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# Supporting Survivors of Stroke in Low Resource Settings

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## Abstract

Stroke occurs suddenly and has major impact on both the survivor and their caregiver. A third of stroke victims usually die from its direct effects or complications. The survivors usually have functional deficits resulting in the need for caregiver support. The caregivers may have inadequate knowledge of how to care for their affected relatives. The result is high caregiver burden and complications among the survivors. Once a person has stroke, it becomes important that their caregivers and their needs are determined so that they get the necessary support from the health professionals. Education of both the stroke survivors and the caregivers, and follow-up to determine if their needs are being met may be the support required. This is important in low resource settings where the survivors and caregivers may not always afford to go to stroke clinics for support visits and follow-up. Furthermore, stroke will result in reduced quality of life, poor functional outcomes, and poor community reintegration, which are important areas in life. Caregivers who look after the survivor for long periods may suffer burnout and have poor quality of life. Educating both the stroke survivor and their caregiver may result in better quality of life and survival rate.

**Keywords:** survivors of stroke, caregivers of stroke, low resource settings, outcomes of stroke, caregiver training

## 1. Introduction

Stroke is a common neurological problem and one of the leading causes of death in developing countries of the world [1]. It is one of the most disabling diseases and has great emotional impact on both the survivors of stroke and their relatives [2]. Stroke can affect virtually all human functions and unlike other disabling conditions, the onset is sudden, leaving the survivor and family unprepared to deal with the consequences which can be clinical, social and economic [3]. In most developing countries, people affected by stroke present late to hospital and even then, are only kept in hospital for a short period until they are medically stable. They are then discharged home while still functionally dependent to the care of relatives who lack knowledge on what to do hence the need to be trained [3–5]. There are no institutions where they can get community support and the few that are available are beyond the reach of many. This puts the burden of care at home on the relatives. This is the case in Zimbabwe, Rwanda, Tanzania and South Africa [5, 6]. The chapter therefore gives information on supporting informal caregivers in order to

improve functional outcomes among survivors of stroke and quality of life among both the survivors and caregivers [7].

It also gives an overview of the extent and consequences of the stroke problem in low resource settings, length of hospital stay and the implications on stroke survivors and their caregivers, and the impact of stroke in terms of mortality and morbidity. Furthermore, the chapter looks at the rehabilitation of stroke patients, the impact of stroke on caregivers, and how patient and caregiver training can improve outcomes for both the patient and caregiver in low resource settings. In addition, it highlights the reason why supporting survivors of stroke and their caregivers are important in these settings considering that there are no consistent hospital-based services to support them. Finally, it outlines how a training programme for stroke patients and their caregivers can be developed using Kern's six step model [8].

## **2. Epidemiology of stroke**

Projected figures indicate that stroke is reaching epidemic proportions due to increased non-communicable diseases and HIV, and will be the number one killer by 2020 [9–11]. According to the Centre for Disease Control and Prevention, the incidence of stroke has increased by 100% in middle-to-low-income countries since 2002 [10, 12]. Although this increase is related to the increasing burden of cardiovascular risk factors and the ageing population, infectious causes of stroke are also thought to contribute. According to the World Health Organisation, 15 million people suffer from a stroke worldwide each year, and of these, 5 million die, 5 million fully recover and another 5 million are permanently disabled and need assistance with activities of daily living [13]. Low- and middle-income countries have 70% of strokes and 87% of both stroke-related deaths and disability-adjusted life years [14, 15] consequently making stroke the major cause of disability in Sub-Saharan Africa [16].

The incidence of stroke varies by race and country [17]. In SSA, most cases of stroke occur in relatively young people (mean age < 60 years in most studies), some 10–15 years younger than patients with stroke in developed countries [11, 17–21]. Earlier, Feigin and colleagues had found the mean ages for men and women to be 70 and 75 years respectively [22]. In Chile, the mean age was reported to be 66.4 years [23]; while it was found it to be less than 50 years for sub Saharan Africa [24]. This was in line with findings in Malawi where the mean age was  $54.2 \pm 16.9$  years [11]. A Gambian study found the mean age to be 58 years (10–15 years) younger than patients in developed countries [25]; as is the case with Brazil where the mean age was 64.1 years [26]. In Ghana the mean age of stroke patients is 63.68 years and the male to female ratio is 1:0.96 [27]. In Sudan the mean age was found to be 56.61 [28]. However in Zimbabwe there were more females than male [5, 20, 29].

It is hoped that improved post stroke care, through caregiver support and training would reduce morbidity and mortality among stroke survivors and improve caregiver outcomes in low income countries. Information on causes and prevention of subsequent strokes may be important to give during caregiver support so as to empower them and improve compliance with medications.

## **3. Length of hospital stay (LOS)**

Generally, LOS in African hospitals and other developing countries is short and range from 2 to 30 days [20, 30–37]. Shorter LOS may be indicative of fewer

rehabilitation sessions and reduced impact on stroke survivor outcomes [6]. In 2012,  $6 \pm 4$  days were reported in South Africa [32]. This was however lower than the 14 days previously reported for public hospitals in the same country in 2002 [34]. Other authors reported up to 30 days of hospital stay in South Africa [37]. LOS has a bearing on the state at which patients are discharged in terms of function. This may mean that the stroke survivor will still need care, and within 2 days, caregivers may not have been trained on care or even have met rehabilitation personnel to get information about their sick relative.

There are other reasons too. In most instances, survivors of stroke and their relatives cannot afford long LOS as this means higher hospital bills [33–35]. Hospitals also need beds for other ill patients so once patient is stable, they are discharged home to the care of relatives more likely due to pressure for beds as survivors of stroke do not pay in the public hospitals in many developing countries [36, 38, 39]. Furthermore, most patients would have presented late to hospital due to several factors and the stroke would have progressed, and condition worsened [5, 40]. This is not unique to African countries as this was also the case in Jordan where 32% of the population was not covered by any health and social insurance, and also spent less time in hospital [41]. Short hospital stay also means that patients are discharged before they are fully functional [39, 42]. This may be an indication that patients are kept in hospital until they are medically stable but not for rehabilitation [6]. As in the Zimbabwean setting, there may be no community services available to cater for the stroke survivors and their caregivers in most instances. Even in developed countries, it was found that caregivers lack knowledge on how to care for their relatives with stroke and are not trained to care [42].

Survivors do better with an organised, multidisciplinary approach to treatment in which they and the caregivers are a part, hence the need to offer support to caregivers [7, 43]. The ideal management of stroke involves several aspects although these are not uniform in different countries. These include rapid response systems to stroke where patients are seen within 3 hours and proper diagnosis is made which includes Computerised Tomography (CT) scans and Magnetic Resonance Imaging (MRI). Patients are also put in Stroke units for transition of care and given thrombolysis. Once stable they start rehabilitation treatment before being discharged home or to institutions. However, well-organised stroke services are virtually absent in the government sector in most developing countries [44]. For example, in Zimbabwe, current stroke management is hospital-based because most of the hospitals are acute care facilities and are not designed to provide rehabilitation in the wards beyond patient's discharge from the acute ward. From experience, rapid response is not available as most patients are not able to present to hospital on time after stroke. Most survivors also cannot afford the diagnostic procedures hence physicians depend on clinical symptoms for diagnosis. This is also compounded by a high staff turn-over making it difficult for patients to get consistent care. Challenges may then occur with coordination, availability of health care professionals and finances [34, 45].

The short length of stay in most hospitals in developing countries, (on average, up to 2 weeks) may be too short considering the time required to restore function post stroke. After the survivors of stroke are stable in terms of blood pressure, they are discharged back into the community usually with a disability, to the care of their family who have to offer physical, emotional and psychological support. This is indicative of a situation where survivors are discharged home to families who may not be fully prepared to cope with the changes that have occurred in the stroke survivors. This scenario has been going on for a long time even in middle income countries like South Africa [32, 34, 46, 47]. It is therefore necessary to involve caregivers in the pre-discharge planning of stroke survivors as failure to do so may



result in unsatisfactory care-giving as a result of higher caregiver burden and poor quality of life for both the stroke survivor and the caregiver.

It is not clear if during the hospitalisation period the rehabilitation personnel in developing countries meet with the caregivers of people who have survived a stroke to discuss ongoing progress and pre-discharge plans. Maybe this could facilitate caregivers' access to information on stroke and its consequences, prevention and management options.

In Zimbabwe, management of survivors of stroke involves acute care in hospitals and not much of the rapid response and thrombolytic therapy in government hospitals. Even in private hospitals the costs of thrombolytic therapies are prohibitive. Most survivors cannot afford the CT scans and MRIs either. Once survivors are medically stable the rehabilitation professionals intervene whilst patients are still admitted. However, rehabilitation systems to support survivors of stroke have also not been fully developed. This means that hospital management of survivors of stroke is also deficient. Survivors are then discharged home with very minimal preparation and notwithstanding the challenges of bringing them back for review. There are also no call centres in communities to assist, hence no support systems for caregivers in communities.

#### **4. Outcome of stroke**

Few studies have been done on the outcomes of stroke in Sub Saharan Africa (SSA) [11, 32, 48]. Initial stroke severity and in-hospital complications were found to be determinants of 28-day case fatality in Mozambique [48]; while in South Africa the case fatality was found to be associated with poor functional ability but not with age [32]. An important outcome post stroke is function which will be discussed in the next section. In Malawi mild stroke and the male gender were associated with favourable outcomes and being HIV positive did not worsen the outcomes of stroke [11]. In Zimbabwe, a 25% in hospital case fatality rate was reported [20]. Some of the patients who died had pneumonia, most probably from aspiration [20].

As mentioned before, a third of all patients with stroke will fully recover, a third will live with some disabilities and the other third will die [13]. Those who survive stroke and are disabled will require some form of care [7, 13, 49, 50]. Several factors affect prognosis post stroke. Some of these include demographic characteristics, type of stroke, severity and immediate and long-term post stroke care [51]. Factors that may contribute to a good prognosis after stroke are youth, mild deficit, speedy resolution of symptoms, no loss of consciousness, independent sitting balance, no cognitive impairment or urinary incontinence [52]. Medical complications are frequent among individuals who have had a stroke, increasing the length of hospitalisation as well as the costs of care. These complications are a major cause of death in the acute and sub-acute stroke phases [53]. Some events, such as cardiac abnormalities, dysphagia and pneumonia, are often apparent early after stroke onset whereas others, such as bed sores, venous thrombosis, and falls, can occur after several days [54, 55]. Potential cardiac complications such as atrial fibrillation and myocardial infarction are also common after stroke [54].

Neurological recovery in stroke occurs mainly within 1–3 months post stroke, whilst functional recovery occurs more fully at 4–6 months [56]. According to Doğan et al., 10% of stroke patients recover spontaneously within the first month, and 80% of patients are candidates for rehabilitation while the last 10% do not respond to treatment [57]. This is however different from the 2007 WHO report [13]. The neurological recovery of stroke often improves significantly within 3 weeks and function may continue to improve up to 18 months [46].

#### **4.1 Mortality among people who suffer from stroke**

Two-thirds of stroke deaths occur in people living in developing countries and 40% of those with stroke aged less than 70 years [58]. The Inter-stroke phase 1 study 2007–2009 reported that 5.7 million deaths in 2005 were due to stroke and the number is projected to rise to 7.8 million by 2030 and 87% of these will be in low or middle income countries. Similar findings were reported when it was estimated that approximately 80% of all deaths by stroke occur in developing countries [59]. However, age adjusted stroke mortality in adults in SSA seemed to be like developed countries [60]. This they attributed to lack of accuracy of longitudinal data collection in different regions.

In Africa, stroke accounts for 0.9–4% of hospital admissions and 2.8–4.5% of total deaths [61]. This is in line with findings elsewhere where it was reported that mortality due to stroke in low- and middle-income countries was the 5th leading cause of death in adults aged 15–59 years [62]. The same study found stroke to be the 7th leading cause of death in SSA with HIV/AIDS at the top. According to UNAIDS, HIV related deaths made up 16% in South Africa, 17% in Nigeria and 6% in Zimbabwe of total death [63]. This makes the need to support survivors of stroke more important so as to reduce mortality in communities.

This high stroke case fatality in Africa was found to be related to limited health-care facilities and uncontrolled risk factors such as hypertension and diabetes which conditions and resultant death can be prevented [64]. Higher values have been found from community studies where deaths due to stroke contribute 5–10% of deaths in Tanzania [65]. Other studies in Africa have reported between 20 and 45% case fatality rates between admission and one-year post stroke [31, 32]. Stroke has been projected to be the 3rd leading cause of death in low income countries by 2030. Therefore, there is need for vigilance in prevention and care of patients with stroke as previously mentioned.

In South Africa based on an 11-disability adjusted number of life years lost per 1000 of the population, stroke was declared a catastrophic illness as the prevalence of stroke in South Africa was reported to be 3000/100,000 people [66], much higher than the 500/100,000 people living with strokes in developed countries [67]. It may be safe to conclude that Sub-Saharan Africa has relatively low stroke incidence and prevalence but has high mortality rates [17]. This may be attributed to high prevalence of smoking and other risk factors for stroke. Factors associated with mortality include severity of stroke, being a woman, haemorrhagic stroke, low level of consciousness upon admission and failing a swallow test, irreversible coma, stroke recurrence and other secondary infections and pressure sores, increased age, diabetes mellitus and stroke subtypes as independent predictors of 30-day case fatalities. Similarly, the relative risk of death from stroke was found to be higher for females in Ghana [68].

Ischaemic stroke patients with a National Institutes of Health Stroke Scale (NIHSS) score of less than 10 have a 60–70% chance of a favourable outcome at 1 year compared with only a 4–16% chance if the score is more than 20 [53]. However, ischaemic strokes have better prognosis, but less functional prognosis compared to haemorrhagic strokes [69]. Upon follow up, 23% of patients with ischaemic stroke had died while 65% of the survivors were functionally independent at 1 year [69]. Meanwhile, among the patients with haemorrhagic strokes, 62% had died, and among the survivors, 68% were functionally independent at 1 year. Among those with subarachnoid haemorrhage, 48% were dead and 76% of the survivors were functionally independent. The differences in mortality during the acute phase between the two types of strokes are said to be due to the fact that haemorrhagic strokes are more severe at onset than ischaemic strokes. This results in

increased pressure in the brain with mass shifting of brain which may be the reason for increased fatality. Later, as resolution occurs, swelling and pressure reduce with resultant reduction in mortality. Function is also better in Haemorrhagic strokes because there is less brain damage and once swelling and pressure have resolved, function is restored [70]. In Zimbabwe, not all patients with stroke can afford CT scans for diagnostic purposes, hence comparison is difficult. This also makes it difficult for typing the strokes although this is an important aspect of this study.

#### **4.2 Functional outcomes in stroke**

Poor functional recovery is associated with bowel and urinary incontinence, long time between stroke onset and hospital admission, more severe hemiparesis, visuospatial deficits and lower FIM scores [71, 72]. Functional recovery after stroke is also closely related to age, aetiology and severity of neurological deficit, nature of lesion and localization including integrity of collateral blood supply [52, 71]. The authors also reported that factors such as patient's education, motivation and socio-economic level may be important in recovery. Psychosocial and cognitive impairments and other neurological and sociodemographic factors have been seen to affect the functional recovery of stroke survivors [73].

Functional prognosis is better among the patients with haemorrhagic stroke in the long term compared to patients with ischaemic stroke even when someone is caring for them [74–81]. This is however different from findings that report worse functional outcomes among haemorrhagic strokes [82]. In line with the study by Bamford et al. [69], Kelly et al., had comparable results when they used the Functional Independence Measure (FIM) and found that among 1064 patients with stroke, 871 had ischaemic stroke and these had better functional abilities at admission compared to those with haemorrhagic stroke [81]. However, at follow up, the patients with haemorrhagic stroke had better recovery in comparison to those with ischaemic stroke. However, the treatment they received was not standardised. Unfortunately there are not many studies where comparison of functional outcomes was done after training in Africa. In South Africa poor functional outcomes were found to be associated with female gender, and more severe stroke and poor physical condition when patients were followed up at 6 weeks, 6 months and 1 year [32]. This was also the case later in Malawi [31]. Stroke has both psychosocial and physical impact upon both the survivors of stroke and their caregivers and it is important to discuss this area. These are aspects that affect quality of life.

#### **4.3 Participation**

Participation restriction means that survivors are unable to take part in areas of life such as usual roles and hobbies. They are the challenges individuals would have 'in involvement in life situations' [83]. Achieving independent ambulation within the community post stroke is not easy [84]. This has an impact on community reintegration post stroke as the survivors may not be able to take part in their former activities and may become isolated [85]. It is therefore important to assess stroke survivor's participation post stroke to get a complete picture of caregiver burden [86]. The relationship between participation and the environment was also highlighted elsewhere where the authors reported that perceptions of danger in the environment may make survivors increase speed for safety as seen when crossing roads [87]. In some cases, fear and the terrain may not be conducive for mobility. This is because there may be stones around and the terrain may be hilly thus reducing wheelchair mobility [6, 87]. Rehabilitation



professionals may face difficulties in trying to equip stroke survivors with the skills for community mobilisation in different terrains. Further, survivors may not be able to manoeuvre wheelchairs given for mobilisation as the environment plays a role in the outcome of rehabilitation and the patient's recovery after stroke as it may act as a barrier [6, 87, 88]. This is more so because the objects, their position and orientation in the environment drives the motor pattern in an action as survivors try to move about [6].

Inability to ambulate within the community by survivors of stroke directly affects their community participation [87]. Reduced ambulation leads to poor accessibility of community facilities and this in turn causes poor social integration of survivors of stroke [89]. Once the survivors cannot access facilities, integration into community becomes poor, leading to non-compliance with medications [85]. This is further compounded by the fact that about 66% of community dwelling survivors of stroke will need help with at least one activity of daily living (ADL) [90]. Availability of support from family, acquaintances, peers, colleagues, neighbours and personal care providers are facilitators to activity participation but these are not always available as they have other roles to play [91]. The impact of stroke on ADLs, emotions, cognition, and participation in social activities therefore significantly compromises survivor well-being and inevitably alters their and caregiver's quality of life [67]. However, stroke survivors generally function better in activities of daily living than they do in social activities [92]. This is because stroke survivors are dependent on their caregivers for single and multiple tasks for up to one-year post stroke thus further compromising social integration [91]. Unfortunately, this need for help may cause dependency as they may continue to play the sick role.

## **5. Rehabilitation and caregiving of stroke survivors**

The occurrence of stroke is devastating and overwhelming for both the survivor who becomes disabled suddenly and the family who are not prepared for the changes brought about in their lives when managing the multiple problems of a patient post stroke [7]. This is because they may face financial worries and are not prepared for the long care-giving hours and emotional stress which are predominant factors in increasing caregiver stress when one is caring for stroke survivors [93]. Caregivers should therefore be involved early on in the rehabilitation phase so that they understand and deal with the problems and prepare for after discharge life. The quality of rehabilitation, timing of treatment and amount of time spent in hospital have a bearing on the functional outcomes of the patients [6, 94–96]. Success of rehabilitation is also determined by emotional and physical challenges that the patient faces post stroke [97]. It is therefore important to identify barriers to an efficient rehabilitation service [6, 98, 99]. This is because availability of resources will affect the standard of stroke rehabilitation that patients receive [6, 100]. Effective rehabilitation initiated early after stroke can help enhance the recovery process and minimise functional disability which in turn improves quality of life of both the patient and the caregiver [42, 43, 97, 101–103]. Caregivers need to be well prepared for the emotional and physical challenges that the survivor faces as they may become barriers to care or even have a bearing on caregiver burden.

Moreover, organised respite care services that are available in developed countries may not be available in Zimbabwe to help with care of stroke survivors. This means that caregivers who have to look after survivors for long periods of time in most cases have no respite support. Disability benefits or allowances and voluntary support services to assist people living with disabilities and their caregivers may



not be available as is the case in Zimbabwe [104, 105]; yet the caregiver's role in the health delivery system and support of stroke survivors is important. The global prevailing economic meltdown may also affect development of community services in most developing countries. This is despite home-based rehabilitation being considered an important complementary component of health-care to address stroke related disability as advocated by WHO in the case of HIV/AIDS. In South Africa, Hale et al. noted that stroke care leaves the caregiver who has no knowledge of what is going on in a predicament of what to do as information provided may not meet all their needs [33]. This results in increased caregiver strain as they may be the only source of rehabilitation available to the survivors of stroke as most cannot afford formal services due to poverty [34, 98]. There is therefore a missing link between hospital rehabilitation and survivors of stroke and their caregivers post discharge within the community.

The large numbers of people affected by stroke may also mean that the caregiver burden will increase and quality of life among many people will be affected. It is therefore important that caregivers of stroke survivors receive adequate caregiver support. When caregivers do not receive support, they may become strained resulting in inadequate support to survivors that will affect their quality of life. It is hoped that equipping caregivers by training them to look after stroke survivors may hopefully improve their outcomes and those of stroke survivors they care for. This is because elsewhere it has also been previously reported that disability affects quality of life and functional independence among survivors of stroke and increases burden of care among the caregivers [7].

## **6. Community management of stroke**

Post stroke, many stroke survivors want to return to the roles they had prior to the stroke and integrate into their communities [46, 106]. However, the specific support systems required in helping stroke survivors and their caregivers remain unclear as the onset of stroke is sudden and patients and relatives are ill prepared to deal with the subsequent disability [7, 93, 107]. Survivors of stroke are primarily rehabilitated as inpatients and are then discharged home once it is felt that the person and their primary caregivers can cope [108]. In most low-income countries community support for stroke survivors and their families remains fragmented and poorly coordinated [6, 42, 101, 107]. In rural areas this problem is further compounded by physical geographical surroundings which are not conducive for mobility in any form [109, 110]. This results in patients receiving minimal therapeutic interventions to assist with recovery due to lack of access to rehabilitation services. In addition, this further strengthens the need for home-based rehabilitation [111, 112]. Due to low numbers of rehabilitation personnel and inaccessibility of communities, family caregivers are important among survivors of stroke.

After experiencing a stroke, 60–74% of survivors need caregivers to take care of them since some recover with physical and cognitive limitations [7, 90, 113]. This is usually provided by informal caregivers [114]; who are mainly women [38, 115]; and may be children, spouses or other relatives of the stroke survivors [116, 117]. Due to shortage of resources in low resourced countries, support of caregivers to enable them to offer home rehabilitation may be the option of choice. Many caregivers end up suffering from emotional, physical and psychological burnout due to the burden of caring for stroke relatives over a long period [7, 116]. They are also left with little time for their own responsibilities. Financial constraints may limit visits to hospitals to get support and distances to health centres may be prohibitive [32]. The fate of stroke victims has been documented

elsewhere where many die or live with morbidities [13, 32, 93]. The challenges that caregivers face require that they get support from the health professionals to carry out the caregiving duties.

Earlier on, the importance of caregivers as part of the community support for survivors of stroke was highlighted [118]. Their involvement may help reduce stroke recurrence and complications associated with stroke, improve function and physical health as well as community reintegration [42, 47, 107, 119]. Caregiver involvement may reduce disability and depression [120] which can occur due to increased caregiver burden [114, 121]; and improve quality of life [122]; among survivors of stroke. Women, younger caregivers and caregivers with poor physical health are at a higher risk of suffering caregiver burden [123]. Caregiver support programmes should focus on self-efficacy, social support and coping strategies among these caregivers. Financial constraints are the chief causes of burden in caring for stroke survivors post discharge and could be minimised by educating caregivers on basic stroke management principles to reduce the economic burden when accessing rehabilitation services [32].

After suffering a stroke, stroke survivors and relatives are faced with physical, emotional and mental problems and health care providers should educate them about basic care before the patient is discharged to adequately prepare for life at home [124, 125]. As previously mentioned, after experiencing a stroke, 66–78% of survivors world-wide need caregivers to help with activities of daily living since some recover with physical and cognitive limitations [7, 66, 67, 113]. Caring for a stroke survivor is a complex, stressful, life changing experience for both the survivors and their family caregivers especially when one had not prepared for it [7, 117].

Caring for a stroke survivor requires both informal and formal caregivers. While formal caregivers are trained, the informal caregivers are not, and are also not paid for the services they offer yet play an important role in the survival of patient with stroke after discharge [38, 126, 127]. Most caregivers are therefore put into a carer role without any idea of what to do with the resultant increase in caregiver burden and poor quality of life [38, 42, 47, 100, 108]. As previously discussed, this lack of training can overwhelm caregivers who are ill prepared to care for someone with these limitations [7, 38, 42, 128–130]. The caregivers and survivors of stroke rarely receive information on the nature of stroke, its cause, management and prognosis [131]. In support of this finding other authors also noted that the specific caregiver needs were information on causes of stroke, stroke progression, prevention of recurrence, practical care, emotional care and guidelines on use of medicines as needed by people who have survived a stroke [42, 132, 133]. This further complicates their lives as their duties will also involve administration of drugs, assisting with rehabilitation exercises and performing medical procedures for which they are not trained [90, 134]. Assisting with rehabilitation exercises make them play an important role in rehabilitation [127].

Stroke is also associated with many complications such as falls, pressure sores, urinary tract infections, chest infections and caregivers must deal with these too [135]. The amount of time needed to look after an individual varies depending on several factors which may include severity of the stroke and relationship of caregiver to stroke survivor [136, 137]. Caregivers were found to complain of long hours of caregiving which in turn leads to increased caregiver strain and reduced sleep [138]. Caregiver strain also increases over time [139, 140]. Length of care is determined by the severity of the stroke where the more severely affected stroke survivors need constant care thus more strain in the caregivers [141, 142]. In contrast, another in their study found no difference in strain between those who had looked after a survivor of stroke over a long time compared to those who had cared over a short period [123]. This is because the authors found that other factors such

as cognitive, emotional and behavioural changes in the survivor have a negative influence on caregiver strain. On the other hand, high confidence knowledge about efficacy, high satisfaction with social support and frequent use of coping strategy confronting all had a positive influence [123]. They therefore concluded that caregiver support programs should include education about self-efficacy, stimulation of the use of the coping strategy confronting and training in mobilising social support in a way that is satisfactory to caregivers. Furthermore, support programs should be offered both to caregivers who recently started to take care of a survivor and to caregivers who have been taking care of a patient for a longer time [123].

The mean age of caregivers ranged from 36 to 70 years [100, 142]. The most common informal caregivers are spouses and adult children or other relatives most of whom are poor [100, 116, 121, 143, 144]. Most of the caregivers are females [32, 100, 123, 142, 145]. In most cases there is no one else to carry out the caregiving task [146]. Female caregivers usually encounter more caregiving demands than male caregivers [147, 148]. This is because the female caregivers spend more time doing care giving tasks and other multiple family responsibilities [147, 149]. They are also the cornerstone for development and implementation of community care policies [141]. Further to this it was also found that 93% of men were cared for by women (their spouse in 73% of cases), while 55% of women were cared for by men [100]. Governments should make sure that poor people are educated on reduction of chronic diseases [150]. This is because they will end up caring for their sick relatives.

An attractive option is the use of formal caregivers, but they are expensive and for low resources settings like SSA, where accessibility to health settings is difficult [6, 109]. Home rehabilitation using informal caregivers is therefore the option of choice and if they receive support, may provide alternative cost-effective care compared to usual care [36, 151]. However, caregivers may end up giving up their jobs to care for the stroke survivor full time, give up their houses to stay with the stroke survivor and give up some social activities like going out with friends and going to church [38, 116, 138]. As discussed before, caregivers have not been made an integral part of the health care system [118], yet are responsible for the improvement of quality of life and survival of stroke survivors post discharge and suffer burnout themselves [38, 122].

In most SSA countries, most of the caregivers are informal [36]. Due to the high HIV burden the occurrence of stroke in HIV positive patients causes a dual burden of care [10, 31, 32]. Lack of support systems in poor countries also pose challenges as most of those affected are poor and cannot afford outside support [6, 44]. It was further noted that caregivers in developing countries are usually family not educated about care and face challenges in dealing with patients' problems [32]. At the same time, they are expected to help lower the risk of stroke recurrence, reduce stroke related complications, improve function and subsequently improve community integration [42, 46, 47]. There is need to address the perceived needs of caregivers of stroke survivors to improve quality of life and reduce caregiver burden which may arise from long term caregiving. Caregiver training may be the best choice as these are available and will not need payment.

## **7. Training of caregivers of survivors of stroke**

To help support survivors of stroke, stroke rehabilitation services should address caregiver issues and include practical training in nursing skills and counselling



sessions, which will help in reducing the caregiver burden and improve stroke survivor recovery. Survivors of stroke spend most of their time with caregivers who therefore need to be trained and educated on how to take care of the survivor and on what to expect [42].

In high income countries, caregiver training consisting of basic skills of moving and handling, facilitation of activities of daily living and simple nursing tasks have been seen to reduce caregiver burden and improve quality of life [42, 101]; and was cost-effective [101]. Trained caregivers were also followed up over time in South Africa, and the structured caregiver training positively impacted on survivors' quality of life post discharge [98]. They recommended an exploration of different caregiver education programs to determine those that would produce the best outcomes in patients and caregivers so that they can be adopted regionally and internationally [98]. That education of caregivers reduce the burden of care and was also later reported in other studies on home-based care in HIV [32, 152]. The authors reported that those who received support from a nurse or community care worker had a lower caregiver burden and had more than twice the odds of wanting to care for another person living with HIV in the future [152]. Any training or educational program should start during the acute phase of rehabilitation to prepare patients and caregivers for the trajectory of problems they may face during the recovery period [153].

Education may benefit both the survivors of stroke and caregivers by preventing stroke. Education is defined as 'a planned experience that uses a combination of methods such as teaching, counselling and behaviour modification techniques to influence knowledge and behaviour' [154]. Various interventions have been developed and evaluated with the intention of supporting informal caregivers. However, there are conflicting reports on their effectiveness and even for those with positive outcomes, only modest effects are reported [155, 156]. Caregiver training is a non-pharmacological intervention to reduce the burden on informal caregivers and facilitate patient recovery after stroke [131, 157].

Caregivers should receive information regarding stroke survivor handling, positioning and how to communicate with the stroke survivor [42, 101, 158]. These findings were supported by authors who reported that caregivers' training programs should mainly be focused on practical demonstrations on physical activities which they do whilst performing their roles to reduce physical strains among caregivers [158, 159].

Education should be given to family caregivers as this will benefit the community as they may relay the information to others for sustainability and improve quality of life of stroke survivors [42, 132]. They should be educated on how to look after the stroke survivor to prevent complications as well as recurrence [64, 160]. Training should cover self-efficacy and enable coping strategies like how to mobilise social support and also help the stroke survivor [123]. Training caregivers will also reduce adverse outcomes [145] However, the long-term impact of training on caregivers is not known in that they may end up thinking that the training is a qualification.

In Africa, about two thirds of caregivers of stroke survivors in rural areas receive no basic stroke education before discharge due to scarcity of rehabilitation services [6, 161]. On a positive note, educating the public and health care providers about prevention of stroke, warning signs and symptoms of the disease has been found to be useful when treating patients with hypertension [64, 162]. Lack of training is associated with high mortality among stroke survivors and severe forms of disabilities which could be minimised if training is done prior to discharge [161, 163]. Comparing the effects of training on the outcomes of caregivers and stroke survivors may highlight the importance of this aspect of care.



The training should not be generic, but tailor made or individually adapted for clients and include written information for caregivers given during the training session together with pictorial charts [156, 157, 164–166]. Stroke survivors should also be educated about their condition, treatment, prognosis and what they may need to do or not do and about hypertension as their knowledge was found to be suboptimal [64, 154, 160]. This finding strengthened findings from South Africa, which reported that 79% of hypertension and 64% of strokes said they did not know about the risk of stroke [167]. Development of a caregiver training programme that can be adapted to individual needs is important as any caregiver may receive this mode of support.

Any assistive devices used during training should be offered to them to take home to prevent regression of the stroke survivors' condition and difficulties in execution of the exercise programs [168]. Any training involving stroke survivors should be done after the acute phase, when they are less overwhelmed and able to comprehend the information [158, 169]. It is also important for stroke survivors and caregivers to be educated about the importance of incorporating the survivor back into the family [170]; although in some instances it may not result in improved perceived health status [171]. This is because education may improve carers' knowledge about stroke and its consequences but may fail to provide positive solutions to their problems hence lack of improvement in perceived health status [171]. It is therefore important for health workers to disseminate the training to other staff for sustenance of the training programme [172]. Training after the acute phase may be a challenge in situations where beds are required for other patients. In that case the caregivers may only receive training and later survivors of stroke may be included once they are ready.

## **8. Patient and caregiver outcomes after training**

Several studies were carried out to determine effect of training on the outcomes of survivors of stroke and their caregivers. Most of the studies compared intervention and control groups. Most studies that found better outcomes in the intervention group were from developed countries and looked at functional status of patients and physical/emotional health of family caregivers, quality of life, caregiver optimism, task difficulties and use of intervention [42, 101, 173–176]. In some instances, 89% of the control group was functionally independent at 3 months compared to 93% in the intervention group. At 6 months, this was 86 and 89% respectively. Similarly, Foster and colleagues found a significant difference in two of the satisfaction questions on satisfaction with hospital services [177].

The differences found between the intervention and control group were largely attributed to extended training time and longer call durations in the intervention group [175]. Effects of the intervention can persist over a long-term period as the intervention can sustain home care by reducing institutionalisation and mortality as well as improve clinical outcomes for caregivers [173, 175]. On the other hand, some findings showed no difference in outcomes between the control and intervention groups and in other cases are contrasting [42, 175, 177, 178]. These authors found no statistically significant difference between groups in functional Barthel Index score or functional independence at 6 months among patients. They did not give caregiver outcomes. No significant differences in patient activities of daily living or functioning or in caregiver emotional distress, anxiety, depression and strain were also reported [177]. On the other hand, the intervention group had more patients

referred for depression in one study [178]; although stroke recurrence was similar in both groups. It was therefore concluded that there was no evidence of a clinically significant benefit of the intervention to both patients and caregivers [177]. However it is important to consider the differences in this study with those that found positive results.

Studies that involved caregivers only were carried out in other places [176, 178]. One study in the rural areas in the United States found that all caregivers were satisfied with the intervention and were willing and able to use the intervention [178]. The intervention helped the caregivers make informed decisions about health care needs of stroke survivors thus reducing stress. This was further supported when the caregiver training program was found to have a positive impact on the functional status, post stroke depression and caregivers' knowledge and practices [179].

Caregivers were trained alone or in some instances together with the stroke survivor [42]. In other instances, both the caregivers and patients were trained [101, 176]. However different findings were reported in that some found the intervention to improve quality of life in both caregivers and patients [42]. On the other hand, improvement in quality of life among the caregivers was found but not in the other outcomes [101]. No significant differences in survivors' activities of daily living or functioning or in caregiver emotional distress, anxiety, depression and strain were found in other studies [177]. On the other hand, in South Africa, improvement in quality of life, mobility and reduction in caregiver burden were found in the intervention group [98]. When training caregivers it is important to take into account other factors that may confound the outcomes such as culture and level of education.

All the results point towards a trend for caregiver targeted interventions having some value, but there is need for further research to confirm this and improve generalizability [155]. A caregiver training programme in low resource settings may be of value to offer support to stroke survivors and caregivers.

## **9. Developing a caregiver training programme**

Education of caregivers is important [32, 42, 47, 101, 158]. However any developed training programme should be repeatable [8]. To come up with a training programme that is relevant, objective and feasible, it is important to consider the cultural and socio-economic context in which it will be used. The Kern model of curriculum development for medical education a six-step approach that links health needs to the education process was used to develop a caregiver training programme. The process does not usually proceed in sequence but is rather an interactive and dynamic one and can be adapted for low resource settings. According to Kern et al., the curriculum development is based on the following six steps [8]:

### **Step 1. Problem identification and general needs assessment**

This begins with identification and analysis of health care needs. A general analysis of the current approach to address the identified needs is done. The difference between the ideal approach and the current approach represents a general needs assessment. This helps identify the gaps that exist in the care of stroke survivors. There is need to assess how other countries are dealing with training issues and compare outcomes of the stroke survivors and those in one's country. In most cases key informant interviews are carried out and other training programmes are assessed for adaptability. The observed gaps help in coming up with a targeted needs analysis.

### **Step 2. Targeted needs analysis**

This involves assessing the needs of the targeted group of caregivers and stroke survivors which may be different from their needs in general. A

triangulation of methodologies is used to come up with their needs and challenges that they face. This should be done among those that are likely to have faced challenges, meaning that they have experienced the challenges for a certain length of time.

**9.1 Syllabus**

Based on the findings from the targeted needs assessment, the syllabus for the training programme includes information on the condition and presentation of stroke, physical changes, causes, complications and risk factors, and related

Topic	Notes to assist with topic development
The disease stroke	What is stroke? What are the causes of stroke? How does stroke present? How is the diagnosis made? What is the prognosis?
Identifying stroke	Use appropriate evaluation procedures to assess psychological and physical state of patients. Accurate identification of the patient's immediate and potential problems
Problems that patients face	These range from sudden change in body image, immobility, dependence on others for activities of daily living and care and personality changes. Also includes fears of loss of self-care and income and insecurities
Problems that caregivers face	Sudden changes from being thrust into caregiver role. Patient dependent on caregiver
Complications and prevention of stroke	Changes in motor and sensory problems. Secondary issues from immobility in cardio-respiratory and muscular skeletal systems. Issues with urinary system, particularly incontinence
Progression time frames	Changes in status from flaccidity to spasticity, immobility to mobility and recovery of lost function.
Comorbidities	Additional diseases that may be found in stroke patients such as HIV and other potential infections
Infection control	Use of gloves and disinfectants to minimise exposure to HIV and other potential infections
Handling of stroke patients	Handling and training for positioning, preventing shoulder-hand syndrome and shoulder subluxations
Lifting and transfers	Different methods of lifting stroke patients. Use of one-man method as well as methods for patients who are completely dependent. Help with facilitation of mobility and transfers as well as correct application of lifting and transferring techniques for safety reasons.
Activities of daily living	Teach feeding, bathing, toileting and alternatives to assist with dressing and any other personal activities of daily living
Treatment	Devising a plan of care for treatment that includes an appropriate progression and post discharge program of management. Recognition of contraindications and precautions for treatment, delivery of effective treatment and progression based on regularly scheduled evaluation of the patient's progress.
Communication	Tailored to the needs of each individual with identification and referral to appropriate resource persons or sources within the hospital and community
Dealing with bereavement	Explain the different stages of bereavement from shock, anger, denial, depression, acceptance and that the cycle may repeat.
Role of different departments and of the community in patient care	Establishment of appropriate relationships with the patient and other caregivers and members of the health care team.

**Table 1.**  
*Notes to assist with topic development [166].*

diseases are also included. The syllabus also addresses the activity limitations, participation restrictions and treatment needs of the stroke survivors in a practical way. **Table 1** presents the notes to assist with topic development for training.

Step 3. Developing goals and objectives

After identifying the needs of caregivers and the stroke survivors, goals and objectives for the training programme are developed. The objectives may include cognitive (knowledge), affective (attitudinal) and psychomotor (skill and behaviour) for the caregivers and stroke survivors. Objectives help determine the content of the training programme, learning methods/educational strategies and communicate what the curriculum is about and provide the basis for evaluation.

Step 4. Developing educational strategies

Educational strategies are based on the objectives and the content of training programme. After the educational needs of caregivers and stroke survivors have been identified, it is decided on what has to be taught based on the needs and the methods of delivery that will be effective. The selected strategies are the ones most likely to achieve the educational objectives.

Step 5. Implementation

Implementation of the training programme includes getting buy-in from the people who will allow use of the training programme, and the identification of any barriers to the use of programme. Usually these are the health professionals who will do the training later on or even Directors of health who have to enforce the training of caregivers and stroke survivors. The programme is introduced and

Resources	Outputs	Program outcomes	Impact
Caregivers of stroke survivors Stroke survivors Training materials Places where training will be held Support from communities of interest.	Number of CGs enrolled Number of caregivers trained Number of drop outs Number of caregivers who develop competencies in looking after stroke survivors Number of CGs who are satisfied with the training program Number of CGs confident to look after SS after training	All caregivers of stroke survivors are knowledgeable, compassionate, dedicated in caring for stroke survivors. Caregivers of stroke survivors demonstrate competencies in the following areas: Explaining the causes and symptoms of stroke Explaining how to handle and lift a patient with stroke Can handle, lift, mobilise and help a stroke survivor to perform activities of daily living. CGs have confidence and good attitude in dealing with problems of stroke Stroke survivors have increased access to home based support.	Hospitals have optimal holistic health care that reduces the impact of stroke on caregivers and people who have survived a stroke.
<b>Underlying Assumptions:</b> <ul style="list-style-type: none"><li>• The caregiver training program is fully implemented with fidelity to written goals and objectives.</li><li>• Government policies and resources are supportive</li><li>• The total health care system is improved to support the work of caregivers</li></ul>			

**Table 2.**  
*Logic model for the training programme implementation [166].*



administered. Implementation is critical for success of programme as it converts a mental exercise into reality [8]. A logic model (**Table 2**) is used to help with the implementation process as exemplified below.

#### Step 6. Evaluation and feedback

In this phase the caregivers and stroke survivors as well as the training programme are evaluated. This may be either formative (at the beginning) or summative (at the end) [8]. Evaluation of the content and delivery of the programme to caregivers is important as it leads to its acceptance [42, 172]. Evaluation is also important for recognition of caregiver and stroke survivor needs during and after training leading to appropriate and timeous interventions which are perceived as beneficial by the caregivers and the survivors of stroke [180].

## 10. Conclusion

Stroke occurs suddenly and affects functional outcomes in stroke survivors and the quality of life of both the caregivers and the stroke survivors. Most of the survivors end up with disabilities and have to depend on caregivers to survive. Unfortunately, most of the caregivers are not knowledgeable about looking after stroke survivors and end up with high caregiver burden. This chapter explained how the caregivers can be assisted in supporting stroke survivors. It also outlined the steps that can be followed in developing a training programme that can be adapted for low resource settings, and for conditions that may also affect function and quality of life. This is because supporting survivors of stroke is best done through training their caregivers. The training programme should take into account the cultural issues surrounding the caregivers and the stroke survivors. It is worth noting that over and above training the caregivers, health departments should continue to offer support to the stroke survivors through provision of appropriate rehabilitation services so that they become functionally independent. The support and training should be ongoing.


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