

Challenges faced by nurses and midwives in the care of children & pregnant women on the autism spectrum: a review of resource limited nations

Abstract

Persons with autism (ASD) experience disparities in healthcare service delivery and utilization. Autism is a developmental disability, which occurs as a result of atypical development that alters typical development and affects the child's communication, social interaction, behavior and activities. It is a lifelong disorder affecting people of all race and background, and requires support throughout the developmental stages. Despite the fact that the number of children with ASD is on the rise, there is limited awareness and knowledge regarding ASD among healthcare providers including nurses and midwives, especially in developing countries. Thus, these healthcare providers may be facing challenges in caring for persons with ASD particularly children and pregnant women. Hence, nurses and midwives need to understand the unique challenges of caring for individuals with ASD. Therefore, this paper highlights the characteristics of children and pregnant women having autism, birth experiences, nursing care guidelines and challenges faced in resource limited nations.

Published articles on autism spectrum disorder, caring for children with autism and women on the spectrum and challenges faced were reviewed. Literature revealed that due to the nature of the disorder persons with autism may have difficulty communicating their needs, reporting their symptoms and may not understand health education or whatever is being said during care. In addition, pregnant women having autism have complained that nurses do not pay attention to their worries; their wishes were ignored, and they were not involved in communication and education during the birth process. Thus, nurses and midwives need to be aware of the fact that this special group of children and expectant mothers experience exaggerated symptoms and hence, have to be patient enough to render individualized care that is very supportive and gentle.

Keywords: autism, nurses, midwives, pregnancy and birth experiences, children, challenges, resource limited nations

Volume 11 Issue 3 - 2025

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Received: July 2, 2025 | **Published:** August 08, 2025

Introduction

Persons with autism experience disparities in healthcare service delivery and utilization¹ even though they frequently suffer from associated conditions such as gastrointestinal disorders, eating and feeding problems, and anxiety among others.² This special group is more likely to have unmet healthcare needs for preventive care, physical and mental health.³ According to the American Psychiatric Association (APA) Autism Spectrum Disorder (ASD) is a range of neurodevelopmental disorders which occur early in childhood characterized by persistent deficits in social communication and interaction, and restricted, repetitive patterns of behavior, interests, or activities [4]. Autism occurs as a result of atypical development that alters typical development mostly affecting the child's ability to communicate verbally and nonverbally,¹ interact with others, and adapt to new environments.^{5,6}

In addition, children with autism display tantrums, social isolation. Self-destructive acts and other forms of abnormal behavior.⁵ Autism is a lifelong disorder affecting people of all race and background, and requires support to move from one stage of development to another. This special population requires support in order to live healthy and achieve to their maximum potential. According to Ballantine, ASD is common neurodevelopmental disorder with an increasing prevalence globally.⁷ In 2012 the prevalence of autism worldwide was at 62 per 10,000 children,⁸ which increased exorbitantly in 2013. The World

Health Organization (WHO) indicated that 'epidemiological data estimates the global prevalence of ASD to be one person in 160.^{9,10} In 2014 Statistics at the Centre for Disease Control and Prevention (CDC) reported that 1 in 68 American children were on the autism spectrum.^{10,11}

According to WHO the prevalence of ASD in most African countries is not known⁹ however; in Cameroon, there has been a steady rise in the number of children with autism. Overall, it was estimated that 100,000 children were affected by autism in 2011¹² and at least 130,000 children were affected in 2013.¹³ According to Nzie¹⁴ one child out of 50 in Cameroon has autism. Recently, a study conducted by Eta in two primary schools Buea Cameroon revealed that 13 out of 288 children had autism.¹⁵ This rise in the number of children diagnosed with autism could partly be due to increased awareness and improved diagnosis.¹⁶ Despite the fact that the number of children with autism globally is on the rise, there is limited knowledge regarding autism among healthcare providers especially in developing countries.¹⁷

A study conducted by Sampson *et al* revealed that psychiatric nurses as well as Pediatric Nurses had low knowledge on autism.¹⁶ Also, a study on autism in Nigeria revealed a low-level of knowledge and awareness on autism among healthcare workers.¹⁸ Furthermore, a survey of Knowledge among Nurses Caring for Adults with Autism in an Emergency Department confirmed limited knowledge and resources available for nurses.¹⁹ It is worth mentioning that the

core characteristics of autism and associated behaviors could present additional difficulties, which may hamper or even prevent the delivery of appropriate health care. Thus, healthcare providers including nurses and midwives may be facing challenges in caring for persons with autism as well as pregnant women and children. Therefore, nurses in particular need to understand the unique challenges of caring for individuals with autism.

Pregnant women having autism have complained that nurses did not pay attention to their worries, their wishes were ignored, and they were not involved in communication and education during the birth process. Thus, nurses and midwives need to be aware of the fact that this special group of expectant mothers experience exaggerated pregnancy symptoms and thus have to be patient enough to render individualized care that is very supportive and gentle. Autism is one of the most challenging developmental disabilities nurses may encounter as pregnant women and children with autism will likely behave differently from normally developing counterparts. Hence, nurses and midwives should be able to adapt and modify their plan of care based on their knowledge on autism²⁰ in order to fully include them in the care process. This may in turn reduce stress and anxiety in an unfamiliar environment.

Therefore, this paper highlights the characteristics of children and pregnant women having autism, their birth experiences, nursing care guidelines and challenges faced in resource limited nations. This could significantly improve awareness and knowledge regarding autism and in turn help improve the birth experiences, as well as the quality of care render to children with autism. Also, information on this paper may be used by policy makers to develop and implement strategies for inclusive healthcare, which is directed towards individualized needs, as well as provides basis for further research.

The information presented in this paper was obtained from published articles, book chapters and books having similar terms and concepts, and or topics related to the title of this paper. These included terms and concepts such as autism spectrum disorder, autism, characteristics of persons with autism, caring for children with autism and women on the spectrum as well as challenges faced in caring and supporting these special group of individuals especially in resource-limited nations like Cameroon. The information was synthesized, analyzed and presented in a comprehensive manner for better understanding.

Characteristics of children and pregnant women having autism

According to CDC,²¹ infants and children on the spectrum present with different signs and symptoms under two broad headings as described below:

Impaired social communication and interaction skills; where the child displays the following:

Avoids or does not keep eye contact: This may be due to sensory overload, cognitive challenges, and difficulty understanding social cues. In addition, while others may find eye contact intensely stimulating or even threatening, some may simply not understand the social meaning behind it. Also, some of them may prefer to focus on verbal information without the additional sensory input from facial expressions. According to Hirsch *et al.*,²² less activity in the dorsal parietal cortex could explain the difficulty children with autism are having with making eye contact. It has been suggested that the behavior of avoiding eye contact with other people may help to

decrease unpleasant excessive arousal stemming from over-activation in a particular part of the brain.²³

Does not respond to name by 9 months of age: The child's lack of constant response to his or her name by 9 months of age can be a possible red flag for autism, but it is not always a conclusive diagnosis. A study revealed that at 9 months of age, infants developing ASD were more likely to fail to orient to their names, persisting through 24 months.²⁴

Does not show facial expressions like happy, sad, angry, and surprised by 9 months of age:

A lack of facial expressions by 9 months of age can be a red flag for autism spectrum disorder (ASD). This special group of children sometimes display emotional expressions that differ from those used by typically developing children. For instance, infants and children with ASD show differences in their smiling behaviors. Specifically, they may show delayed smiling, and reduced frequency and duration of smiles.

Does not play simple interactive games like pat-a-cake by 12 months of age: According to CDC,²¹ a child's inability to engage in simple interactive games like pat-a-cake by 12 months of age can be a sign of autism. This is because typical development entails social interaction and play by this age.

Uses few or no gestures by 12 months of age (for example, does not wave goodbye): A child's use of few or no gestures by 12 months of age can be a possible pointer of autism. However, not all children with autism show this symptom, but it is an important early sign, especially when combined with other red flags. Deficits in gestures act as early signs of impairment in social interaction and communication in children with autism.²⁵

Does not share interests with others by 15 months of age (for example, shows you an object that they like): This might be indicating an early sign of autism, if a child does not show or share an object they like with love one. This, along with other signs like avoiding eye contact or not responding to name, may indicate a potential concern. Usually, by 15 months of age, children begin to show and share their interests (such as pointing to or showing an object they like) with parents and other caregivers.²¹

Does not point to show parents something interesting by 18 months of age: Children with autism may have problems with social interaction and communication, which includes understanding social cues and gestures like pointing. A lack of pointing to show something interesting to caregivers by 18 months of age can indicate an early sign of autism, a potential red flag that may suggests developmental delays or difficulties with social interaction, communication, and understanding others' emotions-Children's health.²⁶

Does not notice when others are hurt or upset by 24 months of age: According to CDC,²¹ a child who does not notice when others are upset may struggle with comprehending and reacting appropriately to social cues and emotions, which is a key aspect of autism.

Does not pretend to be something else, like a teacher or superhero, during play by 48 months of age: Children with ASD may have problems with pretend play because of difficulties in understanding and expressing emotions, taking on different perspectives, and engaging in social interaction. A pretend play, where a child acts out different roles or scenarios is an important developmental milestone. A child who does not engage in pretend play by 48 months of age (4 years) may be displaying signs of autism.²⁷

Early signs of ASD in the first two years of life

According to Hodara,²⁸ the child with autism manifests with the following:

- i Lack of appropriate gaze
- ii Lack of warm, joyful expressions with gaze
- iii Lack of sharing enjoyment or interests
- iv Lack of alternating to-and-fro vocalizations with parents
- v Lack of response to name
- vi Delayed onset of babbling past nine months of age
- vii Decreased or absent use of pre-speech gestures (waving, pointing, showing)
- viii Not speaking single words by 16 months
- ix No two-word utterances by 24 months
- x Repetitive movements or posturing of body, arms, hands, or fingers
- xi Loss of language or social skills at any age

Impaired communication/social interaction, at two years six months the child:

- i Does not have functional play skills
- ii Is not interested in peers
- iii Is non-verbal
- iv Cannot communicate wants and needs effectively

Restricted, repetitive patterns of behavior/ interests/activities, at two years six months the child:

- i Eats a limited number of foods
- ii Throws self on floor and hits parents
- iii Throws objects when unable to communicate wants and needs

Autism in older children: These include common characteristics in difficulties with social communication and interaction, restricted or repetitive behaviors, and sensory sensitivities. These may include challenges understanding social cues, difficulty making friends, and intense interests in specific subjects. Specifically, the child:

- i Seems not to understand others thoughts/feelings
- ii Has difficulties expressing thoughts
- iii Gets very upset with changes in daily routines
- iv Gets very upset if asked to do something/task
- v Has difficulties making friends, prefers to be on their own
- vi Taking things very literally – for example, he/she may not understand phrases like “break a leg”

Communication/social interaction at four years: According to Kuei-Cheng *et al.*,²⁹ the child with autism manifests with the following:

- i Communicates only when he initiates the interaction
- ii Interacts with others only to get items that he wants
- iii Does not participate in most age-appropriate activities

- iv Shows no interest in peers
- v Content to be by himself
- vi Does not sing, dance, or act for you by 60 months of age

Restricted, Repetitive Patterns of Behavior/ Interests/Activities displays at four years:

- i Lines up toy cars, instead of playing with the toys as a typically developing child will do
- ii Tantrums when given instructions or asked to participate in non-preferred activities

Characteristics at 10years

Impaired Communication/Social Interaction; the child:

- i Makes unsuccessful attempts to interact with peers
- ii Has difficulty with language

Restricted, repetitive patterns of behavior/ interests/activities; the child:

- i Is obsessed with comic book superheroes; he or she excessively quotes and acts out scenes from their stories.

Differences in girls and boys; autism can be harder to spot in girls because autistic girls maybe quieter, and may hide their feelings as they appear to cope better with social situations.²¹

Characteristics of autism in a girl at 15 years; these are presented according to the core domains

Communication/social interaction; for this domain she:

- ii Is outspoken with adults and peers
- iii Has difficulty taking cues from her social partners
- iv Violates others' personal space
- v Has difficulty making friends at school

Restricted, repetitive patterns of behavior/ interests/activities; for this domain she:

- i Is obsessed with outer space
- ii Rocks back and forth in her chair

The subsequent subsections present the manifestations of pregnant women on the Autism Spectrum during pregnancy, labor and delivery.

Characteristics of pregnant women autism

- i Always felt misunderstood by nurses or midwives
- ii Not always knowing which details were appropriate to share with professionals²⁶
- iii Autistic women always find it challenging to cope with uncertainty, and pregnancy can be an uncertain period
- iv May wave hand/fingers in front of her eyes repetitively when in distress
- v Experience higher levels of anxiety and stress, that might lead to depression²¹
- vi Autistic mothers are more likely to experience additional psychiatric conditions

Complications during pregnancy include elevated rates of:

- i Preeclampsia
- ii Preterm birth
- iii Fetal death (after 20 weeks)
- iv Caesarean delivery
- v Prolonged hospitalization after delivery

Pregnancy experiences in autism

The expectant woman may withdraw from the care and support needed for herself and baby.³¹ They perceived that midwives and other caregivers are being judgmental when delivering care. In addition, they usually face challenges during pregnancy, birthing and early mothering.

Birthing Experiences in Autism; these include the following:

- i **Communication difficulties;** this usually varies among women. They do not understand what is being said or was said to them and always have problems reporting needs and difficulties communicating to nurses when they fell ill or have new symptoms
- ii **Feelings of stress, anxiety, and fright in an uncertain environment,** which inhibits attempts to participate in discussions during care process.
- iii **Being an autistic pregnant woman,** which makes difficult to cope with the sensory aspects of giving birth; noise and being touched. This special group of women experience extra difficulties such as with planning and organizing, exhaustion, loss of control over routines and a lack of social support.³¹ They will always wish to better understand their baby's needs.²¹ They are more likely to experience both prenatal and postnatal depression because they have difficulties understanding the process of birth.²¹ As a result they experience lower satisfaction with birth-related and postnatal healthcare services. They found it challenging to communicate with strange people, since they have a particular fear of unfamiliar people. In addition, they dislike the left-hand side of their body being touched. Furthermore, they are hypersensitive; these special group of women find the bright lights, strange smells, tastes and unexpected noises very irritating. In the last trimester, the women can have an increased feeling of irritability and physical discomfort and experience very painful contractions during labor and delivery.

The following subsections present nursing care guidelines for children and pregnant females on the spectrum and challenges faced care delivery in resourced limited nations.

Nursing care guidelines for children with autism

Children with ASD frequently have difficulty transitioning from one activity to another, resulting in an escalation of challenging behaviors. Therefore, the nurse is expected to do the following:

- i Prepare the patient for the multiple alterations necessary in providing adequate and proper nursing care
- ii Modify the plan of care accordingly
- iii Approach the patient using evidence-based practices, and methods that have been scientifically proven to improve outcomes

- iv The nurse should involve the patient's parents at all stages of care, according to Patrizzi and Gialari³³ the importance of involving the patient's caregiver throughout the process of care cannot be underestimated
- v Be non-judgmental and accept all attitudes display by the child
- vi Tailor nursing care to the needs of each child is very important in providing a good standard of care
- vii The Autism Treatment Center of America recommends joining the child in their repetitive behaviors. This is in order to create rapport and then use this bond to enhance provision of quality care

Nursing care guidelines for women during pregnancy, labor and delivery

In order to meet the health needs of pregnant women on the spectrum, the nurse is expected to:

- i Provide good quality support and care to ensure that the same quality of care is rendered as it would be for a typically developed pregnant female²⁶
- ii Be aware that communication needs would vary for each woman as each woman on the spectrum is unique. Hence, individualized interventions to facilitate safe and effective communication should be taken in to consideration³⁴
- iii Communicate more clearly and be patient with the woman noting that sensory and communication adjustments should be made during pregnancy and the birthing process.
- iv Seek more knowledge and training, this will enable nurses and midwives to be continually be updated with recent information from research regarding autism. This will assist them to adapt and modify care plans based on their knowledge of autism,²⁴ and in turn render care properly by giving clear information about pregnancy and delivery.
- v Put the women in their own room, where possible in order to reduce sensory challenges
- vi Provide information in a variety of formats e.g. Picture Exchange Communication System-PECS³³
- vii Provide one-to-one support through smaller classes or online classes to enhance understanding
- viii Draw up a comprehensive care plan which involves relatives to enhance communication of needs
- ix Make her environment as low-stimulating as possible; the light level should be lowered and unnecessary equipment removed from the room
- x Avoid natural pain-relieving methods; massage or a wheat bag, because they cause a sensory overload
- xi Keep her voice at a normal volume and speed when communicating with the autistic woman
- xii Allow longer than normal time to receive reply to any questions or conversation because many people with autism experience an auditory processing delay.³³

Get them involve in conversation with you by asking questions directly to them and ask only questions that are necessary. The Royal College of Midwives advocates woman-centered care.³⁵

Challenges faced in resource limited nations

Studies have revealed that healthcare providers especially nurses face the following challenges in caring for children and pregnant women on the spectrum:

- i Lack of awareness and knowledge about autism by healthcare personnel.³¹ There is need for greater autism understanding among professionals, acceptance and greater support for autistic children and expectant women as this guide adjustments to the routine plan of care leading to the delivery of appropriate and quality care.
- ii Lack of autism resources for early diagnosis and support (“a lack of awareness and support for my autism”). It is important to note that not having an autistic diagnosis will worsen autism symptoms during pregnancy and delivery. Women and couples in collaboration with midwives are generally advised to develop a birth plan to ensure a smooth birthing process. In addition, a good antenatal assessment of needs, together with a good care plan can both significantly improve a woman’s experience in the hospital and make her admission process smoother.
- iii There exist barriers such as communication differences, differences in pain, expression and sensory differences. The Picture Exchange Communication System (PECS) was designed to be an augmentative and/or alternative communication system.

Conclusion

Nurses and midwives face challenges in caring for autistic pregnant women and children. The lack of knowledge about autism may further exacerbate communication difficulties. Greater understanding and acceptance amongst nurses and midwives who interact with autistic children and mothers is needed. This will allow this special group of individuals to benefit from additional and better-tailored support. It is important to note that a lack of autism understanding among professionals may discourage nursing care for autistic individuals. This may prevent their diagnosis and may be a barrier to the implementation of autism-related adjustments and modifications during care.

In addition, autistic women may have an increased risk of postnatal depression and anxiety. This highlights the need for effective mental health screening and support for autistic people during the postnatal period. Adjustments to the sensory environment should be made for autistic people during childbirth and where possible. For instance, provision should be made for their own room on the postnatal ward to reduce sensory challenges. Furthermore, provision of one-to-one support, smaller classes or online classes may be beneficial for effective communication and the delivery of appropriate and effective care. It is worth mentioning that this special population want healthcare professionals particularly nurses to understand their neurodiversity.

Acknowledgements

None.

Conflicts of interest

None.

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