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The need for high quality clinical research in occupational therapy

The editors of this journal, South African Journal of occupational Therapy (SAJOT), have been working with the Occupational Therapy Association of South Africa (OTASA) Research Committee to determine the main research methodologies and levels of evidence of articles published in relation to the research priorities identified by the Research Standing Committee. With the advent of the NHI and universal coverage in health care, it is essential that research evidence for occupational therapy be available from within the South African context[1]. However, most of the articles submitted to and published in SAJOT are in the ranks of lower levels of evidence which includes largely qualitative, small group research. Very few articles that provide Level 1 and 2 evidence, such as systematic reviews or randomized control trials, are published.

Occupational therapists contemplating research projects should focus on research priorities identified in South Africa which could help to expand and add depth to the evidence-base for our profession in a meaningful way. This could support not only better, more effective practice, but also client compliance as well as justifying costs to funders such as medical aids and the proposed NHI services in public health care and buy-in. Therapists need to promote change and ensure that effective rehabilitation continues to be included in a cost-effective manner at all levels of health care by engaging in clinical research which provides evidence for best practice. A project to support the inclusion of rehabilitation in primary health care mapped rehabilitation recommendations into 82 standard treatment guidelines (requested by the national essential medicines list committee) included occupational therapists. Much work is still to be done in providing supporting evidence for the treatment guidelines which are based on diagnostic categories[2].

Basing research priorities in occupational therapy on frameworks such as the International Classification of Functioning, Disability and Health (ICF) - which can support rehabilitation services in the NHI - has also been suggested. In the United Kingdom, research priorities had been developed to provide research from a service perspective rather than from a medical or disability perspective, which is another option in supporting the provision of evidence for the effectiveness of occupational therapy. This project[3] suggests research considering unanswered questions about treatments or interventions including:

- How does occupational therapy make a difference and have impact on everyday lives?
- How can occupational therapists ensure that person-centred practice is central to how they work?
- How can occupational therapists work more effectively with the family and carers of people who access services?
- What are the long-term benefits of occupational therapy intervention?
- What are the benefits or impact of occupational therapy in primary care settings?
- How can occupational therapy services be more inclusive of both mental and physical health?
- What is the role of occupational therapy in supporting self-management? (e.g., helping people with illness to manage their health on a day-to-day basis)
- What is the role or impact of occupational therapy in reducing hospital admissions?
- How can occupational therapists work most effectively with other professionals to improve outcomes for people who access services?
- What is the cost-effectiveness of occupational therapy services? [3:5]

Whether research is diagnostic, framework or service-based, it must provide sound scientific evidence to secure support from scientific bodies, funders and decision-makers and support best practice. High quality study methodologies from levels 1-3 for research evidence should be considered when planning research to make a real difference to the ability of occupational therapists to provide services in South Africa.

Our profession's future existence is in our hands. We have a choice here: do we go forward as onlookers, entrusting others with the task of shaping our future, or do we join in and keep control.

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SCIENTIFIC LETTER

Determining the research priorities for the profession of occupational therapy in South Africa

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INTRODUCTION

Occupational Therapy is a profession that focuses on enhancing the functioning of individuals who experience functional limitations particularly when engaging in occupation related activities. The setting of research priorities is seen as an important activity for every organisation[1]. The Occupational Therapy Association of South Africa (OTASA) wanted to understand the current occupational therapy research focus areas in South Africa and possibly develop recommendations for occupational therapy priority research areas for the future.

METHOD

The scientific investigation was conducted in two phases, namely, a quantitative descriptive research design was used in **phase one** of the study and **phase two** used a qualitative research design. The aim of phase one of the study was to determine the views of occupational therapists about the research priority focus areas for the profession of occupational therapy in South Africa. Phase two of the study was to analyse a shared university database in order to describe the main research areas in which occupational therapists conducted research for the period 2017 to 2019.

During **phase one** of the study the researcher conducted a survey with all 3304 occupational therapists registered with the Occupational Therapy Association of South Africa (OTASA) at the time of the study. However only 97 individuals completed the survey that focused on what the research priorities. The questionnaire used in the current study was adapted from the WHO research priority questionnaire, it was used to identify research priorities for the occupational therapy profession[1].

In **phase two** of the project the researchers utilised content analysis in order to analyse a research database linked to all 8 universities in South Africa. The research database consists of all published research and unpublished research (degree and non- degree purposes) that have been documented by the 8 universities who offer occupational therapy training programmes in South Africa. The Framework for Disability Strategy and Rehabilitation[2] was used as a theoretical framework in the current scientific enquiry. Further content analysis allowed the researchers to analyse written content and to highlight common areas of significance. The study obtained ethics clearance from the University of the Western Cape, the ethics approval number for the project being HS20/3/1

RESULTS

The results of phase one of the study indicated that the following research focus areas were regarded as areas of priority for future research: effectiveness of occupational therapy intervention, evidence-based occupational therapy practice and the development of valid and reliable occupational therapy measurement tools. The results of phase two of the study indicated that Occupational Therapy Education and training-based research and Mental Health Disorders (including substance abuse) were the most common areas of occupational therapy research in South Africa (Table I page 7).

CONCLUSION

The research evidence-based hierarchy as described by Miller & Forest[3] describes research evidence according to 5 levels of quality of evidence. Research at Level 1 is regarded as the highest or strongest level of research evidence, this level is described by studies such as systematic reviews (meta- analysis) and randomised control trials. Research at Level 4 to 5 being regarded as the weakest level of evidence, this level is described by studies that uses case reports or case series and narrative reviews to answer the research questions linked to the study[3]. The results of the current study

Table I: Results of Phase one and Phase two of the study

PHASE ONE (Areas of research priority based on survey results as a %)	**PHASE TWO** (Dominant research focus areas identified from universities in South Africa's research database as a %)	**RESEARCH PRIORITY NEEDS** (Needs identified according to the Disability and Rehabilitation Framework)
Effectiveness of Occupational Therapy Intervention [74%]	Occupational Therapy Education and training-based research [58%]	• Hearing loss in children • Neural tube defects and Spina bifida • Neurodevelopmental disorders • Non-communicable diseases • Tuberculosis • Visual and Hearing impairments in adults.
Evidence-based Occupational Therapy Practice [67%]	Mental Health Disorders (including substance abuse) [49%]	
Development of Valid and Reliable Occupational Therapy Measurement tools [57%]	Participation: Leisure pursuits and driving [32%]	

indicate that there were minimal occupational therapy related studies conducted between the years 2017- 2019 that are regarded as research evidence at level 1. With the majority of occupational therapy related research being regarded as research evidence at level 4 to 5. In conclusion the results of the study suggested a need to conduct Level 1 studies that require evidence-based occupational therapy practice. Furthermore, there is a need to conduct research that relates to the focus areas identified by the Framework for Disability Strategy and Rehabilitation.

Recommendations and Implications for practice

Departmental research committees develop Think Tanks together with clinicians, communities and faculty in order to plan research that focus on the priority research areas identified in this study.

Emphasis be placed on developing the research methods skills of undergraduate students, post graduate students, clinicians and academic skills particularly in designing Level 1 A and Level 1B research studies.

Research funding and awards be prioritised for Level 1A and Level 1B type of research in Occupational Therapy.

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RESEARCH ARTICLE

The needs of individuals with autism spectrum disorder when transitioning into the labour market

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ABSTRACT

Introduction: South Africa, like other regions of the world, has an increasing prevalence of autism spectrum disorder (ASD). The transition of these individuals into the labour market is of concern. The aim of this study was to explore the perceptions of individuals with ASD and their parents in terms of their unmet needs in relation to transitioning into the labour market and the role an occupational therapist can play.
Methods: A qualitative explorative descriptive research method was used. Purposive sampling selected young adults with ASD currently or previously employed in the open labour market. Data were collected using email interviews with individuals with ASD and face to face interviews with their parents. Data were analysed using inductive thematic analysis.
Results: Two themes were identified: Transitioning was really hard, and Occupational therapists can do more. The results emphasised the lack of services in preparing adults with ASD for finding and maintaining employment, as well as suggestions for the role of occupational therapy in facilitating prevocational skills, job seeking skills and supported employment.
Conclusion: There is a lack of services for individuals with ASD transitioning into the labour market particularly in relation to vocational orientation and rehabilitation. Occupational therapists are ideally situated to provide services to meet needs of individuals with ASD transitioning into the world of work.

Implications for practice

- Occupational therapists need to play a role in developing vocational rehabilitation services in preparation of individuals with ASD into the labour market.
- There is a need to investigate what is currently offered and what can be added regarding occupational therapy programs supporting transition from school into employment for individuals with ASD in South Africa.
- Vocational rehabilitation services and transition programs should be developed in conjunction with individuals with ASD to ensure issues that are relevant to the population of individuals with ASD are addressed.

INTRODUCTION

The global prevalence of Autism Spectrum Disorder (ASD) is reported to be increasing and this complex disorder has considerable impact on the individual, their families, communities and societies[1]. The same increase in prevalence is true in South Africa although this has not been well researched. It has been suggested the prevalence of ASD in South Africa may reflect the global prevalence of 1 to 2% of the population, with research indicating a prevalence of 0.08% in the Western Cape and an average increase of 15.18% per year[2].

Although more services have been provided over the last 20 years in South Africa for individuals with ASD, these services are mostly for children and not adolescents and adults[2,3]. Longitudinal research in developed countries has found that only about 20% of adults are able to live independently. Only an average of 49% of adult ASD participants who were followed up in studies, were in paid, sheltered, or voluntary employment positions or educational programmes[4]. Research by Meiring et al.[5] indicates that even a higher percentage of adults with ASD make up a proportion of the unemployed people with disabilities in South Africa. This indicates that the transition to the worker role is challenging for many of these individuals and their families and is impacted by reduced support from formal education structures and a lack of appropriate resources to assist with transition to work[5]. These individuals therefore have few resources to meet their transition to employment needs[6].

Current research reports gaps in understanding the challenges associated with transitioning into employment for individuals with ASD. Thus, Renty and Roeyers[7] suggest that professionals, such as occupational therapists, should consider the met and unmet needs related to transitioning into employment, from the viewpoint of individuals with ASD and their parents, since their services could play role in employment outcomes for these individuals[8]. However, occupational therapists have limited information on which to base decisions regarding services for this population in the South African employment context. This has resulted in a lack of vocation specific services offered to adolescent and adult individuals with ASD.

Literature Review

Worldwide, employment of people with disabilities (PWDs) is a complex issue influenced by many factors and systemic issues that are interrelated[9]. While progress has been made in recent years with regards to the development of the legislative framework to support employment of PWDs in South Africa, the success of these policies is questionable as only 1.8% of the employees in the labour market are PWDs[10]. Even though the Equity Act and its Code of Good Practice[11] have been promulgated, these acts and codes appear to have made little difference to the percentage of PWDs who are employed. One group of PWD with difficulty in transitioning into and finding employment are those with ASD[12].

There is a wide range of individuals on the ASD spectrum, with differing abilities which pose various challenges in transitioning into work. This study considered individuals with the diagnosis of ASD, who had completed their secondary education and had received further education or training. Research indicates disappointing employment outcomes for this group globally[5] due to specific challenges individuals with ASD report in developing personal relationships and participating in social interactions. Increased levels of anxiety, stress, and depression in these individuals is exacerbated by fear of change and has been reported to result in social isolation and self-injurious behaviour[13]. While change can be daunting for anyone, individuals with ASD have a particular need for stable routine, predictability and sameness[14]. Thus, they sometimes present with recurring behavioural patterns resulting in inappropriate melt down behaviours when emotionally and sensorially overwhelmed.

These features of ASD contribute to the individual's ability to successfully or unsuccessfully transition between development levels, particularly to adulthood where they are learning to take responsibility for themselves. Individuals with ASD experience complex challenges during the transition period which means they need specific supportive transition services to function within the same level as their counterparts. Therefore, extra support for this transition into adulthood is required in the light of significant developmental changes and challenges in acquiring and amalgamating essential life skills[5]. However, as Shattuck et al.[15] indicated these individuals are faced with lack of support from particularly secondary and post-secondary formal education systems and lack of other resources important for a successful transition into adulthood.

Even though finishing secondary school symbolises a remarkable watershed for these individuals, many leave school, with no clear idea of how they will transition to the next phase of their life including how to find employment and how to start to fulfil their adult obligations[16]. Thus, literature suggests that decreased employment rates of individuals with ASD observed globally are possibly due to all these complex individual and environmental factors[17]. At the personal level, behavioural aspects, cognitive difficulties, poor social communication and interpersonal skills were usually reported as challenges to finding and maintaining employment[18,19]. Decreased executive functioning skills which cause individuals with ASD to struggle with processing abstract information may also play a role. Misunderstandings and lack of problem solving skills, all needed for improved performance in the work environment have been reported as impacting employment[20].

At the environmental level, literature indicates that the social environment, mostly the system of empathetic and accepting individuals close to the individual with ASD, is a strong facilitator for successful employment[17]. This includes customised workplace accommodations[17], support from co-workers, support staff[21], family and others in their community[22]. It was postulated that the real obstacles to employment for individuals with ASD may lie in society's labelling of the peculiarities related to ASD as deficits rather than an appreciation that they have unique qualities to offer in many workplaces[23]. Therefore, it is essential to appreciate the perspectives of the individuals with ASD within the situation and refrain from making assumptions on their behalf. In a study conducted by Magan[24], individuals with the diagnosis of ASD stated that they are the ones living with ASD therefore, their opinions must be appreciated and taken into consideration because a neurotypical society excludes and fails to understand ASD. Considering the concerns expressed by individuals with ASD might assist in accessing resources that will minimise some of the challenges they encounter post-school[25]. Understanding the gap in transition into adulthood for adolescents with ASD from all perspectives will allow appropriate support from stakeholders including occupational therapists, in areas of education, social interaction, communication, interpersonal skills[17], vocational possibilities and community integration to be provided[5].

The American Occupational Therapy Association has identified 'Transition Services' as one of the eight standards of practice for occupational therapy[26], emphasising the provision of support in the significant life area of work. Guidelines regarding how to prepare and support individuals attending learners with special needs (LSEN) schools for the worker role has also been published in South Africa[27] which supports the role of occupational therapists with respect to vocational rehabilitation services for youth with disabilities. However, occupational therapists are not always fully utilised as part of teams which support learners transitioning out of high school and no published research for the transition from high school or post-secondary education to the labour market for individuals with ASD in this country was found.

The intervention and employment model which has been presented by occupational therapists for the South Africa context[28] requires further development to be applied across an inter-sectoral domain of practice including individuals with ASD. Literature also suggests occupational therapy should play an advocacy role for the transition of individuals to employment, such as providing education to society and employers[29]. Guidance to employers by the occupational therapist on how to optimally work with employees with the diagnosis of ASD was recommended[30,31].

Aim of study

The aim of this study was to explore the perceptions of individuals with ASD (who are or have been employed in the open labour market) and that of their parents, about their needs in terms of transitioning into the labour market and the perceived role that the occupational therapist can play in addressing their unmet needs.

METHOD

This study used a qualitative explorative, descriptive design with phenomenological characteristics to explore the meaning people ascribe to their own experience[32]. In this case the perceptions of individuals with ASD and those of their parents on their unmet needs in relation to transitioning into the labour market as well as their views as to how occupational therapists could assist with this process, was explored. Cognisant of the social difficulties of individuals with ASD the data was collected in email interviews while the parents were interviewed face to face[33].

Research setting

The research population was individuals with ASD who were members of an Autism Support Group. The support group provides support for both individuals with ASD and their parents. The membership is diverse in terms of gender and age; including children who are as young as five years and adults as old as 75 years old. The purpose of the group was to discuss daily life challenges encountered by the families and individuals affected by ASD and provide peer support to members. The researcher, an occupational therapist, joined the group as a health care professional when treating clients who needed support. With the groups permission she attended the group meetings to experience the support offered and was later invited to remain in the group and was inducted as a member of the group.

Sampling

Purposive sampling was used to select participants with ASD who had completed their Grade 12 education and had received further training. The participants had been employed for at least three years, while two had been employed in multiple jobs. The sample therefore consisted of young adults with ASD who were currently employed in the open labour market or who had been previously employed and were looking for a job, so they could provide rich data by drawing on their own experience of transitioning into work. Eight individuals with ASD consented to be interviewed and this was done via email, which allowed the participants the opportunity to process information and to remove the experience of social anxiety or awkwardness. Ten parents of individuals with ASD were also purposively selected. Some were the parents of the individuals with ASD who were interviewed and others were parents of a young adult with ASD who was currently employed, had been employed or was still looking for a job[34]. The final sample size of five individuals with ASD and eight parents was determined by data saturation.

Research procedure and ethics

Once ethical clearance from the Human Research Ethics Committee (M170928), at the University of the Witwatersrand and permission from the manager of the support group was obtained, recruitment of the participants for the study was initiated. The researcher presented the proposed study to the support group members at one of the meetings. An interview schedule for the email interview was developed and checked for content validity by a colleague and the study supervisor to ensure that the questions were representative of the objectives of the study. Interviews were practiced with them in separate instances, using the same interview questions that were to be used with the participants. The participants were interviewed over a three-month period using either email or face to face interviews. For participants with ASD, emails were sent back and forth (between three and five times with each participant) until there were no more probes from the researcher and the participant had no more information to add. Face to face interviews lasted approximately one hour and were recorded with permission of the participants. These interviews were transcribed word for word and the email interviews de-identified for data analysis.

Data analysis

Participants gave signed consent for demographic details used in this study to be presented. Six steps of data analysis recommended by Creswell[32] regarding inductive thematic analysis (codes, categories and themes) were used in the study. This included organising and preparing the data by transcribing the interviews, reading the transcripts and emails to reflect on the overall meaning, coding the data, developing categories and themes for analysis, and interpreting of the findings.

Trustworthiness

Trustworthiness included member checking by sending through summary of themes after data analysis by email to the participants in order to ensure data analysis truly reflected the opinions and perspectives of the participants[35]. Thick description to convey the findings from individuals with ASD and their parents was ensured since the researcher was able to interpret the data within the particular context. Clarification of bias was addressed in frequent meetings between the researcher and the supervisor to achieve an objective view[32] and allow the researcher to reflect on her own expectations and biases[36] so that she was aware of them before interviewing the participants so as not to influence the participants in any way. The researcher kept a reflective journal and created an audit trail. Negative or discrepant information that was contrary to the literature and expectations was included and supported by peer debriefing with a colleague and the supervisor[37].

RESULTS

Demographic data

The demographic data of the five individuals with ASD and the eight parents who participated in the study as well as their pseudonyms are represented in Table I (below). All the individuals with ASD had been employed for at least three years and two had been employed in multiple jobs. The parent participants, except one, were employed at the time of the study.

Themes emerging

Two themes emerged from the interview data in relation to the objectives of the study, and are shown in Table II (below).

Theme 1: Transitioning was really hard.

The theme Transitioning was really hard describes the experiences of individuals with ASD in seeking and maintaining employment. This theme highlighted several unmet needs for individuals with ASD.

> "Moving to the labour market is, from my perspective, is difficult for everybody. But I think for people with ASD it is even more difficult as they don't know what to expect." **(I1 Warwick)**

Getting employment is difficult.

Difficulties mentioned by participants clustered around the issue of finding a job, being prepared for the job seek-

Table I: Demographics of individuals with ASD and parents

Pseudonyms		Gender	Age	Employed	Employment	HLOE
I1	Warwick	M	32	Yes	Environmental specialist for – 5 years	Doctorate
I2	Matthew	M	37	Yes	A support specialist - 4 years	Matric Certificate
I3	Marietta	F	34	Yes	Secretary – 3 years	Matric Certificate
I4	Hope	F	27	No	Nurse - 6 years, looking for a job	Certificate
I5	Carlo	M	25	Self-employed	Repair of musical instruments - 3 years	Technology certificate
Pseudonym and child's name		**Gender**	**Age**		**Parental Employment**	
P1	Nadia (Carlo)	F	45	Yes	Teacher	
P2	Anne	F	54	Yes	Secretary	
P3	Isabella	F	47	Yes	Accountant	
P4	William (Matthew)	M	56	Yes	IT support engineer	
P5	Annemarie (Hope)	F	54	Yes	Secretary	
P6	Thabiso	M	66	Yes	Doctor	
P7	Regina (Warwick)	F	71	No	Pensioner	
P8	Hattie	F	53	No	Unemployed	

Table II Themes, categories, and subcategories

Theme	Category	Subcategory
Transitioning was really hard	Getting employment is difficult	• did not understand the process and we lack job seeking skills
		• find life changes difficult and it is not easy finding the right fit
		• schools do not equip with transitioning skills
	Challenges in the workplace	• just don't fit in and struggle with workplace attitudes
		• lack of reasonable accommodation
Occupational therapists can do more	Perceptions of and suggested role for occupational therapy	• perceptions were positive and negative
		• role such as case managers and in skills training, job hardening and adaptation to a workplace

ing process, and keeping a job. Participants elaborated on why individuals with ASD found it difficult to find a job thus contributing to difficulties in transitioning into the workplace after school. They **did not understand the process** and had unrealistic expectations, misunderstanding of how the job seeking process worked:

> "Understanding how the job market works was a challenge. I expected jobs to ask me, not me having to look for a job. I misunderstood the job market." **(I2 Matthew)**.

The **lack job seeking skills** meant that participants had relied on other people who they know to get jobs for them regardless of how skilled they were in certain jobs. They reported that they did not know how to apply for jobs.

> "Autistics who do get jobs tend to be the ones that have a big support system, especially within their fields of interest, and 'expedition assistants' helping to get jobs through the back door. As a group and in general, Autistics tend to be round pegs and the typical job search application submission and especially the interview are square holes." **(I5 Carlo)**

It was clear that finding gainful employment was hard for this group of individuals with ASD and many reported they felt side-lined when disclosing their diagnosis. However, the difficulty did not end with the successful job application. This was only the first hurdle in transitioning successfully into the workplace. Participants reported that they **found it difficult to adapt to change** and having to adapt to a new environment is a challenge This makes it difficult to adjust to workplace demands, especially if there are changes in those demands.

> "think if it's a person that had already built a relationship with the individual with ASD, it will help them, as the transitioning into labour market is a big adjustment for the individual with ASD. Any change to them make them to be unsettled……" **(P3 Isabella)**

Participants stated that it was a struggle for them to **find a right fit** in the job market and that individuals with ASD appeared socially awkward. As a result, they felt that they were left out of the job market. Participants admitted that there were certain skills they felt they need to learn to combat some of the challenges they are faced with, such as life skills.

> "People with ASD will have to get training on People skills, conflict resolution and office etiquette." **(I1 Warwick)**

Schools that they had attended, did not **equip the children with any transitioning skills** or the necessary skills to function in the labour market.

> "………And the schools do not train them for any opportunity to go and work. They train them mostly to be able to be functional and to be self-sufficient so that they can almost become adult like. But there isn't anything of specific, of [work] type of training for any type of situation." **(P6 Thabiso)**

Their perception was that at LSEN schools, the child's individual needs and interests were never supported. They reported the Programme-to-Work Linkage suggested by the Department of Basic Education, for LSEN schools, in which learners master the required skills at school level to enter adulthood with sufficient education, to obtain and maintain successful employment[38:33] was not being implemented.

Challenges in the workplace

From the interviews it was clear that getting a job was only the first step in transitioning successfully into the working environment and that keeping a job was in some cases even more difficult than finding one. Fitting in, workplace attitudes and stigma contributed to the failure of individuals with ASD to navigate this transition successfully. Issues around fitting in also seriously affected individuals with ASD's ability to keep a job. Issues identified by the participants were a struggle to read verbal cues, and a lack of social and communication skills.

> "It was difficult for me to find a job; I was emotionally very young and struggled to fit in with my peer group." **(I4 Hope)**

> "…. It makes it difficult because they can't fit in. They just don't fit in and my son doesn't fit in, and that's it. He does not have friends and does not mingle with others." **(P8 Hattie)**

Participants perceived workplace attitudes as both positive or negative since not everyone in the workplace treated them unfairly. However, even though some participants described a supportive work environment,

> "…. They are very objective at first because they are unaware of his disability. They haven't been exposed to this disability. But the minute they are exposed, they accept them." **(P1 Nadia)**

most felt they were not being treated fairly by their co-workers.

> "At my workplace, I principally work individually on "my" projects but with help and input with other colleagues who go on to be listed as co-authors. I would call this environment "quasi-collaborative". Office environment/ colleagues are very supportive/friendly and understanding." **(I5 Carlo)**

As a result of negative treatment, some participants reported they **struggled with workplace attitudes** and were not comfortable disclosing their diagnosis. They reported discrimination when others knew about their ASD and they found themselves settling for menial jobs and they overworked themselves just so that they could be accepted.

> "Autistic people have to be double as good in what they do to prove themselves…. Or that they do lowly work." **(I3 Marietta)**

Sometimes when they disclosed their ASD at their workplaces, rather than being well accommodated they were ill-treated, got demoted or certain responsibilities were removed. Participants were also concerned about the **lack of reasonable accommodation** within the workplace and felt that this seriously impeded their ability to keep their jobs and thus make a success of the transition into the job market.

> "And then also the work environment accommodation such as light, sound and so on. That is also an educational part to the employers to keep the environment conducive." **(11 Warwick)**

In some cases, parents still supported their children in managing their work environment to ensure they maintained employment. They have to attend their children's work functions with them, arrange for their work trips and follow-up with their children's employers on how these individuals are managing at work.

Theme 2: Occupational therapists can do more

Participants indicated they perceived that occupational therapists have the potential to provide more services than those they are offering at the moment. They stated that with the skills the occupational therapists' have, individuals with ASD could be better assisted through their transition into the labour market. They felt that currently the focus of occupational therapy intervention is more on children than adults.

> "I think the research that you are doing is really needed because there is almost a perception out there that autism is a childhood condition, and it will be outgrown at some stage. The reality is, it's not and I think people tend to forget about the ASD children when they leave school, and they are left to try and figure out the way to survive in the adulthood world. And I think it is very important to try to get a support system in place." **(P7 Regina)**

Participants **positive perceptions** of occupational therapy included improved functionality and assistance for individuals with ASD in understanding their diagnosis. Therapists were seen as having taught them life skills that are beneficial during their transition into the labour market.

> "The value of occupational therapy is finding something that works for them [people with ASD]. But I mean there is definitely value for occupational therapy intervention, but I think that, occupational therapist should go to the next level." **(P1 Nadia)**

> "OT brought about the truth and proof of my autistic behaviours. I think without OT I wouldn't be able to function or have my diagnosis." **(I5 Carlo)**

Other participants had **negative perceptions** reported it was difficult to work with some occupational therapists who showed no interest in helping individuals with ASD. They were seen as impatient and as not respecting the individuality of the person but only effects of the diagnosis. The therapists focused more on what the individuals with ASD could not do rather than assisting them to improve their level of functionality

> "Professionals that keep on hampering on normalcy – they try to get everybody as much to the same as possible, instead of developing the individual's personal experiences of their world into something workable." **(I3 Marietta)**

There are a number of perceived roles that occupational therapists, perceived as the experts in the field of vocational rehabilitation by participants, can fulfil, including **case managing, skills training, job hardening and adaptation to the workplace.** This includes assessment of the client, identification and placement of a client in an identified suitable job aligned with the client's skills as well as raising awareness about mental health issues in the workplace:

> "I mean advocacy for these individuals will be really great. Getting people more exposed to people with this disability as it still has more negative connotation that people with disability can't do anything. Advocacy that these people may have disabilities, but they do have abilities." **(P1 Nadia)**

> "It could help if employers could be better informed about what it [ASD] is and what the person with Asperger's is capable of doing. If this comes from professionals like you. It may carry more weight than the word of the person who has Asperger's or autism." **(I4 Hope)**

Participants wanted occupational therapists to help ease the transition and help both individuals with ASD and the people who employ or work with them to understand what is needed during the transition into the labour market.

The participants also expressed a need for the individuals with ASD to be **trained in certain skills** that would assist during transition process.

> "They need to be assisted in developing life skills e.g., developing friendships, participating in activities of everyday, engaging in productive conversations." **(P5 Annemarie)**

> "…. Self-regulation (e.g. what to do if you get emotional, if you feel a meltdown coming, when you get angry, etc." **(I4 Hope)**

> "I think preparing them for what to expect in life after school in a sense and teach them skills on how to cope with difficult situations that they have not encountered as yet." **(P3 Isabella)**

Apart from skills training, the participants felt **job hardening** during transition process into the labour market would be desirable. It was stipulated that, individuals with ASD get appointed into different jobs not knowing what is expected of them. The participants expressed the need to have an occupational therapist available to prepare individuals with ASD on how job markets operate and how they must carry themselves.

> "Explain the reasons for having to actually look for a job. Coach us in confidence for interviews and what to expect." **(I1 Warwick)**

> "Yes, training in how to conduct yourself in an interview, how to sell yourself and social integration as well as sensory issues." **(I4 Hope)**

The participants were also concerned that individuals with ASD struggled to adapt in a work environment. They therefore indicated a need for the individuals with ASD to be taught **adaptation to a workplace.**

> "I also think that it would have been much easier for most people with autism if there were someone that could help them with the adaptation into a new work environment." **(I1 Warwick)**

> "They need skills to keep themselves calm and how to cope in a work environment. Teach them to be independent in a way." **(P3 Isabella)**

DISCUSSION

Data from the participants in the study supported issues transitioning into work since they were purposely selected and represented high functioning individuals with ASD. These participants had an opportunity to complete school and post-secondary training and were able to find and maintain employment in the open labour market in South Africa. The sample is similar to that described by Soeker[17] in his study on transition for this population into work in South Africa. Most of the parents, who were also included in the study were employed, many in professional positions, that suggested a socio-economic status which meant they had resources to assist their children. This supports research that reported that adults with ASD who were from higher-income households, had better conversational or functional skills, or attended postsecondary schools had more positive employment prospects[38].

Participants in this study (both those with ASD as well as parents) reported that the transition from school to the labour market was a difficult and stressful time – even more so than the usual stress of raising a child without a disability. They concurred that individuals with ASD lack of job seeking skills and prevocational skills necessary for labour market due to the non-availability of services for specific work transition including a lack of career preparation services and a poor knowledge about suitable careers, the work environment and employment activities[15,40]. The parents reported a lack of public special schools which could accommodate their children as it is only since 2016 that the Gauteng Department of Education has opened ASD units in LSEN schools[40] to reduce waiting lists. The parents in this study were unable to benefit from these recent changes that do provide more accessible and financially affordable public schools for individuals with ASD[41], although problems with accommodating all children still exist.

The first step in navigating the transition to the labour market successfully is finding a job. Participants in this study found the job seeking process difficult. The literature confirmed that regardless of their education level, individuals with ASD struggle to get employed and spend a significantly longer time looking for a job[39,42]. Participants with ASD had many misconceptions as to how one goes about finding a job. They believed that job opportunities should come knocking on their doors and were surprised by the need to actively look for a job. Participants with ASD, even those who were highly qualified, reported they therefore attained their jobs through the help of known others, relying on friends, family and on teachers[42], due to the negative attitude they experienced from prospective employers. Baldwin et al.[43] report that 41% of the participants with ASD in their study were assisted by the people they know to obtain jobs and as reported in the current study disclosing a diagnosis of ASD cost them a number of job opportunities[31]. It seems when known others assist with finding a job, employers may have better knowledge about ASD and this confirms the need to inform employers about the ability of individuals with ASD, to overcome the negative connotation experienced by participants in this study.

If individuals with ASD did manage to get a job, higher expectations for communication skills, than those in the school situation meant participants with ASD felt unprepared[44]. Briel and Getzel[44] indicate the importance of career guidance that will support an individual with ASD in choosing a career that does not rely on good interpersonal skills but accommodates their strengths. However the parents of individuals with ASD reported that their children were just not fitting in at work and that transition process needs to be done over a prolonged period[31]. Both personal and environmental factors contributed to the inability of the participants with ASD, to keep their jobs[45] and they agreed with their parents that they struggled to fit in with a peer groups, could not make friends and struggled in adapting to change. Added to the personal challenges were the environmental challenges including being stigmatised for having a diagnosis of ASD.

Disclosure was associated with limitations in terms of employment advancement and promotion which sometimes resulted in participants resigning from their jobs. There is controversy in the literature about disclosure by the individual about their diagnosis of ASD to their employer. The act of disclosing requires a level of emotional, and social conversation that may be difficult for an individual with ASD due to their communication deficits and social anxieties[46]. Ohl et al.[47] however reported that disability disclosure actually contributed to successful employment retention in the United States since disclosure allowed for reasonable workplace accommodations. These findings were supported by some of the participants in this study because their immediate supervisors knew of their ASD diagnosis and therefore provided them with the support they needed. These findings confirm that a strengths-based approach which could be used to assist those in the workplace understand the positive aspects that an individual with ASD such as *punctuality, low absenteeism, high quality of work, prompt task commencement and strong work ethic* [48:882].

Some of the ASD participants indicated that they sometimes got frustrated as they struggled to cope with environmental characteristics such as light, noise and the office set-up that were *too much for them*. This occurred even if their colleagues and employees accommodate them and Baldwin et al.[43] indicate that workplaces are often unsuccessful in providing accommodations and adjustments and maximisation of the *person-environment fit* for the individuals with ASD. This is due to the characteristics of the workplace and their impact on a person with ASD being poorly understood. It has been suggested that people who supervise, interact, or collaborate with the individuals with the diagnosis of ASD need to be patient, flexible and tolerant in order for those individuals to maintain their employment[20] and employers and colleagues also need to be educated about the characteristics of people with the diagnosis of ASD. In this study some participants who were employed reported that they were fortunate enough to work in environments which did not negatively affect their work performance as they had been accommodated by changes to communication processes because of supportive employers or a mentor and the right fit in their job. Thus, keeping a job was depended not only on the work but more importantly on the people in the work environment and the implementation of specific accommodations[20]. Parents reported that they were very involved in the support their children and one parent indicated that she had to travel with her son on his business trips. Other parents in this study also reported that they assisted their children through the transition process and had to continue to support their children for long periods. As indicated in literature parents often continue to be the primary caregiver until individuals with ASD reach well into their adulthood years[49].

The participants reported that they felt that there was no support at all for them and their children in terms of preparing them for employment and supporting them in employment. They voiced the need for vocational services so that their children could be trained and prepared for suitable future professions and work endeavours. The participants believed therefore that occupational therapists have a role in supporting the individuals with ASD to transition smoothly into the labour market. Participants reported however that some occupational therapists were not at all supportive and sympathetic to individuals with the diagnosis of ASD and that generally occupational therapists do not provide intervention for older individuals with ASD during transition period into work[17]. On the other hand, some participants reported that there was value to occupational therapy services and that occupational therapists could play a key and more effective role in enhancing the service delivery to improve employment outcomes for individuals with ASD[8].

The strategies suggested in the study by Frank[50] and Hillier et al.[13] include life skills, employment skills and other skills that apply to adapting to either college life or adult life. Research indicates that individuals with ASD that receive these vocational rehabilitation services have more positive employment outcomes[51]. Occupational therapists are able to evaluate the individual's psychological, and cognitive functions then link the individual's functional abilities to those required by the job. Participants felt that if the occupational therapists exercised this role the individuals with ASD would not find themselves in the work environments where *they don't fit* and fail to keep their jobs. Therefore, this suggested that occupational therapists can indeed play a role in the life of the individual with ASD in transition into the workplace, since they are well equipped and trained to provide such services[30].

The participants reported that it was important that occupational therapists coached the individuals with ASD as a preparation to the labour market transition by providing work practice on different job types. This is a service which occupational therapists could provide meaningful opportunities to improve general employment skills and career readiness. Employment training could also include on-site experiences in a variety of work settings, both paid and non-paid[27,52.] Scaffolding techniques and referral to job coaches or professional supports should also be utilised to ensure proper transition in the work place[53].

The participants emphasised that most of their colleagues and employers are not informed about ASD and that occupational therapists could work together with employees and supervisors to improve adaptation of individuals with ASD in different labour markets. The International Society for Research[54] added that instead of using *blanket training*, training the unique needs of each individual with ASD should be considered and how to support them. They believed that occupational therapists have skills for advocating for individuals in the workplace [31].

Study Limitations

Participants were from a middle-class socioeconomic background and had access to significant financial resources to provide for training for their children with ASD. Most individuals with ASD had jobs and some form of income. Their experiences may not represent those with fewer economic resources, who are not financially stable and therefore could not access the same services as the participants of this study.

There was no diversity in cultures involved as Afrikaans speaking people predominated. People who failed with their employment transition and who have not got employment were not interviewed. Thus, the research findings are not transferable to many other individuals with ASD in South Africa.

CONCLUSION

Individuals with ASD and their parents voiced the opinion that it was a real struggle to navigate the transition from schooling into the labour marked successfully in South Africa. Analysis of the data confirms that individuals with ASD require more support in both preparing for the transition as well as while navigating the transition itself. The unmet needs in relation to employment support are increasing for the population of adults with ASD in South Africa. Vocational rehabilitation programmes to provide training and supported employment for individuals with ASD are needed.

The participants suggested that occupational therapist have a role during the transition of individuals with ASD into the labour market. They identified services which could be offered by occupational therapists and the areas where they can effectively assist to facilitate transitioning process such as case management, work hardening, skills training and advocacy. It is crucial that occupational therapists in South Africa consider what they could be doing to prepare individuals with ASD for transition into the workplace. Occupational therapy services to improve career choice, modification of occupations or the environment to support occupational engagement in work and the enhancement the ability of individuals with ASD to engage in the work occupations want to, need to, or are expected to do should be implemented and collaboratively researched with individuals with ASD and other stakeholders.

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Conflict of interest declaration

The authors have no conflicting interests to declare.

Author Contributions

Bonang Mhlekwa conceptualised the study and completed data collection and analysis and interpretation of data. Denise Franzsenand Lindsay Koch supervised the research study and provided guidance during research for analysis and interpretation of data. All authors contributed to the conceptualisation and writing of the article.

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RESEARCH ARTICLE

Development and evaluation of face and content validity of a survey to examine wound management by occupational therapists in hand therapy practice within the South African context

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ABSTRACT

Background: Wound management is internationally recognised as part of hand therapy practice. However, the role of occupational therapists in this area of upper limb rehabilitation in South Africa is unclear.
Aim: To develop and validate a survey to examine occupational therapists' wound management practices in hand therapy within the South African context.
Methods: A sequential exploratory mixed methods study design was utilised to develop a survey. Thereafter, a panel of 11 occupational therapists with relevant experience in the field rated the relevance of survey items to produce item-content validity indices (I-CVIs).
Results: An initial survey containing 27 questions containing 214 items was presented for review. Experts rated 171 items (69%) relevant with an I-CVI of 0.90-1.00. A further 32 items (13%) were rated relevant with an ICVI of >0.80 <0.90. A total of 45 items (18%) were irrelevant with I-CVIs ≤0.80. The final survey consisted of 19 questions containing 139 items, excluding those that obtained relevant demographic data.
Conclusions: The survey demonstrated good content and face validity but is limited to use with occupational therapists in South Africa. Validation for use with different populations in different settings is recommended.

Implications for practice

This article offers researchers within the field of occupational therapy methodology for the development and validation of a survey. Suggestions for improving the overall validity of the survey are given. The survey may be used in future studies with occupational therapists providing hand injury care in South Africa. Use of the survey with different populations requires validation using the intended target population.

INTRODUCTION

Wound management is internationally recognised as part of hand therapy practice[1,2]. The hand therapy practice profile, as presented by the International Federation of Societies for Hand Therapy, outlines wound management as a specialist therapeutic skill[1]. Furthermore, the American Society of Hand Therapists' position paper on hand therapists' scope of practice outlines that hand therapists assess characteristics of the wound and the impact of activities and positioning of the hand on wound healing[2]. A survey conducted with hand therapists across sixteen countries to determine contemporary upper limb rehabilitation practices further supports that wound management activities are part of holistic intervention[3].

In South Africa, formal hand therapy accreditation is not a requirement for practice. Even though there is a demand placed on occupational therapists within the South African context to treat complex upper limb injuries[4], there is limited literature on the practice profile or core skills for hand therapy practice in the country, including wound management.

Compared to global statistics, South Africa has a very high burden of injury[5]. Although statistics on the burden of hand injuries in South Africa are limited compared to global statistics, South Africa has higher rates of interpersonal violence and road accidents[6], which have been reported to contribute to a greater prevalence of hand injuries[7]. High rates of hand injuries in a population of manual labourers contribute to hand injuries in a South African state hospital[8]. These work-related injuries, together with traumatic injuries[8], firework-related hand injuries[9] and tendon injuries[10] treated in South African hospitals, indicate a high prevalence of hand wounds. Anecdotal evidence based on the first authors experience and engagement with colleagues in the field further suggests that in practice, occupational therapists in South Africa regularly encounter hand wounds during therapy interactions with patients with hand injuries.

The views of practising occupational therapists on their role in wound management in hand therapy within the South African context have not been determined. Furthermore, an in-depth investigation of the practices of occupational therapists in providing interventions related to wound management to hand injured patients and their level of preparedness to manage hand wounds in South Africa has not been conducted. Given the unique context, a need to examine wound management in hand therapy within the South African context was identified.

The authors developed a survey following similar stages to those reported by other scholars[11] that involved reviewing relevant literature, conducting individual semi-structured interviews, thematic analysis of qualitative data, initial item generation, and review of generated items. To ensure the reporting of credible research findings, consideration was given to the rigorous development of the survey[12]. It is well understood and documented that drawing accurate and valid inferences from research findings relies upon the instrument's validity, in this case, the survey and that in the absence of rigorous development, the credibility of reported results may be disputed[12, 13, 14, 15, 16].

The use of mixed methods research, in which qualitative data informs item generation, for developing an appropriate survey has been documented by authors such as Onwuegbuzie and colleagues[17]. Using qualitative findings to inform item generation enhances the survey's content validity[11, 13, 16-19]. Using qualitative findings enhances the value of generated items as they are obtained from the population of interest and reflect their opinions, perspectives, perceptions and experiences[11, 16, 18].

The evaluation of generated items by individuals who are part of the target population and who are considered knowledgeable in the field is documented as a further means to enhance the overall validity of a survey[11, 13, 18, 20-22]. Qualitative feedback on the acceptability of a survey is a means to ensure face validity[23], which has been described as the extent to which the items appear relevant, important, and interesting to the respondent[17 (p.60)]. A described method of content validation by quantitative review involves rating the relevance of items to produce a content validity index (CVI) for each item[11, 13, 22]. Content validity has been described as the relevance and representativeness of items in an instrument for its intended setting and purpose[11, 20]. The minimum requirements for excellent content validity of an instrument, as reported by Pilot and Beck[24] are I-CVIs ≥0.78 for a panel of six or more reviewers and a scale level CVI (S-CVI), calculable by adding the I-CVIs and dividing by the number of items to obtain an average, ≥0.90.

The aim of this paper is to describe the development of a survey for use with an occupational therapy population to examine wound management in hand therapy within the South African context. The process of evaluating the face and content validity of the survey by both qualitative and quantitative review by occupational therapists knowledgeable in the field is described in detail. Other aspects of validity, construct validity, were not assessed.

MATERIALS AND METHODS

Process for survey development

The survey was developed in two stages: initial item generation and survey review. A sequential, exploratory mixed methods study design informed the development of the survey[25]. The process of using qualitative data for the development of a quantitative data collection tool - the survey - is described in detail in this paper.

Study setting

The survey was developed for use with occupational therapists providing interventions to patients with hand injuries in South Africa. South Africa has a total population of 57,73 million within nine provinces. Both public and private health care are available in South Africa.

Stage one: Initial item generation

Relevant literature and qualitative data from individual interviews with occupational therapists with appropriate work history and experience in the field of hand therapy informed the generation of initial survey items. Expert opinion was used as a source of information due to the dearth of evidence of the role of occupational therapy and current wound management practice in South Africa.

Review of relevant literature: Given that the purpose of the survey was to examine wound management with specific reference to hand injuries, literature on wounds resulting from pressure sores or ulcers and burn injuries was excluded from the review. A literature search was conducted using Google Scholar, and literature on the role of occupational therapy and current practice in wound management in hand therapy was identified. A minus sign is used in search strings to specifically exclude a word or phrase from the search, in this case burn, pressure and ulcer. The following are sample search strings that yielded the highest number of relevant results: 'occupational therapy OR therapist' AND 'wound treatment' -ulcer -burn; 'Hand therapy OR therapist' AND 'wound management OR care' -pressure -ulcer; 'certified hand therapy OR therapist' AND 'wound management OR care'; 'hand rehabilitation' AND 'wound management OR care' -burn -pressure -ulcer; 'occupational therapy OR therapist' AND 'wound management OR care' AND 'Injured hand OR hands'; 'hand rehabilitation' AND 'wound management OR care' AND 'hand injury OR injuries'. Items were drawn from a position paper brought forward by the American Occupational Therapy Association

(AOTA)[26], which describes the role of occupational therapy in wound management, to partly examine what occupational therapists in South Africa perceive their role to be. Further items drawn from this paper were specified interventions that occupational therapists may perform to ameliorate wounds that AOTA states to be within the scope of practice of occupational therapists in United States of America. These were utilised in the survey to determine the wound care activities used by occupational therapists in South Africa to facilitate wound healing in patients with hand injuries. Specified interventions for wound healing as discussed by Keller et al.[3] were further used to augment this section of the survey. These interventions were further used to partly inform specific areas of inquiry within the survey addressing the confidence of occupational therapists in using wound management interventions and when they acquired the knowledge and skill for using such interventions. Findings reported in Keller et al's[3] study, also partially informed response scales in the survey examining when and how occupational therapists acquired the expertise to use wound management interventions.

Qualitative data from individual interviews: A semi-structured interview guide was constructed following phases of development described by Kallio and colleagues[27]. Non-probability purposive sampling[28, 29] was utilised to select knowledgeable and experienced participants in the South African context of hand therapy. Maximum variation sampling[29], a purposive sampling technique, was employed to obtain varying points of view on the role of occupational therapy in wound management in hand therapy. Semi-structured interviews were conducted with seven occupational therapists meeting the predetermined selection criteria. The inclusion criteria were (i) qualified occupational therapist; (ii) registered with the HPCSA; (iii) working in the field of hand therapy and/or an academic in the field of hand therapy; (iv) holds post-graduate qualification/s in hand therapy or has more than 15 years of experience in the field of hand therapy. In the view of the authors, holding a post-graduate qualification in hand therapy indicated that the individual participant would have the relevant experience in the field as post-graduate courses require that therapists have experience in hand therapy to enrol. Therapists also need to be treating hand injured patients throughout the course of their post-graduate studies. Occupational therapists who obtained the majority (more than fifty percent) of their expertise in hand therapy in a country other than South Africa were excluded. Interviews were conducted over a two-week period. Twenty occupational therapists were screened for eligibility, and 12 did not meet the selection criteria. Eight were invited to participate, and one occupational therapist declined due to reportedly not being involved in wound management in practice. Table I (page 23) illustrates the demographic profile of the participants. All (n=7) of the occupational therapists that were interviewed were female with a median age of 36 years (range 26-48 years). The median number of years of experience working in the field of hand therapy was 14 years (range 4-21 years). Postgraduate qualifications in hand therapy were held by all (n=7) of the participants. 71% (n=5) of the participants obtained most of their experience in hand therapy in public health care settings and 29% (n=2) in private practice. Participants hailed from four of the nine provinces in the country.

Interviews were audio-recorded and transcribed verbatim by the first author. Interviews focused on participants' views of the role of occupational therapy in wound management in hand therapy, the current wound management practices, and factors influencing the preparedness of participants to manage hand wounds. A thematic analysis[30] of qualitative data from semi-structured interviews ensued by the first author. Debriefing with the second and third authors assisted in ensuring credibility[31]. The process of debriefing ensured that results were representative of data provided by participants[32]. An inductive approach allowed for data emerging from semi-structured interviews to inform the content of the survey (item-generation). Questions were structured, and items were grouped to reflect emerging themes. Qualitative data were used to identify factors related to specific areas of interest for which no literature was identified to draw on. For example, interviewed occupational therapists discussed factors that support or hinder their practice in the provision of wound management interventions to patients with hand injuries within their various practice settings, including access to supervision and mentorship and communication in the MDT. These factors were then used as items in the survey to determine to what extent a larger sample of the population experience these factors as barriers or enablers.

Data from the qualitative enquiry were also used to complement items drawn from literature. This enhanced the overall validity of the survey to obtain information from its intended target population. Items examining when occupational therapists acquired the knowledge and skill for the use of wound management interventions were developed using literature and findings from individual interviews. This also applied to items investigating any previous training and experience that might have influenced their level of preparedness for providing such interventions. Through using an inductive approach to thematic analysis, data were also used to further inform additional research objectives, such as examining the wound management training needs of occupational therapists, for example. Items generated from information provided in interviews were reflective of qualitative statements and included the language used by participants to enhance content validity[18]. Table II (page 24) illustrates the use of qualitative data to generate survey items. The survey, following development and review, contained 19 questions, excluding questions used to gather participant demographic data, and each question had several items included within. For example, question 15: *With specific reference to treating patients with hand wounds, to what extent do you agree or disagree that occupational therapists have a role to play in the following?* had 11 items, each requiring a response. Two item examples are cited: educating patients on wound care and providing sensory education to prevent wounds. Participants were required to select either agree, neither agree nor disagree, or disagree for each item in this question.

Stage two: Survey review

To assess the survey content and face validity, the initial pool of items was reviewed between a month period by a panel of occupational therapists meeting the predetermined selection criteria. Reviewers were more in number than those who participated in interviews for qualitative data collection and were not necessarily the same occupational therapists as those who were interviewed for initial item generation as mentioned in stage one. The inclusion criteria differed from the initial phase only in terms of two criteria, namely occupational therapists working in the field of hand therapy between 2015 and 2020 and those who held postgraduate qualification/s in hand therapy and/or had a minimum of five years' experience in the field of hand therapy. The exclusion remained as aforementioned. Reviewers were selected using non-probability maximum variation purposive sampling[28, 29]. A total of 27 occupational therapists were invited to review the survey, and 16 declined. A panel of 11 reviewers was acceptable as a minimum of three is recommended in literature[24]. Table III (page 25) illustrates the demographic profile of reviewers. 100% (n=11) of the reviewers were female with a median age of 34 years (range 30 - 51). 9% (n=1) had five years' experience in the field of hand therapy, and 91% (n=10) had six years or more experience. 64% (n=7) worked in private health care settings, and 36% (n=4) worked in public health care settings. Reviewers hailed from five provinces in the country. 36% (n=4) had obtained postgraduate qualifications in hand therapy, and 46% (n=5) held a Master's degree in occupational therapy. The panel (n=11) completed the survey online and provided quantitative and qualitative feedback which guided the survey revision prior to the presentation of the final survey.

Quantitative review: For review, survey questions and their related items were all considered items. Reviewers rated the relevance of each item within the survey on a four-point rating scale: 1-not relevant, 2-somewhat relevant, 3-quite relevant, 4-highly relevant[24]. A CVI calculation was used to determine the content validity of individual items (I-CVIs)[13]. The number of reviewers that rated an item as either quite relevant or highly relevant, thereby dichotomising the scale into relevant and not relevant, was divided by the total number of reviewers to produce an I-CVI for each item. For items to be considered relevant, they had to achieve a minimum I-CVI of 0.81, which is above the recommended CVI of 0.78 for a panel of six or more reviewers[24]. Items with an I-CVI of 0.80 and lower were removed from the survey, except for two items (the reason for this is explained under survey review and validation below). Microsoft Excel was used to perform CVI calculations.

Qualitative review: Reviewers provided written feedback on the time necessary to complete the survey, the overall coherence of the content of the survey, the ease of using Google Survey as an online platform, any additional items identified as relevant for the survey, and any questions/items that were unclear or ambiguous[33]. Reviewers were also invited with an open-ended question to provide any additional comments. All comments were considered for survey revision. Rating scales, demographic and work history information that was required were confirmed. Due to time constraints related to the predetermined quantitative data collection timeframe, the survey was not resubmitted to the panel following revision.

Ethical considerations

Ethical clearance for the study was obtained from the Biomedical Research Ethics Committee (approval number: BREC/00001029/2020) of the University of KwaZulu-Natal. Participant confidentiality was ensured by de-identification of personal identifying information, and informed consent was obtained from all participants.

RESULTS

Survey description

A self-administered electronic survey was developed using Google Forms, a survey administration application. The final survey presented for use in the study consisted of three sections indicated with headings to make the flow of the survey easy to follow. Section A obtained informed consent. Section B covered relevant demographic and work history, including information pertinent to identifying participants meeting the predetermined selection criteria for participation in the study. Qualitative feedback from a panel of reviewers led to minor changes to the demographic and work history information, including information related to the work setting within which therapists primarily provide wound care interventions. Before review, the survey inquired if participants work in the public or the private health care sector, for example, and reviewers indicated that allowance should be made for both as therapists may work in both sectors. Demographic information finally included respondents age, gender, undergraduate qualification information, registration status with the HPCSA, postgraduate qualification information, history of work experience, and information on respondents' work setting. Figure 1 (below) illustrates the flow of questions to identify individuals that did not meet the criteria who were then redirected to submit (exit the survey).

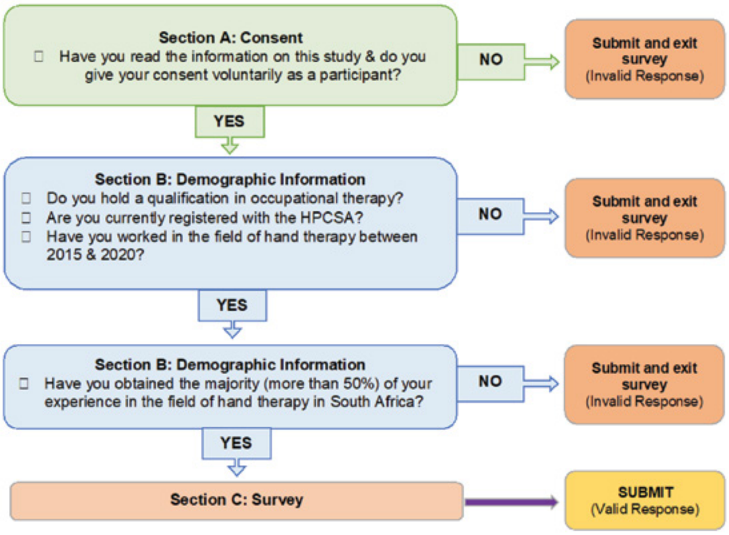

Figure 1: Flowchart of survey design to identify participants who meet predetermined inclusion and exclusion criteria.

Table 1 Demographics of study participants who participated in individual interviews (qualitative data collection) (n=7)

No.	Age (years)	Gender	Undergraduate degree in occupational therapy (University from which and year obtained)	Postgraduate qualification/s in hand therapy (Qualification and year obtained)	Years of Experience (n) working in the field of hand therapy	Setting where majority (>50%) of hand therapy experience obtained	Province where working in hand therapy	Setting where working in hand therapy
001	34	Female	University of Pretoria, 2007.	Postgraduate diploma in hand therapy, University of Pretoria, 2009. MSc dissertation with hand therapy focus	12	Public health care – Tertiary academic hospital	Western Cape	Public health care – Tertiary academic hospital
002	44	Female	Stellenbosch University, 1998.	Postgraduate diploma in hand therapy, University of Pretoria, 2007. MSc dissertation with hand therapy focus	21	Public health care - Specialised hand unit	Western Cape	Academia and Public health care - Primary health care setting affiliated with an academic hospital
003	40	Female	University of the Free State, 2001.	Postgraduate diploma in hand therapy, University of Pretoria 2019.	17	Private health care -Private practice	Eastern Cape	Private health care -Private practice
004	36	Female	University of Cape Town, 2005.	MSc dissertation with hand therapy focus	14	Public health care - Specialised hand unit	Gauteng Province	Academia
005	48	Female	University of Kwa-Zulu Natal, 1994.	Postgraduate diploma in hand therapy, University of Pretoria 2002. Certified hand therapist, Hand therapy certification commission, USA, 2015.	20	Private health care -Private practice	Kwa-Zulu Natal	Academia
006	26	Female	Stellenbosch University, 2016.	Postgraduate diploma in hand therapy, University of Pretoria 2019	4	Public health care - Primary health care setting and District hospital	Eastern Cape	Public health care - District hospital
007	29	Female	Stellenbosch University, 2013.	Postgraduate diploma in hand therapy, University of Pretoria 2019.	4	Public health care - Tertiary academic hospital	Eastern Cape	Public health care - Tertiary academic hospital

Section C captured information relevant to the purpose of the study. Survey questions were categorised according to different fields of inquiry related to the research objectives. Response types included closed multiple choice and checkbox answers, scaled items as well as open short answers allowing for elaboration, justification or specification[33]. All questions apart from the latter required a response. Following initial item generation, this section consisted of 27 questions containing a total of 214 items both drawn from literature as well as qualitative data obtained from interviews and a further seven items prompting respondents to clarify, specify or elaborate upon their answers within specific fields of inquiry, as outlined in Table IV (page 26). Following a review of the initial survey, the number of questions in section C was reduced to 19, containing a reduced number of 139 items.

Table II Some examples of the use of the qualitative data to inform the survey items

Research Questions	Survey questions	Examples of terms that appeared within the survey question, informed by verbatim quotes	
The perceived role of occupational therapy in wound management within hand therapy	With specific reference to treating patients with hand wounds, to what extent do you agree or disagree that occupational therapists have a role to play in the following?	Understanding the impact of a wound on function and participation	(the occupational therapist should) … do a thorough occupational therapy assessment to understand how a wound restricts participation and function. (P002)
The current practices of occupational therapists in providing interventions related to wound management	How confident are you in the use of wound management interventions?	Basic wound care, clean procedures for infection control	…infection control-wise I kind of feel quite comfortable. (P004)
	Why do you feel that there may be a demand for you to be involved in the management of wounds of patients with hand injuries? (please indicate to what extent you agree or disagree with the following statements)	Patients follow up more frequently with OT	patients often follow up with us (occupational therapists) more frequently… (P001)
	Why do you feel that there may be no demand for you to be involved in the management of wounds of patients with hand injuries? (please indicate the extent to which you agree or disagree with the following statements)	Wound care nurse does the wound care	…the occupational therapists didn't need to fill that (wound management) role…because there was nursing staff that did that. (P004)
	How frequently, when conducting an assessment of a patient with a hand wound, do you consider the factors listed below	Access to running water and clean area for wound care	(I would consider) …access to running water, cleanliness of home environment… (P001)
	How frequently, when treating patients with hand injuries, do you use each wound management intervention listed below?	Baths	So, almost every session (for patients with hand wounds), I just start off with a hand bath. (P006)
	How frequently, in relation to wound management, do you provide patient education on the following?	Cleaning and dressing the wound	I'm talking about specifically going through how to do it (with a patient) How to clean it, how to open it, how to redress it (at home). (P003)
	How frequently do you provide any of the following interventions to facilitate participation in meaningful occupations that a hand wound may hinder?	Communicate with a patient's employer	Communication (from the occupational therapist) with employers can be helpful. (P004)
	In your place of work, which team member is primarily responsible for the management of basic wounds of patients with hand injuries? (please select all that apply)	Doctor, Nurse, Occupational therapist	(The team member responsible for wound care) depends on availability of team member. Primarily doctor then nurse but occupational therapist if nobody else available. (P002)
	How frequently, in relation to working with other members of the MDT for the treatment of patients with hand wounds, do you do any of the following? (please indicate frequency for each item listed)	Request dressings that allow movement	…and we can advise (nursing staff) on doing dressings that allow movement and that are not too bulky. (P003)
	In your setting, to what extent are the following a barrier or enabler to you providing wound management interventions to patients with hand wounds?	our knowledge and skill, Access to courses	…correct knowledge, taught the correct skills, being able to go on courses (are enablers). (P001)
The perceived level of preparedness to manage hand wounds	When did you acquire the knowledge and skill to use each wound management intervention listed below? (select all that apply)	Undergraduate education	…your basic understating of physiology and wound healing, I mean you acquire some of that as an undergraduate. (P004)
	How has your previous training and experience influenced your preparedness to provide wound care interventions to patients with hand injuries?	Working alongside and observing other more knowledgeable professionals, consultation of academic texts	…my knowledge (of wound care) is, obviously speaking to doctors and surgeons and, and reading up on wound care. (P007)
	In relation to treating patients with hand injuries, to what extent do you agree or disagree with the following statements regarding the wound care training needs for occupational therapists (please select an option for each item listed)	Wound care does not need to be included in undergraduate training as not all new graduates treat patients with hand injuries	I don't know if you would really say that you would have to do that in University because if you are not going to work in hands you probably don't need to do wound care. (P005)

Table III Demographics of reviewers (n=11)

No.	Age (In years)	Gender	Undergraduate degree in occupational therapy (University from which and year obtained)	Postgraduate qualification/s in hand therapy (Qualification and year obtained)	Years of Experience (n) working in the field of hand therapy	Province where working in hand therapy	Setting where working in hand therapy
001	34	Female	University of the Free State, 2008.	MSc Occupational Therapy. Certified Hand Therapist, 2015.	6-15	Kwa-Zulu Natal	Private health care
002	33	Female	University of the Free State, 2009.	Postgraduate diploma in hand therapy, 2015.	6-15	Free State	Public health care - Tertiary academic hospital
003	30	Female	University of Pretoria 2012.	Postgraduate diploma in hand therapy, 2015.	6-15	Gauteng Province	Private health care
004	30	Female	University of Kwa-Zulu Natal, 2011.	No postgraduate qualifications.	6-15	Eastern Cape	Public health care - Tertiary academic hospital
005	30	Female	University of Kwa-Zulu Natal, 2012.	MSc Occupational Therapy.	6-15	Kwa-Zulu Natal	Public health care – Regional or district hospital
006	41	Female	University of Cape Town, 2002.	No postgraduate qualifications.	6-15	Western Cape	Private health care
007	32	Female	University of the Witwatersrand, 2011.	No postgraduate qualifications.	1-5	Gauteng Province	Private health care
008	38	Female	Stellenbosch University, 2003.	No postgraduate qualifications.	6-15	Western Cape	Private health care
009	41	Female	Stellenbosch University, 2001.	MSc Occupational Therapy.	≥ 16	Western Cape	Private health care
010	51	Female	University of Kwa-Zulu Natal, 1992.	MSc Occupational Therapy.	≥ 16	Kwa-Zulu Natal	Private health care
011	44	Female	Stellenbosch University, 1998.	MSc Occupational Therapy. Postgraduate diploma in hand therapy, 2007.	≥ 16	Western Cape	Public health care – Primary health care and Tertiary academic hospital

Survey review and validation

Quantitative review

An I-CVI was calculable based on reviewer ratings of the relevance of individual items[24]. To calculate I-CVI's, individual questions and their related items were all considered items. Reviewers agreed that 203 items (82%) were relevant. A total of 171 items (69%) were awarded an I-CVI of 0.90 – 1.00, of which 129 (52%) were awarded an I-CVI of 1.00. A further 32 items (13%) were deemed relevant with an I-CVI of >0.80 <0.90. 45 items (18%) were considered irrelevant, having an I-CVI ≤0.80. These items were not revised and resubmitted to reviewers for re-evaluation. The majority, 43 items (I-CVI = 0.56-0.80), were removed from the survey. One question with an I-CVI of 0.75 remained as all four related items had I-CVIs of 1.00. A second question with an I-CVI of 0.75 remained as nine associated items had an I-CVI of either 0.90 or 1.00. Following the removal of 43 items, further revision of the survey was guided by reviewer commentary and feedback from the second and third authors.

Qualitative review

Reviewers provided commentary on the use of language and items that were unclear, ambiguous, repetitive or redundant. They also suggested items that they deemed relevant but were missing from the survey and items for removal. They further provided feedback on demographic information to be obtained and one confusing response scale. All comments were considered whilst finalising the survey.

Reviewers made several suggestions regarding the use of language. For example, with reference to the frequency of provision of patient education (refer to Table IV, page 26), one reviewer suggested changing the item smoking cessation advice and commented that

> "I would rather say information as advice is something

Table IV Outline of the initial pool of survey items

Research Questions	Research objectives	No. and scope of enquiry of survey questions	
The perceived role of occupational therapy in wound management within hand therapy	Perceived role of occupational therapy in the treatment of patients with hand wounds	3	What occupational therapists perceive their unique role to be
			What occupational therapists perceive their role to be, as shared with other members of the MDT
			Reasons for occupational therapists taking on a role in wound management
	Confidence in the use of wound management interventions	1	How confident occupational therapists are in using wound management interventions
The current practices of occupational therapists in providing interventions related to wound management	Nature and prevalence of wounds of patients with hand injuries	3	Percentage of patients with hand injuries treated by occupational therapists on a monthly basis that present with wounds
			Type of hand injuries treated by occupational therapists that may require wound management
			Most common hand injuries treated by occupational therapists that may require wound management
	Demand placed on therapists to manage wounds of patients with hand injuries	3	Is there a demand for occupational therapists to be involved in wound management?
			Reasons for demand experienced
			Reasons for no demand experienced
	Consideration of all components within the ICF framework in treatment planning for wounds	1	Factors considered when assessing individuals with hand wounds
	Wound management interventions used by occupational therapists for the treatment of patients with hand wounds	4	Frequency of provision of patient education
			Frequency of provision of interventions to prevent wounds
			Frequency of provision of interventions to facilitate participation in meaningful occupations
			Frequency of provision of wound care for the amelioration of wounds
	How occupational therapists work with other members of the MDT in providing wound management interventions to patients with hand injuries	5	Team member primarily responsible for wound management
			How members of the MDT work together
			How frequently occupational therapists engage in activities to advocate and educate
			How frequently occupational therapists seek support for wound management interventions
			Examining occupational therapists' relationship with other members of the MDT
	Perceived barriers and enablers to providing wound management interventions	1	The extent to which various factors are barriers or enablers to the provision of wound management interventions
	Factors related to ethical and scope of practice issues	1	Frequency of considering ethical and scope of practice issues
The perceived level of preparedness to manage hand wounds	When occupational therapists acquired the knowledge and skill for the use of wound management interventions	2	When the majority of practical skill was acquired
			When the majority of theoretical knowledge was acquired
	Why wound management knowledge and skill was acquired	1	Reasons for obtaining wound management knowledge and skill
	Previous training and experience that has influenced preparedness to provide wound management	1	How previous training and experience has influenced the preparedness of occupational therapists to provide wound management interventions
	Wound management training needs for occupational therapists	1	Perceived wound management training needs of occupational therapists

No. of items	Examples of items within each survey question
6	Facilitating ongoing employment (1 of 6 items)
7	Educate individuals on caring for their own wounds (1 of 7 items)
6	Improved outcomes of therapy (1 of 6 items)
20	Identifying signs of infection, application of dressings (2 of 20 items)
-	
-	
-	
-	
14	Patients are scared of caring for their own wounds (1 of 14 items)
4	Doctors follow up with their own patients with wounds (1 of 4 items)
21	Medical history, phase of wound healing, social support (3 of 21 items)
12	Educating patients on cleaning and dressing the wound (1 of 12 items)
4	Sensory education for insensate skin (1 of 4 items)
11	Issue assistive devices for one handed use, practice functional use of the affected hand in therapy (1 of 11 items)
16	Application of topical medications, Negative pressure wound therapy (2 of 16 items)
-	
6	Nurses apply dressings according to what the doctor prescribes (1 of 6 items)
5	Advocate for dressings that are less bulky and that facilitate movement (1 of 5 items)
10	Consult for advice for more complex wounds (1 of 10 items)
13	I feel free to engage with other team members (1 of 13 items)
23	Knowledge and skill in the MDT, patient compliance (2 of 23 items)
6	My own level of competence, the potential risk to cause harm (2 of 6 items)
6	Undergraduate education, postgraduate education, first two years practicing in hand therapy (3 of 6 items)
6	
3	It was an interest (1 of 3 items)
11	Undergraduate education (theoretical training), clinical experience (2 of 11 items)
4	Including basic wound management in undergraduate training is a need (1 of 4 items)

> that is offered when asked for it. We don't advise persons to stop smoking, we inform them of the risks and then they have to decide." **(Reviewer 011)**

Reviewers also identified items that lacked clarity. For example, concerning *factors considered when assessing individuals with hand wounds* (refer to Table IV, page 26), one reviewer stated that it was unclear if the item social support was referred to as support within the patient's home environment. The question asking participants to specify which *team member (was) primarily responsible for wound management* (refer to Table IV, page 26) was seen as too vague. A suggestion was made to either clarify if the question refers to basic or complex wounds or to break the question down to differentiate between basic and complex wounds.

Questions that were very similar and that could be integrated were identified. For example, with reference to the *nature and prevalence of wounds of patients with hand injuries* (refer to Table IV, page 26), reviewers felt that the difference between *what type of hand injuries do you treat…* and w*hat are the most common hand injuries that you treat…* was too subtle and that the response to both questions was likely to be the same. They recommended choosing one and expressed a preference for the latter.

Eight items were added on the recommendation of reviewers. These included *access to wound management supplies/consumables and access to wound management instruments to items related to the extent to which various factors are barriers or enablers to the provision of wound management interventions* (refer to Table IV, page adjacent). Reviewers felt it beneficial to differentiate between availability and access. One reviewer stated

> "occupational therapists don't always have access to wound care items as it is presumably not within our scope of practice. So, it's always a struggle to order sterile items, dressings, etc., and to procure equipment such as forceps, hand baths, etc"**(Reviewer 005)**.

In addition to removing items based on I-CVI calculations, comments of reviewers were also considered. *Negative pressure wound therapy and application of physical agent modalities including whirlpool, electrical stimulation and ultrasound are examples of items removed from those listed to investigate the frequency of provision of wound care activities for the amelioration of wounds* (refer to Table IV, page 26). Reviewers primarily reported that they did not know what these interventions were. Thus, they were deemed irrelevant to the population for which the survey was designed.

Discussion

This paper focused on the development and content validation of a survey for use as a quantitative data collection instrument. The survey was developed as no research instruments that would adequately address the aims of the study were identified. The aims included examining the perceived role of occupational therapy, the current practice of occupational therapists, and the perceived level of preparedness of occupational therapists in providing interventions related to wound management (within hand rehabilitation) within the South African context. The authors of the current paper endeavoured to achieve a survey that will collect data that will be useful for its intended purpose by considering aspects of validity in both the process of generating survey items as well as the process of evaluating generated items.

Generating survey items

Several strategies were employed to ensure rigour in qualitative inquiry to enhance the content validity of the survey[18]. As little is known about wound management in hand therapy in the South African context, a sequential exploratory mixed methods design[18] was selected as the most appropriate study design. Using maximum variation, purposive sampling[34] ensured the selection of appropriate participants with the necessary qualifications and experience in the field of hand therapy. The use of a semi-structured interview guide allowed for engagement in discussion arising from questions[35] and allowed for participants to freely provide an in-depth account of their experiences and views[18].

The rigorous development of a semi-structured interview guide further enhanced credibility and included pilot interviews, critical self-evaluation by the researcher[36], and review of the semi-structured interview guide by the third and second authors[37]. Further measures that were taken in data collection included being well-prepared for interviews[31] and accurate verbatim transcription[38]. To enhance credibility in data analysis, a rigorous process of thematic analysis was undertan[35]. Through tabulating coded data, an assessment could be made of the extent to which categories created encapsulated and adequately incorporated all relevant data[36]. A process of debriefing[31] ensured that results were representative of data provided by participants[32]. Finally, a reflexive journal was kept to document and acknowledge biases and assumptions throughout the research process[39, 40].

Evaluating survey items

The evaluation of the survey involved a qualitative and quantitative review. Reviewers provided qualitative feedback on the acceptability of the research tool. The commentary was used to revise demographic information to be obtained to be more relevant, the structure of response scales for ease of use, the use of language to be more appropriate, and items to be more transparent and eliminate ambiguity. The commentary was also used to remove items not relevant to the study setting and add items that were relevant to the setting. These actions were taken to enhance the acceptability of the survey to the intended respondent.

Quantitative review involved rating the relevance of items to produce a CVI for each item as a method of content validation[11, 13, 22]. Content validity Index calculations were performed at an item level, and the content validity was not calculated for the survey as a whole. All the items which appeared in the final survey received a minimum I-CVI of 0.81 with the exception of eight items that were added on the recommendation of a panel of reviewers. Two questions with low I-CVIs were retained, one of which, for example, enquired why therapists may feel that there is no demand for them to be involved in the management of wounds of patients with hand injuries within their setting. This question was deemed essential as qualitative inquiry, as well as anecdotal evidence based on experience of the first author and engagement with colleagues in the field revealed that not all therapists experience a demand to be involved in wound management in practice and that the demand is frequently related to various contextual factors. One reviewer commented that the question felt repetitive of the previous question, which enquired as to the reasons why therapists do experience this demand in practice. The question was retained, and the flow of the survey was designed for therapists to answer only one of the questions by first asking if they experience a demand requiring a yes, no response.

Limitations

Respondent validation, whereby the interpretation of qualitative findings is presented to individuals who participated in interviews to confirm if the interpretation of the information they provided is correct[41] was not conducted, which should be considered a limitation of this study. A second limitation that should be considered is that due to time constraints, interviews were unable to continue until a point of data saturation, where further interviews were not anticipated to obtain any new information, had been achieved[11,18]. A third limitation of this study is that the survey was not resubmitted to reviewers following revisions to re-evaluate face and content validity. Although possible to calculate, a S-CVI would not have been indicative of the validity of the final survey due to revisions following qualitative review of the initial survey. Furthermore, items that were removed based on I-CVI calculations might have also benefited from revision. For example, the item the occupational therapist being in charge of the wound management improves the outcomes of therapy scored low and reviewers expressed that occupational therapists don't have the training to be in charge of a wound. The item needed to be revised to convey the intended meaning of interview participants, which was that they felt that the functional outcomes for patients might be improved if they provided interventions to facilitate healing, thereby being in charge of the wound care, such as suture removal because they had insight into the necessary precautions required to protect structures that were repaired, for example. Further limitations of this study that need to be considered include the limitations of the literature review. Excluding the word burn in the search strings may have excluded relevant studies for consideration within the item generation phase of the survey.

CONCLUSIONS

The rigorous development of a survey was identified as a crucial step in obtaining information that would be useful in addressing an identified gap in scientific knowledge as well as in informing relevant audiences about the need for education, training and mentorship for occupational therapists treating patients with hand injuries and conditions in South Africa. This survey demonstrated good content and face validity for use in a population of occupational therapy practitioners within the South African context. It cannot be extrapolated to different groups in different settings. Other ways to improve the overall validity of the survey for future studies include the use of focus groups to complement individual interviews[18], and conducting cognitive interviews, which involves conducting a pilot study and receiving verbal feedback from participants to determine if the intended meaning of questions is understood by respondents[11, 42].

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Declaration of conflicting interests

The authors have no conflict of interests to declare.

Authors contributions

Lezanne Esterhuizen was the primary researcher as a Master of Occupational Therapy candidate and was involved in the conceptualization of the study, instrument development, data collection and analysis and drafting of the manuscript. Pragashnie Govender and Deshini Naidoo served as supervisors of the study and provided critical input into research design, concept development, design of the instrument and review and critique of the article and in writing assistance.

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RESEARCH ARTICLE

Sensory Processing Dysfunction and Genito-Pelvic Pain/Penetration Disorder: Women share their experiences of participating in a sensory-based home programme

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ABSTRACT

Introduction: Sensory processing dysfunction (SPD) has only recently been described in women with genito-pelvic pain/penetration disorder (GPPPD). However, female sexual pain is a virtually unknown area of practice for occupational therapists providing intervention for adults with SPD.
Aim: To describe the experiences of women with GPPPD with identified sensory processing dysfunction (SPD) who followed a sensory-based home programme.
Methods: Purposive, non-probability sampling was used to recruit participants for the qualitative arm of the study after they presented with SPD in the quantitative part of the study. Semi-structured individual interviews were used to gather information and sufficient information power was reached after five participants were interviewed. Data were analysed descriptively using inductive thematic and saliency analyses.
Results: Two themes were identified. Theme one: Changes experienced after participating in a sensory-based home programme, reflected increased insight into SPD (allowing participants to identify sensory triggers) and intra-personal changes (increased tolerance of sensory stimuli, feelings of control and *I can breathe again*). Theme two: Coping strategies employed by women with SPD and GPPPD, included sensory seeking, changes to home and work environments, positive reinterpretation/growth, acceptance, and socio-emotional support (*you're not the only one. There are plenty of us out there.*).
Conclusion: A sensory-based home programme, catering to specific sensory profiles is beneficial as a non-invasive occupational therapy intervention approach (based on sensory integrative therapy) for women with both SPD and GPPPD.

Implications for occupational therapy:
- SPD in the context of sexual pain is an emergent field in occupational therapy, thus occupational therapists need to expand service-delivery to this population and other practitioners such as gynaecologists must be alerted to occupational therapy as a non-invasive, and non-pharmaceutical intervention option for patients.
- Contribute to the knowledgebase of sensory integration in the adult population.
- Improve the occupational therapist's role in sexuality.
- Emphasize the importance of insight as part of a treatment programme.

INTRODUCTION

Atypical sensory processing has been found to continue into adulthood, impacting significantly on quality of life (QoL)[1–5] and sexual function. Sensory processing dysfunction (SPD) has only recently been described in women with genito-pelvic pain/penetration disorder (GPPPD)[6], a diagnosis related to female sexual dysfunction which usually includes pain, described in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM5)[7]. Very little is known about the co-occurrence of these two conditions in women. Several studies have reported an increased sensitivity to pain in women suffering from sexual pain disorders such as GPPPD[8]. Pain perception, which is central in women who suffer from GPPPD[9], is not only part of the focus of sensory integration (SI), but is also influenced by SPD[3,10] Increased pain sensitivity in women with vulvovaginal pain has also been associated with psychosocial aspects, such as anxiety and depression[11]. Some commonalities have been described between GPPPD and SPD, including pain perception[10], predisposition for developing affective conditions[12] and negative impact on QoL[13].

Women with both GPPPD and SPD may therefore require occupational therapy intervention in addition to other therapies. However, sexual aspects[14] are a virtually unknown area of practice, for occupational therapists who use a sensory integrative approach with adult clients. Occupational therapists who treat atypical sensory processing, or sensory processing dysfunction (SPD), in adults have mostly addressed the interpersonal and relationship aspects affected by SPD, seldom considering female sexual pain.

Even if the small number of occupational therapists with postgraduate SI qualifications who also work with adults are willing to provide intervention for GPPPD, this may result in clients having to travel great distances to get the necessary treatment rendering them unable to see occupational therapists on a regular basis[15]. A home programme used as part of the treatment plan is often a pragmatic solution to address this concern[16]. It can assist with overcoming logistical problems, including limited time for appointments and/or distance from HCPs[17] such as occupational therapists. Home programmes have previously been used effectively in persons with sensory processing difficulties and various other conditions[5,18].

There is a gap in the literature regarding the use of sensory-based home programmes (SBHP) as an intervention option for women SPD and GPPPD because little is known about the co-occurrence of these two conditions. This study aimed to describe the experiences of women with GPPPD diagnosed with SPD who followed an occupational therapy SBHP. The importance of this study is that it could improve the understanding of the role of occupational therapy in sexual activity and sexuality[14,19,20] and more specifically, female sexual pain and elucidate the role of occupational therapy SBHPs in treating SPD co-occurring with GPPPD.

Literature review

Genito-pelvic pain/penetration disorder is described as a sub-category of female sexual dysfunction in the DSM5[7]. This sub-category combined the previous diagnoses of dyspareunia (recurrent or persistent genital pain associated with sexual intercourse) and vaginismus (defined as recurrent or persistent involuntary spasm of the musculature of the outer third of the vagina that interferes with sexual intercourse) found in the DSM IV TR[8]. According to the DSM[5] GPPPD refers to four commonly co-morbid symptom dimensions: difficulty having intercourse, genito-pelvic pain, fear of pain or vaginal penetration, and tension of the pelvic floor muscles. Symptoms of chronic pain related to the female sexual functioning are present, and have a significant impact on the lives of women of all ages[21].

The literature regarding the aetiology of female sexual pain disorders suggests complexity, indicating biomedical, psychological and relationship factors[21,22]. A recent review of GPPPD not only emphasised the complex aetiology, assessment and treatment of the condition, but also emphasised the devastating impact GPPPD has on interpersonal relationships, psychosocial health and QoL[8]. Sexual activity is often adversely affected and women with sexual pain avoid affectionate and sexual contact as they are afraid that it will lead to painful intercourse[23]. Importantly, women with vaginismus and dyspareunia experienced more negative emotions, anxiety and fear related to sexual functioning[22].

Formal diagnosis of, and intervention for female sexual pain are often delayed. This is due to initial confusion about symptoms, attempts to self-manage the condition[24] and help-seeking barriers such as embarrassment about the problem, lack of confidence in a healthcare solution, relationship characteristics, professional approachability, awareness of services and perception about the problem[24]. Healthcare professionals therefore play a major role in the treatment or non-treatment of women with sexual dysfunction[25] and need to be more sensitive to these issues.

Best evidence intervention protocols to address female sexual pain conditions require a holistic (bio-psychosocial) and multi-professional approach[21]. Conventional treatment of GPPPD includes topical treatments, injections, vestibulectomy, laparoscopic surgery, physical therapy (including electromyographic biofeedback, electrical stimulation, vaginal dilators), cognitive behavioural therapy (including coping strategies, desensitization, relaxation techniques, mindfulness, education, communication skills training), sensate focus (including light touch), couples therapy, acupuncture and hypnosis[26]. Alarmingly, pain is the only sensory aspect that has been investigated in women suffering from sexual pain[8], despite the involvement of other sensory systems in the best evidence treatment protocols, utilising, among others, soft touch.

Sensory processing dysfunction which has a complex interrelationship with, and may be a predisposing factor for, the development of psychiatric conditions has been described in women with genito-pelvic pain/penetration disorder (GPPPD)[6]. These conditions may include affective conditions, especially anxiety and depression[27], adult attachment and coping[28], attachment and emotional distress, anxiety levels in adults[29] and psychological health complaints[30]. Thus, both SPD and GPPPD play a role in anxiety, attachment and emotional distress. The impact of SPD on sleeping[31], substance abuse[32], impulsivity[33], parenting and attachment styles[34] has also been documented, but the literature is largely silent on sexuality and sexual activity in relation to SPD, beyond merely commenting on interpersonal relationships.

As in the case of GPPPD, persons with SPD have a tendency to self-manage the condition and employ various coping strategies to deal with the impact of SPD[3,13]. These coping strategies may include active and passive strategies[3]. Active strategies involve mechanisms such as coping self-statements, increasing activities level, ignoring pain, diverting attention, planning, using social support, acceptance, humour, venting of emotions, reflecting on self-growth and avoiding sensory stimuli, while passive strategies incorporate catastrophizing, praying/hoping, denial, using alcohol/drugs and mental disengagement[3,13] Sensory avoidance, an active coping mechanism, may result in avoiding relationships, while persons with sensory sensitivity may experience increased anxiety related to relationships[28]. Furthermore, sensory sensitivity (low neurological thresholds) could affect social participation through avoiding social situations, resulting in perceived introversion[30]. It is evident from the literature that SPD not only affects personal feelings, but also the fulfilment of various life roles, social participation, interaction with the environment as well as occupational performance[18,35]. Individuals with sensory sensitivity displayed greater pain sensitivity affecting their QoL negatively[1], while a recent study highlighted the association between sensory processing and pain coping strategies[3].

Treatment approaches for SPD in occupational therapy have mostly focussed on children and adolescents[18,32], however, of late, the focus has also shifted to the adult population[4,18,36]. Interventions for sensory processing difficulties include therapeutic use of self, sensorimotor activities (individual and group), sensory-based modalities, sensory diet, environmental enhancements,[35 (p.CE-4)] environmental modifications[4,37], cognitive and occupation-based interventions[38], education and coaching[39] and Ayres Sensory Integration® (ASI®)[40] .

The therapeutic use of self, refers to the therapist's ability to provide verbal and non-verbal feedback during assessment and treatment, to create a safe space[35 (p.CE-4)] and to encourage participation in purposeful activities and roles[4]. Components of self-regulation, namely attention, response to sensory stimuli, feelings and learning, can be addressed in both occupation-based and cognitive interventions[38]. Occupation-based interventions at home, work and in the community[41], are fundamental to occupational therapy and are based on the principle that engagement in activities of daily living (occupations) results in improved participation, QoL, and general well-being[38,41]. Sensorimotor activities are activities in which persons engage due to their therapeutic benefits e.g., yoga, exercises groups and art classes. Sensory modalities include the use of special techniques or equipment e.g., sound therapy, neurofeedback, aromatherapy, or the use of weight. A sensory diet consists of sensorimotor activities that provide regulated sensory input and that can be included in a person's daily routine[36] and is compiled in collaboration with the person with SPD[4].

Environmental adaptions aim to either increase, decrease or avoid certain sensory input in the physical environment throughout the day[4,42], affecting sensory arousal levels with the goal to improve self-regulation[43]. These adaptations are important when treating persons with SPD and include adjustments to sensory input such as lighting, sounds, touch and movement in occupations (activities of daily living) in the home, work, leisure and social environments[42,44]. Environmental adaptations also include psychosocial support and strategies to develop and maintain social support networks[35].

Literature regarding the treatment of SPD supports the inclusion of several approaches and techniques. However, it is important that the interventions are client centred and individualised according to the persons' activity profile, needs and preferences[4,18,36,38,45,46]. An example of such an intervention described in the literature was based on a home-programme treatment protocol, and included three components, namely patient insight, regular daily sensory input and participation in physical activities (providing proprioceptive, tactile and vestibular input) chosen by the patient[36]. Home programmes have been used to increase the frequency of therapy, or to provide intervention when a break is taken from therapy[16]. A study by Novak & Berry[16] found home programmes are effective if the content is based on proven effective interventions, the client's preferences are accommodated and client receives support e.g. coaching, during the implementation thereof.

There appears to be some commonality in symptoms and difficulties between GPPPD and SPD, specifically related to pain sensitivity, impact on relationships and QoL. There also appears to be some overlap in the treatment approaches that can be used for GPPPD and SPD, specifically from a cognitive-behavioural and sensory perspective. However, the absence of investigations into sensory modalities in the GPPPD literature, means that an occupational therapy sensory integration approach has not been investigated in targeting the needs of the client with GPPPD, in relation to their specific sensory processing patterns which could be accommodated in a holistic intervention that includes occupational therapy.

METHODOLOGY

Study design

A qualitative study design, using semi-structured individual interviews was used to gather information regarding participants' experience of participating in an occupational therapy sensory-based home programme(SBHP)[47]. A descriptive approach was used to describe participants' experiences[47,48].

Ethics

Ethical clearance was obtained in 2017 from the Human Research Ethics Committee (Medical) at the University of the Witwatersrand (HREC-M) (Certificate Number M170829).

Participants/Sampling

The incidence of GPPPD is not known and sexual dysfunction is a sensitive topic, necessitating a more focused, non-probability sampling strategy to recruit this hard-to-reach population. Participants who were diagnosed with SPD via the Adolescent/Adult Sensory History (ASH) questionnaire in a previous study[6] using purposive, non-probability sampling[49] were asked to volunteer to participate in the SBHP. The inclusion criteria included females from the age of 18 who have a diagnosis of GPPPD who lived in Gauteng or KwaZulu-Natal (KZN) for logistical reasons, but at the conclusion of the study the sample included only participants from Gauteng. Exclusion criteria were (i) previous treatment for SPD; (ii) diagnosis affecting the neurological system e.g., multiple sclerosis; (iii) cancer related diagnosis; and (iv) being pregnant.

Participants from Gauteng were selected due to logistical reasons as initial interviews were conducted face-to-face. This was necessary to establish a good rapport with participants, especially since the sensitive topic of sexual pain was to be discussed, as well as to gather sufficient information about participants to design a client-centred intervention strategy. Initial face-to-face interviews further helped to ensure treatment techniques (where applicable) were demonstrated adequately to the participants. These interviews also served to confirm eligibility for inclusion.

The model of information power[49], whereby sample size is determined by the aim of the study, sample specificity, use of established theory, dialogue, and analysis of data, was used to guide data collection, and ultimately sample size. Preliminary analysis and appraisal of information power were done throughout the collection of in-depth data, and enough relevant data were collected after interviewing five participants, reaching sufficient information power. Information power was increased by the narrow study aim, describing specific perceptions and experiences not previously described in a 'hard-to-reach' population[49]. Information power was further increased as the current study is supported by some theoretical background, even though most research regarding home programmes have been conducted in the paediatric population[16]. The current study could therefore combine existing knowledge and contribute to new knowledge regarding the use of home programmes in this specific population, resulting in a smaller sample size required. Specificity was increased via purposive sampling, as the sample consisted of participants with specific characteristics, namely women with GPPPD and SPD. Specificity was further increased by participants' specific and unique knowledge as well as experiences related to women with GPPPD and SPD.

Intervention

First, an initial, face-to-face semi-structured individual interview which lasted approximately 1½ hours was conducted. When making appointments with participants, two hours were allowed for initial interviews to prevent rushing participants, which could potentially have negatively affected the depth and quality of data[50]. Participants shared personal experiences and the impact of sensory difficulties on daily life. The theory of SI and atypical integration of sensory stimuli were explained in layman's terms and made practical by linking it to their personal experiences. Possible interventions/strategies based on SPD-specific issues identified previously, were discussed and personalised interventions/strategies explained and demonstrated when necessary. Initial interviews were conducted over a period of eight months. The client-centred SBHP consisted of additional reading resources, exploring therapist-guided changes to home and work environments, adaptations to tasks, identifying and managing and/or avoiding potential sensory triggers, and self-regulation strategies, including implementing a progressive muscle relaxation (PMR) programme (via a video link), yoga, mindfulness, and therapeutic brushing (TB). The SBHP was personalised to participants' interests/beliefs/abilities/resources and implemented over a period of six to eight weeks. The researcher was available telephonically to provide assistance and guidance if necessary[16].

Data Collection

Follow-up interviews (either face-to-face or via Skype) lasted between 30 and 60 minutes. Information regarding participants' experience of participating in a SBHP was obtained during the follow-up interviews. Open-ended questions included have you experienced any change?, what strategy did you find most helpful? and what would you change? The follow-up interviews took longer than expected to arrange due to logistical challenges and most were done between eight and 12-weeks post implementation. The interviews were conducted by the researcher who is experienced in the field of SI. Participants were put at ease and appeared to share information, including sensitive information, readily. The aim of the study, as well as what was expected of them, were explained clearly, in layman's terms, facilitating trust and reducing uncertainty and anxiety[51].

One participant's interviews were conducted in English, whilst the remaining interviews were conducted in Afrikaans. Semi-structured interviews were used, as it provides the opportunity for both participant and researcher to clarify certain concepts and to maintain the privacy of the participant. Interviews also allow for psychoeducation[52], which is important not only because SPD is an unfamiliar condition, but also due to the sensitivity of the topic of sexual pain/difficulties[53]. The quality of the interview dialogue was important and strong, clear, open communication allowed for maximum data gathering in a non-threating environment[51]. All interviews were audio-recorded and transcribed, and the researcher took field notes during the interviews. The researcher was aware of potential power imbalances during the interviews[47], and care was taken to show respect to participants whilst also protecting professional and research ethics, and building rapport with participants[50,51]. Researcher bias was a possibility as the researcher did the intervention and conducted the interviews, but parameters of trustworthiness were implemented to reduce the possible impact thereof[48].

Data Analysis

Only data of the follow-up interviews were analysed, in keeping with the study objectives. Descriptive data analysis, specifically inductive thematic analysis[50,54] was used, and the thematic network approach included saliency analysis (lower frequency codes that are pertinent to research aim are included in the analysis to enhance the coding process)[55]. Once checked, transcribed interviews were entered into Atlas.ti[8] (a computer-assisted qualitative data analysis software programme), and coded systematically[50]. In vivo coding was used where possible, but due to the large number of Afrikaans participants, this was not necessarily possible. Themes were constructed via thematic analysis from across the data sets[54], and visually represented via a thematic network diagram[47]. After analytic reflection, in vivo codes were added to specific categories and themes, adding another dimension as participants' words[52] were used to report their personal experiences.

Trustworthiness

Various parameters of trustworthiness[49,50,52,56–59] were applied to ensure rigour and are displayed in Table I (page 35).

Table I Parameters of trustworthiness

CRITERIA	STRATEGY	APPLICABILITY
Credibility	Information power[49]	Quality of data more important than number of participants.
	Member checks[56]	Done via an e-mail to participants to ensure data were interpreted accurately[56].
	Peer examinations/debriefing	
	Confidentiality	Transcripts were anonymised and audio recordings were stored using a participant number. Identifying information was stored separately.
	Interview protocol[50]	Open-ended questions supporting the research question, to ensure a consistent style of data collection.
	Use of participants' words	Direct quotes from participants were used to illustrate the findings, as well as some in vivo codes derived from participants' words.
Transferability	Providing thick descriptions[57,58] of research, participants, methodology, interpretation of data.	
	Purposive sampling	
Dependability	Create an audit trail of procedures and processes[59]	Atlas.ti8 helps with the audit trail. Field notes, audio files and supervisor's feedback, electronic data files, assisted with checking procedures followed, and conclusions reached.
	Peer coding	A codebook was developed, and codes were checked with the second author. Both authors coded one interview and compared their analyses. Minor adjustments were made to the codebook thereafter.
	Coding & recoding of data[52]	Enhanced accuracy of the coding process.
	Sceptical peer review	This was done by the second author, who questioned the use of specific quotes in relation to the codes, as well as the organising of the codes into categories and themes.
Confirmability	Practice reflexivity	Continuous self-examination was done to ensure that researcher-subjectivity did not interfere with data collection.
	Audit trail of data analysis process.	Kept records of field notes, raw data and transcripts. Stored raw data in organised archives.

RESULTS

Five women ranging in age from 35 years to 42 years participated in the study. All resided in Gauteng, were married, and varied in terms of the number of children, ranging between no children (P2, P3, P4), one child (P1) and two children (P5). Participants met the inclusion criterion of having SPD, since their Total score on the ASH fell in the definite category and they presented with atypical sensory modulation, sensory discrimination and/or social/emotional functioning[6]. Tactile processing was most affected, and a significant number of participants had an atypical pain response and presented with aggressive/impulsive behaviour. Two themes related to participants' experience of a SBHP specifically related to the SI content emerged from the data: 1) Changes experienced after participating in a SBHP, and 2) Coping strategies employed by women with SPD & GPPPD. Themes and related categories are reflected in Table II (page 36).

Theme one: Changes experienced after participating in a SBHP

Two categories emerged in theme one.

Category 1: Increased awareness /insight

A key finding, which relates closely to self-growth, was that participants displayed greater awareness and insight into SPD and its impact on everyday life after participating in the SBHP.

> "One lives with these things, and you start to develop strategies without even knowing it." **(P2)**

> "I now know how, when to..., when things are getting too noisy for me etc." **(P4)**

Participants found it easier to express sensory related difficulties/dislikes because of increased insight into SPD.

> "So you kind of tolerated it, where afterwards (i.e. after the SBHP) I was able to kind of go, I don't like it, but I will hold your hand. And it's actually okay, if that makes sense." **(P1)**

Because of her insight, one participant (P4) also discussed her SPD-related needs with the human resources manager, and they were able to adjust at work, thus indicating the impact of increased awareness reached beyond sexuality. Participants further became more aware of sensory triggers that could result in sensory overload. Sensory triggers included high-pitched barking of dogs, light touching in the neck, clutter, kissing without brushing teeth, strange noises, overtiredness and being hugged unexpectedly from behind.

Participants were able to identify fluctuations in their daily functioning. One participant (P4) mentioned that she was able to tolerate music in the mornings, but not in the evenings. Other participants indicated that some days, or even moments, are better than others:

> "There are days where I'm just like, 'Leave me alone.' Like I just want to go and sit outside, where a gecko lands on my shoulder. ...Then there's other days when it actually doesn't bother me at all." **(P1)**

> "I will be fine and the next moment I will just explode and say 'get away from me', you know, that type of thing, yes, where it is just too much for me." **(P4)**

Interestingly, participants liked the fact they were able to identify sensory difficulties in others, with P3 mentioning

Table II Summary of themes and categories

THEME	CATEGORY	SUB-CATEGORY	CODE
Changes experienced after participating in a SBHP	Increased awareness/insight		Express SPD related issues
			Able to identify triggers
			Identify fluctuations in daily functioning
			Identify sensory difficulties in others
	Intra-personal changes		Increased tolerance for sensory stimuli
			Feeling more in control
			I can breathe again
			Feeling safe & secure
			not as clumsy as I used to be
Coping strategies employed by women with SPD and GPPPD	Problem-focused coping	Active coping: Sensory Seeking	Seeking touch/tactile input
			Seek movement and repetitive movements
			Oral-motor actions to cope
		Active coping: Coping in the environment	Activities engage in for relaxation
			Avoidance of sensory stimuli
			Reduce and eliminate irritating sensory stimuli
			Looking for / going to quiet space
			Avoiding personal contact with others/ increased personal space
			Creating order at home/work
	Emotion-focused coping	Positive reinterpretation/ growth	Aware of changes within self
			Self-talk used as tool to calm or motivate self
			Thank you
		Acceptance	Acceptance of condition and/or impact
		Socio-emotional support	You're not the only one
			Shared personal experience of SPD with others
			Partners' reactions to SPD and SBHP

that she is much more attentive to the way other people process sensory information e.g. a child that does not like being touched.

> "Yes, it made me aware of myself and other people because I will, I will notice something. You can see he is not a touchable child, or something like that. So, those are things that I've noticed." **(P3)**

Category 2: Intra-personal changes / Changes experienced in own body

Participants displayed an increased tolerance of sensory input, either tolerating previously unpleasant sensory input for longer periods, and/or by engaging in new activities with unfamiliar sensory input.

> "But I can at least walk on the grass a little bit better than I could before." **(P1)**

> "Previously, it would have bothered me a lot if they just touched my phone or handle it in a certain way. It does not bother me at all. I am a lot more... I'm a lot more chilled (relaxed)." **(P3)**

Participants felt more in control of themselves and the environment. Not only were they able to identify sensory triggers (discussed above) but they could also regulate their emotional state better. One participant (P4) called it a blessing, as she did not feel like a victim anymore, while she also mentioned that she prefers predictability and dislikes a change in routine/plans. Another participant (P5) was able to control herself better in stressful situations, whilst P1 felt more secure and safe after making changes to her environment:

> "The programme helped me, because I could...the minute when I got into a situation that pushed my revs into the red [i.e., sensory overload], I was almost..., I was able to control myself." **(P5)**

Participants (P1 & P5) reported less clumsiness.

Changes in intimate life were reported and P3, P4 and P5 reported they are calmer/more relaxed before and during intercourse. One participant (P4) explained to her husband why she prefers firm touch, opposed to light touching during intercourse, and this adaptation has enabled her to tolerate more tactile input during intercourse.

> "I think he (my husband) is getting better with touching me more firmly." **(P4)**

Feelings of increased calmness and being able to breathe rather than feeling overwhelmed, were reported.

> "No, there's more calmness. I feel like I can breathe again." **(P1)**

Theme two: Coping strategies employed by women with SPD & GPPPD

A prominent theme through all the transcripts was that several coping strategies were used by women to cope with daily living. Two categories, namely: 1) Problem-focused coping, 2) Emotion-focused coping and five sub-categories, namely: 1) active coping: sensory seeking, 2) active coping: coping in the environment, 3) positive reinterpretation & growth, 4) acceptance (reflecting on self-growth), and 5) socio-emotional support (see Table II page 36) emerged from the second theme

Category 1: Problem-focused coping

Sub-category: Active coping: Increased sensory seeking

Touch, especially deep tactile input, was sought by participants, who specifically reported that they preferred the TB to be done very hard (P1, P3), and vigorously (P3). One participant (P4) mentioned that she would have preferred a deep massage to the TB. Nonetheless, all participants found the deep touch comforting.

> "That brush, I, used it like this (press firmly on arm). But I could feel that I shouldn't..., I have to do it firmly, you know, firmly, not that soft touching." **(P3)**

> "Something like, you know, a deep massage would have been nicer than the brushing. Yes, you know, firmer pressure." **(P4)**

All participants mentioned increased movement activities including exercise, getting up frequently and repetitive movements e.g. moving body parts (especially fingers, legs and feet when seated), light stroking and brushing vigorously, as important activities which helped to reduce stress/irritation levels. One participant (P4) mentioned starting to fiddle with a pen when having to speak to colleagues.

> "Or, if I have to go and speak to a colleague, then I take a pen along to keep in my hand." **(P4)**

> "But they (my dogs) really helped me a lot. I think just to touch them, just to watch them, that is, that calms me a lot. For me, just to stroke them." **(P5)**

Oral-motor activities, especially chewing crunchy food, such as apples and popcorn, and sucking sweets, were found to assist with sensory modulation.

> "I think for me, the awareness to either have something like a peppermint, or something to nibble on, or something to read when I'm standing in a queue, that I can zoom out..., you know, to remove myself from a situation." **(P4)**

Sub-category: Active coping: Coping in environment

Participants avoided unpleasant sensory stimuli e.g., food and clothing textures, noise, busy environments, through removing and/or moving away from unpleasant stimuli.

> "I just want to get home and get all of this off, and get into my comfy pyjamas with no bra, and I'm happy." **(P1)**

> "That is one thing, I hate, absolutely hate make-up." **(P5)**

> "I cover my ears when somebody whistles. That is a sound that I absolute cannot handle. A telephone that rings, also irritates me. I don't like a phone at all." **(P5)**

Participants engaged more in relaxation activities e.g., building a puzzle, reading, playing a game on a phone, scrapbooking, crossword puzzles and spending time with pets. Listening to music was mentioned by all participants and included different genres, including classical, contemporary, and pop rock music. Two participants (P1, P4) mentioned listening to nature sounds and white noise, while P4 did not like what she called doef-doef' music (music with a prominent bass drum rhythm).

> "The thing that works best for me, is to go sit upstairs in my room and listen to music, with my cat and a crossword puzzle or my iPad, just to play a game, and a mindless game like Candy Crush, or something like that. It's just something that keeps you busy and absolutely mindless. I must say, music also." **(P5)**

Headphones/earphones were used, not only to listen to music, but in some instances to also eliminate/reduce background noise.

> "I've put ear plugs in to try and block that out." **(P1)**

> "So, I always wear my headphones, and when I have it in, I cannot hear anyone." **(P5)**

Participants also expressed avoiding personal contact/touch and interaction with other people, resulting in increased need for bigger personal space.

> "So, then I told her (sister), I hate a 'bus' (running together in a group). I feel so blocked in, and I've ran in a 'bus' once and I was unable to get out, there were too many people around me, and it was..., So, usually when I run a race, I avoid a 'bus' as much as possible." **(P2)**

> "Yes, and I like to be left alone in the evenings." **(P4)**

Participants coped better in their environments by creating order and reducing clutter in both home and work environments. Planning, organising, and neatness created a sense of control and assisted with emotional regulation e.g., feeling more relaxed. One participant (P4) also mentioned that her house might not appear messy/disorganised to other people, but to her it was very messy/disorganised which increased feelings of being out of control.

> "I moved my office around, so my Zen space, whatever you want to call it, is far better. So, I did a lot of like scaling down in a sense, where I've taken all my stuff that is of no value from a work perspective, and from a space perspective, and I just got rid of it. So, everything is more clean, more open. I feel like I can breathe again. So, I don't know if that makes sense." **(P1)**

Interestingly, P3 and P5 mentioned that they preferred sexual intercourse to be spontaneous, and not planned, with P3 specifically mentioning that she is more stressed/anxious if sexual intercourse is planned/scheduled:

> "And it must not be something that is planned. I hate a planned thing…, because then I'm not as tense, and I'm not stressed about it, but when it is planned then I worry… shit, is it going to be okay, am I going to…?" **(P3)**

Category 2: Emotion-focused coping

Sub-categories: Positive reinterpretation/growth & acceptance

Participants used positive reinterpretation to manage negative emotions and showed increased self-awareness and acceptance of their conditions/circumstances throughout the interviews. One participant (P2) changed her perception about herself, whilst P5 mentioned that she now understands that there is nothing wrong with her but that she is just different. Understanding why she is different, helped a lot. She (P5) also mentioned that she realised she is fine and that she is not really such a 'witch' or bad person, as she previously perceived herself to be. Participants P2 and P5 explicitly expressed gratitude for the study, but this sense of gratitude was reflected in field notes and expressed by other participants after the formal interviews.

> "I think, firstly for me, it was basically self-insight, because I've never self…., like I've told you during the previous interview, you know, I've never saw myself as being tactile defensive, or you know, that it really is a problem for me. So, I think in light of that, it did change my…, my perception about myself, you know, after I got the information from you… […] I just want to thank you for this study, because I think it is, it helps. It is not an easy topic that you, you know, are addressing. But I do think there is a big gap which is now being addressed, because I do think there are still lots of other people who can benefit, but do not come forward, because it is a sensitive, you know, topic." **(P2)**

> "Self-knowledge has always been very, very important to me, because I realised how it absolutely helped me to understand who I am, and I'm okay, you know? There is nothing wrong with me. It's just, I am just different… just understanding why I'm different, and how I'm different, and how to make it known to the world, you know, in an acceptable manner." **(P5)**

Self-talk, a meta-cognitive strategy[60] was prominent in three of the participants (P1, P3 & P5) with P3 and P5 also using counting (repetitive action) and repetitive phrases such as relax, relax, relax to cope. Self-talk was used as a meta-cognitive tool to assist with positive self-statements, emotional regulation, and as self-motivation, facilitating self-growth.

Sub-category: Acceptance "you're not the only one. There are plenty of us out there."

A key finding was that participants did not feel alone anymore and were able to relate to others with SPD.

> "And also, that 'Too light, too bright' book, she speaks of her own personal experiences, so it's …, she herself is experiencing. So, I was able to kind of connect with her in a way, not to just understand that you're not the only one. There are plenty of us out there." **(P1)**

Participants shared their experience of SPD with others, while it also made them more aware of SPD in others, including their partners.

> "This book is for you, my buddy (her friend). You have to read this." **(P1)**

> "It was also easier to discuss it with my family and tell them that I have spoken to a professional person. The professional person says this, so, I am not full of nonsense." **(P4)**

Subcategory: Support

Support from partners was vital and participants reported their partners to be understanding, supportive and non-judgemental.

> "[My husband] could see a difference. So, he's like, But you're not bouncing off the walls, you're not like freaking out." **(P1)**

> "I have an amazing husband. Since the beginning he has been very understanding." **(P2)**

DISCUSSION

The present study sought to describe the experiences of women with GPPPD and SPD who participated in a SBHP. The findings suggest that participants benefited from participating in the SBHP. Participants experienced change and described coping strategies implemented.

Changes experienced after participating in a SBHP

Increased awareness and insight into understanding SPD and the impact thereof on daily life, as well intra-personal changes were prominent changes reported. These findings tie in well with previous studies wherein cognitive approaches and the importance of insight were emphasised as part of a addressing SPD in adults[18]. Insight enables persons with SPD to better manage atypical processing patterns by assisting with identification and implementation of coping strategies[42] and empowering them to make choices supporting their sensory needs. Education/information (regarding SPD and its impact on daily living) was a vital aspect of the SBHP during the initial interview, as it empowers people by increasing health literacy[61]. Insight, gained via information, empowered participants to experience self-growth and self-regulation (incl. sensory processing, emotional regulation, cognitive regulation and social perspective taking[62]).

Notably, increased tolerance for sensory stimuli together with improved emotional well-being were prominent among participants' intra-personal experiences. The results are in line with a retrospective pre-post treatment study of occupational therapy intervention for children with SP difficulties, in which improvements in adaptive behaviour, withdrawal and inattention; a reduction in aggression, anxiety, depression; a decrease in sensory symptoms and improvement in motor skills were noted post-treatment[63]. Like our study, earlier studies, including a literature review involving the treatment of adults with sensory defensiveness (SOR), found an increased tolerance to sensory input, improved functioning in daily life, reduction in symptoms of sensory defensiveness and improved emotional functioning[18,36]. Importantly, the literature review[18] also reported that the treatment effect/improved functioning was still present [16] months post treatment and sensory processing was improved by seeking and implementation of activities recommended previously, to manage the sensory environment[18]. This has not been established in the current study and future research should consider collecting additional data to determine participant experiences in the longer term.

Coping strategies implemented

Problem-focused coping

Active coping skills (a problem-focused strategy) used by participants in this study included sensory seeking and strategies employed to better cope in the environment. Participants reported improved emotional functioning as reflected in intra-personal changes, also related to using active coping strategies, which is supported by findings in the literature. Problem-focused coping typically involves activities/strategies (occupation) employed to improve coping in stress-inducing situations by either changing the stressor or oneself[64]. The use of activities related to daily living makes this an occupation-based intervention, which have been found to support social, sensory and emotional outcomes in children SPD[38]. Active coping strategies, such as exercise, social comparison and positive self-statements (coping statements),have also been found to reduce distress in healthy adults[3], to be adaptive coping strategies in persons with pain[3,64], and improving mental QoL in persons with emotional disorders[13].

Notably, passive/negative coping styles were not reported by participants in the current study despite previous studies describing sensory processing styles, pain and coping strategies that included passive coping styles[3,13,28]. It was, however, beyond the scope of the current study to explore coping styles specifically, and this, coupled with participants reported overall improvement in socio-emotional well-being, may have contributed to participants not mentioning passive coping strategies.

Participants actively sought sensory stimuli (based on their sensory functioning) as reflected in increased activity, seeking repetitive movement, eating crunchy food, and deep touch pressure. Sensory seeking assisted with sensory regulation, resulting in decreased emotional outbursts and increased feeling of calmness and control reported. This resonates with previous studies that found sensory seeking, an active self-regulation strategy, improves emotional regulation and contributes to positive affect[29] and improved socio-emotional functioning in children with sensory craving (sensory seeking), post-treatment[65]. Sensory seeking has also previously been found to be an active pain strategy[3]. A recent systematic review suggested deep touch pressure improves the effectiveness of interventions in children and youth with SPD[46], while another study involving young people with autism, found deep pressure to be beneficial if it is adapted to the needs of the person[66]. The latter is noteworthy as one participant in the current study adapted the TB, resulting in prolonged periods of vigorously brushing her face and another participant specifically asked for deep pressure during intercourse.

Participants employed several actions to improve coping in the environment. The most significant was avoidance of sensory input to reduce/eliminate obnoxious sensory stimuli and participants actively seeking out quiet spaces. Avoidance of sensory input has been associated with persons with emotional disorders[13], resonating with the current study's participants who also presented with atypical social/emotional functioning on the ASH. Even though avoidance is sometimes seen as a maladaptive response[13], participants found it beneficial, and in most cases avoidance of unpleasant sensory stimuli as a coping mechanism, seemed to have been implemented prior to participating in the SBHP.

Significantly, participants now understood why they avoided certain sensory stimuli as it may prevent sensory overload, ultimately improving self-regulation. They were also able to communicate their needs regarding sensory avoidance more effectively to others. Participants used increased personal space and/or avoiding personal contact with others as a coping strategy. This has significant implications for interpersonal relationships and will be discussed together with socio-emotional support below.

Participants implemented changes in the both the home and work environments, especially organising the environment and engaging in activities for relaxation which contributed to feelings of calmness and control/improved emotional well-being. This is similar to a study that found that home and work changes provided a supportive environment[37]. Furthermore, organising and ordering (decluttering) the environment is often used to reduce sensory stimuli[67], while a multi-faceted approach that includes environmental changes/modifications has been recommended as interventions for children with SPD[46,68]

Emotion-focused coping

Participants used positive/coping self-statements, through self-talk, to self-motivate and self-regulate, possibly contributing to a willingness to try new sensory experiences (sensory seeking) which are closely related to active coping strategies discussed above.

Participants increased socio-emotional support as they shared information regarding SPD with life partners, family members and colleagues, providing opportunities to be better understood and accepted by others. This is supported by a previous study which found social relationships improve health outcomes in adults[69], while collaborative sexual communication between women with sexual pain and their partners has been associated with improved outcomes related to sexual and psychological functioning[70]. Communication is facilitated by a trusting, balanced relationship as it creates a safe space in which critical/negative information can be shared[71] and strong relationship goals can be established, which has been linked to greater sexual satisfaction in women with sexual pain[72].

However, communication and socio-emotional support could be adversely affected by increased personal space and avoidance of personal contact as a coping strategy, which some participants did report and has previously been described in the literature[28]. This may happen when participants experience irritability/sensory overload, resulting in fight-and-flight reactions, leading to avoidance of interpersonal contact and increased personal space[28]. Avoiding personal contact may further impact negatively on intimate life as physical contact and touch are crucial to intimate relationships[73]. However, the potential negative impact on relationships may be mitigated by improved communication, sharing information and explaining the reason for certain behaviours to others[70].

Limitations of the study

The current study needs to be considered in light of the following limitations: Only persons who had access to the internet and mostly private healthcare for sexual pain could volunteer to participate in this qualitative study. While we endeavoured to describe our sample in detail, transferability of the results to populations who do not have access to e-mail/internet or private healthcare may be limited.

CONCLUSION

Occupational therapists specialising in sensory integration are increasingly getting involved with adults with SPD, either as clinicians or in the evolving role as consultant[74]. Literature regarding the impact of SPD on sexual activity, intimate relationships, sexual expression, and sexuality are limited to non-existent. Furthermore, sexual activity (specifically sexuality), is also expressed through other occupations such as caring for a partner, grooming, dating and intercourse[20]. However, these occupations are often negatively affected in persons with SPD, further affecting emotional well-being, relationships and ultimately QoL[13]. Participants' experiences suggest/reflect that an individualised, client centred SBHP contributed to improved QoL of women with GPPPD and SPD. Importantly, previous studies[16,40,42] recommend intervention strategies to be individualised and based on the needs of the client.

Most of the participants were newly diagnosed with SPD and were therefore unfamiliar with SPD although they might have been aware of some of their own sensory issues. Information regarding SPD facilitated insight and self-growth. Insight gained through education lead to intra-personal changes and increased awareness and insight. Better insight facilitated self-growth, improved coping in the environment, increased activity (sensory seeking) and increased socio-emotional support.

Recommendations and future research

The use of a coping measurement during the initial interview may provide additional information regarding participants' coping styles and may assist in identifying more client-centred intervention strategies. It is suggested that future research investigate the (self-perceived) effectiveness of SBHP, including pre-and post-testing, and ideally a control group should be included. Future research, investigating the impact of SPD on sexual activity/sexuality/intimate life, and possibly developing a measurement to assess this, would contribute to occupational therapy knowledge in this specialised field. From a treatment perspective, goal setting (i.e. goal attainment scaling [75]), should be included in the SBHP as it will enhance practitioners' and patients' ability to track improvement, also enhancing a client-centred approach. Interpersonal goal setting, involving partners, has been linked to improved sexual and relationship satisfaction[72]. A relational approach, including assessment of partners' sensory integration/processing, should be considered in treatment. The inter-relationship between individual, potentially conflicting, sensory profiles within intimate relationships, should be explored as part of the intervention strategy. Both in the clinical and research context, information, and strategies, based on priority goals, should be introduced via a staggered approach in follow-up sessions, to minimise potential information overload.

Author contributions

Elsie Labuschagne was involved in data collection, formal analysis, and writing of the original draft and secured funding. Elsie Labuschagne and Matty van Niekerk designed the study. Matty van Niekerk reviewed and revised the manuscript. Both authors read and approved the final manuscript. The study was conducted by the first author for higher degree purposes, supervised by the second author.

Conflicts of interest

The authors have no conflicts of interest to declare

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RESEARCH ARTICLE

Physical activity resource needs of occupational therapists in primary public health care in Gauteng, South Africa

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ABSTRACT

Introduction: Resource constraints in primary health care settings in South Africa give rise to challenges for occupational therapists. This study aimed to determine the physical activity resource needs (including objects used and space demands) of occupational therapists in the primary health care context of Gauteng, South Africa.
Method: A qualitative, descriptive research design was used. The participants were occupational therapists working in primary health care settings in Gauteng. Convenience and snowball sampling were used. Data were collected through two online asynchronised focus groups, conducted over three days each. Thematic analysis was used to analyse the data.
Findings: Findings included the resource constraints experienced by occupational therapists and how the occupational therapists' adaptability helped them overcome these constraints. Space, resources for basic and instrumental activities of daily living, assistive devices, Bobath plinths and recyclable and low-cost materials were identified as being particularly useful physical activity resource needs.
Conclusion: Although limited physical activity resources were available in the settings, therapists' skills in adaptability proved useful in using unconventional resources instead. This study's results identify physical resources deemed as most useful to provide occupational therapy services in primary health care. Furthermore, the results provide information to the education faculty in order to adapt the undergraduate curriculum to better prepare occupational therapy students for practice in primary health care.

Implications for practice

- The findings can be communicated to management of primary health care facilities in order to procure or advocate for the procurement of resources deemed as essential in primary health care practice contexts.
- Innovation, problem-solving and adaptability can be valuable characteristics used in professional reasoning that may enable occupational therapists to overcome physical resource barriers.
- Faculty at tertiary educational institutions may utilise the findings in order to adapt curriculums to better prepare occupational therapists for work in the South African primary health care context.
- Occupational therapy students should gain experience in developing and adapting activities using recyclable and reusable materials for diverse clients, including children and adults.

INTRODUCTION AND LITERATURE REVIEW

The World Health Organisation states that *Primary health care (PHC) facilities are an essential part of health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and citizens afford to maintain*[1 p.42]. In South Africa, the majority of the population has access to and makes use of public PHC facilities[2]. Rehabilitation services are provided in PHC as part of the continuum of care as set out by the National Department of

Table I: Types of physical activity resources and examples (Adapted from Table 11 in the OTPF10)

Type of physical activity resource	Examples
Objects used: Tools, supplies, equipment, resources required in the process of carrying out the activity or occupation.	Scissors, shoes, paint, workbench, stove, money, transportation.
Space demands: Physical environment requirements of the occupation or activity.	Size, arrangement, surface, lighting, temperature, humidity, noise, ventilation.

Health[3]. This is aligned to the recommendations in the World Health Organization's *Rehabilitation 2030: a call for action*[4].

South Africa is a resource-constrained context, where the rehabilitation workforce is stretched to provide services to the large population requiring their services[5,6]. Historically, rehabilitation services have not been a priority in the South African health system, with higher emphasis placed on medical and curative approaches[5,7]. This has contributed to limited resources available for rehabilitation services with therapists reporting limited budget allocation and difficulties in procurement[7].

Occupational therapists work in PHC facilities alongside other members of the rehabilitation team[8]. Occupational therapists use activities during therapy and select these activities through professional reasoning[9]. The fourth edition of the Occupational Therapy Practice Framework (OTPF) explains that during professional reasoning, occupational therapists have to consider the activity demands of the activities they want to use[10]. Activity demands are what is commonly required in order to perform an activity or occupation. Among the many factors included in the activity demands are the objects used, as well as the space demands. The aforementioned objects include tools, supplies, equipment and resources used to carry out the activity[10]. In this study, these objects as well as the space demands are referred to as physical activity resources. Table 11 in the OTPF was used as a framework for this study as it encapsulates the relevance and importance of physical activity resources in occupational therapy intervention and describes how the absence of physical activity resources creates a barrier for occupational participation[10]. Table I (above) illustrates an adapted version of Table 11 of the OTPF.

The OTPF additionally explains that occupational therapists consider the activity demands during their professional reasoning and that these activity demands can potentially act as a barrier to participation in activities and occupations[10]. Physical activity resources are integral to the planning and execution of interventions - the availability of physical activity resources essentially govern which activities can be used.

Schell's Ecological Model of Professional Reasoning[9] encapsulates the factors that an occupational therapist considers during professional reasoning. Some of the factors that are considered during professional reasoning and activity selection are payment options, working space and the equipment and resources available. Several studies have shown how these factors may pose challenges in South African PHC settings[2,5], similar to how the OTPF describes how activity demands, which are also considered during professional reasoning, may act as a barrier[10].

The availability of resources is one of the most influential factors on rehabilitation services in the rural environment[11]. In a study done by van Stormbroek and Buchanan[12] on the practice of occupational therapists in rural health contexts, participants reported that limited resources prevented the occupational therapists from developing a professional identity. Participants felt they had to treat performance components in the same way physiotherapists do, instead of treating performance within occupations[1,2]. Additional challenges faced by occupational therapists in resource-constrained contexts (as noted by Toal-Sullivan[13]) include managing the load of patient responsibilities and struggling with professional reasoning .

In South Africa, newly qualified occupational therapists are typically placed in PHC settings in their first year of practice in order to complete their compulsory community service year[14]. It was reported by a therapist doing community service in rural Eastern Cape, South Africa, that many of the occupational therapy departments in PHC do not have allocated budgets[14]. Other participants in the same study reported using their own money as soon as the recyclable materials, out of which they made their own physical activity resources, were exhausted[14]. With regards to financial resources, De Beer et al. state that the absence of financial resources can lead occupational therapists to feel inadequate or frustrated as they cannot provide the service they want to provide, that can contribute to burn out[15].

Literature thus illustrates how the scarcity of objects such as tools, supplies, equipment, and resources, as described by the OTPF, may act as a barrier during professional reasoning as it limits the possible activities and services that can be provided and may therefore limit the ability of occupational therapists to navigate PHC contexts in South Africa[10]. This is of particular concern as inexperienced community service therapists often have to navigate these challenging resource-constrained contexts.

Although several studies report on the scarcity of resources for occupational therapy services in PHC, it is not clear exactly what physical activity resources occupational therapists use and what they feel is necessary to provide effective rehabilitation services in PHC[12,14]. As this information is not available, it may be more difficult to advocate for additional resources to use in these contexts. Therefore, the aim of this study was to determine the physical activity resource needs of occupational therapists in the PHC context in the Gauteng province of South Africa. To achieve the aim of the study, the researchers formulated two objectives: to explore which physical activity resources are currently used by occupational therapists in PHC in Gauteng; and to explore which physical

Table II: Demographic details of participants (n=8)

Demographics	Number of participants (n)	Percentage of sample
Highest level of qualification		
Bachelor's degree	n=8	100%
Years of experience in PHC		
1-3 years	n=5	62.5%
5-10 years	n=1	12.5%
More than 10 years	n=2	25%

Table III: Characteristics of the practice environment (n=8)

	Number of participants (n)	Percentage of sample
Mainly provides therapy in an urban or rural area		
Urban	n= 3	37.5%
Rural	n=2	25%
Both	n=3	37.5%
Mostly sees individual patients or groups		
Individual	n=3	37.5%
Group	n=1	12.5%
Both	n=4	50%
Do they have an allocated therapy room?		
Yes	n=5	62.5%
No	n=3	37.5%
Do they feel that they have enough space to provide therapy?		
Yes	n=3	37.5%
No	n=5	62.5%

activity resources occupational therapists deem necessary to provide adequate intervention in their specific context.

METHOD

Study Design

This study was conducted using a qualitative, descriptive research design, as described by Lambert and Lambert[16]. Data were collected during two asynchronized online focus groups.

Population and Sample Selection

The population for this study were occupational therapists practising in PHC settings, in the Gauteng province of South Africa, during the year 2021. The researchers were based in Gauteng and therefore familiar with the context. As the PHC setting in South Africa consists of clinics and district-level hospitals, the inclusion criteria for the study were occupational therapists that work in PHC clinics or hospitals in Gauteng.

Non-probability sampling methods, convenience and snowball sampling were used. In terms of time and financial resources available, these sampling methods were the most suitable for this research study[17,18]. Participants were contacted through email via the alumni database of the University of Pretoria Occupational Therapy Department. Potential participants then passed the invitation on to colleagues who may meet the inclusion criteria, thereby employing snowball sampling. Occupational therapists that were interested to participate contacted the research team.

Five to eight participants are seen as the ideal number of participants to use for focus groups[17,19]. Although eight participants were recruited for the first focus group, only four participated. Therefore, a second focus group was held with an additional four participants. Potential participants were contacted via email and snowball sampling was used again to reach more participants that met the inclusion criteria. Participants of all ages and with varied years of experience were included to increase the diversity of perspectives. Table II (above) illustrates the demographic information of the participants.

Table III (above) provides a summary of where and to whom services are provided by the participants.

Research Tools

Before data were collected, two experts reviewed the proposed focus group questions. The experts were both academics with expertise in the PHC context. The feedback provided by the experts was primarily related to the wording of the questions. The suggested feedback enabled the researchers to adapt the questions before the focus groups could commence. Table IV (page 47) illustrates the focus group questions.

Data collection procedures

Data were collected for this study by means of two asynchronized online focus groups, each presented over three days. Asynchronized focus groups (where participants do not all have to be online at the same time), were preferred over synchronized focus groups where participants all

Table IV: Online asynchronous focus group questions

Question number	Question
1	Ice breaker question - What is your favourite activity to do during your free time and why?
2	Tell us about the activities/occupations/tasks that you like to use during your therapy sessions, either at the clinic or in the community and why?
3	Considering the activities/occupations/tasks that you most often use during therapy, which physical activity resources do you use for these activities? Physical activity resources refer to the physical objects, materials, and tools that you use during therapy sessions.
4	What physical activity resources do you not have that you would like to have? This could include any physical activity resources that you believe will enable you to provide adequate therapy for your clients.
5	If the activity resources that you need are not readily available, due to financial constraints or limited available equipment, how do you go about overcoming this barrier?

meet online at the same time. Asynchronous groups were advantageous as it allowed the research participants time to reflect on the questions posted in written format by the facilitator before answering them, in writing. This provides opportunity for depth and accuracy in the presentation of their perspective[20,21]. Furthermore, participants are also allowed the opportunity to respond to each other. The asynchronous groups could accommodate the research participants with limited time as they could respond to the questions and add to the discussion at any time that suited them best throughout the three days[22]. Additionally, by using an online focus group, the researchers could comply with the regulations imposed to curb the COVID-19 pandemic.

The focus groups were conducted via an online platform, Google Groups. Google groups provided a discussion platform where the focus groups could be hosted and where the data could be securely captured. Each participant was invited to the group through their email addresses. Access to the group forum was tested before the onset of the group to ensure that participants had access.

The focus groups were facilitated by the research supervisor. This was in alignment with the ethics committee requirement that the focus groups be facilitated by an experienced facilitator. On the first day, the participants were required to read the instructions of the focus group, complete a short questionnaire via a link contained within the instructions and answer an ice breaker question. The questionnaire included demographic questions, as well as questions pertaining to where and to whom services were provided, as reported in Table II and III. Additionally, on the first day, they received the first focus group question. Two focus group questions were posted on the second day followed by the final question that was posted on the third day. Participants responded to all questions in written format. The facilitator accessed the platform multiple times daily to ensure that optimal facilitation was provided throughout the discussion. Participants were encouraged to respond to each other's contributions in the focus group instructions as well as by the facilitator throughout the discussions.

Data Analysis

Thematic data analysis was used to analyse the data. The phases of thematic data analysis, as described by Braun and Clarke, were followed[23]. Phase 1 required the researchers to familiarise themselves with the data. Transcripts were obtained by copying the discussions from both online focus groups. ATLAS.ti software was used to assist with the organizing and coding of the data. Phase 2 consisted of generating initial codes. The coding was done by a group of two researchers on ATLAS.ti. The analysis was then discussed within the bigger group of six researchers and changes were incorporated based on consensus reached between the researchers. A framework for coding was created as the data emerged [24]. Both focus groups produced similar codes, leading the researchers to believe that data saturation was reached.

During phase 3 the codes were collated and organised into themes and sub-themes. Thematic maps were used to illustrate how the codes were separated into themes and subthemes. This process was completed by two researchers that discussed the results with the bigger group. Phase 4 required the reviewing of the themes. The group of six researchers reviewed the themes and reached consensus on the identified themes and sub-themes. In phase 5 the identified themes were defined and named. The 6th and final phase consisted of producing the report.

Trustworthiness

The trustworthiness of the study was addressed by looking at four principles namely credibility, transferability, dependability and confirmability[25]. Credibility was ensured during the data collection process by making sure that the researchers used peer debriefing continuously. The researchers also developed an increased sensitivity to the participants' experiences through prolonged engagement and persistent observation during the research process as suggested Novell et al [26]. The research group of six communicated multiple times daily during data collection and met weekly during data analysis.

Dependability was promoted in that the researchers provided an in-depth description of the research process. The process was logical and clearly documented. This was done to familiarise readers with the process that was followed for them to make a judgement on the dependability of the study. To promote potential transferability, the researchers provided a clear and comprehensive description of the contexts of the participants in the research report as well as the findings. Therefore, readers can make their own judgement on the transferability of the study to their specific context.

Confirmability aims to ensure that the results obtained

Table V: Themes, sub-themes and examples of codes identified in the study

Themes	Definition of theme	Sub-themes	Examples of codes
Resource constraints	The barriers faced in PHC with regards to physical resources.	Contextual constraints	Environmental barriers Low socioeconomic status of the community Insufficient funds of clients Limits regarding multidisciplinary team
		Space constraints	Limited space / no allocated space
		No physical resources available	No resources Lack of maintenance of physical resources Limited resources influencing activity choice
Current resources used	The ways in which occupational therapists in PHC overcome the problem of limited physical resources.	Strategies used by occupational therapists in resource constrained environments	Advocating for resources Borrowed resources Use of own body Transporting resources
		Alternative sources of resources	Low-cost materials Low-cost toys Recyclable materials Client resources Donations Other clinic's resources
		Maximizing effectiveness of therapy within resource- constrained environments	Education & training Groups Home programme Multipurpose resources
		Overcoming space constraints	Home visits
		Utilizing human resources	Using personal resources Using the client's own body Utilizing Community Health Workers
Most useful physical activity resources	The physical activity resources identified as most useful in the rendering of occupational therapy services.	Required resources	Activities of daily living resources Assistive devices Plinth Sufficient space Craft activity resources Kitchen activity resources Low-cost materials Pillows Recyclable materials Rollers/wedges Splinting Standing frame Therapy mat Environmental resources

could be confirmed by others[26]. This was facilitated by making use of reflexivity. The regular communication between all members of the research group and weekly group meetings enabled the researchers to reflect on their role in the research.

Ethics

Ethics approval (number 800/2020) was obtained from the Research Ethics Committee at the University of Pretoria which complies with ICH-GCP guidelines and has US Federal wide assurance. The fundamental ethical principles used in this study were: respect for persons, beneficence and justice[27]. The participants had the right to autonomy, through informed consent and voluntary participation. It was ensured that the participants were aware of their right to withdraw at any time during the study without negative consequences. All data collected during the focus group remained confidential and any identifying information was omitted during the process of data analysis.

FINDINGS

Three themes emerged during the process of data analysis. Table V (above) provides the definition of each of the themes, the subthemes and examples of codes included under each theme.

Theme one precedes the findings for the research objectives. To explore the resource needs of occupational therapists in PHC settings in Gauteng, it is important to first understand the resource constrained contexts of the participants.

Theme 1: Resource constraints

The first theme that emerged was resource constraints experienced in PHC workplaces. Several participants asserted that they had few physical resources and limited space available in their PHC setting, often compromising the extent of the services that they were able to render. The lack of physical activity resources acted as a barrier to occupational therapy services.

> "This lack of space and limited equipment often prevented us from providing the best intervention we could to each client we saw" **(P6, an occupational therapist working in urban and rural environments with less than three years of experience)**.

> "I want to mention that we outreach to another clinic ..., where we have nothing, and our rehab team (physio, OT, social worker, and STA) share one consultation room. At our 'main' clinic and outreach clinic space is really making it difficult to render services. ... It is also difficult to take all our equipment to our outreach clinic, so often we do not have anything to use" **(P5, an occupational therapist with less than three years of experience, working in a rural setting).**

Limited space as a resource constraint seemed to be the most problematic barrier faced by the participants in their PHC settings.

> "A big problem within most of the clinics where I worked was space. Often, we were pushed into small offices and there was no equipment available" **(P6)**

Theme 2: Current resources and strategies used

The second theme that was identified highlighted the ways in which occupational therapists make adaptations to therapy in order to reach the same goal despite resource constraints. The findings show that there are many different sources of physical activity resources that occupational therapists use when activity resources are not available at the facility where they are employed. Two participants describe having to borrow or share resources from nearby clinics as well as having to transport resources such as wheelchairs when travelling between clinics.

> "We are coping with what we have, but if the other clinic takes back the equipment, we will need similar equipment for muscle strength and ROM exercise" **(P5)**

> "... we had to travel with equipment and often up to 5 wheelchairs in a car to ensure that we could provide intervention to our clients" **(P6)**

Due to the limited space, many therapists either did therapy outside or preferred to do home visits instead. Participant 4 (an occupational therapist working in urban and rural areas with more than 10 years of experience) said:

> "We have limited space in all the clinics that I service. This contributes a lot to the choice of activities that I use for groups. We do our activities outdoors because there is no space indoors".

> "I do home visits to compromise for lack in space" **(P5, a participant that has to share the therapy room she has access to with other professionals)**

Participant 8 (with less than three years of experience) faced the same problem:

> "... if anything I think my greatest challenge is the lack of enough space. I could always hold some parts of sessions outside".

Due to resource constraints, some therapists have to get creative by using environmental resources such as sand or stones. Participant 1 (with more than 10 years of experience working in an urban environment) said:

> "I have to add, that being based in the community, I often have to use everyday objects for therapy. I've used rice grains, pasta, pegs, beans, wool, cotton wool and also flour from home. Even sand".

The other noise makers we and students have made, using toilet rolls filled with stones, sand, rice, etc. (P2, an occupational therapist with between 5 and 10 years of experience, working in urban and rural contexts)

> "... bottles filled with sand for weight, balls sometimes we use old clothes to make one".**(P4)**

Within this theme the adaptability and innovativeness – particularly of more experienced participants - became evident. The participants described using recyclable and low-cost materials as physical activity resources.

> "I use low cost recycled materials, such as the bottle caps, tins, toilet rolls, take away containers, etc. I have also used cut off pieces of sponge (leftover from the Buggy seatings) to do stacking activities, sorting them according to shape, size and colour. The toilet rolls are so versatile! I use them to make shakers, 'binoculars' for visual acuity, rolling them to one another, I cut them into smaller circles that can be used for threading necklaces... I have also used them as stamps by dipping the edges into paint and then stamp circles onto paper" **(P2)**

> "So, I use stacking cups, wooden blocks, plastic bottle caps in various colours, plastic buckets for sorting, large, coloured beads, matching games and cards, scrap paper and crayons, and threading shapes and shoelaces" **(P1)**

Participant 2 took further initiative by organizing a fundraiser with her students:

> "We received a donation of soft toys a few years back, which another group of students, as part of their project, sold to do fundraising for needed resources. With the funds they bought blocks, noise makers, small flashlights, ingredients to make homemade playdough with, rice, beans, bean bags, and cellophane".

Many participants have relied on donations from organizations and fellow colleagues.

> "I am also fortunate to have access to ..., which provides

> resources to therapists in need if it helps in any way with patient services or therapy". **(P3, an occupational therapist with less than three years of experience, working in the urban environment)**

> "I also was aware of getting access to free/scrap materials in the hospital and my own community and encouraged other colleagues to bring second hand items which they weren't using, such as an old baggy t-shirt for dressing activities" **(P7, an occupational therapist with less than three years of experience working in a rural context)**

Other therapists asked patients to bring their own equipment and materials to use during therapy.

> "For the ADL activities I will ask everyone to bring shoes with laces, a shirt with buttons, etc." **(P2)**

> "I also took my own equipment such as blocks and cars as this was not available at the clinics. I learned that it is important to be adaptable and context specific within therapy therefore I also asked caregivers to bring the toys they have available at home." **(P6)**

Theme 3: Most useful physical activity resources

The third theme created was the physical activity resources identified as most useful in the rendering of occupational therapy services. Certain objects, equipment, tools and resources seemed to stand out amongst others, either for being very useful and often utilized in the participants' context or for creating a strong barrier in the absence of the object or resource.

Naturally, the absence of space proved to be the barrier most often faced by the participants as described in theme one.

> "I must first have space and then the rest will follow **(P4, occupational therapist working in urban and rural areas without access to an occupational therapy treatment room)**, implying that space forms the foundation for the rendering of occupational therapy services".

Furthermore, many participants mentioned that they desire to have more resources that are used in rehabilitation for clients who face difficulties within their basic and instrumental activities of daily living.

> "Tools and equipment ... to be able to engage in occupation [sic] such as BADL and IADL like cooking, activities to be used for leisure ..." **(P5)**

> "I would have liked ... more ADL tools, such as clothes, kitchen equipment, etc. as most of the kitchen equipment were [sic] missing or broken" **(P6)**

Assistive devices and Bobath plinths were often mentioned by the participants. Assistive devices were either often used by the participants or solutions had to be found to compensate for the absence of these assistive devices.

> "For example, I often used rolled-up bed sheets or blankets for positioning or educated families on what they could make or buy at home" **(P7)**

> "... we had to travel with equipment and often up to 5 wheelchairs in a car to ensure that we could provide intervention to our clients" **(P6)**

> "I use the physio mats and physio balls, rollers and wedges during our developmental delay group ... I use the paediatric standing frame as well, especially when the physio and I have joint sessions. This works extremely well to reach our objectives together" **(P2)**

> "I often made use of a Bobath plinth, ... and wheelchairs or walking frames ..." **(P6)**

> "I also very often make use of the therapy mats and Physio ball for gross motor activities" **(P2)**

The physical activity resources that were most often discussed were recyclable and low-cost materials. It is exactly these resources that are creatively utilized by occupational therapists when typical resources are not available.

> "I use the bottle caps to do sorting activities - size and colour sorting. The tins I use for stacking, as well as using them to sort the caps into. ... I also bring things from home sometimes but try to recycle/upcycle 'trash' to make low cost toys with. I also brought a bunch of old magazines to the clinic to use during therapy" **(P2)**

> "I make use of ... different coloured plastic bottles with matching rings, ... chalk to draw a tandem line (for dynamic balance)" **(P8)**

These recyclable and reusable items are found to be distinctly valuable in the under-resourced practice contexts in which the participants render therapy.

DISCUSSION

Firstly, the findings suggest that the PHC practice contexts where the participants are employed are under-resourced. This supports previous studies where participants have highlighted the limited physical resources they have available to provide rehabilitation services in PHC[12,14]. The available space as well as the objects, tools and materials needed are important considerations in the activity selection and professional reasoning process[9]. Therefore, limited access to space and other physical activity resources will invariably influence the intervention provided by therapists.

Not surprisingly, several participants in this study experienced the limited availability of physical resources as a barrier to their service provision in PHC. Inexperienced therapists have been described to experience the influence of aspects pertaining to the environment (such as available resources) as more influential on their practice than more experienced therapists[28]. Experienced therapists are said to view environmental factors not so much as barriers, but rather as merely among the many factors to be considered in the professional reasoning process[29]. As most participants in this study were relatively inexperienced, this may – at least in part – have contributed to the experience that resource constraints were such a barrier.This insight is important for managers to keep in mind when supervising and managing inexperienced professionals (that often work in PHC) to guide them to develop the ability to recognise the opportunities and strengths within the resource constrained PHC context.

Aspects pertaining to the resource limitations as reported in Theme 1 enable the reader to understand the context in which the participants work. Reporting on the context is important in order to increase the potential transferability of the findings to other contexts. Therefore Theme 1 essentially preludes the objectives of this study that aimed to identify the resources and strategies that occupational therapists in PHC utilise and those physical activity resources they deem to be most important to ensure effective services can be provided.

Several authors[5,7, 12,14] have called for adequate resources for rehabilitation. It is hoped that the findings reported in Themes 2 and 3 will assist managers to advocate for additional resources for occupational therapy services in PHC.

Theme two indicates the resources and strategies that occupational therapists in PHC currently use. This theme answers objective 1 of this study (current resources used). The resources consist of a combination of typical occupational therapy resources and unconventional resources used to compensate for limited resources. Invariably linked to the resources used at the time of this study are the strategies occupational therapists utilise to adapt to the limited resources in their practice context. Contexts with limited resources appear to create opportunities for creativity and resourcefulness. The adaptability and resourcefulness of therapists have also been reported by van Niekerk[6].

The use of recyclable materials was highlighted as an important resource. The use of recyclables aligns with sustainable and environmentally responsible practice[30]. By linking with established community recycling projects or developing such projects can provide occupational therapists with the required recyclable resources for their practice and support participants in the recycling projects.

Importantly, students should be trained to provide services in resource constrained environments during their studies. Lorenzo et al. reported that there is a misalignment between undergraduate training and the demands of PHC contexts[31]. This corresponds with van Stormbroek and Buchanan's research in which a participant stated that they felt that most of the training they received during undergraduate studies was difficult to apply in a resource-constrained environment[14]. Training undergraduate students to be adaptable and resourceful may better enable inexperienced community service therapists to cope with the challenges posed by the PHC context.

The second objective was to explore which physical activity resources occupational therapists deem necessary in order to provide adequate intervention in their specific context. This objective is primarily answered by Theme 3. However, without the availability of the resources mentioned in theme [2], the possibility of rendering adequate intervention in resource-constrained contexts would be substantially limited. These resources, first and foremost, include space, basic and instrumental activities of daily living resources, assistive devices, plinths, recyclable and low-cost materials. These resources cannot be compensated for, as they have been identified as either most useful within occupational therapy intervention or are used by occupational therapists to overcome resource barriers.

Limitations

The study had a limited sample size. There are few PHC clinics in Gauteng and many of these facilities do not employ occupational therapists. A second focus group was conducted due to the attrition in the first focus group. The target population was sampled as planned, but the findings of this study cannot be generalised and do not reflect the situation in any of the other 8 provinces in South Africa. Additional limitations included that participants were difficult to recruit and had limited time available to participate in the study.

CONCLUSION

The consideration of physical activity resource demands during professional reasoning is an integral part of planning intervention. In the absence of physical activity resources such as objects and space, occupational therapists may experience various barriers related to their professional identity and self-esteem[15]. It is evident that the PHC context is under-resourced compelling occupational therapists to use unconventional resources to overcome contextual barriers. Certain physical activity resources have been identified to be particularly useful in occupational therapy intervention in PHC.

This study is relevant to the clinical practice of occupational therapy in that it contributes to the body of knowledge regarding the physical activity resource needs of occupational therapists in PHC. The research may contribute to the preparation of newly qualified occupational therapists for the PHC context. It further creates a base of knowledge from which future studies can be conducted regarding what occupational therapists regard as essential resources in PHC as well as studies on how available funds can be maximised.

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Authors' contributions

Karin van Niekerk was the supervisor of the study and conceptualised the study. She guided design of the study, performed the data collection, and assisted with data analysis and interpretation and edited the manuscript. Sabrina Raquel da Silva, Clarette Swart, Marnique Hugo, Zolani Phiwokuhle Flatela, and Ansa Janse van Vuuren were investigators in this study and were responsible for the study design, sourcing relevant literature, recruiting participants, analysing the data and interpretation of the results. They were primarily responsible for drafting of the manuscript.

Conflicts of interest and bias declaration

The researchers declare no conflicts of interest. The views expressed in the article are the authors' own and not an official position of the relevant institution.

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RESEARCH ARTICLE

Older adults' adaptiveness to disruptions during South Africa's COVID-19 lockdown: Keep your head up and continue breathing

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ABSTRACT

Introduction: Adaptiveness fosters resilience through increasing capacity to transcend barriers in individuals, their environment and occupational engagement. The COVID-19 pandemic and lockdown may have decreased adaptiveness in older adults by disrupting occupational engagement, thus negatively influencing health and well-being.
Methods: A qualitative, meta-analytic design was used to explore the adaptiveness of older adults to disruptions experienced during South Africa's COVID-19 lockdown. Four student researchers' primary studies were reviewed and findings synthesised for this paper. Individual, semi-structured interviews were conducted with 16 participants during April and May 2020. The transcripts were analysed thematically and reported in the primary studies. The authors conducted thematic analysis across all four primary studies to develop themes for this paper.
Findings: Three dominant themes emerged: (1) COVID-19 as an illness, (2) occupational disruptions experienced by older adults, and (3) developing a state of adaptiveness. Older adults developed adaptiveness through changing perspective, adapting to new environments, learning to use technology, expanding roles and routines, and strengthening the spiritual self through engagement in eudemonic occupations.
Conclusions: The study provides insights into challenges and adaptiveness of older adults during the COVID-19 lockdown. Findings inform interventions with older adults presenting with reduced adaptiveness.

Implications for practice
This study is valuable as it provides occupational therapists with a deeper understanding of older adults' experiences and challenges during the COVID-19 lockdown, thus, laying the potential for strengthening client-therapist interpersonal relationships. Although the sample observed in this study was older adults, the findings can be considered among other vulnerable clients such as individuals with disease, illness and/or disability. Additionally, these findings may provide occupational therapists with insights that can assist in framing intervention strategies for clients with a decreased state of adaptiveness. This is significant as adaptation requires reasonable social, emotional, and cognitive processes. Lastly, this study aimed to contribute to a wealth of research exploring adaptiveness, rooted in the reality that change is inexorable; however, how we respond to change can be transformative for individual and population well-being.

INTRODUCTION

At the core of the human experience is an overwhelming desire to be engaged in meaningful and purposeful occupations, and this is integrated with the process of striving for, and achieving, mastery in said occupations. Schultz and Schkade[1] described this internal primitive process as occupational adaptation. Adaptiveness is a life-long dynamic process that fosters resilience through an individual's capacity to transcend barriers presenting in personal factors pertaining to the person, their environment and occupational engagement[2,3,4]. An increased state of adaptiveness empowers persons to engage in diverse and meaningful occupations, which in turn has the potential to promote a holistic state of well-being[2,3,5,6]. The advent of the COVID-19 pandemic and consequent restrictions resulting in lockdowns in South Africa may have decreased levels of adaptiveness in more vulnerable populations, such as older adults, who were identified as a higher risk population for the development of moderate-severe COVID-19 complications with a higher mortality incidence. O'Leary[7] and Cloete[8] have noted significant disruptions in roles and routines due to COVID-19 restrictions. The top-down implementation of the lockdown restrictions may have furthered a decreased state of adaptiveness through the removal of individual autonomy, free-will, occupational choice and power, thus, highlighting a potential social justice crisis on top of a health crisis.

Previous studies such as those by Blacker[4], Lexell[5], Cahill[6] and Johansson[9] have examined adaptiveness in the context of population vulnerability, illness, and disability. However, limited research has explored the adaptiveness of persons within the context of a pandemic or lockdown. Moreover, research is further restricted when investigating one of the most vulnerable populations to the causation of the pandemic, such as older adults, in South Africa. This is noteworthy when considering that South Africa is a developing country with a complex set of challenges suspended in a precarious narrative of inequality. The question that arises is how did older adults adapt to the disruptions of the COVID-19 lockdown in South Africa during 2020?

Literature review

COVID-19 in South Africa

In December 2019, a novel, acute respiratory syndrome SARS-CoV-2 appeared in Wuhan, China[10]. SARS-Cov-2 or COVID-19 presents with myriad flu-like symptomology including fever, malaise, dry cough and dyspnea[11]. This presentation is characteristic of numerous viral conditions such as pneumonia, the common flu/cold and seasonal allergies. This made it challenging initially to distinguish COVID-19 from other viral conditions, causing the virus to spread rapidly on a global scale. On 30 January 2020, COVID-19 was flagged as a public health emergency of international concern by the World Health Organisation[12]. On 5 March 2020, South Africa's former minister of Health, Dr Zweli Mkhize confirmed the arrival and spread of COVID-19 in the country. The South African population met the news with great concern, angst, hysteria, fear and frustration[13]. This response was not unfounded when considering that COVID-19 was a novel virus with limited evidence surrounding transmission and clinical management. Moreover, South Africa is a developing country with a weakened healthcare system and a significant immunocompromised population owing to a high prevalence of HIV/AIDS, tuberculosis, malnutrition, and lifestyle diseases[14]. As findings related to COVID-19 emerged, it was established that the risk for COVID-related severe illness and death increases with age due to possible changes in lung anatomy and muscular atrophy which results in physiological dysfunction, reduction of lung reserve, reduction of airway clearance, and reduction of the defence barrier function[14,15]. Older adults' risk was exponentially increased through the prevalence of comorbidities such as hypertension, diabetes mellitus, obesity, chronic obstructive pulmonary disease or any other respiratory illness[16,17]. The Centers for Disease Control and Prevention[18] further stated that persons from racial or ethnic minorities are at risk of developing moderate-severe COVID-19 complications, or even dying, because of where they work and/or live as well as poor health service accessibility.

The implications of the COVID-19 lockdown on South Africans

To safeguard vulnerable populations such as older adults, the South African government followed international trends and declared a National State of Disaster. South Africa was placed on lockdown alert level 5 effective from 26 March 2020 in an attempt to flatten the first wave of COVID-19 infections. The lockdown highlighted disparities amongst South Africans when considering the argument of equality versus equity as a determinant of privilege[19]. Amongst individuals in a higher-middle socioeconomic bracket, lockdown restrictions were well adhered to[20]. People were able to isolate comfortably in their homes, transitioned to working remotely with access to electronic devices and the internet, dedicated time to home school their children and families reported being happier during the lockdown[20]. The situation in disadvantaged communities, particularly in informal dwellings, stood in stark contrast to this image[21]. Challenges in disadvantaged communities were overcrowding, poor sanitation, lack of access to personal protective equipment such as masks[22], and most notably, a dire lack of food and basic supplies. This contributed to hunger riots[23], shop looting[24] and confrontation with the South African National Defence Force (SANDF) and the South African Police Service (SAPS)[25]. The SANDF and SAPS militantly surveyed communities, utilised intimidation tactics and brutality and incarcerated those in violation of lockdown restrictions[26]. To mitigate economic challenges many organisations lobbied donations to collect and distribute food parcels whilst the South African government allocated ten percent of the COVID-19 stimulus package toward social assistance including an increase in the amount of all existing grants and the addition of a new COVID-19 social relief or distress grant[27].

These efforts, however, were minimal in addressing the grave inequalities rooted in disadvantaged communities.

Occupational justice perspective

Durocher describes occupational justices as the promotion of fairness, equity, and empowerment that enables opportunities for participation in occupations for the purposes of health and well-being[28]. According to Townsend and Wilcock[29] and Wilcock[30], an occupational justice perspective observes individuals as occupational beings with idiosyncratic occupational needs, wishes and habits dependent on their circumstances and capacities, with each individual requiring different occupational opportunities to realise their talents and flourish. The occupational justice perspective observes participation through a socio-political lens by examining the degree of individual and population right to meaningful, purposeful and varied occupations that aim to improve quality of life, meet basic needs and realise potential[29,30]. The South African lockdown highlighted numerous occupational injustices more rampant in lower-middle class individuals. These injustices stem from the residual remnants of occupational apartheid that saw the unequal distribution of occupational opportunities in accordance with a system of racial classification[31]. Restrictions on social participation, community mobility and gathering for connectedness resulted in occupational deprivation[32] and marginalization[33]. Restrictions to participate in occupations for work for financial gain furthered the pre-existing challenges of lower-middle class individuals to meet basic needs such as food, water, medical care and personal protective equipment. This was compounded by the fear and anxiety around the uncertainty of when or if the lockdown would end and if individuals would have a job to return to. Imposed home isolation for prolonged periods of time has resulted in occupational imbalances such as being unoccupied and under-occupied as not everyone was afforded the same set of privileges[29,30].Transcending the barriers of class and privilege, the lockdown resulted in widespread occupational alienation[32] when examining participation in occupations linked to religious observance and culture through the closure of sacred religious and cultural institutions. An argument can be made that efforts have been made to adapt through the use of technological platforms, however, it can be proposed that this adaptation was insufficient and lacking in meaning through unfamiliarity. Most notably, the lockdown has resulted in the grave removal of individual occupational choice and autonomy thus leading to powerlessness. This state of powerlessness was more debilitating to those subjected to multiple occupational injustices and with a lesser degree of privilege. This resulted in occupational disruptions[34].

Occupational disruptions

Nizzero describes occupational disruption as a temporary disturbance in an individual's typical pattern of participation[34]. Emotional responses such as uncertainty, anxiety, and vulnerability are common when experiencing occupational disruption due to the loss of occupations and/or social connections, as well as feeling a lack of control. This is supported by Klinger who stated that occupational disruptions could have a negative influence on health, well-being, and quality of life[35]. O'Leary[7] and Cloete[8] noted that significant disruptions in roles and routines have been observed amid the COVID-19 pandemic. Routine is significant as it allows individuals to shape the manner in which they spend their time, whilst roles form the essence of who we are and can reflect priorities and values in life[7]. When roles and routines are negatively influenced it can affect mental well-being as well as the individual's perspective of their world[36]. Nizzero posited three adaptive strategies to overcome occupational disruption including: (a) modifying previous occupations; (b) maintaining order or routine; and (c) adopting new occupations or routines[34]. These strategies align with Doroud, Fossey and Fortune's conception of gradual re-engagement in occupations that promote health recovery by establishing structure, routine, hope, empowerment, sense of self and connectedness[37]. These strategies are guided by the overarching theory of occupational adaptation[1,3].

Occupational adaptation

Occupational adaptation is described by Schkade and Schultz[1] as an internal normative process wherein the overwhelming desire to be engaged in meaningful occupations is integrated with the process of striving for, and achieving mastery, in occupations. Adaptation is an interdependent relationship between the person, environment, and the interaction between the person and the environment[1]. Nelson[38] positioned adaptation as a process wherein the person has the internal capacity to alter their sensorimotor, cognitive and psychosocial reserves by engaging in meaningful occupations. Nelson and Jepson-Thomas[39] defined adaptation as the effect of occupational performance on the individual's developmental structure and further stated that occupational adaptation does not always yield a satisfactory or optimal resolve. Frequent and reoccurring errors in occupational performance may result in a sense of learned helplessness or maladaptation when confronted with future occupational challenges. Kielhofner[3] described occupational adaptation as the process of constructing an occupational identity and achieving competence over time in the context of one's environment. Research centred on occupational adaptation emphasises the significance of the interaction between the person and the environment. The lockdown has underscored the improved adaptive responses of South Africans to occupational challenges resulting from novel environmental barriers. Throughout this, we have observed increased desires and efforts to socialise and connect to others on walks to communal taps or toilets in townships, neighbours sitting in front of their closely positioned homes talking, strangers waving or nodding in passing or whilst queuing in grocery store lines to collect supplies, and mothers neglecting their own occupational needs to assume the role of caretaker, nurse, counsellor, teacher and more, to meet her children's occupational demands. Although occupational adaptation cannot be measured instrumentally, we can observe a strengthened adaptive response through the emergence of three predictive outcomes namely; (1) an improved self-initiation, (2) generalisation, and (3) improved relative mastery[1]. Eudemonic occupations have long been attributed to the instillation of adaptiveness during challenging times[40,41].

Eudemonic occupations

Eudaimonia infers a state or condition of existing in good spirits which can commonly be translated to one's state of happiness or well-being[40,41]. Eudemonic occupations can be observed as those going beyond the mere utility of survival and, instead, nurture the essence of who we are as beings whilst reflecting our hearts, dreams and purpose. Fulfilment of eudemonic occupations fosters eudemonic well-being described by Ryan[42] as when an individual's life activities are the most congruent or interconnected with deeply held values or beliefs and they are holistically or fully engaged. Waterman[43] further posits that eudemonic well-being is enriched by doing what is worth doing. Spirituality is observed as a significant dimension in the attainment of eudemonic well-being through the introspection, strengthening and expression of the inner self. Spirituality in alignment with occupational therapy literature is reflected as an inner resource independent of religion or denomination, and rather of occupations that restore and contribute to the self[44]. Thibeault proposed five occupational gifts[45] that were expanded upon by Zafran[46] that reflect resilience through an exploration and development of the spiritual self. Connecting occupations[45,46] are those in which we experience belonging to others and to life through connecting online or in person, giving back to the community and interconnectedness to pets and nature. Centring occupations[45,46] foster awareness, presence, and calm through meditation, walks in nature, repetitive activities such as knitting or grooming a pet. Creative occupations[45,46] aim to meet the human need to explore, create and play without judgment or the need to develop product or skill mastery. Contemplative occupations[45,46] are those that induce awe of life by focusing on the bigger picture through prayer, journaling, or reflective walks in nature. Contributing occupations[45,46] allow us to give back within the communities that support and nurture us. Engagement in eudemonic occupations has the potential to provide predictability, structure and routine; belonging and connectedness; and a sense of hope for the future[45].

In summary, the review of literature revealed some evidence that the COVID-19 lockdown affected the occupational engagement of individuals through disruptions experienced in meaningful occupations. Disruptions further highlighted grave societal inequalities through the widespread incidence of occupational injustice. These occupational injustices simmered back down to the persisting argument of equality versus equity as rooted in South Africa's complex history regarding racial classification. Not all participants were provided with equitable opportunities for holistic engagement during the lockdown, thus, laying the potential for a decreased state of health and well-being. To foster occupational engagement for improved health and well-being, literature suggests a need to develop resilience to disruptions through an increased state of adaptiveness. It is possible that engagement in eudemonic occupations has the potential to facilitate resilience in individuals and enable them to adapt to challenging situations. However, there is limited research exploring the adaptiveness of older adults in South Africa within the context of a pandemic or lockdown.

METHOD

This study aimed to explore the adaptiveness of older adults to disruptions experienced during South Africa's COVID-19 lockdown. The research design for this study was qualitative meta-analysis, which is a method for reviewing qualitative studies that entails a rigorous secondary qualitative analysis of primary qualitative findings[47]. Qualitative meta-analysis provides a more comprehensive description of a phenomenon researched by a group of studies[47].

Primary qualitative studies

Four primary qualitative studies conducted by student occupational therapy researchers under the supervision of two of the authors were reviewed for this paper. This allowed researchers to gain an in-depth and contextually rich understanding of the process by which older adults have developed adaptiveness to disruptions experienced during the South African lockdown[48,49]. The student researchers voluntarily consented for their studies to form part of the meta-analysis. According to the method outlined by Timulak[47], two of the authors critically appraised the four primary studies to ensure data quality and trustworthiness. The studies were screened and included in the meta-analysis based on similarity in focus, key research question, aim and objectives, context, and the theoretical and methodological frameworks. All four studies employed a qualitative, exploratory-descriptive design and semi-structured interviews to explore and describe the influence of COVID-19 on the roles and routines of adults aged 55 years and older during the hard lockdown period in April and May 2020. The findings of the primary studies became the data for the meta-analysis[47].

Study selection and participant selection

All four primary studies utilised purposive[50] and snowball sampling[51] to recruit a total of 16 participants. These sampling methods allowed researchers to gather participants whose lived experiences were central to the studied phenomenon whilst strictly adhering to the COVID-19 restrictions on travel and person-to-person contact. Researchers primarily used strategic word of mouth directed to key friends, family and/or community populations to identify potential participants meeting the inclusion criteria: aged 55 years or older, male or female, and resident in South Africa during the COVID-19 lockdown. Participants were then recruited through the use of technological platforms including: telephone calls, WhatsApp Messenger, Short Message Service and email. In contexts where potential participants were not technologically proficient or did not have access to technological devices, researchers recruited them in person. Most participants were from lower-middle socioeconomic backgrounds in two provinces – the Western Cape and Mpumalanga (Table I, page 58).

Data collection

Data for the four primary studies were collected in May 2020 through face-to-face contact or using technological

Table I: Participant demographic information

Pseudonym	Gender	Age	Ethnicity	Socioeconomic background	Location (Province)
P1	Male	72	Coloured	Low-middle	Western Cape
P2	Female	70	Coloured	Low-middle	Western Cape
P3	Male	64	White	Low-middle	Western Cape
P4	Male	63	Unspecified	Unspecified	Western Cape
P5	Female	64	Black	Low-middle	Mpumalanga
P6	Female	75	Unspecified	Unspecified	Western Cape
P7	Female	88	White	Low-middle	Western Cape
P8	Female	73	Coloured	Low-middle	Western Cape
P9	Male	55	Black	Low-middle	Mpumalanga
P10	Male	66	Coloured	Low-middle	Western Cape
P11	Female	54	Black	Low-middle	Mpumalanga
P12	Female	77	White	Low-middle	Western Cape
P13	Female	71	Coloured	Low-middle	Western Cape
P14	Female	69	Coloured	Low-middle	Western Cape
P15	Female	58	Black	Low-middle	Mpumalanga
P16	Female	60	Unspecified	High	Western Cape

platforms such as: telephone calls, WhatsApp Messenger, and email. Researchers utilised individual interviews guided by semi-structured and open-ended questions to facilitate discussions. The key questions focused on older adults' experiences of the influence of COVID-19 and the South African lockdown, how this influenced their occupational engagement, and how they adapted. Telephone calls were recorded and voice notes were saved and transcribed verbatim, whilst written responses were saved. These transcripts were then analysed separately for each primary study and the findings were written up as chapters of the four research reports. The four research reports, with a focus on the findings chapters, comprised the data sources for the qualitative meta-analysis presented in this paper.

Data analysis

Relevant information from the primary studies was mapped onto a data extraction spreadsheet, and included title, research question, study aim and objectives, theoretical framework, methodology, research setting, findings, discussion, and recommendations. Subsequently, all data extraction spreadsheets (transcripts) were imported to generate one master transcript, and organised using a coding framework to be analysed thematically[52].

The first author utilised Braun and Clarke's six steps of thematic analysis to guide data analysis through the process of familiarisations and noticing similarities and patterns[53]. This process is marked by the review of the transcripts numerous times with the intention of making sense of the data. Secondly, initial codes were identified and grouped together based on a similar narrative and were organised using a data extraction sheet. Thirdly, codes were further grouped together and organised to create sub-themes that aligned more closely with the research topic. Themes were then loosely created in representation of the data housed in each sub-theme. Fourthly, themes were reviewed based on the coded extracts and full data set and some of the themes were collapsed. In the fifth step, themes were named by providing a brief description of the narrative represented by the grouping of the sub-themes and supportive data extracts. The final step involved the written reporting of the findings, which was done through analytic narrative and data extracts. Two of the authors closely monitored the process of data analysis to ensure neutrality in the representation of the data as well as a consensus of the article's overriding narrative.

Trustworthiness

Trustworthiness was ensured by means of the above-mentioned critical appraisal of the primary studies[47], and ensuring credibility, transferability, dependability and confirmability[54]. Credibility was ensured through the process of triangulation[55] of data sources (multiple participants from two provinces in South Africa and four primary research reports) and multiple researchers. One researcher acted as auditor, monitoring procedures in the meta-analysis and maintaining distance from the analysis process in order to check bias in the analysis[47].Transferability was ensured by sourcing a diverse sample across the primary studies[56] to produce a robust and well-developed narrative. Dependability and confirmability were ensured through the provision of an audit trail and dense descriptions of the context, the sampling method and characteristics of participants, data collection and analysis.

Ethics

Ethics approval was obtained from the University's Biomedical Research Ethics Committee (BM20/9/3). All participants in the four primary studies and the meta-analysis study took part voluntarily, provided informed consent and were aware of their right to withdraw from the study at any stage without concern of repercussions. All health and safety protocols to prevent the transmission of COVID-19 were strictly adhered to throughout the study. Participant confidentiality and privacy was maintained throughout. Participants were assigned pseudonyms and all data were stored on password-protected devices only accessible to persons directly involved in the study.

FINDINGS

Data analysis yielded three dominant themes: (1) Insight into COVID-19 as an illness, (2) occupational disruptions experienced by older adults, and (3) developing a state of adaptiveness. These themes comprised twelve sub-themes and are supported by data extracts (Table II adjacent).

Table II: Themes and sub-themes

Themes	Sub-themes
Insight into COVID-19 as an illness	What is COVID-19? Older adults are vulnerable
Occupational disruptions experienced by older adults	Roles and routines Social participation Travel/community mobility Work participation Religious observance Deteriorating mental well-being
Developing a state of adaptiveness	A change in perspective Adapting to new environments Adapting by using technology Strengthening the spiritual self

Theme One: Insight into COVID-19 as an illness

The first theme deals with the older adults' insight into COVID-19 as an illness, which highlights their understanding of the pandemic. This theme further captures the awareness about the vulnerability of older adults in developing moderate-severe health outcomes.

What is COVID-19

Participants perceived COVID-19 as a novel virus similar to the common cold or flu in its presentation of a dry cough, fever, tiredness and fatigue, however, emphasised its severity in likening it to a terrible virus grave enough to cause death.

> "My understanding is that it is a terrible virus and people have died from it." **(P1)**

> "Somebody that I knew died, she was a nurse." **(P2)**

Older adults are vulnerable.

It was determined that the risk of developing moderate-to-severe COVID-19 health outcomes was more prevalent in older adults due to their progressing age. This risk was exponentially increased by the prevalence of comorbidities such as diabetes mellitus and other immunocompromising conditions such as HIV/AIDS. Participants positioned older adults living with comorbidities as the most vulnerable South African population.

> "COVID-19 affects us in old age because we have a lot of underlying medical problems. I have diabetes and I take ARV [antiretroviral] pills, so this puts you at risk. We are vulnerable." **(P3)**

Theme Two: Occupational disruptions experienced by older adults.

The second theme focuses on the occupational disruptions experienced by the older adults that influenced their occupational engagement during South Africa's COVID-19 lockdown.

Roles and routines

Participants reported that the abrupt enforcement of the South African COVID-19 lockdown during the COVID-19 pandemic caused significant disruptions in occupational engagement through the immediate suspension of previously held roles and routines. Previously engaged in roles and routines that provided participants with structure, predictability, autonomy through decision-making abilities, and the power to select meaningful or purposeful tasks or activities that filled up the day, were no longer possible during the lockdown.

> "The lockdown has caused so much change and without warning. It really has a big impact on my ability to fulfil my daily routines. I don't know what to do anymore." **(P4)**

The lack of engagement in meaningful roles and routines caused confusion, frustration, uncertainty and led to participants questioning who they were and what they were doing with their time.

> "My roles have changed overnight. Sometimes I don't know what to do because who I was, I can't be anymore." **(P5)**

Social participation

COVID-19 can largely be considered a social spreader in that the virus spreads more rapidly through social contact with infected persons or contaminated surfaces. The South African government, thus, more stringently regulated occupational engagement in social activities. Participants reported how vastly these restrictions negatively influenced their social and family roles resulting in loneliness, isolation, and disconnectedness.

> "I used to visit friends and have them visit me three or four times a week and now we cannot do that. I feel alone." **(P6)**

> "I used to see my family a lot. Now I only get to see my family once a week when they drop off my shopping, but they always say, 'Ma I'm staying in the car.' I wish they stayed longer." **(P7)**

Travel/community mobility

Participants highlighted restrictions on travel and community mobility as being instrumental in hindering their social participation and the fulfilment of family roles. This significantly affected participants as travel and community mobility was fundamental in aiding their connections to others.

> "My children can't visit even though I live close-by. People are not allowed to travel." **(P6)**

> "I used to visit my family but now I can't drive anywhere so I don't see them." **(P8)**

Travel, community mobility and social activities were closely monitored by the South African Police Service and National Defence Force through constant community surveillance and the implementation of a national curfew. Participants reported feeling anxious and fearful when leaving their homes out of concern that they could be arrested.

> "I like being able to walk around my area but now I am worried I will get arrested." **(P7)**

Work participation

The South African COVID-19 lockdown called for the immediate closure of all business sectors, which fundamentally impacted upon participants' ability to engage in work. This is significant, as participants reported that the fulfilment of their worker role provided structure, predictability, meaningfulness, purpose and financial means. Without some form of income, participants feared that they or their families would struggle to meet basic needs such as food.

> "Lockdown prohibits me from doing my work." **(P4)**

> "It [lockdown] has a great impact on my ability to fulfil my role as breadwinner. My ability to provide has been reduced to almost zero and it's concerning because my family will go hungry." **(P8)**

One participant reported drawing money from his unemployment fund to cover basic expenses however, that this was insufficient and that the amount became less each time.

> "I am getting money from the UIF [Unemployment Fund], but it's not the same. It's not enough to cover all my expenses and it gets less every month." **(P15)**

Another participant highlighted that community soup kitchens were closed under the lockdown restrictions which further reduced opportunities for hunger relief for persons with financial challenges.

> "I am involved in a church community soup kitchen, but it's closed, and the people don't have food around here." **(P1)**

As findings from the medical and science communities emerged and the lockdown alert levels were eased to facilitate the increased but still regulated movement of individuals, participants highlighted still being unable to work due to their age and the presence of chronic illnesses.

> " I am not able to work because I am 55 and have a chronic sickness." **(P9)**

Religious observance

The South African COVID-19 lockdown caused the immediate closure of places of worship, resulting in disruptions in religious observance. Participants reported being unable to attend church and elucidated a longing for connectedness through a shared religious experience. Participants further positioned the social self as being interlinked with the religious self.

> "I can't go to church. The fact that you can't see your friends by the services in church is something I miss a lot." **(P6)**

Several worship facilities adjusted their approach to religious observance as the lockdown alert levels eased through the use of technology and implementation of government recommended precautionary measures. Participants, however, reported still being unable to participate due to their progressed age and lack of technological proficiency.

> "The staff and I collect for the church charity project; I can't get it to the people anymore because of my age and that's frustrating for me." **(P2)**

> "I am an esteemed member of my congregation and not being there for meetings is affecting me. Other members continue with meetings on their phones, I don't know how to do that and I am an old man, I don't want to be a burden to anyone." **(P3)**

Deteriorating mental well-being

Disruptions in the occupational engagement of participants caused deterioration in mental well-being. Participants reported feeling sad, miserable, empty, helpless, burdensome, neglected and forgotten.

> "I have been feeling miserable. I feel as if something has been taken away from me. Like the rug has been pulled from under me." **(P10)**

> "I have to sit at home and feel helpless." **(P8)**

> "I feel empty inside." **(P1)**

Disruptions exacerbated symptomology in participants diagnosed with depression.

> "I have a history of depression. My daily routine helps me get my mind off things. Now I feel trapped in the house." **(P11)**

Theme Three: Developing a state of adaptiveness.

The third theme highlights how participants developed a state of adaptiveness to disruptions experienced in their occupational engagement. This was achieved through (a) a change in perspective, (b) adapting to new environments, (c) adapting by using technology, and (d) strengthening the spiritual self.

A change in perspective

Participants believed that the first stage to developing adaptiveness is through a change in perspective of oneself in relation to the various environments. With time, introspection and critical reflection, participants were able to accept the unpredictability of their environment, develop hope that COVID-19 and the lockdown were temporary and were optimistic that the opportunity to reintegrate, re-engage and reconnect would come soon.

> "I know that this lockdown isn't going to last forever, and I know that I will be with my family and friends again. I just need to stay positive." **(P7)**

> "I have learnt that I would rather miss my family for a little bit now and know that they are safe, than miss them forever if they died." **(P12)**

Adapting to new environments

Participants adapted to their new environments by establishing a state of peace with external circumstances and by implementing changes that fostered re-engagement. Participants reported readying their homes for re-engagement in social participation through the implementation of a designated area for visitors to practice good hand hygiene through hand-washing and/or sanitizing.

> "I have sanitiser at the door and a bucket of water if you want to wash your hands." **(P13)**

Participants further reported overcoming barriers in their environment by designating a relative to fulfil high risk occupations such as shopping. Additionally, participants reported adjusting their times of engagement. This allowed participants to regulate their contact with others, thus reducing risk of potential COVID-19 infection.

> "My daughter does my shopping for me now." **(P8)**

> "I can only go early in the morning to the shop because then its empty and nobody is gonna [sic] bump into me". **(P12)**

Adapting by using technology

Technological tools such as a cell phone, laptop, tablet, and radio have been instrumental in facilitating re-engagement. One of the most noteworthy applications utilised by participants was WhatsApp messenger as it allowed participants to connect with family and friends through instant messaging, voice notes, sharing multimedia and voice and video calling.

> "WhatsApp and social media help a lot because you still have access to others." **(P2)**

> "I can talk to all of my friends at the same time now, not just one at a time. Yesterday I video-called with 4 friends on WhatsApp." **(P8)**

> "I use WhatsApp to talk to my church friends and Father sends his sermon as a voice-note to us now. I listen to that every Sunday." **(P12)**

Strengthening the spiritual self

The South African COVID-19 lockdown was perceived as an enabler that facilitated participants to engage in occupations that strengthened the spiritual self. Participants reported that families now had the time to come together, pray and perform acts of worship. This allowed participants to focus on life's bigger picture.

> "Families are spending lots of time together performing these acts of worship together. In this way this lockdown has been a blessing." **(P14)**

Participants used their abilities to engage in crafts such as knitting that occupied their time and calmed their mind through repetitive work activities. The knitted products motivated the participants to engage in occupations that fulfilled the purpose of giving back and being supportive to the communities.

> "I knit bed socks and beanies [caps] for my family and the people in the road." **(P7)**

Participants experienced a sense of belongingness because they were able to engage in occupations that facilitated caring for others as part of intergenerational relations and occupational legacy. It was noted that the participants achieved a sense of meaning and purpose because they gave back to their families in need of care.

> "Just before the lockdown my grandson was detoxing from his drugs at my house. This was difficult for him, and he needed me to look after him. I like that I am able to be here for him all the time and we are always together, so he doesn't feel alone during this difficult time." (P12)

> "My mother has been very sick for some time, and I was only able to visit her at most once in a month. I can at least take care of her now since I am not going to work during this time. She will now definitely get better, I'm sure of that." **(P15)**

Participants engaged in occupations that encouraged a strengthened connection to the self, nature, and pets.

> "I spend more time working in the garden and with my pets." **(P4)**

Participants engaged in occupations that fostered improved awareness, presence and calm through exercise, yoga, meditation, mindfulness and rest.

> "I used to go to the gym before all of this started, that used to relax and help me. Now I do things like home

> exercises and yoga to help me." **(P15)**
>
> "I have started meditating and reading the bible more." **(P11)**
>
> "I feel like my mind is resting. I can connect with myself." **(P11)**

DISCUSSION

This study provided an insight into older adults' adaptiveness through the occupational disruptions that emanated from the eruption of the COVID-19 pandemic. Overall, the findings accentuated that there were vulnerabilities for older adults, as highlighted in the first theme *(Insight into COVID-19 as an illness).* The findings are congruent with Kaseje[14], Adhikari[15] and Chen[57] who indicated that older adults had the highest risk regarding exposure to COVID-19 and had the potential to develop moderate-severe COVID-19 related complications that can potentially result in death. This risk is exponentially compounded by the prevalence of comorbidities such as hypertension, diabetes mellitus, obesity, chronic obstructive pulmonary disease or any other respiratory illness[16,17]. In the findings, participants reflected on themselves as the vulnerable population due to their progressed age. Participants 3, 9 and 11 further identified their vulnerability by indicating that they were living with comorbidities. This vulnerability was compounded when considering that South Africa has a weakened healthcare system that's efforts have been prioritised to mitigate a high population incidence of HIV/AIDS, tuberculosis, malnutrition, and lifestyle diseases[14] and when considering that COVID-19 was a novel virus with limited research around transmission and management. This caused significant stress, anxiety and apprehension in the study sample. These findings corroborate Chen's study[57], which indicates that older adults' lives were disrupted because they experienced tremendous stress and psychological burden.

The findings in the second theme *Occupational disruptions experienced by older adults* underscored that the measures implemented to mitigate the influence of the pandemic and consequent lockdown, such as confinement, community restrictions, stay-at-home and social distancing, resulted in social isolation and loneliness among older adults. These findings indicated that the older adults were occupationally alienated because they experienced prolonged disruption, which is resonant with Townsend and Wilcock[29,30]. It can be argued that all populations experienced a degree of occupational alienation during the COVID-19 lockdown as marked by social isolation and loneliness; however, the findings indicate a clear discourse in terms of reduced freedom of opportunity owing to age. Additionally, the disruptions of the older adults' routines made them experience emptiness and a sense of meaningless, which affected their sense of identity. The results of the synthesis revealed that older adults' rights to exert individual autonomy and benefit from fair privileges seemed to have been infringed because they were occupationally marginalised and imbalanced[29,30]. This is supported by the extracts in the subtheme *Roles and routines,* which indicated that older adults experienced a sense of idleness, as they did not know what to do anymore.

In the subtheme *Social participation*, it was evident that the older adults experienced a sense of disconnectedness as they were unable to spend meaningful time with relatives, friends, and families. Furthermore, in the subtheme *Travel/community mobility*, the findings reinforced Maldonado-Torres' assertion that the structures of coloniality of power have emerged during South Africa's COVID-19 lockdown and restrictions, as the government-controlled people's movements[58]. This is further indicated that the coloniality of power was evident in the findings that reported that older adults feared being arrested if they were found driving or traveling around their community. Therefore, these findings indicated that government restrictions resulted in coloniality of being, because older adults' meaning of humanity was violated and led them to experience dehumanisation[58]. Older adults' right to exert individual autonomy through choice in occupations was violated because lockdown regulations prohibited them from continuing with economic occupations as highlighted in the subtheme *Work participation.* This is resonant with Manahan[59] who shared that social distancing and stay at home orders can also negatively impact older adults' jobs and economic stability. Most notably, the lack of opportunity to participate in economic occupations highlighted disparities amongst societal classes. Within this narrative, it was observed that the lockdown restrictions were easier to adhere to by more privileged individuals that perceived the stay-at-home order as an opportunity of respite, family reconnection and transition to a new opportunity to work from home whilst less privileged individuals struggled to meet their basic needs such as food. The South African government implemented social relief strategies in the form of increasing existing social grant amounts and created a COVID-19 relief or distress grant whilst many organisations lobbied for food donations to distribute food parcels. This was furthered by encouraging businesses and employees to draw from the unemployment fund. These efforts however, were minimal in resolving the hunger and food insecurities crisis that plagued so many disadvantaged communities. The lockdown restrictions coupled with South Africa's complexed socio-political history resulted in widespread experiences of disconnection from society, hopelessness, helplessness, isolation and desperation all whilst fearing illness and death.

The findings emerging from the third theme *Developing a state of adaptiveness* indicated that the South African COVID-19 lockdown-related occupational disruptions were powerful events that facilitated the process of occupational adaptation among older adults. These findings reverberated Grajo's explanations of occupational adaptations as a product of engagement in occupations; process that emerges during transaction with the environment; manner of responding to change and life transitions; and process to form a desired sense of self[60]. In one subtheme, *A change in perspective*, the findings indicated that the South African COVID-19 lockdown provided many older adults with the opportunity to engage in a gratitude exercise, as a flourishing activity that facilitated critical reflection and positivity[61]. This is consistent with Grajo who indicated that participation in occupation enables people to regenerate their visions of possibility to ameliorate the occupational challenges, as a transaction with the environment[60]. However, not all older adults were afforded the same opportunity when considering their interaction with their environment. This is largely due to South Africa's complex history owed to the Apartheid regime that has kept many South Africans, including older adults, suspended in a state of lesser privilege. Not all older adults underwent a changed perspective within similar contexts and with the same opportunities.

In responding to change and life transitions, the findings from the present meta-synthesis indicated that older adults experienced occupational adaptation because they altered the situation by reclaiming their roles and participating in alternate occupations to address the occupational challenge. This kind of adaptive gestalt response supported the older adults to configure their sensorimotor, cognitive, and psychosocial involvement in dealing with the occupational disruptions. It was evident that the older adults' occupational responses reflected a relative mastery, as they adapted their environment to achieve role expectations. This corroborates Schkade and Schultz's assumption that relative mastery is achieved when the person experiences the occupational response as efficient (use of time and energy), effective (production of desired result) and satisfying to self and society[1].

The older adults' state of occupational functioning was changed due to the South African COVID-19 lockdown restrictions and subsequent disruptions in occupational engagement. However, the findings indicated that the older adults strived for normality as far as possible, such as using technology to compensate for the loss of connection with others, which reinforced occupational adaptation. The findings are in agreement with recent studies that supported the use of technology to enhance the relatedness, mental and psychological needs of well-being[62]. It was evident the use of technology facilitated occupational adaptation, as older adults were able to connect with others using a variety of social media platforms such as WhatsApp to video call church friends and receive sermons. In accordance with occupational adaptation, the findings of the meta-synthesis indicated that the older adults developed a sense of competence, self-efficacy, and identity, which corroborate other studies[60,63,64,65]. This process of dynamic occupational adaptation by the older adults speaks to a higher degree of resilience to environmental barriers.

It was evident in the sub-theme, *Strengthening the spiritual self* that the older adults strived to address the occupational disruptions, and occupational injustices emanating from the South African COVID-19 lockdown related restrictions that resulted in coloniality of being. Therefore, the findings validated that engagement in eudemonic occupations appeared as adaptive strategies that sustained older adults' adaptiveness so that they may pursue their purpose in life as valuable contributors to society[59].

Engagement in centering[45,46] occupations such as meditation, attending online church and reading bible appeared as religious and spiritual activities that enabled the older adults to experience occupational adaptation, which supported their occupational identity. It is noted that the centring occupations[45,46] was related to human flourishing including happiness and life satisfaction, mental and physical health, meaning and purpose, and close social relationships[61].

CONCLUSION

This study explored the adaptiveness of older adults to disruptions experienced during the South African COVID-19 lockdown. Evidence illustrated that older adults experienced disruptions in roles, routines, social participation, travel and community mobility, work participation and occupations linked to religious observance. These disruptions arose secondary to the South African government's top-down approach in the implementation of lockdown restrictions that, most significantly, stripped citizens of autonomy and resulted in the experience of powerlessness. The disruptions led to the deterioration of individual and population well-being as indicated by sadness, emptiness, helplessness, powerlessness, feeling neglected, forgotten, and burdensome. To surmount their deteriorating mental well-being consequent to disruptions in occupational engagement, older adults improved their state of adaptiveness through (a) a change in perspective; (b) adapting to new environments; (c) adapting by using technology; (d) expanding roles and routines; and (e) strengthening the spiritual self. Most noteworthy, participants reflected on strengthening the spiritual self through engagement in eudemonic occupations, which included the occupational gifts; contemplative, contributing, connecting, and centring occupations. This promoted a reconnection to the self, the community, and a greater life purpose, thus, encouraging and improving resilience to negotiate barriers.

The COVID-19 lockdown was monumental in highlighting the degree of socio-political change that is needed to transform many of the persisting fragments pertaining to society when considering privilege. The South African population should be commended for their increased resilience to transcend many complex barriers and adapt. This continual state of adaptation against environmental barriers however, should not become customary as it has the potential for individuals to neglect their own occupational desire, needs and wants thus laying the potential for a disconnection from one's occupational identity. Future research can look at this relationship or could explore health outcomes of persons unable to develop a state of adaptiveness to overcome disruptions in occupational engagement.

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Declaration of Conflicts of Interest

The authors declare no conflicts of interest.

Author contributions

Aaqil de Vries was involved in the literature review and data analysis and took the lead in writing the manuscript.

Thuli Godfrey Mthembu supervised some of the student research projects which were part of the meta-analysis; and contributed to the conceptualisation of the study, development of the research proposal, literature review, data analysis and writing the manuscript. Lisa Wegner supervised some of the student research projects which were part of the meta-analysis; lead the conceptualisation of the study, development of the research proposal and data analysis; and contributed to writing the manuscript.

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RESEARCH ARTICLE

Support, supervision, and job satisfaction: Promising directions for preventing burnout in South African community service occupational therapists

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ABSTRACT

Background: Community service occupational therapists may be especially vulnerable to experiencing burnout. This study sought to determine the levels of burnout experienced by this population and to investigate the relationship between reported burnout and various contextual, personal, and demographic factors.
Methods: A quantitative, descriptive, cross-sectional survey design was used. The online questionnaire included contextual information of the participants and the Maslach Burnout Inventory. Data were analysed using Statistica 13.5. The effect of contextual, personal and demographic variables on burnout was tested using Kruskal-Wallis tests.
Results: All community service occupational therapists were invited to participate in the study. A response rate of 31.92% was achieved (n=75). High levels of emotional exhaustion were reported by 55% (n=41) of participants. 'Strong' and 'adequate' support systems were associated to a greater sense of personal accomplishment (p=0.02) and 'minimal' social support was associated to increased emotional exhaustion (p=0.01). Dissatisfaction with supervision was associated to increased emotional exhaustion (p=0.017). Job satisfaction was associated to a greater sense of personal accomplishment (p=0.0002). Job dissatisfaction was associated to depersonalisation (p=0.047) and emotional exhaustion (p=0.006).
Conclusion: Support systems, supervision and job satisfaction showed significant association to burnout. Interventions to address these factors, and research that further investigates the impact of contextual factors on burnout is recommended. This is imperative if South African occupational therapy is to take seriously its responsibility to the therapists responsible for taking services to populations with the greatest health needs.

Implications for practice

- Opportunities for occupational therapists to develop professional resilience to prevent burnout should be offered across the lifelong learning continuum.
- Strengthening supervision capacity and implementing mentoring and supervision strategies that provide mutual reward for both parties are needed.
- The responsibility for promoting the vitality and job satisfaction of COSTs should be taken seriously by the Department of Health as CSOTs continue the vital work of taking rehabilitation to South Africa's populations with the greatest health needs.

INTRODUCTION

There is increasing concern around the experience of burnout amongst occupational therapists in South Africa and particularly among community service occupational therapists (CSOTs)[1]. These therapists are tasked with extending occupational therapy access to populations in under-served areas and to those with the greatest health needs[2], while undertaking the challenging[3] transition from university to practice.

Compulsory community service (CS) was legislated two decades ago to increase access to services for rural and underserved populations[2]. Its implementation has had a positive effect on primary healthcare (PHC) in South Africa, increasing the number of occupational therapists in the public sector by approximately 33%[4]. Despite this increase, the number of occupational therapists working in the public sector remains low[5]. Of the 5180 occupational therapists registered with the Health Professions Council of South Africa (HPCSA) in 2018, only 25.2% (n=1320) worked in the public sector, serving 84% of the South African population[5]. Around 17.8% (n=235) of occupational therapists working in the public sector were CSOTs[6]. This means that CSOTs share a substantial part of the responsibility of providing occupational therapy services to rural and remote populations, populations with the greatest healthcare needs[2, 7].

A proportion of CSOTs (44.7% in 2013[3]) are placed in rural settings and the health professions minimum standards exit level outcomes for occupational therapists states that qualified occupational therapists should provide services in various settings and environments[8]. However, rural fieldwork placements are not included in all undergraduate occupational therapy degree curricula. A CS placement may thus be the first exposure to rural areas for the newly qualified occupational therapist[3]. An unfamiliar rural placement, together with having to relocate, could augment the challenges of transitioning from student to therapist[9].

The CSOTs who work in rural areas and on the PHC platform have limited access to physical resources such as specialised occupational therapy equipment, appropriate therapy areas to see clients in, and no specific occupational therapy budget allocation. A long turnover time to receive ordered equipment also poses a problem to access of physical resources[3, 10]. Some CSOTs may also have a lack of professional resources including understaffing, minimal access to continuing professional development (CPD) opportunities, and a deficit in networking opportunities[3,10]. Access to supervision and mentorship is often limited along with restricted opportunity to observe other occupational therapists treating and interacting with clients [3, 10] which may be due to a lack of staffing in the PHC system. Research has suggested that access to these resources is important to provide support in the transition from being a new graduate to a novice therapist [11].

Many CSOTs often work with clients that do not speak the same language as they do and clients often come from different cultural and religious backgrounds, which makes delivery of accessible and appropriate services a challenge[3, 10]. Often CSOTs treat clients with complex health disorders and at times struggle to manage emotionally stressful interactions with clients and their families[12] which may contribute to work stress and burnout[12, 13].

In responding to the aforementioned challenges, many CSOTs have reported frustration around limited or absent budgets, inadequate resources[14], difficulties communicating with clients, unethical behaviours from personnel, and limited learning opportunities[14]. Feelings of being 'alone' have been reported by CSOTs who have had few colleagues, have faced difficult interpersonal relations with colleagues, or have lacked guidance and instruction in the workplace[14]. 'Anxiety' has been reported by CSOTs which was mostly attributed to insecurity about applying professional skills in the workplace and having substantial workloads[14]. The latter also contributing feeling 'overwhelmed'[14]. Feelings of being 'overwhelmed' and 'anxious' are symptoms of stress[15] and CSOTs who are exposed to uncontrolled stress in the workplace over a long period may experience burnout[16].

If burnout is prevalent amongst CSOTs, it is necessary to determine what intrinsic and extrinsic factors are associated with this experience in order for prevention and remediation strategies to be explored[1]. The authors therefore aimed to establish the nature of the relationship between burnout experienced by Community Service occupational therapists in South Africa and the coping strategies that they utilise. However, a limited association was observed when the three constructs of burnout (emotional exhaustion, depersonalisation and reduced personal accomplishment) were correlated with forms of coping (task-oriented coping, emotional-oriented coping and avoidance-oriented coping[17])[1]. Therefore, the objectives of this study were to describe the prevalence of burnout in CSOTs and to determine the relationship between burnout and various personal, education, and work demographic factors.

LITERATURE REVIEW

Understanding burnout

Burnout was first described in the 1970s by Herbert Freudenberger, an American psychologist, to report the consequence of extreme stress experienced by people working in helping professions. Individuals who were burned out lacked energy and could not cope with work demands[18]. Burnout was added to the International Classification of Diseases, 11th Revision (ICD-11) in 2019 where it is defined as:

> "… a syndrome… resulting from chronic workplace stress that has not been successfully managed. It is characterised by three dimensions: feelings of energy depletion or exhaustion; increased mental distance from one's job, or feelings of negativism or cynicism related to one's job; and reduced professional efficacy. Burn-out refers specifically to phenomena in the occupational context and should not be applied to describe experiences in other areas of life[16 1st paragraph.]".

Typical symptoms in burnout are, *emotional exhaustion, depersonalisation, and reduced personal accomplishment that can occur among individuals who do 'people work' of some kind* [19 p. 3]. In occupations where individuals work with people, emotional exhaustion is the most common and is characterised by severe tiredness when an individuals' emotional resources are exhausted, which leads to feelings of being overwhelmed and lack of contribution to work on a psychological level[20]. Depersonalisation refers to feelings of being emotionally detached from the person being treated and depicts cynicism and decreased empathy[20]. Reduced personal accomplishment involves feelings of inadequacy and decreased accomplishment in an individual's profession and may mean that the individual is not satisfied with achievements at the workplace. Thus, the individual may have a decreased work rate, decreased self-confidence and may struggle to cope in the work place[20]. Burnout may have several detrimental effects on places of work if not addressed appropriately. These effects include high work turnover, absenteeism and decreased commitment of employees[21] which impacts on the quality of care delivered. Therefore, the prevention and mitigation of burnout are especially important in both healthcare and social services[22].

Burnout in health professionals and occupational therapists

Burnout can be related to factors such as expanding workloads and impractical requests from clients, families, and employers[23]. Occupational therapists are at risk of burnout as they display empathy and encourage participation in daily life of their clients by using themselves as therapeutic agents and using a client centred approach[23]. Additionally, occupational therapists often have emotionally stressful interactions with clients and their significant others which may contribute to burnout[23]. Their role requires compassion, commitment, selflessness, constant optimism and therapists are required to manage their emotional capacity for client interactions, work duties and their personal lives[24]. These factors all create a vulnerability to burnout[13]. Occupational therapists who experience burnout usually report emotional exhaustion and cynicism which may also have negative effects on client care[25].

In a 2020 study, occupational therapists in Texas were found to have greater levels of job satisfaction and lower levels of burnout as compared to other healthcare workers such as nurses. This was attributed to strict qualification criteria, and experience in different areas of practice with different populations, making occupational therapists an adaptable workforce, lessening feelings of frustration and despair in the workplace which may protect against burnout[26].

Similarly, a 2021 study found that Greek occupational therapists who were found to be more resilient (resilience measured using the Connor-Davidson Resilience Scale) had a greater sense of personal accomplishment and lower risk for experiencing burnout. Participants with less resilience were at greater risk for experiencing burnout[27]. Therefore, it is important for occupational therapy clinicians, educators, and students, to develop self-knowledge and an ability to identify their own risk of burnout. Additionally, they need to develop resilience and skills to prevent burnout and occupational stress [28].

South African occupational therapists and burnout

A shortage of occupational therapists in South Africa exists, with 0.9 occupational therapists for every 10 000 people residing in South Africa[5]. Due to the shortage, South African occupational therapists could face greater work stressors. Despite anecdotal reports of high levels of burnout in this population, the literature on burnout in South African occupational therapists is limited. A single study investigating the prevalence of burnout in therapists (including occupational therapists) in physical rehabilitation units in the South African private sector, highlighted that inadequate dealing with stress strongly influenced emotional exhaustion, and that the standard of physical rehabilitation is affected by the support the therapists receive and how satisfied they are in their positions at work[29]. No published studies could be found that examined burnout in occupational therapists working within the South African PHC system.

The need to investigate burnout in the CSOT population

While there are studies on burnout in new graduate occupational therapists internationally, no study exploring burnout in South African CSOTs specifically could be found in the literature. Thus, it is uncertain if patterns of burnout reported in newly graduated therapists in other countries[30] are similar or different to that found in the South African CSOT population. While it has been suggested that the experience of burnout of CSOTs may be intensified by contextual challenges in the South African healthcare system, this has not been scientifically studied

It is imperative that stakeholders (CSOTs, CSOTs' employers and the occupational therapy profession as a whole) understand CSOTs' the experiences of burnout and that this is addressed appropriately. Addressing the causes of high burnout rates may contribute towards developing an insightful, resourceful and resilient CSOT workforce. This research is thus positioned to describe burnout in CSOTs and investigating the relationship between burnout and relevant contextual, education and demographic factors.

METHOD

Study design

A quantitative, descriptive, cross-sectional survey design was employed. Inductive content analysis[31] was used to analyse extensive comments made by participants to justify their survey responses.

Study population

The 2019 CSOT population under study consisted of 235 therapists[6].

Sampling and sample size

Non-probability sampling was used as the details of each member of the population were not available to enable a random sampling approach[32]. All 2019 CSOTs were invited to participate via professional organisations (OTASA, and Rural Rehabilitation South Africa) and social media platforms (Facebook, WhatsApp groups). Participants were requested to forward the invitation to other CSOTs, thus a measure of snowball sampling[33] was also employed.

With a population of 235 a sample size of 147 was required to achieve a 5% margin of error, 95% confidence interval, and 50% response distribution[34]. This required a 58% response rate.

Instrumentation and outcome measures

The online survey had two sections: demographic information of the participants and the Maslach Burnout Inventory.

Demographic factors were included in the questionnaire where literature suggested them to be significant to the experience of CSOTs[3]. The demographic information included personal demographics, and questions regarding CSOTs' education (education demographics) and work experience (work demographics). The latter component was developed from the literature that identified various factors which posed as stressors to novice therapists[10, 11, 35] and suggested that prolonged exposure to these kinds of stressors may lead to burnout in initial employment[30]. Data were also collected on the number of patients seen, number of sites where they provided services, information regarding staffing levels and the nature and quality of supervision received. Other information included communication challenges with clients, understanding of clients' values, beliefs, attitudes and culture, and job satisfaction as a CSOT. Comment sections and scales were included to add to the richness of data and to allow participants to explain their answers.

Maslach Burnout Inventory Human Services Survey (MBI-HSS)

The MBI-HSS used for this study, is the first version of the MBI and is most commonly used. It aims to determine how individuals working in helping professions experience burnout in relation to their profession and people who they come into contact with at work[36]. The three constructs that the MBI-HSS measures are emotional exhaustion, depersonalisation and personal accomplishment. The emotional exhaustion scale, consisting of nine items, measures participants' feelings of emotional exhaustion at work with high scores indicating high levels of perceived burnout[37]. The depersonalisation scale, consisting of five items, measures uncaring or indifferent responses to clients of participants, with greater scores indicating high amounts of perceived burnout[37]. The personal accomplishment scale, consisting of eight items measures feelings of capability and success when participants work with their clients. Low personal accomplishment scores indicate higher perceived burnout[37].

Internal reliability for the MBI was determined by using data from early samples by using Cronbach's coefficient alpha[38], which showed approximate values of the three burnout constructs. Internal consistency for reliability coefficients for each component of burnout was shown over various samples in research done by the developers of the MBI[37]. In terms of validity, scores for the different constructs of burnout have been correlated with impressions of others[37].

How burnout was measured in the study

Conflicting ideas of what constitutes low, moderate or high levels of burnout exist in the literature, challenging the interpretation of results in this study. Cut-off scores for measures are believed to show borders between norms and different clinical ranges[39] but various studies report difficulty in establishing low, moderate and high cut-offs with the MBI-HSS[40]. Maslach and Leiter advise that burnout be viewed on a continuum rather than as a concrete diagnosis. They caution against using set cut-offs for the MBI and have removed them in the latest MBI manual as cut-offs were believed to have no diagnostic validity[37]. These authors have developed burnout profiles by determining trends of the burnout experience[41], but these profiles could not be used as they have yet to be validated.

Previous burnout studies involving healthcare professionals have not been overt in reporting cut offs for the three dimensions of burnout. A systematic review of 50 articles focusing on the classification and diagnosis of burnout in doctors and nurses found discrepancies between studies when defining burnout and providing cut-offs for low, moderate and high levels of the three components of burnout[40]. Some studies were found to be too conservative, under-reporting burnout rates by strictly reporting burnout when high levels existed for all three burnout components[40].

The cut-offs chosen for this research were specifically taken from a study done with occupational and physiotherapists by Balogun et al[42]. This ensured that the experiences of burnout of the participants would not be under-captured by making use of conservative cut-offs. A high score for emotional exhaustion and depersonalisation and a low score for personal accomplishment indicate high burnout. Emotional exhaustion scores above 27 is high, between 17-26 is moderate and below 16 is low. Depersonalisation scores above 13 is high, between 7-12 is moderate, and below 6 is low. Personal accomplishment scores above 39 is high, between 32-38 is moderate, and 31 and below is low[42].

Permission to use the MBI-HSS was granted by MindGarden prior to data collection[43]. Frequency of the participants' burnout was recorded, and cut-offs were used to capture whether the participants were indeed experiencing high, moderate or low levels of burnout. Implications of using these cut-offs could be under or over-reporting of the experience of burnout in the participants. Ongoing ambiguity around interpreting MBI-HSS scores shows a need for further research.

Research procedure

Ethical Considerations

Completion of survey questionnaire constituted consent to participate. Ethical clearance was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand HREC number: M180719.

Data collection

Completion of the MBI-HSS and demographic questionnaire took approximately 20 minutes. Data were collected between July 2019 and January 2020, allowing for participants to have experienced at least 6 months of clinical work in the Community Service system. Reminders were sent via OTASA and social media during the data collection period. Data were collected and managed using REDCap, an electronic data capture tool hosted by the University of the Witwatersrand[44]. Data were downloaded to Microsoft Excel, cleaned and coded in preparation for analysis. Due to responses being anonymous, potential duplicate responses could not be eliminated from the data set to avoid cross posting.

Data analysis

Questionnaires with missing data were discarded[45], therefore only 75 questionnaires could be analysed. This reduced response rate falls within the 10% margin of error accepted for small samples[46].

Data were analysed using STATISTICA version 13.5[47]. Frequencies and percentages were used to report the personal, educational, and work demographic information of the CSOT participants. Non-parametric statistics were used to analyse the MBHSS ordinal data. However, parametric means and standard deviations were used to present the different types of data from the MBI-HSS. Medians and quartile ranges, as well as means and standard deviations were used to report the experience of burnout of the participants. Nonparametric Kruskal-Wallis tests (ANOVA by Ranks) tests[48], were used to report the effect of personal, educational and work demographic variables on the perception of burnout factors.

Inductive content analysis[31] was used to analyse comments that participants added to justify or explain their answers in the online questionnaire. Data were coded and codes sorted into categories. The frequency of responses in each code and category were reported[49].

RESULTS

A total of 105 responses were received (44.68% return rate). Ten responses were incomplete and thus discarded. A further 20 responses were deleted as the MBI-HSS aspect of the questionnaire was not completed. Seventy-five responses were therefore included in analysis, representing 31.92% of the population.

Demographic and work information

Most of the participants (97.33%; n=73) were female (2.67%; n=2 male participants) and a majority (52%; n=39) were 23 years old (age range 22-30 years). Thirty percent of participants (30.67%; n=23) worked in Gauteng. A similar percentage of participants (41.33%; n=31) reported working in rural areas during CS (48%; n=36). One third of participants (33.33%; n=25) provided services at multiple levels of care with 25.33% (n=19) of them providing services at district level. Just over half (54.67%; n=41) of the participants worked at a single service site. Participants treated a median of 80 (Range:15-400).

Social support

A strong support structure and adequate support structure was reported by 49.33% (n=37), and 36% (n=27) of participants respectively. The main source of support reported by participants were significant others (37.33%; n=28) and nuclear family (33.33%; n=25).

Supervision

Most participants (77.33%; n=58) had a supervisor (no supervisor reported by 22.67%; n=17). Most supervisors (69.33%; n=52) were occupational therapists. Dissatisfaction with supervision by the 58 participants who had a supervisor was similar (40%; n=30) to satisfaction (37.33%; n=28).

Of those reporting dissatisfaction, 56.67% (n=17) reported that this was due to supervision that was *not optimal or of a good standard.* One participant explained,

> "No one really checks on me/watches me and guides me". **(Participant 53, 24-year-old, female)**

Many participants who were dissatisfied with their supervision linked this to *unethical practice and poor interpersonal relations* with their supervisor (50%; n=15). Two participants explained,

> "The supervising therapists do not hold themselves to the [same] standard that they expect the comm serve to adhere to". **(Participant 11. 23-year-old, female)**

> "…develops own rules but doesn't obey them" **(Participant 28. 23-year-old, female)**

Several participants were not satisfied with their supervision because their supervisor was *not an occupational therapist or had limited knowledge in training CSOTs* (30%; n=9). Others attributed their dissatisfaction to *organisational problems* (20%; n=6) or believed their supervisor to have *insufficient administrative and leadership skills (10%; n=3).*

In contrast, eight (50%) participants who were very satisfied with their supervision, attributed this to *available human and non-human resources.* One participant explained,

> "I am gaining experience in different fields of OT, getting great supervision and have the resources available to treat". **(Participant 65, 22-year-old, female)**

Job Satisfaction

Just over a third of participants (34.67%; n=26) were *partially satisfied* with their jobs as CSOTs, with 32% (n=24) of participants reporting being *satisfied.* Sixteen participants (21.33%) were *very satisfied* with their jobs and 12% (n=9) of participants were *not satisfied* with their job as a CSOT.

Twenty-four participants (92.31%) reported that they were only *partially satisfied* with their jobs as CSOTs due to the *lack of human and non-human resources.* One participant explained,

> "I don't feel as if I am giving a type of service that is of great value, due to having no support, no means of assistance, I'm expected to run an entire OT department seeing in and outpatients both paeds and adults. I am also expected to be accountable for the entire rehab department due to having the highest qualification, which I think is unfair to me". **(Participant 13, 26-year-old, female)**

Eight (30.77%) participants were *partially satisfied* with their jobs due to feelings of being *stressed, overwhelmed and discouraged.* One participant provided the following comment,

> "However, I also feel that my responsibilities are substantial, which in turn places an indescribable emotional and physical stress on me. This leads me to often question my happiness with my profession". **(Participant 6, 24-year-old, female)**

Two participants (7.69%) linked their partial job satisfaction to *contextual limitations* and eight (30.77%) participants attributed their partial satisfaction to *positive experiences* in their job.

Of the participants that were *very satisfied* with their jobs (21.33%, n=16), 62.5% (n=10) reported that they were very satisfied with their job due to the *positive experiences* of being an occupational therapist,

> "...[you] can finally have continuity of care for the patient throughout the year which means you see progress and feel like you are truly making a difference in someone else's life." **(Participant 2, 23-year-old, female)**

Of the participants that were *not satisfied* with their jobs as CSOTs (n=9), 66.67% (n=6) reported that their dissatisfaction was due to *a lack of human and non-human resources*. The following participant highlighted the absence of human resources,

> "I have no support as the sole OT within the remote area, it is continually challenging to communicate with other team members, the understanding of OT in the area is limited despite efforts to change." **(Participant 33, 24-year-old, female)**

Five participants (55.56%) linked their job dissatisfaction to *emotions* experienced in the workplace. One therapist described,

> "I feel hopeless and useless as I am not rendering a service of good quality." **(Participant 25, 23-year-old, female)**

Three participants (33.33%) who were *not satisfied* with their jobs attributed this to *client-related frustrations*. One participant explained,

> "I also at times feel that I struggle to find compassion and sympathy for patients that do not take responsibility for their own health and see the professional as an expert rather than a partner (and patients are often reluctant to engage in goal setting with the therapists to guide their own therapy)." **(Participant 9, 23-year-old, female)**

Maslach Burnout Inventory Human Services Survey

The three components of the burnout syndrome, as measured by the MBI-HSS[37], are shown in Table I (page 72) and II (page 72). In Table I the mean score of 3.20, SD±1.35 indicates that most of the participants felt emotional exhaustion a few times a month, but not weekly. Table II indicates the level (low, moderate and high levels classified by Balogun et al.[42]) of burnout participants experienced with 55% (n=41) reporting high levels of emotional exhaustion at the time of data collection.

The mean score of 1.78, SD±1.16 (Table I, 73) indicates that most participants experienced depersonalisation a few times a year or less. Table II (page 73) indicates that 23% (n=17) of the participants reported high levels of depersonalisation at the time of data collection.

Participant's mean score for personal accomplishment was 4.16, SD±0.998 (Table I, page 73) indicating that participants felt a sense of personal accomplishment at least once a week. Table II (page 73) shows that 28% (n=21) of the participants reported high levels of personal accomplishment at the time of data collection. Twenty-five (33%) participants reported low levels of personal accomplishment with lower scores.

Contextual factors affecting perception of burnout

Table III (page 73) shows all the variables that were tested against emotional exhaustion, depersonalisation, and low personal accomplishment. Variables that demonstrated a significant relationship with burnout ($p \leq 0.05$, and $p \leq 0.01$ and lower for highly significant variables) are highlighted. Only six of the twenty-four variables tested were found to be significant and they all fell into the work demographic category of the demographic questionnaire: The participants' support systems, satisfaction with supervision and job satisfaction which had an effect on their experience of burnout is shown in Table IV (page 74).

The effect of support systems on burnout constructs

Participants with strong (median=4.5, quartile range 4.13-5.13) and adequate (median=4.12, quartile range 3.87-4.62) support systems had a greater sense of personal accomplishment. Kruskal-Wallis results for social support and a sense of personal accomplishment were H=9.64, p=0.022, with a mean rank for personal accomplishment of 14.5 for absent social support, 24.83 for minimal social support, 34.96 for adequate social support and 44.69 for strong social support.

Participants who reported minimal social support (median=4.67, quartile range 4.33-4.78) reported greater levels of emotional exhaustion. Kruskal-Wallis results for social support and emotional exhaustion were H=11.22, p=0.01, with a mean rank of 60.28 for minimal social support.

The effect of satisfaction with supervision on burnout constructs

Participants who were not satisfied with the supervision they received (median=4.00, quartile range 2.56-4.67) reported greater levels of emotional exhaustion. Kruskal-Wallis results for satisfaction with supervision and emotional exhaustion were H=5.68, p=0.02, with a mean rank of 34.60 for not satisfied with supervision.

The effect of job satisfaction on burnout constructs

Participants who were very satisfied (median=4.75, quartile range 4.38-5.38) and satisfied (median=4.37, quartile range 3.94-4.88) with their jobs as CSOTs, had a significantly greater sense of personal accomplishment. Kruskal-Wallis results for job satisfaction and a sense of personal accomplishment were H=19.22, p=0.0002, with a mean rank for personal accomplishment of 14.11 for not satisfied with job, 34.98 for partially satisfied, 40.21 for satisfied with job and 53.03 for very satisfied with job.

Participants who were not satisfied with their CS job (median=3.00, quartile range 2.00-3.40) reported a greater sense of depersonalisation. Kruskal-Wallis results for job

Table I Maslach Burnout Inventory-Human Services Survey 4th Edition scoring for participants (n=75)

Variable	Median	Lower quartile	Upper quartile
Emotional Exhaustion	3.22	2.11	4.33
Depersonalisation	1.60	0.80	2.40
Personal Accomplishment	4.25	3.63	4.88

Table II- Level for 3 Constructs of Burnout

Burnout Variables	Level of Burnout		
	High No. (%)	Moderate No. (%)	Low No. (%)
Emotional Exhaustion	41 (55)	23 (31)	11 (15)
Depersonalisation	17 (23)	28 (37)	30 (40)
Personal Accomplishment	21 (28)	29 (39)	25 (33)

Table III-Variables tested against emotional exhaustion, depersonalisation, and low personal accomplishment

Variables tested against emotional exhaustion, depersonalisation and low personal accomplishment:	
Age Gender Marital status Children Social support University Province Rural/urban Level of care Number of service sites Number of clients seen per month Number of occupational therapists in department	Multi-disciplinary team composition Supervisor: yes/no Discipline of supervisor Satisfaction with supervision Opportunity to observe other therapists' practice Years' experience of colleagues Resources for therapy Communication challenges Challenges understanding clients' values, attitudes, beliefs, and cultures Job satisfaction

satisfaction and depersonalisation, were H=7.94, p=0.05, with a mean rank of 51.89 for not satisfied.

Lastly, participants who were not satisfied with their jobs as CSOTs (median=4.11, quartile range 4.00-4.78) experienced greater levels of emotional exhaustion with a highly significant value. Kruskal-Wallis results for job satisfaction with and emotional exhaustion were H=12.39, p=0.006, with a mean rank of 53.39 for not satisfied with job.

DISCUSSION

Burnout experienced by the participants

Notwithstanding the challenges around interpretation of MBI-HSS scores, emotional exhaustion was common amongst participants (55%) with smaller, though sizable, groups reporting reduced personal accomplishment (33%) and depersonalisation (23%). These results are similar to levels reported by South African therapists working in private rehabilitation facilities (57,14 %, 38,77% and 20,40% reported for the three components respectively)[29]. Research done with therapists using the MBI as a measure for burnout is shown in Table V (page 75). The results measured for burnout differ for each country. Results for the Balogun et al [42] study in 2002 is the only result which demonstrates similar results for the emotional exhaustion experienced by South African allied health professionals (55%). Healthcare workers in South Africa face unique contextual stressors which the participants in the studies in the table may not necessarily face, and therefore the results vary greatly.

A well-established link between exhaustion and depersonalisation exists in the research as withdrawal is a reaction to exhaustion[51]. Results may indicate that 77% of the participants did not allow emotional exhaustion to affect their interactions with clients as depersonalisation is usually the phase of burnout that follows after emotional exhaustion[52]. Low levels of depersonalisation for the participants may be due to this being their first year of practice, and further time in the profession could yield greater levels of depersonalisation, which could be an interesting topic for research with participants who have more than one year's experience.

Hospital and governmental rules may decrease the ability to make independent decisions at work when it comes to time spent in client care, which may increase burnout[53]. Working with low-income populations in healthcare with no power to address the origins of medical concerns may also result in burnout[53]. Studies done with nurses report stressors at work caused by decreased access to resources including uncooperative and demotivated work colleagues, equipment unavailability, understaffing, poor supervision and support, insufficient salaries, and poor recognition of work[53]. These contextual factors are also present in the South African context with CSOTs in this study reporting similar experiences.

Burnout influences quality of life, client care, places strain on the economy, and healthcare workers with burnout have been reported to have elevated suicide rates[54]. Long-term effects of burnout have also been described in the literature. Burnt-out employees may influence their colleagues through negative interactions, and burnout is often connected to dissatisfaction and work withdrawal, poor job commitment, absentia and great rates of employee replacement[55]. This effects employee wellness and performance

Table IV- The effect of social support, satisfaction with supervision and job satisfaction on the experience of burnout (n=75)

Burnout variable	Demographic variable	Median (Lower and upper Quartile)		p value	H score
Personal Accomplishment	Social support	Absent	2.18 (0.38-4.00)	0,022*	H=9.64
		Minimal	3.50 (3.13-4.00)		
		Adequate	4.12 (3.87-4.62)		
		Strong	4,50 (4.13-5.13)		
	Satisfaction with job as a CSOT	Not satisfied	3.12 (1.75-3.75)	0,0002**	H=19.22
		Partially satisfied	4.06 (3.50-4.88)		
		Satisfied	4.37 (3.94-4.88)		
		Very satisfied	4.75 (4.38-5.38)		
Depersonalisation	Satisfaction with job as a CSOT	Not satisfied	3.00 (2.00-3.40)	0,047*	H=7.94
		Partially satisfied	1.60 (0.80-2.40)		
		Satisfied	1.80 (1.00-2.60)		
		Very satisfied	1.10 (0.60-1.70)		
Emotional exhaustion	Social support	Absent	2.94 (1.89-4.00)	0,011*	H=11.22
		Minimal	4.67 (4.33-4.78)		
		Adequate	2.78 (2.11-4.00)		
		Strong	3.22 (2.00-4.33)		
	Satisfaction with supervision	Yes	2.61 (2.00-3.72)	0,017*	H=5.68
		No	4.00 (2.56-4.67)		
	Satisfaction with job as a CSOT	Not satisfied	4.11 (4.00-4.78)	0,006**	H=12.39
		Partially satisfied	3.61 (2.44-4.33)		
		Satisfied	3.17 (2.39-4.33)		
		Very satisfied	2.17 (1.61-3.06)		

Significance at p≤0.05* and high significance at p≤0.01**

which influences client management and satisfaction within healthcare negatively[53, 55]. The effects of burnout on individuals shows the importance of identification, intervention and prevention of burnout at work[54]. In the CSOT population the effects of burnout could make the employee question their role in the profession, and seek to provide services in areas which pose less contextual stressors and are not underserved, reinforcing the unfair distribution of occupational therapy services[1].

Approaches for the treatment and prevention of burnout mainly focus on the use of coping mechanisms, fostering resilience, improving the work environment and independence in the work place[56]. These approaches mostly target the clinician, but the employer, tertiary institutions and professional organisations should also play a role in promoting the use of strategies to prevent burnout in the workplace[1]. Burnout intervention can be divided into person-directed and organisation-directed interventions[57]. Person-directed interventions are beneficial in the short term (less than 6 months) and person-directed intervention in combination with organisation-directed intervention has extended effects (greater than 12 months). The effects of these interventions decrease over time which creates a need for implementing additional intervention courses[57].

Support systems

The protective role of social support was a significant finding of this study. A positive relationship between social support and personal accomplishment was observed while emotional exhaustion was associated with poor support. A meta-analysis of 144 published articles demonstrated a similar relationship, however, support sources from outside of the workplace were specifically related to greater personal accomplishment. Work-related social support, however, demonstrated a negative association and was found to be closely related to emotional exhaustion[58]. Work related social support was not included as part of the work demographic survey questionnaire in this study so conclusions regarding whether the social support at work affected the experience of burnout of the participants could not be made. However, only two participants reported receiving their main support from colleagues at work[1]. The main source of support reported by participants were significant others (37.33%; n=28) and nuclear family (33.33%; n=25). The majority of the participants are in the young adulthood stage of development (18-40 years old), where support from family may shift to support from a significant other or friends[59].

Satisfaction with supervision

A number of participants (20%) had no other occupational therapist in their departments or reported being the only allied health professional at their place of work (6.67%), which concurs with older research reporting that CSOTs may be left to run departments in rural practice by themselves with minimal support or supervision[10]. A majority of participants (77.33%) had a supervisor. In a study of the 2013 CSOT population, almost 90% of therapists reported having a supervisor[3]. The increased proportion of therapists without a supervisor is concerning and may be related to the 'freezing of posts' in the Department of Health resulting in fewer permanent staff being employed due to budget constraints[60].

Forty percent of the participants who did have a supervi-

Table V- Studies with occupational therapists, physiotherapists and other health care workers and the MBI

Study	This study	Du Plessis et al.; 2014 [29]	Balogun et al.; 2002 [42]	Gupta et al.; 2012 [23]	Nowakowska-Domagala et al.; 2015 [50]
Study Location	South Africa	South Africa	New York	Canada	Poland
Population	CSOTs (n=75)	Allied healthcare workers including 14 occupational therapists (n=49)	Physiotherapists (n=169) and occupational therapists (n=138)	Occupational therapists (n=63)	Physiotherapists (n=117)
Emotional exhaustion (high)	55%	57.14%	58%	34.8%	17%
Depersonalisation (high)	23%	20.4%	94%	43.5%	16%
Personal accomplishment (low)	33.32%	38.77%	97%	24.6%	15%

sor were not satisfied with the supervision they received (n=30, missing responses=17 participants who did not have a supervisor) whereas 65.9% of 2013 CSOTs reported dissatisfaction with supervision[14] showing that CSOTs satisfaction with supervision has improved.

It is important to have a supervisor and enough guidance and support in the transition from being a new graduate to novice practitioner[35, 61] and supervision has been associated with greater job satisfaction[30]. However, it is common for there to be a mismatch between supervision and expectations[3]. Therefore, decreased satisfaction with supervision in the first year of occupational therapy practice was not surprising in the participants. Novice occupational therapists who have reported dissatisfaction with supervision have provided reasons, such as having unrealistic expectations regarding formal supervision and support[61], and inadequate supervision which does not meet the needs of the CSOT[35].

Thirteen participants were satisfied with their supervision due to the *frequency of supervision* they received which was expected as the frequency of supervision may decrease from being a student to new practitioner and supervision efficaciousness differs over time[62].

Supervisor characteristics have been connected to supervision satisfaction in previous studies. Twenty participants were satisfied with their supervision because their supervisor was *skilled and knowledgeable*, and 14 participants were satisfied with their supervision due to their supervisor's *positive characteristics*. This concurs with the literature that suggests that there is a definite link between satisfaction with supervision and supervisors skill and experience[9]. Positive characteristics of supervisors such as creating a supportive atmosphere which promotes a sense of freedom[63] was also found to have a definite impact on the level of satisfaction of novice occupational therapists.

Participants who had a supervisor reported experiencing greater depersonalisation than those who did not have a supervisor (p=0.050) which was unexpected as literature conveys that clinical supervision of a good standard usually results in decreased depersonalisation[64]. Participants who had a supervisor and were not satisfied with the supervision they received reported greater levels of emotional exhaustion (p=0.017). This finding partly agrees with the literature and the expectations of the researchers. Whole studies (mostly done with the nursing population in healthcare) have been dedicated to the effect of clinical supervision on burnout with common findings being that good clinical supervision often results in decreased feelings of emotional exhaustion and depersonalisation[64]. The question about satisfaction of supervision did not yield a significant p value for depersonalisation (p=0.308) but did yield a significant p value for emotional exhaustion (p=0.011). This suggests that having access to a supervisor is not enough, but satisfaction with supervision is key to avoid emotional exhaustion in the participants.

Job satisfaction

Participants who were satisfied or very satisfied with their jobs as CSOTs had a greater sense of personal accomplishment with a highly significant score (p=0.0002). Participants who were not satisfied with their jobs as CSOTs reported a greater sense of depersonalisation (p=0.047) and experienced greater levels of emotional exhaustion with a highly significant value (p=0.006). This is expected as individuals who experience gratification from working with clients would be thought to have a greater sense of success and competence at work. Work satisfaction may be an indicator of decreased emotional exhaustion and depersonalisation and increased sense of personal accomplishment[65]. It is important to note that these findings cannot simply be generalised to occupational therapists, but they are very similar to the results of this study representing CSOTs specifically.

Participants in this study who were not satisfied with their jobs as CSOTs reported unethical staff behaviour (n=7), lack of support, recognition and learning opportunities (n=3), not being confident in their own skills (n=2), stress in workplace affecting emotional and mental wellbeing (n=4), and clients who do not take responsibility for their own health (n=3). These findings were expected, as job-dissatisfaction in occupational therapy is usually related to the work environment, decreased work status and the unspecified role of occupational therapy compared to other health professionals[66].

Occupational therapists report satisfaction with treating their clients and making a difference in clients' lives. The diverse nature of occupational therapy and the freedom to perform this work coincides with the feeling of satisfaction on the job[66]. Furthermore, the role, identity and recognition of occupational therapy as a profession, and working in an environment which provides sufficient human and non-human resources are reported to contribute to job satisfaction[67]. Pride in occupational therapy as a profession, proper supervision and having occupational therapy colleagues contributes to CSOTs identities. Seeing how occupation-based practice contributes to occupational therapy's role within the multi-disciplinary team further contributes to CSOTs confidence and role within the team[14] and this strong occupational identity leads to job satisfaction. Therefore, these aspects should be strived toward to prevent job dissatisfaction for the CSOT population.

RECOMMENDATIONS

Burnout: prevention is better than cure

CSOTs should have access to learning opportunities that enable them to understand burnout, recognise its symptoms and develop skills that protect against or mitigate its impact. These self-awareness and self-management skills don't develop overnight and need to be supported within the lifelong learning process. This should start with undergraduate students and CSOTs developing various intrinsic strategies to deal with burnout. Learning opportunities could include resilience education and how to foster resilience in preparation for and throughout the CSOT year and developing constructive coping strategies. This training could be offered by universities, OTASA and the employer.

Occupational therapy students can learn the protective value of social support and supervision and be encouraged to develop this throughout their undergraduate and CS years. These topics could be included in the undergraduate curriculum or as part of CPD in the CS year. Learning essential 'soft skills' at an undergraduate level could foster the development of effective self-management and resilience which will assist with navigating through studies, work and life[68]. The World Federation of Occupational Therapists' 2016 minimum standards for education of occupational therapists also speaks to the importance of 'soft professional skills'[69] which could serve as an effective way to develop occupational therapy students' insight into the value of social support and supervision.

CSOT managers should communicate with CSOTs effectively and involve them in decisions regarding client treatment which gives CSOTs a sense of control in the workplace and decreases feelings of stress and burnout. Older (non-novice) therapists should also develop insight into their own risk for burnout and develop appropriate self-management skills. Modelling these important skills for junior therapists may change the work environment and lessen the risk for experiencing burnout.

Supervision and support in the workplace

Successful opportunities for support, supervision, growth, and development need to be made available to CSOTs by putting meaningful supervision, mentoring and educational programmes into place. Some initiatives which offer mentoring and support have been started[70]. Additionally, programmes could be offered as a collaborative effort by the Department of Health, and RuReSA, and be informed by universities, and OTASA as voices of the occupational therapy profession in South Africa to cater for the specific needs of the CSOT population.

Opportunities for therapists to grow in support and supervision roles need to be made. Professional organisations such as OTASA and RuReSA (and potentially universities), and the employer could take a more active role in developing good supervisors by providing CPD accredited courses, mentorship programmes, and communities of practice for therapists to develop their knowledge and skill and own sense of satisfaction within supervision, support and mentorship of younger therapists. Recognition for outstanding supervisors in the profession is valuable to promote growth in support and supervision roles. Currently, RuReSA has annual awards for best practicing rural therapists and outstanding supervisors and mentors could be nominated for these awards[71]. Similarly, annual awards for outstanding supervisors in private and government sectors could be instituted by OTASA to outstanding supervisors.

Job satisfaction

CSOTs employers could promote the determinants of job satisfaction highlighted by participants (positive experiences, having learning and growth opportunities, available human and non-human resources, and cohesion with other staff) for CSOTs at the workplace. Support through colleagues can be facilitated by employing CSOTs in pairs or more. Additionally, CSOTs can create their own resources and develop their own resilience by learning how to extract satisfaction from their jobs when determinants for job satisfaction are not available.

CSOTs should be afforded the opportunity to discover fields of preference by being exposed to a variety of placement areas and develop knowledge and skill across multiple areas of practice. This could be done by giving CSOTs the opportunity to rotate to different institutions in one area or seeing a variety of patients in primary care by travelling to different clinics on different days.

Opportunities to learn by means of observation of other occupational therapists' practice and learning about handling techniques with clients should be included in rotations. Transport arrangements by the employer to allow CSOTs to reach urban areas to access practicing occupational therapists would be beneficial. Where real opportunities to watch other occupational therapists' practice aren't possible, virtual opportunities could be explored. Due to the COVID-19 pandemic, telehealth has been approved by the WHO as an acceptable mode for occupational therapy intervention and can be used in training[72]. A platform like Microsoft Teams for novice therapists to watch treatment sessions done by experienced occupational therapists with all the necessary consent and privacy settings being considered could be considered.

Strengths and limitations

This study is the first to document the prevalence of burnout in the CSOT population 17 years after the year of CS was implemented by the National Department of Health. It has expanded on work done by van Strormbroek and Buchanan in 2014, which describes CSOTs experiences and demographic factors[35] with similar findings being reported even though the sample size only represented 31.92% of the CSOT population. Because of this sample size, generalisation of the findings in this study to the whole CSOT population or to novice occupational therapists in other countries should be done with caution.

It is not known if the research questionnaire reached the whole CSOT population and only 75 complete responses were analysed for the study from a total of 105 responses. This could be due to factors such as the participants not having access to social media or technology such as a computer and smartphone with sufficient data to complete the questionnaire. Additionally, some participants could have received the invitation to participate in the survey but did not do so. These factors may have caused an under-coverage bias[73] and/or a non-response bias[74] which could have skewed the findings in the results.

Data collected in the form of a self-reported questionnaire could create distortion and bias due to the researcher not being able to control situational elements (such as the environmental setting where the participants filled in the questionnaire). Furthermore, the study was a cross sectional study which could create temporal bias as the study was conducted in one point in time[75].

Pilot testing of the survey questionnaire was not done. This could have been a useful way to identify areas of the survey to improve to ensure a better response rate and to effectively recruit more participants[76] which should be considered in future to improve the number of responses for similar studies.

CONCLUSION

High levels of emotional exhaustion, as an indicator for burnout, were common in the CSOT participants. Depersonalisation and a reduced sense of personal accomplishment were less common. The relationship between these components and several personal, education and work demographic factors were tested. Significant associations with support, supervision and job satisfaction highlighted these areas as potential target areas to prevent and mitigate burnout symptoms. Roles for the South African occupational therapy profession, the Department of Health and novice clinicians themselves are described.

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Author/s contribution

Nadia Struwig was an MSc occupational therapy postgraduate student at the time of the research (graduated in 2020). She was responsible for the conceptualization and execution of the project. She drafted the manuscript and was responsible for subsequent revisions. Kirsty van Stormbroek was the research supervisor of the project. She provided critical reviews, comments, and suggestions for revisions of the manuscript.

Conflicts of interest and bias declaration

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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RESEARCH ARTICLE

Community mobility: psychosocial experiences of stroke survivors who use wheelchairs in Worcester, South Africa

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ABSTRACT

Background: Despite policies promoting transport inclusivity, persons with disabilities in South Africa experience difficulties when accessing public transport. Poor community mobility hampers community integration and participation in occupations outside the home. This article describes the psychosocial community mobility experiences, of stroke survivors using wheelchairs in a town in the Western Cape province of South Africa
Method: The study used a descriptive qualitative design. The study population were community dwelling stroke survivors, from Worcester, using wheelchairs. Data was collected from eight participants through semi-structured telephonic interviews. Inductive thematic analysis was used.
Findings: The four themes derived from the data were: Freedom of movement *(My power chair, my Ferrari')*, Social anxiety *(People stare at you like they do not have a heart*), Dependency *(I must dance along to his fiddle)*, and Social isolation *(You feel done in, dejected)*. Participants identified wheelchairs, private vehicles, and mini-bus taxis as modes of community mobility.
Conclusion: When transport barriers prevent dignified, spontaneous community integration negative psychosocial consequences (social anxiety, dependency, and social isolation) followed. Community mobility barriers hampered participants' ability to participate in meaningful occupations and left them isolated. Occupational therapists should take cognisance of the community mobility challenges wheelchair users might experience and implement intervention strategies to mediate these.

Implications for practice

- Community mobility is essential to perform occupations outside the residential setting and must be included in occupational therapy assessment and intervention strategies.
- Occupational therapists can empower individuals with mobility impairments with the life skills to manage psychological challenges caused by accessing public transport and decreased community mobility.
- Occupational therapy intervention for wheelchair users accessing public transport should include effective, appropriate transfer strategies to embark and disembark from minibus taxis.
- In certain circumstances the occupational therapist should consider the possibility of a motorised wheeled mobility device to facilitate community integration.

INTRODUCTION

The United Nations report (2018) on disability and development shows that persons with disabilities are still marginalised and excluded from their communities despite recent progress to achieve the sustainable development goals (SDGs). According to the UN report, more than 30% of persons with disabilities experience challenges with accessing transport and public spaces. Therefore, goal 11 of the SDGs, *Making cities and communities inclusive and sustainable for persons with disabilities,* has not been achieved[1].

The aim of the South African (SA) National Development Plan (NDP) 2030[2], is to reduce poverty and eliminate inequality. However, the NDP does not address transport access and without accessible transport, people cannot get to places where they can develop skills and grasp opportunities for economic growth[3]. The SA White Paper on Rights for Persons with Disabilities[4], recognises transport challenges as a serious barrier to full community integration of persons with disabilities and calls for the rapid development of a flexible public transport structure that is accessible to persons with disabilities.

Despite international agendas and national policies that promote transport inclusivity, persons with disabilities in South Africa still experience difficulties with regards to accessing public transport[5–8]. Challenges are caused by impairments such as speech impairments, hemiparesis, and decreased mobility, in interaction with social and environmental barriers such as negative attitudes, safety concerns, the physical design, transport costs, travelling distance to get to public transport, infrastructure and design of indoor and outdoor spaces connected to transport, transport systems, services and policies[6,9].

Stroke survivors can experience one or more of the above impairments and/or barriers. Physical and cognitive impairments often cause limitations in mobility, communication, and planning after a stroke. Coupled with social and environmental barriers such as stigma, discrimination, and inaccessible environments, they often experience challenges when accessing transport[10], particularly if in a wheelchair.

An overview of commuter transport in South Africa

Some South Africans, especially those living in poverty, do not have access to a private vehicle11. A 2018 General Household Travel Survey found that 36.7% of South African households use public transport[12]. In the Western Cape, 29.3% make use of public transport[12]. Generally, in South Africa, access to public transport is problematic. Historical racial segregation and the development of urban housing projects far from places of employment, education, recreation, shopping centres, health care and other services, mean that commuters must cover long distances, often on a daily basis[3,6,11]. Distances are often compounded by long waiting times in inconvenient, unsafe locations, as well as safety issues in transit and discomfort[3]. Despite numerous policies and strategies as comprehensively described by Walters11, the provision of affordable, safe, and accessible public transport remains a challenge in South Africa[3].

In South Africa, local public transport is mainly provided through bus, commuter rail, minibus taxis and private metered taxi services (Uber, Bolt, Didi, etc). The most common mode of public transport is minibus taxis11. Since these taxis are privately owned and operated, their services are largely unregulated by government. Taxi associations determine routes, fee structures, operating times, and practices. Previous research amongst the general population[11] and persons with disabilities[6] found taxis to be expensive, unreliable, and unsafe. Minibus taxis are the only means of public transport in the current study setting.

Barriers experienced by wheelchair users in accessing minibus taxis

Physical access is problematic, as the design of minibus taxis such as the height difference between the wheelchair and the seat, makes it difficult for wheelchair users to board and disembark[13–16]. Inside the taxi there is little room to manoeuvre a wheelchair[14] or space for the wheelchairs to be stored[16]. The distance from homes to taxi ranks, poor road conditions, unkempt sidewalks, rough and rugged terrain, curbs, and stairs cause further access barriers[13,15,16].

In addition to physical barriers, wheelchair users also experience attitudinal barriers when accessing taxis. Taxi drivers might be unwilling to help and have an impatient attitude and sometimes refuse to transport wheelchair users[6,8,16,17]. It has been widely reported that taxi drivers` attitudes and even the choice not to stop for a wheelchair user, are financially driven. For taxi operators and owners 'time is money'. The extra time wheelchair users need to embark and disembark and load the wheelchair is experienced by them as time that can be put to better use making an extra trip[6,9]. Similarly, fellow travellers are in a hurry and disinclined to wait while a wheelchair user gets on or off a taxi or to assist a wheelchair user[7.] Financial constraints are another concern for wheelchair users in using taxis. The cost of a trip doubles, as they must pay for themselves and the wheelchair, and triples if they are accompanied by a carer[5,17].

In a recent study done by Gudwana[16] with mobility-impaired participants in Knysna, it was found that safety was a concerning matter. Lack of seat belts, reckless driving, and an inability to maintain balance (due to the impairment), enhanced the sense of feeling unsafe when using minibus taxis. Kett, Cole & Turner[9] concurred that persons with disabilities feel unsafe when using minibus taxis. Lorenzo[18] highlighted safety as a barrier in relation to taxi violence in communities, whereby women with disabilities are more at risk due to their mobility impairments. Other safety issues identified by persons with disabilities were overloading of taxis and drivers and not adhering to road regulations, e.g., exceeding speed limits[6].

Occupations, community integration and transport

According to the Occupational Therapy Practice Framework: Domain and Process (4th ed), the term *occupation* as used in Occupational therapy refers to the things people engage in, alone or in groups, that give meaning and purpose to their lives. Occupations have distinct importance and value to a person and is vital to the individual's health, wellbeing, and sense of self. Occupations involve the body, soul, and spirit and as such, are essential to ensure humans to prosper. Ensuring engagement in occupations is the overarching purpose of the occupational therapy profession[19].

Occupational therapists are concerned with the occupation itself as well as the factors that enable a person to participate in a specific occupation[19]. In the context of this study occupations refer to activities related to community integration for example employment, recreation, engaging in shopping, accessing health care, religious, social, and political life, or any other activity that is performed in a setting outside one's immediate place of residence. Community in-

Table I: Participant identification

Sample frame	Sample size	Excluded from study
40	7 (An additional 8th participant was purposively sampled to explore a specific finding further).	Speech & language impairments=7 Relocated= 3 Incorrect contact details/addresses=21 Non-wheelchair user=2

tegration depends on the ability to choose where, when and how to live, work and play. A choice of how, where, and when to do something, implies the ability to move about freely. For that community mobility is a pre-requisite. Therefore, a lack of community mobility creates a barrier that hampers accessing community services and resources and affects participation in meaningful occupations negatively[5,9,20,21]. Conversely, accessible, efficient, and safe transportation facilitates community integration, whereby citizens can access services and opportunities for health care, education, employment and social activities[22,23].

A study done with British teenage wheelchair users, found that poor transport access infringes on their ability to freely move around in their communities. This in turn can lead to social isolation and lack of community integration[21]. Similarly, Kohler et al[20] describe how Malawians with mobility impairments (n=20) experienced participation restrictions and social isolation due to a lack of community mobility. South African studies regarding transport and community integration concurred with the above findings. Maleka, Stewart & Hale[24] conducted a qualitative study in Gauteng and Limpopo with 32 stroke survivors and found that mobility impairments affected their ability to participate in community activities and resulted in social isolation. Other studies identified that persons with disabilities experienced exclusion from accessing health care, employment, and education due to inaccessible transport[5-7]. Focusing on stroke survivors, 88 percent regarded transport as an obstacle to successfully integrating into their communities, according to a study done in the Helderberg Basin in the Western Cape Province[17]. In Worcester, a rural town in the Western Cape and the setting of the current study, 62.5% of stroke survivors identified access to transport as a barrier[10].

A gap identified was that none of the studies investigated, was how stroke survivors specifically, feel about and experience these barriers. Kett, Cole and Turner[9] confirm a dearth of research on what poor access to transport means to persons with disabilities in their everyday functioning in low- and middle-income countries. This paper aims to describe wheelchair dependent stroke survivors' psychosocial experiences when mobilising in the community using private and/or public transport.

METHODS

Study design

The research followed a post-modern worldview, as the study explored multiple realities from a diverse group of participants. The descriptive qualitative design was utilised to discover and understand the phenomenon through the eyes of the stroke survivors. As the reviewed literature shows public transport access for wheelchair users have been researched extensively. However, the influence of transport access or lack thereof on community integration and the persons psychosocial experiences related to that remained rather unexplored[25]. A gap that the current study focussed on.

Population and sampling

The study population included persons who lived in Worcester, Western Cape Province, SA, and had a stroke before August 2019. Worcester is situated in the Cape Winelands District and forms part of the Breedevalley Municipality. The town has a population of 79 000 people. Over 90% of households have access to water; refuse removal, electricity, and basic sanitation. Strokes are the fourth highest burden of disease in the Worcester community[26]. Privately owned vehicles and minibus taxis are the main modes of transport in Worcester. There are also private transport operators that offer shuttle services and services like Uber.

Participants included in the study had to live in town (not on surrounding farms) in the community (not in residential facilities), use wheelchairs for mobility and have access to private and/or public transport. Stroke survivors with speech and language impairments were excluded from the study (because data were collected telephonically due to COVID-19 restrictions). Participants were recruited through the association of the physically disabled (APD) in Worcester. APD's records showed 40 stroke survivors who used wheelchairs for mobility. Of these, 33 had to be excluded based on the exclusion criteria (speech & language impairments, living outside study area) or incorrect contact details as shown in Table I (page above). This left seven possible participants. Due to the small number, the total population was sampled.

During provisional analysis of the data an interesting trend developed. Participants indicated that they thought a power wheelchair would assist them to access the community. We decided to explore this opinion further through purposefully including a stroke survivor that used a power wheelchair in the study. All eight agreed to participate in the study and signed a written informed consent form.

Data collection

The first author collected data via individual, semi-structured telephonic interviews between July and October 2020. The interviews lasted 30 to 45 minutes and were recorded via a digital audio recorder. Seven interviews were done in Afrikaans and one in English as per participant language preference. Telephonic interviews increased the privacy of the participants and allowed for sharing in-depth experiences. It also allowed participants greater power to schedule and terminate interviews according to their wishes. This method was less intrusive, more cost effective, made a need to travel redundant, and protected participants and the data collector from the risk of COVID 19 infection[27].

A semi-structured interview guide, developed by the re-

Table II: Demographic details of participants

Pseudonym	Age	Gender	Language	Impairment	Onset	*Income	Wheelchair type	Transport mode used
Dottie (P1)	56	W	Afrikaans	left hemiplegia	June 2019	Disability grant	Four-wheel folding frame	Minibus taxis
Felicia (P2)	31	W	Afrikaans	left hemiplegia	November 2016	Disability grant	Four-wheel folding frame	Private and minibus taxis
James (P3)	56	M	Afrikaans	right hemiplegia	June 2019	Disability grant	Four-wheel folding frame	Private and minibus taxis
Roslin (P4)	49	W	Afrikaans	left hemiplegia	November 2016	Disability grant	Four-wheel folding frame	Minibus taxis
Jan (P5)	66	M	Afrikaans	left hemiplegia	May 2016	Old Age pension [SASSA]	Four-wheel folding frame	Private and minibus taxis
Carol (P6)	67	W	Afrikaans	right hemiplegia	July 2019	Old Age pension [SASSA]	Four-wheel folding frame	Private and minibus taxis
Xolani (P7)	53	M	English	right hemiplegia	July 2018	Old Age pension [SASSA]	Four-wheel folding frame	Private
Chris (P8)	67	M	Afrikaans	left hemiplegia	December 2015	Old Age pension [SASSA]	Powered wheelchair	Powered wheelchair

***At the time of the study the disability grant was R1860, and the old age pension was R1780.**

search team, was used to explore participants' experiences. The following focus areas were explored:

- How participants moved around town
- Participants' experiences with using transport (private and public)
- The role transport plays in participants' ability to do things in and around town

The completed interviews were transcribed and provisionally analysed. Data saturation was reached after six interviews. However, to confirm data saturation, interviews were conducted with all eight persons who adhered to the inclusion criteria.

Data Analysis

The interviews were transcribed by the first author and analysed in the language that the interviews were done. The first author translated Afrikaans quotes into English for reporting purposes. The correctness of the translation was verified by the second author. The recordings and transcriptions are available for audit purposes. An inductive thematic analysis approach was used according to the six steps by Braun & Clarke[28]. After familiarisation with data, the first two authors separately generated codes and developed provisional themes from the codes. An iterative reviewing and refining process followed where the authors reached consensus on themes. During the process some themes merged, others fell away, and others broke into separate themes. Thereafter, themes were defined and named by identifying the essence of each.

Trustworthiness and Ethics

Credibility, transferability, dependability, and confirmability[29] were strived for. Data saturation, narrative examples, and reaching consensus in data analysis enhanced the credibility of the study[28]. A detailed description of the research setting, and methods was provided to allow for determination of transferability[28]. The detailed description also contributes to dependability and confirmability. Dependability was further supported by a proposal detailing the methods of the research project that was approved by the Health Research Ethics Committee of Stellenbosch University. Maintaining an audit trail that included the raw data, field notes, documents that show the data analysis process and a reflective journal enhance dependability and confirmability[28]. A reflective journal was used by the first author (and researcher) to note his feelings, experiences, and opinions to assist him to bracket these and present the experiences and opinions of participants rather than his own. It also provided a record of the daily logistics of the research processes.

Ethical approval was obtained from the Health Research Ethics Committee of Stellenbosch University (S19/10/242). Written permission was received from the APD that provided support in the identifying and recruitment of participants. All participants gave written informed consent. Telephonic interviews ensured that participants were not exposed to COVID-19 because of the study. The data was stored in a password protected computer at the University of Stellenbosch SUNScholar Research Repository[30].

FINDINGS

Participants' demographic information

Demographic detail of participants is shown in Table II (page above). There was an equal representation of men (4) and women (4) in the study. The ages of participants ranged between 31 and 67 years. All participants were dependent on governmental non-contributary social grants for an income.

Emerging themes

Codes were ordered into categories from where themes were developed as presented in Table III (page 86).

Four themes emerged from the data:

- Freedom of movement, My power chair, my Ferrari.
- Social anxiety, People stare at you like they do not have a heart.
- Dependency, I must dance along to his fiddle.

- Social isolation, You feel done in, dejected.

Theme 1: Freedom of movement, *My power chair; my Ferrari*

Privately owned vehicles, mini-bus taxis and wheelchairs were used by participants to mobilise in the community.

> "I will not put my entire business on the taxi if I can get private transport. Or even better if I can also use the [wheel]chair." **[James]**

These three mobility strategies (privately owned vehicles, mini-bus taxis and wheelchairs) were used interchangeably depending on availability, how much funds the participant had at any given time, and the weather. Wheelchairs were often the preferred mode of community mobility and allowed some participants to assist others.

> "I do not really use [transport]. If I must, when it rains, I will take a taxi, otherwise my husband push [with the wheelchair] me where I want to go…I travel in my wheelchair, and I can hang bags at the back, or put them between my legs and on my lap. Perhaps we see one of the older people that live close to us carrying heavy bags. Then I say, 'Come, here is a taxi. Give the bag to me I will take it home for you`. I carry the bags to my house, and they come and fetch it there. That makes them laugh. I help where I can." **[Roslin]**

Wheelchairs had to be pushed by someone else, often at a price.

> "The wheelchair is a big advantage. But it is also expensive. I must hire people to push me where I wanted to go." **[Jan]**

Participants thought that a powered wheelchair might enhance their freedom of movement, community mobility and integration:

> "If I have an electrical wheelchair, I will just go and sit in the wheelchair and drive the wheelchair with my friends." **[Xolani]**

Chris, who used a powered wheelchair, was purposefully identified to participate in the study, to explore the perception of participants that a power wheelchair might improve community mobility. His narrative showed that powered wheelchairs can enhance freedom and ease of movement in the community.

> "[I use] a battery powered chair. Everywhere in town, I go where I want to go and get where I want to get. Even to the hospital that is about 5km from here [his house]. There are a lot of shops in Worcester that I can drive into. Sundays I can go to church. Drive into the church with my chair. I drive to them [his friends] with my power chair. It is my Ferrari." **[Chris]**

Chris`s experiences also juxtaposed the difference between needing someone to push the wheelchair and being able to control it himself.

> "It is way better. Way, way better joh. That normal chair, I struggled to find someone to push me where I want to go and then he wants money and I do not always have money. I had to pay the man just to get where I want to go… It's a huge difference…there is no more money involved. This freedom of movement had a positive emotional impact." **[Chris]**

> "It is very nice. Since I have this chair, all is well with me. Very well. Before I had this chair it was bitter. I had to sit at home every day." **[Chris]**

Theme 2: Social anxiety, *People stare at you like they do not have a heart*

Social anxiety and experiences of feeling ashamed especially when using minibus taxis were described. Not being able to get into and out of the taxi as quickly and in the same manner as before the stroke seemed to be at the core of these feelings. It seems social anxiety was as much due to internal struggles related to what the participant imagines co-commuters might be thinking as it was generated by overt and covert actions of taxi drivers and co-commuters.

> "… [quiet]…sometimes people stare at you like they do not have a heart. They [co-commuters] stare and it seems like, `What is it? Does she have to get in here?` That always make me sad…That is not a good feeling. It is an awkward feeling. Because everybody is looking at me and they must wait before they can drive off. It takes time one to two minutes before I am out of the taxi or climb into the taxi. There is some on their way to work who says, `Ai jinne this auntie cannot get out quick enough`. But I cannot and that make me feel awkward. Sometimes I have feelings that I do not want to use the taxi because of the people. It feels as if they are watching me. I am human too. I have feelings too…It seems like, maybe it is my brain telling me this, but it is as if the people make a fool of me. I feel hurt, dejected." **[Dottie]**

> "You feel hurt; you do not feel comfortable, because not all your limbs work a 100%. That is the problem, and then you feel uncomfortable. You feel ashamed because you need assistance from others. The other people are not friendly, and all people are not helpful. As a person you do not always feel like asking, 'Sir, please help me or young man help me, pull me up?' Because you are human, you feel ashamed." **[Jan]**

Participants` descriptions showed that boarding the taxi was often an undignified process.

> "…someone must help lift my body from behind, to lift me into the taxi." **[Felicia]**

> "I sit on the step and turn and twist my body. That works." **[Jan]**

Table III: Visual presentation of themes, categories, and codes

Themes	Categories	Codes*
Freedom of movement	**Taxi**	**Driver's attitude:** *The taxis do not always want to load us with strokes who use wheelchairs* (P2) *He wanted a cooldrink or something to eat, a bribe* (P2) *Disrespectful* (P2,4) *Uncaring* (P4) *Unfriendly* (P5) *Little patience* (P5) **Fellow commuters' attitude:** *Impatient* (P1) *Stare* (P1,2) *Careless - bump into you* (P3) *Disrespectful* (P3) *Complaining* (P4) *Unsupportive* (P5) *Unfriendly* (P5) **Boarding and disembarking:** *Difficult (a struggle)* (P1,2,3) *Slow* (P1,5, 3, 7) *Need help* (P1,3,7) *Can hurt self* (P3) *Stressful* (P3,5) *Little space* (P3) **Cost:** *Cheaper than private* (P1) *Pay for carer* (P1) *I cannot afford it* (P1) *Pay for wheelchair* (P2) *No credit* (P3) *Pay double* (P8) **Reliability:** *Not reliant timewise* (P1) *They have a schedule* (P5) **Not all bad:** *Some taxi drivers supportive and helpful* (P1,2,4,5,8) House calls: *Pick up at home, drop off at destination* (P3,5) *Cost double* (P5)
	Private car	*Comfortable* (P2,3) **Boarding and disembarking:** *Easier than taxi (P1,2,7) depends on size of car* (P6,7) *Not rushed* (P3,6) *Driver assists* (P2,3,6) **Cost:** *Pay* (P3,6) *Do not pay* (P2) *Not always money for petrol* (P7) Availability: *Not always available* (P3,5,7)
	Wheelchair	*Replaces walking* (P3,4,7) *Requires someone to push chair:* (P1,2,3,4,5,7,8) *Pay pusher* (P 4,5,8) *Struggle to find pusher* (P1,2,7,8) **Weather permitting:** *Not in rain, strong wind* (P3,4)
	Power chair	**Spontaneous thoughts on power chairs:** *Wheelchairs with batteries* (P3) *I need to get somewhere, but cannot get there because the wheelchair is not electric, and I have no one to push me* (P4) *With that electric wheelchair if I want to go, I can go. I don`t have to ask* (P7) *I will just go and sit in the wheelchair and drive the wheelchair with my friends. It can assist me big time.* (P7) Purposively sampled participant's experience with power chair: **Mobility:** *Just sit and drive* (P8) *Much better (than manual chair)* (P8) *Go with friends* (P8) *Everywhere in town* (P8) *Shops, hospital (5kms), church, child's birthday* (P8) *I go when I want to, I get where I want to go* (P8) *My Ferrari* (P8) **Practicalities:** *Charge battery at night* (P8) *Load shedding* (P8) *Not in rain* (P8) Before: *I sat at home every day* (P8) *It felt alone* Pp8) After: *A world of difference* (P8) *I am happy* (P8)

Table III: Visual presentation of themes, categories, and codes

Themes	Categories	Codes*
Social anxiety	**Humiliating**	**Embarking and disembarking:** *Undignified* (P1,2,5,6) *Difficult* (P1,2,5,6) **Interaction with fellow commuters:** *The people watch me, It is not a nice feeling* (P1) *Ai jinne the auntie cannot get out fast enough* (P1) *It makes me feel different* (P1) *It makes me emotional* (P1) *My brain tells me the people are making a `gai` of me. I feel hurt, despondent* (P1) *People have no heart, they stare…It makes me sad* (P2) *They say the uncle is not lekker* (P3) *You feel hurt, you are not relaxed, you feel shame because you need help from others* (P5)
	Fear when using taxis	*Do not feel safe* (P1,3,5) *Afraid of falling* (P2,3,6) *Afraid of injury* (P2, 6) *Taxis not always in good repair* (P5)
Dependency	**Reliant on others**	*To push the wheelchair* (P1,3,5,7,8) *To drive private car* (P2,3,5,6,7) *To transfer* (P1,2,4,5,6)
	Loss of control	Before stroke: *Walked* (P3,7) *Drove* (P6,7) *Independent* (P3,6,7) After stroke: *Need to ask* (P2,3,6,7) *Reluctant* (P1,2,6) *Difficult to get transport* (P3,4)
	Scheduling	*Wait for taxis, drivers* (P2,5,6) *Driver/car not always available* (P3,5,7) *Must adapt* (P3) *Advance planning needed* (P6)
Social isolation	**Loss of community occupations**	*I was very busy, work, community work, church work. I cannot get to the things I always did.* (P1) *I have to leave stuff because I cannot get there* (P1) *If I could walk, I would have been there already* (P1) *Cannot participate in activities* (P6) *…can I not be like the man who is going to work?* (P3) *Your heart is on fire because you cannot visit family* (P3) *It is difficult for you to go anywhere you want to go* (P7) *Miss clinic appointments and go without medication* (P7) *I am not a gym member anymore because I cannot get there* (P7) *I can`t go and watch soccer* (P7)
	Negative feelings	*Why do you have to be like this?* (P1) *Done in* (P1) *Dejected* (P1) *It is not nice to sit at home and do nothing. It is not pleasure; a long road* (P3) *Worthless* (P4) *You are dependent on others, that is tough on the heart* (P6) *Sad story* (P6) I feel no good (P6) *It makes me feel bad* (P7) *I am not expecting any good stuff after I stroke* (P7)
	Excluded	*Not part anymore* (P1,6) *Stay at home* (P3,6,7)
	Try to adapt	*I have to live with it; I have to be satisfied* (P3) *I told myself not to think too deep* (P3) *You have to work on yourself and accept things* (P4) *Get used to it* (P6) *You have to accept it* (P6) *Not the end of the world* (P6)

Sometimes drivers requested extra incentives.

> "He [taxi driver] had this way, I had to buy him a cool drink or something to eat…it looked like I had to bribe him to get into the taxi." **[Felicia]**

She further indicated that if she refused to do this the driver refused to let her ride in the taxi.

> "Then he gets angry and he does not allow me to get in the taxi." **[Felicia]**

Participants with access to private vehicles preferred that to minibus taxis. This preference was due to convenience, the ease of getting into and out of the vehicle, and a more relaxed atmosphere.

> "When I have to get into a taxi, maybe in passing my crutch get stuck or my foot get stuck in a hole, Oh jissou sorry missus, or sir. Understand. Everything involved. I have to move quickly. But when I go with the car… I get in, in my own time. Put my sick leg in first and then my body; take hold of the car`s door frame, lift myself onto

> seat. When I am in, I close the door, put my crutch next to me. But the taxi is a complicated thing, and it is also a bit dangerous you know. For getting stuck while hurrying and things like that. **[James]**

However, all was not negative. Individual taxi drivers and co-commuters sometimes showed goodwill and consideration.

> When you go to town the taxi has specific pick-up points, but when they see me with the wheelchair they turn and come to me, and they assist me into the taxi. And some people are in a hurry to jump off, but when they see there is a disabled person, they wait for the person to get off calmly and then they drive away…usually they do not make us [people who move with difficulty] sit deep inside. Usually, we can sit in front if we can get in there. **[Roslin]**

> There is sometimes one who is very decent. He will say, come lady I will pick you up, at the taxi rank specifically. **[Felicia]**

> When the guard or the driver see your circumstances, they provide help. They support you. **[Jan]**

Theme 3: Dependency, *I must dance along to his fiddle*

Regardless of whether participants used privately owned vehicles, mini-bus taxis or their wheelchairs, they were reliant on others to reach services and activities in the community. This led to a sense of dependency.

> I must dance along to his [owner of the private vehicle] fiddle, I must fall in with what he says. I must arrange things in his favour. That it doesn't count in my favour, because I can't just tell him what he must do. [James]

> The schools have started again so now I cannot bother her [sister who owns a car] anytime, and she gets home after three in the afternoons. **[Felicia]**

The change from being independent and being able to go where they want to when they want to having to ask and wait on others for every trip created frustration, distress, and even despair.

> It is a terrible adjustment, a terrible adjustment you have to know. I drove…I did not have to ask. When I wanted to go somewhere, I got into my car and there I go…It is miserable to have to ask, 'I want to go, will you please take me? **[Carol]**

> The time I was walking, I did my own thing, but now I must ask someone to…to help me…Even having my own car, if I want to go somewhere I must ask my son, 'Can you please take me to town?' I can't drive myself. **[Xolani]**

> I could move as I saw fit. If I have an appointment at 10, I was there at 10. Now I must wait for a lift before I can go. **[Jan]**

Participants indicated that they no longer drive because of their insecurities regarding their capabilities and based on their doctor's advice.

> …the doctor told me not to drive anymore…, I am also scared that I might cause an accident for others on the road. I will never drive again. **[Carol]**

The dependence meant a loss of spontaneity. Thought and planning were necessary for things as mundane as going to the shops or visiting friends. Going somewhere on the spur of the moment became impossible. When participants knew about appointments, they organised transport. However, one does not always know where one might need or want to go days or even hours before the time.

> On the Monday already I make arrangements and tell him [friend with car] what time I have to go to the physio and whether he is available…but you don't always know beforehand that you need to go to the doctor the next day or sometimes you feel in the morning you want to go somewhere…then I must call and look for someone to take me where I need to be. **[Carol]**

Theme 4: Social isolation, *You feel done in, dejected*

The dependency and loss of spontaneity resulted in an overall sense of social isolation. Participants vocalised that it was not by choice that they did not participate in community activities, but often due to an inability to get to the activities.

> You do not have transport. You want to go to places, but you cannot get there. Then you feel done in, dejected. Ai jinne, why, if I could walk, I would have been there already…I have to leave stuff [things she did before the stroke], I am not part of it anymore, because I cannot get there…because I cannot walk anymore, and I do not have anyone that can push me in my wheelchair. **[Dottie]**

> If I do not have transport, it is difficult for me to go anywhere that I want to go. **[Xolani]**

Money to pay for transport was often a determining factor whether participants could participate in community activities.

> A Taxi must be paid. I cannot just pick up the phone and ask, 'Take me to town, take me to church.' They want to be paid and there is not always money to pay. There are times that I cannot get to the hospital for my appointments because I do not have the money to pay for transport. **[Dottie]**

Participants have resigned themselves to the situation, but the dream to move about freely in the community remains.

> Some days it is a sad story. But you get used to it. It is not the end of the world. But it will be nice to again be able to go everywhere that you have to go. **[Carol]**

DISCUSSION

Freedom of movement, *My power chair, my Ferrari.*

Wheelchairs became the `feet` of participants who previously walked to access the community. Instead of walking they now rolled where they wanted to go. This finding underscored the importance of providing persons with severe mobility impairments with wheelchairs. It is possible that a powered wheelchair or other powered mobility device can enhance community mobility even more than push chairs. Once obtained, this expensive device decreases or eliminates the day-to-day cost of transport. It can create a sense of independence and enhance community mobility and participation[31].However, not every person who had a stroke will be able to mobilise with a powered wheeled device. Physical impairments caused by the stroke such as hemianopia, decreased motor coordination, impaired cognition and/or memory and slow reaction time will negatively impact a person`s ability to operate a power wheeled device safely. Environmental barriers like community infrastructure (poor road conditions, narrow entrances, stairs/hills/slopes), adverse weather conditions (rain, wind, and heat) and negative attitudes can hamper community mobility of both manual and powered wheeled device users[32]. Violence and crime in South Africa are additional challenges with regards to the safety of wheelchair users when accessing communities[17,18,33.] Finally the cost of powered devices might be prohibitive to it being issued in the South African Government sector. Occupational therapists should consider issuing a powered wheeled device only after comprehensive assessment and careful consideration of all the variables that might impact an individual's ability to use it to enhance community mobility. Current findings on the usefulness of a powered wheeled device to enhance community mobility after stroke is preliminary and must be explored through further study.

Social anxiety, *People stare at you like they do not have a heart.*

Current findings highlighted the undignified and degrading nature of transfers in and out of minibus taxis. This experience had a ripple effect, which led to social anxiety when using taxis. Pyer & Tucker[21] referred to this phenomenon as transport anxiety, and highlighted similar emotional discomfort experienced when accessing public transport among a group of young wheelchair users in Britain. In the study setting, minibus taxis lacked adaptive equipment to facilitate navigating in and out of them independently. Therefore, a carer was needed for whom an extra fee had to be paid. Alternatively, assistance had to be sought from taxi guards and/or fellow commuters who are probably not skilled in providing the necessary assistance. Thus, the risk of injury to either party increases. To counteract these experiences, adaptations such as lifts or ramps, and wheelchair docking stations should be investigated[21,34]. The role of occupational therapists is to advocate for adaptations to public and/or private transport to provide dignified access for wheelchair users to these modes of transport. Occupational therapists will have to look at the most effective and appropriate transfer strategies for wheelchair users into and out of minibus taxis to prevent social anxiety when making use of minibus taxis. It is also important that wheelchair users, caregivers, taxi drivers and their guards are trained in appropriate transfer techniques for wheelchair users.

The topic of negative attitudes of taxi drivers and fellow commuters has been widely reported [6,8,16,17] and again it showed its presence in the current findings. Especially telling was the exploitation of a participant to the extent of bribery. This illustrates the power imbalance between minibus taxi drivers and wheelchair users and furthermore highlights the dependency of wheelchair users as also described by others[21,34]. Occupational therapists can explore workshops or group discussions with the hope of changing the negative practices.

A less frequent reported finding was the positive attitudes, respect, patience, and goodwill shown by some taxi drivers, guards, and fellow commuters. The findings showed that attitudes and behaviour of taxi drivers and fellow commuters were not negative across the board as the popular narrative seems to indicate. As in all spheres of life there is a spectrum from the positive to the negative. It is important to acknowledge the positive and to start building a body of evidence in that regard. Acknowledgment can also strengthen individuals in their actions.

Dependency, *I must dance along to his fiddle.*

Participants, previously independent individuals, were now dependent on others for community mobility and thus community integration. The dependency decreased their autonomy[21], led to frustration, and negatively influenced their motivation and ability to participate in community occoupations[34]. An American study with a group of diverse wheelchair users[35], and a British study with teenage wheelchair users[21] also highlighted the increased dependency wheelchair users face in order to participate in community activities.

Social isolation, *You feel done in, dejected.*

Social anxiety and dependency resulted in a loss of spontaneity when it came to community activities. The restrictions to movement and accompanying emotional distress can create a sense of social isolation. Similar findings were documented by others[9,20,21]. Psychologically, feelings of loneliness, worthlessness, and heartbreak can develop, that negatively impact individual health and well-being and increase stress levels and suicide ideation[36].

Occupational therapy intervention concentrates on facilitating participation in life roles and meaningful occupations. To achieve that the occupational therapist is concerned with bodily impairments, the requirements of different occupations important to the client, and the factors that empower or disrupt engagement in a specific occupation[19]. The current study findings are important to occupational therapy practice as it identifies a barrier to meaningful participation in community occupations. The negative impact that insufficient community mobility might have on community integration and occupations that are performed in settings outside the home makes it imperative that community mobility is included in occupational therapy assessment and intervention strategies. Occupational therapists can also empower individuals with mobility impairments with the necessary life skills to address the psychological challenges due to decreased community mobility.

Study limitations

Caregivers, taxi drivers, stroke survivors living on the surrounding farms, and those who could not converse over the phone were not included in the study. Due to COVID-19 restrictions the study population could not be identified with the assistance of community-based therapists as proposed. Therefore, the population sampled from were smaller than anticipated and purposive sampling could not be done. A further limitation imposed by COVID-19 restrictions was the use of telephonic data collection and thus exclusion of people who could not converse over the phone. With in-person data collection persons with communication impairments would have been accommodated. Communication difficulties might lead to additional challenges when accessing transport.

Recommendations

- While not appropriate for everyone, it is recommended that in certain circumstances, after a thorough assessment, stroke survivors be issued with powered wheelchairs for community mobility via DOH or donor funding.
- The taxi drivers who showed goodwill to participants can be approached by DPOs to act as activists to create positive change within the taxi community toward wheelchair users.
- The possibility of placing an identifiable sticker on the taxis of drivers who are happy to provide transport to stroke survivors and other wheelchair users should be explored.
- The possibility of fitting some taxis with adaptations such as ramps, lifts, and wheelchair docking stations, and funding models for these adaptations should be explored in further study.
- The perceptions and attitudes of taxi drivers and/or taxi guards and co-commuters re the use of minibus taxis by wheelchair users must be explored in future research.
- Further research into the use of powered wheelchairs on the enhancement of community integration within the African context, is also called for.

CONCLUSION

Community mobility barriers hampered participants' ability to participate in occupations they found meaningful, increased their dependence, and left them isolated. It is important that occupational therapists are aware of the community mobility challenges stroke survivors and other wheelchair users might experience and implement strategies to mediate these during intervention. The study exposed the negative psychosocial consequences where transport access barriers prevent dignified, spontaneous community integration. It also shows that using a wheelchair, and even more so a powered wheelchair, might negate some of these consequences.

Author contributions

The research was done in partial fulfilment of the requirements for the degree of Masters in Human Rehabilitation Studies at Stellenbosch University for the first author, Waldo Bradley Visagie. He conceptualised the idea, collected and analysed data and drafted the article. Surona J Visagie and Jerome Peter Fredericks were his supervisors and provided input during conceptualisation and data analyses. They were part of the write up and drafting of the article and were involved in submission and revision.

Conflict of Interest

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

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RESEARCH ARTICLE

Barriers experienced by stroke survivors when participating in meaningful occupations in a rural and semirural community

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ABSTRACT

Introduction: There are various personal and environmental factors that hinder the stroke survivors' participation in meaningful occupations within a rural and semi-rural community context. Thus, occupational therapists need to consider such barriers in order to provide holistic treatment.
Aim: This study intended to explore the barriers experienced by stroke survivors on their participation in meaningful occupations in a rural and semi-rural community.
Method: An explorative qualitative study was conducted, using a purposive sampling method to recruit participants at a public healthcare district hospital. Data were collected at the participants' homes using individual semi-structured interviews. The researcher made use of open-ended questions guided by the Occupational Therapy Practice Framework 3rd edition and the Person Environment Occupation Performance model.
Findings: Four themes related to the barriers experienced by stroke survivors on their participation in meaningful occupations emerged: (i) physical barriers, (i) psychological barriers, (iii) financial and (iv) environmental barriers.
Conclusion: The barriers explored in this study compelled the stroke survivors to accept varying degrees of assistance from their caregivers. The findings of this study could assist occupational therapists to consider the factors that hinder the stroke survivors' participation in meaningful occupations in rural and semi-rural South African communities, and inform treatment aims that are relevant to the respective communities. If occupational therapists consider these barriers when planning treatment, this could assist with maximizing independence in all areas of stroke survivors' lives, lessening the burden of care on their caregivers and decreasing the patient load on clinical and community occupational therapists.

Implications for practice

Stroke survivors dwelling in the semi-rural and rural community contexts experience barriers which are unique to such settings. Thus, occupational therapist should be aware of the differences of barriers experienced not only in the hospital setting, but in the community context that stroke survivors are reintegrated to. Such consideration could contribute to intervention focussed on the individual's specific needs with regard to participation in meaningful occupations within the semi-rural and rural contexts they reside in.

INTRODUCTION

Stroke is considered to be second leading cause of death and disability globally[1]. Whitehead & Baalbergen[2] estimated that the global number of stroke survivors will continue to increase to approximately 70 million by the year 2030. In South Africa (SA), a total of 564 000 people are living with a certain degree of disability as a result of a stroke[2].

Occupational therapists are most concerned with the result of participation in meaningful occupations after stroke. Amongst other roles, occupational therapists provide holistic treatment by exploring personal and environmental factors that hinder participation in meaningful occupations, and make necessary adaptations according to the stroke survivors needs in order to enhance participation in occupations. This study explored the barriers experienced by stroke survivors on their participation in meaningful occupations in a rural and semi-rural community in South Africa.

LITERATURE REVIEW

The study focused on the personal and environmental factors that hindered the stroke survivors' participation in meaningful occupations. These factors were investigated using the Person Environment Occupation Performance (PEOP) model[3]. The PEOP model emphasises the challenges related to residual symptoms of stroke that may be caused by the relationship between the community-based stroke survivor and their environment, rather than by the condition itself[3]. The model takes into consideration the person (intrinsic factors) and environment (extrinsic factors) which may interfere with or hinder the stroke survivors' participation in meaningful occupations.

Person factors associated with barriers of stroke survivors when participating in meaningful occupations in the community

Physiological and Neurobehavioral factors

A study conducted in rural China[4] highlighted that muscle tone and muscular endurance were reported as physiological barriers for stroke survivors when participating in meaningful occupations. The findings of the study revealed that physiological factors appeared to have significant impact on their participation. Subsequently, the stroke survivors had to take frequent rest breaks as a result of experiencing fatigue and as such, needed more assistance from their caregivers. These physiological factors are as a result of the impaired neuro-behavioral factors such as decreased active movement on the affected side, pain, poor balance, and incoordination[3,5]. However, findings from research performed in Rwanda and Johannesburg[6–11] identified restricted mobility and pain as the main neurobehavioral barriers that affect aspects of the stroke survivors' lives and their ability to participate in meaningful occupations. Additionally, Braaten et al.[12] revealed that fatigue was more prevalent in the subacute phase of stroke recovery.

Psychological factors

Walsh[8] highlighted the concerns of stroke survivors about being a burden on their family members as they required assistance in order to participate in meaningful occupations. He reported that a sense of satisfaction arose from being given tasks to do for their families, as this increased their sense of personal causation. The participants from the study also expressed concerns about their families offering too much support and feelings of a decreased sense of capacity, or too little support which resulted in feelings of loneliness, neglect and stigma.

Common emotions that have been identified by literature as barriers to participation in meaningful occupations, include feelings of loneliness, sadness, fear, anxiety, frustration, decreased self-esteem and feeling useless[7–8,13]. All of these emotional factors impaired the stroke survivors' participation regardless of the level of disability resulting from the stroke. This has been linked with episodes of depression as they felt like they had lost valuable roles within their families as well as autonomy[7,13–14].

Environmental factors associated with barriers of stroke survivors when participating in meaningful occupations in the community

Social support

Previous studies[8,15–17] revealed that participants interpreted too much support from their immediate family as a barrier as it reinforced dependency behaviour for instance, when families provide assistance to stroke survivor capable of engaging in activities independently. Additionally, too much support did not afford the stroke survivors an opportunity to become independent when participating in meaningful occupations.

Restricted mobility was also identified as a primary factor that caused secondary barriers in receiving social support [6]. This came with being either confined to a wheelchair or not being able to walk independently. As a result, it became difficult for the stroke survivors to visit friends and family. It also became challenging for them to attend social gatherings such as wedding and birthday celebrations, where participation in such social activities enabled them to receive social support. However, due to restrictions in mobility, the stroke survivors reported that they had to wait and see if friends or family members would visit them, which led to them feeling isolated and confined to their homes[18].

Participants in studies conducted in South Africa and China identified a lack of support from friends as a barrier, since they no longer visited to check on them, nor went out with them[11,18]. The results of another study discovered that the stroke survivors' friends considered going out with them to be physically taxing as they had to provide physical assistance particularly if they had restricted mobility[19] .Furthermore, the stroke survivors' friends revealed that they had adjust their physical abilities to those of the stroke survivors[19]. These identified barriers contributed to the stroke survivors feeling like they were a burden to their friends, and that put a strain on the friendships. This resulted in further isolation from their friends which compromised the social support offered to the stroke survivors and their participation in social activities.

Transport

Participants of a study conducted in South Africa identified using a wheelchair as a barrier to participation in meaningful occupations, particularly whereby the stroke survivor had limited or no motor function[11]. Moreover, the barrier of depending on the caregiver to be pushed in the wheelchair restricted participation such as community mobility and social participation Transferring the stroke survivor from the wheelchair into a bus or a minibus taxi to access health care facilities was also seen as a burden on family members. Mudzi et al[11] further reported that stroke survivors had to pay an extra taxi fare for putting the wheelchair in a taxi and for the caregiver, which made the use of public transport more costly.

Participants of another study conducted in China revealed that they made use of buses as a common mode of transport. However, they were not able to get on and off the bus, as the buses were not adapted to accommodate people with physical disabilities[4]. Other studies conducted in China, indicated there was also limited access to assistive devices for personal care devices such as wash mitts, long handled sponges, button hooks, etc[4,18]. The participants had to pay for these personal care devices and financial constraints made the devices inaccessible to some. The study reported that the only accessible assistive devices were canes which were limited to those who had regained movement in the lower limbs[18].

Accessibility

A systematic review study conducted by Jellema et al.[20] identified inaccessible buildings and public spaces such as health care facilities that were not reasonably accommodated for wheelchair use, to be barriers to participation. This included: having limited space in public buildings for the stroke survivor, using a mobility assistive device such as a walker or a wheelchair, to move around. Stroke survivors also identified having steps inside their house, uneven terrain and soil in the yards as a barrier, as this made it difficult for them to move around freely in their homes, particularly, if they used a wheelchair or a walker[20]. As a result, the participants needed to be pushed in the wheelchair or assisted by their caregivers, which further increased the burden of care.

METHOD

Setting

The study was conducted in the rural and semi-rural parts of Hammanskraal situated in the northern region of Gauteng. The common housing structures include houses built as part of the Reconstruction and Development Project (RDP) and those built with corrugated iron (shacks). There is access to a shopping mall, shopping centres, clinics and one public healthcare district hospital. Most of the population is unemployed and cannot afford to own private transport. As such, the community relies on public transport such as taxis (microbuses) and buses as a means of getting from one place to another. The transport is only accessible at the main tar road, which could be within a 2km-5km radius from the stroke survivors' homes. Gravel roads surround the stroke survivors' homes. This research setting was conveniently sampled because the researcher worked as a clinical occupational therapist in this region at the time of the study.

Design

An explorative, qualitative research study was conducted using a phenomenological approach[21].

Population

The population included all the stroke survivors admitted to the district hospital 6-12 months prior to the commencement of the study. The stroke survivors had to be attending occupational therapy rehabilitation at the hospital.

Sampling

A purposive sampling method[21] was used to select the participants with subjective experience about the phenomenon of the barriers experienced when participating in meaning occupations in the community context after suffering stroke. Stroke survivors were included if they were: (i) able to speak Setswana and or English, (ii) above the age of 21, (iii) diagnosed with a stroke six to 12 months prior to the commencement of the study and (iv) attending occupational therapy at the monthly stroke clinic at the district hospital. The participants were excluded from the study if they had global aphasia.

Sample size

The participants were recruited at the occupational therapy department of a public healthcare district Hospital in Hammanskraal, where they attended a multi-disciplinary stroke clinic once per month. The aim and objective of the study were explained in the information leaflet to the stroke survivors. Ten Setswana speaking stroke survivors between the ages of 42 and 77 years consented to participate in the study and for data to be collected at their homes. However, data saturation was reached at seven participants.

Data collection tools

A demographic form and an interview guide were used to collect data. The interview guide consisted of seven open-ended questions that were guided by the Occupational Therapy Practice Framework 3rd edition(OTPF-3)[22]. The interview guide was translated into Setswana, the language commonly spoken by the participants.

Data collection

Data were collected by the researcher using individual semi-structured interviews which were conducted in Setswana. Furthermore, the researcher took notes to record additional information such as observations made that could not be captured by the audio recorder. For instance, participants' non-verbal expressions, emotional expressions, the side affected by the stroke and the terrain around their house was noted. The collected data were stored electronically on dedicated file that was password protected, as well as on a cloud account.

Data analysis

All interviews were recorded in Setswana and then transcribed verbatim in English. To ensure the accuracy of the translations, these were completed by both the researcher and independent checker who was also fluent in speaking, writing and reading Setswana as a first language and English as a second language. Clarke's deductive thematic analysis method was used to analyse the collected data[23]. The PEOP model[3] was used to guide the emerging themes.

Methodological rigour

The credibility of the study was ensured by the use of more than one person to analyse the data which strengthened the rigour and trustworthiness of the results of the study[23]. An occupational therapist with experience in qualitative research served as an independent reviewer after the researcher had analysed all the data. Peer checking[24] was performed by an additional occupational therapist and no discrepancies arose. Transferability was achieved by providing a thorough and accurate description of the participants' profiles and the methodology employed at each step during the study.

Ethical considerations

The study obtained ethical clearance from the University of Pretoria's Faculty of Health Science Research Ethics Committee (REC) and the National Health Research Committee (NHRC). The project number assigned for this study was 06/2020 with the reference number GP_202001_019. The principles of autonomy, justice and confidentiality were applied throughout the study by: explaining the contents of the information sheet in a language the participants understood (Setswana); having signed consent to participate and be audio recorded; making use of a fair inclusion and exclusion criteria which did not discriminate the participants based on factors such as their race, gender, religious beliefs and by using alphanumeric codes in data analysis to ensure confidentiality.

Table I: Demographic information I

Participants' Characteristics	n	%
Gender		
Male	3	42.9
Female	4	57.1
Age group		
40-49	2	28.6
50-59	2	28.6
60-69	1	24.2
70-79	2	28.6
Occupation		
Employed	1	24.2
Unemployed	3	42.9
Pension	3	42.9
Time since stroke at the time of the study		
6-12 months	7	100.0
Mobility		
Confined to bed with no assistive device	1	24.2
Walking using a crutch	4	57.2
Wheelchair	2	28.6

RESULTS

Demographics of the participants

Most of the participants were female, unemployed or on pension and walked with a crutch (Table 1, below).

Themes and sub-themes related to the objective of the research

Overall, four themes and nine sub-themes emerged from the findings. The themes included: physiological, psychological, financial and environmental factors.

Theme 1: Physiological barriers

The physiological factors included fatigue, pain and restricted/limited movement.

Sub-theme: Fatigue

The participants reported that they experienced fatigue, and this has limited their participation in meaningful occupations such as basic activities of daily living (BADL), instrumental activities of daily living (IADL) and social participation. They either performed tasks at a slower rate or had completely stopped participating in meaningful occupations. For the stroke survivors, participating in a simple activity such as bathing, preparing a meal or walking is physically draining.

> "I become easily tired. I just do a bit, and I rest when I feel tired." **P03**

> "I am not able to sit in the taxi because I become easily tired." **P06**

Sub-theme: Pain

The participants who identified localized pain on the affected upper (shoulder and or wrist) or lower limb (hip and or knee) joints as a barrier to participating in occupations, reported that they refrained from using the affected side to avoid experiencing further pain. They reported that the pain was exacerbated by active participation in occupations.

> "Sometimes, I feel pain in my leg. So I don't walk that much." **P02**

> "I have severe pain in my shoulder and hand. I am not able to bend it. I am unable to do most of the things because of the pain in this arm." **P05**

Table II Demographic information II

Pseudonym	Gender	Age	Occupation	Time since stroke (in months)	Mobility
P1	M	58	Unemployed	7	Wheelchair
P2	F	69	Pension	6	Walking with a Crutch
P3	F	42	Unemployed	7	Walking with a crutch
P4	F	76	Pension	6	Walking with a crutch
P5	M	56	Employed (security guard)	6	Walking with a crutch
P6	M	45	Unemployed	8	Wheelchair
P7	F	79	Pension	6	Confined to a bed

Sub-theme: Restricted/no movement in the affected limbs

The participants reported that they had challenges with mobilizing the affected body structures either due to having no movement or having limited movement.

> "My legs become stiff and it becomes difficult for me to move." **P02**

> "The problem is the shoulder. It is heavy and does not move." **P04**

Theme 2: Psychological barriers

Sub-theme: Fear

Two participants reported that they experienced the fear of something bad happening to them. For example, a fear of suffering another stroke, regressing on the recovery process, falling, or leaving the house on their own.

> "I was scared that I might regress." **P02**

> "Sometimes I fear going out on my own because I think I will be stuck, and I am not able to get back home." **P03**

Sub-theme: Feelings of being a burden

The participants reported to feel like they were being a burden to their caregivers as they needed moderate to maximum assistance in order to participate in meaningful occupations.

> "My husband has to wake up in the morning and do everything. I had asked him to stop washing me because it was too much for him, and he had focus on other things such as cleaning and maintaining the yard and other things." **P02**

> "My daughter would be watching TV, and I have to call her to come help with stabilizing the pot. I sometimes feel for her, and I let her be." **P03**

Theme 3: Environmental barriers

The participants identified the following environmental factors as barriers: access to water and sanitation, physical environment, assistive devices, financial constraints, and access to transport.

Sub-theme: Access to water supply systems

The participants identified not having easy access to water and sanitation as a barrier. They reported that having to fetch water from an outside tap by using a bucket limited their independence in BADLs and IADLs as they had to rely on family members to fetch water for them.

> "My child brings me water to wash myself, as I am unable to lift up things using both hands." **P04**

> "My wife prepares water for me to bath. She boils water in a kettle and pours it into a bucket." **P05**

Sub-theme: Toilet and bath facilities

The participants also reported that using an outside pit toilet was a challenge, as the toilets were located at a distance ranging between 10-30 metres from the house. As a result, the participants were not able to reach the toilet on time to avoid bowel and bladder accidents. This restricted the participants' independence in functional mobility (transferring from the wheelchair to the toilet seat) and toilet hygiene Furthermore, the toilet was not wide enough to accommodate a wheelchair and two people inside (participant and caregiver), and the participants therefore resorted to wearing adult diapers (nappies).

> "I wear a nappy. They (referring to his mother and sister) cannot carry me to the toilet because I am heavy." **P06**

> "I wear a nappy because the toilet is outside, and I cannot walk." **P07**

Most of the participants reported that having to use a plastic bowl for bathing which was a barrier due to the instability of the bowl, as it could easily tip over while attempting to get in and out.

> "I would struggle if I try to get inside the plastic dish because it is not stable." **P02**

Sub-theme: Access to public transport

The participants also identified access to transport as the main barrier to their participation in meaningful occupations. They reported that they had to walk a long distance on gravel roads and uneven terrain in order to reach the main road to access a taxi, and this was a challenge due to restricted mobility and fatigue. They indicated that getting in and out of a taxi was a challenge because they need assistance since the taxi was too high for them to climb in and out, and that the taxis do not allow, or are not built to accommodate, a wheelchair. The participants resort to hiring private cars to transport them to and from their destination, usually the hospital for follow ups.

> "We have to walk to the main road to catch a taxi, did you see how far it is." **P02**

> "The leg needs someone to bend it for me to be able to get inside a taxi. You see that a Quantum (a minibus taxi the participants use for transport), it is a bit high." **P03**

Theme 4: Financial barriers

Sub-theme: Financial constraints

A unique theme emerged from this study. Most of the participants reported that they receive social grants (pension and disability grants) from the government which assist with their day to day living. However, they reported that the funds from the grant are not sufficient to meet their daily requirements; they acknowledged the financial support as a barrier to participation in meaningful occupations.

> "We have to hire a car for R50 to take us to church. We

> are both not working." **P01**

> "We live on pension grants. We take care of our grandchild. We have to hire a car for R400 to take me to the hospital for check-ups. Money does not last." **P02**

DISCUSSION

Physiological barriers

The participants identified fatigue, pain and restricted or no active movement in the affected limbs as the main contributing factors that hinder their participation in meaningful occupations. The participants of this study revealed that pain was the main contributing factor to hindering participation in meaningful occupations. The finding is supported by the results whereby pain affected the stroke survivors ability to participate in occupations they considered to be meaningful[6,11]. This resulted in the participants either needing moderate to maximal assistance from their caregivers or ending up experiencing discontinuity with regards to participating in occupations that provide meaning to them, irrespective of the level of disability or severity of the stroke[3,5]. This increased the burden of care on caregivers and decreased the quality of life of the stroke survivors.

Other participants also refrained from actively moving the affected limbs to avoid experiencing pain. As a result, the participants were confined to one space in their house because the less they moved the less pain they experienced. Active movement was restricted by pain, which is expected after suffering a stroke[25]. These factors contributed to the participants' poor participation in meaningful occupations. Even though the stroke survivors were educated about the benefits of including the affected limbs in functional activities, their fear of experiencing pain outweighed the benefits of relieving the spasticity through actively mobilizing the affected limbs.

In addition to pain and restricted or no active movement, the participants in this study identified fatigue as a barrier. Although fatigue was identified as a barrier, the participants continued to participate in meaningful occupations but with a decreased rate of performance. Braaten et al[12] supported the finding of this study by revealing that fatigue in stroke survivors remained prevalent 3-12 months post stroke. The participants often had to wake up more than two hours earlier to ensure that tasks are completed timeously. Such a challenge caused the participants to become frustrated, as they did not have the energy due to lack of sleep to still manage to participate in their meaningful activity. Previous studies only focused on fatigue impacting negatively on the stroke survivors' BADL and IADL[4,26-27], and not occupations such as social participation (going to church) which the participants of this current study identified as meaningful.

Psychological barriers

The findings of this study revealed that the participants experienced the fear of falling and suffering a second stroke, particularly when in a public place. This resulted in them refraining from participating in activities that required them to leave their home regardless of if they were accompanied by a family member or were alone. Walsh et al[28]. presented related findings showing that it is common for stroke survivors to experience the fear of falling, and that the fear was a barrier that restricted their participation in their lived world. The identified feelings of fear were heightened when the participants had to leave home alone. A study conducted in Malysia by Ainuddin et al.[29] further highlighted that the impairments in the stroke survivors' physical, cognitive and sensory systems contribute to the recurrent falls. Furthermore, unfamiliar environments also posed a risk to increased fall. For example, falls may occur when stroke survivors are exposed to uneven surfaces in public places such health care facilities, shopping malls, and other environments they may not be familiar with.

The participants often experienced feelings of being a burden to others as they needed assistance that ranged from moderate to maximum in order to participate in meaningful occupations. The altered level of independence could lead to role loss in occupations they consider to be meaningful as they have to rely on others in order for them to actively participate. The possible role loss has a negative impact on the stroke survivors' self-esteem and mood which could lead to experiencing feelings of depression. A study conducted in Western Cape relates to the findings of this study as it was discovered that gaining independence could improve the stroke survivors' confidence in actively participating in the community and reduce the risk of depression[26].

Financial barriers

Most of the participants were dependent on R1780 received from the government's pension and disability grants as a source of income in the year 2020. However, the funds were not adequate to meet all their day-to-day needs. Most of the participants spent a portion of their grant money towards hiring a private car to take them to and from the hospital as well as church. The money spent on hiring a private car ranged from R250-R450 depending on how far the participants live from the hospital or church. This resulted in few participants missing their monthly appointments at the occupational therapy department stroke clinic. Participants in a study by Mudzi et al.[11] experienced similar financial challenges whereby they had to spend more money on taxi fare. They had to pay for themselves, the wheelchair and the person helping them to get in a taxi.

The findings of the current study highlighted an important factor whereby the stroke survivors had to compromise their health needs to provide for their family's basic needs such as buying groceries. Such a compromise put them at a significant risk of experiencing secondary complications such a contractures and possible readmission to hospital. Similarly, to the participants in study by Mudzi et al.[11], they had to prioritize other needs over spending more money on transport, which compromised their compliance with attending outpatient rehabilitation due to financial constraints.

Environmental barriers

The lack of access to water supply systems, poor toilet and bath facilities and access to public transport were identified as the main barriers in this study. All these factors contributed to the stroke survivors' restricted participation in meaningful occupations such as bathing, toileting, home management, health management and social participation. Findings of previous studies concur that having easy access to resources such as water, electricity and proper sanitation made it easy for participants to be independent in occupations such as BADLs living and IADLs such washing, cleaning, toilet hygiene, cooking and doing laundry[4,18].

There is limited research conducted regarding stroke survivors' ability to participate in the activity of bathing using a plastic bowl, particularly in a semi-rural or rural area. The act of bathing from a bowl is different to that of bathing in a bathtub or a shower as it requires a lot of preparation and physical effort when compared to bathing in a bathtub This method of bathing using a plastic bowl is distinctive in non-urban communities as the participants must warm bathing water by boiling it in a kettle and pouring it into a bucket. They then still have to carry the warm water to the bedroom where they transfer it into the plastic bowl, they will be using to wash themselves. The participants raised a concern of the plastic bowl not being stable and safe for them to transfer into and stand in. This is mainly due to the fact that the bowl has to be placed on a chair or on the bed when bathing the upper body to allow the stroke survivors to stand on the floor in an upright position. Subsequently, the bowl must be lifted and positioned on the floor to allow them to bath the lower body. Therefore, stroke survivors will have to get inside the bowl to wash the lower body. This could possibly pose a challenge to the stroke survivor due restricted active movement in the affected side Furthermore; the plastic bowl could easily tip over when it is being transferred from the chair/bed to the floor, or when the stroke survivors climb in it. These actions could cause the water to spill on the floor and result in the participants slipping on the water and suffering fall injuries leading to multiple re-admissions to hospital.

Additionally, the participants of the current study made use of an outside pit toilet that was located far from their houses and required them to walk a distance. Moreover, even if they did reach the toilet on time, there was not enough space inside the toilet to accommodate both the participant on a wheelchair and their caregiver. This challenge contributed to the participants' decreased independence in toileting and toilet hygiene with the added expense of using adult diapers for some.

The stroke survivors also identified having challenges with accessing and using public transport as an environmental barrier. The stroke survivors had to walk a distance to access taxis which are only available at the main road due to the poor or lack of tar road infrastructure near their houses. Subsequent to the challenge of accessing transport, the stroke survivors often had to make use of two or more taxis for the purpose of accessing the nearest health care facilities, church or shopping malls which is time consuming and adds further discomfort to the participants as they have transfer more than once into the taxi and maintain a sitting position for longer. This is because unlike private transport, taxis do not use direct routes to reach the desired destinations. As cited in Jellema et al.[20] that living in a rural area presented greater barriers to participation in meaningful occupations due to challenges such as uneven terrain, long distances and poor geographical coverage of public transport thus, supporting the findings of this current study.

Limitations of the study

The study only focused on the experiences of a small sample of older adults with ages ranging from 42 to 77 years. Younger stroke survivors did not participate in the study and thus the existing literature requires further research which will include a wider age range and a larger sample size. Another limitation was that the type of stroke the participants suffered was not classified in their medical history as the hospital did not have resources to identify this, at the time of the study.

Recommendations

A more extensive and larger study is recommended for the purpose of developing a practice framework that will be relevant to the South African context in a community setting. The framework will assist in guiding the assessment and treatment processes, as they will be relevant and specific to the South African context within a community setting. Furthermore, a case study method on this specific topic can be considered for close observation of stroke survivors throughout the process of rehabilitation. This will provide a more in-depth insight into the experiences of stroke survivors when participating in meaningful occupations in the community.

The researcher recommends that occupational therapists should assist stroke survivors identify the factors that they perceive as barriers to their participation within their home and community contexts. This should take place during the initial assessment process, so that intervention may address specific factors in order to enhance participation in occupations the stroke survivors perceive as meaningful.

Moreover, the clinicians could advocate for better resources that will facilitate higher levels of participation in meaningful occupations among communities. They may do this by influencing local municipalities (Ward councillors), policy makers and local taxi associations to consider building and maintaining roads that will enable taxis to be available at various places within the stroke survivors' communities and not only at the main road. In addition, they should also advocate for user-friendly taxi minibuses with easily accessible entrances and adequate space to accommodate wheelchairs. Lastly, the researcher recommends for the clinicians to advocate for community-based projects that will afford the stroke survivors opportunities to generate income, as the financial support they receive from grants, is not adequate sustain them.

CONCLUSION

The findings of this study highlighted a significant difference between the barriers experienced by stroke survivors residing in the rural/semi-rural and urban community contexts. These barriers contributed to the stroke survivors experiencing greater discontinuity and or challenges concerning participating in meaningful occupations than has been reported for urban areas. Thus, a screening tool that is relevant to the South African community context is needed for the purpose of making occupational therapy more meaningful to the lives of the stroke survivors residing in the rural and semi-rural communities.

Author contributions

Refilwe Mohotlhoane was involved in designing the study, data collection, formal analysis, writing of the original draft and wrote the manuscript. Refilwe Mohotlhoane and Mashudu Norman Nemakanga reviewed and revised the manuscript. Both authors read and approved the final manuscript. The study was conducted by the first author for higher degree purposes, supervised by the second author.

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Conflicts of interest

The authors have no conflicts of interest to declare.

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RESEARCH ARTICLE

Occupational therapy rehabilitation managers' perspectives on community integration of persons with spinal cord injuries in Nairobi, Kenya

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ABSTRACT

Introduction: Spinal cord injuries (SCI) present complex clinical challenges requiring comprehensive rehabilitation management to facilitate adequate community reintegration. Rehabilitation managers are suitably positioned to enforce and enact policy related to holistic rehabilitation intervention, including preparing patients for community integration. However, due to discrepancies within the chain of care systems, they are unable to ensure individuals with SCI in Kenya are discharged to their respective communities fully prepared for effective community integration. Exploring their perspectives may therefore highlight potential barriers or enablers to ensuring more effective community integration for survivors of SCIs.

Methods: A qualitative, descriptive study was conducted via individual interviews with 12 purposively sampled rehabilitation managers. Data were audio-recorded and transcribed and underwent content analysis.

Findings: The study findings revealed inadequacies in the process of spearheading and facilitating community integration of individuals that sustained a spinal cord injury. On the other hand, the study suggested possible strategies to reinforce community integration for individuals with spinal cord injuries by involving all stakeholders in decision making, addressing training gaps, facilitating research programmes and equipping rehabilitation centres with specialised spinal cord units.

Conclusions: Implementing disability policies to minimise barriers to community integration and access to essential services is required. This includes developing clear guidelines on comprehensively managing individuals with spinal cord injuries in the community within the Kenyan context.

Implications for practice

- Occupational therapy managers have a role to play in the facilitation of empowerment strategies aimed at influencing community (re) integration of survivors of SCIs.
- There is the need for the enactment of an effective rehabilitation framework to enforce the role of occupational therapists as a key role player in facilitating community (re) integration.
- Goodwill is required from the governmental political systems and organisations to spearhead the enforcement of the existing disability legislation if the welfare of survivors of SCIs are to be achieved.

INTRODUCTION

Spinal cord injuries (SCI) present complex clinical challenges, requiring comprehensive rehabilitation and adequate support to allow community reintegration[1,2]. In Sub-Saharan Africa (SSA), persons with SCI who survive their initial injury face difficulty and irreversible challenges accompanied by preventable complications and may finally die in the community due to low quality of care, unfriendly environments and lack of opportunities to participate in community activities[3].

Interestingly, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) articulates how survivors of SCI should be perceived in the global community through the lens of human rights and developmental levels[3]. In fact, among other concepts emphasised by the UNCRPD is community integration, an element strongly advocated for, to benefit survivors of SCIs[3,4]. Following discharge to the community, successful community integration is indirectly influenced by the hospital policies that support the preparation of these individuals for community integration by healthcare professionals training and interventional mechanisms within the hospital setting[5,6]. On the other hand, the macrosystem, which consists of the broader environmental systems surrounding these individuals like the political system and their policies, cultural and existing environment beliefs, will either facilitate or hinder the prospects of these individuals' involvement in community activities. These challenges may occur over a period of time, affecting the transition from a healthy individual to surviving an SCI disability throughout the rest of their life. This considers that the interaction with their respective environments will also be changing[6,7]. In this manner, the success of survivors of SCI community integration depends on several factors: the individual with SCI and society's readiness and willingness to accommodate and accept these individuals through available and implementable mechanisms[3].

Globally, countries have been utilising domestic laws in matters related to disabilities which facilitated inconsistencies in how persons with disabilities are viewed[8]. The UNCRPD changed this type of discourse internationally by emphasising that state parties should facilitate the acceptance of persons with disabilities, including those with SCI, and provide an enabling environment for their full and effective participation in the community like any other member of the society. The enabling environment also includes access to all essential services[3,9].

However, Kovacs and Gordon[10] argue that access to essential services will not be achieved if community perceptions and practices towards persons with disabilities are not influenced by proper legislation and related policies geared towards facilitating this accessibility. These discrepancies can be noted in the Canadian Human Rights Act, which covers issues of comprehensive accessibility for all persons and not specifically to persons with disabilities. It is instead left to every province to implement disability policies[10]. In contrast, in Australia, unlike in Canada, one of the successes of disability policy is due to both national and local governments working concurrently on the issue of persons with disabilities[11]. The European Union (EU) likewise ratified the UNCRPD by encouraging the member states to acknowledge the environment as a contributing factor in allowing persons with disabilities, including those with SCI, to be fully involved in activities in their community[4]. Nakagawa and Blanck[12] found that although UNCRPD ratified Japan's anti-discriminatory law, their laws mostly borrow from ideas in the medical model, which does not comprehensively address the environmental contribution as far as a person with disabilities community integration is concerned.

The implementation of disability legislation is also dependent on government political systems and organisation, which further determine the effectiveness of the response towards the welfare of persons with disabilities. For instance, the United Kingdom (UK)allows the implementation of one national health system. In contrast, Canada, Australia, and USA are governed through a federal system; therefore, implementation of policies and programmes intended for persons with disabilities can be fragmented because of a long chain of bureaucracies[11]. As a result of such discrepancies, Friedner & Osborne[13] reason that disability experts should steer the implementation of disability legislation. For instance, the Indian Disability Act is specific on enforceable guidelines in matters relating to accessibility. The law mentions that the physical environment should be accessible, but it does not indicate any consequences for those violating such laws[14]. However, the Americans with Disabilities Act (ADA) specifically addresses the needs of persons with a disability with enforceable regulations, and any complaints are dealt with accordingly[11].

As noted by Van Rooy et al.[15], Namibia has made good progress in accepting persons with disability in the community. This occurred as a result, among other measures, of a Policy on Orthopaedic Technical Services, which was established to facilitate community mobility, including a community-based rehabilitation (CBR) programme. However, this Policy could have been more effective if the Namibian government had also developed a policy about the role of occupational therapy services as a key role player in facilitating community integration. Schneider et al.[16] concur that for such policies to succeed, all the needs of persons with disabilities should be addressed and specified.

A country's health care system can be measured, among others, by the quality of life of persons with SCI in the community. This may be translated to health policies that guide researchers and healthcare professionals on interventional measures [3]. Reliable data on SCI is therefore crucial in formulating measures to monitor injury occurrences and continuous follow-up programmes starting from initial admission to post-injury community integration[3,17,18]. However, few countries across the globe have well-established SCI registry systems, a tool important in any country to monitor, formulate mechanisms and manage its population of persons with SCI. Canada is an excellent example of countries with an SCI registry via the Rick Hansen SCI Registry (RHSCIR)[17]. Like RHSCIR, the American SCI model database, the Australian SCI registry and the European Spinal Injury Federation provide their respective countries statistical evidence related to SCI[17,18,19].

These SCI registries act as evidence to facilitate the development of long-term care of survivors of SCIs[20]. For instance, RHSCIR, established in 2004 in Canada, aimed at capturing records of survivors of SCIs from as early as admission, during the rehabilitation process, and up to ten years in the community. Though this model had a share of challenges, its benefits had been immense in obtaining internationally acceptable data and facilitating the development of evidence-based practices[18,20]. Such information has been of significant value in highlighting the epidemiology of survivors of SCI in these countries and predicting their quality of life while in the community [21,22.] Unfortunately, developing countries in Africa and Asia do not have such a registry[23]. As noted by Leshota[24] and Musubire et al.[25] the lack of accurate SCI statistics in African countries affects policy implementation, particularly in facilitating community integration processes for persons with disabilities.

The most appropriate policies that consider challenges faced by persons with disabilities should address the social needs of these individuals. This is not to say there are no medical challenges but that social factors contribute primarily to community integration and participation[26]. Germany is a good example of a country that has achieved this with an advanced model of care for survivors of SCI. The country has 15 well equipped SCI Units, an established uniform SCI care guideline, a research centre at The German Medical Society of Paraplegia (DMGP) and implements strategies to reduce complications as a result of SCI and community participation post SCI[27]. The Ministry of Health and Social Welfare in Lesotho, through its National Disability and Rehabilitation Policy 2011, is another country that caters for both the medical and social needs of persons with disabilities; as a result, it provides comprehensive care[24]. In South Africa, however, where the government has established the National Rehabilitation Policy, based on the UNCRPD standard rules of maximum acknowledgement of the human rights of persons with disabilities, Mji et al.[28] argue little attention has been given to avail enough resources for their full implementation and for the policy to benefit concerned parties in the community. This includes ensuring full accessibility and that persons with disabilities live comfortably and independently in the community free from physical barriers, access to rehabilitation, and provide health services. Therefore, it is not surprising that more recently, the United Nations appealed for a commitment from governments to the UNCRPD Articles by reappraising policy implementation and practice of institutions and professionals working with persons with disabilities[26].

In Kenya, the 2010 constitution recognised the rights of persons with disabilities under Article 54. This followed the Persons with Disabilities Act, 2003, earlier ratified through the UNCRPD, in which Kenya was a signatory[29]. Among the Acts established due to Article 54 was the Employment Act, which prohibited discrimination against persons with disabilities in the labour sector and the National Disability Policy that seeks to develop comprehensive community integration of persons with disabilities, including those with SCI[29]. In the same spirit, The National Council for Persons with Disabilities was established to work collaboratively with relevant bodies to support persons with disabilities in advocacy, information provision, and community integration[29].

The Kenya Health Policy 2014-2030 indicates that every citizen has the right to healthcare, social services and participation regardless of their disability. Still, there are challenges in the implementation[30]; for instance, there is a lack of specialised SCI hospital care and clear clinical guidelines for the treatment of SCI and inadequate resources allocated to coordinate follow-up of survivors of SCI to the community. In addition, the country faces other challenges, among them the scarcity of trained occupational therapists to facilitate these programmes[31,32]. Like other developing countries, Kenya does not have an SCI registry. There is no standard guideline to promote community integration of survivors of SCI. Institutional care for survivors of SCI is a challenge because, in a country of over 40 million people, only the National Spinal Injury Referral Hospital in Nairobi provides specialised services[33]. Also, current practice places sole responsibility for change upon the individual and pays little attention to the barriers that hinder their full integration into the community. Occupational therapy managers need to oversee their clients' human and occupational rights with SCI, which could be better achieved if available policies were utilised to advocate for and facilitate community integration for persons with SCI[34,35,36]. However, occupational therapists who are supposed to work within a team to initiate community integration programmes, are under-resourced. These therapists also rely on Western developed clinical guidelines in their interventions that do not necessarily address their clients' contextual needs [34,35, 36].

This study sought to explore the rehabilitation managers' perceived experience of community integration for persons with SCIs. Rehabilitation managers are suitably positioned to enforce and enact policy related to holistic rehabilitation intervention, including preparing patients for community integration. Their perspectives may highlight potential barriers or enablers to ensuring more effective community integration for survivors of SCIs.

METHOD

Setting

The study was conducted in Nairobi, Kenya.

Study design

This was a qualitative, descriptive phenomenological study[37] that explored the experiences and perceptions of rehabilitation managers in Kenya via individual interviews. Rehabilitation managers were generally occupational therapists who oversee rehabilitation programmes for survivors of SCI at various levels. Phenomenology as a qualitative methodology allowed the participants to share their experiences with SCI and their concerns on service delivery and supported the capture of rich information[37].

Study population and sampling strategy

There were 48 rehabilitation managers in Nairobi, of which 12 managers, who qualified in occupational therapy, had worked for more than two years in their respective positions and were overseers of rehabilitation services, including rehabilitation of persons who sustained SCIs, were purposively sampled. Most managers held undergraduate degrees (n=9), and the remaining held diplomas (n=3). The interviews were conducted using an interview schedule[37].

Data collection

Each interview session lasted approximately 90 minutes in a neutral place to ensure confidentiality[37]. The interviewer was careful to distinguish between the role of being a practitioner and researcher to avoid being influenced by his position, as this might have risked losing important data[37]. An interview guide was used during each interview, audio-recorded, and notes were taken to capture the respondents' experiences, including non-verbal expressions[34]. The interviewer ceased

Table I. Participants' profile (n=12)

Participant	Qualification (OT)	Facility	Experience (years)
RM1	Masters	Referral hospital	20
RM2	Degree	County level	15
RM3	Degree	Referral hospital	7
RM4	Degree	SCI Specialised hospital	14
RM 5	Degree	County hospital	25
RM6	Degree	Referral hospital	12
RM7	Diploma	Referral hospital	9
RM8	Diploma	Community	8
RM9	Degree	Referral hospital	11
RM10	Diploma	County Coordinator	8
RM11	Degree	County referral hospital	12
RM12	Diploma	Private facility	7

Integrating survivors of SCI into the Community		
The role of occupationall therapy rehabilitation managers in sprearheading community integration of survivors ofSCI	Occupational therapy rehabilitation managers experiences in aftermath of community integration of survivors of SCI	Strategies to facilitate community integration of survivors of SCI

Figure 1 Emergent theme and subthemes

collecting data when data saturation was reached. Prior to the interviews, informed consent was obtained from the participants to record notes and audio-recording of the sessions[37].

Data analysis

Content analysis was performed[37]. The data were transcribed verbatim before analysis was done. The researcher listened to recorded discussions and cross-checked the transcripts. The first author read the transcribed data to gain familiarity with the text. The interview question guide was instrumental in enabling the first author in organising and summarising the data. Ideas and concepts were identified. The QSR NVivo software version 10 was used to organise and analyse the field notes and recordings derived from the individual interviews[34]. Meaningful units were coded and then these were grouped into categories. Finally, the first author interpreted the findings and connections between categories were established and reduced into themes with assistance of the co-authors. All common themes were coded and categorised in a standard way using the tree node structure to make comparisons for ease of analysis. Summaries in tabular form per thematic area were developed. Verbatim quotes were used to support critical issues and messages[37].

Ethical considerations

The study's ethical approval was obtained from the University of KwaZulu Natal Biomedical Research Ethics Committee (BREC Ref no: BE070/18) and The Kenyatta National Hospital, University of Nairobi Ethics Research Committee. All relevant principles of ethics were upheld during the study[37], including the use of pseudonyms to protect the privacy of all participants, ensuring the accuracy of information by safeguarding the rigour and trustworthiness of the study through bracketing, peer debriefing and use of thick descriptions.

FINDINGS

Those who participated in these individual interviews were rehabilitation managers overseeing rehabilitation programmes for persons living with SCI at various levels. They both had wide experience ranging from 7-25 years in rehabilitation management and academic qualification in occupational therapy. Their qualifications ranged from a diploma in occupational therapy to a master of science in occupational therapy (Table I above).

The findings revealed three emergent subthemes and one central theme around rehabilitation managers' perceived experience of community integration for survivors of SCI (Figure 1 above).

The central theme described the rehabilitation managers' experiences in overseeing rehabilitation programmes for survivors of SCI at various levels. The managers highlighted their overall experience of facilitating the integration of survivors of SCI in the community as inadequate.

> "...this where we fail in offering comprehensive care to our clients probably the reason why we don't do follow-up to the community" **(RM11).**

> "My major role is to ensure sufficient rehabilitation of all clients including those with SCI because we don't have specific specialised hospital for SCI. Where possible we work with other stakeholders for community integration" **(RM3)**.

Subtheme 1. The role of occupational therapy rehabilitation managers in spearheading community integration of survivors of SCI

The managers reported that the majority are aware of their role in facilitating empowerment strategies that will positively influence community integration of survivors of SCIs. They reported that they are also involved in direct service delivery in hospitals and other rehabilitation facilities, offering rehabilitation to survivors of SCI through rehabilitation equipment, assistive aids and to some extent, alternatives where assistive aids are lacking. The therapy activities include ADLs such as self-care, transfers, bladder and bowel control, environmental adjustment and adaptation to enhance independence. It also includes facilitating emotional and psychological adjustment and management of sexuality.

> "As a supervisor, I also have to work to serve as a good example. I do supervise orthopaedics wards; this is where we have among the cases attended to our clients with SCI. My major role is to ensure my colleagues have enough treatment aids, the patients' needs are addressed and to work collaboratively with the rehabilitation team and family members to prepare the clients for possible discharge to the community. Sincere we don't have specialised SCI unit, when there is need for long term care, I facilitate referrals to National Spinal Cord Injury Hospital" **(RM1)**.

The managers added that they are also involved in planning, supervision, and monitoring rehabilitation services in hospitals and the community. This includes using the SOAP (subjective, objective, planning) approach and advocating for the role of occupational therapy in the management of SCIs in the community to enhance the participation of survivors of SCIs. The managers further reported that their role includes advocating for more fiscal allocations for the training of occupational therapists in the rehabilitation of survivors of SCI and ensuring budgets for rehabilitation equipment such as wheelchairs, commodes, and assistive aids.

Other managers like RM3 affirmed that I coordinate OT activities in the hospitals and community centres for people with SCIs. In contrast, others noted that for both inpatients and outpatients, they involve other rehabilitation managers, caregivers and stakeholders in the rehabilitation process of SCI. RM5 indicated that they work closely with partners, including family members, non-governmental organisations, religious organisations, and local administrative agencies, particularly for community integration and home-based care to facilitate the participation of survivors of SCI after discharge from hospital to the community.

> "...(we) visit the home to assess the environment for adaptation and organise transport for the discharged patient and the staff accompanying the patient" **(RM7).**
>
> The managers reported that they ensure appropriate referrals for specialised care and advocate for policy formulation and implementation regarding the management of SCI.
>
> "(We) advocate for SCI specialised hospitals in Kenya, currently we have only one to train not only OTs(but) enough (other) health care workers" **(RM9)**.

Subtheme 2. Occupational therapy rehabilitation managers' experiences in the aftermath of community integration of survivors of SCI

All managers confirmed having had experiences related to unsuccessful community integration of survivors of SCI. Among them were discrepancies observed was the preparation process for survivors of SCI to return to the community. A manager, RM11 lamented that a lack of clear guidelines on managing SCI contributes to increased complications and low community participation. Consequently, people with SCIs are discharged to the community without proper preparation, thus inhibiting their return to work. The managers noted that interventional procedures for community integration are crucial to guide occupational therapists on training survivors of SCIs to access services in the community with minimal difficulty. These include, for example, online shopping or partnering with chain supermarket owners and transport services to serve their unique needs and advocate for those who may be working from home since patients find it difficult to adjust to their working environment, which remains inaccessible if is not adapted to suit their disability. Occupational therapists are, however, unable to adequately attend to most patients at the community level.

It was revealed by a manager, RM8 that financial constraints hinder follow-up to the community. The majority of managers cited the lack of specialised SCI units resulting in inadequate support to address the needs of survivors of SCI comprehensively, lack of proper equipment and infrastructure, and training for occupational therapists as reasons why reasonable interventional procedures are never realised.

> "Imagine one specialised SCI hospital to serve 47 counties and 40 million plus population, that's the greatest barrier. Am not sure even our specialised facility has enough trained OTs, financial resource is also another barrier, because without money you can't train, have proper treatment equipment, you will be less motivated consequently these individuals will be poorly discharged to the community where they will be dependent" **(RM10).**

Both poor interprofessional collaboration between local governments and hospitals and negative societal attitudes towards survivors of SCIs also negatively influence how people with SCI participate in community occupations. It was cited by the manager, RM9 that lack of interprofessional collaboration, coordination and teamwork was the main reason patients were being discharged before other team members could offer their services.

> "The society's attitude, and when I talk of society, I also include OTs we are part of the society, we are not well informed to address the needs of these individuals" **(RM5)**.

Spinal cord injuries are accidental, costly and require long term financial muscle to manage all accompanying challenges, with most medical insurance companies reluctant to compensate for related costs. Therefore, without such cover, the rehabilitation process is frequently disrupted.

> "NHIF (national health insurance fund) does not cover OT services particularly for individual member contributors" **(RM9).**

To care for survivors of SCIs, rehabilitation personnel must possess broad skills and competencies in SCI intervention and evidence-based practice for relevant and appropriate management; however, managers reported inadequate skills training in SCIs and limited exposure.

> "In the hospital, nobody has been trained on SCI rehabilitation, it's individuals' effort, you go for online classes, libraries, you Google because our training institutions, medical training colleges and universities there is no speciality not even for our doctors so when anyone who comes is shocked to realise you are not trained for this and also don't know what you are facing" **(RM7).**

This study found that inadequate formulation and implementation of policies and legislation on management and community care for survivors of SCIs have contributed to the lack of proper and special transport and mobility facilities, thus posing a significant challenge to participating in sports activities leisure. It was reported that it was challenging to realise the required adaptation of homes, work and recreational facilities.

> "…most buildings lack ramps in our hospitals being a typical example. Lack of proper and special transport and mobility is a very big challenge for these people. There is also lack of proper adaptation of their homes (houses, toilets) work and recreational facilities. Most of them are not modified to suit those with SCIs. Their participation in activities such as sports and athletics is not fully exploited" **(RM1)**.

Subtheme 3: Strategies to facilitate community integration of people with SCI

Through their experience, the managers suggested the perceived ways of improving the experience of living with SCIs both in care facilities and the community. They indicated the need to develop proper guidelines supported by stakeholders to ensure a holistic approach to managing survivors of SCI. It was also recommended that rehabilitation facilities be equipped with modern treatment aids and equipment. In the managers' view occupational therapists should be supported and be ready to learn best practices from other countries that have successfully implemented programmes for the rehabilitation and reintegration into the community of people with SCI.

It was suggested that more resources be allocated to the management of SCIs and the county health administrative boards, and the community be involved in making such decisions. These include training, conducting research to identify gaps in interventions, equipping rehabilitation centres, and establishing specialised units/facilities and programmes for survivors of SCI to prepare them for optimal reintegration into the community.

> "To reinforce community participation, it should involve the strengthening of partnerships with stakeholders, government, employers, NGO'S, religious organisations, school's/learning institutions and the general community in addressing the needs of people with SCI" **(RM5).**

The managers also suggested the need to revise the college syllabus to include specialised programmes on SCI to equip health professionals on intervention skills, SCI management, rehabilitation and community integration in addition to programmes meant to educate the community on SCI for attitude transformation and sensitisation of the rights of survivors of SCIs.

> "…this can be done through movements such as scouts, girl guides, presentational award schemes and total involvement voluntary care of SCI and other PWDs while in the hospital and at home" **(RM9).**

DISCUSSION

This study aimed to describe the perception of experiences of rehabilitation managers on factors that influence community integration of survivors of SCIs. The findings confirmed that obstacles faced are related to the discrepancies during the preparation of these individuals for return to the community. A lack of clear guidelines for the management of SCIs contributes to increased complications and poor community participation. This influences occupational therapists' interventional processes, which may fail to rehabilitate these individuals for community reintegration effectively. While Harvey[38] concurred that the absence of clear guidance compromises the rehabilitation process in SCI, Fehlings and colleagues[39] and Wong et al.[40] observed that clinical practice guidelines could promote standardised care and improve a gradual return to community participation. Baradaran-Seyed and colleagues[41] and Samuelsson and Wressle[42] indicate that the lack of clinical practice guideline development to ensure the quality of SCI rehabilitation process in Kenya, can be attributed to a lack of individual responsibility and commitment facilitated by a lack of supervision and guidance. This is additionally compounded by the lack of specialised units for SCI at health facilities.

New et al.[43] established that patients with SCI who were not under the care for SCI specialised units had worse outcomes. Thus, the lack of specialised units for SCI also contributed to the absence of organisational support, which resulted in inefficient efforts to address the needs of survivors of SCIs. Other contributing factors included deficient equipment and infrastructure, no specialisation training in SCI for occupational therapists, and scarcity of resources to follow-up on patients and coordinate various activities. Consequently, people with SCI were poorly prepared before being discharged to the community and follow-ups to facilitate community integration were also compromised. Guilcher et al.[44] and Goodridge et. al.[45] similarly observed the role of the macro health system and environmental networks' in influencing the care of survivors of SCI. Therefore, the healthcare system should consider these factors in determining potential solutions that meet the rehabilitation needs of survivors of SCIs. These solutions should include strong stakeholder involvement in the hospital and the community. This is important because rehabilitation is intended to prepare survivors of SCI for community participation even though, according to Van Loo et. al.[46], rehabilitation does not typically realise this intended goal. Specific barriers related specifically to a lack of specialised skills training also mean the call for occupational therapists' training and education to handle the needs of people with SCI becomes paramount [32,47,48].

On the other hand, societal attitudes such as viewing people with SCIs as incapable of participating in or contributing to society can negatively influence how survivors of SCI participate in community occupations. Such attitudes may result from a lack of interprofessional collaboration, coordination, and teamwork, leading to patients discharge before occupational therapists can offer their services. These findings align with those of Ünver et al.[49] and Falk et al.[50], who acknowledge that working together prevents isolated and fragmented approaches to patient intervention, develops positive attitudes and facilitates knowledge sharing to improve care skills. This was supported by Kraft et al.[51], who also emphasised the importance of leadership and organisational structures for stimulating communication and promoting collaboration between team members. In contrast, Higgins et al.[52] have stated that it is challenging to achieve sufficient depth of understanding of the complexity of collaborative practice. They recommended that managers encourage collaboration within their area of jurisdiction.

This study also established that weak policies and implementation initiatives hamper the facilitation of community integration. As a result, several recommendations were suggested. Occupational therapy rehabilitation managers should develop proper guidelines supported by other rehabilitation teams to ensure a holistic approach to managing SCI survivors. This should include stakeholder involvement towards enhancing interventional skills within occupational therapy practice and implementing rehabilitation (in line with policy) to ensure community participation without hindrances.

Rehabilitation facilities should be equipped with modern treatment aids and equipment with rehabilitation managers to make field visits on the ground. Similarly, Guy et al.[53] and Moreno et al.[54] acknowledge that a lack of standardised guidelines impedes SCI rehabilitation. In contrast, Guilcher et al.[44] indicated that overall failure of policies inhibits a holistic approach to the care of survivors of SCI. Therefore, the solution is to tailor health system structures and review rigid policies.

The study suggested allocating more resources for management in SCIs and involvement of all the stakeholders in decision-making to address the training gaps, facilitate research programmes, and equip rehabilitation centres with specialised SCI units. These efforts include implementing the Disability Act and ensuring, among other aspects, medical comprehensive insurance cover for survivors of SCIs by partnering with insurance companies to cover the interventional relevant costs[45]. Locatelli et al.[55] noted that facility leadership support is required for appropriate resource allocation in line with these findings. At the same time, Kruger et al.[56] and Ziesmann et al.[57] emphasised creating a multidisciplinary curriculum through established healthcare institutions policies towards educating medical professionals on managing individuals with SCI.

CONCLUSION

This study has confirmed inadequacies in community integration of survivors of SCI due to discrepancies within the care system, including the rehabilitation centres, and a lack of clear guidelines and goodwill from the community. However, the study made suggestions on facilitating an enabling environment for community participation, including reinforcement of community participation for SCI survivors. This includes the involvement of all stakeholders in decision-making, addressing training gaps, facilitating research programmes, and equipping rehabilitation centres with specialised SCI units. Additionally, implementing disability policies to minimise barriers to community participation and access to essential services, including comprehensive insurance cover for survivors of SCIs, was recommended. Consequently, developing clear and context-specific guidelines on comprehensively managing people with SCI becomes necessary.

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Declaration of conflicting interests

The authors state that they have no conflict of interest to declare in this study.

Authors' contributions

Evans Obara Obaigwa was the primary researcher in this study, which forms part of a postgraduate degree requirement. Pragashnie Govender and Catharina Jacoba Elizabeth Uys were supervisors of the study and contributed to the conceptualisation of the study and critical review of the paper.

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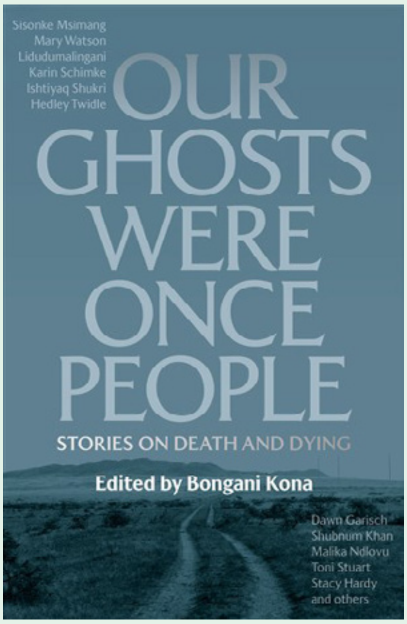
BOOK REVIEW

A review of: OUR GHOSTS WERE ONCE PEOPLE Stories on Death and Dying. Edited by Bongani Kona.



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Editor/Compiler: Bongani Kona is a Zimbabwean born writer and editor. He works in the department of history at the University of the Western Cape and is a member of the curatorial team at the A*rchive of Forgetfulness.* He has written for and been published in Chimurenga, a publication of arts, culture, and politics from and about Africa, The Baffler, a magazine of art and criticism and his work has been broadcasted on the BBC.

Contributing authors all have a connection with Africa and are writers, authors, artists, editors, poets, playwrites, historians, teachers, filmmakers, photographers, journalists, clinical psychologists, and medical doctors. They are: Mary Watson, Karin Schimke, Sindiswa Busuku, Lucienne Bestall, Khadija Patel, Shrikant Peters, Sudirman Adi Makmur, Lidudumalingani, Paula Ihozo Akugizibwe, Stacy Hardy, Rofhiwa Maneta, Madeleine Fullard, Bongani, Kona, Musawenkosi Khanyile, Simon Haysom, Thata Monare, Malika Ndlovu, Angifi Dladla, Nick Mulgrew, Shubnum Khan, Caroline Boulle, Tatamkhulu Afrika, Dela Gwala, Ann Hartford, Dawn Garisch, Hedley Twidle, Toni Stuart, Sisonke Msimang, Gabeba Baderoon, Barry Christianson, Vonani Bila, Khanya Mtshali, and Robert Berold.

The Review

The book is an African anthology on death and dying and is not structured in chapters. Various short forms of writing and photos follow each other as contributing authors share lived experiences: personal, religious, cultural and fictional accounts of death, dying and those left behind. Writing from Cape Town during the COVID-19 pandemic, the editor gives the reason for the book in the Introduction: *This has been a time of unremitting grief. People have lost loved ones, homes, jobs, and suffered all kinds of setbacks, large and small. At a time like this, the promise literature holds out to us is that we are never alone.* Death is the ultimate equaliser. It exposes the fundamental humanness of us all, but the way it is experienced and coped with differs enormously. For me, this was the value of the book: It contextualises this universal inevitability for us as Africans, both within and across our cultural and religious diversities.

The pandemic has heightened the general awareness and experience of death and dying. Healthcare workers have always been more exposed to such than the general population. Less so for occupational therapists than for nurse and doctors, but for anyone working in a hospital setting it is not an unfamiliar reality[1] and there are occupational therapists who work specifically in palliative care[2]. Although there are no specific references to 'occupational therapy' or 'rehabilitation' in the book, there are several mentions of *therapy* in a generic way. Several references are made to nurses and doctors, most of them in a positive tone. With one not so positive mention to healthcare in general*: I think about how you get lost to a healthcare system that only takes care of a financially privileged few* (*A Post box on the Corner of Eternity*, pg. 175).

The book offers armchair access to experiences of loss and hurting which, experiences that, if gained at all, usually only come with many years of life experience and, in the case of healthcare workers, clinical practice. It is good reading for occupational therapist to gain insight into the way loss and grief are dealt with from African-centred phenomenology. Offering insight and opportunity for empathy, to significant life-changing events such as acquiring a disability or having to face the inevitable gradual loss of function and ability.

Khadija Patel (*A Death and Life Experience*, pg. 33 - 37) shares the account of becoming and being a toekamannies (as women who bathe and shroud the dead are known in the Malay communities). A doctor shares his anger and frustration of working in an overcrowded and under-resourced public healthcare facility (*This Nightmare of a Place: A Doctor's Story*, pg. 38 -47). In the *Ferryman* (pg48 - 51), Sudiman Adi Makmur, who works for a firm whose business is to transport those who died in other countries back to their families, shares an insight: *The deceased carry their own baggage: a complex set of morals, values, and relationships; various relations between different individuals and bodies, between disorderly bodies and disciplinary regimes, between communities, governments, and industries* (pg49). Truly thought-provoking is Simone Haysom's piece (Living as Ghosts Do, pg. 101- 109) on heroin addiction in South Africa. She accuses all South Africans for not paying enough attention to the problem: *What you measure matters, and when people don't matter, they aren't measured* (pg 101). She tells how street drugs such as *unga, whoonga, sugar or nyaope* are powered by heroin and used by *people tapping out of the world in … the politest way they know how* (pg102) because there is no political will or plan to address the heroin issue in southern Africa and because our rehabilitation centres are scarce, under-resourced facilities with *revolving doors*. Families, - who can often least afford to – are therefore left with the burden of care. An author with the talent and skill to express himself, tells of suicide attempts, dissociation, and catatonia (*Story of a Name*, pg.146 - 152) making what occupational therapists often medicalise, distressingly more personal. As are accounts of various forms of loss. The relentless losing of a grandmother to Alzheimer's and old age (*Record Keeping*, pg.159- 170). Losing a father (Ancestral Wealth, pg. 226 - 243):

If you were alive today, madala –
I'd buy you a suit and soft ostrich-skin shoes
I'd fly you to Durban or Cape Town
So you can walk on the beach

A father who had worked as a porter and cleaner at Elim hospital (Limpopo) all his life and then when his time came, chose to die at home, because from his many years of working in a hospital, *he knows hospitals are restless places in which to die* (pg 237)

These are just a few of the stories that would be of interest to occupational therapists who are in the business of working with hurting and broken people. Some accounts make for grim reading (pg. 61 - 65) and others are heart-wrenchingly personal (pg. 209 - 210). All of them reflect authentic African knowledge and understanding of death and its associated realities. It is recommended reading for all occupational therapists. Especially those working in palliative care, geriatrics, public healthcare and/or in acute rehabilitation settings

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2. Treggalles K, Lowrie D. An exploration of the lived experience of professional grief among occupational therapists working in palliative care settings. Aust Occup Ther J 2018; 65: 329–337. https://doi.org/10.1111/1440-1630.12477

A review of: The Unicorn Baby. Debunking 10 Myths of Modern Parenting. Written by Roxanne Atkinson

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AUTHOR: Roxanne Atkinson

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Roxanne Atkinson is a Cape Town based occupational therapist. She holds an Honours degree in Occupational Therapy from the University of Cape Town. She has a special interest in paediatrics and neuro-developmental therapy and completed her Bobath training. Graduating in 2006, Roxanne has worked at Milner Road Private Practice, Vista Nova School for children with Cerebral Palsy; Red Cross War Memorial Children's Hospital and Victoria Hospital Wynberg. When she decided to have her own babies, she started her private practice. Her focus has been on early identification, educating and empowering caregivers and giving evidence-based intervention when necessary. Roxanne works mostly with children aged 0-7 years old who have developmental delays or trouble learning age-appropriate skills, and their families. Roxanne is the proud mom of two – and she calls them her non-unicorn babies.

The Review

The author starts this delightful book as follows:

"If you have read a few baby books or searched the Internet for parenting tips, you have most likely stumbled across the mythical Unicorn Baby. This baby is said to pee pure gold and poop rainbows. While most parents have heard about the Unicorn Baby, few have ever seen one.

The Unicorn Baby is elusive, so it may be easier to spot the parents of the Unicorn Baby. These parents will be looking good and claiming to feel great. This is largely because the Unicorn Baby has not changed their lives. Their Unicorn Baby has fitted seamlessly into the ideal routine as prescribed by an accredited, opinionated person. Their babies have breastfed with ease every four hours and, of course, slept through the night since they were six weeks old. Their Unicorn Baby grows and develops above the 50th percentile, leaving very little for their parents to work on or worry about.

These parents attribute their baby's success to their superior parenting practices, as well as the stimulation classes that are sure to turn their Unicorn Baby into an even more super baby. This will be the baby who not only hits their developmental milestones on time but smashes them out of the park. They will go on to speak four languages thanks to a fabulous foreign language app.

Whether this baby exists or not does not really matter. What does matter is this: apparently, you did not get this baby. And that is probably why you are reading this book."

She then continuous to unpack the following 10 myths, that young parents and professionals working with young babies in early intervention have all heard:

Myth 1: Babies are all the same **Reality 1: Every baby is unique**
You have busted Myth 1 when you recognise that you baby is unique. That there is no perfect baby, just as there is no perfect parent. You recognise both the wins and the challenges your baby faces.

Myth 2: A baby does not have to change your life **Reality 2: Your**

baby will change your life

You have busted Myth 2 when you have devised a new normal survival plan. You have made space for your new family to form by pausing as many commitments as you can.

Myth 3: You need to get your baby into the perfect routine **Reality 3: There is no such thing as a perfect routine.**

You have busted Myth 3 when your baby likes you – they fall asleep on your body and calm down at the sound of your voice.

Myth 4: Breastfeeding comes naturally **Reality 4: Breastfeeding is hard work and may be very different from what you expected.**

You have busted Myth 4 when you see breastfeeding as a new skill and know it will take time to learn how to do it. You may not be able to breastfeed. And that's okay.

Myth 5: You should only feed your baby every four hours **Reality 5: You should practice responsive, not scheduled, feeding.**

You have busted Myth 5 when your baby is an active participant in feeding. You let them explore foods and give them feedback when they need it.

Myth 6: You must teach your baby to sleep through the night **Reality 6: There is no magic formula that will make your baby sleep through the night.**

You have busted Myth 6 when your baby likes sleeping (even if you think they should sleep for longer).

Myth 7: Your baby grows and develops everyday **Reality 7: Your baby will grow and develop in spurts.**

You have busted Myth 7 when you are proud of what your baby can do and are enjoying each stage of the first year, rather than rushing towards one milestone.

Myth 8: Your baby needs specialised stimulation classes and educational toys to thrive **Reality 8: You and your baby are not always going to want to play when it is playtime, and that is normal – your baby will learn from you, from everyday objects and from experiences.**

You have busted Myth 8 when you and your baby are getting one dose of shared joy each day.

Myth 9: Your baby must do tummy time for 20 minutes every day **Reality 9: Your baby needs more than tummy time to develop good postural control**

You have busted Myth 9 when your baby is happy in a variety of positions; firstly, horizontally and later, vertically.

Myth 10: Technology gives you and your baby an advantage **Reality 10: You need to learn to trust yourself rather than technology.**

You have busted Myth 10 when you are spending more time getting to know your baby than researching babies on your phone.

This book is a breath of fresh air in modern times, where parents are inundated by unrealistic expectations for raising children. This easy-to-read book will set to rest the anxiety and uncertainty that these myths create. Roxanne looks at the first year of a baby's life from a realistic point of view, combining it with scientific background explained in an easy-to-read fashion. It offers an in-depth but easily digestible narrative of the most important aspects of development in the first year. Roxanne shares practical ideas and activities that support a baby's development. Her approach is a good combination of occupational therapy and down-to-earth advice which is easy to understand and follow – and fits into the hectic schedule of new parents. Her writing style is light but informative. The book is enhanced by the striking and appropriate illustrations done by Lester Atkinson, who happens to be father to Roxanne's non-unicorn babies.

As an occupational therapist working with babies in early intervention, I found that the book confirms those themes that so often come up with first-time, or even third-time parents, and especially parents who are raising those non-typical babies. The book need not be read in the order of chapters, as each chapter attends to an important aspect of development. Roxanne covers these aspects in exceptional detail, without it becoming overwhelming. As a therapist, I have used her explanations that are simple and practical on more than one occasion. I especially like the following example: *"Viewing development as a ladder where one skill is gained before moving onto another can be a barrier to normal development. In reality, development is more like a bowl of spaghetti. Each skill is intricately wrapped up into another, and it is hard to see where one spaghetti strand starts and where it ends. In other words, every area of development affects every other area of development."* The chapter regarding the eighth myth covers a pet subject of mine i.e., the importance of play and how to play. In the current technological era this is a skill that many new parents actually need to be taught as it does not seem to come naturally.

The book is strongly recommended to occupational therapists who work with expecting parents, new parents and even grandparents, and should evoke interesting discussions amongst them. It is a useful resource for therapists working with young children and especially with non-typical, non-unicorn babies who are often the ones seen in occupational therapy practices.

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