Available online at www.sciencedirect.com

SciVerse ScienceDirect

British Journal of Oral and Maxillofacial Surgery 53 (2015) 594–598

BRITISH
Journal of
Oral and
Maxillofacial
Surgery

www.bjoms.com

Review

Contemporary management of cleft lip and palate in the United Kingdom. Have we reached the turning point?

S.D. Colbert [a,*], Ben Green [b], P.A. Brennan [c], N. Mercer [d]

[a] *Cleft Unit, Frenchay Hospital, Bristol, BS16 1LE, Ben Green, BDS, Kings College, Strand, London, WC2R 2LS*
[b] *Kings College, Strand, London, WC2R 2LS*
[c] *Department of Oral and Maxillofacial Surgery, Queen Alexandra Hospital, Portsmouth, PO6 3LY, UK*
[d] *Cleft Unit, Frenchay Hospital, Bristol, BS16 1LE*

Accepted 7 June 2015
Available online 27 June 2015

Abstract

Babies born with clefts of the lip, and the alveolus or palate, or both, require multidisciplinary, highly specialised treatment from birth to early adulthood. We review the contemporary management of clefts and outline the current treatment protocol adopted by cleft networks in the United Kingdom. We also look at the level of evidence and the restructuring of services that has defined current practice. In light of the recent Cleft Care UK study, we ask whether it is now time to adopt a new philosophy towards the surgical techniques that are used.

Keywords: Review; Contemporary management; Cleft lip; Cleft palate; Alveolus; Surgery.

Introduction

In Europe, between 1:500 and 1:700 babies are born alive with clefts of the lip, and alveolus or palate, or both,[1] and presentations can range from a notch in the upper lip to a wide, complete, bilateral cleft of the lip and palate. Highly specialised operations are necessary in the early months of life to maximise function of the face and oropharynx. Deficiencies in facial and dental development, and in speech and hearing, remain frustratingly common and may be accompanied by psychosocial problems. Successful outcomes require multidisciplinary, highly specialised treatment from birth to early adulthood, and a lifetime commitment to the maintenance of oral health.

Treatment starts with perinatal nursing care and primary operation, and is often followed by further procedures, sometimes into early adulthood. Teams that treat patients with clefts are truly multidisciplinary and include clinical nurse specialists, speech and language therapists, orthodontists, and specialist surgeons, as well as specialists in preventive and restorative dental care, audiology and otolaryngology, and clinical, genetic, and psychological counsellors.

Lack of evidence-based practice and background to the present position

As the prevalence of cleft lip with or without cleft palate is relatively low in the general population and there are many subtypes, few clinical studies have included large samples. Before the report by the Clinical Standards Advisory Group (CSAG), treatment in the UK (as in mainland Europe) was not universally evidence-based, and was sometimes based on the preferences of individual surgeons. The Eurocleft project

---

* Corresponding author.
E-mail addresses: serryth@yahoo.com (S.D. Colbert), ben.c.green@kcl.ac.uk (B. Green), peter.brennan@porthosp.nhs.uk (P.A. Brennan), nigel.mercer@nbt.nhs.uk (N. Mercer).

http://dx.doi.org/10.1016/j.bjoms.2015.06.010

(1996 - 2000), which aimed to improve quality of care and research into the condition,[2] found a wide diversity of care, national policies, and clinical practices. Of the 201 centres in the network, 194 followed different protocols for unilateral clefts, no centre followed exactly the same regimen as another, and in some areas even the most basic provision was a major challenge.

The Eurocleft Report[3] estimated the sample sizes required to detect differences for a variety of outcomes. At 5% probability and 80% power, detection of a 0.5 difference in the Goslon Scale[4] in 10-year-olds required samples of 42 cases of unilateral cleft lip and palate (UCLP) in a 2-group comparison. Eurocleft recommended that collaborative research would provide a focus for researchers who wish to improve the understanding, treatment, and prevention of clefts. Rigorously managed evaluation between centres would enable clinicians to identify best practice, to compare outcomes for different protocols and select those based on factors such as the burden on patients and their families, simplicity of treatment, and cost, while maximising outcome.

At that time, cleft care in the UK was fragmented, and the few studies we could find showed poor growth outcomes compared with the best Scandinavian centres. The Craniofacial Society of Great Britain and Ireland agreed that an urgent review of the structure and organisation of the service, and of training, was needed. In 1998, only 7 surgeons in the UK repaired 5 or more UCLP/year, but there were 57 centres and 78 surgeons for 1000 cases/year. As a result, the government instigated a national review through the Clinical Standards Advisory Group (CSAG) under Professor John Murray.

Clinical Standards Advisory Group

A national survey in the CSAG and Health Service Circular (HSC) 1998/238 report[5] showed that in some areas, decentralised services could not provide the full spectrum of clinical care. Until then, less than 10% of cleft surgeons in the UK dealt with 5 or more cases/year, most of them did not know the quality of their outcomes, and many overestimated the numbers and rates of success (the original figure given by surgeons overestimated the case load by 100%). Therefore, the CSAG recommended that surgeons should operate on about 40-50 new patients each year, and the Government accepted it. Although the standard of primary operation is crucial to the quality of the outcome, the decision to centralise treatment was made partly to enable statistical analysis and was not specialty-based.

The Government, through the Cleft Implementation Group chaired by Ms June Crown, rationalised care into “hub and spoke” regional centres where cleft teams following formal service specifications could deal with large caseloads. By this time, members of the cleft fraternity knew that the Veau-Wardill-Kilner palate repair resulted in significantly worse maxillary growth than the von Langenbeck technique used in the Oslo Protocol,[6] and after the review the latter became the workhorse until “flapless” repair, first reported by Reid and Watson was popularised,[7] together with radical intravelar veloplasty by Sommerlad.[8]

The key recommendations were that surgeons should operate on at least 40 new cases each year, and that cleft units should provide a full range of services. Subsequently, interface training programmes for surgeons were established. These changes have shaped contemporary cleft care in the UK.

Contemporary management of cleft lip and palate in the UK

Cleft services now operate through managed clinical networks led by a clinical director with a supporting coordinator or manager, and each regional centre treats a minimum of 80 – 100 babies/year. Multidisciplinary teams with a wide range of specialties treat patients as they grow and develop to the age of at least 20 years, and adults of any age.

Surgeons must have completed designated Training Interface Group courses or their equivalent, and have a proven commitment to the care of patients with clefts. They must also have the ability to work in a team, and maintain good outcomes. Units must audit outcomes and provide an annual report to the commissioners. The main units have strong links with services in the local community, to which they provide advice, education, and support. The changes were overseen by the Cleft Implementation Group, under the umbrella of the Craniofacial Society of Great Britain and Ireland. Contemporary care pathways and centres of care in the UK are shown in Table 1.

Treatment is now safe and of a high quality, and it follows evidence-based practice in line with national policy and guidance. It offers effective, timely, clinical interventions in an appropriate setting, and ensures that the experience for the patient and their family is as good as possible. Care is personal and sensitive to the physical, psychological, intellectual, and developmental needs of the patients and their families or carers, and enables appropriate transition to adulthood.

The service aims to ensure good functional and aesthetic results in all patients who have repair of a cleft lip. In those who have repair of a cleft palate, it aims to achieve good palatal function, normal speech and hearing, and optimal dentofacial development including growth of the jaw. All patients should be able to achieve their full potential without hindrance from a cleft.

The Cleft Care UK (CCUK) study, also known as CSAG 2, was conducted to ascertain the impact of the CSAG recommendations on the standard of care in the UK. It collected data from 86 “hub and spoke” clinics over a 2-year period (January 2011 to December 2012), and preliminary results showed that in 2014, 21 surgeons in 11 centres were treating patients with clefts, and 17 surgeons had each operated on over 40 primary cases/year over the study period. Those who had operated on