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MANAGEMENT OF UPPER LIMB PAIN IN STROKE SURVIVORS: THE CURRENT PRACTICE OF OCCUPATIONAL THERAPISTS IN SOUTH AFRICA

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A research report submitted to the Faculty of Health Sciences, School of Therapeutic Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Occupational Therapy

Johannesburg, 2024

DECLARATION

I, Jenna Cohen, (student number: 547465) hereby declare that this research report is my own work. It is being submitted for the degree of Master of Science (Occupational Therapy) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.



Date: 15/10/2024

PRESENTATIONS ARISING FROM THIS RESEARCH PROJECT

Conference/ Workshop	Date	Venue	Topic
Support and Development of Generalist Occupational Therapists Delivering Hand Therapy Consensus Development Conference	24/02/2023	CSIR International Convention Centre, Pretoria, South Africa	Preliminary results
Post-Stroke Pain at the Gauteng Stroke Workshop on the Management and the Use of Outcome Measures in Adult Neurorehabilitation	08/05/2024	Liberty, Johannesburg, South Africa	Literature on Post-Stroke Pain in the Upper Limb
Occupational Therapy Association of South Africa (OTASA) Virtual Congress	03/07/2024	Virtual	Completed research study

PUBLICATIONS ARISING FROM THIS RESEARCH PROJECT

The submissible manuscript has been submitted by the researcher to the South African Journal of Occupational Therapy (SAJOT) for review and potential publication.

ABSTRACT

Title: Management of Upper Limb Pain in Stroke Survivors: The Current Practice of Occupational Therapists in South Africa

Introduction: Stroke is a significant health concern in South Africa, leading to adult disability and mortality. Post-stroke pain, especially in the upper limb, disrupts survivors' daily lives. Occupational therapists play a pivotal role in managing this pain, but the literature suggests deficiencies in recognizing and addressing it effectively. This study aimed to describe occupational therapists' practices in managing upper limb pain post-stroke in South Africa.

Methodology: A quantitative descriptive cross-sectional study surveyed occupational therapists who routinely treat stroke survivors. Descriptive statistics and content analyses were used.

Results: One hundred responses were included for analysis. The survey revealed that 96.7% of participants recognised pain as prevalent among stroke patients. Notably, 48.9% always included pain management in interventions, while 43.5% lacked necessary skills and 16.3% reported time constraints. Therapists primarily focused on neuromusculoskeletal aspects of pain, with some considering mental functions, activities, participation, and environmental factors.

Conclusion: The study emphasised the burden of post-stroke upper limb pain in South Africa, urging enhanced occupational therapy interventions. Occupational therapists mainly address body structures and functions associated with pain, indicating the potential to strengthen the focus on activity and participation while considering contextual factors. Incorporating pain management into occupational therapy interventions for stroke survivors across all levels of care is recommended, alongside the development of evidence-based guidelines tailored to occupational therapy.

Keywords: Post-stroke pain, stroke rehabilitation, occupational therapy interventions, pain assessment, pain management techniques, South African healthcare

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PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I JENNA COHEN (Student number: 547465) am a student registered for the degree of MASTER OF SCIENCE IN OCCUPATIONAL THERAPY in the academic year 2024.

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Signature: 

Date: 15/10/2024

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Thank you to the five expert occupational therapists who selflessly took their time to review my survey. Your feedback and suggestions added value to my research. Your passion and commitment to the fields of neurology and pain are inspiring.

The sense of community within the occupational therapy field was truly felt when I requested assistance to share my survey across South Africa. Thank you to OTASA, SANDTA, The OT Link, Angela Chetty, Rogini Pillay, and the SCI Workgroup for advertising and distributing my survey. Your assistance allowed me to receive responses from provinces across South Africa which added value to my research. Thank you to Kirsty van Stormbroek for encouraging me and allowing me to distribute my survey at your conference.

Without my occupational therapy colleagues who kindly completed my survey, this research study would not have been possible. Thank you for trusting me with your credible knowledge that allowed me to achieve the objectives of my study.

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To my dad, brothers, sisters-in-law, nieces, nephews, and friends who to me are family, you encouraged me to enrol for my master's degree with full confidence in my abilities. Your constant love, support, and assistance whenever I needed them are appreciated more than words can describe. Mom, when I graduated with my undergraduate degree, I remember thinking that the degree was as much yours as it was mine; well now you have your master’s too. Your love and support during those years are what

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ACRONYMS

AHA/ASA	American Heart Association / American Stroke Association
AOTA	American Occupational Therapy Association
ARAT	Action Research Arm Test
ASG	Australian Stroke Guidelines
CPSP	Central Post-Stroke Pain
CRediT	Contributor Role Taxonomy
CRPS	Complex Regional Pain Syndrome
CVI	Content Validity Index
DASH	Disabilities of the Arm, Shoulder and Hand
FES	Functional electrical stimulation
GDoH	Gauteng Department of Health
GMI	Graded motor imagery
HPCSA	Health Professions Council of South Africa
IASP	International Association for the Study of Pain
ICF	International Classification of Functioning, Disability and Health
ICH	Intracerebral haemorrhage
ISO	International Organisation for Standardisation
MDT	Multidisciplinary team
MAL	Motor Activity Log
NMES	Neuromuscular electrical stimulation
OTASA	Occupational Therapy Association of South Africa
OTPF–4	The Occupational Therapy Practice Framework: Domain and Process Fourth Edition
REDCap	Research Electronic Data Capture
ROM	Range of motion
SA-CSRG	South African-Contextualised Stroke Rehabilitation Guideline
SAH	Subarachnoid haemorrhage
SAJOT	South African Journal of Occupational Therapy
SANDTA	South African Neurodevelopmental Therapy Association
SHS	Shoulder-Hand Syndrome
TENS	Transcutaneous electrical nerve stimulation

WFOT	World Federation of Occupational Therapists
WHO	World Health Organization

DEFINITIONS

Activity: “The execution of a task or action by an individual[1:12].’’

Activity Limitations: “Difficulties an individual may have in executing activities[1:12].”

Allodynia: Pain that is induced by stimuli of an unusually non-painful nature[2].

Body functions: “The physiological functions of body systems (including psychological functions)[1:12].”

Body structures: “Anatomical parts of the body such as organs, limbs and their components[1:12].”

Central post-stroke pain: ‘'Pain initiated or caused by a primary lesion or dysfunction of the central nervous system and occurs in the absence of other nociceptive, peripheral, and psychogenic pain[3:132].”

Complex regional pain syndrome: More commonly known as shoulder-hand syndrome (SHS) in stroke, is a pattern of symptoms that include chronic neuropathic pain, motor limitations as well as vasomotor, trophic, and sudomotor changes[4,5].

Dysaesthesia: A sudden or induced feeling of abnormal sensation that is unpleasant. Hyperalgesia and allodynia may be present[6].

Environmental factors: “The physical, social and attitudinal environment in which people live and conduct their lives[1:12].”

Hyperalgesia: Pain from a stimulus that typically elicits pain but of a higher intensity than usual[6].

Hyperpathia: Refers to a painful response to mostly repetitive stimuli that are unusual and unexpected[6].

Hypoaesthesia: Reduced sensitivity[6].

Hypoalgesia: Reduced pain in response to a typically painful stimulus[6].

Impairment: “Problems in body function and structure such as significant deviation or loss[1:12].”

Neuropathic pain: ‘’Pain caused by a lesion or disease of the somatosensory nervous system[7:5].”

Nociceptive pain: “Pain that arises from actual or threatened damage to non-neuronal tissue due to activation of nociceptors[8:512].”

Nociplastic pain: “Pain that arises from altered nociception, despite no clear evidence of actual or threatened tissue damage causing the activation of peripheral nociceptors or evidence for disease or lesion of the somatosensory system causing the pain[8:513].”

Occupation: Purposeful and meaningful activities done by individuals, and/or groups of people, that fulfil their time including activities of daily living, instrumental activities of daily living, rest and sleep, education, work, leisure, play, health management, and social participation[9].

Occupational performance: Successfully achieving an occupation through the active interaction between an individual, his environment, and his occupation[10].

Occupational profile: A compilation of an individual’s past work experiences, daily routines, interests, values, needs, and pertinent environmental factors[10].

Occupational therapy: A profession centred around maintaining or improving the health and well-being of people through occupational participation and engagement in a range of environments[11].

Pain: “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage[12:1976].”

Participation: ‘’Involvement in a life situation[1:12].’’

Participation restrictions: “Problems an individual may experience in involvement in life situations[1:12].”

Stroke: A vascular disorder that affects the circulation of blood to the brain and results in spontaneous neurological fallout[13].

Upper limb: Also refers to the upper arm or extremity that is comprised of the upper arm, forearm, and hand and includes the shoulder down to the fingers[14].

CHAPTER 1: INTRODUCTION, LITERATURE REVIEW, AND METHODS

1.1. Introduction

The following is presented as a Master of Science research report in the form of a manuscript submission. A brief outline of the three chapters follows.

Chapter 1: This chapter introduces the study by presenting the problem statement, research question, aim, and objectives. It then reviews the relevant literature and discusses the study methodology.

Chapter 2: This section reports the study in manuscript format for submission to the South African Journal of Occupational Therapy. Due to the nature of this research report format, the components of the literature and the methodology from Chapter 1 may be repeated in the manuscript.

Chapter 3: This chapter presents a synopsis of the study with a discussion indicating an interpretation and alignment of the results with the literature, limitations, necessary recommendations, and conclusions.

1.1.1. Introduction to the Study

Due to brain damage and subsequent impairments, stroke is a primary cause of disability[15]. In South Africa, the annual years lived with disability is 95,000[15]. Low- to middle-income countries account for 80% of global strokes, with South Africa at the forefront[16]. The main risk factors for stroke in the country include reduced physical activity, unhealthy diets, increased alcohol use, and a higher prevalence of noncommunicable diseases[16]. Despite an estimate of 75,000 South Africans experiencing strokes per year, the lack of a stroke database may underestimate its true prevalence[17]. With medical advances that improve survival rates, the number of stroke survivors is expected to rise[15], further exacerbating the social and economic burden in the country[18]. A significant proportion of survivors are moderately (40%) to severely (15-30%) dependent on assistance with daily activities[18]. Among the possible

physical, cognitive, and communicative impairments that may present post-stroke, pain substantially influences physical, social, and emotional well-being, affecting the ability of individuals to perform activities and to participate in life areas[19,20].

Pain is one of the main reasons why people seek medical services[10]. This is due to the debilitating effects of pain on body functions, activities and participation such as self-care, carrying out a daily routine, quality of rest and sleep functions, walking, doing housework, education, work and employment, driving, sexual functions, recreation and leisure, and interpersonal interactions and relationships[10]. It has an overall impact on quality of life and can lead to debilitating disabilities[21]. Additionally, deficits in mental functions, neuromusculoskeletal, and movement-related functions are greater in stroke survivors who experience pain[22]. If pain is not effectively managed, changes in the central nervous system can occur, worsening pain levels and increasing the risk of self-harm and prolonged recovery[10].

Post-stroke pain, particularly in the upper limb, is prevalent among stroke survivors often encompassing nociceptive and neuropathic features[20,23]. Post-stroke pain syndromes that affect the upper limb include central post-stroke pain (CPSP) in 1-12% of survivors, hemiplegic shoulder pain in approximately 75%, spasticity-related pain in 72% of these cases, and shoulder-hand syndrome (SHS) in 2-49%[24]. Although specific statistics on the prevalence of post-stroke pain in the upper limb are not available, the fact that hemiplegic shoulder pain is the most common type of post-stroke pain, along with the higher incidence of spasticity and SHS in the hemiplegic upper limb, highlights its significant impact on the upper limb[25,26].

Despite the significant prevalence and impact on occupational performance, a gap is reported in the global identification and intervention of post-stroke pain[20,23]. There are numerous reasons for this gap, including the complexity of post-stroke pain and its various causes[20,27]. Additional factors include the difficulty of stroke survivors in expressing pain due to speech and language deficits, their inability to complete pain questionnaires due to cognitive, perceptual, motor or visual impairments, and the overshadowing of other impairments such as hemineglect, low mood, and poor endurance[20,27]. These factors can make it difficult to identify signs and symptoms of

pain[20,27]. Other contributing issues include premorbid pain-inducing conditions, stroke survivors who do not report pain voluntarily, and the lack of comprehensive guidelines[20,27]. In South Africa, the challenges of accessing rehabilitation services may further contribute to this problem[28].

Although the post-stroke pain intervention is currently suboptimal, pain can be managed with a resulting improvement in activities, participation, and quality of life[27]. Therefore, it is essential to address these issues, and occupational therapists who play a unique and key role in pain management can assist in this process[10]. Occupational therapists are experts in using occupation-based interventions to allow people experiencing pain to participate in their activities despite the presence of pain[10]. Although the key role of occupational therapists in pain management is well-established[10], the quality of evidence specific to prevention, assessment, and treatment techniques to support their role in the management of upper limb pain post-stroke is notably low, as can be seen in the South African Contextualised Stroke Rehabilitation Guideline (SA-CSRG) from 2019[29]. However, occupational therapists play a crucial role in pain management due to their comprehensive understanding of the complex interaction between *people* (the *person*), their *occupations*, and the *environment*, which together influence *occupational performance* and participation[9]. This expertise highlights their important contribution to the resolution of pain-related challenges[10]. This aligns with the philosophy of the International Classification of Functioning, Disability and Health (ICF), which underscores the dynamic interplay between body structures and functions (aspects of *the person)*, activities and participation (*occupations* and *occupational performance*), and environmental factors (the *environment)* and their impact on health[1]. Pain is included in the ICF core set for stroke and is classified as a body function[30].

Despite the distinct role of occupational therapy in pain management, proactive intervention in South Africa appears to be neglected; even though rehabilitation services are provided in state and private health centres at all stages of recovery[28]. Accessibility and intensity of intervention remain suboptimal, particularly in rural areas where approximately 50% of the stroke population resides[17,28]. Despite evidence indicating the need for early intervention, the literature notes that there is limited assessment, diagnosis, and intervention for post-stroke pain[20]. Furthermore, recent

stroke guidelines emphasise that the quality of evidence on post-stroke pain intervention is scarce[22].

Rider (2022), reports that occupational therapists commonly lack knowledge and have negative mindsets about pain[31]. This perception is relevant because the debilitating consequences of pain are strongly evident in the literature and need to be addressed to reduce the burden of stroke in South Africa[27]. However, South Africa lacks best-practice guidelines specific to upper limb post-stroke pain[29,32]. The SA-CSRG includes recommendations for pain management; however, there is no clear delineation of which techniques fall within the scope of occupational therapy, and not all recommendations have conclusive high-quality evidence[29]. Furthermore, the precise nature of stroke rehabilitation, including aspects such as accessibility, content, and effectiveness, remains largely unknown[17]. This study aims to bridge this gap by describing the current practices of occupational therapists in South Africa in the prevention, assessment, and treatment of post-stroke pain in the hemiplegic upper limb. This chapter outlines the relevant literature for this study, critically reviews the evidence, and explains how the researchers have placed the study within the identified literature gaps.

1.1.2. Statement of the Problem

Although 10 to 45.8% of stroke survivors experience post-stroke pain, there are numerous global reports of poor identification and intervention with respect to this complication[20,23,27]. Post-stroke pain is predominantly chronic in 40-65% of stroke survivors[22,23]. Owing to the effect of pain on health and well-being[20], and the unique role of occupational therapists in understanding this relationship, they have an important role to play in the management of pain[10]. However, it appears that therapists neglect proactive pain management, potentially due to limited knowledge and skills, inappropriate attitude towards pain intervention, limited focus on chronic pain in university curricula, and reduced use of comprehensive assessment tools[31].

There is little evidence of optimal diagnosis and management of pain in stroke survivors[16] and in South Africa there is one study that found that only 41.4% of occupational therapists aim to address secondary complications such as pain in their intervention with stroke survivors[33]. Furthermore, both the international stroke

rehabilitation guidelines and the SA-CSRG (2019) lack specific recommendations on the role of occupational therapists in addressing post-stroke pain[29,34–38].

Additionally, disability rates among stroke survivors are alarmingly high, with a significant proportion experiencing moderate (40%) to severe (15-30%) dependence on others for daily activities[18]. As the global population of stroke survivors continues to increase, the burden of disability and unmanaged pain increases, particularly in regions like South Africa, where stroke incidence is significant[15]. Taking into account the prediction that there will be 70 million stroke survivors worldwide by 2030[39] and that up to half of these survivors may experience post-stroke pain, with 70% having daily pain,[40,41] the ineffective management of pain is of concern. The impact that these factors have on activities and participation is worrying; therefore, prioritising pain in stroke management is important[10]. The current practices of occupational therapists in South Africa on the prevention, assessment, and treatment of post-stroke upper limb pain were unknown. Therefore, a deeper understanding of these current practices was essential to inform the development and implementation of best practices in stroke rehabilitation, particularly in the management of pain by occupational therapists.

1.1.3. Research Question

What is the current practice of occupational therapists in addressing upper limb pain post-stroke in South Africa?

1.1.4. Aim of the Research

To describe the current practice of occupational therapists in addressing upper limb pain post-stroke in South Africa.

1.1.5. Research Objectives

1.1.5.1. To describe the strategies used by occupational therapists in South Africa for the prevention of upper limb pain post-stroke.

1.1.5.2. To describe the assessment methods used by occupational therapists in South Africa for the assessment of upper limb pain post-stroke.

1.1.5.3. To describe the treatment techniques used by occupational therapists in South Africa for the treatment of upper limb pain post-stroke.

1.1.6. Justification of the study

This study was conducted using an online survey that allowed the current practices of many occupational therapists in the management of upper limb pain post-stroke in South Africa to be analysed. The findings of this study on the current practices of occupational therapists for pain prevention, assessment, and treatment provide an opportunity for future research to explore various strategies and techniques that are effective in pain management in stroke survivors. Research on effective strategies and techniques for pain management in stroke survivors within the scope of occupational therapy remains relatively underexplored, with a reduced quality of completed studies. Although occupational therapists play a crucial role in the management of pain, there was a notable lack of specific research on customised approaches for stroke survivors. Consequently, more research is needed to explore and identify effective interventions that could improve pain management outcomes and overall well-being of stroke survivors in the context of occupational therapy. However, to do this, the current practice of occupational therapists in South Africa needed to be described.

Describing current practice allowed gaps to be identified in the management of post-stroke pain by occupational therapists. Where the findings indicated that occupational therapists did not prioritise or address pain in stroke survivors, further research could explore why they did not prioritise or address pain, and this could lead to changes to allow this prioritisation. Further research could also explore what could be done to improve pain management by occupational therapists.

Furthermore, this research study could improve current practice guidelines by indicating the emphasis on pain management in the upper limb post-stroke. The dissemination of the findings of this study can contribute to the body of knowledge and skills of occupational therapists on pain management of the upper limb post-stroke, which, in turn, could lead to greater achievement of therapy goals. A reduction in the burden on the healthcare system can be expected, as stroke survivors are likely to

require less intervention once their pain is effectively managed. Improved pain management skills by therapists can also improve the quality of life of stroke survivors by reducing pain-associated psychosocial factors such as low mood and motivation. As pain was known to have an impact on activities and participation of a person, better knowledge about pain management could have a positive impact on improving participation in these occupations. This participation could then positively affect the economy, as stroke survivors would be more likely to return to work and contribute to society. It would also reduce the need for caregivers, allowing family members to continue working and not have to stop their activities to care for the stroke survivor. Furthermore, awareness of the role of occupational therapy in pain management could be promoted to advance the profession.

1.2. Literature Review

1.2.1. Introduction to the Literature Review

Building on the context of Chapter 1, this chapter begins with a definition and introduction to the three possible classifications of stroke. The range of complications after stroke is then introduced with an emphasis on post-stroke pain. Subsequently, pain is described in terms of its definition and possible origins. The role of occupational therapy in pain management is then reviewed. A critical appraisal of the literature around post-stroke pain and the role of occupational therapy in the prevention, assessment, and treatment of upper limb pain post-stroke then follows. The literature related to the common pain syndromes in the upper limb post-stroke, including CPSP, hemiplegic shoulder pain, spasticity, and SHS, is then described and analysed. This chapter concludes with a summary of key findings presented in the literature and a delineation of the gaps within the literature in which this study is positioned.

A narrative literature search was initiated on 6 February 2022 and continued until 18 August 2024. Various databases including Google Scholar, PubMed, and Clinical Key were used. The searched terms included: 'South African stroke rehabilitation guidelines', 'post-stroke pain', 'central post-stroke pain', 'post-stroke complex regional pain syndrome', 'spasticity after stroke', 'hemiplegic shoulder pain', 'complex regional pain syndrome post-stroke', 'stroke occupational therapy'', 'stroke occupational

therapy', 'occupational therapy in pain management' and 'occupational therapy in post-stroke pain.' Filters were added to the search so that recent literature published between 2018 and 2024 could be explored.

1.2.2. Stroke

Stroke is rapidly rising, ranking as a leading cause of adult disability and one of the top causes of mortality in South Africa[42]. Classified as ischaemic stroke/cerebral infarction, intracerebral haemorrhage (ICH), or subarachnoid haemorrhage (SAH)[43], stroke results from vascular disorders that affect blood circulation within or to the brain, leading to spontaneous neurological fallout[13]. Ischaemic stroke constitutes approximately 85% of cases, typically caused by atherosclerosis, systemic hypoperfusion, thrombosis, or embolism, resulting in reduced blood supply to the brain[43,44]. On the contrary, haemorrhagic stroke, which accounts for 10-15% of cases, involves bleeding in the brain due to blood vessel damage[43–45]. Intracerebral haemorrhage involves the parenchyma and ventricles of the brain, and SAH involves the subarachnoid space formed between the pia mater and the arachnoid membrane[43]. Post-stroke impairments are varied and, depending on the area/s of the brain affected, can significantly impact the lives of stroke survivors[46]. These impairments may be of a physical, cognitive, communicative nature, or any combination thereof[19,20]. One of these significant impairments that may present is post-stroke pain, with a higher prevalence in ischaemic stroke[20].

Pain is essential as it alerts the need for behavioural changes to prevent further injury or to facilitate recovery[8]. Pain must primarily be prevented where possible; however, in cases where pain occurs, it must be managed early and effectively, as it can result in high financial expenditure due to the negative consequences it causes[10]. In addition, a better prognosis is seen in the control of pain and quality of life with early and effective intervention[40]. Despite recommendations to prioritise pain management, the literature highlights the suboptimal diagnosis and management of post-stroke pain[20]. The international and South African stroke guidelines scarcely describe an occupational therapy-specific intervention, and the recommendations mentioned are not all well-researched[22]. This compromises the effectiveness of the intervention in the

prevention, assessment, and treatment of pain. Consequently, research on stroke rehabilitation and healthcare practices is imperative to efficiently reduce the burden of stroke in the country. To understand post-stroke pain, it is useful to discuss the definition and nature of pain.

1.2.3. Post-Stroke Pain

The International Association for the Study of Pain (IASP) defines pain as: *"an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage*[12:1976]." Pain is classified into acute and chronic, where acute pain dissipates as the stimulus or damaged tissue heals, and chronic pain continues to present after the expected healing time[8]. Effective management of acute pain is essential to prevent prolonged recovery and numerous medical consults, while chronic pain, lasting more than 3 months, requires specialised treatment[10]. Although post-stroke pain can be acute, chronic pain is primarily prevalent in stroke survivors[47].

In addition to classifying pain temporally, it can also be classified according to its origin, and understanding these origins helps in effective management[8]. The IASP categorises pain into nociceptive, neuropathic, and nociplastic types[48]. Nociceptive pain, an acute pain arising from tissue injury and inflammation,[48] is defined as "*pain that arises from actual or threatened damage to non-neuronal tissue due to activation of nociceptors*[8:5]". Chronic neuropathic pain is the result of injury to the nervous system and is described as "*pain caused by a lesion or disease of the somatosensory nervous system*[7:5]". Areas of the brain that can cause this type of pain include the thalamus, hypothalamus, sensory cortex, amygdala, periaqueductal grey, rostroventral medulla, and the tracts that travel between these structures[8]. Nociplastic pain is defined as "*pain that arises from altered nociception, despite no clear evidence of actual or threatened tissue damage causing the activation of peripheral nociceptors or evidence for disease or lesion of the somatosensory system causing the pain*[8:513]". This type of pain is chronic and arises from irregularities in the pain pathway without actual damage to the pathway[8]. Stroke survivors may experience any combination of these pain origins,[22,48] with common post-stroke pain syndromes such as CPSP and SHS being

neuropathic,[4,5,21] hemiplegic shoulder pain and pain secondary to spasticity primarily being nociceptive, with some origins of hemiplegic shoulder pain being neuropathic[24]. Scuteri et al. (2020) report that 72% of stroke survivors experience musculoskeletal pain, most commonly related to nociceptive origins[49].

1.2.4. Occupational Therapy in Pain Management

Most of the literature on the role of occupational therapy in pain management is focused on chronic pain, which is relevant to this study, as post-stroke pain is predominantly of a chronic nature[50,51]. Occupational therapists are uniquely qualified to intervene in pain management independently or within an interdisciplinary team[10,52]. With their focus on enabling engagement and participation in occupations that are meaningful and purposeful to an individual, they can improve the health and well-being of those experiencing pain[10]. When an individual performs relevant occupations, participation in these tasks themselves can reduce pain[10]. This is supported by evidence that describes the relationship between occupational participation and health and is important, as pain can significantly affect activities and participation[10]. Occupational therapists are guided by numerous models and frames of reference that enable a thorough understanding of the psychological, biological, and social influences of pain[53]. The philosophy and principles of the profession support the biopsychosocial model through a comprehensive understanding of the various factors that influence occupational performance[52]. The biopsychosocial model of pain, which is supported by the ICF,[1] highlights that pain intervention should focus on the control of symptoms and performance in occupations despite pain[10]. Occupational therapists are the only professionals who can use occupation-based intervention to ensure health and well-being regardless of the presence of pain[52]. Through this focus, the potentially unrealistic expectation of pain relief can be altered to achieve pain management[52]. Using a client-centred approach, understanding a person's individual and cultural beliefs about pain is also facilitated[53]. Despite this recognised role in pain management, the quality of evidence that specifically supports occupational therapy in post-stroke pain is reduced.

1.2.4.1. Prevention of pain

Due to the ongoing deficits caused by post-stroke pain syndromes and the significant impact on performance in daily activities, prevention must be an ongoing process from the time of stroke onset[21]. Guidelines specific to the role of occupational therapy in pain prevention are limited and focus primarily on the assessment and treatment of pain[10]. However, the literature related to the general prevention of pain can guide occupational therapy intervention. Prevention of CPSP is scarcely discussed; however, early initiation of treatment increases the chance of recovery and therefore can prevent exacerbation of pain[4]. The prevention strategies used by occupational therapists in the prevention of hemiplegic shoulder pain included educating the stroke survivor and the caregiver involved, daily exercise, positioning, and the prescription of assistive devices[54]. Spasticity-related pain is another post-stroke pain syndrome that must be prevented, as it can be associated with sudden spasms that are painful and can cause permanent and painful muscle and tendon contractures[8,21]. Spasticity accompanies shoulder pain in 60% of stroke survivors, elbow pain in all stroke survivors, and wrist pain in 33% of stroke survivors[26]. Although more research is required to determine whether post-stroke spasticity can be prevented, painful contractures can be prevented by range of motion exercises, stretching, and positioning to counteract the pattern of tone[26,29]. Splinting and taping are not recommended for spasticity prevention; however, further research is required[29]. In conjunction with botulinum toxin A, techniques such as stretching, casting, taping and electrical stimulation may reduce spasticity, thus reducing the risk of contracture development[29]. However, this should be used with caution, as spasticity can positively reduce muscle atrophy, maintain bone mineral density, and improve mobility[26]. Shoulder-hand syndrome can be prevented by active, active-assisted, or passive range-of-motion exercises[29].

1.2.4.2. Assessment of pain

To holistically understand these areas affected by pain, the Fourth Edition of the Occupational Therapy Practice Framework (OTPF-4) guides the assessment of pain through the compilation of an occupational profile, the assessment of cognitive, sensory-perceptual, psychosocial, and physical functions, as well as the identification

of environmental factors that may contribute to pain[31]. Occupational performance is also assessed together with an analysis of how pain contributes to performance[55]. Pain needs to be identified and the location, type, intensity, and frequency of pain need to be determined[10]. Furthermore, individuals' perceptions of pain, coping skills, cognitive and emotional responses to pain, and ability to self-manage the pain are assessed[10,55]. Numerous methods can be used to obtain this information, including interviews, observation, and relevant questionnaires[52]. Subjective methods to assess pain may include using the Brief Pain Inventory, McGill Pain Questionnaire, Numeric Rating Scale, Visual Analog Scale, Wong-Baker FACES Pain Rating Scale, Face, Legs, Activity, Cry, Consolability Behavioural Pain Scale, or the Pain Enjoyment of Life and General Activity Scale[10]. Numerous other assessments such as the Disabilities of the Arm, Shoulder and Hand, Pain Coping Questionnaire, Pain Self-Efficacy Questionnaire, Canadian Occupational Performance Measure, Functional Disability Inventory, or Patient-Specific Functional Scale are also options[10]. The ultimate goal of the assessment is to understand the influence of contextual, personal, and occupational factors on one another and pain[52]. This shows that occupational therapists can assist in the thorough assessment of pain, but current assessment practices of occupational therapists in South Africa are not known.

1.2.4.3. Treatment of pain

Based on the assessment findings, an occupational therapist can develop an individualised treatment plan for pain management, which is important as pain differs from person to person[31,53]. To effectively manage pain, the therapist must be educated about the physiology of pain, pain processing mechanisms, disabilities induced by pain, and successful pain intervention methods[10,56]. Pain intervention is multimodal and it is necessary to include education, occupation, physical, social and psychological aspects[52]. The focus of pain intervention by occupational therapists is to facilitate the individual to manage the pain while performing relevant occupations[10,55]. This is done by guiding lifestyle changes that include changes in daily habits and routines to enable self-regulation and management of pain[53]. Developing a therapeutic relationship with the individual helps to achieve success in this process[10,53]. Before treatment, the individual's goals for therapy must be determined and realistic expectations must be set[10]. Pain neuroscience education is one of the techniques that occupational

therapists can include in pain management[56]. This essential education helps the individual understand the mechanism, origin and type of pain and has been shown to alter the personal perception of pain and; therefore, enables improvement in activity and participation[56]. Fear avoidance behaviours commonly adopted in response to pain have also been shown to decrease with pain neuroscience education[56]. Occupation-based intervention, which includes the use of occupations and activities to reach therapy goals, is used by occupational therapists[10]. Through this approach, physical, mental, and spiritual needs can be met[10]. Self-management techniques that are used during occupational performance are taught and supported by evidence[53]. These may include problem-solving, pacing and graded activity exposure, setting of goals, ergonomics, and energy conservation[55]. Improving body mechanics, joint protection principles, exercise, and sleep are also recomended[10,52]. Incorporation of these techniques into daily life is facilitated by occupational therapists[10]. Problem-solving includes making adaptations to the technique used during an activity or to the environment to reduce barriers to participation[55]. Pacing is an effective technique that helps an individual increase the awareness of how much activity can be tolerated at a time and avoids exacerbation of pain by taking rest breaks, alternating activities before the pain increases, and planning or prioritising activities[55]. Graded activity exposure is another technique used by occupational therapists to upgrade the expectations of activity over time to improve pain tolerance during specific activities[55]. Occupational therapists are also skilled in making recommendations to the environmental setup of activities, possibly using assistive devices, to ensure good postural alignment and positioning during activities that reduce pain; this is known as ergonomics[55]. Energy conservation techniques are also useful in pain management, as fatigue is commonly accompanied by pain and participation in activity is reduced as a result[55]. Preparatory techniques to help manage pain and stiffness should be taught to the patient for use before performance in an occupation[10]. Electrical stimulation, hot or cold temperature modalities, ultrasound, and paraffin are physical agent modalities that have been effective in reducing pain in relevant cases; however, a study reported that pharmacological management was also required, although less frequently[56]. Virtual reality is one of the means through which relaxation and improved movement can be achieved[10]. To assist individuals with pain management, techniques including sensory re-education, desensitisation, mindfulness, biofeedback, and graded exposure can be beneficial[10]. The cognitive consequences of pain also need to be addressed and this

can include attention, executive functions, and memory training[10]. Owing to their training in mental health, occupational therapists can improve coping skills to manage relationships, mood, and sleep, as well as areas of psychological fallout of the stroke survivor that may accompany pain[55]. Relaxation is one of these techniques that can be used[56]. Improving communication and assertiveness skills is also required to facilitate the understanding of others of the pain and its consequences[55]. Cognitive behavioural therapy is also recommended to help manage pain when pain cannot be resolved[56]. Treatment of pain in social situations can also be addressed in occupational therapy, and the IASP recommends group therapy including support groups[52]. Aromatherapy and massage are also effective in pain management[56]. If pain affects work, vocational rehabilitation can be done by the occupational therapist[55]. Other occupational therapy intervention methods can include helping with the management of the medication regimen, advocating for people with pain, and improving the stroke survivors ability to regulate their pain independently[10]. Despite the evidence of effective pain management, whether occupational therapists in South Africa were using recommended techniques to manage pain was not known.

1.2.5. Most Common Post-Stroke Pain Conditions

To link the role of occupational therapy with post-stroke upper limb pain, the most common causes of post-stroke upper limb pain will be discussed.

1.2.5.1. Central post-stroke pain

The first of these syndromes mentioned above to be discussed is CPSP, which is defined by the IASP as: *"pain initiated or caused by a primary lesion or dysfunction of the central nervous system and occurs in the absence of other nociceptive, peripheral, and psychogenic pain*[3:132]". Central post-stroke pain occurs when there is damage to the spinothalamocortical pathway[21]. In 25% of cases, the cause of the syndrome was found in the lateral medulla and 17-18% in the inferior lateral thalamus[4]. The origin of pain is neuropathic and the central pain pathways are affected, resulting in pain despite absent activation of the pain receptors[21]. Central post-stroke pain is difficult to distinguish from other neuropathic pain syndromes as symptoms and pain descriptors can vary from case to case[40]. Due to the identification challenges, it was important to determine whether occupational therapists have a sufficient understanding of the

origins and types of pain to be able to effectively assess the signs and symptoms of the syndrome to ensure prevention and early intervention.

According to Yang and Chang (2021), CPSP is present in 1-12% of stroke survivors and is mainly indicated in the subacute and chronic phases of recovery[24]. It is commonly experienced on the hemiplegic side of the body[57]. It is accompanied by allodynia in approximately 67% of stroke survivors with other sensory consequences such as hyperpathia (a painful response to mostly repetitive stimuli that is unusual and unexpected), dysaesthesia (an unusual and unpleasant sensation) or hypoaesthesia (reduced sensitivity), and hypoalgesia (reduced pain in response to a typically painful stimulus) in 40% of survivors[4,6]. Pain varies in intensity, and some experience pain all day[4]. Central post-stroke pain is often described as burning, cutting, freezing, or squeezing[3], and reports of aching, sharp, dull, stabbing, and shooting pain have also been reported[21]. Approximately half (52%) of stroke survivors who have CPSP do not have weakness, but a high proportion do have ataxia (62%) and fallout in sensory modalities including stereognosis, temperature, pinprick, and touch[4]. A lower temperature of the affected area is generally felt on assessment, particularly when the pain is higher[4]. The majority (63%) of stroke survivors present with symptoms of CPSP within the first month after stroke but not at the time of stroke, 18% experienced the onset of symptoms within the first half year after stroke, and another 18% began with symptoms after this[4]. To diagnose the syndrome, occupational therapists need to assess these possible sensory deficits, but it was unclear whether this was being done in current practice in South Africa.

Central post-stroke pain affects mobility, mood, activity, and participation[3]. Pain may be activated by movement and when the body encounters water[58]. This type of pain is recognised when there are no other possible causes of pain, making it difficult to diagnose[3]. Specialised medical tests are not necessary for the diagnosis of CPSP and the assessment includes a comprehensive history review and physical tests, including sensation of the above modalities[4]. The findings are then correlated with the area/s of brain injury[4]. The SA-CSRG agrees that CPSP can be diagnosed when other possible mechanisms of pain have not been identified and should be based on specific criteria[29]. The challenge is that this evidence is weak and the guideline does not describe how to assess CPSP, nor the strategies currently being used.

The prognosis of this pain syndrome is poor, but early initiation of treatment increases the chance of recovery[4]. Treatment is complex as stroke survivors do not respond to traditional pain management[3]. Certain medications are effective, but the intervention must include both pharmacological and non-pharmacological treatment[40]. The SA-CSRG indicates evidence for interdisciplinary management together with pharmacological intervention[29]. According to the literature, some of the current intervention techniques used include motor cortex neurostimulation and transcranial magnetic stimulation[58]. The first of these has moderately positive evidence in the SA-CSRG (2019) in specific stroke survivors and when all other treatments have been unsuccessful[29]. However, these techniques are not within the scope of occupational therapy practice, and so these guidelines neglect evidence of possible effective occupational therapy techniques. Cognitive behavioural therapy, pain neuroscience education, graded motor imagery, and transcutaneous electrical nerve stimulation (TENS) are also being used in treatment[3]. However, there is low-quality evidence of the effectiveness of these techniques[4]. Although occupational therapists can use these techniques, there is no evidence to confirm whether they are used in South African stroke rehabilitation. According to Plecash et al. (2019), early mobilisation, mirror therapy, stellate ganglion blockade, and psychological intervention are effective[40]. It is essential to determine whether occupational therapists prevent, assess, and treat pain according to the CPSP recommendations, and by determining their current practices in South Africa, this information could be obtained.

1.2.5.2. Hemiplegic shoulder pain

With a prevalence higher than CPSP, the most common area of post-stroke pain is hemiplegic shoulder pain presenting in approximately 75% of stroke survivors[24]. Hemiplegic shoulder pain is identified as the most incapacitating post-stroke pain syndrome[59]. Pain in this area is usually rated as moderate to severe intensity[60]. Within the acute stage, the risk of hemiplegic shoulder pain is highest, as assistance is commonly required for transfers and upper limb positioning; therefore, there is a higher risk of injury through inappropriate handling[60]. Within two weeks post-stroke, pain while moving the shoulder and reduced upper limb range of motion can present in stroke survivors[61]. According to Ada et al. (2020), the presence of pain at two weeks post-stroke predicts the presence of shoulder pain later, and so it is essential that pain

be assessed and managed meticulously[61]. Within the first half year post-stroke, hemiplegic shoulder pain is more common in those with fallout in motor control, perception, sensation, spasticity of the elbow flexors, limited shoulder abduction and external rotation range, trophic changes and type II diabetes[4]. Pain hinders active movement, which in turn reduces motor recovery of the hemiplegic upper limb[60]. In addition, pain affects participation in activities[60]. Rehabilitation and quality of life are hindered as a result[25].

Hemiplegic shoulder pain can be caused by neurological, mechanical, musculoskeletal factors, or any combination of these[25]. Neurological aetiology may be due to spasticity, sensory or motor fallout, or neuropathic mechanisms such as SHS whereas mechanical aetiology may be due to subluxation, poor scapula alignment, injury to the rotator cuff muscles, or poor muscular balance[25]. Musculoskeletal aetiology may be due to tendonitis or bursitis[25]. These causes of pain commonly result from secondary impairments such as significant muscular strength fallout, hemineglect, rotator cuff tendon damage, subluxation, and hypertonia/ spasticity[62]. Post-stroke, 56 to 81% of survivors with absent upper limb muscular strength present with shoulder subluxation and significant weakness of the upper limb[61]. Muscles that stabilise the scapular can be weak instantly post-stroke, and this weakness results in absent upward scapula rotation whilst resting[63]. Owing to this instability, gravity forces the head of the humerus out of the glenohumeral joint, and this results in subluxation[63]. Capsular stiffness is possible within the chronic stage, and this can also be a source of pain[63]. Flaccidity of the hemiplegic upper limb can cause pain through extreme overstretching of muscles which causes soft tissue damage[60]. In contrast, spasticity can also contribute to pain in the hemiplegic upper limb through the flexor patterns of movements that develop as a result[60]. These factors also need to be identified to ensure the prevention and treatment of hemiplegic shoulder pain.

Due to the ongoing deficits caused by hemiplegic shoulder pain and the significant impact on performance in daily activities, shoulder pain prevention must be addressed from the time of stroke onset[21]. Prevention of pain needs to be the greatest component of intervention in stroke survivors[54]. The literature suggests that prevention should include education of the stroke survivor, the caregiver/s, and other health personnel who intervene with the stroke survivor on how to position, manoeuvre, and maintain

full passive range of motion of the hemiplegic upper limb[64]. Physiotherapists and occupational therapists can help educate on how to passively maintain range of motion without causing injury[4]. Education also needs to include avoiding pulling on the hemiplegic upper limb, always supporting the arm during movement, working within a pain-free range, avoiding active and passive shoulder flexion and abduction of more than 90 degrees, and ensuring that passive external rotation of the shoulder is maintained or improved[54]. Delpont et al. (2018) also included education on how to position the upper limb in all positions, as well as the prescription of a wheelchair tray table to support the limb when sitting in a wheelchair[58]. This is also supported by other authors[4]. Positioning prevents malalignment of the joints, and secondary complications such as contractures and pain are prevented through passive range of motion exercises[54]. Ideal shoulder positioning is not evidence-based, but, in contrast to the typical flexor pattern of the hemiplegic upper limb, shoulder abduction, external rotation, and flexion are commonly recommended, as this movement is often limited in shoulder pain post-stroke[64]. The SA-CSRG recommends that the hemiplegic shoulder should be positioned in maximum external rotation during sitting or lying for half an hour each day[29]. This guideline also recommends positioning the arm when resting, during functional mobility, and while seated in a wheelchair using a wheelchair tray or arm trough, especially during the acute or flaccid stage post-stroke[29]. Scapular protraction, neutral wrist, and finger extension are the recommended positions when lying supine[4]. There is mixed evidence for the use of strapping or taping to maintain good shoulder alignment and positioning to reduce pain[4]. A shoulder sling can support the shoulder in positions where gravity pulls the hemiplegic upper limb, but it is important to ensure that the sling does not position the shoulder in adduction and internal rotation, which can affect range of motion[4]. It is recommended to consider a sling when sitting or standing in survivors with flaccidity of the hemiplegic upper limb[4]. In the case of glenohumeral joint subluxation, the SA-CSRG recommends positioning and the use of slings, but does not specify the type of recommended sling[29]. Keszler, Gude, and Heckert (2017) describe a type of sling, namely the GivMohr sling, which assists in supporting the flaccid upper limb, including the shoulder[4]. Shoulder subluxation was reported to be reduced more effectively with this sling compared to a humeral cuff sling[4]. However, the findings of this study from 2005 are outdated and are compromised by the small sample size and the short-term measurement of the effectiveness of the sling[65]. In addition, this sling is an international product that needs

to be shipped to South Africa, so it is costly and not realistic to prescribe it in many South African contexts. A study by Kim et al. (2022) found that a sling that provides both proximal and distal support, such as the elastic dynamic sling, was more effective than a Bobath sling that provides only proximal support[66]. Other types of slings, such as GivMohr and OmoNeurexa that provide proximal and distal input at the humerus and forearm, respectively, were found by Nadler and Pauls (2017) to minimise subluxation[67]. Despite the fact that full arm slings provide a greater reduction of subluxation, these slings allowed free elbow movement and were considered more beneficial[67]. Further research to clarify the effectiveness of these different types of slings is recommended. The SA-CSRG guidelines also recommend strapping, education of stroke survivors, their caregivers, and other health care professionals, or active motor training in stroke survivors with weakness and at risk of shoulder pain[29]. However, the majority of this evidence is considered insufficient[29]. Avoiding the use of assistive devices such as pulleys used to improve functional mobility is also recommended as these devices increase the risk of shoulder injury[60].

Although prevention is key, an assessment of hemiplegic shoulder pain may be indicated. A diagnosis can be made based on the history and physical findings[4]. Assessment needs to be holistic and must include identifying the effect of hemiplegic shoulder pain on daily activities[54]. A history of possible shoulder pain before stroke is necessary, as is the assessment of the musculoskeletal and neurological components of the hemiplegic upper limb[4]. These assessments should include assessment of the neck, shoulder, and elbow, which is important to determine stability and quality of structural components, which in turn can assist in identifying the origin of hemiplegic shoulder pain[54]. As movement of the shoulder requires the scapula and humerus, it is important to assess the alignment of these joints as well as the coordination of these joints during movement[54]. If present, subacromial impingement can be identified during this assessment[54]. Muscles and joints that form part of the shoulder girdle, sensation, reflexes, muscular strength, and muscle tone need to be assessed[4,40]. In addition, the intensity and severity of shoulder pain, postural alignment, oedema, and the trunk must also be assessed[54]. Visual analogue scales and visual rating scales have been found to be the most useful measures for pain, despite limitations[25]. However, within stroke rehabilitation, assessment scales are not appropriate or reliable and are also challenging to use in stroke survivors with deficits in cognition

and perception[4]. The Barthel Index can be used to assess the impact of pain on daily activities, and it is vital that psychosocial components also be assessed[54]. Furthermore, an environmental assessment is important as numerous environmental factors influence occupational performance as well as motor recovery of the hemiplegic upper limb[54]. Keszler, Gude, and Heckert (2018), noted the Positive Neer test, hand-behind neck test and passive external rotation test as tests that can be used to assess for hemiplegic shoulder pain[4]. Although tested in 2007, a study by Rajaratnam et al. identified a probability score of 98% in identifying hemiplegic shoulder pain using these three tests[68].

Based on the findings of the above assessments, an individualised treatment plan needs to be developed to remedy participation in the affected activities[54]. Medications such as analgesics, antispasmodics and anti-inflammatories may be prescribed[58]. Occupational therapy plays a pivotal role in stroke rehabilitation with the goal of enabling performance and engagement in purposeful and meaningful activities and life roles to achieve health and well-being[54]. In addition to pharmacological treatment, occupational therapists can contribute to non-pharmacological modalities for hemiplegic shoulder pain. The ICF facilitates the use of a top-down approach together with a bottom-up approach, and it is recommended that occupational therapists use this approach in the treatment of hemiplegic shoulder pain, as it includes consideration of the specific needs of stroke survivors'[54]. Treatment must also be occupation-based[54]. Assessment and treatment of hemiplegic shoulder pain is multifactorial and it is worthwhile to study whether current strategies and techniques address these factors and are used effectively in South African stroke rehabilitation.

Treatment techniques used by occupational therapists in the management of hemiplegic shoulder pain include electrical stimulation, taping, and dry needling with a combination of these showing fast progress to recovery in daily activities[62]. In addition, wheelchair tray tables, upper limb troughs, shoulder orthoses, and neuromuscular electrical stimulation (NMES) have also been identified as treatment modalities[40]. The SA-CSRG recommends NMES but does not recommend electrical stimulation in the management of shoulder pain, thus affecting the clarity of the effectiveness of these techniques[29]. According to Plecash et al, (2019), evidence has found orthoses and taping to reduce pain, NMES to not be effective and botulinum

toxin to have conflicting findings[40]. However, further research on the effectiveness of these techniques is required[40]. Kumar et al. (2021) also identified that evidence for best practice in hemiplegic shoulder pain management is scarce and noted that shoulder orthosis has low-quality evidence[25]. Manual passive range of motion in pain-free movement can be used in treatment, as it reduces pain in 43% of stroke survivors[4]. Heat and cold modalities can be used with safety precautions and high-intensity TENS is also used in treatment[4]. Heat is beneficial to alleviate pain when joint stiffness is present and when soft tissue needs to be lengthened[54]. Ice also aids pain relief and is beneficial to use in the presence of oedema and spasticity[54]. The choice of modality, therefore, depends on the specific symptoms of hemiplegic shoulder pain[54]. Functional electrical stimulation (FES) can be used on supraspinatus and posterior deltoid muscles to compensate for voluntary muscle weakness[4]. However, intramuscular electrical stimulation, which in contrast to FES provides a more accurate stimulation, has a better outcome of pain reduction than slings[4]. Jacobs-Nzuzi Khuabi, de Klerk and Tapfuma (2021) also identified FES as a treatment modality with other modalities, including vibration, point stimulation, Carr and Shepherd's positional stretching programme, or strapping[54]. Static positioning of the hemiplegic upper limb does not affect pain, range of motion, movement, or performance in daily activities[25]. The SA-CSRG recommends gentle stretching and mobilisation in shoulder pain with a particular focus on improving the range of motion in external shoulder rotation and abduction[29].

Shoulder strapping for both shoulder subluxation and hemiplegic shoulder pain has inconclusive evidence and the evidence to support pain education and self-management techniques, specifically in stroke survivors is lacking[25]. Shoulder strapping to reduce pain is recommended in the SA-CSRG[29]. Improving coordination of the scapular and humerus and scapula mobilisation is effective[54]. Task-orientated approaches that include techniques such as constraint-induced movement therapy, mirror therapy, mental practice, virtual reality, robotics, and observation of action have inconclusive evidence[54]. Alternative therapies such as acupuncture, together with therapeutic exercises, showed greater success than if done alone, and the combination of aromatherapy and acupressure is also beneficial[4]. However, the SA-CSRG indicates that the effectiveness of acupuncture is unconsolidated[29]. Furthermore, strengthening the muscles that support the shoulder joint is also

important[21]. Due to the commonality of hemiplegic shoulder pain, it is vital to determine what occupational therapists are doing to manage it.

1.2.5.3. Pain secondary to spasticity

In addition to CPSP and hemiplegic shoulder pain, spasticity can also be a cause of post-stroke pain[26]. Spasticity refers to *"velocity-dependent resistance to muscle stretch*[69:455]." It may occur when there is a lesion to the central nervous system and is commonly seen in stroke survivors[38]. Spasticity-related pain occurs in 72% of stroke survivors who present with spasticity, which is common in approximately 65% of cases[24]. It can be associated with sudden spasms that are painful and can cause muscle and joint injury[58]. Spasticity is more common in the hemiplegic upper limb than in the hemiplegic lower limb with 79% in the elbow, 66% in the wrist, and 58% in the shoulder[26]. Flexor muscles are the main muscles affected in the upper limb[26]. Muscles that are found over two joints are more prone to spasticity, and in the hemiplegic upper limb, spasticity affects the adductors and internal rotators of the shoulder, the flexors of the elbow, wrist, and fingers, and the pronators in the forearm[69]. Spasticity accompanies shoulder pain in 60% of stroke survivors, elbow pain in all stroke survivors, and wrist pain in 33% of stroke survivors[26]. Further research is required to determine if prevention of spasticity post-stroke is possible[26].

Risk factors for spasticity include the presence of significant weakness and reduced sensitivity of the hemiplegic upper limb as well as a low Barthel Index score on initial assessment[26]. If not managed effectively, spasticity can lead to muscle and tendon contractures that are painful and involve neuropathic and nociceptive origins due to the response of the nociceptors in muscles and tendons[8]. Pain may be irreversible in the case of contractures[21]. Abnormal upper limb positions caused by spasticity can cause secondary complications including reduced function, pain, compromised cleanliness, and hygiene, and can increase the force on upper limb joints[69]. Approximately 70% of stroke survivors who present with spasticity also present with CRPS which is discussed below[58]. The collaboration of a multidisciplinary team (MDT) is recommended for the management of upper limb spasticity and assessment[69].

Once the assessment of spasticity is complete, a comprehensive plan that aims at muscle strengthening, improving range of motion, stretching, and achieving performance in meaningful occupations needs to be developed[69]. Spasticity can be exacerbated by the presence of pressure injury, distention of the bladder, infections of the urinary tract, and kidney stones, and these need to be identified and treated if present[26]. Spasticity can also be managed through prolonged and consistent stretching, as it hinders the shortening of sarcomeres and thus maintains or increases muscle, tendon, and ligament length[26]. Orthoses, in the form of casts or splints, may be indicated to provide stretch like manual stretching[26]. Orthoses are also used to reduce secondary complications and to improve function in upper limb spasticity[69]. Serial casting which encourages progressive stretching at a reduced pace to improve range of motion may also be indicated[69]. Casts or splints assist in improving the range of motion and prevention of contractures by reducing spasticity through less excitatory stimulation to the muscles[69]. Compared to absent intervention during the chronic stage post-stroke, Salazaar et al. (2019) found that a static stretching programme with orthoses used for positioning had very low quality evidence for reducing spasticity in wrist flexors[70]. However, the effectiveness of splinting use in the management of spasticity and the prevention of contractures is not yet determined, and further research in this area is required[38]. The SA-CSRG does not recommend splints for spasticity management[29].

Botulinum toxin type A injections and muscle relaxant medications may also be prescribed to manage spasticity[58]. The SA-CSRG identified chemo-denervation using botulinum toxin A as weak positive evidence within the first half year post-stroke and strong positive evidence as long-term treatment with the impact of reducing pain and improving range of motion in spasticity[29]. Additionally, intrathecal Baclofen has moderate positive evidence in the management of spasticity causing pain[29]. Pharmacological treatment for spasticity depends on whether the spasticity is localised or present in numerous areas[69]. These treatments must be used together with non-pharmacological modalities such as splinting[69]. Non-pharmacological management of spasticity may include positioning of the limbs to counteract the pattern of tone and stretching of affected joints[38]. Motor learning and other repetitive movement therapies can enhance the achievement of goals in upper limb spasticity[69]. Electrical stimulation of spastic muscles can aid in muscle strengthening and improving range of motion[69].

These tasks fall within the scope of occupational therapy but whether they were being used in South African practice was not yet known. In addition to the above conditions, since spasticity is a potential contributor to pain, how occupational therapists in South Africa are managing this was important to determine.

1.2.5.4. Complex regional pain syndrome

Complex regional pain syndrome, more commonly known as SHS in stroke, is another condition contributing to post-stroke pain[4,5]. Shoulder-hand syndrome, present in 2-49% of stroke survivors, is a pattern of symptoms that include chronic neuropathic pain, motor limitations, as well as vasomotor, trophic, and sudomotor changes[24]. Complex regional pain syndrome type 1 is the most common of the two types and the origin is not related to nerve damage; this is the type that presents post-stroke[71]. The exact neurophysiology underlying this syndrome is not yet known[23]. Pain is frequently reported in the shoulder, but may also present in the hand or both[4]. Pain, allodynia, hyperalgesia, oedema, shoulder, wrist, and hand joint range of motion deficits, erythema of hands, and feelings of pyrexia are common in SHS[5]. Vasomotor symptoms may include temperature dysregulation and skin colour changes, sudomotor changes may include oedema and trophic changes may include nail or hair growth changes[4].

Some identified factors may contribute to the onset of SHS, and these may be a prolonged length of admission to hospital, glenohumeral joint subluxation, shoulder soft tissue injury, spasticity, extreme hand weakness, adhesive arthritis, brachial plexus injury, mood disorders, infections such as urinary or lower respiratory tract infections, coronary artery disease and malnutrition[5]. Additionally, the syndrome is also more common in women, stroke survivors with hemiplegia of the left side, and those who are dependent on daily activities[5]. The impact of this syndrome on quality of life is enormous and intervention is thus of utmost importance[72]. Identifying and acknowledging these risk factors is vital in stroke survivors so that appropriate action can be taken.

A MDT is vital for the management of SHS post-stroke[73]. Occupational therapists are one of the health care professionals that play a significant role in the management of

the syndrome[74]. Prevention of shoulder subluxation and positions causing pain is essential as this reduces the incidence of SHS from 27% to 8%[8]. Peripheral and central sensitisation from immobilisation can result in the onset of this syndrome[5]. The SA-CSRG includes passive, active-assisted, or active range of motion exercises as prevention; however, evidence is of a weak positive nature[29].

This syndrome is difficult to diagnose as it is essential to first rule out symptoms that are caused primarily by the stroke[4]. A medical assessment is thus required to determine any other possible causes of pain such as neuropathy or arthritis[72]. Diagnostic criteria include the history of stroke and the presence of the symptoms mentioned above[4]. According to the Budapest criteria, to be diagnosed with CRPS, the stroke survivor must experience continuous pain that is extraordinary for the type of injury and must present with at least one symptom in at least three of the following areas of fallout: sensory, vasomotor, motor, trophic and sudomotor[72]. Symptoms in each area may be either allodynia or hyperpathia for sensory; skin colour changes, skin colour asymmetry or temperature asymmetry for vasomotor; reduced range of motion or fallout in the motor system such as tremors, dystonia, or weakness; hair, skin, or nail changes as trophic changes and sweating changes, sweating asymmetry, or oedema for sudomotor[72]. In addition, one sign in at least two of the same areas mentioned above is necessary for diagnosis[72]. The SA-CSRG states that diagnosis is dependent on clinical assessment with positive findings of finger joint pain and tenderness, oedema of the dorsum of the hand, trophic skin changes, reduced range of motion, and hyperaesthesia[29]. A triple-phase bone scan is also indicated as an addition to the assessment[29].

A global physical assessment including range of motion, sensation, and posture needs to be done and this should include the shoulder girdle and the hemiplegic and non-hemiplegic limbs[72]. Ongoing assessments and re-assessments are important and there should be constant collaboration amongst the members of the MDT to ensure progress and the necessary ongoing management[72]. As immobilisation can contribute to SHS, numerous outcome-based measures should be used to assess the function of the upper limb post-stroke[5]. These may include the Fugl–Meyer Assessment of the Upper Extremity, the Action Research Arm Test (ARAT), and the Motor Activity Log (MAL)[5].

The sooner the treatment of SHS is initiated, the better the prognosis[72]. The overall goals of treatment need to focus on reducing abnormal signs and symptoms of all the above-mentioned areas of impairment and improving function and quality of life[72]. Intervention for any identified nociceptive or other neuropathic causes of pain needs to be done to improve the achievement of goals in SHS management[72]. Typical pain medications are not successful and treatment may include sympathetic nerve blocks in the stellate ganglia[58]. Thus, non-pharmacological treatment is used more frequently than pharmacological intervention[73]. Intervention needs to include hand therapy when the upper limb/s are affected[72]. Hand therapy may include techniques such as desensitisation, contrast baths, manual lymphatic drainage, compression garments, paraffin baths, passive exercises, static or dynamic splinting or casting, ultrasound, electrical stimulation, and fluidotherapy[72]. Elevation, cryotherapy, massage, mirror therapy, and TENS are other techniques that may be used[75]. The SA-CSRG indicated low positive evidence for mirror therapy together with other traditional interventions[29].

The management of anxiety or depression that may arise due to pain must also be included in rehabilitation[4]. The SA-CSRG only mentions pharmaceutical management as a recommendation with non-pharmacological interventions excluded[29]. This emphasises the challenges for occupational therapists in effectively managing post-stroke pain in South Africa as there are insufficient guidelines and evidence to facilitate effective intervention.

1.2.6. Occupational Therapy in Post-Stroke Pain Management

Although the evidence is not specific to post-stroke pain, aligning the role of occupational therapy in pain management discussed above with the various post-stroke upper limb pain conditions, it can be noted that the available evidence can be inferred to stroke rehabilitation. According to the South African Department of Health's Regulations defining the scope of the profession of occupational therapy (2023), occupational therapists consider the environments in which individuals or groups of people perform their occupations and the influence of these environments on their occupational performance[76]. In addition, factors of a biomechanical, neurological, psychosocial, sensory, and interpersonal nature are addressed in achieving occupational performance and engagement[76]. This is congruent with the ICF which,

as mentioned above, also understands the influence of these factors on pain and vice versa. The occupational therapy role in pain management described above is thus within the scope of practice in South Africa.

1.2.7. Conclusion to the Literature Review

In conclusion, post-stroke pain is prominent in stroke survivors. However, globally, intervention in post-stroke pain is scarce and suboptimal. There are many pain syndromes post-stroke, most related to the hemiplegic upper limb. Post-stroke pain is debilitating and significantly impacts occupational performance and quality of life. Considering the prediction that the prevalence of stroke and the prevalence of people surviving a stroke is rising and that daily pain is reported by as many as 70% of survivors, the fact that this pain is not being managed effectively is of concern. The impact that these factors have on personal, societal, and work environments is worrying and the prioritisation of pain in stroke management is thus essential. Occupational therapists play a key role in the management of post-stroke upper limb pain. However, the current practice of occupational therapists in the management of upper limb pain post-stroke is not known in South Africa. This needs to be identified so that best practices can be implemented and developed by occupational therapists in their management of stroke survivors.

1.3. Methods

1.3.1. Introduction to the Methods

Based on the background and context of the study identified above, this section will focus on describing the methods that were used for this study to answer the research question. It will initially discuss the survey design before identifying the target population and describing how the sample size was calculated. The methods of how this population was recruited as well as the inclusion criteria will then follow. Continuing into this section, the process used to develop the research instrument will be discussed. Data collection and management will then be explained and will be followed by the method used for data analysis. Before concluding this section, the ethical considerations taken into account for this study are discussed.

1.3.2. Study Design

A quantitative descriptive cross-sectional survey design was used to investigate the current practice of occupational therapists working with stroke survivors. This design was selected based on its alignment with the study's objectives and the benefits it offers in understanding current practice. According to Brink, van der Walt, and van Rensburg (2018), descriptive designs, such as the one employed in this study, play a crucial role in recognizing challenges, identifying prevailing practices in similar settings, and validating existing approaches[77]. These designs are particularly effective in obtaining relevant data from a characteristic group using surveys[77].

By utilising a cross-sectional design, the study aimed to collect data from occupational therapists working with stroke survivors, facilitating a current investigation[77]. This design allowed for a snapshot of the current practice at a particular point in time, providing valuable insights into the approaches employed by these professionals[77]. Given the objective of examining the current practice of occupational therapists, a typical descriptive study design was considered appropriate[77]. The survey methodology facilitated the collection of data, enabling the researchers to gain a broad understanding of the practices and interventions employed by occupational therapists working with stroke survivors across South Africa.

1.3.3. Study Population and Sample

The population under investigation were registered occupational therapists who had provided intervention for stroke survivors in South Africa within the month prior to the completion of the survey.

1.3.3.1. Sample size

In South Africa, there is no database for occupational therapists working specifically with stroke survivors. Therefore, it was not possible to determine the exact population size for this study. Thus, it was necessary to estimate the population size based on available statistics. In April 2023, there were 6,221 occupational therapists registered with the Health Professions Council of South Africa (HPCSA)[78]. Although the HPCSA does not classify occupational therapists according to the specialty area in which they

work, the Occupational Therapy Association of South Africa (OTASA) does[79]. An estimated population size was derived from available data on the OTASA website. Although membership is not mandatory, the fields of practice of the therapists were indicated on the website. Therapists specifying adult and/or paediatric neurology as their field of practice totalled 154[79]. In May 2023, the website listed 436 registered occupational therapists under the 'Find an OT' tab[79]. Therefore, 35.3% of the registered members indicated working in neurology. However, the study aimed to include occupational therapists across South Africa, so limiting the population to OTASA members was not a true reflection. Thus, out of the 6,221 therapists registered with the HPCSA, 35.3% of them, totalling 2,196 individuals, can be estimated to work in the field of neurology. Using Cochran's sample size formula, with a margin of error of 10% and a 95% confidence rate, a minimum of 93 participants were required for this study[80,81].

1.3.3.2. Inclusion criteria

The inclusion criteria were occupational therapists:

- with an undergraduate occupational therapy degree obtained from a university in South Africa.
- registered with the HPCSA as a community service or independent practitioner.
- who had intervened within the scope of occupational therapy with a stroke survivor of any age within the month before the completion of the survey in South Africa to encourage relevant responses from therapists actively engaging in stroke rehabilitation.

1.3.4. Instrumentation

Guided by the research objectives, an online survey questionnaire was developed from a search of the literature[82]. Research Electronic Data Capture (REDCap) was used for the development of the survey. The survey (Appendix 1) provided an information sheet and allowed participants to complete the survey only if they met the study's inclusion criteria (Section 1). The next part of the questionnaire (Section 2)

included six questions relating to participant demographics and the profile of their practice setting. The section that followed (Section 3) captured data relating to the demographics of stroke survivors with whom the participants intervened, and the nature of pain experienced by stroke survivors in their practice. The participants' approach to prevention, assessment, and treatment of post-stroke upper limb pain (Sections 4-6) was captured using open-ended questions for each aspect and Likert scale responses which consisted of prevention, assessment, and treatment strategies that were discussed in the American Association of Occupational Therapy's Position Statement on the Role of Occupational Therapy in Pain Management as well as from literature on the four most common post-stroke pain syndromes affecting the hemiplegic upper limb. After the Likert scale in each section, participants were allowed to add any other techniques that they used as the Likert scale list was not collectively exhaustive.

To establish content validity, five experienced occupational therapists were selected. They included two occupational therapy lecturers with academic and clinical experience, a clinician with over eight years of experience in neurological rehabilitation, and two founders of the Occupational Therapy Pain Management Group in South Africa with extensive clinical experience. Their combined expertise ensured a comprehensive assessment of content validity in the study.

The experienced therapists were requested to indicate if the survey instructions and questions were easy to follow and understand, grammatical and/or spelling errors, and to record how long it took them to complete the survey. Their suggested changes were also requested, and a collation of their feedback including changes made or not made with reasons can be found in Appendix 2 and 3. Despite one of the therapists providing written feedback without completing the rating scales, the Content Validity Index (CVI) was calculated (Appendix 4 and 5) based on four expert ratings, yielding S-CVI/Ave scores of 0.91 for relevance and 0.96 for clarity. Due to the required CVI rating standard of one[83], the survey underwent refinement, excluding irrelevant questions, rephrasing unclear ones, and improving clarity through added examples and elaborations on ambiguous terms such as the phases of intervention which were elaborated on to ensure uniform understanding. Additional response options, such as biopsychosocial intervention techniques, were also incorporated. The severity of pain

according to the Universal Pain Assessment Tool was removed due to concerns regarding wording and fluctuations of pain that may occur throughout the day.

To prevent response bias, before each section, participants, initially indicated open-ended prevention, assessment, and treatment techniques that they use in practice. They then ranked 23 prevention strategies, 42 assessment methods, and 38 treatment techniques on a Likert scale. Responses were combined into "never/rarely," “sometimes” and "often/always" for presentation purposes. The items of the Likert scale were selected from the literature for relevance.

1.3.5. Data Collection Process

The sections that follow will explain how participants were recruited as well as the process of data collection and data management.

1.3.5.1. Recruitment

Convenience sampling was employed in this study due to practical considerations. It allowed for the selection of readily available participants from the occupational therapy community in South Africa, using the OTASA website as a convenient platform[84]. While convenience sampling may limit generalisability, it facilitated data collection within the study's scope and resources[84]. An element of snowball sampling was also used to encourage the recruitment of occupational therapists who conformed to the inclusion criteria but were not members of OTASA. Snowball sampling is a type of sampling used when accessing the required participants is challenging[85].

Once ethical clearance was received, the survey was sent to OTASA and the South African Neurodevelopmental Therapy Association (SANDTA) who shared the survey with their members via email. The OT Link which is an online-based platform that provides evidence-based workshops and training also assisted in advertising the research study on their social media pages. The survey was posted on numerous social media pages that have occupational therapists as members. These pages included ‘’Allied Health in South Africa,’’ ‘’Occupational Therapists RSA,’’ ‘’Rehab Gauteng Health,’’ and ‘’OTs in Gauteng Health and Education.’’ The survey was also sent to various WhatsApp groups including ‘’Department of Health (DOH) – KwaZulu

Natal (KZN) OT,'' Gauteng Rehab Units,'' ''City of Johannesburg (CoJ) OT Cluster'' and ''Gauteng (GP) Public Health OT's.'' In addition, the survey was also sent to members of a Western Cape based therapeutic services database. The survey was also distributed at events such as the Spinal Cord Injury Workshop and a Consensus Development Forum. Members of these groups were requested to share the survey with relevant therapists who may have fit the inclusion criteria of the research study.

1.3.5.2. Data Collection

The data were collected for three months from 6 February 2023 to 6 May 2023, and the researcher manually entered three anonymous hardcopy survey responses into REDCap. These surveys were available in hard copy at a GDoH workshop for participants who did not have access to data and were collected by the workshop coordinator, therefore maintaining anonymity. Reminders were sent out on social media platforms. As participant's email addresses were not requested as part of the survey responses, the researcher could not remind participants with incomplete survey responses to complete the survey. Data were stored securely on the REDCap platform. After data collection, it was exported to password-protected Excel spreadsheets.

1.3.5.3. Data Management

The online survey data were securely stored on the University of the Witwatersrand's access-controlled platform called REDCap. No identifying information was included in the survey, so anonymity and confidentiality were ensured. Data cleaning and checking were performed within Microsoft Excel, identifying no errors or outliers. The data were exported to password-protected Microsoft Excel spreadsheets on Google Drive for backup. The collected data will be retained securely for two years if there is a scientific publication and six years if not, after which it will be appropriately destroyed.

1.3.6. Data Analysis

Descriptive statistics were used to analyse and summarise the data obtained in this study. These statistics describe and summarise the data to present it visually[86].

Frequency distributions, a form of descriptive statistics was used in this study. These assisted with ordinal data collected from the surveys. Frequency distributions assisted in determining how many occupational therapists identified or did not identify with specific areas explored. Microsoft Excel was then used to transfer this information into a frequency table. Simple descriptive statistics were used to determine percentages. Content analysis for the open-ended questions was used and converted to frequency distributions. This was done through analysis of the responses, coding these responses into categories, and calculating the frequency of the responses in each category. Content analyses were verified by the researcher's supervisor.

The statistics used to analyse the variables to respond to the research objectives can be seen in Table 3.1 below:

Table 3.1. Table summarising the statistics and frequency distribution used to analyse the variables required for the achievement of the objectives of this study indicated by question numbers from the survey (Appendix 1)

	Survey question number (Appendix 1)	**Variable**	**Type of data**	**Descriptive Statistics used**	**Illustration used**
Participant demographics	5	Highest occupational therapy qualification	Ordinal	Frequency and percentage	Table
	6	Province of practice	Nominal		
	7	Sector of practice	Nominal		
		Practice setting			
	8	Number of years	Nominal		
	9	in stroke rehabilitation	Ratio		
	16	Additional courses/ training	Nominal		
Demographics of practice profile	10	Phase of intervention	Nominal	Frequency and percentage	Table
	11	Average age	Ratio		
	12	How often stroke survivors are seen	Nominal		
	13		Nominal		

	14	Structure of intervention Other MDT members involved	Nominal		
Demographics of stroke patients typically seen by participants	17 18 19	Pain: Most common description Most common location Most common duration	Nominal	Frequency and percentage	Table
Frequency of consideration of post-stroke upper limb pain management by occupational therapists	15	Frequency of consideration	Ordinal	Frequency and percentage	Table
Prevention, assessment, and treatment strategies identified via written responses	20 23 27	Prevention strategies Assessment methods Treatment techniques	Content analysis to: Nominal Nominal Nominal	Frequency and percentage	Table
Prevention, assessment, and treatment strategies identified via Likert scale	21 24 28	• Never/Rarely • Sometimes • Often/Always	Ordinal Ordinal Ordinal	Frequencies and percentages	Stacked bar chart

1.3.7. Ethical Considerations

Ethical approval (Protocol number M221071) was obtained from the University of the Witwatersrand Human Research Ethics Committee - Medical (HREC) on the 8th of December 2022 (Appendix 6). Participants were informed of this approval through the information sheet at the start of the online survey, and completion of the survey was considered informed consent. The first question of the survey asked whether participants read and understood the information sheet. If they responded no, they were directed back to the information sheet.

1.3.7.1. Confidentiality and anonymity

Personal data were not identifiable on the completed survey, ensuring confidentiality. Responses were automatically saved onto the REDCap system with assigned numbers. The university complies with the *International Organisation for*

Standardisation ISO 27001 Information Security standards, and data were stored on REDCap in an access-controlled project with encryption.

1.3.7.2. Informed consent

Participants were informed in the information sheet (Appendix 1) that completing the online survey constituted informed consent. Those who indicated they had not read or understood the information sheet were redirected to it.

1.3.7.3. Beneficence and non-maleficence

Participants were informed that participation posed no risks, was voluntary, and they could withdraw at any point without consequences. The online nature of the study minimised potential intimidation. The survey link would have been received via their email address or seen on a social media platform – the online nature protects the study candidate from feeling intimidated to participate or complete the survey.

1.3.7.4. Justice

All eligible participants were invited to participate, requiring only internet access and an appropriate device. The survey was distributed through various platforms accessible to participants across South Africa.

1.3.7.5. Possible risks or benefits from the research

Participants were notified that they would not derive direct benefit from the study but that their participation would assist in further research and training in occupational therapy management of upper limb pain post-stroke.

1.3.7.6. Veracity

An information sheet clarified the research purpose and components. Participants had to confirm their understanding before proceeding with the survey. Measures were taken to prevent response bias, such as presenting open-ended questions before Likert scales and restricting changes to responses. In addition, before presenting the preliminary findings of my study at The Consensus Development Conference, the

participants were requested to complete the survey if relevant. The study findings were submitted for publication in the South African Journal of Occupational Therapy (SAJOT) (Appendix 7). The findings of the study will also be disseminated at relevant conferences or workshops.

1.3.8. Conclusion to the Methods

In conclusion, this study used a quantitative cross-sectional descriptive survey study design. Occupational therapists with an undergraduate occupational therapy degree obtained from a university in South Africa registered with the HPCSA and who had intervened with stroke survivors in South Africa in the month before they completed the survey were invited to participate in the study. The survey was developed and distributed via REDCap and the data were stored on the same platform. Content validity was completed before the final survey was distributed. The survey was distributed via various platforms including emails from databases, social media pages, WhatsApp, and at workshops/ conferences. Microsoft Excel was used to analyse the data using descriptive statistics and frequency distributions and graphs were used to display the data. Content analysis for the open-ended questions was used and conversion to frequency distributions was also done.

CHAPTER 2: SUBMISSIBLE MANUSCRIPT

2.1. Manuscript Details

The following chapter includes a manuscript, in the form of an original journal article, that has been written for submission to the South African Journal of Occupational Therapy (SAJOT). The manuscript was submitted to SAJOT on 27/03/2024 (Appendix 7) with 59 references of which 17 were from the literature review: as per the guidelines. The submission guidelines for SAJOT which were followed in this manuscript can be found in Appendix 8. The format of this chapter has been changed to align with the author guidelines for SAJOT. The chosen journal is affiliated with OTASA and aims to disseminate scientific knowledge related to occupational therapy within Africa, via numerous scopes including in the form of published research articles[87]. Published knowledge applies to current occupational therapy topics and is influential in the global evolution of the occupational therapy profession[87]. Open access to the journal provides greater opportunities for easy and free dissemination and publications can be found on numerous online databases[87]. Preservation of the SAJOT articles is done via Portico https://www.portico.org/publishers/assaf/[87]. The SAJOT is listed on The Witwatersrand Health Sciences Library Emergency Medicine: DHET Accredited Journals[88].

2.1.1. Title of the Manuscript

The manuscript title is: "*Management of Upper Limb Pain in Stroke Survivors: The Current Practice of Occupational Therapists in South Africa*."

2.2. Details of Author Contribution

J. Cohen is the primary researcher in this study with primary supervisor and co-author, F. Breytenbach and co-supervisor and co-author, K. van Stormbroek. Using the Contributor Role Taxonomy (CRediT), the author's contributions are outlined in Table 4[89].

Table 4: Author Contributions

CRediT terms	J. Cohen	F. Breytenbach	K. van Stormbroek
Conceptualisation	✓	✓	✓
Methodology	✓	✓	✓
Data collection	✓		
Sample analysis		N/A	
Data analysis	✓	✓	
Validation	✓	✓	✓
Data curation	✓	✓	
Writing manuscript – initial draft	✓		
Writing manuscript – revisions	✓	✓	✓
Student Supervision		✓	✓
Project leadership		✓	✓
Project management	✓	✓	✓
Funding acquisition		N/A	

2.3. Abstract

Introduction: Stroke is a leading cause of adult disability and mortality in South Africa. Post-stroke upper limb pain affects various functions, hindering activities and participation. Occupational therapists play a crucial role in pain management, enabling occupational performance, despite pain. However, gaps exist in recognising and managing post-stroke pain. This study aimed to describe occupational therapists' practices in managing upper limb pain post-stroke in South Africa.

Methodology: A quantitative descriptive cross-sectional study surveyed occupational therapists routinely treating stroke survivors, using descriptive statistics and content analysis.

Results: One hundred responses were included for analysis. Most participants (96.7%) acknowledged pain as an issue for stroke survivors. Notably, 48.9% always include pain management, 43.5% consider it but lack intervention skills, and 16.3% report time constraints. Occupational therapists primarily focus on neuromusculoskeletal and movement-related functions in pain management, with some considering mental functions, activities, participation, and/or the environment.

Conclusion: The study highlights a significant burden of post-stroke upper limb pain in South Africa. Occupational therapists mainly address body structures and functions associated with pain, indicating the potential to strengthen the focus on activity and participation while considering contextual factors. Incorporating pain management into

occupational therapy interventions for stroke survivors across all levels of care is recommended, alongside the development of evidence-based guidelines tailored to occupational therapy.

Keywords: Post-stroke pain, stroke rehabilitation, occupational therapy interventions, pain assessment, pain management techniques, South African healthcare

2.4. Introduction

Stroke is one of the leading causes of adult disability and mortality in South Africa[1]. Although it is already one of the top ten leading causes of adult disability, the prevalence of stroke is expected to rise[1]. This is due to social and demographic changes in the country, together with global advances in medical care that improve stroke survival rates[1,2]. Consequently, the social and economic burden of stroke is substantial, with a significant number of survivors experiencing moderate (40%) to severe (15-30%) dependence on daily activities, highlighting a considerable problem in the country[1,3]. Stroke survivors may experience physical, cognitive, and/or mood impairments that affect daily life for themselves and their families[4]. Pain is identified as one of these impairments, with studies reporting a prevalence of pain in 10-45.8% of stroke survivors[24]. Many of the post-stroke pain syndromes are related to the hemiplegic upper limb[24].

Pain is defined by the International Association of Pain (IASP) as *"an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage*[6:*512*]**"**. It is categorised into nociceptive, neuropathic, and nociplastic origins, and stroke survivors can experience any combination of these three[7]. Nociceptive pain, resulting from tissue injury and ongoing inflammation, is acute and is defined as pain that "*arises from actual or threatened damage to nonneural tissue due to activation of nociceptors*[6:512]**"**. Neuropathic pain is chronic and is defined as a "*lesion to the somatosensory nervous system that constitutes the ascending (sensory) and descending (modulatory) pain pathway*[6:512]**"**. Damage to the thalamus, hypothalamus, amygdala, sensory cortex, rostroventral medulla, and/or the periaqueductal gray can cause this type of pain[6]. Nociplastic pain, which is also a chronic type of pain, is defined as *"pain that arises from altered*

nociception despite no clear evidence of actual or threatened tissue damage causing the activation of peripheral nociceptors or evidence of disease or lesion of the somatosensory system causing the pain[6:513]*"*.

Common neuropathic post-stroke pain syndromes include central post-stroke pain (CPSP), shoulder-hand syndrome (SHS), hemiplegic shoulder pain and pain secondary to spasticity[8]. Central post-stroke pain affects 1-12% of stroke survivors, while SHS affects a wider range of 2-49% of stroke survivors[8]. Hemiplegic shoulder pain and pain secondary to spasticity are common nociceptive causes of post-stroke pain[8]. With an approximate 75% prevalence rate, hemiplegic shoulder pain is the most common post-stroke pain syndrome[8]. Long-lasting hemiplegic shoulder pain is reported in 20% of stroke survivors, despite pain resolution in many stroke survivors within half a year post-stroke[8]. Among stroke survivors, spasticity is present in approximately 65% of cases, and of those with spasticity, 72% experience spasticity-related pain[8]. According to Scuteri et al*.,* 72% of stroke survivors experience musculoskeletal pain, mainly of nociceptive origin[9]. Although specific statistics for the overall prevalence of post-stroke pain in the upper limb are not available, the high rates of hemiplegic shoulder pain, spasticity of the upper limb and SHS underscore the significant impact on the upper limb[8].

Given that pain negatively affects occupational performance, early effective pain management is crucial to prevent central nervous system modifications, promote recovery, reduce financial expenditure, and ensure a better prognosis and quality of life[10]. Pharmacological treatment alone is often insufficient, requiring non-pharmacological interventions addressing the physical and behavioural components of pain[11]. Multidisciplinary and client-centred approaches are emphasised, with occupational therapists playing a vital role in pain management[10,11].

Despite the significant prevalence of post-stroke pain and its impact on occupational performance, there is a global gap in the identification and treatment of pain[12]. This may be due to the complexity of post-stroke pain, communication difficulties in stroke survivors, inability to complete pain questionnaires, overshadowing of other impairments, pre-existing pain conditions, underreporting by stroke survivors, and lack of comprehensive guidelines[4,5]. In South Africa, the limited access to rehabilitation services exacerbates the issue[13].

Occupational therapists are key players in pain management as they are experts in using occupation-based intervention to enable individuals experiencing pain to participate in their activities despite the presence of pain[10]. Their comprehensive understanding of the dynamic interaction between people, their occupations, and the environment contributes to their unique skills[14]. This aligns with the philosophy of the International Classification of Functioning, Disability, and Health (ICF), which underscores the dynamic interplay between body structures and functions (aspects of *the person)*, activities and participation (*occupations* and *occupational performance*), and environmental factors (the *environment)* and their impact on health[15]. Although the vital role of occupational therapists in pain management is well established, direct evidence specific to their role in the management of upper limb pain after stroke is notably low, as can be seen by the reduced discipline-specific recommendations in the South African Contextualised Stroke Rehabilitation Guideline (SA-CSRG), 2019[16].

Pain is one of the main reasons why people seek medical services[10]. This is owing to the debilitating effects of pain on body functions, activities, and participation such as self-care, quality of rest and sleep functions, walking, doing housework, education, employment, driving, recreation and leisure, and interpersonal interactions and relationships[10]. The Fourth Edition of the Occupational Therapy Practice Framework (OTPF-4) highlights that occupational therapists consider mental, sensory, pain, neuromusculoskeletal, and movement-related functions, as well as contextual factors, to understand their impact on performance in occupations[14]. This is supported by the South African Scope of Occupational Therapy (2023), which describes how occupational therapists address personal, environmental and occupational factors in achieving occupational performance[17].

The framework also includes prevention as a key outcome of occupational therapy and considers avoiding or reducing potential barriers to occupational performance, such as pain[14]. Therapists use assessment frameworks to identify pain characteristics, psychological responses, coping skills, and self-efficacy[14]. Based on the assessment findings, treatment plans that may include education, pacing, energy conservation, health management, exercise, sensory re-education, cognitive interventions, assistive devices, and environmental modification are designed[10]. By holistically addressing the multifaceted nature of post-stroke pain, occupational therapists play a crucial role in

restoring physical and mental well-being and overall quality of life for stroke survivors and their families[10].

Despite the recognised need for post-stroke upper limb pain intervention and the ability of occupational therapists to meet this need, there is little evidence of diagnosis and optimal treatment of pain in stroke survivors[12]. Stroke rehabilitation guidelines focus predominantly on more affluent countries, lacking representation from lower-income countries[18]. With only one of eight guidelines originating in South Africa, Platz (2019) underscores the need for region-specific research, especially in areas like South Africa, where post-stroke pain management is needed[1,3,18]. The SA-CSRG was developed from international guidelines, including the American Heart Association/ American Stroke Association (USA) Stroke Rehabilitation Guidelines 2016 (AHA/ASA 2016), Australian Stroke Guidelines 2017 (ASG 2017), and Canadian Stroke Guidelines 2015 (CSG 2015) and this highlights the reduced availability of research in South Africa[16]. In particular, the SA-CSRG lacks specificity in occupational therapy interventions, and aligning with Platz (2019), who advocates for profession-specific stroke rehabilitation guidelines, this is a significant concern[18].

The current practices of occupational therapists in South Africa on preventing, assessing, and treating post-stroke upper limb pain are unknown. This must be identified to determine whether current practice in South Africa aligns with international practice, available evidence, and best-practice guidelines. It also helps to allow occupational therapists to implement and develop best practices in their management of stroke survivors.

2.5. Literature review

Post-stroke upper limb pain

Central post-stroke pain occurs when there is damage to the spinothalamocortical pathway[12]. Symptoms include a variety of subjective pain descriptions, including dull, throbbing, aching, stabbing, shooting, or burning in areas of the body affected by stroke[12]. The onset generally occurs between one and six months after the stroke and is induced by hyperaesthesia or presents as constant or intermittent bursts of pain without stimulus[12]. Central post-stroke pain is difficult to identify, as all other possible causes of pain must be excluded before a diagnosis can be made[19]. The diagnosis

involves a comprehensive review of the history and physical tests[7]. Early initiation of treatment is crucial, although traditional pain management methods show limited efficacy[7].

Hemiplegic shoulder pain is classified as moderate to severe and can manifest as early as two weeks post-stroke[7]. Causes include neurological, mechanical, and musculoskeletal factors that hinder motor recovery and affect rehabilitation and quality of life[7]. Prevention of hemiplegic shoulder pain must be one of the main components of intervention in stroke survivors[6]. Diagnosis can be made from musculoskeletal and neurological assessments of the hemiplegic upper limb and thorough analysis of the stroke survivor's medical and occupational history[20]. Treatment involves addressing the cause of shoulder pain, and numerous techniques, such as neuromuscular electrical stimulation, shoulder slings, and positioning, are recommended[16].

Spasticity, which affects stroke survivors within three months to one year after stroke, particularly in the flexor muscles of the hemiplegic upper limb, is associated with painful muscle spasms, muscle and tendon contractures, and therefore, poor occupational performance[7]. Risk factors include weakness, reduced sensitivity, and a low Barthel Index score[21].

Complex regional pain syndrome, more commonly known as SHS in stroke, is characterised by chronic neuropathic pain, motor limitations, and various sensory, vasomotor, motor, trophic, and sudomotor signs and symptoms[8]. Risk factors include prolonged hospital admission, joint subluxation, soft tissue injury, spasticity, extreme hand weakness, and mood disorders[8]. Diagnosing this syndrome is challenging and requires the exclusion of other causes, with specific symptoms in multiple domains according to the Budapest criteria[8]. Early treatment of SHS improves prognosis[22]. Non-pharmacological treatments are preferred and include hand therapy techniques such as desensitisation, contrast baths, manual lymphatic drainage, compression garments, passive exercises, and electrical stimulation[22].

Recognising the complexity of these pain conditions, the IASP recommends a comprehensive approach that integrates physical and behavioural components[7]. Addressing both the medical and psychosocial aspects of pain, a multidisciplinary team (MDT), including psychologists, physiotherapists and occupational therapists, is essential[7,23].

Pain Prevention

Due to the ongoing deficits caused by post-stroke pain syndromes and the significant impact on performance in daily activities, prevention must be an ongoing process from the time of stroke onset[12]. Guidelines specific to the role of occupational therapy in pain prevention are limited and focus primarily on the assessment and treatment of pain[10]. However, the literature related to the general prevention of pain can guide occupational therapy intervention. Prevention of CPSP is scarcely discussed; however, early initiation of treatment increases the chance of recovery and therefore can prevent exacerbation of pain[20]. The prevention strategies used by occupational therapists in the prevention of hemiplegic shoulder pain include educating the stroke survivor and the caregiver involved, daily exercise, positioning, and the prescription of assistive devices[24]. Spasticity-related pain is another post-stroke pain syndrome that must be prevented, as it can be associated with sudden spasms that are painful and can cause permanent and painful muscle and tendon contractures[6,12]. A study conducted by Wissel et al., found that out of 103 stroke survivors, spasticity accompanied shoulder pain in 60%, elbow pain in 100%, and wrist pain in 33%[26]. Although more research is required to determine whether post-stroke spasticity can be prevented, painful contractures can be prevented by range of motion exercises, stretching, and positioning to counteract the pattern of tone[16,21]. Splinting and taping are not recommended for spasticity prevention; however, further research is required[16]. In conjunction with botulinum toxin A, techniques such as stretching, casting, taping and electrical stimulation may reduce spasticity, thus reducing the risk of contracture development[16]. However, this should be used with caution, as spasticity can positively reduce muscle atrophy, maintain bone mineral density, and improve mobility[21]. Shoulder-hand syndrome can be prevented by active, active-assisted, or passive range-of-motion exercises[16].

Pain assessment

The OTPF-4 guides a holistic assessment of pain, including the compilation of an occupational profile, the evaluation of cognitive, sensory perceptual, psychosocial, and physical functions, and the identification of relevant environmental factors[14]. It also involves evaluating occupational performance and analysing how pain impacts it[10]. Identification of the location, type, intensity and frequency of pain is essential, along

with assessing perceptions, coping skills, and the ability of individuals to manage their pain[10]. Various methods, such as interviews, observation, and questionnaires, can be used to gather this information[10]. The goal of the assessment is to understand the interaction between environmental, personal, and occupational factors and pain[10].

Pain treatment

Based on these assessment findings, occupational therapists develop individualised pain management plans that respond to the variable nature of pain[10]. Effective pain management requires occupational therapists to understand the physiology of pain, the mechanisms of pain, the disabilities associated with pain, and the successful pain intervention methods[10]. Occupational therapists focus on helping people manage pain while participating in meaningful occupations[10]. Through this approach, physical, mental, and spiritual needs can be met[10]. Occupational therapists use a variety of techniques to manage pain, including problem solving, pacing, graded activity exposure, and energy conservation during occupation[10]. Recommendations also involve improving body mechanics, joint protection, exercise, sleep, and pain neuroscience education that can help stroke survivors understand the mechanism of pain and how they need to manage it[10]. Assistive devices, environmental adaptations, and virtual reality can also be considered to encourage occupational performance despite the pain can also be considered[10]. In addition, techniques such as sensory re-education, mindfulness, cognitive behavioural therapy, coping skills training, and addressing cognitive fallout are used[10]. Occupational therapists also play a role in the management of pain medications, advocating for patients, and facilitating support or education groups[10].

The study aims to describe the current practice of occupational therapists in the prevention, assessment, and treatment of post-stroke pain.

2.6. Methodology

Study Design

A quantitative cross-sectional descriptive survey design was used.

Study population

The study included occupational therapists with an undergraduate occupational therapy degree obtained from a university in South Africa, registered with the Health Professions Council of South Africa (HPCSA), and who had intervened within the scope of occupational therapy with a stroke survivor of any age within the month before the completion of the survey in South Africa.

Sampling and Sample Size

As there is no specific database for occupational therapists who work with stroke survivors in South Africa, it was necessary to estimate the population size from available statistics. Of the 6,221 occupational therapists registered with HPCSA[25], an estimated 35.3% work in neurology[26]. Thus, 2,196 individuals were estimated to work in the field of neurology. Given a 10% error margin and a 95% confidence rate, a minimum of 93 participants were required for the study. The recruitment was carried out through invitations sent through the OTASA, South African Neurodevelopmental Therapy Association (SANDTA), social media and WhatsApp groups, with snowball sampling as an additional recruitment method.

Instrumentation

Based on the research objectives, an online survey questionnaire was developed from the literature findings. Participants who met the inclusion criteria completed the survey, which included participant demographics, practice setting details, stroke survivor demographics, and the nature of post-stroke pain identified by participants in their practice. To prevent response bias, before each section, participants initially provided open-ended responses on the prevention, assessment, and treatment techniques they use in practice. They then ranked 23 prevention strategies, 42 assessment methods, and 38 treatment techniques on a Likert scale. The responses were combined into "never/rarely," "sometimes", and "often/always" for presentation purposes. Items on the Likert scale were selected from the literature for relevance. After the Likert scale in each section, participants were allowed to add any other techniques they used as the Likert scale list was not collectively exhaustive.

The content validity of the survey was established through reviews by five experienced occupational therapists, including two university occupational therapy lecturers, two

founders of the Occupational Therapy Pain Management Group in South Africa, and a neurological rehabilitation clinician. Although one of the therapists provided written feedback without completing the rating scales, the Content Validity Index (CVI) was calculated based on four expert ratings, which gave S-CVI / Ave scores of 0.91 for relevance and 0.96 for clarity. Due to the required CVI rating standard of one[27], the survey underwent refinement, excluding irrelevant questions, rephrasing unclear ones, and improving clarity through added examples and elaborations on ambiguous terms. Additional response options, such as biopsychosocial intervention techniques, were also incorporated.

Ethical Considerations

Ethical approval was granted by the Human Research Ethics Committee (Medical) of the University of Witwatersrand [M221071]. The survey included an information letter before beginning the survey; subsequent completion of the survey constituted consent, and the participants were informed that they could withdraw from the study without negative consequences. The survey did not collect identifiable information and each survey was identified by a participant number.

Data Collection

Online data collection occurred from 6 February 2023 to 6 May 2023 with three hard copy survey responses manually entered into REDCap by the researcher. These surveys were available in hard copy at a Gauteng Department of Health (GDoH) workshop for participants who did not have access to data and were collected by the workshop coordinator, therefore maintaining anonymity. Reminders were sent through social media and data were securely stored on the REDCap platform. After data collection, the data were exported to a password-protected Microsoft Excel spreadsheet.

Data Analysis

The first author performed data analysis using Microsoft Excel. Descriptive statistics were used to analyse and summarise the data as frequency tables and percentages. Content analysis was performed for open-ended questions, involving response analysis, coding, and calculation of response frequencies within categories[28]. To

improve accuracy, the second author reviewed the coding and calculations and made corrections accordingly.

2.7. Results

The response rate exceeded the required sample size of 93 and reached 107.5%. Out of the 125 respondents, 25 were excluded for not meeting the inclusion criteria (n=8), providing no responses (n=3), or only completing the inclusion criteria questions (n=14). Of the remaining 100 responses, 37 contained missing data. Despite the missing data, all 100 responses were included in the analysis, and the presence of missing data was reported for each question. Of the 100 responses, attrition was observed in all nine sections of the survey (Figure 1), possibly attributed to the extended response times for open text-based questions and the extensive Likert scale ratings on prevention, assessment, and treatment methods. Therefore, participant fatigue may have occurred as they progressed. Additionally, participants who took breaks may have faced challenges returning to complete the survey due to the absence of return codes sent by REDCap.

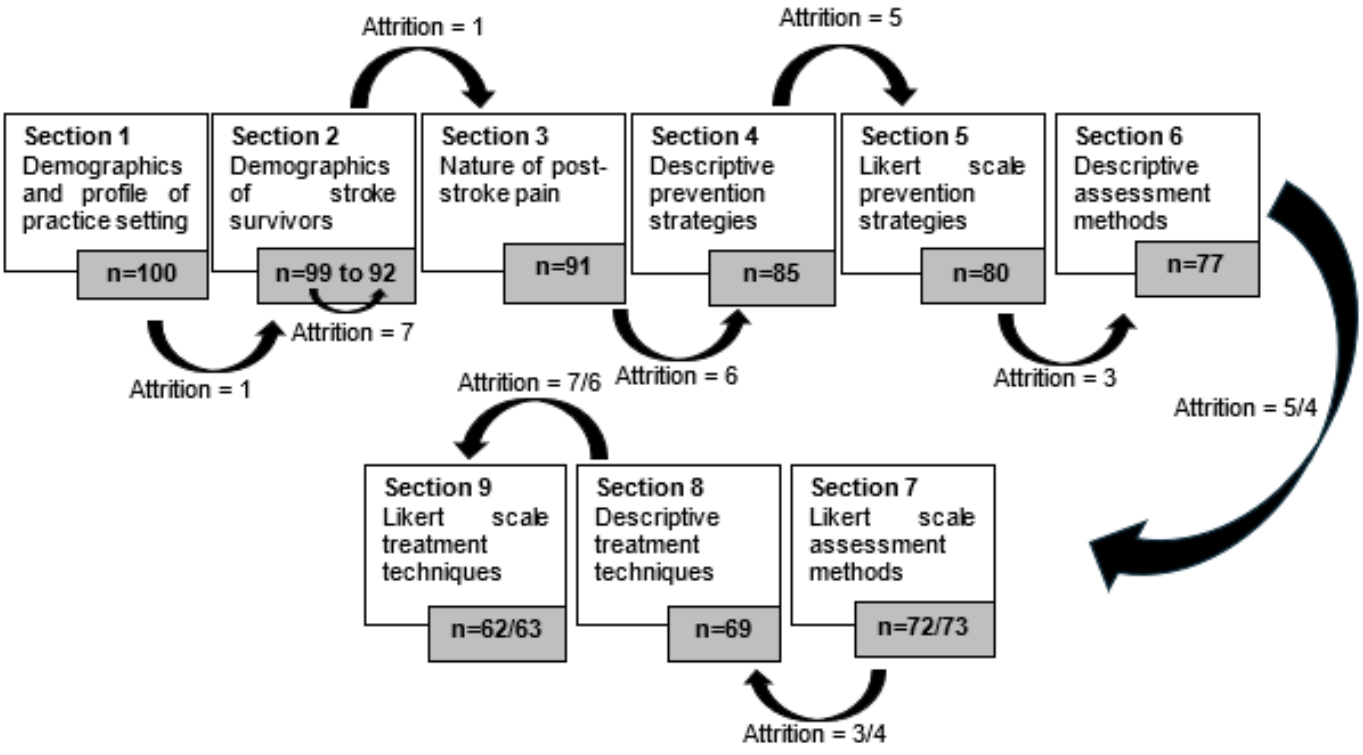


Figure 1: Flow diagram representing the number of attritions across the nine sections of the survey responses.

Demographics and profile of practice setting

Of the 100 participants, 84.0% (n=84) had undergraduate qualifications as their highest level of education. Participants from eight provinces responded to the survey, with the majority (n=42; 42.9%) practising in Gauteng province and 57.0% (n=57) working in the public sector. The range of experience in stroke rehabilitation varied widely, from less than a year to 31-40 years, and the majority (n=36; 36%) had 1-5 years of experience. In particular, 46.7% (n=43) had not received additional training in post-stroke pain management, while approximately one-third (n=28; 30.4%) had attended Bobath/Neurodevelopmental Therapy (NDT) training. Table I provides further demographic information.

Table I: Demographics and profile of practice setting

Variable		**n (%)**
Highest occupational therapy qualification (n=100)	Undergraduate degree (BOT/ BScOT)	84 (84.0)
	Master's degree (MOT/MScOT)	15 (15.0)
	Postgraduate Diploma (PG Dip)	1 (1.0)
Province (n=98)	Gauteng	42 (42.9)
	Western Cape	23 (23.5)
	Kwa Zulu Natal	13 (13.3)
	Free State	7 (7.1)
	Mpumalanga	6 (6.1)
	Eastern Cape	4 (4.1)
	Northern Cape	2 (2.0)
	North West	1 (1.0)
Sector (n=100)	Public	57 (57.0)
	Private	44 (44.0)
	NPO/NGO	2 (2.0)
	Academic	1 (1.0)
Setting (n=100)	District	26 (26.0)
	Primary Facility	17 (17.0)
	Tertiary	13 (13.0)
	Rehabilitation unit	6 (6.0)
	Regional	5 (5.0)
	Central	1 (1.0)
	Private rehabilitation unit	32 (32.0)
	Private hospital	19 (19.0)
	Home-Based	17 (17.0)
	Private outpatient practice	3 (3.0)
	Long-term care facility	1 (1.0)
	School	1 (1.0)
Years worked in stroke rehabilitation (n=100)	Less than a year	21 (21.0)
	1-5 years	36 (36.0)
	6-10 years	24 (24.0)
	11-20 years	14 (14.0)
	21-30 years	3 (3.0)
	31-40 years	2 (2.0)

Additional courses/ training related to pain and/or stroke management (n=92)	NDT/ Bobath training	28 (30.4)
	Pain courses	13 (14.1)
	Postgraduate training	6 (6.5)
	Technical skills	6 (6.5)
	Neurorehabilitation-related courses	6 (6.5)
	On-the-job training	4 (4.3)
	Hand-related courses	4 (4.3)
	Own research	2 (2.2)
	Psychology pre-grad	1 (1.1)
	None	43 (46.7)

Demographics of stroke survivors

Participants intervened primarily with 51 to 60-year-olds (n=77; 77.8%) in the subacute phase of stroke recovery (n=82; 82.8%). Only one participant exclusively used group sessions for intervention, while the majority used individual sessions (n=55; 55.6%) or a combination of individual and group sessions (n=43; 43.4%). Collaboration with other healthcare professionals was common, particularly with physiotherapists (n=90; 97.8%), doctors (n=78; 84.8%), and nurses (n=46; 50%). Table II shows a summary of the demographics of the stroke survivors with whom the participants intervened.

Table II: Demographics of stroke survivors

Variable		**n (%)**
Phase/s of intervention (n=99)	Acute	55 (55.6)
	Subacute	82 (82.8)
	Early chronic	62 (62.6)
	Late chronic	40 (40.4)
Average age of stroke survivors (n=99)	0-12 years	2 (2.0)
	13-20 years	2 (2.0)
	21-30 years	9 (9.1)
	31-40 years	29 (29.3)
	41-50 years	59 (59.6)
	51-60 years	77 (77.8)
	61 years +	63 (63.6)
Structure of intervention (n=99)	Individual	55 (55.6)
	Group	1 (1.0)
	Both	43 (43.4)
Members of the multidisciplinary team (MDT) involved (n=92)	Physiotherapist	90 (97.8)
	Doctor	78 (84.8)
	Nurse	46 (50.0)
	Social worker	31 (33.7)
	Psychologist	28 (30.4)
	Biokineticist	4 (4.3)
	Chiropractor	0 (0)
	Other Speech Therapist Dietitian Music Therapist	 8 (8.7) 2 (2.2) 1 (1.1)

	Podiatrist Orthopaedics	1 (1.1) 1 (1.1)
	None	2 (2.2)

Nature of post-stroke upper limb pain

Among 91 participants, 96,7% (n=88) acknowledged pain in stroke survivors with whom they intervened. The most common descriptions of pain included shooting (n=37; 40.7%), hyperaesthesia (n=33; 36.3%), and cramping (n=30; 33.0%). Although five participants indicated other descriptions, none were different from those presented and were therefore excluded. The participants most frequently reported pain located in the stroke survivor's shoulder (n=82; 91.2%), followed by the wrist (n=42; 46.2%) and the fingers (n=27; 29.7%). Most noted that pain occurred during passive movement of the hemiplegic upper limb (n=63; 69.2%) and was often described as intermittent (n=35; 38.5%). The results, summarised in Table III, summarise the participants' experiences of pain in the hemiplegic upper limb amongst the stroke population with whom they intervened.

Table III: Nature of post-stroke upper limb pain

Variable		**n (%)**
Most common description of pain (n=91)	Shooting	37 (40.7)
	Hyperaesthesia	33 (36.3)
	Cramping	30 (33.0)
	Dull aching	27 (29.7)
	Stabbing	22 (24.2)
	Throbbing	21 (23.1)
	Burning	19 (20.9)
	Allodynia	14 (15.4)
	Non-specified	13 (14.3)
	Pain with temperature changes	12 (13.2)
	Hyperalgesia	12 (13.2)
	Dull	8 (8.8)
	Paraesthesia	2 (2.2)
	Other	5 (5.5)
	I do not assess this	4 (4.4)
Location of pain (n=91)	Shoulder	83 (91.2)
	Wrist	42 (46.2)
	Fingers	27 (29.7)
	Elbow	23 (25.3)
	Arm	21 (23.1)
	Forearm	13 (14.3)
	Thumb	8 (8.8)
	They do not present with/ report pain in the hemiplegic upper limb	3 (3.3)
	I am not sure	2 (2.2)
Most common duration of pain (n=91)	During passive movement of the hemiplegic upper limb/s	63 (69.2)

	Intermittent	35 (38.5)
	During active movement of the hemiplegic upper limb/s	29 (31.9)
	Constant	28 (30.8)
	Other	4 (4.4)
Consideration for post-stroke upper limb pain (n=92)	Not considered as there are too many other factors to prioritise	0 (0.0)
	Not considered as there are other MDT members focusing on this	3 (3.3)
	Considered often but lack the skills and knowledge to intervene	40 (43.5)
	Considered often but do not have the time to intervene	15 (16.3)
	Always considered and included in intervention	45 (48.9)
	Other	2 (2.2)

Overall pain management

Table III above shows the overall intervention of the participants for post-stroke upper limb pain. Notably, 48.9% (n=45) always included pain management, 43.5% (n=40) considered it but lacked intervention skills or knowledge, and 16.3% (n=15) reported time constraints. A minority, 3.3% (n=3), relied on other members of the MDT to manage pain.

Table IV: Strategies, methods or techniques used by occupational therapists in pain, prevention, assessment, and treatment: categories generated from content analysis.

Category generated from content analysis		**Frequency n (%)**
Strategies used for prevention (n=85)	Mobilisation and strengthening	48 (56.5)
	Positioning	36 (42.4)
	Education	28 (32.9)
	Orthoses	21 (24.7)
	Temperature modalities	12 (14.1)
	Neurofacilitatory/ inhibitory techniques	9 (10.6)
	Sensory and awareness training	9 (10.6)
	Massage	7 (8.2)
	Referral to MDT	6 (7.1)
	Relaxation techniques	5 (5.9)
	Mirror therapy	2 (2.4)
	Functional Activities	2 (2.4)
	Oedema Management	2 (2.4)
	Botox Referral	2 (2.4)
	Rest	1 (1.2)
	NDT methods	1 (1.2)
	Scheduling of therapy times	1 (1.2)
	Miscellaneous	1 (1.2)
	Not a component of intervention	15 (17.6)
	Subjective pain assessment	67 (85.7)

Methods used for assessment (n=77)	Objective assessments	39 (50.6)
	Not a component of intervention	7 (9.1)
Techniques used for treatment (n=69)	Mobilisation and Strengthening	41 (59.4)
	Positioning	28 (40.6)
	Temperature modalities	22 (31.9)
	Education	22 (31.9)
	Orthoses	21 (30.4)
	Massage techniques	14 (20.3)
	Relaxation techniques	14 (20.3)
	MDT referrals	11 (15.9)
	Specific pain management techniques	10 (14.5)
	Sensory and awareness training	9 (13.0)
	Functional Activities	8 (11.6)
	Oedema management	7 (10.1)
	Neurofacilitatory/ inhibitory techniques	6 (8.7)
	Scheduling of therapy time	2 (2.9)
	Group sessions	2 (2.9)
	Rest	2 (2.9)
	Not a component of intervention	10 (14.5)

Pain Prevention Practices

The responses of the participants (n=85) to the open-ended pain prevention question are summarised in Table IV. The frequencies reported for each pain prevention strategy are illustrated in Figure 2. The most frequent pain prevention strategies reported in the open-ended question were mobilisation and strengthening (56.1%; n=48), positioning (42.4%; n=36), education (32.9%; n=28), and orthoses (24.7%; n=21). Twenty percent (n=17) of the participants specifically mentioned the prevention of shoulder subluxation. Notably, 17.6% (n=15) of participants indicated that they do not include pain prevention in their management of stroke survivors, while only two participants (2.4%; n=2) mentioned using functional activities for pain prevention.

Among 80 participants, the most frequent strategies identified on the Likert scale used ‘often’ or ‘always’ in the prevention of upper limb pain post-stroke were exercises of active range of motion with assisted movement (97.5%; n=78), exercises (97.5%; n=78), passive range of motion (96.3%; n=77), daily exercise (92.5%; n=74), and education on positioning of the hemiplegic upper limb in sitting (91.3%; n=73) and in bed (88.8%; n=71). The least used approaches, but still used by the majority of therapists, included a shoulder sling that allowed elbow movement (71.3%; n=57), positioning the affected elbow in flexion (61.3%; n=49), and strapping (65.0%; n=52).

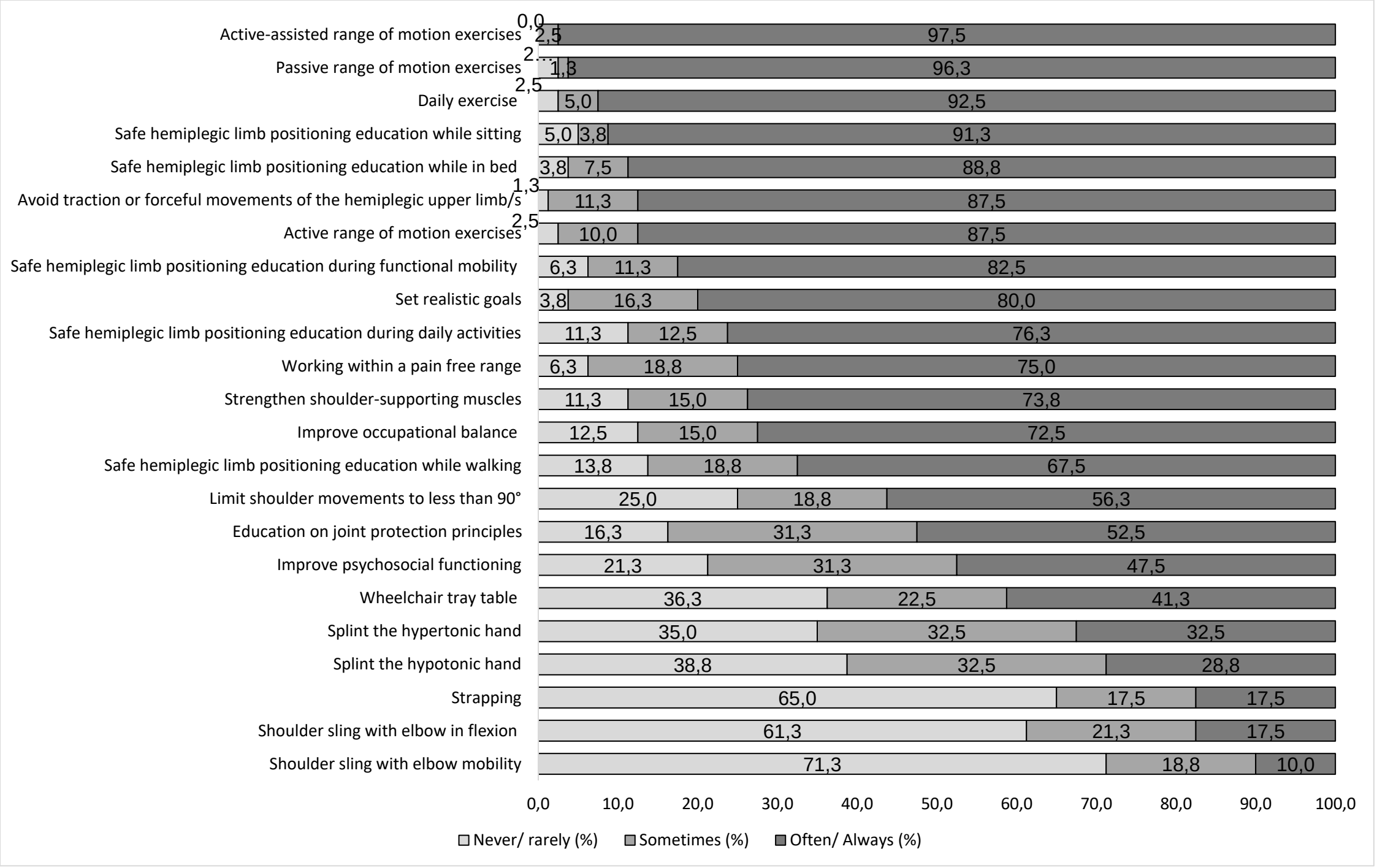


Figure 2: Pain prevention strategies: frequency of interventions used in the prevention of post-stroke upper limb pain by occupational therapists (n=80).

Pain Assessment Practices

The responses of the participants (n=77) to the open-ended pain assessment question are summarised in Table IV. The frequencies reported for each pain assessment method are illustrated in Figure 3. Subjective pain assessment methods were the most used and were indicated by 85.7% (n=67) of the participants. Objective assessment methods were the other category of assessment methods, used by 50.6% (n=39) of the participants. Pain rating scales, questionnaires, and outcome-based measures were the most common subjective assessment (62.3%; n=48), followed by interviews (57.1%; n=44) and obtaining collateral information (3.9%; n=3). Objective assessments primarily included physical assessments (42.9%; n=33), and observation (28.6%; n=22). A smaller percentage of 9.1% (n=7) of participants indicated that they did not assess pain in their management of stroke survivors.

Of the 42 methods presented (Figure 3); more than 90% of the participants reported obtaining subjective and objective information in assessing pain often or always. These included taking a comprehensive history (90.4%; n=66) and determining the needs and priorities (97.3%; n=71) of the stroke survivor. Objective information most commonly assessed often or always was the following: muscle tone (98.6%; n=72), mobility of joint function (97.3%; n=71), sitting posture (95.9%; n=70), muscle power of the hemiplegic upper limb (94.5%; n=69), the need for caregiver assistance in daily activities (94.5%; n=69), location of pain (93.2%; n=68), oedema (90.4%; n=66), and the effect of pain on the daily activities of stroke survivors (90.4%; n=66). Methods such as reviewing X-rays of affected joints (52.1%, n=38), assessing the impact of pain on cognition (28.8%; n=21), and using outcome-based measures (27.8%; n=20) were rarely or never used. Notable for occupational therapy, the less commonly used assessments used often or always include psychological factors (48.6%; n=35), the impact of pain on cognition (52.1%; n=38), and the impact of pain on social participation of stroke survivors (55.6%; n=40), leisure activities (56.9%; n=41), sleep (65.8%; n=48) and work (72.6%; n=53). Although most participants (51.4%; n=37) reported using outcome-based measures often or always, only 27.0% (n=10) were later able to list relevant measures. This discrepancy suggests possible response bias. Pain rating scales included numerical rating scales (4.1%; n=3), the visual analog scale (6.8%; n=5) and two which were not specified (2.7%; n=2). Other outcome-based measures reported were the Abbey Pain Scale (1.4%; n=1), the Disabilities of

the Arm, Shoulder and Hand (DASH/ QuickDASH) (2.7%; n=2) and the Fugl-Meyer Assessment (2.7%; n=2). Five other responses were outcomes of stroke rehabilitation and not outcome-based measures and were therefore excluded.

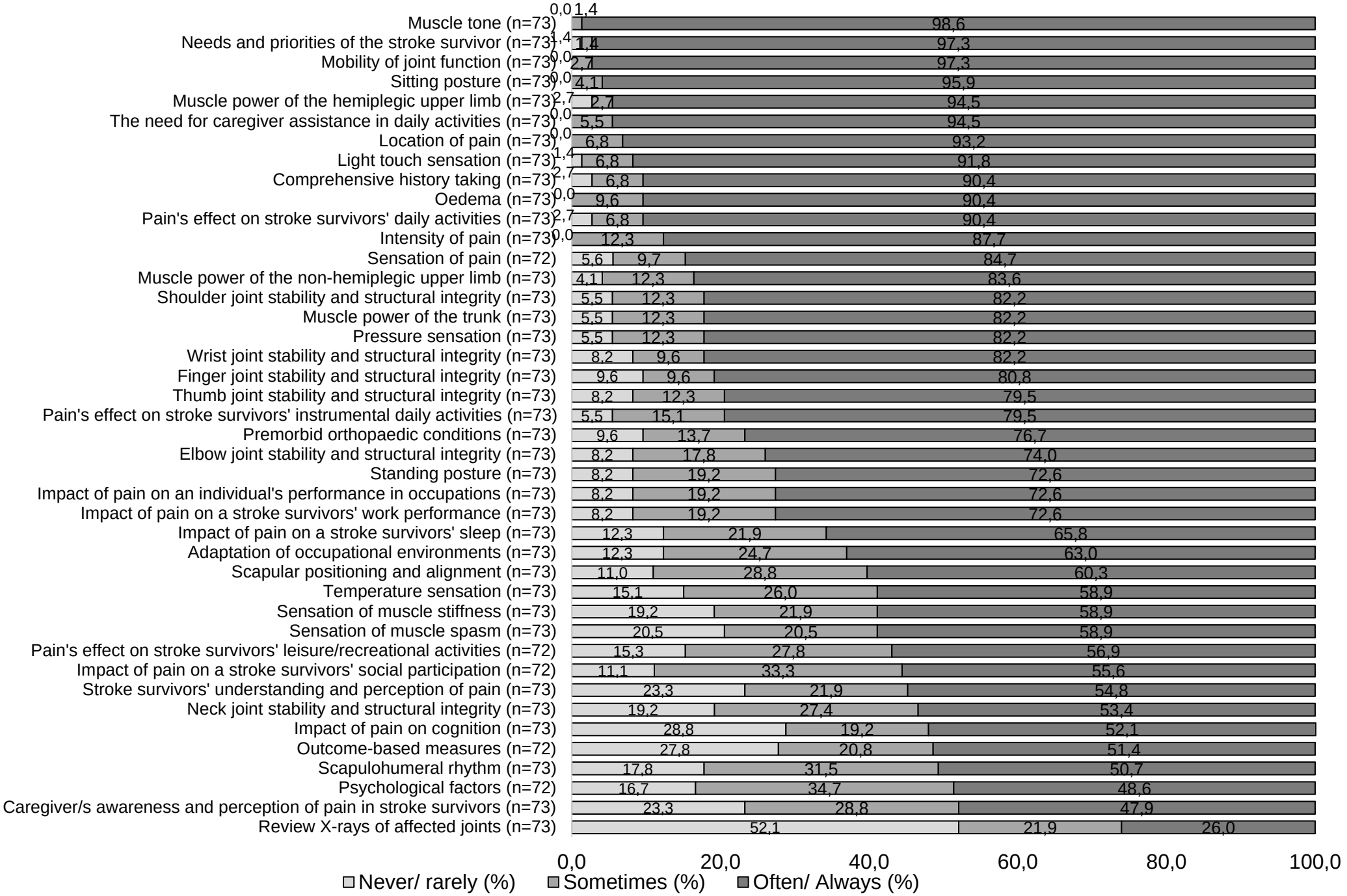


Figure 3: Pain assessment methods: frequency of interventions used in the assessment of post-stroke upper limb pain by occupational therapists.

Pain Treatment Practices

The responses of the participants (n=69) to the open-ended pain treatment question are summarised in Table IV. The frequencies reported for each pain treatment technique are illustrated in Figure 4. Mobilisation and strengthening were the methods most commonly used for the treatment of post-stroke upper limb pain (59.4%; n=42). This was followed by positioning (40.6%; n=28), education (31.9%; n=22), temperature modalities (31.9%; n=22) and orthoses (30.4%; n=21). Other less-reported techniques included massage, neuro facilitatory/ inhibitory techniques, sensory and awareness training, oedema management, and relaxation techniques. Post-stroke upper limb pain was reported as not treated by 14.5% (n=10) of participants.

Among the 38 possible treatment techniques, occupation-based activities (92.1%; n=58), hands-on techniques (92.1%; n=58), auto-assisted upper limb exercises (90.5%; n=57), and bilateral upper limb activities (90.5%; n=57) were used most frequently. Conversely, dry needling (100%; n=63), neuromuscular electrical stimulation (NMES) (87.3%; n=55), and transcutaneous electrical nerve stimulation (TENS) (82.5%; n=52) were rarely or never used.

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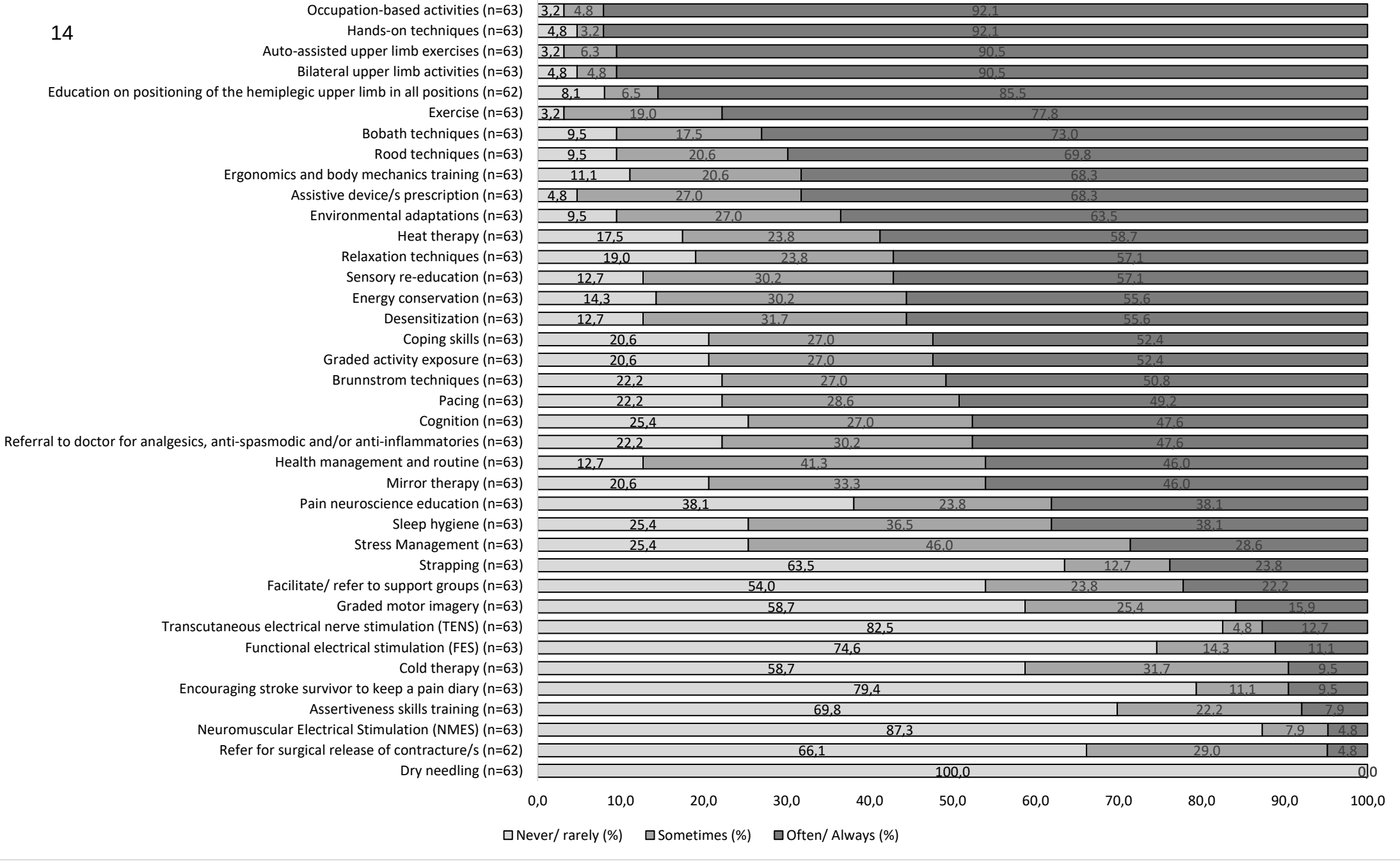


Figure 4: Pain treatment techniques: frequency of interventions used in the treatment of post-stroke upper limb pain by occupational therapists.

2.8. Discussion

Through an online survey, the study described how occupational therapists prevent, assess, and treat post-stroke upper limb pain in South Africa.

Demographic information

Most of the participants had undergraduate qualifications, had less than five years of experience and, in accordance with HPCSA data, worked in provinces that host the most occupational therapists; Gauteng and the Western Cape. Interestingly, more than half of the participants were from the public sector, contrary to the current distribution of occupational therapists in South Africa, where more work in the private sector[29]. However, due to the fact that 84% of the South African population access public healthcare and the high prevalence of stroke risk factors in the country, the frequency of stroke rehabilitation by occupational therapists in this sector is likely high[30].

Characteristics of post-stroke upper limb pain

The study highlighted the substantial problem of post-stroke upper limb pain in South Africans. Almost all participants recognised upper limb pain in stroke survivors with whom they intervened, higher than the prevalence reported in the literature. This may be due to the poor focus on prevention and early intervention and the consequent development of pain as a secondary complication. The age distribution of the stroke survivors managed by the participants varied with majority being between 51 and 60 years of age. Few were below the age of 30 years. This is coherent with the existing literature which indicates that in South Africa, 45% of stroke survivors were under the age of 65, and 27% were under the age of 55[28]. In Gauteng, the average age of stroke survivors is reportedly 51 years and considering that majority of the participants practice in this province, the young age of stroke survivors is validated.

Post-stroke pain was reported to predominantly affect the shoulder, followed by the wrist, fingers, and elbow. This is consistent with the literature that indicates that hemiplegic shoulder pain is the most common post-stroke pain syndrome[8]. However, the prevalence of hemiplegic shoulder pain was higher in this study than reported in the literature[8]. This may be due to more than half of the study participants having less than six years of experience in stroke rehabilitation and many reporting that they lack the skills and knowledge to intervene in post-stroke upper limb pain. Therefore,

hemiplegic shoulder pain may not be effectively prevented or treated. Hemiplegic shoulder pain can be caused by neurological, mechanical, musculoskeletal, or any combination of these factors, and therefore the description of pain depends on the pain mechanism[8].

Pain in the hemiplegic shoulder, wrist, fingers, and elbow, together with the post-stroke pain descriptions identified in the study, correlate with the most common post-stroke pain syndromes[8]. Central post-stroke pain can affect the hemiplegic face, upper limbs, and/or lower limbs, and more predominantly affects the hand[8]. The lower prevalence rate of this syndrome may explain why shoulder pain was higher in this study than the wrist and fingers[8]. Shooting, burning, and throbbing pain, which were within the top seven descriptions of pain reported, are symptoms experienced in CPSP, and the three modes of presentation also align with the findings of this study: continuous pain, sudden intense episodes of pain, and allodynia or hyperalgesia[8].

The high incidence of shoulder, wrist, and finger pain may also be attributed to SHS, where pain is most commonly present in the shoulder but may also present in the hand or both[20]. The lower percentages of participants indicating hyperalgesia and allodynia, which are commonly associated with this syndrome, correlate with the lower incidence rate compared to hemiplegic shoulder pain and spasticity-related pain[8]. The Budapest criteria include the presence of continuous pain, which was the third most common duration of pain reported[8].

In addition to the syndromes mentioned above, spasticity, which is most prevalent in the hemiplegic upper limb, may also explain pain in the elbow, wrist, and shoulder[21]. Pain related to spasticity is often described as night cramps and spasms, which was the third most common pain description reported[31]. Since passive movement is the most common trigger for pain in this study, this pain syndrome may be present in some of the stroke survivors managed by the participants in this study[21].

Pain Prevention

The study found that the prevention of post-stroke pain was included by nearly all participants. Numerous stroke rehabilitation guidelines align with mobilisation as the most common prevention strategy used by occupational therapists in this study. These strategies include motor strengthening, electrical stimulation to prevent shoulder subluxation, passive mobilisation, active and active-assisted exercises, anti-

synergistic patterns and facilitating scapulohumeral rhythm to prevent subacromial impingement[16,24,32,33]. With passive mobilisation being the most widely used technique by study participants, literature supports current pain prevention practice. However, although not listed on the Likert scale, only two participants mentioned electrical stimulation and none mentioned facilitating scapulohumeral rhythm in the open-ended question, highlighting the need for training on these methods and ongoing professional development. Additionally, reduced use of electrical stimulation may be due to limited access and experience, high costs, or difficulty ordering the device in public facilities. Occupational therapists are recommended to initiate or continue to include regular exercise, strengthening shoulder support muscles, and active, active-assisted, and passive range of motion exercises in the prevention of post-stroke pain.

Positioning of the upper limb is a common technique discussed in the literature and about half of the participants use recommendations on joint protection principles. Most use positioning during various activities, and approximately 40% of the participants recommended a tray table when seated in a wheelchair. Reduced use of tray tables may be due to cost, non-adjustable wheelchair armrest height, desk armrests that cannot hold the tray table, stroke survivor preferences, and/or reduced awareness of their benefits. Although the use of shoulder slings in the prevention of hemiplegic shoulder pain remains debatable, a sling that supports the hemiplegic upper limb against gravity, without positioning the shoulder in adduction and internal rotation, is recommended[20]. Shoulder slings that allow elbow movement are used more frequently than those that position the elbow in flexion. This shows that some therapists are complying with evidence-based practice, but the controversial use of slings and inconsistent recommendations make their use questionable. Further research is recommended on the correct type of sling and its benefits. The limited use of splinting and taping by participants is consistent with the literature that discourages its use in spasticity prevention[16]. Education, particularly on the positioning and handling of the hemiplegic upper limb in the acute phase, is highlighted in the literature, and although only a third of the participants reported including education in stroke intervention, it is recommended that the education of the stroke survivor, caregiver and any other involved personnel is included in all cases[16,24]. Pain prevention must be prioritised from the onset of stroke throughout the life of stroke survivors.

Pain Assessment

The study found that most of the participants used subjective means to assess post-stroke pain, followed by objective assessments. Despite the literature indicating the absence of comprehensive, relevant, and easily accessible assessment tools, making post-stroke pain assessment difficult,[24] the participants indicated that they most commonly use pain rating scales followed by questionnaires, outcome-based measures, and interviews. Due to the subjective nature of pain,[35] the high percentage of subjective assessments used by participants is positive. However, there is no known pain scale that has been developed specifically for post-stroke pain, but general pain rating scales such as numeric rating scales, visual analogue scales, faces pain scales, and/or verbal pain descriptor scales have been reported[35]. Although these tools are effective, stroke survivors' deficits in cognition and/or perception can limit their use[24]. Just over half of the participants indicated that they use outcome-based measures, but few listed relevant measures related to pain. This indicates a reduced understanding of outcome-based measures and training on the purpose, and methods of using these measures are recommended. Aligning with a client-centred approach, most participants assess the needs and priorities of the stroke survivor, many obtain a comprehensive history, and just less than two-thirds assess the required adaptations of occupational environments. Just over half of the participants assessed the impact of pain on cognition, and psychological factors were among the least to be assessed. This is significant because cognition, physical performance, and psychological impairments are reportedly higher in stroke survivors who experience pain[2]. A position statement from the American Occupational Therapy Association (2021) explains that occupational therapists must assess an individual’s coping skills, pain perceptions, psychological and mental responses to pain, and his ability to self-manage his pain[10]. Most of the participants assessed the impact of pain on occupations, showing most occupational therapists do exercise their unique role in the assessment of engagement in activities and life participation.

Physical assessments and observations were the two main categories identified for the objective assessment. Many participants assessed shoulder joint stability, with less assessing the elbow and neck. Most of the participants assessed muscle tone, the mobility of joint functions and the muscle strength of the hemiplegic upper limb. These assessment findings provide the occupational therapist with information on the cause

of pain such as spasticity or musculoskeletal impairments. Fewer assessed scapula positioning and alignment which contradicts stroke rehabilitation recommendations[54]. Light touch sensation was commonly assessed followed by pain, pressure, sensation of temperature, muscle stiffness, and muscle spasms.

The need to include less commonly used assessments, such as the impact of pain on cognition, psychological factors, and occupations, should be reinforced in stroke rehabilitation. Occupational therapists who do not assess post-stroke pain effectively, need to prioritise this in their intervention of stroke survivors. The need for stroke-specific pain assessment tools that can be used by occupational therapists in South Africa is also identified.

Pain treatment

Treatment techniques for managing upper limb pain post-stroke were similar to those identified in the prevention of pain and included mobilisation and strengthening, positioning, temperature modalities, education, and orthoses. Other categories less frequently mentioned were referrals to other MDT members, massage techniques, relaxation techniques, sensory and awareness training, functional activities, mirror therapy/ graded motor imagery, oedema management, and neurofacilitatory and inhibitory techniques. A small percentage reported that they do not treat post-stroke upper limb pain likely due to the lack of skills and knowledge and time constraints. As discussed for pain prevention, mobilisation and strengthening included passive range-of-motion techniques or stretching and active range-of-motion techniques or strengthening exercises that align with the SA-CSRG[16]. Participants who use these techniques should continue and those who do not should incorporate them into their rehabilitation programmes.

Although the participants did not report details on how positioning was performed, the SA-CSRG includes positioning of the hemiplegic upper limb in their treatment of post-stroke pain and therefore occupational therapists should continue to use these techniques[16]. Participants who mentioned education as one of their treatment modalities included joint protection principles and education on how to position and handle the hemiplegic upper limb. In the Likert scale ratings, more than 80% of the participants conducted education on the position of the upper hemiplegic limb in all positions and more than 60% of the participants trained in ergonomics and body

mechanics. Splinting, strapping, and slings contribute to positioning. Splinting for spasticity management is not recommended, as the results are inconclusive, and therefore the low percentage of splinting by participants is in line with these recommendations[16]. However, splinting or casting together with intramuscular botulinum toxin is recommended in stroke survivors who present with continuous worsening of spasticity in specific muscles for a maximum of 12 weeks according to the Brazilian Academy of Neurology Practice Guidelines for Stroke Rehabilitation[34]. In cases where botulinum toxin is not used, splinting or casting should be carefully considered from case to case and should not be part of routine treatment for all stroke survivors[32].

In the Likert scale rating, heat therapy was often or always used by more than half of the participants and cold therapy by less than 10%. The use of temperature modalities in the treatment of upper limb pain post-stroke is scarce in the literature.

Non-pharmacological intervention for CPSP is limited in stroke rehabilitation guidelines with a focus on pharmacological treatment only[16,32,33]. However, according to Mhangara et al. (2020) and Keszler et al. (2017), cognitive behavioural therapy, pain neuroscience education, graded motor imagery, and transcutaneous electrical nerve stimulation (TENS) are used in the treatment of CPSP, but evidence on their effectiveness is limited[19,20]. Pain neuroscience education is often or always included by just under 40% of participants, with graded motor imagery and TENS used by few participants. Early mobilisation, mirror therapy, stellate ganglion blockade, and psychological intervention have shown effectiveness[23] and mirror therapy is used by less than 50% of participants, and psychological interventions such as relaxation techniques, coping skills, and stress management are used by some participants. Reduced use of these techniques may be due to the cost and lack of training in the use of the TENS device and the inability of stroke survivors to use the device consistently. Mirror therapy may also not be possible in settings where the ratio between the therapist and the patient is low. As the evidence for the effectiveness of these techniques in the treatment of CPSP is sparse, it is difficult to analyse the data from the participants.

Referral for botulinum toxin A, NMES, or vibration can be used in muscles presenting with spasticity in addition to traditional rehabilitation to reduce spasticity[16]. However,

only five participants reported referring for botulinum toxin A treatment in open responses. In South Africa, the use of these interventions can be limited due to cost implications, high ratios of stroke survivors to therapists, and limited access to rehabilitation services.

Koman et al. (2023) report that treatment goals should aim to reduce abnormal signs and symptoms, improve function, and improve quality of life[22]. Hand therapy, including techniques such as desensitisation, contrast baths, and various modalities, is crucial to improve upper limb function[22]. Desensitisation is used by more than 50% of the participants and, although not included on the Likert scale, contrast baths were alluded to by one participant in the open question. Treatment of pain-related anxiety or depression is also recommended in the management of SHS[20].

Occupational therapists in this study employ techniques that address anxiety or depression with varying frequencies. The study indicates gaps between the recommended guidelines and current practices, particularly in terms of occupational therapy-specific interventions, which emphasises the need for a more standardised and evidence-based approach.

2.9. Conclusion

In this study, a high prevalence of post-stroke upper limb pain is indicated in South Africa with majority of occupational therapists implementing prevention, assessment and treatment. The impact of pain on the occupational performance of a stroke survivor, psychosocial functioning, and cognitive skills highlights the need for occupational therapists to intervene in pain management. Occupational therapists mainly address body structures and functions associated with pain, indicating the potential to strengthen the focus on activity and participation while considering contextual factors. Further research is recommended for pain interventions such as electrical stimulation, prescription of wheelchair tray tables, and the use of hemiplegic arm slings. Due to the subjective nature of pain, the main assessment methods currently used in occupational therapy practice are suitable. However, more assessments are needed, such as the impact of pain on cognition, psychological factors, and occupations. The need for stroke-specific pain assessment tools that can be used by occupational therapists in South Africa is also identified. Although post-stroke pain treatment is similar to the strategies used in pain prevention, it is

recommended to use more techniques in the intervention such as relaxation, energy conservation, coping skills, exposure to graded activities, cognition, health management and routine, sleep hygiene, stress management, assertiveness skills training, and referral to support groups.

Although the SA-CSRG (2019) offers recommendations for pain prevention, assessment, and treatment, its scarcity and misalignment with the principles of occupational therapy emphasise the need for customised evidence-based occupational therapy guidelines. The reliance on international guidelines also causes a contradiction of literature and does not always respond to the needs of the South African population. The rapid increase in the prevalence of stroke highlights the urgency for occupational therapists to improve their knowledge and skills in pain management, crucial to alleviating the burden of care in the country.

2.10. Limitations

A limitation of the study includes the possible response bias of some participants. Incomplete responses may have been due to survey fatigue. Additionally, the potential influence of the Likert scales on the participant's responses to the open-ended questions regarding current practice in the assessment and treatment of post-stroke pain is another limitation influencing the validity of the data, as is the lack of consistent terminology used amongst participants.

2.11. Recommendations

Based on the findings of this study, it is recommended that international and national best-practice guidelines specific to post-stroke upper limb pain management by occupational therapists are developed and regularly reviewed. Further research is also recommended on the effectiveness of the techniques discussed in this study on post-stroke upper limb pain in the South African population, as well as research on the nature of pain specifically experienced by stroke survivors. This can include exploring cultural or demographic factors that influence pain experiences in South African stroke survivors, as understanding the unique nature of pain in this context can inform more targeted interventions. Prevention, assessment, and treatment of pain should be emphasised in undergraduate and postgraduate studies, with additional continuing professional development training provided. The findings of this study should be

distributed via journals, conferences, workshops, and social media to improve the management of post-stroke upper limb pain by occupational therapists.

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CHAPTER 3: SYNOPSIS

3.1. Introduction to the chapter

Post-stroke pain is a significantly debilitating consequence of stroke that affects between 10-45.8% of stroke survivors[24]. In South Africa, stroke is one of the main contributors to disability and is one of the primary countries to experience a high number of strokes with a predicted 75, 000 per year[15,18]. Despite the physical, communicative and cognitive fallout that can exacerbate the extent of disability in stroke survivors, post-stroke pain itself is associated with impairments in body functions, activities, and participation and is the primary reason for seeking medical services[10,19,20,90]. Additionally, deficits in mental functions, neuromusculoskeletal, and movement-related functions are greater in stroke survivors who experience pain[22]. Pain has the potential to exacerbate and cause changes in the central nervous system that can cause long-lasting symptoms[10]. Furthermore, the ongoing medical or therapeutic intervention that a stroke survivor with pain may require contributes to an increased burden of care on the healthcare system and thus the economy[10].

To improve the recovery prognosis post-stroke, pain must be prevented, assessed, and treated as soon after stroke onset as possible[40]. However, despite the clear need to prioritise post-stroke pain in stroke rehabilitation, the literature identifies poor recognition and intervention in post-stroke pain[20,23].

The main causes of post-stroke pain include five syndromes: central post-stroke pain (CPSP), hemiplegic shoulder pain, pain secondary to spasticity, shoulder-hand syndrome (SHS) and headaches[24]. Four of these syndromes are significantly correlated with pain in the hemiplegic upper limb that exhibits features of nociceptive and/or neuropathic pain[20,23]. Central post-stroke pain, which affects 1-12% of stroke survivors, can present in the hemiplegic face, upper, and/or lower limb[24]. With a high prevalence of 75%, hemiplegic shoulder pain is the most common, emphasising upper limb pain[24]. Spasticity-related pain, more common in the hemiplegic upper limb, occurs in 72% of cases, while SHS affecting the shoulder, hand or both occurs in 2-49% of stroke survivors[24].

As discussed in previous chapters, post-stroke pain intervention must be of high quality, but due to the complex nature of these post-stroke pain syndromes, the challenges for stroke survivors with speech and language fallout to report pain, the difficulties for those with cognitive, perceptual, visual, or motor fallout to complete pain questionnaires, and the lack of comprehensive post-stroke pain management guidelines, pain is not easily diagnosed or managed[20,27]. However, pain can be managed with a resultant improvement in activities, participation, and quality of life, and occupational therapists play a vital role in achieving this[27,10]. To ensure that post-stroke pain is managed effectively in South Africa, current occupational therapist practices on prevention, assessment, and treatment of upper limb pain post-stroke should be described. This study aimed to respond to this need.

3.2. Discussion

The study aimed to describe the current practices employed by occupational therapists in South Africa in addressing upper limb pain after stroke.

Demographic Information

The study comprised 100 occupational therapists from diverse backgrounds in South Africa, reflecting varied qualifications, practice settings, and stroke rehabilitation experience (ranging from less than a year to over 30 years). Most of the participants had undergraduate qualifications (82%), with the highest representation from Gauteng (42.9%), followed by the Western Cape (23.5%) and Kwa-Zulu Natal (13.3%). Although the distribution aligns with 2018 HPCSA data (n=5147), where 35.7% of occupational therapists were located in Gauteng, 26.7% in the Western Cape, and 12% in Kwa Zulu Natal[82], the latest geographical data from April 2022 (n=6063) are unavailable[78]. Interestingly, 57% of the participants were from the public sector, contrary to the current distribution of occupational therapists in public healthcare, where the mentioned provinces have lower rates compared to the private sector[91]. However, given that 84% of the South African population accesses public healthcare[17], the frequency of stroke rehabilitation by occupational therapists in this sector is likely high and could explain the reason for the higher number of public healthcare therapists

responding to this survey. This distribution could also be due to the researcher's position in a public health facility, making communication of the invitation to participate and access to public health occupational therapists more frequent.

Characteristics of post-stroke upper limb pain

The study highlighted the substantial problem of post-stroke upper limb pain in South Africans. Among 91 participants, 96,7% (n=88) acknowledged pain in stroke survivors with whom they intervene, higher than the prevalence reported in the literature of 10-45.8%[24]. This may be due to the poor focus on prevention and early intervention and the consequent development of pain as a secondary complication. The age distribution of stroke survivors managed by 99 participants varied with 51-60 years (77.8%; n=77), 61 years and older (63.6%; n=63) and 41-50 years (59.6%; n=59) as the most common. This is coherent with the existing literature which indicates that in South Africa, 45% of stroke survivors were under the age of 65, and 27% were under the age of 55[28]. In Gauteng, the average age of stroke survivors is reportedly 51 years and considering that majority of the participants practice in this province, the young age of stroke survivors is confirmed.

Post-stroke pain predominantly affects the upper limb, shoulder pain being the most common (n=83; 91.2%), followed by the wrist (46.2%; n=42), fingers (29.7%; n=27), and elbow (25.3%; n=23). These findings show a higher incidence rate than the existing literature where de Sire et al. (2021) indicated that 30-65% of stroke survivors experienced hemiplegic shoulder pain within six months post-stroke, with 65% reporting persistent pain[92]. This may be due to over half of the participants in the study having less than six years of experience in stroke and 43.5% reporting that they lack the skills and knowledge to intervene in post-stroke upper limb pain and are thus not preventing or treating hemiplegic shoulder pain effectively.

In addition to shoulder pain, post-stroke pain conditions include CPSP, SHS, and pain due to spasticity or muscle stiffness[8,20,27,93]. Reported pain in the wrist, fingers, and elbow may be related to these conditions. Central post-stroke pain is most commonly described as moderate to severe burning, shooting, or throbbing neuropathic pain that

can be sudden, intense, and unpredictable, continuous, or related to allodynia or hyperalgesia[58]. This potentially aligns with the most common pain descriptor, shooting (40.7%; n=37), burning (20.9%; n=19), dull aching (29.7%; n=27), stabbing (24.2%; n=22) and/or throbbing (23.1%; n=21) as well as continuous (30.8%; n=28) or spasmodic (38.5%; n=35), as reported in the study[58]. Furthermore, nociceptive stimuli can trigger hyperalgesia, which was reported by 13.2% (n=12) of the participants, and nonnociceptive temperature or tactile stimuli can trigger allodynia, reported by 15.4% (n=14) of the participants. Symptoms can present in the upper limb, lower limb, and/or face and are exacerbated by movement of the limb and contact with water[58,94]. which may be related to the participants' reports of pain during passive (69.2%; n=63), and active movement (31.9%; n=29).

Shoulder-hand syndrome, a chronic neuropathic pain condition, presents with symptoms of pain, including hyperalgesia and/or allodynia, oedema, reduced range of motion of the shoulder, wrist and hand joints, as well as a sensation of warmth and erythema in the wrists and hands[5]. The SA-CSRG indicate that the diagnosis of SHS is dependent on symptoms of pain and tenderness of the metacarpophalangeal and proximal interphalangeal joints of the hemiplegic hand and can present with oedema of the dorsum of the fingers, reduced range of motion, trophic skin changes, and hyperaesthesia[29]. Pain is most commonly present in the shoulder, but stroke survivors have also reported pain in the hand and/or both[4]. The study indicates potential SHS in the population of stroke survivors described in this study with 36.3% of the participants reporting hyperaesthesia (n=33), 15.4% (n=14) allodynia, and 20.9% (n=19) burning. Constant pain (n=28) was reported by 30.8% of the participants.

Spasticity, more prevalent in the hemiplegic upper limb[26], may explain pain in the elbow (79%), wrist (66%), and shoulder (58%). Cramping (33.0%; n=30) can be related to spasticity, according to descriptions of night cramps and spasms[58] as well as the most common experience of pain during passive movement. As these pain conditions are common and difficult to diagnose, it is essential for occupational therapists working with stroke survivors to receive adequate training and experience in signs and symptoms, as well as in prevention, assessment, and treatment strategies for each pain condition. This is particularly supported by the fact that 57.0% of the study participants have less than six years of experience in stroke rehabilitation and

43.5% of the participants indicate that they often consider pain but lack the skills and knowledge to intervene.

Pain Prevention

Post-stroke, pain significantly impacts recovery prognosis, correlated with reduced mobility, impaired activities and participation, lower quality of life, and increased risks of depression, low energy, and poor motivation[27]. Therefore, Jacobs-Nzuzi Khuabi et al. (2021) emphasise pain prevention as a key intervention for stroke survivors[54]. While not all conditions are preventable, international guidelines include recommendations for the prevention of spasticity, contractures, SHS, and hemiplegic shoulder pain[29,35,37]. The literature on the role of occupational therapy in pain management provides little evidence on pain prevention. Therefore, in addition to a study by Jacobs-Nzuzi Khuabi et al. (2021)[54] on Occupational Therapy Intervention for hemiplegic shoulder pain, in this discussion, post-stroke pain prevention evidence from the generalised literature was used.

Mobilisation and strengthening (56.5%; n=48), positioning (42.4%; n=36), education (32.9%; n=28), and orthoses (24.7%; n=21) were the strategies most used strategies in post-stroke pain prevention in the study (Appendix 9). All these strategies are related to body structures as well as activities and participation. For example, mobilisation, strengthening, and orthoses are related to joint function mobility and muscle power functions; positioning is related to muscle tone and control of voluntary movement, and education is related to learning and applying knowledge. All of these are associated with activities and participation such as walking, moving around, lifting and carrying objects, sitting, standing, maintaining a body position, acquiring knowledge, and/or self-care. This highlights that the predominant focus of occupational therapists on pain prevention is on body structures.

Mobilisation

Aligning with mobilisation, the SA-CSRG recommends electrical stimulation and or motor strengthening to prevent or minimise shoulder subluxation, which in turn can help prevent associated pain[29]. The National Institute of Health and Clinical Excellence (NICE) National Clinical Guideline for Stroke (2017) also recommends functional

electrical stimulation (FES) to prevent hemiplegic shoulder pain[35]. Regular exercise, used by 92.5% (n=74) of participants, to prevent hemiplegic shoulder pain is reported by Jacobs-Nzuzi Khuabi et al. (2021)[54]. Strengthening of the shoulder support muscles is often or always used by just over half of the participants (73.8%; n=59). Although not provided as an option on the Likert scale, 2.4% (n=2) of the participants mentioned electrical stimulation in the open-ended prevention question, one specifically mentioning the forearm and the other non-specified. This highlights the need to include training in FES in university studies and continuing professional development training. However, the reduced use of FES may also be related to reduced access to FES in various settings due to cost, or difficulty ordering the device in public facilities.

In the prevention of pain-inducing spasticity and contractures, similar mobilisation techniques are recommended, including anti-synergistic patterns, range-of-motion exercises, and stretching are recommended[29]. This is also comparable to CRPS prevention recommendations that include active, active-assisted, or passive range of motion exercises[29]. In this study, active (87.5%, n=70), active-assisted (97.5%, n=78), and passive range-of-motion exercises (96.3%, n=77), were prevalent among the participants. To prevent subacromial impingement, another possible cause of hemiplegic shoulder pain, ensuring scapulohumeral rhythm which assists the scapula and humerus to perform coordinated and smooth movements, is recommended[54]. Although not listed on the Likert scale, no participants mentioned this prevention strategy in their open responses. Therefore, occupational therapists must improve their awareness of the importance of scapulohumeral rhythm and include it in their prevention management. It is recommended that occupational therapists initiate or continue to include regular exercise, strengthening of shoulder support muscles, active, active-assisted and passive range of motion exercises in the prevention of post-stroke pain.

Positioning

The literature demonstrates unanimity in the importance of positioning in the prevention of post-stroke pain[29,35,37]. The SA-CSRG recommends the early use of joint protection principles to prevent hemiplegic shoulder pain[29]. These principles include positioning the upper limb during various tasks including when resting and during

functioning mobility, as well as when seated in a wheelchair through a tray table or arm trough[29]. NICE (2023) and the National Clinical Guideline for Stroke for the United Kingdom and Ireland (2023) agree with these recommendations[36,95]. The principles of joint protection (52.5%; n=42) are used by approximately half of the participants and the use of wheelchair tray tables was divided among the participants, with 41.3% (n=33) using them often or always and 36.3% (n=29) rarely or never using them. The reduced use of tray tables may be due to cost, nonadjustable wheelchair armrest height, desk armrests that do not fit the tray table efficiently, stroke survivor preferences, and/or reduced awareness of their benefits. Jacobs-Nzuzi Khuabi et al. (2021) also reported the provision of external support through assistive devices as well as stabilisation of the shoulder joint through positioning[54]. In the prevention of hemiplegic shoulder pain, Keszler et al. (2017) suggest that a shoulder sling can support the hemiplegic upper limb against gravity, but caution against positioning the shoulder in adduction and internal rotation, which can impact range of motion[4]. In alignment, the SA-CSRG recommends the use of slings for shoulder subluxation, but agrees that slings after flaccidity of the hemiplegic upper limb are controversial[29]. Although further research is recommended, some studies have found that a sling that provides both proximal and distal support, such as GivMohr and OmoNeurexa that provide proximal and distal input at the humerus and forearm, respectively, was found by Nadler and Pauls (2017) to minimise subluxation[67]. Shoulder slings that allow elbow movement and those that position the elbow in flexion are used often or always by 71.3% (n=57) and 61.3% (n=49) of the participants. This shows that some therapists are complying with evidence-based practice, but the controversial use of slings and inconsistent recommendations make their use debatable. However, unrestricted elbow movement slings are assumed to be the superior choice.

Splinting and taping are discouraged in spasticity prevention[29], in line with the low percentage of therapists who often or always use splinting in both the hypertonic (32.5%; n=26) and hypotonic (28.8%; n=23) hand and who use strapping (17.5%, n=14). However, progressive casting and modifiable orthotic devices to reduce elbow contractures and resting wrist orthotics to reduce wrist contractures are recommended by the Brazilian Academy of Neurology practice guidelines for stroke rehabilitation: part I (2022)[35]. This may be beneficial in pain management, as contractures are a potential cause of pain post-stroke[35]. In the prevention of shoulder pain, shoulder

strapping is recommended, particularly for patients with severe motor fallout[29]. The survey did not specify when and where strapping is applied; however, a possible reason for the reduced use by occupational therapists may be due to the need for additional training. According to the NICE Guidelines (2017), orthotics for the prevention of shoulder dislocation are not yet proven[37].

The increased prescription of wheelchair tray tables or arm troughs, shoulder slings that avoid positioning the shoulder in adduction and internal rotation and that allow for free elbow movement, joint protection principles, positioning of the hemiplegic upper limb during various activities and occupations, and strapping for shoulder pain thus need to be considered more frequently by occupational therapists in the prevention of post-stroke upper limb pain. Training in these prevention strategies is also recommended to ensure a general awareness and effective implementation of the intervention.

Education

Together with these positioning techniques, many participants indicated that they often or always provide education on the positioning of the hemiplegic upper limb in sitting (91.3%; n=73), in bed (88.8%; n=71), during functional mobility (82.5%; n=66) and during daily activities (76.3%; n=61) with a lower percentage during walking (67.5%; n=54). The high frequency of participants who consider preventing pain during activities and participation is notable for occupational therapy, as this is a primary role of the profession. The SA-CSRG recommends education and training of health personnel and caregivers on the handling of the hemiplegic upper limb, including avoiding flexing or abducting the shoulder greater than 90 degrees when the scapula is not rotated upward and laterally, how to position the upper limb during transfers and ensure that pulling the hemiplegic upper limb is avoided. These three education recommendations are used often or always by 56.3% (n=45), 82.5% (n=66), and 87.5% (n=70) of participants, respectively. Glize et al. (2022) add that it is also necessary to educate the patient to maintain full passive range of motion of the upper hemiplegic upper limb also be done[64]. The NICE guidelines (2023), also recommend prevention of shoulder pain through education of the stroke survivors, their families, and caregivers, particularly if they have hemiplegic motor fallout or spasticity[95]. Education on how to reduce mechanical overloading and handle the upper limb safely,

avoiding unnecessary range of movement, and ensuring that overhead pulleys or arm slings are not used is also advised[36]. Jacobs-Nzuzi Khuabi et al. (2021) concur with these recommendations[54]. The education of stroke survivors and their families and caregivers on correct and safe handling and positioning of the hemiplegic upper limb during rest and various activities is recommended.

Pain Assessment

Although pain prevention is key, post-stroke pain management requires thorough assessment, including consideration of medical history, and musculoskeletal, psychosocial, and neurological factors[4]. The NICE (2023) Stroke Rehabilitation in Adults Guidelines recommend the assessment of pain as part of the required assessment of stroke survivors[95]. The literature indicates that the absence of thorough, relevant, and easily accessible assessment tools made post-stroke pain assessment difficult[54].

Two main categories were identified from the open-ended responses (Appendix 11) from 77 participants; namely: subjective (85.7%; n=67) and objective (50.6%; n=39) pain assessments. Assessments of body functions, activities, and participation were included by the participants.

Subjective assessment

Pain rating scales, questionnaires, and outcome-based measures were the most used by participants (62.3%; n=48), followed by interviews (57.1%; n=44) and the acquisition of collateral information (3.9%; n=3). Harrison and Field (2015), identify with the subjective nature of pain[41], indicating that the high percentage of subjective assessments used by participants is positive.

According to a study conducted by Jacobs-Nzuzi Khuabi (2021), hemiplegic shoulder pain assessment needs to be initiated with a thorough personal, occupational, and environmental history taking[54]. To ensure a client-centred approach, it is also important to identify the stroke survivors' occupational goals[54]. Owing to the subjective nature of pain, interviews are also an important assessment method, especially as stroke survivors may not express pain[41]. Questions related to pain are thus vital to be

asked[41]. Aligning with these recommendations, the needs and priorities of the stroke survivor were often or always assessed by 97.3% (n=71) of participants and comprehensive history taking by 90.4% (n=66) of participants. Adaptation of occupational environments was assessed by 63.0% (n=46) of participants.

Despite participants indication of using pain rating scales and questionnaires in their assessments of post-stroke pain, there is no known pain scale that has been developed specifically for post-stroke pain but general pain rating scales such as numeric rating scales, visual analogue scales, faces pain scales and/or verbal pain descriptor scales have been reported[41]. Although these tools are effective, stroke survivors' deficits in cognition and/or perception may limit their use[25,54]. Depending on the stroke survivor, different scales should be used; for example, in left hemisphere strokes, faces pain scale is more reliable[41]. The most common pain rating scales mentioned by participants were the Visual Analogue Scale (VAS), Wong-Baker Faces Pain Rating Scale, and the numeric pain scale (rating pain out of 10). The NICE Guidelines (2017) recommended that authentic pain assessment measures be used to keep consistent records of the severity of hemiplegic pain[37].

From the Likert scale responses, outcome-based measures are often or always used by only 51.4% (n=37) of the participants and only fourteen of these listed the measures they use, of which five were irrelevant responses, indicating a reduced understanding of these measures. The Abbey Pain Scale, Fugl-Meyer Assessment of Motor Recovery after stroke and the Disabilities of the Arm, Shoulder and Hand (DASH)/ Quick DASH were other outcome-based measured mentioned by participants. The Abbey Pain Scale, used to assess pain in persons with communication fallout, is a valid assessment tool for use in stroke survivors[96]. The Fugl-Meyer Assessment of Motor Recovery includes a section that assesses joint pain during passive movement only[97] and the DASH/ Quick DASH which includes pain as a subscale, has acceptable validity in its use with stroke survivors[98]. The Barthel Index is a measure that can assess the impact of pain on daily activities[54] but was not mentioned by any of the participants in this study.

Psychological factors were one of the least to be assessed rarely or never (16.7%; n=12) by participants in the study. These outcome-based measures and pain

questionnaires are thus useful tools that can be incorporated into post-stroke pain assessment. However, the need for inclusion of these assessment methods in undergraduate and postgraduate studies as well as in continuous professional development training is highlighted. The need for stroke-specific pain assessment tools that can be used by occupational therapists in South Africa is also identified.

Objective assessment

The study identified two main categories for objective assessment from content analysis: physical assessments (42.9%; n=33) and observations (28.6%; n=22). Hemiplegic shoulder pain assessment involves evaluating shoulder, neck, and elbow stability, along with scapula-humeral alignment[54]. Participants primarily often or always assess shoulder joint stability (82.2%; n=60), followed by elbow (74.0%; n=54) and neck (53.4%; n=39) stability. Muscle tone, strength, range of motion of the shoulder girdle, sensation, postural alignment, oedema, and reflexes are crucial to assess[4,40]. Muscle tone (98.6%; n=72) is commonly assessed, with scapular positioning and alignment checked by 60.3% (n=44) of participants. The NICE Guidelines (2017) recommend that the Arm Activity measure be used to assess upper limb function and activity performance and the modified Ashworth Scale be used to assess hypertonicity[37]. Particularly in stroke survivors with hemiplegia or hemiparesis, spasticity needs to be assessed as it is known to induce pain and contribute to contractures[37]. Range of motion needs to be assessed in joints presenting with increased tone that is hindering active or passive movement[37]. The mobility of joint functions (97.3%; n=71) is a high priority for assessment and 94.5% (n=69) of the participants often or always assessed the muscle strength of the hemiplegic upper limb. Light touch sensation was often or always assessed by 91.8% (91.8%; n=67) of participants, followed by pain (84.7%; n=61), pressure (n=60; 82.2%), and sensation of temperature, muscle stiffness, and muscle spasms by 58.9% (n=43). Sitting posture (n=70; 95.9%) was assessed more frequently than standing posture (n=53; 72.6%). Oedema is always being considered by many therapists (n=66; 90.4%).

Assessment of environmental factors affecting occupational performance and motor recovery also needs evaluation[4] and was being assessed by 63% (n=46) of participants. Specific tests, such as the Positive Neer test, hand-behind neck test, and

passive external rotation tests help identify hemiplegic shoulder pain[4]. Although not listed in the Likert scale, no participants mentioned these tests in the other components of the study, thus indicating poor awareness of these methods possibly due to a lack of exposure to these outcome measures in undergraduate training.

Shoulder-hand syndrome diagnosis involves ruling out other causes, and thus a medical assessment is required to determine any other possible causes of pain such as neuropathy or arthritis[72]. The Budapest criteria define symptoms across sensory, vasomotor, motor, trophic, and sudomotor areas[72]. Clinical assessment, including pain and tenderness of the finger joints, trophic changes, and reduced motion, is crucial[29]. A global physical assessment, which includes range of motion, sensation, and posture, is essential, and outcome-based measures such as the Fugl-Meyer assessment, Action Research Arm Test, and Motor Activity Log assess upper limb function post-stroke[5,72].

Spasticity can be exacerbated by the presence of pressure injury, bladder distention, urinary tract infections, and kidney stones, and these must be assessed and treated if present[26]. Furthermore, moderate to severe muscle weakness and sensory fallout should be used to predict potential spasticity[99]. As mentioned above, muscle tone is the most frequently assessed component of pain in stroke survivors. According to Haslam et al. (2023), cognition, physical performance, and psychological impairments are greater in stroke survivors who experience pain[22].

Literature describing the role of occupational therapy in pain management explains how through their unique understanding of the interrelationship between an individual, his occupations, and his environments, occupational therapists have a key role to play in the management of pain[10]. This is related to the known impact of pain on activities and participation, occupations, mood, and relationships[10]. A position statement by the American Occupational Therapy Association (2021) explains that occupational therapists need to assess an individual’s coping skills, perceptions of pain, psychological and mental responses to pain, and his ability to self-manage his pain[10].

Notably, the impact of pain on occupational performance (72.6%, n=53), the understanding and perception of pain by the stroke survivor (54.8%; n=40) and the

caregiver (47.9%; n=35), the impact of pain on cognition (52.1%; n=38), and psychological factors (48.6%; n=35), often or always assessed is below optimal frequency. This is owing to the concern that if occupational therapists, who are experts in these assessments, are not doing them, there may be a gap in the comprehensive assessment of post-stroke upper limb pain. Numerous objective assessments are identified, and it is recommended that occupational therapists in South Africa either continue to use them or start using them in their assessment of post-stroke pain. Guided by the literature, this can improve the assessment and identification of post-stroke pain.

Pain Treatment

After a thorough assessment, occupational therapists should develop targeted treatment plans that address both pain and associated deficits[10]. The categories (Appendix 14) developed from the content analysis showed some similarities to those identified in the prevention of pain and included: mobilisation and strengthening (59.4%, n=41), positioning (40.6%; n=28), temperature modalities (31.9%, n=22), education (31.9%, n=22) and orthoses (30.4%, n=21). Other categories less frequently mentioned were referrals to other MDT members, massage techniques, relaxation techniques, sensory and awareness training, functional activities, mirror therapy/ graded motor imagery, oedema management and, neurofacilitatory and inhibitory techniques. A small percentage (14.5%, n=10) reported that they do not treat post-stroke upper limb pain.

Mobilisation and strengthening

Mobilisation and strengthening consisted mainly of passive range-of-motion techniques or stretching and active range-of-motion techniques or strengthening exercises. The SA-CSRG confirms that strength training of the upper limb does not exacerbate pain[29] and this indicates that strengthening identified by participants is not a contra-indication to pain management. Improving function through active motor exercises is recommended in patients with significant motor fallout who are at risk of shoulder pain[29]. Together with strengthening muscles of the shoulder girdle and improving postural alignment, active range of motion exercises should be gradually increased[29]. Should hemiplegic shoulder pain be a result of reduced range of motion,

gentle stretching and mobilisation are recommended to achieve shoulder abduction and external rotation and to improve alignment[29,35]. Stretching, and range of motion exercises are also recommended in the treatment of spasticity and contractures[29]. However, The Brazilian Academy of Neurology Practice Guidelines for Stroke Rehabilitation: Part I (2022) reports that the impact of electrical stimulation, stretching, and physical activity on decreasing muscle contractures is not evidence-based[35].

In the Likert scale ratings, many participants indicated to use auto-assisted upper limb exercises (90.5%; n=57), bilateral upper limb activities (90.5%; n=57), and exercise (77.8%, n=49) often or always; all of which involve the recommendations of mobilisation and strengthening. FES (11.1%; n=7) and NMES (4.8%; n=3), alternative forms of mobilisation and strengthening, are used by smaller percentages of participants. The SA-CSRG represents conflicting recommendations with NMES suggested by AHA/ ASA (2016) guidelines, but electrical stimulation is not recommended for the management of shoulder pain by ASG (2017). However, NMES and electrical stimulation are suggested for potential use in the management of shoulder subluxation, a significant cause of shoulder pain[29]. The NICE guidelines (2023), recommend NMES in the treatment of shoulder pain[95].

Positioning

Although details of how positioning was done were not reported by the participants, the SA-CSRG aligns with the participants' inclusion of positioning of the hemiplegic upper limb in their treatment of post-stroke pain[29]. The NICE Guidelines (2023), also recommend that postural adjustment should be done to reduce shoulder pain[95]. The guidelines recommend placing the hemiplegic shoulder in maximum external rotation, either when the patient is seated or lying in bed, for 30 minutes daily[29]. Management of shoulder subluxation should include positioning techniques[29]. Participants who mentioned education as one of their treatment modalities included joint protection principles and education on how to position and handle the hemiplegic upper limb. In the Likert scale ratings, education on the positioning of the hemiplegic upper limb in all positions was done often or always by 85.5% (n=53), and ergonomics and body mechanics training by 68.3% (n=43). Although orthoses were a separate category,

splinting, strapping, and slings contribute to positioning and are thus discussed here. Splinting in spasticity management is not recommended[29] as the results are inconclusive and the low percentage (20.3%; n=14) of splinting by the participants is therefore in line with these recommendations. However, splinting or casting together with intramuscular botulinum toxin in stroke survivors presenting with continuous worsening of spasticity in specific muscles is recommended for a maximum of twelve weeks by the Brazilian Academy of Neurology Practice Guidelines for Stroke Rehabilitation[37]. In cases where botulinum toxin is not being used, splinting or casting should be considered carefully on a case-to-case basis, and should not form part of routine treatment for all stroke survivors[35].

Shoulder strapping may be considered to reduce shoulder pain and slings may be indicated for management of shoulder subluxation[29]. The NICE guidelines (2023), do recommend taping in the treatment of shoulder pain post-stroke[95]. However, as discussed above, slings are controversial post-flaccidity of the hemiplegic upper limb[29]. Splinting was most used (20.3%; n=14), followed by strapping (15.9%; n=11), and then the prescription of slings (13.0%; n=9). The Likert scale rating for strapping was higher with this technique often or always used by 23.8%; n=15) participants.

Temperature Modalities

Participants indicated to mainly use heat modalities (27.5%) in their treatment. In the Likert scale rating, heat therapy was often or always used by over 50% of participants, and cold therapy by less than 10%. The use of temperature modalities in the management of post-stroke upper limb pain is scarce in the literature.

Additional techniques

Non-pharmacological intervention for CPSP is limited in the stroke rehabilitation guidelines with focus on pharmacological treatment only[29,35,36,95]. However, according to Mhangara et al. (2020) and Keszler et al. (2017), cognitive behavioural therapy, pain neuroscience education, graded motor imagery, and transcutaneous electrical nerve stimulation (TENS) are used in treatment of CPSP, but evidence on their effectiveness is limited[3,4]. Cognitive behavioural therapy was not listed on the Likert scale, but no participants reported using this framework in their listed treatment techniques. Pain

neuroscience education is always done by only 38.1% (n=24) of participants with graded motor imagery used by 15.9% (n=10) and TENS by 12.7% (n=8). Early mobilization, mirror therapy, stellate ganglion blockade, and psychological intervention have shown effectiveness[40]. Mirror therapy is always used by 46% (n=19) of the participants and psychological interventions such as relaxation techniques (57.1%; n=36), coping skills (52.4%; n=33) and stress management (28.6%; n=18) are also used by some participants. The reduced use of these techniques may be owing to the cost of the TENS device and the inability for stroke survivors to thus use the device consistently. Mirror therapy may also not be possible in settings where the therapist to patient ratio is low. As the evidence of the effectiveness of these techniques in the treatment of CPSP is sparse, it is difficult to analyse the data from the participants.

Referral for botulinum tox, NMES, or vibration can be used in muscles presenting with spasticity in addition to traditional rehabilitation to reduce spasticity[29]. Only five participants reported to refer for Botox management in the open-ended responses, (85.5%; n=53). However, in South Africa, the use of these interventions may be scarce due to cost implications, high ratios of stroke survivors to therapists, and access to rehabilitation services.

The SA-CSRG and other guidelines only guide the pharmacological management of SHS[29,35,36,95], but Koman et al. (2023) report that treatment goals should aim to reduce abnormal signs and symptoms, improve function, and improve quality of life[72]. Hand therapy, including techniques such as desensitisation, contrast baths, and various modalities, is crucial to improve upper limb function[72]. Desensitisation is used by 55.6% (n=35) and, although not included in the Likert scale, contrast baths was alluded to by one participant (1.4%) in the open-ended question. Management of anxiety or depression related to pain is also recommended in the management of SHS[4].

In all the above-mentioned conditions, the referral for pharmacological treatment is indicated and is often or always done by 47.6% (n=30) of the participants. As seen in Figure 4, techniques that may address anxiety or depression such as relaxation, energy conservation, coping skills, graded activity exposure, cognition, health management and routine, sleep hygiene, stress management, assertiveness skills training, and referral to support groups are used with varying frequencies. The study

indicates gaps between recommended guidelines and current practices, particularly regarding occupational therapy-specific interventions, thus emphasizing the need for a more standardized and evidence-based approach.

3.3. Strengths and Limitations

The study describes post-stroke upper limb pain, a new area of interest, to South African occupational therapy that has been identified globally as a significant complication that is not being effectively managed post-stroke. The study was sent via numerous forums which allowed occupational therapists across South Africa to access the survey. Responses were received from eight of the nine provinces and although most work in Gauteng, Western Cape, and Kwa-Zulu Natal, most areas were represented. This allows for consideration of possible diversity in various regions. Furthermore, both the public and private sectors were represented, allowing for a thorough review of current practices in different sectors. Participants from various levels of health care also allowed for the inclusion of current practice with stroke survivors in the acute to late chronic phases. The response rate exceeded the required sample size of 93 and reached 107.5% (n=100). However, it was difficult to determine the exact size of the population as no available database indicating how many occupational therapists were working with stroke survivors in South Africa at the time of the study. A limitation of the study includes the potential response bias from some participants not responding to the entire survey. Additionally, the potential influence of the Likert scales on participants responses to the open-ended questions regarding current practice in assessment and treatment of post-stroke pain as the participants progressed through the survey is another limitation potentially influencing the validity of the data. The lack of consistent terminology used by the participants also made it difficult to categorise responses accurately.

3.4. Recommendations

Based on the findings of this study, it is recommended that both international and national best practice guidelines specific to post-stroke upper limb pain management by occupational therapists be developed and regularly reviewed. To address the identified gaps, therapists should incorporate evidence-based prevention strategies such as electrical stimulation and scapulohumeral rhythm techniques into their practice. Additionally, the development of stroke-specific assessment tools is crucial

to better assess and manage post-stroke pain. Expanding assessment practices to include cognitive, psychological and occupational factors will provide a more comprehensive understanding of stroke survivors' experiences.

Further research into the effectiveness of the techniques discussed in this study within the South African population is necessary. This research should also explore the nature of pain specifically experienced by stroke survivors, including cultural and demographic factors that may influence pain experiences. Understanding these factors can lead to more targeted and effective interventions.

The prevention, assessment, and treatment of post-stroke upper limb pain should be emphasised in both undergraduate and postgraduate studies, with ongoing professional development training provided to keep practitioners informed of the latest evidence-based practices. Additionally, standardised protocols for prevention, assessment and treatment should be developed to ensure consistency and optimal management.

Enhanced pain neuroscience education is also essential and can be done through the training of occupational therapists and the development of comprehensive materials for stroke survivors and their caregivers. This can improve the understanding of pain management strategies and self-care techniques. Advocating for increased accessibility for modalities and equipment, such as electrical stimulation, mirror boxes, wheelchair tray tables and botulinum toxin treatments, particularly in public facilities, will also support better care.

To disseminate the study's findings and enhance the management of post-stroke upper limb pain, these results should be shared through journal clubs, conferences, workshops, and social media platforms.

3.5. Conclusion

The study described the current practice of occupational therapists in the management of post-stroke upper limb pain within the South African context. Research on this topic, particularly concerning hemiplegic upper limb pain, has been scarce in South Africa, rendering this study a novel area of interest. The study highlighted what prevention strategies, assessment methods and treatment techniques, occupational therapists are using in their management of stroke survivors. The results highlight a high

prevalence of post-stroke upper limb pain in the populations with whom the participants intervene and the need for occupational therapy intervention is emphasised.

An online survey was used to determine whether occupational therapists are preventing, assessing, and treating post-stroke upper limb pain, as well as the intervention they are using to do this. Majority of the participants indicated that they always consider pain, while others reported that they often consider pain but do not have the skills, knowledge, or time to intervene. Occupational therapists mainly address body structures and functions associated with pain, indicating the potential to strengthen the focus on activity and participation while considering contextual factors.

The study highlighted that most participants incorporate prevention strategies for post-stroke pain, aligning with current guidelines. Key strategies included mobilisation, motor strengthening, and range of motion exercises. Passive mobilisation was the most widely used technique, consistent with the literature. However, there was a noticeable underuse of electrical stimulation and techniques to ensure scapulohumeral rhythm, suggesting a need for training and access to electrical stimulation devices. The positioning of the upper limb and the use of tray tables were also common, but cost and accessibility issues may affect their use. The controversial use of shoulder slings and the limited application of splinting highlight the need for further research and refined recommendations.

Participants predominantly used subjective pain rating scales and questionnaires for assessing post-stroke pain, with objective measures including physical assessments. The preference for subjective assessments aligns with the need to account for individual pain experiences, however, a gap for more stroke-specific assessment tools was identified. The study also revealed a gap in assessing the impact of pain on cognition, psychological factors and occupations, areas that are critical given their reported significance in stroke survivors. Recommendations include integrating a broader range of assessments to better address the multifaceted impact of pain.

Treatment practices reflected the prevention strategies with an emphasis on mobilisation, strengthening, and positioning. Participants also utilised temperature

modalities, education, and orthoses, though there was limited use of techniques such as cognitive behavioural therapy, mirror therapy, and TENS. The low frequency of some methods, like botulinum toxin referrals and psychological interventions, suggests potential barriers related to cost and resource availability. The study underscores the need for a more standardised approach and suggests further exploration into the effectiveness of less commonly used techniques.

In conclusion, the findings of this study provide the basis for further research into the effectiveness of the various techniques in post-stroke upper limb pain management in South Africa. The need for occupational therapist training in this area is also highlighted, as is the need for contextually relevant guidelines specifically for occupational therapists.

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APPENDIX 1: INFORMATION SHEET AND SURVEY

Management of upper limb pain in stroke survivors: The current practice of occupational therapists in South Africa

Good day. My name is Jenna Cohen, and I am currently a student completing my master's degree in occupational therapy at the University of the Witwatersrand. As part of my master's degree, I am conducting research to describe the current practice of occupational therapists in addressing upper limb pain post stroke in South Africa. In this study I want to describe the strategies that are being used by occupational therapists in South Africa in the prevention, assessment, and treatment of upper limb pain post stroke. Throughout the research process, I will be under the supervision of Fiona Breytenbach and Kirsty van Stormbroek who are both lecturers at the University of Witwatersrand Occupational Therapy Department.

I am inviting occupational therapists who have intervened with stroke survivors of any age in South Africa within the past month, to take part in this research study. I am requesting your assistance in completion of an online survey that will take approximately 20-30 minutes of your time and will be completed via the RedCap System. A non-experimental quantitative descriptive study design will be used to analyse the findings from the surveys collected. The survey will gather demographic information regarding your history as an occupational therapist working in the field of stroke rehabilitation, your work environment as well as the nature of the stroke survivors that are managed in your current practice. The survey will then list various prevention, assessment and treatment modalities and you will be requested to rate your use of the modalities on a Likert scale.

Participation in the study does not pose risks and your involvement is of a voluntary nature. You will not be required to provide any identifying information and the survey will remain anonymous. You are entitled to withdraw from the study at any point and your decision to do so will not hold any consequences. You will not derive direct benefit from the study, but your participation will assist in further research and training in occupational therapy management of upper limb pain post stroke.

The study would require you to have access to internet and an appropriate device to be able to access the survey link.

Completion of the online survey will be considered as informed consent. Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the Human Research Ethics Committee.

The study will identify the current practices of occupational therapists in the management of post stroke pain in South Africa. The findings of the study will be made available to you at your request.

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee") - protocol number M221071. A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

For further information, please do not hesitate to contact me via email at 547465@students.wits.ac.za. Alternatively, my supervisor and co-supervisor can be contacted via the following e-mail addresses respectively, fiona.breytenbach@wits.ac.za and kirsty.vanstormbroek@wits.ac.za.

Should you have any complaints or problems, you can contact the HREC administrator on 011 717 2301.

Thank you for reading this Study Information Sheet.

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1. Have you read and understood the information sheet?
   - ◯ Yes
   - ◯ No

   (Should you select no, please refer to the start of the survey to read the information sheet. You can then return to the survey and review your answer.)

2. Are you an occupational therapist who obtained your undergraduate degree from a university in South Africa?	○ Yes ○ No (Should you select no, the survey will be ended as you do not meet the inclusion criteria for this study. Thank you for your interest!)
3. Are you registered with the Health Professions Council of South Africa (HPCSA) as either a community service therapist or an independent practitioner?	○ Yes ○ No (Should you select no, the survey will be ended as you do not meet the inclusion criteria for this study. Thank you for your interest!)
4. Have you intervened with a stroke survivor in the past month in South Africa?	○ Yes ○ No (Should you select no, the survey will be ended as you do not meet the inclusion criteria for this study. Thank you for your interest!)
5. What is your highest occupational therapy qualification?	○ Bachelor's degree (BOT) ○ Bachelor of science degree (BScOT) ○ Master's degree (MScOT) ○ PhD ○ Postgraduate diploma
6. Which province do you practice in?	○ Gauteng ○ Limpopo ○ Western Cape ○ North West ○ Mpumalanga ○ KwaZulu Natal ○ Free State ○ Eastern Cape ○ Northern Cape
7. In which sector/s do you practice? (select all appropriate responses)	☐ Public ☐ Private ☐ NPO/ NGO ☐ Academic ☐ Other
Other (specify)	_____
8. In which setting/s do you work? (select all appropriate responses)	☐ Primary facility (Community Health Centre or Clinic) ☐ District hospital ☐ Regional hospital ☐ Tertiary hospital ☐ Central hospital ☐ Private hospital ☐ Private rehabilitation unit ☐ Public rehabilitation unit ☐ Home-based ☐ School ☐ Other
Other (specify)	_____

9. How many years have you worked in stroke rehabilitation?
- ○ Less than a year
- ○ 1-5
- ○ 6-10
- ○ 11-20
- ○ 21-30
- ○ 31-40
- ○ 41-50
- ○ 51+

10. Within what phase/s of intervention do you most commonly intervene with stroke survivors in your practice setting/s? (select all appropriate responses)
- ☐ Acute (from day of onset to 2 weeks post stroke)
- ☐ Subacute (from 3 weeks to 3 months post stroke)
- ☐ Early chronic (from 3 months to 6 months post stroke)
- ☐ Late chronic (≥ 6 months post stroke)

11. What is the average age of the stroke survivors with whom you intervene in your setting/s? (select all relevant responses)
- ☐ 0-12 years
- ☐ 13-20 years
- ☐ 21-30 years
- ☐ 31-40 years
- ☐ 41-50 years
- ☐ 51-60 years
- ☐ 61 years +

12. How frequently do you intervene with stroke survivors? Please be specific - eg. in-patients seen twice a week and out-patients seen once a month

_____

13. Do you intervene with stroke survivors individually, in groups or both?
- ○ Individually
- ○ Groups
- ○ Both

14. Which other multi-disciplinary team (MDT) members that intervene with the same stroke survivors as you, intervene with post stroke pain? (select all appropriate responses)
- ☐ Physiotherapist
- ☐ Psychologist
- ☐ Social Worker
- ☐ Biokineticist
- ☐ Chiropractor
- ☐ Doctor
- ☐ Nurse
- ☐ Other
- ☐ None

Other (specify)

_____

15. How frequently do you consider upper limb pain management in stroke survivors? Select the most appropriate answer
- ☐ I do not consider it as there are too many other factors to prioritize
- ☐ I do not consider it as there are other MDT members focusing on this
- ☐ I consider it often but I do not have the skills and knowledge to intervene
- ☐ I consider it often but I do not have the time to intervene
- ☐ I always consider this and include it in intervention
- ☐ Other

Other (specify)

_____

16. What courses/ training, if any, do you feel have equipped you better in managing pain in stroke survivors? (eg. NDT, Train Pain Academy, Diploma in Pain management, Diploma in Hand Therapy, Essential Pain Management (EPM), etc.) If your response is none, please write this in the response box.

_____

17. If this is a component that you assess, what is the most common description of the type of pain experienced by the stroke survivors that you intervene with?

- ☐ Stabbing
- ☐ Shooting
- ☐ Throbbing
- ☐ Cramping
- ☐ Dull
- ☐ Dull aching
- ☐ Burning
- ☐ Non specified
- ☐ Hyperaesthesia (i.e. increased sensitivity to touch)
- ☐ Pain with temperature changes
- ☐ Allodynia (i.e. Pain from a stimulus that does not normally provoke pain - eg. light touch)
- ☐ Hyperalgesia (i.e. increased pain from a stimulus that normally provokes pain)
- ☐ Other
- ☐ I do not assess this

Other (specify)

_____

18. If pain is identified by stroke survivors, what is the most common location/s of pain identified in the hemiplegic upper limb?
(select all relevant responses)

- ☐ Shoulder
- ☐ Arm
- ☐ Elbow
- ☐ Forearm
- ☐ Wrist
- ☐ Thumb
- ☐ Fingers
- ☐ They do not present with/ report pain in the hemiplegic upper limb
- ☐ I am not sure
- ☐ Other

Other (specify)

_____

19. If upper limb pain is identified by stroke survivors, what is the most common duration of pain reported?

- ☐ Constant
- ☐ Intermittent (comes and goes)
- ☐ During passive movement of the hemiplegic upper limb/s
- ☐ During active movement of the hemiplegic upper limb/s
- ☐ They do not report pain
- ☐ I am not sure
- ☐ Other

Specify

_____

20. If prevention of pain in the upper limb post stroke is a component of your intervention with stroke survivors, please describe your most common approach (i.e. what do you typically do to prevent the onset of pain in the upper limb post stroke?)

    If prevention of pain in the upper limb post stroke is not a component of your intervention, please indicate this in your response.

21. **The following responses refer to the frequency of use of various PREVENTION techniques in your current practice for the PREVENTION of pain in the upper limb post stroke. Responses are based on a Likert scale where possible response are:**
- **I never do this**
- **I rarely do this**
- **I sometimes do this**
- **I often do this**
- **I always do this**

	I never do this	I rarely do this	I sometimes do this	I often do this	I always do this
Education on safe positioning of the hemiplegic upper limb/s in bed	○	○	○	○	○
Education on safe positioning of the hemiplegic upper limb/s in sitting	○	○	○	○	○
Education on safe positioning of the hemiplegic upper limb/s during functional mobility (eg. in-bed mobility, transfers)	○	○	○	○	○
Education on safe positioning of the hemiplegic upper limb/s when walking	○	○	○	○	○
Educate on safe positioning of the hemiplegic upper limb/s during activities of daily living (eg. shaving the underarm, dressing, washing etc.)	○	○	○	○	○
Avoid traction or forceful movements of the hemiplegic upper limb/s	○	○	○	○	○
Working within a pain free range	○	○	○	○	○
Avoid active/ passive shoulder movements greater than 90 degrees	○	○	○	○	○
Strengthening of the muscles supporting the shoulder joint	○	○	○	○	○
Education on joint protection principles	○	○	○	○	○
Prescribing/ issuing of a wheelchair tray table	○	○	○	○	○

Prescribing/ issuing a shoulder sling which positions the affected elbow in flexion	○	○	○	○	○
Prescribing/ issuing a shoulder sling which allows for free movement of the elbow	○	○	○	○	○
Daily exercise	○	○	○	○	○
Splint the hypotonic hand	○	○	○	○	○
Splint the hypertonic hand	○	○	○	○	○
Strapping	○	○	○	○	○
Active range of motion exercises	○	○	○	○	○
Active-assisted range of motion exercises	○	○	○	○	○
Passive range of motion exercises	○	○	○	○	○
Improve psychosocial functioning (eg. stress management, anxiety management, improve self-esteem etc.)	○	○	○	○	○
Set realistic goals	○	○	○	○	○
Improve occupational balance (eg. engagement in meaningful activities, activities health etc.)	○	○	○	○	○

22. Please list other prevention techniques or modalities used to prevent post stroke pain in the affected upper limb/s (if not listed above). No response will indicate no other techniques. _____

23. If assessment of pain in the upper limb post stroke is a component of your intervention with stroke survivors, please describe how you assess pain (i.e. what do you typically do to assess pain in the upper limb post stroke?) _____

If assessment of pain in the upper limb post stroke is not a component of your intevention, please indicate this in your response.

24. **The following responses refer to your frequency of ASSESSMENT of various components related to the hemiplegic upper limb/s of stroke survivors.**
The following responses are based on a Likert scale where possible response are:
• I never assess this
• I rarely assess this
• I sometimes assess this
• I often assess this
• I always assess this

	I never assess this	I rarely assess this	I sometimes assess this	I often assess this	I always assess this
Thorough history taking including medical, occupational and social history	○	○	○	○	○
Adaptation of occupational environments	○	○	○	○	○
Outcome-based measures	○	○	○	○	○
Impact of pain on an individual's performance in occupations	○	○	○	○	○
Muscle tone	○	○	○	○	○
Muscle power of the hemiplegic upper limb	○	○	○	○	○
Muscle power of the non-hemiplegic upper limb	○	○	○	○	○
Muscle power of the trunk	○	○	○	○	○
Oedema	○	○	○	○	○
Light touch sensation	○	○	○	○	○
Temperature sensation	○	○	○	○	○
Pressure sensation	○	○	○	○	○
Sensation of muscle stiffness	○	○	○	○	○
Sensation of muscle spasm	○	○	○	○	○
Sensation of pain	○	○	○	○	○
Intensity of pain	○	○	○	○	○
Location of pain	○	○	○	○	○
Sitting posture	○	○	○	○	○
Standing posture	○	○	○	○	○
Mobility of joint functions (i.e. range of motion)	○	○	○	○	○
Stability of joint functions & structural integrity of the neck	○	○	○	○	○
Stability of joint functions & structural integrity of the shoulder	○	○	○	○	○

Stability of joint functions & structural integrity of the elbow	○	○	○	○	○
Stability of joint functions & structural integrity of the wrist	○	○	○	○	○
Stability of joint functions & structural integrity of the thumb	○	○	○	○	○
Stability of joint functions & structural integrity of the fingers	○	○	○	○	○
Premorbid orthopaedic conditions (eg. arthritis, previous fracture etc.)	○	○	○	○	○
Scapular positioning and alignment	○	○	○	○	○
Scapulohumeral rhythm (i.e. shoulder abduction and/or scapula elevation as a result of coordinated movements of the humerus and scapula)	○	○	○	○	○
Review X-rays of affected joints	○	○	○	○	○
The stroke survivor's needs and priorities for intervention	○	○	○	○	○
Impact of pain on a stroke survivors' performance in basic daily activities (eg. feeding, dressing, washing oneself, toileting etc.)	○	○	○	○	○
Impact of pain on a stroke survivors' performance in instrumental activities of daily living (eg. Home maintenance, meal preparation and clean up, sexual activity, functional and community mobility, shopping, care of others etc.)	○	○	○	○	○
Impact of pain on a stroke survivors' work performance	○	○	○	○	○
Impact of pain on a stroke survivors' sleep	○	○	○	○	○
Impact of pain on a stroke survivors' social participation	○	○	○	○	○
Impact of pain on a stroke survivors' performance in leisure/ recreational activities	○	○	○	○	○

Impact of pain on cognition (eg. Focusing attention, thought functions, memory functions, solving problems, making decisions etc.)	○	○	○	○	○
The need for a caregiver/s to assist with performance in daily activities	○	○	○	○	○
Stroke survivors' understanding and perception of pain	○	○	○	○	○
Caregiver/s understanding and perception of stroke survivors' pain if relevant	○	○	○	○	○
Psychological factors (eg. Handling stress, mood, self-esteem, motivation, energy level, emotional functions etc.)	○	○	○	○	○

25. Please list other assessment techniques or modalities used to assess post stroke pain in the affected upper limb/s (if not listed above). No response will indicate no other techniques. _____

26. If you identified to use pain related outcome-based measures, above, please list the outcome-based measures that you most commonly use. No response will indicate that you do not use any pain related outcome-based measures. _____

27. If treatment of pain in the upper limb post stroke is a component of your intervention with stroke survivors, describe your most common approach (i.e. how do you typically treat pain in the upper limb of a stroke survivor?)

If treatment of pain in the upper limb post stroke is not a component of your intevention, please indicate this in your response. _____

28. **The following responses refer to your frequency of use of various TREATMENT techniques in managing upper limb pain in stroke survivors**
Responses are based on a Likert scale where possible responses are:
• I never treat this/ use this treatment technique
• I rarely treat this/ use this treatment technique
• I sometimes treat this/ use this treatment technique
• I often treat this/ use this treatment technique
• I always treat this/ use this treatment technique

	I never treat this/ use this treatment technique	I rarely treat this/ use this treatment technique	I sometimes treat this/ use this treatment technique	I often treat this/ use this treatment technique	I always treat this/ use this treatment technique
Pain Neuroscience Education (i.e. education on the neurophysiology of pain)	○	○	○	○	○
Coping skills	○	○	○	○	○
Relaxation techniques (eg. meditation, breathing techniques etc.)	○	○	○	○	○
Stress management	○	○	○	○	○
Ergonomics and body mechanics training	○	○	○	○	○
Assistive device/s prescription	○	○	○	○	○
Environmental adaptations	○	○	○	○	○
Pacing	○	○	○	○	○
Energy conservation	○	○	○	○	○
Health management and routine	○	○	○	○	○
Exercise	○	○	○	○	○
Sleep hygiene	○	○	○	○	○
Sensory re-education	○	○	○	○	○
Desensitization	○	○	○	○	○
Graded activity exposure	○	○	○	○	○
Transcutaneous electrical nerve stimulation (TENS)	○	○	○	○	○
Functional electrical stimulation (FES)	○	○	○	○	○
Neuromuscular Electrical Stimulation (NMES)	○	○	○	○	○
Strapping	○	○	○	○	○
Dry needling	○	○	○	○	○
Cognition (eg. motivation, attention, memory etc.)	○	○	○	○	○

Bilateral upper limb activities	○	○	○	○	○
Mirror therapy	○	○	○	○	○
Graded motor imagery (GMI)	○	○	○	○	○
Heat therapy	○	○	○	○	○
Cold therapy	○	○	○	○	○
Hands on techniques (eg. Scapula mobilization, range of motion, massage, gentle stretching and mobilization etc.)	○	○	○	○	○
Auto-assisted upper limb exercises (range of motion stretches using the unaffected side)	○	○	○	○	○
Occupation-based activities	○	○	○	○	○
Rood techniques (eg. Facilitatory techniques such as sweep tapping, quick stretch, vibration and/or inhibitory techniques such as neutral warmth, prolonged stretch etc.)	○	○	○	○	○
Brunnstrom techniques i.e. stages of recovery 1. Flaccid paralysis 2. Movements in synergy pattern 3. Voluntary synergy movement 4. Voluntary movements outside of synergy pattern 5. Isolated movements 6. Normal motor function	○	○	○	○	○
Bobath techniques (eg. Encourage normal motor patterns, normalize tone to facilitate active movement, discourage compensatory movements etc.)	○	○	○	○	○
Refer for surgical release of contracture/s	○	○	○	○	○
Education on positioning of the hemiplegic upper limb in all positions	○	○	○	○	○
Facilitate/ refer to support groups	○	○	○	○	○
Assertiveness skills training	○	○	○	○	○
Encouraging stroke survivor to keep a pain diary	○	○	○	○	○

Referral to doctor for analgesics, anti-spasmodic and/or anti-inflammatories	○	○	○	○	○

29. Please list other treatment techniques or modalities used to treat post stroke pain in the affected upper limb/s (if not listed above). No response will indicate no other techniques. _____

APPENDIX 2: EXPERT FEEDBACK COMPILATION RATINGS

Key:

Relevance rating scale:	**Clarity rating scale**
1- Not relevant 2- Item needs some revision 3- Relevant but needs minor revision 4- Very relevant	1- Not clear 2- Item needs some revision 3- Clear but needs minor revision 4- Very clear

	Expert 1		**Expert 2**		**Expert 3**		**Expert 4**	
Item	**Relevance rating**	**Clarity rating**	**Relevance rating**	**Clarity rating**	**Relevance rating**	**Clarity rating**	**Relevance rating**	**Clarity rating**
1. Have you read the information sheet?	4	4	4	4	4	4	4	3
2. Are you an occupational therapist who obtained your undergraduate degree from a university in South Africa?	4	4	4	4	3	4	4	4
3. Are you registered as an occupational therapist with the Health Professions Council of South Africa (HPCSA)?	4	4	4	4	1	4	4	4
4. Have you intervened with a stroke survivor in the past month in South Africa?	2	4	4	4	4	4	3	4
5. How old are you?	4	4	4	4	1	4	4	4
6. Please indicate your biological sex	4	4	4	4	1	4	3	
7. What is your highest level of qualification?	4	2	4	4	1	4	4	3
8. How many years have you worked as an occupational therapist?	4	4	4	4	1	4	4	4
9. How many years have you worked in stroke rehabilitation?	2	4	4	4	4	4	4	4
10. How many stroke survivors do you treat monthly, on average?	4	4	4	4	4	4	4	4
11. Please record any specialized training in stroke management that you have completed since completing your undergraduate OT degree. No response will indicate no specialized training.	4	4	4	4	4	4	4	3
12. Please record any specialized training in pain management that you have completed since completing your undergraduate OT degree. No response will indicate no specialized training.	3	4	4	4	4	4	4	3
13. Within what phase of intervention do you most commonly intervene with stroke survivors in your practice setting/s? (select all appropriate responses)	4	4	4	4	4	4	4	4
14. In which sector/s do you practice? (select all appropriate responses)	4	4	4	4	4	4	4	4
15. Which province do you practice in?	4	4	4	4	2	4	4	4
16. In which setting/s do you work? (select all appropriate responses)	4	4	4	3	4	4	4	4
17. In what age range do your stroke survivors most frequently fall? (select all relevant responses)	4	4	4	4	4	4	4	4

18. How frequently are stroke survivors seen in your setting? Please be specific - eg. in-patients seen twice a week and out-patients seen once a month	4	4	4	4	4	4	4	4
19. Do you intervene with stroke survivors individually, in groups or both?	4	4	4	4	2	4	4	4
20. Which other multi-disciplinary team (MDT) members who work alongside you, intervene with regards to management of post stroke upper limb pain? (select all appropriate responses)	4	3	4	4	4	2	4	4
21. If prevention of pain in the upper limb post stroke is a component of your intervention with stroke survivors, please describe your most common approach (i.e. what do you typically do to prevent the onset of pain in the upper limb post stroke?)	4	4	4	4	4	2	4	4
22. The following responses refer to the frequency of use of various prevention techniques in your current practice for the prevention of pain in the upper limb post stroke. Responses are based on a Likert scale	2	4	4	3	4	4	4	4
23. Please list other prevention techniques or modalities used to prevent post stroke pain in the affected upper limb/s (if not listed above). No response will indicate no other techniques.	4	4	4	4	4	4	4	4
24. If assessment of pain in the upper limb post stroke is a component of your intervention with stroke survivors, please describe how you assess pain (i.e. what do you typically do to assess pain in the upper limb post stroke?)	4	4	4	4	4	4	4	4
25. What is the most common description of the type of pain experienced by the stroke survivors that you intervene with?	3	3	4	3	4	4	4	4
26. What is the average severity of pain rated by the stroke survivors with whom you intervene? The brackets indicate the rating out of 10 on the Universal Pain Assessment Tool?	4	3	2		4	4	4	4
27. What is the most common location/s of pain identified by stroke survivors in the upper limb? (select all relevant responses)	4	4	4	4	4	4	4	4
28. What is the most common duration of pain reported by stroke survivors?	4	4	4	4	4	4	4	4
29. The following responses refer to your frequency of assessment of various components related to the affected upper limb/s of stroke survivors. The following responses are based on a Likert scale	4	3	4	4	4	4	4	4
30. Please list other assessment techniques or modalities used to assess post stroke pain in the affected upper limb/s (if not listed above). No response will indicate no other techniques.	4	4	4	4	4	4	4	4
31. If you identified to use pain related outcome-based measures, above, please list the outcome-based measures that you most commonly use. No response will indicate that you do not use any pain related outcome-based measures.	4	4	4	4	4	4	4	4
32. If treatment of pain in the upper limb post stroke is a component of your intervention with stroke survivors, describe your most common approach (i.e. how do you typically treat pain in the upper limb of a stroke survivor?) If treatment of pain in the upper limb post stroke is not a component of your intervention, please indicate this in your response.	4	4	4	4	4	4	4	4
33. The following responses refer to your frequency of use of various treatment techniques in managing upper limb pain in stroke survivors. Responses are based on a Likert scale	4	3	4	3	4	4	4	4
34. Please list other treatment techniques or modalities used to treat post stroke pain in the affected upper limb/s (if not listed above). No response will indicate no other techniques.	4	4	4	4	4	4	4	4

APPENDIX 3: COMPILED EXPERT FEEDBACK: CONTENT VALIDITY COMMENTS, CHANGES & REASONING

Item	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Changes made/ not made with reasoning
Time taken	N/A	26 minutes, 3 seconds 15-20 minutes may be too little time to complete the survey – unless I'm a slow reader or over think things?	16.5 minutes	23 minutes, 51 seconds	No feedback	• The first expert did not meet the criteria for the survey, so she did not complete the survey with a timer. • The suggested time required to complete the survey was changed on the information sheet to 20-30 minutes.
Any problems with the survey	I was unable to continue with the survey as I responded "no" to one of the initial questions on whether I had "intervened with a stroke survivor in the past month". This question may need rewording, perhaps in terms of a longer time frame (I may have intervened in *the past year*) or in terms of working in *pain management that may include working with post-stroke patients* as it could cut out a large proportion of pain practitioners (like myself) who don't work in stroke rehab per se but may see post-stroke pain patients occasionally as part of their clientele. Pain management is, itself, a field of OT practice. So there is an overlap of 2 fields of practice in your research.	Survey ran smoothly and if an item not marked it didn't let you continue There are no real questions about whether pain is assessed in a biopsychosocial vs a biomedical model- which I think would be imperative to know, so that we can start creating awareness of the multidimensional nature of pain and how to assess and treat the potential mechanisms more effectively. The majority of the questions relate more to a biomedical model and patient/ caregivers "perceptions" of pain.			No feedback	• Intervention with a stroke survivor within the past month was kept as an inclusion criterion as this was relevant for the objectives of the study and ensured that occupational therapists who responded to the survey were actively working with stroke survivors so that their responses were relevant and valid at the time as well as responsive to stroke rehabilitation intervention (i.e. a strong focus on stroke rehabilitation was required rather than practitioners focusing predominantly on pain and seeing stroke survivors specifically for pain management.) • Considered adding a question enquiring if the occupational therapist uses more of a biomedical approach or a biopsychosocial approach but it was decided that this information would be obtained from the responses of the participants. More biopsychosocial-related intervention methods were included such as: • improve psychosocial functioning (e.g. Stress management, anxiety management, improve self-esteem, etc.)

	I started to complete your survey but immediately ran into a problem - I do not work in stroke rehabilitation. I work in pain management. This means that I cant complete your survey. How would you like me to proceed? I could still comment on /rate your questions...? I think this may be something for you to consider: as pain practitioners we see all kinds of pain and we might see post-stroke pain even if we don't do stroke rehab....					• set realistic goals • improve occupational balance (e.g. engagement in meaningful activities, activities health, etc.)
1. Have you read the information sheet?				There is important information that needs to be read to understand the context of the survey Maybe include '… and understood the information sheet?" People might not read it or screen it but in saying understand, they would go back to read it	Management of upper limb pain in stroke survivors: The current practice of occupational therapists in South Africa findings from the survey's collected ? any	• Corrections to grammar were made on the information sheet including changing the title to a capital ''T'' for ''The'' • The first question in the survey was changed to ''Have you read **and understood** the information sheet?'' from ''Have the read the information sheet?''
2. Are you an occupational therapist who			I assume that this question is to establish the participants who			• This question was kept ensuring that participants met the inclusion criteria.

obtained your undergraduate degree from a university in South Africa?			qualified in SA and to establish similarities in their training as opposed to a participant who studied outside of SA? What if this was better developed post qualification but not necessarily through specialised training?			
3. Are you registered as an occupational therapist with the Health Professions Council of South Africa (HPCSA)? (community service or independent practitioner				It may be valuable to know if they are a comm serve or independent practitioner.		• This comment was erroneously left out of the research survey. It is recommended that this be considered in further research.
4. Have you intervened with a stroke survivor in the past month in South Africa?	See my initial comments above			Why only a month and not 3/6 months? A therapist who works in rotation might not then meet these criteria and not complete the survey because they feel that they have not had consistent exposure. Also, in the public setting, compliance to appointments is often poor and waiting		• These comments were considered but the inclusion criterion was kept for one month as the study particularly aimed to focus on occupational therapists working in the thick of stroke rehabilitation.

				times for f/u appointments long.		
5. How old are you?			I think years of experience working in stroke rehabilitation is more important than age?	For demographic reasons?		• This question was removed as it was irrelevant.
6. Please indicate your biological sex				For demographic reasons?		• This question was removed as it was irrelevant.
7. What is your highest level of qualification?	Your examples only give OT ones. May need to specify that you are referring to a medical qualification? E.g. I have a Masters' in Theology and qualifications in Labour Law in addition to OT or medical ones.		Any specialised training in stroke or pain management is more important – which is addressed later	Would this only apply for OT specifically?	You might want to add some diplomas of Postgraduate courses? As pain and stroke both have many courses, not degree related	• This question was divided into two separate questions, i.e. What is your highest occupational therapy qualification, and what courses/ training, if any, do you feel have equipped you better in managing pain in stroke survivors? (e.g. NDT, Train Pain Academy, Diploma in Pain management, Diploma in Hand Therapy, Essential Pain Management (EPM), etc.) If your response is none, please write this in the response box. • This assisted in clarifying that their highest qualification was specifically related to occupational therapy and that the question relating to courses/ training could be any training, including that done outside of occupational therapy specifically.
8. How many years have you worked as an occupational therapist?						• This question was excluded as it was more relevant to know the number of years worked in stroke rehabilitation.
9. How many years have you worked in stroke rehabilitation?	What about pain management experience? OTs may have no experience in pain management.				I've been qualified now for 20 years, and I'm 42, so I wonder if you're not making this bracket too big? Someone until	• Pain management experience would be obtained from the question asking about other training related to pain/ stroke management, so no additional questions were included.

					retirement age can work 40 years	• The intervals for the responses were changed from 21+ to ○ 21-30 ○ 31-40 ○ 41-50 ○ 51+
10. How many stroke survivors do you treat monthly, on average?					I remember from my MSC I also asked this question, and it caused confusion. Just keep in mind some OTs see in-patients, some out-patients, so they may see only 8 patients a month but intensively for rehab daily, or someone could see 5 - 10 per day in groups. If you're trying to ascertain how much experience they have, try and ask this in a different way	• This question was removed as it would have been difficult for participants to quantify. The years of experience above was kept instead.
11. Please record any specialized training in stroke management that you have completed since completing your undergraduate OT degree. No response will indicate no specialized training.				Give examples to offer more clarity. People might think that the courses they have attended would be classified as specialised training.	Some examples will be useful, for example NDT, or perhaps mention some of the courses you've come across? People often don't answer because they don't think the course can be labelled as "specialised". Perhaps ask it as follow: Which courses do you feel have equipped you better in managing pain in stroke patients... or something similar. Be more specific in relation to your study **Text box	• These suggestions were used, and the question was changed to: ‘’What courses/ training, if any, do you feel have equipped you better in managing pain in stroke survivors? (e.g. NDT, Train Pain Academy, Diploma in Pain management, Diploma in Hand Therapy, Essential Pain Management (EPM), etc.) If your response is none, please write this in the response box.’’ • Examples were also added, and a text box was used for the response so that any courses/ training could be included and not just those specified by the researcher.

12. Please record any specialized training in pain management that you have completed since completing your undergraduate OT degree. No response will indicate no specialized training.	Wonder if you may want to give examples here? E.g. PG Diploma in Interdisciplinary Pain Management, certifications in pain management….?			Give examples to offer more clarity. People might think that the courses they have attended would be classified as specialised training.	Same comment as above	• This question was included with the question above as the study aims to describe the current practice of pain management within stroke rehabilitation.
13. Within what phase of intervention do you most commonly intervene with stroke survivors in your practice setting/s? (select all appropriate responses)					I recommend that you define these, as universities teach very different terminology and OTs are very confused about these. Give the type of intervention and time frame post-stroke so that you obtain useful info	The definitions for each phase were included in brackets as follows: • Acute (from day of onset to 2 weeks post-stroke) • Subacute (from 3 weeks to 3 months post-stroke) • Early chronic (from 3 months to 6 months post-stroke) • Late chronic (≥ 6 months post-stroke)
14. In which sector/s do you practice? (select all appropriate responses)					Ensure to have an option to tick several options as most OT work in a few places. What about voc rehab and functional capacity?	• The responses allow for more than one response. • Vocational rehabilitation and functional capacity would be either public or private so no changes were made here. • The option to select ''other'' with a space to specify the sector was also included if required.

15. Which province do you practice in?			Is this relevant to this study?			• This was kept as a question as it is necessary for demographics and sampling.
16. In which setting/s do you work? (select all appropriate responses)		? private practice setting not easy to understand where this fits in – perhaps it is under regional, central or tertiary hospital – I was unsure			Include options related to the sectors above, for example academia and NGO, the setting is not clear	• More response options were included here to make it clearer to select appropriately and an option of ‘‘other’’ with the requirement to specify the setting was added so that all settings were included. These included: o Primary facility (Community Health Centre or Clinic) o District hospital o Regional hospital o Tertiary hospital o Central hospital o Private hospital o Private rehabilitation unit o Public rehabilitation unit o Home-based o School o Other
17. In what age range do your stroke survivors most frequently fall? (select all relevant responses)					This should rather be re-phrased to something more specific. Perhaps ask "In the past 6 months, what would you consider the most common age range of patients you've managed in your practice” Rather don't state "your" stroke survivors	This question was reworded to: ‘’ What is the average age of the stroke survivors with 0-12 years whom you intervene in your setting/s?’’
18. How frequently are stroke survivors seen		I think I missed this question in the survey, and it didn’t ask me to go	Perhaps another question enquiring how often pain is		"Seen" is a vague term - rather specify in term of assessment and	• The question was set that a response must be included before moving onto the next question in REDCap.

in your setting? Please be specific - e.g. in-patients seen twice a week and out-patients seen once a month		back and complete it, now that I think about it?	addressed during this frequency will be valuable?		treatment, or management	• Another question regarding the frequency of addressing pain was added. • The question was reworded to: “How frequently do you intervene with stroke survivors? Please be specific - e.g. in-patients seen twice a week and out-patients seen once a month.”
19. Do you intervene with stroke survivors individually, in groups or both?			Is this relevant to the purpose of this study?		This might need further elaboration - what if they treat 10 patients individually, and one group per week, then it is not clear. Perhaps you can ask "what is the most common structure/format of your sessions"	• This question was included as it is relevant to the study. The literature discusses pain management in both individual and group settings with the effectiveness of each/ both for different outcomes. • The question was rephrased as: “Do you intervene with stroke survivors individually, in groups, or both?
20. Which other multi-disciplinary team (MDT) members who work alongside you, intervene with regards to management of post stroke upper limb pain? (select all appropriate responses)	Wording may need a little reshuffle… e.g. “Which other members of the MDT that you work with also intervene with regards to ….		mistakenly read this twice and missed the pain part. Perhaps it can be rephrased to “With regards to upper limb pain post stroke, which other MDT members do you work alongside? /which other members address this?		This can also be clearer, for example, they might work with them in managing the patient, but never meet or discuss the patient, for example several private practitioners at different practices. Do you want to find out members of the team? Then perhaps ask who is in their building, or do you have team and family meetings when discussing clients? Thus, is there team work and how are	• This question was simplified and reworded as follows: “Which other multi-disciplinary team (MDT) members that intervene with the same stroke survivors as you, intervene with post-stroke pain? (select all appropriate responses).”

					decisions communicated	
21. If prevention of pain in the upper limb post stroke is a component of your intervention with stroke survivors, please describe your most common approach (i.e. what do you typically do to prevent the onset of pain in the upper limb post stroke?) If prevention of pain in the upper limb post stroke is not a component of your intervention, please indicate this in your response.			It's important to highlight or ensure that the participant is cognisant that this is preventative techniques and not pain management techniques. I cannot recall if the survey gives you options but perhaps providing a few preventative techniques and having an "other" option could ensure accurate answering of this question		I would suggest some kind of measurement here of frequency, for example, How often do you consider upper limb pain management in stroke survivors? Is it uncommon or do you leave it to other team members? Is it very common but you don't have the skills to treat it?	• Giving options were not included as the purpose of this question was to prevent response bias as the Likert scale that followed gave options that could influence participants' responses. However, "prevention'" and "prevent" was underlined to raise cognisance that this question was specifically related to prevention. • This question was added to the survey: "How frequently do you consider upper limb pain management in stroke survivors? Select the most appropriate answer." ○ The response options included were: ▪ I do not consider it as there are too many other factors to prioritize. ▪ I do not consider it as there are other MDT members focusing on this. ▪ I consider it often, but I do not have the skills and knowledge to intervene ▪ I consider it often, but I do not have the time to intervene ▪ I always consider this and include it in ▪ intervention ▪ Other
22. The following responses refer to the frequency of	One of the primary ways to prevent the development of pain is	Avoid active/ passive shoulder movements greater than 90 degrees			Later on you specify "education of carer, nurses and stroke	• Pain neuroscience education was included in the Likert scale as this is the term used in the literature.

use of various prevention techniques in your current practice for the prevention of pain in the upper limb post stroke. Responses are based on a Likert scale	educating about pain itself (we call this Therapeutic pain science education, and it has level 1A evidence to support it) Your listed techniques seem to only reflect a biomedical framework for pain and not a biopsychosocial one? So, other techniques for prevention of pain would include addressing psychosocial factors….	Strengthening of the muscles supporting the shoulder joint Prescribing/ issuing of a wheelchair tray table These questions should probably have "if appropriate" added to them as sometimes you do want to work above 90 deg depending on the residual function and at time strengthening is not appropriate if there is no active motion etc?? So the wording makes it difficult to answer.			survivor. I suggest that you make it clear who this education is referring to? The stroke survivor? Theoretically, both sides are affected by stroke. I therefore recommend you rather say "hemiplegic" as this will relate specifically to the more affected side.	• Biopsychosocial strategies were added including: o improve psychosocial functioning (e.g. Stress management, anxiety management, improve self-esteem, etc.) o set realistic goals. o improve occupational balance (e.g. engagement in meaningful activities, activities health, etc.) • All strategies listed on the Likert scale were based on literature so only biopsychosocial strategies that were mentioned in literature were included. • The option to specify who education includes was left to be considered in the open-ended question before the Likert scale as inclusion in the Likert scale would have made the survey too lengthy. • The term 'hemiplegic' replaced 'affected' upper limb.
23. Please list other prevention techniques or modalities used to prevent post stroke pain in the affected upper limb/s (if not listed above). No response will indicate no other techniques.						• No comments: therefore, no changes were made.
24. If assessment of pain in the upper limb						• No comments: therefore, no changes were made.

post stroke is a component of your intervention with stroke survivors, please describe how you assess pain (i.e. what do you typically do to assess pain in the upper limb post stroke?) If assessment of pain in the upper limb post stroke is not a component of your intervention, please indicate this in your response.						
25. What is the most common description of the type of pain experienced by the stroke survivors that you intervene with?	I would maybe use "dull aching" – this best describes the pain experienced from underlying central sensitization Maybe give example of allodynia (e.g. pain from light touch)	Not sure that these descriptors are of value in determining the type of pain (nociceptive, neuropathic, nociplastic) or what you are trying to establish from this question??				• These questions were moved before prevention in the survey to improve the flow. • Dull aching was added to the list of possible descriptions of pain. • Light touch was added as an example of allodynia. • This question was kept as the pain descriptors can assist in determining the possible post-stroke pain syndrome/ condition involved.
26. What is the average severity of pain rated by the stroke survivors with whom you intervene?	This is a problematic question and the assessment tool used has problematic phrasing. (e.g. some people will still mobilise with 10/10 pain – it depends on their	Severity of pain on this rating scale is perhaps not a useful measure, as it doesn't provide helpful info on how fluctuates throughout the day and across the intervention period				• This question was removed as it was agreed that this would be difficult to measure and would provide inaccurate and invalid results. • It was also removed as it assumes that participants always ask the stroke survivors with whom they intervene this

The brackets indicate the rating out of 10 on the Universal Pain Assessment Tool?	psychosocial factors). Pain severity and its interference with functioning are 2 separate things – not necessarily closely correlated. Some people can continue to mobilise with rated 10/10 pain… Pain severity is a subjective experience. Pain's interference with functioning can be more objectively rated or described. I would suggest just asking therapists to rate the average that pain interferes with functioning as per the Brief Pain inventory (BPI) section 2. This has 7 items out of 10…	It may be more useful to determine how frequently pain is experienced by the stroke survivor population the clinician is seeing and the frequency in an acute/sub acute vs a chronic population of survivors???				rating, particularly using the Universal Pain Assessment Tool which is unrealistic.
27. What is the most common location/s of pain identified by stroke survivors in the upper limb? (select all relevant responses)					again suggested to use hemiplegic	Hemiplegic was added before the term 'upper limb.'
28. What is the most common duration of pain reported by stroke survivors?						• No comments: therefore, no changes were made.

The following responses refer to your frequency of assessment of various components related to the affected upper limb/s of stroke survivors. The following responses are based on a Likert scale						
29. The following responses refer to your frequency of assessment of various components related to the affected upper limb/s of stroke survivors. The following responses are based on a Likert scale	How are you differentiating between the “sensation” and the “quality” of pain? Perhaps sensation of pain is a heading for the items that come thereafter?				It might be more useful to your study to specify that this is the initial assessment? I.e. is this one of the first assessments done? In my experience the pain assessment gets done later in rehab when it is almost to late, and a solution will be to indicate on your study that pain assessment should be done early or upon first assessment Muscle power - Again, rather hemiplegic and non-hemiplegic	• Sensation of pain and quality of pain are terms from the ICF and were therefore, not changed. • Muscle power of the ‘affected’ upper limb and ‘non-affected’ upper limb were changed to ‘hemiplegic’ and ‘non-hemiplegic’ upper limb. • Assessment for this study includes any assessment done throughout the intervention process and so initial assessment was not included.
30. Please list other assessment techniques or modalities used to assess post						• No comments: therefore, no changes were made.

stroke pain in the affected upper limb/s (if not listed above). No response will indicate no other techniques.						
31. If you identified to use pain related outcome-based measures, above, please list the outcome-based measures that you most commonly use. No response will indicate that you do not use any pain related outcome-based measures.						• No comments: therefore, no changes were made.
32. If treatment of pain in the upper limb post stroke is a component of your intervention with stroke survivors, describe your most common						• No comments: therefore, no changes were made.

approach (i.e. how do you typically treat pain in the upper limb of a stroke survivor?) If treatment of pain in the upper limb post stroke is not a component of your intervention, please indicate this in your response.						
33. The following responses refer to your frequency of use of various treatment techniques in managing upper limb pain in stroke survivors. Responses are based on a Likert scale	I would remove the item “underlying cause of pain” since all these are treating multiple underlying causes. There is no single underlying cause and no single way to treat it. How do you distinguish between “pacing” and “energy conservation”? In pain management we would prefer the term pacing which may incorporate energy conservation but emphasises activity over rest. You could add “Graded Motor Imagery” to distinguish from Mirror therapy to see if therapists are up to date	Perhaps change mirror therapy to /or add graded motor imagery as mirror therapy should not be used alone for pain it should be preceded by the first 2 stages of GMI			Cognition - This is quite vague, perhaps elaborate or give example Therapeutic activities - all activities are therapeutic, thus I recommend you rather use something like "occupation based activities"	• Underlying cause of pain was removed as a technique on the Likert scale. • Pacing and energy conservation were two separate terms in the literature discussing the role of occupational therapy in pain management and so they were both kept. • Graded motor imagery was added in addition to mirror therapy. • Motivation, attention, memory etc. were added as examples to cognition. • ‘Therapeutic activities’ was changed to ‘occupation-based activities.’

	with this more advanced intervention?					
34. Please list other treatment techniques or modalities used to treat post stroke pain in the affected upper limb/s (if not listed above). No response will indicate no other techniques.						• No comments: therefore, no changes were made.
Other					Remember to say thank you and that this is the end	Upon submission of the survey, a message saying: ‘’Thank you for taking the time to complete this survey. Your assistance is greatly appreciated!’’ was set to appear.

APPENDIX 4: CVI CALCULATIONS - Relevance

Item	Expert 1	Expert 2	Expert 3	Expert 4		Experts in agreement	I-CVI	UA
Q1	1	1	1	1		4	1	1
Q2	1	1	1	1		4	1	1
Q3	1	1	1	0		3	0,75	0
Q4	0	1	1	1		3	0,75	0
Q5	1	1	1	0		3	0,75	0
Q6	1	1	1	0		3	0,75	0
Q7	1	1	1	0		3	0,75	0
Q8	1	1	1	0		3	0,75	0
Q9	0	1	1	1		3	0,75	0
Q10	1	1	1	1		4	1	1
Q11	1	1	1	1		4	1	1
Q12	1	1	1	1		4	1	1
Q13	1	1	1	1		4	1	1
Q14	1	1	1	1		4	1	1
Q15	1	1	1	0		3	0,75	0
Q16	1	1	1	1		4	1	1
Q17	1	1	1	1		4	1	1
Q18	1	1	1	1		4	1	1
Q19	1	1	1	0		3	0,75	0
Q20	1	1	1	1		4	1	1
Q21	1	1	1	1		4	1	1
Q22	0	1	1	1		3	0,75	0
Q23	1	1	1	1		4	1	1
Q24	1	1	1	1		4	1	1
Q25	1	1	1	1		4	1	1
Q26	1	1	0	1		3	0,75	0
Q27	1	1	1	1		4	1	1
Q28	1	1	1	1		3	0,75	0
Q29	1	1	1	1		4	1	1
Q30	1	1	1	1		4	1	1
Q31	1	1	1	1		4	1	1
Q32	1	1	1	1		4	1	1
Q33	1	1	1	1		4	1	1
Q34	1	1	1	1		4	1	1
						S-CVI/Ave	0,91	
Proportion relevance	0,91	1	0,97	0,79		S-CVI/UA		0,65
	Average proportions of items judged as relevance across the four experts				**0,92**			

APPENDIX 5: CVI CALCULATIONS - Clarity

Item	Expert 1	Expert 2	Expert 3	Expert 4		Experts in agreement	I-CVI	UA
Q1	1	1	1	1		4	1	1
Q2	1	1	1	1		4	1	1
Q3	1	1	1	1		4	1	1
Q4	1	1	1	1		4	1	1
Q5	1	1	1	1		4	1	1
Q6	1		1	1		3	0,75	
Q7	0	1	1	1		3	0,75	
Q8	1	1	1	1		4	1	1
Q9	1	1	1	1		4	1	1
Q10	1	1	1	1		4	1	1
Q11	1	1	1	1		4	1	1
Q12	1	1	1	1		4	1	1
Q13	1	1	1	1		4	1	1
Q14	1	1	1	1		4	1	1
Q15	1	1	1	1		4	1	1
Q16	1	1	1	1		4	1	1
Q17	1	1	1	1		4	1	1
Q18	1	1	1	1		4	1	1
Q19	1	1	1	1		4	1	1
Q20	1	1	1	0		3	0,75	0
Q21	1	1	1	0		3	0,75	0
Q22	1	1	1	1		4	1	1
Q23	1	1	1	1		4	1	1
Q24	1	1	1	1		4	1	1
Q25	1	1	1	1		4	1	1
Q26	1	1		1		3	0,75	
Q27	1	1	1	1		4	1	1
Q28	1	1	1	1		4	1	1
Q29	1	1	1	1		4	1	1
Q30	1	1	1	1		4	1	1
Q31	1	1	1	1		4	1	1
Q32	1	1	1	1		4	1	1
Q33	1	1	1	1		4	1	1
Q34	1	1	1	1		4	1	1
	0,97	0,97	0,97	0,94		S-CVI/Ave	0,96	
Proportion relevance						S-CVI/UA		0,85
	Average proportions of items judged as clear across the four experts				**0,96**			

APPENDIX 6: HREC CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research and Innovation)

TO:	Ms J Cohen School of Therapeutic Sciences Department of Occupational Therapy Medical School University E-mail: 547465@students.wits.ac.za
CC:	Supervisor: Mlles F Breytenbach and K van Stormbroek <Fiona.Breytenbach@wits.ac.za> and <HREC-Medical Research Office@wits.ac.za>
FROM:	Mr Iain Burns Human Research Ethics Committee (Medical) Tel: 011 717 1252 E-mail: Iain.Burns@wits.ac.za
DATE:	2022/12/08
REF:	R14/49
PROTOCOL NO:	**M221071** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)
PROJECT TITLE:	*Management of upper limb pain in stroke survivors: the current practice of occupational therapists in South Africa*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R49 Ms J Cohen

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M221071

NAME: (Principal Investigator) Ms J Cohen

DEPARTMENT: School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

PROJECT TITLE: *Management of upper limb pain in stroke survivors: the current practice of occupational therapists in South Africa*

UNIVERSITY OF THE WITWATERSRAND
OFFICE OF THE DEPUTY VICE CHANCELLOR RESEARCH
2023 -01- 27
RESEARCH OFFICE HREC (Medical) RECEIVED
JOHANNESBURG

DATE CONSIDERED: 2022/10/28

DECISION: Approved unconditionally

CONDITIONS:

NOTE: If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>

SUPERVISOR: Mlles F Breytenbach and K van Stormbroek

APPROVED BY: Dr CB Penny, Chairperson HREC (Medical)

DATE OF APPROVAL: 2022/12/08

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

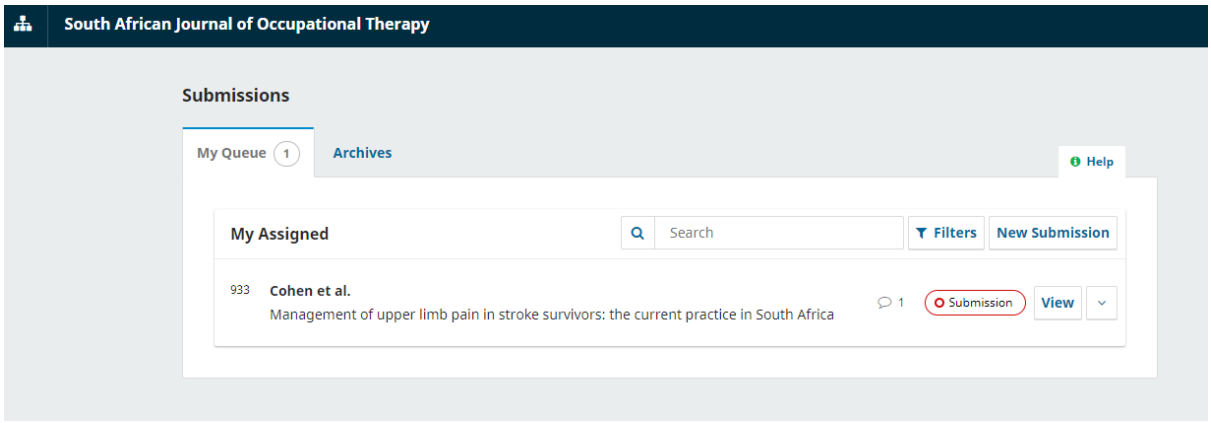
To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report.** When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **October** and therefore reports and re-certification will be due in the month of **October** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator

Date 27/01/2023

APPENDIX 7: PROOF OF ARTICLE SUBMISSION TO SAJOT



APPENDIX 8: SOUTH AFRICAN JOURNAL OF OCCUPATIONAL THERAPY AUTHOR GUIDELINES

Guidelines for Publishing in the South African Journal of Occupational Therapy

The South African Journal of Occupational Therapy (SAJOT) accepts scientific articles, scientific letters, scoping /systematic/integrative reviews, commentaries, opinion pieces and book reviews for publication.

The language of the Journal is South African English (abstracts may be provided in Afrikaans or the Vernacular as well as in English).

Referencing

Vancouver style referencing is used and each reference in the text must be indicated by a number in the text. This number should be inserted in superscript without brackets.

e.g.**12**. A reference list should be provided on a separate numbered page following the article text. References must be cited **in the order that they appear in the tex**t. Please check references from predatory journals are avoided. Predatory journals can be checked at https://predatoryjournals.com/journals/ or https://beallslist.net/.

ALL references must be linked through **CrossRef i.e., each reference must show its DOI number** (if it has one).

Examples of referencing

Journal article

Format: Author. Article title. Journal. Year; Volume (No): Page numbers. DOI number Barnard-Ashton P, Adams F, Rothberg A, McInerney P. Digital apartheid and the effect of mobile technology during rural fieldwork**.** *South African Journal of Occupational Therapy*. 2018; 48(2): 20-25. doi: http://dx.doi.org/10.17159/23103833/2018/vol48n2a4.

Journal names must be written out in full and italicised. Please not that this format must be used NOT doi:10.17159/23103833/2018/vol48n2a4

Book

Format: Author(s)**.** Book title. Edition. City: Publisher; Year. DOI if one is available

De Vos AS, Strydom H, Fouché CB, Delport CSL. Research at Grass Roots: A primer for the Social Sciences and Human Service Professions. Pretoria: Van Schaik Publishers; 2011. https://doi.org/10.4102/hsag.v2i3.337

Chapter (Section) in a Book

Format: Author(s). Chapter title. Book title. Editor. City: publisher; Date/Year published: page numbers. DOI number

Amis, M. Silk, M. Eisenhart, M. Freeman, K. deMarrais, J. Preissle, R. Roulston, E. St. Pierre, K. Howe, P. Lather, Y. Lincoln, G. C. In: Annella, D. Polkinghorne & H. Torrance.

Chapter 10, Standards for Evaluating Qualitative Research. In: Understanding and Evaluating Qualitative Educational Research. M Lichtman, Editor. New York: Sage Knowledge; 2011: 253-260. doi: https://dx.doi.org/10.4135/9781483349435.n10

Webpages

Format: Author(s)(may be corporation or organisation).Name or title of webpage. The date accessed and the URL.

South African Government. Special Needs Education: Education White Paper 6. 2021 [accessed 2021 Jan 12]. https://www.gov.za/documents/special-needs-education- education-white-paper-6

General Requirements

Type of manuscript	**Abstract (words)**	**Pages**	**Tables and figures**	**Words (without tables and references)**	**References**
Scientific Articles	200	±16-19	8	5000- 7000	Max 35 for the literature review section. Max 60 references

Manuscripts must be clearly typed in **MS Word 1.5 spacing with a legible font (Arial, size 11 is preferable)**. Set English (South Africa) as the default language.

Occupational therapy and occupational therapists should not be capitalised or abbreviated.

If quoting from a reference the following format must be used: Gibson2:30 stated that "Occupational therapy is an important service for the rehabilitation of persons suffering from HIV/AIDS". where 2 is the reference number and 30 is the page number on which the quote appears. All quotes from literature must be in quotation marks " ". Quotes from participants in qualitative research should be in quotation marks *and* italics

Tables should have the heading at the top of the table and labelled with Roman letters

e.g., Table II.

Figures should be labelled at the bottom of the figure with Arabic numbers e.g., Figure. 2.

Tables and figures (which may include graphs) **should not be scanned** but formatted and included in place in the manuscript. Figures should be clear to the reader when photocopied.

Figures which consist of illustrations, diagrams or photographs may be of any size. They must be very sharp, taken close-up, and photographs should have a lightish over-all tone and without dark backgrounds. If the photograph, diagram, and illustrations photocopy well, they will print well. Please check this before you send the manuscript.

GUIDELINES FOR AUTHORS OF SCIENTIFIC ARTICLES

Articles submitted to the SAJOT must be original and must not have been published elsewhere. Articles should contain new information, add to existing knowledge, resolve controversy, or provoke thought and discussion. The content of the article must justify the length, which should be about **16-19 pages (**between **5000- 7000 words)**.

Authors should consult the article "The pitfalls of "salami slicing": focus on quality not quantity of publications" by Fenseca M. Editage Insights. Nov 4; 2013. https://www.editage.com/insights/the-pitfalls-of-salami-slicing-focus-on-quality- and-not-quantity-of-publications

Abstract and Key Words

The article must be accompanied by an abstract not **exceeding 200 words** in length. The abstract must contain a succinct structured summary of the study- headings may be used in the abstract (introduction, methodology, results, conclusion). There should be no references or abbreviations in the abstract.

Key words: a list of "key words" which contain words that might be helpful for tracking your article. Try not to 'repeat' key words from the title of the article, as this will limit the search opportunities.

Introduction

This should provide a brief rationale for the study and an outline of the aims or questions. The introduction should present a clear indication of the need for, and purpose addressed by the article. Authors should not assume that the readers know the **context** in which the article is set. The content needs to be organised in a coherent and logical manner and may require concise descriptions and definitions of terms to elucidate the content as well as the aim of the study. The literature review may be included in the introduction.

Literature Review

A separate review of the **relevant literature** can be provided. This should be a **critical** appraisal of the current relevant literature identifying the limitations in the work already conducted on the subject and a rationale for the study. **A maximum of 35** references should be included.

The aim or objectives of the study should appear at the end of the literature review

Method

The section on **research methods** should include if appropriate:

+the research design used,

the population and manner of selecting the population sample,

the research tools used,

the method of data collection,

the methods used to analyse the data including details of the statistical methods, information on validity, reliability, trustworthiness, and credibility.

Details of the ethical clearance and informed consent must be provided without the name of the institution at this stage (replace name with XXXX)

Results/Findings

The results must be presented in a way that makes them accessible to the readers and are clearly linked to the aims and methods of the research.

Discussion

The discussion should summarise the main findings and explore the reasons for these. New knowledge must be highlighted, and the limitations of the study given. The implications for occupational therapists and or other health professionals/groups/ contexts must be outlined and the contribution that the study makes to the current state of knowledge of the profession/s stated. Limitations must also be discussed.

Conclusion

The conclusion must be brief, drawing the article to a close by relating the results to the aim of the research and indicating the key findings this research has added.

Acknowledgements and conflict of interests

All assistance and funding for the research must be acknowledged and any conflict of interests stated.

Tables and figures

Articles may include up **to eight (8) tables or figures** and should be numbered and **clearly labelled and included in the manuscript** in the appropriate place.

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authors agree to make articles available to users, without permission or fees, for any lawful, non-commercial purpose. Users may read, copy, or re-use published content provided that the author and original place of publication are properly cited. See http://userguide.sajot.co.za/wp-content/uploads/2019/10/FINALPublication-Ethics-Practice-comments.pdf

APPENDIX 9: CONTENT ANALYSIS FOR THE PREVENTION OF PAIN IN THE UPPER LIMB POST-STROKE

(Colour coded as per similar responses/ categories)

Participant responses	Category and number of responses n=85 (%)
1. Do not have the tools/ knowledge to prevent pain 2. I don't think pain can be prevented post CVA as it is commonly as a result of neuropathic changes and incorrect processing of sensory information at a neurological level. It can however be addressed and treated 3. Prevention of pain is not currently amounts my top 3 goals for intervention but I think it's an important component to address. Government setting just make it difficult and so other aspects are prioritized 4. Pain prevention is not part of my intervention 5. None 6. Prevention of pain in UL post stroke is not a component in my intervention 7. None 8. not a component 9. I don't usually focus on *preventing* pain, but do attempt to *manage* the pain and encourage movement during the onset of pain. 10. None 11. None 12. prevention of pain is not a component of intervention 13. none 14. Not a component 15. I have not done anything to prevent the pain from occurring, but have rather addressed their specific pain when I am told by a patient.	Not a component of intervention 15 (17.6)
1. weight bearing 2. Joint approximation/ weight bearing 3. weight bearing exercises 4. making use of neuro facilitation techniques (weight bearing) 5. weight bearing to manage tone, stiffness and shoulder subluxation 6. I also use weight bearing to prevent this during therapy sessions 7. Tone management strategies 8. Weight bearing, especially in closed chain activities. 9. humeral dissociation	Neuro facilitatory/ inhibitory techniques 9 (10.6) a. Weight bearing 7 (8.2) b. Joint approximation 1 (1.2)

	c. Tone management strategies – not specified 1 (1.2) d. Humeral dissociation 1 (1.2)
1. heat or cold 2. Heat 3. Maintaining soft tissue mobility with heat 4. Heat 5. Heat for tight pectoral muscles if pulling into a sublux 6. temperature management 7. Ice and heat 8. Heat 9. Use heat at times 10. Heat therapy 11. heat therapy 12. commonly found that the use of heat/ice was effective in managing pain especially in instances prior to passive movements or after & during temperature conditions that are colder, pt's have been recommended that they apply heat and have noticeabley reduced pain	Temperature modalities 12 (14.1) a. Heat 8 (9.4) b. Heat and/or cold 3 (3.5) c. Temperature management not specified 1 (1.2)
1. mindfulness 2. Relaxation techniques 3. use breathing techniques when pain is elicited during movement 4. Pain techniques such as deep breathing a. or the STOP technique can also be used	Relaxation techniques 5 (5.9) a. Mindfulness 1 (1.2) b. Relaxation techniques not specified 1 (1.2) c. Breathing techniques 2 (2.4) d. STOP method 1 (1.2)

1. slow passive stretch and hold 2. Passive mobilization 3. Passive stretching to prevent stiffness 4. slow, passive stretch 5. Start with PROM as soon as possible in the UL. If possible allow the patient to do what active movement they can do within their pain range 6. ensure they are following a good stretching (and positioning) programme 7. Passive movements 8. frequent passive exercise 9. Pssive mobs 10. Supportive or passive movement of the limb to prevent contracture and reduce pain 11. early passive mobilizing 12. Regular stretches 13. maintaining Rom 14. Maintaining good scapular and shoulder passive ROM 15. maintaining ROM of the upper limb with prolonged passive stretches, encouraging active use/integration of the hemiplegic UL into daily activities 16. Increased mobility, specifically assisted mobility and "hemi-exercises", 17. Passive range exercises 3 x daily to reduce stiffness. 18. Early passive mobilisation to prevent stiffness 19. gentle passive mobs 20. Maintain ROM. Passive ROM exercises - in supine, facilitate shoulder flexion with the non affected arm 21. passive range of movement 22. maintaining passive range of motion in therapy and at home 23. maintaining ROM in upper limb 24. Maintain PROM (and encouraging AROM if present) 25. ROM / stretches within pain limits 26. Slow gentle and well aligned passive range of movement 27. passive range of montion exercises 28. Maintain range of motion (with splinting) and stretches 29. mobilization and improvement or maintenance of ROM 30. passive movements within a range that is comfortable for them & progressively increasing the range 31. passive range of motion, active assisted exercises 32. Perform and encourage passive, active-assisted or active movement to maintain ROM and avoid stiffness and pain.	Mobilisation and Strengthening 48 (56.5) a. Passive stretch/ mobilisation/ ROM 30 (35.3) b. Active movement or stimulation/ active-assisted exercises 15 (17.6) c. Stretching/ maintaining ROM – not specified 8 (9.4) d. Neural stretches 3 (3.5)

33. PROM and self stretches of the hemiplegic upper limb, Electrical stimulation on forearm 34. I try to facilitate active movement as soon as possible to prevent joint pain. If active movement has not yet returned I focus on regular passive movement done either by the patient or the therapist 35. Mobilisation techniques 36. and demonstration of passive ROM at shoulder to prevent stiffness, this is done within patients pain tolerance 37. maintaining ROM 38. Shoulder exercises in the form of home programmes - passive, active, resisted and auto-assisted to keep the shoulder girdle strong to avoid subluxation of the gleno-humeral joint which causes pain. 39. Electronic muscle stimulation , strengthening of anchor muscles 40. Exercises depend on level of UL functioning and may include Active assisted ROM exercises 41. Improve trunk strength and prevent overuse of the non-affected side, improving shoulder girdle on affected side 42. Advocating for normal movement patterns as much as possible in and out of the therapeutic setting 43. Strengthening of the shoulder 44. Flaccid arm - attempt activation of shoulder muscles to prevent pain 45. Stimulating the upper limb through exercises or in occupations 46. Neural stretches 47. neural stretches 48. neural stretches	
1. Mirror therapy 2. Mirror therapy to decrease disuse of the affected arm.	Mirror therapy 2 (2.4)
1. by letting patient wear sling when not in sessions 2. Splinting Strapping 3. Slings for subluxed shoulders if appropriate 4. Splint the upper limb or strap the shoulder 5. strapping, sublux shoulder cuff 6. strapping, splinting, brace ie omo-neurexa 7. if deemed necessary I consider splinting the patient 8. Flaccid arm - immobilisation with hemi sling 9. Splinting of the wrist and hand Hemi-arm sling 10. Strapping Splinting if indicated 11. Issuing splints 12. hemi sling or strapping to prevent subluxation 13. K-tape, sling if indicated 14. Wrist brace 15. preventative splinting for clients who have significant increased tone - soft elbow splints	Orthoses 21 (24.7) a. Slings 10 (11.8) b. Splinting 12 (14.1) c. Strapping/ Taping 10 (11.8)

16. Maintain range of motion with splinting 17. issue devices such as arm sling if patient present with Flaccid upper limb to prevent Subluxation 18. Strapping of shoulder if subluxation is present acute phase 19. orthotic devices to protect joins such a sling or wrist brace 20. Resting splint fabrication shoulder strapping 21. Taping	
1. Manual massage to relax stiff muscles 2. Soft tissue release 3. Soft tissue mobilisation of stiff/hypertonic muscles 4. deep tissue massage 5. massage 6. soft tissue massage 7. Massage	Massage/ soft tissue release or mobilisation 7 (8.2)
1. Correct positioning (using pillows, tray table, etc.to position limb) 2. Provide that arm with support (tray table). 3. Passive positioning 4. Positioning with splinting and/or external supports in lying or sitting such as blankets/pillows 5. correct handling and positioning 6. Positioning of the affected UL including issuing of tray table and positioning foam etc stuck to tray table if required. Limit PROM to max 90 degrees and within pain limitation 7. supporting the upper limb 8. Shoulder stabilization and positioning 9. adequate positioning 10. Preventing subluxation by preventing the arm from hanging down 11. Positioning 12. positioning of UL 13. Positioning 14. Positioning 15. Correct positioning of affected hand and arm to prevent "hanging" of the arm 16. Correct wheelchair seating in the correct wheelchair with arm rests at a suitable height Tray table 17. Positioning of a flaccid limb - place in a sling (if available), put hand in pocket, hook in handbag, hold with non-affected arm rather than hanging 18. Positioning 19. Joint hygeine and correct positioning 20. correct positioning of the hemiplegic flaccid upper limb	Positioning 36 (42.4)

21. Positioning of the upper limb 22. Positioning during activity and rest(seated and lying) 23. Priotise proper positioning with pillows and towels, focusing on neutral positioning of joints 24. Positioning 25. Positioning of the upper limb when sitting up. Positioning of the upper limb in side lying 26. Positioning in bed and in sitting 27. Correct positioning and handling of the affected upper limb at all times 28. Positioning 29. positioning to prevent injury/pain 30. Practise the skill of positioning and handling of UL in self care tasks, Issue of a tray table to support the UL and add "foam blocks" to the tray table to prevent the hemiplegic arm form hanging/ sliding off the Tray table - specifically for flaccid UL and for clients who have hemi neglect or decreased awareness 31. Positioning to decrease shoulder pain 32. Flaccid arm – positioning 33. Postural correction to prevent pinching of nerves in the shoulder region 34. Correct positioning and handling of the affected upper limb. 35. correct positioning 36. positioning programme	
1. Oedema management 2. Oedema Management – with a boxers wrap bandaging technique and elevation	Oedema management 2 (2.4)
1. Botox management (if indicated) 2. Refer for Botox	Botox Referral 2 (2.4)
1. Reporting pain to doctor for medication if required 2. Make known to doctor regarding medication change 3. Refer to Dr if spasticity related 4. When appropriate, ask Physio to perform neural stretches/management 5. For shoulder subluxation, that often causes pain, I will ask the Physiotherapist to strap for support 6. Refer where necessary	Referral to MDT 6 (7.1) a. Doctor 3 (3.5) b. Physiotherapy 2 (2.4) c. Not specified 1 (1.4)
1. Patient and family education on positioning the upper limb and home exercises 2. Education on optimal positioning of the upper limb at rest 3. Education on management of the UL during transfers, ADLs etc	Education 28 (32.9)

4. education to porters , nurses and caregivers 5. Teaching the patient and family appropriate positioning of the hemiplegic UL 6. Educate patient on positioning, exercises and pain management 7. Education 8. Education 9. teaching the patient to be aware of and care for affected arm 10. education 11. Education from the very start of therapy on how to protect the hemi upper limb. Education for the patient but also all other role players in their lives 12. Patient education regarding care and handling of upper limb 13. Precaution education (e.g. not pulling on the affected limb and positioning at home) 14. Educate the patient on pain and create realistic expectations. Teach the patient coping mechanisms and non-pharmacological techniques of relieving pain 15. training in managing the UL correctly and safely 16. Education 17. Educating patient and / caregivers on management of the hemi arm 18. - Education family and client regarding positioning and handling of hemiplegic UL - Train and inform nursing staff of positioning of hemiplegic UL whne they are seated in their wheelchair or in bed 19. education on risks, caregiver training 20. Advising patient to take pain meds, Pain management education, Education and demonstration of passive ROM at shoulder to prevent stiffness, this is done within patients pain tolerance 21. education regarding positioning and handling of the limb 22. home management education, home exercise programme . hemi neglect education, (stretches) and handling 23. Education on positioning and handling of stroke arm 24. positioning education to prevent subluxation 25. educate on positioning 26. flaccid arm- education 27. Preventative measures agains shoulder subluxation i.e. not pulling on arm and not moving past 90°- family/caregiver education on this. 28. Joint protection principles and care of the hemi-side	a. Positioning and handling of the hemiplegic upper limb 18 (21.2) b. Home exercises 6 (7.1) (including 2 from sections above) c. Pain Management 3 (3.5) d. Flaccid arm 1 (1.2) e. Joint protection principles 1 (1.2) f. Not specified 6 (7.1)
1. Sensory stimulation 2. sensory re-training 3. desensitization 4. promoting sensory re-education 5. Sensory stimulation or desensitisation during therapy	Sensory and awareness training 9 (10.6)

6. sensory stimulation for sensory re-education of the upper limb (e.g. with cold and warm water, textured washcloth or sponge) 7. sensory stimulation 8. Increasing awareness of the upper limb 9. Increase awareness of arm (if neglect present)	a. Stimulation/ re-training 6 (7.1) b. Desensitisation 2 (2.4) c. Increasing awareness (not specified) 2 (2.4)
1. encouraging rest	Rest 1 (1.2)
1. NDT methods	NDT methods 1 (1.2)
1. functional activities to help prevent pain 2. functional use of limb	Functional activities 2 (2.4)
1. Therapy can also be scheduled within time frame of the patient taking their pain medication, but before they become too drowsy	Scheduling of therapy times 1 (1.2)
1. Delay walking and mobility until trunk and leg strength is adequate to prevent increasing tone in affected upper limb	Miscellaneous 1 (1.2)
No responses	No responses 7 (8.2)

APPENDIX 10: CONTENT ANALYSIS FOR OTHER PREVENTION STRATEGIES FOR PAIN IN THE UPPER LIMB POST-STROKE

Participant responses	Category and number of responses n=85 (%)
1. caregiver education of above in cases of younger children 2. Family and staff education 3. Recommending patient is compliant with pain medication routine.	Education 2 (2.4)
1. heat management 2. heat 3. Ice and heat. 4. Application of home-made heat therapy packs for pain experienced in the mornings when it is cold, and during cold weather.	Temperature modalities 4 (4.7)
1. I am not skilled in strapping but often refer to physio for strapping. If indicated I refer to a doctor for botox or other medical intervention.	Referral to MDT 1 (1.2)
1. Weight bearing on affected limb	Neuro facilitatory/ inhibitory techniques 1 (1.2)
1. Oedema management if and when necessary to prevent limitations on active and passive range of motion which may contribute to pain - especially in the hand and fingers 2. Oedema management	Oedema management 2 (2.4)
1. Improve trunk strength and symmetrical movement of the trunk	Trunk strengthening 1 (1.2)
1. Strapping	Orthoses 1 (1.2)
1. Therapeutic functional stimulation	Mobilisation and Strengthening 1 (1.2)
1. Sensory stimulation of the upper limb for sensory reeducation.	Sensory and awareness training 1 (1.2)
1. Hydro Therapy	Hydrotherapy 1 (1.2)
1. relaxation techniques	Relaxation techniques 1 (1.2)
1. Adapting ADLs to conduct them within a pain free manner (eg. wing long handled bath brush for the back)	Functional activities 1 (1.2)

APPENDIX 11: CONTENT ANALYSIS FOR THE ASSESSMENT OF PAIN IN THE UPPER LIMB POST-STROKE

(Colour coded as per similar responses/ categories)

Participant responses	Category and number of responses n=77 (%)
1. Using a visual analogue scale Asking the patient where they feel pain, how often they feel pain. What type of pain they feel (I.e asking interview questions about their pain) 2. Subjective pain assessment 3. Verbal indication of pain and using VAS when appropriate 4. Pain scale (if cognitively intact and verbal) 5. patient telling you they are in pain. Assessing severity on scale of 0 to 10. Get a description of the pain 6. Use a pain rating scale (Wong-Baker faces pain rating scale) at various points throughout the session to assess pain at rest, with passive and active movement and during activity. 7. VAS 8. I would ask the patient if they feel pain and how they would describe the pain. What makes the pain better/worse. One scale of 1-10 how bad is the pain? I would ask this during movement and when the arm is resting. 9. Subjective interview on the pain 10. Make use of visual pain scales relating to specific activities of daily living 11. VAS 12. pain rating scale 13. VAS pain scale 14. Screening for pain during initial interview and assessment Spending time in n-depth discussion around pain, allowing patient to discribe it and understanding the patient's pain from their perspective. Asking questions relating to what affects pain both positively and negatively and gathering insight into how much the patient understands about their pain 15. Ask if pain is felt in the arm, location, as well as type of pain and duration/occurance/frequency. 16. Verbally asking patient if they feel pain during certain movements 17. use a wong Baker pain scale 18. Pain assessment scale involving: Describing type of pain Cause of pain (resting pain/upon passive movement, etc) Rating pain out of 10 Positions which relieve/exacerbate pain levels 19. ask the patient where the pain is, what type of pain, does it come and go and what helps relieve the pain. What tines is pain worse and to rate the severity of the pain. 20. interview	Subjective pain assessment 67 (87.0) a. Pain rating scales, questionnaires and outcome-based measures 37 (48.1) b. Interviews 44 (57.1) c. Self-initiated subjective reports of pain 4 (5.2) d. Obtaining collateral information 3 (3.9)

21. Pain scale 22. VAS Ask to describe type of pain and location of pain 23. Ask patient if they have any pain and where and what type Ask patient ton rate pain on Visual Analogue Scale Check what meds they are taking for pain 24. When assessing pain, I consider the following factors: the location of pain (localized vs widespread), the frequency of pain, precipitants of the pain (e.g. occurs during certain activities or under certain environmental conditions), current methods which the patient is using to provide relief from pain, or exploring under what conditions the pain subsides for the patient (e.g. when bathing, when resting), I also ask the patient to describe the pain that they are feeling (e.g. dull, aching, burning), I also ask about how the pain impacts their daily function 25. Interview and pain questionnaire 26. Interviewing 27. Patient subjective view of pain on a visual scale, pain questionnaires 28. Use a pain screening form 29. Verbal pain score determined by patient - VAS (visual analogue score of pain) 30. Subjective interview of patient where they rate their pain on a scale of 1 to ten 31. pain scale 32. Use of subjective pain scales 33. VAS scale Ask for description of pain How movement affects pain 34. Pain scale - rating pain with numbers or faces depending on the client's communication abilities. - - asking for description or history of the pain (where do you feel it, when does it happen, what helps to take it away, what doesn't help, etc) 35. using the VAS for pain DASH 36. Pain scale 1-10 37. Visual analogue scale 38. Visual Analogue scale where appropriate Informal questions 39. I will talk to them about the pain, use a VAS and get them to rate the pain, we talk about what makes it better and worse, the type.of pain and when the pain comes. 40. Patient feedback on pain when UL is mobilized (ask about type of pain and rating) 41. Self-reporting questionnaires Collateral information VAS 42. Pain analog scale to rate pain - Ask patient to describe the pain 43. Interview: ask about pain and elaborate on type of pain, pain scale(1-10) location of pain, activities that improve or worsen pain 44. I use a pain assessment scale and then ask them to localise and describe the pain.	

45. Ask if there is any pain (where, rate out of 10, what type of pain, is it all the time, can you still move it, how much, show me, is the pain present pre or post-stroke) Ask if I can move the arm and ask them to let me know when it hurts and what it feels like 46. Interview with the patient to determine if they experience pain, where they experience pain, how it feels (their description of the pain), when it normally occurs and what makes it feel better. 47. Interview Questionnaire - DASH and other 48. Ask specific questions of the patient re pain 49. verbal report 50. interviewing the patient on their subjective pain experience 51. Interview patient 52. subjective assessment VAS pain scale - location, intesity, description 53. Interview Pain scale 54. patient interview and collateral consulting with members of MDT 55. assess by asking patient if any pain is experienced and when/where. also patient to report any pain during the rest of the assessment e.g. PROM and AROM, patient to rate pain on scale 1-10 56. Numeric pain rating scale (0 - 10) 57. move the limb slowly through the client's range of motion, slowing down when the show signs of pain. then locate where the pain is & ask them to rate it on a scale of 1 - 10. 58. Ask the patient 59. localise pain - understand the type of pain - rate the pain - understand how it is managed 60. pain scale 61. Ask the patient their feelings of pain 62. Pain scales if the patient's cognition is high enough to communicate 63. I often use a pain scale of 1-10 with 1 being little pain to 10 being unbearable pain, if necessary I will use accompanying facial expression pictures / smiley faces for the patient to rate their pain. I also ask the following questions: When does the pt feel pain, description of the pain (throbbing, sharp, stabbing, cramping etc.) Does the pain differ might vs day and during different weather conditions. Where is the pain - pt to answer verbally, or to show with the unaffected side etc. 64. interview 65. Ask the patient to describe their pain from 1-10, what makes it better/ worse, etc. (all subjective questions from a pain ax form). 66. pain scale 67. pain skale (linkert) - pain questionairre - simply asking the pt.	
1. sensation ax, observe compensation strategies with functional tasks 2. Observing pain responses: facial grimacing, protection of upper limb, etc (if non-verbal/ poor cognition)	Objective assessments

3. When doing the screening, observe facial expressions, gestures, ROM assessment to see where the pain is, what movements trigger it or make it worse. Sensation assessments for Allodynia or hyperalgesia. Palpate for hypertonic/overly stuff muscles 4. Observation of facial expression and body language during activity. 5. Informal assessment of body language, reactions etc 6. Observe patient's response (facial expression, verbal expressions) to certain movements 7. I usually use guided movements to assess pain 8. facial expressions during rehab, avoidance in using the arm, holding it or positioning it on a cushion, not wanting to attend rehab, alwayz postponing appointments 9. moving the limb to determine what causes pain 10. Assess for subluxed shoulder Assess pain through passive ROM 11. I will assess the patients pain throughout the session while working in different positions as well as with passive ROM to determine where, when and what elecits the pain. I will also Ax the shoulder joint to determine possible dislocation fir further management. 12. sensation assessment, assessment of pain during PROM and AROm 13. sensation assessments 14. Sensation assessment - light touch and pressure specifically Tone assessment by palpation and passive mobilisation of the upper limb 15. Assess ranges and observe subjective and objective signs of pain Assess sensation and stereognosis 16. Observing for visual cues from the patient regarding pain experienced 17. Indicate with non-affected arm where the pain is. Look for signs of pain while assessing ROM/Muscle strength 18. Passives and observing the pain 19. Observation and examination 20. Physical examination: movement and palpation of painful area, sensation assessment to assess for hyper or hypo sensitivity. Observation: how arm is positioned during session, if arm is neglected, which actions/movements causes pain during session - during ADL activities and HEP 22. Then asking the patient to move through their AROM (if they can) and PROM and asking if they experience pain at a certain point (also observing body language). 23. Watch patient facial expression during active and passive range of movement assessment. 24. observe in activity 25. Perform passive and active movements and then observe either pain responses (face twitching, resisting movements) 26. Move the limbs affected by stroke to determine the level of pain experienced 27. physical assessment	39 (50.6) a. Observations 23 (29.9) Physical assessments 33 a. Tone 2 (2.6) b. ROM/ movement 15 (19.5) c. Shoulder subluxation/ dislocation 2 (2.6) d. Sensation 7 (9.1) e. Activities 1 (1.3) f. OBM's 2 (2.6) g. Physical assessment – not specified 2 (2.6)

28. objective assessment in various activities 29. active and passive movements of upper limb use of activities 30. move the limb slowly through the client's range of motion, slowing down when the show signs of pain. then locate where the pain is 31. ROM assessment 32. physical expression, reaction to movement 33. observe for pain reactions during passive mobilisations observe patient during ADL or basic task engagement 34. I use observation to observe things such as facial grimacing or limb protection which indicate pain. 35. One can also assess pain when slowly carrying out passive movements and asking the patient to let you know when to stop (when they feel pain) and to describe the pain, and make note of the range achieved in order to work within pain threshold and ranges. I will also make note of any facial expressions or grimacing suggesting pain. 36. feel - comfortable range see - shoulder / scapula rhythm 37. observation 38. MAS Full meyer 39. Using the Abbey Pain scale for patients that are non-verbal	
1. Not a component in intervention. 2. None 3. I do not assess pain 4. Not assess 5. It is not a component of intervention 6. None 7. Not a component	Not a component of intervention 7 (9.1)

APPENDIX 12: CONTENT ANALYSIS FOR OTHER ASSESSMENT METHODS FOR PAIN IN THE UPPER LIMB POST-STROKE

Participant responses	Category and number of responses n=77 (%)
1. standardized tests	1 (1.3)
1. Note: In the setting I am in, it is unfortunately not always possible to educate caregivers in the acute setting - why I chose sometimes (as this often needs to occur in the OPD setting rather then the ward).	N/A

APPENDIX 13: CONTENT ANALYSIS OF OUTCOME-BASED MEASURES USED IN THE ASSESSMENT OF UPPER LIMB POST-STROKE

Participants response	n=73 (%)
1. Functional pain scale	Functional pain rating scale 1 (1.4)
2. Pain rating scale	Pain rating scales – not specified 1 (1.4)
1. Pain scale 1-10 2. Mainly Pain Scales (rating 1-10) 3. Pain scale (linkert 0-10)	Numerical Pain Rating Scale 3 (4.1)
1. VAS for pain 2. Visual Analogue scale 3. VAS 4. Visual Analogue Scale 5. VAS	Visual Analog Scale 5 (6.8)
1. Abbey Pain scale	Abbey Pain Scale 1 (1.4)
1. Dash and Quick DASH 2. DASH	DASH/ Quick DASH 2 (2.7)
1. Fugl-Meyer 2. Fugl-Meyer Assessment of Motor Recovery after Stroke	Fugl-Meyer Assessment 2 (2.7)
1. SMART 2. Improving knowledge and skill of pain management Increasing mobility of affected joints where applicable to decrease pain 3. Management of pain to facilitate better mood and therefore engagement in therapy in order to meet the patient's functional outcomes 4. Improvement in functional engagement in ADLs and IADLs, including taking into consideration improvements in components. 5. frequent passive & active (if possible) mobilisation & use of functional activity	Outcomes but not outcome-based measures - excluded 5 (6.8)
None	57 (78.1)

APPENDIX 14: CONTENT ANALYSIS FOR THE TREATMENT OF PAIN IN THE UPPER LIMB POST-STROKE

Participant responses	Category and number of responses n=69 (%)
1. Through correct therapeutic positioning 2. Correct positioning of the upper limb 3. Then I work on postural adjustments 4. positioning 5. positioning 6. positioning tray table 7. Positioning including use of tray table and positioning devices 8. Correct/Anti deformity positioning 9. Positioning 10. Positioning posture and alignment 11. It depends on the reason for and the location of the pain. If it is an untreated dislocated shoulder, therapy focus on preventative measures and positioning 12. Ongoing positioning 13. positioning 14. positioning 15. Positioning 16. Positioning 17. Positioning 18. Wheelchair seating (with tray table IF available and have funds) 19. Positioning 20. Positioning 21. Positioning in bed/chair 22. Positioning 23. Again focus on better positioning of hemiplegic arm in sitting and in bed 24. Positioning 25. Demonstration of positioning of upper limb 26. Positioning	Positioning 28 (40.6)

27. Positioning 28. Correct contributing positional or movement related concerns	
1. Splinting Strapping Sling (if required) 2. Splinting 3. Strapping 4. Strapping Subluxation cuff with elbow free for movement 5. sometimes splints and slings 6. Strapping subluxed shoulder Slings or splints 7. neuro splinting 8. strapping splint or glenohumeral support if indicated 9. Splinting 10. strapping 11. Splinting, strapping 12. Subluxation hemislings and strapping for subluxation causing pain 13. Strapping 14. Kinesiotaping 15. Soft splinting 16. splinting / sling if applicable 17. providing slings, refer to hospital/clinic for splinting 18. Strapping for subluxed shoulder - not for improvement but for pain management 19. splinting if needed 20. use of orthotic devices such as sling or wrist brace 21. splinting	Orthoses 21 (30.4) **a.** Strapping/ taping 11 (15.9) **b.** Splinting 14 (20.3) **c.** Slings 9 (13.0)
1. Heat 2. Physical agent modalities (heat) 3. Heat 4. heat 5. Heat 6. Heat 7. Heat therapy 8. Heat and cold alternating 9. Heat 10. Heat 11. pain reducing techniques such as heat 12. heat	Temperature modalities 22 (31.9) **a.** Heat 19 **b.** Heat and/or cold 2 **c.** Cryotherapy 1

13. Heat 14. Apply heat to area of pain, esp if muscular 15. sometimes I use warm bean bags(and passive range of motion) I'd there is a lot of tone in the arms causing a frozen shoulder 16. Heat if appropriate 17. Heat therapy 18. Heat 19. Heat 20. Warmth 21. cryotherapy 22. pain mx such as heat/ice application	
1. Soft tissue release 2. More often than not the pain is coming from either a subluxation or overly stuff/hypertonic muscles supporting the shoulder joint. Patients adopt a 'protective' posture where they carry the shoulder in an elevated and slightly protracted position. my treatment focuses on softening those stiff muscles with soft tissue mobilisation 3. soft tissue massage 4. Massage 5. muscular skeletal release 6. Soft tissue release 7. release of muslces in region 8. Soft Tissue Massage and Release of shortened muscles 9. myofascial release 10. soft tissue release 11. Myofascial release 12. Massage 13. Massage 14. Massage	Massage techniques 14 (20.3)
1. Joint approximation of the upper limb 2. In acute upper limb pain, weight bearing, closed chain activities 3. normalization of tone 4. Normalizing tone during sessions as well a shome techniques 5. Try increase awareness of hemiplegic arm even if there is pain by Weight bearing 6. joing approximation, weightbreaing	Neurofacilitatory/ inhibitory techniques 6 (8.7) a. Joint approximation 2

	b. Weight bearing 3 c. Normalising tone 2
1. Gentle passives 2. Stretching, an exercise I like to use is pendulum swings while holding a weight. it encourages slight separation in the joint space and allows for gentle movement of the muscles around the shoulder 3. Slow passive mobilization 4. PROM, AROM 5. Stretches 6. Passive movements 7. Electronic muscle stimulation Strengthening of anchoring muscles 8. Exercise 9. slow passive movements, slow stretching 10. Maintaining ROM and increasing SCOM and strength 11. Passive prolonged stretch of the hemiplegic upper limb 12. And ROM is implemented 13. Strengthening of the affected joints 14. Active/ active assisted exercises 15. passive stretching and encouraging active movement to affect tone 16. passive rain of movement 17. Passive mobs A/P//P/A grd 1-3 mobs of the forearm, wrist and finger joints Active assisted and active exercises 18. Slow active or passive movements through partial ROM 19. Strengthening of underlying weaknesses, range of movement exercises 20. Strengthening, passives 21. Passive range of motion I'd there is a lot of tone in the arms causing a frozen shoulder, active range exercises to strengthen muscles around joints 22. Maintain ROM with active-assisted mobs 23. Strengthening, active movements 24. AROM or PROM Improve trunk control, mobility and strength in the affected limb as possible 25. Gentle passives, active-assisted or active movement 26. Exercises (active or assisted) 27. gentle stretches, ROM within limits 28. Gentle passive ROM 29. Strengthening of muscles around painful joints	Mobilisation and strengthening 41 (59.4) a. Passive ROM techniques/ stretching 25 b. Active ROM/ strengthening exercises 27 c. ROM not specified 7

30. Through exercises 31. teach active assisted passive movements to allow for mobilisation of the joint but for the client to direct these movement and to limit the anticipation of pain 32. Maintaining ROM 33. Exercises 34. Strengthening, passive and active movements 35. passive & active (when possible) movements 36. passive stretch, active assisted exercise 37. rom exercise, muscle strengthening, active assisted exercises 38. Electrical stimulation, passive stretches, neural stretches 39. Self-assisted +- gravity excluded mobilisation / stretching Strengthening of, and mobilising of trunk and UL muscles 40. Stretching of the painful limb/ affected area 41. Limit passive range and only work in pain free range	
1. Depending on the etiology of the pain, mostly desensitization of paresthesia 2. Sensory re-education 3. desensitisation 4. Desensitisation if hypersensitive 5. desensitization 6. Desensitisation 7. increase awareness and prevent neglect of limb 8. sensory stimulation 9. re-education try increase awareness of hemiplegic arm even if there is pain by Weight bearing, tactile stimulation	Sensory and awareness training 9 (13.0) a. Stimulation/ re-training 3 (4.3) b. Desensitisation 5 (7.2) c. Increasing awareness (not specified) 1 (1.4)
1. Oedema management 2. Manage oedema 3. oedema management if necessary 4. oedema management 5. oedema management n- 6. Compression 7. elevation, compression	Oedema management 7 (10.1) a. Non-specified 5 (7.2) b. Compression 2 (2.9) c. Elevation 1 (1.4)

1. Mirror therapy 2. Mirror therapy/ GMI 3. mirror therapy 4. Mirror therapy GMI 5. mirror box 6. Mirror therapy 7. Mirror therapy 8. Mirror therapy 9. TENS 10. TES	Specific pain management techniques 10 (14.5) a. Mirror therapy/ GMI 8 (11.6) b. TENS/ TES 2 (2.9)
1. Not a component 2. None 3. Not a component 4. I do not typically treat it 5. I don't treat pain 6. Mostly focussed on prevention. PT focusses on intervention ie myofacial release 7. Not treat 8. None 9. Treatment of pain is often not part of my intervention 10. it is not a component of intervention	Not a component of intervention 10 (14.5)
1. deep breathing exercises 2. Visualisation 3. Asking the patient to breathe when doing stretching too 4. Relaxation techniques 5. breathing in and out slowly, respect pain (stop before it becomes worse) 6. guided imagery 7. breathing techniques 8. depending on the type of pain- I teach the patient deep-breathing exercises 9. Deep breathing pain treatment techniques 10. Relaxation therapy and deep breathing 11. Breathing 12. Breathing techniques and STOP technique 13. Relaxation techniques (eg. visual imagery) 14. breathing exercises	Relaxation techniques 14 (20.3) a. Breathing techniques 10 (14.5) b. Visualisation/ guided imagery 3 (4.3) c. STOP method 2 (2.9) d. Non-specified 2 (2.9)

1. Education on depressing and retracting the scapula 2. Education 3. Joint protection principles 4. First educate patient on the types of pain, various causes of pain, the relation between pain and neuropathology. Then identifying patient's pain, the cause and the reason behind the sensation. Educating patient on various ways to manage pain, exploring each of these with the patient and evaluating the effective of each in turn as well as when implementing a combination approach. 5. Joint protection principle, advise on how to carry out basic ADL activities using both hands or aiding the hemiplegic UL to prevent pain 6. Insight development into pain and importance of mobilisation 7. Educating patient and caregivers 8. Education 9. patient education 10. Education 11. Education Caregiver training 12. Patient education regarding pain 13. Education is very improtant: positioning, precautions and handling of the effected limb, not pushing into pain 14. educate re pain, cycle, handling and how to manage pain 15. education 16. Education on pain management 17. education regarding positioning and handling of limb 18. JPP 19. Home Program depending on the abilities of the client 20. Normalizing tone during sessions as well a shome techniques 21. Same as how I prevent - home programmes to stretch and strengthen shoulder girdle 22. Daily program including pain management techniques	Education 22 (31.9) a. Joint protection principles 3 (4.3) b. Positioning and handling 5 (7.2) c. Pain neuroscience education 4 (5.8) d. Pain management education 4 (5.8) e. Education non-specified 7 (10.1) f. Home programmes 4 (5.8)
1. Medication/ injections- by doctor Botox 2. Botox referral Communication with dr regarding medication 3. Refer to psychology from the onset 4. Liase with physio for pain management techniques 5. PT focusses on intervention ie myofacial release 6. Referral for BOTOX 7. Referral to team MDT for therapy and medication if required 8. Often consult with Physio when there is intense shoulder pain to assess the stability and structure f the joint and get some guidance Refer to Psych if anticipation of pain is severe consult with Dr regarding medication	MDT referrals 11 (15.9) a. Botox referrals 4 (5.8) b. Doctor referrals for medication 5 (7.2)

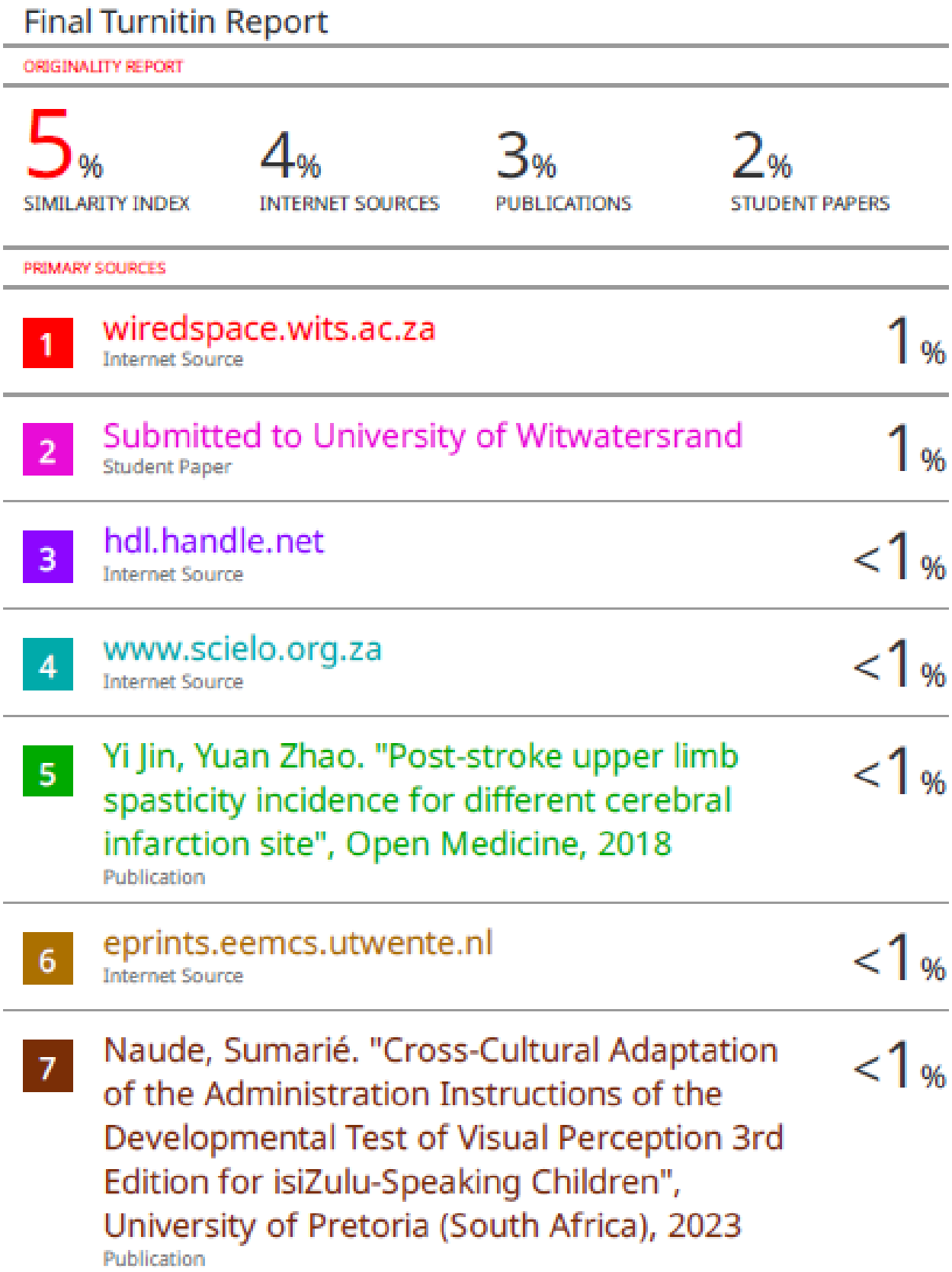
9. Our physio team assist with strapping 10. discuss with Dr regarding medication for pain 11. BOTOX	c. Psychology referrals 2 (2.9) d. Physiotherapy referrals 4 (5.8)
1. Pain medication- Rx after 30mins of consuming pain medications 2. Medication and scheduling exercises accordingly	Scheduling of therapy time 2 (2.9)
1. ADL training - how to perform ADL and mobility activities without increasing or causing pain 2. functional activities including group sessions 3. use of functional activities 4. In acute upper limb pain, closed chain activities 5. Actibities 6. use of UL in functional tasks 7. Use of neurorehab techniques to regain movement in the upper limb starting from proximal to distal function or using what the patient has in terms of movement. i do this through functional activities within their ward room. 8. Review activity participation techniques and correct where indicated e.g. dressing, bathing	Functional activities 8 (11.6)
1. chronic group sessions 2. (Through exercises and functional activities) including group sessions	Group sessions 2 (2.9)
1. Rest 2. Rest	Rest 2 (2.9)

APPENDIX 15: CONTENT ANALYSIS FOR OTHER TREATMENT TECHNIQUES FOR PAIN IN THE UPPER LIMB POST-STROKE

Participant responses	**Category and number of responses n=63 (%)**
1. Botox 2. referral for BOTOX	Botox referral 2 (3.2)
1. By Bobath techniques – do you mean NDT techniques?	N/A 1 (1.6)
1. Splinting	Splinting 1 (1.6)
1. Oedema management	Oedema management 1 (1.6)

APPENDIX 16: TURNITIN REPORT

Please refer to the full Turnitin Report attached to the email for submission for examination.



Final Turnitin Report

ORIGINALITY REPORT

5%	4%	3%	2%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	wiredspace.wits.ac.za Internet Source	1%
2	Submitted to University of Witwatersrand Student Paper	1%
3	hdl.handle.net Internet Source	<1%
4	www.scielo.org.za Internet Source	<1%
5	Yi Jin, Yuan Zhao. "Post-stroke upper limb spasticity incidence for different cerebral infarction site", Open Medicine, 2018 Publication	<1%
6	eprints.eemcs.utwente.nl Internet Source	<1%
7	Naude, Sumarié. "Cross-Cultural Adaptation of the Administration Instructions of the Developmental Test of Visual Perception 3rd Edition for isiZulu-Speaking Children", University of Pretoria (South Africa), 2023 Publication	<1%

APPENDIX 17: DECLARATION: STUDENT'S CONTRIBUTION TO ARTICLE(S) AND AGREEMENT OF CO-AUTHOR(S)

Declaration: Student's contribution to article(s) and agreement of co-author(s)

I, Jenna Lee Cohen, student number 547465, declare that this Research Report is my own work and that I contributed adequately towards research findings published in the article(s) stated below which are included in my Research Report .

Signature of Student ..... **Date** 19 July 2024

Name of Primary Supervisor Fiona Breytenbach

Signature of Primary Supervisor ..... **Date** 19 July 2024

Agreement by co-authors: By signing this declaration, the co-authors listed below agree to the use of the article(s) by the student as part of her Research Report. In cases where the student is not the 1st author of a published article, the primary supervisor must explain (under comments) why the student is entitled to use the paper for her degree purposes.

Article 1: Title: Management of upper limb pain in stroke survivors: the current practice of occupational therapists in South Africa

Journal name, year, volume and page numbers: .....

Authors	Name	Signature	Date
1st author	Jenna Lee Cohen		19 July 2024
2nd author	Fiona Breytenbach		19 July 2024
3rd author	Kirsty van Stormbroek		19 July 2024

Comments by primary supervisor:

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Both supervisors have reviewed and approved final draft of manuscript for submission to journal

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