

# SAJOT Article

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## **Factors influencing stroke survivors' reintegration into the community: A Molemole local municipality in the Limpopo Province perspective**

### **Abstract**

**Background:** Stroke incidence remains high in South Africa. Access to rehabilitation services is critical for stroke survivors to successfully reintegrate back into community. The aim of this research was to explore the factors that influence stroke survivors' reintegration into the community to inform contextually relevant rural rehabilitation strategies.

**Methods:** Sequential explanatory mixed-method research design was used. Quantitative data collected through a file audit of 30 participants. The qualitative data was sourced through semi-structured interviews with purposively selected 15 stroke survivors and three rehabilitation team members. The file audit data was analysed using descriptive statistics. The semi-structured interviews were analysed thematically.

**Results:** The five themes identified included stroke survivors' meaningful occupations, enablers for community reintegration, barriers for community reintegration, stroke survivors and caregivers' perceptions on rehabilitation and lastly the rehabilitation team perceptions on rehabilitation strategies for improved stroke rehabilitation. Work was the most affected occupation reported, followed by socialization and the least affected was ADL and IADL. Facilitators included accessibility of assistive devices, positive attitude and community support of the rehabilitation team. Main barriers included residual impairments and limited hospital resources.

**Conclusion:** Early intervention, provision of assistive devices and continued community interventions strengthen the stroke survivors' community reintegration.

**Key words:** Community reintegration, stroke survivor, facilitators, barriers.

## Introduction

Stroke has been identified as a major cause of death second only to HIV in South Africa<sup>1</sup>. Every year, stroke causes 25,000 fatalities and leaves over 95,000 survivors living with disabilities<sup>2</sup>. Due to stroke's sudden onset and persistent physical, psychological and cognitive impairments, the majority of stroke survivors continue to experience difficulty with engaging in occupations such as activities of daily living six months post-stroke<sup>3</sup>. Additionally, the sequelae of stroke might prevent or hinder the individual's ability to return to their previous roles and occupations; hence, stroke survivors are usually dependent on their families and friends for support<sup>4</sup>.

The rehabilitation team's key role is to facilitate transition of stroke survivors from in-hospital rehabilitation to community reintegration. Community reintegration aims at aiding stroke survivors to return to their previous roles despite impairments caused by stroke. Elloker and Rhoda's<sup>5</sup> study on disease burden of stroke in rural South Africa highlighted a lack of literature on incidence and morbidity of non-communicable diseases in South African rural communities. Several studies in South Africa have examined factors influencing reintegration of stroke survivors into their communities in different provinces. However, there has been limited studies that evaluated factors influencing reintegration of stroke survivors into their communities in the Limpopo Province. Maleka et al<sup>6</sup> examined the experience of living with stroke in low urban and rural socioeconomic areas of South Africa (This study included Limpopo Province as a rural area). In these authors' study, only barriers experienced by stroke survivors were identified, and facilitators were not considered. Identifying factors that facilitate stroke survivor reintegration in Limpopo, Molemole local municipality (MLM) would assist in formulating rehabilitation strategies for more context specific stroke rehabilitation in the province.

## Literature review

Stroke survivors' ability to reintegrate into the community depends on rehabilitation services provided to stroke survivors and the environment to which they are being discharged. Although rehabilitation services aim to reintegrate stroke survivors into their community, studies<sup>7,8</sup> have shown there is more attention given to the functional recovery in acute rehabilitation and there is less focus on the transition to previous meaningful roles. Consequently, stroke survivors are not sufficiently prepared to go home in terms of caregiver education, coping mechanisms and advice on adaptations that need to be completed in their homes for successful community reintegration<sup>9-11</sup>. Rouillard et al.<sup>12</sup> found that stroke survivors were found to be independent in BADLs except for areas of IADLs and community mobility, while Gretschel et al., Rhoda et al., Ntsiea, Kusambiza-Kiingi et al. and Ntsiea et al. found that stroke survivors are not fully integrated in the spheres of work and education<sup>13-17</sup>. Additionally, Walsh et al., Govender et al. and Mayo et al. reported on impairments such as mobility, hand function, and cognitive impairments that hindered community reintegration<sup>18, 9, 19</sup>. While Rhoda et al.,'s study attributed decreased community reintegration to personal and environmental contextual factors such as inadequate financial resources, lack of accessible rehabilitation services or inaccessible or expensive transport.<sup>14</sup> Ntsiea<sup>15</sup> attributed the lack of community integration to limited hospital stay. Furthermore,

Visagie & Swartz<sup>20</sup> reported that insufficient community outreach programmes, the absence of linked referrals to peer support groups for stroke survivors and the lack of assistive devices were factors that contributed to limited community reintegration. Mudzi<sup>21</sup> and Cawood & Visagie<sup>22</sup> reported family members support as one of the key facilitators for community reintegration. Furthermore, Govender et al.<sup>9</sup> reported other community members such as relatives, church members, neighbours, friends and employers' support were significant facilitators of community reintegration for stroke survivors. Caregivers strain, both physically and financially, were reported as a barrier<sup>16,15</sup>. Mobility challenges such as difficult terrains, long distances to healthcare facilities, poor transportation created major setback for stroke survivors in terms of accessing healthcare services<sup>23,24</sup>, performing of ADLs and hindering community participation<sup>6</sup>.

Perceptions about rehabilitation services varied in different contexts. Cawood & Visagie's<sup>25</sup> Western Cape study revealed that there was perceived lack of support from the rehabilitation workers which acted as a barrier for community reintegration while Govender et al.'s<sup>9</sup> Kwa-Zulu Natal study found that stroke survivors appreciated receiving advice on adaptations that facilitated improved participation in occupations such as such assistive devices and ramps provided by the rehabilitation team and therapy offered by the occupational therapists and physiotherapists. The literature highlighted was mainly conducted in urban areas and services offered in Limpopo Province, remains a gap in the knowledge base. This study aimed to identify meaningful roles of stroke survivors in MLM and to identify factors affecting their reintegration in the community to inform rehabilitation intervention in the Limpopo Province.

## Methodology

### Study setting

The study was conducted in a rural MLM community. MLM is one of four municipalities in the Capricorn district and makes up 17% of the Capricorn district geographical area with a current population of 127 000<sup>26</sup>. MLM is served by a district hospital which has 80 bed capacity and by eight primary health care clinics. According to Municipalities SA<sup>26</sup> Molemole local municipality has only 9% of residents with higher education, 21, 5% with only matric certificate and 20% with no schooling. Only 11% of residents have flush toilets connected to sewage and 97% have electricity<sup>26</sup>.

### Study design

The study adopted sequential explanatory mixed-method research. Creswell et al.<sup>27</sup> defined mixed method design as the method of collecting or analysing both quantitative and qualitative data in a single study, and the data are either merged or reported sequentially at one or more phases of the research process. Sequential explanatory design is characterized by the collection and analysis of quantitative data in the first phase, followed by the collection and analysis of qualitative data in the second phase of the research, which expands on the quantitative results obtained in the first phase<sup>28</sup>. In this study, quantitative data were collected and analysed followed by qualitative data collection and analysis, and both analyses were merged for interpretation of the results. The quantitative data were collected by means of the file audit and qualitative data were collected by means of semi-structured interviews.

### **Sample and recruitment strategy**

Saturation sampling was used for the file audit. While there were 47 stroke survivors who received intervention at the district hospital between 2018 and 2019, only 30 files were included in the file audit as 17 files were not found.

<sup>3</sup> Purposive sampling was used to select participants for qualitative semi-structured interviews. Purposive sampling involves selecting participants who are knowledgeable about or experienced with a phenomenon of interest, able to communicate and show a willingness to participate<sup>29</sup>. Of the 30 stroke survivors whose files were audited, 17% (n=5) of stroke survivors were not contactable and not found at the addresses provided to the hospital, 10% (n=3) of stroke survivors relocated to other provinces, 23% (n=7) were deceased. Fifteen stroke survivors and their caregivers (ten females and five males) who were over the age of 18 years, had received rehabilitation in a district hospital in Molemole between 2018 and 2019 were included in the qualitative interviews.

Rehabilitation health professionals (occupational therapy technician, physiotherapist and a dietician) who provided rehabilitation for those stroke survivors and their caregivers during 2018 and 2019 and had at least two years' experience with stroke rehabilitation were sought. The stroke survivors and caregivers were requested via telephone calls and interviewed during home visits and the health professionals were emailed to request their participation and interviewed in their offices.

### **Pilot study and data collection**

Data were collected using a file audit and semi-structured interviews. <sup>2</sup> A data extraction tool was designed for the study based on the research objective of creating a sociodemographic profile such as age, gender, education and employment history and clinical profile of the stroke survivors such as year of stroke, hospital length of stay, co-morbidities, and the rehabilitation offered. The tool was piloted on three files and adjusted to include caregiver education. This tool was used to extract data from the files of the stroke survivors.

<sup>23</sup> The semi-structured interview guide consisted of open-ended questions that aimed at exploring participants' experiences on stroke reintegration in the community. The research questions for stroke survivors and caregivers were developed by the researcher in English using the theoretical framework i.e., categories from the PEOP model, literature and the research questions. The researcher conducted a pilot study using the semi-structured interview schedule on a stroke survivor who met the study criteria. The pilot study aimed to identify any ambiguity in the research questions and to review the interview schedule. Amendments to the interview schedule were made to ensure ease understanding of the questions and the author's interviewing prompts were refined. The interview schedule was translated to Sepedi, which is the participants' home language and back translated to ensure veracity. The interviews were conducted in the stroke survivor's home and were 30 to 60 minutes in duration.

The research questions for rehabilitation staff and the schedule were in English. The interviews took approximately 45 minutes to one hour. All the interviews, which were conducted by the first author after informed consent was given, were audio-recorded.

### **Data analysis**

The variables from the data extraction tool were given codes, which the researcher entered into a Microsoft Excel 2013 spreadsheet. Descriptive statistical analysis was conducted on the file audit data. The mean was used to present the data. The data were represented by means of the bar charts.

The data from the interviews were translated from Sepedi to English and back to Sepedi to ensure veracity of the data. The English transcribed data were, thereafter, analysed thematically using Braun & Clark's<sup>30</sup> six phases thematic data analysis method. Codes, categories and themes were then identified for reporting results.

The quantitative data from the file audit were merged with the qualitative data from the semi-structured interviews.

### **Reliability and validity**

Reliability in this study was ensured by consistently using one data extraction tool in extracting data from all the files which were audited without changing variables. All the files yielded the same results without diverging from the data extraction tool.

Content validity in this study was ensured by designing a tool which encompassed all aspects of stroke rehabilitation and involving two experts in the field of stroke in designing data extraction tool. This increased the validity of the study. The tool was piloted to ensure that the tool extracted relevant data and similar data fields could be extracted from all the files.

### **1 Trustworthiness**

Credibility of the study was ensured by using purposive sampling method whereby stroke survivors, caregivers and the rehabilitation team were known to the researcher, had knowledge on stroke rehabilitation, shown willingness to participate and fitted the criteria for the study. Additionally, verbatim quotes were used to represent the participants' voices and the researcher did member checking after each interview through checking with the participants if the main points captured were true representation of their views. Dependability was ensured by means of an audit throughout the research process by the other two authors of the study. To ensure confirmability, the first author used an audit trail, and the transcribed data were reported using verbatim quotes. Data were also triangulated by integrating the two data sets from phase one and phase two to strengthen the study results. Transferability in this study is not well established since the results cannot be applied to any setting because the experiences vary in different contexts.

### **10 Ethical considerations**

The researcher obtained ethical clearance from the University Biomedical Research Ethics Committee (BREC/00004146/2022) and Limpopo National Health Research Database (LP-2022-09-022) before commencing with data collection. Gatekeeper permission was received from the district level hospital head of institution, three tribal authorities in MLM and ward councillors within the wards where participants resided. Participation in the study was voluntary and written consent was obtained from all the participants. Information on benefits, risks and the right to withdraw from the study was given to all participants to make an informed decision to participate. The interviews were conducted in a comfortable space to minimise harm. Privacy and confidentiality were maintained throughout the study by allocating numbers to each transcript rather than names to ensure that the transcripts were anonymised.

## Results

### **Demographic profile of stroke survivors (n=15)**

Stroke survivors who participated in this study comprised 67% (n=10) females and 33% (n=5) males. Participants had a diverse age range with 7% (n=1) between the ages of 20-39 years, 33% (n=5) between ages of 40-59 years, 47% (n=7) between the ages of 60-79 years and 13% (n=2) of participants were between the ages of 80-99 years during the time of stroke. Only 7% (n=1) of participants were still employed post stroke, 40% (n=6) were on disability grant and 53% (n=8) were on old age pension. The majority of the participants (53%; n=8) had secondary education while 27% (n=4) had primary education and 20% (n=3) of participants had no formal education. The majority of the participants (67%; n=10) had survived their stroke in 2019 while 33% (n=5) survived stroke in 2018. Eighty percent (n=12) had experienced only one stroke and 20% (n=3) had experienced two strokes. Most of the participants (60%; n=9) had a right-side hemiplegia and 40% (n=6) had a left side hemiplegia. Most of the participants (86%; n=13) were residing with their immediate families while 7% (n=1) resided with their extended families. In some households 7% (n=1) resided with the external caregiver.

### **Co-Morbidities**

The participants indicated that hypertension (HPT) was the predominant co-morbidity with 40% (n=6) of participants diagnosed with hypertension (HPT). Several participants had varying two co-morbidities, these included 20% (n=3) having diabetes mellitus (DM) and HPT, 13% (n=2) having HIV and HPT, 13% (n=2) had osteoarthritis (OA) and HPT, 7% (n=1) had HPT and cardiac diseases. Only one participant (7%; n=1) had no co-morbidities



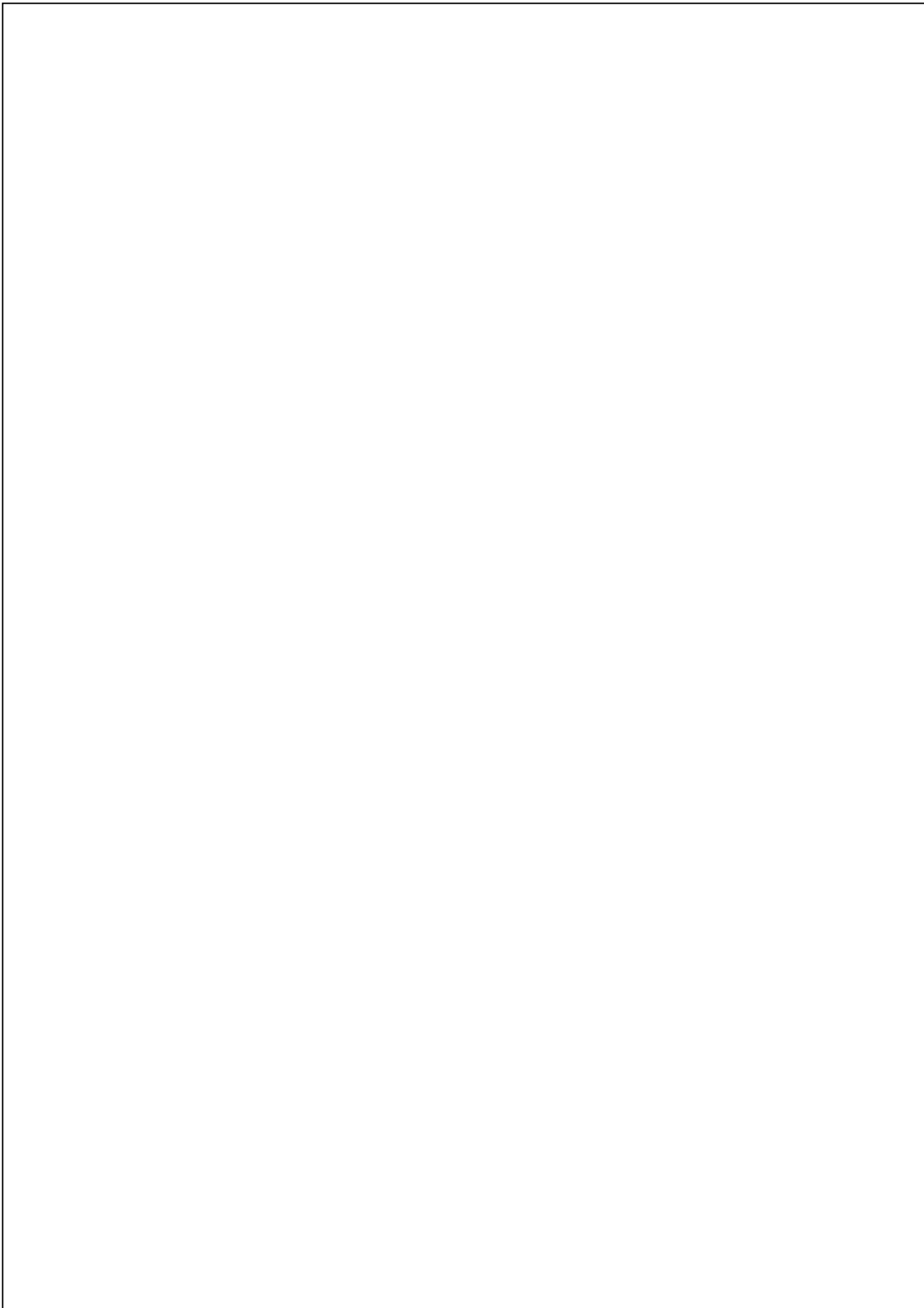
Hospital duration	3	2	1	1	1	6	1	1	5	6	1	4	2	1	1	2	3	6
Weeks	1	1	1	1	1	1	1	1	2	2	1	1	1	1	1	1	1	1
Number of strokes	1	1	1	1	1	1	1	1	2	2	1	1	1	1	1	1	1	1
<b>Side affected</b>	L	R	R	L	R	R	R	R	R	R	L	R	L	L	R	R	R	R
<b>Caregivers</b>	Ext	Imm	Imm	EC	Imm	Imm	Imm	Imm	Imm	Imm	Imm	Imm	Imm	Imm	Imm	Imm	Imm	Imm
<b>In-hospital rehabilitation</b>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<b>Community rehabilitation</b>	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y
<b>Assistive devices</b>	W/C	Cru	W/C	Cru	W/C& W/F	Cru	Cru	W/C	W/C	Cru	Quard ripot	Cru	None	Cru	Cru	W/F	W/C	

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**Key.**

**F- Female, M-Male, Yes- Y, No- N, P- Pensioner, DG- Disability grant, E-Employed , Pri- Primary, Sec- Secondary L- Left, R- Right Imm- Immediate family members, Ext-extended family members, EC-External caregiver, W/C- Wheelchair, Cru-Crutch, W/F- Walking frame**

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**Table 4. The Rehabilitation Team Profile (n=3)**

<b>Variable</b>	<b>P1</b>	<b>P2</b>	<b>P3</b>
<b>Gender</b>	Male	Male	Female
<b>Profession</b>	Physiotherapist	Dietician	Occupational Therapy Technician
<b>Registered with the Health Professions Council of South Africa (HPCSA)</b>	Yes	Yes	Yes
<b>Provided stroke rehabilitation from 2018 to 2019</b>	Yes	Yes	Yes
<b>Years of Experience in stroke rehabilitation</b>	Eight	Seven	Twelve

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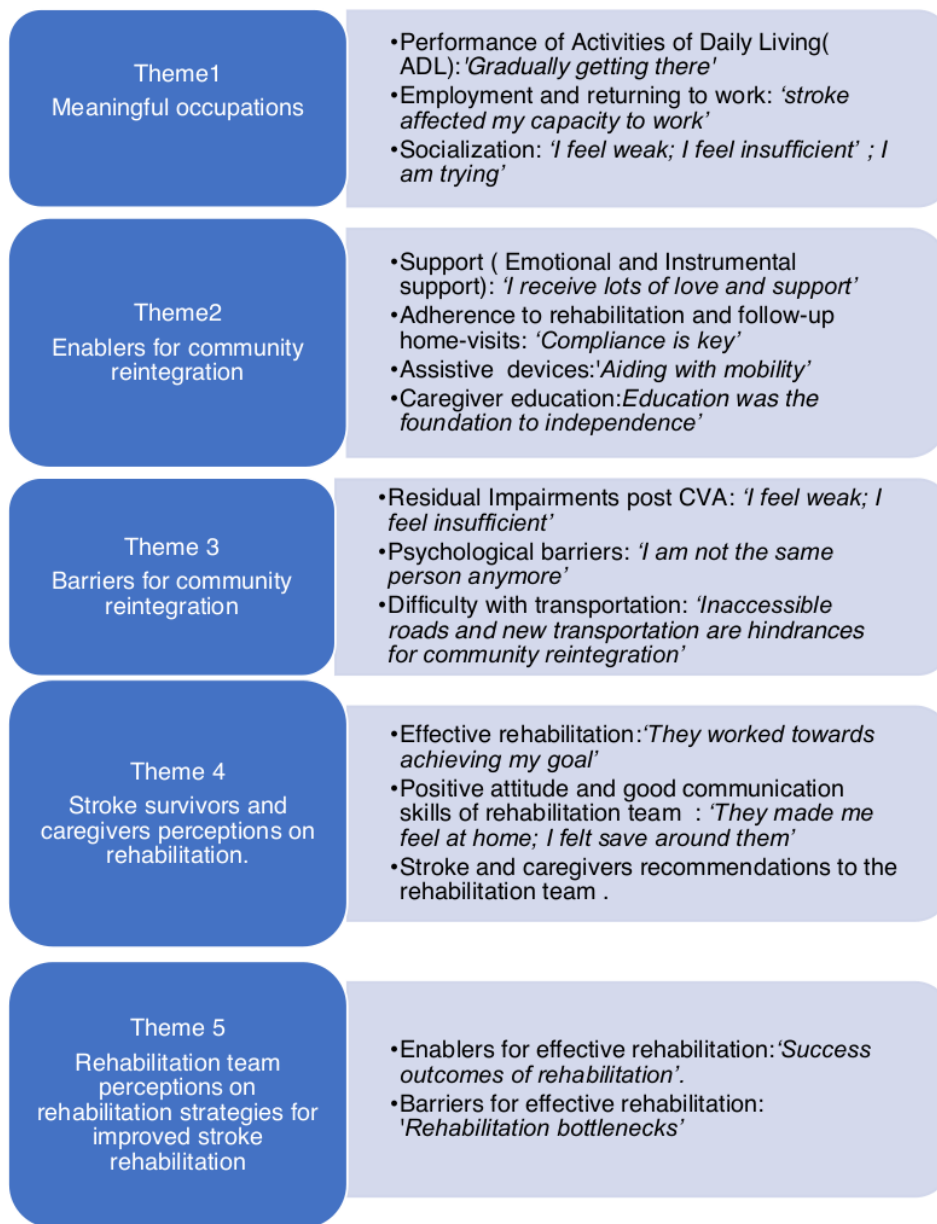


Figure 3: Themes and Sub-themes

Theme 1: Meaningful occupations

**Sub-Theme 1: Performance of activities of daily living (ADL): *'Gradually getting there.'***

Most of the participants received intervention for balance and activities of daily living (ADL). Sitting and standing balance (SB & STB), ADL and mobility retraining (MoR) were the activities introduced to 40% (n=6) of the participants. Sitting balance (SB) and ADL were retrained with 13% (n=2) of the participants. Standing balance (STB), mobility retraining (MoR) and ADL were retrained with 13% (n=2) of the participants. Seven percent (n=1) of the participants had facial and hand functioning exercises, 7% (n=1) received rehabilitation for standing balance and mobility retraining. Orientation (OR), facial exercises (FE), sitting balance (SB) and ADL interventions were the focus for 7% (n=1) of the participants.

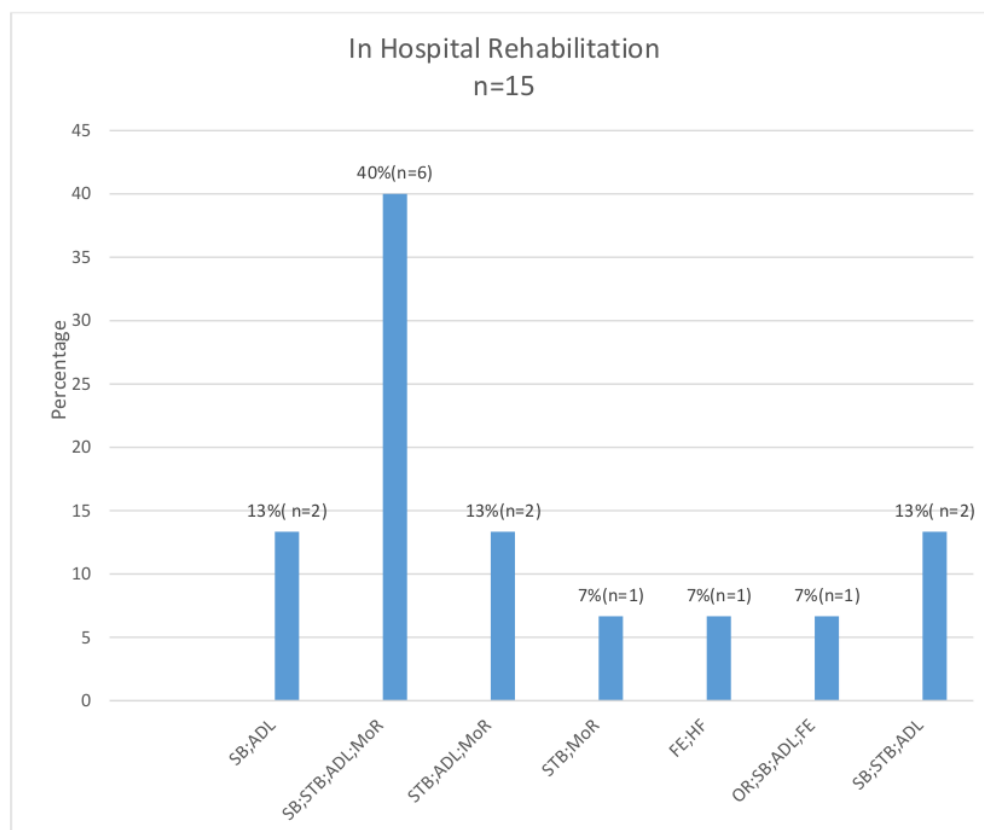


Figure 4: In-hospital rehabilitation

Most of the stroke survivors reported that they could participate in basic and instrumental ADL independently; a few stroke survivors still had difficulties performing ADL and were extremely dependent on their caregivers. Some stroke survivors developed adapted ways of participating in ADLs or used assistive devices to engage maximally in ADLs.

An excerpt from a survivor

*I pour water in the kettle and prepare myself some breakfast. After having some breakfast, I wash some dishes, clean the house... I also cook for my family'. (Interview-Stroke survivor P5).*

*'...I have come up with the techniques to cook and do other chores. When I cook, I only use the back plates to prevent the pot from tipping and I stir from front to back to prevent spillages.' (Interview- Stroke survivor P10)*

*'We assist her to wake from her mattress, bath her, dress her, carry her into and out of her wheelchair, turn her put her to bed. She can't do much on her own because her arm is no longer working. She cannot even sit without support'. (Interview, Caregiver-P3)*

**Sub-theme 2: Employment and returning to work: 'stroke affected my capacity to work.'**

Only 7% (n=1) of participants returned to their previous work after stroke, 40% (n=6) of the participants were unemployed, on disability grants and 53% (n=8) were receiving old age pension. The stroke survivors reported to have lost the capacity to work following the stroke and had not reintegrated into the community due to loss of income. The majority of the participants depended on government grant and no longer participated in their previous work.

*'I could say that the stroke affected my work, work is the main occupation to me, stroke deeply affected me and how I take care of my children. (Interview- Stroke survivor P9)*

*I used to fetch firewood from the bushes with a wheelbarrow and sell it to the community members' '... make traditional beer and sell it. I am unable to do ...work now (Interview-Stroke survivor P1).*

*I used to work for myself... I was building houses; installing fiber; painting and making Mag wheels. Being a laborer has taught me many jobs but now I can't even do one. (Interview-Stroke survivor P10).*

**Sub-theme 3: Socialisation: 'I feel that I do not belong anymore; I am trying.'**

Some stroke survivors expressed interaction with other community members as meaningful to them and engaged in community gatherings such as social clubs and tribal meetings. Some stroke survivors lacked social participation due to their insecurities and discomfort of being around other people.

*...At times I do not have confidence to go and attend those (tribal) meetings because I feel that people have a different opinion about me since my stroke'. '...some (community members) are distant, and they feel that I am no longer within their league after this*

*stroke. They no longer take a few minutes to talk to me like they used to, they just greet me in passing. (Interview- Stroke survivor P13).*

*It hasn't been bad after the stroke because I was not that noticeable, and I tried by all means to interact with people to avoid loneliness. (Interview- Stroke survivor P11).*

## **Theme 2: Enablers for community reintegration**

### **Sub-theme 1: Support (Emotional and instrumental support): 'I receive lots of love and support.'**

The majority of the participants - 86% (n=13), were staying with their immediate families and 7% (n=1) were staying with their extended families while 7% (n=1) were staying with an external caregiver. Stroke survivors reported to have received support mostly from their immediate family members while other stroke survivors received support from the community members. The support received aided in reintegrating the stroke survivor into the community and with their recovery to some extent. The following remarks of the way survivors felt and their experiences:

*Yes, my mom, she came and stayed with us to assist me with cleaning, laundry, cooking so that my husband gets some relief...' (Interview- Stroke survivor P6)*

*My sister played a very big role because she is the one who built this house and made sure that I was comfortable'. (Interview- Stroke survivor P5)*

*...My neighbour offered to drive me around with that (my daughter's) car... They (neighbours) used to take turns to assist with my exercises. (Interview- Stroke survivor P7).*

### **Sub-Theme 2: Adherence to rehabilitation and follow-up home visits: 'Compliance is key.'**

The majority of the stroke survivors and caregivers reported to have had follow-up home visits from the rehabilitation team except for a few who reported to have not received follow-up home visits post discharge as shown in figure 5. Follow-up home visits were reported to have positively impacted on stroke survivors' reintegration into the community.

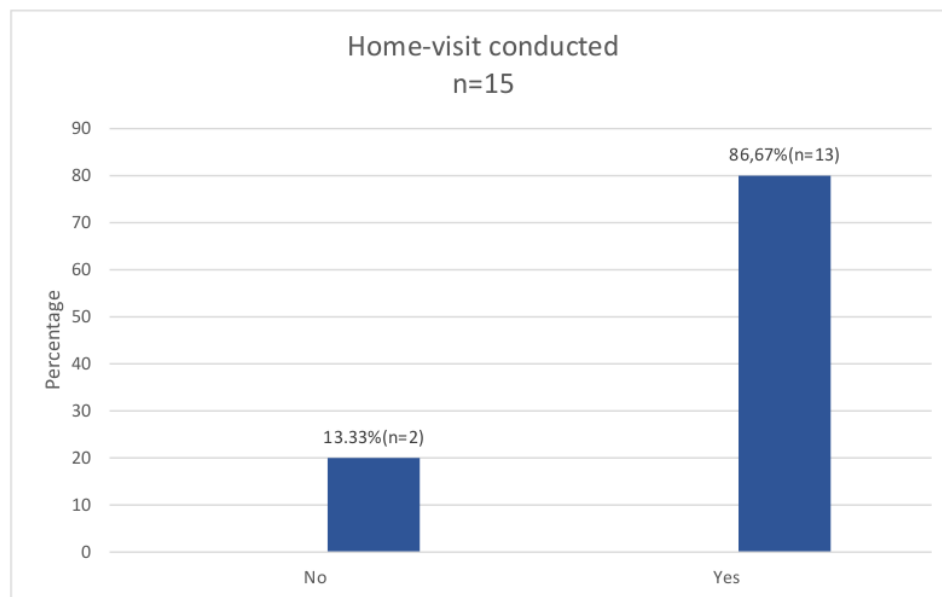


Figure 5. Home Visits Conducted.

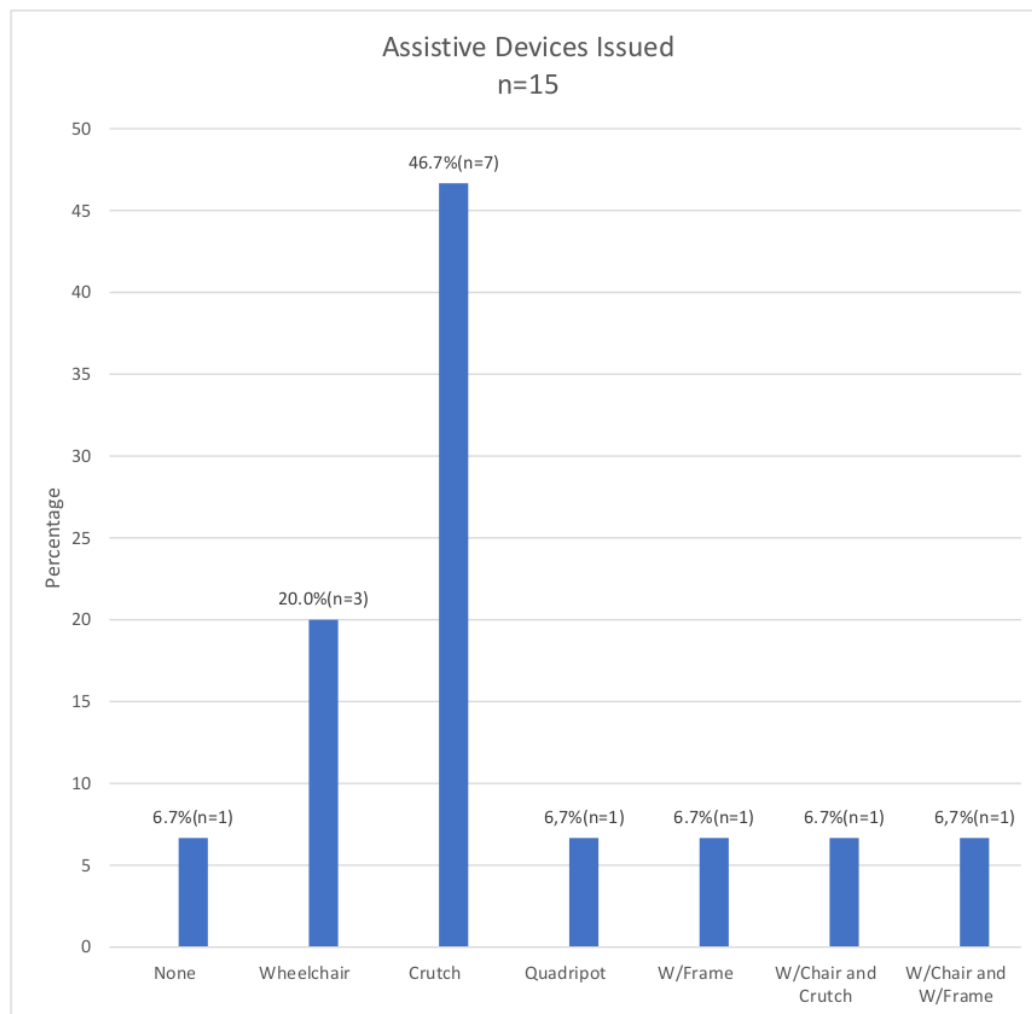
Trust in the rehabilitation team and the participant's personal motivation aided in adherence to rehabilitation as expressed by some stroke survivors. Rehabilitation team home visits yielded positive results in mobility retraining.

*...I was very much compliant to the exercises they gave me at the hospital' ...therapy assisted me a lot and I trusted you because you knew better, so I had to comply to reach recovery. (Interview- Stroke survivor P6).*

*They (rehabilitation people) have done enough for me. They came here several times until I was able to use this crutch. (Interview- Stroke survivor P4)*

**Sub-Theme 3: Assistive devices 'Aiding with mobility.'**

Assistive devices allocated to stroke survivors were reported as enablers for community reintegration as they assisted with mobility within home and the community.



*Figure 6. Assistive devices issued*

A collective of 93.3% (n=14) participants were issued assistive devices and 6.7% (n=1) of participants were not issued any device as they were able to mobilise without support. Figure 6 was validated by the participants during the interview.

*I used to have a walking frame, they exchanged it for a quadripod and after I got better, they exchanged the quadripod for a crutch... (Interview- Stroke survivor P12).*

*During their (rehabilitation team) first visit they brought me a wheelchair and they came again to check my progress. They assessed my ability to stand and I was still finding it difficult to stand. During their next visit, they brought me a walking frame to assist me with walking. (Interview- Stroke survivor P5).*

#### **Sub-Theme 4: Caregiver Education: ‘Education was the foundation to independence.’**

Caregiver education assisted caregivers and stroke survivors to understand about stroke, home programmes and enabled the stroke survivor to learn alternative methods to participate in meaningful occupations.

*What I liked the most is how therapy people spoke to us about stroke. They gave us education and we were satisfied and felt no need to seek the second opinion. (Interview- Stroke survivor P3).*

*I liked the fact that they taught me to do all the activities of daily living, how to do them and taught me alternatives to go about doing some activities. They even taught me to walk again at therapy...We did all the exercises and trained him to stand and walk as you had directed (said the caregiver). Guys, I was very sick and you assisted me a lot. (Interview- Stroke survivor P7)*

### Theme 3: Barriers for community reintegration

#### **Sub-theme 1: Residual Impairments post CVA: ‘I feel weak; I feel insufficient.’**

Stroke survivors reported residual impairments such as weakness, fatigue, pain, inability to use the affected limbs as barriers that affected their participation in meaningful occupations such as fetching water. Memory challenges led to irritability and lack of functioning as reported by the caregivers. Speech difficulties were also barriers for socialisation within the family and in the community.

*Pushing the wheelbarrow to fetch some water is very, very difficult for me because it needs two hands and the other hand is still weak to push the wheelbarrow. (Interview- Stroke survivor P11).*

*Sometimes I feel that I am not audible enough to submit my opinion because this stroke has affected my speech... (Interview- Stroke survivor P13).*

*...He forgets things and becomes irritable easily. (Interview-Caregiver P7)*

#### **Sub-theme 2: Psychological barriers: ‘I am not the same person anymore.’**

Psychological barriers such as low mood, low self-esteem, lack of insight into stroke and lack of motivation were some of the sequelae experienced by participants. The loss of their previous roles and their low self-esteem contributed toward low mood and a lack of motivation to engage in occupations, to socialise and to venture into the community. Some participants felt rejected as the family members believed that they were bewitched. The psychological barriers resulted in lack of adherence to the home-programmes which hindered rehabilitation progress and that impacted negatively on activity participation.

*I also used to sweep, cook and do laundry before the stroke now I am very miserable on my wheelchair and often wish I could help out with chores such as dishes. (Interview-Stroke survivor P3).*

*Feeling rejected:*

*I do go to the family meetings but my ideas are not valuable to them and I feel rejected by them'... They (close relatives) believe that I was not attacked by stroke but I was bewitched... (Interview- Stroke survivor P12).*

*Losing one's will to engage:*

*I constantly ask myself why I am like this. My motivation has even decreased; I am no longer eager to initiate some activities at home... This stroke has affected my mind a lot. (Interview- Stroke survivor P13).*

Some caregivers reported that they feel burdened by taking care of the stroke survivors. They expressed feelings of irritability and inability to cope when caring for the stroke survivors.

Being unprepared for the added responsibility:

*...my sister and I are drained by taking care of him and we will discuss the issue of taking him to the care home with his children because they do not feel a burden that we are feeling at all, they seldom come home. (Interview- Caregiver, P1)*

### **Sub-Theme 3: Difficulty with Transportation: *'Inaccessible roads and new transportation are hindrances for community reintegration.'***

Inaccessible roads were reported as a barrier by some stroke survivors. Stroke survivors reported that uneven roads made it difficult for them to exercise or travel within the community. Some stroke survivors and caregivers reported using new methods of transportation post stroke, for example, hiring a private transport to run their errands due to residual impairments such as weakness, fatigue, pain and

their inability to cope with stigma. New methods were financially burdening as most of them depended on disability and old age grant.

*...The roads here are not that user friendly because they are not even. I once went to some lady who is staying around here and it took me long to reach her place due to the slopes that I had to go through. I never went back there... I always have to hire a car to take me to the clinic and hospital... Going to the hospital costs R200 and going to the clinic costs R100 which is expensive for us because we use social grant to pay. (Interview- Stroke survivor P8)*

Theme 4: Stroke survivors and caregivers' perceptions on rehabilitation intervention

**Sub-theme 1: Effective rehabilitation: 'They worked towards achieving my goal.'**

Stroke survivors and caregivers described rehabilitation intervention as effective and worked towards improving their ability to mobilise and participate in ADLs as evidenced by the quotes below:

*They did exercises, shoulder therapy, holding cups, dressing, and trained me to be able to stand and walk... (Interview- Stroke survivor P7).*

*Yes, they taught me how to sit from lying, bathing, dressing, and now I am able to turn, relief pressure and turn. (Interview- Stroke survivor P15).*

**Sub-Theme 2: Positive attitude and good communication skills of rehabilitation team: 'They made me feel at home; I felt safe around them.'**

Most of the stroke survivors and caregivers viewed the positive attitude and good communication skills of rehabilitation team as enablers that drove their motivation to adhere to rehabilitation and effectively reintegrate into the community. They felt safe, loved and encouraged to participate in therapy.

*The way therapy people treated me was outstanding. They have positive attitude towards their clients. I didn't wait for a long time to get treated and I liked their attitude towards me....I also like the way they carry themselves,....They speak in a polite manner to people... (Interview- Stroke survivor P13)*

**Sub-Theme 3: Stroke survivors and caregivers' recommendations to the rehabilitation team.**

Stroke survivors and caregivers expressed the need for regular home visits for continued support and relieving caregiver burden. They recommended special visits to assist with self-care activities.

*...I think coming here twice a month will be more beneficial and the stiffness will be reduced a bit. (Interview- Caregiver, P1).*

*.... I also would like therapy people to send someone at times to bath her so that we take a break'. (Interview- Caregiver, P 3).*

Due to non-adherence to the home programme, some stroke survivors had deteriorated and recommended that the rehabilitation team re-initiate the rehabilitation programme so that they can optimally participate in daily activities.

*... I started deteriorating after coming back at home...I would like you to train me again, I would also like you to help with my tongue and mouth. (Interview- Stroke survivor P8).*

The need for assistive devices to relief fatigue and assist with mobility was also highlighted by some stroke survivors.

*...Sometimes I feel that I still need the crutches because at times I just wake up with a numb lower limb and I am unable to walk. So, during those days I really need it to balance myself...' (Interview- Stroke survivor P6).*

Stroke survivors support groups in the community was recommended by some stroke survivors to aid with coping strategies.

*I feel that there is a need for a support group where people with stroke can gather or do walks to improve their progresses. (Interview- Stroke survivor P13).*

Some stroke survivors expressed that hospital therapy area was not sufficient for effective rehabilitation and recommended that a large rehabilitation area would be more effective to implement rehabilitation strategies.

*If you can be provided with a huge space to do your exercises especially to train those who are at early stages of recovery. When you provide therapy, you should not bump against the walls or other things in your treatment area. You don't really have enough space to work in your therapy area... (Interview- Stroke survivor P6).*

Caregiver education was also highlighted as crucial to effective rehabilitation by some participants above all the therapy that is provided by the rehabilitation team.

*One thing that I would like therapy personnel to keep doing is to keep explaining the condition to the patients and do counselling before starting with exercises.... (Interview- Stroke survivor P12).*

Theme 5: Rehabilitation team views on rehabilitation strategies for improved stroke rehabilitation

**Sub-Theme 1: Enablers for effective rehabilitation: 'Success outcomes of rehabilitation.'**

The rehabilitation team voiced success outcomes of stroke rehabilitation strategies that are implemented for stroke rehabilitation despite the challenges relating to staff shortage, inadequate equipment and poor infrastructure. Determination cultivated the success outcomes such as the ability to mobilise, use of limbs, caregiver education and community reintegration.

Gradually seeing rehabilitation success outcomes:

*I was very happy with the patients who were able to use both upper and lower limbs and I am very happy about the success. Being able to climb the stairs, mobilising, even though they are still having minor disabilities. (Interview-Rehabilitation team P1).*

*They (stroke survivors) initially can't do any activities; they can't chew but after some time with rehabilitation you will see them progressing. (Interview-Rehabilitation team P2).*

**Sub- Theme 2: Barriers for effective rehabilitation: 'Rehabilitation bottlenecks.'**

The rehabilitation team reported delays in referrals, at times, for initiation of rehabilitation which delayed the rehabilitation process. Referrals depended on referrer knowledge on stroke rehabilitation. Limited hospital stay was also reported as a barrier as the restricted time as an in-patient reduced the time that could be used to implement the rehabilitation process. The above information corroborated with the file audit report as illustrated in figure 7. High number of stroke survivors spent a week at the hospital, allowing the rehabilitation team less time to implement rehabilitation process.

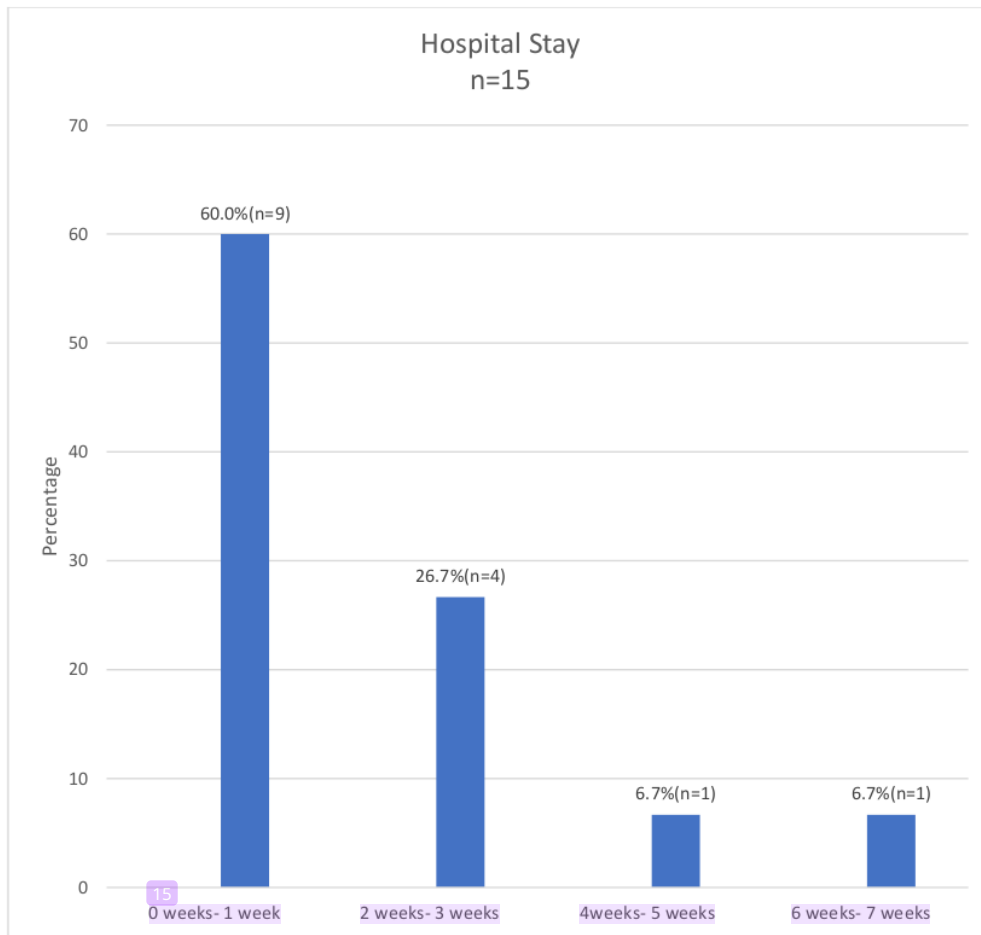


Figure 7. Hospital stay (n=15)

*Sometimes we get the referrals quickly and sometimes there are delays with referrals, which delay the initiation of the rehabilitation processes. (Interview –Rehabilitation team P3)*

*It just depends on who is managing the referrals at the given time, based on the knowledge of stroke and if they understand the role of the rehabilitation team... Looking at the level of our hospital, hospital stay is not enough. Some patients are not having the care they need from the caregivers. We want the patient to be able to do most of the basic staff before discharge so that they can assist themselves even if they are staying alone. (Interview- Rehabilitation team P1)*

Poor infrastructure, lack of equipment, and insufficient staff were reported as barriers for effective stroke rehabilitation. Poor infrastructure denied stroke survivors privacy during rehabilitation and

having limited rehabilitation staff limited the staffs' ability to complete regular home visits for stroke survivors post discharge.

*We need privacy (there are not enough screens) when working with the patients as they feel uncomfortable because of other patients staring ... We also do not have enough staff. At times you find that the hospital is operating with only one therapist who has to do in hospital and outreach services.* (Interview- Rehabilitation team P3).

Food supplements were reported to be adequate for providing stroke survivors in need, although some participants raised assistive devices backlog as a barrier that hindered effective rehabilitation.

*There are backlog challenges... We wait for a long time for suppliers to deliver assistive devices.* (Interview-Rehabilitation team P1).

Despite rehabilitation strategies (both in-hospital and community) being implemented, effective reintegration depended on stroke survivor and caregiver compliance to home programme post discharge. Non-compliance to home programme was also reported by some participants as a barrier for effective rehabilitation.

Progress depends on compliance:

*Sometimes home program is effective and at times not, depending on the family engagement. Some caregivers comply and others don't.* (Interview- Rehabilitation P3).

The lack of a dedicated rehabilitation centre and difficulty locating houses of stroke survivors for continued support in the community was reported as a barrier for effective community reintegration. Rehabilitation centre would assist in continued support post discharge.

*If we could have a rehabilitation centre so that we can refer our stroke survivors and they occupy themselves therapeutically unlike sitting at home doing nothing.* (Interview- Rehabilitation team P3).

## Discussion

This study was aimed at understanding factors affecting community reintegration of MLM stroke survivors to generate strategies for improved community reintegration post-stroke. Five themes that were identified in the study included stroke survivors' meaningful occupations, enablers for community reintegration, barriers for community reintegration, stroke survivors and caregivers' perceptions on rehabilitation and the rehabilitation team's perceptions on rehabilitation strategies for improved stroke rehabilitation. The study resonated with literature indicating that community reintegration varies from area to area, depending on rehabilitation strategies such as policies, resources and demographics of the specific population<sup>31, 14, 32</sup>. In the paragraphs below, the findings of the study will be discussed.

This study revealed occupations that MLM stroke survivors find meaningful and how they engage in those activities post-stroke. Participants in this study highlighted basic activities such as self-care, care of immediate environment, meal preparation, mobility, care of the loved ones (children, grand-children, siblings, partners and parents), attending community gatherings and work as occupations which are meaningful to them. Some participants' remunerative work included collecting firewood, making traditional beer and selling vegetables. The Limpopo study by Maleka et al.<sup>6</sup> similarly revealed that some stroke survivors lost the ability to perform occupations such as collecting firewood which affected their livelihood. The inability to go back to work post stroke led to feelings of depression since most of the participants were the breadwinners. Similarly, to other South African studies findings, only one participant in this study was able to go back to work post-stroke<sup>32, 15</sup>.

Residual impairments such as weakness, fatigue, pain, inability to use the affected limbs, memory loss and speech difficulties limited participants' performance of meaningful occupations. Correspondingly, Jørgensen et al., Wolf et al., Chimatiro & Rhoda, Mamabolo et al. and Hall et al.)<sup>33, 34, 32, 35, 36</sup> found that most stroke survivors have decreased ability to perform meaningful occupations due to residual impairments. Some stroke survivors required maximum assistance from their caregivers and others developed new ways of participating in previous occupations. Stroke survivors that required maximum assistance required a full-time caregiver which at some instances led to caregiver burden. Caregiver burden was also identified across the studies of Muthucamarana et al., Kusambisa-Kiingi et al. and Ntsiea<sup>11, 16, 15</sup> as a barrier to reintegration.

Some stroke survivors experienced memory loss which led to their irritability. Irritability might affect family relations and lead to decreased motivation to support the stroke survivor emotionally or with participation of ADLs. Participants revealed that regular therapy sessions, such as an out-patient rehabilitation or home visit, led to the stroke survivors improving gradually and finding ways to cope with some occupations, which decreased tension in the home.

In terms of socialisation, some stroke survivors were socially integrated, however the study highlighted feelings of fatigue, insecurities and discomfort around other community members as barriers to social

participation. They even succumbed to financial strain of hiring expensive transport to do shopping, accessing medical services and attending community gatherings. In some cases, stroke survivors felt isolated due to some community members viewing stroke as a spell rather than a medical condition. This was an indication of the lack of insight into stroke by caregivers, stroke survivors and the community.

There were those stroke survivors who felt that community members rejected and devalued them post-stroke, especially as their appearance and abilities had changed. This led to their isolation rather than being accepted in participating in community activities. Similarly, both international studies of Magwood et al. and Nanninga et al.<sup>37,38</sup> and South African (SA) studies of Cawood & Visagie<sup>22</sup> revealed that lack of social support and insight into stroke by some community members can be a barrier for community reintegration. Some participants reported that some of the community roads were in poor condition and difficult to use which contributed to the stroke survivors being unable to leave their home, thereby resulting in further isolation and inability to improve in mobility<sup>6, 24, 22</sup>.

Adherence to rehabilitation, home visits, assistive devices, caregiver education and emotional support received from the caregivers, extended families and community members were the enablers for community reintegration identified in the study. Emotional support assisted in raising the mood and motivation to participate in meaningful occupation and socialisation. Elloker & Rhoda and Govender et al.<sup>4,9</sup> also revealed social support and participation as enablers for participation in leisure activities and work. Environmental support such as ramps, having nearby toilets and adding more stairs to improve mobility was also evident in this study and provided stroke survivors with comfort and a sense of being accepted in the family.

The rehabilitation team home visits enabled continuity of therapy to ensure proper reintegration and created support throughout rehabilitation process. However, inability to locate some houses when conducting home visits and lack of stroke survivor support groups in the community were reported as barriers and impacted on continuity of support to other stroke survivors. Positive attitudes of the rehabilitation team elevated the moods of stroke survivors and aided in adherence to rehabilitation, however, the rehabilitation team revealed that some stroke survivors did not adhere to given rehabilitation strategies. Non-adherence to treatment impacted negatively on their functioning, hence, some participants requested for re-initiation of rehabilitation to improve their functional abilities.

The study highlighted that barrier for community reintegration included residual impairments post stroke, psychological barriers and difficulty with transportation. Having lost the ability to participate in meaningful occupations independently, some stroke survivors developed emotional sequelae, feelings of low self-esteem and low mood that led to them feeling demotivated to participate in occupations. Due to emotional sequelae, low mood and lack of motivation, some stroke survivors had deteriorated in functioning and felt the need to re-initiate therapy to be able to be independent again in some areas

of self-care and use of the affected limbs. Stroke survivors may suffer sequelae that can affect their self-concept and hinder their ability for social role functioning<sup>39</sup>. Similarly, Elloker et al., Lewis et al. and Govender et al.<sup>31, 3,9</sup> reported that altered mood state negatively impacted on community reintegration.

Stroke survivors and caregivers viewed rehabilitation services as effective to community reintegration. The ability to do self-care activities, being able to use the affected limbs and getting to mobilize again were achievements to most stroke survivors and caregivers, however they felt the need for more regular home visits for caregiver relief. A lack assistive devices affected mobility for some stroke survivors who reported to have residual impairments such as fatigue though they were able to mobilize on their own. Due to financial constraints the Limpopo department of health is facing, some assistive devices as soon as the stroke survivors can mobilize are repossessed to be allocated to other clients who need them the most.

Although Department of Health<sup>40</sup> indicated that provision of rehabilitation at community level is core to community reintegration, this study revealed that there are limited community structures aiming at community reintegration. Home visits conducted by the rehabilitation team are the only support provided to stroke survivors in the community. Support groups for stroke survivors and caregivers were deemed beneficial to community participation by the stroke survivors as they might reduce caregiver burden, improve education and motivate stroke survivors. Naidoo et al.<sup>24</sup> study suggested that services for stroke survivors are required at a primary healthcare level. Furthermore, rehabilitation team voiced limited or lack of a rehabilitation centre as a barrier for community reintegration as stroke survivors are discharged home before they are fully functional. Rouillard et al., Magwood et al. and Cawood & Visagie<sup>12, 37, 25</sup> affirmed that support like targeted community programs can improve level of participation such as community mobility.

The delay of some referrals in the hospital was reported as a barrier for initiating rehabilitation. Referrals depended on referrer knowledge on stroke rehabilitation and stroke survivors who were referred later had limited time for rehabilitation. It was evident that some multi-disciplinary team members were not well conversant with stroke guidelines of Bryer et al.<sup>41</sup> for promotion of early intervention and preventing further complications. Short hospital stay was reported as a barrier to stroke rehabilitation by the rehabilitation team as they had limited time to implement intervention strategies and prepare stroke survivors for discharge. Studies conducted by the SA authors revealed that late referrals, (Visagie & Swartz)<sup>20</sup> and limited length of stay (Govender et al. and Ntsiea)<sup>9,15</sup> in the hospital leads to less favourable functional outcomes to acute stroke survivors discharged from the hospital without receiving rehabilitation from the trained rehabilitation team<sup>42</sup>. However, some stroke survivors and the rehabilitation team identified hospital rehabilitation area as insufficient for proper rehabilitation. The limited acute rehabilitation service was further compounded by lack of referral to the clinic or outpatients where the stroke survivor could receive further services thus limiting continuity of care.

National Framework and Strategy for Disability and Rehabilitation<sup>43</sup> also highlighted some of the factors that hinders rehabilitation services as lack of coordination between service levels.

Insufficient budget to purchase assistive devices such as wheelchairs, crutches, walking frames and ADL equipment was reported as a barrier by the rehabilitation team. The lack of provision of assistive devices impacted on stroke survivors' ability to function in the community. This study yielded the same results as the SA studies conducted in Kwa-Zulu Natal and Northern Cape which revealed that a lack of resources such as assistive devices act as a barrier for community reintegration<sup>24,20</sup>. A lack of human resources was also reported by the rehabilitation team as a barrier and contributed to poor implementation of community rehabilitation. This is despite the emphasis in the National Framework and Strategy for Disability and Rehabilitation that emphasis on the need for rehabilitation to be at a primary healthcare level<sup>43</sup>.

## Conclusion

Stroke burden is increasing by the day and there are still gaps that are yet to be filled in terms of stroke reintegration in the LP. The study identified gaps such as partial implementation of the national rehabilitation policy, limited length of stay, improper rehabilitation facilities, insufficient budget allocated for rehabilitation services, inadequate number of rehabilitation staff, insufficient assistive devices and lack of implementation of stroke rehabilitation at a primary health care level. The study revealed that limited hospital stay reduces stroke survivor basic independence and care-giver training prior to discharge. Early intervention and continued community interventions strengthen the stroke survivor's capacity to reintegrate into the community. Inadequate rehabilitation facilities for in and outpatients' rehabilitation limits the implementation of modalities for stroke interventions. Furthermore, there are no coordinated referrals for the community-based intervention due to unavailability of community-based rehabilitation workers.

This study has found that the biggest impact faced by the stroke survivors is in the area of work, followed by socialisation and the least affected were BADLs and IADLs. The study also revealed that support from the rehabilitation team, family members and the community at large play a huge role in community reintegration. Continued support to the stroke survivors and caregivers through support groups in the community is needed to aim at insight stimulation, caregiver relief and social participation.

To overcome barriers such as unemployment post-stroke, the findings of this study suggests that in the acute rehabilitation phase, OTs should assess the feasibility to return to previous work or contact employers to look at whether reasonable accommodation can be made. In preparation for return to work, the stroke survivors should be engaged in a routine vocational rehabilitation program that is individually structured to assist the stroke survivors to get used to the work routine. OTs should also initiate vocational training such as entrepreneurial skills and subsistence agriculture in collaboration with other sectors such as the Department of Agriculture to assist the stroke survivors and their caregivers to support their families. Home based carers should also form a part of the vocational training program to assist with support and maintenance of the programme.

In implementing proper community- based rehabilitation to stroke survivors, there is a need for increased human resources to enable proper dissemination of services in the community. Early referrals of stroke survivors in the hospital are critical to allow the rehabilitation team enough time to undertake early intervention for provision of the best holistic stroke care possible. Having sufficient assistive devices, improvement of rehabilitation facilities for in and outpatient hospital care, continued community support for stroke survivors and caregivers and initiation of vocational rehabilitation and training were the key recommendations that emerged from the study.

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