Journal of Multidisciplinary Healthcare

Dovepress
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ORIGINAL RESEARCH

"The People Criticized Me and Insulted Me Due to Having a Child with Defect": Experiences of Somali Parents of Children with Anorectal Malformation

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Background: Treatment of anorectal malformations (ARM) and the management of clinical outcomes are challenging for families. While most studies focus on mothers suffering from care burden, high stress, and low quality of life, there is limited knowledge of what fathers of children with ARM experience; therefore, this study aimed to examine how both mothers and fathers have experience caring for children with ARM and how beliefs and cultural issues affect the perception of congenital anomalies.

Methods: A qualitative design. Consolidated criteria for reporting the qualitative research guidelines were used in this study. The guidelines for thematic analysis were followed for data analysis.

Results: Ten mothers and six fathers were interviewed, and their mean age was 32.5 ± 4.2 years. Of the 75% (n = 12) illiterate and 93.7% (n = 15) had an expanded family type, all their religious affiliations were Muslim. The four main themes were (1) ambiguity, (2) challenges, (3) stigma, and (4) coping, which were determined in line with the results of the data analysis of parents' views on having and caring for children with ARM.

Conclusion: In this study, many Somali parents reported that they lacked disease and treatment knowledge, physical exhaustion, and some difficulties related to a lack of access to the hospital because of living in rural areas, caring for the child, and dealing with long-term complications, colostomy, anal dilatation, and enema before or after anoplasty. While all parents mentioned that having a child with ARM was a fate, it was seen as punishment by their close social environment. Consequently, this study could serve as a foundation for planning comprehensive healthcare and physical and psychosocial support for multidisciplinary health professionals.

Keywords: anorectal malformation, pediatric colorectal, parenting, quality of life, care burden, congenital abnormalities

Introduction

Anorectal Malformation (ARM) is a congenital colorectal malformation that requires early diagnosis, surgical treatment and comprehensive care.[1–3] Treatment, anorectal malformation involves a gradual and challenging process requiring hospitalization and multiple surgical interventions immediately after the birth of the child. In some cases, treatment is possible with single-stage primary repair, whereas in others, colostomy can be opened with multistage surgical treatment.[4,5] The treatment of anorectal malformation involves a gradual and challenging process that requires hospitalization and multiple surgical interventions immediately after the birth of the child. In some cases, treatment is possible with single-stage primary repair, whereas in others, colostomy can be opened with multi-stage surgical treatment.[3–5] Treatment of ARM not only affects the child but also has a lifelong impact on both the child and the parents. In the postoperative period, children with ARM must live with conditions such as incontinence, regular enema, genital reconstruction, catheterization and scarring.[6,7]

The fact that children with congenital anomalies face many challenging processes after birth may cause parents to feel overwhelmed, tired, tense and anxious.[8] Although there are a limited number of studies on the stress factors and difficulties that parents face after delivery, studies have reported that parents experience significant levels of maternal stress, isolation, anxiety about the future, and lack of information about the disease.[9,10]

Received: 12 March 2024
Accepted: 27 May 2024
Published: 7 June 2024

There are studies showing that parents with children with ARM have high care burden and low quality of life.[11,12] In a study conducted by Pruthi and Mohta, it was found that the quality of life of parents with a child with ARM was negatively affected as the care burden increased.[11] In a study conducted by Bhartiya et al to evaluate the quality of life and care burden of parents with children with ARM, it was found that they experienced high levels of care burden and had a lower quality of life.[13]

Parents of children with anorectal malformations not only have the heavy responsibility of caring for the child at home, such as anal dilatation, colostomy care, and enemas, but also have to face economic and psychological problems.[14] Many studies have demonstrated that the psychosocial well-being and disease acceptance of the family, especially the mother, is the strongest determinant of the child's psychosocial and behavioral well-being.[15–18] Kubota et al found that patients' quality of life was directly related to the mother's quality of life.[19] Parental acceptance and adaptation to the disease enables the child to acquire better coping strategies.[20] Although this process requires a multidisciplinary approach, when combined with professional psychological support systems, it helps to strengthen children's self-esteem, encourage the child and family to use effective coping strategies, support interpersonal relationships in children, and promote independence and autonomy.[21,22]

In the literature, studies investigating the effects of treatment and care of a child with ARM on parents are limited to survey-based methods.[11–14,23–26] Moreover, one study was found in which the impact of parents' having a child with ARM on their lives was examined through in-depth interviews.[10] For families struggling with the life-changing effects of surgery on the child's later life, such as incontinence, regular enemas, genital reconstruction, catheterization and scarring, little is known about the psychosocial, emotional and behavioral impact of illness and treatment.[10] Therefore, in this study, a qualitative study was conducted to investigate the physical, emotional and social effects of having a child with anorectal malformation (ARM). This study is the first to be conducted in Somali, and it is thought that the results of this study will contribute to the literature by revealing Somali parents' attitudes towards congenital anomalies and their methods of coping with their children's diseases.

Material and Methods

Study Design and Setting

In this descriptive study, a qualitative research design was used, using semi-structured interviews with parents of children who underwent ARM surgery in this descriptive study. A qualitative descriptive approach is a research method that aims to explore the experiences and perceptions of participants within a particular phenomenon and which can facilitate understanding of the phenomenon of interest by obtaining a rich description of participants' perspectives.[27] In consideration of the fact that this study aimed to explore the impact of the illness and care of the child with ARM on the caregiver's life from their own life experiences, a qualitative descriptive design was used in which life experiences were explicitly described and elicited.

This study was conducted in the pediatric surgery outpatient clinic of Somalia Turkey Recep Tayyip Erdoğan Training and Research Hospital in Mogadishu, East Africa, between December 2022 and January 2023. Surgical treatment and nursing care for new born babies with ARM are performed in neonatal units. Follow-up of children with ARM after discharge is performed in the pediatric surgery outpatient clinic. For surgery older children are admitted on a 12-bed ward with staff including two specialist doctors, three pediatric surgical assistants and nine nurses, where ARM surgery has been performed for 10 years. The follow-up of children with ARM after discharge was performed in a pediatric surgery outpatient clinic.

Participants

Purposive sampling was used to obtain the study sample. The participants in this study were 10 mothers and six fathers with children who underwent ARM and were admitted to the pediatric surgery outpatient clinic of the hospital for their children after surgery. Participants were included if they (i) had children who had undergone surgery for ARM, (ii) were admitted to the pediatric surgery outpatient clinic of the hospital for follow-up of children after ARM surgery, and (iii) agreed to participate in the study. When data saturation was achieved, the interviews were stopped.

Data Collection

Data were collected using interview questions Form (IQF). The IQF consists of descriptive characteristics of the child and parent, including age, gender, associated anomalies, child order for children with ARM, education, and seven open-ended questions (See Box 1). All interviews lasted 25–45 minutes and were tape-recorded by the researcher (RYHM) in the education room of the pediatric surgery outpatient department at the hospital.

Ethical Considerations

The study was approved by the Non-Interventional Clinical Research Ethics Committee of the Mogadishu Somalia-Turkey Recep Tayyip Erdoğan Training and Research Hospital, and written permission was obtained from the hospital where the study was conducted (approval number: MSTH −12,766/748, Date: December 19, 2022). Written and verbal consent was obtained from all the participants. The study followed the ethical principles in accordance with the Declaration of Helsinki. The participants informed consent included publication of anonymized responses.

Data Analysis

The guidelines for thematic analysis included familiarization with data, developing initial codes, identifying possible themes, refining preliminary themes, finalizing relevant themes, and producing a scholarly report by Braun and Clarke for data analysis.[28] The interviews were recorded using a voice recorder, and the recordings were transcribed verbatim into Somalian and then translated into English by the same researcher (RYHM), whose native language is Somalian and proficient in English (RYHM). Subsequently, expressions with similar meanings in the written text were identified, and "coding" was performed by the same researchers (RYHM, DS).The researchers (RYHM and DS) independently mapped the codes according to appropriate themes in terms of their similarities and differences. Themes were formed by discussing the codes of the authors (RYHM and DS). The researchers continued to analyze the data until new themes were created. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were used as a guide for reporting this study.[29] The participants were anonymized using a letter (mother, M; father, F).

Trustworthiness

To ensure the trustworthiness of the study, the consistency, transferability, credibility, and confirmability stages were carried out.[30] For consistency, data were collected (RYHM) and analyzed by the same researchers (RYHM, DS). For transferability, the same researcher (RYHM) directly transcribed the recorded participants' statements into written text without including their own interpretations. To ensure credibility, the interviewed parents were re-interviewed and asked whether the themes were appropriate; no changes were made to the themes because of their feedback. For verifiability, a pediatric surgeon verified the findings of the study and the researchers (RYHM and DS) reached a consensus.

Results

Sixteen parents were interviewed, and their mean age was 32.5 ± 4.2 years. Of 62.5% (n = 10) these were mothers, 75% (n = 12) were illiterate, and 93.7% (n = 15) had expanded family type, all of the irreligious affiliation was Muslim Sunni and all of their monthly income was under \$1000. Of 75% (n = 12) children with ARM of participants were male, mean age of them was 10.5±6.2 months (minimum= 1, maximum = 24), 37.5% (n = 6) had associated anomalies (Table 1).

Box 1 Interview Questions

- What do you know about anorectal anomalies (diagnose of your baby)?
- How did you feel when you learned the diagnose of your baby?
- Please tell me which factors evoked negative responses to your experience in caring for your child after ARM surgery?
- Please tell me which factors evoked positive responses to your experience in caring for your baby after ARM surgery?
- How would you describe your feeling with about illness of child now?
- Please describe how your baby's illness influences your/family' daily life.
- How do you think your family members/friends look at your baby' illness? How do you feel about their responses?

Four main themes were determined in line with the results of the data analysis of parents' views on children with ARM and their care. The themes included ambiguity, challenges, stigma, coping (Figure 1).

Theme 1: Ambiguity

All parents needed to learn what ARM was and how to care for their infants after hospitalization. They stated that they first heard about ARM when they had a child and that there were no children with the disease in their circle. The interviews revealed that encountering the disease for the first time caused them to experience uncertainty and ambiguity regarding how to parent their children with ARM. The parents expressed how she made sense of ARM, a congenital anomaly in her child, as follows.

> I didn't know anything about anorectal anomalies before I delivered my baby. When I learned the diagnosis of my baby, I felt sadness and nervous. No stool came out from the baby. I asked my mother how I cared for my baby. (M1)
>
> …. When I gave birth a day later and the child was not defecating, I checked on my baby and then I saw my baby's anas was close. I feel sad. I called my mother to tell what happened. (M3)

Table 1 Characteristics of Parents and Children (n=16)

Variable	
Child	
Gender n (%)	
Male	12 (75)
Female	4 (25)
Age (month), mean± SD (min-max)	10.5±6.2 (1–24)
Associated anomalies n (%)	
Uro-genital	4 (25)
Tracheo-esophageal malformations	1 (6.25)
Chromosomal anomaly	1 (6.25)
No	10 (62.5)
Child order n (%)	
7	1 (6.25)
8	5 (31.25)
9	3 (18.75)
10	5 (31.25)
12	2 (12.5)
Parent	
Parent n (%)	
Mother	10 (62.5)
Father	6 (37.5)
Age (year), mean± SD (min-max)	32.5 ± 4.2 (29–44)
Education status n (%)	
Illerate	12 (75)
Elementary school	4 (25)
Family type n (%)	
Nuclear family	1 (6.3)
Expanded family	15 (93.7)
Religious affiliation (%)	
Muslim Sunni	16 (100)
Monthly income n (%)	
<$ 1000	16 (100)

Abbreviations: SD, standard deviation; Min, minimum; Max, maximum.

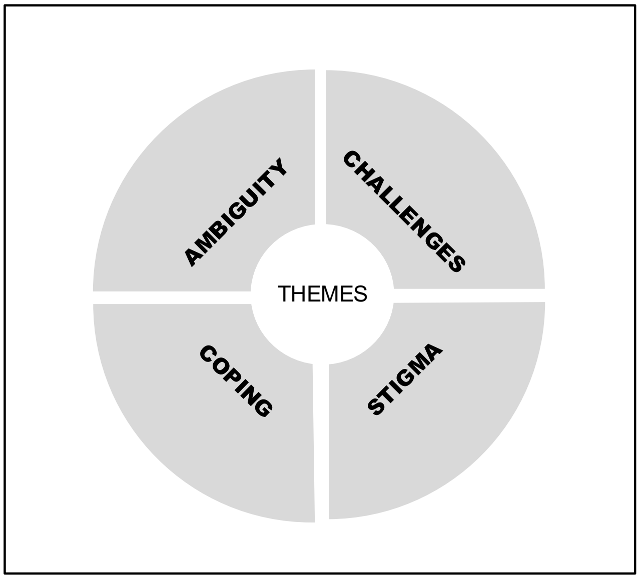

Figure 1 Research themes.

> After 24 hours of delivery, no stool from the baby I noticed that there was a problem. I didn't know what to do at that moment. I've never heard anything like that from anyone before and I've never seen anything like that. I honestly didn't have any prediction of what was going to happen. I didn't know if it was a curable disease. (M5)

Four parents expressed uncertainty about how the child would be accepted by the environment and how to tell them about it when they had limited knowledge about the nature of the disease. One mother and one father stated as follows:

> …I was shocked because I had never heard of it. I don't know anything. I felt sad, and worried. I called my husband and father to tell them what happened to my baby. What worried me was that when people heard about my child's condition, I wondered what my friends and neighbors thought about him… (M10)

> I heard about this disease for the first time, none of the families around me have children with this disease. When our child was born, we called my first mother-in-law and father-in-law. I did not know how to explain it. (F12)

Theme 2. Challenges

Challenges included the living in a rural area, care burden, and physical exhaustion. When asked about factors would evoked negative experience in caring for their babies after surgery, six mothers and two fathers described the difficulty related living in a rural area. Parents stated as follows:

> I take care of my baby alone. I am tired and feel lonely. I don't want anyone to take my baby. I came from a rural area to do surgery for my baby and it was difficult to live with relatives because our family had not lived in the urban area. This made me feel sad… (M1)The most challenging thing was to come to the hospital from a distant place for the operation. It affected both economically and our lives adversely. (F14)We had to go to the hospital not only once but every time we had problems, and after the surgery there were many problems with the hole in her abdomen. (F16)

Living with children who underwent ARM surgery was associated with a care burden which led to lifestyle restrictions and physical fatigue by all mothers. Mothers' narratives clearly identified the fact that they were alone in caring for the child with ARM, that they did all the care for their children alone and that they were tired. Two mothers of them expressed that this physically restricted their lives:

> For long time I didn't take care of myself, including my husband and my other children, I didn't go anywhere, I only focused on my sick baby.I didn't sleep well. (M6)

> It’s difficult to care baby alone because all family members they afraid to care baby with colostomy”. (M8)

Themes 3. Stigma

All participants stated that they were blamed by their neighbors, close friends, and family members and that God gave this disease to their child as a punishment for the mother’s own mistakes or crimes. These findings are remarkable because they show how congenital anomalies are culturally perceived in Somalia, an underdeveloped country. The fathers and mothers stated that ARM was treated as a stigma as follows:

> People have told me that the reason you have a child with anorectal anomalies is because I have done something wrong before. (M2)

> When people heard about my child’s condition, they criticized me and insulted me, but when the colostomy closure was done, they thought better. (M7)

> My some of my family say that I have already committed crimes that is why I delivered this baby. The family is still afraid of my baby. (M5)

> All family blamed my wife because she delivered baby with anorectal anomalies… (F11)

> Before the operation they judge me but after operation now they love my baby (F16)

Theme 4. Coping

One of the most striking themes of this study was coping with the situation. In this sample, beliefs facilitated the adoption of a child with congenital anomalies by parents. In this study, parents’ approaches and responses to their children’s illnesses were shaped by their views on religion and spirituality. Moreover, the interviews showed how the religious beliefs of parents influence their explanation of the cause of a child’s illness and their perception of the severity of the illness. Acceptance, prayer, dua, and supportive care were identified by parents as factors that facilitated coping with caring for children with ARM.

> I am coping with the condition by making dua to recover my baby. Everything is okay, and I am satisfied with what God has written for me. (M3)

> Talking with my friend, my friend helps me to recover from stress and also prayer and Dua and making prayer. (F14)

Discussion

An important strength of this study is that it is the first in Somalia to offer insight into how parents have experience caring for children with ARM and how beliefs and cultural issues affect perceptions related to congenital anomalies. Moreover, in a systematic review which was conducted by Svetanoff (2022) it was indicated that there is a lack of study in which was explored to experience of fathers with children who had ARM.[31] In regarding, this research is the pioneer to explore to experience of both mothers and fathers of children with ARM in the literature. In addition, this study contributes to the literature by showing how children with congenital anomalies are perceived by their parents and society, and how all parents use their belief systems to cope with their child’s illness.

Parents identified the following issues that experience on care for children with ARM: (1) ambiguity; (2) challenges; (3) stigma; and (4) coping with condition. One important theme of our study was the ambiguity related to encountering the disease for the first time. Parenting a child with ARM is stressful.[25,32] Parents have to deal not only with caring of their child’s disease but also need to have better information about the congenital malformation, treatment, care management of children with ARM.[33] In this study, both mothers and fathers indicated that they lacked knowledge of the disease and how to be parent their child with ARM. Families need to have clear communication between the nursing staff and physicians.[34] In a study from Sweden, it has been suggested that parents of children with ARM need to have information and education about this disease and close follow-ups.[35] A study conducted by Reppucci et al has shown that the first source of information on Instagram was from personal accounts, the second source was on Facebook was from support groups, and the last one was on Twitter was from health care providers.[33] Considering that internet access is insufficient in families in relation to their economic situation in the population of this study, encouraging parents to have better information about illness and participating in caring for their children before discharge can reduce parents' stress, which can lead to ambiguity for family.[31] Initially, physicians and pediatric nurses need to be aware of both the mother and father, who have insufficient knowledge about the disease and care of their children.[36]

Challenges

Another important theme of this study was the challenge. In this study, all parents lived in rural areas that needed access to the hospital for treatment and follow-up of their children in urban areas. A lack of access to community and home health resources could be related to feelings of isolated and stressful situations in caring for their child.[31,37] In developing countries, parents' fear may increase with economic insufficiency and problems in commuting long distances to obtain an appointment for surgery.[38] This study shows that easy access to healthcare is extremely difficult for Somalian families with a child with a congenital anomaly requiring long-term surgical treatment in an underdeveloped country. Similar to our study, a study that aimed to investigate the present situation of quality of life and negative emotions of parents of children diagnosed with ARMs in China found that parents who live in rural areas, pay for medical treatment out of pocket, and have multiple children are more likely to be anxious about the need to take their children across urban areas to seek professional treatment.[14]

Having a child with a chronic illness or congenital malformation has a heavy impact on family members.[11] Parents of children with ARM suffer a high level of stress related to parenting.[32] Some caregivers have reported that the constancy of care contributes to the burden of that care and can be overwhelming and isolating.[39,40] As most mothers in this study were exhausted from dealing with the long-term complications, colostomy, anal dilatation, and enema before or after anoplasty and caring for their other children, they reported that they suffered from not being able to do anything for themselves in daily life.[14,41,42] In addition, while fathers did not mention physical exhaustion, all mothers suffered from physical exhaustion related to their own caring for their child with ARM. Meeting the needs of a child with a chronic condition may lead to caregiver burden and a sense of being overwhelmed by responsibilities. This can be exacerbated by chronic fatigue.[43] The result of this study is consistent with a multicenter study in the Netherlands indicating that the mothers of children with ARM are significantly less satisfied about their physical functioning that fathers.[42] Based on most often, often mothers assume the primary responsibility of caregiver and are at greatest risk for caregiver burden.[12,43] It appears that it is critical for healthcare providers to have awareness of the especially mothers are likely to face with physical exhaustion and facilitate involvement of fathers and other family members in discharge education during hospitalization.

Unmet needs in the lives of parents and the care of children with ARM lead to a low quality of life, increased care burden, and increased stress. In a study that aimed to assess the quality of life and care burden of parents of children with ARM, most parents of children with ARM had moderate to severe care burden.[13] In another study by Pruthi and Mohta (2010) showed that about half of the parents of children with ARM perceived a moderate care burden.[11]

Stigma

Another striking finding in the present study was that most mothers of children with ARM reported an extremely high level of stress-related blaming in the social environment. Similar to our study, Yue mentioned that patients with anorectal illness in China must deal with shame from social stigma and difficulties in the medical context.[44] Because of cultural perceptions, the anorectal area is viewed as a private domain overlaid with a sense of shame and stigma. In contrast, a child born with a congenital heart condition is not treated as a silent matter and the awareness, empathy, and understanding in the wider community provide such families with a sense of comfort and support that is not available to ARM families.[45] In regard, it is thought that it could be effective that should also be included in multidisciplinary team for families of children with ARM requiring lifelong follow-up. It is important to consider a multidisciplinary approach, including a psychologist, to ensure appropriate support from the caregivers.[32]

Coping

Disease acceptance of the family, especially the mother, is closely related to the psychosocial and behavioral well-being of children with ARM.[16,17,31,46] Acceptance to disease in the family leads to better coping skills acquired by the child with ARM.[20]

Diseases may lead families to turn to spiritual guidance as a method of understanding and coping with the disease. Trust in a higher being or purpose provides meaning for many children and their families that assists them as they cope with disease.[47] All parents in this study reported that they head towards spiritual guidance for coping. Considering that the vast majority of Somali individuals practice Islamic faith, it is crucial that making dua and prayer cannot be overlooked a scoping strategies for families.[48] Moreover, it should not be forgotten that nurses need to assess the family's coping and respect the family's view and avoid being judgmental towards their beliefs.[49]

Culture influences the concepts of health and healthcare in several ways. The worldview of people in the family determines how health is viewed.[49] One of the views of health beliefs identified by Andrews and Boyle (2008) is magico-religious paradigm.[50] This view argues for health and disease being determined by supernatural forces such as God, gods, magic, spirits or fate. Parents who believe in this paradigm find relief through prayers, rituals, and faith healing. In this study, while parents saw ARM as fate, the social environment of parents saw it as punishment for the actions of mothers who had children with ARM. In line with our results, it is wise to ask parents what they think causes congenital anomalies, or how they believe they can stay well.

This study has several limitations. First, the study had a small sample size for the following reasons:16 participants led to data saturation. Second, although the study including both Somali mothers and fathers of children with ARM is pioneering research for other studies, the results could not be generalized. Other studies have compared the outcomes between parents in developing and developed countries.

What the Study Has Added

This is the first study to show attitudes towards caring for children with ARM and the experiences of parents of children with ARM in the Somalia region. While this is only descriptive research, it is the first to explore the experiences of both mothers and fathers of children with ARM.

The results of this study could serve as a foundation for planning comprehensive health care, including both physical and psychosocial support, for parents of children with ARM.

The perceptions of Somalian parents could be informative to be aware of the culture and beliefs of society, and how these affect the views of parents on caring for children with ARM.

Conclusion

To deliver comprehensive and high-quality healthcare, it is important to identify how parents perceive care for children with ARM. Consequently, the results of this study could serve as a foundation for planning comprehensive healthcare and physical and psychosocial support by multidisciplinary health professionals. Pediatric nurses should be aware of the perception of illness, challenges, and coping strategies of parents to care for children with ARM. Moreover, they must identify culturally and socially stigmatized facts regarding children with ARM and their families to provide appropriate and competent care. Early identification and parental groups could be helpful for parents in the expression of thoughts and feelings, improving quality of life, and decreasing stress in parents.

Disclosure

The authors report no conflicts of interest in this work.

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