Functional Outcomes of Children on Discharge from a Paediatric Intensive Care Unit

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DECLARATION

I, Stacey Kennedy, declare that the work contained in this research report is my own work, except to the extent indicated in the acknowledgement sections.

This research report is being submitted for a degree of Masters in Physiotherapy, at the University of the Witwatersrand, Johannesburg, South Africa.

This work has not been submitted for any other degree or examination in this or any other university.

Stacey Kennedy — 23/10/2024

Name Surname — Date

ABSTRACT

Background

Paediatric critical care is a constantly evolving field of health care and has changed considerably over the past two decades. Improved care and paediatric intensive care unit (PICU) protocols have resulted in increased survival rates of patients presenting to PICU. However, this also means that the number of surviving patients with long term functional impairments has increased. Research acknowledges that children are at risk of recurrent serious acute illness and more PICU admissions, yet how children and their families recover after surviving a critical illness is poorly understood.

Objective

This cross-sectional study aimed to assess the functional outcomes of paediatric patients on discharge from a private hospital PICU using the Functional Status Scale (FSS).

The objectives included describing demographic characteristics and clinical characteristics of participants admitted to a particular PICU in Gauteng, South Africa. Secondly to establish functional outcomes in six domains – mental status, sensory, motor function, communication, feeding, and respiratory function, at the time of discharge from PICU, using the FSS and furthermore, to investigate the association between admission diagnosis, age, sex, length of stay (LOS), duration of ventilation of participants and functional outcomes, at the time of PICU discharge.

Methods

Conducted between May 2023 and December 2023, this study included paediatric patients aged 1 month to 13 years, where the appropriate consent and assent was obtained. All patients were admitted to a private hospital PICU, in Gauteng South Africa, for more than 24 hours, to meet the inclusion criteria. The FSS (total score = 30; sub scores per domain = 5), which assesses functional status across six domains, was administered on the day of discharge from PICU.

Data capturing was conducted by the primary investigator and statistical analysis was done by a senior data scientist using MATLAB R2024a and Spearman correlation co-efficient to draw correlations between variables. using Spearman correlation co-efficient to draw correlations between variables.

Results

The cohort consisted of 28 participants that completed the study. Based on the findings of this research it was concluded that, within this cohort the median (IQR) age of the participants was 24 (14-72) months old and the median (IQR) LOS was 21 (8-32) days. The sample was equally distributed for males (50%) and females (50%). Most common causes for admission were either respiratory (n =11; 39.3%) or neurological (n=11;39.3%) in nature and this was the first PICU admission for 64% (n = 18) of cohort. The FSS mean and median overall score was eight (8/30). The highest mean scores were noted in the mental status and motor function domains and 36% (n = 10) of participants had a score of more than or equal to nine indicating 'mild' to 'moderate' dysfunction. Common trends within the correlations, included that longer duration of ventilation results in higher FSS mental status scores ($r = 0.74$; $p = <0.01$; worse dysfunction); longer duration of ventilation results in higher FSS scores for the respiratory domain ($r = 0.74$; $p = 0.0005$; worse dysfunction) and lastly, the longer PICU LOS the higher the FFS motor function scores ($r = 0.61$; $p = 0.0007$; worse dysfunction).

Conclusion

Children admitted to this particular PICU are most likely to be younger than or equal to 24 months old and have a longer LOS (median = 21 days). Evaluation of functional status indicated higher scores in the mental status and motor function domains of the FSS and an overall score falling within either the normal or mild dysfunction category. Participants with greater functional impairments had longer PICU stays and longer duration of mechanical ventilation.

The FSS provided a rapid and effective assessment of functional status in PICU patients. The observed correlations suggest that prolonged duration of ventilation and extended PICU stay are associated with increased functional dysfunction, particularly in mental status, respiratory and motor domains. This is important to consider when re-evaluating PICU protocols such as ventilation weaning protocols and discharge criteria. The FSS's ability to quickly assess multiple domains is a valuable tool for evaluating post-PICU functional status, to allow for early identification of patients who are at high risk for developing medium-to long -term disability.

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LIST OF ABBREVIATIONS AND DEFINITIONS

CCC – Complex chronic conditions

Long term (lasting longer than 12 months) medical conditions involving multiple organ systems (Penela-Sánchez et al., 2021).

CCP – Complex chronic patients

Patients presenting with multiple chronic system diseases (Penela-Sánchez et al., 2021).

ADL – Activities of daily living

Essential and routine everyday life tasks that healthy individuals perform without assistance, such a bathing, dressing, toileting and eating (Pollack et al., 2009).

FSS – Functional status scale

This is an outcome measure used to assess functional status of a hospitalised patient in the following domains: mental status, sensory, communication, motor, feeding and respiratory function (Pollack et al., 2009).

GCS – Glasgow Coma Scale

An objective measure used to describe the level of impaired consciousness in all types of medical or trauma patients (Pollack et al., 2009).

HRQoL – Health related quality of life

An individual's or a group's perceived physical and mental health over time. Focuses on the impact of health on a person's ability to live a fulfilling life (Watson et al., 2018).

ICU – Intensive care unit

This is a specific hospital ward designed to treat and care for severe or potentially life-threatening cases (Knoester et al., 2008).

IQ – Intelligence quotient

A measure of a person's reasoning ability (Watson et al., 2018).

LLC - Life limiting conditions

A terminal illness or condition that cannot be cured and is likely to shorten someone's life span (Fraser and Parslow, 2018).

LOS – Length of stay

A clinical measure of the time elapsed between a patient's hospital admittance and discharge (Pollack et al., 2015).

LRTI - Lower Respiratory Tract Infection

An infection that affects the airway, below the level of the larynx, including the trachea and alveolar sacs (Corten and Morrow, 2020).

NICU – Neonatal intensive care unit

A specialised ward in a hospital, dealing in critical care of newborns admitted for a number of medical reasons (Royer and Busari, 2021).

PCPC – The paediatric cerebral performance category

Global assessment that can quantify overall morbidity and cognitive impairment specifically for children (Pollack et al., 2014).

PICU – Paediatric intensive care unit

A specialised ward in a hospital, that provides continuous treatment to children who are critically ill (Fink et al., 2020).

PICS-P – Post Intensive Care Syndrome – Paediatrics

Survival from critical illness is frequently accompanied by new or worsened impairments in physical, psychological, cognitive and social domains that impact recovery and life functions, and this is characterised as PICS-P (Fink et al., 2020).

POPC - The paediatric overall performance category

Global assessment that can quantify overall morbidity and cognitive impairment specifically for children (Pollack et al., 2014).

PTSD – Post traumatic stress disorder

A mental health condition experienced by people who have experienced or witnessed a traumatic event or series of events (Watson et al., 2018).

RCWMCH - Red Cross War Memorial Children's Hospital

CHAPTER 1: INTRODUCTION AND SCOPE OF THE RESEARCH REPORT

1.1 Introduction

Paediatric critical care has drastically changed over the past two decades resulting in increased survival rates of patients presenting to paediatric intensive care units (PICU). This is as a result of advances in technology, improved care of patients, including a multidisciplinary team approach and the frequent use of outcome measures and protocols (Pereira et al., 2017). However, this also means that the number of surviving patients with lasting functional impairments has increased (Pereira et al., 2017).

Paediatric critical care is evolving and there has been a shift from assessing mortality as an outcome to assessing functional status and quality of life of patients (Madurga-Revilla et al., 2020; Pollack et al., 2014). Globally, adult and paediatric intensive care units have shown a decrease in mortality rates, at 2% per year since 2000 (Pereira et al., 2017).

A variety of illnesses ranging from acute conditions like asthma or traumatic injuries to less common metabolic disorders or congenital conditions are recorded as reasons for admission to PICU (Ibiebele et al., 2018). Some studies found that more than half of their participants, who were healthy pre-admission had developed morbidity after discharge from PICU. The reasons for poor recovery post-discharge included pulmonary and upper airway complications, such as the insertion of a tracheostomy, neurological and neurocognitive problems as a result of hypoxic or traumatic brain injuries, meningitis or intracranial bleeds (Knoester et al., 2008). Surviving PICU can lead to considerable adverse complications as a result of premorbid conditions and complications from procedures during admissions (Herrup et al., 2017).

The term post-intensive care syndrome has been used to describe both adult and paediatric patients with long-term impairments after an ICU admission (Bossen et al., 2021). This includes clinical, psychological and functional disorders such as the insertion of a feeding gastrostomy, sleep disturbances, anxiety, pain and musculoskeletal weakness (Ekim, 2020). Due to advancements in critical care and declining mortality rates, measuring success solely through mortality rates is no longer sufficient (Ekim, 2020). Consequently, research has shifted towards evaluating outcomes, morbidity, and overall well-being (Ekim, 2020). It has become essential to assess functional outcomes of paediatric patients to determine the severity of

functional impairments, the appropriate level of care required after PICU discharge and to ensure timely and effective early rehabilitation.

Historically, three common outcome measures have been used in PICU to evaluate functional status. The Paediatric Overall Performance Category (POPC) and the Paediatric Cerebral Performance Category (PCPC) scales are qualitative outcomes that were originally adapted from the Glasgow Coma Scale (GCS) to be used in a paediatric setting (Pollack et al., 2014). More recently to these, is the Functional Status Scale (FSS), which was developed based on ideas of activities of daily living (ADL) and adaptive behaviour (Pereira et al., 2019; Pollack et al., 2014). The FSS provides a more defined and accurate assessment of surviving paediatric patients in PICU, making it more objective compared to the POPC and PCPC (Madurga-Revilla et al., 2020). It is an easily learned tool that has the potential to be used in large-scale studies (Pollack et al., 2014). Domains include mental status, sensory, communication, motor, feeding and respiratory function.

Pollack et al. (2014), established in their pilot study that FSS correlates well with the POPC/PCPC. The original FSS interclass correlation was 0.95 indicating high reproducibility (Pollack et al., 2009). The FSS has also been translated into other languages and demonstrated that it can be culturally adapted and it is still a validated measure (Pereira et al., 2019). It has good interobserver reliability and adequate content and construct validity (Pereira et al., 2019). The interobserver reliability for total scores on the FSS – Brazil was excellent with an interclass correlation of 0.98, and values over 0.9 indicate excellent reliability (Pereira et al., 2019).

As survival rates have increased so have the number of surviving patients with medium-to long-term disability (Matsumoto et al., 2019). It is therefore critical that we understand the level of function that is affected so that appropriate intervention can be made available to these patients.

1.2 Problem Statement

At an international and national level there is a gap in the literature, addressing functional status of paediatric patients in PICU, as well as appropriate screening tools that can be used to assess global function. There is a need to determine if PICU in South Africa, are discharging patients with poor functional status, in order to better understand the medium-to-long term disability that surviving PICU patients may develop. Early identification is vital in order to establish appropriate follow up and intervention, as early intervention improves overall prognosis. Furthermore, there is a need to establish the use of reliable functional outcome measures in

PICU, such as the FSS. This will aid in determining function on discharge from a specific critical care unit. Similar studies have been done in other countries, but not in a South African context, and not comparing public health care and private health care institutions.

1.3 Research Question

What are the functional outcomes of patients on discharge from a Paediatric Intensive Care Unit based on the Functional Status Scale?

1.4 Aim of the Study

To evaluate the functional outcomes of patients on discharge from a Paediatric Intensive Care Unit using the Functional Status Scale.

1.5 Objectives of the Study

To describe demographic characteristics (age, sex, length of stay (LOS), duration of ventilation) and clinical characteristics (admission diagnosis and previous admissions to PICU) of participants admitted to a particular PICU in Gauteng, South Africa.

To establish functional outcomes in six domains – mental status, sensory, motor function, communication, feeding, and respiratory function, at the time of discharge from PICU, using the FSS.

To investigate the association between admission diagnosis, age, sex, LOS, duration of ventilation of participants and functional outcomes, including the total score of the FSS as well as the scores per the six subsections, at the time of PICU discharge.

1.6 Significance of the Study

Due to the intense nature of a PICU admission, paediatric patients are often discharged from PICU requiring further therapy or intervention to assist in returning to their baseline function. Functional outcomes post critical illness are poorly understood and researched in a paediatric setting. This study aims to identify the functional status of paediatric patients on discharge so that the level of medium- to long-term disability can be determined. For future research, this will assist in early identification of the developed disability, and furthermore evaluating what kind of additional intervention program would be required to address areas of concern. Additionally, this study aims to highlight the importance and feasibility of functional assessments and the use of standardised outcome measures when assessing patients in a PICU.

Any child admitted to PICU is at risk for developing poor functional outcomes. Standardised outcome measures need to become part of PICU protocols, so that there is consistent and

accurate identification of potentially lasting adverse impairments. It is important to acknowledge that there is a great need to develop consensus around research methodologies, reporting standards, domains, instruments and patient follow up, to standardise research efforts specific to paediatric critical care (Maddux et al., 2020), globally. Multidisciplinary teams working in a PICU environment would also be able to streamline overall care and effectively work together with improved protocols.

These acquired impairments not only affects the patient but the family as well on an emotional, practical and financial level (Matsumoto et al., 2019) and it is the responsibility of critical care workers to aim to reduce this burden of care. Therefore, establishing protocols and ongoing functional assessments in a PICU setting is crucial, to better support the affected patients and families.

1.7 Organisation of the Research Report

The outline of the research report per chapter is depicted in Figure 1.1

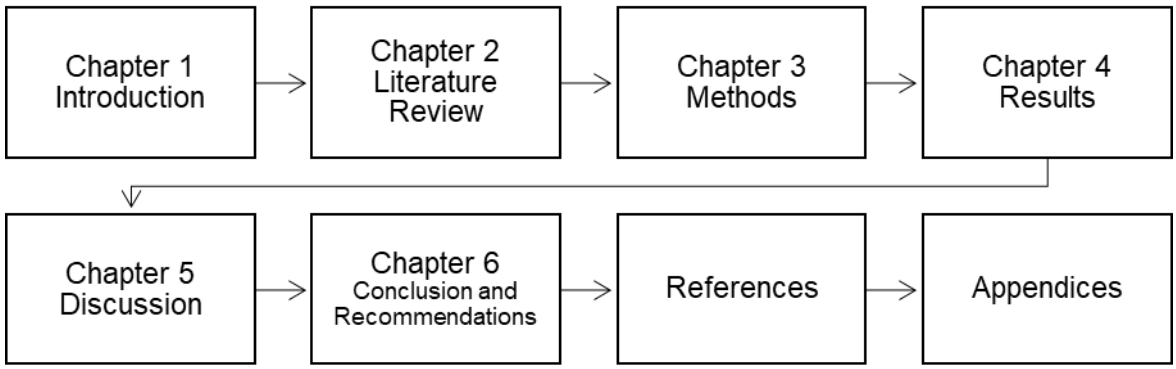

Figure 1.1: Organisation of the research report

The literature that informed this study is presented in Chapter two.

CHAPTER 2: LITERATURE REVIEW

The literature search was conducted and relevant articles were obtained through the following data bases: Cochrane Library, PEDro and PubMed. Keywords and terms, based on MeSH terms, included in the search were, paediatric intensive care units, paediatric critical care, post-intensive care syndrome, neurocognitive function, functional status, functional outcome measures, functional status scale, health related quality of life. The time period reviewed was between 2013 – 2023. This timeline was selected due to the development of research in paediatric critical care during this time as well as to obtain the most current literature. All systematic reviews, scoping reviews, randomised control trials, cross-sectional studies, retrospective and observational studies, in multiple languages but that had been translated to English, were included.

2.1 INTRODUCTION

Paediatric critical care is evolving, with a notable shift from focusing solely on mortality as an outcome to assessing the functional status and health related quality of life (HRQoL) of patients (Madurga-Revilla et al., 2020; Pollack et al., 2014). The number of children requiring critical care is increasing yearly because of a changing spectrum of paediatric disease, technological advancements, and improved survival among extremely premature neonates and children with complex health needs (Choong et al., 2015). Internationally, medical and technological advances, in the last few decades, have led to historically low rates of mortality in PICU (Herrup et al., 2017). However, as patient mortality declines, so long term morbidities among survivors have become more prevalent (Maddux et al., 2020; Pereira et al., 2019).

Globally, intensive care units (ICU) are showing a decrease in mortality rates, at 2% per year since 2000, reflecting these advances in patient care (Pereira et al., 2017). In the United States, there are nearly four million ICU admissions annually, with a mortality rate ranging from 8 - 19% (Ahmed, 2022). In contrast, an Egyptian tertiary hospital reported a PICU mortality rate of 33.1% between 2013-2014 while other African and Middle Eastern countries have reported mortality rates between 30.9 -37.4% between 2013 and 2016 (Zaitoun et al., 2022). In South Africa, Red Cross War Memorial Children's Hospital (RCWMCH) PICU has an estimated mortality rate of 7% (Lozano Ray et al., 2023), similar to that of the United States.

The 2019 Global Burden of Disease Study provided a comprehensive assessment of health challenges faced by children worldwide between 1990-2019 (Vos et al., 2020). The study's analysis of 369 disease and injuries across 204 countries and territories, offers valuable insights into mortality, morbidity and disability among children (Vos et al., 2020). It identified two main trends: an overall decline in global child mortality rates over the last three decades because of improved access to health care, vaccination programs and socioeconomic developments; and a shift in disease patterns, from communicable diseases (lower respiratory tract infections (LRTI) like pneumonia, diarrheal diseases or malaria in endemic regions) and neonatal disorders (preterm birth complications, neonatal infections and birth asphyxia) towards non-communicable diseases (congenital defects, nutritional deficiencies and mental health disorders and injuries (unintentional injuries like drowning, burns, or motor vehicle accidents, or violence and self-harm), particularly in low– and middle-income countries undergoing epidemiological transitions (Vos et al., 2020). Preterm birth complications remains a leading cause of death among neonates, particularly in sub – Saharan Africa and South Asia, where LRTIs are one of the major causes of death in children under five (Corten and Morrow, 2020; Vos et al., 2020). South Africa's third Sustainable Development Goal focuses on ensuring healthy lives and promoting well-being for all, as well as targeting the elimination of preventable deaths among newborns and children under five years old (Street, n.d.).

Research acknowledges that children are at risk of recurrent serious acute illness and more PICU admissions, because of developing respiratory systems, immature immune systems, high exposure to pathogens in a school environment, underlying health conditions such as congenital heart defects and an increased dependence on caregivers for their health care needs (Choong et al., 2015). Yet, how children and their families recover after surviving a critical illness is poorly understood (Choong et al., 2015).

Increased survival rates have also created a population of medically complex patients, due to associated complications and co-morbidities, that spend longer periods in a hospital environment (Pereira et al., 2017). In the last decade children admitted with significant underlying chronic health conditions have doubled and PICU re-admission rates have tripled, due to advances in medical care and increased survival rates of children living with chronic conditions requiring more frequent hospitalisations (Choong et al., 2015). Bennett et al. (2015), reported that functional outcomes in children are lower after critical illness and therefore the

focus in PICUs should move from “saving lives” to “saving functional lives” (Pollack et al., 2014). This is again echoed by Ekim et al. (2020), our goal needs to expand into improvement of quality of life of patients who survive a PICU admission.

An admission to any ICU as a result of critical illness is a stressful and chaotic event for patients and their families. About half of all PICU admissions are unexpected (Bossen et al., 2021). Patients inevitably are exposed to life saving interventions such as: mechanical ventilation, endotracheal intubation, chest tube insertion, central venous and arterial catheterisation and intensive medication administration (Bennett, 2015). The severity of illness, opioid or sedative exposure and extracorporeal life support may influence both the level of functional decline and the rate of recovery (Bennett, 2015). Symptoms of PICU survivors range from psychological problems, cognitive dysfunction, worsening respiratory function and development of neuromuscular complications (Pereira et al., 2017). Although there is well described literature in adult critical care, attention also needs to be brought to this subgroup of PICU patients as it is lacking in research (Herrup et al., 2017).

2.2 PAEDIATRIC INTENSIVE CARE UNIT ADMISSIONS

2.2.1 Global Picture: Age, Diagnosis, Length of Stay, Sex

Paediatric intensive care units (PICU) admit a mixture of patients presenting with conditions ranging from acute conditions like lower respiratory tract infections (LRTIs), asthma or traumatic injury and to less common metabolic disorders, such as diabetes, or congenital conditions such as heart defects, neural tube defects or Down syndrome (Ibiebele et al., 2018; World Health Organisation, 2023). Respiratory illness such as bronchiolitis are common causes for an admission to PICU of previously healthy children (Shein et al., 2021). Infections such as pneumonia, are among the leading causes of mortality in children under five internationally (Liu et al., 2015). In South Africa, similar to worldwide data, LRTIs constitute a major burden of disease and are one of the most common reasons for hospital admissions in infants and children (Morrow, 2019).

The international literature reviewed, looked at seven research studies based across a number of continents; Australia; North America - The United States; Europe – Portugal and Spain South America - Brazil and in Asia – Japan. In a population-based cohort study in New South Wales, Australia, researchers described data from 150 public hospitals, where most of the acute care in paediatrics is provided, over three years. The study population included all new paediatric hospital admissions that included PICU time and 6124 children were included.

Notably, 85.6% had one PICU admission and 10% had two and 4.3% had three or more (Ibiebele et al., 2018). A large prospective cohort study was conducted in the United States, and included 5017 paediatric patients, younger than 18 years old, from eight children's hospitals with PICUs. (Pollack et al., 2014). There was a 2.0% mortality of the total cohort. The Notably, 23.6% of the cohort present with a history of developmental delay prior to admission (Pollack et al., 2014).

Across Europe, a cross-sectional study was conducted in Portugal with a moderate sample size of 50 patients (Pereira et al., 2017). Penela-Sánchez et al., (2021) conducted a single-centre retrospective and descriptive study in Barcelona, Spain, which reported on a large sample of 1433 paediatric hospital admissions. Admissions were classified according to the following groups: acute disease (57.1%) chronic disease (28.5%) and chronic complex disease (14.4%) of patients. They also reported that 10% of the total paediatric hospital admissions were from complex chronic patients (CCP), which are medically complex patients (Penela-Sánchez et al., 2021). Another descriptive, retrospective, observational analysis conducted at a tertiary Hospital in Spain, reviewed a large sample of 266 patients (Madurga-Revilla et al., 2020). In South America, a cross-cultural adaption study regarding the FSS, was conducted in Brazil, that described data for a large sample group of 314 patients (Pereira et al., 2019). In Asia, at a tertiary hospital in Japan, a retrospective, observational study reported on 1082 PICU admissions (Matsumoto et al., 2019).

Across these various studies, the age at admission to PICU shows considerable variation, but the trend is towards children under five. In large scale studies from Australia and the United States, the average age at admission was between one and four years, with a median age of 3.6 years respectively (Ibiebele et al., 2018; Pollack et al., 2014). Other studies found lower median ages, such as 19 months (Pereira et al., 2017) and 24 months old (Pereira et al., 2019), while another reported a mean age of 3.6 years (Penela-Sánchez et al., 2021) and lastly a median age of 4.8 years (Madurga-Revilla et al., 2020).

The studies reveal that respiratory conditions are the most common reason for PICU admissions. In Australia, primary admitting diagnoses recorded were, respiratory illness (28.5%), congenital abnormalities (22.7%), neurological disorders (8.5%) and injury and external cause (7.1%) (Ibiebele et al., 2018). In the United States the main reasons for admission were respiratory dysfunction (29.9%), cardiovascular (24.9%) and neurological (18.4%) (Pollack et al., 2014). In Brazil, the study found that the main causes for admission

were; respiratory failure (40%), postoperative recovery (16%), sepsis and shock (12%) and liver failure (12%) (Pereira et al., 2019). Across Europe, studies reported that respiratory disease was the most common reason for admission (50.4%), followed by infectious disease (27.5%) and gastrointestinal disease (8%) (Penela-Sánchez et al., 2021); and in another PICU reasons for admissions included cardiovascular (37.3%), neurological (9.9%) and respiratory conditions (8.6%) (Pereira et al., 2017). The distribution of diagnoses reflects a broad range of critical health issues among paediatric patients.

The literature describes the following LOS data: In Australia the average LOS in PICU was 47 hours and average days in hospital was six (Ibiebele et al., 2018). In the United States the median LOS was 2.0 days (Pollack et al., 2014). In Europe, one study had a median LOS of two days (Madurga-Revilla et al., 2020), and two studies had an average LOS of five days (Penela-Sánchez et al., 2021; Pereira et al., 2019). One study looked specifically at patients who had a long PICU admission of more than 14 days, and 12.5% of this sample had a prolonged PICU admission (Matsumoto et al., 2019). They further noted that the number of paediatric patients that have prolonged PICU stays is increasing, putting them at high risk for developing mortality and disabilities (Matsumoto et al., 2019).

Within this set of studies, males had higher admission rates. Males had higher admission rates at 55.7% in Australia (Ibiebele et al., 2018), 60% in Portugal (Pereira et al., 2017), 61.3% were males and 38.7% were females in one of the Spanish studies (Madurga-Revilla et al., 2020). And in the cross-cultural adaption study based in Brazil the cohort was predominantly male at 54.1% (Pereira et al., 2019).

The international evidence collectively suggests, that the typical demographic profile of a PICU admission includes; children under five years of age, predominantly male, with a primary diagnosis of respiratory illness, and an average LOS of five or less days (Ibiebele et al., 2018; Madurga-Revilla et al., 2020; Matsumoto et al., 2019; Penela-Sánchez et al., 2021; Pereira et al., 2019, 2017; Pollack et al., 2014).

2.2.2 African and South African Picture: Age, Diagnosis, Length of Stay, Sex

In a comparative analysis of studies from African countries with socioeconomic contexts similar to South Africa, relevant data can be drawn from studies conducted in Egypt and Ethiopia. A cross-sectional study in an Egyptian PICU at a tertiary paediatric hospital reviewed 50 patients, with a mean age of 6.08 years and an age range of 2-16 years (Zaitoun et al., 2022). The cohort consisted of 54% males, with admissions split between medical (38%) and

postoperative (62%) cases. The mean LOS in the PICU as 5.9 days. Additionally, it was also reported that sedation was required for 54% of the patients, ventilation for 38% and inotropic support for 12% (Zaitoun et al., 2022)

Similarly, a retrospective observational study in Ethiopia, conducted at the University of Gondar Comprehensive Specialised Hospital PICU, reviewed 305 patients aged one month to 14 years old (Ahmed, 2022). The male to female ratio was 1.3:1, with 57.4% being male and the majority of children were in the age range of 10-14 years. The LOS for the majority (44.3%) was between two and seven days. Neurological (23.6%), respiratory (19%) and cardiac (11.8%) conditions were the primary reasons for admission (Ahmed, 2022). The overall mortality rate was 23.6% and the leading cause of death was related to neurological causes (meningitis) (Ahmed, 2022).

When compared to the other international literature reviewed, similarities include that admissions were made up of predominately male patients and that medical, a neurological or respiratory diagnosis, were common cause for admission. In contrast the average age is much higher than that of Australia, United States, Brazil and Europe, and the average LOS was over five days (Ahmed, 2022; Zaitoun et al., 2022).

Local literature reviewed included two studies based at Red Cross War Memorial Children's Hospital (RCWMCH) a public hospital in Cape Town, South Africa. The first was a descriptive single centre point prevalence study in the PICU of RCWMCH, that describes data for 354 patients (Lozano Ray et al., 2023). The median age was 10.1 months old, and 57.6% of the sample was male. The median LOS was 5.0 days. Admissions for respiratory disease was 13.3%, cardiac 25.4%, trauma 12.7%, neurology/neurosurgery 17.2% and general surgery 14.4% and invasive mechanical ventilation was reported on 53.6% of the sample (Lozano Ray et al., 2023).

Secondly, a retrospective a patient file review from RCWMCH reviewed a total of 1208 cases admitted for acute LRTI. The median age (IQR) was 7.6 (2.8-19.0) months. The median (IQR) duration for hospitalisation was 2.3 (1.5-5.0) days and the overall mortality rate was 0.7%. Males accounted for 59.6% of the total. Reviewing ventilation support, 17% received non-invasive and/or invasive mechanical ventilation. The median (IQR) duration of ventilator support was 3.0 (2.0-5.0) days (Corten and Morrow, 2020).

Another South African retrospective descriptive study conducted in the Western Cape, found that within a cohort of 185 children admitted to a particular public hospital PICU, there were

patients ranging in age between one month and one year old, presenting with acute lower respiratory tract infections, acute gastroenteritis, acute flaccid paralysis and upper airway obstructions (Kruger, 2014). There was a male predominance of a ratio 1.3:1 and the age distribution indicated that 83% of patients admitted were younger than 12 months with a median age of 3.7 months (mean age of 8.5 and range of 0-151 months). Neonatal admissions were 4% of total paediatric admissions to the hospital. The mean LOS was 2.5 days (Kruger, 2014).

Significantly, research was conducted across eight study sites, all within public or non-profit private hospitals, spanning four provinces in South Africa, and included three hospitals in Gauteng, (Morrow et al., 2023). This was a descriptive, cross sectional, multicentre, point-prevalence, study included 310 paediatric patients under 18 years old. Males comprised 53.5% of the cohort, with a median age was 9.8 months. The majority (70.6%) of patients were under two, and 56.1% were under one. Emergency admissions accounted for 78.4% of cases, with respiratory (39.9%) and cardiac (17%), the median LOS 6 was days and 62.9% required invasive mechanical ventilation (Morrow et al., 2023).

Compared to international research, South African reports show a similar trend in PICU admission, with a significant proportion of admissions being for children under two years old, predominantly males, and with respiratory conditions being the most common diagnosis and a LOS of five days or less. However, South African studies, such as those by Morrow et al. (2023), highlight a higher percentage of emergency admissions (74.4%) and a higher reliance on invasive mechanical ventilation (62.9%). Although South Africa is classified as an upper middle-income country, it is important to note that the majority of children managed in most PICUs live under highly impoverished circumstances, which likely influences the healthcare outcomes and access to resources for this vulnerable population (Lozano Ray et al., 2023).

2.2.3 Pre -Admission Health Status

Not all paediatric patients admitted to a PICU have healthy or typically developing pre-admission status or function. With the improvements in medical care and technological advancements, survival has improved for many life-threatening childhood diseases. However this has also caused an increase in the number of children living with chronic diseases, related to all physiological systems, related to disability and complex health care needs (Penela-Sánchez et al., 2021). Paediatric patients with special health care needs are those that have or are at greater risk for chronic physical, developmental, behavioural or emotional conditions

and who require a disproportionate amount or type of health care services compared to the general paediatric population (Penela-Sánchez et al., 2021). Within this group is a sub group referred to as complex chronic patients (CCP). CCP are patients with several chronic diseases that result in medical fragility, functional limitations and substantial health care needs (Penela-Sánchez et al., 2021). CCPs make up 10% of the total paediatric hospital admissions in the United States (Penela-Sánchez et al., 2021). Children with complex chronic conditions (CCC) have an increased risk of a prolonged length of stay in a PICU, greater than 15 days (Fraser and Parslow, 2018; Penela-Sánchez et al., 2021).

A national cohort, data linkage study done in the UK reviewed records from several databases of high quality and validated information regarding paediatric intensive care. This study concluded that children with life limiting conditions (LLC) made up approximately 58% of admissions to PICUs, of which 87.5% were admitted for more than 28 days (Fraser and Parslow, 2018). Notably, the cohort study based in the United states reported that 23.6% of the cohort presented with a history of developmental delay prior to admission (Pollack et al., 2014).

In South Africa, two studies highlighted the prevalence of comorbidities among paediatric patients. According to (Corten and Morrow, 2020), 52.6% of patients presented with comorbidities during at least one of their hospitalisations. Additionally, (Morrow et al., 2023), found that of all admissions, paediatric patients presented with one or more comorbid conditions.

2.3 SURVIVING PICU

2.3.1 Post Intensive Care Syndrome

The term post intensive care syndrome (PICS) has been used to describe patients with long-term impairments post an ICU admission (Bossen et al., 2021). The Society of Critical Care Medicine defined PICS as “new or worsening impairments in physical, cognitive or mental health status arising after critical illness and persisting beyond the acute care hospitalisation” (Ekim, 2020). In paediatrics it is referred to as PICS – P (Bennett, 2015). The interaction between pre-admission health status, reason for admission, the PICU admission course and how families handle significant impairments, are thought to contribute to a child’s overall outcomes (Zaitoun et al., 2022). Ekim, (2020), describes the paediatric population as already at high risk for PICS -P due to immature organ systems, dependence on family, and overall level of development. Despite more children surviving critical illness there are few studies that have observed the recovery trends of these children following discharge from a PICU

(Madurski et al., 2018). The current challenge is addressing the needs of paediatric patients with new cognitive, emotional and physical morbidity after surviving critical illness (Madurski et al., 2018).

Multiple studies have described cognitive, physical, psychological, quality of life and family sequalae developed by paediatric survivors of critical care (Bennett, 2015; Herrup et al., 2017; Matsumoto et al., 2019). Notably, PICS – related morbidities effect a substantial proportion of children discharged from PICUs (Herrup et al., 2017). In a systematic review conducted in the United States, Herrup et al. (2017), identifies 19 global studies, which summarised that majority of paediatric patients do survive their illness, but the questions should now focus on the impact of new or worsening morbidities that these children experience as a result of critical illness. Internationally, the proportion of PICU survivors living with moderate to severe disabilities has increased significantly (Matsumoto et al., 2019).

Knoester et al. (2008), found that more than half of their participants, who were healthy pre-admission had developed morbidity after discharge from PICU. The listed complaints included pulmonary and upper airway complications, such as the insertion of a tracheostomy due to prolonged ventilation. Surviving PICU can lead to considerable adverse consequences as a result of premorbid conditions and complications from procedures during an admission (Herrup et al., 2017). In a prospective cohort study the new incidence of morbidity was 4.8%, twice the mortality rate (Pollack et al., 2015).

2.3.2 Physical Function

Watson et al. (2018), provided a scoping review that looked at 25 studies which described a wide range of physical impairments including respiratory dysfunction, pain, reduced sensation, poor mobility and impaired self-care and feeding. Measures used to identify impairments included the Vineland Adaptive Behaviour Scale-2, the Modifies Glasgow Outcome Scale, the Paediatric Overall Performance Category (POPC) and the Functional Status Scale (FSS) (Watson et al., 2018). Residual functional disabilities at six months post PICU discharge occurred in 73% of patients but decreased to 10 - 19% two or more years after a PICU admission (Watson et al., 2018). Watson et al. (2018), also reported that previously well children continued to require intervention for up to three years post critical illness. Using the FSS, a cross sectional study, previously discussed, found that motor function was one of the most affected domains (Pereira et al., 2017). Bossen et al. (2021), reported that all studies, from this scoping review, documented disabilities in physical function during or after a PICU or

hospital stay and those survivors' reported difficulties for years after their initial discharge. In another systematic review, nine out of nineteen studies reported physical or functional morbidities in paediatric patients post a PICU stay (Herrup et al., 2017). In the same review, three studies investigated change in mobility of PICU survivors reporting that approximately 49% of patients had poor mobility at the time of PICU discharge and at one year follow up there was improvement in overall mobility (Herrup et al., 2017).

Poor physical function following a PICU stay has significant implications of the burden of care, health care costs, and health related quality of life (HRQoL) (Herrup et al., 2017). Children with impaired physical function often require extensive rehabilitation, prolonged medical care, and increased support form caregivers, which places a heavy burden on families and health care systems, and this can lead to increased healthcare costs (Herrup et al., 2017). Moreover, reduced physical function can negatively impact a child's HRQoL, limiting their ability to engage in normal activities and affecting their overall well-being (Watson et al., 2018).

2.3.3 Cognitive and Psychological Function

Minor interruptions to development, in any aspect of cognitive function during the early years of development can have a substantial impact on children (Watson et al., 2018). Data is limited, but what we do know is that cognitive dysfunction after critical illness can be significant and last for many years (Watson et al., 2018) and well into adolescence and adulthood (Madurski et al., 2018). During a PICU admission, risk factors for cognitive impairment are increased while positive cognitive stimuli are decreased (Royer and Busari, 2021) because patients inevitably are exposed to life saving interventions such as: mechanical ventilation, endotracheal intubation and intensive medications, such as opioids and sedatives, that negatively impacts cognitive development (Bennett, 2015).

Lower intelligence quotient (IQ) and moderate to severe shortfalls in attention and memory are common issues and negatively affect learning (Watson et al., 2018). Studies using the Paediatric Cerebral Performance Category (PCPC) found new cognitive problems in up to 73% of survivors (Watson et al., 2018). Risk factors for cognitive deterioration included admission diagnosis of trauma, injury, neurological problems, cancer, unscheduled admissions, increased risk of mortality, invasive mechanical ventilation, extracorporeal life support and increasing LOS. The risk of psychological illness is increased with any cognitive impairment (Watson et al., 2018).

Another systematic review looked at 12 observational studies that examined cognitive outcomes of critically ill children (Madurski et al., 2018). The studies reviewed included participants between the ages of 3 -18 years old without premorbid conditions, and standardised tests including at least one domain of cognitive function. All studies reported poorer cognitive functioning in at least one domain. These were variable across domains tested but it repeatedly acknowledged impairments related to intelligence, memory, attention, executive functions and visuomotor integration and motor development (Madurski et al., 2018).

Risk factors for poor cognitive outcomes include the age at critical illness, and age at follow-up, poorer socioeconomic status, oxygen and mechanical ventilation requirements and opioid use (Madurski et al., 2018). Other factors, like variability of patient demographics, diagnosis at admission and pre-morbid health status, may affect long term outcomes of cognitive function, regardless of events during a PICU stay (Zaitoun et al., 2022).

Royer and Busari (2021), conducted a broadly researched systematic review to look at current trends regarding the association between ICU hospitalisation and neonatal and paediatric survivor cognitive status and development. Within this review, two studies looked at Neonatal ICU (NICU) population and concluded that NICU admissions have a negative relationship on various cognitive outcomes up until two years post discharge. Another four articles looked at PICU populations, and all four found a significant relationship between LOS and a variety of cognitive outcomes. A longer LOS was associated with lower cognitive functional scores. Results suggest that patients with a PICU or NICU stay of longer than two and a half days and with two or more of the following factors; increased mortality risk, invasive interventions and neurological diagnosis, should be considered a high risk for developing functional impairments (Royer and Busari, 2021). Neonatal intensive care unit and PICU survivors have reported suffering from a variety of psychiatric disorders including anxiety, depression, and PICS (Royer and Busari, 2021). Surgical interventions, sedation, mechanical ventilation, and pain medication used are closely associated to psychological stress (Royer and Busari, 2021). Risk factors for psychological impairments include unexpected PICU admissions, the quantity of medical procedures undergone in the PICU as well as history of distressing life events, psychological problems prior to a PICU admission, poor social support and adverse memories of PICU admission (Watson et al., 2018).

In Herrup et al. (2017), systematic review, nine out of nineteen studies also reported on psychological dysfunction. Most commonly reported were post-traumatic stress disorder

(PTSD) symptoms. Patients reported, poor recall of the event leading to an admission, hypervigilance, avoidance of thoughts or feelings, difficulty concentrating (Herrup et al., 2017).

2.3.4 Health Related Quality of Life and Family Centred Approach

Another factor to consider post PICU discharge is HRQoL. When considering HRQoL together with overall function, it adds valuable depth to understanding the total effect of critical illness and how it may impact a child's life (Watson et al., 2018). A systematic review of 78 studies assessing HRQoL in PICU patients, identifies important and persistent HRQoL impairments (Watson et al., 2018). Notably, HRQoL does improve in children after discharge from a hospital for up to a year (Watson et al., 2018).

Children alone don't face these challenges but so do their families, as a result of caring for a child with new impairments and these include increased financial demands and emotional stress (Madurski et al., 2018). A family-centred approach is essential for improving outcomes after a child is discharged from the PICU, and this approach recognises that family involvement is crucial in supporting the child's recovery, both emotionally and physically (Madurski et al., 2018). By actively engaging families in the care process, they can better understand the child's needs, participate in decision-making, and provide continuous support at home (Madurski et al., 2018). This holistic involvement leads to improved survival rates, enhanced HRQoL and better long-term health outcomes for the child (Watson et al., 2018).

Studies from many countries, with different follow up schedules, and diverse methods for diagnosis, repeatedly report on the overall effect of critical illness on families. Close to one third of parents have acute stress disorder after their child's PICU admission. Up to 84% report post traumatic symptoms, 10-21% have PTSD, 15 – 50% have anxiety, 15-30% have depression and many require specialised care for depression and anxiety (Watson et al., 2018). Symptoms may persist for months, and many families report delayed processing of the event at one year post discharge (Watson et al., 2018).

2.4 FUNCTIONAL STATUS

Functional status encompasses a child's ability to participate in activities of daily living, that are essential to health and wellbeing, meet basic needs and fulfil purposeful roles (Watson et al., 2018). The difficulty has been trying to assess function and not just mortality in a PICU setting an so outcome measures need to address morbidity at the time of discharge or after a PICU admission (Herrup et al., 2017) to assess the full impact of this kind of hospital

admission. Monitoring functional status in a PICU, provides valuable insights into the child's physical, cognitive, psychological, and emotional well-being, helping to identify early signs of dysfunction or disability (Madurga-Revilla et al., 2020). Additionally, tracking functional status helps to inform care plans, optimise resource allocation, guide discharge planning, ultimately improving the efficacy of healthcare delivery and reducing healthcare costs (Herrup et al., 2017).

2.4.1 Outcome Measures

Historically, three outcome measures are commonly used in PICUs to evaluate functional status. The Paediatric Overall Performance Category (POPC) and the Paediatric Cerebral Performance Category (PCPC) scales are qualitative outcomes that were originally adapted from the Glasgow Coma Scale (GCS) to be used in a paediatric setting (Pollack et al., 2014). However, their limitations include lengthy assessment time and additional training that may be required to administer the tool. For over twenty years the majority of large-scale research has relied on two screening tools, the Modified Glasgow Coma Scale or the POPC. However, the parameters of both are limited as they do not fully capture the complexity of functional impairments, particularly in areas like motor function, cognition and emotional well-being (Watson et al., 2018).

2.4.2 The Paediatric Overall Performance Category (POPC) and the Paediatric Cerebral Performance Category (PCPC)

The POPC and PCPC are global scoring scales based on observer impressions. Scores include one for good, two for mild disability, three for moderate disability, four for severe disability, five for a vegetative state or coma and six indicates death (Pollack et al., 2014). The POPC/PCPC system was developed first specifically for large scale studies. They have good content validity because they are an adaption of the GCS that is widely used in adult populations (Pollack et al., 2014). Soon after the initial publication of this scoring system, the potential lack of precision of the POPC/PCPC scales were identified, and the concerns raised were that only major health care changes would be detected by investigators, and this would be limited in younger populations due to the diverse nature of overall childhood development (Pollack et al., 2009). The variability of POPC/PCPC scores and more specific neuropsychological tests were very large in validation studies and therefore, this indicated that this scoring system lacked precision and would only be beneficial if used in very large scale paediatric research (Pollack et al., 2014).

2.4.3 Functional Status Scale

More recently to these, is the Functional Status Scale (FSS), which was developed based on ideas of activities of daily living (ADL) and adaptive behaviour (Pereira et al., 2019; Pollack et al., 2014). Pollack et al. (2014), from the National Institute of Health Collaborative Paediatric Critical Care Research Network, developed the FSS. The FSS provides a more defined and accurate assessment of all cases presented in PICUs making it more objective (Madurga-Revilla et al., 2020). It provides an age independent, rapid assessment of functional status, that bridges the gap between time intensive functional assessments and simplified screening tools (Watson et al., 2018). The FSS was not developed to substitute for more patient-specific scales, but rather as an alternative for lengthy measures of functional status (Pollack et al., 2014). It is also important to note, that a limitation of the FSS, is that it does not measure HRQoL (Pollack et al., 2015).

The FSS is an easily learned tool that has the potential to be used in large scale studies (Pollack et al., 2014). Domains include mental status, sensory, communication, motor, feeding and respiratory function. Domain scores range from one (normal) to five (severe dysfunction) with a total low score of six and a total high score of thirty. A higher score indicates more severe dysfunction (Pollack et al., 2009; Watson et al., 2018). It is valid in patients from birth to 18 years old (Pollack et al., 2009).

2.4.4 Validity and Relatability of the FSS

In a prospective cohort study, conducted in the United States, it was established that the POPC/PCPC and the FSS are well correlated. This study included over 5000 patients from eight children's hospitals with PICUs, and included all paediatric patients younger than 18 years old (Pollack et al., 2014). Scores for all three outcome measures were recorded at baseline and then at PICU discharge. The FSS and POPC/PCPC scores were almost identical in both assessments (Pollack et al., 2014).

The FSS has also been translated into other languages and demonstrated that it can be culturally adapted and it is still a validated measure (Pereira et al., 2019). This tool provides a significant advance for paediatric outcome studies as it is well defined, quantitative, rapid and reliable measure of functional status. It is also not dependant on subjective assessments and well suited to large paediatric hospital studies (Pollack et al., 2009). The original FSS interclass correlation was 0.95 indicating high reproducibility (Pollack et al., 2009) and it has good interobserver reliability and adequate content and construct validity (Pereira et al., 2019). The interobserver

reliability for total scores on the FSS – Brazil, which involved applying the final version to 314 children and adolescents post PICU discharge, was excellent with an interclass correlation of 0.98, and values over 0.9 indicate excellent reliability (Pereira et al., 2019). This is similar to the original interclass correlation of 0.95 as noted previously. This indicates high reproducibility when being used by other health care professionals (intensivists, physiotherapists and nurses) and in different hospitals (public and private) (Pereira et al., 2019). The validity of the FSS -Brazil during clinical validation was not provided as a single numerical value, instead the validation process highlighted the strong correlations between domains and evaluators (Pereira et al., 2019). While these results imply good validity, this study did not explicitly provide a separate coefficient or measure and the focus was more on the tool's reliability and the correlation between its domains (Pereira et al., 2019).

The improved representation of specific impairments results in increased sensitivity to post PICU discharge functional impairment compared with the POPC (Watson et al., 2018). In this systematic review, studies across eight PICUs using the FSS identified new morbidity in 4.8% of patients at PICU discharge, twice the overall mortality rate, indicating that functional morbidity may be an important measure of quality, effectiveness and efficacy of care (Watson et al., 2018).

A cross-sectional study, conducted in Portugal with a cohort of 50 paediatric patients, showed the mean score of the FSS was 11.5 and the range was between 7 -15. The highest scores were observed in motor function (3) and feeding (4) domains. Patients who were readmitted presented with worse overall scores in the motor function, feeding, and respiratory domains and higher mortality rate according to the Paediatric Index of Mortality 2. Of the 50 patients in the cohort, 15 (30%) had normal status, 20 (40%) moderate dysfunction, seven (14%) mild dysfunction, and one had severe dysfunction. A total of 18% of the patients presented with a normal FSS score and only 6% had an overall score on the FSS of more than 20, which is either severe or very severe dysfunction. Notably, 40% were readmitted and 12% demised. There was no statistical significance difference between male and females in relation to the overall score and FSS domains (Pereira et al., 2017).

Pereira et al., (2019), also conducted a cross-cultural adaption study in Brazil. The FSS Brazil confirmed good psychometric performance, signifying that it is useful for evaluating critical paediatric patients. It had acceptable content validity (high relevant and representative items), construct validity (correlation with external variables and discriminant validity) and high

interobserver reliability and reproducibility (p = 0.489 and K coefficients all above 0.7, agreement either good or excellent) allowing comparison between results and from different health care professionals. Clinical validation was applied to 314 children and adolescents after discharge from the PICU (Pereira et al., 2019). This study also found a high correlation, with strong significance between the mental status and communication domains (r = 0.501; p = <0.001), and a high correlation between feeding and respiratory domains (r = 0.566; p = <0.001) and respiratory and motor function domains (r = 0.56; p = <0.001)). A moderate correlation was found between communication and motor function domains (r = 0.422; p = <0.001). For the other domains the correlation was weak or non-existent. (Pereira et al., 2019). This was the only cross-cultural adaption study found and reviewed in the literature. There was no information related to the FSS, functional status and PICU functional status in Africa or South Africa.

The FSS is a clear and easily learned outcome measure of functional status, suitable for use in large scale studies (Pollack et al., 2014). Overall, greater standardisation of outcome measures and cross-validation would be valuable for both future research and evidence based practice, specifically in Africa and South Africa where there is a noticeable gap in the literature as no studies using the FSS in a PICU setting were found (Bennett, 2015).

2.5 CONCLUSION

Medium and long term follow up is especially necessary for children with poor functional outcomes (Bossen et al., 2021). These results highlight the importance of post PICU interventions for both children admitted to the PICU and their families. In addition, early identification of children at risk for functional impairments, can help put measures in place to prevent these complications and develop suitable interventions to improve a particular area of function, if impairments persist (Bossen et al., 2021). Developing assessment standards may improve our understanding of post discharge outcomes and support development of interventions after paediatric critical illness (Maddux et al., 2020). Of the vast majority of children surviving critical illness, more than one million children will be at risk of developing post PICU impairments, or PICS-P symptoms, in the United States in the next decade, and many more family members will potentially be impacted as well (Watson et al., 2018). However, there is a notable gap in the literature, as there is no data available on the prevalence or characteristics of PICS-P among African or South African paediatric patients, underscoring a critical area for future research.

PICU survival leads to substantial physical sequalae related to underlying illness, complications from procedures or both (Herrup et al., 2017). As survival rates have increased so have the number of surviving patients with moderate to severe long-term disability (Matsumoto et al., 2019). It is therefore critical that we understand the level of function that is impacted and furthermore, what areas are most affected so that appropriate intervention can be made available to these patients. This kind of disability not only impacts the patient but the family as well on an emotional, practical and financial level (Matsumoto et al., 2019) and it is the health care providers responsibility to aim to reduce this burden of care.

Management of these paediatric patients does not end at discharge from the PICU (Madurski et al., 2018). It is known that many children are left with new physical, cognitive and other morbidities that can have potentially life-long consequences for functional independence and HRQoL. Increasing our understanding of the short and long term morbidities and their specific risk factors following paediatric critical illness is time sensitive and crucial (Madurski et al., 2018).

While paediatric critical care is a rapidly evolving field, research in this area significantly lags behind that of adults, especially in an African and South African context, and remains largely fixated on immediate, short term morbidity and mortality outcomes (Choong et al., 2015). Only after we understand how to measure and quantify functional outcomes, can we determine the lasting effect of PICU interventions and early rehabilitation, on functional recovery in children who survive a critical illness (Choong et al., 2015).

Currently there are no clinical practice guidelines for assessment strategies focusing primarily on function of paediatric patients following critical illness (Madurski et al., 2018). Determining core areas that reflect functional outcomes valued by patients and their families, and then implementing assessment measures specific to these areas is the next step in understanding morbidity following paediatric critical illness (Madurski et al., 2018). Once we better understand the impact of paediatric critical illness, can we plan for improved overall care of this population.

CHAPTER 3: METHODOLOGY

This chapter describes methods used for data collection over a period of seven months, May 2023-December 2023. This chapter includes the inclusion criteria, outcome measures used, data collection procedure, ethical considerations as well as the process for data analysis.

3.1 Study Design

The study design chosen was an observational cross-sectional study design. In a cross-sectional study design, the primary investigator measures the outcome and exposures in the study participants at the same time without changing any variables (Setia, 2016). Participants selected for a cross-sectional study are only based on the inclusion and exclusion criteria set and this study design is used for population based research (Setia, 2016).

This was most appropriate, as this was an observational study assessing a specific population at a set point in time – at discharge from PICU. It also allowed for a once off assessment to be completed without the need for any follow up.

3.2 Study Population

The participants involved in the study were patients admitted to a PICU at one private hospital in Gauteng, South Africa. This hospital was selected as the study site due to the professional affiliation with the hospital. The sampling technique was convenience, non-probability sampling.

3.2.1 Study Setting

Participants that were admitted to a private hospital PICU in Gauteng. This is a ten bed PICU accepting patients from one month old to thirteen years old. It does not include any neonatal patients.

3.2.2 Sample Size

Initial calculations were based off unit statistics between July - December 2021, which showed that 103 patients were admitted to the PICU during this period. Using a Roasoft sample size calculator and anticipating that 10% of children will have functional deficits (Bone et al., 2014)

a sample of 60 participants was initially recommended, to give a 95% confidence interval and a 5% margin of error.

3.2.3 Eligibility criteria

Inclusion criteria for the study were as follows: Participants were required to have been admitted to the PICU for a duration exceeding 24 hours, consistent with international literature standards (Ibiebele et al., 2018; Pereira et al., 2019, 2019). Eligible participants were between the ages of one month and thirteen years, which corresponds to the admitting age range for the unit used as the study site. Both male and female patients were included in the study.
There were no exclusion criteria for this study.

3.3 Instrumentation and Outcome Measures

The outcome measure used to assess function on discharge was the Functional Status Scale (FSS) (APPENDIX I: The FSS). The FSS is an observational outcome measure based on a score sheet that is made up of six domains. These domains are mental status, sensory, communication, motor, feeding and respiratory function. Each domain allows for a score from 1 to 5 – a score of 1 being "normal" and a score of 5 "very severe dysfunction". The total score is out of 30 (highest score of five, in each domain) and a higher score will indicate worse dysfunction. Participants were observed in all of these domains by the principal investigator, and a score was given per domain on the FSS data sheet. The scoring was reviewed and verified by an experienced colleague in the PICU. This is a well-defined, quantitative, rapid and reliable measure of functional status (Pollack et al., 2009). The original FSS interclass correlation was 0.95 indicating high reproducibility (Pollack et al., 2009). It has good interobserver reliability and adequate content and construct validity (Pereira et al., 2019). The interobserver reliability for total scores on the FSS – Brazil was excellent with an interclass correlation of 0.98, and values over 0.9 indicate excellent reliability (Pereira et al., 2019).

To collect all other demographic information required, a demographic and clinical data collection sheet was created to capture this data (APPENDIX II: Demographic and clinical data sheet). The data sheet encompassed all pertinent information including age, sex, primary admitting diagnosis, length of stay (LOS), duration of ventilation, medical procedures, relevant past medical history (such as previous admissions to PICU) medication prescriptions and pre – admission functional status as reported by the caregiver.

3.4 Procedure

No pilot study was conducted; instead, the methodology was reviewed by a panel of university assessors and the project supervisor. Additionally, the FSS had been previously utilised in clinical practice, as it is straight forward and an easy-to-use screening tool, and was known to the principal investigator. The data collection sheet was independently developed based on clinical experience and a review of current literature. It was subsequently discussed and reviewed with a panel that included the project supervisor and assessors.

Ethical clearance was first sought and obtained from the Human Research Ethics Committee at the University of Witwatersrand. Following this approval, an application for ethical clearance was submitted to the private hospital group and the physiotherapy practice based in the PICU. Following the receipt of ethical and hospital approval, data collection was conducted from May 2023 – December 2023. Participants who met the inclusion criteria were identified, on admission to the PICU, and consent for the study was sought from the parents or primary caregivers of the paediatric patients. This consent process was facilitated by an independent third party, either a nurse within the unit or an allied healthcare provider, such as the unit-based dietician. Caregivers received an information leaflet about the study and were given the opportunity to ask questions. Upon obtaining consent, all relevant demographic and medical information was recorded on the demographic and clinical data sheet. When the paediatric participant was ready for discharge from the PICU, the principal investigator was notified the day before or on the day of discharge. Subsequently, the FSS assessment was conducted with the participant. The assessment took place on the day of discharge and required approximately 10 minutes to complete, including scoring and caregiver feedback.

Parents or primary caregivers were present during the assessment as well as the independent third party, either a nurse or the dietician in the unit. All FSS assessments were completed by the principal investigator so that scoring was consistent throughout.

The results of the demographic data and FSS are highlighted in the next chapter.

3.5 Data Analysis

Patient characteristics and conditions provided nominal descriptive data. Therefore, statistical measures such as frequency distributions, standard deviations and medians were used to visualise the data set, in order to understand normality, dispersions and correlations.

The only demographic and clinical characteristics that were used in the data analysis, were age, sex, LOS, duration of ventilation, primary admission diagnosis and previous admission to

PICU. This data was captured, however, other demographic information on the data collection sheet, such as pre-admission functional status was not documented in as much detail and with too much variability due to relying on caregiver feedback.

With regards to the information obtained from the FSS, this was an ordinal data set. Frequency distribution and percentages were used to recognise trends. Correlation analysis was conducted to examine the relationships between key variables within the dataset. The analysis was performed using MATLAB R2024a which included the Machine Learning Toolbox. A senior data scientist from a software consultancy firm voluntarily assisted with the statistical analysis. The analysis focused on identifying any significant correlations between demographics, the FSS, and other variables recorded in the study to determine the relevance of the FSS as a measure.

Table 3.1: Objective breakdown for statistical analysis

OBJECTIVE	TYPE OF DATA	STATISTICAL TESTS
1. Patient Characteristics and conditions	Nominal descriptive data (Independent variable)	Frequency distribution Mean (SD) and medians (IQR)
2. Functional Status Scale scores	Ordinal data (Dependent variable)	Frequency distribution Percentages Mean (SD) and medians (IQR)
3. Correlation between the independent and dependent variables	Nominal and ordinal data	Correlation analysis Spearman Correlation coefficient

Spearman's correlation coefficient is used to assess the strength and direction of the relationship between two variables, measuring this relationship on a scale without dimensional constraints (Ali Abd AlHameed, 2022). It indicates how changes in one variable are associated with changes in another, whether through an increase or a decrease. The coefficient reflects whether the relationship is positive or negative, and can vary in strength from weak to strong. The guidelines provided in Table 3.2 were used to determine the strength of correlation between variables (Ali Abd AlHameed, 2022).

Table 3.2: Spearman's Correlation Coefficient

Value of Correlation Coefficient	Relationship
+1	Completely positive correlation
From 0.70-0.99	Strong positive correlation
From 0.50-0.69	Average positive correlation
From 0.01-0.49	Weak positive correlation
0	(No correlation)

(Ali Abd AlHameed, 2022)

3.6 Ethical Considerations

Approval was obtained from the Human Research Ethics Committee at the University of the Witwatersrand, 09/12/2022 (M220824, APPENDIX III: WITS ethics approval).

Approval from the Private Hospital Group, 31/03/2023 (APPENDIX IV: Private hospital group approval) as well as the physiotherapy practice Joffe and Rosie Physiotherapy, 1/12/2022 (APPENDIX V: Joffe and Rosie Physiotherapy Approval).

Written informed consent from the parents or legal guardian for all paediatric patients participating in the study and assent from children over seven (APPENDIX VI: Participant consent form; APPENDIX VII: Participant assent form) were obtained. As this is a vulnerable population consent was obtained by an independent third party who was known to the parents.

Record keeping of all assessments done, including all demographic information and the information obtained using the FSS tool, done in accordance with the POPI Act, to maintain confidentiality of all medical information

Data obtained have been stored and saved on an encrypted external data drive that will only be accessible by the principal investigator and the supervisor to this research. Data will be stored for two years if published and for six years if not published whereafter it will be deleted

All results and data analysis from this study will be presented in the next chapter.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter describes the data collected from a private hospital paediatric intensive care unit over a period of seven months. The data is represented with tables, figures, and correlations. This statistical analysis included only those that completed the FSS on discharge from PICU.

During the data collection period 30 participants consented to participate in the study and 28 participants were able to complete the study.

The total number of admissions to the PICU from May – December 2023 was 143 patients. The total number that met the inclusion criteria (admitted for longer than 24 hours and within the age range stipulated) was 128 patients (89.5%). The total number of participants, who met the inclusion criteria that were contacted to participate was 76 (59%). There were more challenges around recruiting than expected, such as caregivers not available, due to high number of inter - provincial and international patients admitted whose families could not travel with the patient, transfers out of the unit and deaths in the unit before recruiting could take place. There were also 19 participants whose primary caregivers did not consent to participate in the study after being contacted. The final number of participants that consented to participate in the study was 30 (23.4%). The challenges around obtaining consent are further discussed in chapter 5. A sample of 30 reduces the confidence interval level of the study to 70%.

4.2 Demographic Data Description

This describes the distribution of the sex and age of the participants assessed.

Thirty parents or primary caregivers gave consent for their children to be included in the study. One child passed away prior to completing the study and one was not able to complete the FSS during the data collection period, as they had not yet been discharged from the PICU due to long term admission complications. Therefore, these two participants were excluded from the final statistical analysis. The total cohort that completed the study was 28 participants.

4.2.1 Sex Distribution Data

In the cohort of 28 participants that completed the FSS assessment, a total of 14 (50%) were males and 14 (50%) were females.

4.2.2 Age Distribution Data

The age range of the total cohort (n=28) was 2 to 144 months old (12 years old). As shown in the boxplot (Figure 4.1: Boxplot for participant Age (months) the data is skewed inferiorly, indicating that a larger portion of the cohort was made up of younger participants but with a larger spread. Half (50%) of the cohort were between 2-24 months old and 50% of the cohort were between 24 -144 months old. The median (IQR) age was 24 months (14-72).

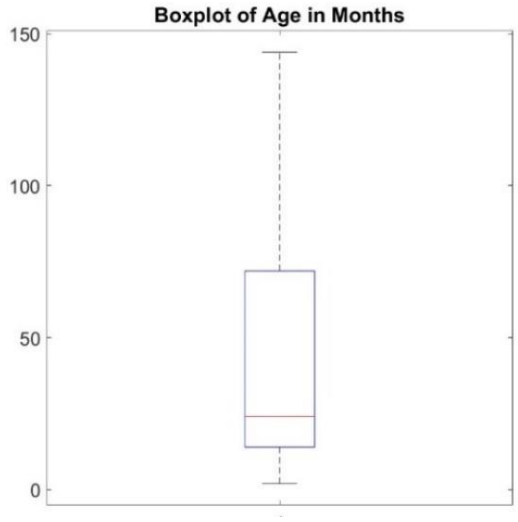

Figure 4.1: Boxplot for participant Age (months)

n =28

4.3 Primary Diagnosis

There was a large range of diagnoses from the cohort (Figure 4.2: Admitting diagnoses). Most common: Six (21.4%) acute respiratory failure; five (18%) burns, four (14.3%) acute respiratory distress syndrome; three (11%) drowning and non-fatal submersion.

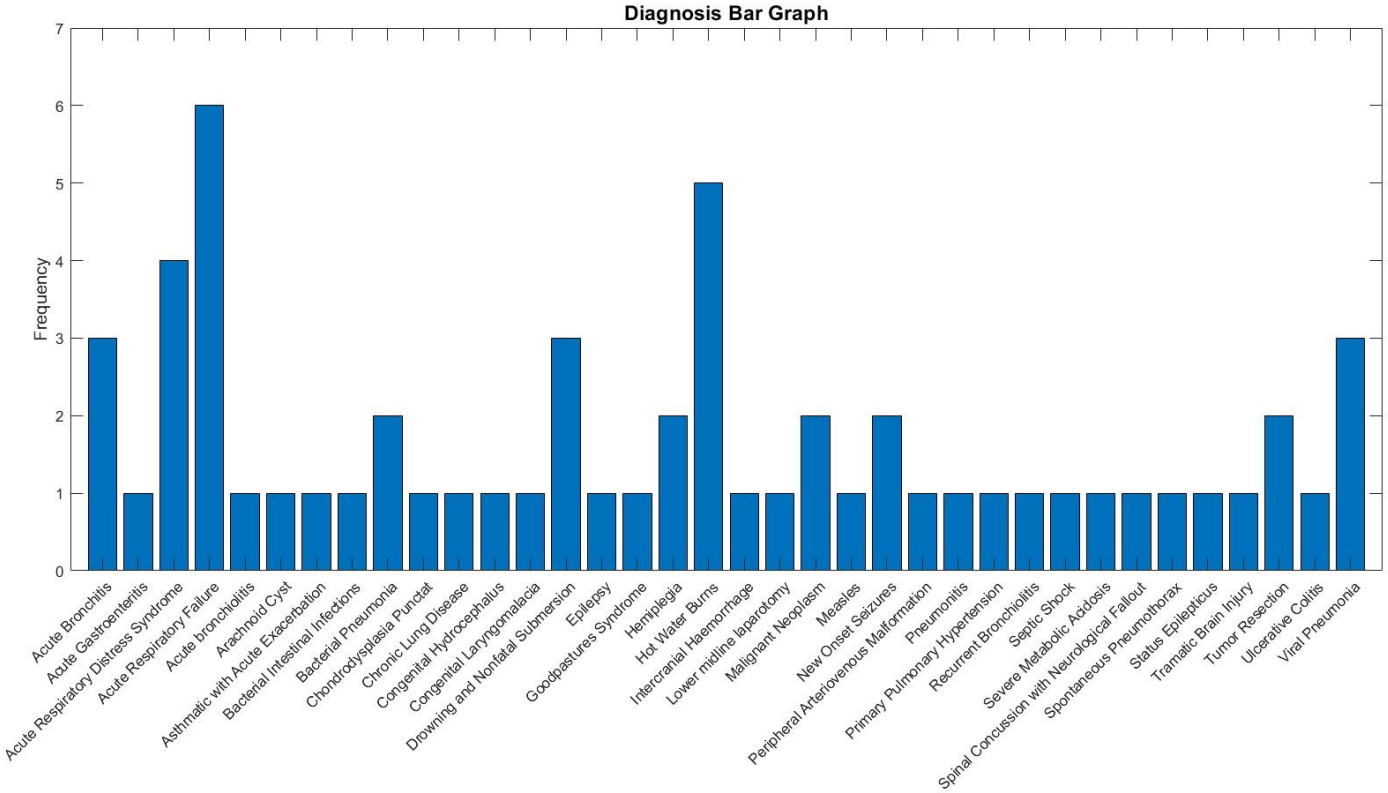

Figure 4.2: Admitting diagnoses (n=28)

The main primary diagnoses can be described in three main groups: Respiratory (n=11; 39.3%), neurological (n =11; 39.3%) and surgical (n=6; 21.5%). Males had a higher ratio of respiratory admissions (2:1), males and females had an equal ratio of neurological admissions (1:1), and within the surgical category, females presented with more burns (4:1).

4.4 Previously Admitted to PICU

In the cohort of 28 participants, 18 (64%) had not been admitted to a PICU before, and 10 (36%) had been previously admitted to PICU (nine during a previous hospital admission and one during the same hospital admission).

4.5 Length of Stay (LOS)

In this cohort (n=28), eight (28.5%) participants had a short LOS of between three to 10 days and seventeen participants (60.5%) were discharged within 30 days, this was the most common

frequency group. The median (IQR) LOS was 21 days (8-32). Two (7%) participants had a long duration of stay 70 -80 days, skewing the data and one participant (3.65) had a LOS of 101 days (Figure 4.3: Distribution of Length of Stay).

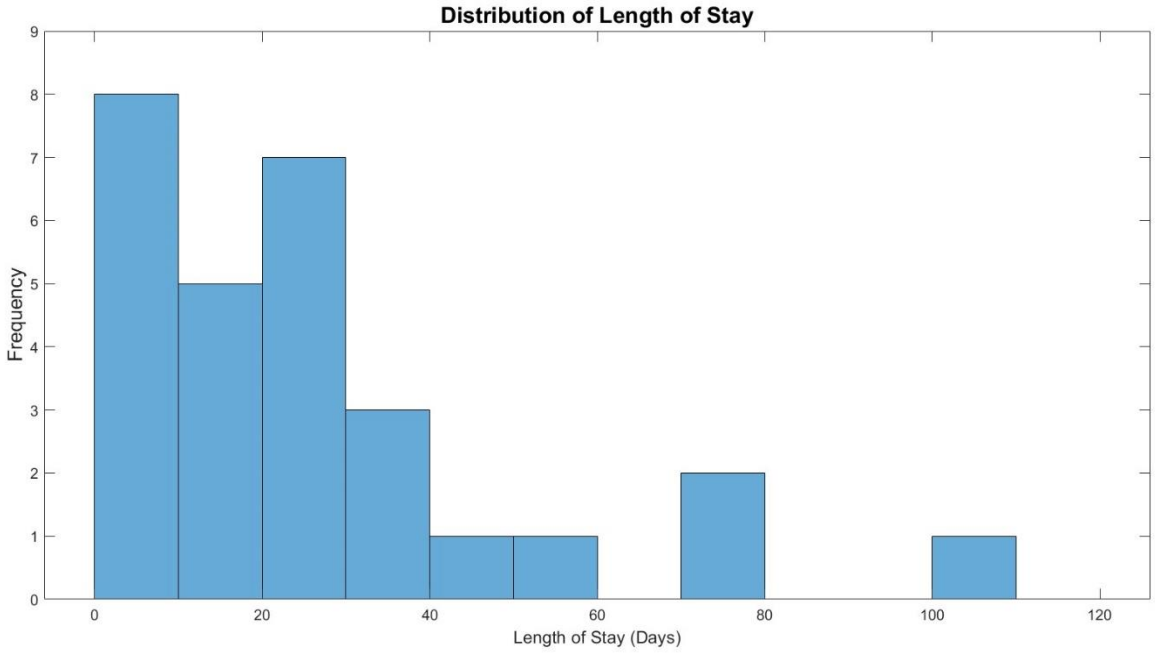

Figure 4.3: Distribution of Length of Stay n=28

The following box plot graphs, describes 100% of the cohort (n=28). Figure 4.4: a*) All participants n=28 b)* looks at the total group. Within the data set, 93% of the data is distributed in the range of one to 50 days and 7% of the data were outliers.

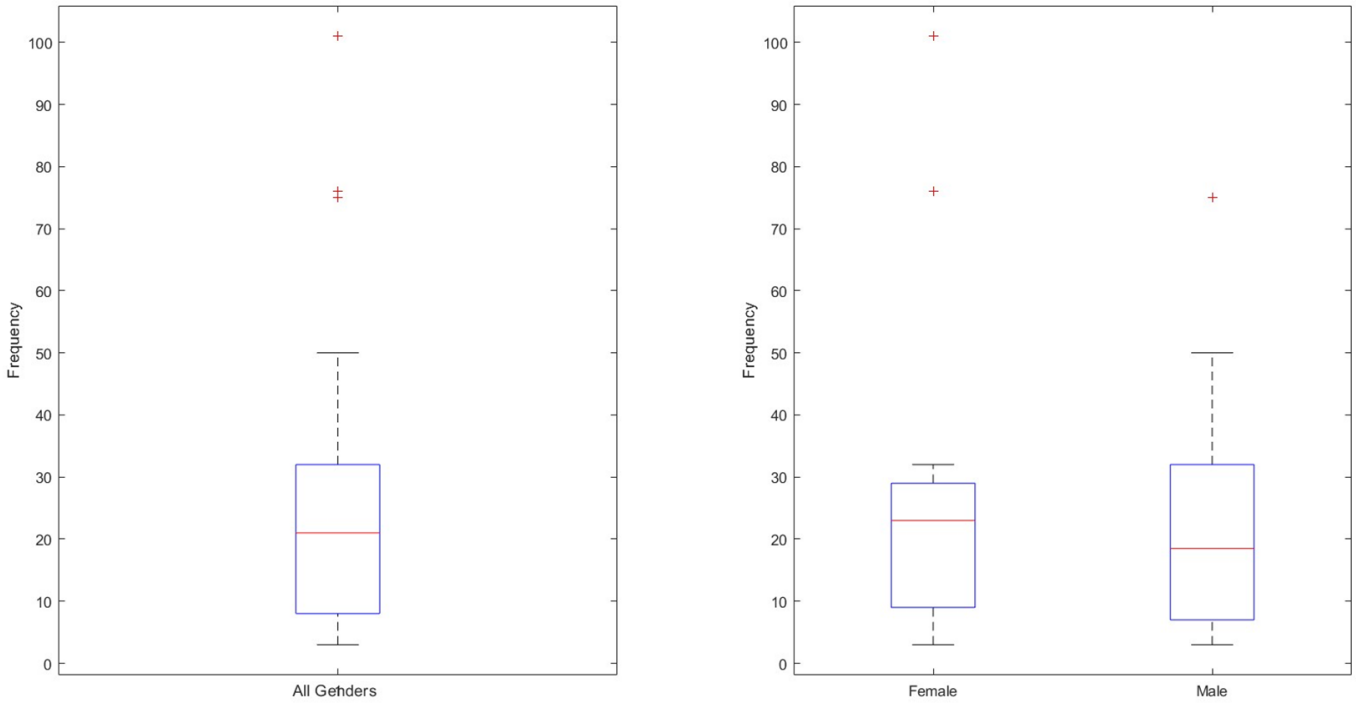

Figure 4.4: a) All participants n=28 b) Female vs male participants n=28

Figure 4.4: a) All participants n=28 b) describes the range of LOS between female and male participants. Males had a larger interquartile range. The median (IQR) for this group was 18 days (7-32). Females presented with a higher median (IQR) of 25 days (9-29). Both male and female groups had one outlier.

The scatter plot (Figure 4.5: Scatter plot of age vs LOS) looks at correlations between age and LOS. It presents with a cluster of participants between 0- 60 months and 0-25 days however this excludes a larger portion of the dataset, therefore no noticeable correlation (R= -0.096) between age (months) and LOS (days).

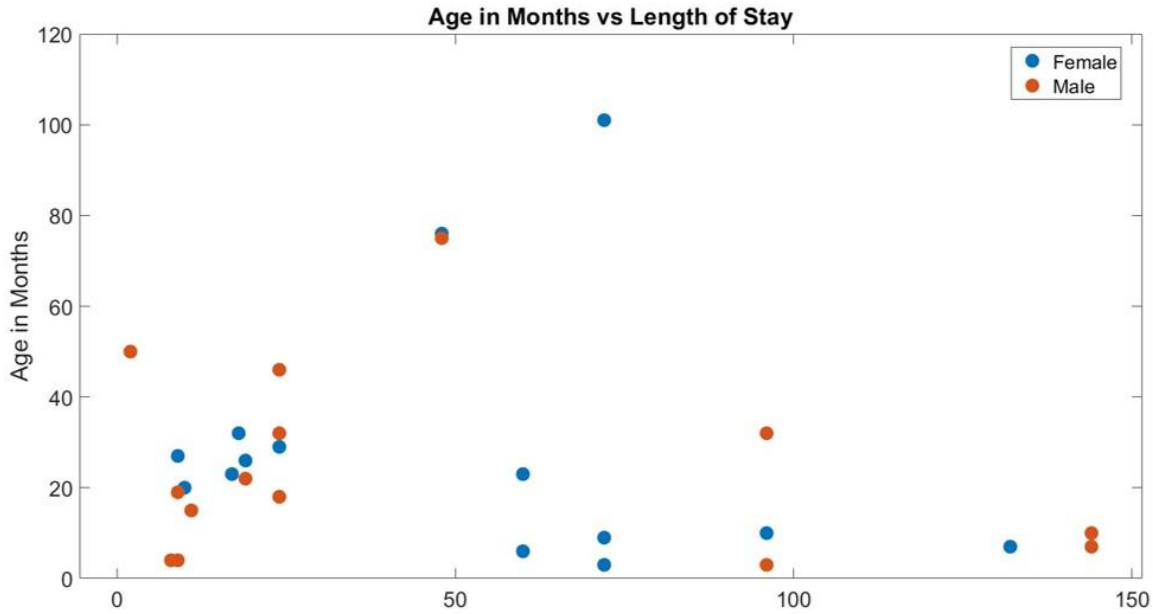

Figure 4.5: Scatter plot of age vs LOS (n=28)

4.5.1 Duration of Mechanical Ventilation

The statistical measures are not a true representation of the cohort due to the reduced sample size of patients who experienced ventilation. The evident outlier of this cohort reached 50 days of mechanical ventilation from a complex burns diagnosis. Twelve patients (n=28;43%) received mechanical ventilation within the cohort. The median was 0 (0-9) days of ventilation.

4.6 Functional Status Scale Scores

This sub section describes the FFS scores captured (Table 4.1: FSS scores of the total cohort) and the correlations found between different variables.

The highest score was 12, and both the mean (SD=1.61) and median (IQR) score was 8 (6.75-9.00) and the range was 6 -12. Out of the cohort (n=28), six (21.4%) participants had normal scores (6/30), scoring the lowest (1) in each domain.

Table 4.1: FSS scores of the total cohort n = 28

Patient Number	Mental Status	Sensory	Communication	Motor Function	Feeding	Respiratory	Total Score
1	1	1	1	2	1	2	8
2	1	1	1	2	1	1	7
3	2	1	1	2	1	1	8
4	2	1	1	2	1	1	8
5	2	1	1	2	1	2	9
6	2	1	1	2	1	1	8
7	1	1	1	2	1	1	7
8	1	1	1	1	1	1	6
9	1	1	1	3	1	1	8
10	1	1	1	1	1	1	6
11	1	1	1	2	1	1	7
12	2	1	1	3	1	1	9
13	2	1	2	1	1	2	9
14	1	1	1	2	1	2	8
15	1	1	1	1	1	1	6
16	1	1	1	2	2	1	8
17	2	1	2	2	1	1	9
18	2	1	1	2	1	1	8
19	2	1	2	2	1	2	10
20	1	1	1	1	1	1	6
21	1	1	1	1	1	1	6
22	1	1	1	1	1	1	6
24	2	1	1	3	1	2	10
25	2	1	1	3	2	3	12
26	2	1	1	2	1	2	9
27	2	1	2	2	2	2	11
28	2	1	2	2	1	1	9
29	1	1	1	1	1	1	6
Mean (SD)	1.5 (0.51)	1 (0)	1.18 (0.39)	1.86 (0.65)	1.11 (0.32)	1.36 (0.56)	8 (1.61)
Median (IQR)	1.5 (1-2)	1 (1-1)	1 (1-1)	2 (1-2)	1 (1-1)	1 (1-2)	8 (6.75-9.00)

Table 4.1 shows that six (21.4%) participants had a total score of '6' indicating a 'normal' FSS score and no dysfunction at the time of discharge from PICU. A further ten (36%) participants had a score of more than or equal to nine indicating 'mild' to 'moderate' dysfunction. The motor function (mean score = 1.86; SD = 0.65) and mental status (mean score = 1.5; SD = 0.51) had higher mean and median scores, indicating more scores of two or more compared to the other domains. In the mental status domain, 14 (50%) participants had a score of '2'. In the communication domain 5 (18%) had a score of '2'. In the motor function domain 16 (57%) had a score of '2' and 3 (14%) had a score of '3'. In the feeding domain 3 (11%) had a score of '2' and in the respiratory function domain 8 (29%) had a score of '2' and 1 had a score of '3'.

The sensory domain has been excluded from all correlations results since all participants scored a one therefore it has no statistical significance in the calculations of the Spearman's correlation coefficient. Participants 23 and 30 were excluded as they did not complete the study.

4.7 Spearman Correlation Coefficient

Based on bio-demographic characteristics and the FFS scores of the participants the following correlations were identified with statistical relevance.

4.7.1 All Participants

Table 4.2: Correlation of all participants shows the significant correlations between all participants, FSS scores and demographic variables (APPENDIX VIII: Correlation of all participants). Notably, mental status and duration of ventilation showed the strongest correlation (0.74), with a P value of < 0.01 there is a strong statistical significance.

Table 4.2: Correlation of all participants n = 28

Variable 1	Variable 2	Spearman Correlation Coefficient	P Value	Correlation Interpretation
Duration of Ventilation	Length of Stay	0.50	0.01	Moderate Positive
Motor Function	Length of Stay	0.60	0.0007	Moderate Positive
Mental Status	Duration of Ventilation	0.74	0.0000066	Strong Positive
Respiratory	Duration of Ventilation	0.61	0.0005	Moderate Positive

4.7.2 Male Participants

Table 4.3 shows the significant correlations between all male participants, FSS scores and demographic variables (APPENDIX IX: Correlation of all male participants). Among male participants, mental status and duration of ventilation showed the strongest correlation (0.72). The P value of 0.004 shows there is a strong statistical significance.

Table 4.3: Correlation of all male participants n = 14

Variable 1	Variable 2	Spearman Correlation Coefficient	P Value	Correlation Interpretation
Mental status	Length of Stay	0.52	0.06	Moderate Positive
Feeding	Length of Stay	0.51	0.06	Moderate Positive
Mental status	Duration of Ventilation	0.72	0.004	Strong Positive
Communication	Duration of Ventilation	0.62	0.02	Moderate Positive

4.7.3 Female Participants

Table 4.4 shows the significant correlations between all female participants, FSS scores and demographic variables (APPENDIX X: Correlation of all female participants). Among female participants, mental status and duration of ventilation (0.77); motor function and length of stay (0.88); and respiratory function and duration of ventilation (0.83) showed the strongest correlations. The respective P values all showed statistical significance.

Table 4.4: Correlation of all female participants n = 14

Variable 1	Variable 2	Spearman Correlation Coefficient	P Value	Correlation Interpretation
Duration of Ventilation	Length of Stay	0.51	0.06	Moderate Positive
Mental Status	Length of Stay	0.54	0.05	Moderate Positive
Mental Status	Duration of Ventilation	0.77	0.001	Strong Positive
Motor Function	Age	-0.57	0.03	Moderate Negative
Motor Function	Length of Stay	0.88	0.00003	Strong positive
Respiratory	Duration of Ventilation	0.83	0.0003	Strong Positive

4.7.4 Long Stay Participants (greater than 30 days)

Table 4.5 shows the significant correlations between all participants, FSS scores and demographic variables (APPENDIX XI: Correlation of all long stay participants). Among long stay participants, respiratory function and duration of ventilation (0.94) showed the strongest correlation with a corresponding P value of 0.01 showing statistical significance.

Table 4.5: Correlation of long stay participants n = 8

Variable 1	Variable 2	Spearman Correlation Coefficient	P Value	Correlation Interpretation
Communication	Length of Stay	-0.65	0.21	Moderate Negative
Motor function	Length of Stay	0.60	0.093	Moderate Positive
Feeding	Age	-0.57	0.21	Moderate Negative
Respiratory	Duration of Ventilation	0.94	0.01	Strong Positive
Mental status	Duration of Ventilation	0.65	0.21	Moderate Positive
Motor function	Communication	0.62	0.29	Moderate Positive

4.7.5 Medium Stay Participants (14 – 30 days)

Table 4.6 shows the significant correlation between all participants, FSS scores and demographic variables (APPENDIX XII: Correlation of all medium stay participants). Among medium stay participants, mental status and duration of ventilation showed the strongest correlation (0.71). The corresponding P value was 0.023, strong statistical significance.

Table 4.6: Correlation of medium stay participants n = 10

Variable 1	Variable 2	Spearman Correlation Coefficient	P Value	Correlation Interpretation
Mental status	Duration of Ventilation	0.71	0.023	Strong Positive
Communication	Duration of Ventilation	0.51	0.13	Moderate Positive
Feeding	Duration of Ventilation	0.54	0.11	Moderate Positive

4.7.6 Short Stay Participants (less than 14 days)

Table 4.7 shows the significant correlation between all participants, FSS scores and demographic variables (APPENDIX XIII: Correlation of all short stay participants). Among short stay participants, mental status and duration of ventilation showed the strongest correlation (0.74). However, the P value was high (0.76) showing weak/poor significance.

Table 4.7: Correlation of short stay participants n = 10

Variable 1	Variable 2	Spearman Correlation Coefficient	P Value	Correlation Interpretation
Age	Length of Stay	0.51	0.13	Moderate Positive
Respiratory	Age	-0.53	0.12	Moderate Negative
Mental status	Duration of Ventilation	0.74	0.76	Strong Positive
Respiratory	Duration of Ventilation	0.61	0.76	Moderate Positive

4.7.7 Diagnosis

Due to the small sample and variation of diagnoses, correlations could not be tested for this cohort.

4.7.8 Conclusion

The study aimed to describe the demographic and clinical characteristics of paediatric patients admitted to a specific PICU in Gauteng, South Africa, and to evaluate their functional outcomes at discharge. The results revealed an equal distribution of male and female participants, with a median (IQR) age of 24 months (14-72), indicating a younger demographic profile. The primary reasons for admission were respiratory and neurological conditions, each accounting for 39.3% of the cases. Most participants (60.5%) were discharged from the PICU within 30 days, with a median (IQR) LOS of 21 days (8-32).

In assessing functional outcomes using the FSS, the study found that the highest total FSS score was 12, with a mean (SD) and median (IQR) score was 8 (SD = 1.61; IQR = 6.75-9.00) indicating mild to moderate dysfunction. The motor function and mental status domains had the highest scores, suggesting these areas were the most affected at discharge.

The investigation into the associations between clinical variables and functional outcomes showed notable correlations. An average positive relationship was observed between duration of ventilation and LOS ($r = 0.50$; $p= 0.01$), as well as between motor function and LOS ($r = 0.60$; $p = 0.0007$). A strong positive correlation was found between mental status and duration of ventilation ($r = 0.74$; $p = < 0.01$), indicating that the longer ventilation periods were associated with worse mental status outcomes on the FSS. These findings underscore the impact of prolonged ventilation on mental and functional health at the time of PICU discharge.

The results from this study will be further discussed in chapter five.

CHAPTER 5: DISCUSSION

5.1 Introduction

The study objectives were to describe demographic (age, sex, LOS, duration of ventilation) and clinical (admission diagnosis, previous PICU admissions) data. Secondly to establish function at discharge from PICU using the FSS and the final objective was to determine the correlations between these variables.

The expected cohort of 60 participants was not attainable. Although 76 participants we contacted to participate in this study only 30 gave consent and a final number of 28 participants were able to complete the study. This vulnerable population and the timing of gaining consent and assessment is important to consider. Any PICU admission is a stressful life event and often research is not the priority of parents and caregivers. This was a very emotional time for the participants and their families, and when approached shortly after admission, if the patient was still requiring mechanical ventilation or critically ill, they did not want to consider participating. The best time to recruit participants proved to be when patients were stabilised, once families had received more counselling from the medical staff around the PICU procedures, the patients had been extubated, and there was more reassurance that the overall patient condition was improving. Offering thorough explanations of the research process, such as costs involved, that the assessment will not prolong a child's PICU admission, that the assessment is non-invasive, and providing opportunity for the caregivers to ask questions were essential to ensure buy in.

5.2 Demographics

5.2.1 Sex

This study showed an equal ratio (1:1) of male (50%) and female (50%) participants. Compared to the international and national literature this was different, which reported that male admissions are predominately higher than females. In Australia, a population-based study reported on over 6000 paediatric patients from multiple public hospitals with a PICU. The number of male patients admitted was a total of 55.7%. The European studies included a cross-sectional study conducted in Portugal with a moderate sample size of 50 patients that reported 60% of the cohort was male (Pereira et al., 2017) and another descriptive, retrospective, observational analysis conducted at a tertiary hospital in Spain, found that 61.3% were males and 38.7% were females (Madurga-Revilla et al., 2020). In South America a cross-cultural adaption study conducted in Brazil, also looked at a large sample group of 314 patients was predominantly male at 54.1% (Pereira et al., 2019).

Within in Africa two studies reported similar findings. A cross sectional study in an Egyptian PICU, from a tertiary university paediatric hospital, that reviewed a total cohort of 50 patients were male admissions made up 54% of the total cohort (Zaitoun et al., 2022). An Ethiopian retrospective observational study conducted at a University Hospital PICU, reported on a large group of 305 patients and the male to female ratio was 1.3:1 (males 57.4%). (Ahmed, 2022).

Locally in South Africa, two-point prevalence studies reviewed large samples of 354 and 310 patients respectively. The research conducted in the PICU of RCWMCH in Cape Town, South Africa had 57.6% male PICU admissions (Lozano Ray et al., 2023). The second study based across four provinces, in public hospitals, in South Africa, males made up 53.5% of the group (Morrow et al., 2023).

Comparatively, this study's sample size was smaller than those documented in the literature and may account for the difference. It is also important to note that this study was conducted in a private hospital, unlike the literature, where all studies were conducted in public facilities, and further research would be required to explore differences between the two different types of hospital settings.

5.2.2 Age

Of the international studies reviewed, there were variations on the median age of admission. However, the majority of all admissions were under five years old (Ibiebele et al., 2018; Madurga-Revilla et al., 2020; Penela-Sánchez et al., 2021; Pereira et al., 2017; Pollack et al., 2014). These studies were conducted across Australia, Europe and South America and the United States.

The age range of this study was between 2-144 months old (12 years) and 50% of the cohort were between 2-24 months old, showing a younger admission demographic. The median age was 24 months old (two years old) and this is similar to Pereira et al., (2017) cross-cultural adaption study conducted in Brazil - mean age was also 24 months old.

It is known that children under five, especially those with respiratory conditions such as LRTI, are more likely to have hospital admissions (Liu et al., 2015). Based on clinical experience the period of data collection took place over winter in South Africa, which is also RSV/flu and burns season. This correlates as to why the demographic of this study was much younger, as children under two are more susceptible to contracting respiratory infections and sustaining burns, and both are listed as primary admitting diagnosis for this cohort.

Interestingly, both African studies had higher admitting age ranges, with a mean age 6.08 years in Egypt (Zaitoun et al., 2022) and an average of 10 -14 years in Ethiopia (Ahmed, 2022). This older demographic profile, is possibly related to the region in North/East Africa, where access to health care is less accessible for younger children, lack of resources, economic status and high mortality rates of children under five.

However, the other South African studies reviewed, reported an overall younger median age group. Firstly, Kruger. (2014), described that 83% of patients admitted were younger than 12 months old and had a median age of 3.7 months, this was a younger population compared to this study, but both had similar age ranges (Kruger, 2014). Secondly, the median ages of Lozano Ray et al. (2023), and Morrow et al. (2023), were 10.1 and 9.8 months respectively. All three of these studies were conducted in the Western Cape, which could account for the difference compared to this study based in Gauteng. Early identification protocols may be different in the Western Cape, and would require further investigation. The public verses private hospital setting is also a consideration here as well as the small sample size of this study.

5.2.3 Primary admitting diagnosis

Respiratory dysfunction was repeatedly reported as a common reason for admission into a PICU in the literature reviewed (Ahmed, 2022; Lozano Ray et al., 2023; Morrow et al., 2023; Penela-Sánchez et al., 2021; Pereira et al., 2019, 2017; Pollack et al., 2014). However, there were a wide range of primary diagnosis documented, including neurological, cardiovascular and emergency admissions.

The study conducted in the United States reported that the main reasons for admission were respiratory dysfunction (29.9%), cardiovascular (24.9%) and neurological (18.4%) (Pollack et al., 2014). The South American studies reported the main causes for admission were; respiratory failure (40%), postoperative recovery (16%), sepsis and shock (12%) and liver failure (12%) (Pereira et al., 2017); and cardiovascular (37.3%), neurological (9.9%) and respiratory conditions (8.6%) (Pereira et al., 2019). The study in Barcelona, Spain and reported that respiratory disease was the most common reason for admission (50.4%), followed by infectious disease (27.5%) and gastrointestinal disease (8%) (Penela-Sánchez et al., 2021). In Ethiopia, the primary reason for admission were identified as neurological (23.6%), respiratory (19%) and cardiac (11.8%) (Ahmed, 2022). In the South African context, PICU admissions were for respiratory disease was 13.3%, cardiac 25.4%, trauma 12.7%,

neurology/neurosurgical 17.2% and general surgery 14.4% (Lozano Ray et al., 2023). From the multisite study, mostly emergency admissions (78.4%) were reported followed by respiratory (39.9%) and cardiac (17%) (Morrow et al., 2023).

All the literature, demonstrates the diverse nature of admitting diagnosis within a PICU setting. This is not unexpected, and consideration needs to be given to the speciality of the specific PICU, for example if it is a cardiovascular unit or a trauma unit, does it have specialist intensivists and who is involved in the multidisciplinary team. The nature of any PICU, is to manage and treat a variety of patients. South African studies, such as those by Morrow et al. (2023), highlight a higher percentage of emergency admissions (74.4%). Despite South Africa's classification as an upper middle-income country, it is crucial to recognize that the majority of children managed in most PICUs are from highly impoverished backgrounds, and this socioeconomic disparity likely impacts healthcare outcomes and access to resources for this vulnerable population (Lozano Ray et al., 2023), resulting in more emergency admissions.

Similar to all the literature reviewed, this study had a large variety of diagnoses. The primary admission diagnosis was recorded and split into three main categories based on similarities, namely, respiratory, neurological and surgical cases. In line with the literature, respiratory (39.3%) and neurological (39.3%) conditions were the primary reason for admission in this study. This is expected due to the time of data collection, during the winter months in South Africa, during RSV and flu season resulting in a higher prevalence of respiratory admissions. Notably, the data collection period also fell over public and private school holidays, which resulted in more admissions that were neurological in nature, such as near drownings, or surgical admissions, such as burns, as children were spending more time at home and therefore more prone to injury. Males had a higher ratio of respiratory admissions (2:1), males and females had an equal ratio of neurological admissions (1:1), and within the surgical category, females presented with more burns (4:1). The global literature reviewed did not report on male and female admitting trends, and this would be interesting to further investigate and compare.

5.2.4 Previous Admissions

In this study 18 participants (64%) had not been admitted to a PICU before, and 10 (36%) had been previously admitted, only one participant was readmitted to PICU during the same hospital admission due to a deterioration in condition.

The population-based study that took place in New South Wales, Australia, looked at data from 150 public hospitals over three years. The study population included all new paediatric hospital

admissions that included PICU time. Of the 6124 children reported on in the study, 85.6% had 1 PICU admission and 10% had 2 and 4.3% had 3 or more PICU admissions. This is difficult to compare to the current study, as those who were previously admitted, only recorded as 'yes/no' and not, how many times was a patient readmitted to PICU. Therefore, this is a consideration for future research.

Not all paediatric patients admitted to a PICU have healthy or typically developing pre-admission status or function. With the increase of PICU survivors, there is now a population of paediatric patients living with complex health conditions putting them at risk for PICU re-admissions (Penela-Sánchez et al., 2021). Based on clinical experience, re-admissions are often as a result of children with complex medical needs, ex-premature babies, children with chronic lung disease, epilepsy, hydrocephalus, cerebral palsy, children living with feeding tubes and tracheostomies. They appear to be at higher risk for recurrent infections that require hospital and PICU admissions.

In the last decade children admitted with significant underlying chronic health conditions have doubled and PICU re-admission rates have tripled (Choong et al., 2015). This study did not record pre-morbid health conditions, and this should be a consideration for future research and its impact on readmission rates, as well as what those rates are in South Africa.

5.2.5 Length of Stay

In this study 60.5 % of participants were discharged from PICU within 30 days. The median was 21 days. There was a large range of 0 – 101 days due to an outlier who had a complex and prolonged admission. This is different to the international literature, which reported a median LOS of between 2 – 5 days (Ibiebele et al., 2018; Madurga-Revilla et al., 2020; Penela-Sánchez et al., 2021; Pereira et al., 2017). Similarly, the African studies reviewed also had a median LOS of between 2 -7 days (Ahmed, 2022; Zaitoun et al., 2022). The South African literature was also well correlated to international reports. Median LOS was described as 5 days (Lozano Ray et al., 2023) and 6 days (Morrow et al., 2023).

This study's median of 21 days is three times that of the literature, and this is strikingly different. Different protocols with regards to ventilation, sedation and implementation of early intervention in different PICUs could account for this variation. This is important to note and would require further investigation. Future studies conducted in South Africa should include PICUs at public hospitals and compare the length of stay to that in private facilities such as the one in this study. The literature reviewed for this study was all conducted through public

institutions, so a difference has not been noted in the available research. This would be of value to paediatric critical care research, to determine the level of services received, resource availability and PICU discharge protocols because the standard of care should be the same for all children within the health care system.

The difference could also be related to higher overall hospital admissions, as public hospitals often service larger catchment areas and so the demand for beds is higher. Based on experience in the private sector, PICU is often treated as a high care unit as well, and patients can be discharged home straight from the PICU, without step down to a general paediatric ward. This would also account for this study's long LOS.

It is important to note that a longer PICU LOS (more than 2.5 days) is associated with poorer functional outcomes (Royer and Busari, 2021).

5.2.6 Duration of Mechanical Ventilation

Twelve patients in this cohort (n = 28;43%) required mechanical ventilation. The median (IQR) was 0 (0-9) days of ventilation. Given the small sample size and the presence of a significant outlier, these results should be interpreted with caution. Additionally, more detailed data on ventilator types (non-invasive vs invasive) should have been collected. In contrast two South African studies reported a higher reliance on invasive mechanical ventilation (62.9%) (Morrow et al., 2023), while (Corten and Morrow, 2020), noted that 17% of patients received either non-invasive or invasive mechanical ventilation with a median (IQR) duration of ventilator support was 3 (2-5) days.

There are notable differences in the reported data across studies, which warrant further investigation. Factors such as distinction between public and private health care institutions and unit specific ventilation and weaning protocols could contribute to these discrepancies. Understanding these variations is crucial for developing standardise approaches to mechanical ventilation and optimising patient outcomes.

5.3 FSS Scoring

The FSS was quick and efficient, as it took approximately two minutes to administer the tool to all the participants as described in the literature. As an observational scoring tool, the assessment time was minimal and the six domains were appropriate to evaluate, as they were closely linked to ADLs.

In this study, the highest total FSS score was 12, with mean (SD) and median (IQR) score was 8 (SD = 1.61; IQR = 6.75-9.00). The highest scores were in the motor function and mental status domains indicating mild (2) to moderate (3) dysfunction. This cohort shows that six (21.4%) participants had a total score of '6' indicating a 'normal' FSS score and no dysfunction at the time of discharge from PICU. A further ten (36%) participants had a score of more than or equal to nine indicating 'mild' to 'moderate' dysfunction. The motor function (mean score = 1.86; SD = 0.65) and mental status (mean score = 1.5; SD = 0.51) had higher mean and median scores, indicating more scores of two or more compared to the other domains. In the mental status domain, 14 (50%) participants had a score of '2'. In the communication domain 5 (18%) had a score of '2'. In the motor function domain 16 (57%) had a score of '2' and 3 (14%) had a score of '3'. In the feeding domain 3 (11%) had a score of '2' and in the respiratory function domain 8 (29%) had a score of '2' and 1 had a score of '3'. These are the identified high-risk participants from this study, for medium-to-long term impairments.

This highlights that in this study if a child were to score highly in a FSS domain it would most likely be in mental status or motor function. Although the standard deviations for all FSS domains are relatively low, the motor function standard deviation (0.65) was the highest in the group, highlighting that the results of these scores had the most variable spread. None of the participants scored higher than '3' in any of the domains. This difference could be associated with a longer average LOS in this study.

These low mean scores also identifies that the FSS is rigid in its scoring metrics, with quite broad differences between each dysfunction level, and not accounting for smaller functional changes. The 'Sensory' domain was challenging to score due to the broad explanations between each score, especially between normal and mild dysfunction as described in the score sheet (APPENDIX I: The FSS) and so the total cohort of 28 all scored '1' – normal function. This challenge has not been described elsewhere in the literature and warrants further investigation.

Comparatively, in the cross-sectional study conducted in Portugal, participant FSS scores had a median score of 11.5 and range from 7-15. Highest scores were in motor and feeding domains. The majority of this cohort, 40% had moderate dysfunction and 30% normal function, similar to this study, with no statistical difference between males and females (Pereira et al., 2017).

Literature tells us that motor function is one of the most affected areas of function (Herrup et al., 2017; Pereira et al., 2017) and that cognitive function is also widely impacted (Madurski et al., 2018) from surviving paediatric critical illness. Furthermore, this correlates to this study,

where motor function and mental status are the areas of function most likely to be affected. Given what we know about PICS-P this is not unexpected, due to PICU acquired weakness from prolonged admissions, less mobilisation and the impact on mental status from complications of extended mechanical ventilation and sedative use.

Interestingly, there may also be a correlation to consider between the longer LOS and lower mean score of the FSS within this study. Possibly, due to the average LOS of 21 days in this study (which is longer than other international studies), participants may have received more early intervention in the PICU setting, resulting in overall lower mean FSS scores. This would require further investigation.

5.4 Correlations

Based on all the data, correlations were established between the following variables within the total group of participants; age, LOS, duration of ventilation, mental status, communication, motor function, feeding and respiratory domains.

Notably, there were average positive relationships between duration of ventilation and LOS ($r = 0.50$; $p = 0.01$) motor function and LOS ($r = 0.60$; $p = 0.0007$); respiratory and length of ventilation ($r = 0.61$; $p = 0.0005$). The extended duration of mechanical ventilation is logically associated with a longer LOS in the PICU, which also impacts respiratory function, as indicated by higher scores on the FSS, denoting worse dysfunction. Prolonged hospitalisation, particularly in a critical care setting, often results in reduced physical activity and increased bed rest, which in turn can negatively affect motor function, also reflected in higher FSS scores. This relationship underscores the impact of extended PICU stays on both respiratory and motor outcomes.

There was a strong positive correlation, with a strong significance, between mental status and ventilation ($r = 0.74$; $p = <0.01$) indicating, a longer period spent ventilated results in higher scores (worse dysfunction) for mental status on the FSS. This was a trend noted between all correlation groups, and due to the nature of ventilation and sedation protocols in PICUs this could account for more dysfunction in mental status. As discussed in the literature it is known that younger children, as with this cohort with a mean age of 24 months old, lower socioeconomic status, increased oxygen and mechanical ventilation requirements and opioid administration will result in poor mental status outcomes (Madurski et al., 2018). Age did not have any significant correlations when looking at the total participant group. This finding aligns with other studies, which also did not report a relationship between age and functional status

(Pereira et al., 2019, 2017). The FSS was intentionally designed to be applicable across a wide age range without developmental bias, and the results from this study are consistent with the scale's intended purpose.

The cross-cultural adaption study conducted in Brazil, was the only other study in the literature that reviewed associations between FFS domains, however it did not include associations between the FSS and other variables. (Pereira et al., 2019), found high correlations between mental status and communication domains ($r = 0.501$; $p = <0.001$), feeding and respiratory domains ($r = 0.566$; $p = <0.001$) and respiratory and motor function domains ($r = 0.56$; $p = <0.001$); moderate correlations between communication and motor functions ($r = 0.422$; $p = <0.001$). This particular study expected weaker correlations, because the FSS evaluates independent body systems and functions, however, there were still high correlations found. Although the FSS evaluates individual body systems, it is important to recognise that these systems function interdependently to support overall functional success. The interconnectivity of these systems means that impairment in one area can influence the performance of others, emphasising the holistic nature of functional health. This is also demonstrated in the findings of this report.

No other studies were available in the literature to compare additional variables to FFS scores and this is an area lacking in the research.

With further break down of the correlation analysis, male participants, also had a strong positive correlation between mental status and length of ventilation ($r = 0.72$; $p = 0.004$) and an average positive correlation between LOS and mental status ($r = 0.52$; $p = 0.06$). Feeding and LOS ($r = 0.51$; $p = 0.06$) and communication and length of ventilation ($r = 0.62$; $p = 0.02$) had an average positive correlation.

Female participants had many more notable correlations compared to the male participants. This could be due to several factors, including biological differences like lung volumes and capacity, variations in how diseases and conditions manifest between sexes and possibly differing responses to treatment. Additionally, females might be more affected by certain social and environmental factors, which can influence health outcomes and lead to more significant correlations. These differences may also reflect varying rates of development, hormonal influences and other physiological factors between sexes. Females also presented with a more densely populated younger age range and therefore could relate to more statistically relevant correlations. Females had a strong positive correlation with strong statistical significance

between mental status and duration of ventilation, ($r = 0.77$; $p = 0.001$); motor function and LOS ($r = 0.88$; $p = 0.00003$) and respiratory function and duration of ventilation ($r = 0.83$; $p = 0.0003$). Meaning that with increased duration of ventilation and LOS there were poorer functional outcomes in mental status, respiratory and motor function domains. The literature confirms that prolonged ventilation and PICU stays are associated with poorer functional outcomes and PICS related morbidities (Herrup et al., 2017). Lastly, there was an average negative correlation between age and motor function ($r = -0.57$; $p = 0.03$), meaning that older participants exhibited lower (more normal) motor function scores. This outcome aligns with developmental trends, as older children are generally more capable of independent and safe mobilisation, leading to better motor function outcomes.

Long stay participants (more than 30 days) had an average positive correlation between LOS and motor function ($r = 0.60$; $p = 0.093$), mental status and duration of ventilation ($r = 0.65$; $p = 0.21$). The p values indicate a weaker significance. An average negative correlation between communication and LOS ($r = -0.65$; $p = 0.21$). Remarkably, a longer time spent in PICU correlated to lower scores for the communication domain (less dysfunction), indicating that children might become more accustomed to procedures and staff in the unit, and therefore, better at communicating their needs. A strong positive correlation with respiratory function and duration of ventilation ($r = 0.94$; $p = 0.01$) indicates that patients who required longer periods of mechanical ventilation tended to have worse respiratory function at discharge. This is likely because prolonged ventilation is often necessary for more serve respiratory conditions, which can lead to greater impairment in respiratory function. Additionally, extended ventilation can contribute to other complications such as muscle atrophy and ventilator -associated lung injury, further compromising respiratory function.

Medium LOS (14 – 30 days) participants and short LOS (less than 14 days) participants had a strong positive correlation with mental status and duration of ventilation ($r = 0.71$; $p = 0.023$); ($r = 0.74$; $p = 0.76$). Even if the PICU admission was shorter, those that spent more time ventilated had more dysfunction in the mental status domain. This likely because prolonged mechanical ventilation can lead to factors such as sedation, delirium, or hypoxia, which negatively impact mental function. Extended sedation and immobilisation can disrupt normal brain activity, play and exploration, typical development patterns and therefore contribute to cognitive impairment.

The last notable correlation was with short stay participants had an average positive correlation between respiratory and duration of ventilation ($r = 0.61$; $p = 0.76$). The p value, however shows weak significance. This correlation is expected, because prolonged ventilation is often associated with increased respiratory dysfunction, due to factors such as respiratory muscle weakness, challenges in weaning off ventilation, the prolonged use of sedatives and other medications and the higher risk of ventilator-associated lung injury (Lozano Ray et al., 2023; Morrow et al., 2023). Extended ventilation can lead to the development of chronic lung disease, further contributing to impaired respiratory function.

Common trends between all correlations, included: longer duration of ventilation results in higher FSS mental status scores, (worse dysfunction); longer duration of ventilation results in higher FSS scores for the respiratory domain (worse dysfunction) and lastly, the longer PICU LOS the higher the FFS motor function scores (worse dysfunction). What this tells us, is that the intrusive nature of a PICU admission including ventilation of a young patient will have a larger dysfunctional impact on their developing system. Sedation, opioid use, repeated painful procedures and a lack of normal positive stimuli will impact a patients physiological and cognitive status. Children still have immature respiratory systems and so respiratory dysfunction, such as the development of chronic lung disease, is to be expected if prolonged mechanical ventilation is required. Prolonged LOS often results in limited normal movement, play and crucial aspects of normal development for children. Being confined to a PICU cubicle restricts their physical activity, leading to muscle deconditioning and negatively impacting motor function. This paediatric population is at high risk for Post- Intensive Care Syndrome (PICS-P) due to their ongoing organ maturation, especially in preterm infants, dependence on family and critical stages of development (Ekim, 2020) that is interrupted with a PICU admission.

Despite more children surviving critical illness there are few studies that have examined the recovery trajectories of these children following discharge from a PICU (Madurski et al., 2018). With the data and correlations reported for this study, it has been highlighted that majority of patients will be discharged from PICU with a mild dysfunction, most likely in the mental status and motor function domains. Further follow up and continued functional assessments are recommend for this paediatric population.

The next chapter will summarise the information discussed in this research report.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS FOR FUTURE RESEARCH

6.1 Conclusions

Paediatric critical care is an ever evolving field of health care and in recent years there has been a shift from assessing mortality as an outcome but rather to assessing functional status and HRQoL of patients (Madurga-Revilla et al., 2020; Pollack et al., 2014). However, this area of critical care is not as well researched and the trajectory of recovery of these patients is poorly understood (Choong et al., 2015). The number of children requiring critical care is increasing annually because of a changing spectrum of paediatric disease, as a result of medical and technological advances, improved neonatal care and younger surviving premature infants, and the increased number of children living with complex chronic conditions (Choong et al., 2015). As patient mortality declines so long term morbidities in survivors increases (Maddux et al., 2020) and it is vital that as health care workers we determine this change in functional status so that appropriate assessments and interventions can be put in place in order to improve HRQoL. This also aligns with South Africa's third sustainable development goal: ensure healthy lives and promote well-being for all at all ages (Street, 2023).

Due to the intense nature of a PICU admission paediatric patients are often discharged from PICU requiring further therapy or intervention to assist in returning to their baseline function. The main aim of this study was to assess the functional status of paediatric patients upon discharge from a PICU, with the goal of identifying those who may be at risk of developing medium to long-term disabilities.

International evidence suggests that PICU admissions predominantly involve children under five years old, mostly male, with respiratory illness, and an average LOS of five days or less (Ibiebele et al., 2018; Madurga-Revilla et al., 2020; Matsumoto et al., 2019; Penela-Sánchez et al., 2021; Pereira et al., 2019, 2017; Pollack et al., 2014). However, in African countries, the average age and LOS tend to be higher (Ahmed, 2022; Zaitoun et al., 2022). South African data align with these global trends, showing most admissions involve children under two years old, with respiratory conditions being common and LOS typically under five days (Corten and Morrow, 2020; Lozano Ray et al., 2023; Morrow et al., 2023). Additionally, motor function is frequently impacted, with notable correlations between FSS domains such as mental status, communication, feeding and respiratory function (Pereira et al., 2019).

This study was a cross-sectional observational study, conducted between May 2023 - December 2023, on a final cohort of 28 participants. All participants were assessed using the FSS on the day of discharge from a private hospital PICU based in Gauteng, South Africa. Data analysis was then conducted on the data collected and correlations were observed between different variables.

Based on the findings of this research we can conclude that, within this cohort the median age of the participants was 24 (14-72) months old and the median LOS was 21 (8-32) days. The sample was equally distributed for males and females. The most common cause for admission were either respiratory or neurological in nature and it was the first PICU admission for 64% of cohort. The FSS had the highest mean/median scores in the mental status and motor function domains. The mean and median for the total score was eight, and most notably, 36% of participants had a score of more than or equal to nine indicating 'mild' to 'moderate' dysfunction. Common trends within the correlations, included that longer duration of ventilation results in higher FSS mental status scores, (worse dysfunction); increased duration of ventilated results in higher FSS scores for the respiratory domain (worse dysfunction) and lastly, the longer PICU LOS the higher the FFS motor function scores (worse dysfunction).

Children admitted to this particular PICU are most likely to be younger than or equal to 24 months old and have a longer LOS (median = 21 days). Evaluation of functional status indicated higher scores in the mental status and motor function domains of the FSS and an overall score falling within either the normal or mild dysfunction category. Participants with greater functional impairments had longer PICU stays and longer periods of mechanical ventilation.

6.2 Strengths of this Study

A key strength of this research study was the use of the same scorer for all of the FSS assessments. This allowed a standardised approach to how the FSS was administered ensuring better accuracy and validity of the results. It also minimised the inter-rater variability and ensures reliability in the data collection process.

Another notable strength was the variety of demographic data obtained including the diverse range of diagnoses recorded.

This was the first study in South Africa to use the FSS to assess functional outcomes. This study also provides a foundation on which further research can be based.

6.3 Limitations of this Study

This study did encounter several challenges which need to be acknowledged. Firstly, the small sample size of 28 participants restricted the generalisability of the findings to a broader population. Efforts were made to recruit more participants, however due to dealing with an extremely vulnerable population and their families, timing of consent needed to be considered, as many parents and caregivers did not consent to participate. This was a very emotional time for the participants and their families, and when approached shortly after admission or if the patient was still requiring mechanical ventilation or critically ill, they did not want to consider participating. The best time to recruit participants proved to be when patients were stabilised, once families had received more counselling from the medical staff around the PICU procedures, the patients had been extubated, and there was more reassurance that the overall patient condition was improving.

The wide variety of diagnoses did also pose as a challenge in collecting data and drawing meaningful correlations between the diagnosis and the FSS scores.

While conducting the FSS assessment, it became apparent that the scale exhibits a floor-ceiling effect, particularly in domains like sensory function. The broad gaps between scoring categories make it difficult to accurately capture subtle differences in functional abilities. The scaling is not specific enough to reflect nuanced changes in function, which may limit the sensitivity of the FSS in certain clinical contexts.

During the research process, it became evident that documenting premorbid health status was crucial, yet the demographic data collection sheet lacked sufficient detail in this area. The assessment of premorbid conditions could have been more thoroughly documented, as this information is vital for understanding patient outcomes. Enhancing the specificity of the data collection tool would have improved the accuracy and comprehensiveness of the health status documentation, aligning with the recommendations of Madurski et al. (2018).

6.4 Clinical Recommendations

Clinically, this study would recommend the continued use of the FSS. It is an easy tool to administer and should be done routinely on all PICU patients at the time of discharge. However, it is important to note that the FSS is designed as a rapid screening tool, and that more specific functional assessments should then take place with high-risk patients. This will allow the inter-professional team and the hospital to identify patients at high risk for medium- and long-term

impairments. Furthermore, this will allow for appropriate monitoring through the necessary follow up appointments.

Clear and accurate documentation of admitting diagnosis, number of previous admissions premorbid status, age, LOS and duration of ventilation in a more specific demographic data sheet is recommended for improved note keeping.

6.5 Recommendations for Future Studies

Recommendations for future studies would be to recruit participants from multiple PICUs in both public and private facilities in order to access a larger and more representative sample and to then compare findings between these different settings. Specific documentation of pre-morbid health status is important, to identify correlations between patients already presenting with medium- and long-term impairments and functional status. This could include the use of assistive devices, such as tracheostomy's, feeding gastrostomies, conditions such as hydrocephalus or cerebral palsy, and a history of delayed milestones, birth history and HIV status should also be documented. Careful consideration must be taken to ensure appropriate grouping of premorbid conditions and specific outcomes should be used. Primary admission diagnosis and functional status can also be a specific correlation to assess.

Furthermore, this study can recommend further use of the FSS in large scale studies. There may be opportunity to refine his tool/make it more sensitive or to look at a combination of a follow up study at three- or six-months post discharge form PICU. Consideration should also be given to nuanced changes in function and involving other professionals, like occupational and speech therapist, in function assessments.

When dealing with a vulnerable paediatric population it is important to consider the impact on the families and how we approach participants to participate in future research. Timing of consent should take place after admission to the PICU, once a patient has stabilised and parents have received counselling pertaining to their child's condition. Offering thorough explanations of the research process, such as costs involved, that the assessment will not prolong a child's PICU admission, that the assessment is non-invasive, and providing opportunity for the caregivers to ask questions are essential to ensure buy in.

This study had a high readmission rate. Future research could focus on this vulnerable population to determine the underlying factors contributing to repeated admissions.

This study highlighted the value of holistic early identification, of high-risk patients, through functional screening in order for health care practitioners to be pro-active in their management strategies. This will then allow for early intervention and follow up for children both during their PICU admission and post discharge. This is necessary to ensure that the children in our care in PICU not only survive but thrive.

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APPENDIX I: THE FSS (POLLACK ET AL., 2009)

Functional Status Scale in Paediatrics

	1=Normal	2=Mild dysfunction	3=Mod dysfunction	4=Severe dysfunction	5=very severe dysfunction	Score
Mental status	Normal asleep and awake	Sleepy but arousable to all stimuli and/or periods of non-responsiveness	Lethargic or irritable	Minimal arousal to stimuli	Unresponsive, coma or vegetative state	
Sensory	Intact hearing/vision Responsive to touch	Suspected visual/hearing loss	Non-reactive to auditory or visual stimuli	Non-reactive to stimuli	Abnormal response to pain and touch	
Communication	Normal expression, age-appropriate vocalisation	Diminished vocalisation, expression or social interaction	Absence of attention seeking behaviour	No demonstration of discomfort	Absence of communication	
Motor	Normal movement and muscle control	One limb with functional impairment	Two or more limbs with functional impairment	Poor head control	Spasticity, paralysis, decerebrate or decorticate pattern	
Feeding	Oral feeding with age appropriate help	NPO or need for age-inappropriate help	Combination of oral and tube feeding	TPN with NG tube or orogastric tube feeding	All parenteral nutrition (TPN only)	
Respiratory	Room air	Oxygen dependent and/or suctioning	Tracheostomy or ETT	CPAP for all or part of the day and/or mechanical ventilatory support for part of the day	Full mechanical ventilatory support	
Total score						

APPENDIX II: DEMOGRAPHIC AND CLINICAL DATA SHEET

Patient No: ____

Demographic and clinical information sheet

Date of assessment		
Name of assessor		
Current age		
Gender	Male	Female
FSS DONE	Yes	No
Length of stay		
Diagnosis		
Relevant past medical history (Birth History as indicated)		
Previous admissions	Yes	No

Current medical management		
Relevant family/social history		
Milestones/pre admission status		
OBJECTIVE		
Ventilation requirements	RA NPO2 High flow	CMV HFVO2
Length of ventilation		
Medication		
Attachments	NGT/OGT CVP NTT/ETT Trache	Catheter A Line PEG Drains
Investigations		

Feeding Method	
Mobility	
Other relevant information	

APPENDIX III: WITS ETHICS APPROVAL

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

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

TO: Ms S Kennedy
School of Therapeutic Sciences
Department of Physiotherapy
Medical School
University

E-mail: staceyken@hotmail.com

CC: Supervisor: Professor J Potterton
<Joanne.Potterton@wits.ac.za>
and <HREC-Medical Research Office@wits.ac.za>

FROM: Mr Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 2022/12/09

REF: R14/49

PROTOCOL NO: **M220824** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)

PROJECT TITLE: *Functional outcomes of children on discharge from a paediatric intensive care unit*

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

MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R49 Ms S Kennedy

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M220824

NAME: (Principal Investigator)	Ms S Kennedy
DEPARTMENT:	School of Therapeutic Sciences Department of Physiotherapy Medical School University
PROJECT TITLE:	*Functional outcomes of children on discharge from a paediatric intensive care unit*
DATE CONSIDERED:	2022/08/26
DECISION:	Approved unconditionally
CONDITIONS:	
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Professor J Fotheringham
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2022/12/09

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

DECLARATION OF INVESTIGATORS

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

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

Signature of Principal Investigator _____ Date _____

APPENDIX IV: PRIVATE HOSPITAL GROUP APPROVAL

RESEARCH OPERATIONS COMMITTEE FINAL APPROVAL OF RESEARCH

Approval number: UNIV-2023-0003

Ms S Kennedy

E mail: stacey@physikids.co.za

Dear Ms Kennedy

RE: FUNCTIONAL OUTCOMES OF CHILDREN ON DISCHARGE FROM A PAEDIATRIC INTENSIVE CARE UNIT

The above-mentioned research was reviewed by the Research Operations Committee's delegated members and it is with pleasure that we inform you that your application to conduct this research at private Hospital, has been approved, subject to the following:

i) Research may now commence with this FINAL APPROVAL from the Committee.

ii) All information regarding the Company will be treated as legally privileged and confidential.

iii) The Company's name will not be mentioned without written consent from the Committee.

iv) All legal requirements regarding patient / participant's rights and confidentiality will be complied with.

v) All data extracted may only be used in an anonymised, aggregated format and for the purposes of this specific study as specified in the proposal. The data may under no circumstances be used for any other purpose whatsoever.

vi) The research will be conducted in compliance with the GUIDELINES FOR GOOD CLINICAL PRACTICE IN HUMAN PARTICIPANTS IN SOUTH AFRICA (2016).

vii) The Company must be furnished with a STATUS REPORT on the progress of the study at least annually on 30th September irrespective of the date of approval from the Committee as well as a FINAL REPORT with reference to intention to publish and probable journals for publication, on completion of the study.

viii) A copy of the research report will be provided to the Committee once it is finally approved by the relevant primary party or tertiary institution, or once complete or if discontinued for any reason whatsoever prior to the expected completion date.

ix) The Company has the right to implement any recommendations from the research.

x) The Company reserves the right to withdraw the approval for research at any time during the process, should the research prove to be detrimental to the subjects/ Company or should the researcher not comply with the conditions of approval.

xi) APPROVAL IS VALID FOR A PERIOD OF 36 MONTHS FROM DATE OF THIS LETTER OR COMPLETION OR DISCONTINUATION OF THE TRIAL, WHICHEVER IS THE FIRST.

We wish you success in your research.

Yours faithfully 5/2/23

Prof Dion du Plessis
Full member: Research Operations Committee & Medical Practitioner evaluating research applications as per Management and Governance Policy

Dr Shannon Nell
Chairperson: Research Operations Committee
Date: 31/3/2023

This letter has been anonymised to ensure confidentiality in the research report. The original letter is available with author of research

APPENDIX V: JOFFE AND ROSIE PHYSIOTHERAPY APPROVAL

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

Permission:

I Jessica Joffe (designation) physiotherapy practice owner acknowledge and grant permission for the following study to take place.

Signature:_____

Date: ____01/12/22_____

Principal Investigator: Stacey Kennedy

Signature:_____

Date: 2/12/22_____

APPENDIX VI: PARTICIPANT CONSENT FORM

Consent to Participate in a Research Study

Information sheet

Title of Study: Functional outcomes of children on discharge from a Paediatric Intensive Care Unit

Investigator: Stacey Kennedy

Dear Mr and Mrs _____

My name is Stacey Kennedy and I am a Masters Student at WITS. As part of obtaining this degree I am required to complete a research study and I have chosen to do it in this private hospital PICU. The title of my research is: Functional outcomes of children on discharge from a Paediatric Intensive Care Unit. I would like to take this opportunity to explain this study further.

Purpose of the Study

It is important that we understand what areas of a child's function are most affected during a PICU admission so that appropriate therapeutic intervention can be made available to all the children in the Unit.

Therefore, the aim of this study is to evaluate the functional outcomes of paediatric patients on discharge from a Paediatric Intensive Care Unit using the Functional Status Scale.

This research study involves two parts. Firstly, some medical and demographic information would need to be documented with regards to your child's admission to the PICU. This information includes, age, date of birth, date of admission, diagnosis, relevant past medical history and any relevant current medical management. Please see the data sheet attached. Once this information is obtained and your child is ready for discharge home or to the paediatric ward, I will conduct an observational assessment using an outcome measure called the Functional Status Scale (please see document attached). This is a tick list looking at six categories, namely mental status, sensory, communication, motor, feeding and respiratory function. I will observe what your child can do and then score them according to this scale.

This assessment only needs to be done once, on the day of discharge from the PICU. It will take approximately 10 – 15 minutes to complete and you are welcome to be present at the time of the assessment. This does not require any follow up assessment, will not add additional time to their PICU stay and will not be of any additional cost to the family. I will also be able to share the results of the Functional Status Scale with you and your child once the assessment is done.

Confidentially

- The study will be completely anonymous. Upon the completion of the study no information pertaining to you or your child will be shared.
- The medical records used in this study will be kept strictly confidential, only available to the investigator and study supervisor.
- The results of the Functional Status Scale will only be reviewed by the investigator and study supervisor when compiling the data.
- Your child's information regarding the results of the study (i.e., age, diagnosis and FSS results) will be disclosed in the final report findings, however in no way will the information be able to trace back to you.

Right to Refuse or Withdraw

- The decision to participate in this study is voluntary.
- At any time during, before or after the study you may refuse participation without affecting any relationships in the PICU or with the investigator.
- You have the right to refuse to give out information or answer any questions during the study.
- If you so desire you have the right to request that the investigator does not use any of your information throughout the report.
- You have the right to request the results of the Functional Status Scale for your child.

Right to Ask Questions and Report Concerns

This study has been approved by the Human Research Ethics Committee (Medical) of the University of Witwatersrand, Johannesburg ("Committee"). 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.

- You have the right to ask questions about this study at any time, and to have those questions answered to your satisfaction. You are welcome to contact me during before, or after the study. You may contact me at any time via email at stacey.ken@hotmail.com or telephonically on 0721020399.
- If you wish to have a summary of the results of the study you may request for them to be sent to you.
- If you have any concerns over the way the study is being conducted or any of your questions have not been answered to your satisfaction, please contact the Chairperson of this committee - Professor Clement Penny - telephonically on 011 717 2301 or via email Clement.Penny@wits.ac.za. The telephone numbers for the committee secretariat are 011 717 2700/1234 and the email addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za
- You can also contact the study supervisor, Professor Joanne Potterton, via email joanne.potterton@wits.ac.za or telephonically on 011 717 3702.

Thank you for your time and for going through this information sheet. If you would like your child to participate in this research study, please refer to the consent form below.

Kind regards

Stacey Kennedy

BSc Physiotherapy (WITS)

Student Number: 669424

Consent to Participate in a Research Study

Consent form

Title of Study: Functional outcomes of children on discharge from a Paediatric Intensive Care Unit

Investigator: Stacey Kennedy

Consent

I have read this information and consent form and understand the risks involved in participating in this research study. I agree to allow my child's data to be collected and to be assessed using the Functional Status Scale as outlined above.

Child's name: _____

Parent/Caregiver/Guardian name: _____

Parent/Caregiver/Guardian signature: _____

Date: _____

Independent third-party name: _____

Independent third-party signature: _____

Date: _____

Investigator's name: _____

Investigator's Signature: _____

Date: _____

APPENDIX VII: PARTICIPANT ASSENT FORM

Information sheet for participants

Title of Study: Functional outcomes of children on discharge from a Paediatric Intensive Care Unit

Investigator: Stacey Kennedy

Dear _____

My name is Stacey and I am a Masters Student at WITS University. As part of my studies, I have to complete a research project and I have chosen to do it here, in the Netcare Waterfall City Hospital PICU. This is where you are currently staying and so I would like to inform you about the research I would like to do.

This research study aims to evaluate the functional outcomes of paediatric patients on discharge from the PICU using something called the Functional Status Scale. This means that I would like to assess patients staying in this unit, like you are, using a document called the Functional Status Scale. This document is a tick list that includes six sections and allows me to pick the right answer by observing what you can do by yourself in the PICU. From this observation I can give you a score that will tell me how strong you are and if you can do certain activities by yourself, like eating your breakfast. I only need to use this tick list once; on the day you move out of the PICU. Lastly, I would also have to ask for some other important information like your age, how long you have been in hospital for and if you had any procedures while you have been staying here.

A research study is a way to learn more about people. If you decide to be a part of this study, you will be asked if it is okay to allow for the observational assessment before you leave as well as for some of your important information I mentioned above.

There are some things about this study you should know. The assessment on the day you leave the unit will take about 10 – 15 minutes to complete together. Once all the information has been gathered, I will let you and your parents know the results so the right recommendations can be made for you. When this study is finished, I will write a report about what was learned. This report will not include your name or that you were in this study.

You and your parents must both consent before you can participate in this study, if you are 7 years or older. If you do not want to be in this research study, you don't have to be and if you decide to stop after we begin that's okay too.

You have the right to ask questions about this study at any time, and to have those questions answered to your satisfaction. You are welcome to contact me during before, or after the study. You may contact me at any time via email at stacey.ken@hotmail.com or telephonically on 0721020399.

You can also contact the study supervisor, Professor Joanne Potterton, via email joanne.potterton@wits.ac.za or telephonically on 011 717 3702.

Thank you for your time and for going through this information sheet. If you would like to be a part of this research study, please go to the assent form.

Kind regards

Stacey Kennedy

BSc Physiotherapy (WITS); Student Number: 669424

Assent form for participants

Title of Study: Functional outcomes of children on discharge from a Paediatric Intensive Care Unit

Investigator: Stacey Kennedy

Assent

I, _____ (full name), have read this information and give my permission to participate in this research study.

Date: _____

Parent/Caregiver/Guardian name: _____

Parent/Caregiver/Guardian signature: _____

Date: _____

Independent third-party name: _____

Independent third-party signature: _____

Date: _____

Investigator's name: _____

Investigator's Signature: _____

Date: _____

APPENDIX VIII: CORRELATION OF ALL PARTICIPANTS

	Age	Length of Stay	Length of Ventilation	Number of Diagnosis	Mental Status	Communication	Motor Function	Feeding	Respiratory
Age	1.00	-0.20	-0.33	0.01	-0.40	-0.18	-0.39	-0.27	-0.35
Length of Stay	-0.20	1.00	0.50	0.16	0.49	0.19	0.60	0.34	0.37
Length of Ventilation	-0.33	0.50	1.00	0.56	0.74	0.50	0.31	0.30	0.61
Number of Diagnosis	0.01	0.16	0.56	1.00	0.23	0.39	-0.04	0.17	0.45
Mental Status	-0.40	0.49	0.74	0.23	1.00	0.47	0.46	0.12	0.39
Communication	-0.18	0.19	0.50	0.39	0.47	1.00	-0.03	0.14	0.25
Motor Function	-0.39	0.60	0.31	-0.04	0.46	-0.03	1.00	0.26	0.31
Feeding	-0.27	0.34	0.30	0.17	0.12	0.14	0.26	1.00	0.32
Respiratory	-0.35	0.37	0.61	0.45	0.39	0.25	0.31	0.32	1.00

APPENDIX IX: CORRELATION OF ALL MALE PARTICIPANTS

	Age	Length of Stay	Length of Ventilation	Number of Diagnosis	Mental Status	Communication	Motor Function	Feeding	Respiratory
Age	1.00	-0.08	-0.28	0.20	-0.31	-0.02	-0.23	-0.31	-0.43
Length of Stay	-0.08	1.00	0.50	0.21	0.52	0.17	0.45	0.51	0.24
Length of Ventilation	-0.28	0.50	1.00	0.40	0.72	0.62	0.05	0.20	0.41
Number of Diagnosis	0.20	0.21	0.40	1.00	0.06	0.33	-0.07	0.03	0.39
Mental Status	-0.31	0.52	0.72	0.06	1.00	0.45	0.22	-0.06	0.08
Communication	-0.02	0.17	0.62	0.33	0.45	1.00	-0.27	-0.21	-0.05
Motor Function	-0.23	0.45	0.05	-0.07	0.22	-0.27	1.00	0.31	0.08
Feeding	-0.31	0.51	0.20	0.03	-0.06	-0.21	0.31	1.00	0.24
Respiratory	-0.43	0.24	0.41	0.39	0.08	-0.05	0.08	0.24	1.00

APPENDIX X: CORRELATION OF ALL FEMALE PARTICIPANTS

	Age	Length of Stay	Length of Ventilation	Number of Diagnosis	Mental Status	Communication	Motor Function	Feeding	Respiratory
Age	1.00	-0.43	-0.29	-0.32	-0.45	-0.31	-0.57	-0.17	-0.28
Length of Stay	-0.43	1.00	0.51	0.08	0.54	0.30	0.88	0.10	0.49
Length of Ventilation	-0.29	0.51	1.00	0.70	0.77	0.45	0.54	0.42	0.83
Number of Diagnosis	-0.32	0.08	0.70	1.00	0.51	0.51	0.14	0.47	0.64
Mental Status	-0.45	0.54	0.77	0.51	1.00	0.47	0.67	0.32	0.73
Communication	-0.31	0.30	0.45	0.51	0.47	1.00	0.23	0.68	0.65
Motor Function	-0.57	0.88	0.54	0.14	0.67	0.23	1.00	0.16	0.56
Feeding	-0.17	0.10	0.42	0.47	0.32	0.68	0.16	1.00	0.44
Respiratory	-0.28	0.49	0.83	0.64	0.73	0.65	0.56	0.44	1.00

APPENDIX XI: CORRELATION OF ALL LONG STAY PARTICIPANTS

	Age	Length of Stay	Length of Ventilation	Number of Diagnosis	Mental Status	Communication	Motor Function	Feeding	Respiratory
Age	1.00	0.28	-0.36	-0.33	0.00	-0.45	0.07	-0.57	-0.32
Length of Stay	0.28	1.00	-0.05	-0.36	-0.26	-0.65	0.68	0.00	-0.29
Length of Ventilation	-0.36	-0.05	1.00	0.82	0.65	0.26	0.29	0.13	0.94
Number of Diagnosis	-0.33	-0.36	0.82	1.00	0.66	0.66	-0.19	-0.13	0.82
Mental Status	0.00	-0.26	0.65	0.66	1.00	0.33	0.28	-0.33	0.69
Communication	-0.45	-0.65	0.26	0.66	0.33	1.00	-0.62	-0.33	0.28
Motor Function	0.07	0.68	0.29	-0.19	0.28	-0.62	1.00	0.21	0.13
Feeding	-0.57	0.00	0.13	-0.13	-0.33	-0.33	0.21	1.00	0.14
Respiratory	-0.32	-0.29	0.94	0.82	0.69	0.28	0.13	0.14	1.00

APPENDIX XII: CORRELATION OF ALL MEDIUM STAY PARTICIPANTS

	Age	Length of Stay	Length of Ventilation	Number of Diagnosis	Mental Status	Communication	Feeding	Respiratory
Age	1.00	0.19	-0.14	-0.30	0.08	0.38	0.12	-0.08
Length of Stay	0.19	1.00	0.26	0.29	0.11	-0.11	0.29	-0.08
Length of Ventilation	-0.14	0.26	1.00	0.68	0.71	0.51	0.54	0.39
Number of Diagnosis	-0.30	0.29	0.68	1.00	0.24	0.32	0.55	0.56
Mental Status	0.08	0.11	0.71	0.24	1.00	0.43	0.22	-0.05
Communication	0.38	-0.11	0.51	0.32	0.43	1.00	0.51	0.05
Feeding	0.12	0.29	0.54	0.55	0.22	0.51	1.00	0.51
Respiratory	-0.08	-0.08	0.39	0.56	-0.05	0.05	0.51	1.00

APPENDIX XIII: CORRELATION OF ALL SHORT STAY PARTICIPANTS

	Age	Length of Stay	Length of Ventilation	Number of Diagnosis	Mental Status	Motor Function	Respiratory
Age	1.00	0.51	0.12	0.35	-0.41	-0.18	-0.53
Length of Stay	0.51	1.00	0.47	0.55	-0.23	0.09	-0.23
Length of Ventilation	0.12	0.47	1.00	0.00	-0.11	-0.22	-0.11
Number of Diagnosis	0.35	0.55	0.00	1.00	-0.37	-0.14	-0.37
Mental Status	-0.41	-0.23	-0.11	-0.37	1.00	0.43	-0.11
Motor Function	-0.18	0.09	-0.22	-0.14	0.43	1.00	0.43
Respiratory	-0.53	-0.23	-0.11	-0.37	-0.11	0.43	1.00

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

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

TO:

Ms S Kennedy
School of Therapeutic Sciences
Department of Physiotherapy
Medical School
University

E-mail: staceyken@hotmail.com

CC:

Supervisor: Professor J Potterton
<Joanne.Potterton@wits.ac.za>
and <HREC-Medical Research Office@wits.ac.za>

FROM:

Mr Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 2022/12/09

REF: R14/49

PROTOCOL NO: **M220824** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)

PROJECT TITLE: *Functional outcomes of children on discharge from a paediatric intensive care unit*

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

MSWorks2000/Iain0007/Clearscan.wps

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R49 Ms S Kennedy

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M220824

NAME: **(Principal Investigator)**	Ms S Kennedy
DEPARTMENT:	School of Therapeutic Sciences Department of Physiotherapy Medical School University
PROJECT TITLE:	*Functional outcomes of children on discharge from a paediatric intensive care unit*
DATE CONSIDERED:	2022/08/26
DECISION:	Approved unconditionally
CONDITIONS:	
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Professor J Potterton
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2022/12/09

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

DECLARATION OF INVESTIGATORS

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

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

Signature of Principal Investigator _____ Date _____

RESEARCH OPERATIONS COMMITTEE FINAL APPROVAL OF RESEARCH

Approval number: UNIV-2023-0003

Ms S Kennedy

E mail: stacey@physikids.co.za

Dear Ms Kennedy

RE: FUNCTIONAL OUTCOMES OF CHILDREN ON DISCHARGE FROM A PAEDIATRIC INTENSIVE CARE UNIT

The above-mentioned research was reviewed by the Research Operations Committee's delegated members and it is with pleasure that we inform you that your application to conduct this research at private Hospital, has been approved, subject to the following:

i) Research may now commence with this FINAL APPROVAL from the Committee.

ii) All information regarding the Company will be treated as legally privileged and confidential.

iii) The Company's name will not be mentioned without written consent from the Committee.

iv) All legal requirements regarding patient / participant's rights and confidentiality will be complied with.

v) All data extracted may only be used in an anonymised, aggregated format and for the purposes of this specific study as specified in the proposal. The data may under no circumstances be used for any other purpose whatsoever.

vi) The research will be conducted in compliance with the GUIDELINES FOR GOOD CLINICAL PRACTICE IN HUMAN PARTICIPANTS IN SOUTH AFRICA (2016).

vii) The Company must be furnished with a STATUS REPORT on the progress of the study at least annually on 30th September irrespective of the date of approval from the Committee as well as a FINAL REPORT with reference to intention to publish and probable journals for publication, on completion of the study.

viii) A copy of the research report will be provided to the Committee once it is finally approved by the relevant primary 'party or tertiary institution, or once complete or if discontinued for any reason whatsoever prior to the expected completion date.

ix) The Company has the right to implement any recommendations from the research.

x) The Company reserves the right to withdraw the approval for research at any time during the process, should the research prove to be detrimental to the subjects/ Company or should the researcher not comply with the conditions of approval.

xi) APPROVAL IS VALID FOR A PERIOD OF 36 MONTHS FROM DATE OF THIS LETTER OR COMPLETION OR DISCONTINUATION OF THE TRIAL, WHICHEVER IS THE FIRST.

We wish you success in your research.

Yours faithfully

5/2/23

Prof Dion du Plessis
Full member: Research Operations Committee & Medical Practitioner evaluating research applications as per Management and Governance Policy

Dr Shannon Nell
Chairperson: Research Operations Committee
Date: 31/3/2023

This letter has been anonymised to ensure confidentiality in the research report. The original letter is available with author of research

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Stacey Kennedy (Student number: 669424) am a studentregistered for the degree of Masters of Science in Physiotherapy in the academic year 2022/2023.

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: 23/10/2024