

Psychological Burden of Care in Parents/Caregivers of Children with Surgical Conditions: A Local Experience

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Abstract

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Background: There is a paucity of literature on the psychological burden on parental caregivers of children with surgical conditions. Knowledge of the peculiar psychological challenges faced by the parents or caregivers could help to advocate for the incorporation of a psychologist or psychiatrist as part of a multidisciplinary approach to patient care. The objectives of the study were to determine the prevalence of psychiatric morbidity and the burden of care among caregivers of pediatric patients undergoing surgery and to ascertain the correlation between psychiatric morbidity and the burden of care of caregivers. **Materials and methods:** This was a cross-sectional study over six months on caregivers of pediatric surgical patients at the Lagos University Teaching Hospital. Zarit's Caregiver Burden Scale (ZCBS) and the General Health Questionnaire-28 (GHQ-28) were used to obtain data on the burden of care and psychiatric morbidity. Data obtained was analysed using SPSS (version 23). A ZCBS score ≥ 21 and a GHQ-28 value above 4 were considered indicative of significant caregiving burden and psychological morbidity respectively. **Results:** A total of 120 caregivers were recruited into the study, with 106 (88.3%) females. The mean age was 34.7 (SD7.7) years. The mean GHQ score was 6.3 (SD5.9) whereas the mean ZCBS was 24.96 (SD14.67). Sixty (50.0%) caregivers had a GHQ score greater than four and seventy-one (59.2%) had a ZCBS score ≥ 21 . **Conclusions:** The care of children undergoing surgical procedures is associated with a significant caregiving burden and psychological distress among first-degree family caregivers. There is a need for further studies to determine the pattern of their psychological ill health as this could impact negatively the quality of care rendered.

Keywords: Paediatric care; Psychological; Surgery; Parental; Burden

Introduction

Caregiver's burden is defined as the discomfort experienced by the principal caregiver of a family member, including effects on their health, psychological wellbeing, finances, and social life [1]. A caregiver in this context is defined as one who provides unpaid care for a sick child and who has an established relationship, whether biologically or by friendship and in most instances, these are the mothers, less commonly

fathers, grandmothers and aunts [2]. Most of the existing literature relates to parents having children with medical disabilities such as cerebral palsy while a few cite parents having children with cancers [3-5]. There is a paucity of literature on the psychological burden on caregivers of children with surgical conditions. A surgical condition in this context is any disease that would require surgical intervention as its prime treatment. The presence of a sick child in the family is distressing, most especially if the child has a

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disorder that requires continuous care, surgery and repeated hospitalization [6]. Surgery has been associated with distress and strong psychological reactions in patients and caregivers due to anticipated pain and physical discomfort, worries concerning anesthesia and fears about having cancer or dying [7]. These have been documented to adversely influence surgical procedures as well as the patient's recovery, even in surgeries that physicians consider as "minor" [8]. Knowing the obvious, yet important role that parents play in the management of children with surgical condition, it would be germane to have an insight into the burden of care on caregivers. Aside from ascertaining the nature of these psychological burdens, such knowledge would enable the primary physician to proffer the appropriate psychological support to parents so that they could successfully scale over the psychological hurdle posed by their child's disease. Furthermore, knowledge of the peculiar psychological challenges faced by parental caregivers would serve as a platform to advocate for the incorporation of psychologists or psychiatrists as part of a multidisciplinary approach to patient care, particularly in centers lacking psychological facilities or support. This study, therefore, set out to determine:

- The prevalence of psychiatric morbidity among caregivers of pediatric patients undergoing surgery.
- The burden of care among caregivers of pediatric patients undergoing surgery.
- The relationship between psychiatric morbidity, socio-demographic variables and clinical variables.

Materials and Methods

Study design and location

The study was a cross-sectional, questionnaire based study over six months that took place at the Lagos University Teaching Hospital (LUTH), a Federal tertiary health institution within the Lagos Metropolis, Nigeria that caters for a population of 20 million.

Study population and sampling

The questionnaire was administered consecutively to consenting caregivers of paediatric patients who had been operated on and were attending the out-patient paediatric surgery clinic and caregivers of postoperative patients within the Paediatric surgical ward. The questionnaire consisted of two parts. The first part aimed at capturing the socioeconomic/demographic qualities of the caregiver and the patient. This was self-administered. The second part contained the instruments, which was administered by a Psychiatric resident, working in conjunction with the authors. The inclusion criteria were caregivers of patients who had had surgery within one month, irrespective of the type of surgery, those who were at least 18 years old and who gave written consent. Excluded were those with overt psychiatric illnesses or who refused to give consent. All eligible caregivers seen were serially recruited during the study period. Data obtained was entered into a standard proforma.

Baseline demographic and clinical data were obtained by direct questioning and from records in the case notes. Demographic variables such as age, gender, level of education, occupation and marital status of caregivers and the age, the gender of the patient were entered into the proforma. Clinical information on the duration of illness, type of surgery, other forms of treatment and the presence of other comorbid medical conditions were obtained. Questions relating to how the caregiver was adjusting to the patient's illness, covering areas like the effect on family life, work, mobility, and sexual life were also asked.

Instruments

The General Health Questionnaire-28 (GHQ-28 or GHQ) and Zarit's Caregiver Burden Scale (ZCBS) were used to obtain data on psychiatric morbidity and the burden of care respectively. The ZCBS and the GHQ were chosen because of their ease of use and conciseness. The ZCBS consists of 22 items, each with a corresponding 5-point Likert scale, ranging from 0 (Never) to 4 (Nearly Always). It assesses the caregiver's perceptions of the burden that may inadvertently affect their health and personal, social, or financial well-being. There are four subscales. The first subscale A assesses somatic symptoms. Subscales B and C check for anxiety and social dysfunctions, respectively. The last subscale D addresses severe depression. The total score is most often used and higher scores denote a greater burden. The maximum score attainable is 88 and a score ≥ 21 is regarded as indicative of a significant caregiving burden [9]. The internal consistency of this instrument has been judged excellent with values of Cronbach's alpha of 0.89 being reported and it has been deployed in a similar study in Nigeria involving caregivers of children with Attention-Deficit Hyperactivity Disorder (ADHD).

The GHQ 28 on the other hand is a 28 items instrument used in ascertaining psychological well-being and detecting possible cases of psychiatric disorders (Psychiatric morbidity) [10]. It has been used in several studies in Nigeria and has been validated with high sensitivity and specificity in Nigerian subjects. One additional advantage of the GHQ is that it focuses on the respondent's current state and is therefore sensitive to short-term psychiatric disorders. It consists of 28 questions, with four subscales which assess the presence of somatic symptoms (questions 1-7), anxiety disorders (questions 8-14), social dysfunction (questions 15-21) and depressive symptoms (questions 22-28) [11]. There are two different ways to score responses using this instrument. The 0-1-2-3 method and the binary or 0-0-1-1 method. For the former, responses are on a Likert scale, 'Better than usual', 'Same as usual', 'Worse than usual', and 'Much worse than usual', and are serially scored from 0 to 3. With the latter method, responses falling within the first and the second Likert scales are accorded a score of 0, and the last two Likert column responses are registered as 1. The maximum score using the first method is 84, whereas 28 is the highest score attainable using the binary method of calculation [12]. The scores obtained for each element was

summated to give the overall or global score. The GHQ 28 has been used as a screening test for the presence of psychiatric problems and an overall value greater than the cut off of 4, using the binary method calculation, indicates the need for further psychological or psychiatric evaluation [13]. Data obtained was analysed with SPSS version 23 (IBM SPSS Statistics for Windows, Armonk, NY: IBM Corp). Continuous variables were expressed as means (with standard deviation). Categorical variables were compared using the Chi-square test. Pearson's correlation was used to determine the relationship between psychiatric morbidity, socio-demographic and clinical variables.

Results

A total of 120 caregivers were recruited into the study. The administration of the questionnaires took an average of 20 minutes per participant. Sociodemographic and socioeconomic characteristics of caregivers (Table 1).

Table 1: Sociodemographic characteristics of caregivers.

Variables	Frequency (%)
Gender	
Female	106 (88.3)
Male	14 (11.7)
Age group (years)	
≤ 20	1 (0.8)
21-30	32 (26.7)
31-40	70 (58.3)
41-50	10 (8.3)
51-60	7 (5.8)
Marital status	
Single	4 (3.3)
Married	113 (94.2)
Divorced/separated	1 (0.8)
Widow/widower	2 (1.7)
Highest education attained	
No formal	5 (4.2)
Primary	7 (5.8)
Secondary (high school)	30 (25.0)
Tertiary (University)	67 (55.8)
Undisclosed	11 (9.2)
Religion	
Christianity	93 (77.5)
Islam	21 (17.5)
Undisclosed	6 (5.0)
Employment status	

Employed	81 (67.5)
Unemployed	25 (20.8)
Undisclosed	14 (11.7)
Average monthly income (in US dollars)	
Less than 100	
100 to 199	15 (12.5)
200 to 299	3 (2.5)
>300	9 (7.5)
Undisclosed	44 (36.7)

The mean age of respondents was 34.7 (SD7.7) years. There were 106 (88.3%) females and 14 (11.7%) males, giving a female to male ratio of 7.6:1. Seventy-four per cent of the caregivers were mothers. One hundred and thirteen (94.2%) were married and 67 (55.8%) had tertiary education. One hundred and fourteen (95.0%) belonged to the two mainstream religions: Christianity, 93 (77.5%) and Islam, 21 (17.5%). Eighty-one (67.5%) were employed and 49 (40.8%) received monthly emoluments below a hundred dollars.

Characteristics of the patients

Seventy-four (61.7%) were males and 71 (59.2%) were less than a year old. Fifty (41.6%) were firstborns. Seventy-five (62.5%) of the patients were managed for acquired conditions and in 74 (61.7%), the duration of the illness was less than a month before the presentation. Eighty-one (67.5%) were indications for major corrective surgeries and 119 (99.2%) had general anaesthesia during the surgery (Table 2).

Table 2: Relationship between socio-demographic characteristics of caregivers and psychiatric morbidity.

Variables	Psychiatric morbidity present using the GHQ 28 score				
	No (%)	Yes (%)	X ²	df	p-value
Gender			1.008	1	0.315
Female	52 (49.1)	54 (50.9)			
Male	5 (35.7)	9 (64.3)			
Marital status			1.617	4	0.806
Single	2 (50.0)	2 (50.0)			
Married	52 (48.6)	55 (51.4)			
Divorced/separated	0 (0.0)	1 (100.0)			
Widow/widower	2 (66.7)	1 (33.3)			
Undisclosed	2 (33.3)	2 (66.7)			
Highest Education attained			1.813	4	0.77
No formal	2 (40)	3 (60.0)			
Primary	2 (28.6)	5 (71.4)			
Secondary (high school)	15 (50.0)	15 (50.0)			
Tertiary (University)	32 (48.5)	34 (51.5)			
Undisclosed	6 (60.0)	4 (40.0)			
Religion			2.593	2	0.274
Christianity	45 (49.5)	46 (50.5)			
Islam	11 (52.4)	10 (47.6)			

Undisclosed	1 (16.7)	5 (83.3)			
Employment status			0.182	2	0.913
Employed	38 (47.5)	42 (52.5)			
Unemployed	13 (52.0)	12 (48.0)			
Undisclosed	7 (53.8)	6 (46.2)			
Age of caregiver(years)			2.624	4	0.623
=/ < 20	1 (100)	0 (0)			
21 to 30	16 (53.3)	14 (46.7)			
31 to 40	39 (56.5)	30 (43.5)			
41 to 50	4 (40.0)	60 (60.0)			
=/ > 50	5 (71.4)	2 (28.4)			

Psychological assessment of caregivers

Eighty-two (68.3%) caregivers admitted that their child's illness had its toll on their leisure. Seventy-six (63.3%) received some form of social support from other family members. The mean GHQ score was 6.3 (SD5.9) whereas the mean ZCBS was 24.96 (SD14.80). Sixty (50.0%) caregivers had a GHQ score in excess of 4 while 71 (59.2%) had a ZCBS score \geq 21. There was a weak but statistically significant positive correlation between the GHQ 28 and

Zarit's burden scale scores ($r=0.263$; $p=0.01$). No statistically significant association was observed between scores and the duration of illness of a child (GHQ28 $p=0.943$; Zarit $p=0.427$), parental marital status (GHQ 28 $p=0.806$; Zarit $p=0.895$), the sex of the caregiver (GHQ28 $p=0.315$; Zarit $p=0.571$) or employment status of the caregiver (GHQ28 $p=0.913$; Zarit $p=0.430$). There was statistical significance between the diagnosis and the GHQ score ($p=0.002$) (Tables 3 and 4).

Table 3: Relationship between patient factors and psychiatric morbidity of caregivers.

Variables 28 Score		Psychiatric morbidity present using the GHQ		
p-value	No (%)	Yes (%)	X ²	df
Gender of patient			1.643	1
Male	34 (45.9)	40 (54.1)		
Female	23 (50.0)	23 (50.0)		
Patient's diagnosis			9.388	1
Congenital	27 (54.0)	23 (46.0)		
Acquired	30 (42.9)	40 (57.1)		
Type of surgery			3.894	2
Minor	1 (33.3)	2 (66.7)		
Intermediate	18 (39.1)	28 (60.9)		
Major	33 (46.5)	38 (53.5)		
Type of anaesthesia			1.066	1
Local	2 (100.0)	0 (0.0)		
General	55 (46.6)	63 (53.4)		
Duration of child's illness			0.971	3
<1 month	3 (42.9)	4 (57.1)		
1 month to 1 year	26 (54.2)	22 (45.8)		

>1 year	25 (59.5)	17 (40.5)
Undisclosed	14 (60.9)	9 (39.1)

Table 4: Relationship between socio-demographic characteristics of carers and caregiving burden.

Variables Scale (ZCBS)	Psychological burden present using the Zarit's Caregiver Burden				
	No (%)	Yes (%)	X ²	df	p-value
Marital status			3.548	8	0.895
Married	3 (75.0)	1 (25.0)			
Divorced/separated	1 (33.3)	2 (66.7)			
Widow/widower	1 (33.3)	2 (66.7)			
Undisclosed	1 (33.3)	2 (66.7)			
Highest Education attained			3.158	8	0.924
No formal	1 (20.0)	4 (80.0)			
Primary	2 (28.6)	5 (71.4)			
Secondary (high school)	17 (56.7)	13 (43.3)			
Tertiary (University)	29 (40.0)	38 (60.0)			
Undisclosed	4 (36.4)	7 (63.6)			
Religion			3.698	2	0.448
Christianity	41 (44.1)	52 (55.9)			
Islam	13 (61.9)	8 (38.1)			
Undisclosed	1 (16.7)	5 (83.3)			
Employment status			3.83	2	0.430
Employed	32 (39.5)	49 (60.5)			
Unemployed	12 (48.0)	13 (52)			
Undisclosed	4 (28.5)	10 (60.5)			
Age of caregiver(years)			14.43	8	0.071
(= < 20)	1 (100)	0 (0)			
21 to 30	14 (43.8)	18 (56.3)			
31 to 40	25 (35.7)	45 (64.3)			
41 to 50	4 (40.0)	6 (60.0)			
(= > 50)	4 (57.1)	3 (42.9)			

No statistical significance was however demonstrated between this variable and Zarit's burden score ($p = 0.165$) (Table 5).

Table 5: Relationship between patient factors and caregiving burden of career.

Variables	Psychological burden present using the Zarit's Caregiver Burden Scale (ZCBS)				
	No (%)	Yes (%)	X ²	df	p-value
Gender of patient			2.074	1	0.722

Male	29 (39.7)	44 (60.3)			
Female	19 (40.4)	28 (59.6)			
Patient's diagnosis			3.606	1	0.165
Congenital	22 (48.9)	23 (51.0)			
Acquired	26 (34.7)	49 (65.3)			
Type of surgery			12.621	2	0.049
Minor	5 (38.4)	8 (61.6)			
Intermediate	14 (38.9)	22 (61.1)			
Major	29 (40.8)	42 (59.2)			
Type of anaesthesia			1.634	1	0.442
Local	5 (45.5)	6 (54.5)			
General	43 (39.4)	66 (60.6)			
Duration of child's illness			2.874	3	0.411
<1 month	1 (14.3)	6 (85.7)			
1 month to 1 year	22 (45.8)	26 (54.2)			
>1 year	17 (40.5)	25 (59.5)			
Undisclosed	8 (34.8)	15 (47.8)			
Age of caregiver(years)			2.58	4	0.63
(=/ \leq 20)	1 (100)	0 (0)			
21 to 30	16 (53.3)	14 (46.7)			
31 to 40	39 (56.5)	30 (43.5)			
41 to 50	4 (40.0)	60 (60.0)			
=/>> 50	5 (71.4)	2 (28.4)			

Discussion

Most of the respondents in our study were females (88%). This finding is consistent with other studies where the burden of care of the sick child rests squarely on the shoulders of the mothers. We agree with the explanation proposed by Babalola, et al. that this is most probably tied to the age-old African belief which views women as home-keepers and men are accorded the role of breadwinners. We did not observe any statistically significant association between the psychological burden of caregivers and their demographic details, as observed in Rosenberg's study (which looked at psychological distress in parents of children with advanced cancer). We, however, did not observe any relationship or correlation between economic status and the psychological burden, contrary to other studies conducted in parents of patients with chronic illness. In Nigeria, where the National Health Insurance Scheme is still experiencing teething problems and only a minority of its citizenry can access it, many caregivers are faced with the grim reality of footing unbudgeted expenses. The authors believe that 'out of pocket' payments of unplanned bills may be demoralizing and could result in some psychological burden. Although we observed from our study that cost of care, in most instances,

closely approximates the monthly income of most caregivers, this did not appear to correlate with higher psychological morbidity. One plausible reason for this is that the majority of the caregivers in our study were mothers with a stable relationship and the financial weight of caring for the hospitalized child would most likely have been borne by both spouses. More so, the traditional role of men as breadwinners means that the bulk of the economic burden would be on the fathers and that the women would only assume a complimentary financial role with whatever monthly remunerations they receive. Another possible explanation for why our study did not reveal any statistically significant relationship or correlation between economic status and the psychological burden, could be the high level of social support obtained by the parental caregiver in the care of the sick child. Over sixty per cent of our respondents claimed to have benefited from this level of support. There exists an entrenched communality in an African society where both the nuclear and the extended family members constitute one large family and each member sees it as their responsibility to financially support others in a dire situation. This no doubt ameliorates, to some degree, the impact of the burden of care on primary caregivers. In a similar study carried out to

determine the level of psychological distress and morbidity among mothers of children undergoing elective surgery at the Lagos State's tertiary hospital, Osuoji, et al. reported that 47% of respondents had scores higher than the cut-off value, with the GHQs scores indicating probable psychological distress. While that particular study focused on the preoperative screening of caregivers, our study targeted caregivers of sick children that had been operated on. Fifty per cent of the respondents in our study had GHQ scores above the cut-off value, whereas 59% had Zarit's scores above the normal range, revealing a significant psychological burden. Osuoji's findings serve to highlight the importance of pre-surgical screening of caregivers, as the prospect of a sick child requiring surgery, may be too heavy for some to cope with, resulting in impaired health and the inability to care for the sick. The findings from our study stress the need for postoperative evaluation, as the child's treatment is a continuum and no clear distinction exists between the preoperative and postoperative phases of a child's care. Several studies have identified certain factors as contributing to the psychological burden on caregivers, notably uncertainty of the eventual outcome of a child's condition, unconducive or unfamiliar hospital environment and limited information, unbudgeted expenses and unanticipated financial burden of care, unplanned disruption in the workplace and unsupportive spouse and relations. The significant psychological burden reported in our study is likely to be multifactorial. Periodic psychological evaluation or screening of caregivers would be a laudable task. This would enable hospital teams and healthcare planners to adopt treatment programmes that would be inclusive of the caregivers and targeted at mitigating the stress they may be facing. However, implementing such a policy may not only be challenging in our third world setting but unrealistic due to the paucity of psychologists and high patient load in many centres. Nevertheless, it is advised that psychological screening of caregivers should be an integral part of the multidisciplinary approach to patients' management and when indicated, there should be a prompt referral to a psychologist [14-19].

Limitations

The study was limited in its scope, as it only aimed at ascertaining the psychological burden in caregivers and not to investigate the specific factors responsible. In addition, the pattern of psychiatric diagnosis among the subjects was not ascertained as the instruments used only served as screening tools. Identification of these specific factors as well as the psychiatric diagnosis following evaluation for those with high scores would help in formulating a more robust treatment plan and make both treatment and counseling more goal oriented. These two areas should be points for further studies. Although the GHQ 28 and ZCBS have both been used in several studies in Nigeria, these tools have not been validated and using such tools in settings other than where they were originally designed for may limit their effectiveness and may not give a true portrayal of the psychological

morbidity and the caregiving burden of the target population [20].

Conclusion

The care of children undergoing surgical procedures at the Lagos University Teaching Hospital is associated with a significant burden among caregivers.

Ethical Considerations

Ethical approval was obtained from LUTH health research ethics committee. The study did not interfere with the patients' treatment and it was non-invasive in its design. Informed consent for enrolment into the study was obtained from each parental caregiver, each of whom had been properly briefed and assured that declining to participate in the study would not in any way affect the care of their child. Confidentiality of information was assured.

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