

ORIGINAL ARTICLE

## Social life aspects of young adults with cleft lip and palate: Grounded theory approach

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### Abstract

**Objectives.** The findings of many questionnaire and inventory studies suggest that people with cleft lip and/or palate report a decreased quality of life. Common problems include dissatisfaction with the external appearance of the lips and nose, speech problems, depression, and anxiety. This qualitative study aimed to explore the subjective perceptions and values of young adults with clefts, particularly with regard to their social lives. **Material and methods.** Twelve persons participated in an in-depth interview. Among those, seven had a repaired isolated cleft palate involving only the hard/soft palate. Five had a repaired bilateral cleft lip and palate that had been a continuous lesion of the lip, the alveolar process, and the palate. A grounded theory approach was used to conduct and analyze the interviews. **Results.** The study revealed seven important categories – hoping to be like other people, being treated differently from others, experiencing deviation from others, regarding oneself as being different from others, lack of recognition, low self-esteem, and receiving recognition from significant others – with hoping to be like other people as the core category. **Conclusion.** Young adults with either cleft lip and palate or isolated cleft palate who received recognition from significant others reported increased self-esteem and greater ability to cope with their social lives.

**Key Words:** Cleft lip and palate, grounded theory, quality of life, social life, well-being

### Introduction

An increasing number of studies into quality of life (QOL) have been published over the past decade. QOL has been recognized as an important aspect of health, and this is reflected in the World Health Organization's definition of health as "a complete state of physical, mental and social well-being and not just the absence of disease and infirmity" [1]. There has, therefore, been growing interest in associations between the treatment of morphological deviations and self-perceived health and QOL. The focus has shifted towards the patients' own perceptions rather than professional evaluations of morphology and treatment, and acknowledging the patient perspective is now considered important in planning future therapy [2,3].

Oral cleft is one of the most common craniofacial anomalies, with an incidence of approximately 2 per 1000 newborns in Europe and the USA [4]. Among

the different types of cleft, bilateral cleft lip and palate (CLP) usually has the greatest effect on facial appearance. Constructive surgery, together with orthodontic and prosthetic treatment, improves disfigurement, but may not result in a completely normal morphology. Several research groups have looked at QOL in people with CLP. Ramstad et al. [5] and Marcusson et al. [6] compared adults with repaired CLP and non-clefts of similar ages and found that overall QOL was high, but that well-being and social life were poorer in CLP patients. The Norwegian study by Ramstad et al. [5] also found that anxiety and depression were more frequently reported, fewer people with CLP were married, and marriages occurred later in life. Negative responses were related to concerns about appearance and to speech problems in a study by Marcusson et al. [6]. Oosterkamp et al. [7] looked at satisfaction with facial appearance and function and at health-related

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quality of life (HRQOL) in CLP patients using quantitative and qualitative assessment tools: These revealed that CLP patients were significantly less satisfied with the appearance of the upper lip and nose and with nasal breathing. Satisfaction with facial appearance correlated positively with HRQOL. The authors stressed that patients were more concerned with visible defects than with functional problems. Sinko et al. [8] studied 70 adult patients with a repaired complete CLP. Their questionnaire revealed low scores for only two subscales, social functioning and emotional role.

Warschausky et al. [9] examined parents' perceptions of health and HRQOL in a series of children and adolescents with craniofacial abnormalities with a Child Health Questionnaire. Both physical and psychological scale scores largely fell within normal limits for the children with CLP and physical health, behavior, and psychological status were highly correlated. Damiano et al. [10] suggested that speech and esthetic concerns were important factors affecting HRQOL for children with clefts. These factors become more important as children approach adolescence, when acceptance by peers becomes more critical. They found that children with less severe speech problems had higher total Pediatric Quality of Life Inventory scores (PedsQL), as well as higher physical and psychological health domain scores. Hunt et al. [11] systematically reviewed the published scientific research and concluded that the majority of children and adults with clefts do not experience major psychosocial problems, although some specific problems may arise, such as behavioral problems, dissatisfaction with facial appearance, depression, and anxiety.

Hallberg [12] argued that the strength of a qualitative method is that it enables the researcher to grasp the informants' points of view in unbiased ways. In quantitative research, the construction of questions or hypotheses is initially based on an existing theory, which may narrow the research topic. Grounded theory is particularly useful when there is no existing theory. For new areas of research where the subjective meaning of a phenomenon is essential, the best tool is often qualitative research. This study aimed to develop a theory in order to gain a deeper understanding of subjective perceptions and values from young adults born with either bilateral CLP or isolated cleft palate, and to investigate how cleft treatments affect HRQOL.

## Method

### *Grounded theory*

The inductive method of grounded theory was used in this study [13]. Grounded theory is rooted in symbolic interactionism and includes the assumption that meaning is constructed and changed by

interactions among people [14]. Grounded theory can also be seen as a product of pragmatism and factor analysis [15]. The method aimed to develop a theory in order to explain and/or predict phenomena, rather than to test hypotheses derived from existing theories. It is especially suitable for exploring social processes and for studying areas where little is yet known, where the researcher intends to gain a deeper understanding or new knowledge in an area incompletely explored. Grounded theory was the most suitable research method in this study because the research questions concerned an area that, to date, has been only sparsely studied by qualitative methodology.

Grounded theory was originally developed by two sociologists, Glaser & Strauss [13], whose ideas are now referred to as "classical grounded theory". Classical grounded theory has an ontological position close to positivism, because it is implicitly assumed that there is a "real" reality out there that can be discovered through emerging categories without being affected by the "objective" researcher [12]. According to Glaser & Strauss, "all is data" and what is important in the studied field will become evident and emerge without the researcher making any effort [13]. Strauss & Corbin further developed grounded theory by presenting a coding paradigm for facilitating the process of analysis [16]. Their version is now referred to as "reformulated grounded theory". The basic methodological principles are maintained, but Strauss & Corbin stated that the researcher interprets data rather than seeing categories emerging from the data. They also stressed the importance of listening to the voices of the participants. Ontologically, their position seems to be more post-positivistic than Glaser's original version [12]. Later in 1995, Charmaz developed a "constructivist grounded theory" aimed at producing an interpretative understanding of the studied area. Ontologically, she assumed that there are multiple realities, rather than the one and only real reality and argued that "grounded theories are constructions of reality" [17,18].

### *Study group*

The 12 participants, 6 men and 6 women, were strategically selected with initial open sampling from patient records at the cleft palate unit of the University Clinic of Orthodontics in Gothenburg. According to grounded theory, a heterogenic sampling of participants is recommended to maximize the variations of experiences in the group studied [13]. Later in the process, the participants were theoretically selected in order to saturate the emerging categories. Among those 12, seven had a repaired isolated cleft palate that involving only the hard/soft palate. Five had a repaired bilateral CLP that had been a continuous lesion of the lip, the

alveolar process, and the palate on both sides. They were between 24 and 33 years old. All were living in western Sweden and working up to full time.

### Qualitative interviews

An informational letter was sent out to each participant asking them to contact the interviewer (U.H., a sociologist and doctor of public health science) if they were willing to participate in the study. Owing to practical conditions, such as long distances and the full-time work commitments of some of the participants, the interviews were carried out by telephone and tape-recorded. The interviewer was not known to the participants and was not involved in their further care or treatment. An open-ended interview lasting up to 45 min was conducted with each participant. The interviewer transcribed verbatim into text; so-called verbatim transcribed interviews. An interview guide was used and covered the participants' experiences, thoughts, and feelings about their lives. Themes such as childhood, school, daily life, treatments, the meaning of the diagnosis, social participation, and thoughts about the future were raised by the participant and/or the researcher in a conversational way. The participants could bring up their own themes and the interviewer asked relevant follow-up and probing questions. Data collection and analysis were conducted simultaneously and continued until new interviews did not provide additional information, i.e. until saturation was reached. The study was approved by the ethics committee of the University of Gothenburg.

### Analysis

The verbatim transcribed interviews were analyzed using open and selective coding processes. The axial coding was done in the selective coding process [13]. Short, exemplary quotations translated from Swedish are presented in this study after each category explanation. Open coding means line-by-line reading of the data, asking "What is expressed here? What is the meaning of this?" By this means, the substance of the data was captured and segmented into substantive codes, which were given concrete labels. Codes with similar content were clustered into summarizing categories. These categories were given more abstract labels than the substantive codes belonging to them. During selective coding, categories were saturated with additional information, assessed by new interviews or added by re-coding previously assessed data; in other words, during theoretical sampling emerging theories directed further analysis. The core category was the psychosocial process that described the main concern for the informants. This core category was central to the data and was related to other categories. During the entire process of analysis, ideas,

preliminary assumptions, and theoretical reflections were written down in notes or "memos" [13].

### Results

The process of living with cleft during childhood, adolescence, and early adulthood was revealed. The core category described the participants' desire to be like other people (Figure 1). The figure also shows the relationships between the core and other categories. Six other categories were identified: being treated differently from others, experiencing deviation from others, regarding oneself as being different from others, lack of recognition, low self-esteem, and receiving recognition from significant others.

During early childhood, the participants were not aware of their condition and felt like everybody else. When they became aware of their condition, they felt different to other people because of their appearance and/or speech difficulties and they were treated differently in that they needed to undergo cleft treatments such as surgery and speech therapy. They lacked recognition from the opposite sex, their self-esteem was low, and some felt they were outsiders. However, if they received recognition from others, the focus moved away from their appearance and speech difficulties and their self-esteem increased.

#### *Hoping to be like other people*

The core category describes how the participants wanted to be like everyone else. Participants who looked different wanted further treatment, hoping

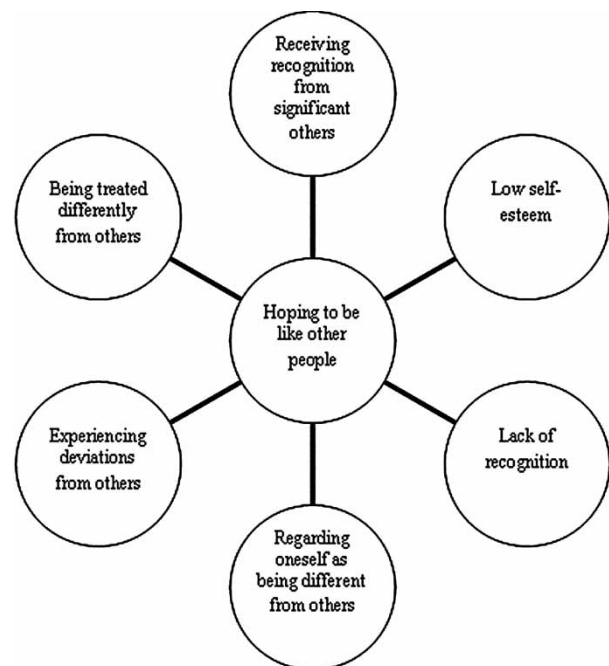


Figure 1. The relationship between the core category of concern for young adults with cleft lip and/or palate and other categories identified from telephone interviews.

for a more normal appearance. The younger the participant, the greater the subjective need to be like everyone else, except when they were very young. In early childhood, the participants were not aware that they had a medical condition causing appearance and/or speech deviations. In some cases, their different facial appearance became very much the focus during adolescence. Generally, the participants who were married or had long-term partners were more satisfied with their facial appearance than participants without partners or spouses.

“Well, you always want to look better ... like everyone else.”

#### *Being treated differently from others*

Participants told their childhood story that they spent time at the hospital for treatment. They missed school during surgery and in the postoperative recovery phase and spent time with speech therapists, often during school time. This made them different from their friends and schoolmates. Some participants who suffered from speech difficulties were ashamed of their speech therapy sessions and were happy when this treatment was over. The process of surgery and hospitalization was seen as inconvenient, but the participants were grateful for the gentle and positive approaches of their medical and dental health care professionals.

“Well it’s like ... when I was a kid you had to go to these ... speech therapists and I hated it. Went to some old man and he’s sitting there saying that you should ... sit up straight and think about how you breathe ... well I thought it was a big pain ... there has been quite a bit of nagging about it too.”

#### *Experiencing deviations from others*

Participants with speech difficulties experienced feelings of being different from other people. They described how they had difficulties speaking clearly, especially when they became nervous, which they often did when they were urged to speak in public or to perform at school. Participants with bilateral CLP were aware that their facial appearance differed from friends and schoolmates. Female participants, in particular, described how they focused on their appearance and used a lot of make-up, such as lip pencils and lipsticks, to hide their scars and improve the shape of their lips.

“Well I guess it was ... during the teens, that’s when it all starts. What you look like and guys and why you aren’t ... well ... recognized by ... so ...

instead they look at you for a different reason. That you look different.”

#### *Regarding oneself as being different from others*

Participants with speech difficulties felt that they had been, and in some cases still were being, regarded as different by others. They perceived themselves as deviating from others in a negative way and felt ashamed because of their difficulties in speaking clearly. These difficulties increased when they felt nervous. Many of them tried to avoid speaking in public places or with people who were unfamiliar to them. For example, during job interviews they tried to talk as little as possible. They did their utmost not to become nervous, because nervousness negatively affected their speech. Because of fears of being rejected, they also described avoiding meeting or talking to people of the opposite sex. Participants could also feel ashamed because of their appearance, which also made them feel different from others. Bullying at school and at work, because of their speech difficulties and/or deviant facial appearance, was frequently reported. Even when their speech had improved, owing to training or surgery, memories of these insulting actions, especially during childhood and adolescence, still worried them.

“It’s been with words and ... making faces ... and they would press down their noses and ... you know, tried to imitate that I have a flat nose. And I was called flat nosed and all sorts of silly things. Even to this day I experience this.”

#### *Lack of recognition*

Especially during and after puberty, lack of recognition from the opposite sex was a problem. Teenagers or young adults in general often receive affirmation from the opposite sex by flirting or entering relationships. Participants with different facial appearances seldom or never received this attention or recognition, which led to lower self-esteem. Participants who later in life had partners or were married felt that they had received recognition and that this affected their self-esteem in a positive way which helped them to reconcile with their condition.

“I met my husband towards the end of my operations and it was a recognition that I was OK and ... and so on. It’s an acknowledgement when you ... when someone loves you and you have someone to love back that you love so much ... well it’s very important if you ask me.”

*Low self-esteem*

The participants felt that they had been, and sometimes still were being, regarded as different, resulting in low self-esteem. They described feelings of not being good enough or being different from other people. Some participants judged individuals without clefts as being more valuable than they themselves were. These feelings were especially common during the teenage years. As the participants grew older, some tired of always thinking negative thoughts about themselves. They tried to think of themselves as being good enough and thereby accepted their physical deviation. If they received recognition by others, especially persons significant to them, their self-esteem could be increased. However, those who had not received recognition from others tended to isolate themselves and their low self-esteem existed.

“It’s probably because I’ve grown tired of belittling myself. I mean sitting and saying to myself or thinking to myself that I don’t look good, that I . . . that there are others much better looking and of course they have a better chance and . . . things like that. I’ve grown tired of thinking that thought the whole time and it has, you know, changed to . . . well, that it doesn’t matter any more.”

*Receiving recognition from significant others*

Participants who received recognition from significant others, such as partners, felt that they were just as valuable as everyone else. This made them focus less on their condition, thus increasing their self-esteem. Participants who had children worried during the pregnancy that their child would also have cleft lip and/or palate and go through the same experiences. Participants who had not received recognition from significant others had persistently low self-esteem and were focused on their condition.

“It was really difficult in the beginning because I thought that no one could think that I looked good. But then . . . when you finally realized that it’s actually this way, your self-confidence sets a boost.”

**Discussion**

For a long period, most evaluations of the treatment of people with clefts focused on associations between different treatment modalities and the best possible craniofacial and occlusal development. One consequence of this is that some types of plastic surgery are postponed in order to minimize its negative influence on growth and development [19]. As well as facial and dental disfigurement and impairments in oral function, people with clefts may have

additional malformations influencing their daily life [20]. It appears that only some cleft teams around the world routinely carry out psychological assessments of their patients. This is despite findings that psychological problems such as low self-esteem, depression, palpitations, and difficulties in social interactions are not uncommon in clefts [5,21].

Oral-health-related QOL may be affected in a number of different domains. Inglehart & Bagramian [21] suggested a model with influences from function and pain/discomfort and which included psychological and social aspects. In a review article, Lockhart [22] identified social isolation, speech difficulties, and poor self-image as problem areas. Recent studies evaluating QOL revealed that differences in people with CLP, compared to non-clefts, are usually moderate [5–9]. Dissatisfaction with the appearance of the lips and nose and with breathing problems has been reported [7,10]. However, it is questionable whether the instruments for measuring QOL are sensitive enough to reflect the special conditions experienced by people with clefts. Another question involves patient education: Information about clefts is primarily given to the parents and it is not known to what extent it is transferred to the patients themselves [6]. There may be a number of items that deserve clarification.

The study group consisted of individuals with either repaired bilateral CLP or isolated cleft palate. It aimed for a variety of types of cleft because, in qualitative studies, diversity theoretically increases the explanatory power of a phenomenon [16]. One of the main concerns of the participants was the experience of appearing different from others when growing up and as young adults, and this was an issue regardless of the type of cleft. In previous studies, psychological problems were strongly associated with dentofacial appearance, speech difficulties, and the desire for further treatment [5,23]. Visible tooth malpositions have also been reported to affect QOL, self-perception, and social interaction in persons who do not have CLP [24–27].

Supporting the model proposed by Inglehart & Bagramian, the result showed that the feeling of differing from others could be related to several domains. Psychological and social differences are obviously important, but functional problems such as breathing and speech have also been identified as being important [21]. Additionally, Richman [28] found that a significant number of adolescents with CLP have self-perceived social adjustment problems not in the least related to concerns about facial appearance. Popularity cluster scores for people with CLP have been found to be below those for the general young population [29,30]. Complaints about visible scars have been reported [31]. Some of our interviewees with external clefts described attempting to ease social interactions by using lip pencils, lipsticks, and other kinds of make-up that they felt

would reduce feelings of difference. The adjustment process for people with CLP is possibly influenced by the way disfigured individuals interpret their disfigurement, their selves, and their encounters with others, among other things [32]. Regional differences may also play a role [33].

Instead of comparing the relative importance of different factors, this qualitative study shows their interactions. The unit of comparison in grounded theory is events and stories, rather than individual participants [17]. We found that lack of recognition from others varied with appearance, function, and social interactions. This is in agreement with earlier reports on behavioral problems associated with facial appearance [34]. Thompson & Kent [32] and Hunt et al. [35] found greater behavioral problems and more symptoms of depression in people with CLP than healthy controls. They were also more often subjected to teasing and were less happy with their appearance and speech. It is interesting to note the different coping strategies that these subjects used, such as talking less in certain situations. One possible consequence of this is that fewer subjects with CLP marry and they tend to marry later [5].

The timing and quality of treatment is of great interest. On the one hand, extensive treatment contributes to feeling different. The subjects were, however, usually grateful to those who have provided therapy. On the other hand, these young adults were not completely satisfied with the morphological and functional results of their treatment. Bullying at school and at work was reported. Should we, therefore, re-evaluate the timing of treatment? Turner et al. [23] discussed whether people with CLP could benefit from counseling or training in social interaction skills. This may reduce the risk of treatment sessions' contributing to feelings of being different, a problem we identified with the participants.

Most available studies on patient attitudes are based on questionnaires and/or QOL inventories. These tools have not always been designed for specific subjects such as CLP. Fields of research with limited knowledge and insufficient theories could benefit from new perspectives gained by using a qualitative approach such as grounded theory [13,16]. Grounded theory is a suitable tool for exploring social processes and is therefore useful when assessing patients' perception of CLP. In our study, an experienced interviewer carried out the telephone interviews, and while some aspects of non-verbal communication may have been missed, the method may have reduced participants' feelings of inferiority and created a more neutral environment. The interviewer is not a dental professional but has a broad knowledge of dental problems in different age groups. Short quotations from the Swedish interviews were translated and presented in this article. This was done despite the fact that the

contents cannot be fully comparable between languages; these quotations are believed to illustrate some important parts of the basic material.

## Conclusion

The conclusion derived from the study was that individuals with either CLP or isolated cleft palate wanted to be like everybody else, but felt different and experienced decreased self-esteem owing to their speech difficulties and/or dissatisfaction on external appearance. This low self-esteem could be increased by receiving recognition from a significant other, which also made them feel more like everybody else.

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