

Mothers' Knowledge and Practices regarding Caring of their Children with StomaManal Mohamed Ahmed Ayed¹, Afkar Ragab Mohammed², Madiha Hassan Bayoumi³, Ahmed Medhat Zaki⁴¹. Assist.Prof of Pediatric Nursing Faculty of Nursing, Sohag University.². Prof of Pediatric Nursing, Faculty of Nursing Cairo University.³. Prof of Pediatric Nursing, Faculty of Nursing Benha University.⁴. Prof. Ped. Surgery Faculty of Medicine Ain Shams University.Corresponding author email: manal_ayed@yahoo.comPhone number: [002-01021079610](tel:002-01021079610)**Abstract**

Stoma in children may occur anywhere along the gastrointestinal tract because of the wide variety of congenital and acquired conditions that necessitate stoma formation. Understanding enterostomal construction and physiology is essential for providing these children with optimal care. Aim of the study was to assess mothers' knowledge and practices regarding caring of their children with stoma. Subjects and Methods: Design: A descriptive research design was utilized. Setting: The study was applied in Benha Specialized Pediatric Hospital in the pediatric surgical ward and pediatric surgery outpatient clinic. Sample: A purposive sample consisted of 70 mothers of children with stoma. Tools for data collection: Tool I: Questionnaire sheet which included three parts; part one: demographic data of the mothers, part two: demographic data of children with stoma, and part three: Medical history of the child, Tool II: Questionnaire sheet to assess mothers' knowledge and Tool III: observational check list to assess mothers' practice regarding stoma care. Results: 62% of the studied children had colostomy for Hirschsprung's disease, and had temporary colostomy, while nearly one third had permanent colostomy. The main source of information among mothers was doctors. All of the studied mothers had unsatisfactory level of knowledge and had bad practice about stoma care. Conclusions: All mothers had poor level of knowledge and more than half of them had poor level of practice regarding stoma care. Recommendations: Establishing educational program for mothers of children with stoma about caring of their children to become more knowledgeable and had good practices.

Key words: Children with stoma, Knowledge, Mother, Practices**Introduction**

Gastrointestinal and genitourinary surgeries have become increasingly complex; many procedures have been developed to achieve faecal and urinary diversion, following resection for both benign and malignant diseases **Primary Children's Medical Center, (2013)**. This procedure called a stoma which is defined as a surgical opening made in the skin as a way for waste products to leave the body from the intestines (ileostomy or colostomy) or from the bladder (urostomy). Stoma formation in childhood is generally a temporary method in the surgical correction of congenital abnormalities **Fin, (2014)**.

Stoma in children may occur anywhere along the gastrointestinal tract because of the wide variety of congenital and acquired conditions that necessitate stoma formation. Understanding enterostomal construction and physiology is essential for providing these children with optimal care. The role of stomas, temporary and permanent, continent and incontinent has expanded. The diagnosis at an early stage, location of stomas, techniques of constriction, the rate of complications, duration of hospitalization and good post-operative management by enterostomal therapist and other health care professionals has vastly improved the quality of life of an ostomate. There are different types of stomas i.e. sigmoid or transverse colostomy, ileostomy and urinary diversion, may be end, loop, or double,

barrell, which require different management **Fazeli, (2012)**.

Ostomies are created for variety of reasons and depending on the disease and the problems involved. Abdominal stomas are being constructed with increasing frequency in the treatment of various malignant, congenital, inflammatory and traumatic conditions. Ostomy is done to some conditions such as imperforated anus, inflammatory bowel syndrome, trauma, tumor, Hirschsprung's disease and spina bifida **Bass et al., (2012)**.

Support for mothers is very important to be able to find help and support. Whether parents need emotional support or help managing the household duties, they must not hesitate to consult health care provider or hospital about resources in the community **Bennett, 2011, & Hampton, (2012)**. The mothers should have special knowledge and and should be well equipped with evidenced based practice care to be able to care with their children with stoma **Soomro et al., (2014)**.

Mothers are the first caregiver of children with stoma and achieve optimal growth. Maternal knowledge, attitudes, and practices affect the change of the children's care. Mothers with sufficient knowledge will implement a good practice ~~practice~~; hence, their children will be healthy and free from complications while they following better healthy practices **Kyle and Carman, (2013)**.

The nurse has to select required nursing systems to provide care for the child with stoma: wholly compensatory, partly compensatory or supportive and educative system. The care will be provided according to the degree of deficit the child is presenting with. The role of nurse for the child with stoma includes pre-operative education and counseling, pre and postoperative technical advice, emotional support; discharge planning, outpatient follow up and ongoing rehabilitation care to child and family **Tomey & Alligood, 2006 and Meleis, (2012).**

Significance of the study

Good practices of mothers are influenced by knowledge, awareness, and skill levels that affected the outcomes of children and might help more effective interventions. The number of children admitted to specialized hospital of children at Benha city according to hospital records in 2014 were about 140-160 cases from 2014-2015. The quality of secondary and tertiary care can be improved by increasing the number of training sessions and meetings with parents of children with stoma. There are many mothers don't know how to take care of their children. Parents should know how to deal with the stoma and communicates with the child and cope with problems of everyday life. Hence, the current study was aimed to; assess mothers' knowledge and practices regarding their children' stomas.

Aim of the study

To assess mothers' knowledge and practices regarding caring of their children with stoma

Research question

1. What is the mothers' knowledge regarding caring of their children with stoma?
2. What are the mothers' practices regarding caring of their children with stoma?

Subjects and methods

Research design

A descriptive research design was used in this study. Descriptive research aims to accurately and systematically describe a population, situation or phenomenon. It can

answer what, where, when and how questions, but not why questions **Shona, (2019).**

Settings

The study was applied in Benha Specialized Pediatric Hospital in the pediatric surgical ward and pediatric surgery outpatient clinic.

Subjects

A purposive sample consisted of 70 mothers of children with stoma, were participated in this study.

Inclusion criteria for children included

1. Children with any type of stoma
2. Both gender
3. Age ranges from one month – 5 years

Exclusion criteria included:

1. High risk neonates
2. Children in Pediatric Intensive Care Unit (PICU)

Tools for data collection

The following tools were designed and used by the researchers after reviewing the related literature.

Tool I: Demographic and clinical data questionnaire: It included the following three parts:

Part one: It included demographic data of the mothers of children with stoma as age, occupation, residence, and level of education.

Part two: It included demographic data of children with stomas such as age, sex and birth order.

Part three: It included medical history of the child as previous hospitalization causes for stoma, investigation, and type of stoma....etc.

Tool II: Questionnaire sheet was to assess mothers' knowledge such as definition, types, causes, and knowledge about care of child with stoma (30 questions).

Scoring system

A total score of knowledge was "120" divided into three levels, where mothers who had knowledge scores less than 60 (50%) considered unsatisfactory, while score 60 to 80 (50 %- 65%) was considered as fair level and those who got more than 80 (>65 %) were on good level of knowledge.

Tool III: observational check list to assess mothers' practice about the stoma care, diaper care, skin care, breast feeding, washing colostomy bag as well as diet and nutrition of the child with stoma etc..... (20 sub- items).

Scoring system:

The total score of practice was 80 scores, mothers' practice score of less than 48(60%) was considered poor, scores from 48-52 was considered fair, and mothers who had practice score more than 53 were considered on the good level of practice

Validity

Five specialists from pediatric nursing and pediatrics had an agreement on the face and content validity of the constructed tools with content validity index (CVI) 0.96%.

Reliability

Tool reliability was assessed for internal consistency by alpha Cronbach, The correlation coefficient for knowledge was 0.93 and for practice was 0.89 by Cronbach's alpha.

Pilot study

It was carried out on 10 % of the mothers and their children, for the purpose of clarification. The designed tool was tested on those mothers and their children, who fulfilled the inclusion criteria to evaluate the content of the tools and to estimate the time required to fill in the sheets. Unclear items were clarified, unnecessary items were omitted, new variables were added, and changing in the phrasing.

Data Collection Procedure

An official permission to carry out the study was obtained from the official personnel in Children

Specialized Hospital at Benha City, and from the chairpersons of the surgical ward. An explanation was given to mothers about the nature of the study, its aims, benefits and study tools. Data collection was started from April 2012 to October 2012 (over 7 months) one day per week in the morning and afternoon shifts to prevent work interruption. Each mother was interviewed individually, assessment of mothers' knowledge and practice regarding stoma care for their children. Interview was conducted in the child's room in the surgical ward.

Ethical considerations:

Each mother was informed with the nature, process and expected outcomes of the study. The researcher explained to the mothers the purpose of the study and that all data will be confidential and used only for research purpose. All rights were given to the subjects to complete or withdraw from the study at any stage. The study's proposal was approved by the ethical committee at Benha nursing college.

Statistical design:

The data obtained were reviewed, prepared for computer entry, coded, analyzed and tabulated. Data entry and analysis were done using SPSS 17.0 statistical software package. Data were expressed as mean, SD and number, percentage. Using Manwhitiny test to determine significance for numeric variables and using Chi. Square to determine significance for non-parametric variables. Using person's correlation for numeric variable in the same group, $P > 0.05$ was considered not significant $P < 0.05$ significant $P < 0.01$ moderate significant $P < 0.001$ highly significant

Results

Table (1) represents that the mean age of studied mothers was (28.84 ± 6.16) years, more than one third of the mothers' age ranged from 25- 29 years. Regarding mother's job the highest percent (81.42%) of them was house wife and 18.57% of mothers were Employers and (53%) of them were living in rural areas. As regard the level of education, less than two thirds (64.28%) of mothers were illiterate and (5.71%) of mothers had university education.

Table (2) reveals that the mean age of children was (16.42 ± 12.71) months. Regarding the children sex, this table illustrates that about two thirds of children (67.14%) were males. In relation to child's current weight, this table reflects that the mean weight of them is (8.72 ± 2.35) , and noted that about two thirds (64.28%) of children' weight ranged

from 6-8 kg, while 42.85% of children birth; weight ranged from 3- 3.75 kg. As regard gestational age of children it was noted that half of children (50.0%) their gestational age ranged from 39-40 wks.

Figure (1) shows that less than two thirds (62%) of the children' diagnosis was congenital megacolon, while 33 % & 5% of them had imperforated anus and necrotizing enterocolitis respectively.

Figure (2) illustrated that less than two thirds (64.4 %) of children had temporary stoma and more than one third (35.6%) had permanent stoma.

Table (3) concerning the mother's knowledge about stoma of their children, this table points out that all the mothers did not have knowledge about items of stoma. Regarding mothers' source of previous knowledge, about their children stoma, more than forty percent (40%) reported that both doctors and nurses were their source of information followed by (33%) of mothers reported that the nurses were their source of information.

Table (4) illustrates that all of the studied mothers had poor level of knowledge regarding to their children with stoma

Table (5) shows that the studied mothers did not know the ideal preparation for stoma care as regard tray and warm water, wash cloth, clean pouch gloves, zinc oxide ointment and adherent tap except tray and clean water and clean gauze all of mothers reported them during preparation.

Table (6) presents that (62.8%) of the studied mothers wash their hands before procedure for stoma care, (57.14%) of mothers assess skin around stoma before procedure and (72.8%) of them clean skin with gauzes

Table (7) illustrates that (55.7%) of the studied mothers had poor level of practice and only (3%) of them had good practice regarding to their children with stoma

Table (8) displays that there was no statistical significant difference ($P=0.283, 0.824$) between mothers' knowledge and practice as regard their age,. It is clear from the same table that no significant difference between mothers' work and total knowledge ($p= 0.343$). Meanwhile, a statistical significant difference was found between mothers' work and total practice ($P =0.02$). Also, reflected that there was highly statistical significant relation between mother's level of education and total knowledge score ($P <0.002$). Meanwhile, no statistical significant relation was found between mother's level of education and total practice ($P= 0.941$).

Table (1): Percentage distribution of the studied mothers by their demographic characteristics

Characteristics of mothers	No	%
1- Age(years)		
• 20– 24	18	25.71
• 25–29	26	37.14
• 30–34	15	21.43
• 35–40	11	15.72
Age (years)	Mean± SD	28.84 ± 6.16
Mothers' occupation		
- House wife	57	81.43
- Working	13	18.57
Residence		
- Rural	53	75.7
- Urban	17	24.3
Mothers' education:		
-Illiterate	45	64.28
-Read & write	9	12.85
-Primary education	8	11.43
-Preparatory education	0	0.0
-Secondary education	4	5.72
-University education	4	5.72

Table (2): Percentage distribution of children with stoma according to their characteristics

Characteristics of children	n=70	100.0%
1-Age(months)		
• 1-11	14	20.00
• 12-23	29	41.42
• 24-35	18	25.72
• 36-48	9	12.86
Mean± SD	16.42 ± 12.71	
2-Birth order		
• First	0	0.0
• Second	22	31.42
• Third	24	34.29
• Fourth	14	20.0
• Fifth	10	14.29
Mean± SD	8.72±2.35	
3-Gestational age of child at birth:		
• < 38 wks.	15	21.42
• 38-39 wks.	20	28.58
• 39 – 40 wks.	35	50.0

Figure (1): Distribution of children with stoma according to their diagnosis

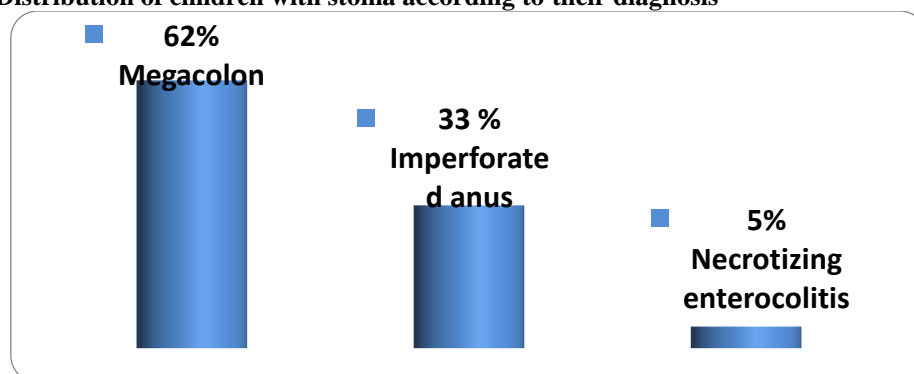


Figure (2) Distribution of children's colostomy as regard to permanence and temporary

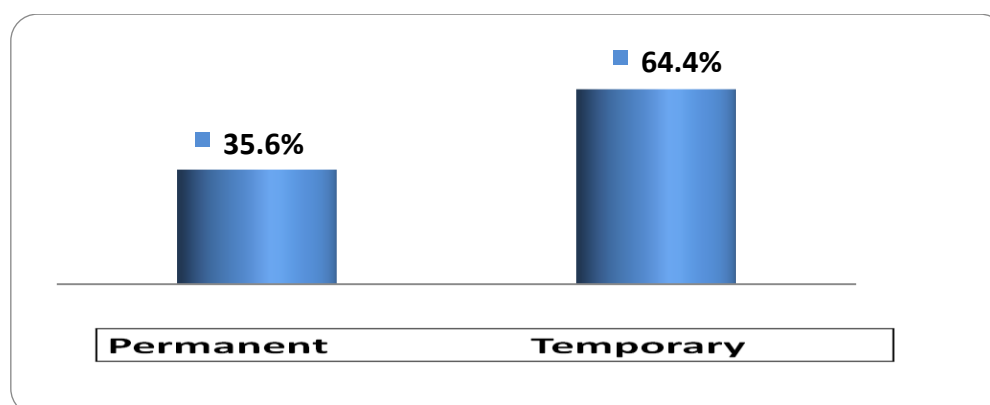


Table (3): Distribution of mother's knowledge regarding stoma

Items	N	%
Definition of stoma		
Know	70	100
Don't know	0	0
Types of stoma		
Know	70	100
Don't know	0	0
3-Causes of stoma		
- Congenital anomalies	70	100
- Cancer colon	0	0
- Urinary incontinence	0	0
- Others	0	0
4- Indications of stoma		
-Don't know	70	100
-Input stoma	0	0
-Output stoma	0	0
-Others	0	0
5- Complications		
- Don't know	70	100
- Know	0	0
6-Types of diet		
- Don't know	70	100
- Easily digested	0	0
- warm food	0	0
- balanced diet	0	0
7-Types of clothes to be weared		
-Don't Know	60	85.7
-Cotton clothes	10	14.3
8-Precaution should follow during food intake.		
-Don't Know	70	100
-Know	0	0
9- Prescribed food		
-Don't Know	70	100
-Balanced & easy digested	0	0
10-Source of mother's knowledge about stoma care:		
- No knowledge	5	7
- Doctor& nurse	14	20
- Only nurse	23	33
- Only doctor	28	40

Table (4): Distribution of mothers' level of knowledge related to their child with stoma

Items	n=70 100%	
	No	%
- Poor < "50 "	70	100%
-Fair "50- 65"	0	0.0
-Good"> "65"	0	0.0
Total knowledge	5.68±0.69	

Table (5): Distribution of mothers' preparation for stoma care

Preparation for stoma care	no=70 100%	
	No.	%
-Tray and warm water	0	0.0
- Tray and clean water	70	100
- Wash cloth	3	4.28
- Clean pouch	0	0.0
- Gloves	0	0.0
- Zinc Oxide ointment	0	0.0
- Clean gauze	70	100
- Adherent tap	0	0.0

Table (6): Distribution of mothers' actual stoma care

Items	No.	%
1-Hand washing	44	62.8
2- Wear gloves	0	0.0
3- Close windows	6	8.5
4- Observe stoma site and signs of infection	6	8.5
5- Put child in comfortable position	16	22.8
6- Put equipments in a tray	0	0.0
7- Put waterproof under child	0	0.0
8- Assess the stoma output	3	4.28
9-Gently clean skin around stoma with warm water	70	100
10-Assess skin around stoma	40	57.14
11- Clean skin with gauzes	51	72.8
12-Empty pouch	0	0.0

Table (7): Distribution of mother's level of practice related to their children with stoma

Items	n=70 100%	
	No	%
- Poor < "50 "	39	(55.7%)
-Fair "50- 65"	28	(40.0%)
-Good"> "65"	3	(4.28%)
Total practice mean Score	16.17±1.60	

Table (8): Correlation between total mothers' knowledge and practice scores regarding their demographic data

Items	Mother's age					P- Value	
	no=70		100%		P- Value		
	20-24(yrs)	25-29(yrs)	30-34(yrs)	35-40(yrs)			
- Total knowledge	5.28±1.1	5.00±0.00	5.50±0.98	12.00±0.23	0.283 N.S		
- Total practice	16.23±1.51	17.00±0.00	15.95±1.84	16.00±0.00	0.824 N.S		
Mother's work							
Items	House Wife		Working		P- Value		
- Total knowledge	6.00±2.10		4.25±2.42		0.343 N.S		
- Total practice	15.89±4.67		17.25±1.16		0.02*		
Items	Mother's level of education						P- Value
	Illiterate	Read & Write	Primary	Prep	Secondary	University	
Total knowledge	5.89±0.88	5.50±0.54	6.20±1.09	0	6.00±0.98	8.60±0.60	<0.002
Total practice	16.06±1.921	16.00±1.09	16.40±0.54	0	17.00±0.00	16.00±0.00	0.941 N.S

Discussion

An ostomy is an artificial opening in the body for the purpose of eliminating excretions from a working organ or for providing nourishment **Deitz & Gates (2010)**. Artificial openings may be from the stomach, intestine, urinary bladder, kidney or trachea. An ostomy may be the best and safest form of treatment for number of conditions such as cancer of colon and rectum, trauma, obstruction of the bowel, complications of diverticulosis, and Grohn's disease **Breckman, (2012)**.

As regards the characteristics of the studied children, the results of the current study revealed that the mean age of them was (16.42 ± 12.71) months. More than forty percent of the children' age ranged between 12 -23 months. This study is supported by **Al-Basrah, (2009)** who found that children of any age can develop a stoma, and typically children are between the ages of 1-48 months. More than two thirds of the studied children were males; these results goes in the same way with the study conducted by **Williams, (2008)** who found that there were 66 male and 36 females of different ages with stoma. These results also agreed with the study conducted by **Luiz, (2009)** who indicated that a total of 23 children (16 males, 7 females) have stoma in his study. In addition many studies of congenital megacolon and other congenital anomalies are linked with male gender for unexplained reasons.

As regards mothers' characteristics, the finding of the present study revealed that the mean age of the studied mothers was (28.84 ± 6.16) years, more than one third of the mothers' age was 25-29 years and about two thirds of them were illiterate. The majority of them were housewives. These results

are agreed with the result of **Hoebcke et al., (2011)** who studied the quality of life of children with stomas the children and mothers' point of view and found that mothers have incomplete elementary education.

Regarding the diagnosis associated with children stoma the present study illustrated that about two thirds of children had Hirschsprung disease with colostomy, while the minority of them had enterocolitis. This result is in agreement with the result of **Waller, (2009)** who discussed that colostomy was the commonest procedure and congenital anorectal anomalies were the most common indications for stoma surgery. This result is also in agreement with the result of **Bray & Sanders, (2006)** who found that the commonest indication seen in 90% of children followed by congenital abnormalities. An old study conducted by **Bison et al., (1997)** concluded that congenital megacolon was about (15%) and imperforated anus was (14%), this result goes inconsistent with our study, the researchers' opinion is that it is a warning signs for increasing ratio of congenital anomalies.

In the present study's results more than half of children had peristomal skin inflammation as complication of stoma this result almost related to the lack of facility to use colostomy bags which require hospital policy attention, so some families had financial problems. This result is supported by **Nicholas et al., (2008)** and **Mollitt et al.,(2008)** who discussed peristomal skin inflammation was the most common complication in children with stoma, also it was in agreement with **Justin (2006)**, **Al-Basrah, (2009)** who found that skin irritation is common and can be caused by various factors in the stoma.

In the same context **Goldberg et al., (2010)** found that complications of infection and granulation

tissue occur frequently and likely are a cause of stress and increased burden of care for children with stoma and their families. Furthermore **Olejnik et al., (2005)** found that skin changes (33%) were the most common complications in case of stoma, which could encounter for inappropriate care. Other complications included hemorrhage (20%), prolapse (13%), and stoma narrowing (10%).

As regard types of stoma, the present study revealed that the less than two thirds of children had temporary stoma and more than one third of them had permanent stoma. This result was in agreement with the result of **Hampton, (2012)** who mentioned that anorectal diseases for which temporary colostomy performed to deal with the primary cause later on and protect surgical anastomosis distal to colostomy. This result also was supported by **Waller, (2009)** who found that most intestinal stomas were constructed as emergency and of temporary measures, in addition **Chandramouli, (2009)** concluded that colostomy represented the second most common type of stoma which was due mainly to infants and children for whom were constructed as temporary diverting stomas for treatment of congenital colorectal disorders. On the other hand this result was disagreed with **Frojd et al., (2007)** who stated that stomas were mostly indicated for permanent diversion.

In the present study it was found that among all mothers had poor knowledge about stoma. This is indicated the need to conduct this study in order to manage problem of knowledge deficit.

Results of the current study revealed that more than half of the studied mothers had poor practice this is reflected knowledge deficit which always associated with poor practice.

In the current study mothers' age was negatively correlated with their knowledge and practice ($P=0.283$, 0.824 respectively). The current study showed that mothers' education was positively correlated with their knowledge ($P < 0.01$). In this approach in the same context **Williams, (2008)** and **Noone, (2010)** concluded that stoma formation also has an impact on the well - being and lifestyle of the children and their family whatever their age. Quality of life can deteriorated following a stoma procedure and specialist support during the first few weeks post-stoma is vital issue.

Conclusion:

In light of the current study results, it was concluded that the main source of information among high percentage mothers was **doctor**. All of the studied mothers had poor level of knowledge regarding to their children with stoma. More than half of the studied mothers had poor level of practice and regarding to their children with stoma

Recommendations:

From the previous findings the following recommendations are suggested: -

- Establishing educational program for mothers of children with stoma about caring of their children through verbal and written instructions regarding home care for stoma to become more knowledgeable and had good practices.

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