Iraqi National Journal of Nursing Specialties, Vol. 31 (2), 2018

Psychological Burdens of Children with Anorectal Malformation on Mothers at Pediatric Teaching Hospitals in Baghdad City

ألاعباء النفسيه لتشوهات المقعد والمستقيم للأطفال على الأمهات في مستشفيات الأطفال التعليمية لمدينة بغداد

Ola A. Lateef, MScN *

Khamees B. Obaid, PhD **

*** Clinical Nurse specialist, Mdical City, Ministry of Health.**
E-mail: ula_cat89@yahoo.com
**** Assistant Professor, Pediatric Nursing Unit, College of Nursing, University of Baghdad**
E-mail: bkhamees@yahoo.com

الخلاصة

الأهداف: الهدف الرئيسي من الدراسة هو تحديد مستوى الأعباء النفسيه التي تعانيها الأمهات ممن لديهن أطفالا يعانون من تشوهات في المقعد والمستقيم.

منهجية البحث: تم إجراء دراسة وصفية في مستشفى حماية ألاطفال التعليمي والمستشفى التعليمي المركزي للأطفال في مدينة بغداد . فترة أجراء الدراسه من ١٥ لشهر تشرين الثاني ٢٠١٧ إلى ٢٩ لشهر نيسان لعام ٢٠١٨. كانت هذه الأستبانه ذات سمه تطبيق عالميه. تم إجراء مقابلة مع عينة عشوائية متوفره تتكون من (١٤٠)أم من أمهات ألاطفال المصابين بتشوهات في المقعد والمستقيم. تتكون ألأستبانه من ستة أجزاء للأمهات متعلقة بالأعباء النفسية وألاجتماعيه كنتيجة لوجود طفل يعاني من تشوه في المقعد والمستقيم. تم تحديد صلاحية ألاستبانه من خلال لجنة من الخبراء وتم تحديد موثوقية الاستبيان في دراسة تجريبية بين (١٤) أم ، تم استبعاد الأمهات الذين شاركوا في الدراسة التجريبية من عينة الدراسة الكليه . كان تحليل البيانات المستخدمة هو الإحصاء الوصفي والإحصائي الاستدلال ، من أجل إيجاد مستوى ألاعباء للتشوهات المقعد والمستقيم على الأمهات.

النتائج: تشير نتائج الدراسة إلى أن هناك تأثير ألاعباء النفسية كبيرة للغاية على الأم التي لديها طفل يعاني من تشوهات المقعد والمستقيم ، هو مؤثر و بمعدل مرتفع.

التوصيات: أوصت الدراسة بأن يتم توفير الدعم النفسي من قبل أخصائيي الرعاية الصحية للأمهات اللواتي لديهن أطفال يعانون من تشوهات المقعد والمستقيم.

الكلمات ألمفتاحيه: معاناة الامهات ،تشوهات المقعد والمستقيم ، وحدة جراحة ألاطفال،مستشفيات مدينة بغداد.

Abstract:

Objective(s): The main aim of the study is to determine the level of burden on mothers toward children with anorectal malformation.

Methodology: A descriptive study was carried out at Welfare Pediatric Teaching Hospital and Central Pediatric Teaching Hospital in Baghdad City. From November 15th, 2017 to April 29th, 2018. Convenient sample comprised of (140) children mothers with anorectal malformation were interviewed for the study. The instrument of study is composed of six domains related mothers' burden toward psychosocial burden as a result of child with anorectal malformation. Validity of the study instrument was determined through a panel of experts and the reliability of the questionnaire is determined in a pilot study among (14) mothers. Mothers who participated in the pilot study are excluded from the total study sample. The analysis of the data used was descriptive statistics and statistical inferential, in order to find the level of burden of congenital anomalies on mothers.

Results: The study findings indicate that there are highly significant burden impact on a mother who has a child with anorectal malformation.

Recommendations: The study recommended that Psychological support should be provided by health care professionals for the mothers who have children with anorectal malformation.

Keywords: Mothers Burden, Anorectal malformation, Pediatric Surgical unit, Baghdad City Hospitals

Introduction

A child's birth represents a great event in parents' life. Parent feeling is compared with joy. If a child birth associates with anomaly, there is a demand for hospital stay for a period of time with special care that can transmit hopefully any occasion for another situation. [1]

Anorectal malformation (ARM) represents as malformed of the rectum or absence of normal rectum. Constipation and fecal incontinence resulting from this stoma as a result of this malformation. ARM has an impact on specific part of a child body that is hidden from others. Physical negative impact resulting from ARM can be appeared as shameful or stigma matter leading to psychosocial complication for this condition.[2] Shameful feeling that affects a child's suffering from ARM and continues along child life leads to psychological problems, such as being outcast or rejected in his/her school. Children may be also fool around with other children in school. Depravation and secret behavior will be acted by a child who has experience with ARM.[3]

ARM is a congenital anomaly that affects anal and rectum tract. The prevalence of ARM is 1 in 4000-5000 births. ARM is ranging from high and low anomaly. During the embryonic period elevator muscle of the rectum develop any anomaly through this period can lead to ARM.[4] Early surgery performed to reconstruct anomaly with special treatment and follow –up.[5] This malformation can lead to incontinence of urine and stool and sever constipation. The quality of life QOL is affected by these problems and leads to psychological problems.[6] These problems also influence child's bond with his/her parents, ties and child's psychological status.[7] Colostomy performed within first 24 hours of child life. When a child is born with high or intermediate ARM to allow children bowel be empty.[8] When a child needs colostomy, it can be an extremely traumatic time for the family.[9] Re-building of the anus and the anorectal canal with normal manner is performed when the child in his/her first three months. And then anorectal dilatations instructed to avoid constipation.[10]

ARM represents as chronic condition, request for stoma to empty bowel content until age 3 months when the new anorectum reconstructed. Dilatation is done (With Hegar dilators) to resize the rectum suitable with a child's age. Specific Health education performed on child's parents to dilatation twice daily for several to months. If neoanus reached to target dilatation size, stoma should be closed and stool would pass through normal canal as reconstructed rectum.[11]

Functional problems such as constipation and soiling affect a child suffering from ARM even rectum tract reconstructed achieve which require daily enema in addition to bowel management program.[12]

Another complication has huge impact on child, parents and healthcare member, represented by sepsis, wound infection, prolapse and wound lesion effect on a child have colostomy as difficulties happen postoperative. Moreover, it has negative impact on child acceptance especially for a child who lives in developed countries.[5]

Methodology

A descriptive design was carried out at Baghdad City Hospitals for the period November 15th, 2017 to April 29th, 2018. Convenient sample of (140) mothers was selected from the Surgical Wards and consultations in the Children Welfare Teaching Hospital, Central Pediatric

Teaching Hospital. A lot of surgical anomaly cases admitted to these hospitals from different Baghdad city areas. So researcher chosen these cases in the consultation department and surgical wards. The study instrument (questionnaire) was consisted of two major parts to meet the purposes of study. International scale was used through the review of related literatures scale with a research about (Impact of a child with congenital anomalies on parents (ICCAP) questionnaire; a psychometric analysis) written by. [20]

The first part is related to mothers' demographic characteristics such as age, number of children in family, number of child's sibling, father's age, level of education for parents, monthly income for family, family history affected member with congenital anomalies, any diseases affect child, any congenital anomalies associated with anorectal malformation, drugs in use, how long parents married and residency. The second part is related to burden of children with Anorectal malformation on mothers. It consists of 36- items (Agree, extremely agree, disagree, extremely disagree, and not accept) questionnaire divided into 6 main dimensions which are: Contact with caregivers, Social network, Partner relationship, State of mind, Child acceptance by his/her family and Fears and anxiety. The validity of the study and questionnaire was established through a panel of (9) experts of different specialties related to the field of the present study. They were asked respectively to review the questionnaire for clarity and adequacy in order to achieve the present study objective. The reliability for constructed questionnaire was determined by using pilot study. The pilot study was carried out on 10% of total sample (14 mothers) selected randomly from Welfare Teaching Hospital chosen from 1st February, to 12th February 2018 to avoid bias the internal consistency of the questionnaire is found to be (0.92) on Cronbach's alpha. The Pilot Study was done to test the questionnaire for clarity and the reliability, to determine the time required for filling the questionnaire and to discover the barriers that may be encountered during the study process.

The pilot study sample was excluded from the original sample of the study. Data were analyzed using the statistical package for social science (SPSS) for windows Version 24 (Chicago, IL). Descriptive statistical measures of frequency, percent, mean, and standard deviation will be used. Furthermore, the inferential statistical measures of Bivariate correlation and linear regression will be used. Moreover, the non-parametric tests of Kruskal-Wallis tests and Mann-Whitney-U test will be used.

Classification for Socioeconomic Status for families:

The summation of scores of educational qualification and monthly income is computed as follows: [22]

Lower	< 4
Upper lower class	5-8
Lower middle class	9-12
Upper middle class	13-20
Upper class	21-24

Results:

Table (1): Participants' Sociodemographic Characteristics (N = 140)

Items		Freq.	%
Child's Gender	Male	92	65.7
	Female	47	33.6
	Undifferentiated	1	0.7
Child's Age group	1-7 days	17	12.1
	< One month	19	13.6
	< 6 months	36	25.7
	< One year	14	10.0
	1-2 years	31	22.1
	> 2 years	23	16.4
Count of infants in the house	One	19	13.6
	Two	26	18.6
	Three	35	25.0
	Four	21	15.0
	Five	19	13.6
	≥ 6	20	14.3
Child's birth rank	First	23	16.4
	Second	29	20.7
	Third	32	22.9
	Fourth	19	13.6
	Fifth	19	13.6
	Sixth	13	9.3
	Seventh	5	3.6
Table 1. (Continued)			

Mother's Age mean	**15-22**	**28**	**20.0**
	23-30	**53**	**37.8**
	31-38	**40**	**28.6**
	39-47	**19**	**13.6**
Father's Age mean	**18-26**	**35**	**25.0**
	27-35	**48**	**34.3**
	36-44	**40**	**28.6**
	45-53	**13**	**9.3**
	≥ 54	**4**	**2.9**
Socioeconomic Status **SES**	**Lower**	**9**	**6.4**
	Upper lower class	**68**	**48.6**
	Lower middle class	**40**	**28.6**
	Upper middle class	**21**	**15.0**
	Upper class	**2**	**1.4**
Residency	**Urban**	**69**	**49.3**
	Suburban	**32**	**22.9**
	Rural	**39**	**27.9**
Family history of congenital anomalies	**Yes**	**22**	**15.7**
	No	**118**	**84.3**

Freq =Frequency; % =percentage

Table (1) shows the demographic characteristics of the study sample which was 65.7 male, majority of them 25.7% at age less than six months, Count of infants in the house were three children by 25.0%, 22.9 of child's birth rank are third, mother's age mean 23-30 years by 37.8, Father's Age mean 27-35 years by 34.3, 48.6 represent as majority of families at Upper lower class to socioeconomic status SES, 49.3 of families urban residency and 84.3 of families reported that they do not have such a history of congenital anomalies.

Table (2): The Difference in the Burden Related to the Social Network Among the SES Groups

Ranks				Chi-Square	df	Asymp. Sig.
	SES	N	Mean Rank			
The social network	Lower	9	67.28	6.794	4	.147
	Upper lower class	68	64.65			
	Lower middle class	40	72.90			
	Upper middle class	21	80.95			
	Upper class	2	126.00			
	Total	140				

N= number p-value =.147

Table (2) presents the differentiation in the burden related to the social network was greater for the family that was in the upper lower SES class, followed by the family that was in the upper lower SES class, the family that was in the lower middle lower middle SES class, the family that was in the upper middle SES class, and the family that was in the upper SES class. This represents a descending order. However, there is no statistical significant difference in the burden related to the social network among the family SES class groups.

Table (3): The Difference in the Burden Related to the Child's Acceptance Among The Existence of Family History Of Congenital Anomalies Groups

Ranks					Mann-Whitney U	Asymp. Sig.
	Does the receive any medications?	N	Mean Rank	Sum of Ranks		
Child Acceptance	Yes	102	71.02	7244.50	1884.500	.800
	No	38	69.09	2625.50		
	Total	140				

N= Number Sig. = Significant

The burden related to the child's acceptance was greater for the child who doesn't receive any medication. This represents a descending order. However, there is no statistical significant difference in the burden related to the child's acceptance between receiving any medication for the sick child groups.

Table (4): The Difference in the Overall Burden Among the Existence of Other Congenital Anomalies Groups

Ranks					Mann-Whitney U	Asymp. Sig.
	Has the child had other congenital anomalies?	N	Mean Rank	Sum of Ranks		
Overall Burden	Yes	44	53.08	2335.50	1345.500	.001
	No	96	78.48	7534.50		
	Total	140				

Table (4) indicates that the overall burden was greater for the child who has another congenital anomaly. This represents a descending order. There is a statistical significant difference in the overall burden between the existence of another congenital anomaly in the sick child groups (Mann-Whitney U = 1345.500, p-value = .001).

Discussion:

Part I: The Demographic Characteristics Distribution

1. Gender of child:

The present results revealed that most were males (65.7%). The findings of the present study supportive evidence is available in the study that showed (the high percentage of their sample were male, 52.8%). [13]

2. Age of Children:

According to the results show that majority of children with age less than six months (25.7%). These results supportive evidence is available in the study that showed (49% of children in his study were <5 years of age.[14] But disagree with the results that showed (the highest percentage of children 33.3% early neonates at the age (1-7 days).[15.]

3. Number of children in the family:

Regarding the number of children in the family, a quarter have three children (25.0%). The findings of the present study supportive evidence is available in the study that showed that four children in the family by (32.0 %). [9]

4. Child's birth rank:

Finding of the present study revealed that the child's birth rank was the third rank, that the highest percentage were in (22.9%), The findings of the present study supportive evidence is available in the study that showed (the high percentage of their sample were third position, 29.2%). [15] The result of this study disagree with result that showed (highest percentage 42.8%) of these children were the first born.[16]

5. Mothers' age:

The present study showed mothers' age, the age mean was 29.3 ± 7.1; more than a third were within the age group of (23-30) years-old (37.8%). The findings of the present study supportive evidence is available in the study that showed (the highest percentage of the mothers were in age group of 21-25 years with 44.9%). [13] But disagree with the results that showed (the highest percentage of mother's age were above 35 years at conception (59.96%). [17]

6. Fathers' age

The majority of fathers' age were within the age group of (27-35) years-old (34.3%). The findings of the present study supportive evidence is available in the study that showed (the highest percentage of the fathers were in age group of 25-34 years with 55.4%).[15] But disagree with the results that showed (the highest percentage of father's age were above 50 years at time of conception was detected in (30%). [17]

7. Family class

Concerning the family's SES, less than a half were classified in the upper lower class (48.6%), found that with respect to parent education 33.1% of mothers and 24.7% of fathers had a college degree.[18] Moreover, another statistic found that more than half of children's families have somewhat sufficient monthly income (59.0%). [9]

8. Residency

Regarding the residency majority of families live in urban areas (49.3%). These results supportive evidence is available in the study that showed (52.9%) of families residency was urban area.[19]

9. The family history of congenital anomalies

Concerning the family history of congenital anomalies, the majority reported that they do not have such a history (84.3%). These results supportive evidence is available in the study that showed that 94% of the patients did not report of any family history of birth defects.[15]

Part II: Mother's Burden:

Correlation between the families' SES and the burden related to the social network

A positive statistical correlation between the families' SES and the burden related to the social network table (2). The findings of the present study supportive evidence is available in the study that showed(These results are in accordance with the study showed that children with anorectal malformation missed more school, spent more days in bed and need care, had greater healthcare utilization, and had parents who missed more work days with greater work impact.[18]

Part III: Correlation between burden related to the child's acceptance with the family that has a history of congenital anomalies

The burden related to the child's acceptance was greater for the family that has a history of congenital anomalies are shown in table (3). The findings of the present study supportive evidence is available in the study that showed that (the higher levels of agreement for both parents were reached on acceptance of the child and partner relationship, with lower agreement between parental levels on fears and anxiety, contact with caregivers and social network).[20] Furthermore, 28% of the mothers and 25% of the fathers of children with anorectal malformation had received psychological help owing to their children's congenital anomaly. [11]

Part IV: The difference in the overall burden among the existence of other congenital anomalies groups Table (4)

The results showed significant association between overall burden and existence of other congenital anomalies among children**.** The findings of the present study supportive evidence is available in the study that showed (children who underwent multiple operations and those who required home medical treatment HMT was significantly higher than that of patients who underwent single operation, and those who did not require HMT). [21]

The study also showed a positive statistical correlation between the families' socioeconomic status SES and the burden related to the social network. The present study supportive evidence is available in the study that shown that majority (94%1) of all the congenital malformations occur in middle and low income countries where mothers are exposed to factors of low socioeconomic status such as macro and micro-nutrient deficiencies, infections and other factors. Advanced maternal age also increases the chances of certain chromosomal abnormalities.[15]

Recommendations:

1. There is a pressing need to increase the public awareness to avoid the early marriage of girls.
2. There is a need for the health care givers to reassure parents of children with congenital anomalies; especially those whose ages between (1-6) months regarding the course of illness for their children.
3. Special efforts should be devoted by health care professionals to families that have a history of congenital anomalies with the goal of overcoming burden related to the contact with caregivers.
4. Psychological support should be provided by health care professionals for the families that have a history of congenital anomalies, having a child who has a history of congenital anomalies, and having a child who receive any medication with the goal of overcoming the burden related to the state of mind and child's acceptance.

References

1. Hopia H, Paavilainen E, Astedt-Kurki P. (2005). The diversity of family health: Constituent systems and resources. Scand J Caring Sci; 19:186-95.

2. Nisell, Margret. (2005). Psychsocial consequences of high and intermediate imperforate anus. Institution för kvinnors och barns hälsa/Department of Women's and Children's Health.Nursing, 29(3), 209–216.

3. Öjmyr-Joelsson, M., Christensson, K., Frenckner, B., Nisell, M., & Lindholm, T. (2008). Children with high and intermediate imperforate anus: remembering and talking about medical treatment carried out early in life. Pediatric surgery international, 24(9), 1009.

4. Holschneider, A., Hutson, J., Peña, A., Beket, E., Chatterjee, S., Coran, A., ... & Iwai, N. (2005). Preliminary report on the International Conference for the Development of Standards for the Treatment of Anorectal Malformations. Journal of pediatric surgery, 40(10), 1521-1526.

5. Amanollahi, O., & Ketabchian, S.(2016). One-stage vs. three-stage repair in anorectal malformation with rectovestibular fistula. African Journal of Paediatric Surgery:AJPS, 13(1), 20–25.

6. Rintala RJ, Lindahl HG (2001): Fecal continence in patients having undergone posterior sagittal anorectoplasty procedure for a high anorectal malformation improves at adolescence, as constipation disappears. J Pediatr Surg, 36:1218-21.

7. Shabas, S. (2016). Relationships Between Parents and Preschool-Age Children Attending Kindergartens. Procedia-Social and Behavioral Sciences, 233, 269-273.

8. Pena A, Levitt M. (2007). Anorectal malformations. In: Stringer M, Oldham K, Mouriquand PDE, editor. Pediatric Surgery and Urology: Long term outcomes. 2. Cambridge: Cambridge University Press;. pp. 401–415.

9. Adraa H. Shauq. (2015). Burden of Mothers' Care for Children with Colostomy at Baghdad Medical City Teaching Hospital: *Iraqi National Journal of Nursing Specialties, Vol. 28 (2).*

10. Kyrklund, K. (2016). Anorectal malformations-outcomes up to adulthood.

11. Nisell, M., Öjmyr-Joelsson, M., Frenckner, B., Rydelius, P. A., & Christensson, K. (2009). Psychosocial experiences of parents of a child with imperforate anus. Journal for Specialists in Pediatric Nursing, 14(4), 221-229.

12. Pruthi, G. K., & Mohta, A. (2010). Psychosocial burden and quality of life in parents of children with anorectal malformation. Journal of Indian Association of Pediatric Surgeons, 15(1), 15–18.

13. Correa, C., Mallarino, C., Peña, R., Rincón, L. C., Gracia, G., & Zarante, I. (2014). Congenital malformations of pediatric surgical interest: Prevalence, risk factors, and prenatal diagnosis between 2005 and 2012 in the capital city of a developing country. Bogotá, Colombia. Journal of pediatric surgery, 49(7), 1099-1103.

14. WU, Victor K.; POENARU, Dan; POLEY, Marten J. (2013). Burden of surgical congenital anomalies in Kenya: a population-based study. *Journal of tropical pediatrics, 59.3: 195-202*

15. BARI, C. Fazle Mubarak (2014). Spectrum of congenital anomalies among children attending the pediatric departments of dhaka medical college hospital. IOSR Journal of Dental and Medical Sciences, 13.2: 20-46.

16. John, V., Chacko, J., Mathai, J., Karl, S., & Sen, S. (2010). Psychosocial aspects of follow-up of children operated for intermediate anorectal malformations. Pediatric surgery international, 26(10), 989-994.

17. Shawky, R. M., & Sadik, D. I. (2011). Congenital malformations prevalent among Egyptian children and associated risk factors. Egyptian Journal of Medical Human Genetics, 12(1), 69-78.

18. Varni, J. W., Bendo, C. B., Nurko, S., Shulman, R. J., Self, M. M., Franciosi, J. P., ... & Pohl, J. F. (2015). Health-related quality of life in pediatric patients with functional and organic gastrointestinal diseases. The Journal of pediatrics, 166(1), 85-90.

19. MOHSEN, Khetam M. Hattab Mohsen Q., (2016). Assessment of Mothers' Information and Believestowards Colostomy of theirChildren at Pediatric Hospitals in Baghdad City. Kufa Journal for Nursing Sciences.

20. Mazer, P., Gischler, S. J., Koot, H. M., Tibboel, D., van Dijk, M., & Duivenvoorden, H. J. (2008). Impact of a child with congenital anomalies on parents (ICCAP) questionnaire; a psychometric analysis. Health and Quality of Life Outcomes, 6(1), 102.

21. Kubota, A., Yamakawa, S., Yamamoto, E., Kosugi, M., Hirano, S., Shiraishi, J., ... & Watanabe, T. (2016). Major neonatal surgery: psychosocial consequence of the patient and mothers. Journal of pediatric surgery, 51(3), 364-367.

22. Shaikh, Z., & Pathak, R. (2017). Revised Kuppuswamy and B G Prasad socio-economic scales for 2016. International Journal of Community Medicine and Public Health, 4(4), 997-999.