Chapter

Stroke Rehabilitation and Occupational Therapy in Low Resource Settings

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Abstract

The long-term complications of stroke interfere with function, and the level of disability varies based on the type of stroke, location, and the extent of damage. Rehabilitation services are important in the recovery of stroke patients, but not all survivors have access to the services especially in low resourced settings where accessibility and economic challenges are the major barriers. Inadequate fulfilment of stroke survivors' rehabilitation needs contribute to poor functional outcomes and slow recovery. The objectives of this chapter is therefore to give an overview of stroke and stroke rehabilitation with specific emphasis on occupational therapy, discuss the activities and areas of participation considered important by stroke patients, stroke patients' needs and perceived fulfilment of these needs in order to provide targeted interventions. Data to inform the chapter is based on research done in a low resource setting. The perceived important activities and participation areas, and the needs of stroke patients are discussed in light of literature on the subject and findings from the studies done in Zimbabwe.

Keywords: stroke, rehabilitation, occupational therapy, activities, functional outcomes, participation areas, stroke survivor needs, ICF

1. Introduction

1.1 Overview of stroke

Stroke is an insult to the brain tissue caused by a sudden interruption to the blood supply to the brain [1]. Sacco et al. gave an elaborate definition of stroke as a neurological deficit attributed to an acute focal injury of the central nervous system (CNS) by a vascular cause, including cerebral infarction, intra-cerebral haemorrhage (ICH), and subarachnoid haemorrhage (SAH) [2]. Stroke is highly prevalent and a second major cause of death and disability worldwide [2–4]. Stroke is a leading cause of dementia and depression. It can be classified on the basis of its aetiology as either ischaemic (87%) or haemorrhagic (13%) [5]. Ischaemic stroke results from occlusion of a cerebral artery which can be thrombotic or atherosclerotic (50%), embolic (25%) and micro-artery occlusion (lacunar stroke or infarcts) (25%) [5]. Haemorrhagic stroke is caused mainly by spontaneous rupture of blood vessels or aneurysms or secondary to trauma [5]. Early definitions of stroke and

transient ischemic attack (TIA) focused on the duration of symptoms and signs. However, Sacco et al. [2], noted that use of clinical observations and modern brain imaging showed that the duration and reversibility of brain ischemia is variable. Brain tissue that is deprived of needed nutrients can, in some patients, survive without permanent injury for a considerable period of time, that is, several hours or even, rarely, days, while in most other individuals, irreversible damage (infarction) occurs quickly [2].

There has been a rise in the prevalence of stroke related disability in many countries [6]. A rise in the incidence of stroke in Zimbabwe from 31/100,000 to 57/100,000 in a decade was reported with fatality rates ranging from 22 to 58% at one month following stroke reported in Zimbabwe and other African studies [7].

The risk factors for stroke are generally similar to those for coronary heart diseases and other vascular diseases [4]. High blood pressure is one of the leading primary and secondary modifiable risk factors [5]. The other risk factors for stroke include smoking, low physical activity levels, unhealthy diet, abdominal obesity, diabetes and excessive consumption of alcohol [4]. Effective prevention strategies should include targeting the key modifiable risk factors such as hypertension, elevated lipids and diabetes.

Clinical manifestations of each stroke differ based on the part and side of the brain affected, extent of the lesion and the person's general health. Some of the effects of stroke include numbness, weakness or paralysis on one side of the body opposite the side of the brain affected, slurred speech, difficulty thinking of words or understanding other people, confusion, sudden blurred vision or sight loss, being unsteady on your feet and severe headache [8]. Concerning the stroke warning signs, numbness on one side was surprisingly identified as the commonest warning (44%) while unspecified pain was the least cited (11%) in one of the studies [9]. Stroke can also result in psychological problems such as depression, anxiety, feeling helpless and thoughts of death or suicide, trouble sleeping and feelings of worthlessness [10]. In general, a right cerebrovascular accident may result in left hemiplegia or hemiparesis, difficulties with visuo-spatial memory, neglect of the left side of the body, poor judgement, and impulsivity, while a left cerebrovascular accident may cause right hemiplegia or hemiparesis, apraxia, and aphasia due to the location of the Broccas' and Wernicke's areas [11].

Stroke was associated with 43.7 million disability-adjusted life years annually around the world [5]. It is one of the most common neurological diseases in the black African and the leading cause of adult neurological admissions in West African sub-region, constituting up to 65% of such admissions [9]. Globally, 70% of strokes and 87% of both stroke-related deaths and disability-adjusted life years occur in low- and middle-income countries [4]. Approximately 60% of stroke patients acquire permanent disabilities and experience limitations in terms of mobility, vision, voice, speech, swallowing (dysphagia) and sexual function globally [4]. Stroke can cause multiple impairments which might need a variety of rehabilitation interventions [12]. Motor impairment is the most common deficit after stroke and the motor deficits increase fall risks and fall-related injuries. This in turn significantly affects the patients' mobility, participation in their activities of daily living, social events and other occupational performance areas [13].

Stroke is a leading cause of functional impairments; with 20% of survivors requiring institutional care after three months and 15–30% being permanently disabled [14]. Many stroke patients experience activity limitation, restricted social participation, and psychological issues such as anxiety and depression some years after having stroke [15]. Approximately 65% of stroke patients are dependent on others to help them with everyday activities and the quality of life 2–5 years after stroke has been reported by many stroke survivors as poor [15].

Several researchers have studied the stroke survivor's physical, social, psychological and emotional needs [16–19]. Although most stroke patients receive rehabilitation, the lifelong need for care of stroke patients with disabilities has not been fully explored [17]. Despite calls for comprehensive stroke services to address long-term needs of patients, there had been little investigation of the perceived needs of stroke survivors in the long term or what determines such needs [20]. This area lacked a systematic approach to problem identification, had a poor evidence base, and was not underpinned by sound theoretical concepts hence there was need for further research in the area [15]. Similarly, needs of caregivers for stroke patients need further exploration.

1.2 Stroke rehabilitation and occupational therapy

Stroke Rehabilitation is a progressive, dynamic and goal-orientated process aimed at enabling a person with impairment as a result of stroke to reach their optimal physical, cognitive, emotional, communicative, social and functional activity level [21]. Stroke rehabilitation begins in the acute care hospital after the person's overall condition has been stabilised, often within 24–48 hours after the stroke [22]. Stroke rehabilitation plays a vital role in lessening the effects of impairments and activity limitations, and in facilitating the return to active participation in community life and economic self-sufficiency after the stroke [12]. Internationally recognised best practice in the early management and rehabilitation of individuals following stroke includes collaborative and multidisciplinary assessment and treatment by a coordinated team of health care professionals [23]. A collaborative approach improves quality of life in stroke patients [12].

In the first weeks and months of recovery, the goals of rehabilitation are to help survivors become as independent as possible and to attain the best possible quality of life [21]. Although rehabilitation may not reverse the brain damage, it can substantially help people achieve the best possible long-term outcomes [22] through various ways that include facilitation of neuroplasticity of the brain. Rehabilitation is especially crucial during the early stages of recovery to regain independence when patients have little or no control over their affected muscles [22].

As part of stroke rehabilitation, occupational therapy (OT) involves the use of activities or training to improve or maintain the ability to live independently and cope with daily life for people with stroke [16]. The philosophy of occupational therapy is based on the concept that all humans have a need to become engaged in occupations [24], and that need is present even after stroke. Therefore, the role of the occupational therapist is to facilitate the patient's continued participation in meaningful and purposeful daily activities and adaptation to the patient's changed status. These occupations (all goal-directed engagement in self-care, work or leisure activities) can be termed as activities and participation areas in the International Classification of Functioning, Disability and Health (ICF) terminology [25]. According to the ICF framework, stroke results in activity limitation and participation restriction [26]. The ICF is a globally agreed framework and classification to define the spectrum of problems in the functioning of patients [27]. The ICF was also shown to be an essential tool for identifying and measuring efficacy and effectiveness of rehabilitation services [28]. Using the ICF takes a biopsychosocial approach which addresses the quality of life gap which is often left in favour of quantity of life.

Occupational Therapy in general, focuses on the assessment and treatment of individuals who are limited by physical injury or illness, psychosocial dysfunction, developmental or learning disabilities, or the ageing process through the use of purposeful activity and adaptive equipment and technology in order to maximise

independence, prevent disability and maintain health [29]. Occupational therapists play a crucial role in the rehabilitation of stroke patients as they are experts at training patients to relearn complex bodily movements and avoid complications that could derail their progress later [30]. Occupational therapy is concerned with promoting health and wellbeing through participation in activities of everyday life and this is done by modifying the occupations and the environment in a therapeutic way to better support participation [23]. Occupational therapists also employ neurophysiologically based handling techniques meant to facilitate neuroplasticity of the brain. In some instances, occupational therapists can teach compensatory strategies when the old ways of functioning are no longer possible [30]. Therefore, occupational therapy for stroke includes interventions for physical, social, psychological and cognitive impairments [30]. The role of occupational therapists in stroke rehabilitation is particularly important because they focus on functional outcomes and getting clients back to doing everyday activities [11] which is usually unique to the profession. It is important that the interventions suit a patient's needs [30].

The period of receiving services in stroke rehabilitation depends on the severity of disability and specific needs of the stroke survivor, although it has been proved that a great deal of stroke recovery occur within the first six months to a year following the onset of the stroke [31]. Occupational therapists work collaboratively with the patient to establish the impact of stroke on their performance of daily tasks, including personal care, domestic tasks, work and leisure activities; and in formulating a goal-focused program to develop the required skills for participation in daily life [23]. Given the variability in stroke complications, occupational therapists need to have a wide repertoire of techniques to help each client [11]. The treatment techniques in occupational therapy may include using occupational tasks to help improve cognitive abilities, teaching adaptations to meaningful activities to keep the client involved, and using task-specific movement to help with range of motion and motor control [11]. The occupational therapist can provide a patient with an assistive device or adjustments and adaptations in the environment, for example, in a patient's home. This enables the patient to perform his/her ADLs independently and also dealing with other emotional or social issues that may result from stroke [30].

The occupational therapy process for stroke patients begins with an assessment of the patient's roles, tasks and activities that are important for the patient [30]. An assessment is conducted to understand the impact of changes in motor function, sensation, coordination, visual perception, and cognition on the stroke patients and on the capacity to manage daily life tasks [23]. Assessment is also used to identify areas of individual and environmental difficulties and to enable patient-centred goal setting with the participation of both the patient and the caregiver [23]. The occupational therapist will then assess the ability to perform the roles, tasks and activities and if a limitation or restriction in some area is found, the occupational therapist will identify the performance components and craft the solution or intervention meant to restore, improve or maintain patient's maximum level of performance [30]. Some of the performance components may include neuromuscular, cognitive and perceptual, language and psychosocial problems.

The occupational therapy interventions should therefore be able to address the patient's needs and be provided in both the acute and rehabilitation phases [30]. For some stroke survivors, rehabilitation will be an on-going process to maintain and refine skills and could involve working with occupational therapists and other specialists in that field for months or even years after the stroke [22].

2. Activities and areas of participation considered important by stroke patients

In order to adequately address challenges stroke patients face, there is need to identify the activities and areas of participation they consider important. This section is therefore based on a study done in Zimbabwe which sought to find out the activities and areas of participation considered important by stroke patients, the level of difficulty experienced in carrying out these activities and the reasons for attaching importance to these areas [32]. The study was cross sectional descriptive in nature and was done with 40 stroke patients consecutively selected as they came for their reviews at an outpatient stroke clinic at a central hospital in Zimbabwe [33]. An interview questionnaire adapted from the ICF checklist version 2.1a clinician form was administered by the researchers with consent after ethical approval (JREC....). Excluded were patients with significant cognitive and language impairments as it would have been difficult to communicate with them. In the study, 25 were female and 15 were male. Participants' ages ranged from 34 to 81 years with the 50–59 years age group being the mode. These demographic characteristics are consistent with a study done by Mlambo et al. [34], which was done in South Africa and the participants' ages ranged from 32 to 81 with a mean age of 52 years. The activities and areas of participation assessed during the study were obtained from the domains in the ICF checklist as alluded to earlier.

2.1 Mobility and hand function

Half of the patients reported severe difficulty in lifting and carrying objects, while 43 and 38% of participants experienced complete and severe difficulties in fine hand use respectively [32]. About 20% had flexion contractures of the elbow and wrist joints of the affected side. These difficulties were due to the condition (stroke) which causes disturbances in muscle tone and loss of selective and isolated movements in the hand and arm [35] and this hinders execution of functional movements [36]. Thirty three percent of the participants had moderate difficulty in walking and used mobility aids while 20% had complete difficulty [32]. Half of the participants reported experiencing complete difficulty in using transportation like cars or buses. On driving, only 18 participants were drivers and 78% of them reported complete difficulty in the area [32].

On importance attached to these domains, all participants considered fine hand use and walking important, while 98% considered being able to use transportation important [32]. However, it was noted that none of the participants who were drivers had driving addressed by their therapist. Driving rehabilitation is an area that has not been fully explored by OTs in Zimbabwe. Driving is an important ADL and many stroke patients who were driving prior to their stroke wished to resume driving as noted by Kneebone and Lincoln [37]. A study by Duncan et al. [38] found that hand function and mobility were some of the key areas considered important by stroke patients.

2.2 Self-care

Half of the participants in the study reported severe difficulties in dressing, 33% had moderate to severe difficulties in grooming while 65% had severe difficulty in bathing themselves [32]. About 73% had no difficulty in feeding and this can be explained by the exclusion of patients with speech and cognitive problems in the study. Speech and cognitive problems are often associated with feeding

problems. Thirty three percent did not experience any difficulties in toileting while the remainder had mild to severe difficulties and used sanitary wear or were catheterised [32].

All aspects of self-care were considered as very important by all participants as they viewed these activities crucial for human survival [32]. This was also noted in a study by Aberg et al. [39] where the participants valued their independence in self-care activities.

2.3 Domestic life

In Chimusoro's study [32], 78 and 75% of participants had complete difficulties in acquisition of goods and services, and preparing meals respectively. About half of the participants considered being able to prepare meals important, while 32% consisting mainly of male participants and elderly female participants did not view it as important since they had their meals prepared for them by caregivers. On doing housework, all male participants considered it as not applicable to them. This is common in the Zimbabwean and most African cultures where most if not all men, do not consider household chores as part of their ADLs. Therefore it would be irrelevant to engage a male patient in therapy sessions focusing on retraining household chores unless found necessary during the assessment process. The same notion applied to the elderly female patients who had long stopped doing those chores before suffering a stroke. These duties were done for them by children, grandchildren and/or caregivers [32]. This is where the aspect of interdependence is seen in the African culture. The elderly in Africa usually end up living with their children and grandchildren as compared to the Western culture where the elderly can be living alone and independence in home maintenance tasks becomes an important aspect of their lives.

2.4 Interpersonal interactions and relationships

All the participants did not have any difficulties in basic interpersonal interactions, formal and informal interactions [32]. Participants considered these areas important. However, 10 and 4% had mild and moderate difficulties in intimate relationships respectively. They attributed their problems in sexual function to their condition and felt it hindered maximum enjoyment of intimate relationships. They viewed their intimate relationships as important but were reluctant to share this with their therapist since they were not aware that the issue could be addressed in occupational therapy. Resumption of sexual activity for stroke patients is very important as cited by Edmans, although they may fail to articulate this to the therapist [40].

2.5 Major life areas

In this domain remunerative employment was not applicable to half of the participants as some were retired and some did not work prior to suffering the stroke. For the remaining half they reported complete difficulty and had not yet returned to their previous jobs. This is consistent with the findings by D'Alisa et al. [41] in which 40% had severe restrictions in employment issues. About 95% of patients to whom employment was applicable considered it as very important [41].

About 33% had moderate difficulties in economic self-sufficiency as they had financial problems due to their unemployment status. All the participants considered being self-sufficient important. In D'Alisa et al. [41], 15% had moderate

to severe restrictions in economic self-sufficiency. This difference may be due to lack of a national social security system that cushions persons with disabilities in Zimbabwe as compared to more developed countries.

2.6 Community, social and civic life

All participants considered it important to be reintegrated into the community. About 85% did not report any difficulty in participating in religious and spiritual activities and 95% considered them very important [32].

Fifty eight percent considered recreational activities as important. These recreational activities were mainly visiting friends and relatives, watching television, reading or listening to the radio [32]. There is a stark contrast in the type of recreational activities cited by the Zimbabwean sample as compared to other studies where participants reported restrictions in activities like golf, bowling, tennis and attending social clubs. The differences in the recreational activities can be explained by the differences in the socio-economic statuses of the samples. The culture of participating in recreational activities for leisure purposes need to be reinforced and further explored especially in low income groups where people mostly engage in productive activities whether paid or unpaid than they do in recreational activities.

2.7 Areas that stroke patients wanted to return to

Out of the 40 participants, 53% wanted to return to their work. They considered it very important because some were breadwinners and wanted to be able to look after their families [32]. In a study in Singapore by Kong and Yang [42], 14 out of 54 participants continued to be gainfully employed [42]. Of these 14, 11 were able to go back to previous jobs while 3 had to change jobs due to their physical limitations [42].

Thirty four percent wanted to be able to do their instrumental ADLs again [32]. These were mainly female participants who valued being able to look after their children and homes. Only 10% did not wish to return to any activity in particular and these were mainly elderly patients who had not been engaging in any activities that they considered important enough to return to [32]. In such cases, it would be necessary for the therapist to try to look for areas of interest for the patient so as to build a passion for doing activities that are meaningful to them and can also be used during therapy.

In summary, these findings give insight into the areas stroke patients consider important in the Zimbabwean context. They are consistent with other studies, for example, one study by Sumathipala [20], where stroke patients considered ADLs, social participation, mobility aids, home adaptations, housing and financial support as important [20].

The ICF is an important framework in guiding management of stroke patients as it can be used to assess and address all aspects of a person's life without just focusing on his/her diagnosis [43]. Occupational therapy has an important role of facilitating a patient's optimal functioning and independence through participation in meaningful and purposeful daily activities. The strength of occupational therapy lies in the ability to analyse activities/occupations. The occupations in which a person engages and the amount of time one spends doing the occupations is very specific to the circumstances and the culture in which a person lives [44]. Therefore, the effectiveness of occupational therapy and the quality of care can improve when culturally relevant occupations are selected and interventions are important to a person with stroke.

3. Needs of stroke patients

3.1 Introduction

This section is based on a cross sectional pilot study done in Harare, Zimbabwe in 2020 with 35 stroke patients attending rehabilitation [45]. Mean age of participants was 58 years (S.D 8.8) and the greater proportion were female (n = 19, 54.3%). The majority (94.3%) belonged to the Christian faith similar to 92% found in Seremwe *et al.* [46]'s study in the same context [46]. About 57% were married. In the Zimbabwean setting and from previous experiences with stroke patients, this might be due to good social and financial support from the spouse making them able to afford the hospital services. Those widowed or single due to other reasons may not seek for medical or rehabilitation services due to lack of financial and social support [46]. A study by Liu et al., [13] reported an independent association between marital status and post-stroke outcomes in patients with acute ischemic stroke [13].

About 49% were employed [45], consistent with another study done on stroke survivors in Zimbabwe where less than half were working and the rest had no source of income [46]. Left cerebral Vascular Accidents accounted for 74.3% of the strokes. Study participants had a median duration with stroke diagnosis of 104 days (inter-quartile range 44–270). This is mainly the situation in Zimbabwe where most of the patients who come for rehabilitation have stroke duration of less than two years. Those who had stroke for more than two years will have inadequate funds to continue treatment, hence will not come for rehabilitation services.

The needs of participants were grouped into physical, instrumental, social, informational and emotional needs. Highlighted in **Table 1** are the needs according to the groupings and it consists of 28 statements to which participants were expected to answer "yes" or "no" on whether they consider it a need.

3.2 Physical needs

Fourteen statements related to physical needs. All the participants in the study considered pain management, walking and general mobility, performing basic and instrumental activities of daily living (ADLs), engaging in recreational activities, dealing with fatigue and exercising as their physical needs post stroke [45]. Specific self-care needs cited were independent bathing and cutting toenails. Only 40% and about 11% cited swallowing and hearing problems respectively. Thus physical needs were the most common needs of stroke patients. This is because stroke mainly affects the physical components resulting in pain, reduced mobility, poor muscle strength, reduced speech and communication, problems with swallowing and incontinence and many other deficits which might results in decreased functioning and inability to cope [12]. In a similar study done in Australia, patients mostly over the age of 65 years needed assistance with performing ADLs, such as self-care [15], and this shows that this is a major need among all stroke patients regardless of location.

Sight problems, prevention of pressure sores and dealing with bladder and bowel problems were cited by more than 80% of participants as needs indicating that they are also common needs in this group.

3.3 Instrumental and social needs

These two aspects had a combined five needs (**Table 1**). There were two items on instrumental needs, and all participants indicated the need for additional

Item	Need	Considered as a need by stroke patients	
		Yes ***n*** **(%)**	**No** ***n*** **(%)**
	Physical needs		
1	To ease my pain, since nothing seems to ease it.	35 (100%)	0
2	Help on walking and general moving	35 (100%)	0
3	Help on how to get job done in my home (ADLs) such as cleaning, cooking, ironing and laundry	35 (100%)	0
4	Help on how to do things like cutting my toenails, washing myself	35 (100%)	0
5	Help on how to deal with fatigue	35 (100%)	0
6	Learning about exercise	35 (100%)	0
7	Help on how to bath independently	35 (100%)	0
8	Help on dealing with bladder/ bowel problems (accidents, constipation, diarrhoea)	32 (91.43%)	3 (8.57%)
9	Help on how to prevent pressure sores	30 (85.71)	5 (14.29%)
10	Help on sight problems.	29 (82.86%)	6 (17.14%)
11	Help on getting back to driving	19 (54.29%)	16 (45.71%)
12	Help on swallowing problems.	14 (40%)	21 (60%)
13	Help on speech and communication problems	12 (34.29%)	23 (65.71%)
14	Help on hearing problems.	4 (11.43%)	31 (88.57%)
	Instrumental support		
15	Additional aids or adaptations (kitchen appliances, stair lift, grab rails) if other please specify	35 (100%)	0
16	Adaptations outside the home (e.g., ramps, rail) if other please specify	33 (94.29%)	2 (5.71%)
	Social needs		
17	Help on how to occupy my day better (e.g., social outings, hobbies, leisure activities)	35 (100%)	0
18	Help and advocacy in accessing social services	34 (97.14%)	1 (2.86%)
19	Help on how to travel using public transport such as buses and commuter omnibuses	32 (91.43%)	3 (8.57%)
	Informational needs		
20	More information about my stroke (e.g., what is stroke, why has it happened to me, how to avoid having another one)	35 (100%)	0
21	Advice on how to improve my diet	35 (100%)	0
22	Advice on how to manage my money better.	33 (94.29%)	(5.71%)
23	Help on how to do shopping.	32 (91.43%)	3 (8.57%)
24	Advice on employment after stroke	25 (71.43%)	10 (28.57%)
25	Help and information on how to manage my physical relationship with my partner	13 (37.14%)	22 (62.86%)
	Emotional needs		
26	Help on improving self-esteem, anger issues and other emotional issues If other please specify	35 (100%)	0

Item	Need	Considered as a need by stroke patients	
		Yes *n* (%)	No *n* (%)
27	Help on improving my memory and concentration.	33 (94.29%)	2 (5.71%)
28	Help on how to deal with emotional and behavioural changes	34 (97.06%)	1 (2.94%)

Table 1.
Distribution of participants according to need (N = 35).

aids or adaptations in the house while 94% cited need for adaptations outside the home. Under social needs, there were three items and about 97 and 91% respectively indicated the need for help and advocacy in accessing social services and using public transport. All participants needed help on how to engage in social outings, hobbies and leisure activities. Stroke survivors in this study faced societal barriers that can affect engagement in activities of daily living namely problems in using public transportation, lack of adaptations inside and outside the home environment as well as lack of aids and appliances to facilitate independence. Due to the economic situation in Zimbabwe, most places are not specifically adapted for people with disabilities to engage fully in social and daily activities, for example, inadequate provision of rails and ramps in public buildings for those who have problems with mobility [47]. Assistive devices like wheelchairs and modifications to the home environment are not available to the survivor soon after discharge to promote maximum participation [48], hence participants citing them as needs they require occupational therapists to meet. In Zimbabwe, wheelchair service provision and services are fragmented and poorly integrated [49]. The use of mobility devices such as wheelchairs, crutches and canes improves mobility, health and quality of life, and it enables those with mobility issues to mobilise without any restrictions [48]. Another study showed that stroke survivors had more participation restrictions as a result of environmental barriers [50]. Physical/structural and services/assistance were considered the dominant barriers to participation in activities of daily life for stroke survivors in China, hence there were considered to be among the most common needs presented by stroke survivors [51]. In another study on "Identification of rehabilitation needs after a stroke", some of the most expressed needs of the participants were needs relating to adapted means of transportation and home visits from healthcare personnel [52]. Home visits might also help in noting any home adaptations that need to be done [53]. Social support should be provided to stroke survivors, including barrier-free facilities and occupational therapists should advocate for those services in the community.

3.4 Informational needs

Six items related to informational needs. All the participants needed information on their condition (stroke) and advice on diet. Over 90% needed advice on or help on better money management and shopping. Twenty-five participants needed advice on employment after stroke. The least cited as informational need had to do with managing physical relationships with partner/spouse (about 37%) (**Table 1**). The need to give more information about the condition is consistent with findings by Williams et al., where only 38% professed to know stroke warning signs and only 25% correctly interpreted their symptoms [54]. Similarly, Mckevitt, et al., reported more than half of their participants wanting more information about their stroke

(cause, prevention of recurrence) [55]. This shows that this is a major concern among most stroke patients regardless of the part of the world they live, hence the need for occupational therapy intervention. Knowledge about the condition will also help them to adhere to the home programs they will be given and to seek for early treatment before any complications or permanent disability arises. With more knowledge about stroke, they could identify the disease immediately, resulting in a decrease in the time from symptom onset to hospital arrival, and a subsequent increase in the number of patients who may receive appropriate interventions [56]. It might also help them to know how to prevent any future recurrence of the condition and the services that might be beneficial to them in order to minimise any complications that may arise as a result of the condition.

3.5 Emotional needs

Three items related to emotional needs. All items were cited as needs by more than 94% (improving memory and concentration (94.29%), self-esteem, anger and other emotional issues (100%) plus dealing with the emotional and behavioural changes (97.06%) (**Table 1**). This high proportion of more than 90% of the participants having emotional needs after stroke is probably because stroke affects the person's ability to engage in daily living activities, communicate well with others and that can lead to increased dependence, feelings of low self-worth, (e.g., if the patient is incontinent) resulting in many psychological and emotional issues like depression [57]. The findings in this Zimbabwean study are consistent with a study on "Self-Reported Long-Term Needs After Stroke" where over one third of respondents reported experiencing emotional problems (including depression, crying) after the stroke [55]. Since emotional and psychological needs are liable to be neglected, post-stroke depression is a common complication which seriously impairs quality of life [18]. Therefore, psychological expertise and psychological support is needed by stoke survivors [18].

4. Importance of needs as perceived by stroke patients

The majority of the participants in the Zimbabwean study perceived most of the needs in all categories as important and requiring intervention [45]. Physical needs rated as very important in this study were independent mobility and dealing with bladder and bowel incontinence. These aspects enable participants to be independent and to perform daily activities without restrictions. Participants also perceived informational needs as important [45]. Information on dietary issues is important among stroke patients as this might enhance recovery and help in minimising the intake of unhealthy foods such as saturated fats and too much sodium chloride which might even increase the risk of having a recurrent stroke [58]. Knowledge about one's condition will conscientise them on the importance of receiving rehabilitation and adhering to one's treatment and medications. The knowledge can also minimise complications and prevent future recurrence of the condition, hence this information is important among stroke patients [59]. Furthermore, knowledge and information about the condition is important since there is often confusion and a lack of information about surviving after a stroke, prevention of subsequent strokes, treatment, services, benefits and adaptions to property [60, 61]. Stroke survivors had to adapt to changes in their bodies as a result of stroke and adjust their expectations, including roles within the home and community [60]. This was particularly so for those of working age and hence the importance of knowledge on the condition.

In one study, stroke survivors experienced a lack of information about what had happened to them and did not realise they had had a stroke [62]. Relevant information is required at different times after a stroke, for example, information about benefits and services most needed after discharge from hospital [61]. Some survivors and carers are unsure which profession offers which service, and there can be role confusion related to an Occupational Therapist, a Physiotherapist, a Home Carer and a social worker, hence this information is also important among stroke patients who should know which services can address their specific needs [60].

The majority of the patients in the Zimbabwean study indicated that adaptations in the home environment were important [45]. Without these, stroke survivors are restricted in performing their daily activities and social roles resulting in increased dependency [63]. Without assistive technology, stroke survivors and other people with disabilities are often excluded, isolated and locked into poverty, resulting in increased burden of morbidity and disability [63]. This is similar to a study done to identify the long-term needs of stroke survivors using the ICF where the participants reported that home adaptations (such as stair or grab rails) provided after discharge from hospital enabled them to adapt to their physical disabilities by facilitating independence in walking, climbing stairs and ADLs [20]. Stroke patients saw this as important since these factors might create a significant barrier to their physical functioning and independence.

Pfavai [45] also revealed that emotional issues such as dealing with depression and behavioural changes were rated as important by more than 80% of the participants. Most of these are not easily seen unlike physical needs hence their importance might be overlooked by occupational therapists. These issues might affect recovery and engagement in daily occupations hence they were perceived as important by the participants. Emotional problems such as depression might also be fatal, in worst cases leading to suicide and general increased mortality, hence their importance must not be overlooked [64]. A sudden attack and poor prognosis had an appreciable effect on the psychological and emotional wellbeing of stroke survivors [18], hence they are important and should be addressed. Interventions usually focus on treating the disease, rather than the emotional needs of the patients. These emotional and psychological needs are liable to be neglected and post-stroke depression is a common complication which seriously impairs quality of life [18, 63].

Participants in Zimbabwe also perceived the need to engage in recreational pursuits as important in their lives [45]. This is one of the areas which are mostly neglected during intervention by occupational therapists. However, engaging in leisure and recreational activities is of importance since it improves physical health, enhances mental wellness, social interaction with others and it enables the stroke survivors to engage in activities which are meaningful in their lives [65]. In a study done on coping with the challenges of recovering from stroke, participants reported the importance of recreational activities and the great distress which was associated with the loss of hobbies and activities that had previously been a source of pleasure and achievement [62]. This is also in line with Rhoda et al., [66] where the participants highlighted the importance of engaging in recreational activities. Participants experienced social isolation, restriction to their homes which they felt could result in sadness and depression due to inability to engage in those activities which were normally found interesting before [66]. However, these activities should be client centred so that their benefits to each individual can be realised.

Access to public transport which is conducive and specifically adapted for people with disabilities was perceived as important by participants in Pfavai study [45]. This is important since lack of suitable transport results in participation restriction in activities such as religious activities, shopping and other social gatherings

participants might want to engage in [47]. In a study done in China, physical/structural and services/assistance which include inaccessible public transport for those with disabilities were considered the dominant barriers to participation in activities of daily life for stroke survivors in China hence these needs are important and should be addressed [18]. Social support should be provided to stroke survivors, including barrier-free facilities [47]. Furthermore, the social security system for stroke survivors and other disabling conditions needs to be improved in low-income and middle-income countries.

5. Perceived fulfilment of stroke patients' needs

Findings from Pfavai study [45] indicated that most of the needs of stroke patients were not being fully met including those needs participants rated as very important. Perceived unmet needs may reflect expectations and knowledge but may also indicate where service provision should be developed [55]. The needs which were mostly being fulfilled were physical needs such as pain management, exercises to facilitate walking and mobility in general, and self-care including independent bathing [45]. This is because these needs can be easily identified and their physical limitations can be easily noted compared to other needs such as emotional, informational and societal. The later ones are therefore less likely to be addressed. These findings are consistent with McKevitt *et al.*, [55] where most participants experienced problems related to physical needs which were to do with mobility, falls, pain, and incontinence, and those needs were fulfilled in the majority of cases. Thus, the percentages of those with unmet physical needs were small (less than 25%) compared to the unmet emotional needs such as memory and concentration which were reported by 39% of the participants [55].

The emotional needs highlighted included how to deal with depression, anger issues, low self-esteem and behavioural changes as a result of stroke [45]. Emotional needs might be overlooked during the assessment process especially if the patient does not mention any emotional issues they might be experiencing. This is in line with a study done on the unmet needs of stroke patients where cognitive and emotional health needs such as concentration, memory, cognition, fatigue, and emotions were less likely to be fully met than physical needs despite physical needs being more common [15]. This affirms the requirement to implement strategies to help stroke survivors address the range of emotional problems they may experience [55]. Stroke rehabilitation usually focuses on physical impairments and assisting stroke survivors to develop functional independence. This may mean that services aimed at addressing the cognitive and emotional needs of stroke survivors are not adequately resourced [15]. This supports the results obtained in Pfavai [45] study where emotional needs were not being fully met compared to most of the physical needs [45]. Therapists need to be intentional in ensuring that emotional problems experienced by stroke survivors are adequately addressed.

Instrumental needs which were perceived as being unmet by more than 70% of the participants included adaptations outside the home environment and aids and adaptions inside the home environment [45]. Without these aids, stroke survivors are less able to perform their daily activities without restrictions [49]. However, due to the economic situation in Zimbabwe there is lack of resources in hospitals and assistive devices are scarce for those with performance limitations [45, 47]. There is also lack of transport and financial resources for the occupational therapists to do home adaptations for the patients soon after discharge [53]. This need might also be more than the 70% which was obtained in Pfavai study [45] since the study was partly done at a rehabilitation centre where the patients are given assistive devices

such as wheelchairs for them to use before discharge and at a nominal fee after discharge. Stroke survivors have also reported that health systems are not responsive to their changing needs and that there is a lack of long-term re-assessment of their needs, [15]; hence some of the needs which might arise later during intervention may not be met.

Training on getting back to driving and information on how to do shopping were rated by more than 90% of participants as unmet [45]. These are some of the needs which are over looked during intervention. This might be due to lack of expertise among the concerned occupational therapists on driving rehabilitation. At the time of writing this chapter, there was no comprehensive module on driving in the University of Zimbabwe curriculum on occupational therapy undergraduate training. This might result in lack of expertise and confidence in addressing that need. This is also in line with a study done on coping with the challenges of recovering from stroke where loss of ability to drive a car was seen as a major challenge which required intervention and the ability to resume driving was spoken with deep emotion [62]. Driving was seen as representative of independence, a way to regain self-esteem, a means to access social support and to facilitate participation in valued activities [62]. This aspect however needs special training to avoid causing harm to patient and society.

Skills on shopping independently were also perceived as unmet in Pfavai study [45], and this might be due to lack of resources to simulate the shopping environment or lack of funds to teach the patients in the actual environment. In a study that looked at the combined perceptions of people with stroke and their carers regarding rehabilitation needs one year after stroke [67], patients reported having to give up a task in advance and had limitations in more physically demanding activities such as going to buy groceries among other tasks, supporting the need to address shopping needs among stroke patients [67]. The importance of this need might be overlooked during interventions. Information and knowledge needs of stroke survivors should not be underestimated and should be considered when developing strategies to meet the rehabilitation needs of stroke survivors [68].

Another unmet need in the Zimbabwean study [45] was financial/money management after a stroke. Most stroke survivors lose their jobs after the incident of stroke, and cognitive components might also be affected resulting in inability to adequately manage their money. However, this need seemed to have been overlooked. Li et al. also noted that few studies have looked at the financial impact of stroke on the survivors and their families, indicating that this area's importance might be underrated [18].

Early discharge of patients due to unavailability of beds might also result in some of the stroke patients' needs not being adequately met. Although many individuals still have rehabilitation needs one year after stroke, rehabilitation is often concluded within the first three months, and follow up is not usually done hence some of the needs might not be adequately fulfilled [67].

6. Closing remarks

The occupational therapist is the health professional who specifically addresses patients' involvement in daily life situations, and as such, she/he should be well conversant with that particular aspect of patients' lives. This in turn addresses one's quality of life which is often neglected. Stroke patients' perceived needs highlighted above provide patients' perspectives which is critical in the development of patient-centred services by service providers. The commonly used functional outcome measures (e.g., the Barthel Index) may underestimate dependence leading

to rehabilitation professionals and patients prioritising different needs. Not using meaningful occupations in treatment; lack of discharge planning, using interventions not perceived as driven by patient's occupational goals, and use of interventions chosen by therapists without considering what the patient needs thereby placing the patient in a passive role were noted as major challenges [69]. The stroke patients' perceptions help the therapists to tailor interventions to meet patients' specific needs.

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