THE INFLUENCE OF A RURAL CONTEXT IN KWAZULU NATAL ON PRIMARY CAREGIVER'S MANAGEMENT OF PAIN IN NON-VERBAL CHILDREN WITH SEVERE NEUROLOGICAL IMPAIRMENT

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A research report submitted to the Faculty of Health 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, Jeanette Pretorius (ID: 8802110076081) hereby declare that this dissertation is my own work. It is being submitted for the degree of Masters of Science in 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.

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Dedication

In honour of my God, my parents and the patients and friends who made this research report possible.

Acknowledgements

I would like to heartily acknowledge and thank my research supervisors: Dr Denise Franzsen and Marica Botha, without your support and guidance, this research report would not have been possible.

Also instrumental in making this research report possible is the KwaZulu Natal Department of Health’s permission for my research. In this regard I would like to specifically thank Mr. LI Hlabe, who assisted me with this procedure.

The help of my head of the institution, head of the department and my colleagues in clinical practice; in particular Mr. NB Mantengu, as well as the help from our human resources office is greatly appreciated.

I would also like to acknowledge the many wonderful caregivers and children with severe neurological injuries who inspired this inquiry and who made this research possible.

Abstract

Untreated pain is known to have negative consequences on the development and wellbeing of “non-verbal” children with severe neurological impairment (SNI). Healthcare workers and caregivers must ensure that pain is managed in this population, even though pain may be difficult to assess. Occupational therapists need to understand how context affects the management of pain experienced by a child with SNI, as well as its impact on the care of the child.

This study determined how a rural KwaZulu Natal context impacted how primary caregivers recognized and manage pain and the care of their child with SNI.

Methods: A multiple descriptive, embedded case study design using a demographic and pain questionnaire, with cross sectional design. There were nine respondents’ qualitative and quantitative information content analysis and descriptive statistics were used to report.

Results: Financial, environmental, emotional and physical strain factors associated with the rural context were identified may be adding to the burden of care and affecting the occupational performance of the child with SNI and their caregiver. Specific difficulties included limits in access to clean running water, the practice of bed sharing and poor infrastructure affecting access to healthcare facilities. Primary care givers also mentioned their other responsibilities in the house and the physical strain of caring for a child with SNI affected them and their child. Despite this, all primary care givers were able to recognise and act when their child was in pain and relied on crying duration and intensity as a reliable sign of pain in their child. All primary care givers were confident in their ability and method of recognising and addressing pain in their child with SNI. More experienced primary caregivers used fewer signs to recognise when their child with SNI was in pain.

Conclusions: A rural African context is associated with barriers and opportunities for the care, the recognition- and management of pain in children with SNI. More research related to supporting participation and occupational performance by addressing the effects of pain in children with SNI on the child and the primary caregiver living in rural contexts is required.

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Operational Definitions

Severe Neurological Impairment (SNI):

This research uses a delphi consensus-based definition of the term based of the work of Allen *et al*. (2020) and is defined as: "... a group of disorders of the central nervous system which arise in childhood, resulting in motor impairment, cognitive impairment and medical complexity, where much assistance is required with activities of daily living. The impairment is permanent but can be progressive or static." (Allen et al., 2020, p.81)

Pain:

This research uses the definition by the International Association for the Study of Pain Terminology Working Group, (2020, p. 1) and is defined as :"An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage " and is expanded upon by the addition of six key notes and the etymology of the word pain for further valuable context:

- "Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors."
- "Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons."
- "Through their life experiences, individuals learn the concept of pain."
- "A person's report of an experience as pain should be respected."
- "Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being."
- "Verbal description is only one of several behaviours to express pain; inability to communicate does not negate the possibility that a human or a nonhuman animal experiences pain." (International Association for the Study of Pain Terminology Working Group, 2020, p. 1)

Primary Caregiver (PCG):

The person who is primarily responsible for the care of another person, in this case specifically the child with SNI. The PCG may be related or not, legally appointed by a court or not. For the purpose of this research study, this person has to live with or spend the majority of their time in the presence of the child with SNI. The reason this term PCG is used is to include caregivers who are informally or formally responsible for the majority of the caregiving of the child with SNI. It is hypothesised that PCG will be more likely to be the 'expert' in the individual child with SNI (McGrath *et al.*, 1998; Hunt *et al.*, 2003a).

Rural:

Areas with lower population densities, as well as low economic activity and low levels of infrastructure, such as farms, traditional areas, and some small mining towns (DoE, 2014). Other considerations for the classification of 'rural' would be if traditional authorities are involved in the governance of an area and if there is a lack of availability of services or infrastructure (Gaede and Versteeg, 2011). It should be considered that the term “non-urban” may better describe the living area of the population in this study, as it includes people living in informal settlements and people living in tribal settlements (Statistics South Africa, 2003). Access to resources in rural settings has been further defined by the Rural Doctors Association of South Africa (2006) with an area considered rural if more than 50% of the population lives more than five kilometres from a tarred road, and/or if 25% of the population has to collect water from natural resources (Wegner and Rhoda, 2015).

For the purpose of this research, it includes the entire area serviced by Port Shepstone Regional Hospital.

Non-verbal:

This research uses the terms in an adapted format based off the Communication Function Classification System (CFCS) (Hidecker *et al.*, 2011, p. 3).

It includes people who are: “effective sender and receiver with familiar partners”;
“inconsistent sender and receiver with familiar partners”,
or a “seldom effective sender and receiver even with familiar partners”.

Communication difficulties:

For this research, children who have a Communication Function Classification System (CFCS) level of communication ability between III to V are described as having “communication impairment”. These may be used interchangeably with the term “non-verbal” (Hidecker *et al.*, 2011, p. 3).

Abbreviations

AAC:	Alternative and Augmentative Communication Devices
CFCS:	Communication Function Classification System
CNS:	Central Nervous System
DOH:	Department of Health
GMFCS-ER	Gross Motor Function Classification System – Expanded and Revised
KZN:	KwaZulu Natal
NCCPC:	Non-Communicating Children’s Pain Checklist
NI:	Neurologic Impairment
NPO:	Non-Profit Organisation(s)
PCG:	Primary Caregiver / Primary Caregivers
PIMD:	Profound Intellectual and Multiple Disabilities
PIUO:	Pain and Irritability of Unknown Origin
PPP:	The Paediatric Pain Profile
PSRH:	Port Shepstone Regional Hospital
PT:	Physiotherapist
RTHC/B:	Road to Health Card or Booklet
SNI:	Severe Neurological Impairment

CHAPTER 1: INTRODUCTION

1.1 Introduction

Pain is perhaps one of the oldest and most feared experiences the human race faces. The pain experience is complicated since it is inherently subjective and influenced by the psychosocial circumstances linked to the pain. Cecily Saunders was one of the pioneers in acknowledging and addressing the impact of the psychosocial aspects of pain (Davis, 1992; Saunders, 1996; Saunders and Clark, 1999; Mehta and Chan, 2008). People attribute different meanings to pain and can have conflicting emotions about pain. Pain is often associated with suffering, which requires some cognitive interpretation of stimuli (Melzack, 1961). This may in turn affect the person suffering to experience some form of existential distress (Warlow and Hain, 2018). There is no evidence that children's experience of pain is any less complicated. The subjective experience of pain and the effect of pain on emotions in children with disabilities, particularly non-verbal children with severe neurological impairments (SNI), is nearly impossible to quantify. Despite this, research has found that children with SNI are more vulnerable to psychosocial problems that may be exacerbated by the presence of pain (Adegboye *et al.*, 2017).

Pain is difficult to assess in children with SNI due to their inability to communicate the presence of pain verbally. These children are known to have pain more often than other children, with 73% of children with SNI reported as having pain of unknown origin (Rizakos *et al.*, 2022). This pain may be related to comorbidities such as increased muscle tone and the inability to position themselves, as well as iatrogenic pain (caused by medical procedures) (Warlow & Hain, 2018). Pain in this population may also be related to the child's GMFCS-ER level (Jayanath *et al.*, 2016). The GMFCS-ER is a system developed to consistently describe gross motor abilities in children with SNI (Andrada *et al.*, 2007; Palisano *et al.*, 2008).

Untreated pain is known to have long-term negative consequences for development and ultimately overall wellbeing of the child (Breau *et al.*, 2007). Children with SNI need their PCG to interpret their distress signals and to address problems timeously. These children and their PCG may also often need the help of healthcare workers to address this pain.

Thus, all healthcare workers have some responsibility to ensure that pain is properly managed for the patients under their care. But pain management in this population poses significant challenges because it is not adequately recognised (Warlow and Hain, 2018). Some children with SNI and communication difficulties may use atypical behaviours (such as grimacing or laughing, or intentionally and repetitively hurting themselves) to indicate pain. This can be confusing for parents and clinicians, which allows for misinterpretation. Despite its complicated nature, observation is still useful to determine if pain is present in the child with SNI (Hauer and Houtrow, 2017). Recently, there has been an improvement in the knowledge base on pain expression and experiences in children with SNI.

In addition to medical management, pain management is possible using a holistic approach that includes the physical, psychological, and spiritual aspects of pain for children and their families. Research by Rosenburg et al., (2017) as well as by Riddell and Racine, (2009) identified some caregiver behaviours that potentially decrease distress during pain in children. These behaviours included soothing actions and vocalisations, as well as knowing the child and reacting to the child’s specific preferences. Decreasing the child’s pain in response to the child’s distress shapes the child’s experience of pain, and may influence future expression of distress (Riddell and Racine, 2009).

Pain affects all domains of function, and therefore better pain management may lead to better adaptive function for the child and his/her family (Breau *et al.*, 2007). A multidisciplinary team that includes occupational therapists, physiotherapists and orthotists has been proven to be beneficial when working with children with conditions such as SNI that result in musculoskeletal pain and atypical tone (Warlow and Hain, 2018). Occupational therapists understand that in children with SNI, pain interferes with all aspects of the child-caregiver dyad’s lives. Occupational engagement in activities and participation of both the child and their caregiver can be impacted because pain may interfere with all aspects of how the child with SNI and their primary caregiver (PCG) “engage with the world” (Engelhardt, 1977). When a PCG is in distress due to their child’s pain, they may be less capable of providing the affective support the child needs during the child’s distress, which in turn could amplify the child's experience of pain (Riddell and Racine, 2009). Pain has been reported to be exhausting for PCG to deal with and has an impact on all aspects of family life (Rizakos *et al.*, 2022).

When a child's pain inhibits their engagement in occupations and interferes with the caregivers' engagement in occupations other than caring for the child, an occupational therapist can help them find ways to either mitigate the problem or adapt to it or to manage it (American Journal of Occupational Therapy, 2020). Pain must be addressed in terms of pain management, as well as normalising sensory responses and increasing participation to facilitate occupational performance and well-being of the child and the family. Collaborating with the PCG to maintain their sense of control and improve self-efficacy can also allow the PCG to be emotionally available to their child in pain (Riddell and Racine, 2009; Rosenberg *et al.*, 2017; Suder *et al.*, 2022).

Children in pain are less able to use their previously achieved abilities (Breau *et al.*, 2007), meaning that these children are confronted with more impediments to learning new skills as well as practice of acquired skills due to pain (Breau *et al.*, 2007). This can have an effect during occupational therapy sessions where iatrogenic pain should also be avoided. In order to maximise therapy, the efficacy of home programmes and the child's well-being, the occupational therapist needs to collaborate with the PCG to recognise when the child is in pain by using effective pain assessment techniques or specific pain assessment tools. The therapist can work with and assist the PCG with developing action plans for the different types of pain using non-pharmacological pain management techniques and coping tools for themselves as well as their child (American Journal of Occupational Therapy, 2020).

1.2 Problem Statement

There is a link between severe neurological disorder (SNI) and the prevalence of pain (Breau *et al.*, 2000). Pain in this population is often under recognised and undertreated (Benvenuto, Trombetta and Barbi, 2022, p. 45) since pain assessment in this population is very difficult due to the presence of impairments in communication and expression, or atypical movements (Breau *et al.*, 2000). Therefore, proxy reporting of pain (via the PCG), as well as observational measures, are frequently used to assess pain in children with SNI, particularly those with communication difficulties (Breau, 2011; Ramstad, Jahnsen, and Diseth, 2016; Bogetz *et al.*, 2021).

The ability to care for a child with SNI and manage their pain may be affected by the environment (discussed under sections 2.6.3 and 2.6.4 in the literature review), which dictates what care modalities are available to the child and their PCG (Coovadia *et al.*, 2009; Johnson, Nilsson and Adolfsson, 2015; Ramstad, Jahnsen and Diseth, 2016; Pretorius and Steadman, 2018). Pain can be better addressed if the context and environment supporting pain is understood, with a focus on the lived experience of the people most often responsible for identifying and addressing pain in children with SNI: the PCG (Bogetz *et al.*, 2021). The available literature on pain in paediatric SNI is mainly based on research conducted in countries that are not comparable to the socioeconomic environment in rural areas of South Africa (Breau, Camfield, Mcgrath *et al.*, 2003). The iconic research by Raiter et al. (2021) on pain in children with SNI was carried out in a tertiary hospital in Minnesota in a high-resource situation, which is not comparable to the population of children with SNI in rural KwaZulu Natal. The rural context is frequently associated with scarcity of specialised medical and other resources (Pretorius and Steadman, 2018; Babalola and Moodley, 2020; Mbunge, 2020; Ned *et al.*, 2020; Magaqa, Ariana and Polack, 2021). For this reason, PCG-child dyads living in rural areas may need different and adapted methods to deal with pain and follow-up.

The PCG is central to the assessment, management and advocacy for pain management of these children (Pretorius and Steadman, 2018; Warlow and Hain, 2018; van der Mark *et al.*, 2019). Clinicians often rely on the PCG for their expert knowledge of their own child and his/her pain. Usually the PCG-report relies on their interpretation of their child’s behaviour. These insights into their child’s pain is learnt through experience and reflection (Carter, McArthur and Cunliffe, 2002). Very little is known about the methods primary caregivers (PCG) use to assess and alleviate pain in this population (Raiter *et al.*, 2021). Behaviours “typical” of pain such as moaning or irritability may not reflect pain, while other behaviours not normally related to pain, such as drooling and intermittent muscle spasms, may be related to pain (Breau *et al.*, 2000; Hauer, 2018). There is evidence that PCG who know the child well (Carter *et al.*, 2017; Bambi *et al.*, 2021) rather than health care providers (Carter, McArthur and Cunliffe, 2002) can more accurately assess pain in children with SNI. Health care workers, such as occupational therapists, may misinterpret and fail to address pain behaviours, which affects the efficacy of therapy and other treatment (Fanurik *et al.*, 1999). Therefore, pain assessment for children with SNI or cognitive impairment has resulted in the development of several proxy pain assessment tools for this population. These assessments rely on the PCG recognising and understanding behavioural alterations caused by pain in non-verbal children (Hauer, 2010; Hauer and Houtrow, 2017). Unfortunately, none of these assessment tools have been studied in children with SNI in South Africa, or children with SNI living in a rural setting (Mabaso, Bhettay, Bandini, Demopoulos, 2022).

1.3 Purpose

The purpose of this study was to investigate the assessment of pain using a proxy assessment tool with PCG of a child with non-verbal SNI from the Ugu district in rural KwaZulu Natal. The assessment requires the PCG to indicate which signs, symptoms, or behaviours are more commonly associated with the presence of pain in their child. The most prevalent types of pain management in the population, and whether the PCG considers it effective will also be considered. Since culture, language and social conventions affect how pain and disability is viewed and approached this will be taken into account when considering how PCG view and address pain in their children (Albertyn *et al.*, 2009; Maree, Dreyer Wright and Makua, 2013; Nortjé and Albertyn, 2015; Pretorius and Steadman, 2018; Burger and Christian, 2020).

1.4 Justification

In literature and practice; the assessment of pain via self-report is preferred to determine the extent and severity of pain, but it is not possible in a situation where the child is an inconsistent sender or receiver of communication or where the child’s attempts at communication are not consistently understood. Children with SNI are at risk for under-estimated and under-treated pain due to the nature of their impairments (Hauer and Houtrow, 2017).

In South Africa, many of these children live in rural areas or areas where access to healthcare is limited. The use of proxy scales and assessment measures to assess pain in children with SNI that are considered non-verbal in the South African rural context has not been established and evidence of the effective use of these scales is not currently available in this population, (to be discussed under chapter 5.2.1, page 74), as they were mostly developed in English-speaking countries, that have very different socio-economic profiles to those found in rural areas of KwaZulu Natal (Hauer, 2010; Hauer and Houtrow, 2017; Bogetz *et al.*, 2021).

1.5 Research question

How do PCG from the Ugu district in rural KwaZulu Natal identify pain in their children with SNI who have communication difficulties; and how does this impact the ability to care for their child and manage their child's pain?

1.6 Aim of the research

The aim of this study is to establish the caregivers' recognition and management of pain in non-verbal children (or children as considered non-verbal) with SNI within the context and factors that impact child care in rural KwaZulu Natal.

1.7 Objectives of the study

The objectives of the study are to:

- Determine the signs and symptoms used by PCG to identify pain in their child with SNI in a rural KZN setting.
- Determine the actions or methods used by PCG to address pain and if these actions or methods are perceived as effective in alleviating the pain in the home setting.
- Describe the context and factors that influence the care and access to health care of a child with SNI in a rural KZN setting.

1.8 Significance of the study

Due to the nature of SNI, affected children rely on their PCG for all aspects of their daily life. The PCG plays a crucial role in the life of a child with SNI. Being a PCG provides special insight into the child with SNI's behaviour and personality, preferences, and needs (McGrath PJ, Rosmus C, Canfield C, Campbell MA, 1998). The PCG is therefore the primary source of information about pain in their child with SNI. Very little is known about how PCG in the South African context relate and react to pain in the child with SNI (Nortjé and Albertyn, 2015; Mabaso *et al.*, 2022).

According to the biopsychosocial approach, the context in which the PCG and child live, and their daily experiences and struggles, will shape how they are impacted by pain and how they approach it (Turk, 1996; Hadjistavropoulos, 2003). Therefore, this study will use the information related to the individual situation of each of the PCG-child dyads in this study, in order to create a coherent picture of the challenges they face and to determine their potential impact when pain is suspected or present in the child who has communication difficulties.

This research report hopes to add to the existing knowledge on SNI in Africa, as well as pain management barriers and opportunities in a rural context. More information related to the behaviours and signs that PCG associate with pain in their child with SNI, and what they do about this pain when living in a rural area of KwaZulu Natal, will be useful for health care workers. This information can be used to train the PCG on the use of a measuring instrument that works for their child. It can also be used to train the PCG on how to use the information to address pain timeously.

1.9 Outline of the research report

This research report consists of six chapters:

Chapter 1 above is the introduction to the study which outlines the aims, objectives and justification for the study.

Chapter 2 consists of the literature review performed in the context of this study.

Chapter 3 describes the methodology of the study, including research design, study participants, instrument, procedure, ethical considerations, and data analysis for the study.

Chapter 4 describes the study results and summarises important findings.

Chapter 5 discusses these findings in the context of recent literature.

Chapter 6 lists significant findings and conclusions of the study, as well as recommendations for future research.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter reviews the current state of the literature on the concepts of severe neurological impairments (SNI) and pain in children with SNI. Factors influencing the management of pain in children with SNI such as communication barriers, rurality, living with disability in rural areas of South Africa, as well as access to health care were also reviewed. Abovementioned factors impact children with disabilities as well as their caregivers and their ability to observe and address pain in their children (Turk, 1996; Hadjistavropoulos, 2003).

Literature was gathered online between January 2020 and October 2022 from a collection of databases, including Elsevier, ScienceDirect, PubMed, American Academy of Paediatrics, Hospital Paediatrics, Academia, Jama open network and the National Institute of Health. The key words used were: “neurological disorder”; “severe neurological disorder”; “profound cognitive impairment”; “pain”; “paediatric pain”; “neurological pain”; “rural”; “rural health”; “disability rural”.

Literature published before 2012 (older than 10 years), reports or articles that were not available in English; were excluded unless it was foundational research work. In the case of iconic older works, these older works were used to provide a background to issues related to pain identification in children with SNI.

2.2 Severe neurological impairment

Severe neurological impairments (SNI) as defined by Allen *et al*. (2020) was selected as the operative term for the research; as it is not a diagnosis, but rather a descriptive term for a heterogeneous group of impairments. Despite the absence of experts from African counties participating in the process of defining this term; this 2020 definition is suited to paediatric cases, such as those often seen in rural areas of the Ugu-district in KwaZulu Natal, South Africa.

This term was recently defined by international consensus:

> *“... a group of disorders of the central nervous system which arise in childhood, resulting in motor impairment, cognitive impairment, and medical complexity,*

> *where much assistance is required with activities of daily living. The impairment is permanent but can be progressive or static."* (Allen *et al.*, 2020, p. 81)

One of the strengths of this descriptive definition is that it is suitable in contexts where a clear diagnosis is not available, such as is often the case in remote rural health care (Wiles and Swingler, 2018). Often, the most useful medical information available at the primary care clinic level is the verbal account of the primary care giver (PCG) of the child's problems and the patient held medical records, such as the Road to Health Card or Booklet (RTHC/B) (Committee on Morbidity and Mortality in Children Under 5 Years (CoMMiC), 2014). The RTHC/B was designed to be a reliable mobile data source to help with the monitoring of child health in situations where health care is fragmented, but these are often incomplete (Crisp and Donald, 1987). Moreover, a 2007 study in Limpopo found that up to 70% of caregivers who brought their child to a primary health care facility did not bring their RTHC/B making it difficult for services to be offered in view of a lack of any health information (Tarwa and De Villiers, 2007). Therefore, health care workers, including occupational therapists, must offer services to children with clear neurological impairment and their caregivers who access a clinic or community health centre with little information on diagnosis or aetiology of the child’s condition. It is likely that a diagnosis will only be available after referral to a higher-level health institution.

In rural health care in KwaZulu Natal, South Africa, a term such as SNI may be applied until a diagnosis is obtained. The term SNI, can be applied to many conditions, such as cerebral palsy, Rett syndrome, traumatic brain injury, epilepsy, hydrocephalus, brain damage due to infections, malignancy or inflammatory disorders, neural tube malformations, and other genetic conditions leading to severe neurological damage causing severe disability in childhood (Breau, Camfield, Symons, et al., 2003). The definition of SNI by Allan, Molloy et al. (2020) does not explicitly include both acquired and congenital conditions, since aetiology was excluded in the third round of their study. Irrespective of the aetiology of SNI, which is often not available to many children in rural areas of South Africa, health care services are offered to address pain, and therefore SNI was chosen as an umbrella term incorporating the various aetiologies.

2.3 Pain

In this study, we used the International Association for the Study of Pain (IASP) latest (2020) definition. Pain for this research study was defined as:

> "…. *An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage"* (International Association for the Study of Pain Terminology Working Group, 2020, p. 1)

This definition should be seen with its expansion key notes, which relate to the personal nature of the experience of pain, which can be influenced by other internal and external factors and can be learnt through experiences. The key notes also stress that an individual's report of pain has to be respected, and that the inability to communicate pain verbally does not negate the potential for that individual to experience pain, and that a variety of behaviours can indicate the presence of pain. This definition specifies that pain is not the same as nociception, and that activity in sensory neurons does not serve as the only means to determine if pain is present. Finally, this updated definition adds that pain may serve an adaptive role, but may also have adverse effects on the individual (International Association for the Study of Pain Terminology Working Group, 2020).

The current study does not seek to differentiate between different types of pain and will not require an identifiable source before considering the presence of pain. The assessment of chronic pain in this population may be different than the assessment of acute pain (Breau, Camfield, Symons, *et al.*, 2003) and will also not be considered in the current study. The study population can have many different sources and types of pain, so the origin of pain in individuals in this population will not be determined. However it is acknowledged that the origin of pain may affect the reaction or expression of pain in both the child with SNI and the PCG (Klick and Hauer, 2010; Hauer and Houtrow, 2017).

2.4 Pain and children with severe neurological impairment

The term SNI has only recently been defined. Therefore, terms such as profound cognitive impairment, severe cognitive impairment, intellectual and developmental disabilities, intellectual disabilities, profound intellectual and multiple disabilities

(PIMD), and cerebral palsy with multiple disabilities were searched in the literature review on pain and pain assessment. These terms were inconsistently used by authors in the field before 2020, with significant neurological impairment being the main consistent term (Allen, Molloy and McDonald, 2020).

The definition of SNI by Allen, Molloy et al. (2020) specifically mentions that this condition causes a child to need much assistance with activities of daily living due to their inability to communicate and move easily. Therefore, neurological conditions that do not result in motor impairment and communication difficulties (such as autism spectrum disorders or spinal cord injuries), were excluded from the current research study.

Historically, some people with SNI were believed to be insensitive to pain (Biersdorff, 1991). This assumption has since been disproved irrevocably. In 2017, a clinical report by Hauer and Houtrow (2017) found that children with SNI have more frequent and more severe 'pain episodes' than those experienced by typically developing children. Severe neurological impairment is often associated with various combinations of impairments (Matthews *et al.*, 2019; Allen *et al.*, 2020; Allen, Molloy and McDonald, 2020; Rizakos *et al.*, 2020; Nelson *et al.*, 2022), which adds to the pain experienced from “normal sources of pain in childhood” such as gastro-intestinal upset, illness, dysmenorrhoea, tooth ache, headache, etc. Pain may also result from the need for more medical procedures than in healthy children. Pain in this population may also be related to abnormal transmission of pain signals in the peripheral or central nervous system (CNS) (Hauer and Houtrow, 2017). Pain sensitization due to repeated nociceptive input (whether due to an internal factor such as dysmotility of the gastrointestinal system or due to repeated medical procedures) can further exacerbate the intensity of pain in this population. This may lead to the child with SNI experiencing pain from non-nociceptive stimuli or pain that is out of proportion for the stimuli in duration and intensity (Warlow and Hain, 2018). Some disorders that cause SNI can also cause a lower pain threshold and therefore a higher likelihood of neuropathic pain (Benvenuto, Trombetta and Barbi, 2022, p. 45). Severe neurological impairment in these children is a medically complex condition, associated with profound impairments in the function of bodily systems that are directly or indirectly controlled or coordinated by the CNS (Allen et al*.*, 2020). This often leads to an increased need for care in individuals with SNI, with those with greater physical and cognitive impairments experiencing increased levels of pain (Breau, Camfield, Mcgrath, *et al.*, 2003).

Unfortunately, the reality is that pain continues to be present in children with SNI (McGrath *et al.*, 1998) and continues undertreated in many situations (Klick and Hauer, 2010; Benvenuto, Trombetta and Barbi, 2022). Due to this situation and the relevance and prevalence of pain in SNI, recognition and management of pain have been emphasised as important research topics (Breau, Camfield, Mcgrath, *et al.*, 2003). The presence of pain has a physiological and psychological effect on any living organism, and if left unaddressed, it can lead to long-term maladaptation, which is not beneficial to the organism (Warlow and Hain, 2018). The physiological consequences of untreated pain in the immature brain may lower the pain threshold of the person and may contribute to chronic pain syndromes. Psychologically, untreated pain in the immature brain can alter emotive development, and untreated pain can also alter cognitive development (Mitchell and Boss, 2002). Pain can affect all aspects of the child's life and pervades participation in all domains of their occupations (Warlow and Hain, 2018). Pain can impact all areas of life, including sleep, mood, and interactions with others (Breau *et al.*, 2007).

Pain care – as an aspect of the right to enjoy the best possible standard of health (and freedom from pain) is also an explicit, internationally defined human right (General Assembly and United Nations, 2009). Therefore, it can be considered a moral / ethical obligation of healthcare workers, including occupational therapists, to address pain in a timely manner.

2.5 Management of pain

2.5.1. Assessment

The assessment of pain is very complex, and more so if pain is present in a child. A Swiss study aimed at developing an interprofessional intervention for pain management in neonates, as they identified that procedural neonatal pain remains undertreated, despite available guidelines to manage pain. This indicates that evidence-based knowledge is not always implemented in the clinical setting (Balice-bourgois *et al.*, 2020). Findings of inadequate pain management for neonates, children and adults in healthcare settings are echoed in research in Canada and South Africa, in qualified and training healthcare workers (Marshall *et al.*, 2018; Lourens, Hodkinson and Parker, 2020; Wall *et al.*, 2020; Brand, 2022).

Iconic work, done in 1997 by Zeltzer, Bush, Chen and Riveral described a few of the misconceptions that shaped pain assessment practices in children without cognitive impairment in the past. These include the mistaken beliefs that “infants do not feel pain”; that “young children and infants do not remember pain”, that “crying often represents fear rather than pain”, and that “pain management with opioids will lead to addiction”(Zeltzer *et al.*, 1997, p. 226; Marshall *et al.*, 2018; Mashanda-Tafaune, van Nugteren and Parker, 2020). These misconceptions have been proven false, yet may still linger in the practice settings where pain-care should take place (Zeltzer *et al.*, 1997; Lourens, Hodkinson and Parker, 2020; Harrison, 2021). Other misconceptions or biases that influence pain assessment are more related to misguided attitudes towards pain care, and include the thought that “pain builds character”, “pain can’t be avoided” and that “pain as punishment” is not a risk factor for children who are resistive or disruptive in a clinical care setting (Zeltzer *et al.*, 1997, p. 226; Zhang *et al.*, 2021).

It has been found that, though self-report is considered the gold standard in pain assessment; this is not appropriate for pre-verbal and very young children – in this case, you can approach pain management based on “pain as expected”. This is problematic when a child has atypical pain expression, as in the case of many children with SNI (Zeltzer *et al.*, 1997, p. 226; Carter *et al.*, 2016; Brand, 2022). In children with SNI, who do not communicate or interact with the environment in a typical way, the assessment of pain becomes exponentially more difficult. In other situations, pain assessment is based on a 'clinical impression' or observational assessment of a child’s behaviour, which is often done subconsciously by the PCG of the person with SNI, and then reported by the PCG as a proxy (McGrath *et al.*, 1998). This phenomenon (of pain assessment in populations that cannot verbally express pain in a manner that is consistently understandable by familiar and unfamiliar conversation partners) has been described and addressed with increasing frequency over the past 10 years. Proxy reports of pain was found to be more prevalent in children with higher levels of GMFCS (more severe motor-impairment). Proxy reports may not be accurate in terms of pain intensity or type, and many clinicians hold the view that pain is under-assessed and under-treated in children with more severe impairment (Fox *et al.*, 2019; Eriksson, Hägglund and Alriksson-Schmidt, 2020; Raiter *et al.*, 2021). PCG of children with SNI often find that developing a sense of their child’s pain is a process of trial and error (Carter *et al.*, 2017). Behavioural pain assessment tools such as the PPP (Pediatric Pain Profile), NCCPC-R (Non-Communicative Child Pain Checklist – Revised) or the r-FLACC (revised Face, Legs, Cry and Consolability) should be considered in this population; however, there is no one ideal measurement tool of pain in populations such as these, and it is unclear if the existing measurement tools are used routinely in healthcare settings (Hauer and Houtrow, 2017; Ostojic and Morrow, 2018; Cascella *et al.*, 2019; Raiter *et al.*, 2021).

Rizakos, Parmar, Orkin and Siden (2022) found that parents of children with SNI and pain in their study felt that they needed more support, and an easier way to reach the diagnosis and proper intervention. The authors of this study suggested creating a framework that will improve pain management and assist parents with information that can help them cope in the long run. Although their study also found that parents and clinicians are able to describe pain behaviours, they found that these behaviours are still very subjective, ambiguous, and hard to interpret accurately – especially as they can reflect a variety of problems other than pain (Hadden and Von Baeyer, 2002, 2005; Breau, Camfield, Symons, *et al.*, 2003; Symons and Danov, 2005; Dubois *et al.*, 2010; Temple *et al.*, 2012; De Knegt *et al.*, 2013; Rizakos *et al.*, 2020).

These studies have led to the development of instruments and technology to detect pain and assess its intensity. Research conducted in Canada by Siden, Carleton, and Oberlander (2013) found that experienced physicians in a specialist pain clinic for children with SNI show variability in their approach to pain management in this population. The study found that only 50% of the children enrolled had improved pain management. Other research by Hunt, Mastroyannopoulou, Goldman and Seers (2003) also found this uncertainty in terms of assessing pain in children with SNI. This indicates the difficulty in assessing and managing pain in this population, despite having access to specialised care (Hunt *et al.*, 2003b; Siden, Carleton and Oberlander, 2013).

Some of the research on the use of technology to detect 'biomarkers of pain' by analysing passively collected saliva of children with SNI for analysis with a spectrometer when pain is suspected shows promise, as it is non-invasive and quantifiable (Symons *et al.*, 2015). However, this may not be a feasible solution for use in resource-constrained rural settings, where such technology is not readily available.

The tools for pain assessment in the communication-impaired paediatric population are therefore often based on the premise of observation of the child and subsequent analysis of behaviours observed (Royal College of Nursing, 2009). A list of the more common pain assessment tools for children with SNI have been reviewed by Benvenuto, Trombetta and Barbi (2022), These authors concluded that there is no one singular assessment tool that performs better on all domains, but that standardised scales perform better than generic pain assessment tools in accurately assessing pain. Health care workers, such as occupational therapists, physiotherapists, speech therapists, nurses, doctors, and others, have different roles to play in the process of pain assessment and management. Where therapists cannot alleviate pain by pharmacological means, it is within their scope to assist PCG to be empowered to assess and manage pain by non-pharmacological means, and to enable them to effectively advocate for their child, by using structured observation tools (Carter *et al.*, 2017; American Journal of Occupational Therapy, 2020).

The literature indicates the need for routine use of individualised pain assessment tools in relation to pain assessment for children with SNI. The Pediatric Pain Profile (PPP), Non-Communicative Child Pain Checklist – Revised (NCCPC-R) or the Revised Face, Legs, Cry and Consolability (r-FLACC)" (Hauer and Houtrow, 2017; Ostojic and Morrow, 2018; Cascella et al., 2019; Raiter et al., 2021) are recommended structured observation assessment tools and include children with different diagnoses and cognitive impairment in their validation studies. These documents are available at no cost online, but are lengthy to complete (such as the PPP) (Hunt, 2003) and needs an observer to be in the child's presence for at least two hours (for the use of the NCCPC (Breau, 2004, p. 2). This supports a wider applicability of these tests, which may be used in all daily care situations. These assessment tools, however, have not been validated for use in African countries (Royal College of Nursing, 2009). The work by Nortjé and Albertyn (2015) investigated differences in perceptions about pain in two South African cultures; the Nguni and the Sotho cultures. Both these cultures hold beliefs about the spiritual meaning of pain and teaches children to endure pain with stoicism. Nortjé and Albertyn (2015) found that there are differences in the experience and expression of pain between these two cultures. Their findings indicate the need for standardising or adapting pain assessment tools for specific populations or cultural groups (Riley *et al.*, 2002; Mphahlele, Mitchell and Kamerman, 2008).

2.5.2 Treatment

Studies by Velazquez Cardona *et al.*, (2019) and Mabaso *et al.*, (2022) indicate that pain care for children in two larger tertiary South African hospitals is suboptimal. A recent study by Velazquez Cardona *et al.*, (2019) found that nearly a third of children had been routinely experiencing pain before admission to a tertiary hospital in KwaZulu Natal. Another study conducted in Gauteng in a specialised mother-and-child hospital found that 59% of the children assessed during the study had pain and had reported pain via caregivers, yet these actions were not associated with health care workers administrating analgesia for these children while they were admitted in this hospital (Mabaso et al., 2022). Mabaso et al., (2022) had found that pain assessment in the cross section of hospitalised children in a tertiary South African Children's Hospital is not performed routinely and pain care was not implemented according to a set protocol. An example of such a protocol (not explicitly stated in the article by Mabaso et al (2002); is as set out in the Standard Treatment Guidelines And Essential Medicines List for South Africa: Hospital Level 2012 Edition (National Department of Health, 2015). Similar problems can exist in the assessment of children with SNI in South Africa who are not hospitalised, but who may also have pain. More research into pain presence and presentation, pain care at home and in health care facilities, and PCG as well as healthcare workers' perceptions about pain care may help to address the phenomenon of pain that is not addressed despite existing protocols. All health care workers should consider using the appropriate standardised assessment in all children with SNI as a baseline and then supplement this with the PCG input, as all children with SNI are different and present their pain in different ways.

In contrast to the options available and the current practises in South Africa, work in Wales and North America indicates that some PCG also rely on alternative methods to address pain, such as using music, aromatherapy, acupuncture, vibratory mats or weighted blankets, or holding and rocking their child to temporarily soothe the child (Hauer and Houtrow, 2017; Warlow and Hain, 2018).

Health care workers can also help address the situation by obtaining more information on how PCG of children with pain currently addresses or advocates for pain care in their children and how this is influenced by the context (Hauer, 2010).

Health care workers can help address this by empowering the PCG with pain prevention methods to perform daily activities. These can be safe positioning and transitioning techniques, distraction and play techniques during bathing or dressing, and providing the means to communicate and advocate for their child’s predicament to others as well as pain relief methods, such as soothing pain with warm water, massage or distraction (American Journal of Occupational Therapy, 2020).

2.6 Factors influencing recognition of pain in children with severe neurological impairment

2.6.1 Expression of pain in the child with severe neurological impairment and reaction of their primary caregiver

Pain in children with SNI is often caused by problems in body structure and function related to deficient motor control (Breau *et al.*, 2004). These motor control problems may also mask or mimic pain episodes, and thus further complicate pain assessment in this population (Hauer and Houtrow, 2017). Some people with SNI have 'ambiguous pain expression', which complicates observational pain assessment (Symons *et al.*, 2015). As communication is often limited in this population, the accepted 'gold standard' of self-reporting pain cannot be relied on in terms of the usual pain assessment in this population. Primary caregivers of children with SNI however, were found to rely on observation of non-verbal communication in these children (Breau *et al.*, 2004).

Carter, Simons, Bray, and Arnott (2016) found that this uncertainty involved in the assessment of pain in this group of people, despite the presence of more formalised assessment methods, can negatively affect the “professional confidence” of healthcare workers, and therefore may result in the under- or overtreatment of pain (Carter *et al.*, 2016).

Reliance on non-verbal communication still requires the person sending the message to have a consistent pattern of behaviours that are consistently linked to certain meanings with a communication partner. With SNI, autonomic nervous system dysfunction can cause pain or appear similar to pain without indicating pain, or mask pain input from different sources (Hauer and Houtrow, 2017). This can further complicate the use of observation to determine the presence of pain in children with SNI. Children with SNI who cannot communicate, may also struggle with the fear of pain, which may exacerbate the experience of pain during actual or potential nociceptive stimulation. Caregiver anxiety, among other factors, may also cause the child with SNI to experience pain as more adverse than the stimuli implies (Craig, 2015).

A potential solution to the problem of pain assessment in this population is the frequent use of a consistent behavioural / observational-based measuring instrument to determine aspects of pain in communication impaired children with SNI as discussed above (Royal College of Nursing, 2009). The efficacy of the use of this approach will depend on the PCG and their willingness / ability to consistently use this measuring instrument – which may prove to become more effective over time, as an individualised system to identify signs that indicate pain and situations that cause pain, is documented (Hauer and Houtrow, 2017).

2.6.2 Communication difficulties in children with severe neurological impairment

Communication barriers can lead to severe consequences, when a person with SNI cannot report pain or discomfort, or when attempts to communicate are not understood (Roy and Simon, 1987; Thunberg *et al.*, 2021). Historically, communication barriers may have contributed to the erroneous belief that people with SNI do not experience pain (Biersdorff, 1991). This belief has been disproven, yet its consequences impact current clinical contexts, where pain continues to be under-recognised and undertreated in children with SNI who cannot communicate (Breau, Camfield, Mcgrath, *et al.*, 2003).

An element of age-appropriate self-reporting of symptoms is preferred in all children, and Alternative and Augmentative Communication Devices (AAC) should be implemented in this regard (Johnson, Nilsson and Adolfsson, 2015; Blackstone and Pressman, 2016; Thunberg *et al.*, 2021). These AAC devices and the knowledge on how to use them are not easily accessible in rural clinics served by Port Shepstone Regional Hospital (PSRH). The implementation of AAC devices requires a speech therapist or occupational therapist with experience in the use of the specific AAC to be involved in the process of learning to use the AAC, and thus a significant amount of individual therapy time. Moreover: Breau *et al.*, (2007) as well as Johnson, Nilsson, and Adolfsson (2015) reported tremendous energy costs in people with CP / neurologic impairment (NI) when self-reporting pain using ACC. Even with a child who can self-report, when they are sick, distressed, or in pain, their pre-existing communication vulnerability may be exacerbated, and health care providers may not be able to elicit communication that is coherent from the child (Blackstone and Pressman, 2016; Thunberg *et al.*, 2021).

The Communication Function Classification System (CFCS) by Hidecker *et al.*, (2011) can be used to determine if a child with SNI has a communication difficulty and can be used to describe its severity. The CFCS is easy to use for health-workers and the PCG and was utilised in the current study to alert the healthcare staff to the need for a PCG to assist in recognising pain. The child with SNI's CFCS level of functioning should be considered before a healthcare worker or a PCG waits for the child to self-report on pain.

In children unable to consistently or effectively self-report; the use of an observational assessment of pain may be more effective than not using a tool. It is fundamental that PCG be included in the pain management process for people with SNI, providing a valuable interpretation of behavioural observations (McGrath *et al.*, 1998; Hauer, 2010). In the absence of language-based communication, PCG can still decode communication attempts of a child with SNI, however subtle. This has been described in some literature as 'knowing the child', 'intuition' and 'parental instinct'. However, this intuitive decoding of the child's behaviour could be problematic if the PCG does not have the confidence or vocabulary to describe the problem (Carter, McArthur and Cunliffe, 2002; Hunt *et al.*, 2003b; Bogetz *et al.*, 2021). It is here that occupational-speech and physiotherapists, as well as nurses involved in child care, can help empower PCG through training in the use of pain assessment measures.

2.6.3 Rurality and Disability

According to the provincial profile KwaZulu Natal, community survey 2016, disability prevalence in the total population of KwaZulu Natal is 8.6%. Previous research on disability prevalence by the World Health Organisation indicates that it is still associated with gender, age, unemployment, and lower income status, and that rural areas have higher rates of disability (Dassah *et al.*, 2018; WHO, 2021, pp. 68, 76, 78). The prevalence of disability was reported to be higher for people with a lower level of education and income. In the Ugu district of KwaZulu Natal, the current study setting, the total percentage of people with disabilities was 10.4% (StatsSA, 2016, p. 36)

It was also found that this group generally tends to reside in under-resourced communities (Maart *et al.*, 2015; StatsSA, 2016; Dassah *et al.*, 2018). This means that specific data are needed to plan health interventions and allocate resources (Maart *et al.*, 2015). The effect of these factors adds to the stressors of limited access and quality of care for health and related services (Sherry, 2015). Strong social networks and the proximity of close family members provide cohesion and support for PCG of children with disabilities and provide help in managing the child (Goudge *et al.*, 2009). However, this sense of community may be lacking in some rural areas when a person has a disability – if it is seen as caused by a spiritual rather than a physical condition (Nortjé and Albertyn, 2015).

The child's disability can also be impacted by the environment and resources available to care for the child (Maart *et al.*, 2015). When disability is present in a rural context, factors such as access to water, sanitation, electricity access, housing, and social grants come into play. Many houses in rural areas have toilets outside the house and water available only from a communal tap. In the 2021 Statistical release of the general household survey of South Africa, 2.7% of KwaZulu Natal households were found to have no access to piped water and 0.5% of households had no toilet, and 47% only had a pit latrine (Department of Statistics South Africa, 2022, pp. 32, 36). The average household size in Ugu (in 2016) was 3.8 people per household (StatsSA, 2016, p. 43). In the 2016 provincial profile; KwaZulu Natal was found to have 18.1% traditional dwellings and a combined 9.2% informal and other dwellings (StatsSA, 2016, p. 57). According to the 2016 provincial profile, 4.8% of households in KwaZulu Natal had no refuse removal and 14.7% of households had no access to electricity (StatsSA, 2016, pp. 77, 86).

The terrain surrounding the homes and access between homes may be rough or difficult to navigate in a higher proportion than in urban areas. Approximately 39.8% of 20-year-olds in KwaZulu Natal had obtained matric (grade 12) and only 9.7% had higher education in the 2021 general household survey (Department of Statistics South Africa, 2022, p. 21). Youth unemployment rates were at 34.5% and adult unemployment was at 13.1% in 2016 (StatsSA, 2018, p. 43). These factors impacted on the physical care of children with disabilities as well as adding to the financial strain of caring for the child and providing adequate health care (Paget *et al.*, 2016)

2.6.4 Access to health care

Having a disability often results in increased vulnerability and more barriers to performing the functions of everyday living, such as accessing healthcare. Rural health care settings are known to be resource poor in many instances; yet is the first level of contact in rural areas is often primary healthcare facilities (PHC). These facilities are then supported or served by district hospitals. The 2020 study by Babalola and Moodley found that a significant proportion of district hospitals in KwaZulu Natal were technically inefficient. This means that they were not optimally providing services. The work of Ned *et al.* (2020) found that district hospitals have inadequate rehabilitation units and the lack of human and other resources in rural settings contribute to lowered standards and lower levels of satisfaction with care, often with severe consequences for patients. Neely and Ponshunmugam (2019) reported cases of patients refusing to access their local health care facilities due to unacceptable care, rude staff, and lack of medication (Neely and Ponshunmugam, 2019).

Some cultural values may inadvertently or intentionally result in discrimination against people with disabilities in some settings. The study by Wegner and Rhoda (2015) investigated the perspectives of rehabilitation workers working in a rural area of KwaZulu Natal (KZN). These therapists believed that cultural beliefs and stigma associated with disability were barriers that led to some patients being refused access to transport due to their disability; and people with disabilities were seen as 'less valuable' to their communities or households – especially if they were not the recipient of a disability grant (Wegner and Rhoda, 2015). Responding therapists in this study also considered other aspects that affected patient use of rehabilitation services for their children; such as beliefs about the cause of the disease, that it is of a spiritual nature and therefore cannot be cured with Western medicine (Nortjé and Albertyn, 2015; Wegner and Rhoda, 2015).

When needing to access health care for a child in pain, in the rural south of KZN (the setting for the current study), a number of factors including distance, lack of finances and reliance on public transport play a role (Moeti *et al.*, 2023). Research should consider more than just the direct distance to healthcare facilities. Demographic characteristics of patients and their caregivers, such as age, race and income, are important factors along with road and transport networks between patient homes and healthcare facilities (Neely and Ponshunmugam, 2019). In addition to this, the safety of the transport networks should be considered. In the Ugu district, rival taxi associations have been known to use violence, including gun, panga, and other attacks on each other. Occasionally, innocent commuters get caught in the fray (Dugard, 2001; Kerr, 2018; Mzobe, 2023).

Access to healthcare is also impacted by natural elements such as significant weather events (Dassah *et al.*, 2018). While the positive aspect of rural living is the proximity to nature and its beauty; people are more vulnerable to droughts, flooding, famines and pests. Flooding in April 2022 damaged infrastructure such as roads and some buildings, affecting access to public transport for many months (Naidoo, Manyangadze and Lokotola, 2022). The Covid-19 pandemic acted to expose, intensify, and magnify pre-existing conditions leading to inequality in accessing health care (Kantamneni, 2020). The state of disaster in South Africa and the measures initiated to curb the spread of Covid-19 resulted in a near-complete stop in outpatient services at Port Shepstone Regional Hospital. One of the lasting effects of this is that the CP-clinic, which serviced children in the catchment area, including children with different diagnoses such as Rhett syndrome; was shut down (Departmant of Women Youth and Persons with Disabilities, 2022). Research done by McKinney, McKinney and Swartz (2021) investigated factors linked to the poor access to healthcare for people with disabilities during the Covid-19 pandemic. They found that transport was not accessible, there was a deep fear for the health of caregivers of people with disabilities, and communication challenges were exacerbated by masks and no-touch policies (McKinney, McKinney and Swartz, 2021).

The effects of Covid-19 awareness campaigns implemented as described by Mbunge (2020), may have contributed to higher levels of suspicion/fear and discrimination against people with disabilities, who may need physical assistance to be able to enter and exit public transport (McKinney, McKinney and Swartz, 2021). In addition to these factors, it is also important to consider findings related to the mental and physical health of caregivers for people with disabilities. A study conducted in Ireland investigating the experiences of 94 caregivers of children with CP; found that 67.1% of these caregivers decided not to attend routine medical visits for their children and 12.8% stopped attending rehabilitation visits. This study also found that the well-being of these caregivers had decreased significantly during the pandemic, for both the caregivers mental wellbeing as well as the physical health (Cankurtaran et al., 2021, p.1).

2.6.5 Culture, biases, and beliefs about disability, pain, and health:

The anticipation of pain can be learnt from previous painful experiences which can then increase distress in certain circumstances (International Association for the Study of Pain Terminology Working Group, 2020). This is also the case in children with SNI. It has been well established that pain perception and effect are influenced by culture and even language in the context – this emphasizes the need for pain assessment that is culturally appropriate and sensitive (Zborowski, 1952; Bates, 1987; Thomas and Rose, 1991; Riley *et al.*, 2002; Albertyn *et al.*, 2009; Brand, 2022).

The 2015 exploratory study by Nortjé and Albertyn, on the influence of culture on pain in adults in the Nguni and Sotho cultural groups, found that pain experience and expression were different between cultures, in that practices and beliefs around pain and expression differ based on gender, as well as urban or rural context. Culture also plays a role in how pain in children is seen and addressed. Their participants believed that children will not express pain in the same way as adults. Most of the participants considered it the responsibility of the mother or grandmother to take care of the child when they are in pain (Nortjé and Albertyn, 2015).

The current study setting in Ugu has a population that is 90.1% Black, 1.0% Coloured, 4.1% Indian / Asian, 4.8% White (StatsSA, 2018, p. 24).It was reported that 82.5% of the population spoke Zulu,12.5% spoke English, 3.1% spoke Xhosa, and 1% Afrikaans (StatsSA, 2016, p. 24). Each of these cultural groups will have their own distinct way of viewing health, pain, and health care (Nortjé and Albertyn, 2015). The rural nature of the study setting may also result in a difference in the importance that people place on traditional medicine. A higher prevalence of people who believe that pain indicates that a person has been 'bewitched' may be observed in rural areas, and others may consider pain, misfortune, or sickness to be caused by an angered ancestral spirit; and therefore, may consult a traditional healer on the matter. There is also a contextual difference based on accessibility and affordability of this type of care (Nortjé and Albertyn, 2015). However, Nortjé and Albertyn (2015) found that most of the participants in their study would more likely take their child to a medical doctor, but will consider a traditional or herbal doctor as a last resort.

Culture also affects how a person engages in all aspects of everyday living such as how a person baths, sleeps, dresses, eats – which in turn affects pain (AOTA, 2014; Guajardo, Kronenberg and Ramugondo, 2015). Bed-sharing or co-sleeping is one of these aspects that is approached with significant personal and cultural differences, and which could potentially impact the child with SNI's physical and psychological comfort – which could affect pain (Jacquier and Newman, 2017; Mileva-Seitz *et al.*, 2017; Barry and McKenna, 2022). Personal and medical factors influence the decision, and may relate to caregiving needs of the child or medical conditions that required nocturnal monitoring (Obrecht *et al.*, 2021). Co-sleeping is not as prevalent in Western cultures, and often discouraged especially in neonates (National Institute for Health and Care Excellence, 2021; Obrecht *et al.*, 2021; Suzuki, 2022). Reasons for discouraging co-sleeping vary from safety concerns for the child, to physical and psychological concerns for the child and the caregiver's wellbeing, however – evidence is emerging that indicates that a blanket statement for or against co-sleeping is not supported scientifically (Obrecht *et al.*, 2021; Patery and Sutomo, 2021; Barry and McKenna, 2022; Suzuki, 2022).

When people access health care in hospitals and clinics, proxy reporting or assessing of pain in a child with SNI is complicated by cultural, personal, interpersonal and social factors (Barney *et al.*, 2020). Cultural associations were found to affect pain experience and processing in bilingual English/Spanish speaking adults (Gianola, Llabre, and Losin, 2021). In addition to this, a Swiss study by Schulz, Hartung, and Riva (2013) found that language has an effect on people's views on pain / disease and the native language used was associated with the participant's inclination to employ active or passive strategies to cope with pain.

2.7. Conclusion:

Pain in children with SNI is not adequately assessed or addressed, although it is more likely to be present than in children without SNI. There appears to be a direct correlation with more severe SNI and more episodes of pain or a higher pain intensity (Breau, Camfield, Mcgrath, *et al.*, 2003; Hauer and Houtrow, 2017). Observational pain assessment tools, in addition to age-appropriate self-report are needed to determine pain prevalence, intensity, and location in children with SNI and communication vulnerabilities (Breau *et al.*, 2001; Royal College of Nursing, 2009; Hauer and Houtrow, 2017; Benvenuto, Trombetta and Barbi, 2022).

Pain expression, as well as the meaning attached to pain, is influenced by culture and context (Engel, 1977; Bates, 1987; Thomas and Rose, 1991). Rural contexts may place people with disabilities at higher risk of undertreatment or mismanagement of pain. This can be due to lack of access to proper assessment, healthcare or lack of resources in health facilities (Pearson *et al.*, 2023). Rural contexts will also influence home care / non-pharmacological care of pain (Nortjé and Albertyn, 2015).

The influence of culture and its effect on biases surrounding pain and disability in South Africa should also be considered (Nortjé and Albertyn, 2015; Pretorius and Steadman, 2018). There is a lack of research literature on how PCG of children with SNI and communication vulnerabilities in the Ugu district assess and address pain in their children. Little is also known about whether these PCG consider their own actions toward alleviating pain as effective or how they know if it was effective. This research study aims to investigate these factors.

CHAPTER 3 – METHODOLOGY

This chapter focusses on the study methodology. It describes the process of developing and validating the questionnaire used, it also focusses on how data collection was completed. It describes the materials and methods used to obtain and extract the data that were analyzed and provides a clear plan for any others wishing to replicate this study.

3.1 Research Design

Due to the small number of mothers with non-verbal children with SNI attending the hospital and the need to obtain individualized detailed information from each primary caregiver (PCG), a case study design was used (Reid, 1996). This decision was also influenced by the complexity of the situation these PCG face when assessing and addressing pain in their child in a rural context (Scholz and Tietje, 2002). Therefore; a multiple descriptive embedded case study design, which provides a practical structure to investigate phenomena in its real-life environment**,** specifically in situations where the event or phenomenon is an integral part of the individual participants lives, was used (Yin, 1981; Scholz and Tietje, 2002).

The research design was non-experimental (no manipulation of independent variables) and is not meant to establish a causal relationship between phenomena (Rowley, 2002). The embedded design allows the description of the process of the phenomenon being investigated within a defined context (Scholz and Tietje, 2002). Multiple cases were used in order to gain analytical power and pervasiveness, as per Verschuren (2003) from Ragin and Becker (1992) and Ragin (2014).

Investigations into pain in the specific group of children with SNI who cannot communicate and their PCG reactions to their pain while living in Ugu in rural KZN; have not yet been done in South Africa. As culture influences pain experience and expression; there may be viewpoints and answers from this population that differ from what the literature has found. The themes in the case study were built around what the literature has found, and evidence was collected and analyzed. The aim of this would be to achieve a case study that can be validated from multiple sources of evidence (Rowley, 2002).

Case study research design was also described to be useful in studying problems of practical significance in occupational therapy professional practice in work done by Salminen, Harra and Lautamo in (2006). This methodology is particularly useful when using an individualistic client centered approach in occupational therapy to understand a phenomenon from the perspective of each PCG of a child with SNI who cannot communicate, within their context in rural KZN, specifically since the context may influence this phenomenon and how it presents (Yin, 1981).

The Dynamic Systems Theory is thought to have originated from Bernstein (1963) but has been applied in a multitude of areas of knowledge development. In Haggis's (2006) work on educational research case studies are considered as a way to use the often-overlooked aspects of research such as the details about context, time, and place as well as the process of research and its effect on the subject studied. In the current study, it is used to better understand the interplay of factors affecting pain management in the study population.

The integration of these concepts is better described in Byrne’s 2005 work on complexity science. The current research report analyses the data from the perspective that individual cases (or systems) can be seen as constantly following a course that is dynamic. These individual systems can be compared based on how they are configured currently and potentially the various ways in which they are different from each other and how actions can influence them to produce a more desired outcome. This means; how the PCG-child dyad relates to each other in the presence or absence of pain or how they differ based on external circumstances. How conditions in the social and natural environment influence these individual cases will be a part of the analysis of the collected data (Byrne, 2005).

In the current research report; the dynamic systems theory is crucial for getting a thorough idea of each case. The PCG all live the experience of caring for a child with SNI who is non-verbal, and who may have pain; but every child will have highly individualised adaptations to indicate pain. Moreover, all the PCG have different home environments and life situations, and these systems interact and often undergo change. These PCG and child dyads also live in environments that are exposed to social and natural changes, which may prove more challenging given their situation or diagnosis.

Both qualitative and quantitative results related to the interpretation by the PCG of unclear signals from their child with SNI to decide if the child has pain or not were used to create a meaningful whole using an interpretative paradigm. The embedded case study design also included consideration of multiple phenomena. These include the caregivers' preferred techniques used to identify pain in their children, how frequently in the past seven days certain non-verbal or behavioural signs of pain their child with SNI displayed, as well as what methods they use to alleviate pain and how effective they perceive these methods to be (Scholz and Tietje, 2002).

3.2 Population and Sample

Purposive sampling was used in order to explore a complex issue in a small group of the population with a limited number of cases (Seawright and Gerring, 2008; Bowling A., 2014). The rationale for using case studies is that the population was primary caregivers (PCG) with their children who are seen for rehabilitation services at the public Port Shepstone Regional Hospital in the Ugu district, Ray Nkonyeni municipal area, and that each case is unique while containing similarities in a dynamic environment.

The families are referred from the local clinics to the hospital outpatient rehabilitation services for assessment and intervention. The sample was taken from the small total population of all PCG of non-verbal children with SNI who attended occupational therapy out-patient-services in the last 24 months. Selection was based on achieving a typical or representative sample of children with SNI of different ages and time in years they had been cared for by the PCG, so PCG with different periods in years and experience in identifying and alleviating pain in these children were included (Cook and Campbell, 1979; Seawright and Gerring, 2008).

The PCG (over 18 years), of communication-impaired children with SNI and their children with SNI (under 18 years), who were willing to participate in the study were thus included in the study. Nine participants met the inclusion criteria and provided informed consent to participate.

Inclusion Criteria

Primary caregivers of a child with non-verbal SNI from the Ugu district in rural KwaZulu Natal.

- Who spend the majority of their time in the presence of the child with SNI with their children with SNI who:
- Cannot speak in a way that is consistently understood correctly by their PCG, or make decisions and with a score of three or higher on the Communication Function Classification Scale (Hidecker et al., 2011). It will be described as a communication difficulty in the rest of this research report.
- Have previously received therapy at the clinics and hospital serviced by Port Shepstone Regional Hospital in Ugu district, Ray Nkonyeni municipal area.
- Are not able to move themselves effectively without assistive devices, and with a score of three and higher on the Gross Motor Function Classification System Expanded and Revised (GMFCS-ER) by (R. Palisano, P. Rosenbaum, D. Bartlett and M. Livingston , 2007).

Exclusion Criteria

- Children with acute, life-threatening conditions.

3.3 Measurement tools

The measurement tools used in the study comprised a demographic questionnaire and a pain questionnaire.

3.3.1 Demographic questionnaire

The demographic questionnaire (Appendix A) was based on a document designed by Malamulele Onward (https://www.cpchildren.org/), but adapted to be specific to the rural area in which this research was conducted (Malamulele, 2016).

This demographic questionnaire gathers information aimed at helping the researcher understand the circumstances of the PCG and child more fully. Questions were asked about the home circumstances / resources available to the PCG. This included questions about access to electricity, tap water in house, toilet nearby, funds / disability grant, the PCG level of education (indirectly their ability to access information), and the PCG level of support in caring, as well as other responsibilities (caring and other). Other questions included the context in which the child was cared for and covered barriers to access to medical care, transport availability, house distance from the road, transport costs to nearest clinic, PCG's beliefs about their, their child's and the healthcare-workers' abilities and about the willingness of healthcare personnel to help. The PCG were also asked about their use of traditional medicine. Perceptions of the PCG about the nature of the problem with the child's functioning and pain, as well as whether there was potentially related grief or other stressors were determined.

3.3.2 Pain questionnaire

The researcher developed a questionnaire suitable for research in a rural area of South Africa (Appendix B) based on the Non-Communicating Children's Pain Checklist - revised (NCCPC-R) by Breau (Breau, 2003, 2004). This specific test was chosen as a foundation for a behavioural observation proxy-reporting tool for the South African context, due to the nature of the questions which describes a wide range of behaviours that could indicate pain or distress in the child with SNI for richer information extraction (Warlow and Hain, 2018). The NCCPC-R is also useful in the cases where very little is known about the specific child's pain expressions, when the diagnosis is uncertain or the health is unstable, or for non-clinical settings (Breau, 2003; Warlow and Hain, 2018; Benvenuto, Trombetta and Barbi, 2022).

This developed tool does not claim to be validated as the NCCPC-R and its precursors are.

The final questionnaire included 22 questions about how pain was identified by the PCG using tick boxes with the options Yes/No to indicate the presence of items. Six other open-ended questions were used to establish how the PCG alleviated the child's acute pain and their plan to address the pain over time as well as their understanding of pain, who they had consulted about alleviating the child's pain and any other issues with pain the child experiences. This was followed by four other Yes/No questions with a tick box to indicate the PCG choice regarding the PCG experience of access to health care services for the child in the context / presence of pain; and a final open-ended question about how the PCG thinks health care workers can assist in addressing the situation.

As with the NCCPC-R, the questionnaire does not distinguish between acute and chronic pain, and also does not distinguish between pain and anxiety. Based on the work of Siden, Carleton and Oberlander, (2013) the assessment of pain in this study was based on the concept of Pain and Irritability of Unknown Origin (PIUO). The term PIUO may be considered a more accurate way to describe what should be assessed in children with SNI who cannot communicate, as the symptoms are indistinguishable, only indicating pain with no clear or obvious cause of acute or chronic pain; but for ease of understanding and ease of use – this research report uses the term: “pain”.

The questionnaire also included a pain map and a visual analogue scale (VAS) to determine the severity of pain, if present, within the seven-day period prior to data collection. The pain map consists of a line drawing of a child, where the details such as facial features and gender-specific body parts are not included (and replaced by a blank space). The reason for including this “pain map” was to allow PCG to draw on the map where they think the child may experience pain. In part, this was done to make the concept more concrete and to accommodate for the language barrier (the mannikins were reproduced with permission from the Childhood Arthritis and Rheumatology Research Alliance (CARRA; CA, USA), and found in Baeyer et al., 2011.)

The visual analogue scale (originally attributed to Hayes and Patterson (1921) in Yeung and Wong, (2019); but simplified and adapted from Scott and Huskisson (1979)) consisted of a rectangle subdivided into 10 blocks starting with white but changing in incrementing shades of grey to black. It had the heading: “Bukhulu kangakanani ubuhlungu” (How much is the pain?). The white block on the left side contained the words: “Akukho Buhlungo” (No pain), and the black block on the right side contained the words: “Kubuhlungu kakhulu” (Too much pain). Caregivers were asked to indicate the level of severity they think the child’s pain is at on this spectrum.

3.3.2.1 Pilot study to establish validity of the pain questionnaire

The validity of the research tool is important to ensure that the research tool measures the appropriate aspects of a phenomenon, and that the items in the research tool are an appropriate representation of the aspects of the phenomenon that is being assessed (Polit and Beck, 2006).

In order to establish the content validity of the pain questionnaire, questions were formulated and placed on an online platform used for Research Electronic Data

Capture or Redcap; to be rated by six experts in terms of its validity, reliability, ambiguity and clarity.

The study required rehabilitation professionals with more than five years of experience in the field of pediatrics, neurology, pain or rehabilitation to assess the questionnaire. These experts were identified through their various associations and places of employment, either public and private sector of healthcare, academia, research, or other NPO (non-profit organisations) that worked with cerebral palsy, pain, or children.

Pain experts and expert caregivers would have been ideal but were not included due to availability or non-response to the original invitation to participate in the pilot study.

All experts were individually approached by email and, if they consented to assist, they were emailed a link to the Redcap site set up by the researcher. Six experts were asked to rate each question. The rating was done on an ordinal 4-point rating scale, from 1- not relevant; 2- somewhat relevant; 3- quite relevant, and 4- highly relevant; for each of the following aspects: its relevance, clarity, simplicity, and the level of ambiguity of the questions.

To determine the validity of the research tool the Content Validity Index (CVI) was calculated (Martuza, 1977). Expert ratings on the content of the questions were compiled and analysed. The results for relevance were dichotomised into 0 – not relevant or somewhat relevant and 1 – quite relevant or highly relevant; with a similar process followed for clarity, simplicity and ambiguity; These results were used to calculate the content validity index (CVI) for each question (known as the item-level content validity index; or I-CVI) as well as the questionnaire as a whole (scale-level content validity index or S-SCI) (Polit and Beck, 2006), as proposed by Davis (1992). For this research report, the content validity index was set to 0.78 as the cut-off point, as there were six expert raters, as recommended by Lynn (1986).

Any item on the list that had more than one expert rate the item as a 0 (this means not relevant / clear / simple / unambiguous or somewhat relevant / clear / simple / unambiguous); needed to be reviewed or removed. The questionnaire was adapted accordingly – to only include items that had acceptable levels of relevance, clarity, simplicity and ambiguity, or items that had been adapted after rating. For the sake of completeness, Appendix C shows the calculation of the I-CVI and S-CVI in relation to the questionnaire, and Appendix B shows the final result of included questions and their phrasing in English as well as their Zulu translation which was done by a professional translating company: Afrolingo. This was then informally translated back by local Zulu speakers in the community to check for retention of meaning.

3.4 Research procedure:

After the appropriate consent was obtained from the Wits Human Research Ethics Committee (HREC) (Appendix D); the KwaZulu Natal Department of Health (DOH) ethics committee (Appendix E), the Hospital Chief Executive Officer (Port Shepstone Regional Hospital / PSRH) (Appendix F) and the research instruments were created, and the distress protocol adapted from Draucker, Martsolf and Poole, (2009); and Wikler, (2010) was in place (Appendix G). The distress protocol was created to protect and support research participants if the questionnaire on pain in their child created distress, due to the distressing nature of the topic of pain in a child. It included a step-by step plan to follow in the case of expressed distress (whether verbally or non-verbally) which included the option to access registered professionals who are experienced in the fields of grief and counselling with minimal inconvenience to the research participants.

With this in place; the data collection started. Data were collected at Port Shepstone Regional Hospital from May 2022 to the end of October 2022.

When staff identified a PCG and communication-impaired child dyad as meeting the inclusion criteria while attending the hospital, they were invited to participate in the study. The PCG received an information sheet in their preferred language (English or Zulu) (Appendix H). After being afforded with the opportunity to discuss any questions they may have with the researcher and they agreed to participate, they were asked to sign an informed consent form (Appendix I).

3.4.1 Data collection

The PCG was then requested to fill out the questionnaires. The researcher was present or available during this time and the PCG was verbally encouraged to ask questions if they needed clarification on any items on the questionnaire. All documentation that the PCG participants used was available in either Zulu or English. Some PCG participants required the researcher to read the questions and write down their answers while others were able to complete the questionnaires independently. Participants were given a clean pain assessment form to take home to complete as they monitored the presence of their child’s pain at home. If they found the form helpful as a tool to monitor their child’s pain in a more concrete manner, they were encouraged to take this form with them when they needed to reach out to the medical team about the child’s pain.

The idea behind this was to provide a structure to follow when assessing pain, as well as a tool to use to find help and advocate for their child. This is in alignment with suggestions for best practice based on work done by Rizakos, Parmar, Orkin and Siden (2020) in their research aimed at developing a more effective and efficient approach to address pain or irritability in children with SNI.

The provision of the empty pain questionnaire form in the current study is aimed at providing a more concrete framework for the PCG to use to monitor the frequency and presence of pain-related behaviours and to and address pain more efficiently.

Data collection was carried out in the clinical setting; with the aim of causing the least amount of inconvenience to PCG of children with SNI. Each participant was individually approached and a secluded or private area was used for them to complete the questionnaires. This was done once off, as the study uses a cross sectional design.

3.5 Data Management

The questionnaires and consent forms were coded with a participant number and placed in a sealed box marked research. This box displayed both of the ethics clearance reference numbers (HREC and DOH). This box was securely stored in a locking cabinet where the researcher alone had access to the key. The researcher alone had access to the datasets and separated the consent forms from the questionnaires. The researcher alone had access to the code list, which was kept separate from the questionnaires, with the consent forms. The data was then collated into an Excel spreadsheet or sorted into tables on Microsoft Word in order to compare the similarities and differences among the participants in their context. Both qualitative and quantitative data were collected at the same time, on the same form, but using closed and open-ended questions in this embedded case study. For qualitative and quantitative data, the participants were able to answer in their preferred language on the form, which was later translated. The translated qualitative data was typed in Microsoft Word in a table format. The translation was done by the researcher using Google Translate; this was then verified by the researcher's Zulu speaking colleagues. The quantitative data was typed into a Microsoft Excel document and analysed from there, after having been translated in the same way as the qualitative data. All data will be stored by the researcher on a secure password protected personal computer and will be available on request when the study is published. All data will be stored for five years from date of collection or two years if the research is published.

3.6 Data Analysis

In the current case study, the quantitative data of the different participants, caregivers and children were analysed individually and then organised into categories as defined in the demographic questionnaire. The information was then considered in the context and time frame in which the research took place. Factors influencing the care of the non-verbal child with SNI in a rural setting were analysed according to care factors.

The similarities and differences in the cases were presented to form a clear picture of the group and their contexts. Quantitative data for the pain questionnaire and qualitative data of experiences and perceptions in managing pain were analysed as text units for individual PCG/child cohorts. Frequencies were used to indicate the most common perceptions and experiences. Triangulation of quantitative and qualitative data, as well as between cases and between cases and theory was used to determine whether patterns in identifying and alleviating pain were consistent when caring for a child with SNI (Eisenhardt, 1989; Salminen, Harra and Lautamo, 2006; Rietjens, 2015).

Association between the recognition of pain and the extent of care was analysed using Spearman's correlation co-efficient to determine if number of years the PCGs had cared for the child and the number of hours they spend a day with the child related to their ability to identify pain. Spearman's correlation co-efficient can be used in small sample sizes ($n < 30$) (Adelson, Osborne and Crawford, 2019).

3.7 Rigour of the study

The rigour of this research report is determined in accordance with the positivist tradition of scientific inquiry. This means that it will use the four criteria of rigour in field research as adapted for use in case studies by (Campbell and Stanley, 1963; Eisenhardt, 1989; Yin, 1994; Gibbert, Ruigrok, and Wicki, 2008) . The criteria used will be: internal validity, construct validity, external validity, and reliability. These criteria can be met by following a set of strategies aimed at ensuring that qualitative research meets the validity and relevance requirements. Mays and Pope, (2000) identified the use of triangulation, member checking, clear exposition of methods of data collection and analysis, “fair dealing” (incorporating a variety of different viewpoints), reflexivity and attention to negative cases as important for ensuring the validity and relevance of qualitative research. Whittemore, Chase and Mandle, (2001) also recommend using the primary strategies of credibility, criticality, authenticity and integrity. Ensuring that the information presented in the research report is sufficiently unambiguous, rich, creative and thorough, as well as ensuring that it is fully represented with understanding, would aid as important secondary criteria of validity.

Careful attention to ensure that these criteria are met in the research framework, and ensuring that the planning is derived from literature, will help defend the research report against criticism. Historically, the main criticism given against the use of case studies in research designs is that they lack rigour as well as objectivity (Gibbert, Ruigrok and Wicki, 2008). It is important to note that qualitative research can be useful on the basis of more than rigour alone. It has been commented that relevance to the profession or to impact social justice may affect its utility, as qualitative research aims to define or explain societal phenomena and human experiences (Fade, 2003).

Despite this, the current research has aimed to establish rigour. This study used some of the strategies suggested by Creswell and Clark Plano (2007); such as triangulation (analyst triangulation, data triangulation, and theory triangulation), as well as elements of peer debriefing (where findings and path of thinking are summarised by peers to evaluate the researcher’s logic and clarity) and thick description, aimed at improving generalisability – including a detailed account of the work (Fade, 2003; Creswell and Clark Plano, 2007; Lincoln and Guba, 2015).

In this study, triangulation is done using two or more different approaches by comparing the PCG tick-list answers with their open-ended answers and comparing these with their evaluation of pain in the VAS and on the manikin. The data in this study were also analysed by two different individuals, the researcher and a lecturer experienced in working with statistics for research purposes from the department of Occupational Therapy at Wits University; as the researcher did not have access to biostatisticians due to the location. The theory was also compared to the findings (Fade, 2003).

Qualitative research can be done within different frameworks: this research falls within the action research framework (the aim was to create knowledge that can be applied in a specific context with the aim of improving the lives of participants (Fade, 2003).

3.7.1 Internal validity

The internal validity of the research report is dependent on the validity of the logic behind the research planning (Cook and Campbell, 1979; Yin, 1994).

The researcher needs to provide sufficient reasons for the existence of the phenomenon being studied, as well as for the set of conditions influencing this phenomenon. This should ensure that the phenomenon is not influenced by factors other than those studied. Techniques such as pattern matching and triangulation can be used during the data analysis phase to verify the accuracy of the conclusions regarding the results of the study (Yin, 1994).

Pattern matching in this context, means that the research results will be compared to either predicted patterns based on existing knowledge or to patterns observed in other contexts (Eisenhardt, 1989; Denzin and Lincoln, 2018). Triangulation with theory and between cases may help to ensure that the researcher considers all perspectives (Guba, 1981; Yin, 1994). Verschuren (2003) argued that internal validity is reliant upon not using a reductionistic approach when studying a phenomenon which is in part rooted in its interconnectedness and that a case study design is useful to achieve this. Based on a positivist view, the variables that participants were asked about were interconnected and well established in the literature. Similarities and differences between variables were established to identify patterns; and theory triangulation was used to verify findings in this unique context (Gibbert, Ruigrok and Wicki, 2008).

Bias in case studies need to be carefully considered. Mood bias, as explained by Jorm and Henderson (1992), could create a situation in which a study participant can report a more dire situation than their reality represents if the participant is in a negative mood. Observer and recall bias may always influence the responses; as the true situation can be mis-recorded due to the observer's point of view being different from the view inside the phenomenon, or if the phenomenon is being reported after the fact of its appearance. There is a chance that the PCG may not recognise the child's pain, yet is the only means of reporting the pain based on observed behaviours. This research does not claim to represent the child with SNI's point of view on pain, but attempts to learn more about how the PCG recognises and responds to the behaviours indicating pain in a child with SNI and communication barriers (Delgado-Rodríguez and Llorca, 2004).

It is not unlikely that PCG may over report (and include items that they have previously associated with pain in their child) instead of reporting the actual items they have observed within the seven days' timeframe on the pain questionnaire. This means that the PCG may rely on general recall in-stead of recall of what has actually been observed.

It was also noted that some PCG may not have fully understood the instructions to the tick-list, given that there were some reactions that were inappropriate to the question asked. The inclusion of questions requesting PCG to describe their reaction to pain in the child and how they see it in their own child in a more open format was aimed at allowing more depth to the answers provided about pain. This may be considered a less biased question in terms of symptom frequency and could therefore be used in triangulation to determine whether bias had played a role for those PCG that answered the questions.

Reporting bias may have played a role, and may have been exacerbated by the language barrier between the researcher and the respondents. Although the researcher had the research documents translated into Zulu and had Zulu-speaking colleagues to ask about the responses, this was often done after the interview. The informal Zulu translator was also not always present for the full duration of the data collection period per respondent, which is different from the original planning done by the researcher due to the difficulty of accessing an interpreter during the patient contact used for research participation in the clinical setting (Delgado-Rodríguez and Llorca, 2004).

The effect of bias had to be considered in terms of the PCG responses to the questionnaires since the pain questionnaire did not have "decoy" items. The questionnaire, however, included items that could be considered atypical descriptions of pain reactions, or non-stereotypical ways of expressing the presence of pain. This means that some of the descriptions provided as options on the tick-list would not necessarily carry the meaning of pain for every PCG. The researcher reasoned that the questionnaire, although rated by experts in the field; was still being used by PCG who have differing levels of health literacy, as well as language or second language capabilities; and who may view the questions against a different cultural background. This means that they might therefore either be confused by some of the descriptions of pain behaviours or might see only a description of a behaviour that does not specify pain to them.

Despite these issues; questions requesting PCG to describe how they recognise pain in the child and their reaction to it in their own child were included in a more open format – allowing for more depth to the answers provided about pain. These quantitative and qualitative responses were triangulated to determine whether bias had played a role in the pain questionnaire. This triangulation can be seen as a strength of case studies (Rowley, 2002).

To ensure methodological rigour as much as possible, language barriers were considered prior to participation in the study by ensuring access to written work (the information about the study, the consent form and the demographic- and pain questionnaires) that has been professionally translated into Zulu.

3.7.2 Construct Validity:

The structure created to measure the subject/phenomenon in the case study needs to be sound. This is crucial during data collection, where the study needs to ensure that it really measures what it set out to measure – which will result in data that is a more accurate representation of reality. The structure in the case of this research is the pain questionnaire. The process describing the development of the pain questionnaire is described under section 3.3 Measurement tools (Denzin and Lincoln, 1994; Gibbert, Ruigrok and Wicki, 2008).

To avoid using subjective data, the research report should provide information that allows the reader to reproduce the results from the same research question and datasets (Yin, 1994). Another aspect that can improve the construct validity is that researchers should also use different perspectives to look at the same phenomenon, such as using different sources or data collection strategies (Denzin and Lincoln, 1994; Yin, 1994).

3.7.3 External validity

External validity is the "generalisability" of the research, meaning how useful this information will be in other situations (Gibbert, Ruigrok and Wicki, 2008).

Since case studies carried out in real life contexts often happen during interaction with practitioners who are trying to deal with real clinical management situations, the researcher needs adequate experience and knowledge to interpret the qualitative data. The researcher is a 35-year-old female occupational therapist employed at PSRH with approximately ten years of clinical experience in the public health care sector.

To ensure the fidelity of the quantitative data; credibility was obtained by ensuring that the measuring instrument actually measures what it is intended to measure (Shenton, 2004). The literature links to the research questions in the pain questionnaire which was further refined for the context using expert rating. This rating addressed the validity of the pain questionnaire; looking specifically at relevance, clarity, simplicity and ambiguity can be found in Section 3.7.4.

Due to the nature of the purposive sampling strategy (participants recruited based on their initiation of hospital visits), it can be said a sample was chosen to be a representative of the population and which is information-rich (Guba, 1981). This was done with the aim of understanding a variety of PCG experiences and challenges and the relative variety in participants reflects this. The generalisability of this research is low due to a lower sample size, but is supplemented by some qualitative data (Eisenhardt, 1989; Patton, 1990; Stenbacka, 2001). The use of both qualitative and quantitative data in this research report may help improve generalisability, which may help clinicians transfer these data to other vulnerable populations in similar contexts.

3.7.4 Trustworthiness of qualitative data (Reliability)

In Shenton (2004) there is a clear explanation of the four strategies to ensure trustworthiness according to Guba. These criteria are: credibility, confirmability, transferability and dependability (Guba, 1981). How the research met these four criteria will be discussed below.

3.7.4.1 Credibility

Credibility was supplemented by adopting the well-recognised research method of using written data collection strategies. These consisted of using a checklist as well as open ended questions about the PCG experiences with pain in the child with SNI in the pain questionnaire. Triangulation was performed by assessing if the data from the questionnaire and the open-ended questions correlate (Guba, 1981; Lincoln and Guba, 1985).

The researcher aimed to develop familiarity with the culture in the area (location based) and has been living and working in the area for more than five years. This included immersive actions such as participating in clinic visits and conducting home visits to people with disabilities as part of the researcher’s job as an occupational therapist at Port Shepstone Regional Hospital (Guba, 1981; Lincoln and Guba, 1985). Living in the area where the phenomenon is being studied during the time frame that it is studied helped the researcher link the data collected to the spatial and specific time context (Denzin and Lincoln, 2018).

The research procedure is carefully documented, with transparency and clarity in terms of all the steps taken, to allow for accurate reproduction. This ensures that random error, non-random error and systemic error is avoided, as these will influence the reliability of the research report. This will also allow peer scrutiny, and others to check data (Guba, 1981; Gibbert, Ruigrok and Wicki, 2008).

Depth of detail is considered important to improve credibility as per Lincoln, (1995) who also advised extended periods of engagement, persistent observation of the phenomenon, triangulation, peer debriefing, the analysis of cases that present data that is dissimilar to the majority of cases / data; known as negative case analysis and member checking, as found in (Barusch, Gringeri and George, 2011).

Reflective commentary was not used specifically due to the limitations in feedback this provide, instead the researcher incorporated a system to contact supervisors on a weekly basis with updates on the progress or barriers of the research (Denzin and Lincoln, 2018).

Thick description of phenomenon under scrutiny was attempted and can be found under the heading: “Rurality and Disability” in Chapter two. This includes references to newspaper articles on events that unfolded during the design of the research and thus influenced the participants (Guba, 1981; Guba and Lincoln, 2001).

3.7.4.2 Confirmability

The de-identified datasets will be made available on request from the researcher in order to aid in ensuring replication of the results by later researchers (Yin, 1994).

Peer debriefing was used during the development of the questionnaire as well as during data abstraction. The researcher initially discussed the potential pitfalls of using certain data collection strategies with a colleague. During data processing, the researcher also often discussed emerging trends in the data with this colleague. The colleague was considered a good peer to discuss the research, as he is a professional in the same career, with a similar level of health literacy as the researcher, a father and an insider in the predominant culture present in the study findings (Denzin and Lincoln, 2018).

The analysis includes the most significant aspects of the case study. The analysis draws on the researcher’s prior knowledge in the area, but was aimed at remaining unbiased / objective, by only using findings that had been derived from participants.

3.7.4.3 Transferability

Even though the case study design is thought to not allow for significant transferability, there are measures as suggested by Guba (1981) that can assist in establishing some element of transferability. One strategy would be to include background data to establish the context of the study and another strategy would be to provide a detailed description to the point where comparisons can be made between phenomena (Guba, 1981). The temporal context of the research (the time in which it was done) also impacted on the transferability of the research – as it took place during a period in which a significant amount of natural and human disasters impacted the participants living in KwaZulu Natal in particular including the aftermath of the covid-19 pandemic, the July 2021 riots and the flooding of April 2022.

The research focusses on a very small population of people in a very specific situation, which results in decreased transferability of the findings (Shenton, 2004). Although case studies cannot be used for statistical generalisation, there is still the possibility of performing analytical generalisation processes, such as generalisation from observation to theory. According to Eisenhardt, (1989)and Yin, (1994), this can be done if there are between four and ten cases.

3.7.4.4 Dependability

As the research is done in the context of a case study design – the researcher had to take great care in the design and implementation of the research. Care was taken to ensure minimum interference by subjectivity of the researcher, and the research implementation was done systematically with thorough record keeping (Rowley, 2002). This facilitates replication logic that is appropriate indicating that the researcher’s biases and agendas did not unduly influence the results (Rowley, 2002; Shenton, 2004).

3.8 Ethical Considerations

- The research was designed to optimise the chance that the PCG / child will benefit from participation. These results can be incorporated into caregiver training and, therefore, will empower PCG to identify and advocate for the child with SNI’s specific needs.
- Ethical clearance for the study was obtained from the Human Research Ethics Committee at the University of the Witwatersrand (M150860)) (Appendix D).
- The researcher compiled a distress protocol which stipulated the actions that needed to be taken in the event that a research participant experienced distress during data collection.
- The researcher had contacted the local hospice as well as the hospital’s social work department and the hospital’s psychology department in order to request

these departments to avail themselves for help for the duration of data collection should any research participant require it. This was agreed upon in writing, that any research participant can access their help on the same day should it be needed (Appendix G).

- Permission to conduct research at Port Shepstone Regional Hospital was obtained from the KwaZulu Natal Department of Health (Appendix E).
- Permission to conduct research at Port Shepstone Regional Hospital was also obtained from the hospital's chief executive officer (CEO) (Appendix F).
- Research participants were recruited during their standard access to the institution. The PCG were verbally asked if they wish to participate in the research.
- Written information sheets explaining the research procedure, purpose and risks of participation were given to the PCGs and the contents of the information sheet verbally explained to the potential participants (Appendix H).
- The signed informed consent of each PCG was obtained prior to their participation in the study. This consent sheet also informed the PCG that they are free to withdraw from the research at any point but are required to inform the researcher if they choose to do so (Appendix I). The researcher also verbally informed the participants that the research is separate from their clinical care and that their participation or refusal to participate will not affect their clinical care.
- Participant information was kept confidential as the questionnaires were numbered with a participant code, but no name or other personal details were completed on the questionnaire form. The demographic information sheet was kept separately from the patient questionnaires, but the researcher will have a list of questionnaire numbers with contact details to contact PCG's to assist them in obtaining the appropriate pain management, should they require it.
- The filled in datasets were kept in a sealed box in a locked cabinet when not in use. When in use it was under supervision by the researcher.
- Data will be kept in a secure file on a password protected computer that only the researcher and her supervisors have access to.
- Data will only be shared for academic or publication purposes and will not include any identifying information.

CHAPTER 4 Results

4.1 Introduction

This chapter contains the data extracted from the datasets. Descriptive statistics were used to describe what the research found for closed-ended questions and summative content analysis for open-ended questions. The chapter considers the three objectives for the study. Data analysis is done according to the demographics of the PCG participants and children with SNI; the context and factors influencing the care of, and access to health care for a child with SNI in a rural KZN setting. Data are also analysed in terms of the measures used by PCG participants to recognise signs and symptoms of pain in the child participants, as well as the actions or methods that PCG participants use to address pain and the perceived efficacy of these in alleviating pain.

4.2 Demographics of caregivers and children

4.2.1 Personal demographics

This research had nine (n = 9) participants, and the detailed demographics are stated in table 4.1. Most of the PCG participants were 40 years and older (n = 5) except P6 and P7, who were in their 20s and P5, who was in her late 30s. The mean/average age of the PCG participants was 41.2 years. Female caregivers (n = 8) were more common than male caregivers (n = 1).

The relationships that the PCG participants have with their child varied: four of the nine (n = 4) children were being cared for by their mother, two were cared for by their aunt (n = 2), one is cared for by the grandmother and one did not answer the question clearly, but is a family member that shares the same surname as the child. Only one child was being cared for by his father. All the children with SNI lived in the community with their caregivers.

In terms of level of education; two of PCG participants did not answer the question, two have some form of training after matric; four did not receive education past grade 11 and one completed up to grade 12. In terms of functional literacy according to STATS-SA (Achievement of Grade 7); seven of the nine PCG participants should have achieved functional literacy, which could aid them in health care settings that require literacy (however, this was not independently assessed for this research).

Only two of PCG participants were employed at the time of the research (Department of Statistics South Africa, 2022).

The children with SNI were predominantly male (n = 6) and their ages ranged from one to 17 years old. The mean/average age was 7.1 years.

Table 4.1. Personal demographics of caregivers and children

	Caregivers	**Age-years**	**Gender**	**Relationship to child**	**Education level**	**Is the caregiver working**	**Children**	**Age-years**	**Gender**
P1		40	F	Mother	No answer provided	N		2	M
P2		47	M	Father	National Diploma	Y		16	M
P3		55	F	Aunt	No answer provided	N		17	M
P4		48	F	Grand mother	Grade 10	N		3	M
P5		39	F	Family member	Grade 11	N		1	F
P6		29	F	Mother	Grade 8	N		10	F
P7		22	F	Mother	Grade 12	N		2	M
P8		43	F	Mother	Tertiary Education (Nursing)	Y		4	F
P9		48	F	Aunt	Grade 10	N		9	M

4.2.2 Health demographics of children

As stated in Table 4.2; the diagnosis of two of the children could not be named by the PCG participants although 55.6% of the PCG participants knew that the child had CP, some with co-morbidities with two (n = 2) having epilepsy as their primary diagnosis. One child had both epilepsy and CP.

The children with SNI were mostly on a GMFCS level of five (n = 5) with two (n = 2) respectively on a GMFCS level of 4 and GMFCS level 3. The PCG participants had varying responses when asked to describe their child's overall health – seven PCG (n

= 7) responded “good” or “right” or “healthy”, one did not answer the question and one stated that the child is alive – which could be seen as a neutral response. The answer from P1 was negative: “Because he can’t do anything” which indicates poor well-being.

Table 4.2. Health demographics of children

	Diagnosis	**GMFCS**	**Health**	**Toileting**	**Can the child see**	**Can the child hear properly**	**Fits / epilepsy**
P1	It’s not serious	4	Because he can’t do anything	Needs a little help	Y	Y	N
P2	CP Floppy	5	Very fit and healthy	Needs help for everything	Y	Y	Y
P3	Down Syndrome and CP	5	He is alive	Not indicated	Y	Y	N
P4	No answer provided	3	OK	Needs help for everything	Y	Y	N
P5	Fits	5	We are going well	Needs a lot of help (nappies)	N	Y	Y
P6	CP Quad	5	Right	Needs help for everything	Y	Y	Y
P7	CP Quad + epilepsy	4	Good	Needs help for everything (nappies)	Y	Y	Y
P8	CP	5	Healthy	Needs help for everything	N	Y	Y
P9	Epilepsy	3	No other problems	Needs help for everything	Y	Y	Y*

*P9 – main diagnosis is Epilepsy according to his PCG, but then she indicated that he does not get fits/epilepsy.

Two children (N = 2) were unable to see and six (n = 6) were reported to have fits or epilepsy. None, according to inclusion criteria, used verbal language but all responded to sound. None of the children had hearing problems according to their PCG.

4.3 Context in which care takes place

When considering the amenities in the households where the children are cared for, between 2 and 14 people lived in the house (Mean 6.4). All of the PCG participants (n= 9) reported having access to electricity in their homes, however, only four (n=4) had access to water in their homes. P4 reported they wash in the river and drink the water from the water tank. She also reported they had an outside toilet at home, as did Participant 5. Four other PCG participants (n = 4) reported they had no bathroom or toilet at their houses, three of whom (P1,6 and 7) had to access water outside of their houses or in the community (Table 4.3).

Table 4.3 Environmental factors for households of participants

	How many people residing in the house	**Electricity in the House**	**Tap Water in the House**	**Is there a bathroom or toilet in the house**	**Are you receiving a grant to care for the child**
P1	7	Y	N	N	Care dependency grant
P2	6	Y	Y	Y	N
P3	5	Y	Y	N	Care dependency grant
P4	6	Y	N	Y Outside	Care dependency grant
P5	14	Y	Y	Y Outside	Care dependency grant
P6	2	Y	N	N	Care dependency grant
P7	3 or more (3 and in-laws)	Y	N	N	Care dependency grant
P8	4	Y	Y	Y	N
P9	11	Y	N	Y	N

Financial assistance in the form of a Care Dependency Grant was being received by six PCG participants (n = 6) who did not have bathrooms or toilets inside their homes which possibly indicated lower income status which allowed them to qualify for such grants. P9 in particular was concerned about finances, as she was not receiving a grant for the child she had recently started to care for.

4.4 Factors influencing care of communication-impaired child with severe neurological impairment in a rural setting

4.4.1 Primary Caregiver familiarity with the child

The PCG participants were familiar with the behaviour and needs of the children with SNI, thus understanding the child’s needs due to the time spent caring for the child. They reported they had been caring for the children for periods ranging between 9 months to 17 years. All but one PCG participant have cared for the child since birth. More than half of the PCG participants (55.6%; n=5) spend 24 hours a day with the children, while the other four care for the child for periods of 2 to 12 hours a day (Table 4).

Between one and nine other people assist with caring for each child, with P3 having no one to assist her. This respite care is limited to 2 hours twice a week for P6 and other PCG participants did not indicate how much assistance they received. Five PCG participants (P3, 6, 7, 8 and 9; n = 5) report being with the child at all times.

Five of the PCG participants (n = 5) cared for between one and seven other children under the age of 18 years while P5 and P8 also cared for other individuals older than 18 years. P7 who cared for seven other children had the help of four sisters for child care. P9 is relatively “new” to caregiving – she had taken over caretaking duties from the child’s mother nine months ago, from:” ...his mother, who abandoned him without doing anything for him”.

Table 4.4 Time spent caregiving

	How long have you been looking after the child	How much time do you spend with the child each day	How many people are helping you look after the child	How many children under the age of 18 are you looking after
P1	From birth (2 years)	3 hours	0	No answer provided
P2	From birth (16 years)	16 hours	4	4
P3	From birth (17 years)	I sit with him every day	0	No answer provided
P4	From birth (3 years)	day and night except when at creche	1	1
P5	From birth (1 years)	Most of the time I stay more than 2 hours with the child	2	5
P6	From birth 10 years	24 hours a day	1 (twice a week for 2 hours at a time)	0
P7	From birth 2 years	all day	4 (sisters)	7
P8	From birth (4 years)	24 hours	2	0
P9	Took over care 9 months ago	the whole time	9	4

4.4.2 Extent of care needed

The extent of care required for children with SNI added to the burden of care in the rural setting where there is a lack of amenities and limited space in which the child could be made comfortable especially when in pain.

Space and access to furniture within the homes was restricted with only two (n = 2) children (age 16 years and 17 years) having their own beds to sleep in, two children (n = 2) sharing a bed with their mother and the others sharing with someone else or sleeping on the floor or other furniture. Five PCG participants (n = 5) indicated that their child does not have his/her own bed. The mean age of the children who do not have their own bed (including the two who shares a bed with their mother) is: 4 years and 7 months.

Table 4.5. Extent of care needed

	How does the child use the bathroom/ Toilet	Does the child have his own bed	How does the child communicate with you	How is the child walking	Other	Does The child go to school
P1	needs help	N	He cries	He is rolling	He can't do anything	N
P2	needs help for every thing	Y	Little gestures and sound	Not walking, pushed in a mobile seating chair	Feeding	N
P3	No answer provided. Child is on GMFCS 5 so needs help with everything	Y	No answer provided	He does not travel (walk)	Skin level PEG, hernia operation and chronic reflux	N
P4	needs help for every thing	N	Crying or laughing	He does not go (walk)	N	Enkulu Creche
P5	needs a lot of help (nappies)	N	Can't speak	N	N	N
P6	needs help for every thing	N shares with mom	Sound and smile	N	N	N
P7	needs help for everything (nappies)	N shares with mom	Sounds and cries	N	N	N
P8	needs help for every thing	N	Facial expressions and sounds	N	N	N
P9	using pampers	N	He is either snoring or making a lot of noise	He walks in chair with four wheels	N	N

Most of the children could not use the bathroom or toilet independently, even if it was available. Most PCG participants 88.9% (n = 8) indicated the children were totally dependent and need to be moved to outside toilet facilities with three relying on nappies for toileting. P3 indicated the question did not apply since they had no bathroom or toilet at home.

The limited mobility, as well as limit to any type of day care centre or stimulation centre were also reported by PCG participants as impacting care. Only one child who was 3 years old attended a creche. All children are transported by carrying or in mobility assistive devices, which indicates limitations in their personal mobility. No information was gathered about what types of assistive devices are available to the PCG-child dyads.

4.4.3 Perceived burden of care

When asked about the problems of caring for the child nearly half of the PCG participants perceived their greatest burden of care as related to emotional strain and the environment in which they had to care for the child. Having to access medical services and physical strain were reported by a third of PCG participants, while less than a quarter reported financial issues. (Table 4.6).

Table 4.6. Participants perceptions of burden of care

Financial	The problem I have is that I can't do another job because of this. Money problems because he doesn't earn as much as his mother does for nothing.	P 1 and P9
Environmental	I wish I could afford to build a house with water and toilet inside so that he can live a better life. It was difficult in the place where we stayed. It was too far from the main road and we could not use the wheelchair properly. The place we stayed was too far from the main road. We could not use the wheelchair properly because of the area. Transporting the child when it is raining.	P1, P3, P4 and P5
Medical services	Going to clinic. Every month I see doctors about the child.	P5, P6 and P7
Physical strain	The problem I have is that I can't do another task, because of taking care of the child. Difficult to wash body. She is growing up and getting heavy, it is not easy to carry her and getting her out of the bath tub.	P2, P6 and P8
Emotional	I am so sad about the condition of my child because I never knew that he will be this disabled. I can't do anything because I feel sad about my child. The pain I feel is that in our society when you have a child like mine people look at you as if you are cursed. It was so painful for God to give us a child like ours. We love him more than all others. there are too many problems.	P1. P3, P4 and P5

The emotional burden of having a child with a disability was mentioned by Participant 1 in the space allocated for the history of pain: “I am so sad about the condition of my child because I never knew that he will be this disabled”, this is a thought she repeated in the pain questionnaire: “I can’t do anything because I feel sad about my child”. The same emotional pain was echoed by Participant 3; who stated: “The pain I feel is that in our society when you have a child like mine people look at you as if you are cursed”. This is a theme that is also mentioned by Participant 4: “It was so painful for God to give us a child like ours. We love him more than all others.” Another caregiver (Participant 5) stated that: “there are too many problems” in taking care of the child, “because every month I must go to the health professionals because of the child’s health.”

4.5 Pain in communication-impaired children with severe neurological impairment

4.5.1 Recognition of pain

Table 4.7 indicates the methods PCGs used to recognise pain in children. PCGs all had unique methods to recognise pain in their child; however, there were some similarities. All PCG (n = 9) had used crying as a reliable sign of pain or discomfort in their children in the last seven days. The amount of time spent crying or the intensity of crying was also used to determine the level of pain. Eight PCG also relied on the other sounds the children made to determine if pain was present or not. Some PCG used other emotive or emotive-behavioural signs, with 44.4% of PCG indicating that a “bad mood”, “facial expressions” or oppositional behaviour (“not getting anything” (done)) alerts them to the potential presence of pain. This was related to behaviour like he / she wants to be comforted or like he / she is needy or moody, reported by 66.6% of PCGs.

Parasympathetic signs, such as sneezing or drooling were used by 22.2% of the PCG in addition to crying; as an indication of the presence of pain. Motor behaviour / actions such as “clenching hands” and “clenching jaws” or stiffening were used by 55.5% of PCG to know when to suspect pain. In addition; two PCG used the child’s willingness and ability to eat food (the child would clench his jaws) when in pain. PCGs did not report sweating and holding of breath as related to recognising pain.

Table 4.7 Non-verbal Child with severe neurological impairment pain checklist Collation.

	P1	P2	P3	P4	P5	P6	P7	P8	P9	Total
Makes sounds like: Crying / Screaming / Moaning	X	X	X	X	X	X	X	X	X	9
Makes sounds like: Laughing / Giggling / Hiccups	X	X	X	X	X	X		X	X	8
Behaves like he/she is not interested in anything	X				X		X		*	3
Does not cooperate or fights me / friends / siblings				*			X		X	2
Behaves like he/she wants to be comforted or like he / she is needy or moody		X		X	X		X	X	X	6
Behaves strangely, like trying to be silly or acting chaotically	X			*						1
Has an unhappy / upset / sad or scared face	X	X		X				X		4
Has had his / her skin colour change slightly (lighter / darker / red / ashen)					X	X			X	3
Has sweated when it is not hot enough for sweating										0
Holds his / her breath				*						0
Has a tight / clenching / grimacing / strange look on his / her face	X									1
Grinds his / her teeth	X			*		X				2
Makes his / her body too tight / stiff (more than he / she usually does)	X				X		X	X	X	5
Becomes too stiff when I help him / her do something (like changing a nappy)	X				X	X	X		X	5
Moves too much / more than usual May twist and turn or fidget	X									1
Tries to protect or favour a body part	X	X			X					3
Bites / chews him / herself (i.e., bites his own hand on purpose)	X		X	*	*		X		*	3
Hits / slaps / bumps or scratches him / herself on purpose	X			X					*	2
Refuses to eat / eats less / vomits				X					X	2
Eats too much, or keeps asking for treats	X			X	X		X			4
Sleeps more than he / she usually sleeps					X					1
Sleeps less than he / she usually sleeps	X					X		X		3
Struggles to fall or stay asleep	X	*	X						X	3
Total for each participant	16	5	4	7	10	6	8	6	9	71

* Not filled in – left blank / conflicting answers

4.5.1.1 Association between the recognition of pain and the extent of care

The association between the number of items on the pain questionnaire the PCG used to recognise pain in children with SNI and the extent of care (number of years the PCG had cared for the child and the number of hours they spend a day with the child – as indicated in Table 4.4) was determined using Spearman’s rho. A strong negative correlation was found between the number of years the PCG had cared for the child and the number of items they recognise as indicating pain in children with SNI. Those PCG who have only cared for the child for <1 to 2 years still identify many signs or behaviour as associated with pain.

Table 4.8. Association between the recognition of pain and the extent of care

	Number of items on the pain questionnaire related to pain
	rho
Years caring for child	-0.92
Hours in the day spent with child	-0.33

*

A similar result was found for the number of hours in a day the PCG spends with the child although the correlation was weak.

4.5.2 Level of pain

A visual analogue pain scale was used to indicate pain levels; here 1 represents no pain and 10 represents the highest level of pain ever experienced for the individual. The PCGs rated the child’s pain on the day of the assessment between 1 (no pain) and 6. Two PCGs did not answer the question.

Table 4.9 Level of pain identified in non-verbal child with severe neurological impairment pain checklist collation on the day of assessment

Visual Analog Scale Number	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
P1	x									
P2				x						
P3										
P4		x								
P5										
P6	x									
P7	x									
P8						x				
P9		x								
	3	2		1		1				

4.5.3 Measures used for intervention for pain in communication-impaired children with severe neurological impairment

Participants reported using analgesics and massage when they felt the child was experiencing pain. Accessing health care was not a first option since many lived in houses far from the road and did not have their own transport.

When caregivers suspect pain, not all would turn to analgesia as a first response. Some PCG would further investigate the situation. P3 and P8 would search for causes of pain or irritation (such as insect bites). P2, P3, P8 and P9 would use massage or stretches, position changes, baths and rocking or cuddling and comforting to relieve pain before using analgesics. It could be seen as a process that would, by nature, also include some form of “searching” for the problem. Analgesia / painkillers were used by 88.9% of the PCG at some point. P1, P2, P3 (something to make it better – later described “rubbing stuff”; tablets and injections from healthcare personnel to relieve pain), P4 described that she will take the child to the clinic for pain and that she used pain killers such as Panado. P5 also stated that she used painkillers such as Allergex.

P6 stated that she will give her child something for the pain, but did not specify what she would give. P7 stated that she gives her child Panado for pain, while P8 uses Stillpane and Mybulin for pain in her child. P9 stated the importance of giving the correct medication to her child; but described her actions in the instance of pain to first be stretches and then a clinic-visit for health professionals to assist.

Table 4.10 Access to health care

	Is the house far from the road, if so how far	**Do you or the family in your house own a car**
P1	Yes	No
P2	No 500m	Yes
P3	Yes	No
P4	Yes Long Distance	No
P5	Yes Walks at least 30 minutes	No
P6	Yes Walks for I hour	No
P7	Yes Walks 10 minutes	No
P8	No	Yes
P9	No It is very close	No

Six participants (66.7%) indicated their houses were far from the road and walking to the road to access transport took between 10 minutes to one hour. Seven (n = 7) of the participants had no access to a car in their families. Only two participants (P2 and P8) reported someone in their family owned a car (Table 4.10).

4.5.5 Actions and methods perceived as effective in alleviating the pain in non-verbal children with severe neurological impairment in the home setting.

All of the PCG indicated that they think the actions they have taken in the past had been effective in relieving pain. P1 and P9 described how they knew their child was feeling better. The child of P1 would “play” a little bit and the child of P9 would fall asleep.

All (100%) PCG had indicated that they had accessed health care services or Inyanga (traditional healer) for pain at some point. All (100%) of the PCG indicated that they feel confident that they can obtain help for the child. All (100%) of the PCG indicated that they feel that medical workers believe and hear them about the pain in their child. Approximately half (55.6%) of the PCG indicated that they can take their child to the clinic or the hospital at any time, while 33.3% of the PCG cannot take their child to the clinic or hospital at any time. One PCG (11.1%) did not answer this question.

4.6 Summary

The PCG who participated in this research were mostly women (88.9%), and their mean age was 41 years and approximately 2 months. All the children in the research lived in the community and were related to their PCG at the time of data collection. The PCG in the research were mostly unemployed (only 22.2% were employed at the time of data collection). Four of the PCG did not have any form of education higher than grade 11, and only 22.2% had some form of training after Matric (Grade 12). Most of the PCG in the research (55.6%) knew that their child had Cerebral Palsy (CP).

All PCGs had access to electricity inside their houses, however, 33.3% did not have running water inside the house and 11.1% had to use river water for cleaning and wait on a tanker system to deliver water for consumption. PCGs identified financial, environmental, emotional and physical strain as well as needing to access medical services as factors adding to the burden of care.

All PCGs were able to recognise when their child was in pain. There was a negative association between how many items PCGs answered on the pain questionnaire as indicating pain in their child with SNI and the amount of time they had cared for the child, as well as how many hours they spent a day with the child. Those who had a higher degree of care in years and hours of the day recognised pain based on fewer specific signs and behaviours.

Some PCGs were able to describe how they knew and how they would gather more information and respond to the pain. Most PCGs were willing to use analgesia, although one described an antihistamine with a sedative effect (Allergex) as the medication she uses in the case of pain. Most PCGs described the painkiller they used. Four of the PCGs would attempt non-pharmacological pain care such as massage, soothing, bathing or rocking the child before resorting to using painkillers.

Access to health care services to deal with pain was limited since many houses were far from roads where transport was available. They also described how / when they would revert to seeking help from health care workers, however; not all were able to access help from health care workers at any time. Only 22.2% of the PCG had access to private transport within their family, which might aid them considerably when in need of seeking help from healthcare workers. All PCGs indicated that they felt that healthcare workers were willing and able to help them relieve pain in their child.

CHAPTER 5 DISCUSSION

5.1 Introduction

This chapter discusses the results for the demographics and the context and factors influencing the care of and access to health care for a child with SNI and communication difficulty in a rural KZN setting. Measures used by PCG participants to identify signs and symptoms of pain, caring factors associated with this and the actions or methods PCG use to address pain in these children and whether their ability to identify pain was associated with caregiving factors are also considered. A discussion on the management of pain by PCG participants is presented last, and this is linked to areas that occupational therapists and other healthcare workers can provide assistance in.

5.2 Demographics of primary caregivers and children

5.2.1 Demographics of primary caregivers

The age of the majority (55.6%) of the PCG participants in this study were 40 years and older. This is slightly older than the median age of PCG in research done in Uganda by Bambi *et al.* (2021), which was 30 years old, however, the Bambi study excluded children older than twelve years old versus the current study that included older children (up to eighteen years old) . They found that children with CP who have PCG older than 30 years were less likely to have pain often (Bambi *et al.*, 2021, p. 6). Their study attributed this phenomenon to the potential impact of more PCG experience in the recognition of pain and, therefore, better support to alleviate pain.

The prevalence of female PCG is higher than that of males. This may be a reflection of the larger global situation where the mothers or relevant female in the majority of cultures assume the caregiving role (however this is context and resource dependent). In the 2015 study by Nortjé and Albertyn the majority of the participants found that it is the task of the mother or grandmother to take care of the child even when they are not in pain (Nortjé and Albertyn, 2015), and that women are the ones responsible for providing care for their family (Gordon, Jare and Roberts, 2012; Knight and Yamin, 2015). It is also in alignment with the South African General Household Survey (2021) findings, that 6.1% of children live with their father, whilst 51.2% of children live with their mother. This is also seen in work done in Uganda by Bambi et al. (2021), where 90% of the PCG were female and 80% of the children lived with their mother (Bambi *et al.*, 2021; Department of Statistics South Africa, 2022, p. 11).

All the children with SNI in this study lived in the community with biological relatives, and not in a residential care facility. The work by Pretorius and Steadman (2018) found that the PCG of children with disabilities in their study did not trust other people to look after their children. In terms of the education of the PCGs in this study: only three of the PCGs had completed high school. This is a concern since Mofoken *et al.*, (2022) reported a correlation between an educational achievement of Grade 9 to 12 (South African Education); and higher levels of health literacy. Health literacy is important in understanding the child's diagnosis and prognosis to provide appropriate care. In many cases it is influenced by English proficiency and the ability to find knowledge and act appropriately on information. It is also influenced by computer/cell-phone (internet) literacy and use, which may be associated with higher income levels than those found in this study (Marimwe and Dowse, 2019). The use of proxy scales to assess pain when a child cannot self-report may either require the PCG to have a certain level of education – in order to understand a paper-based assessment; or it may require the PCG and child to have contact with a health care worker that is able to use these scales effectively. In both these cases, the location of the PCG and child will affect the access to these forms of pain assessment. Moreover- the proxy assessment scales that are freely available; may not have been developed in a population that is comparable to those populations of children and PCG living in more rural areas of South Africa (Walters *et al.*, 2018). Although most PCG participants could name the medication their child was taking, some PCG participants demonstrated concerning behaviours in terms of the medication used to relieve pain, while two of the PCG participants were unaware of the correct diagnosis of the child. Five of the PCG participants (55.6%) stated that their child has CP, which is in line with research in Africa where a child with motor disability is assumed to have a diagnosis of "Cerebral Palsy or CP", whether it is accurate or not (Donald et al., 2014).

Only two PCG participants were employed at the time of data collection. Two PCG participants reported that they could not seek employment because of the requirements of caregiving. The participant PCG indicated financial constraints due to their employment status but their lack of income made most eligible to receive a social grant, to provide financial support for the child. Six of the PCG participants stated that they are receiving a grant for the child with SNI, although they specified it as a "Disability Grant" (DG). Since all children were under the age of 18 years, it is more likely that they were receiving the Care Dependency Grant (CDG). During the time that data collection was carried out, the CDG was R1860.00 per month (SASSA, 2020). The mislabelling of the grants may be an indicator that the participant PCG are not fully empowered to know exactly which types of grant they qualify for. It should be established if those who do not access grants are eligible to do so. This may apply to PCG 9 who had recently assumed caregiving responsibilities for the child in what seems to be an informal adoption. This situation would need to be formalised so that the grant being received by the mother can be redirected to the new caregiver. None of the PCGs noted the financial implications of the child's special needs for nappies or specific food during data collection, however this was the focus of the study. Literature indicates that the effect of disability is exacerbated in low-income contexts where poverty affects the PCG ability to take care of the child with disabilities such as SNI (ACPF, 2011; Donald *et al.*, 2014; Durkin and Yeargin-Allsopp, 2018). This perpetual state of financial need voiced by some of the PCG was linked to improper housing and poor access to amenities.

5.2.2 Health demographics of children

All children in the study were unable to speak in a manner that is consistently understandable by familiar and unfamiliar communication partners. Seven of the nine children had co-morbidities, including hearing problems and epilepsy or Trisomy 21. Two children were reported as being unable to see. The current research project did not look into visual disturbances in children with SNI and how it impacts pain prevalence; yet it may be an important consideration that may influence the risk of incidents that cause pain (Breau et al., 2004).

Epilepsy is considered a common co-morbidity in children with SNI (Rosenbaum et al., 2006; Donald et al., 2014). Of the six participant children with epilepsy (it was the primary diagnosis for two children); only four were on medication for this condition. Five of the children in this study had been classified on a GMFCS level 5, with limitations in their ability to move against gravity, meaning that they need help in head, trunk and limb control. They are dependent on their PCG for all aspects of their daily life, including self-care, feeding, toileting and weight-shifting to ensure comfort (Palisano et al., 2007). Two children, who were two years old, were on a GMFCS level 4. This would mean that they may have head control but still require trunk support when sitting. They may be able to roll, creep or crawl with help, but will be dependent on their PCG for all aspects of their daily life. They may help with some tasks, such as finger feeding, and play (Palisano et al., 2007). Two children aged three and nine years were on GMFCS level 3. The younger child was dependent on his PCG for all aspects of daily life except some finger-feeding and play while the older child may be able to assist with aspects of self-care such as washing or taking off clothes. He would still be reliant on the PCG for most of his transfers and mobility (Palisano et al., 2007).

5.3 Context and factors influencing the care of children with severe neurological impairment in a rural KwaZulu Natal setting

The first objective of the study was to describe the context and factors that impact the care and access to health care of a child with SNI in a rural KZN setting.

5.3.1 Environmental factors in which care of children with severe neurological impairment takes place

PCG participants expressed that they believed that lack of amenities in the low resource environment negatively affects their child's well-being, a finding that is reflected in similar results reported by Van Der Mark et al., (2019).

Only three participants had a toilet inside their house, and only two had their own outside toilet. This means that four of the participants' families must be sharing a communal toilet with other families nearby, or may not have access to a toilet in their vicinity. Lack of proper sanitation places the child and PCG at direct and indirect risk (Pretorius and Steadman, 2018). There will be an increased risk of waterborne illness, foodborne illness, and illness related to poor hand hygiene which may affect the child with SNI and make them more vulnerable (ACPF, 2011; Pearson et al., 2023).

Although all PCG participants indicated that they had access to electricity in their homes, only four had access to piped water in their homes, with the others using a community tap, a water tank, or river water. While this indicates that access to electricity is higher than the norm of 91.6% connected households in 2021 in the province, access to piped water is much poorer than the as expected at 88% (Department of Statistics South Africa, 2022, pp. 31, 42). This means that fetching water might add to the activities of a PCG – a task that is often physically straining (Geere, Hunter and Jagals, 2010). Research also indicates that water in rural areas such as the Ugu district posed a higher risk to its consumers. Additionally, the use of stored water can pose a risk of contamination and indigenous waterborne illnesses and parasites that may constitute a threat to the health of the child and PCG (Khabo-Mmekoa and Momba, 2019; Zulu *et al.*, 2020; Khabo-Mmekoa, Genthe, and Momba, 2022).

The average household size in the study was six people, which can be considered larger than the average household size for in KwaZulu Natal (Department of Statistics South Africa, 2022, p. 8). Not all of the children in the study had their own bed. This may be due to a lack of space for each member of the household to have their own bed, may be a cultural norm, or may be related to other aspects of daily life for children with SNI; more research is required. The effect of co-sleeping or sleeping on a non-bed surface needs to be considered, as only two of the participant children with SNI had their own bed. It was noted that the mean age of the children who did not have their own beds was young, just under five years and there is evidence that co-sleeping can be a valuable bonding and relaxing time for caregivers and their children (Caldwell *et al.*, 2020; Barry and McKenna, 2022). This might even result in the child finding it easier to fall asleep due to the calming and familiar presence of his mother (Adnams, 2010). However, the higher levels of GMFCS classification may be associated with tone changes and positioning, which have been linked to an increased likelihood of pain prevalence and intensity (Breau and Camfield, 2011; Eriksson, Hägglund, and Alriksson-Schmidt, 2020). This could mean that co-sleeping could affect the positioning of the child during sleep, which can influence sleep quality and pain in children with SNI, as well as co-sleeper quality of sleep and well-being. Co-sleeping may also result in daytime drowsiness in the PCG and the child (Volkovich *et al.*, 2015; Grandner *et al.*, 2020; Andre, Lovallo and Spencer, 2021). In PCGs, inadequate sleep may affect mental health and mood and in children with SNI this can be linked to irritability, which in may not be easily distinguished from behaviour indicating discomfort or pain (Jorm and Henderson, 1992; Neves *et al.*, 2018). These children may already be at risk for sleep disorders due to their disabilities (Novak et al., 2013, 2020; Letzkus, Frazier and Keim-malpass, 2021). Research shows that disordered sleep in a child with SNI can also have a negative impact on the child’s function, comfort, risk of injury and well-being (Adnams, 2010; Novak et al., 2013; Grandner et al., 2020; Novak et al., 2020; Andre, Lovallo and Spencer, 2021; Letzkus, Frazier and Keim-malpass, 2021) How the quality of sleep in PCG and the child with SNI might affect “pain” behaviours the PCG perceives requires more research.

The houses in this area are built in a rural context and the distance from the road might mean that PCGs have to walk between 10 and 60 minutes while carrying or pushing their child with SNI in a mobility device to access public transport. Inaccessibility of infrastructure such as roads also impaired the mobility of child-PCG dyads, since poorly maintained sand and gravel on roads restricted the use of the child’s mobility device. Other PCG participants mentioned weather conditions, such as rain, which made sand roads and pathways impassable, as a barrier to community mobility. These findings were supported by other research which investigated accessibility of rehabilitation services in rural areas of South Africa (ACPF, 2011; Pretorius and Steadman, 2018; Magaqa, Ariana and Polack, 2021).

These conditions may also contribute to the challenging level of physical and financial burden in accessing medical services for PCG of children with SNI. There is a lack of access to private- and public transport: usually minibus taxis might not go directly to the healthcare facility, and may not be affordable (Dassah et al., 2018; Pretorius and Steadman, 2018; Neely and Ponshunmugam, 2019). Often patients are able to reach the hospital, but transport back home might be more uncertain (Pearson et al., 2023). The work by Neely and Ponshunmugam (2019) aimed to identify barriers to access by examining the reasons why people would access healthcare outside of their catchment areas. This work brought to light that transport networks are often not aimed at ensuring access to healthcare – it develops around commerce. Of the nine PCG, only five were confident that they are able to pay (the taxi / bus fee) to take the child to the clinic at any time. Public transport is also known to be difficult to use for people with disabilities since taxi drivers are unwilling to load individuals with mobility devices or may require an additional fee for the device (ACPF, 2011; Dassah et al., 2018; Pretorius and Steadman, 2018; Magaqa, Ariana and Polack, 2021).

In the current study other socioenvironmental circumstances also influenced the PGCs in caring for their child and accessing health services. The first incident in 2020 was the shutdown of all non-essential health out-patient services due to the Covid-19 pandemic and the subsequent travel limitation (Siedner *et al.*, 2020; Pillay *et al.*, 2021; Uwishema *et al.*, 2022). In the hospital that the researcher is employed this included the shutdown of rehabilitation services for all out-patients and the group that served PCG and their children with any SNI. Similar situations have been documented in other healthcare facilities (Pillay et al., 2021; Uwishema et al., 2022). Due to the limitations to travel, shopping, and access to social structures that maintain food security; many people also suffered due to food shortages and poverty (Hart et al., 2022). After the end of the initial lockdown period, out-patient services were re-opened. Very few patients returned to rehabilitation. None of the children who had previously been part of the group returned, despite having received a telephonic invitation to return and a date of appointment. Similar observations have been made by (Brennan *et al.*, 2020; Siedner *et al.*, 2020; Akpinar, 2021; Ned, Mckinney, *et al.*, 2021; Ned, McKinney, *et al.*, 2021). Speculations as to the cause include that it could be related to the increased severity of the impact of poverty linked to the pandemic (Hart et al., 2022), or fear for the health of the child with SNI (Akpinar, 2021; Pillay *et al.*, 2021).

In July 2021, civil unrest erupted in South Africa, specifically in Gauteng and KwaZulu Natal (Makoni, 2021). This had a significant impact on all people living in the affected areas, including the Ugu district. Participant PCG and their children with SNI were affected by limitation of movement of civilians (civilian checkpoints were set up which included a brief search or interrogation of all vehicles entering and exiting the area). This was accompanied by an increased risk during the use of public and private transport, which may be linked to general lawlessness, intimidation, an increase in civilians carrying and displaying arms and other factors such as road obstructions as an attempt of self-defence (Mongale, 2022). Ultimately, the uncertainty and likely fear of the situation could also have been exacerbated by the previous experience of lockdown. Needless to say, there was a significant impact on the ability and safety of the research population to access healthcare facilities, and significant increases in other stressors (Makoni, 2021).

Another major event that predated the data collection phase of this research; was the flooding in KwaZulu Natal during April 2022. In addition to the widely reported loss of houses, roads, and bridges; the impact on backroads and less important structures, as well as the deterioration of infrastructure of transport and health, impacted the act of caregiving for PCG of children with SNI (Bouchard et al., 2022). This deterioration could have contributed to real difficulty in transport as well as an increased risk or perceived risk in travelling (for instance to health care facilities) (Naidoo, Manyangadze and Lokotola, 2022). Bouchard et al. (2022), reported that these natural disasters may also impact the psychological wellbeing of exposed people. Port Shepstone and the lower South Coast of KwaZulu Natal, had also been the site of taxi-conflicts, which had been intermittently flaring up between two taxi associations in the area over route disputes (Mzobe, 2023).

Dassah et al. (2018) indicate the interplay between availability, acceptability, geography and affordability determine the health care access of people with disabilities in rural areas. This is reflected in the problems mentioned by participant PCG 4, that certain aspects of caregiving are difficult or impossible in the rain. Rural district rehabilitation services have been found to have constrained capacity and resources which means that people with physical disabilities are further prevented from accessing rehabilitation. Magaqa, Ariana and Polack (2021), suggest that social development, transport and roads, as well as the health system collaborate to ease some of these barriers. This level of collaboration was not yet established in the Ugu district during the time of data collection, resulting in an enduring vulnerability to financial, health, and related harm to the study population.

5.3.2 Caregiving factors

Seven of the PCG participants also cared for other children, and two also had dependents that are older than 18 years old. This means that the PCG is responsible for more caregiving than that which this study assessed. This could mean that the PCG has less time available to engage with the child with SNI or observe subtle pain signals. It may also mean that occasionally, children may be held responsible for watching the child with SNI. This can be harmful to the development of children without SNI and dangerous to those with SNI (Mturi, 2012; Masiran *et al.*, 2023). Another effect of the added responsibilities of other children is increased financial strain (Feudtner *et al.*, 2021; Teicher *et al.*, 2022).

These responsibilities and strains may compound and may result in decreased wellbeing of the PCG. When any person has to spend the majority of their time in one occupation, they run the risk to have occupational imbalance (Wagman, Håkansson and Björklund, 2012). This occupational imbalance in the PCG may lead to burnout or other psychological or physical health problems (Feudtner *et al.*, 2021). Despite these risk factors, none of the participating PCG requested help or accepted a referral via the distress protocol.

This places more stressors in a system of PCG-child, caregiving occupation and environment that has less opportunity to relieve this stress. Ultimately this may result in worsening disease and disability, including unnecessary suffering (Pearlin *et al.*, 2016).

Four of the children who's PCG participated in the research, were of school going age. Only one of the children goes to "school" (Enkulu Creche). This means that 88.8% of school aged children in this study were denied their right to schooling either by circumstance or society. In KwaZulu Natal, about 90.1 % of children older than five were in school (Department of Statistics South Africa, 2022, p. 14). Therefore, research participants have a lower level of school attendance than the norm for the province. The lack of appropriate schools, preschools or care centres for children with disabilities in the area, as well as the lack of funds, and potentially a lack of trust in others' ability to care for the child with SNI may all play a role in this situation.

Magaqa, Ariana and Polack, (2021);as well as Louw *et al.*, (2023) report that rehabilitation services were not sufficiently accessible or available in rural South Africa. The ability to provide care, health care and rehabilitation to the children with SNI in the current study was limited by the environmental factors discussed above and the burden of care discussed below.

5.3.2.1 Burden of care

PCG indicated that caring for the child impacted engagement in all occupational performance they "can't do…" other tasks or activities because of the child, or because of their sadness about the child's condition. The PCG participants indicated that the greatest burdens to care were emotional, environmental, physical, and financial strain. Data were collected after the Covid-19 pandemic, the unrest of July 2021 and the floods of April 2022. All of these events may have affected the context in which the participants lived and their access to health care and services, and may have influenced their answers.

The emotional burden of caregiving was described as feelings of sadness, exclusion, and despair at the constant recurring of medical problems and the unanticipated level of severity of disability in their children. This finding reflects that of qualitative research in developed countries on parent's psychological experiences when caring for a child with life limiting or life threatening conditions (Bally *et al.*, 2018). Being exposed to this level of health-related uncertainty, as well as loss, grief and a lack of control on a daily basis may have adverse long-term consequences for the PCG, and may influence the PCG ability or capacity to engage in the unrelenting increased caregiving demands of living with a child with a disability like SNI (Pearlin *et al.*, 2016). Research by Van Der Mark *et al.* (2019) explored the daily lives of 30 mothers of children with disabilities in a poor urban area in South Africa, and found that the occupation of caregiving in the role of mother for a child with a disability affects the psychological and physical wellbeing of mothers both positively and negatively.

However, the majority of PCG participants were positive about their child's overall health, which could indicate that the well-being of most children with SNI is considered good by their PCG. This may indicate that having a child with a disability also has positive implications and connotations for the PCG. All of the participant PCG indicated that they were confident in their ability to advocate for their child and obtain help for the child when it is needed. They had also indicated that they have been successful in relieving pain in their child in the past. These successes and confidence could act as a mediating factor against the impact of the strains of caregiving – however, research is needed to determine if this is sufficient (Pearlin *et al.*, 2016). Some of the PCG participants in this study have expressed how grateful they are for their child with SNI. An example would be PCG 4, who said: "kwaba kuhlungu kakhulu ukube ubukulunkulu asipho umntena onjena simthanda kunabobonke abantwana" which can be translatedas: "It was very painful if God did not give us such a child, we love him more than all the children." Another PCG described her relationship with the child with SNI as "the most beautiful among us (ZU): "buhle kakhulu phakathi kwethu"

Of concern is that one PCG described the problem with the child as “not serious”, and yet she is of the opinion that her child: “…can’t do anything”. This may come across as contradictory and may indicate a lower level of health literacy or point to a state of ambivalence. This may be an area to explore further – the lived experience of the PCG of a child with SNI: on the one side hoping that there is not really anything wrong with the child and on the other hand, seeing daily that the child is not able to develop basic skills alongside his/her peers. These mixed responses may indicate some of the conflicting emotions that a PCG of a child with disabilities has to contend with on a daily basis (Bally et al., 2018; Feudtner et al., 2021). It may also be an indication of the complexity of understanding the caregiving experience for the PCG of a child with SNI (Lowes, Clark and Noritz, 2016).

Some of the participants stated that they feel sadness, wish things to be different, they worry about their children, they feel disillusioned (“I did not know he will end up with a disability” PCG 1), and they feel emotional pain. Two of the PCG had neutral or negative responses, one of which was about the child’s health, framed in terms of the child’s inability to perform activities. Even though her child is on a GMFCS level of four, he is only two years old where it could be considered appropriate for a child to still need his mother’s help in most of his areas of life. Healthcare workers, including occupational therapists should be aware and mindful of the PCG state of mind when providing intervention, as this will influence adherence and therefore the level of success that intervention can provide, as well as the overall wellbeing of the PCG-child dyad. Hopelessness related to the constant need for medical intervention or clinic visits was also a problem that some participant PCG mentioned (PCG 5 and PCG 6 stated that going to the clinic is a problem for them). The need to access medical services frequently was also identified as an additional burden on PCG in other African research (ACPF, 2011, p. 52; van der Mark *et al.*, 2019). Further research is required to determine why some PCG show elements of hope and others do not.

The socio-cultural environment described was linked to social shunning and lack of support – as was also reported in other research (Lowes, Clark and Noritz, 2016; Pretorius and Steadman, 2018). This lack of support and social shunning might be linked to the heavy emotional burden expressed by some of the PCG (Adnams, 2010; Carter et al., 2017). Van Der Mark *et al.*, (2019) found that the mothers of children with disabilities in their study led isolated lives. One of the mothers in the current study specifically mentioned social exclusion due to the stigma that her child's disability is linked to a curse, a finding that is also prevalent in other African countries. The literature reports incidences of PCG being chased away from the family home due to having a child with a disability (ACPF, 2011; Pretorius and Steadman, 2018). One participant, PCG 3 mentioned that people look at her as if she had sinned (Donald *et al.*, 2014; Nortjé and Albertyn, 2015; Wegner and Rhoda, 2015; Pretorius and Steadman, 2018). The current study did not ask about displacement related to child disability – and further research is required in this population to provide adequate support.

This isolation adds to the emotional burden by limiting respite from caregiving duties, and denying an important mediator of stress – social support. Research had found that some of the PCG of children with SNI in South Africa's rural and urban resource poor environments are also burdened by uncaring attitudes and disrespectful behaviour by medical personnel when they do reach out for help (Saloojee, Rosenbaum and Stewart, 2011, p. 37). A systematic review and meta-analysis on the efficacy of interventions aimed at the PCG of children with CP found similar and other burdens that affect PCG of children with SNI (Irwin, Jesmont and Basu, 2019; Feudtner et al., 2021).

PCG often struggle with grief and/or chronic-sorrow or long-term sadness, which can affect their physical wellbeing (Irwin, Jesmont and Basu, 2019; Feudtner et al., 2021). Research done on PCG of children with CP in Canada (Ontario), reported no less social support than PCG of the general population (Brehaut et al., 2004). In fact, these PCG reported statistically significant more support contacts and equal support in parenting; however, their psychological and physical health was still poorer than that of PCG in the general population. This might indicate that social support alone is not enough to mitigate the effect of the strain of having a child with a disability, PCG should be aware of their own health due to the physical toll caregiving a child with SNI can take (Brehaut et al., 2004).

Caring for a child with complex medical needs can have a negative impact on the caregiver's physical well-being (Mann et al., 2019; Munambah, 2020; Feudtner et al., 2021). The PCG would be responsible for most to all caregiving needs with minimal to no assistance from the child with SNI. The level of musculoskeletal strain a PCG experiences during caregiving may be influenced by a combination of factors; however research by Woolf and Pfleger, 2003; Morris et al. (2018) found that heavy work, lifting, bending, pulling and pushing actions may play a role in the prevalence of lower back pain. They also found that age and female gender were more prevalent risk factors for bone loss leading to fractures and hip and knee osteoarthritis (Woolf and Pfleger, 2003). The majority of the participant PCG in this study are female, and are over the age of 40 years, placing them in the higher risk group for conditions.

A third of the participant PCG also mentioned physical strain on themselves during daily care activities such as washing or dressing the child. Lifting the child was also identified as a physical burden, with one caregiver framing the problem that all the other PCG's either will encounter or have considered as: "she is growing up and getting bigger". Currently the average age of the children in this study is 7.1 years old, with the oldest one being 17 years old. Even if the child with SNI is still physically small, it is expected that the children will grow over time. Other specific medical burdens were that two of the children have difficulty with feeding (one requiring a skin level PEG, and with a history of having had surgery for hernia repair as well as chronic reflux).

The ergonomic setup that a child with SNI is in can also affect the PCG risk of injury. As only two of the children with SNI in this study have their own beds, the surface on which many of the caregiving actions take place may require more assessment, as this may contribute to physical strain on the PCG, as well as increase the risk of injury to the child with SNI. This could cumulatively cause significant strain on the physical wellbeing of the PCG which is supported by a study conducted in Kilifi; Kenya; where they found that caregivers of children with SNI may have more complex physical healthcare needs than anticipated. The Kilifi study suggested that overall health status monitoring should be provided for these PCG(Geere et al., 2013).

It appears that the main PCG stressors might differ based on the child's context, but in a North American study, reported PCG stresses were also linked to the presence of pain in the child and the financial impact of having a child with a disability (Lowes, Clark and Noritz, 2016). Financial stressors are common in families, as in the current study, who are caring for a child with a disability (Geere *et al.*, 2013; Mitra, Posarac and Vick, 2013; Dassah *et al.*, 2018; Durkin and Yeargin-Allsopp, 2018; Pretorius and

Steadman, 2018; van der Mark *et al.*, 2019; Magaqa, Ariana and Polack, 2021; McKinney, McKinney and Swartz, 2021). Costs related to medical care and transport were identified as significant barriers to seeking healthcare, particularly for people living in rural areas (Donald et al., 2014). Some PCG participants felt that they did not have the means to provide a proper, comfortable shelter for the child. One of the PCG wished for money to build a proper house with water and toilet inside: "so that he can live a better life", referring to her child with SNI (The Office of Deputy President, 1997; ACPF, 2011; Freeman, 2018). An added financial burden indicated by three participant PCG was that their children continued to rely on nappies which may add a substantial financial burden.

5.4 Recognition of pain in non- verbal children with severe neurological impairment

Objective 2 of the study was to determine measures used by PCG to identify signs and symptoms of pain in their child with SNI.

All of the PCG indicated that they were able to describe how they knew and how they would gather more information to identify when their child was in pain and identified and related some of the behaviours or actions provided in the pain questionnaire, to potentially indicating pain. This is an anticipated result based on what literature had found in other cultures and health care systems (Solodiuk, 2013; Raiter et al., 2021). The data that this study found on the methods that the PCG use to determine their child's level of pain is similar to that reported in other research (Raiter *et al.*, 2021) even though most of the research was carried out in high income countries with better access to more advanced technology related to pain assessment (Hunt et al., 2007; Symons et al., 2015; Hauer and Houtrow, 2017; Barney et al., 2020; Dreier et al., 2022). The results indicate that even though some participating PCG with potentially low levels of health literacy and low levels of access to health care, rehabilitation or technology; they were able to create individualised action plans for determining when they perceive that their child is in pain.

All nine of the participant PCG reported that they relied on crying to indicate the presence of pain which can be assumed to be the most culturally appropriate way of indicating pain or proving the presence of pain in another person such as a child. The PCG was also able to determine a suspected level of pain from either the amount of time the child had spent crying (which may be interpreted as “consolability”) and the intensity of the crying, however – their accuracy for the suspected level of pain intensity was not verifiable due to the nature of the study. No note was made of the pitch or tone of crying, but 88.8% of the participating PCG also indicated that they considered other sounds their child is making in the process of distinguishing if the child has pain. It is important to note that even the PCG who stated that her child does not communicate to her at all, was able to identify specific pain behaviours in her child, such as crying, laughing, being disinterested or needing more than usual PCG attention, slight skin colour changes, changes in muscle tone (such as stiffening during certain caregiving activities such as a nappy change), guarding a body part, eating or sleeping more than usual.

Two participant PCG relied on the child’s gestures and facial expressions to determine what is being communicated. Some of the participant PCG were able to recognise and relate back to potential pain, some very subtle behavioural changes in their children with SNI such as oppositional- or comfort seeking behaviour, or a bad mood. These behaviours are in line with what we know about pain expression in non-verbal children with SNI as mentioned in Hauer and Houtrow (2017). A weakness of the questionnaire was that it did not require the participant PCG to indicate which specific actions or behaviours indicated a bad mood in their child. Very few PCG interpreted parasympathetic signs and motor behaviour as indicating the presence of pain, and those that did also relied on the presence of crying in addition to the parasympathetic signs (examples of these parasympathetic signs would be sweating, breath-holding, shivering, changes of skin colour, tears or tachycardia) (Hauer and Houtrow, 2017). Two of participant PCG mentioned sneezing or drooling were present. Motor behaviour or actions such as “clenching hands” and “clenching jaws” or “stiffening” were used by up to five of PCG to know when to suspect pain. One PCG (PCG3) considers her child’s willingness and ability to eat food as an additional indicator of the presence of pain. None of the participating PCG indicated that their child had signs such as increased sweating or breath-holding. This may be influenced by the humid and warm climate, where sweating is not too unusual, and therefore does not stand out as a potential indicator of pain. The absence of breath-holding and sweating as an indicator of pain might also be linked to the severity or chronicity of pain.

The PCG of children with SNI have lived the experience of being constantly vigilant and attentive about their children, and are frequently required to learn to make decisions since they know and understand their children better than any professional, and therefore felt the need to constantly advocate for their children (Bogetz *et al.*, 2021). These actions may be supported by skills which have developed during caregiving, which can be learned and practiced, and therefore improved. This might serve as support for the finding that the participant PCG with more experience in caregiving, generally have more skills. Work in Uganda by Bambi et al (2021) found similar results when the association between identifying pain in a child with SNI and the extent of caregiving in the numbers of years the PCG has cared for the child was determined. A strong association was found with the years that the participant PCG had spent with the child and a small number of different signals on the pain questionnaire they selected as indicating pain in their child. This may translate to the ability to be more specific about the behaviours that indicate pain, (fewer behaviours needed before the presence of pain is suspected) or to other factors, such as personal or cultural views on pain as well as the chronicity of pain (Hauer and Houtrow, 2017; Bambi *et al.*, 2021; Raiter *et al.*, 2021). Only a weak correlation was found against hours spent caregiving per day and the number of signs PCG use to identify pain, it may suggest that the PCG that have spent more years with their child, know their child's pain behaviours better and can identify when the child is in pain more confidently. This finding reflects that of Bambi et al (2021).

Only three (n = 3) of the participant PCG indicated the area of suspected pain on the pain map. The reason for this is not clear, and the PCGs were not specifically asked about this. The participant PCGs who used the pain map, indicated the abdominal area generally, the hips and pelvis and the toes since this child tends to get cramps in his feet, but also gets pain in his joints such as the hips and knees.

The participant PCG did not all use the Visual Analogue Scale (VAS) at the end of the questionnaire. Of those who did use it, six indicated their child had no pain in the past seven days and one participant indicated a score of 1. The researcher thus believes that the pain questionnaire did not lead the PCG into over-reporting the level of pain in their child even though the questionnaire provided no decoy options (in terms of pain severity). It is clear that although participant PCG could identify when their child is in pain, to identifying the intensity and site of the pain in the format that this research took; may be difficult. Also, measuring pain levels accurately is further complicated by the dynamic nature of the child and the PCG’s health, levels of fatigue and other contextual factors during the past seven days. This may lead to results that appear that the pain was not intense or may have been chronic due to positioning and cramps, which may not be reflective of the child’s reality. More research on this topic is required (Hauer, 2018, pp. 899–900).

5.5 Measures used by participants to alleviate pain in non-verbal children with severe neurological impairment

The third objective of the study was to determine the actions or methods PCG use to address pain and if these actions or methods are perceived as effective in alleviating the pain in the home setting.

All participant PCG saw the signs of pain in their child as a first step toward a process of further search for causes and using different forms of non-analgesic pain management options and comforting, and all but one will use analgesia at some point in this process. Recent research on the topic found that PCG would interchange or combine pharmacological and non-pharmacological strategies to address pain caused by different sources (Raiter *et al.*, 2021).

Work by Warlow and Hain (2018) indicates that PCG also value a more comprehensive approach as effective. Focus on pain linked to an identifiable cause can assist in finding pain management strategies, but should not come at the cost of ignoring chronic or more long-term pain and its management. Addressing pain, whether it is acute or chronic pain; can be done through the use of pharmacological and non-pharmacological strategies (Warlow and Hain, 2018). The non-pharmacological strategies can include sensory calming input: “…swaddling, rocking, repositioning and massage.” Occupational therapists, physiotherapists and orthotists may assist in treating musculoskeletal pain in children by teaching new PCG these techniques to help their children more holistically (World Health Organization (WHO)., 2012; Novak *et al.*, 2013; Hauer and Houtrow, 2017).

Some PCG indicated that they used warm baths to address pain non-pharmacologically. This is not a viable option for most patients, either due to not having a bathroom in the house or due to not having tap water in the house. Considerable effort would be required to fetch water, heat it up and then lift the child manually into the water, to use the bath. This may also take a significant amount of time, and may place unnecessary strain on the PCG and the child; who may face a delay in pain relief. Other non-pharmacological pain-relief strategies that might still be available to these PCG are: swaddling and rocking, repositioning and massage (often done instinctively). Very few of these instinctive actions were expressed during data collection, but have been observed during rehabilitation sessions, and therapists are experienced and well positioned to teach these strategies to new PCG, or PCG with a child who has been newly diagnosed with SNI. Therapists are also in a good position to help PCG translate their instinctive soothing actions into a more quantifiable format when reporting on a child's pain to other health care providers or when monitoring the child's pain.

In rural KwaZulu Natal, PCG also indicated the possibility of insect bites causing the child's pain or discomfort. One PCG described using "rubbing stuff" from the clinic (often known as Rub-rub) for pain relief.

Research by Warlow and Hain (2018) also identified swaddling, rocking, repositioning and massage as options – none of these barring "rubbing" (massage) were indicated by the PCG as useful. Audio-therapy, acupuncture, aromatherapy, vibratory therapy and weighted blanket were not mentioned, and are not available to the majority of the population, as these are not available under public-health care services currently. One of the PCG mentioned that she will rely on therapy (occupational- and physiotherapy) in conjunction with medication to assist in terms of pain management / prevention (PCG 9). This PCG mentioned stretching the child for pain relief (this can be seen as a non-pharmacological strategy to temporarily lessen the effects of spasticity) but did not elaborate on how she anticipated this to assist.

All PCG expressed confidence in their ability to address pain, or obtain help for their child if it is needed. This is supported by their belief that their actions to address past pain had been successful. Again, the PCG had subtle and individualised ways of "knowing" that their attempts at pain management for their child were successful. In the current study it was not possible to determine at what point the PCG would divert to using analgesia. More research is needed on this topic, as well as the availability and perceptions of PCG about the availability of pharmacological pain management options in a rural setting. The details might differ for the type of pain suspected (whether it is suspected that the pain is linked to a specific position the child is in or the transfer between positions). Some professionals working with children similar to the population of this study also found that communication and oral care can be painful for some children (Oberlander and O'Donnell, 2001; Siden, Carleton and Oberlander, 2013).

The PCG usually has the responsibility to judge the severity of the pain in addition to attempting to distinguish the cause and possible method of alleviation. When using analgesia most PCG know and use over the counter paracetamol while one participant used an antihistamine which may result in insufficiently managed pain. If the child appeared to be in severe acute pain some of the PCG did know that there is help in the form of "injections" at the clinic.

Occupational therapists can play a facilitatory role for knowledge and skill transfer between PCG of children with SNI about pain assessment and management at home. Non-pharmacological strategies which may include distraction, some form of massage or soothing actions such as alternative and safe ways of using warmth, as well as preventative handling and positioning, or structuring a care plan to decrease potentially painful care-tasks can be constructed and practiced with the PCGs. Other less direct strategies may include teaching the PCG's effective advocacy strategies (knowledge of how to keep track or and quantify their child's pain, and of their and their child's rights). All rehabilitation professionals may also assist in referring the child or PCG to appropriate care if needed. Occupational therapists can also assist PCG to learn about and maintain their own health and their child with SNI's health, and how to advocate for their own as well as their child with SNI's health (American Journal of Occupational Therapy, 2020). This research provides a starting point for further research to enhance knowledge on how to support similar vulnerable PCG and their children with SNI proactively, and to minimise the severity and prevalence of pain in a more rural South African setting.

Chapter 6: Conclusion

6.1 Introduction

This chapter contains a summary and conclusions of the research, as well as a description of the weaknesses and limitations of this study, and recommendations for practice.

6.2 Summary of the main findings

Severe neurological impairments (SNI) as defined by Allen et al. (2020) to describe children with significant disorders affecting the neurological system, who are cognitively impaired, non-verbal, and reliant on others for mobility was found to be a suitable term for use in the rural health context (for this study, where a clear diagnosis is not easily available). These impairments are associated with more risk factors causing pain, with a direct correlation for a greater severity of pain. This appears to be linked to more frequent episodes of pain, greater exposure to painful stimuli and a heightened experience of the severity of the pain (Breau, Camfield, Mcgrath, *et al.*, 2003).

This study addressed the context and factors influencing the care of and access to health care for a child with SNI in a rural KZN setting and determine measures used by PCGs to identify signs and symptoms of pain and actions used to address pain in a child with SNI.

Factors that affect the care of the child with SNI in the rural context included limited access to water within the home, potentially placing the PCG and the child at increased risk of unsafe water and extra physical strain related to water carrying (Geere, Hunter and Jagals, 2010; Geere *et al.*, 2013; Khabo-Mmekoa and Momba, 2019; Khabo-Mmekoa, Genthe and Momba, 2022). Sleep arrangements with the lack of a separate bed for the child with SNI was an unexpected finding in this study. This could impact the PCG-child dyads who co-sleep and could potentially impact pain presence (Volkovich *et al.*, 2015; Caldwell *et al.*, 2020; Andre, Lovallo and Spencer, 2021).

The PGCs responsibilities in the home, having to care for other children and the financial implications due to not receiving a social grant or being unable to work due to need to care for the child with SNI full time, also added to the burden of care in this context. This study found that PCG felt that the lack of amenities increased this burden and negatively affected their child’s well-being. Infrastructure weaknesses such as gravel roads, and greater distances of PCG homes from the road, as well as weather conditions such as rain limited the mobility of the PCG-child dyad’s in their communities.

A minority of the participant PCG had a negative or neutral response to questions about their child’s overall health but reported that the emotional burden related caregiving was linked to the negative emotions regarding their child’s health. This was due to the PCG experiences about the severity of their child’s disability and frequent medical needs, as well as some level of exclusion or lack of support from their communities or support systems. This emotional burden was somewhat counterbalanced by positive emotions related to their special relationship with their child. The physical strain of caregiving as the children grew may make it harder to handle the child physically during caregiving, and was a concern for many PCG since they had little assistance. Most PCG cared for their child 24 hours a day.

When determining how PGCs identified when their child is in pain, it was found that all were able to do so, and were able to express how they know. They had unique ways of assessing pain, but all considered the duration and intensity of crying as a sign of pain in their child. Some PCGs would consider other sounds the child makes, as well as affective or emotive expression in their child, to indicate possible pain. They also related comfort-seeking behaviour in their children, as well as specific individualised motor behaviour of their child to potential pain. Parasympathetic signs were used by only two PCG but sweating or holding breath were not reported or related to pain in this study. Only one PCG considered the potential presence of pain if her child refused or was unable to eat food. There was a negative association between the number of items on the pain questionnaire reported as indicating pain and the number of years the PCG had been caring for the child. This may indicate that the more experienced PCG needs less variety or can rely on a smaller repertoire of signs to know when to suspect pain.

When determining the actions or methods PCG use to address pain in children with SNI, the study found that most were able to manage pain and had a successful history of having managed pain in the past. They had subtle ways to know when their pain management attempts were successful. Some mentioned that the child will stop crying or start “playing” a little, when their pain is alleviated.

Almost half of the PCG indicated that they attempt non-pharmacological pain care before using medication. Some PCG had limited access to some forms of non-analgesic pain care, such as bathing. Other measures mentioned included massage (rubbing), stretching, repositioning and soothing the child. One PCG also mentioned that she will search for insect bites on her child when she suspects pain.

These actions or methods are perceived as effective in alleviating the pain in the home setting but if not, most PCG were willing to use paracetamol as an analgesic. Although 77.8% of the participant PCG had functional literacy levels (STATS-SA, 2023), one PCG displayed concerning understanding of appropriate pain management when using medication intended for other conditions than pain with their child, and it is possible that there are more PCG who have limited knowledge about the appropriate pharmacological intervention for their child’s pain. This matter will need further research.

It was not clear at which point the PCG makes the decision to use analgesia. Some PCG mentioned that they will take the child for an injection in the clinic to manage pain if it is too severe; however, access to health care services was limited by infrastructure and resources. Only two PCG were confident that they could afford to take the child to a health facility at any time, since they had access to private transport. All PCG were confident that healthcare workers are willing and able to help them and believe them about their child’s level of pain.

The PCG all indicated that they had been successful in managing their child’s pain in the past. These successes and subsequent confidence in their abilities may act as a barrier or buffer to the stresses caused by caregiving in the presence of SNI. More research is required to determine how occupational therapists can assist in building up the confidence and skill in PGC advocacy and caregiving in rural communities or places with lower levels of health literacy and access. The recognition of more subtle pain signals, as well as appropriate pain prevention strategies can be taught along with ensuring that PCG themselves can balance out the stresses of caregiving to allow for PCG wellbeing despite the potential significant strain of caregiving, especially in a rural or resource constrained environment.

6.3 Limitations of the study

A limitation of the current study is that it specifically included PCG and children with SNI who had accessed the hospital. This may have introduced bias and increased the likelihood that only those with access to services were sampled (ACPF, 2011). The difference between chronic and acute pain was not considered a separate event that should be investigated, as it may not be indicated by a clear start and end of a sign of pain such as crying.

Not all PCG participants were dependent on public health care at all times. Two children with SNI had received private physiotherapy and other health care services – including orthotic devices and surgery. The two participant-PCG were employed at PSRH, may have had better access to healthcare and may have been less affected by resource limitations usually seen in the more rural areas. The study did not follow up and investigate the appropriateness of medication being administered to the children with SNI. The fact that this question was answered by PCG accessing healthcare facilities and asked by healthcare workers may have influenced the responses of the PCG. Recruiting participants from the community or potentially from traditional medicine practitioners etc. may result in a more varied finding in terms of PCG beliefs about healthcare providers.

6.4 Recommendations

Pain should be considered as seriously as items related to body-structure and function when assessing a child with SNI. More emphasis should be placed on the environment and socio-cultural impact of pain and vice versa in the child and PCG. This is especially relevant to consider in South African clinical practice.

This information regarding the factors found to impact pain and pain assessment practices, as well as information on how to improve assessment and management practice for pain, should routinely be shared with the PCG as an equal stakeholder in the wellbeing of the child. Other PCG strategies to assess and manage pain in their children can be shared with PCG of newly diagnosed or very young children with SNI.

The occupational therapist should consider the child and PCG as a dyad and work to optimise the health and wellbeing of both the child and PCG. The occupational therapist and PCG can develop a pain plan as well as a pain diary, to optimise the

PCG ability to advocate for their child, or to respond in the presence of pain. The occupational therapist can assist the PCG to incorporate pain management or preventative practices into the daily care routine (such as gentle stretching while getting dressed or elements of pain relief massage during bath-time). The occupational therapist should also consider pain management and prevention in all activities and especially seating and resting arrangements, whether it is in a formal adapted wheelchair or in more rural houses.

It can be seen as an omission of this study that more attention was not paid to the physical or psychological wellbeing of the PCG. In future research that looks at aspects of caregiving, specific questions related to musculoskeletal pain, as well as specific and prevalent chronic health conditions in PCG should be included. The needs and stresses of the PCG should be anticipated and specifically investigated in order to optimise the wellbeing of the PCG-child dyad. Examples of aspects of the PCG needs that the occupational therapist can address would be: assisting the PCG to adopt back-protection strategies during caregiving activities, planning caregiving activities to allow time for self-care, building up resources in communities to allow for occasional respite care etc.

More information about pain prevalence, experience and the emotional aspects of pain distress and how it is impacted by co-sleeping between PCG and child dyads is needed. This is an area that may prove potentially impactful for PCG and their children with SNI in more rural areas of South Africa. Current research found that most of the participant PCG think their child generally has good well-being, but more research is needed to find out how some PCG come to this conclusion in different contexts, what influences their perception of their child’s well-being, and how health care workers can help ensure better well-being for both the child and the PCG.

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APPENDICES

*These appendixes use the term “non-communicating” to indicate “non-verbal” as these documents were used in this format before the differentiation between the terms was made as is seen in the corrected final research report.

Appendix A

Ikhasi labantu / Demographic sheet

Ucwaningo olubheka ukuthi abazali noma abantu abanakekela abantwana abaphila nokukhubazeka ngokobuchopho futhi behlala ezindaweni zasemaphandleni KwaZulu Natal, bababona kanjani abantwana babo ukuthi bezwa ubuhlungu ngenxa yokhuthi abakwazi ukuzikhulumela.

An investigation into primary caregiver’s recognition of pain in non-communicating children with severe neurological impairment in rural KwaZulu Natal.

Ithathelwe kwikhasi labantu ku-Malamulele Onward. /Adapted from Malamulele Onward demo sheet.

Igama lomntwana / Name of child: ______________________________

Usuku / Date: ______________________

Iminyaku yomntwana / Child’s Age:		**Ubulili / Gender:**	**M/F**	**Isifo / Diagnosis:**	
GMFCS score: (khetha okukodwa) (choose one)	1: Uyakwazi ukuhamba / ukugxuma / ukugibela izitebhisi eyedwa. Child can walk / jump / climb steps alone. 2: Uyakwazi ukuhamba / agibele izitebhisi ebambelele ngento.		CFCS Score: (khetha okukodwa) (choose one)	1: Ngabe umntwana uyakwazi ukuthola futhi athumele umbiko ngokuxhumana nabantu abaziyo nangabazi. Child can receive or send a message or communicate with people he/she knows or don’t know.	

	Child can walk / climb steps leaning on something. 3: Uyakwazi ukuhamba esebenzisa izinsiza kusebenza / nomu isihlalo esinamasondo. Child can walk using walking aids or a move with a wheelchair. 4: Uyakwazi ukushishiliza noma azihudule phansi. Child can drag him/herself. 5: Akakwazi ukushishiliza phansi noma azigingqe. Child cannot drag him/herself or roll over independently.		2: Ngabe uyakwazi kodwa kancane uthola futhi athumele umbiko nokuxhumana nabantu abaziyo nangabazi. Child can receive or send a little bit of a message or communicate with people he/she knows. 3: Ngabe uyakwazi ukuxhumana ngokuphelele nabantu abaziyo. Child can only be understood by people he/she knows. 4: Ngabe akusona sonke isikhathi lapho akwazi ukuxhumana nabantu abaziyo. Child can only sometimes be understood by people he/she knows. 5: Umntwana akakwazi futhi akazami ukuxhumana Child does not communicate or try communicating.
Uhamba kanjani? How is he/she walking?		Uxhumana kanjani nawe? How is he/she communicating with you?	
Ezinye izifo / izinkinga: Other Diseases / problems:	Ngabe umntwana uyabona? Can the child see?	Yebo Yes	Cha No
	Ngabe umntwana uyezwa kahle? Can the child hear properly?	Yebo Yes	Cha No
	Isifo sokuwa (Isithuthwane) Fits / Epilepsy	Yebo Yes	Cha No

	Ezinye izifo? Other Diseases?				
	Okunye? Other?				
Usuku lokuzalwa: Date of Birth:		Indawo lapho azalelwa khona: Place of birth?			
Usuku lapho odokotela bakwazisa ngesifo somntwana ngokupheleleyo: Date when the doctors told you about the child's condition?		Ngabe untwana uyafunda isikole? Does he/she go to school?	Yebo Yes	Cha No	Igama lesilkole? The name of the school?
Ulimi lwasekhaya lomzali: Home language parent:		Ulimi lwesibili lomzali: Second language parent:		Ubuhlanga bomzali: Race parent:	
Ulimi lwasekhaya lomntwana: Home language child:		Ulimi lwesibili lomntwana: Second language child:		Ubuhlanga bomntwana: Race of child:	
Ngabe umntwana uyayithola imali yesibonelelo? Is the child receiving any grant?	Yebo / Cha Yes / No	Hlobo luni? What kind?		Inkolo yakho noma isiko lakho (mzali)? What is your religion and tradition?	
Ngabe umzali uyasebenza? Is the parent / caregiver working?	Yebo / Cha Yes / No				

Umlando ngobuhlungu: History of pain:				
Imithi / amayeza: Medication:				
Umtholampilo oseduze, nendlela okuhanjwa ngayo kwezokuthutha: (taxi/bus/private) Closest clinic that the child uses and transport used:				
Ikheli eligcwele: Full Address:				
Ukhona ugesi ekahya? Electricity in the house:	Yebo Yes	Cha No	Uma kungu-cha - chaza? If no – explain?	
Amanzi akhona endlini: Tap water in the house:	Yebo Yes	Cha No	Uma kungu-cha - chaza? If no – explain?	
Indlu yangasese Ikhona na endlini? Is there a bathroom or toilet in the house?	Yebo Yes	Cha No	Uyisebenzisa kanjani umntwana? How does the child use it?	☐ Akadingi usizo No help needed ☐ Udinga usizo Needs a little help ☐ Uludinga kakhulu usizo Needs a lot of help ☐ Udinga usizo ngakho konke Needs help for everything
Bangaki abantu enihlala nabo endlini?		Ngabe umtwana unawo umbhede wakhe?	Yebo Yes	Cha No

How many people are residing in the house?		Does the child have his/her own bed?		
Iqhele kangakanani indlu emgaqeni wetiyela: Is the house far from the tar road:	Yebo Yes	Cha No	Kangakanani? How far?	Ngabe unayo imoto yakho noma eyasekhaya? Do you or the family in your house own a car?

Igama lomzali noma umuntu onakekela umtwana? ________________________________

Name of the parent or guardian looking after the child?

Iminyaka yomzali: Caregiver's age:		Ubulili bomzali: Caregiver's gender:		Ubudlelwane nomtwana: Relationship of the caregiver to child:	
Isikhathi esingakanani osichitha nomntwana ngosuku? How much time do you spend with the child each day?		Sekuyisikhathi esingakanani unakekela umntwana? For how long have you been looking after the child?		Ngabe uyazi kwenzakalani ngomntwana? Do you know what is happening with the child?	
Ibanga lemfundo? Your educational level?					
Sinjani isimo sezempilo? How is your health?					
Yiziphi izinkinga obhekene nazo ngokunakekela umntwana? What problems are you facing in taking care of the child?					

Bangaki abanye abakusiza ukunakekela umntwana? How many people are helping you look after the child?		Bangaki abantwana abangaphansi kweminyaka engu – 18? How many children under 18 are you looking after?		Obanye abantu obanakekelayo? Any other people you are looking after?	

Appendix B

Izingane Zase maphandleni eziphila nokuKhubazeku / okugula isifo esiphazamisa ubu chopho eNingiZimu Africa: Ubuhlungu Checklist

Non-communicating child with Severe Neurological Impairment Pain Checklist (Rural)

Usuku: **Date:**		**Isikhathi (sokuqala): Time (start):**	
Umongo: **Context:**	☐ Ekhaya / Home ☐ Umtholampilo / Clinic ☐ Esibhedlela (isiguli esingaphandle) / Hospital (out- patient) ☐ Esibhedlela (isiguli eslalisiwe) / Hospital (admitted) ☐ Isikole (Inkulisa) / School (Crèche) ☐ Okunye (chaza) / Other (specify):		

Appendix C

Data analysis

A score of 0 is given for a score of 1 & 2

A score of 1 is given for a score of 3 or 4

Non-Communicative Child with Severe Neurological Impairment Pain Checklist –South Africa: Rural KwaZulu Natal

Please mark the score you observed in the child:

Gauteng: Amount of options needs some revision, Asking parents to report these may be unclear / doubtful / not simple

Gauteng (Limpopo and Kzn experience)

Gauteng: Almost everything was 100% and zero comments

Eastern Cape: question about questionnaire for rural or rural and townships, Asking parents to report issues related to pain may need revision, and the defined time period needs revision.

Gauteng: Pain is often underestimated in this population. Pain management options and guidelines are hard to find and pain is very poorly managed. Older children and young adults are more likely to experience pain and getting them to a hospital or clinic is expensive and difficult.

Amount of options needs some revision and is doubtful and not simple, amount of days needs some revision, simplify wording and language. Use words that would make sense to parents. relook at my items included – may have missed out on some items IE grimacing, moaning or movement / body becomes stiffer when changing nappy

Gauteng: Add a body figure for a child to point / confirm with head that it is in a specific location. Ask how much hurt there is (thermometer scale / robot colours / combined faces pain scale) Tell me more about your hurt? Self-report is golden and then by-proxy. use communications-board. Ask the parents: Does the child choose not to move in an attempt to prevent feeling pain in a specific area? How do you know that your child is in pain? Find out about “easy English” and how to put these questions in the simplest way. Use question marks. Needs revision: asking parents, and based on the past 7 days and number of options to choose from.

Ask the questions in a simpler way. Do not include 2 options in one sentence. IE Is your child sleeping more than he/she used to?

Is it difficult for your child to fall asleep?

Does your child wake up in the night, more than he/she used to ?

Simplify the term of Self Harming

Do not use “normal”, say more than he/she used to

0 = Not present at all (in the past seven days).

1 = A little bit present / I think I have seen it once or twice this past seven days.

2 = Present / I see it every day

3 = Present / I see it more than often, several times a day, several days a week

4 = Not applicable / My child cannot do this.

TODAY My child will:	0	1	2	3	4
Making sounds: Crying / Screaming / Moaning 1x Needs revision					
Making sounds: Laughing / Other 1 x Needs revision 1x Needs revision					
Social: Not interested in anything, Not cooperating 1 x Needs revision 1x Not relevant, needs revision 1x Needs revision 1 x Needs revision					
Social: Seeking comfort / “needy” / “moody” 1x Needs revision 1 x Needs revision					
Social: “silly” / “giddy” / “out of control” 1 x Not relevant, unclear, needs revision 1x Not relevant, needs revision					

1x Needs revision, doubtful, not simple 1 x Needs revision					
Facial: “upset face” / “unhappy” face 1x Needs revision					
Facial: Clenching / wide, tight smile not indicating happiness / grinding teeth 1x Needs revision, not simple 1 x Needs revision					
Activity: Moving less than normal / extra floppy or tight 1x Needs revision 1 x Needs revision					
Activity: Moving more than normal / twisting or posturing more pronounced Examples of posturing needed for clarity, needs revision 1x Not relevant, needs revision 1x Needs some revision of the word posturing 1x Needs revision 1 x Needs revision					
Body and limbs: Protecting / favouring / guarding body part / moving body in a specific way that indicates pain (repetitive or pronounced movements) 1x Needs some revision 1x Needs revision 1 x Needs revision					
Body and limbs: Self harming / hitting, biting, scratching (repetitive, deliberate) 1 x Needs revision, unclear, 1x Not relevant, needs revision 1x Needs some revision 1x Needs revision 1 x Needs revision					
Eating: less / refusing food / vomiting food Needs revision – some parents might not understand how vomiting relates to pain 1x Needs revision					

1 x Needs revision					
Eating: seeking constant comfort food or sweets 1 x Needs some revision, unclear 1x Not relevant, needs revision 1x Needs revision 1 x Needs revision					
Sleeping: more / less than normal / more tired than usual despite usual sleep 1 x Relevant but some parents have no idea 1x Not relevant, needs revision 1x Needs revision 1 x Needs revision					
Sleeping: struggle to fall or stay asleep 1x Needs revision 1 x Needs revision					
Action: How did I try to help make this less, and what helped in the past? 1x Needs revision 1 x Needs revision					
What will I do about pain now: Not relevant, doubtful question 1 x Needs revision					
Plan for the next 24 hours: 1 x Needs revision					
Plan for longer term: Rating scale may be difficult for caregivers to complete, as it is a subjective experience. Consider yes/no options. Questions need simplification, Speak to a focus group of caregivers to ask them how they recognize that their child is in pain and use this to guide my questions. 1 x Needs revision					

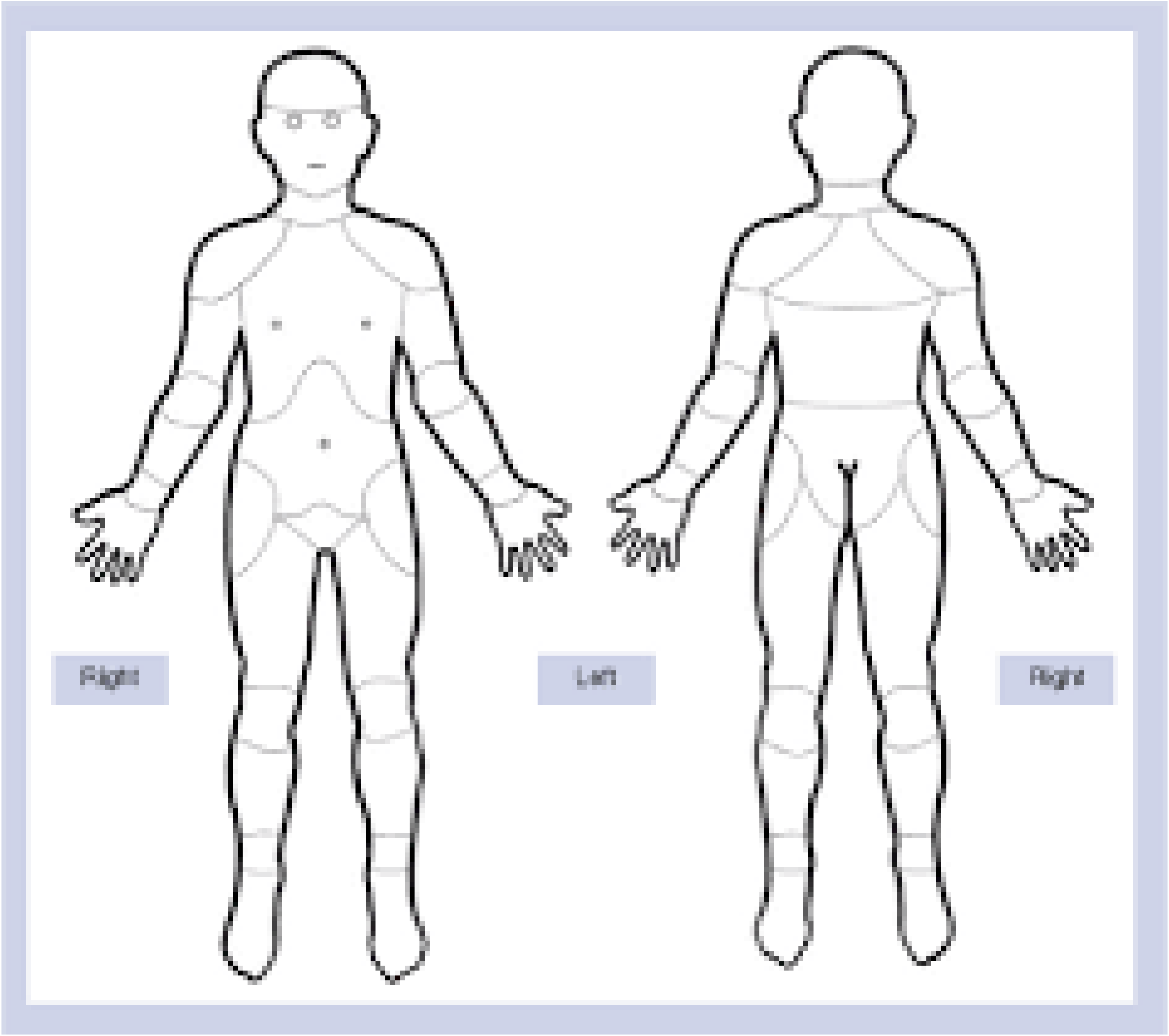
Pain Map ***Subject to change – awaiting feedback about the use of the image from the first user of the image**

Non-Communicative Child with Severe Neurological Impairment Pain Map: Rural KwaZulu Natal

Why do people get pain sometimes?	1 x Not relevant, Unclear, doubtful 1x Not relevant, needs some revision, not simple 1x Needs revision, not clear, doubtful, not simple 1 x Needs revision				
What is pain? What do you think it is?	Parents often seem to have no idea about the pain that their child might be experiencing. They don't seem to be able to reflect on the idea. This is most especially a problem with children who cannot speak. Not simple 1x Not clear 1x Needs some revision				
How do you try to make pain better for yourself?					
Have you ever gone to the doctor/ clinic/ Inyanga for pain relief for your child? 1x Not relevant, needs revision 1x Not clear, doubtful, not simple 1 x Needs revision	0 = No, never 1 = Yes, within the last month 2 = Yes, within the last week 3 = Yes, today 4 = **I** don't know / can't remember	Do you feel that you **can get help for pain in your child** from medical workers? 1 x Not relevant, needs revision 1x Not relevant, not clear, needs revision 1x Not relevant, not clear, doubtful, not simple 1 x Needs revision	0 = No, not at all 1 = Yes, if I fight / bring proof / insist 2 = Yes, but I have to ask for it specifically 3 = Yes, it is not a problem 4 = **I** don't know / can't remember	Do you feel that medical workers **believe and hear you** about your child's pain? 1x Needs revision, not clear, doubtful, not simple 1 x Needs revision	0 = No, not at all 1 = Yes, if I fight / bring proof / insist 2 = Yes, but I have to ask for it specifically 3 = Yes, it is not a problem 4 = **I** don't know / can't remember

Is there anything about your child’s pain that you want to add?	How can we improve the quality of life for this child? Do not insinuate that all non-communicating kids have behaviour issues Sleep, mood or appetite or life events may be affected by pain. Self-harming children may do this for other reasons than pain.

Where is your child’s pain today?



RELEVANCE	Expert 6	Expert 5	Expert 4	Expert 3	Expert 2	Expert 1	Expert in agreement	I-CVI	UA
Q1	0	1	1	1	1	1	5/6	0.83	0
Q2	1	1	1	1	1	1	6/6	1	1
Q3	0	1	1	1	0	1	4/6	0.66	0
Q4	1	1	1	1	1	1	6/6	1	1
Q5	1	0	1	1	1	1	5/6	0.83	0
Q6	1	1	1	1	1	1	6/6	1	1
Q7	1	1	1	1	1	1	6/6	1	1
Q8	0	0	1	0	0	1	2/6	0.33	0
Q9	1	1	1	1	1	1	6/6	1	1
Q10	1	0	1	1	0	1	4/6	0.66	0
Q11	0	1	1	1	0	1	4/6	0.66	0
Q 12	1	1	1	1	0	1	5/6	0.83	0
Q13	1	1	1	1	0	1	5/6	0.83	0
Q14	1	0	1	1	0	1	4/6	0.66	0
Q15	1	1	1	1	0	1	5/6	0.83	0
Q16	0	0	1	1	0	1	3/6	0.5	0
Q17	1	1	1	1	0	1	5/6	0.83	0
Q18	1	1	1	1	0	1	5/6	0.83	0
Q19	1	1	1	1	1	1	6/6	1	1
Q20	1	0	1	0	0	1	3/6	0.5	0
Q21	1	1	1	0	0	1	4/6	0.66	0
Q22	1	0	1	1	0	1	4/6	0.66	0
Q23	1	1	1	1	1	1	6/6	1	1
Q24	0	0	1	1	0	1	3/6	0.5	0
Q25	1	0	1	1	0	1	4/6	0.66	0
Q26	1	1	1	1	0	1	5/6	0.83	0
	20/26	17/26	26/26	23/26	9/26	26/26			
	0.77	0.65	1	0.88	0.35	1			
							S-CVI/Ave	0.78	
Proportion Relevance							S-CVI/ UA		0.27
Average proportion of items judged as relevance across the 5 experts									0.78

CLARITY	Expert 6	Expert 5	Expert 4	Expert 3	Expert 2	Expert 1	Expert in agreement	I-CVI	UA

Q1	0	1	1	1	0	0	3/6	0.5	0
Q2	1	1	1	1	0	0	4/6	0.66	0
Q3	1	1	1	1	0	0	4/6	0.66	0
Q4	1	1	1	1	0	0	4/6	0.66	0
Q5	1	1	1	1	1	1	6/6	1	1
Q6	1	1	1	1	1	0	5/6	0.83	0
Q7	1	1	1	1	1	0	5/6	0.83	0
Q8	0	0	1	1	0	0	2/6	0.33	0
Q9	1	1	1	1	0	0	4/6	0.66	0
Q10	1	0	1	1	0	0	3/6	0.5	0
Q11	1	1	1	1	0	0	4/6	0.66	0
Q 12	1	1	1	1	1	1	6/6	1	1
Q13	0	1	1	1	1	1	5/6	0.83	0
Q14	0	0	1	1	0	0	2/6	0.33	0
Q15	1	1	1	1	0	0	4/6	0.66	0
Q16	0	0	1	1	0	0	2/6	0.33	0
Q17	1	1	1	1	0	1	5/6	0.83	0
Q18	1	1	1	1	0	1	5/6	0.83	0
Q19	1	1	1	1	0	1	5/6	0.83	0
Q20	1	1	1	0	0	1	4/6	0.66	0
Q21	1	1	1	0	0	0	3/6	0.5	0
Q22	0	1	1	1	0	0	3/6	0.5	0
Q23	1	1	1	1	0	1	5/6	0.83	0
Q24	0	1	1	1	0	1	4/6	0.66	0
Q25	1	1	1	1	0	0	4/6	0.66	0
Q26	1	1	1	1	0	0	4/6	0.66	0
	19/26	22/26	26/26	24/26	5/26	9/26			
	0.73	0.85	1	0.92	0.19	0.35		0.67	
							S-CVI/Ave	0.67	
Proportion Clarity							S-CVI/ UA		0.08
Average proportion of items judged as clear across the 6 experts									0.68

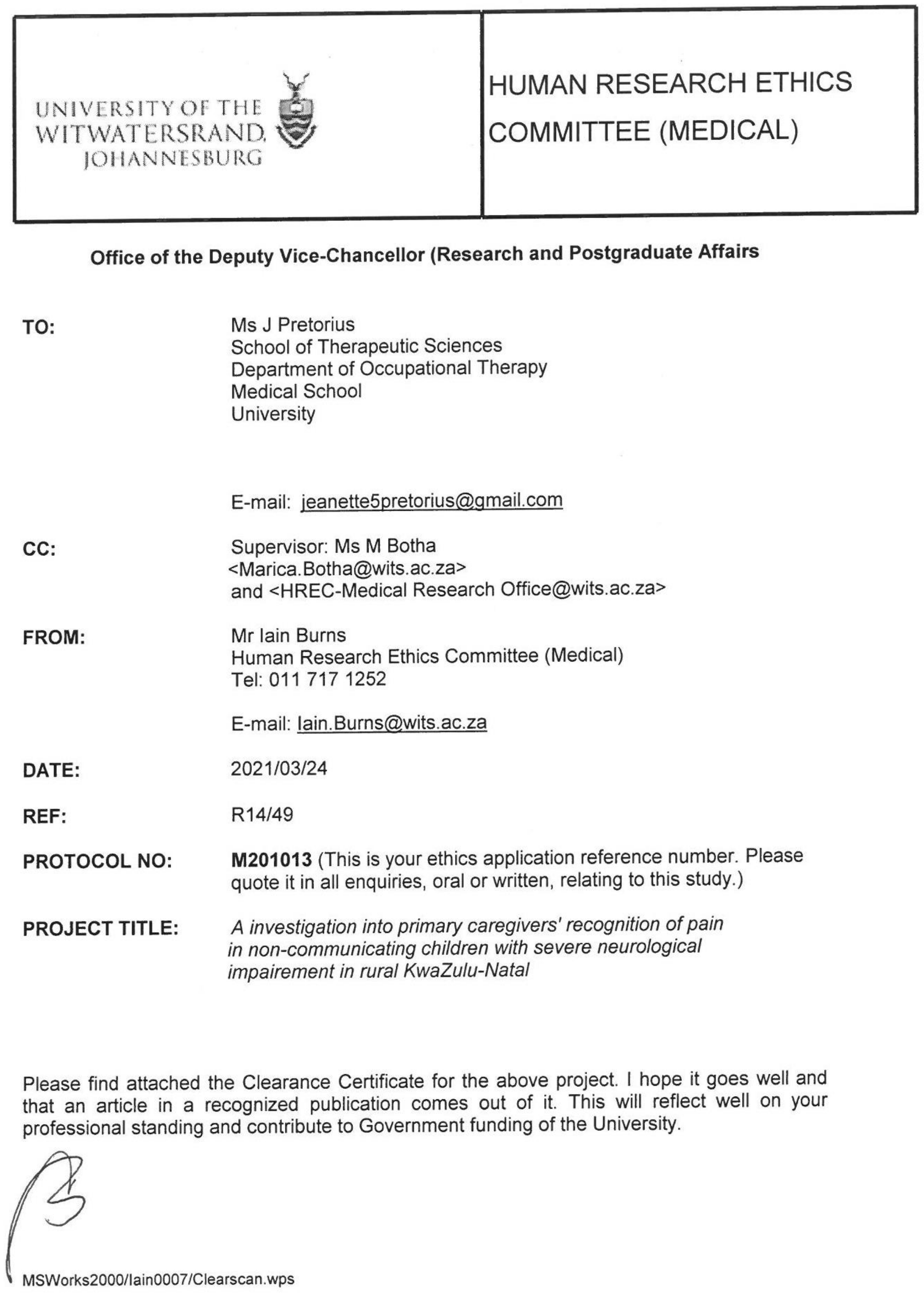
AMBIGUITY	**Expert 6**	**Expert 5**	**Expert 4**	**Expert 3**	**Expert 2**	**Expert 1**	**Expert in agreement**	**I-CVI**	**UA**

Q1	0	1	1	0	0	1	3/6	0.5	0
Q2	1	1	1	0	1	1	5/6	0.83	0
Q3	1	1	1	1	0	1	5/6	0.83	0
Q4	1	1	1	1	0	0	4/6	0.66	0
Q5	1	0	1	1	1	1	5/6	0.83	0
Q6	1	1	1	1	1	0	5/6	0.83	0
Q7	1	1	1	1	1	0	5/6	0.83	0
Q8	0	0	1	1	0	0	2/6	0.33	0
Q9	1	1	1	1	0	1	5/6	0.83	0
Q10	0	0	1	1	0	0	2/6	0.33	0
Q11	0	1	1	1	0	1	4/6	0.66	0
Q 12	1	1	1	1	1	1	6/6	1	1
Q13	1	1	1	1	0	1	5/6	0.83	0
Q14	1	0	1	1	1	1	5/6	0.83	0
Q15	1	1	1	1	0	0	4/6	0.66	0
Q16	0	0	1	1	0	0	2/6	0.33	0
Q17	1	1	1	1	0	1	5/6	0.83	0
Q18	1	1	1	1	0	0	4/6	0.66	0
Q19	1	1	1	1	1	1	6/6	1	1
Q20	0	0	1	1	0	1	3/6	0.5	0
Q21	1	1	1	1	0	0	4/6	0.66	0
Q22	0	0	1	1	0	0	2/6	0.33	0
Q23	1	1	1	1	1	0	5/6	0.83	0
Q24	0	0	1	1	1	0	3/6	0.5	0
Q25	1	0	1	1	1	0	4/6	0.66	0
Q26	1	1	1	1	1	0	5/6	0.83	0
	18/26	17/26	26/26	24/26	11/26	12/26			
	0.69	0.65	1	0.92	0.42	0.46		0.69	
							S-CVI/Ave	0.69	
Proportion Ambiguity							S-CVI/ UA		0.08
Average proportion of items judged as not ambivalent across the 6 experts									0.69

SIMPLICITY	Expert 6	Expert 5	Expert 4	Expert 3	Expert 2	Expert 1	Expert agreement	I-CVI	UA
Q1	0	1	1	1	0	0	3/6	0.5	0

Q2	1	1	1	0	1	0	4/6	0.66	0
Q3	1	1	1	1	0	1	5/6	0.83	0
Q4	1	1	1	1	0	0	4/6	0.66	0
Q5	1	1	1	1	1	1	6/6	1	1
Q6	1	1	1	1	1	0	5/6	0.83	0
Q7	1	1	1	1	1	0	5/6	0.83	0
Q8	0	0	1	1	0	0	2/6	0.33	0
Q9	1	1	1	1	0	0	4/6	0.66	0
Q10	0	1	1	1	0	0	3/6	0.5	0
Q11	0	1	1	1	0	0	3/6	0.5	0
Q 12	1	1	1	1	1	1	6/6	1	1
Q13	0	1	1	1	0	1	4/6	0.66	0
Q14	1	1	1	1	0	0	4/6	0.66	0
Q15	1	1	1	1	0	0	4/6	0.66	0
Q16	0	1	1	1	0	0	3/6	0.5	0
Q17	1	1	1	1	1	1	6/6	1	1
Q18	1	1	1	1	0	0	4/6	0.66	0
Q19	1	1	1	1	0	0	4/6	0.66	0
Q20	0	1	1	1	0	0	3/6	0.5	0
Q21	1	1	1	1	1	0	5/6	0.83	0
Q22	0	1	1	1	0	0	3/6	0.5	0
Q23	1	1	1	1	0	0	4/6	0.66	0
Q24	0	1	1	1	0	0	3/6	0.5	0
Q25	1	1	1	1	0	0	4/6	0.66	0
Q26	1	1	1	1	0	0	4/6	0.66	0
	17/26	25/26	26/26	25/26	7/26	5/26			
	0.65	0.96	1	0.96	0.27	0.19		0.67	
							S-CVI/Ave	0.67	
Proportion SIMPLICITY							S-CVI/ UA		0.12
Average proportion of items judged as simplicity across the 6 experts									0.67

Appendix D:



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research and Postgraduate Affairs

TO: Ms J Pretorius
School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

E-mail: jeanette5pretorius@gmail.com

CC: Supervisor: Ms M Botha
<Marica.Botha@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: 2021/03/24

REF: R14/49

PROTOCOL NO: **M201013** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)

PROJECT TITLE: *A investigation into primary caregivers' recognition of pain in non-communicating children with severe neurological impairement in rural KwaZulu-Natal*

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

HUMAN RESEARCH ETHICS
COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research and Postgraduate Affairs

TO:
Ms J Pretorius
School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

E-mail: jeanette5pretorius@gmail.com

CC:
Supervisor: Ms M Botha
<Marica.Botha@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

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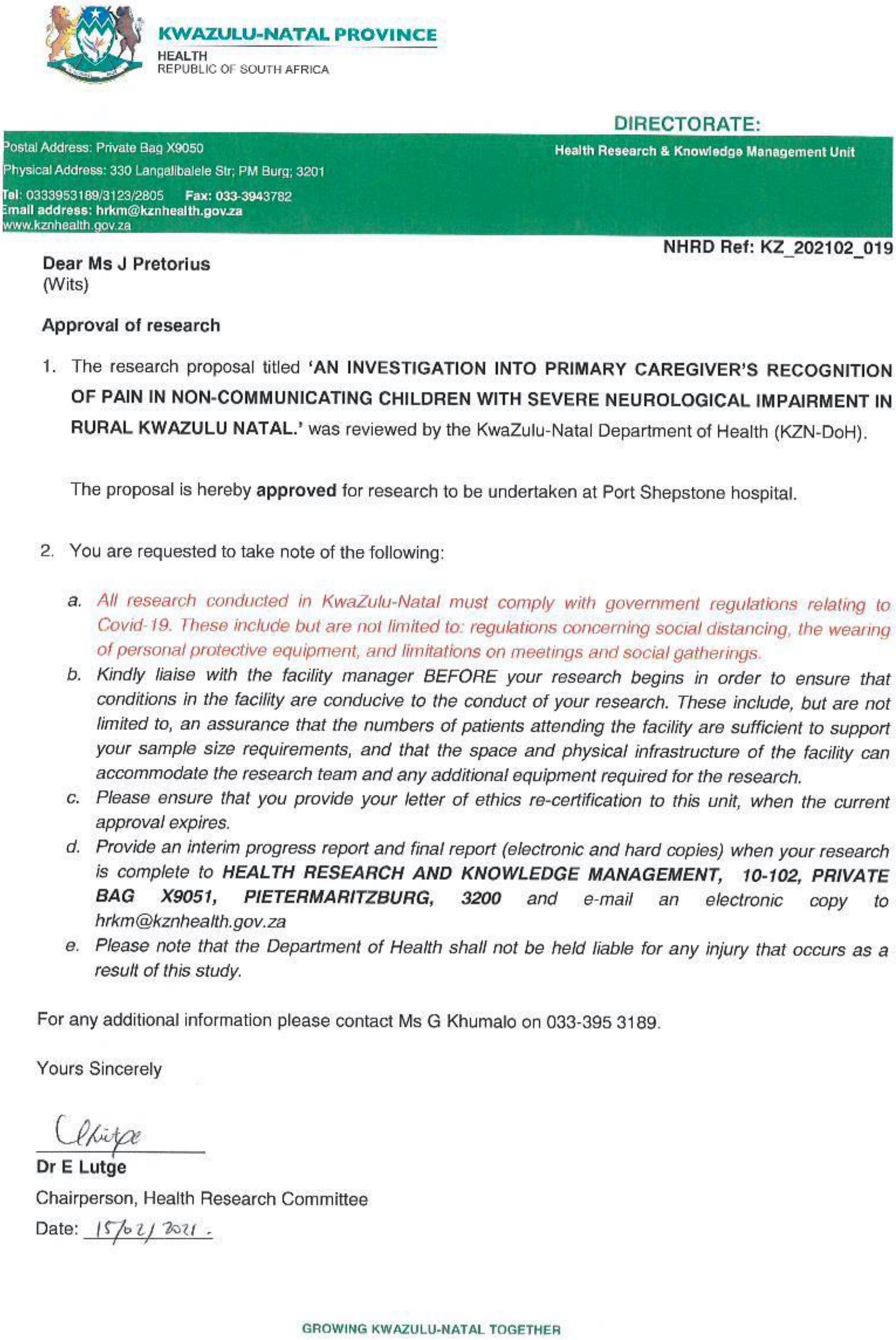
MSWorks2000/Iain0007/Clearscan.wps

Appendix E:



KWAZULU-NATAL PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

DIRECTORATE:
Health Research & Knowledge Management Unit

Postal Address: Private Bag X9050
Physical Address: 330 Langalibalele Str; PM Burg; 3201
Tel: 0333953189/3123/2805 Fax: 033-3943782
Email address: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

NHRD Ref: KZ_202102_019

Dear Ms J Pretorius
(Wits)

Approval of research

1. The research proposal titled **'AN INVESTIGATION INTO PRIMARY CAREGIVER'S RECOGNITION OF PAIN IN NON-COMMUNICATING CHILDREN WITH SEVERE NEUROLOGICAL IMPAIRMENT IN RURAL KWAZULU NATAL.'** was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

   The proposal is hereby **approved** for research to be undertaken at Port Shepstone hospital.

2. You are requested to take note of the following:

   a. *All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.*
   b. *Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.*
   c. *Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.*
   d. *Provide an interim progress report and final report (electronic and hard copies) when your research is complete to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za*
   e. *Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.*

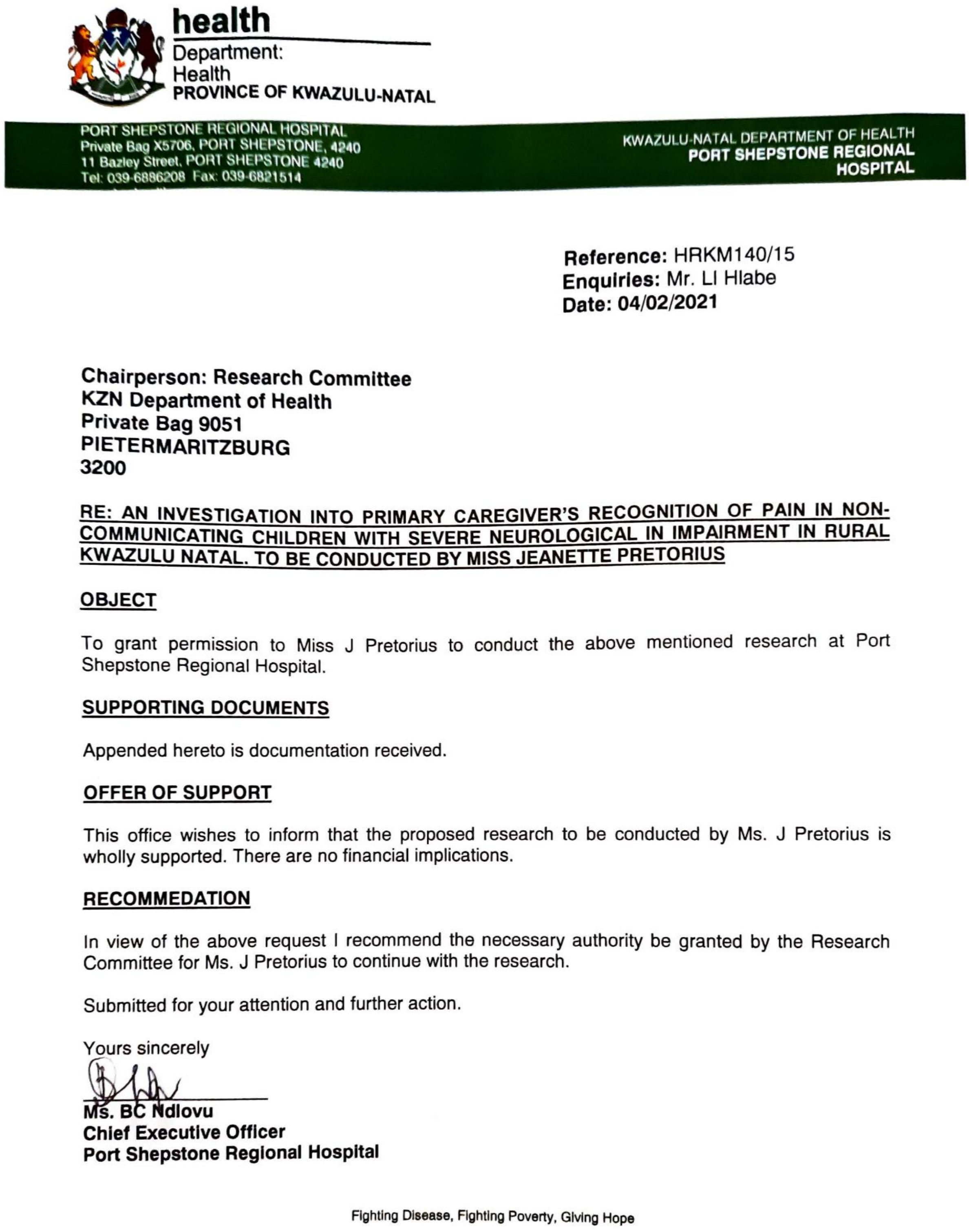
For any additional information please contact Ms G Khumalo on 033-395 3189.

Yours Sincerely

Dr E Lutge
Chairperson, Health Research Committee
Date: 15/02/2021.

GROWING KWAZULU-NATAL TOGETHER

Appendix F:



health
Department:
Health
PROVINCE OF KWAZULU-NATAL

PORT SHEPSTONE REGIONAL HOSPITAL
Private Bag X5706, PORT SHEPSTONE, 4240
11 Bazley Street, PORT SHEPSTONE 4240
Tel: 039-6886208 Fax: 039-6821514

KWAZULU-NATAL DEPARTMENT OF HEALTH
PORT SHEPSTONE REGIONAL HOSPITAL

Reference: HRKM140/15
Enquiries: Mr. LI Hlabe
Date: 04/02/2021

Chairperson: Research Committee
KZN Department of Health
Private Bag 9051
PIETERMARITZBURG
3200

RE: AN INVESTIGATION INTO PRIMARY CAREGIVER'S RECOGNITION OF PAIN IN NON-COMMUNICATING CHILDREN WITH SEVERE NEUROLOGICAL IN IMPAIRMENT IN RURAL KWAZULU NATAL. TO BE CONDUCTED BY MISS JEANETTE PRETORIUS

OBJECT

To grant permission to Miss J Pretorius to conduct the above mentioned research at Port Shepstone Regional Hospital.

SUPPORTING DOCUMENTS

Appended hereto is documentation received.

OFFER OF SUPPORT

This office wishes to inform that the proposed research to be conducted by Ms. J Pretorius is wholly supported. There are no financial implications.

RECOMMEDATION

In view of the above request I recommend the necessary authority be granted by the Research Committee for Ms. J Pretorius to continue with the research.

Submitted for your attention and further action.

Yours sincerely

Ms. BC Ndlovu
Chief Executive Officer
Port Shepstone Regional Hospital

Fighting Disease, Fighting Poverty, Giving Hope

Appendix G:

Distress protocol

Definitions:

APPENDIX 1 Glossary

Accountability – the measure by which it can be demonstrated that responsibilities have been or are being fulfilled; it may involve reporting upwards in a hierarchical structure

Adolescent – a child between 12 and 17 years of age

Anonymous data or specimen–data or biological materials without any overt identifying information or link to a specific donor

Autonomy – the capacity to understand information; to act on it voluntarily; to use own judgement to make decisions about own actions, including whether to participate in research Biobank – see Repository

Caregiver– a person who in fact cares for a child (s 1 Children's Act, 38 of 2005); a caregiver must safeguard the child's health, well-being and development; and protect the child from abuse and other harms; a caregiver exercises the parental right to consent to medical examination or treatment of the child

Child – a person under 18 years (s 28 Constitution; s 1 Children's Act)

Coercion – extreme form of undue influence, involving a threat of harm or punishment for failure to participate in research; see Undue influence

Confidentiality – the responsibility to protect information entrusted to researchers for research purposes from unauthorized access, use, disclosure, modification, loss or theft

Conflict of interest – incompatibility of duties, responsibilities or interests (personal or professional) of a person or an institution as regards ethical conduct of research so that one cannot be fulfilled without compromising another

Consent – indication of agreement to participate in research, based on adequate knowledge and understanding of relevant information, and freely given

Guardian – a person appointed by a court to look after the financial and welfare interests of a minor, or a person appointed by a parent with sole responsibility for the minor in terms of that parent’s Will

Harm – anything that has a negative effect on participants’ welfare, broadly construed; its nature may be physical, emotional, psychological, social or legal

Incentive – anything offered to encourage participation in research

Inconvenience – a minor negative effect experienced in research less serious than discomfort

Low risk research – where the only foreseeable risk is one of discomfort

Minimal risk research – where probability and magnitude of possible harms implied by participation are no greater than those posed by daily life in a stable society or routine medical, dental, educational or psychological tests or examinations

Minor– a person under 18 years (s 17 Children’s Act)

Privacy risks – potential harms to participants from collection, use and disclosure of personal information for research purposes

Protocol – document that provides background, rationale and objectives of research; describes its design, methodology, organization and conditions under which it is to be conducted and managed

Reimbursement – payment to participants to ensure they are not disadvantaged financially directly or indirectly by participation in research; directly means actual costs incurred and indirectly means losses that arise because of participation

Risk – function of the magnitude of harm and the probability that it will occur

Risk of harm to likelihood of benefit ratio – analysis of whether the risk of harm implied is justifiable in light of the likelihood of benefit Therapeutic intervention – interventions directed towards direct health-related benefit for a participant (NHA Reg 135)

Undue influence – effect of an unequal power relationship on voluntariness; may occur when recruitment of participants is done by authority figure

Vulnerability – diminished ability to fully safeguard one's own interests in the context of a specific research project; may be caused by limited capacity or limited access to social goods like rights, opportunities and power

From: (Wikler, 2010)

Steps / Methodology:

During the course of the research, an interview will be held with the primary caregiver of a child/ children with severe neurological impairment including communication impairments. Due to the nature of the phenomenon being studied, there is a minimal risk of inconvenience, discomfort or distress in the research participants.

This document aims to provide a clear step – by step method to address potential discomfort, distress or inconvenience in research participants.

Step 1: Before the participants are recruited, the potential participants are handed an information paper that explains the nature of the research and potential risks, including the risk of emotional distress during assessment. This information will be supplemented with verbal information in the potential participant’s language of choice as well as the opportunity to ask relevant questions about the research.

Step 2: When participants have been recruited, as the appointment is made for the interview, the participants will be informed again of the nature and risks involved in the research. The names and contact details of institutions and organisations nearby that offers distress counselling, counselling or psychological services will be provided to the participants in written format.

Step 3: Before the interview, the participant is verbally informed that they are under no obligation to complete the interview in one sitting, should they feel distressed. They will again be provided with the contact information of institutions and organisations nearby that offers distress counselling, counselling or psychological services.

Step 4: The interview should be conducted in an area that is private, comfortable and familiar to the participants. Before the interview commences, the participants are orientated as to the location of the bathroom. Clean drinking water and disposable cups, as well as tissues will be made available to the participants.

If during the interview, a participant should appear to become emotionally distressed; the distress protocol should be followed in conjunction with the researcher’s clinical reasoning and the participant’s expressed needs: (Draucker, Martsolf and Poole, 2009)

Step 1: The researcher should ask the patient if they would like the interview to be terminated, reiterating that the participant is under no obligation to complete the interview.

Step 2: If the participant wishes the interview to be terminated, it is terminated. If the participant wishes to continue with the interview, the researcher suggests a rest-period / respite period for the participant, and offers to join or leave participant based on the participant’s expressed need.

Step 3: The researcher suggests to the participant that they can also find help at one of the institutions / organisations in the list and offers to call and make an appointment on behalf of the participant.

Step 4: The researcher implements the participant's choice of either phoning and making an appointment for some form of counselling on behalf of the participant or not.

Step 5: The researcher implements the participant's choice, of either terminating, postponing or continuing the interview.

Step 6: The day after the interview, the researcher phones the participant to follow up on the participant's emotional wellbeing.

<u>If during the interview a participant or a participant's child should appear to become physically distressed; the physical distress protocol should be followed in conjunction with the researcher's clinical reasoning and the participant / child's needs:</u>

Step 1: Assess the need for CPR (if needed, commence and dispatch assistant to fetch a doctor and an emergency trolley or an ambulance as is needed and relevant.)

Step 2: If no need for CPR or an emergency doctor, assess need for referral for a general medical check-up and refer if appropriate.

Step 3: If no need for a general medical check-up, assess need for toilet, water, food, repositioning or movement and provide opportunity for the caregiver to satisfy this need.

Step 4: Provide opportunity for caregiver to discern if the interview should be terminated, postponed or continue.

Step 5: The day after the interview, the researcher phones the participant to follow up on the participant's or child's emotional and physical wellbeing. Reiterate where help can be found for emotional distress or for the specific type of physical distress observed.

Appendix H:

Ikhasi lolwazi mayelana nocwaningo / Information page about research

Ucwaningo olubheka ukuthi abazali kanye nabantu abanakekela abantwana abakhubazekile ngokwengqondo ukuthi bababona kanjani ukuthi bezwa ubuhlungu uma bengakwazi ukuzikhulumela futhi abahlala ezindaweni ezisemaphandleni Kwazulu Natal.

An investigation into caregiver's recognition of pain in non-communicating children with severe neurological impairment in rural KwaZulu Natal.

Ngiyabingelela / Greetings

Igama lami ngingu Jeanette Pretorius. Ngingumsebenzi wezempilo ohlwini lwabantu abakhubazekile. Okwamanje ngithatha izifundo zobuchwephesha emkhakheni wokusebenza ngabantu abakhubazekile (Masters degree in Occupational Therapy) enyuvesi yase Witwatersrand.
My name is Jeanette Pretorius. I am a health worker for people with disabilities. I am currently pursuing a career in the field of rehabilitation for people with disabilities (Masters degree in Occupational Therapy) at the university of Witwatersrand.

Ngenza ucwaningo olukhuluma ngezindlela ezahlukahlukene; zabazali kanye nabantu abanakekela abantwana abakhubazeke ngengqondo noma abanesifo esiphazamisa ubuchopho, futhi behlala emaphandleni. Ngokunjalo ngifuna ukwazi ukuthi babubona kanjani ubuhlungu obuziwa ngabantwana babo njengoba bengakwazi ukuzikhulumela.
I am doing an investigation into the different ways people who are taking care of children with neurological disabilities living in rural areas see pain or recognise pain in these children if the children cannot speak for themselves.

Ukukhubazeka kwengqondo siye sikubalule ngokuthi kungukulimala ebuchosheni, okuholela ekutheni umtwana akhubazeke nangokomzimba.

Kwezinye izikhathi eziningi labatwana abakwazi ukuhamba/ukunyakaza kanye nokukhuluma.
Kuyenzeka futhi bafune usizo kakhulu kodokotela kanye nabanye abasebenzi bezempilo.
Lokhu kusho ukuthi kubenza babhekane nezimo ezingabenza bangazizwa kahle futhi kubangele ubuhlungu obukhulu.
Neurological Impairment or brain damage can lead to children being disabled. In some cases, this can be so severe that these children cannot move or talk. Sometimes these children also need help from doctors and health workers. This can also cause them pain and make them feel uncomfortable.

Ubuhlungu buziwa nguwo wonke umuntu. Abacwaningi kanye nabezempilo bathanda ukuthi abantu mabasho/noma babike ngobuhlungu babo. Kodwa izikhathi eziningi izingane azikwazi ukuzibika. Ezinye zezingane ezinokukhubazeka ngengqondo noma ukulimala kobuchopho azikwazi ukukhuluma noma basebenzise ezinye zezindlela zokuxhumana ukuze bazibike ngokusobala. Lokhu kungabanga ukuthi labantwana babonise ubuhlungu babo ngenye indlela ehlukile kwabanye abantwana.
Pain is felt by everyone. Health workers usually expect people to voice out about what they feel, especially if it is pain. It is difficult for children like this to report pain themselves. Most severely disabled children use other ways of communication to report pain, and relies on their caregiver to interpret it and get help for the pain.

Uma ke singazi ngobuhlungu kulababantwana asikwazi ukusiza senze ubuhlungu babo bube ngcono. Akhona amathuluzi esikhona ukuhlola ngawo uma umuntu ezwa ubuhlungu kanye nokuthi ke ubuhlungu buziveza njani ebantwaneni abangakwazi ukuzikhulumela. Kodwa lamathuluzi awazange enzelwe abantu ngqo base Ningizimu Afrika abahlala emaphandleni.
If we do not know about the pain these children have, we cannot help them. There are questionnaires and toolkits to assess this pain, but these are usually not made in South Africa or for the South African population.

Ngakho ke ngizamile ukwenza imibuzo emifushane ekhuluma ngendlela esingabona ngayo uma sizithola kufanele sisebenze nomuntu onenkinga yokukhubazeka noma

alimale ubuchopho futhi ongakwazi ukuzikhulumela uma ezwa ubuhlungu. Ngiwenzile nomfanekiso womzimba ongababonisa izindawo lapho umuntu ezwa khona ubuhlungu (kanye nesigaba lapho kukhuluma ngokuthi uma sisekhaya singenza njani ukusiza sehlise ubuhlungu emuntwini uma engumuntu osizayo noma umzali wombatwana okhubazeke ngendlela esike sayichaza ngaphambili).
I decided to ask a few questions to find out when we work with someone who is in this situation, who has severe disability or brain injury and who cannot speak for themselves when they are experiencing pain. I have also made a body image that can be used to show areas where you think the person is in pain.

Ngithanda ukusebenzisa lawa mathuluzi uthola kabanzi ngemininingwane ekhuluma ngobuhlungu kulababantwana.
I would like to use these tools to find out more about the pain of these children.

Lemininingwane sinethemba ukuthi ingasetshenziswa ngabazali kanye nabantu abanakekela abantu abakhubazekile kanye nabasebenzi bezempilo abasiza labantwana ukwenza ubuhlungu bube ngcono ngokushesha.
We hope this information can be used by parents and caregivers of people with disabilities and health workers to help decrease these children’s pain faster.

Ngithanda ukumema wena nengane yakho ukuthi nizibandakanye kulolucwaningo.
I would like to invite you and your child to take part in this study.

Uma ungathanda ukuba yingxenye yalolucwaningo, ngicela ubhale igama lakho kanye nenombolo yocingo ebhokisini elibhalwe Research e-Occupational Therapy ePort Shepstone Hospital. Uma kungenjalo, ungathumela umqhafaso ngefoni kulenumbolo evela kulelifomu.
If you would like to be a part of this research, please write your name and contact details of a piece of paper and place it in the box that is labelled Research in the Occupational Therapy Department at Port Shepstone Hospital. If you prefer, you could also send a text message to the number supplied on the form and we will phone you back.

Ngemva kwalapho uzobe usuyafonelwa ukuze kwazeke ukuthi unemibuzo ngalolucwaningo noma awusenalo uthando lokuba yingxenye yocwaningo. Lezizinombolo futhi zizosetshenziswa ukwenza imihlangano nomcwaningi (oyimina) ukuze kugcwaliseke ifomu elisinika imvume ukuthi umuntu ngamunye uyavuma ngokwakhe ukuba yingxenye yocwaningo.
After you have placed your contact details in the box, you will be phoned to ask if you have any questions about this study and if you are still interested in participating in it. We will also use this opportunity to set up a meeting between you and the researcher (myself) where we should complete a consent form if you agree to participate in the study.

Awuphoqelekile ukuvuma lolucwaningo, ungazikhethela uma ufuna ukubamba iqhaza.
You are **not** obliged to consent to this study, you can choose yourself if you want to participate.

Uma ukhetha ukubamba iqhaza kucwaningo, kuzofanele usayine ifomu lokuthi uyavuma futhi unolwazi ngalolucwaningo. **Noma ngabe ulisayinile ifomu lokuvuma, uvunyelwa ukuyeka ukubamba iqhaza ocwaningweni nganoma yisiphi isikhathi. Kufanele wazise umcwaningi ukuthi ufuna ukuyeka ukubamba iqhaza.**
If you choose to consent to the study, you will have to sign the informed consent form. Even if you sign the informed consent form, **you are allowed to stop participating in the study at any time if you tell the researcher that you want to stop participating**.

Kulolucwaningo kuzoba khona umcwaningi kanye nomhumushi noma angabibiko umhumushi osemthethweni kuyoyonke imihlangano ephathelene nalolucwaningo. Kulowo mhlangano kuzoba khona umzali noma umuntu onakekela umntwana kanye nomntwana. Futhi lemihlangano izobanjelwa endaweni lapho ukhethe khona kanye nesikathi esikhethwe nguwe. Ngaleso sikhathi uzonikheswa ifomu elinemibuzwale kanye nomfanekiso obonisa ngobuhlungu ukuze uyigcwalise. Uma udinga usizo ngokugcwalisa imininingwane uzosizwa, kodwa izimpendulo kulemibuzo kufanele kube liqiniso eliphuma kuwe.

The study will consist of the researcher with or without an informal translator meeting with you (as the caregiver of the child) and the child at a time and place that is convenient for you once. During this meeting, the researcher or translator will give you a form, a questionnaire and a pain map to fill in. If you need help to fill in these papers, we can help – but the answers on there must be your own truth.

Imininingwane ephathelene nawe izobe yehlukene kwimibuzo ephathelene nobuhlungu kanye nomfanekiso wobuhlungu. Imininingwane efana negamalakho, igama lomntwana, isibongo kanye nenombolo yakho yocingo ngeke kunikezelwe ngazo.
Siye sicele imininingwane yakho ukuze uma kukhona ezinye izinto ongase ufune usizo ngazo ukwazi ukuthi uxhunyaniswe nosiso oludingayo. Imininingwane ephathelene nawe izogcinwa ngumcwaningi (oyimina) futhi izokhiyelwa endaweni ephephileyo.

The demographic information will be separate from the pain questionnaire and the pain map. No personal details (your name and surname, your child's name and surname, your cell phone number) will be published. We request the personal information, because if it is found that your child has a problem with pain, we will need to help you with advice about where to go to get treatment for the pain if you decide its needed. The demographic forms with your personal information will be kept by the researcher (myself) and it will be locked away.

Umhlangano mayelana nokugcwalisa ifomo lemibuzo kanye nomfanekiso wobuhlungu akufanele uthathe isikathi esidi ngaphezu kwehora. Kubalulekile ukuthi ingane yakho nayo ibekhona uma ugcwalisa ifomu.
Uma ufisa ukuthola ikhophi lefomu lemibuzo ungalifumana, kodwa kufanele wazise umcwaningi ngalokhu ngokuthi umazise ngocingo.

The meeting with filling in the questionnaire and pain map should not take longer than one hour. It is necessary that your child is present when we fill in these documents.
If you wish, you can get a copy of your own documents. You will have to tell the researcher that you want this over the phone when we set up your meeting.

Uma unemibuzo ungangabazi ukufonela umcwaningi (oyimina).

If you have any questions, please do not hesitate to contact me.

Obuhle kodwa, ngiyabonga
Kind regards and thank you

Jeanette Pretorius
i-imeyili / Email: jeanette5pretorius@gmail.com
Ifoni / Cell phone: 079 325 6953

Appendix I:

Imvume enolwazi: Ukuba yingxenye yocwaningo

Informed consent: Research participation

<u>Ucwaningo:</u> **<u>Izingane zase maphandleni eziphila nokukhubazeka okukhulu kobuchopho, nokugula yisifo esiphazamisa ubuchopho eNingizimu Africa behlala esifundazweni saKwa-Zulu Natal</u>**

<u>Research:</u> **<u>Rural children living with severe neurological disabilities in South Africa, in Kwa-Zulu Natal.</u>**

Igamu Lomzali: ____

Isibongo: ____

Mina____ ngiyavuma kulokhu okulandelayo:

1. Ngifundile futhi ngizwile incazelo ngalolu cwaningo.
2. Nginikiwe ithuba lokubuza imibuzo ngalolucwaningo.
3. Ngenelisekile ngazo zonke izimpendulo engizitholile.
4. Ngizizwa nginolwazi olugcwele ngalolucwaningo ukuze ngikwazi ukuthatha isinqumo sokuba yingxenye.
5. Ngiyagonda ukuthi kulindeleke ntoni ngami nangomtwana ukuze sibe yingxenye yalolucwaningo.
6. Ngiyazi ngikhululekile ukukhetha ukuthi ngibe yingxenye noma ngiyeke ukubu yingxenye yocwaningo.

Ngiyavuma ukuthi:

I hereby acknowledge that:

1. Umcwaningi noma umhumushi uzonginika ifomu lemininingungu ukuthi ngibhale ngobuhlungo noma ngiligcwalise.
2. Umcwaningi noma umhumushi uzongisiza ukugcwe lisa ifomu uma ngishilo ukuthi ngidinga usizo.

Sayina igamu, Isibongo lomzali: ____________________Usuku: ____________________

Sayina igamu umcwaningi: ________________________Usuku: ________________________

Appendix J: Turnitin report

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