

Sexual and Reproductive Health Needs for Adolescents with Autistic Spectrum Disorder in Rwanda, A Phenomenological Study

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Background: Adolescents with autistic spectrum disorder have unique sexual and reproductive health needs that are often overlooked in health service planning and delivery. Despite their right to access accurate information and appropriate care, they face significant barriers.

Objective: This study aims to explore the sexual and reproductive health needs for adolescents with autistic spectrum disorder in Rwanda.

Methods: A phenomenological qualitative study was conducted in February 2025 at two centers in Gasabo District, Rwanda. Data were collected through focus group discussions from autistic spectrum disorder centers selected via purposive sampling. Data was saturated after conducting 3 FGDs. Transcripts were analyzed using NVivo and thematic analysis.

Results: This study revealed that adolescents with autistic spectrum disorder struggle with interpreting social cues and managing relationships, affecting their social and emotional development. A major barrier to accessing sexual and reproductive health services is the limited awareness among both adolescents and their families, along with a lack of information tailored to their specific needs. Challenges such as long travel distances, financial constraints, and cultural stigma rooted in misconceptions about their sexual and reproductive health needs further discourage families from seeking appropriate care due to fear of judgment and social rejection.

Conclusion: The study found that adolescents with autistic spectrum disorder face challenges in understanding social cues and forming relationships, affecting their sexual and reproductive health experiences. Barriers include limited awareness among families about specialized SRH services, logistical difficulties, and lack of tailored information. Cultural stigma and misconceptions further prevent families from seeking appropriate care, highlighting the need for inclusive and accessible SRH support.

Keywords: autistic spectrum disorder, adolescent, sexual and reproductive health, Rwanda

Introduction

Autistic Spectrum Disorder (ASD) is a neurodevelopmental disease that can range in severity from mild to severe. Eugen Bleuler, a German psychiatrist, first used the term “autism” in 1908 to characterize a symptom of the most severe forms of schizophrenia, a term he had also developed. Childhood desires to escape unpleasant reality and substitute them with delusions and hallucinations, according to Bleuler, were the hallmarks of autistic thought.¹

Autistic spectrum disorder affects approximately 1 in 100 adolescents worldwide, though prevalence estimates vary significantly between regions due to differences in diagnostic criteria and reporting practices.² Adolescence is defined by the World Health Organization (WHO) as the second decade of life (10–19 years of age). It is a time when significant physical, psychological, and social changes occur.³ In developed countries like the United States, the prevalence of ASD is reported to be around 1 in 54 adolescent.⁴ In Africa, the prevalence of autistic spectrum disorder is about 1 in 160 adolescents.⁵ In Rwanda, the country is ranked 62nd in the world with an Autistic Spectrum Disorder rate of 394.77 per

100,000 people. Rwanda's adolescent Autistic Spectrum Disorder rate is 432.57 per 100,000 ranking it at 65th in the whole world.³

The exact cause of ASD is unknown, although a number of variables most likely have a role in its development. Genetic variables (both common and unusual variations) are a source of population diversity in ASD-related behaviors.⁶ Globally, the sexual and reproductive health (SRH) needs of adolescents with autistic spectrum disorder (ASD) are often overlooked in health policies and programs. This neglect stems from pervasive misconceptions that individuals with autistic spectrum disorder are asexual or uninterested in intimate relationships.⁷ Despite these misconceptions, studies have shown that adolescents with ASD experience similar sexual development and curiosity as their neuro typical peers. However, they face unique challenges due to their difficulties in social communication and interaction, which can hinder their ability to form healthy relationships and understand sexual norms.⁸

In developed countries, there is a growing recognition of the need to address the SRH needs of adolescents with ASD. For instance, in the United States and parts of Europe, specialized sexual education programs are being developed to cater to the unique needs of these adolescents.⁹ These programs often emphasize clear, concrete language and visual aids to help individuals with autistic spectrum disorder understand complex concepts. However, access to these tailored programs can be inconsistent, and there is still a lack of comprehensive research on their effectiveness.¹⁰

In Africa, the situation is more challenging due to limited resources, cultural taboos, and a general lack of awareness about autism. Adolescents with ASD often do not receive appropriate sexual education, and there is a significant gap in healthcare services tailored to their needs.¹¹ Social stigmatization and the prioritization of other public health issues further complicate efforts to address their SRH needs. As a result, many adolescents with autistic spectrum disorder in Africa are vulnerable to sexual abuse and exploitation.¹²

Adolescents with ASD and their families are vulnerable to a range of negative behaviors and issues due to coexisting behavioral disorders that can impair daily functioning, education, and the effectiveness of interventions, thereby impeding the child's progress in multiple developmental domains. Negative emotional states and early deficits in self-regulation have been shown to predict both internal and external behavior in adolescents. Early language impairment has also been linked to an increased risk of violence, particularly in conjunction with difficulties controlling emotions and regulating mood in young adolescents.¹³ The understanding and experience of thoughts, emotions, drives, and circumstances around sex is known as sexual awareness.¹²

Research affirmed that adolescents with ASD often face difficulties in understanding social cues and norms, which can complicate their ability to navigate relationships and sexual health. These challenges can lead to increased vulnerability to misinformation and exploitation.¹⁴ Tailored education programs that use clear, straightforward language and visual aids can help bridge this gap, but such resources are not universally available.¹⁵ Early interventions is crucial in addressing the SRH needs of adolescents with autism. Programs that incorporate sexual education into early childhood education for adolescents with autistic spectrum disorder have shown promise in improving understanding and reducing vulnerability. These interventions can help adolescents develop a better understanding of their bodies, consent, and healthy relationships, which are critical for their overall well-being.

In Rwanda, autistic spectrum disorder awareness and support services are still in their nascent stages. The country faces significant challenges in addressing the SRH needs of adolescents with ASD due to limited resources and a lack of specialized training for healthcare providers.¹⁶ Cultural perceptions and stigma surrounding both autistic spectrum disorder and sexual health further hinder efforts to provide adequate care and education. Despite these challenges, there are emerging efforts by the Government, local NGOs and international organizations to improve autistic spectrum disorder awareness and support in Rwanda.

In the study area, research about sexual and reproductive health (SRH) needs of adolescents with ASD are scarce, primarily due to limited resources, insufficient healthcare infrastructure, and pervasive cultural stigmas surrounding both autistic spectrum disorder and sexual health. This scarcity of research results in a significant gap in understanding and addressing the unique challenges these adolescents face, leaving them vulnerable to misinformation, exploitation, and inadequate healthcare services. Consequently, this study is crucial as it aims to shed light on the SRH needs of this underserved population, inform policy and program development, and ultimately contribute to the creation of inclusive and effective healthcare and educational strategies in Rwanda. It also increases community knowledge of the particular

difficulties experienced by adolescents with Autistic Spectrum Disorder and assist them better support their autistic adolescents by emphasizing social and emotional needs.

Methods and Materials

Research Area, Design and Period

This study was conducted in two settings: Rwanda center for autistic spectrum disorder located at Gisozi sector, Nyarugenge District, Kigali city and Humura Center, a school having adolescent with disability including autism, located at Ndera Sector, Gasabo District in Kigali city. This study used a phenomenological study design with a qualitative research approach. It was conducted in February 2025.

Study Population

The population of this study was comprised of adolescents with autistic spectrum disorder and their care givers from Rwanda center for autistic spectrum disorder and Humura autistic spectrum disorder center.

Sampling

Sample Size and Sampling Strategy

Three focus group discussions were conducted from all autistic spectrum disorder centers. Each FGD had 7 participants. It comprises 5 adolescents with autistic spectrum disorder and 2 caregivers. After conducting 3 FGDs; there is no new information and data saturation was declared. Purposive sampling strategy was used to select participants of the study.

Inclusion Criteria

Being an adolescent with autistic spectrum disorder and a caregiver of 2 years of experience or above in Humura Center or Rwanda Center for autistic spectrum disorder and consenting to participate to the study were the inclusion criteria for this study.

Exclusion Criteria

Adolescents or Caregivers who refused to participate in the study were excluded from the research.

Data Collection Methods and Instruments/Tools

The study was conducted using the qualitative methods. The researcher collaborated with caregivers to reach the participants. Adolescents with autistic spectrum disorder were met at their respective centers. The researcher chose 5 adolescents and 2 caregivers purposively to participate in each focus group discussion among the 3 FGDs conducted; Two from Humura Center and another one at Rwanda Center for Autism. The concerned institutions provided rooms in which the discussions were held and this ensured privacy for the respondents. Open-ended questions were used to encourage detailed responses and allow for the emergence of personal narratives while discussing on common themes and shared experiences related to the SRH needs of adolescents with autism.

The FGD guide includes topics about sexual reproductive health of adolescents with autism, experience of the participants about sexual health education for autistic adolescent, how sexual and sexuality education is considered useful, the supportive factors to implement comprehensive sex education for autistic adolescent, the barriers perceived to practice the provision of reproductive health service among adolescents with autism.

Data Quality Management

One FGD was done as a pre-test with two caregivers and 5 adolescents with autistic spectrum disorder who met the inclusion criteria at “Le Centre de jour TUBITEHO prior to the actual data collection. Adjustments were made in light of the results of the pretest. After data collection and data analysis, data records and the study’s results will be kept for five years before being discarded according to university of Rwanda guidelines. They will then be stored on a locked, virus-protected computer.

Data Collection Procedure

Following approval from the University of Rwanda institutional review board (IRB), the researcher got in touch with the Gisozi autistic spectrum disorder center and Humura autistic spectrum disorder center directors to ask for permission to carry out the study at their facilities. Following confirmation of permission, the researcher met with adolescents diagnosed with autistic spectrum disorder and their caregivers and provided them with an explanation of the purpose, goals, and advantages of the study. Adolescents with autistic spectrum disorder and their caregivers who met the inclusion criteria and gave their consent to participate in the study were welcomed by the researcher and the other two research assistants who received training in data collection. They were provided with an FGD guide ahead of data collection. The focus group discussion took between 40 and 60 minutes.

Adolescents with ASD and their caregivers received a thorough explanation of the study in local language including its significance, goal, and data collection techniques. Informants were given the assurance that their queries and information will remain private regarding the study. The consent forms were signed by caregivers and assent form was used for adolescents with autistic spectrum disorder who agreed to engage in the study. They also had time to explain themselves in response to the questions posed to them. At the end, the study participants were thanked for their participation and time.

Data Analysis

For this study, thematic analysis was used. After conducting data collection, the researcher proceeded with FGD transcription. Verbatim transcription, data organizing and analyzing by using NVivo software were conducted. List of codes were created and grouping related codes into themes and sub-themes were made. Finally, interpreting the data and placing research findings in the context of existing literature, theories and frameworks and discussions were made.

Results

Sociodemographic Characteristics of the Study Participants

The study involved a total of 21 participants, comprising 15 adolescents with ASD and 6 caregivers. The age range of the caregivers spanned from 30 to 52 years. Among the adolescents, the majority were between the ages of 14 and 18, with mean age of 16.6 years. Caregivers, on the other hand, were aged between 30 and 52, highlighting their maturity and likely caregiving experience (Table 1).

Table 1 Sociodemographic Characteristics of Participants on Sexual and Reproductive Health Needs for Adolescents with Autistic Spectrum Disorder in Rwanda, A Phenomenological Study (n=21)

Participants	Ages	Gender	Religion	Occupation	Experience
FGD I					
P1	14	F	Catholic	Student	–
P2	18	M	Catholic	Student	–
P3	17	F	Adventist	Student	–
P4	45	F	Protestant	Caregiver	5 years
P5	52	M	Protestant	Caregiver	8 years
P6	16	F	Protestant	Student	–
P7	18	F	Adventist	Student	–

(Continued)

Table 1 (Continued).

Participants	Ages	Gender	Religion	Occupation	Experience
FGD 2					
P1	39	M	Catholic	Caregiver	6 years
P2	17	F	Catholic	Student	–
P3	18	M	Protestant	Student	–
P4	41	F	Catholic	Caregiver	4 years
P5	17	M	Protestant	Student	–
P6	16	M	Protestant	Student	–
P7	18	M	Catholic	Student	–
FGD 3					
P1	16	M	Catholic	Caregiver	—
P2	17	M	Protestant	Student	–
P3	16	M	Catholic	Student	–
P4	45	F	Protestant	Caregiver	4 years
P5	16	F	Catholic	Student	–
P6	30	M	Catholic	Student	6 Years
P7	15	F	Catholic	Student	–

Specific Sexual and Reproductive Health Needs of Adolescents with ASD

General Understanding of Unique SRH Needs

The findings from the Focus Group Discussions (FGDs), conducted at Humura Center and Rwanda Center for Autism, provide insights into the unique sexual and reproductive health (SRH) needs of adolescents with ASD compared to their neurotypical peers. Participants highlighted that adolescents with ASD often struggle with understanding abstract SRH concepts, such as bodily autonomy, consent, and appropriate social interactions, which are typically more easily grasped by neurotypical adolescents. Sensory sensitivities, communication difficulties, and a preference for routine significantly impact how they process and respond to SRH information.

One adolescent participant expressed confusion about the concept of personal boundaries, stating, “I don’t always know when I am too close to someone, and sometimes people get upset with me, but I don’t understand why” (FGD-2, P-3). This statement underscores the difficulty that some autistic adolescents face in recognizing social norms related to physical space and interpersonal relationships.

From the caregivers’ and educators’ perspectives, one of the most pressing concerns is the lack of tailored educational resources that align with the cognitive and communication abilities of autistic adolescents. Caregivers expressed that traditional SRH education, which primarily relies on verbal instruction and complex explanations, is often ineffective for this group. They emphasized the need for structured, visual, and repetitive teaching approaches to reinforce key SRH concepts. One caregiver highlighted this challenge, stating,

When I try to explain certain topics, the children does not understand unless I use pictures or show them step by step. It takes a lot of patience and repetition to do this (FGD-1, P-4)

Furthermore, educators noted that adolescents with ASD may exhibit difficulties in recognizing social cues and distinguishing between safe and unsafe relationships, making them more vulnerable to exploitation and abuse. The

discussions also revealed that while neurotypical adolescents often acquire SRH knowledge through peer interactions and media exposure, adolescents with autistic spectrum disorder rely heavily on direct guidance from caregivers and educators, underscoring the importance of a supportive learning environment.

Key SRH Topics for Adolescents with Autistic Spectrum Disorder

Participants identified puberty, consent, personal hygiene, safe relationships, and reproductive rights as the most essential areas requiring tailored education. Caregivers working in these centers and educators emphasized that autistic adolescents often struggle with understanding bodily changes during puberty and may have difficulty recognizing appropriate social and physical boundaries.

One adolescent participant expressed confusion about bodily changes, stating, “I don’t understand why my body is changing. Sometimes it scares me, and I don’t know who to ask” (FGD-1, P-6). This statement highlights the need for structured, accessible education on puberty and self-care to help autistic adolescents navigate these changes with confidence.

Center-based caregivers also noted significant knowledge gaps and misunderstandings, particularly regarding consent and safe relationships. Many adolescents with ASD may not fully grasp the concept of personal boundaries, making them more vulnerable to exploitation. One caregiver from the center shared their concern:

Some of the adolescents here do not recognize when someone is invading their personal space or taking advantage of them. They might not understand that they have the right to say no (FGD-1, P-5)

This perspective underscores the importance of teaching clear, concrete lessons on recognizing appropriate and inappropriate behavior, as well as strategies for setting personal boundaries.

Hygiene and self-care were identified as crucial topics, as some autistic adolescents struggle with sensory sensitivities that affect their ability to maintain regular hygiene routines. Center caregivers and educators recommended the use of visual aids, step-by-step demonstrations, and social stories to reinforce these concepts effectively. The discussions further revealed a gap in knowledge about reproductive rights and healthcare services, with center caregivers stressing the need for accessible information that helps adolescents with autistic spectrum disorder understand their rights regarding SRH services.

Effective Teaching Methods for SRH Education

Participants highlighted the importance of using visual aids, interactive activities, and simplified language as the most effective learning approaches. These methods help autistic adolescents grasp abstract SRH topics and reinforce learning through repetition and practical application.

One adolescent participant expressed a preference for visual learning, stating, “I understand better when I see pictures or videos. Words alone are sometimes confusing”, (FGD-3, P-3). This response underscores the necessity of using diagrams, illustrations, and step-by-step guides to explain complex SRH topics such as puberty, consent, and personal hygiene. Interactive activities, including role-playing and storytelling, were also suggested as effective strategies for teaching social boundaries and relationship skills.

Caregivers at the centers emphasized that structured and predictable learning environments are essential for autistic adolescents. One caregiver noted, “When we use pictures, social stories, and demonstrations, they engage more and remember the lessons better” (FGD-3, P-6). This feedback highlights the need for consistency in SRH education, ensuring that lessons are adapted to the cognitive and sensory preferences of adolescents with autism.

The role of technology in enhancing SRH education was also a major point of discussion. Participants agreed that digital tools such as animated videos, interactive apps, and online modules could provide an engaging and individualized learning experience. Some adolescents find digital content more appealing and easier to engage with compared to traditional teaching methods. Additionally, technology allows caregivers and educators to customize content based on the unique needs of each adolescent, making learning more effective.

Role of Families and Support Systems

The Focus Group Discussions (FGDs) at Humura Center and Rwanda Center for Autism highlighted the critical role that families, caregivers, and educators play in providing sexual and reproductive health (SRH) education to adolescents with autism. Participants emphasized that autistic adolescents require structured, repetitive, and personalized support to fully

grasp SRH concepts. While caregivers and educators at the centers take an active role in teaching these topics, parental involvement remains essential in reinforcing learning and addressing individual concerns.

One adolescent participant expressed the need for guidance, stating, “I sometimes have questions, but I don’t know who to ask or how to explain them” (FGD-1, P-1). Cultural stigma, discomfort, and lack of knowledge about autism-friendly teaching strategies were among the main barriers. One caregiver noted, “Some parents avoid discussing these topics because they either assume their child doesn’t need the information or they feel unprepared to explain it” (FGD 1, P-5).

To improve collaboration between families and healthcare providers, participants suggested the implementation of structured support programs, including workshops and counseling sessions tailored to parents and caregivers. These programs could equip families with the necessary knowledge and skills to discuss SRH topics confidently.

Emotional and Social Aspects of SRH

As the FGDs indicate; many autistic adolescents struggle with interpreting social cues, understanding boundaries, and expressing emotions, which can impact their ability to form and maintain relationships. One adolescent participant expressed confusion about relationships, stating, “I don’t always know if someone is my friend or if they like me in a different way” (FGD-3, P-2). This difficulty in distinguishing between different types of relationships can leave autistic adolescents vulnerable to misunderstandings, social isolation, or even exploitation.

Difficulties in forming and maintaining romantic or intimate relationships were also a key concern raised in the discussions. Some autistic adolescents may desire relationships but lack the social skills to navigate them successfully. Others may have limited interest in romantic relationships but still require guidance on appropriate social behaviors. A caregiver highlighted these challenges, saying, “They need help understanding what is appropriate and what is not, especially when it comes to physical contact and consent” (FGD-3, P-4).

To support the emotional and social needs of autistic adolescents, caregivers and educators emphasized the need for targeted interventions, such as social skills training, role-playing exercises, and guided discussions. Visual supports, social stories, and structured peer interactions were identified as effective tools for helping autistic adolescents navigate relationships in a safe and supportive manner.

Barriers to Accessing Sexual and Reproductive Health Services

Awareness and Knowledge Gaps

This study revealed significant gaps in awareness and knowledge about sexual and reproductive health (SRH) among adolescents with ASD and their families. Participants highlighted that many adolescents with Autistic Spectrum Disorder have limited access to accurate, age-appropriate SRH information, and their families often struggle to find reliable resources tailored to their specific needs.

Adolescents with ASD, as noted during the FGDs, often face challenges in seeking out and understanding SRH information. One adolescent participant shared, “I don’t really know where to get this information, and when I ask, I’m not sure if I understand it” (FGD-1, P-2). This statement reflects a lack of structured education and accessible resources for autistic adolescents, which leaves them reliant on informal sources that may not fully address their needs. Caregivers mentioned that, even if information is available, it is often difficult to find materials that are presented in a way that their children can easily understand. “We struggle to find materials that explain things simply, with pictures or videos that help my child understand” (FGD-1, P-5).

In terms of common sources of SRH information, the primary channels identified during the FGDs were schools, healthcare providers, and caregivers. However, these sources are often not fully equipped to meet the specific needs of adolescents with autism. For example, many educators and healthcare providers are not trained in autism-specific teaching strategies, which limit the effectiveness of the information shared. One caregiver explained, “Sometimes, the information shared at school is too general, and it doesn’t cater to the way our child learns” (FGD-3, P-4).

Accessibility Challenges

Accessibility challenges that adolescents with ASD and their families face when attempting to access sexual and reproductive health (SRH) services. These challenges were particularly related to physical barriers such as transportation and clinic accessibility, as well as financial constraints that limit access to necessary services.

One of the most commonly reported physical barriers was the difficulty of reaching healthcare facilities that provide SRH services. Several participants noted that transportation to and from clinics or hospital was not only physically challenging but also time-consuming. A caregiver explained,

Getting to the clinic with these children is difficult because we don't have specific transport means for them, and it's tiring for them to sit in a car for a certain period. (FGD-2, P-1)

This physical barrier disproportionately affects families receiving care far from their homes.

In addition to transportation challenges, participants also reported issues with clinic accessibility. Some healthcare facilities do not have the necessary accommodations to meet the needs of individuals with autism, such as quiet spaces to reduce sensory overstimulation or staff trained to handle the specific needs of autistic patients. One caregiver shared, "The clinics are not always prepared to accommodate the special needs these children, and the waiting times can be overwhelming for them" (FGD-2, P-4). These environmental factors can make it difficult for adolescents with autistic spectrum disorder to access SRH services in a comfortable and supportive manner.

Financial constraints were also identified as a major barrier to accessing SRH services. The cost of consultations, medical tests, and treatment can be prohibitive for many families. One caregiver explained, "The cost of going to the doctor or buying medicine adds up quickly, and sometimes parents can't afford it" (FGD-3, P-6). This financial strain is compounded by the additional expenses that families with autistic adolescents often face, including transportation costs, special therapies, and educational support services. For many families, these combined costs mean that accessing SRH services is not a priority, even when the services are available.

Quality of SRH Services

Regarding the quality of sexual and reproductive health (SRH) services available to adolescents with autism; participants emphasized the lack of specialized services tailored to the unique needs of autistic adolescents and expressed concerns about the training and preparedness of healthcare providers in addressing these needs.

The availability of SRH services specifically designed for adolescents with autistic spectrum disorder was identified as a major gap. While general SRH services exist, they often do not take into consideration the sensory, communication, and social challenges faced by autistic adolescents. One caregiver noted, "The SRH services offered at clinics are not addressing autistic children, and this makes it hard to help them understand the importance of those services" (FGD-2, P-4). Healthcare providers often lack the necessary resources, such as visual aids or simplified language, to communicate effectively with adolescents who may have varying levels of cognitive and communicative abilities. The absence of autism-friendly services creates a barrier for adolescents with autism, making it difficult for them to fully benefit from available SRH services.

In terms of healthcare provider preparedness, many participants pointed out that staff members are not adequately trained to work with adolescents with autism. One adolescent participant shared, "When I go to the clinic, I don't feel like they understand me, and sometimes they welcome me last" (FGD-1, P7). This lack of specialized training means that healthcare providers may struggle to engage effectively with autistic adolescents, which can lead to feelings of frustration and confusion on both sides. Several caregivers echoed this sentiment, explaining that healthcare providers often default to a one-size-fits-all approach that does not take into account the individual needs of adolescents with autism. One caregiver commented, "Sometimes, the healthcare providers just rush through appointments without understanding how these children process information or experience anxiety" (FGD-3, P-6).

Additionally, the study revealed significant gaps in service provision, including the absence of autism-specific programs for SRH education and support. Adolescents with autistic spectrum disorder often do not receive the tailored information they need to understand puberty, consent, and safe relationships, leaving them vulnerable to exploitation or misunderstanding. One caregiver stated, "There are no programs that teach these adolescents in a way they can understand, so they miss out on important information" (FGD-1, P-5).

Participants also suggested several recommendations to improve the quality of SRH services for adolescents with autism. These included the need for specialized training for healthcare providers on autistic spectrum disorder, the creation of autism-friendly clinics with sensory accommodations, and the development of SRH educational materials that are accessible to autistic adolescents. One caregiver recommended,

If the healthcare providers had training in autistic spectrum disorder and used simple, visual tools, I think these children would be more comfortable and would understand better. (FGD-1, P-4)

Cultural and Social Barriers

This study identifies cultural and social barriers that hinder adolescents with autistic spectrum disorder from accessing sexual and reproductive health (SRH) services in Rwanda. These barriers are deeply rooted in cultural attitudes, stigma, misconceptions, and taboos surrounding both autistic spectrum disorder and SRH education, which influence family and community willingness to seek out appropriate services for autistic adolescents.

Cultural attitudes and stigma surrounding both ASD and SRH education play a critical role in limiting access to SRH services. This stigma extends to the sexual and reproductive health needs of autistic adolescents, making it difficult for families to openly discuss and seek services. A caregiver shared,

In our culture, there is a misconception that talking about sexuality with children with disabilities is not necessary. People assume they don't need that kind of education because they believe they don't understand it. (FGD-3, P-4)

This cultural belief can prevent families from acknowledging the SRH needs of adolescents with autistic spectrum disorder and from seeking out services that address these needs.

This study also identifies misconceptions and taboos around SRH education for adolescents with ASD. One of the most common misconceptions is that adolescents with autistic spectrum disorder are uninterested in or incapable of understanding sexual matters. A participant remarked,

Some people believe that children with ASD are not interested in relationships, so they don't need to know about things like consent or safe relationships. (FGD-3, P-6)

These misconceptions stem from a broader lack of awareness about autistic spectrum disorder and sexual development, which leads to a lack of age-appropriate SRH education for autistic adolescents.

Families are often concerned about how they will be perceived by their community if they seek such services, especially when it involves discussing sensitive topics like sexuality. One caregiver expressed,

Some parents are afraid to take their children to a health center for SRH services, people might talk about them negatively. It's hard to even talk about it openly in their family. (FGD-2, P-1)

This reluctance to engage with healthcare services is compounded by the fear of judgment and social exclusion, which leads to a delay or complete avoidance of seeking necessary SRH care.

Another important factor identified in this study was the challenge of breaking taboos surrounding discussions about sexual and reproductive health. For many families, the very act of talking about sex and relationships with adolescents, particularly those with autism, is seen as inappropriate or unnecessary. One participant stated, "In our culture, talking to children about sex or relationships is often seen as something shameful, especially when it involves children with disabilities" (FGD-2, P-4).

Policy and Institutional Barriers

The finding highlighted significant policy and institutional barriers that restrict access to sexual and reproductive health (SRH) services for adolescents with autistic spectrum disorder in Rwanda. While Rwanda has legal frameworks and institutional structures in place aimed at providing SRH services, the implementation of these policies faces several challenges, which hinder their effectiveness in addressing the specific needs of adolescents with autism.

Although Rwanda has progressive policies aimed at improving access to SRH services for adolescents, including those with disabilities, these policies often do not address the unique needs of adolescents with ASD in a clear way. A participant remarked,

The policies are there, but they don't seem to take into account the specific challenges that adolescents with ASD face when accessing SRH services. The services available are general, but they don't address the nuances of ASD. (FGD-1, P-5)

The implementation of policies is also constrained by institutional challenges. Many healthcare providers lack specific training on how to support adolescents with autistic spectrum disorder in navigating SRH education and services. Another caregiver pointed out,

Even though the health centers are supposed to provide these services, many healthcare providers don't have the training to understand autism. The health professionals might not know; how to communicate with these children or how to make sure they get the right services. (FGD-1, P-4)

This lack of training leads to poor quality of care, which prevents adolescents with autistic spectrum disorder from accessing the services they need.

Additionally, institutional barriers are compounded by logistical and resource limitations. There is often a shortage of specialized healthcare professionals, such as counselors or therapists who are trained to work with adolescents with autistic spectrum disorder, in many health centers.

Even though parents are aware of the services available, the nearest health center doesn't have the right staff to provide specialized care for their children. (FGD-2, P-4)

Discussions

This study highlights critical sexual and reproductive health needs and barriers that adolescents with ASD face in Rwanda. These findings align with and expand upon findings from other recent studies, offering a deeper understanding of the specific challenges encountered by autistic adolescents in accessing SRH education and services. Accordingly this study identified three primary SRH needs: clear and autism-friendly education, support for social and emotional aspects of SRH, and improved access to SRH services with trained professionals.

Conceptual Framework from the Finding of Sexual and Reproductive Health Needs for Adolescents with Autistic Spectrum Disorder in Rwanda

This framework illustrates the interplay between individual, community, systemic, and structural factors that shape the sexual and reproductive health (SRH) experiences of adolescents with autism. The model recognizes that adolescents with ASD have valid and diverse sexual needs, yet often face marginalization, misunderstanding, and exclusion from appropriate education, support, and services.

Central to meeting these needs are three critical pillars: autism-friendly SRH education, psychosocial and emotional support, and equitable access to SRH services delivered by trained professionals. However, these are often hindered by several intersecting barriers. Awareness and knowledge gaps among caregivers, educators, and healthcare providers contribute to misinformation and neglect of autistic adolescents' SRH needs. Accessibility challenges, including sensory sensitivities, physical access, communication difficulties, and affordability, further limit service utilization. Inadequacies in the quality of SRH services, stemming from a lack of training and inclusive approaches, compound these issues.

Additionally, cultural and social barriers, such as stigma around both autistic spectrum disorder and sexuality, inhibit open dialogue and education. Policy and institutional barriers, including the absence of autism-inclusive SRH policies and weak inter-sectoral collaboration, exacerbate these challenges. The community environment including caregiver support, school-based education, and community attitudes, acts as either a facilitator or constraint. Addressing these dimensions collectively through inclusive policy-making, education reform, service adaptation, and community engagement will foster a more supportive environment where adolescents with Autistic Spectrum Disorder can exercise their sexual rights, gain autonomy, and achieve overall well-being. The detail interaction of each factor is displayed below (Figure 1).

The emotional and social aspects of SRH, such as understanding social relationships and boundaries, were recognized as crucial by both adolescents and caregivers. This is consistent with the findings of other research that, adolescents with autistic spectrum disorder often struggle with social cues and relationship-building, which makes them more vulnerable to exploitation.¹⁴ These challenges necessitate structured guidance and interventions aimed at helping autistic adolescents develop emotional regulation and understand relationship dynamics.

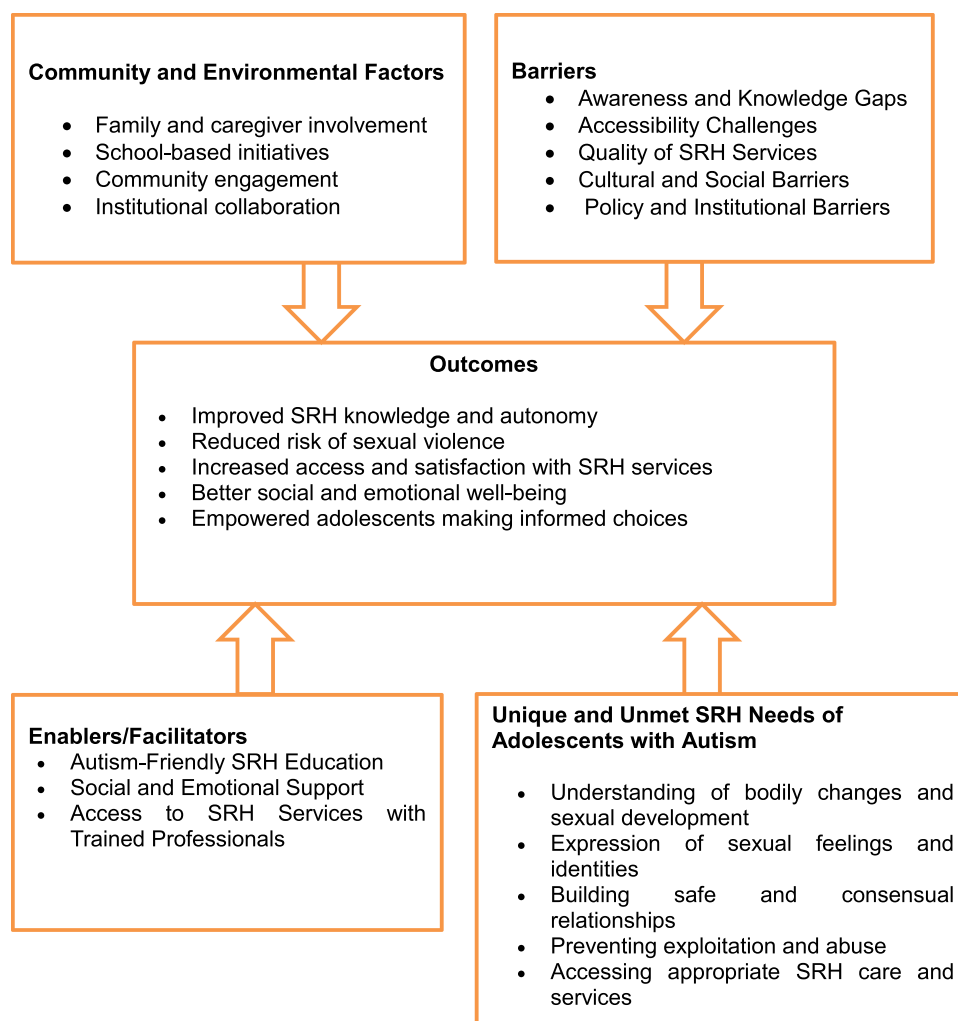


Figure 1 Framework indicating Sexual and Reproductive Health Needs for Adolescents with Autistic Spectrum Disorder in Rwanda.

The third critical need identified was improved access to SRH services and the training of healthcare providers in autism-specific communication strategies. In this study, many healthcare providers are not adequately trained to support adolescents with autism, which limits their ability to access SRH services. This finding is supported by a study that found that healthcare providers frequently lack the necessary knowledge to provide tailored SRH services to autistic individuals.¹¹

Regarding the barriers preventing adolescents with autistic spectrum disorder from accessing SRH services; lack of awareness and knowledge, accessibility challenges, and cultural and social barriers were identified. Those findings were consistent with other studies, such as that of which highlighted significant gaps in awareness of SRH services for individuals with developmental disabilities.¹⁷ The lack of specialized information and tailored resources limits access to necessary care, reinforcing the need for targeted awareness campaigns. About physical barriers including; transportation, clinic accessibility and financial constraints were identified as significant obstacles to accessing SRH services. This finding is corroborated by research from physical accessibility and financial barriers are among the most significant challenges faced by individuals with autistic spectrum disorder in accessing healthcare, particularly SRH services.⁹

Cultural attitudes and stigma surrounding autistic spectrum disorder and SRH in Rwanda were also identified as key barriers. Participants noted that many communities hold misconceptions about the sexual and reproductive health needs of adolescents with autism, often seeing them as asexual or uninterested in relationships. This aligns with findings from a study which highlighted the role of cultural stigma and misconceptions in limiting the willingness of families to seek

SRH services for individuals with autism.¹⁸ Overcoming these cultural barriers requires comprehensive education and awareness campaigns to challenge misconceptions and promote acceptance.

The findings of this study have significant implications for improving sexual and reproductive health education and services for adolescents with autistic spectrum disorder in Rwanda. There is a clear need for tailored SRH education that incorporates visual aids, simplified language, and interactive learning approaches to accommodate the unique learning needs of this group. Healthcare providers must receive specialized training in autism-specific communication strategies to improve service delivery and enhance accessibility. Additionally, addressing the cultural stigma surrounding autistic spectrum disorder and SRH, as well as improving awareness and availability of services, is essential for ensuring that adolescents with autistic spectrum disorder can access the care and support they require. The study's findings also suggest that policymakers should prioritize the inclusion of autism-friendly SRH education and services in national health programs to promote the sexual and reproductive rights of adolescents with autism, while fostering a more inclusive and supportive environment for this often-overlooked population.

Strength and Limitations of the Study

While the qualitative approach enabled in-depth exploration of participants' experiences, several limitations should be acknowledged. The use of a mixed FGD methodology involving adolescents and caregivers may have influenced openness of discussion and limited the expression of divergent views. The sample also lacked clear representation across the autism spectrum, meaning the findings may be more applicable to verbal adolescents and may not reflect the experiences of those with more severe communication difficulties. Given the sensitive nature of the topic, social desirability bias may have affected participants' responses. Additionally, potential power dynamics between the researchers and participants particularly adolescents may have constrained free expression. Data collection from only two ASD centers limits the generalizability of the findings to the wider population in Rwanda.

Conclusion

The findings underscore the necessity of autism-friendly SRH education, specialized support for emotional and social development, and improved access to services that are tailored to this population. The barriers to accessing SRH services, including limited awareness, physical and financial constraints, and cultural stigma, were identified as key challenges.

Recommendations

Based on the findings of this study, the following recommendations are made:

It is crucial to design and implement SRH education programs that are specifically tailored to the learning needs of adolescents with ASD, incorporating visual aids, simplified language, and interactive activities. The Rwandan Ministry of Health, in partnership with professional bodies, should integrate mandatory modules on neurodiversity and disability-inclusive communication into the continuous professional development (CPD) curriculum for all nurses and community health workers. Efforts should be made to raise awareness among families, caregivers, and the general public about the SRH needs of adolescents with autistic spectrum disorder, to combat stigma and encourage open discussions on these topics. Addressing physical, logistical, and financial barriers to SRH service access is essential. This includes increasing the availability of autism-friendly services and ensuring that transportation and financial assistance are made available for families in need. Future research should employ participatory methods, co-designed with autistic individuals, to explore SRH needs.

Abbreviations

ASD, Autistic Spectrum Disorder; ADHD, Attention Deficit Hyperactivity Disorder; DSM, Diagnostic and Statistical Manual of Mental Disorders; FSC, Family Sexuality Communication; IDI, In-Depth Interview; TEACCH, Treatment and Education of Autistic and Related Communication Handicapped Adolescent; SRH, Sexual and Reproductive Health; STIs, Sexually Transmitted Infections.

Data Sharing Statement

All information/data used for this research are available from the corresponding author and can be accessible with request.

Ethical Considerations

The University of Rwanda research IRB provided the researcher with ethical clearance letter (Kigali 17/09/2024, Ref: CMHS/IRB/663/2024). Gisozi Autistic Spectrum Disorder center and Humura Autistic Spectrum Disorder center administration provide the researcher permission to conduct the study. The consent forms were signed by caregivers and assent form was used for adolescents with Autistic Spectrum Disorder who agreed to engage in the study. To maintain privacy and motivate respondents to provide accurate and complete information, no names appended to the consent. Participants were informed that they might leave the study at any time without having to provide any reason. Participants also provided informed consent for publication of anonymized responses/direct quotes. The ethical approach followed in this study aligns with the principles outlined in the declaration of Helsinki.

Acknowledgment

The authors extend their heartfelt gratitude to all study participants for generously sharing their time, experiences, and insights, which were vital to the success of this research. We are equally thankful to the dedicated staff at the University of Rwanda, Schools of Nursing and Midwifery and the College of Medicine and Health Sciences for their unwavering support and collaboration throughout the study. Our sincere appreciation also goes to the staff and administrators at the Rwanda Center for Autistic Spectrum Disorder and Humura Autistic Spectrum Disorder Center for their invaluable contributions, facilitation, and commitment to this study.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Disclosure

The authors have declared that there are no conflicts of interest in this work.

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