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Functional Outcomes of Paediatric Posterior Fossa Tumour Survivors at Two Quaternary Hospitals in Johannesburg, Gauteng

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UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

FUNCTIONAL OUTCOMES OF PAEDIATRIC POSTERIOR FOSSA TUMOUR SURVIVORS AT TWO QUATERNARY HOSPITALS IN JOHANNESBURG, GAUTENG

By

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A Research Dissertation submitted to the Department of Occupational Therapy of the University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Master of Science in Occupational Therapy by Dissertation, Johannesburg,
March 2024

Ethics Clearance Certificate Number: M220427

DECLARATION

I declare that the dissertation, which I hereby submit for the degree Master of Science in Occupational Therapy at the University of the Witwatersrand, is my own work and has not previously been submitted by me for a degree at this or any other tertiary institution.

Jade Tasmyn Flood	30/10/2024
Name	**Date**

PLAGIARISM DECLARATION

FACULTY OF HEALTH SCIENCES

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

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ABSTRACT

Background. In South Africa, posterior fossa tumours (PFT) are among the most common brain tumours in paediatric neurosurgery units. Little literature has been published on the South African population; therefore, the need for occupational therapy (OT) services has yet to be discovered. This research study aimed to identify the cognitive, visual perception, motor and behaviour outcomes experienced by paediatric PFT survivors that impact their ability to participate in age-appropriate categories of occupation and quality of life (QoL).

Methods. This research study was an explanatory, non-experimental multiple case study. Eight children were assessed using standardised assessments before undergoing surgical resection for a PFT, and three children were reassessed six months post-surgery due to the exclusion criteria. The results of the initial assessment and follow-up assessments' results were compared to determine the child's functional outcome.

Results. All three children presented with unique findings regarding their cognitive, visual perception, motor and behavioural outcomes. There was a decline in cognition and behaviour in the male children and visual perception was found to be impacted in the younger children. Motor skills were negatively affected in all the children. Although the children were mostly independent in their activities of daily living (ADLs), the two younger children had developed new onset difficulties with continence and feeding. Regarding quality of life, the children's self-reports differed from the experience of their caregivers.

Conclusion. Paediatric PFT survivors face many challenges that impact their cognitive, visual perception, motor, and behaviour outcomes, which affect their ability to engage in ADLs and their QoL. The results showed that treatment of the PFT rather than the tumour itself resulted in lower QoL in the survivors. By gaining more insight into this population's challenges, OT can be motivated and optimised to suit their specific needs and improve their QoL.

PUBLICATIONS/PRESENTATIONS ARISING FROM THIS STUDY

This research was presented at the 2023 Paediatric Brain Tumour Workshop in Cape Town, South Africa.

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NOMENCLATURE OF ABBREVIATIONS AND SYMBOLS

ADLs – Activities of Daily Living

CBT- Cognitive Behavioural Theory

CHBAH – Chris Hani Baragwanath Academic Hospital

CM – Cerebellar Mutism

CNS – Central Nervous System

COO – Categories of Occupation

CSF – Cerebral Spinal Fluid

DoE – Department of Education

DoH – Department of Health

ETV – Endoscopic Third Ventriculostomy

EVD – External Ventricular Drain

HCP – Hydrocephalus

HIC – Higher Income Country

LIC – Lower Income Country

MDT – Multidisciplinary Team

MIC – Middle Income Country

NDT- Neurodevelopmental Theory

NMCH – Nelson Mandela Children's Hospital

OT – Occupational Therapy

PFT – Posterior Fossa Tumour

PICU – Paediatric Intensive Care Unit

QNST-3R – Quick Neurological Screening Test

QoL – Quality of Life

TIPS – Test of Information Processing Skills

TVPS-4 – Test of Visual Perceptual Skills-4

VMI – Visual Motor Integration

VP – Visual Perception

VPS – Ventriculoperitoneal Shunt

OPERATIONAL DEFINITIONS

Ataxia: umbrella term to describe impairments in coordination of the limbs, gait, oculomotor control as well as the presence of tremors (Hartley *et al.*, 2021)

Attention: the active process of determining what sensory stimuli and experiences are alerting and relevant and being able to focus on something or someone for a determined period (Slack, 1998; Decock *et al.*, 2022).

Cerebellum: The cerebellum is found within the posterior fossa and has two hemispheres separated by the vermis and divided into three lobes: anterior, posterior and flocculonodular (Mumford and Banks, 2018; Jimsheleishvili and Dididze, 2023).

Chemotherapy: the use of toxic compounds and medications to destroy cancerous cells by limiting the cells' ability to grow and divide (Anand *et al.*, 2023).

Executive Functioning: the coordination of attention, memory and cognitive flexibility to be able to problem solve and reason (Harvey, 2019)

Motor Planning: a cognitive process in which execution, timing, and coordination of movement are idealised and initiated (Yeole *et al.*, 2021)

Posterior Fossa: The posterior fossa is the most inferior of the cranial fossa and contains the cerebellum, brain stem, lower cranial nerves, the transverse and sigmoid venous sinuses, and the cerebral aqueduct and fourth ventricle (Sokolov, Miall and Ivry, 2017; Arnold-Day, 2019).

Postural Balance: the ability to assume and maintain the line of gravity related to one's base of support within static and dynamic tasks (Kramer and Hinojosa, 2011; Dreneva and Skvortsov, 2020).

Radiation: the use of high-energy X-rays to destroy tumour cells while preserving the surrounding normal tissue (Grégoire *et al.*, 2020).

Visual Motor Integration: a skill that integrates the coordination of a visual stimulus with an appropriate motor action (Kramer and Hinojosa, 2011)

Visual Perception: the process in which sensory information is integrated and interpreted based on prior development, learnt experiences and stimulation from the environment (*Test of Visual Perceptual Skills-4*, 1017; Kramer and Hinojosa, 2011; Harvey, 2019)

Categories of Occupation: the everyday activities that one engages in that bring meaning and purpose to their life (Boop *et al.*, 2020)

Neurodevelopmental Theory: a problem-solving approach to the assessment and treatment of neurological disorders through the use of therapeutic handling to influence tone and facilitate movement (Howle, 2003).

Tumour: abnormal cell growth that results in a mass; tumours can be either malignant (cancerous) or benign (non-cancerous) (Patel, 2020).

Occupational therapy is the therapeutic use of daily activities to increase participation in the roles, routines, and habits that make up occupations. The activities chosen in therapy are purposeful and valuable to the unique person and aim to treat client factors and performance skills. Occupational therapy can be rehabilitative, habilitative or promote health and wellness (Kramer and Hinojosa, 2011; Boop *et al.*, 2020)

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CHAPTER 1: INTRODUCTION

1.1 INTRODUCTION TO THE PROBLEM

In South Africa, posterior fossa tumours are among the most common brain tumours in paediatric neurosurgery units. There is little literature published on the South African population, and therefore, the need for occupational therapy services is unknown, and children with posterior fossa tumours often do not receive the support services that they need. Although many studies have been done internationally on paediatric posterior fossa tumour survivors and the occupational therapist's role, to this researcher's knowledge, this will be the first study on the topic in South Africa.

Due to South Africa's socioeconomic status, average level of education and unequal access to healthcare, there is a need to study paediatric posterior fossa tumours within this context to assess whether the challenges faced by survivors internationally are the same as those experienced in South Africa. With this knowledge, the need for occupational therapy services can be advocated for, and occupational therapists can be empowered to provide targeted rehabilitation to meet this population's needs.

1.2 BACKGROUND AND SETTING OF THE PROBLEM.

In South Africa, paediatric brain tumours are the second most common cancer in children, as reported by the National Cancer Strategic Framework for South Africa 2017-2022 (National Department of Health, 2017). Of these brain tumours, 54-70% occur in the posterior fossa (Meenakshisundaram and Dhandapani, 2018). The posterior fossa is the most inferior of the cranial fossa and contains the cerebellum, brain stem, lower cranial nerves, the transverse and sigmoid venous sinuses, and the cerebral aqueduct and fourth ventricle (Sokolov, Miall and Ivry, 2017; Arnold-Day, 2019). The survival rate for children diagnosed with posterior fossa tumours (PFT) is increasing as advances are made within the neurosurgical and radiation-oncology fields (Meenakshisundaram and Dhandapani, 2018; Stavinoha *et al.*, 2018). As the survival rate is increasing, it is now more important than ever to determine the long-term consequences of treating these tumours on the functional outcomes and quality of life (QoL) of the survivors (Lassaletta *et al.*, 2015). However, there is little objective research on the consequences of these tumours on a child's occupational participation, which affects their QoL (Lassaletta *et al.*, 2015).

To optimise the treatment of children diagnosed with a PFT, it is essential to understand the functional deficits commonly associated with a tumour in this area of the brain. Early direct

targeting of these deficits in occupational therapy (OT) treatment will allow the child to reach their full potential and increase their participation in age-appropriate categories of occupations. The Occupational Therapy Practice Framework: Domain and Process Fourth Edition by Boop et al. (2020) defines occupations as the everyday activities that one engages in that bring meaning and purpose to their life: for children, these would include activities of daily living (ADLs), education, play and leisure, and rest and sleep (Boop *et al.*, 2020).

Research conducted by Stavinha et al. (2018), Lassaletta et al. (2015) and Nair (2017) indicates that children who survive a PFT show deficits in their executive functioning, visual perception, behaviour and, personality, linguistic abilities and motor coordination, which affects their ability to engage in their occupations. It has been reported that survivors of a PFT struggle with their schooling and, therefore, do not graduate from high school and often remain unemployed (Lassaletta *et al.*, 2015; Nair, 2017; Stavinoha *et al.*, 2018). However, historically, there has been little research by occupational therapists determining how the deficits experienced by these children affect their overall participation in their occupations (Demers, Gelinas and Carret, 2016).

Fischer et al. 2016, call for a multidisciplinary team (MDT) approach to the management of children with central nervous system (CNS) tumours with a focus on early education, baseline neurocognitive testing and OT, physiotherapy and speech therapy intervention (Fischer *et al.*, 2016). Occupational therapists (OTs) have the unique ability to analyse an individual holistically and work to optimise their function within their environment through the use of meaningful activities (Sleight and Duker, 2016). Research conducted by Demers et al. (2016) found that timely assessment and intervention by OTs in children with brain tumours improves the child's participation and independence in ADLs. They also report that objective assessments give the OT better insight into the specific areas of dysfunction the child presents with (Demers, Gelinas and Carret, 2016). In South Africa, there are no protocols on how to manage childhood brain tumours and no research on the functional prognosis of survivors of PFTs (Parkes, Davidson and Figaji, 2014).

Therefore, there was a need to participate in research on the topic to determine the functional ability of a child to engage in their occupations and QoL of survivors of PFTs and the OT's role in returning to participation in age-appropriate occupations.

1.3 PROBLEM STATEMENT

There is international research indicating that paediatric survivors of PFT show deficits in many domains, which influence their age-appropriate participation in their occupations

(Lassaletta *et al.*, 2015; Boop and Chuang, 2018). However, there is limited research in South Africa on the effects of PFT and subsequent treatment on its survivors and their participation in their occupations. A better understanding of the effects would allow for optimised long-term treatment planning and specific rehabilitation.

In South Africa, children with brain tumours often only present to medical institutions once they are experiencing life-threatening symptoms which require immediate medical attention (Geel *et al.*, 2021). By this stage, their symptoms affect their participation in their occupations. Due to late presentations to healthcare, the tumour often has had a mass effect on the brain, and non-reversible damage has occurred. Once the child presents to the hospital, there are frequent delays in getting neurological imaging and scans, delayed surgery due to limited theatre operating time and poor access to intensive care units (ICU), as well as delayed initiation of chemotherapy and radiation.

Pre- and post-surgery children with PFTs often receive inadequate neuro-rehabilitation due to limited access to therapy within an inpatient context, lack of public paediatric rehabilitation centres for outpatient therapy and poor access to OT services within the Department of Education (DoE) and Department of Health (DoH). Due to long waiting lists, children who require access to services from the DoH often only receive OT once a month (Morris *et al.*, 2021). The waiting list for children requiring specialised schooling is long, and these children usually do not attend formal education while waiting for a placement in the appropriate school (Education, 2009).

If specific areas of deficit could be identified in children who survive treatment for their PFT, this would allow OTs to provide early, well-directed, resource-saving rehabilitation, increasing their ability to participate in their occupations, return to mainstream schooling and have work opportunities.

This study aimed to determine if paediatric PFT survivors in Johannesburg, South Africa, have lasting deficits in their cognitive abilities, motor abilities, visual perception and behaviour impacting their participation in their occupations and QoL using quantitative data in a non-experimental case study design.

As observed within the clinical setting, there is a high number of children with PFTs admitted into neurosurgical units in South Africa, so this research could help OTs focus on specific outcomes to improve the child's activity participation.

1.4 RESEARCH QUESTION

What are the cognitive, motor, visual perception and behaviour outcomes experienced by paediatric posterior fossa tumour survivors that impact their ability to participate in age-appropriate activities of daily living and quality of life?

1.5 RESEARCH AIMS AND OBJECTIVES.

This study aimed to determine the changes paediatric PFT has on a child's cognition, visual perception, motor skills, participation in activities of daily living, and quality of life.

1.5.1 Objectives of the Study

1. To determine the **demographics** (age, sex, race) of children diagnosed with posterior fossa tumours at Chris Hani Baragwanath Academic Hospital (CHBAH) and Nelson Mandela Children's Hospital (NMCH)
2. To describe the **change in the cognitive, visual perception, motor, and behaviour outcomes** of children pre and post posterior fossa tumour surgery and medical management.
3. To describe the change in the **ability of the children to participate** in age-appropriate activities of daily living pre and post posterior fossa tumour surgery and medical management.
4. To describe the change in perceived **quality of life** of children pre and post posterior fossa tumour surgery and medical management

1.6 SIGNIFICANCE OF THE STUDY

Brain tumours are the second most common tumours in South Africa, the majority of which occur in the posterior fossa. Yet, there is very little research on the impact the tumours and consequent surgical and medical management have on their functioning (Parkes, Davidson and Figaji, 2014).

This study has the potential to add to the current body of literature on the influence of PFT on a child's occupational performance before and after medical intervention. In-depth information regarding survivors' visual perception, cognition, motor skills, behaviour, and participation in categories of occupation would empower OTs to provide targeted neurorehabilitation that can

address these specific issues. It will also aid OTs in facilitating the transition back to formal schooling within the appropriate school environment.

1.7 PHILOSOPHICAL ASSUMPTIONS

This research used a postpositivist paradigm to discover phenomena that can be generalised to a population group to make a tangible change in the OT management (Brown and Dueñas, 2020). Children with PFTs in South Africa do not receive the OT rehabilitation that they need due to a variety of factors, including a lack of resources with the DoH and DoE and a poor understanding of the disease process. Conducting research into the functional outcomes of PFT survivors would assist OTs in providing targeted rehabilitation, optimising the time spent per session, allowing for earlier discharge, and decreasing the long-term burden on society.

Table 1.1 Philosophical Base of the Study

Axiology	Ontology	Epistemology	Methodology
This study will be guided by the principles of autonomy, beneficence, non-maleficence and justice. All participants will be allowed to provide informed consent (caregivers) and informed assent (children) and will be allowed to withdraw from the study at any point in time without any negative consequences. The participants will also have access to their results if they wish. Since the study is non-experimental, the participants will have access to rehabilitation (OT, PT and ST) as required, and therefore, no harm will be done.	Children with posterior fossa tumours experience long term dysfunction in their motor, cognitive, visual perception and ADL performance which impacts their QoL. Due to the overburdened South African healthcare system, many of these children do not receive the rehabilitation services they require to be able to resume participation in their occupations. If common trends of dysfunction could be identified, it would allow OTs to provide targeted rehabilitation and hopefully decrease the time to discharge. Children with disabilities in SA have difficulties accessing	In paediatrics the neurodevelopmental theory (NDT) is the most commonly used theory in which neurorehabilitation principles are drawn from. NDT was developed in 1948 and is based on the understanding that lesions in the central nervous system leads to functional impairments as the result in changes in muscle tone, coordination and movement patterns (Howle, 2003). These functional impairments impact the ability of a child to engage in age appropriate occupations Research into the impairments that occur after an injury to the structures within the posterior fossa when a tumour occurs will aid in adding to the knowledge base of what treatment principles would be the most advantageous for children with these types of tumours.	The postpositivist assumption was used for this study and, the research design for this study makes use of a non-experimental test-retest methodology to be able to accurately observe and report on the objectives (Brown and Dueñas, 2020). The measurement instruments that will be used are: - Demographical questionnaire - Test of Information Processing Skills (TIPS) - Beery-Buktenica Developmental Test of Visual-Motor Integration, Sixth Edition (Beery VMI) - Test of Visual Perceptual Skills-4 (TVPS-4) - Quick Neurological Screening Test 3rd Edition, Revised (QNST-3R)

The distress protocol will be followed during the assessment process to avoid undue harm.	specialised schooling and therefore having targeted rehabilitation may allow them to return to mainstream schooling instead of being placed on the waiting list for specialised schooling.	The quantitative data can be used to assist the occupational therapy, neurosurgical and oncology fields in gaining more knowledge on paediatric posterior fossa tumour survivors in South Africa.	- Peds-QL – Brain Tumour Module (Peds-QL) - Barthel Index

(Kivunja and Kuyini, 2017)

1.8 ORGANISATION OF THE DISSERTATION

The general outline of the dissertation is summarised as follows:

Chapter 1: Introduction

Chapter 2: Literature Review

Chapter 3: Methodology

Chapter 4: Results

Chapter 5: Discussion:

Chapter 6: Summary of Main Findings, Strengths and Limitations of the Study, Conclusion and Recommendations.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION TO THE LITERATURE REVIEW

Brain tumours are the second most common malignancy in children and the leading cause of cancer-related death in children (Vara Prasad *et al.*, 2017; Mathilde *et al.*, 2018; Meenakshisundaram and Dhandapani, 2018). The age of children at diagnosis varies according to the type of tumour, but Prasad et al. (2017) and Chieffo et al. (2022) report that the average age of diagnosis of a posterior fossa tumour (PFT) is under ten years old (Vara Prasad *et al.*, 2017). The young age at diagnosis dramatically affects a child's development as it disrupts the ongoing myelination and neuronal growth occurring within the brain compared to a fully matured brain of an adult (Doris *et al.*, 2022). Tumours of the CNS result in physical, neurocognitive and psychosocial deficits that impact the QoL of children who survive them (Arnold-Day, 2019).

International research indicates that paediatric survivors of posterior fossa tumours (PFT) show deficits in many domains, which influence their categories of occupation, including activities of daily living (ADLs), play and school (Chieffo *et al.*, 2022).

2.2 POSTERIOR FOSSA TUMOURS

2.2.1 Background

Brain tumours can be divided into intra-axial and extra-axial; intra-axial tumours are divided into two categories based on anatomical location: supratentorial and infratentorial (Boop and Chuang, 2018; Mathilde *et al.*, 2018). The posterior fossa is within the infratentorial compartment; tumours in the posterior fossa account for 50% of all childhood brain tumours, according to Boop et al. (2018), however Mathilde et al. (2018), Zilli et al. (2021) and Dorner et al. (2007) placed that number higher at 60-70% (Dörner *et al.*, 2007; Mathilde *et al.*, 2018; Zilli *et al.*, 2021). Kayode et al. (2020) propose the percentage may be higher due to the limited access to diagnostic equipment in developing countries, leading to undiagnosed and unreported cases (Abolanle AA *et al.*, 2020). In South Africa, limited data is available on paediatric brain tumours due to a lack of data registries. To date, no funded research has been conducted in this area (Arnold-Day, 2019).

Posterior fossa tumours are the most common tumours o the CNS; they make up 50-70% of all CNS tumours (Voth, 2001; Mathilde *et al.*, 2018; Cohen, 2022). PFTs have a higher

morbidity and mortality rate compared to other tumours of the CNS due to their proximity to the brainstem (Boop and Chuang, 2018).

Diagnosis of a PFT is often delayed compared to other malignancies as the symptoms are non-specific, and therefore, children are frequently misdiagnosed (Boop and Chuang, 2018).

In 2007, Dorner et al. (2007) reported that the average time from initial symptoms to diagnosis was 142 days however, Boop et al. (2018) reported an improvement in diagnostic time to an average of 60 days, with 33% of children being diagnosed within a month (Dörner *et al.*, 2007; Boop and Chuang, 2018). These diagnostic times were reported in high-income countries (HIC); the average time in middle and low-income countries (MIC and LIC) is likely to be longer due to the lack of knowledge of signs of brain tumours, poor access to healthcare and lack of radiology equipment (Beringer *et al.*, 2021; Geel *et al.*, 2021).

Boop et al. (2018) reported that, on average, children were seen by two different medical specialities before undergoing radiological tests needed for a diagnosis (Dörner *et al.*, 2007; Mathilde *et al.*, 2018). Presenting symptoms depend on the tumour's location, growth rate, increased intracranial pressure, and histology of the tumour (Abu *et al.*, 2021). Children with PFT often present with complaints of headaches, vomiting and nausea, ataxia, behavioural and personality changes, and cranial nerve palsies (Voth, 2001; Vara Prasad *et al.*, 2017; Boop and Chuang, 2018; Mathilde *et al.*, 2018).

2.2.2 Types of posterior fossa tumours

Multiple different types of tumours occur in the posterior fossa. Tumours occurring in the posterior fossa can be divided into two categories: gliomas and CNS embryonal tumours. There are four primary tumours, and they are classified as gliomas: paediatric-type diffuse – low-grade gliomas, juvenile pilocytic astrocytomas, paediatric-type diffuse – high-grade gliomas and ependymal tumours (or ependymomas), (Cohen, 2022). CNS embryonal tumours are medulloblastomas, and other CNS embryonal tumours such as atypical teratoid-rhabdoid tumours (ATRT), embryonal tumours with multilayer rosettes, CNS neuroblastomas, FOXR2-activated tumours and CNS with BCOR internal tandem duplication tumours (Cohen, 2022). The most common tumours found in the posterior fossa are ependymomas, juvenile pilocytic astrocytoma (JPA), medulloblastomas and paediatric-type diffuse gliomas (Vara Prasad *et al.*, 2017; Boop and Chuang, 2018; Mathilde *et al.*, 2018; Meenakshisundaram and Dhandapani, 2018; Bose *et al.*, 2023).

Table 2.1. Type of tumours

Tumour Type	Location	Incidence	Age	Survival Rate	Treatment	Functional Implications
Ependymoma	Floor of the fourth ventricle and within the spinal cord (Boop and Chuang, 2018; Cohen, 2022)	5-10% of CNS tumours (Boop and Chuang, 2018; Cohen, 2022) in the United States Unknown in South Africa due to lack of registries	Under five years (Boop and Chuang, 2018)	30-60% progression free survival at ten years (Vara Prasad *et al.*, 2017; Mathilde *et al.*, 2018; Pollack, Agnihotri and Broniscer, 2019; Cohen, 2022).	Maximal safe resection and focal irradiation Role of chemotherapy is not well established	High risk of HCP and PFS
Juvenile pilocytic astrocytoma (JPA)	Cerebellar hemispheres and very rarely invade the floor of the fourth ventricle (Boop and Chuang, 2018; Cohen, 2022)	0-35% of brain tumours in children under the age of 20 years old (Voth, 2001; Zilli *et al.*, 2021; Cohen, 2022).	The mean age of diagnosis is nine years old (Voth, 2001; Boop and Chuang, 2018)	Ten-year survival rate of 90%, however reoccurrence is common (Voth, 2001; Zilli *et al.*, 2021; Cohen, 2022)	Complete resection can be curative, chemotherapy and radiation not indicated (Voth, 2001; Boop and Chuang, 2018; Mathilde *et al.*, 2018; Cohen, 2022)	Increased risk of HCP
Medulloblastomas	Occur mainly on the roof of the fourth ventricle, within the cerebellar hemispheres and 35% invade the brain stem (Boop and Chuang, 2018)	Approximately 40% of PFTs (Voth, 2001; Boop and Chuang, 2018; D'arco *et al.*, 2018; Cohen, 2022)	Average age at diagnosis is under five years old (Vara Prasad *et al.*, 2017; Boop and Chuang, 2018)	five-year survival rate of 70% in children diagnosed over the age of three (Liu *et al.*, 2022)	Maximal safe resection, craniospinal radiotherapy and multi-agent chemotherapy. (Vara Prasad *et al.*, 2017; Boop and Chuang, 2018; Pollack, Agnihotri and Broniscer, 2019).	Increased risk of HCP and PFS Impaired balance and coordination skills Poor oculomotor skills
Peadiatric type diffuse gliomas – High grade.	midline of the brainstem, pons, thalamus, and spinal cord (Voth, 2001; Cohen, 2022)	10% of brain tumours in children (Cohen, 2022).	Six-eleven years old (Arnold-Day, 2019)	70-90% die within two years of diagnosis and the five-year survival rate is 2% (Voth, 2001; Mathilde *et al.*, 2018; Cohen, 2022).	Radiotherapy is the most effective treatment as the role of chemotherapy is not yet established (Mathilde *et al.*, 2018; Pollack, Agnihotri and Broniscer, 2019; Cohen, 2022).	Increased risk of HCP and PFS
Peadiatric type diffuse gliomas – Low grade.				Five-year progression free survival rate of 69% (Cohen, 2022).	Maximal safe resection (unable to achieve if tumour is in the midline), and chemotherapy (Cohen, 2022)	

2.2.3 Anatomical location of tumour

2.2.3.1 Posterior Fossa and cerebellum

The posterior fossa is the most inferior of the cranial fossa and contains the cerebellum, brain stem (midbrain, pons and medulla oblongata), lower cranial nerves, the transverse and sigmoid venous sinuses, and the cerebral aqueduct and fourth ventricle (Sokolov, Miall and Ivry, 2017; Arnold-Day, 2019). The boundary of the posterior fossa is the tentorium cerebelli superiorly, the dorsum sella and clivus anteriorly and the petrous part of the temporal and occipital bones laterally. The foramen magnum at the base of the occipital bone forms the largest opening in the posterior fossa (Mumford and Banks, 2018).

The posterior fossa holds one of the most vital brain structures, the brainstem, which controls the respiratory centre, cardiovascular centre, and reticular activating system. These systems control respiration, heart rate and blood pressure, consciousness, and the ability to protect one's airway. Damage to this structure often results in death, and therefore, a tumour within the posterior fossa is life-threatening (Mumford and Banks, 2018).

The cerebellum is also found within the posterior fossa and has two hemispheres separated by the vermis and divided into three lobes: anterior, posterior and flocculonodular (Mumford and Banks, 2018; Jimsheleishvili and Dididze, 2023). Two transverse fissures separate the three lobes. The cerebellum contains nearly 80% of the brain's neurons (Hull, 2020; Sereno *et al.*, 2020; Jimsheleishvili and Dididze, 2023). The cortex of the cerebellum is made of a thin sheet of neuronal tissue which is folded to decrease the overall volume; the folds are composed of grey matter covering a white matter core (Hull, 2020; Jimsheleishvili and Dididze, 2023). The cortex of the vermis coordinates the movements of the proximal body, such as the trunk, shoulders, and hips, whereas the cerebellar hemispheres coordinate the distal muscles. According to Mathilde et al. (2018), the interior vermis is related to intelligence (Mathilde *et al.*, 2018). The lateral area of the hemispheres plays a role in the motor planning of the entire body (Jimsheleishvili and Dididze, 2023). Motor planning is essential for the ability of the body to produce accurate and controlled movements needed to participate in ADLs.

Although the functional cerebellar anatomy is poorly understood, it plays a role in controlling coordinated movement, postural balance, muscle tone and gait (Lassaletta *et al.*, 2015; Dreneva and Skvortsov, 2020). The cerebellum cannot initiate movement but rather uses learnt experiences to refine motor outputs (Jimsheleishvili and Dididze, 2023). King et al. (2021) proposed ten functional areas of the cerebellum (Figure 1), with large areas dedicated to motor planning, attention, and language processing (Haley and Freeman, 2018). As the cerebellum plays a role in coordination, children diagnosed with PFTs (PFT) present with ataxia, gait disturbances,

poor balance and oculomotor control dysfunction (Dreneva and Skvortsov, 2020; Hartley *et al.*, 2021).

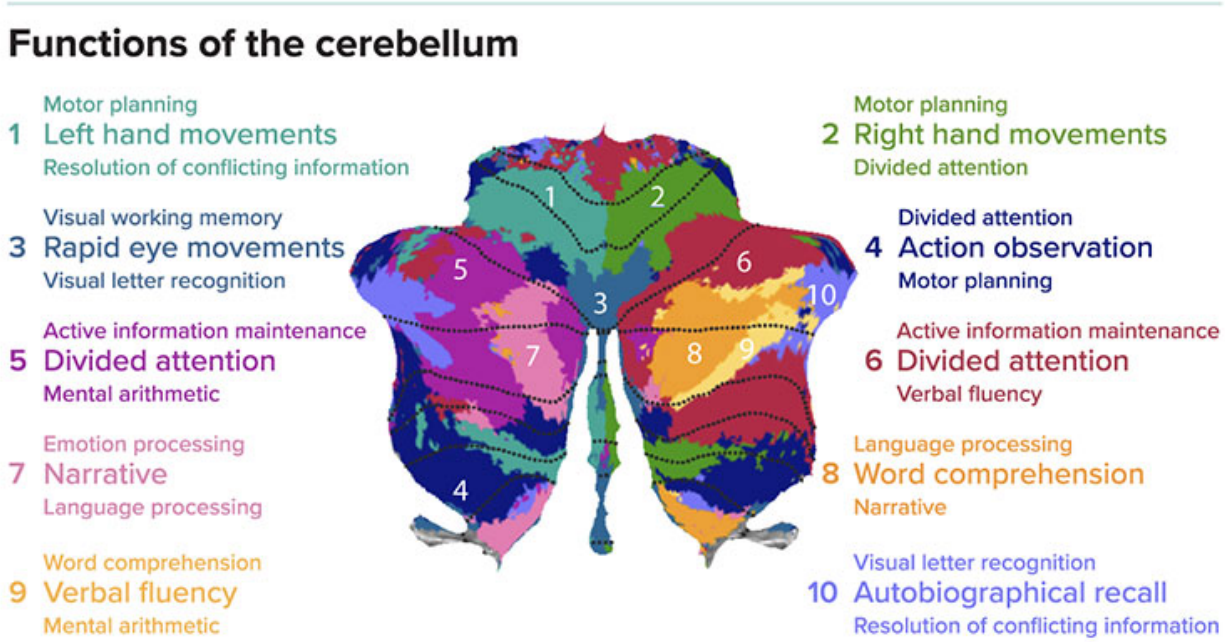


Figure 2.1 Functional anatomy of the cerebellum (Haley and Freeman, 2018)

Tumours in this area result in compression of the brain stem, herniation and death if not treated (Meenakshisundaram and Dhandapani, 2018). Damage to the cerebellum and brain stem can result from the tumour, the surgery to remove it, and the chemotherapy and radiotherapy used to treat the malignancy (Fischer *et al.*, 2016). Only a tiny percentage of children are cured by surgery alone, and the majority of cases require chemotherapy and radiotherapy (Rizzo, Daniela. Peruzzi, Laura. Attina, Giorgio. Triarico, Silvia. Maurizi, Palma. Ruggiero, 2017)

The cerebellum plays a vital role in four domains defined by Lessaletta et al. (2015): executive functioning, spatial cognition, personality and linguistic abilities (Lassaletta *et al.*, 2015; Hull, 2020). Stavinoha et al. (2018) published that 40%-100% of PFT survivors have an impairment in at least one of the above domains (Stavinoha *et al.*, 2018). Zilli et al. (2021) reported that damage to the cerebellum could result in difficulties in acquiring higher-order skills as there is prevention, modification or delay in the child's developmental trajectory (Zilli *et al.*, 2021). Disruption of the cerebellum by a tumour, injury or cerebral vascular accident results in the reorganisation of function, affecting developmental processes later on (Zilli *et al.*, 2021).

2.2.4 Medical Intervention

Treatment of PFT is challenging as it requires professional expertise, costly resources, and access to specialised equipment (Arnold-Day, 2019). Most often, treatment consists of a trimodal approach: surgery, chemotherapy and radiotherapy; however, it may differ according to the histology of the tumour (Arnold-Day, 2019; Hartley *et al.*, 2019). The factors that impact the success of treatment include the tumour type, location, presence of metastases, and the general health of the child (Arnold-Day, 2019).

Since the improvement of surgical techniques, greater knowledge, faster diagnosis and more effective treatment, the prognosis and lifespan of children are improving. Therefore, there needs to be an emphasis on rehabilitation to improve survivors' QoL, cognitive outcomes and long-term functioning in their categories of occupation (Panwala *et al.*, 2019; Chieffo *et al.*, 2022).

2.2.4.1 Surgery

PFTs are a challenge to treat due to their proximity to the brainstem, and therefore, they have a higher morbidity and mortality than supratentorial tumours (Boop and Chuang, 2018). Treatment for PFTs varies according to the type of tumour, age of the child at presentation and position of the tumour. However, gross total resection is appropriate for all tumour types except brainstem gliomas (Abu *et al.*, 2021; Cohen, 2022). Surgical treatment aims to decompress the posterior fossa and send a biopsy for histology to allow for further treatment planning (Abu *et al.*, 2021).

The gold standard treatment for PFTs is gross total resection, which doubles the five-year survival rate. However this is often unachievable due to the tumour's location to the brainstem and cranial nerves (Boop and Chuang, 2018; Cohen, 2022). Arnold-Day (2019) reports the extent of the resection is closely related to the child's overall prognosis (Arnold-Day, 2019). There are multiple factors to consider when planning for the resection of a PFT, including positioning, approach, and intraoperative monitoring (Boop and Chuang, 2018).

Multiple surgical approaches can be used; however, the safest and most direct approach is the midline suboccipital approach (Boop and Chuang, 2018). The aim of all approaches should be to avoid the floor of the fourth ventricle and irritation of the obex, which will result in persistent vomiting post-surgery with a high risk of aspiration (Boop and Chuang, 2018). Another consideration is avoiding incising through the cerebellar vermis, as this is known to cause a reduction in intellectual quotient (IQ) in PFT survivors (Mathilde *et al.*, 2018). Vermian lesions, including damage from surgery, have been shown to increase the risk of posterior fossa syndrome and more significant behavioural disturbances (Lassaletta *et al.*, 2015).

Besides the risk of injury to the brain during the surgery, numerous post-operative complications may occur. According to Gaudra et al. (2018), children who have undergone surgery within the posterior fossa should be monitored for two-three days in the PICU; however, this is often not done in South Africa due to limited PICU beds and prioritisation for those said beds (Mumford and Banks, 2018; D. Ballot *et al.*, 2019) as the posterior fossa contains vital structures that if damaged can cause catastrophic long-term cognitive, visual perceptual and motor deficits. Another complication pre and postoperative is HCP, which may cause further neurological impairment.

2.2.4.2 Adjuvant Treatments

Although gross total resection of a PFT is the aim of surgery, due to the proximity of the tumour to the brainstem, this is often not achievable (Vara Prasad *et al.*, 2017; Boop and Chuang, 2018; Hartley *et al.*, 2019). Chemotherapy and cranial radiotherapy therapy are two of the most commonly used adjuvant treatments to treat PFTs (Vara Prasad *et al.*, 2017; Mathilde *et al.*, 2018). The use, type and duration of chemotherapy and radiotherapy are determined by the histology of the tumour (Mathilde *et al.*, 2018).

Chemotherapy is the treatment of choice if the child is younger than three years old at diagnosis due to the detrimental impact that cranial radiotherapy has on the developing brain (Vara Prasad *et al.*, 2017; Mathilde *et al.*, 2018). Chemotherapy in brain tumours is less optimal compared to other cancers due to the blood-brain barrier, which restricts the delivery of chemotherapeutic agents (Arnold-Day, 2019). Chemotherapy is divided into cycles; the number of cycles and the drugs used are determined by the tumour's histology and the drugs' availability within the country of treatment (Abolanle AA *et al.*, 2020).

Chemotherapy has also been found to cause long-term motor and sensory problems secondary to toxicity (Boop and Chuang, 2018; Hartley *et al.*, 2019). Chemotherapy-induced neuropathy has also been reported to be a long-term side effect (Hartley *et al.*, 2019). A study done by Decock et al. (2022) reported that children who received chemotherapy as part of their treatment regime for their PFT performed poorly on tests of fine motor skills, speed and dexterity of bilateral hands, showing the detrimental effects of chemotherapy-induced neuropathy (Decock *et al.*, 2022). Deficits in fine motor skills will impact school performance and participation in ADLs and, therefore, need to be addressed in rehabilitation to allow for greater independence in children when they reach adulthood.

Cranial radiotherapy is radiation of the whole brain, focal areas of the brain or the entire brain and spinal cord. It is used to reduce the chance of tumours spreading through the CNS, prevent

reoccurrence or for palliation (Arnold-Day, 2019). Cranial radiotherapy plays an integral role in the treatment of PFT; however, it has many adverse effects on the brain as it results in white matter damage and associated necrosis due to decreased vascular density, apoptosis, and hypoxia (Lassaletta *et al.*, 2015; Arnold-Day, 2019; Baliga *et al.*, 2021; Zilli *et al.*, 2021). The disruption of myelination and neuronal growth impacts the developing brain and results in deficits in attention, short-term and working memory, IQ and processing speed. This, in turn, affects a survivor's ability to achieve independent living (Lassaletta *et al.*, 2015; Panwala *et al.*, 2019). Cranial radiation is the most effective treatment of medulloblastomas, ependymomas and brainstem gliomas (Vara Prasad *et al.*, 2017; Boop and Chuang, 2018; Arnold-Day, 2019).

The chronic effects of radiation include cognitive deficits, growth abnormalities, severe sensorineural hearing loss and secondary neoplasms (Boop and Chuang, 2018; Lundar *et al.*, 2020). Research has found that the higher the dose and frequency, the greater the long-term neurocognitive impairments (Panwala *et al.*, 2019; Baliga *et al.*, 2021). It has also been reported that the effects of radiation accumulate over time and result in deficits in executive functioning into adulthood (Lundar *et al.*, 2020).

Fischer et al. (2016) and Arnold-Day (2019) call for a multidisciplinary (MDT) approach to the management of children with central nervous system (CNS) tumours with a focus on early education, baseline neurocognitive testing and occupational therapy (OT), physiotherapy and speech therapy intervention (Fischer *et al.*, 2016; Arnold-Day, 2019). Decock et al. (2022) reported that therapy should focus on counteracting the effects of the surgery, chemotherapy and radiation to prevent cognitive and physical decline and secondary complications (Decock *et al.*, 2022).

2.2.5 Handling of Secondary Problems of Posterior Fossa Tumours

2.2.5.1 Hydrocephalus

Hydrocephalus (HCP) is defined by Greenburg (2019) as the pathological accumulation of cerebral spinal fluid (CSF) within the ventricle system (Voth, 2001). The flow of CSF is from the lateral ventricles, where it is produced, through the bilateral foramen of Monroe, into the 3rd ventricle, down the aqueduct of sylvuis and into the 4th ventricle. HCP may occur if there is an obstruction within the flow of CSF or malabsorption of the CSF.

HCP can be progressive and may result in a life-threatening emergency due to raised intracranial pressure (ICP), which applies pressure on the brainstem. Signs of increased ICP include headaches, nausea and vomiting, papilledema, gait changes and a persistent up-gaze, which all affect participation in ADLs (Voth, 2001). Even when not related to a PFT, HCP has been proven

to affect cognition in children significantly (Lassaletta *et al.*, 2015). Long-term treatment for HCP is surgical with two main options: CSF shunting or an endoscopic third ventriculostomy (ETV) (Voth, 2001; Lin and Riva-Cambrin, 2015; Mathilde *et al.*, 2018).

Up to 70-80% of children diagnosed with a PFT develop HCP, and 30% require neurosurgery to divert the build-up of CSF. The development of HCP is a result of compression of the fourth ventricle and/or the Sylvian aqueduct (Dörner *et al.*, 2007; Lassaletta *et al.*, 2015; Stavinoha *et al.*, 2018; Arnold-Day, 2019). Chih et al. (2015) reported that treatment of HCP pre-surgery improves the surgical resection of the tumour, which leads to decreased postoperative mortality and improves the postoperative course (Lin and Riva-Cambrin, 2015).

According to Boop et al. (2018), 10-20% of children will develop chronic HCP and require permanent CSF shunting post-resection of their PFT (Boop and Chuang, 2018). Chih et al. (2015) propose that this percentage may be closer to 40% depending on a variety of factors such as young age, larger preoperative ventricle size, midline tumour location and the presence of metastatic disease (Lin and Riva-Cambrin, 2015; Boop and Chuang, 2018). They also reported that the younger the child the more likely the child will develop persistent HCP (Boop and Chuang, 2018). The pathology of the tumour may also play a part in the development of chronic HCP, according to Chih et al. (2015). Medulloblastomas and ependymomas, which usually occur in the midline, have an increased risk of HCP (Lin and Riva-Cambrin, 2015). Chih et al. (2015) also reported that a gross total resection of the tumour decreased the risk of developing HCP (Lin and Riva-Cambrin, 2015; Cohen, 2022).

Mathilde et al. (2018) and Chieffo et al. (2021) both reported that presurgical HCP leads to a poorer cognitive outcome in comparison to children without HCP when they are diagnosed (Mathilde *et al.*, 2018; Chieffo *et al.*, 2021). This results from the neurotoxic effect on periventricular white matter due to decreased perfusion of these areas of the brain (Zilli *et al.*, 2021). Therefore, diagnosing HCP promptly and treating it timeously is essential to reduce its impact on the developing brain. Although an endoscopic third ventriculostomy (ETV) has the least number of complications, a ventriculoperitoneal shunt (VPS) is frequently used as the treatment for chronic HCP. (Voth, 2001). Another postoperative complication is posterior fossa syndrome, which also impacts engagement in occupations.

2.2.5.2 Posterior Fossa Syndrome

Posterior Fossa Syndrome (PFS) is the most common surgery complication within the posterior fossa. PFS often occurs between 12 – 72 hours post-surgery with a mean onset of 1.7 days (Voth,

2001; Lassaletta *et al.*, 2015; Boop and Chuang, 2018). The incidence is estimated between 11 – 30%; however, the severity of PFS is not well defined, and therefore, this number could be higher (Voth, 2001; Lassaletta *et al.*, 2015; Boop and Chuang, 2018; Mathilde *et al.*, 2018). The discrepancy in the incidence could be due to the majority of healthcare professionals defining PFS as a spectrum diagnosis rather than a defined condition (Wickenhauser *et al.*, 2020).

PFS is defined as a triad of 1) delayed onset of mutism, 2) cerebellar dysfunction and 3) neuro-behavioural affective symptoms, including emotional lability, irritability and apathy secondary to a cerebellar injury most frequently seen in children postoperatively after resection of a PFT (Voth, 2001; Boop and Chuang, 2018).

The causes of PFS are poorly understood however there are a few theories such as oedema as a result of vasospasm, cerebellar ischemia or transient dysregulation of neurotransmitter release post-surgical resection, damage to the dentothalamocortical pathway due to a midline tumour or surgical approach and pre-surgical language impairment as a contributing risk factor (Voth, 2001; Lassaletta *et al.*, 2015; Boop and Chuang, 2018; Arnold-Day, 2019). The type of tumour has also been hypothesised to impact whether a child develops PFT, with the highest risk being a medulloblastoma followed by an ependymoma and astrocytoma, respectively. This could be due to medulloblastomas and ependymomas often occurring within the midline of the cerebellum and within the fourth ventricle (Voth, 2001; Boop and Chuang, 2018).

There is no definitive medical treatment for PFS; therefore, the role of the MDT is crucial to the child's recovery (Boop and Chuang, 2018). Recovery from PFS varies; Greenburg (2019) reports a mean of 6.8 weeks, and Boop et al. (2018) reports 8.3 weeks. Greenburg (2019), Boop et al. (2018) and Mathilde (2018) all agree that although there is recovery, there are residual deficits that impact a child's QoL (Voth, 2001; Boop and Chuang, 2018; Mathilde *et al.*, 2018). Between 95-98.8% of children have speech and language impairments that are still present one year post-surgery, along with neuropsychiatric deficits such as cognitive impairment, executive functioning and memory deficits and emotional difficulties (Voth, 2001; Lassaletta *et al.*, 2015; Lin and Riva-Cambrin, 2015; Boop and Chuang, 2018; Mathilde *et al.*, 2018).

2.2.6 Functional impact of a posterior fossa tumour

Zilli et al. (2021) and Chieffo et al. (2022) reported that, unlike adults, a deficit affecting a single neurophysiological function can impact the acquisition, integration and application of further skills (Zilli *et al.*, 2021; Chieffo *et al.*, 2022). Therefore, it is essential to understand what client factors, the physiological functioning of body functions and structures, are affected to be able to address them within this sensitive window and allow for the development of the following skills and prevent

cognitive, motor and psycho-emotional delays (Boop *et al.*, 2020). PFT are more prevalent in children under the age of 10 years, an age at which many motor, cognitive, and psychosocial skills develop. Therefore, the tumour and subsequent treatment have a significant effect on their development as a whole (Dörner *et al.*, 2007).

2.2.5.1 Motor skills

The cerebellum is responsible for coordinated and refined movements. Therefore, damage to the cerebellum will influence the body as the child will show signs of ataxia (Hull, 2020). Ataxia presents as poor balance, gait disturbances, tremors of the limbs, speech disturbances and general incoordination. Of children with PFT, 58-90% of children present with ataxia (Hartley *et al.*, 2019; Chieffo *et al.*, 2022; Decock *et al.*, 2022).

It Is widely accepted that the cerebellum predictively modifies motor output to produce a well-coordinated, smooth and accurate movement through a neural connection to the basal ganglia and motor cortex which allows for motor planning (Hull, 2020; Tanaka *et al.*, 2021). Motor planning is a cognitive process in which execution, timing, and coordination of movement are idealised and initiated. Children with PFTs have difficulty with planning and execution of gross and fine motor movements; as Yeole et al. (2021) reported, this is most often affected by reoccurrences of the tumour post-treatment (Yeole *et al.*, 2021).

Postural balance is also one of the most affected physical domains of children with PFT (Decock *et al.*, 2022). Postural balance is the ability to assume and maintain the line of gravity related to one's base of support within static and dynamic tasks. This requires good motor function and an effective interaction between the somatosensory, visual and vestibular systems (Kramer and Hinojosa, 2011; Dreneva and Skvortsov, 2020). Postural balance demonstrates the complexity of the functions of the cerebellum as it integrates multiple systems to produce a stable upright position. The proprioceptive system is also required to have postural balance as it gives the cerebellum information regarding a person's position in space.

Another motor skill impacted is hemiparesis, which can occur in approximately 25% of children diagnosed with a PFT (Kakar *et al.*, 2020; Abu *et al.*, 2021). Kohler et al. (2021) report that children display marked lower limb weakness following treatment that persists into adulthood (Kohler *et al.*, 2021). There is very little literature on hemiparesis in PFT; however, clinical observations have shown that most children present with a marked weakness and non-use of the ipsilateral side of the tumour, which improves postoperatively.

2.2.5.2. Executive functioning

Executive functioning is required for all tasks throughout the day, and deficits in this area impact one's ability to complete schooling, maintain a job and complete age-appropriate ADLs (Magalhães *et al.*, 2020; Doris *et al.*, 2022). Executive functioning relies on the interplay between neural circuits in both the cortical and subcortical areas (Zelazo, 2020; Chieffo *et al.*, 2022). Although executive functioning has been linked to the lateral hemispheres of the cerebellum, it is the result of the connection between the cerebellar areas, frontal and prefrontal areas of the cerebrum (Lassaletta *et al.*, 2015; Tanaka *et al.*, 2021; Chieffo *et al.*, 2022; Doris *et al.*, 2022). The cerebellum modulates function via neural loops (Decock *et al.*, 2022).

Doris et al. (2022) propose that executive functioning develops in a stepwise manner and, therefore, requires sequential acquisition of sensory regulation, perception, motor skills, attention and concentration, and memory (Harvey, 2019; Doris *et al.*, 2022). These elements form the three skills of executive function: inhibitory control, working memory, and cognitive flexibility (Zelazo, 2020; Doris *et al.*, 2022).

Inhibitory control pertains to attention, selective and sustained, to focus on a task. Attention is a multifaceted construct that requires an active process to determine what sensory stimuli and experiences are alerting and relevant and has been associated with the neocerebellar areas of the hemispheres and vermis (Slack, 1998; Decock *et al.*, 2022). 50% of children who received treatment for a PFT struggled with alternating attention (ability to alternate back and forth between tasks), sustained attention and selective attention (ability to activate and inhibit responses to be able to focus on an important task) (Slack, 1998; Lassaletta *et al.*, 2015; Zilli *et al.*, 2021). Inhibitory control leads to working memory, as one can now attend to information, keep it in mind, and manipulate it functionally (Zelazo, 2020).

Working memory is the most affected component of memory by PFT and its treatment (Lassaletta *et al.*, 2015; Laliberté Durish *et al.*, 2021; Decock *et al.*, 2022). Working memory is defined by Harvey (2019) as the ability to attend to information for practical use continuously. It has two components: maintenance of information and manipulation of information (Harvey, 2019). Working memory requires the integration of sensory input and manages the information received to be laid down into long-term memory (Webster, 2009a; Harvey, 2019). Working memory is required for reasoning, comprehension, learning and long-term memory (Lassaletta *et al.*, 2015). Working memory is also needed for conversations and recall of information in social circumstances (Levitch *et al.*, 2022). Working memory has been found to decline over time post-treatment of a PFT, resulting in long-term difficulties in engaging in schooling, social participation and the ability to live independently (Doris *et al.*, 2022).

Lastly, cognitive flexibility allows one to think of information in multiple ways and switch between knowledge of concepts, judgment and problem-solving to perform a goal-directed activity (Magalhães *et al.*, 2020). Cognitive flexibility allows one to learn from mistakes, use feedback, adjust responses, and process new information (Magalhães *et al.*, 2020). Impaired cognition is one of the three most common complications of a brain tumour, with 80% of survivors impacted (Lassaletta *et al.*, 2015; Laliberté Durish *et al.*, 2021; Chieffo *et al.*, 2022). Cognition can be impaired due to the tumour itself, surgery or the adjuvant treatment given (Lassaletta *et al.*, 2015; Yeole *et al.*, 2021). Executive functioning is needed for academic achievement, adaption to the environment, and abstract thinking which is required for day-to-day functioning (Lassaletta *et al.*, 2015).

Due to the complexity of executive function, it should be assessed through behavioural observations, collateral information from the family, and standardised assessments (Doris *et al.*, 2022). Hoffman et al. (2022) reported discrepancies between parent's reported evaluation of their child's abilities compared to their actual performance. The difficulty in assessing executive functioning impacts the ability to provide accurate, component-specific rehabilitation; therefore, it is vital to get a better assessment of these functions (Doris *et al.*, 2022). Children who survive treatment show a gradual decline in their executive functioning and cognitive skills as the executive functioning demands increase from childhood to adulthood, thus affecting their ability to function within society (de Vries *et al.*, 2018; Laliberté Durish *et al.*, 2021).

Previously literature further reported that the younger a child was at diagnosis, the lower the child's IQ after treatment however, Yeole et al. (2021) reported that the younger the child at diagnosis the higher their IQ post-treatment, they hypothesised that younger children received targeted treatment in an attempt to spare their IQ and had the additional benefit of neuroplasticity (Yeole *et al.*, 2021). Chieffo et al. (2021) didn't consider age as a factor when looking at neurocognition in PFT survivors. However, they did report that the location of the tumour, lower level of cognition at diagnosis and the presence of HCP were indicative of lower IQ outcomes. Post-surgery, the tumour grade and use of adjuvant treatments indicated lower levels of IQ (Chieffo *et al.*, 2021).

2.2.5.3 Vision and Visual Perception

For adaptive, functional vision, there are three necessary components: integrity of the optic system, processing of sensory and proprioceptive information and integration of the response (Slack, 1998)

Many children presenting with a PFT have difficulty with their optic system due to papilledema, diplopia, nystagmus and/or strabismus (Voth, 2001; Dörner *et al.*, 2007; Boop and Chuang, 2018), Gadgil et al. (2018) reported that only 2% of PFT survivors have moderate to severe visual acuity loss, and 88% with good visual acuity at their last follow up, approximately 12 months from presentation (Gadgil *et al.*, 2019). Therefore, it is justified to extrapolate the PFT survivors' VP deficits result from damage to the cerebellum rather than to the cranial nerves. The degree to which oculomotor control was affected correlates with the type of tumour with medulloblastomas at the highest risk compared to low-grade gliomas (Peeler *et al.*, 2017). However, Peeler et al. (2017) reported that overall survivors had good visual outcomes and children with persistent visual dysfunction could compensate for their visual loss (Peeler *et al.*, 2017).

VP is defined as the process in which sensory information is integrated and interpreted based on prior development, learnt experiences and stimulation from the environment (*Test of Visual Perceptual Skills-4*, 1017; Kramer and Hinojosa, 2011; Harvey, 2019). VP requires visual acuity, visual accommodation, bi-ocular fusion, convergence, oculomotor skills and vision in all visual fields (Kramer and Hinojosa, 2011). A common issue in children with PFTs is poor oculomotor skills due to poor coordination and nystagmus; this impacts a child's ability to shift from one object to another, fixation, pursuits and saccadic eye movements (Kramer and Hinojosa, 2011). All these skills are needed to read, search for an object, or engage in sports.

VP is affected in 50% of children post-treatment, with deficits in visual motor integration and spatial cognition (Chieffo *et al.*, 2021; Zilli *et al.*, 2021). VP includes attention and visual memory, object discrimination and visual-spatial skills (Kramer and Hinojosa, 2011)

VMI (visual motor integration) is a skill that integrates the coordination of a visual stimulus with an appropriate motor action (Kramer and Hinojosa, 2011). As a PFT impacts both VP and motor coordination, children with this condition often struggle with VMI, which affects their ability to write, engage in sports and copy visual images (Zilli *et al.*, 2021)

Vision plays a significant role in our ability to interact and adapt to the environment, have postural control and good motor planning and therefore, many ADLs are reliant on our ability to make use of vision, VP and visual motor integration (Slack, 1998). Thus, an in-depth vision and VP assessment of children diagnosed with a PFT is essential. The gold standard tests for VP and VMI are the Beery-Buktenica Developmental Test of Visual-Motor Integration (Beery-VMI) and Test of Visual Perceptual Skills (TVPS), which are both used in this research study.

2.2.5.4 Psychosocial functioning

Although researched less often, PFT affects a child's psychosocial functioning and puts them at higher risk for anxiety, depression and behavioural problems (Stavinoha *et al.*, 2018). Cerebellar damage in childhood can disrupt the normal development of psychosocial skills, which persist into adulthood (Lassaletta *et al.*, 2015; Lanier and Abrams, 2017). Lanier et al. (2017) call for clinicians to understand better the long-term psychosocial impairments these children face to aid in collaborative care, supportive services and rehabilitation (Lanier and Abrams, 2017). Executive function deficits often impact a child's social participation, impacting their behaviour (Slack, 1998).

2.2.5.5 Behaviour

Behaviour is defined as the ability to regulate impulses, inhibit action, tolerate changes and reflect on emotion (Doris *et al.*, 2022). Behavioural difficulties may be present pre or post-surgery and can be disabling for the child and the family, especially when they last long-term (Lassaletta *et al.*, 2015; Chieffo *et al.*, 2022). The younger the age at diagnosis, the more severe the issues appear (Doris *et al.*, 2022). Behaviour is directly related to the location of the tumour, frontal neuroanatomical areas, and the use of chemotherapy and radiation (Chieffo *et al.*, 2022).

Behaviour difficulties require prompt treatment to allow for active engagement and interest in post-surgical rehabilitation (Chieffo *et al.*, 2021, 2022). Chieffo et al. (2021) reported that survivors showed persistent distractibility, hyperactivity, impulsiveness, aggression, disinhibition, rumination and obsessive behaviours, all of which impact performance and engagement in ADLS, most importantly education and social participation (Chieffo *et al.*, 2021).

2.2.5.6 Emotions

Children with PFT often struggle with emotional regulation and affect; this has been associated with damage to the cerebellar vermis (Arasanz *et al.*, 2012; Lassaletta *et al.*, 2015). Children are often emotionally labile and struggle with mood stability and regulation (Chieffo *et al.*, 2021). For years post-treatment, survivors also struggle with anxiety and depression (Chieffo *et al.*, 2021).

Yeole et al. (2021) reported that children from households with higher maternal education reported less worries and anxiety than children from homes without maternal education (Yeole *et al.*, 2021). Durish et al. (2021) reported that brain tumour survivors from high socioeconomic status (SES), well-functioning families and two-parent households had better psychosocial outcomes. They hypothesised that it was due to better attachment and emotional stability within the household that

allowed for communication, cohesiveness, and opportunities to practice emotional regulation (Laliberté Durish *et al.*, 2021).

2.2.7 Survival rate

With recent medical advances, the survival rate for children diagnosed with PFTs is increasing (Stavinoha *et al.*, 2018). As the survival rate is rising, it is now more important than ever to determine the long-term neurocognitive and neuromotor consequences of treating these tumours on the functional outcomes of the survivor's (Lassaletta *et al.*, 2015). Pollack et al. (2019) stated that although the survival rate is increasing, it comes at a cost when considering the long-term effects the treatment has on the survivor.

Meenakshiundaram et al. (2018) reported the survival rate of PFTs is 85% in children diagnosed over the age of three (Meenakshisundaram and Dhandapani, 2018), Fischer et al. (2016) reported a 75% five-year survival rate in children between the ages of zero to 19 (Fischer *et al.*, 2016). With this increase in survival, successful treatment should aim to treat the tumour with minimal risk of neurocognitive and motor impairments (Lassaletta *et al.*, 2015). Stavinoha et al. (2018), Rizzo et al. (2017) and Lassaletta et al. (2015) all report that the younger the child is at diagnosis, the more significant the impairment to the child's intellectual quotient, processing speed and working memory (Lassaletta *et al.*, 2015; Rizzo, Daniela. Peruzzi, Laura. Attina, Giorgio. Triarico, Silvia. Maurizi, Palma. Ruggiero, 2017; Stavinoha *et al.*, 2018). However, when looking at PFT survivors, it is essential to note the multifactorial nature of the condition and the confounding factors that surround it; the precise location of the tumour, the use of radiotherapy and the presence of hydrocephalus (HCP) also play a prominent role in the overall functional prognosis of the child (Johnsen, 2017; Rizzo, Daniela. Peruzzi, Laura. Attina, Giorgio. Triarico, Silvia. Maurizi, Palma. Ruggiero, 2017; Panwala *et al.*, 2019).

(Pollack, Agnihotri and Broniscer, 2019). Therefore, emphasis needs to be placed on reducing the morbidity of the treatment and increasing the rehabilitation the child receives to minimise these long-term deficits (Pollack, Agnihotri and Broniscer, 2019).

2.2.8 Rehabilitation

Although it is widely recognised that a posterior fossa tumour and its treatment affect multiple systems and impacts the survivor's QoL and engagement in their occupations, there are no standardised rehabilitation interventions for these children internationally (L'Hotta, Beam and Thomas, 2020; Houdeshell *et al.*, 2021; Rossi *et al.*, 2024). The lack of rehabilitation programs can be attributed to difficulties in scheduling intensive rehabilitation between multiple doctor's

appointments, chemotherapy sessions, and radiation treatments, as well as down referrals hospital programs to community-based care, which result in poor continuity of therapy and the lack of MDT collaboration (L'Hotta, Beam and Thomas, 2020; Houdeshell *et al.*, 2021; Rossi *et al.*, 2024).

The treatment of children with PFT should follow a MDT approach focused on improving muscle strength, flexibility, neurocognition and quality of life using a neuromotor, sensorimotor and cognitive frames of reference (Michel *et al.*, 2020; Houdeshell *et al.*, 2021; Rossi *et al.*, 2024). Neurorehabilitation should be initiated as soon as the child is stable post-surgery to maximise the effectiveness, with personalised joint goal setting involving the patient and family (Rossi *et al.*, 2024). Rossi et al. (2024) reported that the length of rehabilitation should be based on the needs of the child and not determined by resources or therapy setting (Rossi *et al.*, 2024).

Although need for physical rehabilitation is well recognised, Michel et al. (2020) reported that there needs to be a focus on psychological care as children with CNS tumours showed greater rates of psychological distress post treatment and high levels of anxiety when reintegrating into school impacting their academic performance and leading to neurocognitive fallout (Michel *et al.*, 2020).

It is imperative to address the complex, multi-dimensional needs of children who have undergone treatment for PFTs. The absence of standardized international rehabilitation protocols highlights the need for coordinated, MDT efforts to support physical recovery, address neurocognitive impairments and QOL. Effective neurorehabilitation should begin early and be individualised to each child's needs, with collaboration between healthcare providers, children and the family. By prioritizing a holistic, child-centred approach, paediatric PFT survivors will have improved QOL and reintegration into school timeously.

2.3 POSTERIOR FOSSA TUMOURS IN THE SOUTH AFRICAN CONTEXT

2.3.1 Medical Context

Although it is well published that PFTs result in morbidities, there is no published data in South Africa looking at the functional outcomes of survivors and how their access to resources, medical professionals or treatment centres, and rehabilitation protocols impact them further (Arnold-Day, 2019).

In low-middle countries, children often present late, receive inadequate treatment and are frequently lost to follow-up due to high default rates (Arnold-Day, 2019). Arnold-Day (2019) reported that in Africa, children with intracranial tumours are less likely to be diagnosed due to the lack of diagnostic equipment and failure to present to medical facilities (Arnold-Day, 2019). This could also be accounted to the lack of awareness of the signs and symptoms of intracranial tumours by the community and healthcare workers (Ndlovu, 2019; Geel *et al.*, 2021). At a national level, there are no protocols or guidelines on managing paediatric brain tumours, nor are there any guidelines on who should be involved in the care (Arnold-Day, 2019).

In South Africa access to PICU is limited and therefore, children presenting with signs of increased ICP are observed in the general ward as PICU beds are reserved for children requiring ventilatory support and not neuromonitoring (D. E. Ballot *et al.*, 2019). This poses a risk for increased morbidity and mortality as these children do not receive the monitoring they need, and emergent signs of raised ICP may not be noted until significant damage to the brain has occurred (Voth, 2001; Boop and Chuang, 2018).

Post-surgery access to paediatric cranio-radiation is often limited as it requires specialist training, experience and equipment to be done and therefore many South African centres cannot provide it (Arnold-Day, 2019). Africa has the lowest access to radiation despite it being the most cost-effective tool in the treatment of cancers. Some of the barriers to access are the availability of the machine due to high demand, geographical access, affordability, availability of accommodation near a machine and lack of awareness of the importance of radiation as a treatment option (Ndlovu, 2019). As children in South Africa often don't receive the treatment they require, it is crucial to study their functional outcomes.

2.3.2 Occupational Therapy Context

As a PFT diagnosis is often made late in African countries, it is therefore vital for occupational therapists (OTs) to be educated on the deficits that these children present with so that intervention can be optimised, specific and provided timeously. The provision of rehabilitation, both pre and post-operatively, that targets the unique deficits this population presents with will decrease the burden on the healthcare system due to less time to discharge and allow for the transition into the appropriate formal schooling.

OTs have the unique ability to treat cognition, visual perception (VP), motor abilities, behaviour and categories of occupation, which facilitates functioning within the community and improves

QoL (Avello-Sáez *et al.*, 2022). Therefore, OTs should play an essential role in the planning and execution of neurorehabilitation of children with PFTs. Greater knowledge of the functional outcomes of paediatric PFT survivors would allow for more advocacy for the creation of protocols on how to manage childhood brain tumours in South Africa (Parkes, Davidson and Figaji, 2014).

Yeole et al. (2021) reported that cognition is impacted by many factors, such as genetics and environmental stimulation (Yeole *et al.*, 2021). Their study found that the higher the family's income, the higher the child's IQ after undergoing treatment for a PFT. They postulated that this may be a result of greater access to schooling. They also reported that maternal education level also played a role in IQ outcomes, with children from homes with higher maternal education having higher IQs compared to low maternal education; this could be a result of higher levels of environmental stimulation (Yeole *et al.*, 2021; Hoffmann-Lamplmair *et al.*, 2023). Durish et al. (2021) published that children from functional families and two-parent households have higher IQ outcomes than their counterparts (Laliberté Durish *et al.*, 2021). In South Africa, the average level of education is below completion of grade 12, and therefore, the effect of the lower level of education on the functioning of children with PFTs should be examined (Khuluvhe and Ganyaupfu, 2022).

There are no published studies in South Africa reporting on the incidence of learning disabilities after the surgical and medical management of paediatric brain tumours; however, it can be extrapolated from studies done by Stavinha et al. (2018), Nair (2017), Ajithkumar (2017) that children in South Africa will show the same cognitive decline as that of children internationally (Ajithkumar *et al.*, 2017; Nair, 2017; Stavinoha *et al.*, 2018). Yeole et al. (2021) call for protocols for both follow-up and assessment of neurocognitive function, special school education and cognitive support groups for children and parents (Yeole *et al.*, 2021).

2.4 OCCUPATIONAL THERAPY IN POSTERIOR FOSSA TUMOURS

Occupational therapy (OT) is the use therapeutic use of daily activities to increase participation in the roles, routines and habits that make up occupations. The activities chosen in therapy are purposeful and valuable to the unique person and aim to treat client factors and performance skills. Occupational therapy can be rehabilitative, habilitative or promote health and wellness (Kramer and Hinojosa, 2011). OTs have the unique ability to treat, either by improving, maintaining or compensating, all domains impacted by a PFT: physical skills, cognitive and visual perceptual abilities, participation in ADLs, and positively impacting QoL through activity participation and individualised treatment (Avello-Sáez *et al.*, 2022).

Decock et al. (2022) reported on the effects of individualised rehabilitation programmes on the functioning of PFT survivors. They found that after rehabilitation, there was a positive effect on body coordination, strength and agility, object manipulation and fine motor control. There was, however, no improvement in postural balance, deterioration in lower limb functioning, visual-motor integration and executive functioning (Decock *et al.*, 2022).

A limitation of their study is that it doesn't report who the MDT team members were; therefore, it is difficult to establish whether OT was involved in the treatment of these children. However, it still adds value to the treatment planning of OTs as it identifies areas that should be improved and compensated for. This study was conducted in Belgium and indicated a further need to determine whether South African children experience the same deficits as their population for accurate OT assessment and treatment (Decock *et al.*, 2022).

2.4.1 Impact of posterior fossa tumours on participation in occupations

2.4.1.1 Activities of daily living

Research on how physical impairments resulting from a PFT and its treatment affect a child long-term is sparse. However, deficits in postural balance and motor planning, ataxia, weakness and poor executive functioning will impact a child's developmental milestones and ability to engage in age-appropriate ADLs such as dressing, bathing, toileting and eating (Decock *et al.*, 2022).

Panwala et al. (2019) published that HCP was also a contributing factor when looking at a survivor's ability to engage in their ADLs and function independently because of lower IQ, attention and informational processing impairments leading to poor adaptive functioning (Lassaletta *et al.*, 2015; Panwala *et al.*, 2019).

Kohler et al. (2021) report that children showed symptoms of fatigue months to years after completing treatment for a PFT. They proposed that this fatigue then impacted the child's participation in ADLs, thus contributing to poor cognition, working memory and difficulties with attention (Kohler *et al.*, 2021). This fatigue also impacts the child's ability to participate in school and age-appropriate play.

2.4.1.2 Play:

Children with PFTs often have long-term gross and fine motor deficits, ataxia, poor motor planning and postural control, impacting their ability to participate in physical activity (Hartley *et al.*, 2021; Chieffo *et al.*, 2022; Decock *et al.*, 2022). Another deficit that impacts a child with a PFT to be able

to engage in play is fatigue, both physical and mental, due to deconditioning and side-effects of chemotherapy and radiation (Decock *et al.*, 2022; Levitch *et al.*, 2022).

Participation in sports, an age-appropriate form of play in the paediatric population, positively impacts social participation and the formation of relationships. As a result, they need help to keep up with their peers in play activities. Not participating in play influences their ability to form relationships and engage in play (Hoffmann-Lamplmair *et al.*, 2023).

2.4.1.3 Social participation:

Children with PFT struggle with social participation due to a variety of factors, including difficulties with speech and language, poor executive functioning, extensive periods of hospitalisations and side effects of the lifesaving treatments that they go through.

Cerebellum lesions can result in speech disturbances such as dysfluent speech patterns, dysarthria and slower speech rate (Lassaletta *et al.*, 2015; Chieffo *et al.*, 2022). it is postulated that speech dysfunction will impair a child's ability to relate to their peers, engage within the classroom and put them at risk for bullying. Although brain tumour survivors have reported an increased incidence of bullying at school, this has not been formally studied. Chemotherapy and radiation also play a role in social participation, as children with PFTs have reported being bullied about their appearance as a result of chemotherapy and radiation (Law *et al.*, 2023).

Besides the effects of the PFT and treatment, children miss extended periods at school due to prolonged hospitalisations, and they often report loss of previous friendships (Hoffmann-Lamplmair *et al.*, 2023; Law *et al.*, 2023). Since social participation is an essential occupation, poor performance in this domain decreases QoL.

Children with PFT are often also impulsive, tangential and socially inappropriate, leading to social ostracisation (Slack, 1998). PFT survivors have difficulty with social behaviour, forming and maintaining relationships and building romantic relations in adulthood, which is also impacted by low self-esteem, which many survivors suffer from, according to Law et al. (2023). (Hoffmann-Lamplmair *et al.*, 2023; Law *et al.*, 2023).

Another element of social participation that is impacted by treating a PFT is the child's family structure. The stress of treatment puts strain on marital relations, places the caregiver at the centre of the child's medical care and decreases the ability of the family to socialise and engage in their ordinary occupations. The treatment also puts strain on siblings as attention, time and resources are focused on the child going through the treatment. Research has shown that siblings of children

undergoing treatment have a reduction in their participation in their ADLs due to isolation and an increased risk of developing anxiety and depression (Alghamdi *et al.*, 2023; Law *et al.*, 2023).

Law et al. (2023) reported that children with brain tumours develop a greater dependence on their family continuing into adulthood and often cannot achieve full independence (Law *et al.*, 2023). Therefore, reintroducing them to formal schooling as soon as possible is essential to decrease dependency on the family and increase independence in occupations.

2.4.1.4 Education:

Academic performance relies on integrating executive functions, attention, memory, and visual perceptual skills. Attendance at a mainstream school also requires coordination, postural balance and stability, and motor planning to mobilise around the school and engage in sports. A PFT impacts all these abilities, making it difficult to participate in education. Besides the effect of the PFT, the need for CSF diversion due to persistent HCP and high-dose radiation demonstrated worse academic outcomes in comparison to those who went without; this indicates a need for clinicians to take note of what postoperative complications were present when planning a treatment program (Lassaletta *et al.*, 2015; Hoffmann-Lamplmair *et al.*, 2023). Behavioural disturbances also affect the ability to participate in school (Lassaletta *et al.*, 2015).

Neurocognitive changes, therefore, contribute to the functional impairments experienced by paediatric fossa tumour survivors. Lessaletta et al. (2015) and Stavinoha et al. (2018) reported that internationally, there is an increased risk of PFT survivors dropping out of high school or college and ending up unemployed due to impairment in their executive functioning (Lassaletta *et al.*, 2015; Stavinoha *et al.*, 2018). This is substantiated by the report, Children with Disabilities in South Africa: A Situation Analysis: 2001-2011, which reports that 37% of adolescents with disabilities between the ages of 16-18 drop out of school, compared to the 14% without disability (DSD, DWCPD, UNICEF 2012).

Of PFT survivors, approximately 60% are able to go back to school, with a delay of one year; however, approximately 30% of these children will require specialised schooling (Yeole *et al.*, 2021; Hoffmann-Lamplmair *et al.*, 2023). At five years post-treatment, this number increases to 55% and at ten years, 80% (Yeole *et al.*, 2021). This is consistent with reports that cognitive decline in children with PFT is accumulative and has a detrimental outcome on their overall cognition and ability to be independent as adults.

In 2018, it was reported that 70% of children with disabilities were not enrolled in schools, and only 30% enrolled in special schools (Kiru and Cooc, 2018). In 2019, the waiting list for placement

in a school across the nine provinces had over 2352 children with disabilities. It is, therefore, unlikely that the survivors of PFTs will have timeous placement in an appropriate school (Ms B Mbinqo-Gigaba (ANC), 2019).

Although the Guidelines to Ensure Quality Education and Support in Special Schools and Special Schools Resource Centres 2014 published by the Department of Basic Education states that all special schools should have professional specialist support personnel, including OTs, no data supports that this is reality. This is echoed by the Director General of the Department of Education, who reported during the Parliamentary Monitoring Group that as of the 30th of October 2019, he was unsure of the ratio of members of the MDT to learners in special schools (Ms B Mbinqo-Gigaba (ANC), 2019).

2.4.1.5 Quality of life

Quality of life measures how content they are in different aspects of their lives; it includes emotional well-being, overall mood and sense of fulfilment and satisfaction within their ADLs (Lassaletta *et al.*, 2015). Chieffo et al. (2021) wrote that the first step to being able to improve a child's functioning and QoL is to recognise and measure the effects of both short-term and long-term consequences of a PFT and subsequent treatment (Chieffo *et al.*, 2021). Demers et al. (2016) and Kohler et al. (2021) reported that survivors of PFT have the lowest self-reported QoL when self-evaluating using the health-related QoL; however, there is little research to date that looks at the QoL of children (Demers, Gelinas and Carret, 2016; Kohler *et al.*, 2021; Yeole *et al.*, 2021).

The most significant contributors to this low QoL are unemployment, poor educational outcomes and less independence in ADLs due to poor physical and intellectual function and psychological disturbances (Lassaletta *et al.*, 2015; Demers, Gelinas and Carret, 2016). Yeole et al. (2021) reported that QoL depended on geographical, social, economic and cultural influences (Yeole *et al.*, 2021). This was demonstrated in India, where QoL was influenced by income; the lower the family income, the lower the reported QoL was for the child (Yeole *et al.*, 2021). Lassaletta et al. (2027) reported that those who experienced HCP and from lower socioeconomic status experienced lower QoL (Lassaletta *et al.*, 2015).

Poor QoL, along with functional deficits, shows the overall burden experienced by these children. Therefore, it is essential to determine the specific areas that lead to poor QoL of paediatric PFT survivors to be able to focus on early rehabilitation in these areas (Decock *et al.*, 2022). Holistic treatment of the functional deficits in these children will lead to an improved QoL.

Adequate assessment of a child's functioning is essential to address their occupation deficits. Several assessments will assist the occupational therapist in determining these difficulties in performance.

2.4.2 Assessments

2.4.2.1 Quick Neurological Screening Test (QNST-3R)

The QNST-3R is a standardised assessment of motor planning and control, as well as the integration of sensory information. It is individually administered and can be used from ages five to geriatric. The QNST-3R is designed to assess neurological soft signs (NSS), which are subtle abnormalities in the connection between subcortical and cortical regions of the brain. These NSS are related to difficulties in learning, neurocognitive performance and participation in ADLs and include involuntary movements, dysrhythmia, dysmetria, dysdiadochokinesia, dysgraphesthesia and impaired fine-motor coordination. NSS are nonspecific signs that may indicate a risk of developing or the presence of a variety of conditions. Therefore, diagnosis of a condition should only be made after a thorough evaluation of the patient (Mutti *et al.*, 1998).

The QNST-3R is a series of 11 administered tasks and two observable components: left-right skills and behaviour. The processes assessed in the QNST-3R include motor maturity and development, tactile and kinaesthetic processing, gross and fine motor control, motor planning and sequencing, spatial organisation, visual and auditory perception, balance and vestibular functioning and inhibition of associated movements. The QNST-3R is a screening tool and should only be administered by OTs, psychologists, rehabilitation specialities and educators (Mutti *et al.*, 1998).

The QNST-3R takes approximately 20 minutes to administer and 10 minutes to score. Although it can usually be administered in a single session, it can be broken up over multiple sessions if the participant requires frequent breaks. The testing environment should be free of visual and auditory distractions, and the participant should feel comfortable and at ease. The scoring of the QNST-3R is interpreted as functional classifications and not as standardised scores, which means that these scores cannot be directed compared to the scores of the TIPS, TVPS-4, and Beery-VMI. However, the information obtained from the QNST-3R is unique and, therefore, was important to include in this research so that the data collected on each participant was holistic (Mutti *et al.*, 1998).

Based on both Cronbach's alpha and McDonald's omega coefficients demonstrate that the QNST-3R has an acceptable level of internal consistency. The QNST-3R has excellent temporal stability

with coefficients between 0.53 – 0.93, with a test-retest correlation for the Total score of 0.90 (Mutti *et al.*, 1998).

2.4.2.2 Test of Information Processing Skills (TIPS)

The TIPS was designed to assess the executive function of children and adults and is used to assess processing skills required to acquire, organise, retrieve, use, and manage information that is seen and heard. These skills are all needed to participate in age-appropriate ADLs, including school and work (Webster, 2009a).

The TIPS is comprised of four parts: visual modality, auditory modality, delayed recall, and word fluency. The visual and auditory modalities are scored based on ordered and unordered skills, short-term memory, working memory 1 and 2, and delayed recall. Word fluency uses oral and written responses to identify language generation, word finding and retrieval, and semantic fluency and processing (Webster, 2009a).

The scoring structure of the TIPS allows for the calculation of subtest scaled scores and standard scores with age-adjusted norms. These scores enable the examiner to analyse the data through various scores and determine patterns to understand the examinee's information processing and memory skills fully. Using the scores together allows for understanding a person's information acquisition and ability to store and retrieve the information. Although the norms are based on a representative sample of individuals living in the United States of America, in this research, the scores of each participant were compared to their own scores longitudinally. Therefore, the norms were not utilised (Webster, 2009a).

The most appropriate method of determining the TIPS's internal consistency is through item intercorrelations and factor analysis. Scores within modalities had a higher intercorrelation than when compared to each other. Overall, the TIPS showed temporal stability over time, as evident in the test-retest correlations, which ranged between 0.67 and 0.95. Based on the high internal consistency and temporal stability the TIPS provides a consistent measure with a high degree of confidence (Webster, 2009a).

The TIPS has been found to provide helpful information to special needs education, psychology and therapists, occupational therapy, and speech therapy to be able to develop learning strategies for atypical learners and determine the effects of brain injuries and dementia on the ability to process information and memory skills (Webster, 2009a).

2.4.2.3 Test of Visual Perceptual Skills-4 (TVPS-4)

The TVPS-4 assesses two-dimensional visual perceptual skills without a motor response. The TVPS-4 can be used for both diagnostic and research purposes, as well as by OTs, psychologists, and professionals who need a reliable method to assess the various domains of visual perception. The TVPS-4 is the most consistently used assessment in the paediatric OT practice. There is an increasing recognition of the importance of visual perception deficits as they influence functional and academic outcomes (Brown and Peres, 2018).

The TVPS-4 includes seven subtests: visual discrimination, visual memory, spatial relationships, form constancy, sequential memory, visual figure-ground and visual closure. One hundred twenty-six black and white designs are used in the TVPS Test Plates. The test takes approximately 30 minutes to administer and two to ten minutes to score. Testing may be broken up into multiple sessions if required if the examinee fatigues during the session. As with the TIPS, the testing environment should be free of visual and auditory distractions. To minimise the impact of previous practice effects and their influence on the scores, the TVPS-4 should not be re-administered less than six months from the original testing (Brown and Peres, 2018).

The TVPS-4's standard scores can be compared to tests with the same standard score scale (mean of 100, SD of 15); as the TIPS has the same standard score scale, the TVPS-4 is an appropriate assessment to triangulate results (Brown and Peres, 2018).

There is strong evidence for the internal consistency of the TVPS-4, with an overall score of 0.94. However, the individual ages at the subtest level were below the cut-off of 0.7. Therefore, the confidence levels are a more accurate method of reporting and interpreting individual subtest results. Overall, the TVPS-4 showed good temporal stability with an overall score of 0.97 and, therefore, can be used for this study as it had a test-retest design (Brown and Peres, 2018).

2.4.2.4. Beery-Buktenica Developmental Test of Visual-Motor Integration, Sixth Edition (Beery VMI)

The Beery VMI is a standardised, norm-referenced, culture-free assessment aimed to assess the visual perceptual skills of people between the ages of two and 99 years old. It has been norm referenced six times between 1964 and 2010 on more than 13000 participants (Coallier *et al.*, 2014; Visser *et al.*, 2017). Each test obtains a raw score, which is converted based on the norms for that age. This allows the test results to be compared equally between children of different ages. The Beery VMI has a test-retest reliability of 0.88 and interrater reliability of .93, making this assessment the gold standard for assessing visual motor integration skills (Coallier *et al.*, 2014).

The Beery-VMI can only be interpreted by a professional within the fields of psychology, learning disabilities or similar professions.

The Beery-VMI aims to identify persons with significant difficulties in visual-motor integration, help obtain the needed services for those with difficulties, determine the effectiveness of interventions and as a research tool. The Beery-VMI hopes that with early identification of visual-motor integration difficulties, individuals will be able to be referred to the appropriate professionals for further assessment and treatment (Crotty and Baron, 2011)

It contains one central assessment, Visual Motor Integration, with two optional subtests, a Visual Perception Test and a Motor Coordination Test. Although the Visual Motor Integration test is untimed, it usually takes 10-15 minutes, with the subtests taking five minutes each (Visser *et al.*, 2017).

Each test obtains a raw score, which is converted based on the norms for that age. This allows the test results to be compared equally between children of different ages. The Beery VMI has a test-retest reliability of 0.88 and interrater reliability of .93, making this assessment the gold standard for assessing visual motor integration skills (Coallier *et al.*, 2014). The Beery-VMI can only be interpreted by a professional within the fields of psychology, learning disabilities or similar professions.

2.4.2.5 Barthel Index (Barthel Activities of Daily Living (ADL) Index

Dr. Mahlon Barthel developed the Barthel Index in the 1960s to measure an individual's ability to participate in basic ADLs and self-care tasks. It consists of ten activities, which are scored based on the individual's level of independence; the scoring system ranges from 0 to 15 or 0 to 10, depending on the item. Each score is totalled to provide an overall measure of a person's level of independence in ADLs; the higher the score, the higher the level of independence. The items include feeding, bathing, grooming, dressing, bowel control, bladder control, toilet use, transfers, mobility, and stairs (Rendeli *et al.*, 2021). The ability to engage in ADLs impacts one's QoL (Kiru and Cooc, 2018).

2.4.2.6 Pediatric Quality of Life Inventory (PedsQL) Brain Tumour Module

The Pediatric Quality of Life Inventory (PedsQL) Brain Tumour Module is a self-report and a parent-proxy report form that contains six scales. The scales include cognitive problems, pain and hurt, movement and balance, procedural anxiety, nausea and worry. The assessment uses a

three-point Likert scale, which is scored; the higher the score, the higher the health-related QoL is. The Likert scale could also be adjusted to use faces for younger children who did not understand the traditional scale. The questionnaire is divided into three categories that differ slightly according to the child's age group. The groupings are five-seven years, eight-12 years and 13-18 years (Caru *et al.*, 2019). The forms differ to account for the different demands expected from children at various ages. This assessment will be used as a child's ability to participate in ADLs impacts on their QoL. Therefore, the information from the assessment gives a holistic view of the child and their abilities.

The PedsQL can be used in clinical and research settings and has undergone extensive validation to ensure that it is a reliable and valid tool for assessing health-relation QoL. The PedsQL provides a total score and not a standardised or scaled score, and therefore, in this research, it was used in isolation and not compared to the standardised scores of the TIPS, TVPS-4 and the Beery-VMI (Bull *et al.*, 2020).

2.5 CONCLUSION

In conclusion, literature internationally has shown that paediatric PFT survivors have impairments that impact their participation in their categories of occupation and QoL. Yet, in South Africa, there is no research or treatment protocol in place to guide the management of these children. Improved knowledge of the impairments that these children acquire will assist OTs to personalise the treatment to target these specific impairments to ensure the child achieves their full potential.

CHAPTER 3: METHODOLOGY

3.1 TYPE OF STUDY AND GENERAL DESIGN

This research used a non-experimental multiple case study design with a postpositivist philosophy (Harrison *et al.*, 2017). As per the postpositivist philosophy, the study was an empirical enquiry into the functional outcomes of paediatric posterior fossa tumour (PFT) survivors, making use of multiple sources of data, which provided a holistic and in-depth analysis of the child within their physical setting (Carolan, Forbat and Smith, 2016; Harrison *et al.*, 2017; Ebneyamini and Sadeghi Moghadam, 2018). This research design was chosen as there were many confounding variables to consider, many of which the investigator had no control over and random assignment was not feasible. Therefore, by using multiple case studies, the complexity and uniqueness of each case could be studied (Larrinaga, 2017; Ebneyamini and Sadeghi Moghadam, 2018).

The population studied had a diverse range of neurological clinical presentations, histology of their posterior fossa tumour, surgical approaches, lengths of hospital stays and postoperative complications. Thus, it could not be grouped according to a set criterion to allow for direct application of statistical analysis. By compiling multiple case studies using a non-experimental design with quantitative data from various sources, pattern-matching and triangulation of the results were able to be done, and therefore, generalisations were able to be made about the population of children being studied (Carolan, Forbat and Smith, 2016; Harrison *et al.*, 2017).

The study was non-blinded. Since no intervention was provided, the study did not include a control group.

3.1.1 Research Approach

An explanatory prospective longitudinal panel was used as the same participants were assessed using the same tests at different points in time (test-retest). As there were multiple predictor variables, this research study was able to answer questions regarding the inferred causality of the results. One of the benefits of this design is that the data was captured concurrently with the participant's surgery, chemotherapy, and radiation, allowing for the continuity of data (de Klerk and Harmse, 2020). One of the limitations of this study design is that the repetition of the same assessments could affect the participants' responses. However, this was mitigated in this study as the tests were repeated six months after the initial assessment as recommended by the

standardisation manual of the tests. Longitudinal studies are the preferred method of study as they have the greatest reliability and external validity (de Klerk and Harmse, 2020).

This research study used quantitative data, demographical questionnaires, and six standardised assessments. All information gathered, and tests conducted on the participant were done by a registered occupational therapist, the researcher. The demographical information sheet allowed for gathering objective information on the participant's medical and developmental history, social and economic circumstances, and familial education level. Quantitative data regarding the participant's cognition, visual perception, motor skills, quality of life and activities of daily living was collected using standardised assessments. All assessments were completed before the participant underwent their posterior fossa tumour resection/and or biopsy. These standardised assessments were used to compare the participant's performance pre- and six months post-surgery to determine their overall functional outcomes. The current standard of care in state hospitals for children diagnosed with a posterior fossa tumour does not include the use of standardised assessments. Therefore, this research study deviated from the typical services provided to gain better insight into the functioning of the children included in the study.

The study was conducted over one year at Nelson Mandela Children's Hospital and Chris Hani Baragwanath Academic Hospital. If the participant required occupational therapy, physiotherapy, speech and audiology, and dietetic services during the study period, they received these services from their base hospital.

3.1.2 Population

The population chosen for this study were children diagnosed with posterior fossa tumours at Chris Hani Baragwanath Academic Hospital (CHBAH) and Nelson Mandela Children's Hospital (NMCH) in Johannesburg, Gauteng, South Africa. During the one-year data collection period, 29 children with posterior fossa tumours were admitted to the CHBAH and NMCH neurosurgical units. Twenty-two children were admitted to NMCH, and seven to CHBAH.

3.1.3 Sample selection

Purposeful sampling was used for this study as the researcher selected participants who met a set criterion: a posterior fossa tumour diagnosis and met the inclusion criteria listed below.

Purposeful sampling allowed for the in-depth study of the phenomenon experienced by posterior fossa tumour survivors (Durrheim, 2004).

Esene et al. (2014) suggested that a minimum sample of five cases is required for a valid case study. However, this research included all children who met the inclusion criteria to account for loss to follow-up and mortalities (Esene, Kotb and Elhusseiny, 2014). The population size was 29 children during the one-year data collection period, and eight children met the inclusion criteria and were invited to participate in the study.

3.1.3.1 Inclusion and Exclusion Criteria

The following inclusion and exclusion criteria were used to select participants for the study:

Inclusion criteria

Children who

- Children were diagnosed with a posterior fossa tumour using a diagnostic scan, Computerised tomography (CT) or magnetic resonance imaging (MRI) and confirmed by a neurosurgeon.
- Were admitted to the CHBAH and NMCH neurosurgical units between 01/09/2022 and 31/08/2023.
- Were offered neurosurgical management (resection) by the neurosurgical department.
- Male and female children between the ages of five years and 0 months and 16 years and 11 months were included
- Signed informed assent to be a participant in the study.

Children whose caregivers:

- Gave consent to participate in the research study.
- Gave consent for surgical intervention for their child's posterior fossa tumour.

Exclusion criteria

Children who

- Have undergone previous neurosurgery within the posterior fossa
- Were deemed medically unstable by the neurosurgical department.
- Have been diagnosed with a metabolic, genetic, or other neurological disorder.

- Are unable to understand instructions in English or unable to translate them into their home language.

3.1.4 Data Collection Instruments

The researcher designed a demographic questionnaire, which was used to determine the demographics such as the age, gender, race, and socio-economic background of each participant, and it was divided into sections: personal information, medical, neurosurgical, surgical, chemotherapy and radiation history and rehabilitation history. The surgical and medical history included information on the type and location of the tumour, surgical procedures and approaches, and the types of chemotherapy and/or radiation used.

The researcher completed a demographic questionnaire with the caregivers of each child who participated in the study. Additional medical history was obtained from the child's medical file with permission from the caregiver. Previous developmental status of the child was recorded as per the admitting doctor's medical notes.

Standardised assessments assessed the children's cognitive function, visual perception, motor skills, behaviour, quality of life and occupational performance. These tests gave a standardised score that was statistically analysed. The following assessments were used;

Table 3.1 Standardized assessments used

Client factor and category of occupation	Test Name	Measurement Domain	Age Range (years)	Time to Administer (mins)	Psychometric Properties
Cognition	Test of Information Processing Skills (TIPS)	Executive functioning, working memory, auditory and visual processing, learning, retaining, and using new information.	5-90	20 -45	Reliability: 0.67 - 0.95 (Chittooran, 2014)
	Test of Visual Perceptual Skills -4 (TVPS-4)	Visualization, flexibility of closure and visual memory	5-21	25	Reliability: 0.97 (Brown and Peres, 2018)

Visual Perception	The Beery-Buktenica Developmental Test of Visual-Motor Integration (Beery-VMI)	Visual motor integration, motor-coordination, and visual perception	2-18	25	Validity: 0.93 Reliability: 0.88 (Coallier *et al.*, 2014)
Motor Skills	Quick Neurological Screening Test (QNST-3R)	Motor maturity and development, sensory processing, gross and fine muscle control, motor planning, sense of rhythm, spatial organization, balance, vestibular function, and disorders of attention.	5-80	30	Validity 0.5 Reliability: 0.81 (Mutti, Margaret; Sterling, Harold M; Spalding, 1978)
Quality of Life	PedsQL- Brain Tumour Module	Quality of life	5-18	15	
ADLs	Barthel Index	Activities of daily living		5	Validity: 0.849 Reliability: 0.74-0.96 (Mahoney and Barthel, 1965; Duffy *et al.*, 2013)

- See the literature review for a full description of assessments.

3.1.4.1 Test of Information Processing Skills (TIPS)

The TIPS was chosen for this study as it is designed for OTs to assess a person's ability to process information and their memory skills. As the test was designed for a comprehensive developmental range, it was appropriate for this study as the inclusion criteria were children between the ages of five and sixteen years eleven months. The test also has a reliability of 0.67 to 0.95 for ages five through to nineteen, which is acceptable for academic application (Webster, 2009b).

As the test results can be converted into standard scores, percentile ranks and scaled scores, it allowed the researched to compare the child's scores on the TIPS to their scores on the TVPS-4 and the Beery VMI to get a holistic picture of the child's performance (Webster, 2009b).

3.1.4.2 Test of Visual Perceptual Skills -4 (TVPS-4)

The TVPS-4 was chosen because it provides detailed information about a child's visual perceptual skills and consists of seven scored subtests addressing different elements of visual perception. The test scores can also be converted into standard scores, percentile ranks and scaled scores, allowing for the comparison to the TIPS and Beery VMI (Brown and Peres, 2018).

The test can be used on children from five years and zero months to twenty-one years and eleven months, which makes it appropriate for the study. The test could also be readministered after four to six months while maintaining its integrity (Brown and Peres, 2018).

The TVPS-4 is also motor-free, allowing an accurate picture of a child's visual perception without a motor disability impacting scores, unlike the Beery VMI. The use of the Beery VMI and the TVPS-4 allows the researcher to provide detailed information about which areas of visual perception are impacted by a PFT (Brown and Peres, 2018).

3.1.4.4 Beery-Buktenica Developmental Test of Visual-Motor Integration, Sixth Edition (Beery VMI)

The Beery VMI consists of three subtests: VMI, motor coordination and motor-free visual perception. The combination of the three subtests gives the examiner information regarding which elements of VMI and visual perception are impacted by a PFT. As stated before, the test results can be compared to the TIPS and TVPS-4, which aids in getting a holistic view of the child.

The Beery VMI is one of the gold standard tests for assessing VMI with high reliability and validity and, therefore, is appropriate for this study (Crotty and Baron, 2011).

3.1.4.5 Quick Neurological Screening Test (QNST-3R)

The QNST-3R was chosen for this study as it assesses neurological soft signs, which are subtle deviations from normal neurological development. It accounts for the continued acquisition of skills as the neurological system develops with age (Mutti *et al.*, 1998). As this study is longitudinal, it was essential to have a test that compares a child's performance over time, accounting for their developmental milestones, which this test provides. Children with PFTs receive neurorehabilitation, and therefore, the motor deficits that they present with might be less overt. Thus, this test offers the opportunity to identify these deficits.

The QNST-3R is often more effective than tools like the Movement Assessment Battery for Children (M-ABC 2), the Gross Motor Function Measure (GMFM), and the Pediatric Evaluation of Disability Inventory (PEDI) for evaluating children with brain tumours due to its focus on neurological functioning (Berg *et al.*, 2004; te Velde and Morgan, 2022; Scarfò *et al.*, 2024). Unlike the M-ABC, which assesses coordination and fine and gross motor skills, the QNST-3R identifies neurological deficits, such as cognitive processing, VMI, and sensory processing, all of which may be significantly impacted in children with PFTs (Mutti *et al.*, 1998; Scarfò *et al.*, 2024). Although the GMFM is designed to assess children with motor impairments such as cerebral palsy, it may miss the subtle neurological changes specific to PFT cases, especially if the child has not experienced a noticeable loss of gross motor skills (te Velde and Morgan, 2022). The PEDI focuses on participation in daily tasks, which is valuable information but may not accurately assess the neurological impairments common in PFT patients (Berg *et al.*, 2004). The Pedi cannot be used for children over the age of seven and a half years old and therefore would not be appropriate for this study (Berg *et al.*, 2004). The QNST-3R, therefore, offers a more comprehensive neurological assessment by identifying motor, sensory processing and visual perceptual impacts (Mutti *et al.*, 1998).

The scoring of the QNST-3R is interpreted as functional classification and not as standardised scores, which means that these scores cannot be directed compared to the TIPS, TVPS-4, and Beery-VMI scores. However, the information obtained from the QNST-3R is unique and, therefore, was important to include in this research so that the data collected on each participant was holistic (Mutti *et al.*, 1998).

For analysis, the 11 administered tasks were categorised into functional subgroups as seen in the table below:

Table 3.2: Breakdown of QNST-3R components for analysis

	Figure Recognition and Production	Palm Form Recognition	Eye Tracking	Sound Patterns	Finger to Nose	Thumb and Finger Circle	Rapidly Reversing Repetitive Hand Movements	Arm and Leg Extension	Tandem Walk	Stand on One Leg	Skipping
Motor Maturity and Development					x	x	x	x	x	x	x
Tactile and Kinaesthetic Processing		x						x	x	x	x
Gross and Fine Muscle Control	x				x	x	x	x	x	x	x

Motor Planning and Sequencing	x			x	x	x	x	x	x	x	x
Sense of Rate and Rhythm					x	x	x		x		x
Spatial Organisation	x								x		x
Visual and Auditory Perception	x		x	x							
Balance and Vestibular Function								x	x	x	x
Attentional Control	x	x	x	x	x	x	x				

3.1.4.6 Pediatric Quality of Life Inventory (PedsQL) Brain Tumour Module

The PedsQL was chosen as it allows the opportunity to collect self-reported data from various age groups, including the caregiver. The layout of the assessment makes use of Likert scales in both written form and with pictures, which cater for different developmental levels, which was needed in this study. The PedsQL has developed different questionnaires for various diagnoses, and therefore, the Brain Tumour Module is the most appropriate for this study and makes this questionnaire superior to generalised health-related quality of life questionnaires (Germain, Aballéa and Toumi, 2019).

The PedsQL is used frequently in research, making it a reliable tool for academic application (Germain, Aballéa and Toumi, 2019; Kohler *et al.*, 2021).

3.1.4.7 Barthel Index (Barthel Activities of Daily Living (ADL)) Index

The Barthel Index is a quick evaluation of a person's participation in the ADLs of self-care, continence (toileting), and mobility, and it takes five minutes to score. This assessment was chosen as it was an efficient tool to determine participation in ADLs and allowed for comparison over time. The tool doesn't require equipment, is freely available for use, and has been used in successful research related to PFTs (Lundar *et al.*, 2020).

3.1.5 Data Collection Process

Quantitative data was collected on participants diagnosed with posterior fossa tumours who met the inclusion criteria. The neurosurgical wards at the participating hospitals were screened daily by the researcher at NMCH and the production-level occupational Therapists at CHBAH. The

information about children diagnosed at CHBAH was telephonically communicated to the researcher.

The caregivers were given an information sheet explaining the study's details; the researcher also verbally explained the study and answered any questions the caregivers had. The caregivers were informed that they had the right to withdraw from the study at any point and were given a consent form to sign. Each child was given an assent form with written and picture instructions regarding what participation in the research study would entail, and they were asked to sign it. Once informed consent and assent were obtained, the participant's demographic data was collected using collateral information from their caregiver and their hospital file and recorded on the participant information sheet. Each participant was allocated a participant code to ensure confidentiality.

Each participant was discussed with the attending neurosurgeon to determine whether the participant required a cerebral spinal fluid (CSF) diversion procedure to treat increased intracranial pressure before starting with the standardised quantitative assessments. If the participant required CSF diversion, the researcher waited until day one post-procedure to commence the assessment process. The researcher had to wait for the CSF diversion before assessing the participant as hydrocephalus results in neurological fallout and would have skewed the assessment results. If the participant did not require a procedure, the assessments commenced on the same day signed consent and assent were received.

Quantitative data regarding the participant's cognition, visual perception, motor skills, quality of life and activities of daily living was collected using the standardised assessments. All assessments were completed before the participant underwent their posterior fossa tumour resection/and or biopsy. The standardised tests assisted in determining the participant's baseline cognition, motor skills, visual perception, behaviour, quality of life and participation in activities of daily living pre-surgery. The testing was broken up over a couple of days as the participants could not cope with completing the assessments in one day.

During the participant's admission, regular follow-ups were done to note specific variables necessary for the case study, such as type of tumour and location, tumour resection approach, whether the child presented with posterior fossa syndrome post-operatively, post-operative infections, length of hospital stay, number and types of revision surgeries, whether radiation or chemotherapy was provided and type of rehabilitation that occurred during the child's hospital stay and at home.

Six months after the surgery, the participants were contacted to determine their subsequent follow-up with the doctors, and appointments to readminister the assessments were arranged for the same day. At their follow-up appointment, information regarding their chemotherapy and radiation regime was captured. Additional information, such as return to school and therapies received, was also obtained. The six standardised assessments were re-administered during the follow-up appointment, and the results were captured on an Excel spreadsheet. All of the assessments were completed during that follow-up appointment with breaks as needed by the participant. Caregivers who requested a report were sent one which compared the child's preoperative and postoperative results.

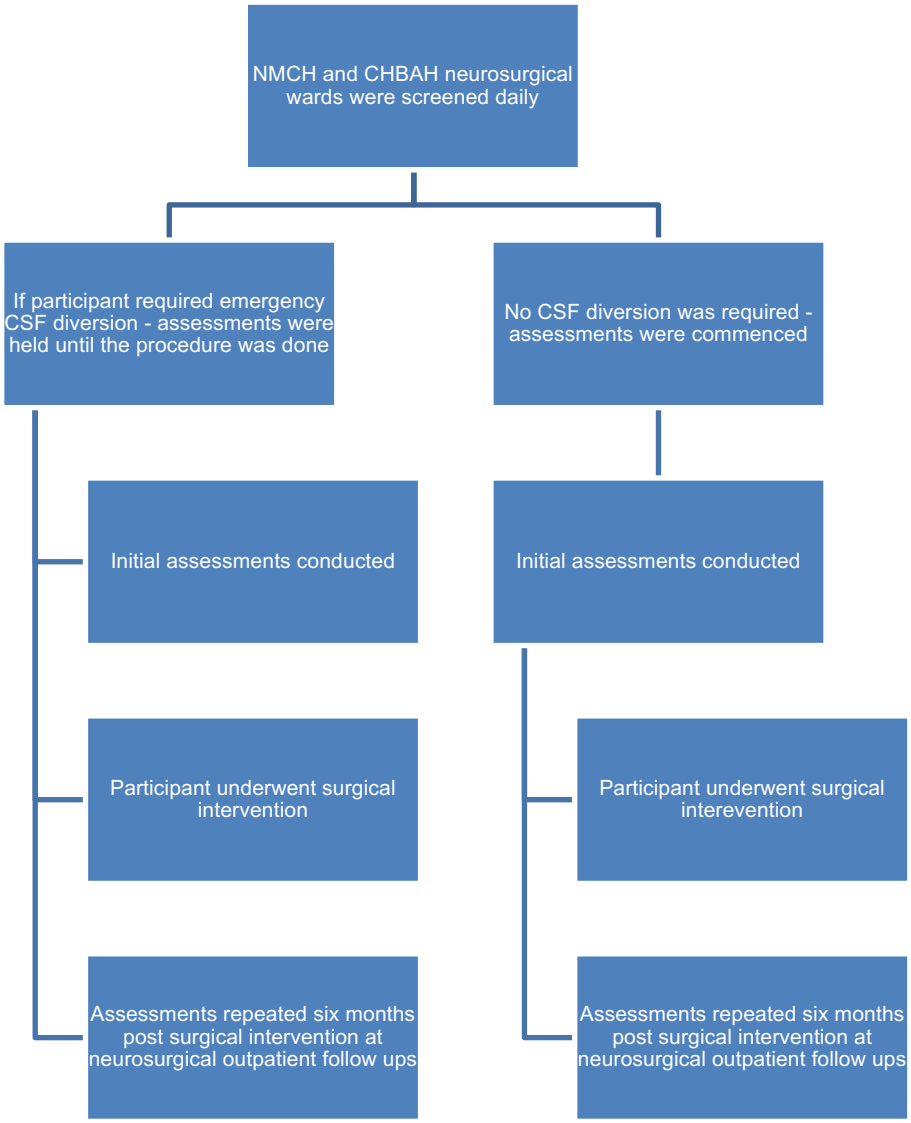


Figure 3.1 Assessment process

3.1.6 Data analysis

The demographic data was captured on an Excel spreadsheet, and participant codes were used to ensure confidentiality and to allow for more straightforward calculations. Each assessment was scored according to the specific guidelines in the manuals. The TIPS, TVPS-4 and Beery-VMI scores were converted to scaled scores for comparison. The QNST-3R, PedsQL and Barthel Index were analysed separately. Excel Microsoft 365 (2021) was used to organise data and Excel statistical function for graphs and tables.

Table 3.3 Types of data and analysis

<table>
<tr><th>Objective</th><th>Quantitative/Qualitative</th><th>Type of data</th><th>Variables</th><th>Type of analysis</th></tr>
<tr><td>Demographic information</td><td rowspan="8">Quantitative</td><td>Descriptive, categorical data, nominal, ratio</td><td>Independent – age, gender, type of tumour</td><td rowspan="8">Mode, mean, median, range</td></tr>
<tr><td>TIPS</td><td rowspan="5">Ordinal</td><td rowspan="6">Independent - standard score, scaled score. percentile rank, and z-score</td></tr>
<tr><td>TVPS</td></tr>
<tr><td>Beery-VMI</td></tr>
<tr><td>QUICK</td></tr>
<tr><td>BRIEF</td></tr>
<tr><td>PedsQL</td><td>Nominal, ordinal</td></tr>
<tr><td>Barthel Index</td><td>Nominal, ordinal</td></tr>
</table>

3.1.7 Ethics:

Ethical clearance for the study was obtained from the Human Research Ethics Committee at the University of the Witwatersrand (M220427). The proposal was submitted to the Gauteng Department of Health for approval. Approval was obtained from the Chris Hani Baragwanath Academic Hospital, Nelson Mandela Children's Hospital Research Protocol Assessment Committees, and the relevant departmental heads from the occupational therapy and neurosurgery departments. The nursing staff in the neurosurgical departments were informed about the study as caregiver interviews and standardised assessments were conducted in the units.

Caregivers willing to participate in the study were given an information letter. The information letter included the purpose of the study, what it involved and that participation in the study is voluntary, and they may withdraw from the study at any time without reason. All caregivers were asked to sign a consent form stating they were willing to participate in the research, and each consent form was witnessed. An assent form, which included writing and drawings, was given to each child to sign that they agreed to participate in the study. Autonomy was observed through a signed consent and assent form; included in the form was a clause stating that withdrawal from the study could be made at any point in the process and there would not be any adverse outcomes from this decision.

The caregivers were given the results of their child's assessments if they wished, and participants who required intervention based on their results were referred to the appropriate institution to receive rehabilitation.

Each participant was assigned a number, which was used to identify them on test booklets and Excel Microsoft 365 (2021) spreadsheets to ensure that their information was kept confidential. The researcher kept all assessment information in a locked cupboard to ensure that only the researcher and the had access to it. The electronic data documents were password-protected and stored on a password-protected laptop.

3.2 CONCLUSION

This research used a non-experimental multiple case study design with a postpositivist philosophy. An explanatory prospective longitudinal panel was used. The same participants were assessed using six quantitative, standardised assessments before treatment for a posterior fossa tumour and six months post-treatment to determine their functional outcomes.

CHAPTER 4: RESULTS

4.1 INTRODUCTION TO RESULTS

Of the eight children assessed, only three were reassessed six months postoperatively. One child was lost to follow-up, one child withdrew from the study, one demised, and two were not offered tumour resections and, therefore, excluded from the study. As follows are the results of the three cases:

4.2 DEMOGRAPHICS OF SAMPLE

The three cases used in this study were all diagnosed with posterior fossa tumours and underwent surgery, chemotherapy and radiation as part of their treatment. Of the three cases, two children were male, and one was female. All three children identified as black in terms of race; and two were from South Africa, and one was Zimbabwean but was living permanently in South Africa at the time of his diagnosis. All three children were thriving and developmentally appropriate for their age at diagnosis.

Table 4.1 Demographics of the sample

	Case 1	**Case 2**	**Case 3**
Gender	Male	Male	Female
Race	Black	Black	Black
Nationality	South African	Zimbabwean	South African
Developmental Status	Appropriate for age	Appropriate for age	Appropriate for age
Current level of Schooling	Grade 4	Grade 0	Grade 1
Type of School	Mainstream Public school	Mainstream Public school	Mainstream Public school
Repeated a Grade	No	No	No
Maternal Education Level	Diploma	Diploma	Senior School Certificate
Access to Amenities	Water and Electricity	Water and Electricity	Water and Electricity

All three children in this study were diagnosed with a medulloblastoma tumour and presented with similar symptoms. Two children sought and funded private healthcare before their diagnosis as they struggled to access the medical care they required in the state sector. All of the children

required the insertion of an external ventricular drain (EVD) before resection surgery to treat high intracranial pressure secondary to acute hydrocephalus. Two of the children required a ventriculoperitoneal shunt (VPS) before discharge as they had developed chronic hydrocephalus. The average length of hospital stay for the tumour resection surgery was 32 days with an average paediatric intensive care unit (PICU) stay of 2 days. Of the three children, only one required a second admission due to secondary complications.

During their hospital stay, the children received an average of nine OT sessions, nine physiotherapy sessions, and one speech therapy session.

All three children underwent chemotherapy and cranial-spinal radiation, with the average number of chemotherapy sessions of eleven and radiation sessions of twenty-three.

Table 4.2 Medical history of the sample

	Case 1	**Case 2**	**Case 3**
Type of Tumour	Medulloblastoma	Medulloblastoma	Medulloblastoma
Location of the Tumour	Arising from the fourth ventricle	Midline of the cerebellum	Midline of the cerebellum
Symptoms	One Week history of: • Headaches and photophobia • Vomiting and nausea • Unsteady gait • Intermittent diplopia	Two Month history of: • Headaches • Vomiting One Week history of: • Ataxic gait	Three Week history of: • Headaches • Vomiting
Number of doctors seen before diagnosis	Six	Four	Four
Sought Private Healthcare	Yes	Yes	No
Medical intervention	EVD insertion Near total resection VPS insertion	EVD insertion Total tumour resection	EVD insertion Total tumour resection VPS

Complications	• Chronic HCP • Weight loss of 1,1 kg	• Weight loss of 2,6 kg	• Meningitis requiring two EVD washouts • Chronic HCP • Wound breakdown 6 months post-surgical resection requiring a debridement and wound closure • Weight loss of 4 kg
Length of Stay in Hospital	27 days	27 days	43 days (1st admission) 6 days (2nd admission)
Length of Stay in PICU	Two days	One day	Two days
Rounds of chemotherapy	Six	10 (defaulted session 11)	16
Radiation Sessions	21	28	21
OT inpatient sessions	Six	Five	16
OT frame of reference	Model of Creative Ability	Model of Creative Ability	Model of Creative Ability
OT therapeutic aims	Facilitation of active participation ADLs Facilitation of independent functional mobility	Facilitation of active participation ADLs Facilitation of independent functional mobility	Facilitation of active participation ADLs Facilitation of independent functional mobility Activate client and affect mood
Other inpatient interventions	Seven Physiotherapy sessions One Speech therapy session	Eight Physiotherapy sessions Zero Speech therapy sessions	12 Physiotherapy sessions One Speech therapy session
OT outpatient sessions	Zero	Zero	Zero
Other outpatient interventions	Zero	Zero	Zero

4.3 CASE 1

4.3.1 Medical background

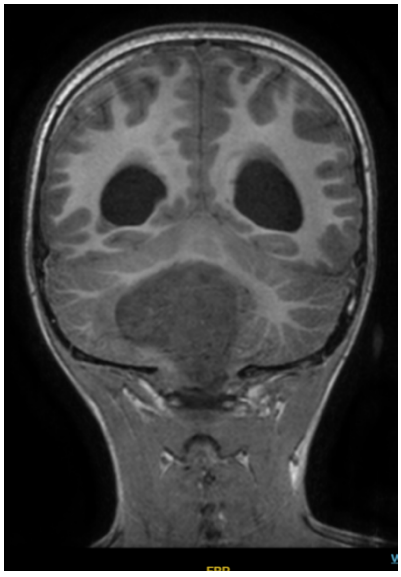
Ten year and nine-month-old black male was diagnosed with a medulloblastoma occupying the fourth ventricle. He presented with a three-week history of headaches and photophobia, vomiting and nausea, unsteady gait, and intermittent diplopia. He consulted six doctors, including a privately funded neurologist and dietician, before having a computed tomography brain (CTB) scan, which revealed a mass within the posterior fossa.

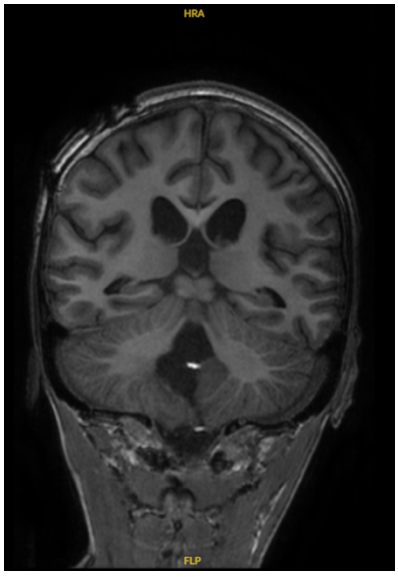
He was admitted to Nelson Mandela Children's Hospital (NMCH) and had an EVD inserted before undergoing a near-total resection. The total EVD insertion time was 12 days. His postoperative course was complicated by hydrocephalus (HCP), and he had a VPS inserted. He was admitted for a total of 27 days, including a two-day admission to the PICU post-tumour resection surgery for postoperative monitoring.

During his hospital stay, he received six OT sessions, seven physiotherapy (PT) sessions and one speech therapy (ST) session. The mode of discharge was walking.

Post-surgery, the child underwent six rounds of chemotherapy and 21 craniosacral irradiation sessions. The child had lost 1,1kgs in the six months from his admission to the end of his treatment. After completing his adjunctive therapies, he returned to school (Grade 5) virtually.

A





B

Figure 4.3.1 Child 1's pre- and postoperative MRI images of a midline cerebellar mass. *(A)* Preoperative scan showing the presence of the cerebellar mass in the midline region. *(B)* Postoperative scan demonstrating near-total removal of the mass

4.3.2 Cognition

4.3.2.1 Test of Information Processing Skills

Visual processing: Preoperatively and after treatment, the child presented with age-appropriate scaled scores on the Test of Information Processing Skills (TIPS). A scaled score between seven and ten represents the performance of 50% of the population (Folse, 2010). On follow-up, the child demonstrated improvement in all visual domains, performing above average for his age.

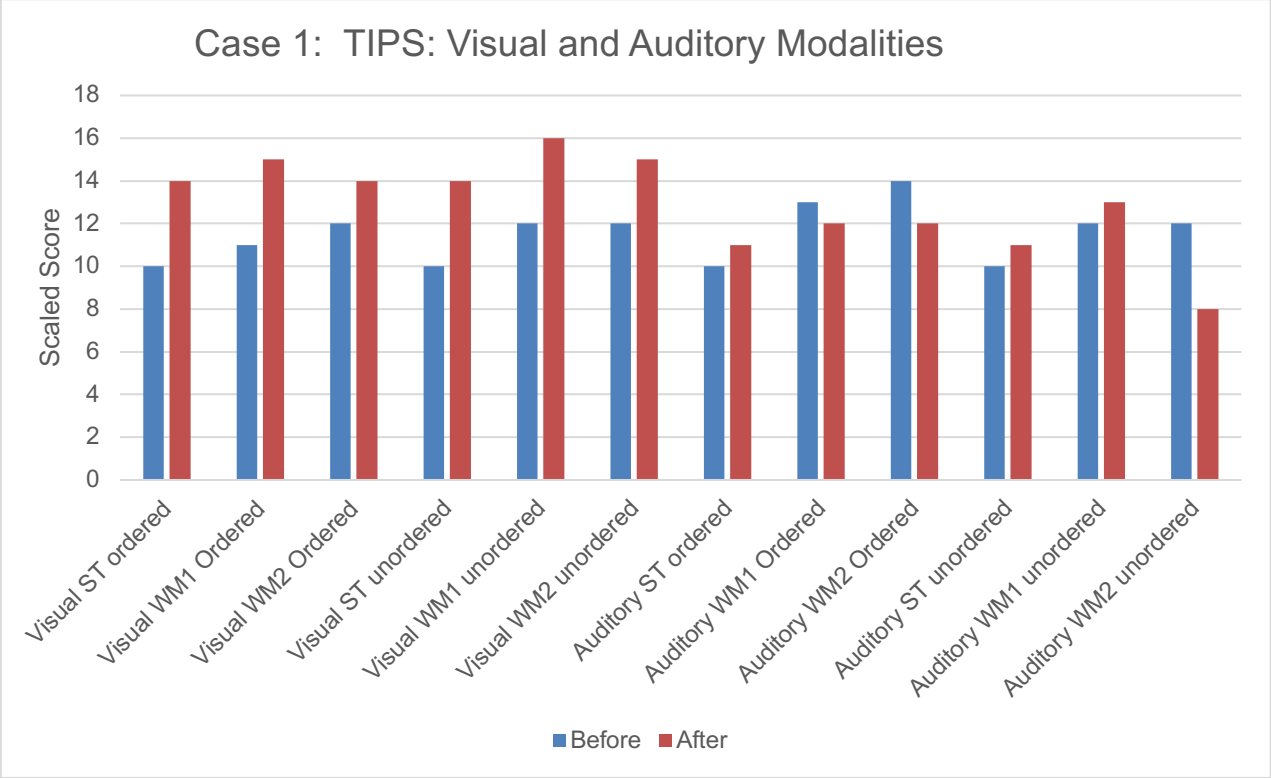


Figure 4.3.2: Case 1: Pre and post-treatment scores for the TIPS visual and auditory modalities

Auditory processing: His performance in delayed recall and oral word fluency improved. He showed a slight decrease in written word fluency, but the scaled scores of nine and eight for oral and written word fluency were still age-appropriate. The child showed a decline in all auditory domains compared to his baseline assessment; however, the scores were within the age-appropriate range. Both his acoustic intrusions and proactive interference scores were average for his age.

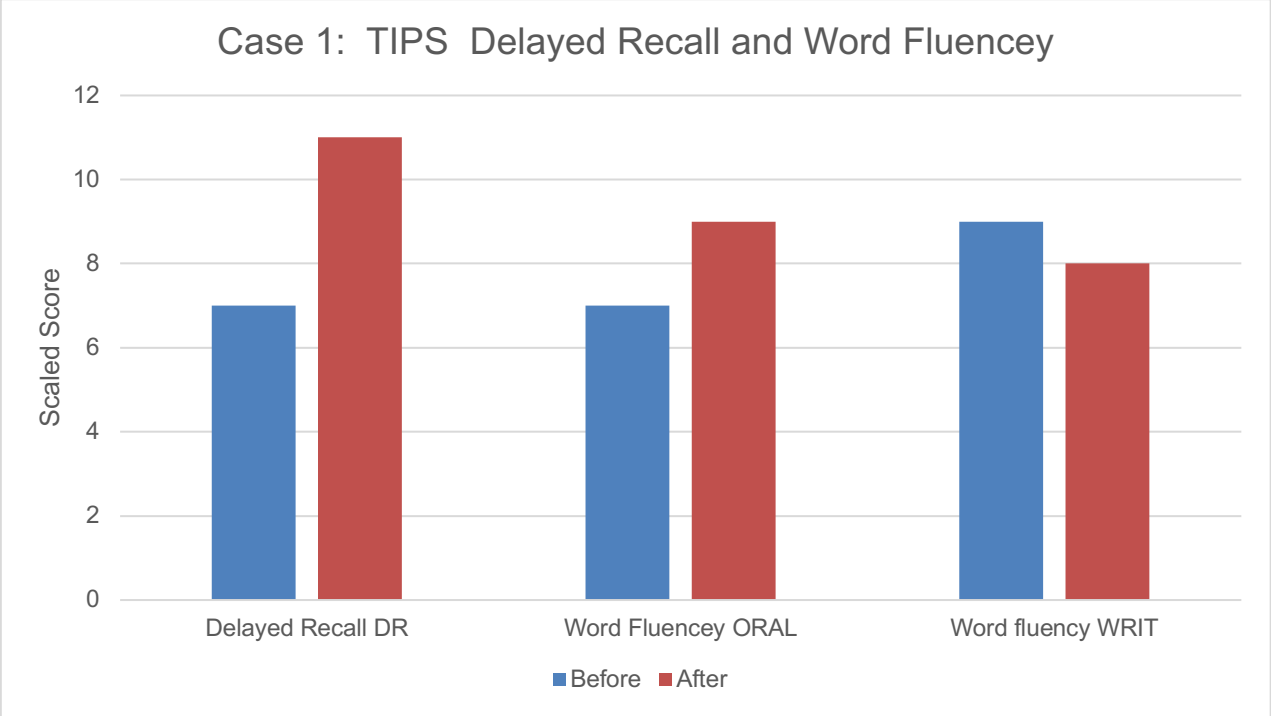


Figure 4.3.3: Case 1: Pre and post-treatment scores for delayed recall and oral and written word fluency on the TIPS

4.3.2.2 PedsQL: Self-reported cognition

Subjectively, the child reported a decline in cognition from the baseline assessment when using the PedsQL Brain Tumour Module Standard Version 1.0 (PedsQL) in mathematical ability, writing skills, attention, memory, and information processing, which he previously reported to be 100% satisfied in his ability. On the PedsQL, 100% represents complete satisfaction in the skills; therefore, the lower the score, the less the child is satisfied. The child showed a decline in attentional control on the QNST-3R, which correlates with his self-reported attentional ability. The child's mother reported an improvement in all these domains post-treatment except writing.

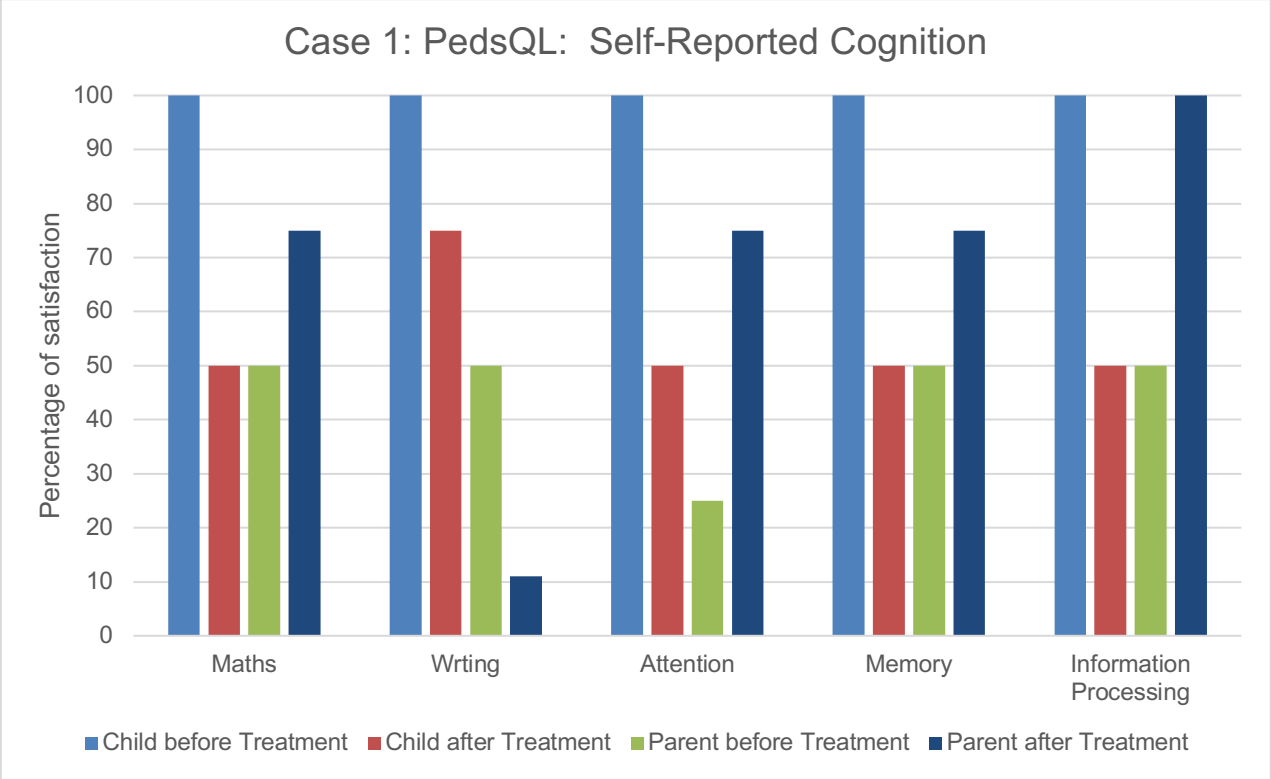


Figure 4.3.4: Case 1: PedsQL: Self-reported cognition scores (%)

4.3.3 Visual perception

4.3.3.1 TVPS-4

Preoperatively, the child performed in the normal range for the Test of Visual Perceptual Skills 4th Edition (TVPS) in all domains except form constancy.

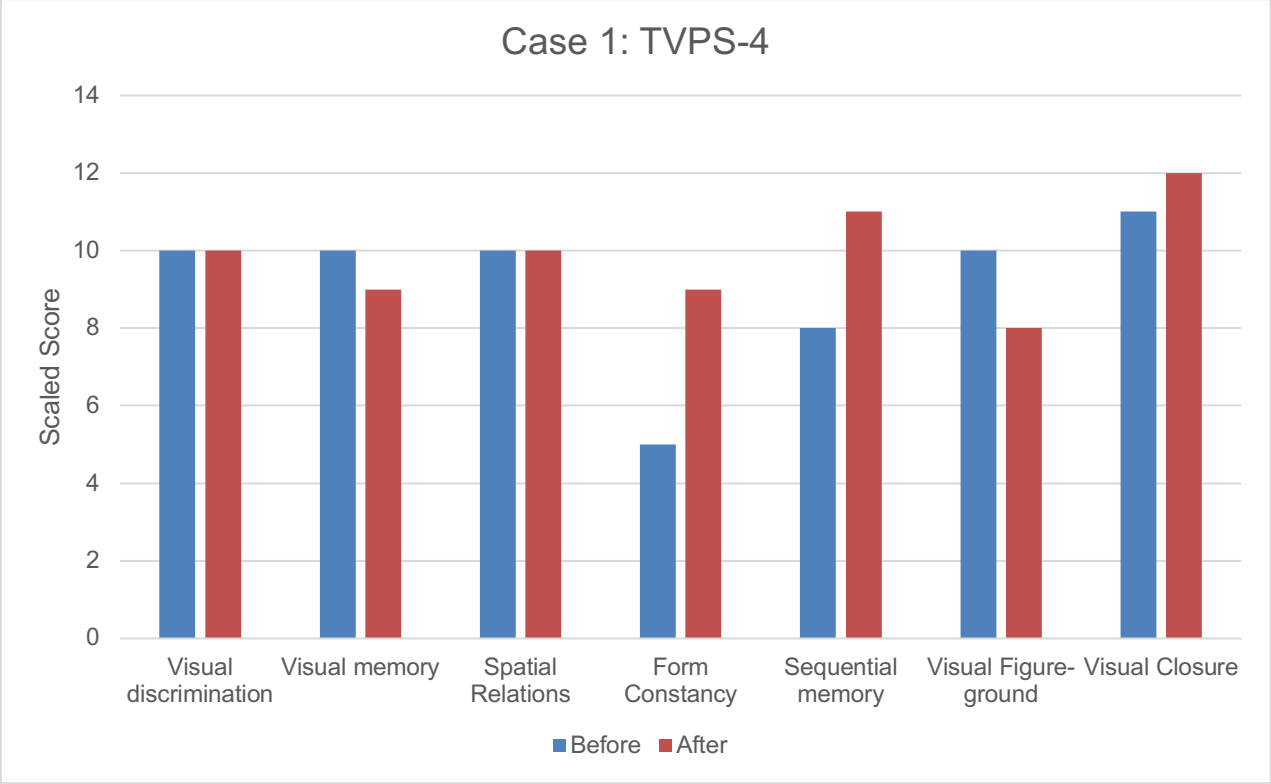


Figure 4.3.5: Case 1: TVPS-4 scaled scores

On follow-up, he demonstrated an overall improvement in non-motor visual perception in all domains except for visual memory and visual figure-ground. All his scaled scores were above eight, which is the average performance for his age group. His scores for form constancy, sequential memory and visual closure improved, and visual discrimination and spatial relations remained the same.

4.3.3.2 Beery-VMI

On The Beery-Buktenica Developmental Test of Visual-Motor Integration (Beery-VMI) assessment, the child scored within the age norm for visual perception and motor coordination but performed below average for visual motor integration.

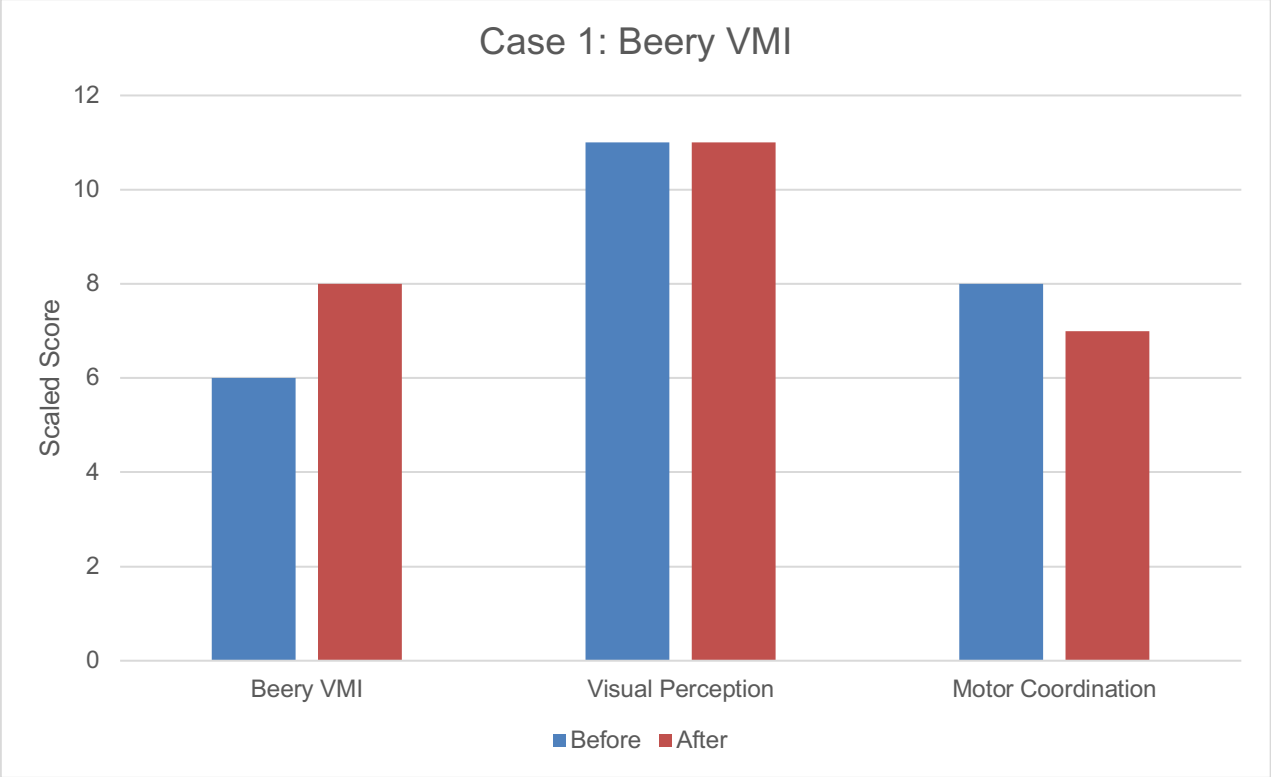


Figure 4.3.6 Case 1: Beery-VMI scaled scores

On follow-up, the child's visual motor integration score improved and was age-appropriate, with a scaled score of eight. His motor coordination score declined but was still within the normal range, with a score of seven. His visual perception score remained the same.

4.3.4 Motor skills

4.3.4.1. QNST-3R

Preoperatively, the child had a moderate impairment in his Quick Neurological Screening Test–3R (QNST-3R). Preoperatively, the child had a moderate impairment in his overall Quick Neurological Screening Test–3R (QNST-3R). On follow-up, he had an average performance. However, he still had deficits in balance and vestibular functioning, as seen in the graph, with scores above the threshold. A score above the threshold level indicates a functional impairment. He had developed new deficits in attentional control. All other domains improved.

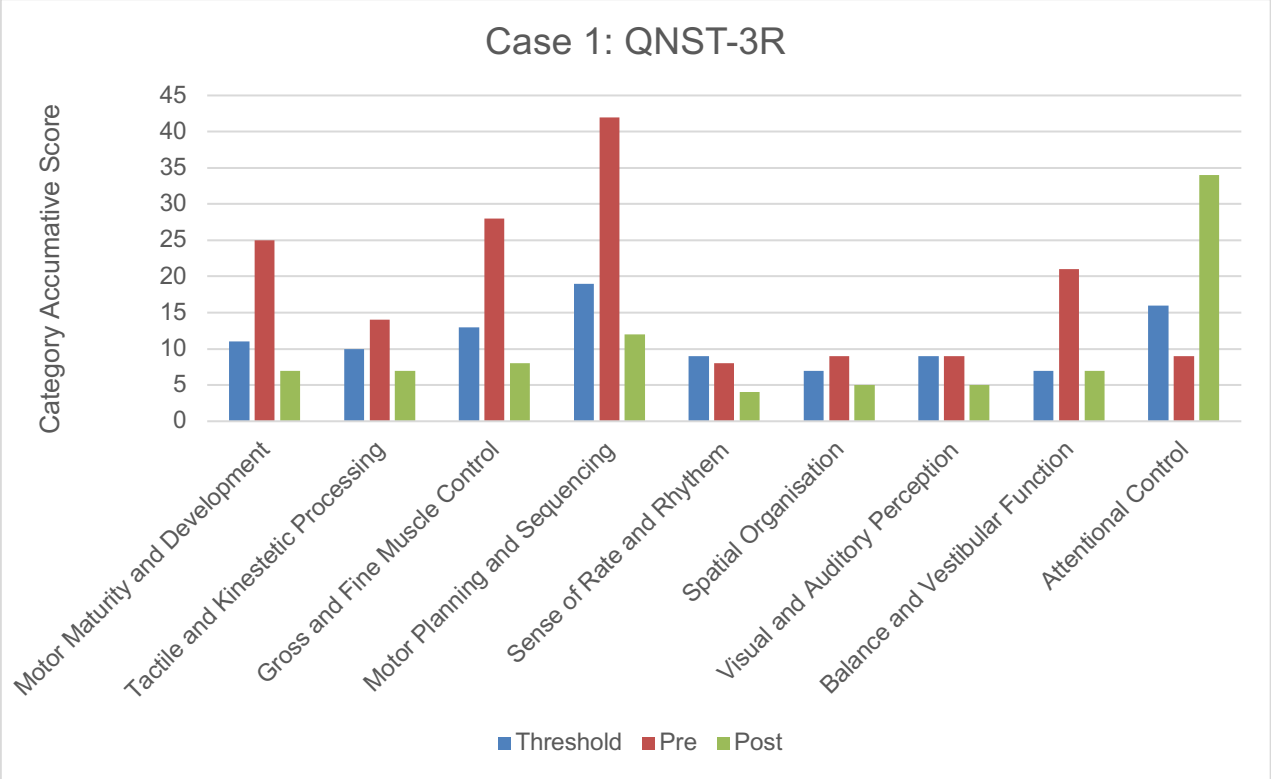


Figure 4.3.7 Case 1: Categorised scores for the QNST-3R

4.3.5 Behaviour

Overall, the child reported a decline in the ability to reflect on emotions and confusion, whereas the parent-reported an improvement in these skills in the PedsQL. Both the child and the parent-reported improvement in anxiety surrounding procedures. The child reported increased anxiety about his future; however, the parent reported a decrease in future concerns.

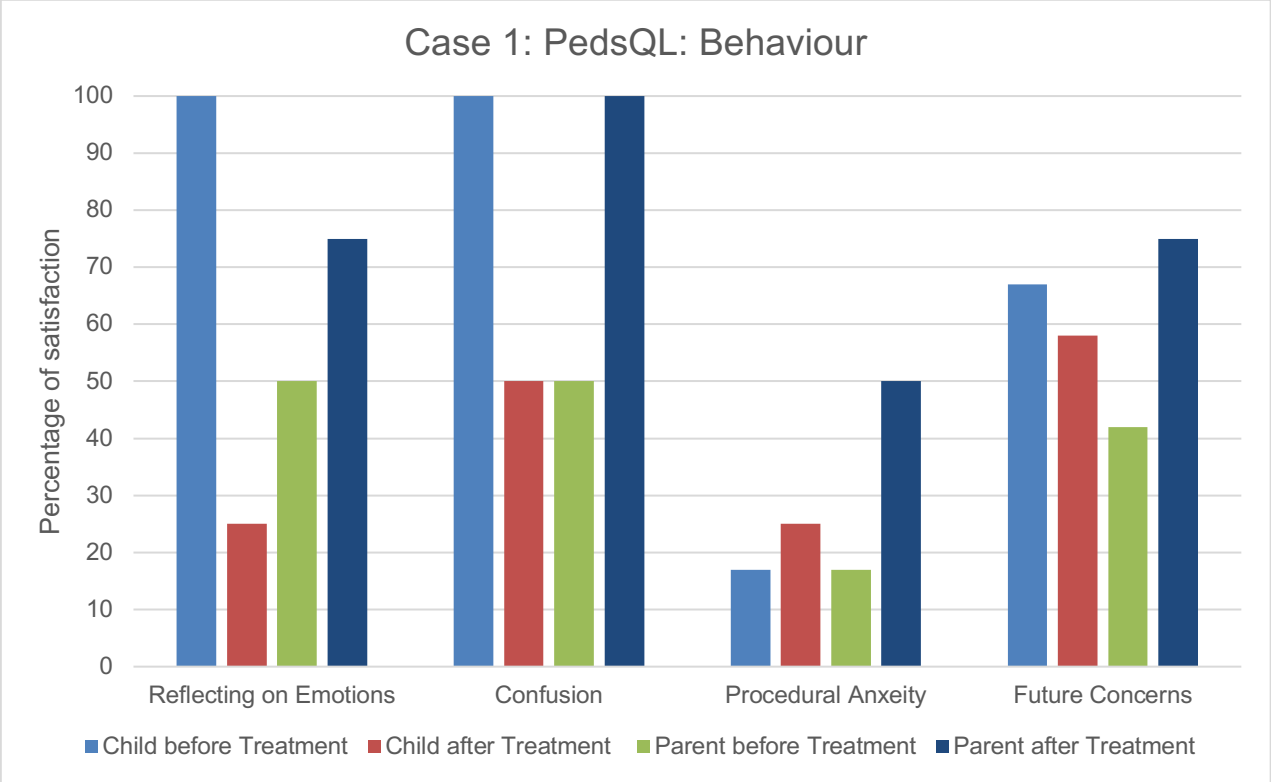


Figure 4.3.8 Case 1: PedsQL Behaviour (%)

4.3.6 Activities of Daily Living

4.3.6.1 Barthel index:

At baseline, the child was independent in his selfcare and toileting activities of daily living (ADLS) but required assistance with walking independently and mobilising up-stairs. At his follow-up assessment, he was independent in all three domains of his ADLs: selfcare, toileting and mobility as per the Barthel Index.

Table 4.3 Case 1: Level of Independence on the Barthel Index

Category	Activity	Before Treatment	After Treatment
Self-care	Feeding	Independent	Independent
	Bathing	Independent	Independent
	Grooming	Independent	Independent
	Dressing	Independent	Independent
Toileting	Bowels	Independent	Independent

	Bladder	Independent	Independent
	Toilet use	Independent	Independent
Mobility	Transfers	Independent	Independent
	Mobility	Required assistance	Independent
	Stairs	Required assistance	Independent

4.3.7 Quality of Life

4.3.7.1 PedsQL child and parent questionnaires

Overall, the child reported a decrease in his quality of life (QoL) in all domains except a slight improvement in procedural anxiety. The child's overall score declined from 77% to 56%.

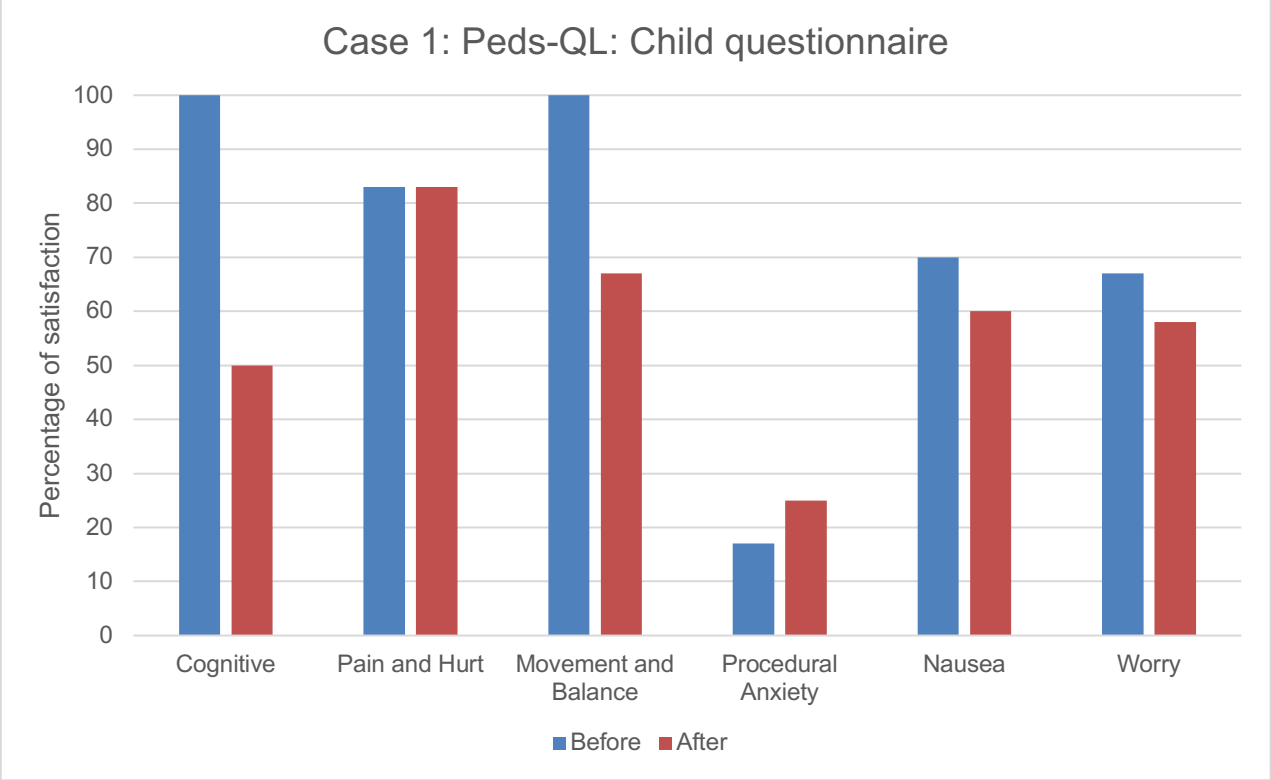


Figure 4.3.9 Case 1: PedsQL Result (%)

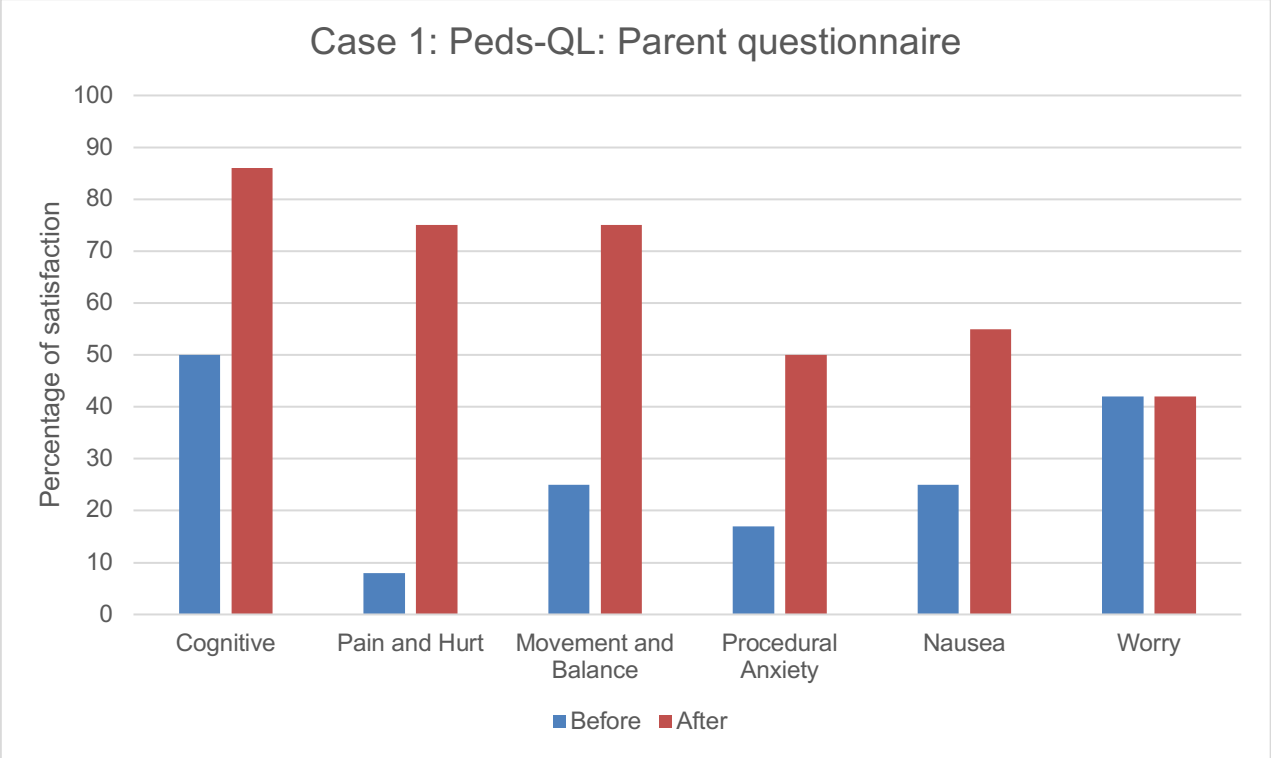


Figure 4.3.10 Case 1: PedsQL Parent Result (%)

The child's mother reported an improvement in his QoL in all domains, with an improvement from 30% to 67%.

4.3.8 Summary case 1:

After treatment, Child 1 had improved scores on the standardised assessments: TIPS, TVPS-4 and Beery VMI, which assessed visual perception and cognition. There were a few areas of decline; however, his scores on these elements were still appropriate for his age. The areas of decline were auditory processing, visual memory and figure-ground and motor coordination. On self-report, the child reported struggling with cognition, but his mother reported an improvement. Regarding motor skills, the child improved overall but had a new onset of attentional control issues and still struggled with balance and vestibular function. Post-treatment, he was now independent in his ADLs as defined by the Barthel Index.

The child reported struggling with three components of behaviour on the PedsQL; reflecting on emotion, confusion and future concerns. He had less procedural anxiety. His mother reported that all the elements of his behaviour had improved. Based on all the findings above, the child reported that his QoL had declined, but his mother reported an overall improvement.

4.4. CASE 2

4.4.1 Medical background

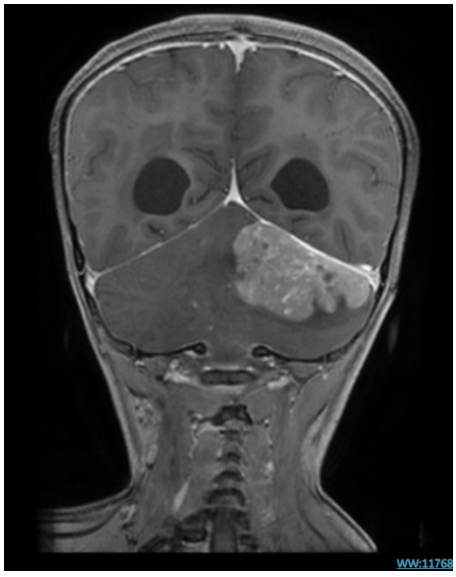
Five year and nine-month-old black male was diagnosed with a medulloblastoma in the left cerebellar hemisphere. He presented with a two-month history of vomiting and headaches and a one-week history of an ataxic gait. He consulted four doctors, including a privately funded general practitioner, before paying privately for a CTB, which revealed a mass within the posterior fossa.

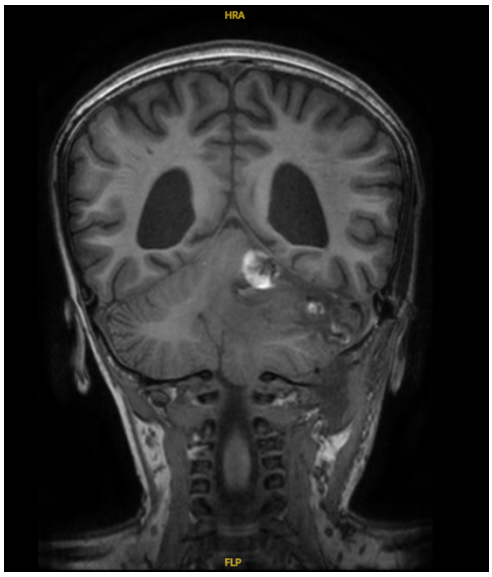
He had an EVD inserted and underwent a total tumour resection a week later. He had the EVD for a total of 16 days before it was successfully removed. He was admitted for a total of 27 days, including a one-day admission to the PICU for postoperative monitoring.

During his hospital stay, he received five OT sessions, eight PT sessions and no ST sessions. His mode of discharge was walking.

Post-surgery, the child underwent ten rounds of chemotherapy and 28 craniosacral irradiation sessions in his native country. He defaulted his last chemotherapy session as the family moved back to South Africa. The child had lost 2,6kgs over the six months from his admission to the end of his treatment. He has not returned to formal schooling.

A





B

Figure 4.4.1 Child 2's pre- and postoperative MRI images of a left cerebellar mass. *(A)* Preoperative scan showing the presence of a left cerebellar mass. *(B)* Postoperative scan demonstrating complete removal of the mass

4.4.2 Cognition

4.4.2.1 Test of Information Processing Skills

Both pre-treatment and post-treatment, Child 2 was unable to identify the letters of the alphabet and, therefore, was unable to complete the TIPS.

4.4.2.2 PedsQL: Self-reported cognition

Preoperatively, the child reported no deficits in number functions, attention, memory, or information processing, whereas his mother reported difficulties in all domains. After treatment, the child reported severe deficits in number functions, memory, and information processing with maintenance of his attentional ability. His mother reported a decline in memory, improvement in number functions and maintenance of attention and information processing. However, his number functions, attention, memory, and information processing were all still deficient for his age.

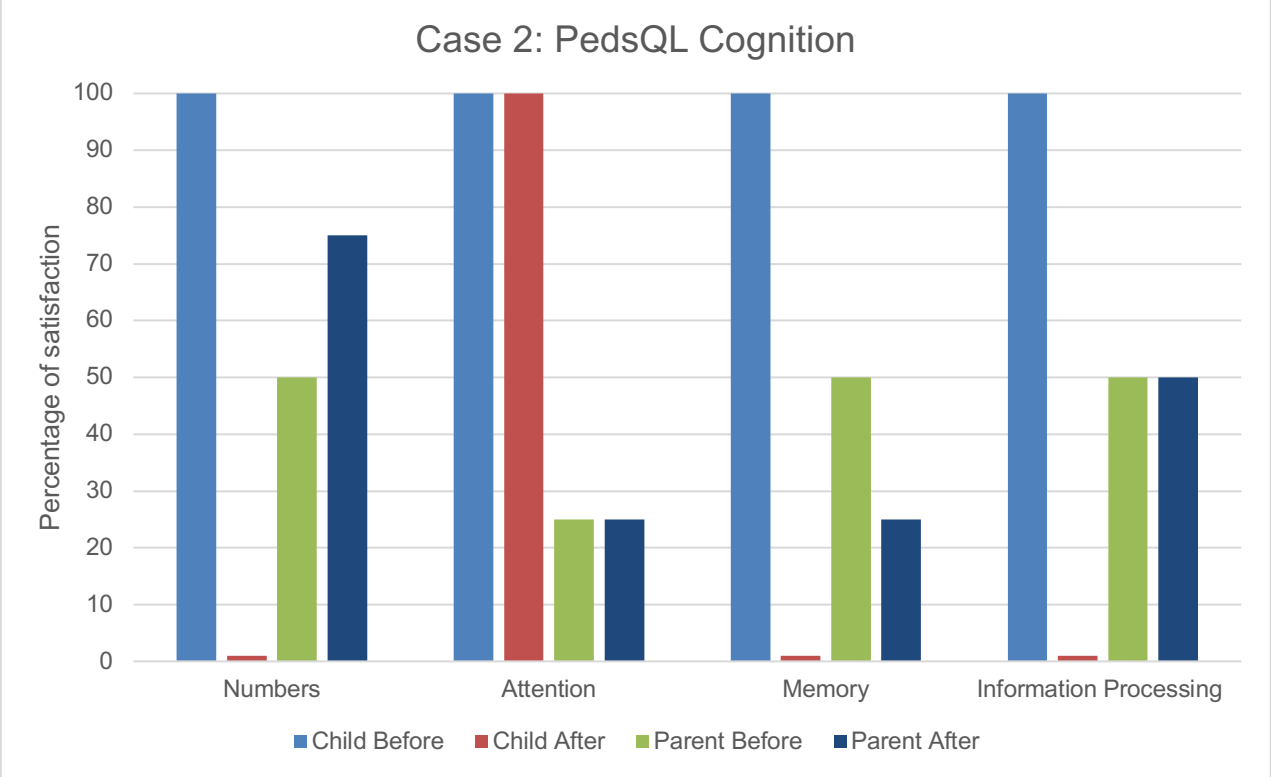


Figure 4.4.2 Case 2: PedsQL Self-reported Cognition Scores (%)

4.4.3 Visual perception

4.4.3.1 TVPS-4

Preoperatively and post-treatment, the child performed in the normal range for his age in the TVPS-4 overall in all domains with scaled scores above seven except for sequential memory. This sequential memory scaled score was six, slightly below average for his age. On follow-up, he performed above average for visual discrimination with a scaled score of 15. The child's performance on sequential memory, visual figure-ground and visual closure declined post-treatment for his PFT.

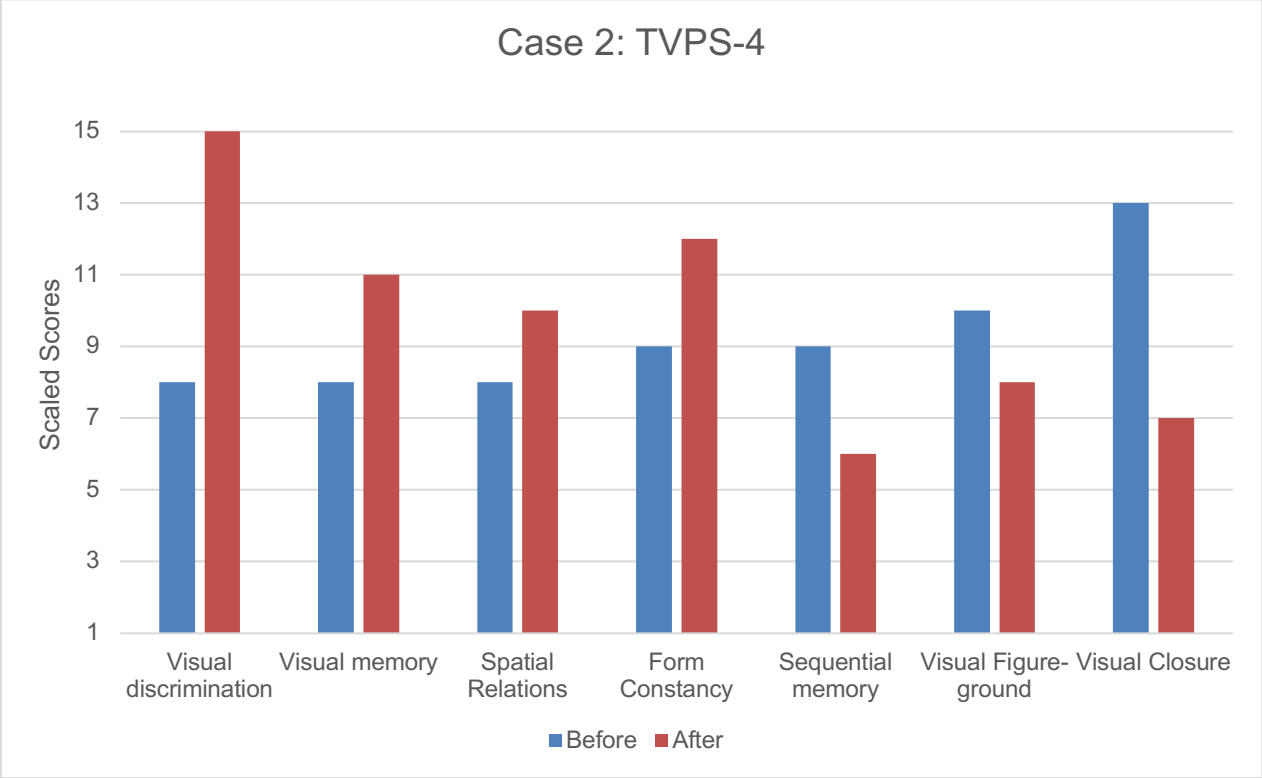


Figure 4.4.3 Case 2: TVPS-4 Scaled Scores

4.3.3.2 Beery-VMI

On the Beery-VMI, the child's results, both preoperatively and at follow up, were appropriate for his age, but he did decline in all domains over time.

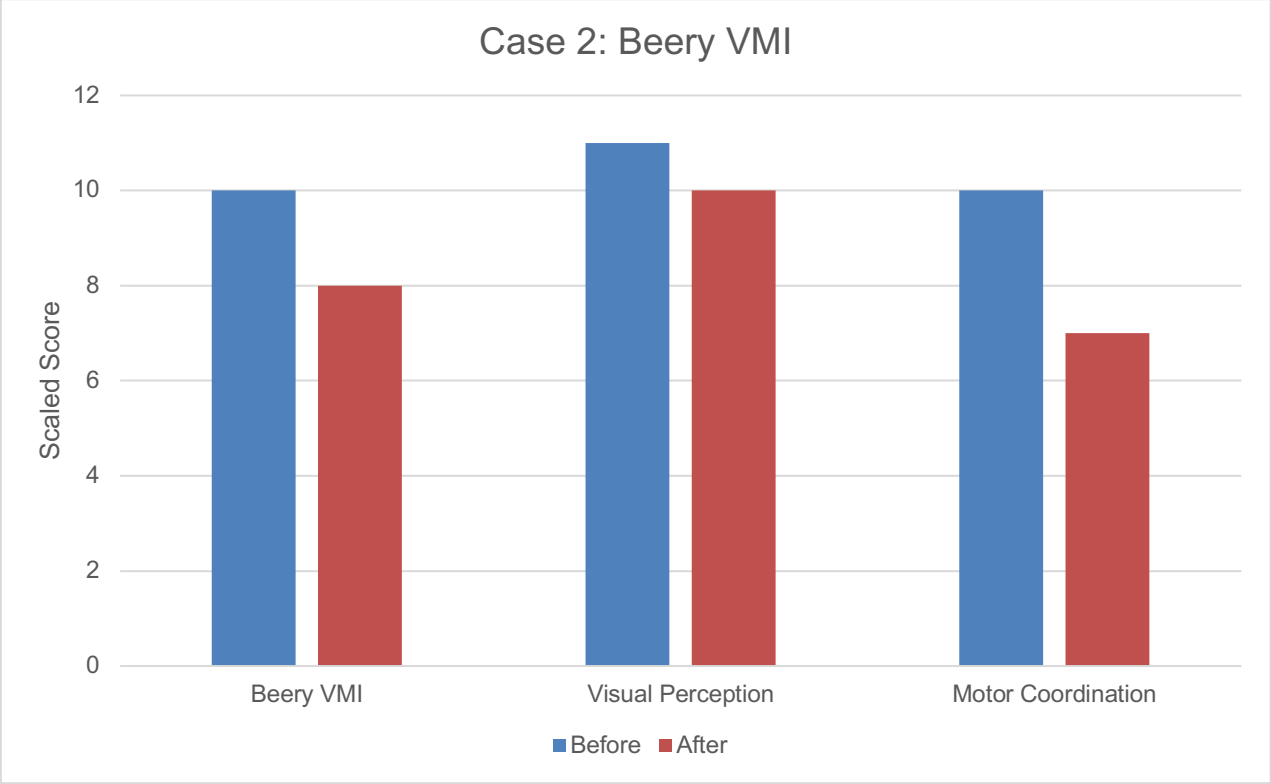


Figure 4.4.4 Case 2: Beery VMI Scaled Scores

4.4.4 Motor skills

4.4.4.1. QNST-3R

Preoperatively, the child an overall normal QNST-3R score but had a severe difficulty with tactile and kinesthetic processing, and a moderate impairment in motor maturity and development, motor planning and sequencing, spatial organization, and balance and vestibular functioning. On follow-up he presented with a moderate impairment score overall. His performance in tactile and kinesthetic processing, sense of rate and rhythm, and balance and vestibular function worsened. His performance in terms of motor maturity and development, gross and fine motor muscle control, and spatial organization improved.

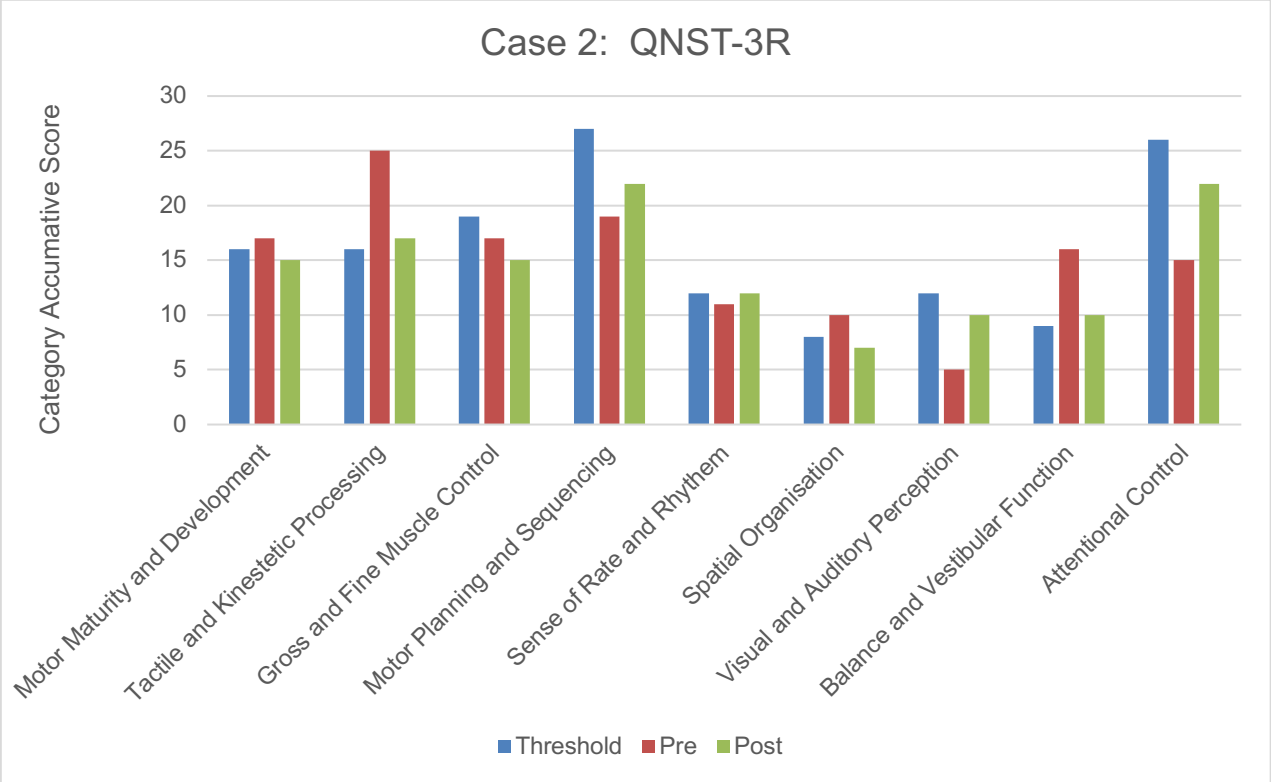


Figure 4.4.5 Case 2: Categorised scores for the QNST-3R

4.4.5 PedsQL: Behaviour

Overall, the child reported no behavioural deficits preoperatively but reported difficulties with confusion, procedural anxiety and concerns for the future after treatment. His mother reported that preoperatively, the child struggled with reflecting on emotions, confusion, procedural anxiety and a slight worry for the future, which all improved post-treatment.

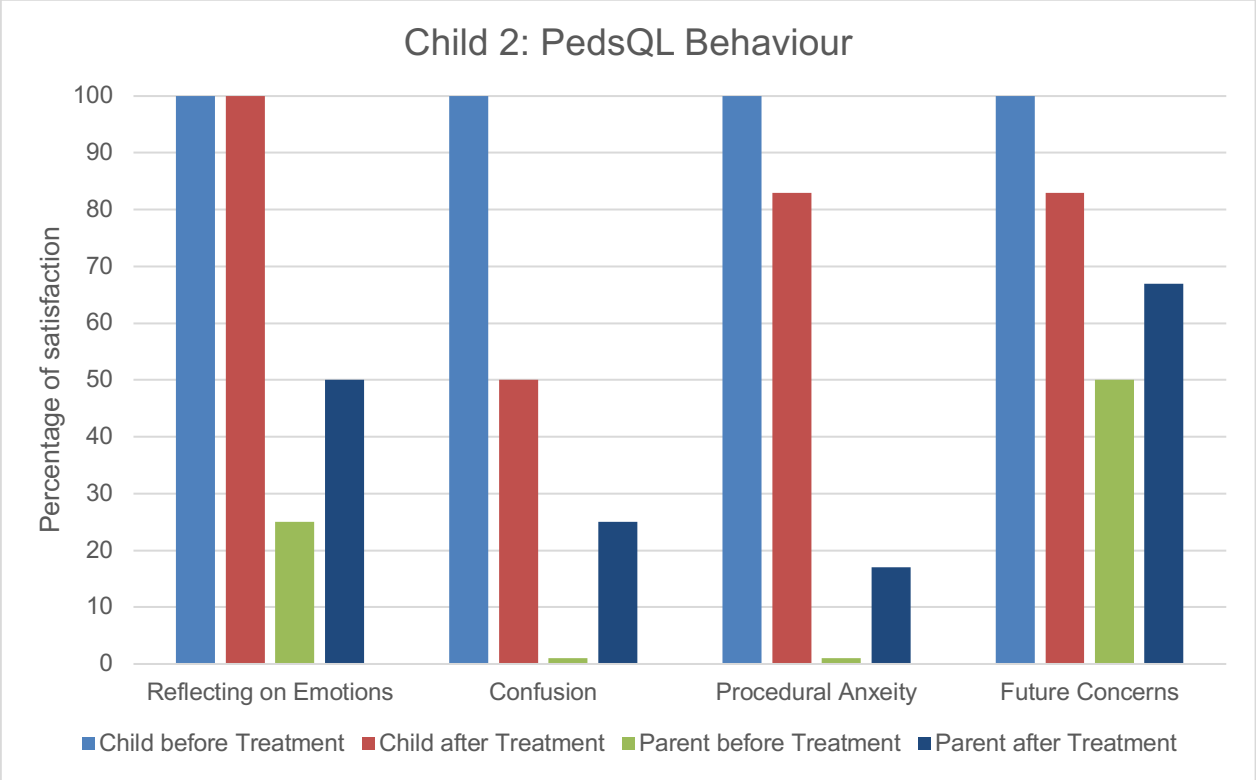


Figure 4.4.6 Case 2: PedsQL Behaviour results (%)

4.4.6 Activities of Daily Living

4.4.6.1 Barthel index:

Preoperatively, the child had deficits in selfcare and mobility, requiring assistance with dressing, transfers, walking and stairs. On follow-up, his independence in his ADLs had improved overall, but he developed occasional incontinence at night and required assistance with feeding.

Table 4.4. Case 2: Level of Independence on the Barthel Index

Category	Activity	Before Treatment	After Treatment
Self-care	Feeding	Independent	Required assistance
	Bathing	Independent	Independent
	Grooming	Independent	Independent
	Dressing	Required assistance	Independent
Toileting	Bowels	Independent	Independent
	Bladder	Independent	Occasional accident

	Toilet use	Independent	Independent
Mobility	Transfers	Required assistance	Independent
	Mobility	Required assistance	Independent
	Stairs	Required assistance	Independent

4.4.7 Quality of Life

The child reported a decrease in his QoL in cognitive functioning, pain and hurt, procedural anxiety, nausea, and worry. His reported that his movement and balance had improved. Overall he reported that his QoL decreased from 95,7% to 69,6%. His mother reported an increase in the child's QoL in all areas except nausea, which remained the same as the preoperative score. Overall her score increased from 33,7% to 45,7%.

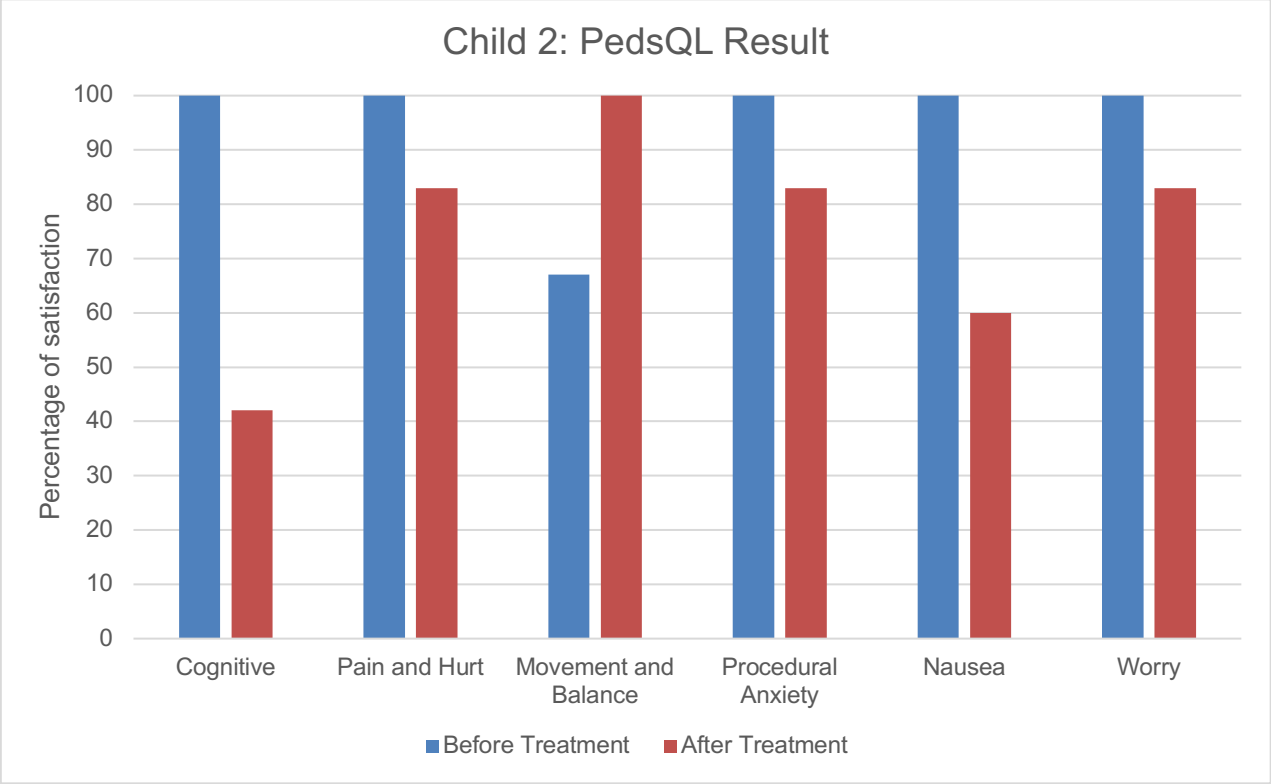


Figure 4.4.7 Case 2: PedsQL Result (%)

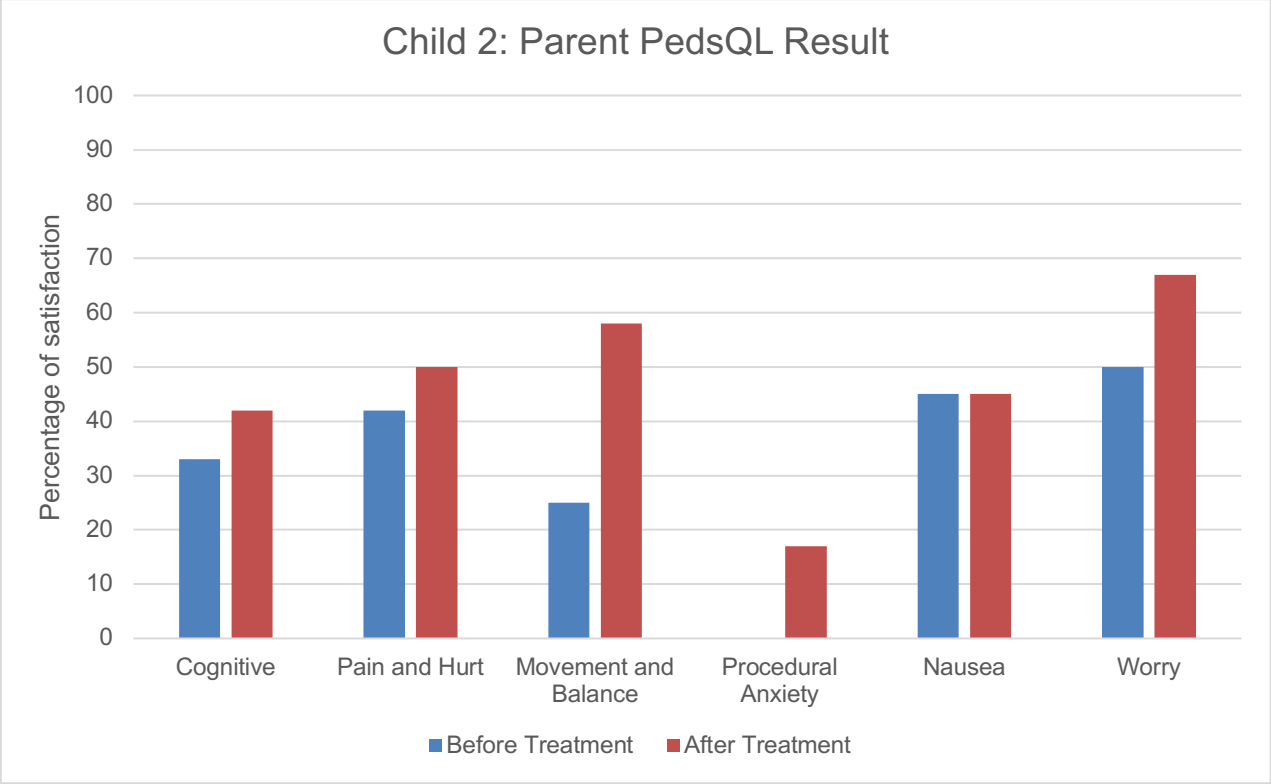


Figure 4.4.8 Case 2: PedsQL Parent Result (%)

4.4.8 Summary of case 2

Although it was difficult to assess Child 2's cognition with a standardised assessment, the child self-reported declining in all his cognitive skills except for attention. His mother reported that Child 2's memory declined, and although his attention and information processing had not changed, it was still deficient. She reported that his numerical abilities had improved. Overall, the child's visual perception on the TVPS-4 had improved slightly, with all of his scaled scores within the normal range except for sequential memory. On the Beery-VMI, all his scores declined, but he still scored within the normal range for the three subtests.

Of note, Child 2's motor performance declined from normal pre-treatment to a moderate impairment post-treatment. The main areas of deficits were tactile and kinesthetic processing, sense of rate and rhythm, and balance and vestibular function. In terms of ADLs, the child was now independent in self-care and mobility but presented with new onset nocturnal incontinence.

The child reported worsening confusion, procedural anxiety and future concerns but no problems with reflecting on emotions. This mother reported that all aspects of his behaviour had improved,

but his confusion, procedural anxiety, and reflecting on emotions were still deficient. As a result of the above, the child reported that his QoL had decreased in all domains except for movement and balance. His mother reported a slight QoL increase but still below 50%.

4.5 CASE 3

4.5.1 Medical background

A seven-year-old black female was diagnosed with a medulloblastoma in the midline of the cerebellum. She presented with a three-week history of vomiting and headaches before presenting to her local clinic for medical treatment. She consulted four doctors before undergoing a CTB, which revealed a mass within the posterior fossa.

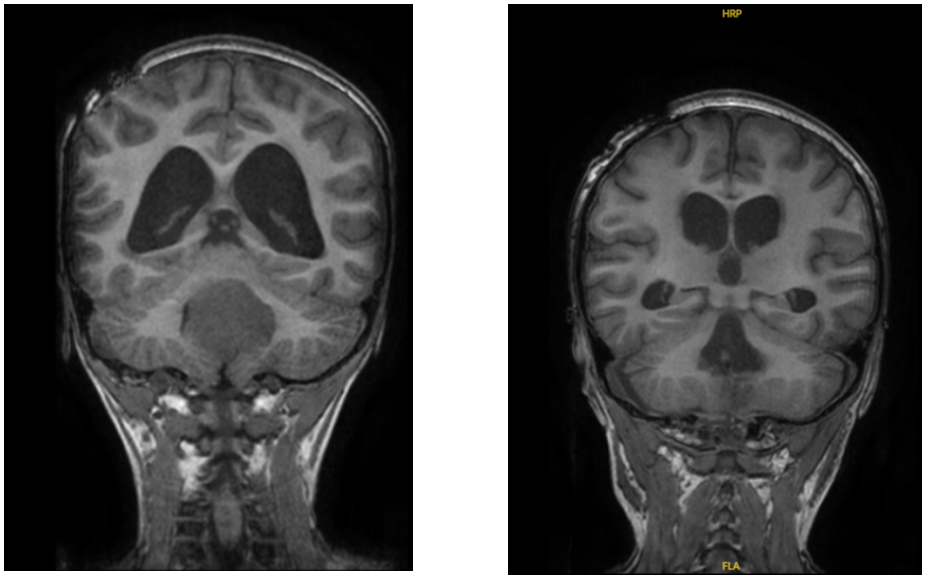
She underwent emergency surgery to have an EVD placed to reduce her raised intracranial pressure (ICP). She had a craniotomy for a total resection of her tumour. She had a complicated postoperative course and required two EVD washouts and replacements due to persistent infection. She had an EVD for a total of 13 days before having a VPS inserted. Her overall hospital stay was 43 days, including a two-day admission to the PICU post-tumour resection surgery.

During her hospitalisation, she received 16 OT sessions, 12 PT sessions and one ST session. Her mode of discharge was via a wheelchair.

Post-surgery, the child underwent 16 rounds of chemotherapy and 21 craniosacral irradiation sessions. The child had lost 4kg from the start of her treatment until the time of follow-up.

Six months after her tumour resection surgery, the child was readmitted due to wound breakdown at the original EVD site. She required a six-day admission and a surgical debridement and wound closure.

A



B

Figure 4.5.1 Child 3's pre- and postoperative MRI images of a midline cerebellar mass. *(A)* Preoperative scan showing the presence of the cerebellar mass in the midline region. *(B)* Postoperative scan demonstrating complete removal of the mass

4.5.2 Cognition

4.5.2.1 Test of Information Processing Skills (TIPS)

Both pre-treatment and post-treatment, Child 3 was unable to identify the letters of the alphabet and, therefore, could not complete the TIPS.

4.5.2.2 PedsQL: Self-reported Cognition

The child and the mother reported no deficits in cognition preoperatively and on follow-up.

4.5.3 Visual Perception

4.5.3.1 TVPS-4

Preoperatively, the child performed within the normal range for the TVPS overall but had deficits in form constancy with a scaled score of six, below the normal range of seven to ten. On follow-up, she demonstrated a slight improvement in her overall score but performed above average in the form constancy and sequential memory subtests. She performed below average for visual memory and sequential memory, with a scaled score of five and four, respectively.

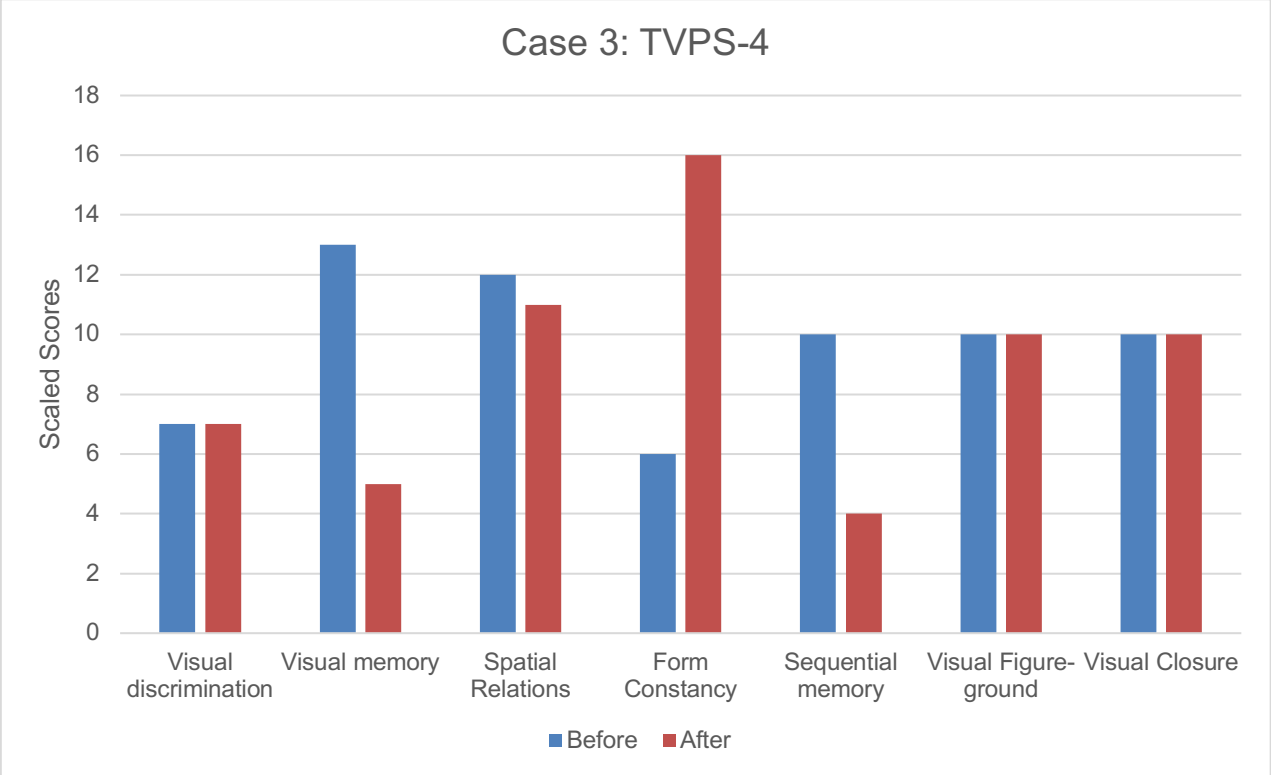


Figure 4.5.2 Child 3: TVPS-4 scaled scores

4.5.3.2 Beery-VMI

On the Beery-VMI, the child performed within her age norm preoperatively. On follow-up she declined in two of the three domains; Beery-VMI and visual perception, with scaled scores for both tests of eight. She maintained her motor coordination scaled score of eight.

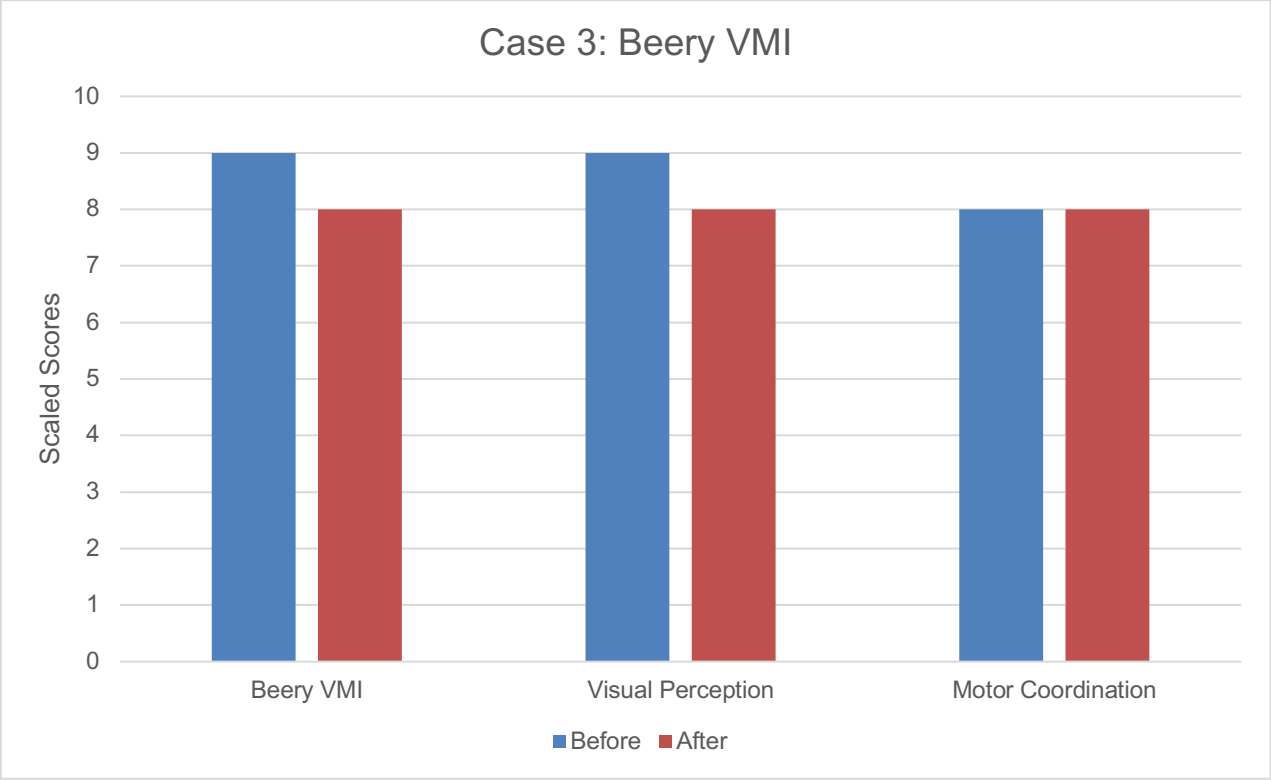


Figure 4.5.3 Child 3: Beery VMI scaled scores

4.5.4 Motor skills

4.5.4.1. QNST-3R

Preoperatively, the child had a normal performance on the QNST-3R with impairment in tactile and kinesthetic processing, and balance and vestibular functioning. On follow-up, she maintained a normal performance on the QNST-3R, but had impairments in motor maturity and development, tactile and kinesthetic processing, gross and fine motor muscle control, sense of rate and rhythm, spatial organization, and balance and vestibular function. Her motor planning and sequencing declined but were still within the normal range. She had improved performance in attentional control and maintained her performance for visual and auditory perception.

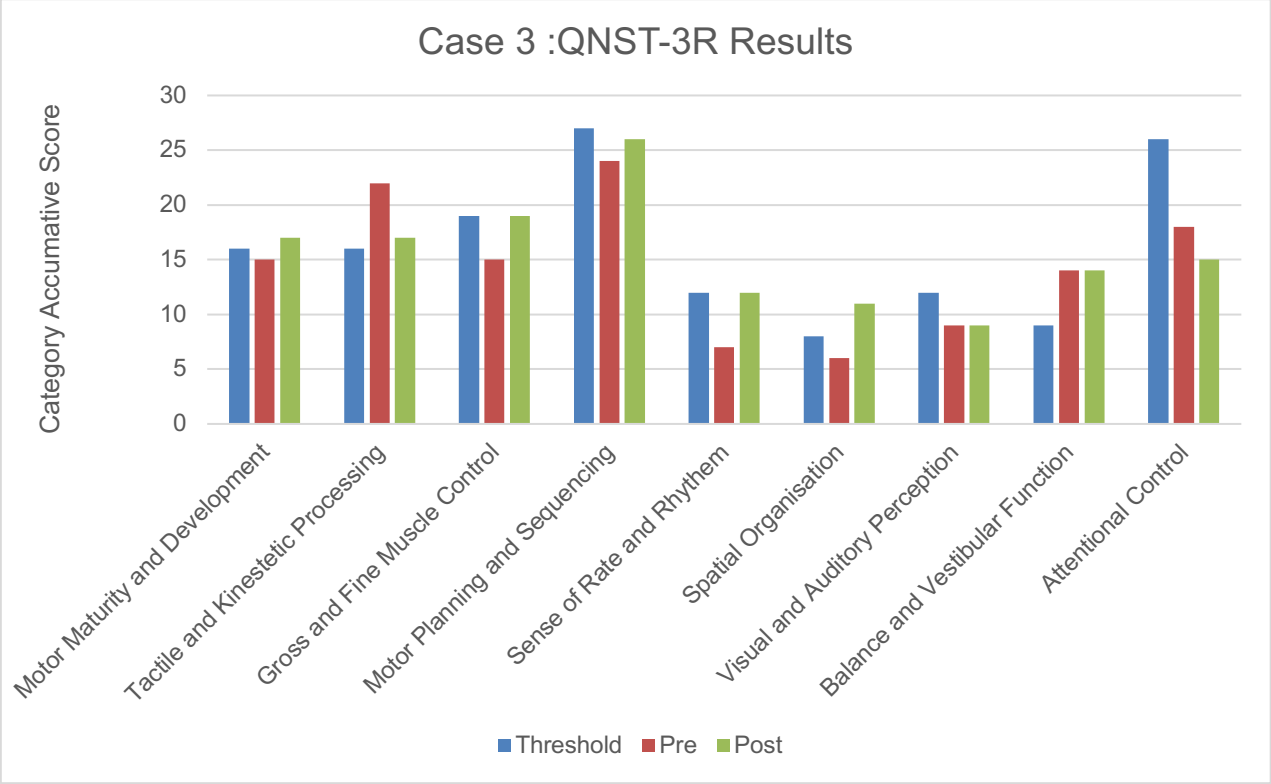


Figure 4.5.4 Child 3: Categorised scores for the QNST-3R

4.5.5 PedsQL: Behaviour

Preoperatively, the child and the mother reported no concerns regarding reflecting on emotions, confusion, and future concerns. The child had slight procedural anxiety preoperatively, which improved on follow-up.

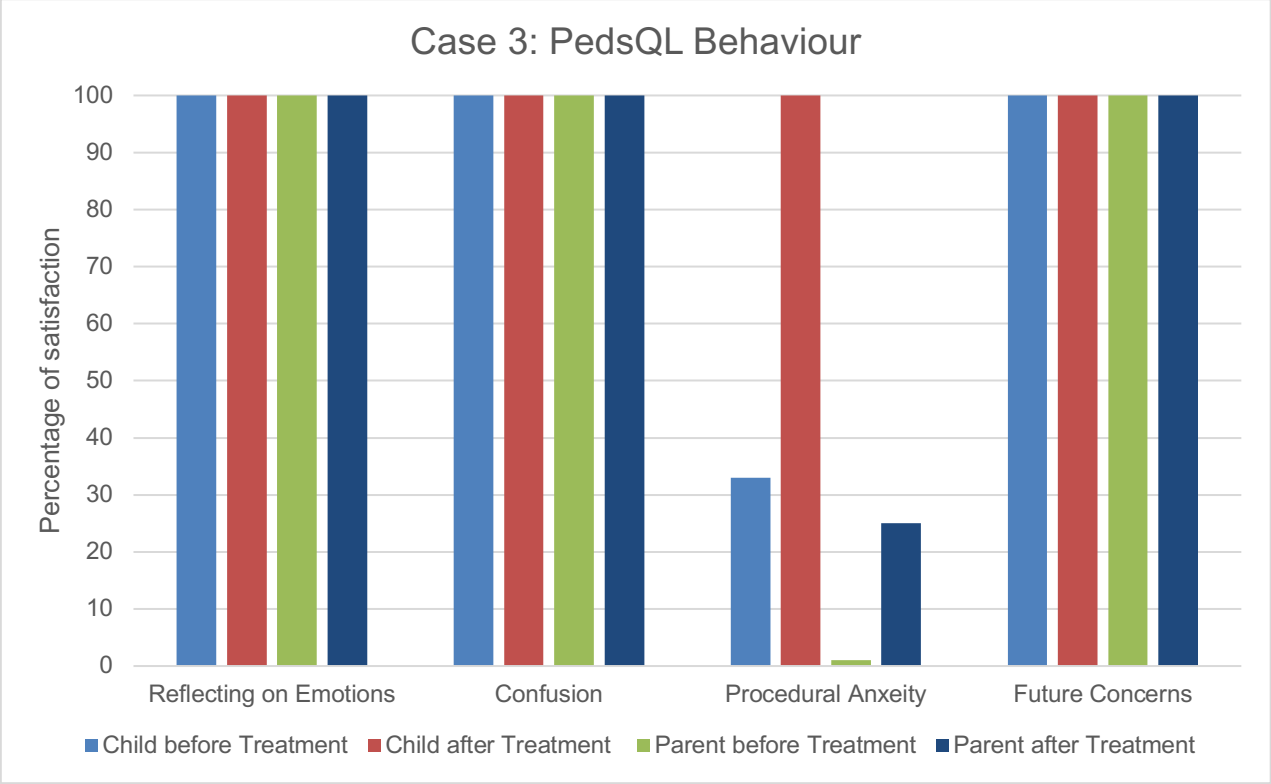


Figure 4.5.5 Child 3: PedsQL Behaviour (%)

4.5.6 Activities of Daily Living

4.5.6.1 Barthel index:

Preoperatively, the child was independent in her ADLs; selfcare, toileting, and mobility as per the Barthel Index, on follow-up she had difficulties with feeding secondary to decreased muscle strength.

Table 4.5. Case 3: Level of Independence on the Barthel Index

Category	Activity	Before Treatment	After Treatment
Self-care	Feeding	Independent	Required assistance
	Bathing	Independent	Independent
	Grooming	Independent	Independent
	Dressing	Independent	Independent
Toileting	Bowels	Independent	Independent

	Bladder	Independent	Independent
	Toilet use	Independent	Independent
Mobility	Transfers	Independent	Independent
	Mobility	Independent	Independent
	Stairs	Independent	Independent

4.5.7 Quality of Life

4.5.7.1 PedsQL child and parent questionnaires

Overall, the child reported no problems with cognition, movement and balance, and worry both preoperatively and at follow-up. She reported that her pain and hurt, and procedural anxiety had improved. On follow-up the child reported that her nausea had gotten worse. Overall, the child reported that her QoL had improved from 82,6% to 84,4%.

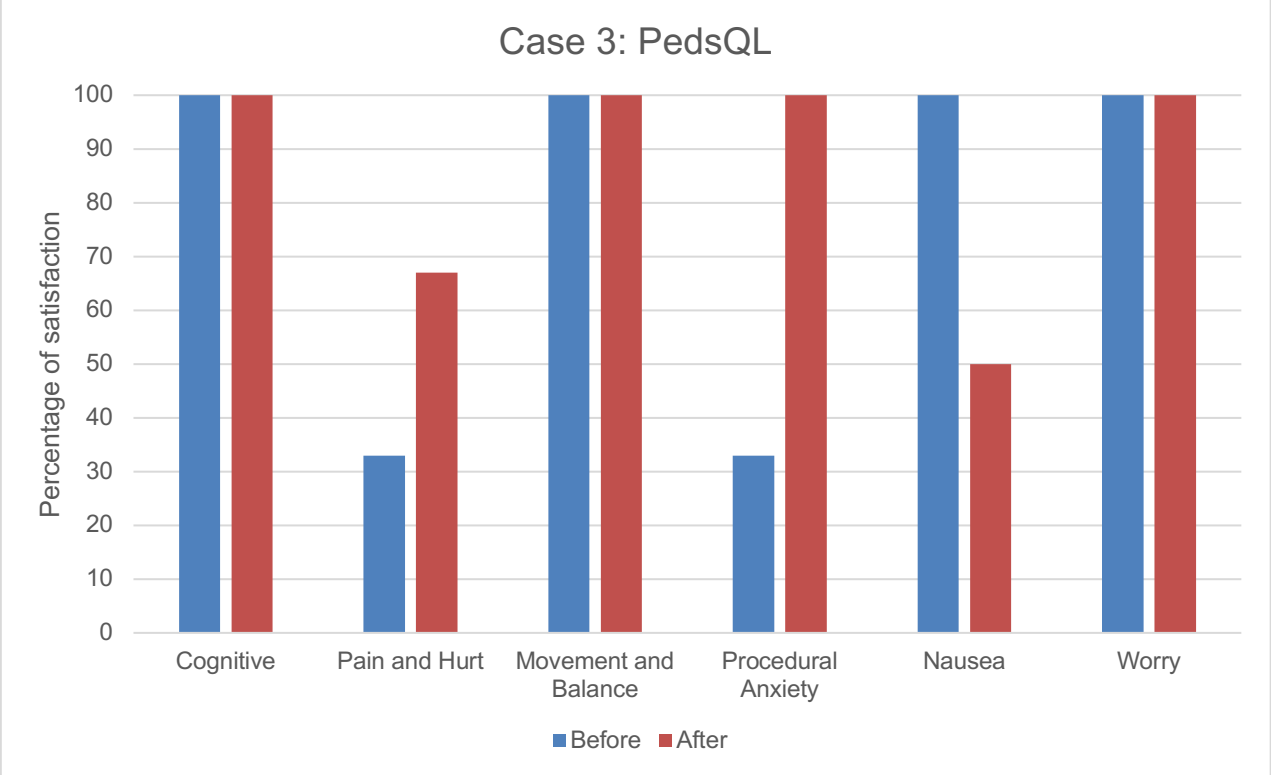


Figure 4.5.6 Child 3: PedsQL (%)

Her mother's responses on the PedsQL echoed her child's, but reported that her procedural anxiety had improved but not to the same extent as what her child reported. Overall, she reported that the child's QoL had declined from 77,2% to 76%.

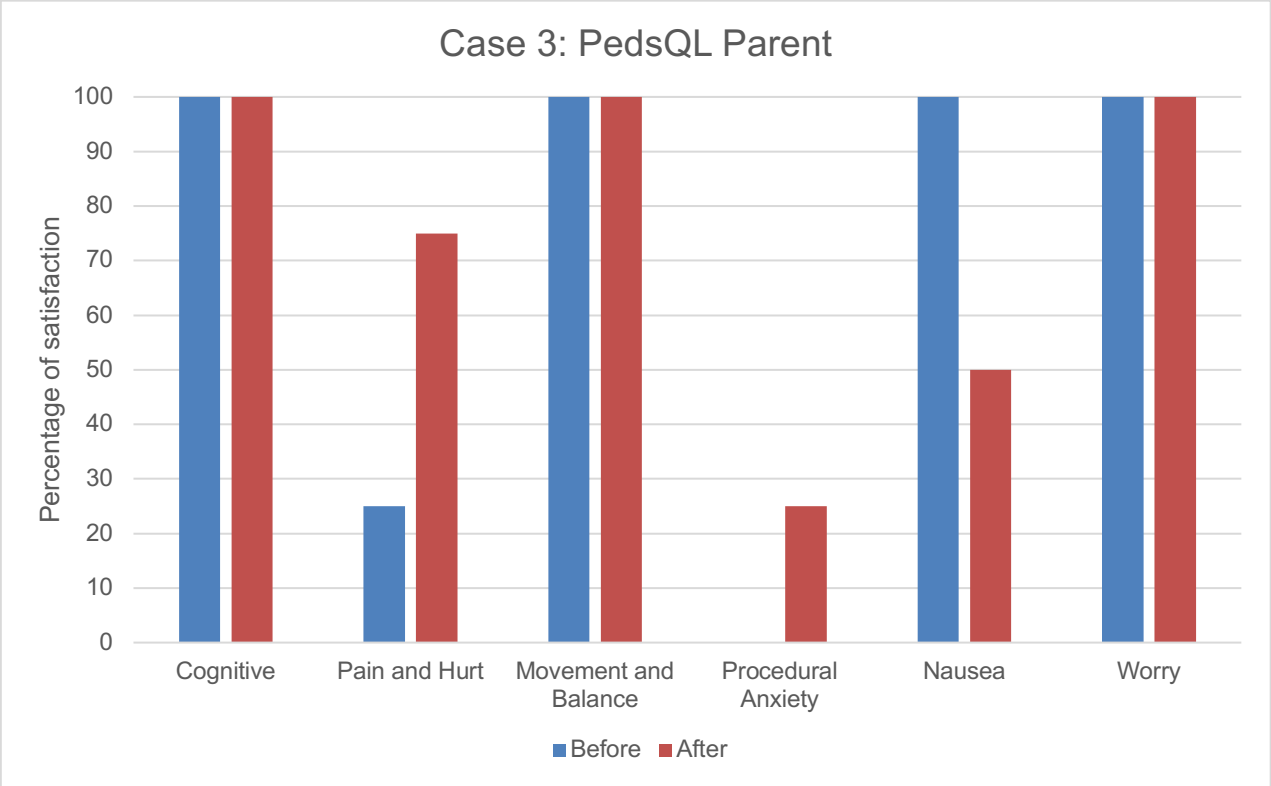


Figure 4.5.7 Child 3: PedsQL Parent Response (%)

4.5.8 Summary of case 3

Although it was difficult to assess Child 3's cognition with a standardised assessment, the child and mother self-reported no decline in her cognitive skills. Overall, the child's visual perception on the TVPS-4 had improved slightly with all of her scaled scores within the normal range except for visual and sequential memory. On the Beery-VMI, all of her scores declined but she still scored within the normal range for the three subtests. Child 3's motor performance remained normal but she had new onset deficits in motor maturity and development, tactile and kinaesthetic processing, gross and fine motor muscle control, sense of rate and rhythm, spatial organisation, and balance and vestibular function. In terms of ADLs, the child now required assistance with feeding but was independent in continence and mobility.

The child reported improved procedural anxiety and no problems with reflecting on emotion, confusion, or future concerns. Her mother agreed with the child's report. Overall, the child reported a slight decline in her QoL related to increased nausea, and her mother reported a slight increase in her QoL due to less pain and hurt and procedural anxiety.

4.6 CONCLUSION

All three children presented unique findings regarding their cognitive, visual perception, motor, and behavioural outcomes: there was a decline in cognition and behaviour in the male children, and visual perception was found to be impacted in the younger children. Motor skills were negatively affected in all the children. Although the children were mostly independent in their ADLs, the two younger children had developed new onset difficulties with continence and feeding. Regarding QoL, the children's self-reports differed from the experience of their caregivers. All these points will be discussed in the next chapter.

CHAPTER 5: DISCUSSION

5.1 INTRODUCTION

As demonstrated in the results chapter, each child had a unique set of results that could not be statistically compared. Therefore, each case will be discussed separately, and commonalities will be highlighted.

5.1.1 Objective 1: To determine the demographics of children diagnosed with posterior fossa tumours

The three children in this study were all above the age of five at diagnosis, which is higher than the average age at diagnosis reported by Prasad et al. (2017) and Boop et al. (2018) (Vara Prasad *et al.*, 2017; Boop and Chuang, 2018). The older age at diagnosis is in line with the longer time to diagnosis seen in lower to middle-income countries (LMICs). This is secondary to poor awareness of the signs of paediatric brain tumours and limited access to diagnosis imaging (Arnold-Day, 2019). Children with a posterior fossa tumour (PFT) often have nonspecific symptoms such as headaches and nausea. Therefore, many healthcare professionals in LMICs misdiagnose the children and do not escalate care to diagnostic imaging (Boop and Chuang, 2018).

Of the three children followed up, all were diagnosed with a medulloblastoma, which is in line with the international literature, which has shown that medulloblastomas are the most common tumours of the posterior fossa (Voth, 2001; Boop and Chuang, 2018; D'arco *et al.*, 2018; Cohen, 2022).

In this study, two out of the three children sought private healthcare to facilitate their diagnosis. Between four and six doctors examined the children before getting their diagnostic CT scan; this is far above the average number of doctors, two, that was reported by Dorner et al. (2017) in Germany, a high-income country (HIC) (Dörner *et al.*, 2007).

At presentation, all three presented with raised intracranial pressure secondary to acute hydrocephalus and had external ventricular drains (EVDs) inserted to decrease the pressure. Internationally, it is reported that 70-80% of children diagnosed with a PFT present with hydrocephalus (HCP), and therefore, in South Africa, we have similar results (Dörner *et al.*, 2007; Lassaletta *et al.*, 2015; Stavinoha *et al.*, 2018; Arnold-Day, 2019). The literature differs in terms of the percentage of children who develop chronic HCP requiring permanent cerebral spinal fluid

(CSF) diversion. In this study, 67% required a ventriculoperitoneal shunt (VPS), which appears to align with the literature (Lin and Riva-Cambrin, 2015; Boop and Chuang, 2018).

5.1.2 Objective 2: To describe the change in the cognitive, visual perception, motor and behaviour outcomes of children pre and post posterior fossa tumour surgery and medical management.

5.1.2.1 Case 1:

Child 1 was a ten-year nine-month-old male at initial assessment who was diagnosed with a medulloblastoma and underwent a near-total resection, six rounds of chemotherapy and 21 craniospinal radiation sessions. The discussion of his results is as follows.

Cognitive

The child performed within the normal range for cognition on the Test of Information Processing Skills (TIPS) both preoperatively and post-treatment, and he showed an improvement in his visual modality scores, both ordered and unordered. This improvement can be attributed to a decrease in papilledema after having a ventriculoperitoneal shunt (VPS) inserted to treat his hydrocephalus (HCP) and a resolved horizontal nystagmus post-tumour resection, allowing for an improvement in the ability to identify and retain visual information (Voth, 2001). Many published articles agree that children with PFTs show a gradual decline in their cognitive skills. Although this child presented with normal cognition on follow-up, over time, his performance on this test would likely decline (Lassaletta *et al.*, 2015; Rizzo, Daniela. Peruzzi, Laura. Attina, Giorgio. Triarico, Silvia. Maurizi, Palma. Ruggiero, 2017; Chieffo *et al.*, 2022).

On the TIPS, the child declined in his oral modality scores, which is in line with the Stavinoha et al. (2018) publication that stated that PFT survivors presented with impaired verbal memory skills. They also reported that PFT survivors demonstrated poor visual memory skills that stabilised, whereas their verbal memory skills continued to decline (Stavinoha *et al.*, 2018).

Although the child's cognitive performance did not decline objectively, he self-reported that his cognitive abilities, mathematics, attention, memory, learning and confusion had all declined. His mother, however, reported an improvement post-treatment; this may be due to her comparing her child's performance post-treatment to when he started displaying symptoms instead of his

baseline functioning. Many studies have been conducted to determine the reliability of child vs proxy (caregiver) reports of health-related quality of life (QoL), and a conclusion has not been made; in some studies, there was a high correlation, and others differed. It has been suggested that information regarding the proxy's own QoL should also be collected as their QoL could impact how they perceive the child's QoL and abilities (Germain, Aballéa and Toumi, 2019).

In this case, the child is old enough to fully understand the questions on the PedsQL that relate to cognition. Therefore, his opinion should be considered when considering his overall cognition functioning. The TIPS assesses the ability of a child to receive and process information. Although information about the child's attention and memory can be inferred through the results, it is not explicitly assessed. Therefore, although his performance on the TIPS is typical, there might be subtle cognitive deficits the child can identify that the test didn't highlight.

Based on the location of the tumour, the functional areas impacted are visual working memory, attention and information maintenance (Haley and Freeman, 2018; Guell and Schmahmann, 2020). These skills correspond with the child's self-report of his abilities.

Research has shown that the higher the maternal education level, the better the child's cognitive outcome (Yeole *et al.*, 2021; Doris *et al.*, 2022). This child's mother had earned a diploma, and with only 14,6% of South Africans obtaining a post-matric qualification, this places her in the higher level of education bracket (Khuluvhe and Ganyaupfu, 2022). Greater stimulation level at home and early return to school may play a role in his retained cognitive abilities.

Literature has shown that HCP has been proven to have a significant detrimental effect on a child's cognition. However, this child showed an improvement in his ability to process new information (Lassaletta *et al.*, 2015). This child sought private medical attention, which facilitated a faster time to diagnosis and treatment of his HCP. As a result, it can be hypothesised that the prompt treatment of the HCP reduced the risk of cognitive fallout compared to delayed treatment. The early treatment of his HCP may also have impacted his visual perception results.

<u>Visual perception</u>

Visual perception is found to be affected in 50% of children treated for a posterior fossa tumour; in this case, the child presented with an improvement in his visual perceptual skills (Chieffo *et al.*, 2021; Zilli *et al.*, 2021). On follow-up, the child's nystagmus and papilledema, secondary to hydrocephalus, had resolved. Oculomotor control is required for visual perception, and one needs

to be able to fixate, locate and shift between visual stimuli to process it. Therefore, a resolved nystagmus and papilloma would improve his visual perceptual skills.

This child returned to school virtually; learning material on the computer requires visual fixation, pursuits, and visual motor integration (copying information from the screen onto paper); this early participation in academic activities most likely aided in stimulating and developing his visual perceptual skills.

Motor

Although this child showed overall improvement in his motor functioning, he still had difficulties with balance, vestibular function, and motor coordination.

The Flocculonodular lobe of the cerebellum is responsible for body equilibrium and vestibular input (Guell and Schmahmann, 2020). In this child's case, his tumour was predominantly located in the cerebellum's posterior and flocculonodular lobes. Therefore, persistent problems with both balance and vestibular processing are expected. Another factor in this child's poor balance and vestibular processing was the use of Cisplatin and Vincristine. Cisplatin and Vincristine have been known to cause vestibular toxicities, which impact the balance (Medina *et al.*, 2021; Decock *et al.*, 2022).

The child's tactile and kinesthetic processing improved; this is unexpected as chemotherapy results in peripheral neuropathies, often impacting fine motor control (Hartley *et al.*, 2019; Decock *et al.*, 2022).

The child had an improvement in his motor maturity and development, motor planning and sequencing skills, and gross and fine motor muscle control. The improvement in these skills can be attributed to the preservation of the cerebellar tracts and nuclei, as seen on the MRI scan after his surgical resection of the tumour, which previously compressed these tracts. The cerebellar tracts mediate motor output, movement initiation, planning, and coordination (De Benedictis *et al.*, 2022).

Coordination is one of the three primary roles of the cerebellum, mainly located in the cerebellar hemispheres medially, and therefore, any injury to the cerebellum will result in deficits in these areas (Guell and Schmahmann, 2020; Lehman *et al.*, 2020; Jimsheleishvili and Dididze, 2023). The location of the child's tumour would explain the difficulties with motor coordination of the right

hand as the motor planning and right-hand movements functional area was affected (Haley and Freeman, 2018).

Behaviour

As reported before, there were discrepancies between the child's report of his behaviour and his mother's. The child reported that he had difficulties with the ability to reflect on emotions and struggled with confusion. Both these findings are consistent with the literature, which reports that children with PFTs struggle with emotional regulation and affect, especially when the cerebellar vermis is affected by either the tumour or resection surgery (Arasanz *et al.*, 2012; Lassaletta *et al.*, 2015). This child's tumour involved both cerebellar hemispheres and the vermis. The child's mother reported that the child had an improved ability to reflect on emotions; however, her perception was based on the behaviour output she saw; the ability to reflect on emotions is an internal cognitive process and can only be reported on by the child himself.

Both the child and his mother reported increased anxiety, which is common with PFT survivors, as reported by Chieffo et al. (2021) (Chieffo *et al.*, 2021).

5.1.2.2 Case 2:

Child 2 was a five-year nine-month-old male at initial assessment who was diagnosed with a medulloblastoma and underwent a total resection, ten rounds of chemotherapy and 28 craniospinal radiation sessions. Discussion of his results is as follows.

Cognitive

A standardised assessment was not conducted on this child preoperatively, and on follow-up, he could not identify the letters of the alphabet even though he had completed nine months of formal schooling. The child reported that on follow-up he felt that he had severe deficits in number functions, memory and information processing; this would correlate with the location of his tumour as it impacted his left cerebellar hemisphere, which controls working memory and information processing skills (Guell and Schmahmann, 2020; Lehman *et al.*, 2020). Difficulties with number functions could also be attributed to the child not returning to formal schooling; therefore, he has not learnt any new number concepts.

The child reported no problems with attention. However, his mother reported poor attention preoperatively and on follow-up. Due to the location of his tumour, we would expect to see attentional difficulties. In a study done by Diaz et al. (2018), they found that children as young as six years of age were able to self-report their attentional abilities that correlated with their episodic memory abilities (requiring attentional processes) (Diaz, Blankenship and Bell, 2018). The child at follow-up assessment was over the age of six years and, therefore, should be able to provide an accurate perception of his skills; however, research done by Conijn et al. (2020) found that child self-reports on the PedsQL were only similar to informant data from the age of seven years old (Conijn, Smits and Hartman, 2020). It was noted that this child's performance on the TVPS declined as the test progressed, possibly due to potential attentional difficulties. Therefore, based on observations, his mother's report and the location of his tumour, it can be concluded that this child had attention difficulties post-treatment.

Visual perception

This child had an overall improvement in his visual perceptual skills on the TVPS; however, as reported previously, as the test progressed, his scores declined. His scores on the Beery-VMI all declined; however, this assessment was done towards the assessment session, and therefore, these scores could be related to poor attention and poor sustained effort rather than visual perception abilities. Decock et al. (2022) and Levitch et al. (2022) reported that PFT survivors often experience fatigue, impacting their ability to engage in their activities of daily living. The fatigue results from deconditioning and the side effects of chemotherapy and radiation (Decock *et al.*, 2022; Levitch *et al.*, 2022). This child has not returned to school and, therefore, is not being cognitively stimulated and underwent both chemotherapy and radiation. Thus, his inconsistent visual perception scores could be a result of fatigue.

The improved TVPS scores could result from his resolved nystagmus, which impacted his ability to see clearly preoperatively. He also did not develop chronic HCP; therefore, the papilledema caused by his acute hydrocephalus would have also resolved, further improving his visual abilities.

Although the child improved his visual perception skills overall, his sequential memory, figure-ground, and visual closure had declined. In children with posterior fossa tumours, working memory is the most affected component of memory; therefore, it can be expected that this child would have difficulties with his visual sequential memory (Lassaletta *et al.*, 2015; Laliberté Durish *et al.*, 2021; Decock *et al.*, 2022). The cerebellum has also been associated with visuospatial organisation, including the ability to determine fore-ground from figure-ground (Arasanz *et al.*, 2012; Lassaletta

et al., 2015). The child's decline in his visual figure-ground skills is most likely associated with damage to the cerebellum from the surgery and subsequent craniospinal radiation.

Motor

Overall, the child had a decline in his motor skills during follow-up. According to the functional areas defined by Kig et al. (2021), the child's tumour impacted the motor planning and movement motor areas of the left cerebellar hemisphere. Therefore, a decline in his overall motor skills can be expected. The child presents with deficits in tactile and kinesthetic processing, balance and vestibular functions, and sense of rate and rhythm.

Kinesthetic processing is the ability to determine where your body parts are in relation to parts; it incorporates vision, touch, and vestibular input to interpret the environment and object properties (Taylor, 2022). Kinesthetic processing is linked to proprioceptive input. The decline in the above aspects could be attributed to his ten rounds of chemotherapy, which Boop and Chuang (2018) and Hartley et al. (2019) both reported results in motor and sensory processing disorders (Boop and Chuang, 2018; Hartley et al., 2019). This is congruent with the child's worsening performance on the motor coordination subtest on the Beery-VMI subtest.

The child's poor balance and vestibular functions can be attributed to the same factors as Child 1: tumour location and chemotherapy agents (Medina et al., 2021; Decock et al., 2022). The child's performance increased slightly but was still within the moderate impairment category, and this could be the result of the resolution of his acute hydrocephalus post-tumour resection. Raised intracranial pressure (ICP) can result in gait changes and ataxia that improve with treatment (Voth, 2001).

As with Child 1, Child 2's improvement in his motor maturation and development and gross and fine motor control could be attributed to the preservation of the cerebellar tracts and nuclei after surgical resection of his tumour.

Behaviour

Similarly to Case 1, this child also presented with difficulties with confusion, procedural anxiety and concerns for the future. His mother reported that he had difficulties reflecting on emotions, which the child did not report. Reflecting on emotions is a higher-order skill that is not expected to be fully developed in a child of this age. Therefore, he cannot be a reliable informant of this

component of behaviour. Based on the location of his tumour, there is damage to the resolution of conflicting information, and therefore, difficulties with this skill can be expected (Haley and Freeman, 2018; Habas, 2021).

5.1.2.3 Case 3:

Child 3 was a seven-year-old female at initial assessment who was diagnosed with a medulloblastoma and underwent a total resection, sixteen rounds of chemotherapy and 21 craniospinal radiation sessions. The discussion of her results is as follows.

Cognitive

As with Child 2, Child 3 was also unable to identify the letters of the alphabet preoperatively and on follow-up and, therefore, was not assessed using the TIPS.

The child and her mother reported no problems with cognition preoperatively and on follow-up in any of the four domains. Some of the possible reasons for this could be due to the child not returning to school and not being required to complete any academic work to compare her performance, a lower maternal education level and the acute onset of her symptoms before diagnosis.

The child's tumour was located in the midline of the cerebellum and encroached on the vermis. We wouldn't expect a significant cognitive decline based on the location, as the right posterior cerebellar hemisphere was mostly spared. The right posterior cerebellar hemisphere is responsible for cognition and executive functioning (Guell and Schmahmann, 2020; Lehman *et al.*, 2020; Habas, 2021).

Visual perception

On follow-up, Child 3 had a slight improvement in her TVPS score, performing in the age-appropriate range for all domains except visual memory and sequential memory; out of all the children, this child received the highest number of craniosacral radiation sessions, which is known to cause memory deficits (Lassaletta *et al.*, 2015; Panwala *et al.*, 2019). Sequential memory is the ability to recall visual details in a specific order, which is essential for reading and writing, following visual instructions, and performing mathematical calculations. Child 3's poor performance in sequential memory may impact on her learning capacity, as Atuanya (2024) reported that reading

ability plays a crucial role in academic achievement (Atuanya, 2024). This child's tumour also involved functional area 3, which is involved in visual working memory, and therefore, this result on her TVPS is expected (Haley and Freeman, 2018; Habas, 2021).

The overall improvement in her TVPS scores can also be attributed to the preservation of her left cerebellar hemisphere, which is related to the visuospatial relations (Bostan *et al.*, 2018; Guell and Schmahmann, 2020).

The child performed within her age norm for visual motor integration and visual perception on the Beery-VMI assessment, but her scores did decline from her preoperative assessment. As with Child 2, Child 3 fatigued quickly, and this could be a possible reason why her Visual Perceptual subtest results declined on this test but improved on the TVPS. The Beery-VMI Visual Perception subtest only looks at one element of visual perception. In contrast, the TVPS assesses multiple components, and therefore, her results on the TVPS should be the results considered when looking at her overall visual perception functioning.

Visual perception is affected in 50% of children post-treatment, with deficits in visual motor integration and spatial cognition (Chieffo et al., 2021; Zilli et al., 2021). Although the child's overall visual perception scores were average, her VMI score had declined, and she struggled with spatial organisation on the QNST-3R, which is in keeping with the literature. The child's lower score on the Beery-VMI visual motor integration subtest could also be impacted by her poor gross and fine motor skills, as seen on the QNST-3R results.

Motor

Child 3's motor skills remained within the normal range on the QNST-3R, but she still has deficits in motor maturity and development, tactile and kinaesthetic processing, gross and fine motor control, sense of rate and rhythm, spatial organisation and balance and vestibular functioning.

Motor maturity and development are required to produce controlled, accurate movements and therefore, deficits in these skills will impact fine and gross motor skills (Yeole et al., 2021). Decock et al. (2022) found in their cohort of 56 children, the majority had difficulties with gross motor function and balance, which did not improve with rehabilitation (Decock et al., 2022). This emphasises the cerebellum's role in gross and fine motor skills and balance.

As with Child 2, Child 3 also had difficulties with kinesthetic processing. The decline in the above aspects could be attributed to her 16 rounds of chemotherapy, which Boop and Chuang (2018)

and Hartley et al. (2019) both reported results in motor and sensory processing disorders (Boop and Chuang, 2018; Hartley et al., 2019). This is congruent with the child's worsening performance on the motor coordination subtest on the Beery-VMI subtest.

The child's poor balance and vestibular functions can be attributed to the same factors as Child 1 and 5; tumour location and chemotherapy agents (Medina et al., 2021; Decock et al., 2022).

Behaviour

Both the child and the child's mother reported no behavioural difficulties preoperatively or on follow-up except for procedural anxiety. The child reported that her procedural anxiety improved from 33% to 100%, and her mother reported an improvement from 0% to 25%. Children with cancer undergo many invasive, painful procedures throughout their treatment, which causes anxiety (Loeffen *et al.*, 2020; Lopez-Rodriguez *et al.*, 2020). These procedures are often done without adequate pain management (Loeffen *et al.*, 2020; Lopez-Rodriguez *et al.*, 2020). The child's anxiety is most likely not a direct result of the tumour but rather the number of painful procedures experienced.

As children go through their treatment journey, they learn more about each procedure, which decreases their anxiety, which is why this child reports less anxiety around procedures on follow-up. The child's mother is witness to the child's reaction to procedures and, therefore, bases her perception of the child's anxiety on her behaviour and, as such, might judge her anxiety as higher than what the child reports.

Although the child's current anxiety is not related to the brain tumour, having a PFT puts her at a greater risk of developing chronic anxiety, according to Stavinoha et al. (2018) (Stavinoha *et al.*, 2018).

5.1.2.4 Comparison

Overall, the cognitive, visual perception, motor and behavioural outcomes for the three children were unique to each child; however, a few trends were noted.

Table 5.1 Cognitive, visual perception, motor and behaviour outcomes commonalities

Outcome	Commonality	Factor
Cognitive	Decreased memory and information processing skills	Male (Child 1 and 2)
Visual Perception	Decreased sequential memory	Younger age (Child 2 and 3)
	Decreased visual motor integration	Younger age (Child 2 and 3)
Motor	Poor balance and vestibular function Decreased motor coordination	Medulloblastoma (all)
Behaviour	Increased procedural anxiety	Tumour location – midline (Child 1 and 3)
	Increased confusion, ability to reflect on emotions and concerns for the future	Male (Child 1 and 2)

5.1.3 Objective 3: To describe the change in the ability of the children to participate in age-appropriate activities of daily living pre and post posterior fossa tumour surgery and medical management.

5.1.3.1 Case 1:

As discussed, the child's motor abilities had improved overall on follow-up, which aided in his ability to develop independence in his activities of daily living (ADLs), as he now can climb steps independently.

This child was also able to return to mainstream school, which is an important occupation for a child of his age. Yeole et al.(2021) and Hoffmann-Lamplmai et al. (2022) reported that 60% of children with PFT return to school often with a delay of one year; in this case, the child was able to return without a delay (Yeole *et al.*, 2021; Hoffmann-Lamplmair *et al.*, 2023). Online schooling most likely aided in the return to school without delay as online schooling decreases with the physical demands of in-person schooling, which accommodates this child's poor balance and coordination. The use of online schooling would also compensate for his poor motor coordination as he is able to submit his work in typed version rather than written.

5.1.3.2 Case 2:

Preoperatively, the child depended on his caregiver for dressing and mobility, most likely secondary to HCP and the tumour (Voth, 2001). On follow-up, he was now independent in mobility but had developed difficulties with feeding and nocturnal urinary incontinence. His challenges with feeding could result from his 2,6kg weight loss, resulting in fatigue and poor sustained effect. This was also seen in his poor sustained effort during the assessment process. Treatment for a PFT has a lasting psychological and physiological impact on both the child and the family (Alghamdi *et al.*, 2023). In the case of this child, he and his mother moved back to their home country, leaving their family behind, to receive chemotherapy and craniospinal radiation, which caused great stress for the mother and the child. de Azevedo et al. (2014) reported that disorders of the bladder that are not anatomical or neurological are often the result of emotional issues and stress (de Azevedo *et al.*, 2014). Since this child only struggles with nocturnal urinary incontinence, it is most likely not anatomical or neurological but somewhat related to emotional stress from being separated from his family, relocated to a new environment and requiring chemotherapy and craniospinal radiation.

5.1.3.3 Case 3:

Preoperatively, the child was independent in self-care, continence, and mobility. On follow-up, the child needed assistance with feeding (cutting food, using utensils, and completing feeds). The child had severe muscle wasting and had lost 4kg from the initial assessment to her follow-up, approximately 20% of her body weight. Her weight loss has resulted in poor physical endurance and overall fatigue. The weight loss can be attributed to both chemotherapy and radiation, which often causes nausea, vomiting, loss of appetite and repeated periods of nil per os for radiation sessions, resulting in decreased daily caloric intake (Beauchemin *et al.*, 2020; Uemura *et al.*, 2022). This is corroborated by the child and her mother's answers on the PedsQL Brain Tumor Module, where they reported that her nausea had increased from her preoperative assessment to follow-up.

5.1.3.4 Comparison

Of the three children, only Child 1 was completely independent in his activities of self-care, toileting and mobility. Of the two who required assistance, the limiting factor was not the tumour itself but

rather the side effects of the treatment, nocturnal incontinence from emotional distress and loss of muscle strength secondary to weight loss.

5.1.4. Objective 4: To describe the change in perceived quality of life of children pre and post posterior fossa tumour surgery and medical management

5.1.4.1 Case 1:

Demers et al. (2016) and Kohler et al. (2021) both reported that PFT survivors have the lowest self-reported quality of life (QoL) when self-evaluating; this is in line with this child's report, his QoL decreased from 77% to 56% (Demers, Gelinas and Carret, 2016; Kohler *et al.*, 2021). The 2015 study by Lassaletta et al. (2015) reported that children who had hydrocephalus had lower QoL scores than those who didn't. Bull et al. (2020) found that children treated with chemotherapy and craniospinal radiation also had lower QoL scores compared to children who only received chemotherapy (Bull *et al.*, 2020). This child had HCP requiring a VPS and both chemotherapy and craniospinal radiation; these may be a contributing factor to his lower QoL score.

His mother reported that his quality of life had improved from 30% to 67%. However, she may be comparing his QoL now to when he first got diagnosed, and his symptoms were the most severe rather than to his premorbid functioning. As discussed in the cognition section, assessing the proxy's QoL is essential as this may impact their answers (Germain, Aballéa and Toumi, 2019). This study did not assess the proxy's QoL; this would need further assessment in future research.

5.1.4.2 Case 2:

As in the case of Child 1, Child 2 reported a decrease in his QoL from 95,7% to 69,6%, and his mother reported an improvement from 33,7% to 45,7%. Although the mother reported an improvement, the improvement was minor and demonstrated an extremely low overall QoL.

The child reported that the reduction in his QoL was related to cognitive decline, pain and hurt (headaches) and nausea. Surgery, chemotherapy and radiation can all result in chronic headaches due to physical or cytotoxic damage; these headaches can be long-term and may impact a child's QoL depending on the severity and duration (Neil, Hanmantgad and Khakoo, 2016). The PedsQL Brain Tumor Module doesn't assess the intensity or duration; it only asks how

often a child experiences headaches. Therefore, it is difficult to determine how much the child's headache impacts his QoL. However, his mother also reported that he often struggled with headaches.

According to Beauchemin et al. (2020), children are at a higher risk of developing nausea and vomiting during and after chemotherapy treatment compared to adults. They also reported that consistent vomiting has an effect on a child's QoL and creates fear and anxiety (Beauchemin *et al.*, 2020). Uemura et al. (2021) studied the impact of craniospinal radiation on nausea. They reported that nausea was a major side effect of radiation and resulted in a decreased QoL (Uemura *et al.*, 2022). Therefore, the decrease in QoL in the child can be explained by both chemotherapy and craniospinal radiation.

The mother reported the most remarkable improvement was in the child's movement and balance, which aligns with his motor results, where his balance and vestibular functioning improved slightly.

5.1.4.3 Case 3:

The child reported that her QoL had minimally improved from 82,6% to 84,4%. The child's mother reported a slight decrease in QoL from 77,2% to 76%. The child's QoL increased due to improved procedural anxiety and less pain and hurt. These can both be attributed to improved regulation of procedures and a reduction in negative, painful symptoms that were associated with acute hydrocephalus, which she presented to the hospital with (Voth, 2001). Unlike Child 2, she didn't experience headaches as a side effect of her craniosacral radiation, which improved her QoL score (Neil, Hanmantgad and Khakoo, 2016). As expected, the child's QoL score was impacted by her increased nausea.

5.1.4.4 Comparison

When considering the three children, the two males reported a decline in their QoL, with the caregivers reporting a slight increase. However, their scores were still below 50% satisfaction with their QoL. From Child 1 and 2's responses, it can be seen that their poorer QoL outcomes are a result of the treatment of the PFT, such as procedural anxiety, nausea from chemotherapy and radiation and worry about the future. Both children also highlighted that a decline in their cognitive skills has also contributed to their lower QoL. Child 3 reported a slight increase in her QoL related to an improvement in procedural anxiety and less pain and hurt. As with the male children, her

nausea had also increased. Overall, the results show that the treatment of the PFT rather than the tumour itself resulted in a lower QoL in survivors.

In all three cases there was a discrepancy between the child and the caregiver's report of the child's QoL. There are many possible reasons for this, with the most significant contributing factor being that QoL is subjective and difficult to quantify. The children in this study may have used a different internal criteria to assess why specific aspects of their life improved or declined and how that affected their QoL, compared to the criteria their caregiver used. For example, the children may have compared their current life to their premorbid functioning or their QoL when they were at their worst. Another factor may be the caregivers own QoL and experiences throughout their child's journey, which could impact the way in which they perceive their child's QoL (Germain, Aballéa and Toumi, 2019). Although there were discrepancies between the reports, the children all experienced specific symptoms that impacted their QoL, that could be addressed and treated through the use of occupational therapy.

5.1.5. The role of occupational therapy in the treatment of children with posterior fossa tumours.

As seen in the above discussion points, although children with PFTs present with different results in terms of their client factors and ADLs, some commonalities can be addressed in occupational therapy treatment.

Unlike many other neurorehabilitation therapies, occupational therapy (OT) is client-centred and is focused on improving health and well-being through active participation and engagement in categories of occupation that are motivating and meaningful (Boop et al., 2020; Avello-Sáez et al., 2022).

OTs are guided by the Occupational Therapy Practice Framework: Domain and Process fifth edition (OTPFIV), which defines an assessment and treatment planning approach that looks at the client holistically (Boop et al., 2020). Therefore, OTs are able to use standardised assessments alongside observations and client feedback to determine what client factors, performance patterns, performance skills and contexts that are impacting the child's ability to engage in their occupations (Demers, Gelinas and Carret, 2016; Şahin, Akel and Zarif, 2017; Boop et al., 2020). In the context of PFT survivors, it is essential that OTs address the client factors of balance and

vestibular functioning, visual perception and cognition to facilitate their participation in the occupations of ADL, education, social participation and play/leisure.

Occupational therapy is not diagnosis-led; it focuses on the unique symptoms that the client experiences (Şahin, Akel and Zarif, 2017). Occupational therapists have the ability to plan and anticipate further problems that might prevent a child from engaging in their occupations, and therefore, greater knowledge of the outcomes of children with posterior fossa tumours would give them the ability to prepare for possible future issues. (Şahin, Akel and Zarif, 2017). As discussed in the previous section, the children in this study reported that their QoL was impacted by the treatment side-effects rather than the tumour itself. Therefore by addressing these areas before dysfunction presents, there could be greater engagement in their categories of occupations and improved QoL.

There is a call for movement away from pharmacological management to non-pharmacological treatments, which have minimal side effects. Therefore it is crucial for OTs to be involved in these children as they are able to use NPTs to address client factors, performance patterns and performance skills to improve QoL (Avello-Sáez *et al.*, 2022). Some of the NPTs that occupational therapists can use include neurodevelopmental treatment to address motor skills, cognitive behaviour theory for anxiety, adaptations and compensatory methods for impairments and declining skills to increase engagement in their categories of occupations.

5.2 SUMMARY

Each child with a posterior fossa tumour presents with different outcomes based on the location of their tumour, treatment protocol and early facilitation into schooling. It was also seen that the treatment of PFTs is a significant contributing factor to the children's lower QoL. It is, therefore, vital that OTs understand the anatomy of the cerebellum and the impact of the treatment of the PFT to predict and anticipate possible impairments that a child may present with. It is also imperative that OTs make use of the OTPFIV assessment and treatment planning approach to ensure they are addressing the child's unique needs.

CHAPTER 6: SUMMARY OF MAIN FINDINGS, STRENGTHS AND LIMITATIONS OF THE STUDY, CONCLUSION AND RECOMMENDATIONS.

6.1 INTRODUCTION

This chapter presents the conclusions of this research study, including the implications for occupational therapy, limitations and recommendations for further research.

6.2 SUMMARY OF FINDINGS AND IMPLICATION FOR OCCUPATIONAL THERAPY

As seen in the discussion chapter, although the children had the same histological posterior fossa tumour, medulloblastoma, they each presented with different challenges regarding cognition, visual perception, motor behaviour, activities of daily living (ADLs) and quality of life (QoL). The children all struggled with motor coordination, and balance and vestibular function. It appears that decreased memory and information processing skills were impacted in males more than females, whereas deficits in sequential memory and VMI were more prevalent in younger children.

These results show that occupational therapists should assess and treat each child uniquely and focus treatment on their individual needs. The commonalities in motor function, motor coordination, balance and vestibular function indicate that a protocol could be developed and researched to determine its efficacy in treating motor difficulties in posterior fossa tumour survivors.

The results have demonstrated that understanding the cerebellum's functional anatomy and posterior fossa may aid occupational therapists in choosing screening assessments based on the challenges predicted by where the child's tumour is located.

Based on the Barthel Index and QoL results, occupational therapists should focus on minimising the side effects of treatment through cognitive rehabilitation, advocating for better nausea management, and psychosocial support.

6.3 LIMITATIONS OF STUDY

6.3.1 Literature

- There is a lack of research in South Africa on paediatric brain tumours
- There is limited information regarding the prevalence, treatment outcomes and survival rates in South Africa due to a small number of registries documenting this information
- There are no formal protocols in South Africa for the holistic treatment of paediatric posterior fossa tumours

6.3.2 The sample

- The sample did not accurately represent paediatric posterior fossa tumour survivors in South Africa.
- The sample size was smaller than the study anticipated because the standardised assessments required the participants to be older than five years and zero months, which eliminated many potential participants.
- As the study locations were at quaternary hospitals, participants travelled from other provinces to access care and were then lost to follow-up when they defaulted on their medical appointments.

6.3.3 Testing

- TIPS was not suited for the South African environment as many children could not name and identify the letters of the alphabet despite attending formal schooling.
- The PedsQL questionnaire assessed health-related QoL, not overall QoL, which limited the information that could be extrapolated from the results.
- The Barthel Index assessed self-care, toileting and mobility but didn't provide information regarding play, social participation, sleep, and leisure, which would have benefited this study.
- There are limited assessments for behaviour in South Africa, and therefore, information regarding the child's behaviour had to be extrapolated from the PedsQL instead of a more comprehensive evaluation.
- The six-month follow-up was not sufficient to determine the long-term effects of the treatment of a PFT.

6.4 RECOMMENDATIONS

6.4.1 Literature

- Further research is required to:
    - Determine the number of children diagnosed with a PFT, the type of PFT and the age at which they were diagnosed in South Africa
    - Determine the survival rate of children with PFT in South Africa
- An MDT protocol needs to be developed to define the treatment of children with a PFT, including the need for rehabilitative services in South Africa.

6.4.2 The sample

- The study should be replicated with the following adjustments:
    - Using a multiprovincial model to allow data to be collected from the different provinces in South Africa and to allow for a bigger sample size
    - A travel budget to complete follow-ups at the participant's local hospital
    - Include Private hospitals as data sites to compare the outcomes of children treated by State vs Private.

6.4.3 Testing

- The researcher would recommend the following:
    - A collaboration with an educational psychologist who is qualified to administer cognitive assessments to conduct the standardised cognitive testing
    - Using a combination of QoL questionnaires to assess both health-related QoL and general QoL to get a holistic view of the child
    - Using a paediatric-orientated ADL assessment to be able to assess play, social participation, sleep and leisure
    - Using qualitative data for a better understanding of each child's behaviour
    - Following the participants at six months, one year and two years to get a better understanding of the long-term functional outcomes of paediatric PFT survivors

6.5 FINAL CONCLUSION

In this chapter, the study concludes with a summary of the findings. The study's limitations were acknowledged, and future recommendations were suggested for further research into the functional outcomes of paediatric posterior fossa tumour survivors in South Africa.

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APPENDICES

Appendix A: Plagiarism Declaration



PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I _____ (Student number: _____)

am a student registered for the degree of _____ in

the academic year _____.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: _____ Date: _____

Appendix B: Human Research Committee Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Miss Jade Flood

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M220427

NAME: (Principal Investigator)	Miss Jade Flood
DEPARTMENT:	Occupational Therapy
PROJECT TITLE:	*Functional outcomes of paediatric posterior fossa tumour survivors at three quaternary hospitals in Johannesburg, Gauteng*
DATE CONSIDERED:	29/04/2022
DECISION:	Approved unconditionally
CONDITIONS:	This approval applies only to the study sites listed in Annex 1 attached. Further sites may be added on presentation of evidence of management approval to the HREC (Medical)
SUPERVISOR:	Dr Janine van der Linde
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	25/08/2022

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions.Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. I **agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **April** and will therefore be due in the month of **April** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

25/08/2022

Date

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

R14/49 Miss Jade Flood

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M220427

NAME: (Principal Investigator)	Miss Jade Flood
DEPARTMENT:	Occupational Therapy
PROJECT TITLE:	*Functional outcomes of paediatric posterior fossa tumour survivors at three quaternary hospitals in Johannesburg, Gauteng*
DATE CONSIDERED:	29/04/2022
DECISION:	Approved unconditionally
CONDITIONS:	This approval applies only to the study sites listed in Annex 1 attached. Further sites may be added on presentation of evidence of management approval to the HREC (Medical)
SUPERVISOR:	Dr Janine van der Linde
APPROVED BY:	CB Penny Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	25/08/2022

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions.Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. I **agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **April** and will therefore be due in the month of **April** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

25/08/2022

Principal Investigator Signature

Date

Annex 1

Protocol No. M220427

Miss Jade Flood

Study sites approved under this Clearance Certificate

Study site	Date of HREC (Med) Approval
Chris Hani Baragwanath Academic Hospital	25/08/2022
Nelson Mandela Children's Hospital	25/08/2022

Dr CB Penny
Chair: HREC (Medical)
University of the Witwatersrand, Johannesburg

Date: 25/08/2022

Appendix C: Chris Hani Baragwanath Academic Hospital Permission Letter



GAUTENG PROVINCE

REPUBLIC OF SOUTH AFRICA
MEDICAL ADVISORY COMMITTEE

PERMISSION TO CONDUCT RESEARCH

Date: 21 st June 2022

TITLE OF PROJECT:

Functional outcomes of paediatric posterior fossa tumour survivors at three Quaternary Hospitals in Johannesburg, Gauteng

UNIVERSITY: Witwatersrand

Principal Investigator: J T Flood

Department: Neurosurgery /Occupational Therapy

Supervisor : Dr. Janine van der Linde

NHRD Number: GP_ 202206 008

Permission Head Department (where research conducted): Yes

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani

Baragwanath Academic Hospital. The CEO / management of Chris Hani Baragwanath Academic

Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.
- The Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital .
- The MAC will be informed of any serious adverse events as soon as they occur

half of the MAC)
21/06/2022

GAUTENG PROVINCE

REPUBLIC OF SOUTH AFRICA

CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

- Permission is granted for the duration of the Ethics Committee Approval.

Recommended
(On behalf of the MAC)
Date: 21/06/2022

Approved/~~Not Approved~~
Hospital Management
Date: 30/6/2022

OCCUPATIONAL THERAPY DEPARTMENT
Tel: 011 933 8294/8187

Date: 05/07/2022

Attention: Medical Advisory Committee (MAC)

Re: Research in Occupational Therapy (OT) department by Masters student

Ms J. Flood is currently employed at Nelson Mandela Children's Hospital. She is a student at the
University of the Witwatersrand. She is completing her Master of Science in Occupational Therapy.

The above-mentioned researcher is requesting permission to do research on "Functional outcomes of paediatric posterior fossa tumour survivors at three Quaternary Hospitals in Johannesburg, Gauteng".

The researcher has registered with the NHRD. She has been granted provisional ethics approval by the WITS HREC (Medical).

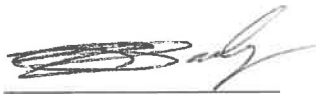
Permission has been granted by the HOD of OT, with the following conditions:

- Approval obtained by the CHBAH MAC.
- Final ethical clearance is obtained through the WITS HREC (Medical).
- The CHBAH OT department will not be able to provide an OTT or OT for translation services (referred to on page 9 of protocol, under Data Collection Instruments).
- The CHBAH OT department will not be able to provide a research assistant (referred to on page 11 of protocol, under Data Collection Procedure).

- The CHBAH OT department will not be able to do the follow-ups while the patients are in the ward to note specific variables necessary for the case study (referred to on page 11 of protocol, under Data Collection Procedure). This will need to be done by the researcher.

The CHBAH OT department will be able to screen G3 weekly and inform the researcher if there are any children admitted with posterior fossa tumours.

Thank you.
Kind regards



Lynn Soulsby
Assistant Director
Occupational Therapy Department
CHBAH
011 933 8187
#6468

Appendix D: Nelson Mandela Children's Hospital Permission Letter

Nelson Mandela Children's Hospital
A family dedicated to care

Date: 18 April 2022

Title of Research Project	**: FUNCTIONAL OUTCOMES OF PAEDIATRIC POSTERIOR FOSSA TUMOUR SURVIVORS AT THREE QUATERNARY HOSPITALS IN JOHANNESBURG, GAUTENG.**
Department of Programme	**: Department of Occupational Therapy**
Principal Investigator	**: Ms Jade Flood**
Supervisor	**: Dr Janine van der Linde**

Dear Ms Jade Flood,

You have been given permission to conduct research at Nelson Mandela Children's Hospital. Please note that the following conditions should be met:

1. Ethical Approval should be sort from a Human Ethics Research Committee of any recognised institution. Once such approval is granted, it must be submitted to the Hospital Research and Ethics Committee for record-keeping.
2. There will be no cost to the hospital associated with conducting this research.
3. Once the research is completed, the Hospital will be notified, and a report of the results provided.
4. The hospital will be acknowledged in any publications and presentations that will be given in relation to this research.

Documents submitted and required:

Title of document	Required documents
Approval from Ethics Committee	
Ethics Clearance Certificate	
Research Protocol	
Report of the results	

All the best with your research

Recommended/Not Recommended

Prof. Hopewell Ntsinjana
Academic Committee Chairperson
Date:

Supported/Not Supported PP Prof Ntsinjana

Dr Andrew Grieve
Deputy Chairperson
Date:

NPC Registration No: 2011/009134/08
Web address: http://www.nelsonmandelachildrenshospital.org
P.O. Box 797, Highlands North, 2037. 6 Jubilee Road, Parktown 2193. Tel: (+27 10) 133-0600

Directors
Phuthuma Nhleko (Chairperson) • Moses Kgosana • Richard Lebethe • Jacko Maree • Sibongile Mkhabela
Sam Mokgokong • Kgomotso Moroka • Moss Ngoasheng • Victor Sekese • Joe Seoloane • Sithembiso Velaphi • Martin Veller

Nelson Mandela Children's Hospital
A family dedicated to care

Title of Research Project : **FUNCTIONAL OUTCOMES OF PAEDIATRIC POSTERIOR FOSSA TUMOUR SURVIVORS AT THREE QUATERNARY HOSPITALS IN JOHANNESBURG, GAUTENG.**

Supported/~~Not Supported~~

Dr Pinky Chirwa
Acting: Clinical Director
Date: 25/04/2022

Approved/~~Not Approved~~

Dr Nonkululeko Boikhutso
Acting: Chief Executive Officer
Date: 25/04/2022

Appendix E: Study Information Document



STUDY INFORMATION DOCUMENT

Functional outcomes of paediatric posterior fossa tumour survivors at three Quaternary Hospitals in Johannesburg, Gauteng

Good day

My name is Jade Flood and I am a paediatric occupational therapist working at Nelson Mandela Children's Hospital (NMCH). I am currently completing my Master of Science degree in Occupational Therapy at the University of the Witwatersrand. I would like to invite you and your child to participate in my study titled: Functional outcomes of paediatric posterior fossa tumour survivors at three Quaternary Hospitals in Johannesburg, Gauteng.

This study aims to identify if children who have received treatment for their posterior fossa tumours struggle in a variety of different areas. These areas include their ability to move, remember and learn new information and complete the daily activities expected of them. I will also be looking at whether their behaviour has changed and what their quality of life is after surgery. The study aims to be able to provide information to occupational therapists in the future on the specific areas that should be focused on in therapy.

Participation in the study is completely voluntary and all caregivers will be required to sign a consent form stating that they are willing to allow their child to participate. The child will be

given an assent form with pictures to sign to show that they understand and are willing to participate. Children and their caregivers may at any time withdraw from the study without penalty or loss of benefits. All personal information such as names will be kept confidential as each participant will be assigned a code that will be used on all forms and assessment sheets.

Children whose parents/caregivers have given their approval will be assessed before having surgery to remove the tumour and then again at six months after the surgery at their Neurosurgical Outpatient Department doctor's appointment. While the child is admitted to the hospital, I will continue to get information about the child's condition from their hospital file. The first assessment will be done in the hospital ward and will take about two hours. I will be using four different tests, for these tests I will ask the child to answer some questions, repeat words, draw and copy images and complete some gross motor activities. If the child needs a break the assessments can be done over two days. I will also ask the caregiver to complete three assessment forms, these forms will ask about the child's behaviour, ability to learn and complete the daily activities expected of them. This will take about 35mins to complete.

All assessments will be done in hard copy and the completed forms will be stored in a locked cupboard that can only be accessed by the researcher and research assistant for confidentiality. The child will receive ongoing occupational therapy assessment and treatment in ward as per the hospital's occupational therapy protocol.

This study has been approved by the Human Research Ethics Committee of the University of the Witwatersrand, Johannesburg. A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

Please ensure that you understand the above before signing the consent form. Please feel free to ask any questions or queries. These can be directed to;

Jade Flood (researcher) 0785732734 or jade@floodgates.co.za/jade.flood@nmch.org.za

Date: April 2022

Appendix F: Parent Consent Document



PARENT CONSENT DOCUMENT

Functional outcomes of paediatric posterior fossa tumour survivors at three Quaternary Hospitals in Johannesburg, Gauteng

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I best understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Contact details:

- Jade Tasmyn Flood, Principal Investigator, telephone no. 0785732734, or by e-mail at jade@floodgates.co.za
- Professor CB Penny, Chairperson of the Human Research Ethics Committee (Medical) at the University of Witwatersrand, on telephone no. 011 717 2301, or by e-mail at Clement.Penny@wits.ac.za.
- Ms. Z Ndlovu or Mr Rhulani Mkansi, Committee Secretariat, telephone nos.: 011 717 2700 or 1234, or by e-mail at: Zanele.Ndlovu@wits.ac.za or Rhulani.Mkansi@wits.ac.za

Name of parent/caregiver: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

Appendix G: Assent Information Document



ASSENT STUDY INFORMATION DOCUMENT

Functional outcomes of paediatric posterior fossa tumour survivors at three Quaternary Hospitals in Johannesburg, Gauteng

Hello,

I am an occupational therapist and I am looking at how children with your type of brain tumour are able to do different things. Research is the process of collecting information and discovering new knowledge. The information that I get from you will hopefully help children who aren't able to do things as well as you are.

Your parents have given me permission for you to join my research, but I want to ask if you would like to help me? This is your choice and you won't get into trouble if you say no. You can also stop anytime that you want to and you can ask me any questions that you have.

If you want to work with me, we will do four activities together which will take about 3 hours. I'll give you breaks during the activities and we can do it over a couple of days.

These activities are:

1. Answering questions:



2. Drawing:



3. Moving your body:





<u>Write your name or make a X on this form to say that you want to participate, but only if you:</u>

- have understood what you will be doing for this study,
- have had all your questions answered,
- have talked to your parent(s)/legal guardian about this project, and
- agree to take part in this research

I,_____(Print your name) would like to be in this research study.

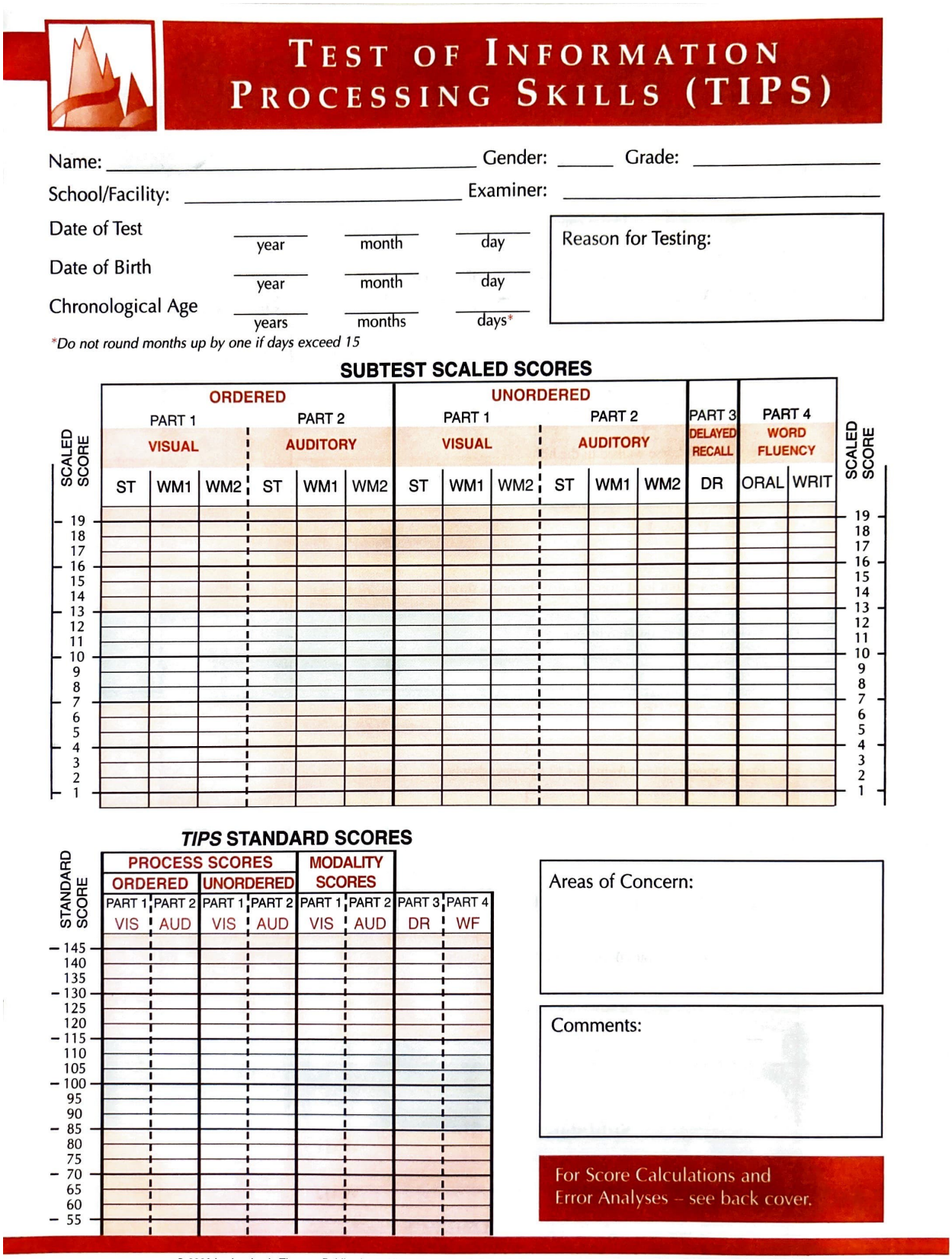
_____(Date of assent)

_____(Name of person who obtained assent)

_____(Signature of person who obtained assent and Date)

_____(Local Principal Investigator name)

Appendix H: Test of Information Processing Skills Front Page



TEST OF INFORMATION PROCESSING SKILLS (TIPS)

Name: _____ Gender: _____ Grade: _____

School/Facility: _____ Examiner: _____

Date of Test _____ year _____ month _____ day

Date of Birth _____ year _____ month _____ day

Chronological Age _____ years _____ months _____ days*

**Do not round months up by one if days exceed 15*

Reason for Testing:

SUBTEST SCALED SCORES

SCALED SCORE	ORDERED						UNORDERED						PART 3	PART 4		SCALED SCORE
	PART 1 VISUAL			PART 2 AUDITORY			PART 1 VISUAL			PART 2 AUDITORY			DELAYED RECALL	WORD FLUENCY		
	ST	WM1	WM2	ST	WM1	WM2	ST	WM1	WM2	ST	WM1	WM2	DR	ORAL	WRIT	
19																19
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4																4
3																3
2																2
1																1

TIPS STANDARD SCORES

STANDARD SCORE	PROCESS SCORES				MODALITY SCORES			
	ORDERED		UNORDERED					
	PART 1 VIS	PART 2 AUD	PART 1 VIS	PART 2 AUD	PART 1 VIS	PART 2 AUD	PART 3 DR	PART 4 WF
145								
140								
135								
130								
125								
120								
115								
110								
105								
100								
95								
90								
85								
80								
75								
70								
65								
60								
55								

Areas of Concern:

Comments:

For Score Calculations and Error Analyses – see back cover.

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Appendix I: Test of Visual Perceptual Skills 4th Edition Front Page

TEST OF VISUAL PERCEPTUAL SKILLS 4TH EDITION

Name:_____ Gender:_____ Grade:_____

School:_____ Examiner:_____

Reason for Testing: _____

Date of Test _____ year _____ month _____ day

Date of Birth _____ year _____ month _____ day

Chronological Age _____ year _____ month _____ day*

**Do not round months up by one if days exceed 15*

SUBTESTS	SUBTEST SCORES				
	Raw Score	Scaled Score	CI 90% 95%	Percentile Rank	Age Equivalent
1. Visual Discrimination (DIS)			—		
2. Visual Memory (MEM)			—		
3. Spatial Relationships (SPA)			—		
4. Form Constancy (CON)			—		
5. Sequential Memory (SEQ)			—		
6. Visual Figure-Ground (FGR)			—		
7. Visual Closure (CLO)			—		
Sum of Scaled Scores					
Overall Standard Score			—		

SUBTEST SCALED SCORES

%ile Rank	Scaled Score	Visual Discrimination	Visual Memory	Spatial Relationships	Form Constancy	Sequential Memory	Visual Figure-Ground	Visual Closure	Standard Score	%ile Rank
>99	19								145	>99
>99	18								140	>99
99	17								135	99
98	16								130	98
95	15								125	95
91	14								120	91
84	13								115	84
75	12								110	75
63	11								105	63
50	10								100	50
37	9								95	37
25	8								90	25
16	7								85	16
9	6								80	9
5	5								75	5
2	4								70	2
1	3								65	1
<1	2								60	<1
<1	1								55	<1

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The Beery–Buktenica
Developmental Test of Visual–Motor Integration



Beery™ VMI Sixth Edition

Ages 2 through 100 (FULL FORM)

by Keith E. Beery, Norman A. Buktenica, and Natasha A. Beery

Name: _____ Sex: ○ F ❑ M
Last First

School: _____ Grade: _____

Examiner: _____

Test Date: _____ year _____ month _____ day

Birth Date: _____ year _____ month _____ day

Chronological Age: _____ year _____ month
(Count more than 15 days as one month.)

SUMMARY

See the Beery VMI manual (sixth edition) for norms.

	Beery VMI	Visual Perception	Motor Coordination
Raw Scores:	_____	_____	_____
Standard Scores:	_____	_____	_____
Scaled Scores:	_____	_____	_____
Percentiles:	_____	_____	_____
Other Scaling:	_____	_____	_____

Comments and Recommendations:

PROFILE

Standard Score	Beery VMI	Visual Perception	Motor Coordination	Percentile
145	-	-	-	99.7
140	-	-	-	99.2
135	-	-	-	99
130	-	-	-	98
125	-	-	-	95
120	-	-	-	91
115	-	-	-	84
110	-	-	-	75
105	-	-	-	63
100	-	-	-	50
95	-	-	-	37
90	-	-	-	25
85	-	-	-	16
80	-	-	-	9
75	-	-	-	5
70	-	-	-	2
65	-	-	-	1
60	-	-	-	.8
55	-	-	-	.3

Begin testing on page 1. Turn booklet over with bound edge toward the examinee. If subtests are used, always test in this order: VMI → Visual → Motor.

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The *Beery*™ VMI Developmental Test of Visual Perception

Visual Perception

Sixth Edition

by Keith E. and Natasha A. Beery

Ages 2 to 100

TURN

Name: _____ Sex: ○ F ❑ M
Last First

School: _____ Grade: _____

Examiner: _____

Test Date: _____ year _____ month _____ day

Birth Date: _____ year _____ month _____ day

Chronological Age: _____ year _____ month

(Count more than 15 days as one month.)

Items 1–3 are for children; credit for adult if Item 4 is answered correctly.

Item 1. Points to one body part on self when asked: __ eye __ hair __ ear

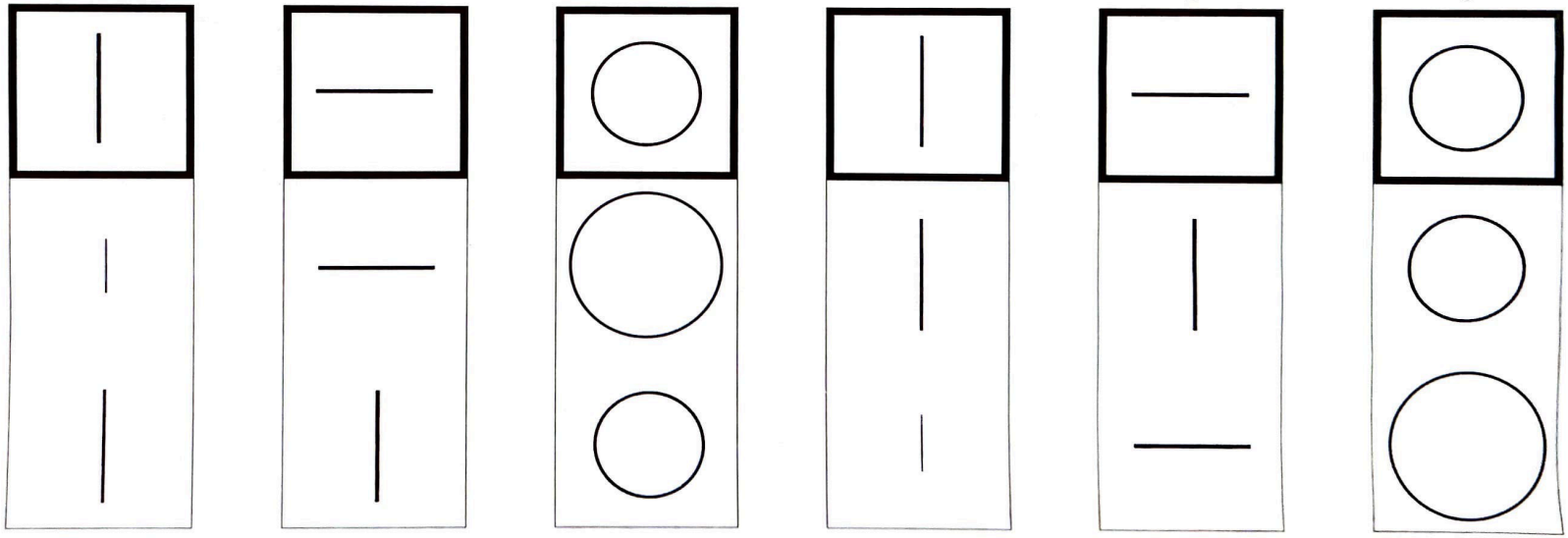
Item 2. Points to at least 2 of 3 outline pictures: __ cat __ dog __ pig

Item 3. Points to 6 of 8 pictured body parts when asked:
__ hair __ nose __ ear __ foot __ mouth __ hand __ tummy __ eye

Visual Perception Raw Score: _____ (Also enter on the front of the Beery VMI test booklet.)

See the Beery VMI manual (sixth edition) for administration and scoring instructions.

Start timing here.



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The *Beery* VMI Developmental Test of Motor Coordination

Motor Coordination

Sixth Edition

by Keith E. and Natasha A. Beery

Ages 2 to 100

TURN

Name: _____ Sex: ○ F ❑ M
Last First

School: _____ Grade: _____

Examiner: _____

Test Date: _____ year _____ month _____ day

Birth Date: _____ year _____ month _____ day

Chronological Age: _____ year _____ month

(Count more than 15 days as one month.)

Motor Coordination Raw Score: _____ (Also enter on the front of the Beery VMI test booklet.)

See the Beery VMI manual (sixth edition) for administration and scoring instructions.

Let's Draw!

Use a No. 2 pencil (or another pencil with soft black lead) or a ballpoint pen with black ink.

Remember, you get one try with no erasing.
Keep the booklet straight in front of you and don't tilt it.
Just do the best you can on both the easy ones and the hard ones.

Don't skip any!

Please turn the page from the top to begin.

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Appendix K: Quick Neurological Screening Test-3R Front Page

QUICK NEUROLOGICAL SCREENING TEST-3R (QNST-3R)

Record Form

Name: _____ Gender: _____ Grade: _____

School/Facility: _____ Examiner: _____

Date of Testing _____ year _____ month _____ day

Date of Birth _____ year _____ month _____ day

Chronological Age _____ year _____ month _____ day*

** Do not round months up by one if days exceed 15.*

QNST-3R SCORE SUMMARY

	Task 1	Task 2	Task 3	Task 4	Task 5	Task 6	Task 7	Task 8	Task 9	Task 10	Task 11	Task 12	Task 13	Total Score
Raw Score														
N														
M														
S														

Directions: Enter the raw score for each task in the appropriate box, then place a checkmark in the boxes marked "N" (no discrepancy), "M," (moderate discrepancy), and "S" (severe discrepancy), to indicate the functional category.
(See Tables B.1 and B.2)

Reason for Testing:

Recommendations:

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Appendix L: The Barthel Index Front Page

THE BARTHEL INDEX

Patient Name: _____
Rater Name: _____
Date: _____

Activity	Score
FEEDING 0 = unable 5 = needs help cutting, spreading butter, etc., or requires modified diet 10 = independent	_____
BATHING 0 = dependent 5 = independent (or in shower)	_____
GROOMING 0 = needs to help with personal care 5 = independent face/hair/teeth/shaving (implements provided)	_____
DRESSING 0 = dependent 5 = needs help but can do about half unaided 10 = independent (including buttons, zips, laces, etc.)	_____
BOWELS 0 = incontinent (or needs to be given enemas) 5 = occasional accident 10 = continent	_____
BLADDER 0 = incontinent, or catheterized and unable to manage alone 5 = occasional accident 10 = continent	_____
TOILET USE 0 = dependent 5 = needs some help, but can do something alone 10 = independent (on and off, dressing, wiping)	_____
TRANSFERS (BED TO CHAIR AND BACK) 0 = unable, no sitting balance 5 = major help (one or two people, physical), can sit 10 = minor help (verbal or physical) 15 = independent	_____
MOBILITY (ON LEVEL SURFACES) 0 = immobile or < 50 yards 5 = wheelchair independent, including corners, > 50 yards 10 = walks with help of one person (verbal or physical) > 50 yards 15 = independent (but may use any aid; for example, stick) > 50 yards	_____
STAIRS 0 = unable 5 = needs help (verbal, physical, carrying aid) 10 = independent	_____
TOTAL (0–100):	_____

Provided by the Internet Stroke Center — www.strokecenter.org

Appendix M: PedsQL Brain Tumor Module Standard Version 1.0 Front Page

ID# _____

Date: _____

PedsQL™

Brain Tumor Module

Standard Version 1.0

YOUNG CHILD REPORT (ages 5-7)

Instructions for interviewer:

I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these things might be for you.

Show the child the template and point to the responses as you read.

If it is not at all a problem for you, point to the smiling face

If it is sometimes a problem for you, point to the middle face

If it is a problem for you a lot, point to the frowning face

I will read each question. Point to the pictures to show me how much of a problem it is for you. Let's try a practice one first.

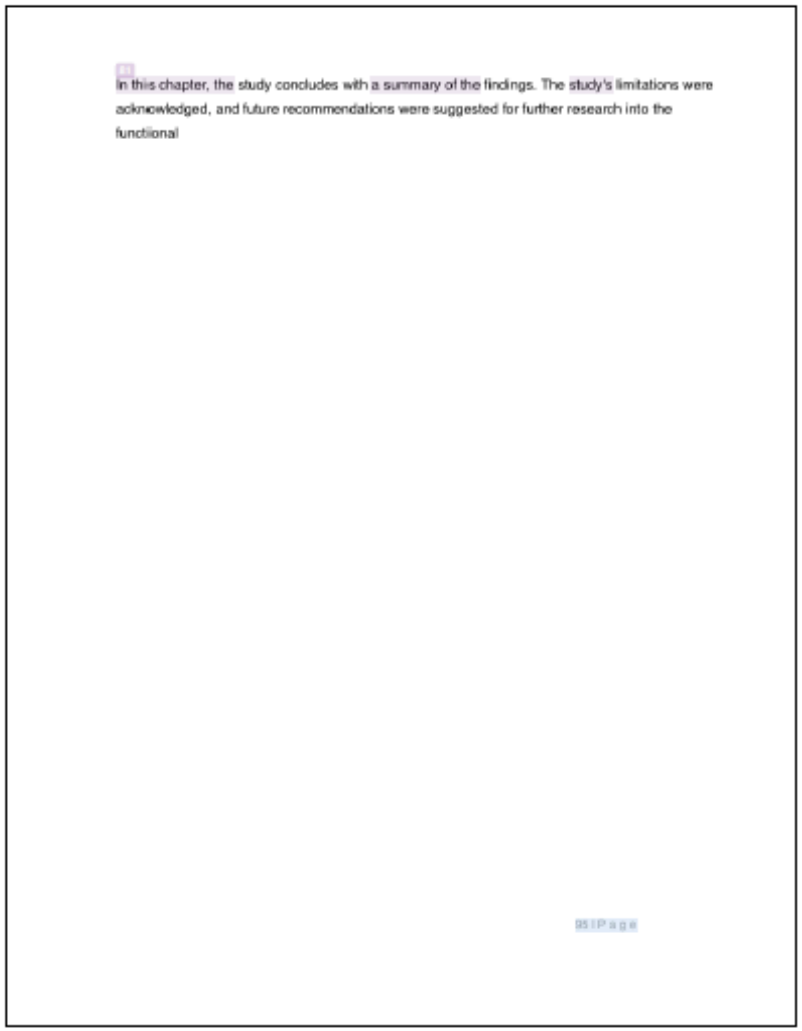
	Not at all	Sometimes	A lot
Is it hard for you to snap your fingers	☺	😐	☹

Ask the child to demonstrate snapping his or her fingers to determine whether or not the question was answered correctly. Repeat the question if the child demonstrates a response that is different from his or her action.

PedsQL 1.0 (5-7) Brain Tumor
2/06
PedsQL-1.0-BrainTumor-YC – United States/English – Original version
PedsQL-1.0-BrainTumor-YC_AU1.0_eng-USori

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In this chapter, the study concludes with a summary of the findings. The study's limitations were acknowledged, and future recommendations were suggested for further research into the functional

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