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[RESEARCH ARTICLE]

Environmental facilitators and barriers to community reintegration experienced by stroke survivors in an under-resourced urban metropolitan sub-district

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ABSTRACT

Background: Despite inpatient rehabilitation many stroke survivors struggle with community reintegration on returning home. The environment to which the stroke survivor returns affects and may limit participation in home and community-based activities.
Aim: To describe stroke survivors' lived experiences of the environmental barriers and facilitators to community reintegration in an under resourced urban metropolitan sub-district in the Western Cape, South Africa.
Methods: A descriptive, qualitative study design with a phenomenological emphasis used semi-structured interviews to collect the data from purposefully selected stroke survivors who had been discharged for more than one year following inpatient rehabilitation. Supporting data were collected from interviews with two occupational therapists providing rehabilitation services to the stroke survivors. Deductive priori coding of semi-structured interviews with 11 stroke survivors, based on the environment subsystems described in the Person-Environment-Occupation-Performance (PEOP) model explored the barriers and facilitators to their community reintegration.
Findings: Of the six environmental sub systems in the PEOP model the systems and policy, access to information and health education, social determinants of health in the form of poor rehabilitation planning and loss of income as well as the built and natural environment presented the greatest barriers to the stroke survivor participants' community reintegration. However, reintegration was facilitated by social support and social capital, social determinants of health in the form of support groups as well as assistive technologies.
Conclusion: Community reintegration continues to be a challenge for stroke survivors in an under-resourced urban sub-district due to environmental barriers associated with factors such as poor social support, inadequate implementation of policies and systems, poor compliance with home programmes, low socioeconomic status, poor access within the built and natural environment and inappropriate assistive devices. Several facilitators that occupational therapists can focus on to enable community reintegration included ensuring effective social support, access to community-based organisations, the introduction of home visits and provision of appropriate assistive devices.

Implications for practice
All stroke survivors must receive a comprehensive discharge plan to facilitate adequate access to continued rehabilitation and support for successful community reintegration.

- There must be a specific referral to primary health care rehabilitation services on discharge from hospital.
- Occupational therapists at community level have the responsibility to:

- advocate for, or assist stroke survivors to self-advocate, the removal of inter-sectoral environmental barriers that limit their community reintegration and community participation,
- where possible provide services in the home and involve midlevel workers when conducting home visits to enable successful reintegration into the home and resumption of occupational roles where possible,
- look to other resources in their community that can assist in facilitating the community reintegration of stroke survivors to enable access to health, education, productive activities, and social and leisure participation opportunities,
- improve their collaboration with the communities that they service.

INTRODUCTION

Worldwide, stroke is one of the leading causes of death and disability in adults and continues to increase in prevalence[1,2]. In South Africa, a low-middle-income country, stroke ranks fourth as a leading cause of death[3], with similar trends noted in the Western Cape province[4]. Despite the high mortality rate, medical advancements in stroke management have resulted in more people surviving the acute stage[5]. Thus, more stroke survivors are being discharged home from hospitals[6].

In South Africa, hospital-based admissions post stroke tend to be short (5-14 days)[7] and only a small number of stroke survivors receive intensive in-patient rehabilitation at specialised hospitals such as the Western Cape Rehabilitation Centre (WCRC)[7]. Despite this intensive inpatient rehabilitation most stroke survivors are discharged to their homes and communities still requiring rehabilitation to promote their maximal recovery, which can take a year or more, and to adjust to their disability to ensure their wellbeing[8]. The Western Cape Department of Health requires that stroke survivors be discharged from in-patient rehabilitation only when they achieve an acceptable level of independent functioning to return home but may not yet be able to monitor their own health or manage their finances (Lundrum Level III)[9]. Further community-based rehabilitation should be provided for these patients to achieve community integration[10] (Lundrum Level IV)[9] and if appropriate productive activity (Lundrum Level V)[9,11,12].

These community re-integration rehabilitation programmes offer interventions which support the re-establishment of age, gender and culturally appropriate pre-morbid roles and activities wherever possible in the home, family and community[13]. Facilitating community reintegration is an internationally accepted occupational therapy outcome for stroke survivors[14]. Thus, at the community level occupational therapists play a key role in facilitating the community re-integration process consistent with the holistic, person-centred and occupation-based philosophy of the profession and its view that the nature and extent of occupational engagement contributes to health and wellness[14,15]. Additionally, services offered in the community are more cost-effective than in a hospital or clinic and ultimately reduce the fiscal demands on the health system[16].

Research has found that personal factors and stroke outcomes are associated with successful community reintegration for most stroke survivors. These include being younger, having greater motor function and functional independence as well as a longer duration since the stroke[17]. These findings concurred with a Nigerian study where an inability to work, perform domestic activities and participate in recreation and leisure time impacted stroke survivors community reintegration[18]. Graves et al.[19] and Honado et al.[20] confirmed these findings but indicated self-efficacy and motivation were also strongly associated with successful reintegration into the community, even for those with mild stroke[19]. Comorbidities such as diabetes mellitus, impaired cognition and depression were reported as barriers to community reintergration[17].

Environments to which stroke survivors are discharged differ and impact community reintegration. Nayak[17] reported that support from the family and community facilitated higher levels of community reintegration. Higher levels of education and income have been found to better enable community reintegration post stroke. Conversely, the lack of social support systems and services contribute to social isolation and decreased community reintegration[19]. Additional social barriers to community reintegration are inaccessible therapeutic services, limited social networks and negative attitudes such as stigma[21]. Persons with neurological disabilities are often considered as less able in the community[22] by their families and are frequently socially excluded from participating in activities such as shopping and other family and community activities. These factors may play a role in the low levels of successful community re-integration of stroke survivors reported in the Western Cape as indicated by Hassan et al[11] and Joseph and Rhoda[23]. Over 80% of participants are from low socioeconomic areas in their studies since they were either unemployed or had not achieved a secondary school education[23]. Due to the limited evidence showing the effect of environmental factors influencing reintegration post stroke in low resourced communities, the subsystems related to the environment in the Person-Environment-Occupation-Performance (PEOP) model[24] were used as an occupational therapy lens and frame of reference to explore and conceptualise critical issues in this respect.

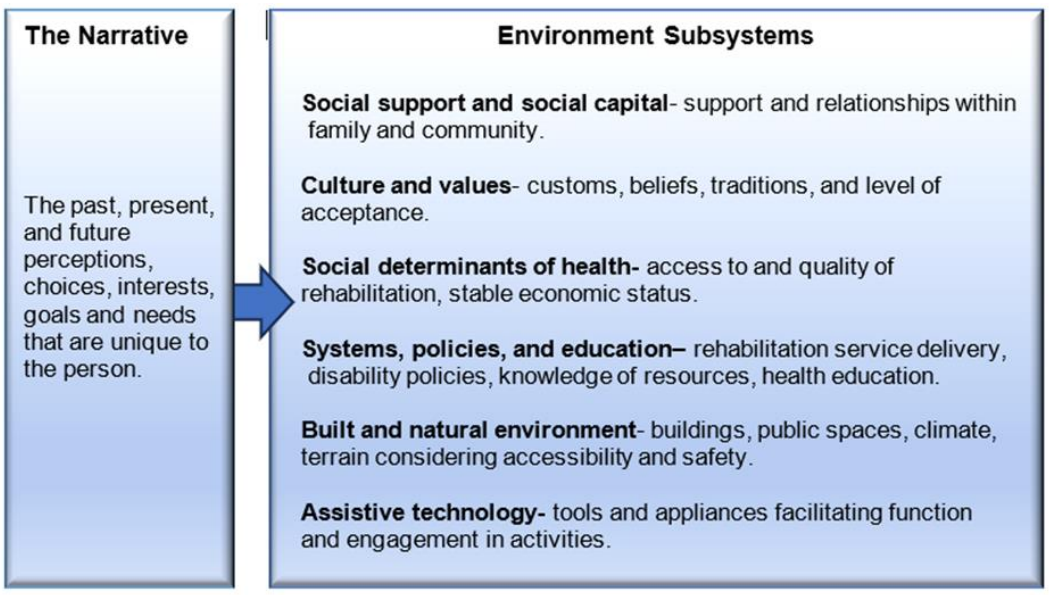

Figure 1: Environment subsystem of the Person-Environment-Occupation-Performance (PEOP) model: Enabling Everyday Living

The PEOP model considers the interaction between the environment, person, occupation and participation that is being performed in terms of factors such as social support and social capital, culture, social determinants of health, systems policy and education, the built and natural environment as well as assistive technology[24].

Other studies conducted to evaluate the levels of community reintegration achieved by patients, including stroke survivors, in the Western Cape[25] were quantitative in nature and provided limited data regarding the effect of the environment from a stroke survivors' perspective on their community reintegration. This study provides a client's perspective of environmental barriers and facilitators impacting community reintegration post stroke to support the development of contextually relevant, person-centred outcomes and community-based occupational therapy programmes. This will allow therapists to understand and advocate for policy changes to address the identified

environmental barriers and capitalise on the facilitators to strengthen service delivery[26].

METHODS

Research design

A descriptive, qualitative study design using a phenomenological approach and constructivist world view was used to conduct this study[27]. The study explored the lived experience of the impact of the environment on the community re-integration after a stroke from the perspective of stroke survivors who had completed a period of rehabilitation at WCRC. Occupational therapists who provided community-based services were also interviewed to develop a comprehensive understanding of the effect of the environment. This data source provided triangulation by converging the information provided by the therapists with that which emerged from the stroke survivor participants[28].

Research setting and sample

The research was conducted in the Eastern Sub District (ESD) of the Western Cape which is a low-socioeconomic area with an unemployment rate of 30% and where 20.5% of the population live in informal dwellings[29] and approximately 88.3% of the population are dependent on the public health system[29].

Purposive non-probability sampling[30] was used to recruit participants from those listed in the WCRC discharge records. One hundred and ninety stroke survivors living in the ESD were identified from a retrospective record review and 69 potential participants gave consent for their medical records to be reviewed to establish if they met the inclusion criteria. These criteria included - a mild to moderate stroke according to the Canadian Neurological Scale Scores[31], one to three years post discharge from WCRC and a rehabilitation outcome at Lundrum level III[9] on discharge. Stroke survivors with expressive aphasia, a communication disorder or severe cognitive fallout on discharge that hindered independent participation in an interview were excluded. Based on the recommendations of Hagaman and Wutich[32] a sample size of 12 participants was identified as sufficient for the study. Twelve participants were interviewed, and data saturation was confirmed by a data saturation table used to determine that no new information emerged after the completion of these interviews. Two occupational therapists providing intervention for stroke patients at community clinics in the ESD were also interviewed.

Research instrument

Participant demographic data were collected from the participants' medical records and during the semi-structured interviews, using a questionnaire specifically designed for this study. The research objectives and current literature guided the development of the semi-structured interview guide[27]. The semi-structured interview guide for the stroke survivor participants consisted of seven open ended questions each with a number of prompts used to ensure consistency between the interviews[27]. The second author, having piloted the interview schedule, interviewed all participants. An interview schedule consisting of four open-ended questions was then used by the second author to explore the occupational therapists' experiences of the environmental facilitators or barriers to the patient's ability to reintegrate into their community . Data from the interviews with the two occupational therapists were not reported as findings but were used to triangulate and support participant information as recommended by Krefting[33] and ensured dependability of the study[27].

Research procedure

Ethical approval for this study was obtained from the University of the Witwatersrand Human Research Ethics Committee (M190530), as well as the Western Cape Department of Health. All potential participants were provided with an approved information sheet detailing the purpose and nature of their involvement in the research. If they agreed to participate, they signed informed consent for participation as well as for the audio-recording of the interview. Data were collected through semi-structured interviews. Nine interviews were conducted face-to face in participants' homes, two were conducted telephonically and one interview took place at a clinic. Conducting the interviews in the stroke survivors' homes gave the principal researcher the advantage of collecting data in situations where stroke survivors' community reintegration could be directly observed[27]. The interviews were conducted in either English or Afrikaans by the researcher and one was conducted isiXhosa. This was to ensure ethnic inclusiveness of the sample as far as possible. The open-ended questions encouraged participants to express their views about their experiences of community reintegration freely. Recordings of the interviews were anonymised and transcribed word-for-word.

Data Analysis

Twelve participants consented to take part in the study and participated in the interviews however, only 11 interviews were analysed as the 5th participant had a severe speech impediment that was not reported in the medical record and was therefore excluded from the study sample. As the data became saturated by the 12th interview, despite the exclusion of participant 5, an additional interview was not conducted. The demographic information was analysed descriptively using frequencies. The transcripts were analysed using concept analysis[27] and MAXQDA software[34]. Based on the identified themes related to barriers and facilitators, a deductive a priori data analysis using the PEOP model environmental subsystem for coding of the categories was completed (Figure 1, page 37). The principles of trustworthiness were used to ensure the rigour of the data analysis: credibility[35], bracketing[36]. reflexivity[36], and confirmability[35].

FINDINGS

Of the 11 stroke survivor participants, 64% were male and most were married (72.75%). The majority were Afrikaans speaking (91%) and had an education level lower than a secondary school. Over 90.9% had had some form of employment prior to their stroke but only one was able to return to work on an informal basis post stroke and two retired. At the time of the study 73% of participants were in receipt of a disability grant. (Table I, page 39).

Table I Stroke Survivor Participants (SSP) (n=11)

CODE	AGE-YEARS	GENDER	MARITAL STATUS	LIVING WITH	HOME LANGUAGE	LEVEL OF EDUCATION	EMPLOYMENT PRE-STROKE	EMPLOYMENT POST STROKE	DISABILITY GRANT / PENSION
SSP 1	67 yrs.	M	Married	Partner and children	Afrikaans	< High school	Permanently employed	Retired	State Pension
SSP 2	32 yrs.	F	Never married	Grandparents, sister, cousin and daughter	Afrikaans	< High school	Permanently employed	Informal worker	Disability Grant
SSP 3	51 yrs.	M	Never married	Mother	Afrikaans	Highschool/ equivalent	Informal worker	Disabled, unable to work	Disability Grant
SSP 4	60 yrs.	F	Married	Partner, children and grandchildren	Afrikaans	< High school	Permanently employed	Disabled, unable to work	Disability Grant
SSP 6	57 yrs.	M	Married	Partner and children	Afrikaans	< High school	Informal worker	Disabled, unable to work	Disability Grant
SSP 7	62 yrs.	F	Widow	Children and grandchildren	Afrikaans	< High school	Unemployed, not looking for work	Retired	State pension
SSP 8	62 yrs.	M	Married	Partner	Afrikaans	< High school	Self-employed	Disabled, unable to work	Disability Grant
SSP 9	51 yrs.	M	Married	With family	Afrikaans	< High school	Unemployed, not looking for work	Disabled, unable to work	Disability Grant
SSP 10	68 yrs.	M	Married	Children and grandchildren	Afrikaans	< High school	Contract employment	Retired	No
SSP 11	60 yrs.	M	Married	Partner, children and grandchildren	Afrikaans	< High school	Self-employed	Disabled, unable to work	Disability Grant
SSP 12	48 yrs.	F	Married	Partner and children	isiXhosa	< High school	Self-employed	Disabled, unable to work	Disability Grant

The priori coding supported the aims of the study in identifying the stroke survivors' experiences of the environmental facilitators and barriers which formed the two themes reported in this paper. Both themes were confirmed by the perceptions of the occupational therapists.

The first theme was the environmental barriers perceived and experienced by the stoke survivors that hindered community reintegration. The second theme described the environmental facilitators that stroke survivors and occupational therapy participants perceived to have enabled their community reintegration supported by perceptions of occupational therapists.

Theme 1: Perceived and experienced environmental barriers to community reintegration

Table II (below) details the categories, subcategories and codes from the deductive priori analysis using the PEOP model.

Table II Theme 1 Perceived and experienced environmental barriers to community reintegration

THEME 1	CATEGORIES	CODES	FREQUENCY
Perceived and experienced barriers to community reintegration.	Social support and social capital.	Lack of social support.	3
		Excessive support from family	4
	Cultural.	Fearing the communities' attitude.	4
		Personal values such as not wanting help	1
	Social determinants of health.	Poor co-ordination of rehabilitation and discharge services.	7
		Inadequate treatment.	3
		Loss of income.	8
	Systems and policy and access to information and health education.	Poor implementation of disability policies.	4
		Inaccesible transport.	11
		Inadequate knowledge of resources.	3
		Ineffective health education.	5
	Built and natural environment.	Factors like stairs and small spaces hindering access.	5
		Long travel distances.	7
		Factors like flooding and uneven terrain.	5
	Assistive technology.	Inappropriate assistive devices.	2
		Lack affects community mobility	5

The effect the environment had on the community reintegration of the stroke survivors was experienced as both a **lack of and excessive social support.** Human capital relationships within the family were often experienced as a barrier to community reintegration firstly with families not allowing stroke survivors to attempt completing activities alone.

"Sometimes when I want to do something they scold, mommy, go sit, or so on …. I must then sit." **[SSP 7]**

The family also affected their reintegration in the home by limiting participant's previously valued activities by someone else in the family having been assigned to do them.

"At the moment I'm not doing activities inside the house anymore. Because here is someone that can do it, I just make myself coffee and a sandwich and so on." **[SSP 9]**

A second barrier experienced by other participants was that there was insufficient practical support from the family such as practical and financial assistance.

"No … I haven't been in church forever. They do not want to push me …with the wheelchair." **[SSP 7]**

"My other daughter works … but at the end of the month [she] doesn't give her money." **[SSP 4]**

Stroke survivor participants also experienced **the culture and values** in the community, for example: negative attitudes, as a barrier to their community reintegration.

"If I … go to a braai with my friends. I will not go sit there with them and chat.... Because they will tease me and say look at how this guy looks, you know.... Because when I walk, I feel … someone is [always] looking at me." **[SSP 8]**

"Many, many of them have changed in their attitude towards me …. Like before, before the stroke we communicated a lot … but now then don't even speak to me …." **[SSP 9]**

Social **determinants of health** were perceived as: adequate access to health care at the community level. Access was experienced to be hampered by **poor discharge policies, inadequate referral for rehabilitation and limited rehabilitation services** at local clinics. These were perceived to be barriers to their continued

rehabilitation following discharge and thus negatively influencing community reintegration.

"No [follow-up therapy] has not been available at the clinic.... Again, and again when I get there. But it remains like that at the clinic. The people of the therapy are not there." **[SSP 6]**

Some who had been referred considered the support group to be unhelpful.

"Oh, those two weeks, three weeks .... I get there, we sit in a circle, then we chat and drink tea, eat cookies and stuff. Then they throw you a big ball. Now you can't catch the ball. Then I just left that [referring to the stroke support group his wife took him to]." **[SSP 11]**

Economic factors, also a social determinant of health, were experienced as a major barrier to community reintegration. The loss of or very limited finances prevented stroke survivors from engaging in previous leisure activities, accessing rehabilitation and a struggle to cover basic living costs.

"Look, they told me I should go to the clinic, … for the classes. The reason [for not going] is that I did not have money every time to go to there …. That is actually the main reason …." **[SSP 2]**

"[Before the stroke] I did not need money because there was always money .... We could always pay for everything that we wanted, could always go out, me and my wife, now we can't anymore .... [It's a] very big change ... very big." **[SSP 8]**

Several **system and policy barriers** in their communities were identified as influencing community reintegration. **Inaccessible public transport** due to minibus taxis not being disability friendly was a barrier. Taxi drivers were often in a hurry, rude and charged the disabled with assistive devices an extra fee to use their minibus taxi.

"I walk slowly, and usually struggle to get into a taxi. [It is difficult] to get into the door where I sit, and many of the taxi drivers are rude with how disabled I am ...., they hurry you along." **[SSP 9]**

In addition, participants experienced **poor implementation of disability policies** regarding service users with mobility limitations which also limited their ability to access services in the community.

"[Getting service at the] SASSA is a problem in the sense of you aren't seen as disabled if you walk with a crutch or a cane." **[SSP 3]**

Another barrier perceived by participants was due to a **lack of sufficient information** on accessing further social and health services and support in the community after discharge.

"I don't want to be helped sooner but … if the information [about accessing the SASSA grant] was given correctly in the beginning, then one would not have such problems." **[SSP 3]**

The low levels of community reintegration that were being achieved by stroke survivors was, according to the occupational therapists, associated with poor buy-in and compliance with **home programmes** making them ineffective.

"So, in all honesty, their mobility can improve but compliance is the problem .... I think going home and continuing or reinforcing what we've been teaching them at the facility, that does not happen, and I think that's what hinders the physical mobility more." **[OTP 2]**

Stroke survivor participants experienced **built environmental** barriers to their community reintegration. The built environment like stairs and small spaces often made independent mobility a challenge.

"Stairs remain my problem. If there are no railings, then it can be very [challenging]." **[SSP 3]**

Stroke survivor participants also perceived the **natural environment** as a challenge citing factors like uneven terrain, inadequate drainage, and the long travel distances to basic community resources.

"Because I can't get to the shops …. I mean, I cannot walk until there … it's a bit far for me " **[SSP 7]**

"What I find difficult man. I want to go to that place, alone. But someone has to go with me, ... I don't like using the wheelchair that I can only use one hand to pedal, you know." **[SSP 6]**

Assistive technologies or tools and appliances.
During the interviews it emerged that stroke survivors experienced that inappropriate devices were prescribed by the rehabilitation professionals causing problems with their independent community mobility and participation in everyday activities.

"I got that walking [frame] … at the club, the stroke club. I can't really use the thing because I don't [get it down the stairs] to the bottom on the ground level." **[SSP 7]**

All six environment subsystems identified in the PEOP presented barriers to community reintegration post stroke to varying degrees.

Theme 2: Perceived and experienced environmental facilitators to community reintegration

Table III (below) details the categories, subcategories and codes from data following the deductive priori analysis using the PEOP model for Theme 2.

Table III Theme:2 Perceived and experienced facilitators to community reintegration

THEME 3	CATEGORIES	CODES	FREQUENCY
Perceived and experienced facilitators to community reintegration.	Social support and social capital.	Encouraged independence.	8
		Motivators such as dependants.	3
	Cultural.	Expectations of the community	2
		Role fulfilment	1
	Social determinants of health.	Stroke support groups.	10
		Home visits.	3
	Systems and policy and health education.	Social welfare system and policies.	5
		Accessible or alternative public transport.	4
		Implementation of home visits.	1
	Built and natural environment.	Provision of external support.	4
		Less crowded areas and even surfaces.	4
	Assistive technological.	The availability of assistive devices.	10
		Assisted mobility outside of the home	5

Some stroke survivors perceived the social support from family **and their community** as a facilitator to community reintegration. They appreciated the support which facilitated their attempts to participate in homecare tasks independently.

"Because in the beginning, when I came home, she did everything. She dressed me, everything. Later, she said 'Come, mommy, dress like that … I'm not going to do everything for mommy.' And I struggle-struggled, but now I'm fine." **[SSP 7]**

Some participants recognised that the needs of dependent family members provided the motivation to getting stronger and complete tasks independently.

"… and my little daughter, I fought for her … that was actually my main thing, I needed to fight for my little daughter. I [could] not [just] sit in a wheelchair when I come home." **[SSP 2]**

Both stroke survivors and occupational therapists perceived support from the community as a facilitator, particularly neighbours and church communities.

"… the church people were the people that also supported me…When I had the stroke … the church also motivated me a lot …." **[SSP 2]**

Stroke survivor participants also perceived the expectations of role fulfilment in the community that were culturally appropriate served as a facilitator to activity participation and therefore community reintegration.

"Yes, I am the one that controls, money, everything. Shopping and such, I [have to] do everything myself, that's my job, according to my culture...." **[SSP 6]**

Access to services which supported **social determinants of health** in the community were viewed as supportive to community reintegration. The availability of community stroke support groups were facilitators to regaining functional skills and the opportunity to socialise.

"[The stroke group] helped a lot … because [before] I just sat here and spoke to nobody but now, I can speak to them and so and I do [the] exercises that they give me and so." **[SSP 9]**

In terms of **economic factors** stroke survivors reported that access to community-based organisations such as stokvels (communal savings schemes run by a relatively small group of people who know each other)37, helped them to save money and thus better manage their finances.

"I joined stokvels so I can save my money. Whatever I am thinking of doing I am able to do. But now I am assisted." **[SSP 12]**

Some stroke survivor participants perceived that some **systems and polices** provided by the government, such as grants and pensions, facilitated community reintegration post -stroke.

"My SASSA [disability grant] money, hey, it's a little, but okay, it helps. It helps a bit for the things in the house and so on." **[SSP 11]**

The availability of accessible and subsidised public transport provided the opportunity to move around independently in the community which was confirmed by the occupational therapists.

"… when I go to the stroke club … then a taxi [organised by the stroke club] comes to pick me up…now, the taxi that comes for us, they at least have a small step that … that we step on and climb in…." **[SSP 7]**

The occupational therapists experienced their ability to conduct **home visits**, work as an MDT member, and have the assistance of health care workers as a facilitator.

I think, in terms of service delivery, I can say that we offer a multi-disciplinary approach. Like … if we are visiting the patients in home … it's never in isolation - I think, the multi-disciplinary aspect also aids the patient in … offering them the best in terms of rehab services so that they can be integrated into the community." **[OTP 1]**

In the **built and natural environments** stroke survivors experienced some facilitators to activity participation which assisted community reintegration.

"There has to be railings [when I walk upstairs] ...the railings were not here [by these steps] ...My son came to put them up for me." **[SSP 8]**

"No, it is easy for me to move … At the church, where we hold the stroke club, I move easily there. … space is bigger, and the chairs and stuff are out of your way." **[SSP 9]**

The last facilitating factor that the most participants identified, was the availability of **assistive technology** in the form of assistive mobility devices such as walking sticks and wheelchairs. These assisted with managing their balance and fatigue when mobilising outside their homes or in allowing mobility in the community which would otherwise not be possible.

"Yes, look, I don't go out without my cane. So yes, the cane, it's just definitely for safety, because my balance is not quite, and I think … the experts will recommend that one takes the cane with you." **[SSP 3]**

DISCUSSION

The sample in this study although small, is consistent with qualitative research sample sizes utilised[27] and that for relatively homogeneous groups[32].

The mean age for the 11 stroke survivor participants was 56 years, which is congruent with trends for stroke in Africa, where many survivors are between the ages of 40 and 602. Over 70% of stroke survivor participants were married and living with their spouse while others lived with other family members, which has been associated with increased independence in activities in daily living (ADLs) and better general health than living alone[38]. In terms of education only 9.09% of the participants reported finishing high school which may have affected their health literacy[39] which in turn could have had a negative effect on their health and continued functional improvement post discharge from WCRC. While most participants had been employed prior to their stroke only one participant had returned to work and then only part time. This finding is consistent with the finding by Duff et al.[40] in Buffalo City in the Eastern Cape.

The high percentage of comorbidities found in the participant group concurs with work by Ranganai and Matizirofa[41] who reported hypertension, diabetes and hypercholesterolaemia as associated with stroke patients.

Barriers to community integration

One of most disabling environmental barriers that emerged was the lack of, or too much support from family. Stroke survivor participants as well as occupational therapists experienced that overprotective families create dependency with the stroke survivors feeling a loss of control and being a burden. Families can preclude stroke providers from performing meaningful activities which was often perceived as a barrier to community reintegration[42]. This was confirmed by one occupational therapist who indicated that in her experience stroke survivors seldom carried out their responsibilities within the home mostly due to the expectation that their family members should take care of them and take over their responsibilities. She also reported this mindset often kept the stroke survivor housebound.

However, a lack of social support from family and the community results in isolation since continued interaction with other people is essential for successful community reintegration[42]. Some participants in this study reported family members were unwilling or unable to assist them in activities and attending community events. The occupational therapist speculated that it seemed families may not adequately value the stroke survivor's need for community interaction which limited their community reintegration. However, she acknowledged safety in the community was a concern for someone with mobility issues as to go out alone in the community was associated with a high risk of falling or being a victim of crime.

The participants also perceived cultural barriers associated with community attitudes acted as barriers to community reintegration and this deterred them from asking for assistance[25]. The occupational therapist confirmed experiencing community stigma for stroke survivors[43], particularly those with confusion and the

cognitive fallout. In some cases, these stroke survivors are believed to be cursed, kept indoors, or hidden away.

Environmental barriers to community reintegration related to the social determinants of health were challenges in accessing rehabilitation, health care and loss of income. In this study, participants experienced that rehabilitation staff were not at the clinics, and they were unable to get an appointment. Literature highlights several reasons for the lack of continued rehabilitation of stroke survivors in South Africa at community level[44]. This reflects problems with the referral pathways between health care providers and levels of health care[44] and some referral forms not indicating occupational therapy as an option[45]. Follow-up appointments are often poorly scheduled requiring multiple trips to the clinic[46] which participants had difficulty funding.

The findings of this study reflect the shortage of rehabilitation professionals, including occupational therapists, in the public health sector at the PC level. Community based occupational therapist are required to provide services at multiple facilities[47] with overbooking on some clinic days and limited bookings on others. Thus, therapists often prefer that appointments are made directly with them, which in turn makes booking appointments difficult if the therapist is not at a specific facility when the stoke survivor attends other appointments. The occupational therapists in this study also reported challenges in providing services at the clinics, long waiting-times for files and other medical appointments clashing with rehabilitation times. Similar barriers reported by Cawood and Visagie[48] in 2016 do not seem to have been resolved. Another barrier to rehabilitation was the stroke survivors perceived irrelevance of the therapy they received as supported by Mlenzana et al.[46] who found rehabilitation that is not personalised is a barrier to accessing the service.

Only 9% of stroke survivors were able to return to work with many others becoming dependent on social grants. Loss of finances limited engagement in previous leisure activities and made it challenging to cover basic costs like accommodation and food as well as access to health care. Scheffler and Mash[7] found that the loss of income had even wider repercussions, as some caregivers needed to resign from their work to assist stroke survivors, further adding to the financial burden of the family. One of the occupational therapists concurred this was particularly true when the stroke survivor was the breadwinner in the family.

Systems, policy and education affecting the community reintegration of stroke survivor participants included the implementation of rehabilitation services which are hindered by policies such as the Western Cape Health Service Delivery Platform 2030 Policy[7]. This policy states that rehabilitation services at PC level should focus on body structure and function impairments which can be resolved quickly with the provision of assistive devices. Furthermore, it states that services will be nurse driven, supported by a medical officer with no clear indication of the role of rehabilitation personnel except for playing a supportive role. Thus, the ability of the multidisciplinary team to provide personalised, home-based care to overcome the social determinants of health is of concern particularly for persons with newly acquired permanent disabilities. Task shifting to midlevel healthcare workers (CHWs) employed by non-government organisations to increase service delivery in areas that have a limited number of occupational therapists has been proposed in the Community-Orientated Primary Care (COPC) programme[49]. Nonetheless, the efficacy of this has not yet been proven and currently CHW's do not have the skills and knowledge to provide rehabilitation services to stroke survivors[47]. This in turn can result in a shortfall in continued therapy [6,50].

The inaccessibility of the public transport system due to physical barriers and expense is supported in several studies[21,48] in the Western Cape. Stroke survivor's experience of issues with taxi drivers has resulted in them paying exorbitant fees to hire private transport to access the community or health services[51]. The need to hire private transport or use an Uber to travel to access health care was confirmed by the occupational therapists. Although the Dial-A-Ride alternative transport is available to people with disabilities in the Western Cape metropolitan area[52], it is inundated with long waiting lists. The traveling routes are also lengthy making users late for appointments.

A lack of information regarding inter-sectoral systems which provide services such as disability grants was noted by stroke survivors and occupational therapists. One of the occupational therapists agreed, indicating stroke survivors often relied on neighbours or friends to get information about how to apply for a disability grant. Literature indicates that patients have reported a lack of information regarding support services in the community being provided on discharge[6].

Only the occupational therapists and not the stroke participants experienced home programmes and health education as affecting community reintegration. The therapists felt education around the importance of home programmes was affected by the health literacy of the stroke survivors and their families as well as other barriers such as lack of support and contextual relevance[53]. Even though family education was provided, the continuation of home programmes was reported by the occupational therapists as a problem and some stroke survivors found alternate programmes from other sources such as the internet which they considered more appropriate and meaningful. The importance of personalising home programmes consistent with the beliefs and attitudes of the stroke survivors, their routine, and joint decision making on the collaborative goals to be achieved needs to be considered[53].

The natural and built environment posed barriers to mobility and community reintegration of the stroke survivor participants due to the lack of adaptations and maintenance of roads and pavements resulting in the ability to move around in the community being problematic and wheelchair bound persons having to navigate busy roads, many with pot holes[54]. The occupational therapist confirmed these environmental barriers affected mobility and stroke survivor participants were therefore dependent on family or community members to push their wheelchairs outdoors. These barriers are not uncommon in South African poorly resourced communities[20,55]. Other structural barriers such as stairs, lack of lifts, narrow passages and small rooms were also reported which is exacerbated by the failure of South African municipalities to deliver services and adequate housing, thereby endangering people with disabilities and compromising their human rights[56]. The occupational therapists indicated homes in informal settlements were a challenge for stroke survivors with walking frames, wheelchairs, or crutches. The terrain around the houses often have loose stones and sand so entering the property and exiting the home is difficult. Some stroke survivors live in third floor apartments in buildings with no lift resulting in the person and wheelchair having to be carried up and down the stairs. Even accessing health care in the built environment becomes an issue when the lifts do not work during loadshedding and services for stroke survivors are not on the ground floor. This makes it especially challenging for occupational therapists to facilitate community reintegration because as reported, the stroke survivor cannot mobilise in or outside their house.

The last environmental barrier related to technology that arose during the study was having inappropriate devices or experiencing problems with the devices. Govender et al.[44] found that wheelchair-bound individuals often become homebound due to an inability to mobilise using the issued assistive devices. This occurred when devices were issued without training and there was not a holistic view of where and for what the device was needed[55]. The occupational therapists reported challenges in not having stock of the appropriate or limited assistive devices to issue so they

are not able to appropriately facilitate participation in home and community activities[57]. They reported budgets for medical services are often prioritised leaving limited resources for assistive devices[58] with cheaper alternatives such as scooters not on tender and being too expensive for families to afford.

Facilitators to community reintegration

Factors facilitating their community reintegration reported by stroke survivor participants was the "just right" social support from family which facilitated the stroke survivor in attempting tasks independently, encouraging them to succeed and offering practical help to adapt tasks. Families play an important role in how stroke survivors reintegrate into their communities and having others dependent on them facilitated return to previous roles and activities[6].

Cultural facilitations included gender and cultural norms that expected the stroke survivors to contribute to household and community activities also played a role with the occupational therapists noting that some stroke survivors set goals and found ways to continue previous household activities. Facilitators were associated with the church, which provided many stroke survivors with financial and emotional support as well as social interaction opportunities. Another South African study found that stroke survivors perceived their church as a source of support[44] and highlighted that for many stroke survivors, leisure activities are associated with attending church and engaging in religious activities.

Social determinants of health that provided some financial support in facilitating community reintegration included disability grants, stokvels, burial societies or informal self-help groups of people that pool their funds to provide financial support[37]. Stroke support groups in the community have been highlighted as a factor that facilitates community reintegration[48]. The occupational therapist viewed the stroke group as an opportunity to build relationships and friendships, therefore facilitating reintegration of the stroke survivors into the community.

The occupational therapists were aware of the COPC programme[59] which advocates for support teams to provide treatment for stroke survivors in their homes and experienced this as a facilitator. Although not mentioned by the stroke survivors, rehabilitation professionals from some clinics, were conducting home visits with CHWs to provide home based intervention post stroke. Providing appropriate education and ensuring appropriate home programmes were implemented, were also achieved through home visits. The occupational therapist felt random visits were an external motivator since the stroke survivor worked harder as they were unsure when the rehabilitation team would be coming again. Where home visits had been instituted the occupational therapist indicated these visits improved their own understanding of the home environment and allowed for appropriate goal setting with the patient and prescription of appropriate mobility devices. The ability to work within an MDT and with CHWs facilitated the rendering of community services with the possibility of providing early supported discharge and reducing healthcare costs[60].

Systems that facilitated community reintegration for stroke survivors included services at the clinics to expedite the flow through for those in wheelchairs and prevent long waiting times for them, as well as the availability of accessible transport. Such transport was provided by a stroke support groups using an accessible taxi or by online cabs. The use of online cabs could address the lack of accessible public transport in metropolitan areas, but unfortunately, it is expensive and would not be accessible to all stroke survivors. It has been suggested that Uber introduce wheelchair accessible vehicles and train drivers on how to interact with and assist clients with disabilities61 but no research on the use of these cabs by people with disabilities in South Africa was sourced.

Built and natural environments were perceived to be accessible where external structures to hold onto when walking were available, as well as less crowded areas, and availability of even surfaces to manoeuvre on were experienced as a facilitator to community reintegration. The occupational therapists also identified accessible homes and access to basic amenities such as an indoor bathroom made is easier for participants to be independent.

When appropriate assistive technology was available this was perceived as a facilitator to community reintegration. Stroke survivor participants experienced mobility assistive devices like walking sticks and wheelchairs as assisting them in managing their fatigue and mobilising outside their homes. This was confirmed by the occupational therapists who found that the availability of wheelchairs allowed stroke survivors to go out of the home and attend activities such as going to church. In confirmation, Algurén et al.[62] argued that assistive devices specifically for indoor and outdoor mobility such as wheelchairs and walking frames are crucial for the health related quality of life of stroke survivors.

CONCLUSION

The stroke survivors' perspective of environmental barriers and facilitators impacting community reintegration in an urban metropolitan sub-district, post stroke is vital in providing effective community reintegration services.

Most environmental barriers were perceived to be associated with the social determinants of health, inaccessible resources and poor policy and service implementation in the sub-district in which they lived. Poor infrastructure was compounded by the provision of inappropriate assistive devices.

The environmental subsystems perceived as facilitators to community reintegration were social support from the family, social determinants of health in the form of access to community organisations where they could socialise, and assistive technologies that allowed mobilisation in and outside the home. The occupational therapists perceived home programmes as more important than the stroke survivors in achieving community integration.

This study emphasised the importance of stroke survivor being referred to the community-based services to ensure more effective community reintegration and the role of occupational therapists in advocating for disability friendly access within our communities.

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Conflicts of Interest

None to declare.

Author Contributions

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