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Assessment of Parents' Awareness about the Care of Their Neonates with Neural Tube Defects

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Abstract

Background: Neural Tube Defects are one of the most congenital anomalies of the Central Nervous System that may happen in the neonatal period. **Aim of the study:** this study aimed to assess parents' awareness about the care of their neonates with neural tube defects. **Research design:** A descriptive study design was used. **Setting:** the study was conducted at the outpatient clinic for pediatric Neurology at Ain Shams Educational Hospital. **Methods**: A convenient sample of 40 parents accompanied by their neonates who suffered from neural tube defects. **Tools:** Data was collected using three **tools.** Tool (I) A structured questionnaire sheet composed of 2 parts, part 1: assessing demographic data of the studied parents. In addition to part 2: assessing parents' knowledge regarding care of neural tube defects. Tool (II) reported practice checklists and tool (III) Parental Stress Index. **Results: The results of this study** revealed that most of the studied parents have unsatisfactory knowledge and incompetent reported practices regarding the care of Neural Tube Defects**. Conclusion:** It was concluded that most of the studied parents have a poor level of awareness regarding the care of their neonates with Neural Tube Defects. **Recommendations:** It was recommended to provide further instructions and guidelines for parents who have neonates with Neural Tube Defects to enhance their awareness of better neonates' outcomes**.**

Keywords: Parents Awareness, Neonates, Neural Tube Defect

Introduction

Congenital anomalies refer to a wide range of physical defects present from birth. These anomalies can vary in severity, and some of them can be life-threatening or result in lifelong disabilities if not detected and addressed promptly. According to the Centers for Disease Control and Prevention, congenital anomalies are responsible for most infant deaths during the first year of life **(CDC, 2018).**

Neural Tube Defects (NTDs) are one of the neurological congenital anomalies that occur incredibly early in pregnancy. The defects develop between the 17th and 30th day after conception (four to six weeks after the first day of a woman's last menstrual period), usually before a woman knows she is pregnant. During this critical time of pregnancy, the proper formation and closure of the neural tube, as development progresses, the top of the tube becomes the brain, and the remainder becomes the spinal cord. NTD occurs when this tube does not close completely somewhere along its length, resulting in a hole in the spinal column or another type of problem **(Blom et al., 2016).**

The neonatal period is an extremely critical stage for the baby as it requires numerous physiological and biochemical changes to transition from intrauterine to extrauterine life. This is the highest period of mortality risk during life. During this period, the infant's body functions are no longer supported by its mother and the placenta, and it must adapt to self-sufficient functioning. Poor adaptation due to asphyxia, preterm birth, congenital anomalies, or adverse effects of delivery can cause specific problems for the newborn **(Kliegman, 2020).**

Neonates with NTDs are at a higher risk of experiencing depression and anxiety. Additionally, the parents of these individuals often experience stress and depression due to the financial costs, time, and physical energy required to care for their children. Caring for individuals with spina bifida can lead to a substantial financial burden, as they incur 13 times more medical costs than those without the condition. Furthermore, parents of

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individuals with spina bifida may face issues related to employment, as one parent often needs to stay at home to support their child **(Nahal et al., 2017).**

It is essential to apply a family-centered care approach when dealing with parents of children with neural tube defects. This involves implementing family-centered care principles and policies effectively. The approach should encourage parents to view their child's care holistically, considering not only the child's medical needs but also their emotional, social, and developmental well-being. It is vital to involve parents as active partners in decision-making, seeking their input and respecting their preferences. Recognizing that each family's needs and circumstances are unique, care guidelines should be tailored accordingly **(Kucuk et al. 2021).**

In a more involved nursing role, nurses act as educators. They provide education to expectant mothers about the importance of folic acid supplementation before conception and during early pregnancy, Nurses also explain the diagnosis of NTDs to parents, addressing their concerns and providing emotional support. Furthermore, nurses discuss treatment options, including surgical interventions, with families and provide information on managing NTD-related complications such as mobility issues, bladder, and bowel control, and learning disabilities **(EDWARDS and COYNE, 2019).**

Significance of the study:

Neural tube defects (NTDs) affect an average of 1 in every 1000 established pregnancies worldwide, although variations in NTD prevalence have been reported from 0.2-10 per 1000 in specific geographical locations. Worldwide, more than 300,000 babies are born with a neural tube defect each year. In the United States, NTDs occur in about 3,000 pregnancies each year **(CDC, 2019).**

recent study conducted a global systematic review of the prevalence of neural tube defects. The researchers searched for articles published in English and Spanish between January 1990 and July 2014, which reported prevalence rates or contained data that could be used to calculate the prevalence of neural tube defects. Data came from 75 countries. The coverage by WHO region varied in completeness (i.e., % of countries reporting) as follows: African (17%), Eastern Mediterranean (57%), European (49%), Americas (43%), South-East Asian (36%), and Western Pacific (33%) **(Zaganjor et al., 2015).**

In Egypt, the incidence rate of neural tube defects in the Neonatal Intensive Care Unit at Ain Shams University Hospital was 40 per 520 cases admitted to the NICU from December 2022 to April 2024, which accounted for 8% of total admissions. Therefore, it is an important issue that needs to be addressed. Moreover, it is considered a preventable public health issue, but concerns about neural tube defects still persist. Addressing these issues is crucial for reducing the burden of NTDs and improving the quality of life for affected families. The study emphasizes the need for more comprehensive and higher-quality awareness sessions directed at parents and caregivers to enhance the quality of life for neonates and their families **(Zaganjor et al., 2015).**

Aim of the Study

The study aimed to assess parental awareness regarding the care of neonates with neural tube defects. This aim was achieved through the following:

1. Assess parents' level of knowledge regarding the care of their neonates with neural tube defects.
2. Assess parents' level of reported practice regarding the care of their neonates with neural tube defects.
3. Assess parents' level of stress regarding the care of their neonates with neural tube defects.

Research questions:

1. What is the parents' level of knowledge regarding the care of their neonates with neural tube defects?
2. What is the parents' level of reported practices regarding the care of their neonates with neural tube defects?
3. What is the parents' level of stress regarding the care of their neonates with neural tube defects?

Operational Definition

The term **"Parents Awareness"** in this study refers to the assessment of the knowledge, reported practices and stress levels among studied parents who have neonates with neural tube defects.

Subjects and Methods

Research design

A descriptive design was utilized in conducting the current study.

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Research setting

The study was conducted in the outpatient clinic for pediatric Neurology at Ain Shams Educational Hospital.

Research subjects

A convenient sample technique was used to recruit the subjects of the current study which were 40 parents accompanied by their neonates who suffered from NTDs who attended in the previously mentioned settings regardless of their characteristics and accepted to participate in the study.

Tools and techniques of data collection

Data required for the current study were collected using the following tools:

(I) Pre-designed Questionnaire Sheet:

This questionnaire was developed by the researcher after reviewing the related literature in a simple Arabic language to suit all parents and aimed to identify studied sample demographic data and assess their knowledge related to the care of their neonates with NTDs. This questionnaire was completed using a structured interview method with the studied sample. The time consumed to fill out this tool for each parent was 30 minutes (the researcher conducted the interview and filled out the tool for parents who could not read and write). It consisted of two parts as follows:

Part (I) included the characteristics of the studied parents and the studied neonates' including gender, age, marital status, level of education, consanguinity, family history of congenital anomalies, family history of chronic illness, pregnancy history, antenatal care, labor history, neonatal diagnosis, pre-and post-natal history and NICU admission.

Part (II) included data aimed to assess parents' knowledge about neural tube defects which includes definition, causes, types, signs and symptoms, diagnosis, management, and preventive measures.

Scoring system for the knowledge questions

Items of parents' knowledge assessment regarding caring for their neonates consist of (15) questions, 5 questions in the form of MCQ questions and 10 questions as Yes or No questions. The score of each question ranges from zero for incorrect answers and one score for correct answers. The total score was (15). All questions are corrected, summed up and turned into percentages. According to parents' responses, their knowledge scores were classified into satisfactory knowledge if the total score is equal or more than 75 % and unsatisfactory knowledge if the total score is less than 75 %.

(II) Parents Reported Practices checklists

The researcher adopted standardized checklists to assess the reported practices of the parents regarding specific procedures such as positioning, feeding, and wound care.

Scoring system for the practice checklists

Items of parents' practices consist of 46 items. The score of each item ranges from zero for not done and 1 for completely done. The total score was 46. All steps are tallied, converted to percentages, and summed up. According to parents' reported practices, their practice scores were classified as Adequate practice if the total score was equal and above 85%. If it is below 85%, it is considered inadequate practice**.**

(III) Parental Stress Index

The Parenting Stress Index (PSI) adapted from **Abidin, R. (1995)** was used to evaluate parents' stress levels towards the disease. The index consists of 15 items on a Likert scale, ranging from strongly agree (5) to strongly disagree (1).

Scoring system for the Parental Stress Index

The scores were added up, converted into percentages, and then classified based on a cutoff point of 60%. A total parenting stress score of ≥ 60% is considered high stress, while scores < 60% are considered low stress.

Validity and Reliability: -

The adapted tools were evaluated by a gory committee - a group of three experts in Pediatric Nursing - to assess the content validity, layout, and structure. Required modifications were applied based on the experts' revisions and feedback. Cronbach's Alpha test was used to test the reliability of proposed tools through SPSS computer package version 28. It was 0.950 for "Knowledge of the parents regarding Neural Tube Defects," 0.919 for "Practice of the parents regarding positioning, feeding and wound care procedures checklists" and 0.944 for the parenting stress index.

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Ethical Consideration

Ethical approval to conduct the planned study was obtained from the Scientific Research Ethics Committee at the Faculty of Nursing at Helwan University. Participation in the study was voluntary, and parents were given a full explanation about it before signing the informed consent. The ethical considerations included an explanation of the purpose and nature of the study, stating the possibility to withdraw at any time, confidentiality of the information and all the results and data will be used for research purposes only. Ethics, values, culture, and beliefs were respected during the implementation, following, and evaluation of the study process. Every study technique was carried out following the ethical standards delineated in the Declaration of Helsinki and its later amendments.

Statistical design

The collected data were organized, revised, tabulated, and analyzed. A computer using the statistical package of social science (SPSS 28) did the statistical analysis. Suitable statistical tests were used to determine whether there was a significant statistical difference between study variables or not.

Results

Table (1): Distribution of the Studied Parents according to their Characteristics (No=40).

Items	N	%
Gender		
Male	15	37.5
Female	**25**	**62.5**
Age		
20 < 30 years	8	20
30 < 40 years	**21**	**52.5**
40 ≤ 50 years	11	27.5
Mean ($\bar{x}$) ± SD	**34.05 ± 4.50**	
Education		
Illiterate	4	10
Can read and write	5	12.5
Primary education	5	12.5
Medium education	**22**	**55**
Higher Education	4	10
Employment status		
Employed	7	17.5
Not employed	12	30
Free job	**21**	**52.5**
No. of Children		
1-2 Child	17	42.5
3-4 Child	**20**	**50**
More than 4	3	7.5
Mean ($\bar{x}$) ± SD	**3 ± 1.1**	

Table (1) shows that 52.5% of the studied parents aged from 30 < 40 years with a mean age of 34.05 ± 4.50 years and 62.5 % of them were female. Moreover, this table reveals that 55% and 52.5% of the studied parents had medium education and free jobs, respectively. In addition, 50% of the studied parents have 3-4 children with a mean no. of children 2.8 ± 1.1.

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Table (2): Distribution of the Studied Children according to their Characteristics (No=40).

Items	N	%
Gender		
Male	17	42.5
Female	**23**	**57.5**
Age		
30 < 40 days	12	30
40 < 50 days	7	17.5
≤ 50 days	**21**	**52.5**
Mean (x̄) ± SD	**53.2± 22.8**	
Ranking		
First	13	32.5
Second	4	10
Third and more	**23**	**57.5**
Type of delivery		
Normal Vaginal Delivery (NVD)	**24**	**60**
Cesarean section (CS)	16	40
Fetal distress during labor		
Yes	4	10
No	**36**	**90**

Table (2) presents that 57.5% and 52.5% of the studied neonates were female, aged more than ≤ 50 days with a mean age of 53.2 ± 22.8 days. In addition, 57.5% ranked 3rd and more between their sliding. Moreover, this table revealed that 60% of the studied neonates were delivered by normal vaginal delivery. In addition, 90% of the neonates did not experience fetal distress during labor.

Table (3): Distribution of the Studied Mother according to pregnancy history (No=40).

Items	N	%
Taking folic acid		
Yes	8	20
No	**32**	**80**
Exposing to radiation		
Yes	3	7.5
No	**37**	**92.5**
Taking any chronic medications		
Yes	15	37.5
No	**25**	**62.5**
Type of Medications		
Anti-convalescent drugs	**10**	**66.7**
Diabetes Mellites medication	2	13.3
Hypertension medication	2	13.3
Others	1	6.7
Duration of hospitalization		
10 < 20 days	12	30
20 < 30 days	**19**	**47**
≤ 30 days	9	22.5
Mean (x̄) ± SD	**21.7± 5.7**	

Table (3) shows that 80% of the mothers of the neonates did not take folic acid during pregnancy. Additionally, 92.5% of the sample were not exposed to radiation. About 62.5% of the sample did not take chronic medications, while 37.5% took medications, particularly anticonvulsant drugs 66.7%. As regards hospitalization duration, 47% of the neonates were hospitalized for 20 to 30 days, with a mean (x̄) ± standard deviation (SD) of 21.7 ± 5.7.

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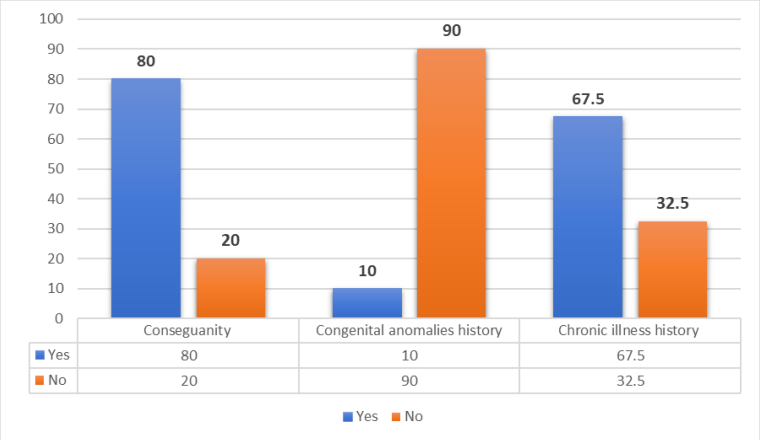

Figure 1: Percentage of the Studied Parents according to their Characteristics (No=40).

Fig (1) shows that 80% of the studied parents have consanguinity. Most of the study sample 90% had no history of congenital anomalies. Additionally, 67.5% of them have a history of chronic illness.

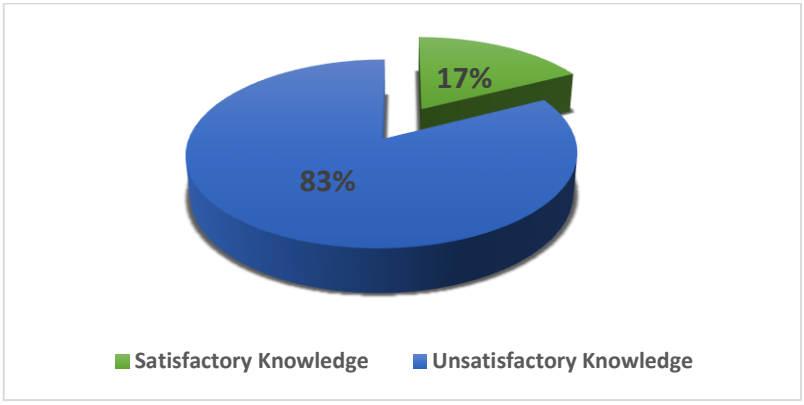

Figure (2): Percentage of the Studied Parents according to their total Knowledge level regarding Neural Tube Defects (No=40).

It was obvious from this figure that the majority (83 %) of the studied parents had unsatisfactory knowledge regarding Neural Tube Defects.

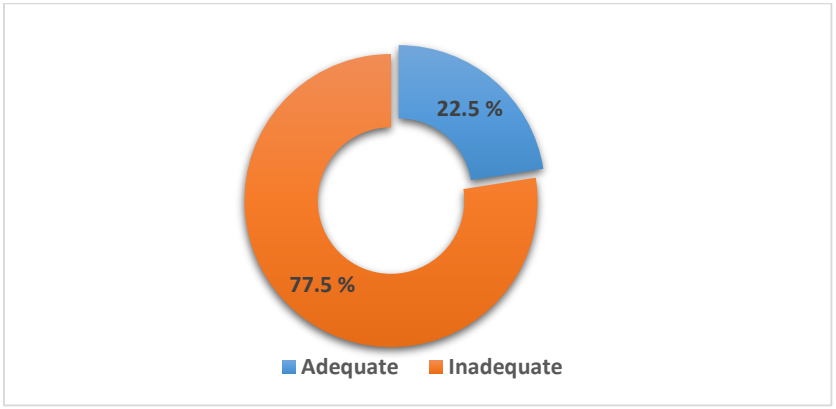

Figure (3) Percentage of the Studied Parents according to their Total Reported Practices level regarding Neural Tube Defects (No=40).

As regards the studied parents' total practices, figure 3 presented that, almost three-quarters (77.5%) of the studied parents have inadequate practices regarding care for their Neonates with Neural Tube Defects.

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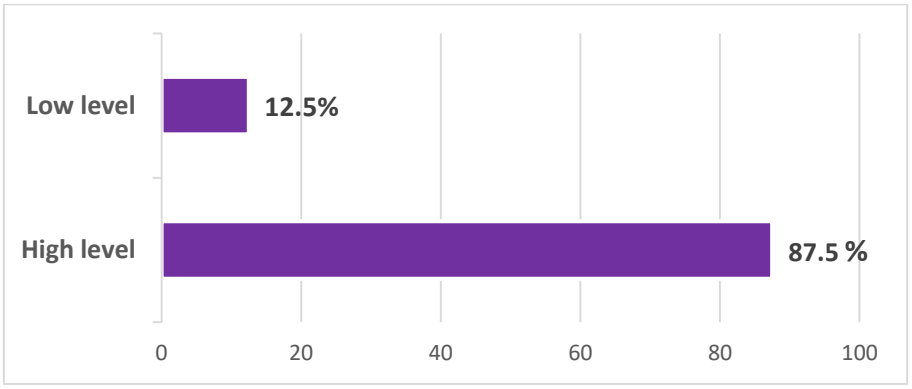

Figure (4) Percentage of the Studied Parents according to their Parental Stress level regarding their care of their neonates with Neural Tube Defects (No=40).

Fig 4: shows that the majority **(87.5%)** of the studied parents had elevated levels of stress regarding the care of their neonates with neural tube defects compared with only **(12.5%)** who had low levels of stress.

Table (4): Relation between Parents' Characteristics and their knowledge level regarding their neonates' care with Neural Tube Defects (No=40).

Items	Knowledge level				X^2	P-Value
	Satisfactory (n=7)		Unsatisfactory (n=33)			
	No	%	No	%		
Gender						
Male	3	42.8	12	36.4	0.104	**0.001****
Female	4	57.2	21	63.6		
Age						
20 < 30 years	1	14.3	7	21.2		
30 < 40 years	3	42.8	18	54.6	1.742	2.361
40 ≤ 50 years	3	42.8	8	24.2		
Education						
Illiterate	1	14.3	3	9.1		
Can read and write	1	14.3	4	12.1	0.582	0.567
Primary education	1	14.3	4	12.1		
Medium education	3	42.8	19	57.6		
Higher Education	1	14.3	3	9.1		
Employment status						
Employed	2	28.6	5	15.2		
Not employed	4	57.2	17	51.5	1.328	1.388
Free job	1	14.3	11	33.3		
Consanguinity						
Yes	6	85.7	26	78.8		
No	1	14.3	7	21.2	0.173	**0.002****

**** Highly Statistical significance difference**

Table (4) shows that there was a highly statistically significant relation between gender and consanguinity of the studied parents and their total level of knowledge at P-value= 0.001 & 0.002, respectively. While there was no statistically significant relation between age, education and employment status and their total level of knowledge.

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Table (5): Relation between Parents' Characteristics and their reported practices level regarding their neonates' care with Neural Tube Defects (No=40).

Items	Reported Practice level				X^2	P-Value
	Adequate (n=6)		inadequate (n=34)			
	No	%	No	%		
Gender						
Male	3	50	12	35.3	0.471	**0.05***
Female	3	50	22	64.7		
Age						
20 < 30 years	0	0	8	23.5		
30 < 40 years	3	50	18	53	3.541	5.108
40 ≤ 50 years	3	50	8	23.5		
Education						
Illiterate	1	16.7	3	8.8		
Can read and write	0	0	5	14.7	1.640	0.802
Primary education	1	16.7	4	11.8		
Medium education	3	50	19	55.9		
Higher Education	1	16.7	3	8.8		
Employment status						
Employed	2	33.3	5	14.7		
Not employed	3	50	18	53	1.438	0.487
Free job	1	16.7	11	32.3		
Consanguinity						
Yes	5	83.3	27	79.4		
No	1	16.7	7	20.6	0.491	**0.001****

*** Statistical significance difference**
**** Highly Statistical significance difference**

Table (5) shows that there was a highly statistically significant relation between the consanguinity of the studied parents and their reported practices at P-value= 0.001. In addition, there was a statistically significant relation between the gender of the studied parents and their reported practices. While there was no statistically significant relation between age, education and employment status and their total level of reported practices.

Table (6): Relation between Parents' Characteristics and parental stress level regarding their neonates' care with Neural Tube Defects (No=40).

Items	PSI				X^2	P-Value
	High stress (n=35)		Low stress (n=5)			
	No	%	No	%		
Gender						
Male	13	37.1	2	40	0.015	**0.003****
Female	22	62.9	3	60		
Age						
20 < 30 years	8	22.8	0	0		
30 < 40 years	19	54.4	2	40	4.357	0.360
40 ≤ 50 years	8	22.8	3	60		
Education						

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Illiterate	3	8.6	1	20		
Can read and write	5	14.3	0	0		
Primary education	4	11.4	1	20	2.140	0.710
Medium education	19	54.3	3	60		
Higher Education	4	11.4	0	0		
Employment status						
Employed	6	17.2	1	20		
Not employed	18	51.4	3	60	0.272	0.291
Free job	11	31.4	1	20		
Consanguinity						
Yes	27	77.2	5	100		
No	8	22.8	0	0	1.429	0.232

**** Highly Statistical significance difference**

Table (6) shows that there was a highly statistically significant relation between the gender of the studied parents and their parental stress index at P-value= 0.003. While there was no statistically significant relation between age, education, employment status and consanguinity and their total level of stress.

Table 7: Correlation between studied parents' Knowledge, reported practices and Parental Stress levels for their neonates with neural tube defects (N= 40).

Item		**Total Knowledge**	**Total reported practices**
Total Knowledge	**Correlation coefficient (r)**		
	P-Value		
Total reported practices	**Correlation coefficient (r)**	0.912**	
	P-Value	0.000	
Parental Stress Index	**Correlation coefficient (r)**	0.821**	0.900
	P-Value	0.000	0.000

*Correlation is highly significant at the 0.001 level

It is obvious in Table 7 that, there was a high statistical significance correlation (r = 0.912, 0.821 and 0.900 p < .001) respectively between the studied parents' Knowledge, reported practices and Parental Stress Index for their neonates with neural tube defects

Discussion

The current study aimed to assess the awareness level of the studied parents in caring for their neonates with (NTDs). The findings indicate that there is a significant gap in parental knowledge regarding NTDs, with a majority (83%) of the participants displaying an unsatisfactory understanding of these conditions. This lack of knowledge is concerning, given the critical role parents play in the early intervention and management of NTDs.

The age range of the studied parents studied was 30 to 40 years, with a mean age of 34.05 ± 4.50 years. This demographic is particularly important as it represents the typical age group of parents with young children. This finding is consistent with a study by **Gedefaw et al. (2018),** titled "Magnitude of Neural Tube Defects and Associated Risk Factors at Three Teaching Hospitals in Addis Ababa, Ethiopia," which reported that more than half of the parents studied were aged 30 to 39 years. On the other hand, I disagree with **Hassan, (2021)** in her study titled "Prevalence, Associated Factors, and Outcome of Neural Tube Defects: A Retrospective Study" revealed that of neonates having NTDs in their mothers aged from 20-29 years.

The gender distribution of the studied parents was skewed towards females, who made up two-thirds of the sample. This is reflective of the traditional caregiving roles often assumed by women, highlighting the need for

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targeted educational interventions for this group. This finding was consistent with **O'Brien et al., (2019),** who conducted a study entitled "A Comparison of Students and Parent Knowledge and Perceived Confidence About Brain Injury and Concussion" and reported that female parent's proportion were more than two-thirds, while male parents' proportion were more than one third. From the researcher's point of view, this similarity in finding was related to mothers being the first and ultimate caregivers in this period and for this vulnerable age group.

In education and employment, over half of the parents had medium education levels and were engaged in free jobs. This suggests that while they may have some foundational knowledge, there may be a lack of specific information regarding NTDs. Furthermore, the average number of children per family was 2.8 ± 1.1, with half of the parents having 3-4 children. This family size may impact the amount of time and resources parents can dedicate to each child, potentially affecting their ability to manage complex health conditions like NTDs.

The study's additional findings provide a deeper understanding of the factors contributing to the care of neonates with Neural Tube Defects (NTDs). A significant concern is that most of the studied mothers did not take folic acid during pregnancy, which is crucial in preventing NTDs. This aligns with the observed knowledge gap and suggests a dire need for public health initiatives to educate expectant mothers about the importance of prenatal vitamins.

The study results indicate that the studied sample were not exposed to radiation suggests that other factors, such as genetics and nutrition, may play a more significant role in the development of NTDs within this population. The fact that almost two-thirds of them did not take chronic medications, while only a third did, particularly anticonvulsant drugs, which are known teratogens, further emphasizes the need for careful medication management and counselling during pregnancy.

Hospitalization duration, with half of the neonates hospitalized for 20 to 30 days and a mean of 21.7 ± 5.7 days, reflects the severity of NTDs and the intensive care required. This also highlights the emotional and financial strain on families, which can be mitigated with better prenatal care and early intervention.

The high rate of consanguinity among the studied parents could suggest a genetic predisposition to NTDs, warranting genetic counselling and screening programs. The lack of a history of congenital anomalies in the sample indicates that NTDs may not be readily anticipated in families without prior occurrences, further complicating early detection and prevention efforts. This finding aligned with **Maged A. et al, (2015)** study, which revealed that 70% of the study sample who have SB have a positive consanguinity.

Furthermore, **Hassan, (2021)** indicated that in her research titled 'Prevalence, Associated Factors, and Outcome of Neural Tube Defects: A Retrospective Study,' almost half had parents' consanguinity. The finding was supported by **Mohammed A. et al. (2013),** who reported in their study 'Congenital Anomalies among Children: Knowledge and Attitude of Egyptian and Saudi Mothers' and **Tayebi N. et al., (2010),** who conducted a study 'The Prevalence of Congenital Malformations and its Correlation with Consanguineous.' This suggests that consanguinity is considered one of the most common contributing factors in transferring genetic traits related to congenital anomalies.

The unsatisfactory level of knowledge among the studied parents about NTDs underscores the need for comprehensive educational programs. Such programs should aim to improve understanding of NTDs, their causes, preventive measures, and the importance of timely medical intervention. Healthcare providers and policymakers must collaborate to develop accessible and effective educational materials and resources to empower parents with the knowledge and skills necessary to optimize the care and outcomes for their children with NTDs.

Regarding the reported practices of the studied parents found a highly statistically significant relation between gender and consanguinity of the studied parents and their reported practices, these findings is supported by **Iqbal et al., (2022)** who conducted a research paper titled "Consanguineous marriages and their association with women's reproductive health and fertility behavior in Pakistan: secondary data analysis from Demographic and Health Surveys, 1990–2018" that shad and support the findings and emphasizes the need for community-level awareness programs about the risks to women's reproductive health and fertility.

As presented in Table 5 there was a statically significance relation between gender and their reported practices, these findings were supported by **Murry et al, (2013)** in the handbook of marriage that supports the study findings of how gender manifests in contemporary families and their interaction with diseases, especially with neonates.

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Concerning Parental stress, it was obvious from the study that most of the studied parents had high stress levels according to parental stress index. These findings were supported by **Fang et al., (2024)** who published research tilted "A systematic review published in European Child & Adolescent Psychiatry investigated factors related to parenting stress in mothers and fathers" that found evidence of an association between maternal depression and parenting stress evidence of an association between maternal depression as female gender and parenting stress in addition to adequate social support can mitigate parenting stress. In other perspective, this evidence is inconsistent for associations between maternal anxiety, family income, and parental parenting stress. Moreover, there were not associated \ related variables as maternal age and child sex regarding parental stress levels.

Another study by Dervish **Aliaj (2013)** who conducted a research paper titled "Parental Stress in Families of Children with Disabilities: A Literature Review." that assessed the level of psychological stress among parents varied based on the severity of intellectual disability in their children meanwhile it did not specifically mention gender differences, but it highlights the overall stress experienced by parents in this context.

The study's most alarming revelation is the inadequate practices of two-thirds of the studied parents in caring for their neonates with NTDs. This is corroborated by a strong correlation ($r = p < .001$) between parental knowledge reported practices and stress level. This stark discrepancy underscores the urgent need for practical training and resources to empower parents with the skills to effectively care for their children. These findings follow **Okelo, et al., (2024)** who investigated research titled "Parental stress and child stimulation practices: examining associations with child developmental outcomes over time in Kenya and Zambia" This study explores the associations between parental stress, caregiving practices, and child developmental outcomes over time. It suggests that improved caregiver stimulation practices are likely to enhance children's developmental outcomes. in the same context, Fang et al., (2024) conducted a study titled "Parent, child, and situational factors associated with parenting stress: a systematic review" that provides an overview of factors related to parenting stress, which may include the impact of parental knowledge and practices.

Conclusion

In conclusion, the study sheds light on a poor level of parental knowledge regarding the care of their neonates with Neural Tube Defects. Parents had inadequate reported practices and high-stress levels about the care of their neonates. It calls for a multifaceted approach involving education, support, and healthcare services to improve parental performance and neonatal outcomes.

Recommendations

Based on the findings of the current study the following recommendations are:

- Provide instructional guidelines to parents through verbal explanations and distribute illustrated booklets to reinforce their knowledge and practices at home.
- Ensure that parents took these instructions from supported team as nurses in different areas, such as the Neonatal Intensive Care Unit (NICU), Pediatric Surgical Department, and outpatient clinics, are provided with comprehensive instructional guidelines for caring for neonates with Neural Tube Defects (NTDs).
- Emphasize the role of the multidisciplinary team in caring for children with NTDs and their families by facilitating collaboration among healthcare professionals and social and community services.

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