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**DEVELOPMENT OF
A COMMUNICATION ASSESSMENT PROTOCOL
FOR YOUNG CHILDREN WITH CLEFT LIP AND/OR PALATE
(CL/P) IN MAURITIUS**

BY

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ABSTRACT

TITLE	Development of a communication assessment protocol for young children with cleft lip and/or palate (CL/P) in Mauritius
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Research guides the parameters for assessment and treatment of individuals with cleft lip and/or palate (CL/P). Most developing countries cannot provide an adequate standard of cleft care, due to limited resources. Speech-language therapists and audiologists in developing countries can contribute to improving cleft care through early communication intervention to minimise/prevent the negative impact of a cleft on a young child's communication ability and to support the families. However, they require linguistically and contextually relevant assessment instruments for early identification of communication disorders in these children.

The aim of the research was to develop and evaluate a communication assessment protocol for young children with CL/P, for use in Mauritius, a developing country in the Indian Ocean with a multilingual and multicultural population. A further aim was to develop an electronic database of children with CL/P in the public health sector of Mauritius. Eighty-eight children, with CL/P, 0-6 years, were selected by consecutive sampling and their parents acted as participants. Four

speech-language therapists and audiologists from the public health sector of Mauritius participated in the data collection and appraisal of the newly developed assessment protocol.

A mixed methods research design was selected. Based on exploratory research of cleft care in Mauritius and international recommendations for assessment of young children with CL/P, a comprehensive Communication Assessment Protocol was compiled and speech elicitation materials in Creole and French were prepared. Speech-language therapists and audiologists conducted assessments, using non-invasive procedures to assess feeding, hearing, communication skills development, emergent literacy skills, speech production and voice of the participants. Digital video and audio recordings of the elicited speech samples were made and auditory-perceptual procedures for speech analysis and inter-rater comparisons for reliability were employed.

The communication assessment protocol was useful in describing the characteristics of the children with CL/P treated in the National Health System in Mauritius. The speech-language therapists and audiologists together with the parents of the children as partners in assessment were successful in early identification of communication delays/disorders in children with CL/P (73%) and also referrals to other health care professionals. The protocol was evaluated and accepted for application in clinical practice.

The newly developed Communication Assessment Protocol was applied by local speech-language therapists and audiologists with the possibility of implementing this assessment

instrument nationally. This was an important contribution to improve cleft care in Mauritius where interdisciplinary team-based cleft care has not occurred to date.

Key Terms: Cleft lip and/or palate; communication assessment protocol; early communication intervention; developing country; Mauritius; speech-language therapists and audiologists.



OPSOMMING

TITEL	Development of a Communication Assessment Protocol for young children with cleft lip and/or palate in Mauritius
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Die parameters vir die assessering en behandeling van individue met gesplete lip en/of verhemelte word deur navorsing gerig. Die meeste ontwikkelende lande kan nie sorg van 'n toereikende standaard aan individue met splete voorsien nie, hoofsaaklik as gevolg van beperkte hulpbronne. Spraak-taalterapeute en oudioloë in ontwikkelende lande kan deur vroeë intervensie bydra tot die verbetering van spleetsorg en sodoende die negatiewe impak van 'n spleet op die lewe van 'n jong kind se kommunikasievermoë minimaliseer/verhoed en ondersteuning bied aan gesinne wat daar deur geraak word. Spraak-taalterapeute en oudioloë benodig egter assesseringsinstrumente vir vroeë identifikasie van kommunikasie-afwykings in hierdie kinders.

Die doel van hierdie navorsing was om 'n omvattende kommunikasie-assesseringsprotokol vir jong kinders met gesplete lip en/of verhemelte saam te stel en te evalueer vir gebruik in Mauritius. 'n Verdere doel was om 'n elektroniese databasis te ontwikkel om kinders met

gesplete verhemelte aan te teken in die publieke gesondheidsektor van Mauritius. Mauritius is 'n ontwikkelende land met 'n multilinguistiese, multikulturele bevolking in die Indiese oseaan.

Deelnemers: Agt-en-tagtig kinders met gesplete lip en/of verhemelte in die ouderdomsgroep 0-6 jaar is deur opeenvolgende steekproefneming geselekteer en het saam met hulle ouers aan hierdie navorsingsprojek deel geneem. Vier spraak-taalterapeute en oudioloë van die openbare gesondheidsektor van Mauritius het deel geneem aan die data-insameling en evaluering van die navorsingsprotokol wat ontwikkel is.

Die navorsingsontwerp het op gemengde metodes berus. Op grond van verkennende navorsing oor spleetsorg in Mauritius en internasionale aanbevelings vir die assessering van jong kinders met gesplete lip en/of verhemelte, is 'n omvattende assesseringsprotokol saamgestel. Verder is ontlokkingsmateriaal vir spraak in Kreools en Frans saamgestel. Spraak-taalterapeute en oudioloë het die assessering van voeding, gehoor, ontwikkeling van kommunikasievermoëns, ontwikkelende literêre vaardighede asook spraak- en stemproduksie van die deelnemers deur middel van nie-indringende assesseringsmetodes uitgevoer. Digitale video- en audio-opnames is van die ontlokte spraakmonsters gemaak en ouditief-perseptuele prosedures vir spraakanalises en inter-beoordelaarvergelykings is vir die doeleindes van betroubaarheid gebruik.

Die bevindinge het aangetoon dat die kommunikasie-assesseringsprotokol nuttig was in die beskrywing van die kenmerkende eienskappe van kinders met gesplete lip en/of verhemelte wat deur die Nasionale Gesondheidstelsel in Mauritius behandeling ontvang. Die spraak-taalterapeute en oudioloë, tesame met die ouers van die kinders as vennote in die assessering,

was suksesvol in die vroeë identifisering van vertraagde kommunikasie-ontwikkeling en -afwykings in 73% van kinders met gesplete lip en/of verhemelte. Kinders in hierdie groep wat verwysing na ander kundiges in gesondheidsorg benodig het, kon ook geïdentifiseer word. Die protokol is toepaslik verklaar en aanvaar vir aanwending in kliniese pratyk.

Slot: Die nuut-ontwikkelde '*Communication Assessment Protocol*' is plaaslik toegepas deur spraak-taalterapeute en oudioloë met die moontlikheid dat dit as nasionale assesseringsinstrument gebruik kan word. Hierdie protokol verteenwoordig 'n belangrike bydrae tot die verbetering van spleetsorg in Mauritius waar 'n interdisiplinêre span-gebaseerde benadering tot op hede nog nie bestaan nie.

Sleutelwoorde: Gesplete lip en/of verhemelte; kommunikasie-assesseringsprotokol; vroeë kommunikasie-intervensie; ontwikkelende land; Mauritius; spraak-taalterapeute en oudioloë.

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CHAPTER 1:

INTRODUCTION AND ORIENTATION

The aim of the chapter is to review the current best practice for cleft care and the challenges in providing an optimal standard of care for young children with cleft lip and/or palate in developing countries. The rationale for this study is presented. In addition, an overview of the content of the study and justification for terminology used is presented.

1.1 INTRODUCTION

Craniofacial anomalies (CFA) are the fourth most common birth anomalies that occur in approximately 1 in 700 live births (ACPA, 2007: 5; Peterson-Falzone, Hardin-Jones & Karnell, 2010: 15; WHO, 2002: 10). Cleft lip and/or palate (CL/P) is the most common type of CFA and it affects all races across worldwide. The exact cause of CL/P is not known but it is linked to environmental influences, genetic factors and gene-environment interaction (Peterson-Falzone et al., 2010: 38; Watson, Sell & Grunwell, 2001: 10; Wyszynski, 2002: 283). The CL/P causes a pervasive impact on speech, hearing, appearance and cognition. This has a prolonged and adverse influence on the health and social integration of an individual with CL/P. There are considerable costs of cleft care in terms of health care, emotional disturbance, and social and employment factors impacting individuals with CL/P, their families and society on the whole (WHO, 2002: 2).

The management of CL/P involves a multidisciplinary approach and most developed countries have well established protocols for cleft care. The American Cleft-Palate Craniofacial Association (ACPA, 2007), the Eurocran Speech Project (2000) and the World Health Organization (WHO, 2002), have emphasized the need for a well-coordinated, effective team-based approach and early intervention programmes. However, there are numerous challenges to providing cleft care in resource limited developing countries. It is estimated that 80% of the population of individuals with clefts live in the developing or less developed world and may not receive adequate cleft care (Mars, Sell & Habel, 2008: 1).

The surgical team is at the core of management of CL/P in most countries. However, role of the speech-language therapists and audiologists in providing cleft care is not well established in countries with limited resources. It is well recognised that children with CL/P are at risk of communication delays/disorders (ACPA, 2007: 5; Peterson-Falzone, Trost-Cardamone, Karnell & Hardin-Jones, 2006: 9; Rossetti, 2001:3; Strauss, 2004: 150). Early identification and management of communication difficulties by a speech-language therapist and audiologist has a positive impact on the child's overall development (Billeaud, 2003: 53; Bzoch, 2004: 19; Rossetti, 2001: 267; Scherer, D'Antonio & McGahey, 2008: 30). The number of speech-language therapists and audiologists in developing countries is limited (D'Antonio & Nagarajan, 2003: 308). As a result there is a lack of awareness of their contribution to cleft services. These factors clearly indicate a need to establish the roles of speech-language therapists and audiologists at an early stage in the management of CL/P.

In acknowledgement of the many challenges to cleft care in developing countries, clinicians and researchers are currently focusing their attention towards global strategies for improved cleft care. The WHO (2002: 33) recommended international research collaborations and guidelines to improve clinical practice. However, local needs for the cleft care are likely to vary, thus clinical decision-making in speech-language therapy should be guided by research evidence, as recommended by Reilly (2004: 115).

International collaboration is a prerequisite for research into the etiology, prevention and treatment of cleft lip and palate. A critical mass of clinical researchers including epidemiologists and basic scientists is required to generate comprehensive research evidence (WHO, 2002: 2). In order to facilitate international collaboration it is recommended that a set of guidelines for the provision of clinical services and the maintenance and analysis of minimum clinical records are adopted internationally (WHO, 2001b: xi). Developing countries invariably face economic constraints in complying with these recommendations; however, the guidelines should serve as long-term desirable goals in providing an optimal standard of cleft care.

1.2 OVERVIEW OF INTERVENTIONS FOR YOUNG CHILDREN WITH CLEFT LIP AND/OR PALATE IN DEVELOPING AND DEVELOPED COUNTRIES

Health care service delivery models vary across the world and are dependent on the availability of resources. Developing countries differ markedly from developed countries in various aspects of interventions from prevention, identification of developmental concerns to assessments, service delivery, programme evaluation and the formulation of policy. Moreover, even amongst

developing countries there are differences in the type of health care delivery (Mars et al., 2008: xi). The common factor in the developing world is the discrepancy between the overwhelming numbers of patients and the limited resources available for their management (Mars et al., 2008: 32). Since many individuals with a cleft have no access to care in developing countries, their cleft may often remain untreated. The priority is undoubtedly to surgically repair the clefts but a long-term interdisciplinary approach is essential to achieve optimum anatomical, physiological and functional results of the cleft repair (ACPA, 2007: 5; Bzoch, 2004: 35).

There are many variations in the treatment protocols used by the various teams all over the world. However, there is consensus that the best outcomes of surgical repair are achieved with a multidisciplinary team-based approach (ACPA, 2007: 5; Bzoch, 2004: 35) and that early repair is associated with positive outcomes for speech development (ACPA, 2007: 14; Peterson-Falzone et al., 2010: 149; Shprintzen & Bardach, 1995: 109; Watson et al., 2001: 162). Surgical repair of the CL/P is effective and available in several developing country settings. Services of visiting surgeons supported by charity foundations such as Interplast, Operation Smile, The Smile Train (Bale, Stoll & Lucas, 2003: 83; Mars et al., 2008: 10) are increasingly available in underdeveloped regions of the world. A major challenge in these contexts is coordinating the timing of surgical intervention and the availability of an inter-disciplinary team. In most developing countries setting up a team for care of young children with cleft may not be possible due to the unavailability or limited number of professionals in specialized fields such as orthodontics, speech-language therapy and audiology.

Children with CL/P exhibit a spectrum of communication problems from delayed speech-language development, to abnormal resonance and speech articulation, and hearing impairment (Kummer, 2008: 299; Peterson-Falzone et al., 2010: 221; Trost-Cardamone, 2004: 463). Evidence from research conducted in developed countries has demonstrated that early communication intervention (ECI) reduces the risk of communication delays and disorders (Guralnick, 1997: 11; Rossetti, 2001: 264; Scherer et al., 2008: 26). However, speech-language therapists and audiologists require a comprehensive communication assessment protocol to assess children with CL/P who may have associated impairment of important functions such as feeding, hearing and developmental delays. The clinical purpose of assessment is to identify the problems, manage them and allow therapists to communicate their findings to other professionals involved in care of children with CL/P (D'Antonio, 2002: 27).

The assessment protocol that is appropriate for the context where it will be utilised needs to take into account the languages and dialects spoken within the child's home and other places of care. Speech measurement procedures across cultures and languages need to be standardised to make meaningful comparisons of clinical outcomes of treatment procedures through multicentre studies to improve the standard of cleft care globally (Henningsson et al., 2008: 1-17). Assessment instruments and procedures for young children with CL/P in developed countries are now being standardised. For example, a universal system for reporting speech outcomes in individuals born with CL/P allows comparisons to be made across centres for either clinical or research use (Henningsson et al., 2008: 1; Lohmander-Agerskov & Olsson, 2004: 64).

Currently, many developing countries do not have access to appropriate speech and hearing services and assessment instruments (D’Antonio, 2002: 1). In the following Figure 1.1, the continuum of cleft care available in developing versus developed countries is depicted from the perspective of speech-language therapists and audiologists.

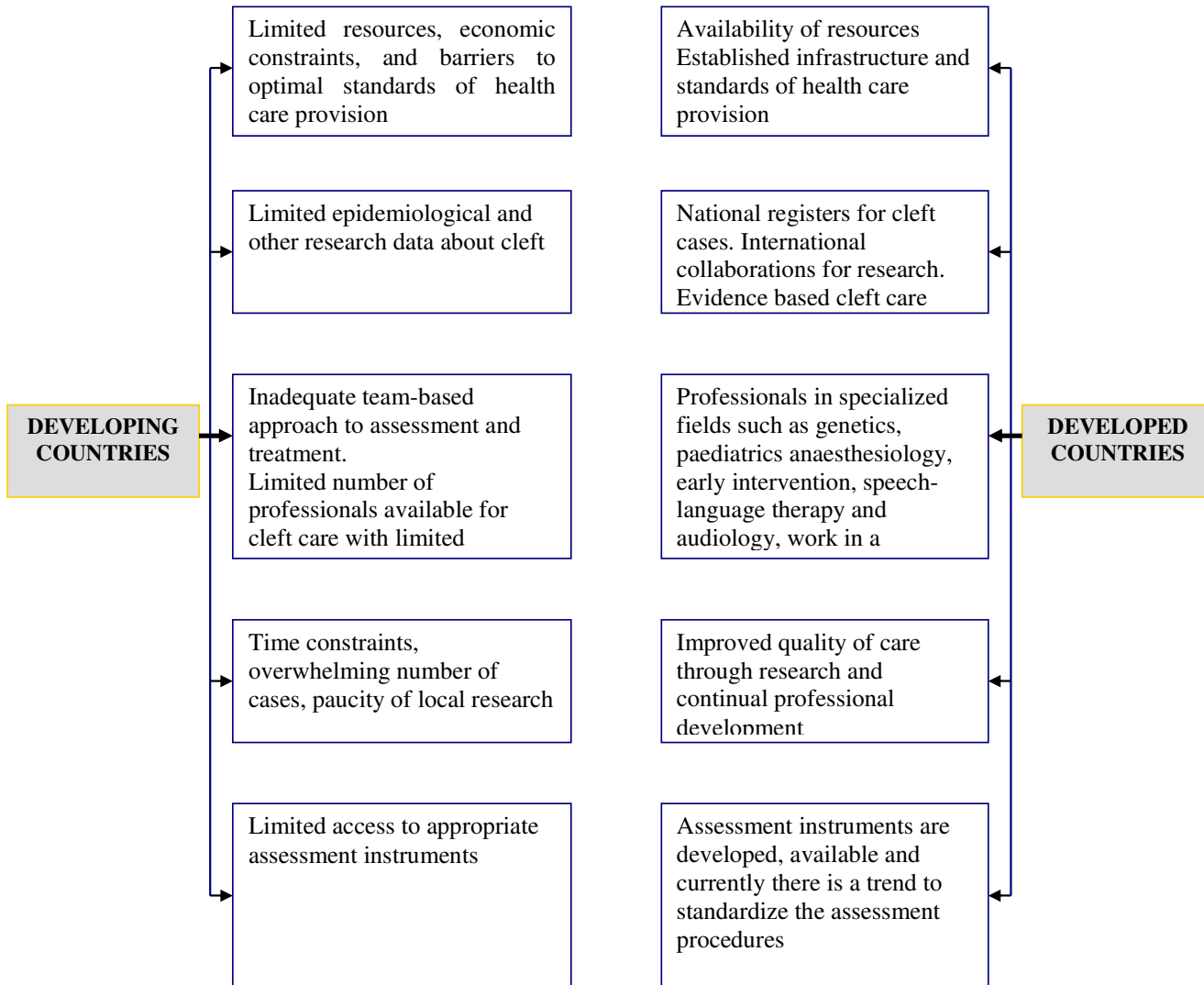


FIGURE 1.1 Continuum of cleft care

Children in sub-Saharan Africa face greater challenges to healthy development than children in any other region of the world (Garcia, Pence & Evans, 2007: 13). In sub-Saharan Africa clinical resources for cleft care are scarce as a consequence of prevailing economic problems and the greater challenge of communicable diseases, particularly HIV/AIDS (WHO, 2002: 38). Mauritius, a small island in the Indian Ocean and forming part of the African continent, is representative of a developing country. Geo-economically it is similar to other developing middle-income countries in sub-Saharan African countries such as Botswana, Namibia, and South Africa. The middle-income economies are defined as ones with a Gross National Income (GNI) per capita of more than \$875 but less than \$10,726. These countries are important because they contribute to the overall economic health of nations as well as to knowledge development and are helping to show the way through political stability and steady economic development (<http://web.worldbank.org>).

The general state of health in Mauritius is good and has been improving steadily over the years. Life expectancy, in the last 30 years has increased from 63 years to 71 years and first year infant mortality has fallen from 64 to 14 deaths for every 1000 live births (Ministry of Health & Quality of Life, 2006). In Mauritius, the government is committed to improve health care during early childhood (0-6 years) through policies that include provision of free primary health care, institution-based facilities that are supported by community-based health workers and free educational services (<http://portal.unesco.org>). Although Mauritius has been doing well in comparison with other developing countries, new measures are required to improve its performance to reach the levels achieved by developed countries. Cleft care in Mauritius is,

however, not yet organised to include interdisciplinary cleft care and a protocol of assessment and treatment is not established.

1.3 STATEMENT OF THE PROBLEM

There are many parts of the world for which little or no information is available on the prevalence of orofacial clefts, in particular parts of Africa, Central Asia, Eastern Europe, India and the Middle East. The lack of information needs to be addressed urgently to establish health care needs of the population (WHO, 2002: 13). In Mauritius, there is a lack of information regarding children with CL/P. The prevalence of children born with CL/P in Mauritius; timing of operations; the investigations and results relevant to CL/P care (feeding, hearing, and speech-language tests) are not documented uniformly. Thus an important first step towards the improvement of cleft services is to channel efforts towards organizing a cleft database and to develop cleft care systems appropriate to the context.

In Mauritius, there is also a need to describe the characteristics of children born with CL/P so that services can be planned and quality care can be provided to these children. There is presently no standardised assessment protocol or guidelines that the speech-language therapists and audiologists follow to conduct assessments of young children with CL/P. Moreover, limited access to assessment instruments undermines the effectiveness of the speech-language therapists' and audiologists' intervention in cleft care. Speech-language therapists and audiologists from countries such as India, Singapore, and sub-Saharan Africa have also voiced the need for realistic assessment tools that have local relevance (Pickering & McAllister, 2000: 94). An important

priority in these countries is to develop assessment instruments and treatment materials in local languages based on local experiences and norms.

1.4 RATIONALE FOR THE STUDY

CL/P causes communication disorders and consequently limits the opportunity for education, employment and the development of relationships of the individual (Mars et al., 2008: xi). The WHO (2002) has called for global strategies to reduce the burden of cleft care through standard treatment protocols, improved quality and improved levels of awareness regarding cleft care. However, the access to an optimal standard of cleft care in a developing country is dependent on its resources and health care policies. To improve the health care service delivery to children with CL/P, measure the outcome of surgery and plan efficient service delivery, it is important to have a standard communication assessment protocol. The essential background information concerning individual children should be recorded in a standard and uniform format (CSAG 1998; <http://www.who.int>). Timely interventions by speech-language therapists and audiologists in the period from birth to primary school entry level are crucial for children with CL/P as they are at risk of developing communication delays and disorders (Kuehn & Moller, 2000: 348; Rossetti, 2001: 3).

In a developing country, following the 'bottom-up' approach may focus on the child with CL/P and his/her family as a first step to improving cleft care as illustrated in Figure 1.2. The way to achieve international collaboration is to produce evidence of the needs and the strengths of what

a developing country can offer to improve cleft care. Research is required to follow the route from bottom up.

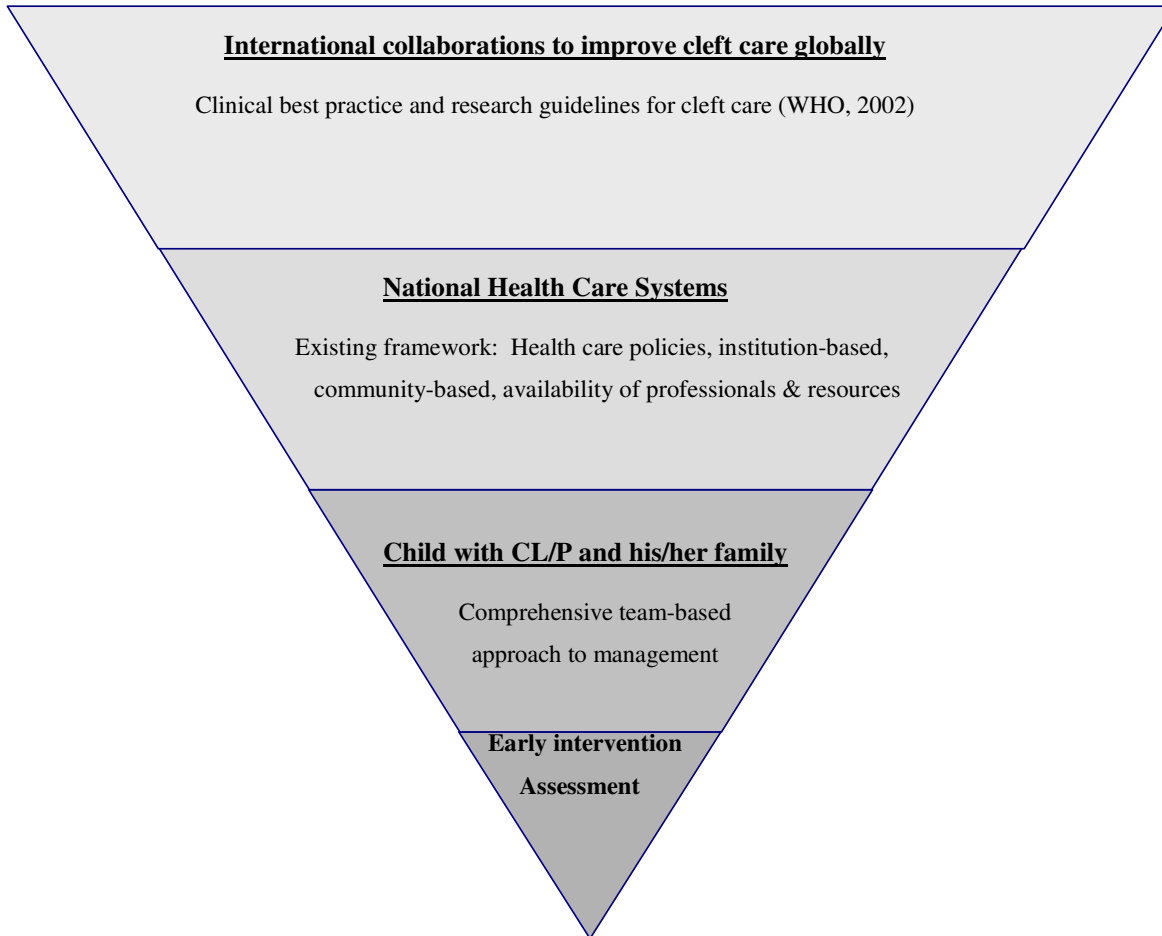


FIGURE 1.2 Bottom up approach as a strategy to improve cleft care in a developing country

A bottom up approach integrates the best external evidence with individual clinical expertise (Threats, 2006: 255). Evidence available from developed countries holds that early communication intervention is beneficial to children with cleft lip and/or palate (Billeaud, 2003:

34; Guralnick, 1997: 11; Hardin-Jones, Chapman & Scherer 2006: 8; Owens, 2001: 458; Rossetti, 2001: 264). In a developing country such as Mauritius, a tangible start to comprehensive cleft care could be early communication intervention. The communication assessment practice should lead to appropriate intervention strategies (Bagnato, Neisworth & Munson, 1997: xiv; Blackman, 1995: 155) and be of immediate value to children with CL/P and their families. However, speech-language therapists and audiologists require an assessment instrument that has local relevance, and documents serial assessments to plan intervention for individual cases with clefts. In addition, access to easily retrievable demographic information and a uniformly recorded assessment database, can help to organise and plan cleft care at a national level (WHO, 2002: 33). The WHO (2001b: ix) has recommended establishing databases of craniofacial anomalies that can be linked for the purpose of international collaborations.

A critical review of clinical practice often helps to generate interesting research questions. (Reilly, Douglas & Oates, 2004: 344). The clinical experience of providing speech-language therapy and audiology services in Mauritius raised questions to be addressed by the research: What is the nature of an appropriate and comprehensive communication assessment protocol for routine clinical use for standard assessment of young children with CL/P in Mauritius? Can a database for individuals with cleft be initiated so that information can be easily retrieved, processed and be used for both clinical services and future research.

The aim of this research study is to develop an appropriate communication assessment protocol for young children with CL/P in Mauritius. A new clinical assessment instrument should be

evaluated prior to routine clinical use to determine its accuracy, acceptability and cost effectiveness. The focus of this study is to apply and evaluate the new communication assessment protocol in terms of its applicability and acceptability for clinical use by speech-language therapists and audiologists. A communication assessment instrument may not find its use in clinical practice if it is not applicable and acceptable to the users in a clinical setting.

1.5 THE RESEARCH APPROACH

In this study an action research approach is adopted as it is particularly suited to identifying problems in clinical practice and helping to develop potential solutions to improve practice (Denzin & Lincoln, 2000: 96). Action research is focused on finding a solution to a local problem in a local setting (Leedy & Ormrod, 2005: 108). The mixed methods design to conduct action research is useful as in a single study; practical questions can be addressed using a combination of data gathering methods, analysis and interpretation approaches (Denzin & Lincoln, 2000: 617-618; Onwuegbuzie & Johnson, 2006: 49). The complementary information derived from quantitative and qualitative data can more effectively address the need for a new communication assessment tool that speech-language therapists and audiologists can use in clinical practice. Furthermore, a participatory action research approach (from a combined quantitative and qualitative approach) is required to utilize existing human resources, to build motivation and awareness and ensure sustainability of the research results. Focus groups, in-depth interviews and participant observations may be used to determine the acceptability of the research study (De Vos et al., 2005: 413).

Speech-language therapy focuses on human communication and social interactions, the orientation in this field is 'social' (Damico & Simmons-Mackie, 2003: 132). The social model of cleft care emphasises the role of the society/community to accept and adapt to a person and the clinician's role to transfer skills, act in a supporting role and to develop extensive family support. (D'Antonio & Nagarajan, 2003: 308; Prathanee, Dechongkit & Manochiopinig, 2006, 503). Contextual, cultural and linguistic aspects are important when conducting speech-language assessments (Carter, Lees, Murira, Gona, Neville & Newton, 2005: 386). Therefore, speech-language therapists in countries with limited resources cannot directly import assessment tools from developed countries. In order to develop/adapt an assessment protocol to improve clinical practice of cleft care in a developing country a critical review of current literature is required. The principles which guide assessment and the recommended assessment procedures for young children with CL/P have been documented (ACPA, 2007). However, these recommendations cannot always be directly applied to clinical practice because there is diversity in the health care systems and the characteristics of the children and families who access these services. The development of a communication assessment instrument requires 'contextualised' and 'authentic' research so that the variables that may act to influence these phenomena may be detailed and analysed (Damico & Simmons-Mackie, 2003: 132). A need therefore exists to conduct empirical action research to develop an assessment instrument that has sound theoretical underpinnings, a computer database, and the instrument is acceptable to the professionals who will utilise the assessment instrument and the electronic data storage tool.

Research is not a priority of health systems in most developing countries. Some general factors inhibiting research in developing countries are:

- Poor health care infrastructure - materials, manpower, political will
- Limited financial resources
- Poor training in research methods, epidemiology and statistics
- Little incentive for busy practitioners who may be overwhelmed due to lack of resources
- Employment systems where only service is rewarded (Horton, 2000: 2231).

In developing countries such as Mauritius, there is a need to focus and prioritize research that will optimize health benefits and prove to be relevant for clinical practice (Reilly, 2004: 121). An instrument based on sound research and developed for a specific community has the potential to be of great sustained value.

1.6 TERMINOLOGY

The following frequently used terms within the context of this study are clarified below.

Craniofacial anomalies: Craniofacial anomalies (CFA) are a diverse group of congenital deformities in the growth of the head and facial bones. According to WHO (2001a: 10) the term CFA covers a poorly defined group of congenital anomalies that could include any etiologic category (chromosomal, environmental, multi-factorial) as well as any pathogenic mechanism (malformation, deformation, dysplasia) or any clinical category (isolated defect, sequence, syndrome). Craniofacial anomalies are of numerous types; Orofacial clefts that include all types of cleft lip and/or palate are relatively common type of craniofacial anomaly (Mossey, 2005: 31; <http://www.who.int/genomics/anomalies>). Therefore, in this study the term cleft lip

and/or palate, a typical example of CFA has been used and includes isolated forms as well as CL/P associated with a syndrome/sequence.

Cleft lip and/or palate: The term includes cases with oral cleft of any type. Some texts use the term CL +/- CP, but the abbreviation CL/P was selected for use throughout the text and includes all types of cleft. A simple and easy to document classification of the CL/P was selected (Bzoch, 2004: 45) as it is based on description of unrepaired clefts of the lip and palate:

- Cleft lip and alveolus (left, right, bilateral)
- Cleft lip and palate (complete, left, right and bilateral)
- Cleft palate (hard, soft and submucous)

In this study distinction between syndromic and isolated orofacial cleft is not made, although the two types have been shown to be epidemiologically distinct (Shprintzen & Bardach, 1995: 7). The communication assessment should be generic; therefore the term CL/P as used in this study includes any type of cleft, isolated CL/P and CL/P associated with a syndrome/sequence.

Cleft palate speech and language characteristics: A spectrum of speech-language disorders has been reported among children with CL/P. The cleft type speech characteristics include: hypernasality, inaccurate articulation and frequent glottal stop, nasal emissions during production of fricative sounds. In addition characteristics may include delayed development of language and speech that is accompanied by undesirable facial distortions or mannerisms such as the nasal grimacing (Bzoch, 2004: 404; Hardin-Jones & Jones, 2005: 12; Kuehn & Moller, 2000: 352; Kummer, 2008: 184; Peterson-Falzone et al., 2006: 37; Watson et al., 2001: 235).

Cleft Palate Interdisciplinary Team: Refers to a group of multidisciplinary professionals, specialized in the identification, evaluation and management of individuals with cleft who work together to coordinate the patient's care. These specialists include the surgeon, speech-language therapist, orthodontist, ENT specialist, psychologist, paediatrician, social worker, audiologist, clinical geneticist, radiologist, anaesthetist and nutritionist (ACPA, 2007: 7; Kummer, 2008: 301-302; Shprintzen & Bardach, 1995: 14). The use of this term in the study denotes agreement with best practice guidelines as formulated by ACPA.

Emergent literacy: Children are in the emergent literacy stage of development from birth through to approximately five years of age. Emergent literacy is defined as the reading and writing behaviours of young children before they become readers and writers in the conventional sense (Justice, 2006: 1-4). These precursors to reading include knowledge about print and books, and have their roots in early home and preschool experiences (Hoff, 2005: 398). This term is used to refer to a specific aspect of communication development of children with CL/P in this study.

Young children: The term young children in this body of work will refer to infants, toddlers and preschool children in the age range 0-6 years. Within this group of young children, infants are younger than 12 months, toddlers are between 12 to 36 months and preschool children are in the age range of 3-6 years (<http://en.wikipedia.org/wiki/Infant>). As the early years of life are crucial to fully develop thinking, language, emotional and social skills the focus of this study is young children with CL/P.

Early Communication Intervention (ECI): Refers to early intervention services from a communication-based perspective, covering health and all developmental areas that begin at birth and continue to age three years (ASHA, 2008: 1). Early communication intervention includes screening and assessment and is characterised by an emphasis on family involvement and education (Rossetti, 2001: 147; Roth & Worthington, 2005: 136). Early childhood intervention is the term preferred by Shonkoff and Meisels (2000: xii) and it consists of multidisciplinary services provided to children from birth to five years of age to promote health and well being, enhance emerging competencies, minimise developmental delays, remediate existing or emerging disabilities, prevent functional deterioration, and promote adaptive parenting and overall family functioning. In this study, although young children were in the age range of 0-6 years the term ECI was selected to include the key concept of communication intervention for the entire spectrum of early childhood years.

Communication Assessment: The term communication assessment as used in this study includes communication skills development, speech, language and hearing. The term 'communication assessment' has an expanded meaning relevant to this study of young children with CL/P as feeding, oral motor functions and developmental aspects are also included. Assessment in early communication intervention is defined as the ongoing procedures used throughout the child's development that include the identification of the child's unique strengths and needs, a family-directed assessment of the concerns, priorities, and resources of the family; the identification of the nature and extent of the early intervention services needed by the child and family; and the identification of supports necessary to enhance the family's capacity to meet the developmental needs of the infant or toddler (ASHA, 2008: 10).

Communication disorders and delays: Refers to impairment in the ability to receive, send, process and comprehend concepts or verbal, nonverbal and graphic symbol systems in this study. A communication disorder may be evident in hearing, language and/or speech. Individuals may demonstrate one or any combination of the three aspects of communication disorders. A communication disorder may result in a primary disability or it may be secondary to other disabilities' (ASHA, 1993). It broadly includes all types of speech/language delays, disorders, and disabilities. A speech disorder may be an impairment of the articulation of speech sounds, fluency and or voice and a language disorder is impairment of comprehension and/or use of spoken, written or other symbol systems (ASHA, 1993: 108). The term communication delay in this study refers more specifically to a level of functional communication that is significantly below the expected or typical levels based on a child's age, and refers primarily to speech/language delay.

Developing countries: Countries that are defined to be low- or middle-income countries by the World Bank, where living standards are thought to be low relative to high-income countries (World Trade Organisation, 2004) will be referred to as developing countries. Although there is no precise definition, there are thought to be more than 125 countries with populations in excess of 1 million that display these characteristics. There are significant differences in development levels among these countries and even within the same country. The context of this study, Mauritius is classified as a developing country by the International Monetary Fund (United Nations, 2004: 1). In this text the terms developed and developing countries have been used, while recognizing that others such as first/third world countries, minority/majority countries, less

economically/ more economically developed countries may be equally appropriate (Sell, 2007: 13) to the context being studied.

Speech-language therapists and audiologists: In the USA, the UK and many other developed countries the practice of speech-language therapy and audiology are two separate specialized fields. However, in developing countries for example in India, South Africa, Brazil and Mauritius, the speech-language therapy and audiology traditionally are combined professions. Therefore, the appellation ‘speech-language therapists and audiologists’ is preferred throughout the text as it denotes the profession as practiced in Mauritius.

1.7 ABBREVIATIONS

ACPA	American Craniofacial Cleft-Palate Association
ASHA	American Speech-Language and Hearing Association
CFA	Craniofacial Anomalies
CL/P	Cleft lip and/or palate
CHRIB	Clinic for High Risk Babies
CSAG	Clinical Scientific Advisory Group
ECI	Early communication intervention
GOS.SP.ASS	Great Ormond Street Hospital Speech Assessment
WHO	World Health Organization

1.8 ORGANISATION OF THE STUDY

The research presentation is outlined forthwith.

TABLE 1.1 Outline and description of the sections comprising this study

<p>CHAPTER ONE INTRODUCTION AND ORIENTATION</p>	<p>The first chapter provides an orientation to the study, the problem addressed and the rationale for the development of a Communication Assessment Protocol for young children with CL/P, in Mauritius. The terminology selected within the context of this study, a list of abbreviations used and outline of the chapters are also presented.</p>
<p>CHAPTER TWO CLEFT CARE PRACTICES FOR YOUNG CHILDREN</p>	<p>Chapter 2 describes the impact of a cleft on the child and his/her family as a backdrop to the current practice of care for young children with CL/P. The existing barriers to providing an optimal standard of cleft care in developing countries are discussed along with strategies to improve cleft care.</p>
<p>CHAPTER THREE COMMUNICATION ASSESSMENT OF YOUNG CHILDREN WITH CLEFT LIP AND / OR PALATE</p>	<p>An overview of the current speech, language and hearing assessment practices of young children with CL/P is presented. The need for an appropriate comprehensive communication assessment instrument in developing countries is highlighted and the chapter includes a framework for the development of such a communication assessment protocol.</p>

TABLE 1.1 Outline and description of the sections comprising this study (continued)

<p>CHAPTER FOUR METHODOLOGY</p>	<p>Chapter 4 provides a thorough description of the research methodology employed to develop a communication assessment instrument. It includes the aim of the research, the research design, the research ethics, materials, pilot studies conducted and the training of the speech-language therapists and audiologists to conduct the assessments according to the protocol. Along with the data collection and data analysis the reliability, validity and trustworthiness of the assessment instrument are described in this chapter.</p>
<p>CHAPTER FIVE RESULTS AND DISCUSSION</p>	<p>In chapter 5 the results of the communication assessments of the sample population are analysed, descriptions of the characteristics of the children with CL/P in Mauritius are presented and compared to the literature reviews. The chapter then focuses on the clinical applicability, and acceptability of the protocol by the local speech-language therapists and audiologists.</p>
<p>CHAPTER SIX CONCLUSIONS AND IMPLICATIONS</p>	<p>In this chapter a critical evaluation of the research, conclusions drawn from the research, implications for clinical practice and recommendations for future research are presented. The last chapter closes with a final comment from the researcher.</p>
<p>REFERENCES</p>	<p>A list of all works to which reference is made in the text is presented.</p>
<p>APPENDICES</p>	<p>The nine appendices included at the end of the chapter are the ethical clearances, informed consent letters, questionnaires and interview schedules, speech elicitation materials and the Communication Assessment tracking form. The digital video recordings of the children's speech patterns and the focus group discussion are also enclosed.</p>

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1.9 CONCLUSION

Cleft lip and/or palate is a complex congenital disorder that requires coordinated care by a team of multidisciplinary specialists. Early intervention is crucial to prevent or minimise the negative impacts of this congenital anomaly which may be pervasive. The recommendations for best practice in cleft care are the application of multidisciplinary team-based approach and early intervention to improve the outcomes of treatment of young children with CL/P. However, health service provision and cleft care services vary considerably from developing to developed countries. The concept of a team-based approach to cleft care and early intervention that may be taken for granted in developed countries may be non-existent in many developing countries.

In contexts where individuals have poor access to basic health care, the services offered by the small number of speech-language therapists and audiologists for communication disorders have a different meaning. They are required to share their skills with parents, other health care professionals and community workers (Pickering & McAlister, 2000: 96) to provide and sustain speech-language therapy intervention (D' Antonio & Nagarajan, 2003: 308; Prathanee et al., 2006: 501). With the help of available resources and access to an appropriate communication assessment instrument and an electronic database, speech-language therapists and audiologists in developing countries can meet the challenge of effective cleft care.



1.10 SUMMARY

The overview of cleft care in developed countries and the limitations associated with the system in developing countries provided the rationale for the research as well as the research questions and aim of this study. Description of the terms and justifications for their selection, abbreviations and the organisation of the contents provided the orientation to this study.

CHAPTER 2:

CLEFT CARE PRACTICES FOR YOUNG CHILDREN

The aim of this chapter is to review the impact of a cleft on a young child and his/her family in order to identify the current best practice of care. Furthermore, the role of speech-language therapists and audiologists in cleft care is critically reviewed with implications for developing countries.

2.1 INTRODUCTION

Young children with cleft lip and/or palate (CL/P) have been extensively studied from different perspectives. The causes of CL/P are linked to genetic factors, environmental influences and gene-environment interaction (Peterson-Falzone et al., 2010: 38; Watson et al., 2001: 10). In more than 30% of the cases the cleft may be a part of a syndrome. Children with a syndrome often have associated developmental problems and the documentation of a syndrome increases understanding of the cleft condition (Watson et al., 2001: 91).

Infants with CL/P are at risk of feeding problems, hearing difficulties, communication delays and/or disorders and adverse parent-child interactions (ACPA, 2007: 5; Kummer, 2008: 38; Peterson-Falzone et al., 2006: 9; Strauss, 2004: 150; WHO, 2002: 2). Parameters for evaluation and treatment of patients with CL/P and craniofacial anomalies have been provided by national and international bodies, for example the American Cleft Palate Craniofacial Association (ACPA, 2007) the Clinical Scientific Advisory Group (CSAG, 1998) and the Eurocleft group

(Shaw et al., 2001). The early years (0-6) are critical for children with CL/P, when they require primary surgery for repair of the cleft. The challenge faced by professionals involved in cleft care is to cater for the multiple and diverse needs of both the child and the family, in order to optimize the potential for development despite the congenital anomaly (Bzoch, 2004: 19-20).

The majority of developing countries are unable to provide adequate care for young children with CL/P due to various limitations (refer to Figure 1.1). The World Health Organization (WHO) developed guidelines for improving cleft care globally through an international network for consensus building, planning, protocol development and collaborative research (Shaw, 2004: 238). One of the priorities in developing countries is to establish the health care needs for craniofacial anomalies in the population. This can be achieved by a systematic collection of data and establishing a database/national registry for children with CL/P. In developing countries inadequate ascertainment of the cases is due to many births not being registered. Other reasons are the heterogeneity of cleft cases, the failure to use comparable classification system for CL/P, and lack of agreed criteria for data collection (Shaw, 2004: 241).

The health and well-being of patients with CL/P is dependent on the clinical expertise of care providers (ACPA, 2007: 5). In many developing countries, scarcity of health care professionals is a major limitation for the application of best practices. It is difficult to plan cleft care services if the information about current care/practice is not known. There is a need to improve cleft care in developing countries to prevent the negative impact of the cleft on a child and his/her family.

Speech-language therapists and audiologists play an important role in improving the standards of care for young children with CL/P in developing countries as they can apply the existing knowledge base of best practice for cleft care from the developed countries to local context. However, are recommended best clinical practices in developed countries, applicable to a developing country? Is there a need to adapt the guidelines to suit the local context without compromising the standards of optimal care? To answer these questions contextual action research is required.

2.2 IMPACT OF A CLEFT ON A YOUNG CHILD AND THE FAMILY

The cleft may adversely affect both the child and the family, but this can be addressed by timely repair, a team-based approach and early communication intervention (ECI). There is no clear relationship between the type and severity of the cleft and its impact on the child and family, as their coping skills and compensatory behaviours are determined by a variety of factors such as temperament of a child, parental coping skills, family's socio-economic status, and the support services available to child and family (Watson et al., 2001: 376).

The overall impact of the cleft on the child and his/her parents, is schematically represented in Figure 2.1 and is discussed.

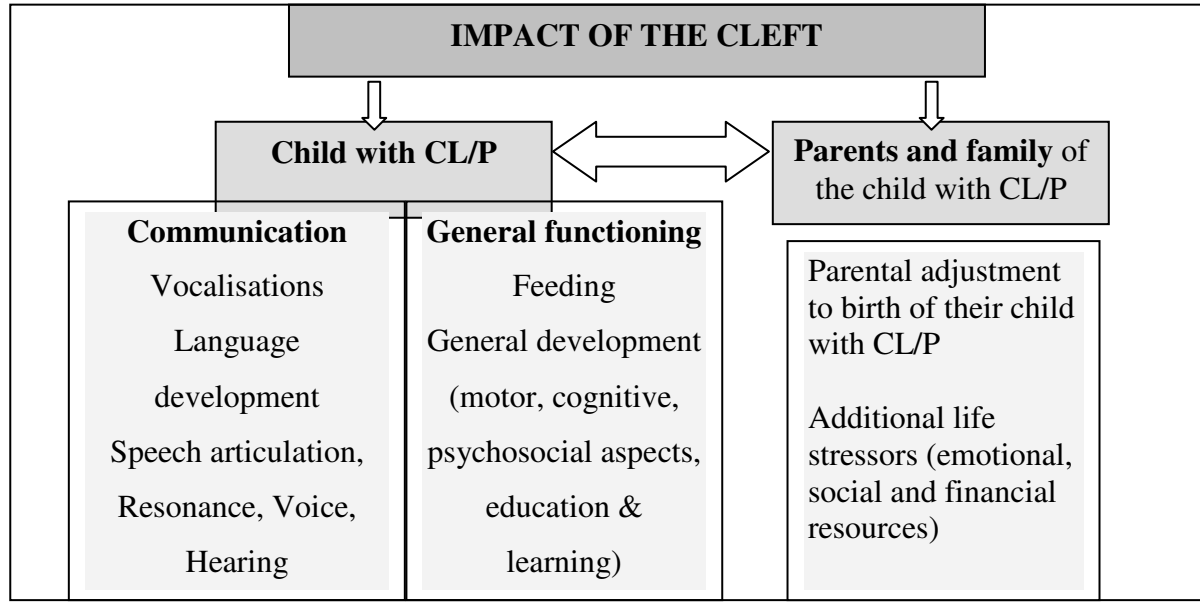


FIGURE 2.1 Impact of the cleft

2.2.1 Impact of a cleft on communication development

Communication skills play a pivotal role in the cognitive, psychosocial, behavioural and social development of a child (Billeaud, 2003: ix). In the USA 6-10% of children younger than three years are reported to have a speech and language development disorder/delay (Billeaud, 2003: x; Rossetti, 2001: 1). In children born with CL/P a higher risk of communication delays/disorders has been reported than children without CL/P (Kuehn & Moller, 2000: 348; Rossetti, 2001: 3). Children with CL/P may also have other risk factors such as the presence of a syndrome, low birth weight (Billeaud, 2003: 55) or HIV/AIDS, to adversely affect their development. The most significant impact of a cleft on communication development is summarised in Table 2.1.

TABLE 2.1 Impact of a cleft on communication development

Communication development (reported by)	Impact	Contributing etiological factors	Some gaps identified in current research
Vocalizations (Chapman et al., 2003 : 174; Hutters, Bau & Brondsted, 2001 : 451-452; Neiman & Savage, 1997: 224; Scherer, 1999: 90)	Delayed canonical babbling Reduction in use of consonants Frequent use of nasal consonants and glottal stops Delayed communication development Mother-child interactions may be altered.	Interplay of biological risk factors (abnormal oropharyngeal structure and function, intermittent hearing loss associated with middle ear effusion) of the child with CL/P and environmental factors (mother-child interactions, timing of surgery to repair cleft)	Insufficient evidence from research regarding predictive value of vocalisations to identify infants at-risk for later speech-language acquisition in view of the variability of vocalisations in infants.
Language development (Broen et al., 1998 : 682; Hutters et al., 2001: 456; Kuehn & Moller, 2000: 353; Morris & Ozanne, 2003: 464 ; Peterson-Falzone et al., 2010: 241- 242 ; Scherer & D’Antonio, 1995)	Language acquisition is delayed and/or disordered particularly among children with syndromes and sequences	Hearing and surgical history, neuro-linguistic deficits, low birth weight, adverse early communication interactions, psychosocial issues and socio-environmental factors	Research needed from developing countries (where there are inadequate cleft services and lack of early interventions) on speech- language development in children with CL/P.

TABLE 2.1 Impact of a cleft on communication development (continued)

Communication development (reported by)	Impact	Contributing etiological factors	Some of the gaps identified in current research
<p>Articulation (Hardin-Jones & Jones, 2005: 12; Kummer 2008 : 182-191; Persson, Lohmander-Agerskov & Elander, 2006 : 295; Peterson-Falzone et al., 2010: 222-237; Sell, Harding & Grunwell, 1999 : 17-33; Trost-Cardamone, 2004: 463-468)</p>	<p>Weak pressure consonants, nasal emissions accompanying pressure consonants, phonetic errors increase with phonetic complexity, nasal grimace, flare, or facial grimace. Compensatory articulation & obligatory errors</p>	<p>Myriad of structural and learning factors, hearing loss, dental and occlusion problems, phonologic developmental problem, developmental factors (syndromes) and strategies employed to compensate for the cleft</p>	<p>Research needed to examine relationship between articulation, and learning/cognition factors of children with CL/P. A need to standardize descriptions of articulation, phonologic features and patterns of errors in local languages that have cross-linguistic relevance</p>
<p>Resonance (Kummer, 2008: 178-182; Trost-Cardamone, 2004: 463-468; Whitehill, 2002: 55)</p>	<p>Hypernasality: more severe for high versus low vowels and for voiced consonants Hyponasality: reduced or absent nasal resonance with nasal consonants /m/, /n/, /ŋ/ Mixed resonance Cul-de-sac nasality</p>	<p>Velopharyngeal dysfunction, large nasopharyngeal space. Hypertrophied tonsils or adenoids nasal septum deviation, pharyngoplasty. Persistent learned habits from the pre-surgery phase</p>	<p>Need for refined measures of reliable auditory perceptual resonance analysis and standardisation in local language for use of consistent rating scale of resonance (nasalence varies across languages and dialects)</p>

TABLE 2.1 Impact of a cleft on communication development (continued)

Communication development (reported by)	Impact	Contributing etiological factors	Some of the gaps identified in current research
<p>Voice (Kummer, 2008 : 190-191; Peterson-Falzone et al., 2010: 240-241)</p>	<p>Hoarse voice, unusual breathiness, and reduced loudness</p>	<p>Inadequate vocal tract variations to regulate air pressure for voicing Compensatory strategy (soft voice, hyperfunction of vocal cords)</p>	<p>Need for further research to conduct differential diagnosis of voice quality of young children with CL/P</p>
<p>Hearing (Broen et al., 1996 : 132; Paliobei, Psifidis, & Angnostopoulos, 2005 : 1373; Peterson-Falzone et al., 2010: 207; Schonweiler et al., 1999: 277; Shprintzen & Bardach, 1995 : 164 ; Watson et al., 2001 : 91).</p>	<p>Risk of otitis media and associated conductive hearing loss Sensorineural or mixed hearing loss</p>	<p>Poor Eustachian tube function Abnormality of the velopharyngeal muscles and poor drainage of the middle ear Presence of syndrome/sequence Genetic factors</p>	<p>Research evidence required for impact of hearing loss on speech- language development of young children with CL/P. The impact of cleft on auditory processing behaviour of children with CL/P</p>

The different areas of communication development that the cleft impacts include: vocalizations, language development, articulation, resonance, voice and hearing.

- **Vocalizations**

The impact of a cleft on an infant's prelinguistic behaviour is important as the infant moves progressively towards speech through the emergence and development of oral motor control, vocalizations, social interactions and language use. Chapman et al. (2003: 175) compared 15 children with CL/P to 15 children without clefts, to determine the relationship between early and later speech development. The findings of this comparative and longitudinal study indicated that children with post cleft repair surgery continued to exhibit speech delays at age 21 months. Thus, children with cleft palate may have fewer 'practiced' forms to call upon for word production. Also, they may receive less reinforcement from parents for communicative attempts as there are fewer instances of canonical babbling for parents to respond to. There is a possibility that parental expectations regarding what sounds the child can or cannot produce prior to cleft surgery may influence patterns of parent-child interactions (Chapman et al., 2003: 192).

The patterns that are evident in children's pre-speech vocalisations persist and are also evident in their early speech (Watson et al., 2001: 195). The prelinguistic consonant inventory of toddlers may impact on the presence or severity of future speech problems (Oller, Eilers, Neil, & Schwartz, 1999: 238; Peterson-Falzone et al., 2010: 235). Hence assessment of early vocalizations is crucial to ECI planning, as specific targets can be set to facilitate early development and include parents in the intervention process.

- **Language development**

Language development is influenced by inherent biological and cognitive abilities of the child and interactions with caregivers (Billeaud, 2003: 33; Guralnick, 1997: 7; Popich, Louw & Eloff, 2007: 65; Rossetti, 2001: 2). Congenital disorders occurring ‘in-utero’ (such as craniofacial disorders) have a more pervasive effect on the learning of speech and language than do similar disorders acquired later in life (Bzoch, 2004: 23).

Expressive language delays have been consistently reported in the majority of children born with CL/P (Kuehn & Moller, 2000: 354). In addition children with clefts may have language delays with the same frequency as children without clefts (Golding-Kushner, 2001: 42). This is understandable as there are multiple risk-factors (established risk factor due to the cleft, biological and environmental risk factors) during the critical period for language acquisition that negatively impact communication development in young children with CL/P (Kritzinger, Louw & Hugo, 1996: 77). A higher prevalence of language delays and speech disorders are reported among children (without cleft) from socio-economically deprived environments compared to their peers (Billeaud, 2003: 45; Guralnick, 1997: 6; Golding-Kushner, 2001: 43; Pamplona et al., 2004: 81). In developing countries children with cleft may be living in poverty and adverse health care contexts, such as inadequate maternal-child care and cleft care services, therefore they have additional risk factors for delayed language development. Research into the interaction between clefting and language development is limited and complex because of the heterogeneity in severity of original deformity and variables such as medical, familial, social and educational factors (Peterson-Falzone et al., 2010: 241). Thus, research evidence for impact of cleft on language development is difficult to find.

In normal speech production the processes of articulation, resonance and phonation are intimately related (Watson et al., 2001: 72) and the impact of the cleft on these are described below.

- **Articulation**

Children with CL/P demonstrate a remarkable variability in articulation performances due to the heterogeneity of cleft types, age groups under consideration and surgical management protocol. However, as a group they often demonstrate poor articulation skills as compared to their peers without clefts (Hardin-Jones & Jones, 2005: 9; Kuehn & Moller, 2000: 352; Peterson-Falzone, et al., 2010: 222). The articulation errors due to structural abnormalities (such as dental anomalies due to the cleft) are termed ‘obligatory errors’ and distinguished from ‘compensatory errors’ made due to a modification in the placement of the tongue and lip movements to compensate for the structural abnormalities (Peterson-Falzone et al., 2010: 224). The place of production of articulation of oral sounds may be shifted to the pharyngeal, laryngeal, and velar loci as a learned behaviour to compensate for the cleft palate (Watson et al., 2001: 198). However, these learnt articulation errors may persist after management of the structural abnormality (Peterson-Falzone et al., 2006: 83). In addition young children with CL/P may have developmental articulation errors (Hutters et al., 2001: 465; Morris & Ozanne, 2003: 464).

- **Resonance**

Despite cleft palate repair surgery, hypernasality may persist in young children with CL/P due to velopharyngeal insufficiency, inadequacy or dysfunction, palatal fistula and/or mislearning (Kummer, 2008: 192). Hypernasality is perceived in connected speech and in vowel production

and its negative impact is increased with the rapid rate of speech and muscular fatigue. Other resonance disorders due to the cleft that may impact on speech intelligibility of children are hyponasality and mixed nasality. Hyponasality may be due to nasopharyngeal obstruction (hypertrophied adenoids), maxillary retrusion as a phenotypical feature of a syndrome (for example, Crouzon syndrome, Apert's syndrome), or due to complications of the surgery conducted to reduce the velopharyngeal gap. Mixed resonance may occur when both velopharyngeal dysfunction and nasal blockage are present (Kummer, 2008: 182). Moreover, nasal emissions, turbulence and grimace often occur simultaneously and have similar etiology to resonance problems and articulation errors. These overlapping problems may be due to learned behaviours 'habituated nasal and facial grimacing' or due to velopharyngeal dysfunction (Bzoch, 2004: 406) and are visually distracting in communication.

Resonance varies across languages and dialects and this may have an impact on how far the child's resonance deviates from 'normal' nasal resonance. Knowledge of the language and/or dialect is essential to determine typical or deviant resonance. Speech-language therapists and audiologists are faced with a challenging task to delineate the contributing etiological factors of resonance, articulation and voice that often co-occur in children with CL/P. Determining the etiological factors contributes to making appropriate management decision (for example physical treatment or behavioural modification).

- **Voice**

In a study by Hocevar-Boltezar, Jarc and Kozelj (2006: 27), voice abnormalities such as hoarseness, unusual habitual pitch, breathiness and reduced loudness were reported among

12.5% of the children with CL/P. Children with CL/P and velopharyngeal inadequacy are at risk of hoarseness due to vocal hyperfunction. The interaction of velopharyngeal inadequacy and the laryngeal compensatory behaviour may result in gottalisation of the stop consonants and it has been hypothesized that these may be the cause of voice disorders in children with CL/P (Bzoch, 2004: 409; Peterson-Falzone et al., 2010: 240). The impact of a cleft on voice quality should be assessed (hoarseness may indicate underlying velopharyngeal insufficiency) and appropriate intervention provided (Kummer, 2008: 190; Peterson-Falzone et al., 2006: 36).

- **Hearing**

Research spanning over years has provided evidence that children with CL/P are at risk of recurrent otitis media and associated conductive hearing loss due to poor Eustachian tube function (Broen et al., 1996: 132). Ear disease, congenital malformations of the auditory system, and congenital sensorineural or mixed hearing loss are frequently seen in children with multi-anomaly disorders such as Pierre Robin sequence, Treacher Collins syndrome, Stickler syndrome, Velo-cardio-facial syndrome and Crouzon syndrome (Shprintzen & Bardach, 1995: 19). The extent and type of hearing loss in children with CL/P is reported to vary, depending on the age, pre and post palatoplasty status and other genetic defects of the sample population (Peterson-Falzone et al., 2010: 209).

In a study by Schonweiler et al. (1999), of 417 of children with cleft palate, it was reported that 80% of the children had hearing problems predominantly of a fluctuating conductive nature caused by otitis media with effusion. In a recent study of 40 infants with CL/P, a moderate hearing loss was found in 35% of the infants, indicating that these infants may be at risk of

speech-language delays/disorders (Andrews et al., 2004: 10-17). The incidence of hearing loss in children with CL/P, in developed countries where audiology and ENT services are available is approximately 58% (Kemker & Antonelli, 2004: 357; Merrick, Kunjur, Watts & Marcus, 2007: 532). In countries where preventive measures such as early myringotomies and placement of ventilation tubes or early intervention for hearing loss among children with CL/P, are not practiced, the incidence is likely to be even higher.

Middle ear disease and hearing loss constitute a major risk for communication delays and disorders in children with CL/P, as even a mild fluctuating hearing loss may have a negative impact upon speech and language (Schonweiler et al., 1999: 215). Early identification and management to protect otologic and audiologic function is critical to the normal development of cognition, language and speech (Mars et al., 2008: 212; Merrick et al., 2007: 532).

An important aspect of hearing is functional listening. Hugo, Louw, Kritzinger and Smit (2000: 47-53), identified the need for a simple and quick tool for the evaluation of listening behaviour that could be easily applied to the high risk population between birth and three years of age and guide early intervention efforts. Yet, auditory processing disorders in young children with CL/P have not been the focus of research to date.

Knowledge of the impact of clefting on communication, language and speech production in young children with CL/P is important as speech-language therapists and audiologists can conduct appropriate assessments and share the results with parents and other professionals involved in cleft care to make appropriate management decisions.

2.2.2 Impact of a cleft on general development

The cleft condition can also affect other functions of the developing child with CL/P namely feeding and general development such as motor development and psychosocial aspects. These associated problems may also negatively impact on communication development of the child and are viewed as stressors to the child's family (Watson et al., 2001: 192).

- **Feeding**

The cleft palate may have a negative impact on the neonate's feeding skills (Reid, Kilpatrick & Reilly, 2006: 702) which in turn may have an adverse effect on the adequacy of nutrition, cause stress to parents, adversely affecting mother-child interactions and may also potentially affect oral-motor and oro-sensory development (Kummer, 2008: 121; Reid et al., 2006: 702; Shprintzen & Bardach, 1995: 63). Feeding difficulties of neonates with cleft palate may include poor oral suction, poor intake with lengthy feeding times, nasal regurgitation, and choking, gagging and excessive air intake (Kummer, 2008: 127; Reid et al., 2006: 702; Shprintzen & Bardach, 1995: 65). The primary concern of most parents when an infant is born with CL/P is feeding due to its importance for survival and growth. During the first few months of any infant's life, parent and other caregivers find that most interactions involve feeding and communication (Arvedson & Brodsky, 2002: 527; Young, O'Riordan, Goldstein & Robin, 2001: 55).

Chatoor et al. (1997: 80) and Reid et al. (2006: 702) reported that the cleft palate may not be the main or only cause of the feeding difficulties. Other factors such as the presence of a sequence,

syndrome, prematurity, low birth weight, cardiac or pulmonary disease, functional or structural abnormalities of the oro-pharynx or gastrointestinal tract may contribute to the feeding difficulties. Anomalies such as micrognathia, macroglossia and neuromuscular coordination problems may cause swallowing difficulties which are exacerbated by the cleft. Several secondary problems may occur due to feeding difficulties such as poor weight gain, lengthy feeding times, and stressful feeding interactions between the infant and caretaker (Kummer, 2008: 128; Shprintzen & Bardach, 1995: 63-74).

The anatomical structures for feeding, swallowing and speech are the same although the neurophysiological function differs (Peterson-Falzone et al., 2006: 11). Speech-language therapists are trained to and can offer guidance to parents regarding feeding problems in their children with CL/P. Information concerning feeding is of the highest priority to parents of neonates with CL/P (Young et al., 2001: 57). They may require support, information and intervention concerning feeding from professionals such as speech-language therapists and nursing personnel.

- **General development**

Infants with clefts may exhibit other risk factors such as a syndrome, sequence, congenital malformations, associated anomalies, and environmental risk factors that interact in a synergistic fashion and place them at double risk for developmental delays (Neiman & Savage, 1997: 218; Peterson-Falzone et al., 2010: 376; Shprintzen & Bardach, 1995: 182). Literature has been inconclusive regarding the outcome of general development of infants with CL/P because clefts present as a heterogeneous group of impairments.

In a comparative study of infants with CL/P matched to infants without clefts, Neiman and Savage (1997: 223-224) reported slower developmental performance among infants with CL/P in motor, self-help, cognitive and expressive language domains. Kritizinger, Louw and Hugo (1996: 83) also provided data to support their view that infants and toddlers with CL/P are at risk for developmental delays. Therefore, screening of general development is required to identify children with CL/P and guide appropriate interventions.

In the preschool years (3-6 years), the cleft condition may have an impact on the child's self-image and socialization (Peterson-Falzone et al., 2010: 378). Psychosocial aspects include a range of aspects such as psychological functioning, personality and adjustment, self concept, body image and satisfaction with appearance, social functioning, development and learning (Broder, 1997: 402; Peterson-Falzone et al., 2006: 14). The heterogeneity of aspects that the various studies focus on and the variety of methodologies used (observations, questionnaires, interviews) raises the question whether young children with CL/P have a higher prevalence of psychosocial problems. This question has not been answered conclusively to date.

Hunt, Burden, Hepper and Johnston (2005: 274) conducted a systematic review of published scientific research on the psychosocial impact of CL/P among children and adults. Their study analyzed 64 articles and the conclusion was that overall adjustment and functioning in children with CL/P appears to be reasonably good. The ability to communicate plays a crucial role in the development of appropriate psychosocial skills and behaviours (Hauer, Shriberg, Kwiatkowski & Allen, 2005: 636). Therefore, poor speech intelligibility in children with CL/P may have a negative impact on the speaker's self concept and may affect social development. Limited

research findings on psychosocial aspects are available especially from contexts where cleft care may be of inadequate standard. In developing countries where plastic surgery is not available/accessible to all children with CL/P, or surgery is performed late, the facial appearance due to an unrepaired CL/P may cause irretrievable damage to the psychosocial well being of the individual.

Children with CL/P are also at risk of learning disability, low school achievement, reading difficulties and grade retention due to cognitive deficiencies that are reported to be secondary to language disorders, speech problems, and psychosocial underachievement (Broder, Richman & Matheson, 1998: 129; Richman & Ryan, 2003: 154). In a multicentre study conducted by Broder et al. (1998) to determine the prevalence of learning disability amongst children with CL/P it was found that 46% of the participants with clefts had learning disability, 47% made poor educational progress and 27% had repeated a grade in school. Although the educational difficulties may be attributed to the presence of a syndrome and cognitive deficiencies, research indicates that even children with nonsyndromic CL/P are more likely to have learning problems when compared to children without clefts. Team members are required to be sensitive to the impact of a cleft on the education of young children with CL/P and help to develop effective psychosocial and educational strategies to enhance and support the learning experiences of these children (ACPA, 2007: 22).

Thus, a cleft may have an adverse effect on a child's health and social integration, due to the multiplicity of etiologic factors related to the cleft that impact on communication, appearance, and general developmental functions.

2.2.3 Impact of a cleft on parents and families

The birth of an infant with a cleft is a shocking and traumatic experience for parents. They may experience feelings of sadness, guilt, anger and fear for their child's appearance (Peterson-Falzone et al., 2010: 371; Strauss, 2001: 227; Watson et al., 2001: 118). Parents are often aware of the cleft condition and/or presence of a syndrome in their to-be born child as prenatal diagnosis with imaging techniques is possible in many developed countries. However, the subject of concern is how this information is communicated to parents. An experienced professional who cares should communicate the prenatal diagnosis, and then the family has the opportunity to work through much of their distress before the infant is born (Ter Poorten & Louw, 2002; 56-67; Watson et al., 2001: 118). Strauss (2001: 230) suggests that health care professionals portray children with congenital conditions in positive terms to encourage the family and community to become more accepting of these children.

The infant's feeding difficulties and maintaining adequate weight gain may have a further negative impact on parental coping strategies (Young et al., 2001: 57). The cleft may also impact mother-infant attachment and interactions (Speltz et al., 1993: 487). However this is a controversial topic as recent studies (Baker, Owens, Stern & Willmot 2009: 234; Maris, Endriga, Speltz, Jones, & DeKlyen, 2000: 262) have shown that enhanced personal and social resources helped parents cope with the stress and consequently resulted in positive psychosocial outcomes for young children with CL/P.

Parents of infants with CL/P show elevated levels of stress during infancy and toddlerhood. Early parenting stress was associated with higher levels of adjustment problems when children reached toddlerhood (Pope, Tillman & Snyder, 2005: 558). Parents may also have to balance their time among siblings of the child with CL/P and the siblings need to understand that the young child with CL/P may require longer time to feed, and have several medical visits (Kummer, 2008: 281). Parental stress may relate to accessing professionals and community services, securing adequate financial resources and coping with the stress of sending a child for surgery (Collett & Speltz, 2006: 264). The post surgical period stressors that parents of children with CL/P experience are related to aspects such as a feeding plan, arm splints and pain management. As the child grows, the parents may have other concerns such as the child's fluctuating hearing loss, speech problems, and scholastic and behaviour problems. Clefts may be associated with syndromes such as the Velocardiofacial syndrome (VCFS) that is known to be associated with learning difficulties and later psychological disorders (Kummer, 2008: 103; Peterson-Falzone et al., 2010: 72; Watson, 2001: 263).

In addition to the above factors, reactions of extended family members and friends will have an effect on the child and his/her family and the support that parents may receive in caring for the child with CL/P (Peterson-Falzone et al., 2006: 10). The adverse effects on family functioning can be minimised through family-focused and community-based support services (Rossetti, 2001: 268).

The WHO (2002: 28) recognizes the burden of care to the families of children with CL/P and to society as a whole. Elucidating the pervasive and negative impact of the cleft on

communication, appearance, and general development functions of the child and its impact on parents, provides the underpinnings for a description of the current recommendations for best clinical practice.

2.3 RECOMMENDED BEST PRACTICE FOR THE CARE OF YOUNG CHILDREN WITH CLEFT LIP AND/OR PALATE

Recommendations for the optimal care of young children with CL/P have been made by various groups across the world such as the Clinical Standards Advisory Group (CSAG, 1998) in the UK, the Eurocran group (2000), the World Health Organisation (2001) and the American Cleft Palate and Craniofacial Association (ACPA, 2007). As illustrated in Figure 2.2 recommendations for care a young child with CL/P and his/her family include a team-based approach, early communication intervention and treatment outcome measures. The WHO (2001 b: ix) has recommended the establishment of local databases of children with clefts in order to organise and plan cleft care services and facilitate inter-centre and international collaborations to improve cleft care globally.

RECOMMENDATIONS FOR A CHILD WITH CL/P AND THE FAMILY
Team-based approach to assessments and treatment
Early communication intervention and parental participation
Treatment outcome measures
(ACPA, 2007)
National registry and databases on individuals with craniofacial anomalies linked to global registry on craniofacial anomalies (WHO, 2001b: ix)

FIGURE 2.2 Recommended best practice for the care of young children with CL/P

The recommendations depicted in Figure 2.2 are discussed in the following sections.

2.3.1 Team approach

Children with CL/P require surgical repair of the congenital defect, and cleft care involves a variety of specialists representing many disciplines, working in an interdisciplinary and coordinated team. A team approach to care for young children with CL/P increases the awareness and treatment of the full spectrum of health problems associated with these anomalies. Moreover, comprehensive assessments conducted by experienced professionals in cleft care, and long term follow-up results in the best outcomes of cleft care (ACPA, 2007: 7; Kummer, 2008: 299). In a team approach, professionals specialized in cleft care, assess and provide coordinated treatment to children with CL/P and care for their families, and engage in inter-professional communication within the team (ACPA, 2007: 8; CSAG, 1998: 28). A team approach allows for a comprehensive assessment, with fewer visits which makes the care of patients easier for providers, yet more effective for the patients (ACPA, 2007: 5; CSAG Report, 1998: 21; Nackashi, Dedlow & Dixon Wood, 2004: 269-279; Shaw et al., 2001: 9; Shprintzen & Bardach, 1995: 12-15; WHO, 2002: 143; Wyszynski, 2002: 293). An important concept in the team approach is the inclusion of parents as full team members in the assessment and management process of young children with CL/P.

In order to provide quality care, the team members need to have special training in cleft care (Kummer, 2008: 305). Furthermore, the number of patients referred to the team should be sufficient (at least 40-50 new cases annually) to sustain the experience and specialist skills of all

team members (WHO, 2002: 142), most importantly the surgeon. The Clinical Standards Advisory Group (1998: 98) in the UK recommended that cleft services be centralized to allow fewer centres to function as high volume, high quality ‘hubs’ where experienced team members would provide assessment and diagnostic services while outreach clinics (spokes) conduct follow-up and therapy. Although high volume centres may not guarantee a good outcome, they do provide the means whereby outcomes can be monitored and assessed (Watson et al., 2001: 59). Such a model of cleft care service delivery could be considered to maximise the use of limited professional resources.

The main barrier to following a team-based approach for treatment of individuals with CL/P, in developing countries, is that the professionals who represent the cleft care team are either unavailable or limited in number. For example, in developing countries the availability of surgeons experienced in cleft surgery is a major concern and limited hospital facilities and services may exist (Wyszynski, 2002: 424; Yeow et al., 2002: 18). International teams sponsored by charity organisations (such as Interplast, Rotoplast, Operations Smile, The Smile Train, Transforming Faces) provide surgical interventions in countries where the facilities for repair of the cleft are not available (Mars et al., 2008: 10). However, the dental and orthodontic services for children with CL/P require long term follow-up. These services are not readily accessible or affordable to children with CL/P in developing countries. Speech-language therapy services are often absent or extremely limited in developing countries (D’Antonio & Nagarajan, 2003: 307; Sell, 2007: 14). Training of health care professionals regarding aspects of speech-language therapy and improved level of awareness of cleft care were some of the strategies applied during the Smile Train initiated Pan African Congresses on Cleft Lip and Palate

(PACCLIP) held in Nigeria (2006, 2007) and Ethiopia (2009), to improve cleft care in Africa (<http://www.adventisthealthinternational.org>).

2.3.2 Early communication intervention and parental participation

Early Communication Intervention (ECI) is crucial for young children with CL/P as both biological and environmental factors place these children at risk of communication delays/disorders. Biological risks include the cleft, its associated anomalies and hearing impairment. In addition to these biological risk factors, environmental risk factors affect communication development namely psychosocial issues, early mother-child communication interactions, and family stressors such as financial aspects and social supports (Guralnick, 2005: 14; Kritzinger et al., 1996: 77; Kuehn & Moller, 2000: 354; Savage, Neiman & Reuter, 1994: 222). ECI is reported to promote child health and well being, enhance emerging competencies, minimize developmental delays, remediate existing or emerging disabilities, prevent functional deterioration and promote adaptive parenting and overall family functioning (Shonkoff & Meisels, 2000: xvii).

In developed countries, the role of speech-language therapists and audiologists in ECI has been expanded to include prevention of communication delays and disorders (ASHA, 2008: 9). It is easier and more efficient to prevent the development of speech and language problems than to treat them after they have occurred (Golding-Kushner, 2001: 46). Speech-language therapists and audiologists assess feeding, hearing, prelinguistic communication assessments, parent-child interactions and provide interventions from the neonatal stage of a child with CL/P (ACPA,

2007: 6). Early monitoring and preventive measures have the potential to enable the child with a cleft to achieve normal speech development and hearing acuity by five years of age (Blakely & Brockman, 1995: 25).

Health care professionals can provide appropriate and effective clinical treatment for CL/P and need to empower parents of children with CL/P through education and training (Labuschagne & Louw, 2005: 117; Watson et al., 2001: 379). The most important aspect in the care of young children with CL/P is the partnerships between parents and health care professionals (Nackashi, Dedlow & Dixon Wood, 2004: 274). Young children with CL/P were reported to benefit from early language intervention, such as naturalistic intervention models, enhanced milieu teaching and focused stimulation implemented by early interventionists, speech-language therapists and parents (Pamplona & Ysunza, 2000: 231; Scherer & Kaiser, 2007: 359).

As mentioned previously, the recommended best practice for cleft care is evaluation and treatment by a transdisciplinary team, from the moment of birth in partnership with the parents of the child (ACPA, 2007: 6). However, outcomes of these expensive health care models need to be measured so that scientifically derived findings guide best clinical practice (Reilly, 2004: 113). Moreover, effective ECI requires local speech-language therapists and audiologists with cultural and linguistic competence. But in developing countries only a limited number of speech-language therapists are available who cannot meet the needs of the population. A possible solution to this problem is the development of training programmes for the professions in countries where it has not existed before but this proposition is very costly and requires long term planning (D'Antonio & Nagarajan, 2003: 308). An inspiring example is the Sri Lankan

Cleft Lip and Palate Project that became the catalyst for the development of the profession of speech-language therapy in that country (Mars et al., 2008: 108).

2.3.3 Treatment outcome measures

Highly complex and varied protocols are used to treat individuals with CL/P by different teams. The Eurocleft survey (Shaw et al., 2001: 1) showed that there were 194 different protocols followed for unilateral clefts in Europe alone. Evidence-based practice integrates research findings with clinicians' experiences and patient preferences (Reilly, 2004: 113). If decisions on intervention are to be based on evidence, it is important that treatment outcome measures are in place to judge the effectiveness of the treatment, to compare the results and to improve the quality of cleft care (Watson et al., 2001: 386).

Currently in cleft care, the important measures of treatment outcome are the degree of handicap that persists despite surgical treatment, such as dento-facial development, speech, and psychosocial well being of the child with CL/P (Wyszynski, 2002: 433). From the perspective of clinicians, monitoring and tracking treatment outcomes requires the use of appropriate, consistent and reliable recording of assessments and of interventions (ACPA, 2007: 24; Phillips, 2004: 297).

Speech has been identified as a key outcome measure in children with CL/P (Kuehn & Moller, 2000: 369; Sell, 2005: 116; Lohmander-Agerskov & Olsson, 2004: 68; Persson, Lohmander-Agerskov & Elander, 2006: 307). Speech outcome measures are crucial and need to be

conducted periodically to assess speech at stages of growth and development; for example 0-3 years; preschool age, school age and in adulthood (Kuehn & Moller, 2000: 369). However, the main challenge is to define the speech characteristics to be measured and develop methods that are valid and reliable for how the speech characteristics will be measured and compared (Henningsson et al., 2008: 4; John et al., 2006: 273; Lohmander-Agerskov & Olsson, 2004: 65). Recently the Universal Parameters for Reporting Speech Outcomes (Henningsson et al., 2008:1-17) were developed by a group of speech-language therapists as a tool to measure speech outcome and allow international comparisons for individuals with CL/P. Although this continues to elicit debate (Lohmander-Agerskov, 2008: 452) an important step to standardise speech outcome measures has been taken. In order to guide evidence based practice of cleft care, speech-language therapists require explicit criteria of standardized outcome measures for speech and access to reliable and measurable speech outcomes (John, Sell, Sweeney, Harding-Belle & Williams, 2006: 272; Sell, 2005: 105).

An additional perspective of treatment outcomes that guides best practice is the satisfaction of patients and their families with the treatment provided (ACPA, 2007: 6; Kuehn & Moller, 2000: 370). Quality of life is challenged in individuals with CL/P as a result of impaired function, appearance and social integration. To develop and standardize psychological and quality of life outcome measures, there is an urgent need to either create collaborative groups or improve the networking capabilities of existing groups (Prahll & Prahll-Andersen, 2007: 120; WHO, 2002: 97).

Outcome measures for cleft care that are undertaken on a national/international basis can provide robust evidence to governments for implementing major changes regarding the delivery of cleft care. The development and standardization of valid outcome measures in the treatment of children with CL/P was identified as an important strategy to improve cleft care globally (ACPA, 2007: 6; Bearn et al., 2001: 33; Watson et al., 2001: 391; Wyszynski, 2002: 433). However, a challenge to determining outcome measures for children with CL/P is that interventions are provided at an early stage of life and their consequences are revealed some years later (Wyszynski, 2002: 434). This requires longitudinal, long-term follow-up of the individuals with CL/P and a database can greatly assist in this endeavour. Moreover, as the CL/P may impact many structures and functions, the quantification and weighting of diverse outcomes is required (WHO, 2002: 26). Outcome studies require large data sets that can be used as a basis for outcomes data in clinical trials investigations (Hathorn et al., 2006: 404; Henningsson et al., 2008: 15). However, obtaining large data samples may be problematic unless there is international collaboration (WHO, 2001b: 13). Most studies and reviews on CL/P conclude that more research is needed to validate the findings as there is a lack of uniform outcome measurements (Prahl & Prahl-Andersen, 2007: 218). Despite the many issues related to outcome measures it is clear that best practice will only evolve if valid outcome measures that have contextual relevance are in place (Bearn et al., 2001: 42).

2.3.4 National registry and databases for individuals with craniofacial anomalies

The WHO (2001b: 45) has formulated guidelines to formalize and standardize population based birth-defect registries at national and regional level to contribute to improving cleft care globally.

Access to such statistics and epidemiological information concerning young children with CL/P is crucial to the planning of health care services, prevention, international comparisons and collaboration. The rationale for the registry of individuals with craniofacial anomalies is that it will identify global variability in the prevalence of craniofacial birth defects, estimate the burden of need for public health services, identify priorities and underpin research initiatives that will address primary, secondary and tertiary prevention.

Appropriate documentation and uniform record keeping of individual cases are essential to set up a national congenital anomalies' register using a computer-based data system. However, in developing countries recording of congenital anomalies at a national level may not be possible unless there is a legislation to make such data recording compulsory and there is close collaboration between the public and private health sectors with the National Central Statistics Office (Hammond & Stassen, 1999: 155). A practical way of ascertainment of cases with CL/P would be from the medical/surgical files. Four established networks for registering birth defects are the ECLAMC in Latin America, the EUROCAT, in Europe, the NBDPN in North America, and the ICBBD located in Rome which is the most widespread programme as it includes 34 countries across the 5 continents (WHO, 2001b: 48). These systems could serve as models for the setting up of a national database that could be linked to an international database. Creation of national registers and international databases are of primary importance if developing countries are to strive to provide best practice for children with CL/P.

The evolution of computerized records may facilitate the challenging task of creating databases but the maintenance of a reliable national register system is difficult, time consuming and

expensive (WHO, 2001b: 5). An organised register of individuals with CL/P should allow the required information to be easily retrieved, processed and used for both clinical services and future research. Furthermore, setting up a global registry of cases with CL/P and craniofacial anomalies maximizes opportunities for preparatory work on outcome measures (WHO, 2002: 30).

While developed countries continue with their efforts to improve the standard of care for young children with CL/P, the current reality in developing countries is that more pressing health care priorities such as malnutrition, under nutrition and communicable diseases such as HIV/AIDS overshadow the care of children with CL/P (Mars et al., 2008: 1; WHO, 2002: 36). Furthermore, the financial burden of care and problems of access to professionals in cleft care put treatment beyond the reach of vast numbers of individuals with CL/P in developing countries, (WHO, 2002: 2). However, by addressing the specific barriers to providing cleft care in developing countries and by suggesting strategies based on the guidelines of best practice these challenges may be overcome.

Research from developed countries can inform and provide the theoretical underpinnings for improving cleft care in developing countries. For example Scherer et al. (2008: 25) provided evidence that mothers of children with CL/P could be trained to deliver intervention reliably under the guidance of speech-language therapists. This has implications for developing countries where the number of speech-language therapists is limited. However, there is a need to conduct local empirical research to adapt, and/or develop identification and subsequent management programmes for children with CL/P that have socio-cultural relevance (D'Antonio

& Nagarajan, 2003: 310; Sell, 2007: 17). Contextual research is required to determine the potential of utilizing family centred intervention (Louw et al., 2006: 48).

2.4 CONCLUSION

The negative impact of a cleft on a child's oral structures (velopharyngeal closure, dentition), development (feeding, communication skills development, psychosocial development, and education) and auditory system are well known. Professionals from various disciplines have agreed that to meet multiple and complex needs of children with CL/P and their families the best practice for cleft care requires:

- An interdisciplinary, team-based approach to assessments and treatment to provide coordinated cleft care
- Early intervention to minimize the impact of the cleft
- Outcome measures to review clinical practice and continually improve cleft care (ACPA, 2007:24-25; WHO, 2002). There is a need for assessment and outcome measures to be locally relevant and
- Creating collaborative groups and a global registry and database on craniofacial anomalies (WHO, 2001b: ix).

The guidelines for best practice in cleft care are available from developed countries. However, as discussed, the application of these guidelines in developing countries is challenging. Strategies to improve cleft care globally need to be planned whilst taking into account the

diversity of systems and contexts. Developing countries will have to take responsibility to develop their local capabilities, to improve and sustain cleft care.

The WHO report (2002: 100) recommends the establishment of national registers and databases for individuals with craniofacial anomalies so that data is readily available for clinical and public health action. Professionals and institutions may use this knowledge for international collaborations to address the gaps in cleft care identified through research. A strategy that could be applied to improve cleft care, despite limited number of available speech-language therapists and audiologists, is the leveraging of other resources (training parents, community health workers and other available resources) in communication development. However, to play such a proactive role speech-language therapists and audiologists require access to contextually appropriate assessment instruments.

2.5 SUMMARY

This chapter described the pervasive impact of a cleft on a developing child and on his/her parents and families. An in-depth review of literature was carried out to describe the communication, speech and language characteristics of children with CL/P. The recommendations for standard of care for young children with CL/P from developed countries, namely team approach to assessments and treatment, early interventions and outcome measures of treatment were discussed. Gaps in the service delivery model for young children with CL/P in developing countries, as well as the challenges to upholding optimal standards of care in developing contexts, were also discussed. Additionally, strategies were identified to overcome

specific barriers to cleft care in developing countries. These were to set up database/national register for individuals with CL/P, and provide an interdisciplinary team approach, with an early communication intervention by the speech-language therapists and audiologists for young children with CL/P.

CHAPTER 3:

COMMUNICATION ASSESSMENT OF YOUNG CHILDREN WITH CLEFT LIP AND / OR PALATE

The aim of this chapter is to critically review the recommended assessment practices for young children with CL/P. This will provide a framework for the development of a generic, and holistic communication assessment protocol and creation of a database for speech-language therapists and audiologists, with an aim to improve the standards of cleft care in a developing country.

3.1 INTRODUCTION

Children born with cleft lip and/or palate (CL/P) are at risk of communication delays and/or disorders and early communication intervention (ECI) can improve outcomes (Bzoch, 2004: 19; Hardin-Jones, Chapman & Scherer 2006: 8; Rossetti, 2001: 264). Early identification of communication delays/disorders requires effective and efficient systems for screening, assessment and referral (Bzoch, 2004: 35; Guralnick, 2005: 74; WHO, 2002: 143).

Parameters and guidelines for the assessment of patients with CL/P, based on consensus of experts from various disciplines in cleft care are available (ACPA, 2007; CSAG, 1998, Eurocran Speech Project, 2000; WHO, 2002). According to these guidelines, the assessment of young children with CL/P needs to be an interdisciplinary and a collaborative process where the

findings contributed by all team members are used in the planning of comprehensive services. Important recommendations regarding the areas of assessment, ages of assessment and procedures for collecting speech samples, recording and analyzing cleft speech across different languages are now available (ACPA, 2007:10-24; Henningsson et al., 2008; 1-17; Sell, 2005: 103-121). The guidelines could be used internationally to ensure consistency and uniformity in reporting speech outcomes.

However, health care services differ from country to country. In the absence of a team-based approach for assessments, speech-language therapists and audiologists in developing countries have a challenging task to assess communication skills in young children with CL/P without follow-up from other team members such as geneticists, occupational therapists, psychologists and social workers. One solution suggested to address this challenge is to ‘import’ assessment instruments from developed countries. However, this may not be appropriate because of the prevailing cultural and linguistic differences and diversity among countries (Guralnick, 2005: 14; Shonkoff & Meisels, 2000: 433).

Given that personal, environmental and contextual factors greatly impact assessment it is important to develop assessment instruments which are designed for and appropriate to a given context. It is therefore imperative that speech-language therapists and audiologists in a developing country conduct contextually relevant research to adapt an existing assessment tool or develop a new assessment protocol and evaluate its applicability and acceptability. In this chapter, the areas and procedures for assessment of young children with CL/P are described to

identify the features which could be incorporated in the development of a communication assessment protocol.

3.2 PURPOSES OF COMMUNICATION ASSESSMENT

Shprintzen and Bardach (1995: 137) explicitly state that the quality of cleft care services depend on accurate diagnosis for planning effective and efficient interventions. The purposes of communication assessment are illustrated in the Figure 3.1.

PURPOSES OF COMMUNICATION ASSESSMENT	
A clinical perspective	<ul style="list-style-type: none"> • Identifying children with communication delays/disorders early in life • Monitoring developmental changes of the child and addressing new concerns of parents (ECI) as the child develops and undergoes cleft repair/s • Describing communication difficulties that guide intervention plans • Allowing differential diagnosis of contributing etiological factors in order to make appropriate communication intervention decisions • Referring to other team members/professionals for implementation of appropriate interventions, for example surgical/medical/dental • Storing results in a database to derive data for descriptive statistics (with a view to improving clinical assessments through research)
A long term perspective	<ul style="list-style-type: none"> • Conducting outcome studies to evaluate the impact of individualised treatment or interventions (pre and post treatment/therapeutic interventions) • Utilising a database to conduct programme evaluation and clinical audits and to track the progress of cleft care in a particular context.

FIGURE 3.1 Purposes of communication assessment of young children with CL/P

(Based on: ACPA, 2007: 24; Bzoch, 2004: 346; D'Antonio, 2002: 27; Hegde, 2008: 119; John et al., 2006: 278; Rossetti, 2001: 88).

Traditionally, the purpose of assessment of young children with CL/P by the speech-language therapists has been to describe speech characteristics commonly associated with CL/P and/or velopharyngeal dysfunction and to plan therapy that is realistic and structured (Kuehn & Moller, 2000: 361). Speech-language therapists and audiologists need to establish and document a pre-surgical baseline and longitudinal assessments of speech behaviours, for planning surgical and/or dental interventions and modifying inappropriate learned speech behaviours (ACPA, 2007: 23). Speech-language therapists and audiologists who serve on an interdisciplinary cleft team conduct in-depth diagnostic assessments to determine the contributing etiological factors, the need and rationale for physical management procedures, including secondary palatoplasty by consulting with families and team members (Bzoch, 2004: 377; Kummer, 2008: 341; Peterson-Falzone et al., 2010: 272).

In addition to assessment for diagnostic purposes, speech-language assessments serve to monitor changes following interventions (D'Antonio, 2002: 27). Data derived from detailed and structured assessment protocols is required for research and descriptive statistics to provide evidence of the need for ECI and for surgical repair of the cleft. The speech-language assessment results are important to provide a basis for programme evaluation, treatment outcome studies and clinical audits (ACPA, 2007: 24; CSAG, 1998: 104; McLean, Wolery & Bailey, 2004: 14; WHO, 2002: 29). Audit of treatment outcome measures contribute to improve patient care through systematic review of care against specific criteria before determining best treatment protocols and implementation of changes when indicated (John et al., 2006: 273). Scientifically

derived findings that serve to inform clinical practice contribute to cost effectiveness of the interventions that are implemented (John et al., 2006: 273; Zinkin & McConachie, 1995: 58). The evaluation of programme effectiveness is an important issue especially in contexts where resources are limited and there is a need to justify any additional costs such as costs incurred for equipment, materials and professional expertise (WHO, 2002: 29).

Valid, reliable and comprehensive assessment instruments and a database are required to simultaneously fulfil many purposes as presented in Figure 3.1.

3.3 RATIONALE FOR A NEW COMMUNICATION ASSESSMENT PROTOCOL IN A DEVELOPING COUNTRY

International recommendations for areas and procedures for assessment (ACPA, 2007; Eurocran 2000) from developed countries are based on the availability of interdisciplinary team and ECI services. The young child with CL/P who undergoes surgical, medical interventions during the early developmental years requires ongoing assessments of communication skills. In this section, the justification for the development of a holistic and generic communication *assessment* protocol for young children with CL/P, that could be applicable in a developing country, is presented.

Speech-language therapists and audiologists require access to an effective communication assessment protocol that is relevant within the health care context as well as in the family of the child with CL/P. The family resources to cope with the challenges of having a child with CL/P,

their socio-economic status and the literacy levels of the parents with their varying needs for support and information need to be described during assessment. These aspects impact on the child's development and reflect the family's ability to adhere to the treatment protocol. Moreover, it is a basic principle that a child's communication assessment should be conducted in his/her home language(s) and dialects spoken within the home (ACPA, 2007: 8; Hegde, 2008: 12) to ensure valid and reliable assessment results. A holistic approach to assessment that integrates knowledge gained from the fields of ECI and CL/P provides the most comprehensive information on general development, thus guiding intervention to the maximum benefit of the child and his/her family. A generic communication assessment protocol could accommodate individual children and families, while ensuring that all assessment areas are targeted to provide a consistent data collection instrument.

A generic communication assessment protocol would be applicable to the whole population of children with CL/P (with syndromic or non-syndromic clefts) and, simultaneously be useful to identify the unique problem areas associated with each cleft type. Children with CL/P are a heterogeneous group as they may include different types and severity of clefting either with or in the absence of syndromes/sequences. The type of cleft and its severity has a tenuous link with the characteristic communication symptoms of this population (Persson, Elander, Lohmander-Agerskov & Soderpalm, 2002: 407; Shprintzen & Bardach, 1995: 94). The type of cleft should alert the speech-language therapist to consider such relationships for example the variability in resonance and articulation in young children with CL/P is partly attributed to the type of cleft (Peterson-Falzone et al., 2010: 222; Winder, Imagire & Peterson-Falzone, 2004: 101). Children with cleft palate, as opposed to children with cleft lip only, are likely to have velopharyngeal

dysfunction that causes speech and resonance abnormalities (Kummer, 2008: 49). Furthermore, children with cleft palate are at greater risk of otitis media and associated conductive hearing loss due to Eustachian tube dysfunction compared to children with cleft lip only (Peterson-Falzone et al., 2010: 211). A comprehensive communication assessment protocol applicable to all types of cleft with any severity and that captures different characteristics of this heterogeneous population should therefore be very useful.

In addition to the cleft type, it is paramount that the generic assessment instrument be applicable to children with syndromic CL/P in a presence of a sequence or with multiple anomalies as this knowledge guides the speech assessment. For example, children with Velocardiofacial syndrome (VCFS), are at risk of higher occurrence of abnormal speech characteristics (smaller consonant inventories, greater developmental articulation errors and higher frequency of glottal stop use) compared to children with non-syndromic CL/P cases (D'Antonio et al., 2001: 460). Based on the assessment results the speech-language therapists may plan intensive therapy for certain children.

When conducting a communication assessment of young children with CL/P speech-language therapists, should take into account the timing and surgical technique of the cleft repair. Different teams in various centres follow variable treatment protocols such as the surgical technique and additional presurgical orthopaedic/orthodontic treatment that may impact on communication development and skills (Watson et al., 2001: 386). Together with information on the timing of surgery assessments at three age-based stages namely: birth to palate repair (at approximately 12 months of age), immediately after the cleft repair and at a later stage (30 -36 months) provide

valuable information for intervention planning (Scherer & Kaiser, 2007: 362). For example, stop consonants can only be targeted post cleft palate repair. Surgical repair of the cleft at an early age of the child has been proven to result in better speech outcomes (Bzoch, 2004: 322; Chapman et al., 2008: 106; CSAG, 1998: 30; Peterson-Falzone et al., 2010: 150). Cleft repair may, however, be delayed due to various factors such as the health system structure, availability of experienced plastic surgeons and availability of an interdisciplinary team. Despite variations in health care services and the heterogeneous nature of the cleft population a generic communication assessment protocol is necessary to provide consistent data collection instrument and procedures. The results of a generic communication assessment can be compared over time, and data can be entered in a database for future research and outcome studies.

Recognising that young children with CL/P have special health care needs that vary according to their developmental stages, professionals from various disciplines recommend *longitudinal clinical assessments* of children with CL/P (ACPA, 2007: 3; Peterson-Falzone et al., 2010: 232) to monitor development and guide management. For example, in the neonatal stage early identification and treatment of feeding and early identification of hearing problems prior to cleft repair is important. In infancy, mother-child interactions, communication means and functions as precursors to linguistic development, need to be assessed. During the preschool stage (after the cleft repair), there is a shift in concerns regarding feeding, the development of intelligible speech and adequate velopharyngeal functioning (ACPA, 2007: 16; Kuehn & Moller, 2000: 348; Peterson-Falzone et al., 2010: 268). Developmental stages determine the focus of communication assessment necessitating a generic communication assessment protocol that allows for ongoing, serial assessments.

The recommended areas of assessment according to the stages of the child’s development are discussed in section 3.4 followed by a discussion of the instruments and procedures for conducting such assessment in section 3.5.

3.4 AREAS OF COMMUNICATION ASSESSMENT AND DEVELOPMENTAL ASSESSMENT STAGES

In clinical practice it is crucial to examine all areas of communicative functioning, as well as associated areas related to the child’s ability to use language, as shown in Table 3.1.

TABLE 3.1 Areas of communication assessment and developmental assessment stages

AREAS	STAGES			
	Neonatal (0-1 mo.)	Infancy (1-12 mo.)	Toddlerhood (12-36 mo.)	Preschool stage (36-72 mo.)
Case History	+	+	+	+
Genetic screening	+	+	+	+
Feeding	+	+	+	-
Hearing and listening skills	+ -	+ +	+ +	+ +
Communication interactions, pragmatics, and speech-language development	+ -	+ +	+ +	+ +
Emergent literacy	-	+	+	+
Orofacial examination and oral motor function for feeding and speech	+	+	+	+
Speech production	-	+	+	+
General development	+	+	+	+

In Table 3.1, + indicate areas requiring communication assessment; (Based on: ACPA, 2007: 13-23; Bzoch, 2004:281-284; Kummer, 2008: 319-372; Peterson Falzone et al., 2010: 265-288; Shprintzen & Bardach, 1995: 176-220; WHO, 2002: 142).

The broad areas of assessment are similar for neonates, infants, toddlers and preschool children with CL/P but the level, content and manner of assessment needs to be adapted to the developmental stages of the child. The reasons for conducting assessment in specific aspects within each area of assessment is presented according to the developmental stage of the child are discussed below.

3.4.1 Case history

A standard and common procedure used by speech-language therapists and audiologists is to start the assessment with a case history of the child. To plan and implement effective early communication intervention, the case history should include demographic information, family context, cultural background, bilingual/multilingual status, education, occupation, and general level of sophistication of the family (Guralnick, 2005: 137; Hegde, 2008: 12; Paul, 2007: 24).

At every stage of the child's development the assessment should include a comprehensive clinical history. The major elements of the case history in the neonatal stage are pre- and postnatal development history, family history, medical history and physical examination (Kummer, 2008: 322-323). In sourcing the prenatal history, information needs to be elicited about prenatal history, such as maternal illnesses, chronic conditions, use of medications, use of alcohol, use of tobacco, or substance abuse during pregnancy (Wyszynski, 2002: 305).

Furthermore, a detailed birth history including birth weight and the general condition of the neonate should also be obtained. The perceptions of the parents and their concerns at each stage of development should also be determined (Hegde, 2008: 119). For example, in the neonatal stage the main concern of parents is usually feeding, but as the child grows, develops and the cleft is surgically repaired, new concerns such as speech-language development arise that need to be addressed.

During the child's developmental progress speech-language therapists and audiologists should continually obtain further information about the child's medical-surgical treatment, essentially noting age at time of cleft surgery and any other surgeries such as the insertion of grommets for middle ear problems (Hegde, 2008: 119) as this information is important in planning ECI and management of the communication delay/disorder. Peterson-Falzone et al. (2010: 265) stated that 'children with CL/P receive continuing interdisciplinary care throughout childhood and the history obtained during the initial interview will provide only a glimpse of an ever-changing story that will unfold over time'.

Part of the holistic evaluation of every child with a cleft lip and palate is a genetic screening, as clefts are associated with an estimated 350 syndromes and a high probability exists that additional anomalies may be present in the child (ACPA, 2007: 11; Gerber, 2001: 132).

3.4.2 Genetic screening

Obtaining information pertaining to any family history of clefting is recommended for selective referral of cases for geneticist's assessment (Gerber, 2001: 142) as 53% patients with cleft are

reported to have a syndrome and new syndromes are discovered continually (Gerber, 2001: 132). Genetic screening is necessary to plan management of potential medical, developmental, communication delays/disorders and provide counselling and family support (Kummer, 2008: 90-91). All clinicians including speech-language therapists should be aware of the importance and possibility of multiple anomaly syndromes. They should carefully obtain a description of family characteristics, phenotypical descriptions and be prepared to make referrals and consult with team (Shprintzen, 1997: 49).

Genetic screening is a collaborative process whereby other team members such as surgeons, paediatricians and speech-language therapists can help identify children who may need referrals to a geneticist and for genetic study. For example, speech-language therapists may identify communication behaviours and phenotypical features in children with VCFS during the communication assessment and refer the child for genetic evaluation and confirmation of the syndrome.

3.4.3 Feeding

Speech-language therapists have an important role in the interdisciplinary team (in conjunction with nurses and paediatricians) to assess the swallowing and feeding ability of the child with CL/P, in order to make recommendations regarding feeding interventions and parental support. According to Arvedson and Brodsky (2002: 528), at the *neonatal stage* three important aspects of feeding assessment are: adequate oral sensorimotor development, availability of nutritionally adequate food and the interaction between the caregiver and the infant. Neonatal feeding

assessment should also include the state of the neonate during the feed, the feeding time, type of milk (breast/formula milk), equipment used for feeding, and positioning of the neonate (Shprintzen & Bardach, 1995: 165; Watson et al., 2001: 141). Clinical signs and symptoms of an airway deficit and upper airway obstruction such as inspiratory stridor, glossoptosis and micrognathis (as in cases with Pierre Robin Sequence) should signal the need for in-depth feeding assessment (with instruments if necessary) by an interdisciplinary team (Arvedson & Brodsky, 2002: 530; Watson et al., 2001: 143). The *infant stage* is a transition/weaning phase from breast/bottle feed to semi-solid diet therefore, assessment of sip-swallow and appropriate tongue movements, pre-chewing skills and ability to direct the feed towards the oropharynx need to be assessed. Infants with neurological problems, airway disorders, Pierre Robin sequence and pre-term infants are at risk of persistent, feeding problems due to abnormal oral motor function (Reid, Kilpatrick & Reilly, 2006: 708). At the *toddler stage* feeding assessment should include assessment of oral motor functions such as lip closure, chewing, ability of the tongue to direct bolus towards the oropharynx and swallowing. Feeding assessments also identify parental needs and concerns that need to be addressed during intervention. In addition, weight gain should be monitored.

Reid et al. (2006: 708) found a high prevalence of poor feeders in their clinical cohort, and they concluded that early detection and management of feeding difficulties is important. However, their study also indicated that by three months of age poor feeding is likely to resolve as cleft repair improves the ability to feed. But feeding problems may persist in young children with CL/P and neurological involvement, Pierre Robin sequence or in children HIV/AIDS. Therefore, an assessment protocol should include feeding assessment procedures from neonatal stage through to toddler stage until there are no concerns for the child's feeding.

3.4.4 Hearing and listening skills

Conducting hearing evaluations to diagnose hearing loss and to monitor hearing in developmental stages of young children with CL/P is crucial (ACPA, 2007: 13, Broen et al., 1996: 132; Bzoch, 2004:361; Kernahan, Rosenstein & Dado, 1990: 236; Peterson-Falzone et al., 2010: 216; Watson et al., 2001: 222) as the incidence of middle ear disease is very high. Furthermore, children with syndromes/sequences are at risk of sensorineural or mixed hearing loss (Peterson-Falzone et al., 2010: 215; Shprintzen & Bardach, 1995: 164). A persistent/fluctuating hearing loss adversely affects communication development and may have consequences for cognitive development of the child (JCIH, 2007: 898). Making a differential diagnosis of hearing loss requires the collaboration of the audiologist, physician and parents of the child with CL/P.

Examination of the ears for phenotypic features (for example: atresia), newborn hearing screening, and if indicated, diagnostic hearing evaluations need to be conducted at the *neonatal stage* (ACPA, 2007: 10). Additional high risk factors for hearing loss should be identified from the perinatal history. At the *infant stage* an assessment of hearing sensitivity for each ear and hearing screening should be continued at least annually through to the age of six years to ensure adequate monitoring of hearing by an audiologist and ENT specialist (ACPA, 2007: 11). At the *toddler stage* audiologists should continue to monitor hearing ability and middle ear functioning as in the early years, middle ear disease may be recurrent (Jocelyn, Maureen, Penko & Rode, 1996: 533; Blakely & Brockman, 1995: 30; Kritzinger et al., 1996: 80; Peterson-Falzone et al., 2010: 216). Schonweiler et al. (1999: 214), conducted a large-scale study of 370 toddlers with

CL/P, and found that even mild fluctuating hearing loss had a major influence upon speech and language, necessitating regular monitoring of hearing. Even in the absence of otologic disease or hearing loss, *preschool age* children with CL/P require annual hearing evaluations to adequately monitor hearing (ACPA, 2007: 14). Children presenting late for surgical repair also require a hearing assessment to determine hearing acuity and identify hearing loss. Even children identified with congenital hearing loss, require monitoring of their hearing levels (JCIH, 2007: 901).

In addition to monitoring hearing levels, the impact of hearing impairment on the neuromotor encoding and auditory decoding skills of the infant with CL/P and on listening behaviour, should be assessed. The latter has not received sufficient attention from researchers. Auditory processing has a negative impact on communication development of young children (Cole & Flexer, 2007: 76; Hugo et al. 2000: 141; Kritzinger & Louw, 2002: 8). Therefore, young children with CL/P require regular hearing evaluations and listening skills evaluations.

3.4.5 Communication interactions, pragmatics and speech-language development

Screening and assessment of communication interactions, pragmatics and speech-language development conducted from the neonatal stage (refer to Table 3.1) allows speech-language therapists and audiologists to identify problems early and to take preventive measures to minimise the negative impact of the cleft (ACPA, 2007: 23; Bzoch, 2004: 408; Scherer et al., 2008: 25). If language delays or disorders are identified, during a team visit screening of

communication functions, then a scheduled and structured in depth language assessment should be conducted (Bzoch, 2004: 378; Peterson-Falzone et al., 2010: 267).

Assessment of parent-child interactions is important to the child's development and long term care (ACPA, 2004: 11; Nackashi, Dedlow & Dixon-Wood, 2004: 281). At the *neonatal stage* communication assessments should include the many psychosocial concerns of parents to address the information needs of parents and to help them adjust to the neonate with a CL/P (Peterson-Falzone et al., 2010: 267). ECI studies of children with CL/P have reported problems with communication interactions, functions and parent-infant bonding due to the cleft condition and related stress factors, such as feeding problems (Hardin-Jones, Chapman & Scherer, 2006: 8; Neiman & Savage, 1997: 223; Scherer & Kaiser, 2007: 355). The assessment of *infants* with CL/P needs to focus on: communication behaviour (parent-child interactions), communication means (nonverbal, gestures, verbal) and receptive and expressive language skills (especially phonological development and vocabulary acquisition). The direct effect of the cleft palate on the babbling, vocalisations and prelinguistic communication behaviours, in infancy, can be monitored through assessments prior to the surgical repair of cleft palate and compared later with the post cleft palate repair assessments in the toddler stage of development (Chapman et al., 2003: 193).

Assessment of the prelinguistic communication skills, receptive and expressive language skills of *toddlers* with CL/P is recommended to be carried out at least twice annually until the age of two years (ACPA, 2007: 23). Specific aspects of speech-language development screening in toddlers should include comprehension, communicative gestures, pragmatics, phoneme repertoire, syllable structure, word use and play, since these communicative behaviours indicate whether the

child is following a trajectory of normal development (Rossetti, 2001: 137; Shprintzen & Bardach, 1995: 183). The findings of Hardin-Jones and Chapman, (2008: 95) indicate that speech-language therapists can appropriately identify toddlers with cleft palate who are at risk for later delays in speech-language development. They reported the presence or absence of oral stop consonants as a key clinical finding that may assist speech-language therapists in identifying children who will need early intervention services (Hardin-Jones & Chapman, 2008: 95).

A longitudinal monitoring of progress in phonological development permits the identification of new concerns on a timely basis (ACPA, 2007: 13; Nackashi, Dedlow & Dixon-Wood, 2004: 280). At the *preschool stage* an assessment of both early receptive and expressive language skills is recommended for preschoolers with CL/P as research has proven that a wide range of language delays/disorders occur more frequently among children with cleft than children without cleft (Bzoch, 2004: 6; Hardin-Jones & Jones, 2005: 11; Morris & Ozanne, 2003: 468). Screening results during team visits are used to identify children with CL/P and language delays/disorders and based on these results, in-depth language assessments by the speech-language therapist are scheduled. In the preschool stage, the language screening should include the child's receptive and expressive vocabulary, phonology, appropriate expressive use of morphology and syntax, and pragmatics (Shprintzen & Bardach, 1995: 169).

3.4.6 Emergent literacy skills

Literacy skills are language based and the development of emergent literacy extends from infancy through preschool years (Pence & Justice, 2008: 224). Research on young children with

CL/P showed that 30% to 40% young children with CL/P had reading difficulties (Broen et al., 1998; Richman & Ryan, 2003: 156). Hence communication assessment protocols for young children with CL/P should include emergent literacy skills as an assessment area so that parents can be given appropriate guidance and future literacy development can be facilitated. Early intervention to prevent later reading and writing difficulties in children with CL/P is important to attaining the goal of school readiness at five years of age (Blakely & Brockman, 1995: 25; Zimmerman & Castilleja, 2005: 239). Assessment for emergent literacy skills should start at the infant stage (refer Table 3.1). *Infants'* early language and literacy experiences, such as exposure to books, attending to nursery rhymes, looking at pictures and joint story book reading interactions with their parents are observable early literacy development behaviours which need to be assessed (Hoff, 2005: 398). At the *toddler stage* assessing adult-child shared book reading that stimulates verbal interaction to enhance language development and print knowledge, and assessing activities that highlight the relations between print and speech need to be included in the assessment (Restrepo & Towle-Harmon, 2008: 10). Emergent literacy development is a continuous process. Children with CL/P who display phonetic and phonologic developmental disorders may experience difficulty in developing reading and writing skills (Nathan, Stackhouse, Goulandris & Snowling, 2004: 377). Information obtained from assessment results can inform ECI and recommendations to parents of children with CL/P on emerging literacy. Emergent literacy skills' assessment at the *preschool stage* should include the child's knowledge of environmental print, knowledge of print conventions, and letter-name and letter-sound knowledge, as well as analyses of narrative abilities (Kaderavek & Justice, 2000: 82-93; Pence & Justice, 2008: 225; Restrepo & Towle-Harmon, 2008: 10). Assessment of specific literacy aspects that the child is developing, indicate the emergent literacy level.

3.4.7 Orofacial structures and oral motor function

Examination of orofacial structures and oral motor functions should always be included as part of the communication assessment in young children with CL/P (Kummer, 2008: 351). Oral motor function needs to be assessed to differentiate the role of the structural restrictions (obligatory speech errors) from impairments of speech function (compensatory errors) (Peterson-Falzone et al., 2006: 183; Shprintzen & Bardach, 1995: 184). Furthermore, if abnormal facial features or dysmorphology are observed a genetic evaluation may be suggested to identify the presence of a syndrome or sequence.

At the *neonatal stage* a brief screening examination of the neonate's face, eyes, ears and mouth is generally conducted by the midwife, paediatrician or doctor just after birth. A speech-language therapist may need to be involved to assess the neonate's baseline description of the type and severity of cleft, structures that relate to speech production and the impact on feeding (ACPA, 2007: 11). Assessment includes checking suckling reflex and a detailed examination that may help distinguish neonates with associated malformations or a syndrome as the results of the assessment determine the management of the neonate. At the *infant stage* speech-language therapists and audiologists should describe the phenotypic facial features (for example profile, eyes, and ears) of an infant with CL/P that may indicate the presence of a sequence or syndrome as part of genetic screening of the infant. They may contribute to a diagnosis by discussing their observations with other team members for example the paediatrician and/or geneticist (Gerber, 2001: 130; Kummer, 2008: 88-91; Shprintzen, 1997: 152). The type of cleft should also be noted and whether it has been repaired or not should be recorded. Although complete

assessment of the oral motor function is only possible when the infant is older and able to cooperate, observations of feeding allow assessment of oral motor function as well as spontaneous movements such as pursing lips when the infant kisses a parent (Shprintzen & Bardach, 1995: 184). The speech-language therapist should conduct an orofacial examination and oral motor function assessment again at the *toddler stage* and post cleft repair to determine if there are physical factors that could be interfering with articulation and resonance. For example, the labial competence, dental occlusion, the hard palate, the oral structure of the velum, the uvula, tonsils and the tongue mobility and accuracy of tongue movements (Bzoch, 2004: 471; Kummer, 2008: 350; Peterson-Falzone et al., 2006: 104). The presence of palatal fistulae should be determined and the effects on eating, drinking and speech should be assessed. Dental structures should be examined for any occlusal problems, supernumery or missing teeth (Shprintzen, 1997: 158). The soft palate should also be examined carefully as hypernasality may be due to inadequate velopharyngeal closure or a submucous cleft palate may be present causing hypernasality. Visual inspection of velar closure may however, be deceptive (Shprintzen & Bardach, 1995: 189) and instrumental assessments that provide more diagnostic information are recommended for further examination of the velopharyngeal closure. *Preschool age* children with CL/P are at an increased risk of developing and habituating structurally based speech disorders. At this stage, facial growth is taking place and relationships between structures may change. The examination of the orofacial structures at every stage of development helps to identify the contributing etiological factors to abnormal speech (Kuehn & Henne, 2003: 105) such as maxillary-mandibular disproportion, dental malocclusions. The structural anomalies may appear to be significant but may not have an impact on speech articulation (for example a fistula or a large oropharyngeal space). An orofacial examination is necessary in children with

CL/P in conjunction with a perceptual speech assessment for the accurate interpretation of speech errors that may require physical management and/or speech-language therapy (Kummer, 2008: 361; Peterson-Falzone et al., 2006: 69).

3.4.8 Speech production

As a CL/P may have a pervasive effect on speech production, it is crucial that the speech-language therapist conducts a thorough assessment of speech, voice and resonance (Hardin-Jones & Jones, 2005: 12; Kummer 2008, 328-332; Peterson-Falzone et al., 2010: 268; Sell et al., 1999: 17-33; Trost-Cardamone, 2004: 463-468; Whitehill, 2002: 55). Based on the results of the speech-production assessment, speech-language therapists together with team members make treatment and management decisions (ACPA, 2007: 23; D'Antonio, 2002) therefore a reliable and valid speech production assessment is required.

As illustrated in Table 3.1 the *neonatal stage* speech production assessment is not practicable since language-specific speech production starts at the infant stage.

At the *infant stage* the size of consonant inventories and early developing consonants during the infant's babbling stage should be assessed as early speech sound development is a good predictor of early word productions and later speech production accuracy (Chapman et al., 2003: 193; Peterson-Falzone et al., 2010: 234). Infants who have limited oral-motor practice through vocalisations, especially prior to cleft palate repair, are likely to develop phonological articulation errors (Peterson-Falzone et al., 2010: 235; Watson et al., 2001: 197). Early speech

production assessments provides therapists and parents with information regarding the quantity and quality of consonants' inventories and speech-language therapists can guide parents to stimulate the child with CL/P to produce a variety of consonants (Watson et al., 2001: 192). **Toddlers with CL/P** remain at risk for both phonetically and phonologically based speech sound disorders (Peterson-Falzone et al., 2010: 234). The assessment of speech production post-surgery in toddlers should include the process and pattern of phonological development as well as phonetic errors (Peterson-Falzone, 2010: 235). Although speech production is reported to improve as normal speech immaturities get resolved and the cleft is repaired, speech production should be assessed and tracked to determine changes in post-operative speech production (Chapman et al., 2003: 177). Assessment of speech sound production at the toddler stage should also identify any compensatory strategies that the toddler may be developing and which risk becoming habitual (Peterson-Falzone et al., 2006: 7; Watson et al., 2001: 192). Information gained from such speech analyses helps the speech-language therapist to efficiently plan therapy and correct the child's speech disorder. At the **preschool stage** speech assessments and orofacial examinations are necessary to identify contributing etiological factors of speech disorders such as velopharyngeal inadequacy or insufficiency, palatal fistulae, abnormal dentition and malocclusion, and abnormal learned speech patterns (Peterson-Falzone et al., 2010: 237; Watson et al., 2001: 196). Children with CL/P often develop compensatory articulation patterns/active speech characteristics that should be differentiated from obligatory errors/passive errors (Harding & Grunwell, 1998: 330; Kummer, 2008: 328). Furthermore, these need to be distinguished from developmental speech articulation errors that children may exhibit, such as omissions (Peterson-Falzone et al., 2010: 232). Such differential diagnostic speech production assessments are

required at the preschool stage to determine whether speech-language therapy and/or physical management are required (Peterson-Falzone et al., 2006: 87).

3.4.9 General developmental screening

Assessment of developmental domains, such as cognitive function, motor development and personal social behaviour is particularly relevant for young children with CL/P (Blackman, 1995: 13; Kritzinger & Louw, 2002: 4; Paul, 2007: 38; Rossetti, 2001: 147). Motor milestones are an indicator of general development and relate to speech and language acquisition (Shprintzen & Bardach, 1995: 182). Children with CL/P are a heterogeneous group with known risk factors for developmental delays that may be due to medical diagnoses and environmental factors (Broen et al., 1998: 683; Neiman & Savage, 1997: 218). Screening of general development is required to determine the level of functioning of the child. Identification of delays and unusual patterns in his/her development will necessitate referral of the child to the services of an early interventionist, psychologist, paediatrician and nursing personnel as the goal of early intervention is holistic patient care (Guralnick, 2005: 137; Wyszynski, 2002: 304).

During the *neonatal stage*, risks associated with development such as syndromes should be identified and then followed up during the infant stage by team assessments as developmental delays may appear later during the infant stage. Developmental domains such as motor development, self-help, cognitive and social interaction skills should be included in assessments of *infants* with CL/P. Neiman and Savage (1997: 224) compared developmental quotients of 186 infants and toddlers with CL/P at 5 months, 13 months and 36 months with normative

sample group and found delays in motor and cognitive development at 5 months and attributed it to surgical events and feeding difficulties. As communication development is related to cognitive and motor development it is important to screen the general development of the infant to determine the level of communication assessment. At the *toddler stage* continued developmental screening is necessary as attainment of developmental milestones and psychosocial adjustment continues to be a matter of concern at toddler stage (Nackashi, Dedlow & Dixon-Wood, 2004: 283). In a study by Neiman and Savage (1997: 223) toddlers with CL/P who were developmentally delayed in motor development, were also significantly delayed in expressive language. Delayed communication development is the most important common symptom of developmental delay in children younger than three years (Bzoch, 2004: 402; Rossetti, 2001: 106). Broen et al. (1998: 685) based on a comparative study of children with cleft and non-cleft children, also reported that the differences identified in cognitive skills were language based. All developmental areas are interrelated, and development in one area influences either positively or negatively development in another area (Papalia, Olds, & Feldman, 2002: 7). For example, active participation in play, exploration of the environment facilitates communication, speech-language development (Rossetti, 2001: 226). Therefore, based on such a holistic approach to assessment the speech-language therapist can plan an effective communication intervention plan. At the *preschool stage* developmental screening with a special emphasis on cognitive and psychosocial functioning is a pivotal need, as preschoolers with CL/P may face social adjustment issues that children with a facial deformity may experience (Wyszynski, 2002: 303). Information sourced from parents of the child with CL/P regarding social interactions can provide indicators of possible subtle language impairments (Shprintzen & Bardach, 1995: 202).

In conclusion, serial assessments conducted at regular intervals by a team of health care professionals can serve to better inform the interventions. Serial assessments are necessary to identify young children with communication problems and track developmental progress of those children. Many interrelated factors (child's biological factors and his/her environment) play a role in the child's development implying that the assessment approach should be generic, comprehensive and holistic.

In section 3.4, the areas of assessment at the various developmental stages and the related justifications were presented. In the following section, the procedures and instruments that speech-language therapists and audiologists use to assess these areas are critically reviewed.

3.5 ASSESSMENT PROCEDURES AND INSTRUMENTS FOR YOUNG CHILDREN WITH CLEFT LIP AND / OR PALATE

Given the importance of communication assessment, it is imperative that the assessment instruments selected are appropriate, valid, reliable, and fulfil the purposes of assessment (Bagnato, Neisworth & Munson, 1997: 35; Blackman 1995: 79; Weitzner-Lin, 2004: 36). Children with CL/P have typical speech production errors that require a specific framework to best describe these errors. Research reports and debates on procedures and measurement standardization of speech of young children with CL/P abound in academic literature (Kuehn & Moller, 2000: 348). However, communication development can be assessed by using general assessment instruments and procedures as it is not necessary to have specific procedures just for children with CL/P.

Professionals should be sensitive and flexible in the selection and use of assessment procedures and accommodate the diversity of children with CL/P and their families (ACPA, 2007: 8). Recommendations for appropriate assessment instruments and procedures to assess the various areas of communication (Table 3.1) in young children with CL/P are discussed in the following sections.

3.5.1 Procedures for case history taking

Obtaining a reliable case history is the first step in any assessment procedure. The speech-language therapist and audiologist may obtain medical and surgical history from hospital records, but these may not be complete or accessible to them. Parent interviews are therefore important to complete the required information/history and to verify the information from hospital records (Blackman, 1995: 63-64) as parents often possess information unavailable to professionals. The procedure of taking case history provides an opportunity to make contact with the parents of the child with CL/P. The ACPA (2007: 11) also recommends arranging for a psychosocial interview of the family to obtain information regarding the family history and adjustment levels to the child, and to assess cultural and linguistic influences affecting the family and to gain a better understanding of family background.

Socio-demographic information may be gathered by using standard case history questionnaire forms (Hegde, 2008: 339). A variety of assessment instruments, to produce the most valid appraisal of developmental status and to achieve the related assessment purposes of

identification, prescription, progress evaluation and prediction should be used (Bagnato et al., 1997: 18; Rossetti, 2001: 147).

3.5.2 Genetic screening

Genetic screening consists of case history information and clinical observations. A case history that probes pregnancy and family history might indicate genetic factors in the child with CL/P can be elicited through parent interview schedules and questionnaires (for e.g. Genetic Screening Questionnaire, accessible from:

http://www.acpa-cpa.org/educMeetings/educ_ScreeningTools.htm).

Based on a family history of clefting and observations of phenotypical descriptions that may be guided by checklists during genetic screening such as CHRIB case history form (Louw & Kritzinger, 1995) so that the presence of obvious phenotypic features (such as in Treacher Collins syndrome or Apert syndrome), can be identified. Gerber (2001: 142) recommends selective referral of cases for genetic assessment. Genetic screening is an ongoing process because some structural anomalies are not obvious at birth and cannot be detected until later childhood. Speech-language therapists should include genetic screening procedures as a geneticist may not be available in all multidisciplinary teams.

3.5.3 Feeding assessment

Feeding assessments at every stage of development should begin with a structured interview designed to capture medical (risk factors for feeding and/or developmental problems), surgical

and family resources and needs (Masarei et al., 2007: 321; Reid et al., 2006: 703; Young et al., 2001: 57). Mothers/caretakers may be questioned on whether coughing, choking, gagging, nasal regurgitation, or a wet or gurgly voice quality (i.e., feeding sequelae) occurs during or immediately after feeding. Speech-language therapists may conduct direct assessments by observing specific feeding behaviours and/or conducting the feeding assessment according to a checklist at the respective development stage of the child (Table 3.2).

TABLE 3.2 Feeding assessment procedures

Procedures	Stages			
	Neonatal	Infancy	Toddlerhood	Preschool stage
Medical records and parental/care giver reports	Peri-natal history and parents'/care givers' concerns about feeding	Medical records of child's growth, developmental history, surgical & medical history Parental reports of feeding concerns		
Observations Check-lists (Masarei et al., 2004)	Infant state Observe breathing-sucking- swallowing sequence Feeding method, equipment used and feeding options (breast milk/formula milk) Positioning of the neonate during feeding	Feeding method, equipment used Weaning/ transition to semisolid food Examinations of airway, neuromotor control, chest examination, examination for submucous cleft	Post cleft palate repair assessment Examine oral-motor function Observe and question parents regarding nutrition, chewing, swallowing, nasal regurgitation	-
Instrumental Procedures	-	In severe cases, Fibreoptic endoscopic evaluation of swallowing (FEES) by surgeon and/or Video fluoroscopic swallowing study (VFSS) by radiologist with speech-language therapist		-

(Based on: Arvedson & Brodsky, 2002: 527; Kummer, 2008: 144-145; Masarei et al., 2007: 321; Reid et al., 2006: 704).

The feeding assessment procedure should be specific to the developmental stage of the child with CL/P. At the neonatal stage, the ability to sustain effective sucking and coordinate respiration with the suck/swallow reflex should be assessed (Watson et al., 2001: 137). When feeding

difficulties are significant, such as airway compromise (for example in cases with Pierre Robin sequence) which may be indicated by coughing, choking, colour change, and increased respiratory rate, objective studies of swallowing function need to be performed (Shprintzen & Bardach, 1995: 67).

For many children born with CL/P, assessment checklists of the feeding patterns are appropriate and sufficient as the feeding process may only require minor adjustments (Arvedson & Brodsky, 2002: 189). Recommendations for assistive feeding devices and safe swallowing strategies for infants with CL/P can be made based on this assessment instrument (Masarei et al., 2007: 326).

3.5.4 Hearing and listening evaluations

Hearing impairment in young children with CL/P may be fluctuating, static, progressive or have delayed onset (Shprintzen & Bardach, 1995: 148). Therefore, ACPA (2007: 14) recommends repeating hearing evaluations annually. The approach adopted to assess a child's hearing depends on the developmental stage of the child (Table 3.3). Ear-specific assessment is the goal for both behavioural and physiologic procedures because a unilateral hearing loss, even in the presence of a normal-hearing ear, may place a child at significant developmental and/or educational risk (ASHA, 2004: 6). Technological advances such as evoked otoacoustic emissions (OAE) and auditory brainstem response (ABR) have made it possible to diagnose hearing impairments as early as the neonatal stage (Burkard, Don, & Eggermont, 2007: 260; Northern & Downs, 2002: 266). Hearing evaluation procedures are summarised in the following Table 3.3



TABLE 3.3 Hearing evaluations

Procedures	STAGES			
	Neonatal	Infancy	Toddlerhood	Preschool stage
Case history	High risk register	Genetic Screening, Medical (otitis media) and ear surgery, Otitis media or pressure equalization ear surgery (grommets/T-tubes)		
Examine and Observe	Examine ears for phenotype features	Examine ears for phenotype features Observe auditory behaviour and listening skills		
Electroacoustic instruments used in appropriate quiet environment and when necessary sound treated rooms	New born hearing screening with: Otoacoustic Emissions (OAE) &/or auditory brain stem evoked responses (ABR) Immittance measures using high frequency probe	Otoacoustic Emissions (OAE) Auditory Brain stem evoked responses (ABR) Immittance measures using high frequency probe	Immittance tests using 220 Hz probe Free field audiometry (VRA) Auditory Brain stem evoked responses (ABR)	Diagnostic audiometry (PTA) ear specific with conditioning and masking if necessary and obtain thresholds of hearing Speech audiometry Immittance tests using 220 Hz probe

Sources: (ACPA, 2007: 13-14; ASHA, 2004: <http://www.asha.org/members/deskref/default>; Cole & Flexer, 2007: 110-111; Hugo et al, 2000 : 47; JCIH, 2007: 899).

Hearing evaluation procedures require the use of expensive electroacoustic instruments, infrastructure such as sound proof booths or sound treated rooms for pure tone audiometry as well as audiologists specifically trained in conducting hearing evaluations of neonates, infants, toddlers and pre-school age children (JCIH, 2007: 910).

Although hearing procedures have been specified, information on auditory processing and listening skills is still lacking in young children with CL/P. The Listening Evaluation Scale (Hugo et al., 2000: 47-53) assesses listening in two situations:-

- during the communication assessment where the child's listening behaviour is observed and rated according to a three point rating scale a score of 1 indicates 'good listening' and a score of 3 indicates 'poor' listening
- during hearing evaluation in which standard audiometric techniques are utilised. The consistency of responses during hearing evaluations and distractibility are also rated on a three point scale.

The scale provides an indication of poor as well as good listeners. This listening evaluation procedure is easily applicable, rapid and can be useful for intervention programmes by giving equal attention to hearing and listening impairment (Hugo et al., 2000: 52).

3.5.5 Assessment of communication interactions, pragmatics and speech-language development

A comprehensive assessment of communication interaction, functions and pragmatics is performed by speech-language therapists; they use a combination of standardised tests, developmental scales, criterion-referenced assessment procedures and behavioural observations (Owens, 2001: 275; Peterson-Falzone et al., 2010: 280). In early communication assessment, the use of criterion-referenced assessment procedures has gained preference over norm-referenced assessment, as the developmental rate of very young children is variable. A criterion-based assessment approach describes the child's functioning along a continuum of developmentally

sequenced objectives and facilitates intervention planning (Bagnato et al., 1997: 8; Kritzinger & Louw, 2002: 5; Rossetti, 2001: 100).

The assessment of speech-language development of children with CL/P can be conducted by selecting procedures and tools developed in the field of ECI to identify those who may then require an in depth comprehensive language assessment. A functional, descriptive and qualitative approach to the assessment of communication interaction and functions is recommended to obtain information about infants and toddlers at risk for communication delays and/or disorders. Research has demonstrated that parent questionnaires can be a valid and time efficient means of screening speech-language development when compared with a speech-language screening (Scherer & D'Antonio, 1995: 12). A joint parent-professional assessment process is combined with direct ongoing naturalistic observations of a child, allowing speech-language therapists to identify children who will require in-depth communication assessments (Kuehn & Moller, 2000: 355; Peterson-Falzone et al., 2010: 280; Prizant & Wetherby in Blackman, 1995: 156; Shonkoff & Meisels, 2000: 270). A checklist of receptive and expressive language skills that includes an articulation screener and behaviours considered as precursors to language development and emergent literacy skills should be utilised. Examples of procedures and instruments used in early communication intervention that may be used for communication assessment of young children with CL/P are shown in Table 3.4.

TABLE 3.4 Assessment procedures and instruments for communication interactions, pragmatics and speech-language development

Procedures & Instruments	Stages			
	Neonatal	Infancy	Toddlerhood	Preschool stage
Parent questionnaire for screening early communication speech-language development	Smile, eye gaze, responsiveness	Parent child interactions Gestures, social interactions, joint attention and behaviour regulation	Social interactions, joint attention and behaviour regulation	Receptive and expressive vocabulary, use of syntax and conversational skills
Observations of communication interactions functions & pragmatics Elicit language development information	Interaction-attachment	Informal observations to identify children who require a comprehensive language assessment.	Criterion referenced measure of communication and interaction; preverbal and verbal aspects of interaction are observed (0-3 years)	Direct child-centred assessment of language development
Examples of instruments	MacArthur-Bates Communicative Development Inventory (CDI) (Fenson et al., 1993) The Rossetti Infant-Toddler Language Scale: A Measure of Communication and Interaction (Rossetti, 1990) Observation of Communication Interaction (Klein & Briggs, 1987) Communication and symbolic behaviour scales (Wetherby & Prizant, 1995)			Preschool Language Scale (PLS-4) (Zimmerman Steiner & Pond, 2002). Pragmatics Profile of everyday language (Dewart & Summers: 1995)

Sources: (Blackman, 1995; Hegde, 2008: 258-262, Kritzinger & Louw, 2002: 7; Rossetti, 2001: 144)

Early speech-language development assessment requires knowledge of the developmental patterns and stages of both receptive and expressive language skills. During the emerging language development stage children also develop emergent literacy skills which need to be assessed.

3.5.6 Emergent literacy skills assessment

Questionnaires and parent interviews may be used to describe parental practices regarding the emergent literacy development.

TABLE 3.5 Assessment procedures for emergent literacy skills

Procedures	STAGES			
	Neonatal	Infancy	Toddlerhood	Preschool stage
Parent report based on a questionnaire/ checklist Speech-language therapists' observations Checklists For example, Kadevarek & Justice (2000: 82-93); Van Heerden & Kritzinger (2008: 37-48).	-	Home environment for literacy development Infant's interest in books, handling books, joint book reading practices Types of books parents read to child	Recognising pictures Print knowledge Joint book reading with parent (facilitation of emergent literacy development) Phonological development	Phonological awareness, identifying initial sounds, rhyming words, print knowledge Listening to stories and retelling them, writing own name

Sources: (Hegde, 2008: 278-279; Kritzinger and Louw, 1997: 2; Nathan et al., 2004: 377-391; Pence & Justice, 2008: 225; Van Heerden & Kritzinger, 2008: 48).

Integrating emergent literacy skills assessments using procedures and instruments described in Table 3.5 is the basis for appropriate recommendations to parents of young children with CL/P and an opportunity to help improve future academic performance of their children.

3.5.7 Orofacial examination

Various forms, checklists and guidelines are available to guide an orofacial examination.

TABLE 3.6 Procedures for orofacial examinations

Procedures and equipment	STAGES			
	Neonatal	Infancy	Toddlerhood	Preschool stage
Examination, observations (visual inspections) of oral structures and elicitation tasks of the speech production mechanism: Lips, teeth, tongue, jaw, velopharyngeal, and hard palate and respiratory system Use gloves, flashlight, tongue depressors, dental mirror, alcohol swabs to wipe surfaces and equipment	Presurgical observations of oral structures to describe type and severity of cleft	Observe, examine and describe post cleft repair Non-speech tasks such as, smile, blowing a kiss Imitation of tongue movements	Observe and describe repaired cleft Non-speech and speech tasks such as repeating mama Repeating syllables to observe tongue functions (ta, ka) Mirror test and other methods to test nasal emissions	Observe, examine and describe repaired cleft (adequacy of repair, if a palatal fistula is present, velopharyngeal closure) Non-speech and speech tasks as for toddlers including tasks such as phonation of vowels for voice quality and respiration Mirror test and other methods to test nasal emissions

Sources: (Kummer, 2008: 319-342; Peterson-Falzone et al., 2006 : 104 ; Peterson-Falzone et al., 2010 : 280-284 ; Shprintzen & Bardach, 1995: 212-215; Watson et al., 2001: 202).

It is important to solicit a child's cooperation to elicit non-speech and speech tasks of specific significance to children with CL/P. Orofacial examinations are possible and necessary at the toddler/preschool stages when secondary surgical decisions need to be made based on an accurate diagnosis of velopharyngeal closure.

3.5.8 Speech production assessment

Objective and accurate assessment of speech production is crucial in determining treatment outcomes. Currently, the best practice recommendation for speech evaluation and velopharyngeal functioning in children with CL/P is a thorough auditory-perceptual evaluation and use of instrumental techniques namely, videofluoroscopy, nasopharyngoscopy and electropalatography (Kuehn & Moller, 2000: 352; Peterson-Falzone et al., 2010: 272; Watson et al., 2001: 265).

3.5.8.1 *Perceptual speech assessment procedures*

Speech production assessment at the *infant stage* includes assessment of the phonetic repertoire through parental reports of the infant's vocalizations and canonical babbling. At the *toddler stage* frequency and diversity of consonant production is assessed. In addition to parent reports speech productions are elicited during play-based assessment (Peterson-Falzone et al., 2010: 267). Audio and video recordings and analysing transcriptions of the babbling and vocalisations are recommended methods used to complement the information obtained from the parents regarding the babbling and vocalisations of the infant with CL/P (Sell, 2005: 107). At the *preschool stage*, comprehensive phonetic and phonologic assessments using appropriate assessment instruments such as articulation tests, to elicit a speech sample, are recommended (Watson et al., 2001: 202). Perceptual speech assessment is the most commonly used procedure as listening is the best indicator of whether or not there is a speech problem (Henningsson et al., 2008: 1; Peterson-Falzone et al., 2010: 285). The perceptual speech assessment of preschool

children may be conducted using a standardized articulation test to identify the types of errors for example the commercially available The Goldman-Fristoe Test of Articulation (2000) or articulation tests specifically developed for the cleft population such as the Great Ormond Street Hospital Speech Assessment (GOS.SP.ASS'98, Sell et al., 1999). Controversies persist regarding how to measure and report speech characteristics due to the variations among the various systems used to collect and analyze perceptual data related to speech (Hutters & Henningson, 2004: 544; John et al., 2005: 273; Kuehn & Moller, 2000: 348; Lohmander-Agerskov & Olsson 2004: 64; Sell et al, 1999: 117; Sell, 2005: 113; Whitehill, 2002: 53; Wyatt et al., 1996: 147). A need to standardize speech measurement procedures across cultures and languages has been identified so that meaningful comparisons of treatment outcomes can be made internationally through multicentre studies to improve the standard of cleft care globally (Henningson et al. 2008: 1-17). Selected examples of perceptual speech assessment instruments that measure the cleft type speech characteristics are presented in Table 3.7.

TABLE 3.7 Examples of perceptual speech assessment instruments and procedures

Instrument and Procedure	Source	Description
GOS.SP.ASS.'98 (revised) Perceptual standardized screening procedure	Sell et al. (1999)	A comprehensive speech assessment protocol used for both clinical and research purposes. Nasal resonance, emission, turbulence and grimace are rated in terms of severity and consistency, according to defined categories. Articulation of consonants is analysed in terms of cleft type characteristics (CTCs) for example: active (dentalisations, palatalisation) and passive (nasal realizations, absent pressure consonants) CTCs. It includes a systematic approach to an oral examination, the mirror test and description of the visual appearance of speech.
Cleft Audit Protocol for Speech-Augmented (CAPS-A)	John et al., (2006)	Speech outcomes for intelligibility, voice, resonance, nasal air flow, consonant production and cleft type speech characteristics are judged by speech-language therapists based on an elicited speech sample.
Universal parameters for reporting speech outcomes in individuals with CL/P	Henningsson et al., (2008)	A set of five universal speech parameters have been devised for reporting. Hypernasality, hyponasality, audible nasal emissions, consonant errors and voice disorders. Two global parameters namely speech understandability and speech acceptability have also been included.

In order to assess the speech of a child with CL/P using any of the above procedures, a speech sample elicited with the use of standardized speech elicitation materials and a spontaneous speech sample is recommended (Henningsson et al., 2008: 9; Lohmander-Agerskov & Olsson 2004: 64; Sell, 2005: 106-107). The assessor's knowledge of the target language and its phonetic characteristics is also an important factor in assessing the phonological development of young children with CL/P (Brondsted et al., 1994: 110). The complexities of standardization and reliability checks should be taken into account during elicitation of speech samples from young children. The universal parameters in reporting speech (Henningsson et al., 2008: 5) may be

used as guideline to prepare language specific speech elicitation materials and ensure consistency in types of sounds sampled across languages. The elicited speech sample needs to be analysed to identify and describe cleft speech characteristics (e.g. consonant errors, nasal emissions/turbulence and hypernasality). Perceptual rating scales of resonance for speech assessment of young children with CL/P have been widely studied and validated as reliable measures (Hirschberg & Van Denmark, 1997: 161; Lohmander-Agerskov & Olsson, 2004: 65; Sell, 2005: 103).

The use of digital audio and video recordings of speech is recommended for speech analysis as high fidelity recordings that are amenable to computer storage and playback increase reliability of inter and intra-rater speech analysis (Sell, 2005: 107; Shriberg et al., 2005: 356). Low-tech procedures such as the mirror test and nostril-pinching tests can be used to evaluate the child's ability to achieve velopharyngeal closure and to determine whether nasal emissions and/or hypernasality are present (Kummer, 2008: 332). Repetition of syllables with pressure-sensitive phonemes, and high and low vowels (papapapa; pipipipi; sasasasa; sisisisi) are adequate speech samples for these low-tech speech assessments that can be elicited from very young children (Kummer, 2008: 332-333). However, Peterson-Falzone et al. (2006: 42) argued that the reliability and validity of these methods are doubtful and clinicians often rely on an 'objective' backup for their judgements. Non-instrumental test procedures are based on auditory-perception of the therapist to judge and analyze the speech of the patient. This can be problematic in terms of reliability, validity of the measurement procedures and when comparisons need to be made from one centre to another (Shaw, 2004: 239).

Instrumental speech assessment procedures provide supplementary information to perceptual speech measure of resonance and guide recommendations for the specific type of treatment, especially surgery (Kuehn & Moller, 2000: 364; Kuehn & Henne, 2003: 106; Peterson-Falzone et al., 2006: 41).

3.5.8.2 Instrumental speech assessment procedures

Instrumental speech assessment evaluates what cannot be observed during an oral examination and also quantifies and documents velopharyngeal closure. The most frequently reported instrumental assessments and procedures to assess speech and velopharyngeal function in preschool age children (Kuehn & Moller, 2000: 365; Lohmander-Agerskov & Olsson, 2004: 68) are:

- Videoflouroscopy: radiographic images of the velopharyngeal closure as the individual repeats a variety of phonemes in connected speech are recorded on video tape or digitally. However, the risk of radiation, although minimal does exist.
- Naspharyngoscopy/videoendoscopy: a fiberoptic nasopharyngoscope can be used for a clear view of the velum, pharyngeal walls and size, shape and site of any velopharyngeal gap. The procedure requires the individual to repeat a standard list of sentences and velopharyngeal function during connected speech that can be observed and recorded.
- Nasometry: acoustic energy is measured using a microphone and micro-computer software to obtain objective data of nasal resonance for speech analysis. The

individual reads a passage or repeats a standard list of sentences; the nasalance scores are compared to standardised norms.

(Kummer, 2008: 377; Peterson-Falzone et al., 2010: 292-314; Shprintzen, 2004: 572).

Management decisions about surgical procedure, prosthetic management and speech therapy intervention for the perceived speech abnormality need to be made based on both perceptual speech analysis and instrumental assessment of the velopharyngeal closure (Peterson-Falzone et al., 2006: 42-43; Shprintzen, 2004: 588;).

3.5.9 Developmental screening

Annual monitoring of development by a cleft palate team is recommended as best practice (ACPA, 2007: 12; Scherer & Kaiser, 2007: 12; Wyszynski, 2001: 304) as developmental delay is a common feature of children with CL/P, especially in syndromic cases. Developmental screening is a pivotal need of young children with CL/P and serves as an entry point for children to enter the ECI process (Kritzinger, 2000: 44).

There is a wide range of instruments available for developmental screening that use a combination of direct assessment with checklists, observations, and parental interview (Guralnick, 2005: 78). The views and perceptions of teachers, psychologists and others who have contact with the child may also be obtained to complement the speech-language therapists' observations. Speech-language therapists and audiologists may use developmental screening

instruments to identify children who may require further assessments by other professionals for example, the paediatrician, psychologist and occupational therapist.

TABLE 3.8 Developmental screening procedures and instruments

Procedure & Instrument	Stages			
	Neonatal	Infancy	Toddlerhood	Preschool stage
Case history	Parent interview detailed prenatal, natal and family history	Motor developmental history (milestones such as head holding, sitting, walking)		Motor and cognitive developmental history and adaptation to school environment
Observations	Reflexes, and screening for presence of congenital anomalies	Gross and fine motor skills Cognitive, personal social behaviour Self help skills Play observations: exploratory, symbolic		Psychosocial, cognitive, social interactional development
Examples of instruments	-	Use of milestones and developmental screening tools For example Denver II, Bayley Scales of Infant Development II, Battelle developmental inventory Minnesota Child Development Inventory		Developmental screening of learning problems, school related issues, and psychosocial functioning Minnesota Child Development Inventory

Sources: (Blackman, 1995: 82-84; Shonkoff & Meisels, 2000: 244; Wyszynski, 2002: 304-305).

Speech-language therapists and audiologists have to be knowledgeable and resourceful in selecting the most appropriate assessment procedures and instruments. They may need to develop new assessment instruments or adapt and even translate existing instruments to suit the local context and compensate for the lack of certain services and a team approach. The

challenges posed to conducting communication assessments in developing countries are discussed forthwith.

3.6 CHALLENGES TO COMMUNICATION ASSESSMENT IN DEVELOPING COUNTRIES AND POSSIBLE SOLUTIONS

The quality of cleft care provision is dependent on the existing health care service and developing countries lag behind in cleft care services, primarily because cleft care is not a health priority (Mars et al., 2008: xi). Many developing countries, despite the challenges to cleft care are striving to provide improved services to all individuals with CL/P (WHO, 2002) through local capacity building and collaborating with international organisations. The interdisciplinary team-based approach allows the various professionals to conduct assessments from their specialized perspectives and construct a collaborative coordinated intervention plan based on these assessments can then be implemented (ACPA, 2007: 5; Kummer, 2008: 299; Mars et al., 2008: 15).

Some of the challenges that speech-language therapists and audiologists in developing countries may face in conducting assessments of young children with CL/P possible solutions are presented in Figure 3.4.

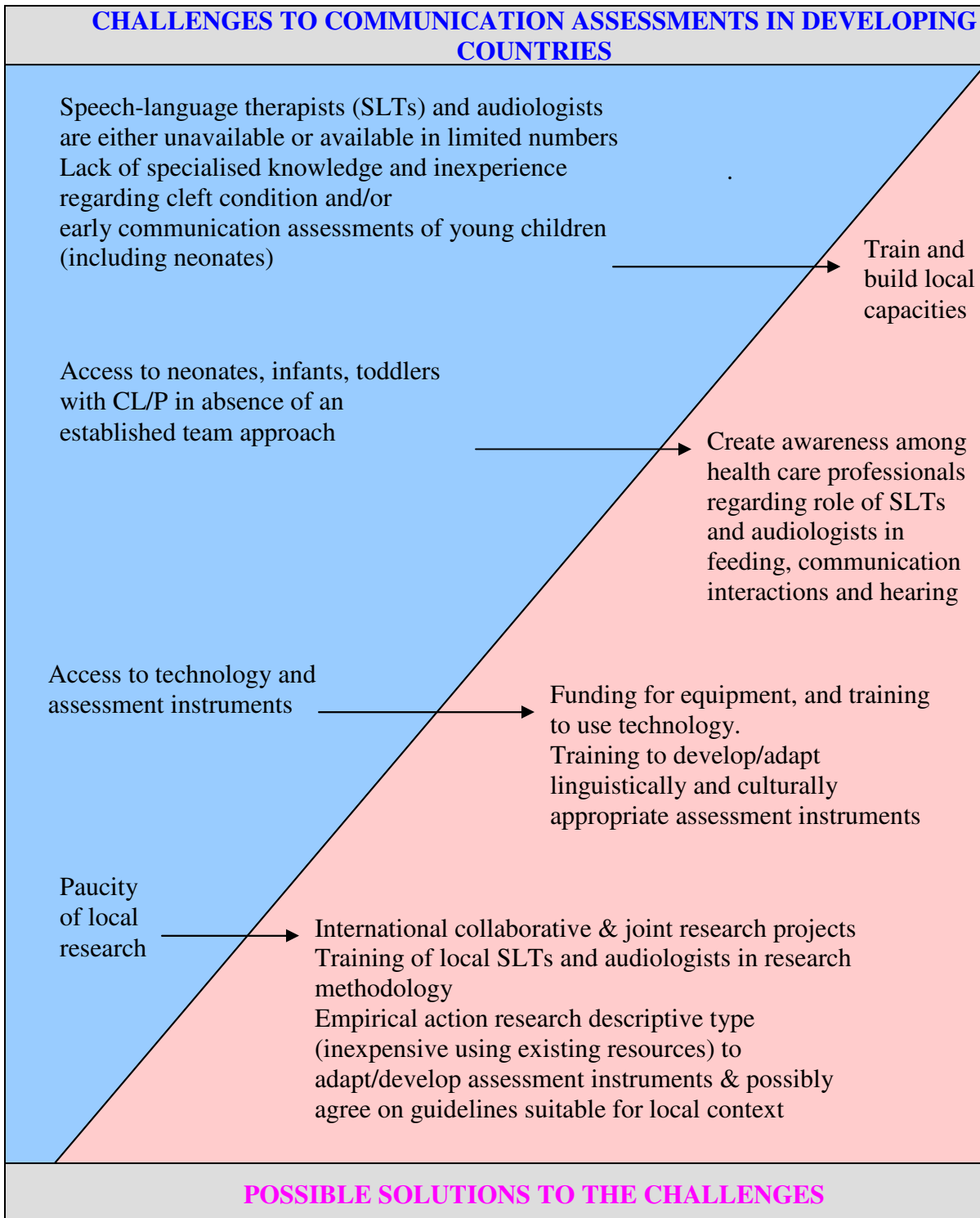


FIGURE 3.2: Challenges to communication assessments in developing countries and possible solutions

(Based on: Bzoch, 2004: 572; D'Antonio, 2002: 1; Kuehn & Henne, 2003: 365; Mars et al., 2008: 198; Prathanee et al., 2006: 501; Sell, 2007: 17; Winterton 1998: 112; WHO, 2001b).

Many speech-language therapists and audiologists in developing countries may be unfamiliar with the concepts and techniques involved in the care of a child with craniofacial anomaly and CL/P (Kuehn & Henne, 2003; Grames, 2008: 10-12; Pannbacker, 2004; Vallino-Napoli et al., 2008: 374). Their knowledge and experiences in early communication intervention including assessment of neonates, infants and toddlers may also be limited (Mroz & Hall, 2003: 125). Training and local capacity building in speech-language therapy for cleft care has been strongly advocated by the Smile Train (D' Antonio, 2002), and Sell, (2007: 17).

The recommended interdisciplinary team based approach to conduct effective, efficient assessments and coordinate interventions through effective referral systems (ACPA, 2007) may also be inadequately applied in many developing countries (Mars et al., 2008: 192). The lack of a coordinated interdisciplinary team-based approach to assessment due to a limited number of professionals and resources implies that professionals cannot focus on specific areas. Health care professionals involved in cleft care may not be aware of the role of speech-language therapists and audiologists in early communication intervention of young children with CL/P. A possible solution to this problem is to create awareness regarding the benefits of ECI by speech-language therapists and audiologists from neonatal stage of a child with CL/P.

Speech-language therapists and audiologists in developing countries often do not have access to an assessment instrument that is contextually appropriate and applicable (D'Antonio, 2002: 1). They may adapt published protocols informally to suit their local context but may not conduct

research to determine its applicability and acceptability. A newly developed assessment instrument should be validated as well, but validation against an existing ‘gold standard’ assessment instrument from a developed country may not be appropriate. The lack of assessment instruments, limited specialised knowledge and experience of the team members conducting assessments, may further complicate the assessments of young children with CL/P. Furthermore, objective measurements and technology (videofluoroscopy, brain-stem evoked response audiometry) that improve the accuracy, validity, reliability and effectiveness of speech language therapy and audiology services may not be available in many developing countries. Some laudable efforts have been made through grants to acquire equipment and surgical supplies to improve overall hospital standards (Mars et al., 2008: 65) but these should be extended to instruments required by speech-language therapists and audiologists to conduct assessments using sophisticated technological instruments as well. A possible solution would be to develop a communication assessment instrument and to evaluate its applicability and acceptability for routine clinical use by the speech-language therapists and audiologists. As mentioned earlier a well validated tool may not find its use in clinical practice if it cannot be applied in the local setting or if it is not acceptable to the user.

In developing countries, local speech-language therapists and audiologists may require specialist input in cleft care through capacity building and research collaborations such as action research. This highlights the need for collaborative research between speech-language therapists and audiologists from developed and developing countries to adapt and develop appropriate assessment instruments and procedures (Trindade, 2006: 724; WHO, 2002: 31). Examples of such capacity building projects are the Sri Lanka Project (Wirt et al., 1990) and the Ethiopia

Project (Holmefjord & Berntsen, 2005). Collaborative research with developed countries that have assessment instruments and procedures in place for example the European cleft project, could assist and support speech-language therapists from developing countries to contribute local cultural and linguistic knowledge in adapting and developing appropriate assessments instruments.

In some contexts, although the core team members may be present, the lack of organisation of services to provide a coordinated team-based approach assessments with appropriate assessment instruments could result in a fragmented approach to assessments and interventions that are detrimental to quality cleft care. Therefore, collaborative research is a catalyst for action to develop, improve and build local capacities. This may be achieved by focusing on specific obstacles and improving resource use and availability (Walley et al., 2007: 424).

3.7 CONCLUSION

Cleft teams in developed countries have established protocols and guidelines for best practice to ensure comprehensive, coordinated and quality cleft care. Management of young children with CL/P is best provided by regular, formal, interdisciplinary team assessments to monitor the child's development, and measure treatment outcomes in individuals with CL/P (ACPA, 2007: 5). Although best practice guidelines for assessments and management are accessible to all, the implementation of these is not universal. Certain developing contexts may be so unique and different that the guidelines may fail to encapsulate their local realities.

In developing countries, such as Mauritius, the implementation of best practice guidelines remains a challenge due to limited research, limited number of professionals to participate in the multidisciplinary team approach and the lack of appropriate tools for assessments of the children by the team members. Given the importance of communication development in young children, speech-language therapists and audiologists need to be resourceful and adopt diverse roles and responsibilities to apply the current best practice as a guiding framework to communication assessment. A framework for the development of a communication assessment protocol, that may be applicable in a developing country, is presented in Figure 3.3.

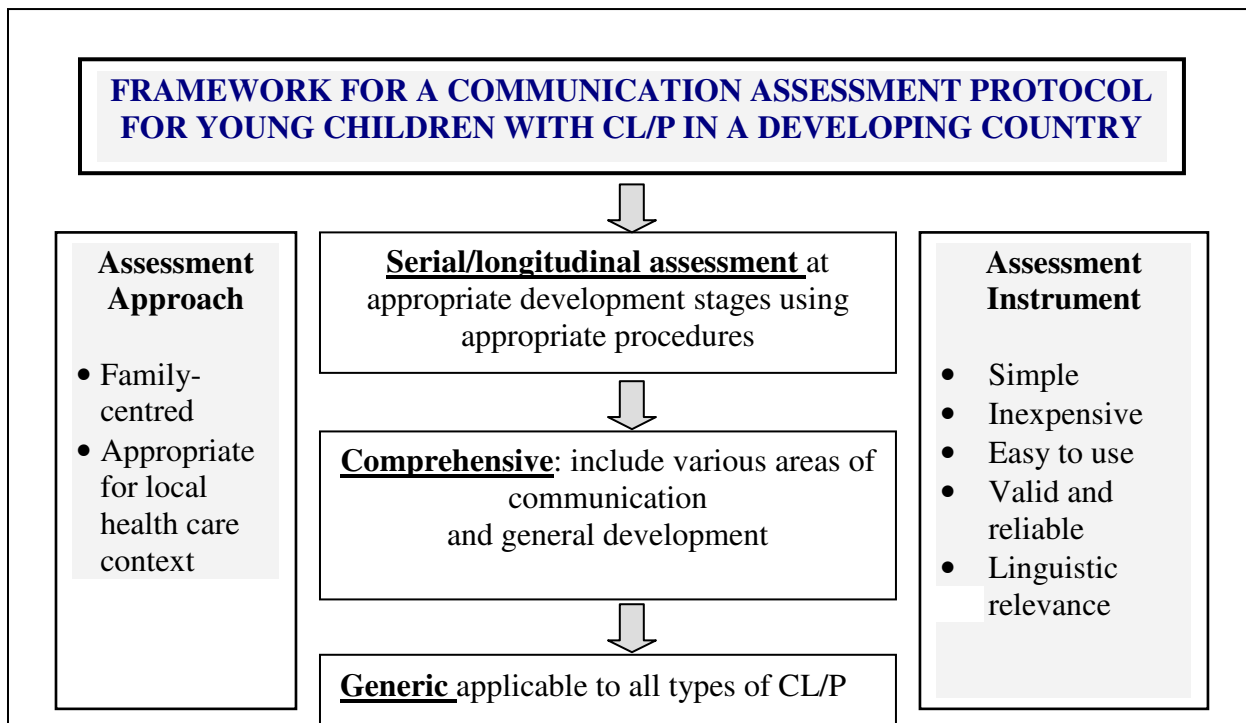


FIGURE 3.3 Framework for development of a Communication Assessment Protocol for young children with CL/P in a developing country

The proposed framework is adapted from available best practice guidelines for assessment of young children with CL/P and may be used to develop a comprehensive, holistic communication assessment protocol for clinical use by speech-language therapists and audiologists.

3.8 SUMMARY

In this chapter, the recommendations on the areas of communication assessment and serial assessments according to developmental stages of young children with CL/P have been described. These recommendations are based on existing models of cleft care in developed countries. The developing countries face specific challenges for communication assessment, such as access to locally acceptable and applicable instrument. The challenges for assessment procedures were identified and possible solutions to meet these challenges were proposed.

A framework for the development of a generic and holistic communication assessment protocol of young children with CL/P was proposed. It provides the underpinnings for the empirical research conducted.

CHAPTER 4:

METHODOLOGY

The aim of this chapter is to describe the methodology used to conduct empirical research for developing a Communication Assessment Protocol and database for young children with cleft lip and/or palate in Mauritius.

4.1 INTRODUCTION

The speech-language therapy and audiology services in Mauritius are not well developed. This is due to scarcity of resources and a lack of research facilities. There are only four therapists employed in the public health sector to serve a population of 1.2 million inhabitants. The therapists have heavy clinical workload and they use their clinical experience to assess and manage individuals with a variety of communication disorders across a wide age range without any structured protocol. Best clinical practice needs to integrate research evidence with clinical expertise and incorporate patient values (Johnson, 2006: 20). The importance of an evidence-based approach to clinical practice is well recognised for the management of communication disorders (Maxwell & Satake, 2006: 9).

In developed countries, the guidelines for assessment of speech-language and hearing of children with cleft lip and/or palate are based on evidence from extensive research (Bzoch, 2004; Kummer, 2001; Peterson-Falzone et al., 2010; Shprintzen & Bardach, 1995; Watson et al., 2001). However, it is not known whether the guidelines are appropriate for speech and language

assessments in less developed countries with limited resources and multilingual and multicultural populations. There is an unmet need to develop or adapt existing tools for assessment, especially in developing countries where such resources are rare (Carter et al., 2005: 385). Research into the assessment and treatment methods for communication disorders can strengthen the scientific and technological bases of service delivery (Hegde, 2003: 19; Johnson, 2006: 21). In this study, empirical research was conducted to develop a Communication Assessment Protocol, establish if the protocol is applicable and acceptable and initiate a database for children with CL/P in Mauritius.

4.2 CONCEPTUAL FRAMEWORK

A conceptual framework maps the thought process of the researcher and helps to shape and guide how the research will be conducted (De Vos et al., 2005: 35). The literature review has shown that children with CL/P require a team approach to assessment and management. The recommendations for best care for children with CL/P suggest early intervention (from the neonatal stage) and longitudinal assessments to measure the outcome of treatment (ACPA, 2007: 24). Moreover, the ACPA (2007) recommends that the assessment protocol should also be sensitive to linguistic, cultural, ethnic, psychosocial, economic and physical factors that affect the dynamic relationship between the team and the family. However, in resource-limited developing countries, such as Mauritius, where a team approach to cleft care is not in place and no database exists on individuals with cleft, the speech-language therapists and audiologists have the challenging task to conduct appropriate assessments under resource constraints.

The conceptual model determines which questions are to be answered by the research, and how empirical procedures can be used to answer these questions (De Vos Strydom, Fouche, & Delpont, 2005: 35). Research questions are often generated from a critical review of existing clinical practice (Reilly et al., 2004: 344). The following research questions arose from clinical experiences of a researcher managing children with CL/P in Mauritius.

- Is there a database available to access information on children with CL/P in Mauritius?
What are the demographic characteristics of the children with CL/P in Mauritius?

In the absence of an appropriate database and a standard Communication Assessment Protocol and the need for compiling, a new protocol further questions that need answers:

- Which data needs to be stored in a database of children with CL/P in Mauritius?
- Which aspects of communication need to be assessed and at what ages?
- Is the Communication Assessment Protocol clinically applicable for assessment of young children with CL/P in Mauritius?
- Is the Communication Assessment Protocol acceptable to the speech-language therapists and audiologists in the Mauritian context?

Answering these questions required action research that focused on finding a solution to a local problem in a local setting. Action research is a small-scale intervention in the functioning of the real world and involving a close examination of its effects (Johnson, 1994: 116). The present study was conducted in a small developing country (Mauritius) with limited resources for the purposes of developing a tool for routine clinical use by speech-language therapists and audiologists. The research was conducted to describe the characteristics (demographic and clinical) of children with CL/P. An appropriate communication assessment protocol was

developed within the framework of international trends in cleft care (ACPA, 2007; Eurocran 2000; WHO 2002). A participatory action research approach was adopted (De Vos et al., 2005: 409; Leedy & Ormrod, 2005: 108; Maxwell & Satake, 2006: 13) for the development of the protocol. Participatory action research encourages a feeling of ownership of the project and motivates participants to action and change that continues after the research is completed (De Vos et al., 2005: 420). The speech-language therapists and audiologists from the public health sector in Mauritius participated to develop the Communication Assessment Protocol. This was followed by field evaluation of the protocol to determine applicability and acceptability of its use to the speech-language therapists and audiologists in their routine practice.

4.3 RESEARCH AIM AND OBJECTIVES

The main aim of the study was to develop a Communication Assessment Protocol for young children with cleft lip and/or palate in Mauritius. The following objectives were set:

- To create an electronic database and document descriptive characteristics of children with CL/P in Mauritius
- To compile a Communication Assessment Protocol and evaluate its applicability
- To evaluate acceptability of the protocol in the local context.

4.4 RESEARCH DESIGN AND RESEARCH PHASES

The research design refers to the general strategy for solving the research problem with a plan for data collection and data analysis (Leedy & Ormrod, 2005: 85). The assessment of

communication disorders in children with CL/P is a very complex phenomenon. Therefore a combination of quantitative and qualitative research methods was employed to answer the questions in the study. Participatory action research in this study was adopted for collaborative action to 'learn by doing' (De Vos et al., 2005: 410) and implement change to communication assessment of young children with CL/P. Some of the quantitative data were collected using questionnaires (face-to face interviews) with parents of the children with CL/P and review of hospital records, to obtain data for descriptive characteristics of the children. The other quantitative data collection instrument was a communication assessment protocol that was compiled from a review of existing assessment protocols from developed countries. Furthermore, to evaluate the applicability of the protocol the speech-language therapists and audiologists assessed the communication behaviours of children with CL/P using the newly compiled assessment instrument. Audio-visual recordings were made of the children's speech. Descriptive statistics (Maxwell & Satake, 2006: 280) were used for classifying, organising, and summarizing the data in terms of frequency counts, a convenient manner for numerically evaluating the attributes of the available data.

The qualitative research component in this study refers to in-depth interviews and focus group discussions (Hakim, 2000: 10) that were conducted with the speech-language therapists and audiologists to determine the acceptability of the protocol. Priority was given to quantitative data while qualitative results were used to assist in explaining and interpreting the findings of the primarily quantitative study. In this research study, a mixed methods research design (Creswell, 2003: 215), characterised by the collection and analysis of quantitative data followed by the collection and analysis of qualitative data, was adopted. Triangulation is common in mixed-

method designs in which both quantitative and qualitative data are collected to answer the research questions (Leedy & Ormrod, 2005: 99). Two types of triangulation (Denzin & Lincoln, 2000: 391) were applied in this research:

- Data triangulation: the use of a variety of data sources namely medical documents, parental reports and direct observations.
- Investigator triangulation: the use of several different researchers for gathering data.

The research objectives were achieved through planning and conducting research in the following three sequential phases, as depicted in Figure 4.1.

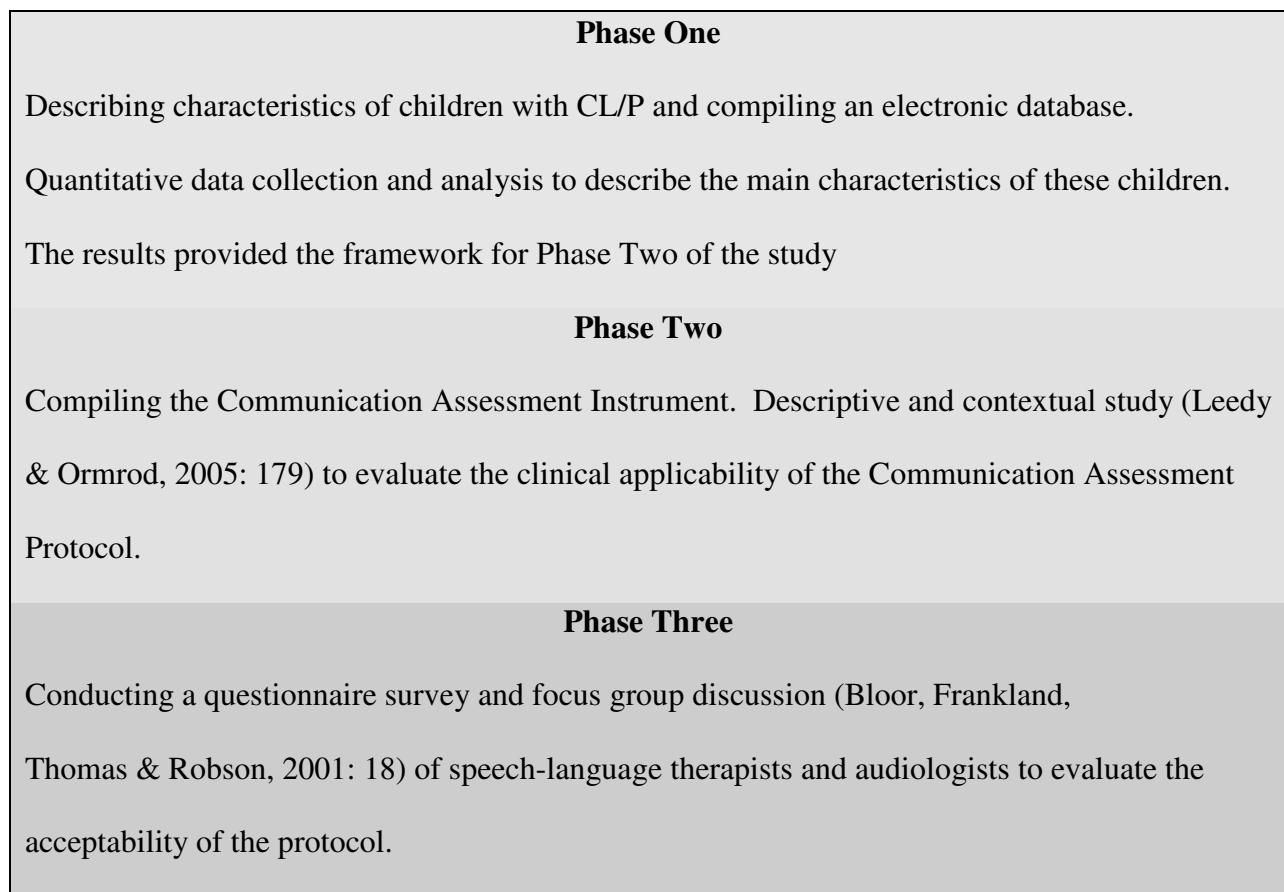


FIGURE 4.1 Research phases to develop the communication assessment protocol

A detailed description of the three phases is provided following the description of the study site and research ethics.

4.5 CONTEXT OF THE STUDY

The island of Mauritius was the context of the current research project. Mauritius is a very small island in the Indian Ocean, shown in Figure 4.2.

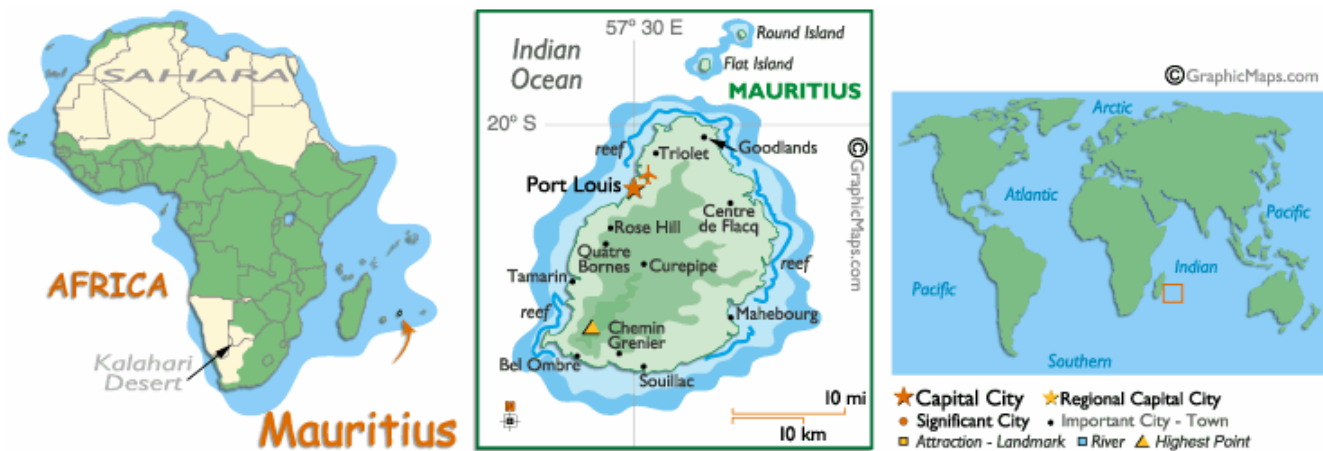


FIGURE 4.2 Context of the study: Mauritius

Mauritius is a densely populated island with 1.2 million people living on a landmass of less than 1000 square kilometres (Central Statistics Office, 2003). The population is heterogeneous and composed of three ethnic groups namely, Asian, Caucasian and of African origin. The official language is English but French and a local dialect Creole are widely spoken. The Human Development Report (2004) published for the United Nations Development Programme (UNDP) ranked Mauritius as 16th amongst developing countries and classified it as a country with “medium human development”. Primary education is free and compulsory; therefore, literacy levels are high in Mauritius. In 2002, 84.3 % of the population was literate. Skilled persons

attend to 99% of births, the fertility rate is 1.9 (2000-2005) and the public sector spends 2% of GDP on health; an indicator of the level of resources attributed to the provision of health services. Despite the limited resources, health care provision in the public sector in Mauritius is free. The National Health Service is well structured and public health services are accessible to the public at five regional hospitals across the island.

- Victoria Regional Hospital (VH) and a specialized ENT Centre situated in the central part of the island.
- Sir Seewoosagar Ramgoolam National Hospital (SSRNH) situated in the northern region.
- Dr. Jeetoo Hospital (Jeetoo) situated in the capital city, Port Louis.
- Jawaharlal Nehru Hospital (JNH) situated in the southern region.
- Flacq Regional Hospital situated in the eastern region.

At the time of the study, there was only one plastic surgeon in the public health sector and four speech-language therapists and audiologists. The plastic surgery clinic is centralized at the Victoria Regional Hospital and surgical repairs of clefts are performed at this hospital. Victoria hospital was the location for conducting this study. The speech-language therapy and audiology services are combined and provided at four of the five regional hospitals. The Victoria Regional Hospital has a specialized centre that provides ENT and speech-language therapy and audiology services to all referred cases including children with CL/P. The other professionals required in the management of children with CL/P namely orthodontists, paediatricians, nutritionists, psychologists are available and their services are provided at each of the five different regional hospitals. However, the multidisciplinary team approach at one centre is not available to children with CL/P and their families.

4.6 RESEARCH ETHICS

Ethical principles in research are important whenever human beings are the focus of a study and particularly when vulnerable groups such as children are the research participants (Creswell, 2003: 64; Leedy & Ormrod, 2005: 101). As the research study included a vulnerable group (children with CL/P), the researcher was particularly sensitive to observing the principles of research ethics. The following three ethical principles and guidelines (Morgan, Gliner & Harmon, 2006: 19-23) directed the researcher's actions.

- Respect for Persons: Participants should be treated as autonomous individuals and vulnerable groups such as children should be protected.
- Beneficence: A good outcome should be maximized for the participants as well as science and humanity. Researchers should not harm the participants.
- Justice: Research should not be exploitative and selection of participants should be justified.

The principle of respect for three sets of participants (children with CL/P, their parents and the speech-language therapists and audiologists) was applied in the current study as follows:

Informed consent - The adult participants were provided information regarding the research procedure purpose and benefits (Leedy & Ormrod, 2005: 101). The information was provided to parents of the children in a clear intelligible written language and explained verbally. For adult participants a written signed consent was obtained in the presence of a neutral witness. However, for young children as participants, parental consent was obtained and when possible assent was elicited from the children before administering the communication assessment. The

consent was voluntary (Appendices III and IV) and no monetary compensation was offered as an incentive to the participants (Morgan et al., 2006: 20).

Withdrawal - The participants had the right to withdraw at any time they wished to and were assured that this would not be detrimental to them (Leedy & Ormrod, 2005: 102).

Anonymity and confidentiality - Since the aim of this research project was to develop a Communication Assessment Protocol and test its clinical applicability, face-to-face interviews and observations of the participants were also necessary. The individual's identity was confidential when reporting the results. Babbie (2001: 472) pointed out that 'anonymity' cannot be guaranteed when interviews are planned in a research project. The names of children as participants appeared on the record forms only to aid the researcher in compiling the correct individual profiles, and to provide parents or caregivers with appropriate feedback on their children. The allocated numbers were used for statistical analysis and publication. The same would apply to future publications to ensure confidentiality.

The principle of beneficence requires that the assessment procedure does not involve any risk of physical harm to the children with CL/P. Rapport was established with the children before proceeding with the communication assessment, and parents were present throughout the communication assessment. The children felt safe during the assessment procedures.

The research ethics principle of justice is reflected in the selection of participants namely the speech-language therapists and audiologists, children with CL/P and their families. All children with CL/P in Mauritius had an equal opportunity to be included in the study. Researchers are ethically obliged to ensure that they are competent and adequately skilled to undertake the

investigations (De Vos et al., 2005: 69). Only qualified speech-language therapists and audiologists conducted the research procedures. Researchers also have an ethical obligation to colleagues in the scientific community to report the results in an honest manner (Babbie, 2001: 475). Due acknowledgements were given to sources consulted and people who collaborated in this research.

The following sections provide a description of the three phases in which the research was carried out.

4.7 PHASE ONE

The objective of Phase One, the participants involved, data collected and analysis procedures employed are described in this section.

4.7.1 Objective of Phase One

The objective of Phase One was to describe demographic and clinical characteristics of young children (0-6 years) with CL/P and to create a database. Figure 4.3 illustrates the steps taken to achieve this objective.

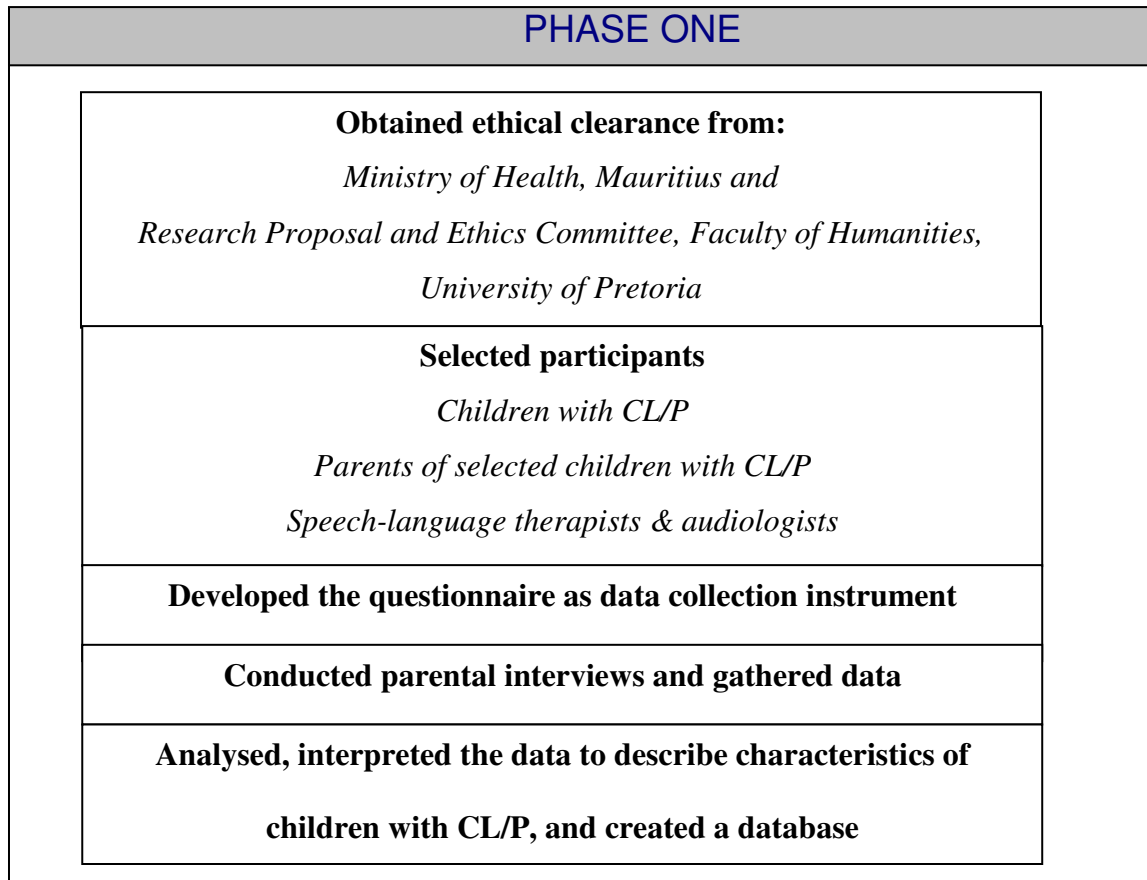


FIGURE 4.3 Steps taken to describe the characteristics of the children with CL/P in Mauritius (Phase One)

Ethical clearance was obtained from both the Research Proposal and Ethics Committee, Faculty of Humanities, University of Pretoria, and the Ministry of Health, Mauritius to conduct research and develop a Communication Assessment Protocol for young children with CL/P in Mauritius prior to the data collection (refer to Appendices I and II).

4.7.2 Phase One participants

The participants of Phase One consisted of three groups:

- Children (0-72 months) with CL/P
- Parents of the selected children
- Speech-language therapists and audiologists, employed by the Ministry of Health, Mauritius collaborated in the participatory action research.

The sampling method, selection criteria, selection procedure and description of each group of participants in Phase One are described below.

4.7.2.1 Children with cleft lip and/or palate

The target population in this study was children in the age range 0-72 months with CL/P in Mauritius.

- Sampling method

The incidence of CL/P in Mauritius has been reported as 1 in every 1500 births (Sevanandee, 2004). The birth rate for the past five years in Mauritius has remained constant and is approximately 18,500 live births annually as reported by the Health Statistics Unit, Ministry of Health. Therefore, the number of children with CL/P in Mauritius is estimated to be low. The incidence of CL/P varies in different parts of the world. The average birth incidence of CL/P in the western world is reported as 1 in every 700 live births to 1 in every 1000 births (WHO, 2002: 4). As the available participant data pools in Mauritius are limited a consecutive sampling method was used. Consecutive sampling is a type of non-probability sampling technique that involves selecting all individuals who agree to participate, provided they meet pre-established criteria (Maxwell & Satake, 2006: 96).

- Selection criteria

The following criteria were established for selection of the children as participants:

- Cleft lip and/or palate

The children as participants were required to have been born with a cleft lip and or cleft palate. Any one of the manifestations of cleft for example: unilateral or bilateral clefts of the lip, incomplete or complete clefts of the palate, overt or submucous clefts (Peterson-Falzone et al., 2010: 10-18) were included as this congenital anomaly was the focus of the current study.

- Age range 0-72 months

Children had to be between the ages of 0-72 months as the aim of the study was to develop a Communication Assessment Protocol for young children with CL/P. It is during these early years that the primary surgeries to repair the clefts are performed. Communication assessments in individuals with CL/P begin in infancy (Bzoch 2004: 23; Peterson-Falzone et al., 2010: 2). Potential communication difficulties can be identified and preventive work undertaken to promote more normal patterns of speech-language development (Watson et al., 2001: 191). Therefore, the period from birth to 6 years is critical for young children with CL/P and their families.

- Registered as patients at the Victoria Regional Hospital

Children with CL/P had to be registered at the Victoria Regional Hospital. Children born with CL/P from any part of the island of Mauritius are referred to the centralized plastic surgery unit at the Victoria Regional Hospital for plastic surgery. The records available here can be considered as the Mauritian database for children born with clefts. All children selected were required to be registered at this public hospital, as the purpose of this research was to develop a Communication Assessment Protocol for use in the public health sector of Mauritius. Children

with CL/P from the private sector were not included in the study as the context of this study was the public health sector.

- Syndromes and associated anomalies

Clefts are generally multi-factorial in origin and children with clefts may also have syndromes and associated anomalies with severe communication disorders (Shprintzen & Bardach, 1995:16). Research studies on clefts generally do not group multi-anomaly disorders that include clefts with isolated cleft cases (Peterson-Falzone et al., 2010: 57) because the symptoms and nature of problems for the two groups are variables that are considered to confound results and render conclusions to be questionable. In planning the current study, the researcher was cognisant of this methodological issue but included all children with CL/P in the public health care system in Mauritius. This implied that the study included children with syndromes, sequences and associated anomalies. This decision was based on the aim of the research namely to develop a national database for Mauritius that would include all children with clefts and to ensure the applicability of the communication assessment protocol across the spectrum of cases involving clefts. Race, gender, cultural family background, socio-economic status, educational background of parents were not considered as delimiting factors as the objective of the study was to describe the characteristics of children with CL/P.

- Selection procedure

The selection procedure for children with CL/P as participants was as follows:

- Permission was obtained verbally from the records officer to access the medical files for the purpose of selection of children with CL/P for research. Ethical clearance had been obtained from the Ministry of Health (Appendix I).

- A search from the hospital records of Victoria Regional Hospital (plastic surgery service is centralized) was made and a list of registered children with CL/P was compiled.
- The medical files of the selected children were reviewed and children who met the above selection criteria were identified. The contact details of the children with CL/P were obtained from their hospital records.
- A list was compiled which consisted of the name, date of birth, contact details (namely address and telephone number) and file number for each child. A total of 125 case records were reviewed. The sample frame of children is described in Table 4.1
- Parents of 88 children from the 91 contacted agreed to participate in the study.

TABLE 4.1 Sample frame of children with CL/P

All children registered at Victoria Regional Hospital with CL/P selected from the medical records	
Target population	125 children born as from January 2000 in the age range of 0-6 years with CL/P
Of these 125 medical records studied	<ul style="list-style-type: none"> - 16 records did not have contact details; telephone number & address was unknown. - 11 children were over 6 years (age instead of date of birth was registered) - 5 files were duplicates - 2 of these children had passed away <p>Therefore 91 children were selected for the study. The parents of 88 children agreed to participate in the study.</p>

Although the total number of children was 88, only 80 participated in the main study as eight were selected for the pilot study.

- Description of the children as participants

The selected children were from various regions of Mauritius. The distribution of children with CL/P according to region where they reside and receive the speech- language therapy and by age group: birth to younger than 36 months and 36-72 months is depicted in Figure 4.4.

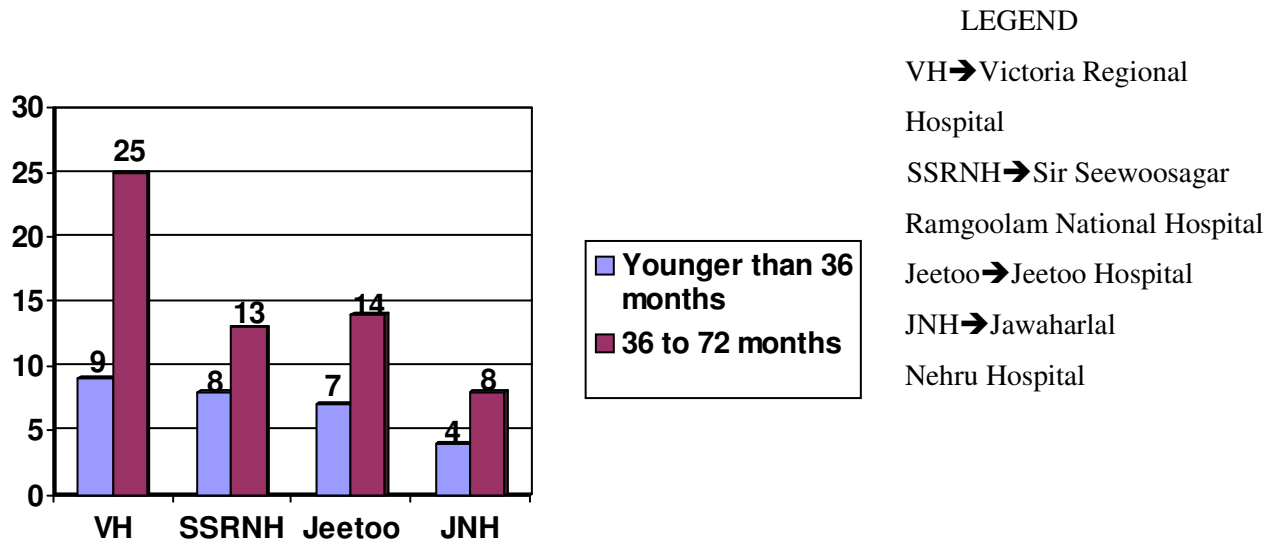


FIGURE 4.4 Age distribution of children as participants

The majority of the children (60/88) were in the age group of 36-72 months. Only 28 children were younger than 36 months. As mentioned previously, the public health sector has five regional hospitals but speech-language therapy and audiology services are available in only four of these regional hospitals. Therefore, the children residing in the east part of the island access the service at Sir Seewoosagar Ramgoolam National Hospital (SSRNH; north region).

Cleft lip occurred only amongst 13.6% of the children included in the sample, whereas cleft palate only, occurred amongst 42% (refer to Table 4.2). Cleft lip and palate occurred in 42% of the children. The proportion of *cleft type* as estimated in the literature is 25% cleft lip, 25% cleft palate alone and 50% cleft lip and palate (Peterson-Falzone et al., 2010: 24). The sample in this study does not reflect the reported distribution and further research will be required to confirm these results. As only two children had submucous cleft type in the sample it is hypothesised

that an estimate of the frequency of submucous cleft palate may be artificially low. Peterson-Falzone et al. (2010: 18) also report artificially low estimates of children with submucous cleft palates, as many submucous clefts remain undetected. It is possible that submucous type cleft palates are not detected at an early age.

TABLE 4.2 Characteristics of children with respect to cleft types

TYPE OF CLEFT / AGE GROUP	Cleft lip	Cleft palate	Cleft lip and Palate	Submucous cleft palate
Younger than 36 months	6	11	11	0
36-72 months	6	26	26	2
<i>Total</i> <i>N=88</i>	12 (13.6%)	37 (42%)	37 (42%)	2 (2.4%)

In the sample, 60% were female and 40% were male. The frequency of cleft palate only was also higher. The *gender distribution* reported in literature is variable depending on the racial group and type of clefts (Peterson-Falzone et al., 2010: 24). Overall cleft lip with or without cleft palate are more frequent in males and cleft palate only are more frequent among females (Wyszynski, 2002: 136).

It is important to distinguish between syndromic and nonsyndromic CL/P for determining management and recurrence risks for families (Wyszynski, 2002: 47). The distribution of the children in the sample, according to presence of syndromes is illustrated in Figure 4.5.

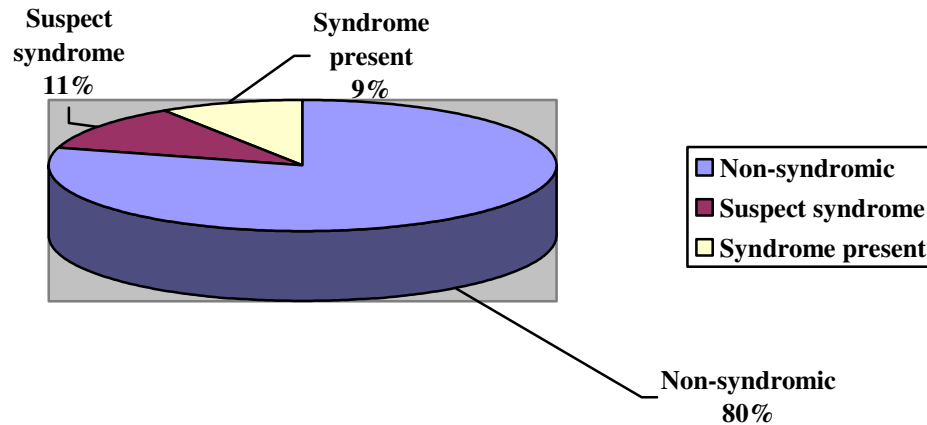


FIGURE 4.5 Presence of syndromes in the children as participants

Nonsyndromic CL/P has been reported between 70% and 80% of all cases (Wyszynski, 2002: 48). Shprintzen and Bardach (1995: 34) reported that more than half the children with clefts had a recognisable syndrome, sequence or associations and identifying the possible syndrome leads to better patient care. The local data indicate a possible under-identification of syndromes amongst these children; a possible reason is that in Mauritius the services of geneticists within the public health sector are not available. Identifying the presence of a syndrome is important for management of the children with CL/P.

4.7.2.2 Parents of the children as respondents

The participation of the parents was necessary to obtain the essential background information from them about their child with CL/P and their perceptions regarding the communication ability of the child. Parents are considered partners in early intervention as language develops in children's larger familial contexts through meaningful and reciprocal engagement (Bagnato et al., 1997: 52; Blackman, 1995: 64; Golding-Kushner, 2001:35).

- Sampling method for parents as respondents

A convenience sampling method (Maxwell & Satake, 2006: 96) was used to select parents as respondents. All parents, whose children had been selected and agreed to participate, were included.

- Selection criteria for parents as respondents

The following criteria were established for selection of the parents as respondents in Phase One of the study:

- Biological or adoptive parents

The adults selected as participants were required to be the biological or adoptive parents of the children with CL/P. Parents are the most important sources of information when describing child characteristics (Rossetti, 2001: 94).

- Parents of children with CL/P registered at the Victoria Regional Hospital

All the parents whose children met the selection criteria for the research were chosen as respondents in the study.

- Selection procedure of the parents as respondents

-An information sheet regarding the study was provided to parents and their voluntary informed consent to participate along-with their child in the study was obtained (refer to Appendix III).

- Description of the parents as respondents

Parents of the eighty children selected for the main study, as respondents were described according to diverse characteristics such as their marital status (Figure 4.6) and educational levels (Figure 4.7).

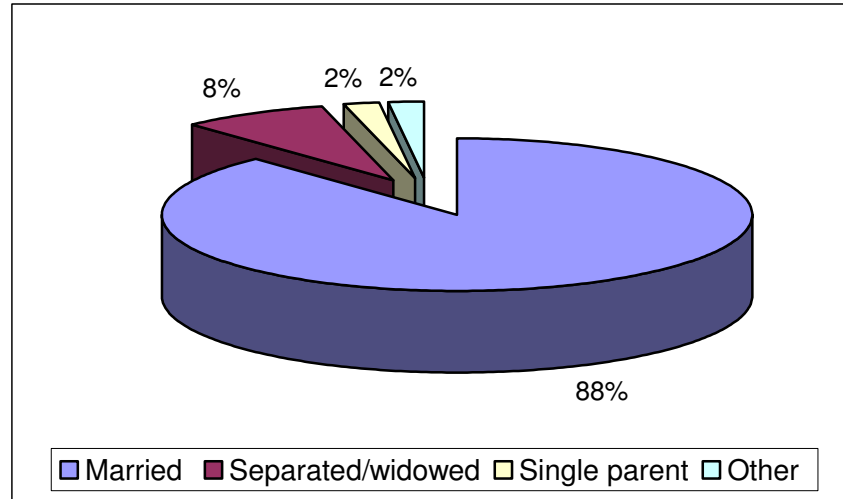


FIGURE 4.6 Marital statuses of the biological parents of children with CL/P

The majority of the parents were married and living together indicating that children came from stable families. The category-‘other’- included couples living together (Figure 4.6). The evidence for genetic disposition to CL/P comes from family and twin studies (Watson et al., 2001: 88). Respondents were questioned regarding type of marriage as consanguineous marriages are documented as a high risk factor for birth of a child with congenital anomalies (Watson et al., 2001: 88). 97.5% of the marriages did not have any history of consanguinity. Only two marriages were consanguineous. The majority of the participating parents had obtained secondary education (Figure 4.7).

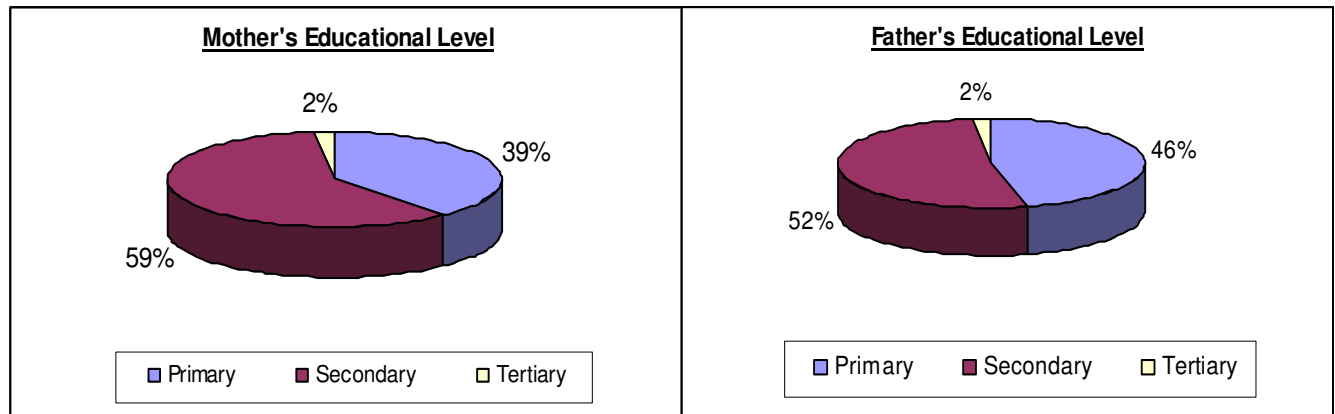


FIGURE 4.7 Highest educational qualifications of the parents

According to Shonkoff and Meisels (2000) higher educational levels enable the parents to be literate, self-supporting and parental educational levels are important in early intervention.

4.7.2.3 Speech-language therapists and audiologists as participants

In this participatory action research study, the speech-language therapists and audiologists were participants in all three phases of the research.

- Sampling method for speech-language therapists and audiologists

Convenience sampling as an all-inclusive criterion was applied in selection of the speech-language therapists and audiologists (Maxwell & Satake, 2006: 96). The available pool of participants was very small. At the time of the study, the Ministry of Health, Mauritius employed only four speech-language therapists and audiologists (including the researcher). Therefore, all were included provided they met the selection criteria and were willing to participate in the study.

- Selection criteria for speech-language therapists and audiologists

The following criteria were established for selection of the speech-language therapists and audiologists as participants:

- Qualifications

The speech-language therapists and audiologists were required to have at least an undergraduate degree in Speech-Language Therapy and/or Audiology, as they were required to perform communication assessments on the child participants and interviews with the parents of the children (ASHA, 2001: 1-25). Professional training would equip the participants to participate effectively in the research.

- Employment context

As the context of the study was the public health sector, the speech-language therapists and audiologists had to be employed by the Ministry of Health at the time the study was conducted. In routine clinical practice, speech-language therapists and audiologists in the public health sector are required to manage children with clefts for communication difficulties. Thus, they have experience in the management of these children and are familiar with the public health sector.

- Language proficiency

The speech-language therapists and audiologists were required to be proficient in the local language, Creole, and the other languages commonly spoken in Mauritius namely French and English, as they were required to complete the face-to-face questionnaire addressed to the parents and conduct assessments of the children with CL/P in the child's first language.

- Selection procedure for speech- language therapists and audiologists
- Permission was obtained from the Regional Health Directors for the speech-language therapists and audiologists posted in their regions to participate in the study.

- The three speech-language therapists and audiologists were invited for a meeting at the speech-language therapy unit, ENT centre of Victoria Regional Hospital and provided information regarding the research aim and objectives. Their voluntary informed consent to participate in the study was obtained (Appendix IV). The response rate was 100% as all the speech-language therapists and audiologists agreed to participate in the study.
- Description of the speech-language therapists and audiologists as participants (Table 4.3)

TABLE 4.3 Description of speech-language therapists and audiologists

Participants	Work Context	Years of experience	Gender and Age	Qualifications
Participant 1 (the principal researcher)	ENT/ Victoria Hospital (VH) in the central region)	23 years	F/ 47 yrs	M. Communication Pathology. Registered for D. Phil Communication Pathology degree
Participant 2	Sir Seewoosagar Ramgoolam hospital (SSRNH) in the north	2 years	F/ 26 yrs	B.Sc. Speech therapy & Audiology).
Participant 3	Dr. Jeetoo hospital (JH) the capital city hospital	7 years	F/ 30 yrs	M.Sc. Speech-Language Pathology
Participant 4	Jawaharlal Nehru hospital (JNH) in the south	7 years	F/ 29 yrs	B.Sc. Audiology & Speech-Language Pathology

The speech-language therapists and audiologists were female professionals employed by the Ministry of Health and worked at the four regional hospitals.

4.7.3 Phase One materials

Materials for data collection tools in Phase One included hospital medical records and a face-to-face questionnaire survey.

4.7.3.1 Hospital medical records

The hospital records include demographic information such as name, gender, date of birth/age and religion of the child. The plastic surgeon's notes such as cleft type, reviews, dates of operations and the operative notes are also available in the hospital medical records. The information was used to prepare a data collection sheet that included the following information: code number, gender, name, contact number, date of birth, age group of the child, type of cleft, whether any syndrome was present, the regional hospital according to residence of the child, date of assessment and the therapist who would conduct the assessment.

4.7.3.2 Interview schedule

An interview schedule (De Vos et al., 2005: 296; Neuman, 2000: 250) as data collection instrument was developed to gather and document information to describe the characteristics of the group of children with CL/P selected to participate in this study. An interview schedule has many advantages namely (De Vos et al., 2005: 299; Leedy & Ormrod, 2005: 185):

- Face-to-face interviews enhance response rate.
- The researcher can elicit specific information to meet the aims of the study.
- Open-ended questions can be added to allow respondents to express their specific concerns.
- Reading and writing skills of the respondents are not a concern as the interviewer completes the interview schedule.

The disadvantages of interview schedules are that they are time consuming and can be expensive (Leedy & Ormrod, 2005: 185). In this study, an interview schedule was deemed suitable as four speech-language therapists and audiologists had to interview 88 parent respondents.

The questionnaire included mainly closed-ended questions that were easy to answer, code, score and reduced subjective bias during the interview. It was based on the recommendations of the WHO (2001 b) 'Global Registry and Database on Craniofacial Anomalies'. The interview development of the interview schedule is described in Table 4.4 and the schedule is provided as Appendix V.

TABLE 4.4 Development and description of the interview schedule

INTERVIEW SCHEDULE PHASE ONE		
Sections	TYPE OF INFORMATION	OBJECTIVES AND QUESTIONS INCLUDED
A (A1 to A4)	Biographical information	To create a record of children with CL/P. Questions were included on demographic characteristics of the child: name, gender, date of birth and address (CRANE 2000; WHO 2002: 140).
B (B1 to B6)	Family background	To describe the background information relevant for description of the characteristics of the children with CL/P. Questions included the marital status of the parents, parental ages and educational background. Also information regarding family structure, number of siblings, and position of the child with CL/P was gathered. Questions pertaining to any history of consanguinity or family history of CL/P were also probed (Peterson-Falzone et al., 2010: 25). Questions regarding the main languages spoken at home and the most commonly spoken language were also asked. Cultural and linguistic sensitivity is recommended (ACPA 2007: 6; Eurocran Speech Project 2000) during communication assessment.
C (C1 to C6)	Birth history	To describe the characteristics of children with CL/P. Questions pertaining to prenatal and peri-natal conditions of the mother and child were included. Information regarding presence of any syndrome or suspicion of a syndrome was also sought. The etiological heterogeneity of cleft condition includes antenatal factors, genetic factors and environmental conditions (Shprintzen & Bardach, 1995: 7; Watson et al., 2001: 10). The birth weight of the child was also noted as children born premature are at risk for other anomalies such as congenital hearing loss, developmental delay. Clefts may occur as part of a syndrome/sequence or in association with other congenital anomalies (Watson et al., 2001: 87). Presence of syndromes in children with clefts affects communication development (Shprintzen & Bardach 1995: 38).
D	Type of cleft	To describe types of cleft classified as: Cleft lip only, cleft lip and palate, cleft palate only and submucous cleft palate (Watson et al., 2001: 19). A further description of the type of cleft was noted for example if cleft palate only, whether hard and soft palate were involved or only soft palate. As the group under study was a heterogeneous it was important to document the types of cleft amongst these children. Cleft description is important when reporting a series of cases, as there is a need to compare one group with another and cleft type has implications for the management of the child (Watson et al., 2001: 23).

TABLE 4.4 Development and description of the interview schedule (continued)

INTERVIEW SCHEDULE PHASE ONE		
SECTIONS	TYPE OF INFORMATION	OBJECTIVES AND QUESTIONS INCLUDED
E (E1 & E2)	Surgical History	To describe characteristics of care provided to the children with CL/P. Information regarding the age of repair of lip, palate and if there were any secondary repairs was obtained. The timing of surgeries should be identified as the child's age at the time of repair has an impact on early speech-language development (Peterson-Falzone et al., 2010: 151). Questions regarding other surgeries that the child may have undergone were also asked for example, ears or heart or surgery for any other malformations.
F (F1 to F3)	Feeding, Speech and Hearing	To describe parental perceptions of feeding and communication difficulties the child with CL/P exhibits and to address these concerns (Watson et al., 2001: 379). The other part of this section was the speech- language and Audiology services that the child was receiving and how frequently to describe the care provided to these children.
G (G1 & G 2)	Pathway of care	To describe the clinical context of care provided to children with CL/P. Questions regarding who identified the cleft, when was the child first seen by the plastic surgeon, whether the child received services from other professionals were included. Children with CL/P require the services of an interdisciplinary team (ACPA, 2007: 5).

- Pre-testing of the interview schedule

The aim of pre-testing the interview schedule was to identify potential problems prior to finalising the contents of the interview schedule and the data collection procedure. Pre-testing was also carried out to improve the reliability and validity of the interview schedule (Neuman, 2000: 166).

- Pre-test participants

- The pre-test participants had to be similar to the participants who would take part in Phase One. In order to detect potential problems that may be experienced when conducting the interview schedules on selected children with CL/P (De Vos et al., 2005: 209-211).
- Two children with CL/P who were older than six years were selected from the children with CL/P attending speech-language therapy services at ENT centre where the principal researcher works.
- Their parents participated as respondents of the interview schedule.
- In addition to the principal researcher, the three speech-language therapists and audiologists also participated, as they evaluated the tool.

- Materials for pre-testing the interview schedule

- The interview schedule was based on an in-depth literature review.
- The interview schedule was presented to the participating speech-language therapists and audiologists for comments and approval.
- The interview schedule developed was used as materials for the pre-test (refer to Appendix V). The hospital files and parents of the two children were the data sources in the pre-test.

- Procedure for pre-testing the interview schedule

- The principal researcher explained the purpose of the interview schedule to the parents of the two selected children. Voluntary consent to participate was obtained from the parents as respondents.
- The site for the interviews was the Speech Therapy unit at ENT hospital where families with children with CL/P access therapy services.
- The principal researcher conducted the interviews according to the interview schedule.

- Results

The pre-test assisted the researcher in minimising the possibility that technical problems with the wording or layout may affect the data obtained by the questionnaire as survey instrument (Leedy & Ormrod, 2005: 188). The main results of the pre-test are listed below:

- Speech-language therapists and audiologists who acted as participants agreed that the *interview schedule was appropriate* as all the necessary information could be elicited to describe the characteristics of the children with CL/P using this tool.
- The *questions* were found to be clear and the respondents did not have any difficulty in answering the questions.
- *Parents* remained the primary source of information throughout the interview although hospital and medical records were available to verify information provided by them.
- It was determined that the average time to complete the interview schedule was approximately ten minutes.

Based on the results the data collection was carried out as described below.

4.7.4 Phase One data collection procedure

The data collection procedure for Phase One was as follows:

- During a brief meeting, the principal researcher presented the interview schedule to the participating speech-language therapists and audiologists and gave clear instructions on data collection procedures. All four participating speech-language therapists and audiologists (including the principal researcher) used the interview schedule to gather information in uniform manner from the respondents.
- Parents were contacted by telephone or letters to attend an interview at the regional hospital where they follow therapy. Interviews were planned during a routine appointment or at a time mutually convenient to the respondent (parent) and the therapist conducting the interview schedule. The regional hospital where the children attended routine follow-up appointments with the speech-language therapist and audiologist served as the venue.
- Medical records of each child were available to aid the respondents in recalling information for example the date of surgical repair of the cleft as a respondent may not recall past events when answering questions (Neuman, 2000: 255). The medical records were also useful in extracting information regarding the child's health.
- The principal researcher monitored that all information gathered by the speech-language therapists and audiologists was appropriately entered in the coded boxes provided in the interview schedule.

4.7.5 Phase One data recording and analysis

All data collected from the interview schedule were coded for statistical processing. The data were entered in Microsoft Excel and the statistician (Ministry of Health, Mauritius) used

statistical programme SPSS 10.0 for the data analysis. Descriptive statistics were applied for data analysis (Maxwell & Satake, 2006: 280; Morgan et al., 2006: 40). Discrete frequency counts were calculated for the variables (Morgan et al., 2006: 43). The data were displayed as bar charts and as pie charts. The numerical data such as ages were analysed for the mean while categorical data such as type of cleft and the binary data were analysed for percentages or proportions; (Morgan et al., 2006: 37). The data analysis is tabulated according to the objectives of Phase One of the study and illustrated in Table 4.5.

TABLE 4.5 Descriptive statistical analysis of Phase One (description of children with CL/P).

Data from Phase One	Purpose	Descriptive Statistical Procedure
A. Biographical Information	Compile a list of children with CL/P and provide a framework for future data entry into the electronic database	None
B. Family history	Description of the families Languages spoken at home	Mean number of children in the families. Number of consanguineous marriages Frequency count, number of languages and percentages of children for variable languages (Maxwell & Satake, 2006:282)
C. Birth History	Characteristics of children, high risk factors for other anomalies and presence of syndromes	Percentages of children with non-syndromic CL/P, presence of syndromes or possibility of having syndromes (Morgan et al., 2006: 43).
D. Type of cleft	Classification in categories of the types of clefts	Frequency count of variable: cleft types depicted as bar chart according to sex of the child (Maxwell & Satake 2006: 282).
E. Surgical History	Description of surgical management	Age range; mean age and median age when cleft repair surgeries were performed (Leedy & Ormrod, 2005: 257).
F. Feeding, Speech and Hearing	Parental perceptions of child's difficulties Indication for speech-language and audiology services	Frequency count of children perceived by parents as having feeding, speech and hearing difficulties. (Leedy & Ormrod, 2005: 257).
G. Pathway of care	Description of identification and care provided	Frequency count and percentages of children managed by the various professionals involved in cleft care in Mauritius (Maxwell & Satake, 2006: 289).

The data of Phase One were analysed and interpreted to describe the characteristics of children with CL/P and pertinent information regarding family and languages spoken at home. The results were used to create a framework for compiling the Communication Assessment Protocol.

4.7.6 Phase One validity and reliability

The characteristics to be described concerned demographic information and care provided to the children with CL/P. The following strategies were applied to enhance validity and reliability, as they are central issues in all measurement (Neuman, 2000: 164).

Validity ensures that the instrument used for measurements in the study is measuring truth or close to truth and not subject to any errors of measurement (De Vos et al., 2005: 160; Maxwell & Satake, 2006: 127). The contents of the interview schedule (see Appendix V, Sections A-G) were prepared specifically according to the objectives of Phase One of the study. The process of establishing content validity is to see if the test items assess what the researcher wants them to (Maxwell & Satake, 2006: 128-129). Guidelines provided by the WHO (2001:70) and Craniofacial Anomalies Network (CRANE, 2000) regarding elements that need to be included when planning a database of children with CL/P and describing their characteristics, were followed. The core data elements for children included demographic information, maternal, and birth histories, and the types of clefts. Furthermore, the results obtained from the interview schedule were supported by the information available in the hospital records. Criterion related validity refers to the extent to which the results of a measuring instrument agree with those existing tests that are presumed to be valid (Maxwell & Satake, 2006: 130). The hospital records contributed to criterion validity. A detailed description of the study setting and systematic procedure for data collection were provided for any future researcher to judge the degree of transferability to another context and conduct a similar study. The largest sample possible was recruited (Maxwell & Satake, 2006: 30).so that the findings could be representative of Mauritius and possibly generalised to other contexts.

Reliability refers to the consistency with which the measuring instrument yields a certain result (Leedy & Ormrod, 2005: 29). In this phase the reliability of measurements was ensured by pre-testing the interview schedule (see Section 4.7.3.2). The method of data triangulation as described by Leedy and Ormrod (2005: 99) was employed whereby medical records, parental interviews and observations of the child (type of cleft) were utilised when completing the interview schedule. The face-to-face interviews ensured a high rate of response that is important for the reliability of the research results. The researcher's generalisations may not be accurate if the number of non-respondents is high (Leedy & Ormrod, 2005: 209). In order to avoid bias the principal researcher utilized the other researchers to cross-check data that were gathered and often discussed the data collection procedures with them to ensure uniformity of data collection and recording. As depicted in Figure 4.1 this research was conducted in three sequential phases. The results of Phase One provided the necessary underpinnings for Phase Two.

4.8 PHASE TWO

Phase Two was conducted to compile a Communication Assessment Protocol and to conduct assessments on selected children with CL/P in the Mauritian context.

4.8.1 Objectives of Phase Two

The objectives of Phase Two were to:

- Compile a Communication Assessment Protocol as a standard clinical tool for the assessment of children with CL/P in the age range 0-72 months, by speech-language therapists and audiologists working in the public health sector of Mauritius.

- Compile appropriate speech material (in locally spoken languages) for eliciting standard speech responses.
- Conduct assessments using the Communication Assessment Protocol on selected children with CL/P to evaluate the applicability of the tool.

The following Figure 4.8 illustrates the steps taken to achieve these objectives

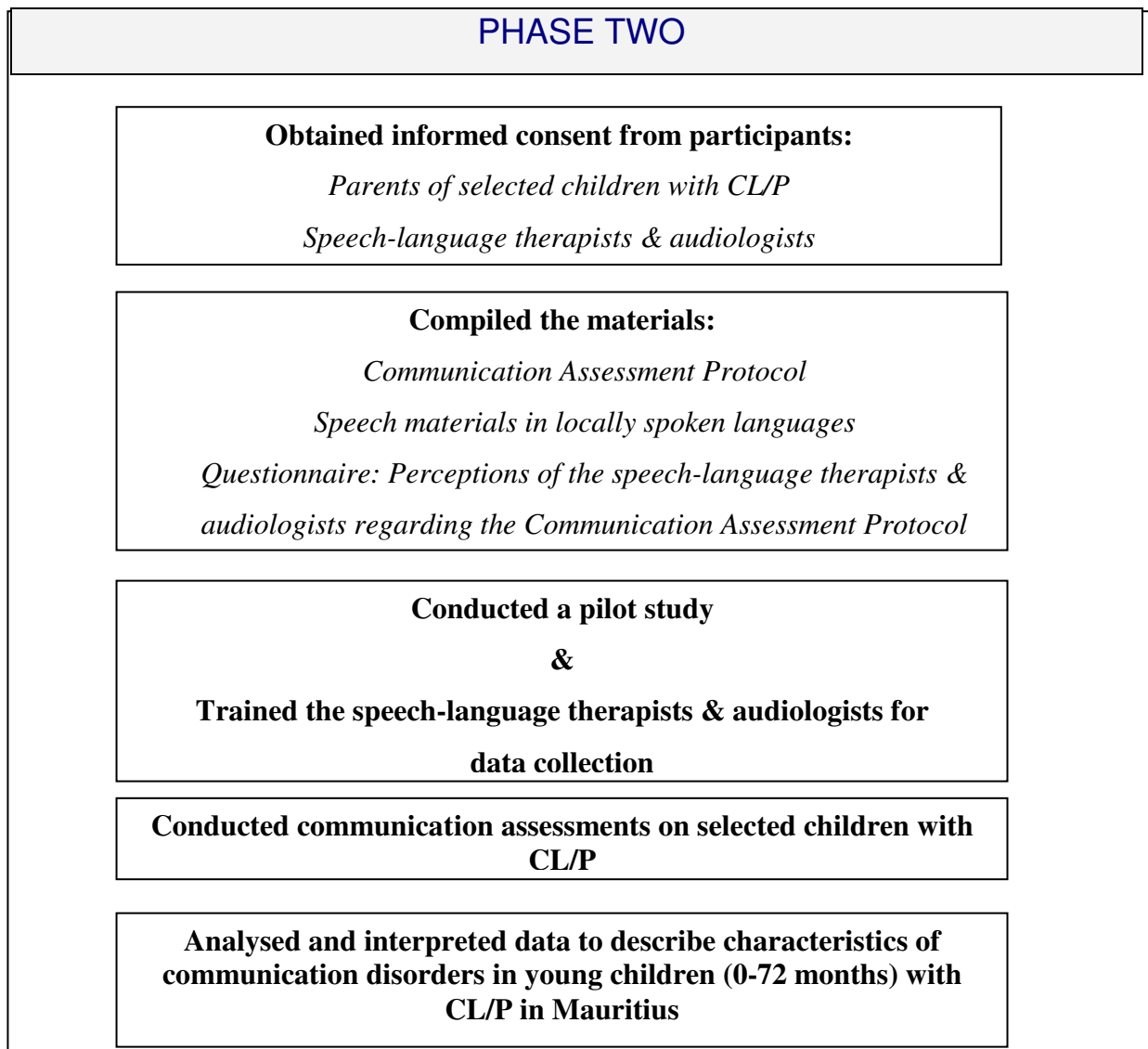


FIGURE 4.8 Steps taken to compile and evaluate the applicability of the Communication Assessment Protocol

4.8.2 Phase Two participants

The participants selected in Phase One of the study and the additional support staff also participated in Phase Two.

4.8.2.1. Children with cleft lip and/or palate

Eighty-eight children born with CL/P and described in Phase One (refer to section 4.7.2.1) also participated in Phase Two of the study.

4.8.2.2. Speech-language therapists and audiologists

Three speech-language therapists and audiologists and the principal researcher described in Phase One (see Table 4.3) conducted the communication assessments of the selected children with CL/P and collected the data.

4.8.2.3. Additional support staff

The following support staff working at the Speech Therapy and Audiology unit, ENT centre participated during Phase Two:

- The *clerical officer* arranged the appointments for scheduled interviews and assessments of the children with CL/P.
- The *speech and hearing assistant* helped to make the audio and video recordings. The support of an additional staff member was required to carry out the recordings whilst the speech-language therapists and audiologists elicited speech from the children with CL/P.

The speech and hearing assistant has a one-year in service training and five years of work experience to assist the speech-language therapist and audiologist.

4.8.3 Phase Two materials and apparatus

The materials used during Phase Two of this research are described in Table 4.6.

TABLE 4.6 Materials compiled for use in Phase Two

Materials	Purpose
Communication assessment tracking form	To record the observations and the assessments conducted on the selected children with CL/P by the speech-language therapists and audiologists
Speech material	To elicit speech samples from children with CL/P in age range 36 to 72 months in the locally spoken languages
Questionnaire: Perceptions of the speech-language therapists and audiologists regarding the Communication Assessment Protocol	To determine the perceptions of speech-language therapists and audiologists regarding the Communication Assessment Protocol

The following Table 4.7 presents the Apparatus used during Phase Two.

TABLE 4.7 Apparatus used during Phase Two

Apparatus	Specifications	Purpose
Electro-acoustic instruments for hearing evaluations These apparatus are available in the Speech-Therapy and Audiology Unit at ENT hospital and routinely used for hearing evaluations)	1. Screening Otoacoustic Emissions Make: Echocheck Otodynamics	To screen hearing amongst children younger than four months
	2. Brain Stem Evoked Response Audiometry. Make: Pilot Blankenfelde Evoselect 2 channels diagnostic testing	To diagnose hearing loss amongst children younger than 36 months
	3. Diagnostic Audiometer Make: GSI 61	To determine hearing thresholds amongst children 36-72 months
	4. Middle Ear Analyser Make: Interacoustics AZ 26 (Probe 220 Hz).	To detect presence of fluid in the middle ear and acoustic reflexes
Video and audio recording equipment	Digital video Make: Sony Handycam Sony tripod stand VCT-R640 8 cms DVD + RW	To make high fidelity recordings of the elicited speech sample amongst children 36-72 months and carry out auditory perceptual speech analysis Recorded observations minimize interviewer bias allow for multiple judges and estimation of inter-rater reliability (Maxim, 1999: 300)
High fidelity recordings are ensured by digital recordings	Digital audio mini-disc Make Sony MD Walkman MZ-NH1 Recordable mini discs (80 minutes) External microphone tie pin ECM-C115 Headphones Sony stereo MDR-CD-280	To audio record the speech sample. An external microphone was used to ensure high fidelity recordings. Headphones were used by the therapists when listening to the recorded speech for analysis

TABLE 4.7 Apparatus used during Phase Two (continued)

Apparatus	Specifications	Purpose
Training video Speech Assessments GOS.SP.ASS. '94 and '98	The Speech and language therapy Department at Great Ormond Street NHS Trust and DeMontford University Cleft Lip and Palate Association,	To provide the speech-language therapists ear-training on the phonetic characteristics associated with cleft lip and palate.
Computer	Laptop, Make: Dell Pentium IV	To store the digital recordings and replay for speech analysis.

4.8.3.1 Compilation of the Communication Assessment Protocol

The Communication Assessment Protocol was compiled as a clinical tool allowing speech-language therapists and audiologists to observe and enquire from the parents of the children with CL/P, and conduct series of communication assessments. The assessment tool was designed for children with CL/P in the age range 0-72 months. It is based on best practice (ACPA, 2000; Eurocran Speech Project, 2000; Kuehn & Moller, 2000) and recommendations in the literature as described in Chapter Two. The children were divided into two age groups as follows:

- Group 1: children with CL/P younger than 36 months and
- Group 2: children with CL/P in the age range of 36-72 months.

The CHRIB assessment protocol developed by the Department of Communication Pathology, University of Pretoria (Kritzinger & Louw, 2002) was the main reference source for the compilation of the Communication Assessment Protocol for Group 1 children. The protocol provides a description of a wide range of developmental areas related to early communication

development such as listening skills, pre-cursors for communication development and parental concerns regarding communication ability of their children (Kritzinger, 2000: 170).

For children in Group 2, the Great Ormond Street Hospital Assessment Protocol (GOS.SP.ASS.98) (Sell, Harding & Grunwell, 1999: 17-33) was selected as a main reference source because it provides a framework for speech assessment and analysis in a standardised way. It covers all features of speech associated with CL/P that are recommended for assessment (Henningsson et al: 2008). It includes evaluation of resonance, nasal emission, nasal turbulence, grimace, articulation characteristics and phonation together with systematic approach to an oral examination, the mirror test and description of the visual appearance of speech. It also facilitates systematic treatment planning (Sell et al., 1999). It was selected as an appropriate assessment tool for the age group 36 to 72 months because it uses simple perceptual methods to record and analyse speech.

A checklist for language acquisition (Shipley & McAfee, 2004: 233) and emergent reading skills (Snow, Burns, & Griffin, 1998) was also compiled. In the absence of local norms of language development, the speech-language therapists in Mauritius routinely use the checklist for language assessment from Shipley and McAfee (2004: 233). Therefore, it was selected as a checklist of language development in the Communication Assessment Protocol.

The content of the Communication Assessment protocol that was compiled from the literature review is depicted in Table 4.8.

TABLE 4.8 Contents of the Communication Assessment Protocol

Areas of assessment	Age range	Aim	Compilation & test administration
A. Background Information	0-72 months	To describe characteristics of the child being assessed and the care provided to them by the Mauritius, public health sector	Described in section 4.7 Phase One and refer to Tale 4.4. Based on recommendations by WHO (2001) ‘Global Registry and Database on Craniofacial Anomalies.
B. Feeding	younger than 36 months	To assess, advise parents regarding feeding & ensure adequate nutrition and weight gain, and if necessary refer to paediatricians and/or nutritionists	Based on Masarei et al. (2004). Two sub-sections are included: Bi) Pre-cleft repair feeding and B ii) Post-palate surgical feeding assessments. SLTs and audiologists observe, assess feeding, and describe parental caregiver coping skills for feeding the child with CL/P.
C. Hearing	0-72 months	To monitor hearing, identify hearing pathology, and refer to ENT specialist	Based on Hugo, Louw, Kritzinger and Smit (2000) listening behaviour and established age appropriate hearing evaluations SLTs and audiologists note the history (high risk factors for congenital hearing loss), parental report of auditory behaviour, listening behaviour and evaluate hearing with electroacoustic instruments: TEOAE, BSERA, immittance measures, pure tone audiometry.
D. Orofacial Examination	0-72 months	To describe facial oral structures and function, report to plastic surgeon; refer for dental care and paediatric opinion.	Compiled from Kummer (2008: 351-375); Shprintzen and Bardach (1995: 211-215) SLTs observe oral facial features and functions and check the appropriate items on the checklist format of the tracking form.

TABLE 4.8 Contents of the Communication Assessment Protocol (continued)

Areas of assessment	Age range	Aim	Compilation & test administration
E(i) Communication Speech-language, assessment	0-36 months	To monitor communication identify difficulties/delay note consonant inventory, emergent reading skills and advise parents and provide therapy	Based on assessment at Facial Deformities Clinic at the University of Pretoria and the CHRIB Early communication skills screening assessment, parental input of information and based on Thameside community health care NHS trust consonant inventory. Speech-language therapists' and audiologists' observations
E(ii) Speech-language, articulation and voice, assessment	36-72 months	To monitor speech-language development, plan management of speech and voice	Based on GOS.SP.ASS.98. SLTs and audiologists will assess and record elicited speech samples. A checklist for language acquisition (Shipley & McAfee, 2004: 233) and emergent reading skills (Snow, Burns & Griffin, 1998), is also included
F. General development	0-72 months	To monitor general development, note child's education history & make referrals.	Based on Shipley and McAfee (2004), parental reports and the speech-language therapists and audiologists' observations

- Design and layout of the Communication Assessment Protocol tracking form (refer to Appendix VI).
- A checklist questionnaire format was selected for the Communication Assessment Protocol in order to ensure uniform and accurate data recording by the speech-language therapists and audiologists. The observations and assessments of communication behaviours could be simply recorded by checking appropriate items on the list provided in the communication assessment tracking form. The checklist format facilitates data coding and analysis (Leedy & Ormrod, 2005: 185).
- The communication assessment tracking form consists of 15 pages and six sections: corresponding to the areas of assessment namely: background information, feeding, hearing, orofacial examination, communication, speech-language and general development. For each area of assessment, a different colour paper was used to improve clarity and easy identification of the various areas of assessment.
- The first 'summary' page is for recording background information regarding the child for example, demographic information, type of cleft and whether a syndrome is present. The summary page also contains areas of assessment, dates of assessment, name of the speech-language therapist and audiologist who carried out the assessment and the main recommendations.
- At the end of each section there is a box for the speech-language therapists and audiologists' recommendations and/or referrals for further management.

4.8.3.2 Compilation of the speech material for children with CL/P

The development of a standard procedure for assessing speech of children with CL/P is emphasized in current literature for reliable perceptual speech assessment and consistent reporting to allow for comparison of speech outcomes in the cleft population (ACPA, 2007: 3, Eurocran Speech Project 2000, Henningson et al., 2008: 1-17; Lohmander-Agerskov & Olsson, 2004: 64, Sell et al., 2005: 103). In Mauritius, speech-language therapists use informal tests and procedures to assess speech production as no standardized tests have been developed for the local population. In order to overcome this gap, customised speech material to elicit speech samples from children in the age group 36 to 72 months was compiled, in accordance with international guidelines for developing suitable speech material for children with clefts within a country/language (Eurocran Speech Project, 2000).

Languages differ in relation to the distribution of speech sounds that are vulnerable versus relatively insensitive to the cleft palate condition (Hutters & Henningson, 2004: 544). The two most commonly spoken languages, in Mauritius, are Creole and French (Phase One: Appendix V, item B.6). Speech articulation tests in French are available however a special articulation test for children with clefts was not found. A description of phonology of Mauritian Creole, contents of the speech material compiled and the procedures employed to prepare and pre-test the list of words and sentences in Creole follows.

- Phonology of Creole

There are 26 phonemes in Creole namely 8 vowels, 14 consonants and 4 approximants (Baker, 1972: 40). In Creole the sibilant sound /ʃ/ is substituted by the phoneme /s/ (Pudaruth, 1972: 41). For example: /La bouche/ is pronounced /labousse/. The affricates /tʃ/ and /dʒ/, that are most vulnerable in cleft-type speech (Grunwell, 1993: 108), are absent in Creole. The linguapalatal rhotic sound /r/ of English and French is classified as an approximant in Creole (Baker, 1972: 40). The 14 consonants are shown in Table 4.9

TABLE 4.9 Consonants in Creole

CONSONANTS N=14	m	p	b	F	V	n	t	d	l	S	z	ŋ	K	G
-----------------	---	---	---	---	---	---	---	---	---	---	---	---	---	---

- Content of the speech material

A word list was compiled to elicit speech responses from the children with CL/P. The word list consists of the 14 consonants in Creole, tabulated above. Approximants and vowels are not included for assessment. The list includes 28 words in Creole to target syllable initial word initial (SIWI) and syllable final word final (SFWF) (Sell et al., 1999: 28). The French translation of the words is included in italics. These words are nouns that can easily be depicted by pictures (see Appendix VII) to facilitate the repetition task. In Creole the sounds /ʃ/ and /j/ are not used but in French these sounds are present therefore pictures representing these sounds were also included.

A list of sentences in Creole to target the 14 consonants is also included as repeating sentences is the recommended context for judging voice quality and resonance (Grunwell, 1993: 145;

Peterson-Falzone, Trost-Cardamone, Karnell & Hardin-Jones, 2006: 71; Peterson-Falzone et al., 2010: 279). Sentence repetition is a useful, economic and controlled way of collecting a data sample. Sentences chosen should be meaningful and relevant whilst containing maximal numbers of each target sound known to be vulnerable to the effects of cleft palate (Watson et al., 2001: 231-232). In clinical practice the speech-language therapists and audiologists in Mauritius use the French material from the 'Troubles de l'articulation', prepared by Equipe du Centre d'Orthophonie (n.d.). In accordance with guidelines by Eurocran, 2000 for preparing sentences to elicit speech samples a list of sentences was compiled from this resource material. Sentences in English have been standardized for this age group (36 to 72 months) of children with CL/P in GOS.SP.ASS.98. The English list of sentences was compiled along-with the Creole and French lists (refer to Appendix VII).

- Procedure for preparing and pre-testing the compiled speech material

The following steps were taken to compile the speech material.

Step 1: A preliminary list of speech material was prepared based on guidelines by Eurocran Speech Project (2000) and presented to the following experts in their respective field for their views and suggestions.

- A linguist at the University of Mauritius
- The director of a group of pre-primary schools
- Speech-language therapists and audiologists working in the public health sector of Mauritius.

Based on their suggestions the final list was prepared.

Step 2: A booklet with pictures of the words to be presented to and repeated by the children was compiled. Pictures facilitate the child's task of repetition and motivate children to repeat the words and sentences (Bernthal & Bankson, 1998: 250; Watson et al., 2001: 231). The pictures representing the words were selected and downloaded from the internet, printed in colour and compiled in a booklet (refer to Appendix VII).

Step 3: A pilot study was conducted to pre-test the speech material prior to using it to elicit speech samples from the selected children with CL/P. Pre-testing the material helps to determine whether all the items are easy to understand, how long it takes to complete and identify possible problems (Leedy & Ormrod, 2005: 180). The aims, participants, materials, procedures and results of the pilot study are presented in Table 4.10.

Step 4: The *speech material* was presented to the speech-language therapists and their opinion regarding acceptability of the material was sought. The consensus of the speech-language therapists and audiologists was that the speech material in Creole and French was age appropriate, culturally sensitive and acceptable for the main study. The English sentences were compiled from the standardised GOS.SP.ASS.1998 and were accepted as speech elicitation material by the speech-language therapists and audiologists.

TABLE 4.10 Pilot study to develop the speech material

Aims	Participants	Materials	Procedure	Results
<p>To determine whether children in age range 36-72 months can repeat the list of words and sentences.</p> <p>To determine the amount of time needed for conducting the repetition to elicit speech samples</p>	<p>N=8 children</p> <p><i>Sampling method:</i> Consecutive and convenience sampling procedure</p> <p><i>Selection criteria:</i></p> <ul style="list-style-type: none"> -Gender: 4 male and 4 female -Age range: 36 to 72 months -Children with no speech-language problem -Children who speak Creole at home and could express in French (exposure to French at school). -Siblings of children attending the speech-language services 	<p>The compiled speech material Creole and French.</p> <p>The picture booklet</p> <p>The English speech material in GOS.SP.ASS.98</p> <p>APPARATUS</p> <p>Digital audio mini-disc of make Sony MD Walkman MZ-NH1</p> <p>Recordable mini discs (80 minutes)</p> <p>External microphone tie pin ECM-C115</p>	<p>Verbal assent was obtained from the children to repeat the words</p> <p>Speech sample was elicited by requesting the children to repeat the words then the sentences after the principal researcher.</p> <p>Pictures representing the words were shown to the children whilst repeating the words as support material.</p> <p>If the child spoke English only then speech sample in English was elicited</p> <p>Digital audio recordings were made of each child's speech sample.</p>	<p>The speech material was age appropriate as more than 80 % of the children could repeat the compiled list of words and sentences in Creole and French (Carter et al., 2005: 394)</p> <p>The children were co-operative and repeated all the words and sentences</p> <p>It became clear that between each word repetition at least 5 seconds should be lapsed otherwise when listening to the recording speech analysis is difficult</p> <p>The recording time ranged from 5 minutes to 7.30 minutes.</p>

4.8.3.3 Questionnaire: Perceptions of the speech-language therapists and audiologists regarding the Communication Assessment Protocol

A questionnaire was designed to determine the perceptions of the speech-language therapists and audiologists regarding the Communication Assessment Protocol (refer to Table 4.8) based on Streicher (2005: 21-22). The questionnaire (refer to Appendix VIII) consisted of two sections, namely: Section I: Preliminary evaluation of the Communication Assessment Protocol.

Section II: Clinical applicability of the Communication Assessment Protocol.

Section I of the questionnaire was completed by the speech-language therapists and audiologists *prior* to conducting the Communication Assessment Protocol on the selected children with CL/P.

Section II was completed during Phase Three *after* conducting the communication assessments.

Section I, of the questionnaire, had 5 subsections and sought information regarding qualifications, work experience of participants, their opinion regarding the layout, content and design of the communication assessment tracking form. The self administered questionnaire design was preferred to an interview schedule to avoid interviewer bias (Babbie, 2001: 271; Neuman, 2000: 272). Closed-ended questions were included as the answers of different respondents are easier to compare and to provide response choices that can clarify question meaning for respondents (Neuman, 2000: 261). As the aim of the questionnaire was to determine the perceptions of the speech-language therapists and audiologists, open-ended questions were mixed with the closed-ended questions for the therapists to add and or explain their opinions. Results of the preliminary evaluation of the Communication Assessment Protocol by the speech-language therapists and audiologists prior to using the Communication Assessment Protocol are presented in Table 4.11.

TABLE 4.11 Perceptions of speech-language therapists and audiologists regarding the Communication Assessment Protocol

Section I: Perceptions of the speech-language therapists and audiologist regarding the Communication Assessment Protocol prior to using it.				
No	Question	Responses of the speech-language therapists (SLTs) and audiologists: N= 3 (excluding the principal researcher)		
		P1	P2	P3
1.	Did the SLT and audiologist participate in Phase One of the study?	Yes	Yes	No as she was abroad
2.	-Did the SLTs and audiologists find the Communication Assessment Protocol clear? - Would they like to include/exclude any of the areas? - Whether training would be required? If yes in which area?	Yes No No	Yes No Yes in section E of the protocol	Yes No Yes in section E of the protocol
3.	- Whether SLTs and audiologists could carry out auditory- perceptual analysis of speech-voice according to the GOS.SP.ASS. 1998 and make the audio and video recordings planned. - Whether the speech material is appropriate	Yes Yes	Yes Yes	Yes Yes
4.	- Opinion regarding length of the Communication Assessment Protocol for application in the hospital context	May need more than one session to complete	Unsure: may not complete if child does not cooperate	Yes it is suitable for the hospital context
5.	-An open question seeking their views.	Comprehensive	Very detailed	Excellent protocol

As seen in Table 4.11 there was consensus among the speech-language therapists and audiologists regarding the feasibility of using the protocol clinically for conducting the communication assessments. The speech materials compiled in the locally spoken languages were also viewed to be appropriate. However, the three speech-language therapists and audiologists indicated a need for training in completing the communication, speech-language assessment for Group 2 children (refer to Appendix VI, Section E ii). The section is compiled from GOS.SP.ASS 1998 and requires perceptual speech and voice assessments. The local speech-language therapists required training to rate the voice resonance and note the cleft type speech characteristics during speech articulation in a uniform and standard manner. Therefore, training was provided to them prior to the data collection (refer to section 4.8.4.4).

4.8.4 Phase Two pilot study

The pilot study was conducted to carry out a smaller, preliminary version of the extensive study planned and to check the feasibility of the study. By rehearsing the actual steps to be followed in the full-scale study, both small and big flaws are often revealed (Maxwell & Satake, 2006: 62).

4.8.4.1. Objectives of the pilot study

The objectives of the pilot study were to:

- Train the speech-language therapists and audiologists to administer the procedures for data collection purposes accurately and reliably.
- Evaluate the context (facilities) where the assessments would be conducted.
- Determine the feasibility of making the audio and video recordings.

4.8.4.2 Pilot study participants

The participants were the principal researcher and the three speech-language therapists and audiologists described in Table 4.3.

Eight children from the selected sample of 88 children with CL/P as participants were selected for the pilot study by a purposeful sampling method. These eight children were not included in the main study as communication assessments were conducted on them as part of the pilot study. The selected children and the speech-language therapists and audiologists conducting the assessment for the pilot study are described in Table 4.12.

TABLE 4.12 Description of children with CL/P selected for the pilot study.

Children with CL/P N= 8	Gender	Date of Birth	Group	Type of Cleft	Speech-language therapist & audiologist (N=4) conducting the assessment in her work context
1	F	01.03.05	1	CP	Participant 2 (SSRNH)
2	M	20.02.05	1	CLP	Participant 1
3	M	02.05.06	1	CL	Participant 4(JNH)
4	M	12.06.05	1	CP	Participant 3(Jeetoo hospital)
5	F	18.03.00	2	CP	Participant 4(JNH)
6	F	31.01.00	2	CP	Participant 1
7	M	29.10.00	2	SCP	Participant 2(SSRNH)
8	M	22.07.02	2	CLP	Participant 3(Jeetoo hospital)

Legend: CP-Cleft Palate only CL- Cleft lip only CLP- Cleft lip and Palate SCP- Submucous Cleft Palate
SSRNH: Sir Seewoosagar Ramgoolam National Hospital, VH: Victoria Hospital, JNH: Jawaharlal Nehru hospital

* The pilot study was conducted between May and July 2006

4.8.4.3 Pilot study materials and apparatus

The materials and apparatus described in section 4.8.3 (see Tables 4.6 and 4.7) were used for the pilot study.

4.8.4.4 Training of the speech-language therapists and audiologists

In this participatory action research, the speech-language therapists and audiologists were trained to conduct the assessments and complete the Communication Assessment Protocol in a uniform manner at the ENT hospital. This would in turn enhance the reliability and accuracy of the data collecting procedure. The speech-language therapists and audiologists studied the different items in the various areas of assessment that were to be observed and assessed. The principal researcher provided clear instructions regarding assessment procedures and checking of the observations in the Communication Assessment Protocol tracking form. The speech-language therapists and audiologists observed the principal researcher conducting the assessment according to the Communication Assessment Protocol. They were encouraged to ask the principal researcher for clarifications regarding the assessment procedure.

No additional training was required for conducting hearing evaluations, as using the apparatus in the audiology unit was a familiar task for the speech-language therapists and audiologists participating in the research. However, they were given explanations regarding age appropriate hearing evaluations for the purpose of this study.

The audio-video recording procedure was demonstrated to the speech-language therapists and audiologists to familiarise them with the recording equipment. The recording apparatus (refer Table 4.7) is very user friendly, formal training in its use was not indicated.

In preparation for the research, the principal researcher had previously received training in the use of GOS.SP.ASS.98 at Great Ormond Street Hospital. The administration and speech analysis procedures were shared with the speech-language therapists and audiologists participating in this study. The training procedures were as follows:

- The *objective* of training was to familiarize the participants with the description and rating of resonance and cleft type speech characteristics for children with CL/P according to the GOS.SP.ASS 1998 (Sell et al., 1999). Moreover, training the speech-language therapists and audiologists would ensure uniform data collection, and improve listener judgement for speech analysis.

- The *apparatus* used was the training video Speech Assessments GOS.SP.ASS 1994 and 1999. The 35 minutes training video focuses on the administration and scoring of the speech elicited responses. The video provides a description of resonance characteristics (hypernasality, hyponasality and mixed nasality) and explains the evaluation procedure using a rating scale. Other cleft speech characteristics such as nasal emissions, nasal turbulence and identifying their presence are illustrated in the training video as well. The video also covers speech patterns of individuals with cleft palate and provides an overview of phonetic transcriptions with appropriate diacritics of these error patterns (dentalization, lateralization, palatization, glottal speech). Perceptual differences between nasal resonance, nasal emissions and between cleft type speech errors and developmental errors are demonstrated. The training video concludes with

practice sentences as an opportunity to practice identifying, rating and transcribing cleft speech characteristics.

- The speech-language therapists and audiologists viewed the GOS.SP.ASS. '98 training video twice (a week apart for each viewing). They watched the video and discussed the procedures for applying the GOS.SP.ASS protocol in the Mauritian context using the speech material compiled in Creole. The video was available for individual viewing and practice in listening to cleft speech patterns. The viewing sessions were followed by discussions on speech assessments. Furthermore, the principal investigator, who, as described earlier, had training in administration and scoring of speech in accordance with GOS.SP.ASS, demonstrated its application to the participating speech-language therapists and audiologists.

- The original GOS.SP.ASS 1998 was modified for the purposes of this study. The participants did not transcribe the speech using phonetic and diacritic symbols for cleft type speech as described in the video as they had limited training in transcribing speech phonetically. They used letters representing the consonant sounds and descriptions of the speech sound production. The GOS.SP.ASS '98 rating conventions were modified and reduced to binary judgments of presence or absence of speech errors. The speech elicitation material in this study was in 'Creole' and 'French' (described in section 4.8.3.2), and the speech-language therapists and audiologists in Mauritius are inexperienced in transcribing spoken Creole/French. In the future, training in transcribing speech and phonetic diacritics to record cleft type speech characteristics in the local language should be included to conform with best practice recommendations (Henningsson et al., 2008:7-8; Peterson-Falzone et al., 2010: 274; Sell, 2005: 106).

- Each child with CL/P in the sample was requested to repeat the words and sentences contained in the speech assessment material while digital audio and video recordings of their speech

production in Creole and French were made simultaneously. If the child did not respond, a further attempt was made to elicit speech production by showing the pictures depicting the words and encourage repetition of the speech material. The digital video and audio systems were high fidelity recordings that are amenable to computer storage, and playback of audio and video information (Sell, 2005). The participating speech-language therapists, assessed speech based on perceptual analysis of the audio and video recording of the speech samples (repetition of words, sentences and global impression of speech). Recorded observations minimize assessor bias and allow for multiple speech analyses and estimation of inter-assessor reliability. The principal researcher ensured that the stored data were available for further analysis (inter-assessor reliability checks) and as archives to aid future research.

4.8.4.5 Pilot study data collection procedure

Telephonic appointments were scheduled to conduct the assessments on the eight children selected as participants for the pilot study at the ENT centre: Speech Therapy and Audiology Unit. The test administration procedure was explained to the parents by the principal researcher. Parental consent to make audio-video recordings for children from Group 2 (36-72 months) was obtained. Whenever appropriate for the child, his or her assent was obtained prior to making the recordings.

The principal researcher herself carried out the first two assessments so that the speech-language therapists and audiologists could observe the data collection procedure. Written instructions regarding completing the Communication Assessment Protocol tracking form were given to each

of the speech-language therapists and audiologists. Each speech-language therapist and audiologist conducted the communication assessment as per the protocol on two children. The assessment included the interview with the parents of the child, observations of the child, eliciting speech responses, conducting hearing evaluations and recording the data on the Communication Assessment Protocol tracking form by checking the appropriate choice in the box provided. The speech-language therapists and audiologists were encouraged to ask the principal researcher for clarifications and help in recording the data while carrying out the assessment during the pilot study.

The principal researcher made the digital audio and video recordings for children from Group 2 whilst the participant speech-language therapist and audiologist requested the children to repeat the speech material. The principal researcher also noted the time taken to complete the communication assessment.

4.8.4.6 Pilot study results

The results are presented in accordance with the objectives of the pilot study:

- The sequence of the tracking form was feeding, hearing, orofacial examination, communication, speech-language and finally general development. During the pilot study the following sequence for assessment was found to be more convenient and practical:

feeding, orofacial examination, general developmental history, followed by communication, speech-language assessment and lastly the hearing evaluations. The revised sequence was agreed upon by the speech-language therapists and audiologists for the data collection procedure in the main study.

- The hearing evaluation apparatus (Table 4.7) was easy to use as the speech-language therapists and audiologists were experienced in differential diagnostic hearing tests using the same apparatus. The apparatus are used regularly and calibrated annually. Thus the speech-language therapists and audiologists were able to collect accurate, valid and reliable data.
- It was found that the speech-language therapists and audiologists could not simultaneously prompt the children (in age Group 2) to repeat the words and make audio and video recordings. Therefore, it was decided that the principal researcher would record whilst the speech-language therapist and audiologist encouraged the child to repeat the speech material. The principal researcher was responsible for transferring the audio and video recordings to the computer for storage and back-up of the digital recordings.
- The speech-language therapists and audiologists felt the need to watch the training video again to clarify the completion of speech assessments (refer to Appendix VI, Items E26-E31). However, they did not feel competent to transcribe the cleft type speech phonemes with the diacritic symbols as proposed in the training video. More detailed transcription provides greater information, but has limited reliability (Bernthal & Bankson, 1998: 239; Gooch, Hardin-Jones, Chapman, Trost-Cardamone, Sussman, 2001; Kent, Weismer, Kent, Vorperian & Duffy, 1999: 144). Therefore, consensus was reached that the following symbols would be used; + if the phoneme was articulated correctly and – if any type of error in the phoneme production was perceived.
- The speech therapy and audiology unit at the ENT centre of the Victoria Regional Hospital was deemed to be a suitable site for carrying out the assessment as it was the most centrally located hospital on the island with easy access for the participants. The test environment was quiet; with heavy carpets and curtains and a blue background for the video recording (recommended by

Eurocran, 2000) already in place. Hearing evaluation apparatus was available with the infrastructure of sound treated rooms (a facility not available at each of the regional hospitals). Therefore it was decided that all the assessments for data collection would be conducted at the ENT Centre.

- The average time taken for completing the assessment varied. The assessment of children in Group 1 took 40 minutes for those in Group 2 approximately 60 minutes were required as speech samples were also collected. This was considered to be a reasonable time for completing communication assessment in a clinical context (Williams, 2002: 211) and therefore no modification of the protocol was deemed necessary. As the speech-language therapists and audiologists became more experienced in applying the protocol, the time to complete the assessments decreased.

- The 15 pages of the Communication Assessment Protocol tracking form were printed on white paper. To facilitate the assessment process and improve the appearance of the form, a different colour paper for each of the six areas of assessment was chosen. Please refer to the Communication Assessment Protocol in Appendix VI.

4.8.5 Phase Two data collection procedure

After completion of the pilot study and the training of the participating speech-language therapists and audiologists, the data collection process for the main study was initiated. The 80 children selected as participants for the main study were divided into two groups based on age.

Group 1 consisted of 24 children younger than 36 months and Group 2 consisted of 56 children between 36 and 72 months (Table 4.2). Eight children from the eighty-eight participants in

Phase One of the study had been selected for the pilot study therefore these children were excluded from the main study.

The clerk scheduled the assessment appointments for the 80 children acting as participants. The appointment schedule for the communication assessment was on an individual basis at a convenient day and time for the speech-language therapists and audiologists and the parents who were expected to bring their children to the hospital. Two children with CL/P were assessed per day and appointments were made over four days of the week. The appointments were made by telephone at the beginning of each week. In cases where the telephone number was not available appointment letters were sent out suggesting a time when the parent could attend or they could call to change the appointment. The data collection for Phase Two of the study was conducted over a five-month period starting in August 2006.

The purpose of the assessment and process were communicated to the parents. They were requested to sign a consent form before proceeding with the assessment. The hospital clerical officer signed as a witness. Child assent, if possible, was obtained before proceeding with the Communication Assessment Protocol. The speech-language therapist and audiologist who would conduct the assessment made the child comfortable and established rapport prior to conducting the assessment. Firstly, the speech-language therapist and audiologist conducting the assessment noted the essential background information and relevant details from the questionnaire completed during Phase One of the study and then proceeded with the communication assessment.

The sequence of areas of assessment for children in Group 1 followed was feeding, orofacial examination, general development, communication, speech-language and finally hearing. Feeding assessment was conducted only for children younger than 36 months. Hearing evaluations were carried out at the end, as the children were more comfortable and responsive towards the end rather than beginning of the assessment. All the data pertaining to the various areas of assessment were summarised and reported on the first page of the tracking form (Appendix VI).

Assessments of children in Group 2 were conducted in the following sequence: hearing evaluation, orofacial examination, general development, communication speech and language assessment and finally summary of the results. Speech samples were obtained from the children in Group 2 and simultaneous audio and video recordings were made.

The procedure for obtaining the speech sample from children in Group 2 (Appendix VI: Items E26 to E33) was as follows:

- The conversation with the child was recorded and each child was requested to describe a picture (a seaside scene).
- In addition to the elicited speech responses, the Eurocran Speech Project (2000) recommends rote speech and a small amount of spontaneous speech as this makes it possible to detect any major differences between a child's speech in conversation and in controlled speech. Therefore, the children with CL/P were requested to count either 1-5 or 1-10. Counting is a means of eliciting connected speech from very young children (Kummer, 2008: 327).

- The speech-language therapists and audiologists obtained speech samples for recording and analysis by requesting each child to repeat the words and sentences using the speech material prepared in Creole and French. If the child did not respond, a further attempt was made to show the pictures depicting the words to elicit speech.

- The speech-language therapists and audiologists conducting the assessments had checked the appropriate coded items. In each of the sections, B through F of the compiled Communication Assessment Protocol (refer to Appendix VI) boxes are provided for checking the recommendations and or referrals based on the assessments carried out.

After completing the communication assessments, the speech-language therapists and audiologists explained the reasons for making referrals or recommendations to the parents. Children who required regular speech-language therapy sessions were given subsequent follow-up appointments. The speech-language therapists and audiologists checked the tracking form to make sure that all the areas of assessments had been completed. They also noted the time taken to complete the assessment. The principal researcher made a back-up copy of each digital video and audio-recorded speech sample to ensure storage of data for further analysis (inter-rater reliability checks) and as archives for future research.

Perceptual speech analysis of the recorded speech sample of the children from Group 2 was carried out by the speech-language therapist and audiologist who conducted the assessment based on the video and audio recordings immediately after completing the communication assessment. The principal researcher checked the tracking forms for completeness before handing over the forms to the medical statistician in the ministry of health for data entry in Microsoft Excel 2000 and statistical analysis with the SAS programme.

4.8.6 Phase Two data analysis

Descriptive statistics were used for the data analysis (De Vos et al., 2005: 225). The categorical data (cleft type) and the binary data were analysed for percentage or proportions; (Morgan, 2006: 37). The data were presented in a tabular or bar diagram for the discrete frequency counts of the selected variables. Cumulative frequency graphs were used to represent the number of children with CL/P referred for further management to specialists. Qualitative analysis of textual data, for example parental concerns regarding communication, was carried out and described. For the purpose of this study the following items were analyzed as shown in Table 4.13.

TABLE 4.13 Data analysis of Phase Two

Items from data collected (refer to Appendix VI)	Purpose	Descriptive Statistical Procedure
<i>A. Summary sheet</i> A5 Type of cleft and A6 Presence or absence of syndrome/sequence	The demographic information and essential background information concerning the child at a glance the dates of assessment, the professional conducting the assessments and the recommendations.	Frequency counts of children displaying each of these characteristics
<i>B. Feeding assessment</i> Bi) Pre-cleft repair feeding assessment Items B12 to B15 current feeding method. B36 identify risk for poor weight gain	Children younger than 36 months: N= 24 To describe the feeding methods and identify whether the child with CL/P is at risk for poor weight gain.	Description of feeding method Frequency count of children referred to other professionals as at risk of poor weight gain according to type of cleft (Maxwell & Satake, 2006:282).
<i>B ii) Post-surgical feeding assessment</i> Item B 45, B 46, B47 B52	Identify the child with oronasal fistula, nasal regurgitation and feeding difficulties and risk for poor weight gain post-operatively.	Frequency count of children (Maxwell & Satake, 2006: 282).

<p><i>C. Hearing evaluation</i> Item C4 Item C7 Item C8 Item C17 Items C18, C19</p>	<p>N= 80 Past history of ear surgery To determine risk factors for hearing loss. Listening skills of the children To determine the type and degree of H.L. Identify children with hearing loss requiring referral to ENT specialist and or recommendations for hearing aids.</p>	<p>Frequency count Description of the risk factors Frequency count of the children identified with hearing loss. A cross tabulation with listening skills and hearing loss. (Maxwell & Satake, 2006: 282).</p>
<p><i>D. Orofacial examination</i> Items D20, D21, D22 and D23.</p>	<p>N= 80. Identify the contributing factors to speech production errors. Number of children referred for further assessment to dentist, ENT specialists and/or other referrals.</p>	<p>Frequency counts and number of referrals for opinion of other professionals (Maxwell & Satake, 2006:282).</p>
<p><i>E. Communication, speech and language assessment</i> <i>E i) Children younger than 36 months</i> Items E9, E12,</p>	<p>The sample was divided into to age groups N= 24 Identify child with speech-language difficulties and or delay.</p>	<p>None Description of characteristics of the children with CL/P Frequency count of children requiring in-depth assessments and parental guidance.</p>
<p><i>E ii) Children 36- 72 months</i> Items E35</p>	<p>N= 56 To identify children having speech-language difficulties</p>	<p>Frequency count of children requiring regular speech-language therapy (Maxwell & Satake, 2006:282).</p>
<p>Item 34</p>	<p>Identifiable causes of communication, speech and language difficulties</p>	<p>Frequency count according to type cleft (Maxwell & Satake, 2006:282).</p>
<p>Items E26, E27, E28, E31, E32, E33</p>	<p>According to GOS.SP.ASS '98 description of type of resonance problems and cleft speech characteristics identified</p>	<p>Description and discussion of speech and voice production based on perceptual analysis of audio and video recordings of the speech samples. (Sell, 1999)</p>
<p><i>F. General Development</i> Items F9 F10 Item F12.</p>	<p>N= 80. To note number of children attending school To note any parental concerns regarding general development of the child. To determine the need for other team members' assessment.</p>	<p>Frequency count of children attending school. Number of children referred for in depth assessments to other professionals (Leedy & Ormrod, 2005: 257).</p>

4.8.6 Phase Two validity, reliability and trustworthiness

In Phase Two a mixed methods approach (both quantitative and qualitative) to data collection was used. In quantitative research the quality criteria are validity and reliability whereas in qualitative research the quality criteria is trustworthiness (De Vos et al., 2005: 351). Therefore validity, reliability and trustworthiness are discussed.

Validity of the compiled Communication Assessment Instrument was ensured by the following strategies:

- An in-depth literature review was carried out to identify important areas of communication for young children with CL/P, 0-72 months. A measurement instrument has high content validity if its items reflect the various parts of the content domain and the particular behaviours and skills that are central to the domain (Leedy & Ormrod, 2005: 92). Moreover, the Communication Assessment Protocol was compiled from existing protocols that are used in established centres of speech-language therapy and audiology such as University of Pretoria (South Africa) and the Great Ormond Street Children's Hospital (UK) for communication assessment of children with CL/P.
- Speech assessment material for children in age group 36-72 months in the Mauritian Creole language was included in the instrument for measurement of speech sample. Eurocran (2000) guidelines on preparation of speech material for children with CL/P were followed. On the basis of the judgment of the experts (refer section 4.8.3.2) and opinions of the participants namely the speech-language therapists and audiologists who carried out the assessments, content validity was ensured (De Vos et al., 2005: 161; Leedy & Ormrod, 2005: 93).

- External validity was ensured by providing detailed descriptions of the clinical context of management of children with CL/P within the public health sector and the setting where the Communication Assessment Protocol was administered (Morgan et al., 2006: 50).

Reliability: The principal researcher and three other speech-language therapists and audiologists were the observers and data gatherers. The following steps were taken to ensure accuracy and consistency of measurements (De Vos et al., 2005: 162; Leedy & Ormrod, 2005: 29).

- A pilot study was conducted prior to proceeding with the main study to improve the reliability of the measure (Neuman, 2000: 166).

- The data gathered by the speech-language therapists and audiologists was in a uniform manner using the same Communication Assessment Protocol. Administration of the test in a consistent way enhances the reliability of the measuring instrument (Leedy & Ormrod, 2005: 93).

- Training of the speech-language therapists and audiologists in completion of the form, particularly the auditory-perception assessment of the cleft type speech characteristics, enhanced uniform assessment procedures and replication.

- Perceptual analysis of the audio and video recording of the speech samples were carried out by the speech-language therapists and audiologists (Sell, 2005: 103-121). Recorded observations minimize interviewer bias; allow for multiple judges and estimation of inter-observer reliability (Sell, 2005: 107). In order to establish inter-observer reliability, the four speech-language therapists independently listened to the audio and video digital recordings of a random selection of eight recordings. The percentage agreement among the four speech-language therapists was calculated for hypernasality, nasal emission and cleft type speech characteristics of the recorded speech samples. The 'trustworthiness' of conducting assessments using the Communication Assessment Protocol is depicted in the following Table 4.14.

TABLE 4.14 Trustworthiness of Phase Two

Trustworthiness	Strategy
<p>Credibility</p> <p>Within the parameters of the setting, population and theoretical framework the research will be valid (De Vos et al., 2005: 346)</p>	<p>The principal researcher has been involved in the care of children with CL/P with the plastic surgeon at Victoria Regional Hospital since 15 years. This prolonged involvement ensured trust between the researcher and the participants. An in-depth description of the setting and participants allows the reader to judge the credibility of this phase of the study.</p> <p>The Communication Assessment Protocol was based on a thorough literature review and consultations with experts; Prof. B. Louw at University of Pretoria and Dr. D. Sell, Lead Speech-language therapist at the Great Ormond Street Hospital, London. The compilation of the Communication Assessment Protocol was based on areas of assessments that had sound theoretical underpinnings and standardized and credible components were incorporated for example the GOS.SP.ASS '98 for perceptual speech assessments. Maxwell & Satake (2006: 129) suggest seeking expert opinion to establish content validity of a measuring instrument.</p> <p>Member checking, consensus of the speech-language therapists and audiologists during data analysis and inferring the results further ensured the credibility (Denzin & Lincoln, 2000: 96)</p>
<p>Transferability</p> <p>Designing a study in which multiple cases, multiple informants are used can strengthen external validity (De Vos et al., 2005: 346)</p>	<p>Detailed description of the children as participants (including demographic information) and systematic description of the research methodology such that any investigator could judge the degree of transferability to set up a communication assessment protocol in another context. The researcher involved other speech-language therapists and audiologists, in the use of the Communication Assessment Protocol throughout the research project to encourage their active participation in the development of the protocol so that they would be more willing to use the protocol in their clinical practice.</p>
<p>Dependability</p> <p>Reliability of the study (De Vos et al., 2005: 346)</p>	<p>Feedback (peer opinion) from the speech-language therapists and audiologists regarding the Communication Assessment Protocol, through questionnaire survey and discussions were strategies incorporated in Phase Two to ensure reliability and dependability of the Communication Assessment Protocol.</p>
<p>Conformability</p> <p>Objectivity of the study (De Vos et al., 2005: 347)</p>	<p>The four speech-language therapists and audiologists; working in the public health sector of Mauritius, conducted administered the Communication Assessment Protocol using the same form and methodology. Inter-observer agreement percentage helped remove researcher bias and enabled data collection procedure that was objective to some extent. A combination of digital audio and video recordings was made for confirming the speech assessment procedures and interpretations by the researcher.</p>

4.9 PHASE THREE

Phase Three was conducted at the end of the study and adopted a mixed sequential methodology approach for data collection and analysis. Both the quantitative and qualitative data was analyzed and interpreted.

4.9.1 Objective of Phase Three

Phase Three was conducted to determine the perceptions of the speech-language therapists and audiologists regarding the acceptability of the Communication assessment Protocol. In Figure 4.9 the steps taken to achieve this objective are illustrated.

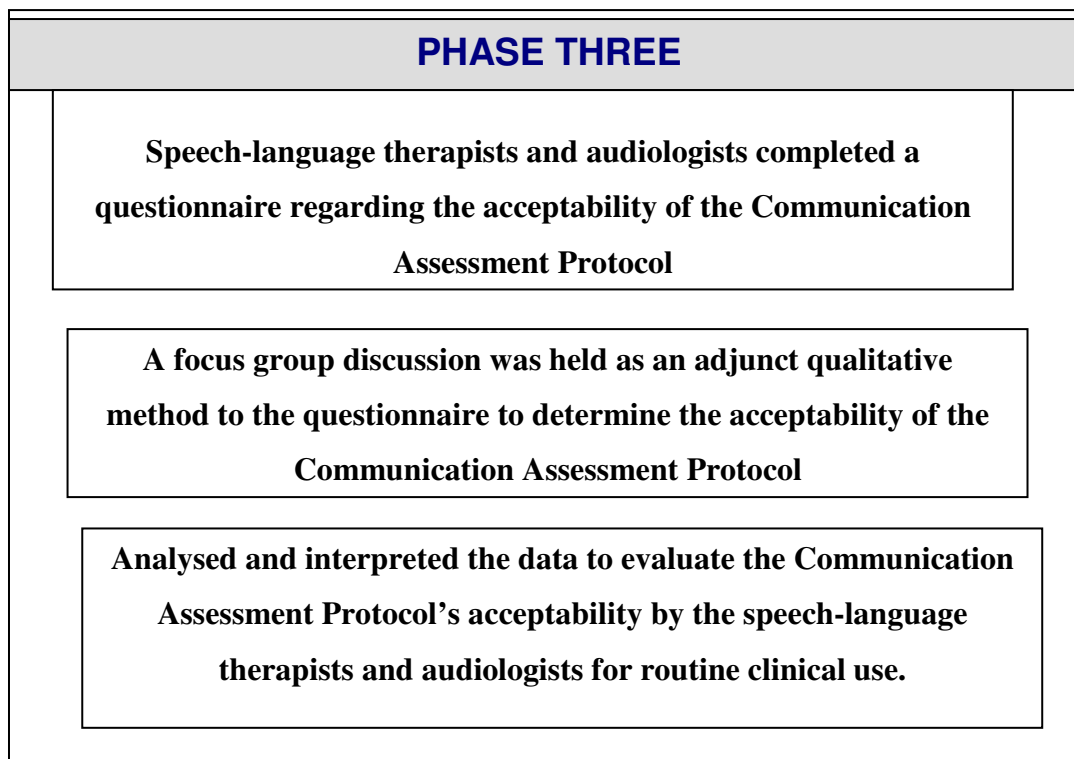


FIGURE 4.9 Steps taken to evaluate the acceptability of the Communication Assessment Protocol

4.9.2 Phase Three participants

The participants of Phase Three are described in this section.

4.9.2.1 Speech-language therapists and audiologists

The speech-language therapists and audiologists who took part in Phases One and Two also participated in Phase Three. They were chosen for determining the clinical acceptability of the protocol because they had gathered the data in the first two phases of the study, were knowledgeable and experienced with regards to the topic of discussion and could provide rich information (Patton, 1990: 169; Welman et al., 2005: 202).

4.9.2.2 Additional support staff

The speech and hearing assistant described in section 4.8.2.3 participated in Phase Three to record the focus group session. She previously contributed to Phase Two by carrying out the audio and video recordings of the children's speech while the principal researcher conducted the assessments. She was selected for Phase Three to share her experiences of the recordings.

A facilitator for the focus group discussion was selected, to limit the principal researcher's bias (Creswell, 2003: 189), on the basis of following criteria:

- *Employment context*: The facilitator was required to be employed by the public health sector, so that he/she is familiar with the clinical service delivery system of the health sector in Mauritius.

- *Experience*: The facilitator should have experience in holding focus group sessions and adequate knowledge of the topic (De Vos et al., 2005: 307; Krueger, 2007). For this study the facilitator was required to be aware of the methodology employed in developing the Communication Assessment Protocol to facilitate the discussions.

- *Language*: The preferred language for the focus group session was English as the speech-language therapists and audiologists communicate amongst themselves in English. It was therefore necessary that the facilitator is fluent in English to conduct the focus group interview.

- *Gender*: The participants must feel comfortable with the facilitator. As the participants of the focus group discussion were female a facilitator of the same gender was deemed to be appropriate (De Vos et al., 2005: 307).

A female medical practitioner, employed as a training officer at the Mauritius Institute of Health since 1992, met all the above criteria and agreed to act as the facilitator.

4.9.3 Phase Three materials and apparatus

4.9.3.1 Data collection instrument: Questionnaire

A questionnaire was developed to determine the perceptions of the speech-language therapists and audiologists regarding the Communication Assessment Protocol based on that of Streicher (2005: 38). The questionnaire (section 4.8.3.3 and Appendix VIII) consisted of two sections; section I for the preliminary evaluation of the Communication Assessment Protocol and section II for clinical applicability and acceptability. Section I was administered during Phase Two, prior to the conduction of the Communication Assessment Protocol and was described with results in section 4.8.3.3.

Section II of the questionnaire was completed by the participants *after* conducting the communication assessments on children with CL/P (section 4.8). The aim was to determine perceptions of the participants regarding the clinical applicability and acceptability of the Communication Assessment Protocol. Both closed-ended and open-ended questions were used

in the self-administered questionnaire in a check-list format to determine the perceptions of the speech-language therapists and audiologists (refer to Appendix VIII, Section II). Closed questions were asked to help the speech-language therapists and audiologists answer the questions within the same framework and response choices clarified the responses (De Vos et al., 2005: 175). Closed questions offer an easier analysis and statistical processing of the data (De Vos et al., 2005: 175). However, to determine what the speech-language therapists and audiologists' perceptions were, open-ended questions were used to encourage the participants to express their opinions and views freely (Babbie, 2001: 240; Neuman, 2000: 261).

TABLE 4.15 Section II: Contents of questionnaire to determine the clinical applicability of the Communication Assessment Protocol

SECTION II Question and sub-questions	Contents of the questionnaire
1	Experience in applying the protocol based on the number of children with CL/P that the therapist as participant researcher assessed using the communication assessment protocol.
2	Experiences regarding administration of the Communication Assessment Protocol
3	Perceptions regarding the rating scale of resonance and description of the cleft type speech characteristics when conducting the communication assessments on children with CL/P in group 2 (36-72 months).
4	Experiences regarding compliance of children with CL/P during the assessment.
5	Opinion regarding intervention goals and referrals based on the Communication Assessment Protocol.
6	Experiences regarding the practical application of the Communication Assessment Protocol in the hospital context.
7	Open-ended question for comments and recommendations of the speech-language therapists and audiologists

4.9.3.2 Focus group topic guide

A focus group discussion was held after administration of the questionnaire to collect additional data (Stewart & Shamdasani, 1990: 15). The facilitator was provided with the topic guide and the Communication Assessment Protocol so that she understood the intent of the questions (Stewart & Shamdasani, 1990: 61).

Three main topics to conduct an in-depth exploration of the views of the participants regarding the acceptability of the Communication Assessment Protocol were identified. A topic guide was prepared to ensure that the focus is the research problem and most of the questions related to it are discussed during the focus group session (Bloor et al., 2001: 43; Leedy & Ormrod, 2005: 147; Stewart & Shamdasani, 1990: 60). The discussion started with general topics and gradually dealt with more specific topics pertaining to the acceptability of the Communication Assessment Protocol.

Topic One: An overview

The aim of introducing topic one was to obtain participants' holistic views of the acceptability of the Communication Assessment Protocol. The suggested trigger question in the topic guide was: What are your opinions and views regarding the Communication Assessment Protocol?

Topic Two: Specific details: Contents of the protocol and the practicalities of conducting the assessments

The aim of topic two was to obtain the participants' views regarding assessment, training and practicalities of conducting the assessment.

The suggested trigger questions were:

- What did you think about the training provided in administration of the communication assessment protocol?
- Would you like to share your experiences?
- Your comments regarding the materials provided: for example the speech elicitation materials, the pictures to elicit speech responses from the children.
- Would you like to comment on the apparatus that was used for hearing evaluations and for making the audio and video recordings?
- Please comment on your experiences when analyzing the speech of children in group 2 (36-72 months). What did you think about the recordings during play back for analysis?

Topic Three: Implementation of the Communication Assessment Protocol

The aim of topic three was to gather views regarding clinical implementation of the protocol.

The suggested trigger questions were:

- What do you think about the clinical applicability of the communication assessment protocol? Could you base your intervention goals on the Communication Assessment Protocol?
- Could you identify the possible etiological factors and make referrals on the basis of the assessments conducted? Do you think that you will use the Communication Assessment Protocol in the future?

The sequence of the topics and trigger questions were planned to focus the discussions in such a way that the data analysis and interpretations would enable the principal researcher to conclude whether the Communication Assessment Protocol was acceptable for clinical use to the speech-language therapists and audiologists.

4.9.3.3 Apparatus

The video and audio recording apparatus (described in Table 4.7) was used to record the focus group discussion. Three DVD-RW discs (30 minutes each) were used for video recording. One recordable audio mini disc (80 minutes) and an external multidirectional microphone were the accessories that were used for high fidelity recordings.

4.9.4 Phase Three data collection procedure

The data collection procedures of Phase Three included a self administered questionnaire that was completed by the speech-language therapists and audiologists. The last phase of the participatory action research was their participation in a focus group discussion.

4.9.4.1 Self-administered questionnaire

The principal researcher individually contacted each speech-language therapist and audiologist and handed over section II of the questionnaire for completion. Participants were requested to complete the questionnaire one week before the scheduled date of the focus group interview so that they could express their unbiased opinion individually. The principal researcher collected the completed questionnaires from the three speech-language therapists and audiologists and analyzed the responses.

The topics selected for the focus group discussion were based on the results of the questionnaires.

4.9.4.2 Focus group discussion

The *objectives* of the focus group discussion were:

- To supplement and enrich the interpretation of responses from the speech-language therapists and audiologists (Bloor et al., 2001: 9).
- To generate collective views of the participants. Babbie (2001: 294) suggests that group dynamics bring out aspects of the topic that the researcher may not have anticipated.

The small number of participants meant that each participant was able to express her views fully. The potential risk of a small group is cancellation if even one or two participants fail to turn up (Bloor et al., 2001: 26-27). To ensure attendance of all the participants the venue, date and time of the focus group was planned in consultation with the participants.

The venue selected was the Mauritius Institute of Health (MIH) as the required facilities; a comfortable quiet room free from any interruptions, table and chairs to accommodate six persons are provided. Also the MIH is conveniently situated close to the Speech Therapy and Audiology unit at the north region hospital the SSRNH. In addition the facilitator works at the MIH. The participants agreed that MIH was a suitable and accessible venue. Transport facilities were offered to them to reach the venue.

The duration of the focus group discussion was 90 minutes as recommended in the literature for a focus group discussion (De Vos et al., 2005: 309; Leedy & Ormrod, 2005: 146). The principal researcher confirmed the focus group interview one week before with each of the participants and made follow-up phone call to every participant the day before the scheduled date (De Vos et al., 2005: 305).

The facilitator and the principal researcher welcomed the participants and refreshments were served. Rapport was quickly established (Leedy & Ormrod, 2005: 147) as the speech-language therapists knew each other and shared similar professional experiences.

The facilitator introduced herself and instructed the participants of the ground rules of the focus group session. The beginning of a group session sets the tone and agenda for all that follows (Stewart & Shamdasani, 1990: 92). The language in which the participants usually communicate amongst themselves is English, therefore the group agreed to converse in English. Consent was obtained from the participants to video and audio record the proceedings. The non-verbal cues are invaluable in the data analysis of focus group interview (Stewart & Shamdasani, 1990: 16). When recordings are made it is customary to acknowledge its presence while assuring group members that the recording will remain confidential and that its circulation will be limited (Stewart & Shamdasani, 1990: 92). The audio recording was made to facilitate writing the transcript for analysis (Bloor et al., 2001: 41-42). The speech-language therapists and audiologists gave their consent to the video recordings (refer to video recording of focus group discussion attached to back cover). The facilitator opened the discussion for the themes prepared and encouraged each participant to express their views. The speech and hearing assistant video recorded the focus group discussion. The assistant helped with the video and audio recordings of the children's speech recordings during Phase Two; therefore, she participated in the discussion to express her experiences as an assistant. During the session, the principal researcher made descriptive notes of the focus group discussion and was a silent observer participant so as to avoid any form of bias (Creswell, 2003: 189).

The facilitator gave short summaries of each topic discussed and member checks were made to clarify the perceptions expressed by the participants by asking the members if they agreed, disagreed or would like to bring up other issues related to the clinical application of the Communication Assessment Protocol. This procedure was followed to enhance trustworthiness.

After completion of the focus group interview the facilitator and principal researcher thanked the participants for their time and contributions. The focus group participants were then provided with lunch.

Data collected in Phase Three was a combination of the questionnaire and the focus group discussion. According to Bloor et al. (2001: 17-18) data on same topic collected by different tools deepens and enriches the understanding of the subject.

4.9.5 Phase Three data analysis

The data were analyzed to determine the acceptability of the Communication Assessment Protocol by the speech-language therapists and audiologists. Both quantitative and qualitative data analysis was used during Phase Three.

There were three respondents to section II of the questionnaire; therefore description of their responses in a tabular form was more appropriate than using descriptive statistics or factor analysis. The responses to both closed and open-ended questions were analyzed qualitatively.

Content analysis of participants' viewpoints and emerging themes (Maxwell & Satake, 2006: 262) formed the basis for the topic guide for the focus group discussion.

Supplementary information concerning applicability and acceptability of the Communication Assessment Protocol gathered by holding the focus group discussion was transcribed in detail by an independent rater using the audio recordings (Bloor et al., 2001: 59). The principal researcher studied the data in detail by reviewing the video recordings and listening to the audio recordings in addition to reading the transcripts to carry out content analysis. The content of the focus group discussion was unstructured and needed to be converted into specific units of information that were analyzed by the researcher (Stewart & Shamdasani, 1990: 108). The data were converted to manageable form by indexing manually and bringing under one heading all data relating to a particular theme (Bloor et al., 2001: 72). The principal researcher viewed the video recording, listened to the tapes and reviewed the transcripts of the focus group discussion. Key phrases and words were highlighted by the principal researcher in the transcript to be used as direct quotes when interpreting the findings of the focus group session. Perspectives of the participants were analyzed and shaped into a general description, as in a phenomenological approach (Creswell, 2003: 194). The transcript of the focus group discussion is included as Appendix IX and the recordings are also available for verification. The interpretation of the text data from the focus group discussion is presented in the chapter on results and discussion.

4.9.6 Phase Three validity, reliability and trustworthiness

A quantitative research method was employed during the self-administered questionnaire. Validity of the data collection tool namely the questionnaire for the speech-language therapists and audiologists was ensured by preparing section II of the questionnaire (Appendix VIII) specifically according to the objective of Phase Three. The questionnaire was based on Streicher's (2005) previously tested questionnaire. The study targeted a very specific population of speech-language therapists and audiologists in the public health sector of Mauritius.

The reliability of a study as stated during Phase Two refers to the consistency with which the measuring instrument yields a certain result (Leedy & Ormrod, 2005: 29). The questionnaire provided concise and simple instructions and the questions were straightforward to obtain the perceptions of the therapists. The method of triangulation was employed whereby the speech-language therapists and audiologists responded to the questionnaire after conducting assessments on children with CL/P. They subsequently participated in a focus group discussion to express and discuss their views.

The following strategies depicted in Table 4.16 were applied to account for the trustworthiness of the data from Phase Three.

TABLE 4.16 Trustworthiness of Phase Three

Trustworthiness	Strategy
<p>Credibility</p> <p>(De Vos et al., 2005: 346)</p>	<p>Multi method triangulation: namely questionnaire survey and focus group discussion (Leedy & Ormrod, 2005: 99) was applied during data collection to evaluate the acceptability of the Communication Assessment Protocol</p> <p>During the focus group discussion, video and audio recordings were made (Stewart & Shamdasani, 1990: 16). A transcript of the audio recording was also made.</p> <p>A facilitator was used to limit any biases by the principal researcher (Stewart & Shamdasani, 1990: 17).</p> <p>Member checking by the facilitator after discussion of each topic for clarifications further ensured the credibility, as data was not open to misinterpretations.</p> <p>An in depth description of the setting and participants for the focus group session was provided so that the reader can judge the credibility of this phase of the study (Creswell, 2001: 196).</p>
<p>Transferability</p> <p>(De Vos et al., 2005: 346)</p>	<p>Systematic description of Phase Three to evaluate the acceptability of the Communication Assessment Protocol was provided such that any investigator could judge the degree of transferability to another context. The researcher involved all speech-language therapists and audiologists, in the evaluation process. They had conducted assessments on children with CL/P. They were also the end users of the Communication Assessment Protocol. Their opinions and views individually and as a group formed the basis for determining the acceptability of the protocol.</p>
<p>Dependability</p> <p>(De Vos et al., 2005: 346)</p>	<p>The concept of replication was problematic during this phase as the four speech therapists and audiologists assessed many children with CL/P. However, they participated in the evaluation of the Communication Assessment Protocol by sharing their experiences, to corroborate, elaborate and illuminate the research topic (De Vos et al., 2005: 311)</p>
<p>Confirmability</p> <p>De Vos et al., 2005: 347)</p>	<p>The four speech-language therapists and audiologists; working in the public health sector of Mauritius, conducted the Communication Assessment Protocol using the same form and methodology.</p> <p>A combination of digital audio and video recordings was made for confirming the views expressed by the participants.</p>

4.10 CONCLUSION

The research addressed the development of a Communication Assessment Protocol for young children with CL/P that is relevant to the clinical work conducted by speech-language therapists and audiologists in the Mauritian context. The description of the children with CL/P showed that the study sample was representative of the different types of cleft and included children with syndromes. Researchers are cautioned against combining these two groups due to their inherent differences. However, the aim of the compilation of the Communication Assessment Protocol was to provide a generic assessment tool that needs to accommodate all children with CL/P. The background information of each child that was gathered assisted in the compilation of a database for children with CL/P. Furthermore the description of characteristics of the children with CL/P in Mauritius, guided the development of a functional and authentic Communication Assessment Protocol. The participation of the speech-language therapists and audiologists, their training in the tool's administration, and the clinical experience of conducting the assessments according to the protocol contributed to the evaluation of the protocol's applicability and acceptability.

4.11 SUMMARY

The main aim and objectives of the research were described and the rationale for selection of mixed methods approach was provided. The ethical principles for conducting research were addressed and applied from the beginning of the research.

The empirical research was conducted in three sequential phases. Phase One provided data that described characteristics of the children with CL/P and were the underpinnings for initiating of a database and the development of the Communication Assessment Protocol. The second phase was descriptive. The steps taken to compile the protocol, the pilot study conducted, the data collected and analysed were described in detail. The speech-language therapists and audiologists in Mauritius participated throughout the research process and in Phase Three, they participated to discuss the clinical applicability and acceptability of the protocol.

CHAPTER 5:

RESULTS AND DISCUSSION

The aim of this chapter is to present and discuss the results of the evaluation of the clinical applicability and acceptability of the newly developed Communication Assessment Protocol in Mauritius.

5.1 INTRODUCTION

Research requires collection and interpretation of data in an attempt to resolve a problem (Leedy & Ormrod, 2005: 5). The development of a new tool is dependent on what is available in the context (Denzin & Lincoln, 2000: 4). This is particularly relevant in a developing country where resources for the development of a new tool are limited. In Mauritius, a need for the research was identified to bridge the gap between current practice of cleft care and the best practice model. The main aim of the research was to develop a Communication Assessment Protocol for young children with cleft lip and/or palate (CL/P) that was applicable for routine clinical practice and acceptable to speech-language therapists and audiologists for ECI and improvement of cleft care. In this chapter, the results of descriptive and qualitative studies conducted to achieve the aim are presented.

The results are presented as illustrated in Figure 5.1



Background information

Background information of children with CL/P in Mauritius
Family characteristics and home language/s of the children in the sample
Parental perceptions of feeding, hearing & speech problems

THE COMMUNICATION ASSESSMENT PROTOCOL

COMMUNICATION ASSESSMENTS

of the children with CL/P in the sample

Descriptions of:

Feeding methods
Hearing and listening
Communication, speech, language, emergent literacy skills and development of the children

CLINICAL APPLICABILITY

Success in the identification of children with communication delays/disorders & referrals or recommendations

Reliability of the perceptual speech assessment

CLINICAL ACCEPTABILITY

Perceptions of the speech-language therapists and audiologists

Quantitative and qualitative analysis of data

FIGURE 5.1 Schematic overview of the presentation of the results

5.2 BACKGROUND INFORMATION

The results in this section depict the context in which the Communication Assessment Protocol was implemented. Involvement of the affected child's parents and family is crucial to successful ECI (Blackman, 1995: 63; Guralnick, 1997: 3; Rossetti, 2001: 94). Therefore a description of family characteristics, particularly the language(s) spoken at home, and parental perceptions of feeding, hearing and speech problems in their child with CL/P is provided.

5.2.1 Background information of the children with CL/P in the sample

Descriptive characteristics of the children with CL/P were collated from interview schedules (Appendix V), clinical observations and medical case-records. These included maternal history, birth history, surgical history and the services accessible to the children with CL/P. The parental responses were analysed quantitatively and the results are described and discussed in this section.

- *Maternal history*

The relevant maternal history is shown in Table 5.1.

TABLE 5.1 Maternal histories of children with CL/P (n=80)

Characteristic	Category	Percentage of mothers
Significant maternal antenatal history; examples: maternal history of convulsions, miscarriages, anaemic mothers	• Yes	25%
	• No	75%
Type of delivery	• Normal	63%
	• Caesarean	37%
	• Other (forceps)	0%
Maternal age	• Younger than 20 years	8.5%
	• 20-40 years	86%
	• Older than 40 years	5.5%

The age of most mothers of the children with CL/P was between 20-40 years. The national statistics, showed that only 1.8% of the mothers were older than 40 years at the time of birth of their first child (National Maternal Health Statistics, Mauritius: 2000-2006) as compared to those participating in this study where this percentage was three times higher. The risk of CL/P increases with an increase in maternal age (Cooper, Stone, Hu, Melnick & Marazita, 1999: 278; Forrester & Merz, 2004: 625; Vallino-Napoli et al., 2004: 189; Wyszynski, 2002: 44). In addition to maternal age, various external and environmental factors during pregnancy such as alcohol intake have also been linked with an increase in risk of a child with CL/P (Shaw, 2004: 246; Watson et al., 2001: 90). The other risk factors for cleft, in Mauritius, were not in the scope of this study.

- ***Birth History***

Information obtained from the parents regarding the birth place of the children in this study, revealed that almost all births (99%) occurred under the supervision of skilled medical care either in hospitals or private health care facilities. This probably contributed to an early identification of the cleft condition which makes early intervention possible. Information about the birth weight was obtained from the health card of the children with CL/P. The average birth weight of the children with CL/P was 2.8 kg. However, seven children (9%) had very low birth weight (less than 1.5 kg) and five of them were also diagnosed with a syndrome. Low birth weight is an important risk factor for craniofacial anomalies including CL/P (Kritzinger, 2000: 239).

- ***Age of identification of the cleft***

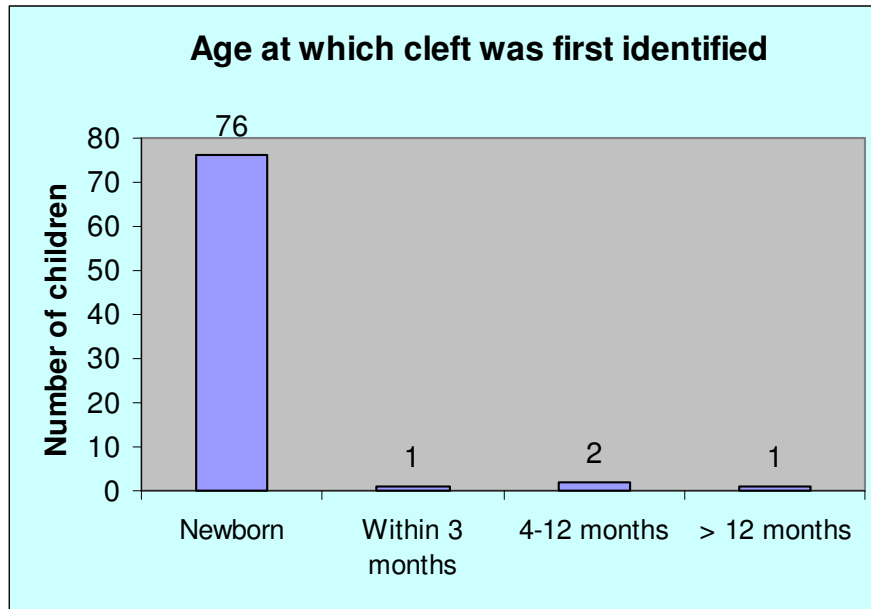


FIGURE 5.2 Ages of the children when the cleft was first identified (n=80)

Except for one child, with a submucous cleft palate, all other children's clefts were diagnosed before the age of one year. The diagnosis of a submucous cleft palate requires specific instrumentation and techniques such as nasal endoscopy (Peterson-Falzone et al., 2010: 23).

In none of the children, the CL/P was diagnosed antenatally although diagnosis during this period is possible by using imaging techniques such as ultrasonography (Watson et al., 2001: 107). In Mauritius, despite the availability of ultrasound facilities, it has not been used for prenatal diagnosis of CL/P. Prenatal diagnosis of CL/P may help parents to prepare themselves emotionally and to come to terms with the need for surgery after birth of the child (Watson et al., 2001: 115). However, Ter Poorten and Louw (2002: 66) reported that there was no great difference in the emotions expressed by mothers with pre- or post-natal diagnosis of the cleft condition as long as the information was conveyed by a caring professional.

The above results suggest that favourable conditions exist in Mauritius for the initiation of early interventions in accordance with best practice guidelines (ACPA, 2007).

- *Surgical history*

Information regarding the cleft repair was obtained from reviewing the surgical case records, plastic surgeon treating the children and parents of the children. The plastic surgeon in Mauritius (personal communication) mainly uses the Tennison's technique (Peterson-Falzone et al., 2010: 146; Watson et al., 2001: 165; Wyszynski, 2002: 326) to repair the lip and the Veau technique (Peterson-Falzone et al., 2010: 154) to repair the cleft palate. Palate repair is performed in one stage but in cases with a wide and complete cleft palate the repair is performed in two stages; the lip and soft palate are repaired first and at a later stage the hard palate is repaired. Alveolar grafts are planned for children with maxillary arch problems by the plastic surgeon after the age of six years when the secondary dentition appears. A summary of the surgical history of the children with CL/P in this study is provided in Table 5.2.

TABLE 5.2 Surgical histories of the children with CL/P (n=80)

Surgical History	Category	No. of Children	Percentage	
Number of times a child has been operated	• None	17	21%	
	• Once	33	41%	
	• Twice	17	21%	
	• Thrice	7	9%	
	• More than three times	5	6%	
	• Missing data	1	2%	
Repair of : Lip (primary repair)	Age range: 1-24 months Mean age: 6.8 months Median age: 5 months SD: 4.9	43	-	
	Palate (primary repair) Age range 5-36 months Mean age: 15.4 months Median age: 12 months SD: 7.7	Lip and palate repairs	17	-
		Lip, palate and secondary repairs	5	-
		Missing data	1	-
		Other than cleft repair surgeries	13	-
Other than cleft repair surgeries	• Insertion of grommets in the ears	3	-	
	• Cardiac surgery	4	-	
	• Other (for congenital anomalies)			

A total of 63 children had surgical repair of CL/P and the remaining were still on a surgical waiting list at the time of data collection. Complete details of the surgical repair were available for all children except one. The median ages of children for cleft lip repair were 5 months and for cleft palate were 12 months. All children were operated by the same plastic surgeon and the repairs were performed either in one stage or two stages. Twenty-nine children were operated more than once; the secondary surgeries were performed to repair a break down in the operated palate and repair of the alveolus area in children with wide clefts. Although the plastic surgeon aimed at repairing the cleft lip by the age of three months and the palate before the age of six months, the cleft palate repair was carried out at an average of 12 months in the cohort of children studied. In some cases delay in the cleft repair, was due to availability of only one

plastic surgeon. In few other cases, the delay was due to poor general health of the child, and upper respiratory tract infections that placed the child with CL/P at high risk of anaesthesia complications.

The recommended timing of surgery for primary repair of palate to achieve the best possible speech is at six months before the onset of canonical babbling (Watson et al., 2001: 159). Late repair is associated with delayed speech development and severe articulation errors (Peterson-Falzone et al., 2006: 7). Nevertheless, a child's general health and width of cleft palate may not permit early repair in some children. In these children repair, even at the age of 12 to 18 months, can still achieve good speech (Bzoch, 2004: 327). Secondary surgery at a later age is required in up to 41% of the children with CL/P to eliminate signs of cleft type speech associated with velopharyngeal inadequacy (Haapanen & Rantala, 1992: 71; Ysunza et al., 1998: 675). The current practice by the plastic surgeon in Mauritius is to follow the one-stage approach except in children with a wide and complete cleft palate.

While the recommended timing of primary repair of palate is between 6 and 18 months the preferred time of cleft lip repair is between one and three months to achieve the best speech outcome (ACPA, 2004: 14, Kernahan et al., 1990: 33). However, the majority of surgeons prefer to wait until the child is three to six months to repair the lip (Peterson-Falzone et al., 2010: 144; Watson et al., 2001: 161). This is to allow time for the pre-surgical oral orthopaedics alignment of the alveolar arch. In Mauritius, the pre-surgical orthopaedics alignment for cleft lip is not performed by orthodontists. Currently they are not trained in the management of orthodontic problems in infants and toddlers with CL/P. This can have a negative impact on the appearance outcomes in children with CL/P in Mauritius. Interestingly, the primary cleft repair of lip (5

months) and palate (12 months) in Mauritius were still found to be in accordance with the recommended timing of cleft repair, even though later than the surgeon intended (Table 5.2).

- ***Health care professionals involved in cleft care***

Information regarding the health professionals involved in the care of these children were obtained from the parents (refer to Appendix V, Section G).

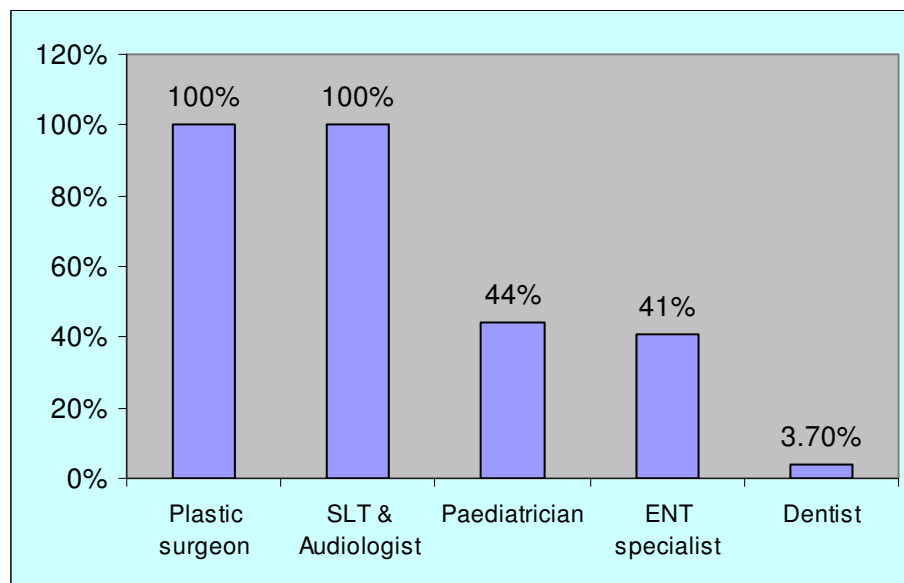


FIGURE 5.3 Consultations of the children with CL/P with health care professionals (n=80)

In Mauritius, the plastic surgeon referred all children with CL/P to the speech-language therapists and audiologists. This is attributed to the fact that a speech-language therapist and audiologist and the plastic surgeon see children referred with CL/P simultaneously in the clinic. This practice was established in 1984 when the principal researcher of this study started the speech-language therapy and audiology services in Mauritius. However, other professionals needed for a cleft care team, namely an orthodontist, ENT specialist, paediatrician, nutritionist

and psychologist, are not located in the same health centre in Mauritius. This may be one of the reasons for not establishing a coordinated multidisciplinary team-based approach for cleft care, in Mauritius.

In this study, only 44% of the children were seen by the paediatricians. In a well-established multidisciplinary team, paediatricians play a pivotal role in the care and management of children. Their main role is to identify associated medical and psychosocial problems; syndromes associated with CL/P and provide nutritional assessments (Kernahan et al., 1990: 28; Watson et al., 2001: 123). This requires attention in Mauritius, as less than half the number of children in the sample had follow-up appointments with paediatricians.

The study also revealed that only 41% of the children had consultations with an ENT specialist. Children with CL/P have a high incidence of hearing loss and middle ear infections. Prior to primary palatal surgery, middle ear problems such as otitis media are universal (Broen et al., 1996: 132; Bzoch, 2004: 337). In young children even a mild and fluctuating hearing loss as a result of otitis media has a detrimental effect on development of communication skills (Friel-Patti & Finitzo, 1990: 192; Kemker & Antonelli, 2004: 361). In Mauritius, it is therefore important that the hearing of all children with CL/P is monitored and managed by ENT specialists in collaboration with audiologists.

In addition to the services of paediatricians and ENT specialist, children with CL/P also require the services of dentists. In this study only three children were seen by a dentist as compared to the U.K., where 91% children with CL/P were registered with a dentist (McDonagh, Pinson & Shaw, 2000: 432). Furthermore, none of the children with CL/P in this study were examined by

an orthodontist as the latter, in Mauritius, only intervenes after the appearance of secondary dentition of the children with CL/P. None of the children had any consultations with other specialists such as a nutritionist, psychologist, or community health worker. Although few of these specialists are available in Mauritius, they need to be involved in interdisciplinary team cleft care.

The results show that in Mauritius, despite the availability of most of the specialists required for cleft care, a coordinated multidisciplinary team-based approach to assessment and treatment is lacking. Nevertheless some positive aspects of cleft care in Mauritius are: early identification of the children, timely surgery and availability of key professionals for cleft care, namely plastic surgeon, speech-language therapists and audiologists, ENT specialists, paediatricians, nutritionists, dentists and psychologists. It is important to set up an interdisciplinary team so that children with CL/P and their families can benefit from organised, well-coordinated and comprehensive approach to cleft care (ACPA, 2007: 5; CSAG, 1998: 30; WHO, 2002: 143). Quality improvement in cleft care is the outcome of a holistic approach to the children with CL/P and their families that takes account of growth, function and appearance of the child with CL/P (ACPA, 2007: 6).

5.2.2 Family characteristics and home languages of the children

Parents of 88% of the children with CL/P were living together. While the father was the only working member in most of the families interviewed, both parents worked in 28% of the families and only two children's neither parent was employed. The family characteristics were further

analysed according to size, number of siblings, history of consanguinity, family history of CL/P, and the languages spoken at home.

Data on the family size of children with CL/P revealed that a maximum of two children per family was the norm in this study. The average number of children per family in Mauritius is 1.87 (Central Statistics Bureau of Mauritius, 2005). The above findings show that the majority of children with CL/P were from stable and small-sized family with both parents living together, educated (refer to Figure 4.7), and mothers staying at home to care for the children.

Children born with CL/P are at risk for communication disorders and any additional family stressors are likely to compromise the effectiveness of early intervention. If family characteristics constitute stressors such as extremely limited financial resources, marital difficulties then family patterns of interaction may not be optimal for a child's development (Guralnick, 1997: 6). Therefore, it is necessary to view the child in the family context and it is important for the health team to be familiar with the profile of the families and their situations (Bagnato et al., 1997: 11; Guralnick, 1997: 6; McLean, Wolery & Bailey, 2004: 19; WHO, 2000: 42).

Information regarding consanguinity was sought and the responses indicated that only 2 out of the 80 children's parents were in a consanguineous marriage. There is a positive correlation between incidence of a cleft and consanguinity as shown in a study from Iran which showed that consanguineous marriages were more frequent among parents who had a child with CL/P (Jamilian, Naveri & Babavan, 2007: 176; Watson et al., 2001: 88). Clearly in Mauritius,

consanguinity is not an etiological factor for CL/P. Interestingly, 21% (n=17) of the children had a family history of CL/P. Three mothers had CL/P and five children had siblings with CL/P but none of the children were twins. It is reported that for monozygotic twins (identical twins) the likelihood of both children being affected with CL/P is 35% (Watson et al., 2001: 88). For one child, the grandparent had a cleft and for the remaining eight children, cleft was also reported for an aunt or uncle. The estimation of recurrence risks for cleft in a child with family history of CL/P requires a highly trained geneticist to conduct physical examination, of an index case together with detailed prenatal, birth history and investigations such as imaging to determine the risk factors in an individual case. As the services of a geneticist in the public health sector are presently lacking in Mauritius, parental questions concerning future children being born with CL/P, remain therefore unanswered from a specialist's perspective. However, the plastic surgeon and speech-language therapist and audiologist provide some general information to parents of the children with syndromes.

- *Home languages*

From the interview schedule (Appendix V, section B6) and parental responses, data on the languages spoken in the families studied revealed that two languages were spoken at home (Figure 5.4).

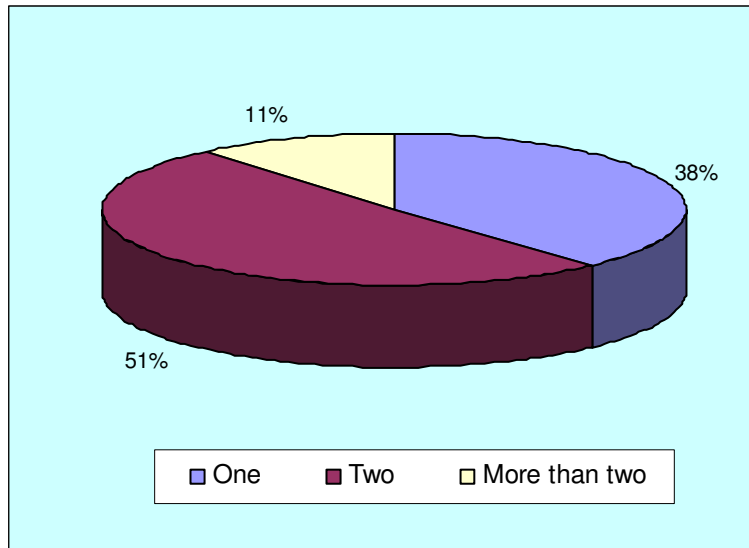


FIGURE 5.4 Number of languages spoken in the children's homes (n=80)

Hoff (2005: 336) points out that globally, exposure to more than one language and bilingualism in childhood may be more prevalent than monolingualism which appears to be the case in the current study as well. One of the basic principles of early communication intervention is that it should be sensitive to a child's linguistic background (Roth & Worthington, 2005: 5). This implies that appropriate standardized and uniform assessment of communication and identification of communication disorders can be a challenging process in young children from a bilingual/multilingual home and pertains to the Mauritian context as well.

Information relating to the most commonly spoken language at home was obtained from the parents and confirmed the predominance of Creole over French (Figure 5.5).

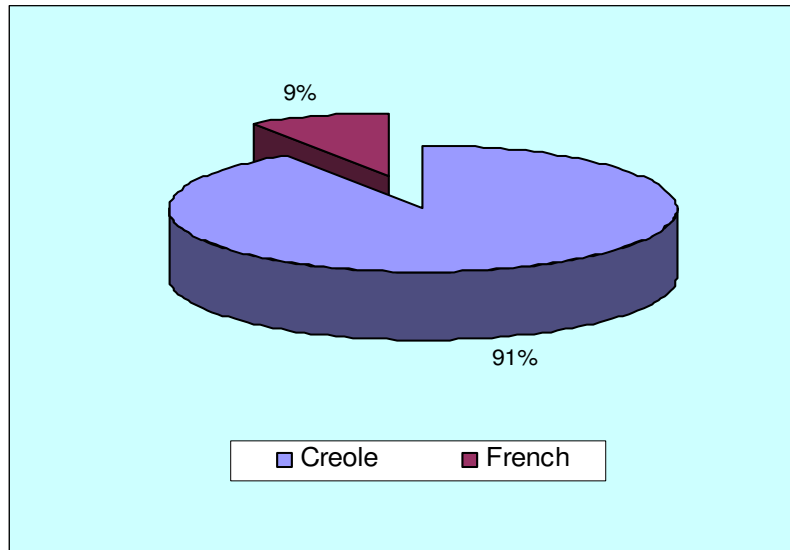


FIGURE 5.5 The most commonly spoken language in the children's homes (n=80)

Only nine families (out of 80) spoke three languages at home: - the third language being English in five of the families, Bhojpuri (a regional language from India) in two and the remaining two spoke Chinese. The challenge posed by using two languages at home may contribute to communication problems of young children with CL/P as these children are already at risk of speech-language delays/disorders. Moreover, hearing impairments are prevalent in this population which may further compromise language development.

Communication assessment of children requires linguistically appropriate assessment materials to be valid and reliable (ACPA, 2007: 6). In Mauritius, the official language is English but the most commonly spoken languages are Creole and French. Thus, speech assessment, in Mauritius, requires a standard list of words and sentences in Creole.

5.2.3 Parental perceptions of feeding, speech and hearing problems in children with CL/P

Parent's opinions regarding feeding, speech and hearing difficulties of their children with CL/P were analyzed (Appendix V, Section F). The number of children perceived to have histories of difficulties in feeding, speech and hearing varied according to cleft type (Figure 5.6).

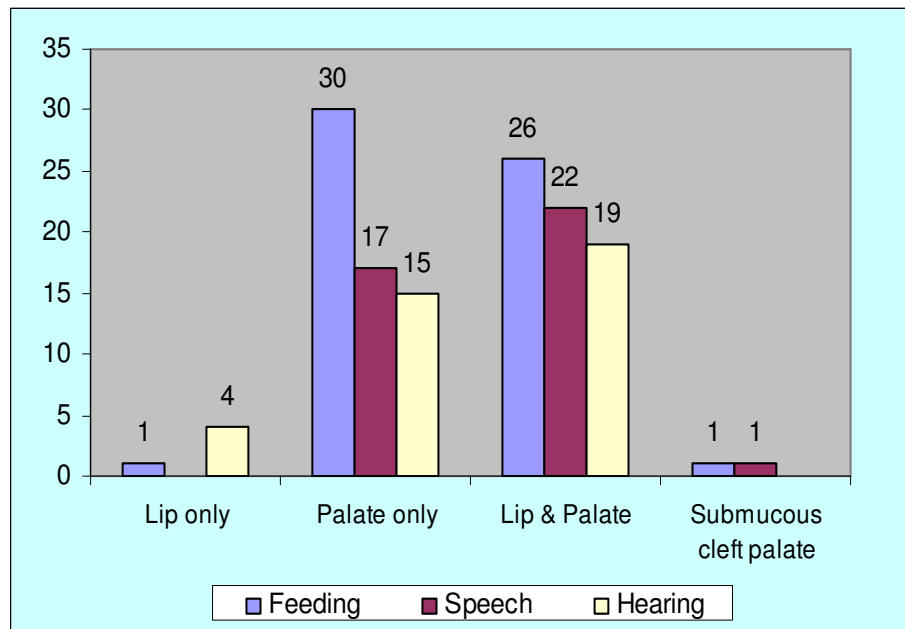


FIGURE 5.6 Feeding, speech and hearing problems among the children: parental reports (n=80)

- **Feeding problems**

Parental responses showed that 73% of the children with CL/P had feeding problems soon after birth. These were partly attributed to the difficulties parents faced in coping with the stress of feeding a child with an oral cleft. A high parental concern regarding feeding during the neonatal period has been reported in the literature (Oliver & Jones, 1997: 529; Young et al., 2001: 57),

and this was confirmed by this study. In addition to the speech-language therapists and audiologists, other professionals namely doctors, nurses, and family members gave them advice regarding feeding. The different types of advice may be confusing because they are not based on any formal, uniform infant feeding assessment. This study demonstrates a need for conducting feeding assessments by speech-language therapists in collaboration with pediatricians and nurses in infants with CL/P before providing appropriate cohesive guidance to the parents.

- ***Hearing problems***

A significant proportion of parents (48%) perceived that their child had hearing problems. Early identification and management of hearing impairments is crucial to communication development. Parents require information concerning their children's hearing abilities (Moss & Fonseca, 2006: 421). Therefore, a detailed hearing evaluation of children with CL/P by an audiologist is mandatory to provide accurate information and guidance to the parents. In developing countries, hearing impairment in children is more often identified by parents than professionals (Zinkin & McConachie, 1995: 108). However, a systematic standard protocol for the surveillance and monitoring of hearing would be beneficial to identify a hearing impairment early and prevent the negative impact of hearing loss on communication development skills.

- ***Speech problems***

Speech problems in children with CL/P were reported by 50% of the parents. Parental concerns are recognized as important indicators for further assessment to identify communication disorders (WHO, 2002: 140). The incidence of speech problems in children with CL/P is variable and depends on the heterogeneity of cleft type, presence of syndrome, hearing loss, and

age group of children (Hardin-Jones et al., 2003: 458; Peterson-Falzone et al., 2010: 231; Shprintzen & Bardach, 1995: 138). Speech-language therapists and audiologists need to be alert to parental concerns about their child's communication skills. It was interesting to note that in Mauritius parents were aware of the speech problems in their young children with CL/P as participation of parents is of prime importance in early intervention. This finding is attributed to the early identification and information received from the health care professionals. This finding indicates that ECI in Mauritius is a feasible option.

Based on this study the first electronic database for young children with CL/P in Mauritius, to record the essential demographic and background information in a uniform and consistent manner, was created. Parental perceptions of feeding, speech and hearing problems in their children demonstrated that they can provide valuable information contributing to communication assessments in young children. Moreover, a description of the identification and the current care provided to these children in Mauritius was necessary to implement the newly developed Communication Assessment Protocol within the existing framework of the health care system.

5.3 CHARACTERISTICS OF THE CHILDREN WITH CLEFT LIP AND/OR PALATE BASED ON THE COMMUNICATION ASSESSMENTS

The implementation of the Communication Assessment Protocol was tested on 80 children with CL/P. The characteristics of children are presented according to the areas of assessment namely feeding, hearing, orofacial features, communication, speech-language, emergent literacy skills and general development (refer to Appendix VI).

5.3.1 Feeding

Feeding problems in newborns and infants mainly occur prior to the closure of the cleft (Reid et al., 2006: 702). Therefore feeding assessment was conducted for children in Group 1 only and findings are illustrated in Table 5.3.

TABLE 5.3 Feeding methods of children in age Group 1 (n=24)

Feeding aspects	Description	Frequency in percentage
Type of milk	Formula milk Breast milk	100% 0
Method	Oral diet (no children currently with naso/orogastric tube feeding)	100%
Equipment	Bottle Cup Syringe Combinations: - cup and bottle - spoon and cup	31% 19% 0 44% 6%
Modifications/special adaptations	Bottle type: standard Texture of teat: - normal - soft - silicon Hole of teat: - normal - enlarged - cross-cut	100% 92% 4% 4% 65% 28% 7%
Observations of feeding	Positioning: appropriate No nasal regurgitation Nasal regurgitation	100% 77% 23%
Oronasal fistulae & Special devices	Oronasal fistula (post primary palate surgery) Obturator	33% 0%

None of the infants with CL/P in this age group were breast-fed or received breast milk despite a national health care policy and breast-feeding campaigns in Mauritius (Ministry of Health & Quality of Life, Mauritius, 2002). All infants in the sample were fed with formula milk. This

differs significantly from normal practice in Mauritius as shown by a recent survey concerning breast-feeding practice in Mauritius (Sunkur, Akaloo, & Ameerbeg, 2002) in which 93% of infants were breast-fed. The same survey carried out by Sunkur et al. (2002) indicated the mean duration of any breast-feeding was 13.6 months and the mean duration of exclusive breast-feeding was two months. The results obtained in this study are not different to those obtained by Kritzinger (2000: 249) in South Africa who found that only one out of 79 children with CL/P was breast-fed. The exact reason for this practice is not known but it is possible that the cleft condition is a deterring factor for mothers not to breast feed the infants because of their worries about sucking abilities of the infant with the cleft. Breastfeeding requires greater skill and sucking endurance than bottle feeding. The feeding difficulties of neonates with CP are a challenge to successful breast feeding. Furthermore mothers of infants with CL/P may not be supported and encouraged by nursing staff, due to lack of knowledge, to attempt feeding breast milk via bottle. Yet, research indicates that breast milk decreases the incidence of otitis media (Paradise, Elster & Tan, 1994: 859) and contributes to normal growth of young children (Smedegaard et al., 2008: 632). The promotion of extracted breast milk to be given to infants with CL/P could therefore be potentially beneficial to them.

The infants in the study were bottle fed but none of them were using special types of feeding bottles, for example soft plastic squeeze bottles or a Habermann feeder that facilitate feeding (Reid, 2004: 271; Shaw, Bannister & Roberts, 1999: 266). This may be due to the fact that the special equipment is not easily available and that the parents do not receive any guidance regarding the importance and use of special equipment for feeding.

Speech-language therapists and audiologists observed that all infants with CL/P were held in appropriate positions during feeding and 77% did not exhibit any nasal regurgitation during

feeding. The reported nasal regurgitation of oral feed in some children was possibly due to oronasal fistulae. None of the children were using obturators as the services of paediatric orthodontists are not available in Mauritius for such feeding aids.

In addition to the feeding methods, information regarding weight gain and growth was noted from the health card. This was recorded in the local health care centres by nursing personnel. A total of 96% of the children had age appropriate weight gain and growth. This positive finding can be attributed to maternal-child health care services that are free and easily accessible to all Mauritians and early surgical repair of the cleft (see Table 5.2). Contrary to the findings of the weight gain and growth in Mauritius, in a study conducted in Brazil (Amstalden-Mendes, Magna & Lopez, 2006: 332), weight gain was affected in 92% of the children with clefts associated with syndromic conditions and in 72% of non-syndromic cleft children, despite the guidance provided to parents. Furthermore, surgical planning for lip or palate correction was delayed in 67% of the children due to inadequate weight gain.

The valuable information obtained from the feeding assessments can be used to provide appropriate guidance to mothers of infants with CL/P. This may consequently reduce the stress experienced by the mother and promote growth and development of the infant (Reid, 2004: 275).

5.3.2 Hearing abilities

Risk indicators for ear disease, hearing loss and congenital malformations of the auditory system for children with CL/P are well documented in the literature (JCIH, 2007: 921; Peterson-Falzone et al., 2010: 216). Early identification of hearing loss and referrals for management to the ENT

specialists reduces the prevalence of hearing impairment in children with CL/P and the impact thereof on development (Broen et al., 1996: 132; Watson et al., 2001: 216; WHO, 2002: 142). Hearing evaluations of the 80 children in the sample were conducted according to the Communication Assessment Protocol (Appendix VI, Section C) and the results are presented forthwith.

- *Risk indicators*

Risk indicators other than the craniofacial anomaly for congenital hearing loss are presented in Table 5.4.

TABLE 5.4 Hearing risk indicators (n=80)

Risk indicators other than craniofacial anomaly	Description (refer to Appendix VI, item C7)	Children with CL/P		
		No.	Percentage	
Yes	Children with: <ul style="list-style-type: none"> • Pierre Robin Sequence or suspected syndrome and high risk of hearing loss • Prematurity/ very low birth weight (less than 1.5 kg.) • Prolonged mechanical ventilation • External ear anomaly • History of consanguinity • NICU stay of more than 48 hours? • Maternal history of viral infections during pregnancy • Other postnatal illnesses, such as meningitis? 	8 7 3 2 2 - - -	Overall 19% displayed risk factors	
No	Parents did not report any of the risk factors on the high risk register	62		77%
Missing data	Information not available	3		4%

It is noteworthy that 19% of the parents of the children could confirm the presence of high risk factors. The possible reason for their awareness is that the birth place of these children was

hospitals and parents may have already been informed by the health care professionals of the risk factors for hearing loss. There is also a possibility that more than one risk factor for hearing loss such as a syndrome and very low birth weight were present in some of these children. The JCIH (2007: 898) recommends that all infants with risk indicators for auditory disorders, and/or speech and language delay should receive ongoing audiologic and medical surveillance and monitoring for communication. In Mauritius, although universal newborn hearing screening is not in place, diagnostic equipment for hearing evaluations is available and speech-language therapy and audiology services are established in the regional hospitals. Therefore, routine hearing evaluations are possible for children with CL/P and are strongly recommended.

- ***Hearing Loss***

The results with respect to age appropriate hearing evaluations showed that a large percentage of children, (65%) were identified as having hearing loss, of which 60% had conductive hearing loss and 5% of the children were identified as exhibiting a mixed and sensorineural type of hearing loss (see Table 5.5). This finding confirms literature reports that children with CL/P frequently exhibit hearing loss (Bzoch, 2004: 356; Peterson-Falzone et al., 2010: 209). Moreover, the fact that 48% of the parents perceived that their child has a hearing loss (refer to Figure 5.6) again confirms literature reports (Rossetti, 2001: 94; Zinkin & McConachie, 1995: 108), that parental reports can be relied upon to identify children with hearing loss.

TABLE 5.5 Type and degree of hearing loss (n=80)

	No of Children	Percentage
Type of hearing loss (HL)		
Conductive	48	60%
Sensorineural	2	2.5%
Mixed	2	2.5%
No hearing loss	28	35%
Degree of hearing loss		
Mild (15 dB to 30 dB HL)	20	25%
Moderate (30 dB to 50 dB HL)	22	28%
Severe (50 dB to 70 dB HL)	3	4%
Profound (>70 dB HL)	1	1%
No hearing loss	28	35%
Missing data	6	7%

In general, children of 0-78 months are vulnerable to conductive hearing loss. The prevalence of a conductive hearing loss is highly variable, primarily because conductive hearing loss typically fluctuates. Kemker and Antonelli (2004: 357) reported that the incidence of hearing loss across studies is 58%. A recent study in Greece (Paliobei, Psifidis, & Anagnostopoulos, 2005: 1379) found that 69% of the children with CL/P presented with mild and moderate hearing loss. Vishwanathan, Vidler and Bruce (2008: 189) assessed hearing of 90 infants with CL/P with auditory brain stem response audiometry and reported that 82% of infants had a hearing loss and in the majority of cases it was conductive type of hearing loss.

Responses from the parents indicated a low incidence of surgical intervention for the management of conductive hearing loss. Only 16% (n=13) of the children were reported to have undergone surgical interventions, mainly grommet insertion. The literature recommendations are

for aggressive forms of management whereby ventilation tubes or grommets should be inserted in the ears of all children with CL/P due to the known risk of otitis media amongst these children (Broen et al., 1996: 132; Peterson-Falzone et al., 2010: 216; Watson et al., 2001: 220). Moreover, even mild and moderate hearing loss has a negative impact on communication, speech-language development and later academic outcomes (ASHA, 2004: 2; Friel-Patti & Finitzo, 1990: 192; JCIH, 2007: 900; Northern & Downs, 2002: 84). The large percentage of children with CL/P and hearing loss implies there is a double risk of communication disorders and the recommendation for aggressive forms of management should be implemented in Mauritius to minimise/prevent the impact of hearing loss on these children.

- *Listening behaviour*

The Listening Evaluation scale (Hugo et al., 2000: 53) was administered to determine the listening behaviour of the children with CL/P (Appendix VI, Section C8). Children were divided into two groups, namely those with and those without hearing loss. The results are illustrated in Table 5.6.

TABLE 5.6 Listening behaviours of the children during communication assessments (n=80)

Reaction to:	Children with hearing loss (n=52)		Children without hearing loss (n=28)		Comparison
	Good (1)	Poor (2-3)	Good (1)	Poor (2-3)	P-Value Fisher's exact test
Environmental sounds	67%	33%	85%	15%	0.1112
Whispered speech	40%	60%	69%	31%	0.0297
Non speech sounds	44%	56%	78%	22%	0.0336
Speech	60%	40%	78%	22%	0.1365

The difference between the two groups was statistically significant ($p < 0.05$) only for reaction to whispered speech and non speech sound. Comparisons of the two groups, using the Fisher's exact test revealed that children with hearing loss were rated as manifesting 'poor' listening behaviour more frequently (33%) than children without any hearing loss (15%). On the other hand, children without any hearing loss were rated as 'good' listeners more frequently as compared to children with hearing loss for reacting to environmental sounds (85% vs. 67%), whispered speech (69% vs. 40%), non-speech sounds (78% vs. 44%) and speech (78% vs. 60%).

It was observed that there was an association between the presence of hearing loss and both, reactions to whispered speech and to non speech sounds (noise makers). The association ($p < 0.05$) of the listening behaviour for whispered speech and non-speech sounds were observed during the assessment due to the fact that the majority of the children in the study had mild to moderate conductive hearing loss, which could easily affect hearing ability for whispered speech and non-speech sounds. Thus it can be inferred that listening behaviour results could differentiate between children with hearing loss and without hearing loss on two parameters namely whispered speech and responses to noise makers. Listening behaviour for environmental sounds and speech was not significantly different between children with and without hearing loss possibly because this was based on parental reports. The results based on elicitation reflect the expected difference between children with and without hearing loss, whereas the results based on parental perceptions may not be reliable. The method of data collection for all four categories of listening skills of the listening scale should be similar, and preferably by means of elicitation rather than parental report. Thus the Listening Evaluation scale (Hugo et al., 2000) is useful and a clinically relevant tool for high risk population between 0-36 months. Its implementation helps identify children with poor listening skills even though they may have normal hearing.

It is deduced from the above findings that parental perception of hearing loss, the use of a high risk register and listening behaviour evaluations all provide valuable information about hearing status. However, a comprehensive test battery including electrophysiological measurements needs to be carried out to identify hearing loss, which should be monitored regularly, and when necessary, referred for ENT management.

5.3.3 Orofacial characteristics

The descriptions of the orofacial characteristics of children with CL/P in this study are based on orofacial examinations that were conducted by the speech-language therapists and audiologists according to the Communication Assessment Protocol (refer to Appendix VI, Section D). The results are shown in Table 5.7.

TABLE 5.7 Orofacial characteristics contributing to speech production errors (n=80)

Orofacial factors contributing to speech production errors	Percentage of children with presence of the contributing factor
Abnormal lip movements (example: restricted lip movements)	8%
Abnormal tongue movements (example: poor tongue neuromuscular control)	3%
Abnormal dentition (malocclusion, missing teeth, supernumerary teeth)	5%
Palatal fistulae	23%
Suspected velopharyngeal dysfunction	35%
Suspected syndrome	11%
Other etiology suspected	3%
No identifiable contributing factor	44%

** The total percentage of children in the table is more than 100 as some children had more than one contributing factor.*

The most frequent contributing factor to speech production errors among 35% of the children was suspected velopharyngeal inadequacy. The results were based on listener perceptual evaluations only. A perceptual speech evaluation is the first step to determine whether the velopharyngeal functioning is adequate (Kuehn & Henne, 2003: 107; Sell, 2005: 103). The use of instruments for visual examination of the structures of the velopharyngeal area is recommended (Shprintzen & Bardach, 1995: 267; Whitehill, 2002: 92-93). However, Kummer (2008: 319) states that the velopharyngeal dysfunction is only a problem if it affects speech therefore perceptual judgement has face validity. In this Communication Assessment Protocol, perceptual speech analysis was conducted to judge the adequacy of the velopharyngeal closure and to make recommendations for instrumental assessment. Although, instrumental assessments for velopharyngeal closure are not currently used in public health service for cases with CL/P, the possibility of speech-language therapists collaborating with ENT specialists to use the nasopharyngoscope for assessment of velopharyngeal function can be considered. The speech stimulation material in Creole could be used during nasopharyngoscopy and the recordings of velopharyngeal closure analysed to make important management decisions for speech and resonance disorders.

According to this study, 5% of the children evidenced occlusion and dentition problems such as missing or supernumerary teeth and malocclusions. As shown earlier (Figure 5.3) only 3.7% of the children were receiving dental care mainly for treatment of caries. This is contrary to the ACPA (2007: 18) recommendation that children with CL/P receive dental examination and referral to appropriate providers for caries control, preventative measures, restorative dental treatment and space management. Also, active orthodontic treatment is indicated from the stage of primary dentition (0-72 months). However, in the Mauritian context and many of the other developing

countries, children with CL/P cannot access orthodontic treatment as the personnel may not be available or the treatment is unaffordable by the families (Watson et al., 2001: 299). Unavailability of orthodontic treatment from the stage of primary dentition will negatively impact outcome measures, not only for dental treatment but also speech aspects among young children with CL/P (Bearn et al., 2001: 33; Mars et al., 2008: 116; Wyszynski, 2002: 433).

The orthodontic treatment of young children with CL/P also includes prosthetic obturation of palatal fistulae and prosthetic speech appliances for velopharyngeal inadequacy in some children (ACPA, 2004: 18). Among the children sampled, 23% had palatal fistulae caused either by a breakdown in repaired cleft palate or left deliberately by the plastic surgeon to be closed later by a bone graft (Table 5.9). Depending on the location, size, aetiology and how long the palatal fistulae have been present, they can affect both the degree of hypernasality and speech sound production (Kummer, 2008: 192; Shprintzen & Bardach, 1995: 316). There is a controversy regarding the effect of fistulae on speech; some authorities maintain that they always result in speech disorders (Karling, Larson, & Henningson, 1993: 197; Shprintzen & Bardach, 1995: 328) while others suggesting that this is not the case (Harding & Grunwell, 1993: 65). The significant number of children with palatal fistulae in this study indicates that it might be an important contributing factor to the speech impairments observed among them.

The orofacial features and oral movements among children with syndromes are reported to be atypical and may contribute to speech production problems. The presence of syndromes among 11% of the children was found to be a contributing factor for speech production errors. Compensatory errors (for e.g. lateral distortion) may occur due to structural abnormalities such as maxillary retraction and/or micrognathia observed in children with syndromes/sequences (Kummer, 2008: 185). Speech-language therapists and audiologists along with surgeons and

paediatricians may be required to take a proactive role in describing the phenotypical features that may indicate the presence of a syndrome. The confirmation of a syndrome, however, remains problematic until genetic services are available in Mauritius. Syndrome diagnosis is very important for a treatment plan and the future development of the young child. For example young children identified with VCF syndromes can be better managed through an early intervention programme as future learning difficulties can be predicted and preventive measures taken. The Communication Assessment Protocol was useful in identifying one or more abnormal orofacial characteristics of the children with CL/P.

5.3.4 Communication, speech and language characteristics

The characteristics of communication, speech and language development skills among children with CL/P in the sample are presented according to the two age groups; Group 1: younger than 36 months and Group 2: 36-78 months (Appendix VI, Section E).

- ***Characteristics of the children in age Group 1 (younger than 36 months)***

Parental reports were obtained concerning prelinguistic communicative behaviours in age Group 1 (refer to Appendix VI, Sections E8 & E9).

TABLE 5.8 Pre-linguistic communicative behaviours of children in age Group 1 (n=24)

Prelinguistic behaviour Items	Percentage of children		
	Yes	Unsure	No
Non-verbal communication	100%	0	0
Behaviour regulation	88%	8%	4%
Social interaction	95%	0	5%
Joint attention (1 record missing information)	52%	18%	30%
Discourse structure: respond to and initiate communication (1 record missing information)	57%	30%	13%

The majority of the children younger than 36 months were reported to have developed behaviour regulation and social interaction. However, in this study the descriptions of functional communication development such as joint attention indicated that the cleft may have a negative impact on parent-child interactions and attempts by the child with CL/P to communicate may not be recognised by the parents as the beginnings of verbal communication. Behaviour regulation, social interaction and joint attention follow a developmental sequence, with behaviour regulation as the most basic form of communication. Joint attention, unlike behaviour regulation and social interaction, requires ongoing turn taking (Blackman, 1995: 158). Mothers require training to promote vocabulary use and speech production (Pamplona & Ysunza, 2000: 231).

Based on the assessment results of prelinguistic communication behaviour, speech-language therapists can plan early communication intervention and train mothers to deliver the intervention reliably (Scherer, D'Antonio & McGahey, 2008: 18-31).

- *Phonetic development*

The consonant repertoire produced by the children with CL/P in the sample was obtained from parental reports (Appendix VI, Section E10).

TABLE 5.9 Consonant repertoire of children in age Group 1 (n=24)

Consonant repertoire	Frequency	Percentage
Age appropriate	6	25%
Limited	13	54%
No identifiable consonant	4	17%
Missing Data	1	4%

A total of 71% of the infants and toddlers had limited or no identifiable consonants according to their parents (Table 5.9). Kritzinger et al. (1996: 81) reported that 80% infants with CL/P displayed a limited phonetic repertoire in comparison with normal developmental levels. A comparative study by Chapman et al. (2001: 1277) regarding prelinguistic vocalisations between 9 month old infants with and without cleft suggested that infants without cleft produced two to three times as many consonants as the babies with clefts. Various studies (Chapman et al., 2003: 193, Harding-Jones et al., 2006: 8; Kummer, 2008: 161; Morris & Ozanne, 2003: 465; Scherer, 1999: 90) have provided evidence of a link between the development of expressive language and the increase in the phonetic repertoire in young children with CL/P. These findings highlight the importance of assessing the consonant repertoire of children with CL/P and providing intervention when required, in the early speech development stage. Delays in consonant production during the prelinguistic phase have been linked to delayed language and speech (Peterson-Falzone et al., 2010: 232). Jones et al. (2006: 9) identified increasing the consonant repertoire of a child with CL/P as an important ECI goal. Therefore, assessment of phonetic

repertoire during the prelinguistic stage is a preventative measure for future language delays or speech disorders. In addition to parental reports, speech-language therapists should elicit and record (video and audio recordings) the babbling and vocalizations of infants for perceptual analysis of phonetic repertoire.

- ***Language characteristics***

In Group 1 (children younger than 36 months), 54% of the children had delayed language, possibly due to the inclusion some with syndromes/sequences in the study sample. The presence of a syndrome increases the risk of developmental problems (Peterson-Falzone et al., 2010: 58; Scherer & Kaiser, 2007: 355).

- ***Characteristics of the children in age Group 2 (36-72 months)***

The children in Group 2 were assessed by the speech-language therapists and audiologists, and information derived from parental reports and elicited standard speech responses with respect to language, speech and voice characteristics.

- ***Language characteristics***

The language screening results of children in Group 2 (refer to Appendix VI, Section E24) indicated that 52% of them required referrals for in-depth speech-language assessment due to a suspected or confirmed language delay which closely correlates with the findings from Group 1.

This may be attributed to any one or a combination of the following reasons:

- the presence of congenital risk factors for hearing loss in addition to the cleft and confirmed hearing loss in a large percentage of children
- inclusion of children with syndromes/sequences in the sample (11%)

- limited phonetic repertoires (in 71% of the children in the sample) in which the speech production capabilities were compromised and may partly explain the expressive language delays.

Data from this study confirm the reported developmental language delays among children with CL/P (Broen et al., 1998: 682; Jocelyn, Maureen, Penko & Rode, 1996: 532; Morris & Ozanne, 2003: 469; Pamplona et al., 2000: 88). It is therefore imperative to include language acquisition screening followed by in-depth language assessments and interventions for young children with CL/P.

- *Speech characteristics*

Speech samples were elicited from the children in the age Group 2 and digital recordings were made for speech analysis (refer to Appendix VI, Section E26 to E33). The speech characteristics of 47 children were completed as speech recordings for 9 children could not be made due to non-compliance and limited expressive abilities (Table 5.10).

TABLE 5.10 Speech characteristics as determined by perceptual speech analysis in age Group 2 (n=47)

Speech characteristic	Number of children		Percentage of children presenting with the cleft type speech characteristic
	Yes	No	
RESONANCE:			
i) Hypernasal	35	12	75%
ii) Hyponasal	2	45	4%
iii) Mixed nasality	2	45	4%
NASAL EMISSION	14	33	30%
NASAL GRIMACE	12	35	26%
VOICE			
	Dysphonia	Normal	
	13	34	28%
ARTICULATION			
Cleft type speech characteristics (CTCs)	33	12	70%
* Some children had more than one type of CTC			
i) Anterior CTS	15		
ii) Posterior oral	9		
iii) Non oral	15		
iv) Passive CTC	27		
	* for 2 children the SLTs were unsure		
DEVELOPMENTAL ARTICULATION ERRORS			
	Yes	No	
	14	24	30%
	*for 9 children the SLTs were unsure		
VISUAL APPEARANCE			
i) unremarkable	28		-
ii) asymmetry of facial movements	2		
iii) tight upper lip	10		-
iv) tongue tip appearing (interdental lisping)	3		
*Some children had more than one type of remarkable appearance			

The ratio of children judged as having hypernasal resonance and articulation errors was high. The findings of this study are similar to those by Hardin-Jones and Jones (2005: 10) where among 212 preschool children 68% required speech-language therapy services for speech

disorders. However, the CSAG report (Sell et al., 2001: 35) in the UK reported only 18% of the children with CL/P exhibited consistent hypernasality and 19% of the five year-olds with craniofacial anomalies were judged to be unintelligible to strangers. This disparity in the literature may be attributed to differences in inclusion criteria of children with different types/severity of cleft. In the Hardin-Jones and Jones study (2005: 8), children with bilateral CL/P were included whereas the participants in the CSAG study were all children with unilateral CL/P and they were receiving speech-language therapy services (some cases for more than two years) and were treated by a multidisciplinary team of professionals.

Results from this study also indicate that 30% of the children in the sample had developmental articulation errors. Hutter et al. (2001: 465) reported that developmental speech characteristics are more frequent in consonants produced by children with CL/P than children without CL/P.

The speech delays/disorders of the sample may be partly attributed to lack of ECI and a coordinated team approach to management as young children with CL/P in Mauritius may not have had timely access to the range of professionals required to ensure good speech outcome. This indicates the importance of a perceptual speech analysis which distinguishes the types of articulation errors and guides therapy planning by the speech-language therapists.

- ***Voice problems***

In this study, 28% of the children with CL/P were identified with voice problems such as hoarseness and low intensity. This incidence is higher than that reported in a recent study by Hocevar-Boltezar, Jarc and Kozelj (2006: 279) where only 9.2% of the children with clefts had functional dysphonia. Voice problems among children with CL/P are usually characterised by

weak and/or aspirate (breathy) voice (Bzoch, 2004: 409). This phonatory characteristic is more prevalent in the cleft group than in the general population (Peterson-Falzone et al., 2010: 240). Identifying the interactions of voice and resonance can be challenging and the judgment of voice quality on basis of auditory-perceptual voice analysis is subjective. Therefore, the significant discrepancy in the voice quality of this sample compared to results obtained elsewhere is understandable.

- ***Identifiable etiological factors of the speech disorders***

In addition to the cleft condition, other etiological factors contributing to speech disorders among children in age Group 2 (refer to Appendix VI, Section E34) were determined.

TABLE 5.11 Identifiable etiological factors of the speech disorders in age Group 2 (n=56)

Identifiable etiology	Frequency count	Percentage of children
i) Hearing loss	25	45%
ii) Developmental delay	16	28%
iii) Oral fistulae	11	20%
iv) Dental abnormalities	4	7%
v) Syndrome	5	9%
vi) Other (for example learning difficulty)	4	7%

* The total is more than 56 as some children had more than one identifiable etiology

Hearing loss and developmental delays accounted for a significant proportion of the etiological factors for speech disorders in children from 36-72 months (Table 5.11). The palatal fistulae appeared to cause speech disorder in a high proportion (20%) of children assessed. Harding and

Grunwell (1998: 342) reported that fistulae influence articulation and phonological development and Kummer (2008: 192) added speech outcomes depend on the size and location of fistula. The orthodontist, plastic surgeon, oro-facial-maxillo surgeon and speech-language therapist need to make joint decisions on management of the cases with fistulae.

In addition to factors listed in Table 5.11, velopharyngeal inadequacy (VPI) is an important etiological factor of speech disorders. The VPI was assessed by perceptual assessment as part of the orofacial examination procedures and was identified as a contributing factor to speech production errors in 35% of the children.

The combination of etiological factors, in the study sample, confirms literature reports (Broen et al., 1998: 685; Hutters et al., 2001: 465) that the cleft itself is not the only cause of speech disorder and that the speech-language therapist and audiologist should conduct a holistic assessment of children with CL/P.

5.3.5 Emergent literacy skills

The children's emergent literacy skills were described based on information elicited from the parents (Appendix VI, section E11). As three of the 24 children in age Group 1 were younger than six months they were not included in the sample. The results of parental responses for the 21 children between six and 36 months are illustrated in Table 5.12.

TABLE 5.12 Emergent literacy skills in age Group 1 (n=21)

Emergent literacy skill (as reported by the parents)	Frequency in percentage	
	Yes	No
i) Parents have introduced the children to books	76%	24%
ii) Child responds to being read to	62%	38%
iii) Child shows an interest in books	67%	33%
iv) Child pretends to read books	52%	48%

The results for emergent literacy skills are positive as the majority of children under the age of 36 months were introduced to books (Table 5.12). This may be attributed to the fact that all parents of children in this sample had, at least, received primary school education and that parents in Mauritius have a high literacy rate in general. Joint book-reading enhances language and literacy development of all infants and should be actively promoted in early intervention programmes (Kritzinger & Louw, 1997: 2).

Emergent literacy skills (refer to Appendix VI, Section E25) were also studied among 54 children in Group 2. The trend that was established by parents in the younger group of participants was found to be sustained with children above 36 months (Table 5.13).

TABLE 5.13 Emergent literacy skills in age Group 2 (n=54)

Emergent literacy skill (as reported by the parents)	Frequency of children in percentage	
	Yes	No
i) Shows an interest in books and reading	96%	4%
ii) Listens attentively to parent/teacher reading	91%	9%
iii) Is sensitive to some sequences of events in a story	87%	13%
iv) Correctly answers questions about stories read aloud	75%	25%
v) Displays attempts at reading	80%	20%
vi) Recognises and can name a few letters	69%	31%

Children with speech and language problems are particularly vulnerable to deficits in early literacy skills (Broder et al., 1998: 130; Nathan, Stackhouse, Goulandris & Snowling, 2004: 377-391). As far as could be determined, the emergent literacy skills of children with CL/P have not been explored *per se*. However, literature reviews indicate that children with CL/P are at risk for learning difficulties and poor academic performance (Broder et al., 1998: 130; Endriga & Kapp-Simon, 1999: 7; Peterson-Falzone et al., 2010: 378; Strauss, 2004: 170). Assessment of emergent literacy skills is recommended to facilitate the literacy process in young children (ASHA, 2001:17-27; Pence & Justice, 2008: 225).

5.3.6 Developmental and educational aspects

Information concerning developmental aspects of the children was also obtained from parental reports (refer to Appendix VI, Section F) and the findings are presented with respect to the general development and educational aspects.

- **General development**

Concerns regarding the delayed motor milestones were raised by 21.25% of parents of the children in the sample of 80 children with CL/P. Literature review suggests that the motor milestones and the average age for attaining them may be used as benchmarks for investigating the presence of developmental delays (Kapp-Simon & Krueckeberg, 2000: 69; Neiman & Savage 1997: 222; Swanenburg de Veye et al., 2003: 300). However, to determine the developmental motor patterns of infants with CL/P longitudinal data is needed (Savage et al., 1994: 227). As this study was a cross sectional study, the children's developmental patterns could not be determined. Developmental delays have important implications for early diagnosis and intervention among children with CL/P. Speech-language therapists and audiologists identified and referred 19% of the children to paediatricians for in-depth assessments and 3% of the children for a psychological assessment. In contexts similar to Mauritius where a multidisciplinary team approach is not available, speech-language therapists and audiologists need to have a holistic view and include a general developmental assessment when conducting communication assessment of the child with CL/P

- **Educational aspects**

The children's educational history was obtained from the parents (Appendix VI, item F 9). Among the 56 children in Group 2, almost all (54/56) were attending school. This is an encouraging finding as it indicates that in Mauritius, children with clefts have access to same educational facilities as children without any cleft lip and /or palate. In some countries, for example Madagascar (another island in the Indian Ocean), many children with CL/P are not sent to school due to the stigma associated with facial anomalies (personal experience of the

researcher during an Operation Smile mission to Madagascar in November 2007). However, in Mauritius, children with CL/P have equal opportunities and the system supports their integration in mainstream schools.

The implementation of the Communication Assessment Protocol allowed for a rich description of the characteristics of children with CL/P in Mauritius. This information was captured the electronic database.

5.4 CLINICAL APPLICABILITY OF THE COMMUNICATION ASSESSMENT PROTOCOL

The clinical applicability of the protocol in Mauritius was evaluated by conducting assessments using the newly developed assessment tool on a cross section of 80 children with CL/P and determining if it was effective in identifying children with communication delays/disorders.

5.4.1 Identification of communication disorders using the Communication Assessment Protocol

The compilation of the Communication Assessment Protocol was based on recommendations for best practice in assessments (ACPA, 2007) and it was specifically adapted for the Mauritian context (refer to section 4.8.7 and Table 4.8). The content validity of the instrument was assured by including various areas of communication assessment and specific aspects of each area were included in the checklist format of the communication assessment tracking form (refer Appendix VI) according to best practice recommendations (ACPA, 2007). The clinical applicability of the Communication Assessment Protocol was established as various speech-language therapists and

audiologists (investigator triangulation) could use the assessment instrument to identify children in the sample with communication problems. This is a useful measure of internal validity of an instrument (Denzin & Lincoln, 2000: 391; Leedy & Ormrod, 2005: 97).

Data collection, data analysis, and data interpretation are interactive and cyclical steps in the mixed-methods research process (Collins, Onwuegbuzie & Sutton, 2006: 72). Assessments through implementation of the Communication Assessment Protocol generated sufficient data pertaining to characteristics of young children with CL/P in Mauritius. The analyses of the results from assessments of the young children with CL/P established that the ratio of children identified with the various communication problems in general concurred with literature reports. This provided evidence to suggest that the Communication Assessment Protocol was a clinically applicable instrument for assessment of young children with CL/P in Mauritius.

The clinical applicability of the instrument was verified as follows:

- In the empirical research, use of the Communication Assessment Protocol identified 73% of the young children with speech-language delays/disorders and recommended them for speech-language therapy. This is similar to results of studies undertaken in other parts of the world where 70% of young children with CL/P in preschool age group required intervention by speech-language therapists (Brunnegard & Lohmander-Agerskov, 2007: 33; Hardin-Jones & Jones, 2005: 10; Hirschberg, 2001: 1259; Peterson-Falzone et al., 2010: 243).
- Previous studies have reported that 58% of children with CL/P exhibit hearing loss (Bzoch, 2004: 357). This was found to be similar to percentage of children identified with hearing loss (65%) using the Communication Assessment Protocol. Moreover, correlations were determined between the hearing test results and the listening scale to compare and corroborate the results.

This provides further support that the protocol was successful in identifying children with speech-language and hearing impairments.

- The Communication Assessment Protocol allowed a comprehensive assessment of children with CL/P (ACPA, 2007: 3). In addition to communication assessment it included assessments of feeding methods, general developmental and educational aspects of the child. Although emergent literacy skills *per se* in young children with CL/P have not been extensively studied, few studies, for example, by Broder et al. (1998: 129) and Richman and Ryan (2003: 159) have reported that 46% of children with CL/P had reading and writing difficulties. The emergent literacy section of the Communication Assessment Protocol identified that 43% of the children's parents required guidance to facilitate emergent literacy skills in their young children. This provides additional credence to the concurrent validity of the Communication Assessment Protocol.

The Communication Assessment Protocol procedures followed a holistic approach which focused on identifying strengths and problems in order to make referrals and to include all areas of concern into early communication assessment. The Communication Assessment Protocol was based on the theoretical construct that the outcome of broad screening of communication and other related functions (feeding, general development) of young children with CL/P would make it feasible for speech-language therapists and audiologists to refer the identified children to the concerned specialists for further assessments and management. Therefore, using the protocol, the speech-language therapists and audiologists should identify children with communication problems as well as problems related to communication development.

-The feeding methods' assessment and observations on growth (from health card of infants and toddlers) identified 4% of the children as being at risk and were referred to paediatrician for further management.

- Using the orofacial examination checklist helped to identify 5% of the children in the sample (refer to Table 5.8) with abnormal dentition who would require orthodontic intervention.

- The screening of general development (motor, social interactions, educational history) of the children (refer to Section 5.3.6) allowed the speech-language therapists and audiologists to identify 19% of the children who required referrals to a paediatrician and psychologist

In conclusion, the clinical applicability of the Communication Assessment Protocol was verified by implementing the protocol in Mauritian children with CL/P and comparing the assessment results to international research findings.

For perceptual speech analysis the reliability of data, recording, analysis and interpretation are of utmost importance (Eurocleft Speech Group 2000; Sell, 2005: 113). The reliability of the data collection was discussed earlier (refer to 4.8.7). It involved using pre-tests, pilot studies and training to conduct the assessments in a uniform manner. However, speech assessments of children in the age group 36-78 months were based on perceptual speech analysis by speech-language therapists who made subjective judgements of the speech characteristics. Interobserver consistency of judging speech elicited from preschool age children in the sample is based on recommendation by John et al. (2006) and discussed in the following section.

5.4.2 Reliability of the perceptual speech analysis

The reliability of perceptual speech analysis was determined by randomly selecting eight speech samples from the 47 video and audio recordings of the children's speech assessments and speech analysis by each of the four speech-language therapists and audiologists for hypernasality, nasal emissions and cleft type characteristics. The speech analysis results from each assessor were compared. The results are presented in Table 5.14.



TABLE 5.14 Percentage agreement of perceptual speech analysis: interobserver reliability

Subjects' Speech Parameters	Subject 1 ID 15 Age: 68 months		Subject 2 ID 23 Age: 54 months		Subject 3 ID 25 Age: 72 months		Subject 4 ID 28 Age: 62 months		Subject 5 ID 68 Age: 40 months		Subject 6 ID 82 Age: 75 months		Subject 7 ID 84 Age: 71 months		Subject 8 ID 86 Age: 49 months		Mean Age: 61 months	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Percentage Agreement	
Hypernasality E26 a																		
P 1	+			+		+	+			+	+			+		+	97% Missing data: 1	
P 2	+		+			+	+		+		+			+		+		
P 3	+		+				+		+		+		+			+		
P 4	+			+		+	+		+		+		+			+		
Nasal emission E27																		
P 1		+		+		+	+			+						+	62% Missing data: 12	
P 2		+			+					+						+		
P 3		+		+						+			+			+		
P 4				+		+				+			+			+		
Cleft type speech E31																		
P 1	+					+	+		+		+		+			+	94% Unsure (U=1) Missing data: 1	
P 2	+			+		+	+		+		+		+			+		
P 3	+		+			+	+		U		+		+			+		
P 4	+			+		+	+		+		+		+			+		

There was 97% agreement on findings among the four assessors for hypernasality and 94% agreement for cleft type speech characteristics (Table 5.14). There were, however, less consensus with respect to the judgements of nasal emissions (Percentage agreement 62% only). The missing data for nasal emissions indicates that the speech-language therapists and audiologists did not feel confident about making their judgement from digital recordings regarding the presence or absence of nasal emissions. This may be attributed to the fact that the judgement of nasal air emissions requires actual observations of the child (mirror fogging) while he/she is speaking (Kummer, 2001: 283).

Consistency in perceptual speech assessment results is an important consideration in research to determine the protocol's reliability. Sell's (2005: 106) recommendations for clinical practice to perceptual speech analysis such as training of the therapists in listening to speech samples, eliciting speech samples through repetition of standard sentences and high fidelity digital recordings of speech samples for comparisons were followed and contributed to agreement of the therapists regarding the speech characteristics of preschool age children. The speech-language therapists and audiologists were not able to transcribe the children's speech using the International Phonetic Alphabet (IPA) and the diacritics described for cleft type speech (Trost-Cardamone, 2004: 263). This could probably be ascribed to their limited clinical experience (refer to Table 4.3) as well as to inadequate practice in transcribing cleft type speech characteristics. In the future training in transcribing cleft type speech patterns will be necessary.

A reliable Communication Assessment Protocol that could be implemented to assess communication of young children with CL/P accessing public health service in Mauritius was

developed. An important question that remained to be answered was whether, from the perspectives of speech-language therapists and audiologists who would be using the protocol, it was clinically applicable and acceptable.

5.5 CLINICAL ACCEPTABILITY OF THE COMMUNICATION ASSESSMENT PROTOCOL

The qualitative approach used to judge the perceptions of the speech-language therapists and audiologists sought an answer to the question: *Is the Communication Assessment Protocol a clinically acceptable tool?* As the speech-language therapists and audiologists first completed a questionnaire on the Communication Assessment Protocol before participating in the focus group discussion, an equal status was provided to both methods in the interpretation of the results (Leech & Onwuegbuzie, 2005).

The perceptions of the three speech-language therapists and audiologists who participated in the implementation of the Communication Assessment Protocol are presented and discussed in sections 5.5.1 and 5.5.2. The fourth participant was the principal researcher who developed the Communication Assessment Protocol.

5.5.1 Speech-language therapists' and audiologists' perceptions as obtained by the questionnaire

All three participants were of the opinion that the Communication Assessment Protocol was user friendly and comprehensive and felt that they would use the protocol in the hospital context.

TABLE 5.15 Perceptions of the speech-language therapists and audiologists regarding the Communication

Assessment Protocol (n=3)

QUESTIONS & SUB-QUESTIONS	RESPONSES OF PARTICIPANT 1 P1	RESPONSES OF PARTICIPANT 2 P2	RESPONSES OF PARTICIPANT 3 P3
<p>1. Number of children assessed (n=80) Group 1: younger than 36 months Group 2: 36-72 months <i>* 32 children were assessed by the principal researcher.</i></p>	<p>Pilot study: 2 Main study Group 1 = 7 Group 2 = 13 Total = 20</p>	<p>Pilot study: 2 Main study Group 1 = 2 Group 2 = 7 Total = 9</p>	<p>Pilot study: 2 Main study Group 1 = 3 Group 2 = 16 Total = 19</p>
<p>2.1 Suitability of the protocol for hospital context</p>	<p>Yes- as assessment of all areas of communication on one form. Could conduct assessments in the hospital context</p>	<p>Unsure- as found the protocol lengthy and some children did not maintain attention throughout the assessment. Recording equipment available only in one hospital</p>	<p>Yes- as different areas of communication are assessed that are appropriate and useful. The layout is easy as different areas are on different colour paper</p>
<p>2.2 Detailed enough in the specific areas assessed</p>	<p>Yes- as all important aspects having an impact on communication were included</p>	<p>Yes- as there were checklists for every section</p>	<p>Yes- as protocol contains all the areas for a complete assessment and it forms a basis for a good management plan. Protocol also provides the therapist with concrete clear grounds for referral to other professionals</p>
<p>2.3 Ease of assessment</p>	<p>Could assess - some difficulty in the hearing and the communication sections</p>	<p>Could assess- some difficulty for section E of the protocol, communication, speech and language</p>	<p>Could assess -with ease</p>
<p>3.1 Rating of resonance for children from group 2</p>	<p>Could rate with ease as training was provided</p>	<p>Could rate with ease as the scale was described well</p>	<p>Could rate with ease as checklist provides sufficient information</p>
<p>3.2 Description of cleft type speech characteristics</p>	<p>Had some difficulty- needed to view the video training programme once more and familiarise with the speech characteristics</p>	<p>Had some difficulty- needed prior training and listening practice</p>	<p>Could describe with ease- the training video and observations during the pilot study were helpful</p>

TABLE 5.15 Perceptions of the speech-language therapists and audiologists regarding the Communication Assessment

Protocol (n=3) (continued)

QUESTIONS & SUB-QUESTIONS	RESPONSES OF PARTICIPANT 1 P1	RESPONSES OF PARTICIPANT 2 P2	RESPONSES OF PARTICIPANT 3 P3
4. Were some children difficult to assess ?	Yes- in group 1 for hearing evaluations and in group 2 for speech recordings probably the children were shy or not familiar with the therapist	Yes- in group 2 for speech recording due to decreased attention and shortage of time to establish rapport with the children	Yes- in group 2 some children did not cooperate for hearing test, orofacial examination for example the mirror test and speech assessment Probable reasons were no rapport with the therapist, unfamiliar environment
5. Guidelines for intervention could be determined from the results?	Yes the assessment provided guidelines for referring and redirecting the children. Clear goals regarding speech correction could be identified	Yes as speech sound correction is easier when you know exactly what the child is doing wrong. Short term and long term goals became clearer	Yes as the protocol is detailed and the results provide a good basis for intervention and appropriate referrals. The therapist on completion of the assessment has a clear idea of how, where and when to start intervention.
6. Will you use the protocol in the future?	Yes- as all the required information available on one form. Now I am familiar with the protocol and it is easy to conduct assessment. The checklist is good for pre- therapy and post therapy assessments	Yes- especially the section E as a tool for diagnosis initially and for evaluating progress in therapy periodically	Yes as the protocol is useful, complete and appropriate for clinical practice. The checklist helps to save time.
7. Open-ended question for additional comments regarding clinical applicability	Time constraint to conduct the protocol especially if the child is not co-operative for example for the hearing test. The equipment provided was of good quality. The protocol included all important information to plan therapy.	This protocol is the first standardised test that can be used in each of the speech-therapy and audiology units in the Mauritian context. A useful tool in evaluating progress of the child following speech therapy The protocol also has potential to evaluate outcome of surgery from point of view of communication development.	Difficult to complete assessment in all areas in one session as therapist has a heavy case-load and the child may not co-operate. The video recording is very helpful in management but apparatus is not available at all regional hospitals Protocol provides information that is helpful in management of the child.

The training provided in perceptual speech analysis (Sell et al., 1999: 26) was reported to contribute positively in describing cleft type speech characteristics and in rating the nasal resonance of the children assessed. In some cases where difficulties were experienced in describing the speech characteristics, the audio and video recordings were reported to be very helpful as they could listen and watch the video recordings and analyse the speech reliably. The good quality digital audio and video recordings used in the study were appreciated by the participants.

The main issues that were raised, in response to the open ended question, were the time constraints for the use of the Communication Assessment Protocol in the clinical practice and the availability of apparatus for making digital audio and video speech recordings during clinical practice. The average time taken for completing one assessment was 30 minutes for children in Group 1 (0-36 months) and 40 minutes for children in Group 2 (36-78 months). The maximum time taken for completing the communication assessment was 60 minutes. A lengthy assessment of more than 60 minutes may affect clinical applicability especially in a busy clinical context (Zinkin & McConachie, 1995: 107). Although, two participants perceived the assessment of 30 to 40 minutes to be lengthy, the protocol was completed well within a reasonable time of less than 60 minutes. It is most probable that time required for the assessment would reduce with familiarity with the Communication Assessment Protocol.

5.5.2 Speech-language therapists' and audiologists' perceptions shared in the focus group discussion

A focus group discussion was conducted as an extension of the questionnaire to provide an interpretive aid to the findings (Bloor et al., 2001: 9). Topics for discussion and excerpts of representative quotes of the participants are presented in Appendix IX. A Digital Video Disc (DVD) recording of the focus group discussion is also included in the slip of back cover of the thesis. The focus group discussion permitted interaction among participants. In this section the themes identified for discussion, the perceptions of the participants and the principal researcher's interpretation are presented.

Topic One: Overview of the Communication Assessment Protocol

While discussing their general perceptions of the clinical applicability of the Communication Assessment Protocol all participants agreed that it was a complete and useful tool. They considered the protocol complete as areas of assessment included feeding, hearing, general development in addition to the speech-language assessments and they could focus on each area of assessment. They also found it practical, user-friendly, easy to use and appreciated the checklist format for noting their findings. Including parents in the assessment process was considered to be an important aspect of the protocol and this concurs with literature where parents are considered as an invaluable source of information regarding their child's communication (Guralnick, 1997:3; Rossetti, 2001: 94).

The main concern that was voiced by the three participants was the lack of digital audio and video recording apparatus at the various regional hospitals. It is interesting to observe that the participants found the recordings so useful that they were concerned how auditory perceptual speech analysis could be conducted in clinical practice if the apparatus for making high fidelity recordings was not available. Sell (2005: 103), in recognition of the importance of perceptual speech assessment, recommends blind independent analysis of speech data based on high fidelity recordings as the best practice when reporting audit and research outcomes for children with CL/P. Acquiring the high fidelity recording equipment may have important budget implications.

Topic Two: Content and implementation of the Communication Assessment Protocol

Specific aspects of the Communication Assessment Protocol and its implementation in clinical practice were the second topic of the focus group discussion and included: training in conducting the assessments, the contents of the Communication Assessment Protocol and the implementation of the various areas of communication assessments.

- **Training**

The speech-language therapists and audiologists were trained to conduct the communication assessments and they found it to be adequate. The video training and observing the principal researcher conducting assessments were reported to be very helpful in conducting the assessments. Ongoing training, in listening skills for speech-language therapists to standardise approach to auditory perceptual speech assessment and analysis, is recommended (John et al., 2006: 279; Sell, 2005: 118) and contributes to increasing the assessor's reliability in speech analysis.

- **The assessment tracking form**

The participants made positive comments regarding the assessment tracking form. They also expressed their satisfaction on the layout of the tracking form which was attractive due to colour coding of the various assessment areas. The checklist style was reported to be a time saver, as the therapists could simply ‘check’ their observations. It is important to maintain the same format of the tracking form in clinical practice.

- **Speech elicitation materials**

The participants found the list to be very helpful in eliciting speech from the young children in the sample. The list was the first of its kind, and the only speech elicitation material available in Creole. The need for linguistically relevant speech materials has been emphasized for the speech assessment of young children with CL/P (ACPA, 2007: 6; Eurocran Speech Project, 2000). Therefore, the list in Creole filled an important need in Mauritius and provided linguistically appropriate speech elicitation material to conduct speech assessments.

- **Apparatus for speech recordings**

The digital audio and video recording apparatus was considered to be of high quality by the speech-language therapists and audiologists as they could analyze the children’s speech reliably from the high fidelity recordings. The video recordings in particular were appreciated as non-verbal communication could be analysed. High fidelity recordings contribute to the reliability of perceptual speech analysis as random, independent speech analysis based on the recordings can also be used to measure treatment and speech therapy outcomes (Gooch et al., 2001: 61; John et al., 2003: 279; Sell, 2005: 107; Shriberg et al., 2005: 356; Wyatt et al., 1996: 148).

- **Areas of assessment**

The consensus of the speech-language therapists and audiologists was that the Communication Assessment Protocol provided a comprehensive approach to assessment, as all areas relating to communication were included. In addition to the universal parameters for speech evaluation namely, speech resonance, voice, language, hearing (Henningsson et al., 2008: 5; Lohmander-Agerskov & Olsson, 2004: 64-70; Sweeney & Whitehill, 2004) the Communication Assessment Protocol included emergent literacy skills, motor and educational development that provided the therapists conducting assessment a holistic view of the child with CL/P. This may be the reason for the speech-language therapists and audiologists to refer to the Communication Assessment Protocol as ‘a complete assessment protocol’. The participants during their completion of the survey questionnaire felt that all the areas included in the communication assessment protocol could not be assessed in one session. Discussion of this issue revealed that the hearing evaluations were time consuming, especially if the child being assessed was not cooperative. However, one of the participants suggested that rapport with the child was an important factor and added that children responded better to a familiar person. Therefore, it was suggested by one of the participants that in clinical practice the Communication Assessment Protocol should be conducted by the therapist who is conducting therapy with the child and that the assessment should be a longitudinal, ongoing assessment process. The ACPA parameters for evaluation of patients with CL/P (ACPA, 2007: 8) also recommend longitudinal assessments.

- **Intervention goals**

The therapists reported that they were able to make referrals, and establish short term and long term intervention goals based on the assessment results of each child obtained from the

Communication Assessment Protocol; this was a positive aspect concerning the clinical applicability of the protocol (ACPA, 2007: 7; Bzoch, 2004: 346; Rossetti, 2001: 88).

In conclusion, the speech-language therapists and audiologists felt that the protocol covered all the areas required for a complete assessment and was a reflection of the content validity, the strong theoretical underpinnings of the Communication Assessment Protocol.

Topic Three: The clinical applicability and the future use of the Communication Assessment Protocol

The third and final topic discussed was the clinical implementation of the Communication Assessment Protocol. The speech-language therapists and audiologists were unanimous in their affirmation that they would use the protocol in the future to assess young children with CL/P. One participant shared that she was using the speech elicitation material for all children referred with speech articulation problems. This comment initiated discussions around the potential application of the Communication Assessment Protocol to assess different types of cases.

The apparatus for hearing evaluations were available in three of the four centres in Mauritius and for the purposes of the study; the tools (for e.g. the digital recording equipment) of detailed assessment of the speech were available. However, the speech-language therapists and audiologists felt that it was important in clinical practice to have access to all these tools for detailed and complete evaluation of the children's speech assessments.

The participants also discussed their experiences and reasons for not completing the assessment in one session. One of the participants voiced the opinion that some children were not easily conditioned for hearing evaluations, whilst another participant was concerned about some children being unwilling to repeat the words. Ideas to overcome these constraints were discussed, for example establishing rapport with the child. The discussion moved on to the implementation stage of the protocol. The participants felt that viewing the video recording of the child's speech sample as a group would facilitate the auditory perceptual speech analysis. But group discussions are not possible as the therapists work in different centres and have to cope with a heavy case load. P3 thought it would be ideal if the therapists could confirm the findings and plan the management as a group '...in an ideal setting'. Perceptual speech assessment is of utmost importance and a complex process corroborative listening for speech analysis is recommended to reduce measurement error (John et al., 2006: 279; Sell, 2005: 116).

The Communication Assessment Protocol was perceived to address an urgent need for access to an assessment tool that has contextual and linguistic relevance. From the discussions of theme three, it was apparent that the speech-language therapists and audiologists were looking forward to apply the Communication Assessment Protocol in the future. This will entail detailed and accurate assessment and early identification of children with CL/P and guide intervention that will improve the overall care of the children with CL/P in Mauritius.

From the converging evidence of the survey results, the focus group discussion and the personal experiences of the principal researcher, it can be concluded that the Communication Assessment

Protocol is suitable for use in the hospital context in Mauritius, and would serve its proposed purpose in early intervention.

5.6 CONCLUSION

The results and subsequent discussion confirm that the three research objectives were achieved. In Mauritius, a description of the characteristics of young children with CL/P and an electronic database are available. The speech-language therapists and audiologists implemented the new Communication Assessment Protocol and confirmed the clinical applicability and acceptability of the protocol

In Mauritius, not all children with CL/P currently benefit from the services of the paediatricians, ENT specialists and dental specialists. However, speech-language therapists and audiologists receive early referrals from the plastic surgeon. This implies that in Mauritius, the speech-language therapists and audiologists are well positioned to implement early identification and management of communication delays/disorders in children with CL/P. Moreover, parents could participate in the assessment process by providing pertinent information concerning their children's history and communication behaviours. Consequently, there is a possibility of an interdisciplinary approach to assessment of young children with CL/P using the Communication Assessment Protocol.

The questionnaire and the focus group session established that the speech-language therapists and audiologists perceived the tool as being practical, comprehensive and clinically applicable.

Moreover, the focus group discussion confirmed that the speech-language therapists and audiologists' favoured the use of the Communication Assessment Protocol in the future.

5.7 SUMMARY

This chapter presented the results of the empirical research conducted to develop a Communication Assessment Protocol for young children with CL/P for use by speech-language therapists and audiologists in the public health sector of Mauritius. Conducting assessments on 80 young children with CL/P tested the possibility of implementing such a protocol for routine clinical use in Mauritius. Speech-language therapists and audiologists were able to identify children with communication disorders and associated problems and to initiate early intervention. Also, based on the early identification of associated problems referrals could be made and management goals planned accordingly. Moreover, they recorded the communication assessment findings in a uniform manner. In the focus group discussion they confirmed the acceptability of the Communication Assessment Protocol for clinical use in Mauritius.

CHAPTER 6:

CONCLUSIONS AND IMPLICATIONS

The aim of this final chapter is to critically evaluate the results of the empirical research, to draw conclusions and to discuss the implications of the research findings. Areas for future research are identified and final comments by the researcher are provided.

6.1 INTRODUCTION

The plight and vulnerability of young children with CL/P and the negative impact of this congenital anomaly on their personal and family life, places responsibility on health care professionals to provide a good level of care for all children with CL/P. The WHO (2002: 96-97) emphasises the importance of research and international collaborations between developed and developing countries to improve cleft care worldwide.

The sub-Saharan African region, including Mauritius, has a population of 130 million children younger than 6 years (Garcia, Pence & Evans, 2007: 11). It is estimated that many of these children have some form of disability with delays/disorders in communication that can seriously hamper their future development (WHO, 2001: 36; <http://web.worldbank.org>). A physical impairment such as cleft lip and/or palate may lead to disability in the absence of early intervention to prevent or minimize the negative impact of the cleft on the child and his/her family.

The quality of life of children with cleft is dependent on the availability and prioritization of health care resources (Wickenden in Mars et al., 2008: 146). In many developing countries, speech-language therapy and audiology services are either limited to meet the need of large populations or not available at all. Mauritius is a middle income group developing country (<http://web.worldbank.org>), with a high literacy level (86%) and free health care access. It should be possible to provide better cleft care than the existing services, despite the scarcity of speech-language therapists and audiologists. The existing framework of free access to health and education services can be expanded to offer improved, team coordinated and comprehensive cleft care. However, improving cleft care in Mauritius requires health care professionals to review the existing health care systems to identify gaps or limitations in current cleft care. This should guide and influence policy makers' decisions regarding prioritizing of health services for cleft care.

In contrast to developing countries, developed countries have implemented principles of cleft care based on extensive research evidence. It is well established that comprehensive and interdisciplinary treatment by experienced health care professionals is the key to high quality care of individuals with cleft lip and/or palate (ACPA, 2007: 5; Bzoch, 2004: 52; Mars et al., 2008: 15). However, 'importing' policies on cleft care from developed to developing countries without adaptation to local context of Mauritius may not deliver desired results. The experiences of International Outreach Missions from developed to developing countries support the view that establishing a good cleft care in a developing country requires continuous and sustained levels of attention (Mars et al., 2008: 13). In a developing country, the goal of cleft care should be to

build infrastructure, train personnel and develop a self-supporting and sustainable system of cleft care (D'Antonio & Nagarajan, 2003: 308; Mars et al., 2008: 9).

Improving cleft care may appear straightforward, as cleft anomaly can be corrected surgically. However, surgical repair of the anatomical anomaly alone cannot alleviate the impact of the cleft on the child and his/her family. The affected child may have persistent communication problems despite surgical correction (Reeve, Groce, Persing & Magge, 2004: 170). There may be persistent hearing concerns as well. It is therefore of paramount importance that communication and audiological interventions should fit in with the existing cleft care services to support the child with CL/P and his/her family to adapt to the long-term issues (Sell, 2007: 17). Families in developing countries often have limited knowledge of treatment (for example, the need for early surgical intervention and a multidisciplinary approach to treatment), the pathway of care, including the consequences of clefting conditions (Prathanee et al., 2006: 502).

This study on cleft care in Mauritius, found that existing facilities (the free access to health care, the availability of plastic surgical treatment and the presence of speech-language therapy and audiology services within the public health system) could facilitate the improvement of cleft care. However, prior to the research project, the speech-language therapists and audiologists working in public health sector of Mauritius did not have access to contextually appropriate communication assessment tools for any communication disorders. Moreover, uniform and consistent services could not be provided to young children with CL/P and their families due to the lack of an interdisciplinary approach to assessments in Mauritius.

Figure 6.1 is an overview of discussion of main themes of the concluding chapter.

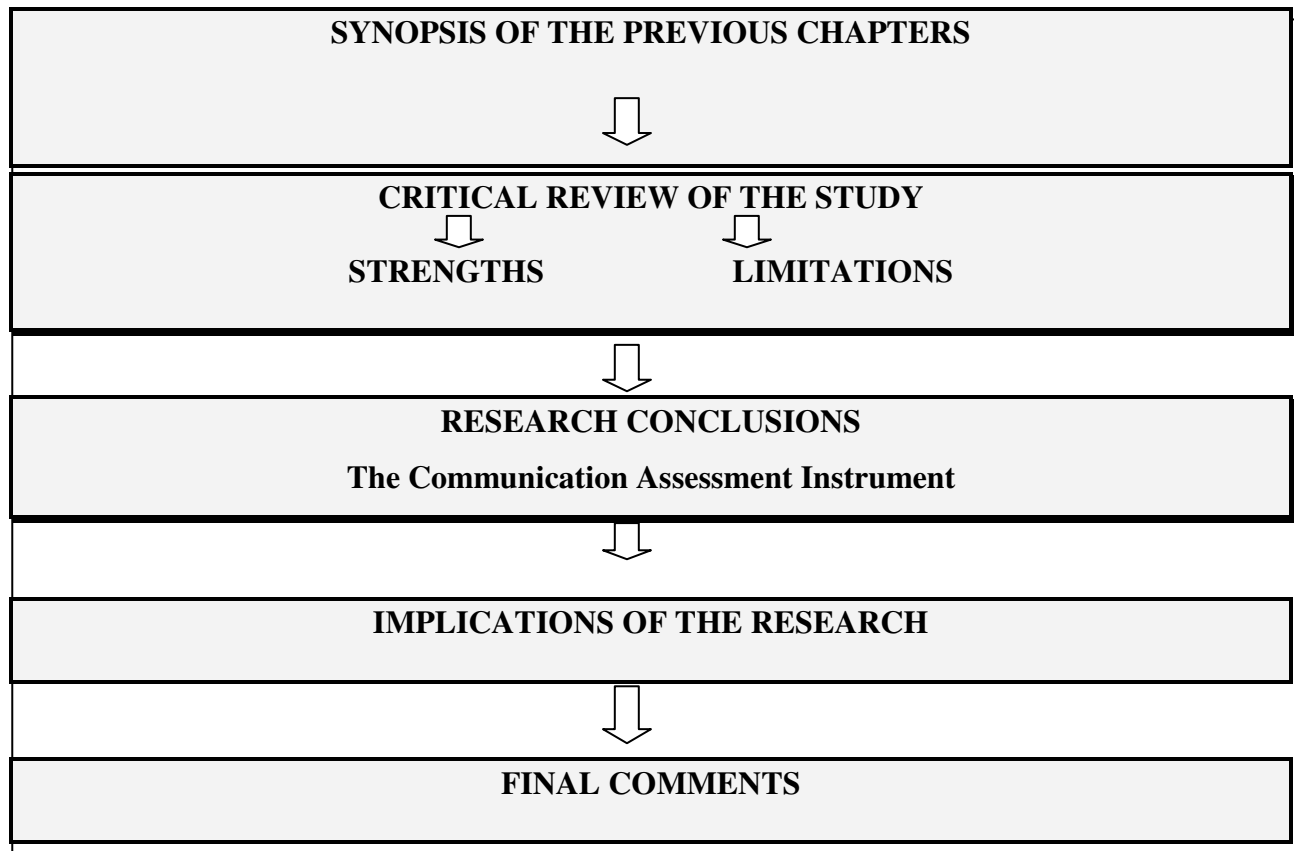


FIGURE 6.1 Presentation of the main themes discussed in Chapter Six

6.2 SYNOPSIS OF THE PREVIOUS CHAPTERS

The first chapter presented an overview of recommended best practice for young children with CL/P in developed countries. The continuum of cleft care from developing to developed countries was also described and the barriers to the provision of an optimal standard for cleft care in developing countries were identified. Mauritius was introduced as the context within which the research would be conducted. An urgent clinical need for the development of an appropriate

assessment instrument and the uniform documentation of the assessment information of children with CL/P was identified as the impetus to address the barriers to improving cleft care in Mauritius.

In Chapter Two, a critical review of the literature on the impact of a cleft on the child with CL/P and his/her family was presented. Research from developed countries on cleft conditions was discussed and provided evidence for the importance of continued and sustained cleft care by an interdisciplinary team of professionals from birth, and at every stage of early communication development of the young child with CL/P. The best practice recommendations for cleft care from developed countries were analysed to identify strategies which could be applied to improve the standards of cleft care in developing countries. A strategy to provide holistic and effective cleft care by speech-language therapists and audiologists by having access to a contextually appropriate assessment instrument for early intervention to young children with CL/P was proposed.

The third chapter focused on the importance of early intervention and the thorough assessment of speech, language and hearing of young children with CL/P to ensure a quality treatment plan. The uniform standard documentation and electronic storage of assessment results was identified as a key strategy to monitor programme effectiveness, measure treatment outcomes and improve quality of cleft care. Access to a linguistically appropriate assessment instrument is a major challenge to speech-language therapists and audiologists working in Mauritius and other developing countries. The framework for a communication assessment protocol (refer to Table 4.8) for young children with CL/P was conceptualized. This was based on an in-depth literature

review and related to the needs of developing countries with limited numbers of speech-language therapists and audiologists. Access to such a generic, comprehensive communication assessment instrument positions speech-language therapists and audiologists strategically to improve cleft care services especially in developing countries where team-based cleft care is not readily available.

Chapter Four provided a detailed description of the methodology used to compile a comprehensive communication assessment instrument and database for young children with CL/P in Mauritius and to test its clinical applicability and acceptability. The research questions that emerged from the clinical experiences of the researcher guided the research design, selection of participants, materials and apparatus as well as the procedures for data collection and analyses.

The participatory action research with a mixed methods research approach was effective in providing descriptive characteristics of the participants and formed the underpinnings of the development of a new assessment instrument with linguistic relevance in Mauritius. A checklist format of the assessment tracking form was created. The speech elicitation materials were prepared in the local languages (Creole, French and English), a pilot study performed, speech-language therapists and audiologists trained in conducting the assessments, and digital audio and video recordings of the speech samples were obtained. This allowed data collection to be uniform in the young children with CL/P selected by the speech-language therapists and audiologists.

The fifth chapter presented the results and interpretation of the empirical research findings. It was possible to provide a clear and detailed description of the characteristics of young children with CL/P and their families based on the data analysis of the sample population. The clinical applicability of the newly developed Communication Assessment Protocol was evaluated by all four participants (speech-language therapists and audiologists working in the public health sector). The ‘end users’ of the protocol gained hands-on experience in the assessment procedures. The acceptability of the protocol was analysed based on information gained from the focus group discussion by the participating speech-language therapists and audiologists. The implementation of the protocol in a clinical setting of the existing public health care system in Mauritius showed that it is a simple to use assessment tool, has local relevance and envisages ECI for children with CL/P.

6.3 CRITICAL REVIEW OF THE STUDY

A critical review of the study allows reflection on the extent to which the aims of the research were achieved, limitations of the study and how the research design could have been improved for future studies.

6.3.1 Strengths of the study

This was the first study conducted in Mauritius to develop a communication assessment instrument for use by local speech-language therapists and audiologists to improve clinical practice for young children with CL/P. The following strengths were identified:

- Rigorous methodology

A rich data-set was gathered by using the mixed methods approach (Cresswell, 2003: 15) including the participation of speech-language therapists and audiologists who had rapport with the participants (children with CL/P and their families). The trustworthiness of the data gathered (De Vos et al., 2005: 161; Leedy & Ormrod, 2005: 93) was ensured as data collected from the hospital records were complemented by information gained from interviews with parents of the children with CL/P. The research involved all the speech-language therapists in the public health sector as providing a uniform service of agreed upon standard at a national level is important to improve cleft care. Families of the children selected as participants were also included in the assessment procedure to facilitate ECI, by establishing partnerships between speech-language therapists and audiologists, and parents of young children with CL/P.

A description of family characteristics and parental perceptions of feeding, hearing and speech problems in their children with CL/P in Mauritius was documented in a uniform manner. The description served as a framework of essential components to design the database. A varying method of collecting functional data allowed both quantitative and qualitative data analyses which provided a broad description of the characteristics of these children, as well as of the health and cleft care in Mauritius. The use of mixed methodology also allowed the combination of empirical and descriptive precisions in a single study (Johnson & Onwuegbuzie, 2004: 15) thus providing greater insight into a social reality, which allowed for a more comprehensive study (De Vos et al., 2005: 364).

- **Holistic approach to communication assessment**

The Communication Assessment Protocol was designed to encourage comprehensive assessments of the children with CL/P as the cleft condition has a pervasive impact on the feeding, hearing, communication development and speech production of the developing child. The approach to assessment was holistic as it included thorough family and background information of the child being assessed. The Communication Assessment Protocol was comprehensive as it covered many areas of functioning, namely: feeding, hearing, and general development in addition to the speech and language assessments. Furthermore, attention was paid to elements of school readiness of young children with CL/P by including assessments of listening skills and emergent literacy skills. Such a holistic and comprehensive approach to assessment is particularly beneficial in a developing country where the interdisciplinary team approach is inadequate. The speech-language therapist and audiologist often work in isolation and has to play a proactive role in referring the cases requiring assessment by other professionals (for example dental/ENT specialists). The development of the Communication Assessment Protocol also built on the fact that in Mauritius, the audiology and speech therapy services are combined. This allowed for diagnostic hearing evaluations to be part of the protocol.

- **A user friendly Communication Assessment Protocol that was acceptable to the speech-language therapists and audiologists**

The Communication Assessment Protocol was compiled from selected assessment components to suit the local needs, thus reflecting best practice in assessment (ACPA, 2007: 6). The theoretical framework and use of existing protocols and tools to guide the process ensured that the Communication Assessment Protocol reflects current trends in assessments of young children

with CL/P. Moreover, it was compiled from assessments that are used in clinical practice in established centres for the care of young children with CL/P. For example, Section E of the protocol (refer to Appendix VI) was compiled from the Communication Assessment Protocol, Facial Cleft Deformities Clinic, Department of Oro-Maxillo-Facial Surgery, University of Pretoria; and the speech assessment was compiled from the GOS.SP.ASS 98 which is a comprehensive practical tool for clinical and research purposes in the UK (Sell et al., 1999: 26).

The tracking form followed a checklist format (Shipley & McAfee, 2004: 233). Such a format allows all necessary information to be gathered and recorded in a uniform assessment procedure and to facilitate the evaluation and quantification of complex communication behaviours (Leedy & Ormrod, 2005: 185). With the Communication Assessment Protocol, the child's development can be tracked on the same instrument from birth to age 6 years and it covers the most critical period for children with this congenital anomaly.

Furthermore, the complex task of assessment of young children with CL/P by speech-language therapists and audiologists who are inexperienced in cleft care was facilitated and guided by the use of a checklist format of the communication assessment instrument. This addressed one of the main challenges that speech-language therapists and audiologists face in developing countries, namely the lack of specialist knowledge and training in assessment and treatment of children with craniofacial anomalies. Although the speech-language therapists and audiologists may have been inexperienced at the outset of the research, they received training by the principal researcher in conducting assessments of young children with CL/P according to the Communication Assessment Protocol. Moreover, their participation in implementation of the

protocol ensured that they gained experience in the assessment of young children with CL/P and their families.

The speech-language therapists and audiologists were successful in identifying the children with feeding, hearing and communication delays/disorders and children who required in-depth language assessments. A standard speech-sampling protocol is now available for use in Mauritius, in Creole, French and English, to capture cleft type speech errors and to facilitate inter-centre comparisons from an adequate speech sample. The Communication Assessment Protocol may also be used for early communication assessments of young children with risks other than craniofacial disorders. The versatility of the Communication Assessment Protocol was identified by the participants during the focus group discussion.

The reliability of the material for perceptual speech analysis was also established. This was an important step given that instruments for assessment of velopharyngeal functions, such as videofluoroscopy, are not currently available in Mauritius to complement the information derived from auditory-perceptual speech assessments.

- **Contextual sensitivity**

The Communication Assessment Protocol was compiled specifically for the Mauritian context making it culturally and linguistically relevant. The speech materials in Creole and French allowed speech production assessment in the two most commonly spoken languages by the sample population. Added value to the protocol was achieved by reviewing its implementation for the purposes of communication assessment of children with CL/P in the local context, and by

determining its' acceptability by the speech-language therapists and audiologists. The Communication Assessment Protocol was developed for use in a clinical setting and the ecological validity (Morgan et al., 2006: 135) of the assessment procedures was ensured by conducting the assessments in a realistic setting (the hospital context). A fair chance to participate was given to all children with CL/P from the central plastic surgery service within the public health sector of Mauritius.

6.3.2 Limitations of the study

While interpreting the clinical implications of the research findings, account has to be taken of some of the limitations of the present study

- The Communication Assessment Instrument

The Communication Assessment Instrument was not suitable for in-depth communication assessments of young children with CL/P as it is a comprehensive screening tool that provides a broad overview of the child with CL/P. For example, if a child was identified with a language delay, further in-depth assessments of semantics, syntax and socio-communicative aspects will be required (Peterson-Falzone et al., 2010: 280; Shprintzen & Bardach, 1995: 169). In this study, priority was given to the development of an assessment protocol for a specific clinical situation, where time constraints do not permit lengthy and exhaustive assessments.

The cross-sectional design did not allow for recording a complete chronology of the children's development. In clinical practice serial assessments are required (ACPA, 2007: 13) to provide

continuity of care and identification of new concerns on a timely basis. A longitudinal research design (Leedy & Ormrod, 2005: 183) in which serial assessments were conducted during follow up visits would have allowed the researcher to describe developmental trends based on assessments at the various stages of development of a child with CL/P from birth to age 6 years. However, the cross-sectional research design is a starting point in a context where no structured and consistent approach to assessment of communication disorders existed before.

- **Research limited to public health sector of Mauritius**

The implementation of the Communication Assessment Protocol was limited to the children with CL/P treated within the public health sector of Mauritius. Neither the children with CL/P who are treated in the private sector nor those who seek help outside the country were included in the study as the research targeted the public health context. Some Mauritian families choose to seek treatment for their children with CL/P in the private health sector and even abroad. In the local context the private sector does not offer a team approach. The children, who are treated abroad, in well established cleft care centres, probably benefit from the team approach offered there. Therefore, the results of this study may not be reflective of the children with CL/P who are treated in the private sector of Mauritius.

Moreover, the number of speech-language therapists and audiologists as participants in the research were limited to four including the principal researcher. However, this is the total number of speech-language therapists and audiologists employed in the public health sector and they all participated in the study. There are six more speech-language therapists and audiologists in Mauritius in the private sector. As the aim of this study was to establish a uniform service in

the public sector, the therapists in the private sector were not included as participants. In the future the Communication Assessment Protocol will be made available to them as a clinical tool. Nevertheless, this study helped to introduce uniform and standard documentation of the communication assessments of young children with CL/P in the public health sector.

- **Researcher bias**

Measures were taken to avoid any form of researcher bias, such as using a self-administered anonymous questionnaire. But as the number of therapists was small (only three besides the principal researcher), anonymity could not be guaranteed. The qualitative part of the study was a focus group discussion in the presence of a facilitator to determine the acceptability of the protocol. Again the speech-language therapists and audiologists may have responded positively (positive bias) to appear in agreement with the protocol for any one or more of the following reasons:

- They were relatively inexperienced in cleft care,
- They were in the presence of the principal investigator who is also their Chief in the established hierarchy of the public health sector in Mauritius

The probable presence of bias in this type of research is acknowledged (Leedy & Ormrod, 2005: 210). The principal researcher was aware of 'researcher bias' and took care not to influence the speech-language therapists and audiologists in any way. Including speech-language therapists from the private sector in future may minimize the positive bias identified in this study.

- **Descriptive nature of the study**

The nature of this study was descriptive (Tetnowski & Franklin, 2003: 156) in order to initiate a clinically and locally applicable communication assessment protocol. To assess the accuracy of a new test, results obtained from the new instrument had to be compared with some other established test(s) viewed as the ‘gold standard’ in yielding valid results (Maxwell & Satake, 2006: 233). The accuracy of the new Communication Assessment Protocol could not be fully determined as no such assessment protocol existed before to compare assessments of children with CL/P using Communication Assessment Protocol.

Although intervention studies (Kirschner et al., 2000: 2127-2132; Ysunza et al., 2004: 1500) have shown that early surgical intervention improves speech outcome, to the knowledge of the researcher, there are no analytical or interventional studies to show if an intervention such as using a structured and uniform protocol has impact on the outcome for young children with CL/P. The results of the present cross-sectional study may be used to instigate a future interventional study.

The limitations of this research are important to note for clinical implementation of the Communication Assessment Protocol as well as for future research on the communication abilities of young children with CL/P in Mauritius. There is scope for further research to refine and improve the Communication Assessment Protocol.

6.4 CONCLUSIONS

The main aim of the empirical research was achieved with the development of a generic Communication Assessment Protocol for a heterogeneous group of French and Creole speaking children with CL/P (including children with syndromes and sequences) during the crucial early years of their development. It was an innovative response to the need for developing an appropriate assessment instrument that was both locally applicable and acceptable and incorporated the recommendations for best practice in cleft care. The following conclusions were reached based on the empirical research:

Sub-aim One: Description of the characteristics of children with CL/P in Mauritius

Important demographic and clinical characteristics emerged from the descriptions of participants in Phase One of the study. This helped the creation of a database for the registration of cases with craniofacial disorders. The implementation of the Communication Assessment Protocol in a clinical setting of the existing public health care system and the analyses of results showed that favourable conditions exist in Mauritius for early identification of children with communication delays and disorders. Speech-language therapists and audiologists with the participation of parents of the children with CL/P were successful in identifying specific aspects of communication skills development from the neonatal and infancy stages. Furthermore, the principles of assessment from ECI literature (ASHA, 2008: 4; Bagnato et al., 1997: 35; Billeaud, 2003: 142; Rossetti, 2001: 102) and recommendations for assessment of young children with CL/P (ACPA, 2007) were integrated in this holistic assessment protocol.

Sub-aim Two: Compilation and application of the Communication Assessment Protocol for clinical use in Mauritius

The Communication Assessment Protocol followed international guidelines and recommendations for development of a standardised early communication and speech assessments (for example, CHRIB from the University of Pretoria and GOS.SP.ASS from the UK). It was successful in fulfilling its purpose, in Mauritius, to assess children with CL/P and identify those exhibiting communication delays/disorders. Moreover, results of these assessments allowed speech-language therapists to refer children to the various professionals who have specific roles in cleft care. For example, children identified with hearing loss were referred to the ENT specialists for management. As speech-language therapists and audiologists in Mauritius work in the absence of an established interdisciplinary team approach, the Communication Assessment Protocol helped them to face the challenge of conducting assessments in young children with CL/P.

The methodology adopted to test the applicability of this protocol involved the training of the speech-language therapists and audiologists in Mauritius, in the assessment procedures that contributed to consistency and uniformity in assessment procedures. Through participation in each of the three phases of the empirical research a sense of ownership of the assessment protocol was established. This was in line with international recommendations for local capacity building in developing countries (Mars et al., 2008: xi) and for developing contextually, linguistically appropriate protocols (ACPA, 2007: 6).

The Communication Assessment Protocol has immediate value as its implementation was tested and was given positive feedback from the participating speech-language therapists and audiologists from the public health sector of Mauritius, regarding its usefulness as an applicable assessment instrument.

Sub-aim Three: Determining the acceptability of the Communication Assessment Protocol

The Communication Assessment Protocol addressed the identified need to conduct holistic assessments of communication skills from infancy through to preschool age children with CL/P. The communication assessment procedures using the protocol were successfully implemented by the speech-language therapists and audiologists in a clinical situation in the hospital using existing facilities.

In a busy clinical situation, the time taken for assessment is a significant factor in considering the applicability of the tool. The speech-language therapists and audiologists could conduct communication assessments of the young children with CL/P, by using the protocol, within what the participants felt was a reasonable time (40-60 minutes) which added to the acceptability of the protocol for clinical use.

The results obtained from the questionnaire and the focus group session established that the speech-language therapists and audiologists perceived the Communication Assessment Protocol as being practical and acceptable.

Another important aspect of this research study was that an attempt was made to develop a protocol and database within Mauritius itself as opposed to importing or borrowing one from a developed country or relying on an international outreach mission to develop local services. Local speech-language therapists and audiologists developed a communication assessment protocol and stimulus material in three languages to serve the Mauritian population of children with CL/P. The methodology clearly described the process. It may be used by professionals in other developing and developed contexts with adaptations (for example, compiling speech elicitation materials in local language/s) to implement an appropriate Communication Assessment Protocol (refer to Appendix VI).

6.5 IMPLICATIONS OF THE RESEARCH

Research in developing countries should have immediate added value for clinical practice as the resources are limited (Walley et al., 2007: 424). The focus of the empirical research was therefore to contribute to the improvement of cleft care in Mauritius, by addressing the barrier to early communication intervention and the lack of an appropriate communication assessment instrument and a database. Important theoretical and clinical implications that were deduced from the results of the empirical research and recommendations are presented forthwith.

- National register

The present study resulted in the creation of an electronic database for young children with CL/P which in future will serve as a national database of persons with craniofacial anomalies. All children with CL/P should be included in the national register, irrespective of whether they are treated in the public or private health sectors. However, in order to include children being

treated in the private sector participation through legislation (Hammond & Stassen, 1999: 155) or close collaborations between the private and public health sector in Mauritius will be required to register all children born with craniofacial anomalies in the national register. The registry will facilitate the ascertainment of cases with oral clefts to establish health care needs and plan improvement in services. It can also be used to track individual child progress in the system: - vital information that was previously not available in Mauritius. Policy/decision makers within the Government of Mauritius can use the comprehensive information system developed to access information and plan strategies and resources that will be required to improve cleft care in future. The background information that has been documented in a uniform format can form the basis for future epidemiological research.



CLEFT PALATE-CRANIOFACIAL ANOMALIES REGISTER

IDENTIFICATION DETAILS OF PATIENT	MOTHER'S DETAILS	FATHER'S DETAILS	BIRTH / FAMILY HISTORY																									
Health Region <input type="text"/> Unitnumber: <input type="text"/> Surname <input type="text"/> Name <input type="text"/> Sex <input type="text"/> Date of Birth <input type="text"/> Age <input type="text"/> Ethnic Group <input type="text"/> Street <input type="text"/> Locality <input type="text"/> Vil_Town <input type="text"/> Telephone Number <input type="text"/> Mobile Number <input type="text"/>	Age (Yrs) <input type="text"/> Education Level <input type="text"/> Age group when child was born <input type="text"/> Occupation <input type="text"/>	Age (Yrs) <input type="text"/> Education Level <input type="text"/> Occupation <input type="text"/>	Place of Delivery <input type="text"/> Language/s Spoken <input type="text"/> Type of Delivery <input type="text"/> Are parents blood related <input type="text"/> Weight birth (kg) <input type="text"/> Family History <input type="text"/> Birth Weight Type <input type="text"/>																									
TYPES OF CLEFT																												
<table style="width: 100%;"> <tr> <td style="width: 30%;"></td> <td style="width: 10%; text-align: center;">Right</td> <td style="width: 10%; text-align: center;">Left</td> <td style="width: 10%; text-align: center;">Bilateral</td> <td style="width: 40%;"></td> </tr> <tr> <td>LP</td> <td><input type="text"/></td> <td><input type="text"/></td> <td><input type="text"/></td> <td>Hard Palate <input type="text"/></td> </tr> <tr> <td>Alveolus</td> <td><input type="text"/></td> <td><input type="text"/></td> <td><input type="text"/></td> <td>Soft Palate <input type="text"/></td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td>Submucous Cleft <input type="text"/></td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td>No cleft but seen for YPI <input type="text"/></td> </tr> </table>					Right	Left	Bilateral		LP	<input type="text"/>	<input type="text"/>	<input type="text"/>	Hard Palate <input type="text"/>	Alveolus	<input type="text"/>	<input type="text"/>	<input type="text"/>	Soft Palate <input type="text"/>					Submucous Cleft <input type="text"/>					No cleft but seen for YPI <input type="text"/>
	Right	Left	Bilateral																									
LP	<input type="text"/>	<input type="text"/>	<input type="text"/>	Hard Palate <input type="text"/>																								
Alveolus	<input type="text"/>	<input type="text"/>	<input type="text"/>	Soft Palate <input type="text"/>																								
				Submucous Cleft <input type="text"/>																								
				No cleft but seen for YPI <input type="text"/>																								
SURGICAL HISTORY			FOLLOW UP TREATMENT																									
Date first seen by surgeon <input type="text"/> Operation_Cleft <input type="text"/>			Treating Professional/s <input type="text"/> Health Institution <input type="text"/> Date Registered <input type="text"/> Remarks <input type="text"/>																									
Site_operation 1 <input type="text"/>	Age Operation 1 <input type="text"/>	Date operation 1 <input type="text"/> Plastic Surgeon 1 <input type="text"/>																										
Site_operation 2 <input type="text"/>	Age operation 2 <input type="text"/>	Date operation 2 <input type="text"/> Plastic Surgeon 2 <input type="text"/>																										
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Record: 1 of 1

FIGURE 6.2 Sample page from the proposed national register for cleft palate-craniofacial anomalies in Mauritius

The setting up of a national registry is also in line with the WHO (2001b: ix) recommendation for a global registry to facilitate international collaborative research in the field of craniofacial anomalies. The maintenance of records and a database of individuals with CL/P at a national level is an important objective of this study.

- Longitudinal communication assessment: an outline for clinical practice. In the current study, the Communication Assessment Protocol was applied for the assessment of the children with CL/P in two age groups namely younger than 36 months and 36-78 months age groups, in a

cross sectional sample. However, it should be possible to use the Communication Assessment Protocol for the longitudinal assessment and monitoring of the child with CL/P in clinical practice as outlined in Figure 6.3.

The guidelines recommended by the ACPA (2007) for a longitudinal communication assessment plan can be followed in Mauritius. The results of the empirical research indicated that four stages for serial communication assessments could be implemented in Mauritius namely: infancy (younger than 18 months), toddlerhood (~18-36 months), pre-primary school entry level (~36 months) and primary school entry level (~72 months) (refer to Figure 6.3). The Communication Assessment Protocol was developed to conduct such serial assessments. Serial assessments of children have several advantages such as measuring developmental patterns, rates of development and change (Rossetti, 2001: 104). Moreover, serial assessments serve the important purpose of measuring treatment outcomes.



**COMMUNICATION
ASSESSMENT PROTOCOL
(Longitudinal Assessment plan)**

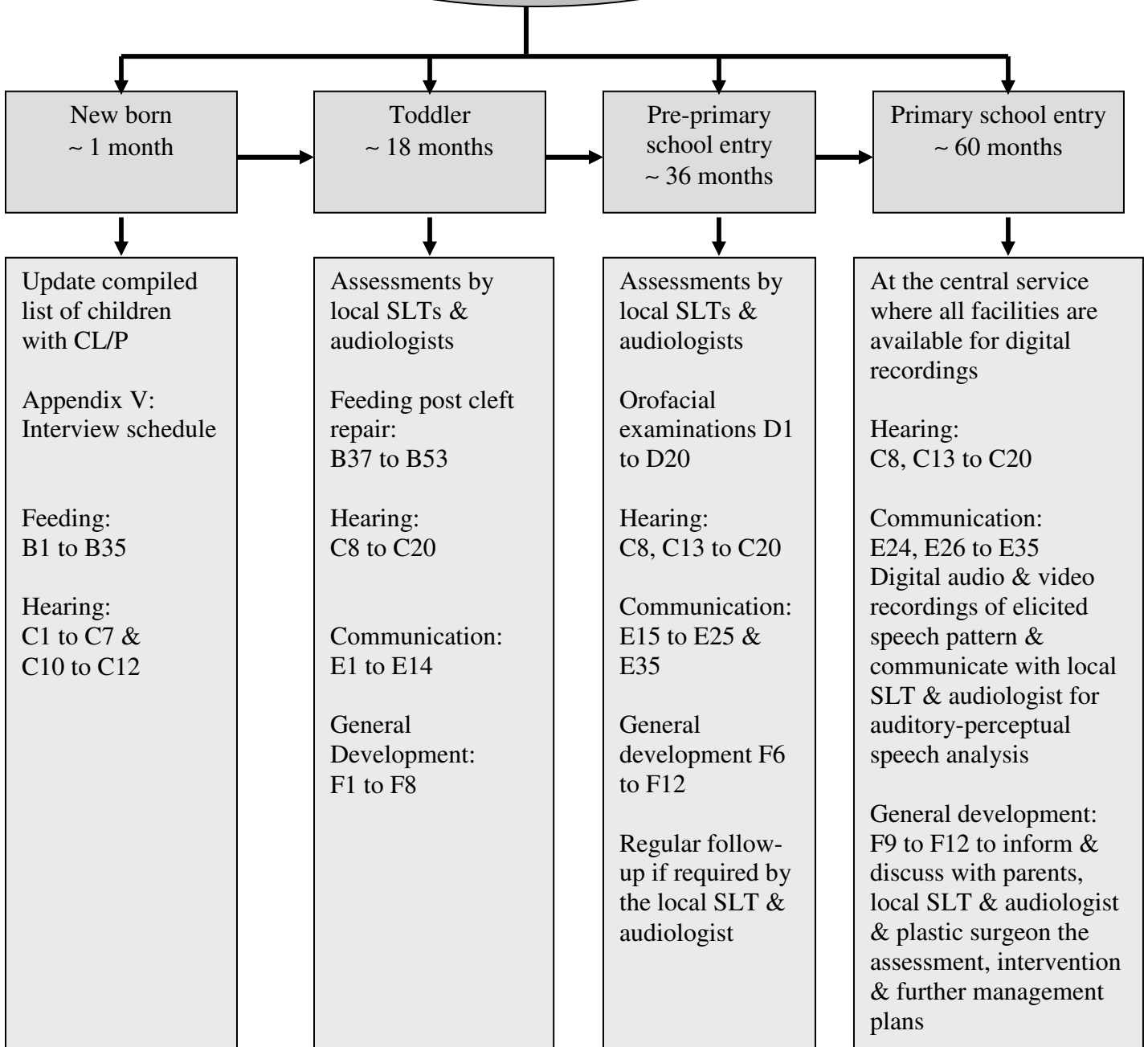


FIGURE 6.3 A plan for longitudinal communication assessments

Legend: For test items refer to Appendix VI; SLT- Speech-language therapist

- Speech elicitation material

In response to the international call for standardised speech elicitation materials (Eurocran speech project, 2000; Henningsson et al., 2008: 4; Hutters & Henningsson, 2004: 456) the speech materials were compiled in three languages namely Creole, French and English so as to be relevant to the Mauritian context. The speech elicitation materials were applicable to the small multilingual community in Mauritius to improve assessments and subsequently improve the quality of care to young children with CL/P. The speech elicitation materials will allow for future participation in outcome studies and international collaborative research. Prior to this research no speech elicitation materials in Creole or French were available in Mauritius, that could be uniformly used by all speech language therapists in the public health sector and resulted in an inconsistent and non-comparable approach to assessments and treatment programmes. A need was identified for normative studies in Mauritius and compiling speech material for use with children with other communication disorders.

- Team care

The speech-language therapists and audiologists can play a pivotal role in steering cleft care in Mauritius, towards an interdisciplinary team-based approach. The Communication Assessment Protocol allows the speech-language therapists and audiologists to identify the contributing etiological factors to communication delays/disorders and alert health care professionals of areas of concern in the child with CL/P. The protocol requires input from parents of the children with CL/P and parental involvement can be utilised to increase awareness of ECI and encourage their participation (Rossetti, 2001: 94; Scherer et al., 2008: 27). The clinical implications of team cleft care in the context of Mauritius are conceptualised in Figure 6.4.

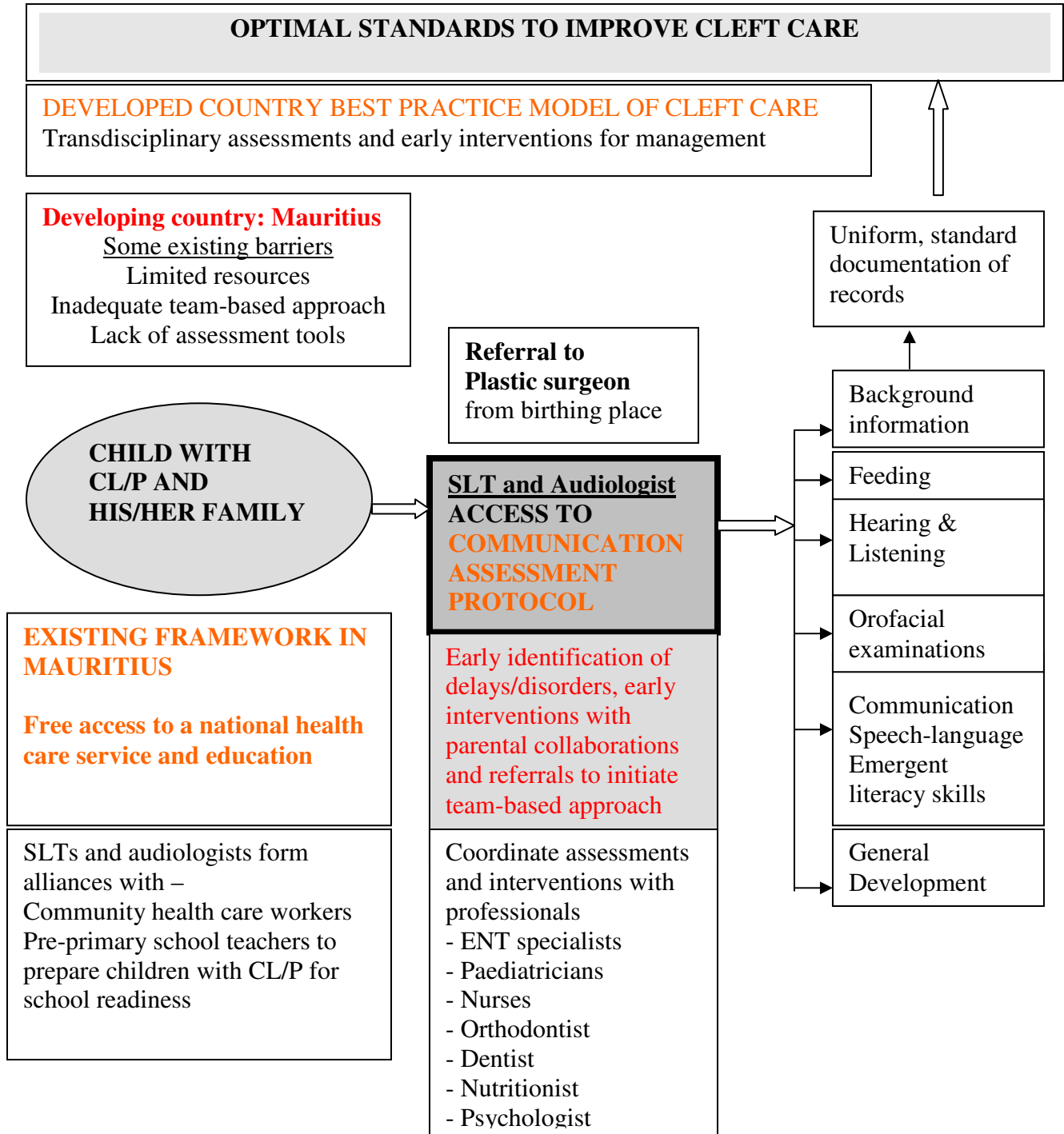


FIGURE 6.4 Clinical implications of the Communication Assessment Protocol

In accordance with practice guidelines for cleft care that recommend an interdisciplinary coordinated team approach to cleft care (ACPA, 2007:7-8; WHO, 2002:142) the Communication

Assessment Protocol fills an urgent need to initiate an interdisciplinary team approach in Mauritius (refer to Figure 6.4). The health care professionals need to liaise, collaborate and coordinate assessments and interventions to meet the optimum standards in cleft care. A holistic view of a child's communication skills can be obtained given the all inclusive, multifaceted nature of the Communication Assessment Protocol. Moreover, such a planned and consistent approach to assessment is necessary and of immediate value in the Mauritian context.

Cleft care in Mauritius can also be expanded by actively involving other available resources, for example community health workers and teachers, to help speech-language therapist deliver cleft care services at community level. In Sri-Lanka, training of community health workers and utilization of their services was developed into a successful service delivery model for individuals with CL/P (Wirt et al., 1990: 172), India (D'Antonio & Nagarajan 2003: 309) as well as in Thailand (Prathanee et al., 2006: 505). The government of Mauritius collaborated with the WHO (1990) to initiate a formal training programme for community health workers. Currently 236 such workers operate within the community to provide home visits for surveys, identification and interventions to persons with disabilities (http://www.afro.who.int/hrh-observatory/country_information/Mauritius.pdf). Speech-language therapists and audiologists can further contribute to training community health workers in the early identification and intervention of communication and hearing disorders in young children with CL/P and their families. Thus, families of young children with CL/P can benefit from services provided by these trained community health workers.

In Mauritius, there has been free access to primary and secondary education since 1977 and since 2005 the Education Act rendered education compulsory until the age of 16 years (Garcia, Pence

& Evans, 2007: 250). The enrolment ratio of pre-primary school in Mauritius is 100% (Garcia et al. 2007: 24). This creates opportunities for speech-language therapists to form new collaborative relationships with teachers as the educational system is an appropriate setting for a collaborative approach to the promotion of language, speech and literacy development and intervention for those children who exhibit delays and disorders.

- **Application of the Communication Assessment Protocol in other contexts**

The participatory action research was conducted in Mauritius and the applicability and acceptability of the Communication Assessment Protocol (refer to Appendix VI) was confirmed. Although the results cannot be generalized to other contexts, the protocol has potential for use along the continuum of developing to developed countries. In contexts similar to Mauritius (middle income economies for example Namibia), where speech-language therapists and audiologists are available, the Communication Assessment Protocol, is a valuable and organised checklist (refer to Appendix VI) approach to assessment. Important information regarding the key areas (feeding, hearing, communication, general development) can be obtained reliably and such information can then form the basis of intervention to help improve care provided to children with CL/P and referrals can be made to other professionals as well. Thus, even speech-language therapists and audiologists who work in schools or in the community and are required to provide therapy for children with CL/P, can access a comprehensive communication assessment protocol. Moreover, the protocol uses parental reports concerning their child's communication that may be useful in alerting them to strengths and weaknesses in their child's communication skills and speech pattern. The high literacy levels of parents in contexts similar to Mauritius, implies that such parents can participate in developing communication skills of

children with CL/P. Speech-language therapists and audiologists may adapt the Communication Assessment Protocol to suit their local needs. The steps followed in developing the speech elicitation materials in Creole and French in this study may be used as a guide to prepare speech elicitation materials for assessment in local language/s.

The Communication Assessment Protocol also has potential for use in contexts where speech-language therapists and audiologists are not available. As suggested by D'Antonio and Nagarajan (2003: 308) existing resource persons may be trained to perform some functions of the speech-language therapists and audiologists in cleft care. The Communication Assessment Protocol has certain sections that could be applied in such circumstances. For example, in resource poor countries where the mortality of children is high due to feeding issues particularly for infants with cleft palate (Amstalden-Mendes, Magna & Lopez, 2006: 332; Mars et al., 2008: 127) the Feeding section (refer to section B, Appendix VI) of the protocol may be used by nursing personnel. Assessment of feeding methods and observations on growth may be helpful in guiding parents regarding some of the cleft palate related feeding issues. Formal training of local resource persons for example teachers and, community health workers, by speech-language therapists and audiologists from cleft teams in developed countries would enable them to perform the speech assessment section as well as basic treatment of cleft palate related speech disorders (D'Antonio, 2002: 34; Sell, 2007: 17).

Thus, the initiation of a team-based approach and expansion through collaboration with available local resources is important for the provision of quality care to young children with CL/P. The envisaged holistic approach whereby the social, medical, psychosocial and pedagogical needs of

young children with CL/P and their families are met is likely to improve and sustain cleft care in Mauritius. Generalizing the results of the Communication Assessment Protocol in developed and developing contexts is also possible with appropriate adaptations of the protocol and training of locally available resources.

6.6 RECOMMENDATIONS FOR FUTURE RESEARCH

Research is a helical process that begins with a problem but the resolution of the problem opens up new problems to be addressed (Leedy & Ormrod, 2005: 7). Despite limited resources there is a significant need and great scope for further research on CL/P in developing countries. The current research has led to the identification of several issues which warrant future research in Mauritius.

- Epidemiological research on Craniofacial Anomalies in Mauritius

The compiled database (national register and assessments) may be used for research on the epidemiology and prevalence of craniofacial anomalies in Mauritius. Epidemiological research is possible through regional and international collaborative research, and setting up a website for the registry (Shaw, 2004: 239). The database is an exciting response to the WHO (2001b: ix) recommendation for a global registry and database recording of craniofacial anomalies to improve the current level of knowledge available on birth prevalence of craniofacial anomalies and their associated international, geographical, ethnic and cultural variations. An epidemiological study would ensure that information is readily accessible for taking preventive measures, planning and allocating appropriate resources to improve cleft care. A major issue in

the descriptive epidemiology of craniofacial anomalies is the identification of ascertainment sources (Wyszynski, 2002: 128). In Mauritius, as 99% of births take place under skilled medical care and the average number of annual births is only between 18000 to 20000 (Central Statistics Office, 2006), conducting epidemiological research on craniofacial anomalies is a feasible research recommendation and would allow Mauritius to participate in the WHO (2002: 41) initiative to improve cleft care globally.

- Evaluation research to determine the effectiveness of the Communication Assessment Protocol for serial assessments

The effectiveness of the Communication Assessment Protocol needs to be verified with a longitudinal/cohort type of research design (Leedy & Ormrod, 2005: 108; Neuman, 2000: 30) for serial assessments. This cross-sectional research study established baseline data per participant that can be utilised to conduct serial assessments on the group of subjects over a period of time. Such a longitudinal study could track the developmental changes of the child with CL/P. A cohort/prospective study (Maxwell & Satake, 2006: 214) over a predetermined time frame can be conducted to determine the effectiveness of implementing the Communication Assessment Protocol on young children with CL/P in Mauritius. Information on a child's development over time could also provide data for treatment/therapy outcome measures that are necessary for evidence based clinical practice (Johnson, 2006: 30).

- Intervention research to initiate the establishment of an interdisciplinary team approach to assessments and interventions of young children with CL/P

Research on the perspectives of other professionals (for example ENT specialists, paediatricians, nurses, teachers) regarding the implementation of the Communication Assessment Protocol also needs to be conducted. The perspectives of all professionals in cleft care is required to ascertain the value of the Communication Assessment Protocol as a resource for describing the children with CL/P and to support the establishment of an interdisciplinary team-based approach to cleft care. The outcomes of the assessment results and the follow-up process need to be evaluated to provide the evidence for such structured assessments. This may be possible by conducting intervention research (Mouton, 2000: 160) using sequential mixed methodology approach. Firstly a descriptive, quantitative, survey research project (Leedy & Ormrod, 2005: 183) is recommended to determine whether the professionals received referrals of children with CL/P following the assessments conducted by the speech-language therapists and audiologists and whether they found the referrals to be appropriate. The latter will require a qualitative research project, focus group discussions (Bloor et al., 2001: 18) aimed at eliciting the perspectives of the concerned professionals in cleft care in Mauritius. Such perspectives are important to facilitate communication among the professionals to offer a coordinated team-based approach to assessments and interventions for young children with CL/P. Next, the opinions and recommendations of important stakeholders (for example parents, health care professionals and teachers) could be sought regarding coordinating cleft care for effective assessments and interventions. De Vos et al. (2005: 394) describe such research as intervention research whereby, repeated ‘tinkering’ with the intervention helps to ensure that it will produce intended effects.

The aim of this research study to develop a Communication Assessment Protocol and determine its applicability from the perspectives of the speech-language therapists and audiologists in

Mauritius was achieved. Further research to verify its effectiveness for the full range of intended stakeholders (children with CL/P and their families, other health care professionals involved in cleft care) is deemed to be necessary.

The current research that was initiated and conducted in Mauritius took into account international trends and best practice and adapted these to the local context. It also serves as a catalyst for future research efforts in the field of cleft care in Mauritius.

6.7 FINAL COMMENTS

‘Knowing is not enough; we must apply. Willing is not enough; we must do’

Johann Wolfgang von Goethe (1749-1832).

This research has established that it is possible for speech-language therapists and audiologists in developing contexts to develop clinical tools for use in their country, in languages which are both applicable and acceptable to the populations they serve. The application of this comprehensive Communication Assessment Protocol and national registry for children with CL/P who are known to exhibit a myriad of communication problems contributes to the goal of making quality cleft care available to all children with CL/P in Mauritius. This research was facilitated by the support of two government institutions in Mauritius namely ‘The Mauritius Research Council’ and the ‘Ministry of Health and Quality of Life’. This reflects the commitment of the government to support research to improve clinical practice. The results of this research may be used to guide future policy towards cleft care in Mauritius.

REFERENCES

- ACPA: American Cleft Palate-Craniofacial Association. (2007). *Parameters for evaluation and treatment of patients with cleft lip/palate or other craniofacial anomalies*. <http://www.acpa-cpf.org>. (Date of access: 7 August 2007).
- ACPA: American Cleft Palate-Craniofacial Association. (n.d.). Genetic Screening Questionnaire. http://www.acpa-cpf.org/educMeetings/educ_ScreeningTools.htm. (Date of access: 2 June 2009).
- ASHA: American Speech-Language and Hearing Association. (1993). *Definitions of Communication Disorders and Variations*. <http://www.asha.org/policy>. (Date of access: 28 August 2007).
- ASHA: American Speech-Language and Hearing Association. (2001). *Scope of practice in Speech-language Pathology* (Position Statement). <http://www.asha.org/members/deskref/default>. (Date of access: 11 April, 2007).
- ASHA: American Speech-Language and Hearing Association. (2004). Guidelines for the Audiologic Assessment of children from birth to 5 years of age. http://www.asha.org/docs/pdf/GL_2004-00002.pdf. (Date of access: 2 May 2007).
- ASHA: American Speech-Language and Hearing Association. (2005). *Evidence-Based Practice in Communication Disorders* (Position Statement). <http://www.asha.org/members/deskref/default>. (Date of access: 11 April 2007).

ASHA: American Speech-Language-Hearing Association. (2008). *Roles and responsibilities of speech-language pathologists in early intervention* (Position statement). <http://www.asha.org/policy>. (Date of access: 3 May 2008).

Amstalden-Mendes, L.G., Magna, L.A., & Lopes, V.L. (2006). Neonatal care of infants with cleft lip and/or palate: feeding, orientation and evolution of weight gain in a nonspecialized Brazilian hospital. *The Cleft Palate-Craniofacial Journal*, 44(3): 329-334.

Andrews, P.J., Chorbachi, R., Sirimanna, T., Sommerlad, B., & Hartley, B.E.J. (2004). Evaluation of hearing thresholds in 3 month old children with a cleft palate. *Clinical Otolaryngology*, 29: 10-17.

Arvedson, J.C., & Brodsky, L. (2002). *Paediatric swallowing and feeding: Assessment and management* (2nd ed.). Australia: Singular, Thomson Learning.

Babbie, E. (2001). *The practice of social research* (9th ed.). Belmont: Wadsworth.

Bale, J.R., Stoll, B.J., & Lucas, A.O. (2003). *Reducing birth defects: Meeting the challenges in the developing world*. Washington, D.C.: The National Academies Press.

Bagnato, S.J., Neisworth, J.T., & Munson, S.M. (1997). *Linking assessment and early intervention*. Baltimore: Paul H. Brookes.

Baker, P. (1972). *Kreol: a description of Mauritian Creole*. London: C. Hurst & Co.

- Bearn, D., Mildinhal, S., Murphy, T., Murray, J.J., Sell, D, Shaw, W.C., Williams, A.C., & Sandy, J.R. (2001). Cleft lip and palate care in the United Kingdom-the Clinical Standards Advisory Group (CSAG) Study Part 4- outcome comparisons, training and conclusions. *The Cleft Palate-Craniofacial Journal*, 38(1): 38-43.
- Bernthal, J.E., & Bankson, N.W. (1998). *Articulation and phonological disorders*. Boston: Allyn & Bacon.
- Billeaud, F.P. (2003). *Communication disorders in infants and toddlers: Assessment and intervention*. Boston: Butterworth-Heinemann.
- Blackman, J.A. (Ed.). (1995). *Identification and assessment in early intervention*. Maryland: Aspen.
- Blakeley, R.W., & Brockman, J.H. (1995). Normal speech and hearing by age 5 as a goal for children with cleft palate: a demonstration project. *American Journal of Speech Language Pathology*, 4: 25-32.
- Bloor, M., Frankland, J., Thomas, M., & Robson, K. (2001). *Focus groups in social research*. London: Sage.
- Broder, H.L., Richman, L.C., & Matheson, P.B. (1998). Learning disability, school achievement, and grade retention among children with cleft: a two center study. *The Cleft Palate-Craniofacial Journal*, 35(2): 127-131.
- Broen, P.A., Moller, K.T., Carlstrom, J., Doyle, S.S., Devers, M., & Keenah, K.M. (1996). Comparison of the hearing histories of children with and without cleft palate. *The Cleft Palate-Craniofacial Journal*, 33(2): 127-133.

- Broen, P.A., Devers, M.C., Doyle, S.S., Prouty, J.M., & Moller, K.T. (1998). Acquisition of cognitive and linguistic skills by children with cleft palate. *Journal of Speech Language and Hearing Research, 41*: 676-686.
- Brunnegard, K., & Lohmander-Agerskov, A. (2007). A cross-sectional study of speech in 10-year-old children with cleft palate: results and issues of rater reliability. *The Cleft Palate Craniofacial Journal, 44*(1): 33-44.
- Burkard, R.F., Don, M., & Eggermont J.J. (2007). *Auditory evoked potentials: basic principles and clinical applications*. London: Lippincott, Williams & Wilkins.
- Bzoch, K.R. (2004). *Communicative disorders related to cleft lip and palate* (5th ed.). Texas: Pro-ed.
- Carter, J.A., Lees, J.A., Murira, G.M., Gona, J., Neville, G.R., & Newton, J.C. (2005). Issues in the development of cross-cultural assessments of speech and language for children. *International Journal of Language and Communication Disorders, 40*(40): 385-401.
- Chapman, K.L., Hardin-Jones M.A., Schulte, J., & Halter, K.L., (2001). Vocal development of 9-month old babies with cleft palate. *Journal of Speech Language and Hearing Research, 44*: 1268-1283.
- Chapman, K.L., Hardin-Jones M.A., & Halter, K.L. (2003). The relationship between early speech and later speech and language performance for children with cleft lip and palate. *Clinical Linguistics and Phonetics, 17*(3): 173-197.
- Chapman, K.L., Hardin-Jones M.A., Goldstein, J.A., Halter, K.L., Havlik, R.J., & Schulte, J. (2008). Timing of palatal surgery and speech outcome. *The Cleft Palate- Craniofacial Journal, 45*(3): 297-308.

- Chatoor, I., Getson, P., Menvielle, E., Brasseaux, C., O'Donnell, R., Rivera, Y., & Mrazek, D.A. (1997). A feeding scale for research and clinical practice to assess mother-infant interactions in the first three years of life. *Infant Mental Health Journal*, 18(1): 76-91.
- Cole, E.B., & Flexer, C. (2007). Children with hearing loss: *Developing listening and talking*. San Diego: Plural Publishing Inc.
- Collett, B.R. & Speltz, M.L. (2006). Social-emotional development of infants and young children with orofacial clefts. *Infants & Young Children*, 19(4): 262-291.
- Coissard, E. (n.d.). *Troubles de l'articulation*. Equipe du centre d'orthophonie. Cedex: Clisson.
- Craniofacial Anomalies Network (CRANE). (2000). <http://www.perinatal.org.uk/crane>. (Date of access 12 December 2004).
- Creswell, J.W. (2003). *Research design: Qualitative, quantitative and mixed methods approaches* (2nd ed.). London: Sage.
- CSAG Report – Clinical Standards Advisory Group 1998, *Cleft lip and or palate*, London: HMSO.
- Damico, J.S., & Simmons-Mackie, N.N. (2003). Qualitative research and speech-language pathology: a tutorial for the clinical realm. *American Journal of Speech-Language Pathology*, 12: 131-143.
- D'Antonio, L. L., Scherer N.J., Miller, L.L., Kalbfleisch, J.H., & Bartley, M.D. (2001). Analysis of speech characteristics in children with Velocardiofacial Syndrome (VCFS) and children with phenotypic overlap without VCFS. *Cleft Palate- Craniofacial Journal*, 38(5): 455-467.

- D'Antonio, L. L. (2002). Role of the speech-language pathologist in interdisciplinary team care. Proceedings of the symposium and workshop on '*Speech disorders in individuals with cleft lip and palate-assessment, therapy and surgical management*' Supported by the Smile Train and Rehabilitation Council, India.
- D'Antonio, L.L. & Nagarajan, R. (2003). Use of a consensus building approach to plan speech services for children with cleft palate in India. *Folia Phoniatrica et Logopaedica*, 55(6): 306-313.
- Denzin, N.K., & Lincoln, Y.S. (Eds.). (2000). *Handbook of qualitative research* (2nd ed.). London: Sage Publication Inc.
- De Vos, A.S., Strydom, H., Fouche, C.B., & Delpont, C.S.L. (2005). *Research at grass roots*. (3rd ed.). Pretoria: Van Schaik Publishers.
- Dewart, H., & Summers, S. (1995). The Pragmatics Profile of everyday Communication Skills in Children. http://wwwedit.wmin.ac.uk/psychology/pp/documents/Pragmatics_Profile_Children.pdf. (Date of access: 12 December 2004).
- Endriga, M.C., & Kapp-Simon, K.A. (1999). Psychosocial issues in craniofacial care: State of the art. *Cleft Palate- Craniofacial Journal*, 36(1): 3-11.
- Eurocran Speech Project. (2000). <http://www.eurocran.org/content>. (Date of access: 12 December 2004).
- Fenson, P., Dale, P.S., Reznick, J.S., Thal, D., Bates, E., Harung, J.P., Pethick, S., & Reilly, J.S. (1993). *MacArthur Communication Development Inventories*. San Diego: Singular Publishing Group.

- Friel-Patti, S., & Finitzo, T. (1990). Language learning in a prospective study of otitis media with effusion in the first two years of life. *Journal of Speech and Hearing Research*, 33: 188-194.
- Garcia, M., Pence, A., & Evans, J. L. (2007). *Africa's future, Africa's challenge: Early childhood care and development in Sub-Saharan Africa*. Washington D.C.: World Bank Publications.
- Gerber, S.E. (2001). *The handbook of genetic communicative disorders*. London: Academic Press.
- Golding-Kushner K.J. (2001). *Therapy techniques for cleft palate speech and related disorders*. Canada: Singular.
- Gooch, J.L., Hardin-Jones, M., Chapman, K.L., Trost-Cardamone, J.L., & Sussman, J. (2001). Reliability of listener transcriptions of compensatory articulations. *Cleft Palate- Craniofacial Journal*, 38(1): 59-67.
- Grames, L.M. (2008). Advancing into the 21st century: Care for individuals with cleft palate or craniofacial differences. ASHA leader online. <http://www.asha.org/about/publications/leader-online/archives/2008/080506/f080506a.html>. (Date of access: 9 June 2008).
- Grunwell, P. (Ed.). (1993). *Analysing cleft palate speech*. London: Whurr Publishers.
- Guralnick, M.J. (1997). *The effectiveness of early intervention*. Baltimore: Paul H. Brookes Publishing Co.
- Guralnick, M.J. (2005). *The development systems approach to early intervention*. Baltimore: Paul H. Brookes Publishing Co.

- Haapanen, M.L., & Rantala, S.L. (1992) Correlation between the age at repair and speech outcome in patients with isolated cleft palate. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery*, 26(1): 71-78.
- Hakim, C. (2000). *Research Design*. (2nd ed.). London: Routledge.
- Hammond, M., & Stassen, L. (1999). Do you care? A national register for cleft lip and palate patients. *British Journal of Orthodontics*, 26(2): 152-157.
- Harding, A., & Grunwell, P. (1998). Active versus passive cleft-type speech characteristics. *International Journal Language and Communication Disorders*, 33(3): 329-352.
- Hardin-Jones, M.A., Chapman, K.L., & Schulte, J. (2003). The impact of cleft type on early vocal development in babies with cleft palate. *The Cleft Palate-Craniofacial Journal*, 40(5): 453-459.
- Hardin-Jones, M.A., & Jones, D.L. (2004). Speech production of preschoolers with cleft palate. *The Cleft Palate-Craniofacial Journal*, 42(1): 7-13.
- Hardin-Jones, M., Chapman, K. & Scherer, N.J. (2006). Early intervention in children with cleft palate. *ASHA Leader*, 11: 8-11.
- Hardin-Jones, M., & Chapman, K.L. (2008). The impact of early intervention on speech and lexical development for toddlers with cleft palate: a retrospective look at outcome. *Language, Speech, and Hearing Services in Schools*, 39: 89–96.
- Hathorn, L.S., Atack, N.E., Butcher, G., Dickson, J., Durning, P., Hammond, M., Knight, H., Mitchell, N., Nixon, F., Shinn, D., & Sandy, J.R. (2006). Centralization of services: Standard setting and outcomes. *The Cleft Palate Craniofacial Journal*, 43(4): 401-405.

- Hauner, K.K.Y., Shriberg, L.D., Kwiatkowski, J., & Allen, C.T. (2005). A subtype of speech delay associated with psychosocial development. *Journal of Speech, Language and Hearing Research, 48*: 635-650.
- Hegde, M.N. (2003). *Clinical research in communicative disorders*. (3rd ed.). Texas: Pro-ed.
- Hegde, M.N. (2008). *Hegde's pocket guide to communication disorders*. New York: Thomson-Helmar Learning.
- Henningsson, G., Kuehn, D., Sell, D., Sweeney, T., Trost-Cardamone, J., & Whitehall, T. (2008). Universal parameters for reporting speech outcomes in individuals with cleft palate. *The Cleft Palate-Craniofacial Journal, 45*(1): 1-17.
- Hirschberg, J., & Van Denmark, D.R. (1997). A proposal for standardisation of speech and hearing evaluations to assess velopharyngeal function. *Folia Phoniatica et Logopaedica, 49*: 158-167.
- Hirschberg, J. (2001). Functional consequences of cleft palate and its management. <http://www.ncbi.nlm.gov/sites> (Date of access: 10 October 2007).
- Hocevar-Boltezar, I., Jarc, A., & Kozelj, V. (2006). Ear, nose and voice problems in children with orofacial clefts. *Journal of Laryngology Otology, 120*(4): 276-281.
- Hoff, E. (2005). *Language development*. (3rd ed.). Wadsworth: Thomson Learning.
- Horton, R. (2000). North and South: bridging the gap. *Lancet, 355*: 2231-2236.
- Hugo, R., Louw, B., Kritzinger, A., & Smit, G.J. (2000). Listening behaviour in children at risk for communication delay. *Infant-Toddler Intervention. The Transdisciplinary Journal, 10*(1): 47-53.

- Human Development Report. (2004). Published for UNDP (accessed at WHO office, Mauritius). (Date of access: 12 August 2008).
- Hunt, O., Burden, D., Hepper, P., & Johnston, C. (2005). The psychosocial effects of cleft lip and palate: A systematic review. *European Journal of Orthodontics*, 27: 274-285.
- Hutters, B., Bau, A., & Brondsted, K. (2001). A longitudinal group study of speech development in Danish children born with and without cleft palate. *International Journal of Language and Communication disorders*, 36(4): 447-470.
- Hutters, B., & Henningsson, G., (2004). Speech outcome following treatment in cross-linguistic cleft palate studies: methodological implications. *The Cleft Palate- Craniofacial Journal*, 41(5): 544-549.
- Jamilian, A., Nayeri, F., & Babayan, A. (2007). Incidence of cleft lip and palate in Tehran. *Journal of Indian Society of Pedodontics and Preventive Dentistry*, 25(4): 174-176.
- Jocelyn, L.J., Maureen, A. Penko, M. & Rode, H.L. (1996) Cognition, communication, and hearing in young children with cleft lip and palate and in control children: A longitudinal study. *Pediatrics*, 97(4): 529-535.
- John, A., Sell, D., Sweeney, T., Harding-Belle, A., & Williams, A. (2006). The cleft audit protocol for speech-augmented: A validated and reliable measure for auditing speech. *Cleft Palate-Craniofacial Journal*, 43(3): 272-288.
- Johnson, D. (1994). *Research methods in educational management*. Essex : Longman Group.
- Johnson, R.B., & Onwuegbuzie, A.J. (2004). Mixed research: A research paradigm whose time has come. *Educational Researcher*, 33(7): 14-26.

- Johnson, C.J. (2006). Getting started in evidence-based practice for childhood speech language disorders. *American Journal of Speech-Language Pathology*, 15: 20-35.
- Joint Committee on Infant Hearing (JCIH), (2007). Year 2007 position statement. Principles and guidelines for early hearing detection and intervention program. *Pediatrics*, 120: 898-921.
- Justice, L.M. (2006). *Clinical approaches to emergent literacy intervention*. San Diego: Plural Publishing Inc.
- Kaderavek, J.N., & Justice, L. (2000). Children with LD as emergent readers: Bridging the gap to conventional reading. *Intervention in School and Clinic*, 36(2): 82-93.
- Kapp-Simon, K.A., & Krueckeberg, S. (2000). Mental development in infants with cleft lip and/or palate. *The Cleft Palate-Craniofacial Journal*, 37(1): 65-70.
- Karling, J., Larson, J., & Henningsson, G. (1993). Oronasal fistulas in cleft palate patients and their influence on speech. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery*, 27(3): 193-201.
- Kemker, B.E., & Antonelli, P.J. (2004). Audiologic management of patients with cleft palate and related disorders. In K.R. Bzoch (Ed.). *Communicative disorders related to cleft lip and palate*. (5th ed.). Texas: Pro-ed.
- Kent R.D, Weismer G, Kent, J.F., Vorperian H.K., & Duffy J.R. (1999). Acoustic studies of dysarthric speech: methods, progress, and potential. *Journal of Communication Disorders*, 32: 141–180.
- Kernahan, D.A., Rosenstein, S.W., & Dado, D.V. (1990). *Cleft lip and palate a system of management*. Baltimore: Williams & Wilkins.

- Kirschner, R.E., Randall, P., Wang, P., Jawad, A. F., Duran, M., Huang, K., Solot, C., Cohen, M., & LaRossa, D. (2000). Cleft palate repair at 3 to 7 Months of Age. *Plastic and Reconstructive Surgery*, *105*(6): 2127-2132.
- Klein, M.D. & Briggs, M.H. (1987). Observation of communicative interaction. *Journal of Childhood Communication Disorders*, *10*(2): 95-106.
- Kritzinger, A., Louw, B., & Hugo, R. (1995). Communication skills of biologically at-risk neonates. *The South African Journal of Communication Disorders*, *42*: 7-17.
- Kritzinger, A., Louw, B., & Hugo, R. (1996). Early communication functioning of infants with cleft lip and palate. *The South African Journal of Communication Disorders*, *43*: 77-84.
- Kritzinger, A., & Louw, B. (1997). A description of joint book-reading practices of mothers and their young children, 0-2 years. *Clinica, Applications in Clinical Practice of Communication Pathology*. Monograph 2. Department of Communication Pathology. University of Pretoria.
- Kritzinger, A. (2000). Establishing a computer-based data system for early communication intervention in South Africa. Unpublished D.Phil. Thesis. Department of Communication Pathology, University of Pretoria.
- Kritzinger, A., & Louw, B. (2002). A comprehensive assessment protocol for infants and toddlers at risk for communication disorders. *Clinical Applications in Clinical Practice of Communication Pathology*. Monograph 6. University of Pretoria.
- Kritzinger, A., & Louw, B. (2005). Communication profile of infants and toddlers with cleft palate in an early intervention clinic. Presentation at the *10th International Congress on Cleft Palate and related Craniofacial Anomalies*: 105-106. Durban.
- Krueger, R.A., (2007). *Focus group interviewing*. http://www.tc.umn.edu/~rkrueger/focus_moderating.html. (Date of access: 28 January 2007).

- Kuehn, D.P., & Moller, K.T. (2000). Speech and language issues in the cleft palate population: The state of the art. *The Cleft Palate-Craniofacial Journal*, 37(4): 348-406.
- Kuehn, D.P., & Henne, L.J. (2003). Speech evaluation and treatment for patients with cleft Palate. *The American Journal of Speech-Language Pathology*, 12: 103-109.
- Kummer, A.W. (2008). *Cleft palate and craniofacial anomalies: Effects on Speech and Resonance* (2nd ed.). New York: Delmar learning Cengage.
- Labuschagne, C., & Louw B. (2005). Early intervention in cleft palate: parental experiences of the information sharing process. Presentation at the 10th *International Congress on Cleft Palate and related Craniofacial Anomalies: 117*. Durban.
- Leedy, P.D., & Ormrod J.E. (2005). *Practical research* (8th ed.). Merrill: Prentice Hall.
- Leech, N.L., & Onwuegbuzie, A.J. (2005). A typology of mixed methods research designs. Paper presented at *annual meeting of the American Educational Research Association*, Montreal, Canada.
- Lohmander-Agerskov, A., & Olsson, M. (2004). Methodology for perceptual assessment of speech in patients with cleft palate: a critical review of the literature. *The Cleft Palate-Craniofacial Journal*, 41(1): 64-70.
- Lohmander-Agerskov, A. (2008). Letter to the editor. *The Cleft Palate-Craniofacial Journal*, 45(4): 452.
- Louw, B., & Kritzinger, A. (1995). CHRIB Case History Form. Clinic for High Risk Babies, Centre for Early Intervention in Communication Pathology. Department of Communication Pathology, University of Pretoria.

- Louw, B., Shibambu, M., & Roemer, K. (2006). Facilitating cleft palate team participation of culturally diverse families in South Africa. *The Cleft Palate- Craniofacial Journal*, 43(1): 47-54.
- Maris, C.L., Endriga, M.C., Speltz, M.L., Jones, K., & DeKlyen, M. (2000). Are infants with orofacial clefts at risk for insecure mother-child attachments? *The Cleft Palate- Craniofacial Journal*, 37(3): 257-265.
- Mars, M., Sell, D., & Habel, A. (2008). Management of cleft lip and palate in the developing world. Sussex: John Wiley & Sons Ltd.
- Masarei, A., Wright, S., Hughes, J., & Lake, R. (2004). Infant feeding assessment for newborn infants with cleft lip and/or palate. North Thames Regional Cleft Team (unpublished).
- Masarei, A., Sell, D., Habel, A., Sommerlad, B.C., & Wade, A. (2007). The nature of feeding in infants with unrepaired cleft lip and/or palate compared with healthy noncleft infants. *The Cleft Palate-Craniofacial Journal*, 44(3): 321–328.
- Maxwell, D.L., & Satake, E. (2006). *Research and statistical methods in communication sciences and disorders*. Canada: Thomson Delmar Learning.
- McLean, M., Wolery, M., & Bailey, D.B. (2004). *Assessing infants and preschoolers with special needs* (3rd ed.). Ohio: Pearson Merrill Prentice Hall.
- McDonagh, S., Pinson, R., & Shaw, A. (2000). Provision of general dental care for children with cleft lip and palate-parental attitudes and experiences. *British Dental Journal*, 189(8): 432-435.
- Merrick, G.D., Kunjur, J., Watts, R., & Marcus, A.F. (2007). The effect of early insertion of grommets on the development of speech in children with cleft palate. *British Journal of Oral and Maxillofacial Surgery*, 45: 527-533.

- Mitchell, L.E., Beaty, T.H., Lindral, A.C., Munger, R.G., Murray, J.C., Saal, H.M., & Wyszynski, D.F. (2002). Guidelines for the design and analysis of studies in nonsyndromic cleft lip and palate in humans: Summary report from a workshop of the international consortium for oral clefts genetics. *The Cleft Palate-Craniofacial Journal*, 39(1): 93-100.
- Morgan, G.A., Glinner, J.A., & Harmon, R.J. (2006). *Understanding and evaluating research in applied and clinical settings*. New Jersey: Lawrence Erlbaum Associates.
- Morris, H., & Ozanne, A. (2003). Phonetic, phonological and language skills of children with a cleft palate. *The Cleft Palate- Craniofacial Journal*, 40(5): 460-470.
- Moss, A.L.H., & Fonseca, S. (2006). Audiological issues in children with cleft lip and palate in one area of the U.K. *The Cleft Palate Craniofacial Journal*, 43(4): 420-428.
- Mossey, P.A. (2005). Global involvement in craniofacial anomalies: 31. Presentation at the 10th *International Congress on Cleft Palate and related Craniofacial Anomalies*. Durban.
- Mouton, J. (2000). *Understanding social research*. Pretoria: Van Schaik.
- Mroz, M., & Hall, E., (2003). Not yet identified: The knowledge, skills, and training needs of early years professionals in relation to children's speech and language development. *Early Years an International Journal of Research and Development*, 23(2): 117-130.
- Nackashi, J.A, Dedlow, E.R., & Dixon Wood, V.L. (2004). The craniofacial team: Health supervision and coordination. In K.R. Bzoch (Ed.), *Communicative disorders related to cleft lip and palate*. (5th ed.). Texas: Pro-ed.
- Nathan, L., Stackhouse, J., Goulandris, N., & Snowling, M.J. (2004). The development of early literacy skills among children with speech difficulties: A test of the critical age hypothesis. *Journal of Speech, Language and Hearing Research*, 47: 377-391.

- Neiman, G.S., & Savage, H.E. (1997). Development of infants and toddlers with clefts from birth to three years of age. *The Cleft Palate-Craniofacial Journal*, 34(3): 218-225.
- Neuman, W.L. (2000). *Social research methods* (4th ed.). Boston: Allyn & Bacon.
- Northern, J.L., & Downs, M.P. (2002). *Hearing in children* (6th ed.). Baltimore: Williams & Wilkins.
- Oliver, R.G., & Jones, G. (1997). Neonatal feeding of infants born with cleft lip and/or palate: parental perceptions of their experience in South Wales. *The Cleft Palate Craniofacial Journal*, 34(6): 526-530.
- Oller, D.K., Eilers, R.E., Neil, A.R., & Schwartz, H.K. (1999). Precursors to speech in infancy: the prediction of speech and language disorders. *Journal of Communication Disorders*, 32(4): 223-245.
- Onwuegbuzie, A.J. & Johnson, B.R. (2006) The Validity Issue in Mixed Research. *Research in the Schools* 13 (1) 48-63.
- Owens, R.E. (2001). *Language development* (5th ed.). Boston: Allyn & Bacon.
- Paliobei, V., Psifidis, A., & Anagnostopoulos, D. (2005). Hearing and speech assessment of cleft palate patients after palatal closure: Long term results. *International Journal of Pediatric Otorhinolaryngology*, 69: 1373-1381.
- Pamplona, C., & Ysunza, A., (2000). Active participation of mothers during speech therapy: Improved language development of children with cleft palate. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery*, 34: 231-236.

- Pamplona, C., Ysunza, A., Gonzalez, M., Ramirez, E., & Patino, C. (2000). Linguistic development in cleft palate patients with and without compensatory articulation disorder. *International Journal of Pediatric Otorhinolaryngology*, 54: 81-91.
- Pamplona, C., Ysunza, A., & Ramírez, P. (2004). Naturalistic intervention in cleft palate children. *International Journal of Pediatric Otorhinolaryngology*, 68(1): 75-81.
- Papalia, D.E., Olds, S.W., & Feldman, R.D. (2002). *A child's world: Infancy through adolescence* (9th ed.). New York: McGraw-Hill Higher Education.
- Paradise, J.L., Elster, B.A., & Tan, L. (1994). Evidence in infants with cleft palate that breast milk protects against otitis media. *Pediatrics*, 6: 853-860.
- Patton, M.Q. (1990). *Qualitative research and evaluation methods* (2nd ed.). Newbury Park, CA: Sage.
- Paul, R. (2007). *Language disorders from infancy to adolescence: assessment and Intervention* (3rd ed.). St Louis: Mosby.
- Pence, K.L., & Justice, .M. (2008). *Language development from theory to practice*. New Jersey: Pearson Prentice Hall.
- Persson, C., Elander, A, Lohmander, A., & Soderpalm, E. (2002). Speech outcomes in isolated cleft palate: impact of cleft extent and additional malformations. *The Cleft Palate-Craniofacial Journal*, 39(4): 397-408.
- Persson, C., Lohmander, A., & Elander, A. (2006). Speech in children with isolated cleft: A longitudinal perspective. *The Cleft Palate Craniofacial Journal*, 43(3): 295-309.
- Peterson-Falzone, S.J., Hardin-Jones, M.A., & Karnell, M.P. (2010). *Cleft palate speech*, (4th ed.). St. Louis: Mosby, Elsevier.

- Peterson-Falzone, S.J., Trost-Cardamone, J.E., Karnell M.P., & Hardin-Jones, M.A. (2006). *The clinician's guide to treating cleft palate speech*. St Louis: Mosby, Elsevier.
- Phillips, B.J. (2004). Collaborative clinical research and the craniofacial outcomes registry. In K. R. Bzoch (Ed.). *Communicative disorders related to cleft lip and palate*. (5th ed.). Texas: Pro-ed.
- Pickering, M., & McAllister, L. (2000). A conceptual framework for linking and guiding domestic cross-cultural and international practice in speech-language pathology. *International Journal of Speech-Language Pathology*, 2(2): 93-106.
- Pope, A.W., Tillman, K., & Snyder, H.T. (2005). Parenting stress in infancy and psychosocial adjustment in toddlerhood: A longitudinal study of children with craniofacial anomalies. *The Cleft Palate Craniofacial Journal*, 42(5): 556-559.
- Popich, E., Louw, B., & Eloff, I. (2007). Caregiver education as a prevention strategy for communication disorders in South Africa. *Infants and Young Children*, 20(1): 64-81.
- Prahl, C., & Prahl-Andersen, B. (2007). Craniofacial anomalies and quality of life. *Seminars in Orthodontics*, 13(2): 116-121.
- Prathanee, B., Dechongkit, S., & Maniochiopinig, S. (2006). Development of community-based speech therapy model: for children with cleft/palate in northeast Thailand: *Journal of Medical Association of Thailand*, 89(4): 500-508.
- Prizant, B.M., & Wetherby, A.M. (1995). *Communication and language assessment for young children*. In Blackman, J.A. (Ed.). *Identification and assessment in early intervention*. Maryland: Aspen publications.
- Pudaruth, B.L. (1972). *Le Creole Mauricien*. Unpublished doctoral dissertation. University Paul Valery of Montpellier, France.

- Reeve, M. E., Groce, N. E., Persing, J.A., & Magge, S.N. (2004). An international surgical exchange program for children with cleft lip/cleft palate in Manaus, Brazil: Patient and family expectations of outcome. *The Journal of Craniofacial Surgery*, 15(1): 170-174.
- Reid, J. (2004). A review of feeding interventions for infants with cleft palate. *The Cleft Palate Craniofacial Journal*, 41(3): 268-278.
- Reid, J., Kilpatrick, N., & Reilly, S. (2006). A prospective, longitudinal study of feeding skills in a cohort of babies with cleft conditions. *The Cleft Palate Craniofacial Journal*, 43(6): 702-709.
- Reilly, S. (2004). The challenges in making speech pathology practice evidence based. *Advances in Speech-Language Pathology*, 6(2): 113-124.
- Reilly, S., Douglas, J., & Oates, J. (2004). *Evidence-based practice in speech pathology*. London: Whurr publishers.
- Restrepo, M.A., & Towle-Harmon, M. (2008). Addressing emergent literacy skills in English-language learners. *The ASHA Leader*, 13(13): 10-13.
- Richman, L.C., & Ryan, S.M. (2003). Do the reading disabilities of children with cleft fit into the current models of developmental dyslexia? *The Cleft Palate Craniofacial Journal*, 40(2): 154-157.
- Rossetti, L.M. (1990). The Rossetti infant-toddler language scale. Illinois: LinguiSystems Inc.
- Rossetti, L.M. (2001). *Communication intervention. Birth to Three* (2nd ed.). Australia: Singular Thomson Learning.
- Roth, F.R., & Worthington, C.K. (2005). *Treatment Resource Manual for Speech-Language Pathology* (3rd ed.). UK: Thomson Delmar Learning.

- Savage, H.E., Neiman, G.S., & Reuter, J.M. (1994). A developmental perspective on assessment of infants with clefts and related disorders. *Infant-Toddler Intervention: The Transdisciplinary Journal*, 4(3): 221-234.
- Scherer, N.J., & D'Antonio, L.L. (1995). Parent questionnaire for screening early language in children with cleft palate. *The Cleft Palate-Craniofacial Journal*, 32(1): 7-12.
- Scherer, N.J. (1999). The speech and language status of toddlers with cleft lip and/or palate following early vocabulary intervention. *American Journal of Speech-Language Pathology*, 8:81-93.
- Scherer, N. J., D'Antonio, L. L., & Kalbfleisch, J. H. (1999). Early speech and language development in children with velocardiofacial syndrome. *American Journal of Medical Genetics*, 88: 714-723.
- Scherer, N.J., Chapman, K., Hardin-Jones, M., & D'Antonio, L.L. (2005). Early assessment and intervention for children with cleft palate. *American Speech-Language Hearing Convention*. San Diego.
- Scherer, N.J., & Kaiser, A.P. (2007). Early intervention for children with cleft palate. *Infants & Young Children*, 20(4): 355-366
- Scherer, N.J., D'Antonio, L.L., & McGahey, H. (2008). Early intervention for speech impairment in children with cleft palate. *The Cleft Palate-Craniofacial Journal*, 45(1): 18-31.
- Schonweiler, R., Lisson, J.A., Schonweiler, B., Eckardt, A., Ptok, M., Trankmann, J., & Hausamen, J.E. (1999). A retrospective study of hearing, speech and language function in children with clefts following palatoplasty and veloplasty procedures at 18-24 months of age. *International Journal of Paediatric Otorhinolaryngology*, 50: 205-217.
- Sell, D., Grunwell, P., & Mars, M. (1994). A methodology for the evaluation of severely disordered cleft palate speech. *Clinical Linguistics & Phonetics*, 8(3): 219-233.

- Sell, D., Hardin, M.A., & Grunwell, P. (1998). A training video of speech characteristics- Speech Assessment GOS.SP.ASS '98', CLAPA The Speech and Language Therapy Department at Great Ormond Street Hospital NHS Trust, London.
- Sell, D., Harding, A., & Grunwell, P. (1999). GOS.SP.ASS. 98: an assessment for speech disorders associated with cleft palate and/or velopharyngeal dysfunction. *International Journal Language & Communication Disorders*, 34(1): 17-33.
- Sell, D., Grunwell, P., Mildinhal, S., Murphy, T., Cornish, T.A., Bearn D, Shaw W.C., Murray, J.J. Williams, A.C., & Sandy, J.R. (2001). Cleft lip and palate care in the United Kingdom. The clinical standards advisory group (CSAG) study, Part 3: Speech outcomes. *The Cleft Palate-Craniofacial Journal*, 38(1): 30-37.
- Sell, D. (2005). Issues in perceptual speech analysis in cleft palate and related disorders: a review. *International Journal Language Communication Disorders*, 40(2): 103-121.
- Sell, D. (2007). Part 1. Cleft lip and palate in the developing world: speech pathology issues. In Perspectives on speech science and orofacial disorders. *American Speech-Language-Hearing Association Division 5 Newsletter*, 17(1): 13-18.
- Sell, D. (2007). Part 2. Cleft lip and palate in the developing world: speech pathology issues. In Perspectives on speech science and orofacial disorders. *American Speech-Language-Hearing Association Division 5 Newsletter*, 14(2): 16-20.
- Sevanandee, V. (2004). A study of the incidence of cleft palate in neonates in Mauritius and its possible causes. B.Sc. Medical Sciences dissertation, University of Mauritius, accessed at the University of Mauritius.
- Shaw, W.C., Bannister, R.P., & Roberts, C.T. (1999). Assisted feeding is more reliable for infants with clefts-a randomized trial. *The Cleft Palate-Craniofacial Journal*, 36(3): 262-268.

- Shaw, W.C., Semb, G., Nelson, P., Brattstrom, V., Molsted, K., Andersen, B. & Gundlach, K.K.H. (2001). The Eurocleft Project 1996-2000: Overview. <http://www.idealibrary.com>. (Date of access: 28 August 2007).
- Shaw, W.C. (2004). Global strategies to reduce the health care burden of craniofacial anomalies: Report of WHO meetings on international collaborative research on craniofacial anomalies. *The Cleft Palate-Craniofacial Journal*, 41(3): 238-243.
- Shaw, W.C., Dahl, E., Brattstrom, V., Molsted, K., Prah-Andersen, B., Roberts, C., & Semb, G. (2005). The Eurocleft study: Inter-center study of treatment outcome in patients with complete cleft lip and palate: Part 5: Discussion and conclusions. *The Cleft Palate-Craniofacial Journal*, 42(1): 93-98.
- Shipley, K.G., & McAfee, J.G. (2004). *Assessment in Speech-Language Pathology: A Resource Manual* (4th ed.). San Diego: Singular publishing.
- Shonkoff, J.P., & Meisels, S.J. (2000). *Handbook of early childhood intervention*. (2nd ed.). England: Cambridge University Press.
- Shprintzen, R.J., & Bardach, J. (1995). *Cleft palate speech management: A multidisciplinary approach*. St. Louis: Mosby Inc.
- Shprintzen, R.J. (1997). *Genetics, Syndromes and Communication Disorders*. London: Singular.
- Shprintzen, R.J. (2004). Nasopharyngoscopy. In K. R. Bzoch (Ed.). *Communicative disorders related to cleft lip and palate*. (5th ed.). Texas: Pro-ed.
- Shriberg, L.D., McSweeney, J.L., Anderson, B.E., Campbell, T.L., Chial, M.R., Green, J.R., Hauner, K.K., Moore, C.A., Rusiewicz, H.L., & Wilson, D.L. (2005). Transitioning from analogue to digital audio recording in childhood speech sound disorders. *Clinical Linguistics & Phonetics*, 19(4): 335-359.

- Smedegaard, L., Marxen, D., Moes, J., Glassou E.N., & Sciantsan, C., (2008). Hospitalization, breast-milk feeding, and growth in infants with cleft palate and cleft lip and palate born in Denmark. *The Cleft Palate and Craniofacial Journal*, 45(6): 628-632.
- Snow, C.E., Burns, M.S., & Griffin, P. (1998). Preventing reading difficulties in young children. <http://www.nap.edu/catalog/6023.html>. (Date of access: 06.02.2009).
- Speltz, M.L., Morton, K., Goodell, E.W., & Clarren, S.K. (1993). Psychological functioning of children with craniofacial anomalies and their mothers: Follow-up from late infancy to school entry. *The Cleft Palate-Craniofacial Journal*, 30(5): 482-489.
- Stewart, D.W., & Shamdasani, P.N. (1990). *Focus groups: Theory and practice*. London: Sage.
- Strauss, R.P. (2001). Only skin deep: health, resilience, and craniofacial care. *The Cleft Palate-Craniofacial Journal*, 38(3): 226-230.
- Strauss, R.P. (2004). Social and psychological perspectives on cleft lip and palate. In K. R. Bzoch (Ed.). *Communicative disorders related to cleft lip and palate*. (5th ed.). Texas: Pro-ed.
- Streicher, D. (2005). Preliminary speech assessment protocol for pre-school Sepedi speaking children with cleft palate. Unpublished undergraduate research report, Department of Communication Pathology, University of Pretoria.
- Sunkur, J., Akaloo, N., & Ameerberg, S.A.G. (2002). Executive Summary of the Contraceptive Prevalence Survey. *Report from Evaluation Unit: Ministry of Health & Quality of Life, Mauritius*.

- Swanenburg de Veye, H.F.N., Beemer, F.A., Mellenberg, G. J., Wolters, W.H.G., & Heineman-de Boer, J.A. (2003). An investigation of the relationship between associated congenital malformations and the mental and psychomotor development of children with clefts. *The Cleft Palate-Craniofacial Journal*, 40(3): 297-303.
- Sweeney T., & Whitehill, T. (2004) Evaluation. *Workshop on Universal Reporting for the Speech of Individuals with Cleft Palate*. April-May 2004: Washington D.C.
- Ter Poorten, L. & Louw, B. (2002) Mother's experiences when their infants were diagnosed with cleft lip and/or palates. *Health SA Gesondheid*, 7(2): 56-67.
- Tetnowski, J.A., & Franklin, T.C. (2003). Qualitative research: Implications for description and assessment. *American Journal of Speech-language Pathology*, 12: 155-164.
- Threats, T.T. (2006). Towards an international framework for communication disorders: Use of the ICF. *Journal of Communication Disorders*, 39: 251–265.
- Trindade, I.E.K. (2006). Scientific research in Latin America: Experiences of collaborative projects on craniofacial anomalies. *The Cleft Palate-Craniofacial Journal*, 43(6): 722-725.
- Trost Cardamone, J.E. (2004). Diagnosis of specific cleft palate speech error patterns for planning therapy or physical management needs. In K.R. Bzoch (Ed.). *Communicative disorders related to cleft lip and palate*. (5th ed.). Texas: Pro-ed.
- Vallino-Napoli, L.D., Riley, M.M., & Halliday, J. (2004). An epidemiological study of isolated cleft lip, palate or both in Victoria, Australia from 1983 to 2000. *The Cleft Palate-Craniofacial Journal*, 41(2): 185-194.
- Vallino-Napoli, L.D., Lass, N.J., Bunnell, T., & Pannbacker, M. (2008). Academic and clinical training in cleft palate for speech-language pathologists. *The Cleft Palate-Craniofacial Journal*, 45(4): 371-379.

- Van Heerden, C., & Kritzinger, A. (2008). Parental perceptions and practices of emergent literacy development in young children with Down syndrome: The development of intervention guidelines. *South African Journal of Communication Disorders*, 55: 37-48.
- Walley, J., Khan, M.A., Shah, S.A., Witter, S., & Wei, X. (2007). How to get research into practice: first get practice into research. *Bulletin of the WHO*, 85(6): 424-425.
- Watson, A.C.H., Sell, D.A., & Grunwell, P. (Eds.). (2001). *Management of Cleft Lip and Palate*, London: Whurr Publishers.
- Weitzner-Lin, B. (2004). *Communication Assessment and Intervention with infants and Toddlers*. St. Louis: Butterworth Heinemann.
- Welman, C., Kruger, F., & Mitchell, B. (2005). *Research methodology* (3rd.ed.). Southern Africa: Oxford Press.
- Williams, A.L. (2002). Perspectives in the assessment of children's speech. *American Journal of Speech-language Pathology*, 11: 211-212.
- Winder, A.E., Imagire, R., & Peterson-Falzone, S.J. (2004). Basic genetic concepts in craniofacial anomalies. In K. R. Bzoch (Ed.). *Communicative disorders related to cleft lip and palate*. (5th ed.). Texas: Pro-ed.
- Winterton, T. (1998). Providing appropriate training and skills in developing countries. *International Journal of Language and Communication Disorders*, 33: 108-113.

- Wirt, A., Wyatt, R., Sell, D., Grunwell, P., & Mars, M. (1990). Training assistants in cleft palate speech therapy in the developing world: a report. *The Cleft Palate- Craniofacial Journal*, 27(2): 169-175.
- Whitehill, T.L. (2002). Assessing intelligibility in speakers with cleft palate: a critical review of the literature. *The Cleft Palate-Craniofacial Journal*, 39(1): 50-57.
- WHO. (2001a). International Classification of Functioning, Disability and Health (ICF) <http://www.who.int/classifications/icf/en>. (Date of access: Retrieved on 08 May 2008)
- WHO. (2001b). Global registry and database on Craniofacial anomalies. http://www.who.int/genomics/anomalies/en/chapter_05.pdf. (Date of access: Retrieved on 12 August 2004)
- WHO. (2002). Global strategies to reduce the health-care burden of craniofacial anomalies. <http://www.who.int/genomics/anomalies>. (Date of access: 12 August 2004).
- World Trade Organisation (2004). Developing country. http://en.wikipedia.org/wiki/Developing_country. (Date of access: 15 August 2006).
- Wyatt, R., Sell, D., Russell, J., Harding, A., Harland, K., & Albery, E. (1996). Cleft palate speech dissected: a review of current knowledge analysis. *British Journal of Plastic Surgery*, 49: 143-149.
- Wyszynski, D.F. (Ed.). (2002). *Cleft Lip and Palate from Origin to Treatment*. London: Oxford Press.
- Yeow, V., Lee-Seng-Teik, T., Lambrecht, T.J., Barnett, J., Gorney, M., Hardjowasito, W., Lemperle, G., McComb, H., Natsume, N., Stranc, M., & Wilson, L. (2002). International task force on volunteer cleft missions. *Journal of Craniofacial Surgery*, 13: 18-25.

- Young, J.L., O’Riordan, M., Goldstein, J.A., & Robin, N.H. (2001). What information do parents of newborns with cleft lip, palate, or both want to know? *The Cleft Palate-Craniofacial Journal* 38(1): 55-58.
- Ysunza, A., Pamplona, C., Mendaza, M., Garcia-Velasco, M., Anguilar, P., & Guerrero, E. (1998). Speech outcome and maxillary growth in patients with unilateral complete cleft lip/palate operated on at 6 vs 12 months of age. *Plastic and Reconstructive Surgery*, 102(3): 675-679.
- Ysunza A., Pamplona, M.A., Molina, F., Drucker, M., Felemovicius, J., Ramírez, E., & Carmeluz, P. (2004). Surgery for speech in cleft palate patients. *International Journal of Pediatric Otorhinolaryngology*, 68: 1499-1505.
- Zimmerman, I.L., Steiner, V.G., & Pond, R.E. (2002). *Preschool language scale*. London: The Psychological Corporation Limited.
- Zimmerman, I.L., & Castilleja, N.J. (2005). The role of a language scale for infant and preschool assessment. *Mental Retardation and Developmental Disabilities Research Reviews*, 11: 238-246.
- Zinkin, P., & McConachie, H. (1995). *Disabled children and developing countries*. Cambridge: Mac Keith Press.



APPENDIX I

**PERMISSION FROM THE RESEARCH ETHICS COMMITTEE
OF MINISTRY OF HEALTH AND QUALITY OF LIFE,
MAURITIUS**



The National Ethics Committee

Decision

Title of Research Proposal: Development of a communication assessment protocol for young children with cleft palate in Mauritius

Research Protocol No.: MHS 458/27

Submitted on: 27 January, 2005

Applicant: Mrs R. Gopal

Address of Applicant: c/o Dr J.C. Mohith, Mauritius Institute of Health

National Ethics Committee Meeting held on Monday 28 February, 2005 has

awarded ethical clearance

to the above project proposal.

The applicant during the research activity is required to:

- (a) Submit a Progress Report every month;
- (b) Notify the Ethical Committee of any amendment of recruitment of material or of consent form, or of information to be submitted to the research participant;
- (c) Report to the Ethical Committee any serious or unexpected unforeseen circumstances;
- (d) Report to the Ethical Committee termination of the study;
- (e) Provide relevant information to the Ethical Committee ongoing review; and
- (f) Give a copy of the Final Summary or the Final Report to Ethical Committee.

(Dr R.S. Sungkur)
Chief Medical Officer
for Permanent Secretar

01 March 2005



Ministry of Health &
Mauritius

MHS 458/27

01 March 2005

Madam,

Ethical Clearance

I am directed to inform you that the Ethical Committee of the Ministry of Health and Quality of Life, has, at its meeting of 28 February 2005 considered the request made by you on **27 January 2005**.

2. The Committee has consequently awarded Ethical Clearance subject to the conditions laid down in the annex.

Yours faithfully,

(S.K. Sobee)
for Permanent Secretary

Mrs R. Gopal
c/o Dr J.C. Mohith
Mauritius Institute of Health

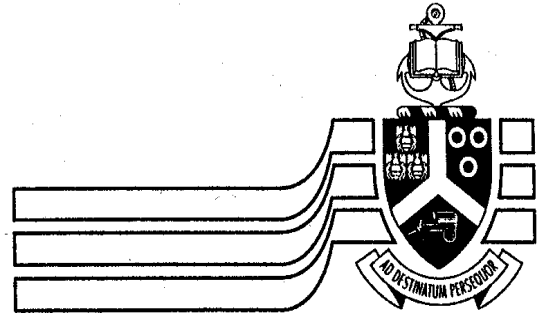


APPENDIX II

**PERMISSION FROM THE RESEARCH PROPOSAL AND
ETHICS COMMITTEE, FACULTY OF HUMANITIES,
UNIVERSITY OF PRETORIA**



Project: *Development of a communication assessment protocol for young children with cleft lip and/or palate (CL/P) in Mauritius*
Researcher: R Gopal
Supervisor: Prof B Louw
Department: Communication Pathology
Reference number: 98023137



University of Pretoria

Thank you for the application you submitted to the Research Proposal and Ethics Committee, Faculty of Humanities.

I have pleasure in informing you that the Research Proposal and Ethics Committee formally approved the above study on an *ad hoc* basis. The approval is subject to the candidate abiding by the principles and parameters set out in her application and research proposal in the actual execution of the research.

The Committee requests you to convey this approval to Mrs Gopal.

We wish you success with the project.

Sincerely

CSL Delport

Prof CSL Delport
Vice Chair: Research Proposal and Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA



APPENDIX III

LETTER OF INFORMATION AND INFORMED CONSENT

FOR PARENTS AS RESPONDENTS



**Department of Communication Pathology Speech,
Voice and Hearing Clinic**

Tel : +27 12 420 2355

Fax : +27 12 420 3517

Email : brenda.louw@up.ac.za

Date:

Information sheet for parents participating in the study.

Presented in English, but a verbal translation will be done in Creole or maternal language of the subject and the parents.

My name is Mrs. Rachna Gopal, I am the senior Speech-language therapist and Audiologist in M.O.H, Mauritius. I am currently registered as a doctoral student at the University of Pretoria. I shall be carrying out this project with the approval of Ministry of Health, Mauritius and the University of Pretoria. My supervisors are Prof. Brenda Louw and Dr. Alta Kritzinger.

The main aim of this project is to develop a communication assessment protocol for young children with cleft lip and or palate (CL/P). The speech language therapists and audiologists working with children with CL/P need an assessment tool that is appropriate and standardized for use in Mauritius.

You are requested to participate in this study, on a voluntary basis. If your child is able to give assent we will also request his/her permission to participate in this study.

You will be interviewed regarding background information relating to your family, child's birth history and your opinion regarding the feeding, speech and hearing of your child.

During the second part of the study the therapist, in the hospital where your child is currently following speech therapy will carry out speech and hearing assessment of your child. You will be required to bring the child for the assessment to the hospital and the test will last less than one hour. It will be arranged at a time convenient to you. The results will be recorded with an audio recorder and a video tape recorder.

All information that is gathered will be presented as a thesis and a scientific paper. Neither your name nor your child's name will be individually mentioned, in fact great care will be taken to keep your child's information confidential. Only those directly concerned with the care of your child in the hospital will be able to access this information. These recordings and data may also be used in the future, for research purposes.

You are requested to participate voluntarily and you may withdraw from the study if you wish to. This will not affect your follow-up appointments at the hospital in any way. I would like to add that neither you nor your child will receive any money or reimbursement for participating in this research.

Your kind cooperation will be greatly appreciated and you will be informed of the results of the study when it is complete. Should you have any further questions please do not hesitate to ask me.

Thank you for your cooperation. Kindly sign the attached letter.

Project Title: Development of a communication assessment protocol for young children with cleft lip and or palate in Mauritius.

1. I have read and the information relating to this project has been explained to me by Mrs. R. Gopal
2. I have had explained to me the purposes of this project and what will be required of me and my child, and any questions have been answered to my satisfaction, I agree to the arrangements described in the information sheet in so far as they relate to my child's participation in this project.
3. I understand that participation is entirely voluntary and that I have the right to withdraw at any time from the project, and that this will not affect any care or services I may be receiving in the future.
4. I understand that my child's full name will not be used and that details of my child's case history will be treated in confidence.
5. I have been informed that the completed forms and data will be stored in the child's hospital files and be available for future research.

Name:

Signed:

Date:

Principal Investigators: Mrs. Rachna Gopal. Email: Rachna@intnet.mu Tel: 6863854

Prof. Brenda Louw. Email: Brenda.Louw@up.ac.za



APPENDIX IV

LETTER OF INFORMATION AND CONSENT FORM FOR THE SPEECH LANGUAGE THERAPISTS AND AUDIOLOGISTS

Department of Communication Pathology Speech,

Voice and Hearing Clinic

Tel : +27 12 420 2355

Fax : +27 12 420 3517

Email : brenda.louw@up.ac.za

Date:

Information sheet for speech language therapists and audiologists participating in the study.

You are requested to participate in a research project: “Development of a Communication Assessment Protocol for Young Children with Cleft Lip and/or Palate in Mauritius”. I, Mrs. R. Gopal, Senior Speech-Language Therapist and Audiologist, am registered as a doctoral student at the University of Pretoria. I shall be carrying out this research project with the approval of Ministry of Health, Mauritius and the University of Pretoria. My supervisors are Prof. Brenda Louw and Dr. Alta Kritzinger.

The aim of this project is to develop a communication assessment protocol that will help improve service delivery to children with CL/P and their families, monitor their progress objectively and document the treatment outcomes. In addition, the Speech Language Therapists and Audiologists working with children with CL/P will have an assessment tool that is appropriate, uniform and standardized for use in Mauritius

You are requested to participate in this study, on a voluntary basis. This research study will be carried out in three phases. During Phase One of the study, you will be requested to complete a questionnaire survey form by interviewing parents to gather essential background information regarding the children with CL/P and their families.

In Phase Two of the study the compiled Communication Assessment Protocol, will be presented to you and you will answer a questionnaire regarding your perceptions of this communication assessment tool. Furthermore, you will be requested to participate in testing the clinical applicability of this protocol, on children with CL/P, who have been selected and their parents have voluntarily agreed to participate in this research project. Finally, in Phase Three you will be requested to attend the focus group session with other professionals and express your views

regarding the communic
trustworthiness of the assessment protocol.



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

participation will improve the

Should you have any further questions please do not hesitate to ask me. You are requested to participate voluntarily and you may withdraw from the study if you wish to without any repercussions. I would like to add that you will not receive any money or reimbursement for participating in this research. Your kind cooperation will be greatly appreciated and you will be informed of the results of the study when it is complete.

If you agree to participate please sign the letter of consent.

Thank you for your cooperation.

Contact Persons: Mrs. Rachna Gopal. Email: Rachna@intnet.mu Tel: 6863854

Prof. Brenda Louw. Email: Brenda.Louw@up.ac.za



Project Title: Development of a Communication Assessment Protocol for Young Children with Cleft lip and or Palate in Mauritius.

1. I have read and the information relating to this project has been explained to me by Mrs. R. Gopal
2. I have had explained to me the purposes of this project and what will be required of me. I agree to the arrangements described in the information sheet.
3. I understand that participation is entirely voluntary and that I have the right to withdraw at any time from the project.

Name:

Signed:

Date:

Contact persons: Mrs. Rachna Gopal. Email: Rachna@intnet.mu Tel: 6863854

Prof. Brenda Louw. Email: Brenda.Louw@up.ac.za



APPENDIX V

INTERVIEW SCHEDULE FOR RESPONDENTS PHASE ONE

OF THE STUDY



Cleft lip and or palate: Data collection instrument for research project ‘Development of a communication assessment protocol for young children with cleft lip and or palate in Mauritius’

Please circle appropriate choices:

SOURCE OF INFORMATION:

For office use

Medical records at:

Victoria Hospital 1

If other 2 Specify _____

Interview of:

Mother 1

Father 2

Both parents 3

If other 4 Specify _____

Place of interview:

Hospital 1

If other 2 Specify _____

Questionnaire filled in by:

Speech Therapist & Audiologist 1

Speech & Hearing Assistant 2

If other 3 Specify _____

Interview respondent/s’ consent _____

DATE: _____

PLEASE FILL IN ALL SECTIONS OF THE QUESTIONNAIRE

- SECTION A BIOGRAPHICAL INFORMATION
- SECTION B FAMILY BACKGROUND
- SECTION C BIRTH HISTORY
- SECTION D TYPE OF CLEFT
- SECTION E SURGICAL HISTORY
- SECTION F FEEDING, SPEECH AND HEARING
- SECTION G PATHWAY OF CARE



SECTION A: BIOGRAPHICAL INFORMATION

A1 **UNIT NUMBER** _____ At Plastic Surgery Clinic Victoria hospital
SURNAME _____ **NAME** _____

A2 **GENDER:** MALE **1** FEMALE **2**

A2	
----	--

A3 **DATE OF BIRTH** ____/____/____
dd mm year
AGE AT DATA COLLECTION (IN MONTHS) _____

A3	
----	--

0-18 months **1** 19-36 months **2** 37-60 months **3**

A4 **ADDRESS** _____ **Tel:** _____
Please indicate the hospital situated in child's catchment area

HEALTH REGION: DR JEETOO HOSPITAL **1**
SSRN HOSPITAL **2**
FLACQ HOSPITAL **3**
VICTORIA HOSPITAL **4**

A4	
----	--

J.N. HOSPITAL **5**

SECTION B FAMILY BACKGROUND

B1 **MARITAL STATUS OF BIOLOGICAL PARENTS:**
MARRIED AND LIVING TOGETHER **1**
SEPARATED/ DIVORCED **2**
SINGLE PARENT **3**
IF OTHER **4** SPECIFY _____

B1	
----	--

B2 INFORMATION REGARDING BIOLOGICAL PARENTS

MOTHER

B2 a) **Mother's AGE (IN YEARS)** _____
Mother's AGE GROUP when this child was born.
Less than 20 years **1** 21-39 years **2** More than 40 years **3**

B2a	
-----	--

B2 b) **Mother's EDUCATIONAL LEVEL:**
Primary **1** Secondary **2** Tertiary (University) **3**

B2b	
-----	--

B2 c) **IS THE MOTHER WORKING?**
YES **1** NO **2** PART TIME **3**

B2c	
-----	--



FATHER

B2 d) Father's AGE (IN YEARS) _____

B2 e) Father's EDUCATIONAL LEVEL

Primary **1** Secondary **2** Tertiary (University) **3**

B2e	
-----	--

B2 f) IS THE FATHER WORKING?

YES **1** NO **2** PART TIME **3**

B2f	
-----	--

B3 THE FAMILY UNIT IS COMPOSED OF? (NUMBER OF CHILDREN)

ONE **1** TWO **2** THREE **3** MORE THAN THREE **4**

B3	
----	--

If more than one what is this child's position? _____

B4 ARE PARENTS BLOOD RELATIVES (CONSANGUINITY)?

YES **1** NO **2**

B4	
----	--

If yes specify the relationship _____

B5 IS THERE ANY FAMILY HISTORY OF CLEFT LIP AND/OR PALATE?

YES **1** NO **2**

B5	
----	--

If yes specify the relationship to the child _____

B 6 a) NUMBER OF **LANGUAGES** SPOKEN AT HOME BY THE HOUSEHOLD MEMBERS

ONE **1** TWO **2** MORE THAN TWO **3**

B6a	
-----	--

B6 b) Circle the Languages spoken at home (circle more than one if appropriate)

CREOLE **1** FRENCH **2** ENGLISH **3** BHOJPURI **4** HINDI/URDU **5** IF OTHER **6** SPECIFY _____

B6b	
-----	--

B 6 c) CIRCLE THE MOST COMMONLY SPOKEN LANGUAGE AT HOME (**circle one only**)

CREOLE **1** FRENCH **2** ENGLISH **3** BHOJPURI **4** HINDI/URDU **5** IF OTHER **6** SPECIFY _____

B6c	
-----	--

SECTION C BIRTH HISTORY

C1 ANY SPECIFIC MATERNAL ANTENATAL HISTORY

YES **1** NO **2**

C1	
----	--

If yes specify the nature of problem _____

C2 PLACE OF DELIVERY: HOSPITAL **1** PRIVATE CLINIC **2** HOME **3** OTHER **4**

C2	
----	--

C3 TYPE OF DELIVERY: NORMAL **1** CAESAREAN **2** BREACH **3** FORCEPS **4** OTHER **5**

C3	
----	--

C4 BIRTH WEIGHT OF CHILD _____ KGS.

C4	
----	--

WITHIN NORMAL RANGE **1** LESS THAN NORMAL **2** MORE THAN NORMAL **3**

C5 DOES THE CHILD HAVE AN
YES 1



C5	
----	--

C5 a) If yes describe the syndrome_____

C 6 DOES THE CHILD HAVE ANY OTHER MALFORMATION/DISEASE
YES 1 NO 2 NOT KNOWN 3

C6	
----	--

C6 a) If yes describe the malformation/disease_____

SECTION D TYPE OF CLEFT

- LIP ONLY 1
- PALATE ONLY 2
- LIP AND PALATE 3
- SUBMUCOUS CLEFT PALATE 4

D	
---	--

PLEASE SPECIFY UNILATERAL / BILATERAL
COMPLETE / INCOMPLETE

For **Unilateral Cleft Lip** please specify RIGHT/LEFT

For **Cleft Palate** specify HARD / SOFT

SECTION E SURGICAL HISTORY

E1 HOW MANY TIMES HAS THE CHILD BEEN OPERATED FOR CLEFT LIP AND OR PALATE?
NONE 1 ONCE 2 TWICE 3 THREE TIMES 4 MORE THAN THREE TIMES 5

E1	
----	--

IF OPERATED:

E1a) SITE OF OPERATION

LIP REPAIR 1 PALATE REPAIR 2 SECONDARY REPAIR 3_____

E1a	
-----	--

E 1b) AGE AT THE TIME OF OPERATIONS (IN MONTHS)

E1c) ANY BREAKDOWN? YES 1 NO 2

E1c	
-----	--

E1 d) PLASTIC SURGEON:

AT VICTORIA HOSPITAL 1 IF OTHER 2 SPECIFY_____

E1d	
-----	--

E2 HAS THE CHILD UNDERGONE ANY OTHER OPERATIONS?
YES 1 NO 2

E2	
----	--

E2a) IF YES, OPERATION INVOLVED:

EARS 1 CARDIAC 2 IF OTHER 3 SPECIFY_____

E2a	
-----	--



F1 a) WERE ANY **FEEDING DIFFICULTIES** EXPERIENCED JUST AFTER BIRTH?
YES 1 NO 2

F1a	
-----	--

b) IF YES WHO ADVISED THE MOTHER ON HOW TO FEED?
SPEECH THERAPIST 1 NURSE 2 DOCTOR 3 IF OTHER SPECIFY 4

F1b	
-----	--

c) TYPE OF FEEDING JUST AFTER BIRTH: (circle the most common frequent type)
Breast 1 Bottle 2 Spoon 3 Cup 4 Nasogastric tube 5 If other 6 Specify _____

F1c	
-----	--

d) ARE THERE ANY FEEDING DIFFICULTIES AT PRESENT? YES 1 NO 2

F1d	
-----	--

If yes describe _____

F2 IN YOUR OPINION DOES YOUR CHILD HAVE ANY **SPEECH PROBLEM**?
YES 1 NO 2

F2	
----	--

If yes describe _____

F2 a) DOES YOUR CHILD RECEIVE SPEECH THERAPY?
YES 1 NO 2

F2a	
-----	--

F2 b) IF YES HOW FREQUENTLY?

Weekly 1 Fortnightly 2 Once in a month 3 Once in three months 4 If other 5 specify ...

F2b	
-----	--

F3 IN YOUR OPINION DOES YOUR CHILD HAVE ANY **HEARING DIFFICULTY**?
YES 1 NO 2

F3	
----	--

F3 a) HAS THE HEARING EVALUATION BEEN DONE?
YES 1 NO 2

F3a	
-----	--

F3 b) IF YES DOES YOUR CHILD HAVE A HEARING LOSS:
YES 1 NO 2 DON'T KNOW 3

F3b	
-----	--

SECTION G PATHWAY OF CARE

G1 WHO FIRST IDENTIFIED THE CLEFT?

DOCTOR 1 NURSE 2 PARENT 3 IF OTHER 4 SPECIFY _____

G1	
----	--

G1a) AT WHAT AGE WAS YOUR CHILD'S CLEFT FIRST IDENTIFIED?

Just born 1 Within three months 2 Four to twelve months 3 More than twelve months 4

G1a	
-----	--

G1 b) AT WHAT AGE WAS YOUR CHILD FIRST SEEN BY THE PLASTIC SURGEON?

Just born 1 Within three months 2 Four to twelve months 3 More than twelve months 4

G1b	
-----	--



G2 IS YOUR CHILD BEING FOLLOWED-UP BY THE FOLLOWING PROFESSIONALS?

Health care professional	YES	NO	If Yes, Hospital Unit no/ Private
G2a. Plastic Surgeon	1	2	
G2b. Paediatrician	1	2	
G2c. ENT Specialist	1	2	
G2d Speech Therapist & Audiologist	1	2	
G2eDentist	1	2	
G2f. Orthodontist	1	2	
G2g Social Worker	1	2	
G2h. Psychologist	1	2	
G2iNutritionist	1	2	
G2jOther	1	2	

G2a	
-----	--

G2b	
-----	--

G2c	
-----	--

G2d	
-----	--

G2e	
-----	--

G2f	
-----	--

G2g	
-----	--

G2h	
-----	--

G2i	
-----	--

G2i	
-----	--

G3 DO YOU SEE MORE THAN ONE OF THE ABOVE PROFESSIONALS AT THE SAME TIME PLACE? YES 1 NO 2

G3	
----	--

If yes specify_____

Principal Investigator: Mrs R. Gopal_____

Date:_____



APPENDIX VI

THE COMMUNICATION ASSESSMENT PROTOCOL



COMMUNICATION ASSESSMENT PROTOCOL

FOR YOUNG CHILDREN

WITH

CLEFT LIP AND/OR PALATE (CL/P)

Mrs. R. Gopal
Senior Speech-Language Therapist & Audiologist
ENT Hospital, Vacoas, Mauritius

University of Pretoria

July 2006

Please read carefully

Below is a list of instructions you are requested to follow when carrying out the complete assessment of the child with cleft lip and/or palate (CL/P).

- (i) This Protocol contains **six sections**:
- Section A: Summary sheet**
 - Section B: Feeding**
 - Section C: Hearing Evaluation**
 - Section D: Orofacial Examination**
 - Section E: Communication, speech and language**
 - Section F: General development**
- (ii) Indicate your choice of response with 'X' in the appropriate box and provide descriptions whenever required.
- (iii) The children participating in the study have been divided in two groups:
Group 1: younger than 36 months (All **six sections** to be completed)
Group 2: 36-72 months (**five sections** to be completed, omitting **section B: Feeding**)
- (iv) **Special considerations:**
- (a) For **Section C:** the Hearing evaluations to be carried out need to be age appropriate. Where not applicable write NA.
Question C8, listening evaluation scale is to be completed as described: Situation 1 during communication evaluation
Situation 2 with reference to hearing evaluation
 - (b) For **Section E:** Resonance, voice and speech assessment only for children who can express themselves in sentences.
Kindly arrange with Mrs. R. Gopal when you need to make audio and video recordings of the speech of children 36-72 months.
- (v) After completing the assessment, please record a summary of the communication assessment on Page 1.
- (vi) Please enclose the essential background information of this child with CL/P (questionnaire A), whom you will be assessing.

Thank you very much for your cooperation.

Mrs. R. Gopal
ENT Hospital
Tel: 6863854



FOR YOUNG CHILDREN WITH CLEFT LIP AND/OR PALATE IN MAURITIUS

Tracking form to be completed by the speech-language therapist and audiologist

A. SUMMARY SHEET

A1. Child's Name:

A2. File Number:

A3. D.O.B:

d	d		m	m		y	y

A4. Contact person's name and telephone number:..... (Office use only)

A5. Type of cleft:

A5

1. Lip only 2. Palate only 3. Lip and palate 4. Submucous cleft palate

Please specify Unilateral Bilateral

Complete Incomplete

For **Unilateral Cleft Lip** please specify Right Left

For **Cleft Palate** please specify: Hard Soft

A6. 1. Non-syndromic CL/P 2. Suspect syndrome 3. Syndrome present

A6

If syndrome is present, describe.....

Section: Area of Assessment	Dates of Assessment	SLT and/or Audiologist	Recommendations	Code
A: Questionnaire				
B: Feeding				
i) Pre-surgical				
ii) Post-surgical				
C: Hearing				
i) 0-36 months				
ii) 36-72 months				
D: Orofacial				
E: Communication				
Speech-Language				
i) 0-36 months				
ii) 36-72 months				
F: General Development				



(1) pre-surgical feeding assessment

B1. Child's Name:

B2. File number:.....

B3. D.O.B:

--	--	--	--	--	--

B4. Date of assessment:

d	d	m	m	y	y

B5. Age:.....days/months

Birth history:

B6. Birth weight:kg

B7. Gestational age weeks

B8. Delivery type:

B9. Any significant antenatal history

Respiration:

B10. Assisted ventilation after birth: 1. yes 2. no

B11. Infant still has respiratory problems: 1. yes 2. no

Current feeding method:

B12. Current feeding method: 1. full oral diet 2. nil by mouth
3. oral feeds and supplementary 4. NGor OG tubes

B13. If full oral diet: 1. breast 2. bottle 3. cup
4. spoon 5. syringe 6. other if other describe.....

B14. Type of milk: 1. breast milk 2. formula milk

B15. If bottle-fed indicate:

(i) texture of teat: normal soft latex silicone

(ii) hole of teat: small medium large cross cut

(iii) bottle: standard soft other if other describe..

Observations during feeding:

B16. Respiration: 1. steady/quiet 2. noisy 3. apnoeic 4. sternal retraction

B17. Predominant infant state during feeding: 1. alert and calm 2. alert and restless
3. light sleep/drowsy 4. deep sleep
5. irritated 6.crying

B18. Positioning for feeding:

1. appropriate
2. inappropriate

(e.g. child's head position, caregiver position uncomfortable)



- B19. Lip seal: 3. absent
- B20. Nutritive sucking: 1.rhythmical 2. arrhythmical 3. no sucking
- B21. Coordination of sucking, swallowing and breathing 1. yes 2. no
- B22. Aspiration risk 1. yes 2. unsure 3. no
(for example: coughing/choking during feeding/altered respiration)
- B23. Winding during and after feed: 1. yes 2. yes, but infrequent 3. no
- B24. Nasal regurgitation 1. yes 2. no
- B25. Presence of milk/formula in nostrils 1. yes 2. no
- B26. Excessive drooling and/or vomiting 1. yes 2. no

Feeding schedule:

- B27. Number of times the infant is fed in 24 hours
- B28. Duration of each feed: 1. less than 15 minutes 2. 15-30 minutes 3. more than 30 minutes
- B29. Do the parent/carer's cope with infant's feeding: 1. yes 2. no

If no, please describe the difficulties.....
.....

- B30. Child's weight /growth within normal limits 1. yes 2. no
(according to health card of the infant)

Transition phase (infants and/or toddlers on semi-solid) Please complete if child on semi-solid diet

- B31. Smooth transition to semi solid diet 1. yes 2. no If no, explain.....
.....
If yes biting, chewing and swallowing movements 1. normal 2. abnormal If abnormal, describe.....

- B32. Excessive drooling and/or vomiting 1. yes 2. no
- B33. Nasal regurgitation 1. yes 2. no 3. occasional for liquids only
- B34. Child's weight /growth within normal limits for age 1. yes 2. no
(according to health card of the infant)

B35. Guidelines to parent/care giver regarding: i) feeding method ii) equipment used
iii) positioning iv) feeding schedule v) other if other, describe.....
.....

B36. Feeding difficulties and high risk for poor weight gain: 1. yes 2. unsure 3. no
If unsure or no, recommendation, refer to: 1. paediatrician 2. nutritionist



B37. Child's Name:

B38. File number: **B39.** D.O.B:

d	d	m	m	y	y

B40. Date of assessment:

d	d	m	m	y	y

B41. Age of infant:months

B42. Dates of surgery:

d	d	m	m	y	y

 Type of repair:..... Surgeon.....

d	d	m	m	y	y

 Type of repair:..... Surgeon.....

Observations during feeding:

B43. Lips: 1. unremarkable 2. restricted movements 3. open mouth posture
4. drooling

B44. Tongue movements while feeding 1. normal 2. abnormal

If abnormal, describe.....

(For example, tongue thrust during swallowing, cannot use tongue to clean away food)

B45. Oronasal fistula 1. yes 2. no

If yes does the fistula interfere with feeding:.....

B46. Nasal regurgitation 1. yes 2. occasional for liquids only 3. no

B47. Biting, chewing and swallowing movements 1. normal 2. abnormal

If abnormal, describe

B48. Food aversion (to certain foods) 1. yes 2. no

B49. Oral hygiene 1. good 2.adequate 3. inadequate 4. poor

B50. *Frequent history of chest infections:* 1. yes 2. no

B51. Child's weight /growth within normal limits for age 1. yes 2. no
(according to health card of the infant)

B52. Feeding difficulties and high risk for poor weight gain: 1. yes 2. unsure 3. no
If unsure or no, recommendation refer to: 1. paediatrician 2. nutritionist
B53. Guidelines to parent/care giver regarding feeding.....



C1. Child's Name:

C2. File number: C3. D.O.B:

d	d	m	m	y	y

C4. History of ear surgery: 1. yes 2.no
If yes, please specify type and date of surgery.....

C5. Any history of ear infections and/or ear aches 1. yes 2. no

C6. External ear anomaly 1. yes 2. no
If yes, describe (e.g. ear tags, atresia, malformation of the pinna).....

C7. Risk factors other than cleft palate associated with hearing loss 1. yes 2. no

If yes, check (X) the risk factor/factors:

- a. family history of childhood sensorineural hearing loss
- b. premature/ birth weight less than 1.5 kgs
- c. low APGAR scores
- d. high bilirubin levels
- e. bacterial meningitis
- f. maternal history of viral infections during pregnancy
- g. ototoxic medication
- h. presence of Pierre Robin sequence or a syndrome
- i. respiratory distress
- (known to include sensorineural hearing loss)
- j. prolonged mechanical ventilation for more than 10 days
- k. Any other risk factor for sensorineural hearing loss

Please specify.....

C8. Based on **Listening evaluation scale** (Hugo, Louw, Kritzinger & Smit 2000)

Situation 1: During communication evaluation			
Reaction to	Good (1)	(...2...)	Poor (3)
Environmental sounds			
Whispered speech			
Non-speech sounds (toys)			
Speech			
Situation 2: During hearing evaluation			
Responses	Clear (1)	(...2...)	Unclear (3)
Distractibility	Never (1)	(...2...)	Very/Hyper (3)



Age appropriate Hearing evaluations	Date of hearing evaluation	Age in months	Results: attach report/reports			
C9. Parental report regarding auditory behaviour <input type="checkbox"/>			Normal	<input type="checkbox"/>	Suspect hearing difficulties	<input type="checkbox"/>
C10. Listening evaluation scale (Hugo, Louw, Kritzinger & Smit 2000) <input type="checkbox"/>			Normal	<input type="checkbox"/>	Further investigations	<input type="checkbox"/>
C11. TEOAE (Screening) <input type="checkbox"/>			Pass	<input type="checkbox"/>	Further investigations	<input type="checkbox"/>
C12. BSERA: Diagnostic <input type="checkbox"/>			Normal	<input type="checkbox"/>	Hearing loss in either/both ears	<input type="checkbox"/>
C13. Behaviour Observation Audiometry <input type="checkbox"/>			Normal both ears	<input type="checkbox"/>	Suspect hearing pathology	<input type="checkbox"/>
C14. Tympanometry <input type="checkbox"/>			Normal both ears Tympanogram Type: Right Ear	<input type="checkbox"/>	Suspect hearing pathology Right Ear <input type="checkbox"/> Left Ear <input type="checkbox"/>	<input type="checkbox"/>
C15. Acoustic Reflexes <input type="checkbox"/>			Present	<input type="checkbox"/>	absent in either/both ears	<input type="checkbox"/>
C16 Pure Tone Audiometry <input type="checkbox"/>			Normal hearing	<input type="checkbox"/>	Hearing loss in either/both ears	<input type="checkbox"/>

C17. If hearing loss is detected,

C17(i) Type: 1. conductive 2. sensorineural 3. mixed

C17(ii) Hearing loss in: 1. right ear 2. left ear 3. bilateral

C17(iii) Severity of hearing loss: 1. mild (15-30 dB HL) 2. moderate (30-50 dB HL) 3. severe (50-70 dB HL) 4. profound (>70 dB HL)

C18. Recommendations refer to ENT specialist for follow-up 1. yes 2. no

If yes name and file number for ENT specialist follow-up.....

C19. Child will need referral for hearing aid/aids 1. yes 2. unsure 3. no

C20. Follow-up appointment with audiologist 1. yes 2. no



D1. Child's Name:

D2. D.O.B:

d	d	m	m	y	y

D3. Age:.....months

D4. Date of assessment:

d	d	m	m	y	y

D5. Dates of surgery:

 Type of repair:..... Surgeon:.....

 Type of repair:..... Surgeon:.....

 Type of repair:..... Surgeon:.....

D6. Face and facial profile: 1. unremarkable 2. asymmetrical 3. dysmorphic features

D7. Jaw: 1. normal 2. micrognathia 3. macrognathia

D8. Relationship between maxilla and mandible: 1. normal
2. abnormal if abnormal please describe.....
.....

D9. Eyes: 1. appear normal
2. appearance suggestive of syndrome/midfacial developmental problems
(e.g. excessive epicanthal folds, abnormal spacing between the eyes)
describe.....

D10. Ears: 1. appear normal 2. external ear deformity describe.....
3. appearance suggestive of syndrome (eg. low set ears) describe.....

D11(i) Nose: 1. unremarkable 2. nasal bridge flat 3. deviated septum
4. obstructed nasal airway

D11(ii) Nasal columella: 1. normal 2. appears abnormal (e.g. too short/absent/deviated)

D12(i) Dentition: 1. unremarkable 2. supernumerary teeth 3. teeth missing 4. other
If other describe.....

D12(ii) Occlusion: 1. normal 2. overbite 3. under bite 4. crossbite teeth 5. open bite

D12(iii) Dental Hygiene: 1. good 2. adequate 3. poor

D13 Lips: (i) appearance 1. unremarkable 2. scarring 3. open mouth posture



D13 (ii) speech task: 1. yes 2. no
3. /p, t, k/: 1. yes 2. no
4. /b, d, g, /m/: 1. yes 2. no

D14. Tongue: (i) appearance 1. unremarkable 2. suggestive of syndrome (e.g. size)
3. abnormal posture 4. frenum abnormal

D14. (ii) speech tasks: 1.mobility for tongue tip sounds /t/ /d/ /n/ 1. yes 2. unsure 3.no
2. mobility for velar sounds /k/ /g/ 1. yes 2. unsure 3.no

Post palate repair:

D15. Alveolar ridge: 1. normal 2. wide 3. collapsed 4. cleft

D16. Palatal fistula: 1. present 2. absent

D16(i) If fistula is present, location:

- 1. soft palate 2. junction soft/hard palate 3. hard palate-post sulcus
- 4. buccal sulcus 5. hard palate and buccal sulcus 6. if other

describe.....

D16(ii) Fistula size: 1. small 2. medium 3. large 4.complete breakdown of repaired palate

D16(iii) Is oronasal fistula interfering with speech sound production: 1. yes 2. no

D16(iv) Soft palate: 1. normal 2. apparently short velum 3. split uvula

D17. Palatal mobility 1. Marked 2. Moderate 3. Slight 4. None

D18. Nasopharynx: 1.appears normal 2. apparently deep pharynx
3. tonsils appear enlarged 4. pharyngeal flap

D19. Any airway obstruction suspected: 1. yes 2. no
(e.g. mouth breathing, parental report of child's loud snoring, strenuous breathing)

D20. Contributing factors to speech production errors:

- D20(i) Abnormal lip movements D20(ii) Abnormal tongue movements
- D20(iii) Abnormal dentition D20(iv) Palatal fistula
- D20(v) Suspected VPI D20(vi) Suspected syndrome
- D20(vii) Any other etiology suspected D20 (viii) None

D21. Referral for dental follow-up	1. yes <input type="checkbox"/>	2. no <input type="checkbox"/>
D22. Referral for ENT specialist's opinion (tonsils)	1. yes <input type="checkbox"/>	2. no <input type="checkbox"/>
D23. Any other referral please specify..... (for e.g. genetic testing, paediatrician)		

E1. Child's Name:

E2. D.O.B: d d m m y y

--	--	--	--	--	--	--

E3. Age:.....months

E4. Date of assessment: d d m m y y

--	--	--	--	--	--	--

E5. Dates of surgery	<table border="1" style="width: 100%; border-collapse: collapse; text-align: center;"> <tr> <td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td> </tr> <tr> <td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td> </tr> <tr> <td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td> </tr> </table>																			Type of repair:..... Surgeon..... Type of repair:..... Surgeon..... Type of repair:..... Surgeon.....
E6. Home language: 1. Creole <input type="checkbox"/> 2. French <input type="checkbox"/> 3. English <input type="checkbox"/> 4. Bilingual <input type="checkbox"/> 5. Other <input type="checkbox"/>																				

E7. Parental concerns regarding communication.....

E8. Communication skills (based on Communication Assessment Protocol Facial Deformities Clinic University of Pretoria)

- E8(i) Non-verbal communication
 (e.g. eye contact, social smile, facial expressions) 1. yes 2. unsure 3. no
- E8(ii) Behaviour regulation
 (e.g. requests objects, requests action, protests) 1. yes 2. unsure 3. no
- E8(iii) Social interaction
 (e.g. requests attention, calls a person) 1. yes 2. unsure 3. no
- E8(iv) Shared attention
 (e.g. comments, requests information, explanations) 1. yes 2. unsure 3. no
- E8(v) Discourse structure
 (e.g. turn taking, imitation, responds) 1. yes 2. unsure 3. no
- E8(vi) Mode of communication
 (e.g. gestures, vocal, gestures and verbal) 1. yes 2. unsure 3. no



E9. Therapist's observations: Major milestones of language acquisition (Shipley, 2004 p.233)

Age Range Typical Language Behaviours

0-1 mos.	Startle response to sound; quieted by human voice
2-3 mos.	Cooing; production of some vowel sounds; response to speech; babbling
4-6 mos.	Babbling strings of syllables; imitation of sounds; variations in pitch and loudness
7-9 mos.	Comprehension of some words and simple requests; increased imitation of speech sounds; may say or imitate 'mama'
10-12 mos.	Understanding of 'No'; response to requests; response to own name; production of one or more words
13-15 mos.	Production of five to ten words, mostly nouns; appropriate pointing responses
16-18 mos.	Following simple directions; production of two-word phrases; production of I or mine
24-30 mos.	Response to some yes/no questions; naming of everyday objects; production of phrases and incomplete sentences; production of the present progressive, prepositions, regular plurals, and negation 'no' and don't

E9. Language development: 1.no concerns 2. suspect 3. delayed/disordered
(Receptive and expressive)

E10. Consonant Inventory

	NASAL	PLOSIVE	FRICATIVE	APPROXIMANT
LABIAL	m	p b		w
LABIO DENTAL			f v	
ALVEOLAR	n	t d	s z	l
POST ALVEOLAR			ʃ ʒ	
VELAR	ŋ	k g		
GLOTTAL		ʔ		

Heard by therapist

Reported by parents

* phoneme /r/ is not expected before 36 months. Some other phonemes for eg. /t/ and /ø/ are absent in Creole.

E10. Consonant repertoire (based on consonant production inventory):

1. age appropriate 2. limited 3. no identifiable consonants



E11. Emergent literacy skills:

- E11(i) Parents have introduced the child to books: 1. yes 2. no
- E11(ii) Child responds to being read to: 1. yes 2. no
- E11(iii) Child shows an interest in books: 1. yes 2. no
- E11(iv) Child pretends to read books: 1. yes 2. no

- | | |
|---|--------------------------|
| E12. Recommendations for further in depth communication assessment | <input type="checkbox"/> |
| E13. Parental guidance regarding consonant production by the child | <input type="checkbox"/> |
| E14. Parental guidance regarding emergent reading skills | <input type="checkbox"/> |



E15. Child's Name:

E16. D.O.B:

d	d	m	m	y	y

E17. Age:..... months

E18. Date of assessment:

d	d	m	m	y	y

E19. Dates of surgery:

d	d	m	m	y	y

 Type of repair:..... Surgeon:.....
Dates of surgery:

 Type of repair:..... Surgeon:.....
Dates of surgery:

 Type of repair:..... Surgeon:.....

E20. Home language: 1. Creole 2. French 3. English 4. Bilingual 5. Other

E21. Is child exposed to any other languages (for e.g. at school) please specify.....

E22. The child usually expresses himself/herself in:

- 1. sentences
- 2. short phrases
- 3. single words
- 4. gestures

E23. Parental concerns regarding communication.....
.....
.....

E24. Therapist's observations: Major milestones of language acquisition (Shipley, 2004 p.233)

Age Range	Typical Language Behaviours
3:0 –3:6 yrs.	Production of three- to four-word sentences; production of the possessive morpheme, several forms of questions, negatives 'can't' and 'don't'; comprehension of 'why', 'who', 'whose' and 'how many' and initial production of most grammatical morphemes.
3:6- 6 yrs	Greater mastery of articles, different tense forms, copula, auxiliary, third person singular, and other grammatical morphemes; production of grammatically complete sentences.

E24. Language expressive 1.no concerns 2. suspect 3. delayed/disordered

E25. Emergent literacy skills:

- E25(i) Shows an interest in books and reading 1. yes 2. no
- E25(ii) Listens attentively to parent/teacher reading 1. yes 2. no
- E25(iii) Is sensitive to some sequences of events in a story: 1. yes 2. no
- E25(iv) Correctly answers questions about stories read aloud 1. yes 2. no
- E25(v) Displays attempts at reading: 1. yes 2. no
- E25(vi) Recognises and can name a few letters 1. yes 2. no



If child is expressing himself/herself with the auditory-perceptual assessment for resonance, voice and speech (GOS.SP.ASS. '98)

Stimulus: Counting 1-5 (10). Picture description 1 minute (standard sea side scene)

Conversation 2 minutes (standard questions to elicit spontaneous continuous speech)

Audio recording reference number..... Video recording reference number.....

Rating scale for E26, E27, E28 as per GOS.Sp.ASS '98.

E26. Resonance

E26(i) Hypernasal

1. yes

2. no

- Normal tone 0
- Hypernasal voice perceived on vowels and approximants 1
- Hypernasal tone of vowels, weakened consonants and nasalisation of voiced consonants 2
- All the above and substitution of /b, d, g/ by /m, n, ŋ/ 3

E26(ii) Hyponasal

1. yes

2. no

- Normal tone 0
- Moderate hyponasality where nasal consonants are slightly denasal 1
- Nasal consonants are perceived as plosives 2

E26(iii) Mixed Nasality

1. yes

2. no

(hyper and hyponasality co-occur)

E27 Nasal Emission/Turbulence 1. yes

2. no

- Nasal emission/turbulence absent 0
- Slight nasal emission/slight nasal turbulence 1
- Marked nasal emission/distracting nasal turbulence 2

Mirror Test

	R	L
papa pipi		
kaka kiki		
sssss		

E28. Grimace

1. yes

2. no

- No grimace 0
- Nasal flare 1
- Nasal grimace involving the nostrils and upper lip 2
- Facial grimace which includes the mid and upper face 3

E29. Voice

1. normal

2. dysphonia

E29(i) If child has dysphonia then request the child to phonate vowels /a/ /o/ and /i/ and describe:

a. voice quality (for e.g. hoarse, breathy).....



b. pitch (for e.g. inappr

c. Intensity (for e.g. re

E29(ii) Parental report of vocal abuse: 1. yes 2. no

E30. Speech

Consonant Production (repetition of words and sentences; from speech elicitation material included with instructions to participants)

Please indicate (+) if sound is correctly articulated, (-) if error in sound articulation.

Analyse the consonants that were indicated as (-) and in E29 note the type of errors

	Labial			Labiodental			Alveolar					Post-alveolar		Velar		
	m	p	b	f	v	n	t	d	l	s	z	ʃ	ʒ	ŋ	k	g
SIWI																
SFWF																
Sentences																

E31. Cleft Speech Characteristics: 1. yes 2. unsure 3. no

If yes type of errors:

E31(i) Anterior oral CTCs e.g.

E31(ii) Posterior oral CTCs e.g.....

E31(iii) Non oral CTCs e.g.....

E31(iv) Passive CTCs e.g.....

E32. Developmental errors: 1. yes 2. unsure 3. no

If yes e.g.....

E33. Visual appearance of speech

1. unremarkable 2. asymmetry of facial movement

3. tight upper lip 4. tongue tip appearing

E34 Identifiable etiology of communication, speech and language impairment in conjunction with C] hearing evaluations and D] orofacial examination

E34(i) Hearing loss E34(ii) Developmental delay

E34(iii) Oral fistula E34(iv) Dentition abnormal

E34(v) Syndrome E34(vi) Other specify.....

E35 Recommendation: Regular Speech-language therapy 1. yes 2. no



F. General Development

F1. Child's Name:

F2. File number: **F3.** D.O.B:

d	d	m	m	y	y

F4. Date of assessment:

d	d	m	m	y	y

F5. Age:.....months

F6. Speech-language therapist's opinion regarding motor development (based on developmental milestones for example:sitting, walking..)

1. normal 2. delayed

F7. Parental report/observations of the child playing with toys (for eg. imitation, symbolic play, exploratory play)

1. age appropriate 2. need for further in depth assessment

F8. Social interactions as reported by parents (e.g. interactive, shy, aggressive, uncooperative)

-
 1. normal 2. need for further in depth assessment

F9. Educational history:

i)Is the child attending a school: 1. yes 2. no

If yes, is the child in:

- 1.day care center 2.pre-primary school 3.primary school 4. special school

ii) Is the child coping academically/preacademically 1. yes 2. unsure 3. no

(based on parental and/or school report)

F10. Does the parent have any concerns regarding child's development 1. yes 2. no

If yes, describe parental concerns regarding general development of the child

.....

F11. Provide any additional information that might be helpful in this assessment

.....

F12. Recommendations: refer for in-depth assessment by:

- Paediatrician Occupational Therapist
 Clinical Psychologist Other please specify.....

.....

The Communication Assessment Protocol has been compiled by Mrs. R. Gopal based on literature review and the following main sources:

Section B: Feeding assessment is based on:

Masarei, A., Wright, S., Hughes, J., & Lake, R., 2004 “Initial feeding assessment for Newborn Infants with cleft lip and or palate”: North Thames Regional Cleft Team, UK.

Section C: Hearing evaluations are based on:

ASHA ‘*Joint Committee on Infant Hearing Year 2000 Position statement*’
<http://www/jcih.org> accessed: Jan. 2006

Hugo, R., Louw, B., Kritzinger, A., Smit, G.J., 2000, ‘Listening behaviour in children at risk for communication delay’ *Infant-Toddler Intervention. The transdisciplinary Journal*, vol. 10, No 1, pp 47-53

Section D: Orofacial examination is based on:

Shprintzen, R.J., & Bardach, J., 1995, ‘Cleft palate speech management: A Multidisciplinary approach’, St. Louis, Mosby Inc (pp 212-215)

Watson, A.C.H., Sell, D.A., & Grunwell, P. 2001, *Management of Cleft Lip and Palate*, London and Philadelphia, Whurr Publishers (pp 232-233).

Section E: Communication, speech-language assessment is based on:

Communication Assessment Protocol Facial Deformities Clinic, University of Pretoria

Consonant Inventory as devised by the Thameside community health care NHS trust

GOS.SP.ASS 98 in Watson, A.C.H., Sell, D.A., & Grunwell, P. 2001, *Management of Cleft Lip and Palate*, London and Philadelphia, Whurr Publishers (pp 232-233)

Shipley, K.G., McAfee, J.G., 2004, *Assessment in Speech-Language Pathology: A Resource Manual 4th ed.*, San Diego, Singular publishing grp. (p. 233).

Snow C.E., Burns, M.S., Griffin, P., 1998, *Preventing Reading Difficulties in Young Children* Washington, National Academy Press

Section F: General Development is based on case history form for children in:

Shipley, K.G., McAfee, J.G., 1998, *Assessment in Speech-Language Pathology: A Resource Manual 2nd ed.*, San Diego, Singular publishing grp



APPENDIX VII

SPEECH MATERIAL FOR ELICITING SPEECH



Creole, French and English words and sentences for eliciting a speech sample

Following is the list of words and sentences that have been prepared in Creole based on Eurocran speech project guidelines (<http://www.eurocran.org/content>) for speech elicitation materials that are standard cross-linguistically. The French translations are provided in *italics*.

Creole and French (*in italics*) word list

Initial

[m] marto (*marteau*)

[p] poul (*poule*), poupet (*poupée*)

[b] bol (*bol*), boul (*boule*)

[f] fey (*feuille*)

[v] ver (*verre*)

[n] nene (*nez*), navir (*navire*)

[t] tapi (*tapis*), torti (*tortue*)

[d] desin (*dessin*), dokter (*docteur*)

[l] lili (*lit*), lapin, loto

[s] soley (*soleil*), seve (*cheveux*)

[z] zako (*singe*), zero, zoli

[k] kado (*cadeau*), koki (*coquille*)

[g] gato (*gâteau*)

[gn] * No [gn] in word initial position

Final

lagom (*gomme*), lasam (*chambre*)

lasoup (*soupe*), lalamp (*la lampe*)

rob (*robe*), latab (*table*)

bef (*boeuf*), dizef (*oeuf*)

mov (*mauve*), lalev (*lèvre*)

ravann (*ravane*), laline (*lune*)

latet (*tête*), savat (*savate*)

lapoud (*poudre*), koud (*coude*)

lekol (*école*), disel (*sel*)

labous (*bouche*), tas (*tasse*)

rouz (*rouge*), zimaz (*image*), lagorz

sak (*sac*), labek (*bec*)

bag (*bague*), lareg (*règle*)

pagne

Creole sentences



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- /m/ Mo mami pe dormi dan lasame
- /p/ Popo faire pipi dans pot
- /b/ Bebe so biberon lor latab
- /f/ Fifi pe ferme lafnet / Fifi pe frire dizef
- /v/ Dev ek Vina viv dan vilaz
- /n/ Nelly donne li ene ti banane
- /t/ Toto pe gratte so latet
- /d/ Dadi pe dodo endans
- /l/ Soley levé la-haut dan leciel
- /s/ Soonil pe lapesse poisson dan bassin
- /z/ Enn ti zwazo dan lakaz pe bate lezel
- /dj/ Jenny ena so badge lor so jean
- /k/ Karina kas koko zet so lakok
- /g/ Maggy goute gateau la



French sentences (compiled from: Trouble de l'articulation, Equipe du Centre d'Orthophonie, Etienne Coissrd, by Mrs. R. Gopal)

- /m/ *Maman mange à midi*
- /p/ *Apporte un petit pot*
- /b/ *Bébé a une belle robe*
- /f/ *Fifi fera du café*
- /v/ *Tu vas vite*
- /n/ *Bonne année!*
- /l/ *Il est malade depuis lundi*
- /t/ *Ta tortue est toute petite*
- /d/ *Didier a une idée*
- /s/ *C'est assez salé*
- /z/ *Les oiseaux gazouillent dans les arbres*
- /ʃ/ *Le chocolat est chaud*
- /j/ *J'ai bien joué dans la neige*
- /k/ *Quel beau bouquet*
- /g/ *Apporte un légume pour le ragout*

English sentences (GOS. SP.



- /m/ Mum came home early.
- /p/ The puppy is playing with the rope
- /b/ Bob is a baby boy
- /f/ The phone fell off the shelf
- /v/ Dave is driving a van
- /n/ Neil saw a robin in the nest
- /l/ A ball is like a balloon
- /t/ Tim is putting on a hat
- /d/ Daddy mended a door
- /s/ I saw Sam sitting on a bus
- /z/ The zebra was at the zoo
- /j/ John's got a magic badge
- /k/ Karen is making a cake
- /g/ Gary's got a bag of lego



/m/



/marto/



/lagom/

/p/



/poul/

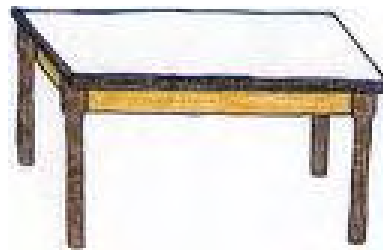


/lalamp/

/b/



/boul/



/latab/



APPENDIX VIII

QUESTIONNAIRE FOR SPEECH LANGUAGE THERAPISTS

AND AUDIOLOGISTS

Development of a Communication Assessment Protocol for Young Children with Cleft Lip and/or Palate in Mauritius

Aim of this research project: To develop a Communication Assessment Protocol for Young Children (0-6 years) with Cleft Lip and/or Palate in Mauritius. This will help improve service delivery to children with CL/P and their families, monitor their progress objectively and document the treatment outcomes. In addition, Speech- Language Therapists and Audiologists working with children with CL/P will have an assessment tool that is appropriate, standardized and uniform.

Aim of this questionnaire: This questionnaire has two sections each with its own aim.

The aim of section I of the questionnaire is to determine perceptions of speech-language therapists and audiologists regarding the compiled assessment tracking form.

Section II, the aim is to gather feedback regarding the clinical applicability of this protocol from the speech-language therapists and audiologists after they have conducted the communication assessment protocol on children with CL/P.

Instructions: Please complete your biographical information. The questionnaire has two sections. Please indicate your choice or choices with an X, and provide descriptions. You should only complete Section II of this questionnaire after you have clinically assessed children with CL/P participating in this study.

Your opinions and input are very important, as they will influence the development of the protocol. In addition, testing the clinical applicability of the communication assessment protocol for children with CL/P will help improve the trustworthiness thereof.

Thank you very much for your co-operation.

Rachna Gopal

Senior Speech-Language Therapist and Audiologist

Ministry of Health, Mauritius



Biographical information of speech-language therapist and audiologist completing the questionnaire

Name:.....

Designation:..... Hospital:.....

Your qualifications in Speech-Language Therapy & Audiology:

Bachelor's degree Master's degree Doctorate Other specify.....

Years of experience as a Speech-Language Therapist & Audiologist.....

Total number of children (0-72 months) currently receiving SLT services from you.....

Number of children with CL/P currently receiving SLT services from you.....

Your prior experience in CL/P:

Extensive Average Limited None

SECTION I

Preliminary evaluation of the Communication Assessment Protocol for children with CL/P

1. Did you complete the survey questionnaire Section A] part 1, of this study (April to August 2005) during which the essential background information of children with CL/P participating in this study was gathered?

Yes No If no why not.....

If yes, in your opinion did the design of the questionnaire allow for accurate and essential capturing of the background information of children with CL/P and their families?

Yes No If no, which other information would you like to include?

2. After reviewing the proposed Communication Assessment Protocol for Young Children with CL/P Sections B to F please answer the following questions:

2.1 Do you find the Communication Assessment Protocol?

Clear Unclear Unsure



2.2 In your opinion, do all the [hearing, orofacial examination, communication, speech-language and general development need to be assessed?

Yes Unsure No

If no, which section would you like to exclude and why?

.....
.....
.....

Would you like to include any other area of assessment?

Yes No

If yes, list the area/areas of assessment you would like to include.....

.....
.....

2.3 Do you feel competent to assess the child with CL/P in all of these areas?

Yes Yes but with additional training Unsure No

If you would like additional training, please indicate in which of the following areas of assessment you would like training:

Section B] Feeding Section C] Hearing Section D] Orofacial examination
Section E] Communication, speech and language Section F] General development

If you answered unsure or no please explain

.....
.....

3. Please refer to Section E] communication, speech, language assessment of the Communication Assessment Protocol and answer the following questions:

3.1 Do you feel that the content of this protocol is sufficient to provide an accurate perceptual assessment of speech characteristics of children with CL/P?

Yes Unsure No

If answered unsure or no, please explain.....

.....
.....



3.2 Do you think that the rating (0- 3: E.26 to E.28 of the form) will be helpful in your perceptual judgments of nasality

Yes Unsure No

If answered unsure or no please explain.....
.....
.....
.....

3.3 Do you think that the descriptions of the cleft palate speech characteristics (anterior, posterior, non oral passive cleft type characteristics, developmental errors:E30 to E33 are:

Necessary Yes Unsure No
Clear Yes Unsure No
Accurate Yes Unsure No

3.4 The Communication Assessment Protocol requires that for group II children with CL/P (36-72 months) you make audio and video recordings of their speech. Would it be practical for you to carry out the recordings in your hospital context?

Yes No If no, please explain.....

.....
.....

3.5 Please, review Appendix 1 of the Communication Assessment Protocol. A list of Creole, French and English words and sentences are proposed as stimulus for eliciting speech responses from children with cleft lip and/or palate in group 2 (36-72 months). In your opinion, are these words and sentences appropriate?

Yes Unsure No

If answered unsure or no, please indicate the words and/or sentences that you would like change and explain why.....

.....
.....
.....



4. Do you feel that the length of the communication assessment protocol is appropriate for use in your hospital context?

Yes

Unsure

No

Any comments please add.....

.....
.....

5. Do you have any further comments regarding the Communication Assessment Protocol for Young Children with CL/P?

.....
.....
.....
.....
.....
.....
.....
.....
.....

Thank you very much for your input regarding the communication assessment protocol

Date



SECTION II

Clinical Applicability of the Communication Assessment Protocol for Young Children with Cleft Lip and/or Palate in Mauritius

1. Did you complete the communication assessment protocol on children with CL/P from both age groups: group 1 younger than 36 months and group 2, 36-72 months?

Yes

No

If no, please provide the reasons

If yes, please complete this table:

Number of children younger than 36 months	
Number of children 36-72 months	
Total number of children	

2. Did you find that administrating the communication assessment protocol was:

2.1 Suitable for use in the hospital context: Yes Unsure No

Please explain your answer.....

2.2 Detailed enough in the areas (sections B-F) that you assessed:

Yes Unsure No

Please explain your answer.....



2.3 You could assess the children with CL/P:

With ease

With some difficulty

With difficulty

If some difficulty was experienced please indicate in which of the following area/areas:

- Section B Feeding
- Section C Hearing
- Section D Orofacial
- Section E Communication speech and language
- Section F General development

Please explain the nature of difficulty you experienced

.....

.....

.....

.....

3. With reference to Section E] ii) auditory perceptual assessment of resonance and speech please answer the following:

3.1 Could you assess the resonance in terms of the rating scales?

With ease

With some difficulty

With difficulty

Please explain your answer.....

.....

.....

Could you describe the cleft type speech characteristics:

With ease

With some difficulty

With difficulty

Please explain your answer.....

.....



4. Were any of the children non-compliant during assessment?

Yes

No

If yes, indicate in which area/areas of assessment.....

Please specify age group of the child/children.....

In your opinion what were the contributing factor/factors for non-compliance?.....

5. Do you feel that the results of the protocol could provide you with the intervention guidelines?

Yes

Unsure

No

Please explain your answer.....

6. Do you think that you will use this protocol in the future?

Yes

Unsure

No

Please explain your answer.....



TOPICS	DESCRIPTION Excerpts of representative quotes of the participants
<p>TOPIC ONE</p> <p>Overview of the Communication Assessment Protocol</p>	<p>The participants agreed that the communication assessment protocol is a complete and useful tool.</p> <ul style="list-style-type: none"> • ‘The protocol is complete...it includes various areas of assessment example feeding, hearing, general development in addition to the speech-language assessment’ • ‘You can follow a child from the time he is born to the time all the operations are complete....I liked this longitudinal aspect’ • ‘It has all the aspects needed for longitudinal assessmentit helps to really focus on each area’ • ‘The protocol is easy to use, simple and the checklist format renders the protocol user friendly’ • ‘The layout of the form was very nice, simple, accessible and very well organised that is what helped me use the tool’ • ‘I found that the participation of the parents formed an important part of the assessment’ <p>The constraints/problems that concerned the participants were; lack of apparatus at the various regional hospitals and unavailability of an assistant to help with the recordings.</p> <ul style="list-style-type: none"> • ‘I am based at Jeetoo Hospital and I do not have the audiology facility nor the video recording equipment I think we should make it a centre based assessment where the equipment and assistant are available’ • ‘Some parents may have a problem to move to one centre’ ‘Maybe we could plan in the future to have the equipment in our own clinic ...’
<p>TOPIC TWO</p> <p>Clinical applicability</p> <p>Specific aspects</p> <p>i) Training</p>	<p>The participants discussed their experiences when conducting the assessments</p> <p>i) The participants found the training adequate</p> <ul style="list-style-type: none"> • ‘The video training was helpful, as we needed fine tuning into listening to the speech characteristics of children with CL/P’ • ‘Initially it was scary as I am not used to analysing speech. Training, observing how the principal investigator conducts the assessments and later analysing the speech was helpful’ • ‘We are speech-language therapists....and assess regularly, observing the principal investigator doing the assessment, analysing speech helped a lot’



<p>ii) Communication Assessment tracking form and the speech elicitation material</p>	<p>The participants regarding the materials, namely the tracking form and the speech elicitation materials.</p> <ul style="list-style-type: none"> • ‘The checklist made it easier to tick the appropriate observations’ • ‘Personally I like the checklist it is a time saver’ • ‘From the aesthetic point of view the protocol had different colours to differentiate each section.....this is very appealing ... we do not have to scan through the whole form’ • ‘The most beautiful part was the speech material that was provided, particularly the French words list’ • ‘The pictures were very helpful in eliciting responses from shy children and made them eager to repeat the words’
<p>iii) Apparatus</p>	<p>The quality of recordings was good and video recordings were useful in speech analysis.</p> <ul style="list-style-type: none"> • ‘I could go back to the tape and listen whatever we missed out so that way easy access for accurate assessment was there...’ • ‘I personally preferred the video recordings...’ • ‘For communication assessment body language is important therefore the video recordings were very helpful.... You can see the facial expression, and if they have tight lip’
<p>iv) Areas of assessment</p>	<p>The protocol was described as complete because all the areas of communication were assessed.</p> <ul style="list-style-type: none"> • ‘The hearing screening is very important for children with cleft palate’ • ‘ I think the feeding aspect as well, we could counsel the parents or make proper referrals’ • ‘It was easy to do the articulation test first ... because the parents were there... the child was fresh..’ • ‘Initially I did not see the utility of adding emergent reading skills but then this helped a lot in guiding the parents afterwards..’ • ‘We see the child as a whole every aspect of development is looked into’ <p>Completing the assessment in one session was sometimes not possible.</p> <ul style="list-style-type: none"> • ‘Initially the protocol appeared long but then with practice it became easier to conduct the assessment’ • ‘I think an assessment should go ½ hr. and sometimes it took me 40 minutes that is long for a child’



APPENDIX IX

FOCUS GROUP DISCUSSION



<p>v) Intervention</p>	<ul style="list-style-type: none"> • ‘I we are going to assess the child over a long time clinical applicability as • ‘I found it takes time to test the baby’s hearing.... Sometimes they don’t respond... rapport has to be built... some children are difficult to condition for hearing evaluation • ‘I think the therapist who was working with the child should test the child....and of course parents are present as comforters’ <p>The protocol was found to be useful in management of the children with CL/P</p> <ul style="list-style-type: none"> • ‘Feeding assessment made it easier to refer to dietician as we had concrete data’ • ‘At the end of the assessment we can be sure we need to make this referral....even ...referrals to the dentist’ • ‘The protocol had an impact on management ... before this protocol we would not have thought of asking parents whether the child is reading/looking at picture books’ • ‘It is a good tool to evaluate as therapy is ongoing’ • ‘It helps us to establish long term and short term goals’ <p>Most of the children could be assessed with ease but some of the children were difficult to assess</p> <ul style="list-style-type: none"> • ‘The parents were there as comforters....and helped the therapist’ • ‘Some children were shy and did not want to repeat the words’ • ‘ Some children were hyperactive and did not repeat the words’ • ‘Babies could not be conditioned for hearing testing in one session’ • ‘Rapport with the child is very important... the therapist who provides therapy should assess and re-assess the child
<p>TOPIC THREE Clinical Acceptability</p>	<p>The participants unanimously affirmed that they would use the protocol in the future for assessments.</p> <ul style="list-style-type: none"> • ‘I think I will use this tool a lot in the future’ • ‘It is clinically applicable in the hospital context’ • ‘It saves time’ • ‘No formalised tools exist this is a formal test we now have. It is based on previous (international) research’ • ‘It is a good tool to evaluate progress in therapy’ • ‘We have a common base as all therapists will use this tool’



Potential **assessment protocol**
was discussed for example:

- 'It can be used beyond 72 months'
- 'I will use the articulation part for other articulation cases'
- 'I could use the feeding assessment for children with feeding difficulties.'