How autistic women are aware of their body and take care of their health? Focus on menstruation cycles and gynecological care

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Abstract

The combination of femininity and inequality is an increasingly studied in the field of social medicine, even more if the girls or women in question experience conditions of disability or neurodivergence. The onset of menstruation, menarche, constitutes a significant and transformative event in women’s lives comprising a true and proper watershed in mental and reproductive health and sexual welfare. The onset of menstruation has a profound effect not just for girls but, in the case of disabled girls, for the whole family. In this scoping review, we have researched the literature in studies which consider the issue of menstruation and autism. The works in scientific literature have been selected which, in the last 5 years, investigated the issue of menstruation for autistic girls and/or women.

Results. Selected studies, although few in number, have all equally evidenced the total lack of in-depth understanding of this theme, notwithstanding the fact that females, girls and women with autism would benefit from specialized services if these existed. Families, girls and women involved, moreover, although not experiencing menstruation per se in a negative light, note a deterioration in their condition particularly in respect of sensorial perception and the intensification of anxious depressive instances. This work highlights the need to deepen the aspects concerning the period in autistic girls/women, up to now the question appears to have been little studied, investigated in an uneven way. We propose a social medical program to improve sexual-affective knowledge and body awareness in autistic people. Clin Ter 2024; 175 (3):168-175 doi: 10.7417/CT.2024.5058

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Introduction

Autism is a neurodevelopmental disorder with onset in early childhood (1), with a genetic-epigenetic basis but without a clear etiology: a series of predispositions such as the role of inflammatory processes (2) and environmental pollution and drug use occurring during pregnancy and familiarity (3) have been highlighted. Autism is a condition that involves by deficits in social communication, and restrictive, repetitive behavioral patterns, with neurodivergence in sensorial perception, and difficulties also at the level of executive functions (4), emerging early in childhood development (5). The issue of autism has been treated mainly from a male perspective, this tendency being justified by the issue of the proportion of autism prevalence (which is calculated at a ratio of 1:4 so males since to 1:11 in higher functioning people) are in the net majority compared with women. This rate difference could be related to biological basis (extreme male brain theory) (6) but also to difficulties in diagnosing ASD in female, that have a more internalized autism syndrome. Even if awareness of neurodivergence in ASD female begins at an early age “I have always felt different from others” is a frequently used expression among female with autism—, the syndrome could be not recognized because they are more biologically empathetic than male ASD (7) (8). A review from 2017 (9), which focused on the gender question came to the conclusion that the true proportion was 1:3 but the picture could change in the coming years. In the light of this brief introduction, we can begin to understand why we decided to take stock of the situation on the autism-menstruation link which, in the light of how autism has been framed up to now, could be a little-developed topic. The onset of menstruation, menarche, constitutes a significant and transformative event in women’s lives comprising a true and proper watershed for mental and reproductive health and sexual welfare (reproductive sexual health) (10). All adolescents, at this period in their lives, experience great physical, cognitive, emotional, and behavioral changes (11). All the same, the approach to menstruation is linked to cultural, traditional, and social stigma variables (12). Even today, it is noted that girls find it difficult to open to their parents or adults they trust in discussing menstruation (13) and there are still too few cases in which girls receive sexual education prior to the onset of menarche explaining what menstruation entails and how this changes a woman’s life (14). The preparation for this event should start at about 11 to 12 years old, as only 10% of females are menstruating at 11.11 years of age; 90% are menstruating by 13.75 years of age (15). Associated with menarche and

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menstruation, occasionally disorders like dysmenorrhea, or physical pain connected with the menstrual cycle may occur. Dysmenorrhea is well documented amongst female adolescents with a rate of prevalence ranging from 40 to 90% (16) and is the primary reason for girls’ school absences and work absences for adolescents. It is very important that we direct our attention to menarche and menstruation in autistic women as such events that divide life into a beginning and then an after, are in and of themselves potentially traumatic (17). The commencement of menstruation, especially, can be experienced as disruptive, creating ambivalence and confusion (18). The greater part of the scientific literature shows that menstruation is mainly negatively perceived and experienced by girls (19). The literature further shows how this is the fruit both of taboos and shame and secrecy which still hangs over the experience of menstruation (20).

With respect to neurodiversity and autism in particular the negative experiences associated with physical and sexual maturity are experienced with great discomfort; physical changes and changes in shape can give rise to difficulties for girls, especially if they require physical assistance (21); practical management of menstruation can become complicated above all in cases of intellectual disability and the caregivers may themselves experience difficulty in its management (22). Parents, indeed, are faced with a number of anxieties regarding their own daughters who seem to be losing the innocence and protection offered by childhood and so worry that their daughters run the risk of attracting attention of a sexual nature. Such anxieties may take on such enormous proportions that some parents prefer to resort to medical intervention to eliminate or control menstruation in their daughters (23). These tendencies seem to spring from issues perceived as taboo as noted by health-workers in the sector. In a survey of gynecology practitioners, Shah (24) et al. found that 14–42% of them felt uncomfortable talking to adolescents with disabilities about typical menstrual and contraceptive-related issues. Only 45% of gynecologists reported being “very comfortable” managing sexual and reproductive care for women with intellectual or developmental disabilities in a more recent study (25). Therefore, training healthcare professionals in these areas can make it easier to raise these issues with families of girls with special needs (26). the families of these patients were most likelyGirls with ASD made up the majority of the patients who sought pre-pubertal counselling, and to express worries about expected behavioral changes with puberty. This is in line with earlier research showing that girls with ASD and their caregivers are more likely to report cyclical behavioral changes and other pre-menstrual symptoms than girls with other types of developmental delay (27). Women with ASD have stated in prior qualitative studies that pre-existing problems, such as sensory challenges and difficulty regulating moods, are made worse by puberty and menarche (28). This is the reason why education concerning sexuality and management of menstruation has become a new objective to attain by health-care workers who experience challenges in discussing sexuality with women with disabilities and with autistic girls and women to improve their understanding of what is happening to them and how to cope with it (29). The effects on autistic girls appear to be the following: increased sensorial perception, emotional and behavioral difficulties (30). In one of the earliest studies on this topic, Hamilton and her colleagues (31) looked into hygiene issues, dysmenorrhea, premenstrual syndrome (PMS), and treatment to assess the experience of 10 25-year-old women with autism spectrum disorders with menstruation through their caregivers. The majority (90%) of the 124 respondents who finished the survey out of the 162 who began it, were mothers of girls with ASD. ASD menstrual symptoms, such as increased aggression before each period, worsening autistic behaviors, increased repetitive movements, and increased obsessive behaviors, were present in 33% of the subjects. The reported ASD premenstrual symptoms did not differ between ASD diagnoses. Despite the fact that for some people, especially at home, dysmenorrhea and PMS interfered with daily activities, neither significantly increased absenteeism from school or other activities. Nowadays, therefore, the issue of autistic women and menstruation is still insufficiently studied. For this reason, we believe that this question is a social medicine question that can be investigated with the tools of social medicine that finds and indicates the most suitable methods so that the entire population is equipped and makes use of the preventive, curative and rehabilitative means of medicine.

Materials and methods

In this scoping review, we studied the literature covering the issue of menstruation in relation to autism. A scoping review can be a useful tool to investigate the scenario regarding a developing issue. The research team searched in three scientific search engines. The scientific literature in the last 10 years concerning autism and menstruation. PubMed, EBSCO and Web of Science were used, and the research team deemed it necessary and sufficient to search these three databases. The review was conducted taking into account the protocol suggested by Arksey and O’Malley (32), especially designed for subjects with disabilities or similar conditions. Here are all the internships. The aim of this study is to review the scientific literature on autistic girls/women and menstrual cycle management. Women, in fact, already appear to be less represented in autism, furthermore, there are few studies that deal with issues of health and psychological well-being closely related to the female gender.

Stage 1: Identify the Research Question

The investigation begins with an overview of the issue at hand and any potential complications. We therefore pondered if this issue had received enough attention in the scientific community. Girls and women with autism struggle to gain a diagnosis, but if they do, are we sure we can provide them with the assistance they require? What have women with autism to say about it? Additionally, what do operators and family members think if they are non-verbal girls or women?

Stage 2: Identify Relevant Studies

To find studies relevant to the given study questions, key words were used. The following search phrases were used:
“Autism and Menstruation.” Rett Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, and Child Disintegrative Disorder are examples of other categories connected to ASD that were left out because they did not increase the total number of research discovered. English language, and publication between 2013 and 2023 were the eligibility criteria.

Stage 3: Study Selection

There were 14 articles from Ebsco, 19 from Web of Science, and 11 from PubMed. The total number of articles was reduced to 5 by the second author after reading the titles of all of them and eliminating any that were obviously unnecessary (such as those on animal models or medical testing or who dealt with autism not specifically but within different disabilities). The non-specificity of various contributions, which have investigated the issue in the vast sea of disability, is a major limitation of this area of research. The next step was to read the whole article, paying close attention to the methodology portion in particular. All the steps are reported in the Prisma diagram (Fig. 1).

Stage 4: Chart the Data

The organization of the data from the chosen articles was the fourth stage of the scoping review framework. This stage was carried out using Microsoft Excel. Author(s), title, publication year, nation where the first author’s university is affiliated, research setting, purpose, participant demographics, research methods, measures, interventions, important findings, and limitations were the data points that were gathered. Table 1 provides a summary of the authors, participants, measurements, and conclusions.

Stage 5: Collate, Summarize, and Report Results

The final step of the Arksey and O’Malley (2005) paradigm involved categorizing the pertinent findings into themes, giving outcomes priority depending on their applicability to the research objectives, and placing a strong emphasis on the type of intervention. Relevant information was provided, such as sample size, participants, procedures, and results. The results section below contains a complete report of all data.

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**Fig. 1. Prisma diagram of study selection process**
Results

Clare Cummins and collaborators (33) conducted a study in 2018 on thirty persons: ten girls diagnosed with autism and intellectual disability aged between 11 and 19 years old, their ten parents (nine mothers and one father) with ten specialist women accustomed to working with the research target subjects. The sample group came from England and Ireland. The diagnosis in this girl sample consisted of autism and intellectual disability, fitting the Tager-Flusberg and Kasari (34) definition of being minimally linguistic. The educators all worked in special schools in England and Ireland. Interviews with parents and educators identified three themes: (1) different experiences and needs; (2) dignity and respect; (3) how to support girls through adolescence. The results revealed that both parents and educators deem puberty to be a positive experience for these girls. It also brought to light parents’ and educators’ concerns regarding pains and their effects during the cycle and both parents and educators reported that increased supervision resulted in easier communication enabling the girls to actually speak about their pains. Lastly, the parents expressed satisfaction with the co-operation of the school institutions while the educators emphasized that there is a need to train the schools better, and even to introduce medical expertise into the system. Fey and collaborators (35) in a study published in 2021, studied the preparation for puberty in the female special-needs population (cognitive and/or physical disabilities) with the aim of identifying such population as well as that of caregivers who created a road map to anticipate and prepare for puberty, address caregivers’ concerns regarding puberty and plan management strategies, options and the resulting outcomes. This ponder included a cohort of 478 patients with disability observed at Michigan medical institutions, up to 26 years. A total of 61 patients reported prepubertal visits, on average 13.5 months before menarche. The mean age at onset was 10.7 years. Compared to the rest of the population of 478 adolescents and young women with special needs, subjects with autism were the most frequent users of services (39%), and within this subgroup about 43% were non-verbal. Met. The study found that more than half of families identified the potential for behavior change as their top concern. Unfortunately, the results of this study relate to the analyzed population as a whole and not to those with autism in particular. The majority of post-menarche patients (80%) desired hormonal control of menstrua-
tion, including his 30% of those who had an intrauterine levonorgestrel device inserted. Overall, 96% of patients were satisfied with the course of their last menstrual bleeding; 50% experienced amenorrhea or light spotting. The great merit of this study is, without a shadow of doubt, it reveals the need to organize a consultation service for menarche and management of menstruation showing that a good part of its use would be used by autistic subjects. Rachel Moseley and collaborators (36): She focused on studying a particular period in the menstrual cycle, menopause. As the author herself points out, it is the first work that investigates menopause in autistic women, there are no others, though literature focusing on menstruation is deficient, literature regarding menopause is even more scarce. Taking after suggestions (37), the authors conducted a litte focus group that included seven members and two facilitators. The average age of the women was 54.8 years. The authors conducted a short but well validated screening, using the Extreme introvertedness Range Remainder (AQ-10), and Ritvo Extreme introvertedness Asperger Symptomatic Scale–14 (39) (RAADS-14). After focus group, the authors conducted a thematic analysis that evidenced menopause is an occasion which, like menarche, can lead to unused challenges with tactile sensitivities, communication, feeling direction and regular living. Members moreover highlighted the lack of professional support as regards management of the menstrual cycle, to the extent that they were unable to determine what was normal and what not. For two participants, in fact, menopause was such a difficult passage that it propelled them to get to the bottom of their problems and to be finally given a formal diagnosis of autism. Given the challenges and general instability of midlife, it’s no surprise that mental health issues and suicidal ideation have worsened. This data appears extremely interesting, above all if correlated with the already high rates of psychiatric illnesses and suicidal tendencies in the autistic population. (40). A study by Annabeth P. Groenman (41) sought to determine whether premenstrual dysphoric disorder (PMDD) and complaints related to menopause are more common in autistic women. The participants came either from mental health institutions across the Netherlands, or from social media appeals, the requirement being to have been diagnosed with autism based on the DSM and an IQ of more than 70 and a good understanding of language. For the comparison group, the authors opted to exclude all those conditions that could be close to ASC, or Autism Spectrum Conditions. The methods used were: PMDD (yes/no) taken from the Mini international neuropsychiatric interview Plus (42). This systematic diagnostic interview examines a number of psychiatric conditions. The Dutch version of the Menopause Rating Scale (43) was used to look into menopausal issues. The SCL-90 (44) symptom checklist’s subscale scores for depression and the sum of general anxiety and agoraphobic anxiety as a stand-in for general anxiety were used to assess psychiatric/psychological symptoms. In addition, the authors used ADHD-self-report (45) to evaluate the current inattention and hyperactive/impulsive symptoms of ADHD. Compared to non-autistic people, autistic people reported more overall menopausal complaints, which translated into higher scores on the subscales of psychological and somatic complaints but not urogenital symptoms. 95% of non-autistic women and 143% of autistic women reported having PMDD at some point in their lives. Statistics did not support this distinction. The results of this study showed that in autistic women, and not in normotypical women, menopausal disorders were related to a depressive picture, while in non-autistic women menopausal disorders were related to impulsivity and hyperactivity. In autism, but not in comparisons, the total number of menopausal complaints was associated with depressive symptoms. Significant correlations between overall menopausal complaints and signs of impulsivity and hyperactivity were seen in non-autistic women. There were no additional notable connections between overall menopausal problems and psychological or psychiatric complaints. Steward and collaborators (46) conducted a preliminary analysis of the responses to a short online survey among post-menarchal autistic (n = 123) and non-autistic (n = 114) individuals. The authors declare that this is the first study in which autistic subjects are solicited to talk about their periods in the first person. The sample was constituted using website posts and social media, 39 of the 276 participants were omitted from the dataset because they either reported never having had periods (n = 11) or did not adequately respond to all pertinent questions (n = 28). Therefore, subsequent analyses were based on complete replies from 237 participants, ages ranging from 16 to over 60 (n=123 autistic; n=114 non-autistic). A great advantage of this study is to have recorded the declarations and reflections of the participants, so this method led to deeper empathy in the reader in regard to the result of the study which bears true and clear evidence. The claims about sensoriality, for instance, are very intriguing: pre-existing hypersensitivities becoming “extra sensitive” during the period, also participants reported being more sensitive and reactive with senses especially in touch, sight and smell. Participants also mentioned how their period made it harder to control their emotions and behavior. The sampled people overwhelmingly described negative sensations, sensory problems and heightened executive and emotion challenges. These issues frequently resulted in serious consequences like “shutdown,” withdrawal, and elevated anxiety, which in turn led to decreased involvement in work, social, and community life. Discussion

Investigating the link between autism and menstruation is particularly difficult as there are few studies, very different from each other in terms of methodology but also in the aspects on which they have focused. Some studies have investigated the premenstrual period and at the turn of the menarche, some the management of menstrual cycles and finally one the arrival of menopause. Furthermore, the authors of two studies were keen to point out that it was the first time that a study of this type had been conducted. The focus of our review are: are we giving autistic girls and women all the assistance they they require? What have women with autism to say about it? Additionally, what do operators and family members think if they are non-verbal girls or women? It is difficult to homogeneously summarize the data as the various researches are based on moments, methodologies and have different protagonists. It therefore seems useful to resume the research objectives below.

1) are we giving autistic girls and women all the assistance they they require?
The studies analyzed agree in underlining the lack of adequate specialist health care aimed at families, girls and then autistic women who face the different periods of the cycle: menarche, cycle, menopause. All the researches highlight the lack of services and the favorable attitude of users in thinking of using specific services. Specific services to help and/or support autistic girls and women in menstruation management are not yet widespread, scientific work appears to be necessary, but also pioneering to be able to think of services that effectively respond to the needs of the target population and arise from the participation of the autistic population in scientific research.

2) What have women with autism to say about it?

Groenam, Mosley and Steward conducted research directly with autistic users. Mosley delves into menopause while Groenam and Steward delve into periods. However, there is a common thread among the studies that underline how the cycle and menopause increase the anxious-depressive instances of the subjects, with important implications on sensoriality.

3) What do operators and family members think about autism and menstruation?

The two studies involving families and operators highlighted a positive attitude towards menarche and the arrival of the period, although there was also fear of the changes that daughters and/or users were going through. Furthermore, these studies have the merit of highlighting that, if services for the preparation for the period and its management were strengthened, the families of autistic girls would adhere with a high percentage. The results of this work review are narrow and restricted, but in general the scientific literature has paid little attention to gender as regards autism, so the menstrual cycle and the changes of a hormonal, physical, behavioral and sensorial nature that are associated with this phase, are poorly studied. In endeavouring to summarize what emerged from the studies analyzed, the review shed light on how necessary it is to work together with the families and autistic girls on matters like sexuality and menstruation long before the onset of menarche. As Frances’ study showed, if there were a possibility of a course dedicated to these issues, families with an autistic daughter would be the greatest beneficiaries. Moreover, it has been shown that issues like sexuality, menstruation and similar matters need to be aired, including amongst health-care workers and professionals who have to care for them. It is essential that health-care workers are properly prepared and that autistic women can access adequate services which they can rely on, be supported and guided regarding questions of menarche, menstruation and menopause and also because such conditions, even when experienced with a healthy psychological attitude, can appear to worsen sensorial and behavioral aspects typical of autism. In a recent INTIMINA report (47), it is shown how 30% of autistic girls only learn to manage menstruation after about 3-4 years and more than half remarked that they have no concept of how their menstrual cycle works and a full 83% mentioned they found menstruation products difficult to use. The very practical aspects of managing the cycle seem not to have been properly explained, so it would be interesting to study how autistic girls succeed in absorbing information as to daily practical management of the cycle. Therefore, beyond the need to explore the abovementioned issues, it must be asked whether everything about the management of menstruation is sufficiently inclusive. There are several limitations in this study: first of all, qualitative research has intrinsic limitations that we tried to stem by following the Prisma statement and the recommendations for a review in the field of neurodivergence. The major limitation, then, is that the research object is not actually thoroughly investigated in the literature, therefore the results from the databases are meager, methodologically very different from each other and deal with different moments in the life of the subject, therefore in the cycle, arriving at I was difficult to synthesize. Furthermore, some of the few studies also have the limit of actually being surveys on the “disabled” population, including autistic people, but not specifically. Therefore some results refer to the population with disabilities, but not to the autistic population. This way of approaching autism is absolutely limiting and does not take into account the paradigm shift of autism in recent years. Autism, in fact, from the contributions onwards is a condition rather than a disability, therefore counting it among the disabilities could be extremely simplistic as well as misleading. There is therefore a need for future research to focus on studies focused only on the autistic condition, trying to give, where possible, a voice to autistic girls and women as well as families and operators.

**Conclusion**

Since the right to health in 1948, with the Universal Declaration of Human Rights of the United Nations, was enshrined as an inalienable right of every human being, serious inequalities remain in the world linked above all to socio-economic conditions, important determinants of health (48), especially life expectancy, both in poor and rich countries, but being a woman is everywhere, socio-economic conditions being equal, a powerful determinant of health. If, alongside being a woman, there is also disability and/or other neurodivergent conditions, the disparity becomes even more marked. Providing appropriate interventions for preparation for menarche, help with menstrual cycle management with services aimed first of all at autistic girls/women and then also at their families would enable the application of medico-social prevention in favor of the application of a right that should be universal according to the specific bio-ethical context(49). The need to continue to deepen understanding of social medical aspects linked to autism in women shines a spotlight on how much gender-based medicine can achieve in this regard. Many professionals (50), including Attwood, recognize that an extensive gender bias still exists which means that female infants, girls and women do not receive even a diagnosis which may, in fact, improve their lives. However, it is necessary to act with caution in this regard; just consider the question of gender identity: according to one study (51) published in August 2020, in persons who do not identify with the sex assigned to them at birth, autism (mentioned in the paper along with other psychiatric/neurodevelopmental diagnoses) is three to six times more common. It therefore makes sense to speak about autism “in women” or it may be opportune to strive for language adapted to gender medicine themes, but without
reinforcing stereotypes and taking into consideration the current fluidity of sexual identity. Furthermore, it would be interesting to foresee possible interventions and solutions to alleviate discomfort and suffering, as has been done for other conditions of suffering (52) (53). To address this need we propose a specific educational program for people with autism in adulthood. The target is to improve the knowledge of the body but also to improve the social skill to create a relationship. The program has three different level, related to the same level of autism spectrum disorder described in DSM 5 (APA, 2013). The teacher-equipe is composed by psychologist, psychiatrist, urologist, and gynecologist. All the teacher are also specialized in autism and disability. The course is gender mixed, involving male and female in the same group. In the ASD level-1 course, only ASD people are admitted. In the ASD level-2 course ASD people could be supported during the lessons by their social coach, that usually support them in daily activities. The ASD level-3 course is directed to patient’s caregivers. Further analysis appears to be necessary to give consideration to and implement mental health services specifically for autistic girls and women who, beyond being poorly researched, are also under resourced in respect of services (54) (55). Successful co-regulation necessitates child and parent skills, with “scaffolding” pivotal in parental support. Strong co-regulation shields against complications like comorbid anxiety and depression. Early interventions involving parents, backed by the broken mirror theory, are promising. Parent-mediated programs, exemplified by cooperative parent-mediated therapy (CPMT), improve socio-communication, ASD symptoms, and alleviate distress. The intricate interplay between co-regulation, autism, and interventions under-score caregiver-child dynamics’ impact on developmental trajectories and well-being for autistic individuals. Limitations of our work are different, first, the field of investigation analyzed is little studied in the literature, furthermore, the results are not only few, but also very heterogeneous. Of the studies intercepted, for example, only three directly involve the autistic population. Therefore, this work certainly indicates that in future work, more voice should be given to the autistic female population and to the family and support network that supports autistic individuals so as to create health and social welfare services that respond to the needs of autistic girls and women.

All the Authors declare the absence of a conflict of interest.

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