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Burden of Care among Mothers of Children with Congenital Heart Disease at Tertiary Hospitals, Addis Ababa, Ethiopia

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Addis Ababa, Ethiopia

February, 2024

Abstract

Background- Congenital heart disease is a problem with structure of the heart that a child born with. Mothers play a key role in caring for their sick children. Their experiences of care were influenced by culture, rules, financial and the system of health and care services.

Objective- To assess burden of care among mothers of children with congenital heart disease at Tertiary Hospitals, Addis Ababa, Ethiopia

Methods- A cross-sectional descriptive study is conducted through Zarit Burden Interview (ZBI), taken from similar study and socio-demographic factors was used to assess the burden of care among caregivers having children with CHD, starting at October 2023 to January 2024, care givers whose child is a range of 0- 18 years are included.

Results- 51% of mothers have moderate to severe burden, using multinomial regression model, , the finding revealed that Women whose age ≥ 30 years had 1.2 folds increase in its mild to moderate burden than little or no burden. Those who have high income had 59% less likely of mild to moderate burden compared to little burden. The study participant who were from rural area were 3.5 folds increase the chance of mild to moderate burden than little or no burden. Participants having higher education level were 47% less likely of developing severe burden.

Conclusion- CHD is associated with a significant caregivers' disease burden. Care givers education status, living at urban areas, and better income level were associated with less burden of care.

Key words- Burden of care, associated factors, congenital heart disease, zarit burden interview

Acknowledgements

First of all I would like to thank GOD for everything and SPHMMC department of pediatrics for accepting my research topic and giving me a greater opportunity to practice this clinical research.

My deepest gratitude goes to my advisor Dr. Temesgen Tsega for taking his time and agreeing to advise me in the whole process of research.

Abbreviations/Acronyms

CHD Congenital heart disease

DS.....Down syndrome

SPHHMC...St Paul Hospital Medical Millennium College

HRQOL.....Health Related Quality of Life

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1. INTRODUCTION

1.1 Back ground

Congenital heart disease (CHD) is a group of structural and functional abnormalities that occur during cardiac embryogenesis and is the most common type of birth defect, accounting for one third of all major congenital anomalies(1).

The prevalence of congenital cardiac disorders varies by location and country. The prevalence in North America is 8.1 per 1000 live births, while it is 9.3 per 1000 live births in Asia (2).

Every year in Africa, an estimated 500,000 children are born with CHD, with Sub-Saharan Africa accounting for the majority of these cases. (3).

CHD is a leading cause of pediatric hospitalizations, medical expenditures, and infant mortality(4). The burden of care refers to the perceived caregiver's sufferings in terms of emotional or physical health, social and financial life, due to caring for loved ones(5).

Careers of children with complex health issues reported worse overall health and more depressive symptoms than careers of children with less complex health issues. (6). Parental caregiving burden, dissatisfaction with care, social isolation, and financial instability were associated with an increased risk of long-standing psychosocial morbidity(7)(8)(9).

Caregivers also experience guilt and often wrongly blame themselves(7). The burden of care is strongly related to caregiver age, CHD severity, and type(10). CHD is typically diagnosed in the perinatal period or early infancy, adding stress to an already challenging transition(11).

The early stages of illness can place high demands on caregivers, especially parents, whose psychosocial coping skills can be tested from diagnosis through childhood, including surgeries (12).

Children with CHD often require specific care related to nutrition, feedings, and intensive medication regimens due to the chronic and complicated nature of the disease, which can lead to

a need for physical, emotional, and social support in various stages of life (13). This burden of care typically falls on family members, particularly parents. However, the fear of an uncertain future for the child, treatment plans, and prognosis can also result in psychological issues, especially for the mother (14)

1.2 Statement of the problem

While the challenges faced by children with congenital heart disease (CHD) have been the primary focus of research, it is important to recognize that it is the parents who assume the role of primary caregivers and carry the greater burden of care throughout the entire period of their child's illness(15).

The discovery of CHD can lead to heightened tension during pregnancy and necessitate immediate medical interventions following birth, placing a significant burden on parents.

They must navigate numerous challenges, including doctor's appointments, screenings, potentially life-threatening interventions such as open-heart surgery, prolonged hospital stays and care, multiple surgeries, developmental delays, near-death experiences, and even death(10)(16). This can be an incredibly difficult trial for families who must provide both medical and emotional care for their newborn child(17).

Parents often experience financial instability due to unemployment, sick leave, and the high medical costs associated with caring for their children, resulting in a decreased standard of living(18).

As a result, they report lower quality of life and difficulties coping with everyday activities due to emotional distress(19). This burden has a negative impact on parental psychosocial adjustment and persists throughout the child's life for.

As a result, parents of children with CHD are at a higher risk of experiencing emotional distress, feelings of hopelessness, and even suicidal ideation, with mothers showing particularly high levels of distress, anxiety, and social isolation compared to non-depressed individuals(17).

Moreover, many children with CHD also have comorbidities, such as developmental delays or other congenital anomalies that further add to the complexity and cost of care.

Previous studies have also highlighted the challenges faced by parents in coping with their child's illness, particularly mothers of newborns with CHD who must manage demanding emotional and hands-on care responsibilities.

Mothers with children with complex CHD experience additional obstacles and emotional responsibilities, while their children face physical and psychological challenges as the disease progresses. while decreasing for father over times.(17)

Therefore this research assesses burden of care and associated factors among mothers having children with CHD, and it will help for future problem solving issues for the caregivers.

1.3Significance of the study

In sub-Saharan communities, the responsibility of child-care and upbringing typically falls on mothers, who may face discrimination for having a child with congenital birth defects. In some cases, this discrimination can even lead to dissolution of marriage.

We hypothesize that the added stress of knowing that invasive treatments for congenital heart disease are not readily available in the country could exacerbate the anxiety experienced by these mothers.

Despite CHD being the second most prevalent chronic illness in childhood, little research has been conducted on its family impact.

These factors are expected to incur different types of burden to parents and such similar studies will come up with recommendations to establish a multidisciplinary team in the management of CHD and will also provide information to policy makers and clinicians to scale up the current services for such patients.

2. LITERATURE REVIEW

The incidence of congenital heart defects is commonly reported to be between 4 and 10 per 1000 live births, with a peak around 8 per 1000 live births(16)(20).

Factors such as financial burden from travel and medical costs, difficulty interacting with those outside the family, emotional turmoil from a sense of isolation, and increased risk for depression or mental health problems are important considerations for families (10).

Each parent has a unique reaction and varying levels of anxiety, but mothers tend to be more strongly affected by their child's CHD than fathers(21).

Additionally, another study found that mothers are at a higher risk for chronic psychosocial problems, including depression, anxiety, somatization, and feelings of hopelessness (18).

Studies analyzing gender differences and the impact of health status and total workload have shown that mothers in Sweden tend to take on greater responsibility for childcare than fathers (19).

The patients described their experiences as coping with a new sense of normalcy, feeling powerless as their health deteriorates, struggling through long medical procedures, and finally establishing new routines (22).

They also commented on the load of childcare, the stress caused by the disease, and the difficulties of the care process.(12)(13) (17).

Specifically a study of disease burden among caregivers of children with congenital heart disease done at Tehran, Iran 2023, mothers suffered from moderate-to severe burden, and, the mean caregiver's burden (ZBI score) was in the range of moderate-to-severe disease burden.

In the above study, the siblings' number and level of caregiver's education had a significant relationship with the caregivers' psychological burden(23).

Same study but with different assessment tool done at Nepal shows mothers having children with CHD have high burden of care; those age less than 30 years, having children up to 2 years, and those having cyanotic CHD are likely to experience high burden(10).

In similar studies assessing the care burden on caregivers of other chronic illnesses, most experienced moderate-to-severe disease burden like care givers of Type 1 DM, down syndrome and even care givers of adults with disability mental illnesses and (24)(25).

A study conducted at Tikur Anbesa Hospital 7 years ago on the health-related quality of life of mothers of children with congenital heart disease found that these mothers had lower performance in all domains of health-related quality of life compared to mothers of children with minor acute illnesses (16).

3. OBJECTIVE

3.1 General objective

Burden of care among mothers of Children with Congenital Heart Disease at Tertiary Hospitals, Addis Ababa, Ethiopia.

3.2 Specific objectives

To assess:

- Type of burden
- Severity of the burden
- And those contributing factors for the occurrence at tertiary hospitals, Addis Ababa, Ethiopia.

4. METHODOLOGY

4.1 Study setting

St. Paul Hospital Millennium Medical College (SPHMMC), situated in Gullele Sub-City, Addis Ababa, is the second largest public hospital in Ethiopia.

It was constructed by Emperor Haile Selassie in 1969 with a mission to offer preventive, promotion, curative, and rehabilitative healthcare services in the country.

The Pediatrics inpatient unit comprises 107 beds and serves an average of 1942 emergency and outpatient clients monthly, with a catchment population of over 5 million. The cardiology unit provides both inpatient and outpatient services, although it does not have a separate ward.

The outpatient unit sees an average of 20 patients weekly, and there is no separate unit for inpatient care.

Children cardiac center is also selected, because it has the largest cardiac follow up clinic and a better patient load as it is the primary referral hospital across all over the country, which is the only center for children with heart disease in Ethiopia. It is the only place, they get corrective surgery for CHD.

4.2 Study design

An institution-based cross-sectional study done from October 2023 to January 2024

4.3 Source population

Those pediatric patients with CHD, admitted in the hospital or being followed at cardiac follow up clinic and being attended by their mothers.

4.4 Study population

Mothers coming with their child to pediatrics cardiac units in the study period.

Inclusion criteria

Mothers coming with their child to pediatrics cardiac units in the study period.

Exclusion criteria

- Another child with pervasive developmental disorders such as autism, pervasive genetic disorders, Down syndrome, and intellectual disability.
- The child with CHD and other comorbid illnesses
- Those who are not attended by mothers

4.5 Sample size

Because there is no study done on assessment of burden of care among mothers of children with congenital heart disease as a country level, I took the p value of participating patients as 50%(0.5). With 95% confidence level and 0.05 margin of error a sample size is calculated by using single proportion formula as :

$$n = (Z)^2 (p)(1-p)/d^2 = (1.96)^2 (0.5)(1-0.5) / (0.05)^2$$

$$n = 384 \text{ patients, } 10 \% \text{ non-response rate added} = 422$$

Adjusted sample size

$$= n / 1 + (n-1)/N$$

$$= 422 / 1 + (384-1)/1350$$

= 322, and 301 were interred for analysis (response rate is >91%), 21 were interrupted the interview or were not volunteer at all.

4.6 Sampling procedure

All mothers of children with congenital heart disease at follow up cardiac unit will be included in the study unit.

4.7 Study variables

Dependent variable:

- Burden of care

Independent variable

- Age
- Sex
- Monthly income
- Area of living
- Type of CHD
- Marital status
- Education level
- Type of burden

4.8 Data collection procedure

A semi-structured interview questionnaire is utilized to evaluate burden of care among mothers of children with congenital heart disease. Zarit Burden Interview Questioner (ZBI) is used for disease burden assessment. It is the most common tool for measuring disease burden. This questionnaire includes 22 questions about the psychological burden and personal, social, emotional, and economic pressures. Each question has a range from 0 to 4: (0), rarely (1), sometimes (2), often (3), and always (4). The results of this questionnaire are based on the sum of the scores. The total score obtained by caregivers shows the amount of stress and the psychological burden they have endured in an estimated range between 0 and 88. A higher score indicates a higher burden of disease.

After data collection, accuracy will be reviewed before encoding and analysis using SPSS version 26.

4.9 Data Processing, Management and Analysis

Data was entered to EPI Info 7 for database construction and exported to SPSS version 26 software package for analysis.

Associations between dependent and independent variables are assessed by multinomial regression model. The result of this study is presented using frequencies, proportions, figures and tables.

4.10 Operational definitions:

- Burden of care... physical, emotional, social, and financial problems that can be experienced by family caregivers.
- Comorbid illness- when a person has more than one illness or condition at the same time.
- 0-20: Little or no burden
21-40: Mild to moderate burden
41-60: Moderate-to-severe burden
61-88: Severe burden
- Congenital heart diseases...Defect in the structure of the heart or great vessels that is present at birth and confirmed by echocardiogram.
 - ✓ Illiterate- no formal education
 - ✓ Low-those learned up to elementary school
 - ✓ Intermediate-those learned up to high school
 - ✓ High- college and above

4.11 Ethical consideration

Before the actual data collection started a clearance from the institutional review board (IRB) of SPHMMC was obtained.

The purpose of the study and the right to participate and refuse were informed to the study participant during data collection.

Verbal consent from each study participant was obtained and confidentiality of the information assured.

4.12 Dissemination of findings

The result of this research will be submitted to St Paul Hospital Millennium Medical College.

If any need arises from this study, it can be used as a reference and presented to any authority.

5. RESULTS

Socio-demographic characteristics of the mother

In this study, 301 patients with their mothers who met the inclusion criteria were included. 55% of mothers are >30 years age and 38.2% has monthly income of 3201-5250 ETB. 62% of mothers are Christians in religion and 79.7% lives at urban. 88% of the partner are married and 32.9% leaned higher education level.

Table 1: The socio-demographic characteristics of the mother having CHD children who have follow up at SPHMMC and children cardiac center, 2023/4.

Variables	frequency	Percent
Age of the mother in years		
<30	135	44.9
>30	166	55.1
Total	301	100
Family income in months		
<3200	60	19.9
3201-5250	115	38.2
5251-7800	25	8.3
7801-10900	63	20.9
>10900	38	12.6
Total	301	100
Religion		
Christian	185	61.5
Muslim	96	31.9
Others	20	6.6
Total	301	100

Area of living		
Rural	61	20.3
Urban	240	79.7
Total	301	100
Marital status		
Married	250	88.1
Single	8	2.7
Separated	35	11.6
Widowed	8	2.7
Total	301	100
Educational status		
Illiterate	50	16.6
Low	57	18.9
Intermediate	95	31.6
High	99	32.9
Total	301	100

Socio-demographic characteristics of children

Almost 44% of children are in a range 1-5 years and 50.8% of children are male and 62.5% are in consecutive birth order. 71% of the participants has acyanotic heart disease and the mean age of the child at diagnosis were 9.16months and 8% of children were managed surgically.

Table 2: Socio-demographic characteristics of a children having congenital heart disease

Variables	frequency	Percent
Age of the child		
0-2 month	14	4.7
2 month-1 year	83	27.6
1-5 years	131	43.5
>5 years	73	24.3
Total	301	100
Sex of the child		
Male	148	49.2
Female	153	50.8
Total	301	100
Birth order		
1 st born	113	37.5
Consecutive born	188	62.5
Total	301	100
Type of CHD		
A cyanotic	213	70.8
Cyanotic	88	29.2
Total	301	100

Age of CHD diagnosis in month		
Minimum	0.03	
Maximum	156	
Mean	9.16	
Surgery		
Done	24	8
Not done	277	92
Total	301	100

Burden of care among mothers of children with CHD

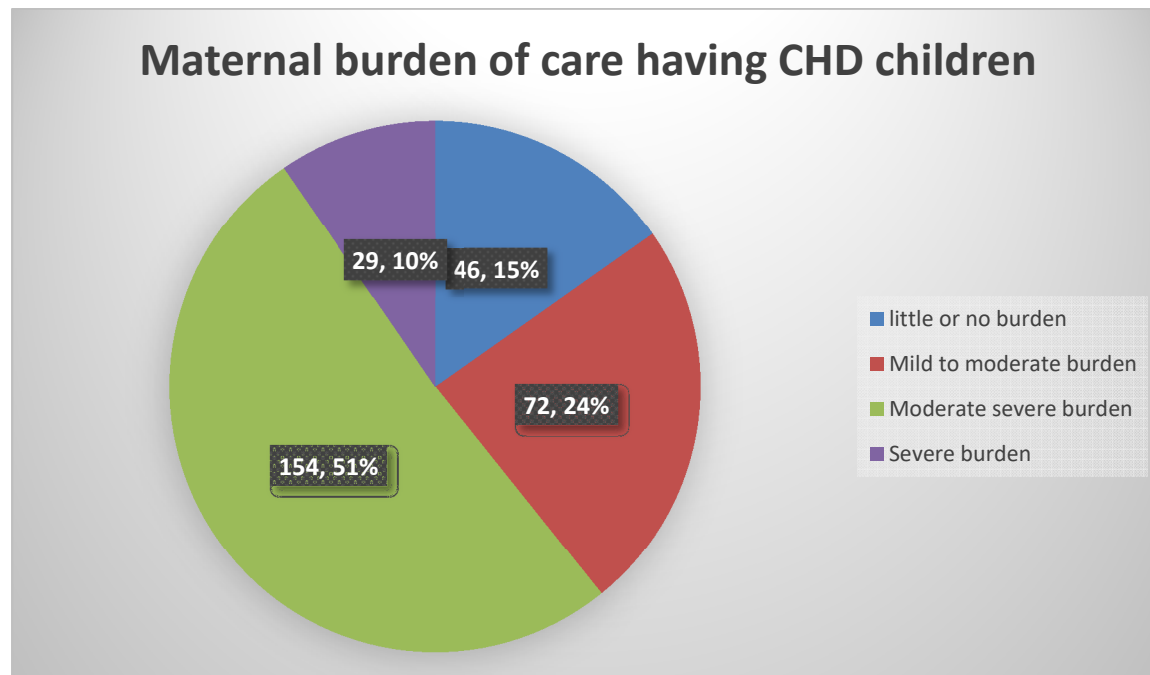


Figure 1- The burden of care among mothers of children with congenital heart disease in the two tertiary hospitals, Addis Ababa.

Regarding to the specific level of burden assessment, 68.4 % of them feel always they should do more for their child, 48.2 % feel always they could do a better job in caring for their child, 34.2% of the participants feel always when their child asks for more help than their need, 32.6% of them always feel uncertain about what to do about their child, 25.6% of the participants feel due to spend more time with child than giving time for their self. 6.6% of the mothers always affect their relationship with other family members or friends in a negative way due to caring with their child as shown in the table below.

Table 3- The Burden of Care among Mothers of Children with Congenital Heart Disease

Variable	Response (score)				
	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
Do you feel that your child asks for more help than he/she needs?	49(16.3%)	22(7.3%)	84(27.9%)	43(14.3%)	103(34.2%)
Do you feel that because of the time you spend with your child that you don't have enough time for yourself?	139(46.2%)	23(7.6%)	77(25.6%)	26(8.6%)	36(12%)
Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?	94(31.2%)	28(9.3%)	107(35.5%)	22(7.3%)	50(16.6%)
Do you feel embarrassed over your child's behavior?	229(76.1%)	22(7.3%)	32(10.6%)	6(2%)	12(4%)
Do you feel angry when you are around your child?	142(47.2%)	26(8.6%)	60(19.9%)	20(6.6%)	53(17.6%)
Do you feel that your child currently affects your relationships with other family members or friends in a negative way?	94(31.2%)	36(12%)	135(44.9%)	16(5.3%)	20(6.6%)
Are you afraid what the future holds for your child?	67(22.3%)	12(4%)	58(19.3%)	67(22.3%)	97(32.2%)
Do you feel your child is dependent on you?	181(60.1%)	26(8.6%)	27(9%)	35(11.6%)	32(10.6%)
Do you feel strained when you are	133(44.2%)	17(5.6%)	100(33.2%)	13(4.3%)	38(12.6%)

around your child?					
Do you feel your health has suffered because of your involvement with your child?	92(30.6%)	14(4.7%)	74(24.6%)	72(23.9%)	49(16.3%)
Do you feel that you don't have as much privacy as you would like because of your child?	80(26.6%)	12(4%)	82(27.2%)	74(24.6%)	53(17.6%)
Do you feel that your social life has suffered because you are caring For your child?	76 (25.2%)	13(4.3%)	99(32.9%)	54(17.9%)	59(19.6%)
Do you feel uncomfortable about having friends over because of your Child?	155(51.5%)	14(4.6%)	77(25.6%)	15(5%)	40(13.3%)
Do you feel that your child seems to expect you to take care of him/her as if you were the only one he/she could depend on?	52(17.3%)	29(9.6%)	135(44.9%)	52(17.3%)	33(11%)
Do you feel that you don't have enough money to take care of your child in addition to the rest of your expenses?	52(17.3%)	10(3.3%)	61(20.3%)	94(31.2%)	84(27.9%)
Do you feel that you will be unable to take care of your child much longer?	111(36.9%)	22(7.3%)	51(16.9%)	22(7.3%)	95(31.6%)
Do you feel you have lost control of your life since your child's illness?	98(32.6%)	23(7.6%)	59(19.6%)	64(21.3%)	57(18.9%)
Do you wish you could leave the care of your child to someone else?	161(53.5%)	22(7.3%)	16(5.3%)	86(28.6%)	16(5.3%)

Do you feel uncertain about what to do about your child?	90(29.9%)	29(9.6%)	55(18.3%)	29(9.6%)	98(32.6%)
Do you feel you should be doing more for your child?	11(3.7%)	7(2.3%)	29(9.6%)	48(15.9%)	206(68.4%)
Do you feel you could do a better job in caring for your child?	18(6%)	10(3.3%)	33(11%)	95(31.6%)	145(48.2%)
Overall, how burdened do you feel in caring for your relative?	59(19.6%)	19(6.3%)	87(28.6%)	38(12.6%)	98(32.6%)

The multinomial regression of association between burden of care and independent variable

In this study the strength of association between outcome and independent variable was measured using multinomial regression. So, the finding revealed that Women whose age ≥ 30 years had 1.2 folds increase its mild to moderate burden than little or no burden. Study participant whose monthly income of >10900 ETB had 59% less likely of mild to moderate burden compared to little burden. The study participant who was from rural area were 3.5 folds increase the chance of mild to moderate burden than little or no burden. The study participant having higher education were 63% decrease the chance of moderate to severe burden compared to little or no burden.

The study participant whose income of >10900 ETB were 68% less chance of severe burden and participant having higher education level were 47% less likely of developing severe burden. While participant whose education level of low were 4.8 folds increase its severe burden compared to little or no burden and study participant who were from rural area were 6.2 folds increase its chance of developing severe burden than little burden.

Table 4- The multinomial regression of association between independent and severity of burden among mothers of children with CHD.

Severity of burden		Sig.	Exp(B)	95% Confidence Interval for Exp(B)	
				Lower Bound	Upper Bound
mild to moderate burden					
Age mothers	<30	0.164	0.54	0.225	1.288
	>30	0.012	1.2	1.110	7.212
Family monthly income	<3200	0.374	0.46	0.084	2.535
	3201-5250	0.067	0.16	0.030	4.806
	5251-7800	0.054	0.06	0.007	1.570

	7801-10900	0.866	1.20	0.141	10.241
	>10900	0.004	0.41	0.321	0.771
Area of living	Rural	0.048	3.46	1.960	12.521
	Urban	0.432	0.12	0.014	2.132
Education status	illiterate	0.608	1.4	0.376	5.332
	Low	0.341	1.8	0.530	6.257
	Intermediate	0.961	1.02	0.400	2.619
	High	0.231	1.21	0.321	4.543
Sex of child	Male	0.453	1.4	0.603	3.110
	Female	0.576	0.13	0.123	12.45
Birth order	1 st born	0.519	1.3	0.565	3.104
	Consecutive born	0.234	3.2	0.121	8.14`
Type of CHD	A cyanotic	0.352	0.62	0.229	1.689
	Cyanotic	0.131	3.2	0.032	9.124
Moderate to severe burden					
Age of the mothers	<30	0.556	0.79	0.368	1.712
	>30	0.114	2.0	0.342	8.0231
Family monthly income	<3200	0.128	0.27	0.052	1.449
	3201-5250	0.115	0.28	0.059	1.361
	5251-7800	0.260	0.36	0.061	2.129
	7801-10900	0.304	2.9	0.375	23.182
	>10900	0.341	0.31	0.123	8.143
Area of living	Rural	0.184	2.3	0.678	7.538
	Urban	0.231	0.22	0.031	7.122

Education status	illiterate	0.289	1.9	0.573	6.456
	Low	0.187	2.1	0.699	6.283
	Intermediate	0.588	1.3	0.548	2.888
	High	0.012	0.37	0.124.	0.879
Sex of child	Male	0.888	0.9	0.455	1.979
	Female	0.421	3.12	0.34	23.13
Birth order	1 st born	0.701	0.86	0.403	1.841
	Consecutive born	0.221	4.22	0.645	12.356
Type of CHD	A cyanotic	0.079	0.45	0.188	1.096
	Cyanotic	0.113	6.23	0.05	9.922
Severe burden					
Age of the mothers	<30	0.072	0.33	0.101	1.102
	>30	0.134	0.33	0.232	4.111
Family monthly income	<3200	0.076	0.08	0.010	4.614
	3201-5250	0.071	0.10	0.018	2.600
	5251-7800	0.211	0.14	0.211	1.230
	7801-10900	0.674	0.61	.060	6.167
	>10900	0.012	0.32	0.232	7.120
Area of living	Rural	0.015	6.2	1.422	27.357
	Urban	0.131	0.25	0.23	7.234
Education status	illiterate	0.419	2.0	0.372	10.764
	Low	0.040	4.8	1.077	21.173
	Intermediate	0.792	1.2	0.300	4.855
	High	0.012	0.53	0.210	0.789

Sex of child	Male	0.455	1.5	0.518	4.335
	Female	0.212	0.87	0.212	6.123
Birth order	1 st born	0.358	0.57	0.175	1.877
	Consecutive born	0.213	1.54	0.361	14.156
Type of CHD	A cyanotic	0.334	0.53	0.147	1.917
	Cyanotic	0.054	3.12	0.421	6.135

a. The reference category is: little or no burden.

6. DISCUSSION

In this study finding the burden of mothers having children with CHD showed that 10% and 51%, of the mother had severe and moderate to severe burden respectively. This finding is consistent with the study done in Tehran, Iran(23). In similar studies examining the burden of disease on caregivers of other chronic illnesses, most caregivers experienced moderate-to-severe disease burden(25)(24).

Having a child with CHD can affect the dynamics within the family. Mothers may need to juggle the needs of their CHD child with those of other family members, which can strain relationships and create tension. This was evidenced by the specific burden assessment tool of 6.6% of the mothers always affect relationships with other family members or friends in a negative way due to waiting with their child.

The finding also showed that 18.9% of the women were always feel of lost control of their life since their child's illness. This is consistent with the study done in Tikur Anbessa on quality of life(16).

The finding of the study also showed that women whose age ≥ 30 years had 1.2 folds increase its mild to moderate burden than little or no burden. The finding was discordant with the study done in Nepal (10). This difference was may be due to the socio-demographic difference, tool difference and the population difference.

Study participant whose monthly income of >10900 ETB had 59% less likely of mild to moderate burden compared to little burden. This was may be due to higher income levels often afford better access to quality healthcare services. Financial strain can exacerbate the burden on mothers of children with CHD.

The study participant who was from rural area were 3.5 folds increase the chance of mild to moderate burden than little or no burden. This was may be due to the fact that rural areas often lack access to specialized medical facilities and healthcare providers, including pediatric cardiologists and cardiac surgeons who specialize in treating CHD, supportive services and a need to travel long distances to access these facilities..

The study participant having higher education were 63% decrease the chance of moderate to severe burden compared to little or no burden and disease burden was more influenced by concerns of disease progression than the disease type and is consistent with a study in Iran(23). This was may be due to the fact that higher levels of education often correlate with better access to information about medical conditions, treatment options, and support services.

7. CONCLUSION

This study found that most mothers have moderate to severe burden (51%).

Care givers education status, living at urban areas, and better income level were associated with less burden of care.

8. LIMITATION OF THE STUDY

It is cross-sectional study and didn't show cause-effect relationship, mothers were not screened for other comorbid illnesses, which may in turn increase the disease burden.

For the future studies fathers and other primary care givers might need to be included.

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10. ANNEXES

Annex I

Participants Information Sheet and Informed Voluntary Consent Form for Participants

Selected for the Study.

My name is_____ I am working as data collector for the study being conducted on burden of care among caregivers having children with congenital heart disease; I kindly request you to lend me your attention to explain you about the study.

Study title-: burden of care among care mothers having children with congenital heart disease at cardiac follow up clinic, SPHMMMC and TASH Addis Ababa, Ethiopia.

Purpose: The study will be helpful to assess the burden of care among mothers having children with CHD.

Procedure and duration: There are about 31 questions to be answered where I fill the questioner by interviewing you. The interview will take around 30 minutes.

Risks and Benefits: There are about 31 questions to be answered where I fill the questioner by interviewing you. The interview will take around 30 minutes. The risk of being participating in this study is very minimal, except taking some minutes, for the interview, there is no other risk that you will face. By participating in this study you will not get direct benefit but the outcome of this study will be useful tool for decision making.

Confidentiality: The information, which you provide us, will be confidential. There will be no information that will identify you. The finding of study will be general for the study population and will not reflect any thing particular of individual person. The questionnaire will be coded to exclude showing names; no references will be made in oral or written reports that could link participants to the research.

Right: Participation in this study is voluntary. You have the right to declare not to participate in this study.

Contact address: If you have any questions or inquiries about the study or the procedures, please contact and communicate with Principal investigator at any time With this address :- Dr Getinet Awoke:- +251913019536, **getinemiruaweke98@gmail.com**

Declaration of informed voluntary consent:

I have clearly understood the purpose of the research, the procedure, risks and benefits, issues of confidentiality rights of participating and contact address for any queries. I have given the opportunity to ask questions for things that may have been unclear. I am informed on that I have the right to withdraw from the study at any time; Therefore, I declare my voluntary consent to participate in this study with my signature.

Name and signature of the participants: -----date-----/-----/

Name and signature of data collector: -----date-----/-----/

Participant interview questionnaires

Questions	Score
1 Do you feel that your child asks for more help than he/she needs?	0 1 2 3 4
2 Do you feel that because of the time you spend with your child that you don't have enough time for yourself?	0 1 2 3 4
3 Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?	0 1 2 3 4 0 1 2 3 4
4 Do you feel embarrassed over your child's behavior?	0 1 2 3 4
5 Do you feel angry when you are around your child?	0 1 2 3 4
6 Do you feel that your child currently affects your relationships with other family members or friends in a negative way?	0 1 2 3 4
7 Are you afraid what the future holds for your child?	0 1 2 3 4
8 Do you feel your child is dependent on you?	0 1 2 3 4
9 Do you feel strained when you are around your child?	0 1 2 3 4
10 Do you feel your health has suffered because of your involvement With your child?	0 1 2 3 4
11 Do you feel that you don't have as much privacy as you would like because of your child?	0 1 2 3 4
12 Do you feel that your social life has suffered because you are caring For your child?	0 1 2 3 4
13 Do you feel uncomfortable about having friends over because of your	0 1 2 3 4

Child?	
14 Do you feel that your child seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0 1 2 3 4
15 Do you feel that you don't have enough money to take care of your child in addition to the rest of your expenses?	0 1 2 3 4
16 Do you feel that you will be unable to take care of your child much longer?	0 1 2 3 4
17 Do you feel you have lost control of your life since your child's illness?	0 1 2 3 4
18 Do you wish you could leave the care of your child to someone else?	0 1 2 3 4
19 Do you feel uncertain about what to do about your child?	0 1 2 3 4
20 Do you feel you should be doing more for your child?	0 1 2 3 4
21 Do you feel you could do a better job in caring for your child?	0 1 2 3 4
22 Overall, how burdened do you feel in caring for your relative?	0 1 2 3 4

Socio-demographic variables of a mother

		Level of burden			
Variables					
Age of the mother	<30				
	>30				
Income	<3200				
	3201-5250				
	5251-7800				
	7801-10900				
	>10900				
Religion	Christian				
	Muslim				
	Others				
Area of living	Rural				
	Urban				
Marital status	Married				
	Single				
	Separated				
	Widowed				
Educational	illiterate				

status	Low				
	Intermediate				
	High				

Socio-demographic variables of a child

		Level of burden			
Variables					
Age of the child	0-2 month				
	2 month-1 year				
	1-5 years				
	>5 years				
Sex of the child	M				
	F				
Birth order	1 st born				
	Consecutive born				
Type of CHD	A cyanotic				
	Cyanotic				
Age of CHD diagnosis					
Surgery	Done				
	Not done				

