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## Mother's Experience in Helping Autistic Teenage Girls Become Independent during Menstruation

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### ABSTRACT

This study aimed to describe the role of mothers in assisting autistic teenage girls during menstruation in Special Needs Schools (SNS). The research used a qualitative approach. The informants in this study were three mothers of autistic teenage girls who attend SNS. The data collection technique used in this study was semi-structured interviews. Data analysis was based on the Miles and Huberman model, which includes data reduction, data presentation, conclusion drawing, and verification. The results showed that the role of mothers in assisting autistic teenage girls during menstruation includes modelling, mentoring, organizing, and teaching. The forms of the mother's role included providing examples of how to manage hygiene during menstruation, guiding the child to maintain cleanliness by changing sanitary pads 3-4 times a day, providing the child's needs, including choosing the type of sanitary pad, and delivering information related to menstruation from the start.

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## 1. INTRODUCTION

Autism Spectrum Disorder (ASD), or autism, is a developmental disorder that affects an individual's ability to interact socially, communicate, and engage in behaviour (Remington & Pellicano, 2019). According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013), autism spectrum disorder is a neurodevelopmental disorder characterized by persistent deficits in communication and social interaction, along with restricted patterns of behaviour, interests, or activities. This condition impacts a child's learning process, communication, integration into the environment, social relationships, and self-care abilities (Kauffman & Hornby, 2020).

Autistic children entering adolescence undergo physical, social, and emotional changes. The physical development of autistic adolescents during puberty is like that of other teenagers; however, emotional changes may not align with chronological age and may be delayed or require a longer time to mature emotionally. The physical development of adolescent girls undergoes significant changes, such as increased height, enlarged hips, breast development, the growth of hair under the armpits and around the genital area, and the onset of menstruation (Wijaya, 2019).

Menstruation is an indicator of sexual maturity in adolescent girls. It is the process of bleeding through the vagina due to the shedding of the endometrium (uterine lining), occurring periodically (Villasari, 2021). Normally, menstruation lasts for 3-6 days, although some girls experience menstruation lasting 1-2 days, while others may have it for up to 7 days. Most girls experience menstruation between the ages of 9 and 14 years (Santrock, 2019; Rizqita et al., 2024).

All adolescent girls experience menstruation, including autistic girls. However, various challenges arise when autistic adolescent girls menstruate, such as underdeveloped social maturity, an inability to understand physical changes, self-esteem issues, complexities in self-care activities, and personal hygiene concerns. Additionally, the communication barriers faced by autistic children limit their access to important information (Wijaya, 2019). Having an autistic child who is approaching adolescence and already menstruating presents unique concerns for parents and caregivers, particularly in managing menstrual hygiene (Dural et al., 2020). In this regard, parents must provide guidance to help their children maintain hygiene and self-care.

Early assistance is necessary to ensure that, by adulthood, the child can perform these tasks independently (Cummins et al., 2020). The role of parents, especially mothers, as sources of information for their children in managing menstrual hygiene is not an easy task. This is due to the communication challenges faced by autistic children, requiring effective methods of conveying information to ensure the child understands and can manage the process independently (Mustofa et al., 2020). Research by Arslan et al (2024) shows that parents should teach their autistic children how to use sanitary pads and panty liners as soon as possible.

Mothers face several challenges, such as feelings of taboo, limited information, and difficulties in communicating with their children. Parents often feel confused about how to support their autistic children as they approach adulthood. The lack of information complicates the process for mothers seeking guidance on how to educate their children about menstruation, what needs to be taught, and how to communicate these concepts to an autistic child. Mothers tend to teach their children based on their own personal experiences with menstruation. This lack of knowledge is intertwined with the cultural taboos around discussing menstruation with children (Wijaya, 2019).

In the school environment, autistic adolescent girls require special attention and care. In addition to parents, teachers play a crucial role as educators in providing information about menstruation. Autistic children entering adolescence will experience menstruation and need education on menstrual hygiene management, such as how to use sanitary pads, maintain cleanliness, and care for themselves during menstruation (Arslan et al., 2024)

Based on a preliminary study conducted with a mother of an autistic adolescent girl in a Special Needs School (SNS), it was found that the mother expressed concerns about the puberty phase. The mother paid close attention, focusing on helping her daughter during the initial menstruation period, dedicating special time to support her. She worried that excessive activity or movement could cause the sanitary pad to shift, potentially leading to blood stains on her daughter's clothes.

Several studies have examined the challenges faced by autistic adolescents, particularly regarding self-care and communication during menstruation. Wijaya (2019) and Groenman et al. (2022) highlighted the difficulties mothers face in supporting their autistic daughters through menstruation, often due to a lack of resources and structured guidance (Groenman et al., 2022). Arslan et al (2024) focused on mothers' view of autistic children about menstrual hygiene, while Lilawati (2020) emphasized the importance of early intervention for self-care at home (Lilawati, 2020). Wardani and Ayriza (2020) explored the challenges on parents but did not specifically address menstruation (Wardani & Ayriza, 2020). This study offered several novel contributions:

- 1.1 It specifically focused on the role of mothers in assisting autistic adolescent girls during menstruation, a topic not explored in depth in previous studies.
- 1.2 It detailed the strategies mothers use, such as modelling behaviour and teaching proper menstrual hygiene practices.
- 1.3 The study employed a qualitative approach with in-depth interviews, capturing rich personal experiences, unlike previous studies that relied on quantitative methods.
- 1.4 It explores the unique context of SNS, addressing how school environments affect maternal support for menstruation management.

Based on the above explanation, this research on the role of mothers in assisting autistic adolescent girls during menstruation was conducted to explore how mothers support their daughters through this significant developmental stage. The purpose of this study was to describe the specific roles that mothers play in guiding their autistic daughters through the menstruation process. This includes the roles of modelling, mentoring, organizing, and teaching, all of which are crucial for helping these girls manage menstruation, maintain hygiene, and adapt to the physical and emotional changes that come with puberty. By focusing on the mother's role in this context, the study aimed to provide insights that can assist other families, caregivers, and educators in supporting autistic adolescent girls during menstruation.

## 2. METHODS

The type of research conducted in this study was qualitative research, which focuses on understanding social phenomena through in-depth exploration of individual experiences. This qualitative approach is based on an inductive reasoning process, where data is gathered and analysed to generate patterns and insights, rather than testing predefined hypotheses. The research relied on objective, participatory observation of the subject matter, ensuring a deep understanding of the context and behaviours of the participants. The observation was specifically directed at selected individuals or social groups, chosen for their relevance to the research objectives and the focus of the problem being studied. In this particular study, the primary data sources were three mothers of autistic adolescent girls, as they are key figures in the support and care of their children during significant developmental milestones such as menstruation. Below is a list of the informants, who provided valuable insights into the roles and experiences of mothers in assisting their daughters through the menstruation process.

**Table 1.** List of Informants

No	Initial	Education	Occupation
1	AA	High School	Housewife
2	AB	High School	Entrepreneur
3	AC	Diploma	Employee

The data collection technique used in this study was semi-structured interviews, which allowed for in-depth exploration of the experiences and perspectives of the participants. The data analysis technique employed was content analysis based on the model by Miles and Huberman, which is commonly used in qualitative research. The analysis process was carried out interactively and continuously, with ongoing refinement of the data until saturation was reached, meaning no new significant information emerged. The Miles and Huberman analysis model includes several stages: data reduction, where irrelevant or redundant information is removed; data presentation, where the findings are organized and summarized; conclusion drawing, which involves interpreting the data to identify patterns or themes; and verification, where the findings are cross-checked to ensure accuracy and reliability. This systematic approach ensured a thorough and comprehensive analysis of the data.

## 3. RESULTS AND DISCUSSION

This research aimed to describe the role of mothers in supporting autistic adolescent girls during menstruation. The results showed that the role of mothers in this process involves four main aspects: modelling, mentoring, organizing, and teaching. Mothers acted as models by demonstrating the proper steps in managing menstruation, such as using sanitary pads and maintaining hygiene. In the mentoring role, mothers guided their daughters through the process, offering reminders and support in changing pads and maintaining cleanliness. The organizing role included preparing necessary supplies like pads and ensuring they are available. Lastly, the teaching role involved educating the daughters about menstruation, helping them understand the physical and emotional changes involved. These roles were crucial for providing effective support, with mothers adapting their approach based on the unique needs of their autistic daughters.

### 3.1. Role of Modelling

The findings indicate that the mother's role in modelling is evident through the demonstration of appropriate behaviour for the child. All informants mentioned that the mothers provided examples of how to use sanitary pads, how to clean genital areas, and how to dispose of used pads. The mothers also demonstrated washing hands before and after changing pads. This process involves frequent reminders and regular practices, especially in teaching the child to wash hands and maintain personal hygiene. One informant practiced these actions directly with her child, while others offered verbal guidance.

The role of modelling is fundamental, as it sets the example for the child. This aligns with Arslan et al (2024), who emphasize the importance of mothers demonstrating the correct procedures for menstruation care (Arslan et al., 2024). By modelling these behaviours, mothers ensure that their daughters learn to independently manage their menstrual hygiene. According to Cummins et al. (2020), demonstrating and practicing these steps helps the child learn to manage menstruation even in public spaces, promoting independence. This role is crucial for teaching proper hygiene routines, and mothers' active involvement in showing how to manage menstruation helps autistic girls build competence and confidence in this aspect of self-care.

### 3.2. Role of Mentoring

The mentoring role involves guiding the child in maintaining menstrual hygiene. The mothers in the study directed their daughters on how to use sanitary pads for comfort and instructed them to replace them every 4-5 hours. There were variations in the frequency of pad replacement. Some children, like those of informants AA and AC, needed assistance, while others, like the daughter of informant AB, could replace pads independently, though the mother still had to step in during moments of reluctance.

The mentoring role is essential for ensuring that autistic adolescents understand and maintain hygiene during menstruation. Hartati et al. (2020) suggest that regular pad changes are necessary to maintain genital health, ideally every 3-4 hours. In this study, the frequency of pad changes varied, reflecting the unique needs of each adolescent. Some children required more guidance or support in managing their menstruation, while others had developed a level of independence. This underscores the importance of the mother's active role in guiding the child and stepping in, when necessary, especially in situations where the child is reluctant or struggles with certain tasks. The mentoring role is thus about providing the necessary support to help the child become more autonomous over time.

### 3.3. Role of Organizing

The organizing role of the mother includes meeting the needs of the child during menstruation, such as preparing sanitary pads, underwear, clothes, and other necessities. The mother also selects the type of sanitary pad based on her own preferences. The mothers emphasized the importance of regularly changing the pads to avoid discomfort. Some mothers also noted that tracking the menstrual cycle, often by marking a calendar, helps them monitor the child's menstrual schedule.

The organizing role is critical in ensuring that all the necessary supplies are available for managing menstruation. Hartati et al. (2020) highlight the importance of mothers selecting appropriate sanitary products and ensuring their daughters change pads regularly. This study found that mothers were proactive in organizing supplies, such as pads, underwear, and other items, to ensure their daughters had everything needed to manage menstruation effectively. The act of marking the menstrual cycle on a calendar reflects the mothers' efforts to stay on top of their daughters' menstrual health and routines. This organizing role is vital in creating a supportive and structured environment for the adolescent girl, ensuring that she has the tools and reminders necessary to manage menstruation with minimal guidance.

### 3.4. Role of Teaching

Teaching is an essential role where the mother provides information about menstruation. The mothers are the primary source of information for their daughters. Informant AA introduced menstruation to her daughter before her first menstruation by showing her how it works, while informants AB and AC explained menstruation once their daughters had experienced it. Teaching about menstruation and self-care is vital to ensure that autistic girls are not afraid of the process and are prepared for it. This aligns with the view of Arslan, et al (2024), who emphasize the importance of educating adolescent girls about what to expect and how to manage menstruation (Arslan et al., 2024).

The teaching role is crucial for ensuring that autistic adolescent girls understand menstruation and are not fearful or confused by it. This is consistent with Arslan, et al (2024), who argue that early education about menstruation helps to alleviate anxiety and fear (Arslan et al., 2024). The findings reveal different approaches to teaching menstruation: some mothers introduced the topic before the first menstruation, while others waited until the event occurred. Regardless of timing, the teaching approach focused on ensuring the child was equipped with the knowledge needed to manage menstruation independently. The role of the mother as the primary source of information is essential, as it helps the child navigate both the physical and emotional changes associated with menstruation. Furthermore, using simple, direct language, as well as practical demonstrations, helps autistic adolescents better understand the process (Stichter et al., 2019).

The findings of this study underline the vital role of the mother in guiding autistic adolescent girls through the challenges of menstruation. The roles of modelling, organizing, teaching, and mentoring provide a comprehensive approach to menstrual care, helping these girls develop independence and confidence. The mothers' efforts to model behaviour, provide guidance, prepare supplies, and educate their daughters are integral to helping them manage menstruation effectively. However, it is important to recognize that each autistic adolescent has unique needs, and further research is necessary to explore how mothers can provide individualized support, considering differences in behaviour, communication abilities, and sensory processing. These findings can serve as a foundation for creating resources and guidelines to support parents, especially in the context of managing menstruation for autistic adolescents in Indonesia.



#### 4. CONCLUSION

The role of mothers in supporting autistic adolescent girls during menstruation is crucial. The findings of this study highlight the importance of the roles of modelling, organizing, teaching, and mentoring. The role of modelling involves mothers providing examples of how to handle menstruation and its process. This modelling is essential because most autistic children require visual examples and step-by-step guidance in managing menstruation. The mentoring role requires mothers to guide and remind their daughters throughout the process of managing menstruation and changing pads during a menstrual cycle.

The organizing role is more dominant, as mothers primarily prepare the necessary items, such as sanitary pads, and guide their daughters on proper disposal, maintaining cleanliness, and changing pads. The teaching role involves mothers continuously providing information about menstruation, its processes, and the associated consequences.

All these roles must consider the child's individual characteristics. Mothers need to pay attention to the child's ability to receive, understand, and develop the necessary skills. These factors will influence the support process. Mothers must find creative and appropriate methods based on the condition of the autistic adolescent to ensure that the guidance provided yields the best possible results.

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#### 6. AUTHORS' NOTE

The authors confirm that there are no conflicts of interest in this authorship. This manuscript is free from plagiarism and has been written in accordance with ethical guidelines and academic writing standards. All sources have been properly cited, ensuring the integrity of the research process.

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