is some selection bias. The parents we interviewed had decided that they wanted such an assessment, so arguably the participants of this study expected that the balance between the positive and negative implications of a diagnosis would be in favour of the former ones.

Moreover, 9 out of 17 parents had an older child diagnosed with ASD, so their experiences of the diagnosis in the younger child was without any doubt influenced by their experiences with the older child. According to the IPA guidelines, we inductively analysed each interview within the participant's personal context to also discern all influences of this particular difference between the parents. We only found a minor influence of parents already having an older child with an ASD diagnosis on the results of this study.

Also, we only interviewed parents of boys without a previous diagnosis of a disability. Parents' views and experiences concerning their child's ASD diagnosis may differ if the child is a girl or has previously been diagnosed with a disability.

Finally, each research method has inherent limitations, so we used specific strategies to enhance the trustworthiness of this study's findings. For example, to increase confirmability, we provided many quotes to demonstrate that our findings emerged from the data and not from our own predispositions; and the research context was 'thickly' described so that the results would be transferrable to another situation with the appropriate translational adaptations [62].

[4] Parents' 'backward-looking' responsibility, consisting of accountability and blameworthiness, was replaced by a 'forward-looking' responsibility, "that of seeing to it that a certain state of affairs obtain" (Goodin in [67], p. 37), in this case for taking care of the child's vulnerability.

Conclusions

Before the start of their child's ASD assessment, parents often hoped that the diagnosis would offer certainty concerning the child's behaviours and would exculpate the child and themselves. After their child got an ASD diagnosis, the interviewed parents mostly viewed their child as more vulnerable and themselves as more responsible for his well-being. Related to this high sense of responsibility, they came to value their child's diagnosis in a pragmatic way: they mainly valued it because of its corresponding entitlements—especially school support—and its protecting effect on the child's relationships with parents and teachers. At the same time, they experienced some disappointment concerning the diagnosis' utility in providing what they had hoped for. Addressing these parental views and experiences during each clinical consultation may lead to a better patient–clinician alignment and satisfaction with the clinical trajectory in both parties.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethics approval The authors assert that all procedures contributing to this work comply with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects were approved by the Ethics Committee of the University Hospitals Leuven (Belgian Registration Number B322201731147).

Informed consent Written informed consent was obtained from all subjects prior to their inclusion in the study, and to its publication.

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