

**Preterm birth in Vietnam:
Direct medical cost assessment and the investigation of parents'
experiences and satisfaction with health care services**

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Dedicated to my beloved mother,
Nguyen Thi Tuan (1949-2003)

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List of abbreviations

BMI	Body mass index
CHC	Commune Health Center
ELBW	Extremely low birth weight
FCCU6	Free Care Children Under 6
IVH	Intraventricular hemorrhage
MOH	Ministry of Health
NCU	Neonatal Care Unit
NEC	Necrotizing enterocolitis
OOP	Out-of-pocket
PDA	Patent ductus arteriosus
ROP	Retinopathy of prematurity
SLE	Systemic lupus erythematosus
WHO	World Health Organization

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Executive Summary

Background

Preterm birth remains a critical public health challenge and the leading cause of neonatal death in Vietnam. Many studies in high-income countries have documented the short and long-term consequences of preterm birth in infants, their families as well as the health system. The aim of this thesis was to assess the financial impact of premature deliveries as well as parental experiences and satisfaction with preterm health care services in Vietnam.

Methods

A mixed methods approach was used to address the main objectives. Both qualitative and quantitative data were collected in the Neonatal Care Units of Vietnam National Children Hospital and Thanh Hoa Pediatric Hospital. The analysis was divided into three main papers. The first objective of the thesis used secondary data from financial and medical records of preterm infants discharged from the two hospitals referenced above to estimate the average of direct medical costs as well as the direct Out-of-pocket (OOP) costs of preterm infants in 2017. In the second objective, we analysed 23 in-depth interviews with mothers or fathers of preterm babies. In these interviews, parents were encouraged to talk freely not only about their feelings and distress of having a preterm child admitted in Neonatal Care Unit (NCU), but also about their thoughts about health care services and the support from health workers. For the last objective, we used a structured questionnaire to assess the satisfaction level of 340 parents with healthcare services at the two hospitals analysed in 2018.

Results

Our results suggest that preterm births create a considerable burden to families as well as the health system in Vietnam. Out-of-pocket expenditure was generally limited for parents who followed national care seeking guidelines. Parents who bypassed lower-level facilities without referral authorization faced out-of-pocket expenditure about six times higher than those of infants who had a proper transfer. Both premature birth and hospital transfers were caused a major psychological burden and stress for parents. The primary reasons for decision to transfer preterm infants to the national hospital were acute illness, positive perceptions of the quality of care of the national hospital and advice of other parents. These perceived quality differences were however not reflected in parental satisfaction scores, which were consistently higher at the provincial hospital.

Longer length of stay and worsening infant health status were the main factors resulting in lower parental satisfaction with the quality of care provided.

Conclusions:

This thesis has shown that preterm births can create a major economic and psychological burden for families as well as the health system. Reducing the impact of preterm births likely requires a close cooperation between health professionals and infants' families. Improving communication between health staff and families, as well as additional support for families while their preterm infants are at the hospital as well as after their discharge could help reducing the psychological burden faced by families and newborns.

Chapter 1: Introduction

1.1. Background

1.1.1. Definition of preterm births

According to the World Health Organization (WHO), preterm is defined as babies born alive before 37 weeks of pregnancy are completed (WHO, 2018b). There are sub-categories of preterm birth which are based on gestational age, they are extremely preterm (<28 weeks), very preterm (28 to <32 weeks), moderate to late preterm (32 to <37 weeks) (WHO, 2018b).

According to the latest estimates, 15 million babies are born preterm every year; the rate of preterm birth ranges from 5% to 18% of babies born across countries, and has been increasing in many settings (WHO, 2018b). Prematurity is the leading cause of newborn deaths and now the second leading cause of death after pneumonia in children under the age of five. Over 1 million children die each year due to complications of preterm birth (WHO, 2018b).

1.1.2. Causes of preterm births

The specific causes of premature birth are not still clear. However, there are known risk factors of premature delivery, including biological, medical, behavioral, psychological, sociodemographic, and environmental factors (Behrman and Butler, 2007).

Studies have indicated the mother with medical conditions have an increased the risk of preterm birth. Chronic conditions such as chronic hypertension and systemic lupus erythematosus (SLE) are associated with an increased risk of preterm birth. Results from a longitudinal study analyzing the Danish National Birth Cohort showed that risk of short gestational age increased 5.5 fold (95% CI: 3.2-9.4) among women with definite chronic hypertension (Catov et al., 2008). Another retrospective cohort study of singleton pregnancies among women who delivered between 2002 and 2015 in San Francisco, USA indicated that preterm births were almost two times more likely for women with pregnancy induced hypertension (OR=1.8; 95% CI:1.5-2.2), more than 1.5 times more likely for women with chronic hypertension preceding pregnancy (OR=1.6; 95% CI:1.3-2.1) (Premkumar et al., 2016). The study included 2929 women in USA who were evaluated at 24 weeks' gestation. It showed that a history of chronic hypertension was a risk factor for preterm birth (OR=4.06) (Meis et al., 1998). A meta- analysis conducted in 2016 analyzing the relationship between SLE and risk of preterm birth reported that the pooled

relative risk (RR) for the risk of preterm birth in SLE patients versus controls was 2.05 (95% CI:1.72-3.32) (Wei et al., 2017). Another important medical risk factor of preterm births is pre-eclampsia. Pre-eclampsia is a pregnancy-specific syndrome that affects 3–5% of pregnancies and is traditionally diagnosed when a pregnant woman presents with increased blood pressure and proteinuria (Fernandez Medina et al., 2018). A study analyzing individual patient-level data on 4.1 million singleton pregnancies from four countries indicated that previous preterm birth and pre-eclampsia were the strongest individual risk factors for preterm birth (Ferrero et al., 2016). Studies also demonstrated that short cervical length, measured by transvaginal ultrasonography, is associated with preterm birth and the shorter the cervical length the greater risk of preterm births (Bulletins-Obstetrics. and Gynecologists, 2012; Barros-Silva et al., 2014). Rarer conditions such as polycystic ovarian syndrome, epilepsy, and bipolar disorder also increase the likelihood of preterm birth (Viale et al., 2015; Männistö et al., 2016; Rusner et al., 2016).

Many studies have found that short inter-pregnancy intervals or intervals between the termination of one pregnancy and the conception of another which are less or equal to 6 months, were associated with a number of adverse perinatal outcomes, including preterm birth, low birth weight, and stillbirth (Al-Jasmi et al., 2002; Blackmore-Prince et al., 2000; Conde-Agudelo et al., 2005).

A large number of studies indicated that tobacco use, alcohol use, and weight during pregnancy are behavioral risk factors related to preterm birth. Studies have demonstrated the associations between smoking and preterm birth; however, this relationship is rather modest and not entirely evident in the results of studies (Cnattingius, 2004; Faber et al., 2017). Literature indicated that high levels of alcohol use during pregnancy increased the risk of preterm birth, and this effect differs at different dose levels and subtypes of preterm birth (Albertsen et al., 2004; Parazzini et al., 2003). Weight during pregnancy is an important risk factors for preterm births. Result from a study in 2929 American woman showed that a low pregnancy body mass index (BMI <19.8) was strongly associated with an increased risk of preterm birth in non- black woman also noted that women with BMIs of less than 20 were nearly four times as likely than heavier women to have a spontaneous preterm birth (OR 3.96; 95% CI 2.61-7.09) (Goldenberg et al., 1998; Moutquin, 2003). The relationship between low pre-pregnancy BMI and spontaneous preterm birth is consistent

(Moutquin, 2003). Another study involving 2910 women in USA demonstrated that obese women had a much lower risk of spontaneous preterm birth (Hendler et al., 2005).

Several studies have identified maternal age as an important social-demographic risk factor for preterm birth. Branum and Schoendorf (2005) also found close to a nearly twofold greater risk of very preterm delivery (less than 33 weeks gestation) among young adolescents (16 years of age or younger) compared with that among young adults (ages 21 to 24 years); the risk decreased with an increase in the age of the adolescent mothers (Branum and Schoendorf, 2005). A meta-analysis of 14 cohort studies found that nulliparous women below 18 years of age had the highest risk of preterm birth across all age/parity categories (OR: 1.52, 95% CI: 1.40-1.66) (Kozuki et al., 2013).

Evidence from studies has showed consistently that experiencing stress and severe life events during pregnancy such as divorce, a death in the family, illness, injury, or the loss of a job are associated with an increased risks of preterm birth (Staneva et al., 2015; Dole et al., 2003; Zhu et al., 2010).

1.1.3. Consequences of preterm births

1.1.3.1. Short and long-term health problems of preterm births

Preterm birth is the leading cause of neonatal deaths, a direct cause of 35% of all neonatal deaths. Although there are different patterns in survival rates across the world. In high-income countries, from about 50% of preterm infants born at 24 weeks survive the neonatal period (the first 28 days of life) compared to 90% born 28 weeks gestation. In contrast, in low-income countries, often less than 10% of those born at 28 weeks survive, and it is only those born at 34 weeks or later that have survival rates of >50% (Blencowe et al., 2013).

Being born too early is associated with short and long-term health problems. There are many short term complications associated with preterm births (Platt, 2014). The most common conditions were seen in the preterm infants are respiratory problems, necrotizing enterocolitis, retinopathy neonatal jaundice, and hypoxicischaemic encephalopathy (Platt, 2014). Premature infants often are at risk of infectious and non-infectious respiratory problems due to an immature respiratory system and it affects from 86% to 95% of preterm infants, depending on the gestational age (Platt, 2014; Patel, 2016)

Extremely preterm infants often have problems such as patent ductus arteriosus (PDA), necrotizing enterocolitis (NEC), retinopathy of prematurity (ROP), and infection

(Patel, 2016). PDA occurred in 32-60% of infants born between 22-28 weeks of gestational age and studies reported associations with a PDA and adverse neonatal outcomes, including intraventricular hemorrhage (IVH), bronchopulmonary dysplasia, and death (Dykes et al., 1980; Schena et al., 2015; Noori et al., 2009). NEC is the most common serious gastrointestinal complication in extremely low birth weight (ELBW). Cause-specific mortality from NEC was high, estimated at 30-40% for ELBW infants (Fitzgibbons et al., 2009). ROP is a leading cause of blindness in extremely preterm infants and is thought to be caused by excessive supplemental oxygen administration (Chen and Smith, 2007). Infection is a serious and potentially lethal complication in preterm infants. Common pathogens included coagulase-negative *Staphylococcus*, *Staphylococcus aureus*, *Escherichia coli* and *Candida albicans* (Stoll et al., 2002).

In the long-term, the most common neurodevelopmental disability associated with preterm birth is cerebral palsy. A systematic review of long-term neurodevelopmental outcomes among preterm survivors reported that the prevalence of cerebral palsy varies by gestational age, with increased risk at lower gestational ages (Milner et al., 2015). Many studies focused on the pulmonary function abnormalities and chronic lung diseases in individuals born prematurely. Preterm birth disrupted these processes and leads to morphologically immature lungs compared with the lungs of term infants (Vollsaeter et al., 2015a; Vollsaeter et al., 2015b). David Barker reported that birth weight was inversely related to adult blood pressure and later showed that lower birth weight was a risk factor for adult cardiovascular diseases, hypertension, and type 2 diabetes (Barker et al., 1989).

Preterm infants are born during the active phase of nephrogenesis, resulting in fewer nephrons. In a study of 40 school-age children with birth weights of less than 1000 grams, the glomerular filtration rate and the magnitude of tubular phosphate transports were significantly diminished due to impaired postnatal nephrogenesis (Rodriguez-Soriano et al., 2005). Preterm birth increases the risk of developing psychiatric disorders later in life, with higher rates of subclinical psychiatric symptoms seen in all gestational age subgroups (Hack, 2009).

Several studies have showed that young adults born preterm have a lower tendency for risk-taking behaviors, such as smoking and drinking than term controls (Cooke, 2004; Saigal, 2014). They are more likely to exhibit social withdrawal, introversion, and neuroticism. Cognitive impairment is also more common among those born preterm. In

the longer term, survivors of preterm birth are 1.3-2.8 times more likely to require special education provision (Platt, 2014).

1.1.3.2. Economic consequence of preterm births

A large body of literature has investigated the economic consequence of preterm births on families as well as the health system during and after the neonatal period (Institute of Medicine Committee on Understanding Premature, 2007).

Many studies in the literature have estimated the costs of hospitalization for preterm infants during the neonatal period. Hospital costs for infants were highest for extremely preterm infants, treatment costs of babies born weighing less than 1000 g were 75% higher than those born weighing 1000-1499 g, and more than four times higher than those born weighing at least 1500g (Russell et al., 2007; Doyle et al., 1989; Petrou, 2003). Gilbert et al estimated neonatal hospital costs for survivors born between 25-38 weeks in hospitals in California, USA reported that the average hospital costs USD 202,700 for babies born at 25 weeks, decreased to 2600 dollars for a 36-week newborn and 1100 dollars for a 38-week newborn (Gilbert et al., 2003).

As for the indirect costs incurred by the family while infants are admitted to the Neonatal Care Unit, McLoughlin et al found that the travel expense of mothers of UK visiting their babies in regional neonatal care unit amounted to £780 (McLoughlin et al., 1993). Another study conducted in families of 224 preterm infants in USA reported that families spent between 2- 4% their income on out- of- pocket expense. The cost incurred during an infant's hospitalization was an average \$ 433, of which transportation was the major expense (Gennaro, 1996).

Other expenditure including lost earnings and accommodation costs incurred by family members during the infant's neonatal stay, have also been reported in the scientific literature. Tommiska et al calculated average mean parental costs before initial discharge of extremely low birth weight (<1000g) to be 2.755 EUR, of which lost of earnings accounted for 30%, and accommodation accounted for 6% (Tommiska et al., 2003).

Studies have also documented the economic costs of preterm birth or low birthweight following the infant' initial discharge from the neonatal unit. A study comparing 32 very low birth weight infants with 34 infants born at term in USA showed that premature and low birth weight infants were significantly likely to use health services during the early years of life than those born at full time (McCormick et al., 1991). Compared to the term

group, the medical costs of very low birth weight children in the first years of life were 24 times higher with an average total of 18.5 physician visits compared with 9.3 in a compared group (Papiernik E1, 1990). After following up a cohort of very low birthweight infants and recorded their use of hospital and family practitioners for 8-9 years, the cohort study found that the low birthweight children used hospital and practitioner services more frequently throughout the follow-up period (Stevenson et al., 1996).

The long-term economic costs of preterm birth and low birthweight infants are not restricted to the health sector. Evidence taken from 8000 school children aged between 6 to 15 years in USA suggests that children who weighed less than 2500g at birth were almost 50% more likely to be enrolled in any type of special education than children who were of normal weight at birth. The incremental cost of special education attributable to low birthweight infants was estimated to be USD 370.8 million per year due to low birthweight (Chaikind and Corman, 1991). Moreover, evidence showed many mothers of low birth weight infants who intended to return to working after the birth either postponed doing so, reduced their hours, or left the workforce altogether to care for their child. This was usually associated with a reduction in family income between 20% to 30% (Gennaro, 1996). Other substantial non-medical expenses incurred by families included travel and childcare costs. These are a consequence of the additional healthcare contacts required during the first year of life also remain substantial (McCormick et al., 1991).

1.1.3.3. Psychological consequences of preterm births

Preterm births are associated with short-and long-term psychological effects for the families of preterm infants. Parents of infants admitted to the Neonatal Unit have been shown to experience higher levels of distress, including increased anxiety, depression, and trauma symptoms, as compared to parents of healthy infants (Younger et al., 1997a; McLean et al., 2000). This was particularly true for the mothers of the preterm infant. The studies demonstrated that the birth and subsequent hospitalization of a very premature infant evoked considerable psychological distress in mothers (Davis et al., 2003; Misund et al., 2014; Trumello et al., 2018). A population-based survey of maternity care in England in 2014 also showed that mothers of preterm babies had less early contact with their baby, more postnatal health problems, substantially fewer positive feelings towards their baby, and made less use of the support options available (Henderson et al., 2016). A longitudinal study following 45 mothers of premature infants in the USA found that approximately half

of the mothers in this study experienced symptoms of depression up to six weeks after bringing their baby home (O'Brien et al., 1999). Depression among mothers of premature infants is particularly challenging because the severity of the situation or the loss that these mothers experience when their pregnancy goes awry can be hard to understand for others, which can lead mothers to feel even more withdrawn and depressed (Golish & Powell, 2003). Furthermore, other studies indicated that parental stress experienced during an infant's admission to the NICU could influence the psychological and behavioral development of the baby (Howe et al., 2014; Dudek-Shriber, 2004).

Such experiences of distress are also thought to be related to an infant's prematurity and the neonatal unit environment. Both physical and emotional isolation from their baby may also be a cause of distress (Gale et al., 2004; J Carter, 2005).

Studies have shown that parental stress associated with preterm birth is associated with exposure to medical devices, experience of several aggressive treatments, changes in parental roles, long-term separations and compatibility with the hospital and environment of Neonatal Unit (Donohue, 2002).

The relationship of parents could also be negatively affected by the stress associated with an premature birth, while the crisis may also serve to bring parents closer together (Golish and Powell, 2003).

In terms of the long-term impact of preterm birth on families and parents, evidence from 196 parents of preterm infants <24 months in the USA suggests that parents of preterm births have a lower emotions scores due to social isolation, unpaid time off from work, financial worry, and unsafe environment (Lakshmanan et al., 2017). Even in the families financed by government, the birth and upbringing of a very low birth weight child has shown to cause long-term stress (Cronin et al., 1995). Family stress can have a negative impact on the child's psychosocial development, thus contributing to negative bidirectional relationships between family and child outcomes (Taylor et al., 2001).

1.1.4. Parental satisfaction with health services for preterm infants

Premature infants have special healthcare needs and demands. From the parent's perspective, the quality of care plays an important role in the development and improvement of health services' performance for premature babies. Patient satisfaction is fulfilled (Ward et al., 2005).

A study conducted with the parents of 206 children hospitalized in two pediatric units and two surgical units in Greece showed that most of the parents were generally more pleased when the level of information was satisfied (Matziou et al., 2011). Parents in the traditional system of NICU of India expressed satisfaction with regard to the emotional support and encouragement received (Sankar et al., 2017a). A cross sectional study conducted in twelve selected government hospitals in Tehran showed that younger age of parents, shorter duration of hospitalization of infants, and experiences from previous hospitalizations were associated with the higher significant level of parents (Salehi. et al., 2015). Another study demonstrated that parental satisfaction was higher among more-educated, older and white mothers but lower among more affluent mothers (McCormick et al., 1991). Basic education level, living in a rural area, short length of stays were associated with the higher levels of parent satisfaction for 550 infants hospitalized in two NICU in Greece (Tsironi et al., 2012). On the contrary, finding from a study at University of Benin Teaching hospital showed that socio-demographic and economic characteristics of parents did not significantly affect parental satisfaction with quality of care (Israel-Aina, 2017).

Results from multivariable linear regression models in a study assessing the family satisfaction in ICUs in Switzerland demonstrated that the more severe of illnesses were associated with higher level of satisfaction (Stricker et al., 2009). Similar results were found in a study conducted in parents of 677 preterm babies who were born between 30 and 34 weeks of gestation in USA. It found that the major predictor of parental satisfaction with neonatal intensive care was treatment outcome as measured by parental rating of the health of the infant at the time of the interview (McCormick et al., 2008). In contrast, in another study conducted in Israel found that there was no relationship between outcome and parents' satisfaction (Auslander et al., 2003).

Likewise, the characteristics of infants such as birth weight were correlated positively with mother's satisfaction in a study assessing the parental satisfaction of parents with moderately premature infants in USA (McCormick et al., 2008). However, in a study of preterm infants in Turkey, the level of satisfactions with health care services was not significantly influenced by the demographic features of the infants like age, gender, diagnosis, gestational age, length of stay and number of admissions (Ylmaz et al., 2016).

Characteristic of health facilities were also associated with the satisfaction levels amongst infant's families. The higher patient- nurse ratio and written admission discharge

policy were associated with the lower satisfaction level of infant's families (Stricker et al., 2009). Findings of a study in Iran showed that satisfaction levels were varied between hospitals in different regions with different quantity services provided (Salehi. et al., 2015).

1.1.5. Health system of Vietnam

Vietnam is located in Southeast Asia and has population of 97.7 million people, of which approximately 35.92% live in urban areas (danso, 2019). In 1986, the Vietnamese Government initiated a program of economic and social reform known as 'Doi Moi' (Hà Anh Đức, 2011). Since then, the country has been moving from a centrally planned economy to being market orientated. Over the past three decades, Vietnam has made considerable progress in improving economic and social well-being and has become a lower middle-income country. GDP growth accelerated to 7.1 percent in 2018 and health spending per capita in 2016 reached USD122.84 (Worldbank, 2019).

Vietnam's health system is divided into four levels: national, provincial, district, and communal level. According to 2015 statistic data, there are 21 health facilities in the central level, including the Ministry of Health, 63 provincial departments of health, 708 district departments and 11.162 commune health centers (CHCs). The Ministry of Health of Vietnam (MOH) is responsible for the care and protection of people's health including issuing laws and other legal documents for the health care, as well as making long-term plans and strategies for the implementation of the health sector. Provincial, district and communal health facilities are under the management of the MOH and responsible for the implementation and development of health care services. The diagram below describes the health system of Vietnam.

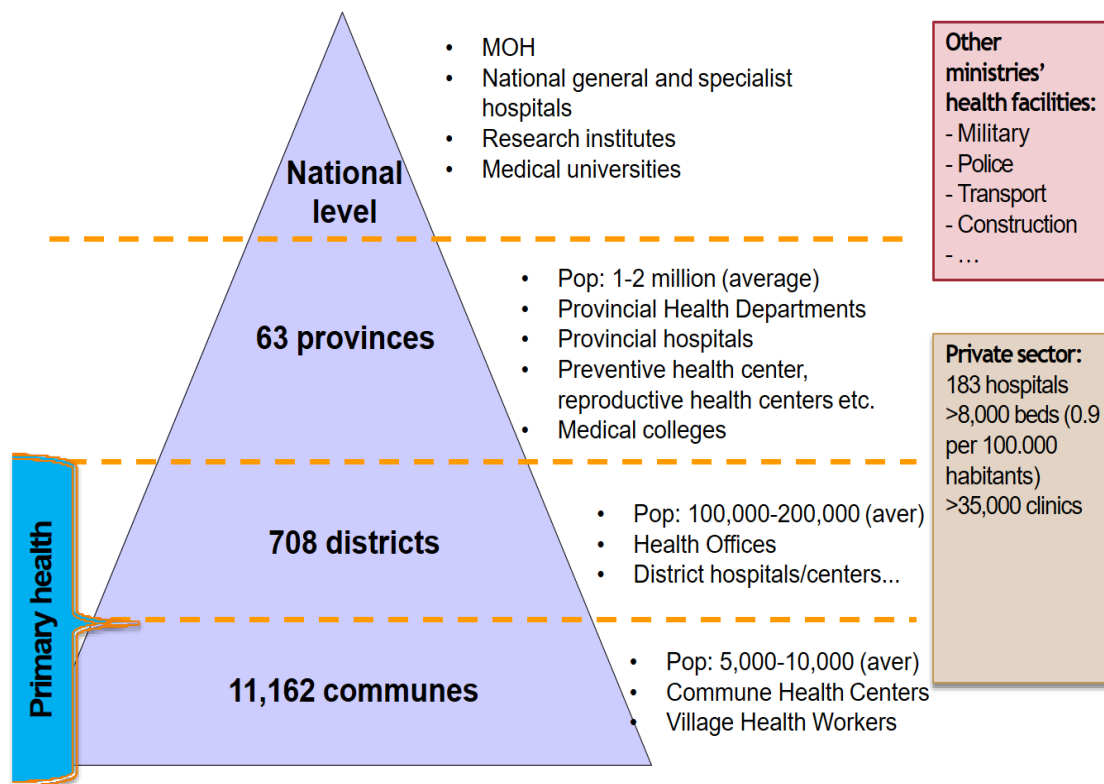


Figure 1.1: Healthcare system in Vietnam

Source: Vietnam health system and health infrastructure: achievements, challenges and orientation (Tuan, 2015)

National facilities include national general and specialized hospitals, national research institutes, training institutions, pharmaceutical companies. These facilities are mostly located in large cities and are subordinate to the MOH.

Provincial facilities include municipal and provincial hospitals. These include general hospitals and specialized hospitals such as pediatric hospitals, obstetrics and gynecology hospitals, hospitals of ophthalmology, and other specialized health centers such as preventive medicine centers and mother and child's health protection centers.

District facilities include district general hospitals responsible for curative services and preventive medicine defined in the national preventive program guidelines. Some rural areas have one or more polyclinics that operate under the guidance of the district hospital. These clinics mainly provide basic curative care for people living in communes of the districts.

Communal facilities mostly include Commune Health Centers (CHC) that are responsible for primary curative and preventive care as well as implementation of national health programs, including maternal and child healthcare programs. Within CHCs, village health workers provide health information, education, and communication. They also provide first aid and care for common diseases, implement family planning, and other national health programs.

The health financing system of Vietnam relies on multiple financing sources including state budget, health insurance premiums, households' out-of-pocket payments, aid and other sources. The level of expenditure on health in Vietnam continues to rise. According to data from the National Health Accounts, the total expenditure on health was 6.5% of GDP in Vietnam in 2016 (WHO, 2018a). Per capita health expenditure is higher than that of other Southeast Asian countries. Expenditure on health per capita in Vietnam in 2012 was VND 2,184,000, approximately USD 300, higher than some other countries in the Southeast Asia (USD 79), as well as compared to countries with a low average income (USD 86). The out-of-pocket payments for health care are still at a high level. The percentage of out-of-pocket payments of households for health care in 2012 was 48.8%. The aid accounted for 1.5%, and the remaining 7.1% from other sources (Tien et al., 2011).

1.1.6. Health insurance and health insurance for children under 6 years old in Vietnam

Social health insurance in Viet Nam was established in 1992 and in 2009, Law on Health Insurance (No. 25/2008/QH12) as promulgated by Order No. 23/2008/L-CTN of November 28, 2008. With the purpose of reaching more people, Law on Health Insurance was amended in 2014 to be mandated health insurance for all citizens (Hoang et al., 2018).

The government uses its tax revenues to subsidize vulnerable groups such as the poor, the ethnic minority, children under 6, and the elderly above 80. The current health insurance coverage is about 87% of the population (2018) (WHO, 2018a). The diagram below summarizes the contributions of health insurance in Vietnam.

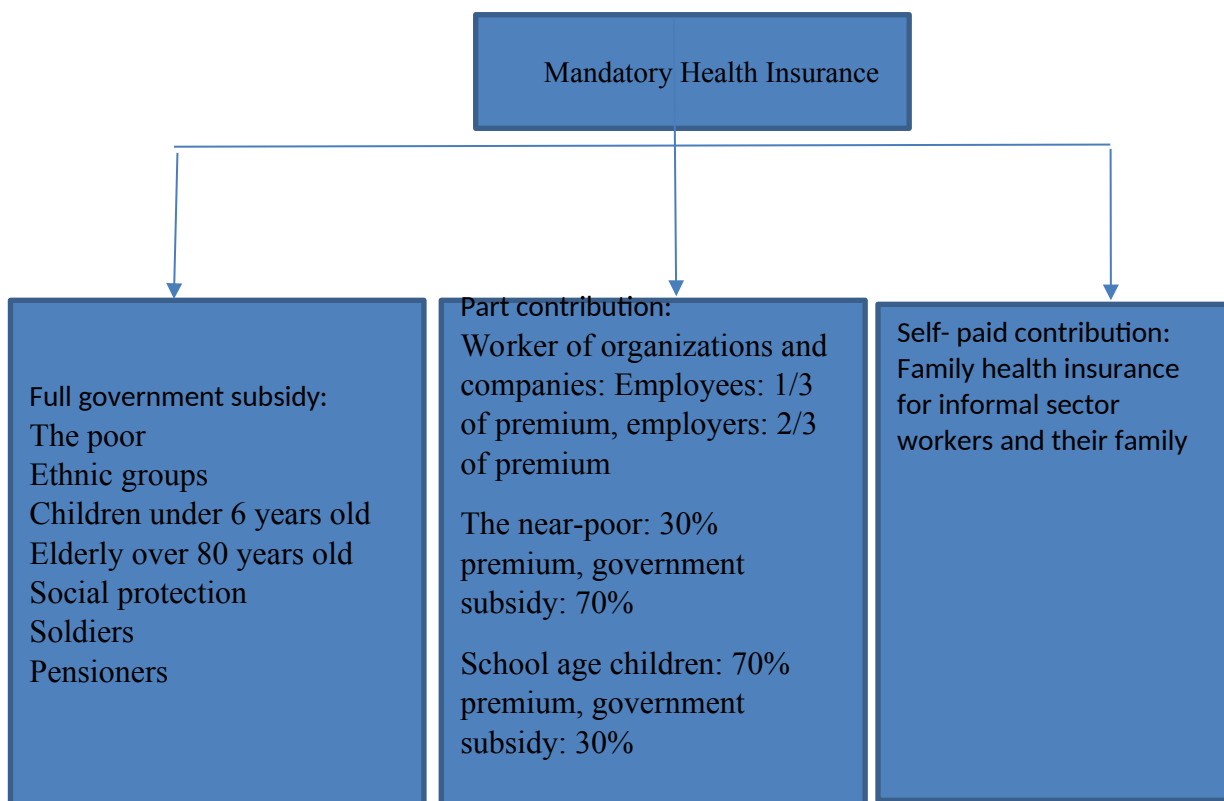


Figure 1.2: Overview of health insurance scheme in Vietnam

Source: Author, based on Health Insurance Law, 2014 (Ministry of Justice, 2014)

In 2005, the government of Vietnam introduced the Free Care for Children Under Six (FCCU6) policy with a mission to provide sufficient health care services. All children under the age of 6 can get free services at public health facilities through this health insurance program. All Vietnamese children being younger than 6 years with a registered health insurance card can freely access almost all medical tests and treatments as well as common medications for both inpatient and outpatient services at public health facilities. The FCCU6 policy has been considered as a critical intervention for ensuring equitable access to health care services among Vietnamese children (Tien et al., 2011). If the local facility, where the child registered in health insurance card does not have adequate expertise and equipment to treat the disease or in the case of an emergency, the child can be formally referred to a higher-level public facility and still receive 100% coverage. If he or she was transferred without a written formal referral of the local health facility, the his

or her treatment costs would be covered up to a different amount by health insurance and depending on the level of the health facility where the child seeks care (MOH, 2008).

A study using the difference-in-differences (DD) method to estimate the effect of child health insurance on health care utilization found that child health insurance tends to increase utilizations for both inpatient and outpatient services in the provincial public health facilities (Nguyen and Wang, 2013). Another study using three waves of Vietnam household living standard survey (VHLSS) taken over three years (2006, 2008 and 2010) to estimate the impacts of child health insurance found that child health insurance plays a very important role in promoting utilization outcomes for both inpatient and outpatient services measured by the probability and the number of visits. However, the studies above only investigated the impacts on children's health care utilizations and neglected to address other effects which may likely arise from the child's health insurance status. Thang Dang (2017) investigated that child health insurance increases the probability and frequency of public inpatient visits and private outpatient visits. In contrast, child health insurance reduces the probability of mothers seeking inpatient or outpatient care (Thang, 2017).

1.1.7. Studies about preterm births in Vietnam.

In Vietnam, the neonatal mortality rate (NMR) was 11 deaths per 1,000 live births in 2015, while the NMR in rural areas is 13 deaths per 1,000 live births and 9 deaths per 1,000 live births. The rate of preterm birth rate was 7 per 1000 live births (2017) and the complications of premature births being the leading cause of neonatal deaths in 2015 (40.5 percent) (UNICEF, 2018)

Maternal and neonatal health has been given a high priority by the Vietnamese MOH. However, preterm births have not received adequate attention as evidences about the impact of preterm birth on families and society is still unavailable. To the best of our knowledge, studies on this topic in Vietnam mainly focused on the risk factors associated with of preterm birth and have not studied about the burden of preterm births on health system and families.

A prospective cohort study conducted in 2002 studying the risk factors associated with preterm in women with singleton live births at Hanoi Obstetrics showed that physically demanding work during pregnancy, two or more prior spontaneous abortions, a history of preterm birth, vaginal bleeding, inadequate prenatal care during the first 20 weeks of gestation, and a history of intrauterine device use with removal less than 12 months before

the current pregnancy were associated with increased risk of preterm birth (Nguyen N, 2004). Study conducted among pregnant women of less than 24 weeks of gestation in Dong Anh also found that antenatal depressive symptoms associated with an increased risk of preterm births (AOR=2.4, 95%CI: 1.1-5.2) (Van Ngo et al., 2018). This cohort study also found that exposure to physical violence during pregnancy was associated with preterm birth or low birthweight and after adjustment for characteristic of the pregnant women, who were exposed to physical violence during pregnancy were five times more likely to have preterm birth PTB (AOR = 5.5; 95%CI: 2.1–14.1) and were nearly six times more likely to give birth to a child of low birth weight (AOR = 5.7; 95%CI: 2.2–14.9) as compared to those who were not exposed to physical violence (Hoang et al., 2016). A study conducted in the largest city of central Vietnam, Da Nang, identified the preterm births accounted for nearly 5% of live births and risk factors for preterm births were age 35 plus, farmer and history of abortion (Giang et al., 2019).

1.2. Objectives of the study.

This study aimed to comprehensively assess the direct medical cost of preterm infants and investigated the experiences of parents as well as their satisfaction with the healthcare services provided.

This study has three objectives as following:

1. To assess the direct medical cost of preterm births in Neonatal Care Units.
2. To investigate the experience of parents of preterm infants in Neonatal Care Units.
3. To assess the satisfaction of parents with the care in Neonatal Care Units.

1.3. Methods

Each objective of this study has an own study design, participants and data resources. Methods for each objectives is described in the Chapter 2, 3, 4.

1.3.1. Setting

Since most of preterm children with severe complications are treated in the national and provincial hospitals, the district hospitals and community health centers do not have not adequate expertise and equipment to treat for these preterm cases. Therefore, this study is based on data from two hospitals: Vietnam National Children's Hospital and Thanh Hoa Pediatrics Hospital. Vietnam National Children's Hospital is a national hospital, located in Hanoi capital. It has 1300 beds and 13 clinical departments, and is responsible for the treatment of children from 38 provinces from the North of Vietnam. It is the largest

paediatric hospital in Northern Vietnam and has 2000-3000 children visit the hospital per day. Among them, about 150 children per day get admitted to the hospital as in-patients. The Neonatal Care Unit of hospital is responsible for the treatment of premature children and other diseases of new-born babies. The unit is a centre of research for new born disease, teaching and training students of specialized postgraduate (Vietnam National Children`s Hospital, 2015).

Thanh Hoa Provincial Paediatrics Hospital, the only public hospital of paediatrics in Thanh Hoa province, has 800 beds and 17 clinical departments. The hospital is responsible of treatment for all children in the province (Thanh Hoa, 2018). Thanh Hoa province is located in the middle of North Central Coast of Vietnam, ranking as third in population among 63 provinces, and is home of many ethnic groups such as the Kinh, Mường, Thái, H'Mông, Dao, Thổ, Khơ-mú. The province has flat, mountainous and seaside areas, and the whole range of economic sectors such as agriculture, forestry, fishery, tourism. It is also an industrial centre of the country (Thanh Hoa Pediatric Hospital, 2015).

1.3.2. Ethical considerations

All the answers and information of the participants were kept confidential and only used for the study purpose. The study was approved by the ethical committee of Vietnam National Children`s Hospital (Approval Number: 166/BVNTW-VNCSKTE) (Appendix 4)

The study was conducted in Vietnam; therefore, did not need an approval by the Ethics Committee of Northwest and Central Switzerland (EKNZ) but the committee confirmed that the research project fulfilled the general ethical and scientific standards for research with humans and opposes no health hazards.

1.4. Description of thesis chapters

This chapter has provided background information of preterm births, described objective, setting and ethical considerations of research. The rest of the thesis is presented as follows:

Chapter 2 is the first paper assessing private and public costs associated with preterm births in Vietnam.

Chapter 3 is second paper describing the parents` experiences with hospital referrals of preterm babies in Vietnam

Chapter 4 is the third paper assessing the parental satisfaction with quality of neonatal care in different ranking facilities

Chapter 5 provides a synthesis of the key findings from the thesis and states how these significant findings contribute

Chapter 6 provides the recommendations and conclusions of this thesis.

Chapter 2: Medical and out of pocket expenditure for preterm infants: Evidence from Vietnam

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2.1. Abstract

Background: The large health costs associated with preterm births have been well documented in high income countries. Relatively little data on this issue is currently available from developing countries. The aim of this study was to assess private and public costs associated with preterm births in Vietnam.

Methods: This cross-sectional study used medical and financial data from one provincial and one national hospital in Vietnam. Cost data for all infants discharged from the two hospitals in 2017 was collected and analyzed.

Results: Average total medical cost per child was USD 1643.52 in the national hospital and USD 668.94 in the provincial hospital. Mean medical out-of-pocket expenditure was USD 60 at the national hospital. No medical out-of-pocket expenditure was reported at the provincial hospital when parents complied with national health insurance policies. Substantial out-of-pocket expenditure was incurred by those who bypassed lower-level facilities. Parents seeking care at specialized hospitals without medical authorization paid on average an additional USD 240, which equates to 111% of the average monthly wage in Vietnam.

Conclusions: This study suggests that the average medical costs of preterm infants in Vietnam are substantial. The average co-payment for families who complied with national health insurance policy was USD 39. The average out-of-pocket costs of preterm infants who bypassed lower-level facilities without referral authorization were about six times higher than those of infants who had a proper transfer.

Keywords: Vietnam, preterm infants, medical costs, out-of-pocket expenditure

2.2. Introduction

According to World Health Organization, 15 million infants are born prematurely worldwide every year (WHO, 2018b). Preterm birth, which is defined as childbirth occurring at less than 37 completed weeks of gestation, is a leading cause of death in children under 5 years in low and middle income countries, and a major determinant of neonatal mortality and morbidity globally (WHO, 2018b). Children born prematurely have higher rates of cerebral palsy, sensory deficits, learning disabilities and respiratory illnesses compared with children born at term. The morbidities associated with preterm birth often extend to later life, resulting in considerable physical, psychological, economic

and social costs (WHO, 2018b). There is a large literature dedicated to understanding the health costs associated with preterm births in high income settings. A systematic review of US data suggested an average cost of USD 203k for preterm infants born at 25 weeks of gestation, and costs between USD 70k and 100k for gestational ages <28 weeks (Institute of Medicine (US) Committee on Understanding Premature Birth and Assuring Healthy Outcomes Behrman RE, 2007). Evidence from the UK suggests that compared to the full-term group, extreme preterm infants generated an additional societal cost of GBP 5658 over a 12-month follow-up period (Petrou et al., 2006). Health service costs for preterm infants generally decrease with gestational age and birth weight, but this also depend on length of stay at health facilities as well as on the number of surgical procedures and respiratory treatments received by the infant (Clements et al., 2007; Petrou, 2003; Soilly et al., 2014; Ringborg et al., 2006).

Only few studies relating to preterm births have been published on Vietnam. A prospective cohort study of 1709 women identified physically demanding work during pregnancy as well as intrauterine device removal less than 12 months before the current pregnancy as primary risk factors for a preterm birth (Nguyen N, 2004). A cross-sectional study from Dong Anh District in 2014-2015 also found that with antenatal depression, employment in the agricultural sector and domestic violence were associated with an increased risk of preterm birth (Van Ngo et al., 2018).

From a health system perspective, Vietnam is an interesting setting to study the cost of preterm births. Even though all clinical expenditure incurred by preterm infants should be covered by the national health insurance in principle, this is not always the case in practice for two reasons: Firstly, health insurance will only cover 100% of the clinical cost at higher-level facilities – where most premature babies are treated – if the child is referred to these tertiary hospitals by lower-level facility staff. Given that the perceived quality of care is higher at tertiary hospitals, bypassing lower level facilities is relatively common, and may result in substantial out-of-pocket expenditure if tertiary care is not approved by the physicians in charge. Secondly, out-of-pocket payments may also arise when hospitals (specifically specialized hospitals) administer drugs or provide services which are not covered by the national health insurance. To assess the total cost of preterm infant treatment, as well as the financial contribution made by families, we worked together with

both a provincial and a national Hospital in Vietnam in 2017, and extracted all medical and financial records for preterm infants treated in this period.

2.3. Method

2.3.1. Study design

This is a retrospective study that used secondary medical and financial data extracted from Vietnam National Children's Hospital and Thanh Hoa Provincial Pediatric Hospital.

2.3.2. Study setting

All data analyzed in this study were collected from two large hospitals in Vietnam. Despite major efforts to reduce neonatal mortality, in 2015, 12 per 1000 live births died during the neonatal period in Vietnam (UNICEF, 2018). Preterm birth complication have remained a leading cause of neonatal deaths (41%, 2015); with 9% of all infants born before 37 weeks of gestation (Heathy Newborn Network, 2018).

Two hospitals were purposively sampled for this study: Vietnam National Children's Hospital (VNCH) and Thanh Hoa Pediatric Hospital. Thanh Hoa Pediatric Hospital is a provincial hospital (second level) and the only public pediatric hospital in Thanh Hoa Province. As such, it is responsible for the treatment of all children with severe health problems in the province. The province comprises 24 districts, 1 town, 2 cities, and a total population of 3.5 million inhabitants (Thanh Hoa, 2018). The area is environmentally heterogeneous including lowlands, mountains, and seaside areas. It also has a whole range of economic sectors such as agriculture, forestry, fishery, tourism, and an industrial center (Thanh Hoa, 2018).

Vietnam National Children's Hospital is a national hospital (the first level) located in Hanoi City. It is a primary referral hospital for all 38 provinces of northern Vietnam, as well as a center for research, teaching, and postgraduate training in newborn diseases. As the largest pediatric hospital in northern Vietnam, the Neonatal Care Unit of the hospital is responsible for the treatment and care of all premature infants and newborns referred from lower-level facilities for specialized care. This covers a total population of 43.2 million people.

2.3.3. Participants

A preterm child in this study was defined as an infant born alive before 37 weeks of gestation. We defined our target population as all infants discharged from the two hospitals between 1 January and 31 December 2017.

2.3.4. Sample size and sampling method

The records for all preterm infants (n=261) discharged from the Neonatal Care Unit of Thanh Hoa Pediatric Hospital in 2017 were selected. Due to the large number of cases, a random sample of infants (n=500) was selected from all those discharged from the Neonatal Care Unit at the National Children's Hospital (n=800) during 2017. This n=500 target was chosen in order to be able to detect a mean difference in total cost between the two hospitals of at least 25% of the standard deviation of individual total costs with 90% power.

2.3.5. Variables

Outcome variables: The primary outcome variable was the total numerical medical cost. All cost data were extracted from the hospital records and converted to USD using an exchange rate of 1 USD=23.245 Vietnamese Dong (VND) (2018).

Total direct medical costs were defined as the total amount invoiced by a hospital after the child was discharged from the hospital. The total direct medical cost was then divided into cost paid by national health insurance and the out-of-pocket cost paid by parents.

Covariates: Social-demographic and clinical characteristics of premature infants were extracted from the hospital records. These included: gender (male, female), ethnicity (Kinh, others), place of residence (urban, rural), length of stay (<14 days, 15-29 days, >30 days), weight at birth (>2500g, 2499-1500g, 1499-1000g, <1000g), gestational age (32-37 weeks, 28-31 weeks, <28 weeks), place of referral (health facility, home), transfer type (proper transfer, improper transfer), and referral type (from home to Thanh Hoa Pediatric Hospital, from health facility to Thanh Hoa Pediatric Hospital, from home to Vietnam National Children's Hospital, and from health facility to Vietnam National Children's Hospital).

2.3.6. Statistical analysis

Firstly, detailed statistics on total direct medical cost as well as costs per service category were generated. Secondly, we estimated the relative cost of being referred to a national rather than a provincial hospital for treatment using a series of linear regression models. We first quantified the average cost differences between the provincial and the national hospital including and excluding child characteristics. The main independent variable of interest was a dichotomous variable for the child being treated at the national hospital, using the provincial hospital as a reference. In the adjusted model, we included

the following covariates to account for potential differences in medical need: gender, ethnicity, place of residence, weight, and length of stay.

Thirdly, we further divided the sample into four types of basic health system trajectories: 1. Infants' families seeking care directly (without prior referral from level III or IV) at Thanh Hoa Pediatric Hospital; 2. Infants referred from a local health facility to Thanh Hoa Pediatric Hospital; 3. Infants' families seeking care directly at Vietnam National Children's Hospital; and 4. Infants referred from lower-level health facilities to Vietnam National Children's Hospital. Following this, we first estimate unadjusted associations with cost (mean cost differences), and then estimated how large the cost differences were adjusting on observable child characteristics. We used robust variance estimates to adjust for heteroskedasticity of residuals in the linear regression models.

Given that appropriate referrals are critical for reimbursement of out-of-pocket payments by the insurance, we also looked directly at the relationship between transfer type and out-of-pocket expenditure in different referral groups. A transfer was considered as a proper transfer to a higher-level hospital if the child had referral documents from a local registered facility or was admitted to the hospital as an emergency case.

All analyses were performed using the STATA statistical software package (Release 14; College Station, TX: StataCorp LP).

2.4. Results.

After the data were cleaned, the final sample included 482 infants from the national hospital and 261 records from the provincial hospital. 18 records from the national hospital were excluded from this study due to a lack of necessary information in their medical records. Figures 2. 1 and 2. 2 illustrate the spatial distribution of the 743 preterm infants in our sample. Figure 2.1 shows the number of premature infants admitted to Vietnam National Children's Hospital by province. Infants were received from all provinces in the area and 23 infants were from Thanh Hoa province. The largest number was from Hanoi City (120 infants), followed by Nam Dinh Province (35 infants) and Bac Giang Province (27 infants). Figure 2.2. shows the number of premature births by district/town in Thanh Hoa Province. The largest number of premature infants came from Thanh Hoa City (37 infants), followed by Tinh Gia District (18 infants) and Tho Xuan District (18 infants)

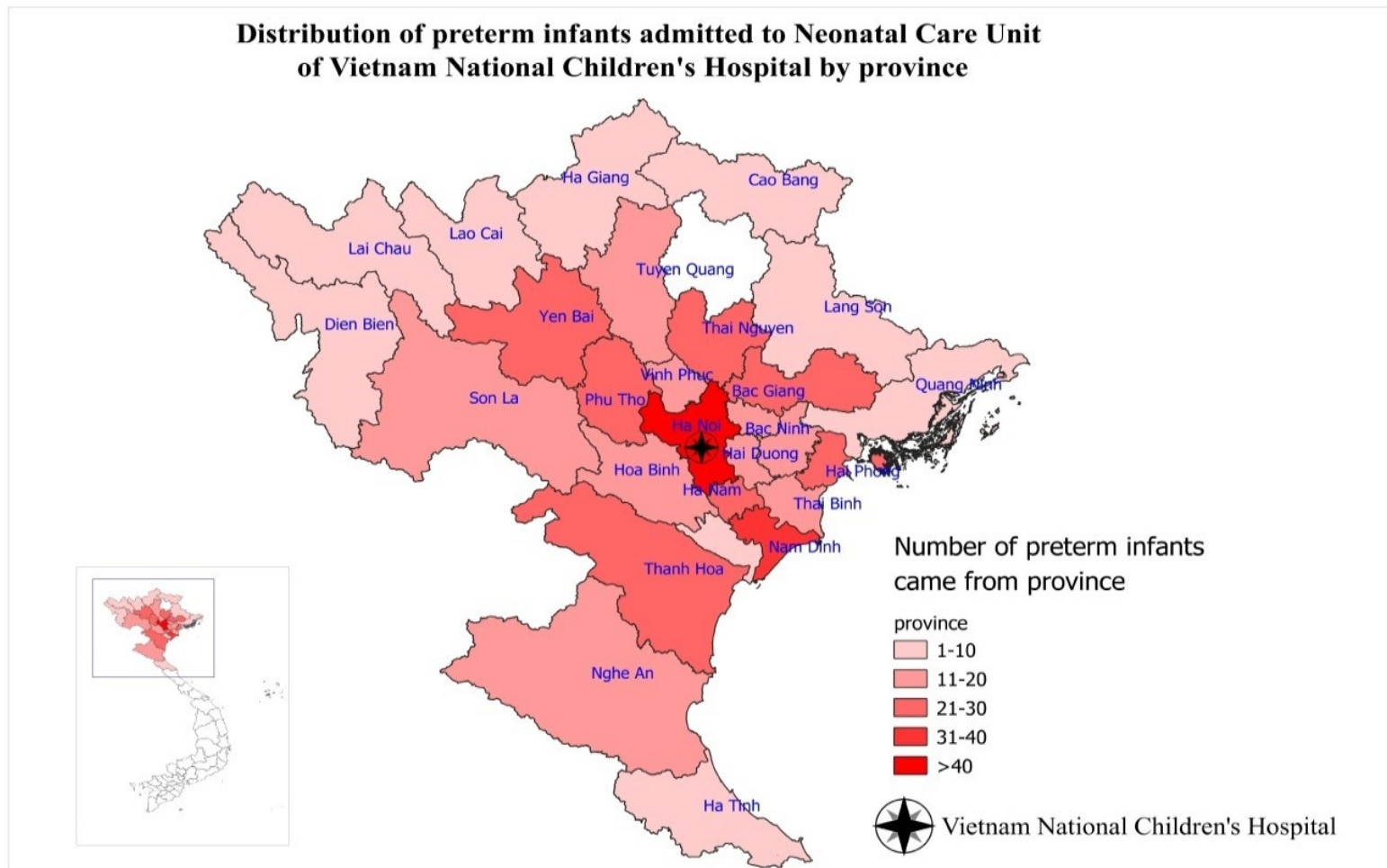


Figure 2.1: Distribution of preterm infants admitted to Neonatal Care Unit of Vietnam National Children's Hospital by province (n=482)

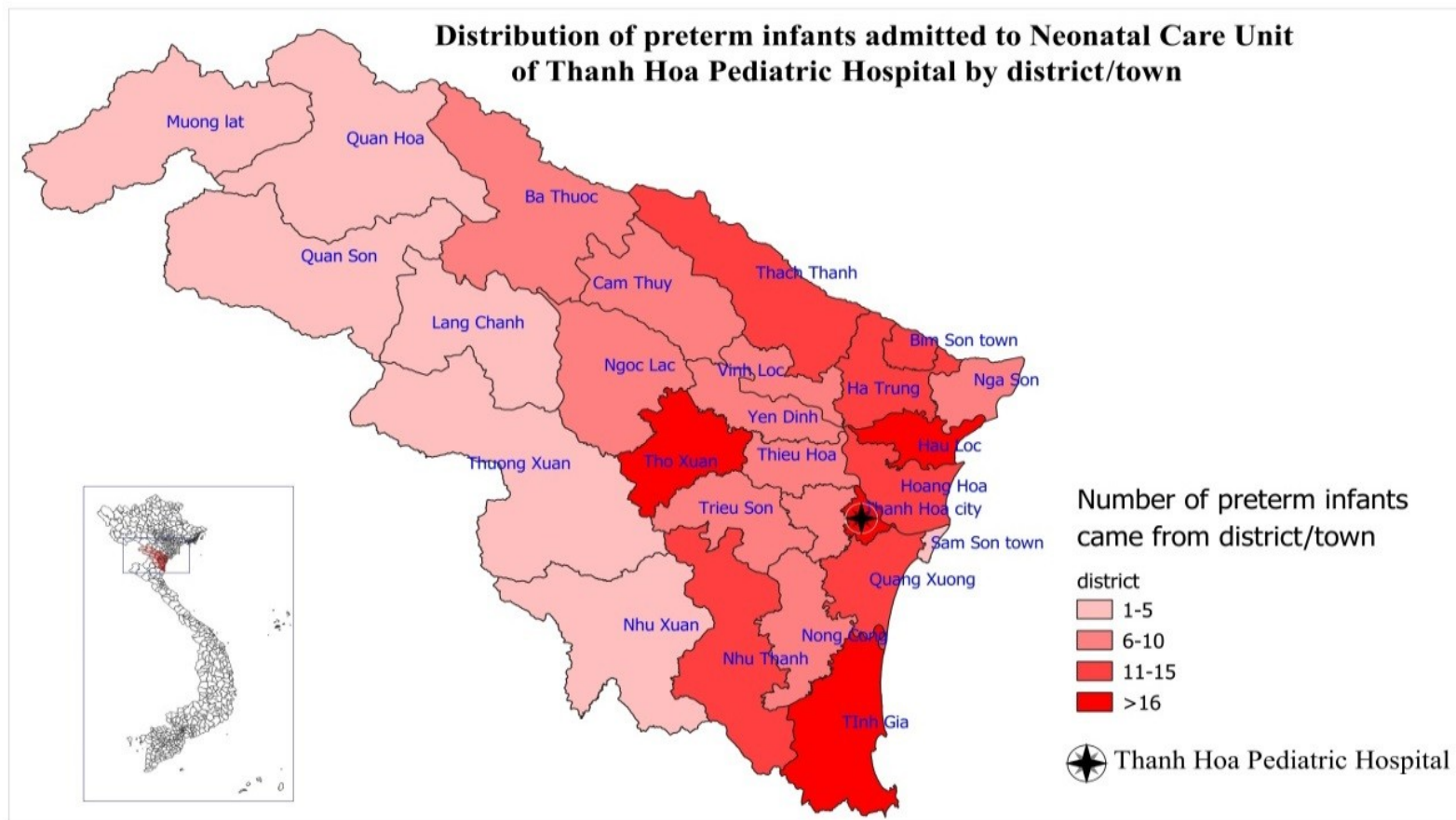


Figure 2.2: Distribution of preterm infants admitted to Neonatal Care Unit of Thanh Hoa Pediatric Hospital by district/ town (n=261)

Table 2. 1 summarizes the main characteristics of study participants. 53.3% of preterm infants were male in the Thanh Hoa Pediatric Hospital and 67% in Vietnam National Children's hospital. Most children belonged to the Kinh ethnic group and resided in urban areas. Gestational age at birth were relatively similar in the two hospitals with about 55% of preterm infants born between week 32 and week 37, and less than 10% of infants were born prior to 28 weeks of gestation. No infant deaths were reported in the Thanh Hoa Pediatric Hospital; 9.8% of infants died in Vietnam National Children's Hospital. With regard to the length of stay in both hospitals, the majority of preterm infants were admitted for less than 14 days of treatment (75.5% in Thanh Hoa Pediatric Hospital and 46.7% in Vietnam National Children's Hospital). Most mothers were in the 20-34 year-old age group (81.6% in Thanh Hoa Pediatric Hospital and 82.8% in Vietnam National Children's Hospital).

Table 2.1: Social-demographic and clinical characteristics of study participants

Characteristics	Total	Thanh Hoa Pediatric Hospital n=261		National Children's Hospital n=482	
		n	%	n	%
Gender					
Male	462	139	53.3	323	67
Female	281	122	46.7	159	33
Ethnicity					
Kinh	674	230	88.1	444	92.1
Others	69	31	11.9	38	7.9
Place of residence					
Urban	163	40	15.3	123	25.5
Rural	580	221	84.7	359	74.5
Gestational age					
32-37 weeks	410	147	56.3	263	54.6
28-31 weeks	272	90	34.5	182	37.8
<28 weeks	61	24	9.2	37	7.6
Weight at birth					
>=2500g	61	12	4.6	49	10.2
2499-1500g	422	166	63.6	256	53.1
1000-1499g	202	63	24.1	139	28.8
<1000g	58	20	7.7	38	7.9
Death					
No	696	261	100	435	90.2
Yes	47	0	0	47	9.8

Length of stay					
<14 days	422	197	75.5	225	46.7
15-29 days	193	52	19.9	141	29.2
>30 days	128	12	4.6	116	24.1
Referral type					
From home to Thanh Hoa Pediatric Hospital	45	45	17.2	0	0
From health facility to Thanh Hoa Pediatric Hospital	216	216	82.8	0	0
From home to National Children's Hospital	42	0	0	42	8.7
From health facility to National Children's Hospital	440	0	0	440	91.3
Place of referral					
Health facility	656	216	82.8	440	91.3
Home	87	45	17.2	42	8.7
Transfer type					
Proper	732	261	100	471	97.7
Improper	11	0	0	11	2.3
Mother's age					
<20 years old	53	25	9.6	28	5.8
20-34 years old	612	213	81.6	399	82.8
>35 years old	78	23	8.8	55	11.4

Table 2.2 shows mean values and the proportions for the main cost categories of the two hospitals. Average medical cost was about two and half times higher in the national than in the regional hospital. In the national hospital, bed-days accounted for the largest share of the total cost while in provincial hospital the largest expense was the cost of drugs. The largest relative difference in cost was observed for medical supplies, which were almost 9 times more costly in the national than in the regional hospital.

Table 2.2: Type of medical direct costs in two hospitals (USD, 2018)

Type of costs	Thanh Hoa Pediatric Hospital. n=261, mean (%)	Vietnam National Children's Hospital. n=482, mean (%)
Total cost	668.9	1643.5
Cost of bed-days	159.1 (23.8%)	515.1 (31.4%)
Cost of laboratory tests	94.1 (14.1%)	201.1 (12.2%)
Cost of surgery	119.4 (17.9%)	403.9 (24.6%)
Cost of medical supplies	18.9 (2.8%)	158.4 (9.6%)
Cost of drugs	249.9 (37.3%)	328.4 (20%)
Other costs	27.59 (4.1%)	36.64 (2.2%)

Table 2.3 shows a first set of regression results for total and out-of-pocket costs. As already seen in Table 2, average total cost per child was substantially higher at the national hospital. Compared to the provincial hospital, the average additional cost per child at the national hospital was USD 974.6 (95% CI: USD 810.8, USD 1139; $P < 0.001$). After controlling for the child covariates displayed in Table 1, the estimated difference declined to USD 471.1 (95% CI: USD 322.1, USD 620.1; $P < 0.001$). The primary cost-factor differing between the two hospitals was the average duration of stay (as already visible in Table 1), which accounted for about 50% of the drop between unadjusted and adjusted differences.

Table 2.3: Social-demographic and clinical characteristics predicting medical direct cost (USD, 2018)

Characteristics	Total cost				Out-of-pocket cost			
	Unadjusted Regression Coefficient (95% CI) (1)	P	Adjusted Regression Coefficient (95% CI) (2)	P	Unadjusted Regression Coefficient (95% CI) (3)	P	Adjusted Regression Coefficient (95% CI) (4)	P
Hospital								
Thanh Hoa Pediatric Hospital	(ref)		(ref)		(ref)		ref)	
Vietnam National Children's Hospital	974.6 (810.8- 1139)	<0.001	471.1 (322.1; 620.1)	<0.001	64.6 (57.9; 71.4)	<0.001	48.8 (41.8; 55.7)	<0.001
Gender								
Male			(ref)				(ref)	
Female			-66.7 (-231.8; 98.4)	0.428			-1.8 (-9.1; 5.5)	0.634
Ethnicity								
Kinh			(ref)				(ref)	
Others			53.4 (-202.9; 309.8)	0.683			-12.9 (-21; -4.9)	0.002*
Place of residence								
Urban			(ref)				(ref)	
Rural			165 (-20.2; 350.1)	0.081			13.3 (3.8; 22.8)	0.006*
Length of stay								
<14 days			(ref)				(ref)	
15-29 days			737.9	<0.001			9.4	0.025*

>30 days	(566.7; 909.1) 2323 (1982.8; 2663.2)	<0.001	(1.2; 17.6) 82.7 (66; 99.3)	<0.00 1
Weight				
>2500g	(ref)		(ref)	
1500-2499g	102.1 (-131.6; 335.9)	0.391	5.28 (-14.8; 25.4)	0.607
1000-1499g	32.7 (-241.1; 306.6)	0.815	0.5 (-20.8; 21.9)	0.960
<1000g	599.89 (224; 975.7)	0.002	22 (-3.3; 47.3)	0.089

Ref: Reference group

***: P<0.05**

Columns 3 and 4 show differences for out-of-pocket expenditures. Rather remarkably, no (zero) out-of-pocket expenditure was reported for the provincial hospital. Therefore, the estimated unadjusted difference of USD 64.6 (95% CI: USD 57.9, 71.4, $P < 0.001$) directly corresponds to the average out-of-pocket expenditure for the national hospital. When we adjusted for child differences, this difference lowered to USD 48.8 (95% CI: USD 41.8, USD 55.7; $P < 0.001$). Ethnicity, remoteness and length of stay had a significant impact on out-of-pocket costs. The Kinh ethnic group was also associated with an average out-of-pocket expenditure increase of USD 12.9 (95% CI: 21, 4.9; $P < 0.05$). Residing in a rural area was associated with an increase of USD 13.3 (95% CI: 3.8, 22.8; $P < 0.05$) compared to urban areas. Stays of more than 30 days were on average associated with an out-of-pocket expenditure increase of USD 82.7 (95% CI: 66, 99.3; $P < 0.05$) compared to stays of less than 14 days.

Regarding point of referral, 47 infants came from home and 214 babies were transferred from a health facility to Thanh Hoa Pediatric Hospital. Of the referred to the national hospital, 43 infants came directly from home, and 439 infants were transferred from other facilities. Table 2. 4 shows regression results for total costs and out-of-pocket costs by referral group.

Column 2 of Table 2. 4 shows that the average total cost per infant transferred from a health facility to Thanh Hoa Pediatric Hospital was USD 262.5 (95%CI: 0.8, 524.1; $P < 0.05$) higher than those infants coming from home to Thanh Hoa Pediatric Hospital. The average total cost per infant seeking care directly from home to Vietnam National Children's Hospital, and those transferred from health facilities increased by USD 561 (95%CI: 61, 1061; $p < 0.005$) and USD 1252 (95% CI: 971.7, 1532.4; $P < 0.001$) respectively, compared to those coming from home to Thanh Hoa Pediatric Hospital.

Table 2. 4: Transfer groups predicting medical direct cost (USD, 2018)

Characteristics	Total cost				Out-of-pocket cost			
	Unadjusted Regression Coefficient (95% CI) (1)	P	Adjusted Regression Coefficient (95% CI) (2)	P	Unadjusted Regression Coefficient (95% CI) (3)	P	Adjusted Regression Coefficient (95% CI) (4)	P
Transfer groups								
From home to Thanh Hoa Pediatric Hospital	(Ref)		(Ref)		(Ref)		(Ref)	
From health facility to Thanh Hoa Pediatric Hospital	262.5 (0.8; 524.1)	0.045	198.4 (6.6; 390.3)	0.043	0		1.3 (-6.1; 8.7)	0.737
From home to National Children’s Hospital	561 (61; 1061)	0.033	376 (36.1; 716)	0.03	75.6 (42.1; 109.1)	<0.001	75.1 (41.5; 108.7)	<0.001
From health facility to National Children’s Hospital	1252 (971.6; 1532.4)	<0.001	662 (455.1; 868.8)	<0.001	63.6 (56.8; 70.4)	<0.001	47.2 (37.8; 56.6)	<0.001
Gender								
Male			(Ref)				(Ref)	
Female			-75.4 (-239.7; 88.9)	0.368			-1.2 (-8.5; 6)	0.736
Ethnicity								

Kinh	(Ref)		(Ref)	
Others	35.2 (-221.3; 291.8)	0.788	-11.9 (-19.8; -4)	0.003*
Place of residence				
Urban	(Ref)		(Ref)	
Rural	140 (-47.9; 328)	0.144	15.9 (5.7; 26.1)	0.002*
Length of stay				
<14 days	(Ref)		(Ref)	
15-29 days	719.8 (547.8; 891.7)	<0.001	10.4 (2.3; 18.4)	0.012*
>30 days	2305 (1959.9; 2650)	<0.001	84.6 (68; 101.2)	0.012*
Weight				
>2500g	(Ref)		(Ref)	
1500-2499g	110.4 (-122.5; 343.3)	0.352	4.20 (-15.9; 24.3)	0.682
1000-1499g	30.8 (-243.7; 305.3)	0.826	-0.6 (-22.1; 21)	0.958
<1000g	594.8 (219.6; 969.9)	0.002	21.2 (-4; 46.5)	0.099

Ref: Reference group

***: $P < 0.05$**

After controlling for child characteristics, the total costs of infants transferred from a health facility to Vietnam National Children's Hospital were still the highest and generated an adjusted difference of USD 662 (95% CI: 455.1, 868.8; $P < 0.001$) in comparison with infants seeking care from home at Thanh Hoa Pediatric Hospital. The adjusted differences for the group of infants coming from home to Vietnam National Children's Hospital and infants transferred from health facilities to Thanh Hoa Pediatric Hospital were USD 376 (95%CI: 36.1, 716; $p < 0.005$), and USD 198.4 (95%CI: 6.6, 390.3; $P < 0.05$) respectively.

Results from the regression models for out-of-pocket costs are presented in Column 3 and 4 of Table 2. 4. Adjusting for other covariates, families of preterm infants coming from home to Vietnam National Children's Hospital paid an average of USD 75.1 as out-of-pocket costs (95%CI: 41.5, 108.7; $p < 0.005$) and families with babies referred from a health facility to Vietnam National Children's Hospital paid an average of USD 47.2 in out-of-pocket expenditure (95% CI: 37.8, 56.6; $P < 0.001$) more than families of infants seeking care directly from home to Thanh Hoa Pediatric Hospital.

Ethnicity, place of residence, and length of stay displayed statistically significant associations with out-of-pocket costs. The Kinh ethnic group was also associated with an average out-of-pocket expenditure increase of USD 11.9 (95% CI: 19.8, 4; $P < 0.05$). Residing in rural areas was associated with greater out-of-pocket costs (USD 15.9; 95% CI: 5.7, 26.1; $P < 0.05$) compared to urban areas. In comparison with stays of less than 14 days, stays between 15-29 days and lasting longer than 30 days increased out-of-pocket costs by an average of USD 10.4 (95% CI: 2.3, 18.4; $P < 0.05$), and USD 84.6 (95% CI: 68, 101.2; $P < 0.05$) respectively.

Out of a total of 482 preterm infants admitted to the national hospital, 440 cases were referred from a lower-level health facility to national hospital and 42 infants were seeking care directly from home to the hospital.

Figure 2. 3a shows the out-of-pocket costs of preterm babies transferred from home to Vietnam National Children's Hospital by transfer type. Of the 42 infants who came from home to the national hospital, 8 cases were classified as improper and 34 cases as proper. The average out-of-pocket expenditure for the improper group was USD 214.3 which was significantly higher than proper group whose average expenditure was USD 42.9 for cases classified as proper (p -value < 0.001).

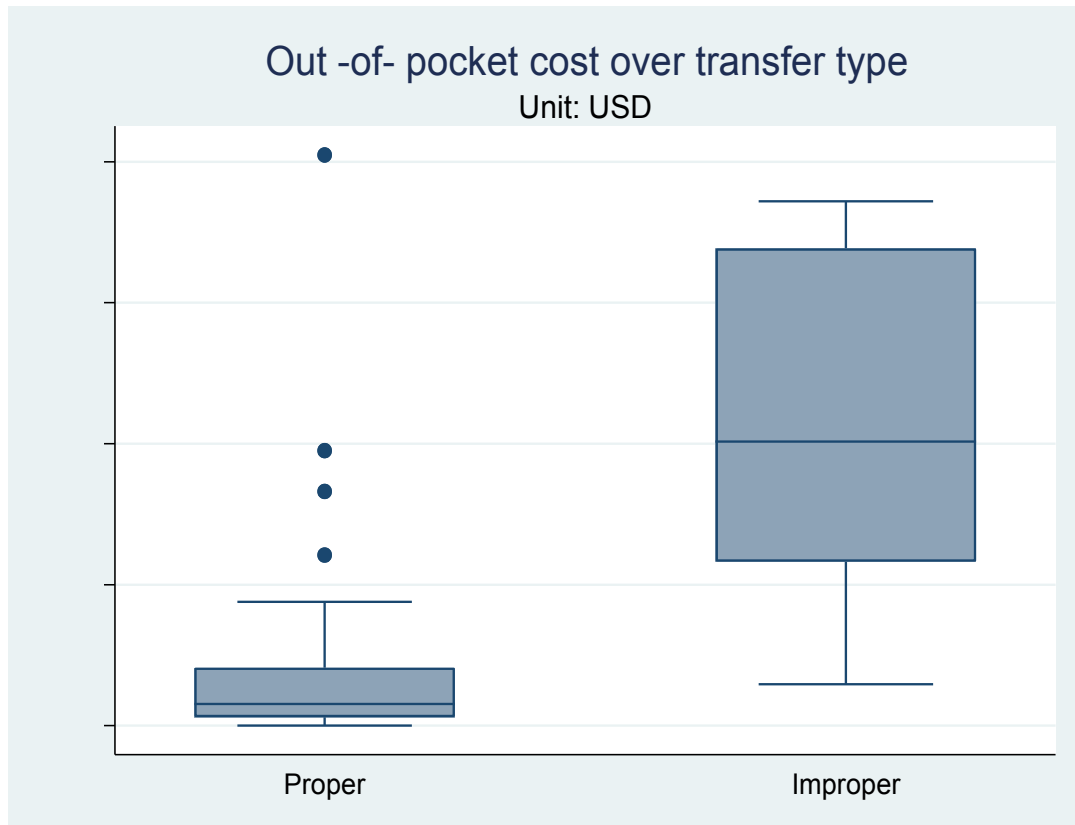


Figure 2.3a: Out-of-pocket costs for preterm infants transferred from home to Vietnam National Children’s Hospital by transfer classification (number of proper cases: 42; number of improper cases: 8)

As seen in Figure 2.3b, of the 440 cases transferred from a health facility to Vietnam National Children’s Hospital, only 3 cases were classified as improper. The average of out-of-pocket costs in the improper group was USD 307, compared to an average expenditure of USD 61.9 for the 437 cases who were transferred appropriately (p-value <0.001).

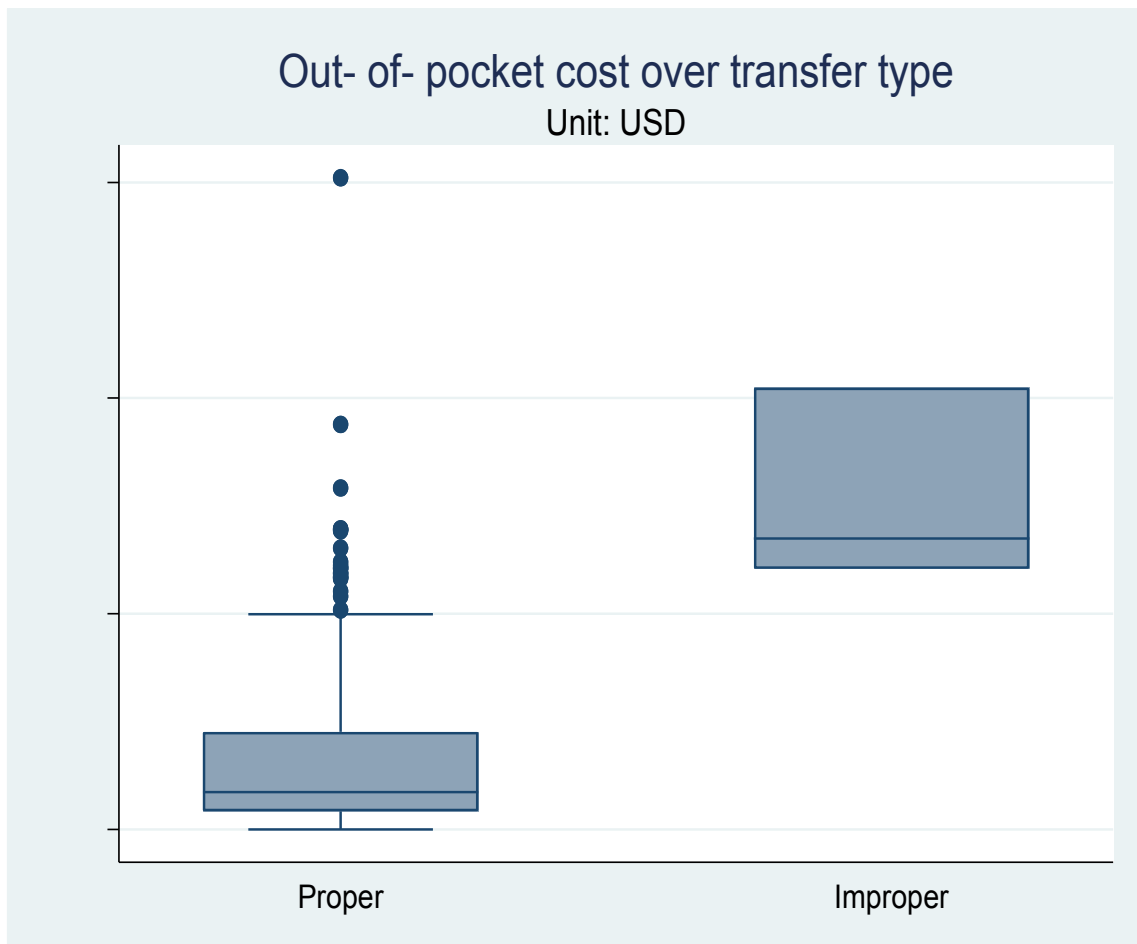


Figure 2.3b: Out-of-pocket costs for preterm infants transferred from a health facility to Vietnam National Children’s Hospital by transfer classification (number of proper cases: 437; number of improper cases: 3)

2.5. Discussion

Preterm birth does not only constitute a major medical challenge (Lockwood, 2002; Green et al., 2005), but it is also a potential threat for the immediate, short- and long-term physical, emotional and financial wellbeing of infants and their families. As we have shown in this study, preterm births also constitute a considerable financial burden to the health system. Our study has yielded several key findings.

Firstly, it is apparent from the literature and from our own findings that the primary driver of cost is gestational age. Infants born very prematurely require intensive care and tend to stay considerably longer in hospital (Behrman and Butler, 2007; Petrou, 2003; Ringborg et al., 2006; Seaton et al., 2016; Russell et al., 2007). Secondly, and

more importantly, from a health system perspective, the location of treatment appears to have major implications for both total and out-of-pocket expenditure. Mean total cost per child at the national hospital level was two and a half times higher than the mean cost observed at the provincial hospital. About 50% of the difference was directly attributable to observable child characteristics, with higher average hospital stays for children treated in the national hospital. The remaining additional cost is likely to reflect both a larger number of tests, treatments and services delivered at a higher cost per unit charged by the national hospital. This is even more apparent if you examine the average cost per bed-day by each hospital. In the provincial hospital, an average of USD 14.3 was charged per bed-day, while USD 23.6 was the average price per bed-day at the national hospital. This should not be taken as evidence that the national hospital is overcharging patients, but likely reflects differences in staffing, equipment, and general infrastructure costs at the higher-level facilities that need to be covered in order to be able to provide appropriate, high quality treatment for severe conditions.

This difference in cost is directly related to our third point. Our results suggest that the Vietnamese system is set up to provide relatively strong incentives for individuals to seek treatment at lower-level facilities prior to seeking care at provincial and national hospitals. According to Vietnam Health Insurance Law, children under 6 years old in Vietnam are fully covered by the national public health insurance as long as they are admitted in accordance with the correct procedure to public hospitals (Ministry of Justice, 2014). Proper admission into the health system requires that patients either arrive at higher-level hospitals with the appropriate referral order from a lower-level provider or as emergency case. While the classification of an emergency case may not always be obvious, health providers do clearly assess some transfers as inappropriate and higher co-payment. In our sample, the average additional co-payment borne out of an improper referral was about USD 240, which equates to 111% of the average monthly wage (2018) (VnEconomy, 2018).

This study had several limitations. Firstly, the study was conducted in only two hospitals. While these hospitals were purposely chosen to represent level I and level II facilities, they may not necessarily be representative of all hospitals of a similar level in the country. Secondly, we were not able to capture the additional medical costs families may have incurred prior to being admitted to our study hospitals. Such costs could for example include direct medical costs in local hospitals such as physician charges and

other professional fees. Our study also showed that preterm infants spent an average of 11 days and 9 days in lower-level health facilities or at home before they were admitted to Thanh Hoa Pediatric Hospital and the national hospital respectively. Applying the daily rate of 14.3 dollars seen at the provincial hospital, this would equal an additional cost of bed-days of USD 157.3 and USD 128.7 respectively. Future studies utilizing additional data sets linking hospital discharge with other databases which include vital statistics such as outpatient care, could provide a more detailed picture of these costs. Lastly, our study did not attempt to measure the indirect costs of premature birth including the cost of transport, accommodation, food, and days of work. It also did not attempt to quantify the social, psychological, or emotional costs to mothers and families.

2.6. Conclusion

The results presented in this study suggest that the average medical costs of preterm infants in Vietnam are substantial for the health system overall. Families complying with national health insurance policies seem to be relatively well protected from these (often very high) costs, with an average co-payment was USD 39 for families who complied with national health insurance guidelines. Out-of-pocket costs were about six times higher for parents who bypassed lower-level facilities without acquiring the appropriate authorization.

2.7. Abbreviations

MOH: Ministry of Health; CHCs: Community Health Centers

2.8. Declarations

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Availability of data and materials

The datasets analyzed for this study are not publicly available due to given approval limited to use for this study only but are available from the corresponding author on reasonable request.

Authors' contributions

TBAN contributed to developing the research question, conducting the data collection, data analysis, and drafting and revising the manuscript. PMH carried out data collection, provided inputs for manuscript, and commented for the manuscript. PHP participated in field supervision, data collection, and provided comments for the manuscript. PVE participated in editing and providing comments for the manuscript. GF contributed to advising on the statistical analysis, editing and providing comments for manuscript. All authors contributed in the development, review and approval of the final manuscript.

Ethics approval and consent to participate

The study was approved by the Ethical Committee of the Vietnam National Children's Hospital Institute

Consent for publication

Not applicable

Competing interests

Chapter 3: Parents' experiences with hospital referrals of preterm babies in Vietnam

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3.1. Abstract

The aim of this article is to examine the experience of parents of preterm infants in Vietnam. It seeks to understand 1) who makes decisions regarding hospital transfers of preterm infants; 2) the reasons underlying these decisions; and 3) Parent's feeling regarding the transfer process. This cross-sectional qualitative study is based on in-depth interviews with 17 parents (11 mothers and 6 fathers) of preterm infants who were transferred from local and regional hospitals to Vietnam's National Children's Hospital in Hanoi. Our results suggest that decisions on hospital transfers are generally taken by parents, with transfers only in some cases proposed by medical staff. The primary reasons for opting to transfer preterm infants to the national hospital are acute illness, positive perceptions of the quality of care of the national hospital, and advice of other parents in a similar situation. The psychological burden and stress as well as the emotional strain of parents associated with hospital transfers as well as the preterm period more generally appear substantial.

Keywords: Vietnam, preterm babies, hospital transfer, parents' experience

3.2. Introduction

Preterm birth, defined as childbirth occurring at less than 37 gestational weeks, is a leading cause of death among children under the age of 5, and a major determinant of neonatal mortality and morbidity globally (Liu et al., 2016; WHO, 2018b). Sustainable Development Goal (SDG) No. 3, and target 3.2 specifically, aims to end, by 2030, preventable deaths of newborns and children under five years of age, with neonatal mortality rates below 12 deaths per 1,000 live births and under-5 mortality rates below 25 deaths per 1,000 live births (UN, 2015).

Globally, many studies have documented the profound challenges premature infants pose for parents. Preterm deliveries cause stress and anxiety among parents, make them psychologically and emotionally vulnerable, and may result in feelings of disappointment and guilt for not having reached full-term pregnancy (Carter et al., 2005; Younger et al., 1997b; Aagaard and Hall, 2008; Arockiasamy et al., 2008; Eriksson and Pehrsson, 2002; Lindberg and Ohrling, 2008; Lee et al., 2009). Due to lack of personal preparation, parents may have feelings of detachment, despair, and alienation (Fernandez Medina et al., 2018); (Callery, 2002; Lindberg and Ohrling, 2008; Jamileh Malakouti, 2013; Jackson et al., 2003). Infants who are born prematurely are generally admitted to neonatal care units (NCU) for continued care (Berube et al.,

2014). Such transfers often involve traveling major distances, with infants and parents spending weeks to months in various hospital units. Hospital-to-hospital transfers are not only a matter of traveling, but also create stress and anxiety among parents who have to provide care for their child in a different and new medical and social environment, and who may also worry about the affordability of treatment in the receiving hospital.

Although, hospital transfers are common for premature infants in Vietnam, there is currently no study or evidence on parental perceptions and experience of such transfers. The aim of this article is to explore the decision-making process for preterm infant transfers, the primary reasons underlying such transfer as well as parents' feelings regarding the transfer process.

3.3. Methods and procedures

3.3.1. Study design

This is a cross-sectional, explorative study based on qualitative semi-structured interviews. Interviews were conducted with parents of preterm babies who were transferred from local and regional hospitals to Vietnam National Children's Hospital, a tertiary children's hospital in Hanoi, the capital of Vietnam. This study was part of a bigger research project focusing on treatment costs and quality of care assessment of preterm infants' parents at hospitals.

3.3.2. National health system setting

Children aged under six years are entitled to free public health insurance in Vietnam. This free public health insurance plan requires neither co-insurance nor deductibles. The newborn child is registered at a local public health care facility as the primary care entry point. If the child seeks care at this site, 100% of his or her treatment costs will be covered by the Social Health Insurance Fund, including costs for reimbursable items (for example drugs and materials). Only if the local health facility does not have adequate expertise and equipment to treat the ailment or in emergency cases, can the child be referred to a higher-level public facility and still receive 100% coverage. If the child seeks health care at another location or he or she does not have a written formal referral document of the health institution where she or he is registered, the child will receive 60% coverage by health insurance (if the baby was admitted in a provincial hospital) and 40% coverage if admitted to a national hospital (Ministry of Justice, 2014).

The national hospital system of Vietnam is divided into four structural levels, based on number of beds and the health services provided. Vietnam National Children's Hospital, a first (top) level hospital, is a national hospital and located in Hanoi. It has 1,300 beds, 43 clinical departments and is responsible for the treatment of children from 38 provinces in the northern part of Vietnam. This institution is the largest children's hospital in northern Vietnam.

3.3.3. Sampling procedure

A purposeful sample of parents (mother or father) of preterm infants was invited to participate in interview. Sampling was considered adequate as a redundancy in themes was evident. Inclusion criteria comprised: (1) they were literate and being 18 years of age and older; 2) their babies had been transferred to the National Children's Hospital from other facilities, and was in the Neonatal Care Unit of the hospital at least 7 days at the time of interviews; (3) They were different in months of gestation of their infant and in social-economic characteristics such as place of residence, gender, age, education, profession, marital status and economic conditions.

3.3.4. Interviews

Two pilot interviews were carried out to test, assess, and revise the questionnaire (Appendix 1: The final questionnaire). Prior to an interview, selected parents were asked to read the study information document and sign the informed consent form to participate voluntarily in this study. All study subjects were literate and able to read and sign the forms without support. The interviews lasted between 45 and 90 minutes.

Every interview began with a narrative stage in which the participant was invited to 'tell the story' of his or her child: in particular, the health status of the child at the time of being interviewed and the reasons why parents thought their infant was born prematurely. This initial narrative stage was followed by questions and queries about specific topics such as reasons for hospital transfer, the main actor(s) behind the decision transfer, and personal feelings at the time of decision-making. All interviews took place in the hospital guesthouse or in the private room of the Neonatal Care Unit and were audio-recorded. The interviews were conducted in Vietnamese language by the first author of this paper. The study team transcribed the interviews verbatim and imported them into the qualitative data analysis software package MAXQDA (Version 2018, VERBI GmbH) along with the socio-demographic information for each participant.

3.3.5. Data analysis

Analysis already began during data collection so that newly emerging themes could be orally explored in later interviews. Collected data were analyzed thematically by comparison and exploration of both consistent and deviant cases and were coded correspondingly. The coding framework incorporated themes drawn from existing research in scientific literature and significant topics arising from the ongoing analysis. For each main thematic field such as ‘decision to transfer’ and ‘feeling during transfer’, a particular number of meaningful and definable codes and representative sub-codes were developed based on the interview contents. Further analysis steps comprised the exploring of areas of commonality and differences between participants with shared socio-demographic characteristics and patterns of parents’ experiences in the interviews.

3.3.6. Ethical approval

The study setting was reviewed and approved by the Ethic Committee of Vietnam National Children’s Hospital in February 2018.

3.4. Results

3.4.1. Characteristics of the study sample

We interviewed 11 mothers and 6 fathers in the study (N=17). Table 1 shows socio-demographic characteristics of parents, gestational weeks, and referring hospitals of the preterm infants. Parents were between 18 years to 34 years old and more than half of the parents lived in rural areas of provinces in the northern part of Vietnam. Most of the infants had gestational ages between 32 and 36 weeks.

Table 3.1: Description of participants

Interview number	Kin relationship to child	Mother’s or father’s age (in years)	Place of living	Gestational age of child (in weeks)	Referring hospital
1	Mother	20	Urban	28	Bac Ninh Provincial Children’s Hospital
2	Father	28	Rural	33	Moc Chau District General Hospital
3	Mother	23	Urban	35	Mong Cai City General Hospital
4	Mother	32	Rural	30	Bac Giang Obstetrics and Pediatrics Hospital
5	Mother	34	Urban	32	Bac Ninh Provincial General Hospital
6	Mother	35	Rural	30	Vinh Phuc Provincial General Hospital

7	Mother	22	Rural	28	Thanh Hoa Obstetrics and Pediatrics Hospital
8	Father	30	Rural	36	Yen Bai Provincial General Hospital
9	Mother	24	Rural	28	Hoa Binh Provincial General Hospital
10	Father	43	Rural	29	Vinh Phuc Provincial General Hospital
11	Mother	31	Rural	28	Nam Dinh Obstetrics and Pediatrics Hospital
12	Mother	27	Urban	36	Thanh Hoa Provincial Hospital of Pediatrics
13	Father	25	Rural	32	Son La District General Hospital
14	Mother	18	Rural	35	Yen Phong District General Hospital
15	Mother	28	Urban	36	Hanoi Obstetrics and Pediatrics Hospital
16	Father	34	Urban	34	Bac Ninh Provincial Children's Hospital
17	Father	27	Rural	31	Son La Provincial General Hospital

3.4.2. Decision-makers and their reasons of a preterm baby's transfer

The first objective of the study was to identify who decided on the hospital transfer as well as the main rationale underlying this decision. There were two basic types of decision-making processes: the transfer request was (A) initially made by doctors of the particular referring hospital or (B) by the family of the child. There were three main reasons for transfers: (1) the perception that the baby's health conditions were poor, (2) the notion that the national hospital was the better choice for the treatment of the child, and (3) advice of other parents who had previously experienced a transfer of their child to the national hospital.

(A) Doctors as primary decision-makers

If the primary decision-maker was the doctor in a referring hospital, the main reason for an infant transfer was a severe illness of the baby and the general understanding that the referring hospital would not be able to provide the necessary treatment for the infant. The doctor often invited the family of the child – normally the husband – to

come to his or her office in order to inform them about the child's health status and to try to convince them of the necessity of a transfer. One father described it as follows:

“My son had a severe infection so the doctor invited me to his office and asked me if we wanted to transfer my son to the national hospital, and then we agreed to transfer him because we also wanted to transfer the child to the national level as this hospital was better.”

In this case, the transfer process was accomplished very quickly so the child could be treated relatively soon in the national hospital. Not all infants were transferred immediately – some infants were transferred several days after birth, in some cases because specialized surgery was necessary. One father said:

“The doctor said that the hospital was not able to implement the surgery for my baby so she needed to be transferred to this hospital.”

Moreover, the doctors in lower level hospitals emphasized that the national hospital was the best place because it featured all conditions for the treatment and care of preterm babies. One mother recalled:

“The doctor said if we transfer our baby to this hospital we would not have to worry as the hospital has all the best conditions for my baby.”

Though the initial recommendation to transfer the child would be made by the doctor, the final decision still had to always be taken by the family of the child. In the conversation with the parents, the doctor emphasized the situation of the child and the corresponding necessity of this transfer; the physician also informed the parents about the risks of a transfer and finally let the family of the child make the final decision. A father mentioned:

“The doctors counseled my family and talked about a chance of 50:50. They argued that my child was born prematurely so she was weak and that the national hospital has better conditions for such treatment but the journey of transfer would bear many risks so we had to decide and finally we decided to transfer my baby to the national hospital.”

(B) Family of a preterm child as primary decision-maker

If the primary decision-makers were the parents of the child, the transfer took place due to a range of reasons including the health status of the baby, the positive appreciation of the national hospital, and the good experience of other parents.

In most cases, where ‘parents of the child’ were mentioned, this mostly referred to the father. In general, it was the husband who had discussions with doctors about the health status of the child; he was also the key person in the family who made the decision to a transfer since the wife was often still recovering after the delivery. In many cases, mothers were perceived to be under considerable stress after giving birth prematurely, which caused husbands to withhold information regarding the child’s fragile health status from the wife. Some mothers reported that their husbands did not tell them the truth about the child’s health status and they did not know anything about the severe situation of their child until the baby was transferred to the national hospital. One mother said:

“My husband was the person who decided to transfer our baby to this hospital. At that moment, he concealed from me the truth about the situation of our baby since he was afraid that it would make me stressed and I would think too much.”

Health status of the baby

The most common reason for a transfer decision initiated by parents was the notion that premature infants needed specialized care due to birth complications. Parents closely observed the health status of their child and then made the decision based on their subjective assessment. Therefore, when parents did not observe any improvement of their child’s health, they proposed a transfer together with the doctors. One father reported:

“The fact is that we saw that our baby was recovering too slowly; so, we thought that the only way was to request my child’s transfer to the national hospital.”

The positive appreciation of the national hospital

The second key reason for many parents’ decision to request a transfer was the generally very positive perception of quality of care in the national hospital in Hanoi. This perception derived from parents’ notions, for instance, that the national hospital gathers better experts and equipment, and health staffs have better communication skills compared with the referring hospital. Some persons also requested a transfer because they felt that specific resources or expertise were inadequate at the local hospital. One father stated:

“I wanted to transfer my child to this national hospital because I believed in the doctors in this hospital. The expertise level of doctors here is better than that of doctors in the provincial hospital. Even though the doctor in the provincial hospital explained

that the technical equipment and machines of the two hospitals were the same but we still wanted the transfer of my child.”

In another case, there was no immediate medical need to transfer the child to the national hospital, but the family insisted on the transfer to the highest-level hospital because of their very positive perception of that national hospital. One mother told us:

“When my child was born prematurely, the doctors said that she needed to be transferred to the provincial hospital of pediatrics; but we thought the national hospital is the best place that is why we requested to transfer her to this hospital.”

Such positive awareness was assured by notions that the national level hospital was supported by experts of other countries and their child would have a chance to be treated by these doctors if they are transferred to the national hospital

“I thought the national hospital would have many foreign doctors who come to help, so it would be better than a provincial hospital.”

Because of this appreciation, they insisted on the child’s transfer in all circumstances even without the agreement of the referring hospital. Another mother confirmed:

“The provincial hospital still did not have enough supportive things for the treatment, so we requested the transfer and the hospital agreed; but if they would not have agreed, we would have transferred my baby anyway to this hospital.”

In some cases when the referring hospital was still able to treat the preterm child, the parents still wanted to request a transfer because they wanted the best care for their child. One mother said:

“As it was very difficult to have this baby so we wanted to have all the best conditions for my baby and the hospital in Hanoi provides the best conditions.”

Families of preterm children assessed the national hospital as being better than other lower-level hospitals. This was due to the positive perception surrounding the doctor’s medical expertise and their ability to communicate with patients. Poor communication skills of health staff in lower-level hospitals caused more stress for parents. Parents were already under enormous strain due to the premature birth itself. As a result, how they felt about their feelings and emotions about the quality of conversation with the health staff were important reasons affecting their decision-making process. A mother complained:

“The way of discussion of doctors when talking about the situation of my child was quite bad. For example, when we did not understand or when we needed more

information – but we did not get any detailed explanation as well as the counseling voice in these conversations. The doctors, here in the national hospital, are different.”

Parents of preterm babies needed detailed, but easily comprehensible information about the health situation of their child. When physicians in referring hospital did not provide it, it often increased the parents’ level of anxiety. In another case, a mother described and compared the difference in communication skills between hospitals as follows:

“Doctors in the provincial hospital did not explain like in this hospital, we did not get any information. When we visited our child in the incubator, you know, we just saw the child and did not know about the real situation of my child. They only said that my child still increased in weight. In contrary, here in the national hospital, doctors gave me detailed information each day such as whether my child could eat or how big was the quantity of milk each time.”

Moreover, parents needed to be reassured; they already felt worried about the many bad things that could happen if their child remained in a referring hospital. Such high levels of stress and anxiety could affect the decision-making ability of parents. One father recalled:

“Doctors asked me if I would agree on the transfer of my child to this hospital. The doctor said if our family did not have the necessary financial means for a transfer, the child could still stay in the provincial hospital. But I said to him that although we did not have enough economic means, we would try our best for my child. If there was any bad thing happening, we would regret it so much, and finally we brought my child here.”

When the doctors in the lower-level hospitals consulted with the family that there was no need to transfer the child and even health risks could occur during the transfer, the family still requested the transfer in order to get a feeling of reassurance. A mother said:

“So, the doctors explained that there is no need to transfer the child to the national hospital but to be reassured I still wanted to transfer my child to this hospital.”

Likewise, another mother stated:

“The doctor did not consult with us about the transfer and said that the hospital provided adequate treatment. Yet, the doctor also said that the health status of preterm

children normally changes quickly and suddenly, so we thought we should be careful when my child needed to be transferred here.”

The good experience of other parents.

The third important factor that affected the decision-making of parents was the experiences and opinions of other premature babies’ parents. Despite the fact that health conditions of preterm infants could vary, parents watched narrowly that other premature infants were transferred to the national hospital. By this, they believed that the national hospital was the best place for treatment of their premature child. One father said:

“I saw preterm infants from all other provinces that came here for treatment; so, it meant it is the best hospital, so I transferred my child here.”

3.4.3. Feelings of parents around hospital referrals

Uncertainty and anxiety

While the parents’ reason for requesting a transfer varied, there were commonalities in parents’ feelings around the transfer realization. Since the transfer journey itself bore many risks, parents of preterm babies endured a hard time of stress and worries before and during the transfer. The main concern was about the health of the preterm child: parents did not know whether their child could sustain the journey and if it would do the child any harm during this travel. On several accounts thoughts of uncertainty arose about where they were going, what would happen during the journey itself and who tend to them after they arrived at the hospital and who would look after them in the hospital. One mother described it as follows:

“We were afraid of many things. We worried that something could happen during the transfer journey. We were afraid of the traffic jam on the road and my baby could not endure the journey.”

The majority of reasons such as mentioned above was beyond the parents’ control and happened often unanticipated. They had definitely an impact on parents’ experience of uncertainty regarding this potentially insecure and risky transfer of preterm babies.

Concerns about the financial cost

The national hospital is located in Hanoi, a big and relatively expensive city. When parents thought about a transfer to Vietnam National Children’s Hospital, they also considered the likely cost of treatment in the hospital and other indirect costs as well. Though the transfer decision was made by the parents, the transfer itself had to be carried out by the hospital. A hospital ambulance and the necessary equipment for the

transfer were required. Moreover, the family of a preterm child needed the formal transferal documents from the referring hospital, which are very important for the coverage by the public health insurance. Therefore, the parents had to persuade the doctors to issue the transferal documents from the hospital since without these documents the cost for treatment for the child would be very high for the parents. A father summed up the situation:

“We needed to consult doctors because this decision depended on the economic condition of the family. It is a big problem, for all families here, because if we did not have a proper transfer attestation, the cost would be very high. That was why we needed the transferal document from doctors.”

They also emphasized that the cost of treatment was an important consideration which affected the final decision of the family since the treatment term for premature babies could take time ranging from weeks up to several months. In the event that a family lacked the financial means, they would be forced to bring the child back home. A mother described another case observed in a referring hospital:

“There was a family from a far-away district, and the doctors told them that their child needed to be transferred. But they did not have the economic means so they could not transfer the baby and then they took the baby back home.”

3.5. Discussions

Consistent with previous research (Gombeski et al., 1997; Weiss et al., 2016) the results presented in this paper suggest that in the Vietnamese context it is normally parents who make the final decision on preterm infant transfers to other hospitals. In some cases, referrals appear to be proposed by medical providers; in other instances, parents insist on a transfer without the requisite recommendation from a doctor.

In most cases, parents appeared to agree that physicians’ expertise and physician-patient communication were definitely better in the national hospital. Doctors at local hospitals were generally supportive, issuing the referral documents needed in order for specialized tertiary care to be fully covered by the national health insurance.

Consistent with previous studies we found parent-physician communication to be crucial for parents’ judgments of various care options (Khan et al., 2015; Dy et al., 2005; Masterson and Brenner, 2016). Reasons for parents’ request for more professional medical care are often non-medical and subjective (Donohoe et al., 1999; Dy et al., 2005); evaluating the outcomes of additional medical measures is clearly very

challenging for parents. Different perceptions regarding the severity of an illness (Suarez-Almazor et al., 2001) – particularly parents who perceive health problems to be more severe than health providers – is one of the primary motivators for parents to request that their child should be moved to higher level facility .

The findings of this study also highlight the immense stress, uncertainty, and anxiety experienced by the parents of preterm infants. The uncertainty surrounding the decision to move and treat a child at another health facility is, undoubtedly, a potential source of parental distress (Kolotylo et al., 1991; Kuhnly and Freston, 1993; Granrud et al., 2014; van Manen, 2012). These factors influence their perception and judgment of hospital care, communication with health staff, and even the level of risk associated with transfer journey. Overall, our results are consistent with the notion that many transfers might be avoided by improving the quality of care at the referring facility, including the quantity and quality of communication and other intrinsic health system factors (Dy et al., 2005).

In sum, our study outcomes are consistent with other research findings about the crucial influence of parents' perception and attitude with regard to (1) the quality and thus the reputation of the tertiary hospital, (2) the severity of the illness of the preterm child, and (3) the degree of professionalism in the communication with the physicians (Khan et al., 2015; Dy et al., 2005) which emphasizes again the importance of a respectful and balanced patient-doctor relation.

Medical transfers to tertiary hospitals are common and increasing in frequency in Vietnam (Tran et al., 2017; Takashima et al., 2017a). A better understanding of how and why they occur will improve particularly the quality of care of preterm babies. We need additional studies examining how to manage transfers effectively are needed. These could assist health system administrators and policy planners to understand parents' preferences for services which could be made available at the local level and may thus foster a regionalization or decentralization of high-quality care. Further qualitative investigations into these fields will provide insights into prospects for a quality improvement that will increase parents' satisfaction with transfers of preterm babies and reduce thus also unnecessary and harmful transfers.

Study limitations

This study aimed at representing the various experiences of affected parents; though it has some limitations. Firstly, like most qualitative studies, its goal was not to obtain a statistically 'representative' sample or 'generalizable' result, but to investigate and

analyze the quality and characteristics of parents' personal experiences. Our interviews with parents about the decision-making procedure for a referral were carried out after the transfer had already occurred; by this, they represent exclusively a retrospective construction of past experiences. Moreover, we conducted this study only in one single tertiary hospital; therefore, the results may not be applicable to areas where there are fewer choices for higher-level professional health care provision. The venue of interviews may have affected participants' responses in an adverse way. Our interviews were conducted with parents in a room of the hospital's guest house or in a private room beside the ICU patient room. Parents of preterm babies may have been more open about their experiences and attitudes, especially about negative feelings, if the interviews were conducted outside the hospital environment or at the parents' home.

3.6. Conclusions.

Our study identified parents of preterm babies as primary decision-makers for preterm infant hospital transfers even though some transfers were suggested by health providers initially. Parental reports suggest that a number of transfers of preterm infants may not be necessary, and that parents could make more informed decision if quantity and quality of communication between parents and health staff at lower level health facilities could be improved.

3.7. Acknowledgements

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3.8. Authors' contributions

TBAN contributed to developing the research question, conducting the data collection and data analysis, and drafting and revising the manuscript. NTKN participated in data analysis. PHP participated in field supervision and provided comments for the manuscript. PVE participated in editing and providing comments for the manuscript. GF contributed to advising on the statistical analysis, editing and providing comments for manuscript. All authors contributed to the development, review and approval of the final manuscript.

Chapter 4: Facility rank and parental satisfaction with quality of neonatal care: Evidence from Vietnam

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4.1. Abstract

Background: Most health systems provide the most specialized, and presumably also the highest quality of care at a central level. This study assessed the relationship between formal health facility ranking and parental satisfaction in the context of neonatal care in Vietnam.

Methods: In this cross-sectional quantitative study, parents of 340 preterm infants admitted to neonatal care units of a national and a provincial hospital in 2018 were interviewed using structured questionnaires. Unadjusted and adjusted linear regression models were used to assess the relationship between parental satisfaction and hospital rank.

Results: The mean parent satisfaction score was 3.74 at the provincial, and 3.56 at the national hospital. These satisfaction differences persisted when parent and child characteristics were adjusted for in multivariate analysis. Longer length of stay and worsening infant health status were associated with parents reporting lower levels of satisfaction with the quality of care being provided at the healthcare facility.

Conclusions: This study suggests that despite the more specialized care provided at the national pediatric hospital, parents are, on average, more satisfied with the quality of care they receive at the provincial hospital.

Keywords: Vietnam, preterm infants, parent satisfaction, health facility ranking

4.2. Background

Perceived quality of health care services plays an important role in the development and improvement of health services. Achieving full patient satisfaction requires fulfilling expectations, needs, and/or desires with regard to health care (Crow et al., 2002).

The studies on parent's satisfaction concerning paediatrics care account for numerous domains including interpersonal relationships, accessibility of services, and provision of information and health decision-making processes. For Neonatal Care Unit (NCU) services, communication and information sharing, emotional support and mental caring, family involvement, treatment skill and environmental conditions have been shown to be particularly important (Matziou et al., 2011; Zahra Salehi, 2015; Sankar et al., 2017b; Wigert et al., 2013; Lanlehin, 2012; McCormick et al., 2008). Social-economic factors that affect parental satisfaction are diverse from different studies. In the literature, age, sex, level of education, and income of parents have been documented to be determinant factors (Haviland et al., 2005; Tsironi et al., 2012; Conner and Nelson, 1999; Lanlehin, 2012; McCormick et al., 2008).

In Vietnam, most past patient satisfaction research has focused on adult patients in general hospitals. Results from these studies indicated that key areas of patient dissatisfaction with health services included waiting time, attitude of health workers, and communication of health staff (Thanh, 2013; Tuong, 2002; Nhu, 2003). In accordance with the Vietnamese health insurance law (2014), all children under six years of age are automatically covered by the national health insurance. While preterm infants who show severe complications and special health care needs are mostly treated in higher-level facilities, to the best of our knowledge, there are no studies examining parent satisfaction of preterm babies with different level health facilities in Vietnam.

In this study, we assess the relationship between formal health facility ranking (health system status) and parent satisfaction. While highly specialized national hospitals were designed to provide the highest quality of care in the country, we hypothesize that differences in medical expertise may not be fully reflected in parental perceptions due to the generally larger number of patients at central hospitals and potentially more limited time for care provision for patients at specialized central hospitals.

4.3. Method

4.3.1. Study design

This is a cross-sectional, quantitative study using a structured questionnaire to interview parents of premature infants in the Neonatal Care Units of a provincial and a more specialized (higher level) national hospital. The data collection period lasted from January to June 2018.

4.3.2. Study setting

Two hospitals were purposively selected for this study: Vietnam National Children's Hospital (VNCH) and Thanh Hoa Pediatric Hospital (THPH). Thanh Hoa Pediatric Hospital is the only provincial public pediatric hospital in Thanh Hoa province. Thanh Hoa province is located in the North Central Coast region of Vietnam and comprises a total population of 3.5 million people across 24 districts. The primary economic activities in this province are agriculture, forestry, fishery, and tourism. It is also an industrial center (Province, 2018).

Vietnam National Children's Hospital is a national referral hospital located in Hanoi City, the capital of Vietnam. It is the primary referral hospital for all 38 provinces of northern Vietnam (with a total population of 43 million people) as well as a center for research, teaching, and postgraduate training in newborn diseases. As the largest pediatric hospital in Northern Vietnam, the neonatal care unit of this hospital is responsible for the diagnosis, treatment, and care of all premature infants and newborns referred to from lower-level facilities for specialized care.

4.3.3. Participants

We interviewed parents (mother or father) of preterm babies admitted to the two neonatal care units for 6 months in 2018. The inclusion criteria for interviewees were that they are at least 18 years old and their children had stayed for at least 7 days in the neonatal care unit at the time of interview.

4.3.4. Sample size and sampling methods

All parents meeting the inclusion criteria were invited to join the study from January to June of 2018. If both parents were available, the mother was given preference and only she was interviewed.

4.3.5. Tool and variables

Tool: In this study, we used a structured questionnaire adapted from the questionnaire of McPherson's Parental Satisfaction Survey (PSS) (2000). The questionnaire includes 35 items was adapted, piloted and tested for validity and reliability. It has two parts: the first one are 13 questions about social-economic and demographic features of parents and the characteristic of preterm children, the second part is twenty-two questions covering three domains: care and treatment, communication, and hospital environment measured on a Likert scale ranging from one to five. Level of agreement for each statement in the questionnaire was scored from 1 to

5 with 1 indicating the lowest level of agreement (totally disagree) and 5 indicating the highest level of agreement (totally agree). The diagram below describes the data collection process

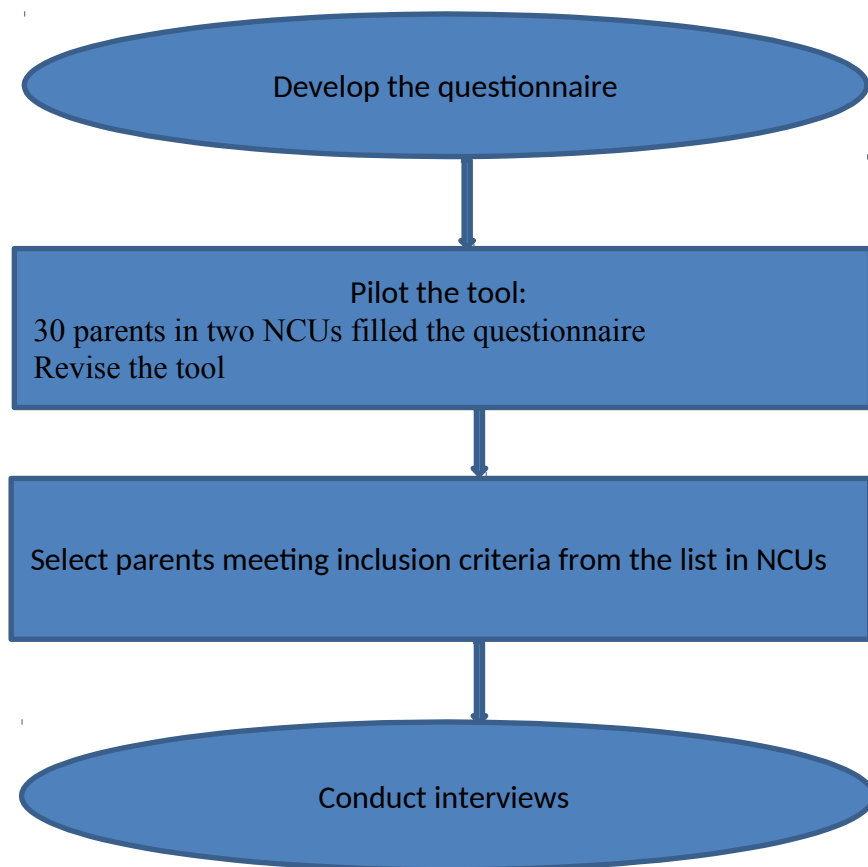


Figure 4. 1: Data collection process

To pilot the questionnaire, 30 parents (20 of those in national hospital and 10 in the provincial hospital) were invited to answer the questionnaire to check that all contents

in the questionnaire were understandable for parents. The final questionnaire after revision is in the Appendix 2.

Variables

Outcome variable: The primary outcome of interest was parental satisfaction with the level of care provided. Parental satisfaction was modeled as the average satisfaction score measured across the 22 questions asked.

Covariate variables: Social-demographic characteristics of parents as well as clinical characteristics of premature babies included: gender of respondents (female, male); marriage status (married, divorced/separated); parental age group (15-25, 26-35, 35+ years); ethnicity (Kinh, others); level of education (high school and lower, undergraduate and postgraduate); job (farmer/fisherman/worker, officer, freelancer, students); residence (rural, urban); income per month ($\leq 1.950.000$ VND, $> 1.950.000$ VND); gender of the child (female, male); gestational age (32-37, 28-31, < 28 weeks); birth weight (≥ 2500 g, 1500-2499g, 1000-1499g, < 1000 g); health status of the infant (improved, no change or worsen) and length of stay (≤ 14 days, > 14 days).

4.3.6. Data analysis

Firstly, descriptive statistics (percentage, mean, min, max) for all variables of interest were calculated. Following this, we estimated the average difference in satisfaction score between the provincial and the national hospital, both unconditional and conditional on all infants' and parents' characteristics. The main independent variable of interest for this analysis was a dichotomous variable for location of child treatment, be it at the national or provincial hospital, with the provincial hospital serving as the reference. Thirdly, we estimated the same differences by population group. Our data was stratified according to income, length of stay, and health status of infants. We then estimated the difference in satisfaction between two hospitals adjusting for parent and child characteristics.

4.4. Results

After 6 months of data collection, data from 340 parents were included in the study, 90 of which had infants admitted to Thanh Hoa Pediatric Hospital (26.5%) and 250 parents with infants admitted to Vietnam National Children's Hospital (73.5%). Table 4.1 provides characteristics of the parents and infants. Most of the participants were female (61.2%) and married (98.5%). Parents aged between 26 to 35 years old

constituted 60% of the respondents; 25.6% of parents were aged between 15-25 years, and 14.4% of parents were 35 years of age and older. More than half of parents (52.1%) had high school or lower level education. A greater percentage of respondents (66.8%) reported an income over 1.950.000 VND (USD 85/per month); and 60.6% of the infants were male. More than half of the infants (58.2%) had a birth weight between 1500-2499g; and 3% were under 1000g. Two-thirds of the infants (68.2%) were admitted to hospitals for less than 14 days and in 61.5% of the cases, parents reported that the condition of their infants had improved since admission.

Table 4.1: Characteristics of participants (parents and infants)

Characteristics	Hospital (n, %)		Total	
	Thanh Hoa Pediatric Hospital (n=90)	Vietnam National Children's Hospital (n=250)	Frequency (N=340)	Percentage (%)
Social-economic characteristics of parents				
Gender of respondent				
Male	48 (53.3)	84 (33.6)	132	38.8
Female	42 (46.7)	166 (66.4)	208	61.2
Marriage status				
Married	88 (97.8)	247 (98.8)	335	98.5
Divorced/Separated	2 (2.2)	3 (1.2)	5	1.5
Age				
15-25	12 (13.3)	75 (30)	87	25.6
26-35	62 (68.9)	142 (56.8)	204	60.0
35+	16 (17.8)	33 (13.2)	49	14.4
Ethnicity				
Kinh	77 (85.6)	200 (80)	277	81.5
Others	13 (14.4)	50 (20)	63	18.5
Level of education				
High school and lower	32 (35.6)	145 (58.0)	177	52.1
Undergraduate and higher	58 (64.4)	105 (42.0)	163	47.9
Job				

Farmer/fisherman/worker	33 (36.7)	106 (42.4)	139	40.9
Officer	32 (35.6)	57 (22.8)	89	26.2
Freelancer/self-employed	20 (22.2)	77 (30.8)	97	28.5
Student	5 (5.6)	10 (4.0)	15	4.4
Residence				
Rural	40 (44.4)	128 (51.2)	168	49.4
Urban	50 (55.6)	122 (48.8)	172	50.6
Income (per month)				
>1.950.000 VND	77 (85.6)	150 (60.0)	227	66.8
≤1.950.000 VND	13 (14.4)	100 (40.0)	113	33.2
<i>Characteristics of preterm infants</i>				
Gender				
Male	56 (62.2)	150 (60.0)	206	60.6
Female	34 (37.8)	100 (40.0)	134	39.4
Gestational age				
32-37 weeks	52 (57.8)	94 (37.6)	146	42.9
28-31 weeks	30 (33.3)	120 (48.0)	150	44.1
<28 weeks	8 (8.9)	36 (14.4)	44	13.0
Birth weight				
≥2500g	13 (14.4)	22 (8.8)	35	10.3
1500-2499g	67 (74.5)	131 (52.4)	198	58.2
1000-1499g	8 (8.9)	89 (35.6)	97	28.5
<1000g	2 (2.2)	8 (3.2)	10	3.0
Health status of the infant (at the interview time relative to admission)				
Improved	68 (75.6)	141 (56.4)	209	61.5
No change or worsened	22 (24.4)	109 (43.6)	131	38.53
Length of stay of the infant (LOS) (at the interview time)				
<14 days	79 (87.8)	153 (61.2)	232	68.2
≥14 days	11 (12.22)	97 (38.80)	108	31.76

Table 4.2: The satisfaction of parents with health services

<i>Content (n=340)</i>	Thanh Hoa Pediatric Hospital (n=90)		Vietnam National Children's Hospital (n=250)		<i>Total (N=340)</i>	
	<i>Mean (Min-Max)</i>	<i>SD</i>	<i>Mean (Min-Max)</i>	<i>SD</i>	<i>Mean (Min-Max)</i>	<i>SD</i>
Care and treatment						
At admission our child's medical history was known by the doctors and nurses.	4.01 (3-5)	0.32	3.74 (1-5)	0.74	3.81 (1-5)	0.66
During acute situations there is always a nurse to support us.	4.02 (3-5)	0.33	3.78 (1-5)	0.75	3.84 (1-5)	0.67
The correct medication is always given on time.	4.02 (3-5)	0.30	3.65 (1-5)	0.75	3.75 (1-5)	0.68
Our child is always well taken care of by the nurses while in the incubator/bed.	3.98 (3-5)	0.37	3.45 (1-5)	0.80	3.58 (1-5)	0.75
The health staff team cares to my child's needs and to us.	3.79 (3-5)	0.49	3.34 (1-5)	0.86	3.46 (1-5)	0.80
Every day we know who of the doctors and nurses was responsible for our child.	3.30 (1-5)	0.79	2.90 (1-5)	1.04	3.00 (1-5)	0.99
I would recommend this NCU to friend or family member who needed to be hospitalized.	3.68 (3-5)	0.56	3.76 (1-5)	0.72	3.74 (1-5)	0.68
Communication						
We are given clear information about our child's disease.	3.91 (1-5)	0.47	3.82 (1-5)	0.77	3.84 (1-5)	0.71
The doctor clearly informs us about the consequences of our child's treatment.	3.93 (3-5)	0.42	3.78 (1-5)	0.79	3.82 (1-5)	0.72

We receive clear information about the examinations and tests.	3.49 (2-5)	0.64	3.48 (1-5)	0.87	3.48 (1-5)	0.81
We receive understandable information about the effects of the drugs.	3.67 (2-5)	0.56	3.46 (1-5)	0.78	3.52 (1-5)	0.73
The doctor informs us about the expected health outcomes of our child.	3.67 (3-5)	0.52	3.70 (1-5)	0.74	3.69 (1-5)	0.69
We are always informed right away when our child's physical condition worsened.	3.92 (3-5)	0.48	4.02 (1-5)	0.67	3.99 (1-5)	0.62
My child's privacy and confidentiality are respected during his/her NCU stay.	4.03 (3-5)	0.32	3.95 (1-5)	0.70	3.97 (1-5)	0.62
The information provided by the doctors and nurses is understandable.	3.91 (3-5)	0.36	3.61 (1-5)	0.71	3.69 (1-5)	0.65
Our questions are clearly answered.	3.61 (3-5)	0.53	3.4 (1-5)	0.84	3.45 (1-5)	0.77
The doctors and nurses always take time to listen to us.	3.41 (2-5)	0.62	3.19 (1-5)	0.89	3.24 (1-5)	0.83
We receive sympathy from the doctors and nurses.	3.37 (2-5)	0.57	3.23 (1-5)	0.92	3.27 (1-5)	0.84
Nurses and doctors always introduce themselves by name and function.	2.69 (1-5)	0.81	2.94 (1-5)	0.96	2.87 (1-5)	0.93
Hospital environment						
My child's room/incubator is clean and comfortable.	3.93 (3-5)	0.32	3.78 (1-5)	0.62	3.82 (1-5)	0.56
There is enough space around our child's incubator/bed.	4.01 (3-5)	0.44	3.75 (1-5)	0.68	3.82 (1-5)	0.64
My child's room is quiet enough for him/her to rest.	3.90 (2-5)	0.58	3.70 (1-5)	0.97	3.75 (1-5)	0.89
Overall Satisfaction Score	3.74 (3-5)	0.25	3.56 (1-4.95)	11.70	3.61 (1-5)	0.48

Table 4.2 describes mean parental satisfaction by the hospital. Average satisfaction scores were 3.74 and 3.56 at the regional and national hospitals, respectively. In both hospitals, parents were most satisfied with the information from doctors regarding the expected health outcomes of their infants (3.99 over 5). In this domain, the provincial hospital scored lower (3.92) than the national hospital (4.02). Participants were less satisfied with the manner in which doctors and nurses were introduced to them (2.87 overall) and information related to who was responsible for their child (3.00 overall). For most other aspects of health services, satisfaction scores at the regional hospital were higher than the scores at the national hospital.

Table 4.3 shows the main regression results. Compared to the provincial hospital, average satisfaction scores were 0.18 points lower at the national hospital (95% CI: -0.29, -0.06, $P < 0.05$). After controlling for the child and parents' covariates displayed in Table 1, the estimated difference declined marginally to -0.13 (95% CI: -0.26, -0.01; $p < 0.005$).

Table 4.4 shows the stratified regression results. When stratifying parents by income group, we found larger differences in satisfaction among lower income parents, even though the differences in estimated effect sizes are not statistically significant (Table 4, columns 1 and 2). When we stratify our analysis by duration of stay at the hospital, we found greater gaps for children with shorter stays (Table 4, columns 3 and 4). Lastly, when we stratified by health trajectory, we found larger gaps in satisfaction scores for parents of children not recovering (columns 5 and 6). Once again, confidence intervals overlapped for the subgroup estimates. Across all the subgroups analyzed, the national hospital received lower satisfaction scores than the regional one in the fully adjusted model

Table 4.3: Hospital ranking predicting parental satisfaction

Characteristics	Overall Satisfaction Score			
	Unadjusted Regression Coefficient (95% CI) (1)	P	Adjusted Regression Coefficient (95% CI) (2)	P
Hospital (Main covariate)				
Thanh Hoa Pediatric Hospital*	Ref	-	Ref	-
Vietnam National Children's Hospital	-0.18 (-0.29, -0.06)	0.003	-0.13 (-0.26, -0.01)	0.03
Parent's gender				
Male			Ref	-
Female			0.05 (-0.06, 0.15)	0.38
Education (Main covariate)				
High school and lower			Ref	-
Undergraduate and higher			0.06 (-0.07, 0.19)	0.35
Marriage status				
Married			Ref	-
Divorced/Separated			0.02 (-0.38, 0.42)	0.91
Age				
15-25			Ref	-
26-35			0.03 (-0.09, 0.16)	0.59
35+			-0.04 (-0.21, 0.13)	0.62
Ethnicity				
Kinh			Ref	-
Others			0.03 (-0.12, 0.18)	0.69

Job				
Farmer/fisherman/worker			Ref	-
Officer			0.15 (-0.009, 0.31)	0.07
Freelancer			0.16 (0.04, 0.27)	0.01
Students			0.03 (-0.25, 0.30)	0.84
Residence				
Urban			Ref	-
Rural			0.06 (-0.06, 0.18)	0.33
Income (per month)				
≤1.950.000 VND (> USD 85)			Ref	-
>1.950.000 VND (≤ USD 85)			0.06 (-0.07, 0.18)	0.40
Infant's gender				
Female			Ref	-
Male			0.07 (-0.03, 0.16)	0.18
Gestational age				
<28 weeks			Ref	-
28-31 weeks			0.06 (-0.10, 0.22)	0.46
32-37 weeks			0.06 (-0.12, 0.24)	0.52
Birth weight				
≥2500g			Ref	-
1500-2499g			-0.01 (-0.19, 0.16)	0.88
1000-1499g			0.04 (-0.17, 0.25)	0.69
<1000g			0.09 (-0.26, 0.44)	0.61
Health status of the infant (at the interview time)				
No change or worsened			Ref	-
Improved			0.32 (0.22, 0.43)	<0.001

Length of stay of the infant (at the interview time)			Ref	-
<14 days			0.12 (0.008, 0.23)	0.04
14-29 days				

Ref: Reference group

Table 4.4: Stratified association between parental satisfaction score and participant characteristics (parent and infant)

Characteristic	Income		Length of stay		Health status	
	Under average income (1)	Above average income (2)	<14 days (3)	≥14 days (4)	Improved (5)	No change or worsen (6)
Hospital						
Thanh Hoa Paediatric Hospital	Ref	Ref	Ref	Ref	Ref	Ref
Vietnam National Children's Hospital	-0.28 (-0.56, 0.005)	-0.08 (-0.22, 0.06)	-0.15 (-0.27, -0.02)*	-0.07 (-0.42, 0.28)	-0.03 (-0.17, 0.12)	-0.36 (-0.59, 0.13)*

Ref: Reference group

**: P<0.05*

Covariates in models: Parent's gender, education, marriage status, age, ethnicity, job, place of residence, income (model 3, 4, 5, 6), infant's gender, gestational age, birth weight, health status (model 1, 2, 3, 4), LOS (for model 1, 2

4.5. Discussion

Given that infants cannot express their particular health needs and demands, opinions and satisfaction of parents play a vital role in choosing the most appropriate healthcare for their children (Matziou et al., 2011; Latour et al., 2008). Parental choices are particularly important for preterm infants who have critical needs and depend on receiving the highest quality care for their survival and wellbeing. Considering this, the main results of this study are troubling as they suggest that, on average, parents rate the provincial hospital higher than the national one. This gap may be partially explained by the fact that the national hospital is the primary referral hospital for 38 provinces, resulting in a heavy workload, more impersonal communication, and limited time for counseling with parents. Indeed, findings from previous studies show that satisfaction is strongly affected by institution-related characteristics such as the patient/nurse ratio of the hospital (Azoulay et al., 2001; Stricker et al., 2009; Jha et al., 2008), hospital located in different regions (Zahra Salehi, 2015), hospital reputation (Tokunaga and Imanaka, 2002), and hospital size (Young et al., 2000).

Consistent with the idea of limited communication time in the national hospital, we found that parents rated the communication skills of health workers in the national hospital lower than those of provincial hospital staff. Direct, personal communication of health staff with parents can reduce stress and anxiety for parents (Matziou et al., 2011; Sankar et al., 2017a; Wigert et al., 2013), but may of course be hard to do for staff in crowded national hospitals.

The data collected as part of this study shows infants in the national hospital have, on average, more severe conditions and, therefore, often have to be admitted to hospital for longer periods. This additional time at the hospital may at least partially explain lacking satisfaction of parents at national hospitals as suggested in the related literature (Matziou et al., 2011; Salehi. et al., 2015; Lanlehin, 2012; Ngui and Flores, 2006; McCormick et al., 2008). Furthermore, our study suggests that even though the difference in satisfaction between two hospitals was not statistically significant in both income groups, there was a larger satisfaction difference among parents in the lower income group. This finding contradicts what has been found in other studies, which show a significant association between income and satisfaction, with lower income parents reporting lower levels of satisfaction (Marie C. McCormick, 2008). This may be explained by the fact that care provision for premature infants is fully covered by the

national health insurance; thus, all infants are given the best possible treatment irrespective of the parents' level of income.

This study had several limitations. Firstly, the study was conducted in only two hospitals. While these hospitals were purposely sampled to represent the national and provincial level, they may not be representative of all hospitals of a similar level in the country. Secondly, the study was conducted when the infants were currently being treated in hospitals. Therefore, parents may hesitate to provide critical assessments of the hospitals' health services, increasing the risk of reporting bias.

4.6. Conclusions

The results presented in this study suggest that despite the more specialized care provided by the national pediatric hospital, parents are, on average, more satisfied with the quality of care received at provincial hospitals. Evidence suggests that improving provider-parent interactions may have the greatest potential for improving parent satisfaction at specialized national hospitals throughout Vietnam.

4.7. Abbreviations

NCU: Neonatal Care Unit; VNCH: Vietnam National Children's Hospital; THPH: Thanh Hoa Pediatric Hospital

4.8. Declarations

Ethics approval and consent to participate

All the participants were given an explanation about the purposes of the study and their right to withdraw without any consequences. Written informed consent was obtained from all individual participants included in the study. The study was approved by the ethical committee of Vietnam National Children's Hospital (Approval Number: 166/BVNTW-VNCSKTE).

Consent for publication

Not applicable

Availability of data and materials

The datasets analyzed for this study are not publicly available due to given approval limited to use for this study only but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Chapter 5: General discussions

Preterm birth is not only a major health issue but is also a potential threat for the immediate, short- and long-term physical, emotional and financial wellbeing of infants and their families. Better understanding the impact of preterm births can help finding feasible solutions to this problem and eliminate the burden of preterm births on families and health system through policy and programming interventions. Although preterm birth is a leading cause of neonatal mortality in Vietnam, to the best of our knowledge, this research is the first one to explore the impact of preterm births on families and the health system in Vietnam.

As we can see in the results of first component of this study, preterm births have created a substantial cost to both the health system and families. The total costs for treatment of preterm infants have been placing a heavy burden on the national budget for healthcare. The treatment costs of preterm infants in health facilities are well covered by health insurance program for children under 6 years of age, but the funding of FFC program has to be covered by the national budget for health provided by the government. The average total costs per preterm infant paid by health insurance in the national hospital and the provincial hospital was about USD 1.578 and USD 660, respectively. With an estimated 800 preterm infants in the NCU each year at the national hospital and around 300 preterm births at the provincial hospital the total estimated cost paid by the health insurance each year is USD 1.262.400 for the national hospital and USD 200.700 for the provincial hospital. Given that the rate of readmission of premature children is higher than full-term children (Kuzniewicz et al., 2013), the total medical costs created by preterm children is likely substantially higher than this.

According to health insurance law (2014), when the infants are transferred to the national hospital without formal referral from local hospitals, the maximum percentage of medical costs coverable by the health insurance in the national hospital is 40%; therefore; therefore, in these cases the direct OOPs of infants' families would be very high. The first component of this study also reported that direct OOP costs for families of infants transferred without formal referral equaled 111% of the average monthly wage. Moreover, we did not try to estimate the indirect OOP costs for families including transportation costs, food or accommodation. This means that we have likely underestimated the true costs for families in this instance.

However, results from the first component also demonstrates the positive impact of FCCU6 policy. The direct medical costs of infants who complied with transfer regulations or who were not transferred to the national hospital were fully covered by FCCU6 program, even if their costs were very high. There were no direct out-of-pocket costs for the families of preterm infants only treated in the provincial hospital and for those had a proper transfer to the national hospital. This result is consistent with other studies which assessed the effect of FCCU6 in Vietnam and reported that the program gave a financial protection for families of sick children, with direct OOP payment of children's families being reduced (Shieh et al., 2013; Palmer et al., 2015; Nguyen and Wang, 2013).

Parents of preterm infants endure strains during and after delivery, and this stress might affect the development of premature children (Carter et al., 2005; Younger et al., 1997b; Aagaard and Hall, 2008; Arockiasamy et al., 2008; Eriksson and Pehrsson, 2002; Lindberg and Ohrling, 2008; Lee et al., 2009). Our qualitative work suggests that strains and stress of parents of preterm not only stemmed from taking care of the baby in the NICU but also came from the other factors such as the ineffective communications between health staffs and parents. The support from the health care staff was shown to be a crucial factor for reducing the stress and strains placed on premature families and communication with families of severe patients required special trained skills (Wigert et al., 2013; Wigert et al., 2014). The results from the second components of this study showed that the level of communication and the quality of consultation from health staffs, especially in the lower level hospitals, did not give families sufficient decision making support such as helping families decide whether or not to refer their infant to a higher level health facility. When parents of premature infants have unclear information regarding the treatment and status of their children, coupled with their perceptions and believe that higher-level hospital is the best place for their child to be treated, it may lead parents to decide to transfer their child to the national hospital even in when it is not necessary. This result is likely due to a lack of communication skills training for health staffs in hospitals in Vietnam. This result might also partly explain for the overcrowding situation in many higher level hospitals in Vietnam and provide more evidence to explain why the rate of out-of-pocket payments in Vietnam still high.

In contrast, the overcrowding situation in the national hospitals in Vietnam is one of reasons explaining for health staffs in national hospitals do not have quantity of time for the communication with parents of each preterm baby and might result in lower level of satisfaction reported by parents. The results from the third component of this study approved for this explanation.

This study has some limitations. Firstly, accessing cost data in hospitals in Vietnam is always a challenging task, while data extraction from financial records and medical records can be incredibly time consuming. Due to limited time and resources, data used in thesis were collected from only two hospitals representing for the national and district level. Moreover, we could not access the cost data of preterm infants in local level hospitals prior to admission in provincial or national hospital for instance, in district levels. The reason for this is that the data of direct medical cost between public hospitals have not been currently linked together in Vietnam. Therefore, the results in our study might underestimate the total direct medical costs of infants transferred from different lower level health facilities to the provincial or national hospital. Secondly, we did not capture the indirect costs of infants' families such as the cost for food, transport, and days of work lost. Therefore, the financial burden on infants' families has not been fully assessed in this study. We tried to find a convenient and comfortable place for interviewing parents in the second and third component of the study so parents could feel free to share their experiences, feelings and opinions. However, we interviewed parents while their infants were still in hospitals, which may have caused parents be more reluctant to be critical of the hospital or express certain points of view.

Chapter 6: Recommendations and conclusions

6.1. Recommendations

This study is the first exploration of the impact of preterm births in Vietnam. The following are proposed for consideration in future researches and recommendations for Vietnam.

To have a comprehensive assessment of the economic burden of preterm births, future studies need to include direct medical costs from all hospitals to which an infant is admitted, outpatient care, and the indirect OOP costs of families. Future studies should also follow up with parents after the infants are discharged from hospitals to attain a deeper understanding of parents' experience of taking care of their preterm babies after discharge from hospitals as well as their detailed assessments of the health care services.

A number of potential implications for improving the healthcare for preterm infants can be derived from the results of this study

1) Strengthen professional capacity and provide more technical facilities and equipment for the lower level hospitals, especially provincial hospitals. This will enable them to better care for severe cases of preterm births which may assist in reducing the number of admissions in the national hospitals.

2) Increase the number of activities in Direction of Healthcare Activities (DOHA) framework between pediatric hospitals at national level with lower-level hospitals to enhance the examination and treatment capacity of lower-level hospitals via training and technical skills transfer to reduce the seeking care of preterm families at national level hospitals. DOHA (“Chỉ đạo tuyến” in Vietnamese) is a program in Vietnam requiring healthcare facilities at higher levels to support their lower-level facilities to improve the quality of healthcare services provided to all Vietnamese citizens (Takashima et al., 2017b).

3) Provide readily available information and decision support for families to help avoid unnecessary transfers of preterm infants from lower level to national hospitals. These unnecessary transfers result in the OOP costs for families and overcrowding in national level health facilities.

4) There is a need for more programs which can provide communications skills training to health workers so they can better assist families of preterm babies dealing with strains and stress while taking care their babies in health facilities.

5) It would be advantageous to have programs with the participation of both health workers and social workers of hospital to supports families of preterm babies after discharge from hospital to overcome the difficulties of caring for a premature infant at home.

6.2. Conclusions

Preterm births remain an important health challenge in Vietnam. Three components of this study demonstrate that preterm births have currently placed an economic and psychological burden on both health system and infant's families in Vietnam. Families of preterm infant have been well protected by the FCCU6 policy. However, the direct medical costs of preterm infants are very high placing a burden on the FCCU6 program budget. OOP costs were found to be low on average, but were found to be high among those that bypassed the lower level facilities without formal referral. Although health professionals in local health facilities tried to support families of preterm infants by providing the referral documents when the families require a transfer for their infants, sufficient psychological support was not provided to help families to reduce the stress and anxiety of having a preterm infant. Parents are the primary actors in cases of hospital transfers and the main reason for the hospital transfers is their concern regarding sever health conditions of their babies and their perceptions about the quality of care offered at the national hospital. This leads to the unnecessary transfers of many infants from the local hospitals to national hospital. The level of parental satisfaction of preterm infants in higher health facilities is less than in lower health facilities due to the overcrowding situation in national level hospitals and health staff not having the necessary time to communicate with parents effectively. This explorative study emphasize the importance of having specific support structures for families including both economic and mental support. These structures will help to reduce the burden placed on the families of preterm infants and the healthcare system in general.

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Appendices

Appendix 1: Guides for semi-structured interview of the second objective

Guide for interview

Research: Preterm birth in Vietnam: direct medical cost assessment and the investigation of parents' experiences and satisfaction with health care services

Name of Interviewer:

Hospital:

Date and time:

The number of the interviewee:

Who is present during the interview?

1. Introduction

My name is _____ and as a member of research team “**Preterm births in Vietnam**”. I would like to ask you some questions about your feeling, your problems you have faced when your child is in Neonatal Care Unit as well as your thoughts about health care services and the supports from health workers.

We hope to use results of this research to improve the quality of health services for preterm babies. The interview should take about 30 minutes. If you agree, I am going to record our conversation. The purpose of this is that I can get all contents of our conversation. I assure you that all content of this interview will remain confidential. If you agree to this interview and the tape recording, please read and sign this consent form.

Before we start I would like to remind you that there are no right or wrong answers in this interviewee. We are interested in knowing what you think, so please feel free to be frank and to share your point of view. It is very important that we hear your opinion.

2. Guiding questions

- 1) I would like to start by having you briefly describe yourself and your family
(*Prompts: place of living, job, education, number of children*)
- 2) Could you tell me about what happened with your delivery (or your wife's delivery) and your child (*Prompts: time of delivery, gestation week of the child, place of delivery, places before the child was transferred to this hospital, time of preterm births before*)?

- 3) How the decision-making process of referring your child to this hospital was made? (*Prompts: Who has made the final decision, what were important reasons to make this decision*)
- 4) How are your feelings and emotions when your child is in Neonatal Care Unit? (*Prompts: feeling and emotions of having a preterm child and when the child is in Neonatal Care Unit, why so, problems of your child health at this moment*)
- 5) What are resources of supports to you and your family for the to you and your family for the caring activities for the child while the child was in the Neonatal Care Unit (*Prompts: supports from your family, your company, your neighbours, hospital, other parents in Neonatal Unit, what kind of supports do you receive*)
- 6) How satisfied are you with the supports? (*Prompts: What aspects are you satisfied? What makes you unsatisfied, why so?*)
- 7) What are your experiences of communication with the health workers (both nurses and doctors) during your infant stay at the Neonatal Care Unit (*Prompts: Which kind of information do you receive? How many times per day/week and content of information, your opinion about the communication and attitude health workers*)
- 8) What are your opinions on the regulations for caring activities for preterm child (*prompt: timetable of providing information about the situation of the child, timetable of hospital for seeing the child in a incubator and caring the child in neonatal care unit), time of visiting by doctors and nurses, why so*)
- 9) What are your opinions on the atmosphere of hospital (*noises in room, materials and infrastructure, environment and why so?*)
- 10) What are your expectations from health staff? (*Prompts: expectation on their supports, their communication and information*)
- 11) Could you tell me about the cost you have to pay when your child is in this Neonatal Care Unit (*Loss of working hours, indirect expenditures related to treatment seeking e.g. meal, communication, costs for care arrangement at home, emotional and psychological costs*).

Appendix 2: Informed consent form for the second objective

SWISS TROPICAL AND PUBLIC HEALTH INSTITUTE

INFORMED CONSENT FORM

This informed consent form is for parents of preterm children admitted in Neonatal Care Unit of Vietnam National Children's Hospital and Thanh Hoa Pediatrics Hospital who we are inviting to participate in research titled "*Investigate the experience of parents of preterm children in Neonatal Care Unit*"

Principle Investigator: Nguyen Thi Binh An

Organization: Swiss Tropical and Public Health Institute, Basel, Switzerland

Name of project: *Preterm birth in Vietnam: Direct medical cost assessment and the investigation of experiences of parent and their satisfaction toward health care services*

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate).

Part 1: Information Sheet

Introduction

I am Nguyen Thi Binh An, PhD student of Swiss Tropical and Public Health Institute in Switzerland. I am doing the research on the preterm birth topic in Vietnam. I am going to give you information and invite you to be part of this research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain

Purpose of the research

Preterm birth is a leading cause of death in children under 5 years and a major determinant of neonatal mortality and morbidity and long-term adverse consequence for health. We would like to know your experiences when your child admitted in Neonatal Care Unit as well as your opinions about the supports of health staff. The results of this study might help to improve in health services' performance for preterm babies

Participant selection

You are being invited to take part in this research because you are parents of preterm babies and your experiences and your opinions towards the support of health staff in Neonatal Care Unit

Voluntary participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate it will not affect to the health services that your child are received at this Neonatal Care Unit. You may change your mind later and stop participating even if you agreed earlier.

Procedures

We are inviting you to take part in this research. If you accept, you will participate in an interview with me. During the interview, you can chose a comfortable place and I will sit down with you. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question. No one else but I will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except research members will access to the information documented during your interview. The entire interview will be tape-recorded, but no one will be identified by name on the tape. The information recorded is confidential, and no one else except research members will have access to the tapes.

Risks

You do not have to answer any question if you feel the question(s) are too personal or if talking about them makes you uncomfortable.

Benefits

There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve the quality of health care service for preterm children.

Confidentiality

The information that we collect from this research project will be kept private and it will not be shared with or given to anyone except research members.

Sharing the results

The knowledge that we get from this research will be announced to Neonatal Care Unit and it is reported in my articles and my thesis.

Who to contact

If you have any questions, you can ask me now or later. If you wish to ask questions later, you may contact of the following:

Nguyen Thi Binh An

Swiss Tropical and Public Health Institute, Socinstrasse 57, Basel, Switzerland

Email: an.nguyen@swisstph.ch

This proposal has been reviewed and approved by research commission of Swiss Tropical and Public Health Institute. It has also been reviewed by the Ethics Committee of Vietnam National children's hospital and the EKNZ committee (Ethikkommission Nordwest- und Zentralschweiz) of Switzerland

Part II: Certificate of Consent

I have read the foregoing information. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant: _____

Signature of Participant: _____

Date: _____

Statement by the researcher

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Print Name of Researcher: _____

Signature of Researcher: _____

Date : _____

Appendix 3: Structured questionnaire for the third objective

Investigation of parents' satisfaction of preterm infants with care services of hospital.

Code of form:

Date of interview:

Hospital:

Guidance:

Circle on the appropriate number or write in the blank line

Use a pen, not pencil and avoid erasing

I. Characteristic of parents and preterm infants

1. Socio-economic and demographic characteristic of parents

Number	Content		Note
1.1	Gender Male Female	0 1	
	Marriage status Married Divorced/ Separated Single	0 1 2	
1.2	Age	<i>Sun calendar</i>
1.3	Ethnic Kinh Other ethnic group	1	<i>Please indicate</i>
1.4	Education Primary Secondary school High school Undergraduate Post- graduate	1 2 3 4 5	

	Other	99	
1.4	Job Famer/fisherman/worker Officer Freelancer Student Others (please indicate)	1 2 3 4 5	
1.5	Living place Rural Town City Other (please indicate)	1 2 3 4	
1.6	Income(per month) <1 million (Vietnam Dong) 1-1.3 million 1.3-1.95 million >1.95 million	1 2 3 4	

2. Characteristic of preterm infants

Number	Content		Note
2.1	Gender Female Male	1 0	
	Weight ≥2500 g 2499-1500 g 1499-1000 g <1000g	1 2 3 4	
2.3	Gestational weeks	
2.4	Length of stay in hospital (days)	At the time of interview
2.5	Number of hospital admission	Number of hospital admission till the moment of interview

Number	Content		Note
		
2.6	Health status of the child after admission in hospital Better Unchanged Worsen Other (please indicate)	1 2 3 ...	Health status at the moment of interview

II. The satisfaction of parent

Totally disagree: 1

Disagree : 2

Neutral : 3

Agree : 4

Totally agree : 5

Guidance: Please circle the most appropriate number of each statement in which correspond most closely to your desired response.

Number	Content	Level of agreement				
		Totally disagree	Disagree	Neutral	Agree	Totally agree
A	Care and treatment	1	2	3	4	5
3.1	At admission our child's medical history was known by the doctors and nurses	1	2	3	4	5
3.2	During acute situations there is always a nurse to support us promptly	1	2	3	4	5
3.3	The correct medication is always given on time	1	2	3	4	5
3.4	Our child is always well taken care of by the nurses while in the incubator/bed	1	2	3	4	5
3.5	The health staff team cares to my child's needs and to us	1	2	3	4	5

3.6	Every day we know who of the doctors and nurses was responsible for our child	1	2	3	4	5
3.7	I would recommend this NCU to friend or family member who needed to be hospitalized	1	2	3	4	5
B	Communication					
3.8	We are given clear information about our child's disease	1	2	3	4	5
3.9	The doctor clearly informs us about the consequences of our child's treatment	1	2	3	4	5
3.10	We receive clear information about the examinations and tests	1	2	3	4	5
3.11	We receive understandable information about the effects of the drugs	1	2	3	4	5
3.12	The doctor informs us about the expected health outcomes of our child	1	2	3	4	5
3.13	We are always informed right away when our child's physical condition worsened	1	2	3	4	5
3.14	My child's privacy and confidentiality are respected during his/her NCU stay	1	2	3	4	5
3.15	The information provided by the doctors and nurses is understandable	1	2	3	4	5
3.16	Our questions are clearly answered	1	2	3	4	5

3.17	The doctors and nurses always take time to listen to us	1	2	3	4	5
3.18	We receive sympathy from the doctors and nurses	1	2	3	4	5
3.19	Nurses and doctors always introduce themselves by name and function	1	2	3	4	5
C	Hospital Environment					
3.20	There is enough space around our child's incubator/bed.	1	2	3	4	5
3.21	My child's room is clean and comfortable	1	2	3	4	5
3.22	My child's room is quiet enough for him/her to rest	1	2	3	4	5

Appendix 3: Informed consent form for the third objective.

SWISS TROPICAL AND PUBLIC HEALTH INSTITUTE

INFORMED CONSENT FORM

This informed consent form is for parents of preterm children admitted in Neonatal Care Unit who we are inviting to participate in research titled “*Assess the satisfaction of parent of preterm children toward health care services in Neonatal Unit*”

Principle Investigator: Nguyen Thi Binh An

Organization: Swiss Tropical and Public Health Institute, Basel, Switzerland

Name of project: *Preterm birth in Vietnam: Direct medical cost assessment and the investigation of experiences of parent and their satisfaction toward health care services*

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate).

Part 1: Information Sheet

Introduction

I am Nguyen Thi Binh An, PhD student of Swiss Tropical and Public Health Institute in Switzerland. I am doing the research on the preterm birth topic in Vietnam. I am going to give you information and invite you to be part of this research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain

Purpose of the research

Preterm birth is a leading cause of death in children under 5 years and a major determinant of neonatal mortality and morbidity and long-term adverse consequence for health. Satisfaction of parent of preterm children plays an important role in improvement of health services in Neonatal Care Unit. We want to assess the satisfaction of parent of preterm babies to know about the opinion of parent about health care services in Neonatal Care Unit and find out what need to improve in health services' performance

Participant selection

You are being invited to take part in this research because you are parents of preterm babies and your opinions toward health care services in Neonatal Care Unit will help us improve the quality of health services for preterm children.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate it will not affect to the health services that your child are received at this Neonatal Care Unit. You may change your mind later and stop participating even if you agreed earlier.

Procedures

We are inviting you to take part in this research. If you accept, you will answer a semi-structure questionnaire and that will take about 20 minutes. If you do not wish to answer any of the questions included in the questionnaire, you may skip them and move on to the next question. The answers in the questionnaire is confidential and your name is not being included on the forms

Risks

You do not have to answer any question of questionnaire if you feel the question(s) are too personal or if talking about them makes you uncomfortable

Benefits

There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve the quality of health care service for preterm children

Confidentiality

The information that we collect from this research project will be kept private and It will not be shared with or given to anyone except research members

Sharing the results:

The knowledge that we get from this research will be announced to Neonatal Care Unit and it is reported in my articles and my thesis.

Who to Contact

If you have any questions, you can ask me now or later. If you wish to ask questions later, you may contact of the following:

Nguyen Thi Binh An

Swiss Tropical and Public Health Institute, Socinstrasse 57, 4051 Basel, Switzerland

Email: an.nguyen@swisstph.ch

This proposal has been reviewed and approved by research commission of Swiss Tropical and Public Health Institute. It has also been reviewed by the Ethics Committee of Vietnam National children's hospital and the EKNZ committee (Ethikkommission Nordwest- und Zentralschweiz) of Switzerland

Part II: Certificate of Consent

I have read the foregoing information. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant: _____

Signature of Participant: _____

Date: _____

Statement by the researcher

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Print Name of Researcher: _____

Signature of Researcher: _____

Date : _____

Appendix 4: Ethics approval from Vietnam

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MINISTRY OF HEALTH
VIETNAM NATIONAL CHILDREN'S HOSPITAL
No.: 166/BVNTW-VNCSKTE

SOCIALIST REPUBLIC OF VIETNAM
Independence – Freedom – Happiness

**BẢN DỊCH
TRANSLATION**

Hanoi, 29th January 2018

APPROVAL CERTIFICATE OF ETHICS COMMISSION IN BIOMEDICAL RESEARCHS

Pursuant to the Decision No. 812/QĐ-BVNTU dated 09 March 2017 by the Director of Vietnam National Children's Hospital on "The establishment of the ethics commission in biomedical researches of Vietnam National Children's Hospital";

Pursuant to the Certificate No. IRB00009162 of United State on approving the Ethics Commission of Vietnam National Children's Hospital dated 21 December 2012;

Pursuant to the working regulations and the approval process of the Ethics Commission in biomedical researches of Vietnam National Children's Hospital;

The Ethics Commission in biomedical researches of Vietnam National Children's Hospital decides to approve the ethical aspects of the research project:

"Preterm birth in Vietnam: Direct medical cost assessment and the investigation of parents' experience and satisfaction with health care services".

Research Investigator: Nguyen Thi Binh An, MPH (PhD student – Swiss Tropical and Public Health Institute, Basel, Switzerland)

Supervision Organization: Vietnam National Children's Hospital

Estimated time of data collection: 15/01/2018 – 30/3/2018

Approval date: 20/01/2018

The attached documents include:

- Checklist of ethical clearance process.
- Research proposal
- Research questionnaires

The research investigator has to report to the Ethics Commission of Vietnam National Children's Hospital about the disadvantages, severely disadvantages in data collection

The research investigator has to implement the data collection in accordance with the contents of the research proposal and report immediately to the Ethics Commission of Vietnam National Children's Hospital if there is a change in implementation of data collection compared to content of the proposal when it is approved.

The research investigation has to submit the annual report and final report of research to the Ethics Commission of Vietnam National Children's Hospital.

To:

- Research Investigator
- Documents officer VNCSKTE

CHAIRMAN OF COMMISSION

(Signed and sealed)

Assoc. Prof.. Tran Minh Dien



BỘ Y TẾ
BỆNH VIỆN NHI TRUNG ƯƠNG
Số: 166./BVNTW-VNCSKTE

CỘNG HÒA XÃ HỘI CHỦ NGHĨA VIỆT NAM
Độc lập – Tự do – Hạnh phúc
Hà Nội, ngày 29 tháng 01 năm 2018

**CHỨNG NHẬN CHẤP THUẬN CỦA HỘI ĐỒNG ĐẠO ĐỨC
TRONG NGHIÊN CỨU Y SINH HỌC**

Căn cứ Quyết định số 812/QĐ-BVNTU, ngày 09 tháng 03 năm 2017 của Giám đốc Bệnh viện Nhi Trung ương về việc “Thành lập Hội đồng Đạo đức trong Nghiên cứu Y khoa Bệnh viện Nhi Trung ương”;

Căn cứ chứng nhận số IRB00009162 của Hoa Kỳ chấp nhận Hội đồng Đạo đức Bệnh viện Nhi Trung ương ngày 21/12/2012;

Căn cứ qui chế làm việc và qui trình xét duyệt của Hội đồng Đạo đức trong Nghiên cứu Y sinh học của Bệnh viện Nhi Trung ương;

Hội đồng Đạo đức trong Nghiên cứu Y sinh học Bệnh viện Nhi Trung ương quyết định phê duyệt về khía cạnh đạo đức cho đề tài nghiên cứu:

“**Sinh non tại Việt Nam: Đánh giá chi phí điều trị tức tiếp, tìm hiểu trải nghiệm của cha mẹ trẻ sinh non và đánh giá sự hài lòng của cha mẹ trẻ sinh non với dịch vụ**”.

Chủ nhiệm đề tài: ThS. Nguyễn Thị Bình An (Nghiên cứu sinh – Viện Nhiệt đới và y tế công cộng Thụy Sĩ, Basel, Thụy Sĩ)

Cơ quan chủ trì: Bệnh viện Nhi Trung ương.

Thời gian nghiên cứu: 15/01/2018 – 30/3/2018.

Ngày chấp thuận: 20/01/2018.

Các hồ sơ tài liệu nghiên cứu chính đệ trình kèm theo gồm có:

- Bảng kiểm lựa chọn quy trình xem xét đạo đức.
- Đề cương nghiên cứu.
- Phiếu điều tra.

Nghiên cứu viên chính phải báo cáo cho Hội đồng Đạo đức Bệnh viện Nhi Trung ương các trường hợp biến cố bất lợi, biến cố bất lợi trầm trọng theo đúng các quy định hiện hành.

Nghiên cứu viên chính phải nghiêm túc thực hiện nghiên cứu theo đúng nội dung đề cương đã phê duyệt, phải báo cáo ngay cho Hội đồng Đạo đức Bệnh Viện Nhi Trung ương khi có sự thay đổi trong quá trình thực hiện đề tài so với đề cương khi được phê duyệt.

Nghiên cứu viên chính phải nộp báo cáo hàng năm, báo cáo kết thúc nghiên cứu cho Hội đồng Đạo đức Bệnh viện Nhi Trung ương.

Nơi nhận:

- Chủ nhiệm đề tài.
- Văn thư, VNCSKTE.

CHỦ TỊCH HỘI ĐỒNG
K/T GIÁM ĐỐC
PHÓ GIÁM ĐỐC


PGS.TS. Trần Minh Điển

