

Research Article

Growing Up with A Cleft Lip and/or Palate - A Qualitative Study

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Abstract

This qualitative Australian study involving 7 participants explored experiences of adults born with a cleft lip and/or palate, in their transition from childhood to early adulthood. It provides an insightful exposé of their lives and the issues they faced during and after treatment for their clefts, and how it affected their development. While there were many difficult times both during and after surgery they showed great resilience and some believed that they benefitted from having had this experience. The information gained from this study has important implications for the medical and nursing professions as well as mental health practitioners, the staged care for the children with clefts and for families who may be faced with similar issues.

Introduction

The aim of this study was to gain descriptions of the experiences of young people who had been born with a cleft lip and/or palate (CLP). The objective of the study was to achieve an understanding of these experiences over the transition from childhood to their early adult years. The study was part of a larger eclectic study investigating possible causes of CLP.

CLP babies may encounter difficulties with breathing, sucking, swallowing, eating, and talking from birth, and endure corrective surgery with extensive hospitalisation throughout infancy, childhood, and adolescence. Speech therapy and orthodontic treatments are commonly required and may continue into early adult life [1]. The treatment does not just restore function but involves mediating facial appearance and can occur when children/adolescents develop their identity and self-esteem [2]. An informed understanding of the long-term effects on physical and mental well-being of CLP individuals is therefore vital for surgeons and other health care professionals working with them as well as those who in the future may face these situations should they have a child born with a CLP.

Background

Cleft lip and palate is a common birth anomaly. In most cases it is an isolated or single malformation, however, in approximately 5-10% of cases regardless of ethnicity it is either an associated or paired malformation [3,4].

Causal research into clefting may have started mid-20th century [5] but no clear linkages between genetics, nutritional, or environmental factors have been established for definitive causal factors. Researchers [5,6,7] refer to clefting as a multi-factorial problem so the cause may be genetic, nutritional or environmental, or a mix of all three. Genetics, familial associations, nutrition, maternal medication and substance use, and environmental toxins have been associated with CLP but no conclusive connection has been established [8,9].

Incidence

In Australia birth defects registries are kept separately by states and territories, with great variation in the quality of data recorded. In Victoria for example the incidence is as per Table 1.1.

Anomaly	1987-1991	1992-1996	1997-2001	2002-2006
	N/10,000	N/10,000	N/10,000	N/10,000
Cleft Palate	6.6	8	7.8	8.9
Cleft Lip	4	3.6	4.1	3.9
Cleft Lip and Palate	6.6	6.2	7.1	6.1
Total	17.2	17.8	19	18.9

Table 1.1 Confirms no appreciable variation in total incidence from 1987 to 2006 in Victoria, except a variation in the type of cleft with CP having the largest increase over this period. This is consistent with countries [10] where accurate statistics exist, and where no calamitous events such as earthquake, war or other pestilence have occurred [10].

Study design

This was a qualitative descriptive study involving adults aged between 25 and 38 years of age who had been born with a CLP. The study was designed to authenticate the participants' experiences and enable their voices to be heard for relevant health professionals to learn from. Interviews involving a semi-structured interview schedule (Draper and Swift 2010) [11] were conducted by the researcher in participants' homes or workplaces with childhood oral biographies obtained. The recorded interviews were transcribed and sent back to each participant for audit review. This was done to ensure that rigour was maintained for the study. Privacy of the individual was protected by immediately changing the names in all documentation. The design and analysis of this study closely followed the principles established by Fade and Swift (2010) in their suggested methods for qualitative research and data analysis.

Ethics Approval

This study was approved by the Human Research Ethics Committee of Southern Cross University, Australia (ECN 9-018).

Participants

Participants volunteered after hearing of the study through Cleft Pals, an Australian family support group for CLP parents. Each gave written consent to be interviewed and for the interviews to be audio-recorded. Inclusion criteria involved being born with a non-syndromic facial cleft and having completed the surgical procedures to correct this birth anomaly. Participants lived in the Australian states of Queensland, New South Wales and Victoria.

Literature Review

The face is important to young people and those who have facial anomalies may experience difficulties moving from childhood through adolescence to adulthood when developing their identities, encountering peer pressure, and engaging socially and possibly romantically. People often draw inferences from the facial appearance of others (Willis and Todorov 2006) which in the case of those with a facial anomaly could be personally hurtful or in a work environment detrimental to their progress or success.

Several early studies had been conducted considering the psychological adjustment of individuals with CLP. They found a high degree of dissatisfaction and self-consciousness regarding appearance [12], a low rating for body satisfaction [13], and CLP individuals appear to be observers rather than participants in social interactions and feel neglected because of their 'handicap' (Van Denmark and Van Denmark 1970). Heller, Tidmarsh et al. (1981) reported that many experienced problems in relation to the opposite sex, tended to marry at a later age than their siblings, and showed a longer dependence on their family with some needing counselling and supportive services outside the family group.

A retrospective study of 63 adults in Iceland involved a wide age range (25 to 50 years) [14]. Many of the adults in the study had time to 'heal any wounds' [14] that had been present during earlier years. The individuals with facial clefts were found to be relatively well adjusted and coped well with day to day life, and it was concluded that the subjects did not seem to perceive that the cleft consequences had influenced their life to any great extent. A further study [3] investigated the experiences of ten teenagers, between 15 and 17 years of age, using both questionnaire-based and semi-structured interviews. Many of these adolescent participants were involved in CLP surgery at the time and were not yet in a position to see how this would affect their career or lifestyle choices. The results of the study did indicate that they had experienced communication and interactional problems throughout their development. Chapados (2000) concluded that both those with a cleft and their families needed greater assistance and education to help them explain to others the implications of being born with a cleft.

A Swedish study [15] investigated the quality of life, satisfaction with treatment and psychosocial distress in a group of 44 men and 24 women with a mean age of 24.2 years (range 19.5-29.2) with treated CLP compared to gender and age matched controls with no clefts. The researchers found that the cleft group rated some detached aspects such as life meaning and family life significantly lower than the controls, but not the more practical and tangible aspects of their daily living. A high degree of dissatisfaction was expressed within the cleft group with the surgical procedures they experienced and this was endorsed by the surgical practitioner group who recommended that further remedial surgery be undertaken on 38 of the 72 cleft participants. This dissatisfaction with the treatments that the participants had previously undergone may well have influenced the psychosocial aspects of the study.

A study involving 113 children and young adults (aged from 8 to 21 years) in Northern Ireland [16] involved self-reports of their psychosocial functioning after being born with a CLP. Many of the participants were in the early stages of their surgical journey. It was reported that participants exhibited more behavioural problems and a higher degree of depression than controls who were recruited from a wide range of children of a similar age [16]. The study group were teased more often, were less happy with their appearance, and with their speech. With regard to anxiety and self-esteem there was no difference between the CLP group and the controls. This study may have had more significant outcomes had there been less disparity in the age group, and their social development as the researchers found that age was a significant predictor of behavioural problems, happiness with facial appearance, and satisfaction with speech. Older subjects had more behavioural problems and were less happy with their appearance and their speech than those in the younger group.

A South African study (Patel and Ross 2003) considered the experiences of 20 adults aged between 18 and 50 years of age and while the study considered a number of aspects its main finding

dealt with speech issues and ability to communicate. The majority were negatively affected by societal perceptions and cultural myths associated with the etiology of clefts.

Other studies [17] were reviewed to determine how self-esteem and confidence were expressed by young adults in their development when they had other non-life threatening disabilities. Mental health issues were said to be related to lower educational achievements, substance abuse, violence and low socioeconomic status. Those with physical disabilities reported good self-esteem, strong family relationships and as many close friends as those in the able-bodied community [17].

A European longitudinal study (Semb, Brattstrom et al. 2005) considered the long-term follow-up of a cohort of participants with complete CLP. This study concentrated on the treatment provided by five different teams, the travel required by patients and families, and how this varying burden of care related to clinical outcome and participant/ parent satisfaction. They found dramatic variations in outcomes depending on the number of treatments, time in hospital and the dislodgement from their normal residential area. The number of operations ranged from 3 to 6 the length of orthodontic treatment from 3 to 9 years and attendance at medical centres ranging from 49 to 94 visits, while the days in hospital ranged from 0 to 146 days.

Data Analysis

Thematic analysis was used to identify themes within the data in this study by determining word patterns based on commonality of occurrence within each of the interviews at a researcher reading level. Once the individual data had been read and approved by each participant, it was coded using the computer program NVIVO to establish the nodes to confirm the themes from the data. Each transcript was uploaded to the program which was then run to provide a cluster analysis of word similarity followed by word frequency. This was then reviewed to determine specific nodes. As each node was established, the sentence or sentences relating to it in each participant's data was copied to the node. On completion, if there was data from two or more participants within each node, the node was considered a theme and a descriptive heading was assigned to it. This concurred with the initial reading of the data by the researcher. Data saturation was achieved after 7 participants.

Results

Participants' demographic data

Participants comprised two males and five females whose ages ranged from 25 to 38 years with a mean age of 28.6 years. All had secure employment, and all but one had achieved tertiary level education. One participant had a unilateral cleft lip at birth, one an isolated cleft palate, two had unilateral cleft lips and palates and three had bilateral cleft lips and palates.

Thematic Findings

- I. At data saturation the following themes and their summary statements were evident:
- II. First recollection - I can't remember. Participants had no recollection of the surgery that had occurred prior to approximately age 4 and were not aware that they were different to other children.
- III. Bullying as normal. Bullying in general was seen as normal schoolyard behaviour.
- IV. The early surgery - a normal part of growing up. The surgery participants endured was at times considered 'fun' and a normal part of growing up.
- V. Why me? I never really asked. All but one of the participants had never questioned why it was they who should have been born with a cleft.
- VI. Friendships - No problems. Gaining friends and friendship was not an issue to these participants.
- VII. Confidence and resilience - I've got plenty! Participants appeared confident with their current status and had shown great resilience following the treatment.
- VIII. My worst experience - There was one. Each participant highlighted a bad time in their medical journey.
- IX. Family support mattered. Family support was considered important and greatly appreciated by the participants.
- X. Career choices- No problems! Having a cleft did not impact on participants' career choices.
- XI. Be positive! The advice from participants to other children born with a cleft.
- XII. Be supportive! The advice from participants to parents of children born with a cleft.
- XIII. Mixed feelings. Reflections on involvement with the medical profession.
- XIV. Disappointment. Reflections on the general community's knowledge of clefting.
- XV. As each theme is presented participants' words are used to substantiate the theme.
- XVI. First recollection - I can't remember!
- XVII. Prior to being five years old no participant could remember their very early surgery or that they were different to other children. Some could not be precise about the age when they first realized that they had a cleft as they had just accepted that it was

normal for them even though they realised that they looked different to other children. One participant was concerned because she spoke differently to other children, while another thought that she was just a 'regular kid' both just accepting the way they were – it was just a part of them.

XVIII. My first memory is at five years of age and realizing that I was different in some way to other children. I looked around at school and everyone was different to me.

XIX. At six years old I realised my speech abnormality was caused by a cleft. I had always had speech abnormalities. I was always being driven to the doctor for something or other, but prior to that I just knew that it was really frustrating at not being understood. I knew that it was also quite frustrating for people to understand me.

XX. A study into early childhood memories based on 11,000 autobiographical memories for the first decade of life (Rubin 2000) confirms that it is not until after the age of 3 that there is any significant recall of events that happened at that age. Rubin (2000) also showed that there was no significant difference in recall between the genders or the age in which the person was asked to recall those events. Usher and Neisser (1993) found that the recall of events that happened in the years 0 to 3 years were not accurate, while the accuracy of events proved much more positive for events that occurred when aged 4-5 years. Howes Siegel et al. (1993) found that early memory was independent of trauma having occurred at an early age.

XXI. The fact that there is little or no memory of early surgery for those who have had a cleft is important for medical staff in supporting families of children undergoing future surgery at a very early age, as it suggests that beyond the normal care for the patient, the staff should carefully consider the needs of the parents who may be struggling to cope.

Bullying

With the exception of one female participant who has still experienced bullying the other participants seemed not to believe that they were bullied more than other children. I was never really bullied as such but children are inquisitive. That's what you do when you are young, isn't it, and so at that time I realised that I had a cleft and that was why I was different.

The worst thing was the teasing, comments, and staring. I'm very self-conscious even now, extremely. It's the first thing I see when I look in the mirror, every day. There is a scar and even if it was smaller it is still a reminder of past events. It's not 'confronting' every day, but I'm very aware of it and very self-conscious. People still comment a little bit, not so much as before.

The schoolyard has always been a place where bullying has occurred, and children who are even slightly different for one reason or another can be the target (Juvonen, Graham et al. 2003;

Hunt, Burden et al. 2006; Christensen 2009). All participants had faced some bullying but, in the main, this was dismissed as being a part of growing up. While this study did highlight a degree of bullying it was not to the extent that might be expected (Hunt, Burden et al. 2006), and in only one case did this go beyond the schoolyard and into adult life. Apart from this one case, bullying does not seem to have had a lasting effect, and the participants appear to have shrugged it off as normal schoolyard behaviour that everyone goes through.

The early surgery - A normal part of growing up

Participants appeared to have accepted that a visit to the hospital and the surgery that followed was a part of their life, sometimes even 'fun' and not something out of the normal. I remember when I was little that the medical procedures were kind of fun ... uncomfortable, but certainly not painful. I remember when braces were a big problem. In a lot of ways they were worse than the problems they were trying to fix at the time. And I kind of resented a lot of the medical treatment when I was twelve or 13, I wasn't really interested, there didn't seem to be much point to it. But then, 13-year-olds are pretty disagreeable anyway.

All participants had endured physical pain from the surgery, and by inference emotional pain and more so when faced with more surgery. This impact on their lives appeared to be dismissed by them when they maintained that the surgery was not frightening, and they expressed their confidence and resilience. I had known that I went to hospital and it is funny that you forget a lot of things that happened at age five or around that time, but you don't forget about going to hospital. My most vivid memory was at age five going to the Hospital with my mother. This was obviously not the first time in hospital but this time was for follow-up procedures and it sticks in my memory. The surgery was to rework both my lips and the palate.

The surgery involved in repairing a cleft is complex and can continue over several years (Schendel, Montgomery et al. 2005; Talesh and Motamedi 2013, p. 563). Going to hospital and facing surgery at any age is not something that anyone looks forward to, and yet as children none of these participants found it frightening, nor did they find the surgeons intimidating. Certainly as they grew older and the surgery impacted more on their lives when different issues were encountered.

(Taylor and Brown 1988) suggested that overly positive self-evaluations, exaggerated perceptions of control, or mastery, and unrealistic optimism, are characteristic of normal human thought. It may be possible that these participants have mastered that optimism, which has been able to impose filters on the past that changes their experiences. Gassling et al. (2012), concluded that adults with CLP have significantly better stress-coping strategies than their healthy peers, probably because of the increased social support they receive during their treatment period. The participants did not appear to have any long term emotional issues despite their clefting.

Why me? I never really asked!

To anyone who has not been exposed to significant surgical procedures or been born with an anomaly of some kind it may be thought that the normal question a child could ask a parent would be “why me?” However, only one participant indicated that question had been asked (six never ever thought to ask) the others just accepted the life they had been dealt.

I just went along with what I was supposed to do. Some kids have a very strong mother (I did), they just do what they're supposed to do. You're going to have an operation, so I'm going to have an operation, and that's it. The findings suggest that they accepted themselves and how they had been created. Stewart (2004, p 783) in describing this phenomenon of acceptance quotes Buddha, “as we think so we become”. One participant, summed this up succinctly stating, “so it's about being yourself, being proud of who you are, and that's not easy for any kid or any person.”

Friendships - No problems!

A child whose face looked different may find it difficult to develop and maintain friendships. Such was not the case with the participants. The fact that my face looked different to others did not stop me making friends although I was a little self-conscious about it. During my childhood, I can say that I never really had a negative experience. On the contrary, there were things I could do that other children could not. For example, I had an under-bite and I could touch my nose with my tongue with absolute ease but none of the other children could come close to that. Even though I used this to my advantage I probably did not fully appreciate it, to be perfectly honest.

Friendships are not always easy to make and even harder to maintain (Gifford-smith and Brownell 2003). Buysse (1993) found that children with disabilities tended to find at least one mutual friend and that this was generally based on similarities between the two. Other researchers since (Pottie, Sumarah et al. 2004) described the factors that foster or inhibit the development of friendships and the communal influences involved. For children with a CLP it could be assumed that they might have fewer friends or struggle to be part of a community due to their inability to speak clearly. This was not the case as all participants seemed to have well developed friendships right from their early school years.

Confidence and resilience - I've got plenty!

All of the participants were positive and seemed to be enjoying their lives just the same as any other person who has not endured these experiences. It was later that I realised how having a cleft had really helped me. It's just that you don't take things for granted. I mean, having solid food, having a shower, being able to laugh without your mouth hurting and having 400 stitches in your mouth that you're waiting to dissolve. I was talking to a guy the other day about one of the parents that I met, where before they

dissolved the stitches you had to lie on your back for about two hours on end, while they took stitches out of your mouth. And I guess going through those things just gives you a good perspective, so when someone complains about having a sore toe or that the Medicare rebate should be higher, or maybe the baby bonus should be an extra \$500, you think get a grip here. It gives you a very good perspective on life. And not to be blasé about it but it gives you that confidence and intestinal fortitude that you can get through a tough experience. And I think it's later in life that it's helped me no end.

An outstanding outcome from all participants was their confidence, resilience, and strength of character. It might be considered that participants could feel sorry for themselves, and yet at no stage was this evident; some actually suggested that their lives were better because of the cleft.

I feel sure that having a cleft has assisted me greatly in being able to cope with life. Not only is the cleft a part of who I am, and part of what I needed to cope with growing up, but it taught me in life how to get up and do things, not to dwell on them, to be more resilient Children are honest and factual and I put it on the table, this is what I had, this is what I've been through in life. I've got resilience but I've had no choice but to have resilience.

Despite having experienced severe pain and hardship they did not see the cleft as an impediment but indicated that it had provided a solid grounding for their future. Linley and Joseph (2004) in studying positive changes in individuals following traumatic stress found that for many, the process of struggling with adversity could propel the individual to a higher level of functioning than that which existed prior to the event. Participants genuinely appeared to see a positive side to their hardship.

My worst experience - There was one!

Participants not only had the normal issues of life to face but had a series of medical procedures to contend with and some were difficult to cope with. The female participants were more conscious of any scarring. Furness Garrud et al. (2006) investigating the ability to come to terms with facial surgery found there were mixed emotions regarding appearance as reactions can be relative to the perceived disadvantage.

The ages ten to fifteen years were the hardest, both from the point of view of any bullying that took place, and any surgical procedures that occurred at that time. The worst time for me was when I had my bone graft. I had my first rhinoplasty when I was 13. I've played sport my entire life, and that was the first time that it brought a halt to my life, and it was like: “Sorry, Jason but you can't play sport for a year.” For the first time in my life it wasn't a one or two months' recovery, I had a 12 months' recovery. That was probably the first time that when I thought that this is a bit unfair, and I wish I didn't have to go through this. This indicates a critical time for both parental and peer support. In recent times CleftPals

(Victoria) has created a youth group for 6-18 year old called Cleft Stars. They meet socially on a regular basis with adults who also had clefts when a child, for ongoing support. For some participants, the worst time was the surgery, for others the dental work, and others the speech therapy, but. They: "just got on with life".

I did have speech therapy - which I really didn't enjoy. I found it almost demeaning and unnecessary, and I really resented it. It was very boring. But the speech therapy's very difficult, it's hard to retrain your tongue to speak in certain ways, so it's a frustrating process anyway. But that was around sort of 13. I had no time for that. I'd go, but I didn't enjoy it at all. In hindsight of course it was extremely worthwhile. In a lot of ways you're comfortable and then someone tells you something's wrong and then it becomes a problem.

Family support mattered

The role the families played was considered extremely important in sustaining the participants during the hard times. I have an amazing mother and have had great support from all members of the family. We didn't have a lot of money but we did have health insurance, but I am sure there were times when my father wished that this [cleft] had not occurred.

The support provided to participants was stated to be pivotal in their ability to cope, rather than just deal with the situation. This support welded the family into a more cohesive unit. Parents had made a commitment to be there for them and the parent-child relationship became strong perhaps due to the sharing of extended time during their treatment experiences.

The challenges of adolescence, did not abate for participants, as one mother identified (in another study as part of this overall project) wanting to dissolve into the floor when her son was being rude to an orthodontist despite her obligation to persist: He was becoming rather uncooperative about the whole thing. I could have throttled him, at least going privately you knew he was going to see the same orthodontist each time, even if he was unspeakably rude to him. Waylen and Wolke (2004) describe how adolescents are particularly concerned with their identity and yet are expected as maturing adults to synchronise their beliefs with the important people around them. This duplicity of demands presents a challenge to teenagers who may typically become disinterested in family involvement and activities (Molinari, Everri et al. 2010). For these participants however it was quite different; family was both needed and highly valued.

Career choices - No problems!

As facial appearance may have an impact on future employment obtaining suitable employment could have been an issue but did not appear to be. All participants indicated they had succeeded in their education including tertiary education and had followed the career of their choice. They did not feel that their cleft had been an impediment.

Having had this experience has not been negative in achieving the career goals I set out to achieve and if anything, I think that it has helped me. I think it has helped me to put life into the proper perspective. You need a few setbacks in life if you want to get where you want to go. They were able to put aside past trauma and concentrate on their studies and excel. Rule and Ambady (2011) indicated from their research that faces affect individuals throughout their lifespan and in particular employment opportunities. It could be expected that having a cleft would impact on the career that one would like to pursue. This was not evidenced in this group of participants.

In terms of my career and choice of vocation I haven't shied away from work that is confrontational or is difficult or requires interaction with other people. It has not affected my willingness to speak publicly or to engage in potentially quite personal episodes within the scope of my work.

Be positive! Advice to other cleft kids

Advice from someone who has had the same experience that you are to face can be beneficial. The advice provided by the participants was very simple - to retain a positive attitude, they showed maturity and insight. It is difficult to advise other children but perhaps the best advice is that this does not stop you from doing anything as it has absolutely no bearing on your mental capacity. Having a positive approach is just absolutely everything. So, when you go for a surgery, if you're positive it will not be as hard to bear.

Participants indicated their willingness to share their experiences with others who have a cleft to motivate them. For other children who may have a cleft I would like them to know that it's not a big deal. I think if things aren't going well it would be easy to use the excuse and pin it on the cleft but for me, and I hope for others, it hasn't been a big thing and I have just been able to get on with it. So you have a choice that you either get on with life or let life get on top of you.

Tuval-Mashiach, Freedman et al. (2004) found that the way in which a person perceives both a traumatic event and their reactions to it can be predictive of recovery. This view is consistent with other cognitive behavioural models of other anxiety disorders (Elders and Clark 2000). This suggests that assisting a patient to be positive, especially by a peer or someone who has had the same experience, will enhance recovery.

Be supportive! Advice to parents

Having had this experience, participants knew how their families had supported them and knew just how it had helped them and so their advice to other parents is invaluable. I don't think you can underestimate how important having family support is. They're the most important people in your life, and from my experience, once you've got their support, you've always got a safe place, and you've always got that support network.

Participants knew that their own parents had suffered due to their cleft but that the support they received was appreciated. Parents in this situation will experience an emotional roller coaster of ups and downs (Kearney and Griffin 2001), and they have to support not only the child, but each other. Kearney and Griffin (2001) found that while parents experienced much anguish and sorrow they also expressed feelings of hope, love, strength and joy. These participants saw the need for the expression of such feelings, and encouraged an optimistic attitude, and in particular, that the parent should emphasise that their child is beautiful, loved, and a valued member of the family.

There is an important role for parents to play: they need to reinforce the fact that their child is beautiful and the most precious thing in all the world. I think sometimes it's nice to hear from your parents that you look ok as well. Young, Dixon-Woods et al. (2003) found that parents find the task of communicating with their children enormously complex, which is influenced by their need to construct a parenting identity on the one hand while trying to protect their children's wellbeing and promote an optimistic version of reality on the other.

Mixed feelings. Reflections on the medical profession.

The participants had had much more exposure to the medical profession than others of the same age for obvious reasons. They shared useful information on their treatment by and experiences with the medical staff. I think the touchy-feely side is lacking in the medical profession, the bedside manner needs to be improved. I think that it's not a big ask for the doctor to spend ten minutes talking once you are able to have a chat.

The initial experiences of these participants with the medical profession were lost in their memory but each had surgical procedures over a long period of time and their reflections related to the period beyond the initial surgery. When I was little, at the Children's Hospital, you're very well case-managed, there's quite a cohesive team, and that was a lot of fun, it was very easy, and that wasn't hard at all. Then there's the period in between when I was no longer at the Children's, and I found it a lot harder to deal with the medical profession. I wasn't interested in it.

In most, the experiences were positive, helped by the personality of the surgical staff and where not they provide important feedback for others to consider. They did specify a need for a more humanistic attitude rather than the more clinical approach in interacting with them. As participants grew older they appear to have at least understood, if not accepted, the more direct approach of the medical profession. I think the medical profession has changed in recent times but when I was going through the system their bedside manner was pretty appalling. I remember sitting in a room and ten of them were staring at me. I don't remember how old I was, I just remember them working out what to do, and staring at me and that was horrible. Young, Dixon-Woods et al. (2003) in their study

confirmed that children resent being invisible when involved with medical professionals who only relate to their parents.

The community - Does it know or care?

Having grown up with a cleft, participants had been exposed to questions from the general community and therefore had some idea of their depth of public knowledge of clefting. They felt that the community was unaware of the issue and did not seem to care:

The community at large is blissfully unaware of the problem. I think if you have any form of cancer, everyone has an appreciation for what you're going through, or even if you have Attention Deficit Disorder, people know all about it, but if you have a cleft very few know what you have been through, or what a child and their parents may still have to go through.

With an incidence of one in every 600-700 children being born with a cleft (Riley and Halliday 2008) it could be assumed that the general public should be aware of this anomaly; however participants' experiences found a lack of awareness. I don't really know how much the community is really aware of clefting but in my experience many do not know what a cleft is. I think people are only concerned with things that happen within their immediate experience.

This last statement is a sad indictment on the community at large as it shows that even from an early age there is scepticism felt about people's concern for each other. It certainly indicates that we should encourage those around us to take a more humanistic approach to life, ensuring that all those who suffer disadvantage are supported as best they can be.

Discussion

In this study participants have been able to speak for themselves and their narratives have provided an insightful understanding of what it is to grow up with a facial cleft. Beyond this, however, the study suggests that there are four distinct areas where care is needed each being discreetly different.

Age 0-4 years

It is clear from the study that the child has little or no knowledge of the surgery that has taken place up to this point. For the child then, the care supplied must be of a technical nature providing the best surgical and nursing staff. Perhaps, attention during this period should be directed towards the parents who will both be experiencing great emotional stress in handing over their child for extremely invasive surgery. In addition to the normal stressors associated with having a new baby, these parents have to cope with many uncertainties about their child's health and prognosis, frequent medical appointments, and procedures, as well as the additional workload of caring for a child with special needs. When coping strategies fall short, these challenges can detract from mar-

ital and other family relationships as well as work and careers, thereby creating further tensions within families [18].

Barnett, Clements et al. (2003) believe that interventions can broadly promote family well-being by focussing on parental emotional, cognitive and behavioural adaptation to their child's condition. Such a process requires the involvement of not just the surgeon involved but all of the nursing and ancillary staff involved with the family.

Age 5-10 years

Children reaching this age were well aware that they were going to hospital and would have some surgery but for most there was some "fun" involved. Wollin, Plummer et al (2004) undertook a study involving the parents of 120 children aged between 5 and 12 years of age who were undergoing surgery. The children were also interviewed prior to the surgery. The parents reported that the time spent by doctors talking to the child in a friendly way was helpful in reducing the child's anxiety, and often more useful than the provision of a television or computer games. However, the majority of parents found that the provision of toys and games was extremely important in providing distractions during waiting periods.

It was not helpful for the doctor to be wearing a mask as that tended to reduce the degree of familiarity between doctor and child. The role for the nursing and ancillary staff is to reinforce the familiarity that the surgeon has created. Where children wear gowns and head gear, taking photos and making them feel important are also ways of creating distractions and reducing anxiety.

Age 11-18 years

The child is now an adult, certainly in awareness and the need for knowledge. It was very clear that the participants needed to know what the procedure would be, and how it would affect them. There is less emphasis for parental involvement, as the young person is now taking some responsibility in seeking information relating to the procedure. Ignoring the young person during a pre-operative discussion does not lead to a positive outcome, "I don't remember how old I was, I just remember them working out what to do, and staring at me and that was horrible". The participant went on to say that "I think that it's not a big ask for the doctor to spend ten minutes talking once you are able to have a chat". There is clearly a need for medical staff to treat young people of this age as they would an adult, even though the language may be phrased in a very non-technical manner.

Age 18+

The child is now an adult and all treatment and support is now almost completely out of the parent's hands with the majority of the focus being most definitely between the medical staff and the patient. Obviously it is important that procedures be clearly outlined together with the desired outcomes. There is still an im-

portant support function for all medical staff beyond the technical discussion relating to the forthcoming procedure. It was clear from the data that the participant had accepted who they were and that they had a cleft and that this would always be a part of their life. For some they had found strength in this but for one there would continue to be some bullying even into the workplace. The role for all staff involved is too provide emotional support as that now is probably the participant's greatest need. They need to feel good, they need to feel normal and beyond that beautiful.

Conclusion

These participants were achieving their goal at the time of this research, and believed that their cleft had seemingly helped them to gain a more authentic perspective on life. Their courage in sharing their experiences for this study is to be applauded. They appear to have a remarkable strength of purpose and character. For health professionals involved in the treatment of children with cleft lip and palate this study provides useful perspectives regarding interaction and the impact of trauma. For parents it provides more than just hope as these participants have all overcome the adversity of having a cleft at birth, the associated surgery, and have not only gone on with a normal life but also achieved success to date in their identified careers. For surgeons and medical staff the study reveals how at different stages during the child's development different care strategies are required.

One of the female participants aptly stated in conclusion: Throughout all these journeys, although my cleft has been a bit of a pain at times, it has never stopped me from doing anything that I wanted. If anything, I believe it has strengthened my character and ability to achieve goals. Although my cleft has had, and will continue to have, a financial and emotional impact on my life I have made it an accepted part of me and have striven to achieve the best for me within this.

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