

Experiences of living with cleft lip and palate A gender perspective

Akademisk avhandling

Som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentligen försvaras i hörsal Arvid Carlsson, Academicum, Medicinaregatan 3, torsdag den 9 december, kl 09.00

av Anna Paganini

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Avhandlingen baseras på följande delarbeten

- I. Paganini A, Hörfelt, C, Mark H. Gender Differences in Surgical Treatment of Patients With Cleft Lip and Palate. *J Plast Surg Hand Surg.* 2018; Apr; 52(2): 106-110
- II. Paganini A, Moss T, Persson M, Mark H. A gender perspective on appearance-related concerns and its manifestations among persons born with unilateral cleft lip and palate. *Psychol Health Med.* 2021 Jul;26(6):771-778.
- III. Paganini A, Persson M, Mark H. Influence of Gender, Dispositional Optimism, and Coping Strategies on Appearance-Related Distress Among Swedish Adults With Cleft Lip and Palate. *Cleft Palate Craniofac J.* 2021 Jun 17 [Epub ahead of print.]
- IV. Paganini A, Engström M, Mark H, Persson M. Being normal yet different: A qualitative study on the dualistic experience of living with unilateral cleft lip and palate. [Submitted]

**SAHLGRENKA AKADEMIN
INSTITUTIONEN FÖR KLINISKA VETENSKAPER**



Experiences of living with cleft lip and palate

A gender perspective

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Abstract

The primary aim of this thesis was to investigate the influence of gender on the CL/P population with regard to treatment, self-reported appearance, psychosocial adjustment, and subjective experiences.

Study I, a retrospective chart review that investigated whether there were any gender differences in the number of esthetic surgical treatment received, found that women received more treatment than men.

Studies II–III used the questionnaires DAS24, LOT-Rs, and Brief-COPE to investigate appearance-related distress as well as dispositional optimism and coping. Study II found that women reported higher appearance-related social anxiety and avoidance than men, and analysis showed that not only cleft features but general appearance issues caused distress. Study III showed that appearance-related distress among women was significantly correlated with several coping strategies as well as low levels of optimism, whereas in men it was found to be correlated with low levels of pessimism.

Study IV was a qualitative interview study of young adults, and a content analysis of the interviews was conducted. The interviews revealed a group of generally well-adjusted young adults, but participants also described a duality where they felt both normal and at the same time different, and this feeling varied over time and in different situations. They all described the influence of gender norms.

This thesis illuminates the need for gender awareness in the treatment and outcomes of CL/P.

Keywords: gender, norms, cleft lip and palate, appearance, adjustment, qualitative interviews