Assiut Scientific Nursing Journal
http://asnj.journals.ekb.eg http://www.arabimpactfactor.com
DOI: 10.21608/asnj.2024.273091.1797 http://olddrji.lbp.world/indexedJournals.aspx
https://vlibrary.emro.who.int/journals/assiut-scientific-nursing-journal

Instructional Guidelines of the Challenges and Adaptation Strategies of Mothers for Caring their Infants with Hydrocephalus

Eman Hassan Mahmoud Hassan[1], Shimaa Hassan khalf allah[2], Nora Abdelhamid Zaki[3], Hanan Azouz Abd Elhay[4] & Atiat Osman[5]

[1.] Assistant Professor of Pediatric Nursing, Faculty of Nursing, Helwan University, Egypt
[2.] Lecturer of Pediatric Nursing, Faculty of Nursing, Assiut University, Egypt
[3.] Assistant Professor of Pediatric Nursing, Faculty of Nursing, Assiut University, Egypt
[4.] Lecturer of Pediatric Nursing, Faculty of Nursing, Assiut University, Egypt
[5.] Lecturer of Pediatric Nursing, Faculty of Nursing, South Valley University, Qena, Egypt

Abstract

Background: Mothers are crucial in the treatment and care of infants with hydrocephalus, as meeting the infant's demands requires daily effort. Hence, this study **aimed to** evaluate the effect of instructional guidelines on the challenges and adaptation strategies of mothers for caring for their infants with hydrocephalus. A pre-experimental **design** was used in this study. **Setting**: The study was conducted at Abo-Elrish-Elmonira Hospital affiliated with Cairo University Hospitals. **Subject**: A purposive sample that involved 120 mothers of hydrocephalus infants. **Tools:** Tool I: A structured questionnaire that included three parts (mothers' socio-demographic characteristics, mothers' knowledge, and practices) and tool II the challenges facing mothers in caring for their infants with hydrocephalus. **Results:** This study displayed a highly statistically significant difference between the pre and post – instructional guidelines among mothers' total knowledge, practice, and challenges regarding hydrocephalus (P value = 0.001). **Conclusion**: Instructional guidelines were important in addressing the challenges and adaptation strategies for mothers caring for their infants with hydrocephalus. **Recommendation:** Provide ongoing education and training that help mothers in caring for their infants with hydrocephalus.

Keywords: Challenges, Guidelines, Hydrocephalus, Infants, Mothers & Strategies

Introduction

The enlargement of the brain's ventricular system caused by an imbalance in the generation and absorption of cerebral spinal fluid (CSF) is known as hydrocephalus. This mismatch causes the ventricular system to dilate, the CSF volume to rise, and frequently the intracranial pressure to rise as well. The onset of hydrocephalus might happen suddenly over a few hours or days. It might also be ongoing, happening over several months or years. In addition to being a standalone ailment, hydrocephalus can also be linked to a wide range of other neurological disorders and illnesses (**Tully & Dobyns, 2014).** According to **Srivatsan et al., (2020)**, it may then be categorized as communicative or non-communicating. According to estimates, 1.1 out of 1000 babies are predicted to have congenital hydrocephalus, with Latin America and Africa having the greatest rates (145–316 per 100,000 births). Compared to higher-income nations (79 per 100,000 births), the incidence was greater in low- and middle-income countries (123 per 100,000 births). Although these figures are underestimates, there will be close to 400,000 new cases of pediatric hydrocephalus globally. For pediatric patients worldwide, the prevalence of hydrocephalus is around 88 per 100,000; it is greater in South America and Africa. There are 1–32 cases of infantile hydrocephalus for every 10,000 live births **Isaacs et al., (2018)**.

Common symptoms of hydrocephalus in infants and early children were irritability and vomiting, which also happened to be associated with several other medical issues. When these symptoms develop together with evidence that point to an intracranial process (such as lethargy, seizures, and an increased circumference of the head), imaging examinations become necessary. A straightforward head Computed Tomography (CT) scan is frequently the first diagnostic investigation **Ragab et al., (2023)**. According to **Ebrahim et al., (2019)**, shows the size of the ventricles and typically indicates the existence of a mass lesion. One of the most popular neurosurgery operations is the implantation of a ventriculoperitoneal shunt (VPS), which is required to treat the majority of hydrocephalus cases. VPS placement-related complications are frequent, and repeated shunt modifications are almost certain for the duration of a patient's life.

Mothers are crucial in the treatment and care of infants with hydrocephalus, as meeting the infant's demands requires daily effort. Hydrocephalus

management necessitates collaboration between medical professionals and the patient's family, particularly the mother. Therefore, by providing the baby with proper instruction, positive reinforcement, and psychological support, pediatric nurses play a crucial role in assisting mothers to become more knowledgeable and confident in their ability to care for their children **Kyarimpa et al., (2020)**. In addition, mothers of small children view their offspring as curses, worthless members of the family, and should not be hospitalized because of the lack of awareness held by the majority of mothers and the neglect of close relatives **Oliveras, et al., (2020)**.

The mothers deal with a lot of difficulties. The majority of mothers who were caring for infants with hydrocephalus had financial difficulties. This is because of the way that babies are cared for, which makes it difficult for them to satisfy everyone's demands. These can include meeting the infant's basic requirements, paying for the hospital, transporting the child to and from the hospital, buying medical equipment to support them, and erecting structures that make their movement easier **Murali et al., (2019)**. To lessen stress and burnout, adaption techniques are also crucial **Kafi & Mohamed., (2020)**. It takes a team effort to manage an infant's hydrocephalus, including the family and medical experts. A nurse's job is to support the family in managing the infant's condition. It is crucial to stress that hydrocephalus is a lifelong condition and that the child will need to be evaluated frequently. The ultimate goal is to set realistic expectations and provide infants with the proper care and education so they can reach their full potential **Hockenberry et al., (2021)**.

Mothers of children with ventriculoperitoneal shunts should receive sufficient information from health care providers to help them understand the health conditions of their children, learn and implement proper childcare techniques, and recognize and report any abnormalities in their children's body temperature or level of consciousness. A sufficient supply of thorough information aids in maintaining the health of the kid, enhancing the quality of life for both the mother and the child, reducing potential difficulties that may arise from poor practices, and enhancing the prognosis and results for the child **Copley et al., (2021).**

Significance of the study:

Hydrocephalus is one of the most prevalent disorders seen in pediatric neurosurgical practices. The National Institute of Neurological Disorders and Stroke estimates that one to two babies out of every 1000 are born with hydrocephalus each year. According to **Mtui et al. (2021)**, there are approximately 160000 ventricular peritoneal shunt implantations and 750000 neonates with hydrocephalus worldwide.

Mothers may find it physically and emotionally taxing to care for a child who has hydrocephalus. Their quality of life and baby's health may be greatly improved by being aware of the unique obstacles they confront and developing practical adaptation techniques. This will also increase public, policymaker, and healthcare professional knowledge. As a result of this raised awareness, policies, programs, and support systems that satisfy the unique needs of these mothers and their babies may be created. Thus, the primary goal of this research was to assess how instructional guidelines affected the difficulties and coping mechanisms mothers had when taking care of their children who had hydrocephalus.

The aim of the study:

The current study aimed to evaluate the effect of instructional guidelines on the challenges and adaptation strategies of mothers for caring their infants with hydrocephalus. This aim was achieved through these objectives:

- Assess the studied mothers' knowledge, reported practices, and challenges regarding the care of their infants with hydrocephalus.
- Design, implement, and evaluate the instructional guidelines for the challenges and adaptation strategies of mothers for caring their infants with hydrocephalus.

Research hypothesis

H0. Mothers who receive instructional guidelines are equally likely to face challenges and employ adaptation strategies for caring their infants with hydrocephalus, compared to those who do not receive such guidelines.

H1. Mothers who get instructional guidelines are expected to have fewer challenges and better adaptation strategies regarding the care of their infants with hydrocephalus.

H2. There is a strong correlation between the challenges faced by mothers and their knowledge and practice regarding the care of their infants with hydrocephalus.

Subjects and Methods

Research Design:

A quasi-experimental design was utilized to conduct this study.

Research Settings:

The current study was conducted in outpatient clinics and inpatient neurosurgery departments at Abo-Elrish-Elmonira pediatric hospitals, affiliated to Cairo University Hospitals.

Research Subjects:

A purposive sample of 120 mothers accompanying their infants with hydrocephalus were included in the study. The sample size was determined using power analysis based on the population flow rate, a confidence interval of 95%, a precision level of 5%, and a p-value of ≤ 0.05. The study included mothers who agreed to participate in the study and had children meeting the following criteria:

- Infants' ages range from one month to twelve months.
- Medical records or a professional diagnostic validate the infants hydrocephalus diagnosis.
- No other physical or mental illnesses are present in the infants.

Data Collection Tools:

The necessary data for this study were gathered using two tools:

Tool 1: Structure Questionnaire

It was created by the researchers to gather the necessary data and had three parts:

Part I: The studied mothers' personal characteristics include (age, marital status, education, residence, mothers' occupation, family number, and the presence of a family history of hydrocephalus).

Part II: Mothers' knowledge regarding hydrocephalus and ventriculoperitoneal shunt. This part consisted of 38 multiple choose questions about (the definition of hydrocephalus, causes, signs and symptoms, complications, home care, follow-up, the meaning of valve, components of a ventriculoperitoneal shunt, the function of the valve, the purpose of operation valve installation, equipment used, and follow-up to operation valve).

Scoring system for mothers' knowledge regarding hydrocephalus:

A scoring system was used to evaluate the knowledge of the mothers under study based on their replies; each question received one (1) grade for a correct response and zero (0) for a wrong answer; the total score of the questionnaire equals thirty-eight grades. The knowledge scores of the mothers under study were divided into three categories: good knowledge for studied mothers who scored 75% and more, average knowledge for scored 50% to < 75%, and poor knowledge for scored less than 50% of total scores.

Part III: Mothers' reported practices regarding the care of their infants with hydrocephalus. It is a pre-valid and reliable tool adapted from **Kafl & Mohamed., (2020).** It included procedures about (measurement of infant head circumference, measurement of infant abdominal girth, infant wound care, measurement of infant vital signs, infant fever management, positioning the infant, and feeding the infant).

Scoring system for mothers' reported practices regarding hydrocephalus:

A grading system was used to evaluate the mothers' stated practices for the care of their children with hydrocephalus based on the replies from the mothers who were the subject of the study. Each step scored (2) if done completely, (1) if done incompletely, and (Zero) if not done step. The total scores of mothers' reported practices were 138 (10 scores for assessing infant head circumference, 12 scores for assessing infant abdominal girth, 14 scores for assessing infant wound care, 42 scores for assessing infant vital signs, 16 scores for assessing infant fever management, 22 scores for assessing infant positioning and 22 scores for assessing infant feeding) then converted into percentage and categorized as the following:

- Satisfactory practices > 65% (More than 90 scores).
- Unsatisfactory practices ≤ 65% (Less than 90 scores).

The cut point of the final categorization (adequate practice-inadequate practice) was adopted from the original form of the tool **Kafl & Mohamed., (2020).**

Tool (2): The challenges facing mothers in caring for their infants with hydrocephalus.

It was adapted from **Hockenberry et al., (2021)**. It included (adherence to medication, financial problems, position of the infant, transportation / carrying manner, lack of social support, psychological problems, and dealing with the physical condition of their infants). These challenges were mentioned by **Hockenberry et al., (2021)** as the main challenges faced by mothers in caring their infants with hydrocephalus. So, close-end questions were used to address these challenges.

Tools validity:

Five pediatric nursing professors evaluated the tools to verify their content. Content coverage, clarity, relevance, application, phrasing, length, structure, and overall look of the tools were all evaluated. Some sentences have been rephrased and rearranged, among other minor changes, in response to the advice and suggestions of experts and its content validity index was 96%.

Tool's reliability:

Cronbach's alpha, which measures the tools' internal consistency, was used to assess the reliability of the instruments. Where the full questionnaire's Cronbach's alpha was 0.806.

Ethical considerations:

The Scientific Research Ethical Committee at South Valley University granted formal approval to carry out the study. Before completing the informed consent form, mothers were fully told about the study and their role, and participation in the study was entirely optional. The research's goal and nature were explained, along with the potential for withdrawal at any time and the confidentiality of the data, which

was only accessible with the participants' consent. These ethical issues were considered in the design of the study. Respect was shown for ethics, morals, culture, and beliefs.

Pilot study:

Before beginning data collection, a pilot study was conducted to evaluate the applicability, validity, and time commitment of filling out the study materials. It was used on 10% equal (12) mothers in the aforementioned settings who had infants with hydrocephalus out of the entire research population (n= 120). The pilot study's outcome assisted in keeping the tools unchanged. Mothers from the main study sample were included in the pilot trial.

Fieldwork:

The actual fieldwork was done over three months, commencing in November 2023 and ending in January 2024. The researchers were available during the morning shift two days weekly, from 8:00 a.m. to 2:00 p.m.

The preparatory phase, several steps were undertaken.

In this phase, the researcher met the managers of the selecting setting to get approval for the data collection phase after explaining and providing the protocol and the used tools of this study. After getting the managers' agreement, the researcher started to collect the data by introducing herself to the eligible women and providing orientation and explanation regarding the purpose and objectives of the study. The primary aim was to seek their collaboration while assuring them of the confidentiality of their responses and the utilization of information solely for scientific research purposes. Written informed consent was obtained from the mothers who agreed to participate in the study.

Assessment phase:

The researcher went to the hospital and took a purposive sample of mothers of infants with hydrocephalus, then made a pretest for the mothers' knowledge, reporting practices, and the challenges facing mothers in caring for their infants with hydrocephalus. The Arabic questionnaire format was used for the daily, two-day data collection.

Implementation phase:

The eight weeks that the instructional guidelines were conducted took place over two days each week. As a result, the material has been organized into 16 sessions. Each session lasted between twenty and thirty minutes, including discussion times. At the commencement of the first session, an introduction to the instructional guidelines was finished. Each session started with a recap of the last, written in simple English and Arabic to suit the mothers' cognitive abilities. There were several different instructional methods employed, such as lectures, demonstrations, and re-demonstrations. To address the substance of the recommendations, modify mothers' knowledge, report reported practices, and reduce challenges faced during the care of their child with hydrocephalus, appropriate teaching aids, such as posters and photographs, were produced and used during the implementation.

Then the researcher instructed the mothers about adaptation strategies that can used to face the challenge of for caring their infants with hydrocephalus which included the following:

- Educate mothers to gain a comprehensive understanding of hydrocephalus.
- Establish a support network: Connect with other parents who have children with hydrocephalus.
- Regular medical follow-ups: Ensure regular visits to the healthcare provider for monitoring and adjusting the treatment plan as needed.
- Observe symptoms and changes: Pay close attention to your infant's symptoms, such as changes in behavior, feeding difficulties, or abnormal head growth. Promptly report any concerns to the healthcare provider.
- Monitor shunt function: If the infant has a shunt to manage cerebrospinal fluid, become familiar with its functioning and signs of shunt malfunction.
- Assisting with developmental milestones: Hydrocephalus may affect an infant's motor skills and developmental milestones. Work closely with healthcare professionals and therapists to develop an appropriate therapy plan to support your child's development.
- Feeding and nutrition: Consult a pediatrician or nutritionist to ensure the infant receives proper nutrition.
- Promote comfort and safety: Create a safe and comfortable environment for infants. Minimize hazards, such as sharp corners or objects that could cause injury.
- Emotional support
- Self-care: Remember to prioritize self-care to maintain mothers' physical and mental well-being.

Evaluation phase:

After three months of the instructional guidelines, the mothers' knowledge, reported practices, and the challenges facing mothers in caring for their infants with hydrocephalus were reevaluated, and comparisons between pre- and post-instructional guidelines were done.

Statistical analysis:

Data analysis was carried out using SPSS statistical software. Qualitative and quantitative variables were analyzed by using descriptive statistics such as frequency, percentage, range, mean, and standard deviation. The paired t-test was used to compare pre and post-data of the program stages.

Results

Table (1): Studied Mothers Personal Characteristics (n=120).

Items	No.	%
Age in years		
- ≤30 : < 40	44	36.7
- 40 : < 50	58	48.3
- 50 and more	18	15.0
Mean ± SD	33.8±6.293	
Range	22-45	
Marital status		
- Married	88	73.3
- Divorced / Widowed	32	26.7
Education		
- Not read and write	20	16.6
- Secondary	30	25
- University	70	58.4
Residence		
- Rural	88	73.3
- Urban	32	26.7
Mothers' occupation		
- Housewife	36	30
- Employee	84	70
Family No.		
- ≤ 4 persons	28	23.3
- 5-7 persons	88	73.3
- > 7 persons	4	3.3
Family history of hydrocephalus		
- Yes	20	16.7
- No	100	83.3

Table (2): Mothers' Correct Knowledge Regarding Hydrocephalus and Ventriculo-Peritoneal Shunt in the Pre and Post- Applications of the Instructional Guidelines (n=120).

Items	Studied Mothers' knowledge					
	Pre - guidelines		post – guidelines		X^2	P Value
	No.	%	No.	%		
Mothers' knowledge about hydrocephalus						
- Definition of hydrocephalus	42	35	104	86.7	10.15	0.000*
- Causes	40	33.3	97	80.8	9.50	0.000*
- Signs and Symptoms	43	35.8	88	73.3	7.88	0.000*
- Complication	37	30.8	86	71.7	7.867	0.000*
- Home Care	42	35	81	67.5	7.999	0.000*
- Follow up	35	29.2	92	76.7	4.740	0.000*
Mothers' knowledge about ventriculo-peritoneal shunt						
- Meaning of valve	66	55	89	74.2	8.510	0.000*
- Components of ventricul-operitoneal shunt	42	35	102	85	7.786	0.000*
- The function of valve	45	37.5	86	71.7	8.336	0.000*
- Purpose of operation valve installation	55	45.8	103	85.8	11.049	0.000*
- Equipment's used	36	30	92	76.7	9.347	0.000*
- Follow up to operation valve	40	33	78	65	6.831	0.000*

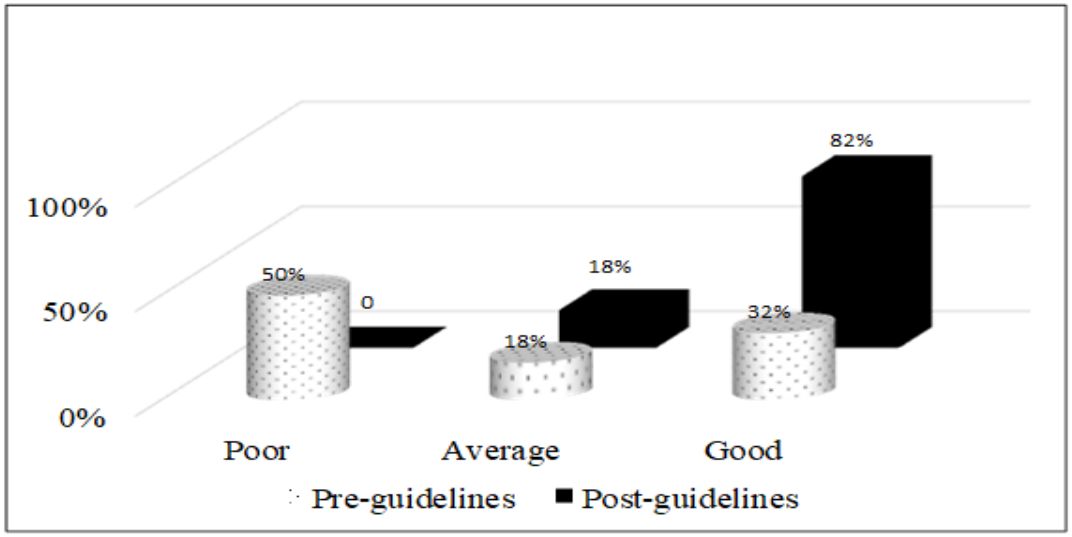

Figure (1): Levels knowledge regarding Hydrocephalus among Studied Mothers in Pre and Post-Application of the Instructional Guidelines (n=120).

Table (3): Mothers' Reported Corrected Practices Regarding Care of Their Infants with Hydrocephalus Pre and Post- Application of the Instructional Guidelines (n=120).

Items	Pre- guidelines			Post – guidelines			X^2	P. Value
	DC	DI	ND	DC	DI	ND		
	%	%	%	%	%	%		
1- Measurement of infant head circumference	25.8	35	39.2	70	15	15	0.408	0.000**
2- Measurement of infant abdominal girth	27.5	30	42.5	61.7	17.5	20.8	0.491	0.000**
3- Infant wound care	30.8	35.8	33.3	70.8	16.7	12.5	0.426	0.000**
4- Taking vital signs	33.3	33.3	33.3	71.7	13.3	15	0.497	0.000**
5- Fever management	10	60	30	56.7	26.7	16.7	0.209	0.000**
6- Infant positioning and handling	27.5	30	42.5	61.7	17.5	20.8	0.491	0.000**
7- Infant feeding	25.8	35	39.2	70	15	15	0.408	0.000**

Note: DC= done completely; DI= done incompletely; ND= note done.

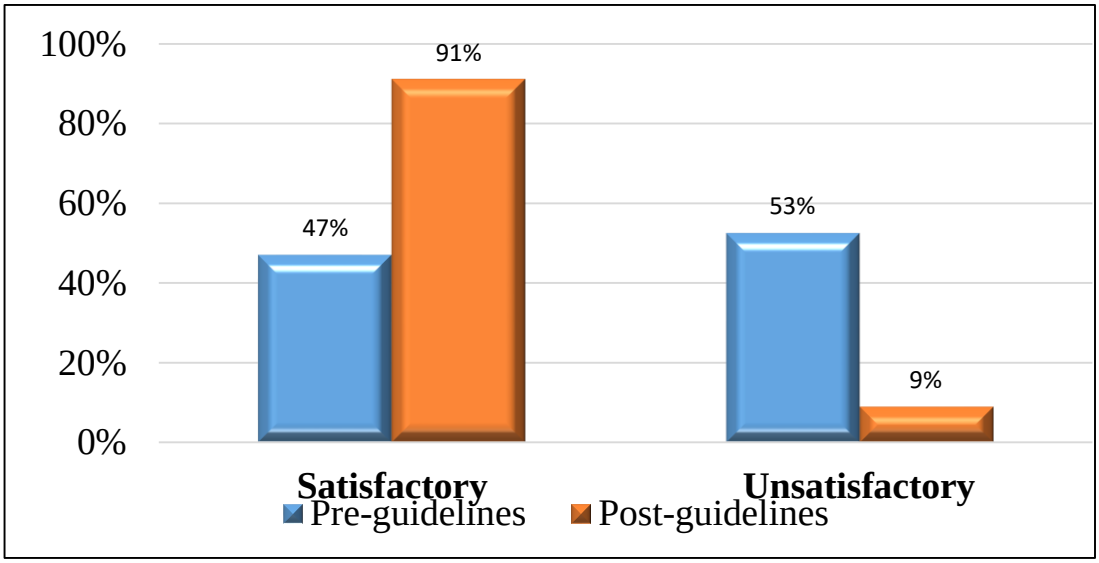

Figure (2): Levels of Reported Practice Regarding Hydrocephalus among Studied Mothers in Pre and Post-Application of the Instructional Guidelines (n=120).

Table (4): The Challenges Facing Mothers in Caring Their Infants with Hydrocephalus Pre and Post-Application of the Instructional Guidelines (n=120).

Items	Pre- guidelines		Post – guidelines		X^2	P value
	No.	%	No.	%		
- Adherence to medication	45	37.5	77	64.2	6.176	0.000*
- Financial problems	47	39.2	82	68.3	6.473	0.000*
- Position of infant	36	30	76	63.3	7.118	0.000*
- Transportation/ carrying manner	45	37.5	88	73.3	7.479	0.000*
- Lack of social support	51	42.5	88	73.3	7.955	0.000*
- Psychological problems	44	36.7	86	71.7	7.527	0.000*
- Dealing with physical condition of their infants	44	36.7	90	75	7.984	0.000*

Table (5): Correlation between the Challenges Facing Mothers with Their Knowledge and Reported Practice related to Hydrocephalus (n=120).

Items	The challenges	
	r	p
Mothers' knowledge related to hydrocephalus	- 0.791	<0.001**
Mothers' reported practice related to hydrocephalus	- 0.845	<0.001**

Table (1): Presents valuable insights into the socio-demographic characteristics of the mothers involved in the study. Less than half of the mothers (48.3%) fall within the age range of 40 to <50 years. Also, more than two-thirds (73.3%) of the mothers are married, while 26.7% are either divorced or widowed. The educational background of the mothers reveals that more than half of them (58.4%) had a university education. It also provided that among the participants, 73.3% reside in rural areas, while the remaining (26.7%) are living in urban areas. Finally, among the studied mothers, 16.7% reported a family history of hydrocephalus, while (83.3%) did not have such a history.

Table (2): It is revealed that a significant improvement in mothers' knowledge about hydrocephalus and ventriculoperitoneal shunt after receiving the instructional guidelines (P.value= 0.000**). The percentage of mothers who correctly defined hydrocephalus increased from 35% pre-application of the guidelines to 86.7% post-application of the guidelines. Similar improvements were seen in knowledge about causes, signs and symptoms, complications, home care, follow-up, and all items related to ventriculoperitoneal shunt.

Figure (1): It illustrates that 50% of studied mothers had poor knowledge in the pre-application of the guidelines compared to no one 0.0% in the post-application of the instructional guidelines.

Table (3): This table demonstrates that there was a highly significant difference (P.value= 0.000**) between the studied mothers' reported corrected practices in the pre-and post-application of the instructional guidelines regarding how they cared for their infants with hydrocephalus. In several areas, including measuring head circumference, wound care, taking vital signs, fever management, infant positioning and handling, and infant feeding, showed notable progress.

Figure (2): It shows that more than half (53%) of the mothers in the study had unsatisfactory practices before the guidelines, compared to only 9% following them.

Table (4): High statistically significant difference regarding challenges faced by mothers in caring for their infants with hydrocephalus in pre- and post-application of the instructional guidelines (P.value= 0.000**). The significant reductions observed in various areas, such as adherence to medication, financial problems, infant positioning, transportation/carrying manner, lack of social support, psychological problems, and dealing with the physical condition of their infants, highlight the importance of providing support and guidance to mothers to address these challenges effectively.

Table (5): Indicates the correlation between the challenges faced by mothers in caring for infants with hydrocephalus and their knowledge and practices related to hydrocephalus. There was a strong negative correlation (-0.791, - 0.845) between the challenges faced by mothers and their knowledge and practice about hydrocephalus. The correlation is statistically significant (P.value <0.001).

Discussion

Mothers of infants with ventriculoperitoneal shunts and hydrocephalus should receive adequate information to help them understand the situation of their infant's health and learn how to care for them properly. A sufficient amount of thorough information

is provided to support the preservation of the infant's health, enhance the quality of life for both the mother and the child, improve the prognosis and results for the infant, and reduce any issues that may arise from subpar practices **(Copley et al., 2021)**. For this reason, this study was conducted to evaluate the effect of instructional guidelines on the challenges and adaptation strategies of mothers for caring their infants with hydrocephalus.

Regarding the characteristics of the mothers under study, it was determined in this research that less than half of the studied mothers fell within the age range of 40 <50 years. This finding contradicted the results of a study conducted by **Prathiwindya et al., (2022)** at Indonesia, titled "Description of hydrocephalus knowledge in pregnant women," which reported that 50% of the subjects were between 19 and 25 years old. Moreover, these findings also disagreed with those of **Rozensztrauch et al., (2021)**, who conducted a preliminary cross-sectional study in Poland titled "The quality of life of children with myelomeningocele" and found that the age of parents ranged from 22 to 25 years.

The current study found that fewer than three-quarters of the mothers were working and that slightly more than half of the mothers had a university degree. These outcomes are in line with those of **Abd-EL Baky et al. (2023)**, who found that less than two-thirds, of the mothers in their study—titled "Effect of educational intervention on the quality of life for mothers having children with ventriculo-peritoneal shunt" were housewives and had only completed secondary education. The study was conducted in Egypt. Furthermore, these results are consistent with those of **Abd-EL Baky et al., (2023)**, who reported that around half of the mothers had a college degree.

According to the study's findings, over one-quarter of the mothers who were part of the sample lived in urban. This finding is consistent with the research conducted by **Rozensztrauch et al. (2021),** which revealed that more than fifty percent of the mothers were living in urban areas. This conclusion is further corroborated by a qualitative study by **Gürol et al. (2018)** titled "The experienced problems of mothers having children with hydrocephalus," which discovered that half of the mothers lived in cities.

Regarding the level of the mothers' knowledge about hydrocephalus, the current study found that, before the implementation of the instructional guidelines program, slightly over one-third of the mothers did not have enough knowledge of what hydrocephalus meant. However, following the program's execution of instructional guidelines, the majority of them showed good knowledge. Furthermore, before the implementation of the instructional guidelines program, over one-third of mothers who were studied exhibited inadequate knowledge about the signs of hydrocephalus; but, following the program's implementation, three-quarters of the mothers showed good understanding regarding these signs.

These findings are incompatible with **Kafi & Mohamed., (2020),** who conducted a study in Ismailia, Egypt, titled (Maternal knowledge and practices Regarding home-care management of their hydrocephalic children with ventriculo-peritoneal shunt), and their results revealed that nearly two thirds of the mothers had unsatisfactory knowledge about the definition, causes, and signs of increased intracranial pressure in hydrocephalus respectively.

As regards the studied mothers' knowledge regarding complications of hydrocephalus, the study results illustrated that less than one-third of the studied mothers had poor knowledge about complications of hydrocephalus. While about two-thirds of studied mothers had good knowledge after the implementation of the instructional guidelines program.

This study's results were similar to those of **Caus et al., (2021),** who carried out a study in Brazil, entitled **(**Caregivers' evaluation of an educational material targeted to children with hydrocephalus) and stated that the response rate of knowledge about the treatment of hydrocephalus was 80%.

In contrast to this finding, the results of **Morgan et al., (2020),** who carried out a study in Nigeria entitled (Assessment of the knowledge of risk factors of congenital hydrocephalus among mothers attending antenatal clinics in a rural tertiary hospital in Irrua) and indicated that more than half of the mothers knew ways of detecting hydrocephalus during pregnancy. This could be due to the differences between the characteristics of the two samples. While the same study agreed with the findings, a minority of the mothers could identify the problems or complications observed in the child.

Regarding the studied mothers' knowledge regarding the meaning, components, purpose, and function of valves, this current study showed that more than half of the studied mothers had poor knowledge about the meaning of valves. While more than two-thirds of studied mothers' had good knowledge after the implementation of the instructional guidelines program. This study finding was incompatible with **Caus et al., (2021),** who mentioned that their knowledge about the definition of a ventriculo-peritoneal shunt was satisfactory.

As regards the studied mothers' reported practices, the current study results illustrate that less than one-third of the studied mothers completed complete practices before the implementation of the instructional guidelines program. While more than two-thirds of them completed complete practices after

the implementation of the instructional guidelines program regarding measurement of infant head circumference, infant wound care, axillary temperature measurement, and infant feeding, respectively. From the researcher's point of view, the instructional guidelines program has a positive effect on studied mothers regarding the care of their infants with hydrocephalus.

These results were in agreement with **Ünver et al., (2020),** who conducted a study in Turkey, entitled (Effect of giving brochures to ventriculo-peritoneal shunted children's mothers about preventing shunt infections) and stated that the mothers were measuring head circumference for their children.

Regarding the overall level of reported practices among the studied mothers, the findings of the current study indicate that less than half of the mothers had sufficient practices before the implementation of the instructional guidelines program. However, the majority of them demonstrated adequate practices after the instructional guidelines were implemented. These results are consistent with the findings of **Abd-EL Baky et al., (2023),** who observed that the majority of mothers exhibited insufficiently reported practices in caring for their children with ventriculo-peritoneal shunts. The researcher posits that this may be attributed to more than half of the studied mothers having poor knowledge regarding hydrocephalus, which subsequently led to unsatisfactory reported practices.

Concerning studied mothers' challenges that they faced during the care of their infants with hydrocephalus. The current study demonstrated that there was a highly statistically significant difference regarding challenges faced by mothers in caring for their infants with hydrocephalus in pre- and post-instructional guidelines and adaptation strategies. Significant reductions were observed in various areas, such as adherence to medication, financial problems, infant positioning, transportation/carrying manners, lack of social support, psychological problems, and dealing with the physical condition of their infants. These findings highlight the value of the instructional guidelines in helping mothers overcome the difficulties they face in caring for infants with hydrocephalus.

These study results are also in agreement with the findings of **Gürol et al., (2015)**, who reported that all mothers primarily encountered transportation and financial difficulties during the treatment period following the diagnosis of hydrocephalus. Furthermore, this study's findings align with **Kyarimpa et al., (2020),** who noted that caring for a child with hydrocephalus presents challenges and frustrations in terms of the caregiver's financial, physical, social, and psychological experiences.

Finally, the present study pointed out that there was a highly statistically significant negative correlation between the challenges faced by mothers and their knowledge and practice about hydrocephalus. This indicates that as the challenges increase, the knowledge and practices of mothers tend to decrease. The negative correlation highlights the importance of addressing the challenges faced by mothers to improve their knowledge and practices related to hydrocephalus.

Conclusion

In view of the results of the current investigation. It can be concluded that:

The development and implementation of instructional guidelines addressing the challenges and adaptation strategies for mothers caring for infants with hydrocephalus have the potential to improve maternal knowledge, and practices, with highly statistically significant differences found in pre and post-instructional guidelines. Also, there was a strong negative correlation between the challenges faced by mothers and their knowledge and practice about hydrocephalus (P value <0.001).

Recommendations

Given the results of the investigation, the following suggestions are made:

- To improve mothers' knowledge and practice for caring for their infant with hydrocephalus by offering ongoing education and training sessions.
- Develop instructional guidelines targeting the unique obstacles encountered by mothers caring for infants with hydrocephalus. These guidelines should offer practical advice, strategies, and resources to assist mothers in successfully managing and overcoming these challenges.
- It is important to ensure the widespread availability and accessibility of these guidelines to all mothers. This can be accomplished through the distribution of printed copies, posters, and booklets in healthcare settings, as well as integration into educational programs and workshops.
- Further study can be replicated in other settings using a large sample size to generalize the findings.

References

- **Abd-EL Baky S., Al Sharkawi S., Mahmoud F. & Abdelaziz, S., (2023):** Effect of educational intervention on quality of life for mothers having children with ventriculoperitoneal shunt, Journal of Nursing Science, 4 (1): 1030.
- **Caus P., Filho H. & Avila M., (2021):** Caregivers' evaluation of an educational material targeted to children with hydrocephalus. Child's Nervous System. 37 (1):81–89.

- **Copley, P., Emelifeonwu, J., Gallo, P., Sokol, D., Kandasamy, J., Wallace, H., & Kaliaperumal, C. (2021):** Guideline for the management of long tunnelled external ventricular drains in chronic hydrocephalus. British Journal of Nursing, 30(7), 416-421.
- **Ebrahim, A., El Shokhaiby, U., & Alkholy, A. (2019):** Management of postoperative ventriculo peritoneal shunt complications in pediatric patients. The Egyptian journal of hospital medicine, 76: (6), 4346-4352.
- **Gürol, A., Erdem, Y., & Tasbasi, F. (2015):** The experienced problems of mothers having children with hydrocephalus: a qualitative study. International Journal of Caring Sciences, 8(2), 435-442.
- **Hockenberry J., Rodgers C. & Wilson D., (2021):** Wong's essential of pediatric nursing-e-book11th edition. Elsevier Health Sciences, Philadelphia. Pp: 524-529; 287.
- **Isaacs, A., Riva-Cambrin, J., Yavin, D., Hockley, A., Pringsheim, T., Jette, N., & Hamilton, M. (2018):** Age-specific global epidemiology of hydrocephalus: Systematic review, metanalysis and global birth surveillance. PloS one, 13(10), e0204926
- **Kafi R. & Mohamed M., (2020):** Maternal Knowledge and Practices regarding Home-Care Management of their Hydrocephalic Children with Ventriculo-peritoneal Shunt". IOSR Journal of Nursing and Health Science (IOSR-JNHS).9 (1): 30-37.
- **Kyarimpa R., Muramuzi D. & Muhwezi T., (2020):** Care giver's experiences of having a child with hydrocephalus: a Phenomenological study at Ruharo mission hospital. Faculty of Nursing and Health sciences, Bishop Stuart University - Mbarara, Uganda. Doi: https://doi.org/10.1101/2020.06.25.20139683
- **Mtui E., Gruener G. & Dockery P., (2021):** Fitzgerald's Clinical Neuroanatomy and Neuroscience E-Book 8th edition. Elsevier, Poland. PP: 283:294.
- **Morgan, E., Agbeboh, P., Poluyi, C., Ikwuegbuenyi, C., Aphiar, A., & Asogun, A. (2020):** Assessment of the knowledge of risk factors of congenital hydrocephalus among mothers attending antenatal clinics in a rural tertiary hospital Irrua, Edo State. Journal of Neurosciences in Rural Practice, 11(01), 045-052.
- **Murali A., Job K. & Udayakumaran S., (2019):** Effectiveness of structured teaching program on knowledge regarding home care management of children with hydrocephalus and shunt among their parents. Journal of Pediatric Neurosciences.14 (3):114-119.
- **Oliveras, L., Ortega, J., Leidinger, A., Haji, M. A., Genovés, M., & Belloch, J. (2020):** Infant hydrocephalus in sub-Saharan Africa: Impact of perioperative care in the Zanzibar archipelago. Neurocirugía (English Edition), 31(5), 223-230.
- **Prathiwindya M., Niryana W., Mahadewa T. and Maliawan S., (2022):** Description of hydrocephalus knowledge in pregnant woman at Puskesmas Denpasar Utara. Intisari Sains Medis. 13 (1): 367-370.
- **Ragab, A.N., Mahmoud, E.H., & Ismail, S.S. (2023):** Assessment of Mothers' Knowledge, Attitudes and Practices Regarding Care of their Infants with Hydrocephalus. International Journal of Membrane Science and Technology.
- **Rozensztrauch A., Iwa´ nska M. & Bagłaj M., (2021):** The Quality of Life of Children with Myelomeningocele: A Cross-Sectional Preliminary Study. International Journal of Environmental Research and Public Health.18 (1): 10756.
- **Srivatsan, A., Burkhardt, J., & Kan, P. (2020):** Commentary: A cohort comparison analysis of fixed pressure ventriculoperitoneal shunt valves with programmable valves for hydrocephalus following nontraumatic subarachnoid hemorrhage. Operative Neurosurgery, 18(4), E104-E105.
- **Tully, H. & Dobyns, W. (2014):** Infantile hydrocephalus: a review of epidemiology, classification and causes, European Journal of Medical Genetics, August ; 57(8): 359–368. doi:10.1016/j.ejmg.2014.06.002.
- **Ünver S., Tutunculer B., Özkan Z. & Findik U., (2020):** Effect of Giving Brochures to Ventriculoperitoneal Shunted Children's Mothers About Preventing Shunt Infections. Pediatric Infection Journal, 14(3):e97-e105.