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BURDEN OF CARE AND ITS ASSOCIATED FACTORS IN MOTHERS OF PRETERM BABIES SEEN AT A NEONATAL INTENSIVE CARE UNIT IN ILORIN, NIGERIA

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ABSTRACT

Background: Mothers of preterm babies, especially those who have their babies admitted in the neonatal intensive care unit experience psychological upheavals associated with caring for their babies which may negatively impact on the quality of care they give.

Objective: To assess the level of psychological distress and burden of care in mothers of preterm babies and their associated factors.

Design: Cross-sectional

Setting: The Neonatal Intensive Care Unit of the University of Teaching Hospital Ilorin, Nigeria

Participants: 144 mothers of preterm babies.

Outcome measures: Caregiver burden in mothers of preterm babies and its associated factors

Results: 16% experienced mild burden of care, 74% experienced moderate burden, while 10% experienced high burden of care. Delivery by caesarean section ($p=0.011$), taking breaks from care ($p=0.001$), belief that the baby will survive ($p=0.045$), and the no of previous children ($p=0.006$), were significantly associated with a high level of burden experienced by mothers. Only the number of previous children of the respondents was predictive of a high burden of care ($p=0.036$).

Conclusion: The results of this study support strongly the urgent need for structured psychological support for mothers of preterm children in the neonatal intensive care unit.

INTRODUCTION

Taking care of a new born baby, irrespective of the gestational age at birth is a stressful task for the new mother.^{1,2} However, taking care of a preterm baby presents additional challenges because of the peculiar needs of this group of babies. The caregiver burden is a construct which describes the physical, psychological, social and economic cost of taking care of a relative or ward with an illness or disability.² This concept not only applies to adults taking care of adults, but of parents taking care of children with illnesses or disability.³

Preterm birth is defined by the World Health Organization (WHO) as birth of a baby which occurs before 37 completed weeks of gestation.⁴ Currently, the gestational age is used as the main indicator of physical and neurological maturation in preterm babies.⁵ Globally, prematurity is the leading cause of death in children under 5 years.⁵ Preterm delivery itself has been reported by earlier researchers to be traumatic and associated with feelings that resemble post-traumatic stress disorder and this is made worse when the baby has to stay in the Neonatal Intensive Care Unit (NICU).⁶ The NICU is an artificial environment where the baby is nurtured and taken care of, it not only houses preterm babies but babies born with complications that require special care within the first few weeks of life.⁷ However, studies have shown that mothers of children in the NICU experience feelings such as feelings of worry, distress and helplessness as their baby stays in there. This distress may become multiplied with exposure to other babies with different complications of prematurity, some of which are life

threatening and even death of other babies within the NICU.

Feelings of anticipatory anxiety as well as helplessness have also been documented in mothers whose preterm infants are close to discharge.^{8,9} Mothers with high perceived burden consequently find it difficult to adequately attend to the physical and psychological needs of their babies, causing a negative impact on the babies' maturity and growth.¹⁰ On the other hand, other researchers on this subject such as Ionio¹¹ opined that mothers who learn new skills to enhance the care of their preterm babies during their stay with their babies in the NICU have an increased sense of self-esteem and all of which may mitigate against a feeling of perceived burden. Little emphasis has been placed on mothers of preterms.^{12,13} This study aims to determine the level of burden of care in mothers of preterm babies and their associated factors in order to create a template for appropriate help for burdened mothers.

MATERIALS AND METHODS

Study Design:

The research was a cross sectional, hospital-based study, which was conducted on mothers of preterm babies, admitted at the NICU of the University of Ilorin Teaching Hospital (UITH) between August 2020 and August 2021

Study Setting:

The study was done at the University of Ilorin, Kwara state, Nigeria. It is a 600 bedded tertiary hospital.¹⁵ which provides some level of primary and secondary care to the Ilorin populace and its adjoining environs. The NICU offers level II care to sick newborns which

includes oxygen therapy, bubble CPAP (Continuous Positive Airway Pressure), improvised bubble CPAP, incubator care to both preterm babies and full term babies with complications.

Study participants

This consisted of mothers of preterm babies admitted in the NICU, who give their consent and have satisfied the inclusion criteria.

Inclusion Criteria

1. Mothers of babies with established prematurity and are admitted in the NICU, who are 18 years and above.
2. Mothers of preterm babies who have been involved actively in the care of their babies for 72 hours and above.

Exclusion Criteria

1. Mothers of preterm babies, who have severe or debilitating medical or surgical illnesses, and mothers with a previous history of psychiatric illness.

A Sample size of 144 was calculated using the Cochran's formula¹⁶ for independent sample size calculation with confidence interval set at 95% and $p=0.05$.

Mothers of Preterm babies admitted for in patient care and who meet the inclusion criteria for this study were recruited via systematic random sampling technique at the Neonatal Intensive Care unit of the UITH. A sampling interval of one in four was determined based on the predetermined sample size and sampling frame. Eligible mothers who give their signed consent will be first interviewed using a socio-demographic questionnaire designed and pretested by the researcher. Care burden was measured using the 12-item Zarit Burden Interview (ZBI). All questionnaires were self-administered except when participants cannot read or write Yoruba or English, they were administered by trained research assistants through face to face interview. All mothers were interviewed

separately to ensure confidentiality. All questionnaires were back-translated by bilingual experts into Yoruba, the predominant language spoken in the study area, for study participants who do not understand English. All questionnaires were administered to participants at the visiting bay of the NICU to ensure that the aseptic environment was unbreached.

INSTRUMENTS:

1. PROFORMA QUESTIONNAIRE.

A socio-demographic questionnaire was used for this study, containing 2 sections was used to obtain relevant biodata and caregiving information about the mothers and their children.

2. ZARIT BURDEN INTERVIEW

This is an instrument that includes the items most frequently mentioned by caregivers as problem areas in providing care for patients with chronic illnesses.¹⁷ It was chosen for use in this study because of its popularity, clarity of items, ease of administration and ability to reliably measure burden of care in varied populations.^{18,19,20} It has been validated for use in Nigeria with good psychometric properties.²¹

DATA ANALYSIS

The Data generated from this study was analyzed using the Statistical Package for Social Sciences (SPSS version 20). Descriptive statistics was used to summarize the data. Continuous variables was expressed as mean $\pm$ standard deviation, while frequencies of categorical variables was expressed as percentages. The chi square was used to analyze categorical and continuous variables. Logistic regression was then used to identify predictors of burden of care. The significance level was set at $p<0.05$. Statistical analysis was further reconfirmed by a trained statistician

ETHICAL APPROVAL

An Ethical approval for the study was obtained from the Ethics and Research Committee of the University of Ilorin Teaching Hospital, with Ethical reference no: UITH/CAT/189/21/317.

RESULTS

Sociodemographic profile

Table 1 shows socio-demographic profile of respondents of this study, revealing that, majority of the mothers (46.5%) were between the ages of 26-30 years, mean age was 29 ± 4.9 , only 4.9% were ≤ 20 years. More than 83% of

respondents were of Yoruba ethnicity and 93.7% of them were married.

Only 11% of these mothers had ever had a preterm baby before. All respondents agreed that the NICU was beneficial to the care of their baby and all of them considered the care given by the medical team adequate. Majority (81.9%) said they prayed mostly when anxious about their babies' health, while only 10.9% said they usually spoke to their doctors about their fears. 70% of mothers had their partners taking up the major financial responsibilities of their babies' care, while 2.8% shouldered all the financial responsibilities of care alone.

Table 1
Socio-demographic characteristics of respondents

Variables	Frequency	Percentage
Age groups of care giver		
≤ 20	7	4.9
21 – 25	28	19.4
26 – 30	67	46.5
31 – 35	32	22.2
≥ 36	10	7.0
Mean $\pm$ SD (Range)	29 ± 4.9	(17 – 45)
Ethnicity		
Yoruba	120	83.3
Hausa	4	2.8
Igbo	6	4.2
Others (Ebira, Fulani,Igala, Nupe)	14	9.7
Religion		
Christianity	59	41.0
Islam	85	59.0
Marital Status		
Single	8	5.6
Married	135	93.7
Divorced	1	0.7
Type of marriage	n=136	
Monogamous	101	74.3
Polygamous	35	25.7
Number of children		
1	50	34.7
2 – 4	89	61.8
≥ 5	5	3.5

Position of presenting child		
First	51	35.4
2 nd to 4 th	87	60.4
5 th or more	6	4.2

Table 2*Attitudes and responsibilities of mothers concerning the care given to their babies*

Variables	Frequency	Percentage
What is done when anxious		
Pray	118	81.9
Talk to others	3	2.1
Talk to partner	2	1.4
Talk to doctor	15	10.4
Nothing	6	4.2
Financial responsibility		
Self	4	2.8
Partner	102	70.8
Both	33	22.9
Other relatives	5	3.5
Baby care had negative health impact		
Yes	33	22.9
No	111	77.1
Negative health impacts of baby care	n=33	
Headaches	7	21.2
Generalized body pains	5	15.2
General weakness	4	12.1
Arm and leg pains	7	21.2
Back pains	6	18.2
Others (Loss of appetite, swollen legs, weight loss)	4	12.1
Wish for a break from baby care		
Yes	26	18.1
No	118	81.9
Taken a break from baby care	n=26	
Yes	3	11.5
No	23	88.5
Duration of break	n=3	
Few hours	2	66.7
Few days	1	33.3
Belief system on baby's health	N=144	
Yes	144	100.0
No	0	0.0
Reasons for Positive belief		

Faith in God/God will heal the baby	86	59.8
Adequate care is being given	32	22.2
Others survived	12	8.3
Baby is getting better	10	6.9
Others	4	2.8

Table 2 showed that 33 mothers (22.9%) admitted that the care of their babies within the NICU environment had a negative impact on their physical health with headaches and body aches being the commonest physical complaints. Twenty-six mothers stated that they wished for a break from the demands of baby care, but could not get time for such, while only 3 out of these mothers had actually taken such breaks, ranging from a few hours to a full day. All mothers that participated in this study were optimistic that their babies will get well, with majority of them stating their belief in God and good care by the managing team as strong reasons for their positivity.

Concerning the experience of burden by the respondent mothers, as depicted in Figure I, 23 mothers (16%) experienced mild burden, 106 out of the 144 mothers, constituting 74%

experienced moderate burden, while 15 (10%) experienced high burden. Twenty-one (21.9%) of mothers aged 31 to 35 years experienced high burden, while none of the mothers less than 20 years experienced high burden, 25% of single mothers experienced high burden, as compared to 10% of married mothers who experienced same burden levels. Sixty percent of mothers who had 5 or more children experienced high burden and this number was much higher than those with between 1 and 4 children. Thirty-three (33%) of mothers who delivered by caesarean section experienced severe levels of burden, while only 8% of those who delivered spontaneously experienced same high burden levels and this relationship was statistically significant. ($\chi^2 = 9.083$), $p = 0.011$)

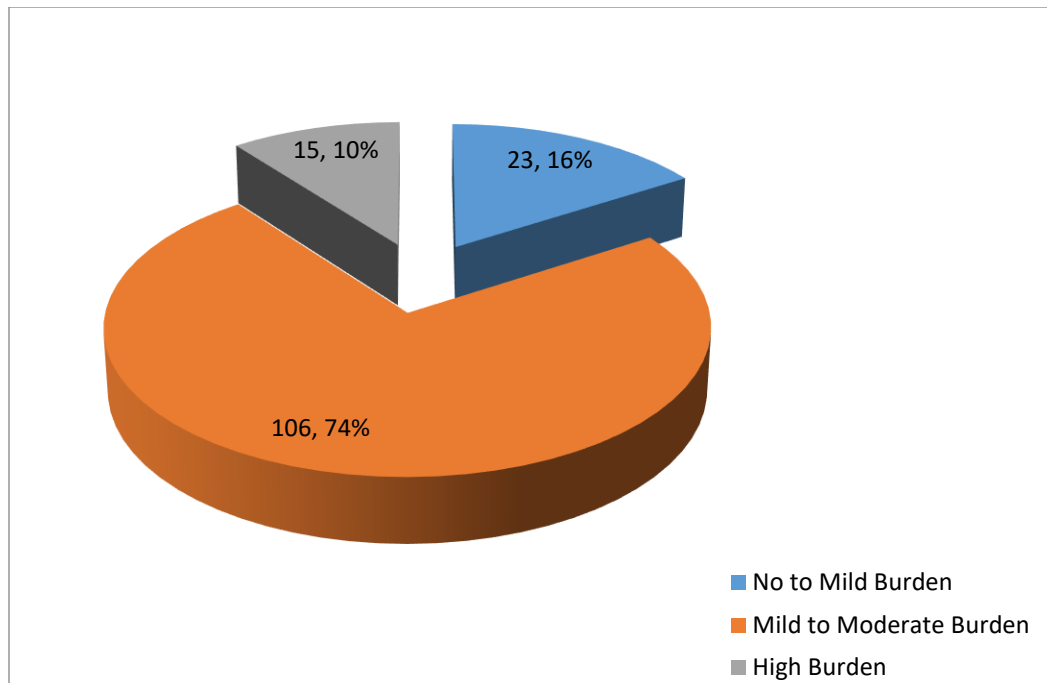


Figure (i): Burden scores of respondents

Table 3

Association between children/birth related information and burden score

Variables	Burden score of respondents			χ^2	p-value
	No to mild (%)	Mild to moderate (%)	High (%)		
Baby care				3.752	0.153
Yes	3 (9.1)	24 (72.7)	6 (18.2)		
No	20 (18.0)	82 (73.9)	9 (8.1)		
Delivery route				9.083	0.011*
SVD	20 (15.2)	101 (76.5)	11 (8.3)		
C/S	3 (25.0)	5 (41.7)	4 (33.3)		
Hospital birth				5.382	0.068
Yes	20 (17.2)	81 (69.8)	15 (12.9)		
No	3 (10.70)	25 (89.3)	0 (0.0)		
Baby's gender				0.020	0.990
Male	12 (15.6)	57 (74.0)	8 (10.4)		
Female	11 (16.4)	49 (73.1)	7 (10.4)		
Pre term baby				1.394	0.498
Yes	2 (12.5)	11 (68.8)	3 (18.8)		
No	21 (16.4)	95 (74.2)	12 (9.4)		
Nursed a child in NICU				3.478	0.176
Yes	5 (27.8)	10 (55.6)	3 (16.7)		

No	18 (14.3)	96 (76.2)	12 (9.5)		
Believe that baby will survive				6.184	0.045*
Yes	21 (15.6)	102 (75.6)	12 (8.9)		
No	2 (22.2)	4 (44.4)	3 (33.3)		
Break from the care				21.297	0.001*
Yes	5 (19.2)	12 (46.2)	9 (34.6)		
No	18 (15.3)	94 (79.7)	6 (5.1)		
Singleton				1.963	0.375
Yes	3 (14.3)	14 (66.7)	4 (19.0)		
No	20 (16.3)	92 (74.8)	11 (8.9)		
Twin gestation				0.091	0.955
Yes	3 (9.7)	12 (70.6)	2 (11.8)		
No	20 (15.7)	94 (74.0)	13 (10.2)		
Number of previous children				14.489	0.006*
One	8 (16.0)	39 (78.0)	3 (6.0)		
2 – 4	15 (16.9)	65 (73.0)	9 (10.1)		
≥ 5	0 (0.0)	2 (40.0)	3 (60.0)		

Table 4*Regression of age and number of children on Zarit burden score*

Variables	Beta	t-test	p-value	95 % C I
Age	-0.067	-0.744	0.458	-0.245 – 0.111
Number of previous children	0.800	2.116	0.036*	0.052 – 1.548

DISCUSSION

The burden of care is a psychosocial construct which describes the negative impact of caregiving on carers. In this study, more than 80% of respondents experienced moderate to severe burden, while 10% experienced no to mild burden. This finding is similar to those reported in previous studies which showed that it was burdensome to care for a child in the NICU.²² This is not surprising as having a child in the NICU comes with affectation of different aspects of the life of the mother. Mothers with the children in the NICU cannot participate in social activities and relaxation throughout this period as they have to stay with their babies, they also cannot go out of the hospital environment for long periods which

constitute a social restriction burden. They also experience serious financial burden related to purchase of medications, lab investigations and sometimes admission fees especially because most of these children have to stay for a relatively long time for treatment and payment of health service bills are usually mostly out of pocket.²³ Furthermore, during this period, these mothers may not be able to engage in their normal employment and money-generating ventures, thereby leading to an indirect loss of income to them. All of these contribute to level of caregiver burden in these mothers. Therefore, though most respondents had strong hopes that their children were getting the best of care and they will do well in the NICU, they still felt burdened psychologically, socially and

economically. Discussions about the burden of caregiving continue to be relevant in different populations as it is in the mothers involved in this study, as high burden levels have been associated with negative health outcomes in the babies being taken care of.²⁴

Our study also found that thirty-three (33%) of mothers who delivered by caesarean section experienced severe levels of burden as opposed to only 8% of those who delivered spontaneously. This is in keeping with similar studies in other parts of the world which reported the same trend²⁵. In a systematic review of experiences of mothers who nursed preterm babies in the NICU, it was reported that mothers who gave birth to their children through a cesarean section had more emotional symptoms such as fear and worry than those who delivered spontaneously.²⁵ Reasons adduced for this includes the fact that the process of healing from a cesarean section may impair effective bonding between mother and child and may worsen feelings of worry, guilt, dissatisfaction and anxiety. It has also been postulated that a mother who delivered by cesarean section may herself have to grapple with her own recovery as well as that of a fragile baby, thereby leading to intense feelings of emotional and physical burden²⁶

Our study also revealed that a larger proportion of single mothers experienced high burden. This may be attributed to the fact that a single mother may not have the full support of a spouse, economically, psychologically or socially which may have otherwise cushioned the feeling of being overwhelmed or burdened by the care of the baby. Thirty-three out of the 144 respondents in this study admitted that the care of their babies within the NICU environment had a negative impact on their physical health with headaches and body aches being the commonest physical

complaints associated with NICU stay in these mothers, this may be due to long hours of sitting and watching over their babies, sometimes through the night and headaches resulting from physical stress. Physical stress has been found to contribute to the feelings of physical burden experienced by caregivers of patients generally.²⁷ More importantly, this finding calls for an attention to also the physical health of caregivers in addition to their psychological health in order to improve their sense of well-being. The above finding is further reinforced by findings in this study that showed an association between taking breaks from caregiving duty in order to rest and the level of burden experienced.

This study also found that 81.9% of mothers said they prayed mostly when anxious about their babies' health, while only 10.9% said they mostly spoke to their doctors about their fears. A study by Brelsford et al ²⁸ which explored religion and spirituality as well as coping in mothers of babies in the NICU reported that many mothers reported that their faith grew significantly because of their children's stay in the NICU and this helped them to cope with stress and subsequently reduced their feelings of being burdened. Our finding however may suggest a hesitancy in respondents to report anxiety symptoms to their doctor and the need to sort these feelings out by religious means and this buttresses the need for more psychoeducation of mothers on expected psychological symptoms when nursing babies in the NICU and the need to reach out to their doctors when they are overwhelmed. This finding also stimulates further interest in the interactions between spirituality and coping in mothers of preterm babies.

CONCLUSION

The results of this study support strongly the urgent need for structured psychological support for mothers of preterm children in the NICU as well as a training of health care providers who deliver care in these units to recognize early signs of burden.

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