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Exploring perceptions and experiences of the parents of patients: intervention services of a Johannesburg multidisciplinary cleft lip and palate team

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Exploring perceptions and experiences of the parents of patients: Intervention services of a Johannesburg multidisciplinary cleft lip and palate team

The discipline of Speech Pathology and Audiology
School of Human and Community Development
Faculty of Humanities
University of the Witwatersrand

In fulfilment of the degree of Masters of Arts
in Speech Pathology

Georgia Haitas-Jammine
May, 2015

DECLARATION

I Georgia Haitas-Jammine hereby declare that this dissertation is my own original work. It is being submitted for the degree of Masters of Speech Pathology in the discipline of Speech Pathology and Audiology, in the School of Human and Community Development, University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination at this or any other university.

_____

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7201619

Date: 18th May 2015 Place: Johannesburg

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DEDICATION

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List of Abbreviations:

ACPA – American Cleft Palate-Craniofacial Association
CBT – Community based therapist
CEP – Cleft Evaluation Profile
CLP – Cleft Lip and Palate
CPF – Cleft Palate Foundation
CPT – Cleft Palate Team
EBP – Evidence Based Practice
ENT – Ear Nose and Throat
GDP – Gross Domestic Product
HIV – Human immunodeficiency virus
HPCSA - Human Professions Council of South Africa
NHI – National Health Insurance
NGO – Non-Governmental Organization
OME – Otitis media with effusions
PACCLAP – Pan-African Congress on Cleft Lip and Palate
P – Participant
QoL – Quality of Life
SACLAPS – South African Cleft Lip and Palate Society
SAJPHEF – South African Joint Public Health Enhancement Fund
TB – Tuberculosis
VPI - Velopharyngeal insufficiency
WHO – World Health Organization

ABSTRACT

Introduction: Cleft lip and palate is one of the most common birth defects. The cleft may affect the patient's aesthetic appearance and may result in feeding difficulties, communication impairment as well as psychosocial problems. Management of the disorder is intensive and long-term, and is best handled through early intervention by a multidisciplinary team of professionals.

Rationale: In contrast to other developing countries in Africa, in South Africa, there are a number of multidisciplinary cleft lip and palate teams; however there is a lack of research regarding the evaluation of their services. This study sought to evaluate the service of a cleft palate team in the private healthcare sector of Johannesburg, and a combined clinic which it ran.

Objective: The purpose of this study was to inform best practice models in cleft palate teamwork by exploring the experiences and perceptions of the parents/caregivers of the patients attending the combined clinic, run by a multidisciplinary cleft palate team in Johannesburg, and described the services it provided.

Method: The study incorporated a self-administered questionnaire, which was completed by 33 parents/caregivers, and a review of the patients' medical records documenting the intervention they had received. Descriptive statistics and content analysis were used to interpret the data.

Results: The record review described the time frame and nature of intervention by the various professionals individually, and within the combined clinic. Analysis of the questionnaire revealed the general satisfaction experienced by the parents/caregivers with the service provided, as well as their reservations regarding some aspects of the service.

Implications and conclusions:

The results indicated that parents/caregivers valued the treatment they received by a multidisciplinary team of expert professionals who met in a combined clinic. Implications emerged that suggested possible improvements to the service as well as recommendations for cleft palate team care in South Africa. The importance of regular evaluation of services and possible tools for conducting them were highlighted.

Keywords: Cleft lip and palate, cleft palate teamwork, process evaluation, combined cleft palate clinic.

CHAPTER 1
INTRODUCTION

Overview

This research was inspired by my experience as a team member in an interdisciplinary cleft palate team based in the private healthcare sector of Johannesburg. For a period of six years, the team had access to private funding, which placed it in a unique position to offer comprehensive cleft care to patients from both high and low socio-economic sectors of society. Patients on medical aid, normally receiving private healthcare services, as well as those normally having no access to private health care could receive plastic and ear nose and throat (ENT) surgery, speech therapy, audiology services and social work counselling. During this period, the team held a monthly combined clinic where all the professional team members met with the parents and patients for a screening assessment, and a discussion of future management. As a team member, I experienced the benefit of an interdisciplinary team both for the professional and for the patient. Because of the close collaboration of the combined clinic, team members gained a greater awareness of each other's roles in cleft care. Inter-professional referrals increased between the team members, including plastic surgery, ENT surgery, speech therapy, audiology, orthodontics and social work, resulting in a more holistic management of cleft patients. Furthermore such referrals were being made earlier in the child's life. With early and appropriate management of cleft lip and palate (CLP) a child may have every chance of leading a normal life, and not being a burden on society (American Cleft Palate-Craniofacial Association, 2009).

During this six-year period, no formal evaluation of the service had taken place. Moreover, it appeared that no formal evaluation had taken place of any cleft palate team in South Africa, or indeed in Africa as a whole. This motivated me to explore the perceptions and experiences of the parents/caregivers of patients who had attended the combined clinic, for the purpose of improving the service provided at the clinic, as well as contributing to best practices in other cleft care units. A further outcome of the study was to gain insight into the usefulness of the selected tools for monitoring the effectiveness of the service.

Cleft lip and palate (CLP) is one of the most common of all congenital deformities, and the incidence appears to be increasing, possibly due to factors such as improved reporting, an increase in environmental teratogens, lower neonatal mortality and increased marriage and childbearing amongst cleft palate patients due to improved medical care (Watson, Sell & Grunwell, 2001). According to the ACPA & Cleft Palate Foundation (CPF) (2010) a child born with a CLP frequently face challenges associated with aesthetics, feeding and speech. These may have further implications for socialisation, education and employment. With appropriate early treatment however, the child may have every chance of leading a normal life and fulfilling a normal role in society. Due to the complexity of problems faced by the patient with CLP, the management of the disorder is intensive and long-term, and is best handled by an interdisciplinary team of professionals (ACPA, 2009).

While multidisciplinary cleft palate teams may be widely accessible in the developed world, little or no access of multidisciplinary teamwork is evident in the developing world (including most African countries). There is a discrepancy between the number of patients and those professionals available to treat them. Consequently many patients may not have access to medical care and the clefts may remain unrepaired. In recent years cleft surgery in Africa has largely been undertaken by pro bono surgical missions from the developed world (Sommerlad, 2008). In South Africa however, there are seven multidisciplinary cleft palate teams associated with university teaching hospitals, which are based in the public health service (Dekker, 2007).

For the purpose of best practice in cleft palate teamwork, it is important to evaluate the service based on the satisfaction of patients receiving treatment at cleft palate clinics. While several studies have been carried out internationally regarding patient perceptions and experiences of intervention services provided by professionals in cleft care, (Paynter, Edmonson & Jordan, 1991; Noar & Orth, 1992; Pannbacker & Scheuerle, 1993; Paynter et al., 1993; Jeffrey & Boorman, 2001; Austin et al. 2010), there is a paucity of published research in Africa. To the author's knowledge, similar research in South Africa and indeed in Africa as a whole is limited.

Organization of the thesis

The chapters that follow provide a theoretical background related to the study and a review of the relevant literature in order to set the context and provide insights into the concepts discussed.

Chapter 2 provides a literary review on CLP, including a definition thereof, the incidence of the defect, and its effect on aesthetics, feeding, communication, aural health and psychological well-being of the patient. A background of cleft palate teamwork is discussed within the setting of developed and developing countries, particularly in Africa and South Africa. The particular cleft palate team which forms the context for this study is described, and the combined clinic which the team provides. The importance of monitoring team function is highlighted. This chapter also introduces the theoretical background to the study including ecological systems theory, collaborative teamwork, and program evaluation. This study seeks to explore the experiences and perceptions of the parents/caregivers of cleft palate patients so as to inform models of best practice.

Chapter 3 describes the research methods selected for the study, namely a questionnaire and a medical record review, and the qualitative and quantitative approaches. The questionnaire, which included both closed-ended and open ended questions, was completed by parents/caregivers of children with CLP, under the age of twelve years, who had attended a combined clinic of the cleft palate team. The review of the patients' medical records reflected information regarding the type of cleft and the dates and intervention procedures undertaken by individual team members.

In **Chapter 4** the data were recorded and analysed, using descriptive statistics and content analysis. The parents/caregivers' perception of the accessibility of the service is explored through their responses to questions about the referral system, affordability, their awareness of the professional team members, their preference for a combined clinic and their use of social services. Their perception of the effectiveness of the clinic is expressed through their experience of professional communication, their feelings of involvement, their general satisfaction, their understanding of the condition, their feeling about their child's cleft and optimism towards the future. A description of the daily running of the service, and of the specific procedures that have been provided to patients by the Plastic Surgeon, the ENT

Surgeon, the Speech Therapist and the Audiologist has been collated from the review of the patient medical records.

Chapter 5 begins with an assessment of the particular methods used to evaluate the combined clinic, based on the information provided by parents/caregivers regarding their experiences and perceptions. The theoretical background pertaining to collaborative teamwork, ecological systems and program evaluation are discussed with reference to the findings. The experiences of the parents/caregivers, as well as their suggestions for improvement are discussed pertaining to the day to day running of the clinic, accessibility to the services offered and effectiveness of the service.

In **Chapter 6** the study concludes by arguing for a multidisciplinary cleft lip and palate team in which professionals meet face-to-face in a combined clinic with the patients. The study also argues for evaluations to be carried out to monitor the services provided by cleft palate teams, so that the service maintains a high ethical standards and patient care. It highlights the value of the service provided by the combined clinic, and the satisfaction parents/caregivers have derived from it. It also addresses areas where the service could be improved, including such aspects as accessibility of the facility through marketing, the referral system, affordability, transport and communication; and effectiveness of the service with regard to parent satisfaction, and their ability to be a part of the joint decision- making process, through informed choice. Strengths and weakness of the study are discussed, and suggestions for future research are indicated.

CHAPTER 2

THEORETICAL FRAMEWORK AND LITERATURE REVIEW

Overview

In this study the management of patients with CLP by a multidisciplinary team is advocated in which the team members, the parents and the patient meet face-to-face in a combined clinic. In order for the level of service of patient care to be monitored and so as to provide a role model for other CLP teams, regular evaluations of the service should be conducted.

In order to examine the efficacy of a CLP team and their clinic, it is necessary to gain an understanding of teamwork in general, how the patient and family members relate to the team and the society within which the patient functions, as well as the processes involved in evaluation of the service. A literature review on CLP is followed by a discussion that will highlight the theory of (a) collaborative teamwork, (b) ecological systems and (c) program evaluation. It should be clarified that although this study seeks to evaluate the service provided by a combined clinic run by the CLP team members, and is not an evaluation of the members of the team per se, it is difficult to separate the two and some discussion on the theory of collaborative teamwork is necessary in order to highlight the different approaches.

Background to cleft lip and palate and its treatment

The following literature review guides the reader through a description of CLP, its incidence and the effect it has on the patient. It discusses teamwork as the optimal approach to the management of the patient, as it exists in developed countries, and contrasts this with developing countries in Africa. After providing a general background to society and healthcare in South Africa, the review concentrates more specifically on cleft care in South Africa. Finally the need to evaluate cleft care service provision is highlighted, and the lack of such evaluation in South Africa, and indeed in Africa as a whole, supports the rationale for this study.

- **Definition of cleft lip and palate**

Kummer (2014) defines a cleft lip as an abnormal opening in the lip resulting from a failure of the parts of the lip to come together during foetal development. A cleft palate is an opening in the roof of the mouth resulting from a failure of the parts of the palate to fuse during foetal development, leaving an opening between the nose and the mouth. While a cleft lip may present with serious cosmetic problems, a cleft palate may have more serious consequences particularly affecting feeding, speech, hearing and aesthetics (Kummer, 2014).

- **Incidence of cleft lip and palate**

Derijcke, Eerens and Carels (1996) point to the importance of having information regarding the incidence rate of children born with a cleft, that is, the number of new cases in a population in a certain time. This knowledge gives an indication of the number of treatment centres that are required; it allows for a comparison between regions and provides a large enough sample for the purposes of research into the etiology of clefts. Cleft lip and palate is one of the most common congenital deformities.

General estimates, according to Peterson-Falzone, Hardin-Jones and Karnell (2010) indicate the frequency of cleft as being approximately 1:500 to 1:750 live births, with differences according to ethnicity, sex and type of cleft. Tanaka, Mahabir, Jupiter and Menezes (2012) report that the incidence of clefting is highest amongst Asians (1:500), followed by Caucasions (1:1000) and lowest in Africans (1:2500). Also there is a 2:1 ratio of males to female for cleft of the lip, and a 1:2 ratio of males to females for clefts of the palate. According to Peterson-Falzone et al. (2010) CLP is more common than either isolated cleft lip or isolated cleft palate, and unilateral clefts are more common than bilateral clefts. Unilateral clefts of the primary palate are more common on the left side than on the right. In addition nearly 30% of cleft cases have been found to be associated with comorbid conditions, such as multiple congenital abnormalities (Calzolari, Pierini, Astolfi, Bianchi, Neville, Rivieri & EUROCAT Working Group, 2007).

Interestingly, Conway, Taub, Kling, Oberoi, Doucette and Jabs (2015) point out that while worldwide epidemiologic reports show a trend of 25% of cleft lip, 50% of cleft lip and palate, and 25% cleft palate, in Africa the distribution of cleft types show a significantly lower rate

of isolated cleft palate than cleft lip. They believe that this is less likely to be related to a genetic variation in the African population, and more likely to be related to other factors, which my result in under-reporting of isolated cleft palate in Africa. These factors include vulnerability to infectious diseases as a result of poor feeding, decreased access to surgery especially for females in whom cleft palate is more common, and less of a concern for functional rather than aesthetic deformities. Olasoji, Hassan and Ligali (2009) stress the urgency for research to be carried out both locally and internationally to establish accurate and reliable data on the incidence and prevalence of orofacial clefts in Africa in order to influence the health providers and government to provide adequate cleft care facilities.

The incidence of CLP in South Africa as reflected by The South African Inherited Disorders Association (2010) is 1.4:1000 in Caucasians and 0.4:1000 in Black South Africans. According to Dekker (2007) South African cleft palate teams record approximately 461 new CLP patients annually, indicating a significant prevalence of CLP patients in the country. As there is no national register for cleft lip and palate patients in South Africa, there is a paucity of recorded data available to show changes in the incidence of the condition in this context.

- **The possible effects of CLP on the child**

Cleft lip and palate may affect the patient in a number of different ways, including appearance, feeding, speech and language, hearing and socialisation.

Aesthetics: Children born with a cleft, particularly involving the lip, have a facial deformity which is frequently judged as unattractive, and therefore the source of negative responses from society. This may result in socialization difficulties, differential responses by teachers, difficulty experienced in dating and a reduced likelihood of employment, if not treated satisfactorily (Kummer, 2014).

Feeding: Feeding the infant with CLP is one of the first care challenges faced by the parents and caregivers. Because of the opening in the palate, the infant is unable to create intra-oral pressure required to suck effectively. This may result in inadequate nutrition, lengthy feeding time, nasal regurgitation, choking, coughing and excessive air intake. Frequently, therapeutic intervention is required to assist the parents to feed the infant so as to encourage adequate weight gain (Kummer, 2014).

Communication: Children born with CLP are at risk for communication impairment (Peterson-Falzone et al., 2010). Velopharyngeal dysfunction, frequently associated with cleft palate may result in a variety of speech disorders including impaired speech articulation, nasal emission of air, nasal resonance and voice disorders. Another common feature of CLP is dental malocclusion, which may negatively affect speech articulation. In addition, a CLP frequently results in middle ear pathology and associated conductive hearing loss. All of these features may result in defective speech, language and hearing skills, and may have a negative impact on communication and educational progress (Peterson-Falzone et al., 2010).

Hearing: According to Sabo and Probst (2009) the incidence of otitis media with effusion (OME) and associated conductive hearing loss in infants with cleft palate has been found to be almost universal. This is due to abnormal eustacian tube function associated with a cleft of the soft palate that is of the tensor veli palatini muscle. Even after the palatal repair, eustacian tube function may not be resolved. Even though OME declines with increasing age, it can in some cases continue into adulthood. Lennox (2001) further highlights that the hearing loss resulting from the presence of fluid in the middle ear may often not be noticed by the parents, and may lead to speech and language difficulties, as well as behavioural and educational problems. Sensorineural hearing loss may also be a feature of particular syndromes which include clefting as one of their features, such as 22q11.2 deletion syndrome (McDonald-McGinn & Zackai, 2009).

Psychosocial aspects: In the early years parents may experience negative social implications to the cleft. Later these may be experienced by the child himself. As a result of poor physical appearance and poor communication skills, the child may experience teasing and poor self-perception, and may find it difficult to make friends and to progress academically at school (Kummer, 2014).

Given the multiplicity of areas affected by a cleft, there are a number of different professionals that are involved in treating the patient. The argument made by Rampp, Pannbacker and Kinnebrew (1984, p. 152) regarding the need for a professional team in treating velopharyngeal incompetency applies equally to CLP as a whole, in that: “No one individual alone, irrespective of background, is equal to the task. Even if such a “super-

practitioner" were to exist, he/she would soon be exhausted and rendered ineffectual by the demands placed upon them."

In recent years there has been a growing interest in the quality of life (QoL) of patients with CLP (Damiano et al., 2007; Klassen et al., 2012; Ward et al., 2013, Piombino et al., 2014). Ward et al. (2013) point out the value of health-related quality of life (QoL) outcomes in helping healthcare professionals to evaluate the burden of disease, its complications and its treatment on the patient, thereby enabling them to make better treatment recommendations.

Klassen et al. (2012) in an endeavour to develop a standardized QoL measurement for children with CLP conducted a systematic review of 26 studies which had measured the QoL of children with CLP with 28 different questionnaires. They identified three key health concepts: namely (a) physical health, included physical function, pain, communication and general health; (b) psychological health, included self-concept or self-esteem, behaviour, satisfaction with appearance, psychological function and cognitive function and (c) social health, included social experience, social adjustment and social competence. Their systematic literary review would be followed up with in-depth qualitative interviewing of the patient population, as well as expert input from the healthcare professionals working with the patients. Their patient-reported outcome instrument for patients with CLP would be aimed at measuring the specific domains of QoL important to those patients, for example, appearance, speech facial growth and psychosocial interaction, and would take into account the effect of age on these factors. While QoL has some relevance for cleft care within a team, and there is clearly a need for further research in this area to improve the outcome of the treatment provided, it was not a major focus of this research.

- **Management of cleft lip and palate by a team: different perspectives**

It has long been recognised that patients with CLP and other craniofacial anomalies face multiple complex issues; hence the need for intervention from a multidisciplinary team of professionals. Not only do these patients require assessment and treatment by a number of professionals, they also require follow-up over a long period of time (Paynter, Wilson & Jordan, 1993). In their historical review of the 'cleft palate team', Kobes and Pruzansky (1960) reported that the first recognized Cleft Palate Clinic was established in 1938 in

Lancaster, Pennsylvania. Cohen (2009) reported that there are currently over 200 teams listed in the ACPA directory for individuals with cleft palate and craniofacial anomalies; however according to Strauss and Broder (1985) CLP teams in the United States vary in terms of:

- location, being part of academic institutions, public and private health services
- funding, where some receive grants, capitation payments or private health insurance benefits
- the size and composition of the team which may range from three to 20 members, and who may either be full-time or part-time members of staff
- the frequency with which the team meets which may range from twice a week to once a month
- the manner in which records are kept which may be centralised and computerised or may be kept separately by each discipline
- the policy of seeing patients individually or at the same time.

Although the members of the cleft palate team may vary from centre to centre, Robin et al. (2006) list the health care personnel in a typical cleft clinic as the following: Clinic Director, Clinic Coordinator, Audiologists, Craniofacial Surgeon, Geneticist, Neurosurgeons, Nurses, Occupational Therapists, Oral and Maxillofacial Surgeons, Orthodontists, Otorhinolaryngologists (ENTs), Paediatrician, Paediatric Anaesthesiologists, Paediatric Dentists and Prosthodontists, Paediatric Radiologists, Physical Therapists, Plastic Surgeons, Speech-Language Pathologists and Surgeons Assistant. The Illinois Association of Craniofacial Teams (IACT) includes the Otolaryngologist/Audiologist as core disciplines (Will, Aduss, Kuehn, & Parsons, 1989).

Such an extensive team may be possible in an ideal situation; however in a developing country such as South Africa, where there is a shortage of specialised personnel, this is an unrealistic target. The American Cleft Palate-Craniofacial Association and the CPF (2010) have suggested that cleft palate teams should include at least the specialists from the three core disciplines of Plastic Surgery, Orthodontics and Speech-Language Pathology, and have access to professionals in other relevant disciplines. Even so, in South Africa, the services of an Orthodontist are not readily available even in many of the large public hospitals.

According to Cohen (2009), psychological and social needs of the patients should always be kept in mind by the team members hence the inclusion of a Social Worker or Psychologist is

essential. Cohen (2009) also stresses the inclusion of a designated patient care coordinator who helps to facilitate patient care and team interaction, and assists the patients in understanding, coordinating and implementing treatment plans. Even though team structure may differ depending on the contexts, effective communication between the specialists and the patients and their families is fundamental. Thus cultural and language differences need to be taken into consideration. In a multi-linguistic context, such as in South African where there are 11 official languages, the inclusion of an interpreter who is competent in some of the African languages should also be considered as a team member, particularly in the public healthcare sector. Finally, McWillliams, Morris and Shelton (1984, p. 43) add that "the patient and the parents complete the make-up of the team".

Within the framework of Bronfenbrenner's (1986) model, one must consider a goal within cleft care being to strengthen *micro-* and *mesosystems*. (Bronfenbrenner's Theory of Ecological Systems is discussed in detail later in this chapter.) Salyer, Cheng, Michienzi and Genecov (2009, p. 300) describe the standard for global cleft care as nothing less than excellence: "The goal for all cleft patients needs to be good to excellent facial aesthetics, normal dental occlusion, and normal speech". The objective of the management of cleft lip and palate is described by Morris, Jokobi and Harrington (1978, p. 2) as "an individual who, for reasons of the cleft, does not differ significantly from his peers in health, educational, or vocational opportunities, and who has the ability to communicate and interact with others".

The American Cleft Palate-Craniofacial Association (2009: p.7) has laid down several fundamental principles for best practice in the evaluation and treatment of patients with CLP or other craniofacial anomalies by the team (Table 1).

Table 1: Fundamental principles for best practice in the evaluation of patients with CLP

I.	Management of patients with craniofacial anomalies is best provided by an interdisciplinary team of specialists.
II.	Optimal care for patients with craniofacial anomalies is provided by teams that see sufficient numbers of patients each year to maintain clinical expertise in diagnosis and treatment.
III.	The optimal time for the first evaluation is within the first few weeks of life and, whenever possible, within the first few days. However, referral for team evaluation and management is appropriate for patients at any age.
IV.	From the time of the first contact with the child and family, every effort must be made to assist the family in adjusting to the birth of a child with a craniofacial anomaly and to the consequent demands and stress placed upon the family.
V.	Parents/caregivers must be given information about recommended treatment procedures, options, risk factors, benefits, and cost to assist them in (a) making informed decisions on the child's behalf, and (b) preparing the child and themselves for all recommended procedures. The team should actively solicit family participation and collaboration in treatment planning. When the child is mature enough to do so he or she should participate in treatment decisions.
VI.	Treatment plan should be developed and implemented on the basis of team recommendations.
VII.	Care should be co-ordinated by the team but should be provided at the local level whenever possible; however, complex diagnostic and surgical procedures should be restricted to major centres with the appropriate facilities and experienced care providers.
VIII.	It is the responsibility of each team to be sensitive to linguistic, cultural, ethnic, psychological, economic, and physical factors that affect the dynamic relationship between the team and the patient and family.
IX.	It is the responsibility of each team member to monitor both short-term and

	long-term outcomes. Thus, longitudinal follow-up of patients, including appropriate documentation and record keeping, is essential.
X.	Evaluation of treatment outcomes must take into account the satisfaction and psychological well-being of the patient as well as effects on growth, function, and appearance.

At the early stage of management, parents/caregivers should be provided with information concerning treatment planning. For any information provision to be effective, it needs to be made available in a form that patients can understand, be it in verbal, written or an electronic format. Assistance with feeding, hearing assessment speech and language development and dental development, should be included in the program. As part of on-going management, surgical repair of the cleft lip and CLP is included. The treatment for middle ear pathology and upper airway obstruction, speech-language evaluation and therapy and psychosocial services should also be part of the management plan and intervention services. The recommendations should be communicated to the parents in a face-to-face discussion as well as a written report (ACPA, 2009). Finally, the patients should be consulted at regular intervals, for consistent evaluating and monitoring of the service.

Shprintzen (1995) describes a “carousel team” in which the patients attending the clinic are seen by each of the professionals separately in one morning or afternoon, and after the patients leave, the professionals meet to discuss the cases, reaching decisions regarding management. On the other hand, in the “triage” system, the patient is first seen by a “gatekeeper”, who does the initial assessment, and then refers the patients to the relevant professional for an in depth evaluation. The professionals then meet to discuss the patient’s management. This is a useful approach, particularly in interdisciplinary teams which manage large caseloads.

Cohen (2009, p. 1026) claims that "teams should meet on a regular face-to-face basis in order to provide interdisciplinary collaboration in the evaluation and treatment of each patient.” With professional staff being stressed for time, it is difficult to motivate them to spend addition time in a face-to-face meeting, and this may not be feasible for all the patients attending the clinic with a large caseload. However, investing some time in discussion regarding specific identified cases may contribute to more efficient use of time in their longer term management.

Cohen (2009) sets a standard for comprehensive and shared records for each patient, which includes the findings and recommendations of each evaluation. These should include: a general medical history, social and psychological history, medical diagnosis, written treatment plans, dental and orthodontic findings, patient photographs, and radiographic findings. She highlights the importance of team care that includes a critical assessment of outcomes both for the types and extent of procedures employed to treat the patients, as well as for the team practices in general. Both long- and short-term goals should be communicated to the parents based on the team's evaluations and recommendations, and these should be revised on a longitudinal basis (Cohen, 2009).

Mechanisms should also be in place for sharing records with other medical professionals outside the team. The system should be available for consumer comment, such as questionnaires provided to patients and their families on a regular basis so that a summary of this information can be shared with professional team members and funding agencies. Feedback from patients can also contribute to improved service provision.

McGrattan and Ellis (2013) acknowledge the vast perceived potential benefits of team-oriented treatment of orofacial clefts. In a systematic review of the literature, however they found limited and variable research examining the direct and indirect impact of team-oriented approaches to care of patients with orofacial clefts. They concluded that further research is needed to address the differential access to team-oriented care and potential health. They also highlight the fact that patients from lower socio-economic backgrounds as well as patients living in rural areas may experience differential access to comprehensive care, and therefore poorer outcomes.

- **Cleft care in Africa**

The countries of Africa as a whole are considered to be part of the developing world (The International Statistical Institute, 2015). Sommerlad (2008) outlines the challenges faced by the developing world in cleft care. Firstly, he points out that the great majority of babies born every year with a facial cleft are born in developing countries. Many of them are born in rural areas, while medical care is concentrated in the large cities. Furthermore, there are a limited number of competent surgeons who can cope with the large caseload. As a result of this, many cleft patients have little or no access to cleft care, and frequently their clefts remain

unrepaired, or they are repaired by less competent and inexperienced surgeons. He adds that patients born with clefts in developing countries may suffer severe limitations in their life prospects, for example by not attending school, not getting married or having families. The cultural and religious beliefs in any particular area may affect society's attitudes towards them, or their parents' willingness to seek surgical care (Sommerlad, 2008).

Adetayo, Ford and Martin (2012) provide a background to the challenges to cleft care in Africa. These include such factors as the environment, genetics, cultural and religious beliefs, lack of education, financial constraints, low life expectancy, poverty and emigration of specialists outside the continent. Adetayo and Martin (2012) reported on a survey of practitioners, who attended the second Pan-African Congress on Cleft Lip and Palate (PACCLAP) held in Ibadan, Nigeria in 2007. The objective of this survey was to analyse the impact of several geographic, cultural, and socioeconomic variables on cleft care delivery in Africa, and to investigate the current status of cleft care delivery in Africa. Although this was a Pan-African Congress, the majority of the respondents in the survey were from the West African region, thus the data obtained may not necessarily reflect the demographics of Southern African countries. Nevertheless, the survey highlights several interesting trends. Plastic surgeons provided the majority of cleft care, followed by oral and maxillofacial surgeons, then orthodontists and ENT surgeons. Over 90% of practitioners practised either in university or government-based facilities, and less than 10% in other facilities or private hospitals. An overwhelming number of the practitioners reported that they received formal cleft training in their respective countries, and that they had a high level of exposure to cleft cases both during their training, and well as in their practices. Nineteen percent of the respondents reported that outside surgeons visited their facilities to offer cleft care, these being equally from Africa and from other continents.

A further challenge faced by cleft care providers in Africa is that of late referrals. Conway, Taub, Kling, Oberoi, Doucette and Jabs (2015) in their report of over 35000 orofacial cleft in Africa, found that more than half the patients presented after the age of four, with an average age at surgery being 9.34 years. They found that the age of surgery correlated with the level of economic development of the particular country. Olasoji et al. (2009) attribute late referrals in Africa to lack of money for treatment, lack of knowledge of the availability of treatment, lack of time and superstition.

Hodges and Hodges (2000) believe that due to the effects of poverty and a lack of education, the cleft patients and their families are often unwilling to travel out of their districts to seek surgical repairs. They are also uninformed about the availability of surgery. This results in thousands of patients of all ages living with unrepaired clefts of the lip or palate, thus giving rise to many pro bono surgical missions, staffed by volunteer surgeons from the developed world, being conducted in the developing world (Sommerlad, 2008), and notably in Africa (Hodges & Hodges, 2000; Pham, Travis & Tollefson, 2007; Elliot, Jovic & Beveridge, 2008; Project Harar, Ethiopia, 2010).

Operation Smile South Africa (OSSA) was founded in 2006, as part of a global non-profit medical service associated with Operation Smile, Inc. South African medical volunteers provide free CLP surgery to children and adults throughout Southern and Central Africa, including South Africa. By early 2013, OSSA had conducted 30 free surgical missions, bringing the total number of surgeries to more than 4000 (Operation Smile South Africa, 2012).

The Smile Train, an organization based in New York City, rather than conducting missions, enhances care by providing local physicians and institutions with training and financial support (Conway et al., 2015). Over a 15 year period, the Smile Train facilitated the repair of over a million clefts in 87 countries, many of which were on the African continent (Smile Train, 2015). Other organizations involved in supporting cleft care in Africa include ReSurge International (formally "Interplast") which partners with local surgeons to perform cleft surgery in Zambia, Mali, Ghana and Zimbabwe (Resurge International, 2015).

Sommerlad (2008) points out that in developing countries, surgeons may carry the sole responsibility for cleft care and multidisciplinary teams may not exist. Even if there is a willingness amongst professionals to provide team management, a paucity of orthodontists and speech-language pathologists may make this impossible. He recommends that multidisciplinary teams need to be encouraged in the developing world, beginning with surgeons, orthodontists and speech-language pathologists, and later expanding to include other professions.

Regarding cleft palate team work in Africa, Adetayo, et al. (2012) reporting on the same survey as that of Adetayo and Martin (2012), found that over a third of practitioners had no access to speech language pathologists, and even where they did have access, 21% rated their

access as difficult. In addition, 22% of practitioners had no access to orthodontists, and 13% had no access to audiologists. They had easier access however to ENT surgery (52%), social work (30%), safe anaesthesia (51%), psychology (21%) and dental services (46%). This highlights the challenges facing the surgeons in having easy access to supporting services by other core disciplines recommended by ACPA (2009) for an effective team. Olasoji et al. (2009) recommend that as in most joint cleft lip and palate clinics in the United Kingdom the minimum number of professionals include a surgeon, and orthodontist and a speech therapist, this would probably be an appropriate number to start with for cleft teams in Africa.

With reference to Bronfenbrenner's (1986) theory of ecological systems, discussed in more detail later in this chapter, sociological factors such as poverty, low educational level and social inequality all fall within the *macrosystem* of the family. When understanding cleft palate teamwork and the provision of cleft services in South Africa, it is essential therefore to take a step back and understand the context in which the patient resides. Providing a background to South African society in general and cleft care in South Africa specifically, thus constitutes the *macrosystem* of the child with a cleft.

- **Background to South African society**

According to the 2011 census, the total population of South Africa was estimated to be 51.8 million. The population is mostly young, with nearly a third of the population (31.3%) younger than 15 years, and approximately 7.7% over 60 years of age (Statistics South Africa, 2011). It is characterized by a wide range of cultures, language groups, religious beliefs and customs. It includes 51.3% males and 48.7% females. Racial demographics indicate that Black Africans make up the largest population group at 79.2%, followed by Whites and Coloureds both at 8.9%; the Indian/Asian population stands at 2.5% and other racial groups comprise 0.5%. Nearly a quarter (23.7%) of population resides in Gauteng, the smallest province (Statistics South Africa, 2011).

There are 11 official languages in South Africa. Although English is South African's lingua franca and the primary language of government, business and commerce, the most common home language, spoken by just over 20% of the population is isiZulu, followed by isiXhosa at 16%, Afrikaans at 13.5%, English at 8.2% (mostly in Gauteng) and Setswana also at 8.2%

(Statistics South Africa, 2011). Around half of the country's population has a speaking knowledge of English. English is the also the language of learning in most schools and tertiary educational institutions. The various religions that are practised include predominantly Christianity, Islam, Judaism, Hinduism and African Traditional Belief (Statistics South Africa, 2011). A large number of the people in the country are unemployed (25.2% in the first quarter of 2014) (Trading Economics, 2014). Unemployment leads to a loss of health insurance and possibly access to specialised healthcare. These statistics have major implications for understanding South Africa's diversity and its social issues, as a developing country.

- **Health Care in South Africa**

Rossetti (2001) identifies poverty as a major risk factor to educational success. Lequerica (1997) suggests that as a result of a low educational level, many low income families may be unaware of services that are available. As a result of South Africa's history of social inequality, many individuals requiring services may not have been able to access even the limited resources that may have been available. Parents/caregivers may experience a language barrier with professionals, and feel uncomfortable dealing with them. Levin (2006) points out the biological risk faced by neonates born in a poor rural community in South Africa. Their mothers cannot afford pre-natal care, have poor health literacy, and are often unable to access, understand or utilize information about health care. Patients and their families frequently live great distances away from healthcare and can therefore not access specialized intervention. Mothers and infants are exposed to communicable diseases, they are victims of malnutrition, and often do not even have clean running water or a sanitary environment.

In a historical report on the roots of current public health challenges in South Africa Coovaida, Jewkes, Barron, Sanders and McIntyre (2009, p. 1) state that as a result of the policy of apartheid, "racial and gender discrimination, the migrant labour system, the destruction of family life, vast income inequalities, and extreme violence have all formed part of South Africa's troubled past, and all have inexorably affected health and health services." As a result of South African history, health services have been fragmented within the public healthcare sector itself, and between the public and private healthcare sectors. Fragmentation

occurred on racial grounds, as well as between curative and prophylactic services. By the end of the era of apartheid there were as many as 14 separate health departments in South Africa, as a result of the previous creation of 'Bantustans'. This term refers to the separate 'homelands' which came into existence under the apartheid regime, with the goal of ultimately having no African citizens in South Africa, and where approximately 75% of the population would reside in 13% of the land. After 1994, the 'Bantustans' were reabsorbed into South Africa (South Africa: Overcoming apartheid, 2014).

Coovadia et al. (2009) also describe the current challenges faced by the South African public health sector as a result of its historical background. Since 1994, and the advent of the new government these 14 health departments were consolidated into one national department and nine provincial departments. The public health system embarked on a journey of transformation so as to provide basic health care to all people, especially the previously disadvantaged people, in urban and rural areas. The health sector has been characterised by major challenges as a result of poor and unskilled administration. Poor skills of some health professionals may also be due to a poor educational system. Many nursing colleges were closed in the late 1990s; many health professionals migrated from the public sector to the private sector, while others emigrated, retired, or were affected by HIV/AIDS. Many of the health policies that have been introduced have been sound, however their implementation, monitoring and assessment has been insufficient (Coovadia et al., 2009).

Comparing the current healthcare systems within the public and private sectors in South Africa, the public sector which is under pressure to cater for about 80% of the population, tends to be under-resourced. The smaller (20%) but fast-growing proportion in the private sector, caters for middle and upper socio-economic status patients who have access to medical aid schemes, which are run largely on commercial lines and attract most of the country's health professionals besides nurses (Health care in South Africa, 2012). As a result of a heavy workload, a lack of resources, poor remuneration and personal issues, there is often a migration of staff from the public to the private healthcare sector resulting in high staff turnover in the public sector. In addition, with globalisation, many professionals choose to emigrate from South Africa to other countries, hence the limited number of trained individuals (Mdindela, 2009).

The gaps and inaccessible services for the majority of the people in South Africa were due the apartheid policies. Since 1994 however, the newly elected South African government,

based on its Constitution (Constitution of the Republic of South Africa 1996), committed to providing free health care to all children under the age of six years who were not covered by a medical insurance, and who live in households that earned less than R100 000 per year (Leatt, 2006; Rendering of free health services, 1994). This policy is nevertheless not without its own glitches.

The national plan to reform health care in South Africa has been described by the Centre for Development and Enterprise (CDE, 2011). The National Health Insurance (NHI) was launched in 2011, with the intention of drawing on the strengths of both the public and the private health care sectors, in order to improving service delivery. Currently, the public sector is criticised for being fragmented, badly designed and badly managed, as well as for its poor health outcomes. Mismanagement has a knock-on effect on finance and human resources. The private sector on the other hand provides high quality healthcare, but with costs which exclude the majority of the population. The aim therefore is to increase the access of the South African population to quality health care, and simultaneously improve the management of resources. Although 8.3 percent of the South African gross domestic product (GDP) is spent on health care, while the World Health Organisation (WHO) recommends that middle income countries spend only 5.8 percent on health care, health outcomes in South Africa still compare poorly with that of other countries with similar national income and health expenditure (CDE, 2011). These negative health outcomes include a decline in life expectancy, an increase in under-five mortality and a discrepancy in the health standards of the poor in rural communities as opposed to those urban communities who tend to be racially mixed. Healthcare outcomes are further affected by the high prevalence of poverty leading to the lack of the necessary infrastructure for a healthy lifestyle, the high incidence of violence, the abuse of alcohol and tobacco and the burden of disease from HIV/AIDS (CDE, 2011).

- **Cleft care in South Africa**

Cleft care in South Africa takes place in a number of different settings, including in the public sector, the private sector and through NGOs. Shaw, et al. (2009) quote a report of the World Health Organization (2002) in which South Africa, as the wealthiest sub-Saharan country has approximately 12 centres that undertake cleft palate surgery. Dekker's (2007) descriptive and exploratory study into CLP teams that exist in South Africa indicated that

most of the centres in South Africa which have multidisciplinary cleft units are affiliated to university departments. These include: University of Cape Town at the Red Cross War Memorial Children's Hospital, University of Stellenbosch at Tygerberg Academic Hospital, University of the Witwatersrand at Charlotte Maxeke Johannesburg Academic Hospital, Chris Hani Baragwanath Hospital, The Medical University of South Africa at Garankua, University of Pretoria at Die Tand en Mond Hospitaal, University of Kwa-Zulu Natal at Grey's Hospital and Albert Luthuli Hospital. At the time of this study, Walter Sisulu University was the only medical school that did not have a cleft unit. It should be noted that all of these hospitals are within the public sector of health care in South Africa.

According to Dekker (2007) the cleft teams in South Africa vary in their composition. All the teams included a surgeon (either a plastic surgeon or a maxillofacial surgeon) and all included a speech therapist. More than half the teams included an audiologist, an orthodontist and an interpreter. Less than half the teams included an ENT surgeon, and only a few included a psychologist or social worker. Dekker (2007) notes that five of the seven teams reported had a regular monthly team meeting. The Cleft Facial Deformities Clinic in the Department Maxillo-Oral-Facial Surgery, at the University of Pretoria was established in the 1980's with team members from 11 different disciplines, meet as a team during each meeting which is held bimonthly (B. Louw, personal communication, March 30, 2015). This was not however the case at least at two of the major hospitals in Johannesburg. From anecdotal reports, the cleft palate clinic at Charlotte Maxeke Johannesburg Academic Hospital is currently attended by specialists from plastic surgery and speech therapy. Referrals are made to orthodontics and ENT, but no meetings of the full team take place (E. A. Christofides, personal communication, April 5, 2014). Similarly, at the Chris Hani Baragwanath Hospital, the cleft palate clinic is attended by specialists from plastic surgery and speech therapy. Patients are referred to ENT at the hospital if necessary, and to Orthodontics at the Charlotte Maxeke Johannesburg Academic Hospital. A parent support group is coordinated by the speech therapist. There are no meetings held for the professional members of the team (N. Lahouel, personal communication, May 28, 2014).

In addition to public hospital clinics, the Smile Foundation, founded in 2000, is a Non-Government Organization (NGO) based in South Africa, which assists children with any type

of facial disfigurement, including CLP, to receive free corrective plastic and reconstructive surgery. It is based at seven Academic Hospitals around South Africa, including Chris Hani Baragwanath Academic Hospital, Charlotte Maxeke Johannesburg Academic Hospital, Dr George Mukhari Hospital, Port Elizabeth Metropole Complex, Tygerberg Hospital, Red Cross War Memorial Children's Hospital and Universitas Academic Hospital. The Smile Foundation provides funding for transporting patients to surgery as well as to speech therapy (Smile Foundation, 2012; M. Gerszt, personal communication, July 30, 2012). The other NGO based in South Africa is Operation Smile South Africa (OSSA), which has carried out free surgical missions in Mount Frere in the Eastern Cape, Nelspruit in Mpumalanga and Klerksdorp in the Northern Province (Operation Smile South Africa, 2012). In view of the role of NGOs in South African cleft care, the motivation for sustainable funding is particularly important. Finally, cleft care is also provided within the private healthcare sector of South Africa.

A lack of collaboration and communication between the various cleft care centres, differing treatment regimens and a paucity of research to support evidence-based practice results in a lack of standardization of services in the country. There is also no national database of clefts in South Africa. Cleft care in South Africa faces a number of challenges, which may preclude service providers from realising the recommendations laid down by ACPA (2009). With regard to early diagnosis, in the private healthcare sector many clefts particularly involving the lip, are now diagnosed in the prenatal period. In the public sector however, there are seldom sufficient professional resources or adequate equipment available for prenatal assessment to be available. While the diagnosis of a cleft should be followed up with genetic counselling, due to the history of healthcare in South Africa, this ideal is unfortunately not feasible in the foreseeable future. In fact, genetic counselling services in South Africa are seriously lacking and even face imminent collapse because of the decline in availability of training and employment in the field (Wessels, 2013).

While ACPA (2009) recommends the early provision of information in an appropriate language, this may provide a significant challenge in South Africa where there are 11 official languages. The majority of specialists are Eurocentric (Levin, 2006) while many of the patients may not have English as their home language. Working through an interpreter might

be a solution but efficacy may not be guaranteed (Lynch, 2011). Although surgery may be available through the public and private healthcare sectors, and through NGOs, treatment for other aspects of the condition, including orthodontics, speech therapy, ENT and psychosocial intervention may not be available, because of a shortage of such professionals in South Africa.

Another challenge in cleft care in South Africa pertains to the diversity of cultural beliefs. Louw, Shibambu and Roemer (2006) stress the importance of professionals having insight into their patients' personal and cultural characteristics, as these may be significant in the families' approach to accessing medical care and following professional recommendations. They also point to the educational level and language background of the patients in accessing information, asking questions and participating in decision-making. Written material is seldom available in African languages, and with a diversity of languages and cultures that exists in Africa, it is common to find a mismatch in the medium of information sharing between the professionals and their patients.

Dagher and Ross (2004) report that eight out of every 10 Black South Africans rely either solely on traditional medicine, or in combination with Western medicine. In their study, they found an inherent conflict between the scientific paradigm of Western-trained practitioners, and the magico-religious paradigm of traditional healers. There were wide differences with regard to opinions on the causes of clefts, the treatment offered, the general training they had received in the field, and their willingness to collaborate with one another. They highlighted the need for workshops to be held for traditional healers so as to provide them with information that could enable them to contribute more to primary health care.

With regard to record keeping, not all of the records stipulated by ACPA (2009) are available in the South African setting. Greater rigor is needed for professionals to keep adequate records that are available to other members of the team. The Human Sciences Research Council of South Africa (HPCSA) (2002) stipulates that medical practitioners and dentists are obliged to keep patient records which include the time, date and place of every consultation and their management, as well as details regarding referrals to other specialists. Records are required to continue the diagnostic process and ongoing management of the patients, to be able to conduct clinical audits, to promote good clinical practice and to be used in research. This ethical standard is echoed by the South African Speech Language and Hearing

Association (SASLHA) (2008) which states that healthcare practitioners should maintain accurate and up-to-date records in order to maintain a professional practice.

Of the South African CLP teams mentioned above, the majority have reported that they follow a multidisciplinary approach (Dekker, 2007) while less than a third reported that they follow an interdisciplinary approach. (A more detailed discussion on various types of team work appears later in this chapter). Five teams out of seven have reported that they meet on a regular basis, but in no cases did these meetings include the parents and patients. The team in this study started as a multidisciplinary CLP team and was established in the private health care sector in Johannesburg in 1980 (L. Chait, personal communication, July 1, 2014) with infrequent face-to-face meetings of the team members. During the period from 1980 up to the time of this study, a period of over 30 years, there has been noticeable continuity of service provided by the professional team members, that is, two plastic surgeons, four ENT surgeons, two orthodontists, four speech therapists, three audiologists and one social worker (L. Chait, personal communication, July 1, 2014). This is in contrast to the high turnover of staff that exists in the public sector (Mdindela, 2009).

For several years prior to 2006, some funding had been available from private funders, purely for the purposes of providing surgery for patients with CLP. In 2006 additional funding became available to sponsor patients who were not on medical aid, and who had previously had access only to public healthcare facilities. This funding enabled this population of patients to access not only surgery, but also speech therapy, audiology and counselling within the private healthcare sector, at no cost to themselves.

At this juncture the team adopted an interdisciplinary nature by introducing a regular combined clinic of professionals and parents. All of the team members had private practices where they consulted the patients and their families individually. They made their own appointments, some employing their own administrative staff, and they kept their own records. In the case where any of the team members felt it was appropriate and necessary to discuss the treatment plan of patients with the whole team, they would then refer those patients to the combined clinic. Written reports from individual consultations with the plastic surgeons and the speech therapist were available at the combined clinic. In order to provide an appropriate amount of time for a team screening evaluation, and team discussion on the plan of treatment, the team decided that a maximum of six patients would attend the

combined clinic on a given day. This process frequently resulted in cross-referral to other members of the team.

Noar and Orth (1992) consider the advantages of a multidisciplinary team approach as providing an opportunity for team members to coordinate the timing of surgery, orthodontic and speech therapy, for patients to discuss their concerns with all the relevant professionals, for the professionals to share ideas, and to promote research in the field. A combined clinic, where professionals and patients meet together provides a platform to enhance all of these attributes.

- **Evaluation of cleft care**

The level of parent satisfaction with cleft care seems to begin at the time of the diagnosis of the cleft. It reflects both the timing and manner in which the diagnosis is conveyed, and what immediate help the parents receive in terms of information and emotional support (ACPA, 2009; Nelson & Kirk, 2013). Once parents are over the initial shock of hearing the diagnosis, they want to be assured that help is available, accessible and affordable, and that the condition is 'fixable'. Feeding is the first challenge faced by new parents of an infant with CLP, hence early intervention by a team member to advise them in this regard is essential. As parents are informed of the short term and long term management of their child, which may include surgery, speech therapy and orthodontic treatment, they may be reassured if they feel confident that they are in good hands (Peterson-Falzone et al., 2010).

Parental trust in the team is enhanced by the knowledge that the professionals are competent and have treated many other children like their own. They want to feel that their child is being treated holistically and that everyone involved will cooperate with one another with regard to the timing and nature of the management of the cleft. Parents also want the reassurance that their own feelings and opinions regarding the cleft are important and taken seriously (ACPA, 2009).

Several stages along the timeline of the child's development may be extremely stressful for the parents, some directly related to the cleft, and others related to milestones in the child's life, as the *chronosystems* described by Bronfenbrenner (1997). These may include the discovery or first visualisation of the cleft, feeding difficulties, times of surgery, receiving speech therapy, starting school, socialisation, dealing with teasing, and undergoing

orthodontic treatment. At these times, parents may need psychological support either through the means of formal counselling or through more informal contact with other parents in order to cope. Naturally, their ultimate feeling of satisfaction and optimism for the future unfolds as they observe the results of treatment leading to their child having an acceptable aesthetic appearance, normal speech, and the ability to socialise and be educated so that he/she can lead a normal adult life (ACPA, 2009).

For the purposes of promoting best practice in healthcare generally, and in team management specifically, evaluation of the service is important and needs to be built into the monitoring process. Johansson et al. (2002) highlight the importance of patient satisfaction as a significant indicator of the quality of health care. In order to maintain and increase patient satisfaction, the quality of health care must be defined, measured and evaluated. They point out that the patient who is satisfied is more likely to adhere to treatment and advice that he/she receives from the health care professionals, to return for treatment and to recommend the service to others.

Noar and Orth (1991) explored the concerns of patients with CLP and their parents. Both the patients and their parents completed a questionnaire investigating their perception of the patients' facial appearance and speech, social and emotional aspects and the success of the specialists that had been involved in their treatment. As the age range of the patients was 16 to 25 years, treatment, including orthodontics, had been for the most part completed. Patients and their parents were found to be generally satisfied with their treatment, and especially with their facial appearance and speech. There were specific aspects which concerned both groups regarding their nose, lip, their profile, speech and teeth, however there were discrepancies between the two groups regarding the social and emotional effects of the cleft. This study was useful in that the perceptions of both parents and patients could be explored and compared, as they showed some inconsistencies between the two groups. Including only closed-ended questions in a questionnaire may have been limiting however, as they did not capture richer information that may have been gained by using open-ended questions or an interview format.

Nelson and Kirk (2013) describe the characteristics of a CLP team that contribute to a sense of trust in the team and result in their satisfaction of the service provided. Professionals should demonstrate expert knowledge and technical competence resulting from a high level of training and experience. They should have good communication and interpersonal skills.

They should demonstrate the ability to show a sense of caring and concern for the child and a sensitive and warm interpersonal manner with the family. They should continue to provide consistent care for the child over a long-term period of time.

Nelson and Kirk (2013) found that parents require specific information about CLP, and the impact it would have on their child. The information includes what future treatment would involve, how to deal with feeding, and how to explain the condition to others. Some parents require more detailed information regarding surgical procedures, the risks involved, the postoperative care that will be required, the immediate consequences of surgery, as well as the reasons for any cancellations of planned surgery. Information provided to parents may need to be in oral or in written form or both, depending on the needs of the family.

Parents become dissatisfied with services if they experience restricted access to services, delayed referrals, a poor coordination of appointments and inadequate communication between practitioners. A single point of contact with the team is needed, particularly when the management of the child is long-term, and the multidisciplinary team is large (Nelson & Kirk, 2013).

Studies investigating the perspectives of patients, parents and professionals on aspects of cleft care have generally taken the form of a structured questionnaire, completed either in a face-to-face or telephonic interview by a qualified interviewer unrelated to the team of professionals treating the patient (Paynter, Jordan & Finch, 1990; Paynter, Edmonson & Jordan, 1991; Paynter, Wilson & Jordan, 1993; Louw et al., 2006; Austin et al., 2010; Nelson & Kirk, 2013). Knapke, Bender, Prows, Schultz and Saal (2010), in their study investigating parental perspectives of children born with CLP, conducted telephonic interviews with parents, which included closed-ended and open-ended questions so as to allow the participants to talk about their experiences. In some studies, questionnaires were mailed to participants (Noar & Orth, 1992; Pannbacker & Scheuerle, 1993; Jeffery & Boorman, 2001). Jeffery and Boorman (2001) point out that a postal questionnaire eliminates any interviewer bias and is a cost-effective method in evaluating parent perceptions of cleft care, but that this method relies on the reliability of the parents' memory.

As previously indicate, there is an understandable paucity of literature on multidisciplinary cleft palate teamwork in Africa where there are few multidisciplinary teams, but this is the case even in South Africa where several multidisciplinary teams exist. In a Nigerian study a survey involving cleft palate practitioners was carried out (Akinmoladun & Obimakinde, 2009) indicating that interdisciplinary cleft care is still in its infancy in that region. In South Africa, Louw and Barnard (1995) conducted a questionnaire survey exploring parents' perceptions regarding the service delivery specifically by the speech-language pathologist on the Cranio-Facial Deformities Team of the Department of Maxillo-Oral-Facial Surgery at the University of Pretoria. Two further studies in South Africa have been conducted, one describing the existing cleft palate teams in South Africa (Dekker, 2007) and the other aimed at facilitating cleft palate team participation of culturally diverse families in South Africa (Louw, Shibambu & Roemer, 2006). To the researcher's knowledge, no African-based literature which has focused on the evaluation of the service provided by an interdisciplinary cleft palate team based on the experiences and perceptions of the parents has been published.

In South Africa, training programs exists for all the professions in the CLP team, as do multidisciplinary CLP teams. There is the potential to improve services in cleft care, by upgrading them to interdisciplinary teams with more favourable outcomes. There is therefore a value in evaluating cleft care in South Africa within a team setting.

Theoretical framework

(a) Collaborative Teamwork

A "team" as defined by Lorimer and Manion (1996, p. 15) is "a small number of people committed to a relevant shared purpose, with common performance goals, complementary and overlapping skills, and a common approach to their work". Körner (2009) points out that in the field of medical rehabilitation, a team brings together different professionals, each with their own assessments and evaluations, with the objective of obtaining a holistic view of the patient's problems. Choi and Pak (2006) have highlighted the increased emphasis on teamwork involving multiple disciplines in health research, health care services, health education, and health policy. Funding agencies are also calling for research that involves

multiple disciplines. These authors describe three different levels of teamwork, namely multidisciplinary, interdisciplinary and transdisciplinary teams.

"**Multidisciplinarity** draws on knowledge from different disciplines but stays within their boundaries" (Choi & Pak, 2006, p. 351). In a multidisciplinary team, the team members therefore work alongside one another but not as an integrated group. Within the context of a CLP team the multidisciplinary team consists of a group of professionals from various disciplines working independently in the evaluation and treatment of patients, with little communication and interaction between the team members (Kummer, 2014).

"Interdisciplinarity analyses, synthesises and harmonizes links between disciplines but stays within their boundaries" (Choi & Pak, 2006, p.351). Therefore in an interdisciplinary team, the members of the team work jointly and integrate their knowledge, although they still maintain their own identity in addressing a particular problem. Kummer (2014) describes the interdisciplinary CLP team as involving greater collaboration, interaction, communication and cooperation among the differently specialists, resulting in a joint plan of care, so that the approximate treatment timelines can be outlined for the patient and the family.

"Transdisciplinarity integrates the natural, social and health sciences in a humanities context, and transcends their traditional boundaries" (Choi & Pak, 2006, p. 351). In a transdisciplinary team the team members share their knowledge and skills with each other, which leads to a merging of roles. Through trust and mutual confidence, they adopt a more holistic approach, and accept that each of the other team members can do more than they were trained to do (Kessler, 1999). Within a transdiciplinary CLP team the members truly understand each other's disciplines allowing them to see the 'big picture' to the ultimate benefit of the patient (Kummer, 2014). Shprintzen (1995) stresses the desirability of CLP team members learning about one another's priorities, as it allows them to make better treatment recommendations.

Choi and Pak (2006) propose that the terms 'multidisciplinary', 'interdisciplinary' and 'transdisciplinary' should be used to describe multiple disciplinary approaches to varying degrees on the same continuum, but that if the exact nature of the multiple disciplinary approach is not known, the general term of 'multiple disciplinary' should be used instead.

Kummer (2014, p. 657) describes the characteristics of a professional CLP team as

- Promoting a better understanding by the team members of each other's discipline and how they related to the total care of the patient
- Encouraging an integration of the separate evaluations and recommendations given by the individual team members
- Encouraging communication between all the specialists and the parents
- Planning a treatment timeline for the patient and the family
- Encouraging patient adherence with recommendations as a result of team consistency and mutual support.

As the team members in the CLP team in this study were involved in a combined clinic, where they were able to get acquainted with one another's terminology, learn about one another's roles, and integrate their knowledge in providing a joint plan of care the patient together with the parents, the service of the cleft-lip and palate team will be henceforth referred to as an 'interdisciplinary team'. Körner (2009) in a study to compare the multidisciplinary and interdisciplinary team approach found that as a result of the greater collaboration that takes place within an interdisciplinary team, the interdisciplinary teams reached consistently better results and are more effective than multidisciplinary teams. She concludes therefore that measures should be taken to transform teams from a multidisciplinary to an interdisciplinary approach.

Cohen and Bailey (1997) provide some useful definitions in their model of what makes teams work. Team effectiveness begins with the *task design,* which refers to those features of the team that can be directly manipulated by the members of the team to create the conditions for effective performance. Its *task features* are characterised by the interdependence of team members who have specialised knowledge and expertise. The *team composition* indicates the size of the team, the definition of its members, the extent of their involvement and their stability. The *team processes* include communication, collaboration, coordination, conflict, leadership, decision-making and participation within a combined clinic. The effectiveness of the team is also influenced by the team's own *psychosocial traits*. These include their cohesion, norms, efficacy and effectiveness in problem-solving. *Team effectiveness* comprises both objective and subjective outcomes. The *objective outcomes* include the patients' functional status and satisfaction, the team's clinical quality of care as well as organisational outcomes such as cost effectiveness. The *subjective outcomes* pertain to the

team's own perceived outcomes and their perceived effectiveness that is their well-being and willingness to work together in the future.

Mickan and Rodger (2005) have proposed a Healthy Team Model based on the experiences of health care practitioners who have worked in various health care teams. They have identified six characteristics as a useful way of evaluating effective health care teams. These general principles are applicable not only to any health care teams but also to cleft palate teams in developing countries. These include:

1. A well-defined and forward-looking purpose, which is relevant to patients and the organization.
2. Specified goals for the team in order to achieve the patient outcomes.
3. Shared team leadership aimed at enhancing decision making, conflict management, sharing of ideas and information, equal coordination of tasks, provision of feedback on the activity of the team and promoting support in trust within the team.
4. Regular and efficient lines of communication including clear written reports.
5. Cohesion, which Mickan and Rodger (2005) describe as the comradery, trust and commitment that results from team members working closely together over a period of time.
6. Mutual respect, where team members developed an appreciation of one another's individual talents, beliefs and professional expertise and contribution. They also came to the belief that working in a team was the best way to integrate all these factors.

Effective teamwork in healthcare depends on intersectoral collaboration, which is defined by Ramduny (1998) as different sectors that work together to achieve a certain developmental goal. In the case of the team in this study, the different members of the team are mutually dependent on each other to achieve the common objective of providing a holistic management of the patient with CLP. The team itself however should be seen within the context of larger group of systems.

(b) Ecological Systems Theory

Bronfenbrenner's (1979) ecological systems theory is a useful approach to adopt with regard to intervention in health care. He describes five types of environmental systems or ecological contexts which influence human development, namely *microsystems, mesosystems, exosystems, macrosystems* and *chronosystems*. *Microsystems* constitute the immediate settings in which the child develops and which the child experiences directly, including the family, the school, and in the case of the CLP child, the cleft care centre where the child is treated. *Mesosystems* constitute the interrelationships that exist between the various *microsystems*, for example the interrelationship between the family and the hospital, the family and the day care, the family and the peer group and the family and the school (Bronfenbrenner, 1986). *Exosystems* are settings that have a bearing on the developing child, but in which the child does not play a direct role. These may include the parent's workplace and social network, the school board, the church council, the political system and other organizations that make decisions which affect the child's day-to-day life. The *macrosystem* refers to the cultures and subcultures, and includes the class, ethnicity, and particular society in which the child lives (Bronfenbrenner, 1979). In the South African context this would refer to such aspects as the child's ethnicity, socio-economic level and religious background. Finally *chronosystems* refer to the impact that a single life transition that takes place at a particular time, has on a family and on the child's development. Such life transitions include events that happen at a particular stage in the child's life such as starting school, parental, divorce and changes in family structure, relocation, and changes in the mother's employment conditions.

This paradigm promotes a holistic approach to cleft care, and moves away from the medical model which focuses only on the child with the cleft. In South Africa however, healthcare to a large extent still follows a medical model, and is not yet sufficiently family driven. The bio-psycho-social model is therefore known in theory but may not be sufficiently evident in practice. To achieve excellence in our intervention, it is necessary to consider how all these concentric circles of the various systems impinge on the child. The following discussion relates to the evaluation of such systems or programs of care provision.

(c) Program theory and evaluation

Rossi, Lipsey and Freeman (2004) recommend that before any program can be evaluated, the evaluator must ensure that the program is sufficiently conceptualized to be evaluable. They indicate that a program's evaluability involves three main activities: firstly, description of the *program model* with particular intention to defining the program goals and objectives; secondly, assessment of how well defined and evaluable that model is, and thirdly, identification of stakeholder interest in evaluation and the likely use of the findings (Rossi et al., 2004).

The evaluability assessment may result in the managers and sponsors of the program realising the need for change and improvement in the delivery of service, in the target population and in the intervention itself. Rossi et al. (2004) caution that if the policymakers or managers are not able or willing to institute change based on the evaluation, then the information gained is unlikely to contribute to an improvement in program performance. These authors describe three components of Program Theory namely *impact theory, service utilization plan and organizational plan*. Even though these terms are explained, the discussion is not exhaustive, as it is not the focus of the study. *Impact theory* implies the effect or impact that the program has on the target population, and whether the program is achieving its goals and objectives in bringing about change in social conditions. The program's *service utilization plan* focusses on how and why the recipients of the service will interact with the intended services and initiate the changes required to realize the impact it is designed to achieve, including the conclusion of the relationship when the service is no longer required. The program's *organizational plan* includes the financial resources, proper facilities and equipment, personnel with appropriate training and experience as well as administrative support, maintenance and political liaison that are required for the program to be able to operate in delivering the required service.

Rossi et al. (2004) suggest that a program may either be based on an *articulated program theory* or on an *implicit program theory*, depending on whether the program's theory is spelled out and documented and well understood by the staff and the stakeholders, or not. In order to articulate program theory, the boundaries of the program should be defined. This is achieved by identifying all the important activities, events and resources linked to the desired outcomes. The goals and objectives of the program need to be determined and documented. The program functions need to be described, including an assessment of the recipients' needs,

the appointment of a case manager, recruitment of referral agencies and the training of staff. The temporal sequencing of the program functions, activities and components must be coordinated in order to realise the expected outcomes of the program. In the case of an implicit program theory, the evaluator needs to describe the expectations inherent in the program's services and practices before it can be assessed.

Rossi et al. (2004, p.16) define program evaluation as "the use of social research methods to systematically investigate the effectiveness of social intervention programs in ways that are adapted to their political and organizational environments and are designed to inform social action to improve social conditions". According to Fouché (2011) at the beginning of the 20th century rigorous social research methods emerged for assessing social programs in a variety of areas. In the last 25 years, evaluation methods applied to public and private investments, process, practices and programs have become more formalised. Program evaluation originally focused on finding out if a program was effective or not. Evaluation research has more recently been directed by the need to focus on value for money, the allocation of scarce resources, accountability and improved service delivery.

Fouché (2011, p. 453) describes the threefold purpose of evaluation which includes:

1. **Formative evaluation** includes a needs assessment, which evaluates whether a new program is needed at all, or whether an existing program should continue. It also includes an evaluability assessment which determines whether a program meets the preconditions to be evaluated. Rossi et al. (2004) define these preconditions of the program as having well-defined and feasible goals and objectives, a plausible change process in its design, well-defined members of the target population, well-defined and sufficient components activities and functions and adequate resources.
2. **Process evaluation or program monitoring** is aimed at improving the program by getting feedback on how it is operating. It is an ongoing activity, and allows for problems to be addressed as they are identified. It allows for a successful program to be maintained and an unsuccessful program to be terminated.
3. **Summative evaluation** examines the impact or outcome of the program and therefore allows the communication of best practice to others involved in similar programs. It refers to the impact or effect that the program has had on its target population, and whether change has occurred as a result of the program. Summative evaluation may

also refer to efficiency evaluation, that is, whether the program has had a cost benefit and is cost-effective.

Rossi, et al. (2004, p.18) identify a number of stakeholders in the field of program evaluation, including policymakers, funding organization, planners, program manager, taxpayers and program clientele, who have a need to distinguish between worthwhile social programs and ineffective ones.

Rossi et al. (2004) suggest that process evaluation may either take the form of a once-off assessment, or a regular event. The latter forms more of a process monitoring evaluation. Furthermore process evaluation may either be done by an evaluator within the program or by somebody external. The process evaluation may be conducted for the purposes of providing feedback to the managers, to the sponsors or to the decision-makers. It may stand alone or form part of a broader evaluation such as impact evaluation.

Shaw, Semb and Nelson (2009) suggest that on the whole treatment protocols with regard to the surgical techniques, their timing and sequencing, as well as the role of oral orthopaedics, orthodontics and speech therapy are frequently a function of the disappointment resulting from former practices rather than the firm evidence that a procedure has been found to be empirically successful. Sackett, Rosenberg, Muir, Haynes and Richardson (1996) define evidence-based practice (EBP) as the integration of clinical expertise with the best available scientific evidence from systematic research. Both are necessary to provide quality care to the patients. For this reason, the present study incorporated information gained from both the parents/caregivers regarding their experiences and perceptions of a service provided for their children with cleft palate, and the treatment protocol followed by the professional team.

As this study involves an exploration into the value perceived and experienced by parents/caregivers of a service team for patients with CLP, the preceding theoretical background regarding collaborative teamwork, the theory and evaluation of programs as well as background on ecological systems within which the patients, the families, the treatment team and the community interact has been provided.

Rationale

Besides the particular composition of a CLP team there are certain of its unique characteristics worth highlighting. Firstly, the involvement of the team may begin in the prenatal stage, when a cleft is diagnosed in utero. The parents may be familiarized with the composition of the team and the role of each team member even before the birth of the infant. Thus teamwork in the CLP setting may begin far earlier in the patient's life than would be the case for other healthcare teams. The involvement of the team may be intensive and long term; but with timeous and effective management, the outcome may be positive for the individual in terms of socialization, education and employment opportunities. On the other hand, inadequate care may result in an individual who is communicatively impaired, educationally handicapped, socially isolated and unemployable.

In order to maintain and enhance standards of healthcare, it is important to evaluate professional team services, based on the levels of satisfaction and psychosocial well-being of patients with CLP (ACPA, 2009). Although there are a number of studies that have been carried out internationally on cleft palate teams, and patient satisfaction with treatment, there is a paucity of such studies in Africa. In South Africa several CLP teams exist, however no research to date has ever addressed the evaluation of outcomes. Choi and Pak (2007) warn that if the success of interdisciplinary work is not properly evaluated, this can lead to that success being hampered, as team members may become demotivated if they are not convinced that working within the team is better than working on their own.

The purpose of this study was to explore the experiences and perceptions of the parents/caregivers of the patients attending the combined clinic of a CLP team, based in the private health care sector in Johannesburg South Africa, so that best practice models and quality care can be promoted.

Research Questions

Against the background of a paucity of research into the evaluation of CLP teams and the service they provide, particularly in developing countries in Africa, the following research questions were formulated for this study:

- What are the experiences and perceptions of the parents/caregivers of children with CLP who have attended the combined clinic of an interdisciplinary CLP team based in the private health care sector of Johannesburg?
- What is the treatment protocol followed by this particular team of CLP specialists?
- How can an exploration of these experiences and perceptions inform best practice models for this and other CLP teams?

Conclusion

This chapter locates the research within the broader context of cleft care in Africa, and more specifically within South Africa. Furthermore, it provides a theoretical framework for the study, and a literature review on CLP, its incidence, its effect on communication, appearance, feeding and socialization, and its management by a team of professionals. The rationale and the research questions for the study are outlined, and are expanded on, in the Methods chapter.

CHAPTER 3

METHODS

Overview

This chapter describes the methods used in this research study. It outlines the research aims, the null hypothesis, the research design, the research setting and procedures, the participants, the data collection and analysis methods. It considers factors that affect reliability and validity, and ethical aspects of the research.

Research Aims:

Main aim:

To record the experiences and perceptions of parents/caregivers of children with CLP, who utilised the services of a cleft palate clinic, located in the private health care sector of Johannesburg.

Sub aims:

The following sub-aims attempted to operationalise the main aim:

- To tabulate the treatment protocol followed by this particular team of CLP specialists, as indicated in the responses of the participants
- To record the treatment protocol of this CLP team based on the record review
- To make recommendations for best practice in this clinic and other CLP teams.

Null hypothesis:

The null hypothesis is defined by Babbie and Mouton (2001) as the assumption that there is no relationship between two variables in the total population. The null hypothesis for the present study is as follows:

- There will be no positive experiences or perceptions described by parents/caregivers of patients attending an interdisciplinary cleft palate team in the private sector in Johannesburg.

- There are no recommendations that can be made on the basis of the evaluation of this CLP service which could inform best practice.

Research Design

The present study was exploratory in nature, using a quantitative approach with some qualitative features described. The decision was taken to describe the study in this way after consultation with several research and mixed methods experts. It was non-experimental as the independent variable was not manipulated, and there was no randomisation or control group. A concurrent nested design as described by Creswell (2003) was used, whereby the data collected was primarily quantitative, by means of a questionnaire consisting of closed ended questions; and simultaneously, qualitative data was embedded in the survey, comprising open ended questions, so as to enrich the descriptions of the participants, and provide reasons for their quantitative responses.

Ritchie and Lewis (2003) point out the advantages to combining qualitative and quantitative research methods, in yielding different types of knowledge about the research topic, provided that the two methods and the data they generate are clearly delineated. While qualitative research would address the nature of a particular field, that is, the how and why, quantitative research would be concerned with the measurements of the levels of particular variables. As each method offers a different epistemological viewpoint of the world, a combination of these two approaches can be very useful in understanding the data (Sandelowski, 2000).

While it may have been useful to gain information from the professional team members regarding their own perceptions and experiences of the clinic, this may have posed ethical issues as any negative perceptions among the team regarding colleagues would undermine the team process. This was therefore not the focus of the study. Furthermore, as the researcher was also a member of the professional team, care needed to be taken to prevent an element of researcher bias into the responses of the participants. This was addressed by having a research assistant, that is, another speech therapist obtaining permission telephonically from the participants before sending them information about the study. A face-to-face interview may have allowed the participants to speak freely about their experiences and perceptions, and to ask for clarification, which may be considered as one of the limitations of the method. A questionnaire method of data collection was therefore used, so as to reduce researcher bias,

and eliminate personal contact with the researcher, whom many of the participants had previously consulted as their child's speech therapist. It was therefore decided that the most appropriate approach would be a questionnaire with a quantitative focus which included some open ended questions, where the respondents were given the opportunity to express in their own words, their feelings, opinions, perceptions and experiences pertaining to their clinic visits and intervention.

Setting

The CLP clinic in the present study aimed at providing interdisciplinary treatment of CLP, velopharyngeal dysfunction and other associated craniofacial disorders, within the private sector of health care in South Africa. This is the only known CLP clinic in South Africa affiliated to a private hospital and is based in Johannesburg. Prior to 2006, this particular team had been running for over three decades as a multidisciplinary team including surgeons, speech therapists, an orthodontist and an ENT surgeon. The same plastic surgeon headed the team from its inception, and there was a very low turnover of staff amongst the other professional team members, indicating a consistency of staff. For the six year period 2006 through to 2012 the CLP team received funding from private funders. Patients who did not have access to a private medical aid scheme, could nevertheless access the services of this team, as a result of this funding scheme. The team composition (Cohen & Bailey, 1997) comprised nine professional team members from six professional disciplines, including those of Plastic Surgery, Orthodontics, ENT Surgery, Speech-Language Pathology, Audiology and Social Work. Where necessary, the team referred to professionals in the fields of Genetics, Paediatrics, Maxillo-Facial Surgery, Dentistry, Radiology, Nursing, Psychology, Education and others. At the end of this six-year period, the funding was terminated, and patients who were not on medical aid were given the option of returning to the public sector for cleft palate management.

Most of the patients were referred initially to the Plastic Surgeons through several avenues, including paediatricians in private practice, the team members of the CLP clinic, friends and family of the patients, and through the clinic's sponsors. At a monthly combined clinic the following professionals consulted with the patients and their families at a single venue: two Plastic Surgeons, an Orthodontist, two ENT surgeons, two Speech-Language Pathologists,

two Audiologists and a Social Worker. Patients were referred to the combined clinic for a screening assessment and a team discussion by the individual specialists, at least one of whom they had previously consulted privately. A maximum of six patients and their parents were booked to attend the combined clinic on any given day. The clinic took place in a large room in a private hospital. Chairs were arranged in a circle to accommodate all the team members, the parents and the patients. The patients were not charged for attending the combined clinic, and nor were the professional team members remunerated for attending the clinic. Before each patient left the clinic, a follow-up appointment was made.

As a result of face-to-face meetings between the team members, the patients and their families in the combined clinic, the characteristics of a professional CLP team described by Kummer (2014) could be achieved. Thus a better interdisciplinary understanding was promoted, evaluation and recommendations could be integrated, communication could be enhanced between specialists and parents, treatment could be planned, and patient adherence with recommendations could be encouraged.

A holistic perspective of the patient was paramount and the clinic endeavoured to achieve this. The team members all contributed to the production of an information booklet for parents on CLP which could be supplied at their first consultation. A second information booklet on feeding for the CLP infant was also compiled and supplied to parents at the time of the diagnosis.

ACPA (2009) recommends that treatment outcomes of a cleft care facility should be regularly evaluated. Rossi et al. (2004) suggest that evaluation should be conducted for the purpose of providing feedback to the managers, the sponsors and decision-makers. No formal evaluation of this clinic had however ever been undertaken since its inception and therefore no information was available of its relevance or effectiveness.

Participants

- **Sampling method**

Purposive sampling was used, so that a sample of participants that had specific characteristics to be studied could be selected (Maxwell & Satake, 2006). Sampling also incorporated a convenience technique (Marshall, 1996), as patients were included if they were contactable and available. Furthermore as the questionnaire was only supplied in English, it was anticipated that only those parents/caregivers who are proficient and literate in English, would complete the questionnaire. The sample for the questionnaire was used for conducting a review of the medical records of the participants' children with cleft palate.

- **Criteria for selection**

The sample involved the following inclusionary and exclusionary criteria:

- The participants included the parents/caregivers of patients who had attended the combined CLP clinic at least once. This would allow for the maximum possible number of participants to be included in the study.
- Each participant's child (the patient) had been diagnosed with CLP or cleft palate. Patients with clefts who have other congenital abnormalities in addition to the CLP were included but patients with isolated cleft lip were excluded as they most often do not require the services of a team.
- The parents/caregivers were selected if their children who presented with CLP were under the age of 12 years, that is, in their pre-primary and primary school years. Thus they were still within the age range where the parents could recall the details of early management they had received by the specialists, and at the combined clinic. For the purpose of convenience, the date of birth of the patients selected included those falling on or after 1st January 2000.

- **Description of participants**

The demographic characteristics of the participants and for the participants' child (the patient) are reflected in Table 2 below:

Table 2: Demographic Characteristics

	Number of patients	Percentage (%)
Total participants who returned questionnaires	**33**	
Participant's relationship to patient		
Biological mother	29	88
Adoptive mother	1	3
Father	2	6
Grandmother	1	3
Gender of patient		
Male	25	76
Female	8	24
Language group of patient		
English	17	52
Afrikaans	9	27
One of the official African languages (Sesotho, IsiZulu, Setswana)	5	15
Other (Language not indigenous to South Africa)	2	6
Ethnic group of patient		
White	18	55
Black	8	24
Asian	4	12
Coloured	3	9
Proximity to clinic		
Greater Johannesburg	24	73
Gauteng Province	3	9
Other provinces of South Africa	3	9
Other African States	3	9
Funding of patient		
Medical aid	19	58
Funded by the sponsors	14	42
Diagnosis of patient		
Unilateral cleft lip and palate	16	48
Bilateral cleft lip and palate	10	30
Isolated cleft palate	7	21
Patients with additional congenital abnormalities/syndromes	12	36
Time of Diagnosis of the cleft		
Prenatal	7	21
Postnatal	26	79
Number of visits to the combined clinic		
Once	16	48
Twice	7	21
Three times	7	21
Four times	2	6
Five times	0	0
Six times	1	3

Data collection: Procedures and measures

The qualitative method used in this study comprised open ended questions which enabled the participants to express their experiences and perceptions that could not be quantified, while the quantitative method comprised two separate sections, namely a questionnaire and a review of medical records. A background on how the questionnaire and the record review were compiled for this study is described below.

- **Questionnaire**

The first phase of the study involved a questionnaire, a method appropriate documenting self-reporting beliefs relating to specific questions (Newman, 2000). It is a cost effective method of evaluation, which affords the respondents more time to think about their responses in the comfort of their own environment (Maxwell & Satake, 2006) although it is limited by its dependence on the memory of the respondents (Jeffery & Boorman, 2001) and may have low response rate.

In this study, a 32-item self-administered questionnaire (see Appendix F) was completed by a group of parents/caregivers of children with cleft palate, who had attended the combined CLP clinic, in order to explore their perceptions and experiences of the clinic.

The following aspects of their experiences and perceptions of the participants were explored in the questionnaire:

- their experience regarding the service provided by the Clinic
- their feelings about the cleft and its management
- their expectations for the future
- their suggestions on how the service can be improved.

The questionnaire was formulated applying guidelines by Neuman (2000) and Delport and Roestenburg (2011). The content of the questionnaire was adapted from the following sources:

a. the model suggested by Paynter, Wilson and Jordan (1993) in which they interviewed families of children with cleft palate using a questionnaire in order to assess their opinion of the team, and to identify variables that may interfere with patient adherence.

b. the questions used in a similar questionnaire by the team at Queen Victoria Hospital, East Grinstead, UK (Jeffery & Boorman, 2001) which included the following:
    - The parents' awareness of the individual team members present, who they felt did not need to be there, and who else should have been there
    - The parents' preference for a combined clinic as opposed to a separate consultation
    - The parents' level of satisfaction with the CLP service
    - The ease with which parents talked about their concerns
    - The parents' feeling of involvement in decision making
    - The parents' knowledge about clefts and their treatment
c. the *Cleft Evaluation Profile (CEP*) developed by the Royal College of Surgeons Cleft Lip and Palate Audit Group (Turner, Thomas, Dowell, Rumsey and Sandy, 1997) to explore the attitudes of parents/caregivers to the cleft.
d. a questionnaire survey by Noar and Orth (1991) which investigated the attitudes and concerns of patients with CLP and their parents.

Structure of the questionnaire:

The following areas were explored in the questionnaire:

a. Demographic information:

The demographic information gained from the questionnaire firstly ensured that the respondent who completed the questionnaire was the individual most familiar with the CLP clinic. Secondly, it was aimed at gaining information about the cleft palate patients who had attended the clinic. Thirdly, it allowed the respondent to answer non-threatening questions first, and more sensitive questions later (Delport, 2005). Furthermore, the demographic information included whether the patients funded their own cleft palate management, as opposed to those whose cleft palate management was funded by a sponsor. Were it not for the funding available, the latter group may have sought treatment in the public health sector. The respondent was asked about their relationship to the patient. The question included the patient's date of birth, gender, type of cleft and language background. Bordens and Abbott (2011) point out that demographics may be used as predictor variables during data analysis, in that correlations may be drawn between the participants' characteristics and their predicted

responses to the survey. Finally, the demographic information aimed to ensure that the inclusionary and exclusionary criteria were maintained.

b. Marketing of the service:

The purpose of this question was to identify sources of referral to the clinic, to assess how well known the services offered by the team were to potential referral agents, and to make suggestions on how marketing of the team can be improved. The participant was asked to identify who originally referred him/her to any one of the team members. Information regarding the source of referral may provide the team with guidelines for increasing the volume of referrals from these and other sources.

c. Accessibility to the combined clinic:

Respondents identified the patients' residential area, in terms of whether they resided in the greater Johannesburg area, within the wider province of Gauteng, in one the other provinces of South African province, or whether they had come from a neighbouring African state. This provided information about the catchment area of the clinic and an appreciation of the effort taken by the patients to attend the clinic, in order to explore the service this clinic provides to the broader community.

d. Comparison between individual consultations and a combined clinic:

The questionnaire explored the parents'/caregivers' experience of meeting the team members in a combined clinic as opposed to private consultations in their own practices. It also explored their awareness of each specialist in the team, and whether they have a preference for having more specialists or fewer specialists at the combined clinic, as well as their perception of the roles of the professionals in the process. It should be noted that attendance at the combined clinic was free of charge, while individual consultations were charged either to the sponsor, in the case of funded patients, or to the patients on medical aid, who would have received compensation from the medical aid, but who may also have had to pay for the excess themselves.

e. Evaluation of care at the clinic:

The questionnaire sought to determine the level of satisfaction of the participants with the level of care at the clinic. In addition to general satisfaction, it explored their experience of

the level of communication with professionals in the clinic and their inclusion as a participating team member.

f. Recommendations for an improved service:

The participants were given the opportunity to suggest ways of improving the current service to patients. Knapke et al. (2010, p. 148) stresses the importance of parents/caregivers being included in this process: "Giving parents the opportunity to express their concerns and offer the suggestions for enhancing their experiences with the healthcare professionals who treat their children is an effective way to empower parents and make them an instrumental part of the craniofacial team."

g. Perception of the cleft:

Question 29 in the questionnaire of the present study was comprised of a Likert Scale based on the *Cleft Evaluation Profile (CEP*) (Turner et al., 1997). Bryman (2008, p. 146) describes the Likert Scale as "a multiple-item measure of a set of attitudes relating to a particular area". Noor and Musa (2007, p. 292) describe the Cleft Evaluation Profile as "a reliable and useful tool to assess patients' level of satisfaction with treatment received for cleft lip and/or palate (which) can identify the types of cleft-related features that are most important for the patients." For the purposes of this study, the CEP was adjusted according to guidelines suggested by Shaughnessy, Zechmeister and Zechmeister (2000) in order to simplify the answering process for the South African population. It was thus adapted from the original 7-point rating scale ranging from 'very satisfactory' to 'very unsatisfactory', to a 5-point rating scale, which included an neutral category, with specific blocks labelled, '1 = very good, 2 = fairly good, 3 = neither good nor bad, 4 = not very good and 5 = not good at all'. The specific aspects of the cleft investigated followed those of Turner et al., (1997) but the wording in some cases was simplified. These included: speech, hearing, the teeth, the lip, the nose, breathing through the nose, the face and the bite. This Likert Scale will be referred to in this study as the "Happiness Index". Cronbach's Alpha yielded 0,69 for the reliability of this scale, indicating that it was adequate as a measurement tool (Howell, 2008).

h. Perception of future outcomes:

Question 30 in the questionnaire consisted of a second Likert Scale, which will be referred to in this study as the "Optimism Index" and was based on the parents/ caregivers' perceived

outcome for their child based on the parameters of appearance, speech, socialization (making friends) and education in 10 years. These parameters were adapted from a study by Noar and Orth (1991) although the older age group of their sample (16 to 25 years) is in contrast to the younger sample in the present study, where for example, orthodontic treatment had not yet commenced. Once again a 5-point rating scale included specific blocks labelled, '5 = very good, 4 = fairly good, 3 = neither good nor bad, 2 = not very good and 1 = not good at all'. Cronbach's Alpha yielded 0,83 for the reliability of this scale, indicating that it was good as a measurement tool (Howell, 2008).

Neuman (2000) points out the limitations of a self-administered questionnaire as a data-collection tool. The participants' limited knowledge of English and low educational levels may result in low return rates or inaccurate responses. As 48% (n = 13) were not first language English speakers, this may have been a factor influencing the accuracy of responses and the return rate. On the other hand, only one potential participant declined to participate because of her home language not being English. Neuman (2000) further found that even if a follow up reminder letter was sent, which added to the cost and time of data collection, response rates may still be low. The researcher cannot control the conditions under which the questionnaire is completed, or who completes it, nor see the participant's reactions to the questions, and verify the likelihood of an honest response. Even though this may be identified as a limitation, an introductory telephonic interview in the present study aimed to reduce these difficulties.

Although an initial cut-off date was stipulated in the information letter, this was later extended to allow for an increased return rate. The return rate was also affected by a local postal strike in the country, which lasted for six weeks. The research assistant made follow-up telephone calls to participants who had not returned their documents, so as to encourage a response and offer any assistance they might require. This resulted in some participants requesting documents to be resent, or sent to a different address.

- **Record review**

The second phase of the study involved reviewing the medical records of the patients who attended the combined clinic, as well as the records of the individual specialists in the team, including plastic surgery, ENT surgery, speech therapy and audiology (See Appendix G). It should be noted that due to the relocation of the Orthodontic clinic, the archiving of records

and the introduction of a new system of record keeping; no Orthodontic records were available for the record review (D. Mistry, personal communication, August 2, 2012). The Social Work records were also not reviewed, as the team Social Worker, for ethical reasons, could not grant permission for the records to be reviewed. Records therefore of the Plastic Surgeon, ENT Surgeon, Speech Therapist and Audiologist were reviewed.

The aim of the record review was to gather demographic information of the patients whose parents/caregivers consented to be participants in the study. It also provided the dates and procedures that were undertaken by the various professional team members on the patients. This information was therefore deemed to be independent of the participants' memory, understanding or interpretation of events. Medical records are considered to be authentic, valid and reliable. The advantages of using a document study as a research method include the relatively low cost and the possibility of studying inaccessible subjects, however the likelihood of such records being incomplete, unavailable or unorganized, and lacking in standardized format, may be a limitation of any study (Strydom & Delport, 2005).

The record review method for the present study was guided by the work of Paynter et al. (1991) who issued a questionnaire to CLP team members in the United States to assess the accuracy of information reported by parents and children. Their questionnaire provided useful aspects regarding the treatment the patients had received with regard to plastic surgery, dentistry, ENT surgery, audiology and speech-language therapy.

Procedure for the Record Review:

The **first** set of records reviewed in the present study were those of the Plastic Surgeon, as this was most often the first professional consulted by the parents/caregivers, and the professional service required in every case. The following information was obtained from these medical records:

- The classification of the patient's cleft: this was classified as a unilateral cleft lip and palate, a bilateral cleft lip and palate, a cleft of the velum and a cleft of the secondary palate.
- The presence of any other congenital abnormalities or the diagnosis of a syndrome.
- The date of the initial contact with the Plastic Surgeon in order to assess the success rate of early intervention.

- The dates at which the patients underwent surgery including: a lip repair, a soft palate repair, a hard palate repair, a fistula repair, secondary cosmetic surgery, a pharyngeal flap, columella lengthening or any other plastic surgery to the cleft, as well as simultaneous insertion of grommets.

The **second** set of records to be reviewed was those of Speech Therapy. The following information was obtained from these records:

- The date of first contact with the Speech Therapist, in order to assess the success rate of early intervention.
- The nature of the intervention including: home program with monitoring, detailed assessment and regular intensive speech therapy.
- The provider of the speech therapy intervention and whether this was the team Speech Therapist, or a speech therapist in the community.

The **third** set of records to be reviewed was those of the ENT Surgeons. The following information was obtained from these records:

- Whether or not the patient was treated by one of the team ENTs or by an ENT outside the team.
- The dates on which patients underwent Myringotomy and had grommets (ventilation tubes) inserted.
- The dates on which other procedures were carried out, and the nature of this intervention, for example tonsillectomy.

The **fourth** set of records to be reviewed was those of the Audiologists in the team:

- The dates when the following Audiological tests were undertaken were recorded: Pure Tone Audiometry, Tympanometry, Speech Audiometry, Otoacoutic Emissions, and Auditory Brainstem Audiometry.
- The category of Audiological diagnoses that were recorded: normal hearing; conductive hearing loss; sensori-neural hearing loss; mixed hearing loss; inconclusive results.
- The provider of Audiological management and whether this was by the team Audiologist, or at a practice outside of the team.

Finally, the records from the combined clinic were consulted in order to record the dates when patients consulted the whole CLP in a group. These records were also used to fill in gaps that existed in the medical records.

Research Procedure:

Figure 1 below lays out the chronological sequence in which the research procedure was carried out.

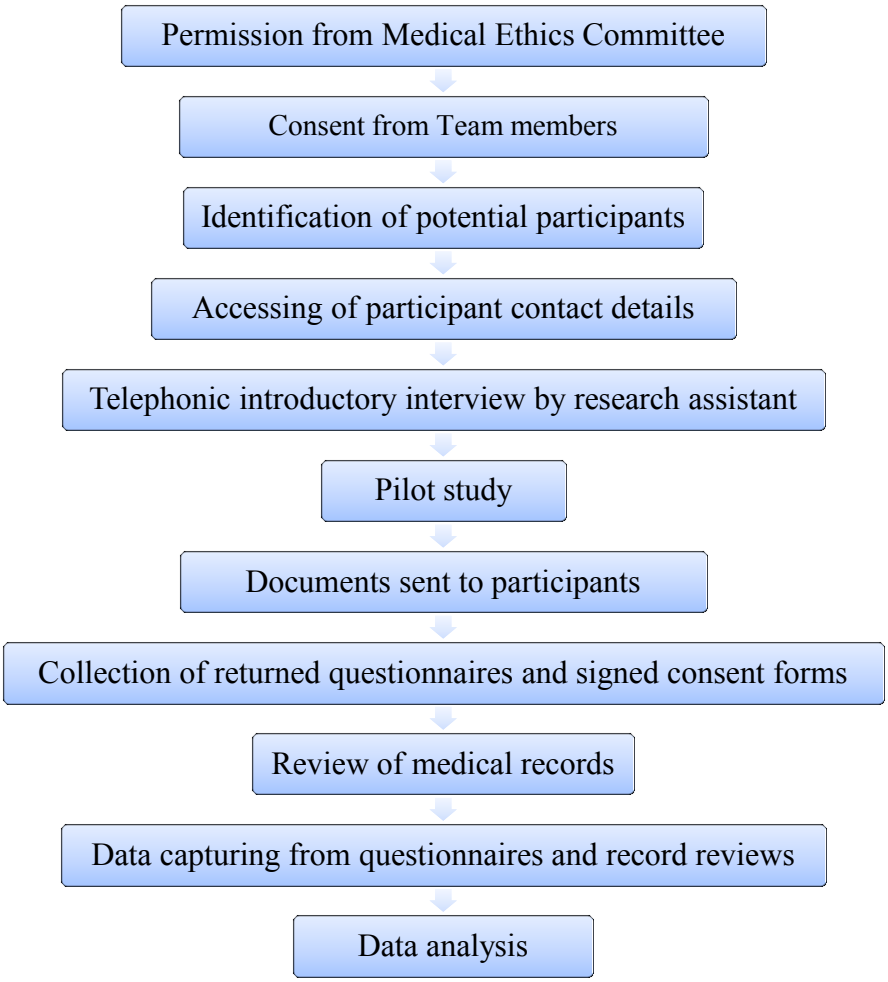


Figure 1: Sequence of study procedure

- **Consent from team members**

An information letter (Appendix A) describing the study was sent to the members of the team, and a consent letter (Appendix B) was obtained from the head of the team, granting permission for the researcher to contact the parents/caregivers of the patients and to gain access to their medical records.

- **Identification of potential participants and accessing of contact details**

As all the patients whose parents/caregivers were potential participants in the study attended the combined clinic, the researcher began by consulting the records of the clinic and listing all the patients who had attended during the period from its inception until May 2012. The patients who did not meet the inclusion criteria of the study, due to their age, or the type of cleft were excluded. Two patients whose age fell above the age range for the study were identified as possible participants for the pilot study.

In order to access the contact details of the potential participants, the researcher consulted the patients' plastic surgery records. As all of the patients had received surgery from the team Plastic Surgeons, these records were likely to be available for all the potential participants. Details were recorded that included the name of the parents/caregivers and their telephone numbers.

- **Telephonic introductory interview**

As indicated earlier, I as researcher was also one of the speech language pathologists on the CLP team, and had treated many of the patients. In order to reduce researcher bias, I was therefore not directly involved in the data collection process. This was important for the validity of the study. It also provided the opportunity for parents/caregivers to refuse the invitation to participate, without any negative consequences. While the information letter did identify the researcher, a research assistant helped to collect data from the participants. The research assistant was purposefully selected on the basis that she was a speech language pathologist, with experience in conducting research projects and she had the knowledge and experience of CLP. She was required to contact each of the potential participants

telephonically to conduct an introductory interview. For this purpose, she was provided with the following: a list of potential participants and their contact details, an interview guide (Appendix E) and a dedicated mobile telephone. All ethical parameters – as described in this chapter - were adhered to.

The purpose of this interview was:

- To confirm that the parent/caregiver whom she had contacted had attended the clinic. This would ensure that the questionnaire would be sent directly to the participant.
- To verify whether the potential participant was willing to receive the information letter, stressing that there was no obligation to participate.
- To establish the most appropriate means of sending the documents to him/her, (post, e-mail, fax, by hand) or to offer the option of answering the questions in the questionnaire telephonically.
- To confirm their contact details.
- To confirm that they were comfortable with completing a questionnaire in English, as it was not translated into other languages, so as to avoid extraneous factors that may have been introduced in translation. Boynton, Wood and Greenhalgh (2004) caution against friends, family members, or untrained healthcare staff acting as translators for questionnaires, as they may alter meanings through an attempt to clarify questions or protect the participants or themselves. Experience in the cleft palate clinic situation however has been that seldom have patients who attended required an interpreter, as they could communicate sufficiently in English. This indicated that a telephonic interview would not have substituted for a written completion of the questionnaire in the case where a participant was not a first-language English speaker.

The research assistant followed up telephonically with participants, who had agreed to receive the information, and from whom questionnaires had not yet been received, to encourage their participation.

- **Pilot study**

A draft copy of the questionnaire was circulated amongst the professional members of the cleft palate team for their comments and suggestions. Their views were incorporated in

adapting the style of the questionnaire. Rossi et al., (2004) point out the importance of engaging key stakeholders in the program evaluation, as this is likely to increase their understanding, their appreciation and the likelihood that they will make effective use of the findings of the research when these become available.

Prior to the main study, a pilot study was conducted with two of the participants who shared similar characteristics as those in the main investigation, except for the patients' ages falling less than a year outside the cut-off age for the patients in the study. Boynton (2004) stresses the value of piloting a questionnaire on the participants who are representative of the definitive sample. A pilot study enables the researcher to note how the participants react to the format of the questionnaire and the specific questions. It may highlight any confusion that may exist and whether any questions may need to be rephrased. The pilot study process should provide an indication of how long it takes to complete the questionnaire. It enables the researcher to plan and test a strategy for getting the questionnaires out to and back from the participants, and provides an indication of when it is appropriate to send out a reminder letter. Finally, possible pitfalls may be highlighted, such as addressing the questionnaire to the wrong participant, giving incomplete instructions or addresses and failing to enclose or attach all the documents.

The questionnaire was first piloted on a volunteer who was reported to have had a limited formal educational level and whose first language was not English. The questionnaire was completed verbally, as she was unable to read English. She was able to understand the questions when they were read to her in English, and they were not translated into her home language. This provided confirmation that the language used in the questionnaire was sufficiently simple to be understood by the participants. It was then piloted on two participants who were representative of the sample but not included in the main study. The pilot study provided a guide regarding the time it would take for the participant to return the completed questionnaire, and the extent to which the research assistant had to follow up before the questionnaire was returned. The pilot study confirmed that the questions did not require rephrasing to achieve a richer response (Boynton, 2004).

- **Documents sent to participants**

The information gained from the telephonic interviews and the pilot study was conveyed to the researcher by the research assistant. The researcher then sent the following documents to each of the potential participants, by whatever means he/she had indicated would be the most appropriate for them:

- The information letter (Appendix C)
- The consent form (Appendix D)
- The questionnaire (Appendix F)

Documents sent by post included a pre-paid envelope for the participants' convenience. A dedicated post office box was utilized for the purpose of receiving the documents. When documents were sent by e-mail, the questionnaire was sent both in a Word format and a PDF format, so that participants could select the easier method of completion. A dedicated email address was established for the purposes of the study. This was to ensure confidentiality in corresponding with the participants and receiving the documents.

- **Collection of returned questionnaires and record review**

Once the signed consent forms and the completed questionnaires were received from the participants, the researcher visited the private practices of the Plastic Surgeons, the ENT Surgeons, the Speech Therapists, the Audiologists as well as the combined clinic in order to consult the records of the patients and record the details indicated on the Record Review Recording Sheet (Appendix G).

- **Data capturing**

The data from the record review together with the qualitative and quantitative details from the questionnaires were recorded electronically on a single Microsoft Excel spreadsheet. All identifying information was removed and a number was assigned to each participant, so that all subsequent processing of the data could be carried out anonymously.

- **Data analysis**

The quantitative and qualitative data from questionnaires were captured electronically on a Microsoft Excel spread sheet and a frequency count of all the responses was calculated. Analysis of the data was as follows:

Quantitative data:
Descriptive and summary statistics including percentage, means, standard deviations, and frequencies were used in order to describe the sample and analyse the quantitative data from the record review and the questionnaire (Howell, 2008).

Qualitative data:
The responses to open ended questions were analysed and reported on qualitatively, using content analysis. The first step in analysing the qualitative data was to distinguish between the relevant and the irrelevant material, that is, material considered irrelevant did not have a direct bearing on the research question for example the words of encouragement expressed by participants towards new parents of children with CLP were not considered to have a direct bearing on the research question.

To carry out the Content Analysis, a data-driven strategy was adopted for building a coding frame, as suggested by Schreier (2012) and indicated in Table 3 below. According to the process suggested by Henning (2004) the written responses to each of the open-ended questions were recorded verbatim. The researcher then read through the text in order to get an overall impression of the content. Using different coloured font, the units of meaning were identified, marked and labelled. All the coded items were grouped in the relevant category using the cut and paste facility. The category was then named as reflected in Table 4 below:

Table 3: Codes and Categories for the Content Analysis of the Open-Ended Questions

Code	Category
o Referral by professionals o Reputation of the team o Referral by family and friends o Immediate access to help o Financial reasons o Professionalism of the team o Contrast with previous negative experience o Multidisciplinary approach	Reasons for their choice of this facility
o Information about surgery o Information about speech development o Information about orthodontics o Information about ear nose and throat issues o Information about etiology of clefts o Information about international trends in management o Information about future management of the cleft	Need for information
o Satisfaction with level of involvement o Confirmation of need to stay involved o Insufficient involvement regarding the future	Involvement in decision making

Code	Category
o No improvement required o Improved attendance by the team members at the clinic, and inclusion of others o Financial assistance o Increased marketing for the facility o Improved verbal and written communication o Improved organization o Improved preparation for patients o Providing written material o Expanding the service to other areas	Suggestions for improvement
o Satisfaction with multidisciplinary approach o Satisfaction with quality of professionals o Satisfaction with patient's appearance o Satisfaction with Audiological services o General vote of confidence in the team o More positive attitude in parents and patients o Criticism of poor administration	Level of satisfaction with the service
o Consult with the cleft palate team o Make contact with other parents o Get information early o Be loving, patient, relaxed, hopeful and grateful. o Have faith	Advice to new parents

The 5- point Likert scale incorporated in the questionnaire was scored with the high level of positive feelings receiving a score of 5 and negative feelings receiving a score of 1 (Bryman, 2008).

Reliability and validity

Reliability and validity are central issues in all empirical research (Neuman, 2000). Reliability is defined as dependability or consistency, and suggests that a particular phenomenon is repeated or recurs in identical or similar circumstances. Validity refers to truthfulness in terms of the degree to which a measure does what it is intended to do (Durrheim & Painter, 2006). Although perfection is virtually impossible, the researcher should strive to achieve a maximum degree of reliability and validity.

Reliability in the methodology was ensured by the following processes:

- The research assistant conducted the initial telephonic interview to verify the contact details of the potential participants, and to confirm that they were willing to receive the information letter.
- A self-addressed postage-paid envelope was included together with the information letter, the consent form and the questionnaire so as to increase the mail response (Neuman, 2000).
- Questions in the questionnaire were presented in a logical sequence.
- The language in the questionnaire was simplified to allow for participants at varying levels of literacy to understand the questions. To achieve this, the questionnaire was piloted on a volunteer with basic literacy and English proficiency levels.
- The inclusion of record reviews was aimed at increasing the reliability of the data collected, as it does not rely on the memory or understanding of the participant (Strydom & Delport, 2005).
- Reviewing the records from plastic surgery, ENT surgery, speech therapy and audiology enabled cross-checking of information between records, and the missing data could frequently be obtained by consulting alternative records, thereby enhancing the reliability of the data.

- Each participant received the same questionnaire, and completed it without consultation with other participants (Delport, 2005).
- A research assistant was included to reduce direct researcher contact- hence researcher bias.
- To ensure reliability of the interpretation of the qualitative data, responses obtained from the open-ended questions were recorded verbatim, and colour coded by the researcher herself, according to units of meaning. These were then categorised and the category named.

In order to assess the reliability of the research process the following rates were calculated as prescribed by Neuman (2000, p. 267):

- the location rate (the number of located respondents out of all respondents)
- the contact rate (the number of respondents contacted out of those located)
- the refusal rate (the number of contacted respondents who refused to participate)
- the completion rate (the number of respondents who began the survey and completed all the items)
- the active response rate (the number of completed questionnaires out of all contacted respondents)
- the total response rate (the number of respondents who completed the questionnaire out of all possible respondents).

The following measures were taken to achieve *validity* in the questionnaire survey:

- In compiling the questionnaire, the researcher followed the guidelines outlined in the literature to achieve content validity. Questions were designed to explore a range of the participants' experiences and perceptions (Neuman, 2000; Kanjee, 2005; Delport, 2005; Maxwell & Satake, 2006).
- In order to obtain construct validity all the participants completed the identical questionnaire (Maxwell & Satake, 2006). It was for this reason too that the questionnaire was only available in English, and that there was no participation by interpreters, as this could introduce bias into the study.
- A pilot study of the questionnaire survey was conducted, as this could greatly enhance the precision of the study (Strydom, 2005).
- The guidelines laid out by Long and Johnson (2000) were followed in order to establish rigour in this research. A reflective journal was kept, so that the researcher

could reflect on her own beliefs in the same manner as she examined the perceptions of the respondents. Respondent validation was used by the inclusion of both quantitative and qualitative questions regarding the same topic, for example, a qualitative rating that had to be substantiated with a reason.

- Peer debriefing was carried out by discussing the emerging findings at regular intervals with supervisors, as well as with colleagues in the team, and by discussing the research at academic meetings and lectures.
- Triangulation aims to increase the accuracy and credibility of the findings (Patton, 2002). For this purpose, both data triangulation and method triangulation were utilized in the present study. Data triangulation is defined by Terre Blanche (2006) as a research design making use of various data sources. This study incorporated the medical records of various professionals who had dealt with the patients, that is, those of plastic surgery, speech therapy, ENT surgery, audiology and the combined cleft palate clinic, in addition to information obtained through questionnaires from the participants. Data triangulation, or "the use of multiple methods to study a single problem" (Terre Blanche, 2006, p. 380) was incorporated by the use of both quantitative data - from the medical records and from closed ended questions in the questionnaire, as well as qualitative data to supplement the quantitative data - from open-ended questions in the questionnaire. The research design selected thus fulfilled the objective of providing a more comprehensive picture of the results, more so than a single method would have been able to do (Morse, 2003).
- An audit of the decision trail was kept, which included records of all sources of data, all experiences, advice given and decisions made concerning each stage of the research. The research was influenced by my involvement in the CLP team and in the combined clinic; however this simultaneously provided me with a unique understanding of the environment, and of the dynamics in the team. I have reflected on my own potential bias, and how this may have impacted on the research.

Ethical considerations

In order to protect the welfare of research participants, a number of ethical principles were applied throughout the research process (Wassenaar, 2006). Ethical clearance was obtained from the Human Research Ethics Committee (Medical) of the University of the

Witwatersrand (Clearance Certificate number: M120720) (Appendix H). The professionals involved in the CLP program received an information letter outlining the details of the research (Appendix A). Written consent was obtained from the head of the program to allow the researcher to carry out a review of the medical records and completion of questionnaires (Appendix B).

All participants whose children with CLP have attended the combined clinic of the Cleft Palate Team, and who met the inclusion requirements, had an equal chance of being selected for the study. The participants were supplied with an information letter (Appendix C), which described the purpose of the study and the basis on which they were selected (Shaughnessy et al., 2000). It supplied the contact details of the researcher and supervisors, and gave a guide as to how long it was likely to take for them to complete the questionnaire. It ensured them of confidentiality in that no names of patients attending the cleft palate clinic, their families, or professionals managing these patients would appear in the research report. It also provided a deadline for returning the questionnaire. Participants were given the choice to decline participation in the research at any stage, with no negative consequences for themselves or their child.

As medical records are confidential, for ethical reasons, informed consent (Appendix D) was obtained from the parents/caregivers (Henning, 2004). A numerical system of coding was developed by the researcher so that patient names did not appear on the questionnaires, which was kept secure at all times, to maintain anonymity and uphold confidentiality.

The professional members of the team were advised that the findings of the research would be presented to them in a verbal presentation, and a copy of the research report would be made to them on request. The findings of the research would also be made available to any of the participants, should they request this, by means of a written summary sent to them by the same means used for sending them the questionnaire.

CHAPTER 4

RESULTS

Overview

The results chapter begins with an analysis of the response rate of the participants and the demographic characteristics of the participants and their children with CLP. The results will be further described in three main sections, namely (a) the daily running of the team and its combined clinic, (b) the accessibility of the service provided by the CLP team and (c) the perceived effectiveness of the service provided by the clinic.

Finally, the results of the participants' responses to two scaled questions regarding their feeling about their child's cleft (referred to as the "Happiness index") and their feelings about the future (referred to as the "Optimism index") will be reflected.

Overall summary of findings

The findings of this study revealed that parents/caregivers held generally positive views regarding the service they had received at a combined clinic of an interdisciplinary cleft palate team in the private healthcare sector of Johannesburg, and that the clinic was important, necessary and helpful. This was borne out by a review of the medical records, which confirmed the willing participation and cooperation of the parents/caregivers in treatment procedures by members of the team. The responses of the participants to the questions in the questionnaire did however qualify their positive response by revealing their unmet needs and suggesting ways in which the service to patients might be improved. Assuming that feedback based on patient evaluations is a tool for quality assurance, the information gained from the study would inform best practice models for this and other CLP clinics.

Presentation of the results

- **Response rate**

A total of 119 potential participants, whose children had attended the combined clinic from its inception in 2006 until the cut-off date in May 2012, were identified. The *location rate* that is the number of located respondents from the entire sample (Maxwell & Satake, 2005) was 106/119 (89%). The *contact rate,* that is the number of respondents contacted out of the

number located, was 77/106 (73%). The refusal rate was 9%, while 70 participants agreed to learn more about participation in the research. The *completion rate,* that is, the proportion of respondents, who received, completed and returned the questionnaire and the consent form, was 33/70 (47%). Thus the *total response rate*, that is the number of respondents who completed the questionnaire out of all those who agreed to consider participating in the study was 33/70 (47%), which is considered to be good, considering that Delport and Roestenburg (2011) suggest that the response rate to a mailed questionnaire is normally low (about 30%) although they do concede that this may increase to 70% if there is a follow-up.

According to the report from the research assistant there were certain difficulties that may have negatively affected the response rate:

- Incomplete records: a number of patient contact details were either unavailable or invalid.
- Memory difficulties: some potential participants felt that they consulted the CLP clinic too long ago to remember the details.
- Negative experience: one potential participant reported to the research assistant that she was unhappy with the clinic, and despite being assured that her input was particularly valuable, she was unwilling to participate.
- Language difficulty: one parent felt her English skills were insufficient to participate.
- Delay in processing documents: Firstly, the postal strike in the Johannesburg area around the time when questionnaires were mailed may have resulted in a delay in receiving material, and consequently a loss of interest. Secondly the time lapse between receiving the phone call and receiving the questionnaire might have been a factor – some people may have been willing at the time of the call, but had either forgotten or lost interest by the time the questionnaire arrived.
- Possibly some participants agreed to participate because it was difficult to refuse in a personal phone call, but then did not ultimately choose to participate.
- Method of delivery of documents: Of the 52 potential participants who requested that the documents be sent by e-mail, 20 questionnaires (38%) were returned, and of the 19 potential participants who requested that they receive hard copies, that is, by hand, by fax or by post, 13 questionnaires (68%) were returned. Thus the return rate of hard copies of the questionnaire was higher than that of electronic copies.

- **Demographic characteristics**

Both the record review and the questionnaire provided information regarding the demographic characteristics of the patients and their parents/caregivers. A number of features of the demographic characteristics are worth noting.

Age of the patients

The patients whose parents/caregivers participated in the study ranged in age from two to ten years, with an average of 5.6 years, and a standard deviation of 2.7 years. This implied that the patients had in most cases undergone their primary lip and palate repair, and had begun to develop speech and language, but had not necessarily commenced with orthodontic treatment.

Gender of the patient

The present study is in keeping with past research in that the male: female ratio was 3:1, where the incidence of clefting was found to be higher in males than in females; however these figures were skewed by the fact that patients with isolated cleft lip were excluded from the study. Mooney (2009) quotes a comprehensive study on birth defects by the Centres for Disease Control and Prevention as finding that there is an approximate 2:1 ratio of males: females for cleft lip with and without cleft palate, and slightly more females than males (3:2) with isolated cleft palate.

Ethnic background and home language of the patients

It is not surprising that more than half of the patients in the clinic were English-speaking White individuals. Firstly, given the clinic was based in Johannesburg, the economic hub of South Africa, and English is the primary language of government, business and commerce, more than a third of the population of Gauteng have English as their home language (SouthAfrica.info, 2014). Secondly, according to Statistics South Africa (2013), White individuals are much more likely to belong to a medical aid scheme than members of other population groups. A survey conducted in 2012 found that 75,1% of Whites, 41.7% of Indians/Asian, 20,9% of Coloureds and 10,4% of Blacks were members of a medical aid scheme. The clinic was also based in the northern suburbs of Johannesburg, which is a high socio-economic area. White English-speaking patients in a high socio-economic area of

Johannesburg would tend to seek medical care from specialists. Black patients in rural areas, on the other hand, are more likely to have difficulty accessing specialist care in urban areas are more likely to seek care from a traditional healers.

Cleft type

The majority of clefts in the sample (48%) were unilateral cleft of the lip and palate, followed by bilateral cleft of the lip and palate (30%) with the least common being isolated cleft palate (21%). Patients with isolated cleft lip were excluded from the study, as they mostly did not require the intervention of a combined team of professionals. This is generally in keeping with the report of Peterson-Falzone et al. (2010) that unilateral CLP is more common than bilateral CLP or isolated cleft palate.

More than a third of the patients in this study (36%) had been diagnosed with additional congenital abnormalities. Milerad et al. (1997) in a prospective population-based study, found that 21% of cleft infants born in greater Stockholm, Sweden, in the period 1975-1992 had associated malformations that either required follow-up or treatment, and that these associated malformations were more frequent in infants who had both cleft lip and palate than in infants with isolated cleft palate or isolated cleft lip. They concluded that a more extensive cleft seems to be associated with a higher risk for associated malformation. Shprintzen et al. (1985) however found associated anomalies in as many as 63.4% of a sample of 1000 patients with clefts of the lip, palate or both. Calzolari et al. (2007) in an epidemiological study of nearly six million births found an incidence of 30% of cleft infants who had comorbid conditions, which is echoed in the present study.

4.1 Daily running of the team and combined clinic

The treatment protocol of the CLP team is a description of the daily running of the individual private practices of the team members, as well as the combined clinic. Information gathered from the clinical records of the Plastic Surgeons, ENT surgeons, Speech Therapists and Audiologists as well as for the combined clinic, informed the treatment protocol of the team. Information regarding social services was obtained from the Social Worker's report, as the

records were not made available to the researcher for ethical reasons. Similarly, no Orthodontic records were available due to the relocation of that department. The team Orthodontist reported however that none of the patients in the study had yet received corrective orthodontic treatment. This may partly have been a result of delayed tooth eruption of patients with CLP (Peterka, Tvrdek & Müllerová, 1993) thus delaying the commencement of Orthodontic intervention. It may also have been related to the fact that no funding was provided for private Orthodontic treatment, and the public sector tends to involve a waiting period for treatment.

Plastic Surgery Intervention

From the medical record review, it was evident that 21 patients of the 26 that had a cleft lip (81%) had their primary lip repair performed by one of the team Plastic Surgeons. Regarding the age at lip repair, 16 patients (76%) had their lip repaired between three and five months of age. This is to be expected as the surgical regimen of the team in this study is to repair the cleft lip between four and six months of age (L. Chait, personal communication, July 1, 2014). The mean age at lip repair of the patients in the study was seven months, which is older that the team regimen. This may have been due to the late referral of some of the patients to the team. In fact, all of the patients (24%, N=5) who had their lip repair at 6 months and older were associated with a late initial referral to the surgeon. The median age for lip repair was four months, which is in keeping with the recommendations of Salyer et al. (2009) who advocate three months of age as a good time to perform the initial repair of the unilateral cleft lip and nose and Chen and Noordhoff (2009) who recommend the timing of the surgical repair for a bilateral cleft lip to be at three to four months of age following pre-surgical orthopaedics.

The protocol of the team in this study is to perform the palatal repair in two stages. The soft palate is repaired first, followed by the hard palate. The mean age for soft palate repair of the patients in this study was 10 months and the hard palate was 24 months, which is more or less in keeping with the team's regimen to repair the soft palate at about nine months and the hard palate either together with the soft palate if the cleft is narrow, or else before the age of two years (L. Chait, personal communication, July 1, 2014).

All of the patients involved in the study (n=33) underwent a surgical repair of the soft palate, and of these, 28 patients (85%) were repaired by one of the team Plastic Surgeons. The age of repair ranged from 5 months to 13 months with a mean age of 9 months. The two cases that had late repairs, at 24 months and 35 months were both late referrals to the team and both lived outside of the greater Johannesburg area. Their late timing of surgery may therefore have been related to the lack of access to earlier surgery.

Of the 30 patients whose cleft involved the hard palate and required a hard palate surgical repair, 27 patients (90%) were operated on by one the team Plastic Surgeons, two patients (7%) underwent a hard palate cleft repair by another cleft palate team, and one patient (3%) had not had the hard palate cleft repaired, as earlier repair of the hard palate cleft was contraindicated in this patient. Of the patients whose hard palate repair was performed by one of the team Plastic Surgeons, the majority of patients (79%) were performed under 2:6 years of age. This is in keeping with the recommendations by Friede (2009) that the repair of the soft palate cleft be performed at four to five months and the repair of the hard palate cleft at 12 to 18 months in narrow clefts and up to three years in wide clefts.

In addition to primary surgery to repair the cleft lip and palate, 21% of the patients (n=7) underwent a pharyngeal flap operation to address the problem of velopharyngeal dysfunction resulting in nasal speech. The mean age for secondary surgery was 4:7 years. This concurred with the recommendations of Chen and Noordhooff (2009) that when velopharyngeal insufficiency (VPI) is diagnosed, it is confirmed by nasendoscopy at four years of age, and surgically corrected before the child goes to school.

ENT surgical intervention

Of the 33 patients in the study, 100% underwent ENT consultation. This is in keeping with the recommendations by Lennox (2001) who recommends that every child born with a cleft palate should undergo regular ENT review. Thirty-two patients (97%) received a myringotomy and grommets (ventilation tubes) at least once, and in some cases up to seven times. The average age of the first grommet insertion was 18 months, with 57% having received grommets in the first year of life. This was skewed by the fact that some patients had been referred late to the team. This figure may have become even higher over time, considering the age range of the patients ended at 12 years.

According to Thomas and Corlin (2000) many healthcare professionals managing patients with CLP believe that grommets should be inserted early and often, however not all agree when the first set should be inserted. Regarding the timing of the first myringotomy and grommets, the majority (75%) received grommets at the time of their lip or velar repairs. Some patients (12%) required intervention at an earlier or later age that did not coincide with their surgery, and the remainder (13%) were referred late to the team and therefore received otological management at the time of referral. One of the advantages of managing patients within an interdisciplinary team is that it offers the opportunity to streamline services. Over a third (37%) of all the grommet insertions were carried out simultaneously with other surgical procedures such as a repair to the lip, soft and hard palate thus reducing the amount of hospitalisation, theatre time and anaesthetics for the patient, and reducing cost for the parent or funder. This is in keeping with the approach by Chafin and Bluestone (2009) of treatment being based on evidence of disease at the time of lip and/or palate repair, with the use of tubes, with frequent and ongoing follow-up.

With regard to tonsillectomy, 24% (n=8) of the patients had undergone this surgery by the time of the study. None of these patients underwent an adenoidectomy, as cleft palate and velopharyngeal dysfunction constitute a contraindication for adenoidectomy (Witt, 2009).

Audiological intervention

Sabo et al. (2009) stress the importance of formal audiological evaluation of all children with cleft as soon as possible so as to establish a baseline of the hearing, regardless of the results of new-born hearing screening. Only 45% (n=15) of the patients in this study had an audiological evaluation with a team Audiologist. These evaluations included Pure Tone Audiometry, Tympanometry, Oto-Acoustic Emissions and Auditory Brainstem Audiometry. Six percent of the participants (n=2) had reported that their children had received audiological evaluation by an Audiologist outside of the team. As one of the two ENT surgeons on the team was reported to have his own tympanometric equipment, he would have carried out this evaluation himself; however no records were available to confirm this.

Of the 29 participants who responded to the scaled question regarding their satisfaction with the patient's hearing, responses indicated that 86% of participants (n=25) felt that hearing was either very good or good (see Figure 2) despite the fact that the results obtained from the

audiological records indicated that 27% of the patients were found to have a conductive hearing loss. Details on the severity of the hearing loss were not available to assess whether parents may have considered a mild conductive loss still to be good.

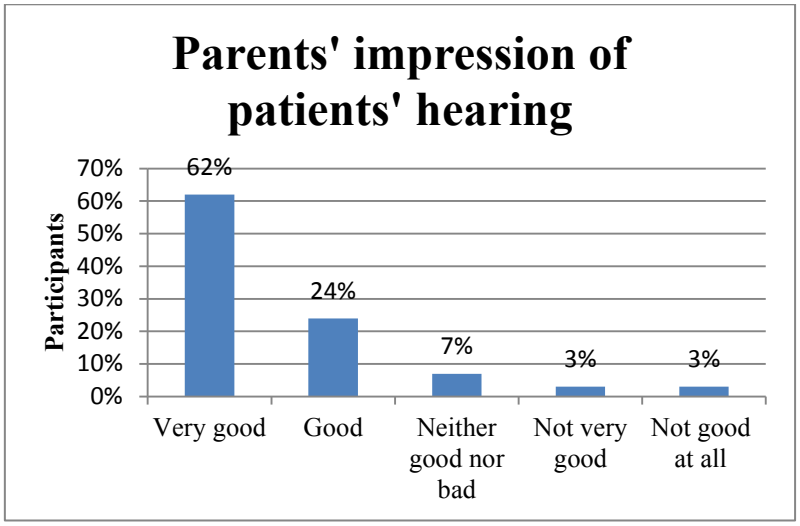


Figure 2: Parents' impression of child's hearing

It should be pointed out that one of the two patients whose parents were unhappy with hearing had never had a hearing test. Although the reason is unclear, it is possible that parents feel that as grommets have been inserted, the problem is being addressed, so further evaluation was unnecessary. This however highlights the need for more rigorous audiological monitoring, and coordination of ENT and audiological intervention, as well as educational information. This is more likely to occur within a team, as suggested by Austin et al. (2010) whose study found that children managed within an interdisciplinary team were more likely to have a had a hearing test in the preceding year than children without team care.

Speech therapy intervention

Of the 33 patients in the study, 27 (82%) consulted with the team Speech Therapist. The age at first consultation with the speech therapist varied, as can be seen in Figure 3 below, but there were two stages which were more frequent. The first was at the perinatal stage at the time of the diagnosis of the cleft, when nearly half the parents in this study consulted the

Speech Therapist. This is consistent with Kummer's (2014) recommendations for speech therapy timetable for intervention, beginning feeding therapy in the first few weeks of life. The second was at the toddler stage when speech and language would be developing.

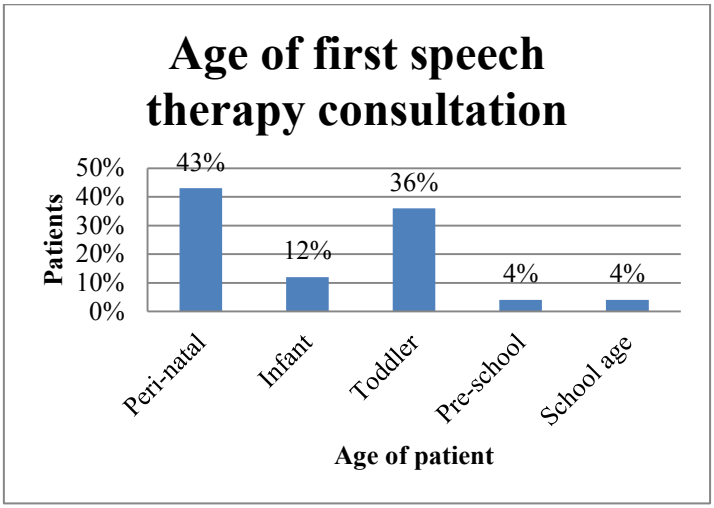


Figure 3: Age of first speech therapy consultation

Once effective feeding has been established, Kummer (2014) recommends that parents should be counselled during the first three years regarding language development. Over a third of patients in this study saw the Speech Therapist for the first time as toddlers, and 92% had seen a speech therapist before the age of two years.

Figure 4 indicates that for the majority of patients, intervention was through monitoring and home programming, and that not all patients born with a cleft palate require regular speech therapy intervention. In this study, 30% of patients required therapeutic intervention in the form of regular speech therapy. This figure is higher than the 20% suggested by Golding-Kushner (2001, p.5) who states that "approximately 80% of children born with non-syndromic cleft palate who undergo palate repaired by 18 months of age develop speech free from compensatory errors without any type of therapeutic intervention". It should be considered however that the sample in the study included children born with additional birth defects which could be syndromic in origin. As the average age for repair of the hard palate cleft in the study was 19 months and therefore above the age suggested by Golding-Kushner (2001), this may also have influenced the need for therapeutic intervention. This may also be

related to frequent late referrals that still occur in the South African context, possibly resulting from poor health literacy, and parents being unable to access, interpret or use information for the care of their child. Transportation costs and travel distance also make their access to specialised care impossible (Levin, 2006; Harris, et al., 2011).

Of the 21% (n=7) of patients who lived too far away to receive speech therapy with the team Speech Therapist, speech therapy was arranged with a community-based therapist (CBT). The team Speech Therapist liaised with the CBT and where necessary offered support such as information and therapy materials. Progress reports were also requested from the CBT so as to keep the team informed.

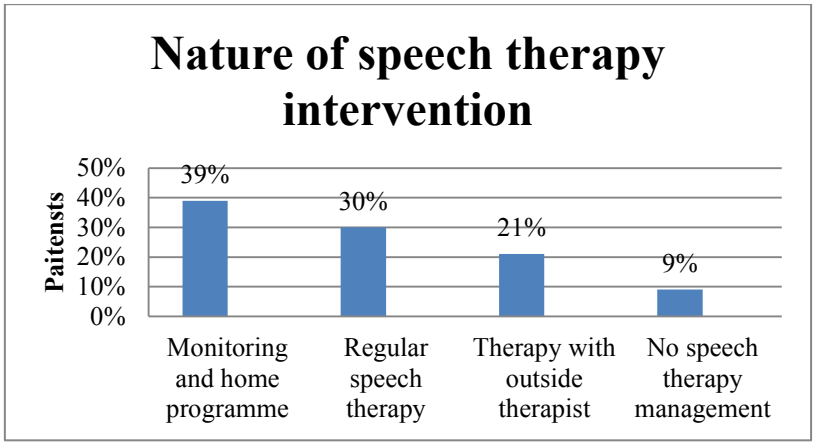


Figure 4: Nature of speech therapy intervention

Social Work intervention

The information gathered pertaining to Social Work was based on the participants' responses to the questionnaire, and not from a record review, as for ethical reasons, these records were not made available for the study. The team Social Worker provided her own report on the service that had been provided to patients, and feedback on their response to the service. The parent support group was run on a monthly basis, in the late afternoon on the same day as the combined clinic took place. This timing was chosen so that working parents, including fathers could attend. They often brought their children with them, especially if they did not have child-minding facilities. Attendance varied greatly from no attendance at all, to 26

parents at a single group, with an average attendance of eight parents. In the year prior to the study however, patient numbers waned, which in the Social Worker's view, was a result of the soaring cost of living and parents having to prioritise their finances.

According to the Social Worker's report, there were two main needs identified by the parents of the support group: firstly information on CLP, and secondly emotional support as they face the various challenges resulting from the condition. Information requested related particularly to etiology, surgery and feeding issues. Emotional support was needed to deal with strong feelings of guilt especially during times of surgery, orthodontic treatment, or even protracted treatment of any kind, and to deal with experiences of teasing. Some parents also requested training in basic counselling and this was offered so that parents could respond to other parents at the time of the birth of the infant with a cleft.

The Social Worker reported that some parents would attend the group once, and drew from it what they needed. Others would consult with her when a child was undergoing surgery and possible feelings of guilt resurfaced, while others became "absolute stayers" and formed some strong bonds with other parents. The benefit derived from the support group was expressed by the participants, in their advice to new parents of a CLP child to *"speak to other moms, get a buddy system with other cleft moms"* (Participant (P) 14) and to *"be in contact with someone who has been thru [through] it so you know to better equip yourself"* (P11).

Combined Clinic

Table 4 below outlines the services that were provided by the various team members to the patients in their individual capacity and of the combined clinic. In each case, the percentage of patients who were evaluated or treated by the particular speciality was recorded. The percentage of patients receiving each type of intervention was recorded, and where appropriate, the mean age and standard deviation, at which intervention was received, were calculated.

The medical record review revealed the following aspects regarding record keeping in the team:

- Each team member kept separate records, and there was no common database.

- The reports from the speech therapy assessments were distributed to other team members, and appeared in their files, but no other records were regularly shared.
- Copies of the report from attendance at the combined clinic were distributed to the team members, but these were not entirely consistent.
- Demographic details could be cross-checked between the various records.
- No orthodontic records were available.

Kummer (2014) stresses that one of the advantages of the team approach is the comprehensive documentation of records from all the professionals involved in the patient's care. In terms of providing a model for best practice as suggested in the research question, it appears that not all of the professionals provided comprehensive reports that were easily accessible by all the other team members. While parents attending the combined clinic were given verbal recommendations, the written recommendations at times failed to be provided, as was commented on by P15 "*It would be nice to receive notes on what was decided/discussed during the clinic."* This may have been a result of the absence of the professional responsible for the report, or facilities for printing the reports being unavailable on a particular day. Rigour is therefore required to maintain consistency of standards in record keeping and record sharing. A common database could be established where all team members could easily access all the records pertaining to a particular patient. While electronic patient records should not replace the paper document and the face-to-face communication may follow, it may reduce duplication and increase efficiency.

Table 4: Treatment protocol of the Cleft Palate Team, based on a review of the medical records

Specialty	Nature of intervention	Patient characteristics	Percentage (%)	Mean	Standard deviation
Plastic Surgery		Patients receiving plastic surgical intervention	100		
	Lip repair	Patients with cleft lip	79		
		Patients who had lip repair by the team	64	7 months	7.9
	Soft palate repair	Patients with cleft soft palate	100		
		Patients who had soft palate repair by the team	82	10 months	6
	Hard palate repair	Patients with cleft hard palate	92		
		Patients who had hard palate repair by the team	85	24 months	16
	Pharyngeal flap	Patients who had a pharyngeal flap	21	4.7 years	1.89
ENT Surgery		Patients receiving ENT intervention	100		
	Grommets	Patients who received first set of grommets by the team	97	18 months	23.4
		Number of grommets received at time of study	24	2.9 times	1.7
	Tonsillectomy	Patients who underwent tonsillectomy without adenoidectomy			

Specialty	Nature of intervention	Patient characteristics	Percentage (%)	Mean	Standard deviation
Speech Therapy		Patients receiving first speech therapy consultation by the team	88	13.5 months	24.62
	Monitoring and home program		39		
	Regular speech therapy		30		
Social Work		Patients receiving Social Work intervention	51		
	Parent support group		33		
	Private consultation		24		
	Both services		9		
	Unspecified		3		
Audiology		Patients receiving an Audiological Assessment by the team	48		
	Pure tone audiometry		45		
	Speech Audiometry		21		
	Oto-acoustic emissions		18		
	Auditory Brainstem Response Audiometry		9		
	Results of Audiological assessments	Normal hearing	66		
		Conductive hearing loss	27		
		Sensori-neural hearing loss	0		
		No result	7		
Combined CLP Clinic	Team consultation	Patients receiving team consultation	100	1.97 times	1.21

The data in table 5 described the intervention regimen followed by this particular CLP team. The timing of surgery is in keeping with the range of international trends Friede (2009). Early speech therapy intervention is practised, if possible at birth or even before. Surgical treatment of middle ear pathology is aggressive, in that all patients with a cleft of the soft palate received grommets. It is surprising however that less than half the patients had formal audiological evaluation. Half of the parents/caregivers had made use of social work services.

4.2 Accessibility of the service provided by the CLP team

In order for patients to be able to access treatment by a team of professionals, and derive the maximum benefit from consulting with the team, certain parameters would need to be in place. Firstly, they would need to be referred to the team by a referral agent, for example a medical or allied medical professional, and preferably early rather than late. Secondly, they would need to be able to access the services financially, either through their own means, with the availability of a medical aid, or through funding. Thirdly, within a group of professionals such as in this team, they would need to be aware of which areas of expertise were represented by the team members.

- **Source and timing of referral to the team**

The American Cleft Palate-Craniofacial Association (ACPA) (2009) states as one of its principles of optimal care for patients with CLP, that the first evaluation should take place in the first few weeks of life, and if possible within the first few days. Eight of the participants (24%) commented on the value of early intervention, by having had immediate access to the team, for example:

"*I was introduced to them as soon as my son was born, so I wanted them to help him"* (P8).
"They phoned me before I could do anything els [else]" (P10).

> *He was born in (name of hospital) and we met (name of plastic surgeon) prior to his delivery, which help [helped] me tremendously. On the day of his birth, (name of speech therapist) assisted us to locate the correct bottle for feeding. The social worker also spend [spent] some time with us during the period of our hospitalisation. Our son ended up in ICU & High Care for 8 days after his birth and the support from the*

professionals mention [mentioned] above were unbelievable and much appreciated (P22).

One of the participants stressed the importance of prenatal contact with team members. *"Do as much research as you can before the birth, if possible and try to meet professional in advance when possible"* (P12).

The comments by the parents stress the importance of early contact with team members and the opportunity to prepare themselves for the immediate management of their child after birth. This supports the principles set by ACPA (2009).

- **Financial implications of the cleft**

Fifty-eight percent of the participants (n=19) had access to a private medical aid scheme and therefore to private healthcare services, while 42% received funding which enabled them to access the services of the CLP team. One third of participants, including funded and non-funded parents/caregivers commented on the financial implications related to the treatment of their child's cleft. A t-test indicated no significant difference in the "Happiness index" between those participants who were on medical aid, as opposed to those who received funding for the management of their cleft palate child (t_{31} = 1,009; p = .32) (Howell, 2008). It appeared that both groups of parents, namely those with medical aid and those who were funded, faced financial challenges.

Most of the participants who commented on their financial challenges (n=4) were on a private medical aid and had to pay the excess amount that private practitioners charge over and above medical aid rates:

I do feel that whichever Dr's [doctors] choose to participate in the team should then, in my opinion charge medical aid rates! As we are on a private medical aid we have had the responsibility of the accounts that are over and above the medical aid rates, and when accumulated amount to a substantial fee. I believe this money could far better to be utilised for visits that are required, that is, speech therapy, ENT, etc. (P7).

"We have medical aids but the prices charged by these Dr/s [doctors] are exorbitant and we have to pay so much from our own pockets. They should charge medical aid rates not 300X rates. Is it about services or making money???" (P11).

Over a third (36%) of the patients in the study had additional congenital abnormalities, which could result in an additional financial burden over and above those related to the cleft. Their own life circumstances also contributed to financial challenges:

"I am a single mother and (name of child) was also born with a club foot [in addition to the cleft] which is additional expenses. I'm struggling to cope financially, and can't afford additional consultation fees above her orthopaedic surgeon" (P28).

"(Name of child) at the moment is attending private (special needs) school. I had to pay for transport travel distance. School fees every month and school trips. Our child need [needs] a better education but for me its [it's] difficult" (P13).

Evidently, both groups of parents, that is, those on medical aid and those who received financial support from the fund, faced financial challenges in meeting their child's needs. The former group still needed to pay for the excess over and above what was covered by the medical aid. The latter group had to pay for extra costs incurred such as school fees for special education, transport, and the costs of management for problems that their child might have in addition to the cleft.

- **Awareness of professionals attending the clinic**

Participants listed the particular professionals whom they could recall had attended the combined clinic on the day of their consultation. As can be seen in Figure 5 below, the majority of participants were aware of the presence of the core team members that is the Plastic Surgeon, the Speech Therapist, the ENT Surgeon and the Orthodontist (Dental Specialist). They were less aware however of the presence of the Audiologist or the Social Worker. As the majority of the patients had consulted individually with certain team members, (100% with the Plastic Surgeon, 100% with the ENT Surgeon and 88% with the Speech Therapist) it is likely that they recognised, or were more aware of, and remembered these particular team members at the combined clinic.

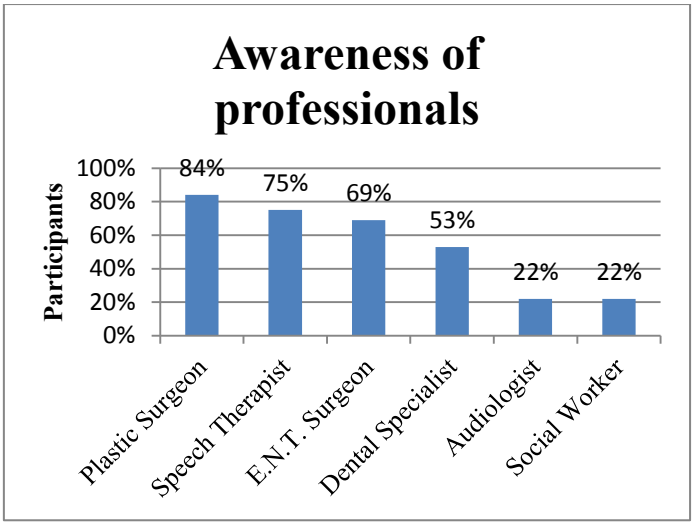


Figure 5: Participants' awareness of professionals attending the combined clinic

Nine of the participants (27%) made suggestions of other professionals that should be represented at the clinic. These included a Psychologist, a Paediatrician, an Occupational Therapist and a Maxillofacial Surgeon. Four of these participants had children with additional difficulties for example syndromes, other birth defects or learning problems, indicating their need for a wider team of professionals. Two of them requested the inclusion of professionals who were already in the team, possibly indicating that those particular team members were absent on the day of their clinic visit, or that the participants were unaware of the professions of those professionals present at the clinic. The absence of team members from the clinic was problematic as was reflected in the comment: *(the service by the Cleft Palate Team can be improved) "by making sure all the specialists that are following the child are present at the clinic day"* (P16).

- **Use of Social Services**

Although the Social Worker's patient records were not made available for the study, the team Social Worker did provide her own report on the service that was rendered. Information from the participants indicated that 52% (n=17) accessed the services of the Social Worker, 33% percent (n=11) had attended the parent support group, 24% (n=8) had received individual consultation and 3% (n=1) did not specify the nature of the intervention. The main reasons that parents/caregivers did not make use of the parent support group, as can be seen in Figure

6 below, were related to accessibility issues, that is, being unaware of the service being provided, travelling distance, transport costs and the timing of the meetings.

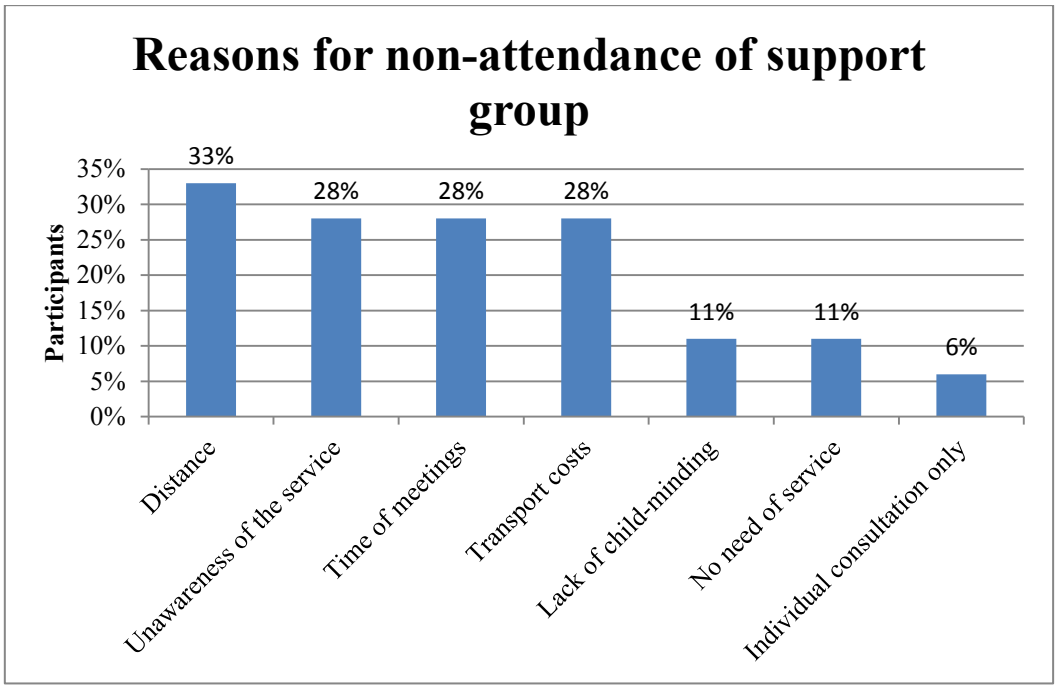


Figure 6: Reasons for non-attendance of the parent support group

Three of the participants stressed the value of parent support groups in their recommendations to other parents, for example: *"Be in contact with someone who has been thru [through] it so you know to better equip yourself"* (P11). *"Speak to other moms, get a buddy system with other cleft moms"* (P14).

These findings suggest that parents/caregivers who had access to the services of the Social Worker and made use of them, had benefited from them. Greater rigor should therefore be practised by all the team members in informing the patients of the services being provided, and an adjustment of the times of the support group could assist in making the service more accessible.

4.3 Effectiveness of the clinic

According to Coulter (2006) questionnaire surveys from patients exploring their satisfaction with the quality of healthcare received, may not be reliable as the basis for assessing the

medical knowledge of the doctors or of their thoroughness in diagnosis and management. This is not to say however that patients are unable to assess the quality of care they receive. In expressing their satisfaction with healthcare, most patients want the assurance that their doctors have sound technical skills, that they have excellent communication skills, that they give good advice and treatment, that they maintain confidentiality, that they respect the patients' dignity, that they provide the patients with sufficient information and that they involve the patients in decision-making (Coulter, 2006). The questionnaire in the present study explored the experience the participants had with in the combined clinic, as well as aspects such as communication, involvement in decision-making, provision of information, satisfaction with current treatment and optimism for the future.

- **A combined clinic versus individual consultation**

Most of the 32 participants (75%) who responded (n=24) expressed a preference for both individual consultation and the combined clinic. Twenty-five percent (n=8) of the participants expressed a preference for the combined clinic. None of the participants expressed a preference for only individual consultations. Of those participants who preferred to attend only the combined clinic, 75% (n=6) were patients who received funding and 25% (n=2) were patients on private medical aid. Of the participants who preferred to receive intervention both through the combined clinic and individual consultation, 82% (n=17) were on private medical aid. Results indicate that none of the parents/caregivers, whether they are on private medical aid, or are being funded, would prefer only individual consultations with the team members. This may be an indication that all the parents/caregivers recognise the value of the combined clinic; however those who were on private medical aid valued the option of a private consultation, while those who were funded recognise the benefit of a consultation with the whole team, without having to make separate visits to individual professionals.

Fifty-two percent of participants (n=17) expressed their satisfaction with treatment by the CLP team, referring to "*good cross functional support"* (P13) and specifically to the combined clinic: "*it's great to have all concerned in one room…I believe that the clinic is hugely beneficial & a great platform for discussion"* (P7). They also advised other parents who had found out that the child had a cleft to consult with the CLP team: *"I will advise her to see a cleft palate doctor more especially the cleft palate clinic team"* (P1).

Participants also expressed their dissatisfaction with certain aspects of the clinic. One of the participants drew attention to the fact that meeting a large group of specialists in one room can be overwhelming for the patients: *"Maybe for many it could be daunting to walk into a room full of professionals. People could be supported to feel a little more at ease."* (P18).

Another participant felt that meeting in a group did not afford the patient enough time with the particular specialists important to that case: *"Spend a little bit more time with the family. If it is impossible for the group, do it with only 2 persons of the group after the group consultation is completed"* (P19).

The organisation of the clinic was also problematic for one participant, for example record-keeping and making of appointments:

> *Patient files should be readily available, all details should be known to the professionals before consultation, so that time can be saved and specific advice can be provided. The sessions must be better organised. Better cooperation and communication between professionals is required. Better preparation by the professionals for the clinic visits. The sessions must be better organised* (P19).

The accommodation and facilities at the clinic were a concern for the following participant:

> *The only recommendation that I can make is that the clinic should obtain an area with an examination bed. This will provide the professionals the opportunity to examine the patient and make suitable recommendations or confirm that all is in order, for examples his ears* (P22).

The feedback received from the parents/caregivers confirmed their appreciation for their child's management by a team of professionals, and especially for a team that met with them in one place so that they could be part of the discussion. They did recommend however, that the patients should be better prepared so that the experience was not daunting, and that better attention be given to administrative issues such as making of appointments and record keeping. While the need for an examination bed may be questioned by the team members, certainly the physical environment, accommodation and facilities in the clinic are important aspects to consider. Unruh, Skeels, Civan-Hartzler and Pratt (2011) identify the physical challenges of a clinical environment as one of the factors that inhibits the capacity of patients to use information effectively while interacting with clinicians. They found that awkward

physical positions were one of the factors inhibiting patients' capacity to "access, use, learn, communicate and remember information effectively" (Unruh, et al., 2011, p.183). They therefore advocate that in order to enable patients to focus their attention, to communicate effectively and to recall information accurately, clinical environments need to be transformed into effective information workspaces for patients.

- **Professional communication**

Communication on a number of levels between professionals and parents/caregivers was explored. These included the ease with which the participants experienced speaking to the professionals, their understanding of recommendations, their feeling of involvement in decision-making and their need for more information about clefts. In response to the question regarding how easy they found it to speak to the professionals in the team, none of the participants indicated that communication was a problem, although four participants found it "very difficult" to speak with the professionals. Fifteen participants felt that speaking to the professionals was "very easy" and twelve felt it was "easy" (see Figure 7 below).

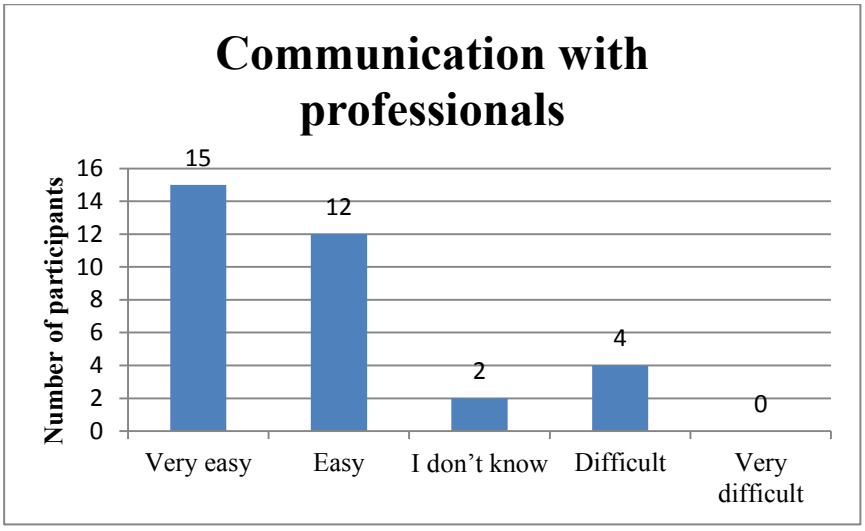


Figure 7: Communication with professionals

Despite this, eight of the participants suggested that communication could be affected by their own home language being one other than English (12%), or factors such as the size of the

team (9%), their own feeling of nervousness (6%), forgetfulness (2%) or fear of being judged (2%). Four participants (12%) gave recommendations regarding improved communication with the professionals. These related to:

- Language medium of communication: *"talking the language that the client is" (*P21).
- Frequency of communication: *"Often was told to wait and will be explained some info later"* (P14).
- Mode of communication, for example verbal and written communication: *"it would be nice to receive notes on what was decided/discussed during the clinic"* (P61).

The parents/caregivers thus requested greater effort by the professionals to communicate clearly, frequently and effectively in a language they could understand giving their findings and their recommendations, preferably verbal as well as written form.

- **Parental feeling of involvement in decision making about the child's treatment**

Thirty of the participants (90%) responded to the question regarding their involvement in decision-making about their child's treatment. On an average, the majority of participants felt that they participated "very much" or "quite a lot" in the decision-making about the child's treatment (see Figure 8 below). Most of the participants (n=17: 53%) who responded to this question did not request any more information about clefts. Figure 7 below suggests that the majority of participants felt sufficiently involved in decision-making about the child.

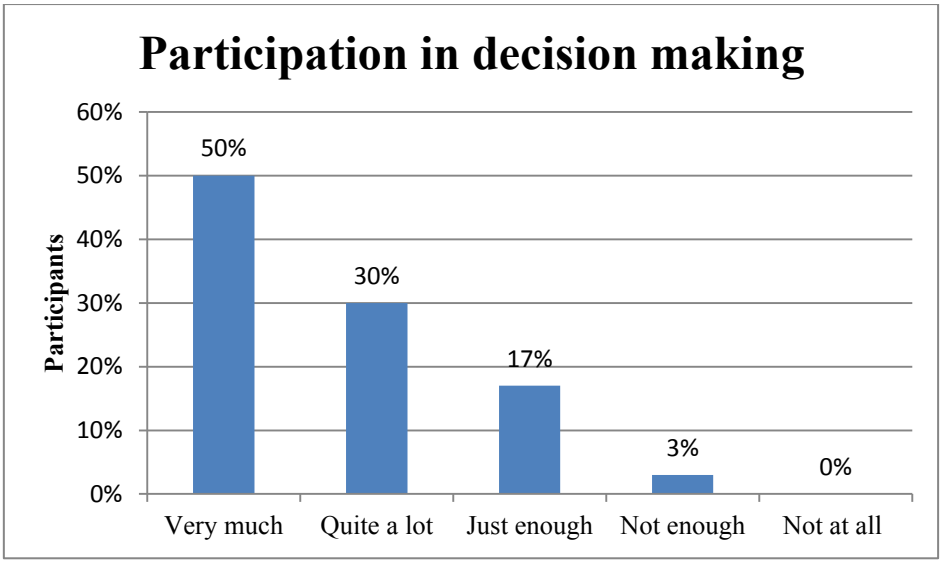


Figure 8: Participation in decision making

Nine participants expressed their satisfaction with their level of involvement in their decision making about their child's treatment. This was reflected in the following statements: *"If there's something the team see about my child, they inform me, then I'll decide if its [it's] OK"* (P1) and *"We don't have enough knowledge and rely on the professional's knowledge"* (P15).

Three of the participants expressed their wish to be involved in decision making, for example: *"I want to be part of everything"* (P10), however three participants expressed insufficient involvement and the lack of a clear plan for the future, for example: *"As age appropriate what are the next steps, not waiting for a year to see*" (P20).

Parents/caregivers have therefore stressed their need to be involved in the decision-making of their child's treatment. This enhances their cooperation with the treatment. While many of them felt they were involved, occasionally there was a sense that they were waiting too long to understand the future of management of their child's condition. In the study by Paynter et al. (1991) one group of parents felt they had all the information they needed in all the areas of CLP management, while another group felt they did not have enough knowledge in any area of management, as they had not understood the information they had been given. The authors suggest that professionals should be aware of the parents who are not asking questions, and provide those parents with additional information.

- **Satisfaction with the service provided by the CLP team**

The majority of patients responded that they were "very happy" (77%) or "happy" (13%) with the service provided by the clinic (see Fig 9 below).

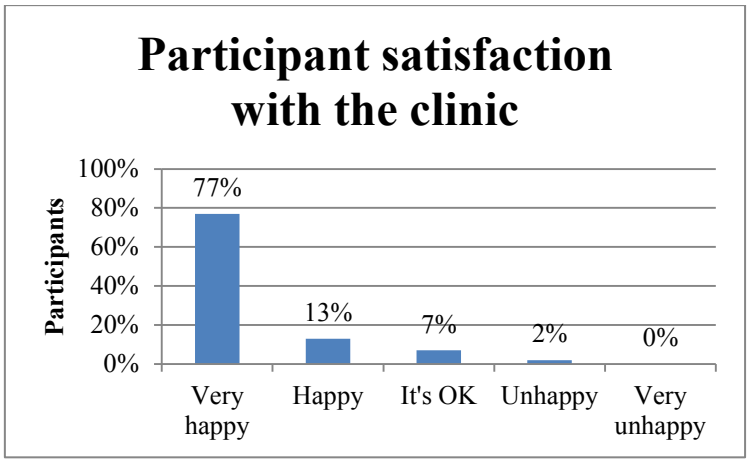


Figure 9: Participant satisfaction with the clinic

Factors contributing to their positive attitude towards the clinic included:

- The reputation of the team (10% of participants responded) for example *"Heard it was the best"* (P14).
- The professionalism of the team (10% of participants responded) for example *"Here I receive special and professional treatment from specialised areas about clefts"* (P30).
- The technical competence of the team, particularly the surgeon (11% of the participants responded) for example *"People don't notice his lip if not told"* (P17), "*My child is now looking very beautiful"* (P32). The level of experience of the team members was a factor that engendered trust on the part of participants, for example *"I trust the professionals completely, for the reason that they (have) been involved in this line of work for a number of years"* (P22).
- The accessibility to team members and early referral (10% of participants responded) for example *"Easily accessible"* (P11). *"I was introduced to them as soon as my son was born"* (P8).

- The interdisciplinary nature of the team (10% of participants responded) for example *"good to see/hear team discussions and treatment plans"* (P15).
- The supportive nature of the team (27% of participants responded) for example *"They've been very helpful and supportive"* (P28).
- The outcome of treatment: 40% of the participants expressed their thanks and gratitude to the team for the service they had received, and 33% expressed general feelings of satisfaction: "*Without the unit I would not have survived and appreciate everything that was done"* (P14) and *"His friends don't even know that he has a cleft"* (P20).

As patient satisfaction is correlated to whether the patient would recommend the services of a healthcare professional to others (Kersnik, 2003), the following advice given to other parents of a cleft palate child indicates the participant's satisfaction with the service received at the clinic: *"Consult with cleft palate clinic professionals & go to [doctor's name] he is the BEST"* (P23).

Regarding suggestions for improvement to the service five participants (15%) specifically stated that there were no suggestions for improvement: "*The services were great I don't think anything needs to change"* (P17) and confirmed by the affirming comment *"Thank you to all, you are superstars and hero's [heroes] to us. Our child is perfect. His friends don't even know that he has a cleft"* (P20).

Responses by the participants suggest that attributes such as a good reputation, professionalism, accessibility, interdisciplinary team work and supportiveness are valued by parents/caregivers and contribute to a feeling of satisfaction with the service. The level of satisfaction expressed confirms that they had experienced these attributes in the management of their child. These findings are similar to those of Nelson et al. (2013) who report that surveys carried out across several countries reflect positive views among parents regarding the organization and delivery of cleft care.

- **Participants' understanding of the cleft condition and need for additional information**

The majority of participants (53%) indicated that they did not require further information about the cleft condition at this time. Those participants who did request additional

information about clefts (47%) identified a number of areas where information was lacking, including:

- surgery: preparing patients for surgery, and planning for future surgery
- genetics: the aetiology of clefts and the chances of recurrence
- speech therapy: speech development and planning of future treatment
- ENT: airway problems and the role of grommets
- orthodontics: planning for the future in terms of dental development
- general aspects, for example, an explanation of technical terms.

Two participants requested information in written form, such as a booklet and written reports to the parents, for example: *"It would be nice to receive notes on what was decided /discussed during the clinic"* (P15). *"The team has so much knowledge that they could write a simple book to explain everything to parents"* (P25).

Although the team had printed an information booklet on cleft lip and palate, this had evidently not been distributed to all patients. More detailed verbal information was also requested in all areas of speciality in cleft care. It is possible that more probing is necessary to ensure that the questions parents have are adequately answered, especially as it is likely that some of their questions were more specifically related to their own child's condition, and not covered by the booklet. In their research on parent's perspectives of the CLP services, Nelson et al. (2013) comment that while parents value receiving a standardized information booklet on CLP that they can keep, these booklets should be supplemented with individualized information appropriate to the child and the parents, so as to improve their experience of cleft care. One participant suggested that the public too needs to be better informed about the availability of CLP services by *"creating more awareness about the team as lots don't know about them"* (P1).

- **Participant feelings of satisfaction with the cleft and hope for the future**

Responses from a 5-point rating scale measuring participants' satisfaction with seven aspects of their child's cleft were recorded, with a high level of positive feelings receiving a score of 5 and negative feelings receiving a score of 1. The particular aspects of the cleft included the patient's lip, face, hearing, nose, bite, speech and teeth. The sum of the scores for each of these seven aspects was calculated and formed the participants' "Happiness index" thus the

higher the score, the greater the participants' satisfaction with the status of the cleft. The scores on the "Happiness index" of $D_{33} = .084$, $p>.05$ according to Howell (2008) indicates that this score does not deviate significantly from the normal curve (see Figure 10 below).

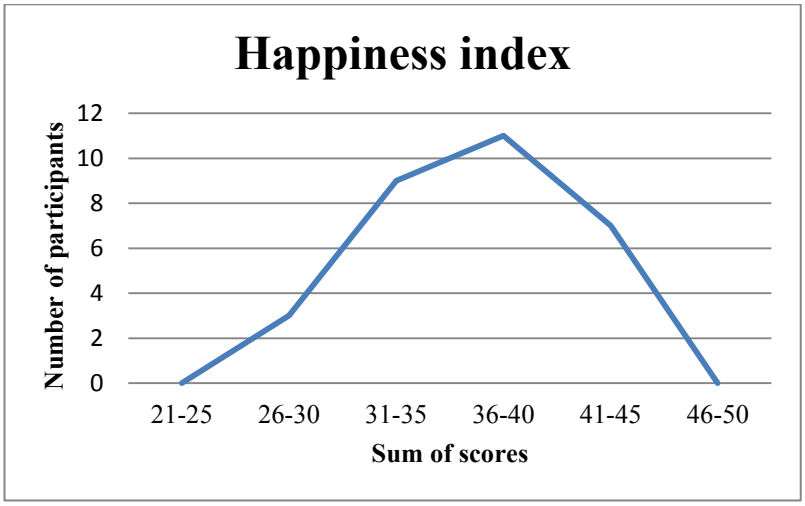


Figure 10: Participants' general happiness with status of the cleft

Results from a 5-point rating scale, measuring participants' satisfaction with each of seven aspects of their child's cleft, was calculated as a mean for the sample of participants, and these are reflected in Figure 11 below. It is significant that the four areas indicating the highest degree of satisfaction, that is, the lip, face, hearing and nose are all addressed early in the child's life, while the results of treatment for the bite, speech clarity and teeth are often manifested later. These findings may therefore have been a function of the age of the patients in the sample, as they had not yet received orthodontic treatment to correct dental malocclusions and may still have been receiving speech therapy to address the cleft type characteristics in their speech.

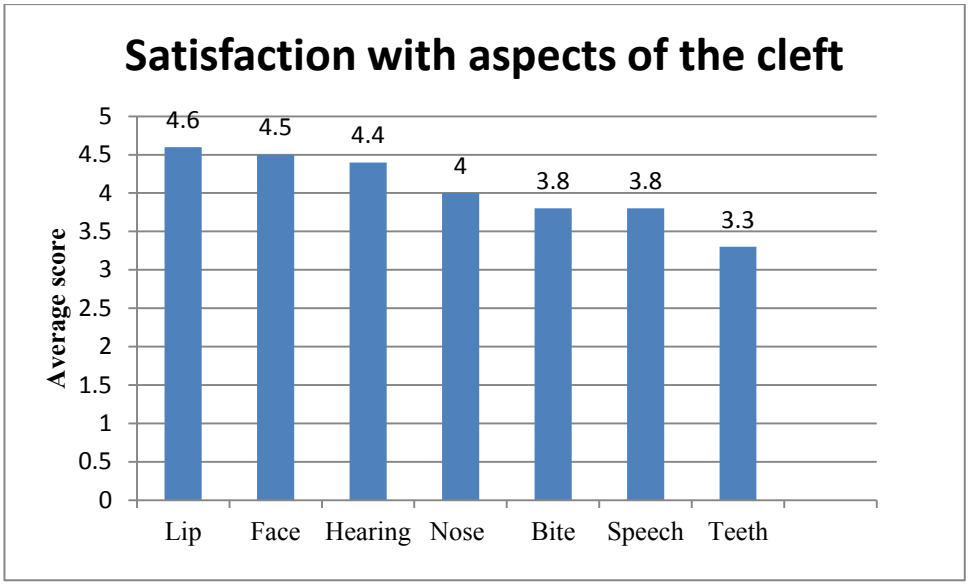


Figure 11: Participant satisfaction with aspects of the cleft

Responses from a 5-point rating scale measuring participants' optimism, with four aspects of their child's future projected for 10 years, was recorded, with the high level of positive feelings receiving a score of 5 and negative feelings receiving a score of 1. Aspects relating to optimism included the child's future in terms of education, appearance, social interactions (friends) and speech. The sum of the scores for each of these four aspects was calculated and formed the participants' "Optimism index" thus the higher the score, the greater the participants' feeling of optimism for the child's future. The scores on the "Optimism index" of $D_{33} = .529$, $p>.05$ (Howell, 2008) do not follow a normal distribution (see Figure 12 below). There is a clear difference between the trends indicated in the "Happiness index" which follows a normal bell curve, and the "Optimism index" which is clearly skewed towards a high level of optimism. This may reflect the stage in the management of the cleft that the parents find themselves. Treatment begins at birth and may only end in adulthood at the completion of orthodontic intervention, or when secondary surgery has been performed to improve aesthetics and speech. It appears that because of the long-term nature of the management of the cleft, parents may go through a normal range of emotions regarding the cleft, but always believe that things will turn out well in the end.

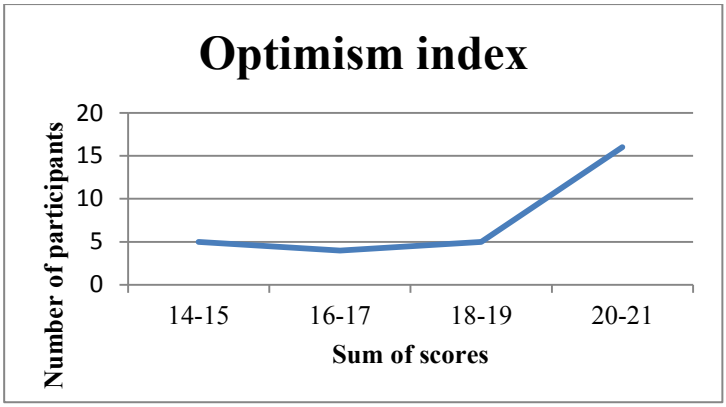


Figure 12: Participants' feeling of optimism for the future

Results from a 5-point rating scale measuring participants' optimism regarding four aspects of their child's future, namely education, appearance, social interactions (friends) and speech appear in Figure 13 below. Scores were calculated as a mean of the participants' responses for each category (Howell, 2008).

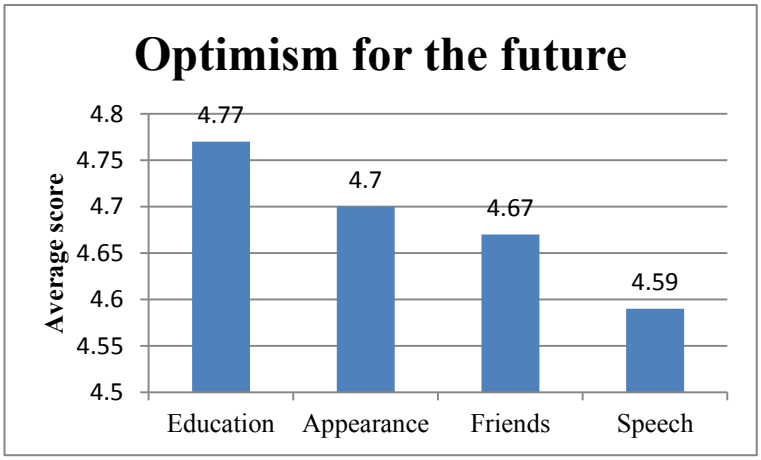


Figure 13: Participant optimism for the future

It appears from the findings that of these four parameters, parents/caregivers were the most optimistic about their child's educational success. Noar et al. (1991) report on a number of studies which indicate that patients with CLP can achieve equal academic success as their non-cleft peer group. In their own study however there were some discrepancies between the beliefs of parents and the beliefs of the patients regarding the effect the cleft had had on

academic achievement, with some parents believing there had been a negative effect. The second aspect reflected the parents/caregivers' optimism for their child's appearance, indicating their satisfaction with the aesthetic results of plastic surgery and hope for the future results of orthodontic treatment. Although the management of the child's facial appearance had not yet been complete, these findings nonetheless supported the findings by Noar et al. (1991) that parents were happy with the outcome of the surgical and orthodontic treatment their children had received.

The third aspect related to the child's ability to socialise, and here again echoed findings from the study (Noar et al., 1991), where parents believed that the cleft had affected their child's friendships. The findings in the present study revealed that parents/caregivers feel the least optimistic about the possibility of their child achieving normal speech. This echoes the findings of Paynter, Jordan and Finch (1990) who found that the majority of respondents are more concerned about the severity of the patient's speech than of any other facet of the condition. Although the finding in the present study related to what parents/caregivers expected in the future, it nevertheless concurs with the study by Noar et al. (1991) where parents and older patients (16 to 25 years of age) commented retrospectively on their satisfaction with outcomes of treatment, and were the least satisfied with speech outcomes.

An attempt was made to correlate the "Happiness index" and the "Optimism index with other parameters, such as the patients' age, race, access to funding, age at first contact with the CPT and type of cleft. Both parametric (Pearsons) and nonparametric (Spearmans) statistical tests were applied (Howell, 2008); however no statistically significant findings were identified. This could in part be attributed to the small sample size associated with a large standard deviation in the findings of each of these relationships. Certain qualitative findings however might be more insightful in assessing the value of the service provided by the clinic.

Summary of Results

The findings of this study indicate that parents/caregivers were generally happy with the service they received from an interdisciplinary cleft palate team based in the private healthcare sector of Johannesburg, and of the combined clinic which the team ran. Some reservations about their unmet needs were also expressed by the parents.

Based on the questionnaire the findings are summarised as follows:

a. Positive comments

- Early referrals, preferably in the prenatal stage assist parents to cope.
- Receiving information and emotional support is helpful.
- A combined clinic with the team is beneficial for the patient.
- Patients appreciate being able to participate in decision making.
- Parents trust professionals who have been involved in the field for a long time.
- Receiving a written copy of the team recommendations is helpful.
- Contact with other parents of children with CLP is useful.

b. Concerns

- CLP poses a financial burden whether or not patients are on medical aid.
- Not all team members were present at every clinic.
- Walking into a clinic with many professional present can be daunting.
- Not enough time is spent with parents.
- Records are not always available at the clinic.
- Follow up appointments sometimes take too long.
- Communication may be difficult if English is not the patient's home language.

c. Suggestions provided by the parents/caregivers

- Parents need better preparation before attending the combined clinic.
- Clinic sessions need to be better organized.
- Patients appreciate a written summary of findings and recommendations following the clinic.
- More information is needed in the areas of surgery, genetics, speech development, the role of grommets, orthodontic treatment and the meanings of technical terms.
- More financial assistance is needed for parents to manage their CLP child.
- Greater public awareness of CLP and of the service offered by the team is needed.

CHAPTER 5

DISCUSSION

Overview

As a professional member of an interdisciplinary CLP team based in the private healthcare sector of Johannesburg, I aimed to explore the perceptions and experiences of parents/caregivers attending this combined clinic, in this study. It is well documented that best practice for patients with CLP is management by a team of professionals (ACPA, 2009). Although this is common practice in the developed world, in developing countries in Africa it is rare (Sommerlad, 2008). In South Africa particularly there are a number of multidisciplinary CLP teams based in the public healthcare sector and frequently associated with academic institutions (Dekker, 2007). In most cases, these teams include only core members, such as a surgeon, a speech therapist and occasionally an orthodontist. These team members seldom meet on a face-to-face basis, and therefore interdisciplinary teamwork, even in South Africa, is uncommon.

This study argues for best practice in the management of patients with CLP within an interdisciplinary team of professionals, which meets face-to-face with the parents and the patient in a combined clinic. It also argues for further investigation into the possibility of funding for public-private partnerships that can make such services available to the wider South African population. Evidence-based practice includes a combination of scientific evidence and clinical care (Grol & Wensing, 2004). An exploration of the experiences and perceptions of the parents/caregivers of patients with CLP provided a means of evaluating the service they received from an interdisciplinary team that met with them in a combined clinic, in order to strive towards the goal of providing best practice. Despite the recommendations of ACPA (2009) that it is important to evaluate CLP team services based on the levels of satisfaction and psychosocial well-being of the patients, there are no studies reported where this has been formally conducted in Africa. Furthermore, evaluations need to be responsive to the context in which the CLP programme operates.

A number of positive effects were realised as a result of the combined clinic. Results of the study confirmed that overall, participants held positive views about the service provided to them by members of the CLP team, and specifically by the combined clinic, thus showing their preference for management by an interdisciplinary team. From their feedback it was apparent that they appreciated the service that had been provided by the team. On the whole they felt involved, informed and satisfied with the level of expertise and communication provided by the team members. They also expressed a high level of optimism for the future outcomes of their child's treatment. Their remarks provided valuable encouragement for the continuation of the service. In addition to their positive experiences however, they also qualified their responses by raising specific issues where their needs were not met, and suggesting ways in which the service can be improved. The findings provided valuable suggestions for the improvement of service delivery at this combined clinic and further contribute to knowledge about CLP care in South Africa.

After a period of six years, the funding of patients with no access to private medical aids was terminated, possibly due to factors relating to donor fatigue. Donor fatigue (Medical Dictionary, 2014) refers to donors who have previously supported specific projects or charities who have ceased to do so because of budgets being exhausted, because of demands being made on them by other projects, or because they are frustrated by the mismanagement of their funds. Fortunately the termination of funding occurred after all the data had been collected, and thus did not influence the study in any way. Anecdotal observation following the study was that the cessation of the combined clinic resulted in a drop in the level of inter-referrals between team members and the general decrease in the size of the caseload, to the extent that the combined clinic was suspended even for patients who did have access to medical aid. While the possibility remained that the combined clinic would be renewed, the temporary suspension of the clinic may have provided an opportunity for reflection; and based on the exploration of the experiences and perceptions of the parents/caregivers, improvements can be made in the future that may provide an even better and more sustainable service to the patients.

Reflection on the Theoretical framework

This chapter continues by locating this study with in the various theoretical frameworks introduced above, namely the theory of Collaborative Teamwork, the theory of ecological systems and the theory of program evaluation. It continues with a discussion on the means utilized to evaluate the combined clinic of the CLP team. The experiences and perceptions of parents who had attended the facility are described, and of a review of the medical records of the professional members who had treated the patients with CLP are outlined. The evaluation is structured to include a description of the everyday running of the clinic, as well as the accessibility and effectiveness of the service. It is aimed at the improvement of this particular facility, and of cleft care in South Africa.

(a) Collaborative teamwork

The framework used by Choi et al. (2006) to classify various levels of teamwork is useful in describing the nature of the particular team in this case study, during the period in which the combined clinic was held, as well as the periods preceding and succeeding it. The team ran for many years as a multidisciplinary team, in which a plastic surgeon, speech therapist, orthodontist and ENT surgeon worked independently in evaluating and treating patients with CLP, referring patients to one another, but not meeting regularly as a group. During the six years in which a combined clinic was held monthly, the team evolved thereby fulfilling the requirements of an interdisciplinary team (CIHR, 2005; Choir et al.; 2006; Kummer, 2014).

In the case of the combined clinic, the *task design* as described by Cohen and Bailey (1997) was one of delivery of holistic care for patients born with CLP. The *task features* pertain to the independence of the particular team members working in their respective practices. The *team composition* in terms of size and definition of members as described by Cohen and Bailey (1997) increased to include an audiologist and a social worker. Additional professionals joined the group from each profession. The skills of the professionals were complementary and overlapping (Lorimer & Manion (1996). The *team processes* (Cohen & Bailey, 1997) also increased to involve regular meetings in a combined clinic with the

patients and parents thus allowing for joint and integrated management, collaboration, regular face-to-face communication and cooperation between team members. These processes promoted efficient lines of communication and cohesion as proposed by Mickan et al. (2005) and effectiveness in problem-solving (Cohen & Bailey, 1997) and had a direct bearing on Körner's (2009) argument that interdisciplinary teams are more effective than multidisciplinary teams.

As the suspension of funding occurred after the data collection phase of the study, it had no bearing on the result. It was my observation as a team member however that one of the results of the suspension of funding was that the caseload that made up the combined clinic was significantly reduced, making it difficult to justify the professional time, especially as the service was voluntary on their part. The parent support group which had grown out of the combined clinic was also suspended at this time, as the Social Worker was no longer remunerated for her involvement in running it. While the team may have continued to benefit from the six years in which members had met regularly, in that there had been a period of increased communication, collaboration, building of mutual respect and problem-solving, it essentially reverted to being a multidisciplinary team, treating only those patients who could afford private health care. It does however raise the question however as to whether the availability of funding has a direct impact on the type of teamwork that can be offered.

(b) Ecological Systems

The ecological systems theory of Bronfenbrenner (1997) is a useful approach in locating the child who was treated within the CLP team in this study. The *microsystems* of the child included the family as well as the professional team which treated the patient, as the child experienced both of these directly. As the child often accompanied his/her parents to the parent support group, this formed an additional *microsystem.* Naturally the child also operated within other *microsystems*, such as the school and peer group. Interestingly, the combined clinic was another *microsystem,* within which the child operated, but was simultaneously a *mesosystem* that enhanced the interrelationship between the *microsystems*. These interrelationships strengthened between the team and the parents, the team and the

school, and the team and other professionals dealing with the child, including the community speech therapist, the geneticist, the psychologist, the dentist, the maxillo-facial surgeon, and others.

The funders of the CLP team formed an *exosystem* of the child, as they had a bearing on the child's management, although the child did not have direct contact with them. According to Garbarino and Ganzel (2000) exosystems may either impoverish or enhance the behaviour of the parents in the *microsystems* which they share with the children, thus both risk and opportunity may flow from the *exosystem*. If funding is suspended therefore, the development of the child is jeopardized, and when it is provided, the child's developmental opportunities are increased. The professionals in the *microsystem* of the patients need to be informing the funders in the *exosystem* as to the services needed by the patient. This will in turn strengthen the *mesosystem* of the patient by enhanced communication between stakeholders.

(c) Program Theory and Evaluation

For a program to be evaluated it needs to be described, and its goals and objectives defined. In an *articulated program* theory, the goals and objectives are spelled out and documented and are well understood by the staff and the stakeholders. In the case of the program in the present study, that is, the combined clinic of an interdisciplinary CLP team, the program theory was *implicit*. The program was aimed at providing patients born with a cleft of the lip and/or palate with a holistic approach of management, where they were more likely to receive the advantages of interdisciplinary care. In addition, it was aimed at providing this service within the private healthcare sector to include those patients who would otherwise not have had access to such a facility, because of the funding provided by the sponsors. Kummer (2008, p. 300), highlights the advantages of interdisciplinary care as having "access to multiple disciplines, centralisation of services, long-term treatment planning from birth to adulthood, better continuity of care, comprehensive documentation, more professionals involved in the patient's care, interdisciplinary evaluations, follow-up studies, and interdisciplinary research and quality assurance." Furthermore a combined clinic would be able to facilitate care by the healthcare providers, and would be more effective for the patient. Rossi et al. (2004) stress the need to identify all of the stakeholders and their likely use of the

evaluation findings in ensuring that the program is evaluable. The stakeholders in this program included the patients, their parents, the professional team members and the sponsors.

The framework for describing the three components of Program Theory advocated by Rossi et al. (2004) is useful in describing the components of the program in this study, namely the combined clinic of the CLP team. In terms of the *impact theory* component of this program, the effect it had on the target population, namely the patients with CLP and their parents, in achieving its goals and objectives was reflected through the participants' responses in the questionnaire. They had the opportunity to express their experiences and perceptions of the clinic and their satisfaction with the service provided. Their interaction with the team including communication and information provided reflects the *service utilisation plan* of the program. The program's *organisational plan* included financial resources, especially from the sponsors, physical accommodation within a private hospital, professional staff members with appropriate training and experience, namely the professional team members from each of the respective fields, as well as administrative support. The participants in this study made use of the open ended questions in the questionnaire to reflect on the perceptions and experiences regarding financial challenges, the competence of the professional staff, the geography of the of the clinic and administrative aspects such as record keeping and making of appointments.

While the head of the program and the members of the professional team agreed to support the evaluation, this does not necessarily suggest that they would be able or willing to use the evaluation information to change the program (Rossi et al., 2004). It should be stressed therefore that future sponsors as stakeholders in the program need to be regularly informed about the service being provided by the team, and the manner in which funding is being utilized, and indeed be encouraged to attend clinical sessions, in order to motivate for sustainability.

While the evaluation in this study was limited to the perceptions of parents/caregivers, there is scope for more in-depth programme process evaluation of this CLP team and the clinic which it runs to be carried out in the future, as in the areas suggested by Rossi et al. (2004):

- The number of persons receiving the service, and whether they are the intended recipients.

- Whether the recipients of the service are receiving the proper amount, type and quality of service.
- Whether there are potential recipients not receiving the service and how they can be reached.
- Whether there is sufficient awareness of the service, and what type of marketing is required.
- Whether there are sufficient resources for the service with regard to staffing, facilities and funding, and if not what is required in this regard.
- Whether the service is efficient, organized and compliant with professional and government requirements.

The methods used to evaluate CLP team

Given that the evaluation was based on the perceptions and experiences of parents/caregivers, the question has been raised as to whether patients can in fact make reliable judgments on the quality of health care and how they have understood the service they have received. Wensing, Vingerhoets and Grol (2003) caution that while patient feedback can help to identify areas of healthcare that require improvement, there are specific barriers which would need to be removed before changes could be implemented based on that feedback. They concluded that while doctors may be very motivated to learn about their patients' views about treatment, they may be reluctant to use the feedback to introduce change to improve their service. The literature therefore questions the value of patient satisfaction surveys as a tool for improving service. Coulter (2006) maintains that while patients' questionnaires should not be used as the sole measure of the quality of healthcare, one cannot suggest that patients are unable to assess the quality of care that they receive. She recommends rather than merely using rating scales, a detailed report on their experiences is more valuable. The findings in this study resonate with those of Coulter (2006) as she reports that patients in their assessment of healthcare focus on aspects such as communication skills, technical skills, being able to give good advice, maintaining confidentiality, respecting patients' dignity and involving them in treatment decisions.

Return rate of Questionnaires:

Despite the fact that questionnaires were sent out in the format requested by the participants themselves, that is by mail, by fax or electronically, and the research assistant followed up with participants who had not responded, it is evident that providing hard copies of the questionnaire increases the likelihood of it being returned. A possible explanation for this is that hard copies are easier to process, and return via the prepaid envelope provided. They may also be constant reminder to the participants to complete them. Electronic mail however is easy to ignore or delete, and would have taken greater effort to print, fax or scan. Possibly a higher response rate may have been achieved if the electronic questionnaire had been followed up with a hard copy by mail.

An alternative method for completing the questionnaire could have been either during a telephonic interview (Paynter et al., 1993; Austin, 2010), or at a specially arranged date collection clinic (Thomas et al., 1997). The respondents could have been tape-recorded while they completed the standardised questionnaires and would have been encouraged to discuss their responses to items in depth. Bowling (2005) points out that a telephone interview makes greater auditory, verbal and language demands on the participant. The least burdensome method however is a personal face-to-face interview. This does not depend on the participant's reading skills, and the interviewer can assist the process by motivating the participant, clarifying the questions and jogging their memory. Cummings et al. (2001) report that mailed questionnaires are probably the most frequently used method for surveying physicians in healthcare services, as they are less costly than telephonic or face-to-face interviews. One of the disadvantages of a mailed questionnaire is that the response rate tends to be lower, and the results are likely to be biased in favour of the sample population that is most interested in the survey. Bowling (2005) on the other hand has found that postal questionnaires followed by at least two reminders can achieve the same response rate as interviews: as high as 85%. A further disadvantage of administering a mailed questionnaire within the South African context is the risk involved in the dependence on a postal system that is frequently unreliable because of strikes in the postal service. Given these constraints, it may be preferable in future similar studies in South Africa to use a telephonic or face-to-face interview in completing a questionnaire. This approach may assist in increasing the response rate, overcoming language and literacy barriers and working independently of the postal and e-mailing systems.

The record review provided the opportunity of cross-checking patient details, such as the surgical dates when cleft repairs were carried out together with grommet insertion. It was beneficial in providing information that participants may not have been able to supply regarding patient management. It also provided an opportunity to compare different approaches to record keeping amongst professional team members. This information could possibly be used in the future to standardise record-keeping practices in the team.

Evaluation of the clinic

The evaluation covered three main areas. Firstly the daily running of the team and clinic, based on the medical record review which included the demographic details of the patients, and the intervention that had been provided by the professional team members. Secondly, the accessibility of the service focused on marketing of the facility, the means of referral to the team, affordability, transport requirements, parents' awareness of team members and their communication with team members. Thirdly, the effectiveness of the service was described in terms of parent satisfaction, the information provided to parents, their involvement in decision making and the effectiveness of a combined clinic. The key findings of these areas are discussed below.

A. Daily running of the team and clinic

A record review of the medical files of team members revealed that records vary greatly in the amount of detail they contain. They were also useful in cross-checking the demographic details of the patients.

Demographic details

Both the record review and the questionnaire provided information regarding the demographic characteristics of the patients and their parents/caregivers. These details were used to compare the population of cleft patients in this group to the South African population and to the international cleft population. The type of cleft and gender trends, for example,

mirrored that of general trends. Information relating to cultural groups and home language is useful in identifying the need for resources such as interpreters. The area of residence of the patients is important information in understanding transport and accommodation needs. Information regarding the source of referral to the team informs the need for marketing and the provision of reports. Possibly an additional question could regarding the educational level of parents/caregivers could have been included, as this may provide greater insight into the level at which to pitch information.

Treatment protocol of the CLP team

The following services were provided to the patients with CLP by the individual professionals within their private practices.

- **Surgical repair of the cleft lip and palate**

The ultimate goal in surgical repair of a CLP is appearance, speech, hearing and maxillo-facial growth that is, within normal limits. There is a great discrepancy which exists regarding the timing of CLP surgical repairs and a report by the Eurocleft Project that in 201 teams in Europe, there were 194 different surgical protocols followed for the repair of unilateral CLP alone (Shaw, Semb, Nelson, Brattström, Mølsted, Prahl-Andersen, & Gundlach, 2001). Salyer et al. (2009) advocate three months of age for the initial repair of the unilateral cleft lip and nose. At this age, the infant has developed beyond the age of 60 weeks gestation, and is therefore considered by many paediatric anaesthesiologists to be safe for a general anaesthetic. In addition, there has been sufficient growth of the lip to facilitate greater precision in the repair.

Shprintzen and Bardach (1995) concede that there is no established protocol for the timing of cleft palate repair, which is universally accepted by surgeons, speech therapists and orthodontists. According to Friede (2009) there are many variations of surgical protocol regarding both the techniques and the time of surgery, resulting in the controversy which continues to exist as to the benefits of the two-stage palatal repair. In the literature, the recommended age for soft palate repair has varied from three to 24 months, while the timing of the hard palate repair has ranged from six months to 16 years. These age recommendations tend to reflect the personal experience of the individual surgeon (Friede, 2009). Even within

South Africa, the protocol for the timing of cleft surgery varies. At Red Cross War Memorial Children's Hospital for example, the protocol followed is to perform primary surgical repair on the lip and palate under a year of age, and preferably at the age of six months (D. Lazarus, personal communication, June 20, 2014). In a literary review on the optimal timing of cleft palate closure, Rohrich, Love, Byrd and Johns (1999) report that early repair of a cleft palate is more likely to result in normal speech development than is a delayed repair, that is, beyond two years of age, as the velopharyngeal mechanism is restored to normal function. Patients receiving early closure are likely to develop better intelligibility and fewer articulation disorders.

With regard to secondary palatal surgical intervention to address problems with velopharyngeal insufficiency (VPI), Kummer (2014) recommends that this be performed between the ages of three and five years. Forrest and Klaiman (2009) agree that the diagnosis of VPI is usually not confirmed until the child reaches four years of age. By then speech and language have had a chance to develop, speech therapy should have been introduced to improve velopharyngeal valving and articulation. With the child being of an age where he/she can cooperate with nasendoscopy and videofluoroscopy to confirm the diagnosis, pharyngeal flap surgery can be performed at around five years of age. Forrest and Klaiman (2009) also estimate that between 10% and 36% of children suffer from velopharyngeal dysfunction following a cleft palate repair.

The finding that the timing of surgical repairs to the lip and palate at times fell outside of the team's regimen because of a late referral concurs with the report by Shaw, et al. (2009) that, patients in developing countries often present for CLP surgery at later ages than is the case in developed countries. It also highlights the need to strive for early referral to cleft care, so that patients can receive surgery within the recommended time frame, and thus reduce the negative effects of late management on speech and language development, aural health, and psychosocial wellbeing. Late referrals may be related to the level of information that parents have regarding CLP and the referral resources available to them.

- **ENT**

According to Dhillon (1988, as cited in Lennox, 2001) otitis media with effusion (OME) is almost universally present in cleft palate children and advocates the insertion of grommets. Chafin and Bluestone (2009) describe two general approaches to the management of middle ear disease in patients with CLP. The first approach advocates early and aggressive intervention with the use of ventilation tubes (grommets) as originally advocated by Paradise and Bluestone (1974). This approach is in response to the high incidence of the disease, with patients universally suffering from eustacian tube dysfunction leading to middle-ear effusion. It concurs with Sabo et al. (2009) who stress the need for aggressive otological management so as to minimise the effect of OME and associated conductive hearing loss, and to maximise optimal outcome particularly in speech and language development. The second approach advocates a more conservative and selective approach, with the aim of reducing the risks associated with grommets and the need for repeated surgery.

The team in this study thus followed the more aggressive approach to the management of middle ear disease. By coordinating plastic and ENT services, wherever possible reconstructive surgery to the cleft was carried out simultaneously with myringotomy and grommet insertion, thus reducing hospitalisation and anaesthetic costs, and the time parents would need to take off work to attend to the patient. Rohrich et al. (1999) concur that the early prophylactic insertion of ventilation tubes at the time of the cleft repair saves an anaesthetic, and also significantly reduces the chances of recurrent OME and possible long-term hearing loss, thus improving the chances of better speech and language development. This once again highlights the value of having a team to manage children with CLP, and that health policy makers should be aware of the importance of a team approach. An aggressive approach may be more effective in a developing country where follow-up visits are unreliable.

- **Audiology**

According to Sabo and Probst (2009) OME is nearly universal in cleft palate infants due to abnormal Eustachian tube function. It may decline with increasing age, but it can also remain

following a palatal repair, and even into adulthood. Conductive hearing loss may be transient or permanent, either associated with fluctuating OME or due to structural anomalies of the ear. They recommend ongoing routine audiological evaluations, either through the multidisciplinary CLP team, or through an audiology clinic in the community.

The fact that early and aggressive management of middle ear pathology was a protocol of this team may have resulted in the fact that participants indicated a high level of happiness with hearing. The low frequency (40%) of formal audiological evaluation amongst patients may however be an indication that both professionals and parents had the perception that hearing was 'under control'. Closer monitoring would be necessary to establish whether patients had in fact been referred to the audiologist but had not followed up with making appointments, or whether they were not routinely referred. I am of the opinion however, that even fewer audiological evaluations may have been conducted if the audiologist had not been present at the combined clinic to make appointments directly with the patients. Dekker (2007) found that less than half of South African cleft palate teams include an audiologist, and limited follow-up is done. It seems therefore that in South Africa, we are still a long way from achieving the target of routine formal audiological evaluations of all children with CLP, and that regular team meetings which include the audiologist would go some way to reaching this target.

- **Speech Therapy**

Kummer (2014) outlines the speech therapy timetable for intervention, beginning at the first few weeks of life with assistance regarding feeding. Nearly half the parents in this study consulted the Speech Therapist in the perinatal period. Once effective feeding has been established, Kummer recommends that parents should be counselled during the first three years regarding language development. Over a third of patients in this study saw the Speech Therapist for the first time as toddlers, and 92% had seen a speech therapist before the age of two years. Given the speech therapist's role in assistance with feeding difficulties though, the referral to speech therapy services should be in the neonatal period for all patients with cleft palate.

Kummer (2014) suggests that during the first three years, the emphasis should be on *quantity* of speech, that is, how much the child understands, the size of the child's vocabulary and the number of words used in their utterances. During this time parents should always be given written information including a home language stimulation program. If language does not develop or if feeding problems persist, then therapy should be initiated immediately. After three years of age the emphasis is more on the *quality* of speech, that is, articulation, resonance and intelligibility. The goal Kummer cites for physical management and speech therapy in the preschool years is to attain age-appropriate speech, or close to it, by the time the child enters kindergarten.

It is not necessary or in fact possible for the team Speech Therapist to treat all the patients who require speech therapy intervention, but she can fulfil an additional role by monitoring and supporting community speech therapists. Despite the fact that all speech therapists receive undergraduate training in the field of CLP, unless they are employed in a hospital and have experience working in the field, they frequently do not see sufficient numbers of patients with CLP to gain confidence in treating them, and they therefore welcome support from a more experienced therapist.

- **Social work**

The recommendations of ACPA (2009) regarding optimal care for cleft palate patients include taking into account their psychosocial well-being. Every effort should be made from the time of the first contact with the family to assist them in adjusting to the baby with CLP and the specific demands that are made on them. According to Kapp-Simon and Gaither (2009) individuals born with CLP face many challenges that may impinge on their psychosocial adjustment. As they are at risk in the areas of stress, parent-child interaction, cognitive functioning and learning, social interaction, and self-concept, the CLP team needs to monitor the psychological functioning of both the patient and the parents during the planning and implementation of their medical treatment. The inclusion of a social worker and/or psychologist on the team enhances the team's ability to address these issues. Not only is this professional able to counsel the patients and parents directly, but he/she is in a position to promote an empathetic attitude amongst the team members. Dekker (2007) found that only

one out of seven South African cleft teams included a social worker, and only two out of seven included a clinical psychologist. Considering the scarcity of social workers relative to the demand for their services in South Africa (Earle, 2008), and the problem of burnout facing those working in healthcare (Antwi, Chigumba, Mutambasere & Seyuba, 2013), the inclusion of a Social Worker in the team to address the psychosocial problems of the patients, and also to heighten the other professionals' awareness of these aspects, was considered a fortunate asset to the team. In addition, her inclusion in the team led to the establishment of a parent support group, a service which was attended by a third of the parents/caregivers in the study, and from their feedback was found to be valuable.

- **Teamwork in the combined clinic**

Greenhalgh (2008) in her discussion on organisational routines stresses that effective and efficient collaborative work in healthcare depends on the people involved. Apart from being competent, they should be capable of undertaking the role that is expected of them. They should be flexible, able to communicate with and be responsive to the input of others. They should be critically aware of their own performance, their limitations and their needs within their clinical work. They should identify themselves as an important role-player in the team, and take it upon themselves to be active agents of the routine.

Anecdotal observation, not based specifically on the results of the study, but in my role as a member of the team reflected that, at the combined clinic, parents were able to participate in the discussion with all the team members simultaneously and hear their views regarding future management of the child. Differing views between the professionals regarding management of the patient were more easily addressed in a friendly and relaxed manner. Team members learned more about one another's roles so that the expectations of one another were more realistic. They were also better able to provide information to patients regarding one another's roles during individual consultations.

Regarding the physical accommodation of the clinic, it should be conducive to relaxed and professional communication. The venue should be accessible, easy to find, comfortable, not cramped or too vast. It should be appropriately furnished with enough chairs for the team members the parents and the child, providing refreshments in the way of tea and coffee for the staff and the patients who are waiting.

A feature of this particular team in the private healthcare sector was that all the professional team members were experienced in the field, and had all been consistent members since the inception of the combined clinic. This feature is not common in the public healthcare sector where there is a high turnover of staff. Despite the fact that they were not remunerated for attending the combined clinic, and that they themselves had busy caseloads, they were motivated to attend, indicating the benefit that they derived from meeting and sharing their ideas and concerns.

The participants in this study pointed out a number of positive features of the teamwork they experienced. These included early involvement of the team, the information provided, the support they received, the holistic management they received, the level of competence of the professionals and the interaction between team members. On the whole they appeared satisfied with the service they received and the effectiveness of their treatment. They also pointed out unmet needs, which often seemed to refer to a lack of consistency and discipline in the team's own objectives. These included inconsistent availability of records, occasional lack of provision of written reports after a clinic, occasional absence of team members from the clinic, the absence of an interpreter who could communicate in the patient's home language, extended waiting periods for a follow-up appointment and inadequate preparation of the patients for meeting a large team of professionals. These are areas in which the team could address in terms of improvement of the service.

The *team processes* described by Cohen and Bailey (1997) was therefore enhanced by holding regular meetings in a combined clinic with the patients and parents, thereby allowing for joint and integrated management, collaboration, regular face-to-face communication and cooperation between team members. These processes promoted efficient lines of communication and cohesion as proposed by Mickan et al. (2005) and effectiveness in problem-solving (Cohen & Bailey, 1997) and had a direct bearing on Körner's (2009) argument that interdisciplinary teams are more effective than multidisciplinary teams.

B. Accessibility

A program can only be effective in providing a service if the recipients have access to it. The findings of this study showed that in order for patients to have access to the services offered by the CLP team members and the combined clinic, a number of factors need to be in place. The following discussion highlights these factors, based on the findings of the study, and suggests what would need to happen to enable the patients to access the service.

- **Marketing**

The service is only accessible to patients if the referral agents are aware of the facility. In order to heighten the awareness of the service to medical practitioners, and especially delivery room personnel and neonatal care personnel, information about the CLP team and the service it provides should be made available through printed material, and through academic publications. In the study, 6% of patients learned about the team through the media. It is therefore important to increase awareness to the public by providing online information regarding the services provided by the team. One participant suggested that media such as television could be used more extensively to advertise the service, particularly showing pictures before and after reconstructive surgery. Another suggested spreading the service into adjacent countries such as Zimbabwe. The demographic characteristics (Table 2) indicate that 9% of patients came from other African states. A dedicated website should provide details on the various professions represented on the team, contact details and the procedure for making appointments. The team involved in cleft care therefore has a responsibility to educate professionals, parents, patients and the public in the services available.

- **Referral to the team**

Patients can only access the service if they are referred to one of the members of the team. Results of this study indicated that 70% of referrals to the team came from medical and allied medical professionals e.g. general practitioners, paediatricians, nurses, gynaecologists, speech therapists etc. In order to encourage the referral agents to refer again, and to

encourage them to inform their colleagues regarding the service provided by the team, it is necessary to provide them with feedback regarding the patient. This underlines the importance of providing written reports to the referral agents regarding the patients' visits to the combined clinic as well as their consultations with individual team members. The individual team members also need to be made aware of the criteria for referring patients with CLP for a combined consultation with the team.

Apart from the initial referral of patients to the team as a whole however, it is also important for the individual team members to be regularly referring the patients to each other. As the team members met face-to-face on a regular basis, inter-professional referrals may have been facilitated. It is likely that this could increase the rate of inter-professional referrals resulting in more early, timely and holistic intervention. It could also result in appointments being more reliably made and kept, and recommendations made by individual team members more likely to be carried out because of an increased sense of accountability by the patients towards the team as a whole.

- **Affordability of the service**

Accessibility of the service depends on whether patients can afford to pay for it, or whether they are sponsored. The fact that this particular CLP team was based in the private healthcare sector posed a number of financial challenges for patients. Patients who had access to private medical aid still had to pay the excess charge by private practitioners contracted out of the private medical aid scheme, and therefore not obliged to charge medical aid rates. While some of these practitioners charged the patients with CLP at a reduced rate, not all of them did so, and this discrepancy was pointed out by some of the participants. Patients who were not on private medical aid schemes were funded and received their surgery, speech therapy, audiology and social services free of charge. The criterion used for providing funding to patients was simply whether they were on medical aid or not. This policy did not take into account whether patients in fact may have had the means to afford either all or a portion of their expenses regarding the cleft, even though they may not have been members of a medical aid scheme.

This suggests that a different approach should be adopted towards the allocation of funds. Each case should be individually evaluated so as to take into consideration the financial status of the parents, the financial burden resulting from the cleft and other associated abnormalities, as well as the social status of the parents for example being a single parent. A more conservative approach regarding the provision of funding could result in greater sustainability of funding and greater access to funding by more patients. Individual evaluations may also have highlighted the financial difficulties faced by patients despite being members of medical aid schemes.

The service provided by this CLP team can be compared to that of the Oro-Facial and Communicative Disorders Program at the University of North Carolina at Chapel Hill described by Strauss and Broder (1985). This program was funded through a grant for the purposes of funding the treatment of patients who had limited financial resources, while the patients who had access to health insurance benefits paid for their own treatment. Patients were certified as being eligible for funding and their financial status was monitored until the age of 22. It is relevant however that even in the study by Paynter et al. (1993), at a clinic associated with an academic institution in a first world country, 40% of parents reported financial challenges associated with the management of their child's cleft. Strauss (1999) points out that funders will frequently refuse to pay for orthodontic treatment even though it is clearly associated with cleft care, their argument being that it is related to dentistry and is therefore elective. In the case of the present team, the fact that orthodontic treatment tends to be long-term and expensive posed a problem for funding this aspect of the CLP child management. While one could still argue for the inclusion of orthodontic treatment as part of a holistic approach to the management of the CLP child, effective orthodontics could only be undertaken if there was good dental health and funding was not available for routine dental care. Bronfenbrenner's (1979) ecological systems theory highlights the problem that this approach raises, in that the management of the dental aspects of the cleft (a *microsystem*) should be included in the funding (an *exosystem*) in order to view the child holistically.

The present study focused on the experiences of parents/caregivers for the purposes of informing best practice, thus comprising a *process evaluation* (Fouché, 2011). In order to counteract donor fatigue, more consistent communication with the funders should be

maintained so as to justify the benefits of their donations to patients. As they are major stakeholders in the program, information should be provided to the funders regarding the outcomes of the program and its cost effectiveness, thus comprising a *summative evaluation* (Fouché, 2011).

There is an obvious advantage to a team such as the one discussed in this study, rather than being based in the private sector, being associated with a university or academic institution. The program might then incorporate more of an educational and research component. Theoretically it could to receive financial support including research grants as well as patient fees. Were the professional staff to hold academic posts they could be involved in the training of health care professionals in the field of CLP. Patient evaluations could take place under one roof, with centralised record keeping. The reality however, certainly in Johannesburg, is that cleft palate teams even in the public sector are facing enormous challenges with regard to funding, staffing and the coordination of interdisciplinary CLP teams. The Centre for Development and Enterprise (CDE, 2011, para. 26) comments on the critical staff shortage in the public sector, stating that "the most able, productive and dedicated staff in the public health sector are overworked, overstressed and cannot always rely on support either from above or below". This may result in burnout, or what Antwi et al. (2013) refer to as 'empathy fatigue' which frequently leads to healthcare providers moving to the private sector (Levin, 2006).

At the Charlotte Maxeke Johannesburg Academic Hospital for example only the plastic surgeon and speech therapist attend the cleft palate clinic, and all other services, such as ENT, audiology and orthodontics are accessed through separate referrals. The Social Work department only offers services to in-patients (T. Christofides, personal communication, April 5, 2014) thus excluding patients attend the CLP clinic as outpatients. Similarly at the Chris Hani Baragwanath Hospital, only the plastic surgeon and speech therapist attend the cleft palate clinic. Patients requiring ENT, audiological and social work services are referred to other clinics within the hospital and those requiring orthodontic services are referred to the Charlotte Maxeke Johannesburg Academic Hospital. A support group is coordinated by the Speech Therapist. No formal meetings are held by the full team (N. Lahouel, personal communication, May 26, 2014). It appears therefore, that without the existence of this particular CLP team in Johannesburg, the patients would not have had access to the holistic

cleft care provided by an interdisciplinary CLP team. The critical staff shortages being experienced in the public sector also results in long waiting lists for cleft surgery, which is not considered an emergency, and consequently in the need to involve NGOs such as Smile Foundation in reducing the waiting lists in a number of public hospitals (Smile Foundation, 2012).

The challenge of funding cleft palate management is not restricted to South Africa. Yazdy, Honein, Rasmussen and Frias (2007) have highlighted the need for more comprehensive data to be obtained regarding the financial costs associated with having a child with an orofacial cleft, both for the family and for society. South Africa however, because of its history, and its particular healthcare structure faces unique problems in addressing the financial challenges of cleft care in its various population groups.

- **Transport**

In order to access the service, patients need transport facilities to attend the clinic. Results of the study indicated that 73% of the patients came from the greater Johannesburg area. The remainder were from the rest of the Gauteng Province, other South African provinces and neighbouring states. Dekker (2007) established that only three of the nine provinces in South Africa have cleft palate teams. This suggests that patients may travel long distances to benefit from a holistic approach. This is a challenge particularly for patients who have to change a number of taxis and leave early from home with a small child to get to an appointment on time. Turner et al. (1997) found that in 10% of their cases, the inconvenience of long journeys to attend the clinic overshadowed the purpose of the appointment. Travelling to the combined clinic and to some of the consultations with team members would have been manageable for the majority of patients, but considerably difficult if they came from other provinces, rural areas and other countries and had to be accommodated while their child underwent surgery. It is suggested that rooming-in facilities should be investigated in such circumstances. Regular and frequent visits for example to the Speech Therapist for ongoing therapy would have posed a challenge to many. While these patients would have received assessments and monitoring with home programs, at times with the use of e-mail for example to send parents therapy material such as flash cards, more intensive therapy would need to be

arranged through community therapists. At times transport was arranged for patients to attend clinics as well as individual appointments with team members, however the transport service was not always reliable. This is a major problem in South Africa, and is related to its inherited past of insufficient transport infrastructure. Nevertheless participants seemed to attend most of the clinics scheduled.

Results regarding lack of attendance at the support group run by the team Social Worker indicated distance and travel expenses were major contributing factors. In addressing this problem it is suggested that the support group should take place at the same time as the combined clinic. In this way, parents who are bringing the child for consultation are already taking time off work and paying for transport.

- **Patients' awareness of the presence and role of each of the team members**

Participants appeared to be more aware of the presence of the core team members at the combined clinic, namely the Plastic Surgeon, the Speech Therapist, the ENT Surgeon and the Orthodontist. In the case of the first three specialties, it is possible that they had previously consulted with these specialists in a private capacity, and therefore recognised and remembered them. In the case of the Orthodontist, who according to his own report had not treated any of the patients in the study, participants nevertheless appeared to be aware of his presence in the combined clinic. This may be a function of the concern that participants expressed regarding the children's teeth. This is borne out by the results indicating that of all the aspects of the cleft, participants were the least satisfied with the teeth (Figure 10). Consultations with the Audiologist and Social Worker were relatively less frequent as can be seen in Table 5. It can be argued however, that the regular face-to-face contact of the specialists and patients at the combined clinic encouraged a higher proportion of inter-professional referrals being made and adhered to. Jeffery and Boorman (2001) also found that parents who attended a joint clinic were most aware of the plastic surgeon, the orthodontist and the speech therapist followed by the ENT, and questions the reliability of the memories of the parents. They reported that a number of parents believed that oro-maxillofacial surgeons had attended the clinic, when in fact they had not.

Their finding points to one of the difficulties experienced by patients attending a joint clinic. The confusion of who some of the team members are relates to the possible feelings of being overwhelmed; information over-load and misunderstanding of the roles of the team members. It can be very daunting to meet with a whole group of specialists in one room, and if they are not made sufficiently aware of the presence and role of each, they will be unable to derive maximum benefit from each one of them. Jeffery and Boorman (2001) therefore recommend that more information should be given to the families about the roles of various specialists they will see at the joint clinic. To increase parent awareness of the professionals involved in the team, the Social Worker, in her preparation of patients to attend the combined clinic, could supply the parents with a list of their names and roles, and mark off those who are present at each particular clinic day; as well as introduce them to the team. Team members could also be encouraged to wear name tags which include their professional titles. Although this practice was introduced by the team; it proved difficult to maintain. Greater consistency is therefore required to apply such practices and to assist with patient understanding.

- **Patients' communication with members of the team**

Ross and Deverell (2004) believe that effective communication between a patient and a practitioner needs to be clear and understandable, and needs to take place within the context of a relationship in which there is trust and respect. If this communication is effective, there is a greater likelihood that the patient will understand the information given and comply with the treatment recommendations. The value of including both scaled questions and open-ended questions in the questionnaire was borne out by the fact that all of the participants rated communication with the team members at the combined clinic as being "easy" or "very easy". Despite this, some suggestions were made on how to improve communication.

Firstly, it was suggested that patients should be given the opportunity to speak in their home language. Dekker (2007) found that over half the South African cleft palate teams had interpreters as team members, so as to address the diverse cultural and linguistic needs of the South African population. As the caseload in the present study consisted mostly of English-speaking White patients, this may not yet have become a priority. As more patients however were gaining access to the services of the team because of the funding available, the demographics of the caseload would possibly have changed over time, thus justifying the

need for an interpreter. Lynch (2011) has described the characteristics of effective interpreters. They need to be proficient in the language of the family and the professional. They need to understand and respect the cultures of the family and the professional, and be educated and experienced in communicating across cultures. They need to be educated in the professional field for which they are interpreting. It is difficult to find interpreters who meet these requirements, and using family members poses the same problems. Using random interpreters such as other patients in the waiting room may introduce the possibility of the interpretation being clouded by the interpreter's own personal issues. Furthermore, interpreters are also vulnerable to burnout (Lynch 2011).

Secondly, it was suggested that recommendations to parents should be provided in a written format. Often parents are overwhelmed by the information they receive verbally, especially at the initial consultations. As a result they do not remember the details, and cannot convey them to the other parent/caregiver who may not have been able to attend the clinic. Paynter, Jordan and Finch (1990) found that over 92% of respondents felt that receiving a written copy of the recommendations made by the team and the obligations to be undertaken by the patients was helpful. While it was the policy of the combined clinic to provide parents with a written summary of the recommendations by each team member, it appeared from the participants' comments that there were instances where this failed to occur. Greater rigor is therefore required in consistently providing written reports to patients.

C. Effectiveness of the service

For the service offered by the CLP team and combined clinic to be highly evaluated, it needs to be effective. The following aspects of care were explored in the present study: parent satisfaction with the services; their perception of their understanding of the disorder and the adequacy of information provided to them; their perception of involvement in decision making about their child's management and of the effectiveness of a combined clinic.

- **Parent satisfaction with the service**

Patient satisfaction is a significant indicator of quality of care (Johansson, et al. 2002). Noor and Musa (2007) identify factors that can contribute to the level of satisfaction with the CLP team. These include the making of appointments, the time it takes to travel to the clinic, the waiting time at the clinic, the information provided about the cleft disorder and its treatment, accessibility, cost, quality of technical expertise of the professionals, and the patient-professional interaction. Nelson et al. (2013) add to these factors: a sense of caring for patient and parents by the professionals, the delivery of information that is adjusted for the needs of the particular family, the provision of more detailed information especially regarding the procedures and risks of surgery and possible postoperative consequences, the need for a single point of contact in the team and continuity of cleft care.

It is difficult to separate the perception of parents/caregivers of the service provided by the individual team members as opposed to the 'combined clinic' specifically. The vast majority of participants expressed that they were "very happy" (77%) or "happy" (13%) with the service provided by the team. One participant who was dissatisfied with the service provided, complained of a lack of availability of the medical records at the clinic. The high level of satisfaction in the combined clinic can be compared to that found in the study by Jeffery and Boorman (2001) in which 96% of parents were either satisfied or very satisfied with the level of care they received in a combined clinic. Knapke et al. (2010) found as many as 100% of participants were satisfied with the services they received at the Craniofacial Center at Cincinnati Children's Hospital Medical Centre. Clearly the highest level of patient satisfaction possible is a target that all cleft palate teams should constantly strive for.

- **Parent Education**

The American Cleft Palate-Craniofacial Association (2009, p. 8) recommends that for optimal care of patients with CLP parents/caregivers must be given information regarding "recommended treatment procedures, options, risk factors, benefits, and costs to assist them in (a) making informed decisions on the child's behalf, and (b) preparing the child in themselves or recommended procedures". Jeffery and Boorman (2001) found that a third of the parents of the patients thought that they had either no knowledge or insufficient

knowledge about clefts. Furthermore, parents who did not feel they have enough knowledge about clefts and their treatment tended to be more dissatisfied with the level of care they received. While participants in the present study were generally satisfied with the amount of information they had been given, they nevertheless requested ongoing input regarding all of the areas related to cleft care, that is the aetiology of CLP and the role of genetics, planning and preparation for surgery, airway problems and the role of grommets, speech development and the planning of speech therapy intervention, dental development and the planning of orthodontic intervention as well as a general explanation of technical terms.

This finding resonates with the Eurocleft Consensus Recommendations which states that information should be provided to parents regarding the condition, the reasons and stages of treatment as well as the risks and benefits of treatment. It should include the risks and benefits of alternative treatments or no treatment at all. Also, if parents request a second opinion, the professionals should assist in obtaining this by providing them with a procedure for so doing. Following a procedure of treatment, the professional should convey to the patient the positive and negative outcomes, and the expectations for the future (Shaw et al., 2009).

There was also a request for written material in the form of a parent booklet. This finding echoes the study of Nelson et al. (2013) who reported that parents may prefer to receive information orally with supplementary written information. The team had in fact produced a booklet with basic information on all the areas of cleft care as well as a glossary of technical terms, as well as a booklet on feeding the infant with a CLP. Although it was team protocol to provide new parents with free copies of these two booklets, it appears that in some cases this failed to occur. It was also team protocol to provide patients with a one-page written report after attending the combined clinic, which stated the recommendations which had been discussed at the clinic by each one of the team members. As one of the participants requested that she receive a written report, it appears that in some instances this this did not happen. Once again, the need for greater rigor in consistently carrying out the protocol of the team is highlighted.

Other than through the printed material provided by the team, parent education also took place through the parent support group, where all the different professionals were invited from time to time to address a group of parents on the subject of the their field. The frequent

poor attendance at parent support groups, as reported by the Social Worker, suggests that parents may have missed this opportunity for further education, either because they were not informed of the existence of the support group, or because the service was inaccessible for them.

- **Parent involvement in decision-making**

The American Cleft Palate-Craniofacial Association (2009) recommends that the team should actively seek parental involvement and collaboration in planning the treatment of the CLP child. McWilliams et al. (1984) view the parents and patients as important members of the team. Pannbacker and Scheuerle (1993) acknowledge that there has not been consistent agreement or clear definition of the role that parents should play in the transdiciplinary treatment of cleft palate, but that the presence of parents is an important factor which has been recognized. According to Louw et al. (2006) however, the role of parents/caregivers in decision-making may be reduced if they tend not to ask questions, resulting in a tendency to receive information in a non-interactive manner. This may be attributed to a number of factors including their discomfort in communicating with the professionals because of a cultural mismatch, a language barrier, their low literacy level in English, a lack of understanding of professional terminology and a reluctance to be honest and open with an authority figure (Louw et al., 2006).

There is a difference in how professionals and parents perceive the role of the family in decision making about health care. Back in 1976, Doernberg, as cited by Pannbacker et al. (1993) identified four levels of parent involvement in health care which are still relevant:

(1) Professionals make all the decisions, and the parents agree.
(2) Families don't wish to participate, but the professionals disagree.
(3) Families do wish to participate but the professionals disagree.
(4) Families and professionals agree that decisions should be made jointly.

Only half of the participants in this study were "very happy" with the amount of participation they experienced in decision-making about their cleft child. This echoes the findings of Noor and Musa (2007) who found that 48% of parents felt that they were "very involved" in decision-making about their cleft child's treatment. These authors stress the importance of

treatment not being forced on patients who do not feel they have a problem, as they are unlikely to cooperate. Jeffery and Boorman (2001) found that parents who felt least involved with the decision-making about their cleft child were also those who tended to feel the most dissatisfied with the level of care they had received.

From the statements revealed in the questionnaire therefore, it appears that there were parents/caregivers in three of the aspects mentioned by Doernberg (1976) as cited by Pannbacker et al. (1993). Some parents were happy that the specialists were making treatment decisions, some expressed satisfaction that they were included in treatment decisions while some expressed frustration at having to wait for decisions to be made. This highlights the need for ongoing communication with the parents to ensure that they are appropriately involved in decision-making for their child, and that parents may differ in the amount of involvement they require.

While the present study did not attempt to probe the type of involvement that parents sought, Dekker (2007) found that South African families tended to be involved in speech-language therapy, in the timing of surgery and in the type of intervention received. Empowerment of the families can be enhanced by encouraging them to make some of the choices regarding suitable times for treatment, and which professional they prefer to administer that treatment. They can contribute to the patient's speech correction by suggesting ways to reinforce the speech therapy program at home, which is particularly important when parents can only see the speech therapist on a monthly basis or less. Parents can also promote good dental hygiene to allow for a favourable orthodontic result. They can contribute to the management process by keeping all their medical appointments. Thus the effectiveness of the team is highly dependent on the empowerment of the parents.

- **The effectiveness of a combined clinic**

Knapke et al. (2010) received feedback from participants in their study that consulting with specialists individually resulted in fragmentation of information, as some members of the team were unaware of the recommendations that are being given to patients by other members of the team. The suggestion made was that it would benefit the patient to meet with

the whole team at once instead of attending only separate appointments. This may result in greater consistency of information between team members. This view is supported by Jeffery and Boorman (2001, p. 189) who state that "the coordination of the various treatment plans is made easier by patients attending a ‘combined clinic’ where they are seen and the case management is discussed at all relevant specialties as a team, rather than seeing each specialist separately". This may however require more time and effort on behalf of the specialists, and it is not universal practice, especially considering the high patient loads that specialists have, and the possibility of burnout.

All of the participants in this study supported the practice of having a combined clinic. A quarter of them even indicated that they would rather have a combined clinic than to see the specialists individually. A number of them specifically valued the benefit of attending a team discussion. A large group of specialists in one room can however be overwhelming for the patients, and especially for young children, thereby lessening the value of the consultation; therefore steps need to be taken in order to reduce anxiety. Good team leadership is essential in structuring the screening evaluations and the team discussion, as there is a danger that large groups can separate into smaller chat groups, leaving the patient to feel like an outsider. This is an important concern when considering family-driven services as best practice (Osher & Osher, 2002). A team coordinator should be identified who can structure the individual team discussions, so that there is only one discussion at a time, and that whatever is discussed is well understood by the patient.

Summary and conclusion

The findings confirmed that their experiences and perceptions had been generally positive, and this was born out by their willing participation and cooperation in treatment procedures by members of the team. Their positive responses were however qualified by their comments regarding their dissatisfaction with some aspects of the service provided and their suggestions for improvement of the service. These included aspects regarding financial support, transport difficulties, information regarding the team members, communication with the team members, parent education regarding clefts and regarding the management of their child, their involvement in decision making and the general organization of the combined clinic.

The crux of the findings relate to the fragmentation of cleft care caused to a large extent by historical legacies. This resulted in poor accessibility of cleft patients to best practice through the management of an interdisciplinary team of professionals. Furthermore, parents have been disempowered by not being incorporated as meaningful members of the team. Referring to Bronfenbrenner's (1986) ecological systems, the combined clinic in this study contributed to enhancing the *mesosystems* and *microsystems* of the cleft child by bringing together the professionals and parents who were managing the child in a holistic interdisciplinary team. This theoretical framework was an appropriate one to provide a background to this study, as in line with best practice, the child with cleft palate should be viewed holistically within an ecological context.

CHAPTER 6:

CONCLUSIONS AND RECOMMENDATIONS

Summary of Findings:

Based on the qualitative and quantitative data obtained from the questionnaire and medical record review, it is evident that the CLP team based in the private healthcare sector of Johannesburg provided a service reported by patients and their families as valuable and much needed. Furthermore the combined team was perceived as a positive forum for the discussion of patient management which included the parents as team members. This study explores both the positive attributes of the clinic which should be upheld, and the negative attributes which should be improved upon. It provides a model for the establishment of other CLP teams in the country, and for increased collaboration at combined clinics for the teams that already exist. The aims of the study were therefore achieved, as it captured the experiences and perceptions of the parents/caregivers of children with CLP who had attended the combined clinic of the team, it provided a description of the treatment protocol of the team, and made recommendations for best practice in this clinic and other CLP teams.

Implications of the study

- **Implications for the running of the clinic**

A number of characteristics of the team process in the present study have met with the recommendations of the ACPA (2009) for optimum cleft care. They are therefore not only positive attributes for this clinic, but also valuable lessons for other CLP clinics in South Africa and globally.

- The team was interdisciplinary in its composition and included specialists from the fields of plastic surgery, speech therapy, audiology, ENT surgery, orthodontics and social work.
- Patients were seen early whenever possible and assistance was provided with feeding, information about CLP and referral to the relevant team members. Parents were provided with information booklets about CLP and feeding.

- Plastic surgery was carried out to repair cleft lip and palate, as well as surgery to correct VPI.
- ENT evaluations were routine, and grommets were inserted early, often at the time of cleft repairs.
- Audiological evaluations were carried out which included pure tone audiometry, tympanometry, oto-acoustic emissions and brainstem audiometry.
- Speech therapy consultations were frequently in the perinatal period and as speech and language were emerging. This finding highlights the importance of referral to the speech therapist, for early intervention.
- Speech therapy services included early counselling, monitoring of speech and language development, home programs and regular speech therapy intervention.
- A parent support group was coordinated by the Social Worker, and provided educational and emotional support.
- Regular face-to-face meetings were held with the specialists, the patients and the families to plan case management.
- Written reports regarding the recommendations made by team members were provided to parents and professionals.

A number of implications emerged from the study that would suggest possible improvements to the service:

- The program theory of the combined clinic of the interdisciplinary team should be articulated, as described by Rossi et al. (2004). Its *impact theory* that is goals and objectives in bringing about social change should be described. The program's *service utilization plan* should describe how the patients will interact with the program to bring about the desired change for example by complying with recommendations. The program's *organizational plan*, including the financial resources, facilities, equipment, personnel should be described, so as to inform evidence-based practice.
- Regular formal assessments of the quality of care provided by the interdisciplinary team should be undertaken. This should include participation from the team members as well as a periodic survey of patient satisfaction. The Eurocleft Consensus Recommendations suggest that best practice suggests that there should be one person on the team responsible for quality improvement and communication with other members of the team (Shaw et al., 2009).

- The team members should meet on a regular basis, to discuss the effectiveness of the teamwork, and whether it is meeting their needs and that of their patients, so as to reduce fragmentation of services. The frequency of such a meeting should be decided upon by the team members so as to ensure consistency.
- More attention should be paid to the physical environment of the clinic, so that patients feel comfortable and relaxed in the room, and do not feel overwhelmed by the size of the group. Ideally visiting professionals and students should be accommodated behind a one-way mirror so that the patients and their families are not overwhelmed by the number of people in the room.
- Regular feedback should also be provided to the sponsors, to keep them informed and motivate for financial sustainability of the service. They should be encouraged to observe the clinics.
- The service provided by the team should be marketed through online information to encourage early referrals so as to increase the accessibility of information. This contributes to increased accessibility of information.
- The parent support group could be timed to coincide with the clinic, or slightly earlier, and should include more structured preparation of new patients for meeting the team for example by providing them with a list of team members and their roles, encouraging patients to list their questions, enquiring about any special language or cultural needs they may have and communicating these to the team, and get feedback from them after the session. This could possibly increase the accessibility of support for parents.
- Patient education through the use of written booklets, preferably in the home language of the patients, written reports, and professional talks at the parent support group should be consistent and ongoing. A clinic website can also be used to upload information and be a forum for answering questions. This would allow for increased empowerment of parents in decision making.
- Parent involvement in the child's treatment should be encouraged, especially with regards to keeping appointments, finding appropriate times for surgery and participating in speech home programs, thereby increasing patient adherence with recommendations. Regular input from parents could highlight other aspects of management where they could be involved in decision making.
- The combined clinic should be more structured and organized. Reports from all the individual team members' private consultations should be available. Each parent

should receive a written summary of recommendations made by the team members. A team leader should be elected to run the discussion so that chat groups are discouraged, and the parent is always part of the discussion.

- Centralized and comprehensive records on each patients should be maintained and be easily accessible to all team members. The record taking protocol should be agreed and clearly laid out by the team. A central database would reduce the number of duplicated records kept in different places, for example there could be a single history taken from the patient on admission. Considering the team members each have a private practice in a separate venue, a Cloud Storage system where reports can be stored in PDF form may be useful. In this way, team members would be able to access one another's reports at any time.
- From the information gathered from the questionnaires, it appeared that the recommendations made by the participants for improving the service by the team, frequently related to maintaining consistency in the aims and objectives that had already been established by the team. Greater rigour may therefore be required in this regard. Based on the feedback received from the participants, the team could, for example experiment with a procedural sequence such as the one presented in Figure 14 below.

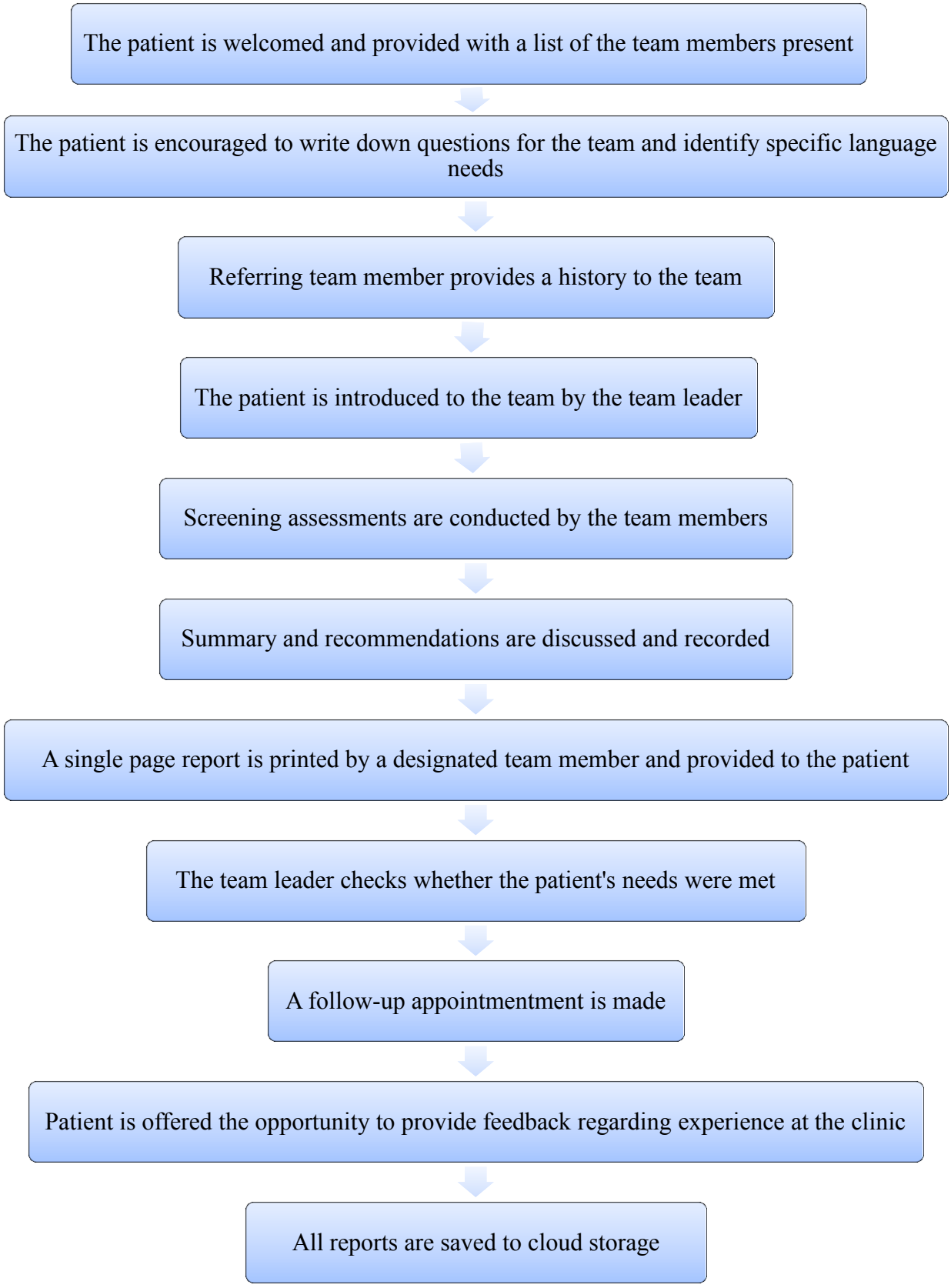


Figure 14: Proposed procedural sequence for combined CLP clinic

- **Implications for cleft palate team care in South Africa**

It appears that cleft care in South Africa is quite fragmented. Patients with CLP are managed in both the public and private healthcare sectors, and private NGOs such as Operation Smile and Smile Foundation. There also appear to be varying degrees of multidisciplinary or interdisciplinary teamwork in the various organizations. According to Stucky (1998, p. 9) effective health care often depends on intersectoral collaboration, which she defines as "looking outside your own four walls and working with other role-players in your community to achieve development". Greater coordination of cleft care in South Africa would be of benefit, and would contribute to addressing the problem of fragmentation by:

- Encouraging an interdisciplinary approach where team members met face-to-face on a regular basis and empowering the parents to become essential members of the team. In South Africa this could be a useful approach in streamlining the process of treatment by a number of different professionals, by reducing the number of visits, and thereby reducing the costs of transport and time taken off work.
- Sharing resources such as printed material for the education of parents of children with CLP, and having these resources available in different African languages.
- Educating health care professionals involved in the evaluation and treatment of patients with CLP.
- Networking of healthcare professionals involved in cleft care for the purposes of support, sharing of knowledge and cross-referrals.
- Establishing a database of patients with CLP in South Africa for the purposes of research, so as to allow for comparisons between patients, to assess the effectiveness of treatment, to plan for training facilities and future cleft care centres, and to set standards for the future. Such registers are kept by a number of cleft care providers worldwide: for the British based Craniofacial Anomalies Register (CARE) (Hammond and Stassen, 1999), the Craniofacial Anomalies Network England and Wales (CRANE Database, 2000) and the Swedish National Quality Registry for Cleft Lip and Palate Treatment (Shaw, Brattström, Mølsted, Prahl-Andersen, Roberts, & Semb, 2005).

It is regrettable that the South African Cleft Lip and Palate Society (SACLAPS) whose stated objectives were "to promote and advance the study, teaching and research into the etiology, prevention, nature, diagnosis and treatment of cleft lip and palate disorders", and "to

represent and further the interests of cleft care including promoting the setting up and growth of multidisciplinary cleft lip and palate units in major centres throughout the country" (SACLAPS, 2009, p. 1) has ceased to operate. It would be of benefit to general cleft care in South Africa, and for the reduction of fragmentation for such an organization to be reinstated.

Results of this study confirm the value of an interdisciplinary CLP team. Not all teams may have access to all the possible team members suggested by ACPA (2009) to create an optimal team. Every effort should be made however to engage at least core members in a basic interdisciplinary team that is a surgeon (plastic surgeon or maxillofacial surgeon who can perform surgical repairs of CLP), a speech therapist, an ENT surgeon and an orthodontist. If possible an audiologist and a social worker/psychologist should be included. Most teams in South Africa are likely to have a multilingual caseload, and therefore an interpreter may be considered a valuable member of the team.

The study also found that a combined clinic where team members, parents and patients can meet face-to-face to discuss patient management is in the best interests of the patient. A combined clinic offers a more holistic approach where cross-referrals can be made and patient adherence with recommendations is enhanced. Treatment can be more co-ordinated, for example, in the simultaneous management of surgical repair and grommet insertion. The timeline for various aspects of treatment can also be coordinated for example whether speech therapy should precede or succeed surgery.

It is acknowledged that a combined clinic can pose challenges for the teams with a large caseload as it is it difficult to incorporate into their schedule. Dekker (2007) found that the annual patient visits varied between 110 and 900 between the seven South African cleft teams. It may be possible however at a CLP clinic for team members to select specific cases who require a team discussion to attend a session with all team members present, at the end of the clinic, such as the "carousel team" described by Shprintzen (1995) discussed above.

Finally, it is also recommended that all CLP teams should evaluate their effectiveness by conducting regular surveys of patient satisfaction.

As mentioned above, the National Health Insurance (NHI) is a South African healthcare scheme aimed at providing universal health care for all South Africans. The Centre for Development and Enterprise (CDE) (2011) however warns against the NHI being seen as an endgame in healthcare reform, and not thinking creatively and comprehensively about the coexistence of the public and private healthcare sectors. The CDE suggests that "extending private sector healthcare to a wider public is a step towards realising universal access to quality healthcare" (CDE, 2011, p. 9). The public sector needs rehabilitation, while the private sector needs to reform in order to make healthcare more efficient and cheaper and thus more accessible. The CDE suggests that public money might be used to subsidise access to services in the private sector. It reports that the government has pledged to appoint qualified people to manage the public health service. The CDE recommends that the issue of shortage of skilled health professionals could be addressed by expanding the training of doctors and intermediate-level professionals, recruiting health professionals from overseas and extending the involvement of the private sector in medical training.

From this study it is evident that better utilization can also be made of the professional expertise that already exists in the country. There is a role for a clinic such as the one run by the CLP team, in this study, in the private sector to provide an educational role in modelling interdisciplinary CLP teamwork for professionals in the public sector as well as students in related fields. While various professionals and students have visited from time to time to observe the procedure of the clinic on an informal basis, this could be more structured and formalised as a public private partnership, to provide a regular teaching service for professionals and students in the field of cleft care.

In order to strengthen the much-needed collaboration between the private and the public healthcare sectors, the South African Joint Public Health Enhancement Fund (SAJPHEF) a non - profit company was launched in 2012. This social compact involves a number of private healthcare companies together with the Ministry of Health. The Fund, to be

administered by the participating companies in the private sector is aimed at making a meaningful and transformative contribution to public healthcare in South Africa, particularly in addressing the twin scourge of HIV/AIDS and Tuberculosis (TB) (Bodibe, 2012). If successful, this partnership may provide a model for similar collaboration in other areas of healthcare, such as in the area of cleft care.

Strengths and limitations of the study

- **Strengths**
  - This study provided the first evaluation of CLP teamwork within the private healthcare sector in South Africa, by exploring the experiences and perceptions of parents of cleft patients.
  - The triangulation of methods employing both qualitative and quantitative data, and both a questionnaire and record review increase the reliability of the data.
  - The open-ended questions provided insight into the participants' experiences and perceptions of the combined clinic of the CLP team, and provided valuable suggestions for improvement of the service. The closed-ended questions may be easier for the participants to answer and easier for the researcher to compare.
  - The record review described in detail the nature of the service that is offered to patients by members of the CLP including the surgical repair of the cleft, management of middle ear pathology and hearing loss, assistance with feeding and speech and language remediation, and a report from the Social Worker provided information on the psychosocial support that was provided.
  - Various measures were taken to increase the reliability and validity of the study, including a pilot study, the employment of a research assistant, regular academic consultation and the maintenance of an audit trail.

- **Limitations**
  - Parents/caregivers were recruited for this study from one particular cleft care centre in South Africa, and consequently their views may not reflect those of other parents using different cleft care centres that are different in nature and organization.

- The sample for the study was obtained on a voluntary basis using a purposive sampling method. This may have introduced an element of selection bias either consciously or unconsciously.
- A questionnaire was self-completed and only available in English and therefore may have posed problems in interpretation.
- The questionnaire was mostly distributed by e-mail, thus requiring participants to scan or fax their completed questionnaires back to the researcher. This may have resulted in a relatively low response rate, thus limiting the reliability and generalizability of the findings. Mailed questionnaire returns may have been negatively affected by a six-week long postal strike at the time, although the return rate was higher than the electric copies.
- No records were available regarding orthodontic evaluation of the patients, although it appears that none of them had yet received orthodontic intervention.

Despite these limitations, this research has contributed towards informing best practice for interdisciplinary team work in cleft care in South Africa.

Future research

This research has highlighted certain gaps that remain in the cleft care literature in South Africa.

- The current study could be replicated in other cleft palate teams in South Africa in order to investigate patient satisfaction regarding cleft care, and to encourage the monitoring of the team process, thus enhancing best practice.
- Many of the possible cleft palate team members identified by ACPA (2009) are trained in South Africa, and yet are not included in cleft palate teams. Further research is needed to identify the challenges that exist that prevent these teams from including those specialties, especially core members such as the ENT surgeon and orthodontist.
- The perceptions and experiences of the professional team members could be explored to establish whether they perceive that a combined clinic saves time through collaboration, increases their interpersonal communication, helps them to develop a good working relationship amongst themselves, increases their knowledge of each other's professions, promotes good record-keeping, provides continuing education and encourages research in

the field, which Kummer (2014) suggests are the advantages of teamwork for the team members themselves.

- A summative program evaluation could be carried out to explore whether the combined clinic has achieved its aims and objectives, and whether it has been cost-effective.
- This study could be extended to focus on the older patients that is into their young adulthood by which time their orthodontic intervention is complete. Once the patient reaches adolescence, he/she is likely to have perceptions that are distinctive from his/her parents, and these need to be taken into account separately.
- Based on the experience of this study, guidelines for an evaluation tool could be formulated to evaluate other CLP programs as well as programs for other disorders.
- Given the paucity of recorded data available to show changes in the incidence of CLP in South Africa, there is a need for further incidence studies to be carried out.

Concluding remarks

The null hypotheses that there will be no positive experiences or perceptions described by parents/caregivers of patients attending an interdisciplinary cleft palate team in the private sector in Johannesburg, and that there are no recommendations that can be made on the basis of the evaluation of this CLP team which could inform best practice for this and other CLP teams are rejected.

In answer to the research question, the perceptions and experiences of the parents/caregivers of cleft palate patients who had attended the combined clinic of the private cleft palate team in Johannesburg were explored, and found to be mostly positive. Participants commented on the value of meeting all the professionals together, and were generally satisfied with the service. They contributed valuable suggestions for improving the service including improved organization, increased funding, increased accessibility to services, more parent information and education, increased marketing of the service and continued improvement of communication with the specialists. It is recommended that other cleft palate teams in South Africa should endeavour to include more professionals in their teams, particularly core members, and to meet with them face-to-face on a regular basis. A combined clinic is a valuable forum, especially for patients with multiple challenges. A review of the records also described the service provided to the patients by the individual team members, and highlighted aspects such as early intervention, and collaboration in management. These issues

should be taken in account in the future planning and delivery of service to the patients with CLP.

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APPENDICES

Appendix A: Information letter to professionals

SPEECH PATHOLOGY AND AUDIOLOGY

SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

FACULTY OF HUMANITIES

UNIVERSITY OF THE WITWATERSRAND

Private Bag 3, WITS, 2050

Tel: (011) 717 4577 Fax: (011) 717 4572

March 2012

Dear Colleague

I, Georgia Jammine, am currently enrolled to study for a Master's Degree in Speech Pathology at the University of the Witwatersrand. My study will examine the perceptions of the patients regarding the services received at the Cleft Palate Assessment Unit, based at the private hospital based in Johannesburg. This knowledge will contribute towards assessing the effectiveness of the services from the point of view of the patients. It is important because it may enable the team to improve the service to our cleft lip and palate patients. It will also have implications for Cleft Lip and Palate teams in the rest of the country.

The methodology will include the following aspects:

1. A questionnaire to be completed by as large as possible a group of parents or caregivers of the patients who have attended our combined cleft palate clinic who are most suited to answering questions concerning their experience of the clinic. Each questionnaire will take approximately half an hour to complete.

2. A record review will be undertaken of the patients whose parents/caregivers have been interviewed. For this purpose, I would like to request your permission to have access to your records on this group of patients.

I would be most grateful if you would support me in this endeavour, as it may be beneficial both for our patients and for us as professionals, and possibly too for the wider South African cleft palate community, and may also be of benefit in motivating for continued sponsorship.

Sincerely

Georgia Jammine
B.A. (Sp. & H. Th.) Wits

Appendix B: Permission letter from head of the program

Appendix G

PROFESSOR L.A. CHAIT
M.B. B.CH(RAND) F.R.C.S
- PLASTIC SURGEON/PLASTIESE CHIRURG –
PR. No. 3600440

Telephone: (011) 484-3703
Fax: 086 5113656
E-Mail – lachait@iburst.co.za

PARK LANE HOSPITAL
JUNCTION AVENUE
PARKTOWN
JOHANNESBURG, 2193

16 April 2012

To Whom It May Concern

Consent Form for Permission to carry out Research in this Practice

I have read and examined an information letter from Georgia Jammine, a Masters student of Speech Pathology and Audiology at the University of the Witwatersrand, in which she outlines the aim to examine the programme effectiveness of the Netcare Vodacom Cleft Palate Program. I am aware that she will require access to the medical records in order to gain information for his study, and that she will arrange to have the parents/caregivers of the patients of this program participate in filling out a questionnaire and in participating in an interview.

I would like to support this research, and give Georgia Jammine full permission on behalf of myself and Netcare to go ahead with her research.

I understand that the identity of my patients will be kept anonymous and that the names, and any other identifying information of participants, will not appear in the research report.

I also understand that I have the right to discontinue this study in my practice at any time without consequence.

PROFESSOR L. A. CHAIT
PARKLANE CLINIC
JUNCTION AVENUE
PARKTOWN 2193

Signed: Prof L.A Chait _____

Date: 16/04/2012

Signed: G.P. Jammine _____

Date: 16/04/2012

Appendix C: Information letter to participants

SPEECH PATHOLOGY AND AUDIOLOGY
School of Human & Community Development
Faculty of Humanities
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4577 Fax: (011) 717 4572

March 2012

Dear Client of the Cleft Lip and Palate Clinic

I, Georgia Jammine, one of the Speech-Language Therapists associated with the Cleft Palate Clinic based at the Park Lane Hospital, am currently a Master's student at the University of the Witwatersrand. I am inviting you to participate in my research to assess how helpful the services of Cleft Palate Team at the Park Lane Hospital (previously at the Donald Gordon Hospital) have been. This research is important because it will enable the team to improve the service to our cleft lip and palate patients. It will also have implications for Cleft Lip and Palate teams in the rest of the country.

The information will be gathered using a questionnaire, which will be about your experiences and the treatment you have received at the cleft palate clinic. It will take you about 20 minutes to complete. When you have completed it, you will be required to post it back to the researcher using the pre-paid self-addressed envelope provided.

Although I am appealing to you to cooperate in the study, you are not obliged to take part if you do not want to. This research is separate from the treatment that you receive from the Cleft Palate Assessment Unit. The team will have no way of knowing if you have participated, and the treatment you receive in the future will in no way be affected by the answers you give in the interview. If for any reason you do not wish to answer a particular question, you may leave it out.

No one will have access to the information in the questionnaires other than me and my university supervisors. The completed questionnaires will be kept in a secure place while the research is in progress and no one will be able to use them for any other purpose. Once the research is complete, the questionnaires will be destroyed. Your name will be kept anonymous with confidentiality maintained.

If you agree to take part in the study, kindly sign the attached consent form and return it together with the completed questionnaire.
If you have any questions or want to know about the study please phone me on 082-773-8644 or e-mail me at georgia@jammine.com

Thank you for your time.
GEORGIA JAMMINE (Researcher)

Appendix D: Consent form from participants in the questionnaire

SPEECH PATHOLOGY AND AUDIOLOGY
School of Human & Community Development
Faculty of Humanities
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4577 Fax: (011) 717 4572

Consent Form for Participants Questionnaire

I accept that I am a voluntary participant in the research study by Georgia Jammine, a Master's student currently studying at the University of the Witwatersrand.

I understand that I will participate in the present study by completing an anonymous questionnaire.

I also understand that as part of the research, the researcher will have access to the medical records of my child.

I understand that I will not receive any reward for choosing to participate in this research.

I understand that my name and any other identifying information will not appear in the research.

I also understand that I may choose to leave out a question or stop the questionnaire at any time, with no negative consequences for my child's treatment.

Name: _____

Signed: _____

Date: _____

Signed: _____
Georgia Jammine

Date: _____

Appendix E: Interview guide for introductory telephonic interview (or in the case of foreign participants, by e-mail)

1. The same interviewer will carry out both the introductory telephone call to the large group of potential participants and the in depth interview to the small sample of participants.
2. The interviewer would contact the potential participant by telephone if he/she is in South Africa and by e-mail if he/she was outside the country, and had an e-mail address. If the participant replied by e-mail that he/she was willing to receive a questionnaire by e-mail, this would be regarded as consent to receive the completed questionnaire by e-mail.
3. The interviewer will introduce herself.
4. She will explain the reason for the call, and briefly the aim of the study.
5. She will verify that she is speaking to the potential participant. This should be the parent/caregiver who brings the cleft palate child to the clinic.
6. The parent/caregiver will be asked if he/she would be willing to receive an information letter giving details about the study, and then participate if he/she agrees.
7. He/she will be asked whether he/she would prefer to receive a questionnaire by post, by hand, by e-mail or telephonically.
8. He/she will be asked whether he/she feels comfortable to answer a questionnaire written in English, and if not, if there is anyone he/she can ask for help in translating it.
9. The interviewer will explain the possibility of following up the questionnaire with an interview should he/she be selected.
10. During this process, contact details may be checked and updated.

Name of patient:

_____

Name of Participant:

_____

Relationship to patient:

_____

Contact telephone number of participant:

_____

Willingness of participant to receive documents pertaining to the study: ☐ yes ☐ no

Most appropriate way of sending the documents to the potential participants:

☐ By Mail ☐ By Fax ☐ By E-mail ☐ By hand ☐ By telephone

Participant' willingness to answer a questionnaire in English

☐ Yes☐ No, but participant will find a translator ☐ No translator is available

Postal address:

_____

E-mail address:

_____

Fax number:

_____

Phone number:

_____

Appendix F: Questionnaire to be completed by participants

Questions for parents of a cleft palate child.

Thank you for taking the time to fill in these questions. It will help us to improve our service to you and your child in the Cleft Palate Clinic. Please put an X in the box which gives your answer. If you can, please write more detail. Please note that when you read 'professional' this means a doctor, therapist or a social worker. Remember that whatever you write will be kept anonymous and confidential.

1. How are you related to the cleft palate patient?
   ☐ Mother ☐ Father ☐ Grandfather or Grandmother
   ☐ Brother or sister ☐ Uncle or aunt
   ☐ Other.
   Please explain:_____

2. Is the child ☐ Male ☐ Female

3. What is the child's date of birth?
   _____

4. What group does the child belong to?
   ☐ Black ☐ White ☐ Coloured ☐ Asian/Indian

5. Is the child on a private medical aid?
   ☐ Yes ☐ No

6. What is your home language?
   ☐ English ☐ Afrikaans ☐ IsiNdebele ☐ IsiXhosa ☐ IsiZulu ☐Setswana
   ☐ SiSwati ☐ Tshivenda ☐ Xitsonga ☐ Sesotho ☐ Sesotho sa Leboa

   ☐ Other home language. Which one? _____

7. When did you first find out about the cleft? _____

8. Before coming to this Cleft Palate Team, did you see any professional from any other Cleft Palate Team?
   ☐ Yes ☐ No

9. Did you see any other medical professional?
   ☐ Yes ☐ No
   If yes, what type of professional was it? _____

10. How old was the child when you first saw someone about the cleft?

_____

11. How did you come to this Cleft Palate Team? – E.g. Who told you about it?

_____

12. How long does it take you to travel to the Park Lane Hospital to see the cleft palate team?
    - ☐ Less than 30 minutes
    - ☐ 30-60 minutes
    - ☐ Over an hour
    - ☐ A few hours
    - ☐ More than a day

13. Which professionals have you seen at the Clinic? (You don't need to give their names)

_____

_____

14. Are there any professionals who you would like to see in the Clinic, but are not there?

☐ Yes ☐ No If yes, please explain:

_____

_____

15. If the professionals said that your child should see someone else who was not at the Clinic, did they help you to arrange it?
    - ☐ Yes. What type of professional? _____
    - ☐ No, my child didn't need to see anyone else.

16. Would you prefer to see each professional only separately rather than altogether?
    - ☐ Separately ☐ Altogether
    - ☐ I would like to see them separately as well as altogether.

17. How easy have you found it to talk about your child with the professionals?

☐ Very easy ☐ Easy ☐ I don't know ☐ Difficult ☐ Very difficult

18. If you have found it difficult to talk to the members of the Team, why do you think it's difficult? (You can give more than one answer.)
    - ☐ English is not my home language
    - ☐ There are too many people in the room
    - ☐ I get nervous

☐ I forget what I wanted to ask
☐ I'm scared they are judging me
☐ Other reason - describe:

_____

19. How much have you felt you could decide about your child's treatment?
    ☐ Very much
    ☐ Quite a lot
    ☐ Just enough
    ☐ Not enough
    ☐ Not at all

20. Would you like to be more involved in making decisions about your child's treatment?

    ☐ Yes ☐ No Please explain:

    _____

    _____

21. How well do you understand what the professionals tell you to do?

    ☐ Very well ☐ Well ☐ I don't know ☐ Not very well ☐ Not well at all

22. Is there anything about your child's cleft that you would like to know more about or that you do not understand?

    ☐ Yes ☐ No If yes, please explain: _____

    _____

23. For what reason(s) did you choose to bring your child to this Cleft Palate Clinic?

    _____

    _____

24. How happy are you with the help you have received from the cleft lip-palate clinic?

    ☐ Very happy ☐ Happy ☐ It's OK ☐ Unhappy ☐Very unhappy

    Why?

    _____

25. How can the service by the Cleft Palate Team be improved?

_____

_____

26. How do you feel about your child's cleft right now? Please put an X in the block that gives your answer.

A. Speech

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

B. Hearing

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

C. The teeth

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

D. The lip

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

E. The nose

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

F. Breathing through the nose

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

G. The face

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

H. The bite

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

27. How do you see the outcome for your child in the next 10 years, in terms of:

A. Appearance (how your child looks)

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

B. Speech

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

C. Making friends

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

D. Education

VERY GOOD	FAIRLY GOOD	NEITHER GOOD NOR BAD	NOT VERY GOOD	NOT GOOD AT ALL

28. After having a child with a cleft, what advice would you give to someone else who found out that their child had a cleft?

_____

_____

29. Is there anything else you would like to say about your child's treatment or the clinic? (Your answer will be kept confidential, and will not affect the child's treatment in any way.)

_____

_____

Thank you very much for taking the time to fill in these questions.

Appendix G: Record Review – Recording Sheet

Record review:

1. Name of patient: _____
2. Date of birth: _____
3. Name of parent: _____
4. Cell number: _____
5. E-mail address: _____
6. Gender: ☐ Male ☐ Female
7. Cleft type
   - ☐ Unilateral cleft lip and palate
   - ☐ Bilateral cleft lip and palate
   - ☐ Cleft palate
8. Are there any other congenital abnormalities/syndromes, etc. ☐ Yes ☐ No

   Describe: _____

   _____
9. Is the child on a private medical aid? ☐ Yes ☐ No
10. Is the child's treatment funded by the sponsors? ☐ Yes ☐ No
11. Age of child at first contact with any member of the Cleft Palate Team?
    - ☐ Pre-natal
    - ☐ Under 3 months
    - ☐ 3 month to a year
    - ☐ 1-5 years
    - ☐ Over 5 years
12. Number of times patient has been seen at the combined clinic: _____
13. The length of time that has passed since the last consultation at the combined clinic:

    _____

    History of plastic surgical intervention: give ages
14. Lip repair ☐ Yes ☐ No _____

15. Soft palate repair ☐ Yes ☐ No _____

16. Hard palate repair ☐ Yes ☐ No _____

17. Fistula repair ☐ Yes ☐ No _____

18. Secondary cosmetic surgery ☐ Yes ☐ No _____

19. Pharyngeal flap surgery ☐ Yes ☐ No _____

20. Other surgery ☐ Yes ☐ No _____

21. If the child was referred for an ENT consultation, did the family comply?
☐ Yes ☐ No

22. Has the child had grommets inserted ☐ Yes ☐ No

23. Has the child had any other ENT intervention ☐ Yes ☐ No

24. Nature of this intervention_____

25. If the child was referred for an audiological assessment, did the family comply?
☐ Yes ☐ No

26. Has the child's hearing been tested by an audiologist? ☐ Yes ☐ No

27. Did the child have a hearing loss? ☐ Yes ☐ No

28. If the child was referred for a speech and language assessment, did the family comply?
☐ Yes ☐ No

29. Has the child's speech been assessed by a speech therapist? ☐ Yes ☐ No

30. Has the child's speech and language development been regularly monitored by the speech therapist? ☐ Yes ☐ No

31. Has the child received regular and intensive speech therapy? ☐ Yes ☐ No

32. If the child was referred for an Orthodontic assessment, did the family comply?
☐ Yes ☐ No

33. Has the child ever received treatment from an Orthodontist? ☐ Yes ☐ No

34. Has the child ever worn an orthodontic appliance? ☐ Yes ☐ No

Appendix H: Human Research Ethics Committee (Medical): Ethics Protocol

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Mrs Georgina Jammine

CLEARANCE CERTIFICATE	**M120720**
PROJECT	Exploring Patients' Perceptions and Experiences of the Services Provided by a Multi-Disciplinary Cleft Lip and Palate Team in Johannesburg
INVESTIGATORS	Mrs Georgina Jammine.
DEPARTMENT	Department of Speech Pathology & Audiology
DATE CONSIDERED	27/07/2012
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 24/08/2012 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Dr Sharon Moonsamy

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.