

## The Scandcleft randomised trials: Parental reports of social and emotional experiences related to their 5-year-old child's cleft diagnosis

*Background and aim:* Parents of children with a cleft lip and palate may be emotionally affected by the child's diagnosis. Their experiences and perceptions are important when evaluating the complexity of satisfactory treatment outcomes. The objective was to examine parents' social and emotional experiences related to their child's cleft diagnosis and their perceptions of the child's adjustment to living with a visible difference.

*Design:* International multicenter study by 10 cleft teams in five countries: Denmark, Finland, Sweden, Norway and UK.

*Methods:* A cohort of 448 children born with a nonsyndromic UCLP were included. A total of 356 parents completed the Scandcleft Parent Questionnaire.

*Results:* The majority of parents experienced practical and emotional support from family, friends, and health professionals. Nevertheless, parents had to cope with other people's reactions to the cleft, experiences that were described as ranging from hurtful to neutral and/or positive. According to parents, 39% of the children had experienced cleft related comments and/or teasing. More than half of the parents reported specific worries related to their child's future.

*Conclusion:* While the majority of the parents experienced positive support and coped well with the child's diagnosis, some parents were at risk for psychological and emotional challenges that should be identified by the cleft team. To optimise outcomes and the child's adjustment, these parents should be offered psychological support when necessary.

**Key words:** Parental adjustment; cleft; social reactions; social support; teasing.

## INTRODUCTION

This paper is one of a series of reports of the Scandcleft Project, consisting of three concurrent randomised trials of primary surgery for infants born with complete unilateral cleft lip and palate (UCLP). The project was developed and executed by ten North European cleft teams: Århus /Copenhagen (Denmark), Helsinki (Finland), Bergen/Oslo (Norway), Gothenburg/Linköping/Stockholm (Sweden), Manchester/Belfast (UK). Recruitment of 448 infants took place over a 9-year period with high subsequent retention of participants. The present series of reports include primary outcomes of speech and dentofacial development at age 5, and perioperative and longer term secondary outcomes. Background information about the project can be found in Semb et al.'s introductory paper [1].

The experience of parents of children with a cleft lip and palate has been explored from many different perspectives (for a review, see [2,3]), highlighting the emotional and psychosocial aspects of having a child with a visible difference and in need of medical treatment. Feelings such as sadness, grief, shock, worry, guilt and self-blame have been described in parents [4,5,6], while other studies have indicated high levels of positive emotions and coping as a result of their child's condition [7,8]. Research has also highlighted challenges related to parents' social experiences due to the child's visible difference [2,9,10]. An association between social support and a positive family impact has also been underlined [7]. Only a limited number of studies, however, include parents across different countries, capturing potential cultural differences within the same design and methodology.

The treatment of a child born with a cleft lip and palate (CLP) is accomplished over a time period from infancy to young adulthood, and involves a wide range of

disciplines (such as plastic surgery, orthodontics, speech therapy, and psychology), which are all of major importance when evaluating the effectiveness of treatment outcomes [11]. Last, but not least, research should also include patients' and parents' evaluations of treatment in the complex picture of outcomes [12]. As reviewed by Nelson [2], few studies have explored parents' perspectives of their child's treatment journey. Parent perspectives add knowledge about processes between patients and clinicians, and perceptions of treatment outcomes, in line with Donabedian's conceptual framework for evaluations of quality of care [13]. Consequently, an evaluation of treatment outcomes of randomised trials such as the Scandleft project need to include information about parents' emotional and social experiences, in addition to an evaluation of surgical, orthodontic and speech outcomes, if we are to fully understand the complexity of satisfactory treatment outcomes and their experiences with cleft teams [10].

### **AIMS**

While the randomized trials in the Scandleft project were designed to compare aesthetic and functional outcomes of different surgical protocols, variations in surgical timing and technique were not expected to produce consistent differences in parent experiences and emotional reactions. Therefore, in the present paper, analyses were performed on the total sample and across country of residence (without any identification of the specific countries). More specifically, this study aimed to assess parents' responses and reactions to the cleft diagnosis, their experience of support from friends, family and health professionals, in addition to their perceptions of their child's early social experiences and reactions.

### **MATERIALS AND METHODS**

### ***Participants***

A total of 448 patients were included in the Scandleft trials, three of whom were lost to follow-up. Parents of 356 children at age 5 years completed the Scandleft Parent Questionnaire (Participation rate: 80%). There were 33.3% girls ( $n = 119$ ) and 67% boys ( $n = 237$ ).

Parents who completed the questionnaires were mostly couples (55.1%;  $n = 196$ ), in addition to 126 mothers (35.4%) and 14 fathers (3.9%). Other informants were foster parents or grandparents (1.2%,  $n = 4$ ), while 16 respondents (4.5%) did not indicate their relationship with the child.

### ***Parent Questionnaire***

A structured, self-administered questionnaire was designed by clinical psychologist Dr. Eileen Bradbury (Manchester, UK), and was translated into the four remaining represented languages. The Scandleft Questionnaire consisted of three sections:

- 1) Section 1: Background information (parents' occupation, siblings, and other family members with a cleft).
- 2) Section 2: The parent(s)' responses to the cleft.
- 3) Section 3: Parental perceptions of the child' responses to the cleft.

The questions included in Section 2 and 3 are presented in Table I. Most questions were presented in a yes/no format, followed by an open response format which enabled the parents to provide some more detailed and personal information.

INSERT TABLE I ABOUT HERE

The questionnaire was handed to the families by the teams' speech and language pathologist/therapist (SLP/T) when attending the child's 5-year-old multidisciplinary

assessment in four of the five participating countries. One country sent the questionnaire by post to the parents prior to the 5-year-old assessment, and parents were asked to return it when attending the cleft centre. One centre did not hand out the questionnaires for parents to complete, reducing the number of participating centres to nine in the present study. The parents were informed about anonymity in the introductory paragraph of the questionnaire. Ethical consent was sought locally by each participating treatment centre and/or country.

### **Statistical analyses**

Analyses were performed using SPSS 22 (IBM Corp, Armonk, NY). Yes/no responses were recorded and registered. Open-ended questions were broadly categorised so that frequencies could be calculated and compared. Information about how responses were categorised is provided within each section of the results. In most cases, percentages did not add-up to 100%, since parents could report several differing experiences on some questions, such as both positive and negative social experiences to the child's initial appearance. Calculations of frequencies were based on the number of parents having answered yes to the specific question. In order to preserve the participating centres' anonymity, as was agreed within the Scandleft project, results are not presented country-wise. However, in order to shed light on potential cultural and social differences between the participating countries, frequencies were calculated separately for each country and are presented as range frequencies in the analyses, without details about the specific countries.

## **RESULTS**

### **Section 1: Background information**

A total of 89.6% ( $n = 319$ ; Range 70.4 - 95.1%) of the participating children had sibling(s). Less than a quarter of the families reported a cleft in other family members (24.7%,  $n = 88$ ), a finding that however varied widely across the five participating countries, frequencies ranging from 3.7% to 42.9%. The same variation was found regarding the reported frequency of an ante-natal diagnosis (Mean frequency: 18.3%;  $n = 65$ ; Range 10.0 – 55.6%).

## **Section 2: Responses to the cleft**

### ***Support from family***

A total of 355 (99.7%) parents responded to this question. Most parents (84.6%;  $n = 301$ ) reported support from their family, while 14.3% ( $n = 51$ ) did not. Some parents answered both ‘yes’ and ‘no’ to this question (0.3%). Specific information about the kind of support received was given by 93% of the parents answering this question in the affirmative. Approximately half of the parents (47%,  $n = 141$ ) had received practical support from their families (such as help with bottle feeding, babysitting, looking after siblings, and help with travelling to appointments). The variations across countries was small and ranged from 36-52%. Perceptions of emotional support (such as reassurance, positive comments, talking and listening, encouragement, and acceptance) were reported by 69% ( $n = 209$ ; Range: 47-83%). Some parents (6.3%,  $n = 19$ ) also mentioned help with finding information about the diagnosis.

### ***Support from friends***

A total of 354 (99.4%) parents answered to this question. A majority of parents (71.5%;  $n = 254$ ) reported support from friends, while 27.3% ( $n = 97$ ) did not. Some parents answered maybe to this question (0.8%). Among the parents reporting support from friends, 90% provided specific information about the kind of support they had

experienced. Parents reported less practical support from friends (21.7%,  $n = 55$ ; Range: 12-27% across countries) than from family members. The majority of parents experienced emotional support by friends (77%,  $n = 196$ ; Range: 61-87%). Less than 5% ( $n = 12$ ; Range 0-10.2%) had received cleft-related information from friends.

### ***Unsupportive experiences***

A total of 13.5% ( $n = 48$ ) of the parents had experienced family or friends who were unsupportive. Most of these parents (70.2%,  $n = 33$ ) had also experienced positive support from family or friends. Examples of unsupportive experiences were other people hiding the cleft while babysitting, reluctance to hold the child, or unhelpful and upsetting comments or questions (38% of parents answering this question in the affirmative; 5% of total sample). Another experience was people keeping their distance or friends staying away, and/or not knowing what to say (29% of parents answering this question in the affirmative; 4% of total sample). Some parents specifically mentioned grandparents as having difficulties coping with the diagnosis (15% of parents answering this question in the affirmative; 2% of total sample). Two parents described how people had blamed them for their child's cleft (4% of parents answering this question in the affirmative; 0.6% of total sample).

### ***Support from professionals***

Most parents (86.2%;  $n = 307$ ; Range: 71-93%) reported support from professionals, while 11% ( $n = 39$ ) did not perceive such support. Some parents answered both 'yes' and 'no' to this question (2.8%). Perceived support from the cleft center varied widely across countries (Mean frequency: 67.1%; Range 55-81%). The variation in perceived support by local health services was even greater (Mean: 54.1%; Range 26-83%). Some parents also mentioned other local services as supportive (Mean 10.7%; Range

6-19%). In three of the cleft centers, perceptions of professional support were explicitly related to specific people in the team: 71% of the parents from one cleft centre specifically mentioned the specialist nurse, 51% of the parents from one country mentioned both specialist and local nurses as very helpful, while 40% of the parents from a third cleft centre mentioned the specialist SLP/T as being particularly helpful and available.

### *Comments from strangers*

A total of 66% ( $n = 235$ ; Range 44-76%) of the parents reported comments from strangers when taking the baby out before lip surgery. Some parents answered both yes and no to this question (0.9%). The majority of parents (95%) specified the content of comments from strangers. As can be seen from Table II, approximately one third experienced negative and hurtful curiosity and comments (30.8%,  $n = 72$ ; Range 26-37%), another third (36.3%,  $n = 85$ ; Range 27-53%) wrote that comments could also be neutral and motivated by a wish for more information about the diagnosis. Some parents reported reassuring comments (29.5%,  $n = 69$ ; Range 5-47%), such as people telling them that “*surgeons are so clever nowadays*”, “*luckily it is a boy, so he can grow a moustache*”, or “*this can easily be fixed*”. However, many parents specified that even if people meant such comments to be reassuring, they were often experienced by the parents as trivialising the challenges related to the diagnosis. Further, approximately a tenth of the parents (12.0%,  $n = 28$ ; Range 4-32%) experienced positive comments, such as “*wow, she has such beautiful eyes*”. Whispers and stares were reported by 17.9% ( $n = 42$ ; Range 5-27%), while 10.7% ( $n = 25$ ; Range 5-13%) said that people felt sorry for them or their child.

INSERT TABLE II ABOUT HERE



### ***Reactions to comments from strangers – past and present***

Past and present reactions to strangers' comments are found in Table II. When looking back to the first months after the child's birth, 28.4% of the parents ( $n = 101$ ; Range 20-40%) reported that they felt vulnerable and sad when first exposed to comments from strangers. As a result, some parents (7.9%,  $n = 28$ ; Range 4-15%) felt they had to protect the child or themselves from reactions and comments, and therefore hid their child or stayed at home. Yet other parents reported irritation and anger when people focused on the cleft (12.6%,  $n = 45$ ; Range 5-16%). In contrast, other parents were happy to be asked questions about the cleft (7.6%,  $n = 27$ ; Range 3-19%). Many parents also reported an open, calm, and practical approach to questions and comments (27.5%,  $n = 98$ ; Range 26-30%).

When answering the question about how they felt at the time of completion of the questionnaire, two thirds of the parents (63.2%,  $n = 225$ ; Range 44-81%) said that they now felt ok and happy about the child's treatment, and did not think about the cleft in their daily life. In contrast, a smaller group of parents still had worries for the future (11.5%,  $n = 41$ ; Range 4-17%), and still struggled emotionally when looking back and remembering the first months (5.1%,  $n = 18$ ; Range 4-7%). A small group of parents (1.7%,  $n = 6$ ; Range 0-3%) explicitly reported that they had become stronger as a consequence of their experiences.

### **Section 3: Responses of the child to the cleft**

#### ***Questions relating to the cleft***

Two thirds of the parents wrote that their child had asked questions about the cleft (67.7%,  $n = 241$ ). Most of these parents (93%) provided specific information about the child's questions (Table III). Questions were related to the appearance of the lip

and/or scar (38.3%;  $n = 93$ ; Range 21-48%), teeth (24.3%;  $n = 59$ ; Range 17-33%), appearance before the first operation (20.6%;  $n = 50$ ; Range 12-38%), and why they had been born with a cleft (36.6%;  $n = 89$ ; Range 15-46%). Some children also had questions related to the palate and/or fistulae (7.4%,  $n = 18$ ; Range 0-13%), or questions related to treatment and operations ( $n = 30$ ; 12.3%; Range 5-17%). Four point nine percent ( $n = 12$ ; Range 2-8%) had questions regarding speech.

INSERT TABLE III ABOUT HERE

### ***Signs of being upset***

According to parents, less than a quarter of the children (23.0%,  $n = 82$ ) showed signs of being upset about the cleft. Ninety two percent ( $n = 75$ ) of the parents reporting cleft-related distress in the child, provided more detailed information about the child's concerns. As can be seen in Table III, 39.6% ( $n = 78$ ; Range 26-52%) were distressed about speech, while 22.9% ( $n = 22$ ; Range 11-67%) had appearance related concerns. Further, 14.6% ( $n = 14$ ; Range 0-19%) mentioned fistulas as worrying the child, mainly related to food coming out of the nose. Treatment related distress was reported by 11.5% ( $n = 11$ ; 0-20%), while a few children were reported by parents to be upset specifically about teeth ( $n = 4$ ), nose ( $n = 2$ ), or breathing ( $n = 3$ ).

### ***Cleft-related comments and/or teasing***

A total of 39.0% ( $n = 139$ ) of the parents said that other children commented and/or teased their child because of the cleft (Table III). Most of the comments/teasing were related to speech (42.6%,  $n = 63$ ; Range 18-52%) or appearance (40.5%,  $n = 60$ ; Range 31-55%), while fewer parents mentioned comments or teasing related to teeth (12.8%,  $n = 19$ ; Range 3-30%). A few parents mentioned hearing and hearing aids ( $n = 3$ ), or the consequences of a fistula ( $n = 6$ ).

Some parents specified that the comments and/or teasing were perceived negatively by the child (55.6%;  $n = 50$ ) and were upsetting, while 44.4% ( $n = 40$ ) of the parents believed that the child was not affected by this. Comments about teeth were often presented as positive (“*Wow, he has lost a tooth already!*”), while comments on appearance or speech could be more difficult to cope with (“*He tells us that other children say he is ugly*” or “*She says other children don’t understand her speech*”). Some parents shared positive remarks such as “*Your scar has a Z-shape, exactly as Harry Potter’s scar!*”. Additionally, parents specified that negative experiences could be single episodes, in contrast to repeated experiences of teasing. Nine parents (6% of those reporting teasing) wrote that other children did not want to play with their child because they found them ugly or did not understand their speech.

INSERT FIGURE 1 ABOUT HERE

### ***Worries about the child’s future***

More than half of the parents reported that they were worried about their child’s future (55.1%,  $n = 196$ ). When specifying the nature of their worries (Figure 1), most parents specifically mentioned the fear of future teasing (41.3%,  $n = 81$ ), which they often linked to current or feared speech problems (33.2%,  $n = 65$ ), and/or appearance concerns (19.9%,  $n = 39$ ). Many parents also had apprehensions related to future treatment (28.1%,  $n = 55$ ). Fear of negative experiences at school was also mentioned specifically (16.3%,  $n = 32$ ). Some parents were concerned about whether their child would risk having children of their own with a cleft when reaching adulthood, or whether they would struggle with finding a partner (12.8%,  $n = 25$ ). Further, fear of reduced self-esteem was mentioned (11.7%,  $n = 23$ ), in addition to fear of social difficulties and not fitting-in (9.2%,  $n = 18$ ). Another 7.1% ( $n = 14$ ) mentioned the development of teeth as a major worry.

Among parents reporting worries about the future, approximately half had one major issue they were concerned about (46.4%,  $n = 91$ ), some mentioned two major issues (28.1%,  $n = 57$ ), while the remaining 24.5% ( $n = 48$ ) had three concerns or more.

### ***Decisions about having further children***

Most parents said that the experience of having a child with a cleft had not affected decisions about having further children (80.9%,  $n = 288$ ). A small number of parents were not certain (4.2%,  $n = 15$ ), while 14.9% ( $n = 53$ ) answered 'yes' to this question.

## **DISCUSSION**

The present study explored parents' social and emotional experiences, and their perceptions of their child's adjustment. Most parents experienced practical and emotional support from family, friends, and health professionals. Nevertheless, parents had to cope with strangers' reactions to the child's cleft. Approximately 40% of the children were reported to have experienced cleft related comments and/or teasing from other children at or before the age of five. More than half of the parents reported specific worries related to their child's future.

### **Support from family, friends, and health professionals**

When facing a diagnosis such as cleft lip and palate, most parents highlight the crucial need and protective effect of support, information, and advice regarding the diagnosis, treatment and daily life [3,7,14,15,16], probably reducing the demands of a diagnosis and offering additional resources to manage the situation [7]. In the present study, most parents reported that they had received practical, emotional, and information-based support from their family (84.6%) and friends (71.5), in line with previous studies [16,17]. Some variations in type of support were found between the five participating countries, which could be related to cultural or social differences.

A small number of parents (13.5%) had experienced unsupportive comments and hurtful encounters with others. Importantly, for the majority of these parents (70.2%), this occurred in the context of also experiencing positive support from others, probably reducing the emotional impact of the reported negative social experiences. However, a small group of parents reported unsupportive experiences in addition to a lack of support from friends and family. These comprise a potentially vulnerable subgroup of parents who should be identified and targeted for clinical follow-up.

Most parents reported support from health professionals (86.2%), mentioning the cleft team and specialist health professionals as particularly helpful, because of their specialism and expertise [10,18,19, 20]. An interesting finding was a significant number of parents explicitly mentioning named care providers they had met along the way, illustrating the importance of having practitioners who communicate well and show sensitivity [2,6], personal characteristics that can be found irrespective of discipline [19]. These findings further suggest that having one dedicated and available person in each cleft team who parents can contact when needed, could be a valuable investment in parents' adjustment to the child's diagnosis, and may possibly also strengthen the treatment-related cooperation between parents and health professionals.

### **Emotional responses to comments/reactions from strangers**

The emotional and social impact on parents of having a child with a cleft has been described previously [2,3,6,18]. Parents from the present study described a variety of emotional responses to the news of the child's cleft, on top of the challenge of coping with other people's reactions and comments. Two thirds reported comments and reactions from strangers when taking the baby out. The emotional impact and interpretation of those experiences varied widely, from hurtful to positive. Less than

20% of the parents reported staring and whispering, while 11% experienced pity from others. Variations in social reactions probably reflect the wide disparity in parents' experiences, mirror individual differences related to fear of negative evaluation by others, or could reflect sociocultural background factors. A better understanding of cross-cultural differences in emotional reactions to a diagnosis such as CLP would improve our delivery of a holistic and culturally sensitive care [4]. However, larger samples, more precise measures, and more complex designs are warranted in future research if we are to disentangle the relationships between parental perceptions of other people's reactions and their interpretations of these experiences.

Parents were asked to report how they felt during the first months after the child's birth (retrospectively), and to describe their feelings five years later (at the time of assessment). Parent responses clearly indicated a shift from distressful and challenging emotional reactions early on, towards more positive adjustment and experiences five years later. During the child's first months, approximately one third of the parents felt very vulnerable and sad, as has been described previously [3,8,21]. Five years later, only 5% of the parents found it difficult to think about the first months after the child's birth. Further, two thirds of the parents reported that they were happy about the results and that the cleft had less impact on their everyday lives than during the first months. A small group of parents (2%) explicitly mentioned that their child's diagnosis had made them tougher and stronger. The shift in emotional reactions after 5 years probably involves a better understanding of the diagnosis and its challenges, in addition to positive experiences of social support [7].

### **The child's social experiences and reactions**

According to the parents, approximately two thirds of the 5-year-old children (67.7%) had asked questions about the cleft. Questions were mostly appearance-related, but many children also had questions about the reasons for the cleft, or questions related to their appearance before the first operation. Very few children had questions regarding speech, in spite of this being one of the main reasons for comments from others and/or teasing. To our knowledge, no other studies have explored children's questions and curiosity about their cleft diagnosis, in spite of clinical experience suggesting that children with a cleft who are comfortable about the visual and/or audible difference, and have more knowledge about their condition, seem to show better psychological adjustment. Future research should aim to investigate possible associations between the child's curiosity and knowledge about the congenital condition, and psychological vulnerability or strength.

According to parents, 39% of the children had experienced comments and/or teasing, mostly in relation to speech (43%) and/or appearance (41%), as has been reported in previous studies [9,21,22]. Several parents importantly specified that approximately half of the children had not reacted negatively to questions and comments, in contrast to the other half, who had shown signs of emotional distress as a result. A subgroup of 6% of the children had told their parents that other children did not want to play with them because they were ugly or had an unusual speech. Reports of frequency of teasing in children with a cleft in the literature are very variable, with figures ranging from 20 to 75% [9,10,21,23,24,25,26]. This variation may reflect differences in informants (self-report, parents, teachers), age, cleft type, and the outcome measures used. Given associations between teasing, psychological distress and dissatisfaction with appearance [22,23,24], irrespective of objective facial difference cleft visibility

[24,27], children at risk for negative social experiences should be identified as early as possible in order to offer appropriate treatment and care.

### **Worries about the child's future**

As mentioned above, two thirds of the parents reported that they were happy about the results of treatment so far and that the cleft was not an issue they thought much about in everyday life anymore. Nevertheless, 55% still had worries for their child's future, such as worries about future teasing (41%), speech problems (33%), future treatment (28%), and/or were apprehensive about future appearance-related distress in their child (20%). The current findings point to the importance of making emotional and psychological support an integrated and regular part of cleft care. Parents' potential apprehensions should be explored by cleft clinicians, irrespective of the parents' level of satisfaction with treatment outcomes, and offer appropriate support when needed.

### **Future pregnancies**

Most parents (80.9%) reported that having a child with a cleft did not affect their decisions about having future children, while 14.9% said that they did not have the strength to cope with cleft-related challenges a second time, and therefore would not risk having another child. This may be a vulnerable subgroup of parents in need of genetic information, advice, or counseling about the heritability of clefts [28].

### **Strengths and limitations**

While cleft research is mostly based on single centre studies, the major strength of the present dataset was its inclusion of a large sample of parents from five different countries, using the same measure across all teams. Further, all children were aged 5, providing a broad cross-sectional picture of parent experiences and coping at one particular developmental stage. This is in contrast to many studies including wide age



ranges, probably in order to get larger samples, hence complicating the interpretations of results. In addition, response rates were high (80%) and based on consecutive birth cohorts of children with CLP.

The study also has a number of limitations. First, the questionnaire were translated without any back-translation, by team members from the different countries. However, the questionnaires were sent to all team members after translation, so that comments could be made. No or few comments were received. Further, the questionnaire was administered retrospectively, and was based on parent reports only. In addition, approximately 20% of the parents did not hand in the Parent Questionnaire, and differences between participants and non-participants cannot be ruled out. Second, the questionnaire has not been validated, and psychometric properties could not be calculated or provided. Further, the questionnaire included several open-ended questions. Forced responses with a selection of choices might have led to different conclusions. However, this potential limitation also means that results have probably not been overestimated, since answers were not suggested. The study was intended to be exploratory in nature, and the questionnaire format contributed to findings that give more scope for parents to report their views than validated and structured measures. Some parents responded “yes and no”, which could indicate a lack of alternative answers in the questionnaire. However, the frequency of a double response ranged from 0.3 to a maximum of 2.8%. We therefore believe that this methodological problem was minimal in the present study. Third, some differences between teams could potentially have affected parental responses. One team sent the questionnaire to the parents by post before attendance to the 5-year-old assessment, while the other teams handed out the questionnaires face-to-face. However, parents completed the questionnaires while waiting for their appointments at the cleft centre,

probably reducing this potential difference in how data were collected. Another difference between teams was that only three of the nine cleft centres had a clinical psychologist working within the team. Potential cultural and social differences may also have affected the results, and comparing outcome measures across countries based on larger samples should be the focus of future research.

## **CONCLUSIONS**

The present study provides a valuable insight into parental experiences and adjustment to their child's diagnosis at one point in time. Parents have to cope with a number of challenges related to their own and the child's emotional and psychological responses to the diagnosis, in addition to other people's reactions and comments. The results highlight the complexity of social and emotional responses to a medical diagnosis such as a cleft. Even if most parents experienced social, emotional and practical support from family, friends, and health professionals, some parents also reported emotionally challenging and hurtful social experiences. Overall, the findings of the present study point to vulnerable subgroups of parents and children who should be identified and offered appropriate psychological support and help. Nevertheless, the majority of parents seem to cope well with the challenges they face on the pathway of their child's treatment.

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