# EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA

by

**NADIA MARAIS**

submitted in accordance with the requirements for

the degree of

**MASTER OF PUBLIC HEALTH**

in the subject

**HEALTH STUDIES**

at the

**UNIVERSITY OF SOUTH AFRICA**

SUPERVISOR: PROF GH VAN RENSBURG

NOVEMBER 2021

Student Number: 57577668

## DECLARATION

I declare that **EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

I further declare that I submitted the thesis to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.

| | |
|---|---|
| ______________________ | 21 January 2022<br>________________ |
| **SIGNATURE** | **DATE** |
| Nadia Marais | |

# EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA

| | |
|---|---|
| STUDENT NUMBER: | 57577668 |
| STUDENT: | NADIA MARAIS |
| DEGREE: | MASTER OF PUBLIC HEALTH |
| DEPARTMENT: | HEALTH STUDIES, UNIVERSITY OF SOUTH AFRICA |
| SUPERVISOR: | PROF GH VAN RENSBURG |

## ABSTRACT

Clubfoot is one of the most common musculoskeletal congenital disorders and annually affects around 174 000 babies worldwide. Untreated clubfoot leads to significant permanent impairment and problems with ambulation, thus presenting a potential public health dilemma. Clubfoot can however be corrected with a non-surgical method referred to as the Ponseti method. This gives a child normal, pain free mobility and the potential to grow up as a productive member of society. Treatment for clubfoot needs to be implemented as soon as possible after birth of the child to produce the best results and avoid possible relapse of the clubfoot. Diagnosis and treatment of clubfoot starting at, or later than three months of age, is regarded as late detection and treatment. The purpose of this study was to determine the healthcare-seeking behaviour of guardians of children with clubfoot at or after the age of three months to promote early detection and treatment.

A qualitative study was conducted to explore the reasons for seeking healthcare at Ponseti clinics for children that were three months or older; and to describe the challenges that the guardians experienced in seeking healthcare for their children. Data collection was done through semi-structured interviews at two public sector hospitals in KwaZulu-Natal Province.

Two major themes emerged from the study, namely discovering the clubfoot deformity, and the challenges guardians experienced in seeking healthcare for their children with clubfoot. There is a lack of knowledge about clubfoot resulting in late detection and initiation of treatment; and that clubfoot is a treatable condition which can result in the child leading a normal life if treated with the Ponseti method. Participants attending antenatal care were not informed by health practitioners of clubfoot being a potential birth defect. In some cases, guardians approached health practitioners early, but were referred late to a Ponseti clinic. Guardians in the study experienced several challenges when seeking healthcare for their children, including financial, transport and family responsibility challenges. They described having a child with clubfoot as an emotionally taxing journey. Recommendations are made for education, practice, policy, and research. An information brochure was designed to promote early detection and treatment of clubfoot.

**Key concepts**

Clubfoot; early detection; healthcare-seeking behaviour; Ponseti; treatment of clubfoot.

## ACKNOWLEDGEMENTS

The writing of this dissertation was one of my biggest challenges but also one of the biggest achievements ever. I am thankful for God's grace that gave me the perseverance to see this through.

I would like to acknowledge and give thanks to the following people:

- Professor Gisela van Rensburg, my supervisor. I admire you for your knowledge and skills. You have been incredible throughout this journey in mentoring me, understanding the challenges of daily life and your support was invaluable especially towards the end. I never thought it would be so uplifting to hear someone say: "Dit lyk baie *nice*".
- My husband Len, thank you for believing in me whenever I doubted myself and encouraging me throughout the process to keep going. Thank you for celebrating each milestone with me like it was your own and sharing my highs and lows during this time. Your patience with me will always be treasured and I admire you for who you are and what you have accomplished in your life.
- My mom Nelouise, you have been my inspiration and role model when it comes to achieving great things. You have been my biggest cheerleader from the start and in your calm manner took a lot of frantic phone calls and just assured me that I can do this. Thanks for believing in me!
- My kids Luc and Zac! You guys are just the best and you keep reminding that life is full of wonderful things and to make the best of every situation. All the high fives when I was one step closer to finishing the "clubfoot thing" I will cherish forever.
- My Dad, even though you are not here I know you would have been proud.
- Dr Piet Mare, Head of Clinical Unit, Paediatric Orthopaedics at Greys Hospital. Thank you for your guidance and support throughout this process. You were an invaluable part of this study from the first brainstorming session about a topic until the end.
- Dr Paul Rollinson, for assisting me at Ngwelezana Hospital; I admire your work ethic and love for Paediatric Orthopaedics.
- Dr Claudette Barnes at Ngewelezana Hospital, for her mutual passion for this study and going above and beyond to assist me and being a co-facilitator during the interviews.

- Simphiwe Gumede for being a co-facilitator at Greys Hospital – dropping everything when there is an interview to assist me.
- RN Nirasha Singh from Orthopaedic Outpatients at Greys Hospital, for her constant help with the logistics and assisting me in screening patients for eligible participants in my study.
- My awesome friend Claudette Storrar, for your assistance with the design and layout of my brochure; and my very talented friend Eloise Clasen for drawing all the images for the brochure.
- Gadge Sibisi my kids' favourite person and Favourite Shembe, my colleague and friend, for assisting me in translating my brochure into Zulu.
- Nikki Solomon, for transcribing my interviews.
- Dr Rina de Swart, for co-coding my work.
- Ronel Davis, who helped me at the last minute with language editing.
- Rina, for assisting with the technical editing.
- Tribe: "a social division in a traditional society consisting of families or communities linked by social, economic, religious, or blood ties, with a common culture". *My Tribe* (my friends) … Thank you! Without you girls this would not have been possible. I absolutely adore each one of you and cannot imagine life without you. I appreciate the extra play dates for my kids when I needed it, the pep talks when I felt defeated, the celebrations when I accomplished, for accepting me for who I am and being by my side during my incredible journey.

# DEDICATION

*I dedicate this study to the most precious people in my life: My husband Len, my children Luc and Zac, my mom Nelouise and to all the moms with small kids that think great achievements are impossible ... it's not!*

## TABLE OF CONTENTS

## LIST OF TABLES

## LIST OF FIGURES

# LIST OF ABBREVIATIONS

| | |
|---|---|
| CCK | Clubfoot Care Kenya |
| CTEV | Congenital Talipes Equinovarus |
| CPD | Continuing Professional Development |
| HPCSA | Health Professions Council of South Africa |
| IOFS | Impact on Family Scale |
| LMIC | Low- and Middle-Income Countries |
| MSPSS | Multidimensional Scale of Perceived Social Support |
| NGO | Non-governmental organisation |
| SANC | South African Nursing Council |
| SASSA | South African Social Security Agency |
| UK | United Kingdom |
| UNISA | University of South Africa |

# CHAPTER 1

# ORIENTATION TO THE STUDY

## 1.1 INTRODUCTION

Clubfoot, or congenital talipes equinovarus (CTEV), is a deformity of the foot where the toes appear to be pointing downwards with the toes and sole of the foot rotated inward as illustrated in Figure 1.1. Outwards movement of the foot is restricted because of shortened tendons and ligaments on the inside of the leg hence the inward rotation of the foot. The Achilles tendon is also tight, and this causes the downward pointing of the toes (Global Clubfoot Initiative 2021; Dibello, Di Carlo, Colin, Barbi & Galimberti 2020:1; Basit & Khoshhal 2018:107; Grimes, Holmer, Maraka, Ayana, Hansen & Lavy 2016:1).

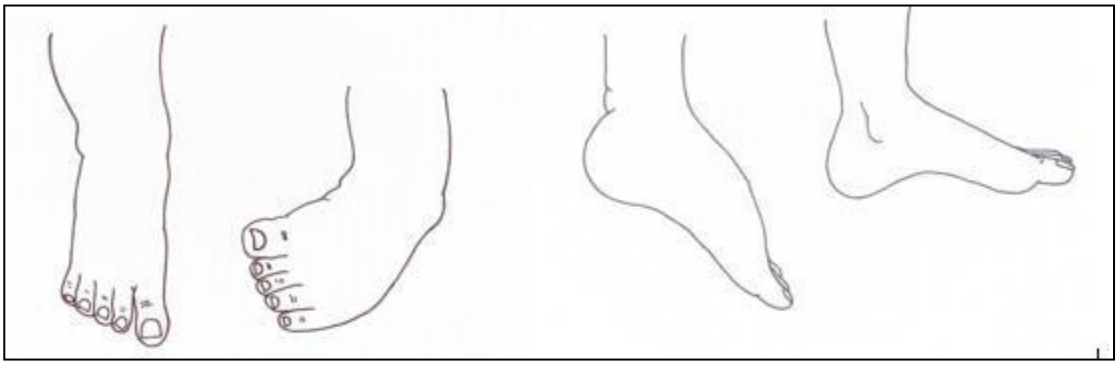


**Figure 1.1 Clubfoot deformity**

(Illustrated by Eloise Clasen)

Clubfoot is one of the most common musculoskeletal congenital disorders and annually affects around 174 000 babies worldwide (Owen, Capper & Lavy 2018:3). It is estimated that 80% to 90% of these babies are from low- or middle-income countries (LMIC) (Global Clubfoot Initiative 2021; Ansar, Rahman, Romero, Haider, Rahman, Moinuddin, Siddique, Mamun, Mazunder, Pirani, Mathias, Arifeen & Hoque 2018:2; Owen et al 2018:3). Globally the incidence of clubfoot is approximately 1:1000 live births and it is more prominent in males than in females with about 50% of cases being bilateral (Ansar et al 2018:2). There is little information on the exact incidence in the South African population, but the estimated incidence of clubfoot as identified at birth in African countries are in the region of 1.1 per 1000 live births (Malhotra, Mohapatra, Arora, Choudhury, Joshi & Patel

2018:1; Smythe, Kuper, Macleod, Foster & Lavy 2017:281). The prevalence in children under the age of 5 years in 2017 in the Southern African region was estimated to be in the region of 29 442,000 cases (Dave, Rankin, Pearce & Foster 2020:5). Using prevalence rate data from Uganda and Malawi, it can be estimated that the incidence in South Africa is 2-2.5 per 1000 live births.

## 1.2 BACKGROUND TO THE STUDY

To prevent permanent impairment and gait abnormalities, clubfoot needs to be corrected as soon as possible after birth. While several surgical or non-surgical treatment strategies have been described, the Ponseti technique remains the international standard for the initial treatment of idiopathic clubfoot (Global Clubfoot 2021; Gelfer, Wientroub, Hughes, Fontalis & Eastwood 2019:639; Mandlecha, Kanojia Champawat, Kumar 2019:603; Malhotra et al 2018:11; Švehlík, Floh, Steinwender, Sperl, Novak & Krause 2017:347; Lykissas, Crawford, Eismann & Tamai 2013:145). The Ponseti technique consists of two phases. The first phase is a series of weekly manipulations and castings of the foot to obtain correction. At the end of this casting period, a high proportion of the children require a percutaneous Achilles tendon tenotomy to complete the correction. Children, who present with clubfoot early, typically require five to seven casts to obtain correction (Dibello et al 2020:4; Mandlecha et al 2019:603; Ganesan, Luximon, Al-Jumaily, Balasankar & Naik 2017:5; Kumar, Suman & Manjhi 2017:25). The second phase consists of maintenance of correction with abduction braces. These braces are worn full time (at least 23 hours a day) for three months and thereafter part-time (14 hours a day) while the child sleeps during the day and night until the child is four years old (Dibello et al 2020:4; Kumar et al 2017:24).

The ideal time to start the Ponseti technique is as soon as possible after birth (Dibello et al 2020:4; Vaishy, Arif, Acharya, Choudhary, Seervi & Kumar 2020:55; Ganesan et al 2017:5; Agarwal & Gupta 2016:1286). On completion of the Ponseti technique, the foot should be strong, flexible and pain free. The Ponseti method provides an excellent degree of primary correction of the deformity with better functional outcomes than that achieved with surgical correction (Gelfer et al 2019:642). When long-term outcomes are compared with surgical management, the Ponseti technique results in greater range of motion and strength of the foot and ankle with a lower risk for the development of osteoarthritis. (Smith, Kuo, Graf, Krzak, Flanagan, Hassani, Caudil, Dietz, Morucuende & Harris

2014:1281). Most orthopaedic surgeons agree that the earlier treatment is initiated, the more likely it is that it will be successful (Dibello et al 2020:4; Aggarwal & Gupta 2016:1286; Herring 2013:794). While several authors have shown that the Ponseti method remains effective beyond the first few months of life, there are several challenges to treating children of a walking age with this method (Adegbehingbe, Adetiloye, Adewole, Ajodo, Nosirudeen, Esan, Hoover, Ior, Lasebikan, Ojo, Olasinde, Songden & Morcuende 2017:628; Ganesan et al 2017:3).

Older children do not tolerate the braces as well as younger children as the deformity is more resistant to correction, more and longer manipulations are needed to get the desired effect, and cast times must be increased (Singh, Gawande & Lakhtakia 2020:73). Street, Ramguthy and Firth (2016:51) also found that children with clubfoot starting Ponseti treatment at a mean age of seven weeks demonstrated a delay in independent walking of about three months. When treatment is delayed further, the full-time bracing phase may extend to the window where independent walking is expected. The effect of delaying treatment initiation beyond three months on the achievement of independent walking is not known. Furthermore, surgical intervention is more frequently required in children presenting late and does not prevent relapse later. This can lead to extensive and painful surgeries (Ferreira, Stefani, Haje & Nogueira 2018:15). Additional counselling might be needed for parents of older children as the results are not visible for the first few visits, and children that used to be mobile are not mobile for the duration of the treatment.

There is no real age limit for the treatment of clubfoot, but it is clear that the earlier treatment starts, the better the outcome and therefore early detection is crucial (Besselaar, Sakkers, Schuppers, Witbreuk, Elgun, Zeegers, Visser, Boekestijn, Marges, Van der Steen & Burger 2017:306-307; Ganesan et al 2017:11; Agarwal 2014:207-209). Late detection (late presentation) is defined as presentation of a child with clubfoot to a clubfoot clinic beyond the age of three months (Liu, Li, Zhao, Yu & Zhao 2018:662). Neglected clubfoot leads to permanent disability, very painful feet, financial and psychological burden on the patient, family as well as the community as the patients are typically unable to work (Adegbehingbe et al 2017:625; Singh et al 2020:72). Therefore, it is essential to create awareness of the importance of early detection and treatment of clubfoot.

With the Ponseti method an initial success rate of up to 90% can be expected (Zhao, Zhao, Liu, Wu & Jin 2014:1333). The reported range of relapse following treatment varies between 2% and 45% (Gelfer et al 2019:641). The most common cause of relapse is non-adherence with the treatment protocol, with brace non-adherence accounting for up to 78% of all relapses (Ganeson, Luximon, Al-Jumaily, Balasankar & Naik 2017:12; Jowett, Morcuende & Ramachandran 2011:1160). Other factors associated with relapse include a delay in onset of treatment or late presentation, initial severity, lower socioeconomic status, parent's level of education, and technical treatment errors (Ganeson et al 2017:12).

There is limited data on the treatment of clubfoot in South Africa, particularly from the public sector. Very few recent studies could be found. In an older study, Firth, Eltringham and Shnier (2009:69) reported the clinical results of 70 patients treated in the private sector in South Africa, with only 7% of cases requiring other surgery. The authors emphasised the need for attention to detail, rigorous parent education and close follow-up. Studies from other African countries, like Uganda, Nigeria and Malawi, have also shown good results with the use of the Ponseti method (Adegbehingbe et al 2017:624: Pirani, Naddumba, Mathias, Konde-Lule, Norgrove, Beyeza, Mbonye, Amone & Franceschi 2009:1154; Lavy, Mannion, Mkandawire, Tindall, Steinlechner, Chinamgeni & Chipofya 2007:854). MiracleFeet (2021:23) a global non-governmental organisation (NGO) involved in clubfoot care, reports in their annual report that 758 new cases were seen in Uganda during the previous year with 2391 all-time cases reported, with Nigeria reporting 309 new cases and 573 all-time cases. A recent systematic review considering the outcomes of treatment with the Ponseti method in Sub-Saharan Africa, reported a success rate of between 68% and 98% after the casting phase (Smythe, Mudariki, Kuper, Lavy & Foster 2017:5). One specific challenge that was identified in this systematic review of 14 studies was the high attrition rate, with some studies reporting up to 35% of patients not complying with the follow-up requirements (Smythe, Mudariki et al 2017:5).

Thus, the lack of compliance with the treatment protocol and follow-up has been identified as significant challenges, particularly in LMICs. Several authors have aimed to investigate the reasons for this in countries other than South Africa. Bedford, Chidotho, Sakala, Cashman and Lavy (2011:212) explored the treatment-seeking behaviour in Malawi and found the four main obstacles to treatment-seeking to be lack of knowledge, resistance from family members, logistical challenges, and socio-economic pressures. This is supported by Johnson, Friedman, Becker and Spiegel (2017:e134). In Bangladesh the reasons for not adhering to treatment were travel distances, not understanding the importance of the bracing phase, and follow up visits (Evans, Chowdhury & Khan 2021:1). In Uganda it has also been noted that some patients have difficulty adhering to the treatment schedule. Challenges included sociodemographic and socioeconomic factors and distance to the clinics (Pirani et al 2009:1160). In a study from Uganda the specific barriers to treatment adherence included caregiver's other responsibilities, challenges around the treatment process, and resource availability in certain regions (McElroy, Konde-Lule, Neema & Gitta 2009:850-852). The authors also identified certain factors that promoted adherence including outreach services, caregiver-practitioner partnerships, and family solidarity. According to Smythe, Kuper et al (2017:282) due to poor surveillance programmes, little data is available for LMICs. This is supported by Saib, Dhada, Aldous and Malherbe (2021:2), highlighting that there is no recent and reliable data available on the extent of congenital birth defects in South Africa. Drew, Lavy and Gooberman-Hill (2016:574) performed a meta-synthesis of existing qualitative studies to investigate the factors affecting clubfoot patient access and engagement in LIMCs. Intrapersonal barriers were lack of funds and other responsibilities. At an interpersonal level, family and community support were highlighted. Organisational factors included travelling distance, duration of treatment, and lack of awareness and information about treatment. At public policy level, a two-tiered healthcare system presented a barrier with patients accessing public healthcare experiencing longer delays then patients accessing private care. This systematic review did not identify any studies from South Africa that explored this theme (Drew et al 2016:575-583).

There is thus limited data on the topic from South Africa and Africa as a continent. Malagelada, Mayet, Firth and Ramachandran (2016:103-106) compared the impact of the Ponseti method on the lives of parents and caregivers of children with idiopathic clubfoot amongst two groups of patients, one from the United Kingdom (UK) and one from South Africa. The authors reported similar levels of impact on family function, as measured by the impact on family scale (IOFS), amongst the two groups. South African families, however, showed a higher level of perceived social support during treatment and higher use of coping strategies as measured with the multidimensional scale of perceived social support (MSPSS). These coping strategies identified by the Brief COPE questionnaire (Malagelada et al 2016:101), included acceptance, religion, denial, emotional support, and active coping. The South African respondents also were happy to source and receive support from family and friends while their British counterparts were less so. Social data from the study highlighted that 75% of South African respondents participating in the study fell below the 50th percentile in terms of the national household income norm as compared to 92% in the UK. While this study did look at coping mechanisms, it did not explore the barriers to seeking help, or adherence to the treatment protocol (Malagelada et al 2016:107). Therefore, there is a need to identify the factors that prevent early detection and present obstacles in seeking treatment and the successful completion of the entire course of treatment for South African patients with clubfoot.

## 1.3 RESEARCH PROBLEM

Uncorrected clubfoot is a public health dilemma. Neglecting the care of children with clubfoot leads to deformed and painful feet and permanent disability. Although the condition can still be treated, late detection (at or after the age of three months) of clubfoot complicates correction. Clubfoot is a deformity that can be corrected with non-surgical methods. This gives a child a normal pain free life to grow up as a productive member of society. To prevent permanent impairment and complications, treatment for clubfoot needs to be implemented as soon as possible after birth to produce the best results and avoid possible relapse.

Therefore, it is essential to create an awareness of what clubfoot is and the importance of early detection and treatment of clubfoot. To address the awareness of the early detection and treatment of clubfoot, there is a need to identify the factors that prohibit early detection, successful completion of the entire course of treatment and identifying challenges that guardians might face in seeking or completing the treatment.

Little data is available about clubfoot in South Africa and the factors causing barriers to healthcare-seeking and adherence to treatment have not been elucidated. This study endeavoured to discover the reasons for guardians only seeking healthcare for children with clubfoot at or after the age of three months; from the point of view of the patient's guardians. Therefore, the question that arose was: What are the reasons for guardians seeking healthcare for children with clubfoot only after the age of three months?

## 1.4 PURPOSE AND OBJECTIVES OF THE STUDY

### 1.4.1 Research purpose

The purpose of the study was to determine the healthcare-seeking behaviour of guardians of children with clubfoot at or after the age of three months to promote early detection and treatment.

### 1.4.2 Research objectives

The objectives of the study were to:

- Explore the reasons for seeking healthcare at the Ponseti healthcare facility for clubfoot in the three months or older child.
- Describe the challenges the guardians experienced coming to the healthcare facility to seek treatment and adhering to the treatment.
- Design an information brochure on clubfoot to promote early detection and treatment.

## 1.5 SIGNIFICANCE OF THE STUDY

Uncorrected clubfoot is a public health dilemma. Neglecting the care of children with clubfoot leads to deformed and painful feet and permanent disability. Late detection of clubfoot complicates correction. This study provides insight into the current state of disease detection, the mean age of presentation, and highlights why guardians present late for treatment.

Data generated from this study could inform healthcare practitioners on the need for health education programmes and awareness campaigns for early detection of clubfoot deformities. An information brochure with pictures of clubfoot and the importance of prompt treatment was developed for distribution at antenatal clinics at various hospitals and clinics, health services in other provinces, doctors’ waiting rooms, or shopping centres. This brochure includes information to ensure early detection and treatment.

## 1.6 KEY CONCEPTS

The following key concepts were defined in order to clarify relevant concepts.

### 1.6.1 Awareness

Awareness is described as knowledge or perception of a situation or fact that exists (*Merriam-Webster Dictionary* 2021; *Oxford Paperback Dictionary* 1991, “awareness”). For the purpose of this study awareness will refer to whether people in the community know what clubfoot is, what the signs of clubfoot are and their awareness of treatment options available.

### 1.6.2 Challenges

Challenge refers to a stimulating task or problem (*Merriam-Webster Dictionary* 2021, “challenge – noun”). In this study it refers to daily circumstances that can present a barrier to guardians detecting clubfoot and seeking early treatment, accessing health services, or adhering to treatment. This can refer to cultural, physical, psychological, or financial constraints.

### 1.6.3 Child

A child is a young person between infancy and puberty (*Merriam-Webster Dictionary* 2021, “child”). In this study, child refers to children presenting at the Ponseti clinic for treatment of clubfoot that are three (3) months old or older, but not older than three (3) years of age. For the purpose of this study child will refer to all infants and children attending the Ponseti clinic.

### 1.6.4 Clubfoot

Clubfoot as referred to in this study, is also known as Congenital Talipes Equinovarus (CTEV) is a congenital musculoskeletal birth deformity of the foot where the toes appear to be pointing downwards with the toes and sole of the foot rotated inward. One or both feet can be affected, and almost half of the cases include both feet. It is the most common musculoskeletal birth deformity (Global Clubfoot Initiative 2021; Dibello et al 2020:4; Kadhum, Lee, Czernuszka & Lavy 2019:1-2; Basit & Khoshhal 2018:107).

### 1.6.5 Clubfoot detection

Clubfoot detection in this study refers to action taken if a child’s foot looks suspicious at any given time. A clinician should be contacted to establish the diagnosis. Ideally all children should be screened at birth (Dibello et al 2020:4; Vaishy et al 2020:55; Basit & Khoshhal 2018:107).

### 1.6.6 Early detection

Early detection of clubfoot ranges from detection during pregnancy with sonography to detection at birth following physical examination of the newborn and before the age of three months. Diagnosis and treatment starting before three months of age. Ideally treatment should start as soon as possible after birth (Dibello et al 2020:4; Vaishy et al 2020:55).

### 1.6.7 Guardian

A guardian is defined as “one who has the care of the person ((*Merriam-Webster Dictionary* 2021, “guardian”). An individual who cares for a child with clubfoot daily and is responsible for the child’s general wellbeing and healthcare. This can be a biological parent or any other caregiver. For the purpose of this study the term guardian will refer to a parent or a caregiver.

### 1.6.8 Healthcare-seeking behaviour

Zhang, Feng, Wong, Ip, Cowling and Lau (2020:2) define healthcare-seeking behaviour as “any action or inaction undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy”. For the purpose of this study the term is related to the guardian seeking healthcare for the child with clubfoot.

### 1.6.9 Idiopathic

Relating to or denoting any disease or condition which arises spontaneously or for which the cause is unknown (*Merriam-Webster Dictionary* 2021; *Oxford Paperback Dictionary*

1991, “idiopathic”). Idiopathic clubfoot and clubfoot therefore have the same meaning in scientific text and is the meaning referred to in this study.

### 1.6.10 Secondary clubfoot

Clubfoot that can develop as a secondary problem due to underlying neuromuscular or syndromic disorders such as spina bifida (Dibello et al 2020:2; De Mulder, Prinsen & Van Campenhout 2018:579; Pavone, Chisari, Vescio, Lucenti, Sessa & Testa 2018:1). A similar meaning was used in this study.

### 1.6.11 Late detection

Late detection refers to diagnosis and treatment of clubfoot starting at or later than three months of age (Liu et al 2018:666) and was used as such in this study.

### 1.6.12 Ponseti technique

This method is a non-surgical, low-cost method used to correct clubfoot. It is the most popular way to treat clubfoot and consist of various steps. The Ponseti technique consists of gentle manipulation in a series of casts. The cast is changed weekly, and the total duration of treatment is usually between four to six weeks. After the casts, the patient will be required to wear a brace and sometimes a small surgical procedure called an Achilles tendon release is required (Dibello et al 2020:4; Malhotra et al 2018:11; Ganesan et al 2017:5; Kumar et al 2017:25).

### 1.6.13 Relapsed clubfoot

When a deformity appears again in a foot that was previously corrected e.g., when the foot rotates inwards and outwards again after successful treatment (Eidelman, Kotlarsky & Herzenberg 2019:1).

### 1.6.14 Rural setting

This could be: “A semi-town (i.e., a town without a local authority) with predominantly formal dwellings, falling outside but sharing at least one common boundary with a proclaimed urban area" (STATSSA 2001) or "A village/settlement without a local authority, not situated within a tribal area and with formal and semiformal dwellings such as houses, huts and rondavels" (STATSSA 2001). In this study rural setting refers to the central mountainous and the northern coastal areas of the KwaZulu-Natal province with little or no transport to tertiary healthcare facilities.

## 1.7 THEORETICAL GROUNDING OF THE RESEARCH

A qualitative research approach was chosen for this study. Qualitative studies are usually grounded in a constructivist paradigm as people construct their own reality (or understanding and knowledge) of the world through their life experiences (Polit & Beck 2021:486).

A paradigm is described as a way to view the world, or an analytical lens, which provides the researcher with a framework or set of assumptions to understand the world we live in and the behaviour of humans (Brink, Van der Walt, Van Rensburg 2018:20; DeCarlo 2018 chapter 6.2). Polit and Beck (2021:7-8) describe it as a general perspective on the complexities of the real world highlighting the four paradigms used by researchers as positivism, constructivism, transformative paradigm, and pragmatism.

While positivists seek the truth, constructivists suggest that the truth varies based on the reality of the context and by the people involved in the research thus allowing several versions of the reality (Polit & Beck 2021:8; DeCarlo 2018:chapter 6.2). The constructivist approach aims to understand the human experience as it is lived (Polit & Beck 2021:10). The search to explore, describe and understand the reasons for guardians to seek healthcare for their children with clubfoot and the challenges they experienced in doing so, lead the researcher to adopt the philosophical ideas of a constructivist. The experiences of guardians of children with clubfoot deformity are subjective and they may therefore give multiple meanings to experiences of their reality. In the search to understand the realities of these guardians, the researcher depended on the perceptions of guardians of children with clubfoot deformity of the reasons for them seeking healthcare for their children and the challenges they experienced in doing so. A constructivist approach makes it possible for the researcher to engage with individuals, in this study the guardians of children with clubfoot deformity, to gain a deeper understanding of the complexity of their experiences in their daily lives when caring for children with clubfoot deformity.

The context of this study was two Ponseti clinics situated in two tertiary hospitals in KwaZulu-Natal in South Africa that the guardians visited for the healthcare treatment of their children. The researcher visited the clinics to meet with and interview the participants of the study.

## 1.8 RESEARCH DESIGN AND METHODS

This section provides the reader with an overview of the design and methods used for this study. A more detailed description will be provided in Chapter 2. Table 1.1 provides an overview of the research methods for the study.

**Table 1.1 Overview of the research methods**

| Objectives | Population | Sampling | Data collection | Data analysis | Trustworthiness |
|---|---|---|---|---|---|
| • Explore the reasons for seeking healthcare at the Ponseti healthcare facility in the three months or older child<br>• Describe the challenges the guardians experienced coming to the healthcare facility to seek treatment and adhering to the treatment<br>• Design an information brochure on clubfoot to promote early detection and treatment | Guardians of all children who started treatment for the first time at a Ponseti clinic, at or after the age of three months but under the age of three years, regardless of where in the first treatment phase they are | Purposive sampling | Semi-structured interviews | Terre Blanche method of qualitative data analysis | • Credibility<br>• Dependability<br>• Transferability<br>• Confirmability<br>• Authenticity |

### 1.8.1 Research design

A research design as an overall plan to respond to the research questions raised, and to enhance the integrity of the research (Polit & Beck 2021:801). A qualitative, explorative, descriptive research design was used. This approach allowed the researcher to engage with guardians to understand the reasons for seeking healthcare for their children with clubfoot deformity and the challenges that they might have faced in seeking treatment as described through their lived experiences (Polit & Beck 2021:472).

### 1.8.2 Research setting

The study was undertaken in the province of KwaZulu-Natal, situated at the most eastern side of the country along the Indian Ocean and is the second most populous province in the country. The province shares borders with three other provinces (Mpumalanga, Free State and Eastern Cape) and three neighbouring countries (Eswatini, Lesotho and Mozambique). There are different geographic areas that can be identified, namely the Durban metropolitan area, Northern coastal, Southern coastal and Inland areas.

The interviews took place at a Ponseti clinic at two public tertiary hospitals in different regions of KwaZulu-Natal, one of the nine provinces in South Africa as indicated in Figure 2.1. The Ponsesti clinic at the Greys Hospital is situated Inland in the Natal Midlands in the uMgungundlovu district, and the clinic at the Ngwelezana Hospital is situated in the Northern coastal area in the King Cetshwayo district.

Both hospitals are tertiary hospitals. Greys hospital is a referral hospital located in Pietermaritzburg offering tertiary services to various health districts in the Western half of KwaZulu-Natal totalling a population of 4.5 million (KwaZulu-Natal Department of Health [s.a.]a). Ngwelezana hospital is a 436-bed hospital serving King Cetshwayo, Zululand and Umkhanyakude districts in the region with several clinics, including a Ponseti clinic, serving the population. The hospital receives referrals from 18 hospitals in the region (KwaZulu-Natal Department of Health [s.a.]b). These hospitals were selected as they serve more rural areas in the province. The researcher has worked at both hospitals on various occasions as an application specialist training staff on digital x-ray equipment and noticed older children with clubfoot at the clinics.

### 1.8.3 Population

A population is a group of individuals or objects with some common characteristics (Polit & Beck 2021:797; Gray, Grove & Sutherland 2017:53). The target population was guardians of children with clubfoot deformity, with the accessible population the guardians and children who attended the Ponseti clinics in KwaZulu-Natal. To develop and understanding of the reasons why guardians only sought treatment for their children after they were three months old, those who started treatment for the first time at a Ponseti clinic were identified for participation.

### 1.8.4 Sample selection

A purposive sampling method was used for this study. Purposive sampling is a non-probability sampling technique where the researcher selects participants that will give the most insight into the phenomenon being studied (Polit & Beck 2021:799) targeting. The researcher targeted people who experienced caring of children with clubfoot deformity. The sample selection was done on the Ponseti clinic days in collaboration with the registered nurse or doctor at the clinic using the inclusion criteria to identify suitable participants for the study.

### 1.8.5 Data collection

Individual, semi-structured interviews were used to collect data from guardians of children with clubfoot guided by an interview guide (see Annexure 12). A semi-structured interview includes topics for discussion rather than specific questions (Polit & Beck 2021:514). The interview guide was reviewed by subject experts and piloted with one guardian prior to the interviews taking place. The guardians were informed of the study and invited to participate. The guardians willing to participate signed a consent form (see Annexure 10) to be interviewed and for the interview to be recorded. The interviews were conducted in a separate room at the clinic while the patients and guardians were either waiting while the cast was soaking in water or after the cast had soaked and they were waiting for the cast to be reapplied.

### 1.8.6 Data analysis

Data analysis is the process of methodically organising and synthesising the data of the study (Polit & Beck 2021:783). The Terre Blanche method was used in the study to analyse the data. The Terre Balance method consists of five analytical steps, namely Familiarisation and Immersion, Inducing Themes, Coding, Elaboration and Interpretation and Checking (Terre Blanche, Durrheim & Painter 2016:322-326).

### 1.8.7 Trustworthiness

To ensure that the findings of the study are a true reflection of the experiences of the study participants, five criteria were applied to ensure the trustworthiness of this study, namely credibility, dependability, confirmability, transferability, and authenticity (Polit & Beck 2021:569-570). This information is discussed in more detail in chapter 2.

## 1.9 ETHICAL CONSIDERATIONS

The research proposal was reviewed by the Research Ethics Committee of the Department of Health Studies of the University of South Africa (UNISA:HSHDC/810/2017, amended 2020 and 2021 by the College of Human Sciences Research Ethics Committee) (see Annexures 1 and 2) as well as the National Health Research Database at Department of Health Province of KwaZulu-Natal (NHRD: KZ_201808_019 − see Annexure 6). All participants received a detailed description of the purpose of study and the data collection methods and had to give informed consent to participate in the study.

The ethical principles of justice, beneficence, respect for persons, and autonomy were honoured throughout the study to ensure that no harm was done to the participants, or the institutions involved. Participants were informed of the study and had the choice to participate, or to withdraw at any stage during the process should they wish to. Assurance was given that their participation would be anonymous. Ethical considerations will be discussed in greater detail in Chapter 2.

## 1.10 SCOPE AND LIMITATIONS

The scope of the study involved guardians of children with clubfoot deformity who visited the Ponseti clinics at the two hospitals in KwaZulu-Natal identified for the study. The guardians sought healthcare for their children with clubfoot deformity when they realised or were informed that the children required healthcare intervention. They were referred to the Ponseti clinics by health professionals at other clinics or health services.

The setting presented a limitation as the data collection was undertaken in two areas of one province. The healthcare-seeking behaviour of the guardians might differ in other areas of the country. Due to inclusion of only patients who attended the clinics, patients who never get to the clinic may be excluded. Thus, the reasons for delay in the most extreme of cases may not be discovered. Going into the rural communities to detect other potential patients would warrant further research.

## 1.11 STRUCTURE OF THE DISSERTATION

The report of this study is divided into five chapters.

Chapter 1: Orientation to the study
Chapter 2: Research methodology
Chapter 3: Presentation of the findings
Chapter 4: Discussion of findings and integration of literature
Chapter 5: Conclusions, recommendations and limitations

## 1.12 SUMMARY

This chapter provided a background and explanation of clubfoot, highlighting the importance of detecting the clubfoot early to start treatment as soon as possible to prevent permanent impairment. An extensive preliminary literature review was conducted to develop an understanding on detection and treatment of clubfoot. The study was undertaken to explore and determine the healthcare-seeking behaviour of guardians of children with clubfoot deformity only after they were three months or older which is regarded as late initiation of treatment for clubfoot. An overview of the research design and methodology, the research setting, and ethical considerations was provided.

In Chapter 2 the research design and methodology will be discussed.

# CHAPTER 2

# RESEARCH METHODOLOGY

## 2.1 INTRODUCTION

This chapter explains the research methodology, which includes the research design and research methods used in this study. Population, sampling, and data collection are discussed as well as ethical considerations and measures taken to ensure trustworthiness. The discussion includes the intention of the chosen design and methods. It further clarifies the role of the researcher in ensuring that all ethical principles related to human participants are adhered to. The reasons for the specific data collection procedures and the data analysis processes are explained. A detailed explanation of measures used to enhance trustworthiness, and ethical considerations were provided.

## 2.2 RESEARCH PURPOSE AND OBJECTIVES

The purpose of the study was to determine the healthcare-seeking behaviour of guardians of children with clubfoot at or after the age of three months to promote early detection and treatment.

The objectives of the study were to:

- Explore the reasons for seeking healthcare at the Ponseti healthcare facility for clubfoot in the three months or older child.
- Describe the challenges the guardians experienced coming to the healthcare facility to seek treatment and adhering to the treatment.
- Design an information brochure on clubfoot to promote early detection and treatment.

## 2.3 RESEARCH DESIGN

The research design can also be referred to as the “blueprint” of a study indicating how the researcher is planning to search for answers to the research question. The research design enhances the control over certain aspects that can affect the validity of the study findings (LoBiondo-Wood & Haber 2018:92; Gray et al 2017:192). An explorative, descriptive, qualitative research design was used for this study (Gray et al 2017:70).

### 2.3.1 Qualitative study

Qualitative research is used to give meaning and describe life practices and experiences through an interactive and holistic approach, thus allowing the researcher to see the world through the eyes of their research participants and to understand the meaning they ascribe to these experiences (Polit & Beck 2021:471; LoBiondo-Wood & Haber 2018:89; Gray et al 2017:63).

Qualitative studies are usually grounded in a constructivist paradigm and inductive in nature. This allowed the researcher to interact with participants to get a deeper understanding of experiences of their daily lives. The researcher became an integral part of the research process by interacting with the participants. The voices and interpretations of the study participants were a crucial part of understanding the phenomenon.

### 2.3.2 Exploratory research

Explorative studies are not intended for generalisation to large populations. These studies are intended to increase the knowledge and understanding of a specific field of study or topic (Grove & Gray 2019:75; LoBiondo-Wood & Haber 2018:89; Gray et al 2017:259). In this study the researcher explored the reasons for guardians seeking healthcare for their children and the challenges they might have faced in obtaining healthcare or adhering to the treatment of clubfoot, as well as observing and documenting the participants' behaviour.

### 2.3.3 Descriptive research

Descriptive studies are created to get more knowledge on certain aspects within a specific field of study. The purpose of these studies is to create an image of a natural sequence of events by observing, describing, and documenting certain aspects. This can be useful to study what others do in the same situation and sometimes serves as a starting point of a theory (Polit & Beck 2021:486; Grove & Gray 2019:75; LoBiondo-Wood & Haber 2018:89; Gray et al 2017:259). The purpose is to describe the phenomenon under study and its characteristics; in this study the healthcare-seeking behaviour of guardians of children with clubfoot. The participant is the measurement tool; therefore, the researcher must ensure that adequate interviews are conducted to gather sufficient data to utilise.

## 2.4 RESEARCH SETTING

The setting is the exact location where the data were collected during a study (Polit & Beck 2021:803). The setting for this study was in a clinical environment at two tertiary hospitals in KwaZulu-Natal, one of the nine provinces in South Africa.

The clinical settings where the study was conducted were two Ponseti clinics at public tertiary hospitals in two of the regions in KwaZulu-Natal. Greys Hospital is in the inland region of the province about 90 km from Durban metropolitan (see Figure 2.1) also known as the Natal Midlands. The hospital serves as a referral hospital for a large portion of the community that live in the more rural areas in the mountains. Most of the participants had to travel long distances to get to the clinic. The Ponseti clinic is located within the hospital at the orthopaedic outpatients' department. The Ponseti clinic is run once a week with dedicated nursing staff assisted by staff from STEPS, a Non-governmental Organisation (NGO) working with clubfoot. The patients are booked weekly for the duration of the Ponseti treatment which is normally 6 weeks. The clinic consists of a large room where the soaking and recasting takes place, but individual clinic rooms are available where the interviews took place.

Ngwelezana Hospital is in the northern coastal area of the province about 140 km north from Durban metropolitan (see Figure 2.1) and receive referrals from far north up to Zululand and sometimes even patients from Mozambique. The researcher travelled about three hours to the hospital for the data collection from her hometown of Pietermaritzburg. The hospital is located fairly central to the main town, but some participants had to travel up to three hours to get to the clinic. The Ponseti clinic is located within the hospital's orthopaedic clinic with dedicated staff that has been trained on how to apply the casts for the children. There was a private clinic room within the clinic where the interviews took place. The participants were taken there with the child and thereafter escorted back to the queue.

These settings were selected as they are some of the largest clubfoot clinics in the province and they both serve more rural communities where there is a lack of awareness of clubfoot and late detection is more common.

**Figure 2.1 Map of KwaZulu-Natal districts indicating the Greys hospital and Ngwelezana hospital research sites**

(Wikimedia Commons 2021)

## 2.5 RESEARCH METHODS

Polit and Beck (2021:801) state that research methods are techniques used to organise a study, gather information, and analyse the data from the study. The research methods consist of the population, sampling, data collection, data analysis and rigour of the research. These are used to gain insight into the life of guardians taking care of a child with clubfoot and the challenges they might face.

### 2.5.1 Population

Gray et al (2017:53) describe population as a group of individuals that share at least one characteristic. This is a group of individuals having the same characteristics that makes them eligible to be part of a research study.

The population for this study were guardians of all children who were born with the deformity called clubfoot and who, for the first time, sought treatment for the deformity at a Ponseti clinic when the child was three months or older. The accessible population is the population of individuals that are available at the time for a particular study (Polit & Beck 2021:777). The participants that were accessible for the study were the ones that had children currently receiving treatment at the clinic during the time of the data collection.

#### *2.5.1.1 Eligibility criteria*

The eligibility criteria evolve from the research problem, and it designates the characteristics of the population that will be included in the study (Polit & Beck 2021:785; Grove & Gray 2019:76).

The eligibility criteria for this study were guardians of children:

- Three months or older, but under the age of three years.
- Attending a Ponseti clinic.
- Receiving treatment for clubfoot for the first time, regardless of where in the treatment phase they were.
- Able to engage in English with Zulu clarification.

#### *2.5.1.2 Exclusion criteria*

The exclusion criteria for the study were:

- Guardians of children who received treatment for relapsed clubfoot
- Participants who could not engage in English

- Guardians of children younger than three months of age

### 2.5.2 Sample and sampling for the study

Sampling in qualitative research is different to sampling in quantitative studies. Qualitative studies aim to get value out of their samples and discover multiple experiences and not necessarily to generalise findings to a certain population (Polit & Beck 2021:497).

#### *2.5.2.1 Sample*

A sample represents a subset of the population to represent the whole population for a specific study (Polit & Beck 2021:803; Gray et al 2017:254). Samples in qualitative studies are not randomly selected, as random samples might not be the best way to get information rich participants. Smaller samples are used in qualitative studies as each individual participant can give a lot of information, therefore samples are not selected for quantity, but rather for quality of data (Polit & Beck 2021:497; LoBiondo-Wood & Haber 2018:93).

#### *2.5.2.2 Sampling process*

A non-probability sampling approach was used in this study. Non-probability sampling refers to a process where the sample is not selected randomly. Not all members of the population would therefore have an equal chance to be selected to participate in the study (Polit & Beck 2021:262). For this study a purposive sampling technique was used. This method can also be referred to as selective sampling where the researcher deliberately selects certain participants to include in the study. They tend to look for information rich individuals that could provide a lot of information regarding the focus of the study (Polit & Beck 2021:265; Grove & Gray 2019:76; LoBiondo-Wood & Haber 2018:93). Purposive sampling techniques are mainly used for studies where the researcher can get an in-depth understanding of an intricate situation. The healthcare-seeking behaviour is a complex and emotional topic and therefore this sampling technique suited the study well. To be eligible for the study, the guardians had to attend one of the two clinics that was part of the study. Guardians were intentionally selected by the researcher in collaboration with the registered nurse and/or doctor at both clinics. Participants were selected if they adhered to the eligibility criteria, if they were willing to engage in interviews and conversations to provide insight into the reasons for seeking healthcare for the child and what other challenges they might have faced in obtaining healthcare and treatment for the clubfoot. The interviews had the potential to be emotional, and the researcher needed participants that were willing to share their experiences in depth rather than participants that did not want to elaborate on their journey.

#### *2.5.2.3 Sample size*

In qualitative studies there are no set rules and regulations for sample size. The size of the sample is determined by the quality of the data collected from participants until data saturation has been reached (Polit & Beck 2021:55; LoBiondo-Wood & Haber 2018:92; Gray et al 2017:255). Participants were interviewed until no new information was gained from the interviews and data saturation had been achieved. It is important to do in-depth interviews so that certain patterns and categories could be established and utilised for data analysis. A total number of twelve interviews were conducted when data saturation was achieved. One interview was a pre-test, no new themes emerged after the eleventh interview and a twelfth was done as a confirmatory interview.

## 2.6 DATA COLLECTION

Data collection is a detailed and systematic gathering of information that applies to the research purpose and objectives (LoBiondo-Wood & Haber 2018:894). Data collection in qualitative studies evolves during the collection period when knowledge is gained about the topic. Although it can be flexible, certain upfront data collection tools/methods should be implemented at the start of the data collection process (Polit & Beck 2021:510-511).

### 2.6.1 Data collection method

Data collection and data analysis occurs simultaneously in qualitative research (Polit & Beck 2021:55; Gray et al 2017:255). This process enables the researcher to turn words into data. Semi-structured interviews were used for data collection during this study. Semi-structured interviews consist of topics to be covered rather than specific questions. A written guide for these interviews is essential and can consist of a list of topics to be covered, or a few questions; the guide enables the researcher to cover all the topics but allowing the participants to tell their own story. Single answer questions, such as ‘yes’ or ‘no’ should be avoided. In this study the researcher preferred to use four topics that addressed in the form of questions, to guide the interview. The participants are encouraged to elaborate on the topic with their answers and the researcher can use probing questions like: “when” or “what happened next” to encourage the participants to elaborate on their lived experience (Grove & Gray 2019: 77-78; Gray et al 2017:259-262) This method of data collection was chosen for this study so that the researcher could ask what the reason for visiting the clinic was and what challenges they might face while adhering to treatment, but the participant could relive their own experience. Before the interview, the participants filled in a demographic data questionnaire (see Annexure 13). Most of the participants could complete the form without assistance. The researcher assisted the participants if they had any queries about the form. The demographic data was utilised to see if the child was mainly cared for by guardians or biological parents. The questionnaire also enquired whether there were other siblings in the family that had the same condition. This information was used to see if there was any previous exposure of the guardians to the deformity.

The interview guide contained four topics that were formulated into questions during each interview (see Annexure 12). The four topics were:

- Reasons for visiting the clinic on that day.
- Challenges in getting to the clinic.
- Knowledge and understanding of clubfoot.
- Whether antenatal clinic was visited and health education on clubfoot received.

Based on the responses of the participants probing questions were asked. The interview guide was discussed with and approved by the supervisor of the study.

### 2.6.2 Data collection process

This is the process undertaken in preparing and collecting data for the study.

Data collection was initiated in July 2019. This process had to be put on hold during 2020 due to the COVID-19 lockdown regulations commencing in March 2020 during which some of the clinics at the hospitals were halted, and then later operated with reduced numbers. Attendance of clinics was further impacted on by the restrictions of the movement of persons and the curfew imposed on the population. Data collection recommenced in March 2021 until May 2021 following the adjusted COVID-19 regulations issued by the National Department of Health with special attention to Section 70 (Department of Co-operative Governance 2021). As participants came from the rural parts of KwaZulu-Natal, they had limited access to digital tools, the internet and computers, which could allow virtual interviews with the result that face-to-face interviews had to be conducted. The prescriptions of the COVID-19 regulations were always adhered to, with the researcher, co-facilitator and all participants wearing masks, maintaining social distancing between the researcher, co-facilitator and the participant and child; providing sanitising containers to sanitise hands; the recorder, table, and chairs where the interviews were undertaken.

#### *2.6.2.1 Planning the data collection*

The researcher started off by obtaining written permission from both hospital managers and unit managers for the Ponseti clinics (see Annexures 3, 4 and 5). The researcher then obtained a quiet private room at the clinic to conduct the interview. The specific day of the week that the Ponseti clinic takes place was established and the researcher liaised with the registered nurse in charge of the clinic the day before to determine if there were any eligible participants booked for the next day. The audio recorder was tested every morning before the interviews to make sure it was functional. On the day of the interview the registered nurse informed the researcher when the participant was at the clinic; the researcher then proceeded to the clinic and waited for an appropriate time to conduct the interview. On the days when there was more than one participant available, the researcher stayed at the clinic the whole morning and interviewed each participant at a suitable time. The time that was suitable for most participants was the time after the cast had been soaked off and they were waiting for the cast to be reapplied. The participant was approached by the healthcare practitioners who informed them about the study and whether they would be interested to participate. If they agreed to participate, they were escorted by the researcher to the private clinic room. The researcher confirmed where in the queue the participant was and to ensure they did not lose their place in the queue.

A co-facilitator was used at both clinics to assist the researcher to make field notes of the participants' body language and translate phrases or words to Zulu for the participants and translate to English for the researcher when there was a language barrier. At Greys hospital the co-facilitator was a bilingual clinical research assistant that is based at the hospital. At Ngwelezana a bilingual medical officer working at the Ponseti clinic co-facilitated the researcher. Both facilitators were briefed about the study before the data collection started and signed a confidentially binding form (see Annexure 11).

#### *2.6.2.2 Pre-test*

To refine the data collection process, an interview guide should be pre-tested to see if it elicits the required data from the participants and to determine whether the interviewer was competent in the interview process (Gray et al 2017:493). A pre-test with one participant was conducted. The researcher felt comfortable in conducting the interview and was able to establish a good rapport with the participant. The participant in the pre-test was fully informed of the study and signed a consent form. Given the limited number of potential participants, the participant was also informed that if the interview guide was acceptable and required no changes, the data obtained during the pre-test will be included in the study. The pre-test confirmed that the questions were clear, that the environment was conducive for interviews, and that the audio recorder was working correctly. The researcher noticed that the participant needed more probing to share her experiences. As a result of the pre-test, no changes were made to the interview guide. Therefore, the data obtained from the participant was included in the main study.

#### *2.6.2.3 Conducting the interview*

When the participant and the child were settled in the private room the interview process began. The participants were informed of the purpose of the study verbally and were given an information leaflet with the information about the study (see Annexure 9). They were also advised that their identities would remain confidential, and that they could withdraw at any stage from the interview. They were then given the opportunity to ask any questions for clarity. While there would be no benefits to their participation in the study, they were advised that the study could benefit future guardians with children born with clubfoot. They were assured that they would not lose their position in the queue to see the doctor to have their casts reapplied. Once they agreed to participate, they were asked to sign a consent form (see Annexure 10) and permission was obtained to record the interview. Before the interview commenced, the participants' demographic data were obtained and completed with the assistance of the researcher and co-facilitator. The participants were asked the four questions related to specific topics in the interview guide and further probing was done based on the participants' answers to elicit a discussion and to gain a deeper understanding of the lived experiences of guardians with children born with clubfoot and the challenges they face. During the interview, it was vitally important to gain the trust of the participants and make them feel at ease to ensure optimal and rich data from the interview. The researcher spent a lot of time engaging with the participant before the recording started. The researcher noticed data saturation after eleven interviews (including the pre-test) and conducted another interview to confirm saturation. Data saturation refers to a stage when no new themes emerge from the interviews and participant responses become repetitive (Polit & Beck 2021:55).

Engagement between the researcher and the participants lasted 30-35 minutes, which included time spent putting the participant at ease and asking questions. Although the interviews did not last long, the information obtained from the four guiding questions, elicited rich and valuable data in terms of the problem identified in this study.

The interviews were audio recorded with a digital recorder with the permission of the participants and transcribed verbatim for the data analysis process (Grove & Gray 2019:85; LoBiondo-Wood & Haber 2018:94; Gray et al 2017:260, 268). Observations were made by the researcher during the interviews and field notes (see Annexure 15) were made in collaboration with the co-facilitator after the interview to capture any non-verbal communication or messages observed during the interview that were not captured in the recordings and transcriptions (Grove & Gray 2019: 85; Gray et al 2017: 257). After the interviews had been concluded and the recorder switched off, some participants made valuable comments relevant to the questions in the interview guide; this was recorded as part of the field notes. There were no instances where participants were not clear on the meaning of a question or probing comments. Code numbers (P1-P12) were allocated to each interview (Grove & Gray 2019:85; Gray et al 2017:270).

The participants and the children were offered something to drink after the interview as a gesture to thank them for sharing their experiences. Participants were assured that the clubfoot brochure that will be developed as a result of the study, will be available at the Ponseti clinic free of charge. They were thanked for their contribution for sharing their experiences. The researcher also ensured that the participants were taken to their specific position in the queue where guardians waited for the child's cast to be reapplied.

## 2.7 DATA ANALYSIS

Qualitative data analysis is a complex procedure utilising themes and concepts unlike numerical coding in quantitative studies (Polit & Beck 2021:532; Grove & Gray 2019:84-85; LoBiondo-Wood & Haber 2018:95). It uses words as the unit of analysis and reasoning flows from the words provided by the participants to create the more abstract themes and subthemes. This entails reading through your data over and over, breaking it down into themes and categories, and then using it to elaborate and interpret the findings (Terre Blanche et al 2016:322). In qualitative studies there is no specific time that the data collection process stops and when the analysis begins as the two processes overlap each other. At first it is more collecting of data, and towards the end its more analysing of the data that had been collected so far (Gray et al 2017:255; Terre Blanche et al 2016:321).

All the interviews were audio-recorded, coded with a number ranging from P1 to P12. An external transcriber transcribed the interviews verbatim. Pauses or gaps were transcribed with dots or dashes and all exclamations like laughter or crying was noted as well (see Annexure 14). This was done to get a transcription as close to the interview as possible. The researcher listened to the recordings and read through the transcriptions to determine whether the transcriptions were a true reflection of the recorded interviews.

The data from this study were analysed using the five steps of the Terre Blanche method of qualitative data analysis. A co-coder, who is an expert in qualitative research, was used to ensure rigour of the study. The researcher and co-coder had an initial meeting where the purpose of the study was discussed. After the data had been analysed, the researcher and co-coder had a meeting to discuss the findings and reach consensus on the themes and subthemes that emerged. Before the co-coder was presented with the transcripts, she was requested to sign a confidentiality binding form (see Annexure 11).

A key concept for a good interpretive analysis is to be involved with the data continuously and interpreting it with an empathetic view and understanding. The idea is to create an understanding and perception of a real-life situation rather than a collection of odds and ends about a situation. The researcher aimed to create an understanding of the guardians' daily life and challenges in seeking healthcare for the children with clubfoot (Gray et al 2017:270; Terre Blanche et al 2016:321).

Transcripts are locked away safely in the home office of the researcher; electronic copies were password-protected and will be kept for at least five years after completion of the study. Only the researcher, supervisor, and co-coder had access to the transcripts. For the electronic copies, only the researcher and supervisor have the password to access the files. These files will be available for secondary data analysis should the need arise.

### 2.7.1 Terre Blanche method

The data were analysed by using the Terre Blanche method (Terre Blanche et al 2016:322-326) as summarised in Table 2.1.

**Table 2.1 Terre Blanche method**

| Step | Action |
|---|---|
| Familiarisation and immersion | • Listening to interview recordings<br>• Reading field notes<br>• Printing and reading verbatim interviews |
| Inducing themes | • Marking key words<br>• Marking key phrases<br>• Grouping together similar key words and phrases<br>• Listing key words and phrases on paper |
| Coding | • Creating themes and subthemes |
| Elaboration | • Scrutinising and exploring themes more closely |
| Interpretation and checking | • Interpreting the findings |

(Terre Blanche et al 2016:322-326)

#### *2.7.1.1 Familiarisation and immersion*

Collecting interpretative data involves development of ideas and theories about the phenomenon being studied. When the data collection process is finished, the data analysis should already have started as the two processes overlap and a preliminary understanding of the data should have been established (Terre Blanche et al 2016:322-323). The verbatim interviews were printed, and the researcher read through the interviews and field notes multiple times to familiarise and immerse herself in the data. This allowed the researcher to recognise emerging thoughts and patterns and new information arising from an interview. After this was done the researcher had a clear understanding of the data, knew where to find most things, and what type of interpretation would be supported by the data.

#### *2.7.1.2 Inducing themes*

This process is the opposite of quantitative studies as the researcher looks at the material and then organise the categories that naturally comes out of the material rather than having pre-set categories. There are no set rules as to what categories and themes are best. It is important that the researcher uses the participants' language and words rather than theoretical language to categorise data (Terre Blanche et al 2016:323). The researcher must strive for complexity of the themes so that the data collected can give information rich results. One or two themes and subthemes will not pose any interesting results, at the same time the researcher must not lose focus of what the study is about.

In this study, the researcher had to focus on the healthcare-seeking behaviour of guardians of children with clubfoot, and the challenges they experienced in obtaining treatment for clubfoot while not getting side-tracked by the results of the actual treatment. The researcher in reading and rereading the transcripts, identified recurring ideas, and thought patterns and highlighted and colour coded key words and phrases in the interviews.

Similar key words and phrases were later grouped together in list form on paper, and broad themes were established. Reading through the grouped key words and phrases, again similar scenarios were grouped together, and these groups were named as subthemes.

#### *2.7.1.3 Coding of the data*

"Coding is the process of breaking up the data in analytically relevant ways" (Terre Blanche et al 2016:324). Whilst developing themes, one should also code the data. In this study, sections of the data were highlighted with different colours as being instances of, or relevant to one or more of the themes that are emerging from the data. As groups of similar data emerged, each was labelled with a code which was reviewed to combine similar data or to reduce overlaps. Codes were used to build a description of the experiences of the participants which were grouped into themes reflecting multiple perspectives of the study participants. In qualitative studies the themes are continuously emerging and therefore the coding should never be referred to as final or static.

#### *2.7.1.4 Elaboration*

Once themes and categories emerged from the data and the researcher had coded the data, it gives the researcher a fresh view of the data to scrutinise and compare different sections and to explore themes more closely. The researcher repeated this process until no further insights emerged from the data. The purpose of this step was to find more detail that might have been missed earlier by dividing the data into broad themes and codes. (Terre Blanche et al 2016:326). Finally, the researcher, with the assistance of a co-coder, considered the coded themes arising from the data to reach consensus on the themes, subthemes, and coded categories.

#### *2.7.1.5 Interpretation and checking*

This is the final step of the data analysis process, and this is when the researcher puts together her interpretation of the collected and analysed data of the phenomenon that was studied (Terre Blanche et al 2016:326). In this step the researcher reflected on the meaning of the data that emerged from the study. Analysis and interpretation of the data obtained with the semi-structured interviews were done simultaneously to derive meaning from the data as the researcher immersed herself in the data. Polit and Beck (2021:545) describe this as "incubation and living with the data" which refers to "living" with the data while talking and reading about the themes identified when making meaning of the data obtained. The authors further argue that interpretation of qualitative data requires some creativity and a lot of time to arrive at insights about the meaning of the data, and then merging the thematic components into an integrated unit.

### 2.7.2 Demographic data

The demographic data obtained was analysed using statistical analysis. The purpose of the statistical analysis was not to provide a measurement of concepts but to enable the researcher to describe the participants of the study. The data provided explained who the guardian of the child was: a caregiver or the biological parent of the child. It further showed the gender and age of the guardian, whether the child had any siblings with the same deformity, and how far they lived from their closest healthcare facility. Although the date of the first visit to the Ponseti clinic was not included in the demographic data form the participants filled out, the researcher captured it on her demographic data notes. This demographic data gave the researcher a closer look at who the guardian of the child is and gave some insight to their daily life.

## 2.8 TRUSTWORTHINESS

The rigour of qualitative research is based on an interactive, open, and flexible approach of the researcher that performs a sensitive and thorough collection of data congruent with the underlying philosophy and perspective of qualitative research. The analysis of this data brings forth the perspective of the research participants (Gray et al 2017:64). Trustworthiness is measures that are put in place to determine the level of confidence the researcher has in the data provided (Polit & Beck 2021:806; Grove & Gray 2019:86; LoBiondo-Wood & Haber 2018:126).

Trustworthiness relates to the meanings that emerge from the data that is not captured in writing (Gray et al 2017:270). Lincoln and Guba have developed four measurement criteria that can be used to determine the trustworthiness of a study: credibility, dependability, confirmability, and transferability (Polit & Beck 2021:569-570; LoBiondo-Wood & Haber 2018:126; Lincoln & Guba 1985). A fifth criterion was later developed, namely authenticity. Authenticity refers to the level the researcher displays a range of realities truthfully (Polit & Beck 2021:570). To ensure trustworthiness in qualitative studies the researcher must take great effort to make sure the findings are indeed a true reflection of the participants' lived experiences and viewpoints (Brink et al 2018:110). The researcher used the five criteria to ensure rigour of the study, as discussed below.

### 2.8.1 Credibility

Credibility refers to the confidence in the truth and believability of the study findings. The researcher must take steps in the data collection process to enhance the believability of the findings and demonstrate it in the reports (Brink, et al 2018:110; Polit & Beck 2021:569).

Researcher engagement was ensured by prolonged engagement in the field of study as the researcher was working in a clinical x-ray department and thereafter providing training on various digital x-tray equipment at different hospitals, becoming aware of the problem. The researcher aimed to get to know the culture and views of the participants, through face-to-face interviews and making field notes directly after each interview in collaboration with the co-facilitators to capture any non-verbal communication. Interviews continued until data saturation was assured (Polit & Beck 2021:55; LoBiondo-Wood & Haber 2018:94; Gray et al 2017:260). The researcher regularly checked with participants during the interview whether she understood them correctly and a Zulu-speaking co-facilitator was present for interpretation when necessary. Audio recordings of the interviews captured the actual data obtained during the interview that could be reread. The researcher deliberately set aside any personal views and perceptions of the phenomenon under investigation by aiming to maintain objectivity and openness to multiple realities when engaging with the participants. Debriefing sessions between supervisor and researcher was done during the study. In addition, a co-coder was used to independently code the data flowing, with a consensus meeting held between the researcher and the co-coder to agree on the themes and subthemes.

### 2.8.2 Dependability

The dependability of a study refers to the reliability and truth value of the study findings, in other words, that findings are consistent and accurate (Polit & Beck 2021:569; Brink et al 2018:111).

The researcher created an audit trail with a detailed description of the research methodology, data collection and analysis creating the opportunity for others to repeat the research. Participants recruited for the study had to meet eligibility criteria to ensure that they can provide information rich data on the phenomenon under study based on their lived experience of caring for a child with clubfoot. All stages of the research process were reviewed by the supervisor who is qualified and experienced in orthopaedic nursing and research.

### 2.8.3 Confirmability

Confirmability is achieved by portraying information that the participants provided during interviews and not the researcher's interpretation, biases, or motivations (Polit & Beck 2021:570; Brink et al 2018:111). The findings, conclusions and recommendations of the study should therefore be supported by the data that were collected. This can be confirmed with the audit trail that was reviewed by the study supervisor and the review of the data analysis by a co-coder.

### 2.8.4 Transferability

Transferability is the possibility to transfer findings of a study to other groups and settings. The researcher must provide enough descriptive data so readers can decide on the applicability of the data to other groups or settings (Polit & Beck 2021:157; Brink et al 2018:110).

A detailed description of the research methodology was provided so that other researchers could replicate the study in other contexts. Providing a dense description of the research processes offers a data base that makes transferability judgement possible. The researcher collected data through semi-structured interviews supported by field notes with consensus discussions with a co-coder on the analysis and supervisor review of the process.

### 2.8.5 Authenticity

Authenticity refers to the degree that the researcher displays multiple realities truthfully (Polit & Beck 2021:778). A report has authenticity when a reader can get a true feeling and reflection of the lived experiences. Authenticity was upheld in this study by including direct quotations made by participants during the interviews to support the interpretation of the data collected (Brink et al 2018:110). Zulu speaking co-facilitators were used during the interview process to ensure that there is a clear understanding of the participant responses.

## 2.9 ETHICAL CONSIDERATIONS

Ethics is a system of moral principles that governs research procedures to adhere to professional, legal, and social obligations of the study participants. Therefore, when humans are utilised as research participants in a study there must be strict measures involved to ensure that their rights are protected (Polit & Beck 2021:133; Grove & Gray 2019:95; LoBiondo-Wood & Haber 2018:139). According to Resnik (2020), adhering to these considerations can be described as acceptable behaviour of researchers in their quest to expand knowledge on an aspect which they are researching. Ethical consideration includes the elements of mutual respect, trust, fairness, and accountability of all parties involved which Chetty (2016) argues includes the intellectual property rights of all involved.

### 2.9.1 Ethical clearance process

The research proposal was reviewed by the Research and Ethics Committee of the Department of Health Studies of the University of South Africa (UNISA) as well as the National Health Research Database (NHRD), KwaZulu-Natal Department of Health (see Annexure 6). Ethical clearance for the study was obtained from the Research Ethics Committee of the Department of Health Studies, University of South Africa (UNISA). The ethics certificate was renewed by the College of Human Sciences Research Ethics Committee twice. Firstly, it was renewed on 24 June 2020 to accommodate the delay in the data collection due to the pandemic and again on 15 December 2021 when the wording of the title of the study was changed slightly. All three certificates were included in this report (see Annexure 1 for original certificate and Annexure 2 for the two revised certificates).

### 2.9.2 Institutional permission

The research proposal was reviewed by the National Health Research Database (NHRD), KwaZulu-Natal Department of Health (Ref: KZ_201808_019). Permission to conduct the study was granted by the Hospital managers as well as the unit manager of the clinic (see Annexures 7 and 8).

The institution was assured that only guardians who consented voluntarily would be included. Their identities would not be made known, and informed consent would be obtained before conducting the interviews. Authorities were further assured that there would be no financial cost to the institution to conduct this study. The researcher also undertook not to disturb the service delivery to the guardian and the children, by ensuring that the participants do not lose their specific appointment time or place in the queue at the clinic.

### 2.9.3 Ethical principles related to participants

The ethical principles that relate to participants include autonomy, justice, beneficence, and non-maleficence and were applied by obtaining informed consent, identifying possible risks for participants, and not offering incentives for participation in the study.

#### *2.9.3.1 Autonomy*

Human participants must be treated as autonomous agents and must be able to control their own actions. Participants have a choice whether to be part of a study or not without being judged or treated unfairly for their choice (Polit & Beck 2021:134; Grove & Gray 2019:95-97; Gray et al 2017:162-164). All participants were provided with information on the study and willingly participated in interviews with the researcher. They had to have a clear understanding of the reasons why the interview was being done and what the researcher plans to do with the information gathered during the interview. All participants were made aware that their interviews were strictly confidential, and that their identity would not or could not be linked to their responses. Participants had the opportunity to exit the study at any given time if they chose to do so, without any penalty.

#### *2.9.3.2 Justice*

Justice to the participants gives them the right to fair treatment and a right to privacy (Polit & Beck 2021:135; Grove & Gray 2019:96; Gray et al 2017:172-173). Informed consent was obtained from participants and engaging in the interviews was a completely voluntary process. They were free to withdraw from the study at any given time, without any penalty. The interview was conducted in a private room, and the participant and the child were made as comfortable as possible. All participants were made aware that their interviews were strictly confidential and in no instance, would any of the participants' names be disclosed. The transcripts are locked away at the home of the researcher and only the researcher, co-coder and supervisor had access to it. All electronic copies of the recordings, demographic data sheets, informed consent and any other documentation are stored on the researcher's computer and password protected to maintain confidentiality and only the researcher and supervisor have the password to access it.

#### *2.9.3.3 Beneficence*

The principle of beneficence refers to always acting in the best interest of the research participants (Polit & Beck 2021:133). The benefits of the study must therefore outweigh the harm to the participant (Polit & Beck 2021:133; Grove & Gray 2019:96; Gray et al 2017:173-174). While this study does not hold any benefits for the participants, they were made aware of how the information provided by them contributed to understanding their reasons for coming to the clinic and the challenges that they might have faced in seeking or adhering to treatment. Although the interview process took some of their time, the participants were made aware that the information gathered from the interview would be beneficial to assist other people in similar situations and an information brochure will be developed with information on clubfoot and early detection.

#### *2.9.3.4 Non-maleficence*

Polit and Beck (2021:133) describe non-maleficence as the obligation of the researcher to ensure that harm is avoided or minimised. The participants were not negatively affected in terms of time as the interviews took place while they sat and waited for the cast to soak off or for their turn for reapplication. They also did not lose their position in the appointment line because of the interview. The participant was made aware that there will be no financial or physical harm for them. Talking about children and deformities can be emotionally draining, and great care must be taken from the researcher’s side not to cause harm to the participant – especially psychological harm. Participants was made aware that the study was done to help understand their challenges and to try and find a possible solution or at least understand their daily lives and struggles. If one of the participants needed psychological debriefing arrangements were available at the healthcare facility. None of the participants seemed upset after the interviews or requested debriefing.

#### *2.9.3.5 Informed consent*

Informed consent implies that the participant has received enough information about the study, understand what is required of them, that it is a voluntary process and that they can withdraw at any time (Polit & Beck 2021:137). It is essential that the participant understands what the study is about so when they participate, they know what is required of them and that they do not have to feel pressured to do anything they do not feel comfortable with. When they give consent, the researcher can comfortably conduct the study. An informed consent form with information on the purpose and procedures related to the study was given to the participants (see Annexure 10). The Zulu speaking co-facilitators explained any unclear aspects to the participants and they then signed the form once they understood the process. Participation was voluntary, and the researcher ensured that no guardian felt obliged to consent to be part of the study.

#### *2.9.3.6 Possible risk factors to participants*

Possible psychological side effects for the participants may have included feelings of guilt for bringing their children to the clinic for treatment at or after three months of age, or participants could have felt ashamed for having a child with a deformity. Participants were assured that they did not do anything wrong. Counselling was offered to the participants after the interview should they need it, but none was required. All interviews were done in a private room without any interruptions. The researcher made sure that it was only herself, the participant and her child, and the co-facilitator in the room so sensitive information shared by the participant wasn't overheard by other people. The participants were assured that their identities will be kept strictly anonymous throughout the process.

#### *2.9.3.7 Incentives*

Participation in the study was completely voluntary and no financial incentives were given to the participants. However, a refreshment was offered to the participant after the interview was concluded. A treat was offered to the child with permission from the guardian during the interview to make them more comfortable while the guardian participates in the interview. The provision of the refreshments was not made known to the participants beforehand to prevent the possibility of coercion as the participants could have seen it as an opportunity to receive refreshments.

#### *2.9.3.8 Scientific integrity*

Scientific integrity includes intellectual honesty and objectivity in undertaking research and reporting research results in research reports and scientific articles; using resources efficiently, accurate reflection of the contributions made to the research including peer reviews and following commonly accepted codes (Mesquita 2017:1-2; NIH Grants & Funding [s.a.]). The researcher took great care not to commit plagiarism at any time. Therefore, all sources used were referenced according to the university standard. The researcher discussed all the findings with her supervisor and a co-coder was used to see if the data was interpreted in the same way; therefore, data were not falsified or fabricated. All data were kept confidential, and all hardcopy documentation is locked away at the researcher's residence and all electronic copies of data are password protected.

## 2.10 SUMMARY

In this chapter an account was provided of the boundaries within which the study took place. This chapter presented the research design and research methods that were used for the study. The data collection and analysis process were described. Trustworthiness to ensure rigour in the study was explained according the five criteria as proposed by Lincoln and Guba. Lastly, the ethical principles were discussed which provides the measures that were taken to protect the institutions and the participants. The findings of the study are presented in Chapter 3.

# CHAPTER 3

# PRESENTATION OF THE FINDINGS

## 3.1 INTRODUCTION

The methodology used for this study was discussed in Chapter 2. In Chapter 3 the researcher discusses the findings of this study obtained by individual semi-structured interviews between the researcher and the guardians of children with clubfoot. The demographic profiles of the participants are presented and then followed by presenting the themes and subthemes that emerged from the data. Detailed field notes taken after each interview was used as supporting data while the data was being analysed. Verbatim transcriptions of the semi-structured interviews were used for the coding of data and a co-coder was used to confirm the coding, themes, and subthemes. Direct quotes of the participants are presented in italic fonts so that the reader can easily distinguish between the participant’s direct words and the researcher’s comments.

## 3.2 FINDINGS

The findings are presented in terms of the demographic data and the thematic data.

### 3.2.1 Demographical data

The demographic data were collected and incorporated in the study’s findings. It provided the researcher with valuable information about the participants’ circumstances which contributed to a better insight into the daily lives and experiences living with a child that has clubfoot. By asking the participants how far they lived from the clinic gave the researcher and idea of the challenges they face adhering to treatment.

There were 12 participants that agreed to partake in the one-on-one semi-structured interviews. The demographic details of the participants are summarised in Table 3.1. The participants were all female, under the age of 40 years − the biological parent, and the mother of the child with clubfoot. While some fathers took the mother and child to the clinic, they did not accompany the mother into the clinic for the child’s treatment as expressed by one participant (P9). Most of the participants were not employed at the time of the interviews. Others did not complete school as they had to drop out of school to care for the child. There were, however, five of them of them that were employed either by running their own business or by an employer. Some of the participants had other children, but none of their other children had the same deformity so it was all the participants' first experience dealing with a child that has clubfoot. The age of the child at the time of the first visit to the Ponseti clinic varied, ranging from three to thirteen months with the majority visiting the clinic for the first time at ages three to six months. All the children visited the Ponseti clinic for the first time at or after the age of three months and this confirmed delayed treatment for all of them. Distance from certain participants' residence to the closest healthcare facility were as close as a ten-minute walk while others lived as far as one and a half hours from the nearest healthcare facility. The Ponseti clinics are based at tertiary institutions which are in the larger towns in more urban areas. The location of the Ponseti clinics made it very far to travel for the participants. The exact time from the participants' house to the Ponseti clinics were not recorded on the demographic data sheet, but the topic was discussed in the interviews.

**Table 3.1 Demographic profile of study participants**

| **Characteristic** | **Number** |
|---|---|
| **Participants** | |
| Parent: | |
| Mother | 12 |
| Father | 0 |
| Guardian | 0 |
| **Age of mother** | |
| 16-20 | 2 |
| 21-25 | 2 |
| 26-30 | 3 |
| 31-35 | 3 |
| 36-40 | 2 |
| **Employment status** | |
| Scholar | 1 |
| Unemployed | 6 |
| Employed | 5 |
| **Age of child: first visit to clinic** | |
| 3-6 months | 5 |
| 7-12 months | 5 |
| 13-18 months | 2 |
| **Travel distance from closest clinic** | |
| Travel ≤30 min | 6 |
| Travel 31-60 min | 5 |
| Travel >1 hour | 1 |

### 3.2.2 Thematic data

As a result of 12 individual interviews, themes and subthemes were identified. The discussion of the themes is supported by quotes from the verbatim transcripts from the interviews. The participants were assigned numbers during each interview and the data analysis included the reference to each participant's number. Where quotes were provided, it was done in italics and the participant number was added at the end of the quote: for example (P6) if the quote was from participant number six. Numbering the quotes eases cross-referencing and secondary data analysis.

Themes and subthemes that emerged from the data are discussed in the subsequent section and are reflected in Table 3.2 below.

## 3.3 DISCUSSION OF THEMES AND SUBTHEMES

In qualitative data a theme refers to a topic that repeatedly emerge from the data analysis (Polit & Beck 2021:805). Subthemes emerge from the theme that entails a more specific element. Two main themes emerged from the data and both themes had various subthemes. The first theme describes the process of discovering the clubfoot and the second theme addresses the challenges that are associated with having a child with clubfoot. Themes and subthemes related to this study are shown in Table 3.2.

**Table 3.2 Themes and Subthemes**

| Themes | Subtheme |
|---|---|
| Discovering the clubfoot deformity | • Time of discovering the deformity<br>• Reason for seeking help with their child's clubfoot<br>• Antenatal care received<br>• The referral process<br>• Clubfoot treatment received<br>• Knowledge about clubfoot<br>• Emotional and other experiences during the discovery of the deformity |
| Challenges of caring for a child with clubfoot | • Financial challenges<br>• Transport challenges<br>• Caring for other family members while seeking treatment for the child<br>• The continuation of schooling or an occupation |

### 3.3.1 Theme 1: Discovering the clubfoot deformity

Faldini, Fenga, Sanzarello, Nanni, Traina and Rosa (2017:248) explain that clubfoot can be detected during pregnancy which is confirmed by Fantasia, Dibello, Di Carlo, Collin, Barbieri, Belcaro, Magni, Faletra, Laura and Stampalija (2021:60). Healthcare practitioners should check for the deformity at birth. If the deformity is detected in-utero or at birth the mothers of the children can be educated on the deformity, the treatment options and guided on where to receive treatment at a Ponseti clinic. The Ponseti method has been set as the gold standard for treating clubfoot. (Gelfer et al 2019:639; Adegbehingbe et al 2017:628; Švehlík et al 2017:347; Global Clubfoot 2021). This theme presents how and when the deformity was discovered by participants in this study, and the reason for the treatment starting late. It highlights the emotional journey of the guardian when discovering that the child has a deformity and the referral process within the healthcare system. The first theme with its subthemes is summarised in Figure 3.1.

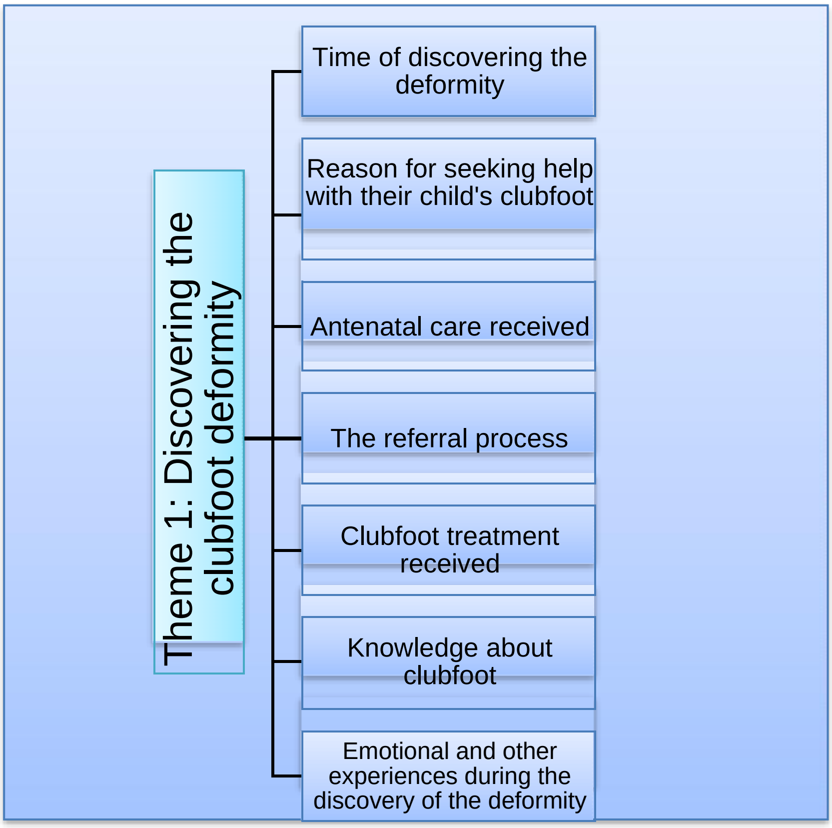


**Figure 3.1 Theme 1: Discovering the clubfoot deformity**

#### *3.3.1.1 Subtheme 1: Time of discovering the deformity*

Although treatment can start at any age it has been proven that the earlier the treatment starts the better the outcome of the treatment and therefore early detection is key (Besselaar et al 2017:306-307; Ganesan et al 2017:11; Agarwal 2014:207-209). Early onset of treatment is better for the child as younger children tolerate the braces better and there is less interference with the gross motor development of the child (Singh et al 2020:73; Street et al 2016:51). Liu et al (2018:666) state that a child that present at a clinic for treatment at or after the age of three months, is classified as late detection. Detecting the deformity as early as possible is therefore essential so that treatment can start for the best outcome. This subtheme explores when the guardian discovered the child has clubfoot.

Some participants noticed the deformity at birth themselves by looking at the child as stated below:

> "I noticed at birth, my baby was premmie at seven months, and then I was told that the reason the feet were not straight is because of the premmie and that it will with time get better. And then after some time I saw it wasn't getting better, then I went to the clinic and was transferred here." (P5)
>
> "Soon after the child was born, and I saw it myself." (P6)
>
> "So, at birth, I noticed that there was a problem with the spine and a problem with the feet, and then I was kept as an inpatient for almost a month while they were waiting for a bed at Inkosi Albert Luthuli for a bed … I noticed, the doctors noticed, and they would also just try and straighten it out and put some splints, because her whole legs were folded up." (P7)
>
> "At birth … No, I see it for myself 'cause I was [INDISTINCT – VOICE CLARITY – 00:01:35] after they have taken the baby out and then they put him in the monitor, I could see that that feet is a problem." (P10)
>
> "After birth." (P11)

Some of the participants were informed of the deformity by healthcare practitioners after the birth of the baby. They said the following:

> “I was worried ‘cause the nurses told me that her feet [INDISTINCT – VOICE CLARITY] skew, so I had to come … The nurses noticed it and then I also noticed it … Just when I was just [INDISTINCT – VOICE CLARITY] then they just told me. They only recognised one foot, so when I came here they told me both … At birth.” (P9)

> “No, they saw first, and when they show me the baby and I saw … From the day I get back, her feet was like this and they told me she is clubfoot. Then I was admitted to the [INDISTINCT – VOICE CLARITY – 00:01:02] and she was having another problem with the spinal.” (P8)

> “So, I went for the vaccine, vaccination for the baby, and that’s when they pick it up at the clinic … that’s when the nurses they realised that the feet is not straight, there’s a problem with the feet. So, they ask me if I can take the baby further, to the hospital … That’s when they noticed with the feet [CROSSTALK]. I actually realised that the feet is not okay but she thought it’s gonna be okay.” (P2)

Where pregnancies were associated with complications such as premature birth or pregnancy complications, the participants experienced the discovery of the deformity differently. These participants reported that they were more prepared for the diagnosis as indicated by the following statements made by two participants:

> “Then I was still on the theatre, they asked me have they told you anything about your pregnancy? Then I told them that, yes, they explained that I have no fluids, so the baby is unable to play everywhere and unable to grow other parts normally. So, they showed me, do you see the leg? It was more than this … The baby has the clubfoot from my pregnancy. I was having no fluid. My fluid was very low” … She was not able to play [INDISTINCT – BACKGROUND NOISE – 00:01:30]. So, on the left elbow there was a problem, but now she’s fine [CROSSTALK] now, the elbow is moving. But the leg, I think it was just horrible like this. But now it’s not, unlike the time when she was born. It was more bent … They told me to expect anything …] some parts will never develop normally. I was expecting …” (P12)

> "I noticed at birth, my baby was premmie at seven months, and then I was told that the reason the feet were not straight is because of the premmie …" (P5)

Detecting clubfoot after the age of three months is considered late detection with one mother saying she noticed the deformity for the first time at five months (P5) and another at eight months (P3). Several of the mothers only discovered a problem with the child's feet later, while others saw a problem, but were hoping it will go away, or only started treatment after three months of age due to a variety of reasons – these reasons will be explored in other subthemes. They had the following to say:

> "I started realising when the baby was starting to stand. That's when I realised that the baby can't stand. So, she used to grab some stuff, like a chair, she would try to stand but she couldn't stand … Eight months." (P3)

> "… and then I was told that the reason the feet were not straight is because of the premmie and that it will with time get better … And then after some time I saw it wasn't getting better, then I went to the clinic and was transferred here." (P5)

#### *3.3.1.2 Subtheme 2: Reason for seeking healthcare*

Subtheme 2 gives insight into the healthcare-seeking behaviour of the participant and the specific reason for going to the healthcare facility for the treatment of clubfoot.

Most of the participants' reasons for bringing the child to the clinic were because they realised there was a problem with the child's feet. Reasons provided for bringing the baby to the clinic were straight forward:

> "It's because I can see that the baby is not walking properly because of the feet is turned around …" (P1)

> "Fix the baby's feet … I started realising when the baby was starting to stand. That's when I realised that the baby can't stand. So, she used to grab some stuff, like a chair, she would try to stand but she couldn't stand." (P3)

> "Because her feet were not normal like her other sisters." (P4)

> “I noticed that the foot wasn’t okay and I was worried that she’s going to become disabled.” (P6).
>
> “No, I see it for myself ‘cause I was [INDISTINCT – VOICE CLARITY – 00:01:35] after they have taken the baby out and then they put him in the monitor, I could see that that feet is a problem.” (P9)

Some guardians noticed something was wrong, sought healthcare and were then referred by healthcare practitioners to visit a Ponseti clinic.

> “I thought there was a problem, but I wasn’t quite sure and then I took the baby to the clinic and then the nurse realised that there’s something wrong.” (P2)
>
> “It’s because I can see that the baby is not walking properly because of the feet is turned around … I noticed from the hospital that she was born in. They put some plastic on the legs. So, then, after that, it turned some … she had some sores around her legs and they didn’t help at that time … Rietvlei … Then that’s when they transport me this side.” (P1)

Others elaborated on the journey of the discovery over a period as the child got older or observing the child while dealing with other deformities. The journey for some includes seeking healthcare for the child and not receiving any at various places and going from the one place to next. Even though clubfoot can be detected in utero this does not always happen. Discovering a child has a deformity of the foot can come as a shock and have a negative effect on the mother and family’s mental health (Mahan, Miller, May & Kasser 2019:500). Dealing with the shock of a discovery and not being able to find healthcare can be stressful. These participants were emotional when talking about their discovery of the deformity.

> “Because her feet were not normal like her other sisters … I went to Umtata … They didn’t do anything because they just … they will call us there because it was that time when the corona started. So, ever since then, they didn’t call me back. So, I went in Kokstad so that [INDISTINCT – VOICE CLARITY –] here … Yes. From there they transfer me here.” (P4)
>
> "It’s because I can see that the baby is not walking properly because of the feet is turned around … I noticed from the hospital that she was born in. They put some

> plastic on the legs. So, then, after that, it turned some … she had some sores around her legs and they didn't help at that time. I took it to the other hospital, Mhlangeni. … Rietvlei. Then that's when they transport me this side." (P1)

> "At three months because the child was admitted in hospital. She's chromosomal issues … I was very upset but then I had to accept it." (P11)

> "Fix the baby's feet … I started realising when the baby was starting to stand. That's when I realised that the baby can't stand. So, she used to grab some stuff, like a chair, she would try to stand but she couldn't stand." (P3)

Healthcare practitioners detected the deformity before the participant noticed the deformity themselves, and they recommended the patient to visit a Ponseti clinic. Once they discovered that there was a problem with the child's feet, they acted as quoted below:

> "I was worried cause the nurses told me that her feet [INDISTINCT] skew, so I had to come … The nurses noticed it and then I also noticed it … Just when I was just [INDISTINCT – VOICE CLARITY] then they just told me. They only recognised one foot, so when I came here they told me both." (P9)

> "I went for the vaccine, vaccination for the baby, and that's when they pick it up at the clinic … they ask me if I can take the baby further, to the hospital." (P2)

Some of the children only came to the clinic quite late as they received alternate treatment first. Thermoplastic splints are a type of splint that some healthcare practitioners apply on children for clubfoot. Ponseti is still the best treatment option around and therefore other methods of treatment should be avoided (Gelfer et al 2019:639). Ponseti clinics mainly run at government healthcare institutions, while most participants went there as their first option, others opted for private healthcare first, but was none of the participants in this study has had successful treatment at a private healthcare facility. The alternate treatment options are not effective as it only delays the treatment for the child. It has been said that the younger the child is the better they tolerate the treatment (Singh et al 2020:73). Participants shared their experiences:

> "… the reason why they sent me her so late this side, they've been trying to put some sort of a plastic." (P1)

> "At birth … No, I see it for myself 'cause I was [INDISTINCT – VOICE CLARITY – 00:01:35] after they have taken the baby out and then they put him in the monitor, I could see that that feet is a problem … still book us for ortho, for ortho, for ortho until the baby was, I think, one month. After that, they book us but as the ortho doctor also postponed … yes private doctor … I went to the nearest hospital [INDISTINCT – VOICE CLARITY – 00:02:28] 'cause I work there, then …' cause some doctors were concerned that the baby now is …h e's older. He's supposed to be in the boots or in the cast. And they said they're gonna refer me here." (P10)

> "I first consulted the other doctors from the [INDISTINCT – VOICE CLARITY] clinic, then they referred me here, so we had to come here … Yes, to a private doctor. I waited and waited, then I had to come. I think she was three months …" (P9)

#### *3.3.1.3 Subtheme 3: Antenatal care received*

Antenatal care is rendered at hospitals or clinics during which physical examination, health education and ultrasounds are done. The participants all lived in rural areas and antenatal care was available at the clinics. Ebonwu, Mumbauer, Uys, Wainberg and Medina-Marino (2018:16) found that rural women are more likely to present late for ante natal care. They name the top five barriers as being too busy, long waiting times, distance to the clinic, transport challenges, and cultural secrecy. Unplanned pregnancies were classified as an independent risk factor for presenting late for antenatal care (Ebonwu et al 2018:8). Other risk factors include lack of education, cultural beliefs, being unmarried and history of obstetric complications. These reasons may be applicable for women not attending antenatal clinics at all. Ebonwu et al (2018:11) motivate that the attitude towards antenatal care must be promoted for all women. Antenatal care is essential for all women as it provides preventative services, curable services, and healthcare education to the pregnant women (Ebonwu et al 2018:2; Al-Ateeq & Al-Rusaiess 2015:240). If the clubfoot can be identified in utero the mother can be educated on the treatment options for the child when it is born. This study was conducted during the COVID-19 pandemic. According to Siedner, Kramer, Meyer, Harling, Mngomezulu, Gabela, Dlamini, Gareta, Majozi, Ngweya and Herbst (2020:1) the number of adult clinic visits did not decrease during hard lockdown, but then child visitations to healthcare facilities in rural KwaZulu-Natal reduced significantly.

In this study none of the participants reported that the COVID-19 pandemic and lockdown regulations prevented them from visiting an antenatal clinic. Siedner et al (2020:1) confirmed that adult ambulatory services were more resilient during the lockdown. Most of the participants received antenatal care and had ultrasound scans done. It is unclear whether the deformity was detected at the time. According to all participants who received antenatal care, no deformity was reported to them:

> “I was going to prenatal since I was one month pregnant … No, they didn’t see it during my pregnancy …” (P5)

> “Yes, I did from the time I was three months pregnant … It was never explained to me during pregnancy and the first time of ever knowing about this was when my child was born.” (P6)

> Yes, I went. It would be much better if they inform us of [INDISTINCT – VOICE CLARITY – 00:06:35] something like this does happen, then you’ll say it’s [INDISTINCT – VOICE CLARITY] it’s not something new and [INDISTINCT – VOICE CLARITY]. It will be nice for the nurses to inform us. ‘Cause they do tell us about other [INDISTINCT – VOICE CLARITY] but not this one … They do tell us about other … Is it possible to pick it up?” (P9)

> “I did go to prenatal clinics, they didn’t pick up anything on ultrasound and I was only diagnosed when I had the baby.” (P11)

None of the participants attending the antenatal clinics received information regarding clubfoot as a deformity as part of the general health education provided during pregnancy as confirmed by their responses (P5, 8, 9, 11). One of the participants stated that she would have appreciated information about this condition before the baby was born and was not even aware that you could detect it during pregnancy. The participant had the following to say:

> “Yes, I went. It would be much better if they inform us of [INDISTINCT – VOICE CLARITY – 00:06:35] something like this does happen, then you’ll say it’s

> [INDISTINCT – VOICE CLARITY] it's not something new and [INDISTINCT – VOICE CLARITY]. It will be nice for the nurses to inform us. 'Cause they do tell us about other [INDISTINCT – VOICE CLARITY] but not this one … They do tell us about other … Is it possible to pick it up?" (P9)

Advice was given to one participant on taking her vitamins during pregnancy; if it is not taken there can be complications with the baby after birth – not specifying what complications, although they did not provide her with the vitamins. She expressed the following:

> "Yes, from when I was two months pregnant … I was just told that I have to take my vitamins because if I don't take them then the child could have problems, but they didn't specifically go into different types of issues the child might have …" (P7)

Pregnancy complications like reduced amniotic fluid were experienced by some participants. The Healthcare practitioner did advise her that this condition might cause complications with the baby after birth. She stated below that she was prepared for anything:

> "They told me to expect anything … It was the first thing that I found out when I searched about what happens if you are pregnant and you have low amniotic fluid? It was the first thing coming up." (P12)

One participant indicated that she received no information regarding this deformity. She delivered the baby at seven months. One cannot be sure if she would have been educated on the matter if she carried to full term. She expressed the following:

> "No, 'cause I gave birth when I was seven months …, I didn't know … I don't understand … Even when I went to ultrasound, they didn't pick up anything, I was fine, and then I was seven months pregnant there was some contractions and then went to hospital and baby came." (P8)

#### *3.3.1.4 Subtheme 4: The referral process*

This subtheme explores the referral process that the participants had to follow to get the correct treatment at a Ponseti clinic. Children with deformities are referred to specialised services by the healthcare practitioners. These specialised services are usually located at tertiary institutions in more urban areas. The majority of the participants referred to a Ponseti clinic lived in the more rural areas, which can lead to long journeys to get treatment. Mojaki, Basu, Letshokgohla and Govender (2011:109) pointed out that the South African public healthcare referral system is ineffective resulting in patients bypassing the system by entering the healthcare system at another level through emergency departments. Clubfoot cannot be classified as an emergency and participants were reliant on the referral system to get the correct treatment as they could not bypass it. Poor referral systems can add extra delays in starting the treatment for the child and then cause extra stress for families with poor resources Saib et al (2021:12). Participants were referred to multiple hospitals to get the correct treatment. The children were referred to the Ponseti clinic in various ways. Certain children were referred to the Ponseti clinic by primary healthcare facilities where they sought help in the beginning, others explored private healthcare first, and some were referred multiple times or visited multiple hospitals and clinics to eventually get the correct treatment. Alternate treatment like thermoplastic splints also caused a delay in referral to the Ponseti clinic. COVID-19 also delayed the referral process for some as discussed below.

Direct referral to the Ponseti clinic after seeking healthcare for the first time:

> “I went for the vaccine, vaccination for the baby, and that’s when they pick it up at the clinic … they ask me if I can take the baby further, to the hospital …, they wrote me a referral letter to Edendale Hospital and that’s when I saw Dr Mare [SP] in the clinic … To come here, yes.” (P2)

> “My baby was premmie at seven months, and then I was told that the reason the feet were not straight is because of the premmie and that it will with time get better. And then after some time I saw it wasn’t getting better, then she went to the clinic and was transferred to here.” (P5)

> “I went to the nearest hospital [INDISTINCT] ‘cause I work there, then … ’cause some doctors were concerned that the baby now is … he’s older. He’s supposed to be in the boots or in the cast. And they said they’re gonna refer me here.” (P10)

Participants were not always referred to the Ponseti clinic directly or immediately. Participants stated that they have been referred to more than one place before they could get to the Ponseti clinic for treatment. One participant said that she first went to a clinic in Umtata and Kokstad before she was referred to the Ponseti clinic:

> “I went in Umtata … They didn’t do anything because they just…they will call us there because it was that time when the Corona started. So, ever since then, they didn’t call me back. So, I went in Kokstad … from there they transfer me here.” (P4)

Another participant was sent from the clinic to Ladysmith Hospital where they sent her to the Ponseti clinic:

> “I started realising when the baby was starting to stand. That’s when I realised that the baby can’t stand she used to grab some stuff, like a chair, she would try to stand but she couldn’t stand … took to clinic … They’ve just checked the baby’s feet and then they wrote a referral … it started at local clinic … they sent me to provincial … From provincial, they sent me here.”(P3)

Other participants opted to seek private healthcare first and were then referred to the Ponseti clinic. At the private healthcare facilities, the waiting period for any intervention from the private healthcare was long. Therefore, some of the participants who were seeking private healthcare opted to then to go to the public clinic for assistance. This is how participants verbalised it:

> “I went to the doctor, the doctor called Ngwelezana to be transported here, and then someone told me to bring the child when she’s three months old.” (P6)

> “I first consulted the other doctors from the [INDISTINCT – VOICE CLARITY] clinic, then they referred me here, so we had to come here … Yes, to a private doctor. I waited and waited, then I had to come. I think she was three months.” (P9)

> “We are follow-up with a private doctor, but they were taking slow. ‘Cause at first they didn’t do anything [CROSSTALK]. I went to the nearest hospital [INDISTINCT] ‘cause I work there, then … ’cause some doctors were concerned that the baby now is … he’s older. He’s supposed to be in the boots or in the cast. And they said they’re gonna refer me here.” (P10).

COVID-19 might have impacted on the referral process for some. According to Siedner et al (2021:1) visits to the clinic for children did reduce during the lockdown. A participant who did seek healthcare for the child was advised that they would contact her which they never did. The researcher cannot assume that she would have been referred adequately if she did not go during the lockdown, but COVID-19 cannot be directly responsible for the late onset of treatment. At a different institution she was referred to the Ponseti clinic. The participant said:

> “I went to Umtata … They didn’t do anything because they just … they will call us there because it was that time when the corona started. So, ever since then, they didn’t call me back … So, I went in Kokstad … from there they transfer me here.” (P4)

The referral process to start treatment at a Ponseti clinic were longer for others as they had other complications after birth that had to be attended to first. The children received treatment for their more serious deformities that even included surgery. After receiving initial treatment, they were then referred to a Ponseti clinic. The treatment of the clubfoot was delayed because of other treatments. They expressed the following:

> “At birth, I noticed that there was a problem with the spine and a problem with the feet, and then I was kept as an inpatient for almost a month while they were waiting for a bed at Inkosi Albert Luthuli … Then I went there, had the spine surgery, and also probably stayed there for about a month, and then the moment I was transferred back to my hospital they made arrangements for her to come here.” (P7)

> “From the day I get back, her feet was like this and they told me she is clubfoot. Then I was admitted to the [INDISTINCT – VOICE CLARITY – 00:01:02] and she was having another problem with the spinal. Then they sent me to [INDISTINCT – VOICE CLARITY]. She had an operation on the spinal. And then they sent for the feet.” (P8)

> “Three months because the child was admitted in hospital……. She has chromosomal issues.” (P11)

According to certain participants they were instructed only to come to the clinic when they were older – the reason for this is unclear.

> "I went to the doctor, the doctor called Ngwelezana to be transported here, and then someone told me to bring the child when she's three months old." (P6)

> "They said that she's over nine months, you can come here now … They never sent me earlier. I was busy at Queen Nandi and I saw no changes." (P12)

#### *3.3.1.5 Subtheme 5: Clubfoot treatment received*

Ponseti treatment is regarded as the best method for treating clubfoot internationally even though other treatment methods exist (Gelfer et al 2019:639; Švehlík et al 2017:347). Gelfer et al (2019:642) said that the Ponseti method has a better primary correction and functional outcome than surgical corrections. Long term outcomes between Ponseti and surgical options were compared and showed that the Ponseti method results in better movement of the foot and the chance of getting osteoarthritis is reduced (Smith et al 2014:1281). Alternate treatment options for the clubfoot were received by some children that were not effective. After these treatment options proved ineffective, they sought healthcare somewhere else or were referred to a Ponseti clinic for further treatment. Alternate treatment that does not work causes a delay in starting the correct treatment. Thermoplastic splints applied by other healthcare practitioners like physiotherapists and occupational therapists were the most common alternate treatment option as indicated by the following:

> "I noticed from the hospital that she was born in. They put some plastic on the legs. So, then, after that, it turned some … she had some sores around her legs and they didn't help at that time. Then I took it to the other hospital, … to stretching her legs. So, sometimes it gets better. And then, when they took it out, it gets worse again …" (P1)

> "The doctors noticed, and they would also just try and straighten it out and put some splints, because her whole legs were folded up." (P7)

> "When I was still on the theatre, they asked me have they told you anything about your pregnancy. Then I told them that, yes, they explained that I have no fluids so

> the baby is unable to play everywhere and unable to grow other parts normally. So, they showed me, do you see the leg? It was more than this. Then I said yes. They made a splint when I was at Queen Nandi. I stayed two months. She was on splint that side, saw no difference … They were just making a splint, telling me to come back after two weeks, but I see no changes. It was a plastic thing on anything bent like this … Physios … I was on the hospital where I stay, Queen Nandi. They made a call for this side." (P12).

The thermoplastic splints caused other complications for the child while wearing them. The mother explained it as follows:

> "They put some plastic on the legs. Then, after that, it turned some … she had some sores around her legs, and they didn't help at that time. Then she took it to the other hospital … The baby had skeppies." (P1).

Others commented that the splints were applied to the child with no instructions other than to come back after two weeks but the mother noticed no change.

> "They made a splint when I was at Queen Nandi. I stayed two months. She was on splint that side, saw no difference. They were just making a splint, telling me to come back after two weeks, but I see no – (difference)." (P12)

Expressions of happiness were apparent when the participants knew that the condition is treatable. At first, one mother was told that the clubfoot will rectify by itself after having a preemie baby, but the mother got worried when the baby got older because the feet did not get better as stated by the following:

> "I am happy that it can be fixed … Doctor told her that the condition will rectify by itself, but I then took the baby back to the clinic at 5 months." (P5)

> "Yes, ma'am, I'm feeling better." (P4*)*

While all the participants' children were still in their first treatment phase during the interviews, some of the mothers noted that there is already an improvement since coming to the Ponseti clinic. They shared their opinions:

> “She’s looking nice, she’s walking nicely. The treatment is fine.” (P9)

> “But the leg, I think it was just horrible like this. But now it’s not, unlike the time when she was born. It was more bent.” (P12)

#### *3.3.1.6 Subtheme 6: Knowledge about clubfoot*

Health education about clubfoot is not necessarily part of the general health education provided during pregnancy. Jacobs, Amuta and Jeon (2017:10) expressed that younger people with a higher level of education and knowledge on how to use the internet were more likely to access information on the internet regarding health. Not all the participants could access to the internet to obtain health information and relied on healthcare institutions to provide material and education about the deformity. Prior to coming for treatment, many of the participants did not know that clubfoot as a deformity exists, what the implications and treatment options are and most importantly that the deformity is treatable. Although participants in this study are already in the treatment phase, they mentioned that they still do now really understand what the deformity is and how the treatment works. Faldini et al (2017:248) state that clubfoot can be detected while the child is in utero, this will make it possible for healthcare practitioners to educate patients on the deformity and treatment options before the child is born. Creating awareness and information brochures that are freely available can aid similar people as the participants to broaden their knowledge about the condition. They expressed their concerns:

> “No, this is my first time, with my child.” (P5)

> “It was never explained to me during pregnancy and the first time of me ever knowing about this was when my child was born.” (P6)

> “No, ma’am, I didn’t know. It was my first time seeing her like this … I don’t understand.” (P8)

Although the child is currently having treatment for clubfoot, there are still some of the mothers that do not really know or understand what the condition entails as indicated when asked if she understood the condition by one response:

> “No, I’m just worried ‘cause I don’t know if it will happen again.” (P9)

> ”But then how long does it going to take for her? Because I don’t know if she will be able to walk or not.” (P4)

The internet helped some of the participants research clubfoot after the diagnosis to get a better understanding of the condition, what the treatment and outcomes are likely to be. This online search increased their knowledge about clubfoot, and they were aware that the condition is treatable. They were more at ease with the condition.

> “Yes, on my Google … It was the first thing that I found out when I searched about what happens if you are pregnant and you have low amniotic fluid? It was the first thing coming up … You can expect a clubfoot. And I also saw the pictures of the babies born and corrected.” (P12)

> “I only know about there’s something called clubfoot … I understand ‘cause I also did some research on my own …Google … Ja, I’m very comfortable.” (P9)

During one of the participant’s pregnancy, they advised her that she has reduced amniotic fluid. When she did her own internet search on reduced amniotic fluid, clubfoot was the first complication that appeared on her search, so she was a bit more prepared for the diagnosis.

> “It was the first thing that I found out when I searched about what happens if you are pregnant and you have low amniotic fluid? It was the first thing coming up.” (P12)

Several participants had some idea about clubfoot, or have heard about it before, but have never had a child or an experience with the deformity. One participant had a family member with a foot deformity but was unsure if it is in fact clubfoot.

> “… only know about there’s something called clubfoot. When I experienced it, it’s [INDISTINCT].” (P9)

> “I know that it’s a bit of a disability and the child was not positioned well in the womb. That’s the best that I could explain it.” (P6)

> "Yes. I have seen some kids with it, but I haven't seen anyone being corrected. I don't know because I'm not working with kids. But I have seen kids with clubfoot." (P10)

One participant commented that there was a family member that has a foot deformity, but it is unclear whether it is clubfoot or not, but she still did not have prior information on the deformity.

> "I have an aunt who has a foot deformity, but I wasn't educated on it prior to the baby." (P11)

Down Syndrome was a much bigger concern for some of the participants than any other possible deformity or complication after birth.

> "The only thing that we were concerned it was Down Syndrome only." (P10)

Although most participants were not aware of clubfoot and what the deformity entails, they said that they would have liked some information on the subject before they had the child, they narrated the following:

> "It would be much better if they inform us of [INDISTINCT – VOICE CLARITY – 00:06:35] something like this does happen, then you'll say it's [INDISTINCT – VOICE CLARITY] it's not something new and [INDISTINCT – VOICE CLARITY]. It will be nice for the nurses to inform us. 'Cause they do tell us about other [INDISTINCT – VOICE CLARITY] but not this one … Yes, but not this one." (P9)

#### *3.3.1.7 Subtheme 7: Emotional and other experiences during the discovery of the deformity*

Lemacks, Fowels, Mateus and Thomas (2013:3467) say parents that received the news of their child having a birth defect goes through different stages of grief, like when one loses a child. Furthermore, caring for a child with a birth defect can affect the parents' mental and physical health in a negative way, this can lead to depression, fear, and anxiety (Lemacks et al 2013:3467). The anxiety levels are high for parents when they discover their child has a foot deformity (Mahan 2019:504). For most of the participants discovery of the deformity has been an emotional journey, some felt sad, others were very upset, and even cried about the condition of their child. The emotional experiences of the guardians were explored at different stages. Although most of them were upset when they discovered the deformity, there was a sense of content when they realised that it could be treated. Participants were emotional and some were even crying then the question was about the discovery was asked. They expressed their feelings below:

> "I was quite sad. I was really sad". (P7)

> "I feel very sad. I even cry." (P5)

The lack of knowledge about the long-term effects of clubfoot, or whether the deformity could be treated scared them. They made the following statements:

> "It is the most painful thing is that she is still not able to walk and that's a bit painful to me." (P5)

> "I was afraid that it might not be able to be corrected and I was very sad." (P6).

> "I was very upset because I was feeling like she won't be able to walk like others … I like to know, 'cause I was very shocked when I see her like this … But then how long does it going to take for her? Because I don't know if she will be able to walk or not." (P4)

Although they were sad about the discovery of the child's clubfoot, they have made peace with it and was trying their best to get the best help for their child as quoted below:

> "I was very upset but then I had to accept it." (P11)

> "I was upset but I have to accept that my baby's like this 'cause I must try by all means to get her help." (P8).

A few participants said that they felt at ease now that they know the condition can be treated and that the child can have a normal life regarding the clubfoot.

> “I was worried. She was very small. The clubfeet. But now I’m fine. Ja, I’m very comfortable.” (P9)

Dealing with children having surgery, or other conditions, while coping with the discovery of this deformity was difficult; participants explaining that the child had to receive spinal surgery prior to being referred to a Ponseti clinic:

> “At birth, I noticed that there was a problem with the spine and a problem with the feet, and then I was kept as an inpatient for almost a month while they were waiting for a bed at Inkosi Albert Luthuli … Then I went there, had the spine surgery, and also probably stayed there for about a month, and then the moment I was transferred back to my hospital they made arrangements for her to come here.” (P7)

> “From the day I get back, her feet was like this and they told me she is clubfoot. Then I was admitted to the [INDISTINCT – VOICE CLARITY – 00:01:02] and she was having another problem with the spinal. Then they sent me to [INDISTINCT – VOICE CLARITY]. She had an operation on the spinal. And then they sent for the feet …. I was upset but I have to accept that my baby’s like this ‘cause I must try by all means to get her help.” (P8)

> “At birth … three months because the child was admitted in hospital … she has chromosomal issues.” (P11)

Complications for an unsuccessful alternate treatment option that was tried before the Ponseti method for the child’s clubfoot, made it much more stressful:

> The baby had skeppies [sic] that is why they didn’t put.” (P1)

Setbacks of treatment for the child due to the mother having COVID-19 made things more difficult for the participant, dealing with the illness herself and trying to obtain healthcare and treatment for her child:

> “I was diagnosed with COVID in PE, so now I’m taking the treatment. So, I’m on sick leave for now.” (P10)

### 3.3.2 Theme 2: Parents' challenges of having a child with clubfoot

Theme 2 discusses the challenges the participants with a child with clubfoot faced as summarised in Figure 3.2. Challenges faced by participants ultimately become a barrier to treatment. Drew et al (2016:574), investigated the factors affecting patient accesses and engagement of treatment of clubfoot in LIMCs. It highlighted several factors like, financial challenges, other responsibilities, lack of awareness of the treatment, and family support were highlighted too. This theme explores and highlights the daily struggles of the participants, such as financial struggles and transport problems, but also other factors at personal and family level while caring for the child with clubfoot.

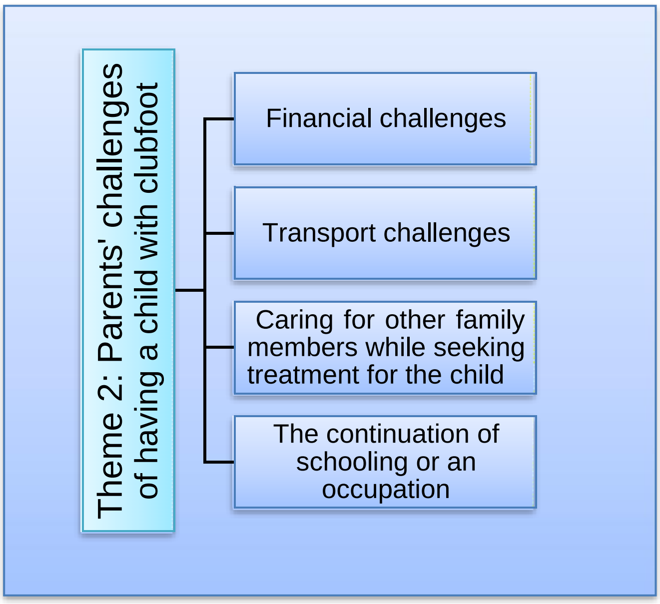


**Figure 3.2 Theme 2 and subthemes: Parents' challenges of having a child with clubfoot**

#### *3.3.2.1 Subtheme 1: Financial challenges*

Participants in this study mostly resided in the rural areas of KwaZulu-Natal and were unemployed with either no income, or dependent on a government grant or family member for money to travel to the clinic. While some had small businesses, on the days they travelled to the clinic there was no income generated. For some this was the biggest challenge as the treatment consists of weekly visits to the clinic for at least six weeks. Malagelada et al (2016:107) presented social data from a study conducted exploring the impact of the Ponseti treatment method on parents and caregivers of children with clubfoot that showed that seventy-five percent of the South African participants earned less that the 50th percentile of the household income norm. Financial challenges that were expressed are provided below:

> “I went in Umtata … First time I was travelling by the transport from the hospital, but now I’m driving by my own money … Yes, ma’am. I think it’s close to fifty rand … I’m staying with my brother now in Maritzburg ... Yes, ma’am, it is better now.” (P4)

> “First goes to Bethesda sleeps over at night, and then takes the bus from there to come here … it’s quite expensive, just from my house to Bethesda one hundred and fifty, and then she’ll take the bus, which is free, and then to get back is another one fifty. So, it’s quite expensive … She just sells things … No salary. So, there’s no work.” (P6)

The Ponseti clinic is usually based at larger healthcare institutions and the participants must travel long distances to get there. They complained that the cost to get to the clinic is very high.

> “Three o’clock, walk to the hospital … to hire a car … it’s three fifty … ’cause I don’t work I, prefer to wake up early, three o’clock, and walk ... ‘Cause the bus leaves at five … at four … My granny will give me money, return money, to come from the hospital.” (P2)

> “It is a bit difficult, not too much to the one close to me but all the way here (Ponseti clinic), and it’s usually financial. I have to pay for the taxi from my house to Nkandla but then the hospital bus I don’t pay for and that’s still sometimes a challenge.” (P5)

> “I walk to the hospital, sleeps over at night, and then comes with the bus in the morning … it is difficult because sometimes I don’t have money or my mom won’t have money and then I will have to borrow some money for the travelling costs.” (P7)

> “Yes, there are ‘cause sometimes [INDISTINCT – VOICE CLARITY] I don’t have money to come to the clinic [INDISTINCT – VOICE CLARITY] I have to make sure that I must go to the clinic.” (P8)

To get to the clinic for treatment, some must make alternate plans when they cannot afford the transport. Some borrow money, others stay with family members that stay closer to the clinic, and others even wake up early and walk long distances

> "I went in Umtata … First time I was travelling by the transport from the hospital, but now I'm driving by my own money … Yes, ma'am. I think it's close to fifty rand … I'm staying with my brother now in Maritzburg ... Yes, ma'am, it is better now." (P4)

> "It is difficult because sometimes I doesn't have money, or my mom won't have money and then I have to borrow some money for the travelling costs." (P7)

> "Three o'clock, walk to the hospital … 'cause I don't work I, prefer to wake up early, three o'clock, and walk … 'Cause the bus leaves at five … at four … My granny will give me money." (P2)

Some has applied for a disability grant from the Government, and this will assist the mother financially to come to the clinic, but she still has not received any of it. She mentioned the following:

> "I don't have too much of an issue bringing him, but I also applied for disability, a child disability grant which will also assist more, but I haven't received it yet." (P11)

Financial challenges weren't so challenging for others as they could afford the transport:

> "No, I don't have any problem 'cause it's fifty rands to go and [INDISTINCT] for the transport on the hospital." (P12)

> "No, it's just normal." (P8)

#### *3.3.2.2 Subtheme 2: Transport challenges*

The participants are from rural communities. As mentioned above the Ponseti clinics are usually located at the bigger healthcare institutions and therefore some of the participants must travel very far to get the child to the clinic for treatment. Van Wijck, Oomen & Van der Heide (2015:2418) describe the distance traveling as a barrier to treatment. This is supported by Poudel, Kumar, Tiwari, Subramani and Khan (2019:3) who found in their study that one third of respondents experienced challenges with transport. Most of the participants in this study do not have their own transport and they rely on either public transport or family members to take them to the clinic. There are usually busses from clinics and provincial hospitals that can transport them for free to the Ponseti clinic, but they must fund the trip themselves to the local clinic or hospital. The hospital transport leaves early in the morning and no accommodation is provided for them at the hospital or clinic the night before, so they must leave in the early hours of the morning. Even though there is transport available for them they travel very long distances to get to the treatment facility. They explained their situations as follows:

> "'Cause I can't sleep in the hospital with the baby. I have to wake at three o'clock and walk quite a long distance so that she will catch a bus that morning." (P2).

Transport from some hospitals and clinics are available to the tertiary hospitals. But even so, the journey to the Ponseti clinic can take up to three hours for some participants which means they have to get up at 01:00 in the morning to get to the clinic or even stay the night before:

> "First goes to Bethesda sleeps over at night, and then takes the bus from there to come here … it's quite expensive, just from my house to Bethesda one hundred and fifty, and then she'll take the bus, which is free, and then to get back is another one fifty." (P6)

> "I have to pay for the taxi from my house to Nkandla but then the hospital bus I don't pay for and that's still sometimes a challenge." (P5).

> "I walk to the hospital, sleeps over at night, and then comes with the bus in the morning … it is a bit difficult because sometimes she doesn't have money or her mom won't have money and then she will have to borrow some money for the travelling costs." (P7)

> "So, from home she travels to Nkandla Hospital and sleeps there overnight and early hours of the morning they take the bus to come here." (P5)

> “From home, I went to the hospital … my hospital, yes, and wait for the transport, then I came here.” (P12)

The travel distance to the clinic as said by some is very far and a big challenge to walk so far:

> “It’s very far.” (P9)

> “It’s very challenging for me ‘cause I have to walk.” (P2)

Public transport is the most common way to get to the clinic, for some it takes multiple taxi’s or busses to get to the Ponseti clinic as seen in the following comment:

> “Yes, there are ‘cause sometimes [INDISTINCT – VOICE CLARITY] I don’t have money to come to the clinic [INDISTINCT – VOICE CLARITY] I have to make sure that I must go to the clinic … I take a taxi to Richard’s Bay, from Richard’s Bay to Empangeni, from Empangeni to Ngwelezana. So, that’s three taxis.” (P8)

The distance for some is achievable and they don’t see it as a challenge.

> “No issues. I [INDISTINCT] the local area, I just take a taxi to here. Two taxis to get here.” (P11)

Others rely on family members or spouses to bring them to the clinic and that is also challenging:

> “My husband. Ja, he brings me.” (P9)

> “Maybe three hours … leave at one … My father transport me … takes us from home to the hospital, to the provincial hospital … take bus.” (P3)

#### *3.3.2.3 Subtheme 3: Caring for other family members while seeking treatment for the child*

Adhering to the treatment for a child with clubfoot includes weekly trips to the Ponseti clinic for at least six weeks. Most of the participants are not employed, therefore cannot afford paid childcare and rely heavily on family and friends. This means that if the guardian bringing the child to the clinic has other dependants, alternate plans must be made to care for their other children. Following the Ponseti treatment protocol can impact the family function as well as be stressful for parents, there is a need for more supportto families in various ways (Poudel et al 2019:3; Wanjiru 2018:1-4; Malagelada et al 2016:104). The participants rely on their family and friends in more ways than one. The main reason is to provide care for other dependants while they take the child with clubfoot to the clinic for treatment. Other reasons include looking after their businesses so there is no income loss and providing accommodation closer to the treating facility. They need a committed support system as the treatment takes approximately six continuous weeks. They acknowledged the following:

> "Younger sister." (P8)
>
> "I ask neighbours to look after them." (P6)
>
> "She's at home with my mother, the granny." (P7)
>
> "I don't work but I have a small business … I have my sister who takes care of it (business) when I'm not around … there is my mom (other dependants)." (P12).

One older child of a participant must come with her to the clinic as there is no one to fetch her after school as the mom and dad are at the clinic, so the five-year-old misses school for the day. There was no quote on the transcript, but it was documented on the field notes by the researcher:

> "My 5yr old child that must travel with to the clinic when the sibling has to come so she misses out on school." (P9)

Not all family members provide care for children but help in other ways like providing accommodation closer to the treatment facility while the participant’s dependants stayed behind with other family members.

> “I’m staying with my brother … Maritzburg … They’re (other dependants) staying … I’m from Montele … Next to Kokstad.” (P4).

### *3.3.2.4 Subtheme 4: The continuation of schooling or an occupation*

Looking after a child with clubfoot can be more time consuming as the child must come to the clinic weekly in the first treatment phase for at least six weeks and then thereafter come for regular check-ups to make sure there is no relapse. This treatment schedule makes it difficult to continue schooling or keep a job. A lot of the participants were unemployed at the time of the interview and had also been unemployed before they had the baby. However, there were others that had to quit their jobs or even drop out of college/school to take care of the child to make sure the child gets the necessary treatment. The continuation of schooling is difficult because when they must bring the baby to the clinic, they miss vital schooldays as a Matric pupil stated:

> “The only challenge that I face when I have to come to Greys Hospital … ’cause I am studying. I have to be absent from [INDISTINCT – VOICE CLARITY] school … I’m still at school. I’m in matric, ja.” (P3)

Others had to drop out of college or school or give up their job to look after the child’s needs and make sure they can come to the clinic. This was captured on the field notes for P4 after the recording stopped and a direct quote for P8.

> “… drop out of college where I was doing her matric to look after the baby.” (P4)

> “No, I’m not working now … Yes, I was working. So, I have [INDISTINCT – VOICE CLARITY – 00:02:12] to look after the baby. There’s no-one to look for me.” (P8)

Some of the participants were small business owners, mostly vendors and they can’t sell anything on the days they have to attend the clinic. So, if they don’t work, they do not have an income for that day:

> “I just sell things … No work no income … no salary today.” (P6)

> “I don’t work but I have a small business … I have my sister who takes care of it (business) when I’m not around.” (P12).

Government employees are fortunate enough to have family responsibility leave to bring the child to the clinic without losing any income:

> “I will take a family responsibility leave.” (P10).

The interviews at Ngwelezana hospital took place during the COVID-19 pandemic when the lockdown level was at level three. Although some routine healthcare services were interrupted, none of the participants indicated that the reason for not seeking healthcare was due to the pandemic. One participant was told at her local clinic that they will phone her when lockdown is over and let her come back. They, however, never phoned her back, but she persevered and visited another healthcare facility.

## 3.4 SUMMARY

Two themes emerged from the data, namely discovering the clubfoot deformity, and challenges of caring for a child with clubfoot. These themes were discussed and supported by the quotations from the participants. The chapter sets the way for interpretation of the findings in the subsequent chapter. In Chapter 4 the findings of the study are integrated with relevant literature to contextualise the phenomenon under investigation.

# CHAPTER 4

# DISCUSSION OF FINDINGS AND INTEGRATION OF LITERATURE

## 4.1 INTRODUCTION

In this chapter the researcher discusses the findings of the study and integrates it with relevant literature. This discussion contextualises the study findings with the existing body of knowledge. The process of integrating the study findings into the existing body of knowledge assisted the researcher to gain insights into the current evidence regarding early detection and treatment of clubfoot and identify gaps in reaching the goal of early detection and treatment. The literature search highlighted the paucity of recent and relevant literature and research on the phenomenon. However, the search supports the notion that not enough research is being conducted on clubfoot and early detection and treatment of this deformity, especially in rural and poorer communities. The integration of the findings with the existing body of knowledge guided the recommendations for future studies in this field.

Multiple methods of integration were used to incorporate the study findings with the current literature. Major electronic research databases such as Google Scholar, PUBMED, EBSCO and Web of Science were used. Key words and simple phrases were entered into the search fields to facilitate the literature search. Phrases such as: ‘Ponseti treatment’, ‘management of clubfoot’, ‘clubfoot detection’, ‘early detection of clubfoot’, ‘late detection of clubfoot’, ‘awareness of clubfoot’, ‘pre-natal screening clubfoot’, ‘maternal attitude about clubfoot’, ‘barriers to treatment’, ‘traditional treatment’, ‘healthcare-seeking behaviour, ‘impact of clubfoot on family’, and ‘mental health clubfoot’ were used.

## 4.2 DISCUSSION OF THE FINDINGS

The findings of this study to discover the reasons why guardians in two districts in KwaZulu-Natal sought healthcare for their children with clubfoot at or after the age of three months, consist of two themes with 11 subthemes. Treating clubfoot for the first time after the age of three months is regarded as late intervention (Liu et al 2018:666; Street et al 2016:53). The findings of this study therefore specifically contribute to the knowledge, and a better understanding, of the healthcare-seeking behaviour of guardians with children born with clubfoot deformity.

## 4.3 DISCOVERING THE CLUBFOOT DEFORMITY

The first theme and its seven subthemes relate to the guardians' discovery of the clubfoot deformity. Although the deformity can be detected prenatally through ultrasonography, the deformity is usually discovered at birth when one or both feet of the child is turned inward, and the sole of the foot points downward as pictured in Figure 1.1 (Dibello et al 2020:2, 4; Kadhum et al 2019:1-2; Basit & Khoshhal 2018:107). The diagnosis of clubfoot should be confirmed by a healthcare practitioner who will refer the child for treatment. Treatment of clubfoot includes non-surgical and surgical strategies with the Ponseti technique regarded as an international standard for the initial non-surgical treatment of clubfoot. The Ponseti technique includes two phases consisting of weekly castings of the foot to correct the foot alignment followed by maintenance with abduction braces (Gelfer et al 2019:639; Manisha & Priyanka 2017:1-4; Švehlík et al 2017:347; Jacqueto et al 2016:658). Ponseti treatment can start at any age, but it has been proven that the earlier the treatment starts the better the outcome is, therefore early detection is important. (Besselaar et al 2017:306-307; Ganesan et al 2017:11).

### 4.3.1 Time of the discovery of the deformity

Ideally all children should be screened within 48 hours after birth for clubfoot as early diagnosis and treatment prior to the age of three months has been found to provide the most effective outcome of Ponseti treatment (Dibello et al 2020:4; Liu et al 2018:666; Street et al 2016:51). Most of the participants noticed the deformity at birth when they looked at the child, while others were immediately informed by the healthcare practitioners at the birth of the child who advised the parents to seek treatment. Several of the participants only discovered that there is a problem with the child's feet after the child was older than three months. Early intervention is key for the treatment of clubfoot, because the earlier the deformity is detected the better the outcome (Dibello et al 2020:4; Liu et al 2018:666; Hamer & Rhatigan 2014:2318). Some of the children's clubfoot was detected as late as eight months or even older. According to Singh et al (2020:73), older children do not tolerate the braces as well as younger children and this can make the treatment process more complicated. If the treatment is not delayed, there is no significant delay in gross motor development of children with clubfoot. Fourteen percent of children can have a minimal delay of about three months in independent walking (Street et al 2016:51). In many cases, the participants were not advised by healthcare practitioners during the birth of the child or during early clinic appointments after the birth of the child, that there was something wrong. It is important that healthcare practitioners do a thorough check within 24-48 hours after the baby's birth as per the KwaZulu-Natal guidelines (KwaZulu-Natal Department of Health [s.a.]c; Consolini 2021) and during clinic visits. This includes screening for clubfoot (Editorial Team & Watkins 2018). Dibello et al (2020:2-3) explain that screening should be done as soon as possible after birth during which the foot should be assessed in its full complexity which includes morphology, skin folds and flexibility of the muscles and tendons. The more flexible the foot is, the better the prognosis for the child. Proper screening of new-borns will lead to earlier detection of the deformity.

### 4.3.2 Reason for seeking help/treatment with their child's clubfoot

According to Mishra, Mohapatra and Kumar (2019:498), proper healthcare-seeking practices of guardians can reduce morbidity. Proper healthcare-seeking practices refer to activities undertaken by guardians who detect that their child has a health problem, in this case a foot deformity, for which they seek healthcare services. The reason for most participants seeking healthcare was simple. The guardian of the child noticed that there was something wrong with the child's feet and she took the child to the healthcare facility. Although they did not know exactly what the problem was, they noticed that something was not right, or that the child could not walk properly which encouraged them to seek help. This lack of knowledge to recognise the deformity as something requiring early intervention, supports the finding of a study by Mishra et al (2019:502) in India that guardians require health education on the signs and symptoms of childhood conditions to reduce morbidity. A study in Turkey highlighted that parents' issues were related to their need for information, the sources of information, and the difficulties that they encountered when seeking information (Kilicarslan-Toruner & Akgun-Citak 2013:176) which was also seen in this study.

Parents naturally compare their children to each other, particularly new mothers (Bradford 2019). All the participants in this study were mothers of the children who brought them to the Ponseti clinic for treatment. One participant stated that she could see the feet of the child were not like that of the child's siblings which prompted her to seek help for the child. Results of a Sub-Saharan study on parental investment in child health indicated that there was evidence that children with a higher birth order (later-born child in the family) tend to be disadvantaged in terms of health investment by their parents as those children are less likely to receive any medical attention for their health problems (Uggla & Mace 2016:9). In the current study, however, guardians were motivated to seek healthcare for the deformity in cases where their older children did not have the deformity. Furthermore, Poudel et al (2019:3) found in their study being a female child or and older child is associated with irregularities in adhering to treatment.

Early referral of the children with clubfoot for corrective treatment is essential to prevent a delay in treatment which could result in a less successful outcome of treatment; or even a situation where they will not be able to walk normally if the clubfoot is neglected (Dibello et al 2020:1). Even though some participants did not notice the deformity, they were advised of the deformity by the healthcare practitioner at the clinic during routine clinic visits for vaccinations or general check-ups. Once the problem was identified, guardians were then referred to a Ponseti clinic for treatment by the healthcare practitioner at the clinic they visited.

Oligohydramnios refers to low amniotic fluid which can occur in a normal pregnancy, usually during the third trimester of pregnancy, which may result in the foetus developing clubfoot in utero (De Bellefonds 2020). A participant who had developed oligohydramnios during pregnancy gave birth to a preterm child with clubfoot. During pregnancy this mother was informed by healthcare practitioners that the child may develop a deformity as a result of the low amniotic fluid without specifying what the deformity could be. She was therefore prepared for the child to possibly have deformities, pre-empted the problem, and immediately sought healthcare after the birth of the child.

Non-idiopathic clubfoot can develop as a secondary problem due to underlying neuromuscular or syndromic disorders such as spina bifida (Dibello et al 2020:2; De Mulder et al 2018:579; Pavone et al 2018:1). Two participants in this study reported that their children were admitted to hospital for spinal surgery prior to bringing the child to the Ponseti clinic. The primary reason for these guardians to seek healthcare, was in fact not for the clubfoot, but for the spinal deformity and the clubfoot was treated as a “secondary” problem. There is, however, no evidence in this study that indicates whether the clubfoot would have been detected if there were no other deformities.

Stigma associated with physical deformities may result in either not seeking healthcare or only seeking healthcare at a late stage, or when other problems arise as complications.

Although Van Wijck et al (2015:2419) stated that the delay in seeking treatment might be due to social stigma within the communities they live in, none of the participants raised this as a reason to delay seeking healthcare intervention for their children.

### 4.3.3 Antenatal care received

Antenatal care involves the regular assessment of the mother during a pregnancy with the purpose of diagnosing high risk pregnancies and to educate women for a healthier pregnancy and outcome (Herval, Olivera, Gomes & Vargas 2019:1; McNellan, Dansereau, Wallace, Colombara, Palmisano, Johanns, Schaefer, Rios-Zertuche, Ziniga-Brenes, Hernandez, Iriarte & Mokdas 2019:2). Health education in antenatal care provides women with information to understand their bodies and health related topics related to pregnancy, childbirth, and the need for antenatal and postnatal care. Bergh (2021) argues that health promotion and health education are context bound and also relies on health literacy (ability to get, process and understand health information) with the latter supported by Rasheed et al (2017:92-93), Azarpira, Emami, Vosoughi and Rahbari (2016:321) and Van Wijck et al (2015:2420). A positive finding of this study was that most of the participants attended antenatal clinics from early in their pregnancies and received ultrasound scans. In none of the cases deformities of the feet were detected during the ultrasound scans. According to Faldini et al (2017:248), ultrasound is the most reliable way of diagnosing clubfoot in the womb. This view is supported by Ngene and Chauke (2020:1) who confirm that limb deformities can be diagnosed prenatally through ultrasonography. The most important benefit of prenatal detection and diagnosis of clubfoot is that it allows guardians to be informed of the deformity prior to the birth of the child which allows for counselling of the parents and early treatment for the child (Sarbu, Socolov, Carp & Ciongradi 2015:690). It is remarkable that Radler, Meyers, Burghardt, Arrabal, Hertzenberg and Grill (2011:659) reported that mothers retroactively seemed to accept the false negative diagnosis when clubfoot was missed during prenatal ultrasonography.

Participants in this study indicated that they did not receive information about clubfoot at any of the clinics. The findings revealed that knowledge about clubfoot was limited or non-existent until they had a child with this condition. Some participants have, however, been informed about other congenital conditions. Participants indicated that they would have liked to know about the deformity before the birth of the child which supports the finding of a study in Egypt, where mothers indicated that they would have liked to be told of deformities early, and would like to receive this information when they are accompanied by their husbands (Abdelmoktader & Abd Elhamed 2012:3). Ponte, Perpinan, Mayo, Milla, Pegenaute and Poch-Olive (2012:S3) supports this finding adding that professionals should know the family that they are informing, and select the time to inform them with great care.

Antenatal care presents the opportunity for healthcare practitioners to engage with mothers to educate them on how to care for themselves to ensure good outcomes during pregnancy and labour, the benefits of breastfeeding, and the need for follow-up visits during the postnatal period (McNellan et al 2019:2; Al- Al-Ateeq & Al-Rusaiess 2015:239). The advice participants received from healthcare practitioners in this study seems to be limited. Some participants were advised by the midwives to take their vitamins to prevent certain problems that can occur after birth. Nonetheless, these professionals did not go into detail as to what could happen, and one participant said that she was not supplied with any vitamins. One participant had reduced amniotic fluid and was advised that she must be prepared for problems as anything can happen to the baby. As indicated in Section 4.2.2 reduced amniotic fluid can increase the risk of clubfoot during pregnancy (Mayo Clinic 2021; De Bellefonds 2020). Although this participant was not advised as to what could go wrong during her pregnancy, she was advised at the birth of the child through caesarean section that the child had clubfoot for which she immediately sought healthcare intervention for the child.

### 4.3.4 Referral process

A hierarchical referral system exists in the South African health sector ranging from primary healthcare clinics, community health centres, regional and tertiary hospitals. The referral process of the public health system is summarised in the Referral Policy for South African Health Services of the National Department of Health as indicated in Figure 4.1 (Department of Health 2020:15). In this figure it is clear that referral takes place from primary health clinics and community healthcare centres to other services in the system. As a Ponseti clinic provides a specialist service, these clinics are based at tertiary hospitals which in this case study was the Greys and Ngwelezana hospitals in KwaZulu-Natal. It can also be noted from Figure 4.1 that the policy indicates that referrals can also be done by the private sector.

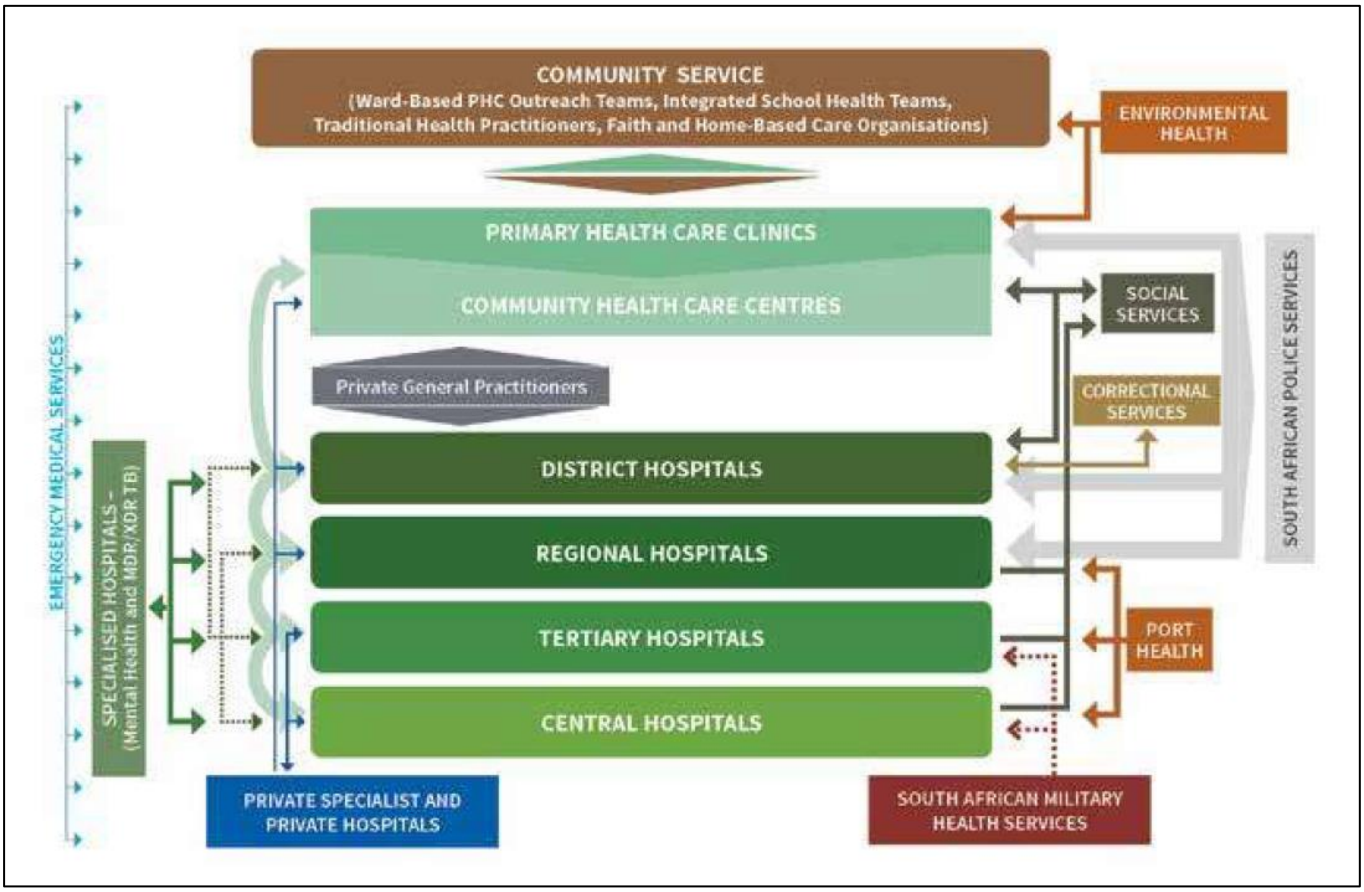


**Figure 4.1 Public sector service delivery platform – integrated referral services**
(Department of Health 2020:15)

All the participants were referred to a Ponseti clinic after seeking healthcare for the first time at public healthcare clinic level or a private practitioner. Even though some participants noticed the deformity at birth, the delays in following the referral process in the public health system resulted in the children only starting the Ponseti treatment after the age of three months. Several of the participants narrated that they were sent to different clinics in different towns before being referred to the Ponseti clinic. Participants could not seem to bypass the hierarchical referral process of the public health system on their own. Mojake, Basu, Letskokgohka and Govender (2011:109) in a study in the Free State (South Africa) reported on the ineffective referral system in South Africa' public health system which includes challenges of accessibility, acceptability, efficiency, and effectiveness. In their study patients bypassed the referral system by getting access to healthcare via emergency services citing reasons for self-referral as perceived poor services at clinic level and the desire to be seen by a doctor. This finding is not supported by the results of this study as participants could not seem to bypass the hierarchical referral process of the public health system on their own and all had to be referred, some with long delays, to the Ponseti clinic. The late referral of patients for specialist intervention creates additional stress on an already poorly resourced system (Saib et al 2021:12).

A few participants opted to seek healthcare intervention at private healthcare services. Generally, private healthcare services are more streamlined in their service delivery, but in this study all the participants that opted for private healthcare consultation received little or no help resulting in delayed treatment for the clubfoot. They either came to the public clinic themselves or were eventually referred by a private doctor to the Ponseti clinic. So even when participants sought healthcare timeously, the child's treatment was delayed. This finding supports the result of a study in Kenya by Kingau, Rhoda and Mlenzana (2015:86) in which patients reported referral systems to practitioners who did not know how to treat clubfoot. Van Wijck et al (2015:2420) indicated lack of physician education on clubfoot as a barrier to initiation of treatment which is supported by Diabello et al (2020:1) who state that paediatricians should have the required knowledge to refer the child early for Ponseti treatment. A participant in this study said that the private doctor kept postponing treatment and she decided to look for treatment elsewhere, while another said she waited and waited for the private doctor to start with the child's treatment and by the time she was three months old she came to the local public hospital to seek treatment.

COVID-19 impacted the referral process as well. Similar to the rest of the world, the COVID-19 pandemic hit South Africa too with the first patient diagnosed in March 2020 according to the Ministry of Health media statement (Minister of Health 2020). This was followed by the president of the country, President Cyril Ramaphosa, declaring a national state of disaster with hard lockdown (level 5) in mid-March 2020 suspending all activities to limit the spread of the virus (*Insession. Official Newspaper …* 2020:1-2; South Africa 2002). The guidelines for the implementation of level five lockdown were set out in regulations (R398) issued in terms of the Disaster Management Act, 2002. These regulations set out the determination that the only services and personnel allowed to continue with service delivery, were emergency, hospital, pharmacy, and laboratory personnel, as well as supporting services for health services and supermarkets (Department of Co-operative Governance and Traditional Affairs 2020). The Defence Force was deployed to ensure that the lockdown requirements were enforced. At first the hard lockdown was declared for 21 days followed with an extension of another two weeks. After this, the lockdown regulations were decreased to different levels allowing more activities but retaining all health-related guidelines. However, it is interesting to note in a study in rural KwaZulu-Natal by Siedner et al (2020:3-4) that clinic visits for adults did not drop during level 5 lockdown, with a 60% stepwise reduction in child healthcare visits during the same time that recovered to pre-lockdown levels three months later. This finding was contradicted by a participant in this study, saying that she went to the clinic when the baby was one month old during lockdown, but was informed by the healthcare practitioner that she should go home for now and that they will phone her to come back once the lockdown regulations change. She never got this phone call and went to another clinic after a while where she was only then referred to a Ponseti clinic. Another participant stated that when she called the Ponseti clinic to make an appointment, she was informed to only come back after the child is three months or older. This advice to the guardians seems to indicate the need to improve the knowledge of healthcare practitioners on the importance of early intervention and treatment for clubfoot which supports the statement by Van Wijck et al (2015:2420) and Drew et al (2018:9) that health practitioners need to be educated on the management of clubfoot.

### 4.3.5 Clubfoot treatment received

The treatment of clubfoot is essential to avoid permanent disability, painful feet, and gait abnormalities in later life (Rasheed et al 2017:90). The Ponseti technique is the “gold standard” for the treatment of clubfoot to permanent disability (Abraham, Wall, Diab & Beaver 2021:1; Gelfer et al 2019:639; De Mulder et al 2018:576; Švehlík et al 2017:347; Lykissas et al 2013:145). Ponseti treatment has been shown to be more effective the earlier the treatment starts (Vaishy et al 2020:55). The Ponseti technique consists of a casting phase with five to seven plaster casts over a few weeks or months, followed by a bracing phase once the foot is corrected when the child is supplied with an abduction brace for maintenance (Kumar et al 2017:24; Ponseti, Zhivkov, Davis, Sinclair, Dobbs & Mocuende 2006:172). While a study showed that a physiotherapist led Ponseti service provided successful outcomes for children (Akhbari, Jaggard, Hillier, Abhishetty & Lahoti 2016:18), the findings of this study did not support it. Receiving alternative non-invasive treatment other than the Ponseti method like splints that are applied to the feet by healthcare practitioners like physiotherapists and occupational therapists are not effective and delays effective treatment for the child’s clubfoot. A study in Iran found that an increased number of casts to accomplish complete correction and more follow-up visits were associated with a possible recurrence rate (Van Schelven, Moerman, Van der Steen, Besselaar & Greve 2021:6; Azarpira et al 2016:319). Leg splints were applied to a few of the children taken to local clinics for treatment by participants before they were referred to the Ponseti clinic. This treatment did not seem to yield any improvement or changes to the deformity. Instead, the splints rather caused damage to the skin of the legs and feet.

Van Wijck et al (2015:2419) in a study of four countries (Netherlands, South Africa, Indonesia, Argentina) found that there were caregivers of children who believed that the clubfoot was caused by a biomechanical/biological reason, and others who believed the clubfoot was caused by supernatural causes, such as God, spirits, or that they were being punished for previous sins. The latter group tends to seek traditional healing first, and these children end up with neglected clubfoot or late presentation for treatment. Although this is described as a common trend, no participants in this study had expressed supernatural beliefs, or opted for traditional healing options prior to attending the Ponseti clinic. What participants in this study did express, was the joy and relief they felt when they were told that the condition is treatable. The progress seen early in the treatment when the child was walking contributed to their relief.

### 4.3.6 Knowledge about clubfoot

Public knowledge of clubfoot and its treatment contribute to early intervention for children with clubfoot (Alsiddiky, Alrwibaah, Alqahtani, Alnujidi, Alhomaidhi, Almasoud & Alatassi 2019:2). Burfat, Mohammed, Siddiqi, Samad, Masoor and Amin (2013:152) found in their study in Pakistan that parents could not distinguish clubfoot from other deformities. Theseresearchers identified numerous misconceptions and incorrect information about clubfoot that impacted on early treatment of clubfoot. Several participants in this study did not know what clubfoot was until the child was born, and they saw the deformity. This supports the finding of Iqbal, Dubey, Thakur, Katiyar and Prasad (2020:4231) in a study in India that some parents did not know about clubfoot until their own child was born with clubfoot. Studies in Saudi Arabia and Pakistan found that the lack of public awareness and knowledge about clubfoot delays treatment of clubfoot deformity and therefore these countries are encouraging public health awareness about clubfoot (Alsiddiky et al 2019:6; Rasheed et al 2017:93). These findings are supported by a participant in this study saying that she had a family relation with the same condition but was not aware of the treatment options available. This seems to indicate that the extended family also did not have the required knowledge and information to advise this participant on a way forward for the treatment of her child.

Low educational level of the mother amongst other reasons, were identified as high risk for especially recurrence of clubfoot (Azarpira 2016:321) with Bergh (2021) highlighting that health literacy is one of the most important concepts in health education. Health literacy refers to the “capacity of individuals to obtain, process and understand basic information and services needed to make appropriate health decisions” (Bergh 2021). Communicating and explaining the Ponseti treatment protocol and outcomes properly to caregivers made a positive difference and could lead to low recurrence rate. Caregivers who understood the treatment and what was expected of them, understood the problem and treatment better, and had better adherence to the treatment which resulted in a better outcome for the patient (Van Wijck et al 2015:2420). Healthcare practitioners, particularly midwives, play an important role in addressing the beliefs about the causes of clubfoot (Van Wijck et al 2015:2420). Except for one participant in this study, the discussions indicated that others understood what clubfoot was and the importance of the treatment that the child was undergoing as they were all attending the Ponseti clinic for the treatment of their child. Lack of understanding raises red lights as Evans et al (2021:4) found that lack of understanding clubfoot and its treatment is one of the contributory reasons for relapse of clubfoot. Furthermore, in some instances, the participants in this study were able to use the internet and Google the diagnosis to educate themselves about the condition and the treatment. This finding is similar to the findings of a study in Hong Kong where online health information seeking by patients was prevalent (Wong & Chueng, 2019:5) and in Ghana where 85.8% respondents used the internet of which only 35.7% used the internet to access health information (Nangsangna & Da-Costa Vroom 2019:e13). Jacobs et al (2017:10) found that younger people, persons with more education, those with higher socio-economic status, and having internet skills were more likely to look for health information on the internet. However, Tonkovich, Baskar and Frik (2021:3) highlighted in their study the wealth of information that are available on Facebook, Instagram, Twitter and TikTok for parents with children with clubfoot. Not all participants in this study tried to access health information through the internet which seems to support the finding of Nangsangna and Da-Costa Vroom (2019:e13) that while the internet can effectively increase knowledge, there are subsets of populations that may not be able to access the internet due to a variety of reasons. In more rural places with no internet, word of mouth acts as education on the condition and its treatment (Van Wijck et al 2015:2421). Participants in this study who could use the internet could educate themselves on the clubfoot deformity while those who could not use the internet, had to rely on the healthcare practitioner to explain or educate them about the deformity. Healthcare practitioners did not share information on congenital birth defects or any other potential complications with participants in this study, even though a participant expressed concern about Down Syndrome while she did not even know anything about clubfoot. This supports the finding of Wong and Chueng (2019:2) that 56.1% of doctors showed little or no interest when their patients asked about information that they obtained on the internet. The information that a participant with oligohydramnios received from health practitioners was non-specific saying that there could be “problems with the pregnancy”. This participant did her own internet search to find out what could happen to the baby when there is not enough amniotic fluid. She discovered that the baby might have a deformity such as clubfoot. She read and informed herself about the condition and was therefore better prepared for the deformity when the baby was born with clubfoot.

The aetiology of clubfoot is still unknown, seems to be multifactorial with many theories proposed, for example intrauterine position, interruption in foetal development, viral infections, muscular alterations, and some others (Kumar et al 2018:23; Pavone et al 2018:1). Clubfoot develops early in gestation and can be detected prenatally with ultrasonography at 18-24 weeks (Mahan 2019:502; Faldini et al 2017:248). The majority of children are born with idiopathic clubfoot, while 20% of children have clubfoot secondary to another congenital deformity, particularly neurological disorders (Dibello et al 2020:2; Pavone et al 2018:1). Globally it is one of the most common birth deformities seen that can be successfully managed with non-invasive treatment if discovered andtreated early in the child’s life (Alsiddiky et al 2019:2). The lack of antenatal and postnatal education seen in this study created concerns among participants. A participant remained unsure of what clubfoot is, and if it could happen to other children as well. Education and information about the condition therefore is vital to ensure that the guardians are counselled, referred for treatment early and to ensure that they can adhere to the treatment regime (Iqbal et al 2021:4231; Mahan et al 2019:500; Azarpira et al 2016:321).

### 4.3.7 Emotional and other experiences during the discovery of the deformity

Children with birth defects have an impact on the whole family causing anxiety in parents when the deformity is discovered, especially when the deformity was unexpected and not diagnosed before the birth of the child, However, parents still would like to be informed of the deformity (Mahan et al 2019:504). Esan, Akinsulore, Yusuf and Adegbehingbe (2017:28) did a study in Nigeria where they found that 15,5% parents, the majority mothers, expressed emotional distress, and 12% parenting stress which was regarded as clinically relevant. Older parents in this study experienced higher levels of distress.

Parents need to be prepared for the impact that a child with clubfoot could have on the family, they need those around them to also understand this impact on the family, and health professionals must improve communication with parents to ensure that they are able to care for their children with a birth defect (Lemacks et al 2013:3466). Malagelada et al (2016:103) found in their study where they compared parents of children with clubfoot from the UK and South Africa, that South African parents showed higher social support and applied more coping strategies than their British counterparts. Other studies found that the distress caused by the discovery of the deformity can impact on the child's relationship and bonding with parents, particularly with the mother. Mothers that had children with clubfoot displayed more depressive symptoms and higher stress levels than the mothers with "normal" children. This is hypothesised to be due to the child's deformity distracting from the parent's expectation of a perfect child (Lemacks et al 2013:3467; Coppola, Costantini, Tedone, Pasquale, Elia, Barnaro & D'Addetta 2012:524). Many parents go through a grieving process after being informed of the diagnosis, similar to parents who lost a child, and can benefit from grief counselling (Lemacks et al 2013:3467). Kübler-Ross, a Swiss psychiatrist, described her grief cycle as five stages consisting of grief, namely denial, anger, bargaining, depression, and acceptance. These stages can appear in any order with some people only going through two or three phases before acceptance. Healthcare practitioners should manage these responses of parents through communication and providing information, emotional support, and guidance and direction (PSYCOM [s.a.]). The participants in this study were very emotional when they discovered the child had a deformity. The fear of the child being disabled for life, caused emotional trauma which concur with the finding by Mahan et al (2017:503) that parents were concerned about the long-term impact of pain and the child's ability to participate in sport.

While most participants' children were healthy, there was one participant who had to manage her own health problems while trying to get the child the necessary treatment. This participant suffered from COVID-19 at the time of her child's diagnosis which made it more difficult for her to adhere to the child's treatment and clinic visits.

Healthcare practitioners have a responsibility to communicate with parents of children with clubfoot to explain the treatment and prognosis to them, to provide them with updated and relevant information, where and how access to healthcare services for treatment, and where there are support groups that they can attend. This could make a difference to the parental anxiety and assist with adherence to treatment (Azarpira et al 2016:321; Van

Wijck et al 2015:2420; Lemacks et al 2013:2471). Most participants in this study stated that now that they know there is a treatment option for this condition, they feel more at ease. This is supported by a study where the anxiety levels of parents with children with clubfoot were measured which indicated that their anxiety levels lowered as soon as they consulted with the paediatric orthopaedic surgeon (Mahan et al 2019:502). Interestingly, Mahan et al (2019:502-503) also indicated that there was no difference in parental anxiety levels of parents who had prenatal counselling for suspected clubfoot and those who had no prenatal counselling.

## 4.4 CHALLENGES OF HAVING A CHILD WITH CLUBFOOT

When a child is born with a physical deformity, all parents experience challenges of various natures. Challenges are multifactorial and could be financial, social, emotional, religious, stigmatisation, lack of education or shortage of health professionals, access to services and transport (Chinyakata, Roman & Msiza 2021:338; Evans et al 2021:4; Poudel et al 2019:3; Malhotra et al 2018:11; Drew et al 2016:571; Malagelada et al 2016:103-104; Kingau et al 2015:84; Van Wijck et al 2015:2420; Lemacks et al 2013:3466). The second theme and four subthemes highlight the challenges experienced by the participants in this study on their journey with their children receiving treatment for clubfoot. All challenges that are faced by the guardians become a barrier to the treatment of the child.

### 4.4.1 Financial challenges

Social data from the study by Malagelada et al (2016:104) on the impact of Ponseti treatment on parents, showed that 75% of the South African respondents in the study were below the 50th percentile for household income in the country at the time of data collection. The researchers believed that this played a role in the level of stress and coping of the respondents in the study. Studies show that there is a direct link between lower income families and relapse of the clubfoot (Azarpira et al 2016:321). Studies in other African countries such as Uganda, found that financial challenges become a barrier to treatment and led to no adherence with treatment and ultimately relapse of the clubfoot (Mcelroy et al 2007*).* In Kenya if the clinic that parents visited was not supported by Clubfoot Care Kenya (CCK), an NGO supporting the treatment of clubfoot, they had to pay for all treatments received. The payments of 1000 Ksh every week were unaffordable with parents going into debt, selling family assets or businesses with devastating results for the families (Wanjiru 2018:2). Van Wijck et al (2015:2419) in their study found that the further away the patient lived from the physical facility for treatment, the higher the travel cost, and the more likely it is for non-adherence to treatment.

In 1994 the then president, President Nelson Mandela, announced free public health services for children under the age of six and pregnant and lactating women. The free access to health services excluded those who were covered by medical aid or families that earned more than R100 000 per annum (Leatt, Shun-King & Monson 2006:1). While the participants in this study did not pay for the Ponseti treatment, there are several other factors causing a financial impact on the participants. The financial impact on the caregiver is huge: they reported having to borrow money, stay with relatives near the clinic, or they chose to walk long distances to the healthcare facility instead of using transport. This finding supports the findings of studies in Bangladesh (Evans et al 2021:4), Kenya (Wanjiru 2018:2), a study in four countries which included South Africa (Van Wijck et al 2015:2419) where parents reported the same need for financial support. To assist with travel cost to the clinic, one participant had applied for a disability grant to assist with the cost of travelling to the clinic. However, at the time of data collection for the study she had not received it yet.

### 4.4.2 Transport challenges

The South African modes of transport consist of those who drive their own vehicle or bicycle/motorcycle with most of the population using public transport. Public transport consists of the traditional rail system and the Gautrain in Gauteng, subsidised and unsubsidised bus transport systems, and a minibus taxi transport system. The mode of transport used by the population in South Africa in 2019 is presented in the 2020 General Household Survey in South Africa (STATSSA 2019:53) as summarised in Table 4.1.

**Table 4.1 Mode of transport used by households to travel to work and school**

| Mode of transport in % | |
|---|---|
| Own vehicle | 33.1 |
| Taxi | 26.3 |
| Walk | 21.5 |
| Bus | 4.2 |
| Train | 1.4 |
| Bicycle/motorcycle | 0.6 |
| Other | 12.9 |

(STATSSA 2019:53)

Despite the availability of transport, the transport system is afflicted by many challenges including low access to public transport in rural areas, congestion, and poor road infrastructure particularly in rural areas (Ngubane [s.a.]:1; Jennings 2015).

The rural areas in South Africa have large open spaces, several small towns, and villages where technical and social infrastructure such as schools, libraries, health services, parks, community centres, often are not well developed. Access to healthcare is limited or not available, particularly medical practitioners and specialists. Many patients must travel long distances to get to the health services they require which is further challenged by poor road infrastructure, the lack of public transport and the challenges of travelling with a child with a brace (Chinyakata et al 2021:338; Latham & Layton 2019:1; Morris-Paxton, Reid & Ewing 2019:4-5; Wanjiru 2018:3). Traveling long distances for clinic visits has been identified as a challenge for treatment adherence (Chinyakata et al 2021:337; Evans et al 2021:3; Morris-Paxton et al 2019:3; Wanjiru 2018:3; Van Wijck 2015:2420; Harmer & Rhatigan 2014:846).

The Ponseti clinics are specialised healthcare services usually located at the larger healthcare facilities in the more urban areas. Many of the study participants live in the rural areas of KwaZulu-Natal and have to travel long distances to the Ponseti clinic. As in other provinces in South Africa, there are daily shuttle services from the local clinic to the larger hospitals at no cost to the patient. The transport leaves very early in the morning and some participants must stay overnight outside the clinic or leave their homes at 01h00 on the morning to be in time for the bus leaving at the clinic. This requires up to another three hours of travel to the treating facility. Several participants were reliant on public transport such as taxis. Some had to take up to three taxis to get to the clinic. In some instances, participants reported that the father transported them to the clinic. In Uganda they opted for decentralising treatment to more clinics than just the larger healthcare facilities, and this enabled the patients not to travel so far. The result was that more children are being treated for clubfoot (Pirani et al 2009:1156). Miraclefeet, an NGO supporting clubfoot clinics in Uganda and other parts of Africa, continues with the decentralisation initiative to train physiotherapists and orthopaedic surgeons in the Ponseti technique in southern and east Africa (Meet Mr Clubfoot, 2021). In a study conducted by Harmer and Rhatigan (2014:845), suggestions were made to train non-physician healthcare workers to administer the Ponseti treatment which could enhance the treatment for clubfoot, improve adherence, and reduce the travel distance for the patient. In South Africa the Ponseti technique is regarded as specialist treatment and is therefore based at tertiary hospitals which can be a challenge for parents in rural areas who want to bring their child with clubfoot for treatment.

### 4.4.3 Caring for other family members while seeking treatment for the child

The mother of a family has multiple roles to fulfil, whether she is employed or a stay-at-home mother. Mothers manage a household; feed a family; care for, mentor and educate children; and often also care for elderly parents. Having a child with a deformity is a life-changing event and stressful for families (Lemacks et al 2013:3466). If the child must go to the clinic for any chronic condition, it will be the mother who is responsible to do so which creates additional stress for the mother and family (Esan et al 2017:28). Ponseti treatment for a child with clubfoot impacts on family function and there is a need for more support of families (Malagelada et al 2016:104; Wanjiru 2018:4; Harmer & Rhatigan 2014:846). Ponseti clinics are based at tertiary hospitals and therefore only available at larger institutions. This requires parents to travel long distances which makes adherence to the treatment more challenging.

The participants in this study raised similar challenges. Adherence to the treatment became challenging because they had other dependants at home needing care. The findings revealed that most of the participants had a good family support system at home where other family members looked after the other dependants while the guardian took the child for regular visits at the clinic. In one instance the guardian had no other option but to bring the older sibling of 5-years old and who attends school, along to the clinic.

Public knowledge of clubfoot and its treatment contribute to early intervention for children with clubfoot (Alsiddiky et al 2019:2). Burfat et al (2013:152) found in their study in Pakistan that parents could not distinguish clubfoot from other deformities. Several misconceptions and incorrect information about clubfoot was identified that impacted on early treatment of clubfoot. Most of the participants in this study did not know what clubfoot was until the child was born, and they saw the deformity. This supports the finding of Iqbal et al (2020:4231) in a study in India that some parents did not know about clubfoot until their own child was born with clubfoot. Studies in Saudi Arabia and Pakistan found that the lack of public awareness and knowledge about clubfoot delays treatment of clubfoot deformity and therefore these countries are encouraging public health awareness about clubfoot (Alsiddiky et al 2019:6; Rasheed et al 2017:93).

Several studies highlighted that public awareness and knowledge of clubfoot is limited (Iqbal et al 2020:4231; Alsiddiky et al 2019:2; Rasheed et al 2017:93; Burfat et al 2013:152). It is therefore essential that parents are educated about the principles of clubfoot treatment to promote compliance. The extended family should be included in the education as they will be providing the support during the treatment phase (Van Wijck et al 2015:2420; Lemacks et al 2013:3471). Parents are not always aware of the bracing phase that follows the initial casting phase. By not following the full treatment procedure, the initial treatment will be wasted, and the child will not have the full benefit of the treatment. Therefore, spending extra time educating the family and their role in the process will enhance the outcome for the child (Azarpira et al 2016:321; Harmer & Ratigan 2014:845). Parents who fully understand the process can become important advocates for early treatment and disseminating information to communities when the opportunity arise (Lemacks et al 2013:3474). However, this type of information sharing, and education did not happen in this study as recounted by the participants. Several participants said that they did not know what clubfoot was until their child was born with clubfoot.

### 4.4.4 The continuation of schooling or an occupation

Schooling and employment are both important elements in the care of a child with clubfoot. The association between education, health and health outcomes is well known keeping in mind that health literacy also is influenced by the culture and beliefs of what a healthy lifestyle comprises (Stars 2018:2, 5).

The level of education that a person has completed is important for health literacy as low literacy levels can contribute to adverse healthcare outcomes and not adhering to the prescriptions given by the health practitioner. In South Africa with its multiple languages, English has become the main language used in primary healthcare clinics when engaging with the patients at the clinic. Completing at least a grade 8 school education, provides for basic numeracy and literacy to read, write, and speak English in South Africa (Janse van Rensburg 2020:2). In the study by Janse van Rensburg (2020:5) on the health literacy of patients in primary healthcare clinics, 90% said they had a grade 11-12 level of schooling, but only 42% of them performed at this level when tested for comprehension. A school grade difference of 3.35 was found between respondents' highest grade level of education completed and their actual level achieved when tested. The implication, the researchers' postulate, is that patients may not be able to understand the health information they receive, even though they may have completed high grades at school (Janse van Rensburg 2020:5). The language use in educational sessions by health practitioners, brochures and posters should therefore be carefully selected to enable easy understanding of the information. Stars (2018:3) cites Nutbeam (2000) distinguishing three levels of health literacy:

- **Basic functional health literacy** as described above allowing the person to function effectively in everyday situations and health contexts.
- **Communicative health literacy** with advanced reasoning and literacy skills enabling use of different forms of communication and the ability to apply new information.
- **Critical health literacy** which enables critical analysis and application of health information to make informed decisions on health matters.

Bayati, Dehghan, Bonyadi and Bazrafkan (2018:3) found in a study in Iran that that educational intervention can improve health literacy. The intervention consisted of a book on "selfcare in minor morbidities" with face-to-face education and self-study.

Basic numeracy and literacy skills are also required for employment. Most parents are in their most productive age range when starting their families and may be employed. Parents, and particularly mothers, who are employed, generally find the caring responsibility of a child with a disability distracting which may ultimately impacts on their productivity and even their socio-economic status (Scott 2018:2661; Esan et al 2017:28: DeRigne & Porterfield 2017:591). Scott (2018:2661) argues that employed parents of children with disabilities makes an extreme case for jobs that allow for work-family-fit for both mothers and fathers. It generally is the mother who changes her job to look for more flexibility or fewer hours, but both men and women who have a child with a disability, miss workdays more often than other employees (DeRigne & Porterfield 2015:590-591). Heinrich (2014:123) is of the view that a child's wellbeing can be affected if the mother works full time or go away for long periods at a time. This will affect her bonding with the child and the child's feeling of security and safety. Many parents feel pressurised if they have to work and care for the child with a disability, but family choices are often determined by family budget and support that the family has.

Most of the participants were unemployed at the time of the interview but did not have a job before having the baby either. Others unfortunately had to give up their employment to look after the child. Looking after a child with clubfoot and adhering to treatment is a laborious process as the child must go to the clinic once a week for weekly castings during the first phase of treatment. This makes it difficult to get off work every week or to maintain a job. Some of the participants were still at school and had to miss school as one stated she is missing a grade 12 examination to bring the child to the clinic. Van Schelven et al (2021:7) found that there is a direct link between education level and relapse of clubfoot – the lower the education level the higher the chances for relapse of the clubfoot.

## 4.5 SUMMARY

The findings of the study were summarised in two themes, namely the discovery of the clubfoot deformity and the challenges that guardians with children with clubfoot experience. In this chapter the findings of the study were integrated with the relevant literature to contextualise the experiences of the guardians of the children. Chapter 5 will discuss the recommendations, limitations, and conclusions of the study.

# CHAPTER 5

# CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

## 5.1 INTRODUCTION

Chapter 4 was a discussion of the findings of the study integrated with the available literature. In Chapter 5 the researcher concludes the study by addressing each objective of the study. The purpose of the study was to determine the healthcare-seeking behaviour of guardians of children with clubfoot at or after the age of three months to promote early detection and treatment.

A qualitative exploratory, descriptive design was employed to reach the objectives of the study. The population of the study was guardians of children with clubfoot deformity, with the accessible population the guardians and children who attended the Ponseti clinics in KwaZulu-Natal. Data were collected by conducting individual semi-structured interviews with guardians (mothers) of children attending the Ponseti clinics. Twelve interviews were conducted over a period of 22 months. The data collection period included the year 2020 where a lot of COVID-19 precautions were taken in the clinics and the researcher were unable to access the clinics and conduct interviews for a period of time. Data were analysed using the Terre-Blanche method of data analysis. Two themes and 11 subthemes emerged from the data. To contextualise the findings, they were integrated into the existing body of knowledge. From these discussions the conclusions were drawn, and recommendations could be made to address practice, education, policies, and further research. Limitations of the study were identified.

## 5.2 CONCLUSIONS

Based on the findings in Chapter 3, and the discussion of the findings and literature in Chapter 4, the researcher formulated the following conclusions. The conclusions are presented for demographic data, and to confirm how the objectives of the study were met. Based on the sound processes and value of the findings, it is the view of the researcher that the conclusions drawn, and recommendations made could be transferable to other communities and regions in the country.

All the participants were the mothers of the children and accompanied them during their first treatment phase at a Ponseti clinic at the time of the data collection. All children were three months or older at the time that they received treatment. Two major themes emerged from the study each with various subthemes.

### 5.2.1 Demographic information

Demographic data were collected prior to the interviews with the 12 participants and were incorporated into the data analysis. It showed that all the participants in the study were in fact the biological mothers of the children. They were all under the age of 40 and more than half were unemployed. The age of the child was recorded as to when they visited the Ponseti clinic for the first time with the average age ranging between three and 12 months. The demographic data also presented the traveling distance to the closest healthcare facility and some participants had to travel between 31 and 60 minutes to their closest facility.

### 5.2.2 Conclusions drawn to address Objective 1

**Objective 1: Explore the reasons for seeking healthcare at the Ponseti healthcare facility for clubfoot in the three months or older child**

Several reasons were highlighted by the guardians for the delay in seeking treatment. Most of the guardians did not know that the child had a deformity which was discovered at a late stage when visiting a clinic for a follow up visit or vaccination, realising that the child’s feet looked different from those of the siblings, and when the child struggled to walk. Delays in the public sector contributed to the late referral and starting of the Ponseti treatment. This finding supports the statement by Mojaki et al (2011:109) that referral systems in South Africa is ineffective. This not only can lead to additional stress on the guardian, but also on an already poorly resource healthcare system (Saib et al 2021:12). A few guardians who noticed the deformity at birth chose to visit a private practitioner where the correct treatment was delayed due to receiving ineffective splints, or no treatment at all, before reverting to the public health sector for treatment. Private healthcare is normally used for people from a higher socio-economic status who can afford it and are often thought to be superior to public healthcare. Although waiting times might be shorter in private healthcare, in this study the participants had no intervention from private healthcare practitioners which delayed effective treatment for the child.

Knowledge of clubfoot was limited, with the participants not having been advised at birth of the child's clubfoot deformity; during antenatal visits or after an ultrasound scan was done. This is an omission on the part of the healthcare practitioners attending to the delivery of the baby as a full assessment of the newborn should be done within 24 hours of birth (KwaZulu-Natal Department of Health [s.a.]c). This raises a question about the awareness of the healthcare practitioners of the importance to initiate treatment for clubfoot deformity early on. A few guardians were able to search on the internet for information and could inform themselves in this way of the deformity and its treatment. One of the participants who had reduced amniotic fluid, was advised that she could expect some problems after birth and were aware that her baby may have a deformity such as clubfoot after searching for information on the internet.

Child visits to clinics in rural KwaZulu-Natal decreased during the lockdown (Siedner et al (2021:1) but the pandemic did not directly influence any of the participants' adherence to treatment. One participant was turned away during hard lockdown as a non-emergency when she tried to access treatment for her child. She was told she will be contacted to come back when coronavirus regulations eased, but they never contacted her. She then sought healthcare elsewhere. Another participant contracted the coronavirus which required her to isolate, but it still did not cause non-adherence to treatment. Her delay in starting treatment was due to a delay in accessing private healthcare where she did not receive any healthcare for her child.

The participants were very emotional during the discovery process, some were in shock and others reported that they were extremely sad when they discovered that there was something wrong with the child's feet. This supports the findings of Mahan et al (2019:504) that anxiety levels for parents are high when they discover that their child has a deformity. Caring for a child with a birth defect can increase the chances of depression and have an influence in the mother's mental health (Lemacks et al 2013:3467). Participants expressed being happy when they knew that the condition is treatable, particularly those participants who could access the internet to obtain information about the deformity. The participants who had no knowledge of the deformity were more concerned as they were relying on healthcare practitioners to provide them with the relevant information which was not forthcoming in this study. Knowledge about the condition prior to starting treatment definitely made the diagnosis easier and less stressful.

### 5.2.3 Conclusions drawn to address Objective 2

**Objective 2: Describe the challenges the guardians experienced coming to the healthcare facility to seek treatment and adhering to the treatment**

All the challenges faced by the participants could ultimately become a barrier to adherence of treatment which can lead to a permanent disability for the child. The intense treatment programme of weekly clinic visits for six continuous weeks exacerbates the challenges the guardians face like, financial challenges, transport challenges, caring for other dependants while adhering to treatment for the child with clubfoot and having to miss work or school to bring the child to the treatment facility.

The biggest challenge for most of the participants was financial. Most of the participants were unemployed and had no income. The Ponseti clinics are situated at the bigger healthcare institutions and some participants have to travel long distances to get to the clinic. The transport is expensive, and when they cannot afford their transport, the child misses crucial appointments within their treatment phase. The treatment protocol consists of the casting phase and then the bracing phase. Low income was also a reason for relapse (Ganeson et al 2017:12). Resorting to borrowing money, walking, or staying with family members that stay closer to the Ponseti clinics were all measures taken by the participants to adhere to the treatment. One participant applied for a disability grant that had not yet been received at the time of data collection. One can qualify for a permanent disability grant from the South African Government when your disability will last more than a year and a temporary one if your disability will last more than six months but less than 12 months. There are strict rules and measures to be adhered to in order to receive a grant and this can take some time. A doctor must complete a medical report and then send it to the South African Social Security Agency (SASSA) (South Africa [s.a]).

The transport itself is a challenge not just the cost, but also the distance and the logistics of the clinics. Some travel up to three hours to the closest clinic, stay overnight to catch the bus service to the Ponseti clinic the next day. To get to the clinic can take multiple taxis, and all the traveling had to be done with a child in casts which makes the journey even more challenging. Travelling costs varied but some guardians stated that it can cost up to R350 to get to the treatment facility.

Family responsibilities were a great concern for participants as there were other dependants that had to be taken care of and businesses to manage. The participants relied heavily on their family for caretaking of other dependants or businesses and support, in order to take the child with clubfoot to the clinic and adhere to the treatment. Schooling of teenage mothers were interrupted, missing vital schooldays in their matric year to bring the child to the clinic for treatment. Mostly there were family members who could assist with these responsibilities, but there were others that did not have similar support and resorted to bringing the siblings to the clinic. Although in the early years of schooling keeping a child out of school once a week for six weeks might not have a negative effect; however, an older child might have repercussions for missing so much school in a short period of time.

### 5.2.4 Conclusions drawn to address Objective 3

**Objective 3: Design an information brochure on clubfoot to promote early detection and treatment**

The third objective was met by integrating the conclusions that were reached by addressing objectives one and two. The purpose of this objective was to ensure that not only parents, but also community members and healthcare practitioners, have basic information related to clubfoot deformity to promote early detection and treatment.

There was a clear lack of awareness of clubfoot among the guardians and possibly also in the communities, as there was one participant with a family member who had a similar foot problem but did not advise the participant where to seek healthcare for her child. Healthcare practitioners have not been forthcoming with information on clubfoot to inform the mothers prior to the birth of the child. It is important that women at the antenatal clinics, or routine paediatric clinics, are made aware of this condition, how it presents, how it is treated and that in fact it is treatable. Family members must be guided on what to look out for and what to do in the case that a child presents with a clubfoot. Educating communities about clubfoot deformity and that it is treatable can reduce social stigma around the deformity and ultimately reduce the stress and anxiety levels on the parent as well as the child. Most of the participants did not have access to the internet and relied on healthcare practitioners and facilities for information.

By designing a brochure with picture illustrations (see Figures 5.1 and 5.2) demonstrating the deformity with clear marks on what the deformity consists of one can even educate illiterate people and give them some guidance on when and where to seek help. Keeping the brochure simple but informative will make it possible to accesses a wide variety of people in various communities even in the rural population. This way the general knowledge and awareness on the deformity will be widespread increasing the early detection of clubfoot. The brochure can be distributed electronically or in printed hardcopy format. By making hard copies available, the subsets of the population that cannot access electronic sources can also receive the information. The brochure has been designed by the researcher in conjunction with a freelance copy writer. The illustrations were hand drawn by a freelance artist and the Isi-Zulu was checked by a teacher’s assistant at an English private school in Pietermaritzburg with his first language being isiZulu.

# CLUBFOOT

## IS TREATABLE

## THE EARLIER YOU ACT THE BETTER THE OUTCOME

### 1 – WHAT IS IT & WHAT DOES IT LOOK LIKE?

- Clubfoot is a deformity of the feet that a child is born with.
- It can be in one or both feet.
- It is when the foot points inwards and downwards making it difficult to put that foot flat on the ground.

### 2 – CAN IT BE TREATED?

**YES!**

- With the correct treatment your child can lead a normal life.
- Doctors use a series of casts, gentle movements and stretches to slowly move the foot into the right position.
- **IMPORTANT –**
  **The earlier you act**
  **The better the outcome.**

### 3 – WHAT SHOULD I DO IF I SUSPECT CLUBFOOT?

- Go to your nearest clinic.
- They will refer you to a specialized clinic for clubfoot treatment.
- **Early detection is key!**
- If you suspect your child has clubfoot, visit your clinic as soon as you can.

**FOR MORE INFORMATION CONTACT:**

**Greys Hospital (033)8973000, Ngwelezana Hospital (035)9017000 or www.kznhealth.gov.za**

**Figure 5.1 Information brochure English**

# CLUBFOOT

## ISIFO SEZINYAWO EZIBHEKENE SIYALAPHEKA

## UMA USHESHA UKUTHATHA IZINYATHELO KUSHESHE KULUNGE

**1 – SIYINI ISIFO SEZINYAWO EZIBHEKENE FUTHI USIBONA KANJANI?**

- Siyisifo sokukhubazeka kwezinyawo umntwana azalwa naso.
- Kuyaba onyaweni olulodwa noma kuzonazombili izinyawo.
- Kwenzeka uma unyawo lugobela ngaphakathi lubheke phansi, okwenza kubenzima ukuthi unyawo ulubeke phansi luqonde.

**2 – SIYA LAPHEKA YINI?**

**YEBO!**

- Ngosizo oluyilona oluqondene naso lesifo, umntwana wakho angaphila impilo ejwayelekile efana neyezinye izingane.
- Odokotela basebenzisa uhla lokhonkolo, nokunyakaziswa konyawo kancane kancane, nokwelulwa konyawo kancane kuzekube lubuyela esimeni esijwayelekile sonyawo oluphilayo.
- OKUSEMQOKA – Uma ushesha ukuthatha izinyathelo, kusheshe kulunge.

**3 – NGENZENJANI UMA NGISOLA UKUTHI UMNTWANA WAMI UPHETHWE ISIFO SEZINYAWO EZIBHEKENE?**

- Iya emtholampilo oseduze nawe.
- Emtholampilo wakho bazokudlulisela emtholampilo onguchwepheshe ekulapheni isifo sezinyawo ezibhekene.
- **Ukushesha kokubonakala kwalesifo yikona okubalulekile!**
- Uma usola ukuthi umntwana wakho unesifo sezinyawo ezibhekene phuthuma uye emthwalampilo oseduze nawe ngokukhulu ukushesha.

**UMA UFUNA ULWAZI OLUGCWELE:**

**Greys Hospital (033)8973000, Ngwelezana Hospital (035)9017000 noma www.kznhealth.gov.za**

**Figure 5.2 Information brochure Zulu**

This information brochure can be used widely, not only at antenatal clinics, but also at other clinics in the research setting. It should further be distributed wider in the province targeted in this study, as well as the other eight provinces in South Africa, doctors' waiting rooms and shopping malls.

## 5.3 LIMITATIONS OF THE STUDY

This study included two of the Ponseti clinics in the public sector in the province. The behaviour and results might be different in other regions of the province or even in the country. The reason for only receiving treatment after the age of three months were explored and the guardians that have not sought treatment yet will naturally be excluded from the study. isiZulu co-facilitators acted as translators during the semi-structured interviews and some expressions might not have been translated properly, however the researcher did make field notes on the participants' behaviour and body language during the interview to try and capture the emotions and expressions accurately. The co-facilitators were trained before the interviews to ensure they understood the purpose of the study and their role as translators.

## 5.4 RECOMMENDATIONS

The recommendations follow the findings of the study and include recommendations for education (healthcare practitioners and community), practice, policy, and further research.

### 5.4.1 Recommendations for education (healthcare practitioners and community)

Creating awareness among the public and healthcare practitioners about the potential of prenatal diagnosis of clubfoot will enhance early detection and early treatment. Clubfoot can be diagnosed in utero and therefore women must be informed about the condition when they receive their routine ultrasound scans. Routine antenatal screening creates the opportunity for discussion of the condition with future parents which further increases the awareness and understanding of clubfoot amongst the community.

Clubfoot deformity is one of the most prevalent congenital birth defects globally with a good prognosis if it is detected early. Healthcare practitioners performing ultrasound scans should be trained on the condition and how to detect it with ultrasound scans. When educating parents about clubfoot, healthcare practitioners should emphasise the fact that the condition is treatable, and that early detection is paramount. Teaching and training curricula and continuing professional development (CPD) initiatives for paediatricians, paediatric nurses, obstetricians, midwives, and sonographers must include the topic of clubfoot detection and treatment.

Access to information is an important component of knowledge sharing. Brochures in the other nine official languages of South Africa could be developed and distributed at antenatal clinics, paediatric clinics, the waiting rooms of general practitioners, shopping malls, and even to other areas within the province and other South African provinces. To reach the public, brochures could be made available at shopping malls and pharmacies. Hard copies of these brochures should be free and electronic copies can be posted on websites, including the various departments of health in the country, to stimulate awareness and educate the community on the subject.

Educating the community on the treatability of the clubfoot deformity might decrease the social stigma of the condition. By educating close family members on the deformity and the phases of treatment, will make them understand the condition better and the challenges the guardians are experiencing and how they could support them. This will contribute to the adherence to the treatment.

Various social media platforms are available that could be utilised to educate the community on the deformity. This is a great way of reaching the younger population. Information brochures can be posted on social media platforms. If the post is shareable, it should reach many more people. However, it is vital that this be done in conjunction with reliable sources and platforms.

### 5.4.2 Recommendations for practice

Resources for addressing the phenomenon under investigation include resources related to the population as well as to the services rendered to the community. Generally, the COVID-19 pandemic has shown that the healthcare practitioner shortage, particularly for specialist services in South Africa, has reached critical levels (Naidoo & Singh 2021). Human resources for the Ponseti treatment are limited. There are only three paediatric orthopaedic units in KwaZulu-Natal. Training healthcare practitioners other than medical practitioners, like nurses or physiotherapists, occupational therapists, and other healthcare practitioners to apply the Ponseti method correctly, can decentralise the access to treatment. This will make it easier for the guardians to travel to the clinic as costs will be lower and adherence to treatment will increase. By having treatment closer to home, it will be easier for guardians to continue schooling, maintain a job, or run a business. One of the biggest challenges of treatment adherence, is the travel cost and distance to the Ponseti clinic.

Education and training of healthcare practitioners, other than medical practitioners, allows for the decentralisation of the Ponseti treatment centres to other clinics closer to communities. These practitioners must be competent to undertake follow up visits for children undergoing Ponseti treatment and after the treatment has been concluded. This requires healthcare practitioners to be knowledgeable of the appearance and how to assess clubfoot, how to do the required castings for the child, and how to detect relapse of the clubfoot after treatment has been concluded so that the family could be referred back to the Ponseti clinic for evaluation and intervention. At the very least, all healthcare practitioners should be able to recognise clubfoot or the relapse of clubfoot and how and where to refer the family to a Ponseti clinic for intervention.

By offering the mothers lodging for the casting phase at the Ponseti healthcare institution it could increase the adherence to treatment. In the tertiary institutions there are lodging facilities for mothers of children that are in a neonatal intensive care unit or receiving weekly chemotherapy. For some this might be easier as there is no weekly transport cost to the mother.

Having a child with a disability could increase the anxiety and stress levels for parents, particularly mothers. Support groups for guardians of children with clubfoot might reduce the social stigma around clubfoot and the mothers can offer each other support, reduce emotional stress and feelings of guilt while dealing with the same congenital deformity. Healthcare practitioners should know which support systems are available for guardians of children with clubfoot, for example the NGO STEPS working with healthcare practitioners at Greys and Ngwelezana hospitals.

Lemacks et al (2013:3467) confirm that parents can grieve the same way when being informed that a child has a deformity as to when one loses a child and can then benefit from grief counselling. Healthcare practitioners must be aware of the possible grieving effects that a disability of a child can have on a parent and provide them with emotional support, adequate information, and guidance on the treatment of the child. Healthcare practitioners must be trained to give basic counselling and know where to refer the patient to for further counselling and support.

### 5.4.3 Recommendations for policy

Healthcare practitioners must be made aware of the importance of early referral to appropriate clinics for Ponseti treatments. This can be done by CPD lectures on birth deformities of the foot, how it looks and what to do when one suspects there is something wrong. Furthermore, it should be emphasised that other treatment strategies have a lower success rate and therefore children with clubfoot must be referred to a Ponseti clinic immediately if clubfoot is diagnosed. The referral system illustrated in Figure 4.1 is the route that health practitioners must follow in the public health service which can become a long process. In this study, the referral system has caused a delay in some of the guardians arriving at the Ponseti clinic for treatment of their children. The referral policy of the public health sector that from primary healthcare level, a patient should be referred to the next level of care. From district or regional level, a patient can be referred for specialist consultations, amongst other services (Department of Health 2020:18-19). Two policy directions are recommended, namely that:

(i) Children be referred directly from primary healthcare to specialist services.
(ii) Additional health practitioners at primary healthcare clinic be trained to assess clubfoot and apply plaster casts.

There may also be a need for continued professional education amongst private practitioners as in some cases they might be the first point of contact for treatment, and by delaying or not referring the patient to a Ponseti clinic will result in delayed treatment for the patient. This can be done by prioritising CPD lectures on the management of clubfoot by the Health Professions Council of South Africa (HPCSA) and South African Nursing Council (SANC). Open days in the Ponseti clinics can be arranged to share information with healthcare practitioners that is not specialised in clubfoot care.

A surveillance programme could be implemented to detect common birth defects including clubfoot.

### 5.4.4 Recommendations for further research

- Similar studies should be done in other regions of South Africa to enable comparison to identify regional differences or similarities.
- Further studies assessing the curriculum on congenital birth defects including clubfoot for doctors and nurses, could be valuable for curriculum development.
- Assess the reasons for the delay in referral within the public health system.
- Surveillance studies could be done to determine the prevalence of clubfoot as a congenital deformity.
- An intervention study could be done to determine whether awareness campaigns had a positive influence on the detection of clubfoot.

## 5.5 CONCLUSION

The purpose of the study was to explore the healthcare-seeking behaviour of guardians with children with clubfoot at or after the age of three months. The researcher gained insight into the reason for the guardians visiting the clinic at a late stage and any challenges they face while adhering to the treatment. These findings as well as the literature reviewed assisted in designing an information brochure on early detection of clubfoot.

There is a lack of knowledge about clubfoot; the fact that it is a treatable condition; and that the child can lead a normal life if treated with the Ponseti method. The earlier the treatment starts after birth the better the outcome for the child. Adhering to Ponseti treatment is a labour-intensive process. The treatment consists of weekly castings for six weeks continuously and bracing boots that should be worn during the night for a period after. The guardians faced financial and transport challenges while adhering to the treatment and that can ultimately become a barrier to treatment. Having a child with clubfoot is an emotionally taxing journey and guardians of children with clubfoot need emotional support from family members and the community during this journey.

The information brochure designed in this study has the purpose of educating parents and members of the community what clubfoot looks like; what they should do when they suspect that their child has it; and that the condition is treatable. The brochure consists of clear illustrations and basic text to make it easy for anyone to understand. This will hopefully create awareness about the deformity and reduce social stigma around the deformity.

The researcher set out to create awareness about the condition and educate the community that it is a treatable condition, and that the child can have a happy normal life and blend into society.

## LIST OF REFERENCES

Abdelmoktader, AM & Abd Elhamed, KA. 2012. Egyptian mothers' preferences regarding how physicians break bad news about their child's disability: a structured verbal questionnaire. *BMC Medical Ethics*, 13(14):3.
From: https://doi.org/10.1186/1472-6939-13-14 (accessed on 23 December 2021).

Abraham, J, Wall, JC, Diab M & Beaver, C. 2021. Ponseti casting vs. soft tissue release for the initial treatment of non-idiopathic clubfoot. *Frontiers in Surgery,* 8:1.
From: https://doi.org/10.3389/fsurg.2021.668334 (accessed on 21 December 2021).

Adegbehingbe, OO, Adetiloye, AJ, Adewole, L, Ajodo, DU, Nosirudeen, B, Esan, O, Hoover, AC, Ior, J, Lasebikan, O, Ojo, O, Olasinde, A, Songden, D & Morcuende, JA. 2017. Ponseti method treatment of neglected idiopathic clubfoot: Preliminary results of a multi-center study in Nigeria. *World Journal of Orthopaedics,* 18(8):624-630.

Agarwal, A. 2014. Ponseti method for late presentation of clubfoot. *International Orthopaedics (SICOT),* 38:207-209.

Agarwal, A & Gupta, N. 2016. The roles of Pirani scoring system in the management and outcome of Idiopatahic Club Foot by Ponseti method. *International Journal of Science and Research,* 5(6):1284-1287.
From: http://dx.doi.org/10.21275/v5i6.NOV164385 (accessed on 23 December 2021).

Akhbari, P, Jaggard, M, Hillier, V, Abhishetty, N & Lahoti, O. 2016. A physiotherapy-led ponseti service versus a standard orthopaedic surgeon-led service: a prospective randomised trial. *Orthopaedic Proceedings,* 98-B(Supp 13):17-18.

Al-Ateeq, MA & Al-Rusaiess, AA. 2015. Health education during antenatal care: the need for more. *International Journal of Women's Health*, *7*:239-242.
From: https://doi.org/10.2147/IJWH.S75164 (accessed on 27 December 2021).

Alsiddiky, A, Alrwibaah, S, Alqahtani, A, Alnujidi, A, Alhomaidhi, A, Almasoud, A & Alatassi, R. 2019. Assessing public awareness of clubfoot and knowledge about the importance of early childhood treatment: a cross-sectional survey. *BMC Pediatrics*, 19(1):1-6.
From: https://doi.org/10.1186/s12887-019-1740-z (accessed on 28 December 2021).

Ansar, A, Rahman, AE, Romero, L. Haider, MR, Rahman, MM, Moinuddin, M. Siddique, MB, Mamun, MA, Mazunder, T, Pirani, SP, Mathias, RG, Arifeen, SE & Hoque, DME. 2018. Systematic review and meta-analysis of global birth prevalence of clubfoot: a study protocol. *BMJ Open,* 8:2. DOI:10.1136/ bmjopen-2017-019246.

Azarpira, MR, Emami, MJ, Vosoughi, AR & Rahbari, K. 2016. Factors associated with recurrence of clubfoot treated by the Ponseti method. *World Journal of Clinical Cases*, 4(10):318-322. DOI:10.12998/wjcc.v4.i10.318.

Basit, S & Khoshhal, K. 2018. Genetics of clubfoot; recent progress and future perspectives. *European Journal of Medical Genetics,* 61(2):107-113.
From: https://doi.org/10.1016/j.ejmg.2017.09.006 (accessed on 1 December 2021).

Bayati, T, Dehghan, A, Bonyadi, F & Bazrafkan, L. 2018. Investigating the effect of education on health literacy and its relation to health-promoting behaviors in health center. *Journal of Education and Health Promotion*, 7:1-6.
From: https://doi.org/10.4103/jehp.jehp_65_18 (accessed on 22 December 2021).

Bedford, KJA, Chidotho, P, Sakala, H, Cashman, J & Lavy, C. 2011. Clubfoot in Malawi: treatment-seeking behaviour. *Tropical Doctor,* 41(4):211-214.

Bergh, A-M. 2021. Chapter. Effective health promotion and health education. In: *The continuous textbook of women's medicine Volume 3,* edited by F Flenadi. Global library women's medicine, ISSN: 1756-222, doi 10.3843/GLOWM.414253.
From: https://www.glowm.com/article/heading/vol-3--elements-of-professional-care-and-support-before-during-and-after-pregnancy--effective-health-promotion-and-health-education/id/414253#.YctPqGhBy3A (accessed on 28 December 2021).

Besselaar, AT, Sakkers, RJB, Schuppers, HA, Witbreuk, MMEH, Elgun, VCM, Zeegers, EVCM, Visser, JD, Boekestijn, RA, Margés, SD, Van der Steen, MC & Burger, KNJ. 2017. Guideline on the diagnosis and treatment of primary idiopathic clubfoot, *Acta Orthopaedica,* 88(3):305-309. DOI: 10.1080/17453674.2017.1294416.

Bradford, EL. 2019. *Avoiding new mom comparison traps. Babycenter*.
From: https://www.babycenter.com/baby/postpartum-health/avoiding-new-mom-comparison-traps_10302207 (accessed on 28 December 2021).

Brink, H, Van der Walt, C & Van Rensburg, G. 2018. *Fundamentals of research methodology for healthcare professionals.* Cape Town: Juta.

Burfat, A, Mohammed, S, Siddiqi, O, Samad, L, Mansoor, AK & Amin, CM. 2013. Understanding the knowledge and perceptions about clubfoot in Karachi, Pakistan: a qualitative exploration. *Iowa Orthopaedic Journal,* 33:149-152.

Chetty, P. 2016. *Importance of ethical considerations in research*. [online]. Project Guru.
From: https://www.projectguru.in/importance-ethical-considerations-research/
(accessed on 30 December 2021).

Chinyakata, R, Roman, RV & Msiza, FB. 2021. Stakeholders' perspectives on the barriers to accessing health care services in rural settings: A human capabilities approach. *The Open Public Health Journal,* 13:336-344. DOI: 10.2174/1874944502114010336.

Consolini, DM. 2021. *Pediatrics: physical examination of the newborn. MSD Manual Professional version*. [online].
From: https://www.msdmanuals.com/professional/pediatrics/care-of-newborns-and-infants/physical-examination-of-the-newborn?query=Physical%20Examination%20of%20the%20Newborn#v55251735
(accessed on 22 November 2021).

Coppola, G, Costantini, A, Tedone, R, Pasquale, S, Elia, L, Barbaro, MF & D'Addetta, I. 2012. The impact of the baby's congenital malformation on the mother's psychological well-being: an empirical contribution on the clubfoot. *Journal of Pediatric Orthopaedics,* 32:521-526.

Dave, M, Rankin, J, Pearce, M & Foster, HE. 2020. Global prevalence estimates of three chronic musculoskeletal conditions: club foot, juvenile idiopathic arthritis and juvenile systemic lupus erythematosus. *Pediatric Rheumatology,* 18:1-7.
From: https://doi.org/10.1186/s12969-020-00443-8 (accessed on 28 December 2021).

DeCarlo, M. 2018. Paradigms, theories, and how they shape a researcher's approach. Chapter 6.2. In: *Scientific inquiry in social work*. Open Social Work Education: Press Books. (Creative Commons Attribution NonCommercial ShareAlike.)
From: https://scientificinquiryinsocialwork.pressbooks.com/chapter/6-2-paradigms-theories-and-how-they-shape-a-researchers-approach/ (accessed on 29 December 2021).

De Bellefonds, C. 2020. *Low amniotic fluid (oligohydramnios) during pregnancy*.
From: https://www.whattoexpect.com/pregnancy/pregnancy-health/complications/oligohydramnios.aspx (accessed on 28 December 2021).

De Mulder, T, Prinsen, S & Van Campenhout, A. 2018. Treatment of non-idiopathic clubfeet with the Ponseti method: a systematic review. *Journal of Children's Orthopaedics,* 12:575-581.

Department of Co-operative Governance and Traditional Affairs. 2020. Disaster Management Act (57/2002): Regulations made in terms of Section 27(2) by the Minister of Co-operative Governance and Traditional Affairs*. Government Gazette*, 657(43148):3-13.
From: 4314825-3cogta.pdf (www.gov.za) (accessed on 30 December 2021).

Department of Health. 2020. *Referral policy for South African Health Services and referral implementation guidelines*.
From: https://www.idealhealthfacility.org.za (accessed on 30 December 2021).

DeRigne, L, & Porterfield, SL. 2017. Employment change among married parents of children with special health care needs. *Journal of Family Issues*, 38(5):579-606. DOI: 10.1177/0192513X15572368.

Dibello, D, Di Carlo, V, Colin, G, Barbi, E & Galimberti, AMC. 2020. What a paediatrician should know about congenital clubfoot. *Italian Journal of Pediatrics,* 46:1-6.
From: https://doi.org/10.1186/s13052-020-00842-3 (accessed on 29 December 2021).

Drew, S, Gooberman-Hill, R & Lavy, C. 2018. What factors impact on the implementation of clubfoot treatment services in low and middle-income countries?: a narrative synthesis of existing qualitative studies. *BMC Musculoskeletal Disorders,* 19:1-10.

Drew, S, Lavy, C & Gooberman-Hill, R. 2016. What factors affect patient access and engagement with clubfoot treatment in low- and middle-income countries? Meta-synthesis of existing qualitative studies using a social ecological model. *Tropical Medicine and International Health,* 21(5):570-589.

Ebonwu, J, Mumbauer, A, Uys, M, Wainberg, ML & Medina-Marino, A. 2018. Determinants of late antenatal care presentation in rural and peri-urban communities in South Africa: a cross-sectional study. *PLoS One*, 13(3):2-16.
DOI: 10.1371/journal.pone.0191903.

Editorial Team, A & Watkins, A. 2018. Examination of the newborn. *Ausmed*, 5 February, viewed 22 November 2021.
From: https://www.ausmed.com/cpd/articles/examination-of-the-newborn (accessed on 22 November 2021).

Eidelman, M, Kotlarsky, P & Herzenberg, JE. 2019. Treatment of relapsed, residual and neglected clubfoot: adjunctive surgery. *Journal of Children's Orthopaedics*, 13:1-3, 293-303.

Esan, O, Akinsulore, A, Yusuf, MB & Adegbehingbe, OO. 2017. Assessment of emotional distress and parenting stress among parents of children with clubfoot in south-western Nigeria. *SA Orthopaedic Journal*, 16(2):26-31.
From: https://dx.doi.org/10.17159/2309-8309/2017/v16n2a2 (accessed on 21 December 2021).

Evans, AM, Chowdhury, M & Khan, S. 2021. A community audit of 300 "drop-out" instances in children undergoing ponseti clubfoot care in Bangladesh − What do the parents say? *International Journal of Environmental Research and Public Health*, 18(3):1-12.
From: https://doi.org/10.3390/ijerph18030993 (accessed on 29 December 2021).

Faldini, C, Fenga, D, Sanzarello, I, Nanni, M, Traina, F & Rosa, MAA. 2017. Prenatal diagnosis of clubfoot: a review of current available methodology. *Folia Medica*, 59(3):247-253.

Fantasia, I, Dibello, D, Di Carlo, V, Colin, G, Barbieri, M, Belcaro, C, Magni, E, Faletra, F, Laura, T & Stampalija, T. 2021. Prenatal diagnosis of isolated clubfoot: diagnostic accuracy and long-term postnatal outcomes. *European Journal of Obstetrics & Gynaecology and Reproductive Biology*, 264:60-64.
From: https://doi.org/10.1016/j.ejogrb.2021.07.009 (accessed on 23 December 2021).

Ferreira, GF, Stéfani, KC, Haje, DP & Nogueira, MP. 2018. The Ponseti method in children with clubfoot after walking age: a systematic review. *PLoS ONE*, 13(11):1-15.

Firth, GB, Eltringham, M & Shnier, G. 2009. Early results of the Ponseti technique for a clubfoot clinic in South Africa. *South African Orthopaedic Journal*, 8(4):67-71.

Ganeson, B, Luximon, A. Al-Jumaily A, Balasankar, SB & Naik, GR. 2017. Ponseti method in the management of clubfoot under 2 years of age: A systematic review. *PLoS ONE*, 12(6):1-18.

Gelfer, Y, Wientroub, S, Hughes, K, Fontalis, A, & Eastwood, DM. 2019. Congenital talipes equinovarus: a systematic review of relapse as a primary outcome of the Ponseti method. *Journal of Bone and Joint Surgery,* 101-B(6):639-645. DOI: 10.1302/0301-620X.101B6.BJJ-2018-1421.R1.

Gray, JR, Grove, SK & Sutherland, S. 2017. *Burns and Grove's The practice of nursing research*: *Appraisal, synthesis and generation of evidence*. 8th edition. Elsevier: Missouri.

Global Clubfoot Initiative. 2021 *Clubfoot*. From: http://globalclubfoot.com/clubfoot/ (accessed 26 December 2021).

Grimes, CE, Holmer, H, Maraka, J, Ayana, B, Hansen, L & Lavy, CBD. 2016. Cost-effectiveness of clubfoot treatment in low-income and middle-income countries by the Ponseti method. *BMJ Global Health*, 1:1. DOI:10.1136/ bmjgh-2015-000023.

Grove, SK & Gray, JR. 2019. *Understanding nursing research building: an evidence-based practice.* 7th edition. Elsevier: Missouri.

Harmer, L & Rhatigan, J. 2014. Clubfoot care in low-income and middle-income countries: from clinical innovation to a public health program. *World Journal of Surgery,* 38(4):839-848. DOI: 10.1007/s00268-013-2318-9. PMID: 24213946.

Herval, ÁM, Oliveira, DPD, Gomes, VE & Vargas, AMD. 2019. Health education strategies targeting maternal and child health. *Medicine*, 98(26):1-7. DOI: 10.1097/MD.0000000000016174.

Herring, J. 2013. *Tachdjian's pediatric orthopaedics: From the Texas Scottish Rite Hospital for Children*. Volume 2, Chapter 23. 5th edition. USA: Saunders.

*Insession. Official Newspaper of the Parliament of the Republic of the Republic of South Africa.* 2020. Coronavirus: President Ramaphosa announces a 21-day lockdown. 01(09)2020.

Iqbal, MS, Dubey, R, Thakur, K, Katiyar, S & Prasad, M. 2021. Assessment of awareness and barriers to clubfoot treatment in the Indian scenario. *Journal of Family Medicine and Primary Care,* 10(11):4229-4235. DOI: 10.4103/jfmpc.jfmpc_2606_20.

Jacobs, W, Amuta, AO & Jeon, KC. 2017. Health information seeking in the digital age: an analysis of health information seeking behaviour among US adults. *Cogent Social Sciences*, 3:1-12. DOI: 10.1080/23311886.2017.1302785

Janse van Rensburg, Z. 2020. Levels of health literacy and English comprehension in patients presenting to South African primary healthcare facilities. *African Journal of Primary Health Care and Family Medicine*, 12(1):1-6.
From: https://dx.doi.org/10.4102/phcfm.v12i1.2047 (accessed on 28 December 2021).

Jennings, G. 2015. *Public transport interventions and transport justice in South Africa: a literature and policy review*.
From: https://repository.up.ac.za/handle/2263/57779 (accessed on 1 January 2022).

Johnson, RR, Friedman, JM, Becker, AM & Spiegel, DA. 2017. The Ponsetti method for clubfoot treatment in low and middle-income countries: a systematic review of barriers and solutions to service delivery. *Journal of Pediatric Orthopaedics,* 37(2):e134-e139.
From: https://doi.org/10.1097/BPO.0000000000000723 (accessed on 2 January 2022).

Jowett, CR, Morcuende, JA & Ramachandran, M. 2011. Management of congenital talipes equinovarus: a systematic review. *Journal of Bone and Joint Surgery*, 93-B 9:1160-1164.

Kadhum, M, Lee, MH, Czernuszka J & Lavy C. 2019. An analysis of the mechanical properties of the Ponseti method in clubfoot treatment. *Applied Bionics Biomechanics,* 25:1-11. DOI: 10.1155/2019/4308462. PMID: 31019550; PMCID: PMC6452541.

Kilicarslan-Toruner, E & Akgun-Citak, E. 2013. Information-seeking behaviours and decision-making process of parents of children with cancer. *European Journal of Oncology Nursing*, 17(2):176-183.
From: https://doi.org/10.1016/j.ejon.2012.03.001 (accessed on 14 December 2021).

Kingau, NW, Rhoda, A & Mlenzana, N. 2015. Barriers experienced by service providers and caregivers in clubfoot management in Kenya. *Tropical Doctor*, 45(2):84-90. DOI: 10.1177/0049475514564694.

Kumar, R, Suman, SK & Manjhi, LB. 2017. Evaluation of outcome of treatment of idiopathic clubfoot by Ponseti technique of manipulation and serial plaster casting. *International Journal of Orthopaedics Sciences*, 3(4):23-27.

KwaZulu-Natal Department of Health. [s.a.]a. *Greys Hospital*.
From: http://www.kznhealth.gov.za/greyshospital.htm (accessed 26 December 2021)

KwaZulu-Natal Department of Health. [s.a.]b. *Ngwelezane Hospital*.
From: http://www.kznhealth.gov.za/ngwelezanahospital.htm (accessed 26 December 2021)

KwaZulu-Natal Department of Health. [s.a.]c. *New-born/neonatal record*.

Latham, A & Layton, J. 2019. Social infrastructure and the public life of cities: studying urban sociality and public spaces. *Geography Compass*, 13:1-15.
From: https://doi.org/10.1111/gec3.12444 (accessed on 23 December 2021).

Lavy, CBD, Mannion, SJ, Mkandawire, NC, Tindall, A, Steinlechner, C, Chinamgeni, S & Chipofya, E. 2007. Club foot treatment in Malawi – a public health approach. *Disability and Rehabilitation,* 29(11-12):857-862.

Leatt, A, Shung-King, M & Monson, J. 2006. *Healing inequalities: The free healthcare policy.* South African Child Gauge 2006, Children's Institute, UCT.
From:
http://www.ci.uct.ac.za/sites/default/files/image_tool/images/367/Child_Gauge/South_African_Child_Gauge_2006/gauge2006_healing.pdf (accessed on 1 January 2022).

Lemacks, J, Fowles, K, Mateus, A & Thomas, K. 2013. Insights from parents about caring for a child with birth defects. *International Journal of Environmental Research and Public Health,* 10(8):3465-3482. DOI: 10.3390/ijerph10083465.

Liu, Y, Li, S, Zhao, L, Yu, B & Zhao, D. 2018. Timing for Ponseti clubfoot management: does the age matter? 90 children (131 feet) with a mean follow-up of 5 years. *Acta Orthopaedica,* 89(6):662-667.

LoBiondo-Wood, G & Haber, J. 2018. *Nursing research methods and critical appraisal for evidence-based practice.* 9th edition. Elsevier: Missouri.

Lykissas, MG, Crawford, AH, Eismann, EA & Tamai, J. 2013. Ponseti method compared with soft-tissue release for the management of clubfoot: a meta-analysis study. *World Journal of Orthopaedics,* 4:144-153.

Mahan, ST, Miller PE, May, CJ & Kasser, JR. 2019. Prospective evaluation of parental anxiety related to newborn foot disorder. *Journal of Children's Orthopaedics,* 13(5):500-507. DOI: 10.1302/1863-2548.13.180209. PMID: 31695817, PMCID: PMC6808067.

Malagelada, F, Mayet, S, Firth, G & Ramachandran, M. 2016. The impact of the Ponseti treatment method on parents and caregivers of children with clubfoot: a comparison of two urban populations in Europe and Africa. *Journal of Children's Orthopaedics*, 10:101-107.
From: https://doi.org/10.1007/s11832-016-0719-7 (accessed on 26 December 2021).

Malhotra, R, Mohapatra, A, Arora, G, Choudhury, P, Joshi, H & Patel, P. 2018. Ponseti technique for the management of congenital talipes equinovarus in a rural set-up in India: experience of 356 patients. *Children,* 5(4):1-13.
From: https://doi.org/10.3390/children5040049 (accessed on 27 December 2021).

Mandlecha, P, Kanojia, RK, Champawat, VS & Kumar, A. 2019. Evaluation of modified Ponseti technique in treatment of complex clubfeet. *Journal of Clinical Orthopaedics and Trauma,* 10(3):599-608. DOI: 10.1016/j.jcot.2018.05.017. Epub 2018 May 28. PMID: 31061597; PMCID: PMC6492221.

Manisha, R & Priyanka, K. 2017. Congenital Clubfoot: a comprehensive review.
*Orthopedics and Rheumatology Open Access*, 8(1):1-5.
DOI: 10.19080/OROAJ.2017.08.555728.

Mayo Clinic. 2021. *Clubfoot.*
From: http://www.mayoclinic.org/diseases-conditions/clubfoot/diagnosis-treatment/treatment/txc-20198084 (accessed on 27 December 2021).

Mcelroy, T, Konde-Lule, J, Neema, S & Gitta, S. 2007. Understanding the barriers to clubfoot treatment adherence in Uganda: A rapid ethnographic study. *Disability and Rehabilitation,* 29(11-12):845-855.

McNellan, CR, Dansereau, E, Wallace, MCG, Colombara, DV, Palmisano, EB, Johanns CK, Schaefer, A, Rios-Zertuche, D, Ziniga-Brenes, P, Hernandez, B, Iriarte, E & Mokdas, AH. 2019. Antenatal care as a means to increase participation in the continuum of maternal and child healthcare: an analysis of the poorest regions of four Mesoamérican countries. *BMC Pregnancy Childbirth*, 19(66):1-5.
From: https://doi.org/10.1186/s12884-019-2207-9 (accessed on 22 December 2021).

Meet Mr Clubfoot, a pioneer of Ponseti in Africa. 2021. *Miraclefeet: news and stories, Uganda*.
From: https://www.miraclefeet.org/stories/meet-mr-clubfoot (accessed on 1 January 2022).

*Merriam-Webster Dictionary*. 2021. Sv ‘idiopathic, awareness’. [online].
From: https://www.merriam-webster.com/dictionary/idiopathic (accessed 10 February 2021).

Mesquita, C. 2017. Integrity in scientific research. *International Journal of Cardiovascular Sciences,* 30:1-2.

Ministry of Health. 2020. Minister Zweli Mkhize reports first case of COVID-19 Coronavirus. South African Ministry of Health. 5 March 2020.
From: https://www.gov.za/speeches/health-reports-first-case-covid-19-coronavirus-5-mar-2020-0000 (accessed on 30 December 2021).

Mishra, K, Mohapatra, I & Kumar, A. 2019. A study on the health seeking behavior among caregivers of under-five children in an urban slum of Bhubaneswar, Odisha. *Journal of Family Medicine and Primary Care*, 8(2):498-503.
From: https://doi.org/10.4103/jfmpc.jfmpc_437_18 (accessed on 27 December 2021).

MiracleFeet. 2021. *Impact report 2021.*
From: https://www.miraclefeet.org/about-us/financials#2021 (accessed on 26 December 2021

Mojaki, ME, Basu, B, Letskokgohka, ME & Govender, M. 2011. Referral steps in healthcare district are side-stepped. *South African Medical Journal*, 101(2):109.
From: http://www.samj.org.za/index.php/samj/article/view/4385 (accessed on 21 December 2021).

Morris-Paxton, AA, Reid, S & Ewing RMG. 2020. Primary healthcare services in the rural Eastern Cape, South Africa: Evaluating a service-support project. *African Journal of Primary Health Care and Family Medicine,* 12(1):1-7.
From: https://doi.org/10.4102/phcfm.v12i1.2207 (accessed on 2 January 2022).

Naidoo, Y & Singh, O. 2021. Staff and oxygen shortages I second wave tremor, front-line workers fear Covid-19 Tsunami. *Times Live.* [online].
From: https://www.timeslive.co.za/news/south-africa/2021-01-03-staff-and-oxygen-shortages-in-second-wave-tremor-front-line-workers-fear-covid-19-tsunami/ (accessed on 3 January 2022).

Nangsangna, RD & Da-Costa Vroom, F. 2019. Factors influencing online health information seeking behaviour among patients in Kwahu West Municipal, Nkawkaw, Ghana. *Online Journal of Public Health Informatics*, 11(2):e13.
From: https://doi.org/10.5210/ojphi.v11i2.10141 (accessed on 17 December 2021).

Ngene, NC & Chauke, L. 2020. Improving prenatal detection of congenital hand defects trough collaborative goal-directed antenatal care: a case report on symbrachydactyly. *Case Reports in Womens' Health,* 27*:*1-4*.* DOI: 10.1016/j.crwh.2020.e00244.

Ngubane, L. [s.a.]. *The state of public transport.* University of KwaZulu-Natal. Saferspaces.
From: https://www.saferspaces.org.za/understand/entry/the-state-of-public-transport-in-south-africa (accessed on 1 January 2022).

NIH Grants & Funding. [s.a.]. *What is research integrity?* NIH Central Resource for Grants and Funding Information.
From: https://grants.nih.gov/policy/research_integrity/what-is.htm (accessed on 29 December 2021).

Nutbeam, D. 2000. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies in the 21st century. *Health Promotion International,* 15: 259-267.

Owen, RM, Capper, B & Lavy, C. 2018. Clubfoot treatment in 2015: a global perspective. *BMJ Global Health,* 3:1-7. DOI: 10.1136/ bmjgh-2018-000852.

*Oxford Paperback Dictionary*. 1991. Sv 'idiopathic, awareness'. 3rd edition. Great Brittan: Oxford University Press.

Pavone, V, Chisari, E, Vescio, A, Lucenti, L, Sessa, G & Testa, G. 2018. The etiology of idiopathic congenital talipes equinovarus: a systematic review. *Journal of Orthopaedic Surgery and Research*, 13:1-11.
From: https://doi.org/10.1186/s13018-018-0913-z (accessed on 30 December 2021).

Pirani, S, Naddumba, E, Mathias, R, Konde-Lule, J, Norgrove, P, Beyeza, T, Mbonye, B, Amone, J & Franceschi, J. 2009. Towards effective ponseti clubfoot care: the Uganda sustainable clubfoot care project. *Clinical Orthopaedics and Related Research,* 467(5):1154-1163.

Polit, DF & Beck, CT. 2021. *Nursing research generating and assessing evidence for nursing practice*. 11th edition. Philidelphia: Wolters Kluwer Williams & Wilkins.

Ponseti, IV, Zhivkov, M, Davis, N, Sinclair, M, Dobbs, MB & Morcuende, JA. 2006. Treatment of the complex idiopathic clubfoot. *Clinical Orthopaedics and Related Research,* 451:171-176.

Ponte, J, Perpiñán, S, Mayo, ME, Millá, MG, Pegenaute, F & Poch-Olivé, ML. 2012. Study on the professional procedures, experiences and needs of parents when they are told their child has a disability or developmental disorder. Breaking the news. *La Primera Noticia Rev Neurology*, 29, 54(Suppl 1):S3-S9. Spanish. PMID: 22374770.

Poudel, RR, Kumar, VS, Tiwari, V, Subramani, S & Khan, SA. 2019. Factors affecting compliance to hospital visit among clubfoot patients: a cross-sectional study from a tertiary referral clubfoot clinic in the developing country. *Journal of Orthopaedic Surgery*, 27(1):1-4. DOI: 10.1177/2309499019825598.

PSYCOM. [s.a.]. *The five stages of grief.*
From: https://www.psycom.net/depression.central.grief.html (accessed on 31 December 2021).

Radler, C, Myers, AK, Burghardt, RD, Arrabal, PP, Herzenberg, JE & Grill, F. 2011. Maternal attitudes towards prenatal diagnosis of idiopathic clubfoot. *Ultrasound in Obstetrics and Gynecology*, 37:658-662.
From: https://doi.org/10.1002/uog.8932 (accessed on 28 December 2021).

Rasheed, N, Zaidi, IH, Rasheed, N & Hussain, G. 2017. Awareness regarding clubfoot in parents. *Journal of Pakistan Orthopaedic Association*, 29:90-94.

Resnik, DB. 2020. *What is ethics in research and why is it important?* National Institute of Environmental Health Sciences (NIH).
From: https://www.niehs.nih.gov/research/resources/bioethics/whatis/index.cfm (accessed on 30 December 2021).

Saib, MZ, Dhada, BL, Aldous, C & Malherbe, HL. 2021.Observed birth prevalence of congenital anomalies among live births at a regional facility in KwaZulu-Natal Province, South Africa. *PLOS ONE,* 16(8):1-16.
From: https://doi.org/10.1371/journal.pone.0255456 (accessed on 27 December 2021).

Sarbu, I, Socolov, D, Carp, S & Ciongradi, CJ. 2015. The Prenatal Counselling Importance in Congenital Talipes Equinovarus Treatment, *Procedia - Social and Behavioral Sciences*, 205:688-692.
From: https://doi.org/10.1016/j.sbspro.2015.09.108 (accessed on 28 December 2021).

Scott, KE. 2018. Mother-Ready Jobs: Employment that works for mothers of children with disabilities. *Journal of Family Issues,* 39(9):2659-2626*.* DOI: 10.1177/ 0192513X18756927.

Siedner, MJ, Kraemer, JD, Meyer, MJ, Harling, G, Mngomezulu, T, Gabela, P, Dlamini S, Gareta, D, Majozi, N, Ngwenya, N, Seeley, J, Wong, E, Iwuji, C, Shahmanesh, M, Hanekom, W & Herbst, K. 2020. Access to primary healthcare during lockdown measures for COVID-19 in rural South Africa: an interrupted time series analysis. *BMJ Open*, 10:1-11. DOI: 10.1136/bmjopen-2020-043763.

Singh, VB, Gawande, J & Lakhtakia, PK. 2020. Ponseti technique in children with idiopathic club foot presenting after 1 year of age: a retrospective study. *Orthopaedic Journal of MP Chapter*, 26(2):70-74.

Smith, PA, Kuo, KN, Graf, AN, Krzak, J, Flanagan, A, Hassani, S, Caudill, AK, Dietz, FR, Morcuende, J & Harris, GF. 2014. Long-term Results of Comprehensive Clubfoot Release Versus the Ponseti Method: Which Is Better? *Clinical Orthopaedics and Related Research,* 472(4):1281-1290.

Smythe, T, Mudariki, D, Kuper, H, Lavy, C & Foster, A. 2017. Assessment of success of the Ponseti method of clubfoot management in sub-Saharan Africa: a systematic review. *BMC Musculoskeletal Disorders*,18:1-10.

Smythe, T, Kuper, H, Macleod, D, Foster, A & Lavy, C. 2017. Birth prevalence of congenital talipes equinovarus in low- and middle-income countries: a systematic review and meta-analysis. *Tropical Medicine and International Health,* 22(3):269-285.

South Africa. 2002. *Disaster Management Act (Act no 57) of 2002*. Pretoria: Government Printer.
From: Disaster Management Act 57 of 2002 | South African Government (www.gov.za) (accessed on 30 December 2021).

South Africa. [s.a.]. *Services for residents: social benefits: disability grant.* [Online].
From: Disability grant | South African Government (www.gov.za) (accessed on 3 January 2022).

Stars, I. 2018. Health literacy as a challenge for health education. *SHS Web of Conferences,* 40:1-8.
From: https://doi.org/10.1051/shsconf/20184002004 (accessed on 22 December 2021).

STATSSA. 2019. *General household survey 2019. Statistical release P0318.*
From: https://www.statssa.gov.za/publications/P0318/P03182019.pdf (accessed on 1 January 2022).

STATSSA. 2001. *Investigations into appropriate definitions into urban and rural areas for South Africa.*
From: http://www.statssa.gov.za/census/census_2001/urban_rural/urbanrural.pdf (accessed on 20 October 2021).

Street, M, Ramguthy, Y & Firth, GB. 2016. Do Ponseti plasters delay gross motor milestones of South African children treated for idiopathic clubfeet? *SA Orthopaedic Journal,* 15(2):49-52.

Švehlík, M, Floh, U, Steinwender, G, Sperl, M, Novak, M & Kraus, T. 2017. Ponseti method is superior to surgical treatment in clubfoot – long-term, randomized, prospective trial. *Gait and Posture,* 58:346-351.

Terre Blanche, M, Durrheim, K & Painter, D. 2016. *Research in practice.* 2nd edition. Cape Town: UCT Press.

Tonkovich, N, Baskar, D & Frick, S. 2021. The impact of the digital age and social media on connecting the Clubfoot community. *Cureus*, 13(7)1-7. DOI: 10.7759/cureus.16780.

Uggla, C & Mace, R. 2016. Parental investment in child health in sub-Saharan Africa: a cross-national study of health-seeking behaviour*. Royal Society Open Science,* 3:1-13. From: http://dx.doi.org/10.1098/rsos.150460 (accessed on 28 December 2021).

Vaishy, AK, Arif, M, Acharya, D, Choudhary, R, Seervi, PM & Kumar, R. 2020. Influence of beginning time of casting for clubfoot treatment by Ponseti method in different age group infants: a retrospective study. *Indian Journal of Orthopaedics*, 54:55-59.

Van Schelven, H, Moerman, S, Van der Steen, M, Besselaar, AT & Greve, C. 2021. Prognostic factors for recurrent idiopathic clubfoot deformity: a systematic literature review and meta-analysis, *Acta Orthopaedica*:6-7. DOI: 10.1080/17453674.2021.1982576.

Van Wijck, SFM, Oomen, AM & Van der Heide, HJL. 2015. Feasibility and barriers of treating clubfeet in four countries*. International Orthopaedics (SICOT),* 39:2415-2422. From: https://doi.org/10.1007/s00264-015-2783-x (accessed on 22 December 2021).

Wanjiru, N. 2018. Experiences of parents/caregivers of children with congenital talipes equinovarus: a qualitative study. *Annals of Physiotherapy Clinics,* 1(2):1-4.

Wikimedia Commons. 2021. *Map of KwaZulu-Natal with municipalities named and districts shaded (2016).*
From: https://commons.wikimedia.org/wiki/File:Map_of_KwaZulu-Natal_with_municipalities_named_and_districts_shaded_(2016).svg (accessed on 02 January 2022).

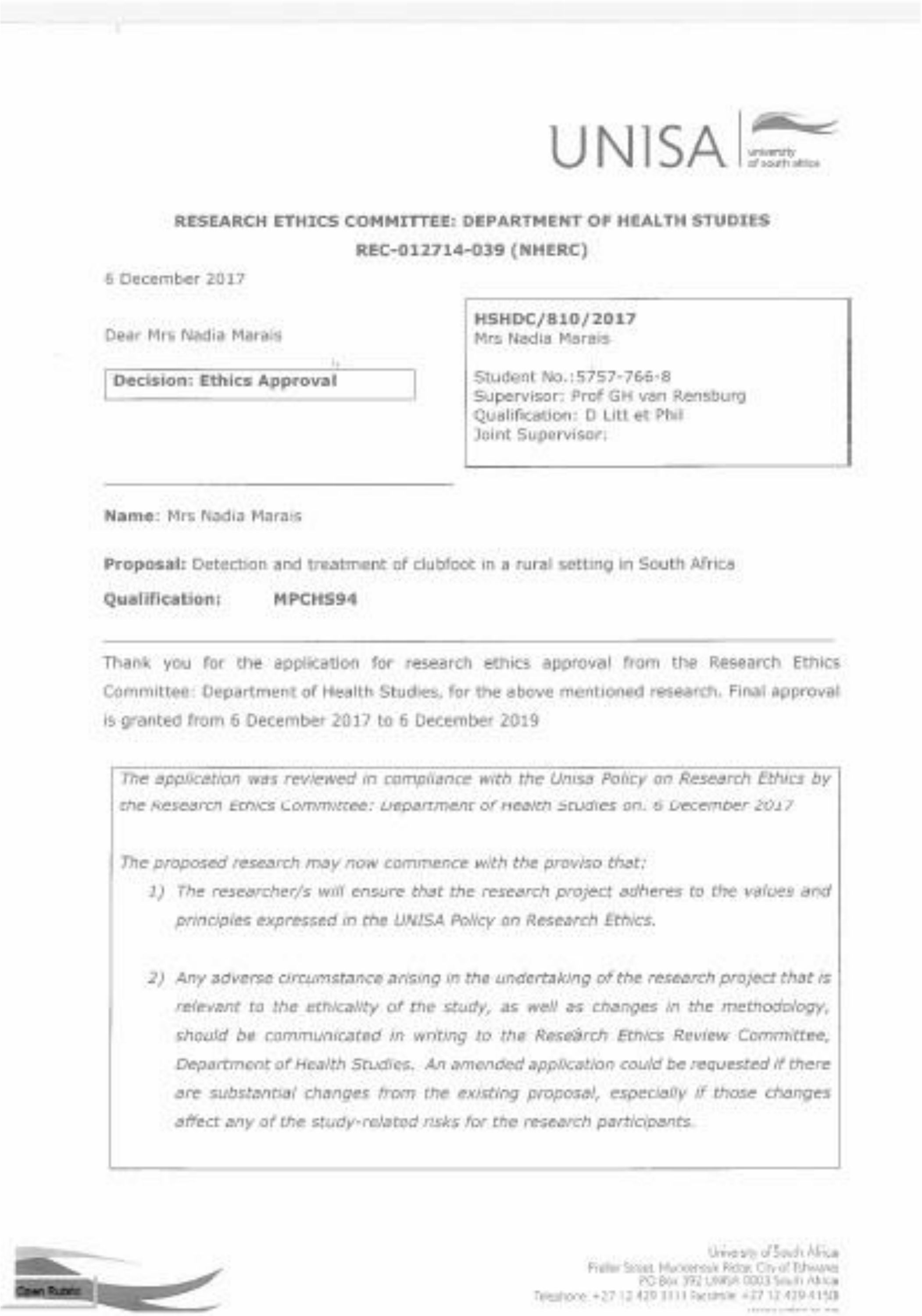
Wong, DK, & Cheung, M. 2019. Online health information seeking and ehealth literacy among patients attending a primary care clinic in Hong Kong: A cross-sectional survey. *Journal of Medical Internet Research,* 21(3):1-13. DOI: 10.2196/10831.

Zhang, Q, Feng, S, Wong, IOL, Ip, DKM, Cowling, BJ & Lau, EHY*.* 2020. A population-based study on healthcare-seeking behaviour of persons with symptoms of respiratory and gastrointestinal-related infections in Hong Kong. *BMC Public Health,* 20:1-10.
From: https://doi.org/10.1186/s12889-020-08555-2 (accessed on 28 December 2021).

Zhao, D, Li, H, Zhao, L, Liu, J, Wu, Z & Jin, F. 2014. Results of clubfoot management using the Ponseti method: do the details matter? A systematic review. *Clinical Orthopaedics and Related Research*, 472(4):1329-1336.

# ANNEXURES

## ANNEXURE 1: Ethical clearance certificate from the Research Ethics Committee: Department of Health Studies, UNISA



UNISA
university of south africa

**RESEARCH ETHICS COMMITTEE: DEPARTMENT OF HEALTH STUDIES**
**REC-012714-039 (NHERC)**

6 December 2017

Dear Mrs Nadia Marais

**Decision: Ethics Approval**

**HSHDC/810/2017**
Mrs Nadia Marais

Student No.:5757-766-8
Supervisor: Prof GH van Rensburg
Qualification: D Litt et Phil
Joint Supervisor:

---

**Name:** Mrs Nadia Marais

**Proposal:** Detection and treatment of clubfoot in a rural setting in South Africa

**Qualification:** **MPCHS94**

---

Thank you for the application for research ethics approval from the Research Ethics Committee: Department of Health Studies, for the above mentioned research. Final approval is granted from 6 December 2017 to 6 December 2019

*The application was reviewed in compliance with the Unisa Policy on Research Ethics by the Research Ethics Committee: Department of Health Studies on. 6 December 2017*

*The proposed research may now commence with the proviso that:*

1) *The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.*

2) *Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Research Ethics Review Committee, Department of Health Studies. An amended application could be requested if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.*

3) *The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.*

4) *[Stipulate any reporting requirements if applicable].*

*Note:*

*The reference numbers [top middle and right corner of this communiqué] should be clearly indicated on all forms of communication [e.g. Webmail, E-mail messages, letters] with the intended research participants, as well as with the Research Ethics Committee: Department of Health Studies.*

Kind regards,

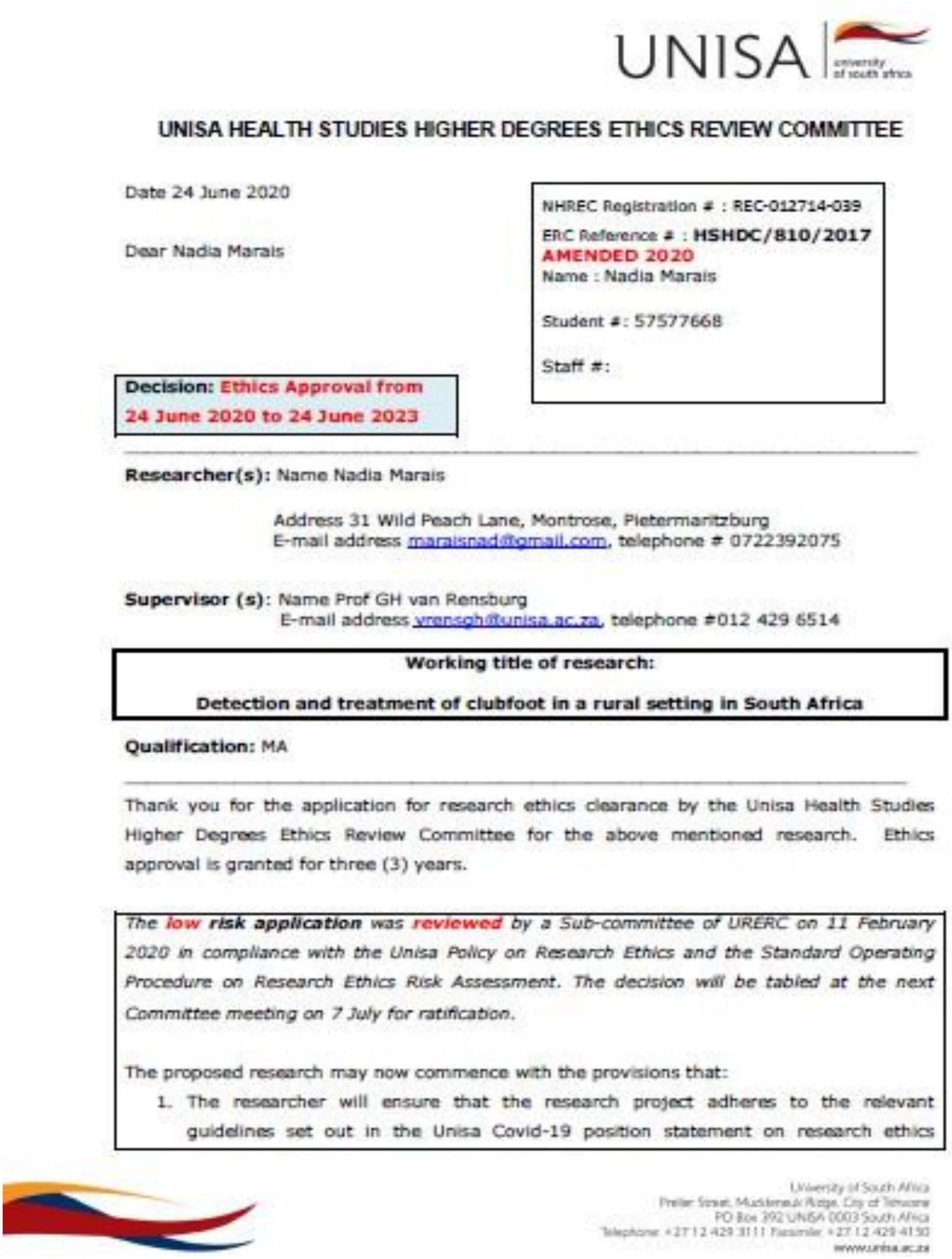
Prof JE Maritz
CHAIRPERSON
maritje@unisa.ac.za

Prof MM Moleki
ACADEMIC CHAIRPERSON
molekmm@unisa.ac.za

Prof A Phillips
DEAN COLLEGE OF HUMAN SCIENCES

Approval template 2014

## ANNEXURE 2: Ethical clearance certificate extension from the Higher Degrees Ethics Review Committee, Department of Health Studies, UNISA and title change from the College of Human Sciences Research Ethics Committee, UNISA



UNISA
university of south africa

**UNISA HEALTH STUDIES HIGHER DEGREES ETHICS REVIEW COMMITTEE**

Date 24 June 2020

Dear Nadia Marais

NHREC Registration # : REC-012714-039
ERC Reference # : **HSHDC/810/2017 AMENDED 2020**
Name : Nadia Marais

Student #: 57577668

Staff #:

**Decision: Ethics Approval from 24 June 2020 to 24 June 2023**

---

**Researcher(s):** Name Nadia Marais

Address 31 Wild Peach Lane, Montrose, Pietermaritzburg
E-mail address maraisnad@gmail.com, telephone # 0722392075

**Supervisor (s):** Name Prof GH van Rensburg
E-mail address vrensgh@unisa.ac.za, telephone #012 429 6514

**Working title of research:**

**Detection and treatment of clubfoot in a rural setting in South Africa**

**Qualification:** MA

---

Thank you for the application for research ethics clearance by the Unisa Health Studies Higher Degrees Ethics Review Committee for the above mentioned research. Ethics approval is granted for three (3) years.

*The **low risk application** was **reviewed** by a Sub-committee of URERC on 11 February 2020 in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment. The decision will be tabled at the next Committee meeting on 7 July for ratification.*

The proposed research may now commence with the provisions that:

1. The researcher will ensure that the research project adheres to the relevant guidelines set out in the Unisa Covid-19 position statement on research ethics

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

attached.

2. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
3. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the Health Studies Research Ethics Committee HSREC@unisa.ac.za.
4. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
5. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the confidentiality of the data, should be reported to the Committee in writing, accompanied by a progress report.
6. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.
7. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.
8. No field work activities may continue after the expiry date (24 June 2023). Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

*Note:*

*The reference number* ***HSHDC/892/2018*** *should be clearly indicated on all forms of communication with the intended research participants, as well as with the Committee.*

Yours sincerely,

Signatures :

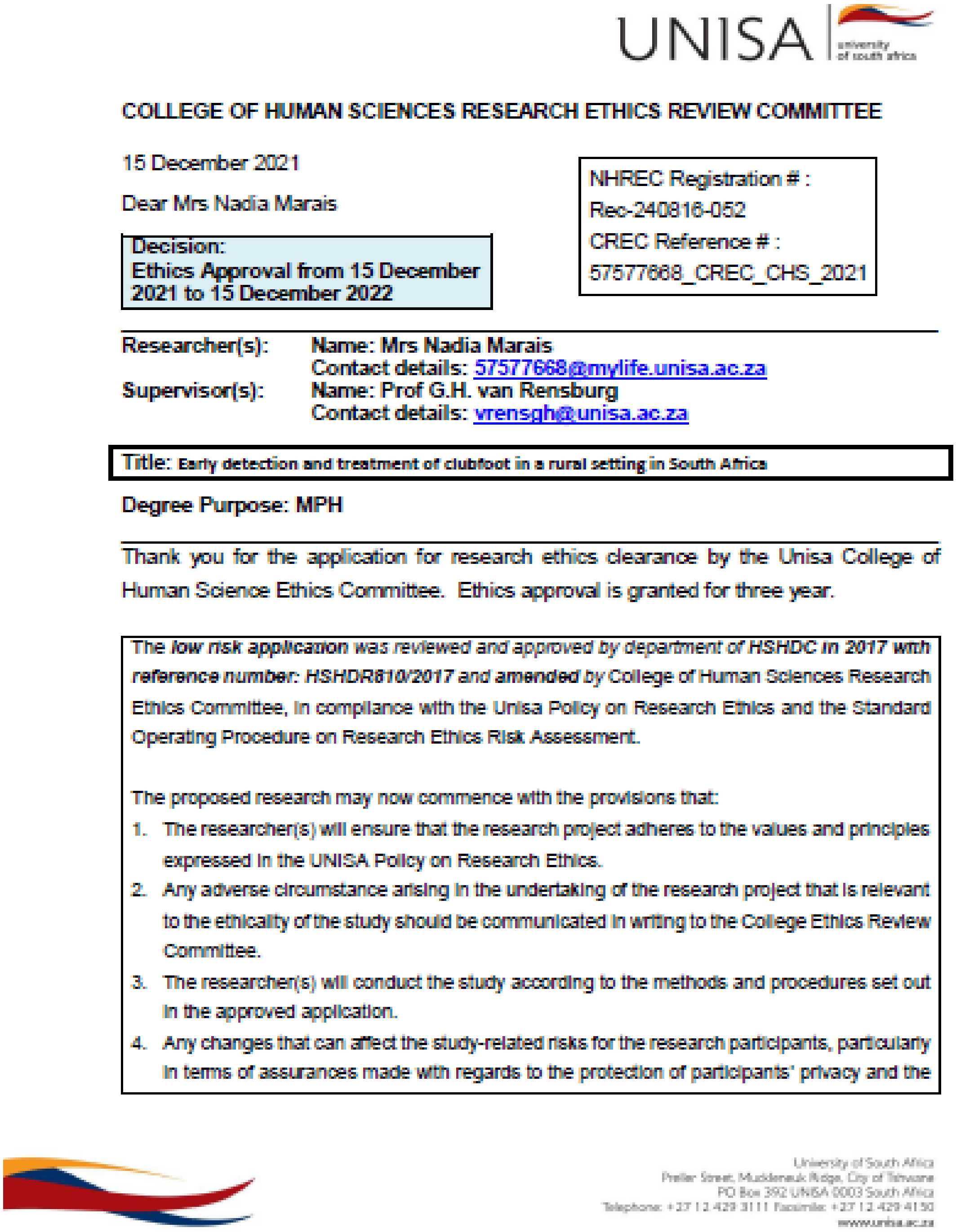
pp

Chair of HSREC : Prof JM Mathibe-Neke
**E-mail:** mathijm@unisa.ac.za
**Tel: (012) 429-6443**

Executive Dean : Prof K Masemola
**E-mail:** masemk@unisa.ac.za
**Tel: (012) 429-6825**

URERC 16.04.29 - Decision template (V2) - Approve

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za



UNISA
university
of south africa

COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

15 December 2021

Dear Mrs Nadia Marais

**Decision:**
**Ethics Approval from 15 December 2021 to 15 December 2022**

NHREC Registration # :
Rec-240816-052
CREC Reference # :
57577668_CREC_CHS_2021

**Researcher(s):** **Name: Mrs Nadia Marais**
**Contact details: 57577668@mylife.unisa.ac.za**
**Supervisor(s):** **Name: Prof G.H. van Rensburg**
**Contact details: vrensgh@unisa.ac.za**

Title: **Early detection and treatment of clubfoot in a rural setting in South Africa**

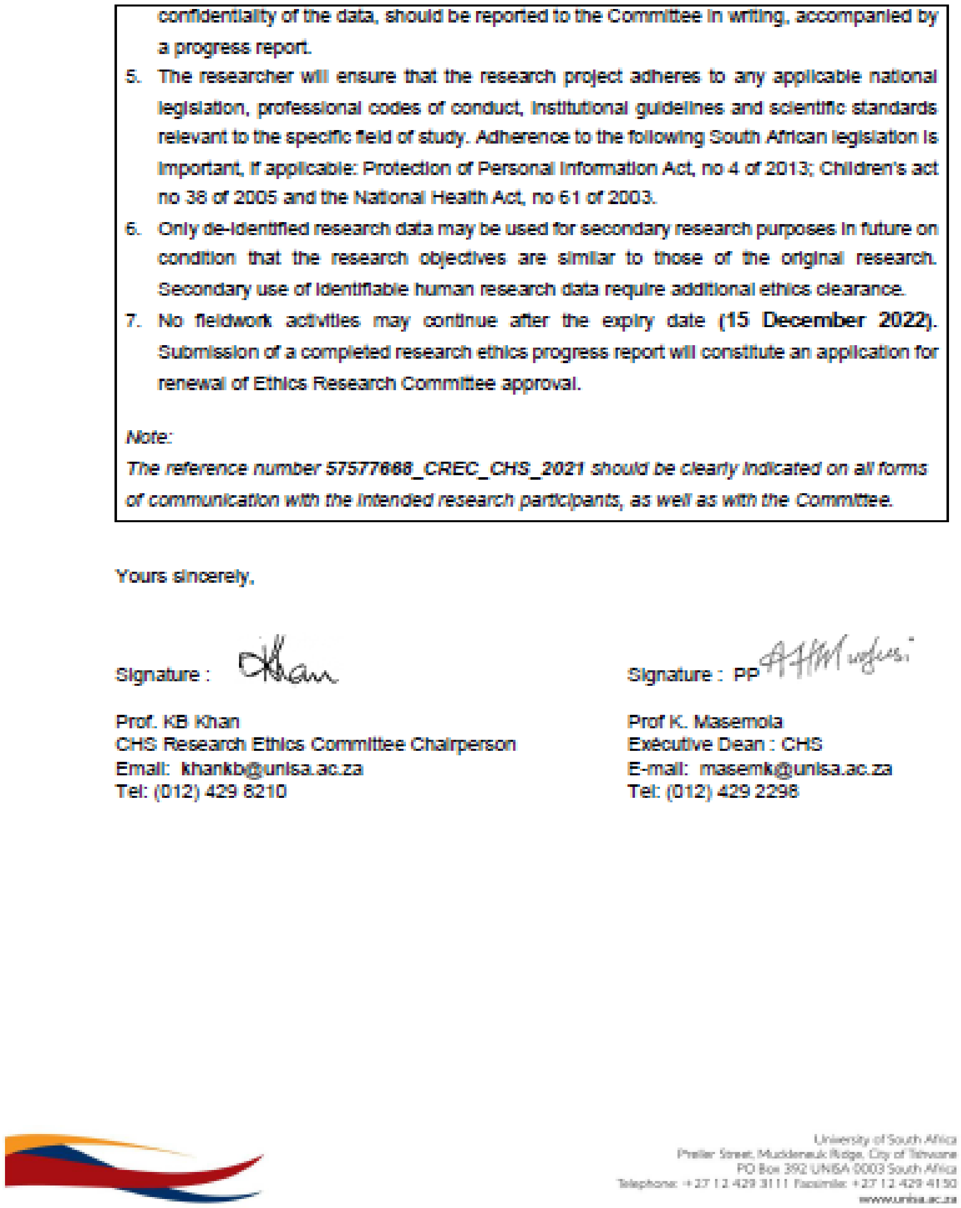
**Degree Purpose: MPH**

Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for three year.

The *low risk application was reviewed and approved by department of **HSHDC in 2017 with reference number: HSHDR810/2017** and **amended** by* College of Human Sciences Research Ethics Committee, in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
4. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the



confidentiality of the data, should be reported to the Committee in writing, accompanied by a progress report.

5. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.
6. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.
7. No fieldwork activities may continue after the expiry date (**15 December 2022**). Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

*Note:*

*The reference number **57577668_CREC_CHS_2021** should be clearly indicated on all forms of communication with the intended research participants, as well as with the Committee.*

Yours sincerely,

Signature : Khan

Prof. KB Khan
CHS Research Ethics Committee Chairperson
Email: khankb@unisa.ac.za
Tel: (012) 429 8210

Signature : PP

Prof K. Masemola
Executive Dean : CHS
E-mail: masemk@unisa.ac.za
Tel: (012) 429 2298

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

## ANNEXURE 3: Letter requesting ethical permission from Department of Health KwaZulu-Natal

Enquiries: Nadia Marais
Student number: 57577668
Address: 31 Wild Peach Lane
Montrose
Pietermaritzburg
3201
Telephone: 0722392075
E-mail: maraisnad@gmail.com

24 July 2018

Chairperson: Research Ethics Committee
Department of Health
KwaZulu-Natal

Dear XXXXX

**REQUEST FOR PERMISSION TO CONDUCT INTERVIEWS FOR A RESEARCH STUDY IN ONE OF THE CLINIC ROOMS IN YOUR CLINIC**

**RESEARCH STUDY TOPIC: EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA**

My Name is Nadia Marais and I am currently studying towards a Master's Degree in Public Health (MPH) at the University of South Africa (UNISA). The research is supervised by Prof GH van Rensburg from Department of Health Studies, College of Human Sciences at the University of South Africa. Tel: 012 429 6514 E-mail: vrensgh@unisa.ac.za.

The purpose of the study is to determine the healthcare-seeking behaviour of guardians of infants with clubfoot at or after the age of three months. Not only will this study provide insight into the current state of disease detection and mean age of presentation, it will also highlight why guardians of infants and children under the age of three years with clubfoot present late (after a certain age) for treatment. The challenges related to late detection will be explored and identified. All this information will lead to a greater understanding of why children with clubfoot who present late for treatment and the challenges they might face to in seeking healthcare. An information brochure will be created after the study has been completed with illustrations as to how clubfoot presents and how it is identified and details of where anyone can obtain treatment.

I hereby request permission to conduct the research in a Ponseti clinic at Greys hospital in KwaZulu-Natal province. Should you give permission I undertake to treat all participants with respect. The interview will not interfere with patient care or treatment at the facility. The participants will be anonymous and all information gathered during this process will be kept confidential. The facility's identity will not be disclosed unless written consent has been given to do so.

Please find attached a copy of the ethical clearance certificate and the research proposal.

Please do not hesitate to contact me should there be any queries. Should you wish to communicate with the supervisor about any matters related to the study, you may contact Prof GH van Rensburg at vrensgh@unisa.ac.za. Alternatively, you may contact the Chairperson of the Research Ethics Committee of the Department of Health Studies at Unisa at maritje@unisa.ac.za.

Regards

Nadia Marais

## ANNEXURE 4: Letter requesting permission for site approval at Government Healthcare Institutions

Enquiries: Nadia Marais
Student number: 57577668
Address: 31 Wild Peach Lane
Montrose
Pietermaritzburg
3201
Telephone: 0722392075
E-mail: maraisnad@gmail.com

24 July 2018

Hospital Management
[redacted] Hospital

Dear Dr [redacted]

**REQUEST FOR PERMISSION TO CONDUCT INTERVIEWS FOR A RESEARCH STUDY IN ONE OF THE CLINIC ROOMS IN YOUR CLINIC**

**RESEARCH STUDY TOPIC: EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA**

My Name is Nadia Marais and I am currently studying towards a Master's Degree in Public Health (MPH) at the University of South Africa (UNISA). My studies are overseen by Prof GH van Rensburg from Department of Health Studies, College of Human Sciences at the University of South Africa. Tel: 012 429 6514 E-mail: vrensgh@unisa.ac.za.

The purpose of the study is to determine the healthcare-seeking behaviour of guardians of infants with clubfoot at or after the age of three months. Not only will this study provide insight into the current state of disease detection and mean age of presentation, it will also highlight why guardians of infants and children under the age of three years with clubfoot present late (after a certain age) for treatment. The challenges related to late detection will be explored and identified. All this information will lead to a greater understanding of why children with clubfoot who present late for treatment and the challenges they might face to in seeking healthcare. An information brochure will be created after the study has been completed with illustrations as to how clubfoot presents and how it is identified and details of where anyone can obtain treatment.

I hereby request permission to utilise one of the clinic rooms in your facility during a Ponseti clinic to conduct interviews with the participants. If this will be possible, I will make sure of the following: the participants will be treated with respect and the interview will not interfere with their patient care or treatment at your facility. All participants will be anonymous, and all information gathered during this process will be kept confidential. The room utilised for the interviews will be kept clean and tidy during and after the interview process. The facility's identity will not be disclosed unless prior written consent has been given from the facility.

Please find attached a copy of the ethical clearance certificate and the research proposal.

Please do not hesitate to contact me should there be any queries. Should you wish to communicate with the supervisor about any matters related to the study, you may contact Prof GH van Rensburg at vrensgh@unisa.ac.za. Alternatively, you may contact the Chairperson of the Research Ethics Committee of the Department of Health Studies at Unisa at maritje@unisa.ac.za.

Regards

Nadia Marais

## ANNEXURE 5: Letter requesting permission to conduct interviews at the clinic

Enquiries: Nadia Marais
Student number: 57577668
Address: 31 Wild Peach Lane
Montrose
Pietermaritzburg
3201
Telephone: 0722392075
E-mail: maraisnad@gmail.com

24 July 2018

The Head
Ponseti clinic
[redacted] Hospital

Dear Dr [redacted]

**REQUEST FOR PERMISSION TO CONDUCT INTERVIEWS FOR A RESEARCH STUDY IN ONE OF THE CLINIC ROOMS IN YOUR CLINIC**

**RESEARCH STUDY TOPIC: EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA**

My Name is Nadia Marais and I am currently studying towards a Master's Degree in Public Health (MPH) at the University of South Africa (UNISA). My studies are overseen by Prof GH van Rensburg from Department of Health Studies, College of Human Sciences at the University of South Africa. Tel: 012 429 6514 E-mail: vrensgh@unisa.ac.za.

The purpose of the study is to determine the healthcare-seeking behaviour of guardians of infants with clubfoot at or after the age of three months. Not only will this study provide insight into the current state of disease detection and mean age of presentation, it will also highlight why guardians of infants and children under the age of three years with clubfoot present late (after a certain age) for treatment. The challenges related to late detection will be explored and identified. All this information will lead to a greater understanding of why children with clubfoot who present late for treatment and the challenges they might face to in seeking healthcare. An information brochure will be created after the study has been completed with illustrations as to how clubfoot presents and how it is identified and details of where anyone can obtain treatment.

I hereby request permission to utilise one of the clinic rooms in your facility during a Ponseti clinic to conduct interviews with the participants. If this will be possible, I will make sure of the following: the participants will be treated with respect and the interview will not interfere with their patient care or treatment at your facility. All participants will be anonymous, and all information gathered during this process will be kept confidential. The room utilised for the interviews will be kept clean and tidy during and after the interview process. The facility's identity will not be disclosed unless prior written consent has been given from the facility.

Please find attached a copy of the ethical clearance certificate and the research proposal.

Please do not hesitate to contact me should there be any queries. Should you wish to communicate with the supervisor about any matters related to the study, you may contact Prof GH van Rensburg at vrensgh@unisa.ac.za. Alternatively, you may contact the Chairperson of the Research Ethics Committee of the Department of Health Studies at Unisa at maritje@unisa.ac.za.

Regards

Nadia Marais

## ANNEXURE 6: Permission from Department of Health KwaZulu-Natal to conduct the study

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:
Health Research & Knowledge
Management

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email: [illegible]
www.kznhealth.gov.za

NHRD Ref: KZ_201808_019

Dear Mrs N. Marais
University of South Africa

**Approval of research**

1. The research proposal titled '**Detection and treatment of clubfoot in a rural setting in South Africa**' was reviewed by the KwaZulu-Natal Department of Health.

   The proposal is hereby **approved** for research to be undertaken at Grey's Hospital.

2. You are requested to take note of the following:
   a. Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.
   b. Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.
   c. Provide an interim progress report and final report (electronic and hard copies) when your research is complete to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

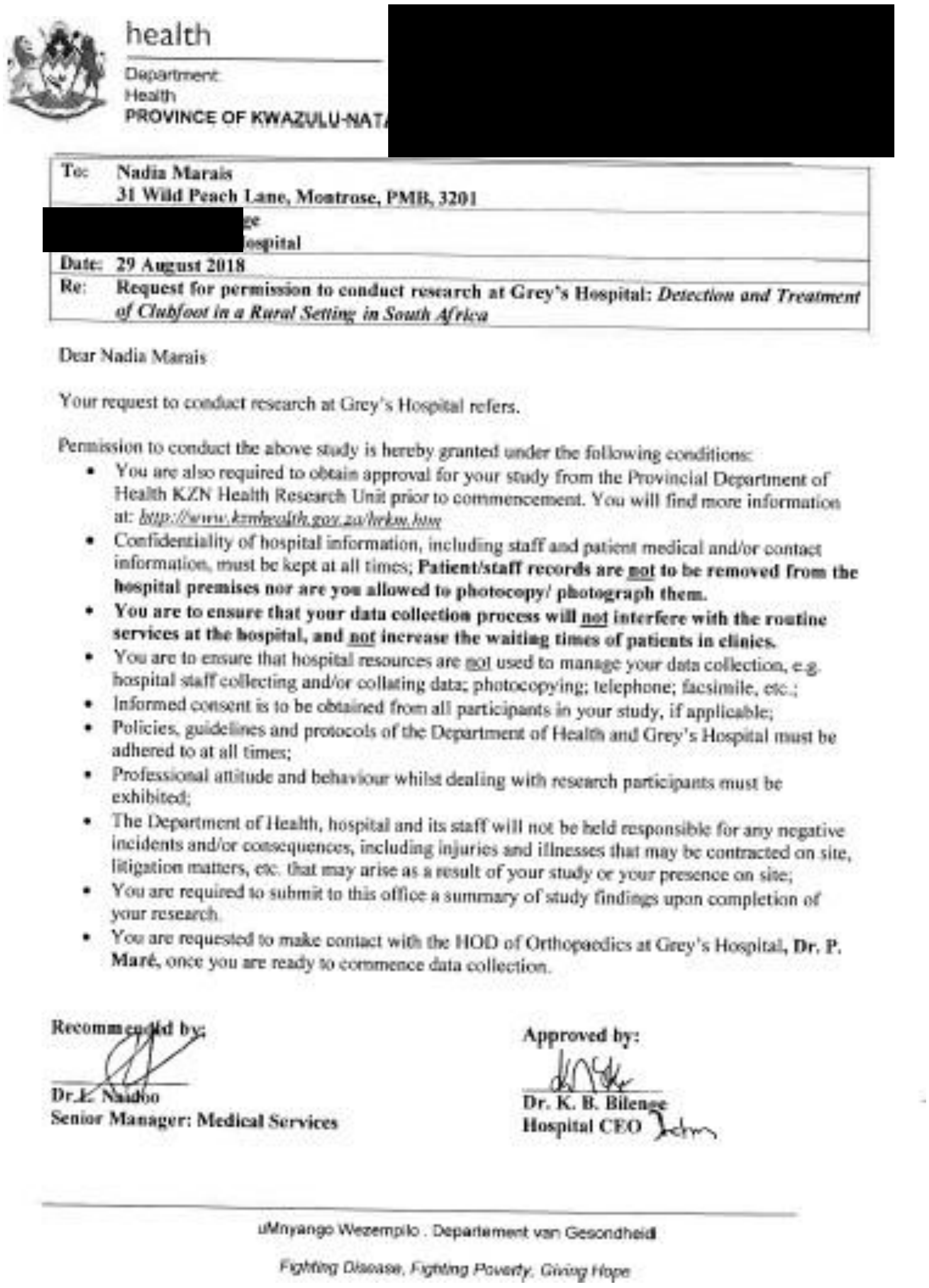
For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

**Dr E Lutge**
Chairperson, Health Research Committee
Date: 27/09/18

Fighting Disease, Fighting Poverty, Giving Hope

## ANNEXURE 7: Permission from hospital 1 to conduct the study



health

Department:
Health
PROVINCE OF KWAZULU-NATA [redacted]

**To:** **Nadia Marais**
**31 Wild Peach Lane, Montrose, PMB, 3201**
[redacted] **ge**
**ospital**
**Date:** **29 August 2018**
**Re:** **Request for permission to conduct research at Grey's Hospital:** ***Detection and Treatment of Clubfoot in a Rural Setting in South Africa***

Dear Nadia Marais

Your request to conduct research at Grey's Hospital refers.

Permission to conduct the above study is hereby granted under the following conditions:

- You are also required to obtain approval for your study from the Provincial Department of Health KZN Health Research Unit prior to commencement. You will find more information at: *http://www.kznhealth.gov.za/hrkm.htm*
- Confidentiality of hospital information, including staff and patient medical and/or contact information, must be kept at all times; **Patient/staff records are not to be removed from the hospital premises nor are you allowed to photocopy/ photograph them.**
- **You are to ensure that your data collection process will not interfere with the routine services at the hospital, and not increase the waiting times of patients in clinics.**
- You are to ensure that hospital resources are not used to manage your data collection, e.g. hospital staff collecting and/or collating data; photocopying; telephone; facsimile, etc.;
- Informed consent is to be obtained from all participants in your study, if applicable;
- Policies, guidelines and protocols of the Department of Health and Grey's Hospital must be adhered to at all times;
- Professional attitude and behaviour whilst dealing with research participants must be exhibited;
- The Department of Health, hospital and its staff will not be held responsible for any negative incidents and/or consequences, including injuries and illnesses that may be contracted on site, litigation matters, etc. that may arise as a result of your study or your presence on site;
- You are required to submit to this office a summary of study findings upon completion of your research.
- You are requested to make contact with the HOD of Orthopaedics at Grey's Hospital, **Dr. P. Maré,** once you are ready to commence data collection.

**Recommended by:**

**Dr. E. Naidoo**
**Senior Manager: Medical Services**

**Approved by:**

**Dr. K. B. Bilenge**
**Hospital CEO**

uMnyango Wezempilo . Departement van Gesondheid

*Fighting Disease, Fighting Poverty, Giving Hope*

## ANNEXURE 8: Permission from hospital 2 to conduct the study

**health**
Department:
Health
**PROVINCE OF KWAZULU-NATAL**

DIRECTORATE:

Ngwelezana Hospital, Thanduyise Road, Ngwelezana Township
Private Bag X 20021, Empangeni 3880
Tel: 035 901 7105 Fax: 035 794 1883 Email: ceosecretary.ngwelezana@kznhealth.gov.za
www.kznhealth.gov.za

Office of the Chief Executive Officer
NGWELEZANA TERTIARY HOSPITAL

**Enquiries: Ms. P.Z Khanyi**
**Telephone: 035 901 7105**

13 November 2019

TO: Mrs. N. Marais

PERMISSION TO CONDUCT RESEARCH IN DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA

I have pleasure in informing you that permission has been granted to you [redacted] research on: *DETECTION AND TREATMENT OF CLUBFOOT IN A RURA*

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. Please ensure that the office of the Finance Manager is informed before you commence your research.
3. The District Office/Facility will not provide any resources for this research.
4. You will be expected to provide feedback on your findings to the District office/Facility.

Thanking you.

Sincerely

**Dr BS Madiala**
**Chief Executive Officer**

[redacted]

Fighting Disease, Fighting Poverty, Giving Hope

## ANNEXURE 9: Information leaflet to the participants

### INVITATION TO TAKE PART IN A RESEARCH STUDY

### TITLE OF THE STUDY: EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA

### ETHICS CLEARANCE REFERENCE NUMBER: HSHDC/810/2017

Dear prospective participant

My name is Nadia Marais and I am doing research with Professor GH van Rensburg, a Professor in the Department of Health Studies, towards a Master's degree at the University of South Africa. We are inviting you to participate in a study entitled: **EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA**

### WHAT IS THE PURPOSE OF THE STUDY?

This study is expected to collect important information on clubfoot, a condition that affects the feet of an infant. Early detection and treatment are important in this condition. Through your participation valuable information could be used to ensure the health and wellbeing of baby and mother.

### WHY AM I BEING INVITED TO PARTICIPATE?

You were chosen to participate in this study because you are the guardian of a baby with clubfoot and it is believed that you have valuable information that will lead to promotion of health. Your details were obtained from the Ponseti clinic at one of the hospitals in KwaZulu-Natal.

### WHAT IS THE NATURE OF MY PARTICIPATION IN THE STUDY?

You will be requested to sign the consent form and there after take part in an interview during which you will be asked some questions. The interview will be audio recorded in order to analyse data at a later stage and the researcher might make some notes from time to time. It should not take longer than an hour and I will ensure that you do not lose your place in the line at the clinic as the interview will be conducted while your baby's leg is soaked to remove the cast. A co-facilitator will be present should you need clarity on any of the questions. You will be contacted after the transcription to verify the correctness of verbatim transcription.

### CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participation in this study is voluntary and you are under no obligation to consent to participation. If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a written consent form. You are free to withdraw at any time without giving a reason; however, withdrawal will not be possible once the data has been analysed.

### WHAT ARE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

Your contribution to this study will help the researcher to develop an information brochure for community members and thereby creating an awareness for clubfoot among both community members and healthcare practitioners on the importance of early detection and treatment of clubfoot.

### ARE THERE ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPAE IN THE RESEARCH PROJECT?

This study does not pose any foreseen physical discomfort, injury or inconvenience; the researcher will only need your time and verbal contribution during the interview. Should you feel upset by the interview I will arrange for you to see a counsellor to support you.

### WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

Your name will not be recorded anywhere and no one, apart from the researcher and identified members of the research team will know about your involvement in this research. Your name will also not be recorded anywhere, and no one will be able to connect you to the answers you give. Your answers will be given a code number, or a pseudonym and you will be referred to in this way in the data, any publications or other research reporting methods such as conference proceedings. Your answers may be reviewed by people responsible for making sure that research is done properly, including the transcriber, external coder and members of the Research Ethics Review Committee.

Data obtained from your participation in the study will be used for other purposes, such as a research report, journal articles and/or conference proceedings. In cases where a report has been sent for publication, you, as a participant will not be identifiable in that report.

### HOW WILL RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Transcripts of the interviews will be stored by the researcher for a minimum period of five years in a locked filing cabinet in the researcher`s place of residence for academic purposes, electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further Research Ethics review and approval if applicable. Should the need arise, hard copies will be shredded, and electronic copies be deleted permanently from the hard drive of the computer through the use of a relevant software programme.

### WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

No incurred cost is foreseen for participating in the study, except for the time you spend on the project as participant. Unfortunately, no financial compensation will be given. You will be acknowledged anonymously in the report of this study.

### HAS THE STUDY RECEIVED ETHICS APPROVAL?

Ethical clearance for the project has been obtained from Unisa as well as the KwaZulu-Natal, Department of Health. Permission was obtained from the Head of Department – KwaZulu-Natal Health Department and the Head of the clinic where the research will be conducted.

### HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, want to contact the researcher about any aspect of the study or require further information please contact Mrs N Marais on 072 239 2075 or email maraisnad@gmail.com. Should you have concerns about the way in which research has been conducted, you may contact Prof GH Van Rensburg at Tel 012 4296514 or email vrensgh@unisa.ac.za or Prof JE Maritz, Chairperson of the Research Ethics Committee of the Department of Health Studies at Unisa (maritjie@unisa.ac.za).

Thank you for taking time to read this information sheet and for participating in the study.

Thank you

Marais

Nadia Marais

## ANNEXURE 10: Informed consent form

### CONSENT TO TAKE PART IN A RESEARCH STUDY

**TITLE OF THE STUDY: EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA**

**ETHICS CLEARANCE REFERENCE NUMBER: ____________________**

### INFORMED CONSENT

I hereby confirm that I have been adequately informed by the researcher about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information. I am aware that the results of the study will be anonymously processed into a research report. I understand that my participation is voluntary and that I may, at any stage, without prejudice, withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and of my own free will declare myself prepared to participate in the study.

Research participant's name…......................................................... (Please print)

Research participant's signature………………………………………….

Date………………………

Researcher's name: Mrs N Marais

Researcher`s signature………………………..

Date……………………….

## ANNEXURE 11: Confidentiality binding form

## CONFIDENTIALITY BINDING FORM

The agreement is between:

| | |
|---|---|
| **Researcher** | **Nadia Marais** |
| Role: Co-facilitator/ Transcriptionist/Co-Coder | |
| Study | **EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA** |
| Expectations | The co-facilitator will be present during the semi-structured interviews for translating purposes to enhance understanding for the researcher and the participant.<br>Transcriptionists will transcribe recorded interviews.<br>Co-Coder will code data. |

I agree to:

1. Keep the identity of the participant strictly confidential.
2. Keep all the research information shared with me strictly confidential and only discuss it with the researcher.

| | |
|---|---|
| Name/Role | |
| Signature | |
| Date | |

I agree to:

1. Provide adequate instructions on my expectations and background to the study.

| | |
|---|---|
| Researcher | Nadia Marais |
| Signature | |
| Date | |

## ANNEXURE 12: Interview guide

### INTERVIEW GUIDE

Enquiries: Nadia Marais
Student number: 57577668
Address: 31 Wild Peach Lane
Montrose
Pietermaritzburg
3201
Telephone: 0722392075
E-mail: maraisnad@gmail.com

18 June 2018

**RESEARCH TITLE**: **EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA**

An introduction to the purpose of the study will be used to ensure that the participants understand the context in which the questions will be asked. Four questions will be asked to address the following topics:

- Reasons for visiting the clinic on that day
- Challenges in getting to the clinic
- Knowledge and understanding of clubfoot
- Whether antenatal clinic was visited and health education on clubfoot received

Based on the responses of the participants probing questions will be asked to elicited rich and in-depth data and to address the objectives of the study.

Probing questions such as “why did you come today’’, ‘’what are the challenges’’ ‘’when did you notice” and “’explain the journey to the clinic’’ will be asked so that the participant can elaborate, and the researcher can get a deeper understanding.

After the interview the participants will be thanked for their participation.

## ANNEXURE 13: Demographic data questionnaire

## TITLE OF THE STUDY: EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA

1. Are you the parent or the guardian? Please tick applicable box.

| | | | |
|---|---|---|---|
| Parent | | Guardian | |

2. Gender (tick)

| | | | |
|---|---|---|---|
| Male | | Female | |

3. Age: ________

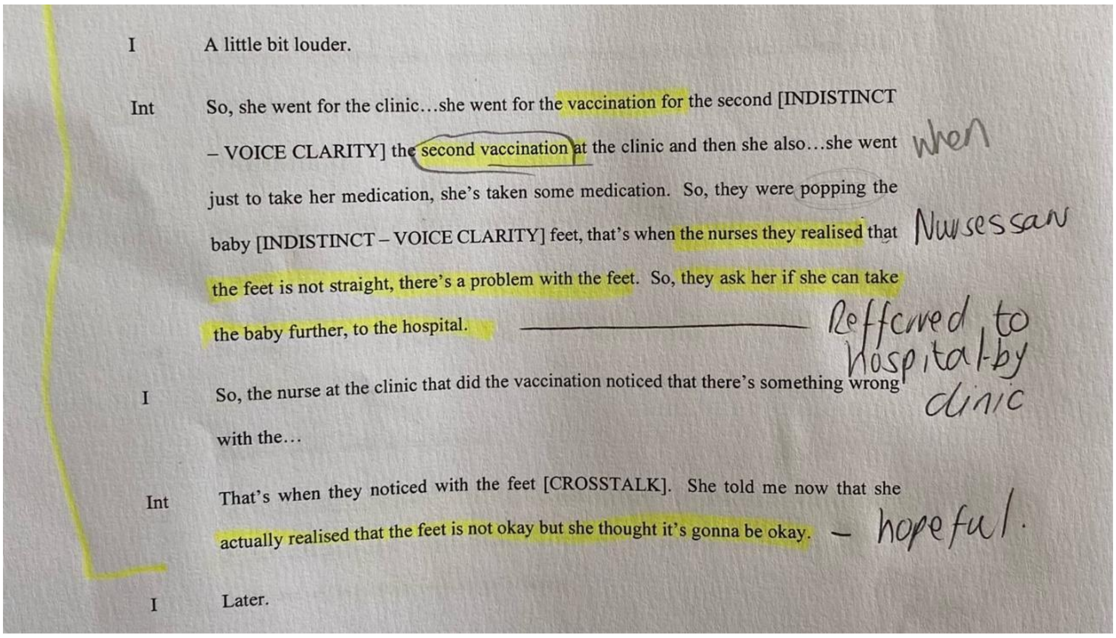
4. Does the patient have any siblings with the same deformity?

| | | | |
|---|---|---|---|
| Yes | | No | |

5. How far do you live from the closest clinic?

______________________________________________

## ANNEXURE 14: Extract of analysed transcribed data



I A little bit louder.

Int So, she went for the clinic…she went for the vaccination for the second [INDISTINCT – VOICE CLARITY] the second vaccination at the clinic and then she also…she went just to take her medication, she's taken some medication. So, they were popping the baby [INDISTINCT – VOICE CLARITY] feet, that's when the nurses they realised that the feet is not straight, there's a problem with the feet. So, they ask her if she can take the baby further, to the hospital.

when

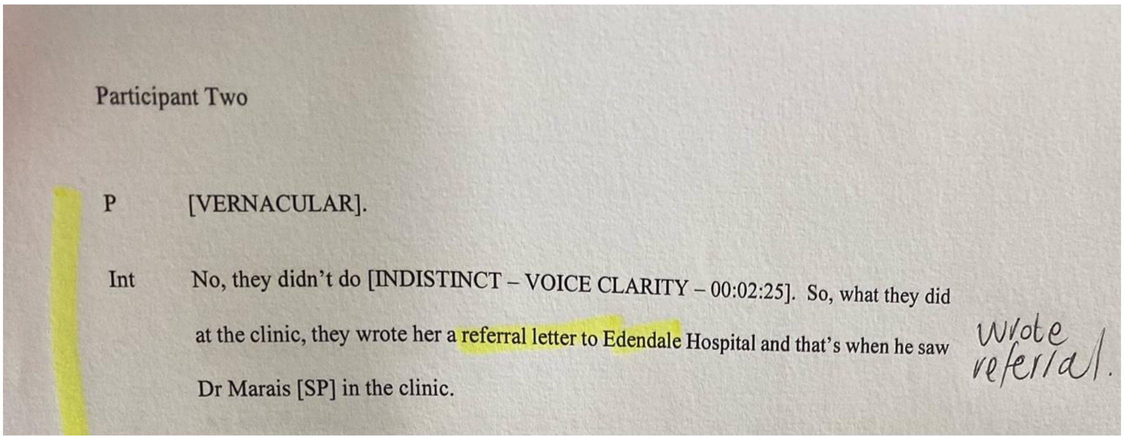
Nursessaw

Refferred to Hospital by clinic

I So, the nurse at the clinic that did the vaccination noticed that there's something wrong with the…

Int That's when they noticed with the feet [CROSSTALK]. She told me now that she actually realised that the feet is not okay but she thought it's gonna be okay. – hopeful.

I Later.

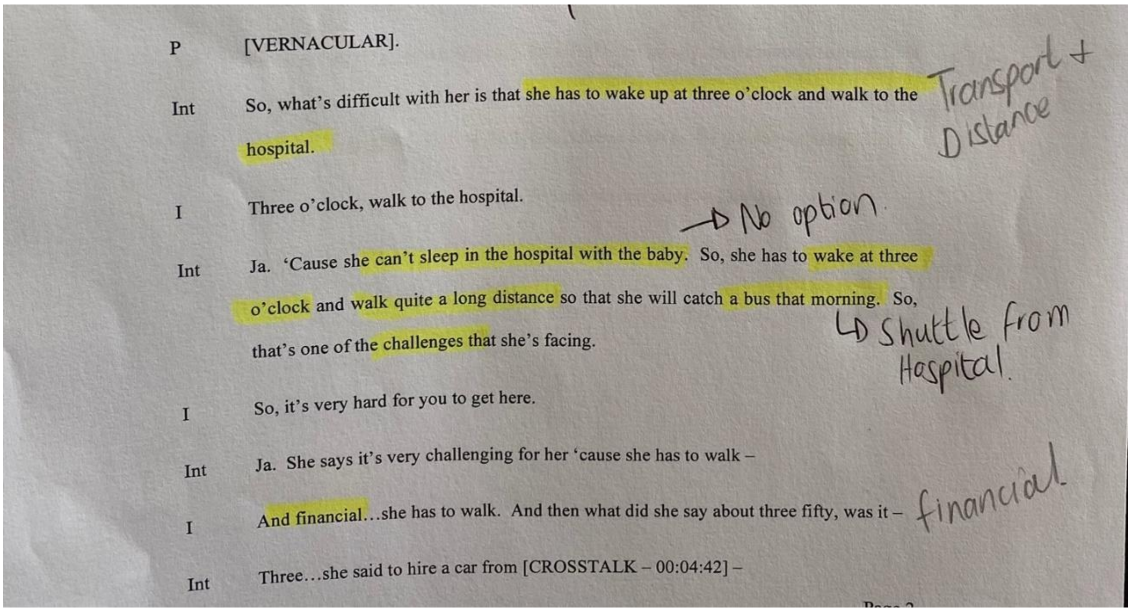


Participant Two

P [VERNACULAR].

Int No, they didn't do [INDISTINCT – VOICE CLARITY – 00:02:25]. So, what they did at the clinic, they wrote her a referral letter to Edendale Hospital and that's when he saw Dr Marais [SP] in the clinic.

wrote referral.



P [VERNACULAR].

Int So, what's difficult with her is that she has to wake up at three o'clock and walk to the hospital.

Transport + Distance

I Three o'clock, walk to the hospital.

→ No option.

Int Ja. 'Cause she can't sleep in the hospital with the baby. So, she has to wake at three o'clock and walk quite a long distance so that she will catch a bus that morning. So, that's one of the challenges that she's facing.

↳ Shuttle from Hospital.

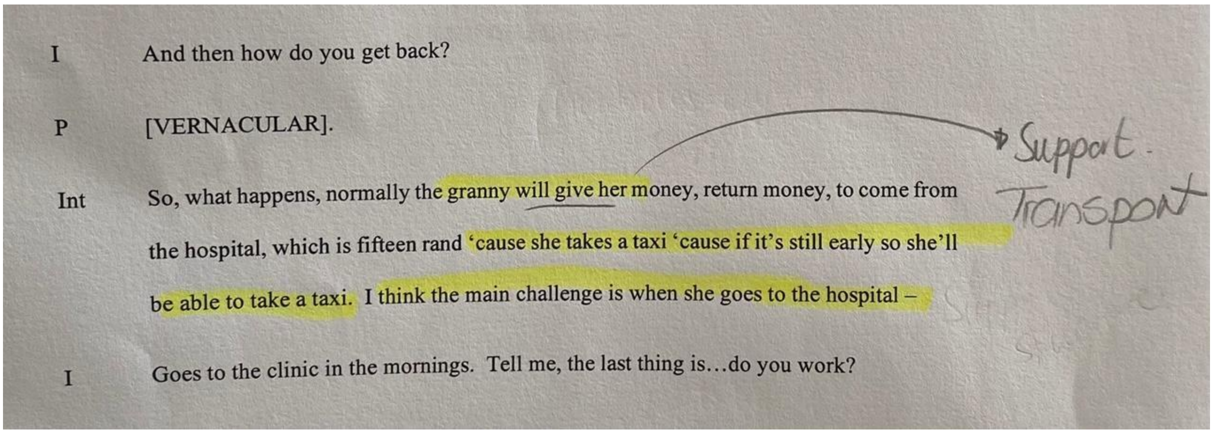
I So, it's very hard for you to get here.

Int Ja. She says it's very challenging for her 'cause she has to walk –

I And financial…she has to walk. And then what did she say about three fifty, was it –

financial.

Int Three…she said to hire a car from [CROSSTALK – 00:04:42] –



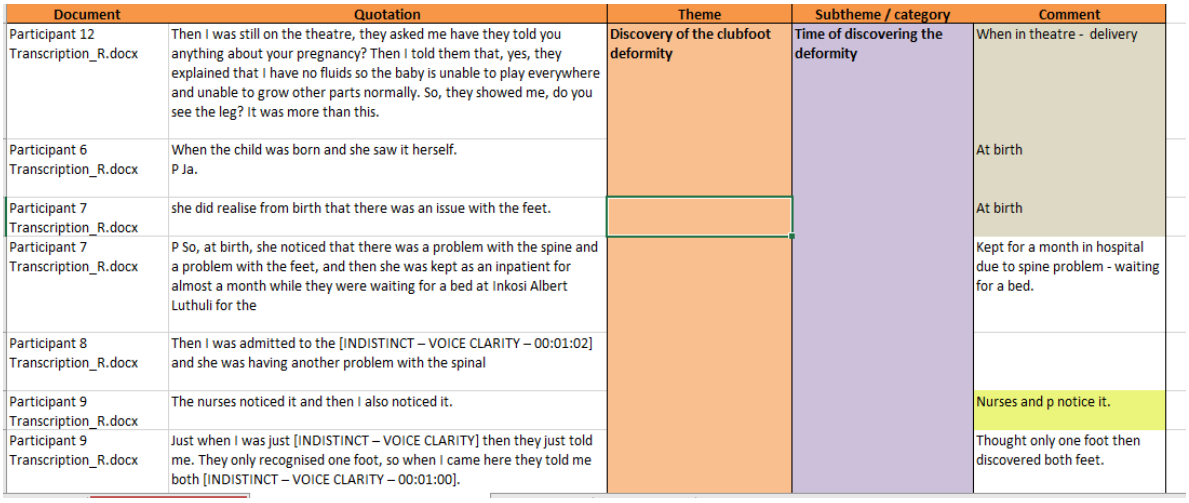
I And then how do you get back?

P [VERNACULAR].

Int So, what happens, normally the granny will give her money, return money, to come from the hospital, which is fifteen rand 'cause she takes a taxi 'cause if it's still early so she'll be able to take a taxi. I think the main challenge is when she goes to the hospital –

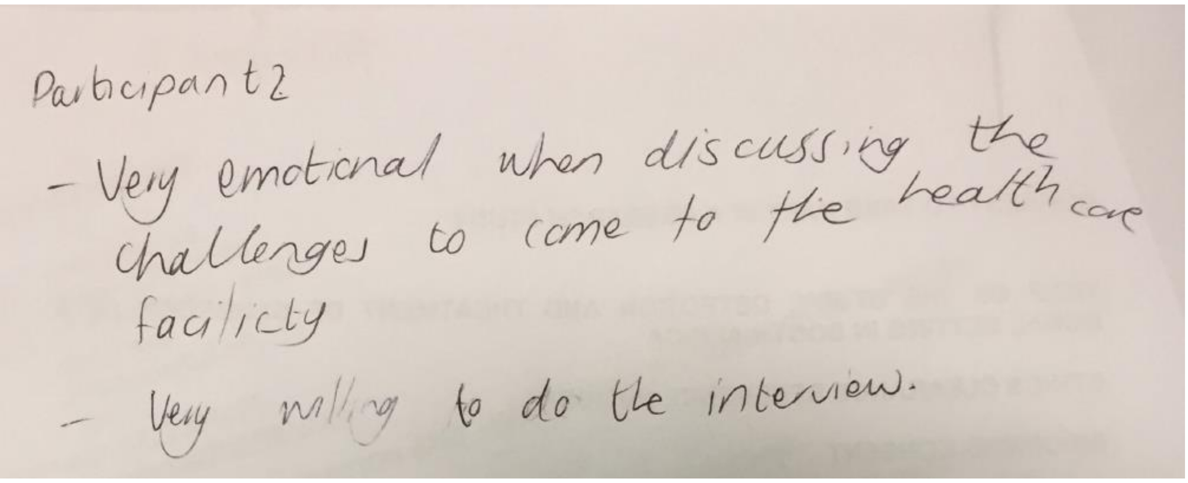
I Goes to the clinic in the mornings. Tell me, the last thing is…do you work?

Support.
Transport



| Document | Quotation | Theme | Subtheme / category | Comment |
|---|---|---|---|---|
| Participant 12 Transcription_R.docx | Then I was still on the theatre, they asked me have they told you anything about your pregnancy? Then I told them that, yes, they explained that I have no fluids so the baby is unable to play everywhere and unable to grow other parts normally. So, they showed me, do you see the leg? It was more than this. | **Discovery of the clubfoot deformity** | **Time of discovering the deformity** | When in theatre - delivery |
| Participant 6 Transcription_R.docx | When the child was born and she saw it herself.<br>P Ja. | | | At birth |
| Participant 7 Transcription_R.docx | she did realise from birth that there was an issue with the feet. | | | At birth |
| Participant 7 Transcription_R.docx | P So, at birth, she noticed that there was a problem with the spine and a problem with the feet, and then she was kept as an inpatient for almost a month while they were waiting for a bed at Inkosi Albert Luthuli for the | | | Kept for a month in hospital due to spine problem - waiting for a bed. |
| Participant 8 Transcription_R.docx | Then I was admitted to the [INDISTINCT – VOICE CLARITY – 00:01:02] and she was having another problem with the spinal | | | |
| Participant 9 Transcription_R.docx | The nurses noticed it and then I also noticed it. | | | Nurses and p notice it. |
| Participant 9 Transcription_R.docx | Just when I was just [INDISTINCT – VOICE CLARITY] then they just told me. They only recognised one foot, so when I came here they told me both [INDISTINCT – VOICE CLARITY – 00:01:00]. | | | Thought only one foot then discovered both feet. |

## ANNEXURE 15: Example of one participant’s fieldnotes



Participant 2

- Very emotional when discussing the challenges to come to the health care facilicty
- Very willing to do the interview.

## ANNEXURE 16: Letter from the language editor

word. services

Cell 083 556 1336 roneldavis430@gmail.com

9 January 2022

### DECLARATION OF PROOFREADING AND LANGUAGE EDITING

To whom it may concern

I herewith declare that I did the proofreading and editing on the dissertation of **Nadia Marais** (Student No. 57577668) in partial fulfilment of the requirements for the degree

**Master of Public Health**

in the subject of

**Health Studies**

**EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA**

at the

University of South Africa

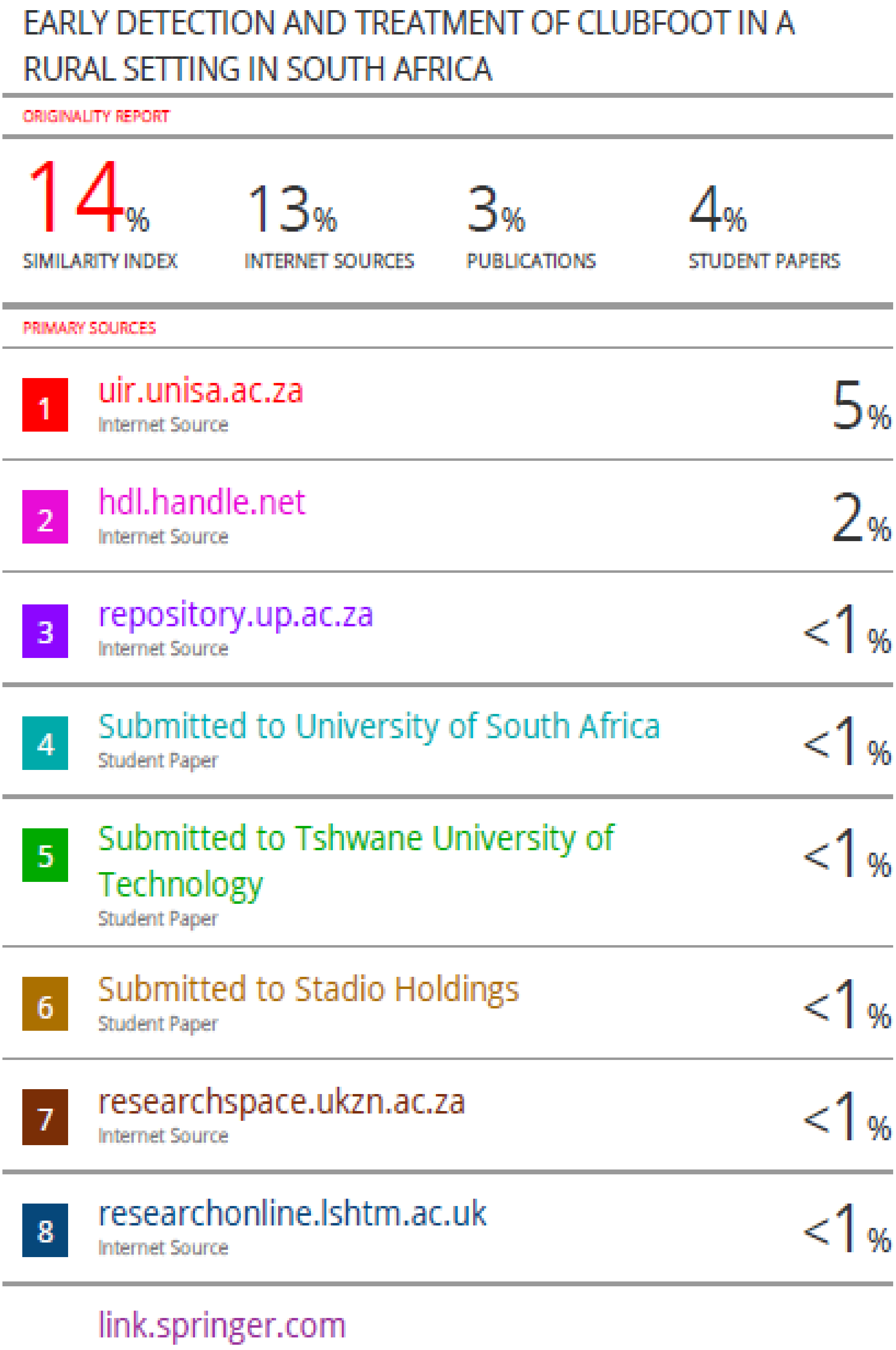
and that I made suggestions for corrections regarding language, grammar, style and syntax, which were communicated to the student.

Please feel free to contact me should any additional information be required.

Sincerely

Ronel Davis
BA (Hons) UP

## ANNEXURE 17: Turnitin originality report



EARLY DETECTION AND TREATMENT OF CLUBFOOT IN A RURAL SETTING IN SOUTH AFRICA

ORIGINALITY REPORT

| 14% | 13% | 3% | 4% |
|---|---|---|---|
| SIMILARITY INDEX | INTERNET SOURCES | PUBLICATIONS | STUDENT PAPERS |

PRIMARY SOURCES

| | | |
|---|---|---|
| 1 | uir.unisa.ac.za<br>Internet Source | 5% |
| 2 | hdl.handle.net<br>Internet Source | 2% |
| 3 | repository.up.ac.za<br>Internet Source | <1% |
| 4 | Submitted to University of South Africa<br>Student Paper | <1% |
| 5 | Submitted to Tshwane University of Technology<br>Student Paper | <1% |
| 6 | Submitted to Stadio Holdings<br>Student Paper | <1% |
| 7 | researchspace.ukzn.ac.za<br>Internet Source | <1% |
| 8 | researchonline.lshtm.ac.uk<br>Internet Source | <1% |
| | link.springer.com | |