Social impact of a colostomy on families of children with colorectal disorders:

A mixed methods study

Thesis submitted to College of Health Sciences, Addis Ababa University, in partial fulfillment of the requirements for the specialty certificate in General Pediatric Surgery

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Declaration

I declare that this paper is a result of my independent research work on the topic entitled "**Social impact of a colostomy on families of children with colorectal disorders: A mixed methods study**" in partial fulfillment of the requirements for the specialty certificate in General Pediatric Surgery at Addis Ababa University, College of health sciences, Department of surgery, Pediatric surgery unit. This work has not been submitted for a degree to any other university. All the references are also acknowledged.

Dr. Samuel Negash

Signature: _____

Date: _____

Confirmation

This is to certify that Samuel Negash has carried out this research work on the topic entitled "**Social impact of a colostomy on families of children with colorectal disorders: A mixed methods study**" under my supervision. This work is original in nature and has not been presented for a degree in any university and it can be submitted for the partial fulfillment of the requirements for the award of the specialty certificate for General Pediatric Surgery.

Dr. Fisseha Temesgen (Assistant professor of pediatric surgery)

Signature: _____

Date: _____

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Acronyms

HD: Hirschsprung disease

ARM: Anorectal malformations

LMIC: Low-income and Middle-income countries

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Abstract

Background: Colostomy is one of the most commonly performed pediatric surgical procedures in Tikur Anbessa Hospital. Even though most of the pediatric colostomies are reversible, patients stay a long time with the stoma because of the long wait list for surgery. Apart from medical complications, this treatment imposes a tremendous change in lifestyle. It can cause social, financial and psychological problems. Since parents play an important role in child's life, it also impacts the whole family as well.

Objective To assess the social awareness to colostomy and the social, economic and psychosocial impact on children and their care givers

Methods: The study was a cross-sectional study with prospective data collection conducted from October – December 2020. Both quantitative and qualitative data was collected in a convergent parallel design. Convenience sampling technique was utilized to select participants from Tikur Anbessa hospital.

Results: Thirty caregivers were interviewed for this study. Most of the parents were married (90%), young (mean age 30.6 years) and living in urban areas (70%). The indications for colostomy were ARM (53%) and HD (47%). The procedure was mostly performed in infants (mean age 6.5 months) and as an emergency (87%). Children stayed with a colostomy from 4 months to 6years (mean 22.8 months). Medical complications occurred in half of the children but only 20% required reoperation.

The first reaction towards the colostomy was anxiety. Most parents stated that they did not get adequate counseling or training from doctors. Learning from other patients was the most helpful source of information. None of the patients used a colostomy bag and they expressed significant issues with stoma care. Almost all participants had to stay home to take care of the child and many lost their jobs. They also faced difficulties in their social life because people are uncomfortable around a colostomy. Older children were not able to attend school. Around half of the participants experienced economic challenges because of the colostomy.

Conclusion: We found a high rate of psychological, social and economic problems on families of children with colostomy. We recommend for the Ethiopian pediatric surgery association to work on educating the public as well as providing materials, training and support groups for families suffering with this condition. These children should also be given priority on surgical waiting lists.

1. Introduction

Colostomy is a common surgical procedure which refers to the creation of an opening on the abdomen to reroute the normal bowel movement. This procedure could be permanent or temporary in which waste passes through the abdominal wall into an opening called stoma into a plastic bag that is emptied periodically. It could be permanent or temporary, to be reversed after the patient's conditions and the reason for the stoma is no longer an issue. In pediatric surgery, this therapeutic approach is an integral part of management for common diseases like Hirschsprung's disease (HD) and anorectal malformation (ARM). [1,2]

Worldwide it is known that the commonest indication for colostomy in children is ARM. According to the study made in one of the developing countries, it was estimated that among 202,000 live births a year 83 of them will be born with anorectal malformation and 40 children will be born with Hirschsprung's disease. [3] In our country Ethiopia the ARM seems to be the leading motive for colostomy as well. [4]

Since parents play an important role in child's life, it is their duty to support their child in accepting the disabilities and cope with the current situation. Regarding this, it has been learnt that colostomy has resulted psychological disturbances on parents especially in coping with the implications of the approach. Parents experience loss in hope, depression, anxiety and despair. Due to the repeated procedure the child experiences, caregivers face financial and social problems. On other studies done in adults, colostomy have resulted in negligence, discrimination. Because of the offensive smell, colostomy results psychosocial problem imposing a significant challenge on the patient as well as the caregivers. [5,6]

To the best of our knowledge, researches have not been conducted in our society concerning the psychological problems arising from the procedure. However, based on our observation we have noticed a negative attitude especially from parents coming from rural areas. In some situations, the caregivers have gone to the extent of refusing a temporary colostomy and chose to take their children home to die.

This study will help us to assess the social awareness and attitude towards colostomy in our country, so that we could provide better counseling and care for these children and their families.

2. Literature Review

Before the start of performing colostomies, surgeons tend to close all types of open abdominal wounds which led to a high mortality rate. Back then stomas were formulated spontaneously as fistulas [7]. In the year 1710 a man called Littré brought the idea of performing a colostomy on a child which lasted for fifty years till the first effective operation was published [8]. Colostomies in children are usually done to alleviate colonic obstructions due to Hirschsprung's disease, colon atresia, imperforated anus and sometimes for pelvic and perineal tumors, crohn's disease and instances of rectal perforation. The stoma usually be functional for 1 to 2 years with the need of skilled care by the patient or his/her parents [9].

Globally, the prevalence of colostomies is 40%, in which most of them are above the age of 50 years with an equal distribution of male and female [10]. In the united states it is known that around one million people have either permanent or temporary stomas [11]. In our country Ethiopia colostomy creation and reversal are commonly practiced procedures [12]. A study in Tikur Anbessa Hospital showed that lots of colostomies are being performed; among the procedures almost half of them are done on children.[12]

Since, the quality of life of a person is said to be determined by his/her psychosocial adaptation, colostomies do have a negative impact on patient's life style [13]. According to the studies that have been conducted in both developed and developing countries, patients with ostomy had faced lots of issues regarding their quality of life.

Studies done in USA show patients with younger age and higher BMI complained in having a difficulty of self-care for the ostomy. In addition to that: peristomal skin irritation (76%), pouch leakage (62%), odor (59%), reduction in previously enjoyed activities (54%), and depression/anxiety (53%) are commonly encountered problems. [14,15].

In accordance to the study held at Iran, It has been mentioned that patients experience rash around the ostomy site, sleep disturbances, bad breath and fear of gas emission in the presence of others [1]. Socially and psychologically Ostomates have explained about their fear of not being clean and bad odor that might arise from the stoma, in which most of the patients led to avoidance of any type of gathering. According to some patients, the ostomy had put them through financial challenges due to the expenses for colostomy bags and gloves [1,14,15].

Specifically, to the psychosocial problems towards children and their caregivers; studies showed that children face lots of problems concerning colostomies. Children with colostomies face discrimination at school, became victim of low self – esteem and mocking by children of the same age. Caregivers also receive a financial burden in addition to the social problems [3, 16]

Moreover, a colostomy done in developing countries can have a higher impact on the parents than those in industrialized nation. One research with such a hypothesis was conducted in Honduras, and targeted only those in very low-income households. For the first time, they have shown, that leaving patients with a colostomy and without repair of the underlying disease for an indefinite period can result in severe social and economic impairments. [3]

Different to industrial countries, where school nurses help to include physically impaired children into the general student population, children with colostomies in Honduras are rejected by nurseries and thus experience a deficient social integration. In addition, they assessed the extra cost due to the disease and stoma care averaged $86USD per month which is insuperable considering the reported annual income of less than $500USD in half of the parents. [3]

Similarly, a pilot study done in Uganda had explained about how Colostomy bags are not available and parents/caregivers use bed sheets to cover the ostomy which led to an issue of odor and feeling of uncleanliness. Most caregivers also faced financial problems due to resigning from their jobs and selling their livestock in order to have enough money for medication, transport and radiology studies. [16]

On the contrary, another study done in Nigeria that tried to assess the acceptance of colostomy by parents found that of the 57 respondents, 77% considered the stoma and its management acceptable. This was much higher than the presumed low rate of acceptance thought to be a hinderance to colostomy in developing countries. From their experience, they recommend with adequate explanation and counseling, most parents and caregivers find the colostomy acceptable [17]

3. Conceptual Framework

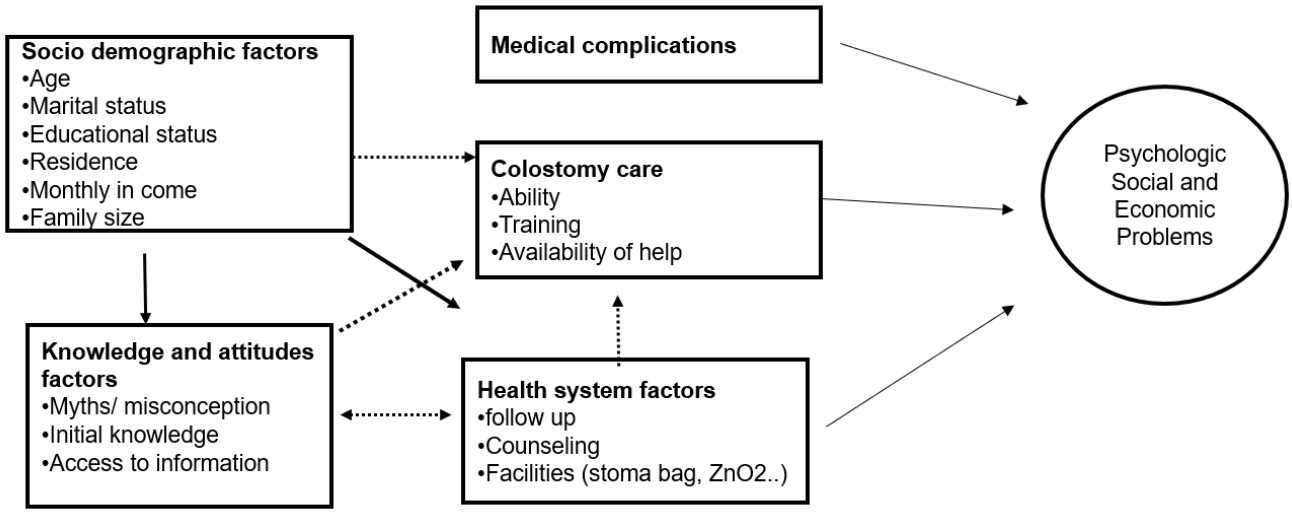

Figure 1: Conceptual framework of psychological, social and economic problems and associated factors in families of children with a colostomy, Addis Ababa, Ethiopia, 2021

4. Objectives

4.1. General objective

- Assess the psychosocial burden, social awareness and attitude towards colostomy so that we could provide better counseling and care for these children and their families

4.2. Specific objectives

- Asses general knowledge and attitude towards colostomy
- Asses Basic colostomy care
- Asses social and psychological impact on caregivers
- Asses social and psychological impact on children
- Asses economic impact on families

5. Study methods

5.1. Study setting:

Tikur Anbessa Specialized Hospital is located in Addis Ababa Ethiopia and is affiliated with Addis Ababa University School of medicine. It is the largest medical school and tertiary care center in the country. It also has a high pediatric surgery load with more than 1500 procedures performed yearly.

5.2. Source population:

All families of pediatric surgical patients admitted to wards

5.3. Study population:

Families of Children < 13 years old with colostomy

Inclusion criteria**:** Families of Children who just underwent closure of their colostomy

Exclusion criteria**:** Families of children with colostomy who have not yet reached the time for reversal of their colostomy and families who don't consent to the study.

5.4. Study design:

Both quantitative and qualitative data were collected. The mixed methods design was utilized using convergent parallel design.

5.5. Sample size determination:

Since there is no study regarding colostomy in children, proportion of 95% is taken for the prevalence of psychosocio-economic problems in families of children from the study done in Honduras [3]. Confidence interval taken as 95% and 5% margin of error.

$$n = \frac{Z^2 P(1-P)}{W^2}$$

$$= \frac{1.96 * 0.95 * 0.05}{(0.05)^2}$$

$$= \frac{37.2}{}$$

5.6. Sampling Technique

A convenience sampling technique was utilized. Eligible patients admitted to the pediatric surgical ward during the study period were interviewed.

5.7 Data collection procedures:

The data collection was conducted by the investigator. The questionnaire was translated to Amharic and pre-tested in around 5 participants before the actual data collection processes. Patients that are eligible were identified from in-patient ward.

5.8. Measurement/variables

Dependent variable – psychological, social and economic burden on children and their care givers due to colostomy

Independent variables

- Sociodemographic characteristics
- Circumstances around the procedure
- Medical problems
- Knowledge and attitude towards colostomy
- Colostomy care practice

5.9. Operational definition

Impoverishing expense: Considering the world bank poverty line of 1.9 USD/person/day and the current currency conversion rate, poverty threshold was considered < 80ETB per person per day.

5.10. Data Management

Questionnaires were returned for data processing, which consisted of office editing, coding of open - ended questions, data entry, and editing computer - identified errors. Data entry and editing was accomplished using EPInfo software.

5.11. Data analysis

Quantitative data was analyzed using STATA. Qualitative data was manually coded.

5.12. Ethical Consideration

Participants or legal guardians were approached by investigator and gave informed consent to indicate their willingness to participate in the study. Confidentiality was maintained and no identifying information was included in the study. Ethical clearance was obtained from ethics committee of department of surgery, as well as the institutional review board of college of health sciences, Addis Ababa University.

6. Results

6.1. Sociodemographic characteristics

Thirty caregivers of children with colostomy were interviewed for the study. Most of the respondents were mothers (66%). Most of them were married (90%). The fathers of the children were more educated with most of them attaining either secondary (29%) or tertiary level education (43%) while most of the mothers attained primary (30%) or secondary level education (50%). Most of the families were from urban areas (70%). Most of the fathers' occupation was farmer (30%) while the mothers were housewives (36%) or unemployed (31%). Detail sociodemographic characteristics of the caregivers is illustrated on **table 1.**

Age was calculated for 25 participants who knew their age. The caregivers age ranged from 22 years – 46 years (mean 30.6 years $\pm$ 5.9 years). Monthly Income was calculated for 24 participants who knew/ could estimate their household income. Monthly household income ranged from 0 ETB – 20,000 ETB (mean 7,200 ETB $\pm$ 6,718 ETB). The number of children in the household ranged from 1-5 (mean 2.2 children $\pm$ 1.2 children). The total members of the household ranged from 3-7 (mean 4.5 members $\pm$1.4 members)

Table 1: Sociodemographic characteristics of caregivers of children with a colostomy

Variable		**N (%)**
Relationship to the child	Mother	20 (66%)
	Father	9 (30%)
	Non-related	1 (3%)
Marital status	Married	27 (90%)
	Separated	3 (10%)
Father's Education	No education	1 (7%)
	Primary school	3 (21%)
	Secondary school	4 (29%)
	College	6 (43%)
Mother's Education	No education	1 (5%)
	Primary school	6 (30%)
	Secondary school	10 (50%)
	College	3 (15%)
Residence	Urban	21 (70%)
	Semi urban	4 (13%)
	Rural	5 (17%)
Mother's occupation	Housewife	10 (35%)
	Merchant	3 (10%)
	Government	2 (7%)
	Other	5 (17%)
	Unemployed	9 (31%)
Father's occupation	Farmer	7 (30%)
	Daily laborer	3 (13%)
	Driver	2 (9%)
	Merchant	2 (9%)
	Other	9 (39%)

6.2. About the procedure

Indication for colostomy was ARM in 16 patients (53%) and HD in 14 patients (47%). Associated conditions were found in 10% (7% Down's syndrome and 3% hypothyroidism). The colostomy was done in Tikur Anbessa Hospital in 80% while 20% were referred after colostomy was done at another center. The procedure was performed on an emergency basis in 26 children (87%) and on an elective basis for 4 (13%). Medical complications of colostomy reported were: Excoriation (53%), Bleeding (43%), prolapse (10%), stenosis/retraction (10%). Six children (20%) required a redo-surgery to correct complications.

Age of children at colostomy ranged from 2 days – 6 years (mean 6.5 months $\pm$ 14.7 months). The current age of children (age at reversal of the colostomy) ranged from 6months – 7 years (mean 29.4 months $\pm$ 20.4 months). The time spent with colostomy ranged from 4 months – 6 years (mean 22.8 months $\pm$16.6 months)

6.3. Knowledge

Twenty-eight participants (93%) state that they did not know about the complication of the procedure. The most common first reaction was anxiety (77%). One mother stated "Immediately after surgery nurses told me how to take care of the colostomy. But I was afraid even to look at the colostomy let alone clean it." Three participants (10%) were relived that the child survived and did not worry about the colostomy while another 3 (10%) had no initial reaction

One caregiver (3%) refused the surgery because he was not satisfied by the information provided by doctors. "I initially refused surgery. I thought that they were intentionally hiding the complications in order to convince me. I didn't think he would survive."

Most of the parents (66%) felt that they did not get adequate counseling preoperatively and even a higher proportion (77%) felt that they did not get adequate counseling postoperatively. Overall 83% of the participants stated that they did not get enough information about how to care for the colostomy and potential complication.

The lack of counseling was a contributor to the anxiety felt by the parents. A mother stated "I wanted to know whether I can carry the child on my back. I did not allow the child to have playmates because I was afraid in the beginning." Another father said "I wanted to know more

about colostomy but was afraid to ask doctors because I felt they didn't have time. I was afraid when I saw minor bleeding from the colostomy site. If I was counseled about it, I wouldn't have been anxious."

Most of the parents (87%) have never heard about or seen a colostomy before. Around half of the caregivers (47%) don't know what the procedure is called (colostomy). None of the parents were provided with teaching materials about colostomy in their local language. Most of the caregivers (59%) have internet access but only 4 parents (14%) tried to search for information about a stoma online. Those that tried to search information online had difficulty understanding. One father said "I tried to search for information on the internet but I couldn't understand the medical terms because they were not explained to me.

Only 3 participants (10%) received training on stoma care. These participants were trained by relatives/close friend who were health professionals. Many patients described they used other source of information. Learning from other patients was described as the most helpful source of information. One mother said "I was afraid when I saw the colostomy, I couldn't contemplate how a person can survive with that. When I saw other patients undergoing closure treatment, I gained hope. I observed how to take care of the stoma"

6.4. Colostomy care

The participants used a lot of locally available materials as stoma appliance but none of them used a colostomy bag. (**figure 2**) The most common reason for not using a stoma bag is not knowing about it (77%). The other participants did not use the stoma bag because it doesn't fit (10%), it is expensive (7%), they didn't know how to use it (3%) and they didn't like it (3%). The most commonly used covering for the stoma was a soft cloth or a diaper tied around the waist. **(figure 3).** Two families have invented a reusable stoma appliance **(figure 4 and 5)** One of these caregivers said "We used to cover the stoma with a waistband but it was not effective. When the child started to walk it was difficult to manage. Stool would leak and fall down. With trial and error, we came up with this appliance. (fig 4) Now he is attending school without any problem"

Most of the parents (90%) feel confident in caring for the stoma but they had many difficulties due to the stoma. The most notable issue mentioned was the frequent stooling and excoriation.

One mother stated “The most difficult part is the frequent stooling (~5times/day). I have to wash the child's cloth daily. I find it difficult sometimes especially if there is no water for 3 days or so.”. Another father said “We used a waistband but it caused excoriation. We have now stopped covering the stoma and leave it open to soil her cloths. We have to wash clothes frequently up to 3 times a day. We also cover her bed in plastic sheet when she sleeps.” Thirteen (43%) participants also stated that they were impaired by the smell of the colostomy.

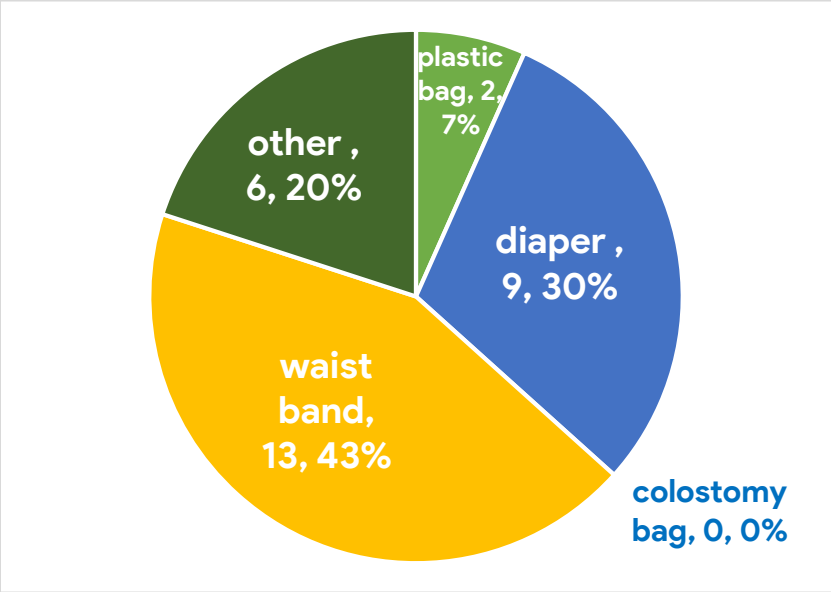

Figure 2: Materials were used to care for (cover) the colostomy

Figure 3: The commonly used coverings for stoma were a second diaper or a soft cloth tied around the waist.

Figure 4: stoma bag locally made by parent using intravenous infusion bag tied around waist

Figure 5: Another stoma appliance made using soft cloth tied around neck and lower part tucked into trousers

6.5. Psychosocial impact

Parents experienced a lot of psychosocial problems due to the stoma. Twenty of the caregivers (67%) had negative feelings because of the colostomy. Nineteen participants (63%) felt ashamed, 16 (57%) were embarrassed to go to public places and 14 (54%) did not go to social events (weddings, funerals, family gatherings) because of the stoma. One mother said “I leave the house for church but only for a short time. If I have to go out, I leave him with his grandparents or aunt. His father can’t do anything” Another mother said “I have avoided all social events due to the child's condition. People don’t know about my situation so I have lost many relationships because of that.”

Seven (23%) haven't shown the stoma to anyone for fear of their reaction. The rest of the participants, mostly close family has seen the colostomy and 19 (63%) said people were uncomfortable around the soma while only 4 (13%) stated people were comfortable seeing the colostomy. One Mother said "People are disgusted and tell us to take the child out of their sight. They frightened and make the sign of the cross. They have told me that there is no hope for the child and I shouldn't waste my money on her treatment." A father also stated "We have to hide the child if guests come over our house. We do not show the stoma to people. If they see it some feel sorry for us, others feel it is because of the sin of ancestors." Another mather said "I don't want to show others the colostomy because I'm afraid they'll tell my child about it when she grows up."

None of the participants entrusted a nanny to take care of the child because of the colostomy. As a result, 37% of the participants or their partner quit their job to take care of the child. The rest of the caregivers were either already housewives or they got another family member to take care of the child with stoma. One family made their older child quit school so that she can babysit the child with stoma. Another father stated "My wife had to quit her job because the stoma required frequent change. It has also affected my life because I had to come home after work to help her out instead of socializing."

Nine participants (30%) had encountered problems with their spouse or family due to the stoma. One caregiver said "We deferred having another child because of our child's illness. Taking care of the colostomy needs more effort". Another mother said "My sister in law used my child's condition to insult me. She told me God made the child this way to punish me. Those kinds of words affected me a lot." One mother, who had a job in addition to taking care of the child, said "Taking care of the child was a burden in addition to managing our store. The father doesn't help out with the colostomy at all. He also expects me to prepare things at home like I used to. I was very overworked, staying up until midnight. I've had fights and disagreements with the father."

Two parents (7%) got divorced because of the colostomy. One of the mother's stated "My husband left me just after the child got the colostomy. He thought it was my sin that brought this disease on the child. We haven't communicated since."

Twenty-three children were toddlers. Of these 21 (91%) had playmates while 2 (9%) were not allowed to play with other kids because of the colostomy. Only four children were in school age

(>4 years). Only one of these children (25%) attended school while the 3 children (75%) were not able to attend school because of the colostomy. One caregiver said “The child dropped out of school for 1 year because of the colostomy. He is now behind his peers because of that.”

Other parents have also stated psychosocial impacts they noticed on their children. One mother said “As the child grew older, she began to notice the colostomy wasn’t normal. She was very happy after colostomy closure when she was able to use the toilet.” Another father said “The child started to take notice that the stoma was abnormal around 4 years of age. He wanted to sit on the toilet like other kids in school. He started asking us when we were going to take him to a hospital to get the colostomy closed.”

6.6. Economic impact

Caregivers spent 200 ETB- 1000 ETB per month (mean 590 ETB + 341 ETB) for stoma care. Fourteen caregivers (47%) stated that the expense of the colostomy has affected their household economy. One father said “We used an additional diaper to cover the stoma. The stoma consumed 3 times more diapers than as other children. It is even more expensive than a colostomy bag.” Another mother stated “The child was not gaining weight so we had to spend more money for food. The cloths we use to cover the colostomy would get rougher because of repeated washing and we also had to buy clothes weekly”

From the twenty participants who estimated both their income and colostomy expense, 13 (65%) were impoverished after stoma expense. One father who is a farmer said “The expense of the colostomy is very difficult for me. Most of the expenditure is to buy soap and clothes for the child. I had to sell my sheep to take care of the child”.

Table 2: Summary of psychosocial and economic burden of a colostomy

Variable	**N (%)**
I am Embarrassed to go to public places	16 (57%)
I Feel ashamed	19 (63%)
People uncomfortable around the child	19 (63%)
No one has seen the colostomy	7 (23%)
I am not able to go to social events	14 (54%)
I have negative feelings	10 (33%)
My partner or I have quit jobs to take care of the child	11 (37%)
I have had conflicts with my spouse or other family members because of stoma	9 (30%)
I don't allow the child to play with other kids (for toddlers)	2 (9%)
The child is not attending school because of the colostomy (for school age children)	3 (75%)
expense of the colostomy has affected the household economy	14 (47%)

7. Discussion

A colostomy can have a negative impact on the families of affected children. The issue is more significant in developing countries [3]. Two studies have recently been conducted to assess the psychosocial impact of a pediatric colostomy in LMIC. The study done in Honduras [3] in 2017 was a quantitative study with 20 participants. The second study from Uganda [16] in 2018 was a mixed study with 15 participants. Our study has the advantage of being a mixed method study with a large sample size compared to both studies. Findings from the 3 studies is compared in **figure 6**.

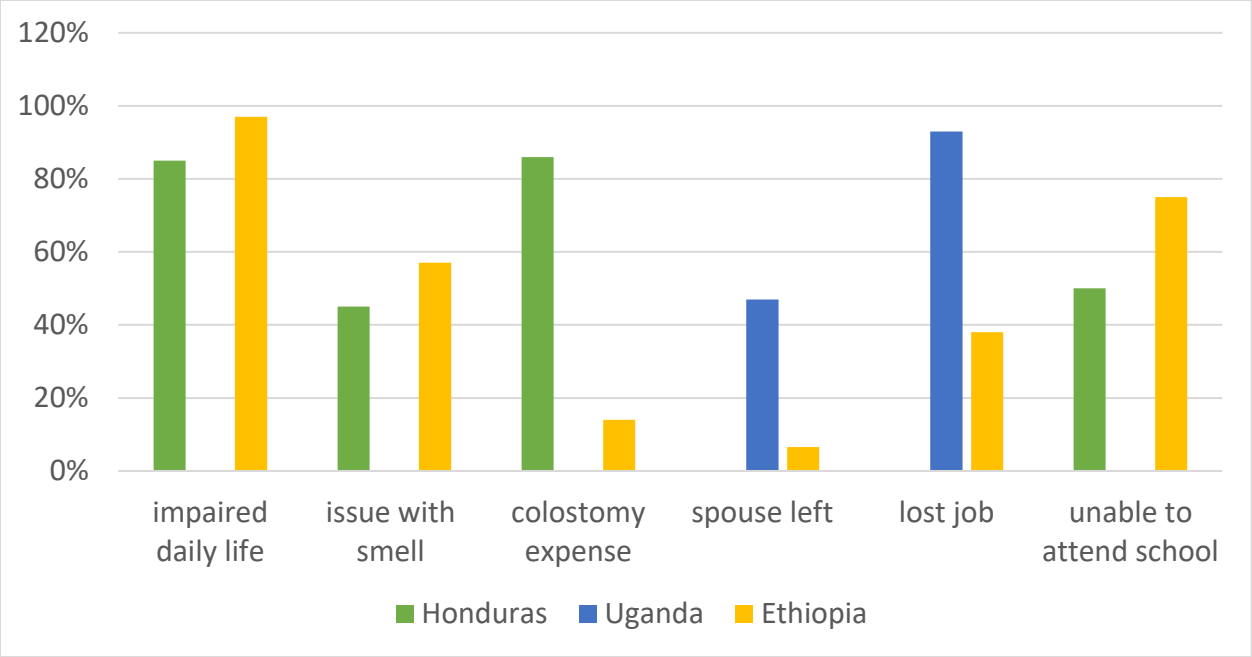

Figure 6: Comparison of the findings of 3 studies performed to assess the psychosocial and economic impact of a colostomy on families of children with colorectal disorders in LMIC

Although the 3 studies evaluated different parameters, all demonstrate a high rate of psychosocial problems. None of the participants used a colostomy bag and daily lives of parents were impaired by the colostomy. A disparity was found in the expenditure to take care of a colostomy which was $86 per month in the study from Honduras compared to only $14 per month in our study. However, despite the low cost in our country, a lot of parents faced challenges due to their poor household income. Another difference was in the rate of the spouse (father) leaving the family. This occurred in a very higher rate in the Uganda study compared to ours. There was also a higher rate of lost jobs in that study.

There are multiple reasons for high psychosocial impact of colostomy in LMIC. One study from Nigeria [18] found that stoma had poor acceptance because of high rate of prolapse (32%), odor (45%) and excoriation (21%). Similarly, our study found a high rate prolapse and stenosis (20%). The reason complications may be technical and needs further study to make appropriate recommendations. However, there was also a high rate of excoriation (53%) and bleeding (43%) in our series, which is related to lack of proper stoma care.

Absence of proper stoma appliances in developing countries is another added cause of suffering. Families from LMIC settings have used different materials to care for their child with a stoma. A study from Bangladesh [19] found betel leaf a cheap, easy to handle, non-allergic option for stoma care. Another study from Nigeria [20], assessing stoma care in children, found diaper collection method the most common, followed by wrap around waistband. These methods were similar to those used in our study. However, all are cumbersome since they require changing and washing multiple times a day. This has been the most significant issue faced by parents in Ethiopia. Some of these parents have innovated improvised stoma bags from locally available materials. If these products are mass produced in our country, it can potentially lessen a lot of the burden caused by this condition.

Lack of knowledge is also a contributing factor. A study from Egypt [21] by pediatric nurses found 100% of caregivers had poor knowledge and stoma practice. In our study we also found 87% of the parents have never seen or heard about a colostomy before. Additionally, most of the participants did not receive proper counseling or training on stoma care which contributed to their anxiety. There were no teaching materials prepared in the local language and they were not able to search for information on the internet as well. All this implies the need of our institution to provide holistic care for these families.

Finally, there is the big issue of stigmatization of children with colostomy in developing counties [17]. Most of our participants also stated that people were uncomfortable around the stoma. Some have associated the colostomy as retribution for the parent's sin. This has been another major reason for distress. Most caregivers are isolated and unable to involve in social functions. This implies the need for media advocacy change the perception of the society as well.

8. Conclusion

The study has found caregivers have increased anxiety about colostomy because lack of knowledge. Most are not satisfied with counseling and have no training. They also have psychosocial problems because the society is not comfortable with stoma.
Furthermore, stoma care is very challenging because lack of stoma appliance. It creates significant economic burden on the family as well. Caregivers have lost their jobs to look after

the child with stoma and the added expenditure of stoma care has been difficult for many of the participants.

9. Recommendations

The Ethiopian pediatric surgery association should work on educating the society on this condition. This can be done by producing teaching materials (both written and video) in our local language which can be distributed on conventional media or on online-platforms. Parents of children suffering from this condition should also be provided better training on stoma care and counseling on psychosocial issues. Having a separate pediatric colorectal super-specialized clinic may help the implementation of this dedicated care. Additionally, organizing support groups can help these families share experience and alleviate psychologic distress.

Since lack of a stoma appliance is a major cause of problems, we should create locally made substitutes which are cheap and can be mass produced in our country. In the meantime, the Ethiopian pediatric surgery association can also advocate for these children to obtain stoma bag donations from abroad. Finally, the minimum that can be done is to give these children priority on the surgical waiting list and close their colostomies as early as possible.

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