



International Journal of
Nursing and Midwifery

Volume 6 Number 4 August 2014

ISSN 2141-2456



*Academic
Journals*

ABOUT IJNM

The **International Journal of Nursing and Midwifery (IJNM)** is published monthly (one volume per year) by Academic Journals.

International Journal of Nursing and Midwifery (IJNM) is an open access journal that provides rapid publication (monthly) of articles in all areas of the subject such as family practice, women's health care, emergency nursing, psychiatry, geriatrics, pediatrics etc.

The Journal welcomes the submission of manuscripts that meet the general criteria of significance and scientific excellence. Papers will be published shortly after acceptance. All articles published in IJNM are peer-reviewed.

Submission of Manuscript

Submit manuscripts as e-mail attachment to the Editorial Office at: ijnm@academicjournals.org, ijnm@acadjourn.org. A manuscript number will be mailed to the corresponding author shortly after submission.

For all other correspondence that cannot be sent by e-mail, please contact the editorial office (at ijnm@academicjournals.org, ijnm@acadjourn.org).

The International Journal of Nursing and Midwifery will only accept manuscripts submitted as e-mail attachments.

Please read the **Instructions for Authors** before submitting your manuscript. The manuscript files should be given the last name of the first author.

Editors

Dr. Alleene M. Ferguson Pingenot

*California State University, Stanislaus
One University Circle DBH 260, Turlock, CA 95382
USA*

Dr. Andrew Crowther

*Charles Sturt University
Leeds Parade, Orange, New South Wales 2800,
Australia*

Dr. Jacinta Kelly

*School of Nursing & Midwifery
24 Dolier St, Dublin 2
Ireland*

Dr. Jafar Alasad

*College of Nursing, King Saud bin Abdulaziz
University for Health Sciences
(MC 3105)
King Abdulaziz Medical City - National Guard
Health Affairs
P.O. Box 22490, Riyadh 11426,
Saudi Arabia*

Dr. Fintan Sheerin

*School of Nursing and Midwifery, Trinity College
Dublin,
24 D'Olier Street, Dublin 2.
Ireland*

Prof. Helen McCutcheon

*University of South Australia, School of Nursing &
Midwifery
GPO Box 2471, Adelaide, South Australia, 5001,
Australia*

Dr. Panagiotis Christopoulos MD,MSc,PhD,IFEPAG

*2nd Dept. Ob/Gyn
Medical School, University of Athens
1 Hariton street,
14564, N. Kifissia, Athens,
Greece.*

Dr. Arun Kumar

*Manipal College of Medical Sciences
Department of Biochemistry, Pokhara, Nepal
India*

Dr. Harunor Rashid

*Barts and the London Queen Mary's School of
Medicine and Dentistry, London
The Blizard Building, 4 Newark Street, London E1
2AT,
United Kingdom*

Editorial Board

Dr. Sawsan Majali

*Dar Al Hekma College
P.O.Box 34801, Jeddah 21478
Saudi Arabia*

Dr. Patricia L. Riley

*US Centers for Disease Control and Prevention (CDC)
1600 Clifton Road, NE
Mail Stop E-41
Corporate Square Bldg 1, Rm 2409
Atlanta, GA
30329-1902
USA*

Dr. Lucille van der Westhuizen

*University of Namibia
P/B 13301 Windhoek,
Namibia*

Dr. Imtiaz Wani

*S.M.H.S Hospital, Srinagar
Amira Kadal, Srinagar
India*

ARTICLES

Research Articles

- Assessment of Adult Patients' Satisfaction and Associated Factors with Nursing Care in Black Lion Hospital, Ethiopia; Institutional based Cross Sectional Study, 2012** 49
Mulugeta Molla, Aster Berhe, Ashenafi Shumye and Yohannes Adama
- Socio-Economic Challenges Of Parents Of Children With Neurological Disorders: A Hospital-Based Study In North West Nigeria** 58
Lawal H., Anyebe E. E., Obiako O. R. and Garba S. N.

Full Length Research Paper

Assessment of adult patients' satisfaction and associated factors with nursing care in Black Lion Hospital, Ethiopia; institutional based cross sectional study, 2012

Mulugeta Molla^{1*}, Aster Berhe², Ashenafi Shumye³ and Yohannes Adama³

¹Department of Nursing, College of Health Sciences, Mekelle University, Ethiopia.

²Department of Nursing and Midwifery, College of Health Sciences, Addis Ababa University, Ethiopia.

³Department of Public Health, College of Health Sciences, Mekelle University, Ethiopia.

Received 19 June, 2014; Accepted 29 July, 2014

Patient satisfaction has been used as an indicator to measure the quality of health care provided by nurses. Moreover, patient satisfaction is one of the ultimate validators of effectiveness and quality of care. The purpose of this study was to assess adult inpatient satisfaction and associated factors of nursing care in Black Lion Specialized Hospital, Addis Ababa, Ethiopia. An institutional based cross sectional study was conducted on a total of 374 adult patients admitted to Medical, Surgical and Gynecologic wards in Black Lion hospital. The data collection tool was modified from Newcastle Satisfaction with Nursing Scale (NSNS). Simple random sampling technique was used. Data were entered into EPI info version 3.5.1 and exported to SPSS version 16.0 for cleaning and analysis. Frequencies distribution, binary and multiple logistic regression were done. OR and 95% confidence interval was computed. The average mean (SD) of satisfaction was 3.93 (0.88). Participants in Gyn/Obs wards had a better satisfaction (mean= 4.02; SD=0.76) with nursing care when compared with participants in medical and surgical ward. Among all respondents females had "Moderate and High" level of satisfaction (95%) than males (86.21%). Being female (3.78 (1.35, 10.56)), Age>50 years (0.36(0.14, 0.93), never married patients (2.74(1.07,7.03)) and admitted in Medical or Gyn/Obs and number of nights spent in the ward were found to be independent predictors of patients satisfaction. Since the overall patient satisfaction was 90.1% in this study, the hospital could be a model for other hospitals.

Key words: Patients' satisfaction, nursing care, medical, surgical and Gyn/Obs, and inpatients.

INTRODUCTION

Patients' satisfaction is considered as an important outcome criterion in health services. In the past few decades, there has been increasing interest in patients' satisfaction with nursing care. Patients' satisfaction with

nursing services gains even more hospitalized patients. According to American Nurses Association (2000), 'patient satisfaction with nursing care' is patients' opinion of care received from nursing staff importance as nursing

*Corresponding author. E-mail: muler.warso@gmail.com Tel: +251-910-883-864

(Author(s) agree that this article remain permanently open access under the terms of the [Creative Commons Attribution License 4.0 International License](http://creativecommons.org/licenses/by/4.0/)

care is the major supportive service provided to during their hospitalization'.(Teng and Norazliah, 2012) On the other hand, patients' satisfaction is also referred as an expression of patient's overall judgment on the quality of care particularly in the aspect of interpersonal process (Donabedian, 1988). Today interestingly, the organization perspective views patient satisfaction as the goal of health care delivery (Merkouris, 1999). Patient satisfaction with nursing care is the degree of convergence between the expectations patients have of ideal care and their perception of the care they really get (Crow et al., 2003, Risser N, 1975, Merkouris, 1999). However, evaluation of the quality of health care is a complex and challenging process. Though medical experts have argued that patient satisfaction is not the best indicator of quality of care (Roohan et al., 2003), it is a category that has received attention as a useful indicator of the quality of care in consumer-driven health care systems (Ganova-lolovska et al., 2008; Johansson et al., 2002; Felesia, 2009).

Nurses spend more time with hospitalized patients than members of any other discipline and therefore have a significant impact upon patients' perceptions about their hospital experience (Crow et al., 2003). Patient's satisfaction will be determined by nurses' role in the hospital; because they are more acquainted bedside nursing care than any other health personnel in the hospital. Nurses are on shifts stay in the hospital twenty four hours, seven days per week and three hundred sixty five days in a year. Nurses stay longer with the patient than the attending physicians. Learning about what consumers want from their health care system and what quality care means to them offers decision-makers a better understanding of their expectations (Ganova-lolovska et al., 2008). That is, satisfaction provides a meaningful focus for improving quality care, planning and evaluation of health care services (Felesia, 2009) and it will change the nursing service practice beyond medication administration, carrying out physicians order and measuring vital sign. Health care environments throughout the world are currently under enormous pressure to improve quality of care, while at the same time restraining the increasing costs. We should, however, not make the market for health care like the market for everything else (example, airplane journeys, restaurants and movies), where customer satisfaction can be almost like the whole story of running a business (Tzeng, 2008). Patient satisfaction in Jordan and Ethiopia was 73% and 67% respectively (Felesia, 2009; Bekelle, 2005). Being a female and admitted to a Gynecological ward, the amount of time nurses spend with the patient and the type of information nurses gave to patients about their condition and treatment, lower income and education, longer period of admission and no history of admission were among factors adversely affecting satisfaction levels (Bekelle, 2005).

The issue of patient satisfaction has drawn much

attention for research particularly in specialized areas such as emergency departments (Thrasher and Purc-Stephenson, 2008, Saiboon et al., 2008) coronary care units (Ho et al., 2006), Orthopaedic wards (Teng and Norazliah, 2012) and psychiatric units (Kuosmanen et al., 2006). In contrast, patient satisfaction among the patients admitted to the medical, Surgical and obs/Gyn wards of government hospital settings, which usually comprise of the highest density of in-patient population of any countries are neglected and here is limited literature. In view of the wide coverage of population in the medical wards, surgical wards and Obs/Gyn wards the evaluations on patient satisfaction would contribute to the knowledge of strategies in nursing care improvement. The Federal Ministry of health (FMOH) in Ethiopia is also striving to provide a quality nursing service in every health institution and it is also developing different reforms, quality management guidelines and evaluation mechanism for nursing care (FDRE, 2012). Since Black Lion is one of the specialized hospitals in Ethiopia, we expect a better quality of nursing care than other hospitals. There were some rumors about patient dissatisfaction with nursing care but there were no adequate studies which expose patients' dissatisfaction with nursing care service. Therefore, this study would inform the community in order to evaluate associated factors and patients' level of satisfaction with nursing care. Research on patient satisfaction was conducted before BPR (Business processing and reengineering) implementation (Bekelle, 2005). But this research was important to evaluate the change and factors affecting the satisfaction level of patients after implementation of BPR. Hence, the purpose of this study was to assess patients' satisfaction and associated factors with nursing care in Black Lion Specialized Hospital, Addis Ababa, Ethiopia.

METHODOLOGY

Study area

The study was conducted in Addis Ababa, the capital city of Ethiopia and seat of African Union and United Nations World Economic Commission for Africa. Addis Ababa has a population size of over 3 million with annual growth rate of 2.1% (data obtained from central statistical agency of Ethiopia). The city is divided into ten sub-cities and 100 Kebeles or districts. The city has 48 hospitals. Thirteen are public hospitals of which, 5 are under Addis Ababa Regional Health Bureau (AARHB) and 5 are specialized referral (central) hospitals. The hospital had 500 beds in medicine, gynecological and obstetrics, Surgical, pediatrics and emergency departments, and facilitated with the outpatient department (OPD) and it has seven x-ray, nine surgical and two laboratory diagnostic rooms. The hospital also has special units (Referral clinics). These are Chest, Renal, Neurology, Cardiology, Dermatology and S.T.D, Gastro intestine, Infectious diseases, Orthopedics, General surgical, gynecologic and obstetrics, Diabetic, Hematology, Medical ICU, Surgical ICU Units. Black Lion hospital offers diagnosis and treatment for approximately 370,000 to 400,000 patients a year. This study was conducted from March 25, 2012 to April 28, 2012.

Study design, population and sampling

An institution based cross sectional was conducted. The study participants were Adult inpatients in Medical, Surgical and Gynaecology wards of Black Lion Hospital; who stay for two or more days and who consented to participate in the study. [The sample size for the study was calculated using single population proportion formula:](#)

$$n = Z^2 \alpha / 2 \frac{P(1-P)}{d^2}$$

Using [the assumption that the proportion of](#) patient satisfaction was 67% (Bekelle, 2005), [95% CI, 5% marginal error, and 10% none response rate, a total of](#) 374 admitted patients [were required for the study.](#) First the number of patients to be taken from each ward was determined based on the number of beds they had. Then, all patients who had been admitted during data collection period was interviewed until the required sample size from each ward was found. Accordingly, 111 patients from the medical ward, 176 from the surgical and 87 from the obstetrics and gynecology wards were taken.

Data collection tool

The data were collected according to the Newcastle Satisfaction with Nursing Care Scales (NSNSs) users' manual. Questionnaire was translated into Amharic and was re-translated back to English to check for consistency. The questionnaire contained both open and close-ended questions. Two non health professional data collectors and one supervisor was recruited and training was given to data collectors and supervisor for a day on the objective, relevance of the study, confidentiality of information, respondent's right, about pretest, informed consent and techniques of interview; after the investigators discussed in depth. Pretest was conducted in 20 patients in other hospitals found in the city. Data was collected by interviewing each patient. The data collectors interviewed the inpatient without wearing a gown in order to reduce bias. The quality, clarity and consistency of the data were checked every day.

Criteria for classification of satisfaction score

The maximum scores for patients' satisfaction were calculated out of 100. The scores were categorized into moderate and high level of satisfaction for those who answered more than 12 (>60%) questions and low level of satisfaction for those who answered 11 and less ($\leq 60\%$) questions.

Data analysis, presentation and interpretation

Data were entered using EPI info version 3.5.1 statistical software. Cleaning and analysis was done by using SPSS version 16. Univariate analysis was done to describe dependent and independent variables; percentages, frequency distributions and measures of central tendency and measures of dispersion were used for describing data. Open-ended questions were coded after data collection for analysis. Then binary logistic regression was made to see the crude significant relation of each variable with dependant variables. Finally, independent variables found significant ($p \leq 0.05$) were entered to multivariate logistic regressions to control the effect of confounding. Stepwise backward LR was used for multiple logistic regressions. Odds ratio with 95% confidence interval to ascertain association between independent and dependent variable was used.

Ethical considerations

Ethical clearance was obtained from IRB of AAU, CHS, department of nursing and midwifery. The permission letter was obtained from Black Lion hospital quality management team before the research commenced. Participation in the study was voluntary and informed verbal consent was obtained from each patient after a thorough explanation of the purpose of the study. Data collection was anonymous and guaranteed confidentiality of the information given and either participating or not participating would have a negative effect on their care.

RESULTS

Socio demographic characteristics of patients

A total of 374 adult in-patients who had spent two or more days in Black Lion Hospital were included in this study with 100% response rate. The mean age of participants was 40.3(SD=1.55) and the minimum age was 18 with the range of 68 (18, 86). Among the participants, 53.5% were females. The majority of the respondents were literate (80.7%) left only 12.8% who were employed. The vast majority of the respondents were Orthodox Christian in religion (65.8%) and 22.7% were Muslim. Of the total respondents 42% were Amharain Ethnicity and 63.9% were married and living together. The median length of stays (nights) were 7 with inter-quartile range being 11 (Table 1). Among the given seven options, 48.7% rated nursing care they received in the ward as very good but 1.1% rated the care they received as dreadful (Figure 1). Almost all of the respondents 357 (95.5%) said nurses had good communication and interpersonal skill and 350 (93.6%) have said that the nurses keep their dignity, emotion and empathy. Among all respondents 354 (94.7%) felt that they would recommend this hospital to the people they know who may be seeking medical care in the future.

Patient satisfaction with nursing care

Patient satisfaction with nursing care, as measured using the PSNCS, is seen in Table 1. Participants in Gyn/Obswards had a better mean satisfaction (M= 4.02; SD=0.76) with nursing care when compared with participants in medical (M=3.78; SD=0.98) and surgical wards (M=3.98; 0.89). In Gyn/Obs wards, participants indicated that they had better satisfaction mean in almost all items and the highest ranking was the amount of freedom you were given on the ward (M=4.52; SD= 0.79) followed by Nurses' manner in going about their work (M=4.47; SD=0.78). The average mean of satisfaction with nursing in medical ward was 3.78 (M= 3.78; SD=0.98). Participants indicated that they had a better level of satisfaction with aspects such as the amount of freedom you were given on the ward (M=4.58; SD; 0.63). Conversely, participants indicated that they had "low" level of satisfaction with aspects such as 'the amount of information nurses gave to you about your condition and treatment (M=3.42;

Table 1. Socio-demographic characteristics of inpatients who had been admitted in Black Lion Hospital from March to April, 2012.

Variable	Category	Frequency	Percent (%)
Age	≤50 years	275	73.5
	>50 years	99	26.5
M (SD)			40.3 (SD=1.55)
Sex	M	174	46.5
	F	200	53.5
Educational status	Illiterate	72	19.3
	Literate	302	80.7
Religion	Orthodox	246	65.8
	Muslim	85	22.7
	Others	43	11.5
Marital Status	Living together	95	25.4
	Never married	279	74.6
Nights in the ward	2-10	235	62.8
	11-21	97	25.9
	≥22	42	11.2
M (SD)			13.56 (SD=19.92)
History of previous Admission	Yes	99	26.5
	No	275	73.5
Occupation	Employed	48	12.8
	Not Employed	326	87.2
Ethnicity	Amhara	157	42.0
	Tigrie	39	10.4
	Gurage	103	27.5
	Oromo	45	12.0
	Others	30	8.0

SD=1.11) followed by the type of information nurses gave to you about your condition and treatment (M=3.42; SD=1.11). The average mean of satisfaction with nursing care in surgical wards was 3.98

(M=3.98; SD=0.89). Participants indicated that they had a better level of satisfaction with aspects such as 'Nurses' treatment of you as an individual (M=4.45; SD=0.72), How often nurses checked to see if you were okay (M=3.90; SD=0.87), and the way nurses explained things to you (M=3.83; SD=0.92). On the other hand, participants had the least level of satisfaction with aspects such as 'Nurses' manner in going about their work (M=4.34; SD=0.84) and the amount of freedom you were given on the ward (M=4.43; SD=0.78) (Table 2).

Bivariate and multivariate analyses of factors affecting inpatients' satisfaction

Based on Table 3; among all respondents females had "Moderate and High" level of satisfaction (51%) than males (40%). Patients who had been admitted in Gyn/Obs ward (22%) had "Moderate and High" level of satisfaction than patients admitted in surgical (43%) and Medical (25 %) wards. Of all interviewed people, 60% of Orthodox Christian had "Moderate and High" level of satisfaction than Muslim (20%) and others (Protestant and Catholic) (11%). Age ≤50 (92.36%) of people had "Moderate and High" level of satisfaction than Age ≥ 50(86.87). Those who were not employed (92.02%) had

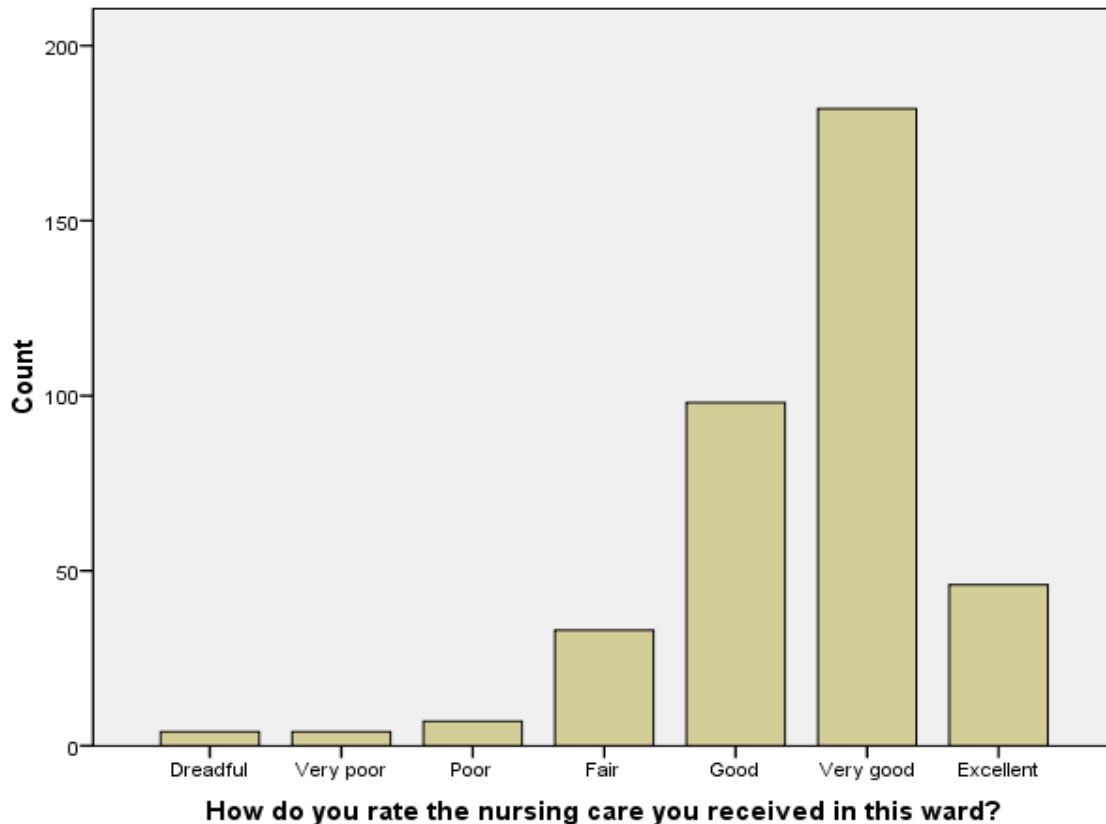


Figure 1. Rating of nursing care received by inpatients in Black Lion Hospital from March to April, 2012.

“Moderate and High level of satisfaction” than employed (83.33%) and those who spent 2 to 10 nights (95.74%) and those who spent ≥ 22 nights (85.71% were having more satisfaction than people who spent 11 to 21 nights (81.44%) in the ward. Of all inpatients’ interviewed, 90.9% had “Moderate and High” level of satisfaction the multivariate analysis result showed that female (95% CI, AOR: 3.78(1.35, 10.56)) were more satisfied than male patients. Those whose Age ≥ 50 years (95% CI, AOR: 0.36(0.14, 0.93)) were less likely to be satisfied than patients’ whose age was < 50 years of age. Among the wards, people who had been admitted in medical (95% CI, AOR (0.35(0.15, 0.83)) ward were less likely to be satisfied than surgical ward. From marital status, never married (95%CI,AOR:2.74(1.07,7.03)) had a better satisfaction than those who were married and people who spent (11 to 21 nights) (95%CI,AOR:0.17(0.07,0.41) and ≥ 22 nights (95%CI,AOR:0.26(0.08,0.82) were less satisfied than those who spent < 10 days in the ward (Table 3).

Patients’ opinions and general comments about Black Lion Hospital

Among the 374 respondents 75(20%), 37(10%) and

262(70%) had negative, neutral and positive opinion respectively. Some of the opinions include; “Nurses must treat every individual equally, there is an interwoven problem in emergency department and card room, and the card room workers and the janitors must be a health professionals or they should be at least 12 grade completed or they should receive special training. There was also a problem of water, linen, toilet, food, sanitation in the hospital, laundry, laboratory, X-ray and pharmacy services and these services must be improved in order to increase patient satisfaction and experiences”. The participants also provided general comments to the government bodies including: “The government should increase nurse’s salary to make them happy/interested at their job, there should be supervision and controlling mechanism, and since there is a work overload in nurses, the government should recruit additional staff”. The participants also provide comments to the hospital administrators to “give reward/ recognition / for those who perform well, information provider in every floor or direction indicator, providing adequate materials for nurses, and recruiting a multilingual person for those people who come from rural parts of Ethiopia/for peoples who cannot speak Amharic/ were among frequently provided recommendations”. They also recommended the nurse’s and

Table 2. Mean and standard deviations for inpatients satisfaction with nursing care in Black Lion Hospital from March to April, 2012.

Item	Medical		Gyn/Obs		Surgical	
	Mean (M)	SD	Mean(M)	SD	Mean(M)	SD
The amount of time nurses spent with you	3.67	0.90	4.00	0.72	3.92	0.87
How capable nurses were at their job	3.69	0.88	3.89	0.67	3.87	0.79
There always being a nurse around if you needed one	3.62	1.02	3.98	0.70	3.84	0.90
The amount nurses knew about your care	3.62	0.98	3.89	0.74	3.85	0.87
How quickly nurses came when you called for them	3.56	1.08	3.93	0.83	3.81	0.96
The way the nurses made you feel at home	3.72	1.20	3.99	0.95	3.95	1.08
The amount of information nurses gave to you about your condition and treatment	3.42	1.11	3.71	0.86	3.71	1.00
How often nurses checked to see if you were okay	3.60	1.03	3.86	0.84	3.90	0.87
Nurses' helpfulness	3.88	1.02	4.28	0.77	4.16	0.87
The way nurses explained things to you	3.61	1.06	3.79	0.78	3.83	0.92
How nurses helped put your relatives' or friends' minds at rest	3.82	0.94	4.14	0.78	4.06	0.98
Nurses' manner in going about their work	4.41	0.77	4.47	0.78	4.34	0.84
The type of information nurses gave to you about your condition and treatment	3.42	1.11	3.69	0.84	3.72	0.99
Nurses' treatment of you as an individual	4.23	0.94	4.32	0.4	4.45	0.72
How nurses listened to your worries and concerns	3.86	1.09	4.10	0.84	3.97	0.91
The amount of freedom you were given on the ward	4.58	0.63	4.52	0.79	4.43	0.78
How willing nurses were to respond to your requests	3.76	0.97	4.00	0.63	4.03	0.76
The amount of privacy nurses gave you	3.80	0.94	3.93	0.66	3.93	0.80
Nurses' awareness of your needs	3.64	0.97	3.87	0.89	3.90	0.91
Average	3.78	0.98	4.02	0.76	3.98	0.89

other health professionals “to give a concern for the patient and for their relatives, to have patient station for those who are not admitted in the ward and waiting their appointment. Nurses are our families, they should be patient, transparent, open minded and well coming enough in their activity/service, like the nurses the doctors should also pay attention to the patients, Nurses must treat every individual equally, and the nurses and other health professionals must do that cooperatively”. Generally, they witnessed as there was a big problem in the management area; and they recommended for continuous monitoring/evaluation mechanism in other services than

nursing care services. They also recommended before assessing the patient satisfaction, the researchers should also assess nurse's satisfaction and other factors, which affect patient satisfaction and experience other than nursing care.

DISCUSSION

Demographic variable and patient satisfaction

In this study, the overall participants' satisfaction with nursing care was 90.1%, which is higher when it is compared with the previous research

done in Ethiopia, which was 67% (Bekelle, 2005) and Jordan (72.9%) (Alasad and Ahmed, 2003). This change was most probably due to the implementation of BPR (Business Processing and Reengineering) reform, due to continuous monitoring and evaluation by Federal Ministry of Health about quality of care for the patients, upgrading different nurses to the next level and may be due to the beginning of nursing process implementation. Of the six independent variables that were entered into both regression models, the type of ward, sex, age, and marital status affected the SNCS. Among hospitalized patients the female patients who had been treated in a surgical ward

Table 3. Bivariate and multivariate analyses for factors affecting inpatients satisfaction in Black Lion Hospital from March to April, 2012.

Variable	Satisfaction of patient with nursing care		COR (95% CI)	AOR (95% CI)
	Low level of satisfaction	Moderate and high level of satisfaction		
Sex				
Male	24	150	1.00	1.00
Female	10	190	3.04(1.41,6.55)	3.78(1.35,10.56)*
Age				
≤50 years	21	254	1.00	1.00
>50 years	13	86	0.55(0.26,1.14)	0.36(0.14,0.93)*
Ward				
Surgical	14	162	1.00	1.00
Medical	16	95	0.51(0.24,1.10)	0.35(0.15,0.83)*
Gyn/Obs	4	83	1.793(0.57,5.62)	0.33(0.07,1.56)*
Educational status				
Illiterate	4	68	1.00	1.00
Literate	30	272	0.53(0.18,1.57)	0.60(0.18,1.96)
Religion				
Orthodox	22	224	1.00	1.00
Muslim	11	74	0.66(0.31,1.43)	0.54(0.23,1.28)
Others ^a	1	42	4.13(0.54,31.44)	4.10(0.50,33.67)
Marital status				
Living together	13	82	1.00	1.00
Never married	21	258	1.95(0.93,4.06)	2.74(1.07,7.03)*
Nights in the ward				
2-10	10	225	1.00	1.00
11-21	18	79	0.20(0.09,0.44)	0.17(0.07,0.41)**
≥22	6	36	0.27(0.09,0.78)	0.26(0.08,0.82)**

*Significantly associated ($p < 0.05$), **highly significantly associated ($P < 0.001$). -a Protestant and Catholic.

surgical ward and had a higher educational level gave lower SNCS scores than the other categories of patient. In this study females (95%CI, AOR: 3.78(1.35, 10.56) had higher satisfaction than males. This finding was consistent with the studies done in Jordan and Ethiopia (Alasad and Ahmed, 2003, Bekelle, 2005). This result might be due to females' ability to have a free discussion with female nurses because majority of the nurses on those study wards were females. Nevertheless, a study done in Turkey (Thomas et al., 1996) indicated that males were more satisfied with nursing care than females. The study done in Ethiopia (Bekelle, 2005) indicated that age(18 to 30) had more satisfaction than older age group which was similar with the research done in Turkey (Ummu Yildiz et al., 2010), but in this research middle aged groups were found to be higher than those

of younger aged groups. Similar to those studies (Bekelle, 2005, Ummu Yildiz et al., 2010) the findings of this study indicated that older people (Age>50 years (95%CI, AOR: 0.36(0.14, 0.93)) are less likely to be satisfied than patients whose age is <50 yrs. This finding is incongruent with a study done in Japan, Jordan (Tokunaga J et al., 2002; Ummu Yildiz et al., 2010). The reason for this might be as the patient's age increase their demand or need for nursing care will increase due to many physiological changes; and this could be the reason for the less satisfaction. People who were admitted in Medical ward (Medical (95%CI, AOR (0.35(0.15, 0.83)) were less likely to be satisfied than Obs/Gyn ward admitted patients. This finding was similar with the study in Ethiopia, Jordan, and Japan (Bekelle, 2005, Alasad and Ahmed, 2003, and Alhusban and Abualrub, 2009). The

reason for this may be due to the presence of specialized Midwife professionals in this ward. In contrast to this study, the study done in Turkey (Ummu Yildiz et al., 2010) patients who were in surgical ward (43%) had more satisfaction than people who were in medical ward (57%). In this study never married (95%CI, AOR: 2.74(1.07, 7.03)) people had higher satisfaction than married. It might be because of never married peoples' lesser expectation. However, there was no association in other studies (Ahmed and Alasad, 2004, Akin and Erdogan, 2007, Alasad and Ahmed, 2003, Alhusban and Abualrub, 2009, Bekelle, 2005; Ummu Yildiz et al., 2010; Vincent et al., 2004).

Patients' number of nights spent in the ward had also an association with patients' satisfaction. In this study those (11 to 21 nights) (95%CI, AOR: 0.17(0.07, 0.41) and ≥ 22 nights (95%CI, AOR: 0.26(0.08, 0.82) had lesser satisfaction than those who had been < 10 days. It may be because those who spent (11 to 21 nights) and ≥ 22 nights might have a higher demand and they might have some other hospital acquired infections as they spent more time in the hospital. It was incongruent with the study in Japan (Tokunaga J et al., 2002). However, it was similar with the study in Jordan (Alhusban and Abualrub, 2009). Other factors like educational status were identified as they do have relation with patients' satisfaction. Study (Bekelle, 2005, Ummu Yildiz et al., 2010) found lesser-educated individuals had higher satisfaction. This could be explained by people who are highly educated might expect a higher standard of care than lower education status people. Such inconsistent results in regard to the associations between the demographic variables of patients and the level of satisfaction calls for further research that controls other variables such as the demographic variables of nurses who provide care for those patients and other organizational variables such like nurses' satisfaction (Alhusban and Abualrub, 2009). It will be also better to add other variables in organizational variables like organizational infrastructure. Since the overall satisfaction level of the patient is 90.1% the rumors of the community was not related to the nursing care service they receive in the hospital. Even though there were some factors which would decrease the patient satisfaction related to nursing care, the majority of patients' dissatisfaction was related to other hospital services. Moreover, as the patients witnessed the community's rumor was not directly related to the nursing care they received in the hospital instead it was the problems of other services including "pharmacy, laboratory, catering, X-ray, medical and other services".

Conclusion

In this research, the overall patient satisfaction were 90.1% and this implies that the quality of nursing care service that was provided in Black Lion hospital was higher when it was compared with different literature

findings. The causes of patient dissatisfaction with the hospital is not majorly due to nursing care instead it is the problems of other hospital services such as pharmacy, radiology, laboratory, catering and other services. In this study, the patients' satisfaction is affected by the amount and type of information they receive about their condition and treatment, and the time that they spent with the nurses have an influence on their satisfaction. The type of ward, age, sex, marital status and number of nights spent in the ward and the number of nights spent in the ward and occupation were found to affect patient satisfaction and experience with nursing care respectively. Surgical ward patients, female, < 50 -yrs-old patients, never married and those who spent 11 to 12 nights and ≥ 22 nights were lesser satisfied than those who spent 2 to 10 nights in the ward. Identifying the level of patients' satisfaction and experience with nursing care was a good indicator of quality in nursing care service provision. Based on the findings of the study, we give the following recommendations:

1. Since the overall patient satisfaction with nursing care was 90.1% in the Black Lion hospital, the nurses should continue their practices to give a better advocacy in nursing care for their patient's individual needs. Likewise nurses at Black Lion Hospital as stated by some of the patients' should practice equality and justice to all patients.
2. Nurse administrators, managers, researchers and FMOH should; (i) give an emphasis on the importance of continuity of nursing care; (ii) hold workshops to foster effective time management and ethical issues among nurses. (iii) The hospital administrator should give reward and accreditation for those who perform well.
3. Moreover; the future researchers should do an exit interview and qualitative study in order to minimize social desirability bias and to identify other confounders. In addition to this, researchers also shall do further research in general hospital services to uncover the major causes of patients' dissatisfaction.

ACKNOWLEDGEMENT

First, we would like to thank our God; the one who gives health, patience, love and allows us to fulfill our dreams. We would like to also thank the NSNS team at the University of Newcastle Upon Tyne for their permission to use the NSNS standardized questionnaire in this study; especially the manager of NSNS team Professor Elaine McColl. We also thank Addis Ababa University for financial support. Our special gratitude also goes to the Federal Ministry of Health Quality Management Team, especially Mohammedamin Adem; Officer, Medical Services Directorate for providing a guideline; Ethiopian Hospital Reform Implementation guidelines. To our data collectors and supervisors for long hours of commitment to data collection for this study without whom would not

have been possible. We highly appreciate their invaluable contributions so this research paper will come into existence. We want to spread out our gratefulness to our study participants for their willingness to participate in our study. Finally, we want to upturn our sincere thanks to the following people, who have been so helpful on us in so many ways: Ato Dawit Birhanu, Dr. Amy Bender and Dr. Verginia C. Cudia (for editing) and our family.

Conflict of Interest

The author(s) have not declared any conflict of interests.

REFERENCES

- Ahmad M, Alasad J (2004). Predictors of patients' experiences of nursing care in medical surgical wards. *Int. J. Nurs. Pract.* 10:235–241.
- Akin S, Erdogan S (2007). The Turkish version of the Newcastle Satisfaction with Nursing Care Scale used on medical and surgical patients. *J. Clin. Nurs.* 16:646–653.
- Alasad J, Ahmad M (2003). Patients' satisfaction with nursing care in Jordan. *Int. J. Healthc. Qual. Assur.* 16(6):279–285.
- Alhusban MA, Abualrub RF (2009). *J. Nurs. Manag.* 17:749–758.
- Bekele C (2005). Adult patient satisfaction with nursing care: unpublished master's thesis. pp. 36-40
- Crow R, Gage H, Hampson S, Hart J, Kimber A, Storey L, Thomas H (2003). The measurement of satisfaction with healthcare; implications for practice from a systematic review of literature. Health Technology Assessment NHS R&D HTA Programme.
- Donabedian A (1988). The quality of care: How can it be assessed? *J. Am. Med. Assoc.* 261(8):1743–1748.
- FDRE (2010). Ethiopian Hospital Reform Implementation Guidelines. 2(1), Chapter 12F:2.
- Felesia SC (2009). Patient satisfaction with nursing care: A Meta synthesis. pp. 1-20 (unpublished).
- Ho SE, Kaur G, Wafa, SR, Zakaria SZS, Omar R (2006). Post-cardiac surgery patient satisfaction with quality nursing care at Institute Jantung Negara (IJN). *Med. Health* 1(1):14-19.
- Tzeng HM, Yin CY, Grunawalt J (2008). Effective assessment of use of sitters by nurses in inpatient care settings. *J. Adv. Nurs.* 64(2):176-183.
- Johansson P, Oleni M, Fridlund B (2002). Patient satisfaction with nursing care in the context of health care: a literature study. *Scand. J. Caring Sci.* 16:337–344.
- Kuosmanen L, Hatonen H, Jyrkinen AR, Katajisto J, Valimaki M (2006). Patient satisfaction with psychiatric inpatient care. *J. Adv. Nurs.* 55(6):655–663.
- Merkouris A, Ifantopoulos J, Lanara V, Lemonidou C (1999). Patient's satisfaction; a key concept for evaluating and improving nursing services. *J. Nurs. Manag.* 7:19–28.
- Ganova-lolovska M, Kalinov K, Geraedts M (2008). Satisfaction of inpatients with acute coronary syndrome in Bulgaria. *Health Qual. Life Outcomes* 6(1):50.
- Risser N (1975). Development of an instrument to measure patient satisfaction with nurses and nursing care in primary care settings. *Nurs. Res.* 24:45–52.
- Roohan PJ, Franko SJ, Anarella JP, Dellehunt LK, Gesten FC (2003). Do commercial managed care members rate their health plans differently than Medicaid managed care members? *Health Serv. Res.* 38:1121–34.
- Saiboon I, Ho SE, Krishnan B, Ali SN, Murad N, Pathnathan A, Choy YC (2008). A study of patients' satisfaction with the emergency department (ED) of Hospital Universiti Kebangsaan Malaysia (HUKM). *Med. Health* 3(1):7-13.
- Teng KY, Norazliah S (2012). Surgical patients' satisfaction of nursing care at the orthopedic wards in Hospital Universiti Sains Malaysia (HUSM). *J. Environ. Health* 3(1):36-43.
- Thomas L, McColl E, Priest J, Bond S, Boys R (1996). Newcastle satisfaction with nursing scales: an instrument for quality assessment of nursing care. *Quality in Health Care* 5(2):67–72.
- Thrasher C, Purc-Stephenson R (2008). Patient satisfaction with nurse practitioner care in emergency departments in Canada. *J. Am. Acad. Nurse Pract.* 20(5):231–237.
- Tokunaga J, Imanaka Y, Nobutomo K (2002). Influence of length of stay on patient satisfaction with hospital care in Japan. *Int. J. Qual. Healthc.* 12(5):395–401.
- Ummu YF, Serap U, Necdet S (2010). Patient satisfaction with nursing care and its relationship with patient characteristics. *Nurs. Health Sci.* 12(2):162-169
- Vincent S, Burman M. Mary B (2004). Continuity of care and other determinants of patient satisfaction with primary care. *Health Serv. Res. Dev.* 8:226–233.

Full Length Research Paper

Socio-economic challenges of parents of children with neurological disorders: A hospital-based study in North West Nigeria

Lawal H.¹, Anyebe E. E.^{2*}, Obiako O. R.³ and Garba S. N.⁴

¹Paediatric Unit, Nursing Services Department, ABU Teaching Hospital, Zaria, Nigeria.

²Research and Training Unit, School of Nursing, ABU Teaching Hospital, Zaria, Nigeria.

³Neurology Unit, Department of Medicine, ABU Teaching Hospital, Zaria, Nigeria.

⁴Department of Nursing Science, Ahmadu Bello University, Zaria, Nigeria.

Received 20 January, 2014; Accepted 26 May, 2014

Parents of children with neurological disorders face several socio-economic challenges in nurturing them. Experiences of parents in the study area have not been explored. This descriptive cross-sectional study was designed to investigate socio-economic challenges faced by parents of children with neurological dysfunctions. Paediatric Neurology Outpatient Clinic, Ahmadu Bello University Teaching Hospital Shika, Zaria, Kaduna State, North-West Nigeria, a tertiary health institution was used. A convenience sample of 60 parents was obtained, from whom data were collected through an interviewer-administered structured questionnaire and in-depth interviews on nine of the parents. Sixty-one children were affected (a parent had 2). Cerebral palsy (50.8%) and seizure disorders (39.4%) were the commonest disorders found. A mean age of 5 years was identified. Male (55%) and the first-born children (44.3%) were more affected. Perceived causes identified were infection/childhood disease (65%), asphyxia (23.3%), and prolonged labour (18.3%). The major socio-economic challenges were poor social life and hampered economic status. Parents were themselves deprived of their normal social lives. Parents of children with neurologic problems were found to have faced a lot of socio-economic challenges that significantly affects the lives of both the affected children and the other siblings. Existing parental poor socio-economic status complicates these challenges. Their economic status and pursuance of family income are hampered, coupled with the high cost of managing the affected children. Social support groups for parents and the affected children should be encouraged by professional bodies, government and non-governmental organizations to enhance social relationships, while ensuring health insurance coverage for these children to reduce economic burden on their parents and enhance maintenance of the healthy status of the other children.

Key words: Socio- economic challenges, parental coping, neurological deficit, children.

INTRODUCTION

Most healthy children enjoy normal growth with little need for specialized health care services. Although care giving

*Corresponding author. E-mail: ejembianyebe@gmail.com or eanyebe@yahoo.com.

Author(s) agree that this article remain permanently open access under the terms of the [Creative Commons Attribution License 4.0 International License](http://creativecommons.org/licenses/by/4.0/)

is a normal function and desired expectation of every parent; challenges occur when a child experiences functional limitation and long term dependence, because disability in a child affects not only the child but the entire family (Raina et al., 2005; Centre for Child Development, 2007), especially when such children experience difficulties that may require long term special care. Because the brain controls every human function, development of a lesion or lesions in any part of the brain results in a neurological deficit which may hinder the performance of activities and tasks undertaken by that part of the brain. World Health Organisation (WHO) has established that neuro deficits are a major global problem (WHO, 2006).

Neurological disorders are the major causes of functional disability in children (Bajraszewski, 2008), and can result from congenital and hereditary causes, or be environmentally caused. Common neurological disorders in children include: head injuries, trauma to spinal cord, exposure to toxic chemicals and various forms of viral, bacterial, parasitic and fungal infections (Batul, 2011; Raiford, 2013). These disorders commonly cause forms of cerebral palsy, epilepsies and epilepsy syndromes, hydrocephalus, microcephaly, attention deficit, hyperactivity, meningo-encephalitis and autism. These are associated with delays in developmental milestones, muscle rigidity and in-coordination, impairment of speech, hearing and vision. Neurological disorders ultimately lead to learning disability and prolonged dependency (Idro et al., 2010); thus posing enormous psychosocial and socio-economic challenges to parents. This is particularly true of those parents who do not have a good knowledge of the condition and possible ways of addressing the problems of the affected children. WHO recognized the socio-economic challenges of such disorders to all strata of society, but acknowledged the paucity of parental experiences of having children or family members with neuro-disorders (WHO, 2006).

Parents of children with neurological disorders experience socio-economic tiredness and exhaustion (Mungo et al., 2007). The marital relationship may suffer unduly from added stress of blame, guilt and anxiety. A child's disability attacks the fabrics of marriage in different ways and reshapes the organization of the family, creating a fertile ground for conflicts (Vijesh, 2007). Other social challenges are inadequate social support and problems with social life (Ambikile, 2012). The social life may become non-existent and parents may be fearful of rejection by friends/relatives (Vijesh, 2007).

Families of affected children suffer significant financial disadvantages as a result of the need to care for the children (Child Neurology Society, 2012). Financially, more is required to raise a handicapped child, with little prospects of the child earning a living of his or her own. Such children need a multidisciplinary approach and series of investigations such as computerized

tomography, magnetic resonance imaging, among others, which poses financial implications on their parents (Batul, 2011). Absence of resources poses a barrier to achieving other outcomes for the parents. Where they exist, family funding services for parents, as opined by Beresford (2007), can be an effective and legitimate way of supporting a disabled child's development and wellbeing. Caplan (2005) identified difficulties in getting insurance coverage for doctor's medication and other treatment as a challenge. Perterson (2011) highlighted that most parents in paid work have to take off time to care for their sick children. Parental income has been positively related to child's outcome. Financial stress, employment loss and overall negative economic impact on families with critically ill child have been demonstrated (Winthrop et al., 2005). A study in California showed that cerebral palsy had the highest life time cost per new case, averaging \$503,000 in 1992 (Ashwal, 2004).

In Nigeria, the National Health Insurance Scheme Handbook (Act 35 of 1999) states the objectives of the scheme to include ensuring that every Nigerian has access to good health care services, protect families from the financial hardship of huge medical bills, limit the rise in the cost of health care services, ensure equitable distribution of health care costs among different income groups, and maintain a high standard of health care delivery services within the scheme. Other objectives include ensuring efficiency in health care services, improving and harnessing private sector participation in the provision of healthcare services, ensuring adequate distribution of health care facilities within the federation, ensuring equitable patronage of all levels of health care and ensuring the availability of funds to the health sector for improved services. National Health Insurance Scheme (NHIS), as a health care risk spreading mechanism, solves the problem of inequality in the provision of health care services, provides comprehensive health care delivery at affordable cost, covers employees of the formal sectors, self-employed rural communities, the poor and vulnerable groups (Ibiwoye and Adeleke, 2007; Ononokpono, 2008). Abubakar (2007), the NHIS categorizes the users of the scheme into three segments which include a formal sector programme covering public sector (Federal, State and Local Government), armed forces, police and other uniform services, an organized private sector, and students of tertiary institutions. The second classification involves the informal sector which includes rural community, urban self-employed and voluntary participation. The last class is a voluntary group programme which covers permanently challenged persons, the aged, children under five years of age and prison inmates.

Despite the major aim of NHIS being mobilising additional sources of funds to expand and improve access to health care, and if properly implemented, has the potential to improve the health and welfare of the citizens of the country (Adatsi, 2006), it has been

found that some health professionals perceived that there is dissatisfaction and inconsistencies about the implementation of the scheme and the level of publicity about the scheme (Anyebe et al, in-press). They further stated that, because of this, many healthcare professionals are not registered with the NHIS. The NHIS users are believed to be limited to public sector workers only. In addition to lack of full registration of providers, certain categories of ailments are not covered including neurologic disabilities. The focus here is on the needs of parents of children with neurologic disabilities.

Little is known about the quality of life of parents with developmental diseased children in Nigeria. Donarld et al. (2014) carried out a systematic review of cases of cerebral palsy in the African continent, a research-challenged environment. This study demonstrated a number of social, economic and psychological burdens of having children with cerebral palsy in the African continent. However, there is insufficient empirical documentation of the needs of the parents of these children in Africa. The present study adds to this literature by specifically studying the needs of parents of neurologically disabled children in the country of Nigeria.

MATERIALS AND METHODS

Study design and setting

This study adopted a prospective cross sectional method to explore the experiences of parents of children with neurological disorders attending the Paediatric Neurology Outpatient Clinic of Ahmadu Bello University Teaching Hospital (ABUTH), Shika, Zaria. Parents whose children were not diagnosed as having neurologic problem were excluded. ABUTH, Shika, Zaria is a 700-bed capacity tertiary health institution located in Kaduna State, North Western, Nigeria. It has many specialized outpatient clinics that receive referrals from a population of more than 15 million people spread across 10 states in Northern Nigeria, the Federal Capital, Abuja and adjoining states in Southern Nigeria. The paediatric neurology clinic is one of the specialist clinics.

Study population

Sixty parents of children with neurological deficits were selected via non-probability, availability sampling. Records at the paediatric neurology outpatient clinic for the previous six months showed an average of 19 of such parents attending the clinic per month. In this prospective study, the investigators estimated an average of 20 parents per month for three months to derive a sample size of 60.

Instrument and data collection

The sixty parents (51 mothers, 9 fathers) were interviewed using a 42-item semi-structured questionnaire comprising three (3) sections: (a) socio demographic characteristics of parents and the affected children; (b) perceived causes of neurological dysfunction(s) by parents; (c) socio-economic challenges faced by parents.

The questionnaire was written in English (the official language in Nigeria), but was translated to Hausa (the common language of

communication in Northern Nigeria) by a bilingual expert, and then back translated to English by another bilingual expert who was blind to the first translation. Both Hausa and English versions were then pre-tested on 10 parents who were literate and fluent in Hausa language, but semi-literate in English language; in order to remove and correct any ambiguity in the questionnaire, simulate investigator-subject interaction and avoid inter-researcher errors. Thereafter, each of the 60 parents was interviewed either in Hausa or English language depending on their proficiency and choice.

Both qualitative and quantitative data were collected by the first author over a period of three months (September to November, 2012). Parents were consecutively selected and interviewed. The quantitative data were entered into an excel spread sheet and analysed using Statistical Package for Social Science (SPSS; version 17). The qualitative data were recorded with a tape recorder. Those done in Hausa were translated into English, and transcribed. Both quantitative and qualitative data were triangulated to meet research objectives.

Data analysis

The data obtained were analyzed descriptively using frequency tables, percentages and charts. Chi-square test was used to define relationships between variables. Level of significance was set at 5%, within 95% confidence interval. The qualitative data were analysed thematically using content analysis.

Ethical clearance

Permission for the study was obtained from the management of the hospital, while informed consent was obtained from parents after explaining the objectives of the study, the voluntary nature of participation, and the confidentiality of participants' responses.

RESULTS

The socio demographic characteristics

Parents

Table 1 shows that 85.0% of the parents were mothers, while 15.0% were fathers. All the parents were married, except one, who was a widow. Majority of the parents were Muslims (85%) and Hausa/Fulani (71.7%), respectively. In Nigeria, most Hausa/Fulani are predominantly Muslims. Many respondents (36.7%) had a tertiary level of education, while 25% had no form of western education. Majority of the respondents (45.0%) were self employed, while 25.0% were full-time housewives. Many (45.0%) of the respondents could not ascertain how much income they get in a month, however, 20.0% earned less than N10,000.00 (about \$62.5 US) per month. Mean income was N57, 666.00 (about \$360 US).

Children

As indicated in Table 2, of the 61 affected children, 55.7% were males. The ages of the children range from

Table 1. Socio demographic characteristics of parents of affected children.

Variable	Mother (n=51, 85%)	Father (n=9, 15%)	Total [N= 60 (100.0%)]
Marital status			
Married	50 (83.3)	9 (15)	59 (98.3)
Widow	1 (1.7)	0 (0.0)	1 (1.7)
Tribe			
Hausa/Fulani	38 (63.3)	05 (8.3)	43 (71.6)
Northern/ Southern minorities	09 (15)	03 (5.0)	12 (20.0)
Igbo	02 (3.3)	01 (1.7)	3 (5.0)
Yoruba	02 (3.3)	00 (0.0)	2 (3.3)
Religion			
Islam	46 (76.7)	05 (8.3)	51 (85.0)
Christianity	05 (8.3)	04 (6.7)	9 (15.0)
Educational attainment			
None	13 (21.7)	2 (3.3)	15 (25.0)
Primary	5 (8.3)	0 (0.0)	5 (8.3)
Secondary	15 (25.0)	3 (5.0)	18 (28.0)
Tertiary	18 (30.0)	4 (6.7)	22 (36.7)
Occupation			
None or full housewife	15 (25.0)	0 (0.0)	15 (25.0)
Self employed	22 (36.7)	5 (8.3)	27 (45.0)
Government employed	14 (23.3)	4 (6.7)	18 (30.0)
Income per 30 days in Dollars (Naira)			
None/I don't know	25 (41.7)	2 (3.3)	27 (45.0)
< \$62.5 (10,000.00)	12 (20.0)	0 (0.0)	12 (20.0)
\$68.75-\$125 (11, 000.00 - 20, 000.00)	2 (3.3)	0 (0.0)	2 (3.3)
\$131.2-\$187.5 (21,000.00 - 30,000.00)	2 (3.3)	0 (0.0)	2 (3.3)
\$ 193.75-\$250 (31,000.00 - 40,000.00)	0 (0.0)	2 (3.3)	2 (3.3)
\$256.25 (41,000.00) and above	10 (16.7)	5 (8.3)	15 (25.0)

Table 2. Distribution of age of affected children and their neurological dysfunction by sex.

Variable	Males (n=34, 55.7%)	Females (n=27, 44.3%)	Total (N=61, 100.0%)
*Age of child (years)			
1.0 - 2.0	8 (13.1)	8 (13.1)	16 (26.2)
2.1 - 4.0	11 (18.0)	7 (11.5)	18 (29.5)
4.1 - 6.0	3 (4.9)	5 (8.2)	8 (13.1)
≥ 6.1	12 (19.7)	7 (11.5)	19 (31.1)
Mean ± SD	5.3 years	4.8 years	5 years
$\chi^2 = 1.911$, df = 3, sig. level = 0.05, CV = 7.815			
Type of neurologic deficit			
Cerebral palsy	15 (24.6)	16 (26.2)	31 (50.8)
Seizures	15 (24.6)	9 (14.8)	24 (39.4)
ADHD	2 (3.3)	2 (3.3)	4 (6.6)
Microencephaly	2 (3.2)	0 (0.0)	2 (3.2)
$\chi^2 = 4.084$, df = 4, sig. level = 0.05, CV = 9.488			

Table 3. Social challenges faced by parents of children with neurologic disorders.

Social issue	Yes (%)	No (%)	Total (%)
Can you travel for days leaving the child at home?	27 (45.0)	33 (55.0)	60 (100)
Does the condition of the child allow you to engage in social activities?	36 (60.0)	24 (40.0)	60 (100)
Have your friends or relatives avoided you due to this problem?	06 (10.0)	54 (90.0)	60 (100)
Do your friends carry the child when they visit you?	44 (73.3)	16 (26.7)	60 (100)

Table 4. Helpers/activities carried out.

Helpers/activities	Bathing	Clothing/Grooming	Feeding	Assist toileting	Carrying/Lifting	Laundry
Other siblings	10	08	12	10	09	09
Domestic workers	05	06	05	02	04	05
Neighbor						
Spouse	01	01	01	01	02	01
Others, e.g family members	09	09	09	06	08	09

one to above six years, with a mean age of 5 years (a mean age of 4.8 years for females and 5.3 years for males). The common deficits seen were cerebral palsy, seizure disorders and attention-deficit hyperactivity disorder. Nearly a quarter of male children, in the study (24.6%) suffer both cerebral palsy and seizure disorders.

Social relationships

In Table 3, 55% of parents stated that their own movement was hampered while a good number of them (40.0%) missed their social interactions due to the health conditions of their children. Complimenting these findings were narratives from parents. For instance, a woman said: "how can I go out? I do not have anybody to stay with the child". Another mother said, "I don't take her out". "I don't attend social functions because some people gossip about us". Expressing her travail, a mother said, "I don't allow friends to carry her even if they visit me, because she drools saliva. A visitor beat her one day".

However, some parents do have social support as demonstrated in the following narratives from interviews. One woman said, "I leave the child with my neighbour, he likes to stay with her, sometimes I take the child to the school where I teach and keep him with the nanny. They sing and I realize he is happy there." Another woman said: "my mate (the second wife) carries him, bathe him and even clothe him, she has been very supportive."

Most mothers had limited avenues for social interaction, a mother said, "I travel when it is inevitable; most times I have to take care of him and other children". Even when they have to leave home, it is usually few days, a mother said, "I travel, but for one to two days". Another said "at most three days". Table 4 shows the nature of assistance friends and other family members offer. Other siblings and neighbours tend to help more;

few are able to hire domestic workers for assistance.

Family relationships

Buttressing these challenges on family relationships, some parents confessed some difficulty moments. A mother said: "Initially, we quarrelled with my husband, at a point we neglected the child, but later, we learnt to take care of him." Some mothers attested to paternal negligence of the affected child. A mother stated that: "He (her husband) abandoned him (the affected child) and gave more attention to the other children. This makes me unhappy", she lamented. A mother said: "the father has no business with the child; I am all he (the affected child) has." This position was then further explored by the first author by interviewing a few fathers that were available and consented to the interview.

From the In-Depth Interviews (IDIs) conducted, fathers also shared their experiences of the socio-economic travails of caring for neurologically challenged children. Some of these challenges revolve around the foundation of family life and marriage. For instance, a father narrated communication and interaction problems, when he said: "we use to have unnecessary arguments and at times I get bored of everything." Some fathers even expressed their emotions towards the affected children; some reported giving extra care to the affected children. A particular father said: "I like him most. I give extra attention to him."

Some mothers also agreed with the fathers' views on caring for the affected children. A mother simply said: "he is his father's favourite" while another mother said that both the father and herself often "discuss and plan for him (the affected son)." In fact, some other fathers had to quarrel if the affected child is not well cared for. This was how two mothers narrated their experiences: "He quarrels if I don't take care of the child". "He quarrels if I give him

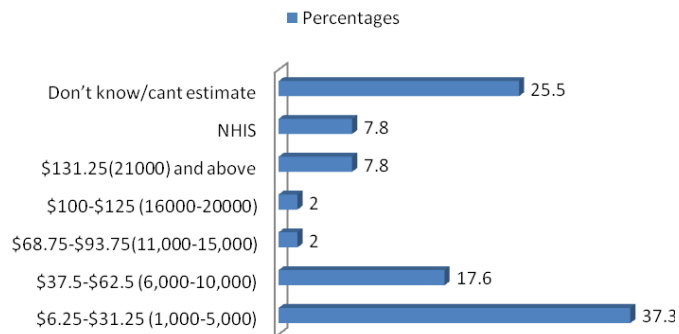


Figure 1. Medical bills and treatment per month.

(the affected child) traditional herbs.”

In terms of relationships between parents and the affected child, there is great variation, but in all cases, the child has a profound impact on family dynamics. For example, some other parents described the situation as frustrating, causing parental withdrawal, paternal neglect, reduced attention and unnecessary arguments. These parental decreased attention and neglect manifest in various forms, such as, women complaining of husbands “not sleeping with me” or “no longer entering my room” (indicating absence of sexual relations), as narrated by two mothers. In the study environment, sex is often not openly discussed.

Economic issues and out-of-pocket expenses

Generally, parents reported that caring for the neurologically affected children is demanding. In further analysis, it was found that some parents (28%) could not engage in their economic activities because of the child's health problem. One of the mothers said, “Because the child (with cerebral palsy) can't do anything for himself, I am always attending to his needs”. Another mother, while commenting on the same issue, sighed and said:

I have to do everything for him, especially in the morning; he takes plenty of my time. Because he can't talk, I use pampers for him, I have to change it any time he sheet.

For some of the parents whose children suffer seizure disorders, the children were said to be able to take care of themselves. However, at times, the parents helped. A mother said: most times I let her do some things but I have to watch her. A mother said, “because the child cannot talk, and feeding him is difficult, we buy some easy digestible food and diapers all the time”.

Some parents had to employ a domestic staff to help. A mother said that she had a worker that watch over her (the affected daughter), and she pays for the services of the staff monthly. The worker employed usually do most physical care; their wages range from N2, 000 to N10, 000 (\$12.5 to \$62.5), per month (Table 4).

Complementing these findings, some parents said that they would not be able to ascertain how much they spend on the children's care. The expenditure on their care included hospital/medical bills and transport fares over long distances to the teaching hospital. They reported that at the onset, they had to carry out a series of investigations and buy different kinds of expensive drugs. For some, the drugs were not readily available. For example, a father lamented: “we spend a lot, we could not get some drugs here, we send to our relations outside Nigeria to help us get the drugs”.

For the few (7.8%) that enjoy NHIS (Figure 1), non-availability of most of the prescribed drugs was a problem. One of the parents complained that the: “NHIS don't have some of the drugs, especially the expensive ones.” According to NHIS Handbook (1999), the National Health Insurance Scheme was established for the purpose of providing health insurance that entitles insured persons and their dependants (up to four children and a spouse with ailments covered by the scheme) the benefit of prescribed good quality and cost effective health services as set out in this decree. However, the coverage of the few cases is atypical, but covers investigative procedures only. Once diagnoses were established, parents claimed that drugs for treatment are covered by the scheme.

Many parents had to travel for over 300 km before they could obtain treatment for their children. A parent narrated how they spent days, coming a day or two before their clinic appointment day and go back a day later because of the distance. He said:

We use three days to meet up with his appointment. We leave home on a Sunday, lodge in a hotel around, and see the Doctor on Monday and go back home on Tuesday. We spend a lot of money.

A mother also reported spending up to N100,000.00 (about \$625 US) at onset. What parents complained as increasing the burden is the non-availability of some investigative procedures recommended; some had to go to other hospitals for some investigations, hence increasing the financial cost. For instance, a mother said: “we had to go to Kano (about 150 km) for some scans and come back to continue with this hospital (the study centre)”.

Because of the frequency of their visit for physiotherapy, ranging from two to three times a week, some parents employ home based care givers. These additional specialist cares are privately arranged. For example, a mother said: “I employed a private physiotherapist for him.”

This economic burden is complicated by inability of some of the parents to attend to their daily businesses. Some parents reported how the care interfered with their business activities. Figure 2 shows the time dedicated to caring for the affected children by parents; some of them

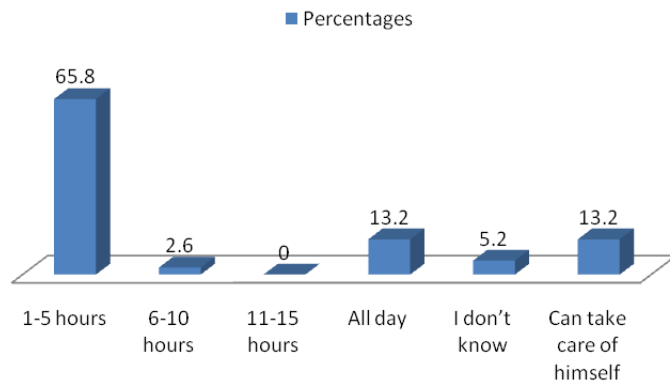


Figure 2. Hours spent to meet child's need per day.

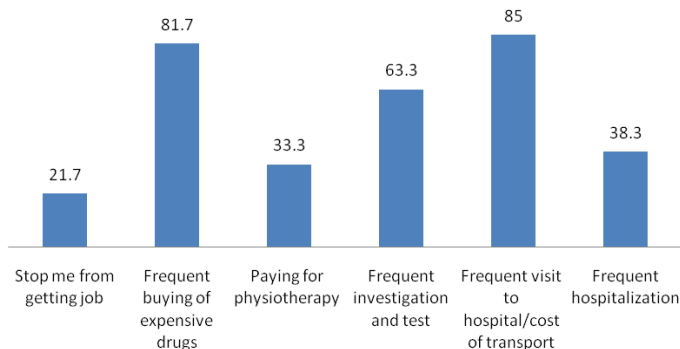


Figure 3. Effect of child's condition on the economic status of the family in percentages.

(13.2%) spent the whole day doing that. As shown in Figure 3, frequent visit to hospital (85%), hospitalization (38.3%) and buying of expensive drugs (81.7%) constitute the major effect of the child's disability on family's economic status. In a narrative, a mother captured this when she said: "I don't open my shop early. I have to take care of him first." The financial implications on unaffected other siblings was also clearly demonstrated when some mothers said that they had to change their other children school from private to Government owned, because they could no longer cope with the payment of the school fees. For others, the feeding and clothing patterns of the family were altered. As a mother regretted, saying: "we don't eat good food like before and we can't buy good cloth for our children," while another lamented how the care of the other children had been compromised because of the increased attention paid to the one with neurologic problem.

DISCUSSION

Social issues

The experiences of the affected parents were overwhelm-

ing. They expressed the difficulties associated in maintaining social interaction and activities alongside the care of the affected children. Many (55%) could not travel for days due to the child's state of health, while 40% could not engage in social activities. This implies a high demand of care with close monitoring of children with neurological challenges. Ambikili (2012) had highlighted that parents of these children face problems with social life. For some (10%) in this study, families and close associates appeared unsupportive. Some parents disclosed avoidance of friends and families following the sequelae as 26.7% claimed that friends/relatives do not carry the affected child even when they visit. Other social problems mentioned by parents were gossiping by people and direct assault of the affected children which may lead to 'stigmatization' and physical injuries. This may make the affected parent prone to depression. Vijesh (2007) reported that the social life may become non-existent and there may be fear of rejection by friends/relatives. Knestrict and Kuchey (2009) described the characteristics of resilient family presented factors that families with children with special needs and disabilities. They pointed out that these parents need social reconstruction of coping with nurturing such children. They found a relationship with the level of socioeconomic status (SES) and such "reconfiguration" in coping with these children socially, psychologically and economically. As can be seen in the present study, the financial burden of parenting children with neurological disabilities negatively affects the socio-economic status of families, compounding the vulnerability the entire family.

Marital challenges

Marriage as an institution with part of its aim being reproduction can be greatly affected when faced with managing a child with neurological deficit. The effect of these challenges on the marital relationship was also narrated. Some parents reported giving more attention to these children and being more loved than the other children in the narrative. These findings are similar to Vijesh (2007) who reported the situation as affecting the fabrics of marriage and creates a fertile ground for conflicts. Mu'ala et al. (2008) also narrated that mothers were first responsible to child's care. However, paternal involvement in managing such children and good coping and stress control strategies will help keep the marriage.

Economic issues

The economic challenges appear voluminous and are described by Child Neurology Society (2012) as significant financial disadvantage. Mu'ala et al. (2008) discovered that parent of such children suffer low socio-economic status, because of the burden of care. Meeting

the needs/care of the affected children was a heavy weight on the parents shoulder. About 28.3% of the parents especially mothers had to stop work, hence reducing the family income. Al-Farsi et al. (2013) in their analysis of SES and burden found that caring for children with neuro-psychiatric disorder (ASD) weigh heavily on parents irrespective of SES. In a comparative study with Emerson (2003), it was discovered that mothers of children with intellectual disability experience poor socio-economic status compared to mothers whose children were not. The demands also affected parents' time. Also, 65.8% spent between 1 and 5 h per day to meet the child's need, while some parents had to make themselves available at all times. These findings were also reported by Patterson (2011) who narrated that most parents in paid work had to stop work to care for the affected child. Other associated problems (inability to talk and walk) compounded the task of caring.

Other challenges were centred on the cost of treatment. NHIS coverage was insufficient as discovered in the study. Ihudiebuke (2011) highlighted some factors that hinder the success of NHIS to include the absence of equity in the distribution of health care facilities and access to them, sustainability of government policies and programmes has been a major issue in the country and failure of some insurance schemes might also be a hindrance for the success of the programme.

Medical visit/cost of treatment per month was said to be up to \$131.3 excluding transportation and other logistics. Rochelle (2005) also described difficulties in getting medical coverage for the affected children. The distance covered to assess medical treatment was an added economic challenge. The treatment difficulties centred on buying expensive drugs, frequent investigations/test (computerized tomography, X-rays, electro encephalogram, etc) and physiotherapy as also highlighted by Baxamusa (2011). Cost of transportation and accommodation bills were other challenges expressed by parents as most of them reported making a long distance trip. The effect reflected on some families as poor feeding pattern, poor clothing and inability to pay for other siblings' school fees.

Winthrop et al. (2005) describe the challenge as having overall negative impact on the families of children who are critically ill. Kneastriect (2009) in his article appears to provide specific interventions for what Emerson (2003) referred to as "combating poverty" and "developing complex models of understanding and intervention". In their specific action plans for families of children with special needs, they suggested a 6-prongs model; namely, making more money, reflecting, observing social norms, positive emotions and effect, resiliency and to live where services are present. Results show that parents' monthly earnings range from meager through poor to no earnings. This poverty level may account for the severity of these challenges. Addition of coverage of neurological disorders to the NHIS would positively affect the

economic lives of these vulnerable families.

Conclusion

This study has shown that parents of children with neurologic problems face many socio-economic challenges. These challenges have significant effects on the lives of both the affected children and other siblings. Poor socio-economic status played an in-enviable role in the lives of the parents. The parents were saddled with meeting responsibilities of their affected children, hence cutting them off from normal social lives. Their economic status and pursuance of family income is also hampered by high cost of management of the affected child, hence making it difficult to maintain optimal socio-economic status and interaction.

RECOMMENDATION

To avoid suspected stigmatization and possible depression, social groups for parents and the affected children should be instituted by both government and non-governmental organizations to relieve stress and enhance social relationships. In addition, health coverage (NHIS) should be made available for these children to reduce economic burden on their parents and to enhance the healthy status of the other children. Further study is suggested to capture the years of other siblings in relation to the socio-economic challenges and traditional safety nets in affected African families.

Conflict of Interests

The author(s) have not declared any conflict of interests.

REFERENCES

- Abubakar MS (2007). NHIS as it affect Nursing Practice in Nigeria. A paper presentation at a Conference of Head of Nursing Services, Lokoja, Kogi State.
- Adatsi R (2006). Factors affecting enrolment in the NHIS - A study from the Ho Municipality. Unpublished Masters Thesis, University of Ghana, Accra. Available at: <http://wiego.org/sites/wiego.org/files/publications/files/alfers-ghana-nhis-case-study.pdf>.
- Al-Farsi YM, Waly MI, Al-Sharbati MM, Al-Shafae M, Al-Farsi O, Al-Fahdi S, Ouhtit A, Al-Khaduri M, Al-Adawi S (2013). Variation in Socio-Economic Burden for Caring of Children with Autism Spectrum Disorder in Oman: Care Giver Perspective. *J. Autism Dev. Disord.* 43(5):1214-1221 DOI: 10.1007/s10803-012-1667-9. Database: Scopus
- Ambikile SJ, Outwater A (2012). Child and Adolescent Psychiatry and Mental Health Available at www.capmh.com retrieved on 6/9/2012.
- Anyebe EE, Bolaji OE, Lawal H, Okeme MI (In-Press). Perceived Effectiveness of the National Health Insurance Scheme Among Health Care Professionals in Zaria, northwest Nigeria. *Int. Professional Nurs. J.*

- Ashwal S, Russman BS, Blasco PA, Miller G, Sandler A, Shevell M, Stevenson R (2004). Practice Parameter: Diagnostic Assessment of the Child with Cerebral Palsy. *American Academy of Neurology*. *America Neurology*. Mar 23; 62(6):851-63
- Bajraszewski E, Carne R, Kennedy R, Lanigan A, Ong K, Randall M, Reddihough D, Touzel B (2008). *Cerebral Palsy: An Information Guide for Parents*, 5th edition. Melbourne: The Royal Children's Hospital.
- Batul NB (2011). *Neurology Disorders*. Available at www.buzzle.com/articles/neurologicaldisorders/; accessed on 29/5/2013
- Beresford B, Rabiee P, Sloper P (2007). *Outcomes for Parents with Disabled Children*. Society Policy Research Unit, University of Newyork.
- Caplan R (2005). *Manual for Parents of Children with Epilepsy*. Epilepsy Foundation through the General Support of Shile US.
- Centre for Child Development (2007); www.childsupport.in/html/adhd/add.html. accessed 29/5/2013
- Donard KA, Samia P, Kakooza-Mwesige A, Bearden D (2014). *Peadiatric Cerebral Palsy in African: a Systematic Review*. In *Seminars in Paediatrics Neurology*. WB Saunders, p.1-2
- Emerson E (2003). Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and self-assessed social and psychological impact of the child's difficulties. *J. Intellect. Disabil. Res.* 47 (part 4/5):385-399. (journal article-research, tables/charts) ISSN:0964-2633 PMID: 12787168, Database: CINAHL Plus
- Idro R, Kakooza-Mwesige A, Balyejjussa S, Mirembe G, Mugasha C, Tugumisirize J, Byarugaba J (2010). Severe Neurological Sequelae and Behaviour Problems after Cerebral Malaria in Ugandan child. *BMC Research Notes*, 3:104. Available at: <http://www.biomedcentral.com>
- Ihudiebuke, Splendor, Chikaodin (2011). *National Health Insurance Scheme in Nigeria: Problem and Prospects: Nurs. Extra*, Edition 3, 3:16-18,36
- Kneastrick T (2009). Welcome to Holland: helping families develop resiliency. *Exceptional parent*, 39(4):36-39. (journal article-pictorial) ISSN: 0046-9157, Database: CINAHL Plus
- Kneastrick T, Kuchey D (2009). Welcome to Holland: Characteristics of resilient families raising children with severe disabilities. *J. Family Studies*. December 2009, 15(3):227-244 DOI: 10.5172/jf.15.3.227, Database: Scopus
- Mu'ala AE, Abas AR, Shawam SS, (2008). Psychological Burden of a Child with Cerebral Palsy upon Care Givers in Erbil Governorate, The Iraqi post graduate med. J. 7(2)
- Mungo D, Ruta L, Genitori DV, Mazzone L (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health and Quality of Life Outcomes*. Available at; www.hqlo.com/content.
- National Health Insurance Scheme Handbook (1999). *National Health Insurance Scheme Decree No 35 of 1999 Laws of the Federation of Nigeria* pp. 4-13.
- Paterson L (2011). *Parenting: Different kinds of parenting*, Te-Ara- the encyclopedia of New Zealand: Ministry of Culture and Heritage, NZ Government.
- Raiford T (2013). *GlobalPost – Parents of Children with Cerebral Palsy*; International New, Available at <http://everydaylife.globalpost.com/parent-children-cerebral-palsy-4578.html>; accessed on 29/5/2013
- Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter S, Russell D, Swinton M, Zhu B, Wood E (2005). *The Health and Wellbeing of Care Givers of Children with Cerebral Palsy* Available at <http://www.ncbi.nlm.nih.gov/pubmed/15930188>
- Vijesh PV, Sukumaran PS (2007). Stress among Mothers of Children with Cerebral Palsy Attending Special Schools, *Asian Pacific Disability Rehabilitation J.* 18(1).
- Winthrop AL, Brasel KJ, Stahovic L, Paulson J, Schneeberger B, Kuhn EM (2005). Quality of life and functional outcome after pediatric trauma. *J. Trauma* 58(3):468-473. discussion 473 464.



International Journal of Nursing and Midwifery

Related Journals Published by Academic Journals

- *International Journal of Medicine and Medical Sciences*
- *Journal of Medicinal Plant Research*
- *African Journal of Pharmacy and Pharmacology*
- *Journal of Dentistry and Oral Hygiene*
- *Medical Practice and Reviews*
- *Journal of Public Health and Epidemiology*

academicJournals