

Holistic Care of Thalassemia, Down Syndrome, and Cleft Lip and Palate in the North and the Northeast of Thailand from 1987 to 2019

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Submitted : 16 Oct 2023; Published : 9 Nov 2023

Citation: Amornrat R., et al (2023). Holistic Care of Thalassemia, Down Syndrome, and Cleft Lip and Palate in the North and the Northeast of Thailand from 1987 to 2019. J Nurs Care Repo; 4(2):1-6.

Introduction

Thailand has faced a critical challenge about how best to improve young people to be healthy adults similar to many countries around the world. In the north and the northeast of Thailand, it faces problems of Thalassemia, Down syndrome, and Cleft lip and palate up to now. Thalassemia is a genetic disease. It is a major health problem in Southeast Asia, including in the north and northeast of Thailand.

From 2006 to 2007, one to two percent of Thai children were Thalassemia cases, and forty percent were carriers. (Fucharoen et al., 1991; Panich et al., 1992; Weatherall et al., 2001) Down syndrome is caused by extra genetic material in chromosome 21 (Trisomy 21) (World Health Organization [WHO], 2014). Its incidence is 1 in 1,000 to 1 in 1,100 live births worldwide (National Down Syndrome Society [NDSS], 2014). In the northeast of Thailand, from 1997 to 1998 the incidence was 8 in 5,420 live births (Ratanasiri et al., 2004).

From September 1996 to December 2011 Srinagarind Hospital found an incidence of 1.1 in 4,033 pregnant women with high risk for fetal chromosomal abnormality during the 17 to 23 weeks, who had performed second-trimester genetic ultrasound (Ratanasiri et al., 2014). Cleft lip and palate are a birth defect that affects infants, their parents, and the nation because of providing high costs of caring for those infants (I-Tuporn et al., 2019).

During 2016 the prevalence rate per 1,000 live births in Asia was 1.00-2.00 (Watkins et al., 2014).

In Thailand, it was 1.05-2.36. It also presented the prevalence rate was 1.50 in the north and 2.49 in the northeast of Thailand. (Panamonta et al., 2015). From October 2007 to September 2016, the prevalence of Cleft lip and palate in Chiang Rai Prachanukroh Hospital was 0.31 to 0.67 per 1,000 live births (I-Tuporn et al., 2019).

Practically, the Thai government's policies of "Good Health and well-being" are responded to by the Ministry of Public Health, including the health sector, private sector, and health volunteers. In the north and the northeast of Thailand, families and their communities have the role of caring for and looking after these three patients every day. Effective caregivers help patients' quality of life (Leungtongkum et al., 1987; Ratanasiri et al., 1989., 1992., 2004; Intraratsamee et al., 2012; Aiewtrakun et al., 2012; Sing Rai et al., 2014, Seesarn et al., 2015; Sansiritaweessook et al., 2015; Teerachote et al., 2017).

This research study aims to present successfully holistic care for these three problems with cooperation from the health sectors, private sector, family, and community participation in the north and northeast of Thailand.

Methodology

The study reviewed the results of the authors' research in three steps as follows:

1. Synthesize contents from staff and the students at Khon Kaen University from 1987 to 2019.
2. Reported experiences of holistic care for children with Thalassemia, Down syndrome, Cleft lip, and palate in the north and the northeast of Thailand.
3. Summarized the experiences of holistic care for children with Thalassemia, Down syndrome, and Cleft lip and palate in the north and the northeast of Thailand.

Results

There are three steps to this research result as follows:

In step 1: We reviewed holistic care of these three diseases as presented in Table 1.

We found that to prevent Thalassemia need medical check-ups for married couples who are carriers.

Type of Disease	The severity of the problem	Prevention	Control	Treatment	Caring	Stakeholders
Thalassemia	<p>It is a genetic disease</p> <ul style="list-style-type: none"> - 1%-2% were cases, and 40% were carriers in Thai people from 2006 to 2007 - Thalassemia patients need caring for continuously throughout their lives. 	<ul style="list-style-type: none"> - Medical check-up for married couple - 20% of a married couple can be Thalassemia if both married couples are carriers. 	<ul style="list-style-type: none"> - Food choices *Avoid iron food *Choose to eat food with folic acid - Splenectomy patient *Avoid infection *Vaccination every year for hepatitis B, pneumococcal, influenza - Should see a doctor if the patient has a fever or infection. 	<p>Categorized into two as follows:</p> <ol style="list-style-type: none"> 1) Supportive treatment <ul style="list-style-type: none"> - Give blood, * High transfusion in case of new cases who severe * Low transfusion in case of tiredness and fatigue - Give folate in case of Erythropoiesis -Splenectomies in case of an enlarged spleen and requiring frequent blood transfusions 2) Bonemarrowtransplantation or hematopoietic stem cell transplantation. 	<p>Caregivers take care of this patient as follows:</p> <ul style="list-style-type: none"> - Give food from all 5 food groups - avoid iron food - abstain from alcohol - avoid secondary smoking - exercise regularly - complete vaccination according to criteria - check patient's teeth regularly every 6 months - consult a doctor immediately in case of discomfort, high fever, tiredness, and pain under the ribcage 	<ul style="list-style-type: none"> - Thai government policies of "Good health and well-being" - The ministry of public health - Health sectors - Private sectors - Healthcare practitioners - Health volunteers (HVS) - Families, and communities' participation - Universities' academic staff, and their students
Down Syndrome	<ul style="list-style-type: none"> - It's caused by extra genetic material in chromosome 21 (Trisomy 21) - Its incidence is 1 in 1,000 to 1 in 1,100 live births worldwide. - In northeast Thailand is 8 in 5,420 live births from 1997 to 1998 - Need specific care of physical and mental health, including necessary skills in daily life. - Caregivers, especially their parents face stress, anxiety, and regret for the child's abnormality. 	<p>Down Syndrome screening is as follows.</p> <ol style="list-style-type: none"> 1) First-trimester screening <ul style="list-style-type: none"> * NT (Nuchal Translucency) * PAPP-A (Pregnancy-associated placenta protein A * hca Human chorionic gonadotropin 2) Second-trimester screening <ul style="list-style-type: none"> *AFP (Alpha-fetoprotein) * hca * UE3 unconjugated estriol 3) First, and Second trimesters <ul style="list-style-type: none"> * Triple test MSFP+hca+UE3 *Quadruple test MSAFP + hca + UE3 + inhA 	<ul style="list-style-type: none"> - Down syndrome screening is a need - Genetic Ultrasound is an alternative method for high-risk pregnancies who refuse genetic amniocentesis - A Down Syndrome child has specific physical such as a small head, flattened occiput, tongue protrusion, etc., and other physical diseases, and low intellectual development, intelligence Quotient (IQ) is about 25-50 - This information is to help enable the women to make decisions on the course of action 	<ul style="list-style-type: none"> - Down syndrome cannot be cured. - Treating physicians to be able to take care of the patient's body and mind to adapt to society, including preventing and treating for their complications e.g.: congenital heart disease, intestinal obstruction, Hyperthyroidism, eye problems, hearing, delayed intellect. - Some patients have seizures, ADHA, and autism. - Some of them have behavior problems and Alzheimer's when aging. - This Down syndrome patients have the risk of Leukemia than normal Child 	<p>Caregivers take care of this patient as follows:</p> <ol style="list-style-type: none"> 1) Help patients' physical development such as Balance exercise, Eating by themselves 2) Take patients to see a doctor for annual health check-ups 3) Talk and encourage the patients to develop intellectual development. 	<ul style="list-style-type: none"> - Thai government policies of good health and well-being - The ministry of public health - Health sectors - Private sectors - Healthcare practitioners - Health volunteers (HVs) - Families, and communities' participation - Universities' academic staff, and their students

Cleft Lip and Palate	<ul style="list-style-type: none"> - It is a birth defect that affects infants, their parents, and the nation because of providing a high budget for caring for those infants. - Prevalence rate per 1,000 live births in 2016 In Asia was 1.00-2.00 In Thailand was 1.05-2.36 In Northeast Thailand was 2.49 In the North of Thailand was 1.50. 	<p>Pregnant women should be educated about these conditions. Healthcare providers should advise:</p> <ol style="list-style-type: none"> 1) to take one tablet of 400 micrograms of folic acid daily in the first trimester of pregnancy. 2) Follow the WHO's new policies about modern antenatal care. 	<p>Pregnant women should practice as follows:</p> <ol style="list-style-type: none"> 1) Refrain from smoking, no alcohol while pregnant 2) consult a doctor about drug use. 3) Exercise properly 4) Get enough sleep 5) Reduce stress 	<ol style="list-style-type: none"> 1) Pediatricians diagnose and treat when there is an indication 2) The surgeon performs corrective surgery 3) Ear, Nose, and Throat doctor for otitis media or permanent deafness 4) Audiologists perform Otoacoustic Emission (OAE), and 1-year follow-up 5) cured with surgery to restructure the face. 	<p>Caregivers take care of this patient as follows:</p> <ol style="list-style-type: none"> 1) Clean your mouth after eating food, milk, and water. 2) After meal abstain from food, milk, and water for at least 6 hours to prevent choking. 3) If the mouth and lips are dry apply glycerin cream. 4) Medical checkup and blood test to check the readiness of the baby. 	<ul style="list-style-type: none"> - Thai government policies of "Good health and well-being" - The ministry of public health - Health sectors - Private sectors - Healthcare practitioners - Health volunteers (HVs) - Families, and communities' participation - Universities' academic staff, and their students
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Table 1: Summarized the experiences of holistic care for children with Thalassemia, Down Syndrome, and Cleft Lip and Palate in the North and the Northeast of Thailand from 1987 to 2019

To control, the patient should eat food with folic acid and avoid iron food, avoid infection, and vaccination of hepatitis B, and pneumococcal influenza, and see a doctor if the patient has a fever or infection.

Treatment is 1. supportive treatment, including giving blood and giving folate, 2. splenectomy 3. Bone marrow transplantation.

Caring by the caregiver, should take care of food, exercise regularly, avoid alcohol consumption and secondary smoking, check patients' teeth regularly every 6 months, and consult a doctor immediately in case of discomfort, high fever, tiredness, and pain under the ribcage.

To prevent Down syndrome, pregnant women should have Down syndrome screening.

To control, genetic ultrasound is an alternative method for high-risk pregnancies who refuse genetic amniocentesis.

For treatment, physicians be able to take care of the patient's body and mind to adapt to society.

To prevent Cleft lip and palate, pregnant women should follow the WHO's new policies about modern antenatal care, and take one tablet of 400 micrograms of folic acid daily in the first trimester of pregnancy.

For treatment, they can see a Pediatrician, Surgeon, Ear Nose and Throat, or Audiologist when there is an indication.

Patients with cleft lip and palate can be cured with surgery to restructure the face.

In step 2: We reported the experiences of holistic care for children with Thalassemia, Down Syndrome, and Cleft Lip and Palate in the Northeast of Thailand.

Three cases present of holistic care:

Thalassemia child

She went to the temple every Buddhist Holy day with her parents. She looked very happy with receiving blessings from the monks since she was 4 years old.

Down Syndrome child

This boy with 5 years old has better growth development from playing with younger siblings.

Case of Cleft Lip and Palate

He received surgery to restructure his face from Cleft Lip and Palate, under the support of the Center of Cleft Lip and Palate, and Craniofacial Deformities, Khon Kaen University, under Tawanchai Royal Grant Projects.

In step 3 We summarized the experiences of holistic care for children with Thalassemia, Down syndrome, and Cleft lip, and palate in the north and the northeast of Thailand. These three diseases need cooperation from the Ministry of Public Health with the Government policies of Good Health and well-being. Health sectors, private sectors, health care practitioners, health volunteers (HVs), family and community participation. Sometimes the University academic staff and the students can help them to better understand these three diseases that are presented in Table 1 and Figure 1.

Thai Government Policies of "Good Health and Well-being"

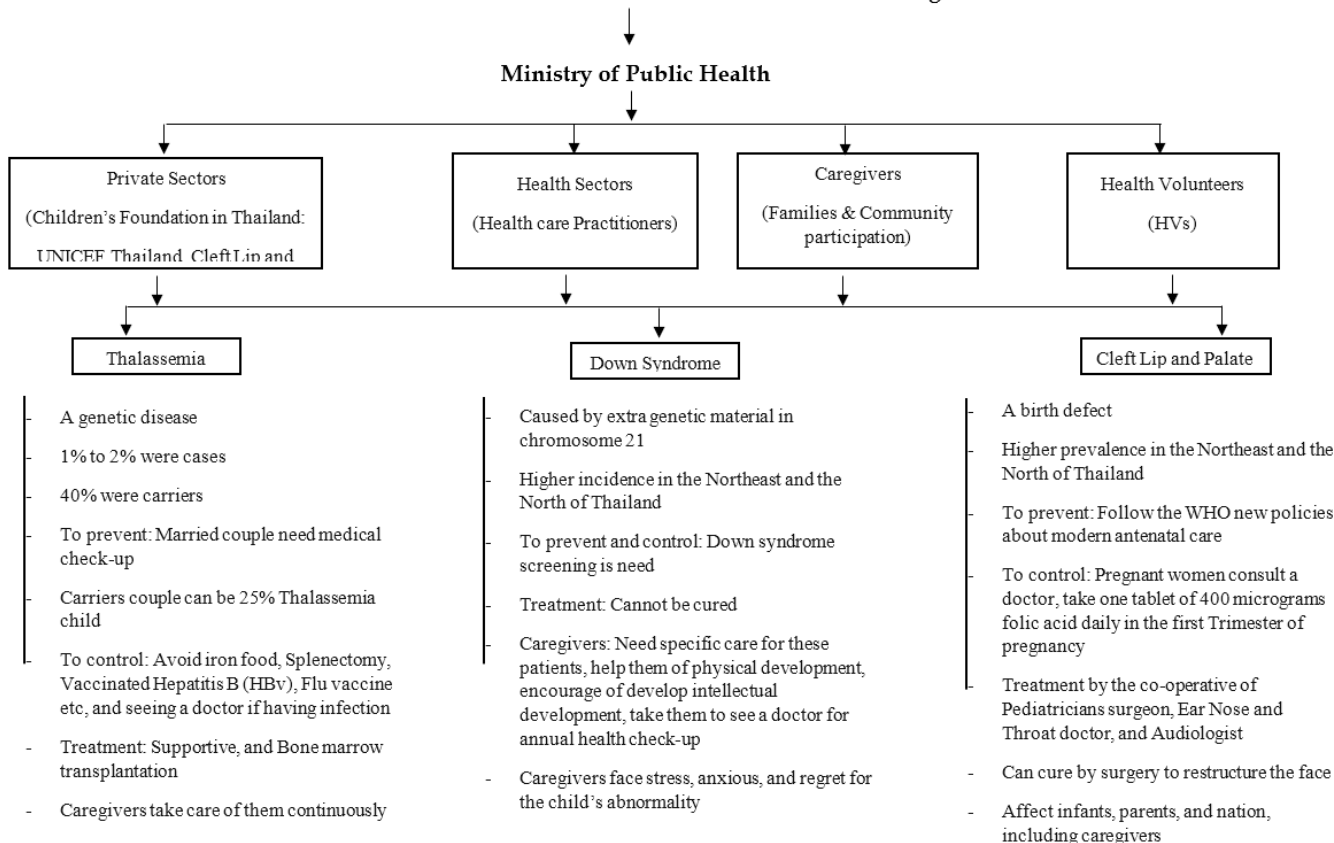


Figure 1: Summarized the Holistic care of Thalassemia, Down Syndrome, Cleft Lip and Palate in the North and the Northeast of Thailand since 1987

Discussions

Our reviewed research found that Thalassemia burden to mothers and their families. Down syndrome presented its effects on women's decisions. Cleft lip and palate need antenatal care.

From our reviewed research study, we found that Thalassemia, Down syndrome, and Cleft lip, and palate in the north and the northeast of Thailand need holistic care.

Thalassemia is a genetic disease that burdens these patients and their families because it negatively impacts these patients' quality of life, such as frequent absences from school, physical limitation, discomfort while receiving blood transfusions, and complications resulting from the illness itself.

The mothers also felt the impact on their economic status, and occupation, and lost time in preventing these problems.

They need psycho-social support. It is necessary to provide more comprehension management of the child with thalassemia.

Mothers of this Thalassemia child in the rural area experienced difficulty in accessing quality health services.

National Thalassemia policy should provide qualified health personnel, and standard guidelines should be established for the whole country. These guidelines will be able to help them

better understand of process and best practices for this patient. (Prasomsuk et al., 2007; Panich et al., 1992; Cappellini et al., 2000).

Similar to the study by (Podhisita et al., (1998), the influence of Thai culture, especially Buddhism which presented respect and concern was shown in one case of our study. This thalassemia girl went to the temple with her family every Buddhist Holy day. She felt very happy with receiving blessings from the monks since she was only 4 years old. Thai Buddhist belief system is anchored by the law of Karma as well as Bun-Krum. In Thai society, those who present gratitude and reply to favors done for them are typically praised (Podhisita et al., 1998).

Our study was consistent with the study by (Subgranon et al., 2000) which described the merit and karma system as important in caring for chronically ill Thai children. Therefore, a family-based approach should be recommended for holistic health care, well-being, and self-health groups for caring for Thai thalassemia children. Down syndrome is caused by extra genetic material in chromosome 21.

This patient cannot be cured. Physician can help their body and mind to adapt to society and prevent complications from this disease. Amniocentesis has been used worldwide for prenatal testing to detect Down syndrome in fetuses (Vergani et al., 2002).

Genetic Ultrasound in our study probably is an alternative method of prenatal prediction for high-risk pregnant women who refuse amniocentesis (Ratanasiri et al., 2014). Although the pregnant woman knew that her baby was at high risk of having Down syndrome, she decided not to terminate the pregnancy because her family believed in karma due to the Thai Buddhist belief system. (Podhisita et al., 1998). Similar to (Vergani et al., 2002) study in San Gerardo Moza Hospital in Italy, it was found that second-trimester ultrasound affected pregnant women's decision-making about their fetuses. (Vergani et al., 2002). Caregivers help patients' physical development, such as balance exercises, be able to help themselves in eating. take the patient to see a doctor for an annual health check-up and encourage him to intellectual development as present in one case who has better growth development from playing with younger siblings every weekend since he was 5 years old.

Cleft lip and palate are a birth defect that affects infants, parents, and the nation because of the high cost of caring for these patients. To prevent this condition many countries, for example, Thailand Nepal, Laos, and Vietnam, Pregnant women take one tablet of 400 micrograms of folic acid daily in the first trimester of pregnancy (Sing Rai et al., 2014; WHO, 2001, 2004, 2008).

This cleft lip and palate can be cured with surgery to restructure the face. There are many specialists who help them with their condition. Caregivers take care of them by a clean mouth after eating food milk, and water, they need to wait at least 6 hours to prevent choking. If the mouth and lips are dry apply glycerin cream. Medical Check-up and blood test to check the readiness of the baby is concern by Khon Kaen University academic staff of Cleft Lip and Palate, under the support of the Center of Cleft Lip and Palate, and Craniofacial Deformities, Khon Kaen University, under Tawanchai Royal Grant Projects. They support the patient who needs to receive surgery to restructure his face as present in our study.

Conclusions

In conclusion of our study, we found that holistic care is needed for these three diseases' problems. The Thai Buddhist belief system can mentally support patients and their parents. Holistic care is needed to prevent, control, and treatment of these three diseases. The cooperation from government and non-government organizations, including family and community participation is necessary to improve those patients' quality of life.

Acknowledgments

The authors thank

- All patients and their families, including their caregivers,
- the Department of Obstetrics and Gynecology, and Department of Pediatrics, Faculty of Medicine, Khon Kaen University, and Chiang Rai Prachanukroh Hospital, and
- Professors and students, including personals of the Center of Cleft Lip and Palate, and Craniofacial Deformities, Khon Kaen University under Tawanchai Royal Grant Project for data support, and publication support.

Ethics Approval

The research reviewed was approved by the Ethics Committee for Human Research of Khon Kaen University (HE561067, HE591199, HE601234). Most of the research studies were based on secondary data. Those who volunteered had signed the consent form.

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