

Mother's Awareness regarding Palliative Care for Children with Autoimmune Inflammatory Bowel Diseases

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Abstract

Background: Inflammatory bowel disease is characterized by chronic inflammation of the gastrointestinal tract. Palliative care is indispensable care that improves the quality of life of children with autoimmune inflammatory bowel diseases. **Aim of study:** Was to assess mother's awareness regarding palliative care for children with autoimmune inflammatory bowel diseases. **Research design:** A descriptive research design was utilized. **Setting:** The study was conducted at Outpatient clinic, Naser Institution Hospital, Cairo. **Sampling:** A purposive sample was used which included 96 mothers. **Tools:** Two tools were used: **First tool:** A structured interviewing questionnaire to assess the socio-demographic characteristics of the studied mothers, personal characteristics of children, children medical history, mother's knowledge regarding autoimmune inflammatory bowel diseases and palliative care and practices of mother regarding palliative care for their children with inflammatory bowel diseases. **Second tool:** Scale of mother's attitude towards palliative care. **Results:** 47.9% of the studied children diagnosed as ulcerative colitis, 56.3% had no family history of the disease. 40.3% of the studied mothers had complete correct total knowledge level about inflammatory bowel diseases, and 30.8% of the studied mothers had complete correct total knowledge level about palliative care, in addition; 73.96% of them had satisfactory total reported practices regarding palliative care, Also, 90.7% of them had positive attitude about palliative care for the children with inflammatory bowel diseases. **Conclusion:** There was a statistically significant relation between mother's total knowledge and highly statistically significant relation between total practices and mother's attitudes regarding palliative care for children with autoimmune inflammatory bowel diseases. **Recommendation:** Develop instructional guidelines for mothers about palliative care, and care of their children with autoimmune inflammatory bowel diseases based on the evolvement of the international evidence-based criteria in mothers and child health setting.

Keywords: Palliative Care, Inflammatory Bowel Disease, Mother's Awareness.

Introduction

Inflammatory Bowel Disease is a chronic inflammatory and autoimmune disorder affecting the Gastrointestinal Tract and is characterized by increased intestinal permeability as well as imbalanced and hyperactive immunological responses caused by environmental factors such as dietary components and gut microbiome.

inflammatory bowel disease is classified into two subtypes: ulcerative colitis and crohn's disease, each of which has unique clinical and pathological features (**Ramadan et al., 2024**).

Many autoimmune diseases are characterized by the production of autoantibodies, which bind to the host's own

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proteins or form immune complexes and deposit in tissues. Any organ of the body may become a target organ for autoimmunity, including skin, joints, kidneys, and blood vessels (**Pisetsky, 2022**).

Palliative care is an approach that improves the quality of life of patients (adults and children) and families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (**Adol Abbaspour and Heydari, 2021**).

Pediatric palliative care focuses on providing holistic and integrated care to enhance the quality of life of children and young people with life-limiting illnesses while also supporting families. A key principle of family-centered care is for professionals to work with families to ensure the best interests (**Aoun et al., 2020**).

Awareness is a method of bringing care issues to the attention of mothers. Mothers play a vital role in the care of their children with inflammatory bowel disease. mothers' caregivers are involved in direct care, decision making, goal setting, and advanced care planning. Mothers' awareness work with palliative care team to satisfy the child's needs and improve quality of life. mothers not only provide physical care but also provide psychological, social, spiritual, religious, and all aspects of care (**Sigvardsson et al., 2024**).

The community health nurse plays an important role for controlling IBD should include several elements, by Connection between the patient and all members of the multidisciplinary team (and with other figures, if appropriate). Holistic support for the patient and their family in both the

hospital and the community. Services managed by nurses: from a clinical point of view, telephone assistance, rapid triage, and organizational management of follow-up appointments. Audit and research systems (patient database). So Teaching and therapeutic education to patients, families, and other health professionals through Support groups (**Rosso et al., 2021**).

Significance of the study:

Globally, incident cases of inflammatory bowel disease in children and adolescents increased in 2019, an increase of 22.8%, an increase of 18.5% over 1990. Overall, the incidence and prevalence of inflammatory bowel disease among children and adolescents stabilized between 1990 and 2019. The incidence and prevalence in 2019 were 0.77 to 1.17 and 2.66 to 4.05 per 100,000, respectively (**Long et al., 2024**).

Prevalence of inflammatory bowel disease increased substantially in many countries, which might pose a substantial social and economic burden on governments and health systems in the coming years. The age-standardized prevalence rate of IBD in Egypt increased from 17.9 to 26.7 per 100 000, between 1990 and 2017 with a 48.9% change. Ulcerative colitis and Crohn's disease are major chronic IBD conditions in addition to indeterminate colitis that cause varying degrees of gastrointestinal tract inflammation (**Alsawak et al., 2023**), So that, the researchers found that it is important to conduct the study to assess mother's awareness regarding palliative care for children with autoimmune inflammatory bowel diseases.

Aim of the study:

This study aimed to assess mother's awareness regarding palliative care for children with autoimmune inflammatory bowel diseases.

Research questions

1. What is the mother's knowledge regarding palliative care for autoimmune inflammatory bowel diseases?
2. What is the mother's reported practice regarding palliative care for children with inflammatory bowel diseases?
3. What is the mother's attitude towards palliative care in inflammatory bowel diseases?
4. What is the relation between mother's knowledge reported practice and attitude towards palliative care for inflammatory bowel diseases?

Subjects and method:

Research design

A descriptive research design was utilized to conduct this study.

Setting

This study was conducted at Outpatient clinic, Naser Institution Hospital in Cairo City.

Sampling

Purposive sample of 96 mothers who are attended to the previously mentioned setting for follow up of their children with inflammatory bowel diseases through a period of six months according to the following criteria: Age 6 <15 year.

Tools for data collection: Two tools were used to collect the data.

The first tool: A structured interviewing questionnaire: It comprised of four parts:

Part I: A. Socio-demographic characteristics of mothers: It included 7 closed ended questions. **B.** Personal characteristics of children that: It included 4 closed ended questions about age, sex, education level, and order of the child in the family.

Part II: Medical history of children that: It included 7 closed ended questions about type of immune disease, the onset of the disease, family history of the disease, symptoms that

appeared, methods treatment regimen, medicines used in drug therapy and surgeries.

Part III: A. Knowledge of mothers regarding inflammatory bowel diseases: Which include 6 closed ended questions meaning of inflammatory bowel diseases, symptoms, causes, diagnosis, clinical examination, complications and treatment. **B.** Knowledge of mothers regarding palliative care: Which include 8 closed ended questions meaning of palliative care, symptoms that need palliative care, providers of palliative care, level of palliative care, factors hinder palliative care, place of palliative care, palliative care domains and time of palliative care provide.

Scoring system of mother's knowledge

The scoring system for mother's knowledge was calculated as follows: 2 score for correct and complete answer, and 1 score for correct and incomplete answer, while 0 score for don't know. The total knowledge score = 28 points, which categorized:

- **Good knowledge** → if the total score of knowledge was $\geq 75\%$ (≥ 21 points).
- **Average knowledge** → if the total score was $50 < 75\%$ ($14 < 21$ points).
- **Poor knowledge** → if the total score was $< 50\%$ (< 14 points).

Part IV: It was concerned with reported practices of mothers regarding palliative care for children with autoimmune inflammatory bowel diseases which included 6 domains that divided into:

1. Structural aspect and care process: It included of 6 closed ended questions.
2. Physical aspects, composed of 8 items which included, nutrition, personal hygiene, exercise, medication, sleep, pain, difficulty breathing and constipation It included of 36 total items.
3. Psychological aspects composed of 2 items which included, anxiety, stress, and fear It included of 8 total items.
4. Spiritual aspects: It included of 3 closed ended items.
5. Social aspects: It included of 5 closed ended

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items. **6. Ethical aspects:** It included of 4 closed ended items.

Scoring system of mother's practices

The scoring system for mother's practices was calculated as follows 1 score for done, and 0 score for not done, the total reported mother's practices score = 60 points, which categorized:

- **Satisfactory** → if the total score of practices was $\geq 60\%$ (≥ 36 points).
- **Unsatisfactory** → if the total score of practices was $<60\%$ (<36 points).

The Second tool: Concerned with mother's attitudes regarding palliative care for the children with inflammatory bowel diseases. It included of 9 closed ended statement.

Scoring system of mother's attitude

The scoring system for mother's attitudes was calculated as follows: 2 score for strongly agree, 1 score for agree and 0 score for not agree answer. The total attitude scores = 18 points which categorized:

- **Positive attitude** → if the total score of attitude was $\geq 60\%$ (≥ 10 points).
- **Negative attitude** → if the score was $<60\%$ (< 10 points).

Content validity:

The tools validity was done by three members of Faculty's Staff Nursing-Benha University Experts from Community Health Nursing Specialties who reviewed the tools for clarity, comprehensiveness, applicability and easiness for implementation and according to their opinion, minor modifications carried out.

Tools Reliability:

The reliability of the tools was done by Cornbrash's Alpha coefficient test which revealed that the two tools consisted of homogenous items as indicated by the moderate to high reliability of each tool. The internal consistency of knowledge was 0.751, practices was 0.766 and attitude was 0.791.

Ethical consideration

Approval from ethical committee in Faculty of Nursing Benha University and an informed oral consent from all study participants was obtained after explaining the purpose of the study to gain their trust and cooperation. Each mother has a choice to continue or withdraw from the study. Privacy and confidentiality were assured. Ethics, values, culture, and beliefs were respected. The data collected were stored in confidential manner.

Pilot study:

The pilot study was conducted on 10 mothers who represented 10% of the total sample size (96 mothers). The pilot study was made to assess the tools clarity, applicability and time needed to fill tools for each mother as well as to identify any obstacles that may hinder the data collection. The pilot study was included as no modifications were done.

Field work:

The researchers introduced themselves and explained the aim of the study. The field work was carried out a period six months from the beginning of May 2024 to end of October 2024. The researchers met studied mothers in waiting area of the Out Patient Clinic of Naser Institution Hospital from 09.00 a.m. to 12.00 p.m. two days per week (Saturdays and Wednesdays) to collect data from mothers. The average time needed to fill the tools was about 15-20 minutes depending upon understanding and response of studied mothers each day the investigator met from 3 to 5 participant mothers.

Statistical analysis:

All data collected were organized, tabulated, and analyzed using appropriate statistical tests. The data were analyzed by using the Statistical Package for Social Science (SPSS) Version 26, which was applied to calculate number and percentages

for qualitative data and mean \pm S.D for quantitative data as well as test statistical significance and associations by using chi-square test (X^2) to detect the associations between the variables for (p value):

- Highly significant (HS) $P \leq 0.001^{**}$.
- Significant (S) $P \leq 0.05^*$.
- Not significant (NS) $P > 0.05$.

Results:

Table (1): Shows that 45.8% of the studied mothers aged from 30 < 40 year with Mean \pm SD 38.5 \pm 7.6, 61.5% of them were married, 36.5% of them had university or more education. and 45.8% of them house wife. Regarding of residence 71.9% of the studied mothers lived in urban area. Also 69.8% of studied mothers their monthly income was not enough and 79.2% of them had family from 3 to 5 person.

Table (2): Demonstrates that 35.4% of the studied children aged from 12 < 15 year with Mean \pm SD 10.5 \pm 2.2, 70.8% were males. 53.1% of them had preparatory education level. Also 36.5% of studied children are the third child within the family.

Table (3): Shows that; 47.9% diagnosed as ulcerative colitis of the studied children, 44.8% suffer from the disease from 1 to 3 year, 56.3% didn't had family history of the disease. As the most common symptoms 66.67% of the studied children had abdominal pain and cramps. regarding methods treatment regimen 58.3% of them treated with drugs and 57.3% of using anti-inflammatory medications. 58.3% didn't treat by surgical intervention.

Table (4): Shows that; 55.2% of studied mothers had complete correct answer about symptoms of inflammatory bowel diseases,

while 65.6% of them had incomplete correct answer about meaning of inflammatory bowel diseases, and 19.7% of them didn't know about the meaning of inflammatory bowel diseases.

Table (5): Shows that; 54.2% of studied mothers had complete correct answer about place of palliative care, while 56.2% of them had incomplete correct answer about symptoms that need providers of palliative care and 40.6% of them didn't know the level of palliative care.

Table (6): Shows that 84.4%, 81.3% and 80.7% respectively of studied mothers had satisfactory practices in spiritual, ethics and social respectively, while 58 % of them had unsatisfactory practices in structural aspect and care process.

Figure (1): Illustrates that; 73.96 % of studied mothers had satisfactory practices about palliative care items for the children with inflammatory bowel diseases, while 26.04% of them had unsatisfactory practices.

Figure (2): Illustrates that; 90.7% of studied mothers had positive total attitudes toward palliative care for the children with inflammatory bowel diseases. While 9.3% of studied mothers had negative total attitudes toward palliative care.

Table (7): Shows that; there was highly statistically significant relation between total practices level and total knowledge level (P-value < 0.05).

Table (8): Shows that there was highly statistically significant relation between total practices level and mother's attitudes (P-value < 0.001).

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Table (1): Distribution of studied mothers regarding their Socio-demographic characteristics (n=96).

Socio-demographic characteristics	No.	%
Age/Year		
From 20 < 30	12	12.5
From 30 < 40	44	45.8
From 40 < 50	35	36.5
≥ 50	5	5.2
Mean ±SD 38.5 ±7.6		
Marital status		
Married	59	61.5
Widower	13	13.5
Divorced	24	25
Education level		
Cannot read or write	8	8.3
Basic education	20	20.8
Preparatory	33	34.4
University or more	35	36.5
Occupation		
Freelance work	14	14.6
House wife	44	45.8
Employee	38	39.6
Residence		
Urban	69	71.9
Rural	27	28.1
Monthly income		
Enough and saved	3	3.1
Enough	26	27.1
Not enough	67	69.8
Number of family members		
From 3 To 5	76	79.2
5+	20	20.8

Table (2): Distribution of the studied children regarding personal characteristics (n=96).

Personal characteristics	No.	%
Age/Year		
6 < 8	12	12.5
8 < 10	32	33.3
10 < 12	18	18.8
12 < 15	34	35.4
Mean \pmSD 10.5 \pm2.2		
Sex		
Male	68	70.8
Female	28	29.2
Education level		
Basic education	45	46.9
Preparatory	51	53.1
Ranking of the child in family		
First	21	21.9
Second	26	27.1
Third	35	36.5
Fourth	14	14.6

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Table (3): Distribution of the studied children regarding their medical history (n=96).

Medical history		No	%
Type of immune disease	Crohn's Disease	23	24
	Ulcerative Colitis	46	47.9
	Both together	27	28.1
The onset of the disease/ year	1 – 3	43	44.8
	4 – 6	29	30.2
	> 6	24	25.0
Family history of the disease	Yes	42	43.8
	No	54	56.3
*Symptoms that appeared of the child	Flatulence	16	16.67
	Abdominal pain and cramps	64	66.67
	Constipation	2	2.08
	Esophageal reflux	6	6.25
	Nausea	6	6.25
	Food allergy	12	12.50
	Blood or mucous the stool	26	27.08
	Skin rash	4	4.17
	Weight loss	22	22.92
	Urgent Need to defecate	10	10.42
	Diarrhea with blood or pus	16	16.67
	Abscesses and ulcers around the anus	4	4.17
	Increase spitting	1	1.04
	Left side abdominal pain	2	2.08
	Mouth ulcers	2	2.08
	Anemia	1	1.04
Methods treatment regimen followed	Drug treatment	56	58.3
	Surgical treatment	0	0
	Both together	40	41.7
Medicines used in drug therapy	Anti-inflammatory medications	55	57.3
	Immune system suppressant medications	13	13.5
	Antibiotics	4	4.2
	Anti-diarrheal medications	7	7.3
	Pain relievers	17	17.7
Surgeries did the child undergo	Rectal resection	4	4.2
	Removal of the colon or part of it	21	21.9
	** Mention the types of other	15	15.6
	No surgical intervention	56	58.3

** Mention the types of other

Table (4): Distribution of studied mothers regarding their knowledge about inflammatory bowel diseases (IBD) (n=96).

Knowledge	Complete Correct answer		Incomplete Correct answer		Don't Know	
	No	%	No	%	No	%
Meaning of inflammatory bowel diseases (IBD)	35	36.4	42	43.7	19	19.7
Symptoms	53	55.2	37	38.5	6	6.3
Causes	36	37.5	54	56.2	6	6.3
Diagnosis and clinical examination	30	31.3	63	65.6	3	3.1
Complications	36	37.5	53	55.2	7	7.3
Treatment	42	43.8	49	51	5	5.2
Total	39	40.3	50	51.7	8	8

Table (5): Distribution of studied mothers regarding their knowledge about palliative care for the children with inflammatory bowel diseases (IBD) (n=96).

Knowledge	Complete Correct answer		Incomplete Correct answer		Don't Know	
	No	%	No	%	No	%
Meaning of palliative care	25	26	46	48	25	26
Symptoms that need PC	21	21.9	54	56.2	21	21.9
Providers of PC	24	25	54	56.2	18	18.8
Level of PC	39	40.6	18	18.7	39	40.6
Factors hinders PC	32	33.3	32	33.3	32	33.3
Place of PC	52	54.2	24	25	20	20.8
Palliative care domains	24	25	52	54.2	20	20.8
Time of PC provide	20	20.8	46	47.9	30	31.2
Total	29.6	30.8	41	42.6	26	26.6

Table (6): Distribution of studied mothers regarding their total practices items for children with inflammatory bowel diseases (n=96).

Children total practices	Satisfactory		Unsatisfactory	
	No	%	No	%
Total structural aspect and care process	40	42.0	56	58.0
Total physical	72	75.0	24	25.0
Total psychological	75	78.1	21	21.9
Total spiritual	81	84.4	15	15.6
Total social	77	80.7	19	19.3
Total ethics	78	81.3	18	18.7

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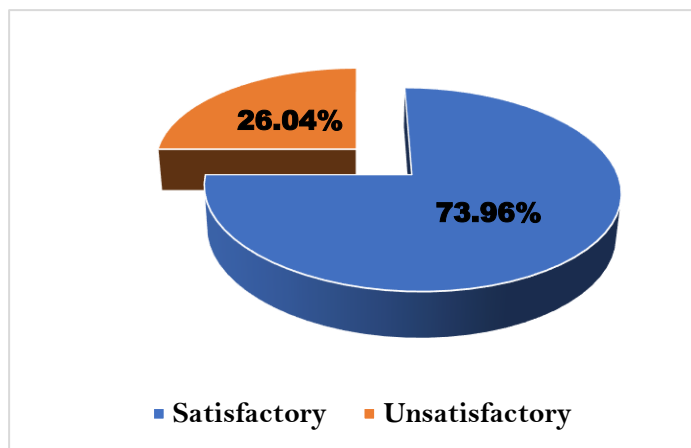


Figure (1): Percentage distribution of studied mothers regarding their total practices (n=96).

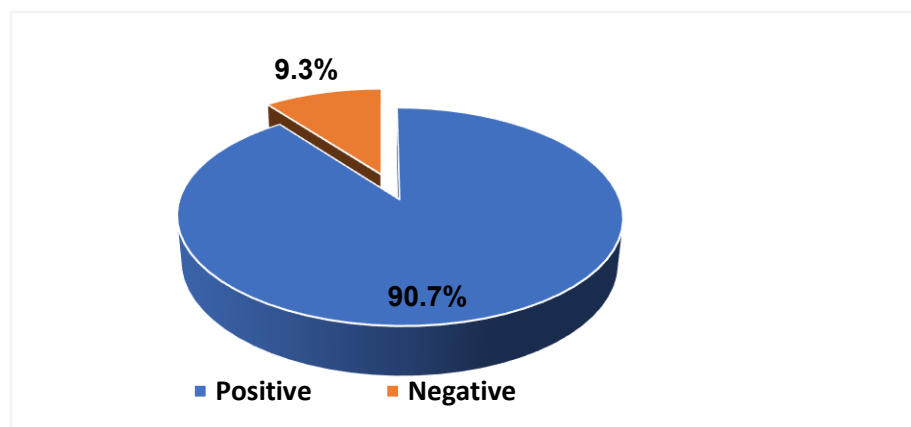


Figure (2): Percentage distribution of studied mothers regarding their attitudes about palliative care for the child with inflammatory bowel diseases (n=96).

Table (7): Statistically relation between total practices level and total knowledge level among the studied mother samples.

Total practices level	Total knowledge level							X ²	P-value
	Poor (n=17)		Average (n=44)		Good (n=35)				
	No.	%	No.	%	No.	%			
Unsatisfactory (n=25).	10	40	15	60	0	0	6.201	.045*	
Satisfactory (n=71)	7	9.9	29	40.9	35	49.2			

**High Statistically Significant

Table (8): Statistically relation between Mother's attitudes, and total practices level.

Mother's attitudes	Total practices level						X ²	P-value
	Poor (n=17)		Average (n=44)		Good (n=35)			
	No.	%	No.	%	No.	%		
Unsatisfactory (n=25).	7	28	17	68	1	4	15. 01	.000*
Satisfactory (n=71)	3	4.3	33	46.5	35	49.2		

**High Statistically Significant

Discussion:

Auto Immune Inflammatory bowel diseases rarely become fatal, but can greatly diminish the quality of life because of pain, vomiting, diarrhea, and other socially unacceptable symptoms. The increased risk of colorectal cancer from 0.5% up to 20% per year of colitis is a serious complication of auto immune inflammatory bowel diseases, particularly ulcerative colitis, so focuses on providing holistic and integrated care to enhance the quality of life for children with Auto Immune Inflammatory bowel diseases and supporting their families through palliative care (**Rashid et al., 2024**).

Regarding sociodemographic characteristics of the studied mothers; the current study showed that; the mean age of the mothers was 2.343 ± 0.78 near to half of the studied mothers ranged from $30 < 40$ years old, about more than half of them was married, and less than half of them had university education level or more. These results were in agreement with **Balbale et al., (2022)**, who studied "Needs and Perceived Differences between Preadolescent 10-13 years old and their Caregivers with A (IBD) in US (n=100)" and reported that the near to half (47.3%) of the studied mothers aged $25 < 40$ years, and 50.5% of them were married.

Regarding to personal characteristics of studied children, the current study demonstrated that more than one third of the studied children aged from $12 < 15$ year, mean \pm SD 2.750 ± 1.066 , more than half were males, half of them were had primary education level and more than one third of studied children within are the third child within the family. these findings were in agreement with **Elkasaby et al., (2023)**, who studied "Epidemiological and Clinical Data of Pediatric Inflammatory Bowel Disease in Egyptian Children in Egypt (n=96) " and reported that the more than one

third (31.5%) of the studied children aged from $12 < 15$ year with mean \pm SD 2.750 ± 1.066 , 77.3% were male, half of them (50.6%) of them were had primary education level and more than one third (38.5%) of the studied children lived with their family.

Also, these results were in the same line conducted by **Catassi et al., (2024)**, who studied "Characteristics and Natural History of IBD in ESPGHAN (n=169) " and reported that the one third (33.2%) of the studied aged from $12 < 15$ year, the three quarters (74.3%) were males and the one third (32.5%) of studied children the third child within the family. This may be due a similarity in the study sample.

Concerning medical history of the children with (AIBD), the current study shows that most of them diagnosed as ulcerative colitis less than half of the total studied child and less than half were onset of the disease from 1 to 3year, more than half didn't had family history of the disease. Most common symptoms; more than quarter of the studied child had abdominal pain and cramps and more than half of them had drug treatment also more than half received anti-inflammatory medications and more than half didn't undergo surgical intervention.

Regarding mothers' knowledge about inflammatory bowel diseases, the current study shows that half of studied mothers had complete correct answer about symptoms of inflammatory bowel diseases, while minority of them had incomplete correct answer about meaning of inflammatory bowel diseases and minority didn't know about knowledge of meaning for inflammatory bowel diseases. This result is disagreement with **Velasco et al., (2024)**.

Results in current study agreement with **Michel et al., (2022)**, who studied "Pediatric inflammatory bowel disease medical home in

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United State (n=168)" and reported that half (52.0%) of studied mothers had complete correct answer about symptoms of inflammatory bowel diseases. This result may be related to level of education, awareness and health education in the countries.

Regarding mothers' knowledge about palliative care for the child with inflammatory bowel diseases, the current study shows that more than half of studied mothers had complete correct answer about place of palliative care while minority of them had incomplete correct answer about meaning of palliative care, and quarter of them didn't know about level of palliative care. This result was in agreement with **Feudtner et al., (2021)**, who studied "Demographic and Clinical Characteristics and Outcomes of Patients who Received Hospital Based Pediatric Palliative Care in Canda (n=501)" reported that more than half (54.2%) of studied sample had complete correct knowledge about place of palliative care while minority (17.5%) of them had incomplete correct knowledge about meaning of palliative care.

Regarding structural aspects and care process about palliative care for the child with auto immune inflammatory bowel diseases, the current study demonstrated that half of studied mothers were documenting the child's condition, diagnosis, also the physical and psychological symptoms he appears. While two thirds of them didn't explain the aspects of palliative care for the child. This result was in the same line with **Wagner et al., (2023)**, who studied "Implementation of the Novel Interventions in Children's Healthcare Program for youth with Inflammatory Bowel Disease and High Social Risk in United State (n=89)" and indicated that more than half (56.1%) of

studied sample were documenting the children condition, diagnosis, physical and psychological symptoms.

Regarding total reported practices about palliative care items for the child with inflammatory bowel diseases, the current study shows that the majority of studied mothers had satisfactory practices in spiritual. While more than half of them had unsatisfactory practices in structural aspect and care process. This result is in agreement with **Miquel et al., (2024)**, who studied "Explore the Parents' own Spirituality, Religiosity, and Philosophy of Life in Coping with the Care of their Child with Palliative.

Concerning statistically relation between total Practices level and measure of mother's attitudes among studied sample, the current study shows that there was high statistically relation between total practices level and mother's attitudes. This result agreement with **Shao et al., (2023)**, who studied "Knowledge, attitude, and practice of children's living with inflammatory bowel disease in China (n=353)" and indicated that there was high statistically relation between total practices level and total mother's attitudes level.

And this result agreement with **Gopalan et al., (2023)**, who studied "Compare the Effectiveness of Education in Disease-Associated Knowledge of IBD children's in India (n=98)" and reported that there was high statistically relation between total practices level and total mother's attitudes level.

Conclusion:

Two fifths of the studied mothers had complete correct total knowledge level about inflammatory bowel diseases, and about one third of the studied mothers had complete correct total knowledge level about palliative care, and less than two thirds of them had

unsatisfactory total reported practices regarding autoimmune inflammatory bowel diseases. Also, most of the studied mothers had positive attitude about palliative care for the children with inflammatory bowel diseases. There was a highly statistically significant relation between practices level, knowledge level and attitude level regarding palliative care for children with autoimmune inflammatory bowel diseases.

Recommendations:

- Develop instructional guideline for mothers about palliative care, and care of their children with autoimmune inflammatory bowel diseases based on the evolvement of the international evidence-based criteria in mothers and child health setting.
- Establish online webpage for mother to facilitate connection with health team for answering any question.
- Disseminate brochure for mothers regarding care of their children with inflammatory bowel disease.
- Further studies are needed for ongoing assessment of children and their mothers including large sample for generalization of results.

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توعية الأم بالرعاية التلطيفية للأطفال المصابين بأمراض التهابات الأمعاء المناعية الذاتية

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يُطلق مصطلح داء الأمعاء الالتهابي على حالتين تتميزان بالتهاب مزمن في الجهاز الهضمي. تُعدّ الرعاية التلطيفية رعايةً لا غنى عنها تُحسّن جودة حياة الأطفال المصابين بداء الأمعاء الالتهابي المناعي الذاتي، وتُساعد الأم على حل مشاكلها. لذلك هدفت هذه الدراسة الى تقييم وعي الأمهات فيما يتعلق بالرعاية التلطيفية للأطفال المصابين بأمراض الأمعاء الالتهابية المناعية الذاتية وتم استخدام تصميم بحث وصفي لإجراء هذه الدراسة وأجريت الدراسة في العيادة الخارجية لأمراض الأمعاء الالتهابية المناعية الذاتية، مستشفى مؤسسة ناصر في مدينة القاهرة استخدام عينة مقصودة شملت ٩٦ أمًا. وقد كشفت النتائج انه تم تشخيص ٤٧,٩٪ من الأطفال الذين شملتهم الدراسة بالتهاب القولون التقرحي، ولم يكن لدى ٥٦,٣٪ منهم تاريخ عائلي للمرض. كان لدى ٥١,٧٪ من الأمهات اللاتي شملتهن الدراسة مستوى متوسط من المعلومات بأمراض الأمعاء الالتهابية، وكان لدى ٤٢,٤٪ من الأمهات اللاتي شملتهن الدراسة مستوى متوسط من المعلومات بالرعاية التلطيفية، بالإضافة إلى ذلك؛ كان لدى ٧٣,٩٦٪ منهن ممارسات مرضية فيما يتعلق بالرعاية التلطيفية، كما كان لدى ٩٠,٧٪ منهن موقف إيجابي تجاه الرعاية التلطيفية للأطفال المصابين بأمراض الأمعاء الالتهابية. كما أوضحت الدراسة أن هناك علاقة ذات دلالة إحصائية بين إجمالي معارف الأمهات، وعلاقة ذات دلالة إحصائية عالية بين إجمالي الممارسات ومواقف الأمهات تجاه الرعاية التلطيفية للأطفال المصابين بأمراض الأمعاء الالتهابية المناعية الذاتية. وأوصت الدراسة بتنفيذ برامج تثقيفية للأمهات والأطفال المصابين برفع وعيهم وممارساتهم عن امراض الامعاء الالتهابية المناعية.