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The history of cleft services in New Zealand

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Abstract

Background: Approximately 100 children are currently born in New Zealand (NZ) each year with an orofacial cleft (OFC). OFC are a heterogeneous group of embryologic developmental structural defects of the facial processes which can occur as either unilateral or bilateral and involve combinations of the lip, alveolus, hard or soft palate. Children born with an OFC often experience complications with feeding, hearing, appearance, dental anomalies, malocclusions, speech and at times, psychological issues. Many require numerous surgical and non-surgical treatments from infancy to adulthood. This treatment can be complex and in NZ this is provided by various health professionals working in five interdisciplinary cleft services, although the locations and structure of these cleft teams have evolved and changed over time.

Objectives: This article examines the history of cleft services in NZ, the role of the multidisciplinary team (MDT) which contribute to current cleft care and provide some insight into the current pathway of treatment and the dispersed nature of its delivery.

Conclusions: Present-day cleft surgical services in NZ have evolved essentially from the expertise and experiences gained by NZ surgeons based in the UK during and following both World Wars. The development of interdisciplinary cleft teams has become integral to the staging of both surgical and non-surgical treatments which can extend from birth to early adulthood. The burden of care undertaken can be extensive and parent support services have also evolved to aid the families understanding of cleft treatment. The way the cleft centres have evolved and the low population density in NZ has resulted in lower case numbers by surgeons than international best practice recommendations.

Introduction

In the current era, approximately 100 children are born in New Zealand (NZ) each year with an orofacial cleft (OFC) with an incidence of approximately 1.79 per 1000 live births (Thompson *et al.*, 2016). This is higher than the average across western countries (1.52 per 1000 live births) and in part reflects a higher incidence of cleft palate (CP) among NZ Māori which is twice that of Non-Māori (1.54 vs 0.74 per 1000 live births) (Thompson *et al.* 2016) and three-fold that of the average incidence of CP (0.5 per 1000 births) reported by the World Health Organisation (Mossey and Castilla 2003).

OFCs are a heterogeneous group of embryologic developmental structural defects of the facial processes

which occurs between 6-8 weeks of intrauterine life and have a considerable range of location and severity. OFCs may involve the lip, alveolus, hard and/or soft palate and be either unilateral or bilateral and be described as either incomplete or complete. Although some OFCs can be associated with craniofacial syndromes, more so if the cleft involves the cleft palate only (Mossey and Castilla 2003), most occur sporadically and are termed non-syndromic OFC. The precise nature of the developmental disturbances and the roles of environmental and genetic factors which lead to non-syndromic OFCs are largely unknown.

Children born with an OFC often experience complications with feeding, hearing, appearance, dental anomalies, malocclusions, speech and at times, psychological issues and require numerous surgical and non-surgical treatments from infancy to adulthood. This treatment can be complex and involve different health professionals working in dedicated multidisciplinary cleft teams and is undertaken to restore form and function minimising any effect on future facial growth. This is currently provided by specialist clinicians working within five multidisciplinary publicly funded cleft teams in NZ (Sanders *et al.*, 2011).

The five units providing cleft care are located at Middlemore Hospital (Auckland), Waikato Hospital (Hamilton), Hutt Hospital (Wellington), Christchurch Hospital and Dunedin Hospital, although the locations and structure of these cleft teams have evolved and changed over time. This article examines the history of cleft services in NZ and the role of the cleft MDT that contribute to the current cleft care pathways. It also provides an insight into the emergence of a health care model that has become disintegrated and is at odds with international best practices.

Pioneering surgical services

Historically prior to plastic surgery developing into a separate speciality, surgeons who became involved in cleft care usually originated from those who had previous surgical training in otolaryngology or oral and maxillofacial surgery (Morrison 2018).

The specialisation of cleft surgical care and the development of plastic surgery evolved largely from the expertise and experiences gained by Sir Harold Gillies (Figure 1) and Professor Henry Pickerill (Figure 2), two prominent NZ surgeons operating in the United Kingdom (UK) during World War I (WWI). This was further enhanced by other prominent NZ plastic surgeons during and following World War II (WWII) (Brown and Klaassen 2018).

Gillies, who was Dunedin born and who undertook medical training in the UK, was an ear nose and throat



Figure 1. Sir Harold Delf Gillies. Permission for use granted by the National Portrait Gallery, London

Figure 2. Henry Percy Pickerill. S P Andrew Ltd: Portrait negatives. Ref: 1/1-018390-F. Cropped. Permission for use granted by the Alexander Turnbull Library, Wellington, New Zealand.

surgeon at the time WWI was declared. He has been described as the “father of the speciality of plastic surgery” and was instrumental in establishing dedicated hospital clinics to provide surgical care of facial and jaw wounds inflicted during WWI (Bamji 2006). In the earlier stages of the war in France Gillies worked with Major Sir Auguste Charles Valadier, a French-American dentist. Valadier undertook many aspects of head and facial reconstructive surgery and developed bone graft techniques to replace shattered or lost bones of the face and jaws (Brown and Klaassen 2018). Following Gillies’ return to England in 1916 he was instrumental to the establishment of a maxillofacial centre in Aldershot. When The Queens Hospital at Sidcup was established in 1917 Gillies was appointed the lead surgeon. Sidcup has been described as “the birthplace of modern plastic surgery” and allowed Gillies and others to develop innovative techniques which included facial reconstruction (Tong *et al.*, 2008). Gillies was responsible for training several prominent NZ Plastic Surgeons who subsequently went on to become influential leaders in their field. Many of the skills and techniques developed during this period were also applicable to cleft reconstruction surgery.

Pickerill, a dental and medically trained surgeon originally from Birmingham, UK, was the Director of the University of Otago Dental School and Hospital when WWI was declared. Although Pickerill has been described as a “pioneer in plastic surgery”, he did not undertake any formal postgraduate qualifications in surgery (Brown 2007). Despite this, prior to the WWI, he had already gained international recognition for his expertise in cleft palate surgery with an award in Vienna in 1912. In 1914 he published a manuscript detailing cleft palate anatomy, physiology and surgical repair (Pickerill 1914). In 1917 Pickerill travelled to the UK and after working initially at the First NZ General Hospital in Brockenhurst and at the Second NZ General Hospital at Walton-on Thames, joined The Queens Hospital at

Sidcup as the Officer in Command of the NZ Facial and Jaw Section, while Gillies was the Officer in Command of the British Section.

Both Gillies and Pickerill, along with other surgeons from the UK, Canada and Australia undertook numerous pioneering surgical operations on injured service personal. Considerable skills and expertise gained during this time would be transferred to many aspects of today’s cleft surgical techniques.

Following WWI Pickerill returned to Otago Dental School in Dunedin until 1927 when he moved to Sydney to establish the first independent Australasian plastic surgery practice and was instrumental in helping to establish the Plastic Surgery Section of the Royal Australasian College of Surgeons. He later returned to NZ to become the senior surgeon at Wellington Hospital and helped establish a Plastic Surgery Unit at Middlemore Hospital. He also specialised in the surgical repair of children with clefts at Bassam Hospital, a private hospital in Lower Hutt (Brown 2007).

When WWII commenced Gillies provided further guidance and training to several NZ plastic surgeons including Archibald McIndoe, Rainsford Mowlem, Frank Hutter and Sir William Manchester who all gained considerable surgical expertise while in the UK. McIndoe gained an international reputation with his rehabilitation of injured aircrew at East Grinstead Hospital and the famous “Guinea Pig Club” was established (Tong *et al.*, 2008). This club was so called by the patients in acknowledgement of the experimental procedures of pioneering surgery they had received.

Establishing cleft surgical services in NZ

In 1939 Pickerill along with his surgeon wife, Cecily (nee Clarkson) established Bassam Hospital in Lower Hutt as the first private hospital dedicated to children’s plastic surgery services. Most of the cleft operations in New Zealand were performed at Bassam Hospital at that time. They introduced the “revolutionary system of children being nursed by their mothers” to limit the spread of infections between in-patients by staff. During this time, they also helped establish the Plastic Surgery Unit at Middlemore Hospital. Pickerill retired in 1945 while Cecily, who was awarded a Damehood in 1977 for services to medicine especially plastic surgery, continued until her retirement in 1967 (Harris 2014).

Sir William Manchester, who also trained with McIndoe at East Grinstead Hospital and Mowlem at the Plastic Surgery and Jaw Unit at St Albans Hospital, returned to Christchurch in 1946. There he established the first dedicated civilian plastic surgical unit within the NZ Public Hospital Service at Burwood Hospital (Brown and Klaassen 2018). This unit also included a dental department which enabled a close integration of plastic, oral and maxillofacial surgical teams. In 1953, David Poswillo, an Otago Dental School graduate who undertook oral surgery training in the UK including East Grinstead, was appointed Senior Oral Surgeon and co-director of the Cleft Clinic until 1969. During his time in Christchurch, he also undertook experiments on the pathogenesis of cleft and other craniofacial

anomalies which led to his appointment as Hunterian Professor and Chair of Teratology in the Royal College of Surgeons England (Morrison 2018). The Christchurch based unit serviced the entire South Island prior to the establishment of the Dunedin cleft unit in the 1990s and an outreach clinic established by the Hutt cleft team in Nelson. In 1998 the Christchurch cleft team was relocated from Burwood Hospital to the Christchurch Hospital. The team has recently added a second cleft plastic surgeon and sees approximately 16 newborns with clefts per year.

Plastic surgeon, Frank Hutter, who also gained experience and training of reconstructive plastic surgery techniques in the UK during WWII, returned to NZ in 1947. He was instrumental in establishing the Wellington Regional Plastic, Maxillofacial and Burns Unit initially at Wellington Hospital. In 1952 this was relocated to Hutt Hospital with close linkage to the dental department which was formalised in 1971 when special cleft clinics were established with appointments of oral surgeons and orthodontists to the team (Mackenzie 1983). The Hutt cleft team services the lower North Island and has outreach clinics in Nelson, Palmerston North and Hastings. The team currently has two cleft plastic surgeons and sees approximately 20 newborns with clefts per year.

In 1950 a plastic surgical unit became known as the Regional Centre for Plastic, Reconstructive, Maxillofacial and Hand Surgery unit at Middlemore Hospital, Auckland. Manchester was appointed the lead surgeon and the unit included members from the dental department (Peat 2002). Manchester and his team became very influential in cleft care internationally, particularly with the development of the Manchester Technique for the surgical repair of bilateral cleft lip and palate (Manchester 1965). This team serviced a large area including the upper North Island until the Waikato Cleft team was established in the late 1970s. It still services the most populous region of the country caring for approximately 40 newborns with clefts per year and until recently had four cleft plastic surgeons before reducing this to two surgeons.

The plastic Surgery unit at Waikato Hospital in Hamilton had two plastic surgeons, Pat Beehan and Keith Wilson with close ties to the dental department (Armstrong 2009). This team serviced children with clefts from Hamilton and the regions of the mid-North Island, including New Plymouth and Gisborne. Currently, the team has one cleft surgeon and sees approximately 20 newborns with clefts per year, with an additional surgeon providing occasional surgical care.

In the mid-1990s the last cleft unit to be established in NZ was based at Dunedin Hospital. The Dunedin team includes the dental services at the University of Otago's Dental School and cleft surgery is undertaken by an otolaryngology (ENT) surgeon. It currently sees approximately 3 newborns with clefts per year.

Development of multidisciplinary cleft teams and support services in NZ

As the cleft centres became established it was not uncommon for the cleft surgeon to call upon the services of other specialities when required. This gradually changed with the development of cleft MDTs where coordinated, staged surgical and non-surgical interventions were planned (Sommerlad 2018). There was always a strong link between dental and surgical services in NZ, but this became more formalised with dedicated cleft clinics which included speech language therapists, orthodontists, paediatric dentists, oral and maxillofacial surgeons, and cleft coordinators (Peat 2002). Several of the cleft MDTs also include or provide access to otolaryngologists (ENT), infant feeding consultants, restorative dentists, genetic and psychological specialists.

There can be an extensive burden of care for the children with a cleft and their families particularly around the initial diagnosis and the various interventions. The NZ Cleft Support Group was established to provide resources, information, and support for the families of children with a cleft as they progress their treatment journey (Cleft Support Group 2006)

The cleft care pathway in NZ

In NZ there is a relatively common care pathway from prenatal diagnosis to early adulthood, although some regional variation exists in team composition and services provided. The overarching aims of treatment and support are to restore as near normal function, development, and facial aesthetics as possible. The most common treatments and interventions are listed in Table 1 and these are provided within an MDT setting.

There is a high antenatal detection rate of children with a cleft that involves the lip by transabdominal ultrasound screenings at 18-20-week although the detection rates vary in relation to other cleft types and the skill of the operator (Mitchell and Stone 2005). Feeding of a newborn with OFC can be particularly challenging and an early feeding assessment with an appropriate plan of care is often required by the specialist cleft nurse or lactation consultant (Bessell *et al.*, 2011). Although the severity of the OFC determines the types of interventions undertaken those who have a cleft which involves the lip will usually undergo primary surgical repair around 3-5 months of age while the cleft palate is then repaired around 9-12 months of age, with the exception of those children with Pierre-Robin sequence who generally have a later repair due to airway management concerns. Some centres undertake presurgical lip strapping and/or maxillary orthopaedic appliances in exceptionally wide clefts or those with bilateral cleft lip and palate with deviated pre-maxilla (Peat 1982).

Most children with a cleft involving the palate are at risk of developing conductive hearing loss due to otitis media with effusion (OME) and often ventilation tubes (grommets) and/or the use of antibiotics are required (Flynn *et al.*, 2013). Deficiencies in speech often include a range of speech sound errors, hypernasality, nasal emission and nasal turbulence and there can also be



Table 1. Cleft care pathway in NZ (Abridged from CLAPA)

Stage	Age	Intervention			Team members		
Diagnosis and birth	Prenatal to 3 months	Contact from cleft coordinator Feeding advice and counselling. Presurgical orthopaedic appliances + lip strapping if cleft wide or displaced premaxilla			Sonographer, Fetal medicine, Cleft coordinator, Speech language therapist, Lactation consultant Orthodontist		
1st Year	3-5 months	Primary lip repair	Ongoing dental prevention and care provided by paediatric dentists and supported by community dentists/ oral health therapists	Ongoing MDT Clinics	Cleft surgeon		
	9-12 months	Primary palate repair and possible grommet placement			Otolaryngologist		
Early years	1-4 years	Formal speech and language assessments					Speech language therapist
		Audiology assessments					Audiologist / Otolaryngologist
School years	5-12 years	Possible revision surgery					Cleft surgeon
	8-12 years	Alveolar bone grafting +/- orthodontic arch pre surgical preparation					Secondary cleft surgeon +/- Orthodontist
Teenage years	13-18 years	Orthodontics			Orthodontist		
Early adulthood	+18 years	Orthognathic surgery (if required)			Cleft / Maxillofacial surgeon + Orthodontist		
		Rhinoplasty +/- lip revision			Cleft surgeon		
		Definitive restorative dentistry			Restorative dentist		

delayed speech development. Speech assessments and therapy are usually carried out from three years of age when the child has developed sufficient language and maturity to co-operate and can often continue throughout childhood (Kummer 2011). Initial deformities following the primary surgical repair may require secondary surgery before the child starts school.

Children with an orofacial cleft in NZ often experience an increased risk of dental caries (Fowler *et al.*, 2020) and poorer oral-health related quality of life (Fowler *et al.*, 2021). Close monitoring of dental development and provision for preventative measures should ideally be undertaken by paediatric dentists supported by community dentists and oral health therapists (Vassen 1999). Due to restricted development of the maxillary dental arch, orthodontic treatment is often required to correct developing malocclusions although this may be delayed until the adult dentition is established or prior to undertaking alveolar bone grafting. Bone grafting of the alveolar cleft is often carried out around the age of 8-10 years old to coincide with the pre-eruption stage of the maxillary permanent canine (Revington *et al.* 2010). Often alveolar bone grafting is preceded by a course of orthodontic treatment to align and expand the collapsed maxillary dental arch form, creating space for surgical access to the cleft site. If unerupted supernumerary or malformed teeth are lying in the line of the cleft, these are often surgically removed before or at the time of the bone graft. If spaces associated with missing teeth are not closed as part of the orthodontic treatment, then the placement of prosthetic replacements is required. Initially, this may involve removal or fixed (acid-etched)

protheses with possible implant placement once facial growth has ceased, assuming there is sufficient bone (Semb and Ramstad 1999).

Due to deficiencies in maxillary growth in anterior-posterior, lateral and vertical dimensions orthognathic surgery is often required where the mandible and maxilla positions are too displaced to allow adequate dental function or due to facial aesthetics (Jack *et al.*, 2011). This treatment is carried out once facial growth has ceased and is preceded by orthodontics to decompensate and align the dental arches. If the skeletal discrepancy between the maxilla and mandible is particularly large, the orthognathic surgery with distraction osteogenesis may be used as opposed to conventional surgical techniques (Meazzini *et al.*, 2018). Rhinoplasty and final lip revision are usually undertaken once any orthognathic surgery and/or orthodontic treatment has been completed and facial growth has ceased.

One of the key elements of cleft care includes the evaluation of treatment outcomes and making improvements. The NZ Cleft audit was initiated in 2010 following concerns raised by orthodontists involved in cleft care relating to poor dental arch and alveolar bone graft outcomes (Fowler 2006). This was the first national cleft audit undertaken and confirmed poor dental arch and alveolar bone graft outcomes as well as established the surgical burden of care for patients up to age 5 years (Fowler 2010, Sanders *et al.*, 2011). This has developed into a series of outcome investigations which have been reported elsewhere and is ongoing (Thompson *et al.*, 2019, Fowler *et al.*, 2020, Fowler *et al.*, 2021).

The outcomes reported to date are generally poor and were discussed at a Ministry of Health workshop which was held in 2020 for key clinicians and administrators. The workshop reviewed the current cleft service, regional inconsistencies, and inequalities of care. The meeting concluded that outcomes of cleft lip and palate services in NZ requires considerable improvement, but any changes will be considered after further extensive consultation.

International comparisons

The evolution of the cleft surgical services at the different locations in NZ, like many other countries including the UK, was not directed by any overarching cleft service plan, but rather appear to have occurred in part to the availability of individual surgical expertise and interest in cleft and the availability of local newborn with cleft. A recent review of the New Zealand plastic and reconstructive surgery workforce has highlighted the lack of central government planning and decentralised DHB control of local services (Peacock *et al.*, 2020). This has resulted in a dispersed service where, due to the relatively low population density and hence low caseloads, no surgeon operating in New Zealand comes close to currently meeting the internationally recommended minimum case number threshold (Shaw *et al.*, 2001).

There have been several key studies undertaken in the UK, Europe and the USA involving multicentre comparisons of cleft care pathways and treatment outcomes (Shaw *et al.*, 1992, Bearn *et al.*, 2001, Russell *et al.*, 2011). These studies have concluded those centres with fewer surgeons and higher patient volumes, limited interventions and standardised treatment protocols have more favourable outcomes. This has been highlighted following the centralisation of cleft services in the UK where the number of centres was reduced from 56 to 11 (with 16 operating sites) and where each cleft surgeon provides care for at least 35 newborns per year (Ness *et al.*, 2015). This was the minimum caseload recommended by the Eurocleft study to achieve improved surgical outcomes (Shaw *et al.*, 2001).

Future directions

The NZ government recently announced the abolishment of 20 district health boards in favour of a single national body (Health New Zealand) following the commissioning of a system-wide review. One of the key drivers of this decision was variability in care pathways caused in part by the fragmented planning within the health system. These reforms are expected to take 3 years to complete and would align more closely with the UK's National Health Service. This could provide for the restructuring of the cleft services to enable the centralisation of surgical services to meet recommended international case loading standards. For those patients who would face travel burdens due to distance from the more centralised units, a hub and spoke delivery of care has proved to be effective in the UK. This is where surgical services and treatment planning are provided at the hub and further auxiliary services are provided at closer spoke centres for more remote based patients.

Conclusion

Present-day cleft services in NZ have evolved essentially from the expertise and experiences gained by NZ surgeons based in the UK during and following both World Wars. Some of these individuals were world leaders and helped to pioneer many of the present-day techniques and protocols. The development of interdisciplinary cleft teams has become integral to the staging of both surgical and non-surgical treatments that can extend from birth to early adulthood. The burden of care undertaken can be extensive and parent support services have also evolved to aid the families understanding of cleft treatment. The way the cleft centres have evolved and the low population density in NZ has resulted in lower case numbers by surgeons than recommended by current-day best practice standards and the dispersed nature of the surgical units is at odds with the establishment of centralised cleft services seen elsewhere.

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