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Research Article

Evaluation of Content of Physiotherapy Care Given by Stroke Informal Caregivers

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ABSTRACT

Informal caregivers taking charge of the continued care. Provision of adequate information, the need for skills in the aspect of home care and aspect in the management of stroke survivors can help create environment where health-care providers and informal caregivers partners in holistic stroke care and rehabilitation towards recovery of stroke survivors and minimise the risk of further injuries. However, there is need to assess the level of involvement of caregivers in home care programme. This study therefore sought to evaluate the content of physiotherapy care given by stroke informal caregivers. This cross-sectional analytic study was conducted among stroke informal caregivers in three secondary and tertiary hospitals in Lagos State. Sample size was 70. The participants were selected using consecutive sampling technique. Data was collected using structured questionnaire that was self-administered to the informal caregivers. Data analysis was carried out using SPSS Version 20 software and summarised using descriptive statistics. This study revealed that 61.4% of the informal caregivers knew the brain was involved in stroke, more than average (54.3%) of the informal caregivers had good knowledge about stroke risk factors, Sixty nine (98.6%) informal caregivers were involved in the home programme. Thirty four percent of the informal caregivers incorporated other physiotherapy programmes other than the prescribed home programme. Majority of the stroke survivors required assistance of caregivers in performing his/her home programme Informal caregivers need further assistance as adjunct for effective rehabilitation to augment hospital care for stroke survivors. The involvement of the informal caregivers must come with proper training to minimise further risk of injury.

Keywords: *Informal caregivers, stroke, stroke survivors, physiotherapy, evaluate, care, content, rehabilitation*.

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INTRODUCTION

Stroke has been reported as the most leading cause of disability compared to other diseases (Ali and Kausar, 2016). Disability following stroke can be seen in form of limitation in activities of daily living (ADL), restriction in social participation and difficulty in community re-integration (Shebl and Elhameed, 2014). The trajectory of care for stroke survivors often begins with the sudden onset, through hospital care, rehabilitation, and culminates in continued care (Cameron and Gignac, 2008).

After discharge from inpatient rehabilitation, stroke survivors return to live in the community, relying on informal caregivers to meet their needs (Cameron *et al* , 2013). Studies have shown that between 25% and 75% of stroke survivors require help with performing their ADL from their informal caregivers (Jeong *et al* , 2018).

It has been reported that informal caregivers play a major role in rehabilitation and long term well-being of stroke survivors. Specifically, they help the stroke survivors with home programme that includes bed transfer, positioning, handling and other specific exercises, all of which are complementary to physiotherapy (Mudzi *et al* , 2012; Kingau, 2018). The involvement of informal caregivers assists in lowering the risk for another stroke; it decreases the post-stroke complications; aids in improving function post stroke; helps stroke survivors to achieve the highest possible functional independence and recovery and assists in community integration (Langhorne *et al* , 2011).Thus, there has been emphasis that stroke rehabilitation should shift from being survivors-focus to an approach focused on both the stroke survivors and their informal caregivers (Gbiri *et al* , 2015).

Despite the potential advantages of involving stroke survivors and their caregivers in care planning, studies have demonstrated that stroke survivors and their informal caregivers often lack the information required to help manage the recovery process after discharge (Lamontagne *et al* , 2019). Many stroke caregivers lack basic information about stroke, strategies for caring for stroke survivors, and the ways

to prevent complication and future attacks of stroke (Kumar *et al* , 2016).

Many informal caregivers assume the role of caregiving in the recovery of their stroke survivors' condition without frequent training or no training (Lutz *et al* , 2016). In order to fulfil the caregiving role, informal caregivers should receive adequate information from the discharging facility or healthcare professionals. It is necessary, for example that the physiotherapy home programme offered by informal caregivers of stroke survivors align with standard physiotherapist's prescription (Marsella, 2009). Hence, this study aimed at evaluating the content of physiotherapy care given by stroke informal caregivers.

MATERIALS AND METHODS

Subject Selection: This study involved consecutively recruited 70 informal caregivers of stroke survivors who have been caring for stroke survivors for a minimum of one month after discharge from in-patient care. They were recruited from physiotherapy outpatient clinics of selected tertiary and secondary health institution in Lagos State. Prior to the commencement of this study, ethical approval was obtained from the Health Research and Ethics Committee of the Lagos University Teaching Hospital (LUTH), Idi-araba Lagos (LUTHHREC No: ADM/ DCST/ HREC/ APP/ 2822). Those who were paid for their care and those who had not spent at least one month with stroke survivors after discharge from inpatient hospital care were excluded from this study. The questionnaire was self- administered to the caregivers. The completed questionnaires were retrieved immediately.

Questionnaire Design: A focus group was created for the designing of the questionnaire consisting of academicians, post-graduate student and clinicians in the stroke rehabilitation field. The questionnaire was sectionalized as follows:

Section A: The socio-demographic characteristics of the informal caregivers such as age, sex, marital status, educational status, employments status, religion status, ethnicity, relationship to patient.

Section B: The socio-demographic characteristics of the stroke survivors such as age, sex, marital status, educational status, employments status, religion status, ethnicity, relationship to caregiver.

Section C: Caregiver's understanding and perception about stroke.

Section D: Caregiver's experience of caregiving.

Section E: Caregiver's physiotherapy care. This includes questions on level of involvement caregivers in home programme for stroke survivors.

Data analysis: The data collected were analysed using Statistical Package for Social Science-SPSS (Version 20).

RESULTS

A total of one hundred (100) questionnaires were distributed, seventy (70) were filled correctly and valid for data analysis, giving a response rate of 70%. Table 1 present the socio-demographic characteristics of both the informal caregivers and the stroke survivors. Table 2 present the caregivers' physiotherapy care.

Table 1:
Socio-demographic information for stroke survivors and informal caregivers

Variables		Caregivers		Stroke survivors	
		F	%	F	%
Age	Young adult	11	15.7	0	0
	Middle-aged adult	43	61.4	2	2.9
	Older adult	11	15.7	46	65.7
	Elderly	5	7.1	22	31.4
Sex	Female	27	38.6	30	42.6
	Male	43	61.4	40	57.1
Marital status	Single	33	47.1	0	0
	Married	35	50.0	47	67.1
	Divorced	2	2.9	10	14.3
	Widowed	0	0	12	17.1
	Separated	0	0	1	1.4
Educational Attained	Non-formal	2	2.9	4	5.7
	Primary	17	24.3	17	24.3
	Secondary	31	44.3	22	31.4
	Post-secondary	5	7.1	13	18.6
	University	15	21.4	14	20.0
Employment status	Self- employed	36	51.4	4	61.4
	Civil servant	1	1.4	9	12.9
	Private-employed	14	20.0	10	14.3
	Retired	1	1.4	7	10.0
	Unemployed	18	25.7	1	1.4
Religion	Christianity	47	67.1	52	74.3
	Islam	21	30.0	16	22.9
	Traditional	2	2.9	2	2.9
Ethnicity	Yoruba	50	71.4	51	72.9
	Hausa	2	2.9	1	1.4
	Igbo	16	22.9	17	24.3
	Others	2	2.9	1	1.4
Relationship	Husband	6	8.6	10	14.3
	Wife	10	14.3	6	8.6
	Relative	54	77.1	54	77

F = frequency; % = percentage

Socio-Demographic Characteristics of the Informal Caregivers: The ages of informal caregivers who participated in this study ranged between 19 and 75 years with a mean age of 36.1±13.6 years. Majority (61.4%) of the informal caregivers were middle-aged adults while (7.1%) were older than 64 years. Forty-three (61.4 %) were males while twenty-seven (38.6 %) were females. Most (50%) of the caregivers were married while (47.1%) were single (Table 1).

Socio-Demographic Characteristics of the Stroke Survivors: The ages of stroke survivors ranged between 33 and 73 years with a mean age of 60.29±8.8 years. Majority (65.7%) of the stroke survivors were older-aged adults while (2.9%) were less than 45years. Forty (57.1 %) were males while thirty (42.9 %) were females. Most (67.1%) of the stroke survivors were married while (14.3%) were divorced (Table 1)

Table 2
Caregivers understanding about stroke

Variables		Yes F (%)	No F (%)	I don't know F (%)
Is brain involved in stroke?		43(61.4)	0(0)	27(38.6)
Stroke can be caused by:	Hypertension	62(88.6)	0(0)	8(11.4)
	Diabetes	17(24.3)	15(21.4)	38(54.3)
	Injury to the head	9(12.9)	20(28.9)	41(58.6)
	Witches/ wizards	16(22.9)	44(62.9)	10(14.3)
	God's punishment	6(8.6)	55(78.6)	9(12.9)
	God's will	10(14.3)	46(65.7)	14(20)
	Too much stress	50(71.4)	8(11.4)	12(17.1)
	Smoking	10(14.3	21(30)	39(55.7)
	Result of bad luck	1(1.4)	52(74.3)	17(24.3)
	Family disease	9(12.9)	23(32.9)	38(54.3)
	Results of infections	3(4.3)	19(27.1)	48(68.6)
Stroke can cause death		60(85.7)	1(1.4)	9(12.9)
Is stroke treatable?		64(91.4)	1(1.4)	5(7.1)

Variable		Frequency	Percentage
Which is the first place to go to treat stroke?	Church or Mosque	6	8.6
	Traditional healer	3	4.3
	Chemist shop	0	0
	Hospital	61	87.1
	Treat at home	0	0
	Others	0	0

Informal Caregivers' Understanding about Stroke and Experience of Caregiving: Table 2 presents the informal caregivers' understanding about stroke. Table 3 shows the experience of informal caregivers

Informal Caregivers' Physiotherapy Care: All the participants' accompanied stroke survivors for physiotherapy treatment in the hospital. All the participants watched the physiotherapists during treatment. Most (98.6%) participated in physiotherapy sessions. 94.3% of the caregivers actively participated in physiotherapy sessions while 5.7% passively participated (Table 4). Majority (74.3%) of the informal caregivers disagreed to change in position of stroke survivors as one of the prescribed home programme by the physiotherapists while 22.9% of the informal caregivers agreed. 70% of the informal caregivers do change position of their care recipient while 30% of the informal caregivers do not (Figure 1). 34.3% of the informal caregivers did other programmes (Figure 2)

Table 3
Informal caregivers' experience about stroke

Variables		Frequency	Percentage
Have you cared for stroke survivor?	Yes	**13**	**18.6**
	No	**57**	**81.4**
How many?	2	10	14.3
	3	2	2.9
	4	1	1.4
How long have you been caring for stroke survivors?	<1year	16	22.9
	1-2years	33	47.1
	3-4years	18	25.7
	5-6years	2	2.9
	7-8years	1	1.4
How long have you been caring for this stroke survivor?	<1year	16	22.9
	1-2years	41	58.6
	3-4years	13	18.6
	5-6years	0	0
	7-8years	0	0
How long do you stay with this stroke survivor in a day?	1-4hours	12	17.1
	5-8hours	38	54.3
	9-13hours	17	24.3
	14-18hours	1	1.4
	18hours and above	2	2.9
Do you live in the same house as the stroke survivor	Yes	56	80
	No	14	20
Do you live in the same room	Yes	19	27.1
	No	37	52.9
Do you have any training on stroke caregiving	Yes	26	62.9
	No	44	37.1
Where did you receive your training	School of nursin	5	7.1
	Physiotherapy clinic	16	22.9
	Community coll	1	1.4
	Internet	4	5.7

Table 4
Informal caregivers' physiotherapy care

Variable		F	%
Do you follow the patient for physiotherapy treatment?	Yes	70	100
	No	0	0
Do you watch the physiotherapists when they treat?	Yes	70	100
	No	0	0
Do you participate in physiotherapy sessions?	Yes	69	98.6
	No	1	1.4
What level of participation do you give?	Passive	4	5.7
	Active	66	94.3
Do physiotherapists give home programme to the patient?	Yes	64	91.4
	No	2	2.9
	I don't know	4	5.7
How are you involved in home programmes	Passive assistance	35	50
	Partial assistance	21	30
	Total assistance	14	20

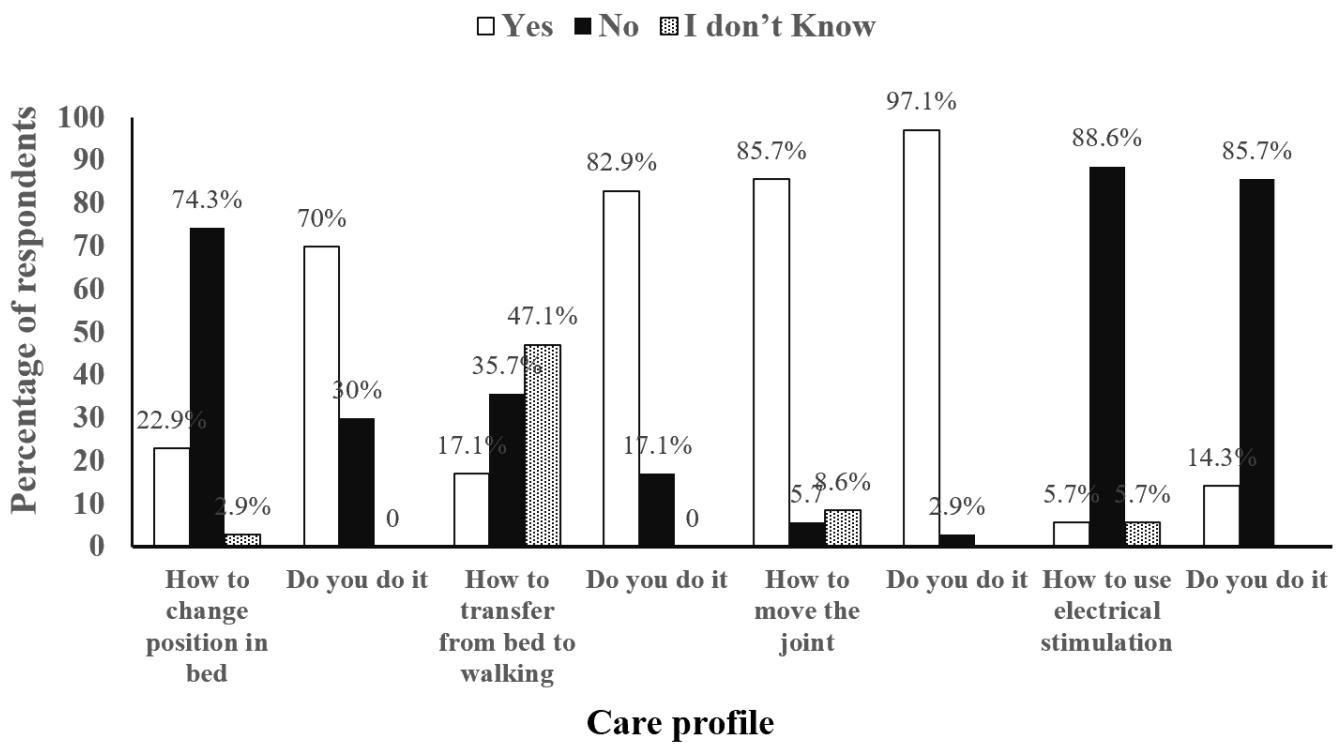

Figure 1:
Content of physiotherapy care prescribed and done

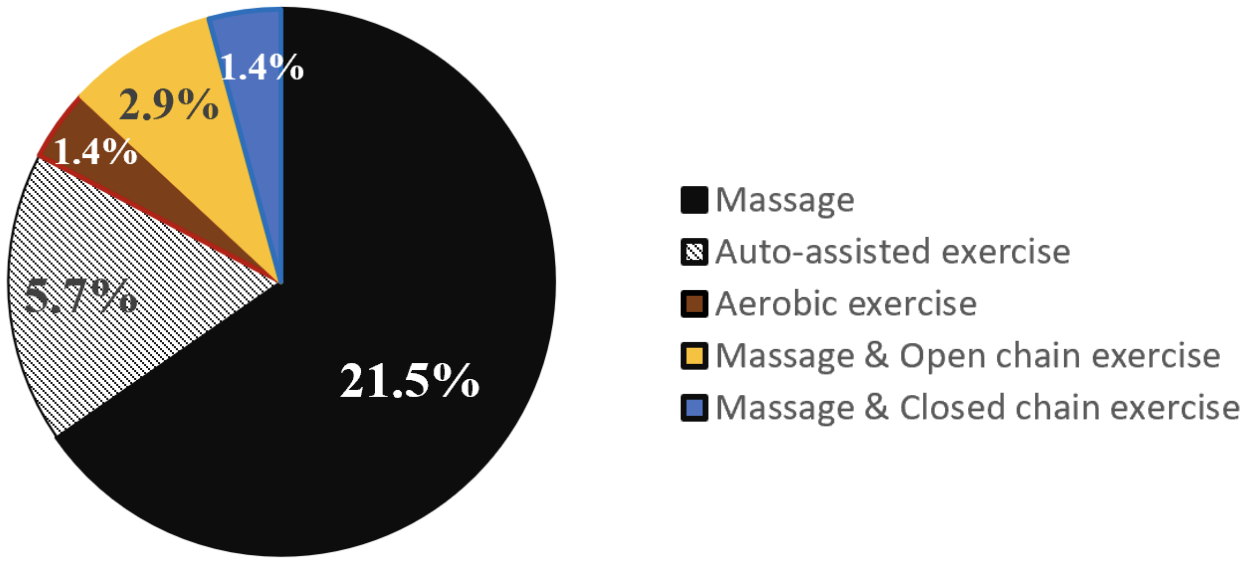

Figure 2:
Other physiotherapy care given by stroke informal caregivers

DISCUSSION

The purpose of this study was to determine the content of physiotherapy care given by informal caregivers to stroke survivors. The stroke survivors' mean age of 60.27years agrees with the finding of Somotun *et al* , 2017 and Abdul-Afeez*et al* , 2017 who reported the mean age of 61.7years.This shows that the stroke survivors fell into older adult classification, indicating the peculiar vulnerability of this group to stroke. Some stroke risk factors such as hypertension are known to increase with age (Vlodaver *et al* , 2017). Finding that stroke is predominant amongst males corresponds with the research done by Zafar *et al* , 2016. Part of this predominance explains the lower global life expectancy

for men compared to women because men are exposed to stroke risk factors like hypertension, diabetes mellitus, hyperlipidemia, atrial fibrillation, cigarette smoking and stress compared to women of the same age group. Nevertheless, studies have shown that prevalence of stroke increases exponentially in both sexes with age (Haast *et al* , 2012). The result that most of the informal caregivers were middle-aged adults is of great national economic importance. It shows that stroke caregiving burden is enormous among the active work force who contributes to national economy. There is need to address the situation especially in a developing country like Nigeria where the capital income is low and household income is always inadequate (Okoye *et al* , 2019). The fact that most of the caregivers are either the children or the grandchildren shows the economic burden of stroke is on the family. Although the involvement of the children is of cultural value, in which African children are supposed to care for their parents at old age (Lamb *et al* , 2017). Compared to other cultures like America, China, Canada (Rigby *et al* , 2009) where we have the spouse doing the role of caregiving and seldom their children.

The involvements of children in caregiving for stroke survivor parents may not be surprising as the African social practice expects children to play a significant role in care of their parents, especially when they are sick or in their old age. An earlier study in Nigeria (Akinpelu and Gbiri, 2009) had reported that stroke survivors in South-Western Nigeria enjoyed the same level of intimacy with their relatives comparable with their apparently healthy individual. This shows that stroke survivors in Nigeria do not suffer neglect from relatives and significant others.

The results showing that most of the caregivers were sons of the stroke survivors could also be attributed to the physical strength of a male child relative to the female child. This agrees with the finding of Vincent *et al* , 2013 who reported that majority of stroke caregivers in Nigeria are males. Study done on stroke informal caregivers in Benin-city by Imarhiagbe *et al* , 2017 showed a predominance of female caregivers compared to male. However, regions like Canada, (Cranswick and Dosman, 2008) reported that majority of stroke caregivers were females, although they reported that male caregivers has been steadily increasing in recent years. The male dominance of the caregivers of stroke survivors in Nigeria and the increasing pattern in other country may be attributed to the fact that caring for stroke survivors and involvement in their home programme requires physical strength and ability and such work are often attributed to the males. Education level, employment status and marital status are major social determinants that correlate with individual and overall population health outcomes (Hertzman *et al* , 2017). The results of educational level of informal caregivers in this study showed that majority of the caregivers have completed a secondary education. People with high education levels are expected to have high levels of literacy and understanding, more involvement in health decision-making, and increased ability to use community resources to affect lifestyle positively compared with those with low education levels (Elkhateeb and Salem, 2018). In developing countries like Nigeria, low education status have strong correlations with increased risk and prevalence of stroke, and increased stroke morbidity and mortality (Okoye *et al.*, 2019). Little is known about how education level of the informal caregivers' correlates with stroke survivors' health outcomes but Elkhateeb and Salem, 2018 came into conclusion that caregivers with high education level will give better care to their care recipients.

The knowledge of caregivers about stroke was assessed based on a number of risk factors; if the brain is involved in stroke; if stroke can lead to death and if it can be treated. The results showed that majority (61.4%) knew that the brain is involved in stroke and had good understanding about the risk factors, which is a positive result that would help in preventing stroke occurrence. This may suggest that the knowledge of the public is good about stroke as a result of their interaction with the health care providers especially physiotherapists since they were recruited from the hospital environment where they followed their relatives for physiotherapy. Hamzat *et al* , 2014 had earlier reported that an average Nigerian had good understanding about the risk factors of stroke. This is different in Uganda where public awareness about stroke and its warning signs were reported to be poor (Mahinda, 2016).

The result showed that majority (81.4%) of the stroke caregivers had cared for only one stroke survivors which is the one they came with. 14.3% have cared for two and the remaining 4.3% have cared for more than two. Most of the stroke caregivers have spent an average of 2years of caregiving to stroke survivors and majority have spent an average of 1year of caregiving to their present care recipients. Majority of the stroke caregivers spent 5-8hours per day with the stroke survivors with 80% living in the same house and 27.1% living in the same room. This is of positive benefits because the caregivers have more time to give care which should improve the quality of life of the stroke survivors but also of negative effects by disturbing the productivity of the caregivers and increase economic burden on them too.

62.9% of the caregivers had no training on stroke caregiving and that is due to inadequate provision of information to stroke caregivers. Research done in Bangladesh by Rahman and Salek, 2016 concluded that structured training of caregiver provided during discharge of hospital admitted stroke patient has positive effects on the outcome of survivor. 22.7% of the caregivers were trained from physiotherapy clinic through the physiotherapists.

The results that most (98.6%) of the caregivers participated in physiotherapy sessions in clinic is complimentary to effective rehabilitation for stroke survivors at home. This will improve the quality of the life of stroke survivors. The results that most physiotherapists gave home programme and most caregivers were involved showed that physiotherapist in Nigeria integrate the caregivers into stroke rehabilitation and value them as progressive partner in effective stroke rehabilitation.

The results that physiotherapists prescribed position change in bed yielded a low result but 70% of the caregivers implemented it, which is of great interest to the physiotherapists. This would help the physiotherapists in clinical decision making by providing enough information on positioning. Bed positioning is of great importance to physiotherapy to prevent the occurrence of pressure sore or musculoskeletal disorder like shoulder subluxation, soft tissue

damage and spasticity. Many may result from trauma caused by incorrect moving and handling. With majority of the caregivers changing position of the patients without proper training by the physiotherapists or nurses, this may account for the predominance of hemiplegic shoulder pain among stroke survivors. Risk of hemiplegic shoulder pain could be reduced if the physiotherapists train the caregivers more by demonstrating to them and ask them to replicate the procedure in the clinic.

This study showed few physiotherapists gave information on walking re-education and this could decrease the chance of early mobility of stroke survivor and reduce lower limb function of the stroke survivors. 85.7% of the caregivers said the physiotherapists gave home programme on joint movement and majority executed the task. This is a positive review in clinical practice that implies that caregiver are of great importance in clinical decision making and involvement of their care should not be ignored. Therefore, there is need to improve knowledge of the caregivers on contemporary stroke rehabilitation approaches. Only few prescribed the use of electrical stimulators and assistive devices. Functional electrical stimulation of muscles is used to augment hand function for stroke survivors. In a research done by (Quandt and Hummel, 2014), in which they reviewed the literature on functional electrical stimulation as one potential treatment option to improve motor recovery after stroke. They concluded that neuromuscular stimulation is one potential rehabilitative treatment option to restore motor function and improve recovery in patients with paresis, especially stroke survivors who often regain only limited hand function would greatly benefit from a therapy that enhances recovery and restores movement. Therefore, if the physiotherapists can educate the caregivers on how to use electrical stimulators, this would improve the motor recovery of stroke survivors.
Some caregivers replicated some of the treatment done in the clinic by the physiotherapists which included massage, handgrip exercises, auto-assisted exercises, open chain exercises like use of pulley for open arm movement and use of multi-gym. Some used hot balm, Shea-butter and all sorts of traditional herbs for massage. This is of concern to physiotherapy because of the tendency to abuse their uses and cause further injuries or complications to recuperating patients. Some caregivers incorporated squats and treadmill walking. This implies that the informal caregivers are ambitious, resourceful and perceptive. However, they need to be guided, motivated and supervised to ensure they handle their care recipients well. This again calls for structured collaborative intervention in the context of shared decision making process.

Therefore, appropriate instruction should be communicated to the caregivers by the physiotherapists on home programmes. This will facilitate adequate and proper execution of home programmes by stroke survivors and they will be minimization of risk of injuries caused due to ignorance of the informal caregivers. Although the caregivers had knowledge of physiotherapy treatments, there is still need to educate them and fully incorporate them in planning goal-oriented functional independent performance activities for rehabilitation of stroke survivors. This will influence positively on the integration of home programme into stroke rehabilitation and make it more impactful and effective as complementary to hospital cares for stroke survivors. This study therefore nevertheless presented with some limitation relating to constraint of establishing the psychometric property of the questionnaire used. The design of the questionnaire itself could be a subject of further study because of the complex intervention that stroke rehabilitation entails.

In conclusion, based on the findings on this study, results shows that more than average of the informal caregivers of stroke survivors had good knowledge of stroke and stroke risk factors, they also have good knowledge about physiotherapy care. Majority of the informal caregivers involved themselves fully in home programme. Also majority of the stroke survivors required assistance of caregivers in performing his/her home programme. Majority of the informal caregivers need further assistance as adjunct for effective rehabilitation to augment hospital care for stroke survivors. Conclusion were also drawn that majority of the informal caregivers are watchful in the clinics and their involvement must come with proper training to minimize further risk of injury.

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