



Research Article

## Public Awareness of Cleft-Lip and Palate: An Australian Study

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### Abstract

This small Australian study was part of a larger study investigating factors surrounding the aetiology of Cleft Lip and Palate (CLP). In this study, we investigated the level of public awareness of this birth anomaly. It was proposed that if people are aware of a potential problem, they will seek measures to minimize the risk, but if they are unaware of potential risks the unintended outcome could prove quite traumatic. Further if a health problem received publicity, public awareness would be increased and more attention would be given to research in that area if the cause of the problem was not known. As the cause of facial birth anomalies has not been fully determined does it follow that there is potential to increase publicity thereby focussing more research into this field of endeavour?

The study was carried out in three of the Eastern States of Australia using an interview technique based on a simple questionnaire. The cohort included both sexes over the age of 18 years. The study showed that thirty percent of the Australian general public is unaware of clefting and more so amongst the younger age groups. The results were independent of place of residence, sex and education. The results present challenges for the medical profession and the Government to better promote healthy pregnancy preparation options.

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### Introduction

The incidence of Cleft Lip and/or Palate (CLP) in Australia is far higher (18.9/10,000 births) than that for Neural Tube Defects (NTDs) (6.2/10,000 births), and yet the Australian public awareness of a link between maternal folate deficiency and NTDs appears to be high [1]. The National Health and Medical Research Council (NHMRC) recommendation for folate supplementation in women planning pregnancy, to help prevent NTDs [2], and the promotion of folate supplementation by government agencies, health authorities and commercial suppliers of folic acid [3,4] contribute to this awareness. To date, the cause (s) of CLP remains unknown and the occurrence of it as a birth anomaly does not receive as much public attention as that for NTDs, despite its higher incidence. Because of Government policy [5] where each child born with a cleft receives immediate financial support, which continues to age 26, it is uncommon ever to see a child with such an anomaly. This could result in some of the public being unaware of the problem.

This reduced knowledge of clefting in the general public presents an ongoing challenge for the organisation called CleftPals [6], a group that tries to obtain funding to assist children born with a cleft palate, such as for speech therapy, and to support research in CLP.

The CleftPals organisation was established first in Victoria, Australia in 1972 by the parents of a child born with a cleft. The organisation successfully lobbied the Australian federal government to provide funding for CLP surgical procedures and extended dental care for children with CLP until the age of 26 years [2,7,8]. While CleftPals provides information about clefting, it is not clear where the public obtain general information on pregnancy health issues apart from their local physician, or how much of that information is understood or considered. A Finnish study [9] found that parents seeking advice on medications for their children primarily sought advice from physicians, followed to a lesser degree by nurses and pharmacists. Researchers in Northern Ireland [10] found that 97% of survey respondents used the Internet and search engines such as Google to find information about pregnancy. The researchers concluded that while the Internet provided information, it also had a significant impact on the decisions made by those accessing the web based sites. There are many websites where the general public may go for information on clefting but it is not always clear whether that information is supported by evidence or provided by experts in the field. Also, it is more likely that the information provided is sought by someone already affected by clefting rather than the general public. In this sense, the Internet may not be the best way to promote awareness of CLP unless it is clearly part of prenatal healthcare sites provided by health or government authorities.

Very little literature describing the general public's views or knowledge of clefting is available. However, reviews on the public understanding of other disabilities both physical and intellectual have been published [11,12]. Hall and Solehdin [11] investigated the relationship between folic acid deficiency and NTDs and found that

while public awareness in the USA had increased from 52% to 55% between the years 1995 and 1997, only 30% of women took a supplement containing folic acid prior to conception. Scior [12] reviewed 75 studies covering public awareness, attitudes, and beliefs regarding intellectual disability and found that public knowledge was under-researched, but that age, educational attainment, and prior contact with someone with an intellectual disability were more predictive of an attitude towards understanding the problem than the gender of the person surveyed.

Professionals working in the field also have a responsibility to inform and promote what is known about a specific condition. A study into parents' and professionals' knowledge and awareness of clefting [13] indicated that while parents of children born with a cleft and many professionals had little information on possible causes and treatment regimes, it was critically important to inform and involve family members, especially parents, in the craniofacial team decision making and treatment planning.

Pannbacker [14] investigated preoperative parental ideas of the usefulness of speech therapy after surgical management of a cleft and found that parents had unrealistic expectations regarding outcomes. Pannbacker et al. [15], gathered information on the personal experiences of cleft palate from medical students, parents and medical professionals and found that while parent groups served a useful purpose, professionals were in a better position to refer individual children with clefts to experienced specialists when needed.

Middleton et al. [16], conducted a telephone survey of 1,200 people located in six cities in four states of the USA. They found that 54.8% of respondents had never heard of a cleft. Only one respondent out of 1,200 was aware of the American Cleft Palate Association, the national body that represented the professionals working in the area of clefting. The authors of this study [16] made ten recommendations which they believed would increase general public awareness of clefting, all of a proactive nature with one being to develop "attention grabbing" methods to disseminate information. Two further studies undertaken in the USA determined that the general public awareness of oral and maxillofacial surgery was poor, with a similarly low level of the population having never heard of oral maxillofacial surgery [17,18].

Community awareness studies have been carried out in many other areas of the health environment leading to a better understanding of how to promote health literacy about kidney disease [19], sickle cell disease [20], mental health disorders [21], and cardiovascular disease [22], for example. All have led to a current understanding of the public's knowledge relating to the topic and have indicated that further action is required if a reduction in the particular disease is to be achieved.

This study is the first Australian cross-sectional study to investigate public perceptions and knowledge of clefting and it would appear to be one of the few since the early work of Middleton et al. [16].

## Ethics Approval

This study was approved by the Southern Cross University Ethics Committee (ECN-09-017).

## Materials and Methods

### Setting

The study was conducted at several locations in three eastern states of Australia: Queensland, New South Wales and Victoria. Venues included shopping centres, pedestrian malls and farmers' market sites, to access a broad cross-section of the community. Permission from the appropriate authorities from all areas was obtained. In all of the stores where surveys were conducted the store owners provided a separate space to ensure privacy during interviews. The researcher wore a badge identifying him, and had a sign at the front of the interview space advising that a research study was taking place. The one researcher was the sole interviewer throughout the extent of the survey. In all cases the participant being interviewed sat beside the researcher. No attempt was made to audio record the interviews.

### Subjects

The subjects were members of the general public who either worked in the area where they were interviewed or were visiting during the day. Most participants, apart from those in central Sydney, lived close to where they were interviewed. A total of four hundred and six participants were interviewed, with 286 females and 120 males. Forty six percent of participants lived in Victoria, thirty percent in New South Wales, and twenty four percent in Queensland. In New South Wales sixty five percent of participants were female and in Victoria and Queensland, females made up seventy five percent of the participants interviewed in those States. The participants were not asked if they had had a cleft when born, or whether they had a family member with a cleft, or knew someone with a cleft. The objective was just to determine their knowledge.

### Study design

A semi-structured survey was administered by a single researcher to a cross-section of the general public during normal working hours of the day. The survey was conducted via face-to-face individual interviews in public places involving consenting participants. The inclusion criteria were defined as a member of the public who, when invited to participate in the survey, gave verbal consent. The exclusion criteria comprised any person under the age of 18 years, as parental consent would have been required. The aim was to interview a random sample of people from the general public to determine their level of knowledge of clefting. The survey collected demographic information such as the participant's age, level of education, and whether they had children or not. Participants were asked if they knew what a CLP was and were then asked to describe it to verify their answer. Participants were asked what they knew about the medical management of children with a CLP: Whether they required surgery or speech therapy, and whether the government provided support for the families affected by CLP. With the exception of asking the participant to describe what a cleft looked like to be sure that they gave a truthful answer all other questions required a yes/no, or i do not know answer.

Participants verbally answered the questions, and their answers were noted on a response sheet by the researcher. Personal details of participants were not recorded other than residential post code, age and sex. Privacy and confidentiality were protected with anonymous responses. Each participant was recorded as a case number so that tracking back to a particular person was impossible. Descriptive

statistics were reported in terms of percentages. Fisher Exact Test was used to test for an association between level of education and knowledge of clefting.  $P < 0.05$  was set as the statistically significant value. Even though post codes were recorded to determine their residential location the numbers in each post code were too small to make any correlation that one suburb was better informed than another.

## Results

A total of 406 people participated in the survey, with 70.2% female. Participants provided concise answers to all questions asked. When referring to the word cleft or clefting, the term ‘hare lip’ was at times used, as some participants may have known the condition by this name. This was not done to influence the participant’s response but merely to be as certain as possible that the question was clearly understood. A summary of the response data is set out in the table 1.

The average age of the participants was 39.9 years and the age range was 20 to 67 years. The age of participants was skewed towards the younger end of the age spectrum with 226 participants (55.7%) under the age of 40. The higher levels of education were greater in the lower age groups, as 142 out of 226 (62.8%) of the 20-40 year old participants had tertiary level education. Three participants in the 50+ age group had only primary level education. Overall, slightly more women held higher education qualifications than men, i.e., 17% compared to 15%. One hundred and ninety one participants (47%) had children of their own and these were mostly the participants in the 30+ age group.

Two hundred and eighty seven participants (70.7%) indicated that they knew what a cleft was. When these participants were asked about the prevalence of clefting in Australia, there was a mixed response: 100 responded with “I don’t know”, 74 thought that clefting was prevalent, and 112 indicated that clefting was not prevalent.

Of the 191 participants who had children, 21% did not know what a cleft was. In the group who did not have children, 36% did not know what a cleft was.

There was no significant association between education level and the knowledge of clefting and this was confirmed by a Fisher Exact Test,  $p = 0.82$ .

Only 66 of the 287 respondents who knew what a cleft was could suggest a possible cause for clefting. Of those, 54 thought that it was genetic, 8 a nutritional issue and 4 thought that it was due either to drugs or toxins. As there is no conclusive evidence relating to the cause of clefting, this result was not surprising.

Ninety per cent of participants who knew what a cleft was, knew that the cleft could be repaired and all of those knew that surgery was involved.

Of the 287 who knew what a cleft was, only 12 knew that the Government provided medical support for children with CLP. Fifty four respondents thought that the Government did not provide support while the balance did not know whether support was provided.

The majority of the 287 participants (i.e., 249 or 87%) who knew what a cleft was thought that all of the children born with a cleft would need speech therapy and 95% of all participants who knew that speech therapy was required believed that this should be provided by the Government via the Medicare scheme.

## Discussion

While 70.7% of participants knew what a cleft was, there appeared to be a general lack of awareness about the treatment associated with repairing CLP. The important factor, however, from this research shows that almost 30% of the population is unaware of this facial anomaly and therefore when considering having a child will not seek out information which may help to avoid such an outcome. Also, participants with a higher level of education did not have any more awareness of clefting than those with lower educational attainment. This suggests that more can be done to increase public knowledge and understanding of the condition across the broad spectrum of society. It was not surprising that the majority of participants who knew what a cleft was, were not aware of the prevalence of clefting in Australia as the statistics on birth anomalies are only published in government bulletins [23], which only those seeking the specific information might access. In addition, the accessibility and availability of information on some government websites is complex, which may impede the effectiveness of this service delivery pathway, or potentially threaten public trust when access is too difficult or not easily comprehended [24].

Age	Sex		Had Children	% with Children	Education			Know of Cleft	
					P	S	T	Yes	No
20-30	F	97	9	9.28%		35	62	72	25
	M	31	1	3.23%		11	20	13	18
30-40	F	76	35	46.05%		32	44	65	11
	M	24	9	37.50%		8	16	7	17
40-50	F	47	38	80.85%		30	17	43	4
	M	28	16	57.14%		12	16	13	15
50-60	F	42	34	80.95%		19	23	31	11
	M	23	18	78.26%	1	5	17	20	3
60+	F	23	21	91.30%	1	14	8	8	15
	M	15	10	66.67%	1	6	8	15	0
Total		406	191		3	172	231	287	119

**Table 1:** Summary of response data presented as actual counts.

**Note:** M=Male; F=Female; P=Primary; S=Secondary; T=Tertiary education

Access to government information, particularly through government publications has been a fundamental component of the Australian democratic system [25]. In 2006 the government proposed to review and consolidate its websites into a more streamlined presence in order to enhance awareness and use. In spite of this, the use of government websites to obtain data has only increased from 31% to 33% in the period from 2004 to 2007 [25]. The Australian Government realised that its website was too complex and difficult to navigate and is now moving away from the policy of a single data source [26].

As Government websites might present challenges as a primary source of information and given that more general websites do not appear to be the primary source of information on CLP, the recommendation by Middleton, Lass et al. [16], that “attention-grabbing” methods that effectively communicate information about clefting might be worthwhile pursuing. Internet services that offer attention-grabbing environments include the social media arena of Facebook, Twitter and YouTube. Chalil and Sendhikumar [27] state that all online social networks follow the fundamental principle of homophily; similarity breeds connection. People become connected to each other on the basis of socio-demographic, behavioural, and interpersonal characteristics that are the same. The researchers indicate that 23% of Facebook users check their account five or more times daily and that 76% of Twitter users are active tweeters an opportunity exists to determine how this technology might be used to provide information on issues such as clefting. Chalil and Sendhikumar [27] in their study proposed a mechanism using social networks to allow the identification of “same wavelength groups” (people with similar interests), and hence target information of specific interest to that cohort. The fact that a large percentage of the social network users are of parenting age would suggest that these channels, as well as blogs or mobile technologies, may be important for disseminating information on clefting and pregnancy planning in general.

Willis and Todorov [28] showed that judgements made about a person on seeing their face for just 100 milliseconds compared favourably with the same judgements made when there was no time constraint, indicating that people often draw inferences from the facial appearance of others almost immediately. This study [28] demonstrated that the face is important to people, and so it was surprising that more of the participants were not aware of issues relating to facial anomalies. This could result from the fact that much of the major surgery is carried out in Australia in the early years of a child’s life.

Most participants who knew what a cleft was also knew that clefts could be corrected by surgical procedures; however, they did not know that the funding in Australia for this was provided by the government. The majority of participants who knew what a cleft was knew that cleft children would need speech therapy at some stage in their lives, and again most believed that this should be provided by the government. This is one area that the government does not assist families. CleftPals, the family support group operating in every state in Australia, continues to run a program called give our kids a voice, to bring this to the attention of the federal government. Being able to express oneself is extremely important in all aspects of life, to educate oneself, to socialize and to obtain employment and hence this is just as important as appearance. Obviously this subject needs to continue being raised with the authorities within the Medicare system.

It was not surprising that the participants did not know what caused a cleft, as no one knows the answer to this and there are no specific

recommendations from researchers how to avoid children being born with a CLP.

It is possible that people may consider clefting less of an issue than 60 years ago because they no longer see people with uncorrected facial anomalies. This is largely because of the surgical procedures and the legislation brought in by previous governments to fund rectification [7,6]. The first surgery is normally carried out at three months of age for the CLP baby, predominantly involving the lip. This reflects positively on the surgeons who repair clefts as techniques and skill levels have greatly increased in the past two decades. However, the public needs to be aware that clefting still exists, and the extent to which it does, in order to further promote optimal preconception health care.

Almost one quarter of the participants believed that the problem was genetic. This may be a reflection of publicity for genetic studies being carried out in other areas of health studies rather than any knowledge relating to clefting. Results of genetic studies often obtain high profile publicity.

An example of how publicity can raise public awareness and lead to increased research and support for those with breast cancer can be seen by visiting the McGrath Foundation website (a former Australian Test Cricketer) [29]. In this instance Glen McGrath’s wife died from breast cancer. Glen launched a foundation based around his wife’s favourite colour-pink. This has caught the imagination of the public and now many millions of dollars have been directed to research and support for sufferers. If this can be done for one condition why should it not be done for others where publicity may be all that is needed to lift public awareness? Having a unique approach gets publicity and the rest follows.

In the USA July is the National Cleft and Craniofacial Awareness and Prevention Month [30] and other countries including Australia should follow this lead to also increase public awareness

## Strengths and Limitations

The strength of this study was the vast geographical spread of the participants (the whole of the east coast of Australia), the breadth of the education level and ages of the participants, and the apparent knowledge of clefting within those surveyed. The higher proportion of participants 40 years old and younger is consistent with workforce statistics relating to people working in the vicinity of where the surveys were conducted [31]. Also, survey questions requesting a description of clefting helped to confirm the accuracy of affirmative answers. The limitations of the study included the small sample size, which limits generalisation, and the lack of representation from any rural and remote areas. Additionally the range of questions may have been problematic as more information could have been obtained had it been possible to conduct longer interviews, however, engaging participants for much longer or using a more structured survey would not have been practicable in the settings.

The study did not identify aboriginal, ethnic or other cultural backgrounds of participants. It also did not identify socioeconomic or economic background, language proficiency, literacy skills, or disabilities of participants and families; these matters were beyond the planned scope of this study.

## Conclusion

This study showed that there is a need to increase the awareness of clefting within the Australian general public, and that the level of education does not relate to knowledge of clefting. The study also showed that even when participants have children of their own, it does not guarantee that they are aware of clefting and its ramifications. This research indicated that the majority of participants thought the government should provide funding to support speech therapy for cleft children. Increasing the awareness of clefting is an area where the government could promote an important public health message to optimise preconception health literacy and pre-and antenatal care. The research proposes that 'attention-grabbing' advertising methods using new and innovative channels, such as social media, to promote preconception planning may help in reducing birth anomalies and these should be explored. This would raise awareness in the public arena and may lead to greater emphasis being placed on further research being undertaken.

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