Bulletin of Faculty of Physical Therapy

ORIGINAL RESEARCH ARTICLE Open Access

Exploring rehabilitation options and resources of support for stroke survivors in Eldoret, Kenya: qualitative study

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Abstract

Background Stroke is a major cause of death and disability in adults globally. Most post-stroke survivors experience various impairments which requires rehabilitation. Likewise, returning home after a stroke represents challenging moments full of struggle. This study, therefore, explores options of rehabilitation and resources of support for stroke survivors in Eldoret, Kenya.

Method A qualitative descriptive approach was used to conduct the study. The study utilised semi-structured interviews. Fifteen dyads of stroke survivors (10 men and 5 women; aged 40–75 years) were enrolled from a rehabilitation outpatient clinic (Medical Park Physical Therapy) in Eldoret, Kenya. Interviews were conducted at the patients' house, and an inductive approach was used to enable thematic content analysis.

Results Two dominant themes and several categories emerged from the participants; these included the following: (1) rehabilitation services available for stroke survivors and (2) resources of support.

Conclusions The study found that stroke units are only available at the national hospitals and not accessible to many. Patients receive physiotherapy and occupational therapy services during hospital stay but has poor access post discharge. Transport, distance, and lack of finances have been highlighted as the main challenges. There is scarcity of speech therapist as well as advanced orthotics for stroke rehabilitation. From a clinical perspective, healthcare system should be better structured to accommodate continuity of care post discharge for stroke survivors.

Keywords Stroke, Rehabilitation, Resources, Support, Survivors

Background

Stroke is the second leading cause of death and disability worldwide [1]. An estimated six million deaths are recorded annually, while 16 million people are affected by disability due to stroke globally [2]. The incidence rates of stroke vary between countries [3]. In the USA, stroke is the fourth leading cause of death with approximately 140,000 deaths from stroke annually [4]. Stroke accounts for 7% of all deaths in Canada [5]. It is estimated that every 7 min, a Canadian dies of heart disease or stroke [5]. Stroke equally affects the Asian countries in equal measure; in a multinational assessment, stroke ranked as the second or third cause of death in Hong Kong, South Korea, and Singapore [6]. In a similar study, Yi et al. reported approximately 3 million new stroke cases in China every year [7].

Although the incidence of stroke has declined considerably in developed countries, it remains a burden facing developing countries especially sub-Saharan countries [8, 9]. In low- and middle-income countries, stroke accounts for approximately 70% of all deaths with 87% stroke-related disability recoded annually [8]. In Africa, data published within the past decade shows

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that stroke has an annual incidence rate of up to 316 per 100,000, a prevalence of up to 1460 per 100,000, and a 3-year fatality rate greater than 80%. Moreover, many Africans have a stroke within the fourth to sixth decades of life, with serious implications for the individual, their family, and society [10].

The epidemiology of stroke in East Africa has not been clearly and extensively documented. Matuja, Munseri, and Khanbhai [11], in a prospective study, found a high burden of stroke in young adults coupled with a high 30-day fatality rate in Zanzibar. Matuja [11] in a similar study reported that 11.3% of all medical admission is stroke, with 1 year mortality of 80% in Tanzania.

Olum et al. [12] and Diaz et al. [13] highlight an overall 30-day stroke mortality of 38.1% in southwestern Uganda, with stroke having the highest admission in a Ugandan neurology ward. This is comparable to Kenya statistics; stroke mortality is high, with poor survival [14, 15]. However, there is paucity of epidemiology of stroke in Eldoret, Kenya.

Sixty percent of stroke patients acquire permanent disabilities and experience activity limitations [16]. Impairments caused by stroke may cause loss of individuality in self-care and movement, which increases burden of care on the spouse, family, and community [16]. In addition, financial challenges in some cases also arise because of reduced income caused by failure of the stroke survivor to return to work [16].

Rehabilitation is vital after a stroke [17]. Often, patients must go through long and protracted rehabilitation period [18, 19]. A coordinated stroke rehabilitation care team is extremely essential for supporting stroke survivors from diagnosis through recovery [20]. Stroke care teams include physicians, nurses, neurologists, physiatrists, physiotherapists, occupational therapists, speech therapist, social workers, dieticians, orthotist, pharmacists, psychologists, case managers, and stroke recovery groups, amongst others [17]. Furthermore, family members are an important part of the care team [17]. This team worked closely and considerately to fulfil stroke survivor needs and goals and to enhance recovery. However, many stroke survivors do not access crucial rehabilitation services [21].

Understanding stroke rehabilitation particularly in low-income setting where various rehabilitation options may not be available and/or the survivor may not follow rehabilitative treatment regime is crucial [21]. In most of the low- and middle-income countries, stroke rehabilitation options have neither been described nor documented [22]. It is doubtful that stroke rehabilitation options and resources of support are the same as those in high-income countries.

Kenya is a low-income country with underdeveloped health system. In Kenya, only national health facilities have well-established rehabilitation units. Therefore, the current study sought to gain insight into rehabilitation options and resources of support from the perspective of patients in Eldoret, Kenya.

Method

Fifteen dyads of post-stroke survivors were conveniently sampled from a population of twenty-one stroke patients admitted at the Medical Park Physical Therapy Clinic, between January 2018 and March 2023. The patients were selected for qualitative exploration in a single-centred study in Eldoret, Kenya. The selection criteria for patients included patient with no other medical condition, stage of illness—sub-acute and chronic stages (acute cases were excluded because the acute phase is attended to in in-patient), setting (rural and urban centres), and severity of disability (severe, moderate, and mild).

Ethical approval was obtained from the Institutional Research and Ethics Committee (MTRH/MU-IREC). Participants were informed about the study and its purposes. Informed written consent was obtained before commencing interviews.

Interview guide was developed for data collection. Four participants that were not included in the main study piloted the interview guide. Interviews were carried out at the patients' home; field notes were taken, and the interviews were audiotaped. Interviews lasted approximately 50–60 min, and no repeat interviews were conducted. Data was collected to saturation.

Data analysis

One data coder manually reviewed the transcripts and analysed data by thematic content approach, which involved identifying codes and categorising patterns [23, 24]. Interviews were firstly read for accuracy and then revised to identify the developing themes and potential incongruities [25]. Upon completion of all interviews, the whole set of transcripts was read to obtain a sense of the unbroken and to generate a coding system based on insights identified from the data. The codes were them related to the data to improve the coding development and to determine potential categories [26]. Subsequently, categories were established, and they served to organise codes into meaningful clusters. Codes and categories were collapsed to evaluate evolving outlines and themes until the point was reached where no new information pertaining to the study question was created [27].

Table 1 Patient demographics

Age	Gender	Marital status	Affected side	Duration of illness	Severity of stroke
45	M	Single	Left	8 months	Mild
60	M	Married	Right	14 months	Moderate
50	F	Married	Left	36 months	Severe
61	M	Married	Left	24 months	Severe
52	F	Married	Right	17 months	Moderate
36	F	Single	Right	6 months	Mild
64	M	Married	Left	18 months	Moderate
58	F	Married	Right	22 months	Severe
72	M	Married	Left	34 months	Severe
49	M	Married	Right	6 months	Moderate
55	M	Married	Left	13 months	Moderate
69	F	Married	Left	38 months	Severe
75	M	Married	Right	27 months	Severe
40	F	Single	Left	12 months	Moderate
51	M	Married	Left	18 months	Severe

Table 2 Caregiver/spouse demographics

Age	Gender	Relationship to patient
32	F	Sister
55	F	Wife
62	M	Husband
54	F	Wife
25	F	Daughter
58	F	Mother
56	F	Wife
30	F	Sister
60	F	Wife
41	F	Wife
48	F	Wife
71	M	Husband
68	F	Wife
38	F	Sister
46	F	Wife

Results

Characteristics of the participants

The study sample consisted of 15 dyads with a mean age of 55.8 and 49.6 for patient and caregiver/spouses respectively. The caregiver/spouses were not part of the study but provided assistance to the participants when need arose. The majority of the caregivers were female and mostly spouses (Tables 1 and 2).

Table 3 Emerging themes and categories

Themes	Categories
Rehabilitation services available for stroke patients	Stroke units Physiotherapy and occupational therapy Speech therapy Orthotics
Resources of support for rehabilitation	Social support: family, availability for physical and emotional support, support group Financial support: financing treatment cost and transport to the facility

Main findings

Two dominant themes and several categories emerged and are presented in Table 3. Quotes to support the themes will be presented below.

Rehabilitation services available for stroke survivor

Stroke unit

Stroke was abrupt and had a huge impact on the participants life; most participants had emotive recollections of the events that characterised the incident. Only three participants were admitted in a national hospital in specialised stroke unit.

> *"I was admitted in MTRH in CCU for two weeks. There was a big team of doctors that would review me twice a day. I was really impressed. After the two weeks I was taken to neuro-ward" (P01)*

Participants (P02, P05, P08, P11, and P 13) were admitted in county referral hospitals in the general ward after sustaining a stroke.

> *"I was rushed to Nakuru PGH where I was admitted in medical ward. Several tests were done after which I was put on medication" (P13)*

Physiotherapy and occupational therapy

Stroke brings crisis to patients and families due to abrupt changes in health status, functional capability, and degraded quality of life (QOL). For many participants, stroke was sudden and brought about functional changes that occasioned feelings of dependency. The functional impairments ran from physical impairment to participation restriction.

> *"Stroke brought my life to an abrupt stop, I couldn't sit nor stand, I had to be assisted. I had a golf tournament that weekend but couldn't even think about it" (P3)*

Functional impairments necessitated stroke survivors to seek for rehabilitative services. Data elicited various rehabilitation service needs; these included physiotherapy, occupational therapy, and orthotic and speech therapy. Participants (P2, P4, P5, and P9) indicated that physiotherapy and occupational therapy services were available at the hospital, and they received these services during their hospital stay.

> *".... exercises were done on me every day for the period of time I was in the hospital. I would have a session with a physiotherapist in the morning, and a session with an occupational therapy in the afternoon. It was quite helpful" (P09).*

On the contrary, all participants reported that physiotherapy and occupational therapy services were not easily available after discharge. This was due to the fact that the services were available on outpatient basis, and most of the patients lived far from the hospital. The travel distance and cost were overwhelming. Likewise, most participants did not have a health insurance cover, and the cost of treatment was overburdening.

> *"It was challenging for me to go for physiotherapy sessions after I left hospital, I live far from the hospital. I have to hire a car to the hospital and pay for treatment, yet I lost a job after stroke. It's hard; I can't manage to follow what the doctor wants" (P.04).*

Similarly, stroke survivors reported that physiotherapy and occupational therapy services were not available at the community health facilities.

> *"The health centre near home has no physiotherapy and occupational therapy. So, when I went there, I was told to go to the county referral hospital" (P.08).*

Speech therapy

Most of stroke survivors that had speech impairment had recovered though not fully but were able to communicate. They were equally assisted by their spouses/caregivers where help was needed. Data showed that speech therapy services was very scarce and would only be available under special arrangement and with high-cost implication. Five of the participants reported that they needed the services of speech therapist post stroke. Conversely, these services were not easily available. One participant reported to travel as far as Nairobi (310 km) to get the services of the speech therapists.

> *"My dad had a swallowing problem after the stroke; he therefore needed a speech therapist. There were no trained speech therapists in Eldoret. He was managed by an OT but the results were not impressive. We had to travel to Nairobi where we got one from Ireland practicing in Nairobi hospital" (P.05).*

A majority of the patients with speech impairments could not travel long distances to get a speech therapist. They therefore relied on occupational therapy for speech therapy, but the results were not very good.

> *"My sister has been going through speech therapy from the OT department at Moi Teaching and referral Hospital. The results are not notable. She actually gave up, but she really struggles especially when she wants to express herself" (P.10).*

Deficiencies in speech management led to communication difficulties which affected participants negatively leading to social isolation.

> *"I have some communication challenges, I avoid talking, this has led to me having issues with socialising" (P.11).*

Orthotics

A minority of the participant engaged the services of the orthotist. Some did not seem to understand the role of orthotist in stroke rehabilitation journey. However, one participant (a retired neurologist) indicated that he needed a shoulder brace with an extension harness at the elbow joint after stroke. Likewise, he denoted that he needed an ankle orthosis post stroke to manage the foot inversion and plantarflexion synergy. The participant revealed that the orthopaedic technology department at tertiary hospital in Eldoret did not have the orthotics especially for rehabilitation of stroke survivors.

"I needed a shoulder brace (Omo neurexa to be specific) to support my shoulder, as well as manage the elbow flexor synergy. I was so surprised that at the orthopaedic department, they were oblivious of the existence of such gargets. I had to travel to Nairobi to Ottobock" (P.13).

Also, participant indicated that there was lack of advanced orthopaedic technology departments in almost all tertiary hospitals. Therefore, all post stroke survivors that required advanced orthotics were forced to seek the services from a private institution, which was quite expensive.

"At Ottobock, you meet stroke survivors from all over the country looking for these braces. What does that tell you? government health facilities do not have this advanced technology to produce high-tech braces and orthotic, and its quite expensive for us"

Resources of support

All subjects revealed that they received a variety of resources for support which meaningfully influenced their ability to meet their needs for managing stroke. Two key resources were identified as financial support and social/community support.

Financial support

Data showed that socioeconomic status significantly influenced stroke management, mainly with respect to fulfilling rehabilitation needs to optimize stroke survivor outcomes. Participants pointed that the cost of stroke rehabilitation could be high, and not all stroke survivors were financially endowed with resources needed for rehabilitation. While several stroke survivors reported having medical insurance (which covered some or all post discharge rehabilitation requirements), others paid out of pocket for these services.

"I have good insurance. When I got home, I was able to continue getting physiotherapy services from a private facility" (P.02).

For the stroke survivors that were paying out of pocket for rehabilitative services, they banked on support from family member to finance their treatment.

"My daughter pays for physiotherapy at a private facility, So, we normally go for physiotherapy three times a week, and I've been doing this for the last one year. I don't know what I would do without her. I think I would be dead" (P.0 4).

Social support

Social support seemed to make a notable contribution to the recovery and well-being of stroke survivors. Most stroke survivors indicated that they were supported by a spouse, other family members, and friends.

"My wife and family were crucial in my recovery, they provided a shoulder I needed to lean on, I don't know what I would have done without them. My wife always bath, clothed and fed me every single day. I also have at least four people in the house to take care of me" (P. 15)

Stroke survivors also agreed that the stroke group was vital in stroke recovery. The stroke recovery group substituted the lack of community follow-up programs. The stroke recovery group offered an environment where stroke survivors could obtain emotional support. In addition, the group offered a place where stroke survivors could come together, promote friendships, and rebuild their lives. Participants labelled the stroke recovery group as an encouraging place where members did not feel conscious about their physical and cognitive inadequacies.

"... it provides the emotional support, the friendship and the goodwill. Everyone in the group has walked the same lane, we understand each other more than everybody else, so one doesn't need to explain his/her situation to anybody" (P.14).

The stroke recovery group also provided stroke survivors with access to practical resources, such as assisting each other on disability assessment and registration and tax exemption process as well as issues related to the National Council for Persons with Disability.

"I was assisted with registration of persons with disability, today I enjoy tax exemption for my business. This group has been very instrumental in my life after stroke" (P.11).

The stroke survivor group was labelled as reassuring because it was a place where stroke survivors networked, learned, and supported each other.

"We assist each other, we have started a venture of identifying what each one of us is good at, after which we start an income generating activities that can be done in our current state" (P.03).

Discussion

Most of the participants were male contrary to the global lifetime risk of stroke at 25.1% in women and 24.7% men [28]. Caregivers were predominantly female consistent with Namale et al. and Ae-Ngibise et al. [25, 29]. Our finding on caregiving reflects the Kenyan culture, where caregiving is viewed as a woman's role. The women are commonly devoted to caring for their family members and for managing household chores.

Kenya has only two national hospitals with a specialised stroke unit. All county and sub-county hospitals provide stroke rehabilitation in general medical wards. This is contrary to international guidelines for stroke rehabilitation and the American Stroke Association recommendations [2]. Stroke rehabilitation should take place in organised stroke rehabilitation units [2]. Specialised stroke units involve multidisciplinary teams (MDTs) and provide superior care, hence better outcomes as opposed to general ward care [30, 31]. Stroke rehabilitation units have been embraced by most high-income countries recording high success rates, with patients returning to normal or near normal function.

Although the Moi Teaching and Referral Hospital is one of the national hospitals in Kenya and the third largest in Eastern Africa, with a bed capacity of about 1000, the dedicated stroke unit has only 12 beds. Consequently, most stroke patients are also managed in general medical wards, as they are at county and sub-county hospitals. This is consistent with Cisse et al. [32] who found few stroke units in sub-Saharan Africa. This, therefore, raises a concern as only a small proportion of patients with stroke in Kenya can access this designated stroke unit. There is, therefore, a need for the expansion of stroke units and the establishment of new stroke units in all referral hospitals across the nation.

Findings of the current study likewise illustrate impairments faced by post stroke survivors both in performance of activities of daily living and participation. This is reiterated by Connolly and Mahoney [33] who established that stroke comes with disfunctions. Physical disfunctions amongst other impairment lead to dependence hence need for rehabilitation.

Rehabilitation is a key element of the stroke patient's journey as conceptualised in the World Health Organization Stroke Services Framework [34]. Providing rehabilitation for individuals who have suffered a stroke lowers the risk for death and disability.

The study also highlighted stroke survivor socioeconomic variation which had significant implications for equitable access to on-going rehabilitation. Participants reported high cost of rehabilitation services hence noncompliance with the recommended treatment regime. The results correspond with Sarfo et al., Kamwesiga et al., and Soeker et al. [35–37]. The authors confirmed that cost of care is a common barrier limiting access to rehabilitation services for post stroke survivors in Ghana, Uganda, and Nigeria respectively.

Likewise, data established that geographical distance contributed negatively to access to rehabilitative services. Participants received rehabilitation during hospital stay but had challenges after discharge. Data resound with Ntsiea [38] who confirmed that South Africa stroke survivors have poor access to rehabilitation services post discharge. Oftentimes, the challenges were transport related. These lead to poor functional outcome. Mlenzana et al. and Andrews et al. [39, 40] equally painted a similar situation in a tertiary hospital in Cape Town. The authors found that compliance with treatment regime was a challenge owing to poor attendance caused by transport problems. Relatedly, Soeker et al., Baatiema et al., and Cawood et al. [37, 41, 42] reported similar findings where transport was the major problem affecting attendance for rehabilitation sessions. This remains a challenge, even more recently when Nassib et al. [43] reported comparable challenges in scoping review.

Our study exposed inequities in rehabilitation structures. Most of the rehabilitation services were available at the national specialised hospitals but missing at the community level, consistent with Pindus et al. [44] who demonstrated challenges with continuity of care post discharge. Likewise, Gallacher et al. [45] asserts that stroke management is influenced by micro- and macro-organisation of health services. Oftentimes, the healthcare system is ill equipped to provide care at the community level, making treatment adherence less likely. On the contrary, Ploughman reported good outcome with community rehabilitation post discharge in Canada [46].

This finding provides interesting opportunities for intervention. There is a need to transform the approach to care provision so that services are configured to prioritise patient needs rather than those of healthcare systems. There is need for increased rehabilitative services at the community level.

In Eldoret, Kenya, there is hardly a trained speech therapist. Oftentimes, the services are offered by an occupational therapist who has done a course in speech therapy. Consistent with the current study, Baatiema et al. and Cockburn et al. [41, 47] related exclusive need for speech and language therapy in stroke rehabilitation. The authors affirm that these services are either absent or inefficient in most of the health facilities in Africa. This is likewise, reiterated by Sarfo et al. [35] in a study on structure and process of stroke rehabilitation in the Greater Accra region of Ghana where speech and language therapy were not available at the primary and secondary health facilities.

Aphasia is one of the serious consequences following a stroke and persists in 10–38% of survivors [48]. Aphasia involves language disorder and emotional and psychosocial changes [49]. In our study, communication challenges led to social isolation consistent with Lee et al. [50]. The authors ratify that aphasia is a significant predictor of social isolation and has consequences with negative impact on relationships.

Shoulder subluxation is a common post-stroke complication affecting up to 80% of the stroke subjects [51]. The pathomechanics at the skeletal level post stroke do not provide the structural base for the neural-motor recovery [52]. Hesse et al. [53] in a study on shoulder orthosis found that well-tolerated shoulder orthosis improved repositioning of the subluxated humeral head, offered a good fit, eased performing activities, reduced pain, and improved gait quality.

Therefore, management of subluxed shoulder is an important component in rehabilitation of the upper extremity. Inadequate management of the shoulder can be a challenge, complicating the motor and functional recovery. Contrary to the provisions of evidenced, our study unearthed an area in stroke rehabilitation that has not been paid attention to in Kenya. This calls for active involvement of the orthotist in stroke rehabilitation in Kenya.

Participants who reported extended financial supports were better able to access rehabilitation than those who were economically constrained. Limited resources and lack of support has been reported to limit recovery [54].

Community stroke recovery group was perceived as an important and crucial resource which supported development of empowerment-related skills. The community group also provided a space in which stroke survivors could create new social networks, and participate in learning, from each other [39, 48]. Collaboration and participation between members in the stroke recovery group created a supportive empowerment environment [55].

Conclusion

The study found that stroke units are only available at the national hospitals and not accessible to many. Patients receive physiotherapy and occupational therapy services during hospital stay but has poor access post discharge. Transport, distance, and lack of finances have been highlighted as the main challenges. There is scarcity of speech therapists as well as advanced orthotics for stroke rehabilitation. From a clinical perspective, healthcare system should be better structured to accommodate continuity of care post discharge for stroke survivors.

The study found that stroke units are only available at the national hospitals and not accessible to many. Stroke survivors receive physiotherapy and occupational therapy during hospital stay but have poor access to these services post discharge. Transport, distance, and lack of finances have been highlighted as challenges causing poor compliance to treatment regime. There is scarcity of speech therapist as well as advanced orthotists for stroke rehabilitation. From a clinical perspective, healthcare system should provide more interventions and support to help stroke survivors. Likewise, government should provide accessible stroke rehabilitation facilities at the community level.

Limitations

The findings of this study cannot be generalised for all stroke patients, as this study was only exposed to patients that would come for rehabilitation services. However, the findings help us to gain insight into the experience of the post stroke survivors.

Abbreviations

MTRH/MU-IREC	Institutional Research and Ethics Committee
MTRH	Moi Teaching and Referral Hospital
OT	Occupational therapy
MDT	Multidisciplinary teams

Acknowledgements
The authors would like to thank the staffs and patients at the Medical Park for their invaluable contributions.

Authors' contributions
The article was conceptualised and drafted by N. W.K who contributed to the content of the article.

Funding
This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Availability of data and materials
The data underlying this article will be shared on reasonable request to the corresponding author.

Declarations

Ethics approval and consent to participate
Ethical approval was obtained from the Institutional Research and Ethics Committee (MTRH/MU-IREC). Participants were informed about the study and its purposes. Informed written consent was obtained before commencing interviews.

Consent for publication
Written informed consent for publication of their details was obtained from the study participant.

Competing interests
The authors declare that they have no competing interests.

Received: 1 August 2023 Accepted: 27 September 2023
Published online: 18 October 2023

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