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Aesthetic outcome of cleft lip and palate treatment. Perceptions of patients, families, and health professionals compared to the general public

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ABSTRACT

The aesthetic outcome of cleft treatment is of great importance due to its complex management and the psychosocial consequences of this defect. The aim of the study was to assess the aesthetic evaluations of patients following cleft surgery by various groups and investigate potential associations of the assessments with life quality parameters. Head photos of 12 adult patients with treated unilateral cleft lip and palate were evaluated by laypeople and professionals. A questionnaire was distributed and answered by the patients and their parents. Intra-panel agreement was high ($\alpha > 0.8$) for laypeople and professionals. Between-groups agreement was high for both laypeople and professionals, but not when patients and/or parents were tested. Professionals, parents, and patients were more satisfied with patients' appearance than laypeople, although in general all groups were not highly satisfied. Low satisfaction with aesthetics correlated with increased self-reported influence of the cleft in the patients' social activity and professional life ($0.56 < \text{rho} < 0.74$, $p < 0.05$). These findings highlight the observed negative influence of the cleft on the patient's social activity and professional life and underline the need for the highest quality of surgical outcome for this group of patients.

1. Introduction

Orofacial clefts are common congenital malformations in humans. The frequency is approximately 1 in 700 live births (Mossey et al., 2009) and correction involves prolonged treatment over many years (Witt and Marsh, 1997). A variety of surgical techniques and modifications have been described regarding cleft lip and palate (CLP) treatment (Salyer, 1986; Thomson and Reinders, 1995; Lazarus et al., 1998; Lee et al., 2011). However, patients still seem to have concerns about their facial appearance, especially related to the cleft deformity (Marcusson et al., 2002; Sinko et al., 2005). These are attributed to scar tissue (Ritter et al., 2002) or asymmetries (Fudalej et al., 2009; Meyer-Marcotty and Stellzig-Eisenhauer, 2009), which negatively impact on facial aesthetics.

The importance of facial aesthetics and their strong influence on a patients' psychosocial status have been highlighted by studies on orthognathic surgery patients. The self perceived improvement in facial appearance following treatment had a strong positive influence on quality of life and patient satisfaction compared to other functional or treatment-related factors (Khattak et al., 2012; Rustemeyer and Gregersen, 2012).

The prominent aesthetic location of the cleft may result in negative psychosocial consequences (Rankin and Borah, 2003), ranging from low self-esteem (Broder and Strauss, 1989) to risk of social isolation (Tobiasen, 1987; Anderson et al., 2008). The impact on facial appearance may reduce the ability to make friends, have good family relationships and may affect learning (Noor and Musa, 2007), therefore the aesthetic outcome of a cleft treatment is of great importance (Witt and Marsh, 1997).

Currently, since there is no valid objective model for studying the aesthetic treatment outcome, questionnaire studies have become a valuable tool for assessing subjective perceptions of facial appearance. In such studies, self-assessment by the patient may sometimes be biased as previous experiences may influence

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judgements (Broder et al., 1994; Pitak-Arnnop et al., 2011). However, aesthetic assessments are always subjective in nature. Individuals tend to perceive their own beauty to be greater than others judge it. This might be the result of a psychological mechanism which exists to enhance the self-confidence and resilience of an individual and support its social-standing (Springer et al., 2012). Undoubtedly, self-esteem is influenced by self-perception of appearance and the patient's opinion is important.

Parents' opinion is also important although their assessments may be biased because of their connections, feelings, and inner thoughts towards their child (Shaw, 1981; Broder et al., 1992). Previous studies suggested that children with CLP experience more negative feelings (Kasuya et al., 2000) and lower degree of acceptance by their parents compared to non-cleft controls (Brantley and Clifford, 1979). Parents are however usually highly involved in making treatment decisions related to their child (Noor and Musa, 2007).

The professionals' opinion is influenced by training and experience and they may influence patients' and parents' perception of the need for treatment. They should effectively address patients' concerns with their treatment approach.

A patient's social interactions primarily depend on perceptions in the wider community which are crucial and must be taken into account (Williamson, 1999). Professionals could also be considered as part of the community with distinct characteristics deriving from their medical background (Williamson, 1999). In a previous study, we showed that professionals focus on different features of the face when evaluating facial aesthetics in patients with clefts compared to laypeople (Papamanou et al., 2012). Laypeople without previous knowledge of the problem comprise a more valid opinion than a cleft-associated group such as parents, as this is the wider community or peers which the patient will be in contact with (Rumsey et al., 1986).

Previous research evaluated CLP patients' self-perception and/or parents' perception of their children's appearance (Broder et al., 1994; Hunt et al., 2006; Noor and Musa, 2007) and others have evaluated professional assessments (Sinko et al., 2005; Russell and Tompson, 2009) or compared cleft to non-cleft individuals (Oosterkamp et al., 2007; Russell and Tompson, 2009). However, no study assessed the aesthetic perceptions of these groups in the same conditions (providing the opportunity for comparison) or investigated the possible relations to social parameters that may be influenced by the way that treatment outcome is perceived.

The aim of this study was to compare the satisfaction of young adult patients with CLP, their parents, professionals, and laypeople with the aesthetic outcome of CLP treatment and to explore if and how the self-reported influence of cleft treatment on patient's social activity and professional life could be related to the perception of his/her facial appearance by these distinct groups.

2. Materials and methods

This study followed the Declaration of Helsinki on medical protocol and ethics. The study protocol was approved by the Ethical Committee of the Dental School of the University of Athens (Protocol No. 135/26.01.2010). The study evaluated the assessment of 12 young adult patients who had finished treatment of complete unilateral CLP (right: three, left: nine), by themselves, their parents, 12 qualified professionals (six orthodontists + six maxillofacial surgeons) (cleft-associated groups), and two groups of 12 randomly selected adult laypeople, each matched for gender, age, and residence to the group of patients and parents respectively (cleft non-associated groups). All non-professional participants were of Caucasian origin and represented a wide range of socio-economical status. Age was matched within 1-year divergence between corresponding raters. Professionals had more than 10 years of experience after acquisition of the specialist title. Laypeople and professionals were not related to each other or to the patients and their parents. Professionals were not involved in any stage of patients' treatment.

All patients were treated in the Postgraduate Orthodontic Clinic of the University of Athens for the orthodontic part of their treatment, while variable surgical protocols were applied. Patients with syndromes, other congenital anomalies or psychological disorders were excluded. Patients and parents were informed of the study in a consecutive manner and the first 12 who agreed to participate were included after signed consent was obtained. No patient/parent refused participation.

A set of five head photos (frontal face, right/left lateral face, $^{3}/_{4}$ right/left face) was taken for each patient (nine M & three F, Mean age: 22.1, Range: 17.5–27.4) by one investigator, in one session, under standardized conditions (Papamanou et al., 2012).

Laypeople and professionals evaluated the photos of all subjects using a questionnaire (Fig. 1A), under similar conditions (approximately 20 min for all the evaluations in a quiet office with adequate lighting), and under the supervision of one specific researcher. Another investigator interviewed/consulted the patients and their parents independently, with the same questionnaire allowing assessment of the aesthetic appearance of each subject (Fig. 1A). The questionnaire was tested for reliability (internal consistency) and validity (convergent and discriminant) in a Greek population (data not shown). Answers were registered on a 100 mm visual analogue scale (VAS) (Aitken, 1969) (Fig. 1A). Distance of each rater's marking from the start of the scale ("0") was measured with a digital calliper and ratings were thus transformed to continuous metric variables.

The study sample size was selected in order not to discourage or fatigue raters (Mclaughlin et al., 2009) by presenting too many sets of photos for evaluation, while achieving a satisfactory power for pairwise comparisons. The power of the study was above 0.8 for a difference of 20 mm in the obtained VAS scores (G*power Software, version 3.1.1). This difference was considered clinically significant.

The patients additionally answered two questions about the influence of the cleft on their social activity and professional life. These answers were used for testing possible associations with the

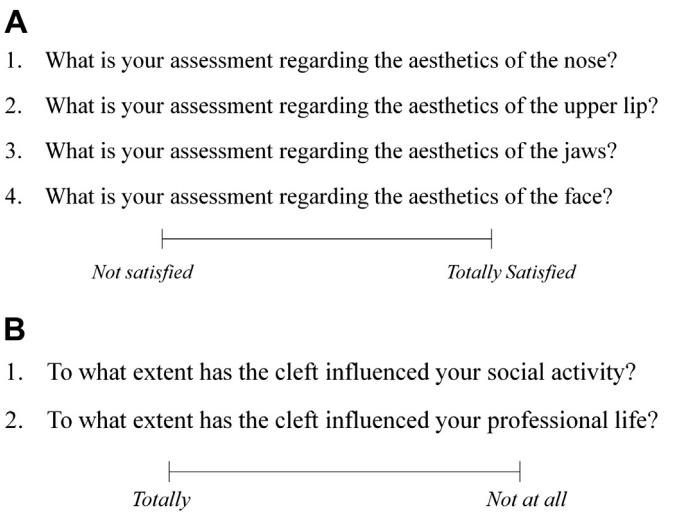

Fig. 1. (A, B) Questions addressed to the raters and 100 mm Visual Analogue Scales used for each group of questions. "Not satisfied" and "Totally" correspond to 0. "Totally satisfied" and "Not at all" correspond to 100.