

PSYCHOSOCIAL EFFECTS OF CLEFT LIP AND PALATE PATIENTS AGED 12 YEARS AND ABOVE IN MALAYSIA

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ABSTRACT

Facial appearance is important in forming first impressions, and acts as a cue for social stereotyping (Tobiasen et al., 1987). There are evidence suggests that physical disfigurement is associated with greater internalizing behaviour (Richman and Millard, 1997). Cleft lip and palate deformities, for example, are considered as a stigma therefore many researches have been conducted to see the effects on patients' psychology and psychosocial well-being. Owing to these deformities, cleft patients were perceived to have lower self-esteem, difficulty in the learning process, and tendency to be more depressed. They were also reported to have problems in their relationships with family and friends including being rated as less social and difficult to make new friends because of their deformity (Richman and Harper, 1980; Heller et al., 1981). Therefore, this prompted us to identify the effects of cleft on psychosocial development of a cleft child as well as the perceived psychosocial effects after receiving treatment in cleft lip and palate among individuals aged 12 years old and above in Malaysia. Questionnaire guided interview was done on 47 parents of cleft lip and palate patients from few centers in Malaysia to obtain demographic data and treatment history. The effects of cleft on the patients as well as perceived effects of treatment on their psychosocial behavior were rated in Likert scale. The results were found that cleft lip and palate deformity has the highest negative impacts on the patients' behavior. This is followed by confidence, academic achievement as well as social ability. Parents perceived that their child's social capability will be positively affected (moderate to most) after further treatment (74.5%) as compared to the effect on their child's current condition (44.7%). Only 12.8% of the parents felt that further treatment will give no effect on their child's capability to socialize. As a conclusion, cleft lip and palate deformity have negative impacts on psychosocial behaviour of the cleft patients and treatment to correct these deformities were perceived to improve these impacts on the cleft patients.

Key words: cleft, psychosocial impacts, perceived need, cleft treatment

INTRODUCTION

Cleft lip and palate by definition is abnormal fissure or opening which may involve the areas of lip, palate, nose, cheek and the eyes resulting from failure of parts of the embryonic face to fuse during antenatal development (Merriam Webster dictionary, 2015). Cleft lip and palate accounts for 65% of all head and neck anomalies, which makes it the most common facial malformation in all populations and ethnic group. About 700 children with cleft lip and/or cleft palate are born in the world every day, which means that a baby with such a cleft is born every 2 minutes or 240 000 every year (Vanderas, 1987). This malformation is reported to be the most prevalent among Asians, intermediate in Caucasians and the least in Africans. In Malaysia, a study by Boo and Arshad in 1990 reported the incidence to be 1.24 per 1000 live birth. The Chinese had the highest incidence of 1.9 per 1000 birth, while the Malays had the lowest incidence of 0.98 per 1000 birth. These figures were underestimated due to incomplete registration. The most common type was reported to be the unilateral cleft of the hard and soft palates (Boo and Arshad, 1990).

These patients are likely to have significant problems that require attention of various specialties in healthcare. The deformities may range from minor irregularities, such as scarring of the philtral area and slight asymmetry of the vermilion, to more major stigmata such as wide alar, shortening and flattening of the upper lip, retrusion of the upper lip, hypernasal speech and flattening of the nose (Johnson and Sandy, 2003, Vegter et al., 1997). These deformities are considered as stigma to these patients.

Facial appearance is important in forming first impressions, and acts as a cue for social stereotyping (Tobiasen et al., 1987). A few researches have shown that children consistently rate photographs of other children with clefts more negatively than photographs of non-cleft children (Tobiasen et al., 1987, Schneiderman and Harding, 1984). In relation to this, cleft lip and/or palate patients were perceived to have lower self-esteem, difficulty in the learning process, and has a tendency to be more depressed (Strieker et al., 1979; Ramstad et al., 1995; Broder et al., 1998). They also have problems in their relationships with family and friends including being rated as less social and difficult to make new friends 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 with feeding, speech and hearing (Noor and Musa, 2007).

However, the relationship between psychosocial adjustment and facial morphology is complex and still not well understood, although some evidence suggests that a greater physical disfigurement is associated with greater internalizing behaviour

(Richman and Millard, 1997). Therefore, the aim of this study is to investigate the psychosocial impacts of the deformity on cleft children and the impacts after receiving further treatment.

OBJECTIVES

1. To identify psychosocial areas that are affected by cleft deformity
2. To investigate perceived effects on psychosocial aspects after receiving perceived treatment
3. To compare current psychosocial effects with effects after expected treatment.

MATERIALS & METHOD

This cross sectional study acquired sample which consisted of subjects (male and female) with the mean age of 15.7 recruited from patients attending the Combined Cleft Clinic in Oral and 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 and informed consent was obtained before data collection.

A case sheet was prepared which included the general data and all the parameters needed for this study. The parameters 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 expected treatment received. The questionnaire was developed from a modification of Cleft Evaluation Profile Questionnaire. The Cleft Evaluation Profile (CEP) originated from the Royal College of Surgeons Cleft Lip and Palate Audit Group (Turner et al., 1997). It was used to assess perceived satisfaction related to cleft care which consisted 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 their satisfaction 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 play a major role in assessing facial appearance among cleft lip and palate 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 determine any significant differences in the parent and child ratings of the features that were related to facial appearance, namely teeth, lips, nose, and facial profile. These are the features patients and parents felt needed attention and were examined for differences of responses between patients and their parents (Noor and Musa 2007). These profiles were then modified to see the effects in psychosocial development in cleft child.

Data from the questionnaire was analysed using SPSS version 12.0. Chi square analysis was done to evaluate the relationship between psychosocial effects on current condition and after future treatment.

RESULTS

Demographic

The total number of subjects was 47 (male and female).

Table 4.1: 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
	Above 17	0	4	0		4
	Total	14	10	1		25
Female	12 to 17	11	2	1	2	16
	Above 17	5	1	0	0	6
	Total	16	3	1	2	22

In this study, 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 4.2: Parents' Perceived Need for Specific Treatment

Perceived need	Type of cleft (%)				Total
	Unilateral cleft	Bilateral cleft	Lip only	Palate only	
Lip revision	26.7	36.4	0	4.4	67.5
Rhinoplasty	48.9	17.8	2.2	4.4	73.3
ABG	34.8	19.6	2.2	4.3	60.9
Orthodontic	51.1	27.7	4.3	4.3	87.4
Orthognathic	0	0	0	0	0
Fistula closure	0	0	0	0	0
Speech rehab	24.4	9.8	0	0	34.2
Dental treatment	51.1	27.7	4.3	4.3	87.4

Unilateral cleft lip and palate showed highest expectation in further treatment. Overall, in descending order, perceived need for treatment of teeth, orthodontic treatment followed by nose repair (rhinoplasty) was found to be the highest need in all types of cleft.

However, no parent indicated the need for fistula closure and orthognathic treatment found in this study.

We also enquired on selected psychosocial parameters that are affected by the subjects' current state of deformity (Table 4.3) Then we evaluate the perceived effects of further treatment on selected psychosocial variables including relationship with siblings, academic performance, temperament, confidence and social ability (Figure 4.4- 4.8).

Table 4.3: Psychosocial effect on current cleft condition (in rank)

Psychosocial effect	Rank	Percentage (%)
Behaviour	1	76.6
Confidence	2	63.8
Academic	3	57.4
Social ability	4	57.3
Relationship with siblings	5	34.1

In this study, we found that behaviour ranks the first in psychosocial effect among the cleft lip and palate subjects. This is followed by low confidence, academic achievement and socialability. Only few parents, however, seemed to perceive that their child's current condition has effect on the relationship among the siblings.

Figure 4.4: Perceived Effects Before and After Receiving Further Treatment on Subject's Relationship with Siblings

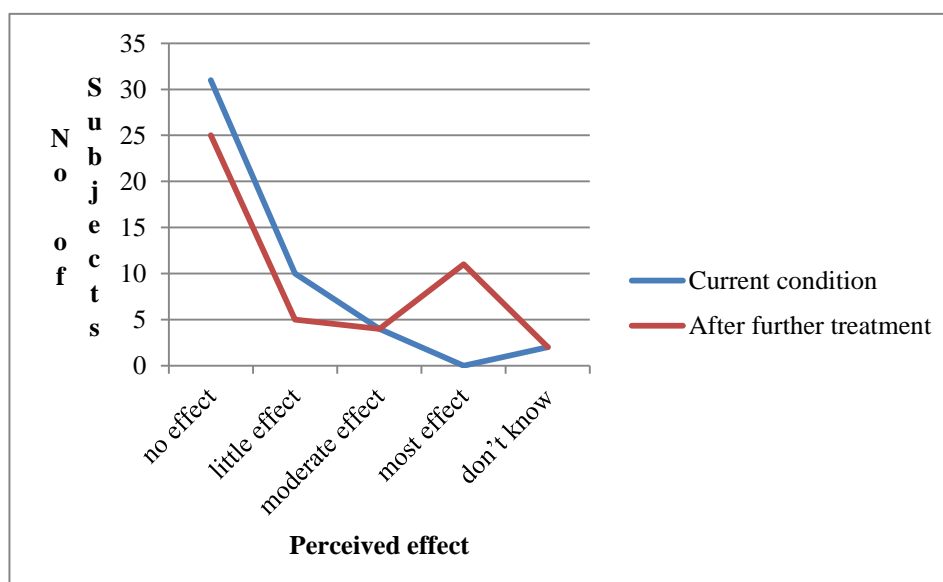
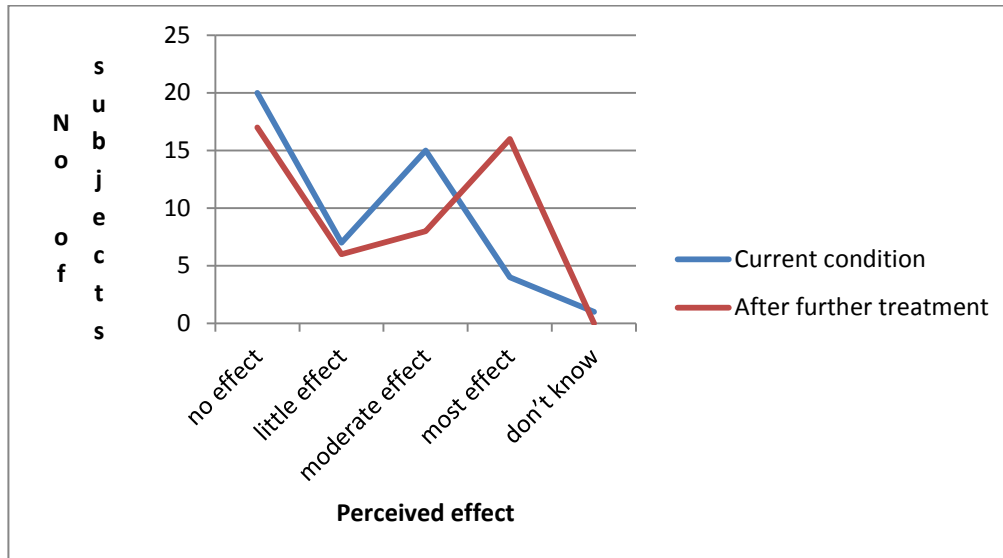


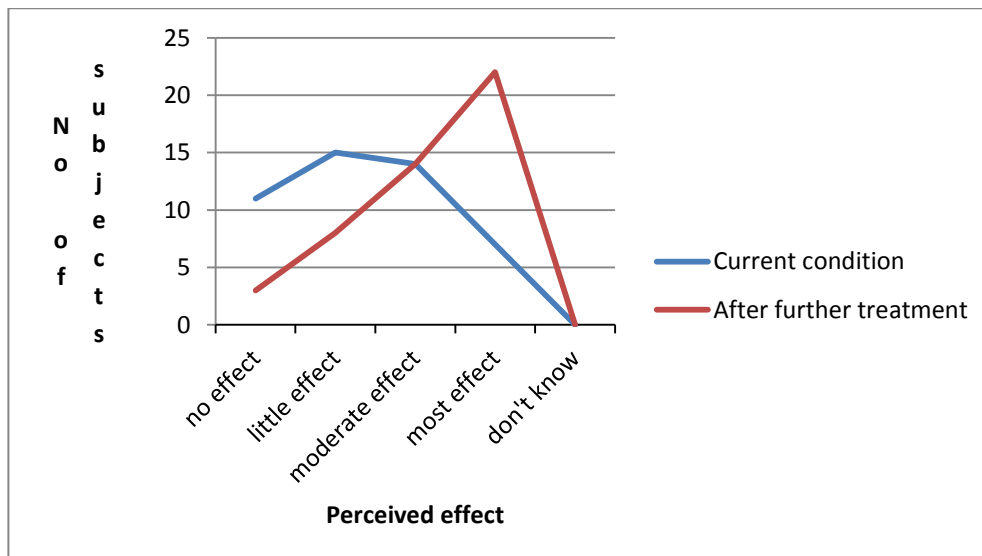
Figure 4.3 showed 23.4% of the parents felt that further treatment will most benefit their child in terms of relationship with the siblings. However, none of the parents perceived that the child's cleft condition has the most the effect on the sibling's relationship prior to the treatment. Almost half of the parents (42.6%) felt that further treatment will affect their child's relationship with the siblings from little to most effect.

Figure 4.5: Perceived effects before and after receiving further treatment on subject's academic performance



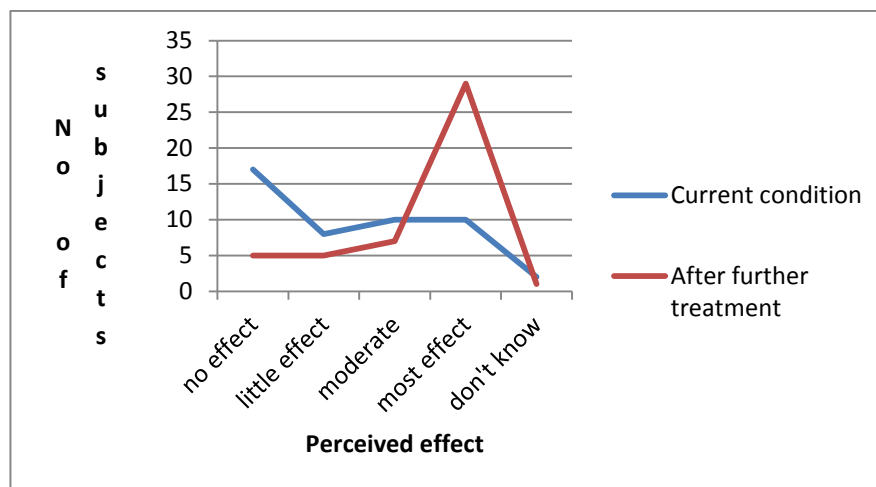
About half (55.3%) of the parents felt that the child's current cleft condition affects the academic performance from little to most effect. However, 63.8% of the parents perceived that the child's academic performance may be affected positively after further treatment. Only 36.2% of the parents perceived that the academic performance will not be affected after further treatment received.

Figure 4.6: Perceived effects before and after receiving further treatment on subject's behavior



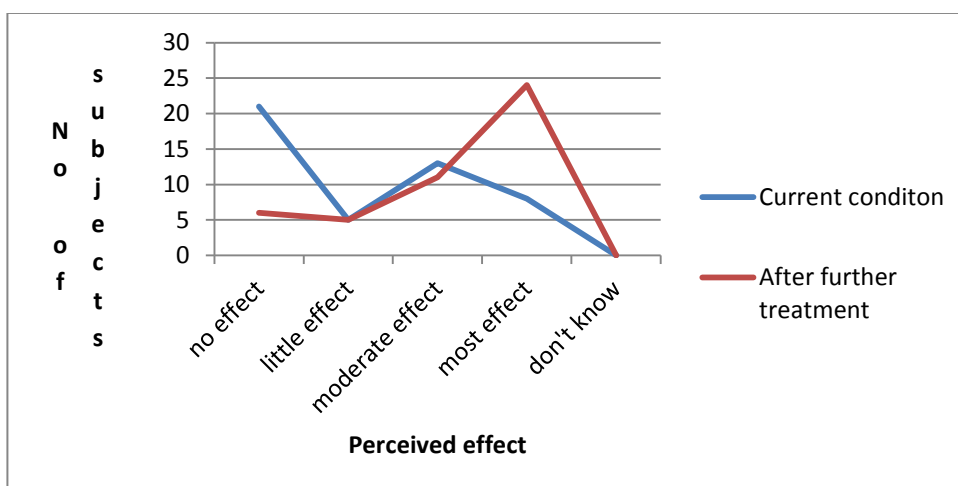
Most of the parents (76.6%) felt that further treatment will affect moderately to most of their child's behaviour, as compared to prior treatment (44.7%). Fewer parents (23.4%) felt that further treatment will not affect their child's behaviour or give little effect as compared to what they perceived before receiving further treatment (55.3%).

Figure 4.7: Perceived effects before and after receiving further treatment on subject's confidence



There is increase in parent's perceived effect on child's confidence after further treatment as compared to child's current condition. 76.6% of the parents felt that further treatment will affect positively their child's confidence.

Figure 4.8: Perceived effects before and after receiving further treatment on subject's socialability.



Parent's perceived that their child's social capability will be positively affected (moderate to most) after further treatment (74.5%) as compared to the effect on their child's current condition (44.7%). Only 12.8% of the parents felt that further treatment will give no effect on their child's capability to socialize.

DISCUSSION

Most of the parents in this study felt that their child's current cleft condition does not or has little effect on the child's relationship with the siblings, confidence as well as academic performance. This is contradicting with findings of some researchers who reported that cleft lip and/or palate patients were perceived to have lower self-esteem, difficulty in the learning process, tendency to be more depressed and have problems in their relationship with the family (Strieker et al., 1979; Ramstad et al., 1995; Broder et al., 1998, Richman and Harper, 1980; Heller et al., 1981).

However, increased number of response noted when they were asked about the effect of cleft on their child's behavior and social ability (moderate to most effect). This finding was also evident in other studies that described cleft patients tend to have psychosocial problems and rated as less social as well as difficult to make new friends because of their deformity (Noor and Musa, 2007). Children with CLP has been described as more external in locus of control (i.e. believe their life is determined by fate, luck or others) and significantly more field dependent (i.e. sensitive to the social environment) than non-cleft controls (Brantley and Clifford, 1979b). Children with CLP also tend to have higher levels of hostility, negative selfworth, a negative outlook and greater dependence compared with the general population (Tyl et al., 1990).

Interestingly, all of the parents responded that their child needs further treatment and the treatment was perceived to improve in all aspects of psychosocial development of their child. Highest positive effect was perceived to increase their child's confidence level and lowest effect was relationship between their child and the other siblings.

Parents and cleft patients however, need to be informed that personality also plays a role in influencing the child's psychosocial development other than corrective treatment. This is because, children who are more accepting of their cleft tend to have higher self-esteem (Starr, 1978), and the more physically attractive a person rates themselves the higher that person's self-esteem tends to be (Starr, 1982).

Therefore, it is imperative to recognize the impacts of cleft on psychosocial development of cleft children as there are studies suggested that the burdens of adjustment for those with CLP persist into adulthood (Bernstein and Kapp, 1981), with some individuals showing a high level of distress as a result of CLP (Cochrane and Slade, 1999). It is also important that parents and teachers to be aware of the different behaviors these children may demonstrate when compared to other children. It is not possible to predict which child may demonstrate detrimental behavior patterns affecting educational and social learning; however, our current data does suggest that as a group, children with cleft lip and palate are at high risk to the development of behavior problems.

With the limitation of this research, we would like to recommend expanding the sampling areas and sizing as well as including cleft child's response in the sample and comparing with the parent's response.

CONCLUSION

1. Parents from 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.
2. 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.
3. Cleft lip and palate deformity has effects to the psychosocial development of the cleft children, highest effect on the behaviour and lowest on sibling relationship.
4. Parents of the cleft children also perceived that further treatment will help to improve these effects significantly.

REFERENCES

- Asher-McDade, C. & Shaw, W. C. 1990. Current cleft lip and palate management in the United Kingdom. *Br J Plast Surg*, 43, 318-21.
- Bardach, J., Morris, H. L., Olin, W. H., Gray, S. D., Jones, D. L., Kelly, K. M., Shaw, W. C. & Semb, G. 1992. Results of multidisciplinary management of bilateral cleft lip and palate at the Iowa Cleft Palate Center. *Plast Reconstr Surg*, 89, 419-32; discussion 433-5.
- Cochrane V M, Slade P 1999 Appraisal and coping in adults with cleft lip: associations with well-being and social anxiety. *British Journal of Medical Psychology* 72: 485-503
- De Ladeira, P. R. & Alonso, N. 2012. Protocols in cleft lip and palate treatment: systematic review. *Plast Surg Int*, 2012, 562892.
- Duffy, S., Noar, J. H., Evans, R. D. & Sanders, R. 2000. Three-dimensional analysis of the child cleft face. *Cleft Palate Craniofac J*, 37, 137-44.
- Eliason, M. J., Hardin, M. A. & Olin, W. H. 1991. Factors that influence ratings of facial appearance for children with cleft lip and palate. *Cleft Palate Craniofac J*, 28, 190-3; 193-4 discussion.
- Farkas, L. G., Forrest, C. R. & Phillips, J. H. 2000. Comparison of the morphology of the "cleft face" and the normal face: defining the anthropometric differences. *J Craniofac Surg*, 11, 76-82.
- Fraser, G. R. & Calnan, J. S. 1961. Cleft lip and palate: seasonal incidence, birth weight, birth rank, sex, site, associated malformations and parental age. A statistical survey. *Arch Dis Child*, 36, 420-3.
- Harding, A. & Harland, K. 1995. Managing cleft lip and palate. Language outcomes are important. *BMJ*, 311, 1432; author reply 1432-3.
- Hodgkinson, P. D. & Rabey, G. P. 1986. Three-dimensional nasal morphology in adult bilateral cleft palate patients: a morphanalytic study. *Br J Plast Surg*, 39, 193-205.
- Hsieh, Y. T., Chao, Y. M. & Shiao, J. S. 2013. A qualitative study of psychosocial factors affecting expecting mothers who choose to continue a cleft lip and/or palate pregnancy to term. *J Nurs Res*, 21, 1-9.
- Mulliken, J. B. 2004. The changing faces of children with cleft lip and palate. *N Engl J Med*, 351, 745-7.
- Pannbacker, M. 1968. Congenital malformations and cleft lip and palate. *Cleft Palate J*, 5, 334-9.
- Ramstad T, Otten E, Shaw W C 1995b Psychosocial adjustment in Norwegian adults who had undergone standardised treatment of complete cleft lip and palate. Part II. Self-reported problems and concerns with appearance. *Scandinavian Journal of Plastic and Reconstructive Surgery and Hand Surgery* 29: 329-336
- Ras, F., Habets, L. L., Van Ginkel, F. C. & Prahl-Andersen, B. 1995. Longitudinal study on three-dimensional changes of facial asymmetry in children between 4 to 12 years of age with unilateral cleft lip and palate. *Cleft Palate Craniofac J*, 32, 463-8.
- Richman, L. C. & Millard, T. 1997. Brief report: cleft lip and palate: longitudinal behavior and relationships of cleft conditions to behavior and achievement. *J Pediatr Psychol*, 22, 487-94.

- Sandy, J., Williams, A., Mildinhal, S., Murphy, T., Bearn, D., Shaw, B., Sell, D., Devlin, B. & Murray, J. 1998. The Clinical Standards Advisory Group (CSAG) Cleft Lip and Palate Study. *Br J Orthod*, 25, 21-30.
- Sandy, J. R., Williams, A. C., Bearn, D., Mildinhal, S., Murphy, T., Sell, D., Murray, J. J. & Shaw, W. C. 2001. Cleft lip and palate care in the United Kingdom--the Clinical Standards Advisory Group (CSAG) Study. Part 1: background and methodology. *Cleft Palate Craniofac J*, 38, 20-3.
- Schneiderman, C. R. & Harding, J. B. 1984. Social ratings of children with cleft lip by school peers. *Cleft Palate J*, 21, 219-23.
- 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. *Cleft Palate Craniofac J*, 38, 30-7.
- Shaw, W. C., Williams, A. C., Sandy, J. R. & Devlin, H. B. 1996. Minimum standards for the management of cleft lip and palate: efforts to close the audit loop. *Royal College of Surgeons of England. Ann R Coll Surg Engl*, 78, 110-4.
- Starr P 1978 Self-esteem and behavioral functioning of teenagers with oro-facial clefts. *Rehabilitation Literature* 39: 233-235
- Starr P 1982 Physical attractiveness and self-esteem ratings of young adults with cleft lip and/or palate. *Psychological Reports* 50: 467-470
- Tobiasen, J. M., Hiebert, J. M. & Boraz, R. A. 1991. Development of scales of severity of facial cleft impairment. *Cleft Palate Craniofac J*, 28, 419-24.
- Tobiasen, J. M., Levy, J., Carpenter, M. A. & Hiebert, J. M. 1987. Type of facial cleft, associated congenital malformations, and parents' ratings of school and conduct problems. *Cleft Palate J*, 24, 209-15.
- Tulley, W. J. 1971. The management of cleft lip and palate. Introduction. *Ann R Coll Surg Engl*, 48, 30.
- Tyl J, Dytrych Z, Helclová H, Scüller V, Matějček Z, Beránková A 1990 Psychic and social stress of children with cleft lip and palate. *Ceskoslovenska Pediatrie* 45: 532-536
- Van Lierde, K. M., Dhaeseleer, E., Luyten, A., Van De Woestijne, K., Vermeersch, H. & Roche, N. 2012. Parent and child ratings of satisfaction with speech and facial appearance in Flemish pre-pubescent boys and girls with unilateral cleft lip and palate. *Int J Oral Maxillofac Surg*, 41, 192-9.
- Vanderas, A. P. 1987. Incidence of cleft lip, cleft palate, and cleft lip and palate among races: a review. *Cleft Palate J*, 24, 216-25.
- Williams, A. C., Bearn, D., Mildinhal, S., Murphy, T., Sell, D., Shaw, W. C., Murray, J. J. & Sandy, J. R. 2001. Cleft lip and palate care in the United Kingdom--the Clinical Standards Advisory Group (CSAG) Study. Part 2: dentofacial outcomes and patient satisfaction. *Cleft Palate Craniofac J*, 38, 24-9.

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