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The ethical and legal permissibility for CP adolescents in South Africa over the age of 12, without significant intellectual disability, to refuse aspects of their physiotherapy

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Title:
The ethical and legal permissibility for CP adolescents in South Africa over the age of 12, without significant intellectual disability, to refuse aspects of their physiotherapy

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Medicine in Bioethics and Health Law

(March, 2022)

DECLARATION

I __Sibabalwe Mama ___ (Student number:1106609) am a student registered for the degree of MSc Medicine – Bioethics and Health Law in the academic year 2022.

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ABSTRACT

Adolescents with cerebral palsy are often assumed to lack health care decision-making capacity by their parents/caregivers and physiotherapists. Parents/caregivers of persons with disabilities are responsible for making decisions for their adolescents in the early stages of development. However, as children transition into adolescence, they are given the freedom to explore their thoughts, feelings, and emotions and engage in society. CP adolescents are not always given an equal opportunity to explore their individuality because of their dependency on parents/caregivers in different domains of life, such as: communication, feeding, and ambulation. The purpose of this research report is to investigate the extent to which CP adolescents over the age of 12, without a significant intellectual disability, can refuse physiotherapy interventions, despite their parents/caregivers advocating for the intervention and how physiotherapists should respond to their refusal. It is essential in circumstances when CP adolescents demonstrate an apparent verbal or non-verbal refusal and are still forced to participate in these interventions. This research has used a normative study to provide an analysis of the moral and legal rights of CP adolescents, in a South African context. In addition, international and local laws that protect the rights of persons with disabilities were analysed to ensure that physiotherapists fulfil their duty to their patients. The moral theory of 'ethics of care' demonstrates that CP adolescents can refuse rehabilitation, and physiotherapists ought to accept their decision and ensure that they are protected from all forms of harm. According to the Children's Act 38 of 2003, the Convention of Rights of Children, the Convention of Rights of Persons with Disabilities and the Health Professionals Council of South Africa's guidelines, CP adolescents have the right to refuse all aspects of rehabilitation and physiotherapists have a professional responsibility to their patients, before their parents/caregivers.

There is limited literature available in the field of autonomy and the right to refuse rehabilitation by CP adolescents. However, the study provides an ethical and legal framework for addressing situations where CP adolescents' autonomy and decision-making capacity are questioned by their parents/caregivers, regarding their health care. Further studies are required to provide clear guidelines for the professional and ethical duty that physiotherapists need to protect CP adolescents' dignity.

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TABLE OF ABBREVIATIONS

CP: Cerebral Palsy

UNCRC: United Nations Convention on the Rights of the Child

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

GMFCS: Gross Motor Function Classification System

HPCSA: Health Professionals Council of South Africa

HREC: Human Research Ethics Committee

OT: Occupational Therapist

Chapter 1

1.1 Introduction

Consent is the foundation of all medical treatment between physiotherapists and their patients. It is a balance between the decision-making capacity of the patient and the physiotherapist's duty to protect their patient from harm (Goldsmith et al., 2008, Wong et al., 1999, Republic of South Africa, 2004, Schmidt et al., 2020). Adolescents with cerebral palsy (CP) need physiotherapy interventions to maintain function and reduce factors that worsen CP, such as: joint dislocations, muscle contractors, muscle weakness, changes in tone and scoliosis (Graham et al., 2016, Schmidt et al., 2020). To prevent these musculoskeletal complications, physiotherapists apply rehabilitative techniques and technologies which often result in adolescents experiencing iatrogenic treatment effects, especially with stretching exercises (Wiart et al., 2010, Barney et al., 2013). When adolescents express verbal or physical resistance to treatment, their parents/caregivers often force them to continue treatment because they believe it is in their best interests (Wiart et al., 2010, Wintels et al., 2018). Refusal to treatment is further complicated when adolescents cannot physically leave the treatment environment or prevent the therapy, as their disability impairs their ability to do this.

In South Africa, physiotherapists face a dilemma, as they are required to have the adolescent's consent throughout the treatment session as the adolescent has the right to consent to medical treatment and to "participate in any decision" affecting their health care, in the case that they are over the age of 12 years, according to the law (Republic of South Africa, 2004). However, the parent/caregiver is perceived as the consenting adult to their adolescent's health care regardless of their age and based only on their physical ability (Delany, 2005, Rachels and Rachels, 2019, Cureton and

Silvers, 2017). Thus, this research focuses on the bioethical and legal issues that physiotherapists face when treating CP adolescents who are over the age of 12, without significant intellectual disability, who refuse physiotherapy treatment despite parental consent in a South African context.

1.2 Background, Literature Analysis and Critique

When children are diagnosed with CP, "a group of permanent disorders of the development of movement and posture causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain", health practitioners classify them according to their motor abnormalities, accompanying impairments, anatomical and neuro-imaging finds, timing, and causation (Rosenbaum et al., 2007). Understanding motor abnormalities and accompanying impairments are essential to the practice of physiotherapy, as the primary goal of therapeutic interventions is to enhance physical ability (Wiart et al., 2010). Motor abnormalities are related to underlying CP pathophysiological disturbances in the brain, resulting in involuntary muscle movements or varying muscle tone. Accompanying impairments are related to the absence or presence of musculoskeletal and non-motor neurodevelopmental problems in the developing adolescent. For example, communication and behavioural impairments due to physical anomalies may limit the ability of adolescents to participate fully in social interactions, and in this way, make them different from other children (Rosenbaum et al., 2007). These motor abnormalities are assessed and classified according to the Gross Motor Function Classification System (GMFCS). The GMFCS groups CP individuals into one of five levels according to the gross motor skills they can achieve,

ranging from ambulant to assisted mobility (Rosenbaum et al., 2007). Focusing on motor function is valuable for physiotherapists to plan and determine appropriate therapeutic goals. However, by focussing solely on physical mobility, it becomes a form of discrimination, as it implies that adolescents' physical abilities are more important than their emotional or mental abilities. In addition to environmental and social factors that impact a CP adolescents daily life, all these factors influence the treatment decisions and goals in physiotherapy, despite the focus solely being on the ability to move (Rosenbaum et al., 2007, Vogts et al., 2010).

The transition from childhood into adulthood occurs when adolescents participate in decisions that affect their well-being and learn to negotiate and adapt their thoughts and feelings when in these situations, extending to more complicated life situations as they reach adulthood. Adolescents are required to have the maturity to make autonomous decisions in situations that occur in multiple domains of their lives, such as: health care, education, finances, relationships, and future employment opportunities. Participation in autonomous decision-making in all aspects of life requires adolescents to have the freedom to make decisions and act based on their reasoning and understanding (Schmidt et al., 2020). Furthermore, developing the skills, maturity, and independence allows individuals to make decisions that protect them from harm and promotes their long-term well-being.

While adolescents develop autonomous decision-making skills during their transition into adulthood, there are additional challenges for adolescents with CP. CP adolescents with communicative and behavioural accompanying impairments may require varying levels of assistance with decision-making, while adolescents without

CP may not (Schmidt et al., 2020). There is limited literature on this complex subject, and what is available is not necessarily relevant to adolescents from developing countries, for example. The article by Schmidt, van Gorp et al 2020, investigates CP individuals from childhood to adulthood (ages 12 to 34) in Holland, without intellectual disability, in domains of finances, leisure (social activities), housing, employment, transportation, intimate relationships, and education to determine their autonomy of participation in decision making. This article found that Dutch CP individuals in lower GMFCS levels III – V were significantly less likely to organise their transport than those in higher GMFCS levels I-II. They were dependent on their caregivers to either transport them or organise transport on their behalf. The researchers compared Dutch CP individuals aged 15-25 years to their Dutch peers of the same age group. They found that Dutch adolescents reached autonomy earlier than Dutch CP adolescents. The autonomy of CP individuals increased significantly in all the domains as they aged, with 90% of the participants reaching autonomy towards or after the age of 27 (Schmidt et al., 2020). The delay in reaching autonomy indicates that CP individuals can develop autonomy, albeit at a slower pace, and it is likely to be in their late twenties. Those with lower GMFCS levels are at risk of not reaching their autonomy. The researchers noted that limited research is available regarding barriers and facilitators to developing autonomy in adolescents and other research related to autonomy in CP adolescents (Schmidt et al., 2020). It is unclear how autonomy can influence participation in different domains of life in South African CP adolescents, especially in lower GMFCS levels and in an environment that does not have the structures to enable disabled persons' full participation in social and community life, for example, access to transport, where there are significant lags in service provision (Ngqakamba, 2021). Furthermore, the researchers acknowledged that region-specific

legislation assumes individuals of legal age to have complete autonomy, thus influencing their participation and requiring the input of parents/guardians until CP individuals are of legal age or are able to make decisions autonomously (Schmidt et al., 2020).

CP adolescents are no different from their adolescent peers. A study by Wintels and Smits et al 2018, discovered that CP adolescents between ages 12-17 years have the same dreams, feelings, hopes, and thoughts that all adolescents have (Wintels et al., 2018). For example, one participant reported that they loved creative activities because they could perform them independently. The investigators found that independence and autonomy were common themes reported by the CP adolescents in different life domains, including school, physical activity, and health care. CP adolescents described that they had experiences of having their autonomy and independence had been limited as other people made their decisions, not always in line with their wishes. Their decision-making is further complicated by behavioural and communication problems that impact the CP adolescents' participation in therapy and influence others' perceptions of their autonomous decision-making ability. For example, a participant reported that their rehabilitation doctor and occupational therapist (OT) had agreed upon treatment to help improve the flexibility in their hands without their consultation. The participant disagreed with the treatment as he did not think the therapy was beneficial and expressed a fear of the chosen treatment intervention because he did not know what to expect in every session. The additional physiotherapy sessions interrupted his homework time and hockey practices. Despite explaining this and objecting to his mother, she continued to enforce their attendance at therapy sessions (Wintels et al., 2018).

Many parents/caregivers advocate for rehabilitative therapy, in the hope of improving their adolescent's body functioning. Indeed, parents with disabled children often report their children to be significantly low functioning in their extremities and global function in the quality of life questionnaires (Gates et al., 2010). Quality of life refers to how individuals perceive their physical and mental health, including parameters of happiness, communication, and function in daily activities (Schiariti et al., 2014). However, in the case of caregivers, parents often relate their adolescent's happiness to their functional abilities, as they have seen how their delayed development in physical function separates them from their peers. However, CP adolescents' experiences are different (Ferreira et al., 2020). The study by Wintels and Smits et al (2018), found that CP adolescents expressed that they understood that they were born with physical disabilities and found happiness in treatment goals that helped them adapt to their social environment, such as making friends and participating in their community (Wintels et al., 2018).

Parents' focus on physical dysfunction and how it impedes function rather than the social and environmental aspects that impede on an adolescent's function and this often leads to differences in opinions regarding the adolescents' best interest. Thus, parents rely on the health professional's decision rather than their adolescent's decision. Health professionals are perceived to be more knowledgeable about adolescents' physical needs than the adolescents themselves (Bernal, 2006, Keywood and Flynn, 2010, Wong et al., 1999). This misconception leads to ethical dilemmas for health professionals who face the challenge of meeting the parents' expectations and

providing appropriate and acceptable care to their patients while assisting patients in participating in their activities of daily living and respecting their decision-making.

1.3 Research Question

When adolescents with cerebral palsy, over the age of 12, refuse to participate in their physiotherapy, from an ethical and legal perspective, what ought the physiotherapist to do?

1.4 Rationale for the Study

A physiotherapist who treats CP adolescents uses knowledge and skills underpinned by evidence-based therapeutic goals. Their scope of practice is mobility and physical function that has a vast range of research to guide clinical practice. There is limited literature available to guide physiotherapists on addressing ethical dilemmas when treating CP adolescents without significant intellectual disability (Poulis, 2007, Partridge, 2010). An instance like this could occur when the parents/caregivers of adolescents agree with the treatment plan presented by the physiotherapist, but the adolescent refuses to participate (Wiart et al., 2010, Barney et al., 2013). The physiotherapist and parent/caregiver may force the adolescent to participate in treatment because of the potential physical harms that may arise due to not continuing with therapy. This would not be of benefit to the patient and may cause harm in the long term. Because of physical impairments, the adolescent may not be able to intervene to stop the therapy intervention and be effectively assaulted, as a result. However; ethically, the physiotherapist must obtain informed consent from the adolescent and assent from the parent for medical treatment and must respect the patient's decision to accept or refuse treatment (Republic of South Africa, 2004, Health Professionals Council of South Africa, 2016, Republic of South Africa, 2005). In spite

of this, most physiotherapists simply rely on clinical principles to assist with the challenges of choosing between accepting the CP adolescent's refusal and will continue with treatment in spite of their refusal. Ethical principles in medical ethics do not clearly answer the question of what the physiotherapist should do when parents/caregivers force disabled adolescents to participate in treatment interventions that they refuse (Beauchamp and Childress, 2013, Poulis, 2007, Dan, 2021, Boldt, 2018).

1.5 Thesis Statement

To argue that it is permissible for CP adolescents over the age of 12, without significant intellectual disability, to refuse aspects of their physiotherapy despite parental/caregiver consent to treatment (and the physiotherapist must accept the decision), in a South African context. Furthermore, the arguments in the report relate only to CP adolescents in South Africa over the age of 12, without significant intellectual disability, and that further references in the report to “CP adolescents” should be understood to mean those without significant intellectual disability.

1.6 Research Aim

The purpose of this research is to identify and address the bioethical and legal challenges that physiotherapists experience when treating CP adolescents over the age of 12, without significant intellectual disability, who refuse physiotherapy treatment despite parental consent, in a South African context

1.7 Research Objectives

To defend the claim that adolescents have ethical rights and are legally entitled to consent to or refuse their physiotherapy treatment.

To argue that physiotherapists have an obligation to defend their patients' ethical and legal entitlements in this regard.

To critically evaluate international and South African regulations and laws supporting the rights of persons with disabilities, especially pertaining adolescents.

1.8 Research Methods

1.8.1 A normative study

The research is a normative study based on library-based and desktop research. No new data was collected or analysed, and no human participants were involved in the research. This study employed philosophical, bioethical, and legal research methods.

All literature findings were discussed, critically analysed, and interpreted to include the most applicable South African and international legislation and policies in the text. The review of the literature included clarification of concepts and definitions, the description, evaluation, and analysis of theoretical frameworks, and the development, criticism, and defence of arguments. The literature sources primarily used for research data include books, research articles, government policies, and legislation. Academic search engines utilised included Pubmed, EBSCOhost, AccessPhysiotherapy, Clinical Key, ResearchGate and Google Scholar.

1.8.2 Research Design

The research design of this study was purely normative and a review of legal and ethical components. Normative ethics is a branch of philosophical inquiry that sets out to give answers to questions such as, "what ought to be done?" (Sugarman and Sulmasy, 2010). These questions are answered critically and systematically to justify the offered answers (Sugarman and Sulmasy, 2010). In this research study, the normative inquiry is whether it is permissible for CP adolescents over the age of 12, without significant intellectual disability, to reject their physiotherapy despite the parental/caregiver's consent to treatment.

1.8.3 Argumentative Strategy

Adolescents ethical and legal entitlements to treatment

In this section, the argument that an adolescent without significant intellectual disability fulfils the requirements to be involved in the discussions regarding their health care and should be allowed to consent or refuse the treatment, will be made based on the functional approach to medical capacity to consent (Arscott et al., 1999, Buchanan, 2004, Barstow et al., 2018, Wong et al., 1999). In addition, the principle of autonomy will be applied, to highlight the importance of respecting an adolescent without significant intellectual disability as having the capacity to make informed decisions regarding their own health care and not forcing them to participate in treatment interventions that they have refused (Beauchamp and Childress, 2013). Finally, to argue that based on the South African National Health Act No 61 of 2003 and Children's Act, CP adolescents over the age of 12 have the right to participate in decisions affecting their health care and can consent to their medical treatment

(Republic of South Africa, 2005, Republic of South Africa, 1996, Republic of South Africa, 2004).

International regulations on persons with disabilities:

In this section, the argument that adolescents should not be discriminated against based on their disability and protected from discrimination based on their opinions or the beliefs of their parents will be made, based on the United Nations Convention of Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 1989, United Nations, 2006).

Physiotherapy obligations to respect patient's decisions to participate in treatment

To begin with, in this section, the argument that physiotherapists have a moral obligation to include CP adolescents in discussions about their health care and accept their decisions will be made based on the ethical principles of non-maleficence and beneficence, and care ethics (Beauchamp and Childress, 2013, Bernal, 2006, Rachels and Rachels, 2019). Secondly, the argument that physiotherapists have a professional and legal obligation to ensure that CP adolescents understand their diagnosis, the short-term and long-term benefits and the consequences of treatment, and give informed consent to the entire transaction (Health Professionals Council of South Africa, 2016, Partridge, 2010, Republic of South Africa, 2005).

1.9 Ethics

An ethics waiver was acquired from the Human Research Ethics Committee (HREC) of the University of Witwatersrand. No research participants were included in this study. Therefore, further ethical clearance is not required.

1.10 Research Outcomes

This research report will provide physiotherapists with an ethical framework to address situations where CP adolescents' autonomy and decision-making capacity are questioned by their parents/caregivers regarding their health care.

1.11 Limitations

Limitations may arise because of the bioethical journal articles used in this research. Many of the journal articles related to CP adolescents are from international sources and developed countries. Therefore, the results may not be applicable for all South African CP adolescents. In addition to this, the study sample of the journal articles included adolescents in higher GMFCS levels I-II compared to lower GMFCS levels III – V, and this may not accurately reflect the South African CP adolescent population. Research has found that lower GMFCS levels are associated with more communication and intellectual disability levels. However, in South Africa, lack of access to early treatment and input may mean that a CP adolescent's GMFCS level may not accurately reflect their decision-making ability. Therefore, there is uncertainty regarding the autonomy of individuals in lower GMFCS levels compared to higher GMFCS levels. A final limitation is that the study sample size of the journal articles

was small, therefore; this may result in selection bias of the participants, and results may not fully represent the CP adolescent population.

1.12 Overview of Study Sections

Chapter 2 of this research report discusses the assumptions that parents/caregivers and physiotherapists have regarding the medical decision-making capacity of CP adolescents as a result of CP being diagnosed as a non-progressive and permanent disorder that occurs in an infant's brain or developing fetus (Rosenbaum et al., 2007). The ethical and legal entitlements regarding the decision-making capacity of CP adolescents is presented in the chapter. The purpose of chapter 3 is to analyse relevant ethical theories that underpin the caring for patients and bioethical principles of clinical practice that physiotherapists are required to apply in order to fulfil their obligations to act in the best interest of CP adolescent patients. The objective of chapter 4 is to discuss professional guidelines and legislation that physiotherapists are morally obligated to fulfil when treating persons with disabilities, with specific reference to adolescents with CP. Chapter 5 concludes this research report.

Chapter 2: Cerebral Palsy adolescents ethical and legal entitlements to their treatment

2.1 Introduction

Adolescents with CP are assumed to lack decision-making capacity regarding their health care by their parents/caregivers because of their CP diagnosis and associated accompanying impairments, which make them physically different from other children.

Parents/caregivers make this assumption using the status approach to decision-making capacity. In the status approach, an individual's decision-making capacity in a particular population is determined by the absence or presence of particular characteristics (Wong et al., 1999). For example, the presence of disabilities or conditions, such as schizophrenia, cerebral palsy and dementia would be linked (albeit often erroneously) to a lack of legal decision-making capacity. It is a general assumption that persons with specific disabilities do not have the maturity and are incapable of making legally valid decisions regarding their health care. For example, spastic quadriplegia describes a CP adolescent with increased muscle tone that affects bilateral upper limbs and lower limbs. These children are often classified in the lower GMFCS levels IV-V because they have limited control of their postural muscles, arms and legs, need moderate to maximum assistance with all activities of daily living and require assistive devices in all settings. They may have associated digestive, behavioural and communication impairments (Rosenbaum et al., 2007). Parents/caregivers assume that their need for moderate to maximum assistance with all activities of daily living and associated impairments means that their adolescents cannot make autonomous decisions in their daily lives. Parents/caregivers are making an incorrect assumption as the classification for a diagnosis of CP does not include severe cognitive impairment and absent motor activation, excluding minimal hypotonicity (Rosenbaum et al., 2002). Development occurs throughout childhood, and to assume a CP adolescent decision-making capacity to be present or absent because of childhood physical limitation is incorrect. Furthermore, physical impairments exclude the psychological, social and emotional development an adolescent experiences (Rosenbaum and Gorter, 2012, Schmidt et al., 2020). These psychological and emotional factors are required when determining if an adolescent has the maturity to make decisions regarding their health care (Sawyer and

Rosenberg, 2020). Thus, the failure to acknowledge maturity and withholding the adolescent's right to consent based on perception rather than actual pathology is discrimination against CP adolescents.

2.2 Medical decision-making capacity for treatment

To defend the claim that CP adolescents can consent to, and by extension, refuse physiotherapy interventions, an adolescent must have medical decision-making capacity. For the purpose of this study the functional approach to decision making and it's four components will provide a definition for the phrase "without significant intellectual disability". The functional approach to decision-making should be applied to determine a CP adolescent's capacity to make decisions regarding their medical care. In the function approach, the individual's knowledge, skills, understanding and overall abilities are challenged to determine whether they are capable of making legally valid decisions, with a particular context, regarding their health care (Wong et al., 1999).

There are four prominently recognised components to the functional approach of decision-making capacity in medical practice. Individuals need to demonstrate that they have the maturity to fulfil all the components before making their choice. The components are to demonstrate an understanding of the personal risks and benefits to treatment interventions, including the absence of treatment interventions; demonstrate an understanding of all the medical risks and benefits to the treatment, including the absence of treatment interventions, and to demonstrate that they can weigh up all possible interventions when making a decision and be capable of communicating their decision (Wong et al., 1999, Barstow et al., 2018, Buchanan, 2004, Arscott et al., 1999). As previously stated, the transition to adulthood is when adolescents develop the

maturity to make health care decisions. The capacity to make medical decisions is dynamic because it varies over time and is situation specific. It is essential that the adolescent with CP's involvement in their care is aimed at their level of function and that they understand all the information provided irrespective of dysfunction (Wong et al., 1999, Schmidt et al., 2020, Buchanan, 2004). An adolescent's medical decisional capacity needs to be assessed prior to treatment interventions and not assumed as absent. The presence of medical decision capacity is essential to long term medical interventions, like physiotherapy, as the law acknowledges an individual's mental capacity can vary between a more or lesser degree throughout their lifetime (Buchanan, 2004).

Adolescents, like adults, are assumed to have medical decision-making capacity if they fulfil the four components of capacity and demonstrate this during a medical assessment (Barstow et al., 2018, Wong et al., 1999). However, CP adolescents without significant intellectual disability that fulfil the medical decision-making components during their assessment have their capacity questioned due to their physical disability. Their decision-making capacity is further speculated when they have accompanying impairments such as behavioural and communication problems and require assistance from parents/caregivers to communicate their needs. CP adolescents' parents/caregivers limit their decision-making capacity to pre-empt harm, leading to health professionals agreeing to treatment interventions suggested by parents/caregivers instead of their clinical assessment and patient potential. This results in health professionals violating their patient's autonomy rather than creating an enabling environment to demonstrate and exercise their choices and informed consent.

When physiotherapists acknowledge an adolescent's opinion before agreeing to treatment interventions by communicating health interventions in a language or level of function that CP adolescents understand, they reduce perceptions of incapacity by their parents/caregivers because the physiotherapist actively demonstrates the adolescent's ability, both to understand, but to make an informed choice (Republic of South Africa, 2004). The physiotherapist also needs to consider the CP adolescent's values and cultural influences as this can impact their medical decisions. It is essential to consider these factors because physiotherapists must provide substantial evidence that CP adolescents do not have the decision-making capacity to refuse treatment before restricting their autonomy (Buchanan, 2004).

2.3 Adolescents' autonomy in medical treatment

The ethical principle of autonomy requires individuals to give informed consent to their health care without coercion or manipulation (Beauchamp and Childress, 2013). Autonomous individuals have the freedom to make decisions and to act based on their values and beliefs (Buchanan, 2004, Schmidt et al., 2020). Health professionals must balance the patient's autonomy and their professional obligation to protect them from harm. In this instance, medical capacity is the, "measure of how much value should be attached to respecting that autonomy" (Buchanan, 2004). Therefore, if everything was equal, the more capacity an individual has, the higher the probability of respecting their autonomy and their autonomy outweighing potential overall benefits to treatment. However, not everything is equal for CP adolescents, parents/caregivers' scepticism regarding their autonomy. CP adolescents without significant intellectual disability are not perceived to have higher functional abilities. Thus, parents/caregivers do not accept their health care decisions. When physiotherapists limit the autonomy of CP

adolescents based on their disability and not their maturity to make autonomous decisions regarding their health care, they are causing harm to their patients (Buchanan, 2004). For example, when a spastic quadriplegic adolescent refuses to participate in stretching exercises that reduce motor tone in their extremities during a physiotherapy session, forcing the intervention on the adolescent would cause more harm than not doing the intervention. The refusal to stretching exercises during a session is unlikely to cause immediate severe musculoskeletal complications like joint contractures, while the rejection of the patient who has expressed a need at that time will cause a breakdown in trust. A physiotherapist accepting the CP adolescents' decision would indirectly reduce the emotional harm parents' may cause when they perceive their children to lack capacity due to their physical disability by reinforcing their ability to consent. When physiotherapists accept the CP adolescent's decisions, their parents/caregivers are more likely to perceive them as autonomous because, as previously mentioned, parents rely on the health professional's decision rather than their adolescent's decision (Bernal, 2006, Keywood and Flynn, 2010, Wong et al., 1999). Thus, respecting the adolescent's refusal and finding alternative therapeutic interventions would be more appropriate than coercing participation in interventions and reducing parent/caregiver doubts.

2.4 Legal rights to medical treatment in South African

Coercing participation in medical treatment undermines the legal rights adolescents between the ages of 12 and 17 years have in South Africa to participate in medical and surgical treatment. (Republic of South Africa, 2005, Republic of South Africa, 2004).

Part 3 of South Africans Children's Act 38 of 2005 makes reference to the protective measures related to children's health. Section 129(2)(a)(b) states that:

"A child may consent to his or her own medical treatment or to the medical treatment of his or her child if –

(a) The child is over the age of 12 years; and

(b) the child is of sufficient maturity and has the mental capacity to understand the benefits, risks, social and other implications of the treatment."

(Republic of South Africa, 2005)

Thus, according to Section 129(2)(a)(b), CP adolescents without significant intellectual disability fulfil the Children's Act 38 of 2005 because they have the maturity to understand and consent to medical treatment when they comply with the four components of medical capacity. According to the Children's Act 38 of 2005, CP adolescents over the age of 12 years have the legal competency to make autonomous medical decisions regarding non-invasive medical treatments, like physiotherapy, so long as they understand the benefits, risks, social and other implications of the treatment (Republic of South Africa, 2005). Because of this, their parents/caregivers and health professionals cannot coerce them to participate in medical treatment interventions that they refuse. In addition, CP adolescents' can consent to, and by extension, refuse non-invasive physiotherapy medical treatment, despite their parent's assent to treatment (Republic of South Africa, 2005).

2.5 Conclusion

Since the psychological and emotional skills required to make decisions regarding health care are developed during adolescence, limiting CP adolescents' autonomy and medical decision-making capacity impedes learning how to make decisions and learning from the decision made (Sawyer and Rosenberg, 2020). It also puts them at risk of taking longer to develop autonomy and self-determination than other adolescents. CP adolescents may have a physical disability that requires parents/caregivers to assist and guide them through daily activities; however, it is not necessarily related to a lack of medical decision-making capacity. A physiotherapist should enhance self-determination in CP adolescents without significant intellectual disability and involve them in decision-making regarding their health care within the parameters of the law and according to the functional approach to capacity in decision-making. Furthermore, coercing a CP adolescent to participate in interventions that they refuse is classified as paternalism. The following chapter will address the moral and ethical obligations that physiotherapists have when treating CP adolescents who refuse medical treatment.

Chapter 3: Ethical obligations to respect CP adolescent's decisions to refuse medical treatment

3.1 Introduction

Persons living with disabilities are often subjected to conscious and unconscious biases when accessing the health care systems, especially individuals with intellectual

disabilities, who often face challenges locating and accessing appropriate medical care for their health needs (Johnson, 2016). Health professionals and individuals working in the medical community are often guilty of classifying persons with disabilities as abnormal and the majority of the population as normal, which has contributed to the cultural and social discrimination that persons with disabilities face when accessing health services (Johnson, 2016). When the medical community unintentionally places less value on the lives of persons living with disabilities by labelling them as abnormal, it leads to the unconscious bias and false assumptions that parents/caregivers have regarding their adolescent's abilities, particularly their physical and mental capabilities. Physiotherapists are responsible for their patients' physical well-being. However, this goes hand-in-hand with their patient's emotional and mental well-being due to the personal nature of their interaction (Edwards et al., 2005, Poulis, 2007). The personal nature of their relationship is affected when physiotherapists care for patients who experience discrimination, especially vulnerable groups, because it leads to ethical and medical dilemmas that affect decisions regarding patients' medical care (Tseng and Wang, 2021, Mandal et al., 2016). This chapter gives an account of care ethics as a moral theory in contrast to utilitarian and deontological approaches that physiotherapists should apply when treating CP adolescents over 12 years without significant intellectual disabilities. In addition, the role of bioethical principles in the care of CP adolescents.

3.2 The role of utilitarianism and deontology in medical ethics

Decision making in medical ethics is primarily influenced and dominated by utilitarian and deontological approaches (Mandal et al., 2016). The utilitarian approach to decision making is based on Jeremy Bentham's principle of utility and maximising

happiness (Tseng and Wang, 2021). According to utilitarianism, determining whether an act is wrong or right is embedded in the consequences of that act. A decision or act that produces the most significant amount of happiness for the majority of the people involved and which results in the most favourable outcome for those people is the right decision. Despite the positive or negative effect, it will have on people who disagree with the majority. For example, in medical ethics hospitals set targets for the resuscitation of newly born premature babies based on the availability of resources and time (Mandal et al., 2016). Thus, if there are no resources available to treat a newly born baby and resuscitations is required to save their life, it is in the hospital's best interest not to resuscitate even if the parents would like the hospital to resuscitate their child.

Furthermore, when the utilitarian approach is applied in instances where CP individuals refuse physiotherapy interventions, this decision does not maximise the CP adolescent's utility and happiness and the decision should not be accepted. When parents/caregivers and physiotherapists agree that the therapy intervention is in the adolescent's best interest despite the adolescent's refusal. The intervention will continue against the adolescents will, even if they are harmed due to the decision, because the majority agrees that it will yield the most favourable outcome and to the utilitarian's, "the end justifies the means" (Mandal et al., 2016).

Therefore, a utilitarian approach to medical ethics does not always yield the most appropriate decisions because it can harm some while others benefit. Deontology provides an alternative perspective to addressing dilemmas in medical ethics because a deontological approach is based on obligations and duties when making a decision

(Tseng and Wang, 2021). According to Immanuel Kant, human beings are rational beings with an intrinsic worth that have hopes and dreams; thus they should be treated with dignity and respect (Tseng and Wang, 2021, Rachels and Rachels, 2019). Unlike utilitarianism, which is centred around promoting the most significant wellbeing for the greatest amount of people. Deontology is centred around the individual and in this case, intentions are valued more than consequences. Promoting self-reliance and autonomy are essential in respecting the decision making of individuals.

Deontologists generally accept that no harm should be inflicted on any individual, even if the presence of harm yields positive consequences (Tseng and Wang, 2021, Mandal et al., 2016). A deontological approach would assist in supporting CP adolescents' refusal to participate in physiotherapy interventions due to the potential (short term discomfort) harm associated with therapy. However, iatrogenic treatment effects are a part of medical interventions. It would be appropriate for physiotherapists to choose interventions that promote the long-term welfare of their CP adolescent and reduce pain and suffering. It is a physiotherapist's duty to provide care for their patient, and not providing treatment could lead to adverse negative medical complications/consequences for the CP adolescent in the future. Thus, an alternative ethical theory is required to balance a deontological and utilitarian approach to medical ethics.

3.3 The role of ethics of care in physiotherapy

Unlike traditional ethical theories, the foundations of an ethics of care are not based on duties, consequences or bioethical principles to health care. It is a concept that can be understood as explained in the words of James Rachels and Stuart Rachels:

> "…a conception of moral life as a network of relationships with specific people, and it sees "living well" as caring for those people, attending to their needs, and maintaining their trust." (Rachels and Rachels, 2019) p.163

Rachels and Rachels describe the essential characteristics of this theory, developed by Carol Gilligan, as a network of relationships is of paramount importance, and care is realised when someone cares for another person (Maio, 2018). Gilligan takes it a step further by stating that ethics of care requires a personal approach and inner judgment instead of external obligations (Maio, 2018). Gilligan's account is appropriate for physiotherapists as they are often independent practitioners with unique patient relationships (Kirsch, 2018). An ethics of care approach may seem to lead to physiotherapists being overconsumed by patient relationships and unable to make objective decisions. This is not the case. The Paul Ricoeur approach to an ethics of care is most appropriate in medical decisions which involves allied therapies because it demonstrates that caring and empathy lead to objective decisions, and allied therapists providing holistic care to their patients. Ricoeur has unequivocally stated that care is a person's ethical duty and that it can be simply put as "with the other and for them" (Maio, 2018). The phrase is understood as the reciprocal relationship

between two people and the intention of the relationship as being to care for another person. When health care professionals provide care to their patients, this experience changes aspects of their personal and professional lives to better both.

Health care professionals are challenged with facing unfamiliar situations that expand their professional and personal views of life through the care they provide patients. Ricoeur further engages with this ethical approach by explaining that, while the patient is the care receiver, they are also the giver to the health care professional because they challenge the values and inner judgements of the health care professional (Maio, 2018). While the patient is perceived as vulnerable because they place their care in the hands of the health care professional, Ricoeur explains that a shared vulnerability exists in the relationship. For health care professionals to provide care, they need to see themselves as related to the patient, communicate with the patient, and be empathic in their responses when attending to the patient's needs. Ricoeur states this as a "search for equality in the midst of inequality" (Ricoeur, 1992) p. 192.

Physiotherapists apply Ricoeur's ethics of care when treating adolescents diagnosed with long-term disease when these are degenerative, because their diagnosis leads to perceptions of them being incapable of making decisions regarding their health care and thus, as being less than others in society. It is understood that adolescents are unlikely to always agree to extensive daily treatment plans that prevent further disease because of the high demand it places on their bodies. There is also a need on the part of the patient to grasp as much quality of life, and normalcy, as possible. Therefore, physiotherapists are obligated to find alternative treatment plans to achieve intended goals because these adolescents have different perceptions of their well-being that

are influenced by their quality of life, the absence or presence of preventative treatment methods and their disease (Boldt, 2018). In this case, if Ricoeur's account of ethics of care is applied, CP adolescents over 12 years, without significant intellectual disability, can refuse aspects of their physiotherapy despite parental/caregiver consent to treatment simply because it enables them to take control over their circumstances and improve their own quality of life. The physiotherapist, therefore, has a moral obligation to accept the CP adolescent's decision. According to Ricoeur, physiotherapists would have a duty and responsibility to uphold their relationship with CP adolescents and provide them with the care they need. Parents/caregivers are perceived as experts in their CP adolescent's life. They are often perceived to be more knowledgeable regarding successful treatment options. While physiotherapists should respect this, it should not come at the expense of the best interests of the patient (Jeglinsky et al., 2012). The CP adolescent is the patient, and it is this relationship that the physiotherapist is required to uphold. Much like adolescents at risk of long-term diseases, CP adolescents have different perceptions regarding their health care than their parents/caregivers, and physiotherapists are unable to understand this unless they acknowledge the unique nature of their patients as an end in themselves. When physiotherapists disregard refusal of treatment because of an inability to see the world from the perspective of CP adolescents, this is harmful and unjust, as it is discrimination, and they are not challenging their inner judgements and values for the good of their patients. Instead, they are taking the perception of parents/caregivers who, in the case of CP adolescents, are often motivated by the concept of being a 'good parent' (Greenberg and Weingarten, 2015), rather than enabling their child to be a 'good-enough' adult. A 'good parent' is characterised as making health care decisions in the adolescent's best interest,

protecting their adolescent from harm and suffering. While parents/caregivers have good intentions, their actions may cause harm to the adolescent's overall well-being because the decision regarding their health care is being made without their consent, and in doing this, it reduces their humanness.

Furthermore, following Ricoeur's account of ethics of care, respecting a patient's autonomy is intertwined with providing care so long as their decisions do not compromise the patient's well-being in the long term. The relationship in care ethics requires caring, communication and collaboration in decision making. A care ethics approach to patient autonomy requires the physiotherapist to avoid doing both physical and emotional harm to their CP adolescent patients. This includes physiotherapists accepting the CP adolescent's decision to refuse their help, even if refusing the help may be perceived as an incorrect decision, so long as their decision does not harm others, and the CP adolescents have made the decision for themselves (Boldt, 2018). Physiotherapists ought to trust that CP adolescents have the self-determination to engage with themselves, their health care professionals, parents/caregivers and other significant individuals in their lives prior to making a decision (Boldt, 2018). When physiotherapists allow their CP adolescents to be autonomous, they have created an ongoing dialogue that is not limited to verbal communication but also nonverbal communication such as gestures and sounds. In line with Ricoeur's approach to care ethics, autonomy can be understood as the internal dialogue whereby a person forms their own opinions of what is in their best interest through reasoning and evaluating their own and everyone's point of view (Boldt, 2018). Therefore, by consulting everyone in their environment and taking their perspectives into account, their decision is intertwined with others. According to

Ricoeur, if physiotherapists are to care about their own will and freedom, they ought to care about their patients' autonomy. When physiotherapists care about their own freedom, goodwill and passions, then they should be concerned about how others perceive them from their point of view (Boldt, 2018). Therefore, if they cannot see themselves through their CP adolescent patients' eyes, they will not be able to value or appreciate their CP patients' freedom, autonomy, goodwill, and passions, thus, conceding to decisions made by parents/caregivers. Ricoeur's account of care guides physiotherapists in health care dilemmas because refusing a service that can potentially promote well-being is perceived as counter-intuitive in society. However, physiotherapists are encouraged to interact with CP adolescents to come to a mutual decision without manipulating them to change their decision or by choosing to ignore their decision, and continue with treatment, regardless.

Ultimately, when a CP adolescent's ability to partake and express their verbal or non-verbal refusal to treatment is threatened, the interaction is no longer equal and becomes "ethically dubious" (Boldt, 2018). Ricoeur claims people should treat others like they would like to be treated. The opposite would be unethical because it would assume that they are incapable of evaluating, reflecting, and respecting themselves and others (Boldt, 2018). Ricoeur's claims are specifically applicable in the South African context, where a community and togetherness are part of the fabric of society. The word Ubuntu is a common Southern African expression that has been broadly understood as humanness since the 1960s (Metz, 2010). It is the ideology that in society when humans make connections with other humans, they establish an inter-related bond and have a connection with one another. Furthermore, it is this relationship that gives them moral status in society. It is encapsulated in the Nguni

language as ‘umntu ngumntu ngabantu’ and translated to ‘a person is a person through other persons’ in English (Metz, 2010). Ubuntu ethicists believe that people who live in communities have a shared identity because they have something in common with each other, and they share solidarity because they stand together (Metz, 2010, Metz, 2011). Thus, much like Ricoeur’s claims, treating some as if they are less than others in society would be unethical and deny their capabilities as equal members of society.

Physiotherapists ought to trust that when they are absent from treatment sessions and the CP adolescents make a decision regarding their health care, their decision will be accepted and respected without interference from others because they are equal participating individuals in this society (Boldt, 2018). This reaffirms that physiotherapists are responsible for engaging with patients, empowering and encouraging them to make informed autonomous decisions to balance their care with their autonomy, rather than disregarding decisions that differ from their own. Furthermore, physiotherapists ought to support CP adolescents to avoid feelings of insecurity and second-guessing themselves when they make other decisions in their life because others may perceive them as being incompetent of making autonomous decisions.

3.4 The role of ethical principles in physiotherapy

To respect the autonomy of the CP adolescent to refuse physiotherapy interventions, physiotherapists need to balance autonomy with beneficence and non-maleficence (Beauchamp and Childress, 2013). Non-maleficence and beneficence require

physiotherapists to care for their patient's well-being. Beneficence requires physiotherapists to provide and apply treatment interventions that enhance their patient's well-being. In comparison, non-maleficence requires physiotherapists to provide and apply treatment interventions that have few iatrogenic side effects and enhance their patient's well-being. As previously stated, physiotherapists and parents/caregivers may cause unintended harm when they disregard the CP adolescent's decision-making capacity regarding their health care. Physiotherapists need to be aware of the unconscious bias that affects the quality of care persons with disabilities experience, especially adolescents that are often identified and defined by their disabilities and stigmatised for lacking something rather than what they have (Johnson, 2016, United Nations, 2006 , Durham et al., 2014). Applying care ethics in these scenarios will assist physiotherapists in reducing these prejudices as they will have the hindsight to empathise with their patients and advocate for treatment interventions that CP adolescents perceive as being in their best interest. Parents are aware of the physical differences between their adolescents and other adolescents in society and want to protect their children from being identified as different from other children. So much so that they advocate for treatment interventions that reduce the physical differences rather than those that increase the adolescent's happiness (Ferreira et al., 2020). Thus, physiotherapists need to do good by advocating for treatment interventions that enhance CP adolescents' qualities to the extent to which the disability allows, rather than enforcing treatment interventions that emphasise the presence of a disability.

Furthermore, physiotherapy interventions result in adolescents experiencing iatrogenic treatment effects because medical interventions have positive and negative

effects. Physiotherapists need to ensure that when there is a degree of discomfort, they continue to uphold the patient's interest and avoid intentionally causing harm (Beauchamp and Childress, 2013, Kirsch, 2018). Thus, when CP adolescents express their refusal to continue with physiotherapy interventions based on a discomfort level, physiotherapists need to choose less uncomfortable interventions while still in patients' best interest rather than continuing with an intervention to conform to the parent's perceptions of appropriate interventions.

3.5 The influence of the 'best interest principle' in CP adolescent care

The best interest principle is of great importance in the treatment of children. The UNCRC acknowledges as one of their four core general principles and the most appropriate application requires physiotherapists to protect the physical and emotional health and safety of their patients (Iriane et al., 2019, United Nations, 1989). It is often a legal and ethical challenge to decide who is responsible for determining what is in an adolescents best interest, especially when adolescences have capacity to make informed decision. It is therefore important that a collaborative effort in a share-decision making is established between parents, health care professionals and patients is established to determine what is in the child's best interest. Physiotherapist who treat CP adolescent should apply the best interest principle to child care as a framework to decision making rather than solely relying on the principle. This principle has limitations because it may not always yield the best solution, although it helps to ensure that a CP adolescent's dignity is

maintained at all times, because CP adolescents and parents may have conflicting opinions.

3.6 Conclusion

In this section, ethics of care, precisely Ricoeur's approach to care ethics, has been referenced as the most appropriate moral theory when treating CP adolescents. Moreover, when physiotherapists apply Ricoeur's approach when treating CP adolescents with long-term illnesses, they can reflect on the unconscious biases they have, which may affect treatment outcomes (Boldt, 2018). In addition, care and the bioethical principles of non-maleficence, beneficence and autonomy are interrelated. If physiotherapists are to act in the best interest of their CP adolescents, then they ought to allow them to be autonomous in their decision-making while ensuring that they are protected from severe harm. When parents/caregivers override CP adolescent's refusal to participate in health care interventions, then they cause unintended harm that could be avoided through communication, dialogue and trust that in order for CP adolescents without severe intellectual disability to make medical decisions, they need to be able to reflect on all the available knowledge and opinions prior to making their decision. Thus, they are guided by their parents rather than being coerced or manipulated and their free will being limited as a result. The following chapter will discuss the professional guidelines and legalisation that guide and govern a physiotherapist's acts when treating CP adolescents.

Chapter 4: Professional and legal obligations to respecting CP adolescent's decision to medical treatment

4.1 Introduction

In South Africa, physiotherapists are registered health care professionals with a regulatory council called the Health Professionals Council of South Africa (HPCSA), which guides professional conduct and protects the public's well-being. The “ethical guidelines for good practice in health care professionals” booklet set out by the HPCSA acknowledges that a shared trust relationship exists between health care professionals and their patients (Health Professionals Council of South Africa, 2016). Furthermore, health care professionals commit themselves to life-long learning and sound ethical practices to ensure that they serve the interests and well-being of their patients (Health Professionals Council of South Africa, 2016). The nature of physiotherapy treatment requires a close, trusting, emotional and physical relationship with the patient. The physiotherapist is thus required to apply professional, clinical and ethical standards to practice to ensure that they uphold the respect and dignity of their patients (Poulis, 2007). This chapter outlines the appropriate South African professional guidelines, South African and international laws that physiotherapists need to apply to respect the decisions CP adolescents over the age of 12 without significant intellectual disabilities make regarding their health care

4.2 Professional guidelines to caring for Cerebral Palsy adolescents

Thus far, an argument has been made that, physiotherapists ought to accept the refusal of CP adolescents according to Ricoeur’s account of care ethics and their duty to respect the autonomy of their patients, so long as their decisions do not harm

them and others. The following section will focus on how a physiotherapist can apply the HPCSA standards and core ethical values to address dilemmas that occur in clinical practice when treating CP adolescents. The standards and core ethical values booklet of “ethical guidelines for good practice in health care professionals’” presents a range of principles of good practice that all health professionals should act in accordance with when gaining a patients informed consent to treatment.

The notion that physiotherapists should do what is in their patient's best interest is highlighted by 2.3.1, “respect for persons: health care practitioners should respect patients as persons, and acknowledge their intrinsic worth, dignity, and sense of value”(Health Professionals Council of South Africa, 2016). The first standard in the HPCSA guideline is specific to the conduct of physiotherapists as supported by Ricoeur’s account of ethics of care because physiotherapists are expected to treat their patients with dignity and recognise their sense of value (Health Professionals Council of South Africa, 2016). Physiotherapists ought to treat CP adolescents and persons with long-term illnesses with respect and appreciate that they have intrinsic worth; thus, their decision should not be overridden by their parents/caregivers when they refuse physiotherapy interventions. Furthermore, physiotherapists provide a service to their CP adolescents and the community that is primarily aimed at developing, maintaining and restoring function therefore, they promote well-being and should act in the best interest of their patients and communities (Poulis, 2007).

The second standard refers to one of the bioethical principles of non-maleficence, it states in 2.3.2, “best interests or well-being: non-maleficence: health care practitioners should not harm or act against the best interests of patients, even when

the interests of the latter conflict with their own self-interest" (Health Professionals Council of South Africa, 2016). While the third standard in 2.3.3 makes reference to the bioethical principle of beneficence by stating that, "best interest or well-being: beneficence: health care practitioners should act in the best interests of patients even when the interests of the latter conflict with their own personal self-interest" (Health Professionals Council of South Africa, 2016). Two common themes arise in beneficence and non-maleficence: the best interest and a conflict of interests between the health professional and their patient. Physiotherapists ought to conduct themselves professionally because they have a professional responsibility to act in the patient's best interest even when their interest conflicts with the patient's interest. Ricoeur's account of ethics of care mentions that by virtue of health professionals being experts in their field, they are required to correct their patients when they make medical decisions that do not promote their well-being (Boldt, 2018). However, they should not manipulate or coerce patients to accept health professionals' or parents/caregivers' points of view of what is in their best interest. Physiotherapists should communicate with CP adolescents and establish a dialogue that allows CP adolescents to freely express their reasons for rejecting the proposed intervention before making a mutual decision regarding medical treatment.

Moreover, in continuing with the bioethical principles, the fifth standard refers to autonomy and states that, "autonomy: health care practitioners should honour the right of patients to self-determination or to make their own informed choices, and to live their lives by their own beliefs, values and preferences" (Health Professionals Council of South Africa, 2016). Ricoeur's account of autonomy supports the HPSCA's description of autonomy in section 2.3.5. Ricoeur speaks about the internal

dialogue individuals have to form their own will, which allows them to make their own informed choices based on a combination of their own and other individual's points of view. Thus, if physiotherapists respect a CP adolescent's refusal to therapy, they acknowledge that caring for CP adolescents and respecting their autonomy go hand-in-hand. CP adolescents have their interests, preferences, values, and beliefs shaped by their peers, parents/caregivers, and other individuals in their environment. Suppose physiotherapists are to promote their patient's self-determination. In that case, they should allow them to make autonomous decisions and learn from their mistakes while guiding them and ensuring their overall safety at all times.

Throughout the HPCSA guidelines for good practice, there are elements of Ricoeur's account of ethics of care that feature in the text. For example, Ricoeur expresses how physiotherapists' relationships with their patients impact their character and professional conduct. The HPSCA's guidelines describe this as integrity in section 2.3.6, "integrity: health care practitioners should incorporate these core ethical values and standards as the foundation for their character and practice as responsible health care professionals" (Health Professionals Council of South Africa, 2016). CP adolescents and individuals with the long-term illness have unique relationships with their physiotherapists as a result of the ongoing treatment they receive throughout their lives thus, they help shape the ethical values of physiotherapists who interact with and care for CP adolescents.

One of the foundations of care ethics is a trusting relationship between the caregiver and the care receiver, and this is reflected in section 2.3.7, "truthfulness: health care practitioners should regard the truth and truthfulness as the basis of trust in their

professional relationships with patients”(Health Professionals Council of South Africa, 2016). Similar to the ethics of care, relationships founded on trust and truthfulness are fundamental; physiotherapists are required to be truthful to CP adolescents regarding the risk and benefits of treatment and the absence of treatment for CP adolescents to make informed decisions. In addition, they are required to trust that their refusal took careful consideration of the risk and benefits of refusing treatment interventions.

The HPCSA guidelines also require physiotherapists to be compassionate towards the patients and empathise with them as described in 2.3.9, "compassion: health care practitioners should be sensitive to, and empathise with, the individual and social needs of their patients and seek to create mechanisms for providing comfort and support where appropriate and possible (Health Professionals Council of South Africa, 2016). Ricoeur’s account of ethics of care echoes this by stating that physiotherapists are required to empathise with their patients and to see themselves from the point of view of the CP adolescent. This is inclusive of their social needs to participate in physical activity and creative activities that allow independent participation without the influence of parents/caregivers and health care professionals.

If physiotherapists are to act in a manner that is compassionate and empathic then the HPCSA guideline of 2.3.11, “ justice: health care practitioners should treat all individuals and groups in an impartial, fair and just manner” will be fulfilled (Health Professionals Council of South Africa, 2016). It will be fulfilled because physiotherapists will most likely be impartial in their professional conduct when treating CP adolescents and other adolescents with disabilities. They will be fair in

assessing whether the CP adolescent is making an informed decision regarding their health care because, like adolescents without CP, they too have the capabilities to evaluate and reflect on the benefit and risks of treatment before refusing care.

In addition, Ricoeur's account of ethics assumes that health care professionals are experts in their practise fields and the HPCSA guidelines encourage health professionals to commit themselves to lifelong learning as described in guideline 2.3.12, "Professional competence and self-improvement: Health care practitioners should continually endeavour to attain the highest level of knowledge and skills required within their area of practice" (Health Professionals Council of South Africa, 2016). Lifelong learning is essential because it allows the physiotherapist to enhance their current skills, to learn new skills and innovative ways of treating CP adolescents, as well as being aware of limitations so that they can refer to other professionals for assistance. Finally, the HPCSA mentions human rights in guideline 2.3.4, "human rights: health care practitioners should recognise the human rights of all individuals" (Health Professionals Council of South Africa, 2016). Physiotherapists are required to provide adequate services that are inclusive and protect the rights of CP adolescents. CP adolescents are human beings thus, they are entitled to all the rights that human beings have (Dziva et al., 2014).

4.3 South African and international law for caring for cerebral palsy adolescents

Many countries worldwide have different human rights, but the principle idea that human rights are universal and ought to promote dignity, respect and equality still remains (Dziva et al., 2014). While human rights are intended to promote equality,

vulnerable persons in society are inevitably likely to have their rights taken advantage of and for this reason they have additional rights (Dziva et al., 2014). The Constitution of South Africa sets out the human rights of all South Africans and section 28 makes specific reference to children's rights. Moreover, section 28 subsection (1) (d) is a non-derograble right that states:

(1) “Every child has the right –

(d) To be protected from maltreatment, neglect, abuse or degradation.”

(Republic of South Africa, 1996, 1996)

When CP adolescents are forced to participate in activities and are hurt as a result, this violates the essence of a non-derograble right. Forcing CP adolescents over the age of 12 without significant intellectual disability to participate in physiotherapy interventions they refuse to despite the parental/caregiver's consent to treatment that causes physical harm may be perceived as abuse/assault. The parent/caregivers may consent to the physiotherapy interventions, but if the CP adolescent is coerced into interventions and is harmed; as a result, the physiotherapist is liable for the harm caused and should be reported to the HPCSA for an investigation of ethical conduct and a police official for a criminal investigation (Republic of South Africa, 2005). A 2015 study by Hoffmann and Nortje found that physiotherapists who carry out interventions without patient consent to be the second most common HPCSA ethical transgression among South African physiotherapist in 2007-2013 (Hoffmann and Nortjé, 2015). Therefore, it is in the physiotherapist's best interest to communicate with the CP adolescent and have informed consent before engaging in physiotherapy interventions. Furthermore, refusing to accept CP adolescent's refusal to

physiotherapy interventions because of their diagnosis and misconceptions that arise as a result of this is discrimination.

Physiotherapists who treat CP adolescents should be aware of the influence that the 1989 UNCRC legislation has had on protecting the rights of children with disabilities internationally (United Nations, 1989). The UNCRC document was the first human rights agreement to include that children and persons with disabilities are to be protected from discrimination in society. The UNCRC document paved the way for other organisations to protect the rights of children with disabilities, such as the UNCRPD and the Children's Act 38 of 2005 (United Nations, 2006 , Republic of South Africa, 2005). Physiotherapists can reference the UNCRC, UNCRPD and the Children's Act 38 of 2005 when addressing discrimination towards CP adolescents, as reflected in Table 1.

Table 1: Sections in the UNCRC, UNCRPD and Children's Act 38 of 2005 (Children's Act) that protect Cerebral Palsy adolescents from discrimination.

UNCRC	UNCRPD	Children's Act
Article 2 "1. States Parties shall respect and ensure the rights … to each child within their jurisdiction without discrimination of any kind, irrespective of the child's … disability, birth or other status. 2. States Parties shall take all appropriate measures to	Article 5 "1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law. 2. States Parties shall prohibit all discrimination on the basis of disability	Chapter 2 "6(d) protects the child from unfair discrimination on any ground, including on the grounds of the health status or disability of the child …"

ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians …"	and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds. Article 8 1. States Parties undertake to adopt immediate, effective and appropriate measures: … (b) to combat stereotypes, prejudices and harmful practices relating to persons with disabilities … (c) To promote awareness of the capabilities and contributions of persons with disabilities Article 25 States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability."	

The United Nations Convention of the Rights of Children

The UNCRC places the responsibility on states parties to ensure that all children are treated equally and with respect irrespective of their disability and make specific mention of the birth status in article 2 (United Nations, 1989). This is essential to CP adolescents because they are treated differently due to their birth status. While it is

essential to make sure they receive adequate medical attention for their needs, it should not result in them being treated differently by physiotherapists and parents/caregivers. Furthermore, the UNCRC explicitly states that they should be protected from discrimination that arises from the opinions of their parents/caregivers in article 2 (United Nations, 1989). Physiotherapists ought to reference this document when parents/caregivers force CP adolescents to participate in rehabilitation because their parents/caregivers believe that it is in their CP adolescent's best interest, despite their refusal. Physiotherapists should take the CP adolescent's opinion into consideration to protect them from harm and discrimination.

The United Nations Convention Rights of Persons with Disabilities

The UNRPD document reiterates the responsibility of state parties to protect the rights of persons with disabilities because they have equal entitlements to the law as persons who are not disabled and should be protected from discrimination (article 5) (United Nations, 2006). In addition, state parties should have procedures in place to address the stereotypes people may have towards disabled persons and their capabilities (article 8) (United Nations, 2006). Physiotherapists have the duty of enhancing the physical abilities of their CP adolescents and raising awareness to parents/caregivers regarding their capabilities, rather than forcing them to participate in rehabilitation interventions that are harmful and unpleasant (article 8 and 25) (United Nations, 2006).

The Children's Act 38 of 2005

Finally, the South African Children's Act references the UNCRC in chapter 2, section 6(d), when it refers to non-discrimination based on disability or health status (Republic of South Africa, 2005). Physiotherapists have access to documents and legislation

that explicitly state their duty to protect CP adolescents from discrimination and treat them as equals in society. The physiotherapist is also obligated to promote CP adolescents' freedom of expression according to the UNCRC, UNCRPD and Children's Act, as seen in Table 2.

Table 2: Sections in the UNCRC, UNCRPD and Children's Act 38 of 2005 (Children's Act) that promote CP adolescents' freedom of expression of their views

UNCRC	UNCRPD	Children's Act
Article 12 "1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. Article 13 "1. The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.	Article 3 "The principles of the present Convention shall be: (a) respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; … Article 7 States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right. Article 21 …right to freedom of expression and opinion,	Chapter 2 "10. Every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child …. and views expressed by the child must be given due consideration."

2. The exercise of this right may be subject to certain restrictions, but these shall only be such as are provided by law …"	including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice (b) accepting and facilitating the use of … all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions …"	

The United Nations Convention of the Rights of Children

The UNCRC supports the participation of CP adolescents in matters concerning their well-being. It further specifies that they have the right to make their opinions known and their views will be given due consideration in accordance with their maturity and age (article 12) (United Nations, 1989). It is important for physiotherapists to be aware of this point because CP adolescents are transitioning into adulthood and they need to have self-awareness regarding the importance of their decisions and the impact they have on their life. While article 13 of the UNCRC acknowledges that CP adolescents have the right to express themselves freely and that this can be verbally or non-verbally, through writing or technological devices, it does not explicitly state that they can express themselves through gestures (United Nations, 1989). However, the reference to other forms of expressions implies that CP adolescents can use their unique form of communication to express their decisions that is not verbal and this should be respected by their parents/caregivers. If their decisions are to be restricted then it should be supported by the law of the region that they are in (United Nations, 1989).

The United Nations Convention Rights of Persons with Disabilities

The UNCRPD document confirms that it is the responsibility of state parties to ensure that CP adolescent's right to freedom of expressions is respect and given due consideration in accordance with their maturity and age (article 7) (United Nations, 2006). Much like the UNCRC document, article 21 of the UNCRPD document refers to the an individual's freedom of expression and opinion however, it mentions that CP adolescents can make their views and choose the type of communication method they prefer (United Nations, 2006). Therefore, when CP adolescents use gestures to refuse to participate in physiotherapy treatments their decision should be respected by their health professional, as well as parents/caregivers. In addition, article 3 of the UNCRPD document explicitly states that CP adolescents have the right to make autonomous decisions and their individuality should be respected because they have inherent dignity like all human beings (United Nations, 2006).

The Children's Act 38 of 2005

Finally, the Children's Act reiterates CP adolescent's rights to the freedom of express of their views and to participate in matters concerning their life much like the UNCRC and UNCRPD documents (United Nations, 1989, United Nations, 2006 , Republic of South Africa, 2005). However, it also mentions the 'stage of development' which is essential for physiotherapists to consider when treating CP adolescents (Republic of South Africa, 2005). Parents/caregivers tend to think that they always know what is in their adolescent's best interest. However, as CP adolescents go through the different stages of development they mature and have their interest and opinions that may differ from their parents. Physiotherapists ought to acknowledge this and involve CP

adolescents in decisions regarding their health care. In addition, physiotherapists should promote the participation of CP adolescents in their health care and society as expressed in Table 3

Table 3: Sections in the UNCRC, UNCRPD and Children's Act 38 of 2005 (Children's Act) that promote participation of Cerebral Palsy adolescents in their health care and the community

UNCRC	UNCRPD	Children's Act
Article 23 "1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. 3. recognizing the special needs of a disabled child … the disabled child has effective access to and receives … health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development	Article 25 "… States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation … State Parties shall: (b) provide those health services needed by persons with disabilities specifically because of their disabilities, including … services designed to minimize and prevent further disabilities … (d) require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity,	Chapter 2 "11(b) making it possible for the child to participate in social, cultural, religious and educational activities, recognising the special needs that the child may have (c) providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community …"

Article 31 1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.”	autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care. Article 30 2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.”	

The United Nations Convention of the Rights of Children

Article 23 of the UNCRC document requires state parties to acknowledge that children with physical and mental disabilities deserve to experience a decent and fulfilling life in environments that enable community participation, respect of dignity and enhance self-reliance (United Nations, 1989). Also, acknowledging that children with disabilities may have special needs and should have adequate access to health care services, like physiotherapy and be prepared for adulthood where they will be expected to engage in society and employment. Article 31 of the UNCRC document supports the right for CP adolescents to participate in physical activity creative activities and to choose when they would like to rest and not participate in activities (United Nations, 1989). Thus, when CP adolescents refuse to participate in physiotherapy, their health care professional and parent/caregivers should respect their decision and allow them the opportunity to explore other interests other than rehabilitation. Refusal is not

necessarily once-off or permanent, within the ongoing care relationship, the CP adolescent can change their initial decision in the future based on healthcare educational inputs and other factors.

The United Nations Convention Rights of Persons with Disabilities

Access to health care services and rehabilitative services is a priority in the UNCRPD document. It is mandatory for state parties to ensure that persons with disabilities physically access health services, the services are appropriate to their specific health needs and the services aim to prevent and reduce further disability (article 25) (United Nations, 2006). According to article 25(d), physiotherapists are required to deliver care that is equal across all adolescents, despite their disability, and their informed consent to treatment intervention should be obtained (United Nations, 2006). When parents/caregivers force CP adolescents to participate in a treatment intervention they refuse, the physiotherapist should acknowledge their patient's right to refusal respect their autonomy and treatment with dignity according to article 25(d) (United Nations, 2006). Furthermore, the physiotherapist should appreciate that their CP adolescents have the maturity to reason and weigh up their options prior to making a decision, and they should create an environment that allows them to develop their independence in decision making 9 (article 30) (United Nations, 2006).

The Children's Act 38 of 2005

Finally, the Children's Act emphasises the need for a physiotherapist to acknowledge and that CP adolescents may have additional medical, social and emotional needs in order for them to participate in the communities (Republic of South Africa, 2005). Moreover, the physiotherapist should make previsions to guide and encourage CP

adolescents to participate in their community (Republic of South Africa, 2005). Additionally, they should protect their CP adolescents from harm, as expressed in Table 4.

Table 4: Sections in the UNCRC, UNCRPD and Children's Act 38 of 2005 (Children's Act) that protect Cerebral Palsy adolescents from harm

UNCRC	UNCRPD	Children's Act
Article 19 "1. States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment … while in the care of parent(s), legal guardian(s) or any other person who has the care of the child."	Article 17 "(c) every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others."	Chapter 2 "7(l) the need to protect the child from any physical or psychological harm that may be caused by - (i) subjecting the child to maltreatment, abuse … or exposing the child harmful behaviour; or …"

The United Nations Convention of the Rights of Children

The UNCRC document explicitly mentions that states parties have the responsibility to safeguard children from all types of mental and physical abuse or maltreatment, extending to when they are in the presence of their parents/caregivers (United Nations, 1989). Therefore, physiotherapists have a duty to protect their CP adolescents from harm and avoid causing intentional harm, especially when parents/caregivers are present and advocate for the treatment intervention due to the

benefits produced as a result. Additionally, physiotherapists need to apply their clinical reasons to know the extent to which the iatrogenic side effects of treatment violate the dignity and autonomy of CP adolescents.

The United Nations Convention Rights of Persons with Disabilities

In the same way, the UNCRPD affirms that the mental and physical well-being of CP adolescents should be respected at all times and they should be treated as equals to their peers without CP (United Nations, 2006).

The Children's Act 38 of 2005

Finally, the Children's Act upholds the rights of CP adolescents to be protected from mental and physical harm. However, section 7(i) it explicitly states that CP adolescents should not be exposed to maltreatment or behaviour that is harmful to their well-being (Republic of South Africa, 2005). Thus, when CP adolescents make it known that treatment interventions are causing them harm, physiotherapists should communicate with their patients and respect any decision regarding the continuance of the intervention.

4.4 Conclusion

The establishment of the clinical guidelines for good practice document by the HPCSA has set a foundation for physiotherapists and other health professionals to treat their patients with respect and dignity. At the same time, holding all health professionals accountable to the self-development of skills and relevant knowledge regarding their scope of practice (Health Professionals Council of South Africa, 2016). The right to be

treated with dignity and respect is fundamental to all guidelines and legislation both national and international. It demands that all CP adolescents be protected from discrimination and maltreatment from their parents/caregivers and health professionals (Health Professionals Council of South Africa, 2016, United Nations, 1989, United Nations, 2006 , Republic of South Africa, 2005, Republic of South Africa, 1996). The UNCRC document paves the way for other international documents and legislation by acknowledging that CP adolescents are a vulnerable group in society whose rights need to be protected and promoted to help them become self-reliant adults in the future (United Nations, 1989). Thus, it is clear that physiotherapists have a responsibility and a duty to communicate with their CP adolescents and respect their decisions regarding their health care.

Chapter 5: Conclusion

The final chapter of this research report sums up the arguments made in support of the thesis statement that it is ethically and legally permissible for CP adolescents over the age of 12, without significant intellectual disability, to refuse physiotherapy despite parental/caregiver consent to treatment.

Denying CP adolescents the opportunity and right to be involved in decisions regarding their health care is not ethically or legally justified because it can cause psychological, physical and social harm to the individual. Research into the quality of life between adolescents and CP adolescents has shown that CP adolescents have a reduced quality of life and do not live fully independent lives from their parents/caregivers (Rosenbaum et al., 2007, Ferreira et al., 2020, Wintels et al., 2018,

Conchar et al., 2016). The dependence on parents/caregivers is associated with the accompanying impairments to CP, such as communication, feeding, hearing and behavioural impairments (Rosenbaum et al., 2007). Parents/caregivers assume that CP adolescents require assistance in all aspects of their lives and decision making, and they tend to focus on the physical impairments. In multiple quality-of-life research investigations, parents/caregivers reported lower scores in physical health-related questions than CP adolescents, and when adolescents had more chronic illnesses, they were most likely to underestimate their overall abilities. When parents/caregivers underestimate their childrens capacities they limit they opportunities to explore their environment and establish new ways of achieving the intended outcome. Therefore, leading to CP adolescents having psychological and social barriers to trying new things without their parents/caregiver's consent. Most of the quality-of-life perceptions were based on their expectations and experiences instead of adolescents' lives (Ferreira et al., 2020, Jeglinsky et al., 2012, Conchar et al., 2016, Büğüşan et al., 2018). The disparity in adolescent and parents/caregiver quality of life reporting is essential to preventing autonomy and loss of self-determination in CP adolescents. The stress that parents/caregivers often experience when caring for their adolescents can negatively affect the psychological well-being of adolescents (Colver et al., 2015). Thus, physiotherapists need to be aware of the influence parents/caregivers have on the decision making of CP adolescents, and it is their moral duty to uphold the dignity and autonomy of their patients (Maio, 2018).

The ethics of care provides an ethical guide for a physiotherapist's moral duty to CP adolescents. Physiotherapists must first establish intentional relationships grounded on trust and caring for the needs of CP adolescents (Maio, 2018). According to

Ricoeur, medical knowledge, clinical practice, and experiences health care professionals share with their patients influence their care (Maio, 2018). In addition to this, it affects their perceptions because of their vulnerable positions, which forces them to communicate with their patients to act in their best interest. Ricoeur states that if physiotherapists treat CP adolescents with dignity and respect, they have to treat them as equals and believe that they fulfil the functional approach of decision-making capacity components in medical practice, like other adolescents without CP (Maio, 2018, Wong et al., 1999). They have to trust that they have prepared CP adolescents to make independent decisions and created safe environments for them. Thus, when CP adolescents refuse treatment, and their parents insist despite their refusal, it is the physiotherapist's responsibility to communicate with their patient to find an alternative intervention. Denying CP adolescents the opportunity to make a decision on the grounds of having a disability would be a breach of trust and care. When physiotherapists allow CP adolescents to be autonomous, they promote self-determination and better prepare them for adulthood, where they will be responsible for their decisions. They are also fulfilling their duties as carers of their patients and further developing their empathy and understanding of persons with disabilities.

In addition, the bioethical principles of non-maleficence and beneficence guide physiotherapy clinical decision making (Beauchamp and Childress, 2013). The bioethical principles allow physiotherapist to take a step back and assess all the possible scenarios that can occur when a singular decision is made so that they can be as impartial as possible. An inability to recognise that CP adolescents have passions and desires and need the freedom to express themselves causes harm and can lead to psychological problems and failure to holistic patient care (Boldt, 2018,

Colver et al., 2015). The functional approach recognises that consent is dynamic because it varies over time and is situation-specific (Wong et al., 1999). Therefore, parents/caregivers and physiotherapists need to supervise decision-making processes to ensure that no harm is caused to the CP adolescent, but this should be done in the absence of coercing participation in activities they refuse to.

The right to participate in decisions regarding medical care and the refusal to treatment is outlined in the Children's Act 38 of 2005 and the National Health Act No 61 of 2003 (Republic of South Africa, 2005, Republic of South Africa, 2004). CP adolescents with the mental capacity and maturity to appreciate the risks, benefits and absence of treatment have the right to consent to their medical treatment and thus refuse physiotherapy treatment (Republic of South Africa, 2005, Republic of South Africa, 2004). Physiotherapists are guided by the HPCSA's standards for good clinical practice, that mirror Ricoeur's care ethics approach, to accept the decisions made by CP adolescents. The HPCSA's criteria for good clinical practice recognise CP adolescents as equals in society, who should not be coerced to participate in activities they refuse to. Physiotherapists have a professional obligation to be impartial in their treatment of persons with disabilities and decisions made which do not agree with the majority are just and valid (Health Professionals Council of South Africa, 2016). Physiotherapists are required to commit themselves to life-long learning and adhere to international regulations regarding the rights of adolescents, this is crucial as currently there is limited research available to guide decision-making in CP adolescents. Physiotherapists should be aware of this ensure that CP adolescents rights are protected at all times.

The UNCRC document cements the rights of children with disabilities and the governments' responsibilities to protect these rights. It influenced the establishment of the UNCRPD and Children's Act 38 of 2005 by stressing the importance of non-discrimination, freedom of expression, participation in health care and society and protection from harm (United Nations, 1989, United Nations, 2006 , Republic of South Africa, 2005). The Constitution of South Africa makes it clear that adolescents are to be protected from maltreatment/abuse/harm, and physiotherapists face severe consequences if they are found guilty of this, such as practicing licence suspensions and criminal charges. Therefore, to protect the rights and interests of CP adolescents, it would be recommended that the HPCSA provide clear guidelines to addressing situations where CP adolescents and parents/caregivers have differences in opinion towards health care interventions. The guidelines would need to insist on the duty of healthcare professionals to respect the legal and ethical entitlements of adolescents over 12 who meet the conditions of maturity and capacity. The recommendation would be a tool that is available to all South Africans, especially parents/caregivers of adolescents with disabilities, to credit the legal and moral rights of persons with disabilities. The HPCSA should provide training and continuous professional development sessions to physiotherapists in the areas of health education and ethics education. It would also be recommended that physiotherapist and rehabilitation professionals who treat CP adolescents produce literature of their clinical experiences with decision-making dilemmas between parents/caregivers and their patients. While it is clear that decisions are made in the best interest of the CP adolescent, this may not be what they perceive is in their best interest. Physiotherapists are in the best position to communicate with their patients to establish what their needs are and how they would like their needs to be

addressed. They are also in the position to be advocates for persons with disabilities and inform parents/caregivers and society at large about the ethical and legal entitlements they possess.

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Appendix 1: Research Ethics Committee Waiver



University of the Witwatersrand Student Ethics Declaration Form

(To be completed during the protocol assessor meeting)

Background

All Research conducted by a University of the Witwatersrand student, with human subjects or animals, requires approval by the Wits Human Research Ethics Committee or Animal Research Ethics Committee, respectively.

If research has been undertaken without the necessary ethics approvals, this is considered an ethics violation. This will be reported to the relevant structures, the data will have to be discarded, and in the case of students, they cannot use the data towards their degree.

To prevent any ethics violations, the ethics requirements for the proposed project will be discussed with you at the protocol assessment.

Declaration

Based on the current protocol assessment (and any proposed changes suggested by the assessor committee), we, the undersigned, understand that the proposed research requires:

1. Human Research Ethics clearance certificate — Yes (X) / No
   a. Covered under existing supervisor ethics — Yes (X) / No
   b. Requires a new HREC application — Yes / No (X)
2. Animal Research Ethics clearance certificate — Yes / No (X)
3. No Human or Animal Ethics Clearance — Yes (X) / No
4. Unclear, will seek appropriate guidance from the HREC/AREC committees (whichever relevant) — Yes (X) / No

Signatures

Supervisor/s: _____ Student: _____

_____

Date: 9 June 2021

11 March 2019/MP

Appendix 2: Turn-it in report

a0042231:Sibabalwe_Mama_-_Research_Report_(1).docx

by Lizeka Tandwa

Submission date: 29-Mar-2022 04:20PM (UTC+0200)
Submission ID: 1796053010
File name: 43f0-b869-15ab4326afa4_Sibabalwe_Mama_-_Research_Report__1.docx (566.75K)
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