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# A gender perspective on appearance-related concerns and its manifestations among persons born with unilateral cleft lip and palate

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## ABSTRACT

Cleft lip and palate (CLP) affects a person's facial appearance and can cause appearance-related distress. Appearance-related distress and its manifestations are not fully understood. Women with CLP tend to experience a higher degree of distress as well as undergo more aesthetic revisions than men. The aim of this study was to investigate if self-reported appearance-related gender differences occur among adults born with unilateral CLP using the Derriford Appearance Scale 24 (DAS24). One hundred sixty two consecutive patients, 107 men and 55 women, with unilateral CLP and no associated syndromes treated at the same hospital were asked to answer the DAS24. A mixed methods approach was used to analyse the questionnaires both quantitatively and qualitatively. Fifty men and 30 women participated, the results showed that the aspects of appearance considered most disturbing was cleft-related among both genders, most common in regards to the nose. Three themes were found: acceptance, cleft features, and general appearance issues. The quantitative part showed that women reported higher appearance-related social anxiety and avoidance than men. This study demonstrated that appearance-related distress is present in both genders; however, women expressed more distress than men. Moreover, non-cleft as well as cleft features are of importance for self-reported dissatisfaction.

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## KEYWORDS

Gender; DAS24; appearance; cleft lip and palate

## Introduction

Cleft of the lip, alveolus, and/or palate (CLP) is a major congenital anomaly which affects speech, occlusion, and appearance (Crockett & Goudy, 2014). CLP is the most common congenital facial malformation, occurring in approximately one in every 600 births per year and more frequently in men than in women (Mossey & Little, 2002). It can occur unilaterally or bilaterally. The management of patients with CLP from birth to the completion of treatment requires a multidisciplinary team (Crockett & Goudy, 2014) The treatment is challenging to the patients and their families and can, therefore, lead to

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social, emotional, cognitive, as well as behavioural difficulties (Hunt et al., 2005; Stock & Feragen, 2016).

The subjective satisfaction with facial appearance in individuals with CLP differs between studies. Men with CLP have been shown to be more dissatisfied with their appearance than women (Hunt et al., 2007; Semb et al., 2005). However, other studies have demonstrated that women with CLP are more dissatisfied with their appearance than men (Mani et al., 2013; Sinko et al., 2005). Moreover, other studies have found that gender does not affect satisfaction with appearance in individuals born with CLP (Feragen et al., 2015; Hunt et al., 2006). Women with CLP are reportedly requesting surgery of the lip and nose more frequently than men (Marcusson, 2001; Sinko et al., 2005) and also undergo more aesthetic surgery than men (Paganini et al., 2018). The objective severity of disfigurement and the extent of psychosocial distress experienced by an individual have not been found to be correlated (Moss, 2005; Rumsey et al., 2004).

In summary, a cleft appears to cause subjective appearance-related distress among persons born with CLP; however, the extent is unclear. The gendered effect on subjective appearance-related distress and its manifestations among adults with CLP are not fully understood and need to be investigated further.

## **Study aim**

The aim of this study was to investigate if self-reported appearance-related gender differences occur among adults born with unilateral CLP (UCLP) using the Derriford Appearance Scale 24 (DAS24).

## **Ethics**

The study was approved by the regional ethics review board in Gothenburg (970–11). The participants provided written informed consent to participate in the study.

## **Materials and methods**

### ***Participants***

Medical records identified 180 eligible consecutive adults with unilateral CLP and no associated syndromes or malformations: 59 women and 121 men born 1966 to 1986 and treated at the cleft centre at Sahlgrenska University Hospital, Sweden. Four women and 14 men were excluded due to unknown address or being deceased. All 162 participants (107 men and 55 women) received an information letter together with the DAS24 questionnaire and a demographic questionnaire. The participants who did not respond were reminded once telephonically, and two additional reminder letters were sent.

## **Measurements**

### **Demographic questionnaire**

Data were collected for the level of education, occupation, marital status, and living arrangements.

### **Derriford Appearance Scale-24**

The DAS24 is a questionnaire that measures the adjustment to problems of visible differences among adults (Carr et al., 2005). The DAS24 questionnaire is aimed at populations whose medical and surgical conditions may cause visible differences or other appearance-related concerns.

The DAS24 questionnaire comprises three parts. The first part consists of a 'yes' or 'no' question of whether the person is concerned about any part of their appearance. They are then asked to specify which part concerns them, followed by an open-ended question 'The thing I don't like about my feature is ...'. The second part consists of 24 items measuring appearance-related distress (Carr et al., 2005). The respondents rate the items on a four-point Likert scale, with a higher score indicating more distress. A maximum of 96 points can be attained, and there is no threshold score or cut-off point (Carr et al., 2005). The third part of the DAS24 deals with physical pain and physical ability and was not used in this study.

## **Analysis**

A descriptive analysis was carried out on the open-ended answers in the first part of the DAS24 to compare and investigate differences between genders. The answers to the primary question 'The aspect of my appearance about which I am most self-conscious is ...' were listed. The complaints were coded to a body part or feature. The follow-up question 'The thing I don't like about my feature is ...' was used to exemplify the codified answers of the primary question. Themes were identified during the analysis.

Statistical analyses were performed using SPSS (IBM SPSS Statistics, version 22, IBM Corp, Armonk, NY). Descriptive statistics were used. For the comparisons between groups, Fisher's exact test was used for dichotomous variables, a Chi-square test was used for non-ordered categorical variables, and the Mann-Whitney U test was used for continuous variables. P-values less than 0.05 were considered statistically significant.

## **Results**

Eighty persons answered the DAS24, 30 women and 50 men; thus, the response rate was 49%. The response rate was 55% for women and 47% for men (Table 1). UCLP occurs more frequently in men; therefore, the distribution between genders in this study accurately reflects the population with UCLP.

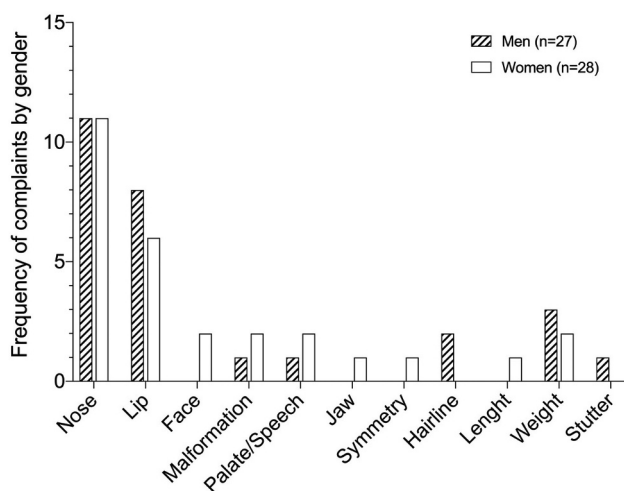
### **Qualitative results**

Twenty men and 19 women answered the open-ended questions; multiple answers were possible which resulted in a total of 55 answers, 27 from men and 28 from women (Figure 1).

**Table 1.** Description of the study population, by gender.

	Men	Women	p-value
Age (years)* Mean (SD)	38.8 (6.4)	37.4 (6.6)	0.38
Level of education			
Not finished nine-year compulsory school (%)	1 (2.0)	0 (0.0)	
Nine-year compulsory school (%)	1 (2.0)	2 (6.9)	
Senior high school (%)	25 (50.0)	15 (51.7)	
University exam (%)	23 (46.0)	12 (41.4)	0.71
Occupation			
Working (%)	41 (82.0)	20 (66.7)	
Studying (%)	1 (2.0)	2 (6.7)	
On disability (%)	1 (2.0)	1 (3.3)	
Retired (%)	0 (0.0)	2 (6.7)	
On parental leave (%)	0 (0.0)	2 (6.7)	
Unemployed (%)	2 (4.0)	1 (3.3)	
Other (%)	5 (10.0)	2 (6.7)	0.19
Living arrangements major part of the week			
Living alone (%)	16 (32.0)	3 (10.0)	
Living with parents, siblings (%)	1 (2.0)	1 (3.3)	
Living with husband/wife or domestic partner (%)	12 (24.0)	6 (20.0)	
Living with children (%)	0 (0)	4 (13.3)	
Living with husband/wife or domestic partner and children (%)	21 (42.0)	16 (53.3)	0.024*

\* Age of participants at the time of answering the questionnaire



**Figure 1.** Frequency of mentioned aspects of appearance as responses to the question 'The aspects of appearance that I am most self-conscious about is.' per gender.

The majority of concerns were cleft-related. The nose was the most frequent complaint in both men and women, followed by the lip.

The results of the descriptive analysis of the main open-ended question, 'The aspect of my appearance about which I am most self-conscious is ...' are shown in [Figure 1](#) and [Table 2](#). Three themes were revealed via the qualitative answers in section 1 of the DAS-24: acceptance, characteristics of the cleft, and general appearance issues ([Table 2](#)).

Regarding the first theme, the answers provided by the participants indicated that they became more accepting of their appearance as time went by.

**Table 2.** Identified themes of the open-ended answers of DAS24.**Theme 1: Acceptance**

If I had a wish, my scar on the lip wouldn't be visible to the degree that it is, even though I've accepted that this is the way I look, and have an amazing life with children and wife. *(man)*

They could have had done it much better, are dissatisfied in 1989 but now in 2013 I don't really care. I'm doing fine anyway. *(woman)*

That I am born hare-lipped is not a big thing ... *(woman)*

The upper lip is not quite nice, even though I'm exceptionally nicely operated compared to many others. However, it is not something I think about daily, mostly when you see pictures etc. Am not affected psychologically by it even though one certainly would like to have a 'nice' upper lip. *(woman)*

My nose. But it is much nicer now than before, but would have liked it straighter. *(woman)*

**Theme 2: Cleft Characteristics**

Not symmetrical. The cleft lip is visible. The nose is crooked. *(man)*

Appearance, speech. *(man)*

The left nostril is 'tight'. Makes my voice nasal. Would like to operate this! *(man)*

[the nose] is crooked, sunken on the left side. *(man)*

My lip is not like others. *(man)*

Profile. Others see me from the side. The face that is. *(man)*

[nose & lip] However self-conscious is the wrong word, just wished to look like others without CLP. *(man)*

CLP – it is too visible, would like to change and try with a plastic surgery. *(man)*

That [the nose] is crooked, flat and not so good looking. *(man)*

[the scar on the lip] creates an unsymmetrical face. *(man)*

The lip is slightly crooked plus the scar is visible. *(man)*

Nose, the look in general, scarring that constantly itches due to 'misplaced' hair sacks.

The upper lip, doesn't move naturally together with a smile.

Speech, don't trust it to be clean (without 'nasal sounds') *(man)*

My features [crooked nose] *(man)*

I look different. [palate & nose] *(woman)*

The nose is still a little crooked, one large nostril and one small, get no air in the small nostril and the nose keeps *(woman)*

The nose is a bit 'weirdly' shaped. The jaw is not symmetrical. *(woman)*

The weight and my 'lightning scar'. That I don't have a 'kiss-mouth. *(woman)*

Partly that it is in the face, it is always visible ... it is difficult to 'oxygenate' one self through the nose (breathing through the nose with closed mouth)

Have gotten a worry crease between the eyes due to scarring. *(woman)*

The upper lip, the nose. Feel quite unwell because the nose is a little flat and the lip and scar is visible. I'm think that if my children get bullied in school because they have a mother that has it . I have been abusing but quit 17 years ago. *(woman)*

The smile is crooked, I think that others look strange at me then. *(woman)*

My nose is crooked and flat on one side despite repeated surgeries. Unfortunately. The speech is leaking. *(woman)*

That one alar wing of the nose doesn't look the way it is should. And that the upper lip makes the mouth look like a drawn line. *(woman)*

[The nose] looks ugly from the side; the profile looks different

Flat and wide + asymmetrical [Nose] *(woman)*

That [the nose and the scar] is abnormal and I have a very hard time with the image in the mirror. This is something I think of every day. *(woman)*

My malformation. *(woman)*

The visible scars. Big nose due to all surgeries. Ugly upper lip. *(woman)*

It exists. It is visible. It looks like hell thanks to the surgeon who did surgery on me when I was 6 years old. *(woman)*

**Theme 3: General Appearance Issues**

The Weight – Too big. *(man)*

That I am overweight. *(man)*

*(Continued)*

**Table 2.** (Continued).

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[high hairline] That my forehead creeps further up. ( <i>man</i> )
That people sometimes make fun of [my stutter]. It may be difficult for those who listens. ( <i>man</i> )
[my potbelly] is too big (am thus somewhat overweight, but am trying to lose weight) ( <i>man</i> )
That my hair on the head is thinning out and that makes me look 'old'. ( <i>man</i> )
That I think I'm too tall. ( <i>woman</i> )

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*They could have had done it much better, are dissatisfied in 1989, but now in 2013 I don't really care. I'm doing fine anyway (woman, 47 years).*

*If I had a wish, my scar on the lip wouldn't be visible to the degree that it is, even though I've accepted that this is the way I look, and have an amazing life with children and wife (man, 46 years).*

Concerning the characteristics of the cleft, the answers reflected both upon the functionality and aesthetics of the nose and lip. There was no gender difference regarding this issue.

*The nose is still a little crooked, one large nostril and one small, get no air in the small nostril and the nose keeps running (woman, 46 years).*

*The lip is slightly crooked plus the scar is visible (man, 34 years).*

The last theme highlighted concerns about general appearance issues, and the majority of respondents were male.

*That my hair on the head is thinning out and that makes me look "old" (man, 28 years).*

*That I am overweight (man, 45 years).*

### **Quantitative analysis**

The mean score of the quantitative part of the DAS24 for the total study population ( $n = 80$ ) was 33.1 (standard deviation [SD] 13.1). A statistically significant difference in scoring between genders was found ( $p < 0.001$ ), with women scoring a mean of 40.2 (SD 17.6) and men a mean of 28.8 (SD 6.5).

### **Discussion**

This study examined appearance-related distress among men and women born with UCLP using the DAS24, and found a gendered effect on appearance-related distress where women express more distress than men. The DAS24 is aimed at adults with visible differences and provides both a quantitative measurement for appearance-related distress as well as the opportunity to qualitatively analyse open-ended answers (Carr et al., 2005; Harris & Carr, 2001). One strength of the present study was the mixed methods approach; the qualitative parts of the DAS24 are rarely used in publications; however, they add an important dimension to appearance-related distress.

It was evident from the qualitative perspective that cleft features affect an individual's appearance-related concerns; however, at the same time, a person born with a cleft also has other concerns with their appearance. A feeling of acceptance can occur, and several participants described that acceptance increased with time, confirming previous research regarding coping strategies (Egan et al., 2011; Hamlet & Harcourt, 2015). To promote acceptance, interventions during treatment are recommended to mitigate potential psychosocial issues.

Cleft-related concerns mentioned in this study were concentrated around issues of the lip and nose which is also in line with previous research (Sinko et al., 2005). However, the general appearance issues added an interesting perspective on living with a cleft as it emphasized that a cleft is only a part of a person's appearance, and it might not be the part that is most important to an individual. Several individuals in the present study mentioned overweight as their main concern, consistent with the findings of an Australian study (Nicholls et al., 2018). Although the majority of individuals who mentioned a general appearance issue were men, the sample was too small for further conclusions regarding gender. However, it is apparent that appearance-related distress is a multifaceted problem for this population.

The quantitative part of the DAS24 demonstrated that the women in the present study experienced more appearance-related distress than the participating men. This gendered effect has been described previously among individuals with visible differences (Carr et al., 2005; Roberts & Mathias, 2012; Rumsey et al., 2004). This gendered difference regarding dissatisfaction with appearance might have more to do with cultural and social perspectives than actual biological differences between men and women (Rumsey & Harcourt, 2012). Further studies are needed to understand gender differences in relation to the treatment of cleft, especially regarding cultural and social perspectives.

In conclusion, this study showed that appearance-related distress is present in both genders; however, women with UCLP expressed more distress than men. Moreover, non-cleft features as well as cleft features are of importance for self-reported dissatisfaction and with aging comes acceptance.

## Disclosure statement

No potential conflict of interest was declared by the authors.

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