

Advances in cleft care over the last 40 years

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Section: **Cleft lip and palate**

Arguably, the greatest advances in the care of patients with cleft lip and palate in the last 40 years have not been improvements in technique or protocols but a greater emphasis on outcome measures, audit and inter-centre comparisons and honest reporting of outcomes. This has been largely responsible for moves in many countries to rationalise and centralise cleft services. Internationally, there has been ongoing development of inter-disciplinary care, moving away from the long-standing tradition that ‘the surgeon is the boss’. Long-term sustainable improvement in cleft care in low-resource countries remains a huge challenge.

Advances in technique

Perhaps the biggest advance in surgical technique in the last 40 years has been the emphasis on muscle reconstruction and function in both lip and palate repair. The use of magnification (and potentially the use of the microscope in palate repair) has led to a better understanding of anatomy and function and greater precision in repair. Techniques have come and gone, often taking many years to be discredited as long-term outcomes become clear. Two randomised controlled trials of two different techniques of presurgical orthopaedics have failed to show long-term benefit. It is too early to assess the long-term benefit of interventions such as nasoalveolar moulding. Arguably, delayed hard palate repair is one such protocol where the evidence suggests that speech outcomes are compromised and that benefits in maxillary growth are unconfirmed.

Outcome measures

Forty years ago, it was acceptable at international meetings for a surgeon to show his or her best results or to simply state ‘my pharyngoplasty rate is...’. A landmark study which began to change this was a paper by the late Harold McComb,¹ reporting his outcomes of primary nasal correction. He waited 10 years before reporting the outcomes and then showed a consecutive series of his first ten patients.

Objective measurement of outcome is difficult in clefts but the use of cropped photographs scored by an independent panel to measure aesthetic outcomes, the GOSLON measure of dental occlusion and international parameters of speech, have all been important developments. More recently, the patient has been given a higher priority with PROMS (patient reported outcome measures), recognising that in the end it is the patient’s view and outcome that matters.

Audit and inter-centre comparison

The EUROCLEFT Study,² first reporting in 1996 and comparing GOSLON dental occlusion scores in six European centres assessed independently, was the first significant inter-centre study. This was followed about 20 years later by AMERICLEFT and similar studies in India and elsewhere. Multi-centre randomised controlled trials have followed, comparing techniques and protocols. The results of the SCANCLEFT trial, comparing four protocols, are being evaluated. The major finding from these studies has been that results are better where few surgeons operate, radical early interventions are minimised and surgical expertise may be more important than technique or protocol.

Another international RCT, the TOPS (the timing of palate surgery—six months vs 12 months) trial has currently been recruited, awaiting outcomes. There are ethical and financial challenges in such major international prospective randomised studies and they may not be the best way forward in the future.

Rationalisation and centralisation

Norway was perhaps the international pioneer in rationalising cleft centres, with centres in Oslo and

Bergen and government initiatives to transport patients large distances to one of these centres. In the United Kingdom, prompted by the EUROCLEFT study, a government clinical standards advisory group in cleft care recommended a reduction in cleft studies from the then 57 to nine centres in England and Wales. Then, uniquely in CSAG studies, an implementation group was commissioned to make this happen. The result has been better cooperation between specialists and teams (who are no longer competing for patients), mandatory multidisciplinary teams, development of regular inter-centre audit and comparison and some evidence of better outcomes.

Such exercises in rationalisation and centralisation are easier in countries with a well-developed government health service (such as the NHS in the UK) but are beginning to happen in other countries such as Sweden and the Netherlands. Inherent in centralisation is that individual surgeons should have an adequate caseload. The UK recommendations were that primary surgeons should be operating on 40 to 50 new babies each year. Many would argue that this is too few, in that even larger numbers are desirable if the surgeon is to find out significant outcomes.

Interdisciplinary teams

Forty years ago, when the author began independent practice as a cleft surgeon, the usual practice was for the surgeon to review the patient and refer as he saw fit to an orthodontist or speech therapist/pathologist. The surgeon was ‘the boss’. This has gradually changed, with the development of genuine inter-disciplinary (suggesting cooperation) rather than multi-disciplinary (suggesting simply co-existence) teams. This process has been accelerated by the development of national cleft lip and palate societies, in which each specialty plays an equal part. In the Indian Society of Cleft Lip, Palate and Craniofacial Anomalies the first three presidents were surgeons but, like other societies, this has moved to a rotating chairmanship. The patient should therefore be assessed and discussed by all members of the team. The psychologist has become a vital member of these teams, ensuring that the patient’s voice is heard.

Cleft care in low-resource countries

There is a long tradition of Western surgeons and teams travelling for short visits to less developed countries to treat and operate on patients. Interplast Australia has been a good example, in that in many places it has helped develop local services. However, in many instances, these ‘parachute missions’ are actually counter-productive in appearing paternalistic, in devaluing local surgeons and services, in not training and in not leaving anything behind (except, often, disasters).

Another model has been that of paying local surgeons to perform operations. This model emphasises primary surgery in babies, is concentrated in private hospitals where trainees are not involved, and has provided only the most rudimentary form of outcome measures.

In the long term, the solution has to be in training, supporting and helping to encourage local surgeons and specialists to develop appropriate and sustainable cleft and craniofacial centres. Western clinicians have a role to play in mentoring, twinning (if appropriate) and supporting these developing teams.

The great majority of cleft patients are born in these low-resource countries and they deserve the same opportunities that patients in more developed countries now enjoy.

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