ADULT WOMEN WITH AND WITHOUT AUTISM SPECTRUM DISORDER: PERSPECTIVES ON THE MENARCHE/MENSTRUATION EXPERIENCE

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For Dr. Kathy DeOrnellas and Dr. Agatha Beins with a multitude of gratitude.

ABSTRACT

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Framed in select MWGS feminist theories, this study's 335 adult women/assigned-female-at-birth responded to the Autism Spectrum Quotient-10 (AQ-10, 2012) and Menstrual Attitude Questionnaire-2nd version (MAQ, 1980a, 1980b). Although without statistical significance ($\alpha = .05$), 29/335 (8.7%) reported high AQ-10 scores (6+) suggesting further ASD testing. The high 8.7 percentage perhaps is a product of AQ-10's screening purpose or underreporting/misdiagnosis due to the female ASD phenotype's camouflaging abilities. Higher AQ-10 (6+) scores had somewhat higher mean MAQ scores for four (Debilitating/Bothersome/Natural/Predictable) and one lower (Denial) MAQ subscales. Exploratory analysis of participants' disclosure of co-occurring gynecological, medical, and mental health concerns highlighted potential impact of such conditions on women's health across ethnicity, age at menarche, and age groups. This study sought to expand MWGS's inclusion of women with disabilities/ASD, empowering all women utilizing a holistic womanist approach. Research on menstruation and autism should replicate this study and devise a female/assigned-female-at-birth-only AQ-10 version.

TABLE OF CONTENTS

Page

DEDICATION ii

ABSTRACT iii

TABLE OF CONTENTS iv

LIST OF TABLES vii

Chapter

I. INTRODUCTION 1

Menarche and Menstruation 3

Autism Spectrum Disorder 4

Menstruation and ASD in Women 5

Definitions 7

Autism Spectrum Disorder 8

Menstruation/Menstrual Cycle 8

Purpose of Study 8

Significance of Study 9

II. REVIEW OF THE LITERATURE 11

Applied MWGS Theories: Feminist Disability Theory, Intersectionality, and Womanism 13

Feminist Disability Theory 13

Intersectionality 14

Womanism 15

Autism Spectrum Disorder 17

Menstruation and Reproductive Issues in Women with ASD 19

Autism Spectrum Quotient-10 (AQ-10) 22

Menstrual Attitude Questionnaire (MAQ)..... 24

Research Question 27

Hypotheses 27

Null Hypothesis 27

Alternative Hypothesis 27

III. METHODOLOGY 29

Research Design..... 29

Population and Sample 29

Procedures 29

Instrumentation 30

Data Analysis 30

IV. RESULTS 33

Demographic Characteristics 33

Participant AQ-10 Responses 36

Menstrual Attitude Questionnaire (MAQ)..... 37

Exploratory Analyses 39

V. DISCUSSION 43

Introduction 43

Results 44

Limitations of the Study..... 46

Contributions to the Field 47

Recommendations for the Field 49

Future Directions 50

REFERENCES 53

APPENDICES

A. SURVEY 64

B. IRB LETTER 75

C. IRB EXTENSION LETTER 77

D. CITI PROGRAM 79

LIST OF TABLES

Table Page

1. Participant Age 34
2. Participant Ethnicity 34
3. Age at Menarche (AMM) by Ethnicity[a] 35
4. AAM by AQ-10 Score 36
5. AQ-10 Scores (*n* = 335) 37
6. MAQ Subscale Means and Standard Deviations by AQ-10 Scores 38
7. Correlations between MAQ Subscales and AQ-10 Scores 39
8. Gynecological Conditions Reported by AQ-10 Scores 40
9. Medical Conditions Reported by AQ-10 Scores[a] 41
10. Mental Health Conditions Reported by AQ-10 Scores 42

CHAPTER I

INTRODUCTION

This U.S.-based study explored whether adult women screened to be positive for autistic traits or autism spectrum disorder (ASD) have attitudes toward menarche and menstruation that display a higher level of concern than adult women screened as lacking sufficient autistic traits or ASD. Inquiry explored whether or not having autistic traits or ASD has an effect on adult women's attitudes toward menstruation. In this study, the gender-related terminology of "female[s]" and "woman/women" is *inclusive of individuals assigned female at birth*. This study's research focus on menarche and menstruation as well as female phenotype autism sought to enhance the inclusion of women with disabilities within Multicultural Women's and Gender Studies (MWGS) research. Of recent discovery is an apparent difference in ASD presentation between males and females. As noted in a study of 14 women aged 22 to 30 diagnosed with ASD in late adolescence or adulthood: "Compared to males (often diagnosed by age 2), females are at an elevated risk of their ASD going undiagnosed: their [emotional, behavioral, social, occupational, and economic] difficulties are frequently mislabeled or missed entirely" (Bargiela, Steward, & Mandy, 2016a, p. 2383).

This study was framed within select applicable MWGS theories. The selected theories were feminist disability theory, intersectionality, and womanism, theories further explored in Chapter 2. Feminist disability theory is rooted in the principles of disability theory espoused by medical sociologist Irving Kenneth Zola (1935–1994), professor at

Brandeis University and survivor of polio exacerbated by a serious automobile accident. An advocate for self-empowerment of fellow people with disabilities and founder of the Society for Disability Studies, Zola asserted that people with disabilities must own their disability[ies] as part, although not all, of their identities (Williams, 1996; Zola, 1993). Feminist disability theory is an extension of Zola's disability theory, espoused by Zola's mentee at Brandeis University, Rosemary Garland-Thomson. Feminist disability theory blends disability with feminist theories. As awareness of disability issues has grown within the past two decades, disability-related issues have found a voice within theories of intersectionality (Saxe, 2017) and potentially womanism. These particular feminist theories share common purposes: gender equality, justice, and empowerment of women to rise above oppression and discrimination. The issues elaborated upon in this study - menstruation or lack thereof, concurrent multiple health and/or disability conditions - are universal concerns of potentially all women. Awareness of disability's universality has arisen especially with the crisis of global aging (Zola, 1989).

Menstruation in particular, historically and globally, has been considered both a woman's disability and a designated taboo used to shame women and to justify limiting and prohibiting a girl/woman's access to and participation in activities. "A taboo is a strong social prohibition or ban relating to any area of human activity or social custom that is sacred and forbidden, based on moral judgment and sometimes even religious beliefs… Menstrual taboos encompass as currently as the 21st century practices in a number of religions" (Kaundal & Thakur, 2011, p. 1). Such practices have included forcing girls and women to live in seclusion, forbidding attendance at religious services, cooking, and engaging in physical intimacy during times of menstruation. Especially,

women of minority ethnicities, different gender and sexual orientations, and women with disabilities have been subject to these restrictions. Garland-Thomson, founder of feminist disability theory, commented: “Indeed, equating femaleness with disability is common, sometimes to denigrate women and sometimes to defend them. Examples abound. Freud delineated femaleness in terms of castration; late 19th century physicians defined menstruation as a disabling and restricting ‘eternal wound’” (2001, p. 7). “Like menstruation, disability often carries stigma” (Wilbur, Torondel, Hameed, Mahon, & Kuper, 2019, p. 3).

Menarche and Menstruation

Menstruation has been a feminist issue for many scholars. One feminist, Randi Koeske (1983), explored a host of reasons why some assumptions about menstruation should be discounted. Research needs to be “reevaluated in a feminist perspective whose potential is to transform menstrual cycle research” (Koeske, 1983, p. 2). In addition, as reported by the Association of Reproductive Health Professionals (ARHP, 2006, pp. 2-3):

> Women do not like having their period. Women have a strong negative attitude orientation toward their period. They simply do not like it. They do not like the symptoms, they do not like that it is something they have to hide, and they do not like the fact that it puts them at a disadvantage relative to men. It is not something they would miss if it went away.

Evidenced by the above quote, menarche and menstruation do not seem to find much favor among women in general. Moreover, for females to adapt to the menstrual cycle and its potential complications in the context of also having to adapt to one or more disabilities and conditions, such as ASD, the consequences arising for everyday life may

be magnified or be more complicated than usual. In addition, low expectations set for the futures of young women with ASD and other disabilities may lead to inadequate preparation for the transition to adulthood and successful, independent self-care, and hygienic care of the menstrual cycle.

Autism Spectrum Disorder

People on the autism spectrum are estimated to account for 1% of the world's population or about 70 million people (University of Cambridge, 2018). Data from 2014 reported an ASD prevalence estimated at 1 in 59 children compared to a previous ratio of 1 in 68. In 2018, ASD ratios were reported as 1 in 37 boys and 1 in 151 girls (U.S. Centers for Disease Control and Prevention, 2018). ASD has been diagnosed primarily among males by a 4:1 male to female ratio. However, recent research suggests ASD may be more common in females than previously thought, even as small as a 2:1 ratio (Szalavitz, 2016). Genetic advances have led to the discovery of a distinct female ASD phenotype (Cridland, Jones, Caputi, & Magee, 2014; Whitehouse, Mayberry, Murray, Hickey, & Sloboda, 2011).

Despite scientific advances, the 4:1 male/female ASD ratio may remain the accepted official ratio for several reasons. The female ASD phenotype tends to escape detection and may lead to misdiagnosis of ASD as other disorders such as ADHD, depression, obsessive-compulsive disorder (OCD), and/or eating disorders (Lai et al., 2011). Following a systematic review of the literature, Loomes, Hull, Polmear, and Mandy (2017) proposed the camouflaging theory as a possible explanation for the ASD 4:1 male to female gender disparity. The camouflaging theory suggests that relatively superior social skills found in females with ASD may mask autistic traits thus leading to

a failure or delay in making an ASD diagnosis or misdiagnosis. Another explanation supported by neuroimaging evidence is the androgyny or "extreme male brain" theory: women with higher levels of the male hormone testosterone may exhibit male autistic traits and behaviors (Jamison, Bishop, Huerta, & Hallady, 2017, p. 773; Szalavitz, 2016; Whitehouse et al., 2011).

Menstruation and ASD in Women

The current study sought to measure attitudes toward menstruation of adult women with and without ASD symptoms. The Menstrual Attitude Questionnaire (MAQ; 2nd version) measured attitudes toward menstruation (Brooks-Gunn & Ruble, 1980a, 1980b). Scores on the Autism Spectrum Quotient-10 survey (AQ-10) screened for presence of autistic traits (University of Cambridge, 2012). Participants also had the opportunity to volunteer comments about any personal experiences with discomforting conditions related or unrelated to menstruation, menarche, and ASD.

Menarche and menstruation affect women across cultures as early as in childhood. However, daily life and menstruation management may be more difficult in the context of having ASD, as well as medical conditions related and unrelated to ASD. During the past century, medical and technological advances have expanded knowledge and have lengthened lifespans, particularly of individuals with disabilities. Once typically relegated to institutions and recipients of third party decision-making, adults with disabilities such as ASD have attempted to seek basic civil rights for self-determination and to make decisions for themselves. Such decisions historically have been delegated to parents, guardians, and caregivers, a practice that has perpetuated and proliferated discriminatory attitudes.

Nonetheless, menstruation for women in general as well as for women with ASD has been associated with serious health problems, including endometriosis, premenstrual syndrome, delayed menarche, dysmenorrhea, amenorrhea, infertility, menstrual pain, polycystic ovary syndrome, and uterine fibroids (Hamilton, Marshall, & Murray, 2011; Whitehouse et al., 2011). Other conditions reported before and during menstruation include irregular bleeding and mood or behavioral changes, the latter more frequently reported by females with ASD (Burke, Kalpakjian, Smith, & Quint, 2010). Burke et al. (2010) studied female adolescents and found that menstruation may be problematic particularly for females with lifelong developmental disabilities such as such as ASD, Down syndrome, and cerebral palsy.

Issues affecting individuals with developmental disabilities may involve dexterity, coordination, sensation, hypersensitivity to touch, and cyclical behavior issues. Thus females with ASD, for example, may have difficulty in mastering the hygienic skills involved in menstruation as well as adaptation to the changes and physical experiences involved in the adolescence to adulthood reproductive transition (American Psychiatric Association [APA], 2013; Burke et al., 2010; Navot, Jorgenson, & Webb, 2017; Turcotte et al., 2015; Van Schalkwyk & Volkmar, 2017). Furthermore, stress is a frequently exhibited trait of ASD and tends to be associated with menstruation issues. Steward, Crane, Roy, Remington, and Pellicano (2018) studied self-reported attitudes toward menstruation among women with ASD, finding that women with ASD do appear to bear additional stress in daily living. While “menses may not be as problematic for [women with ASD] in the context of their other co-morbidities, it may also represent an unrecognized and an undertreated problem” (Hamilton et al., 2011, p. 445).

Steward, Crane, Roy, Remington, & Pellicano (2018) reported that girls with ASD have menarche at a similar age as girls with other developmental disabilities. Steward et al. also cited several reports (including case studies) describing "marked changes linked to menarche and menstruation in autistic girls and women (the majority with additional intellectual disabilities), including cyclical self-injurious behavior…mood symptoms and emotional dysregulation…and an amplification of autistic symptoms (sensory issues and repetitive behaviors)" (2018, p. 1). Research with a homogeneous Australian sample of adolescent females by Whitehouse et al. (2011) independently associated delayed menarche and certain menstruation-related conditions such as dysmenorrhea with certain female genetic autistic trait markers.

Finally, this study in particular provided adult women's first-hand experiential accounts, adding a special perspective to the MWGS literature. Historically, women diagnosed with ASD and other disabilities simply have not been asked for such accounts. Moreover, such individuals were not mentioned in the U.S. Census until 1990. In the past, women and girls with developmental disabilities such as ASD often were accorded one basic option: not having to experience this reproductive transition, through either involuntary sterilization or medical contraception or suppression (e.g., Depo-provera™ or other contraceptives; Dixon, Allen, & Ornstein, 2005).

Definitions

In this study, "female" and "woman/women" terminology is inclusive of individuals assigned as females at birth.

Autism Spectrum Disorder

Autism spectrum disorder is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to the social communication deficits, the diagnosis of ASD requires the presence of restricted, repetitive patterns of behavior, interests, or activities (APA, 2013). For the purposes of this study, ASD includes previous diagnoses of Asperger's Syndrome, high-functioning autism, and pervasive developmental disorder-not otherwise specified (PDD-NOS).

Menstruation/Menstrual Cycle

The menstrual cycle is the hormonal process a woman's body goes through each month to prepare for a possible pregnancy. Regular menstrual periods in the years between puberty and menopause are usually a sign that your body is working normally. Irregular or heavy, painful periods are not normal. Many women also get premenstrual syndrome (PMS) symptoms.

Purpose of Study

The purpose of this study, situated within the framework of feminist disability theory (Garland-Thomson, 2005), feminist intersectionality (Crenshaw, 1989), and womanist theory (Walker, 1983), was to explore via an online survey whether adult women who screened as being potentially positive for ASD displayed more concerned attitudes toward menarche and menstruation than did adult women who were screened as not having potential ASD. For the purposes of this study, only individuals with ASD without significant intellectual impairments were included. Two previously validated instruments,

specifically the MAQ (Brooks-Gunn & Ruble, 1980a, 1980b) and the AQ-10 (Allison, Auyeung, & Baron-Cohen, 2012) were used to determine the participants' attitudes toward menarche and menstruation and to measure the number of autism traits self-reported by participants. A set of demographic questions was used to affirm participants' female gender and ascertain the participants' age, age at menarche, and ethnicity. Participants also were given the opportunity to provide narratives related to their experiences with gynecological, including menstruation, medical conditions, and mental health conditions.

Significance of Study

This study has contributed to the Multicultural Women's and Gender Studies (MWGS) discipline by applying the feminist frames of feminist disability theory (Garland-Thomson, 2001, 2002, 2005, 2012, 2013), intersectionality (Crenshaw, 1989), and the holistic frame of Alice Walker's womanism (1983), to adult women's attitudes toward menstruation. Intersectionality of oppressed identities often has focused on issues of ethnicity, social class, and sexual orientation. This study contributes to the "emerging notion" that "[i]ntersectionality is consistent with the social model of disability and [autistic] neurodiversity.…Being female and disabled results in a qualitatively different experience than that of males with disabilities" (Saxe, 2017, p. 156). Women on the autism spectrum face intersecting oppression and barriers not only as women but also due to their autism. In the same way, womanism's holistic, Universalist approach to diversity may serve as a pathway to overcome oppression targeting the diversities of ethnicity, social class, and/or sexual orientation, as well as, at times, the co-occurring diversity of disabilities such as autism. The study also prioritized application of the sometimes overlooked feminist disability theory (Garland-Thomson, 2005) with respect to ASD in

adult women, as a vital topic for MWGS research on and with females with disabilities. Indeed, females are approximately 49.6% of the world population and women with disabilities, a ratio of 1 in 4 in the U.S. population (U.S. Centers for Disease Control and Prevention, 2019). ASD, a developmental disability, has increased in prevalence (U.S. Centers for Disease Control and Prevention, 2018).

In addition to quantitative assessments, this study provided opportunity for female adult participants (62% responding) to elaborate on multiple co-occurring health issues - gynecological, medical, and mental health - that have affected their lives, in the context of also coping with menstruation and potentially ASD and other disability conditions. These narratives were useful in highlighting the experiences in a female holistic frame: the consideration of a female's entire body and being. Noteworthy in terms of significance is the comment of feminist Susan Wendell (1989, 1996) who in 1985 "awakened" to the need for feminist theoretical research on women with disabilities upon personally incurring a chronic debilitating condition.

This research also was beneficial in its multidisciplinarity, spanning the disciplines of MWGS, disability studies, and allied health fields. The endeavor recognized the increasing need to be proactive in guiding young women with disabilities transitioning to adulthood to build communication skills and to assert self- determination and independent decision-making (Oswald et al., 2018). To assist professionals in fostering self-efficacy for women with ASD, this study was purposefully based on adult females' self-report. This study augmented existing participant self-report research about adult women with ASD regarding menarche and menstruation, following the path of inclusion and self- advocacy of individuals on the autism spectrum set by Steward et al. (2018) and Helmers (2018).

CHAPTER II

REVIEW OF THE LITERATURE

This chapter begins with a review of the relevant scholarly literature in the disciplines of MWGS, ASD, and menstrual issues among women with ASD. This chapter also includes a discussion of the study's two validated instruments: the AQ-10 (Allison et al., 2012) and the MAQ-Version 2 (Brooks-Gunn & Ruble, 1980a, 1980b). The research question and hypotheses follow, transitioning into chapters on methodology, results, and discussion.

This study incorporated principles of three MWGS feminist theories principled by inclusivity – feminist disability, intersectionality, and womanism – to present a one-sample derived snapshot of adult women contending with the feminine biological reality of the menstrual cycle concurrent with potential ASD or autistic traits and other disabilities. As noted in the previous chapter, women historically have been beset by struggles for respect for privacy, equitable reproductive and other civil rights, facing particular discrimination, hardship, and derision regarding their biologically defined menstrual processes. Having a disability and/or menstruation automatically disallowed women's participation in society (Dixon et al., 2005; Garland-Thomson, 2001; Kaundal & Thakur, 2011).

Awaiting medical and technological advances of the 20th century and beyond, women with disabilities' survival rates in times past were lower. Institutionalization meant that their lives often were hidden from society and even family members' view (Larson, 2015). So spurred on by the disability rights movement of the latter 20th century, feminist theories inclusive of women with disabilities followed, emerging in the early

21st century. The intersection of feminist theory inclusive of women with disabilities, particularly ASD, and menstruation has evolved to a new scientific level of inquiry within the past decade to include evidence-based qualitative and quantitative studies as well as practical guides for preparing young women with ASD or autistic traits for menarche. New technology and breakthroughs in genetic research are increasing researchers' capabilities in establishing evidence-based connections between menstrual difficulties and autistic traits. For example, menstruation difficulties among women on the autism spectrum have been associated with delayed menarche as well as painful PMS and primary dysmenorrhea, the most common of menstruation-related disorders also for the population of all women. It also has been theorized that autistic traits may be related to certain menstrual difficulties among women due to excess-androgen (testosterone) (Hamilton et al., 2011; Toy, Hergüner, Arzu, Şimşek, & Hergüner, 2016).

Girls and women with ASD and women with disabilities in general have yet to be accorded full and equitable access to the healthcare decision-making process. The lack of female-focused ASD research (APA, 2013) also has been attributed to the considered authoritative 4:1 male-to-female autism prevalence ratio that has favored research with male participants. However, more recent genetic advances (Whitehouse et al., 2011) offer a potential reason for this gender disparity (Szalavitz, 2016). Apparent genetic links have been found between autistic traits and late menarche, and menstrual abnormalities such as amenorrhea have been associated with (developmental) defects and brain disorders that include ASD (Toy et al., 2016). Do these advances have the potential to promote improved ASD diagnoses for women, reduce misdiagnoses, and perhaps even reduce the stigma of ASD?

With these goals in mind, this research sought to encourage the MWGS discipline to expand its scope of scholarship to promote proactive research, activism, and universal inclusion of women with disabilities such as ASD. Nevertheless, despite the historic absence of MWGS attention to this agenda, in the past two decades, three MWGS theoretical frameworks have become welcoming homes for such research and activism as with women's health issues such as menarche and menstruation: feminist disability studies, intersectionality, and womanist theory.

Applied MWGS Theories: Feminist Disability Theory, Intersectionality, and Womanism

Feminism has been defined as "both an intellectual commitment and a political movement that seeks justice for women and the end of sexism in all forms" (McAfee, 2018, p. 1). Feminism spans a broad spectrum of topics, issues, and interests but with a primary focus on gender identity as the instrument of oppression. A wide range of people, both women and men, of all sexual orientations and abilities has called themselves feminists.

Feminist Disability Theory

The MWGS feminist disability theory (Garland-Thomson, 2001, 2002, 2005. 2011, 2012, 2013) was developed by Garland-Thomson and based on Zola's disability theory (Zola, 1989). This theory complements fellow feminist theories in seeking to understand and destigmatize women's and disability identities and also "to augment and correct traditional feminism, which sometimes ignores, misrepresents, or conflicts with the concerns of women with disabilities" (Garland-Thomson, 2001, pp. 4-5). Elaborating on feminist disability studies' relationship with feminist theory, Garland-Thomson (2013,

p. 2) contends that feminist theories err in dismissing and ignoring disability as a relevant issue of interest, although feminist issues are "intricately entangled with disability."

Intersectionality

Rooted in the barriers that Black women have faced, intersectionality "proposes that an individual who has several oppressed identities will live completely different experiences than someone who shares only one, or some, of those oppressed identities" (Crenshaw, 1989). Saxe (2017, pp. 153-154) stated:

> Intersectionality theory, developed in feminist literature, has been extended to research concerning the experiences of individuals with other identities, including those experiencing disability…. Autistic women represent an important segment of the population of individuals with disabilities …It is only through their involvement within research, policy, and community practices that the barriers currently preventing their full inclusion in society will be dismantled.

Bargiela et al. (2016a, p. 3287) noted that "socialising [sic] as part of large groups was reported as challenging by all of the [14 adult] women interviewed. To cope, many described 'wearing a mask' or taking on a certain 'persona', when in specific social situations." Alternative identities may assist women with ASD that have characteristic atypical behaviors to compensate for lack of social skills and appropriate behavior.

The theory of intersectionality developed from a need to gain a deeper understanding of the barriers and oppression that Black women confront. Examining intersecting identities also has assisted in discovering how best to foster inclusion of marginalized groups such as Black women and people [women] with disabilities (Crenshaw, 1989).

The intersectionality of gender with disability appears appropriate. Respect for women's bodies and women's pursuit of control over their bodies appear to be concepts central to many feminist theories. Disabilities historically have been associated with imperfect, defective, "rejected" bodies. "We idealize the human body.…Idealizing the body prevents everyone…from identifying with loving his/her real body" (Wendell, 1996, p. 112). Some branches of feminism, such as the U.S. feminist movement of the 1970s, have excluded disability as a cultural demographic difference or even a [women's] civil rights matter, awaiting advocacy by parents for their children, and then later, people with disabilities' own self-advocacy for independent living (University of California Berkeley, 2004). Nevertheless, one feminist theory that in its origin has emphasized inclusivity, an additional home for intersectionality and Feminist Disability Studies, is womanism.

Womanism

Alice Walker (1944-) poet, activist, and author of *The Color Purple*, is considered to have originated the term *Womanist* in 1979 in her short story "Coming Apart". Rich in African-American heritage, culture, and spirituality, "womanist is to feminist as purple is to lavender …committed to survival and wholeness of entire people, male *and* female…traditionally a Universalist" (Walker, 1983, p. 19). Although Walker's womanist theory appears to be the most popular, two other prominent womanist strands are 1) the African womanism of Nigerian native Chikwenye Okonjo Ogunyemi (1985); and 2) the Africana womanism of Clenora Hudson-Weems.

In *The Womanist Idea* (2012), Layli Maparyan provides an in-depth comparison of the aforementioned three strands of womanism, placing her own conceptualization of

womanism as closest to the original foundational strand of Alice Walker (1983). In general, womanism as a theory and a descriptor came about as an alternative to feminism and the feminist movement (Ogunyemi, 1985). Multinational womanism, originating in the global experiences of Black women, advanced adoption, and impact of multicultural and multiethnic advocacy and scholarship throughout the MWGS discipline.

In addition to Walker's womanism, Ogunyemi, a native of Nigeria, formulated an Africa-centric African womanism that emphasizes returning to African roots (1985). Clenora Hudson-Weems' Africana womanism represents a third Womanist strand that is closer in theory and spirit to Ogunyemi's Africa womanism than to Walker's womanism.

In summary, Walker's womanism appears to be the most inclusive of the three womanist strands discussed above. It welcomes women of all sexual orientations, ethnicities, and faiths, as well as all men who support the welfare and civil rights of women (Maparyan, 2012). Maparyan's womanism also appears to align well with the principles of feminist disability theory. "Womanism is a social change perspective rooted in Black women's and other women of colors everyday experiences and everyday methods of problem solving in everyday spaces, extended to the problem of ending all forms of oppression for all people, restoring the balance between people and the environment/nature and reconciling human life with the spiritual dimension" (Maparyan, 2012, p. xx). Maparyan also wrote about how womanism may be transformed from 'idea' to 'self-practice' to 'global practice' with focus on self-care and self- healing: practicing womanist tenets first with oneself, then sharing these practices with others. In addition to womanism, over time, feminist approaches and advocacy have recognized more multicultural diversity. Such approaches have included Native American "two-spirit"

non-binary identity culture (Driskill, Finley, Gilley, & Morgensen, 2011) and indigenous Native American feminism (Smith, 2008). Smith (2008) narrated how respect for diversity across communities with fundamental differences may foster positive success through coalition building to solve problems of common interest. For example, South Dakota non-Native farmers and Native farmers joined with each other in "protecting their lands from large corporations and water rights" (Smith, 2008, p. 201) and for prison reform. Yet another feminist, bell hooks (2009), sees the issues of race in the United States as overracialized, envisaging a world where feminists and Womanists together may intersect in their advocacy to end conflicts of race, gender, and class differences.

Nevertheless, respect for and understanding of diversity not only applies to gender, race, national origin, ethnicity, faith, and sexual orientation. For females, disabilities, congenital, acquired, or discovered throughout the lifespan, may affect the ability to cope with menarche and menstruation (Garland-Thomson, 2001).

Autism Spectrum Disorder

Donvan and Zucker (2016) presented a comprehensive history of ASD and a timeline current to 2013, the year of publication of the latest edition of the APA's *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5). ASD originally was diagnosed as schizophrenia and as an intellectual developmental disability. In 1943, American psychiatrist Leo Kanner described 11 cases of what he termed *early infantile autism*, noting distinctions between psychosis and schizophrenia. In 1944, Austrian pediatrician Hans Asperger proposed ASD as *autistic psychopathy* and described a set of young patients who now would be deemed as functioning on the high end of the autism spectrum (Donvan & Zucker, 2016). In 1980, autism was added to the APA's DSM-III

under the terminology *infantile autism*, facilitating differentiation of diagnoses for ASD and schizophrenia. In 1987, the terminology was changed to *Autistic Disorder*. In 1994, the DSM-IV expanded the subcategories of autism to include PDD-NOS and Asperger's syndrome. In the DSM-5, PDD-NOS and Asperger's syndrome were eliminated. The DSM-5's diagnostic criteria for ASD are as follows (APA, 2013):

> Autism spectrum disorder is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to the social communication deficits, the diagnosis of autism spectrum disorder requires the presence of restricted, repetitive patterns of behavior, interests, or activities. Because symptoms change with development and may be masked by compensatory mechanisms, the diagnostic criteria may be met based on historical information, although the current presentation must cause significant impairment. Within the diagnosis of autism spectrum disorder, individual clinical characteristics are noted through the use of specifiers (with or without accompanying intellectual impairment; with or without accompanying structural language impairment; associated with a known medical/genetic or environmental/acquired condition; associated with another neurodevelopmental, mental, or behavioral disorder), as well as specifiers that describe the autistic symptoms (age at first concern; with or without loss of established skills; severity). These specifiers provide clinicians with an opportunity to individualize the diagnosis and communicate a richer clinical description of the affected

individuals. For example, many individuals previously diagnosed with Asperger's disorder would now receive a diagnosis of autism spectrum disorder without language or intellectual impairment. (pp. 31-32)

With regard to cognitive functioning, “31% of children with ASD have an intellectual disability (IQ < 70), 25% are in the borderline range (IQ 71–85), and 44% have IQ scores in the average to above average range (i.e., IQ > 85)” (U.S. Centers for Disease Control and Prevention, 2018. para. 31). As previously noted, only individuals with ASD without significant intellectual impairments potentially were recruited for this study.

The gender ratio of individuals with ASD has been estimated to be 4:1 male to female. However, scientific advances have led to recent discoveries such as genetic markers related to autistic traits that suggest differences in autism spectrum’s presentation in males and females (Szalavitz, 2016). In the past decade, neuroimaging evidence has detected major gender differences in how autism presents in males versus females. ASD in females is now thought to manifest itself as being more characteristic of abilities/behaviors of typical males without autism, for example in socialization, and also associated with testosterone levels. Before genetic advances, autism in girls had more opportunity to remain undetected or misdiagnosed as anxiety disorder or ADHD, leading to underestimation of the number of girls and women who actually may have ASD. As a result, the 4:1 ratio may be closer to a 2:1 ratio (Szalavitz, 2016).

Menstruation and Reproductive Issues in Women with ASD

It appears that MWGS scholarship and advocacy’s inclusion of women with disabilities (i.e., ‘perennial outsiders;’ Begum, 1992) awaited the 21st century for the

scholarly inception of feminist disability theory. Indeed, feminists who envisioned and promoted this inclusive theory often have happened to be women who themselves have disabilities (Garland- Thomson, 2005; Nosek, 2006; Wendell, 1996). Slater, Ágústsdóttir, and Haraldsdóttir (2018) emphasized how different life for a female child with disabilities, particularly intellectual disabilities, can be with regard to transition to adulthood, including menstruation:

> Disability studies researchers…have highlighted that disabled young people are rarely expected to fulfill normative adulthood expectations by, for example, having relationships, going overseas or to college, or having children.… Disabled young people are therefore often denied the questions commonly asked to their non-disabled peers. (p. 413)

Slater et al. (2018) provided the example of a young female infant with multiple disabilities, Ashley X, whose parents, claiming Ashley's best interests in mind, had their daughter sterilized and administered growth attenuation therapy. The procedures were performed without 9-year-old Ashley's consent (in 2007) to prevent and spare their daughter from having to endure puberty, menstruation, and adulthood.

Females with disabilities have a long history of consideration as being or diagnosed as being sterile, regardless of whether or not 1) their disability/disabilities such as ASD and ASD with intellectual disability have any effect on the woman's reproductive system; 2) the girls/women with disabilities have documented normal female reproductive capabilities; or 3) such sterilization is otherwise medically necessary (International Justice Resource Center, 2019). This denial of self-determination to women with disabilities via sterilization may appear beneficent. Menstruation has been associated with a host of potential medical difficulties ranging from severe pain to

ovarian cancer (ARHP, 2005), Menstruation or lack thereof may lead to painful medical abnormalities such as delayed menarche, endometriosis, premenstrual syndrome, irregular menstrual cycles that may involve severe menstrual pain, and an emotional rollercoaster for any woman (ARHP, 2005).

Female transition from adolescence to adulthood involves a set of biological changes designed to enable childbearing during a span of adulthood years. The conclusion of the menstrual cycle and women's childbearing years is met by perimenopause and menopause. These transitions also have medical difficulties of their own, usually coinciding with the aging process. Unfortunately, treatments may be elusive to particularly women with ASD and other disabilities due to lack of access to medical caregivers knowledgeable about and comfortable with the difficulties faced by these women (Christiansen, Ducie, Altman, Khafagy, & Shen, 2013). ASD's characteristic impairments in social interactions, communication, and repetitive behaviors thus may contribute to and magnify menstrual problems. Limited literature indicates that women with ASD tend to experience dysmenorrhea, PMS, and ASD-specific symptoms (Hamilton et al., 2011; Mazur & Chojnowska-Ćwiąkała, 2016; Toy et al., 2016). Obstacles, including those related to self-care and personal hygiene may be exponentially greater for individuals with ASD. This hypothesis is suggested by autism's symptomatology, including lack of behavioral self-regulation, reduced communication skills, and sensorial sensitivities (APA, 2013).

British and Australian researchers compared menstrual experiences of women diagnosed with ASD (n = 123) and without (n = 114). "Although some participants were unsure whether their menstrual experiences were related to being autistic ("I have only

ever been an autistic person having a period!”), many autistic participants felt that their “symptoms worsen dramatically,” often making “life much more difficult to manage during periods” (Steward et al., 2018, p. 4). “Remarkably little is known, however, about the menstrual experiences of women on the autism spectrum. This paucity of research may be unsurprising given the male predominance in autism” (Steward et al., 2018, p. 4). However, Steward et al. noted that their “preliminary study directly elicited, for the first time, autistic people’s views and experiences on menarche and menstruation” (2018, pp. 5-6).

Autism Spectrum Quotient-10 (AQ-10)

The AQ-10 (Allison et al., 2012) is a brief, validated screening instrument used in this study to identify participants with potential symptoms of autism. The AQ-10 was developed in order to be a brief self-report tool to screen for autistic traits in adult individuals. The original Autism Spectrum Quotient (AQ) from which the AQ-10 was derived, is a self-report questionnaire made up of 50 statements that contribute to five domains (social skills, attention to detail, attention switching, communication, and imagination). The AQ uses a Likert scale of four possible responses: *Definitely Agree*, *Slightly Agree*, *Slightly Disagree*, and *Definitely Disagree* (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). The original aim for development of the AQ was to use self-report or report by a significant other to screen individuals for ASD. Adults with ASD typically score significantly higher on the AQ that those without ASD. The AQ uses a cut-off score of 32 and 80% of individuals with ASD had scores equal to or above 32 (Baron-Cohen et al., 2001).

Research conducted on the AQ found that samples from the general population as well as from students at the University of Cambridge did not differ significantly and that intelligence and socioeconomic status did not have a significant effect on scores (Baron-Cohen et al., 2001). Each of the AQ's five subscales reported "moderate to high alpha coefficients" indicating the AQ has "reasonable construct validity" (Baron-Cohen et al., 2001, p. 14). Siebes, Muntjewerff, and Staal (2018) administered the AQ to two samples of majority male adults and spouses across different adult age groups, finding statistical significance across age groups for the Imagination domain.

The AQ-10 applied in this study uses the same Likert scale as the AQ but has only ten statements. The statements were selected from the AQ "by choosing the two items in each of the five domains (Social Skills, Attention to Detail, Attention Switching, Communication, and Imagination) that had the largest difference between cases and controls" (Lundin, Kosidou, & Dalman, 2018, p. 2). Lundin et al. (2018) studied the validity and reliability of a Swedish translation of the AQ-10 for a general population using a Swedish-based sample (n = 44,722 men and women). Although brief versions (i.e., AQ-10 and AQ-23) have been shown in the past to compare well with the 50-item AQ, Lundin et al. (2018) found a lower internal consistency of the AQ-10's scale scores and caution that the AQ-10 should be used only for screening individuals for ASD and not for diagnosing ASD.

For the AQ-10, one point is awarded for *Definitely Agree* or *Slightly Agree* responses on each of items 1, 7, 8, and 10. One point is awarded for *Definitely Disagree* or Slightly *Disagree* on items 2, 3, 4, 5, 6, and 9. An individual's total score of at least 6

out of 10 points suggests that the individual should be referred to a specialist in ASD for a more in-depth assessment (Allison et al., 2012).

Citing Allison et al. (2012), Booth et al. (2013) advocated for "brief screening instruments for ASD that can be used by frontline healthcare professionals to aid in the decision as to whether an individual should be referred for a full diagnostic assessment" (p. 2997). Booth et al. (2013) administered the AQ-10 to a sample of 149 individuals with ASD diagnoses and a control group (n = 134) to test whether the AQ-10 classified the individuals in each group correctly. Using three versions of the AQ (50-item AQ, 28-item AQ-Short, and AQ-10), Booth et al. (2013) found that each version was a good screener for ASD. Booth et al. (2013) concluded that there was little difference in performance between the 50-item AQ and the 10-item AQ-10 and that both were adequate for screening for ASD.

With regard to women with ASD, Murray, Booth, Auyeung, McKenzie, and Kuenssberg (2017, p. 5) found "no significant male bias" in the AQ-10, but suggested that a more female- oriented item be substituted for the AQ-10 item about "liking to collect data" that evidenced a "poor discrimination parameter" among female participants.

Menstrual Attitude Questionnaire (MAQ)

The 33-item MAQ-Version 2 (Brooks-Gunn & Ruble, 1980a, 1980b) was used to compare women participants with and without autistic traits (as determined by AQ-10 scores) in terms of their attitudes toward menarche and menstruation. Brooks-Gunn and Ruble originally developed the MAQ in 1977 "to explore the nature of women's attitudes toward menstruation and to examine possible dimensions or styles of coping related to

menstruation" (1980a, 1980b, pp. 501-502). Three different forms of the MAQ, for women, men, and adolescents, subsequently were constructed using the basic content with only a few minor changes in wording (Gracias, 1983). The MAQ 1980 version reduced the number of items from 46 to 33 based on the factoring structure of the original sample. The authors conceptualized menstrual-related attitudes as multidimensional to ensure that the items on the questionnaire were representative of diverse experiences related to menstruation – both the positive and the negative.

The MAQ scale was constructed to represent five attitude factors:

- Factor I: Menstruation as a Psychologically and Physically Debilitating Event; Factor II: Factor II: Menstruation as a Bothersome Event;
- Factor III: Menstruation as a Natural Event;
- Factor IV: Anticipation and Prediction of the Onset of Menstruation;
- and Factor V: Denial of Menstruation as a Concern.

The MAQ uses a 7-point Likert scale ranging from *Strongly Disagree* to *Strongly Agree* with the option of neither agreeing nor disagreeing.

A study by Hall (1991) using the original MAQ looked at potential associations between locus of control (LOC), attitudes toward menstruation, and perception of distress related to menstruation. Hall (1991) calculated Cronbach's alpha coefficients for each factor and found their range to be from .95 to .97; however, Hall noted that these scores might be inflated since factor analysis techniques can result in inflated coefficients when items are homogeneous.

Participants in Hall's study completed the MAQ, the Multidimensional Health Locus of Control Scale (Wallston, Wallston, & DeVallis, 1978), and the Moos Menstrual

Distress Questionnaire (Moos, 1968). Hall (1991, p. 28) hypothesized that "women who had a more external LOC and who had more negative attitudes toward menstruation, would also rate any menstrual symptoms as more severe." No statistically significant correlations at $\alpha = .05$ were found between any of the subscale items and comparisons of contraceptive use and exercise activity. However, "the MAQ's Debilitating subscale was statistically significantly correlated with all scales of Moos' Menstrual Distress Questionnaire [1968]. This may indicate that only extreme negative attitudes have an effect on one's perception of menstrual distress" (Hall, 1991, pp. 1, 39-40). Hall also called attention to confounding variables evidenced in prior studies.

Reduced from 46 to 33 statements, the 33-item MAQ was designed for adult females and was tested with college women (Brooks, Ruble, & Clark, 1977; Markum, 1985). In Turkey, Kulakaç, Oncel, and Firat (2008) had the MAQ translated into Turkish and evaluated its validity and reliability by comparing the responses of a group of high school students with those of college undergraduates. A confirmatory factor analysis was conducted. Turkish attitudes showed comparative fit index values of 0.776 and 0.797 for the high school and university samples respectively when compared with American samples. Reliability estimates of both scales were satisfactory, being 0.73 for the high school sample and 0.79 for the university sample. Kulakaç et al. (2008) concluded that the MAQ could be useful in assessing the menstrual attitudes of students in Turkish high schools and colleges.

A more recent Turkish study compared attitudes toward menstruation for college athletes with the attitudes of college students who were not athletes (Şahin-Özdemir, 2013). No differences were found regarding age at menarche and both groups were found

to have positive attitudes toward menstruation. A study conducted in Greece by Bargiota, Bonotis, Garryfallos, Messinis, and Angelopolous (2016b) found the MAQ to be reliable and satisfactory for describing the menstrual experiences of Greek women. However, Bargiota et al. (2016b) found that the measure was more appropriate when the findings of each subscale were summed separately. This method, analyzing attitudes separately for each MAQ subscale, was used in the current study.

Research Question

Using the ASD screening instrument AQ-10 (Allison et al., 2012) and the 33-item MAQ - Version 2 (Brooks-Gunn & Ruble, 1980a, 1980b) do adult women whose high (6+) AQ-10 scores suggest additional ASD evaluation is required for a diagnosis of ASD register higher MAQ scores to a statistically significant degree at $\alpha = .05$ than adult women whose low (< 6) AQ10 scores do not suggest ASD?

Hypotheses

Null Hypothesis

As measured by the AQ-10 (Allison et al., 2012), in contrast to adult women not considered as needing additional ASD evaluation (AQ-10 scores < 6), adult women recommended for additional ASD evaluation (AQ-10 scores 6+) do not express more concerned attitudes toward menstruation as measured by statistically significant higher mean scores (α=.05) on the MAQ -version 2; Brooks-Gunn & Ruble, 1980a, 1980b).

Alternative Hypothesis

As measured by the AQ-10 (Allison et al., 2012), in contrast to adult women not considered as needing additional ASD evaluation (AQ-10 scores < 6), adult women suggested for additional ASD evaluation (AQ-10 scores 6+) express more concerned

attitudes toward menstruation as measured by statistically significant higher mean scores ($\alpha = .05$) on the Menstrual Attitude Questionnaire (MAQ-Version 2; Brooks-Gunn & Ruble, 1980a, 1980b).

CHAPTER III

METHODOLOGY

As discussed in previous chapters, this study evaluated attitudes about menarche and menstruation held by adult women with and without symptoms of ASD. As approved by the Texas Woman's University Institutional Review Board, the researcher asked participants to respond to a set of demographic questions and a pair of questionnaires, the AQ-10 (Allison et al., 2012), and the MAQ (Brooks-Gunn & Ruble, 1980a, 1980b) via an online survey. See Appendix B and Appendix C for IRB approval and IRB extension approval letters.

Research Design

Population and Sample

This study recruited a convenience sample of 335 undergraduate college students who self-identified as being female and 18 years of age or older and enrolled at a state university in north Texas. Students in lower level psychology courses at the university are required to participate in research to earn course credit and are given a variety of research opportunities to choose from, including the current study. Participants were primarily nursing and psychology students. None were known by the researcher to have symptoms of ASD or an ASD diagnosis prior to their participation. The participants were assumed to be without significant intellectual impairments due to their status as college students.

Procedures

Data collection began after approval by the university's Institutional Review Board. The survey was posted on the SONA website so that students could access it. After accessing the survey, participants read the consent form and then chose to participate in

the survey or not. Those who elected not to participate were taken to the end of the survey. Individuals who elected to participate were able to skip questions or discontinue their participation at any point in the survey. Most participants who completed the entire survey were able to do so within 30 minutes. Refer to Appendix A for survey.

Instrumentation

This study's instruments included the AQ-10 (Allison et al., 2012), the MAQ (Brooks- Gunn & Ruble, 1980a, 1980b), and a set of demographic questions created by the researchers to collect information about the participants' gender, age, Age at Menarche (AAM), ethnicity, gynecological, physical health, or mental health conditions. Adult women selected the AQ-10 and MAQ instruments for their demonstrated validity and reliability, appropriateness for response, item relevance to this study's research question, and hypotheses and brevity of required participant time.

Data Analysis

The data collected were analyzed using quantitative analyses including descriptive statistics, one-sample *t*-tests, and correlations between scores from the AQ-10 (University of Cambridge, 2018) and MAQ (Brooks et al., 1977). Two-sample independent *t*-tests were used to compare the bifurcated AQ-10 scores – those that did not suggest a potential ASD diagnosis (AQ-10 scores < 6), and those AQ-10 scores that suggested a potential ASD diagnosis (AQ-10 scores ≥ 6). One-tailed tests were used for correlations because the specific alternative hypothesis of this study was one-directional (i.e., that attitudes toward menstruation and menarche would be more extreme than the attitudes expressed by women who did not evidence autistic traits). Correlation was used to test for association, if any, between the dependent AQ-10 score variable and the mean

scores of each of five MAQ independent subscale variables (Brooks- Gunn & Ruble, 1980a, 1980b; Firat, Kulakaç, Öncel, & Akcan, 2009; Karapanou & Papadimitriou, 2010). Dichotomous variables, certain demographics, and the bifurcated AQ-10 scores enabled Chi-Squared analysis. Statistical analyses were conducted in IBM SPSS version 25 (IBM Corp., 2017).

Data inspection and cleaning were conducted to enable importation of the original Microsoft Excel data into SPSS version 25. Select quantitative statistical and qualitative analyses were addressed and transferred to Excel and Microsoft Excel and Word for analysis. Narrative responses to open-ended questions about health concerns were provided by 207 (61.8%) of the 335 participants. It turned out that 117 (56.5%) of these 207 participants offered information on multiple co-occurring conditions: two conditions (n = 51), three conditions (35), four conditions (16), five conditions (9), six conditions (5), and 10 conditions (1). In Excel AQ-10, total individual scores for each of the ten statements were summed according to AQ-10 directions to provide integers with a range of 0 to 10 points for each participant (University of Cambridge, 2018). Participants who scored between 0 and 5 points on the AQ-10 were considered to self- report a few autistic traits, considered typical of a normal population. Participants who scored between 6 and 10 points on the AQ-10 were considered to have reported enough autistic traits to suggest that further ASD testing may result in a diagnosis of ASD.

In keeping with previous analyses of MAQ data (i.e.,Firat et al., 2009; Gunn & Ruble, 1980; Karapanou & Papadimitriou, 2010), each of the five MAQ subscales were treated as independent quantitative variables. Correlations between AQ-10 scores and the five MAQ subscale mean scores were calculated. Demographic factors, especially

ethnicity and AAM were analyzed. Both ethnicity and AAM are factors often measured in relation to menstrual difficulties. Over the years, AAM has occurred at increasingly younger ages, beginning before adolescence; some girls experience AAM as early as 9 years of age.

Because of the categorical dichotomous nature of many of the variables (condition either reported or not), chi-squared tests of independence were used to test for potential statistically significant associations, if any. Chi-squared tests of independence were used to evaluate the likelihood of whether an observed result as compared to a statistically expected result is due to chance or whether there appears to be a relationship (dependence) between any of the categorical variables.

CHAPTER IV

RESULTS

In the past 30 years a great deal of research has been conducted with males diagnosed with ASD; however, because there were significantly fewer females with autism diagnoses, research into the experiences of these young women has been relatively sparse. This study investigated the perceived experiences of young women regarding menarche and menstruation. Specifically, this study determined if there were significant differences in scores on the MAQ for women who had a significant number of autistic traits (AQ-10 $\geq$ 6) when compared to women with fewer autistic traits (AQ-10 < 6).

Demographic Characteristics

Although 402 individuals began the survey, data from only 335 individuals were included in the analysis. This was due to incomplete surveys and participants that did not meet participation criteria (i.e., one student reported being male and three students reported being under 18). Participants ranged in age from 18 to 57 years, with 84.8% of participants being in the age range of 18 to 20 years (*M* = 19.82 years; *SD* = 3.844). There were 34 participants in the 21- to 25-year age range, 10.2% of the total sample (see Table 1).

Table 1

Participant Age

Age Group	Frequency	Percentage
18-20 years	284	84.8
21-25 years	34	10.2
26-30 years	8	2.4
31-57 years	10	3.0
Total	335	100.0

Table 2 demonstrates the ethnic diversity of participants, which is reflective of the university's student body. Caucasian (*n* = 102) and Hispanic (*n* = 99) ethnic categories were the most populated with very similar frequencies, followed by African-American (*n* = 67), Asian/Pacific Islander (*n* = 52), Native American (5) and 10 participants that listed their ethnicity as "Other."

Table 2

Participant Ethnicity

Ethnicity	Frequency	Percentage
Caucasian	102	30.4
Hispanic	99	29.6
African-American	67	20.0
Asian/Pacific Islander	52	15.5
Native American	5	1.5
Other	10	3.0
Total	335	100.0

The frequency of the participants' AAM by ethnicity is reported in Table 3. Biro et al. reported that the median AAM has been estimated to be 12.25 years for a U. S. sample (2018). In this study, 27.5% of participants reported an AAM of 12 years of age

while 23.9% reported being 13 at AAM. African American and Asian/Pacific Islander women (2.4%) reported the youngest AAM (i.e., 9 years).

In addition to ethnic differences in AAM, research has shown an association between delayed AAM and ASD (Hergüner & Hergüner, 2015; Steward et al., 2018; Whitehouse et al., 2011). Table 4 compares AAM (*M* = 12.35) with AQ-10 scores. In this study, higher AQ-10 scores did not yield significantly higher AAM values. Ten of the 29 participants (34.5%) with high (6+) AQ 10 scores reported an AAM of 13 years and above compared with 44.4% of participants with low (< 6) AQ-10 scores. These numbers fail to support the findings of Hergüner and Hergüner (2015), Steward et al. (2018), and Whitehouse et al. (2011) but may be due to the relatively small sample size of women with high AQ-10 scores.

Table 3

Age at Menarche (AMM) by Ethnicity[a]

AAM	Cauc	Hisp	AA	A /PI	NAm	Other	Total	Percent
9 years	0	0	2	2	0	0	4	1.2%
10 years	11	7	11	3	1	2	35	10.5%
11 years	11	22	11	10	0	3	57	14.1%
12 years	34	23	14	16	1	4	92	27.5%
13 years	23	27	19	10	1	0	80	24.0%
14 years	14	10	5	8	2	0	39	11.7%
15 years	5	5	4	1	0	1	16	4.8%
16 years	2	3	1	2	0	0	8	2.4%
17 years	1	1	0	0	0	0	2	0.3%
18+ years	0	1	0	0	0	1	1	0.9%
Total	101	99	67	52	5	11	334	97.1%

Note: [a]*n* = 334, Cauc = Caucasian, Hisp = Hispanic, AA = African American, NAm = Native American. Percentage does not equal 100% due to rounding

Table 4

AAM by AQ-10 Score

AAM	AQ-10 Score Frequency			
	< 6	Percentage	≥6	Percentage
9 years	4	1.3%	0	0%
10 years	32	10.5%	3	10.3%
11 years	55	18%	2	6.9%
12 years	78	25.5%	14	48.3%
13 years	75	24.5%	5	17.2%
14 years	38	12.4%	1	3.4%
15 years	13	4.2%	3	10.3%
16 years	8	2.6%	0	3.4%
17+ years	2	0.7%	1	3.4%
Totals	306	100%	29	100%

Participant AQ-10 Responses

Participants' AQ-10 scores were used to assess the frequency of ASD symptoms in the sample. The AQ-10 consists of 10 statements to which a respondent self-reports agreement or disagreement. Each item is scored as either "1" or "0." Low scores (i.e., below 6) indicate the individual did not report enough symptoms of ASD to be considered for further evaluation. High scores (i.e., above 5) indicate the individual reported symptoms that are indicative of ASD thus indicating that she should be considered for further ASD diagnostic evaluation (University of Cambridge, 2012). The results of this study found that 29 or 8.7% of all participants had an AQ- 10 score of 6.0 or above. A total of 306 or 91.3% of the total sample had scores from 0 to 5. Table 5 depicts the frequency of participants' AQ-10 scores.

Table 5

AQ-10 Scores (n = 335)

	AQ-10 Score												
	0	1	2	3	4	5	6	7	8	9	10	Participants	Percent
AQ-10 <6	12	41	60	83	66	47						306	91.34%
AQ-10 ≥6							20	6	2	1	0	29	8.66%

Menstrual Attitude Questionnaire (MAQ)

The MAQ version utilized for this study consists of 33 items related to attitudes toward menstruation partitioned into five subscales (Brooks-Gunn & Ruble, 1980a, 1980b; Firat et al., 2009). Two subscales portray menstruation in a negative light. In these subscales, menstruation is perceived as either menstruation as a psychologically and physically debilitating event" (variable name "Debilitating") (12 items) or "menstruation as a bothersome event" (variable name "Bothersome") (6 items). Two subscales comment more positively on menstruation as "menstruation as a natural event" (variable name "Natural") (4 items) and "anticipation and prediction of the onset of menstruation" (variable name "Predictable") (4 items). The fifth subscale is "denial of menstruation as a concern" (variable name "Denial") (7 items). Low scores on the Denial subscale are indicative of relatively more attitudinal concern about menstruation.

It turned out that both the two negatively phrased Debilitating and Bothersome MAQ subscales and the more positively phrased Natural and Predictable subscales yielded relatively similar and high mean scores – indicating agreement with these subscales' statements. However, the Denial subscale yielded low MAQ means – indicating disagreement with MAQ Denial statements indicative of a tendency to have concerned attitudes toward menstruation. Table 6 compares means and standard deviation

values for the five MAQ subscales for each of the two AQ-10 groups. A two-sample independent *t*-test was conducted to compare the differences between MAQ mean scores for the AQ-10 < 6 (n = 306) and AQ-10 ≥ 6 (n = 29) groups. The subscale that came closest to having a statistically significant difference at α = .05 was the Predictable subscale (α = .06). For individuals with high AQ-10 scores (≥ 6), of the five MAQ subscales, the Predictable subscale yielded the highest mean score (M = 7.014) with the second highest mean evidenced for the Natural subscale (M = 6.937). The means for the Denial subscale yielded the lowest values for each group (M = 3.081 for low AQ-10 group and M = 3.147 for high AQ-10 group). For each MAQ subscale, the AQ-10 ≥ 6 group had a higher score than the other group. This could indicate that individuals with ASD traits are more sensitive to all aspects of the menstrual process, thus supporting the conclusions of Hamilton et al. (2011) and Szalavitz (2016; see Table 6).

Table 6

MAQ Subscale Means and Standard Deviations by AQ-10 Scores

MAQ Subscale	AQ-10 < 6[a] *M* (SD)	AQ-10 ≥ 6[b] *M* (SD)	Mean Difference[c]	Significance[c]
Debilitating	5.366 (0.6198)	5.425 (0.5855)	-.0597	.625
Bothersome	6.014 (0.7634)	6.202 (0.7824)	-.1880	.207
Natural	6.874 (0.9618)	6.937 (0.9281)	-.0631	.735
Predictable	6.705 (0.8557)	7.014 (0.7008)	-.3093	.060
Denial	3.081 (0.8441)	3.147 (0.9162)	-.0659	.690

Note. [a]n = 306, [b]n = 29 [c]2-Sample Independent *t*-test α = .05 Equality of Means

Table 7 provides one-tailed Pearson correlations, showing some statistically significant correlations at either α = .01 or at α = .05 between certain of the five MAQ subscales (i.e., Natural/Predictable, Natural/Denial, Predictable/Denial, Natural/Debilitating, Natural/Bothersome, and Debilitating/Bothersome), but not between Denial and either Debilitating or Bothersome. Statistical significance also was not found

between AQ-10 scores and any MAQ subscale. The ASD-suggested group (AQ-10 ≥ 6; n = 29) appeared to have higher percentages for each of the five MAQ subscales – except Denial - than did the ASD-not suggested AQ-10 < 6; *n* = 306 group.

Table 7

Correlations between MAQ Subscales and AQ-10 Scores

	1	2	3	4	5	6	7
Debilitating	--	.482**	.215**	.186**	.055	.024	.150
Bothersome	.482**	--	.268**	.228**	.072	-.020	-.137
Natural	.215*	.268**	--	.352**	.164**	-.088	-.040
Predictable	.186**	.228**	.352**	--	.120**	.027	-.184
Denial	.055	.072	.164**	.120*	--	-.026	.039
AQ-10 <6	.024	-.020	-.088	.027	-.026	--	-1.00
AQ-10 ≥6	.150	-.137	-.040	-.184	.039	-1.00	--

Note. *p* < .01* *p* < .05** AQ-10 < 6 *n* = 335 (Pearson correlation) AQ-10 ≥ 6 *n* = 29 (Kendall-tau)

Exploratory Analyses

To learn more about the women who chose to participate in this study, items were formulated for which participants checked any condition that applied to them. Their responses provided perspective and context to their overall health including female gynecological/ menstrual, medical, and mental health issues that may be concurrent with a possible ASD diagnosis. Table 8 lists eight gynecological, including menstrual, conditions reported by participants. Table 9 lists 12 self-disclosed medical conditions. Table 10 lists nine mental health conditions, including ASD.

When asked about gynecological concerns, approximately 75% of participants self- disclosed multiple, possibly debilitating, conditions and provided detailed narratives about their medical struggles/diagnoses, menstrual concerns, and birth control use. Birth control, also prescribed as a treatment for other gynecological issues, had the highest reported prevalence for both the group with AQ-10 < 6 scores and for the AQ-10 ≥ 6

group (*M* = 40.8%, *M* = 31.03% respectively). A higher percentage of cramping was reported by the AQ-10 ≥ 6 group (*M* = 10.34%) compared to the AQ-10 < 6 group (*M* = 8.82%) and more participants with high AQ-10 scores acknowledged weight gain (*M* = 6.90% versus *M* = 0.98%) than did participants with low AQ-10 scores. However, except for birth control use, weight gain, and cramping, the differences between the two groups appear negligible due to the small number of participants in the high AQ-10 scores group (see Table 8).

Participants listed a number of medical conditions with being overweight the major concern for both groups (*n* = 306: *M* = 16.34%; *n* = 29: *M* = 10.34%). However, larger percentages of respondents with high AQ-10 scores reported migraines (*M* = 10.34% versus *M* = 9.8%), insomnia (*M* = 3.45% versus *M* = 2.29%), and skin conditions (*M* = 3.45% versus *M* = 1.96%); however, as previously noted, the higher AQ-10 group was quite small and the differences may be negligible (see Table 9).

Table 8

Gynecological Conditions Reported by AQ-10 Scores

Condition	AQ-10 < 6	Percentage	AQ-10 ≥ 6	Percentage
Birth Control Use	125	40.8%	9	31.03%
Cramps	27	8.82%	3	10.34%
Ovarian cysts	20	6.54%	1	3.45%
Heavy flow	16	5.23%	1	3.45%
Irregular menses	12	3.92%	0	0%
Dysmenorrhea	4	1.31%	0	0%
Menstrual pain	4	1.31%	0	0%
Weight gain	3	0.98%	2	6.90%
Other	4	1.31%	1	3.45%
Totals	246	78.14%	21	72.41%

Table 9

Medical Conditions Reported by AQ-10 Scores[a]

Condition	AQ-10 <6	Percentage	AQ-10 ≥ 6	Percentage
Overweight	50	16.34%	3	10.34%
Migraines	30	9.80%	3	10.34%
Underweight	21	6.86%	0	0.00%
Gastrointestinal	15	4.58%	0	0.00%
Insomnia	7	2.29%	1	3.45%
Acne/Eczema	6	1.96%	1	3.45%
Blood disorders	5	1.63%	0	0.00%
Asthma	4	1.31%	0	0.00%
Diabetes	4	1.31%	0	0.00%
Fatigue	2	0.65%	1	3.45%
Miscellaneous	8	2.61%	1	3.45%
Totals	52	49.67%	10	34.48%

Table 10 illustrates the frequency with which mental health conditions were found to co- occur with gynecological and medical conditions. The frequencies reported for bipolar disorder, PTSD, and OCD reveal higher percentages for the women with high AQ-10 scores; however, due to the low numbers of women reporting these disorders, this may represent an inflation of the scores. Although not statistically significant at $\alpha = .05$, these results may suggest heightened sensitivity of adult women with ASD to both menstrual difficulties and to some mental health conditions. In addition, interestingly, the 20 respondents self-reporting as having been diagnosed with ASD did not score high enough on the AQ-10 to be included with the AQ-10 ≥ 6 ($n = 29$) group. All 20 in the $n = 306$ group had AQ-10 scores of < 6. In contrast, none of the participants who scored high on the AQ-10 reported having a diagnosis of ASD.

Table 10

Mental Health Conditions Reported by AQ-10 Scores

Condition	AQ-10 < 6	Percentage	AQ-10 ≥ 6	Percentage
Depression	53	17.34%	5	17.24%
Anxiety	28	9.10%	2	6.90%
Autism	20	6.54%	0	0.00%
Eating Disorders	10	3.27%	1	3.45%
PTSD	9	2.94%	2	6.90%
Bipolar Disorder	9	2.94%	2	6.90%
ADHD	6	1.96%	1	3.45%
OCD	6	1.96%	4	13.80%
Personality Disorder	4	1.31%	0	0.00%
Totals	145	47.49%	18	62.10%

PTSD = Posttraumatic Stress Disorder, ADHD = Attention-Deficit/Hyperactivity Disorder, OCD = Obsessive Compulsive Disorder

CHAPTER V

DISCUSSION

Introduction

Among the womanist theories discussed in Chapter 2, Walker's womanism (1983) was chosen as the womanist theory that appeared to have the greatest potential relevance for this study. Walker's Universalist perspective of an all-inclusive diversity supportive of the health and well-being of all women, including women with disabilities, mirrors the theme of the universality of disability because, according to Zola, "What we need are more universal policies that recognize that the entire population is "at risk" for the concomitants of chronic illness and disability" (1989, p. 6). Feminist disability theory and intersectionality encompass and directly focus on this study's particular population of interest – adult women with ASD and other disabling, including menstruation-related, conditions - and their struggles with societal oppression, discrimination, violence, conflicting identities, and lack of societal recognition as being a sexual human being.

Regarding the online survey, participants were primarily psychology and nursing students who earned research credit for participation upon completion of the survey. Data were only collected from participants who self-identified as female and age 18 years or older. None of the participants were previously identified as having ASD or autistic traits by the researcher prior to their participation. All participants were assumed to have unimpaired cognitive functioning due to their academic status. So women with Level-1

severe autism potentially including intellectual disabilities (APA, 5th ed., 2013 criteria) were not expected to be among sampled participants.

The online survey was hosted on the SONA system. After obtaining informed consent, participants were asked to voluntarily respond to demographic questions (i.e., age, ethnicity, Age at Menarche), to report any previous diagnosis of a form of ASD (including ASD, Asperger's syndrome, high functioning autism, or PDD-NOS), and to list any gynecological, medical, or mental health conditions incurred.

Participants also were given the opportunity to provide narrative responses. Two instruments were utilized to test for a potential association between ASD and more troubling attitudes toward or concerns about menstruation: the AQ-10, a 10-item validated screening tool for ASD (University of Cambridge, 2012), and the validated 33-item MAQ, which measures attitudes toward menstruation (Brooks-Gunn, 1980a, 1980b). Previous research has shown an association between ASD and AAM, elevated PMS, depression, OCD, and dysmenorrhea (Hamilton et al., 2011).

Results

To recall, participants' self-reported responses to ASD screening (AQ-10), attitudes toward menstruation (MAQ) and co-occurring conditions were collected from a convenience sample of adult female college students (n = 335). This study hypothesized that, as measured by the AQ-10 and MAQ instruments, female adults whose AQ-10 scores were 6 or above would evidence more troubling attitudes or concerns related to the menstrual process than would participants with AQ-10 scores under 6. This evaluation was measured by comparing mean results for the five MAQ subscales. The MAQ subscales categorize the 33 MAQ attitudinal statements toward menstruation as either 1)

a Psychologically and Physically Debilitating Event, 2) a Bothersome Event, 3) a Natural Event, 4) a Predictable Event, or 5) Denial: an event not of concern. Results were calculated for each of the two AQ-10 groups (AQ-10 < 6 and AQ- 10 ≥ 6). Results of a two-sample independent t-test showed a significant difference in the AQ-10 < 6 and AQ-10 ≥ 6 means for the MAQ Anticipation and Prediction of the Onset of Menstruation subscale, but only at $\alpha = .10$. The other subscale means were slightly but not statistically higher for those with the higher AQ-10 scores. The highest mean value was for the Anticipation and Prediction subscale ($M = 7.014$) for the AQ-10 ≥ 6 group of participants. Coincidentally, needing predictability and maintaining a predictable routine happen to be traits of individuals with ASD. The lowest mean values for both AQ-10 groups were for the Denial of Menstruation as a Concern ($M = 3.081, 3.147$), suggesting that menstruation may tend to present concerns for adult women. The results of this research study did not provide sufficient significance to reject the null hypothesis (at $\alpha = .05$); however, the results provided insight into a number of relevant issues and avenues for further research.

Results also appeared to reflect themes found in the MWGS conceptual frameworks of feminist disability theory, intersectionality, and womanism in which the research was conducted. Even relying on one convenience sample, the study recruited an ethnic diversity of adult women who appeared comfortable and sufficiently empowered to [anonymously] disclose sensitive medical information, especially in the narratives. It turned out that 117 of the 335 women disclosed multiple conditions, raising the issue of how participants were affected by the conditions' potential interactions. Responses were well occupied: missing data were minimal, pointing to a suggested value of MWGS

researchers using the AQ-10 and MAQ with adult women, perhaps "fine-tuning" the AQ-10 to be for women.

Limitations of the Study

A number of limitations and confounding issues arose in this research. Firstly, recruitment was limited to one convenience sample located at one university in Texas. Consequently, results were not generalizable. Despite the sample being ethnically diverse (see Table 2 above), participants consisted of only predominately undergraduate college-age women (ages 18–57) who were primarily nursing and psychology majors. In addition, the study's online survey was accessible only to those students recruited at this college. Moreover, the sample was limited to adult women who were able to individually read, comprehend, and complete the online survey instrument. This requirement limited participation to adult women with potentially "high-functioning" ASD rather than women representative of the entire ASD spectrum that includes women who have ASD accompanied by intellectual disabilities.

This research, due to its subject matter, was limited to consenting self-identifying adult females. ASD male to female ratios or speculation that either this ratio has been narrowed from 4:1 to 3:1 or even 2:1 was not addressed (Szalavitz, 2016). In addition, validation of self-reported ASD diagnoses offered by 20 of the 335 participants was not possible so that analysis excluded these data.

Loomes et al. (2017) reviewed the literature on female autism prevalence using the DSM-5 (APA, 2013) criteria. However, none of the studies reviewed had utilized the 2013-published DSM-5 criteria: criteria that introduced major changes to ASD definitions and discarded the Asperger's and PDD-NOS categories (Hyman, 2013). Self-

reporting ASD-related survey respondents, such as those in the current study, may be unclear as to the DSM source of their ASD diagnoses. That aside, Loomes, et al. (2017) noted that individuals diagnosed with ASD under DSM-IV criteria would likely also be diagnosed with ASD under DSM-5. A 2017 study by Jamison et al. (2017, p. 776) used DSM-5 criteria to have 106 ASD clinicians compare their perceptions of male versus female ASD diagnostic methods and to compare gender differences in the nature and severity of ASD traits. Most participants in Jamison et al.'s 2017 study reported not to use different methodologies or instruments to diagnose autism in males and females. At the same time, 36% of the clinicians reported that when diagnosing females, they rely 'more' on clinical impressions based on observational assessments. Participants also took note of gender variability in presence and severity of autistic traits during life's different developmental stages.

Contributions to the Field

This study attempted to contribute to the field of MWGS by expanding the awareness and inclusiveness of MWGS and feminist theories to encompass and give voice to women with ASD, autistic traits, and other disabilities. Feminist issues - the menstrual cycle and women's reproductive health – were prioritized within the context of women having to cope with ASD and other disabilities. The importance of this research was heightened by the effects that ASD may have on menstrual issues particularly when diagnosis of ASD in females may be delayed until adulthood, misdiagnosed, or not diagnosed at all (Bargiela et al., 2016a). Especially with respect to menstruation and reproductive health, the MWGS discipline must champion the self-determination of women with disabilities, including ASD, as MWGS attempts to do for all other women.

Matching the focus of Womanist theory, participant narratives in particular, framed the research as a holistic endeavor, involving not only ASD and menstruation-related conditions, but also multiple co-occurring medical and mental health issues. Disability and people with disabilities were noticeably initially absent as topics of feminist discussion until the third wave of feminist literature (post circa 1990). To recall commentary by Rosemarie Garland-Thomson (2001, pp. 4-5): "feminist theories all too often do not recognize disability in their litanies of identities that inflect the category of woman." Feminist disability studies awaited feminist authors, both men and women with personal experience of disability to initiate the field of feminist disability studies (Garland-Thomson, 2001; Wendell, 1989). Matching a theme of feminist intersectionality, this study also has helped to fill a historical gap in MWGS literature, the exclusion of adult women with disabilities: intersecting coping with the complex identities of being an adult woman coping with menstrual difficulties and being an adult woman with a disability or multiple disabilities, particularly ASD, and coping with menstruation. Moreover, the study integrated discussion about the roles played by ethnic diversity and AAM. The Exploratory Analysis (Chapter 4) added the issue of women also having potentially confounding co-occurring gynecological, medical, and mental health conditions. Despite the above noted limitations, this study potentially appears to have made a useful contribution to research on autism of the female phenotype and the multiple medical issues, particularly related to menstruation, that women face during their adult lives. Examining the narratives, it turned out that 117 of the 335 participants self-reported as having multiple co-occurring conditions: two (51 participants), three (34) four (16), five (9), six (5), and even 10 (1) conditions. Treatment of adults with multiple

conditions or polytrauma has come to the forefront also as a result of the most recent wars (Warden, 2006). The participant listing ten co-occurring conditions happened to be among the four women in this study who self-identified in narratives as being military veterans with multiple service-related, including menstruation-related conditions.

Recommendations for the Field

Replication of this study with expanded evidence-based sampling is suggested. The field of MWGS, in partnership with other disciplines, needs to exhibit the "profound inclusivity" cited by Sadr (2018, p. 12) in proactively welcoming into feminist activism and research the diverse multicultural population of women with disabilities throughout the lifespan. The frame of intersectionality is recommended for considering the presence and interaction of multiple disabilities, also concurrent with other medical and reproductive, and mental health issues. The disability demographic is universal across ethnicities, cultures, genders, and sexual orientations. One may incur a disability at any time and at any age, and, as with female ASD, potentially discover a congenital condition later in life. Reflecting study results, menstruation sometimes may be debilitating and bothersome (as recognized by MAQ subscales) and with co-occurring conditions potentially disabling.

In terms of ASD research, continued emphasis on genetic research and ASD female phenotype research needs to be inclusive of the effects of and association with the menstrual cycle. An important aim also is accurate and timely diagnosis of the apparently considerable number of undiagnosed or misdiagnosed females with ASD (Szalavitz, 2016). Menstruation and reproductive health play vital roles in females' lives. Early timely preparation and learning about the menarche transition especially for young girls

with disabilities, including ASD, are recommended. Consideration needs to be given as to the most medically safe, practical solutions that work successfully for each individual. Recommended also is development of female-only validated [versions of] instruments, such as the AQ-10 and MAQ to screen for women's ASD and related menstrual issues, respectively. Promoting, providing, and preserving the civil rights of women with disabilities are essential.

Future Directions

Directions for future research have arisen not only from results of this study, but also increased advocacy and scholarship by women with disabilities and feminist disability theory scholars, but also from genetic advances in the last decade regarding differentiating male and female ASD phenotypes. The research potentially enables more accurate assessment of female ASD prevalence. Genetic markers have been discovered that contribute to both ASD and menstrual difficulties such as delayed menarche. The androgyny theory hypothesizes that females' autistic traits may originate in females' elevated levels of the male testosterone hormone (Whitehouse et al., 2011).

The 8.7% female ASD rate reported in this research versus the estimated 6.6% rate for ASD diagnoses alludes to two current theories that seek to explain the underreporting of female ASD diagnoses. The ASD-related camouflaging theory (Loomes et al., 2017; Ratto et al., 2018) hypothesizes that females, as opposed to males with ASD, appear to be able to mask or camouflage autistic traits due to better socialization skills and fewer repetitive behaviors. As a result, although children may be diagnosed with ASD as early as 2 or 3 years of age, ASD diagnoses for females may be delayed until adulthood. Moreover, for women, ASD may be misdiagnosed as perhaps

depression, bipolar disorder, or anxiety disorder (Ratto et al., 2018; Sohn, 2019). Ratto et al. (2018) was reported to conduct the first study that explored sex differences in both adaptive behavior and daily social skills among school-age children diagnosed with ASD without co-occurring intellectual disability (ID). This current study also reflected exclusion of participants with co-occurring ID by limiting recruitment to female adult college students. Investigation also may focus on understanding issues of aging throughout the life span and menstrual cycle as a female adult in the context of coping with ASD and other disabilities.

Another useful endeavor prompted by increased research on ASD among females may be testing whether the current ASD diagnostic tools accurately identify the ASD female phenotype and its potential association with menstruation. In previous research, Ratto et al. (2008) questioned the ability of their study's standardized tests (Autism Diagnostic Observation Schedule and Autism Diagnostic Interview-Revised) to detect ASD gender differences. Is the AQ-10 or the 50-item full AQ able to detect such differences, moreover, using DSM-5 ASD criteria? In addition to the theory of females being able to camouflage their ASD (Bargiela et al., 2016a), may there be additional explanations for the tendency for females not to present with ASD until later in life – post-childhood – and the failure of adult women to have such assessment?

In the United States, under IDEA public education law since 1990 (P.L. 101-476; P.L 108-446 as amended), ASD has been among the conditions regularly tested for among pre-school and school age children. However, IDEA provides services for eligible children and young adults only up to high school graduation or in the alternative, age 22. Afterwards, as an adult, college age women must locate their own healthcare and ASD

diagnosticians. Does this concern factor into adult women's [lack of] ASD diagnosis? Researchers have expressed their concerns that there appears to be a group of females who may not be receiving assessment for ASD (Bargiela et al., 2016a; Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015). In agreement with prior research, there appears to be a continued need, as well as a global effort, to define and differentiate gender-based autistic traits using current DSM or other classification systems, such as the International Classification of Diseases, 10th Edition (ICD-10). This effort will assist the ASD spectrum of conditions to be more accurately diagnosed and treated, particularly in females (Green, Travers, Howe, & McDougle, 2019).

Delayed diagnosis of ASD in females also may prevent timely accurate diagnosis and treatment of co-occurring conditions such as those involved in reproductive health and menstruation. Although this study did not find statistically significant correlation between MAQ and AQ-10 scores, further research may find such associations. Inclusively analyzing women with ASD throughout the spectrum, their reproductive health, and attitudes toward menstruation is recommended. A continued focus on defining (also genetically) female congenital autistic traits and ASD (Whitehouse et al., 2011) also may assist in treating often painful menstrual issues of young girls whose AAM is now reported as early as 9 years old.

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APPENDIX A

SURVEY

Adult Women with and without Autism and their Experiences with Menarche and Menstruation

TEXAS WOMAN'S UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

Principle Investigator: Ellen Perlow, Ph.D
eperlow2@twu.edu

Faculty Advisor: Kathy DeOrnellas, PhD
kdeornellas@twu.edu

Explanation and Purpose of the Research

You are being asked to participate in a research study conducted by Ellen Perlow, PhD and Kathy DeOrnellas, PhD at Texas Woman's University. The purpose of this study is to learn how adult women with and without a diagnosis of Autism Spectrum Disorder experience menarche and menstruation. You have been asked to participate in this study because you are an adult female.

Description of Procedures

As a participant in this study you will be asked to spend approximately 30 minutes of your time completing an online survey. The survey asks questions about physical and mental health and your feelings and experience of menstruation. In order to be a participant in this study, you must be female and at least 18 years of age or older.

Potential Risks

This survey will ask you questions that you may feel uncomfortable answering. If you become upset or tired you may skip a question, take a break, or stop answering questions and end the survey. If you feel you need to talk to a professional about your discomfort, you may contact locator.apa.org for assistance in finding a psychologist in your area.

Another possible risk in this study is the loss of confidentiality. Your

confidentiality will be protected to the extent that is allowed by law. You may take the survey on a computer in a private location of your choice. You will not be asked to give your name. Your responses to the survey will be collected on a secure server and the investigators will not know who completed the survey. There is a risk of loss of confidentiality in all email, downloading, and internet transactions. All of the responses to the survey will be deleted from the server within six months of the end of the survey. The results of this study will be reported at professional conferences or in journal articles but your names or any other identifying information will not be included.

The researchers will try to prevent any problem that could happen because of your participation in this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefits

Your involvement in this study is completely voluntary and you may withdraw from the study at any time.

Questions Regarding the Study

If you have any questions about this research study you should ask the researchers; their contact information is at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at IRB@twu.edu.

Thank you for agreeing to participate in this research. Please answer the following questions:

*1)
Do you agree to participate in this research?

○ Yes ○ No

2)
What is your gender

○ Female ○ Male ○ Other

3)
What is your ethnicity?

○ Caucasian ○ African-American ○ Asian/Pacific Islander ○ Hispanic ○ Native American ○ Other

4)
What is your current age?

5)
What was your age at menarche (first menstrual cycle)?

6)
Have you ever been diagnosed with

☐ Autism Spectrum Disorder ☐ High-functioning autism ☐ Asperger's Disorder ☐ Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)

7)
If you have been diagnosed with a form of autism, please explain how it impacts your life, the age at which you were diagnosed, etc.

(1000 characters remaining)

8)
Have you been diagnosed with any of the following psychiatric/psychological conditions?

☐ ADHD/ADD ☐ Depression ☐ Bipolar Disorder ☐ Personality Disorder ☐ Obsessive Compulsive Disorder ☐ Schizophrenia ☐ Posttraumatic Stress Disorder ☐ Other (please specify)

9)
If you have been diagnosed with any of the above psychiatric/psychological disorders, please explain (i.e., severity, age at diagnosis, etc.):

appendix nppendixAPP

(1000 characters remaining)

10)
Have you been diagnosed with any of these medical/physical conditions?

☐ Insomnia ☐ Severe headaches/migraines ☐ Eating disorder ☐ Dysmenorrhea ☐ Ovarian cysts

☐ Seizure disorder ☐ Neurological disorder ☐ Physical limitations ☐ Digestive problems ☐ Underweight ☐ Overweight ☐ Other (please specify)

11)
If you have been diagnosed with any of the above medical/physical disorders, please explain (i.e., severity, age at diagnosis, etc.):

(1000 characters remaining)

12)
Have you ever used any medical procedure (birth control pills, hormones, etc.) to suppress or manipulate your menstrual cycle?
If yes, please explain.

(1000 characters remaining)

Please check one option per question only.

13) I often notice small sounds when others do not.

Definitely Agree **Definitely Disagree**

○ Definitely Agree ○ Slightly Agree ○ Slightly Disagree ○ Definitely Disagree

14) I usually concentrate more on the whole picture, rather than the small details,

Definitely Agree **Definitely Disagree**

○ Definitely Agree ○ Slightly Agree ○ Slightly Disagree ○ Definitely Disagree

15) I find it easy to do more than one thing at once.

Definitely Agree **Definitely Disagree**

○ Definitely Agree ○ Slightly Agree ○ Slightly Disagree ○ Definitely Disagree

16) If there is an interruption, I can switch back to what I was doing very quickly.

Definitely Agree **Definitely Disagree**

○ Definitely Agree ○ Slightly Agree ○ Slightly Disagree ○ Definitely Disagree

17) I find it easy to "read between the lines" when someone is talking to me.

Definitely Agree **Definitely Disagree**

○ Definitely Agree ○ Slightly Agree ○ Slightly Disagree ○ Definitely Disagree

18) I know how to tell if someone listening to me is getting bored.

Definitely Agree **Definitely Disagree**

○ Definitely Agree ○ Slightly Agree ○ Slightly Disagree ○ Definitely Disagree

19) When I'm reading a story I find it difficult to work out the characters' intentions.

Definitely Agree **Definitely Disagree**

○ Definitely Agree ○ Slightly Agree ○ Slightly Disagree ○ Definitely Disagree

20) I like to collect information about categories of things (e.g., types of cars, types of birds, types of plants, etc.

Definitely Agree **Definitely Disagree**

○ Definitely Agree ○ Slightly Agree ○ Slightly Disagree ○ Definitely Disagree

21) I find it easy to work out what someone is thinking or feeling just by looking at their face.

Definitely Agree **Definitely Disagree**

○ Definitely Agree ○ Slightly Agree ○ Slightly Disagree ○ Definitely Disagree

22) I find it difficult to work out people's intentions.

Definitely Agree **Definitely Disagree**

○ Definitely Agree ○ Slightly Agree ○ Slightly Disagree ○ Definitely Disagree

Based on your own experiences, please respond to each of the following items.

23) A woman's performance in sports is not affected negatively by menstruation.

Strongly Disagree **Strongly Agree**

○ Strongly Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Strongly Agree

24) Menstruation is something I just have to put up with.

Strongly Disagree **Strongly Agree**

○ Strongly Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Strongly Agree

25) Menstruation is a recurring affirmation of womanhood.

Strongly Disagree **Strongly Agree**

○ Strongly Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Strongly Agree

26) I can tell my period is approaching because of breast tenderness, backaches, cramps, and other physical signs.

Strongly Disagree **Strongly Agree**

○ Strongly Disagree	○ Disagree	○ Slightly Disagree	○ Neither Agree nor Disagree	○ Slightly Agree	○ Agree	○ Strongly Agree	

27) Most women show a weight gain before or during menstruation.

Strongly Disagree **Strongly Agree**

○ Strongly Disagree	○ Disagree	○ Slightly Disagree	○ Neither Agree nor Disagree	○ Slightly Agree	○ Agree	○ Strongly Agree

28) Women are more tired than usual when they are menstruating.

Strongly Disagree **Strongly Agree**

○ Strongly Disagree	○ Disagree	○ Slightly Disagree	○ Neither Agree nor Disagree	○ Slightly Agree	○ Agree	○ Strongly Agree

29) I expect extra consideration from my friends when I am menstruating.

Strongly Disagree **Strongly Agree**

○ Strongly Disagree	○ Disagree	○ Slightly Disagree	○ Neither Agree nor Disagree	○ Slightly Agree	○ Agree	○ Strongly Agree

30) In some ways I enjoy my menstrual periods.

Strongly Disagree **Strongly Agree**

○ Strongly Disagree	○ Disagree	○ Slightly Disagree	○ Neither Agree nor Disagree	○ Slightly Agree	○ Agree	○ Strongly Agree

31) Menstruation allows women to be more aware of their bodies.

Strongly Disagree **Strongly Agree**

○ Strongly Disagree	○ Disagree	○ Slightly Disagree	○ Neither Agree nor Disagree	○ Slightly Agree	○ Agree	○ Strongly Agree

32) I have learned to anticipate my menstrual period.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree	○ Disagree	○ Slightly Disagree	○ Neither Agree nor Disagree	○ Slightly Agree	○ Agree	○ Strongly Agree

33) Others should not be critical of a woman who is easily upset before or during a menstrual period.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Strongly Agree

34) The physiological effects of menstruation are normally no greater than other fluctuations in physical state.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Strongly Agree

35) Men have a real advantage in not having the monthly interruption of a menstrual period.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Strongly Agree

36) Menstruation provides a way for me to keep in touch with my body.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Strongly Agree

37) My own moods are not influenced in any major way by the phase of my menstrual cycle.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Strongly Agree

38) Cramps are bothersome only if one pays attention to them.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Definitely Agree

39) Menstruation can adversely affect my performance in sports.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Definitely Agree

40) I feel as fit during menstruation as I do during any other time of the month.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Definitely Agree

41) I hope it will be possible someday to get a menstrual period over within a few minutes.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Definitely Agree

42) Menstruation is an obvious example of the rhythmicity which pervades all life.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Definitely Agree

43) A woman who attributes her irritability to her approaching menstrual period is neurotic.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Definitely Agree

44) I barely notice the minor physiological effects of my menstrual periods.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Definitely Agree

45) I am more easily upset during my menstrual or premenstrual periods than at other times of the month.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Definitely Agree

46) I don't believe my menstrual period affects how well I do on intellectual tasks.

Definitely Disagree **Definitely Agree**

○ Definitely Disagree ○ Disagree ○ Slightly Disagree ○ Neither Agree nor Disagree ○ Slightly Agree ○ Agree ○ Definitely Agree

47) Avoiding certain activities during menstruation is often very wise.

Definitely Disagree **Definitely Agree**

Definitely Disagree	Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Agree	Definitely Agree

48) The only thing menstruation is good for is to let me know I'm not pregnant.

Definitely Disagree						**Definitely Agree**
Definitely Disagree	Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Agree	Definitely Agree

49) Women who complain of menstrual distress are just using that as an excuse.

Definitely Disagree						**Definitely Agree**
Definitely Disagree	Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Agree	Definitely Agree

50) I am more easily upset during my menstrual or premenstrual periods than at other times of the month.

Definitely Disagree						**Definitely Agree**
Definitely Disagree	Disagree	Slightly Disagree	Neither Agree nor Disagree	Slightly Agree	Agree	Definitely Agree

APPENDIX B

IRB LETTER

Institutional Review Board
Office of Research and Sponsored Programs
P.O. Box 425619, Denton, TX 76204-5619
940-898-3378
email: IRB@twu.edu
https://www.twu.edu/institutional-review-board-irb/

DATE: November 20, 2018

TO: Ellen Perlow
Multicultural Women's and Gender Studies

FROM: Institutional Review Board (IRB) - Denton

Re: Exemption for Adult Women with and without Autism Spectrum Disorder: Perspectives on the Menarche/Menstruation Experience (Protocol #: 20353)

The above referenced study has been reviewed by the TWU IRB (operating under FWA00000178) and was determined to be exempt from further review.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. Because a signed consent form is not required for exempt studies, the filing of signatures of participants with the TWU IRB is not necessary.

Although your protocol has been exempted from further IRB review and your protocol file has been closed, any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Jonathan Olsen, Multicultural Women's and Gender Studies
Dr. Kathy DeOrnellas, Multicultural Women's and Gender Studies
Graduate School

APPENDIX C

IRB EXTENSION LETTER

Institutional Review Board
Office of Research and Sponsored Programs
P.O. Box 425619, Denton, TX 76204-5619
940-898-3378
email: IRB@twu.edu
https://www.twu.edu/institutional-review-board-irb/

DATE: August 29, 2019

TO: Ellen Perlow
Multicultural Women/Gender St

FROM: Institutional Review Board (IRB) - Denton

Re: Extension for Adult Women with and without Autism Spectrum Disorder: Perspectives on the Menarche/Menstruation Experience (Protocol #: 20353)

The request for an extension of the IRB approval for the above referenced study has been reviewed by the TWU IRB (operating under FWA00000178). This study was originally exempted on November 20, 2018; this study now expires on August 31, 2020.

If applicable, agency approval letters must be submitted to the IRB upon receipt prior to any data collection at that agency. If subject recruitment is on-going and a written consent form is being used, the newly stamped consent form is enclosed. Please use this consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study. A request to close this study must be filed with the Institutional Review Board at the completion of the study. If you do not utilize a signed consent form for your study, the filing of signatures of subjects with the IRB is not required.

Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any unanticipated incidents. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Christina Bejarano, Multicultural Women/Gender St
Dr. Kathy DeOrnellas, Multicultural Women/Gender St

APPENDIX D

CITI PROGRAM

CITI PROGRAM

Completion Date 28-Apr-2019
Expiration Date 27-Apr-2022
Record ID 26729633

This is to certify that:

Dr. Ellen Perlow

Has completed the following CITI Program course:

Social & Behavioral Research - Basic/Refresher (Curriculum Group)
Social & Behavioral Research - Basic/Refresher (Course Learner Group)
1 - Basic Course (Stage)

Under requirements set by:

Texas Woman's University

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?w34cc0641-4c87-460b-b796-17007ab4d1a2-26729633