

## Burden of Mothers' Care for Children with Colostomy at Baghdad Medical City Teaching Hospital

أعباء الأمهات لرعايه بالأطفال ذوي تميم (فغر) القولون في مستشفى مدينه طب بغداد التعليمي

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### المستخلص:

الهدف: تقييم أعباء الأمهات لرعايه بالأطفال ذوي فغر القولون، وإيجاد علاقات بين المعلومات الديموغرافيه الاجتماعيه للطفل والام مع أعباء الأمهات.

المنهجية: دراسه وصفيه أجريت في الأول من شهر اب لعام 2013 ولغايه الأول من أيلول للعام 2014. تكونت العينه من 100 طفل مع امهاتهم في مستشفى بغداد التعليمي لمدينه بغداد. اعدت الاستبانته بالاعتماد على مراجعه الادبيات السابقه، الالتقاء مع أمهات أطفال ذوي تميم القولون و مقياس المقابله ل Zairt للاعباء. جمعت العين من خلال طريقه المقابله واستخدام الاستبانته.

النتيجه: أظهرت النتائج ان الأمهات يشتكين من مستوى متوسط من الأعباء الاجتماعية، النفسيه، الماليه، ومن كل الأعباء بصوره عامه. اكثر من ثلث العينه من الأمهات تتراوح أعمارهم 38-40 سنه، تقرا وتكتب ولديهن اربعه أطفال. اغلبهن لا يعملن (ربيات بيوت) و يراجعن طبيب اطفالهن بانتظام. اكثر من نصف العائلات لديها دخل شهري يكفي لحد ما وتتراوح أعمارهم 1-4 سنوات. اغلب الأطفال ذكور ويعانون من انسلاخ الجلد كاحد المضاعفات لتميم القولون. بالاضافه انه عدد الأطفال في العائله ومراجعه الطبيب و اعمار الأمهات يؤثر على الأعباء الاجتماعيه للامهات. اما عمر الطفل فله علاقه عكسيه بالأعباء الماليه لهن. وأخيرا اعمار الأمهات و المستوى التعليمي لهن، و الدخل الشهري للعائله كان مؤثرا على الأعباء النفسيه للامهات.

التوصيات: يواجهن أمهات الأطفال ذوي تميم القولون مشاعر كثيره وتغيرات في حياتهن ويحملن عبء تقديم الرعايه غالبا. وقد اصبحن ذوي خبره في رعايه اطفالهن لذا يحتجن الى تشجيع ودعم لجهودهن. المستوى التعليمي للامهات والوعي حول استخدام وسائل تنظيم الاسره لابد ان يشجع.

### Abstract

**Objective(s):** To assess the burden of mothers` care for child with colostomy and find out relationships between child and mother socio-demographic data with mothers` burden.

**Methodology:** a descriptive study was conducted from 1 August 2013 to 1 September 2014. The sample consisted of 100 children and their mothers at Baghdad Teaching hospital in Baghdad city. A questionnaire was prepared based on the previous literature review, meeting mothers of children with colostomy, and the Zarit Burden Interview scale. Data has collected through the application of questionnaire and interview techniques.

**Results:** The data shows that mothers suffer from moderate burden socially, psychologically, financially, and overall burden of care. More than one third of mothers are within 38-40 years old, illiterate, with four children. Majority of them are unemployed and visit their children`s physicians regularly. More than half of families have somewhat sufficient monthly income and their child within 1-4 years old. Most of children are male and suffer from skin excoriation as complication. In addition, numbers of children in the family, physician`s follow-up, and mothers` age effects on mothers` social burden. Child`s age negatively correlates with financial burden. Ultimately, mothers` age and their level of education, and family monthly income effect on mothers` psychological burden.

**Recommendations:** mothers of child with colostomy experience a multitude of emotions and changes in their lives, often carrying caregiving burden. They become the experts on their child`s care and should be empowered and supported in their efforts. The level of mothers` education should be increase and awareness about family planning.

**Key words:** burden, care, colostomy

## Introduction:

When a child needs colostomy it can be an extremely traumatic time for the family <sup>(1)</sup>. A colostomy is not a disease, but a change in the way of body works <sup>(2)</sup>. Parents have to deal not only with their child's disease but also need to follow the prolonged therapy schedule, which could be as distressing as the disease itself <sup>(3)</sup>. The care of child with colostomy considers complex, challenging and lengthy process, though colostomy in children is often temporary <sup>(4)</sup>. Managing stomas can lead to physical, psychosocial, and social problems for the parents. Even among the parents, mothers suffer more than the fathers as its responsibility of managing the child's bowel habits is often taken by the mother who most likely performs the regular enemas causing toll burden and extensive follow-up treatments <sup>(3)</sup>.

## Methodology:

A descriptive study was conducted from the 1<sup>st</sup> of August 2013 to the 1<sup>st</sup> of September 2014. The sample consisted of 100 children with colostomy and their mothers treated in pediatric surgical ward at Baghdad Medical City Teaching hospital. A questionnaire was prepared based on the previous literature review, meeting and asking mothers of children with colostomy daily care difficulties and the Zarit Burden Interview scale. The questionnaire of the study was consisted from socio-demographic data for mothers

Recently, the researches on family caregiving has expanded rapidly, several studies have reported great burden and stress among family members caring for sick child <sup>(5)</sup>. Caregiver burden is an all-encompassing term used to describe the physical, emotional, psychological and financial toll of providing care <sup>(6)</sup>. Assessment of caregiver burden is one important element for child care <sup>(7)</sup>.

There has been little work to examine the experiences, negative or positive, for parents of children with colostomy in Iraqi setting. The present study is an attempt to assess the burden of mothers of children with colostomy and understanding their situations will enable better intervention with specific support for them to reduce the burden, child care can be improved, and guide them to deal with their children.

and their child with colostomy, and the burden of mothers' care (social 24 items, psychological 23 items, and economic 7 items). Data has collected through the application of questionnaire and interview techniques. The level of total burden score was low (79-88.5), moderate (88.6-106.9), and high (107-116). The validity and reliability were determined and the data were analyzed through the application of descriptive and inferential data analysis through using the statistical package for social science (SPSS) version (17).

## Results:

**Table (1) Participants' Sociodemographic and Clinical Characteristics (N = 100)**

List	Variables	Frequency	Percent
1	<b>Mother's age (years)</b>		
	< 18	2	2.0
	18-21	1	1.0
	22-25	5	5.0
	26-29	7	7.0
	30-33	13	13.0
	34-37	28	28.0
	38-40	37	37.0
	> 40	7	7.0

*Continues...*

Table 1. (Continued)

List	Variables	Frequency	Percent
2	<b>Level of mother's education</b>		
	illiterate	1	1.0
	Reads and write	37	37.0
	Primary school	31	31.0
	Intermediate school	13	13.0
	High school	5	5.0
	Bachelor	3	3.0
3	<b>Mother's job</b>		
	Employed	11	11.0
	Unemployed	89	89.0
4	<b>Number of children in family (Mean = 3.97, SD = 1.37)</b>		
	The first	3	3.0
	The second	12	12.0
	The third	20	20.0
	The fourth	32	32.0
	The fifth	20	20.0
	The sixth and above	13	13.0
5	<b>Is the father alive?</b>		
	Yes	97	97.0
	No	3	3.0
6	<b>Parents' relationship</b>		
	Live together	95	95.0
	Divorce	2	2.0
	Widow/widowed	3	3.0
7	<b>Family type</b>		
	Nuclear	40	40.0
	Extended	60	60.0
8	<b>Physician's follow-up</b>		
	Yes	91	91.0
	No	9	9.0
9	<b>Interval of follow-up</b>		
	Regular	91	91.0
	Irregular	9	9.0
10	<b>Monthly income</b>		
	Sufficient	4	4.0
	Somewhat sufficient	59	59.0
	Insufficient	37	37.0
11	<b>Have any support from community organization?</b>		
	No	100	100.0
12	<b>Child's age (years)</b>		
	< 1	10	10.0
	1-4	66	66.0
	5-8	20	20.0
	> 8	4	4.0

Continues...

Table 1. (Continued)

List	Variables	Frequency	Percent
13	<b>Child's age on diagnosis</b>		
	< 6 months	80	80.0
	6-11 months	13	13.0
	1-4 years	3	3.0
	5-12 years	4	4.0
14	<b>Child's gender</b>		
	Male	76	76.0
	Female	24	24.0
15	<b>Child's rank (Mean = 3.6, SD = 0.95)</b>		
	First	9	9.0
	Second	6	6.0
	Third	1	1.0
	The last	84	84.0
16	<b>Duration of Colostomy (Mean = 3.75, SD = 0.67)</b>		
	< 3 months	2	2.0
	3-6 months	7	7.0
	1 year	5	5.0
	> 1 year	86	86.0
17	<b>Colostomy complications</b>		
	skin excoriation	70	70.0
	Enterocolitis	25	25.0
	Closed colostomy	3	3.0
	Prolapse	2	2.0
< = less than		> = more than	SD= standard deviation

Table (1) describes that more than one third of mothers are in the age group of 38-40 years old ( $n= 37$ ; 37.0%), followed by those in the age group of 34-37 ( $n= 28$ ; 28.0%). More than one third of mothers are unable to read and write ( $n= 37$ ; 37.0%), followed by those who are primary school graduate ( $n= 31$ ; 31.0%). The vast majority of mothers are unemployed ( $n= 89$ ; 89.0%), the mean number of children in the family is 3.97, SD = 1.37; one third of families have four children ( $n= 32$ ; 32.0%). The vast majority of children's fathers are alive ( $n= 97$ ; 97.0%), the vast majority of children's parents live together ( $n= 95$ ; 95.0%), and most of children's families are extended ( $n= 60$ ; 60.0%). The vast majority of mothers visit their children's physicians ( $n= 91$ ; 91.0%); and the vast majority of these visits are regular ( $n= 91$ ; 91.0%). More than half of children's families have somewhat sufficient monthly income ( $n= 59$ ; 59.0%). All children's families don't receive support from organizations ( $n= 100$ ; 100.0%). Most of children are within the age group of 1-4 years old ( $n= 66$ ; 66.0%); and the majority of them were diagnosed in the age of < 6 months ( $n= 80$ ; 80.0%). The majority of children are males ( $n= 76$ ; 76.0%). The mean of children's rank in the family is 3.6, SD = 0.95; and the vast majority of them are the last rank in the family ( $n= 84$ ; 84.0%). The mean of duration of colostomy for children is 3.75, SD = 0.67. The vast majority of children have a colostomy for > 1 year ( $n= 86$ ; 86.0%). Finally, the most reported type of colostomy complication is skin excoriation ( $n= 70$ ; 70.0%), and enterocolitis ( $n= 25$ ; 25.0%).

**Table 2. Level of Burden**

List	Type of burden	Frequency	Percent
<b>1</b>	<b>Social</b>		
	Low	26	26.0
	Moderate	72	72.0
	High	2	2.0
<b>2</b>	<b>Psychological</b>		
	Low	4	4.0
	Moderate	89	89.0
	High	7	7.0
<b>3</b>	<b>Economic</b>		
	Low	15	15.0
	Moderate	79	79.0
	High	6	6.0
<b>4</b>	<b>Overall burden</b>		
	Low	10	10.0
	Moderate	88	88.0
	High	2	2.0

Table (2) describes that the majority of mothers experience a moderate level of social burden ( $n= 72$ ; 72.0%) and more than a quarter of them experience a low level of social burden ( $n= 26$ ; 26.0%). The vast majority of women experience a moderate level of psychological burden ( $n= 89$ ; 89.0%) and a small proportion of them experience a high level of psychological burden ( $n= 7$ ; 7.0%). The majority of women experience a moderate level of economic burden ( $n= 79$ ; 79.0%) and less than a fifth of them experience a low level of economic burden ( $n= 15$ ; 15.0%). Ultimately, the vast majority of women experience a moderate level of overall burden ( $n= 88$ ; 88.0%) and a small proportion of them experience a low level of overall burden ( $n= 10$ ; 10.0%).

**Table 3. A. Descriptive Statistics for the Social Burdens (N= 100)**

List	Statement	Always F (%)	Sometime F (%)	Never F (%)	Mean (SD)	level
<b>1.</b>	<b>Social Burdens</b>					
<b>1.1</b>	I failed in my duty to my house	46 (46%)	49 (49%)	5 (5%)	1.56± 0.59	H
<b>1.2</b>	I neglect husband`s daily need	7 (7%)	52 (52%)	43 (43%)	2.36± 0.61	L
<b>1.3</b>	I failed my children care	13 (13%)	51 (51%)	36 (36%)	2.23± 0.66	M
<b>1.4</b>	I neglect daily responsibility	16 (16%)	60 (60%)	24 (24%)	2.08± 0.63	M
<b>1.5</b>	I do my work incompletely	40 (40%)	44 (44%)	16 (16%)	1.76± 0.71	M
<b>1.6</b>	I worry from another pregnancy	46 (46%)	37 (37%)	17 (17%)	1.71± 0.71	M
<b>1.7</b>	My husband changed with the family	6 (6%)	51 (51%)	43 (43%)	2.37± 0.59	L
<b>1.8</b>	My husband spends his time after work out side	24 (24%)	49 (49%)	27 (27%)	2.0± 0.71	M
<b>1.9</b>	My husband change with me	8 (8%)	48 (48%)	44 (44%)	2.36± 0.52	L
<b>1.10</b>	My husband decrease buying family needs	11 (11%)	53 (53%)	36 (36%)	2.25± 0.64	L
<b>1.11</b>	My husband makes troubles	8 (8%)	43 (43%)	49 (49%)	2.41± 0.63	L

*Continues...*

Table. 3. A (continued)

List	Statement	Always F (%)	Sometime F (%)	Never F (%)	Mean (SD)	level
1.12	I go alone for follow up	22 (22%)	11 (11%)	67 (67%)	2.45± 0.83	L
1.13	I go outside just for bring necessary things	77 (77%)	19 (19%)	4 (4%)	1.27± 0.52	H
1.14	Moved away from recreational activities	52 (52%)	43 (43%)	5 (5%)	1.53± 0.59	H
1.15	Reduced my visiting friends	81 (81%)	18 (18%)	1 (1%)	1.20± 0.43	H
1.16	Reduced my visiting family	60 (60%)	33 (33%)	7 (7%)	1.47± 0.63	H
1.17	Annoyed glances from others for my child	63 (63%)	30 (30%)	7 (7%)	1.44± 0.63	H
1.18	Bothers me that people are aware of my child condition	57 (57%)	31 (31%)	12 (12%)	1.55± 0.70	H
1.19	I used contraceptive	65 (65%)	30 (30%)	5 (5%)	1.40± 0.58	H
1.20	I try to identify a family has child like my child condition	63 (63%)	29 (29%)	8 (8%)	1.45± 0.64	H
1.21	Stay babysitter house	68 (68%)	29 (29%)	3 (3%)	1.35± 0.54	H
1.22	I hear from people painful words because my child	48 (48%)	41 (41%)	11 (11%)	1.36± 0.68	H
	Mean				39.9± 3.25	M
F= frequency      %= percentage      H= high      M= moderate      L= low      SD= standard deviation Cut-off-point: 1-1.66 = High      1.67-2.33 = Moderate      2.34-3.0 = Low						

This table demonstrates that in the social burden subdomain, the item # 1.13 “I go outside just for bring necessary things” constitutes the highest social burden, mean (SD) (1.27± 0.52), followed by the item # 1.15 “Reduced my visiting friends” mean (SD) (1.20± 0.43).

Table 3. B. Descriptive Statistics for the Psychological Burdens (N= 100)

List	Statement	Always F (%)	Sometime F (%)	Never F (%)	Mean (SD)	level
<b>2.</b>	<b>Psychological Burdens</b>					
2.1	I feel tired	68 (68%)	31 (31%)	1 (1%)	1.33± 0.49	H
2.2	I feel guilty	5 (5%)	53 (53%)	42 (42%)	2.37± 0.58	L
2.3	I thinking always in my child condition	94 (94%)	6 (6%)	0 (0.0%)	1.06± 0.24	H
2.4	My husband blame me	0 (0.0%)	50 (50%)	50 (50%)	2.50± 0.50	L
2.5	I fear of having another child	75 (75%)	19 (19%)	6 (6%)	1.31± 0.58	H
2.6	I feel that my child had an impact on my job and duty	52 (52%)	44 (44%)	4 (4%)	1.52± 0.58	H
2.7	I feel my child different	62 (62%)	37 (37%)	1 (1%)	1.39± 0.51	H
2.8	I do not sleep well because of thinking about my child	70 (70%)	27 (27%)	3 (3%)	1.33± 0.53	H
2.9	I suffer from people look for my child	54 (54%)	42 (42%)	4 (4.0%)	1.50± 0.58	H
2.10	I feel like crying	67 (67%)	33 (33%)	0 (0.0%)	1.33± 0.47	H
2.11	I feel despair about operation	52 (52%)	40 (40%)	8 (8.0%)	1.56± 0.64	H

*Continues...***Table.3 . B. (continued)**

List	Statement	Always F (%)	Sometime F (%)	Never F (%)	Mean (SD)	level
2.12	I afraid of stay my child on his condition	58 (58%)	39 (39%)	3 (3.0%)	1.43± 0.54	H
2.13	I feel like running away	51 (51%)	49 (49%)	0 (0.0%)	1.49± 0.50	H
2.14	fear of hearing bad news about my child success operation	53 (53%)	46 (46%)	1 (1.0%)	1.48± 0.52	H
2.15	I fear from sexual relationship with my husband	11 (11%)	48 (48%)	41 (41%)	2.30± 0.66	M
2.16	I feel nervous and anxiety	30 (30%)	45 (45%)	25 (25%)	1.95± 0.74	M
2.17	I feel loss of womanhood and attractiveness	49 (49%)	49 (49%)	2 (2.0%)	1.53± 0.54	H
2.18	I hate to get out the house	61 (61%)	39 (39%)	0 (0.0%)	1.39± 0.49	H
2.19	I feel hatred toward my child because it affect my	2 (2.0%)	45 (45%)	53 (53%)	2.51± 0.54	L
2.20	I am disturbed by everything	47 (47%)	52 (52%)	1 (1.0%)	1.54± 0.52	H
2.21	I shamed from others	14 (14%)	47 (47%)	39 (39%)	2.25± 0.69	M
2.22	I feel pessimistic	25 (25%)	60 (60%)	15 (15%)	1.90± 0.63	M
	Mean				38.9± 2.86	
F= frequency    %= percentage    H= high    M= moderate    L= low    SD= standard deviation Cut-off-point: 1-1.66 = High    1.67-2.33 = Moderate    2.34-3.0 = Low						

Regarding the psychological burden this table shows that , the item # 2.3 “I thinking always in my child condition” constitutes the highest psychological burden, mean (SD) (1.06± 0.24), followed by the item # 2.5 “I fear of having another child”, mean (SD) (1.31± 0.58).

**Table 3. C. Descriptive Statistics for the Economic Burdens (N= 100)**

List	Statement	Always F (%)	Sometime F (%)	Never F (%)	Mean (SD)	level
<b>3.</b>	<b>Economic Burdens</b>					
3.1	I failing to care of my children	26 (26%)	54 (54%)	20 (20%)	1.94± 0.68	M
3.2	Underestimated buy the basic daily needs	40 (40%)	55 (55%)	5 (5.0%)	1.65± 0.58	H
3.3	We had to sell some of holding house to cover child's cost	1 (1.0%)	35 (35%)	64 (64%)	2.63± 0.51	L
3.4	I had to sell some personal things to pay my child cost	4 (4.0%)	15 (15%)	81 (81%)	2.77± 0.51	L
3.5	We reduced buying necessary things in order to save money	17 (17%)	58 (58%)	25 (25%)	2.08± 0.65	M
3.6	Ask for money to family and friends to pay my child cost	7 (7%)	30 (30%)	63 (63%)	2.56± 0.63	L
3.7	Deprived myself and family from buy necessary thing	37 (37%)	57 (57%)	6 (6.0%)	1.69± 0.58	M
3.8	I thinking to work to cover cost	0 (0.0%)	28 (28%)	72 (72%)	2.72± 0.45	L
	Mean				1.61± 1.69	M
	<b>Grand Mean</b>				94.9± 5.33	M
F= frequency    %= percentage    H= high    M= moderate    L= low    SD= standard deviation Cut-off-point for the subdomain of economic burdens: 8-13.3 = High; 13.4 – 18.7 = Moderate; 18.8 – 24.0 = Low Cut-off-point for the grand mean: 52- 86.66 = High; 86.67- 121.33 = Moderate; 121.34-156 = Low						

With respect to the economic burden this table reflects that, the item # 3.2 “Underestimated buy the daily basic needs because of my child needs” constitutes the highest economic burden, mean (SD) (1.65± 0.58).

**Table 4 . Association regards participants’ socio-demographic and medical data with social burden**

Variables	Unstandardized Coefficients		Standardized Coefficients	T	Sig.
	B	Std. Error	Beta		
<b>Mother’s age</b>	.331	.269	.151	1.229	.222
<b>Level of mother’s education</b>	-.103-	.276	-.037-	-.375-	.709
<b>Number of children in the family</b>	.819	.283	.347	2.894	.005
<b>Physician’s follow-up</b>	2.878	1.226	.255	2.348	.021
<b>Monthly income</b>	.064	.598	.011	.108	.914
<b>Child’s age</b>	.044	.525	.009	.084	.933
<b>Child’s age on diagnosis</b>	-.526-	.378	-.155-	-1.393-	.167
<b>Duration of colostomy</b>	.192	.496	.040	.387	.700
<b>Colostomy complication</b>	-.368-	.480	-.084-	-.767-	.445
<b>B= beta</b>	<b>Std= standard</b>		<b>T =t-test</b>	<b>Sig= significant</b>	

Table (4) reveals that there are significant associations between number of children in the family and physician’s follow-up and the social burden ( $p = .005, .021$ ) respectively.

**Table 5. Association regards participants’ socio-demographic and medical data with psychological burden**

Variables	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
<b>Mother’s age</b>	.214	.255	.110	.839	.404
<b>Level of mother’s education</b>	.472	.261	.192	1.813	.073
<b>Number of children in the family</b>	.185	.268	.089	.692	.490
<b>Physician’s follow-up</b>	-.583-	1.160	-.059-	-.502-	.617
<b>Monthly income</b>	-.241-	.565	-.046-	-.426-	.671
<b>Child’s age</b>	.364	.496	.084	.733	.466
<b>Child’s age on diagnosis</b>	-.128-	.357	-.043-	-.358-	.721
<b>Duration of colostomy</b>	-.322-	.469	-.076-	-.687-	.494
<b>Colostomy complication</b>	-.145-	.454	-.037-	-.320-	.750
<b>B= beta</b>	<b>Std= standard</b>		<b>T =t-test</b>	<b>Sig= significant</b>	

Table (5) shows that there is no significant association between participants’ socio-demographic characteristics and the psychological burden.

**Table 6. Association between participants' socio-demographic data and economic burden**

Variables	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
<b>Mother's age</b>	.265	.145	.232	1.831	.070
<b>Level of mother's education</b>	-.104-	.148	-.072-	-.704-	.483
<b>Number of children in family</b>	-.269-	.152	-.219-	-1.771-	.080
<b>Physician's follow-up</b>	-.766-	.659	-.130-	-1.163-	.248
<b>Monthly income</b>	-.517-	.326	-.169-	-1.584-	.117
<b>Child's age</b>	-.614-	.476	-.239-	-1.291-	.200
<b>Child's age on diagnosis</b>	.041	.424	.018	.098	.922
<b>Child's rank</b>	.138	.203	.078	.680	.498
<b>Duration of colostomy</b>	-.415-	.325	-.165-	-1.277-	.205
<b>Colostomy complication</b>	-.051-	.258	-.022-	-.199-	.843
<b>B= beta                      Std= standard                      T =t-test                      Sig= significant</b>					

Table (6) reveals that here is no significant association between participants' socio-demographic characteristics and the economic burden.

**Table 7. Association between participants' socio-demographic data and overall burden**

Variables	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
<b>Mother's age</b>	.811	.463	.225	1.752	.083
<b>Level of mother's education</b>	.263	.474	.057	.556	.580
<b>Number of children in family</b>	.744	.487	.192	1.526	.131
<b>Physician's follow-up</b>	1.566	2.111	.085	.742	.460
<b>Monthly income</b>	-.755-	1.045	-.078-	-.722-	.472
<b>Child's age</b>	.195	1.525	.024	.128	.899
<b>Child's age on diagnosis</b>	-.403-	1.359	-.054-	-.296-	.768
<b>Child's rank</b>	-.518-	.650	-.093-	-.798-	.427
<b>Duration of colostomy</b>	-.741-	1.042	-.094-	-.712-	.479
<b>Colostomy complication</b>	-.583-	.827	-.081-	-.705-	.483
<b>B= beta                      Std= standard                      T =t-test                      Sig= significant</b>					

Table (7) describes that that here is no significant association between participants' socio-demographic characteristics and the overall burden level.

**Table 8. Association between Mother's Age and Psychological Burden**

Mother's age	Psychological burden			Total	Chi-square	df	p-value
	Low	Moderate	High				
< 18 y	1	0	1	2	25.663	14	.029
18-21y	0	1	0	1			
22-25y	1	4	0	5			
26-29y	0	7	0	7			
30-33y	0	13	0	13			
34-37y	1	25	2	28			
38-40y	1	32	4	37			
> 40 y	0	7	0	7			
<b>Total</b>	4	89	7	100			

< = less than                      > = more than                      df = degree of freedom

Table (8) reveals that there is significant association between mothers' age and the level of psychological burden ( $\chi^2 = 25.663$ ; p-value = .029).

**Table 9. Association between Family S' Monthly Income and Psychological Burden**

Monthly income	Psychological burden			Total	Chi-square	Df	p-value
	Low	Moderate	High				
<b>Enough</b>	0	2	2	4	15.232	4	.004
<b>Somewhat sufficient</b>	4	53	2	59			
<b>Insufficient</b>	0	34	3	37			
<b>Total</b>	4	89	7	100			

Table (10) demonstrates that there is significant association between participants' monthly income and the level of psychological burden ( $\chi^2 = 15.232$ ; p-value = .004).

**Table 10. Correlation among Participants' Sociodemographic Characteristics and Domains of Burden**

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
1. Mother's age	-																		
2. Level of mother's education	.074	-																	
3. Mother's job	-.164	-.137	-																
4. Number of children in family	.571**	-.030	-.054	-															
5. Is father alive?	.125	.041	.062	-.039	-														
6. Parents' relationships	.123	.065	.013	-.051	.964**	-													
7. Family type	-.069	-.049	-.026	-.078	-.096	-.062	-												
8. Physician's follow-up	.011	.043	-.001	.032	-.055	-.066	.185	-											
9. Monthly income	-.041	-.049	.037	-.053	.001	-.022	.045	-.189	-										
10. Child age	-.095	-.094	.000	-.028	-.048	-.057	.131	.074	-.305**	-									
11. Child's age on diagnosis	-.099	-.032	.018	.000	-.076	-.064	.097	.156	-.336**	.734**	-								
12. Child's gender	.051	.212*	-.102	.064	.176	.194	-.115	.069	-.125	-.011	.051	-							
13. Child's rank	.437**	-.162	-.047	.430**	.074	.048	-.065	.059	.023	-.013	-.024	-.059	-						
14. Duration of colostomy	.109	-.100	-.036	.036	.066	.078	.092	-.144	-.075	.309**	-.151	-.070	.047	-					
15. Colostomy complication	.194	-.100	-.031	.231*	-.094	-.085	-.011	.404**	.003	-.063	-.078	.212*	.195	.015	-				
16. Social burden	.268**	.003	.028	.357**	-.048	-.069	-.123	.216*	-.070	.024	.028	.150	.067	.029	.103	-			
17. Psychological burden	.135	.207*	-.046	.115	-.097	-.079	-.136	-.038	-.075	.042	.040	.094	-.004	-.045	-.053	.263**	-		
18. Economic burden	.139	-.017	.040	-.051	-.010	-.012	-.085	-.102	-.057	-.244*	-.117	.148	.075	-.182	-.048	.055	.134	-	
19. Overall burden	.280**	.108	.005	.263**	-.085	-.089	-.175	.079	-.101	-.040	.001	.188	.063	-.064	.019	.768**	.740**	.423**	-

\*\***. Correlation is significant at the 0.01 level (2-tailed).**

\***. Correlation is significant at the 0.05 level (2-tailed).**

Table (8) demonstrates that mother's age positively correlates with each of social burden and the overall burden ( $r = .268^{**}$  at  $p < 0.01$ ;  $.280^{**}$  at  $p < 0.01$ ) respectively. Level of mother's education positively correlates with psychological burden ( $r = .207^*$  at  $p < 0.05$ ). Number of children positively correlates with social burden and the overall burden ( $r = .357^*$  at  $p < 0.05$ ;  $.263^{**}$  at  $p < 0.01$ ) respectively. Physician's follow-up positively correlates with social burden ( $r = .216^*$  at  $p < 0.05$ ). Child's age negatively correlates with economic burden ( $r = -.244^*$  at  $p < 0.05$ ).

## Discussion:

Table (1) describes that more than one third of mothers are within 38-40 years old ( $n= 37$ ; 37.0%), followed by those in the age group of 34-37 ( $n= 28$ ; 28.0%). A study in Baghdad about mothers of child with colostomy appears that 44% were within 30-39 years (8). Mothers' age > 35 years is risky for having a child with congenital anomalies<sup>(7 & 9)</sup>.

One third of mothers are Illiterate ( $n= 37$ ; 37.0%), this result agree with two studies in Iraq about mothers burden of child care which show 60% of them were illiterate (10 & 11). followed by those who are primary school graduate ( $n= 31$ ; 31.0%), another study in Iraqi setting for mothers of child with colostomy represent 40% primary school graduate<sup>(8)</sup>. The low educational level of mothers has certain effect in the pattern of child care<sup>(10 & 12)</sup>.

The vast majority of mothers are unemployed ( $n= 89$ ; 89.0%), and this agrees with studies in Iraq about mothers job<sup>(8, 10 & 13)</sup>.

The mean number of children in the family is 3.97, SD = 1.37; approximately one third have four children ( $n= 32$ ; 32.0%). When the majority of mothers are housewives, children's` number more than three, and the monthly income somewhat sufficient; the burden of care expected heavy.

The vast majority of children's fathers are alive ( $n= 97$ ; 97.0%) and live together ( $n= 95$ ; 95.0%), this results agree with studies in Iraq<sup>(8 & 13)</sup>. This result shows the strength of families relationships.

Most of children's families are extended ( $n= 60$ ; 60.0%). Mostly in Iraq the families' are extended, which may add advantages and disadvantages on mothers' burden. This agrees with a study about mothers care of child with colostomy in Baghdad<sup>(8)</sup>.

The vast majority of participants have

physician follow up regularly ( $n= 91$ ; 91.0%), this compatible with a study in Iraq about family burden of care appears that 98% have regular follow up<sup>(11)</sup>.

More than half of children's families have somewhat sufficient monthly income ( $n= 59$ ; 59.0%). While a study in Iraq about child with colostomy reveals that 74% and 19% have low and moderate socioeconomic status respectively<sup>(8)</sup>.

All children's families don't receive support from community organizations ( $n= 100$ ; 100.0%). Unfortunately, there is no community organizations provide any kind of support for such families in Iraq.

Most of children are within 1-4 years old ( $n= 66$ ; 66.0%), ( $n= 80$ ; 80.0%) medically diagnosed at age < 6 months, and mostly the children have a colostomy for > 1 year ( $n= 86$ ; 86.0%). While a study in Baghdad about child with colostomy shows that 54% of children have colostomy for one year, 78% have colostomy procedure after medical diagnosis<sup>(8)</sup>. The same study shows that 62% of children was male, and the result of the study shows ( $n= 76$ ; 76.0%) of the children are male also. The incidence of male more than female for hirschprung`s disease and anorectal malformation in children<sup>(7, 9 & 14)</sup>.

The mean of children's rank in the family is 3.6, SD = 0.95; and the vast majority of them are the last rank in the family ( $n= 84$ ; 84.0%). While a study in Iraq reveals that 59% of the families have the first and the second child<sup>(8)</sup>.

Finally, the most reported type of colostomy complication is skin excoriation ( $n= 70$ ; 70.0%), then enterocolitis ( $n= 25$ ; 25.0%). This agrees with a study in Baghdad about stoma complication shows that skin excoriation and prolapse were the most common complications<sup>(15)</sup>. Another study about educational aids for parent having child with colostomy show the high infant mortality

rate and death due to enterocolitis from colostomy complications <sup>(4)</sup>.

Table (2) indicated that mothers of the child with colostomy have moderate level of social, psychological, economic, and over all burden, which represent ( $n= 72$ ; 72.0%), ( $n= 89$ ; 89.0%), ( $n= 79$ ; 79.0%).and ( $n= 88$ ; 88.0%) respectively. These findings agree with a study for psychosocial burden of parents care of child with anorectal malformation shows that 34% has moderate level of psychosocial burden <sup>(3)</sup>. Another study for caregivers' burden with stoma revealed that caregivers has varying levels of caregiving burden, one third of the sample has somewhat sever burden <sup>(16)</sup>.

The results can be interpret that majority of the mothers is housewife (not employ) in table 1, which can help them to save time and money for their child and family care. In addition no effects of job`s responsibility on mothers burden.

Also the family relation and parents living together helping mothers in bearing and decreasing the burden of care. In addition they help to get the child regular follow up. In Iraq fathers mostly were responsible financially for their families. All these can decrease the mother burden.

More than half of families 59% are financially enough somewhat that help them in provide the basic live needs for the family members, also 60% live with extended families; sometime it can help them in decrease the burden by sharing the care and support for the mothers and children. In addition the medical care in that hospital is free which can decrease the economic burden. Moreover families having a child with colostomy and being together at that hospital may help them psychologically.

Table (3) demonstrates that in the social

burden subdomain, the item # 1.13 "I go outside just for bring necessary things" constitutes the highest social burden, mean (SD) ( $1.27 \pm 0.52$ ), followed by the item # 1.15 "Reduced my visiting friends" mean (SD) ( $1.20 \pm 0.43$ ). Regarding the psychological subdomain, the item # 2.3 "I thinking always in my child condition" constitutes the highest psychological burden, mean (SD) ( $1.06 \pm 0.24$ ), followed by the item # 2.5 "I fear of having another child", mean (SD) ( $1.31 \pm 0.58$ ). With respect to the economic subdomain, the item # 3.2 "Underestimated buy the daily basic needs because of my child needs" constitutes the highest economic burden, mean (SD) ( $1.65 \pm 0.58$ ).

Poor social network, feeling loneliness, and caring for ill\disable child were significant predictors of higher burden. Marital status (married) and low frequency of meeting friends were significant results in some indices <sup>(3)</sup>. Families with a disable\ill child experience life differently from other families. Their sleep is affected. Holidays and vacations are affected, as it is difficult to plan activities. Mothers appear to carry the larger burden of care, though fathers are not unaffected. Though parents may feel trapped and isolated and experience a loss of freedom, their need to survive as a family continues to motivate them. Parents may feel a need to be with their child at all times and experience stress related to coping with the heavy load of caregiving. The extended burden of caregiving can also have adverse health effects on them. In addition to the caregiving burden, parents experience role conflicts, financial burdens, and the struggle between independence in providing care and the isolation associated with it. It is very difficult to enjoy spontaneous events outside the home because so much planning is necessary <sup>(9)</sup>.

Table (4) reveals that there are associations

between number of children in the family and physician's follow-up with the social burden ( $p = .005, .021$ ) respectively. In table 1 we can see that most of the families have 3-5 children and vast majority have regular physician's follow-up which can participate socially in overload the burden on the mothers.

A study about psychosocial experiences for parents of child with imperforate anus revealed that social burden was more affected among mothers <sup>(17)</sup>. Also limited social interaction, motherhood responsibilities and low frequency of meeting friends are increased social burden <sup>(3)</sup>. Recreational activities and vacations of parents with a disable\ill child will be affected, feeling of isolated and experience a loss of freedom can lead to heavy load of caregiving <sup>(9)</sup>.

Table (5, 6 and 7) reveals that there is no association between participants' psychological, economic and the overall mothers burden with the socio-demographic characteristics.

All children and families manage living with a stoma slightly differently and adapt their lives in different ways. Having a stoma does not need to dominate family life, but this often need negotiation within families <sup>(4)</sup>. In addition, caring for the ill\disable child at home (rather than having the child in a facility) may decrease the parents' burden <sup>(9)</sup>.

A study about parental burden of child with congenital anomalies shows low financial impact on them <sup>(18)</sup>. In addition, home care decreases financial costs, travel costs, and caregiver burden <sup>(7)</sup>.

Table (8) There is an association between mothers' age and the level of psychological burden ( $\chi^2 = 25.663$ ;  $p$ -value = .029). The mothers within 34-40 years are representing 65% (table 1). This agrees with a study about

anxiety and quality of life of parent with children has anorectal malformation reflect that the psychological domain of mothers with infants is higher than older children. This may be explained by coping strategies <sup>(19)</sup>.

Some parents may adapt over time and ultimately accept the child's illness or disability. Others may not accept their child's condition and experience the continual fading and re-emergence of chronic sorrow. They experience a multitude of emotions and changes in their lives. They worry about their child's and family's well-being, and as experts in their child's care often feel burdened with continual care. Though willing to carry the burden, they may experience fear, anger, sadness, guilt, frustration, or resentment. Many parents experience grief as a result of losing the perfect child of which they dreamed <sup>(9)</sup>.

Table (9) There is an association between participants' monthly income and the level of psychological burden ( $\chi^2 = 15.232$ ;  $p$ -value = .004). More than half of the families 59% have somewhat enough monthly income and majority of mothers are housewives. Caring for children with medical needs can be overwhelming for some families. Financial issues can become a large burden. Having one parent at home full time and not earning an income can contribute to increased financial strain, not to mention social isolation of that parent. All of these can lead to increased stress on family members <sup>(9)</sup>.

Table (10) demonstrates that mother's age positively correlates with each of social burden and the overall burden ( $r = .268^{**}$  at  $p < 0.01$ ;  $.280^{**}$  at  $p < 0.01$ ) respectively. This result agrees with a study about mothers' burden with their age in Iraq, that there was a highly significant association between them <sup>(10)</sup>. More than one third of the family 37% within 38-40 years, 32% have 4 children, 59%

with somewhat enough monthly income shows in table 1. These characters can effect on mothers socially (vocation, recreational activities, visiting friends and family).

Level of mother's education positively correlates with psychological burden ( $r = .207^*$  at  $p < 0.05$ ). Mothers who have low levels of education are less likely to provide care for their ill child<sup>(3 & 10)</sup>. More than one third of them 37% reads and writes and 31% has primary school graduation. Unfortunately, this low level of education is effect on mothers' knowledge and attitudes about their child condition. They feel that their child has impact on their duties, different from others, do not sleep well, like crying, running away from reality show table 2.

Number of children in family positively correlates with each of social burden and the overall burden ( $r = .357^*$  at  $p < 0.05$ ;  $.263^{**}$  at  $p < 0.01$ ) respectively. In Iraq most of the mothers have 3-5 children (table 1). This will lead to increase the pressure load of care and burden on mothers. Especially more than half of them have somewhat enough income which can increase the burden. This agree with a results revealed that the low socio-economic status and having more than two children with a disable\ill child will be associated with family burden<sup>(20)</sup>.

Physician's follow-up positively correlates with social burden ( $r = .216^*$  at  $p < 0.05$ ). The vast majority of the mothers have regular follow up, majority of colostomy duration is > one year, and most of them have 3-5 children table 1. These findings lead to increase social burden and decrease vocation, recreational activities, visiting friends and family.

Ultimately, child's age negatively correlates with economic burden ( $r = -.244^*$  at  $p < 0.05$ ). when child's age more than one year the economic burden increase, 66% of children

age is within 1-4 years and more than half of the families have somewhat enough monthly income.

### Recommendation:

The study recommended that:

1. Mothers of child with colostomy experience a multitude of emotions and changes in their lives, often carrying caregiving burden.
2. They become the experts on their child's care and should be empowered and supported in their efforts.
3. The level of mothers' education should be increase and awareness about family planning.

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