

Families' awareness and attitudes towards children with cleft lip and palate in the northern provinces of Vietnam

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Sri Lanka Journal of Health, 2023; 52(1): 66-74
DOI: <http://dx.doi.org/10.4038/sljch.v52i1.10476>

Abstract

Introduction: In Vietnam, awareness from families and society towards children born with cleft lip and palate (CLP) is still lacking. Knowledge and attitude of families towards CLP could help fight against negative beliefs and preconceptions about CLP.

Objectives: To assess the awareness of families with children with CLP in the northern region of Vietnam, who were diagnosed and received treatment at the National Hospital of Odonto-Stomatology.

Method: This is a cross-sectional descriptive study with a convenient sample of 196 patients who were diagnosed with CLP at the National Hospital of Odonto-Stomatology from October 2019 to October 2021. Children, their families, or guardians participating in the study were interviewed using a pre-built questionnaire.

Results: Nearly 90% of parents observed the community's acceptance of their children with CLP. Families received support and management from the government for children with CLP through direct counselling (64.2%), and dialing (45.9%). However, most respondents felt shocked, anxious, and painful when there was a child with CLP in their family. Most families' awareness of childcare methods was relatively limited: About 58-60% parents found their children with CLP had major difficulties in eating and drinking, but 26% reported they did not help

their children in that regard. Nearly two-thirds of parents had no knowledge about childcare devices, more than one-fifth knew about these devices but chose not to use them whilst the rest had known and used these devices. The parents knew the symptoms of pneumonia and nasopharyngitis that children with CLP could experience, and also knew some appropriate prevention measures. However, parents' knowledge about psychological factors such as intellectual disability and poor social integration only ranged from 1-2%. Percentage of parents who were not aware of the conditions to be fulfilled before surgery for children with CLP was 56.6%. Only 18.9% of children were diagnosed and received treatment early (before 6 months of age).

Conclusions: The awareness of families of children with CLP in the northern region of Vietnam, who were diagnosed and received treatment at the National Hospital of Odonto-Stomatology, was inadequate.

(Key words: Cleft lip and palate, Knowledge).

Introduction

Cleft lip and palate (CLP) occur in 1 in 600-800 infants worldwide. The frequency varies among different races and geographic regions, being highest in Asians, moderate in Caucasians, and lowest in Africans^{1,2}. In Vietnam, prevalence of CLP is 20.1 per 10,000 live births³. CLP could cause a significant burden on health, medical costs, quality of life, and social well-being of patients and their families⁴.

Birth of a child with a birth defect is often unexpected and causes shock, shame, anxiety, confusion, guilt, inadequacy, rejection, depression, disappointment, anger, despair, and stigma towards parents, especially mothers⁵. Unfortunately, most parents experience problems with feeding their affected children such as the number of feedings and meals' qualities⁶.

Despite development of the Vietnamese health system, Vietnamese continue to face obstacles when accessing specialized healthcare services such as plastic and reconstructive surgery. Medical costs, distrust towards medical providers and lack of trained doctors are the common obstacles preventing

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(Received on 21 September 2022; Accepted after revision on 21 October 2022)

The authors declare that there are no conflicts of interest

Personal funding was used for the project.

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families from getting surgery from local hospitals⁷. Plastic surgery (primarily funded by many charities) could significantly help children with CLP return to normal and have a satisfactory quality of life.

Therefore, having knowledge about the causes, treatment, and prevention of CLP can help fight against negative beliefs and faulty attitudes towards CLP and even reduce its prevalence. Parents' knowledge about CLP might help develop better health-related behaviours in their children. When knowledge of children's families and the methods of postoperative treatment for the child are still lacking, not only treatment outcome but also comprehensive psycho-physiological development of the children are affected⁹.

Objectives

To assess the awareness of families of children with CLP in the northern region of Vietnam, who were diagnosed and received treatment at the National Hospital of Odonto-Stomatology.

Method

A descriptive epidemiological analysis was carried out from October 2019 to October 2021 in families of children with CLP who received treatment at the National Hospital of Odonto-Stomatology. Children with CLP over 15 years of age who had not had surgery and children with CLP whose parents had mental or neurological diseases were excluded from the study.

Sample size: We applied the formula for calculating the minimum sample size for a descriptive study to determine an incidence as follows¹⁰:

$$N = Z_{1-\alpha/2}^2 \times \frac{p(1-p)}{(\rho\varepsilon)^2}$$

where: N: Minimum sample size;
 p: expected prevalence; p = 0.29 (Proportion of children with CLP examined and received treatment at Hai Phong Medical University Hospital in 2017)
 $Z_{1-\alpha/2}$: the statistic corresponding to the level of confidence, with 95% confidence then $Z_{1-\alpha/2}=1.96$;
 ε: Relative error; ε = 0.25.

With the selected values, the sample size that was expected to add 10% was 165 children; in fact, we collected samples from 196 children.

Sampling method: All parents of children with CLP who bring their children to the hospital for examination were interviewed directly using a pre-built questionnaire. The questions were compiled

with given answers and were practical for parents and families. There were no questions related to religion, culture, and region. In some special cases (monitoring the children's speech function after surgery), when the patients were too far away for a face-to-face interview, the questionnaire was sent by post, phone or social media. The content of the questionnaire was public and uniform for all cases. The questionnaire was built with given answers; the parents only needed to tick V or X in the corresponding answer. The answers were all practical and there were no questions related to sensitive issues, especially religious, cultural, and regional factors.

Ethical issues: All information was kept confidential and for research purposes only. This study was approved by the Ethics Committee of the National Institute of Malaria, Parasitology and Entomology, Vietnam (No. 56/CN-VSR) on 21.03.2019. Written informed consent was obtained from the parents.

Results

The 196 families whose children were diagnosed to have CLP in the National Hospital of Odonto-Stomatology are described in Table 1.

Most of the parents had an educational level from high school or higher; Junior college/College degrees accounted for 45-47.5%, and university/postgraduate degrees accounted for more than 10%. The main occupation was Freelance (30-40%), followed by farmers (26-29%). The average monthly income of family members ranged from 5 to 10 million VND, and the median value was 8.5 million VND.

Table 2 shows the parents' assessment of the support from the community, government and commune/ward health for children with CLP.

According to parents' assessment, nearly 90% of parents observed community and society's acceptance of their children, and only 1.5-2.0% of parents observed that their children received hostility or alienation from form others and 9.7% of families chose not to tell anyone about their children's disease. The parents said that the forms of government support and management for their children were direct counselling (64.2%) and telephone (45.9%). The percentage of parents who said that their children did not receive intervention and support from the government accounted for 16.3%.

Table 1: Demographic details of the parents of the children with cleft lip and palate (n=196)

Parents' details	Number (%)
<i>Father's educational level</i>	
Below high school	83 (42.3)
Junior college/College degree	93 (47.5)
University/Postgraduate degree	20 (10.2)
<i>Father's occupation</i>	
Farmer	51 (26.0)
Manual labourer	41 (20.9)
Intellectual	25 (12.8)
Freelance	79 (40.3)
<i>Mother's educational level</i>	
Below high school	86 (37.6)
Junior college/College degree	89 (45.4)
University/Postgraduate degree	21 (10.7)
<i>Mother's occupation</i>	
Farmer	57 (29.1)
Manual labourer	36 (18.4)
Intellectual	44 (22.4)
Freelance	59 (30.1)
<i>Average income of each person in the family (million VND)</i>	
Median	8.5
Interquartile range	5 – 10
Min - Max	0 - 15

Table 2: Parents' assessment of the support from the community, government and commune/ward health for children with cleft lip and palate (n=196)

Source of support	Number (%)
<i>Recognition from community and society</i>	
Acceptance	174 (88.8)
Hostility	03 (01.5)
Alienation	04 (02.0)
Family undisclosed	19 (09.7)
<i>Management of government, commune/ward health</i>	
Psychological help	11 (05.6)
Direct counselling	118 (60.2)
Telephone	84 (42.9)
Family undisclosed	25 (12.8)
No intervention	32 (16.3)

Table 3 gives information about children with CLP support. The main sources of information on childcare that the parents used were internet and

commune health staff (both reached 60.7%). Other sources of information used were self-study, media and personal experiences.

Table 3: Information about children with cleft lip and palate support

Information	Number (%)
<i>Information sources</i>	
Media	71 (36.2)
Commune health staff	119 (60.7)
Internet	119 (60.7)
Self-study	91 (46.4)
Experiences	01 (0.5)
<i>Information about operable hospitals/organizations</i>	
National Hospital of Odonto-Stomatology	56 (28.6)
2-5 hospitals	130 (66.3)
>5 hospitals	10 (05.1)

Table 4 shows the feelings of parents and relatives towards children with CLP. Anxiety, depression, fatigue, shock and fear were the common emotions experienced by parents of children with CLP. Whilst 80% of cases had anxiety, 30-46% had shock, pain

and fear. About 8-10% of parents felt tired and disappointed when their children contracted CLP. The parents said that their family members also felt the same way.

Table 4: Feelings of parents and relatives towards children with cleft lip and palate

Feelings of parents and relatives	Number (%)
<i>Parents</i>	
Normal	19 (09.7)
Pain	59 (30.1)
Bothered, tired	18 (09.2)
Fear	57 (29.1)
Shock	91 (46.4)
Anxiety	158 (80.6)
Disappointment and depression	21 (10.7)
No answer	01 (0.5)
<i>Relatives</i>	
Normal	27 (13.8)
Pain	58 (29.6)
Bothered, tired	25 (12.8)
Fear	53 (27.0)
Shock	102 (52.0)
Anxiety	151 (77.0)
Disappointment and depression	26 (13.3)

Figure 1 shows the problems faced by children with CLP. About 58-60% of parents found that their children had difficulties in eating and sucking. Some

other parents (31.1%) found that their children had difficulties in speaking. About 25% of the children had no problems due to CLP.

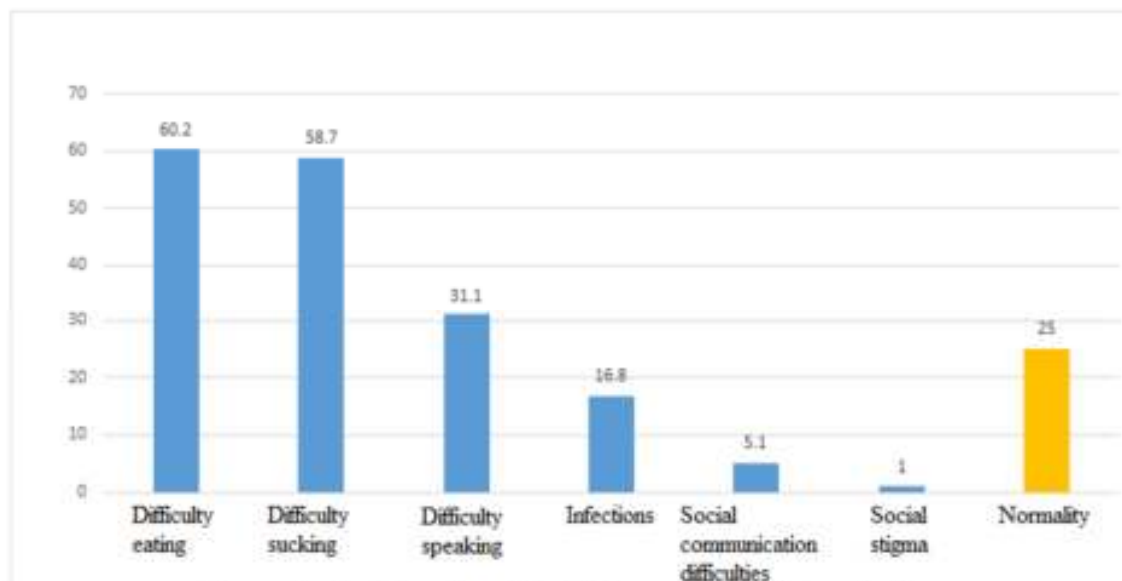


Figure 1: Problems faced by children with cleft lip and palate

Table 5 gives ways of taking care of a child with CLP. The common breast-feeding positions of the children were sitting/ standing (58.2%) and normal bottle feeding (36.7%). The proportion of children who could not suck accounted for 7.1%. When the children had difficulty in eating, 26% of the parents

said that they did not provide any support, and other parents applied some measures to support them such as using spoons, pumping through silanes (61.2%), giving more frequent meals (39.8%), stopping feeding and patting their back (16.3%) when the children choked and using special nipples (14.8%).

Table 5: Taking care of a child with cleft lip and palate (CLP)

Taking care of child	Number (%)
Measures to support the children for eating	
<i>Breastfeeding position</i>	
Sitting/ standing	114 (58.2)
Low lying	09 (04.6)
Normal bottle feeding	72 (36.7)
Specialized bottle feeding	22 (11.2)
Unable to suck	14 (07.1)
<i>Supporting measures when children experience eating difficulties</i>	
Giving more frequent meals	78 (39.8)
Using a spatula, pumping through silane	120 (61.2)
Patting child's back in between meal	32 (16.3)
Using special nipples	29 (14.8)
No measures	51 (26.0)
Heard/used assistive devices to take care of a child with CLP	
Heard/used	34 (17.3)
Heard, did not use	44 (22.4)
Unknown	118 (60.2)
Did the child vomit after eating?	
No	124 (63.3)
Yes	24 (12.2)
Sometimes	48 (24.5)

Despite having a child with CLP, nearly two-thirds of parents did not know about childcare devices, more than one-fifth of parents knew about these devices but did not use them, and the rest heard, knew, and used them. About 12.2% of infants who contracted CLP vomited after eating, 24.5% of them sometimes vomited and most of them did not.

children often have include infections, colds, otitis media, nasopharyngitis, facial asymmetry, pneumonia, hyper-nasal voice, tooth decay, and a misaligned jaw. Around 75% of parents thought that their children were susceptible to infections, colds, sneezing, and runny nose. Only 1-2% thought that the children were prone to stomach diseases, intellectual disability and poor social integration.

Figure 2 shows the prevalent diseases in children with CLP. The diseases that parents thought their

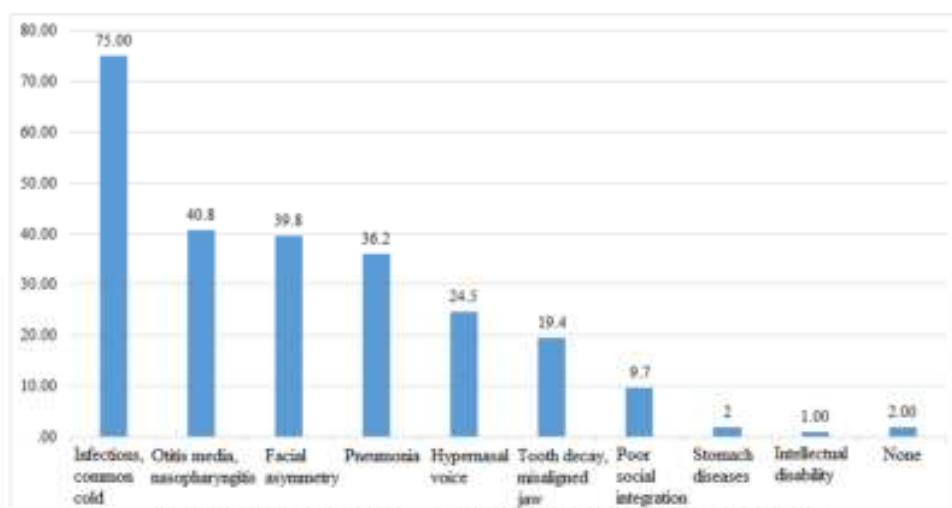


Figure 2: Prevalent diseases in children with cleft lip and palate

Table 6 gives the measures that parents have taken to prevent complications of CLP. To prevent pneumonia and nasopharyngitis in the children, the parents mainly chose to keep the children warm (78.1%), followed by regularly washing children's

noses, house cleaning, and using folk experiences. Only 15% of the parents did not know what to do to prevent pneumonia and nasopharyngitis in their children. The proportion of children who were fully vaccinated was 96.9%.

Table 6: Measures that parents have taken to prevent complications of cleft lip and palate

Measures taken by parents	Number (%)
<i>Measures to prevent pneumonia, nasopharyngitis</i>	
Unknown	30 (15.3)
Keeping warm	153 (78.1)
Regularly washing the child's nose	51 (26.0)
Cleaning house	53 (27.0)
Using folk experience	37 (18.9)
<i>Was the child fully vaccinated?</i>	
Yes	190 (96.9)
No	06 (03.1)

Table 7 gives the preventive measures for dental problems of children with CLP. Over 80% of parents thought that their children needed to be concerned about dental problems and knew about dental disorders including congenitally missing teeth

(45.9%), abnormal tooth position (38.8%), and delayed teething (25.5%). The main ways to help the parents find out about their children's dental problems were dental examination (87.5%) and self-study (17.5%).

Table 7: Preventive measures for dental problems of children with cleft lip and palate

Preventive measures	Number (%)
<i>Was the child concerned about dental problems?</i>	
Yes	158 (80.6)
No	38 (19.4)
<i>Dental disorders in children</i>	
Delayed teething	50 (25.5)
Congenitally missing teeth	90 (45.9)
Abnormal tooth position	76 (38.8)
Normal development	53 (27.0)
Unknown	33 (16.8)
<i>How the parents find out that their children have dental problems</i>	
Dental examination	172 (87.8)
Self-study	38 (19.4)
Asking an acquaintance	10 (05.1)
Internet	09 (04.6)

Table 8 gives the weight problems of children with CLP. 12.8% of children were perceived as underweight by their parents. Over 80% of children were perceived as of normal weight or whose weight was not a concern for the parents. Over 60% of the parents did not know the reasons for their children's being underweight and 56% of the parents did not know the complications of being underweight. The most well-known reasons for the children's being underweight were lack of food (19.4%) and difficulty in eating (15.3%). Complications of the underweight were primarily physical, such as growth retardation and being undersized. The measure most chosen by the parents to control the children's underweight was to feed them more (66.3%).

Table 9 gives the parent's knowledge of surgical conditions for children with CLP. Nearly 50% of parents had no knowledge of the surgical conditions for children with cleft lip, whilst 39.3% of parents

thought that to have surgery, children needed to be 6 months old and weigh over 6kg.

Whilst 56.6% of parents had no knowledge of the surgical conditions for children with cleft palate, 34.2% of the parents thought that the children needed to be 18 months old and weigh over 10kg to be able to have surgery.

Nearly 60% of the parents were not informed of what post-surgery treatment would be required if surgeries were to be performed. Parents thought that maxillofacial surgeons and plastic surgeons had the most important roles in the treatment of children with CLP.

Table 10 gives the age when the children were first examined. Only 18.9% of the children were examined and received treatment early (before 6 months of age). The proportion of children who received late intervention was high, the latest being at the age of 17 years.

Table 8: Weight problems of children with cleft lip and palate

Weight problem	Number (%)
<i>Current perceptions of birth weight</i>	
Normal	149 (76.0)
Overweight	03 (01.5)
Underweight	25 (12.8)
Unconcerned	19 (09.7)
<i>Reasons for being underweight</i>	
Lack of food	38 (19.4)
Difficulty in eating	30 (15.3)
Frequent hunger	02 (01.0)
Lack of nutrients	10 (05.1)
Unknown	123 (62.8)
<i>Complications of being underweight</i>	
Growth retardation	38 (19.4)
Weak immunity	09 (04.6)
Gastritis	03 (01.5)
Undersized	57 (29.1)
Unknown	110 (56.1)
<i>Measures taken by the parents when their children were under-weight</i>	
Medical examination	71 (36.2)
Larger meals	130 (66.3)
Searching the internet	01 (0.5)
Doing nothing	20 (10.2)

Table 9: Parent's knowledge of surgical conditions for children with cleft lip and palate

Parent's knowledge	Number (%)
<i>Surgical conditions for cleft lip</i>	
6 months old and weighing >6 kg	77 (39.3)
No knowledge	94 (48.0)
<i>Surgical conditions for cleft palate</i>	
18 months old and weighing >10kg	67 (34.2)
No knowledge	111 (56.6)
<i>Post-surgery treatment</i>	
Yes	84 (42.9)
No	112 (57.1)
<i>Doctors needed for the treatment</i>	
Paediatrician	76 (33.8)
Maxillofacial surgeon	188 (95.9)
Dentist	89 (45.4)
Psychiatrist	16 (08.2)
Otorhinolaryngologist	91 (46.4)
Plastic surgeon	103 (52.6)
Nutritionist	28 (14.3)
Pronunciation Specialist	39 (19.9)

Table 10: Age when the children were first examined

Children's age (months)	Number (%)
≤6	37 (18.9)
6 - 12	30 (15.3)
12 - 18	26 (13.3)
>18	103 (52.6)
Median	19
Interquartile range	8 - 72
Min - Max	5 months - 17 years

Discussion

Lack of awareness of CLP in many countries of Asia, such as India and China, has been reported^{11,12}. Surgery could make it possible for patients to have a good quality of life¹³. Knowing the causes, treatment, and prevention of complications CLP can help fight negative beliefs and faulty attitudes regarding CLP. In Vietnam, families' awareness of CLP is average. Their knowledge is based on their children's appearances.

Most respondents had an educational level of high school or higher, and they reported that information about CLP could be accessed from sources such as the Internet and commune health staff. However, most respondents underwent shock, anxiety and pain when there was a child with CLP in their family. Furthermore, 9.7% of families chose not to tell anyone about their children's condition and 16.3% of families said they did not receive any intervention or governmental support.

The family's knowledge of childcare methods was relatively limited. Feeding was one of the biggest challenges for families when taking care of children with CLP. About 58-60% of the parents found children with CLP to have difficulties in eating and sucking. In these cases, they said that they did not know the reason, the appropriate time of treatment, and whether CLP was preventable. Similarly, there was a significant knowledge gap in supporting children with eating difficulties; 26% of parents said they did not provide any measures. Nearly 2/3 of the parents did not know about childcare devices. More than 1/5 of parents knew about these devices but did not use them, and the rest had heard, known, and used them.

Majority of the parents understood the possible health problems of a child with CLP, including ear infections, nasopharyngeal infections, and pneumonia. Therefore, the families had actively taken preventive measures for their children. Only 15% of parents were not aware of what to do to prevent pneumonia and nasopharyngitis in their children. The proportion of children fully vaccinated was 96.9%.

There are still children with CLP in low-income areas who have to face many social barriers. This stigma is detrimental to children's education, employment, marriage, and community integration¹⁴. However, only 1-2% of families recognized their children's intellectual disability and poor social integration.

56% of respondents did not know about complications from their children being underweight. Many families were not aware of the causes of underweight in children with CLP and

attributed it mainly to lack of food (19.4%) or difficulty in eating (15.3%). Complications from being underweight were primarily physical, such as growth retardation and being undersized. Measures most chosen by the parents to treat underweight children with CLP were to feed them more (66.3%) and seek medical help (36.2). Still, 10.2% of the families did nothing to improve this condition.

Treatment of CLP lasts from birth to adulthood, surgery to close the cleft being the first basic treatment for children with CLP. Cleft lip surgery is performed when children are 6 months old or older, weighing approximately 10 kg, and cleft palate surgery is performed when the children are 1.5 to 2 years old¹⁵.

Families have a substantial gap in awareness of their children's surgical condition. Nearly 50% of parents were not aware of the conditions required to operate on a child with a cleft lip. The proportion of the parents who did not know the surgical conditions for children with cleft palate is higher, accounting for 56.6%. Nearly 60% of the parents did not have knowledge of what post-surgery treatment their children would need if the surgery was to be performed. In these cases, surgery, rehabilitation, and social integration support faced many obstacles.

In Vietnam, there are still significant knowledge gaps among parents about CLP, especially about surgical methods and how to take care of children with CLP. This limited knowledge causes significant challenges to the well-being of the children. Health education needs to be strengthened in the community to raise awareness and thereby help develop a more positive attitude toward children with CLP.

Conclusions

Awareness of families of children with CLP in the northern region of Vietnam, who were diagnosed and received treatment at the National Hospital of Odonto-Stomatology, was inadequate.

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