The Unexpected Pregnancy Outcome:  
A Child with a Facial Cleft  

Graeme H. Wallace and Heather Mattner  

Abstract: This Australian study was conducted to understand some of the issues involved where a child is unexpectedly born with a cleft lip and/or palate (CLP). Parents involved in this study had followed their child’s development from birth to adulthood having completed all surgery, and each now involved in the community as adults. Because these children were now more than 26 years old, many resources available to parents now were not accessible when these children were young, for example, early ultrasound screening. This study found that there were expected parental concerns for each child, particularly when surgery was imminent. These concerns were minimized by the support provided by the relevant health professionals, as well as CleftPals, an Australian cleft lip and palate support group, together with their immediate and extended families support during the difficult times.

Keywords: facial cleft, CLP, child development  

Being challenged by a traumatic event is a harrowing experience for any individual and must be difficult to comprehend for a parent who is unexpectedly faced with the fact that their newborn baby will have to undergo surgery over an extended period (Ogilvie, 1990). For the parent of a child unexpectedly born with a cleft, it could cause anxiety and concern in relation to how to raise their child, and how to protect them from what could be frightening, and/or demanding experiences. “Outsiders” may be less than tactful in discussions with a person or the family experiencing these difficulties, because of lack of understanding. Knowledge gained

Graeme Wallace OAM, KCSJ, MHSc, is a PhD candidate researching the etiology of cleft lip and palate at Southern Cross University in Lismore, New South Wales. He currently holds a master’s degree in Nutritional Medicine from the University of New England in Armidale, New South Wales. This research has been conducted in Australia and the Philippines, although he has collaborated widely with researchers around the world. Co-author, Dr. Heather Mattner, is a Perinatal Health Psychologist and Midwife with an extensive background in maternal/infant healthcare, midwifery practice, research and education, models of practice development and review, perinatal mental health and wellbeing, perinatal Aboriginal health and wellbeing and primary healthcare. Heather is an Adjunct Associate Professor in the School of Nursing and an Honorary Clinical Senior Lecturer in the School of Psychology at The University of Adelaide. Her publications include, Better Birth, with Lareen Newman, and Evaluation of the National Perinatal Depression Initiative, with Chris Ciancio. She is currently working on a new book about perinatal PTSD and trauma.
from this study may help the general public to be more tactful. An insight into how parents of children with a cleft cope may also assist the medical profession to improve their services, particularly in relation to the parents in the future.

Background, Including Incidence

Cleft lip and palate is a common birth anomaly. In most cases, worldwide, 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 (Chapados, 2000).

Causal research into clefting appears to have started in the middle of the 20th century (Fraser, 1969; Perko, 1986) but no clear linkages between genetics, nutritional, or environmental factors have been established for definitive causal factors. Researchers (Bille, Knudsen, & Christensen, 2005; Fraser, 1969; Gahassobe et al. 2015; Zucchero et al. 2004) refer to clefting as a multi-factorial problem so the cause may be genetic, nutritional, or environmental, or a mix of all three. Literature indicates that genetics, familial associations, nutrition, maternal medication substance abuse, drug use, and environmental toxins have been associated with CLP but no conclusive connection to any one or a combination of these factors has been established (Cedergren & Kallen, 2005; Hozyasz, 2010).

Incidence

In Australia birth defects registries are kept for each state and territory, with great variation in the quality of data recorded. As can be seen from the table below, there has been no appreciable variation in total incidence from 1987 to 2006 in Victoria, other than a variation in the type of cleft with CP the largest increase over this period. These data appear to be consistent with those in many countries (Sayetta, Weinrich, & Coston, 1989) where accurate statistics exist, and where no calamitous events such as earthquake, war or other pestilence have occurred (Sayetta et al. 1989).

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Source: (Riley & Halliday, 2008)
Research Question

The research question for this study was: What are some of the important issues faced by parents whose child had been unexpectedly born with a cleft?

Sample

Parents whose adult children were over the age of 26 who had been unexpectedly born with an isolated cleft lip and/or palate and had now completed all of the surgery required for complete rectification of the anomaly were included in the study. Parents whose child had multiple birth anomalies were excluded. Only those parents who gave signed informed consent were included in the sample.

Literature Review

Limited literature has considered the issues surrounding the parenting of a child unexpectedly born with a CLP (Berger & Dalton, 2009; Black, Girotto, Chapman, & Oppenheimer, 2009; Johansson & Ringsberg, 2004; Nelson, Glenny, Kirk, & Caress, 2011; Nelson, Kirk, Caress, & Glenny, 2012) and none have focussed on Australian families. Many, like Johansson and Ringsberg (2004), investigated only the very early problems when the children were one to five years old and where parents still had many issues to cope with. In general, researchers found that the parents had conflicting emotions, ranging from grief to elation on the completion of the child’s early cleft surgery. Parents were concerned at the uncertainty of the future for their child and the long-term treatment. Parents also had at times a feeling of social exclusion as they faced negative reactions from family and friends. Nelson et al. (2011) reviewed the existing literature regarding parents’ experiences, stating that much of it related to social and service aspects, such as child feeding support, especially in relation to the early stages of the children’s lives. The research relating to parents was variable (Nelson et al. 2011) with a narrow emphasis on cross-sectional deficit-oriented psychological approaches focused mainly on the mother. Research is needed to investigate how both mothers and fathers might experience the long-term and complex treatment journey as children with a cleft become older.

Several studies have been undertaken to determine the lived experience of people caring for those with other disabilities, with most considering intellectual anomalies. All these studies (Broberg, Blacher, & Emerson, 2009; Dukmak, 2009; Gerstein, Crnic, Blacher, & Baker, 2009) conclude that parents caring for children with such disabilities are exposed to greater levels of stress than other families. They also suggest
that these parents appear to risk greater exposure to other adversities such as continually having to change their own lifestyle to cope with the altered requirements of the child throughout the caring process. Other writers (Broberg et al. 2009; Dukmak 2009; Gerstein et al. 2009) indicate that parents develop a resilience that allows them to cope with the stresses as they arise.

Nicolaou and colleagues (2009) investigated maternal experiences of interacting with premature babies within the hospital neonatal unit. They found that the mothers were unsure and anxious about interacting with their infants, and while they felt supported in the neonatal unit, the health professionals in the general community, by comparison, were perceived to lack the knowledge and expertise to assist them. Other researchers (Jackson, Ternestedt, & Schollin, 2003) investigating both maternal and paternal experiences with premature babies found that the mothers reported more stress and poorer adjustment than the fathers. Holditch-Davis and Shandor-Miles (2000) found that healthcare providers and especially nurses have a major role to play in reducing parental distress by maintaining ongoing communication with the parents while providing competent care for their infants. This same feeling of helplessness and/or stress may be experienced by other parents whose children suffer from birth anomalies, and in particular a cleft.

Ethics Approval

This study was approved by the Human Research Ethics Committee of Southern Cross University (ECN-09-016) in New South Wales. The Ethics Committee requested that someone other than the researcher be present when conducting the interview as this could potentially be a very emotional experience for the interviewee.

Research Design

This study used a simple phenomenographic qualitative approach with a descriptive methodology. Thematic analysis was used to derive the themes from the data collected. All parents consented to being interviewed and to having the interview tape recorded in a location of their choice. All names of participants were changed to protect their identity.

In each case a private meeting was held with the participants and the interview was conducted in a semi-structured form based on a series of questions, with flexibility for participants to extend the discussion as they saw fit. Once the interviews were completed the data were transcribed and sent back to the participants for respondent validation. This was done to ensure rigor for the study and for the participants. The technique of referring the data back to a respondent is referred to as respondent
validation (Pilnick & Swift 2010) to ensure that what was recorded was completely accurate.

Qualitative research methods are designed to help researchers understand people and the social and cultural contexts within which they live (Sale, Lohfeld, & Brazil, 2002). In that sense, this study investigated the experiences of the parents in raising and supporting their children unexpectedly born with a cleft through to adulthood, with the research centered on gaining a better understanding of the problems they had to cope with.

Setting

The parents interviewed lived in the Australian states of Queensland, New South Wales and Victoria. All of the interviews were conducted in the parents’ homes. Where a partner was not present a participant had a friend attend for support. In only one case was a father able to attend the interview.

Data Analysis

Once the individual data had been read, and approved by each of the participants, it was coded using the computer program NVIVO (2015) 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 with a specific heading being applied to it.

Results

Participants

Four mothers who met the criteria for inclusion volunteered to be interviewed and one with a father. It is noted that this is a small sample size but this is an exceptional sample group given the “special” context. The participants’ children, now adults, ranged from 25 to 38 years with a mean of 28.6 years. One family lived in Victoria, two in New South Wales and one in Queensland. One of the children was unexpectedly born with a unilateral cleft lip, one an isolated cleft palate, one had a unilateral cleft lip and palate, while one had a bilateral cleft lip and palate. All had completed their surgical procedures and were now fully employed.

Findings
The data are presented in terms of the themes that were derived from the nodes established during the analysis. The headings for each theme were assigned to reflect the question discussed during the interview, and also to provide a synopsis of the responses.

**When Did You Know? – We Didn’t.**

Each of these children was born before it was common to offer ultrasound scans during pregnancy. However, it is quite likely that a parent being told after a scan that their child would be born with a cleft may have a similar reaction:

- “The first we knew that he had a cleft was shortly after he was born. When he was conceived women did not have scans and so we had no inkling that there could be an issue. Of course the realization that in my rush to have a baby so quickly after a miscarriage I may have caused the cleft, was painful. I certainly have thought it but have never spoken it out aloud.”
- “I had no idea that he would be born with a cleft and really only knew when there was deathly silence in the room immediately after he came into the world.”
- “I didn’t know before she was born that she would be born with a cleft and so it was quite a shock to realize that this had occurred. I had an inclination that something was not quite right as I had a very ominous feeling throughout the pregnancy, and I don’t know whether it was because the pregnancy didn’t go well at the beginning, or whether I felt it was going wrong.”

**Distress – Yes There Was.**

Each participant expressed their shock and distress in differing ways but all were obviously very upset when finding out that they were faced with a long period of surgery for their child:

- “[After the birth] my husband and I were in shock. We were looking at each other exhausted – during the delivery I had felt concerned for my own health, for the health of our baby, and felt threatened by the whole situation. My husband looked pale and I assured him that this would be our last [child]. Our doctor came to speak to us. He prefaced his comments with, ‘I think we have a problem.’ We did not pick up the gravity of the situation and answered ‘We don’t care, it’s over.’ It was then he explained our child’s condition. We could not take in what he was saying and it wasn’t until the midwives brought the baby over to us that we
understood. I felt that the first week after the birth must have been very different and difficult [having to relay the news to others] for my husband. We have a large extended family and many friends. While I stayed protected and supported in the hospital, he was the one who had to explain the condition to everyone and field all the questions that caring family and friends asked.”

- “I felt very hurt when the pediatrician told me that my baby had a syndrome [unsubstantiated claim]. I felt like a failure. It then made me feel like rejecting my baby. I was so distressed because they put me in a room with a lady who had a healthy baby and she was phoning everyone and she was really happy and I was really sad. Every time she phoned someone to say ‘I’ve got this Jo Ellen and she’s really beautiful,’ and there’s her baby, and mine wasn’t there; I was just devastated, and so in a way I rejected her. It wasn’t a bonding (sic) at all.”

**The Hospital Experience**

The hospital experience is common for most new mothers and, in general, all patients are dealt with in a kind and considerate way. However, there are always exceptions and where a situation is not normal it is the skill and experience of the health professionals that can make the difference.

- “I remained in the delivery suite to rest and it was here that I met the man who was to be my son’s plastic surgeon. He was amazing and it was a pity that my husband was not able to be there. We had no idea that he would come in. The hospital or our doctor must have called him in. He assured me that the condition was not life-threatening and that my son was, apart from the cleft, a normal healthy baby. He was positive and explained with excitement the inroads being made by doctors in this area. He arranged a time for our first consultation before leaving.”

- “My doctor handled it very well and I had a good relationship with him – he was this gentle lovely competent man who made me feel very comfortable. He answered all my questions and, yes, it was all very straight forward. Yes, I realize there are always risks with surgery, going under anesthetic and all that, but everything was handled so professionally. He knew which specialist to contact and I left that all to him. He knew exactly the person, and he was ideal.”
Before and After Photographs

The question whether mothers should be shown before and after photographs to reduce some of the distress could be problematic depending on the degree of distress that the mother is experiencing. The situation may be quite different where a mother is being told that her child will have a cleft following an ultrasound scan. Sensitivity by the practitioner is vital.

- “Some people might not find seeing the photos as useful as I did, but I think once you’ve had a day or so to look at your own child it could be helpful. It’s such a confronting sight anyway, that once you’ve mentally accepted the fact that your child is OK in every other respect and can look at the child, then you can look at the photos of the stitches and you think it’s wonderful. But if you’re still at the point where you can’t even bear to look at your own child and the gum, and how fleshy the whole thing is, then I think you would find it difficult.”

Family Support – It’s Essential.

All of the participants expressed the need for family support, and in each case the male partner was providing the primary support, but the extended family also had a role to play:

- “I know that my husband felt really hemmed in just by the act of having a baby. He was very accepting and was very good. His parents were fantastic; honestly, I had so much support from all the family.”

- “My husband’s mother was probably a ten-minute drive away from our place, grandparents about a twenty minute drive away. We were all very close and they were all supportive.”

- “My husband was very good, very helpful and more accepting than me. I thought he’s so accepting and I’m not. He did a lot of positive reinforcement, and [later] he looked after her when I went to work.”

CleftPals – They Were Very Supportive.

CleftPals is an Australian family support group made up of families who have already had a child with a cleft. In Australia when it is clear that their unborn child has a cleft, parents are encouraged to make contact with CleftPals. Parents involved in this study were not aware of Cleftpals
until after their child was born. Responses from the parents indicated the value of Cleftpals for them, albeit that this can also be challenging:

- “The following day [after the birth] a representative from CleftPals visited me. She gave me a pack which included a scoop feeder, plastic bottle and literature about the condition and their association. We joined but let our membership drop after two years as we found some in the group to be quite negative and looking for sympathy. I didn’t want to look for problems where there were none.”

- “The doctor had told me that I had to make a bonnet for my baby. I had no idea how to make this bonnet or even where to start. It was overwhelming. I asked him how do you do it and he said the mothers know. I said which mothers and he said the mothers at CleftPals. One of the mothers came in and made the bonnet for me while she was visiting.”

**Why Did This Occur? It’s A Mystery.**

Why had this cleft occurred? Was this pregnancy different to the others? These questions were impossible for participants to answer as there has been no definitive solution to the mystery of why clefts occur. Their comments however suggest that they tended to believe that the problem is nutritionally based.

- “This pregnancy was no different to the others. Of course I was much busier. We had two children at school and two at home. As far as I can recall I was healthy throughout. I had had (sic) a miscarriage two to three months prior to becoming pregnant again. Today doctors would probably advise women to wait a while before trying again but we were given no such advice.”

- “This was my first pregnancy and the only thing that happened when I look back was that I was a vegetarian when I became pregnant. I took folic acid and I did eat legumes, nuts, eggs, cheese and fish to get sufficient protein. I think that I was very careful to try and maintain my protein level. I had a fair bit of morning sickness and as a result of that I couldn’t bear the thought of a sloppy vegetarian meal any longer. All I wanted was a steak, a nice dry steak, and at that point I thought that’s the end of the vegetarianism, I need a steak. I was about 10 weeks pregnant when this happened and I suppose my body was telling me ‘you need protein.’ After making this change to my diet the rest of the pregnancy proceeded without any further problems. I went to my
General Practitioner once a month and more frequently when I approached full-term.”

The Procedures – Ongoing

The node in this section was based on two words, “procedures” and “coping.” The question asked was: Can you explain some of the procedures involved and the way that you and your family coped with these?

“...”

Our only problem all the way through was the knowledge that there would be surgery, after surgery, and although the doctors kept us in the loop, they were always throwing a curve ball in when least expected. We would go along to an appointment understanding what the next stage would hold, only to be told something different. Procedures were being improved all the time, new techniques were being developed, and on top of all of this, my son was growing. As he got older he found this very hard. While he may not appear so, he is a very gentle character with a soft centre. The doctor would talk to him in what seemed the 3rd person with scant regard for his feelings. He never complained, he never said ‘Why me?’ and I have asked him a few times over the years but this approach was hurtful. My son has an aversion to hospitals now and for that you cannot blame him. His initial surgeries were performed at the Children’s Hospital but all the rest took place in private hospitals where the condition and the aftercare needs were not really understood.”

“By age six-and-a-half, her breathing [M] was bad, her voice was nasal and the words were very indistinguishable. I could understand her more than others. Mothers can work out what babies want. So by age six-and-a-half I knew that other children were not able to understand her. We chose our own specialist this time and we found someone who had just started a new experiment called a phalangeal flap, and he had actually invented it. We’d never heard of it, but he said he would take the tissues from the back of the throat to make a flap, but to never let her have a tonsil operation, so that she could block the air to her nose. I remember looking in her mouth after the surgery, I could still see the soft palate was still split, and I asked what happened, and he said you don’t actually sew the soft palate, it’s too soft or something, and it would come together itself. Then she had speech therapy.

She had a lot of difficulty, because my husband and I were from different countries of origin and different accents, but she did really well.
We had the orthodontal work when she was 12 or 13. The orthodontist was an elderly man, and then again, me being completely me I had not checked him out, or asked who is the best? I just took whoever we first met. And I’m not sure if he did a good job because he pulled all her teeth out and she should have had more teeth left, and it was very painful for her each time she went. I felt that’s what she had to have, she had a very crowded mouth with lots of teeth, and you have to have teeth pulled out, but I’m not sure whether it would have been better to leave the teeth and force the jaw to grow more, or wait until she was older to do it. So, I suppose I just went along with this. Had I known what I know now life could have been easier for us all.”

Could We Help Another Family? Perhaps.

If you were aware of another family who knew that their child would have a cleft how could you help them or what advice would you give them? While CleftPals already offer support to families it may be that the parents in this study might offer differing advice and hence this question:

– “My husband said first and foremost he would introduce them to our son. ‘A picture is worth a thousand words’ as far as I’m concerned. The best thing you could do for someone in this position would be to show them a ‘before and after’ photo. Certainly tell them that many surgeries may be involved but this is what your child will look like.”

– “I’d be wary of giving advice of any sort. This is because I know some of them may have been considering terminating. This was not an option in my day as you wouldn’t know at 12 weeks that you’re going to have a child with a cleft. So it’s a whole place for consideration that I have no experience of. I would, however, not have considered termination even if I had known, as I knew that I was a worthwhile person and was confident that my child would also be one. Being alive is worthwhile. If a woman has just given birth to a child with a cleft I would probably tell them that in the whole scheme of things, having a cleft doesn’t affect your ability to fall in love with people, for people to fall in love with you, it doesn’t affect your intelligence, or your integrity as a person. But I wouldn’t tell them it’s only a small thing because it’s not. I’d be really wary of giving advice because it’s still an awful shock when you have the child and they look so confronting.”
Discussion

Today because of the use of antenatal ultrasound, parents who have a fetus diagnosed with a cleft, can if they wish, plan ahead and even see surgeons before the birth occurs. They have the opportunity, if they so desire, via groups, such as CleftPals, to talk to other parents who have been through these experiences. Only one woman in this study had antenatal scans but the cleft was not detected, and because there was no prior diagnosis in any of the cases their planning during pregnancy was limited.

The data above not only show that in each case that the cleft was a surprise to the mother, but they give an insight into some of the feelings associated with first being informed of the diagnosis. They felt pain, fear from the deathly silence in the room, trepidation on the part of a doctor who was unsure what to say to the parent, and shock that triggered the mother to look back over her pregnancy to try and find a reason why this had occurred. Even though one of these women had had an antenatal scan it had failed to detect the cleft and so there was an added element of surprise, and a feeling that she had been let down by the technology. For those working in primary health care, particularly in the neonatal area, it is important to be aware of the mixed feelings and emotional responses to childbirth when the newborn has a cleft.

The responses of shock, exhaustion, hurt, stress, and strain are all synonymous with distress and are part of the emotional response to having just been delivered news that a much sought after new family member was going to need extended medical and surgical treatment. Mixed with these emotions was also a sense of failure that it was the mother’s fault, and yet there was no basis for this. In one case the mother was concerned for her husband as she felt that she had support, while her husband had, in her opinion, the more difficult job of telling the other family members. The distressing times were not just at the birth, as one mother describes the anguish she felt when her child had surgery. It can be seen where healthcare could have been managed better. For example, advice on what might be expected prior to and following surgery may have prepared parents better. The use of more attentive language that was less fear-inducing would have been beneficial. Where medical staff considered the impact of their professional support relationship with the parents and the information they were providing, parents felt assured and less overwhelmed.

Only one of the parents commented on the value of photographs indicating the potential difficulty a person may have in looking at before and after photographs while contemplating the prospects for their child who has either an unrepaired or recently operated on cleft. This highlights the delicacy needed by those involved with women experiencing these
traumatic/emotional issues when their child has been born with an anomaly.

Mothers expressed their need for support and not be left alone to endure this hardship. There was no hesitation by the mothers in praising the support that was provided to them and the immediate family.

The aim of CleftPals (CleftPals, 2013) is to help new families from the moment the fetal cleft is diagnosed through to the child’s teenage years. The organization is fully funded by parents, without government support. The timing of information, and the level of information provided is critical as are the internal group dynamics of such an organization. Within the peer support groups of CleftPals there can be those who are seeking attention and/or pursuing their own agenda and this can impact negatively on others seeking fair-minded information and support.

Where the surgical procedures were discussed, parents dealt with each issue as it arose, even when they had to respond to unexpected challenges. These parents were dealing with an ever-evolving set of circumstances and at times it seemed to them that the child was a peripheral participant. The children needed to be accepted as partners and treated accordingly, not as passive recipients.

Raising a child with any disability can be challenging, and indeed that was the experience of these families. From the outset parents faced uncertainty for their child’s future and the journey for each parent was different. They relied heavily on the medical community for the selection of professionals and for positive reinforcement, and yet some of these staff appeared not to fully appreciate the emotional state of the parents at the time. It was clear from the parents that a gentle, caring, and positive attitude on the part of the doctor was much more helpful in planning a path for the future of the child’s medical treatment than merely a declaration that problems existed but could be rectified. This study shows that every individual case is different and that each person involved must be treated in a very personal manner. Each parent had differing emotions and these changed over the course of the treatment period. The children matured and the relationship with both parent and practitioner changed with time bringing new challenges. The procedures involved were difficult for parents at times as they felt deeply for their child as they entered surgery and could not see an end to these ongoing operations. In relation to these parents helping others who may find themselves in similar positions, they stated they would all give positive reinforcement to them.

This study highlights the need for preconception planning in order to try to minimize the possibility of a birth anomaly. Wallace, Arellano, & Gruner (2011) suggest that stress at or near conception could be a causal factor. This stress may be of a physical or psychological nature, perhaps relating to work or home issues. The authors cited that some mothers were stressed by their workload or the conditions under which they worked. Some, who unexpectedly became pregnant, were challenged by their
partner regarding the possibility of aborting the fetus. It is not difficult to imagine the stress such a comment would place on the woman. It is, therefore, important for couples to discuss whether they are ready to bring a child into their family to avoid such difficult situations.

Other researchers suggest that nutrition could relate to this anomaly (Bergmann, Makosch, & Tews, 1980; Durning, Chestnutt, Morgan, & Lester, 2007; Henly & Nixon 1997; Uriu-Adams & Keen, 2010). Hyman (2014) makes the claim that many people today are overfed and yet undernourished. Given this situation it is possible that many women become pregnant while in an undernourished state. Many nutritional supplement manufacturers have in their portfolio of products specific preconception products. The use of such products prior to conception may reduce the possibility of birth anomalies if taken well prior to conception.

Wallace and Mattner (2017) found that while children who were born with a CLP often had protracted surgery, and the difficulties associated with this, they grew up having almost identical experiences to children who had no birth anomalies. All of those studied achieved their goals in life. None claimed to have ongoing emotional or psychological issues.

The use of ultrasound technology has provided a helpful tool in detecting many of the possible birth anomalies, but it is the accuracy and manner in which this information is imparted to the family that is far more important. It is proposed that those who do have the problem of relaying such information to a parent should also have the answers as to how the problem may be solved, and in particular, the appropriate health professionals to refer the parents to.

Conclusion

Being a parent is challenging when your child is unexpectedly born with a cleft and the problems faced can become exponential. These parents showed the emotion of raising their child and dedicated themselves to accessing the best treatment available. They were not aware that their child would have a cleft and had to face the fear and shock of the unknown. Parents experienced distress in coming to terms with the reality that their child would need ongoing treatment, and felt for the child as they were operated on while often having to contend with insensitive language and care.

While the hospital procedures were ongoing, each family found inner strength to deal with each situation as it arose. The parents felt that the young adults may at times have been frustrated with being ignored or sidelined by the practitioners. They also had distress, joy, sadness, fear, and relief, and finally elation and pride in knowing that their child had ultimately achieved success in their life. They were all prepared to help others in similar need, but each presented different considerations as to
how to provide such assistance indicating that it must be tailored to suit each particular child, family, and context.

References


