

Agnieszka Rynkiewicz^{1,2}, Ewa Ferensztajn-Rochowiak³, Rachel L. Moseley⁴,
Julie M. Gamble-Turner⁴, Nouchine Hadjikhani^{5,6}, Adeline Lacroix⁷, Alicia Brewer Curran⁸,
Kristin Sohl⁸, Dorota Darmochwał-Kolarz⁹

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Treatment of menopausal vasomotor symptoms and sensory issues in a 53-year-old autistic woman – a case report

Leczenie objawów naczynioruchowych w menopauzie oraz problemów sensorycznych u 53-letniej autystycznej kobiety – opis przypadku

¹ Department of Psychiatry, Faculty of Medicine, Medical College, University of Rzeszów, Rzeszów, Poland² Center for Diagnosis, Therapy and Education SPECTRUM ASC-MED, Gdańsk, Poland³ Department of Adult Psychiatry, Affective Disorders Laboratory, Poznań University of Medical Sciences, Poznań, Poland⁴ Department of Psychology, Bournemouth University, Poole, United Kingdom⁵ Department of Radiology, Harvard Medical School & Neurolimbic Research, Boston, United States⁶ Gillberg Neuropsychiatry Center, University of Gothenburg, Sahlgrenska Academy, Göteborg, Sweden⁷ Campbell Family Mental Health Research Institute, Centre for Addiction and Mental Health, Toronto, Canada⁸ ECHO Autism Communities, Department of Child Health, University of Missouri School of Medicine, Missouri, United States⁹ Department of Gynaecology and Obstetrics, Faculty of Medicine, Medical College, University of Rzeszów, Rzeszów, Poland

Correspondence: Agnieszka Rynkiewicz, Department of Psychiatry, Faculty of Medicine, Medical College, University of Rzeszów, mjr. W. Kopisto 2 A, 35-310 Rzeszów, Poland, e-mail: arynkiewicz@ur.edu.pl

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ORCID iDs

1. Agnieszka Rynkiewicz <https://orcid.org/0000-0002-9175-4937>2. Ewa Ferensztajn-Rochowiak <https://orcid.org/0000-0001-7701-8389>3. Rachel Moseley <https://orcid.org/0000-0002-5985-6175>4. Julie Gamble-Turner <https://orcid.org/0000-0002-3286-3244>5. Nouchine Hadjikhani <https://orcid.org/0000-0003-4075-3106>6. Adeline Lacroix <https://orcid.org/0000-0001-6990-5949>7. Alicia Brewer Curran <https://orcid.org/0000-0002-9032-1953>8. Kristin Sohl <https://orcid.org/0000-0003-0588-8742>9. Dorota Darmochwał-Kolarz <https://orcid.org/0000-0002-1590-442X>

Abstract

Considered a taboo topic in many societies, menopause in autistic women is still under-recognised, and little research addresses its impact. Existing studies suggest that this often-difficult transition period is associated with numerous unmet health needs and a frustrating lack of knowledge and support from healthcare professionals. Menopausal vasomotor symptoms, the hallmark of menopause, can intensify and worsen sensory sensitivities in many autistic women. We present the case of a 53-year-old Caucasian autistic woman without intellectual disability or other current psychiatric comorbidities. The patient underwent gynaecologic and hormonal lab testing, and was introduced to hormone replacement therapy to ameliorate symptoms of oestradiol and progesterone deficiency. Menopausal vasomotor symptoms experienced by the patient were monitored over a period of seven months following the implementation of hormone replacement therapy and non-pharmacologic approaches. Hormone replacement therapy decreased menopausal vasomotor symptoms, but not all her initial complaints. Strong sensory issues were linked to more severe menopausal vasomotor symptoms. This case highlights the need for further research and the development of the global Extension for Community Health Outcomes (ECHO) Autism® model to advance medical care offered to autistic women during menopause.

Keywords: autism spectrum disorder, menopause, autistic women, hormone replacement therapy, ECHO Autism

Streszczenie

Menopauza uznawana jest za temat tabu w wielu społeczeństwach. Jak dotąd przeprowadzono niewiele badań na temat jej wpływu na autystyczne kobiety. Z dotychczasowych ustaleń wynika, że ten często trudny okres przejściowy wiąże się z wieloma niezaspokojonymi potrzebami zdrowotnymi, frustrującym brakiem wiedzy oraz wsparcia ze strony lekarzy. Objawy naczynioruchowe – będące głównymi objawami menopauzy – mogą nasilać i pogarszać wrażliwość sensoryczną u wielu autystycznych kobiet. W pracy przedstawiono przypadek 53-letniej autystycznej kobiety rasy białej, bez niepełnosprawności intelektualnej ani współistniejących zaburzeń psychicznych. U pacjentki przeprowadzono badania ginekologiczne i hormonalne oraz włączono hormonalną terapię zastępczą w celu złagodzenia objawów niedoboru estradiolu

i progesteronu. Objawy naczynioruchowe w menopauzie badane były w okresie 7 miesięcy po wdrożeniu hormonalnej terapii zastępczej oraz metod niefarmakologicznych. Hormonalna terapia zastępcza zmniejszyła objawy naczynioruchowe u pacjentki, jednak nie wszystkie początkowe dolegliwości. Nasilone problemy sensoryczne związane były z większym natężeniem objawów naczynioruchowych. Uzyskane wyniki wskazują na potrzebę dalszych badań oraz rozwoju globalnego modelu Extension for Community Health Outcomes (ECHO®) Autism w celu poprawy opieki medycznej oferowanej autystycznym kobietom w okresie menopauzy.

Słowa kluczowe: zaburzenie ze spektrum autyzmu, menopauza, autystyczne kobiety, hormonalna terapia zastępcza, ECHO Autism

INTRODUCTION

Autistic girls and adult women, historically overlooked by researchers and diagnosticians alike, are fast emerging as a group with specific support needs (Rynkiewicz et al., 2024). Many autistic women are only diagnosed in adulthood, often following a string of misdiagnoses (Kentrou et al., 2021; Rynkiewicz et al., 2024), and the experiences of female autistic individuals remain unrepresented in autism literature (D'Mello et al., 2022). While autistic women suffer poorer physical and mental health than their non-autistic female peers (Rynkiewicz et al., 2024; Simantov et al., 2022; Tint et al., 2021; Ward et al., 2023; Weir et al., 2021), some studies suggest that their burden of mental and physical illness also surpasses that of autistic men (Angell et al., 2021; DaWalt et al., 2021; Dubreucq et al., 2023; Martini et al., 2022). In this context, it is notable that as they age into another neglected autistic demographic, that of autistic people at midlife and older age (Mason et al., 2022), the health and support needs of autistic women are especially overlooked (Moseley et al., 2021; Rynkiewicz et al., 2024).

Midlife is increasingly recognised as a pivotal period for later-life health and functioning (Lachman et al., 2015), and has been associated with a nadir in well-being (Stone et al., 2010). From midlife onwards, women report lower levels of life enjoyment and greater stress, worry, and sadness compared to men (Stone et al., 2010). Within this stage of life, menopause is emerging as a particularly salient window of potential vulnerability. The menopausal transition usually begins at around 40 years of age, starting with perimenopause (cessation of menstruations), and is considered established once menstruation has ceased for 12 consecutive months. The process of menopause is associated with a wide range of physical and emotional symptoms, including but not limited to hot flushes, difficulty sleeping, headaches, joint pain, low mood, anxiety, and palpitations. One distinguishable group of symptoms is vasomotor symptoms (VMS), which include hot flushes and night sweats, and are linked to thermoregulatory dysfunction, loss of peripheral vascular reactivity, and neurotransmitter alterations (Deecher and Dorries, 2007). Menopausal symptoms vary in intensity and can persist for several years after menopause (Harlow et al., 2012). They result from an imbalance of reproductive hormones (predominantly oestrogen, progesterone, and testosterone) and the

associated reorganisation of neuroendocrine systems (Falconi, 2017; Hoyt and Falconi, 2015).

The menopausal transition can be an extremely difficult time for women, given the debilitating or disruptive physical symptoms, cognitive difficulties with memory and executive functions, and increased risk of physical and mental health issues, even including a heightened risk of suicidality (Cassidy et al., 2021; Hoyt and Falconi, 2015). A quarter of menopausal women are so severely affected by their symptoms that they consider resigning from work, and according to the Women and Equalities Committee (Women and Equalities Committee, 2022) in just one year (2019), a million workdays were lost due to menopausal symptoms. Importantly, well-being and health during and after menopause are moderated by several psychosocial factors, including socioeconomic status, prior life experience (particularly early life adversity), ethnicity and culture, employment factors, and premenopausal health (Riach and Rees, 2022; Shanmugan et al., 2017). This points to the importance of considering diversity in menopausal experiences and the need to examine the effects of menopause in specific groups of individuals for whom menopause may unveil particularly difficult symptoms.

Although the general healthcare barriers facing autistic children, adolescents, and younger adults have been extensively documented (Doherty et al., 2022; Malik-Soni et al., 2022; Mason et al., 2019), there is little research addressing the specific needs and difficulties encountered by older autistic adults (Mason, 2022; Warner et al., 2019). Healthcare practitioners have expressed uncertainty and inexperience in working with adult autistic patients (Morris et al., 2023; Nicolaidis et al., 2021), and the limited autism-related training they receive centres around children and young people (Clarke and Fung, 2022). For these reasons, documenting the support needs of autistic people during menopause is crucial.

Extension for Community Healthcare Outcomes (ECHO)

The Extension for Community Healthcare Outcomes (ECHO) model® is an effective and scalable telementoring model designed to empower global change in health, education, and civics. The ECHO model leverages video-conferencing technology to share best practices with community professionals through case-based learning and ongoing guided practice (Fig. 1).



Fig. 1. The Extension for Community Healthcare Outcomes (ECHO) model*. Image created by ECHO Autism Communities with permission granted

The model is a “hub and spoke” framework, where the “hub” consists of an interdisciplinary team of content experts who mentor a group of “spokes”, or community professionals who participate in a series of interactive virtual sessions. Each session routinely includes a brief didactic presentation by a hub team member, providing a broad overview of a relevant topic, and a de-identified case presentation provided by a spoke participant that typically generates a rich discussion and yields best-practice recommendations (Arora et al., 2010). The University of Missouri ECHO Autism Communities programme was established in 2016 and has a long history of successfully applying the ECHO model* to autism through a wide variety of programmes. The ECHO Autism framework has been shown to improve the knowledge and self-efficacy of community clinicians, thus creating access to high-quality autism care for autistic individuals and their family members in local communities (Mazurek et al., 2017, 2019). Therefore, the ECHO Autism framework is well positioned to decrease disparities in the care of autistic women during menopause by empowering community gynaecologists with enhanced knowledge and confidence in their ability to treat intensive symptomatology and improve health outcomes. Similarly to those in the USA, the ECHO Autism models in Europe are funded through grants, competitions, and other financial mechanisms that support the dissemination of the best practices and medical care for autistic people (Rynkiewicz et al., 2023, 2022; Sohl et al., 2022).

MATERIALS AND METHODS

Five autistic menopausal women took part in the pilot study, including one case within the ECHO Autism activities on best practice recommendations. The participants

were assessed using standardised tests and clinical interviews, and self-reported questionnaires. Sensory sensitivity and autistic traits were measured using validated tools. Additionally, the participants underwent gynaecological exams and lab tests. The study examined whether the severity of menopausal symptoms in autistic individuals correlates with reproductive hormone levels, sensory issues, and autistic traits. For the purpose of this short report, one case is presented as follows.

A 53-year-old white autistic person, assigned female at birth and identifying as a woman, with no intellectual disability, was diagnosed with autism spectrum disorder (ASD) by a trained psychiatrist. Her medical history revealed pharmacological treatment for mixed anxiety and depressive disorder (F41.2 according to ICD-10) in the past. She had no other co-occurring psychiatric or somatic conditions and was not on any medications. The menopausal period started six months before her participation in the study, and the menopausal symptoms included hot flushes, night sweats, brain fog, vaginal dryness, mood swings, aching in muscles and joints, low back pain, feeling tired and worn out, and difficulties with daily functioning. Additional complaints included headaches, deteriorating vision, significant weight gain, and breast enlargement.

Over a period of seven months, medical and psychological tests were conducted, or test results were retrieved from medical records. These included transvaginal and breast ultrasound, cytological examination, hormonal laboratory tests, and magnetic resonance imaging (MRI) of the pituitary gland. To confirm the diagnosis of ASD, the gold standard of ADOS-2 (Autism Diagnostic Observation Schedule, Second Edition) (Lord et al., 2012), Module 4, designed for use with adults who have “fluent” language skills and independence in terms of making everyday choices; and the ADI-R (Autism Diagnostic Interview-Revised) (Rutter et al., 2003b) were used. Other psychological tests included the SCQ Lifetime (Social Communication Questionnaire) (Rutter et al., 2003a) completed by an available and competent parent, and a modified version of GQ-ASC/Q-ASC (Girls Questionnaire for Autism Spectrum Condition) for adult women (Attwood et al., 2011; Mae Simcoe et al., 2018; Rynkiewicz, 2016; Rynkiewicz et al., 2023) modified by Brown et al. (2020).

To assess menopausal symptoms, the Menopause-Specific Quality of Life (MENQOL) questionnaire was used. The MENQOL consists of 29 questions rated dichotomously as “No”/“Yes” and on a 7-point Likert scale measuring the bothersome effect of each item, ranging from “0” (not bothered at all) to “6” (extremely bothered). The results are presented as a summary score and across four domains, i.e. vasomotor, psychosocial, physical, and sexual.

The Adolescent/Adult Sensory Profile (AASP) (Brown et al., 2001) was used to assess the sensory profile. The AASP is a self-report tool consisting of 60 questions covering six areas of sensory processing: taste/smell, movement, visual, touch, activity level, and auditory. Each question is rated

on a 5-point scale from “almost never” to “almost always”, describing the frequency of engaging in a given activity. The results allow for the assessment of the sensory profile across four quadrants: “Low Registration”, “Sensation Seeking”, “Sensory Sensitivity” and “Sensation Avoiding”, rated on a 5-point assessment scale, i.e. “Much Less Than Most People”, “Less Than Most People”, “Similar to Most People”, “More Than Most People”, and “Much More Than Most People”.

Hormone replacement therapy (HRT) for oestradiol and progesterone deficiency was introduced in the form of System Conti (3.2 mg estradiolum + 11.2 mg norethisteroni acetate), with one patch applied twice a week. Also, there was vitamin D₃ supplementation; 4,000 IU – 1 tablet/day. Additionally, mindfulness sessions were implemented once a week for eight weeks.

The study was approved by the University of Rzeszów Bioethics Committee (No. 2024/02/007), and the patient gave her informed consent.

RESULTS

The results of the ADOS-2 (Module 4) confirmed a pattern of sociocommunicative and cognitive differences characteristic of autism, with clear evidence of unusual sensory interests, albeit no self-injurious behaviour. Scores from the SCQ and ADI-R suggested that the different behaviour and reactions of this autistic woman sometimes caused difficulties in family life. The GQ-ASC for adults (Brown et al., 2020) and the modified version of the GQ-ASC (Rynkiewicz et al., 2023) demonstrated significant oversensitivity to touch and sound. In addition, the GQ-ASC responses suggested that she attempted to camouflage her autistic traits. Considering the results of the ADOS-2 and ADI-R, the diagnosis of ASD was confirmed.

The AASP results showed the following sensory processing profile: “Low registration” – “Similar to Most People” (35/75 points); “Sensation Seeking” – “Less Than Most People” (40/75 points); “Sensory Sensitivity” – “Much More Than Most People” (52/75); and “Sensation Avoiding” – “Much More Than Most People” (56/75). The patient’s profile indicated increased Sensory Sensitivity with Sensation Avoiding. Low Registration and Sensation Seeking were in the average ranges, with a slight decrease in Sensation Seeking. The highest scores were obtained for auditory and visual processing.

The mean MENQOL results at the initial assessment, T0 (before HRT), were 6.15 for the summary score, and 8 for the vasomotor, 6 for the psychosocial, 5.94 for the physical, and 4.67 for the sexual domain. At the secondary assessment (seven months after HRT introduction) showed 4.59 for the summary score, and 4.67 for the vasomotor, 4.29 for the psychosocial, 5.75 for the physical, and 3.67 for the sexual domain. The greatest decrease in the severity of menopausal symptoms was observed for the vasomotor domain (42%), with accompanying substantial decreases in the psychosocial (28.5%) and sexual (21%) domains, along

with the summary score (25%). The results are shown in Tab. 1.

After HRT, hormonal findings revealed a decrease in follicle-stimulating hormone (FSH) (T0 = 82.7 mIU/mL; T1 = 51.45 mIU/mL) and luteinising hormone (LH) levels (T0 = 42.6 mIU/mL, T1 = 36.2 mIU/mL), along with an increase in oestradiol levels (T0 = 7 pg/mL; T1 = 40.25 pg/mL). The initial cortisol concentration was normal at 360.2 nmol/L, with an appropriate adrenocorticotrophic hormone (ACTH) concentration of 13.3 pg/mL, and there was complete cortisol suppression at 32.7 nmol/L in the 1 g dexamethasone suppression test. Normal values of electrolytes, blood glucose levels, TSH, FT3, and FT4 were observed at both T0 and T1. Breast ultrasound revealed cysts, Ø approx. 4.2 to 11 mm, visible in both breasts. Transvaginal ultrasound and cytological exams were unremarkable. At T0, hyperprolactinaemia was diagnosed with a level of 1,425.25 mU/L (normal range: <557.1 mU/L), and in the metoclopramide (MCP) test, there was no increase in prolactin concentration. The levels of 1,176.4 and 1,033.1 mU/L were suggestive of prolactinoma; therefore, an MRI of the pituitary gland was performed, showing a smooth-bordered oval focus with dimensions of approximately 4.5 × 3 × 4 mm in the anterior part of the frontal lobe, consistent with a microadenoma. Additionally, a fluid focus of approximately 2.5 mm was observed between the upper parts of the pituitary lobes, resembling a Rathke’s pouch cyst. Pharmacological treatment with cabergoline 0.5 mg (½ tablet per week) for hyperprolactinaemia was introduced and was well tolerated.

This autistic woman responded positively to mindfulness meditation and continued the sessions beyond the study. She evaluated her participation in the study positively and was satisfied with the reduction in the severity of menopausal symptoms experienced.

DISCUSSION AND LIMITATIONS

The initial evaluation revealed a high intensity of reported menopausal VMS symptoms, along with increased sensory sensitivity as part of the sensory profile. HRT with accompanying mindfulness therapy alleviated most of the menopausal symptoms experienced by this autistic woman. The greatest improvement was observed in VMS symptoms. These results align with previous findings, where individuals with autism spectrum conditions reported increased menopausal complaints (Groenman et al., 2022), which might be related to sensory sensitivities (Karavidas and de Visser, 2022).

In a study of 28 autistic patients, using the Dutch version of the Menopause Rating Scale, higher psychological and somatic menopausal complaints were observed compared with non-autistic women. These menopausal complaints were also associated with higher levels of depression and autistic traits (Groenman et al., 2022). Hormonal imbalance may be more pronounced in neurodivergent women.

Significant differences in the frequency of steroid-related conditions and symptoms between women with autism spectrum conditions and controls were reported (Pohl et al., 2014). In post-pubertal autistic girls, compared to healthy controls, increased levels of several androgens and glucocorticoids, including androstenediol, testosterone, tetrahydroaldosterone, 18-hydroxycortisol, and cortisol were observed (Gasser et al., 2020). In the present case, no in-depth hormonal analysis was performed, as this would have been more applicable to a larger group of women. However, reports on alterations in cholesterol availability, steroid hormones, and pituitary, adrenal gland, and ovarian function (Gillberg et al., 2017) may suggest and potentially explain differences in the experience of menopause in autism. The additional interplay with sensory processing and modulation can worsen menopausal symptoms and make everyday functioning more difficult.

Autistic individuals who menstruate are often highly sensitive to the monthly hormonal fluctuations associated with periods (Steward et al., 2018). Emerging literature suggests that the hormonal changes of menopause present an emotional rollercoaster of particular significance for these and other neurodivergent populations (Antoniou et al., 2021; Groenman et al., 2022; Karavidas and de Visser, 2022; Moseley et al., 2021, 2020; Rynkiewicz et al., 2024). Quantitative data indicate that autistic individuals experience more severe menopausal symptoms (Groenman et al., 2022), while qualitative reports describe a breakdown in established coping skills. This can lead to loss of employment, deterioration in self-care and independent living skills, and can also be accompanied by dramatic increases in self-harm and suicidal behaviour (Moseley et al., 2021; Rynkiewicz et al., 2024).

Therefore, more work is needed to better support autistic women in discussing menopausal symptoms and co-occurring conditions with primary care providers. These women may not be receiving appropriate management and treatment for both symptoms of menopause or other physical and mental health conditions. In addition, studies on this topic remain scarce. Thus, research – even with small samples or individual cases – is valuable despite its limitations, as it helps expand knowledge about the needs of this population. Our further research will focus on a larger group of autistic patients experiencing menopause.

The ECHO Autism telementoring model is well-positioned to empower community practitioners (Sohl et al., 2022) with enhanced knowledge and confidence in their ability to treat intensive symptomatology and improve health outcomes for autistic women during menopause. This work highlights the need for further research to inform treatment plans, encompassing both HRT and non-pharmacologic approaches that could be offered to autistic women through menopause.

Ethical approval

The study was approved by the UR Bioethical Commission (No. 2024/02/007).

Consent

The patient provided informed consent to participate in the study and to have the results published.

Conflict of interest

The authors declare that they have no competing interests.

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Availability of data and materials

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Community involvement

There was autistic representation within the research team and the global autistic community within ECHO Autism activities.

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Author contribution

Original concept of study; collection, recording and/or compilation of data: AR. Analysis and interpretation of data: AR, EFR. Writing of manuscript: AR, EFR, RM. Critical review of manuscript; final approval of manuscript: AR, EFR, RM, JGT, NH, AL, ABC, KS, DDK.

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