



Health-related quality of life among Thai children and adolescents with cleft lip and/or palate: a qualitative study

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ABSTRACT

Background: Having cleft lip and/or palate (CLP) can be challenging for children and adolescents and appears to impact their health-related quality of life (HRQoL). To date, there is limited empirical work in this field, demonstrating a need for further exploration of qualitative research, especially with children and adolescents with CLP in Thailand.

Objectives: To explore the HRQoL perceptions of Thai children and adolescents with CLP.

Materials and methods: The present study was a qualitative approach. Eight children and adolescents with CLP, ages 9 to 14, were selected at the speech therapy clinic at Chiang Mai University, Thailand. Data were collected through a semi-structured interview guideline. The data were analyzed using thematic analysis.

Results: Four main themes were identified: (1) physical well-being, (2) psycho-emotional well-being, (3) social well-being, and (4) school functioning. Five subthemes further described this experience: communicative competence; teasing or bullying; self-perception and self-esteem; family and friend support; and difficulties in academic performance. Each theme was described with illustrative quotes.

Conclusion: The findings of this study provide a more thorough picture of HRQoL in children and adolescents with CLP. They have communicative competence, psycho-emotional well-being, social functioning, and school functioning issues rather than significant physical symptoms. Professionals should continue intervening as part of an interdisciplinary strategy to avoid or at least lessen negative effects on these children and adolescents with CLP.

Introduction

Orofacial clefts (OFCs) comprise cleft palate (CP), cleft lip (CL), and cleft lip and/or palate (CLP). OFCs involve structures around the oral cavity and can spread to facial structures, causing defects in the oral, facial, and craniofacial structures.¹⁻² One in every 500-700 births globally is affected by OFCs³, as well as one in every 500 Asian or Indian American births and one in every 2,500 newborns of African heritage.⁴ In Thailand, CLP affected 2.2% of newborns in Chiang Mai Province between 2015 and 2019.⁵

The growing body of literature concerning having CLP can be challenging for children and adolescents and appears to impact their health-related quality of life (HRQoL). To date, a growing body of quantitative research

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supports this.⁶⁻¹⁰ However, there was little qualitative research conducted in Thailand.¹¹

HRQoL is a broad and multifaceted concept that includes a person's physical, social, and mental health as well as the symptoms of diseases/disorders or health conditions and the side effects of treatment.¹² Pediatric HRQOL instruments should be based on a conceptual framework considering the child's physical, emotional/psychological, social, and developmental concerns.¹³ In a recent systematic review, the primary conceptual framework of CLP QoL concerns, however, was categorized, including physical (e.g., communication, pain, physical function, and general health), psychological (e.g., self-concept, behavior, satisfaction with appearance, psychological distress, and cognition), and social health (e.g., peer relations, school, family, social support, and social function).¹⁴

Regarding physical aspects, previous studies have found that individuals with CLP have speech problems, including compensatory articulation disorders and dysphonia.¹⁵⁻¹⁷ Bickham and colleagues reported that 26.9% to 34.3% of children had issues with families understanding their speech, others understanding their speech, having a conversation with a group of familiar listeners, or having a telephone conversation.⁶ Moreover, individuals with CLP may have a negative impact on various aspects of oral-health-related quality of life (OHRQoL).⁷

Regarding psycho-emotional aspects, Glenner and colleagues found that throughout middle school, children with CLP were more affected by aesthetic concerns, bullying, and challenges with friendship and interaction with others and less so during elementary and high school.⁸ Furthermore, Lovegrove and Rumsey found that adolescents were affected by teasing or bullying regarding their appearance, which caused considerable distress.⁹ A qualitative study by Chimruang and colleagues reported that some Thai adolescents with repaired unilateral and bilateral cleft lip and palate expressed negative views such as classmate harassment and overprotective parents.¹¹ Also, Kanthawong and colleagues reported that self-esteem may be caused by an awareness of their values in general, such as physical characteristics and self-confidence. In addition, the study found that Thai adolescents with cleft lip and palate who received the lowest scores on self-esteem had the most severe clefts, whereas those who received the highest scores had less severe clefts.¹⁸ However, Locker and colleagues reported that adolescents with CLP were well-adjusted and capable of coping with the challenges they confronted as a result of their conditions.¹⁰

In addition, regarding social aspects, Chimruang and colleagues reported that sociability problems had a more significant impact than self-image problems. Also, the study reported that friends and family were generally cited as sources of support and fun.¹¹ Furthermore, some studies found other relevant aspects in terms of academic ability. Richman and colleagues found that children with CP were more likely to have general language difficulties than children with cleft lip and palate, which could lead to

long-term reading disabilities. Children with cleft lip and palate appeared to have reading difficulties that resolved with age.¹⁹ When compared to their peers, children with oral clefts underperformed in all academic areas and grade levels.²⁰

It can be seen that children and adolescents are affected by CLP, which can lead to a decrease in HRQoL in all domains. Also, the fact that there is limited empirical work in this field demonstrates that there is a need for further exploration of qualitative research, especially with children and adolescents with CLP in Thailand. This study aimed to explore the perceptions of HRQoL of Thai children and adolescents with CLP. This may lead to a better understanding of their quality of life and provide them with a voice so that relevant health professionals may learn from them and manage plans since the approaches must be multidisciplinary and timely.

Materials and methods

The present study was a qualitative approach based on the philosophy of phenomenology because its purpose was to explore the perceptions of HRQoL of Thai children and adolescents with CLP. This approach was used to gain more insight and understanding of subjective experiences and capture the complexities of in-depth experiences, such as those of adolescents with CLP.¹¹ In this study, we adopted the conceptual framework of CLP QoL described by Klassen and colleagues.¹⁴

The Ethics Committee, Faculty of Associated Medical Sciences, Chiang Mai University (CMU), Thailand (AMSEC-65FB-007) approved the study. The interviews were conducted while respecting the participants' privacy in a private and quiet space in the speech therapy clinic. The purposes and details of this study were fully explained to the participants and their caregivers. Written informed consent was obtained from participants and their caregivers before entering the study participants who requested to be removed from the research study without providing a reason. The participants' confidentiality and privacy were protected throughout the data collection process.

Participants

Eight children and adolescents with CLP, ages 9 to 14, were selected at the speech therapy clinic at Chiang Mai, University, Thailand. All participants were treated at the craniofacial center and the speech therapy clinic, using a standardized procedure. The research team chose a purposive sample of eight people out of a total of eighteen people. Participants were included in the study if they: (1) were diagnosed as having CLP by a pediatrician or plastic surgeon; (2) were willing to participate in this study and give written consent, as well as their caregiver; and (3) had adequate Thai language skills to contribute to the interview and express their views productively. We continued to recruit participants for the study until we reached data saturation, at which point no more information for the resulting notion could be obtained.²¹

Data collection

Data were collected through a semi-structured interview guideline,²² designed to obtain reliable and comparable data.²³ All face-to-face interviews were held between August and October 2022. The semi-structured interview guideline, questions, and prompts were related

to the perceptions of HRQoL of children and adolescents with CLP (Table 1). These interviews were audio-recorded using a recorder application on Vivo, and notes were also taken during the interviews. The duration of the interviews varied from 30 to 45 minutes. These interviews were transcribed verbatim.

Table 1. Semi-structured interview questions.

Domains	Questions
Physical	<ol style="list-style-type: none"> 1. Do or how do you have a problem with your physical health? 2. Do or how do you have a problem with hearing? 3. Do or how do you have a problem with your oral health, such as teeth, or a problem chewing or choking on food when you eat it? 4. Do or how do you have trouble speaking when talking to other people? If any, can you tell me how difficulties with speaking affect your life?
Psychological	<ol style="list-style-type: none"> 5. How do you feel about your appearance, and how do you think other people see you? 6. Can you describe what things you think you are good at and bad at? 7. How do you feel about yourself now, and how do you see yourself in the future?
Social	<ol style="list-style-type: none"> 8. Who are you closest to in the family, and how do family members take care of you? 9. Do you have a best friend, and why are you so close to this friend? 10. Can you tell me about your experiences with bullying, such as pranks and mocking, and how you dealt with it? 11. Do you have to stop studying often to see a doctor or therapist, and how does the absence of school affect your life?
School	<ol style="list-style-type: none"> 12. Do you want to go to school, play, or talk to your friends? 13. What school subjects do you like most and least; how are your grades; and are you satisfied with your grade?

Data analysis

The data were analyzed using thematic analysis.²⁴ The first step started with the project leader manually transcribing the interviews and reading them several times to become familiar with the content. Then, initial codes were generated and applied to the data set. Codes featuring similar content were then grouped, yielding themes that describe HRQoL as related to physical, psychological, social, and academic factors. Later, the researchers reviewed and refined the main themes and provided definitions for the themes. Finally, the researchers report data analyses are based on the whole sample, which is analyzed in Thai, and the excerpts used to show the results in the paper are translated into English.

Study rigor

Credibility, transferability, dependability, and confirmability were the criteria used to increase trustworthiness, including the prolonged engagement of the researchers in the study, multiple interviews and notes, member checking, and triangulation.^{25,26}

Results

Table 2 illustrates the demographics of the participants' characteristics of eight children and adolescents with CLP aged 9 to 14. The average age of the participants was 10 years old. There were 5 females (62.5%) and 3

males (37.5%). The participants' cleft conditions included craniofacial clefts (N=1), cleft lip and palate (N=3), CP (N=3), and CL (N=1). Participants comprised 6 elementary school students (75.0%) and 2 middle school students (25.0%). All of them were in mainstream schools.

According to the data analysis, four main themes were identified: (1) physical well-being, (2) psycho-emotional well-being, (3) social well-being, and (4) school functioning. Five subthemes further described this perception: communicative competence; teasing or bullying; self-perception and self-esteem; family and friend support; and difficulties in academic performance, as shown in Table 3. Each theme was described with illustrative quotes.

Physical well-being

Communicative competence

The perceptions of all participants vividly noticed and expressed concerns about the impact of CLP on communicative competence. They mentioned how their cleft had affected their confidence in having conversations and how they tried to avoid having conversations, whether in person or front of a class:

"I have problems pronouncing aware consonants, such as [j] and [d]. When I speak, I am overly concerned with whether I will express something

Table 2. Demographics of the participants.

Interviewee	Age (Year)	Gender	Type of Cleft	School	Education
1	9.8	Female	Craniofacial clefts	Elementary school	Mainstream
2	11.7	Female	Cleft lip and palate	Elementary school	Mainstream
3	9.1	Female	Cleft palate	Elementary school	Mainstream
4	9.8	Female	Cleft lip and palate	Elementary school	Mainstream
5	9.7	Male	Cleft palate	Elementary school	Mainstream
6	14.2	Male	Cleft palate	Middle school	Mainstream
7	10.6	Female	Cleft Lip	Elementary school	Mainstream
8	11.11	Male	Cleft lip and palate	Middle school	Mainstream

Table 3. Interview themes.

Themes	Subthemes
Physical well-being	Communicative competence
Psycho-emotional well-being	Teasing or bullying
Social well-being	Self- perception and self- esteem
School functioning	Family and friend support
	Difficulties in academic performance

correctly. It induces stuttering... My communication causes me concern. Therefore, I lack self-assurance; I do not dare to speak and am frightened that others will not comprehend me. I lack confidence when addressing my peers in front of the class." (Interviewee 7)

"It is difficult for others to understand me as I have difficulty speaking clearly, and my voice is hoarse. I will stop talking and be silent. Even though no one makes fun of me at school, I am not very confident." (Interviewee 8)

Psycho-emotional well-being

Teasing or bullying

More than half of the participants reported having experienced negative emotions such as worry about other people's opinions, sadness, or moodiness in the past because they were teased or bullied:

"I was bullied at school. I got teased a lot when I was in kindergarten. I was angry at that time. There was one friend who kicked me in the back. I did not know why he bullied me. But he did not get teased about looks. Also, some friends stared at me. Now I am used to it anyway. So, if someone looks at me, let them look." (Interviewee 1)

"I was being bullied about having a cleft at school. I told my teacher that I was teasing. My teacher summoned that friends and warned him that he would be expelled if he did it again." (Interviewee 4)

"My friends joked that my nose was crooked, and my face was not pretty. At first, it hurt quite a bit." (Interviewee 2)

Self-perception and self-esteem

However, as they grew older, they nurtured positive emotions both in self-perception and self-esteem. They were able to accept this fact and see the positive aspects of themselves. All of the participants were able to adapt and adjust to their condition:

"I am not worried anymore because I cannot change anything. I feel good about myself now. At school, my friend asked me to help them study." (Interviewee 1)

"I am not worried about my condition. I feel confident. I know my strength. I am a fun person, and I am good at art." (Interviewee 4)

"Now I feel nothing. Some other friends told me that I am beautiful, and I rate my beauty at 7 out of 10. I feel confident, and I am happy for who I am." (Interviewee 2)

Social well-being

Family and friend support

Overall, all participants reported having good relationships with family and friends and enjoying attending school. They believed their friendships were valuable, that they were welcomed by their friends, that they could communicate with and rely on their friends, and that they felt cheerful when in the presence of friends:

"My parents look after me perfectly. They support me, so I feel confident in my life. I like to go to school. I have three best friends. I like to do manly things. I like playing football with them." (Interviewee 3)

"My parents will be the ones to give me advice. My parents will warn me when I do bad things."

He also said, "I like to go to school. I have many friends, but I do not know which one is my best friend. They are all close to me. After school, we played in the neighborhood." (Interviewee 6)

School functioning

Difficulties in academic performance

Most participants mentioned their academic achievements. They did not like academic subjects such as Thai language, English, and mathematics. They preferred physical education and the arts, as they felt that they got good grades without studying hard:

"I like physical education and art. I do not like math. I do not understand and do not know how to do it. Overall, I am not satisfied with my GPA." (Interviewee 4)

"I do not like English. I couldn't remember what grade I got last semester, but I did not get an A. My father told me if the regular school system does not work for me when I finish high school, he wants me to study vocational education instead." (Interviewee 5)

"I love reading comics, drawing, and painting. At school, I am waiting for the art class. It makes me feel free and relaxed. I don't like mathematics because I do not know how to solve math problems, and there is too much homework." (Interviewee 7)

Discussion

This study specifically focused on exploring the perceptions of HRQoL of Thai children and adolescents with CLP. The findings of our study found that, in terms of physical aspects, all of the participants mentioned difficulty in communication competence with others understanding their speech and having a conversation with familiar listeners such as friends, similar to Bickham *et al.*⁶ Participants also reported speech problems, including articulation and resonance disorders, even though they had received cheiloplasty, palatoplasty, velopharyngeal insufficiency (VPI) correction and evaluation, and speech therapy according to the protocol for cleft lip and cleft palate at the craniofacial center and at the Chiang Mai University, Thailand. Compensatory articulation disorders can be found in individuals with CLP, resulting in reduced speech intelligibility.^{15,16} In addition, dysphonia is characterized by breathiness, hoarseness, and low intensity of voice and can also be found during speech tasks.¹⁷ Therefore, speech pathologists should be involved in early intervention to prevent or help CLP-related communication problems. Individuals living with cleft lip and palate were determined to maintain their sense of dignity after having their speech treatment.²⁷

In contrast to Defabianis *et al.*,⁷ none of the participants with CLP in this study reported experiencing problems with their physical functioning in terms of

oral health. Similar to Konan *et al.*,²⁸ Thai children and adolescent patients with CLP had generally positive OHRQoL. Our participants could have received dental care since there was a treatment protocol for cleft lip and palate at the craniofacial center in northern Thailand. That cleft lip and/or palate patients should receive immediate care from a dentist.

Additionally, most participants reported that they experienced social stigma due to their appearance. They were teased or bullied in grades 1 or 2 in elementary school. They were in psychological distress. Like Lovegrove and Rumsey, adolescents were affected by teasing or bullying regarding their appearance, which caused considerable distress.⁹ However, all participants reported that, at present, they were satisfied with their appearances. They also should be notified that they may face challenges when they become concerned about their appearance as they age.⁸ In contrast, Prathanee found that Thai children with CLP experienced social stigma due to speech and language problems after surgical treatment²⁹ but not due to their appearance. Our findings provide direct input into teachers' practice. It is critical to help children who have been bullied because of their appearance feel safe at school. This could be facilitated by having a clear school policy on what teachers should do and how they should act.

Importantly, it should be noted that our findings did not explore social stigma for children and adolescents with CLP in the perceptions of their family or friends. Chung *et al.* found that the perception of a child with CLP in low-resource areas is negatively influenced by parental blame or the belief that the cleft results from a punishing supernatural force. A child with CLP is bullied, rejected, and socially isolated, sometimes even from their family. This misery continues in school, resulting in a dropout and adding a further barrier to finding their preferred job. An inability to fully participate in the workforce results in significant financial consequences and decreased productivity.³⁰ Therefore, further study can provide the opportunity to explore in greater depth.

Furthermore, in our findings, female participants reported positive self-esteem as they grew older, while male participants did not mention it. Kanthawong *et al.* found no statistically significant relationship between self-esteem and personal characteristics such as gender or age.¹⁸ Similar to Locker *et al.* it might also be that children born with CLP are well-adjusted and can cope with the adversities they experience due to their conditions.¹⁰ Also, Eiserman found that children born with CLP showed positive self-perception and psychosocial adjustment.³¹ Therefore, it can be seen that self-perception is critical to the adjustment process and is one of the key indicators of positive adjustment.³²

This study also found that participants reported having support from their families and a good relationship with friends at school. Kramer *et al.* mentioned that family functioning is a key component in preventing children with CLP from being exposed to influences that decrease their quality of life.³³ Those who received constant support from

parents, friends, and professionals were also more likely to have a favorable health status and higher treatment satisfaction.¹¹

Our study found that most participants preferred physical education and the arts to academic subjects such as Thai, English, and mathematics. Richman *et al.* found that children and adolescents with CLP had a high rate of reading disabilities, particularly in children.¹⁹ Children with clefts were approximately one-half grade level behind their peers, had greater academic underachievement rates, and used higher rates of special education services.²⁰ On the other hand, Collett *et al.* found that children with clefts did not perform worse than control participants on neurocognitive and academic achievement assessments.³⁴ Further investigation into additional diagnoses, such as cognitive impairments linked to reading difficulties, is needed. As a result, it is essential to consider that children must be evaluated and receive early intervention for academic difficulties to be identified and supported.

Limitation

Several limitations were noted in this study, such as the small sample size because our study was qualitative. The participants included in the study were not representative. Future mixed-method research, such as exploratory research that includes quantitative research with a larger sample size, might be used. Also, more research comparing the views of typically developing children and children with CLP is needed to better understand the importance of these various HRQoL elements in children with CLP.

Conclusion

The findings of this study provide a more thorough picture of HRQoL in children and adolescents with CLP. They have communicative competence, psycho-emotional well-being, social functioning, and school functioning issues rather than significant physical symptoms. Professionals such as a dentist, speech therapists, a teacher, and parents should continue intervening as part of an interdisciplinary strategy to avoid or at least lessen adverse effects in these children and adolescents with CLP.

Conflicts of Interest

The authors declare no conflict of interest regarding the publication of this paper.

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