

Nursing Intervention on the Knowledge of Management of Challenges Faced by Relatives of Children with Epilepsy Attending Neuropsychiatric Hospital Aro, Abeokuta

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Abstract

This study examined nursing intervention on the knowledge of management of challenges faced by relatives of children with epilepsy attending neuropsychiatric hospital Aro, Abeokuta. This study employed pre-test, post-test quasi-experimental research design. The target population for this study was made up of relatives of children with epileptic disorders who come with their children to Child and Adolescent Clinic. The samples for this study are 53 parents/caregivers of children with epilepsy who come with the children on clinic days. Total enumeration sampling technique was used for this study. The Researcher used a semi-structured questionnaire for data collection. The instrument was validated by experts in the field of Tests & Measurement and Psychology. The Cronbach's alpha value for the reliability testing was 0.708. All research questions were analysed using descriptive statistics of frequency, percentages, mean and standard deviation. The only hypothesis was tested using chi square test statistics at 0.05 level of significance. The findings of the study revealed that respondents have inadequate knowledge about epilepsy and knowledge of management of epilepsy but there was significant increase in the knowledge of epilepsy after the intervention programme. It was

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recommended among others that Nurses should educate people on self-care concepts and skills required for long-term management of epilepsy in children and its complication.

Keywords: Intervention, Knowledge, Management, Challenges, Epilepsy,

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Introduction

Care giving is a normal part of being the parents of children but this task takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence. One of the main challenges of care is managing children with chronic health problem effectively and juggling this role with the requirements of everyday living. Consequently, the task of caring for a child with complex disabilities such as epilepsy at home might be daunting for such relatives.

Epilepsy is a neurological condition characterized by recurrent seizures. A seizure is a temporary disturbance of the cerebral function secondary to unusual paroxysms in the brain, which results in a sudden excessive disorderly discharge of the cerebral neurons. The discharge results in an almost instantaneous disturbance of sensation, psychic function or loss of consciousness, convulsive movements or combinations of these (Austin, 2015). Worldwide prevalence rate of epilepsy varies between 2.8 to 19.5 per 1000 of the general population. In developing countries, the disorder is to a significant degree associated with a host parasitic and bacteria infectious diseases that are largely absent in industrialized countries (Ambikile & Outwater, 2016).

Despite the accessibility of effective medications, there is a enormous gap in the treatment of epilepsy in developing countries, predominantly in Africa owing to the illiteracy, poor healthcare system, poor health awareness and cultural inability to accept modern medicine (Mu, 2015). Historically, epilepsy was believed to be a sacred disease that results in the invasion of the body by a god. It was thought that only a god could deprive a healthy man of his senses, throw him to the ground, convulse him and then rapidly restore him to his former self (Thompson & Upton, 2013).

Epilepsy is a challenging ailment especially among children. It affects approximately 50 million people worldwide, with about eighty percent of these individuals residing in developing regions (Long, 2015). Most cases of epilepsy are diagnosed in children under the age of 14 years (Buelow, 2016). Many of the affected children with this ailment often experience complications such as aspiration, fracture, and tongue biting among others during an attack of seizure. This may probably be due to poor management of the condition.

The provision of such care may be detrimental to the physical, emotional and psychological well-being of relatives of children with chronic conditions such as epilepsy. One challenge these relatives face when they have children with epilepsy is stigmatization. People may keep away from them because of such children. People do not want to associate with them as a result of mistaken belief that their own children will catch the condition. Stigma is considered in all cultures to be an important factor that results in negative influence on people with epilepsy and their relatives. There is the presence of stigma, when people with epilepsy are prevented from attending regular schools or participating in other social activities. The impact of epilepsy rests not only on the individual sufferer, but also on the relatives of such individuals. Other people have also stated that as a result of fear of disgrace, families of children with epilepsy typically keep such children at home and their conditions kept secret (Elafros, Sakubita, Atadzhanov, Haworth & Birbeck, 2016).

Managing epilepsy is quite stressful for the parents and caregivers especially in developing countries. Studies have shown that people with less knowledge on the management of challenges of epilepsy tend to have negative attitudes towards the disease and misconception such as being a form of insanity, being untreatable, and contagious. Superstition, cultural beliefs and lack of information about epilepsy have perpetuated such delusions in developing countries (Buelow, 2016).

It remains a stigmatized disease especially in sub-Saharan Africa due to lack of information and literacy. Repeated seizure attacks affect the coping ability of the relatives. This may also involve frequent hospital visits, need for strict adherence to drug prescriptions, close monitoring of patient at home reducing the time for other responsibilities, fear of receiving visitors because of stigma and fear of what future holds for the children are some of these challenges.

Living with epilepsy, its unpredictable seizures, and any comorbid conditions present many challenges over time. Again, continued educational efforts can play a key role in helping people learn to live with and understand epilepsy and its effects over the life span. Thus, individuals and families need education and skills building throughout the course of the disorder, particularly during times of change, such as an increased frequency of seizures, changes in treatment (e.g. switching medication, starting a new treatment option, discontinuing a medication or other treatment option), and a major life transitions (e.g. from youth to adulthood, from adulthood to older adult).

It is on the basis of these observations and submissions that the researcher became interested in nursing intervention on knowledge of management of challenges faced by relatives of children with epilepsy attending child and Adolescent clinic in Neuropsychiatric Hospital, Aro, Abeokuta. Based on the foregoing, the study investigated nursing intervention on the knowledge of management of challenges faced by relatives of children with epilepsy attending neuropsychiatric hospital Aro, Abeokuta. The study specifically:

- i. examined level of pre and post knowledge of challenges face by parents/relatives of children with epilepsy;
- ii. determined the level of pre and post knowledge of management of challenges faced by parents/relatives of children with epilepsy; and
- iii. investigated the relationship between pre and post intervention knowledge of management of challenges of epilepsy by relatives.

Research Questions

The following research questions were raised to guide the study:

1. What is the level of pre and post knowledge of challenges face by parents/relatives of children with epilepsy?
2. What is the level of pre and post knowledge of management of challenges faced by parents/relatives of children with epilepsy?

Research Hypothesis

This hypothesis was generated for this study:

1. There is no significant relationship between pre and post intervention knowledge of management of challenges of epilepsy by relatives

Methodology

This study employed pre-test, post-test quasi-experimental research design to assess the outcome of the knowledge of management of challenges faced by relatives of children with epilepsy attending neuro-psychiatric hospital Aro- Abeokuta. This design is considered necessary because it allows the researcher to determine the effect of the intervention on the set of respondents in other to assess their knowledge of management of the various challenges they faced in caring for children with epilepsy. The target population for this study was made up of relatives of children with epileptic disorders who come with their children to Child and Adolescent Clinic. The samples for this study are 53 parents/caregivers of children with epilepsy who come with the children on clinic days. Total enumeration sampling technique was used for this study.

The Researcher used a semi-structured questionnaire for data collection for this study. Section A addressed socio-demographic characteristics of participants while Section B elicited responses of participants' pre-knowledge of challenges faced by relatives of children with epilepsy. Section C elicited responses of participants' knowledge of management of epilepsy. The instrument was validated by experts in the field of Tests & Measurement and Psychology for critique and adjustment in order to ensure that the questionnaire measures all the important variables of the study. The Cronbach's alpha value for the reliability testing was 0.708.

Data collection was in three stages namely pre intervention, intervention and post intervention. All research questions were analysed using descriptive statistics of frequency, percentages, mean and standard deviation. The only hypothesis was tested using chi square test statistics at 0.05 level of significance.

Results

Research Question 1: What is the level of pre and post knowledge of challenges face by parents/relatives of children with epilepsy?

Table 1: Pre and Post knowledge of challenges faced by parents/relatives of children with epilepsy

Challenges	Pre Intervention (N=53)		Post Intervention (N=53)	
	Freq. (%)		Freq. (%)	
	Yes	No	Yes	No
Knowledge challenges(Knowledge on seizure)				
Prevent the person from injury	27(50.9)	26(49.1)	52(98.1)	1(1.9)
Allow seizure to run its own course during seizure	30(56.6)	23(43.4)	46(86.8)	7(13.2)
Keep the head and neck stable	33(62.3)	20(37.7)	51(96.2)	2(3.8)
pour liquid in the persons mouth	37(69.8)	16(30.2)	53(100.0)	0(0.0)
Loosen any neckties or clothing around the neck	39(73.8)	14(26.4)	48(90.6)	5(9.4)
Knowledge challenges(Knowledge on drug compliance)				
Drug compliance is important in epilepsy treatment	38(71.7)	15(28.3)	49(92.5)	4(7.5)
If medication is properly taken , an individual can live a seizure free life	21(39.6)	32(60.4)	52(98.1)	1(1.9)
If medication doses are missed , further seizure can occur	33(62.3)	20(37.7)	49(92.5)	4(7.5)
Taking of double dose can affect an individual further	34(64.2)	19(35.8)	51(96.2)	2(3.8)
Taking concoction with tablets can prevent the drugs from working?	22(41.5)	31(58.5)	51(96.2)	2(3.8)
Psychological and emotional challenges e.g. stress	25(47.2)	28(52.8)	52(98.1)	1(1.9)
Social challenges e.g. stigmatisation	31(58.5)	22(41.5)	51(96.2)	2(3.8)
Economic challenges e.g. financial constraint	36(67.9)	17(32.1)	50(94.3)	3(5.7)

Table 1 above shows the responses on challenges faced by respondents, majority of respondents have low pre-knowledge and high post-knowledge on challenges face by

parents/relatives of children with epilepsy. The table below summarised the level of pre and post knowledge of challenges face by parents/relatives of children with epilepsy

Table 2: Summary of Knowledge on of challenges faced by relatives

Level of Knowledge	Pre Intervention		Post Intervention	
	Freq.	%	Freq.	%
Low knowledge (1-6)	29	54.7	1	1.9
Moderate Knowledge (7-9)	20	37.7	3	5.7
High knowledge (10-13)	4	7.5	49	92.5
Total	53	100.0	53	100.0

Table 2 above shows the overall knowledge of challenges faced by relatives of children with epilepsy, majority of the respondents have low and moderate knowledge pre-intervention. But respondent's knowledge increased after the intervention programme. It can be concluded that level of pre-knowledge of challenges face by parents/relatives of children with epilepsy was low while level of post-knowledge of challenges face by parents/relatives of children with epilepsy was high.

Research Question 2: What is the level of pre and post knowledge of management of challenges faced by parents/relatives of children with epilepsy?

Table 3: Pre and Post intervention knowledge on the management of challenges faced by parents/relatives of children with epilepsy

Management of challenges	Pre Intervention(N=53)		Post Intervention(N=53)	
	Freq.(%)		Freq.(%)	
	Yes	No	Yes	No
Managing Psychological challenges				
Seeking for new information about epilepsy	35(66.0)	18(34.0)	52(98.1)	1(1.9)
Developing a positive outlook towards your child	25(47.2)	28(52.8)	52(98.1)	1(1.9)
Taking the child for follow up regularly	43(81.1)	10(18.9)	51(96.2)	2(3.8)
Use of religious belief	36(67.9)	17(32.1)	50(94.3)	3(5.7)
Meeting the parent that having children with epilepsy	34(64.2)	19(35.8)	48(90.6)	5(9.4)
Managing social challenges				
Getting a treatment for your child	43(81.1)	10(18.9)	50(94.3)	3(5.7)
Don't isolate the child with epilepsy	33(62.3)	20(37.7)	48(90.6)	5(9.4)
Don't equate your child with the illness of the child	37(69.8)	16(30.2)	48(90.6)	5(9.4)
Discussion with the teachers of your child in school	43(81.1)	10(18.9)	51(96.2)	2(3.8)
Managing economic challenges				
Meeting the social health worker for financial help	32(60.4)	21(39.6)	49(92.5)	4(7.5)
Meeting family members that can assist in the care of the child	26(49.1)	27(50.9)	53(100.0)	0(0.0)
Involving the place of worship by meeting the religious leader	46(86.8)	7(13.2)	53(100.0)	0(0.0)
Talk to experienced parents	45(84.9)	8(15.1)	50(94.3)	2(5.7)

Having little saving towards buying the medication of your child	43(81.1)	10(18.9)	48(90.6)	5(9.4)
Managing Knowledge challenge				
By learning about epilepsy	39(73.6)	14(26.4)	49(92.5)	4(7.5)
By attending seminars on epilepsy	37(69.8)	16(30.2)	48(90.6)	5(9.4)
By watching programs on television.	42(79.2)	11(20.8)	50(94.3)	3(5.7)

Table 3 shows the responses on management of challenges faced by parents/relatives of children with epilepsy, majority of respondents have moderate pre-knowledge and high post-knowledge on management of challenges face by parents/relatives of children with epilepsy. The tables below summarised the level of pre and post knowledge of management of challenges faced by parents/relatives of children with epilepsy.

Table 4: Pre-intervention knowledge on management of challenges faced by parents/relatives of children with epilepsy

Pre-knowledge	Psychological challenges		Social Challenges		Economic challenges		Knowledge challenges	
	Freq.	%	Freq.	%	Freq.	%	Freq.	%
Low knowledge(1-2)	29	54.8	37	69.8	23	43.4	53	100
Moderate knowledge (3)	17	32.1	16	30.2	21	39.6	0	0.0
High knowledge (4-5)	7	13.2	0	0.0	9	17.0	0	0.0
Total	53	100.0	53	100.0	53	100.0	53	100.0

Table 4 showed the pre-intervention knowledge of respondents on the management of challenges of epilepsy covering different areas of management, majority of the respondents have below average knowledge on the management of epilepsy, 54.8% have below average knowledge on psychological challenges, 69.8% have below average knowledge on social challenges while 43.4% have below average knowledge on economic challenges while all respondents have below average knowledge on how knowledge challenges can be managed.

Table 5: Post intervention knowledge of management of challenges faced by parents/relatives of children with epilepsy

Post intervention-knowledge on management	Psychological challenges		Social Challenges		Economic challenges		Knowledge challenges	
	Freq.	%	Freq.	%	Freq.	%	Freq.	%
Low knowledge(1-2)	2	3.8	0	0.0	0	0.0	0	0.0
Moderate knowledge (3)	8	15.1	6	13.2	14	26.5	17	32.1
High knowledge (4-5)	43	81.1	46	86.8	39	73.6	36	67.9
Total	53	100.0	53	100.0	53	100.0	53	100.0

Table 5 shows the post intervention knowledge on management of challenges of epilepsy. The table showed that respondent's knowledge on management of challenges of epilepsy improved after the intervention. Majority of respondents have above average knowledge on the different areas of management of challenges faced by parents or relatives of children with epilepsy.

Testing of Hypothesis

Hypothesis 1: There is no significant relationship between pre and post intervention knowledge of management of challenges of epilepsy by relatives

Table 6: Chi square test statistics of pre and post intervention knowledge scores

		Post intervention			Total	χ^2	P-value
		Low knowledge	Moderate Knowledge	High Knowledge			
Pre intervention	Low knowledge	2	4	5	11	10.254	0.03*
	Moderate Knowledge	1	11	8	20		
	High Knowledge	1	3	17	21		
Total		4	18	30	52		

Table 6 shows that Chi square $\chi^2 = (10.254)$ is significant because the p-value = 0.03 is less than $\alpha = .05$. The null hypothesis is rejected. Therefore, there was significant relationship between pre and post intervention knowledge of management of challenges of epilepsy by relatives. This shows that the increase in the knowledge of respondents on management of epilepsy leads considerable increase in management of epilepsy.

Discussion

The study established that majority of the respondents lack adequate pre-knowledge about challenges of epilepsy. Analysis of the study showed a significant increase in the level of knowledge of respondents after intervention programme. The result from this study is supported by the study of Long (2015) and Frank-Briggs and Alikor (2016) who concluded in their study on the efficacy of an educational program for parents of children with epilepsy that parents of the groups significantly improved in epilepsy-specific knowledge. Also, results from the study is supported by the work of Buelow (2016) who found out that the level of knowledge and understanding among parents of children with epilepsy needs improvement.

The study further established that majority of the respondents also lacked adequate knowledge in the management of challenges of epilepsy as pre intervention knowledge of the relatives showed that 34.8% have below average knowledge on seizure management, 69.8% have below average knowledge on drug compliance and 62.3% have average knowledge on challenges of managing epilepsy. Also, 54.8% have below average knowledge on psychological challenges, 69.8% have below average knowledge on social challenges while 43.4% have below average knowledge on economic challenges. Post intervention study showed a significant increase in seizure management by the relatives with 71.7% having above average knowledge. This result is supported by Modi (2015) who indicated an improvement in seizure management and everyday management over time. Also Andren, Signe and Solve (2014) revealed in a study between two groups that there was improved knowledge on health-related quality of life in the social exclusion dimension amongst children and adolescents but not parents.

Conclusion

It is concluded that respondents have inadequate knowledge about epilepsy and knowledge of management of epilepsy but there was significant increase in the knowledge of epilepsy after the intervention programme. It is important to increase the knowledge of the caregivers of children with epilepsy so as to lessen the burden of care.

Recommendations

Based on the findings from the study, following are the researcher's recommendations;

1. There is a need for improving degree of knowledge of parents/caregivers on management of challenges of epilepsy, which will help in improving their attitudes toward epilepsy.
2. Nurses should educate people on self-care concepts and skills required for long-term management of epilepsy in children and its complication
3. The media, as well as, government authorities should play a major role in increasing the public awareness. Parents, teachers, and school children should be targeted with such educational programs.

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