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Article

Compensatory Strategies in Adolescent Females with a Restrictive Eating Disorder and Later Diagnosed Autism: A Qualitative Study of Patient Records

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ABSTRACT

Purpose: This qualitative study explored descriptions of social development and compensatory strategies concerning young females (YPs) diagnosed with autism during treatment for a restrictive eating disorder (R-ED), as they may represent a subgroup whose difficulties have gone unnoticed earlier in life, potentially contributing to the development of R-ED.

Methods: Thematic analysis was conducted on excerpts from patient records of 41 YPs with R-ED and later diagnosed autism.

Results: Four main themes emerged: (1) YPs attempted to adapt to social interactions by mimicking behaviours and relying on friends, and they strove to adhere to social norms despite the costs; (2) Parents helped YPs navigate social relations and adapted family life to meet the YPs' needs for structure, routine, and sensory issues; (3) Throughout YPs' childhood, parents interpreted YPs challenges as character traits or mental health issues such as anxiety; (4) There were no early childhood concerns.

Conclusion: The compensatory strategies such as mimicking peers, adhering to societal expectations despite costs, and parents meeting YPs' atypical needs may contribute to a late autism diagnosis. Assessing autism characteristics and compensatory strategies in YPs with R-ED may guide interventions and improve treatment effectiveness for this subgroup.

KEYWORDS: adolescents; females; autism; eating disorder; compensating strategies; camouflaging

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INTRODUCTION

In recent years there has been an increased interest in the overlap between the autism spectrum (autism) and anorexia nervosa (AN), due to findings that individuals with AN have elevated characteristics of autism and a higher frequency of autism diagnosis [1–3]. Autism is a

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developmental condition characterized by impairment in social interaction and communication along with so-called repetitive or restricted interests or behaviours [4]. AN most often debuts in adolescence and is characterized by an intense fear of weight gain and persistent restrictive behaviours aimed at weight loss resulting in a significantly low body weight [4]. Despite differences in etiology, studies have highlighted similarities between the two conditions on both neuropsychological and socioemotional levels. Similarities include difficulties recognizing and responding to others' emotions, social anhedonia, reduced performance on theory of mind tasks [5–10], reduced interoception [11,12], and inflexible thinking styles [13,14].

Autistic females are more often underdiagnosed [15], and present with more severe impairment than males to receive a diagnosis of autism [16]. Moreover, females tend to be diagnosed at a later age [17–20]. And a later diagnosis is associated with higher levels of mental health challenges [21]. Examining YPs with eating disorders, many report social difficulties and social isolation prior to eating disorder debut, leading to the hypothesis that unrecognized autism may be a vulnerability factor for eating disorders [22]. For instance, in a qualitative study, women with teenage onset of AN and later diagnosed autism described that AN made it possible to numb the difficulties associated with their undiagnosed autism. Further, they wondered if knowing about autism earlier could have made AN treatment more helpful [18]. This suggests that understanding the processes involved in the late diagnosis of autistic females may improve our knowledge on the development and treatment of AN as well. This is corroborated by AN treatment studies demonstrating that autistic females with AN have longer treatment duration and more often need inpatient/day patient services during treatment for AN [23–26]. Therefore, a more detailed understanding of the processes involved in late autism diagnosis for females with co-occurring AN might aid in understanding the potential interaction between unrecognized autism and AN and inform better targeted treatments in the future.

One hypothesis explaining later diagnosis of autism is that autistic females more often than autistic males engage in compensatory behaviours that camouflage their autism characteristics [27–30]. Compensatory behaviours are e.g., mimicking and copying behaviours of others, monitoring body language and repressing self-stimulatory behaviours, identifying social norms, and developing cognitive scripts for social interactions [17,20,28,31–33]. Several studies indicate that compensatory strategies related to autism increase with age [34,35] and are more frequent in females. Parents may engage in compensatory behaviours as well. Qualitative studies found that parents of autistic children adapt their behaviours, home environment, routines, etc. to support their child, minimize stressors, and prevent meltdowns [36,37]. The ability to engage in compensatory behaviours may on the one hand, be a strength but may come at a cost as it may be exhausting and may imply that the young person's specific needs are not fully recognized nor met [38].

The current study aimed to add to our understanding of late autism diagnosis in female young persons (YPs) with AN by (a) exploring how social development is described in patient records from YPs who receive an autism diagnosis after debut of AN; (b) exploring if and how these patient records reflect compensatory behaviours in YPs and their parents that may have been present prior to autism diagnosis and minimized the appearance of autism characteristics prior to debut of AN. This will inform hypotheses on the trajectories towards a late diagnosis of autism in adolescent girls with AN and autism, including whether compensatory behaviours might contribute to the late diagnosis.

METHODS

Participants and Materials

We included records from female YPs if (1) parents and YP gave informed consent for their clinical information to contribute to research on mediators of response to standard AN treatment; (2) the YP was treated for a restrictive eating disorder (R-ED) (ICD-10 diagnoses of typical or atypical anorexia nervosa (F50.0 or F50.1) [4]) at Child and Adolescence Mental Health Centre in the capital region of Denmark during 2019–2022, both years included; and (3) an autism spectrum condition was diagnosed by a certified professional during the course of R-ED treatment and thus later than debut of R-ED. All eligible records from this period were included in the analysis to avoid selection bias.

The materials included from patient records were written resumés from (a) intake interviews (YP and parents); (b) Schedule for Affective Disorders and Schizophrenia for School-age Children—Present and lifetime version (K-SADS-PL) interviews (YP and parents) [39]; (c) Autism Diagnostic Interview-Revised (ADI-R) interviews with parents [40]; (d) Autism Diagnostic Observation Schedule, version 2 (ADOS-2) interviews [41].

Data was extracted in an anonymized fashion before subjected to thematic analysis of the content.

A total of 610 female YPs were treated for R-ED and included in the study during the targeted period. A total of 11% of YPs treated for R-ED had a comorbid autism. Of these, *N* = 26 (4.2% of the total group, 38% of the autism subgroup) had an autism diagnosis prior to debut of R-ED (the early diagnosis group), whereas *N* = 42 (6.9 % of the total group, 62% of the autism subgroup) were diagnosed after the debut of R-ED and are thus the focus of the present study (the late diagnosis group). Comparing the early diagnosis group and the late diagnosis group revealed no significant differences regarding age or diagnoses; the mean age of the late diagnosis group was 13.9 years (SD 1.4, range 11–17 years) and did not differ significantly from the early diagnosis group (mean 14.5 years, SD 1.7, range 11–17 years) (Independent samples T-test $p = 0.10$). Autism spectrum diagnoses were made using the ICD-10 [4], which was still in use in Denmark by the time of data collection, analysis, and reporting. The distribution of ICD-10 autism diagnoses within the late diagnosis group were infantile autism (F84.0) ($N = 5$, 11.9%), atypical infantile autism (F84.1) ($N = 12$, 28.6%), Asperger's syndrome (F84.5) ($N = 23$, 54.8%) and other pervasive developmental disorders (F84.8) ($N = 2$, 4.8%). The multinominal probability distributions of autism diagnoses were equal between the late diagnosis group and the early diagnosis group (Fisher's exact test 2.967, $p = 0.63$). Further, a total of $N = 31$ (74%) of the late diagnosis group had a R-ED diagnosis of anorexia nervosa (F50.0) at intake, while $N = 11$ (26%) had a diagnosis of atypical anorexia nervosa (F50.1), and this distribution was equal between groups (Chi-square 0.549, $p = 0.32$).

Analysis

The method used for analyzing the written materials was Thematic Analysis (TA) as described by Braun & Clarke [42,43]. This theoretical approach is suited for identifying patterns (themes) within data that may speak to or expand on existing knowledge in relation to the research aim, and it was chosen because the purpose was to understand a predefined problem. The analysis was rooted in a critical realist paradigm, whereby language is understood to be reflective of meaning and reality mediated by culture and language [42]. TA involves six phases: (1) familiarization with data; (2) coding; (3) generating initial themes; (4) developing and reviewing themes; (5) refining, defining, and naming themes; (6) reporting the analysis [42]. Themes are patterns in the data that organize the analytic observations in a specific direction.

Authors MJ, TL, and MB all took part in phase 1 (familiarization with data), where data was read and re-read to ensure familiarity with the data and to generate initial thoughts about the data together. After the initial familiarization, MJ, TL, and MB agreed that the nature of the dataset meant that some data was not related to the research aim and therefore agreed on eight categories to identify and organize data relevant for the research aim (Table 1). The categories were based on diagnostic and theoretical knowledge regarding autism and potential arenas for compensatory behaviours. This initial predetermined categorization can be described as a deductive approach to the data and may be necessary when using documents, e.g., patient records, where not all content is directly related to or relevant to the analysis [44].

Table 1. Categories used to structure data.

Category
The YP's interaction with family
The YP's social interactions in general
Flexibility
Handling demands and rules
Special or repetitive areas of interests or behaviours
Relationships with friends
Early childhood and development
Other

The whole dataset was given equal attention when begin categorized, and if there were doubts about the relevance of certain parts of the dataset, it was categorized under 'other' and kept for coding.

Afterwards, the categorized data was coded by author MJ. Coding was done with an inductive approach on the semantic level [42], focusing on the explicit descriptions of the behaviours and the meaning attributed to these behaviours, using NVIVO 12 qualitative data analysis software [45]. Data items were coded based on them identifying features of the data that were considered relevant in answering the research question. Coding resulted in a list of eighty-seven codes. Thirteen initial themes were generated by grouping and combining codes that were similar or revolved around a pattern in the data. Themes were revised by first reviewing the data material assigned to each theme by exploring if it formed a coherent pattern, and afterwards the themes were considered in relation to each other. This process showed that some themes overlapped and illustrated similar analytical points, leading to the creation of subthemes and four superordinate themes. Themes that didn't have enough data and therefore didn't speak to a pattern across the dataset were discarded (Table 2).

After analytical generation of themes by author MJ based on two-thirds (N = 26, 62%) of the late diagnosis group, MJ, TL, and MB coded the written materials from five randomly selected participants from the late diagnosis group used for code generation and subsequently compared and discussed codes to explore multiple interpretations of the data. Of the remaining 16 cases not used for code generation, one was omitted from analysis due to insufficient patient record descriptions. Authors TL or MB read the materials from the remaining 15 participants of the late diagnosis group in order to explore whether the themes generated from the initially coded 26 cases validly represented the descriptions in the remaining cases. Findings were discussed and consensus reached between all three authors; afterwards, the analysis moved to phase five, where each theme was defined and named by considering the analytic point within the individual theme but also how it related to the overall analysis Author SHP read through the analysis and contributed to evaluate and discuss findings. All authors engaged in the final phase of report production, which involved choosing data excerpts to illustrate the analytical points within each theme.

Reflexive statement: In conducting this study, we recognise that our diverse professional backgrounds have significantly influenced our approach to analysing the written clinical records. MJ, who coded the majority of the material, is relatively new to the fields of both eating disorders and autism. In contrast, TL, SHP, and MB bring extensive clinical experience in the realm of both eating disorders and autism. Additionally, both SHP and MB are active researchers in the field of eating disorders. Finally, MB is an active researcher at the intersection of autism and eating disorders. This combination of expertise within our team has contributed to a comprehensive understanding of the data, with those less familiar with the clinical context offering fresh perspectives that help to mitigate potential biases. Throughout the analysis, we engaged in reflexive practice, acknowledging how our roles as both insiders and outsiders in these fields have shaped the coding process and theme development. By embracing this reflexivity, we aimed to maintain transparency regarding the ways in which our backgrounds influenced the research process and the collaborative construction of meaning within the data.

RESULTS

Four themes emerged from the analysis across the sample, along with seven subthemes (Table 2).

Table 2. Thematic analysis.

Theme	Subtheme
Theme 1: Attempting to adapt to social interactions in everyday life	1a Wanting to adhere to social rules and norms
	1b Being social, despite negative effects
	1c Letting others lead the way in social interactions
Theme 2: Parents try to adapt their own behaviour and family life to support their child	2a Recognizing and meeting the child's atypical needs and behaviours
	2b Being a Guide in social interactions
Theme 3: Alternative understandings of the YPs and their challenges	3a Mental health challenges
	3b Narratives about personality traits
Theme 4: No concerns in early childhood	-

Theme 1: Attempting to Adapt to Social Interactions in Everyday Life

This theme reflects descriptions of the YPs' abilities to engage in social interactions in everyday life. These abilities contribute to the YPs apparently feeling well and engaging in age-appropriate activities outside of the home but spending a great amount of energy, resulting in breakdowns afterwards. The discrepancy between appearance at home and outside the home created divergent narratives about and expectations towards the YPs, and it may have contributed to the parents' difficulty in making sense of their child's needs.

Subtheme 1a: Wanting to adhere to social rules and norms

Many parents reported that their YP would express a desire to behave correctly and therefore was attentive to social norms with only subtle differences to peers. This would often lead to others not recognizing the social communication impairments of the YP.

Example: "She tries as best as she can outside of the home to react appropriately, and it is perceived as polite but not always mutual".

A few parents described that even though their YP had the desire and was able to identify the social norms, she could often not fulfill those, which would result in her being upset. For others, the YPs' desire to fit in had become so important that it resulted in them being very passive and pleasing during social interactions. The reasons behind the desire to behave 'correctly' were not always elaborated on, but some informants framed it as a wish to avoid attention, indicating a discomfort with social attention.

Example: "She would never say anything inappropriate in a situation; she would then rather not say anything".

By extension, the parents often described their YP as having good abilities to adapt to different social contexts, to decode social expectations, and to 'read the room'. These efforts to decode social expectations were sometimes seen as a strength by the parents, who found that their child had great adaptive ability and situational awareness. However, parents more often described it as motivated by a wish to minimize discomfort during or following social situations, which illustrates that social interactions are not always enjoyable for the YP (this will be elaborated further in the following subtheme).

Although the YPs were described as able to perceive and decode the social rules in an everyday context, these abilities seem to have been deliberately learned and practiced, either from parents, peers, or experience. In extension, for several of the YPs, the social behaviours they engaged in appeared forced or felt unnatural and awkward to them.

Example: "She knows that she is supposed to keep a conversation going, but with new people, she does not know what she is supposed to say and therefore perceives it as uncomfortable".

Subtheme 1b: Being social, despite negative effects

Engaging in social situations appears to come at a cost in nearly all cases. The YPs and their parents described that the YPs had participated in social interactions or situations that they did not find enjoyable; for example, some had participated in summer camps and sleepovers because they were asked to and not because of enjoyment. The YPs' abilities to participate in social interactions and activities despite finding it unpleasant seem to point to a degree of adaptive ability. Nevertheless, social situations are often described as exhausting. The exhaustion could for some result in withdrawal and a need for rest; for others it could result in more reactive outbursts, where the YP would get into arguments, have meltdowns, and throw tantrums when they got home.

Example: "She has conversations with friends, but it is a task on which she uses energy and experiences it not as being natural. After school, she often needed "alone time". It is as if she has been filled up by having to be social during a school day".

In only very few cases were meltdowns or externalizing behaviour in public or school settings reported. For the majority, it would primarily be acted out at home with parents or siblings. For some, this resulted in diverging views of the YP.

Example: "The parents' experience of an unusually sensitive girl in need of a lot of adult support contrasts with how persons outside of the family (childrens' institutions, school, social circle) have experienced her. Parents felt that there were unusual challenges with their child, but nobody else understood their concerns, because she was so orderly and controlled, energetic, funny, and outgoing, when she was out".

Furthermore, the parents and YPs reported that despite the YPs' challenges, most of them had a desire for social contact with peers (either in joint activities or small groups). The desire to have social relations, yet experiencing difficulties engaging in them, caused distress for the YPs, because the desired relations did not always work out for them, leaving them feeling left out and lonely despite their efforts to fit in. Some described feeling stressed by the unpredictability of social situations and in doubt whether someone was a friend or not.

Subtheme 1c: Letting others lead the way in social interactions

The YPs perceived abilities to engage in social interactions is also seen in some cases to have been aided by friends and siblings. A specific friend or peer could provide guidance and a feeling of safety when navigating social context. For others, the support or guidance from a friend at school allowed them to be more comfortable and social in the classroom.

Example: "She needs guidance at school (where should I be, whom should I be with) and especially when teaching is rescheduled. She does fine academically but finds it difficult to work in groups other than with a close friend. This friend has been a constant support for her throughout the school".

The friends' function as comfort or guide also contributes to the YPs appearing more typical because it allows them to fulfill age-appropriate expectations in school in situations where they, without that friend, would not be able to do so. However, it also implies taking a passive role and letting others decide the play, and for some appearing "empty" as the YP do not express wishes and ideas, tend to copy the behaviour of others, or letting others speak on their behalf.

Example: "The school as well as parents describe her as having a sweet and friendly facade, responding in a relevant manner to the overtures of others, but she does not take initiatives. She always follows the interests of the others and does not want to draw attention".

Theme 2: Parents Try to Adapt Their Own Behaviour and Family Life to Support Their Child

This theme captures how the parents helped, supported, and guided their YP in everyday life. The parental role required a lot from the parents, and there appeared to be a generally high level of involvement in their YP's life, with attempts to identify and minimize stressors while also trying to aid in the development of typical behaviours.

Subtheme 2a: Recognizing atypical behaviors and meeting the child's needs

A large subgroup of parents articulated that they had perceived their YP to be 'different' early on in development. Most of the parents (including the ones who did not voice any concerns regarding early development, see Theme 4) described being attentive to their child's specific needs, either due to the child's sensitivity or "a strong temperament" and externalizing behaviour. In most cases, this entailed that the parents had identified a need for frequent breaks and for routines and structure for their child to thrive. Examples of parental support were to write activities in a calendar, choose clothes to wear for the day, timing daily activities, thorough preparation before vacations.

Example: "She has not needed fixed routines for the days but has had a strong need for agreed frameworks and structures to be adhered to. As a result, she copes poorly if agreements or plans are changed, and parents describe her reaction as a volcano that you could never quite predict when [it] would explode, which is why many considerations have been taken".

A large subgroup of parents further described their YP having sensory sensitivities, e.g., sensitive to noise at family gatherings, sensations from food, clothes, etc. Parents described having gone to great lengths to meet sensory preferences, whether it be altering clothes or preparing special meals, sometimes at the expense of the parent's needs.

Example: "She is particularly sensitive to tactile sensations in clothes and reacts excessively to this. (…) The mother describes further sensitivity to food from when she was very young. When she started kindergarten, the food had to be cut out in certain ways and could not be mixed up. In addition, she has difficulty with textures, which is why [her] mother has always grated things into the food, instead of cutting them out".

Besides concrete ways of adapting the home life and environment for their YP, a small number of parents also reported that they had to be able to predict and guess their YP's needs and feelings, often with very little guidance or expressions from her.

Example: "Parents report that they find it difficult for her to express her own needs and ask for help. They find that she is most comfortable if they can predict her needs and just give things to her".

Several parents described a progression and learning curve as they adapted the family environment, with the early years of the child's life having more difficulties. As the child grew, the parents found ways for themselves to manage the difficulties.

Subtheme 2b: Being a guide in social interactions

In about half of the cases, parents reported engaging in trying to guide or teach their YP how to act and behave in social contexts and with her friends, by e.g., arranging playdates with friends and choosing the least stressful location for the child, explaining how social interactions worked, including irony, mitigating black-and-white thinking.

Example: "For years, Mom has practiced "conversation and asking curious questions" and despite this, she herself says "I am the world's most awkward person" […] Mom has always spent a lot of time guiding and telling "social stories"".

The parents experienced that they still had to participate in the child's peer relationships to some degree at ages when they saw that other parents did not do the same. Helping their child did have positive effects, and most reported that their child had established and maintained close friendships because of this. However, the parents described that it became harder to guide her through social interactions as her age increased. This was related to the increased complexities of social interactions and growing independence in the teen years.

Theme 3: Alternative Understandings of the YP and Her Challenges

Despite similarities in behaviours across the cases, parents ascribed different meanings and interpretations to their YP's difficulties. For a subgroup of cases, the interpretation of the developmental difficulties was related to suspected undiagnosed autism. For the remaining cases, the challenges were given a different explanation and e.g., seen as evidence of a mental health disorder, or an expression of the child's personality traits.

Subtheme 3a: Mental health challenges

Several different mental health disorders were mentioned or suspected by the parents e.g., depression, obsessive-compulsive disorder, and self-harm. In over half of the cases there were also reports of behaviours described as sign of anxiety or confirmed clinical diagnoses of anxiety. The anxiety symptoms were often seen in social or separation situations and therefore often interpreted by the parents as social- or separation anxiety. Symptoms were often moderate or difficult in character and had affected the level of functioning.

Subtheme 3b: Narratives about personality traits

Difficulties in social situations and having reduced need for social interaction were in many cases attributed to the child's personality. Parents and YPs frequently described the YP as quiet, shy, or introvert, and they attributed the passiveness and discomfort in social interactions to this.

Example: "She has expressed that eye contact is difficult. The parents have previously attributed this to shyness".

Temperamental outbursts were often understood as a reaction to mental overload in a sensitive YP.

Some parents mentioned that their child's personality was like one of the parents' or other family members'. This seemed to elicit a sense of understanding for the child's difficulties.

"Dad has always thought that his daughter was "a kindred spirit" and her curiosity, analytical mind, and her preoccupation with "why" have always been a great pleasure for her, him, and other adults".

Theme 4: No Concerns in Early Childhood

As part of the diagnostic assessments for autism, all parents gave descriptions of their YP's early childhood and developmental trajectories. This provides additional understanding of Theme three: Alternative understandings of the YP and her challenges.

Most of the parents reported not having experienced any concerns for their child's development in the first three years. Several highlighted that professional staff involved in the child's life, e.g., in kindergarten, never raised any concerns about difference in development compared with other children. The parents regarded their child's infancy as typical because she had exhibited age-appropriate behaviours such as using eye contact in communicating with the parents and were reported to have had normal language development without regression and had language comprehension at an average level or above. The parents also experienced good connection with their child, but many were aware that she tended to use lower levels of gestures and facial expressions when communicating with others. However, many did not perceive it as a general problem, because this behaviour was not as prominent in interactions where the child felt safe, e.g., with the parents or friends.

Almost all parents reported that their child had not shown any special or repetitive areas of interests or behaviours throughout their childhood. The only hint of atypical interests was that some YPs, when having an interest, could become quite intense for a short period, but then intensity faded, and the content of interests were typically age-appropriate and common to that of friends and peers.

DISCUSSION

The current study aimed to explore (1) how social development is described in patient records from YPs who receive an autism diagnosis after debut of AN, and (2) if and how these patient records reflect compensatory behaviours in YPs and their parents, that may have been present prior to autism diagnosis.

The analysis revealed four themes summarizing common patterns in the material. The first theme described how the YPs tended to have engaged in social communication similar to their peers albeit often at a cost. The second theme unfolded a range of ways that the parents had recognized the child's atypical needs, supported the YP's daily life, minimized stressors and guided the YP's social life. The third theme illustrated how families made sense of the YP's atypical needs and behaviours as either mental health challenges or personality traits, whereas the fourth theme summarized that these YPs mostly did not show signs of autism in the first three years of life, including no delayed language development or focused or repetitive areas of interests, which further adds to the understanding of why families looked for other explanations to make sense of the child's atypical needs and behaviours.

Descriptions of Social Development

Overall, early development is described as normal, and atypical needs and behaviours only gradually became clear. Even later, most YPs participated in social situations in a way that did not seem too different from peers. However, social interactions were often done in a shy, passive fashion letting others lead the way, and/or it was often supported by the parents' guidance.

The cost of being social for these YPs is evident in several ways. First, social situations were endured although sometimes inducing discomfort or feeling awkward. Second, as the YPs would appear socially capable by following along in school and engaging with the other students, they were being overworked and over-stimulated, because their needs and preferred behaviours were primarily met at home. This may have resulted in the described deterioration of their well-being with exhaustion, withdrawal, or meltdowns after social events.

Parents of the YPs recognized their YP as having different needs than other children and had therefore tried to create routines, meet the needs associated with sensory sensitivities, and guide social relations, and this finding supports previous reports [36,37]. It may be no easy parental task to do so, and it points to advanced skills in these parents to read their child's or YP's specific developmental needs.

Descriptions of Compensatory Behaviours

In identifying the need for structure, sensory sensitivities, and (for some) difficulty in communicating feelings and needs, the parents seem to have acknowledged and been able to work with difficulties that are associated with autism without attributing these behaviours to autism. Thus, the analysis reflected a broad range of compensatory behaviours in YPs and parents, that may have contributed to camouflaging the YPs' social difficulties. In line with other studies [20,28], the YPs used strategies to navigate social interactions e.g., mimicking/following the lead of others and avoiding attention, and this seemed motivated by a desire for being social and having relations with peers.

The parents described contributing in some degree to the child's peer relationships at ages where they saw that other parents did not do the same anymore. Helping their child's social life is described to have positive effects, and the YPs was able to maintain some peer relationships. It appeared easier for the parents to facilitate the child's friendships, when these evolved around a shared interest, whereas guiding became more difficult as the YP grew older. This may be related to the increased complexities of social interactions and expected independence in the teen years. Consequently, the YP's social difficulties may become more evident and concerning with age, adding stressors to the YP.

Late Diagnosis Associated with Discrepancy in Perception of Needs and Social Abilities

The parents and YPs reported that despite feeling uncomfortable and exhausted in social situations, most YPs desired social contact with peers. In mainstream lay opinions, the social desire may not align with core diagnostic characteristics of autism, due to lack of knowledge about autism across the spectrum, and the social desire in these YPs therefore may have counteracted understanding the YPs' behaviours as an expression of autism. Moreover, the YPs' abilities to overcome discomfort and engage socially in school and public settings created inconsistencies in how they were percieved, potentially contributing to delayed diagnosis. Parents seemed more aware of YP's social challenges than teachers or friends of the family who did not see the excessive need for guidance, or the exhaustion associated with being social. This may complicate identifying autism, as highlighted by Hiller et al. [46], and it supports the hypothesis put forward in studies by Halsall et al. [20] and Cook et al. [19] that compensatory behaviours in the YP and parents may prolong the time to diagnosis.

Late Diagnosis Associated with Alternative Understandings of Difficulties

Parents' tendency to understand behavioural difficulties of the YPs as either expressing personality traits or psychological difficulties does on one hand create room for individual differences in development, but on the other hand, this may for some add to the risk of not identifying underlying autism and perhaps add to the stressors on these YPs of trying to meet normative expectations. We note that anxiety was quite often how difficulties was understood by parents and perhaps professionals, and several had received interventions targeting anxiety.

The origin of the different interpretations of the YPs' difficulties cannot be interpreted from the current data material. However, descriptions of the little or no concerns in the YPs' early childhood may contribute to an understanding. As childhood autism is characterized by being present before the age of three [4], it is understandable that the parents would not attribute later difficulties in general well-being to autism. Therefore, when trying to understand problematic behaviours or sudden impairment of functioning, parents interpreted them by their immediate expression (e.g., anxiety), rather than as evidence of an underlying developmental issues.

Late Diagnosis Associated with Functioning Levels and Gender Expectations

The average to above average intellectual ability of these YPs, typical motor and language development, and few or no focused or intense areas of interests or behaviours, may have contributed to the late recognition of autism. Other studies have confirmed that late diagnosis of autism is associated with average or above-average cognitive abilities, lack of language delay, lack of initial parental concern, and less severe autistic features [47–49].

Dworzynski et al. [16] found that girls with autism and without impaired cognitive abilities or behavioural problems are less likely to meet diagnostic criteria for autism, compared to boys matched on the impairment of autism characteristics. Reasons may include abilities to compensate for the appearance of impairments, as the findings in the current study imply.

Moreover, the literature points to a gender bias relating to autism. In an exploration of pre-diagnosis concern from the perspective of parents, Hiller et al. [46] found that externalizing behaviours were a greater concern for parents of girls, whereas internalizing behaviours were of greater concern regarding boys [46]. Studies on gender stereotypes and expectations highlight that aggression and outburst are more tolerated in boys than in girls and that shyness and passivity are more tolerated in girls than boys [50]. For example, passiveness and shyness in girls are less likely to raise concerns of autism [51], and this mirrors our finding that the shy, passive, and introverted behaviours of the girls did not raise concerns from parents or teachers.

Late Diagnosis and Vulnerability for AN

The impact of living with an undiagnosed and unsupported autism condition is hypothesized to have an increasing impact on the well-being of the individual when entering adolescence [52]. The increasing complexity of social demands with growing age, the exhaustion of engaging in social interactions and compensatory behaviours, and the fact that the support of parents become less efficient, may all add nuances to this process. While the current study is not able to illuminate factors associated with AN vulnerability per se, prior qualitative data indicate that autistic women view their AN as a response to the challenges associated with their autism [18]. The current study adds to this with descriptions of how near-normal early development, social desire and abilities, and compensatory behaviours may have contributed to late autism diagnosis in a group of female YPs with AN. It further adds by highlighting the stressors associated with the wish to be social, with maintaining compensatory strategies, and with the discomfort and exhaustion following being social. When these stressors are combined with the complex social demands and search for identity in adolescence, then AN may for some present as a way to meet social demands, and for others perhaps a way to escape the more complex demands for a simpler world of measurable success, such as described by autistic young women with lived experience of ED [18]. The study also adds nuances to understand how adolescence becomes increasingly challenging for autistic YPs We speculate that some YPs have been able to compensate and/or copy social behaviours during childhood, perhaps at the expense of high or increasing levels of stress, that parents have compensated for their child’s difficulties but are less able to do so with increasing age, and that these processes may contribute to a vulnerability to develop AN.

STRENGTHS AND LIMITATIONS

The main strength is the large number of records and rich material on which conclusions are based.

Among limitations is the format of materials: experiences are described retrospectively and summarized by a clinician with the intention of diagnostic assessment. This inherently differs from the data we could have gotten from interviews that followed and unfolded both the parents’ and YP’s stories with the main subject in mind. A further limitation comes from the main coding analysis made by one author; however, we compensated for this limitation by having other authors validate the generated themes in the remaining records, securing richness and complexity in the findings.

CONCLUSION

The study provide insights into how compensatory strategies may relate to late diagnosis of autism for girls diagnosed with autism following the onset of anorexia. The described compensatory strategies in YPs include mimicking their peers and adhering to societal expectations, despite negative effects. The described compensatory strategies in parents include recognizing and meeting the child's atypical needs by creating routines, meeting the needs associated with sensory sensitivities, and guiding social relations. These findings are in line with descriptions of autistic females without a history of AN and confirm that compensatory strategies are present in the subgroup with AN as well [17,20,28,31–33]. Factors that might have contributed to a late diagnosis besides compensatory strategies may be a typical early development, normal cognitive and language ability and the YPs wish for being social despite challenges, and alternative understandings of mental health challenges. Despite efforts to compensate for atypical needs, the YPs' well-being deteriorates with adolescent years, about the same phase of life as the onset of anorexia. While no causal assumptions can be made, our analysis adds to understanding stressors for this subgroup prior to debut of R-ED. Our findings confirm the presence of compensatory processes in the subgroup of autistic females first diagnosed with AN. Potentially assessment of autism characteristics in YPs presenting with R-ED may guide interventions, add considerations for potential autism in treatment, and thus increase effectiveness of treatment for this subgroup in the future. Moreover, the findings show that descriptions of compensatory processes can be found through the well-known assessment tools for diagnosing autism in children and adolescents such as the ADOS-2 and the ADI-R. Thus, added assessment instruments are not needed, but additional attention to the descriptions of compensatory processes is warranted in clinical assessment. Attention to compensatory processes in clinical care may help to highlight the attunement of parents to their YP's specific needs, and this knowledge may be important for parents to recognize and use when helping their YP navigate a recent autism diagnosis. Attention to compensatory processes may also add a nuanced understanding of the unrecognized stressors in the lives of these YPs, as they may need support to minimize stressors of social life in order to recover from their eating disorder.

ETHICAL STATEMENT

Ethics Approval

Regarding the Informed Consent Statement, informed consent was obtained from all subjects involved in the study. The Danish Data Protection Agency and the Institutional Research Review board of Child and Adolescent Mental Health Centre of the Capital Region approved the main study of which this sub-study is part. The Regional Ethical Committee waived approval for this study, as it is purely descriptive and implies no intervention. Direct quotes are adapted and/or combined to ensure full anonymity of participants.

Declaration of Helsinki STROBE Reporting Guideline

This study adhered to the Helsinki Declaration. The Strengthening the Reporting of Observational studies in Epidemiology (STROBE) reporting guideline was followed.

DATA AVAILABILITY

Data related to the coding process are available from the corresponding author upon reasonable request. Transcripts are not shared due to privacy or ethical restrictions.

AUTHORS' CONTRIBUTIONS

Conceptualization, MB; Methodology, MKJ and TWL; Validation, MKJ, TWL, MB, and SHP; Formal Analysis, MKJ and TWL; Data Curation, MB and SHP; Writing—Original Draft Preparation, MKJ and MB; Writing—Review & Editing, MKJ, MB, TWL, and SHP; Supervision, MB; Project Administration, MB and SHP.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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