**DOES CLINICAL ASSESSMENT REALLY REFLECTS WHAT CLEFT PATIENTS WANTS?**

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**CHAPTER 1: INTRODUCTION**

**CLEFT AND RESIDUAL CLEFT DEFORMITY**

Cleft lip and palate (CLP) has become a major public health problem affecting one in every 500-1000 births worldwide ([Williams et al., 2001](#_ENREF_65)). It is the fourth most common birth defect and the most common congenital defect of the face ([Fraser and Calnan, 1961](#_ENREF_20)). These patients are likely to have significant dental problems that require attention of various specialties in healthcare.

Embryologically, the formation of tooth germs and the occurrence of cleft lip (CL) and/or cleft palate (CP) defects have a close relationship both in terms of timing and anatomical position. The odontogenic epithelium over the premaxillary and mandibular processes can be identified as early as the fifth embryonic week, while CL and/or CP anomalies are believed to occur during the fourth and seventh week period([Pannbacker, 1968](#_ENREF_40)).

A child born with a cleft requires coordinated care from a range of clinical specialists from birth until adulthood which involves several anatomical structures and functions including speech, hearing, and social interaction. However, the multidisciplinary treatment protocol including the appropriate timing and method of each intervention, are still heavily discussed and debated. Therefore, different centres produced different outcome, depending on their protocol of care.

Patients who didn’t receive timely treatment or therapy usually will have residual cleft deformities such as deviated nose, impaired speech and malocclusion. These residual cleft deformities therefore, remain as a stigma to the patients with cleft lip and palate if left unrepaired. There are also lack of study done to see perceived need of treatment from the parents and patients of cleft lip and palate deformity (Noor and Musa, 2007).

To our knowledge,there is only limited number of combined cleft clinic throughout the country and expertise is mostly centered in urban areas. We predict that there are still cleft individuals who are deprived of the basic management mentioned earlier. This has never been studied or reported for the Malaysian population and therefore prompt us to write this book.

**CHAPTER 2:**

**INCIDENCE & EPIDEMIOLOGY**

A child with cleft is born every 2 minutes or 240 000 every year ([Vanderas, 1987](#_ENREF_63)). The variation of incidence is in accordance to geographic location, ethnicity, gender, and socioeconomic status. This deformity is reported to be the most prevalent among Asians, intermediate in Caucasians and the least in Africans.

In Malaysia, incidence was reported to be 1.24 per 1000 live birthby Boo and Arshad in 1990. The highest incidence of 1.9 per 1000 birth was reported to be from Chinese, while the lowest incidence of 0.98 per 1000 birth was from the Malays. They also reported that the most common type of cleft is Unilateral cleft of the palate. These figures however, could be underestimated due to incomplete registration (Boo & Arshad, 1990).

The most commontype of cleft reported is cleft lip and palate at 46%, followed by isolated cleft palate at 33%, then isolated cleft lip at 21%. Majority of bilateral cleft lips (86%) and unilateral cleft lips (68%) are associated with a cleft palate. Unilateral clefts are nine times as common as bilateral clefts, and occur twice as frequently on the left side than on the right. Males are predominant in the cleft lip and palate population, whereas isolated cleft palate occurs more commonly in females ([Sauter, 1989](#_ENREF_53)). According to CLAPAM (Cleft Lip And Palate Association Malaysia) registry, there are about over one thousand patients were registered from 1993 to 2011 (please refer table 2.1). Most of the patients were registered in Selangor.

**TABLE 2.1 INCIDENCE OF CLEFT IN MALAYSIA FROM 1993-2011**

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **STATE** | **GENDER** | | **TOTAL** | **RACE** | | | | **TOTAL** | **TYPE OF CLEFT** | | | | **TOTAL** | **MISSING** |
| MALE | FEMALE |  | MALAY | CHINESE | INDIAN | OTHERS |  | UNILATERAL | BILATERAL | LIP ONLY | PALATE ONLY |
| SELANGOR | 313 | 244 | **557** | 385 | 121 | 36 | 15 | **557** | 267 | 101 | 43 | 144 | **555** | 2 |
| KL | 134 | 125 | **259** | 178 | 60 | 14 | 6 | **259** | 114 | 49 | 16 | 67 | **246** | 13 |
| PERLIS | 2 | 1 | **3** | 3 | 0 | 0 | 0 | **3** | 2 | 1 | 0 | 0 | **3** | 0 |
| KEDAH | 6 | 3 | **9** | 6 | 3 | 0 | 0 | **9** | 4 | 3 | 2 | 0 | **9** | 0 |
| PENANG | 6 | 2 | **8** | 4 | 4 | 0 | 0 | **8** | 6 | 1 | 0 | 0 | **7** | 1 |
| PAHANG | 42 | 41 | **83** | 70 | 8 | 3 | 2 | **83** | 38 | 13 | 9 | 23 | **83** | 0 |
| KELANTAN | 3 | 5 | **8** | 7 | 1 | 0 | 0 | **8** | 4 | 2 | 1 | 1 | **8** | 0 |
| TERENGGANU | 4 | 5 | **9** | 8 | 1 | 0 | 0 | **9** | 3 | 2 | 2 | 2 | **9** | 0 |
| NEGERI SEMBILAN | 30 | 21 | **51** | 32 | 10 | 8 | 1 | **51** | 24 | 9 | 5 | 11 | **49** | 2 |
| SARAWAK | 26 | 29 | **55** | 20 | 9 | 1 | 25 | **55** | 24 | 12 | 1 | 16 | **53** | 2 |
| SABAH | 1 | 1 | **2** | 1 | 1 | 0 | 0 | **2** | 1 | 0 | 1 | 0 | **2** | 0 |
| JOHOR | 14 | 14 | **28** | 19 | 8 | 1 | 0 | **28** | 12 | 6 | 1 | 6 | **25** | 3 |
| PERAK | 5 | 11 | **16** | 12 | 4 | 0 | 0 | **16** | 8 | 4 | 1 | 2 | **15** | 1 |
| MALACCA | 6 | 10 | **16** | 12 | 2 | 2 | 0 | **16** | 8 | 4 | 2 | 2 | **16** | 0 |
| **TOTAL** | **592** | **512** | **1104** | **757** | **232** | **65** | **49** | **1104** | **515** | **207** | **84** | **274** | **1080** | **24** |

Courtesy from CLAPAM

**CLASSIFICATION OF CLEFT LIP AND PALATE**

Since 1950’s, a variety of works have been done to develop classification for cleft lip and palate.Kernahan and Stark (1958) classification, for example, is related to the representation of clefts of the primary and secondary palates.Some were reported to modify the Kernahan (1971) ‘‘Y’’ and incorporate new elements, such as premaxilla protrusion and velopharyngeal competence (Elsahy, 1973). In Millard’s (1977) work, certain elements were incorporatedpertaining to nasal deformity, such as the nostril arch (left and right). Friedman et al. (1991) proposed a new symbolic representation by combining both elements in which a score is included to indicate the severity of the anatomical and functional deformity.

Another way to classify clefts was through the RPL system proposed by Schwartz et al. (1993). This system classified clefts using three digits (one for the left side of the Y, another for the right side, and a third for the base of the Y) and was also based on the Kernahan Y. Each digit assumed a value between 1 and 3, reflecting the number of affected components in each limb of the Y.

Although many methods were attempted to describe features of clefts, a methodology still does not exist to adequately characterize other important features that could relate to severity of the clefts. Factors associated with the patient’s aesthetics and functionality is considered only in a limited fashion. More importantly, none of these classifications actually described the residual deformities in a repaired cleft lip and palate patients.

**LAHSAL CLASSIFICATION**

A relatively new recording-system for thediagnosis of deft lip and palate malformations is the**LAHSHAL** system that **Kriens**introduced in Bremenin 1985. He projected the first letter of the Englishterms for Lip, Alveolus, Hard, and Soft Palate in one line. Bilateral complete cleft of Lip, Alveolus, Hard andSoft Palate is recorded as: 'LAHSHAL' and aleft cleft of lip and alveolus is recorded as:'\_ \_ \_AL' in which consequently reading like a roentgenograph. Complete clefts are representedby capital letters and incomplete clefts are representedby small letters.

The LAHSAL codeof the Royal College of Surgeons (1995) uses the same Yconfiguration, but the upper two limbs of the Y represent thelip and alveolus on the right and left sides and the lower limbrepresent the hard and soft palate.

However, this classification does not havethe flexibility of recording the wide variations of cleft lip and palate condition.It does not defines the extent of a cleft in a particular unit. Various degrees of clefting of other structures are not reflected in this classification method; neither subsurface lip clefts northe limits of submucous clefts of hard palate and soft palatecan be recorded using them. It is also does not provide foraddition of detailed descriptors for a full understanding of theclinical condition.The main disadvantage of the LAHSAL system isthe inflexibility to describe a complex cleftmalformation. So, it cannot tell a submucous cleft from amicroform. Generally however, this classification is generally accepted and commonly used (Royal College of Surgeons, 1995, Koul, 2007).

Fig.2.1 LAHSAL diagram



**TREATMENT AND MANAGEMENT**

Cleft affects a number of aspects in patient’s life which includes function and aesthetics. For this reason, a multidisciplinary team approach is highly recommended (Boo & Arshad, 1997, Lam et. al, 2008). Theinteraction and consultation between various disciplinesprovides care for the cleft patients that can be systematicallyand comprehensively plannedenhancesthe treatment outcome and limitations ofvarious treatment approaches.The first team approach treatment was developed in the 1930's in response tothe 1933 Social Security Act in the Western countries([Sandy et al., 1998](#_ENREF_51), [Tulley, 1971](#_ENREF_61)). In Malaysia, treatment of cleft patients is donein main hospitals with only a few disciplines involved. Hence, a number of patients are leftuntreated or partially treated until adulthood.

The main functions of teamwork:

1. Various members of theteam facilitate each other's efforts in the treatment of the condition.

2. It provides a mechanism for recording by variousmeans, all the treatment carried out on the patient.This includes recording the child's growth anddevelopment as well as the results of the variousprocedures performed on the patient.

3. In the combined clinical meetings and combinedconsultation, the set-up provides an opportunity forthe new parents with cleft babies to meet not onlythe the professional team members, but also otherCLAPAM (Cleft Lip And Palate Association Malaysia) members, for advice, counselling andexchange of views and ideas (Ghani SHA et al.,1996).

Perhaps no conditions other than cleft lip and palate and oral cancer assemble teams of dentists and physicians intensely focused on treatment and rehabilitations. The oral and maxillofacial surgeon's (OMFS) role is often pivotal especially in the 20-year term of care for the child born with a cleft lip and palate deformity (CLPD). Issues of basic orofacial functions of mastication, respiration and communication are focused other than patient’s self-esteem and image. The OMFS often provides surgical consultation, educational and emotional support for the family. A clear picture must be painted of the treatment that the patient will undergo over the next two decades.

Treatment protocols for the care of patients with CLPD are constantly under review and revision. Unfortunately, it may take a whole generation to learn that a given technique that produced esthetic results in childhood had a negative effect on facial growth as the patient matured through adolescence and adulthood. There is no question that all intervention further modifies the already impaired potential for normal growth and development in the child with CLPD (Peter Hodgkinson et al.,2005, Lam et al.,2007).

**PRENATAL DIAGNOSIS**

The primary palate and secondary palate areembryologically distinct. The upper lip and the primary palate start to fuse by the 6th week of gestation. The formation of the secondary palate which ends at 17th week occurs with the fusion ofthe palatal shelves. Cleft lip occurs due to failure offusion between the medial and lateral nasal processes andthe maxillary process during the 6th week of developmentClosure of the secondary palate by elevation of the palatalshelves follows that of the primary palate by nearly 2 weeks([Cockell and Lees, 2000](#_ENREF_12)).By ultrasonography, the mandible and maxilla are notclearly visualized until the soft tissues of the fetal face becomedistinct at about 13th to 14th weeks([Arctander et al., 2005](#_ENREF_2)).Three-dimensional (3D) ultrasound imagingand ultrafast magnetic resonance imaging are newertechnologies that are becoming more widely applied in prenataldiagnosis around the world. They present facial images with greater clarity,allowing more precise location ([Johnson and J, 2003](#_ENREF_27), [Platt et al., 2006](#_ENREF_43), [Chmait et al., 2006](#_ENREF_10)). It was reported that prenatal diagnosis of cleft lip and palate was recorded higher with 3D ultrasoundimaging, compared to detection of cleft using conventional 2D ultrasound.([Chmait et al., 2006](#_ENREF_10), [Johnson and J, 2003](#_ENREF_27)).Prenatal diagnosisis important to enables earlycounseling to the prospective parents and support (Chmait et al., 2006).

**AT BIRTH**

Cleft lip and palate parents face the unexpected birth of a baby with a CL/P,and usually experience shock, denial, sadness and great anxiety before being able to bond with their baby. Therefore, healthcare personnels can offer advice to such parents by giving basic information aboutthe immediate newborn period, such as feeding and recognizing illness. Affected children arelikely to have problems with difficulty with both breast andbottle-feeding. These problems can be alleviated bymechanical assistance, such as the use of a feeding plateand squeeze bottle (Haberman feeder) with specially cutnipples ([Skinner et al., 1997](#_ENREF_58), [Clarren et al., 1987](#_ENREF_11)).

*Lip repair*

Surgical closure of a cleft lip is performed as early in infancy as in the contemporary consensus being 10 to 12 weeks of age. The “3 tens rule” is a commonly adopted guideline: aged 10 weeks, weight 10 pounds, and hemoglobin 10 grams. Correcting the lip earlier than this (immediately after birth) offers psychological advantages to the family and was briefly popular in the 1960s (Lam et al.,2007). Correction of lip after 10 to 12 weeks is preferred due to other problems are more likely to be identified (if they exist), and the immune system is better developed to cope with infection (Berkowitz S. Cleft lip and palate: perspectives in management. San Diego: Singular Pub. Group; 1996.)

**8 MONTHS TO 2 YEARS OF AGE**

Ideally palate closure by the age of 12 months is necessary due to acquisition of normal speech is aidedby an intact palate at the time when speech is rapidlydeveloping, early in the second year of life ([Hardin-Jones and Chapman, 2008](#_ENREF_22)). However, the later the secondary palate is closed, the lesser is thetendency towards hypoplastic maxilla, which commonly seen in children with repaired palatal clefts ([Kramer et al., 1996](#_ENREF_30)).

*Hearing assessment and speech evaluation*

Assessment of the type and degree of any hearingloss and its effects on speech perception is essential. This is due to malfunction of muscles at the pharyngeal opening of the Eustachian tube making children with cleft palate are atriskgroup for middle ear infection, especially otitis mediawith effusion, which predisposes to hearing loss. Therefore, all patients undergoing cleft palate repairare referred to the otorhinolaryngologists.Aftercleft palate repair, all patients are referred to the speechtherapists for speech evaluation. Patients who are diagnosed to have speech disorder will undergo speech therapy which includes stimulating speech developmentand the prevention of undesirable compensatory articulations. The therapy should starts around 2 to 3 years of age. If the speech defect are found to be due to velopharyngealincompetence and does not improve with speech therapy,pharyngoplasty may be indicated (Thorn AR. Modern management of cleft lip and palate patient. Dental Update. Dec. 1990; 402-8.,Lam et. Al,2007).

**TODDLER- PRE SCHOOL AGE**

*Regular dental care*

Pedodontist or general dentist should provide topicalfluoride prophylaxis, dietary advice, and restorative care every six monthly. Maintaining good oral health, prevention and control of caries are important for all cleft children (Lam et. al,2007, Ghani SHA,1996).

*Surgeries*

Revision to the lip or nose surgeries can be performed togive the patients the best aesthetic results before they startschool. This is also the time to assess some of thepatients with velopharyngeal incompetence (VPI) with the help of naso-endoscopy todecide on the need of any surgery of the soft palate.Various types of pharyngoplasty can be performedaccording to the findings of the naso-endoscopy (Ghani SHA,1996).

**PRIMARY SCHOOL AGE**

The rehabilitation and maintenance of the dentition at this early stage is important. Almost all cleft lip and palatechildren will have dental anomalies which may includemissing permanent teeth, supernumerary and/orsupplemental teeth, teeth of abnormal morphology,hypoplastic teeth, delayed or abnormal eruption and malocclusion. Therefore, paedodontist takes the responsibility of educating the parents and patients on oral hygiene, diet counselling and early provision of restorative treatment (Ghani SHA,1996, Peter Hodgkinson et al,2005).

The nextessential age for the surgical intervention is at the age of 6 to 12 years. Lateral cephalometric as well as routine radiographic assessment is done with clinical examination to assess bony and soft tissue defects. If indicated, orthodontics treatment will be done to expand the arch of the maxilla. Cleft alveolar is usually closedbetween ages six and nine.A bonegraft is placed in the alveolus to improve the arch formand establish an intact dental arch. This would also alloweruption of the canine which is frequently displaced inthe cleft region. Alveolar fistula is also corrected at thisstage.The presence of a permanent lateral incisor and the state of cuspid development determine the timing for this step. This is followed by active therapy by the orthodontist ([de Ladeira and Alonso, 2012](#_ENREF_15), [Sandy et al., 2001](#_ENREF_52))Lam et al,2007,Ghani SHA, 1996).

|  |  |
| --- | --- |
|  |  |

**FACIAL GROWTH ABNORMALITIES**

The management of cleft patients with anterior-posterior and/or vertical discrepancy need acombined surgical-orthodontic approach usually at the age of skeletal maturity,i.e around 17 to 19 years of age (Ghani SHA,1996). Orthodontictreatment is divided into two phases, pre- and postsurgicalorthodontics.Pre-surgical orthodontics would involve alignment andlevelling of teeth, arch co-ordination and decompensationof the upper and lower dentition. The post-surgicalorthodontics is carried out after orthognathic surgery. This treatment is necessary forfinal tooth positioning to achieve good interdigitation andto close any residual space.

Formal osteotomy for advancement is routinely and safely performed. At the time of this surgery, residual fistulas and additional bone grafting can be performed (Peter Hodgkinson,2007, Hopper R,2007,Ghani SHA,1996,([Sell et al., 2001](#_ENREF_56), [Hodgkinson and Rabey, 1986](#_ENREF_24)).

An outline of the treatment pathway adopted by Lam et. al,2007 is shown in table 2.4.1

Table 2.4.1: Treatment timing for cleft patients

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Age** | **Surgery** | **General dentistry/paedodontics** | **Orthodontics** | **Speech and audiology** |
| **0 months** |  | Evaluation of airway/  feeding problems (feeding  advice; feeding plates) |  |  |
| **3 months** | Lip closure |  |  |  |
| **1 – 2 years** | Palate closure | Dental evaluation;  Preventive care |  | Hearing assessment: degree  of hearing loss/ear disorder  (e.g. middle ear infection [otitis  media]), indirect speech therapy |
| **3-4 years** | Lip/nose revision (before  schooling) |  |  | Speech evaluation  of hypernasality and  nasal airflow (speech  therapy; nasoendoscopy;  pharyngoplasty; fistula closure) |
| **9-11 years** | Alveolar bone grafting |  | Pre-grafting  orthodontics  (transverse  expansion of  palate) |  |
| **14 years** |  |  | Definitive orthodontics treatment |  |
| **18 years** | Orthognathic surgery; lip  and nose revision | Replacement of missing  teeth (most frequently  upper lateral incisors) | Combined  Surgicoorthodontic treatment |  |

This outline of care begins with antenatal diagnosis and continues to adulthood.The patient may be under active treatment by several members of the team at once.Sometime this occurs at the same time and place in multidisciplinary clinics. Atother times specialist treatment, for example speech and language therapy, ENT orpsychological treatment, is provided in a separate environment.The components of the treatment of the cleft patient are described above (table 2.4.1) inapproximately chronological order.

Thereis general consensus that a multidisciplinary team approachis the optimal management strategy for CL/P patients,in order to achieve normal speech, hearing, occlusion,maxillofacial growth, appearance, and psychosocial wellbeing.However, the treatment protocol, including theappropriate timing and method of each intervention,continues to be debate (Hopper R, 2007).

**RESIDUAL DEFORMITY**

Residual cleft deformity is unrepaired cleft deformity in a patient with cleft lip and palate([Cohen et al., 1991](#_ENREF_13)). They are also observed following corrective surgery of cleft lip and palate deformities.

These deformities may range from minor irregularities,such as scarring of the philtral area and slight asymmetryof the vermilion, to more major stigmata such as widealar implantation, shortening and flattening of theupper lip, retrusion of the upper lip, and flattening ofthe nose([Johnson and Sandy, 2003](#_ENREF_28), [Vegter et al., 1997](#_ENREF_64)).

Residual deformities are considered as stigmata therefore many anthropometry research have been conducted, attempting to classify the stigmata and the effects on patients’ psychology and psychosocial well being. Residual deformities that were commonly evaluated includes the width of nasal alar ([Pigott, 1985](#_ENREF_42), [Farkas et al., 1993](#_ENREF_19)), which was expressed using the ratio of alar-alar width.

Facialappearance is important in forming first impressions, andacts as a cue for social stereotyping([Tobiasen et al., 1987](#_ENREF_60)).Children consistently rate photographs of children withclefts more negatively thanphotographs of non-cleft children([Tobiasen et al., 1987](#_ENREF_60), [Schneiderman and Harding, 1984](#_ENREF_54)). However, the relationship between psychosocialadjustment and facial morphology is complex and stillnot well understood, although some evidence suggeststhat a greater physical disfigurement is associated withgreater internalizing behaviour ([Richman and Millard, 1997](#_ENREF_47)).This is the reason why all cleft lip and palate surgeries are done in stages according to certain timeline so that maximal improvement can be achieved under one surgery and to reduce chances of secondary cleft deformity ([Bardach et al., 1992](#_ENREF_6)).

**RESIDUAL DEFORMITY ASSESSMENT**

**ANTHROPOMETRY**

Craniofacial anthropometry allows for assessment of clinical features, treatment planning,monitoring of operative outcomes, and assessment of longitudinalchange ([Farkas et al., 1993](#_ENREF_19)).

In comparison with normal faces, increased CLP lower face height, reducedmouth width, longer nose, wider nose base widths and variableupper lip changes have all been noted in patients treated with cleft lip and palate deformity ([Larson and Nilsson, 1983](#_ENREF_31), [Ross, 1987](#_ENREF_49)).

A variety of methods has been used in assessment of the repaired cleft-associated deformity. These include direct surface assessment to provide anthropometric data (Farkas et al.,1993) or assessment using two-dimensional photographs([Tobiasen et al., 1987](#_ENREF_60), [Asher-McDade and Shaw, 1990](#_ENREF_3)), three-dimensional imaging ([Duffy et al., 2000](#_ENREF_16), [Ras et al., 1995](#_ENREF_46), [Yamada et al., 2002](#_ENREF_67)), or a combination of these methods([Becker and Svensson, 1998](#_ENREF_7)).

Direct clinical assessment has several limitations to the use of direct anthropometry.This includes prerequisite training on live subjects, which is time-consuming nature of performingmultiple direct measurements during an examination. Maintaining patient’scompliance such as requiring subjects to patiently remain still. Furthermore,serial measurements are sometimes needed becausethree-dimensional (3D) abnormalities in craniofacial disordersundergo changes in time ([Mulliken, 2004](#_ENREF_37), [Mulliken et al., 2001](#_ENREF_38)).

Meanwhile, two-dimensional photography, has been used by most investigators because it provides a simple andquick method of depicting the face. Color slides (Tobiasen, 1989), or color prints ([Asher-McDade and Shaw, 1990](#_ENREF_3), [Eliason et al., 1991](#_ENREF_17))have been used for assessment purposes. All these photographic techniques, however, represent the face in two dimensions. This method was reported to lack of standardization of the views necessary forcomparison of assessments, especially in younger subjects (Ras et al., 1995;Duffy et al., 2000).

3D stereo photogrammetry, a new method for craniofacialsurface imaging, overcomes the limitations of direct anthropometry cited above. With this technique, synchronized digital camerasobtain images from multiple angles and reconstruct a digital3D image. The craniofacial image is visualized as a collectionof points in 3D space (termed a ‘‘point cloud’’) resulting fromthe reconstructed craniofacial surface. The surface data are acollection of points interrelated by their position along an x,y, and z coordinate system, and the distances among thesepoints can be readily computed. By using few range of computer software,anthropometric landmarks are identified by the user by markingthem on the surface using a ‘‘soft’’ cursor that deformsitself to the facial contour. Landmarks which appear as color points with reference coordinates can be saved and used for subsequent assessment ([Farkas et al., 2000](#_ENREF_18)).

Evaluation of the facial appearance of patients with repaired cleft deformities has been

carried out by a panel of professionals ([Shaw et al., 1996](#_ENREF_57), [Asher-McDade and Shaw, 1990](#_ENREF_3)), lay people([Tobiasen et al., 1987](#_ENREF_60), [Tobiasen et al., 1991](#_ENREF_59)), or mixed professional and lay people ([Eliason et al., 1991](#_ENREF_17)). Some studies seem to indicate that professionals and laypersons are in agreement ([Roberts et al., 1991](#_ENREF_48)), whereas other studies suggest various degrees of disagreementbetween the expert and nonexpert observers ([Eliason et al., 1991](#_ENREF_17)).

The final objective of all cleft surgery in terms of the outcomerelated to facial appearance is to eliminate the visiblestigmata of the cleft-related deformity as observed by society. With the increasing availability and use of imaging systems, it would be useful to ascertain how assessment ofcleft-related facial deformity made could help to plan for further treatment and identify the stigmata of residual deformity. Should assessments made from three-dimensional imagesprove as reliable as those made clinically, three- dimensionalimages could be a substitute for the clinical assessment([Vegter et al., 1997](#_ENREF_64)).

**SPEECH**

Secondary disorders of cleft lip and palate includesspeech, as well as conductive hearing lossthat would finally, affect speech development([Dames et al., 2009](#_ENREF_14)) . Speech disorders can still present even after reconstructive surgical treatment. The characteristics of speech disorders are usually a combination ofdifferent articulatory features, e.g. altered nasality, a shift in localization ofarticulation (e.g. using a /d/ built with the tip of the tongue instead of a /g/ built with back of the tongue or vice versa), and a modified articulatory tension (e.g. weakening of theplosives /t/, /k/, /p/) (([Harding and Harland, 1995](#_ENREF_23)). Theyaffect not only the intelligibility but also includes socialcompetence and emotional development of a child. In clinicalpractice, articulation disorders are mainly evaluated bysubjective tools ([Schuster et al., 2006](#_ENREF_55)).

Perceptual speech evaluation is the basis of the speech assessment. There has been reported that the final decision regarding whether an individualhas nasality or other speech problems is based on the listener’ssubjective measurement ([Brunnegard et al., 2009](#_ENREF_8)). Therefore, to identify similarities in the speech assessmentof patients with cleft lip and palate in different parts of the world, four procedures were discussedat a symposium at the 9th International Congress onCleft Palate and Related Craniofacial Anomalies in 2001. Thepurpose of the symposium was to set guidelines on an international standardized procedure for perceptualassessment.

The four procedures presented were 1) theGreat Ormond Street Speech Assessment (GOS.SP.ASS) usedin the United Kingdom ([Sell et al., 2001](#_ENREF_56), [John et al., 2006](#_ENREF_26)), 2) the Japanesesystem for assessing cleft palate speech, 3) the perceptualsystem for evaluation of speech in cleft lip and palate used inthe United States (American Cleft Palate–Craniofacial Association,1993), and 4) Cross Linguistic Outcome Comparison(CLOC), a system for perceptual assessment of cleft palatespeech, with special reference to cross-linguistic speech outcomecomparisons.

Speech assessment in cleft palate patients werealso highlighted by Lohmander-Agerskov (1998) who reported on a critical review of published articles on speech and delayedhard palate closure. The report revealed that information was eitherlacking or differed in terms of the inclusion criteria for dependentvariables such as cleft type, age at surgery, and age atspeech assessment ([Lohmander-Agerskov et al., 1998](#_ENREF_33)). Despite these failings, some studies that are now against delaying the timing ofhard palate repair Grunwell et al. (2000) stated that speechproblems ‘‘consequent upon the cleft condition can be predictedand need to be investigated by routine speech assessment procedure’’([Grunwell et al., 2000](#_ENREF_21)) Therefore, it can be concluded that speech needs a routine assessment that needs to be look into despite the type of surgery provided.

**INTRAORAL ASSESSMENT**

**MALOCCLUSION**

The high occurrence of malocclusions in cleft lip and palate patients favours the retention of dental plaque on toothsurfaces, predisposing them to different oral diseasessuch as caries ([Parapanisiou et al., 2009](#_ENREF_41), [Ranta, 1986](#_ENREF_44)).Malocclusions and facial patterns of individuals with cleft lip and palate have been described by variousauthors ([Sakamoto et al., 2002](#_ENREF_50), [Baek and Kim, 2007](#_ENREF_5)). There is limited evidence of malocclusion characteristics of patients with different types of CLP. Dental anomalies (e.g. altered tooth dimensions, tooth development, supernumerary teeth) and deficiencies in horizontal and vertical facial development caused by surgical procedures affect subjects differently with different type of cleft ([Ranta, 1989](#_ENREF_45)). In addition, dental dimensions in cleft lip and palate patientshave been reported to be smaller than in patientswithout clefts in both the affected maxillary and themandibular dental arches ([Akcam et al., 2010](#_ENREF_1)).

However, some methodological issues, including differences related tomalocclusion criteria, age range of participants, and if the patient was underwent surgery for the oral cleft, limit comparisons between these studies.

The Goslon (Great Ormond Street, London and Oslo)Yardstick was first described by Mars et al. (1987). ThisYardstick is used to rate the dental arch relationships in the latemixed and early permanent dentition of patients withunilateral cleft lip and palate (UCLP) into five categories:excellent, good, fair, poor, and very poor. It was proven to be capable of assessing dental arch relationships and facial morphology outcomesbetween different centers ([Mars et al., 2006](#_ENREF_35), [Morris et al., 2000](#_ENREF_36), [Johnson et al., 2000](#_ENREF_29)). TheYardstick has been verified as an easy and practicalevaluation to discriminate between the quality of dentalarch relationships during all stages of dental development([Noverraz et al., 1993](#_ENREF_39)). Moreover, it can be used to predict surgical outcome as early as 5 yearsof age ([Atack et al., 1997](#_ENREF_4)).

The most important features ofthe classification are anteroposterior arch relationships,followed by vertical relationships (deep bite, open bite) andtransverse relationships (extent of crossbite). First study was done in Malaysia using Goslon yardstick to evaluate results of cleft surgery and dentoalveolarrelationships in UCLP Malay children([Zreaqat et al., 2009](#_ENREF_68)). The Goslon Yardstick has been widely accepted and used in many studies ([Lilja et al., 2006](#_ENREF_32), [Williams and Sandy, 2003](#_ENREF_66), [Chan et al., 2003](#_ENREF_9)). Although it has some questionable criteria, the Eurocleft study and the Clinical StandardsAdvisory Group project in the United Kingdom hasestablished it as a sensitive and reliable method of assessingdental arch relationships to compare different approachesin the early management of children with UCLP. Nevertheless,an element of subjectivity based on experience isinherent in the scoring system: Even Lilja et al. (2006)admitted that ‘‘in some cases precise allocation to a Gosloncategory may be ambiguous.’’ Calibration courses andreference models are prerequisites to using the GoslonYardstick, adding to the complexity of the exercise([Lilja et al., 2006](#_ENREF_32)). However, this Yardstick is very useful to assess malocclusion in cleft patients as well as a tool to predict the need for orthognathic surgery.

**Detection of caries**

Other oralhealth conditions associated with children with oral cleftsare early childhood caries and poor feeding habits (Mutarai et al. 2008, Zreaqat et al. 2008).Thus, it is expected that subjects with different types of cleft will present differences in dental health status. Teeth adjacent to the cleft may be misshapen, of poor quality, or missing altogether (Jordan et al., 1966), and so the loss of teeth due to dental caries may severely compromise an already deficient dentition. Poor dental health may compromise the results that can be achieved for cleft patients; orthodontic treatment is contraindicated in the presence of uncontrolled dental caries, inadequate oral hygiene, or both.

Therefore, DMFT (decayed, missing and filled teeth) score is widely used to assess the amount of dental caries in an individual and is a measure of oral health. A DMFT score reflects the total number of teeth that are decayed, missing orfilled.

CRANE annual report in 2012 reported that the proportionof children, particularly in the 5-year-old age group, withuntreated dental caries was worrying. Children born with cleftlip and palate have been identified as a priority group and areentitled to receive dental care from the hospital servicein the United Kingdom. It was also reported that 44% of all 5-year-olds ina recent U.K. survey were found to be in need of dental treatment (Pitts and Evans, 1997). Shaw et al recommendedthat the cleft team should be responsiblefor ensuring that patients are receiving effective dental care (Shaw et al., 1996).

11% of cleft patients in CRANE annual report in 2012 had at least one admission for dental care before the age of seven years. Syndromic children were more likely to have at least one dental care admission than non-syndromic children (18% vs. 10%), and they were also more like to have multiple admissions for dental care. Admission for dental care increased with increasing severity of cleft type, with cleft lip patients being the least likely and bilateral cleft lip and palate patients being the most likely to have at least one dental care admission in hospital.

**PERCEIVED NEED OF TREATMENT IN CLEFT PATIENTS AND PARENTS VS TREATMENT NEED**

Patient’s perceived need of treatment is important to be taken into accountwhen assessing the outcome of cleft lip and palate care received from healthservices. Donabedian (1996) stated that patient satisfactionshould be the ‘‘ultimate validater of the quality of care’’ although this aspect of cleft care has received little attention inoutcome studies to date (Turner et al., 1997, Williams et al., 2001).

Cleft lip and/or palatepatients were perceived to have lower self-esteem, difficultyin the learning process, and a tendency to be more depressed(Strieker et al.. 1979; Ramstad et al.,1995; Broder et al., 1998). They also haveproblems in their relationships with family and friends including rated as less social and difficult to make newfriends because of their deformity (Richman and Harper, 1980; Heller et al., 1981). Psychosocial problems were more frequently found among males as compared with females (Noor and Musa, 2007).

Perceived need of function by the patients frequently arise other than aesthetics. They also experience difficulties withfeeding, speech and hearing (Noor and Musa, 2007).The Cleft Evaluation Profile (CEP) originated from the Royal College of SurgeonsCleft Lip and Palate Audit Group (Turner et al.. 1997). It wasused to assess perceived satisfaction related to cleft care which consist of an eight-item list: speech, hearing, lip, nose, teeth, bite, breathing, and profile.For each item in the CEP, subjects were asked to rate theirsatisfaction on a 7-point Likert scale ranging from very satisfactory(a rank of 1) to very unsatisfactory (a rank of 7). All items in the CEP are related to facial features that playa major role in assessing facial appearance among cleft lip andpalate patients and can be used to determine the perceived need of the patients and their parents with the cleft treatment. The CEP can be employed to determineany significant differences in the parent and child ratingsof the features that were related to facial appearance,namely teeth, lips, nose, and facial profile. These are the featurespatients and parents felt needed attention and were examinedfor differences of responses between patients and theirparents (Noor and Musa 2007).

In U.K., the majority of patients and theirparents appear to be satisfied or very satisfied with the cleft condition after cleft care been given (Noar, 1991; Broderet al., 1992; Turner et al., 1997).

Most studies showed high results of satisfied parents to the patients’ cleft condition. It is probably due to parents confidence in the care delivered and entrusted the care of a childto professionals. They also lack comparative knowledge and therefore acceptthe level of care as being optimal (Noor and Musa,2007, Turner et al., 1997).McCarthy et al. (2001) stated that researchers cannotassume that parents will be accurate in their assessment of theirown child's concerns.

Patients, however, were found generallyless satisfied than their parents with speech and facial appearance. Study done Noor and Musa (2007) showed thirteen percent of 12-year-olds subjects in the sample were dissatisfiedwith the appearance of their teeth, nose, lip and speech.Parents were generally satisfied with both the outcome oftreatment and the care and attention received.

The same study also showed the contribution of the family in deciding the best treatmentfor their child influenced the child's satisfaction of the treatmentoutcome. Approximately 42% of the parents and 32% ofthe patients were "very involved" in making treatment decisions.The child's cooperationis required if treatment is to be successful and unfortunately enthusiastic parent does not always have an enthusiastic andmotivated child (Cunningham. 1999, Noor and Musa,2007).

Therefore, perceived need of treatment among patients and the parents is an important role in determining the success of healthcare delivery in cleft lip and palate patients ([Van Lierde et al., 2012](#_ENREF_62)).

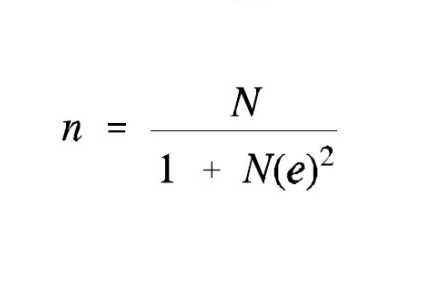
**CHAPTER 3: MATERIALS AND METHOD**

***SAMPLE SELECTION***

The study sample consisted of subjects ( male & female with the mean age of 15.7 recruited from patients attending the Combined Cleft Clinic in Oral & Maxillofacial surgery department, Faculty of Dentistry, University Malaya as well as participants of public forum organised by Cleft Lip And Palate Association Malaysia (CLAPAM) in Hospital Taiping, Perak and PCB Resort, Kota Bharu, Kelantan. Samples were collected from March 2012 until March 2013.

Inclusion criteria were willingness of subjects and the parents to participate in the study, aged 12 years old and above, with cleft lip and palate deformity. Exclusion criteria were syndromic patients and subjects without parents at the time of the interview. Approval of the study was obtained from the Ethics Committee, Faculty of Dentistry, University Malaya (ethics no: ) and informed consent was obtained before data collection.

Sample size estimation was calculated prior data collection to make sure number of subjects was sufficient.



n= sample size N= population size

e= level of precision (0.05), confidence interval of 95%

***METHODS***

**INTERVIEWER GUIDED QUESTIONNAIRE**

A case sheet was prepared which included the general data and all the parameters needed for this book. The parameters were the treatment history which included the surgical and non surgical treatment, such as the specialty and centre, knowledge on timing of surgeries, and reasons for delayed treatment. Interviewer guided questionnaire was constructed to make sure that all of the questions are well understood understandable and answered.

Parents were asked to rate their satisfaction with various aspects of clinical outcome including speech; profile ; and appearance of the teeth, lip, and nose of their child using a Likert scale (1 to 7). These ratings were then categorized into three groups—‘‘very satisfied’’, ‘‘satisfied,’’ and‘‘dissatisfied” administered from Parents and child interview schedule (Turner et al.,1997,Noar JH,1991, Noor and Musa, 2007). To avoid bias, parents and children wereinterviewed separately.

The questionnaires were constructed to look at parents’ perceived need, the effects of cleft deformity on the child’s social well being and achievements as well as treatment milestones that has been received.

Datas from the clinical examination, speech assessment and questionnaire was analyzed using SPSS version 12.0. Chi square analysis was done to evaluate the relationship between factors and treatment need. Kappa interater reliability test was performed to see agreement between parents’ and professional input.

**3D photogrammetry**

Each subjects was then photographed using 3D camera (Vectra) with the frankfort plane raised anteriorly 10 degrees to the horizontal with the mandible in the rest position and the lips were at rest position.Each image is composed of high-resolution 3D surface geometry (x, y, z co- ordinates), color, and texture.



Fig. 3.1: position of the subject with respect to the 3D camera



Fig.3.2: 3D Vectra view system

One consultant from Oral & maxillofacial Surgery Department from Faculty of Dentistry, University of Malaya was involved in analyzing the 3D images. The residual deformities were assessed in the following order:

1. Overall appearance of the face
2. Upper lip including the continuity of the vermillion border and the size, smoothness and the visibility of the cleft scar
3. Nasal form and symmetry of the nostrils
4. Relation of the nose and the upper lip

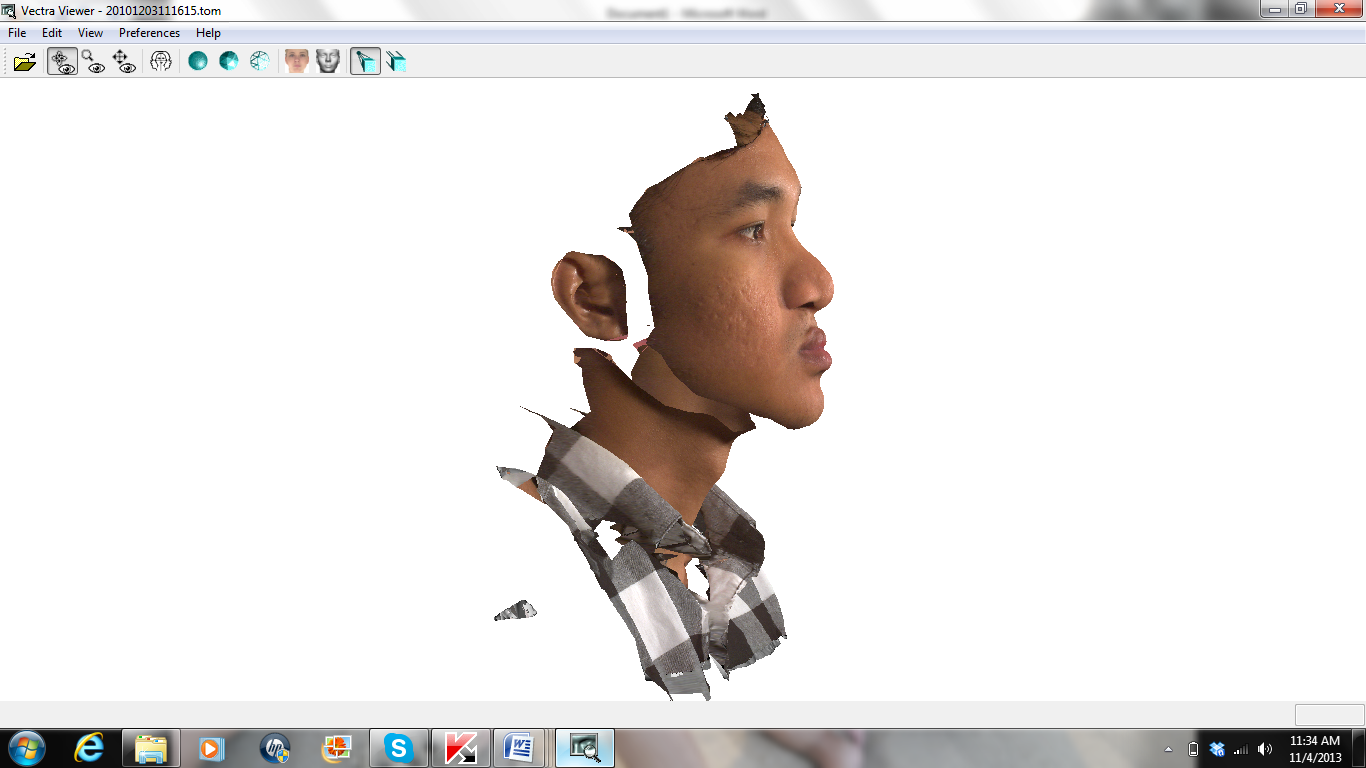
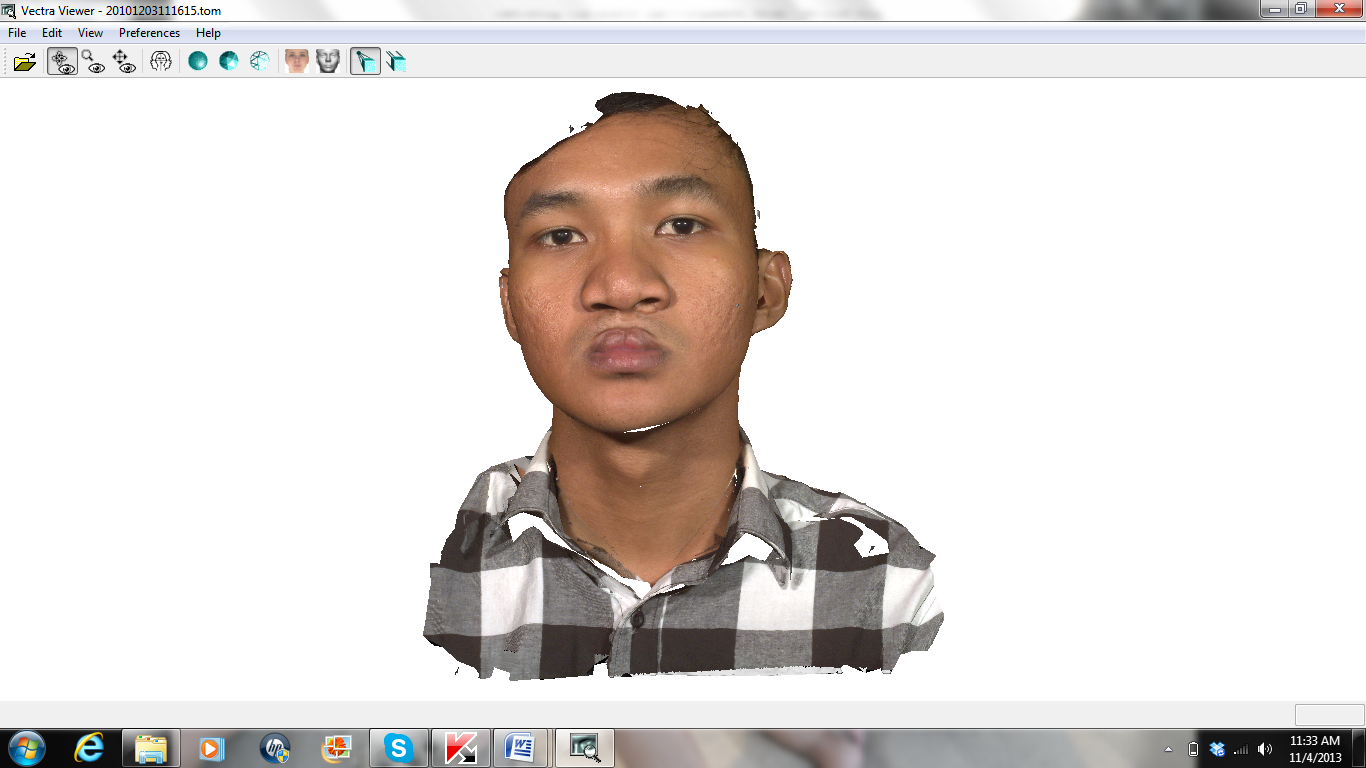


Fig. 3.3: frontal and lateral view

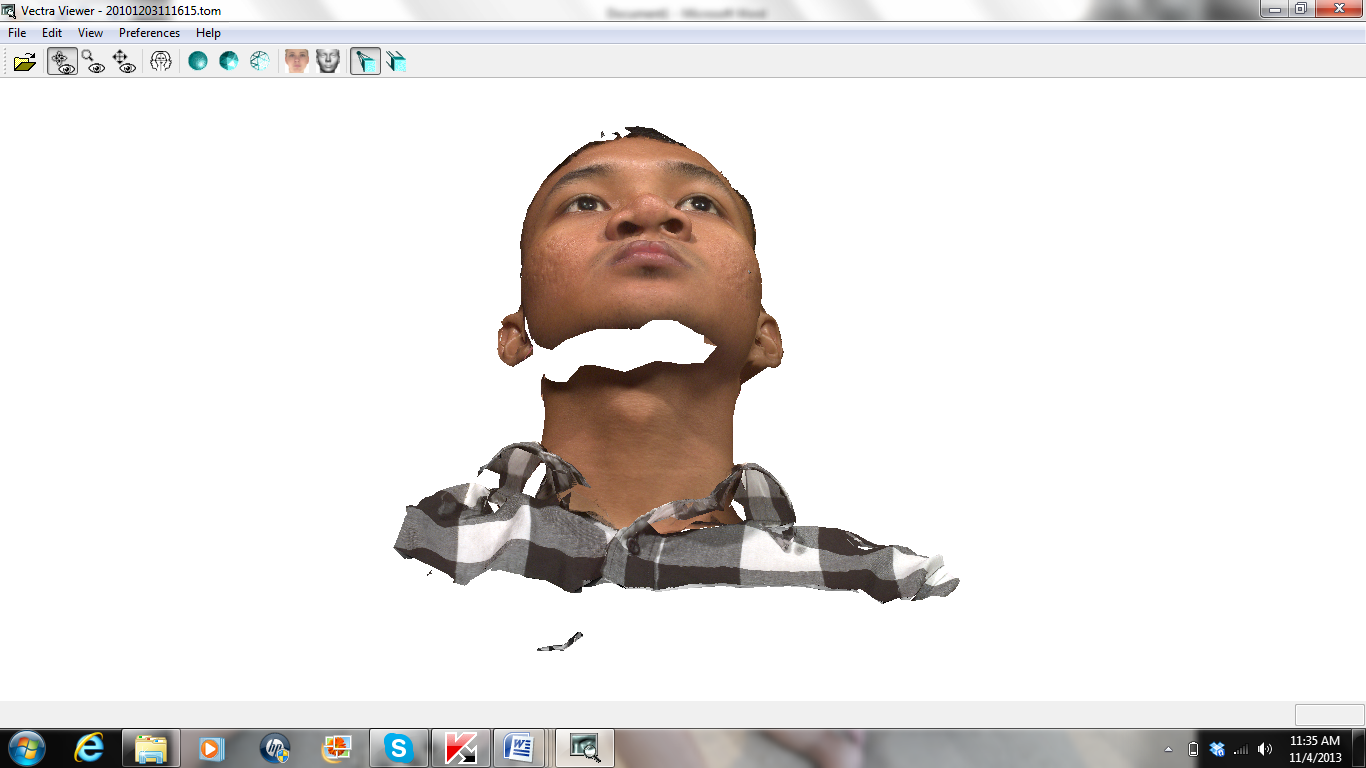
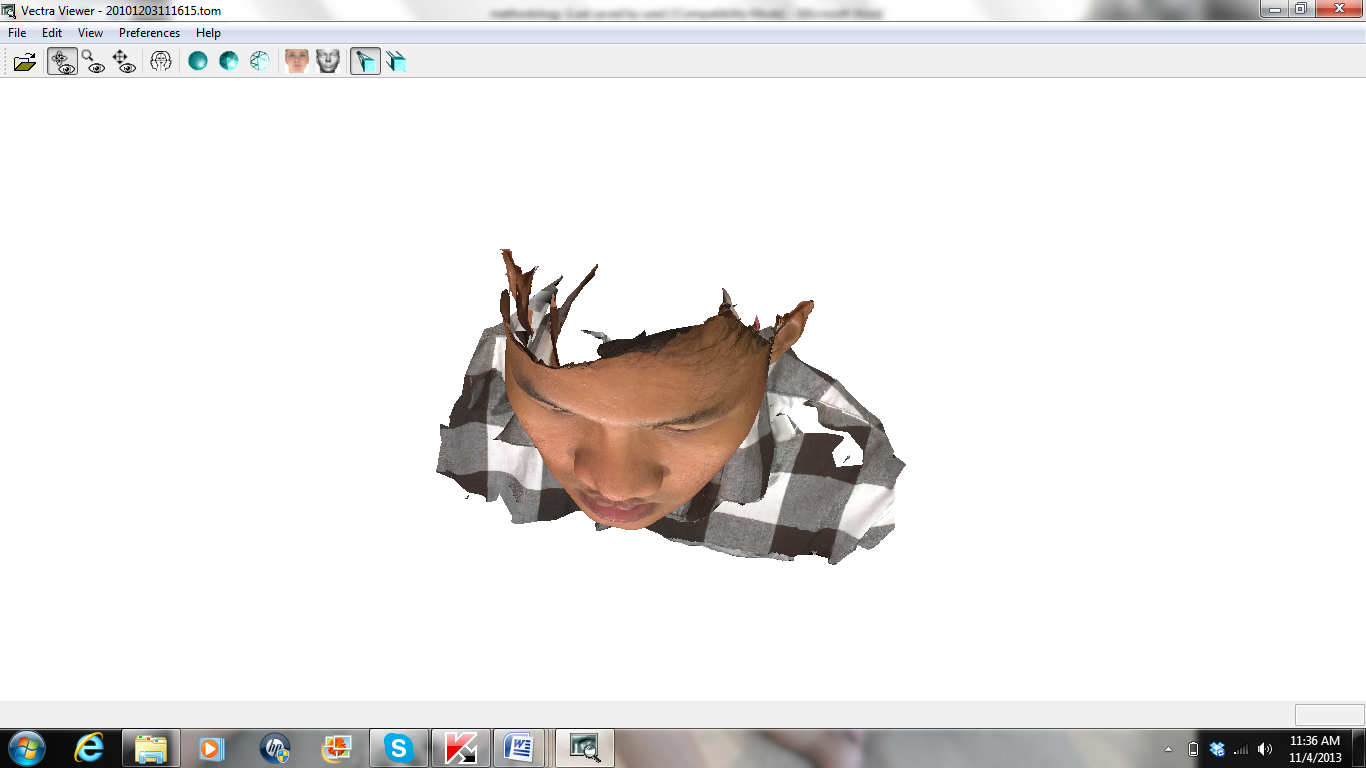


Fig. 3.4: superior and inferior view

All aspects of the face were taken into consideration from anterior, superior, inferior and lateral views of the face.

The stigmata of the residual cleft deformity were assessed by a modification of the method described by Asher McDade et. al (1991). Five points ordinal scale was used as described below:

1. Very good appearance
2. Good appearance
3. Fair appearance
4. Poor appearance
5. Very poor appearance

These scales were then translated into treatment need based on the score given.

**Intraoral Assessment**

Intraoral assessment comprises of 3 main areas:

**Malocclusion (GOSLON yardstick evaluation)**

Intraorally, clinical assessment will be done by looking at these categories, according to GOSLON yardstick groups:

1.Anteroposterior arch relationship:

Class I, Class II, Class III

2.Vertical labial segment relationship

Overbite, open bite

3.Transverse relationship

Canines crossbites

(Mars et al, 2006)

Patients then were grouped into 5 groups according to their clinical assessment and categorized according to the treatment need.

Group 1: Positive overjet with average inclined or retroclined incisors with no crossbite or open bite.

Treatment need group: no need treatment

Group 2: Positive overjet with average inclined or proclined incisors with unilateral crossbite or crossbite tendency with or without open-bite tendency around cleft site.

Treatment need group: may need treatment

Group 3: Edge-to-edge bite with average inclined or proclined incisors or reverse overjet with retroclined incisors.Unilateral crossbite with or without open-bite tendency around cleft site.

Treatment need group: good to treat

Group 4: Reverse overjet with average inclined or proclined incisors. Unilateral crossbite with or without bilateral crossbite tendency with or without open-bite tendency around cleft site.

Treatment need group: need treatment

Group 5: Reverse overjet with proclined incisors and bilateral crossbites

Treat need group: Very need of treatment

**Presence of palatal fistula and sublabial fistula**

Presence of palatal and sublabial fistula was assessed using Gutta Percha and mouth mirror to see the need for fistula closure, intraorally and recorded.

**Presence of caries**

Subjects were screened for dental health status using DMFT system (D=decay,M=missing, F=Filled T=Teeth). Examination was done on the chair and proper lighting using disposable mouth mirrors and probes. All findings were charted and total of DMFT scores was documented.

**Speech assessment**

The development of normal speech is among the most important goals of treatment in Cleft Lip and Palate patients. It is well recognized that patients with cleft lip and palate are usually have speech disorder. Therefore, examination of cleft patients must include speech assessment.

In this study, calibration of gross speech intelligibility assessment was done by speech pathologist at Jabatan pertuturan dan Pendengaran, Universiti Kebangsaan Malaysia prior interview with the patients on the field.



Fig. 3. 5 Fig. 3.6

Conversation with the subjects was analyzed to judge grossly how intelligible each subject's speech was. Subjects were asked simple questions including name, school and favourite colour and finally, were asked to count from 1 to 10.

A five point ordinal scale was used taken from Sell et al.,2001:

0- Normal

1- Different from other children but not enough to cause comment

2- Different enough to cause comment but possible to understand most speech

3- Only just intelligible to strangers

4- Impossible to understand

From the score, subjects were categorized according to their treatment need as perceived by the assessor.

**Fig. 5: FLOW CHART METHODOLOGY**

SAMPLE SIZE ESTIMATION

SUBJECTS SELECTION

QUESTIONNAIRE MAKING AND PRETEST QUESTIONNAIRE

QUESTIONNAIRE VALIDATION

3D PHOTOGRAPH

QUESTIONNAIRE ANSWERED

INTRAORAL EXAMINATION:

SPEECH ASSESSMENT

* GOSLON YARDSTICK
* DMFT

DATA ANALYSIS

**CHAPTER : RESULTS**

**Demographic**

The total sample of subjects was 47. The sample was taken from Combined Cleft Clinic, in Oral & Maxillofacial Surgery Department,as well as attendees from public forum in Taiping, Perak and Pengkalan Chepa, Kelantan. The sample was collected from March 2012 to March 2013.

Table 4.1.1: Distribution of subjects by Age, Gender, and Type of cleft

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Gender Age Group  (years old) | | | Type of cleft | | | | Total |
| Unilateral | Bilateral | Lip only | Palate only |
| Male |  | 12 to 17 | 14 | 6 | 1 |  | 21 |
|  |  | 18 to 30 | 0 | 4 | 0 |  | 4 |
|  | Total | | 14 | 10 | 1 |  | 25 |
| Female |  | 12 to 17 | 11 | 2 | 1 | 2 | 16 |
|  |  | 18 to 30 | 5 | 1 | 0 | 0 | 6 |
|  | Total | | 16 | 3 | 1 | 2 | 22 |

There are about 44.6% of the subjects were male, aged 12-17 years old. 46.8% of the subjects were female, with 72.7% of them were in the age group from 12 to 17 years old. More than two third of the subjects have unilateral cleft lip and palate (63.8%), 28% of them have bilateral cleft lip and palate and 8.5% of the subjects have only cleft lip or only cleft palate. 78.7% of the subjects were in age group of 12-17 years of age.

Table 4.1.3: Relationship Between Awareness Of The Treatment Timing And Parents’ Level Of Education.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Level of education | | Awareness | | Total |
| Yes | No |
|  | Primary | 1 | 2 | 3 |
|  | Secondary | 27 | 2 | 29 |
|  | Tertiary | 15 | 0 | 15 |
| Total | | 43 | 4 | 47 |

There are no difference found between level of education and the awareness of the treatment found. 93.8% of the respondents were aware of the treatment timing despite their differences in the level of education.

Figure 4.1.1: Timeliness of the lip repair and specialty involved

The figure above showed that 61.7% of the lip repair was done by Plastic surgeons, followed by 27.7% done by Oral & Maxillofacial surgeons. 2.1% of the lip repair was done by ENT surgeon. Only 8.5% of the subjects have never had lip repaired before.

Figure 4.1.2: Timeliness of palate repair and specialty involved

Most of the primary palate repair was done by plastic surgeons (46.8%). This is followed by Oral & Maxillofacial surgeons (36.7%). Only 29.4% of the subjects that were treated by Plastic surgeons and 23% of the subjects that were treated by Oral & Maxillofacial surgeons were done beyond recommended time.

Figure 4.1.3: Timeliness alveolar bone graft surgery (ABG) and specialty involved

One third of the subjects have never had ABG surgery done. Most ABG surgery was done by the Oral & Maxillofacial Surgeons (58.1%), followed by Plastic Surgeons (9.3%).Whereas, only 29.4% of the patients treated by Oral & Maxillofacial surgeons were found to be delayed in treatment or didn’t receive ABG treatment.

Figure 4.1.4: Relationship between specialty that repair palate and age where ABG surgery was done

We found that 70.6% of the subjects who received palate repair under Oral & Maxillofacial Surgeon had ABG surgery done within time. However, only 22.7% of the subjects who had palate repair done under Plastic Surgeons had ABG surgery done within the age limit. 50% of the subjects in this group were found did not have ABG surgery done yet.

Table 4.1.4: Type of primary surgery and reasons for delay of treatment

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Type of surgery | Reasons for delay | | | | | Total |
| Financial | Not aware of timing | Don’t know where to get treatment | Not given appointment | Difficult to get appointment |
| Primary lip repair | 3 | 1 | 1 | 0 | 0 | 5  P=0.000 |
| Primary palate closure | 5 | 2 | 3 | 3 | 3 | 16  P=0.033 |
| Alveolar Bone Graft | 2 | 5 | 10 | 4 | 3 | 24  P=0.006 |
| TOTAL | 10 | 8 | 14 | 7 | 6 | 45 |

The highest reason for delay in lip and palatal closure surgery is financial constraint (38%). Whereas the most given reason for ABG delay was the parents don’t know where to get the treatment from (41.7%), followed by they were not aware of the surgery timing (20.8%) and they were also not given appointment for ABG (16.7%).

**4.2: Residual Deformities**

Table 4.2.1: Relationship between residual deformities and type of cleft

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Residual deformity | Type of cleft | | | | Total |
| Unilateral cleft | Bilateral cleft | Lip only | Palate only |
| Upper lip | 28 | 12 | 2 | 1 | 43 |
| Nose | 29 | 12 | 2 | 0 | 43 |
| Midface | 26 | 13 | 1 | 2 | 42 |
| Malocclusion | 29 | 12 | 1 | 2 | 44 |
| Palatal fistula | 8 | 9 | 0 | 1 | 18 |
| Sublabial fistula | 11 | 5 | 0 | 0 | 16 |
| Speech | 27 | 13 | 0 | 2 | 42 |
| Total | 173 | 83 | 7 | 10 |  |

Subjects with bilateral cleft lip and palate were found to have highest number in residual deformity (91.2%), followed by subjectsunilateral cleft lip and palate (82.4%), subjects with cleft palate and lastly, subjects with only cleft lip.

93.6% of the overall subjects showed highest residual deformity in terms of malocclusion. This is followed by deformity on the lip and nose (89.3%). Sublabial fistula is the lowest residual deformity recorded with only 34% of the overall subjects.

**Treatment need**

Table 4.3.1: Relationship between treatment need and type of cleft

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Treatment need | Type of cleft (N) | | | | Total |
| Unilateral cleft | Bilateral cleft | Lip only | Palate only |
| Lip revision | 22 | 9 | 1 | 0 | 32 |
| Rhinoplasty | 21 | 8 | 2 | 0 | 31 |
| ABG | 11 | 5 | 0 | 0 | 16 |
| Orthodontic | 23 | 10 | 1 | 2 | 36 |
| Orthognathic | 20 | 10 | 1 | 1 | 32 |
| Fistula closure | 22 | 4 | 2 | 1 | 29 |
| Speech rehab | 17 | 12 | 0 | 0 | 29 |
| Dental treatment | 15 | 7 | 1 | 2 | 25 |
| Total | 151 | 65 | 8 | 6 |  |

In general, 76.6% of the study population requires further treatment.Unilateral cleft lip and palate subjects (62.9%) and bilateral cleft lip and palate subjects (62.5%) were the highest group for treatment need, followed by subjects with cleft lip only and lastly, subjects with cleft palate only.

A large number of subjects (91.5%) were found to be in need for treatment on the face, including lip revision, rhinoplasty and orthognathic surgery. Unilateral cleft lip and palate subjects were found to be the highest group in need of further treatment, followed by Bilateral cleft lip and palate group, subjects with cleft lip only and lastly, subjects with cleft palate only.

Besides that, a total of 34% of the subjects were in need for ABG. 36.7% of the Unilateral cleft lip and palate subjects and 38.5% of the bilateral cleft lip and palate subjectswere found among the highest group for treatment need for ABG.

Subjects were also found to be in need for orthodontic treatment (76.6%). Most of the subjects were from unilateral cleft lip and palate group (61.7%).

Furthermore, 68.1% of the subjects were found to be in need for orthognathic treatment. Highest number was from patients with bilateral cleft lip and palate subjects (76.9%), followed by unilateral cleft lip and palate (73.3%).

About 38.3% of the subjects were found to be in need for palatal fistula closure surgery. The highest percentage is coming from the subjects from bilateral cleft lip and palate (69.2%).

40.4% of the subjects were found to be in the range of need to must be referred for further speech assessment and therapy. 44.7% of the subjects fell into the range of “may need” to “good to be treated” for speech problem. All subjects of bilateral cleft lip and palate were found to have somewhat speech deficiency and require further assessment and therapy. Only 23.3% of the unilateral cleft lip and palate subjects were found to be no need for speech therapy.

There was considerably high need for dental treatment found among the patients in this study (53.2%). Highest type of cleft that needs dental treatment is unilateral cleft lip and palate patients (31.9%).

**4.4: Perceived Need**

Figure 4.4.1: Parents’ Perceived Need For Further Treatment

The figure above showed that 100% of the parents felt that their child still needs further treatment.

Table 4.4.1: Parents’ Perceived Need For Specific Treatment

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Perceived need | Type of cleft (%) | | | |
| Unilateral cleft | Bilateral cleft | Lip only | Palate only |
| Lip revision | 26.7 | 36.4 | 0 | 4.4 |
| Rhinoplasty | 48.9 | 17.8 | 2.2 | 4.4 |
| ABG | 34.8 | 19.6 | 2.2 | 4.3 |
| Orthodontic | 51.1 | 27.7 | 4.3 | 4.3 |
| Orthognathic | 0 | 0 | 0 | 0 |
| Fistula closure | 0 | 0 | 0 | 0 |
| Speech rehab | 24.4 | 9.8 | 0 | 0 |
| Dental treatment | 51.1 | 27.7 | 4.3 | 4.3 |

Almost 50% of the subjects from all types of cleft perceived that there is a need for further treatment involving the lip. Subjects in bilateral cleft lip and palate showed highest need in further treatment of lip compared to other cleft type.

Unilateral cleft lip and palate showed highest group in perceived treatment need in further treatment of the maxillary alveolus, teeth, nose and others as compared to other types of cleft.

Highest perceived need for treatment was shown in descending order is perceived need for further treatment of teeth, followed by nose and alveolus in all types of cleft.

However, no parent indicates the need for fistula closure and orthognathic treatment.

**Treatment Need Versus Perceived Need**

Table 4.5.1: Relationship between parents’s perceived need and the treatment need

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Treatment need | | Perceived need (N) | | Total | Kappa |
| Important | Not important |
| Lip revision | Yes | 21 | 20 | 41 | 0.083 |
| No | 1 | 3 | 4 |
| Rhinoplasty | Yes | 31 | 11 | 42 | 0.030 |
| No | 2 | 1 | 3 |
| ABG | Yes | 13 | 0 | 13 | 0.313 |
| No | 2 | 16 | 18 |
| Orthodontic | Yes | 37 | 6 | 43 | 0.114 |
| No | 4 | 0 | 4 |
| Orthognathic | Yes | 0 | 32 | 32 | 0.052 |
| No | 0 | 15 | 15 |
| Fistula closure | Yes | 0 | 18 | 18 | 0.064 |
| No | 0 | 29 | 29 |
| Speech rehab | Yes | 9 | 18 | 27 | 0.07 |
| No | 5 | 8 | 13 |
| Dental treatment | Yes | 23 | 4 | 27 | 0.106 |
| No | 18 | 4 | 22 |

(Kappa reference: Landis & Koch., 1977)

There seemed to be poor agreement between parents’ perceived need of treatment for lip revision compared to professional’s assessment. 42.6% of the parents felt that lip revision is not important, although, assessment from the 3D photograph indicates differently. Only 44.7% of the parents’ perceived need seemed to concur with the professional’s indication. However, there are 2 parents who didn’t answer this part of questionnaire.

More than two third (68.1%) of the parents concurred with the professional’s assessment for rhinoplasty. However, kappa intereliability test showed poor agreement between parents’ perceived need for treatment and the professional’s assessment. 27.7% of the parents didn’t concur with the profesional’s opinion on the need for rhinoplasty.

Furthermore, it was found that there is a fair agreement between the parent’s perceived need and the assessment of treatment need in alveolar bone grafting (ABG)(Kappa= 0.313, p<0.013). A total of 34% of the parents and professional assessment agreed that there is no need for ABG. On the other hand, 27.6% of the parents felt that there is a need for ABG and it is also agreed with professional assessment. 25.5% of the parents were not sure whether their child needs ABG, and professional examination showed that the subjects were in need of the treatment.

We found that there was a poor agreement between parents perceived need and the treatment need for orthodontic treatment . 12.8% of the parents didn’t agree with the professional opinion on the need for further treatment. 59.6% of the subjects were found to be in need of further treatment and the parents concurred. An interater reliability for the raters was found to be Kappa=-0.114 (p< 0.424).

Furthermore, none of the parents perceived orthognathic surgery as important, although 68% of the subjects were found to be in need for the treatment. Kappa interraters reliabilty test showed poor agreement between parents and professional opinion.

Finally, 61.7% of the parents agreed with the professional assessment that there was no need for fistula closure surgery. However, 38.3% of the subjects were found to be in need for fistula closure, although, the parents didn’t perceived there is a need for the treatment.

It was found that there is poor agreement between parents’ perceived need and the professional’s assessment on treatment need in terms of speech. There are about 17% of the subjects were found to be not in need for speech therapy which is agreed by the parents. However, 38.3% of the subjects were found to be in need for treatment, although the parents felt that it is not important. Only 19.1% of the parents concurred with the professional finding that their child needs speech therapy. There were 7 parents did not respond to this question.

It was also found that 48.9% of the subjects to be in need for further treatment for dental treatment, and the parents also felt that it is important. Only 4.2% of the subjects were found to be in need of treatment; however the parents didn’t feel the same. 38.3% of the parents felt that it is important for their child to have further treatment for teeth, although professional assessment seemed to disagree. Interrater reliability test was found to be Kappa=0.106 (p<0.297) which shown slight agreement between the parent’s perceived need and the professional assessment for treatment need.

**CHAPTER 5: DISCUSSION**

**Demographic**

Initially, it was planned to select subjects from few states in Malaysia to represent the incidence of residual cleft deformity. However, due to time constraint, samples were only taken from 3 places including Combined Cleft Clinic (CCC) in Faculty of Dentistry, University Malaya, Selangor, as well as participants from public forum that was organised by CLAPAM in Hospital Taiping, Perak and Pengkalan Chepa, Kelantan.

The majority of the parents (61.7%) were found to earn less than RM 3000 per month and only received secondary level of education. Despite low educational level and socioeconomic status, most of the parents were found to have good sound knowledge of the treatment timing of the cleft. However, though the parents seemed to have knowledge on timing of the treatment, there were still delayed of treatment found in this study, especially high in alveolar bone graft surgery. The most popular reason given by the parents for delay in lip and palatal closure was financial issue. This could be acceptable as almost one third of the parents were in low income status (<RM 3000 per month). Meanwhile for alveolar bone graft surgery, most of the parents answered they don’t know where to seek the treatment.

Delay in treatment for cleft surgery is almost always associated with low income and low educated parents. Financial problem is a barrier not only because they have to pay for the treatment, but also the expenses of travelling and staying in at the centre at which the services can be provided. In other studies, parents were also found to have lack of knowledge on the services availability (Schwatz and Khadka et al., 2004). Therefore, it is suggested that more information about the cleft services should be provided using mass media to spread the knowledge on the cleft treatments and accessibility. NGOs such as CLAPAM are strongly recommended to support the families of cleft child in terms of financial and educational support.

**Residual deformities and the treatment need**

Residual deformities on the facial region that could be seen include flaring of alar cartilages, rotation of columella, septal deviation, lip asymmetry, whistle deformity, and loss of vermillion tubercle(Lam et al., 2007). In this book, we found that there were discrepancies between residual deformity and the treatment need. Residual deformity seemed higher than the actual treatment need. The discrepancies can be seen especially in deformity on the lips, nose and midface. This could be due to the deformity is too mild that doesn’t need any further treatment. It could also be there are no further treatments that can be proposed to repair the deformity.

There are many methods proposed for evaluation of the facial residual deformity. The first detailed anthropometric analysis of cleft lip- nose was published by Farkas and Lindsay. This method was found useful as it is reproducible, and reliably consistent (Wong et al., 2007). This is the reason why we chose 3D photogrammetry as the method for facial assessment. In this study, it was found that majority (91.5%) of the subjects were in need for lip revision and rhinoplasty, as well as orthognathic surgery. This findings concurred with other studies that reported most of the cleft lip and palate patients were found to have residual deformity on the face that needs to be treated (Duffy et al., 2000, Farkas et al., 2000, Schwenzer-Zimmerer et al.,2008). The method ology was modified from a study by Asher McDade et al., 1991. Although it is a subjective measurement using a 5 ranks likert scale, it was reported that this technique is quite reliable compared to 2D photograph as well as, high interrater agreement between professional assessor and layperson assessor (Al Omari et al., 2003).

It was also found that, residual deformity involving the upper lip, nose and the midface are slightly lower between the unilateral cleft lip and palate group of subjects (92.2%) compared to bilateral cleft lip and palate subjects (94.8%). These findings concurred with a research that also found residual deformities were higher in bilateral cleft lip and palate group as compared to unilateral cleft lip and palate especially at the nose area. They found that the subjects from bilateral cleft lip and palate group residual nose deformity was noted as wider and more prominent (Duffy et al., 2000).

Other than facial deformity, many authors have described on malocclusions and facial patterns of individuals with cleft lip and palate ([Sakamoto et al., 2002](#_ENREF_50), [Baek and Kim, 2007](#_ENREF_5)). However, there was limited evidence of malocclusion characteristics of patients with different types of CLP. Although in this study contains 4 types of cleft, however, the result was found to be insignificant, most likely due to small sample.

We found that 91.5% of the subjects were in need of treatment for malocclusion. 96.7% of the unilateral cleft lip and palate patients, 84.6% of the bilateral cleft lip and palate patients, 50% of the cleft lip patients and 100% of the cleft palate patients were found to have malocclusion and need orthodontic treatment. 38.3% of the subjects fell into group 4 &5 of the Yardstick, which may indicates the need for orthognathic surgery intervention. Almost similar result was found by a research done by Zreaqat et al., 2008 on 82 Malay subjects with cleft lip and palate in Hospital University Science Malaysia, in which 97.6% of the sample were found to be in the group 2 to 5 of GOSLON Yardstick evaluation.

There are different methods in assessing malocclusion, including qualitative methods, grade index scales and quatitative methods. Qualitative methods do not give overview whether the malocclusion is present and the severity, thus it is not suitable for this study. Grade index scales, for example, four index grade scale & Index of Orthodontic Treatment Need (IOTN) that was developed by the Swedish Medical Board and Shaw et al., 1991 for orthodontics treatment needs will indicate everyone with cleft lip and palate to be in “ very urgent need” of orthodontic treatment. Thus, these methods cannot reveal the severity of malocclusion and different treatment need for cleft lip and palate patients.

Therefore, we chose GOSLON Yardstick as the most suitable method for malocclusion assessment in this book. This Yardstick rates the dentition of the patients with cleft lip and palate into five categories: excellent, good, fair, poor and very poor. It also considers the difficulties in the orthodontic treatment and thus suggested category 4 as limit for orthodontic treatment alone and category 5 will indicate the definite need for orthognathic treatment intervention (Asher-Mcdade et al., 1992, Mars et al., 1992, Shaw et al., 1992).

We also found that 38.3% of the subjects have palatal fistula, whereas, 34% of the subjects have sublabial fistula. This finding was slightly more than what was reported in United Kingdom which about 10% of their 12 year old cleft patients have residual fistula (Williams et al., 2001). The fistula may cause symptoms such as food impaction in the fistula, soft foods such as ice creamescaping down the nose, and regurgitation of fluids into the nose.

Moreover, sublabial and palatal fistula may be the cause of speech deficiency (Peter Hodgkinson et al., 2005). Therefore, it is important that alveolar bone graft is done in time not only for the eruption of teeth, continuation of the arch, alar base support and speech, but it is also to ensure high success rate of the surgery. In our study, 48.9% of the subjects were found to either delay in alveolar bone graft surgery (ABG) or, never had the surgery. The main reason given was they don’t know where to seek the treatment from. We also found that if these subjects were treated under plastic surgery department, there is significant result of delay in ABG surgery (refer appendix). This delay will worsen the residual deformity of the cleft patients especially at the nose area.

Speech is also an important aspect in assessing residual cleft deformity. As mentioned before in the previous chapter, perceptual speech evaluation is the basis of the speech assessment.Kuehn and Moller (2000) reviewed thoroughly methods used for description of speech characteristics relatedto cleft palate during the last 50 years and found that this method is useful to see the need for further speech therapy. Therefore, this is why we chose this method to assess the need for further speech therapy.

We also found that a total of 84.1% subjects need to be referred for further speech assessment and therapy. All subjects of bilateral cleft lip and palate were found to have somewhat speech deficiency and require further assessment and therapy. Only 23.3% of the unilateral cleft lip and palate subjects were found to have good speech. This is slightly higher than what was reported by Berstein and Kapp (1981) who found that almost 60% of the patients with cleft lip and palate require speech therapy in their study.

Other than that, the risk of dental caries is thought to be higher among children with a cleft lip and/or palate compared to normal children (Crane Annual Report, 2011). Although caries is not considered as residual deformity in cleft patients, we feel that it is important to take the findings into consideration as the need for treatment. This is because; Shaw et al (1996) recommendedthat the cleft team should be responsiblefor ensuring that patients are receiving good dental care (Shaw et al., 1996). Good dental care is not only important for preservation of teeth but also important for further orthodontic treatment. Therefore,it is essential to maintain good oral health, prevention and control of caries for all cleft children, regardless of the centre where they are treated at regular intervals, such as topicalfluoride prophylaxis, dietary advice, and restorative care (Lam et al., 2007).

From our findings, 53.8% of the subjects were having DMFT score of more than 3 which indicates the need for dental treatment. The same findings was also reported by Crane Annual Report in the year 2012 which found 44% of their cleft child needs dental treatment. This is probably due to lack of emphasize on the oral hygiene and the dental care to the patients by the healthcare givers.

**Perceived need of treatment by the parents**

One of the assessments for perceived need for cleft treatment includes the need of treatment for residual deformity. Residual deformities can cause stigma to the repaired cleft patients and needs to be taken seriously. These deformities include scarring of the philtral area and slight asymmetryof the vermilion,widealar implantation, shortening and flattening of theupper lip, retrusion of the upper lip and flattening ofthe nose([Johnson and Sandy, 2003](#_ENREF_28), [Vegter et al., 1997](#_ENREF_64)). In our study, we found that there were high demand in further treatment for nose (73.7%) and lip revision (48.9%). Highest demand for nose revision came from parents with unilateral cleft lip and palate child (48.9%), followed by bilateral cleft lip and palate group (17.8%). However, highest demand for lip revision was noted from bilateral cleft lip and palate group (36.4%) followed by unilateral cleft lip and palate group (26.7%).

More than a third of the parents felt that their child needs other treatment than stated above, specifically to improve speech (speech therapy).Speech deformity is a very important disorder in cleft lip and palate patients that needs to be highlighted. It affects not only the intelligibility but therewith the socialcompetence and emotional development of a child (Schuster et al., 2006). It has been reported that childrenwho look and sound physically different are noticed by others, suffer a significant level of teasing and bullying (Noor and Musa, 2007). Therefore, it is anticipated high perceived need of treatment for speech therapy from the parents.

There are studies that indicate patient’s perceived need of treatment is important to be taken into accountwhen assessing the outcome of cleft lip and palate care received from healthservices. Donabedian (1996) stated that patient satisfactionshould be the ‘‘ultimate validater of the quality of care’’ although this aspect of cleft care has received little attention inoutcome studies to date (Turner et al., 1997, Williams et al., 2001). Therefore, maybe it is best to include the cleft patients to express their own perceived need rather than only taking into the parents’ opinion only in the future.

**Treatment need versus Perceived need**

Generally, in this book, it was found that there was poor agreement between parents’ perceived need and the actual treatment need as assessed by the professionals in terms of lip repair, rhinoplasty, malocclusion and speech. Quite a number of parents felt that the further treatment on these areas were not important when there was actual treatment need noted. This could be due to lack of knowledge on available treatment, lack of knowledge on recognising the deformity, or, the parents felt that further treatment on these areas are not important for the time being and can be delayed. This could be an indicator to include the child’s opinion on his own deformity rather than taking the parents’ opinion only.

However, slight to fair agreement was noted between parents and professionals in terms of dental treatment and need for alveolar bone graft. In comparison, professional assessment seemed to concur with all of the parent’s perceived need, but also included the need for orthognathic surgery for the patients. The need for orthognathic surgery or jaw correction was never mentioned by the parents in the options “others”. All parents stated option “others” as the need for speech therapy. This could be due to lack of parents’ knowledge on the treatment available to correct skeletal deficiencies, or they felt that this treatment is not important for their child at the time of the interview.

Low socioeconomic and level of education of the parents may also contribute the disagreement. Parents with low income and education will perceive treatment need only based on their financial and knowledge. About two- third of the parents in this study belongs to this category. This indicates the need for more financial support by the NGO’s and education on cleft treatment to the society, as a whole.

Almost similar study done by the Eurocleft study in six-center European comparing treatment outcomes for children with unilateral cleft lip and palate. The study evaluated craniofacial morphology, dental arch relationships, nasolabial appearance, and speech. It was found that poor outcomes were associated with low-volume surgical involvement, presurgical orthopedics and primary bone grafting during lip repair.

Therefore, it can be concluded that full involvement of the professional team member is important to achieve good outcome of management for cleft lip and palate patients. Hence, this also highlights the importance of a combined cleft team to support and manage the cleft child and family from birth until adulthood. It is wrong to treat a cleft patient only according to one’s specialty and neglecting other areas as this will later cause more apparent residual deformity or untreated deformity of the cleft.

Bernstein andKapp (1981) suggested that it is also important that parents feel accepted by their professional helpers. They need a chance to express their perceived need of treatment regarding their child's condition.In their relationship with professionals, parents can gain support,a realistic perspective, and a chance to move toward active,realistic methods of coping with the problems of cleftlip and palate child.

Noor and Musa (2007) reported that, almost all parents in their study were involved in making treatmentdecision about their child. Cleft patients,however, said thatthey were "never involved" in treatment decision making. They felt that their parents and the specialists were in chargeof the treatment planning. This is not good for the patients' well-being,because parents’ and child’s expectation and perceived need for treatment may not be the same (Noor and Musa, 2007). It may be a good idea to take into account patient’s own perceived need of treatment as well in order to make sure the best of treatment delivered.

Furthermore, McCarthy et al. (2001) stated that researchers cannotassume that parents will be accurate in their assessment of theirown child's concerns. This is because, parents need a certain level of knowledge to know what are the cleft deformities and the treatment options. Therefore, it is important for an elaborate discussion and continuous follow up for cleft patients, parents and the caregiver from birth until adulthood.

**CHAPTER 6: CONCLUSION**

**CONCLUSION**

1. We found that there were poor to slight agreement between parents’ perceived need of treatment and professional’s assessment on treatment need.
2. Residual deformities in the subjects in our study are considerably high. 91.5% of the subjects were found to have malocclusion, 38.3% and 34% presented with palatal and sublabial fistula respectively, 40.4% of the patients have problem with speech.
3. In general, 76.6% of the study population requires further treatment. Unilateral cleft lip and palate subjects (62.9%) and bilateral cleft lip and palate subjects (62.5%) were the highest group for treatment need. 91.5% were found to be in need for treatment including lip revision, rhinoplasty and orthognathic surgery. A total of 34% of the subjects were found to be in need for ABG, 76.6% for orthodontic treatment, 68.1% for orthognathic treatment. 40.4% of the patients were found to be in the range of need to must be referred for further speech assessment and therapy. About 38.3% of the subjects were found to be in need for palatal fistula closure surgery.
4. Subjects in bilateral cleft lip and palate showed highest need in further treatment of lip compared to other cleft type. Unilateral cleft lip and palate showed highest group in perceived treatment need in further treatment of the ABG, teeth, nose and others as compared to other types of cleft. Highest perceived need for treatment was shown in descending order is perceived need for further treatment of teeth, followed by nose and alveolus in all types of cleft. However, no parent indicates the need for fistula closure and orthognathic treatment.

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