INTELLECTUAL DISABILITY (Y LUNSKY, SECTION EDITOR)



Wellness Efforts for Autistic Women

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Published online: 5 September 2018

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Abstract

Purpose of Review Although awareness of the substantial need for appropriate wellness efforts for adults with autism is growing, females with autism may have been under-identified in the past, and consequently, the research to date is largely based in a male-centric conceptualization of autism. The purpose of this narrative review was to ascertain what is known about wellness efforts for women with autism.

Recent Findings Beyond the shared challenges as experienced by autistic men, autistic women may have unique and differing social, physical, and psychological wellness needs; however, there remains limited research to date in many areas of lifespan wellness concerns.

Summary We emphasize the need for future autism and disability research to acknowledge and account for potential sex and gender impact across areas of study. Further acknowledgement of sex and gender impact will play an important role in improving clinicians' capacity to identify autism in girls and women, which is a foundational component of many wellness efforts.

Keywords Autism · Women · Sex · Gender · Wellness · Health · Quality of life · Female

Although autism spectrum disorder/conditions (ASD/ASC, hereafter "autism") has historically been described as a predominantly male condition, with a widely cited male:female

This article is part of the Topical Collection on Intellectual Disability

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ratio of 4 to 5:1 [1], there is growing awareness that autistic girls and women¹ are often under-identified [2]. Recent population-based studies with active case ascertainment (i.e., screening a population-based sample to identify all cases regardless of whether they have been clinically referred) demonstrate a ratio closer to 3:1 and highlight a sex/gender²-related diagnostic bias toward males in real-life clinical practice [2]. Girls and women often need to demonstrate a greater intensity of autistic features or more concurrent cognitive or behavioral difficulties to receive a diagnosis of autism [3–6], and are more likely to have autism misdiagnosed (e.g., as certain personality disorders) or overshadowed (e.g., by anxiety disorders or eating disorders) [7, 8], diagnosed at a later age [9–12], or overlooked entirely [13].

Encouragingly, researchers and clinicians are increasingly turning their attention towards possible explanations underlying the ascertainment bias against females with autism,

² The term "sex/gender" is used to acknowledge the intersection of sexspecific biological and physiological characteristics with gendered socialization processes [14, 130].



¹ The terms "girls and women" refer to individuals who were assigned as female at birth based on biological sex characteristics, while recognizing that some may not self-identify with this gender. We also recognize that some people prefer "autistic person" or a "person on the (autism) spectrum," rather than a "person with autism." We use these terms interchangeably to encompass all of these ways of description.

including sex and gender influences on the expression of autism. Recent literature reviews synthesizing emergent findings in this area [14, 15] have emphasized a subtler, as well as partly qualitatively different, female presentation from that of the traditionally male-based autism phenotype. Females, on average, score lower than males on conventional, standardized measures of restricted and repetitive behaviors [16–19], though lower scores among girls and women may be somewhat reflective of more gender normative restricted interests that go undetected on current measurement tools (e.g., dolls, animals, makeup) [20-22]. Sex/gender differences in social communication tend to vary by age and developmental level [23–25]; however, autistic girls and women are described as being better able than boys and men to "camouflage" their social-communication difficulties [4, 20, 26, 27]. That is, as a social-coping strategy, they may mask behavior viewed as socially unacceptable and/or imitate others' social behaviors, such as engaging in eye-contact during conversation, mimicking others' facial expressions, and using social scripts, to compensate for difficulties [7, 28-31]. These sex/gender differences may play a role in the under-recognition of autism in girls and women, in addition to contributing to unique social and emotional challenges, such as social isolation and cooccurring mental health concerns (see Panel 1 for a clinical vignette).

As the evidence base for a "female autism phenotype" continues to develop, it is equally, if not more, important to achieve a broader and deeper understanding of autistic women's lived experiences and well-being. For individuals with developmental disabilities, including those with autism, transitioning into adulthood and sustaining well-being as adults is a major challenge, yet has not attracted sufficient research and clinical attention until recently [32]. Most longitudinal studies of adults who are diagnosed with autism in childhood find unsatisfactory outcomes: elevated rates of physical and mental health problems, difficulties achieving independence, and high rates of unemployment and social isolation [33–36]. Those who are diagnosed with autism in adulthood also often experience substantial concurrent mental health challenges (e.g., anxiety, depression) [7, 30, 37]. Although awareness of the substantial need for appropriate supports tailored to the individualized wellness needs of autistic adults is growing, the research to date is largely based in a male-centric conceptualization of autism. As such, the purpose of this review was to ascertain what is known about wellness efforts for women with autism. As exemplified in Panel 1's clinical vignette, we describe wellness as an individual's functioning as a whole—socially, physically, and psychologically. In this sense, wellness is multidimensional and describes a positive state of holistic health and active being, as characterized by a sense of well-being or the broader concept of quality of life [38, 39].



Social Dimensions of Autistic Women's Wellness

Conceptualizations of social wellness often emphasize the individual in relation to others and their environments [40, 41]. In this regard, social wellness encompasses effective communication and healthy relationships with others, as well as active participation in, and contribution to, healthy environments (e.g., home, work, and community involvement). Overall, research to date has largely focused on individual and contextual factors negatively impacting autistic women's social wellness, with little emphasis on positive outcomes or associated wellness promotion efforts.

While many females with autism demonstrate greater sociability and motivation for social interaction than their male peers [42, 43], gendered social demands may impose significant barriers to social wellness across the lifespan. For instance, social-communication challenges inherent to autism may pose greater difficulties for school age girls due to the implicitly understood social intimacy and high language demands that characterize female friendships as compared to those of males; the latter of which are often formed within large groups and tend to be more activity focused [44, 45]. Girls with autism may also experience friendship differently from non-autistic girls, preferring to share companionship rather than intimate reciprocal relationships [46]. Indeed, girls with autism and their parents have described difficulties "fitting in" with their same-sex/gender peers due to dissimilar interests [31, 46, 47]. Moreover, adolescent females in the general population are on average more likely to engage in relational aggression, such as social exclusion, social manipulation, and spreading rumors, than males [48, 49], which may place adolescent autistic girls at a heightened risk for peer victimization due to their difficulties identifying and understanding these more nuanced forms of aggression [7, 43, 44, 50]. Experiences of social exclusion may be further aggravated for autistic girls due to inappropriate school environments (e.g., challenging sensory environments) and insufficient staff understanding [51].

Reduced opportunities for social skills development and experiences of peer rejection during childhood and adolescence may, in turn, predispose women with autism for further interpersonal challenges as adults [7]. Regardless of sex/gender, autistic adults report reduced rates of social participation than their peers without autism [52], with a smaller percentage reporting having close friendships or romantic relationships compared to neurotypical people [34, 53–55]. Relative to autistic men, however, marriage and cohabitation may be more common among autistic women [56], though women often feel less well in sexual relationships [57] and are at a greater risk for financial exploitation and sexual victimization [7, 37, 58–60]. Specifically, autistic women's social naiveté, perceived passivity, and limited sexual knowledge and

experiences, may increase their vulnerability to interpersonal abuse [37, 59].

These interpersonal vulnerabilities may similarly impact other domains of social wellness for women with autism. For example, autistic women have reported incidents of overt mistreatment in the workplace [28] and greater difficulty than autistic men in maintaining employment [61, 62]. Researchers have hypothesized that workplace environments may be less responsive to the social-communication needs of women with autism, which may be perceived as more atypical in women than in men in general [61]. Across social contexts, autistic women's "nonconforming" behavior (in contrast to both neurotypical and gender norms) may be misunderstood in the absence of overt behavioral problems, particularly among those without intellectual disability and/or who are academically able [28]. To this point, recent qualitative research highlights the difficulties many autistic women experience meeting social expectations of gendered stereotypes and fulfilling traditionally feminine gendered roles [7, 37]. Incidentally, and perhaps related in part, survey data show that autistic women are also more likely to report variant gender identities and show less identification to their birth-assigned gender, compared to non-autistic women and to autistic men [54, 63]. In addition, autistic women are also more likely to identify as bisexual, homosexual, asexual, or other sexual orientations than non-autistic women or autistic men [54, 64–67].

While there remains a dearth of research focused on efforts promoting autistic women's social wellness, a large body of research centers on fostering autistic individuals' social skills development [68, 69] However, research so far has not documented sex- and gender-modulated efficacy or effectiveness of social skills interventions for individuals with autism [70]; more examination in this respect, including the consideration of contextual factors that may be impacted by gender [71] is much needed for future clinical trials. For example, autistic girls have described the discomfort and ineffectiveness of attending social skills group programming comprised otherwise of only autistic boys, particularly given the differences between male and female friendships [47]. Responding to this need, initial support exists for a female-focused support program, the Girls Night Out Program, which is based on social learning and cognitive behavioral theories and includes both skill-building and naturalistic peer-support components with typically developing female adolescents [72].

In addition to social skills interventions, there is a substantial need to develop evidence-based interventions and support programs that are responsive to the specific and broader social wellness concerns of autistic girls and women. For instance, autistic women have described a mismatch between their socio-sexual needs with extant school-based sex education, which most often consists solely of reproductive knowledge with little information provided about non-heterosexuality, dating and sexual safety skills [73]. Further work is needed

to determine best practices for sex education among autistic girls and women, such as enabling a deeper understanding of a range of gender identities and sexual orientations, proactive prevention of sexual victimization, and explicit teaching of sexual consent practices [59, 73]. Finally, employment and vocational supports are identified as a significant area of need for autistic males and females alike [32]; however, the limited research to date suggests sex/gender-specific employment supports may be necessary [74]. Whereas men with autism appear to benefit from counseling and guidance services, job search assistance services, and other vocational support services (e.g., occupational licenses, tools, and equipment) aimed at obtaining employment, women with autism may require relatively more supports focused on interpersonal job maintenance skills and burnout prevention [74, 75].

Physical Dimensions of Autistic Women's Wellness

Physical wellness is defined as the ability of the body to function effectively and meet the demands of daily life [76]. It is a state of being demarcated by physical health indicators (e.g., disease risk and status), as well as access to effective medical care. Understanding and promoting physical wellness is particularly important for autistic individuals as many chronic medical conditions occur more frequently in children, adolescents and adults with autism than in the general population, including gastrointestinal and sleep disorders, seizure, atopy, obesity, and diabetes [33, 77–80]. Despite these complex care needs, caregivers or parents of children and adolescents with autism consistently report greater difficulties accessing appropriate health services than parents of youth with other special health care needs [81–83], and autistic adults have similarly identified an abundance of service access barriers, including the general unavailability and unaffordability of appropriate care [84, 85]. Clearly, significant physical health disparities exist for individuals with autism and there is a substantial need for enhanced physical wellness promotion efforts.

The burden of co-occurring conditions may be particularly elevated for women with autism. Autistic women, in general, may be at an increased risk of developing co-occurring health conditions than autistic men [33, 79], in addition to presenting with higher rates of female sex-specific physical health conditions than women without autism [67, 86, 87]. For instance, autistic girls and women experience high rates of early as well as delayed onset of puberty, and menstrual difficulties, including premenstrual syndrome, amenorrhea, dysmenorrhea, and menorrhagia [86, 87]. Menstrual difficulties may also be further compounded by challenges with self-care and resulting hygiene issues [47, 88, 89]. Autistic women particularly noted the negative impact of the cyclical amplification of autism-related challenges related to menstruation, particularly



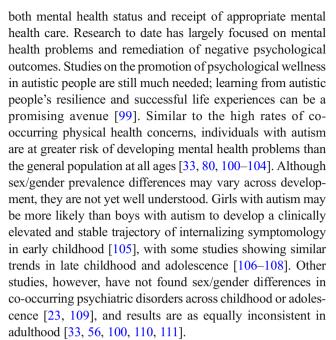
intensified sensory differences and difficulties with regulating emotions and behavior [90]. Although there is a more limited literature base on sex-specific health concerns for women with autism in adulthood, qualitative research details the sensory challenges some autistic women experience during pregnancy and childbirth [91, 92]. However, there remains a dearth of research focused on the physical health during the rest of the reproductive cycle as well as on aging of autistic women.

Overall, women with autism report lower use of preventative health services, higher unmet care needs, and less satisfaction with their healthcare experiences than women without autism [93]. Moreover, autistic women report lower ratings of healthcare self-efficacy and increased healthcare related anxiety than women without autism [92, 93]. Individual and systemic barriers to effective care, which are often multilayered and interlinked, contribute substantially to these difficulties [84]. For example, autistic women report significant challenges with their ability to communicate their care needs to healthcare providers [75, 92], with many autism-related factors that have been similarly identified by men with autism (e.g., verbal communication skills, sensory sensitivities, slow processing speed, and atypical non-verbal communication) [94]. Likewise, health care providers have acknowledged gaps in education and training about autism, as well as time constraints and service reimbursement issues related to time spent providing care for adults with autism [95, 96]. Insufficient understanding of how autism may present in women and autistic women's camouflaging/compensation of social-communication difficulties as well as sensory challenges may further complicate the patient-provider relationship.

In line with these service barriers, physical wellness efforts for women with autism are needed on both individual and system levels. In this regard, recent innovative work has focused on the development and evaluation of an online healthcare toolkit for adults with autism and their primary care providers [97]. More specifically, the AASPIRE Healthcare toolkit (https://autismandhealth.org/) assists adults with autism and/or their supporters in creating a personalized accommodations report, and includes autism-related educational resources for healthcare providers to facilitate patient-provider communication. On a larger systemic level, there is increasing recognition of a considerable need for healthcare models that provide holistic and proactive care for autistic adults [80, 98]. It will be important for future physical wellness targets to not only address the common healthcare concerns encountered by all adults with autism, but also those that may be unique or exacerbated in women with autism.

Psychological Dimensions of Autistic Women's Wellness

Psychological wellness, much like physical wellness, can be conceptualized as a state of positive being, characterized by



It remains unclear what role, if any, misdiagnosis may play in these sex/gender-related inconsistencies. Some women, particularly those without intellectual disability, may not receive an appropriate autism diagnosis due to diagnostic overshadowing (i.e., misattributing autism features to previously diagnosed psychiatric conditions such as anxiety, eating, or personality disorders) [112–114]. However, it is becoming clear that late identification of autism in itself is also frequently associated with negative repercussions for women's psychological wellness [7]. Women diagnosed with autism late in life often recall many stressful or even traumatic life experiences resulting in social alienation and a lack of self-understanding, which may negatively influence self-identity formation prior to receiving their autism diagnoses [7, 37, 115].

While receiving an autism diagnosis later in life is often recounted as a positive reframing experience for many women [7, 37], a pervasive lack of post-diagnostic support services is a significant source of stress [75]. More generally, accessing appropriate mental health care for autistic adults is acknowledged as a systemic health inequity, where service provision does not adequately meet the population's need [116]. In the absence of available and/or appropriate mental health services, autistic adults are disproportionally high users of emergency department psychiatric services [117], and autistic adolescent girls and women use the emergency department at even higher rates than boys and men [118]. Further, when mental health services are accessible, they are often ill equipped to meet autistic adults' care needs [119]. Autistic women have described difficulties with mental health clinicians' apparent unawareness of the nature of autism-related challenges and unwillingness or inability to individualize intervention approaches, which were presumably created for non-autistic individuals [75].



Given the possibility of sex-specific and gendered presentations of psychopathology and responses to pharmacological agents and non-pharmacological therapeutic interventions [120], further research is needed to better understand autistic women's participation in extant psychological wellness efforts and to guide future development of appropriate supports. In the context of a growing body of research about the "female phenotype of autism", a greater understanding of femalecentric and sex/gender-informed aspects of psychological wellness will allow clinicians to better tailor wellness efforts. For instance, evidence-based supports are needed to assist autistic women cope with the negative short-term (e.g., emotional and cognitive exhaustion) and long-term repercussions (e.g., threats to self-perception) of camouflaging autistic characteristics and "autistic burn-out" [2, 7, 37, 121].

Directions for Future Research and Clinical Practice

The current review highlights the marginalized state of autistic girls and women in the research to date, and the ensuant implications on wellness efforts. We offer the following suggestions for future research and clinical practice with the goal of better understanding autistic women's wellness needs and informing future wellness efforts: greater acknowledgement of potential sex and gender impacts across areas of study, increasing capacity to identify autism in girls and women, assuming a lifespan perspective, and adopting a gender lens of analysis.

Underrepresentation of females in biomedical research and across different fields of study is commonplace and severely compromises our fundamental understanding of not only girls and women, but individuals across all sexes and genders [122, 123]. Historical neglect and disregard of sex/gender differences and impact often leads to females receiving care that is largely based in male-centric theoretical, empirical, and clinical knowledge. This is even more the case for autistic females. Males with autism are statistically over-represented in autism intervention studies relative to females, and few studies employ direct sex/gender-based analyses [124, 125]. This would be of little concern if results reliably generalized from males to females; however, it is now well recognized that both sex and gender influence multiple factors and mechanisms across study populations (e.g., gene expression, biology, symptom manifestation, life experience) [118, 126, 127], which imparts potentially deleterious effects on the wellness of underrepresented minorities, such as autistic women. It is imperative for future autism and disability research to acknowledge and account for potential sex and gender impacts across areas of study. Furthermore, given the increased prevalence and variation of non-binary gender and non-heterosexual orientation among autistic individuals [54, 65, 66], increased inclusion of greater sexual and gender diversity is critically needed.

Further acknowledgement of sex and gender impacts will play an important role in improving clinicians' capacity to identify autism in girls and women, which is a key component of many wellness efforts. The impact of receiving an autism diagnosis can be profound and multifaceted for many autistic individuals, particularly in a service system where care provision is often contingent on clinical diagnosis. As the research to date has started to show that standardized assessment instruments demonstrate measurement invariance and equivalent factor structures across males and females [5, 128, 129], it will be important to focus on training efforts to better inform clinicians of the unique behavioral characteristics associated with autism in females, as well as identifying and addressing underlying gender biases in clinical services that might be impacting on ascertainment.

Apart from the diagnostic process for autism, it will be important for future research and service delivery to take a lifespan perspective to fully understand autistic women's experiences and wellness needs. In addition to the abovementioned female-specific social, physical, and psychological concerns that require further study in aging adult females, a greater understanding is needed of the intersection of gender-related stereotypes and roles, and their potential impact on autistic women's wellness across a wide range of social contexts. For instance, little is known about autistic women's experiences of motherhood or their perceptions of parenting and caregiving. Factors that facilitate or hinder autistic women's identity formation, role adjustment, and wellness across various life transition periods (e.g., retirement) similarly remain important areas for future research and clinical improvement.

Finally, future research should adopt a gender lens of analysis, that is, examining female experiences of autism across the lifespan in their own right and in the context of gender as a social-cultural system mediated by power/social relations and structures, and not solely in comparison to male experiences or by a purely biologically oriented (sex-based) perspective. Such an approach allows for a more holistic understanding of autistic women's wellness needs to appropriately direct wellness efforts.

Panel 1: a clinical vignette

VM is a 17-year-old woman who presented to a community psychiatrist with symptoms of anxiety. The community psychiatrist noted "high levels of apathy", some patterns of "disorganized speech", social difficulties, and lack of friendships, and therefore questioned if her presentation represented a "prodromal psychotic state". However,



(continued)

upon reviewing earlier psychiatric assessments, which questioned a diagnosis of "high-functioning Asperger's syndrome", VM was referred to a specialized psychiatric service for an assessment of the autism spectrum.

VM came to the service with her mother. Despite it being an extremely cold winter day, she was dressed in heels, a thin, fashionable, low-cut lace shirt, and a thin jacket, with no makeup and undone hair. Her chief complaint centered on a desire to find an explanation for why, despite her "great social skills" and "love for boys and flirtation", she always had huge difficulties making friends.

VM's developmental history showed that she was always a quiet, introverted girl. She had difficulty with toilet training and continued to have accidents until grade 2 as she "forgot to go to the washroom when she was too interested in learning." She did very well in academics, and teachers never reported any difficulties, except when it came to group work—where she struggled. VM reported never having a friend until grade 7. Her parents, however, did not notice her lack of social activities, secondary to her success at school.

VM was first questioned to have an anxiety disorder in grade 7 when her father passed away. She was thought by others to be "callous" and "unemotional" at the funeral of her father and her mother brought her to a psychiatrist as she noticed she was not using friends to support her and felt that VM needed someone to "talk to." Given VM's unique interpersonal emotional responses, limited friendship, high academic grades, and sensory needs, the psychiatrist questioned whether autism was a correct diagnosis; however, a working diagnosis of "social anxiety disorder" was given following VM's mother's insistence that an autism diagnosis did not feel correct.

VM had her first period at the beginning of grade 6 but it was consistently irregular. She was quite bothered by all the "procedures" involved with taking care of personal hygiene due to this change. By the beginning of grade 8, she was noticed to have increased irritable mood, anxiety, and a sense of fatigue about a week before her menstruation. The following year, she visited a gynecologist who suggested a diagnosis of premenstrual syndrome and recommended VM take "birth control pills" with a brief explanation that such medication would "stabilize your hormones and make you feel better". VM quickly discounted the suggestion and decided to discontinue taking the pills, as she felt she had "no risk of getting pregnant".

In high school, VM developed an intense interest in silk and lace fabrics and started to dress like the celebrities she saw on TV (e.g., "just like Kim Kardashian"). Her fashion choices attracted the attention of her male peers, and for the first time, she developed what she felt were friendships. Encouraged by her male peers, she started attending Comic-Con conferences and noticed that she could develop friendships with the boys she "flirted with". However, these relationships were fleeting as the boys noticed that VM did not spend time with them, instead choosing to "wander around" the conferences alone. Despite her flirtations, she never had a romantic or sexual relationship. She grew confused as she wanted to have friendships, but men often approached her to have romantic relationships. She stated she developed a "fear of men", and at the same time, "was fascinated" by how she could "control them" with the way she dressed and walked. She did not like the feel of others touching her and was repulsed by the idea of sexual intercourse.

Throughout high school, VM's desire for friends increased, but she was met with little success. She felt that she fit in with the "unpopular" girls better, as their academic values were in line with her own; however, they stopped inviting her to events because she talked excessively about fashion magazines and future prom dresses. The "popular" girls excluded her, and she found that their fashion interests were dissimilar to her own. She ran for school council unsuccessfully, despite spending hours researching the meaning of politics and delivering lengthy speeches about the school's history.



In grade 12, she was worried about going to college and returned to psychiatry care. While she was excited for college life where she would "live in a dorm, party and have lots of friends", she revealed that she had never been to a party or had a friendship that lasted more than a few weeks, and was afraid that her future goals would not come true. She wanted to learn how to have conversations with other people and have people "like her" to enable success in university beyond academics.

During clinical assessment, the team interviewed VM and her mother separately. An Autism Diagnostic Observation Schedule, 2nd edition (ADOS-2; Module 4) and an Autism Diagnostic Interview-Revised (ADI-R) were also completed. VM's mother initially denied clear developmental or social difficulties, and indicated that her daughter was a "beautiful, misunderstood girl with lots of anxiety"; upon detailed inquiry in the interview, she proceeded to recognize substantial autism-related characteristics of VM in childhood, although still below the ADI-R diagnostic algorithm cutoffs for an "autism" classification, especially in the domain of restricted and repetitive behavior.

On the ADOS-2, VM initially presented as an outgoing, talkative woman, who developed a quick and easy rapport. However, upon careful analysis, it was clear that she struggled with many activities throughout the assessment. Her eye gaze, though seemingly present during interaction, was hardly direct—she admitted thereafter that she mostly focused on the interviewer's forehead, as this makes her feel "more comfortable". Her speech, which started fluent, gradually became staccato in prosody and extremely loud. She used over-exaggerated and stereotyped emphatic gestures despite having lots of descriptive gestures, which were well modulated with her verbalization. She constantly talked about her "sparkly prom dress" and "loving flirting and the way [she] could get men to do anything". At times, she spontaneously burst into tears and reported that she was crying because she "did not have any friends." VM gave long and pedantic answers to questions about emotions and friendships. She superficially maintained conversations by always responding; however, her responses were marked by a literal understanding (sometimes misunderstanding) of the examiner's statements.

After reviewing all available information, the service provided a confirmed diagnosis of autism spectrum disorder. Upon receiving this diagnosis, VM became tearful. She stated she was torn because the diagnosis described her difficulties in a way she had not heard before; however, she was also sad to have her difficulties confirmed—she had wanted to be told that nothing was "wrong". The service linked VM to an autistic peer-support group. She attended group activities weekly and slowly made friends. VM started reading books by autistic women and resonated with their experiences—she found the "survival guides" provided in the books to be particularly helpful. The service also referred her to a liaison women's health service for her premenstrual syndrome. After detailed explanation, she started to use oral contraceptives and reported having overall more stabilized mood and better spirit.

Funding Part of this work is supported by funding from Women's Xchange (to Meng-Chuan Lai and Yani Hamdani) and the University of Toronto, Department of Psychiatry Excellence Fund (to Meng-Chuan Lai and Stephanie H. Ameis).

Meng-Chuan Lai is additionally supported by the O'Brien Scholars Program within the Child and Youth Mental Health Collaborative at the Centre for Addiction and Mental Health (CAMH) and The Hospital for Sick Children, Toronto, the Academic Scholar Award from the Department of Psychiatry, University of Toronto, the Slaight Family Child and Youth Mental Health Innovation Fund and The Catherine and Maxwell Meighen Foundation (both via CAMH Foundation), and the Province of Ontario Neurodevelopmental Disorders (POND) Network from the Ontario Brain Institute.



Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no competing interests

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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