

Family Care Patterns of Children with Cleft Lip/Palate in Northeast Thailand: A Qualitative Study

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Objective: Our aim was to determine the patterns of family care for children with cleft lip/palate in northeastern Thailand.

Materials and Methods: This was a qualitative study on the parents of children with cleft lip/palate, coming for follow-up at the Tawanchai Center, Srinagarind Hospital. Twenty-one parents underwent in-depth interviews regarding the pattern of care vis-a-vis their children between September and November, 2018. All data were analyzed using content analysis.

Results: The patterns of family care to children with cleft lip/palate varied, depending on the context and the limitations of each family. There was a main caregiver in each family, mostly female (mother or grandmother). Financial problems was the most common burden. The most common concerns were social issues and hereditary penetrance of the disease. Family adaptations included education, family structure, and helping children with socialization.

Conclusion: The family care patterns for children with cleft lip/palate were similar vis-a-vis burdens, concerns, and adaptations. By contrast, the family structure varied, depending on the context and limitations of the family.

Keywords: Cleft lip and cleft palate, Family, Parental migration

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Cleft lip/palate are congenital anomalies of the skull and facial bone⁽¹⁾. The incidence of cleft lip/palate in northeastern Thailand is 2.5 per 1,000 live births⁽²⁾. The children with cleft lip/palate require special care from a multidisciplinary team from birth⁽³⁾. In childhood, the treatment and care should be accomplished in cooperation with the parents; in preparation for surgical correction during the first year of life. Areas of co-operation include bringing the children to hospital, and post-operative care both in and out of hospital, until the end of the treatment process. Previous studies showed that cleft lip/palate significantly affects the parents in different ways than the children, both psychologically and socially^(4,5). Consequently, cleft lip/palate is a whole-family burden⁽⁶⁾, especially regarding expenses^(7,8), and complications regarding eating, ear infection, and speech development. The children and the family, thus, need multidisciplinary interventions because of surgeries, speech training, dental procedures, and repeated psychological traumas^(9,10).

Family is a core aspect of individual development and lifelong stability. Overall family functionality thus affects

the health of each family member including the prevention of illness and successful treatment of disease. When any member of the family is ill, the whole family is affected⁽¹¹⁾. In Thailand, the structure of family has changed significantly in the last 25 years; most particularly due to economic pressures. We, thus, investigated the patterns of care of each family with children with cleft lip/palate.

Objective

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Materials and Methods

The Institutional Review Board (IRB), Office of Human Research Ethics, Khon Kaen University, reviewed and approved the present study (HE611330).

The population and sample of this study were the parents of children, between 2 and 10 years of age, with cleft lip/palate being brought to the Tawanchai Center, Srinagarind Hospital, for treatment follow-up. The number of parents to be interviewed was to depend upon the saturation of information, which is to say 'no more useful information obtained from the further interviews'⁽¹²⁾ this occurred after interviewing 21 parents. The interviewer was a researcher who did not have any clinical background and was not involved in caring of the patients.

The interview tool was the in-depth interview guiding form, which included questions on demographic data,

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the relationship between the affected child and other family members, the data of the various family members, and the details of the type and presentation of cleft/lip palate. All data were collected directly, in writing, and voice recording. The data were analyzed, firstly by extracting the in-depth interview records, word for word. We also recorded the circumstances of the interview. The extracts were further validated by 'Triangulation' method. The data then were indexed, coded, and analyzed for content.

Results

Demographic data

The overall sample was 21 (18 females or 85.7%). Most of the respondents were between 20 and 39 years of age. The interviewee was usually the main care giver (13 cases or 61.9%) and living with the patient (17 cases or 81%) (Table 1).

Family care patterns

After the analysis, we categorized the patterns of family care into 4 aspects, including family structure, family burden(s), family concerns, and family adaptations. The details are provided in Table 2.

Discussion

In this study, we found that most of the interviewees (i.e., mother or grandmother) were the main care giver and living with the patients. The other family members would come with the patient only when the main care giver was not available.

Family structure

We found that the structure of the family with a child with cleft lip/palate varied, depending on the context and limitations of each family. The family with a teenage pregnancy usually experienced either divorce or migration for work of the father and/or mother; consequently, the main care givers were either grandmother or, less frequently the

grandfather. This finding is consistent with the report by East⁽¹³⁾ who found that about half of teenage pregnancies resulted in divorce or absence of both the father and mother. This may be due to parental immaturity and/or financial stressors^(14,15). Parental migration is the main finding in Thailand, particularly in the northern and northeastern regions, due to poverty and the misconception that it is good for children to be raised by a grandmother or grandfather⁽¹⁶⁾. The family structure of a non-teenage pregnancy varied. In the family with all members living together, the mother usually was the main care giver, when the father was only a supporter, visiting only on special occasions (i.e., surgery). It is consistent with the current pattern of parent migration, wherein the father is often absent⁽¹⁷⁾. Illness is the main reason for mothers staying home, and fathers migrate for work. Almost all mothers stay with the child until the first month of life just like other parents in Thailand⁽¹⁶⁾.

Family burdens

The main burdens of the family with cleft lip/palate were care of the children and financial issues followed by changes in the family because of the illness⁽¹¹⁾. The degree of burden regarding care of the patient increased with the degree of disease. Although there are not any medical expenses for treatment of cleft lip/palate, financial strains remain an issue because of transportation costs to hospital and lost time at work^(7,8).

Family concerns

The main concern in these families was social issues because of the appearance of their child. Johansson reported that parents usually over worry caring for children with special needs⁽¹⁸⁾. Differences in appearance can often lead to bullying, especially among adolescents⁽¹⁹⁾; so families take a keen interest in treatment. Caring for children with cleft lip/palate is also difficult as most families have no experience with the disease⁽¹⁰⁾. Families will harbor a concern about hereditary penetrance to the next generation⁽²⁰⁾.

Family adaptation

The parents usually educated themselves about the disease, then adjusted the structure of the family to assign someone as the main care giver. Having a main care giver is necessary, because caring for a patient with cleft lip/palate is more complicated than relatively healthy children, including regarding eating, oral care, post-operative care, speech training, and most importantly psychosocial development⁽¹⁰⁾. Psychological care is closely related to socialization and the family helps the patient in many ways with socialization; including mental strengthening, social preparation, and spending time with the patient. Most of the mothers decided not to work far from home in order to be the main care giver. They were concerned that the grandparents might not be suitable for such a complicated disease⁽¹¹⁾.

The strength of this study was its visualization of in-depth data regarding the family care pattern for children with cleft lip/palate, particularly on how the family structure

Table 1. Demographic data

Data variable	Number	Percent
Sex		
Male	4	14.3
Female	18	85.7
Age (years)		
Less than 20	1	4.8
20 to 39	12	57.1
40 to 59	7	33.3
More than 60	1	4.8
Role		
Main care giver	13	61.9
Supporter	8	38.1
Living status		
Living with patient	14	81
Not living with patient	7	19

Table 2. Family care patterns

Family care patterns	Characteristic
1) Structure	All families had females as main care giver. Role of father included making money, finding treatment details, driving to hospital for follow-up, and sometimes caring for the patient. Grandfathers sometimes helped in a variety of ways. Several patterns of family structure, depending on context and limitation of each family.
1.1) Mother with teenage pregnancy	There was either pre-marital pregnancy or no marriage at all. Parents often lived together when mother was pregnant. Outcome of these families was either divorce or both parents migrated for making money, then grandmother became main care giver with some support from other family members. In case of divorce, mother often acted as main care giver, with support from grandmother. If mother migrated for work, grandmother became main care giver. If children were with the father, he always migrated for work, then grandmother (mother of father) became main care giver. In families where both parents migrated for work, they usually stayed with the child until after early surgeries, migrating when the patient showed clinical improvement. They would telephone to inquire about their child, albeit frequency calls decreased over time. They sometimes came to visit.
1.2) Both parents living together and not teenage pregnancy	Both parents were living together with the child, with mother acting as main care giver. In larger families, they received support from grandparents, while in smaller families they still received support from grandparents who lived next door. Although the father was main income earner, the mother worked. Primary reason for staying with the child was severity of disease. The child with cleft lip/palate needs more sophisticated care and intensive follow-up. Living with the child provided greater benefit for the child.
1.3) Non-divorced parent, non-teenage pregnancy but absence of either father or mother	Father was migrating for work, leaving mother behind to care for the child. Mother still working when living with the child in extended family, having grandmother assist. Role of father included earning income, searching for disease information, caring for the child during admission or operation, and bringing the child to follow up. For example, the 28 years-old man said "I have migrated to another province just because of the better income. When my child need to admitted in the hospital, I left my job for coming back".
1.4) Divorced, non-teenage pregnancy parent Remarkable	Family structure of these families were similar to those families with divorced parents 1) Some parents left their child for a while, mostly for financial needs. When the child grew up, in conjunction with incapability of grandparents, the mother returned being the main care giver. The father still migrated for work. 2) In all families, the mother cared for the child for at least first month of breast feeding. After that it depended on the context of each family. In many families, period of maternal care extended to peri-operative period, until she was assured of smooth post-operative course. Main care giver was one patient most familiar with.
2) Family burdens	
2.1) Cares	There were difficulties caring child with cleft lip/palate, especially during first year of life. Problems included feeding problem, eating, aspiration, needs for special equipment, and peri-operative care. When child growing up, problems trended to be about speech training. Concerns about patient illness and appearance, resulting in a patient inferiority complex. In some families, all patient photos removed to prevent child from seeing him/herself before surgical correction. Daily cares of child started since waking child up, bathing, brushing teeth (some children unable to perform), feeding, and bringing child to school, doing homework. In family with intact father or mother, they would teach child about morality. In parental absence, grandparents usually indulged the child and/or provided incorrect medications.
2.2) Financial issue	Difficulty in breast feeding led to under-production of breast milk. Powdered milk then main food for child, resulting in expense. Greatest expense was traveling to hospital, especially during early period when frequency of follow up more than 3 times per month. Most families did not live in Khon Kaen Province, so had to use either a charter car or multiple rounds of autobus. When driving own car, fuel was main expense. All family members thus needed to earn income, leading to migration of parents, despite concerns for the child. In family where mother decided to live with the child, the maternal income decreased.
3) Family concerns	
3.1) Socialization of patient	Concerns that child would be bullied, because of either appearance or unclear speech. Bullying includes parodying, hate speech, and disrespectful staring by adults.
3.2) Cares	Concerns about sanitation, aspiration, and particularly complications during perioperative period.
3.3) Patient future	Fear of hereditary penetrance of disease, leading to anxiety.

Table 2. Cont

Family care patterns	Characteristic
4) Family adaptations	Some families learned diagnosis from antenatal ultrasound, while others only knew at birth. When diagnosis learned, parents shocked. Few knew about disease care or course of disease, and feared losing the child. They felt love but also pity. Courage arose when they met other similar children at the Tawanchai Center.
4.1) Searching for more information	Searching for information has become easier. Family members, particularly fathers search for information on Internet. Families who knew diagnosis before birth were better prepared.
4.2) Assigning main care giver	In many families, family structure changed after the affected child born. Many nuclear families became extended families. Planning of parent migration was paused in many families so as to care for child.
4.3) Supporting socialization of patient	Socialization was main concern. Adapting started with giving child love and attention to forestall inferiority complex, and included preparing good answer about CLP and appearance. Teachers monitored to prevent bullying. Child mentally strengthened and reassured. Parents briefed schoolmates to prevent bullying.

differs from other families in Thailand. All families were assigned a main care giver, who was always female. Mothers endeavoured to spend more time with their children, which was associated with a decrease in maternal migration. Maternal age affected family structure, while teenage pregnancy was associated with divorce and parent migration.

The current qualitative study had some limitations. The findings may be adapted to societies with similar contexts as northeast Thailand (i.e., vis-a-vis financial status and/or family structure). In the northeastern region, the proportion of parent migration is very high. In regions with a significantly different context, the finding have limited generalizability.

Conclusion

The patterns of family care for children with cleft lip/palate, vis-a-vis family burden, concerns, family adaptation-were similar; notwithstanding, the family structure of each family was different, as it depended on the context and limitations face by the family.

What is already known on this topic?

The family care patterns to the children with cleft lip/palate has never been studied before. It has been expected that the family care pattern to the children with cleft lip/palate was not differ from the other family, which the parent usually migrate for working opportunity and quality of care would be poor.

What this study adds?

In families with non-teenage mothers and non-divorced parents, the mother lived with the children and was the main care-giver. The elder role was as supporter. The father migrated to another region to find work. In the family with a teenage pregnancy, either divorce or migration of both parents was prevalent, while the elder acted as the main care-giver.

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Potential conflicts of interest

The authors declare no conflicts of interest.

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