

PROMOTING BREAST MILK NUTRITION IN INFANTS WITH  
CLEFT LIP AND/OR PALATE IN THE PHILIPPINES

By

NICOLE DIANE LIMHANYONG BURCA

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Approved by:

Connie S. Miller

Connie Miller, MSN, RNC  
Clinical Assistant Professor, College of Nursing

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## ABSTRACT

The purpose of this thesis is to present a best practice model for supplying breast milk nourishment to infants with cleft lip and/or palate in the Philippines, as a means for optimal nutrition and development. The craniofacial defect of cleft lip and/or palate involves an altered physiological anatomy that affects an infant's ability to generate negative pressure for proper suction during feeding sessions. A cleft lip affects an infant's ability to establish a complete seal around the nipple for proper latching while a cleft palate affects the ability to coordinate intraoral muscle contractions for negative pressure generation. Difficulties in feeding may compromise normal growth and development as well as disrupt the maternal-infant bonding process. According to the World Health Organization, the incidence of oral clefts is 1/800 live births with higher rates among persons of Filipino origin. The Philippines has a high poverty rate and financially lacks the necessary resources to facilitate proper feeding in cleft lip and/or palate infants.

The proposed best practice model for education and support for breast milk feeding of infants with cleft lip and/or palate must consider: 1) infants fed breast milk have a decreased incidence of infections, 2) infants have a decreased feeding efficiency compared with infants without craniofacial abnormalities, 3) mothers require additional education and support in feeding their infants, and 4) various methods, equipment, and techniques are available for feeding infants with cleft lip and/or palate. Implementation of this proposed best practice model for supplying breast milk nourishment to infants with cleft lip and/or palate in low-resource countries such as the Philippines requires health care professionals and/or lay health workers to support and educate mothers on the nutritional and overall health benefits of breast milk.

## CHAPTER 1: INTRODUCTION

### **Statement of Purpose**

The purpose of this thesis is to propose a best practice protocol for feeding infants with cleft lip and/or palate living in the Philippines with breast milk nutrition. Compared with other countries, the emerging nation of the Philippines experiences a higher incidence of cleft lip and/or palate (Murray et al., 1997). This orofacial deformity creates feeding difficulties that may compromise normal growth and maternal attachment in infants with cleft lip and/or palate (Martin & Greatrex-White, 2013). Feeding difficulties may lead to malnourishment and ultimately death. Nearly 3% of the Filipino population die before reaching 1 year of age (Hengstermann et al., 2009). For infants preparing for cleft lip and/or palate repair, weight gain is essential in order to tolerate the surgery (da Silva Dalben, Costa, Domide, & Teixeira das Neves, 2003). Breast milk is the optimal form of nutrition for infants (Andres et al., 2012). In addition, the antibodies exclusively found in breast milk help protect against infections (Gil-da-Silva-Lopes et al., 2013). This thesis provides information about feeding techniques and specialized equipment to propose a best practice protocol for educating caregivers on how to supply infants with cleft lip and/or palate with breast milk nutrition.

### **Pathophysiology of Cleft Lip and/or Palate**

The orofacial condition of cleft lip and/or palate is one of the most common birth defects (Mendoza, 2009). Cleft lip and cleft palate are congenital orofacial structural defects that occur when the infant's lip or mouth fail to develop properly early during pregnancy (Center for Disease Control, 2013). The condition is a result of a combination of genetic and environmental factors (Mendoza, 2009). Variations of certain genes responsible for encoding transcription factors in craniofacial structures may contribute to the development of cleft lip and/or palate

(Lanteri, Parcels, Lizarraga, Magee, & Bermudez, 2012). Maternal deficiency in folic acid and exposure to certain medications, nicotine, and alcohol may also lead to the development of congenital orofacial defects in infants (Redford-Badwal, Mabry, & Frassinelli, 2003).

A cleft lip is defined as an opening between the mouth and the nose, while a cleft palate is an opening at the roof of the mouth between the oral and nasal cavities. Both orofacial defects have varying degrees: a cleft lip ranges from a slight notch on the upper lip to an extension into the nose, while a cleft palate may be an opening of the soft palate to an extension into the hard palate. Although a cleft lip has a visible presentation, a cleft palate may not be immediately detected and is, therefore, deceptive in severity (Martin & Greatrex-White, 2013). Since the lip and palate develop separately during the embryonic period, an infant may have an isolated cleft lip, an isolated cleft palate, or both defects (Mendoza, 2009). In addition, the infant's orofacial condition may be unilateral and specific to only one side, or bilateral (Center for Disease Control, 2013).

### **Breastfeeding**

Breastfeeding is defined as "the direct placement of infant to the breast for the purpose of feeding" (p. 349); on the other hand, breast milk feeding is defined as "the delivery of breast milk to infant with alternative means other than the breast" (Reilly et al., 2013, p. 349).

Breastfeeding is considered the single most important intervention to prevent childhood mortality (Hengstermann et al., 2009). Exclusive breastfeeding means the infant is fed with only maternal milk either extracted or directly suckled from the breast (Garcez & Giugliani, 2005). Compared with exclusively breastfed infants, nonbreastfed infants have a 5- to 7-fold increased risk of mortality (Hengstermann et al., 2009). Although the World Health Organization (WHO) recommends that infants be exclusively breastfed for the first six months, infants with cleft lip

and/or palate may benefit by breastfeeding beyond the six month mark (Chuang et al., 2009). In the Philippines, only 1 in 3 infants under the age of six months are exclusively breastfed (Hengstermann et al., 2009). Although specialized pillows, nursing bras, and electronic breast pumps are commercially available, most mothers are capable of breastfeeding as long as they are motivated and have patience (R. Palting, personal communication, October 31, 2013).

### **Significance of the Problem**

In 2002, the World Health Organization (WHO) estimated an oral cleft incidence of 1/600-1000 live births each year, depending on the population (Gil-da-Silva-Lopes et al., 2013). Cleft lip and/or palate incidence varies with ethnicity, race, geographic origin, and socioeconomic status (Redford-Badwal et al., 2003). The incidence of cleft lip and/or palate is approximately 1/800 live births in the United States and 1/500 live births in developing countries (Lanteri et al., 2012). Approximately 2,651 infants with cleft palate and 4,437 infants with cleft lip and/or palate are born in the United States each year (Center for Disease Control, 2013). The incidence of cleft lip and/or palate varies among ethnic groups: the orofacial defect is observed in approximately 1/2000 live African births, 1/10000 live Caucasian births, and 1/500 live Asian births (Lanteri et al., 2012). In developing countries, infants with cleft lip and/or palate face the challenges of inaccessibility and inadequate cleft-related services (Mendoza, 2009).

**Cleft lip and/or palate in the Philippines.** The Philippines is a developing country heavily populated with impoverished individuals living in remote, rural areas known as provinces (Sharp et al., 2008). In 2007, an estimated 40% of the country's 91 million citizens lived below the poverty line (Mendoza, 2009). Globally, the Philippines has one of the highest birth rates of cleft lip and/or palate (Mendoza, 2009). The nationwide incidence of cleft lip and/or palate in the Philippines is estimated to be 1 in 625 births; in addition, the incidence is as

high as 1 in 500 live births among the poor working class (Mendoza, 2009). Annually, an estimated 4500 infants are born with cleft lip and/or palate in the Philippines (Mendoza, 2009). The high incidence of cleft lip and/or palate led to the development of genetic counseling centers in the Philippines (Murray et al., 1997). The reoccurrence rate in siblings with cleft lip and/or palate is 23/1000 patients (Murray et al., 1997). In the Philippines, common sociocultural beliefs, such as fatalism and God's will, prevent individuals from understanding the causes and prevention of cleft lip and/or palate (Mendoza, 2009).

Medical organizations, such as Operation Smile, perform free reconstructive surgery to individuals with cleft lip and/or palate in developing countries including the Philippines. Prior to reconstructive surgery, infants must be of sufficient weight in order to tolerate the surgical procedures (da Silva Dalben et al., 2003). The infant's nutritional status is assessed by comparing the infant's weight, length, and head circumference on appropriate growth charts to determine the infant's percentile rank; generally, the infant must be 90% or above in order to be cleared for surgery (Nahai et al., 2005).

**Mechanical issues in feeding infants with cleft lip and/or palate.** The ability to generate suction is created when the lips seal the oral cavity anteriorly while the soft palate seals the oral cavity posteriorly; infants with cleft lip and/or palate experience difficulty creating suction because the oral cavity cannot be properly separated from the nasal cavity during feeding (Reilly et al., 2013). In an infant with cleft lip, the incomplete structure may hinder an infant's attempt to create a proper seal around the nipple for facilitating sufficient intraoral pressure necessary for feeding (Lindberg & Berglund, 2013). Generally, infants with isolated cleft palates are capable of a proper seal with intact lips (Miller, 2011).



Negative oral cavity pressure involves the coordination of muscle contractions of the palate and tongue (Kogo et al., 1997). Coordinated velopharyngeal function consists of the soft palate rising and closing off the nasopharynx from the oropharynx (Redford-Badwal et al., 2003). In an infant with cleft palate, the levator and tensor muscles attached along the hard palate fail to extend across the midline, affecting an infant's ability to isolate the oral cavity in order to build negative pressure (Redford-Badwal et al., 2003). Air flow through the cleft compromises the ability to establish the negative pressure necessary for adequate suction (Prahl, Kuijpers-Jagstman, Van't Hof, & Prahl-Anderson 2005). The presence of a cleft lip and/or palate compromises the precise synchronization of sucking, swallowing, and breathing necessary for proper feeding (Miller, 2011). Infants with cleft lip and/or palate may benefit from counsel from various health professions, including surgeons, nurses, speech therapists, dentists, orthodontists, and dieticians (Britton, McDonald, & Welbury, 2011).

**Growth and development issues.** The feeding difficulties of infants with cleft lip and/or palate need to be immediately addressed in order to ensure adequate nutrition and minimize complications that may affect optimal growth and development (Gil-da-Silva-Lopes et al., 2013). Infants with cleft lip and/or palate consume less milk, gain less weight, and measure lower on growth curves (Amstalden-Mendes, Magna, & Gila-da-Silva-Lopes, 2007). However, infants catch up with normal growth values after undergoing cleft surgical repair (Smedegaard, Marxen, Moes, Glassou & Sciensan, 2008). Persistent feeding issues may hinder an infant's motor, language, and behavioral development (Martin & Greatrex-White, 2013).

**Maternal-infant bonding.** In addition to feeding problems, infants with cleft lip and/or palates may experience compromised maternal-infant bonding as feeding challenges are frustrating for both the parent and the infant (Miller, 2011). Infants with cleft lip and/or palate

experience difficulty in stabilizing the nipple (Prahl et al., 2005). Mothers of infants with cleft lip and/or palate are at an increased risk of lowered self-esteem and developing maternal depression (Martin & Greatrex-White, 2013). The milk supply of mothers of infants with cleft lip and/or palate may decreased as a result of inconsistent or difficult breastfeeding sessions (Kogo et al., 1997).

**Additional issues.** The abnormal anatomy of the orofacial cavity increases the difficulty in properly cleaning the maxillary incisors and may result in higher rates of dental caries in infants with cleft lip and/or palate (da Silva Dalben et al., 2003). Infants with cleft lip and/or palate are at an increased risk of Sudden Infant Death Syndrome (SIDs), developmental delays, and cardiovascular disease (Beaumont, 2008). In addition, infants with cleft lip and/or palate are more susceptible to recurrent upper airway and ear infections due to the increased risk of nasal regurgitation (Prahl et al., 2005). Inadequate airway protection during swallowing may cause chronic aspiration during feedings and may result in respiratory illness, pneumonia, and lung damage (Miller, 2011).

### **Summary**

Chapter 1 introduces the pathophysiology and incidence of cleft lip and/or palate, focusing on the occurrence in the Philippines. Infants with cleft lip and/or palate encounter various challenges that affect the ability to feed. Mechanical feeding issues may lead to inadequate consumption that may compromise the infant's physical growth and social development. Frequent regurgitation related to the anatomical defects may result in aspiration and infection. Frustrations while feeding may disturb the maternal-infant relationship. In the developing country of the Philippines, caregivers require education, support, and resources in order to provide adequate nutrition to infants with cleft lip and/or palate.

## CHAPTER 2: CURRENT PRACTICE GUIDELINES

The purpose of Chapter 2 is to review the literature and interviews with breastfeeding experts regarding feeding infants with cleft lip and/or palate. The databases CINAHL and PubMed were used to generate the literature review of journal articles from 1987 to 2013. Key words included cleft feeding, cleft lip and palate nutrition, cleft lip and palate breastfeeding, breastfeeding support, and Philippines cleft epidemiology. Thirty-six articles met inclusion criteria. Since there were gaps in the literature, expert opinions were sought after. Interviews were conducted with two registered nurses who are International Board Certified (IBC) lactation consultants and members of the Arizona Breastfeeding Coalition. One of the nurses interviewed is also affiliated with the Arizona Breastfeeding Hotline. These informants have expertise in providing breastfeeding education and experience in supporting mothers of infants with cleft lip and/or palate.

### **Feeding Skills of Infants with Cleft Lip and/or Palate**

The degree of feeding difficulty depends on the type and severity of the infant's cleft (Miller, 2011). The presence of a cleft lip as opposed to a cleft palate has a less profound effect on an infant's ability to generate sufficient sucking pressure for feeding (Miller, 2011). Infants with cleft lips have better feeding skills than those with cleft palate (Reid, Kilpatrick, & Reilly, 2005). For example, infants with a minor cleft lip may not have feeding issues (Goyal, Jena, & Kaur, 2012). However, infants with cleft lip and/or palates may have the inability to properly feed, which may result in malnourishment and classify their health as "failure to thrive" (Fox-Lewis, 2011). Infants with cleft palate have difficulty creating proper suction as evidenced by shorter sucking bursts, faster sucking rates, higher suck-swallow ratios, and increased positive pressure generation (Miller, 2011). In addition, newborns and premature infants tend to generate

less intraoral negative pressure related to sucking than older infants due to less developed muscular strength (Choi, Joos, & Komposch, 1991). In a study of 62 individuals with cleft lip and/or palate, reports of poor feeding decreased from 32% in neonates to 15% in 14 month old toddlers (Reid, Kilpatrick, & Reilly, 2005). Although feeding difficulties still exist, they tend to decrease as the infant with cleft lip and/or palate develops musculature with age (Reid, Kilpatrick, & Reilly, 2005).

The duration of feeding sessions must also be considered. In a study of 90 children affected with orofacial defects, 46% reported feeding sessions lasting more than one hour (Britton et al., 2011). Feeding sessions lasting more than thirty minutes may result in more energy expenditure than consumption (Martin & Greatrex-White, 2013). Infants with cleft lip and/or palate may become fatigued before completing a feeding session (Amstalden-Mendes et al., 2007). Others may fall asleep out of exhaustion instead of satiety (Fox-Lewis, 2011). In addition, infants with cleft lip and/or palate may experience excessive air intake and more frequent burping as a result of the cleft defect (Redford-Badwal et al., 2003).

### **Nutrition for Infants with Cleft Lip and/or Palate**

All infants, especially those with congenital defects such as cleft lip and/or palate, require adequate nutrition for optimal growth and development (Amstalden-Mendes et al., 2007). Infants with cleft lip and/or palate have similar nutritional requirements as other infants without orofacial defects as long as no other systemic issue are involved (Redford-Badwal et al., 2003). Instead of special diets, researchers recommend feeding infants with cleft lip and/or palate a normal diet with increased calories (Redford-Badwal et al., 2003). Unlike infants without orofacial defect, infants with cleft lip and/or palate especially require adequate nutrition in order to increase immune defenses and promote adequate weight gain in preparation for possible

surgical procedures (Redford-Badwal et al., 2003). In order to facilitate feeding efficiency, the goal of infants with cleft lip and/or palate is create integrity in the oral cavity (Choi et al., 1991). Compared with mixed feeding or exclusive formula feeding, exclusive breastfeeding decreases the incidence of diarrhea, pneumonia, and neonatal sepsis in infants (Hengstermann et al., 2009).

**Breast milk.** Breast milk provides infants with a well-balanced mixture of amino acids, sugars, and fats (Bozzette & Posner, 2013). The protein found in breast milk is easier to digest compared with the protein found in formula milk (Stam, Sauer, & Boehm, 2013). The vitamins, minerals, enzymes, and prebiotics found in breast milk aid in digestion in the infant (Bozzette & Posner, 2013). Breast milk also has high levels of cholesterol, which is a form of fat that promotes brain growth, hormone development, vitamin D synthesis, and intestinal bile (Stam et al., 2013). The antibodies found in breast milk stimulate the development of an infant's immune system and decreases the infant's risk of acquiring neonatal infections (Hengstermann et al., 2009). Regurgitation is common in infants with cleft lip and/or palate; however, regurgitating formula is more irritating than regurgitating breast milk because of its anti-inflammatory properties (C. Cote, personal communication, October 17, 2013). Research has shown that breast milk strengthens immunological protection, fosters gastrointestinal function, and increases cognitive development in infants (Chuang et al., 2009). In addition, breast milk may help foster speech development (Goyal, Jena, & Kaur, 2012).

In a study of 399 infants living in Manila, Philippines, breastfed infants had a decreased incidence of hospitalization related to pneumonia, diarrhea, and neonatal sepsis (Hengstermann et al., 2009). In a study of ninety children under six years old with cleft lip and/or palate, 34% of the sample had experienced ear or chest infections: parents of 19% of these children believed that the infection further compromised their children's feeding patterns (Britton et al., 2011).

Breast milk may serve as a protective factor against otitis media, which is commonly found in infants with cleft lip and/or palate (Reilly et al., 2013). Although regurgitation should be avoided, the anti-inflammatory properties of breast milk makes it more favorable than formula (C. Cote, personal communication, October 17, 2013).

Since infants with cleft lip and/or palate have altered suction and compression capabilities, mothers may need to manually express breast milk into the infant's mouth to stimulate the let-down reflex (Reilly et al., 2013). Manually expressing milk may also increase flexibility in the breast tissue and soften the areola to facilitate infant attachment to seal the cleft (Garcez & Giugliani, 2005). In addition, techniques such as applying a warm compress or massaging the breast tissue stimulate the production of milk (Garcez & Giugliani, 2005). If the infant with cleft lip and/or palate is unable to properly empty the breasts during feedings, the mother may express the remaining milk in order to maintain adequate milk production and provide milk for future feedings (Garcez & Giugliani, 2005).

If the infant unable to latch due to the oral deformity, mothers may pump breast milk and bottle feed their infants (Redford-Badwal et al., 2003). Some mothers may decide to pump breast milk for the sake of convenience (Redford-Badwal et al., 2003). Pumped milk may be stored in bottles and refrigerated for future feedings (Kogo et al., 1997). In a study of thirty-one infants with cleft lip and/or palate, nearly 68% of the mothers who pumped breast milk experienced a longer duration of exclusive breastfeeding compared to those who did not (Garcez & Giugliani, 2005). However, some mothers consider pumping breast milk a burden (Lindberg & Berglund, 2013).

**Formula.** Providing infants with cleft lip and/or palate higher-calorie formulas may be necessary to prevent failure to thrive (Beaumont, 2008). In a study conducted in Malaysia, a

majority of the mothers of 60 children with cleft lip and/or palate preferred formula over breast milk due to convenience (Gopinath & Muda, 2005). In addition, thickened formulas may create a more cohesive bolus that gives more time for airway closure and therefore increases airway protection (Miller, 2011).

Since there was a lack of information related to formula feeding infants with cleft lip and/or palate in the literature, the expertise of local breastfeeding consultants was sought out. Infants with cleft lip and/or palate may find thickened formulas easier to swallow and less likely to cause reflux and aspiration; however, thickened rice formulas should be recommended by a speech therapist and prescribed by a pediatrician (C. Cote, personal communication, October 17, 2013). In a study of twelve mothers of infants with cleft lip and/or palate, it was found that mothers express concerns regarding formula and possible consequences for the infants such as abdominal pain and colic (Lindberg & Berglund, 2013). In the Philippines, access to clean water is not guaranteed. Water sources typically include local rivers and crude plumbing systems. The water may be contaminated with chemicals or human waste products. Since formula powder requires the addition of water for consumption, infants have an increased vulnerability to infections and associated health issues.

### **Methods of Providing Milk to Infants with Cleft Lip and/or Palate**

Since infants with cleft lip and/or palate lack the orofacial congruency necessary to generate normal suction, various methods may be used to feed infants with cleft lip and/or palate. Breastfeeding is the preferred method of feeding because breast tissue may be molded to accommodate the cleft (Garcez & Giugliani, 2005). In addition, breastfeeding promotes the development and coordination of the orofacial musculature (Britton et al., 2011). However, the effectiveness of breastfeeding is determined on a case-by-case basis; as a result, some infants

with cleft lip and/or palate may benefit more with bottle feeding, feeding cups, and nasogastric tubes.

**Breastfeeding.** Success with breastfeeding depends on the degree of clefting (Miller, 2011). Infants with cleft lips are more likely to successfully breastfeed than infants with cleft palates (Britton et al., 2011). Although suction may be more difficult in infants with cleft palates, it is not impossible (Garcez & Giugliani, 2005). While breastfeeding, infants use negative intraoral pressure to position and stabilize the nipple (Clarren et al., 1987). Infants rely on the tongue to mechanically lick the milk from the breast (Clarren et al., 1987). Infants with cleft lip and/or palate benefit from the physical act of breastfeeding because it encourages the normal physiological muscular movement and coordination of the mouth and face (Britton et al., 2011). The act of breastfeeding stimulates muscles that contribute to the proper development of craniofacial structures and functions, such as speech and language (Garcez & Giugliani, 2005). Compared with rubber nipples on bottles, the nipples on the mother's breast are more flexible and better accommodate the oral cavity to occlude the cleft (Garcez & Giugliani, 2005). The mother's breast is moldable and creates a better suction (R. Palting, personal communication, October 31, 2013). Skin-to-skin contact between the mother and the infant also facilitates bonding (Garcez & Giugliani, 2005).

The condition of cleft lip and/or palate may interfere with the maternal-infant bond. 100% of mothers of infants without cleft lip and/or palate had positive attitudes about breastfeeding; however, only 76.5% of mothers of infants with cleft lip and/or palate had positive attitudes regarding breastfeeding (Gopinath & Muda, 2005). In a study of 200 infants with cleft lip and/or palate, the infant's inability to create normal suction leads to a low prevalence of breastfeeding; as a result, this difficulty was attributed to the cessation of breastfeeding in nearly



80% of the infants (da Silva Dalben et al., 2003). Nearly 70% of mothers of 215 subjects attributed unsuccessful breastfeeding to the infant's difficulty in latching-on to the breast (Gil-da-Silva-Lopes et al., 2013). Mothers experiencing difficulty with breastfeeding may be encouraged to express milk. However, the majority of the twelve mothers of infants with cleft lip and/or palate described expressing milk as a "hard, mechanical, low-intimate activity" (Lindberg & Berglund, 2013).

Infants with cleft lip and/or palate who breastfed may require feeding supplementation or intervention for adequate nutrition (Amstalden-Mendes et al., 2007). Providing infants with cleft lip and/or palate with breast milk is more important than the mode of ingestion (Gil-da-Silva-Lopes et al., 2013). However, formula may be recommended if prolonged or difficult feeding sessions jeopardize the mother-infant relationship (Smedegaard et al., 2008).

**Bottle feeding.** Some mothers of infants with cleft lip and/or palate find bottle feeding frustrating; others describe it as an uncomplicated process that still allows physical closeness with the infant (Lindberg & Berglund, 2013). Although some mothers of infants with cleft lip and/or palate want to be the sole feeder, other mothers are relieved that other individuals are able to feed the infant (Lindberg & Berglund, 2013). Infants with cleft lip and/or palate described as "poor feeders" are slow to establish bottle feeding (Reid, Kilpatrick, & Reilly, 2006). While bottle feeding, infants primarily use their gums to stabilize the nipple and generate negative pressure to withdraw milk from the bottle (Clarren et al., 1987). In a study researching effective feeding methods to promote weight gain, infants were predominantly bottle fed after trying other feeding methods (Amstalden-Mendes et al., 2007). In a study of 221 children in Malaysia, 76.5% of the sixty children with cleft lip and/or palate were bottle fed while 49.2% of the 161 infants without orofacial defects were bottle fed (Gopinath & Muda, 2005). Contaminated bottles may

contribute to increased infection susceptibility in infants with cleft lip and/or palate (Amstalden-Mendes et al., 2007).

**Feeding cups.** Infants with cleft lip and/or palate may be fed using feeding cups. The soft cup advanced feeder is a contoured cup made of soft, pliable silicone that has a control valve and does not require active sucking (Miller, 2011). In a study of 215 children with cleft lip and/or palate in Brazil, 5.5% of the sample used cup feeding (Gil-da-Silva-Lopes et al., 2013). Another study in Brazil found that 24% (6/26) children with cleft lip and/or palate used a feeding cup as an alternative method for mothers unable or unwilling to breastfeed but required additional supplementary feeding methods (Amstalden-Mendes et al., 2007).

**Nasogastric feeding tubes.** If infants with cleft lip and/or palate are unable to gain weight by other feeding techniques, they may benefit from nasogastric feeding tubes (Beaumont, 2008). In a study of ninety children with orofacial defects, 29% were fed via nasogastric feeding tube while in the hospital or when weight was a concern (Britton et al., 2011). In a study of 215 infants with cleft lip and/or palate in Brazil, 21% of the sample used nasogastric feeding tubes (Gil-da-Silva-Lopes et al., 2013). Although nasogastric feeding tubes are a faster method of feeding, healthcare professionals consider them invasive and should only be introduced in extreme oral feeding difficulties leading to weight loss (Gila-da-Silva-Lopes et al., 2013). A nasogastric feeding tube may also be indicated for infants with additional health conditions such as heart disease, respiratory issues, or hypoglycemia (Smedegaard et al., 2008).

### **Specialized Equipment Utilized in Feeding Infants with Cleft Lip and/or Palate**

Infants with cleft lip and/or palate may require specialized equipment in order to receive adequate nutrition. Specialized equipment decreases the infant's need to generate suction and narrows the infant's responsibility to focus on swallowing (Redford-Badwal et al., 2003).

Increasing the flow rate of bottle feeds resulted in a decreased sucking rate and longer individual suck length, while decreasing the flow rate caused an increase in sucking rate and shorter individual suck lengths (Massarei et al., 2007). A productive decreased sucking rate caused by increasing the bottle's flow rate will result in less fatigue to the feeding infant with cleft lip and/or palate (Massarei et al., 2007). Although increasing the flow rate of bottle feeds may supply more milk, it is important to avoid overwhelming the feeding infant with more milk than can be consumed (Massarei et al., 2007).

**Specialized bottles.** Specialized bottles may foster less challenging feedings in infants with cleft lip and/or palate (Britton et al., 2011). Compressible plastic bottles force milk to flow into the tip of the nipple, avoiding the necessity of negative pressure for milk transfer (Goyal, Jena, & Kaur, 2012). In addition, compressible bottles are inexpensive and relatively easy to use (Shaw, Bannister, & Roberts, 1999). For assisted feedings in infants with cleft lip and/or palate, compressible bottles are easier to use than rigid bottles (Lindberg & Berglund, 2013). In a study of 101 infants with cleft lip and/or palate in England, eleven of the fifty-two infants given rigid bottles transferred to compressible bottles due to feeding difficulties while none of the forty-nine infants given compressible bottles switched to rigid bottles (Shaw et al., 1999). Researchers found that infants with cleft lip and/or palate using compressible bottles while feeding experienced increased weight gain and required less intervention compared with infants using rigid bottles (Shaw et al., 1999).

A popular bottle used widely in the cleft lip and/or palate population is the Haberman (or specialneeds) feeder, which is a compressible plastic bottle with a soft adjustable-flow nipple and one-way valve that prevents backflow; as a result, active suction by the infant is not required in order to feed (Redford-Badwal et al., 2003). The bottle may be squeezed in coordination with the

infant's suck-swallow pattern to assist with milk transfer (Turner et al., 2001). The Haberman feeder is comprised of a bottle, a teat, a disk, a valve membrane, and a collar; some parents complained that the bottle was expensive and was difficult to assemble because it contained too many parts (Martin & Greatrex-White, 2013). Proper technique requires the alignment of the disk valve and the nipple reservoir completely filled with milk to the infant's mouth (Barone & Tallman, 1998). The mouthpiece's adjustable slit-valve controls the flow rate and opens only when the infant attempts to suck, allowing the infant some control during feedings (Turner et al., 2001). The flow rate varies from fast to a complete stop (Barone & Tallman, 1998). The flow rate may be increased when the infant has an audible swallow or less than four sucks per swallow (Turner et al., 2001).

Infants with cleft lip and/or palate may benefit from the use of a Mead Johnson feeding bottle (Miller, 2011). The Mead Johnson is a soft, compressible bottle that helps the flow of milk and may be fitted with a standard nipple (Redford-Badwal et al., 2003). In a study of fifty infants with cleft lip and/or palate, the Mead Johnson compressible bottle was found to be particularly useful in arthritic mothers who had difficulties squeezing other feeding bottles (Martin & Greatrex-White, 2013). However, infants using the Mead Johnson tended to swallow air during feedings (Barone & Tallman, 1998).

A modified Playtex bottle may be used to accommodate infants with cleft lip and/or palate (Barone & Tallman, 1998). Instead of a hard plastic bottle, the Playtex nipple is attached to a plastic bag and facilitates passive milk transfer and air removal during feedings (Barone & Tallman, 1998). The introduction of a plastic bag enables a controlled method of delivering formula during feedings and reduces the amount of air entering the infant's stomach (Barone & Tallman, 1998). The modified Playtex bottle offers the convenience of storing breast milk in the

bag and freezing until later use (Barone & Tallman, 1998). Questionnaires completed by twelve families of infants with cleft lip and/or palate and their six nurses revealed that the modified Playtex bottle was easier to use than the Mead Johnson bottle or the Haberman feeder (Barone & Tallman, 1998). Infants using the Mead Johnson bottle are more irritable and require longer feeding times; however, those using the Haberman have comparable feeding durations and fussiness levels compared with infants using the modified Playtex bottle (Barone & Tallman, 1998).

**Specialized nipples.** In a study of 215 children with cleft lip and/or palate in Brazil, researcher found that ordinary nipples were affordable, easy to find, and best for feeding nearly 37% of the study's cleft palate subjects and 32% of the study's cleft lip subjects (Gil-da-Silva-Lopes et al., 2013). However, the use of specialized nipples, or teats, may improve the transfer of milk during feedings of infants with cleft lip and/or palate (Redford-Badwal et al., 2003). Researchers propose that nipple modification may contribute to weight gain in infants with cleft palates (Kogo et al., 1997). The selection of the teat should be based on the infant's degree of cleft and oral-motor capabilities (Miller, 2011). The specialized nipple should be pliable enough to release fluid with minimal compression yet firm enough to encourage sucking efforts (Miller, 2011). Additional considerations include the nipple's shape, length, and hole size or type (Miller, 2011).

A cross-cut nipple may decrease the need for suction while regulating the flow of fluids during feedings (Gil-da-Silva-Lopes et al., 2013). The cross-cut nipple variation known as the pigeon cleft teat is commonly used in infants with cleft lip and/or palate living in Japan (Miller, 2011). The cross-cut nipple is specially designed for feeding infants with cleft lip and/or palate and includes a thick and a thin side (Redford-Badwal et al., 2003). One side has a thick wall for

placement against the roof of the mouth, while the opposite side has a thin wall to be positioned on the infant's tongue (Miller, 2011). The nipple also contains a unidirectional flow valve that allows fluid flow only during nipple compression and reduces excessive air intake (Redford-Badwal et al., 2003). In a randomized clinical trial of forty-seven infants with orofacial defects, a cross-cut nipple was the most used nipple variation (Prahl et al., 2005).

Research has shown that infants with cleft lip and/or palate may benefit from an orthodontic nipple, commercially known as a cleft Nuk (Gil-da-Silva-Lopes et al., 2013). The orthodontic nipple may create a wider base for sealing off the cleft in the lip, may improve physiological movements of the tongue and lips, and may yield higher negative pressure compared with ordinary nipples (Gil-da-Silva-Lopes et al., 2013). Orthodontic nipples may be recommended more often to infants with cleft palates than to infants with cleft lips (Gil-da-Silva-Lopes et al., 2013). A cleft Nuk offers the advantages of softer pliability, higher flow rate, and a broader base compared with a standard nipple on an ordinary feeding bottle (Miller, 2011). Wide based nipples may help the infant with cleft lip maintain a seal around the nipple (Miller, 2011). However, in a study of twenty-eight infants with cleft lip and/or palate in Germany, higher intraoral negative pressure was generated using a regular Nuk in comparison with a cleft Nuk (Choi et al., 1991).

**Palatal obturators.** Infants with cleft palates may benefit from palatal obturators, which are customized maxillary plates inserted into the oral cavity and cover the surface of the hard palate and alveolar segments (Prahl et al., 2005). By artificially covering the cleft, the infant may maintain a normalized oral environment and facilitate more efficient feeding movements (Prahl et al., 2005). Palatal obturators help close off the nasal pharynx and allow the infant to create adequate suction during feedings (Redford-Badwal et al., 2003). In addition, palatal obturators

stabilize the palate and create an artificial surface for the infant to successfully achieve nipple compression; its application may support high volume intake and decrease infant fatigue while feeding (Turner et al., 2001).

In a study of ninety children with orofacial defects, 26% used palatal obturators but nearly half of the sample experienced difficulties, especially while fastening the device with the strapping tape necessary to secure on the infant's head (Britton et al., 2011). In a randomized clinical trial, the experimental group of infants with orofacial defects wearing palatal obturators during the first year of life failed to show any significant difference in weight or height growth compared to infants without the dental appliance (Prahl et al., 2005). In the study, both groups experienced increased food intake and feeding velocity over time (Prahl et al., 2005). In a study of twenty-eight infants in Germany, the early application of orthodontic plates suggested little significant difference in peak negative pressure between infants with cleft lip and/or palate and infants without craniofacial abnormalities (Choi et al., 1991). The immediate fitting of palatal obturators in newborn infants with cleft lip and/or palate may be considered unethical because infants may have efficient feeding capabilities without the appliance (Shaw et al., 1999).

Since the infant's palate changes in shape and size with growth, palatal obturators may need to be replaced frequently in order to accommodate changes; as a result, the use of palatal obturators may be an expensive process (Goyal, Jena, & Kaur, 2012). Research suggests that the use of palatal obturators may be associated with the colonization of cariogenic lactobacilli, which increases the risk of developing dental caries (Prahl et al., 2005). Improper cleaning of the appliance may also contribute to poor oral hygiene and fungal growth (Goyal, Jena, & Kaur, 2012). Additional disadvantages in using palatal obturators include user difficulty, placement challenge, and oral tissue irritation (Miller, 2011). Since palatal obturators are customized and

require frequent readjusting as the infant grows, this feeding intervention may not be feasible for the targeted population due to limited financial and transportation resources in the Philippines.

### **Techniques Used in Feeding Infants with Cleft Lip and/or Palate**

In order to accommodate the clefting of the orofacial cavity, infants with cleft lip and/or palate may benefit from various positioning and pacing techniques during breast or bottle feedings. Proper body alignment may decrease the risk of nasal regurgitation (Miller, 2011). In addition, special considerations should be made while pacing the feedings of infants with cleft lip and/or palate (Miller, 2011).

**Positioning.** Modified positioning while feeding may be necessary to counteract the anatomical defect in infants with cleft lip and/or palate (Gopinath & Muda, 2005). Proper positioning may facilitate oral-motor patterns, airway protection, and efficient feeding in infants with cleft lip and/or palate (Miller, 2011). In a study of 90 children with cleft lip and/or palate, 70% reported nasal regurgitation in relation to the incomplete structure between the nasopharynx and the oropharynx (Britton et al., 2011). Another randomized clinical trial revealed that children with orofacial defects have an increased risk of choking, aspirating, and vomiting (Prahl et al., 2005). Unsuccessful breastfeeding was attributed to choking in nearly 70% of the 215 children with cleft lip and/or palate in a study conducted in Brazil (Gil-da-Silva-Lopes et al., 2013).

Infants with cleft lip and/or palate may benefit from an upright position during breast or bottle feeding (Gil-da-Silva-Lopes et al., 2013). Infants with cleft palates should be fed in an upright position greater than 60° to allow gravity to facilitate fluid transfer and decrease the tendency for nasopharyngeal reflux (Miller, 2011). In addition, the semi-upright position may enable frequent burping to minimize nasal regurgitation (Prahl et al., 2005). The football hold position, in which the infant's body is positioned alongside the mother's with his shoulders higher



than his body, may prevent regurgitation in infants with cleft lip and/or palate (Reilly et al., 2013). The minimization of milk reflux into the Eustachian tubes may reduce the risk of developing ear infections (Reilly et al., 2013).

General recommendations for body mechanics in infants with cleft lip and/or palate while feeding include the following: head support for neutral alignment of head and neck; arms forward, trunk midline, hips flexed; and lip, cheek, and jaw stabilization to provide a stable platform for sucking movements (Miller, 2011). During breastfeeding, the mother's breast should be supported and positioned toward the side of the palate that remains most intact in order to prevent the nipple from being pushed into the cleft (Reilly et al., 2013). In addition, to stabilize the jaw, the feeder places her middle finger under the infant's chin while his index finger is positioned between the infant's chin and lower lip (Miller, 2011). The dancer-hand position may be used to hold the infant's chin and support the neck while breastfeeding (C. Cote, personal communication, October 17, 2013). If the infant's cleft is large, the mother may tip her breast downward so the nipple remains in the infant's mouth (Reilly et al., 2013). The partner may also be involved by compressing the top of the mother's breast to fill in the gaps left by the infant's cleft lip (C. Cote, personal communication, October 17, 2013).

Infants with cleft lips may initially experience difficulties latching onto the nipple; however, they are generally able to adapt despite the challenge of having an incomplete seal on the nipple (Miller, 2011). The clinical protocols of the 2013 Academy of Breastfeeding Medicine recommend that while breastfeeding, an infant with cleft lip should be oriented to the top of the breast and the mother may occlude the cleft with her thumb (Miller, 2011). Women breastfeeding infants with cleft lips should provide external lip and cheek support in order to maintain lip closure around the nipple and increase the infant's control of oral intake (Miller,

2011). After forming a seal around the nipple, the infant may initiate sucking by using reflexive tongue & jaw movements to efficiently compress the nipple against the intact palate (Miller, 2011).

**Pacing.** In a study of 90 children with orofacial defects, 46% reported feeding sessions lasting more than one hour due to uncoordinated pacing (Britton et al., 2011). By pressing one's index finger on the infant's tongue to stimulate sucking, one may analyze the infant's rhythmic suck (C. Cote, personal communication, October 17, 2013). To help improve the infant's rhythmic suck, the feeder may bend his other index finger to help support the infant's chin while feeding (C. Cote, personal communication, October 17, 2013). Infants with cleft lip and/or palate may benefit from a learned rhythm during feedings (Redford-Badwal et al., 2003). The feeder should monitor the infant's reaction during feeding and identify cues that indicate a pause or change of pace: this includes the infant's color, O<sub>2</sub> saturation, respiratory rate, and sucking rhythm (Miller, 2011). Pacing the feeding in rhythm with the infant's movements and reactions may increase the infant's control of oral intake by helping maintain organization in sucking, swallowing, and breathing (Miller, 2011).

### **Healthcare Professional Involvement of Infants with Cleft Lip and/or Palate**

Families of infants with cleft lip and/or palate may benefit from regular visits by specially-trained health nurses (Smedegaard et al., 2008). In a study of 101 infants with cleft lip and/or palate in England, early feeding success was attributed to specialized home health visitors who provided the families with feeding and parental counsel (Shaw et al., 1999). Mothers of infants with cleft lip and/or palate may have limited knowledge about feeding their infants and may lack information regarding regurgitation, colic, and swallowing during feedings (Lindberg & Berglund, 2013). Mothers may receive poor and/or conflicting advice regarding appropriate

feeding techniques in infants with cleft lip and/or palate within the same institution (Miller, 2011). Mothers may feel stressed or confused when various healthcare professionals share conflicting feeding suggestions (Lindberg & Berglund, 2013). In a study of 215 children with cleft lip and/or palate in Brazil, nearly 65% of families were provided with guidelines regarding the different types of specialized teats (Gil-da-Silva-Lopes et al., 2013). Feeding guidelines are important for parents to develop confidence in properly caring for their infant with cleft lip and/or palate (Smedegaard et al., 2008). In addition, the consistency of a visiting healthcare provider would be helpful to avoid conflicting information.

### **Summary**

Upon analysis of 36 random clinical trials, qualitative studies, and systematic reviews, the evidence presents various methods, specialized equipment, and feeding techniques to provide infants with cleft lip and/or palate breast milk nutrition. Evidence from numerous studies showed a widespread consensus that breast milk is the optimal form of nutrition for infants, especially those with orofacial abnormalities. Interviews were conducted with two registered nurses who are International Board Certified (IBC) lactation consultants and members of the Arizona Breastfeeding Coalition. They disclosed personal experience in providing breastfeeding education and supporting mothers of infants with cleft lip and/or palate. The review of the literature and interviews with educated health care professionals provide insight in developing a best practice protocol for feeding breast milk nutrition to infants with cleft lip and/or palate.

### CHAPTER 3: BEST PRACTICE PROTOCOL

The purpose of this thesis was to develop recommendations for the best practice in promoting breast milk nutrition in infants with cleft lip and/or palate in the Philippines. The first two chapters provided background information related to the feeding complications associated with cleft lip and/or palate as well as suggestions to overcome aforementioned difficulties. In this chapter, the proposed recommendations for assessing infant's feeding abilities, encouraging breast milk, suggesting techniques and equipment, and supporting caregivers are presented.

#### **Assessment of the Infant's Sucking Ability**

Infants with cleft lip and/or palate will be evaluated on an individual basis. The proposed protocol will determine the infant's sucking ability in order to propose the most appropriate feeding technique. The infant's type of cleft (lip, palate, or lip and palate) will be classified as either unilateral or bilateral as well as partial or complete. The evaluator will assess the infant's non-nutritive suck and swallow skills including: ability to achieve lip seal, suck burst, suck strength, and suck-to-swallow ratio (Nahai et al., 2005). A list of recommended feeding techniques based on the infant's condition as part of the proposed protocol is presented in Table 1. In order to determine an infant's level of generation of negative pressure, an apparatus incorporating a pressure transducer may be used (Choi et al., 1991). However, this device may not be readily available in the Philippines. To analyze the infant's ability to make mechanical movements, the evaluator should press an index finger on the infant's tongue to stimulate the sucking reflex (C. Cote, personal communication, October 17, 2013). The assessment of the infant's ability to make mechanical movement requires little-to-no expense and therefore applicable to the impoverished setting of the Philippines.

Table 1.

*Assessment of Suck and Recommended Techniques for Infants with Cleft Lip and/or Palate*

<u>Condition</u>	<u>Assessment*</u>		<u>Feeding Technique</u>
	<i>Generation of Negative Pressure</i>	<i>Ability to Make Mechanical Movements</i>	
Cleft Lip Only	+/-	+	Breastfeeding works well Artificial nipple with large base effective
Cleft Palate Only	+/-	+	Breastfeeding sometimes works well Soft artificial nipples with large openings effective May require delivery of milk into mouth
Cleft of Soft Palate	+/-	+	Breastfeeding usually works well Normal bottle feeding usually works well Nipple shape may make functional difference
Cleft Lip and Palate	-	+/-	Breastfeeding unlikely Requires delivery of milk into mouth

\* "+" = present; "-" = absent; "+/-" = partial

*Note.* Modified from Clarren et al., 1987.

**Nutrition Recommendations**

The proposed protocol will encourage mothers of infants with cleft lip and/or palate to provide breast milk. Compared with formula, breast milk has anti-infective features, better nutritional composition, and more sanitary properties (Hengstermann et al., 2009). The well-balance ratio of amino acids, sugars, and fats increases cognitive development, strengthens immunological protection, and promotes gastrointestinal function; in addition, the maternal antibodies supplied in breast milk decreases the infant's risk of developing infections (Bozzette & Posner, 2013).. Breast milk is a protective factor against otitis media, which is an ear infection commonly found in infants with cleft lip and/or palate (Reilly et al., 2013). According to WHO, "no breast milk substitute, not even the most sophisticated and nutritionally balanced formula,

can begin to offer the numerous unique health advantages that breast milk provides for babies" (Hengstermann et al., 2009, p. 23).

In the developing country of the Philippines, feeding infants breast milk is preferred over infant formula due to high cost, lack of clean water, and poor hygiene (Hengstermann et al., 2009). Citizens of developing countries, such as the Philippines, are able to afford the cost-effectiveness of breastfeeding (Murray et al., 1997). Individuals of developing countries may be unable to afford the expenses associated with bottle feeding and formula feeding. In developing countries, feeding infants powdered formula mixed with water has a higher risk of infection due to possible contaminated water sources. In addition, citizens of the Philippines may experience difficulties with reading or adhering to instructions on how to prepare the formula (Hengstermann et al., 2009). However, if feeding is inadequate, infants should be provided with supplemental formula to promote adequate growth and nutrition (Reilly et al., 2013). Formula may also be recommended if prolonged or frustrating feeding sessions jeopardize the maternal-infant relationship (Smedegaard et al., 2008).

### **Feeding Technique Recommendations**

The proposed protocol will encourage mothers of infants with cleft lip and/or palate to breastfeed. Breastfeeding promotes the development, musculature, and coordination of the oral cavity (Britton et al., 2011). The mother's nipple is more flexible and the breast is more moldable, allowing for better suction; in addition, skin-to-skin contact may facilitate maternal-infant bonding (Garcez & Giugliani, 2005). Manually expressing breast milk may be necessary to stimulate the let-down reflex (Reilly et al., 2013). This also increases the flexibility of breast tissue and softens the areola to better seal the cleft while breastfeeding (Garcez & Giugliani, 2005).

Breastfeeding efficiency and effectiveness may improve with position modifications (Reilly et al., 2013). While breastfeeding, infants should be held with the cleft lip oriented to the top of the breast (Reilly et al., 2013). The infant's cleft lip may be occluded with the mother's thumb to increase closure around the nipple (Reilly et al., 2013). For infants with cleft palate, mothers should position the breast toward the side of the palate with the most intact bone (Reilly et al., 2013). Infants with cleft palate should feed in a semi-upright position in order to reduce nasal regurgitation and reflux of milk into the Eustachian tubes (Reilly et al., 2013). Infants with cleft lip and/or palate should be burped frequently during feedings since they tend to swallow more air. If milk runs out of the infant's nose, the caregiver should wipe the infant's face with a soft cloth.

If the infant is unable to successfully draw milk while breastfeeding, the mother will be encouraged to express milk and feed the infant using a standard bottle. Depending on the severity and type of the cleft, some infants are able to adapt to and successfully feed with a standard feeding bottle (Miller, 2011). If the cleft is severe, specialized feeding equipment designed to decrease the need to generate suction and the rate of sucking should be recommended (Redford-Badwal et al., 2003). Selection of specialized feeding equipment depends on individual orofacial anatomy and oral motor skills (Miller, 2011). The Haberman feeder should be recommended to infants with cleft lip and/or palate who are unable to breastfeed. The bottle's compressible material may be squeezed in synchronization with the infant's sucking pattern; in addition, the soft, pliable nipple has a one-way valve that may be controlled by the feeder (Miller, 2011). Although the Haberman feeder is priced at approximately \$25.12 per bottle, its prevalence and success in developed countries supports its effectiveness ("Medela SpecialNeeds™," 2014). The Haberman feeder may be purchased online if unable to purchase in stores in the Philippines.

The infant should be frequently burped throughout the feeding in order to reduce extra air in the stomach and decrease the risk of regurgitation (Redford-Badwal et al., 2003). A list of recommended feeding techniques and rationales is presented in Table 2.

Table 2.

*Recommended Feeding Techniques for Infants with Cleft Lip and/or Palate*

<u>Technique</u>	<u>Rationale</u>
Expressing breast milk	<ul style="list-style-type: none"> <li>- Manually expressing breast milk stimulates the let-down reflex</li> <li>- Increasing flexibility of breast tissue and softening the areola facilitates infant latch to seal the cleft</li> </ul>
Positioning	<ul style="list-style-type: none"> <li>- Maintaining flexion, midline orientation, and neutral alignment of the head and neck facilitates proper oral-motor patterns, airway protection, and efficient feeding.</li> <li>- Positioning at 60 degrees promotes transfer of fluid and decreases tendency for nasopharyngeal reflux.</li> </ul>
Lip, cheek, and chin support	<ul style="list-style-type: none"> <li>- Supporting lips, cheek, and chin facilitates sucking movements.</li> </ul>
Pacing	<ul style="list-style-type: none"> <li>- Assistive squeezing, in synchrony with infant's sucking efforts, help to compensate infant's inability to create sufficient suction for fluid extraction.</li> <li>- Requires specialized feeding equipment.</li> </ul>
Burping	<ul style="list-style-type: none"> <li>- Burping regularly decreases amount of air in stomach and reduces the chance of regurgitation after feeding</li> </ul>

*Note.* Modified from Miller, 2011.

**Support**

Caregivers may be uneducated about the feeding complications associated with cleft lip and/or palate (Lindberg & Berglund, 2013). The proposed protocol will provide standardized advice recommended for feeding infants with cleft lip and/or palate. Health care professionals should provide feeding and parental counsel as soon as possible for optimal results (Shaw et al., 1999). Each medical mission assigned to perform cleft repair surgeries in the Philippines should



be accompanied by a trained health professional who will educate local health professionals, as well as parents, about the best practices on feeding infants with cleft lip and/or palate. Qualified health professionals for this purpose include nurses, lactation consultants, and occupational therapists. In addition to health care professional support, families of infants with cleft lip and/or palate may also benefit from breastfeeding support groups with local women with experiencing of feeding infants with orofacial defects (Reilly et al., 2013).

### **Summary**

Educated health care professionals should provide feeding information and support to families of infants with cleft lip and/or palate. The feeding abilities of infants with cleft lip and/or palate should be assessed in order to determine the resources necessary for optimal feeding practices. The infant's ability to generate negative pressure and make mechanical movements will determine the recommended feeding technique for that individual infant. The nutritional recommendation for infants with cleft lip and/or palate is breast milk. Compared with formula, breast milk is more economical and readily available in developing countries (Goyal, Jena, & Kaur, 2012). Infants with cleft lip and/or palate should be encouraged to be breastfed in order to facilitate the development, musculature, and coordination of the oral cavity. Specific techniques and positions are recommended for breastfeeding success. However, if the infant is unable to successfully breastfeed, the use of the Haberman feeder should be recommended. Chapter 4 will discuss the plan for implementation.

## CHAPTER 4: IMPLEMENTATION

The purpose of this chapter is to present a hypothetical implementation approach to educate optimal feeding practices for infants with cleft lip and/or palate living in the Philippines. A significant percentage of the Filipino population lacks the access to healthcare knowledge and resources. In addition, medical missions providing cleft lip and/or palate surgical procedures in the Philippines are staffed by foreign volunteers who may be unaware of the local culture. This misinterpretation of local practices may result in patient dissatisfaction and noncompliance, inappropriate care, and missed treatments (Mendoza, 2009). The implementation of educating optimal feeding practices requires consideration for financial limitations and sociocultural barriers. For the purpose of this best practice protocol, this educational program would initiate a year-long pilot study in partnership with local health care leaders of the city of Manila. Successful evaluation of the educational program may lead to program expansion in other provinces.

The framework for the development of the proposed approach will be based on Everett M. Roger's (2003) Theory of Diffusion of Innovations. This five-stage process is frequently utilized to implement evidence-based research and protocols in specific populations. This chapter discusses the Theory's first four stages: knowledge, persuasion, decisions, and implementation. Lastly, this chapter summarizes a hypothetical cost estimate required for implementation. The framework of the Theory of Diffusion of Innovations enhances the implementation of the proposed best practice protocol of feeding infants with cleft lip and/or palate in the Philippines.

**Knowledge**

The knowledge stage of Roger's (2003) Theory of Diffusion of Innovations requires the caregivers of infants with cleft lip and/or palate to become aware of the developmental

advantages of breastfeeding and potential feeding difficulties. During the knowledge phase, caregivers will become educated on the nutritional benefits of breast milk and the mechanical advantages of breastfeeding. If the infant is unable to efficiently breastfeed, the caregiver will be taught alternative methods of feeding. Caregivers will obtain this knowledge from training provided by local healthcare professionals and medical mission volunteers. From this point, the team of medical mission volunteers and local healthcare professionals will be referred as the "Training Team."

The knowledge phase requires professional healthcare support to educate caregivers about standardized feeding recommendations and individualized support. In this proposed best practice protocol, professional medical mission healthcare volunteers will provide training to local healthcare workers in the Philippines. The medical mission team will include healthcare professionals such as nurses, lactation consultants, and speech therapists. This team will be led by a highly qualified feeding nurse specialist with the title "Feeder Leader." The Feeder Leader is qualified as a lactation consultant as well as an educational specialist. Infants with cleft lip and/or palate of industrialized nations have shown success with nurse specialists providing perinatal parental support, complex feeding advice, and home visits (Goodacre & Swan, 2012). Consistent information and support will avoid feelings of frustration. The Feeder Leader will be responsible for overseeing the training of local healthcare professionals and the implementation of the standardized feeding recommendations. Since the population has low access to transportation and resources, local healthcare professionals can visit remote neighborhoods and promote the opportunity for professional education through word of mouth.

**Persuasion**

During the persuasion stage, each individual is able to form an attitude toward the innovation after being informed about the idea (Everett, 2003). The Feeder Leader and the team of medical mission volunteers need to persuade the government and local healthcare professionals about the advantages of their feeding recommendations. The increased communication between both local and volunteer healthcare professionals will result in timely assessment of the infant's cleft severity. This will determine the optimal feeding practices and care for the infant. Since the local healthcare professionals have a basic understanding of nutrition, the Feeder Leader should emphasize the benefits of breast milk and detailed information related to infants with cleft lip and/or palate. A formal evidence-based practice presentation will give creditability to the effectiveness of the proposed best practice protocol. Educational resources for the local healthcare staff will include written protocols, illustrative posters, and live demonstrations performed by volunteer healthcare professionals.

To avoid miscommunication related to language barriers, medical mission volunteers will collaborate with local healthcare professionals fluent in the dialect while communicating with caregivers. A complete understanding of this protocol will promote a smooth transition throughout the implementation process. Local caregivers will be shown pictures illustrating proper breastfeeding positions. In addition, images showing the results of inadequate versus optimal feeding practices will persuade caregivers to adhere to feeding recommendations.

During the persuasion stage, caregivers are interested in the innovation and actively seek further details and information (Everett, 2003). Caregivers have the opportunity to develop favorable or unfavorable attitudes toward the feeding recommendations provided. The protocol should be explained and encouraged by healthcare professionals with patience and supportive

commentary. Caregivers may accept knowledge acquisition and continue with change or resist the recommendations and prevent stage progression (Rogers, 2003). The persuasion stage requires professional support, positive encouragement, and recognition of a need for change (Rogers, 2003).

### **Decisions**

During the decision stage, each individual considers and applies the newfound knowledge. The decision to accept the proposed innovation is individualized to the situation of the infant and his caregiver. Caregivers have the opportunity to incorporate or ignore the feeding recommendations provided to them. Each individual has the decision to either officially adopt or reject the proposed innovation (Rogers, 2003). The local healthcare providers must realize the necessity for change in order to accept the protocol. An important factor in this decision includes the source of funding and a cost-benefit analysis of the proposed protocol. A committee led by the Feeder Leader will establish a working budget outlining the expenses for local staff education and protocol implementation. In addition, the newly-trained local healthcare professionals must feel comfortable and confident with their assessment skills and care actions. After determining the advantages and disadvantages of the innovation, caregivers have the responsibility of either adopting or rejecting the proposed protocol. Factors that may influence their decision include their financial resources, transportation access, and community support.

### **Implementation**

During the implementation stage, the proposed best practice protocol is adopted and put into practice (Rogers, 2003). This stage serves as the transition from mental practice to behavioral change (Rogers, 2003). The implementation stage may encounter operational problems that need to be addressed in later stages of the Theory (Rogers, 2003).

To initiate the proposed best practice protocol, the medical mission team will include a "Feeder Leader," who has experience as an educational specialist and lactation consultant. Led by the Feeder Leader, the team will establish and implement standardized feeding recommendations for infants with cleft lip and/or palate based on evidenced-based research. Feeding recommendations are located under Chapter 3 of this proposal. As an educational specialist, the Feeder Leader is responsible for training the committee members to educate the healthcare staff of local health clinics. Ideally, each health clinic will have at least three staff members to train. The training will be eight hours each day for three days. Refer to Appendix A for a proposed training schedule. The local healthcare staff will be compensated for their time during training. This protocol requires collaboration with the Philippines' government in order to allocate time for healthcare professionals to provide care. However, the medical mission organization will fund the expense of training the local healthcare professionals.

There will be three training sessions and each session will take eight hours to complete. At the conclusion of training, the Training Team will be prepared to educate caregivers of infants with cleft lip and/or palate in the local community. While educating caregivers, the healthcare professionals must consider that each infant's situation and degree of clefting is unique and requires a personalized assessment.

Initially, the infant's anthropometric measurements of weight and height will be recorded for future evaluation. Then, the healthcare professional will inquire about current infant feeding practices, techniques, and difficulties. After the initial assessment of the infant's sucking ability, the healthcare professional will determine if the infant is able to breastfeed. If so, the infant's mother must be taught breastfeeding techniques such as upright positioning and occluding the cleft. If the infant is unable to tolerate breastfeeding, the healthcare professional will encourage

the infant's mother to express breast milk and bottle feed her infant. The Haberman feeder will be recommended based on evidence-based research regarding infants with cleft lip and/or palate. To determine the effectiveness of the feeding recommendations, a local healthcare professional will conduct a follow-up appointment with the infant and his caregiver. Quantitative measurements will include height and weight, while qualitative progress will be documented based on the caregiver's reported experience with feeding the infant. Refer to Appendix B for the "Caregivers' Evaluation of Feeding Recommendations Survey."

### **Cost Estimate**

The major cost associated with protocol implementation is educating and funding local healthcare professionals for caregiver support. Ideally, each clinical site will have at least three nurses proficiently trained in providing feeding recommendations for infants with cleft lip and/or palate. These clinical sites are staffed by government nurses. According to the Philippine Nurses Act of 2002, government nurses earn approximately 13,300 pesos each month ("Salary of nurses", 2007). This is the equivalence of \$305.12 USD, or roughly \$76.28 per week. A government nurse earns roughly \$1.91 per hr according to a 40 hr workweek. Since only monthly salaries are provided, determining the cost to educate and train local healthcare professionals such as nurses is difficult. However, in this proposed protocol, each local healthcare professional will be reimbursed \$10.00 USD per day of training. Since each clinical site is expected to train at least three local healthcare professionals, a budget of \$90.00 USD for training staff will be allocated for each site.

In addition, infants requiring additional assistance will be supplied with assistive feeding equipment. The Haberman feeder is recommended based on its success in industrialized countries. However, this is an expensive feeding device that is priced at \$25.12 per bottle

("Medela SpecialNeeds™," 2014). Ideally, donations collected through the efforts of medical mission volunteers would fund this expense. Since medical mission volunteers are donating their time, the budget does not account for their service.

### **Summary**

The purpose of this chapter was to explain the implementation of the proposed protocol using the Theory of Diffusion of Innovation as a guide. This theoretical process improves patient care and outcomes by introducing change into a clinical setting (Burns & Grove, 2007). By following the sequential steps of the theory, the protocol is introduced, developed, and implemented for optimal execution. The knowledge stage requires the targeted population to become aware of the issue. During the persuasion stage, each individual is expected to develop a positive or negative attitude toward the proposed change. Government officials and local healthcare professionals involved will need to be convinced about the advantages of the proposed change. Learning materials and resources are used to supplement this persuasion. The decision stage involves the official acceptance or rejection of the proposed protocol by the government officials, local healthcare professionals, and caregivers of infants with cleft lip and/or palate. A cost estimate is used to influence this decision. The proposed protocol will be placed into action during the implementation stage. Local healthcare professionals will be appropriately trained and able to provide feeding recommendations for infants with cleft lip and/or palate. Confirmation, the final stage of Roger's (2003) Theory of Diffusion of Innovation, will be addressed in the final chapter.



## CHAPTER 5: EVALUATION

The purpose of this chapter is to discuss the evaluation of the implementation of the best practice protocol for feeding infants with cleft lip and/or palate in the Philippines. The fifth stage of Roger's Theory of Diffusion of Innovations, confirmation, evaluates the effectiveness of the protocol (Rogers, 2003). This chapter identifies the strengths and limitations of the proposed protocol and presents recommendations for future cleft lip and/or palate research.

**Confirmation**

The fifth and final stage of the Diffusion of Innovation Theory is the confirmation stage (Rogers, 2003). This stage involves collecting and analyzing information to determine if the change should be continued, expanded, revised, or discontinued (Rogers, 2003). During this stage, the Feeder Leader and medical mission volunteers would evaluate if the implemented protocol is effective and determine if its implementation will be permanent. The success of the implemented intervention would also be evaluated to determine its efficiency. This best practice proposal requires the evaluation process to begin immediately after teaching. For long-term evaluation, the proposal suggests follow-up after one month of the teaching to allow the caregiver the opportunity to implement the provided feeding recommendations and discover any issues or concerns.

The evaluation process will involve six components: caregivers giving return demonstrations of feeding, follow-up survey with the infants' caregivers, post-intervention discussion with the Training Team, post-intervention anthropometric measurements of infants, and reassessment of sucking ability. Further details related to each evaluation component will be described. These evaluation methods will provide both quantitative and qualitative data for data analysis. The first three evaluation components will be implemented immediately after teaching

while the remaining three methods will be done after a one-month period. Although revisiting the infants after a one-month period may not be realistic, it is ideal based on the proposed best practice protocol.

Qualitative data will be collected immediately after caregivers are educated about feeding techniques. The proposed protocol requires caregivers to perform a return demonstration to a member of the Training Team to ensure proper technique. Based on their performance, the caregiver may require further training and instruction. In addition, the caregivers will be given a survey inquiring about their attitudes of implementing the feeding recommendations specifically provided to them. The survey found in Appendix B provides qualitative data that indicates knowledge, confidence, and further concerns the caregivers may have. This survey will also be translated in writing or verbally into the local dialect by a local healthcare professional. Finally, a discussion based on the questions found in Appendix C will be used to evaluate the Training Team's observations, experiences, and input.

After a one-month period, quantitative and qualitative data will be collected. The infant's anthropometric measurements of height and weight will be obtained and compared with the data obtained during initial assessment. Then, a skilled member of the Training team will reassess the infant's sucking ability to determine if the current feeding recommendations are still appropriate. This is necessary because an infant's orofacial cavity evolves over time. Afterwards, the caregivers will complete the same survey found in Appendix B while a member of the Training Team will answer the same questions located in Appendix C. The data will be compared with the previous information collected in order to address pending issues.

**Strengths**

The primary strength of this proposed best practice protocol is the evidence-based research supporting the protocol's recommendations. The current guidelines for feeding infants with cleft lip and/or palate in industrialized countries have been supported with various resources. These recommendations may be modified for application in areas with fewer financial and healthcare resources. This protocol promotes education to address the public health concern of inadequate growth and development in infants with cleft lip and/or palate related to feeding difficulties.

In addition, the promotion of breast milk instead of formula may decrease the risk of infections among infants. Since access to clean water may be difficult in the Philippines, powdered formula should be avoided because it requires to be mixed with water prior to consumption. Contaminated water increases the infant's risk for developing infections and additional health issues. Also, the promotion of breast milk instead of expensive formula is a realistic and advantageous feeding recommendation. Finally, identifying an infant's sucking abilities using a finger requires no expense.

**Limitations**

Limitations of this best practice proposal involve the knowledge, persuasion, implementation, and evaluation stages. Since many impoverished families are illiterate, they may be unable to fully understand the importance of breast milk and breastfeeding (Sharp et al., 2008). Written material such as brochures may not be a realistic educational resource due to the lower literacy rate of the general population of the Philippines. In addition, consultation with foreign medical mission volunteers may lead to miscommunication and misunderstanding. Language barriers and illiteracy create knowledge, persuasion, and implementation limitations.

Healthcare professionals implementing this best practice protocol need to consider the sacred values and traditional beliefs of the majority of Filipinos (Mendoza, 2009). The traditional value-orientation and belief system of the majority of Filipinos includes fatalism and God's will (Mendoza, 2009). These sociocultural barriers may hinder caregivers' understanding about the causes, treatment, and prevention of orofacial defects (Mendoza, 2009).

Maintaining consistent communication with caregivers may be difficult since many families lack permanent mailing addresses (Sharp et al., 2008). In addition, families may lack the financial resources to travel due to limited access to transportation vehicles and high gas expenses (Sharp et al., 2008). Lack of road maintenance by the local government and heavy rains may create poor road conditions (Sharp et al., 2008). The lack of communication and transportation may result in missed follow-up appointments that provide information regarding the effectiveness of the best practice protocol.

Lack of financial resources is a critical limiting factor in the implementation of the proposed best practice protocol. Although this best practice protocol assumes the establishment of a local healthcare center and develops a cost estimate, some regions of the Philippines may lack the funding for a proper healthcare center. Training local healthcare providers will require funding that may not be covered in the government's current budget. Personalized home visits are costly. Although the Haberman feeder is recommended based on its compressible material and modifiable nipple, the assistive feeding device is expensive. Despite possible funding from charitable organizations, local health clinics may not be able to afford to distribute Haberman feeders.

**Recommendations for Future Research**

Recommendations for future research include determining the role of folic acid in preventing the development of cleft lip and/or palate. This research may lead to the establishment of a folic acid supplemental program in the Philippines that may decrease the incidence of orofacial defects among the impoverished population. Further research concerning the early education and intervention of feeding infants with cleft lip and/or palate may show a decrease in future physiological and psychological issues. In addition, the establishment of cleft lip and/or palate support groups led by local healthcare professionals may encourage caregivers to consistently seek feeding assistance as needed. Further research may also include the development of a lower-cost alternative for supplying milk in infants with cleft lip and/or palate who are unable to breastfeed. Although research supports the Haberman feeder's efficiency, without the financial support of health organizations, local citizens of the Philippines may be unable to afford the assistive feeding device.

**Summary**

The purpose of this thesis was to propose a best practice protocol for promoting optimal nutrition in infants with cleft lip and/or palate in Philippines. Evidence-based research and personal communication with experts in lactation support were utilized to develop a protocol for determining an infant's sucking ability and providing feeding education and support. Roger's Theory of Diffusion of Innovation was used to outline the implementation and evaluation of the protocol. This theory builds on each stage to develop and implement a best practice protocol to provide optimal feeding recommendations for infants with cleft lip and/or palate in the Philippines. This protocol has specific application in the Philippines because of the nation's high orofacial defect incidence and limited resources. By utilizing resources such as written protocols,

illustrations, and live demonstrations, the committee will train the local healthcare staff about feeding recommendations for infants with cleft lip and/or palate. Return demonstrations, follow-up surveys with discussion questions, anthropometric measurements, and reassessment of sucking abilities would be used to evaluate the effectiveness of individualized feeding recommendations. After considering the strengths and weaknesses of the proposed protocol, additional recommendations related to the proposal were suggested for further research.

Appendix A

*Local Healthcare Professional Training Schedule for Feeding Recommendations*

<u>Day</u>	<u>Topic</u>	<u>Important Points</u>	<u>Significance</u>
	<i>Educating Caregivers</i>	<ul style="list-style-type: none"> <li>▪ Cleft Lip and/or Palate                             <ul style="list-style-type: none"> <li>- scientific-based etiology</li> <li>- growth implications</li> </ul> </li>   <li>▪ Breast Milk Nutrition                             <ul style="list-style-type: none"> <li>- protein, carbohydrates, fats</li> <li>- vitamins, minerals, enzymes, prebiotics</li> <li>- no associated expenses</li> </ul> </li>   <li>▪ Breastfeeding                             <ul style="list-style-type: none"> <li>- muscle movements</li> <li>- flexible nipples and breast tissue</li> <li>- skin-to-skin</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>▪ Cultural beliefs (fatalism, God's will) serve as barriers for understanding the etiology of the orofacial conditions (Mendoza, 2009).</li> <li>▪ Adequate nutrition for optimal growth and development (Gil-da-Silva-Lopes et al., 2013).</li>   <li>▪ Nutrients help with digestion, hormone development, immune system, and cognitive development (Chuang et al., 2009).</li> <li>▪ Powdered formula requires water. The easy access to contaminated water sources in the Philippines increases the infant's risk of developing infections.</li>   <li>▪ Breastfeeding stimulates orofacial muscle development and coordination (Britton et al., 2011).</li> <li>▪ Flexible nipple and breast tissues allow for better suction (Garcez &amp; Giugliani, 2005).</li> <li>▪ Skin-to-skin contact facilitates mother-infant bonding (Garcez &amp; Giugliani, 2005).</li> </ul>
	<i>Assessing Sucking Abilities</i>	<ul style="list-style-type: none"> <li>▪ Ability to generate movements</li> <li>▪ Lip seal</li> <li>▪ Suck burst/strength</li> </ul>	<ul style="list-style-type: none"> <li>▪ Infant's ability to suck determines the appropriate feeding recommendations given to providers (Nahai</li> </ul>

*Providing  
Recommendations*

- Suck-to-swallow ratio
  - Expressing breast milk
  - Breastfeeding positions  
- upright positioning
  - Lip, cheek, chin support
  - Pacing  
- identify cues (color, O<sub>2</sub> saturation, respiratory rate, sucking rhythm)
  - Burping
  - Assistive feeding devices  
- compressible bottle  
- specialized nipple
- et al., 2005).
  - Refer to Table 1 for feeding recommendations.
  - Manual expression stimulates let-down reflect and increases breast tissue flexibility (Miller, 2011).
  - Midline orientation and neutral head and neck alignment decreases risk of nasopharyngeal reflux and facilitates proper airway protection (Miller, 2011)
  - Support facilitates sucking movements (Miller, 2011).
  - Assistive squeezing with feeding equipment in synchrony with infant's sucking patterns helps compensate infant's inability to create appropriate suction for fluid extraction (Miller, 2011).
  - Regular burping decreases amount of air in stomach and decreases risk of regurgitation after feeding (Miller, 2011).
  - Squeezable bottle in coordination with infant's suck-swallow pattern may increase fluid extraction (Turner et al., 2001).
  - Specialized nipple should be pliable enough to release fluid with minimal compression while encouraging sucking efforts (Miller, 2011).



Appendix B

Caregivers' Evaluation of Feeding Recommendations Survey

**Caregiver** Age: \_\_\_\_\_ Gender (m/f): \_\_\_\_\_

**Infant** Age: \_\_\_\_\_ Gender (m/f): \_\_\_\_\_ Condition: \_\_\_\_\_

Are you currently breastfeeding? Y \_\_\_ N\_\_\_ Are you giving a bottle? Y \_\_\_ N \_\_\_

1. Has transportation been a concern in accessing medical care? Please explain:

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Please answer items 2-6 by assigning a number. (1: increased) (2: unchanged) (3: decreased)

2. My knowledge of my infant's condition and needs has: \_\_\_\_\_

3. My confidence in feeding my infant has: \_\_\_\_\_

4. My desire to breastfeed my infant has: \_\_\_\_\_

5. My desire to provide breast milk to my infant has: \_\_\_\_\_

6. My feelings of support by healthcare professionals has: \_\_\_\_\_

7. On a scale of 1-10 with 1 being least difficult and 10 being most difficult, rate the ease of feeding your infant: \_\_\_\_\_

8. Please describe your experience with members of the Training Team while learning more about feeding recommendations for your infant:

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9. Please provide any additional comments in the section below:

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## Appendix C

*Training Team's Experiences Discussion Questions*

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Training Input

1. What are some key points that you learned from training?
2. Did you find the educational resources during training effective?
3. Was the time frame and schedule sufficient to properly understand the information and gain confidence in teaching others?

Observations

1. Describe the infant's physical and behavioral characteristics.
2. How did you perceive the relationship and level of bonding between the infant and caregiver?
3. How did the type and degree of clefting influence the infant's ability to feed?

Experiences

1. Describe your experiencing while assessing the infant.
2. What has been the greatest challenge while teaching others?
3. Was the caregiver successful after the first return demonstration?

Suggestions

1. Do you have any suggestions for training future healthcare professionals in feeding recommendations for infants with cleft lip and/or palate?
2. From your experience, how can communication between healthcare professionals and caregivers be improved?
3. What are cultural considerations that need to be addressed during this teaching process?

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