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4 **The Unexpected Pregnancy Outcome:**  
5 **A Child with a Facial Cleft**

6  
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10 Abstract: This Australian study was conducted to understand some of the issues involved  
11 where a child is unexpectedly born with a cleft lip and/or palate (CLP). Parents involved in  
12 this study had followed their child's development from birth to adulthood having completed  
13 all surgery, and each now involved in the community as adults. Because these children were  
14 now more than 26 years old, many resources available to parents now were not accessible  
15 when these children were young, for example, early ultrasound screening. This study found  
16 that there were expected parental concerns for each child, particularly when surgery was  
17 imminent. These concerns were minimized by the support provided by the relevant health  
18 professionals, as well as CleftPals, an Australian cleft lip and palate support group, together  
19 with their immediate and extended families support during the difficult times.  
20

21 Keywords: facial cleft, CLP, child development  
22  
23

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

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33 from this study may help the general public to be more tactful. An insight  
 34 into how parents of children with a cleft cope may also assist the medical  
 35 profession to improve their services, particularly in relation to the parents  
 36 in the future.

37  
 38 **Background, Including Incidence**

39  
 40 Cleft lip and palate is a common birth anomaly. In most cases,  
 41 worldwide, it is an isolated or single malformation, however, in  
 42 approximately 5-10% of cases, regardless of ethnicity, it is either an  
 43 associated or paired malformation (Chapados, 2000).

44 Causal research into clefting appears to have started in the middle of  
 45 the 20<sup>th</sup> century (Fraser, 1969; Perko, 1986) but no clear linkages between  
 46 genetics, nutritional, or environmental factors have been established for  
 47 definitive causal factors. Researchers (Bille, Knudsen, & Christensen,  
 48 2005; Fraser, 1969; Gahassobe et al. 2015; Zucchero et al. 2004) refer to  
 49 clefting as a multi-factorial problem so the cause may be genetic,  
 50 nutritional, or environmental, or a mix of all three. Literature indicates  
 51 that genetics, familial associations, nutrition, maternal medication  
 52 substance abuse, drug use, and environmental toxins have been  
 53 associated with CLP but no conclusive connection to any one or a  
 54 combination of these factors has been established (Cedergren & Kallen,  
 55 2005; Hozyasz, 2010).

56  
 57 **Incidence**

58  
 59 In Australia birth defects registries are kept for each state and  
 60 territory, with great variation in the quality of data recorded. As can be  
 61 seen from the table below, there has been no appreciable variation in total  
 62 incidence from 1987 to 2006 in Victoria, other than a variation in the type  
 63 of cleft with CP the largest increase over this period. These data appear  
 64 to be consistent with those in many countries (Sayetta, Weinrich, &  
 65 Coston, 1989) where accurate statistics exist, and where no calamitous  
 66 events such as earthquake, war or other pestilence have occurred (Sayetta  
 67 et al. 1989).

68  
 69 **Table 1.1 Victorian Cleft Data 1987-2006**

Anomaly	1987-1991 N/10,000	1992-1996 N/10,000	1997-2001 N/10,000	2002-2006 N/10,000
Cleft Palate	6.6	8.0	7.8	8.9
Cleft Lip	4.0	3.6	4.1	3.9
Cleft Lip and Palate	6.6	6.2	7.1	6.1
Total	17.2	17.8	19.0	18.9

70 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, Giroto, 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

116 that these parents appear to risk greater exposure to other adversities  
117 such as continually having to change their own lifestyle to cope with the  
118 altered requirements of the child throughout the caring process. Other  
119 writers (Broberg et al. 2009; Dukmak 2009; Gerstein et al. 2009) indicate  
120 that parents develop a resilience that allows them to cope with the  
121 stresses as they arise.

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

### 137 **Ethics Approval**

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

### 144 **Research Design**

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

152 In each case a private meeting was held with the participants and the  
153 interview was conducted in a semi-structured form based on a series of  
154 questions, with flexibility for participants to extend the discussion as they  
155 saw fit. Once the interviews were completed the data were transcribed  
156 and sent back to the participants for respondent validation. This was done  
157 to ensure rigor for the study and for the participants. The technique of  
158 referring the data back to a respondent is referred to as respondent  
159

160 validation (Pilnick & Swift 2010) to ensure that what was recorded was  
161 completely accurate.

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

169  
170 **Setting**

171  
172 The parents interviewed lived in the Australian states of Queensland,  
173 New South Wales and Victoria. All of the interviews were conducted in  
174 the parents' homes. Where a partner was not present a participant had a  
175 friend attend for support. In only one case was a father able to attend the  
176 interview.

177  
178 **Data Analysis**

179  
180 Once the individual data had been read, and approved by each of the  
181 participants, it was coded using the computer program NVIVO (2015) to  
182 establish the nodes to confirm the themes from the data. Each transcript  
183 was uploaded to the program which was then run to provide a cluster  
184 analysis of word similarity followed by word frequency. This was then  
185 reviewed to determine specific nodes with a specific heading being applied  
186 to it.

187  
188 **Results**

189  
190 **Participants**

191  
192 Four mothers who met the criteria for inclusion volunteered to be  
193 interviewed and one with a father. It is noted that this is a small sample  
194 size but this is an exceptional sample group given the "special" context.  
195 The participants' children, now adults, ranged from 25 to 38 years with a  
196 mean of 28.6 years. One family lived in Victoria, two in New South Wales  
197 and one in Queensland. One of the children was unexpectedly born with a  
198 unilateral cleft lip, one an isolated cleft palate, one had a unilateral cleft  
199 lip and palate, while one had a bilateral cleft lip and palate. All had  
200 completed their surgical procedures and were now fully employed.

201  
202 **Findings**

203

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

248 understood. I felt that the first week after the birth must have  
 249 been very different and difficult [having to relay the news to  
 250 others] for my husband. We have a large extended family and  
 251 many friends. While I stayed protected and supported in the  
 252 hospital, he was the one who had to explain the condition to  
 253 everyone and field all the questions that caring family and friends  
 254 asked.”

255  
 256 – “I felt very hurt when the pediatrician told me that my baby had  
 257 a syndrome [unsubstantiated claim]. I felt like a failure. It then  
 258 made me feel like rejecting my baby. I was so distressed because  
 259 they put me in a room with a lady who had a healthy baby and she  
 260 was phoning everyone and she was really happy and I was really  
 261 sad. Every time she phoned someone to say ‘I’ve got this Jo Ellen  
 262 and she’s really beautiful,’ and there’s her baby, and mine wasn’t  
 263 there; I was just devastated, and so in a way I rejected her. It  
 264 wasn’t a bonding (sic) at all.”

### 266 **The Hospital Experience**

267  
 268 The hospital experience is common for most new mothers and, in  
 269 general, all patients are dealt with in a kind and considerate way.  
 270 However, there are always exceptions and where a situation is not normal  
 271 it is the skill and experience of the health professionals that can make the  
 272 difference.

273  
 274 – “I remained in the delivery suite to rest and it was here that I met  
 275 the man who was to be my son’s plastic surgeon. He was amazing  
 276 and it was a pity that my husband was not able to be there. We  
 277 had no idea that he would come in. The hospital or our doctor must  
 278 have called him in. He assured me that the condition was not life-  
 279 threatening and that my son was, apart from the cleft, a normal  
 280 healthy baby. He was positive and explained with excitement the  
 281 inroads being made by doctors in this area. He arranged a time for  
 282 our first consultation before leaving.”

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

291

292 **Before and After Photographs**  
293

294 The question whether mothers should be shown before and after  
295 photographs to reduce some of the distress could be problematic  
296 depending on the degree of distress that the mother is experiencing. The  
297 situation may be quite different where a mother is being told that her child  
298 will have a cleft following an ultrasound scan. Sensitivity by the  
299 practitioner is vital.  
300

- 301 – “Some people might not find seeing the photos as useful as I did,  
302 but I think once you’ve had a day or so to look at your own child it  
303 could be helpful. It’s such a confronting sight anyway, that once  
304 you’ve mentally accepted the fact that your child is OK in every  
305 other respect and can look at the child, then you can look at the  
306 photos of the stitches and you think it’s wonderful. But if you’re  
307 still at the point where you can’t even bear to look at your own  
308 child and the gum, and how fleshy the whole thing is, then I think  
309 you would find it difficult.”  
310

311 **Family Support – It’s Essential.**  
312

313 All of the participants expressed the need for family support, and in  
314 each case the male partner was providing the primary support, but the  
315 extended family also had a role to play:  
316

- 317 – “I know that my husband felt really hemmed in just by the act of  
318 having a baby. He was very accepting and was very good. His  
319 parents were fantastic; honestly, I had so much support from all  
320 the family.”
- 321 – “My husband’s mother was probably a ten-minute drive away from  
322 our place, grandparents about a twenty minute drive away. We  
323 were all very close and they were all supportive.”
- 324 – “My husband was very good, very helpful and more accepting than  
325 me. I thought he’s so accepting and I’m not. He did a lot of positive  
326 reinforcement, and [later] he looked after her when I went to  
327 work.”  
328

329 **CleftPals – They Were Very Supportive.**  
330

331 CleftPals is an Australian family support group made up of families  
332 who have already had a child with a cleft. In Australia when it is clear  
333 that their unborn child has a cleft, parents are encouraged to make contact  
334 with CleftPals. Parents involved in this study were not aware of Cleftpals



335 until after their child was born. Responses from the parents indicated the  
336 value of CleftPals for them, albeit that this can also be challenging:

- 337
- 338 – “The following day [after the birth] a representative from  
339 CleftPals visited me. She gave me a pack which included a scoop  
340 feeder, plastic bottle and literature about the condition and their  
341 association. We joined but let our membership drop after two  
342 years as we found some in the group to be quite negative and  
343 looking for sympathy. I didn’t want to look for problems where  
344 there were none.”
  - 345 – “The doctor had told me that I had to make a bonnet for my baby.  
346 I had no idea how to make this bonnet or even where to start. It  
347 was overwhelming. I asked him how do you do it and he said the  
348 mothers know. I said which mothers and he said the mothers at  
349 CleftPals. One of the mothers came in and made the bonnet for me  
350 while she was visiting.”

351

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

353

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

359

- 360 – “This pregnancy was no different to the others. Of course I was  
361 much busier. We had two children at school and two at home. As  
362 far as I can recall I was healthy throughout. I had had (sic) a  
363 miscarriage two to three months prior to becoming pregnant  
364 again. Today doctors would probably advise women to wait a while  
365 before trying again but we were given no such advice.”
- 366 – “This was my first pregnancy and the only thing that happened  
367 when I look back was that I was a vegetarian when I became  
368 pregnant. I took folic acid and I did eat legumes, nuts, eggs, cheese  
369 and fish to get sufficient protein. I think that I was very careful to  
370 try and maintain my protein level. I had a fair bit of morning  
371 sickness and as a result of that I couldn’t bear the thought of a  
372 sloppy vegetarian meal any longer. All I wanted was a steak, a  
373 nice dry steak, and at that point I thought that’s the end of the  
374 vegetarianism, I need a steak. I was about 10 weeks pregnant  
375 when this happened and I suppose my body was telling me ‘you  
376 need protein.’ After making this change to my diet the rest of the  
377 pregnancy proceeded without any further problems. I went to my

378 General Practitioner once a month and more frequently when I  
379 approached full-term.”

380  
381 **The Procedures – Ongoing**

382  
383 The node in this section was based on two words, “procedures” and  
384 “coping.” The question asked was: Can you explain some of the procedures  
385 involved and the way that you and your family coped with these?  
386

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

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

419 She had a lot of difficulty, because my husband and I were  
420 from different countries of origin and different accents, but she did  
421 really well.

422 We had the orthodontal work when she was 12 or 13. The  
423 orthodontist was an elderly man, and then again, me being  
424 completely me I had not checked him out, or asked who is the best?  
425 I just took whoever we first met. And I'm not sure if he did a good  
426 job because he pulled all her teeth out and she should have had  
427 more teeth left, and it was very painful for her each time she went.  
428 I felt that's what she had to have, she had a very crowded mouth  
429 with lots of teeth, and you have to have teeth pulled out, but I'm  
430 not sure whether it would have been better to leave the teeth and  
431 force the jaw to grow more, or wait until she was older to do it. So,  
432 I suppose I just went along with this. Had I known what I know  
433 now life could have been easier for us all."  
434

### 435 **Could We Help Another Family? Perhaps.**

436

437 If you were aware of another family who knew that their child would  
438 have a cleft how could you help them or what advice would you give them?  
439 While CleftPals already offer support to families it may be that the  
440 parents in this study might offer differing advice and hence this question:  
441

- 442 – “My husband said first and foremost he would introduce them to  
443 our son. ‘A picture is worth a thousand words’ as far as I’m  
444 concerned. The best thing you could do for someone in this position  
445 would be to show them a ‘before and after’ photo. Certainly tell  
446 them that many surgeries may be involved but this is what your  
447 child will look like.”
- 448 – “I’d be wary of giving advice of any sort. This is because I know  
449 some of them may have been considering terminating. This was  
450 not an option in my day as you wouldn’t know at 12 weeks that  
451 you’re going to have a child with a cleft. So it’s a whole place for  
452 consideration that I have no experience of. I would, however, not  
453 have considered termination even if I had known, as I knew that  
454 I was a worthwhile person and was confident that my child would  
455 also be one. Being alive is worthwhile. If a woman has just given  
456 birth to a child with a cleft I would probably tell them that in the  
457 whole scheme of things, having a cleft doesn’t affect your ability  
458 to fall in love with people, for people to fall in love with you, it  
459 doesn’t affect your intelligence, or your integrity as a person. But  
460 I wouldn’t tell them it’s only a small thing because it’s not. I’d be  
461 really wary of giving advice because it’s still an awful shock when  
462 you have the child and they look so confronting.”  
463

**Discussion**

464  
465  
466 Today because of the use of antenatal ultrasound, parents who have a  
467 fetus diagnosed with a cleft, can if they wish, plan ahead and even see  
468 surgeons before the birth occurs. They have the opportunity, if they so  
469 desire, via groups, such as CleftPals, to talk to other parents who have  
470 been through these experiences. Only one woman in this study had  
471 antenatal scans but the cleft was not detected, and because there was no  
472 prior diagnosis in any of the cases their planning during pregnancy was  
473 limited.

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

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

503 Only one of the parents commented on the value of photographs  
504 indicating the potential difficulty a person may have in looking at before  
505 and after photographs while contemplating the prospects for their child  
506 who has either an unrepaired or recently operated on cleft. This highlights  
507 the delicacy needed by those involved with women experiencing these

508 traumatic/emotional issues when their child has been born with an  
509 anomaly.

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

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

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

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

546 This study highlights the need for preconception planning in order to  
547 try to minimize the possibility of a birth anomaly. Wallace, Arellano, &  
548 Gruner (2011) suggest that stress at or near conception could be a causal  
549 factor. This stress may be of a physical or psychological nature, perhaps  
550 relating to work or home issues. The authors cited that some mothers were  
551 stressed by their workload or the conditions under which they worked.  
552 Some, who unexpectedly became pregnant, were challenged by their

553 partner regarding the possibility of aborting the fetus. It is not difficult to  
 554 imagine the stress such a comment would place on the woman. It is,  
 555 therefore, important for couples to discuss whether they are ready to bring  
 556 a child into their family to avoid such difficult situations.

557 Other researchers suggest that nutrition could relate to this anomaly  
 558 (Bergmann, Makosch, & Tews, 1980; Durning, Chestnutt, Morgan, &  
 559 Lester, 2007; Henly & Nixon 1997; Uriu-Adams & Keen, 2010). Hyman  
 560 (2014) makes the claim that many people today are overfed and yet  
 561 undernourished. Given this situation it is possible that many women  
 562 become pregnant while in an undernourished state. Many nutritional  
 563 supplement manufacturers have in their portfolio of products specific  
 564 preconception products. The use of such products prior to conception may  
 565 reduce the possibility of birth anomalies if taken well prior to conception.

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

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

## 578 **Conclusion**

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

590 While the hospital procedures were ongoing, each family found inner  
 591 strength to deal with each situation as it arose. The parents felt that the  
 592 young adults may at times have been frustrated with being ignored or  
 593 sidelined by the practitioners. They also had distress, joy, sadness, fear,  
 594 and relief, and finally elation and pride in knowing that their child had  
 595 ultimately achieved success in their life. They were all prepared to help  
 596 others in similar need, but each presented different considerations as to

597 how to provide such assistance indicating that it must be tailored to suit  
 598 each particular child, family, and context.  
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