
The Autistic Child During Circumcision Based on Parents Experience

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Abstract

Introduction: One of the reasons for male circumcision is religious reasons, so it is mandatory for a Muslim male, including those with autism spectrum disorder, to be circumcised.

Objectives: this study aims to explore the experiences of parents who have autistic children during circumcision.

Methods: The method used in this study is a qualitative study with a phenomenological study design. This study was conducted on 10 parents who had boys with Autistic Spectrum Disorder using who were selected using a purposive sampling technique. This research was conducted from December 2022 to March 2023 with data collection techniques using face-to-face structured interviews method and then analyzed using a thematic analysis.

Results: the results of this study group parents' experiences into three categories, such as 1) experience before circumcision, 2) experience during circumcision, and 3) experience after circumcision.

Conclusions: health education and counseling are needed for parents before and after their child undergoes a circumcision process.

Keywords: Autism Spectrum Disorder, circumcision, children, parents.

1. Introduction

Circumcision is the surgical removal of some, or all, of the foreskin (or prepuce) from a penis (Blank et al., 2012). Circumcision for men is done for various reasons such as religious, cultural, social and medical (Abdulwahab-Ahmed & Mungadi, 2013; Ullmann et al., 2017). As for Muslim men, circumcision is an obligation ordered by religious law to be carried out in order to fulfil religious orders (Abdulwahab-Ahmed & Mungadi, 2013). Religious requirements are the main reason for circumcision in 92.6% of children. However, 89.6% of respondents think that circumcision also has medical benefits. Half of the children (54.1%) had a delay in circumcision (range from 2.5 months to 13 years), although 81.2% of parents argued that circumcision should be performed within 60 days of birth. According to Answer and colleagues (2017), babies born in facilities had less delay in circumcision (49.1%) compared to babies born at home (60.5%).

Although there is no mutual agreement yet on the age of circumcision, it should be carried out. However, most of the debates about the best age at which to perform male circumcision focus on the following age groups: neonatal and infancy period, phallic stage (Bicer et al., 2015). In this regard, autism spectrum disorder (ASD) is one of the serious developmental disorders that is usually diagnosed below the age of three years (Salari et al., 2022). ASD is a neurodevelopmental disorder characterized by deficits in social communication and the presence of restricted interests and repetitive behaviours (Hodges et al., 2020). ASD Epidemiological studies have shown a rapid increase in the prevalence of ASD in recent years, with a prevalence of four to five times more in boys than girls (Salari et al., 2022). The phenomenon in the field during the study was based on brief interviews with parents who had ASD children, on average, newly circumcised ASD children when they entered the age of 12-13 years when the child completed primary school education.

Parents will experience confusion when they first decide on a child to be circumcised. The results of previous studies have shown that parents' decisions to perform circumcision were affected by their evaluations of the procedure's medical risks and benefits. Additionally, their considerations of the relationship between being circumcised, hygiene, and health, as well as their interactions with healthcare providers. Also, the relevance of

their decision is based on their experiences circumcising previous children (Reeves & Mishtal, 2022). Parents who have a son with ASD who will be circumcised need to make various preparations both physically and mentally before and post-circumcision. Before circumcision, a surgeon needs to explain the procedures to children and parents regarding what to be performed during circumcision and provide education about circumcision to mentally prepare the child so as not to feel afraid during the circumcision process (Rizalar et al., 2017).

Circumcision in children with ASD requires a specific approach and skill from a surgeon. Regarding the circumcision technique that will be used, a Circumciser or a surgeon needs to conduct a preliminary assessment before the implementation of circumcision so that the techniques used are in accordance with the condition of the child with ASD. There are so many techniques used for circumcision such as conventional circumcision, shield and clamp devices, but every technique has its advantages and disadvantages (Andersen et al., 2021).

The results of the initial preliminary study conducted by researchers through brief interviews with several parents, who had children with ASD, who were going to be circumcised felt that they were not exposed to information about circumcision in ASD children. Some parents also did not accompany their children during the circumcision and chose to leave the room on the grounds that they were afraid and could not bear to see the circumcision process being carried out on their children. So far, there have not been many research results that discuss the experiences of parents who have sons with ASD in terms of carrying out circumcision on their children. Therefore, this made researchers interested in exploring how the experiences of parents who have children with autism spectrum disorder during circumcision.

2. Objectives

This study aims to explore the experiences of parents who have autistic children during circumcision.

3. Methods

This is qualitative research with a phenomenological study design. Phenomenological research is a deep investigation of what experiences mean to people. At its core, it concerns the investigation of everyday human experiences in order to learn people's common sense understanding and the meaning they make of their experiences and the experiences of others (Bliss, 2016). This study attempts to explore the experiences and perceptions of parents who have children with autism spectrum disorder when performed circumcision based on the perspective of their respective parents. This study was conducted on 10 parents in Pontianak City, West Kalimantan Province, Indonesia who had boys with autism spectrum disorder. Sampling technique employed a purposive sampling method. The inclusion criteria of participants were parents who had boys with ASD aged 10-14 years old at the time of circumcision. This research was conducted from December 2022 to March 2023 using data collection techniques in the forms of structured interviews, and face-to-face interviews, then the data were analyzed using thematic analysis.

Interviews were conducted at participants' homes with a duration of 45 minutes to 60 minutes for each informant. Before starting the interview, the researcher explained about the research objectives, the benefits and impacts of the research, as well as the rights of key informants. Key informants can withdraw or resign if they object to participating in this research. After the explanation, the researcher also requested the key informants to sign the consent form if they agreed to participate, as proof of their willingness and agreement to participate in this study voluntarily. The instruments used for interviews were developed by researchers based on the purpose of the study. Some examples of key questions based on interviews include 1) what did you prepare before your child circumcision? 2) how did you feel when watching your son with Autism during a circumcision? 3) How did the father or mother persuade her son so that he wants to do circumcision? 4) What did the father or mother do after the child underwent circumcision?

According to Braun & Clarke (2006), thematic analysis consists of six stages including transcribing all audio recording interview data verbatim, coding, searching for themes, reviewing themes, defining and naming themes, and the last process is writing (Braun & Clarke, 2006). At the first stage the researcher first transcribed all the audio recorded in Indonesian. The Indonesian transcripts were then translated into English with the help of bilingual Indonesian-English translators (Indonesian and English) to ensure the accuracy of the translation. The researchers re-read the translation results and crosschecked them so that the translation results are actually transcribed according to what the key informants conveyed. In the second stage the researcher did the coding for the transcribed results. It was done by identifying the data that is considered to be related to the research questions and then encoded all the data items line by line into rows. In the third stage, after coding the researcher then

created sub-themes that are grouped into themes. Finally, at the last stage, the researcher wrote the entire research findings. All the process of stages in analyzing the data was carried out manually in a Microsoft Word document.

In addition to the participant, the researcher also conducted peer checking. The techniques conducted for establishing credibility were member checking and triangulation. Transferability was established by purposive sampling and thick description.

4. Results

Participants in this study were mothers of children with ASD totaling seven participants and fathers totaling 3 participants. The age of circumcised children ranges between 10 – 14 years old, and all of whom are Muslim and male. The results of the study found that there are 3 categories of experiences of the parents whose autistic children were circumcised, such as: 1) experience before circumcision, which consists of two themes: parents looking for information about circumcision in children with autism and children’s mental preparation. 2) experience during circumcision which consists of three themes, such as parents' feelings when they see their child circumcised, the kinds of distractions they give to their child when they are circumcised, as well as providing additional assistance as needed, 3) experience after circumcision consists of one theme: supervising and helping child's activities. The themes of the complete research results can be seen in table 1 as follows.

Table 1. Result of study

Categories	Theme	Subtheme
Experience before circumcision	1. Parents looking for information about circumcision in children with autism	1.1. Finding circumcision methods used for children with autism 1.2. Selection of circumcision site 1.3. Informant sources
	2. Children’s Mental preparation	2.1. Reading prayers for the safety of children 2.2. Giving rewards or gifts to the children if they agree to be circumcised
Experience during Circumcision	1. Parents’ Feelings when watching their child’s circumcision procedure.	Feeling anxiety
	2. providing distraction for the children.	Children play gadgets during circumcision
	3. Giving the child extra help during the circumcision procedure.	3.1. Hugging a child during circumcision 3.2. Being next to the child while holding the child's feet and hands
Experience after Circumcision	1. Supervising child's activities	1.1. Helping meet children's daily needs 1.2. Temporarily limiting a child's physical activity

a. Experience before circumcision

Before doing circumcision in children with ASD, some preparations that parents will do are to find as much information as possible related to circumcision in children with ASD. The followings will describe the themes and sub-themes of the parents' experience before their child is circumcised

Theme 1: Parents looking for information about circumcision in children with Autism

The results of the interviews showed that all participants tried to find information to prepare for the child's circumcision. Some of the information needed by parents includes the method of circumcision to be carried out, the selection of places where circumcision to be carried out either it will be at home, clinic or hospital. Additionally, consultation with doctors and asking other parents who already have experienced carrying out circumcision in ASD children.

Sub theme 1: Finding circumcision methods used for children with Autism

Parents want the methods and techniques used by the circumciser or surgeon to be completely safe for their children because parents realize their children are different from other children. Thus, they need an experienced circumciser, and the methods used are suitable for their children with special needs, as stated by the following participants:

"My husband and I were trying to find information about which type of circumcision that is good for my son who is an autistic, as well as an experienced circumciser so that the child can rest after that, we choose general anesthesia, because we believe that it is safer, if we choose the one who uses the clamps, we are afraid if the child will pull the clamp out later" (M1)

"There are many methods offered for us to choose, but we are also confused about what is right because there is no previous experience, so we are still thinking about it and want to consult again with a therapist with a doctor later" (M5).

"As a father, it is important to me that my son can be circumcised safely, safely, and soundly, whatever model of circumcision it is, the important thing is to be circumcised and be grateful for..." (F8).

Sub theme 2: Selection of circumcision site

Some parents who have children with ASD prefer their child to be circumcised at home. The reason why parents choose to do it at home is so that they can accompany their children when carrying out circumcision and provide comfort for the children, as expressed by some of the following parents:

"If circumcision is carried out in the hospital, he will be traumatized by the hospital environment while in the operating room, it is good to be carried out at the circumciser's house, so we can hold him and we can be next to him..." (M3)

"We prefer to stay at home so that our children feel comfortable when their parents are beside him..." (M4)

"My wife and I agreed to perform the circumcision on our son at home so that (we) parents could stay by his side..." (F9)

In addition, there are parents who choose to carry out circumcision in clinics and hospitals because of consideration of the child's condition that is impossible to do at home as the following parent's expression:

"My son has severe ASD so it is safer to be circumcised in the hospital because, if it is forced to be carried out in the clinic or at home, I am afraid of unwanted risks because my son likes to struggle and cannot calm down..." (F10).

"My son was circumcised in the hospital to make him calmer because my wife and I were also afraid to accompany him, especially my son likes to throw tantrums so that if there are experts in the hospital, there is no need to worry" (F8)

Sub theme 3: Informant sources

Before the child is circumcised, parents will look for information related to circumcision in children with ASD. In this study, parents asked other parents who had children with ASD who had been circumcised as a source of information, as expressed by some of the following participants:

"I called one of the mothers who has an autistic child as well, and she told me a lot about how she prepared their autistic child for circumcision..." (M4)"

"... I went to the house of one of my friends to ask about her experience when her special needs son was circumcised at home" (M3)

In addition to asking other parents, some parents, especially fathers, invite his wife to consult directly with surgeons to ensure them that their children can be circumcised safely, as some parents say:

“My wife and I, before circumcising our son, sought for a consultation with a surgeon so that we could get direct information from the experts because our child is different from other children. So, at least we, as parents, have an idea of what circumcision is like because honestly there is no experience at all” (F8)

“...Not satisfied with hearing stories from other parents who had experience of their children being circumcised, my wife and I went to the doctor practice by bringing the child so that the doctor could see directly the condition of our child and we could hear directly the opinions of the experts...” (F10)

Theme 2: Mental preparation of the child

Various preparations made by parents when the child will be circumcised. The preparations that parents do including mental preparation of child so that the child with autism who is going to be circumcised can undergo the circumcision calmly. There are two sub-themes related to the mental preparation of children carried out by parents, such as the first by reading the prayer of safety or reading the holy verses of the Quran and the second by giving gifts to child if the child wants to be circumcised.

Sub theme 1: Reading prayers for the salvation of children

Most of the participants in this study held a joint prayer activity for the safety of their sons who were about to be circumcised. This activity of reading prayers for safety was carried out before the implementation of circumcision activities, as expressed by some of the following participants:

"As a Muslim family, we asked God through prayers of safety for our son who will be circumcised, may it be smooth and safe and secure..." (M2)

“It is already a habit that if there is an activity, we always invite neighbors to recite prayers, especially this is our son's circumcision activity so we asked God for protection so that the implementation is safe and secure” (M5)

“It is like a tradition that if there are activities such as circumcision in the place where we always invite neighbors and family to read prayers together asking God so that everything goes safely and we as parents have a calm heart...” (M6)

Sub theme 2: Giving gifts to child if they want to be circumcised

Parents have their own way to make their children willing to be circumcised by giving gifts to their children if they want to be circumcised. The prizes given were smart phones and toys. As some of the following participants expressed:

“Before circumcision, my husband and I took my son to a mobile phone store and bought it for his son as a gift if he wanted to be circumcised...” (M7)

“My son loves toys so we bought him his favorite toys so he would be circumcised, as a gift...” (M1)

b. Experience during circumcision

There are three themes obtained from the experience of parents accompanying children during circumcision, such as feelings of anxiety, distracting of children and requiring of extra assistance

Theme 1: Parents' feelings when watching their child's circumcision procedure.

Various feelings arise when parents accompany their children during circumcision both at home and in the hospital. Feelings that arise such as anxiety which was felt by both the father and mother of an autistic child who undergo circumcision. As quoted from the following interviewees:

"As a father, to be honest, I was very anxious when I saw my son being taken to the operating room for circumcision..." (F8)

“...Be anxious, sir, especially me as a father who has also felt circumcision, as a parent, feeling of anxiety and worry must exist, especially my child is with special needs, who is different from other children...” (F10)

“My husband couldn't bear to see him so I tried to accompany my son when circumcised at home, even though I was anxious at the time but I tried to endure that feeling for the sake of my son...” (M2)

“...Anxious, sir, especially when he was injected with anesthetic the first time, my son cried and screamed...” (M4)

Theme 2: Distracting of children

Parents have different ways to distract children when circumcised, almost all parents distract children by giving smartphones so that children can play games on smart phones or watch movies through smartphones. Here are some parents' expressions during the interview:

“He likes to play a mobile phone, so during the circumcision we let my son calm down and we gave him a mobile phone so that he played games during the circumcision process, otherwise he could throw a tantrum and scream ...” (M1)

“Let calm down at that time we distracted him by giving him a gadget and he watched cartoons through a gadget until he finished circumcision...” (M5)

“At first, he cried and struggled, after that we tried to give him a cellphone, thank God after being given a cellphone, he was calm because he watched and played games on his cellphone...” (M7)

Thema 3: Providing extra assistance

Circumcision in children with autism requires a special approach that is different from other children. They are not used to new people around them so the presence of parents and closest people who understand the child's condition is needed. So, the child does not struggle when circumcised, and parents can help calm the child when the child begins to struggle by holding the feet and hands so that the doctor can work calmly and safely, as quoted from the following interview:

“...so, my wife and I help hold it, I hold the legs and my wife hold our child's hands so as not to struggle or tantrum when injected ...” (F9)

“My son went tantrum when he was injected, so we held it so that we would not be wrong with circumcision later...” (M6)

“The doctor who circumcised brought one assistant, and we, who held, were three people because my son was fat so his energy was strong...” (M2)

c. Experience post-circumcision

Only one theme of parents' experiences after their children were circumcised: supervising and helping child's activities.

Theme 1: Supervising and helping child's activities

After circumcision, a child must be monitored by parents in his every activity, especially as the child is with autism disorder so that parental supervision must be extra. In addition, parents also help meet the daily needs of children, both minimal and partial assistance until the wound heals. As quoted from the following interviews:

“Get used to being able to bathe by himself, but after circumcision, I helped and taught him how to bathe so that the wound does not get water and heals quickly...” (M5)

“After circumcision I accompanied my son to sleep because fear of nights he slept restlessly and the wound was bleeding or the bandage came off...” (F8)

“I forbade him from playing outside for temporary because I am afraid of infection or loose stitches, so I really followed him everywhere...” (M6)

“Fortunately, the circumcision time coincided with school holidays, so even his activities were only at home, I kept an eye on him lest he jump or run, worried that he would fall and bleed his wounds...” (M3)

5. Discussion

The principles of circumcision are asepsis, adequate excision of the outer and inner preputial skin layers, hemostasis, protection of the glands and urethra, and cosmesis. Many methods used today belong to one of these

main classes. The shield and tongs adopt the use of devices for the effect of circumcision negating the use of knives in most cases. (Abdulwahab-Ahmed & Mungadi, 2013). The result of this review article is that the technique of using shields and tongs such as Smart Clamp circumcision has several advantages, for examples, minimal bleeding, rarely injures the glans penis and faster. On the other hand, it is disadvantageous because it is more expensive. Besides, , the edema often occurs in the circumcision area, in general, the circumcision method using shielding and clamping tools is more profitable and more practical than conventional methods (Andersen et al., 2021).

According to researchers, each method or technique used has its own advantages and disadvantages, especially for children with ASD. Thus, the selection of circumcision techniques needs to be adapted to the child's condition. Risks that will occur such as severe bleeding during circumcision, penis scratched or cut scalpel due to children who cannot stay still and scream during circumcision require special methods or techniques and professional medical personnel who are experienced in dealing with ASD children. Parents should directly bring a child with ASD to consult with a doctor or surgeon to determine the circumcision method which is suitable for their child. Considering that each ASD child is unique, so it is necessary to consider the child's condition at that time.

Some parents who have children with ASD prefer the child to be circumcised at home so that the child comes to the house. There is a sense of worry from parents to circumcise their children without assistance considering their children with special needs. Therefore, it is not surprising that some parents choose to carry out the circumcision at home so that the children can get assistance from both parents. According to researchers, the selection of circumcision site is very important for children with ASD, especially children who show uncontrolled behavior that can endanger themselves. Accordingly, appropriate methods are needed such as general anesthesia or general anesthesia and can only be done in the operating room and done by a team of experienced doctors. Children with ASD show different symptoms depending on the degree of ASD experienced. In general, children with ASD experience impairments in three aspects, namely social interaction, communication and behavior with restricted and stereotyped interests (Parmeggiani et al., 2020). So, it requires the assistance of parents who understand the condition of their children to be next to their children to make it easier for doctors to communicate with their children because some of the languages that children speak and the behaviors that children show can only be understood by the child's parents.

According to researchers based on the results of this study, sources of information for parents who will circumcise their children who have autism disorders can come from other parents who already have previous experience or come from health workers such as doctors or nurses, or therapists. However, there are no specific research results that explain the sources of information used by parents in finding information about circumcision in autistic children. Nonetheless, it was found that parents occupy the largest percentage as sources of information about circumcision in girls (Dewi H. Susilastuti, Eddy Kiswanto, Novi Widyaningrum, 2017).

Furthermore, mental preparation is necessary not only for children who want to be circumcised but also parents who will witness their children circumcision. Hence, some families hold prayer recitation activities together and recite the holy verses of the Qur'an in order to get calm. Reading prayers can positively affect a person and reduce stress and depression, and provide comfort and hope. In this regard, Islam unquestionably influences many aspects of Muslim life in particular. Therefore, most Muslims practice or participate in at least some religious and spiritual activities to bring tranquility (Yucel, 2010). While some parents give gifts to children, according to researchers, this is one-way parents provide motivation for children to be willing to be circumcised. The gifts referred to here are children's favorite items such as toys or smartphones so that children feel happy and motivated to be circumcised. Previous study has suggested that good support by families ahead of circumcision can reduce anxiety levels (Bitcar et al., 2022). According to researchers, it is important for families to provide support to children before circumcision, where the support provided can increase children's self-confidence and reduce anxiety faced. Support provided by the family can be in the form of mental, financial, spiritual support or in the form of giving gifts so that children want to be circumcised.

As a matter of fact, most parents experienced anxiety and stress when the child underwent surgery in the first 24 hours, but 16% of them displayed suggestive criteria for acute stress disorder (Scrimin et al., 2009). Parents who have children with autism spectrum disorders will feel stress, especially a mother because mothers spend more time with children at home (Begum & Mamin, 2019;Jiu & Rungreangkulkij, 2019). According to researchers, feelings of anxiety are felt by parents when accompanying circumcision children because parents have not had previous experience coupled with the condition of children suffering from autism so that parents feel worried about their children.

Circumcision will cause pain that it is necessary to perform techniques to reduce the pain and anxiety in children. Some previous studies results stated that distraction and hypnosis are effective in reducing needle-related pain and distress in child (Birnie et al., 2014). Mobile video games were found to be more effective in distracting children than watching videos, thereby reducing a child's anxiety (Allani & Setty, 2016).

When performing circumcision at home, parents are always beside the child and help in calming the child such as by holding hands or feet and hugging the child so as not to struggle or move while circumcised. It is because if the child moves a lot or goes berserks while circumcised it can be dangerous for the child and at risk of injury. Parents are also the main and most important link in the care, education and supervision of persons with disabilities. Accepting parents are able to give love to a disabled child, without feeling rejected (Kandel & Merrick, 2007). In addition, parents who can accept the presence of such child positively will provide unlimited affection whatever the child's condition in various situations, including when the child needs the presence of parents beside him (Jiu & Rungreangkulkij, 2019b).

Children with autistic disorder are unique children, who sometimes have hyperactive behavior, so parents should be aware of these behaviors pre and post circumcision. Therefore, extra supervision is needed by parents in the care of children with autism disorders both at home and in the community. Most of those who help meet the needs of children during circumcision are mothers. Mothers help their autistic children to do some activities such as bathing, eating, putting on clothes, and other self-cleaning activities. In this case, the care given by family members to children varies depending on the mildness and severity of autism disorders that children experience (Jiu & Rungreangkulkij, 2019a).

Some parents, too, forbid their children from doing excessive activities after circumcision to avoid bleeding and infection after circumcision. Circumcision complications such as bleeding, infection, phimosis, urinary retention, and necrosis, although not all cases, can cause complications depending on many factors. Particularly, the risk of complications and severity is higher in traditional circumcision than in medical circumcision (Abdulwahab-Ahmed & Mungadi, 2013)

6. Conclusion

Before carrying out circumcision, parents should first consult with a doctor regarding the child's condition in order to get accurate information regarding the method and technique of circumcision to be used. Child circumcision not only causes anxiety for children, but parents also experience the same feelings. Especially those who are circumcised are children with autism disorders so that special approaches and techniques are needed to make the children cooperative during circumcision. Parents are expected to accompany the child before and after circumcision in order to monitor the child's condition so as to avoid post-circumcision complications such as bleeding and infection. Finally, further research studies with various variables such as interventions are expected to be carried out in terms of dealing with anxiety in parents and children with different designs

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