

PSYCHOSOCIAL BURDEN AND SUPPORT FOR PARENTS WITH CHILDREN HAVING ANORECTAL MALFORMATIONS

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ABSTRACT

Background: Anorectal malformation also refer to congenital defects mostly manifested by way of defective development of anus and rectum. Interventions to correct the anomaly can be done by way of surgical procedure. However, the surgery has always been complicated by delayed diagnosis since most of the children were discovered to have the condition while at home. As such, such delays in the diagnosis can lead to complications like distended abdomen due enlarged bowels. The psychological burden experienced by parents and caregivers of these children has continually been problematized in earlier nursing research. KNH provides medical attention to the children affected by ARM. Our study therefore investigated the psychological burden by these parents/caregivers. The study findings are hoped to be informative to the medical practitioners, parents/caregivers, policy makers in the health care sector and other stakeholders on need to put in place mechanisms to address rising incident of psychological burden which adversely affects the caregiving environment at home.

Broad Objective: To find out the psychosocial burden and support for parents with children having anorectal malformations.

Methodology: Cross sectional and descriptive research study. Data collection accomplished using questionnaires

administered to the parents/caregivers drawn from pediatric surgical outpatient clinic and ward 4A in specialized surgery department of the Kenyatta National Hospital.

Findings: Our results indicated that approximately 73% of the respondents received communication about ARM medical condition of their children from the doctors, while just over 26% of them reported that the same information was disseminated by the nurses. Additionally, a small percentage of the respondents (1.2%) received information from the counselors. On the question of psychological burden, 90% of the parent/caregivers received counseling services about the diagnosis and treatment plan upon receiving the news about what the child was suffering from. Further, approximately 88% of them were informed about the type of surgery that was to be conducted on their children.

Recommendations: Establishment of organized psychological support groups to mitigate mental stress experienced by parents and caregivers of children with ARMs. To ease the financial body of the parents/caregivers, more pediatric specialized personnel need to be trained, together with an increase infrastructure in order to develop ARM surgeries at County levels which will translate to reduced financial burden to the families.

Key Words: Anorectal Malformations; psychological burden

INTRODUCTION

Global statistics indicated that occurrence of anorectal malformations (ARMs) has rapidly been on the increase in the recent decades, and is widely regarded as one of the most prevalent congenital intestinal anomalies (Cassina *et al.* 2019). Through a population-based study in Italy, Cassina *et al.* (2019) report that approximately 3.09 per 10,000 births were reported to be cases of anorectal malformation. Additionally, reports from the United States indicated that the national incidences of anorectal malformations occur approximately 1 in every 500 live births (National Library of Medicine, 2021). Cases of congenital malformations have widely been reported in African countries. In Uganda, data collected from Uganda Tertiary Referral Hospitals between 2012 and 2016 suggested among the commonest congenital anomalies comprised anorectal malformations, Hirschsprung's, gastroschisis among others. Further, it was evident from the findings that mortality rates associated with congenital anomalies was relatively higher compared with high income countries (Cheung *et al.*, 2019). Bolia and Joshi (2022) reckon that from the global perspective, occurrences of ARMs are approximately 1-2 in every 5000 live births. Recently, the results of a multi-country analysis by Kancherla *et al.* (2023) indicated that in the 18 selected countries, the reported anorectal malformation rate was 3.26 per 10,000 total births. Subsequently, these and other similar reports provide evidence on the rising cases of ARM that require concerted efforts by various stakeholders and actors to provide adequate medical intervention amongst persons diagnosed with the condition.

Anorectal malformation refers to a wide spectrum of congenital anomalies whereby the anus is either absent or abnormally located outside the normal sphincter muscles (Flynn-O'Brien, Rice-Townsend, & Ledbetter, 2018). Kruger *et al.* (2019) define anorectal malformation as congenital abnormalities which occur at the terminal hindgut (Kruger *et al.*, 2019). Fernandes *et al.* (2020) define ARMs as a rare of congenital colorectal anomaly. ARM can also be defined as a congenital malformation which requires proper correction through surgical procedure (Van Ling *et al.*, 2021). Anorectal malformation also refer to congenital defects mostly manifested by way of defective development of anus and rectum (Saeed *et al.*, 2022). Islam *et al.* (2022) define ARM as the absence of functioning anus with an abnormal attachment of the anus or rectum with urinary or female genital systems in a newborn child and is largely considered as a birth defect which is associated with comorbidities that affect children from early stages. Congenital anorectal malformations normally occur as a result of abnormal hindgut development which are mostly manifested by way of malformations of both the anus and anal canal (Bar & Vélez, 2023). The present study was therefore be guided by these definitions in reflecting on psychological effects of anorectal malformations amongst parents and caregivers of children affected by ARMs.

Clinical research from different parts of the world provide a justification on the need to address medical challenges posed by incidences of anorectal malformation. Through a national birth cohort study, Ford *et al.* (2022) investigated prevalence of anorectal malformations amongst the five-year-olds in England between the years 2002 and 2018. The target population comprised all the National Health Service England Hospitals. Descriptive design was adopted in answering research hypotheses. Amongst the findings, it was established that 3.5 per 10,000

live births experienced cases of anorectal malformations. The findings further revealed that maternal age was one of the factors that affected the cases of anorectal malformations. Pelizzo *et al.* (2023) articulated on the need to improve the quality of life of ARMs patients through surgical interventions to reduce incontinence. The study was a retrospective survey focusing on patients aged between 8 and 18 years. Data collection was accomplished using questionnaires. Amongst other findings, it was established that surgical timing was correlated with the outcome in terms of fecal continence, which was found to improve whenever surgery was conducted before 3 months.

In Africa, several perspectives have been illuminated in extant research relating to an anorectal malformation. Lawal (2019) provides an overview of incidences of anorectal malformations across different African countries. Through a systematic literature review, the author articulates on the need to address challenges such as inadequate resources to provide surgical procedures amongst children affected by (ARMS). As a recommendation, pediatric surgeons need to adapt to low-resourced environments in providing medical attention to children diagnosed with anorectal malformations. In Nigeria, Nwokoro *et al.* (2020) investigated both the diagnosis and classification of the types of anorectal malformations. Through a retrospective study conducted between 2003 and 2013 prospective survey. Based on the findings, it was revealed that lateral invertogram registered 100% accuracy in terms of diagnosis and classification anorectal malformations. In Kenya, Oyania *et al.* (2023) used a case study of a 3-year-old female affected by vestibular fistula, who through an intra-operative procedure was later discovered to be affected by Mayer–Rokitansky–Küster–Hauser syndrome which is associated with skeletal, cardiac and anorectal anomalies. As a recommendation, the need to clearly distinguish between Mayer–Rokitansky–Küster–Hauser syndrome and vestibular fistula during the diagnosis is imperative.

Timely diagnosis is essential in order to provide treatment for patients affected by anorectal malformations. Conversely, delayed diagnosis of ARM it's largely a common occurrence and which can be fatal. Through a retrospective review, Kruger *et al.* (2019) investigated in the rate of delayed diagnosis alongside intestinal perforation in ARM. Data was collected from the Royal Children's Hospital between the years 2000 and 2015. Based on the findings, the most prevalent ARM types included perineal fistula (34%) as well as rectovestibular fistula(16%). Additionally, two patients with delayed diagnosis of ARM suffered intestinal perforation; thus providing justification for the need for early diagnosis of ARM. The results of a survey on tertiary center in Switzerland by Rohrer *et al.* (2020) suggested that prenatal exams including ultrasound(US) and magnetic resonance imaging(MRI) are useful in identifying anorectal malformations. Such diagnostic procedures can be useful in detecting signs of anorectal malformations notably anomalous distal bowel wall and rectal fluid as well as an absent target sign. Soeselo, and Grimaldy (2020) attribute delayed diagnosis of anorectal malformation to delayed presentation of the complaints as well as cases of mis-diagnosis in the past. Moreover, despite the ease with which anorectal malformations can to be diagnosed, there is a persistent challenge of failure to diagnosis especially during physical examinations at birth. Additionally, research by Rohrer *et al.* (2020) illuminated on the significance of imaging for anorectal formations in utero. Through a retrospective evaluation, previous results of the ultrasound and

prenatal MRI of the rectum and ano-perineal region in normal fetuses and patients affected by ARM were summarized. Based on the findings, different types of confirmed ARMS were detected as a result of prenatal US and MRI exams.

Surgical interventions have also proved useful in restoring the anorectal malformations. Firstly, surgical interventions can be improved based on adequacy of skills and knowledge of leading to ARM surgical procedures. This conforms with the findings of a study by Joosten *et al.* (2021), whose focus was on the use of inanimate simulation models related to correction of anorectal malformations. The target population comprised 80 participants consisting of surgical specialists, pediatric surgery fellows as well as residents. Based on the results, The question of “transferability of the skills to the clinical setting” scored a high mean value. Moreover, the participants found it necessary to use the model as a suitable replacement for the animal models. Overall, the study findings laid emphasis on the significance of conducting surgical repair following the diagnosis of ARMS. In addition, Islam *et al.* (2022) reported on the improvement of the medical condition following Posterior Sagittal AnoRectoPlasty surgical procedure that was proved effective in stopping urinary tract infection. Additionally, rectourethral fistula which is yet another form of ARM can be corrected through a combination of preoperative care of the colostomy and urgent corrective surgery. Through a National cohort study in France, Schmitt *et al.* (2022) explored long-term functional outcomes of the anorectal malformation. The study findings confirmed a positive correlation between anatomical status and functional outcomes amongst patients surgically treated for ARM. Subsequently, these and other similar studies provide justification for surgical interventions in order to correct disorders occasioned by anorectal malformations.

Complications arising from surgical procedures on ARM has considerably been dominant in extant nursing research. De Waal *et al.* (2023); through a systematic literature review of scholarly articles published from the inception of the study up to the year 2022 investigated at the outcomes of vaginal delivery amongst women with a previous history of surgically corrected anorectal malformations. To accomplish the study, articles were sourced from bibliographic databases such as Clarivate Analytics and PubMed among others. From the findings, failed vaginal delivery was reported prompting the need for urgent cesarean section; while in some incidences vaginal tearing was reported. Furthermore, Li *et al.* (2022) conducted a retrospective study amongst 83 patients with anorectal prolapse (ARP) after undergoing anorectoplasty. The research questions of the study were aimed at answering the underlying anatomical disorders and surgical outcomes with regard to management of the complication. Logistic regression models were applied in analysis of data, with findings indicating that high type of ARM diagnosed amongst 63% of the response patients. Additionally, both laparoscopic-assisted anorectoplasty, and posterior sagittal anorectoplasty were found to be useful surgical procedures to correct complications arising from anorectal malformation. Further, some of the complications arising from the surgical repair comprised anal stenosis, wound infection and anorectal prolapse recurrence.

Still on the question of surgical procedures, Arunachalam *et al.* (2022) investigated both the pathology and surgical management of urinary retention manifestation as a result of surgical

procedures related to ARMS. From the study results, some of the recommended operative management comprised bladder neck closure, antireflux surgery, urethral reconstruction, excision of the rectal stump among others. Improvement amongst the patients was manifested through normalization of glomerular filtration rate. As a recommendation, urinary retention is critical in the wake of ARM surgery and requires prompt recognition as well as the need for urinary diversion. In addition, continence with safe upper tracts can be achieved through implementation of final reconstruction. Through a systematic review, Evans-Barns *et al.* (2023) explored post-operative anorectal manometry amongst children after undergoing surgical repair as a result of anorectal malformation. Information was sourced from relevant articles published between the years 1985 and 2022 extracted from various bibliographic databases including Cochrane Library, PubMed, and Medline among others. From the findings of the review, there was need to address variability with regards to protocols, manometry equipment as well as interpretations. This implied that there was a deficiency in terms of standardization of the anorectal manometry procedure which is mostly used in assessment of anorectal function amongst children following anorectal malformation repair.

The psychological burden experienced by caregivers of children affected by anorectal malformations has considerably been problematized in earlier research. Firstly, psychological burden within the context of this study can be termed as the negative feeling related to the mental or emotional state of a person experienced by the parents and caregivers (Vailliant, 2020). Through assembly targeting Chinese parents, Dai *et al.* (2019) reflected on the significance of self-efficacy of the parents with regard to caring for their children diagnosed with ARMs. Data was collected through a combination of Delphi questionnaires of the experts and focus group discussions. Following the results of the principal component analysis statistical technique and correlation analysis, it was evident that psychological burden experienced by the parents whose children were diagnosed with ARMs can be mitigated by improved parental self-efficacy. Bhartiya *et al.* (2019) evaluated some of the psychological burdens experienced by parents whose children were diagnosed with ARMs. Data was collected using questionnaires administered to the parents of children. The findings indicated that most of the parents experienced psychological burden; which mostly worsened following surgery. As a recommendation, stakeholders have a responsibility to come up with social support and coping strategies to scale down psychological burden faced by the parents.

Education combined with support mechanisms are useful in providing parents with an opportunity to cope with psychological balance associated with the caregiving for children affected by ARMS. This is reflected in the findings of a study by Ryan *et al.* (2020) who acknowledge the psychological burden experienced by parents of children affected by anorectal malformations, but also underscore the role of recent technological investments especially use of social media platforms in disseminating information relating to how parents of these children can develop coping strategies to deal with the psychological burden. Li *et al.* (2020) investigated both the quality of life and the social support received by parents of children with congenital anorectal malformations in China. Data was collected between January to June 2018 from the Anhui Provincial Children's Hospital of China. The results of multivariate linear regression and canonical correlation analysis indicated that social support networks were useful

in improving coping strategies and quality of life which ultimately reduced the psychological burden experienced by the parents.

Mental health issues facing parents of children with congenital malformations have continually been problematized in earlier research. In Germany, Boettcher *et al.* (2021) explored the mental health challenges experienced by parents of children with congenital malformations. Data was collected using standardized psychometric questionnaire distributed amongst 210 parents. Among other findings, increased stress and mental health challenges were experienced by both mothers and fathers of children diagnosed with ARMs. From the gender perspective, mother's stress levels were significantly reduced as a result of increased intra and extra extrafamilial resources together with perceived family related stress in mothers. Additionally, Sugesh *et al.* (2022) conducted a phenomenological analysis on the lived experiences of parents and caregivers of children diagnosed with ARMs with colostomy. Methodologically, purposive sampling technique was used to identify caregivers of children suffering from ARM. Thematic analysis was conducted following the recording and preparation of the verbatim. Based on the findings, it was apparent that the caregivers underwent difficulties in providing care for children with ARMs. Among the underlying sub-themes identified in the study, lack of specialized training, inadequate support systems contributed to worsening of psychological balance experienced by the parents and caregivers.

On the premise of the psychological burden articulated in the foregoing studies, the present study set out to analyze the psychological burden experienced by the parents and caregivers of children diagnosed with an anorectal malformation receiving medical attention in Kenya National Hospital. Justification for conducting the present study was anchored on the idea that deterioration in the psychological well-being of the parents and caregivers presents a major challenge to the healing process and the quality of life of the persons diagnosed with anorectal malformations. Accordingly, the underpinning methodological considerations for this study are discussed in the subsequent section.

MATERIALS AND METHOD

Setting

The study was conducted in paediatric surgical outpatient clinic and-ward 4A; specialized surgery department of the Kenyatta National Hospital. This healthcare facility is the largest teaching and referral hospital in East and Central sub-Saharan Africa and is located in Nairobi. It has a bed capacity of 1800 and has over 6000 staff members. KNH offers sub specialized services covering curative, preventive, diagnostic and rehabilitation services. It is the public referral Hospital of choice in Kenya and beyond. It offers quality specialized health care to patients from the Great Lakes Region, Southern and Central Africa. These services include open heart surgery, neurosurgery, orthopaedic surgery, reconstructive surgery, burns management, critical care services, new born services, ophthalmology (cornea transplant), oncology, palliative care and renal services (including kidney transplant), among others.

The hospital has dedicated Ward 4A which specializes in pediatric surgery including both open and laparoscopic surgeries. It has a group of qualified professionals including paediatric surgeons, registrars, neonatal nurses, nurse counselors, clinical nurses, nutritionists, physiotherapists, occupational therapists and the support staff. The ward admits the patients in a 24-hour basis since it handles both emergencies and elective cases. Elective cases are admitted as per their booking according to the register. Most patients are referrals from the County hospitals and across East Africa.

Study design and sample

This was a cross-sectional research study, which implies that the study is undertaken on different subjects at the same time as proposed in existing earlier scholarly publications (Qian, Sapongi, & Husin, 2021). The study was conducted with the intent to illuminate on the psychological burden experienced by parents of children who have been diagnosed with ARMs at the hospital. The study population comprised all the participants of the recruited group; treated or still undergoing treatment for ARM condition. We administered questionnaires to the parents/care givers of these children with ARM. Our study participants included in the sample were drawn from the recruited group; treated or still undergoing treatment for ARM condition. We administered questionnaires to the parents/care givers of these children with ARM. The information extracted from the questionnaire was later cleaned, summarized and analyzed descriptively in order to unveil some of the psychological challenges faced by the parents and caregivers of children diagnosed with ARM at the hospital. This was achieved through use of descriptive statistics such as charts, tabulation, frequencies and percentages. This was followed by a concise write up of the findings, particularly by focusing on issues of psychological challenges faced by these parents and caregivers.

Data collection tools and procedures

Participants were identified using existing data and records in KNH. We sought permission from KNH health records to access the files belonging to the participants through a written request. Contact details were retrieved electronically and manually. Upon retrieval, we contacted all the clients, provided information about the study, sought their informed verbal consent and asked them to come and fill the questionnaires. Those who consented within March and April 2021 were administered questionnaires during their usual PSOPC clinic, those admitted in the ward and the others given a specific date to come. We recruited research assistants and did a training for them. Informed written consent was obtained after carefully explaining to the subjects about the study and answering their questions to satisfaction. Interpretation of information was done to clients with language barrier to enhance communication and understanding. Anonymity was maintained by use of codes and privacy by not sharing the information but keeping it secret and safe just for the purpose of the study. Participants were free to withdraw from the study without any implication or effect on their plan of care and management.

Prior to data collection, all the research assistants were acquainted with the research process through training. In this regard, all the interviewers underwent an intensive one-day training programme, conducted by the study investigators, prior to the commencing of the interviews. Training included aspects of how to conduct an interview, good clinical practice, including the importance of informed consent and confidentiality, defining of key concepts in anorectal malformation and the process for completing the questionnaire. Our team also found it necessary to conduct a pretest of the research instrument through piloting. In order to accomplish this, field-testing was done by administering questionnaires using the method intended for the main study. Questionnaires were pretested to check for relevance to the study and whether it had the same interpretation when given to two different participants in the study, we checked this with our colleagues who are familiar with the field of study. The pretest tested the clarity, applicability of the study tools; identify the difficulties that could be faced during the application and the estimated time for filling the questionnaire.

The data collection process comprised administering the questionnaires to the respondents through the guidance of the researcher. The questionnaires contained both structured and unstructured questions. Interpretation was done to the participants who did not understand the language used. The administration was done as scheduled with the study participants. Additionally, the data collection process was conducted within the confines of the ethical framework. As such, the first ethical consideration was for the researchers to seek permission from Kenyatta National hospital-university of Nairobi research ethics committee to carry out the study. We also sought permission from the head of department specialized, senior assistant chief nurse in charge specialized surgery department and nurse manager in charge of ward 4 A. In addition to this, informed consent was sought from the participants and only those who accepted participated in the study.

Moreover, other ethical considerations comprised ensuring that all the gathered information were kept private and confidential with anonymity being observed. There was no harm for the participants included in the study. There was no direct benefits to the participants other than using the results to improve the process of management of patient with anorectal malformation condition. The study is useful for policymaking and the results are disseminated to pediatric surgery department and relevant authorities for planning and improvement of care delivery.

Data management and analysis

The data collected was coded, edited and checked for consistency and completeness. Quantitative data was analyzed using descriptive statistics comprising frequencies and percentages. Qualitative data extracted from the respondents' verbatim was described in themes and narrative. The entire process was in conformity with the widely acknowledged procedure for reporting qualitative data. The data was analyzed by use of various statistical tools. Quantitative data was analysed using SPSS statistical software, while qualitative data was analyzed using Nvivo software.

RESULTS

Introduction

This section focuses on the presentation of the findings relating to the psychological burden experienced by parents and caregivers whose children have been diagnosed with anorectal malformations; which is in tandem with the stated research objective. Both descriptive and inferential analysis will be useful in answering the overarching research questions. The sample size consisted of 88 respondents, where 85 were drawn from 25 counties across Kenya, while 3 respondents did not indicate their County of origin.

Communication about the condition

The communication about the ARM condition was also within the purview of this analysis. Previous studies have identified communication as critical factor when addressing psychological burden experienced by caregivers and parents of children affected by a medical condition (Svetanoff *et al.*, 2022). As such, the responses relating to the communication were depicted in Figure 1, which shows that slightly more than two third (72.6%, $n = 61$) of the parents got a communication from the doctor about the child having the anorectal condition, (26.2%, $n = 22$) were informed by the nurse and (1.2%, $n = 1$) were informed by the counsellor.

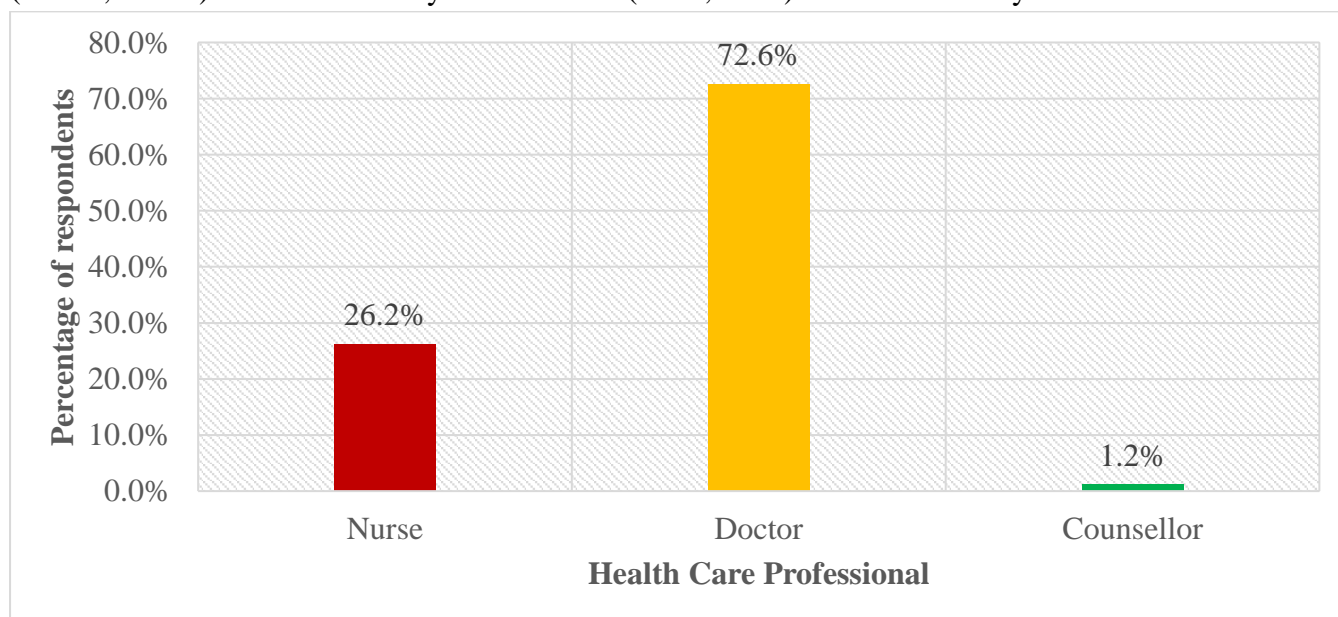


Figure 1: Communication about condition of the child

Reactions after knowing the child suffers from anorectal condition were different among the parents. Common reactions from the parents were; the parents were shocked and worried since the condition was new to them, some parents lost hope about the survival of the child, disbelief, suicidal thoughts rang into some parent's mind and some broke down.

Table 1. Psychosocial burden on parents

| Statement | <i>n</i> | % |
|---|----------|------|
| Were you counseled about diagnosis to treatment plan? | | |
| Yes | 79 | 90.0 |
| No | 9 | 10.0 |
| Were you informed about the type of surgery to be done? | | |
| Yes | 77 | 87.5 |
| No | 11 | 12.5 |

As Table 1 depicts, most (90.0%, $n = 79$) of the parents were counselled about the diagnosis and the treatment plan after receiving the news about what the child was suffering from, while (10.0%, $n = 9$) were not counseled. Accordingly, this attested to the efforts put in by the medical practitioners and other stakeholders towards ensuring implementation of counseling services to the parents of the children affected by ARMs. This corroborates what was observed in earlier empirical research by Kassa *et al.* (2020) who articulated on the significance of receiving counseling services in order to improve coping strategies amongst caregivers and parents of children affected by anorectal malformation.

Additionally, the results in Table 1 also indicate that majority (87.5%, $n = 77$) of the parents were informed about the type of surgery to be done on the child while (12.5%, $n = 11$) were not informed. This was indicative of the health care professional's awareness with regard to the need to provide adequate information to the parents and caregivers prior to performing surgical procedures, a finding which resonates with what was observed by Dai *et al.* (2019) who reflected on the criticality of providing parents and caregivers with information relating to the type of diagnosis and surgery on their children affected by anorectal malformations. Similarly, the findings attest to what was noted by Saysoo, and Dewi (2020), with regard to divulging information to the parents and the caregivers on the type of surgery, which can later translate to improved quality of life under the care of the parents/caregivers in future.

Moreover, from verbatim responses given by the respondents, different parents had different expectations after the surgery. The tabulated expectations included; the parents hoped that the baby would be able to pass stool normally, the child will be alive and okay, be treated and go back home and the problem will be resolved successfully. This was a clear expression of the expectations of the parents and caregivers with regarded to the improvement in the children's situation after undergoing the operation. As such, the need to adequately prepare parents and caregivers on the coping strategies relating to the ARM medical condition was imperative hence investigated in the present study.

Discussion

The present study was intent on analyzing the psychological burden shouldered by the parents and caregivers of children diagnosed with anorectal malformations. The question of whether there was communication regarding the ARM condition was posed to the parents and caregivers of the affected children. Based on the responses, three categories of the health care professionals—nurses, doctors and counselors working in KNH provided the communication to the parents and caregivers. From the results, approximately 73% of the respondents reported that the communication came from the doctors, with just over 26% of the respondents indicating that the communication was divulged from the nurses. This reaffirms the results of a study by Ryan *et al.* (2020) who recognize the role of family especially the parents in a caring for the children affected by ARMs and more importantly underscored the need to create various forms of communication to their parents in order to understand how to provide care for their children. Similarly, the findings were corroborated in various empirical studies, including a survey across different European countries by Violani *et al.* (2022), who reported that hospitals have a responsibility to draft some form of communication to the parents and caregivers of children diagnosed with ARMs, by way of drafting a transitional program to provide guidance on providing care for ARM patients.

A small percentage(1.2%) of the parents and caregivers also reported that counselors were responsible for providing information related to the ARM medical condition of their children. Halleran *et al.* (2019) reflected on the importance of providing counseling services to parents of the patients affected by ARMs. This implies that counselors have an important role to play when it comes to dissemination of information to the parents and caregivers regarding the condition. As such, these findings were validated in the present study, albeit with a small percentage of respondents acknowledging the role of counsellors in providing information relating to ARM condition. Additionally, the study findings were also in tandem with what was established by Judd-Glossy *et al.* (2019), regarding the criticality of engaging counsellors to disseminate information regarding anorectal malformation, together with offering advice to the parents with regard to coping strategies in caregiving for the diagnosed patients.

Conclusions

Based on the study findings in the present study, the researchers concluded that parents with children suffering from anorectal malformations experience different psychological problems, including neglect, rejection and divorce. To make it worse, children with ARM condition are considered as bad omen or a burden to the family. The child requires much support and attention throughout treatment. Most mothers are forced to drop out of their employments leaving only one spouse to carry the financial burden of the family. The parents also are stigmatized by the rest of the family members and community due to the demand of the condition. Social life of the parents with children suffering from the condition is affected due to the attention required by the ailing child. Colostomy bags are not readily available and are expensive, caregivers use a cloth to cover the stoma which has to be changed frequently and also the smell emitted puts away a lot of people. Additionally, parents with children having

anorectal malformations are financially burdened since the child has to undergo several investigations, admissions and surgeries for a minimum of 3 years. Travels involved when taking the child to hospital for clinics and admissions coming from different and furthest part of the country financially drains the parent. Parents are forced to sacrifice their time and give the child much attention.

Recommendations

Our results give a strong indication of the psychological burden experience by the parents of children diagnosed with ARM. This implies that there is need for strong psychological support for the parents and caregivers to improve their coping strategies. We therefore strongly recommend that there is need to establish well organized psychological support groups in order to help mitigate mental stress experienced by parents and caregivers of children with ARM. Additionally, part of the psychological burden can be attributable to the financial challenges experienced by these parents/caregivers. In this regard, we also recommended that there is need for training of more paediatric specialized personnel, together with increasing infrastructure in order to devolve ARM surgeries at County levels. Consequently, this will ease the financial burden the families and eventually decongest KNH.

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