Dental fear among adolescents with cleft

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Abstract

Background: Dental fear is a prevalent phenomenon among children and adolescents globally.

Aim: To investigate dental fear among 18-year-olds with cleft lip and/or palate (CLP) at their final follow-up cleft clinic visit, and to evaluate the association between dental fear and OHRQoL.

Design: This cross-sectional study included the cohort of children with CLP treated at the Oulu University Hospital Cleft Lip and Palate Center, in northern Finland since 1995. A total of 62 of 64 individuals participated in this study. The validated Finnish version of the Oral Health Impact Profile (OHIP-14) was used to assess OHRQoL. Dental fear was studied using the validated Modified Dental Anxiety Scale (MDAS) and cognitive vulnerability model (CVM).

Results: Almost two fifths of the participants reported moderate dental fear. Participants with cleft including lip and participants reporting impact on OHRQoL reported higher mean MDAS scores. In an unadjusted model, adolescents with cleft including lip had risk for higher dental MDAS scores compared with the ones with cleft including only palate.

Conclusions: Dental fear is common among adolescents with CLP, specifically among those with clefts involving the lip. OHRQoL and dental fear seem to be associated.

Keywords

cleft lip, cleft palate, dental fear

Why this paper is important to paediatric dentists

• Dental fear is common among adolescents with cleft lip and/or palate, specifically among those with clefts involving the lip.

• Adolescents with clefts who have poor oral health–related quality of life also suffer more from dental fear.

• Feelings of uncontrollability and unpredictability during a dental procedure seem to be critical factors for developing dental fear and could be promoted in dental care.
1 | INTRODUCTION

Cleft lip and/or palate (CLP) are the most common congenital craniofacial birth defects. Generally, the incidence of clefts is estimated to be between 1 and 2.21 per 1000 live births or one in 1000 infants and one in 1000 infants. The overall incidence of clefts in Finland is remarkably high at 2.56 cases per 1000 live births and abortions. The incidence of isolated cleft palate in Finland is among the highest in the world. Children with clefts often need multidisciplinary treatment including complex surgical procedures, speech therapy, and psychological counseling. They also often have caries, dental anomalies, and a high treatment need for orthodontic treatment.

The children with clefts in northern Finland receive their special medical care by the same cleft team in the same tertiary healthcare center in Oulu University Hospital from birth to adulthood. Oulu University Hospital follows the Eurocleft program, which includes regular checkups at the hospital, the last scheduled checkup being at the age of 18. Oral health care is free for children and adolescents up to 18 years in Finland.

Dental fear is a prevalent phenomenon among children and adolescents, which is estimated to afflict between 10% and 20% of children globally. Severe dental fear has been reported by 8% of 18-year-old adolescents and approximately 20% of 11- to 16-year-old Finns reported severe dental fear in a follow-up study. Most commonly reported dental fears include needles, injections, and painful or uncomfortable procedures. Complaints such as not being in control, not knowing what the dentist will do, having a sense of danger, and feeling disgusted have also been reported as common characteristics of dental fear.

The Modified Dental Anxiety Scale (MDAS) is one of the measures used to assess dental anxiety. MDAS is a modified version of the Corah Dental Anxiety Scale (CDAS). In MDAS, the respondents are asked about their dental anxiety level before dental appointment and procedures concerning the anticipation, tooth drilling, scaling, and local anesthetic injection. Similarly, the cognitive vulnerability model (CVM) proposes that perceptions of uncontrollability, unpredictability, dangerousness, and disgustingness of a situation are critical determinants of fear and can be studied. CVM is based on a model of the etiology of fear, which positions cognitions, rather than experiences, as the main element in fear acquisition and expression.

Oral health–related quality of life (OHRQoL) is a patient-reported outcome measure for evaluating the subjective components of oral health. OHRQoL can be assessed using the validated Oral Health Impact Profile (OHIP-14) that consists of seven domains including functional limitation, physical pain, psychological discomfort, physical disability, psychological disability, social disability, and handicap. A systematic review and meta-analysis reported low OHRQoL among children with cleft lip and/or palate. A recent study on OHRQoL in this study population also revealed a distinct association between OHRQoL and the clefts, especially involving pain and psychological discomfort.

In a Swedish national survey, low OHRQoL was found to be associated with high dental fear. Dental fear has been also shown to have a negative impact on OHRQoL among Chinese children. A study conducted among 11- to 14-year-old Finnish children showed no statistical difference in dental fear between those with a cleft compared to those without. Contrary to this, dental fear was found to be higher among Dutch children with cleft aged 4-6 years and 9 years compared with those without cleft. It is, however, important to evaluate dental fear among children born with a cleft in late teenage after having been exposed to several surgical and dental procedures since infancy. Besides, they often need specialized care all their lives. Multiple procedures and low OHRQoL might predispose children with clefts to dental fear.

Therefore, the aim of this study was to investigate the prevalence of dental fear among CLP patients at their final follow-up cleft clinic visit at the age of 18. Another aim was to evaluate the association between dental fear and oral health–related quality of life (OHRQoL). It was hypothesized that patients with clefts including the lip have more dental fear than patients with clefts including only the palate and that patients with low OHRQoL suffer more from dental fear compared with those with high OHRQoL.

2 | METHODS

This cross-sectional study included the cohort of children born with cleft lip and/or palate (CLP) and who had been treated at the Oulu University Hospital (OUH), Cleft Lip and Palate Center, in northern Finland since 1995. The treatment of cleft children was provided by the OUH cleft team, which comprised a group of professionals including oral and maxillofacial surgeons specialized in operating clefts, an orthodontist, paediatric dentists, an otorhinolaryngologist, a psychiatrist, a phoniatrist, and a speech therapist.

The Northern Ostrobothnia Hospital District Ethical Committee gave their positive statement for the study protocol (permission number 10/2012). The study participation was voluntary, and those who agreed gave their verbal consent. Answering the questionnaire was also considered as agreement to attend. Participants were asked not to register any identification details in the form for confidentiality. A total of 62 of 64 individuals participated in the survey at their last follow-up visit in OUH at the age of 18. The data were collected between 2015 and 2019.
2.1 | Questionnaire

A self-administered, manual questionnaire was given to the participants during their last visit for this study. The follow-up visit included only an examination, and no procedures were performed during it. Participants completed the form by themselves. Parents could assist those participants who were unable to answer the questionnaire by themselves due to mild intellectual disability; however, the number of such cases was not registered and could not be identified due to the anonymous nature of the questionnaire. After completion of the questionnaire, the participants were asked to deposit the forms in a sealed container. The questionnaire included background information (gender and date of birth), and type of cleft, oral health–related quality of life (OHIP-14), and dental fear and anxiety (MDAS and CVM) were requested. The OHIP-14 and MDAS had been validated previously into the Finnish language, and the CVM was used here for the first time, respectively. The categories of the CVM were incorporated as described by Armfield.

2.2 | Cleft type

The participants chose one of the cleft types: cleft lip, cleft palate, unilateral cleft lip and palate, bilateral cleft lip and palate, and a bony defect of the hard palate. For analyses, cleft types were dichotomized as clefts involving the palate only (cleft palate and a bony defect of the hard palate) and clefts involving the lip (cleft lip, unilateral cleft lip and palate, and bilateral cleft lip and palate).

2.3 | Oral health–related quality of life (OHRQoL)

The validated Finnish version of the Oral Health Impact Profile (OHIP-14) was used to assess the oral health–related quality of life (OHRQoL) in this study. OHIP-14 consists of seven domains (Functional Limitation, Physical Pain, Psychological Discomfort, Physical Disability, Psychological Disability, Social Disability, and Handicap), each with two questions. For each question, participants were given a reference period of one month. The response options for each question were made using a Likert scale as follows: very often, fairly often, sometimes, very seldom, never, and don’t know. Using the additive scoring method, the score for each domain and total OHIP-14 score were calculated. The maximum score for each domain ranged from 0 to 8, and consequently, the total OHIP-14 score ranged from 0 to 56. For analyses, OHIP-14 score was dichotomized using the median score as no impact (OHIP score ≤ 2) and impact on OHRQoL (OHIP score ≥ 3) as explained in our previous study.

2.4 | The Modified Dental Anxiety Scale (MDAS)

Dental fear was studied using the validated Modified Dental Anxiety Scale (MDAS). The MDAS consists of five hypothetical questions concerning feelings about treatment tomorrow, waiting room, tooth drilled, teeth scaled and polished, and local anesthetic injection. The responses of MDAS were coded as ‘not anxious’ = 1, ‘slightly anxious’ = 2, ‘fairly anxious’ = 3, ‘very anxious’ = 4, and ‘extremely anxious’ = 5. The answers were analyzed by each question separately, and the total score for MDAS was calculated adding the responses of all five items, ranging from 5 to 25; commonly, sum score values 5–9 represent mild or no dental fear, 10-18 moderate, and ≥19 severe dental fear.

2.5 | Cognitive vulnerability model (CVM)

The perceptions of uncontrollability, unpredictability, dangerousness, and disgustingness associated with dental procedure were examined using the validated cognitive vulnerability model as part of the questionnaire. The CVM consists of four questions. The responses of the CVM were coded as ‘fully disagree’ = 5, ‘fairly disagree’ = 4, ‘neutral’ = 3, ‘fairly agree’ = 2, and ‘fully agree’ = 1. When translated into Finnish, the answers 1 and 5 were changed from ‘strongly agree’ and ‘strongly disagree’ to ‘fully agree’ and ‘fully disagree’. The answers of each question were analyzed separately.

2.6 | Statistical analysis

All data were transferred into an electronic database for analyses using the SPSS software (IBM SPSS Statistics for Windows, version 24.0; IBM Corp.). The analysis for MDAS items and total MDAS score was done separately. The proportions, means, and standard deviations (SD) were calculated. The MDAS was dichotomized based on the median score as no anxiety (score ≤ 9) and some degree of anxiety (score > 9), for analyses. The difference in proportions between groups was assessed using the chi-square test. To compare the difference in means between groups, the t test was used.

As the distribution of the outcome variable (MDAS score) was overdispersed, the negative binomial regression was conducted to examine the association between the outcome variable (MDAS score) and covariates (gender, cleft type,
RESULTS

Girls dominated the study population (n = 40 vs 22). The most common cleft type in this study population was cleft palate (n = 41). Almost 80% of the participants reported some anxiety toward tooth drilling and local anesthetic injection. Almost 65% reported some anxiety toward tooth scaling and polishing. (Table 1).

The mean (SD) MDAS score was 10.0 (4.5). Almost 40% of the participants reported moderate dental fear (MDAS score > 9). Participants with cleft including lip reported higher mean MDAS scores than those with cleft including only palate. Participants who reported impact on OHRQoL (OHIP-14 score ≥ 3) reported higher MDAS scores compared with the participants with no impact on OHRQoL (Table 2).

Adolescents with at least some degree of dental fear (MDAS > 9) reported more sensations of uncontrollability and unpredictability during a dental procedure. A majority of those who did not report any feelings of uncontrollability, unpredictability, dangerousness, or disgustingness did not report dental anxiety according to MDAS either (Table 3).

In an unadjusted model, adolescents with a cleft including the lip had risk for higher dental MDAS scores compared with the ones with cleft including only the palate (RR: 1.31; 95% CI: 1.05-1.64); however, the association was not significant when the model was adjusted with other possible covariates (RR: 1.06; 95% CI: 0.83-1.36). Unlikely, were the risk estimates accentuated in an adjusted model for those participants who fully agreed with the feeling of unpredictability during a dental procedure (ARR: 2.89; 95% CI: 1.62-5.15) (Table 4).

DISCUSSION

This study aimed to investigate dental fear among CLP patients in northern Finland at their final follow-up visit (at the age of 18) at the Oulu University Hospital Cleft Center. Another aim was to evaluate the association between dental fear and oral health–related quality of life (OHRQoL) among adolescents with CLP. Almost 40% of the participants reported dental fear of at least some degree, and the proportion was higher for the participants with a cleft including the lip than the ones without. Participants with dental fear of at least some degree reported more sensations of uncontrollability and unpredictability during a dental procedure than the ones reporting no or mild dental fear. The participants reporting impact on OHRQoL also reported higher dental fear.

Children with CLP were treated by the same cleft team from birth to adulthood, making it one of the strengths of this study. The subjects received special medical care in OUH but visited their local dentist in their primary health care centers for regular dental care. The local dentists might not be aware of the cleft patients’ special needs, and consequently, the care given to them might vary. The sample size in this study can be considered small although the incidence of CLP in Finland is among the highest (2.56 cases per 1000) in the world.3
our study comprised practically all (62/64 or 97%) of those who were born in northern Finland since 1995 and had turned 18 years. There was no control group, which can be considered a weakness of this study.

The literature about dental fear among cleft patients is scarce. In a Finnish study conducted among 11- to 14-year-old children, dental fear was not found to be significantly higher among those with a cleft than children without.23 This is not in line with our findings, as in our study almost two fifths of the study participants reported dental fear of at least some degree. Despite the lack of the control group in our study, there are previous studies that have estimated dental fear rate to be 10%-20% in average population.8,10 Our findings therefore show a clearly higher dental fear rate among patients with clefts.

Dental fear among cleft patients has been suggested to gradually decline over time.24,25 The same is true for a healthy population.14 This study was performed at one age point when all the participants were 18 years old; therefore, dental fear (measured by MDAS) within other development stages could not be studied. Dental fear among the same study participants was examined earlier at the ages of 11 to 14.23 In their study, dental fear was categorized to fear of treatment for dental decay, fear of attending the dentist, and general dental fear. The dental fear rate for those were 30%, 12%, and 15%, respectively. In our study, dental fear (measured by the hypothetical questions of MDAS) was reported by 38% of the participants; however, comparing the figures is challenging due to differences in indices used. Interestingly, our participants reported high rate of dental fear despite being in their late adolescence. It has been suggested that dental fear may be elevated in children exposed to medical intervention at a young age; however, this phenomenon seems to be equalized when growing older, resulting in similar levels of dental fear with cleft children and controls.23,24 It must be borne in mind that CLP patients often need various treatments through the course of their lives. Participants with

| MDAS categories                        | No anxiety (score ≤ 9) | Some degree of anxiety (score > 9) | P-value |
|----------------------------------------|------------------------|----------------------------------|---------|
| Cognitive vulnerability model           |                        |                                  |         |
| Uncontrollability (n = 59)             |                        |                                  |         |
| Fully disagree                         | 83.3                   | 16.7                             | <.001   |
| Fairly disagree                        | 10.0                   | 90.0                             |         |
| Neutral                                | 70.0                   | 30.0                             |         |
| Fairly agree                           | 25.0                   | 75.0                             |         |
| Fully agree                            | 100.0                  |                                  |         |
| Unpredictability (n = 58)              |                        |                                  | .023    |
| Fully disagree                         | 77.8                   | 22.2                             |         |
| Fairly disagree                        | 64.0                   | 36.0                             |         |
| Neutral                                | 75.0                   | 25.0                             |         |
| Fairly agree                           | 12.5                   | 87.5                             |         |
| Fully agree                            | 33.3                   | 66.7                             |         |
| Dangerousness (n = 59)                 |                        |                                  | .125    |
| Fully disagree                         | 69.8                   | 30.2                             |         |
| Fairly disagree                        | 40.0                   | 60.0                             |         |
| Neutral                                | 40.0                   | 60.0                             |         |
| Fairly agree                           | -                      | 100.0                            |         |
| Fully agree                            | -                      |                                  |         |
| Disgustingness (n = 59)                |                        |                                  | .138    |
| Fully disagree                         | 72.7                   | 27.3                             |         |
| Fairly disagree                        | 70.6                   | 29.4                             |         |
| Neutral                                | 66.7                   | 33.3                             |         |
| Fairly agree                           | 50.0                   | 50.0                             |         |
| Fully agree                            | 16.7                   | 83.3                             |         |

Note: P-value computed from the chi-square test.
CLP need restorative, orthodontic, prosthetic, and even surgical care also in adulthood. It can be assumed that this study group has passed the most sensitive time to experience dental fear, but on the other hand, many of them have been exposed to many dental procedures during the years which might explain the high dental fear rate. Vulnerability and susceptibility to dental fear must be taken into consideration while treating CLP patients of any age.

Participants with high impact on OHRQoL (measured by the OHIP-14) had higher MDAS sum scores in this study than the rest. This finding is in line with previous studies.\(^{21,23,28}\) This may also support the idea that the OHRQoL is a component of the vicious circle of dental anxiety (VCDA). The VCDA is thought to start with anxiety-related avoidance of dental care that leads to deterioration of oral health, which in turn can cause feelings of shame and inferiority as discussed by Carlsson and colleagues.\(^{21}\) In contrast, the participants of this study were adolescents with CLP who received comprehensive treatment throughout their childhood including psychological counseling.

For the clefts involving the lip, the timing and sequence of management differ from those clefts involving only the palate. Patients with a cleft lip receive a closure of the lip first, then palate surgery and possibly later an alveolar bone graft, which potentially exposes the lip patients to more surgical procedures at later ages. Both groups might also require speech improvement surgery. Clefts involving lip are also more visible than CP and can affect OHRQoL more. Clefts including lip often need more procedures, which might lead to lower OHRQoL and dental fear. Scarring associated with cleft lip repair might also make the delivery or administration of local anesthesia more painful in cleft lip patients compared with cleft palate patients. Cleft lip patients may require more treatment of the cleft-associated teeth in the anterior maxilla.\(^5\)

In our study, participants with cleft including lip reported higher dental fear scores compared with patients with cleft palate only. The findings suggest the importance of a good esthetic outcome. They also support the association between dental fear and vast treatment need; however, being exposed to many medical procedures could also help children to become accustomed to them.\(^{13,29}\) Many of our participants required orthodontic treatment, which can cause latent inhibition, in which non-invasive procedures could help a patient get used to medical procedures. This acclimatization to non-invasive procedures can later help with coping during invasive treatment too.\(^{12,23,29}\) Those who use oral health services regularly have been shown to be less afraid of visiting a dentist than those who use them irregularly\(^{13,30}\); however, this has been seen more in older adults.\(^30\)

The cognitive vulnerability model proposes that uncontrollability, unpredictability, dangerousness, and disgustingness are critical factors for developing dental fear.\(^{15}\) This was also true for cleft patients, as the ones who reported dental fear also often reported feelings of uncontrollability and unpredictability during a dental procedure. The use of CVM is also supported by the fact that a majority of those who did

### Table 4

| Covariates | MDAS | RR (95% CI) | ARR (95% CI) |
|------------|------|-------------|--------------|
| Gender     |      |             |              |
| Boys       | 1    | 1           |              |
| Girls      | 0.95 (0.75-1.21) | 1.11 (0.90-1.36) |
| Cleft type |      |             |              |
| Cleft palate | 1   | 1           |              |
| Cleft including lip | 1.31 (1.05-1.64) | 1.06 (0.83-1.36) |
| OHIP-14    |      |             |              |
| No impact  | 1    | 1           |              |
| Impact     | 1.12 (0.89-1.41) | 0.96 (0.79-1.17) |
| Cognitive vulnerability model | | | |
| Uncontrollability |      |             |              |
| Fully disagree | 1  | 1           |              |
| Fairly disagree | 1.38 (1.04-1.83) | 1.26 (0.94-1.70) |
| Neutral    | 1.02 (0.75-1.40) | 1.06 (0.77-1.45) |
| Fairly agree | 1.68 (1.26-2.25) | 1.32 (0.93-1.87) |
| Fully agree | 0.58 (0.19-1.76) | -          |
| Unpredictability |      |             |              |
| Fully disagree | 1  | 1           |              |
| Fairly disagree | 1.08 (0.85-1.37) | 1.01 (0.80-1.28) |
| Neutral    | 1.15 (0.76-1.73) | 1.06 (0.64-1.76) |
| Fairly agree | 1.63 (1.22-2.17) | 1.14 (0.76-1.69) |
| Fully agree | 2.16 (1.50-3.10) | 2.89 (1.62-5.15) |
| Dangerousness |      |             |              |
| Fully disagree | 1  | 1           |              |
| Fairly disagree | 1.24 (0.93-1.65) | 1.05 (0.75-1.46) |
| Neutral    | 1.36 (0.93-1.97) | 1.21 (0.78-1.89) |
| Fairly agree | 2.63 (1.35-5.10) | 2.16 (1.12-4.16) |
| Fully agree | -    | -           |              |
| Disgustingness |      |             |              |
| Fully disagree | 1  | 1           |              |
| Fairly disagree | 0.95 (0.71-1.28) | 0.87 (0.65-1.17) |
| Neutral    | 1.06 (0.79-1.43) | 0.98 (0.73-1.30) |
| Fairly agree | 1.18 (0.86-1.62) | 1.03 (0.75-1.41) |
| Fully agree | 2.04 (1.48-2.81) | 0.86 (0.52-1.41) |

Abbreviations: ARR (95% CI), adjusted rate ratio (95% confidence interval); RR (95% CI), rate ratio (95% confidence interval).

Model 2: adjusted for gender, cleft type, oral health-related questionnaire, and cognitive vulnerability model items (uncontrollability, unpredictability, dangerousness, and disgustingness).

\(^*P<.05; \quad **P<.001.\)
not report any feelings of uncontrollability, unpredictability, dangerousness, or disgustingness also did not report dental anxiety.

In order to help professionals create practices to prevent dental fear, more studies are needed to investigate the etiology of dental fear among patients with clefts. Cleft patients are a special group in dental care, and despite their great treatment need, also their tendency for dental fear must be taken into account in their early years and when treating them as grown-ups. Specialists should do their best to help cleft patients with their fears and guide them to get further help if needed. The key is to aim for treatment causing the minimum pain and discomfort. A simple way would also be to promote the patient's sense of being in control and sense of predictability during the dental appointment. Since patients with clefts have high treatment need, it is crucial for them to feel comfortable about visiting a dentist regularly also after the scheduled follow-up visits at the hospital. Taking care of their oral health in later years also naturally supports their OHRQoL, which we suggest as being associated with dental fear.

Dental fear is common among cleft patients in their early adulthood, which is most likely due to their extensive treatment history. OHRQoL and dental fear seem to be associated, specifically with a sense of unpredictability. The role of esthetics was not evaluated here, but may have an important role, since dental fear was more commonly reported by those with cleft involving lip than the rest. The esthetics and patients' sense of control and predictability could easily be promoted in dental care, and indeed should be. Future studies could concentrate on interventions on this topic.

In conclusion, dental fear is common among adolescents with CLP, specifically among those with clefts involving the lip. The feelings of uncontrollability and unpredictability during a dental procedure were reported mostly by those participants with some degree of dental fear. Moreover, those with poor OHRQoL had high dental fear scores measured by the MDAS. CVM appears to be a useful tool for investigating dental fear among cleft patients.

CONFLICT OF INTEREST
The authors report no conflict of interest.

AUTHOR CONTRIBUTIONS
AL, GKS, and VA made conception and designed the study. MC, SK, and VA performed the analysis and interpretation of data, and prepared the manuscript. VH, AL, YL, and GKS reviewed the manuscript and gave their comments.

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