

## Strengthening health service delivery to stroke survivors in the community: A case of an African community

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### Abstract

Health service delivery for stroke survivors has been a challenge in most African countries due to the chronic nature of the stroke and weak health systems. Studies indicate that community dwelling stroke survivors are unable to regain a good quality of life after experiencing a stroke, they are unable to socially integrate and there are a lot of strains within close family support networks. This study set out to explore methods of strengthening service delivery to stroke survivors in the African community from the health workers and caregivers' perspective. An exploratory study, employed a focus group discussion to collect the data was employed to achieve the study objective. The study was conducted in a community of Livingstone District in Southern Province of Zambia, Southern Africa. A focus group discussion consisting of 17 participants involving caregivers and health workers was done using a discussion guide which was developed by the authors to collect information needed. A combined focus group discussion was done involving 10 caregivers and 7 health workers all drawn from the Livingstone community. Themes and categories were transcribed from audiotape recording verbatim by an independent consultant. The study found that the stroke survivors had challenges in accessing health services as they were more at institutional level. The availability and affordability of the health services was another challenge. The patients alluded to challenges in transport, paying of user fees, and distance from the health facility, lack of information on strokes and stroke prevention as well as the non-availability of well-informed and skilled community support services. In order to strengthen the health systems in Africa, there is need to have well-coordinated stroke health services that link institutions to the community. Well-informed and skilled community support services are a must and must be driven by the community themselves. Constant technical supports from the health providers need to be established to strengthening the health systems.

**Keywords:** Stroke survivors, health services, strengthening health systems, Africa

### 1. Introduction

Health service delivery for stroke survivors has been a challenge in most African countries due to the chronic nature of the condition<sup>[1]</sup>. These challenges could lead to increased burden of stroke in Africa resulting into severe disabilities among the stroke survivors as well as severe poverty due to increased inability of stroke survivors to fend for them. As a result, stroke victims take longer to recover and end up losing their means of livelihood thereby getting impoverished. Efforts aimed at strengthening service delivery for stroke survivors are being put in place in most developed countries<sup>[2,3]</sup>; unlike most African countries which are still struggling to eradicate infectious diseases that include HIV/AIDs, Malaria and Tuberculosis and have inadequate resources to effectively strategize on how to combat the rise in non-communicable diseases<sup>[4]</sup>.

Despite employing strategies like community based rehabilitation to strengthen the health systems by improving rehabilitation services of the stroke survivors, these efforts have not reached optimum levels in many African countries<sup>[1]</sup>. This is attributed to mainly to resource constraints<sup>[5]</sup>, though valuable contributions to the design and organization of effective health services are being made by communities in

urban, peri-urban and rural set ups in conformity to the Addis Ababa Declaration<sup>[6]</sup>, the World Health Report<sup>[7]</sup> and the Ouagadougou Declaration<sup>[8]</sup>.

Studies indicate that community dwelling stroke survivors are unable to regain a good quality of life after experiencing a stroke, they are unable to socially integrate and there are a lot of strains within close family support networks.<sup>[9,10]</sup> A significant number of stroke survivors in the community develop severe disabilities as a result of isolation and fear making the recovery process difficult<sup>[11]</sup>, and particular health services to curb this situation are not necessarily available in most African countries.

Research has also showed that stroke survivors in Africa experience adverse social economic impact due to the disabling consequences of stroke<sup>[9]</sup>. Therefore, the objective of this study was to explore methods of strengthening service delivery to stroke survivors in the African community from the health workers and caregivers' perspective.

### Methodology

#### Research design

An exploratory study, which used focus group discussions to collect the data, was employed to achieve the study objectives.

## Research setting

The study was conducted in a community of Livingstone District in Southern Province of Zambia in Southern Africa. Livingstone is an urban district of Southern Province with a total population of 139,509 with 30,461 households<sup>[12]</sup> and lies 485 kilometres south of Lusaka, the Zambian capital city. Livingstone district has only one hospital which was recently upgraded from general hospital to a central one and like any other urban district in Africa, is experiencing an epidemiological transition from communicable diseases to non-communicable diseases and stroke survivors are on the increase in the district<sup>[9]</sup>. The District has 10 health centres but rehabilitation services are mainly offered at the hospital.

## Participants

The study involved two groups of participants namely the caregivers' group consisted of spouses or any other caregiver or guardian of the stroke survivor from the community; and the other group consisted of health workers who provided health services to the stroke patients, who were mainly drawn, from in Livingstone Central Hospital. Ten caregivers were conveniently selected from the hospital register following their availability and willingness to discuss, and their being key informants.

The list of the health workers group was obtained from Livingstone Central Hospital and consisted of one medical officer, three rehabilitation workers and three nurses. The health workers were also purposefully selected as they worked with stroke survivors. A combined focus group discussion was done.

## Data collection and analysis

A focus group discussion consisting of 17 participants was done using a discussion guide was used to collect information needed. Discussions were done in both English and local languages and discussants were asked to freely answer the questions. Open-ended questions and inductive probing were adopted during the audio taped data collection process.

Discussion notes were transcribed from the tape recorders by independent transcribers and thereafter all data translated into English. Transcribed data was entered into computer files. Data was coded. The tape records were stored in a locked filing cabinet for confidentiality. Data was transcribed verbatim by an independent person. In transcribing, confidentiality was ensured by use of codes instead of names. Transcribed data was read and re-read by the researcher several times for familiarity and general understanding of the scope of context of key information<sup>[13]</sup>. When the scripts were read and re-read, interesting contents based on themes were grouped together into categories.<sup>[14]</sup> The categories that were coded were then analysed using content analysis and then compared to existing literature concepts.

## Ethical clearance

Ethical clearance for the study was obtained from The Biomedical Research Ethics Committee of the University of Zambia, School of Medicine and written permission was granted from the Hospital Management for the study to be conducted as well as for use of the hospital register. Detailed information about the study was provided to the participants

and they were asked to sign consent forms and the participants were also told that they were at liberty to withdraw at any given time if they felt like. Participants were assured that their not participating in the study would not affect treatment. It was indicated that there were no anticipated risks of not receiving adequate treatment if they did not participate in the study and all information collected from all participants was treated with confidentiality as names of the participants were not required during data collection and was not given to any partner or project for further analysis. Participants were informed that there were no direct benefits to them but the study could perhaps shed light on how service delivery to stroke patients in the community could be strengthened.

## Results

### Socio-demographic characteristics

There were seventeen respondents in this study. The respondents had two categories as follows;

### Caregivers

Ten caregivers of stroke survivors took part in the study whose age ranged from 26 years to 71 years with mean age of 43. Of the ten caregivers, three were males and seven were females. Two of the caregivers went up to primary school education, six of them had gone up to secondary school, and two had tertiary education. Only two of the caregivers were fully employed.

### Health workers

Seven of the health care providers who took part in the study, were in the age range of between 31-53 years with mean age was 41.1. Only one of the health care providers was male. The health workers mean years in health service provision was 18.3.

### Availability of stroke health services

The study revealed that stroke health services were not readily available as they were only provided by health facilities in the district but not at community level. The respondents showed that every time stroke survivors needed health services, they had to access them from health facilities, meanwhile not all services were offered at the nearest health centres but the hospital.

*“Services are not available in the community...there is no one to help with health needs in the community, unless you personally know someone. When you need something for stroke, you have to go the hospital. Here at the clinic they just do blood pressure”* Caregiver 2

Health centres provide hypertension monitoring services amid other vital signs monitoring, but do not provide rehabilitative services or information on stroke.

*“There is nowhere you can go to get information. By the time you get information regarding stroke, you would have wasted a lot of time on myths”* remarked Caregiver 8.

*“We do not have rehabilitative services in the clinics yet...so when stroke patients need such services, they have to come to the hospital”* said health worker 4.

Health Centres refer patients to the hospital when they are in need of rehabilitative services. Not all stroke services are readily available.

### **Accessibility of existing stroke health services**

Stroke survivors undergo challenges when accessing health services as this was shown by the response from all the groups. Both groups revealed that it is very difficult for stroke survivors to access stroke health services due to distance from their homes to the hospital. Most of the services needed by stroke survivors in this community were not available hence reducing accessibility of health services.

*“At the hospital, the use of rehabilitation services is not enough lasting to less than two hours per week for each individual patient”.* Health worker 6 complained of time limitations for the stroke patients seeking rehabilitation services.

*“Medical clinic is also congested...so all patients are delayed including hypertensive patients. In medical clinic, hypertensive patients are reviewed monthly if they faring well, but its congested like I said”*, explained health worker 7.

Since stroke health services are only offered in hospitals, there is overcrowding and hence increasing the clinician-patient ratio. This leads to less time being devoted for one stroke survivor leaving no time for other issues such as offering patients health education. Most of the stroke services are centralized making it very difficult for stroke survivors to access the services as they have to move a distance coupled with their loss of function.

*“We only come to the hospital for exercises on Tuesday and Thursday. This is the only time patients are seen and we are told to continue rehabilitation at home ...but we don’t know much also...they teach us but they are in a hurry to attend to other patients so it’s difficult”*, complains Caregiver 10.

The respondents revealed many factors affecting stroke survivors’ accessibility to health services including distance, time and money. Home rehabilitation was revealed to be challenging because most of the care takers lacked knowledge and skill in rehabilitation.

### **Affordability of existing stroke health services**

Affordability of stroke health services was found to be a challenge. Inasmuch as families could afford to pay for user fees of health services at the hospital, other expenses were difficult to meet. Transport was costing a lot of money in form of booking taxis from home to the hospital and back home again. Transportation is inevitable as most of the stroke survivors could not use public transportation.

*“At the hospital we pay monthly but it is not much...the problem is transportation for us without our own cars”*, said Caregiver 3.

Most of the caregivers had to forgo other income generating activities for them to take care of stroke survivors. This was in form of employment, business of farming.

Caregiver 9 said was told to quit, *“they could not allow me to miss work every week...so they told me to resign”*.

### **Type of stroke health services needed**

The respondents revealed varied health services needed by stroke survivors. Their health care providers specifically elaborated that services should include information about stroke, increased activity through sport or gymnasiums, good lifestyle involving nutrition, management of hypertension, rehabilitation of stroke survivors, health education and counseling. Social welfare programmes need to be put in place. They argued that stroke being a non-communicable disease, if the above preventive measures are put in place, risk factors may significantly reduce. Management of stroke should not only be institutional based. The community should be empowered with necessary skills to continue rehabilitating the stroke patients at home as they further suggested.

Health worker 2 said *“Rehabilitation in all its forms is very important for stroke at community level; this will help the survivors to get back to their old life as they reach the fullest functional level and prevent residual complications”*.

The caregivers group also revealed the need for emotional support and informational services’ provision. They alluded to the fact that strokes are only known by few in the community who have being exposed to the experience.

*“Information about stroke is needed like what causes it, how to prevent it and how to manage it...we only got the true information when we got to the hospital. In the community, we were misled, some even saying its witchcraft because my husband was recently promoted at work and we did not know that he had blood pressure”* said Caregiver 1.

The caregivers need for emotional support reveals adverse impact of strokes and hence caregivers together with their survivors thought emotional support in the community was very necessary.

*“Sometimes we need someone like a counselor who understands the situation... It is a burden really”*, said Caregiver 10

### **Methods of strengthening stroke health services**

When asked on methods to strengthen stroke health services, both groups suggested similar ideas. They suggested extending stroke health services into the community. Acknowledging that the services being offered by the health facilities were good, they said there were are not enough to remedy the situation for stroke survivors. They insisted that taking services to the community could reduce the challenges faced by the stroke survivors and their families and hence improve recovery and minimize residual disability. The health care providers further

suggested that though extending stroke health care services to the community was very important, the community should own them and take a leading role in ensuring that they get the necessary information from the health care providers to help them play their role in the rehabilitation process.

*“It should be the community themselves providing the services to stroke patients...we already have shortages just here in the hospital, so community work would be non-starter. We have outreach services but the programme is not reliable due to finances. So the community themselves need to do this programme”,* said health worker 7.

The caregivers group thought they could do the programme at community level but they showed lack of capacity to do it.

*“It would be better if a lot of us are taught, even those without stroke survivors in their families. Some people learn fast others don’t...in that way, we can be helping each other”,* suggested caregiver 5.

Of particular interest was that the health workers were willing to impart knowledge and skills in the community and continue giving them technical support, but they emphasized that the programme should be owned by the community themselves.

*“The community needs to form a support group among themselves, and then we can impart knowledge in them and give them technical support. Support would come in form of information about stroke, teach blood pressure monitoring but management of hypertension can be done in health facilities”,* advised health worker 6.

Health worker 4 explained *“we can also teach rehabilitation skills to a group and therefore they can support one another”.*

The caregivers further suggested that all interested community members should be incorporated so that they act as a source of support to their colleagues who may be seeing stroke survivors for the first time.

*“It will be better if we spread the programme to the entire Livingstone so that others can join us. Many people have interest in health issues. It can be like what happens for HIV...not all involved are positive or have family members who have the disease, they just teach how to prevent because they are interested”,* said caregiver 7.

This was amplified by health worker 5 who said *“What we need is a stroke support group to spearhead the community based rehabilitation. Outreach services have not been sustainable because we go once in a week if there are resources....if there are no resources, even one month may elapse without us going there”.*

## Discussion

Strengthening health service delivery for stroke survivors in the communities is of paramount importance in the improving of the health service delivery in Africa, which may overly result in strengthening of the entire health systems<sup>[15]</sup>. Inasmuch as

health service delivery is influenced by other World Health Organization building blocks<sup>[16]</sup>, other methods of health service delivery improvement lie within the building block of service delivery itself. In the case of strengthening stroke health service delivery, the community need to participate as indicated in the Ouagadougou Declaration<sup>[8]</sup>. This means that the community should come up with their own ideas on how to strengthen health service delivery.

As shown in this study, stroke health services are a challenge in African communities as they are mainly found at hospital level, not in the community. This is due to the lack of comprehensive primary health care services in many African countries<sup>[17]</sup>. Many primary health care services in Africa have been selective, leaning towards communicable diseases, maternal and child health as these have been the many health burdens in African countries<sup>[18]</sup>. That being said, Africa is experiencing epidemiological transition with an increase in non-communicable diseases including stroke which is the sequelae of hypertension, the commonest non-communicable disease<sup>[19]</sup>. Stroke health services are not easily accessible to many stroke survivors due to various factors, and paramount of all is the distance to hospitals<sup>[17]</sup>. This is coupled with congestions as many survivors try to access these available services at one central health facility thereby reducing time dedicated to each individual stroke survivor hence negotiating access<sup>[20]</sup>. As shown in this study, access is affected by expenses both direct and indirect, meanwhile the expenses are inevitable<sup>[21]</sup>.

Stroke health services comprise of preventive and management services. In many African communities, stroke as a condition is not well known<sup>[22]</sup>, therefore for prevention, information on the causes of stroke, its management is critically important. Promoting good lifestyle to prevent non-communicable diseases should include increased physical activity, as sedentary lifestyle has been linked with increase in non-communicable diseases<sup>[23]</sup>. In promoting good lifestyle, good nutrition should be encouraged. Case management of hypertension in hypertensive patients is an important way of preventing stroke occurrence. In stroke management services, rehabilitation is paramount and research has shown that rehabilitation provided in the home environment of stroke survivors yields better results than that away from home<sup>[24]</sup>. This should be coupled with health education on handling stroke survivors due to its impact on lifestyle. Counseling services in all forms is necessary as they help in lessening the emotional burden of stroke<sup>[25]</sup>. Social welfare activities are very important in the mitigation of the impact of stroke in the community because of the adverse impact of stroke<sup>[26]</sup>. Stroke health services needed at community level must be comprehensive owing to the nature and chronic situation of strokes<sup>[27]</sup>.

Strengthening service delivery for stroke survivors in the community, calls for innovation in health service delivery system. Support groups have been a trademark in the management of certain conditions in Africa e.g HIV/AIDS, diabetes etc. Support groups provide the necessary community service to complement the existing services, but are usually owned by the community<sup>[2]</sup>. Support groups are even the trademark of some conditions in developed countries and hence are known to strengthen service delivery and thereby strengthening health systems<sup>[2]</sup>. This is similar to what the

health workers indicated that the support group be formed but they should be owned by the community as the health care services are in already resource strained. The ownership of support groups is similar to community based rehabilitation which is usually the initiative of the community but can be supported by other stakeholders, while the health care provider only gives technical support [28]. Shifting delivery of health services from the main health care provider has shown to be helpful in improving the quality of services as health facilities are strained and burdened [29]. Empowering the community with health services has been a recurrent theme of many African Conferences [8, 30]. Empowering community participation is sustainable unlike providing outreach health services as the World Health Assembly attested [31]. Health sustainable development goals can be achieved through health service delivery innovations like support groups and community health services including rehabilitation services. Strengthening services delivery through support groups and community based health services equally responds to the needs of investing health in Africa which could improve development in the long run.

### Conclusion

The study has shown that strengthening stroke service delivery in the communities could lead to improvement in the health services delivery system in African communities. From both health workers and caregivers of stroke patients, it has been shown that extending stroke health services to the community is important. This can be done in form of support groups and community rehabilitation programmes which should be owned by the community with health workers providing technical support to the programmes. The study shows that extending of health services delivery could help reduce the impact of stroke at community level and improve accessibility. In order to strengthen the health systems in Africa, there is need to have well-coordinated stroke health services that link institutions to the community. Well-informed and skilled community support services are a must and must be driven by the community themselves. Constant technical supports from the health providers need to be established to strengthening the health systems.

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