



## The Psychological Impact of Ethnicity on Cleft Lip and Palate: A Preliminary Study

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### Abstract

It has been postulated that those with facial disfigurement are prone to increased stigma within certain ethnic communities. For children with cleft conditions, this is likely to have a significant impact upon their growth and development. In this preliminary study, we aim to explore the psychosocial issues surrounding cleft conditions through interviewing ethnic minority parents (n=10), and comparing their opinions from Caucasian parents (n=14). Results show that ethnic minority parents report fewer incidences of teasing/bullying compared to Caucasians (29% vs. 0%). Furthermore 0% of ethnic minority parents feel their children would benefit from specialist psychological support, as opposed to 71% of Caucasians. However, in a social gathering organized for ethnic minority parents, issues surrounding discrimination from family and friends became more evident. Apart from calling for more research into this field, our study suggests that psychological services should actively engage with the needs of this specific subset of individuals.

**Keywords:** Craniofacial growth; psychosocial adjustment; Cleft lip and palate

### Introduction

One in seven hundred babies are born with cleft lip and/or palate in the UK [1]. The incidence varies amongst different ethnic groups, with highest rates being found in Asians [2]. The psychological implications of cleft lip and palate can be severe. It has been advocated that in our modern society where much emphasis is placed on aesthetics, those who are deemed to be less attractive are more likely to be stigmatized [3]. It has also been previously suggested that family acceptance [4] and the strength of the bond formed between babies and their parents may play a role in psychosocial adjustment [5]. Therefore, it could be argued that parents' opinions of their own children would affect their quality of life and development to full potential.

Even though we live in the west, it is clear that our increasingly multicultural society by definition continues to incorporate values and traditions from ethnic groups from around the world. In many of these communities, there is still much stigma associated with facial disfigurement. In India, families that acquire children with disfigurement are considered to be of lower social status [6], whilst in some African tribes, those with facial disfigurement are prohibited from rising to chieftaincy [7]. Little work has been carried out to investigate whether these cultural differences affect parents' perceptions of their own children with cleft lip and palate as this may affect them throughout growth and development. Our preliminary study aims to explore this within the United Kingdom, in view of tailoring our services to meet the needs of these individuals.

### Methods

The study was based at the Department of Cleft Lip/Palate, Addenbrooke's Hospital.

#### Part 1

Consecutive parents of children aged 5 years old of various ethnic groups (Caucasian, Afro-Caribbean, Asian Oriental, and South Asian) were sought consent from and recruited in routine clinic appointments. Questionnaires (previously validated by Psychology Specialist Interest Group of the Craniofacial Society of Great Britain) were completed in a semi-structured interview format, addressing their own opinions of their child's appearance and quality of life.

#### Part 2

With the primary intention of tailoring services provided to children and their parents, we

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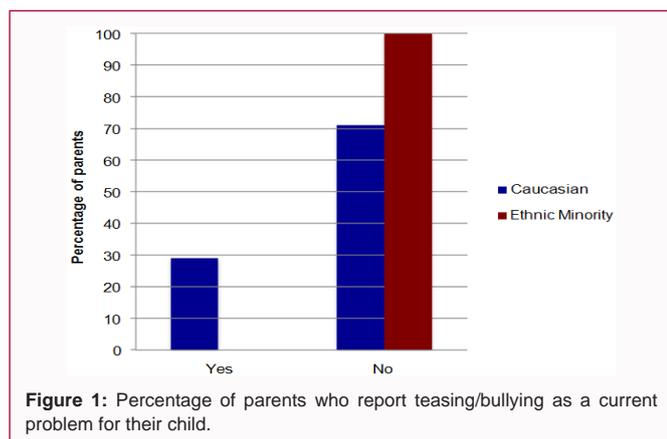
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devised a further needs questionnaire in order to determine how satisfied parents are in general with the care they received, and whether they would benefit from any further resources. This was given to 40 consecutive patients in clinic.

## Results

### Part 1

Parents of 24 children were recruited: 10 were from ethnic minority groups (8 were of South Asian origin, 2 were Afro-Caribbean origin) and 14 were Caucasian. The cohort was evenly divided between the sexes. All ethnic parents had migrated to the UK independently.

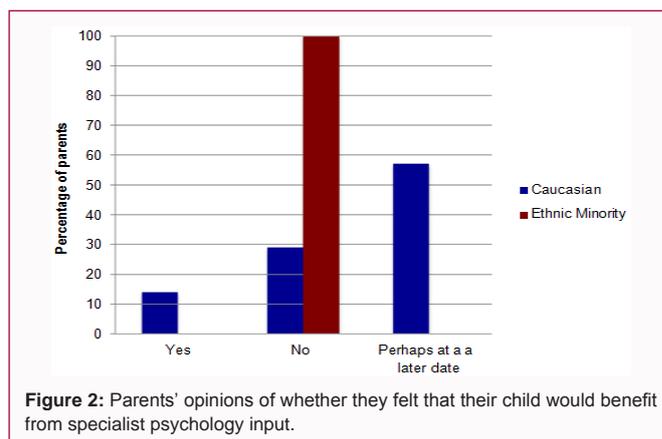
When parents were asked to rate how their child's self-confidence was affected by their cleft lip/palate by giving a numerical value on a scale of 0 (has a very negative affect) to 10 (has a very positive affect), the mean score given by Caucasian parents was 4.7, whilst that given by ethnic minority parents was 7. Interestingly, in one case, parents had decided specifically not to tell close family about the cleft palate due to fear of stigma.

29% (4/14) of Caucasian parents reported teasing or bullying as a problem their child experienced, whilst no ethnic minority groups reported such episodes (Figure 1). 57% (8/14) of Caucasian parents and 80% (8/10) of ethnic minority parents report their children as having no difficulties in emotions, concentration, behavior, or ability to get on with other people. Interestingly, both ethnic minority children who were reported by their parents to have such difficulties were known to have evident syndromes resulting in global developmental delay.

From our results, 0% of Ethnic minority parents thought that their children could benefit from specialist psychology input at any point in time, as opposed to 71% (10/14) of Caucasian parents: 14% (2/14) of Caucasian parents thought they could benefit from now onwards, and 57% (8/14) suggested that they may benefit at a later date (Figure 2).

### Part 2

Parents of 40 children were recruited; 12.5% (5/40) were parents of the ethnic minority population. Objectively it was clear that the majority of the latter group would benefit from translators, however only 1 child's parents were willing to use this resource. Interestingly, 57% (20/35) of Caucasian parents were not interested in attending a social gathering/workshop, whilst 20% (4/5) of ethnic minority parents were very willing to attend such an event-with the majority seeking an informal gathering with a social focus (as opposed to a



formal meeting with an educational focus).

As a result, a social gathering was organized in partnership with the British Cleft Lip and Palate Association for ethnic minority parents and their children, which proved very popular amongst participants. In this informal setting, parents were evidently willing to engage with other parents and share their experiences with each other and ourselves. Some mothers, in particular, reported that they have often been blamed for giving birth to children with such conditions in their respective communities, and in some cases, communities have explained this as "karma" - punishment for a sin they have committed in the past. As a result, they have suggested that this can result in marital and family bonds being broken; however on some occasions, this has also resulted in parental and marital bonds being further strengthened.

## Conclusion

It was interesting to discover that ethnic minority parents have suggested that their child's cleft lip/palate has had a positive impact upon their self-confidence giving a mean score of 7, as opposed to Caucasian parents who have given a score of 4.7. In agreement with this, no ethnic minority parents have reported any episodes of teasing/bullying. There are many possible explanations. First of all, there may be very little occurrence of such events within this specific cohort of children. Children may have not reported such events to their parents. Indeed, Sawyer et al. [8] have suggested that ethnic minority children are less likely to report such episodes. It could also be the case that parents were not willing to confide in healthcare professionals, perhaps as they are not aware of the extent of specialist psychology support they can receive, or perhaps due the language and cultural barriers that many evidently faced. Furthermore, we noted that many of the ethnic minority parents had migrated from areas where they were victims of persecution, hence such parents and children may not view teasing or bullying as a significant issue.

Our work suggests that Caucasian parents are more likely to report their child's difficulties in various areas such as emotion, concentration, behavior, or being able to get on with other people. Ethnic minority parents only reported such issues when their children were syndromic with global developmental delay (i.e. when these difficulties are less avoidable). This could be an example of the disengagement coping strategies (avoidance of stressful situations as a coping mechanism) that have been suggested to be more commonly used by those from ethnic minority groups [9].

No ethnic minority parents thought that their children could

benefit from specialist psychology services. Once again, this could be as part of a disengagement coping mechanism. However, there could also be an element of avoidance of healthcare services due to stigma and fear of gossip, as has been previously suggested by Bradby et al. [10] when exploring the under-representation of South Asian children in Scottish Child and Adolescent Mental Health Services.

However, many ethnic minority parents were willing to engage in a social gathering when specifically catered for individuals from their communities. They were able to share similar experiences, and parents of older children were able to give advice to those with younger children. The event, being the first such event in the United Kingdom, was a great success and parents were very willing to actively organize further gatherings.

This study has limitations. The sample size is small (n=24). Furthermore, it may be the case that the cultural context for Asian will be different from Afro-Caribbean.

Within the small scope of our study, it would be reported that teasing and bullying seems to be under-reported by first generation ethnic minority parents, who are less active in pursuing specialist psychology help for their children. However, many find that informal gatherings within their communities to be a useful experience for themselves and their children. It is evident that a complex web of psychological factors plays a role in the relationship between parents and children when affected by cleft conditions, and this is likely to impact on them throughout their development.

The aim of this preliminary study to increase awareness of the issues faced by parents of ethnic minority children affected by cleft conditions not only to propel research into this field, but also so that we can tailor our multi-disciplinary team approach for to cater for the needs of such individuals.

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