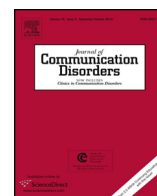




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Parental satisfaction in Ugandan children with cleft lip and palate following synchronous lip and palatal repair



Anke Luyten^{a,*}, Evelien D'haeseleer^a, Dorte Budolfson^b, Andrew Hodges^c, George Galiwango^c, Hubert Vermeersch^d, Kristiane Van Lierde^a

^aGhent University, Department of Otorhinolaryngology, Logopaedic and Audiologic Sciences, De Pintelaan 185, 2P1, 9000 Gent, Belgium

^bKids of Africa, Plot 49 Bwerenga, P.O. Box 22117, Kampala, Uganda

^cComprehensive Rehabilitation Services, P.O. Box 46, Kisubi, Uganda

^dGhent University, Department of Head and Neck Surgery, De Pintelaan 185, 2P2, 9000 Gent, Belgium

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ABSTRACT

The purpose of the present case control study was to assess parental satisfaction with speech and facial appearance in Ugandan children with complete unilateral or bilateral cleft lip and palate (CLP), who underwent a synchronous lip and palatal closure. The results are compared with an age- and gender-matched control group. The experimental group consisted of the parents or guardians of 44 Ugandan patients (21 males, 23 females) with complete unilateral or bilateral CLP (mean age: 3;1 years). The control group included the foster mothers of 44 orphan children matched by age and gender (mean age: 3;7 years). A survey based on the Cleft Evaluation Profile was used to assess the perceived satisfaction for individual features related to cleft care. Overall high levels of satisfaction were observed in the experimental group for all features (range: 56–100%). No significant differences could be established regarding age, gender, age of lip and palatal closure, cleft type or maternal vs. paternal judgments. In participants who were dissatisfied with the appearance of the lip, the time period between the cleft closure and the survey was significantly larger compared with satisfied participants. Furthermore, significantly lower levels of satisfaction were observed in the cleft group for speech and the appearance of the teeth and the nose compared with the control group. Satisfaction with speech and facial appearance in Ugandan children with cleft lip and/or palate is important since normal esthetics and speech predominantly determine the children's social acceptance in the Ugandan society.

Learning outcomes: As a result of reading this manuscript, the reader will be able to explain the attitudes of parents toward the surgical repair of their children's cleft lip and palate. As a result of reading this manuscript, the reader will be able to identify differences in parental attitudes toward synchronous lip and palate repair.

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* Corresponding author. Tel.: +32 9 332 08 63.

E-mail addresses: Anke.Luyten@UGent.be (A. Luyten), Evelien.Dhaeseleer@UGent.be (E. D'haeseleer), dorte@budolfson.dk (D. Budolfson), andrewhodges3001@gmail.com (A. Hodges), george.galiwango@corsu.or.ug (G. Galiwango), Hubert.Vermeersch@UGent.be (H. Vermeersch), Kristiane.Vanlierde@UGent.be (K. Van Lierde).

1. Introduction

Research and clinical practice in patients with cleft lip and/or palate (CL/P) often focuses on the differences in body structures and functions (Neumann & Romonath, 2012). However, according to the International Classification of Functioning, Disability, and Health: Children and Youth Version (ICF-CY), developed in 2007 by the World Health Organization (WHO), other aspects, including activities and participation (e.g. eating, drinking, speaking), environmental factors (e.g. individual attitudes, family and friends) and personal factors (e.g. coping style, psychological assets) should not be overlooked (World Health Organisation, 2007). Analysis of these personal factors necessitates assessment of how the esthetic aspects of children with CLP are handled (Neumann & Romonath, 2012). Therefore, the most relevant aspect to determine treatment success is satisfaction with the facial appearance and speech as judged by both patients and parents (Sinko et al., 2005). Satisfaction with appearance as well as ability to verbally communicate highly influences psychological well-being (Turner, Dowell, Rumsey, & Sandy, 2007). Persons with an esthetic and/or speech disorder might therefore be more at risk for developing psychological problems, such as social withdrawal (Berger & Dalton, 2011; Bernstein & Kapp, 1981), depressions and anxiety disorders (Feragen, Borge, & Rumsey, 2009). However, as reported by Hunt, Burden, Hepper, and Johnston (2005), the majority of children and adults with a repaired cleft lip and palate (CLP) do not appear to experience major psychosocial problems.

In the past two decades, numerous studies have been conducted on patient and parental satisfaction with esthetics and speech (Broder, Smith, & Strauss, 1992; Noor & Musa, 2007; Oosterkamp et al., 2007; Van Lierde et al., 2012; Williams et al., 2001). In a literature review Hunt et al. (2005) reported that children and adults with repaired CL/P are generally positive about their body, facial appearance and speech. However, several authors mentioned that some cleft features are considered less than satisfactory to a sizable group of patients. Regarding facial appearance after closure of the cleft, patients are the most dissatisfied with the nose, the upper lip, the teeth and the facial profile (Marcusson, 2001; Noar, 1991; Noor & Musa, 2007; Oosterkamp et al., 2007; Semb et al., 2005; Van Lierde et al., 2012). Furthermore, patients report persistent dissatisfaction with speech (Noor & Musa, 2007), hearing (Van Lierde et al., 2012) and nasal breathing (Oosterkamp et al., 2007; Van Lierde et al., 2012). Oosterkamp et al. (2007) hypothesized that patient and parental expectations are an important factor influencing satisfaction. Therefore, if the treatment outcome proves in line with the patients' and parental expectations, a maximum satisfaction could be reached. Consequently, the authors stressed the importance of providing honest and realistic information about the possible outcome of surgery to create more realistic expectations and reduce dissatisfaction with treatment outcome.

The effect of race (people with certain hereditary characteristics) and/or ethnicity (people sharing a common and distinctive racial, national, religious, linguistic, or cultural heritage) on satisfaction with the facial appearance and speech in these patients has rarely been reported in literature. To our knowledge, only two studies have been conducted in non-white populations. Noor and Musa (2007) and Reekie (2011) both determined the satisfaction with CLP repair in patients of Asian ethnicity. Noor and Musa (2007) assessed the satisfaction regarding cleft-related features in 60 Asian teenager–parent pairs in Malaysia, using the Cleft Evaluation Profile (CEP). Seventy-seven percent (46/60) of the patients and 75% (45/60) of the parents were satisfied with the overall clinical outcome. For both groups, the lowest level of satisfaction was observed regarding the appearance of the teeth. Reekie (2011) used the Satisfaction with Appearance Questionnaire (SWA) in order to compare 15 Asian and 95 Caucasian adults with clefts in the UK. Compared with the Caucasian group, Asians showed lower mean scores for all the SWA-components, except for profile and hearing. However, for cleft-related features, the only differences reaching statistical significance were satisfaction with the nose and the speech. No controlled satisfaction study has yet been performed in an East African population. However, studying parental satisfaction on facial appearance and speech in East African children with CLP would be interesting, considering that disabled people in East Africa have limited opportunities for accessing education, health, housing and employment due to stigma and negative attitudes in the community (International Labour Organization, 2009). Disabilities are often associated with evil spirits, curses and punishment for ancestral wrong doings (Dagher & Ross, 2004), resulting in abuse and discrimination by strangers, neighbors and even family members and in the denial of basic provisions such as food, clothing, and shelter (Human Rights Watch, 2010).

In Uganda, the life expectancy at birth in 2010 was estimated at 54 years with an under-5 year mortality rate of 99 per 1000 children (UNICEF, 2003). The main causes of death among children under 5 years of age are prenatal conditions, neonatal disease, and malaria. For the population of approximately 35 million people, fewer than 5000 doctors are active in the country (Wasswa, 2012). Traditional healers are still strongly integrated into Ugandan Society. According to Abbo (2011), at least one traditional healer lives in each village and the World Health Organisation (2002) estimates that more than 80% of the population attend traditional healers for health reasons, particularly in rural areas. Regarding CLP, the incidence in Uganda is 0.73 per 1000 live births, indicating that approximately 1100 babies are born with a cleft each year (Dreise, Galiwango, & Hodges, 2011). Walker, Obua, Mouton, Ttendo, and Wilson (2010) reported that 80% of the CLP operations executed between 1 August 2007 and 31 July 2008 were performed by externally funded surgeons. Since 2009, children and adults with CL/P can be operated for free in the Comprehensive Rehabilitation Services in Uganda (CoRSU) hospital in Kisubi, a nonprofit and nongovernmental organization supported by Christian Blind Mission (CBM) that focuses on children with physical impairment. In CoRSU, one experienced British plastic and reconstructive surgeon (A.H.) performs the surgery in patients with CL/P. Moreover, local plastic surgeons are trained in order to stimulate maintenance and sustainability of cleft care. In 2010, a Speech-Language Therapy (SLT) department was established in the hospital in order to follow-up speech and

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