

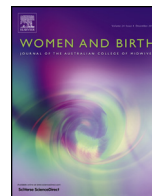


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Original Research - Qualitative

Perinatal issues for women with high functioning autism spectrum disorder

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ABSTRACT

Problem: Autistic Spectrum Disorder (ASD) is an increasingly commonly diagnosed disability. People with ASD commonly report challenges in social interaction and a heightened sensory perception. These challenges may be particularly difficult for women during pregnancy, birthing and beyond.

Background: Very little is known about the experiences and needs of birthing women who have ASD. There is a large body of literature about women who have autistic children, but almost nothing about women who may have this disability themselves. Internet blogs provide some insights and suggest that birthing women with ASD may have particular challenges related to communication, decision making and sensory overload.

Question: This study explores the particular issues and experiences of birthing women who have ASD, through pregnancy, birth and early mothering.

Method: This qualitative research used a case study approach, with in-depth interviewing and email exchange providing the data for the study. This data was verified, transcribed and analysed thematically.

Findings: The findings of this case study identified three key issues: communication and service difficulties; sensory stress and parenting challenges.

Discussion and conclusion: Findings suggest that women with ASD may face particular challenges during pregnancy, birthing and early mothering. These challenges evolve from perceptions of the woman about her midwives and other caregivers. If a woman perceives that her midwife is judgemental about her, then she may withdraw from the care and support she and her baby need.

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Statement of significance:

Problem or issue

- Women with Autism Spectrum Disorder (ASD) have many challenges when they become pregnant and progress to motherhood.

What is already known

- Women who become pregnant face a host of life-changing experiences. Women with ASD, may find the challenges they face with social interactions and sensory experiences exacerbated when pregnant.

What this paper adds

- The challenges faced by these women, including early parenting, should be handled sensitively by health care workers, recognising the requirement to balance regular health care protocols with the specific needs of the women with this disorder.

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1. Introduction

Living with high functioning autism (also commonly known as Asperger's Syndrome) can create a range of life challenges for both children and adults, which may be exacerbated at periods of life change and stress. For all women, pregnancy, childbirth and adjusting to a mothering role are significant life experiences that are likely to involve some challenges, and a need for a period of transition and personal growth. For a woman with autism, this transition may be even more challenging.

Women who do not face challenges of communication and social interactions find vaginal examinations less than desirable. It may be more challenging for women with ASD.

As pregnancy progresses, the accompanying physical and emotional changes may be especially problematic for women with high functioning autism. For example, morning sickness may be a significant challenge, as well as dealing with the sensations of her baby moving around as pregnancy progresses. A woman with high functioning autism may find such experiences to be particularly stressful due to her propensity to experience sensory overload,¹ as well as physical changes that as yet have not been fully explored by researchers² and experiences that lead her to feel that she is losing control over her body.³

The experience of childbirth may bring a range of other challenges. Regarding pain, for example, it is suggested that attendants to pregnant women be given a numerical pain rating scale to assist them communicate their pain level.⁴ This avoids an issue of communication with their midwives and obstetricians when one of the problems typical of a person with ASD is that of communicating. Childbirth, particularly in busy maternity units, is likely to occur in noisy environments with a number of people entering and leaving the birthing unit; again this may be confronting and possibly overwhelming for women with high functioning autism.

There is some literature about the experiences of women with disabilities having babies, which explores the relative absence of awareness or informed and individualised responses from maternity providers to the varying needs of women with physical or other disabilities.^{3–5} This literature has limited applicability to the needs of high functioning autistic women, however, because it mostly applies to women with physical disabilities or significant anxiety, depression or other major mental illness.

Limited references provided some clues as to the issues confronted by women with high functioning autism, as they journeyed through pregnancy, childbirth and early mothering.^{2–4,6} There is limited research on this topic, with extensive literature searches identifying a very significant body of literature about the risk of having autistic babies but very little relating to women with any form of autism having their babies, a situation confirmed by Gardner et al.²

There is a need for a program of research to explore the issues and needs of women with high functioning autism. This resonates with changing models of maternity care in Australia and elsewhere, which emphasise women-focused care, where women feel in control and have their individual needs and issues respected.^{7,8} However, without research outcomes which identify what those needs may be for different cohorts of women, it is difficult to educate midwives, obstetricians and other maternity workers on how best to respond effectively to women who may have additional, or at least specific, needs, such as women with high functioning autism.

1.1. Autism in Australia

The prevalence of people regarded as having Autism Spectrum Disorder (ASD) in Australia is confirmed by an Australian Bureau of Statistics (ABS) publication⁹ where statistics collected through the Survey of Disability, Ageing and Carers, indicates that in 2012, 115,400 Australians were regarded as having ASD, a 79% increase from those estimated to have the condition in 2009. Males were four times more likely to have ASD than females. The ABS indicated that this percentage was consistent with other overseas estimates. Of these 115,400 people, over one half were between the age of 5 and 18, the ages when most are at school.

While the above data indicates by implication that there are approximately 23,000 females with ASD in Australia, there are no data indicating how many women become pregnant.

This inquiry sought to identify important issues relating to the perinatal (prenatal, birthing and postnatal) experiences of high functioning women with ASD, with the view to exploring these issues in a subsequent in-depth study.

1.2. Research question

The question that this research study sought to answer was:
What are the issues for women with high functioning ASD during their perinatal period?

1.3. Overview

This study covered the existing literature relating to this question and is supplemented by less formal and more experiential and anecdotal evidence through the internet blogs of women who have experienced pregnancy and childbirth. Central to this study is the emotional experiences of one woman who was interviewed in-depth. Some broad issues relating to autism are now discussed followed by more specific reproductive health related issues.

1.4. Definitions

Autism Spectrum Australia defines ASD as “a lifelong developmental disability that affects, among other things, the way an individual relates to his or her environment and their interaction with other people”.¹⁰

In its fifth edition, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)¹¹ brought the four terms frequently used in describing autism under one classification, Autism Spectrum Disorder. (These four earlier terms were autism disorder, Asperger's disorder, childhood disintegrative disorder and, the broad term pervasive developmental disorder.) The Work Group responsible for the development of the Manual found that this better reflected the current state of understanding of autism.^{11,12} While this development was not without criticism,^{13,14} and response,¹⁵ the more recent 'official' abandoning of the designation 'Asperger's disorder' had to be disregarded in this current study because women who were recognised as having ASD were often regarded as having Asperger's disorder, or were, as they often regarded themselves, 'Aspies'.¹⁶ The recent change of designation may be reflected in the future but the former designation was recognised by people who could be potentially involved in this research. It was important to ensure that no one would be excluded in the research because of a change in terminology.

Autism Spectrum Australia regards Asperger's disorder as high functioning autism.¹⁷ The organisation suggests that while people

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