

Full Length Research Paper

Opinion and perception of family caregiving following stroke

Adika V.O*, Ezonbodor- Akwagbe R.E. and Nwachukwu C.P.

Faculty of Nursing, College of Health Sciences, Niger Delta University, Wilberforce Island, Bayelsa State, Nigeria

Abstract

Stroke patient caregiving remains a huge burden and challenge for family caregivers, because of the major importance of family caregivers in the process of caregiving. It is intended to assist in the provision of quality patient care at home as well as generate satisfaction with care provided after discharge home. Unfortunately, this is not entirely so. Hence, this study evaluates the opinion and perception of nurses on family caregiving of stroke patients following discharged home. A descriptive survey design was employed in obtaining data from participant nurses (N =100) who gave consent to the study. Results obtained were analyzed using the statistical package (SPSS) to obtain descriptive and inferential statistics. Our result revealed that most nurses have negative opinion and perception on family caregiving of stroke patient. This is expressed by 80%, 93% and 87% who stated that family caregiving of stroke is very tasking, caregivers experience depression and caregivers experience confusion for caregiving of stroke patients respectively. Similarly, 90.0%, 91.0% and 88.0% perceived lack of basic knowledge and adequate skills account for poor care, as well as complexity of patients need and lack of communication respectively. Whereas, 97.0% and 87.0% of the nurses expressed the opinion and perception that nurses should support in preparing family caregivers before discharge and should have a positive relationship/attitude with family caregivers . Hence, a need for education of caregivers and encouragement of positive attitude following discharged was emphasized. Follow-up of these patients and rehabilitation centers were recommended as cornerstones in preventing deterioration and possible death at home of stroke patients.

Keywords: Family caregiving; Stroke; Nurses; Opinion; Perception; Bayelsa.

INTRODUCTION

Stroke is a global health problem affecting mostly older adults, the third leading cause of death, and a leading cause of adult disability among survivors (Han and Haley, 1999). Stroke is a medical event that affects approximately 500,000 people for the first time in the US, and 200,000 people experience a recurrent attack each year (American Heart Association/American Stroke Association (AHA/ASA), 2007). In the UK and Sub-Saharan Africa the estimated individual having a stroke each year are 150,000 and 147,000 (Lloyd and Jones, 2009; Ogungbo, 2005).

Stroke survivors have residual neurological impairment, which requires long-term support and care (Chow et al., 2006). Family caregiving is the act of assisting someone you care about who is chronically ill or disabled and no longer care for themselves (Family Caregivers Association [FCA], 2010). Most stroke patients are discharged home, to rely on their family members, who have no adequate knowledge on how to care and manage the condition, so as to prevent complications associated with it, as well as death (Bucher et al., 2001; Scherbring 2002 and Schumacher et al., 2000). A successful discharge to the community often hinges on the expectation that family members or close friends will provide the necessary care. Thus, stroke patients in the hospital return to the community to rely on their family

*Corresponding Author E-mail: adikavictor@yahoo.ca

members (Dobkin, 1995; Clark, 2004). Family caregiving after stroke has a profound impact on family caregivers of stroke patients as family caregiving of stroke patients with well-functioning families and strong social and emotional support have better outcome (Bhagal et al., 2003). However, family caregiving after stroke though very important may lead to disabilities and high incidence of mortality of stroke patients.

There is the need therefore, to determine the opinion and perception of nurses on family caregiving after stroke in this part of the globe where stroke units and institutionalized home care after stroke hardly existed. The opinion and perceptions on family care giving are expected to come from formal caregivers of whom nurses are one. The opinion and perception of nurses on family care giving generated will determine efforts made in ensuring the continuity of care, given to stroke patients and family caregivers after discharge. In fact, (Lutz and Young, 2010) wants nurses to broaden their scope of care and develop different approaches to providing supportive care to patients and their family affected by stroke after discharge, and this can be sourced from knowledge generated. Despite the high prevalence of stroke in the global and the potential high burden of family care giving, few studies have been noted to be carried out (Han and Haley, 1999). In Nigeria, no one study have been conducted or reported on nurses opinion and perception on family care giving, nor properly looked at this topic even when stroke is considered a catastrophic event.

The main objective of this study is to determine nurses' opinion and perception on family caregiving of patients after stroke. Specifically our goals are to (1) determine the nurses' opinion on family care giving after stroke (2) determine the nurses' perception of family caregiving after stroke and (3) determine the nurses' opinion and perception of support on family care giving after stroke.

MATERIALS AND METHODS

This study was carried out at the two most referred hospitals in the Niger Delta area of Bayelsa state. The research was conducted in the wards where nurses of different cadres worked. The study employs a descriptive survey design to ascertain the opinion and perception of nurses on family care giving after stroke among nurses. A cohort of nurses who have had experience of stroke nursing from a total of 433 staff nursing strength from 110 staff nurses from the (Niger Delta University Teaching Hospital, NDUTH) and 323 nurses from the (Federal Medical Center, FMC) were sought to participate. A total of 100 nurses who had completed the questionnaires

information for analyses were included for the study based on convenience sampling technique to draw the sample of nurses who volunteered to answer the questionnaire for their opinion and perception as nurses on family caregiving. A self-report questionnaire made to suits the purpose of the research was administered face to face to the nurses that were on duty in different wards at the time of the study. The questionnaires which were all written in English language then distributed to the respondents' nurses; all were filled in the presence of one of the researchers and were collected by the same researcher to ascertain how well they were completed.

Validity of the instrument was ascertained based on previous research works gathered from literatures and prior research experience of the investigators, for the questionnaire suitability and its applicability for the study as well as the reliability of the instrument. To ensure consistency of instrument, a pre-test was conducted using 20 respondents from a different health facility and this category of respondents has similar characteristics with the population of study. After the test-retest, the instrument were further refined for final production for use. This study is in compliance with Helsinki Declaration. The study was approved by an institutional committee that is properly constituted - the relevant committee on research for the two hospitals namely Niger Delta University Teaching Hospital (NDUTH) and The Federal Medical Center (FMC) Yenagoa, Bayelsa State and the respondents consent also gained with all information collected, treated confidentially to protect the subject's rights as an individual. Data were analyzed by means of (SPSS) software for windows version 16 (Chicago IL). Descriptive and inferential statistical were calculated for demographic, opinion and perception of family care giving whereas, the relationship by means of chi-square.

RESULTS

Table 1; shows the socio-demographic characteristics of respondents: of a total of hundred respondent (N=100), 29.0% are males while 71.0% are females; 20.0% are enrolled nurses, 21.0% are registered nurses, 7.0% are registered midwives, 18.0% are Bachelor degree (BNSc) nurses while 34.0% belong to other category. 61.0% have < 5years of work experience while 39.0% have attained more than 5years of experience in service; 24.0% are assigned to the medical and surgical ward, 12.0% to the female medical and surgical ward, 13.0% to orthopedic ward and 51.0% belong to other wards; 95.0% of respondents are Christians, 4.0% are Muslim while 1.0% is an African traditional religious worshiper; 45.0% are married, while 55.0% are singles; 50.0% are Ijaws,

Table 1. The Socio-Demographic data of respondent Nurses (n=100)

Variable	Frequency (N)	Percentage (%)
Sex		
Male	29	29
Female	71	71
Level of education		
Enrolled nurse	95	95
RN	20	20
RM	21	21
Degree Nurse	7	7
Other	18	18
Years employed in service		
<5 years	34	34
>5 years	61	61
Area of primary assignment		
Male medical and surgical ward	12	12
Female medical and surgical ward	24	24
Orthopedic ward	13	13
Others	51	51
Religion		
Christianity	95	95
Muslim	4	4
Traditional	1	1
Marital status		
Married	45	45
Single	55	55
Ethnicity		
Ijaw	50	50
Igbo	26	26
Yoruba	6	6
Others	18	18
Total	100	100

26.0% Igbos, 6.0% are Yoruba's while 18.0% of the respondents belong to other ethnic groups.

Table 2, shows nurses opinion on family caregiving after stroke: 49.0% agrees that poor family caregiving of stroke patient after discharge home may result to a negative outcome, whereas 45.0% disagree with this, and 5.0% indecisive; 80.0% are of the view (agree) that family caregiving of elderly stroke patients is very tasking as they usually are uncooperative, with 16.0% having a contrary view (disagreed) while another 4.0% were indecisive; 68.0% are of the opinion (agree) that stroke patients do not receive adequate care from family caregivers, 27.0% disagreed, while another 5.0% were indecisive; burden and depression following inadequate care of their relative was (agreed) upon by 93.0% of the

respondents, 6.0% disagree, while 1.0% are indecisive; 79.0% are of the opinion (agree) that institutionalized care of elderly stroke patient will alleviate the frustration and depression experienced by family caregivers, 14.0% disagree, while 7.0% are indecisive; 89.0% are of the view (agree) that poor family caregiving may lead to disabilities among elderly stroke patients, 8.0% disagree, while 3.0% are indecisive.

Table 3, shows nurses perception on family care given on elderly stroke patient in Bayelsa state, Nigeria: 90.0% of the respondents perceive that lack of basic knowledge and adequate skills account for poor care of stroke patients at home, while the other 10.0% had a contrary concept for this; 82.0% of the nurses perceive that mortality following family stroke patient care may be

Table 2. Distribution of Nurses Staff opinion on family care-giving after stroke (N=100)

STATEMENT/QUESTIONS	RESPONSE (%)		
	Agree	Disagree	Indecisive
Family caregiving of stroke patients has a negative outcome.	49.0	46.0	5.0
Family caregiving of stroke patients is very Family caregiving of stroke patients is very patients are uncooperative.	80.0	16.0	4.0
Family caregiving of stroke patient contribute to the increasing rate of stroke mortality	49.0	47.0	4.0
Stroke patients don't receive effective and adequate care-giving from Family caregivers	68.0	27.0	5.0
Family caregivers experience depression and burden whenever they cannot adequately care for their relatives suffering from stroke	93.0	6.0	1.0
Family caregiver may experience confusion and frustration in relation to the need of stroke patients.	87.0	11.0	2.0
Institutionalized cares of stroke patient will all alleviate the frustration and depression experienced by caregivers.	79.0	14.0	7.0
Family caregivers insufficient care may lead to disabilities of stroke patients.	89.0	8.0	3.0

Table 3. Distribution of Nurses Perception on Family Caregiving

STATEMENT/QUESTIONS	RESPONSE (%)	
	Yes	No
Family care givers are unable to carryout, the demanding needs of stroke patient because they lack basic knowledge and skill.	90.0	10.0
Environment of stroke patients may not be conducive for them and this contributes to their mortality rate.	82.0	18.0
Increasing death of stroke patients after discharge may be as a result of their inability to adapt.	84.0	16.0
Family caregivers out of frustration may show abusive behaviors to stroke patients.	95.0	5.0
Complexity of stroke patients need and condition lead to family caregivers depression and frustration.	91.0	1.0
Stroke patients may feel guilty of causing much harm to their family caregivers and this result to isolation and failure of communicating their needs.	88.0	12.0

accounted for by unconducive environment while the remaining 18.0% said no to this; 84.0% are of the perception that patients poor adaptation accounts for an increasing death of stroke patient following discharge home while the other 16.0% had a different perception; 95.5% strongly felt that frustration of family caregivers accounts for their use of abusive words to patients while

the remaining 5.0% did not see it that way; 91.0% supported the fact that the complexity of elderly stroke patients needs accounts for family members depression and frustration unlike the other 9.0% who had a contrary perception; 88.0% of respondents are of the perception that poor communication or non-communication of elderly stroke patients to family members could be traced to

Table 4. Distribution of Nurses Opinion and Perception of Support of Family Caregiving

STATEMENT/QUESTIONS	RESPONSE (%)	
	Yes	No
Should Nurses support in preparing family care-giver before discharge		
Family care-giving of stroke patients is dependent on the positive relationship of Nurse's support	97.0	3.0
Family care-giving is less burdensome and frustrating when there is nurses educating and training of the family care-givers before discharge	89.0	11.0
Positive outcome of Family care-giving depends on the Nurses supportive measures and continuity of care after discharge of stroke patient	89.0	11.0
Stroke patients' recovery depends on the positive relationship between family care-givers and nurses after discharge	91.0	9.0
Family care-givers experience confusion and anxiety due to lack of adequate support from nurses after discharge	89.0	11.0
Nurses' supportive role to stroke patients at home will include Cooperating and communicating their needs	74.0	26.0
	92.0	0.8

feelings of guilt and causing harm with stress to family members while the other 12.0% has a different perception. Table 4; shows opinion and perception of nurses on support of family caregivers after stroke; 97.0% agreed that nurses should support in preparing family caregivers before discharge while 3.0% disagreed. 89.0% said family caregiving of stroke patients is dependent on the positive relationship of nurses' support, 11.0% had a contrary view. 89.0% are of the view that family caregiving will be less burdensome and frustrating when nurses educate and train family caregivers before discharge, while 11.0% had a different view. 91.0% are of the view that the positive outcome of family caregiving also depends on continuity of care after discharge, 9.0% had a contrary view. 89.0% of the respondent insisted that stroke patients' recovery depends on the positive relationship of family caregivers and nurses after discharge. 74.0% said that family caregivers will experience confusion and anxiety when nurses don't support them while 26.0% had a contrary view. 92.0% had the opinion that nurses' supportive role should include cooperating and communicating to stroke patients needs while 8.0% had contrary view. 24.0% recommended counseling/Health education, 1.0% enhanced social support, 48.0% with regards to Home visit, follow-up and continuity of care, while 3.0% counseling/Health educations, Home visit, follow-up, continuity of care, and automated interactive voice response telephone.

DISCUSSION

Stroke is the third leading cause of death and a leading

cause of adult disability among survivors (Han, and, Haley, 1999).

Unfortunately, due to the shorter stay of stroke patients in the hospitals, they return to the community to rely on their family members or others (Dobkin, 1995; Clark, 2004 and Laloux, 2003). And this has a great impact on both the stroke patient and the family caregiver (FCA, 2006)

Therefore, nurses opinion and perception on family care giving after stroke becomes vital especially at reducing the challenges faced by family caregivers of stroke. The result was drawn from a total of hundred (100) respondents, who were all nurses from the most referred hospitals in Bayelsa state. Deleted

Nurses opinion on family care giving following stroke

Our result revealed that nurses have negative opinion about outcomes of family caregiving of stroke patients. Similarity of our finding is observed with Naylor's (2003) who indicated a break down in care during the transition from hospital to home results to negative outcome. The result further shows that 80.0% are of the opinion that family caregiving of stroke patients is tasking for family caregivers. This result is again comparable with results from Reinhard et al. (2008), where family caregivers' efforts to make decision for the stroke patients are considered stressful, since this is not part of their normal role. The monitoring and observing of stroke patient's for early signs of problems. E.g. drug side effect, are tasking for family caregivers, who are often are unable to carry out this responsibility.

Our results further revealed that nurses agreed that

family caregiving of stroke patients contributes to the increasing rate of stroke mortality as 68.0% of nurses are of the opinion that stroke patients don't receive effective and adequate care from family caregivers. This again agrees with Naylor (2003) statement that family caregiving by family members with little or no knowledge lead to increase number of mortality. The later account can be explained to be respondent (nurses) beliefs after the, survivors are left alone.

Furthermore, our result found that caregivers experience depression and burden whenever they cannot adequately care for their relatives suffering from stroke. This is in agreement with the view of Lutz and colleagues (2010), as well as Grant et al. (2002) who observed depression to be common among caregivers in their study. The nurses were of the opinion that family caregivers may be confused about the need of stroke patients and that institutionalize care of stroke will solve the frustration and depression experienced by family caregivers and insufficient care by family caregivers led to disabilities of stroke patients. This opinion is again congruous with explanation of Lutz et al. (2010).

Nurses' perception on family caregiving after stroke

Our result reveals 90.0% of respondent perceived family caregivers lack the knowledge and skill to carry out the demanding needs of stroke patients. Again, this concurs with the study reported by CDC, (2008) and Reinhard et al. (2008). This study also showed that nurses' perception of stroke patients' environment not to be conducive for them and that the increasing death of stroke patient is as a result of their inability to adapt. Research reports indicated adverse reaction to noise in the provision of care (Overman Dube et al., 2008) and distractions from families as contributing factors.

Furthermore, the finding of this study reveals 95.0% had the perception that family caregivers may show abusive behaviors to stroke patients out of frustration. This agrees with the assertions of Cooper et al. (2010); Lutz et al. (2010); Miller et al. (2006); Beach et al. (2005); Han and Haley (1999) on family caregiving. However, it is perceived that the complexity of stroke patients needs leads to care givers depression and frustration, which is congruous with an earlier work by Han and Haley, (1999) which showed the effectiveness of stroke caregiving on caregivers. Our result also indicated that stroke patients may feel guilty of causing much harm to their family caregivers and isolate themselves and not communicate their needs.

Opinion and perception of nurses on family caregiving support after stroke

Our study revealed that nurses support in preparing family caregivers before discharge, and family caregiving will be less burdensome and frustrating for family caregivers when nurses educate and train caregivers before discharge. Our finding is in concordance with an earlier study reported by Grant and colleagues, who revealed greater caregiver preparedness; less depression and significant improvement in vitality; social functioning; mental status when supported by nursing staff after discharge (Grant et al., 2002). Our study reports that family caregiving of stroke patients leads to a positive outcome with nurses' support and stroke patient's recovery depends on nurses' support. This report finding also agreed with Grant et al. (2002) who stated that caregivers who receive interventions from health personnel were less negative. Furthermore, we report family caregivers experience anxiety and confusion due to lack of adequate support from nurses. This finding is similar to previous report on family caregiving, as anxiety, depression and poor physical health are reported to be common sequelae among family caregivers of stroke (Chow et al., 2006; Brereton et al., 2002; Reinhard et al., 2008)

Furthermore, it was the finding of this study that nurses' supportive role to stroke patients at home should include cooperating and communicating their needs and counseling on health, home visit, follow-up, continuity of care as the best supportive measures that should be given to family care givers by Nurses. This finding is in agreement with the statement of Kalra et al. (2004) on training/supporting care givers in skills essential for the day to day management of disabled stroke survivors which is likely to have a role in reducing the burden of care.

Implication for Nursing Practice

The implication of this study to nursing field is that, since majority of the nurses are of the opinion that family caregiving of stroke will have a positive outcome with nurses' support. Nurses should hence play the vital role of educating family caregivers of stroke patients before discharge.

Nurses should equip family caregivers with knowledge and skills on how to care for stroke patients after discharge.

Nursing practice, also involves community of care, fellow-up, health education and counseling. Nurses will help caregivers in realizing ways to adapt and this will reduce their depression and frustration.

CONCLUSION

The study which focused on nurses' opinion and perception of family caregiving reported a negative outcome of opinion and perception with family caregiving as family caregivers found the job to be very tasking, with profound impact of increasing incidence of stroke patient mortality, frustration and depression and poor quality of health. Findings suggest intervention and support from nurses' staff reduce death after discharge and recovery.

RECOMMENDATION AND SUGGESTIONS

Following the completion of this study, the following recommendations are made; considering the fact, that family caregiving of stroke patients will have a positive outcome with nurses support, nurses should involve in educating family caregivers of stroke patients extensively before discharge. Nurses should ensure Home visiting, follow-up, and continuity of care of stroke patients after discharge. Furthermore, the government should provide material that will enable the nurses' perform the work effectively.

ACKNOWLEDGEMENT

Special thanks go to all the staff nurses that participated as well as Dr Abdul A. of Basic Medical Sciences, Niger Delta University and Apiyanteide A. Franco for their words of support.

REFERENCES

- American Heart Association/American Stroke Association (2007). Heart Disease and Stroke Statistics Update. Available at: www.americanheart.org
- Bhagal SK, Teasell RW, Foley NC, Speechley MR (2003). Rehabilitation of aphasia: is more better. *Top. Stroke Rehabil.* 10: 66-76.
- Brereton L, Nolan M (2002). 'Seeking': a key activity for new family carers of stroke survivors. *J. Clin. Nurs.* 11: 22-31.
- Bucher JA, Loscalzo M, Zabora J, Zabora J, Houts PS, Hooker C, Brintzenfeszoc K (2001). Problem-solving cancer care education for patients and caregivers. *Cancer Pract.* 9(2):66-70.
- CDC (2008). Centers for Disease Control and Prevention and the Kimberly-Clark Corporation, Assuring Healthy Caregivers, A Public Health Approach to Translating Research into Practice: The RE-AIM Framework, 2008, <http://www.cdc.gov/aging/caregiving/index.htm>
- Chow SKY, Wong FKY, Poon CYF (2006). Coping and Caring: Support for family caregivers of Stroke survivors. *J. Clin. Nurs.* 16(76): 133-143.
- Clark PC, Dunbar SG, Shields C, Aycock DM, Viswanathan B, Wolfs SL (2004). Influence of stroke survivors Characteristics and family conflicts surrounding recovery on caregivers' mental and physical health. *Nurs. Res.* 53, 406-413.
- Cooper C, Selwood A, Blanchard M, Walker Z, Blizard R, Livingston G (2010). The determinants of family carers' abusive behaviour to people with dementia: results of the CARD study. *J. Affect. Disord.* 121, 136-142.
- Dobkin B (1995). The economic impact of stroke. *Neurology*; 45 (2 suppl 1):S6-9.
- FCA (2006) Family Caregiver Alliance, Caregiver Assessment: Principals, Guidelines and Strategies for Change, Report from a National Consensus Development Conference, held September 7-9, 2005, www.caregiver.org/caregiver/jsp/content/pdfs/v1_consensus.pdf
- Grants JS, Elliott TR, Weaver M, Bartolucci AA, Giger JN (2002). Telephone Intervention with Family caregivers of Stroke after Rehabilitation. *Stroke.* 33: 2060- 65.
- Han B, Haley WE (1999). Family caregiving for patients with stroke. *Stroke.* 30:1479 – 85.
- Kalra L, Evans A, Perez I, Melbourn A, Patel A, Knapp M Donaldson N (2004) Training carers of stroke patients: randomised controlled trial. *BMJ.* 328: 1099-1103.
- Lloyd-Jones D, Adams R, Carnethon M, De Simone G, Ferguson TB, Flegal K, Ford E, Furie K, Go A, Greenlund K, Haase N, Hailpern S, Ho M, Howard V, Kissela B Kittner S, Lackland D, Lisabeth L, Marelli A, McDermott M, Meigs J, Mozaffarian D, Nichol G, O'Donnell C, Roger V, Rosamond W, Sacco R, Sorlie P, Stafford R, Steinberger J, Thorn T, Wasserthiel-Smoller S, Wong N, Wylie-Rosett J, Hong Y, American Heart Association Statistics Committee and Stroke Statistic Committee (2009). A report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. *Circulation* 119; e21-e181
- Laloux P (2003). Cost of Acute Stroke A Review. On behalf of the Belgium Stroke Council. *Acta Neurol. Belg.* 103, 71-77
- Lutz BJ, ME Young (2010) Rethinking intervention strategies in stroke family care giving. *Rehabilitation Nursing,* 35 (4) 152 – 159
- Miller SL, Lewis MS, Williamson GM, Lance WK, Dooley WK, Schulz R, Weiner MF (2006). Caregiver cognitive status and potentially harmful caregivers behavior. *Age & Mental Health.* 10(2):125-133.
- Naylor MD (2003) Transitional care of older adults. *Ann Rev Nurs Res* 20, 127 – 47
- Overman Dube JA, Barth MM, Cmiel CA, Cutshall SM, Olson SM, Sulla SJ, Nesbitt, JC, Sobczak SC, Holland DE (2008). Environmental noise sources and interventions to minimize them: a tale of two hospitals. *J. Nurs. Care Qual.,* 23(3): 216-24.
- Ogunbo B, Ogun SA, Ushewokunze S, Mendelow AD, Rodgers H, Walker R (2005) How can we improve the management of stroke in Nigeria, Africa? *AJNS.* 24 (2):9-19.
- Reinhard S, Brooks-Danso A, Kelly K, Mason DJ (2008). "State of the Science: Professional Partners Supporting Family Caregivers," *American Journal of Nursing,* 108(9 Supple.), www.nursingcenter.com/ajnfamilycaregivers
- Scherbring M (2002). Effect of Caregiver Perception of Preparedness on Burden in an Oncology Population. *Oncol. Nurs. Forum* 29(6):70-6.
- Schumacher KL, Stewart BJ, Archbold PG, Dodd MJ, Dibble SL (2000). Family caregiving skill: Development of the concept. *Res Nurs Health.* 23:191-203.