

A Qualitative Study of Health-Related Quality of Life and Psychosocial Adjustments of Thai Adolescents with Repaired Cleft Lips and Palates

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Objective: The purposes of the present study were (1) to study the meaning of Health-Related Quality of Life (HRQoL) from the insider's perspective and (2) to explore the relevant psychosocial adjustments involved in the HRQoL of Thai 12-to-17-year-old adolescents with repaired cleft lip and cleft palate (CLP).

Material and Method: The study included a sample of 18 adolescents with non-syndromic repaired CLP and 6 parents of these adolescents. The participants were recruited from an orthodontic clinic in the Faculty of Dentistry, Mahidol University, and all were in-depth interviewed.

Results: HRQoL can be categorized into four domains: physical symptoms, functional limitations, emotional well-being and social well-being. In the affected group they were striking differences in psychological assets, psychosocial resources and socioeconomic disparities. The majority of these participants were well-adjusted and able to cope with the adversities they experienced as a result of their conditions; hence it was noted that, participants with consistent support from parents, friends and professionals were likely to have a positive health status and satisfaction with treatment.

Conclusion: These findings have important implications in measuring a multidimensional HRQoL construct, and will enhance issues regarding adaptation strategies which have an impact on HRQoL of adolescents with CLP.

Keywords: Health-Related Quality of life, Cleft lip, Cleft palate, CLP

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The impact of craniofacial anomalies on healing, speech, appearance and cognition are prolonged and can cause adverse effects on health and social integration. Morbidity, healthcare, emotional disturbance, social exclusion and unemployment-in Brief World Health Organization Quality of life-are considerable⁽¹⁾. Prevalence of craniofacial anomalies (CFA) in Thailand are 2.5/1,000 births (total of 100,000 CFA)- most of them are non-syndromic cleft lip and cleft palate (CLP)⁽²⁾.

While much of the research on HRQoL in children has involved quantitative assessments,

qualitative research involving children and parents can achieve a greater understanding of the quality of life of children. Qualitative methods would offer the opportunity to hear from children themselves about the areas of their lives affected and allow further exploration of the interplay of psychosocial factors^(3,4). To date, little research has been conducted to capture in-depth information from children on how their oral and orofacial conditions affect quality of life despite qualitative techniques being used successfully in other fields⁽⁵⁾. These elements suggest the need for advanced qualitative research methods that aim to describe multiple and diverse experiences within the CFA population-rather than a single "picture"-triangulating information from a variety of sources and engaging participants in the research process as a means for establishing trustworthy and credible findings⁽⁶⁾.

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Objective

The purposes of the present study were (1) to investigate the meaning of Health-Related Quality of Life (HRQoL) from an insider's perspective and (2) to explore the relevant psychosocial adjustments involved in the HRQoL of Thai 12-to-17-year-old adolescents with repaired cleft lips and palates (CLP).

Material and Method

The study included a sample of 18 adolescents with non-syndromic repaired CLP and 6 parents of these adolescents. The participants were recruited via purposeful sampling for representation of sex and cleft type (as diagnosed by a plastic surgeon or orthodontist). The congenital CLPs with any additional disabilities or syndromes were excluded. The participants were identified at an orthodontic clinic at the Faculty of Dentistry, Mahidol University, Thailand. According to Crabtree and Miller (1992), a sample size of between 6 and 20 participants would be acceptable for a qualitative research⁽⁷⁾.

The current study reports on a subset of information gathered as part of a larger study. The present study was approved by the Ethics Committee of Srinakharinwirot University. The interview was conducted after his or her dental visit each. The parents of all participating subjects provided written informed consent while the participants gave assent.

Before starting the in-depth interview by a trained interviewer, each participant was informed about objectives of the interview and the approximate duration of the present study. The interviews were anonymous and confidential, in order to encourage freedom of expression. Adolescents and their parents were interviewed separately. The session began with a general question, with a paper-and-colored pencils given to the subject, "Draw me a picture of how you see yourself"; the interviewer makes each of participants feel less nervous when they first meet. The interview schedule was developed to allow participants to speak freely about their perceptions and life experiences. The probes included, "What do you mean?", "Like what, for example?", "What/How is that?" or "How do you see this each day?" However, the self-rating scale from 0 to 10 was used to assess the affected level of self-image and sociability problems on the individual's life over the six month period. At the end, as soon as the interviewee demonstrated signs of interview fatigue, the interview was concluded and a small token of appreciation is given. The interview recordings were transcribed verbatim and open-ended

questions were inducted to content analysis.

Results

The participants were between 12 and 17 years of age (mean, 14.33; SD, 1.53). A total of eleven adolescents had repaired unilateral CLP; seven had bilateral CLP. No other disability or syndrome was found. The time since the last surgical repair averaged 6.55 years, reflecting a range of 6 months to 16 years. The number of members in each family ranged from 3 to 7. Half of the samples were living in Bangkok while the other participants were in the surrounding provinces. Half (n = 9) had a family income over 30,000 baht/month and 22% (n = 4) between 7,000 and 30,000 baht. The financial data were missed for five participants because they refused to reveal. Public and private transportation were used by 10 (55.6%) and 8 (44.4%) of the participants respectively when receiving CLP care. Eight (44.4%) patients went to the treatment by themselves and 10 (55.6%) were accompanied by their parents. The professional first, recalled by the participants, was: an orthodontist (50%), a plastic or maxillofacial surgeon (27.8%), a nurse (16.7%) or a speech therapist (5.6%).

Health-Related Quality of Life (HRQoL) can generally be grouped under two main self-perceptions: (1) objective assessment and (2) subjective assessment. Within the objective assessment, the HRQoL can be categorized into two broad themes: (a) physical health and (b) functional limitations. Subjective evaluation of HRQoL can be divided into two major themes: (a) emotional well-being and (b) social well-being; within each theme, the data can be further subdivided or classified. Based on our analyses, codes or items are identified that may be used in the construction of HRQoL (Table 1).

Two important physical symptoms sub-themes emerged: (1) oral symptoms, and (2) general symptoms. The main effect of the condition on physical health was oral symptoms in the previous six months. Typically, the response of adolescents could be summarized by a 15-year-old girl who said, "Because I've got a toothache (or sharp pain in my tooth), I can't do anything." General symptoms have mixed effects on participants' physical health. Although some participants felt weaker than their peers, some would not admit to it. For example, a 14-year-old boy commented, "It was very troublesome to stay healthy because I had was cold for a long time and a buzzing in my ears".

The impact of cleft lip and cleft palate on chewing, drinking, breathing, hearing, speech and facial

expression and cognition can all have a prolonged and adverse effect on health. For example, a 13-year-old boy commented, "Selecting the type of food is important because I try to avoid sticky or strong sweets, because they make chewing difficult and I am slow to finish a meal." The majority (15/18) of participants reported experiencing speech problems, three reported experiencing ear infections and two mentioned problems with hearing. Problems reported included pronunciation problems with /s/, /d/ and /r/. Three of them received speech therapy for periods ranging from 2 to 10 years and felt that this intervention was helpful. By contrast, a 16-year-old boy remarked, "It's impossible to pronounce clearly and correctly since the orthodontic treatment". A few individuals said that their speech was easily understood by others.

The participants represented themselves by their detailed and colored pictures about leisure activities and abstract concepts (*e.g.*, freedom and the loving bonds of family). Some participants used negative adjectives; while the others described themselves positively. For exam two sub-themes related to emotional well-being were identified from the analysis, including (a) positive emotions and (b)

negative emotions. The positive emotions expressed by the participants included 'satisfied', 'proof', 'glad' and 'strong'. Table 2 presents the information on how the majority of their living was slightly affected by self-image problems. For example, a 14-year-old boy was asked whether he would like to be the same person if he could change life at all. He replied, "I would be the same person because of my warm family". A 15-year-old girl similarly echoed, "In reality [silence as she ponders her answer], actually, I actually can't make my cleft go away, but I am not hated in the community. People speak with me, accept me".

The negative emotions that participants expressed included 'worry', 'uncertainly', 'shyness', 'boredom or ennui', 'moodiness' and some even wept openly when they fell ill. Eleven individuals felt that they had experienced severe adjustment problems, most often related to the attribution of negative societal perceptions. For example, a 12-year-old boy worried that his facial appearance was so different from his peers that he feared rejection. Other participants were also concerned about other peoples' opinions. By way of compensation, two of the girls mentioned that they used make-up to enhance their good features. Fifteen

Table 1. Summary of major themes and codes that arose from the meaning of HRQoL

Themes	Codes categories
Physical symptoms	
Oral symptoms	Toothache/mouth sores/breath odor/bleeding gum
General symptoms	Buzzing in the ears/ getting a chronic cold
Functional limitations	
Orofacial functional limitation	Difficult chewing/unpronounceable/mouth breathing/difficult sucking/facial expression
Daily activity restriction	Trouble sleeping/hard of hearing/academic performance/physical activity limitation
Emotional well-being	
Positive emotions	Glad/satisfied/yourself proof/strong
Negative emotions	Worry about people's opinions/uncertainly/shyness/boredom/sadness/ moodiness
Social well-being	
Positive social relationships	Social participation/get social support/forming social contact
Negative social relationships	Withdraw/ school placement/ absent from school

Table 2. Summary of affected CLP persons HRQoL self-rating (0 to 10 scores) over a six-month period (n = 18)

Questions	Least	Most	Mean	SD
How much did self-image problems affect your life?	1	8	3.44	3.01
How much did sociability problems affect your life?	1	10	5.66	3.08

individuals believed that their CLP condition worsened their academic performance because of frequently missing school due to hospitalizations and dental visits. The load of homework loomed large and they feared falling behind others academically.

The next major theme that emerged was social well-being. Friends and family were generally cited as a source of support and fun although some expressed negative views such as classmate harassment and overprotective parents. Table 2 shows that sociability-problems have a greater impact than self-image problems; unsurprisingly, since the activities that the adolescents participated in were at school or on Internet social networks. Five participants perceived their cleft to be a handicap to some degree in their social relationships. Most (16/18) commented that they were teased or bullied by their peers.

Feelings of being teased and/or neglected were a big problem for psychosocial activities. Strategies developed to diminish the magnitude of the problem included (a) compensation (being a supporter and/or increasing social life), (b) acceptance (CLP was from Karma) and (c) strengthening the ego (feeling support from parents). Most participants had a satisfaction in their relationship with healthcare providers. The participants felt involved in the healthcare teamwork, they felt some control over decisions and appreciated being communicated with about their health.

Family capacity to be supportive was noted as contributing to positive adaptation and quality of life. Family support may take the form of parental concern and positive outlook in their adolescent's essential health and good prospects for the future. Most (15/18) of the participants had siblings who did not have the CLP condition or any anomalies. Siblings usually defended an affected sibling from negative peer situations (*e.g.*, teasing, mockery, questioning and staring). Some mothers reported treating a CLP child more gently than his/her siblings, while other mothers reported being unequivocally overprotective. One mother described the parenting practices for a CLP affected child as more intensive and the treatment costs burdensome. Four adolescents were raised by single-mothers; three of whom worried that the intrusiveness of multiple and frequent surgeries and medical appointments would have a negative effect on their son/daughter's emotional stability and self-image.

Discussion

The subjective experience of participants with CLP is of value in seeking to build an emphasis on

promoting HRQoL. The participants have additional stressors (*e.g.*, hospitalizations and peer teasing) that are intrinsic to their adjustment and part of the rehabilitation process. This process may be indicative of the burden or may provide experience in developing coping strategies. People with craniofacial anomalies-characterized by high self-efficacy, optimism and successful coping patterns-are called psychologically "hardy"⁽⁸⁾. Thus, interestingly, CLP was also perceived to affect social interactions positively as most of the participants felt the people generally reacted well toward their speech. People were often curious and asked questions about their facial scars and articulated speech, the participant could get on well with people and could have many friends. Seven of the participants reported having a large group of friends. When asked about romantic relationships, five had a steady boyfriend or girlfriend, and two were decided to discontinued in their relationships.

The findings support the shift in emphasis-from deficits to strengths-for promoting health and well-being as particularly appropriate in the craniofacial field. The presented information identifies some of the difficult situations which adolescents face. Evidently, all participants are affected by complications that affect physical appearance and self-esteem, but many adapt and adjust to their handicap. Their ability to adapt was facilitated when the surrounding social environment was favorable and accessible. Various aspects included a need to be able to explain to peers, classmates and the community about the effects of CLP and the sequelae of treatment and also a need for family education so that family members would be able to clarify any misunderstandings that the youth might have. In contrast to most previous studies which have suggested that parents may be overprotective of their children, the authors found that mothers provided experiences to develop a strong and positive sense of self.

The authors have documented the multiple dimensions of the HRQoL that youths with CLP described as influencing their live-a-day lives so the study expanded the concept of HRQoL by placing it within the context of the everyday lives of adolescents with CLP. Awareness of the moderating role played by the environment and the positive potential of many disabilities has influenced current concepts of oral health and disability⁽⁹⁾. The findings have demonstrated that repaired orofacial clefts should not necessarily be thought of as functional limitations or handicaps.

It is unclear to what extent the findings from

this small group of highly selected adolescents can be generalized to the broader group of adolescents with repaired CLP. All adolescents in this study were repaired non-syndromic CLP, located in the central part of Thailand, and from an orthodontic clinic; these adolescents, though were widely diverse in terms of cleft severity, age group, sex and socioeconomic backgrounds. The authors plan to select a broader group of adolescents with CLP, including community-based subjects, and use condition-specific measures to assess health outcome of adolescents with CLP in the further research.

Conclusion

The HRQoL is a multidimensional construct that challenges the lives of participants as a result of impaired physical function, appearance and social integration as well as the necessary extensive reconstructive surgical interventions. This, in turn, places more emphasis on patient-based outcome measurement, including changes in HRQoL. Consequently, the authors findings highlight how adolescents with CLP integrated the experience of disability into their lives; demonstrating the influence of coping strategies used by people with CLP to prevent or limit the handicap of their disability. Personal and social interaction factors and skills therefore have a significant role in quality of life particularly with regard to CLP.

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Potential conflicts of interest

None.

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การศึกษาเชิงคุณภาพของคุณภาพชีวิตด้านสุขภาพและลักษณะการปรับตัวทางจิตสังคมของวัยรุ่นไทย ที่เย็บปิดปากแหว่งเพดานโหว่แล้ว

จุฑารัตน์ ฉิมเรือง, วิชาสลักษณ์ ชั่ววัลลี, อ้อมเดือน สดมณี, พัชรารวรรณ ศรีศิลป์นนท์, นิรมล พัจนสุนทร,
นันทินี นันทวนิชย์

วัตถุประสงค์: การศึกษานี้มุ่งศึกษาการให้ความหมายของคุณภาพชีวิตด้านสุขภาพผ่านมุมมองของวัยรุ่น และค้นหา
ลักษณะการปรับตัวทางจิตสังคมที่เกี่ยวข้องกับคุณภาพชีวิตของวัยรุ่นไทยผู้เคยรับการเย็บปิดปากแหว่งเพดานโหว่
วัตถุประสงค์และวิธีการ: กลุ่มตัวอย่างของการศึกษาเป็นวัยรุ่นที่เคยรับการเย็บปิดปากแหว่งเพดานโหว่จำนวน 18 คน
และผู้ปกครองของวัยรุ่นกลุ่มนี้จำนวน 6 คน ผู้นี้พนธ์คัดเลือกมาจากวัยรุ่นที่มารับการรักษาในคลินิกทันตกรรมจัดฟัน
ของคณะทันตแพทยศาสตร์ มหาวิทยาลัยมหิดล โดยใช้การสัมภาษณ์กลุ่มตัวอย่างทุกคนที่ยินยอมเข้าร่วมการศึกษานี้
ผลการศึกษา: จากข้อมูลของวัยรุ่นกลุ่มตัวอย่าง ความหมายของคุณภาพชีวิตด้านสุขภาพสามารถจำแนกได้เป็น 4
ด้าน ได้แก่ อารมณ์ทางร่างกาย การทำหน้าที่ของร่างกายได้จำกัด สภาพอารมณ์ และการเข้าร่วมกิจกรรมทางสังคม
ผู้ให้ข้อมูลแต่ละคนมีสภาพจิตใจ บทบาททางสังคม และระดับเศรษฐกิจที่หลากหลาย โดยส่วนใหญ่มีการปรับตัว
และสามารถเผชิญอุปสรรคจากผลกระทบของภาวะปากแหว่งเพดานโหว่ที่เกิดขึ้นในการดำเนินชีวิตประจำวันได้
อีกทั้งการสนับสนุนทางสังคมจากผู้ปกครอง เพื่อน และบุคลากรทางการแพทย์มีส่วนช่วยให้วัยรุ่นมีสถานะทางสุขภาพ
ที่ดีและพึงพอใจต่อการรักษาพยาบาลที่ตนได้รับ

สรุป: ผลจากการศึกษาพบว่าคุณภาพชีวิตด้านสุขภาพของวัยรุ่นปากแหว่งเพดานโหว่ ควรประเมินอย่างพหุมิติ
และวัยรุ่นกลุ่มตัวอย่างนี้มีแนวทางการปรับตัวให้ใช้ชีวิตอยู่ร่วมกับผู้อื่นในสังคมได้ดี
