BURDEN AND COPING STRATEGIES OF PARENTS OF CHILDREN UNDERGOING SURGERY IN A TERTIARY HOSPITAL IN NIGERIA

Faronbi Joel O.; Adefemi Funmilayo O.; Adereti Stella C.; Famakinwa Timothy T. & Bello Cecelia B.

ABSTRACT

Parents are an indispensable part of the healthcare team, and they are exposed to a gamut of burden when their children are hospitalized. The objectives of this study are to explore the burden experienced by parents of children undergoing surgery, identify various coping strategies employed by the parents and explore the association between burden, socio-demographic characteristics and coping ability of respondents. A cross-sectional study was conducted among fifty purposively selected mothers of children undergoing surgery in the paediatric surgical unit of Obafemi Awolowo University Teaching Hospitals Complex, Ile-Ife, Osun State. Data was collected using a structured questionnaire measuring the burden and coping strategies of respondents. Data were analyzed descriptively and inferentially. Findings revealed that parents experienced severe burden (54.0%) which manifested as stressors such as fear of surgery (80%), financial burden (77%), disturbed mind when transferring child to the operating room (76%), separation from the child (78%), fear of child stop breathing (66%), seeing the child in pain (72%), and meeting the daily needs of other children (58%), In addition, 76% of the respondents cope moderately with the burden associated with their children surgery. Identified coping pattern includes: reading more about child's condition (62.0%), talking to people with previous experience (62.0%), and turning to God (98.0%). Furthermore, there is a significant association between religion and coping (x =7.22, p=.007. The study concludes that parents of children undergoing surgical procedure experienced severe burden and cope moderately with the burden, through reading, talking to people and turning to God.

Keywords: Burden: Challenges: Children: Coping strategies: Parents: Surgery**.**

INTRODUCTION

Care giving has been identified as a major source of stressor for informal care givers (Ghane, Ashghali, Seyedfatemi, and Haghani 2016). The care of a sick child, especially those undergoing surgical procedures, places both physical and emotional drain on parents of such children (Shah, Varma, Patel, Nimbalkar, 2018). Parents are important part of the healthcare team. When a child undergoes surgery, they are expected to help their child by providing information in a language he/she understands as well as providing necessary comfort. They are usually in the position to advocate for the child's need. Parents often participate in their children's care in the hospital and thereafter, they take on all caregiving duties when the child is at home recuperating (Melo, Ferreira, Lima, & Mello, 2014). In recent time, this has led to a higher survival rate as well as a reduction in associated morbidity and mortality risk. Despite these improvements, many parents are faced with a high level of distress when their children are awaiting any invasive surgical procedure (Lang, Viegas, Bleeker, Bruhn, & van Geffen, 2017).

Existing studies have submitted that children do not experience the same disease as adults neither do they respond to the same surgical solutions rather, they have specific illnesses

that require specialists with knowledge and training in surgical treatment for children (Breiner, Ford, & Gadsden, 2016). The authors also emphasize that the paediatric surgery team should take a compassionate, family-centred approach to care. Parents of children undergoing surgery are definitely going through what they were not looking forward to, filled with stress, emotional turmoil, relationship strains, and at times depression (McMahon, & Chang, 2020). Their lives are suddenly turned down when they are told that their child needs an operation. At that point, it is not really relevant what the diagnosis is; what is important and scary is the word "operation". They are stunned, terribly afraid and may have a million questions running through their minds, most of which remain unasked in the shock of that moment. The external support that parents need comes in form of meeting their needs and helping them to cope with the challenges they may be facing.

According to Montes and Halterman (2015), a child with a surgical condition has a negative impact on parental psychological functioning, and is associated with a high level of stress. Parent's psychological wellbeing and their ability to cope with the rigors of the child's surgery determine the child's emotional wellbeing during the surgical experience. Furthermore, parents are temporarily relieved after a successful surgery; they then face uncertainty and fear of infection and/or rejection (Young, Mintzer, Seacord, Castaneda, Mesrkhani, & Stuber,2003). Young *et al*. (2003) further opine that when the child is finally well enough to be discharged and return home, parents must adjust to the increased responsibilities of caring for their children in the face of possible infection without the constant medical, information and emotional network of the hospital and the surgical team (Lang, Viegas, Bleeker, Bruhn, & van Geffen, 2017). Recently, the role of surgery in global health has gained greater attention, although paediatric surgery has received little emphasis (Ozgediz & Poenam, 2015).

These authors further reiterate that paediatric surgical conditions should also be a part of global public health as there has been a global burden of paediatric surgical conditions (Ozgediz & Poenam, 2015). When parents are stressed as a result of their children awaiting a surgical operation, several responses and feelings can be identified such as anxiety, shock, guilt, denial, acceptance and adjustment. It is therefore pertinent for healthcare professionals to provide better information which may improve families' surgical experience whilst reducing anxiety, distress and physical discomfort (Mark. Gabriel et al., 2019).

Previous studies have focused on problems experienced by children during surgery. Oftentimes, parents of the children, the primary caregivers bear the burden of care and pressures throughout the period of child's peri-operative experiences (Woolf-King et al., 2017; Vainberg, Vardi & Jacoby, 2019). Despite these, little attention has been focused on parents as the subject of interest. The objectives of this study are to explore the burden and determine the coping ability of parents of children undergoing surgery in Obafemi Awolowo University Teaching Hospitals Complex (OAUTHC), Ile Ife, and explore the relationship between burden, socio-demographic characteristics and coping pattern of the parents.

RESEARCH QUESTIONS

1. What are the sources of burden experienced by respondents used in this study?
2. What are the coping strategies utilised by respondents used in this study?

HYPOTHESIS

There is no significant association between socio-demographic characteristics and coping ability

METHODOLOGY

A cross-sectional study was conducted among parents and caregivers of children undergoing surgery in the Paediatric Surgical Unit of OAUTHC, Ile-Ife, Osun State. This study was conducted at the Paediatric Surgical Ward of OAUTHC. OAUTHC is one of the leading teaching hospitals in Nigeria that render primary, secondary and tertiary services. The hospital enjoys a wide range of patronage from within and outside Osun State. OAUTHC comprises among other wards and units, the Paediatric Surgical Ward where the study was conducted. The population for this study includes all mothers whose babies had surgery in the hospital between February and March 2018 (4 weeks). Fifty mothers were purposively selected from the list of all mothers of children admitted for different surgical procedures in the paediatric surgical unit of the hospital, during the period of study. Respondents included were mothers whose children underwent surgery, admitted for at least 24 hours after the surgery, oriented in time person and space and consented to participate in the study.

The instrument used for this study was a structured questionnaire developed from an extensive review of the literature. It is made up of 3 sections namely; Section A: This contains the socio-demographic data of the respondents. Section B is made up of 12 items in 5-point Likert scale with answers of *never*, *rarely*, *sometimes*, *often*, and *always* corresponding to scores of 0 to 4. The total score ranges from 0 to 48, with higher scores indicating greater burden. The third section, Section C comprises 13 items on a 4-Likert scale for assessing the coping ability of the mothers. It gives an overall score of 13 (minimum) to 52 (maximum) and the coping is rated as poor (1-18), moderate (19-36) and good coping (37-52).

The Cronbach alpha for the instrument yielded 0.80 and 0.76 for Section B and C respectively, and it was deemed suitable in its present form. Permission to conduct the study was obtained from the Head of Department of Nursing Science and the administrative head of the study setting. In addition, informed consent was also obtained from all the participants. After gaining consent, questionnaires were administered to the selected participants in the ward. Approval for this study was received from the Head of Department of Nursing Science and the administrative head of the study setting. In addition, written consent was gained from the respondents before the questionnaires were administered. They were informed about the purpose of the study, and that their participation was voluntary, they could withdraw at any time. They were also assured of their anonymity and confidentiality of their information.

RESULTS

The socio-demographic characteristics of respondents are shown in table 1. The age ranges from 18 to 48 years with a mean 28.23+3.39. The result shows that majority of respondents (55.6%) are above 30 years, majority (80.0%) are married, 64.0% are Christians, and 38.0% earn less than #20,000 monthly.

TABLE 1
Socio-Demographic Characteristics of Respondents

		Frequency	(%)
Age of Mother (years)	Below 20	2	4.0
	21-25	7	14.0
	26-30	14	28.0
	Above 30	27	54.0
	Total	50	100.0
Marital status	Single	5	10.0
	Married	40	80.0
	Separated	5	100
	Total	50	100.0
Religion	Christian	32	64.0
	Muslim	16	32.0
	Others	2	4.0
	Total	50	100.0
Monthly salary	Less than 20000	19	38.0
	20000-40000	18	36.0
	40000-60000	6	12.0
	60000-80000	7	14.0
	Total	50	100.0

Research question one

What are the sources of burden experienced by respondents used in this study?

As presented in Table 1 and figure 1, majority of the respondents (54%) are experiencing severe burden. This is manifested as the following **Intrapersonal** stressors: fear when informed that child has been scheduled for surgery (80%), the financial cost of the procedure (77%), my mind is not at peace when my child is being transferred to the operating room (76%), the sight of the surgeons and various machines scared me (56%), separation form from my child (78%), and feeling helpless about how to help my child, (90%). Similarly, the interpersonal stressors include being afraid of the child stopping to breath (66%), when my child seems to be in pain scares me (72%), and seeing other sick children around (66%). In addition, the extra-personal stressors include: leaving the child alone (42%), meeting the daily needs of other children (58%), and meeting financial responsibilities and parental duties (68%).

TABLE 2
Sources of Burden

Variable	Never	Rarely	Sometimes	Often	Always
Intrapersonal stressors					
I was afraid when I was told that my child had been scheduled for surgery.	19(38)	21(42)	6(12)	2(4)	2(4)
I became bothered about the cost of the procedure immediately. I was told about the surgery.	22(44)	15(30)	10(20)	2(4)	1(2)
My mind was not at peace when my child was being transferred to the operating room.	19(38)	19(38)	7(14)	2(4)	3(6)
The sight of the surgeons and various ma chines scared me	9(18)	24(48)	8(16)	8(16)	1(2)
I became terrified when I was being separated from my child.	15(30)	24(48)	5(10)	6(12)	0(0)
Feeling helpless about how to help my child.	18(36)	27(54)	4(8)	1(2)	0(0)
Interpersonal stressors					
Seeing my child stop breathing can be very dreadful.	20(40)	13(26)	10(20)	2(4)	5(10)
When my child seems to be in pain scares me.	23(46)	13(26)	7(14)	4(8)	3(6)
Seeing other sick children around ma kes me bother about my child	13(26)	20(40)	12(24)	4(8)	1(2)
Extra-personal stressors					
Times I am away from the hospital, leaving my child alone.	9(18.0)	12(24.0)	14(28.0)	7(14.0)	8(16.0)
Meeting the daily needs of my other children.	11(22.0)	18(36.0)	11(22.0)	9(18.0)	1(2.0)
Meeting up with financial responsibil ities and parental duties.	12(24.0)	22(44.0)	6(12.0)	8(16.0)	2(4.0)

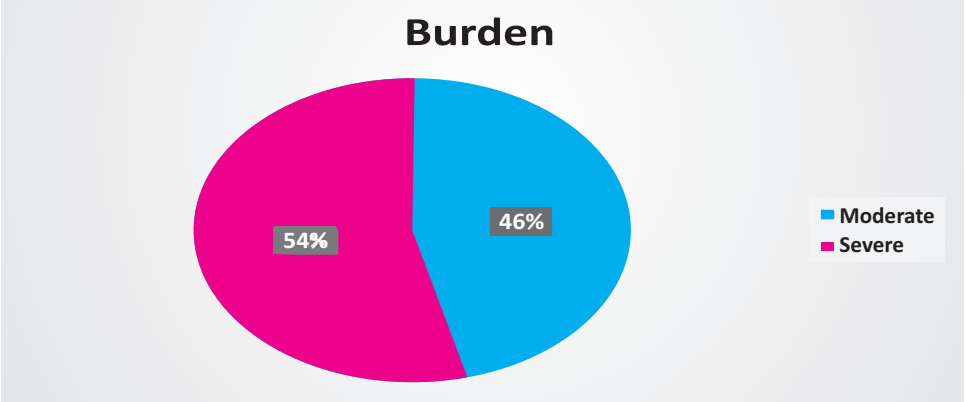

FIG1: Burden Experienced by the Respondents

Research question two

What are the coping strategies utilised by respondents used in this study?

As presented in Table 3 and figure 2, the coping strategies utilised by the respondents were reading more about child's condition (62.0%), talking to people who have gone through such situations before (62.0%) seeking God for healing 98.0%) and confiding in family and friends (46.0%). In addition, figure 2 reveals that 76% of the respondents' cope moderately with the burden.

TABLE 3:
Coping Strategies Utilised by Respondents

Variable	1	2	3	4
I try to read more about my child's condition, if possible to find out about the outcome.	16(32.0)	15(30.0)	11(22.0)	8(16)
I do what has to be done at the right time, not getting bothered.	22(44.0)	17(34.0)	5(10.0)	6(12)
I think about how best I might handle the situation.	11(22.0)	34(68.0)	2(4.0)	3(6)
I try to forget about the stressful situation by engaging in other activities.	10(20.0)	15(30.0)	13(26.0)	12(24)
I confide more in my friends and family.	11(22.0)	12(24.0)	16(32.0)	11(22)
I talk to someone who has gone through a similar situation.	11(22.0)	20(40.0)	11(22.0)	8(16)
I pray to God and put my trust in Him	35(70.0)	14(28.0)	1(2.0)	0(0.0)
I visit worship places and see religious leaders.	18(36.0)	17(34.0)	7(14.0)	8(16)
I say to myself, "this isn't real."	11(22.0)	11(22.0)	18(36.0)	10(20)
I use alcohol or drugs to make myself feel better.	1(2.0)	4(8.0)	11(22.0)	34(66)
I daydream about things other than this.	2(4.0)	7(14.0)	11(22.0)	30(60)
I accept that this has happened and cannot be changed.	8(16.0)	15(30.0)	8(16.0)	19(38)
I try to see it in a different light, to make it seem more positive.	18(36.0)	18(36.0)	7(14.0)	9(18)

1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

Hypothesis

There is no significant association between socio-demographic characteristics and coping ability. Two variables are in this hypothesis; the independent variable is socio-demographic characteristics while coping ability is the dependent variable. Chi-square test was used as the statistical tool used to establish either to accept or reject the null hypothesis and result presented in Table 4.

As presented in Table 4, there is statistical significant association between religion and coping ability ($X^2 = 7.22$; $p < .05$), but there is no statistical significant relationship between respondents age and coping ability ($X^2 = 0.32$; $p > .05$), and respondents' marital status and coping ability ($X^2 = 0.03$; $p > .05$), this is because the calculated X^2 value of 0.32 and 0.03 was less than the critical X^2 value of 3.08. Therefore, the null hypothesis which states that, there is no significant association between socio-demographic characteristics and coping ability was rejected and the null hypothesis upheld.

TABLE 4
Association Between Socio-Demographic Characteristics and Coping Ability

Variable		Coping ability			X^2	P
		Moderate (n=39)	Good (n=11)	Total		
Age (Years)	<25	5	4	9	0.32	0.298
	26-29	12	2	16		
	> 30	22	5	27		
Marital status	Non-married	8	2	10	0.03	0.865
	Married	31	9	40		
Religion	Christian	11	8	19	7.22	0.007
	Muslim	28	3	31		
	Less than 20000	11	8	19	0.4	0.528
	Above 20000	28	3	31		

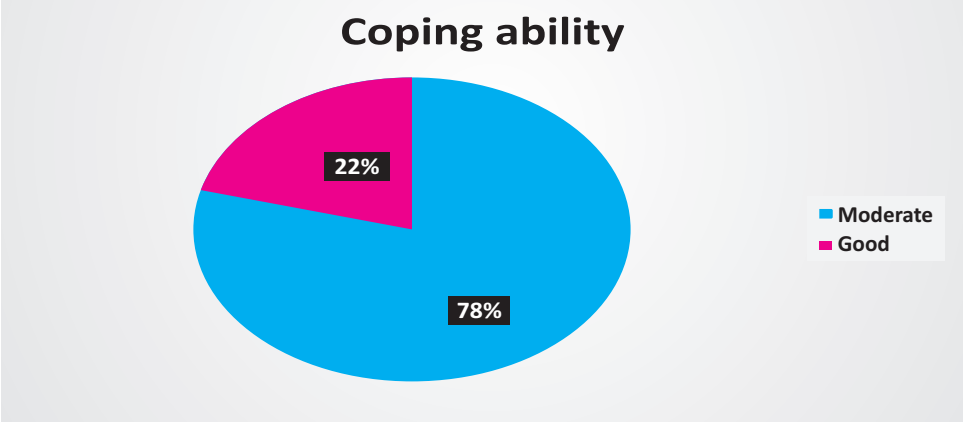

FIG 2: Coping ability of the Respondents

DISCUSSION

Information on the burden of parents of children undergoing surgery is significant to providing support to parents in order to promote positive surgical outcome for the children and reduce parental burdens. This study identifies challenges experienced by parents (mothers) of children undergoing surgery. It also identifies the coping strategies employed by the parents as well as explored the relationship between some parents' socio-demographic variables and their coping ability.

The result of the study shows that majority (55.6%) of the respondents are above thirty (30) years of age, married (80%), and of the Christian faith (64%). The result of this study also reiterates the fact that women perform more informal caregiving duties than men as almost all the respondents in this study are mothers of the children (Faronbi & Olaogun, 2017). This is, however, expected as the fathers are expected to run around to meet the financial obligations as appropriate. This result is similar to the result of other studies where women are also available as the primary caregivers of hospitalised children and majority are above 30 years (Ghane, Ashghali, Seyedfatemi, and Haghani, 2016).

The ability of the parents to cope moderately may be contrary to the expectation as the majority are married and being married has been reported to provide the better coping ability for parents of sick children (Ghane, Ashghali, Seyedfatemi, and Haghani, 2016). Additionally, many of the parents earn below the national minimum wage which may suggest that many of the parents might not be normally employed or have any form of health insurance which may pose tremendous financial burden on such families who may result into borrowing to meet the financial obligation of the child's surgical operation. This result is also similar to the study by Shah, Varma, Patel & Nimbalkar, (2018)) where parents resort to borrowing money from family and friends to pay hospital bills of their children; as a result of poor income and lack of health insurance.

The severe burden experienced by the majority of the parents in this study has also been reported in other studies (Razera, Trettene, Tabaquim and Niquuerito (2017). A previous study by Woolf-King et al. (2017), reports that care givers report fear, feeling helpless, anxiety and emotional distress before their children's surgery also support this finding. This finding is also in line with the work of McMahon and Chang, (2019) and Brosig, Whitstone, Frommelt, Frisbee & Leuthner who opine that parents of children with severe congenital heart disease experience a high level of psychological stress even at the time of diagnosis, let alone when going for surgery. Similarly, Razera, Trettene, Tabaquim and Niquuerito, (2017) observe moderate to severe burden among informal female caregivers of children with cleft palate in their pre-operative period. Additionally, Shah, Varma, Patel, Nimbalkar, (2018)) reports a mild depression among parents of children undergoing surgeries.

The results of the study also reveals that a large proportion of the respondents utilise diverse coping strategies which include: Seeing the situation in a more positive way, thinking about how best to handle the situation, talking to someone who has gone through a similar situation, visiting worship places and seeing religious leaders and praying to God and trusting in Him. This result is in tandem with that of Jackson, Higgins, Frydenberg, Liang and Murphy (2018) who reports the use of both positive and non-productive emotional responses to coping with children's hospitalisation among parents. These include a support system, parental management and avoidance as reported by parents of children with congenital heart diseases undergoing surgeries (Lutimsden, Smith, & Wittkowski, 2019).

Additionally, this result also corroborates the findings of Wen Jing Hui & Hong-Gu He (2020), who affirms that respondents utilised positive thinking such as, thinking how similar things are handled in the past, seeking a support system, use of a step by step approach to solve the problem and sharing problems with others. In the Study of Vainberg, Vardi and Jacoby (2019) that explore parents' experiences as

primary caregivers of children with congenital heart defects, it is reported that parents of these children experience both positive and negative feelings in their inner and outer worlds. The parents in this study report an experience of uncertainty, confusion, and helplessness when their children have to undergo surgery, as seen in this present study.

Nurses as care givers need to expand their knowledge and the information gained, therefore, will allow a holistic, family-centred philosophy to flourish and boom, as this will ultimately help the parents psychologically A study carried out by Brosig et al. (2007) conclude that although the medical team may assume that families do fine once their child has survived the surgery, there are ongoing stressors these parents experience. Education by nurses regarding what the parenting experience may be life long after the surgery would be helpful as well as ongoing psychological intervention.

Nursing implication

Nurses have a vital role in helping parents cope with stressful situations. This will go a long way in helping them to cope with the situation during the pre-operative, intra-operative and post-operative phases because parents need proper counselling during these phases. This will give reassurance to the parents while their children are being scheduled for surgery. Also, giving a report about their children's condition from time to time will let their minds to be at ease, thus reducing their burden and letting them cope well with the situation. Nurses should also be experts in recognising coping strategies used by parents to be able to provide adequate counselling and guidelines to them and to promote their level of coping.

CONCLUSION AND RECOMMENDATIONS

The study concludes that parents of children undergoing surgical procedure experienced a severe burden and they cope moderately using strategies such as reading more about child's condition, talking to people who have gone through such situations before, seeking God for healing and confiding in family and friends.

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