

# A retrospective audit of population service access trends for cleft lip and cleft palate patients

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Population prevalence of orofacial clefts (OFCs) is well documented but the service utilisation patterns of these patients have received limited consideration. **Objective:** To analyse 10-year trends in the utilisation of subsidised OFC related services in Australia. **Design:** Retrospective audit of service utilisation and claims datasets. **Methods:** Using state-wide hospital admission data, all persons treated for Cleft Palate Only (CPO) and Cleft Lip Only (CLO) as their primary diagnosis from 1999 to 2009 in Western Australia were included in the data frameset. Additionally, National Medicare out-of-hospital claims from 2003 to 2013 were added to the data frameset. The socio-economic status and accessibility to services were analysed as effectors of service-mix such as age group, gender and geographic location. **Results:** Of 721 in-hospital care episodes in Western Australia, 69% had CPO and 31% CLO as their principal diagnosis. Hospitalisations occurred from 0-69 years of age, but three quarters of all episodes occurred from 0-4 years of age (averaging one to two episodes per child). Whilst total hospitalisations were about four times higher for patients resident in high access areas, adjustment for population found the poorest 20% of the population having substantially lower hospital admission rates than the rest of the population. In Australia, claims for out-of-hospital cleft-related services varied between States. The overall pattern of out-of-hospital Medicare claims nationwide showed orthodontic services having the highest number of claims, followed by prosthodontic then oral surgical services. **Conclusion:** These data provide a picture of diverse service utilisation and leads to some interesting conclusions about geographic and economic access as well as cost-shifts between State and Commonwealth.

**Key words:** cleft; lip; palate; survivor; population; trends; services; Australia

## Introduction

Orofacial clefts (OFCs) constitute one of the most common congenital anomalies in humans affecting about 1 in 1,500 people worldwide (Bell *et al.* 2013; Carlson *et al.* 2013; Christensen *et al.*, 2004). Sufferers' quality of life is generally negatively affected (Klassen *et al.*, 2012) by the functional and social impacts of the facial defects and they (or families or state) are burdened with high costs associated with the multidisciplinary management of their condition (Berk and Marazita, 2002). Significant advances have been made world-wide in OFC research including etiological studies involving genetic and environmental factors, associations with other disorders, management of clefts, their complications and their epidemiology (Bianchi *et al.*, 2000; Romitti *et al.*, 1999; Wong, 1988). Many organisations undertake research in the area including the International Clearing House for Birth Defects Surveillance and Research (ICH-BDSR) which undertook the International Collaborative Research on Craniofacial anomalies project in 2000 funded by the WHO. Communities, Non-Governmental organizations and countries have also set up programmes aimed at alleviating the psychosocial, socioeconomic and financial burdens borne by OFCs sufferers and their families. Examples of such programs in Australia include CleftPALS, Operation Clefts and the Medicare Cleft Lip and Cleft Palate Benefits Scheme.

Prevalence studies on OFCs have commonly used birth

registries as their main source of data. Studies of people living with OFCs are few and have usually been restricted to case studies and hospital-based series (Klassen *et al.*, 2012). There is thus the need for population level analyses of health service utilisation by affected people. Using hospitalization data from the Western Australia Department of Health and claims data from the Medicare Cleft Lip and Cleft Palate Benefits Scheme, this study details trends in in-hospital service demands for cleft lip and palate services in Western Australia and out-of-hospital Medicare claim trends in Australia as a whole. The aim of the study was to identify opportunities to enhance services for cleft lip and palate patients.

## Methods and Materials

The Western Australia Department of Health, as custodians of the in-hospital data, gave their ethical approval for its use. The data frameset included all hospital inpatient events coded in Q35 and Q36 classes of the International Classification of Diseases and related health problems 10<sup>th</sup> revision (ICD-10) from 1<sup>st</sup> July 1999 to 30<sup>th</sup> June 2009. All patients with OFC were identified using the ICD-10-CM diagnosis codes for Cleft Palate Only (CPO) (Q35.1, Q35.3, Q35.5, Q35.7 and Q35.9), and; Cleft Lip Only (CLO) (Q36.0, Q36.1 and Q36.9). The data were not available for patients who suffered cleft lip and palate

(CLP – Q37.0 to Q37.9). All hospitalisation (in-patient events) were included in the study complete with any primary closures. Basic demographic data (gender, age at diagnosis, and Aboriginal status i.e. Aboriginal and Torres Strait Islanders) were collected from the database. Based on residential location, the five-category Accessibility/Remoteness Index for Australia (ARIA) was used to code access to service centres by road (DHAC, 2001; AIHW, 2004). This index is independent of socio-economic status and is stable over time. Socio-economic status was coded using Socio-Economic Indexes for Areas (SEIFA), Australia 2011 based on the census of population and housing (ABS, 2013).

The second part of the study made use of all Australia out-of-hospital treatment cost reimbursement claims data from the Medicare Benefits Scheme (MBS) for the cleft lip and cleft palate scheme from 1<sup>st</sup> January 2003 to 31<sup>st</sup> December 2013. This dataset is accessible online at <http://www.medicareaustralia.gov.au> published and updated regularly by the Australian government under Medicare Australia Statistics through the Department of Human Services. The choice of the period for analysis of claims data was made to approximately coincide with the period between the initial diagnosis of clefts from the Western Australian data, and the laying of first claims which was assumed to take from three to five years. Items of service were identified under three major groups using the MBS classification of services as follows: i, Orthodontic services claims, C<sub>1</sub>(75004-75051); ii, Oral Surgical services claims, C<sub>2</sub>(75150-75621); and, iii, General and Prosthodontic services, C<sub>3</sub>(75800-75854).

Service claims for WA and Australia were analysed by gender, type of service, year of claim, and age of claimant. The general distribution of services by state/territory was also examined. Results are presented for CPO and CLO in Western Australia, and service use in Western Australia and Australia as a whole. Annual rates of hospitalisation were calculated by SEIFA and ARIA, for both the total population, as well as the population under the age of four years. Confidence intervals were determined for each rate, with significance set at the 95% level. All analyses used SPSS v.19 or Excel 2010.

## Results

Between 1999 and 2009, 721 episodes of WA in-hospital care were isolated from the database: 498 (69%) had CPO and 223 (31%) had CLO as their principal diagnosis. Most episodes for both types of clefts occurred between the ages of 0-4 years: 77% CPO (n=384), 70% CLO (n=157). Of the episodes for 5-20 year-olds, 18% (n=90) were for CPO, 23% (n=53) for CLO. The remainder were for ages up to 69 years: CPO (5%, n=24), CLO (6%, n=14). About 60% (n=134) of the CLO hospitalisations were for males, while about 55% (n=273) of the CPO hospitalisations were for females. About 88% (n=197) of CLOs were unilateral, and 12% (n=26) were bilateral while none were midline (Table 1). Although, Aboriginal and Torres Strait Islanders were hospitalised for bilateral labial clefts (29%, n=4) more than non-Aboriginal people (11%, n=22) the number of events were too low to make reasonable or valid assumptions from these data.

While there was no regular pattern from year to year in the occurrence of CPO and CLO hospitalisation in WA, distribution by accessibility and remoteness found that 80% (n=658) were from highly and moderately accessible areas, while there were just 8% from those in remote to very remote areas (n=58) (Table 1). Adjusting for population size it was evident that the rate of hospitalisation was the highest for patients resident in highly accessible areas, and significantly lower in moderately accessible and very remote areas (p<0.05). The same outcome was also found in the population under age of four years (Table 1) In both total population and under-four populations, the hospitalisation rate was almost three times higher in the highly accessible areas, than the average. When adjusted for population size the rate of hospitalisation for the poorest 20% of the population was significantly (p<0.05) higher than the rest of the population (Table 2). When examining just hospitalisation for the 0-4 year olds (the greatest proportion of cases), a similar (approximately 9x higher rate of hospitalisation) was seen for the poorest 20% of the population (Table 2).

**Table 1.** The number of hospital admissions (identified by ICD codes) for residents of various levels of remoteness of living (ARIA) by Aboriginal and non-Aboriginal

<i>Levels of remoteness, (ARIA):</i>	<i>Highly Accessible</i>	<i>Moderately Accessible</i>	<i>Accessible</i>	<i>Remote</i>	<i>Very Remote</i>	<i>All levels</i>
Aboriginal	0	7	10	4	22	43
Non-Aboriginal	132	443	66	18	14	673
All hospitalisations	132	450	76	22	36	716
Percentage of all	18.4	62.8	10.6	3.1	5.0	100
Whole population	124,970	1,607,907	84,714	27,865	115,188	1,960,544
Population 0 to 4 years	8,046	99,152	5,779	2,082	10,002	125,061
Annual hospitalisation rate (95%CI)	10.6 (8.8-12.4)	2.8 (2.5-3.0) <sup>1</sup>	9.0 (7.1-10.8)	7.9 (4.9-10.9)	3.1 (2.5-3.8) <sup>1</sup>	3.7 (3.4-3.9)
Annual hospitalisation rate 0 to 4-year-olds (95%CI)	164.1 (136.0-191.9)	44.7 (41.2-49.5) <sup>1</sup>	114.2 (104.0-159.1)	105.7 (65.7-145.6)	36.0 (28.7-43.3) <sup>1</sup>	57.3 (53.0-61.4)

Key: Annual rates are per 100,000 population; <sup>1</sup>Hospitalisation rates were lower in moderately accessible and very remote areas compared to the others, for both the whole population and 0-4 year-olds (p<0.05)

**Table 2.** Number of hospital admissions (identified by ICD codes) for residents of various levels of socio-economic deprivation (SEIFA) by Aboriginal people and non-Aboriginal

Deprivation quintiles:	SEIFA 1 Poorest	SEIFA 2	SEIFA 3	SEIFA 4	SEIFA 5 Wealthiest	Overall
All Ages:						
Aboriginal	24	13	2	3	2	44
Non-Aboriginal	112	126	158	137	143	676
Total hospitalisations	136	139	160	140	145	720
Total population	33,700	149,540	747,300	524,580	505,440	1,960,540
Annual hospitalization rate (95%CI)	40.33 (33.60-47.13) <sup>1</sup>	9.29 (7.74-10.82)	2.14 (1.79-2.45)	2.67 (2.21-3.10)	2.86 (2.39-3.32)	3.67 (3.40-3.94)
0 to 4-year-olds:						
Aboriginal	23	13	2	3	1	42
Non-Aboriginal	85	82	126	107	98	498
Total hospitalisations	108	95	128	110	99	540
Total population	2,702	10,289	50,507	34,359	27,204	125,061
Annual hospitalization rate (95%CI)	399.7 (324.2-474.9) <sup>1</sup>	92.3 (73.6-110.7)	25.3 (20.1-28.5)	32.0 (25.9-37.9)	36.4 (28.6-42.7)	43.2 (39.6-46.8)

Annual rates are per 100,000 population; <sup>1</sup>Hospitalisation rates were significantly higher in SEIFA 1 areas (compared to the others) for both the whole and 0-4-year-old populations (p<0.05)

**Table 4.** Numbers of Medicare out-of-hospital claims by year for Australia as whole and Western Australia alone

Year	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2003-13
National												
Orthodontic services	4,646	4,718	4,558	5,068	4,873	4,945	4,891	6,185	6,110	5,799	5,537	57,330
Oral surgical services	460	540	457	465	436	463	473	689	677	808	685	6,153
General and prosthodontic	1,554	1,601	1,634	1,859	1,740	1,707	1,273	1,653	1,741	1,841	1,664	18,267
All above services	6,660	6,859	6,649	7,392	7,049	7,115	6,637	8,527	8,528	8,448	7,886	81,750
Western Australia (WA)												
Orthodontic services	168	66	71	56	36	38	23	32	32	16	12	550
Oral surgical services	5	5	12	0	2	3	9	148	109	132	82	507
General and prosthodontic	16	16	26	19	25	19	30	25	19	12	22	229
All above WA services	189	87	109	75	63	60	62	205	160	160	116	1286
WA as percent of National	2.8	1.3	1.6	1.0	0.9	0.8	0.9	2.4	1.9	1.9	1.5	1.6

Note: Western Australia, by population, is about 11% of the national total.

An analysis of the Medicare cleft lip and cleft palate related claims for Australia from 1<sup>st</sup> January 2003 to 31<sup>st</sup> December 2013 found that a total of 81,750 claims were made and WA contributed only 1.6% (n=1,286) of these claims (noting that WA is considered to be about 11% of the total population of Australia) (Table 3). There was a general pattern of claims across Australia by service type with orthodontic service claims constituting most of the claims 70.1% (n=57,330), followed by prosthodontic service claims 22.5% (n=18,268), and then oral surgical claims 7.5% (n=6,153). Most of the claims 87% (n=70,875) were made by claimants with ages ranging from 5-24 years. By gender, males generally made more claims than females, but the female population made more oral surgical claims than the male population.

In WA the general pattern of Medicare claims by service type differed from the national pattern (Table 4). Mostly they were for orthodontic services 43% (n=550), followed by oral surgical (39%, n=507) and then prosthodontic services (18%, n=229). There was a sustained rise in oral surgical claims from 2010 to 2013. The 5-24 year age group contributed 88% (n=1,137) of the claims. Similar to the national data, males were responsible for more claims, but females had more oral surgical claims (Table 4).

**Table 3.** Medicare out-of-hospital claims for each state of the Australian Commonwealth

State	Claims, n (%)	Pop <sup>1</sup>	Rate <sup>2</sup>
Victoria	32,866 (40.2)	5800	567
New South Wales	23,667 (29.0)	7400	320
South Australia	16,123 (19.7)	1700	948
Queensland	2,931 (3.6)	4700	62
Tasmania	2,534 (3.1)	510	497
Australian Capital Territory	1,692 (2.1)	380	445
Western Australia	1,286 (1.6)	2500	51
Northern Territory	651 (0.8)	240	271
All states	81,750 (100)	23,230	

<sup>1</sup>2010 population estimates in thousands;

<sup>2</sup>Rate is per 100,000 people

## Discussion

This study reveals that from 1999 to 2009, CPO and CLO patients from all age-groups, 0-69 years old, were hospitalised in WA for treatment related to their condition. Most hospitalisations occurred for patients aged 4 years old and younger with CPO (77%) and with CLO (70%).

This is not unexpected as early surgical intervention is dominated by a single state-wide cleft service unit at the WA's only dedicated children's hospital.

The rate of cleft-related hospitalisation in WA for 0-4 year olds was about 18 per 10,000. The reported prevalence range for Australia is 15-21 per 10,000 (Bell *et al.*, 2013). Therefore a single or maybe two hospitalisations between 0 and 4 years were the most likely experience. There was a marked difference in distribution of cleft hospitalisation by socioeconomic status. The poorest 20% (by residential address) had higher rates of hospitalisation than other SEIFA groups, calculated against either total population, or just 0-4 year olds when adjusted for population size.

Over 90% of those hospitalized were from moderate to high access (to service centres) areas of the State. Western Australia has a subsidy scheme to cover the costs of transport and accommodation for patients (and parents) of cleft-lip and palate sufferers. Thus the cost impacts of a geographically large state should not be a factor in this distribution. A possible explanation could be that parents of cleft patients move to the city very early to be closer to services. However, this would have to be a relatively rapid decision and the social and cultural implications could be substantial. Alternatively, and disturbingly, it may point to these (rural and remote) patients receiving sub-optimal care pathways due to the complexities associated with living long distances away from services.

Analysis of Medicare OFC-related claims in Australia, indicated that claims were not proportionate to population sizes of the states and territories. It is evident that different states are using the mix of Commonwealth and State-funded services in a consistent manner over time (albeit different in each state). No particular annual trend for claims was observed from 2003 to 2013 but generally, the orthodontic service group had the most claims, followed by the prosthodontic service group and then the oral surgical services group. This is possibly related to the technicalities involved in the use of these services for the management of clefts. While orthodontic services are required from childhood through adolescence to adulthood, prosthodontic services are more limited to rehabilitation, and oral surgical services often end with successful repair of the defects. Over 85% of all claims were made by claimants with ages ranging from 5-24 years of age. In WA, there was a sustained step rise in claims for oral surgical services from 2010-2013 making it the second-most claimed service group in the state. It is possible that a new specialised service centre might have been created in WA during this time, and could also be in response to changed eligibility for care between the State and Commonwealth systems. The pattern of claims by gender and age group in WA remained similar to that of all Australia.

This study provides population-based hospitalisation rates for OFCs and related trends in service use by cleft patients in Australia and Western Australia. Though both the hospitalisation and the Medicare benefits claims datasets were not primarily designed for research purposes, and the MBS dataset is not limited to claims for CPO and CLO, analysis from these data sources still provide valuable and valid information, depicting changes in service patterns both within a state, and also across the Commonwealth of Australia. The study clearly identified a series of interesting access anomalies (socio-economic and regional), changed

claiming practices through the Medicare system, as well as substantial trans-state differences. Clearly, further research is needed to identify the causes of these variations.

The research points to variations in service usage dependent on social factors (such as place of residence) as well as different service delivery mixes dependent on modes of delivery (Federal versus State systems). These issues are clearly issues that transcend borders and investigations of their status in other countries would be a valuable adjunct in understanding of the way services can be better arranged to support patients.

## Conclusion

The aim of the study was to identify opportunities to enhance service targeting for cleft lip and palate patients. The results clearly identify patients from relative poverty and those in remote Australia have less access service than others. In addition, the study finds that the mix of care accessed through State and Federal systems differs from State-to-State. Clearly, opportunity exists to reflect and refine systems to address these possible inequalities.

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