SEVERE MATERNAL AND NEONATAL MORBIDITY STATUS AND QUALITATIVE EXPLORATION OF HIGH-RISK, REFERRAL REFUSALS AND QUALITY OF CARE IN MORANG DISTRICT, NEPAL

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SEVERE MATERNAL AND NEONATAL MORBIDITY STATUS AND QUALITATIVE EXPLORATION OF HIGH-RISK, REFERRAL REFUSALS AND QUALITY OF CARE IN MORANG DISTRICT, NEPAL

by

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LIST OF ABBREVIATIONS

ANC   antenatal care

APGAR   appearance, pulse, grimace, activity, and respiration

BMI   body mass index

BP   blood pressure

CI   confidence interval

DHS   Demographic and Health Surveys

EDD   expected date of delivery

FHR   fetal heart rate

GDM   gestational diabetes mellitus

HIV   Human immunodeficiency virus

HR   heart rate

HRP   high-risk pregnancy

IUGR   intrauterine growth restrictions

LB   live births

LBW   low birth weight

LNMP   last normal menstrual period

MMR	**maternal mortality ratio**
MNM	**maternal near miss**
NAOI	**neonatal adverse outcome indicator**
NICU	**neonatal intensive care unit**
NM	**near miss**
NNM	**neonatal near miss**
OR	**odds ratio**
PHCC	**primary health care centre**
PIH	**pregnancy induced hypertension**
RR	**relative risk**
SAMM	**severe acute maternal morbidity**
SBA	**skilled birth attendant**
SDG	**Sustainable Development Goals**
SMM	**severe maternal morbidity**
TBAs	**traditional birth attendants**
UN	**the United Nations**
UNICEF	**United Nations International Children Emergency Fund**

USM   **Universiti Sains Malaysia**

WHO   **World Health Organization**

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STATUS MORBIDITI IBU DAN NEONATAL YANG TERUK DAN EXPLORASI KUALITATIF BERISIKO TINGGI, KEENGGANAN RUJUKAN DAN KUALITI PENJAGAAN DI DAERAH MORANG, NEPAL

ABSTRAK

Pengenalpastian awal wanita hamil yang berisiko mengalami komplikasi semasa kelahiran, adalah asas untuk penjagaan antenatal (ANC) dan strategi penting untuk mencegah kematian ibu. Ketersediaan perkhidmatan tidak selalu meningkatkan penggunaannya. Kualiti penjagaan harus dipantau berdasarkan persepsi pesakit. Kajian ini bertujuan untuk menentukan stratifikasi risiko, morbiditi ibu yang teruk (SMM), dan neonatal *near miss* (NNM). Ia meneroka hubungan antara stratifikasi risiko dan SMM dan faktor-faktor yang berkaitan dengan SMM dan NNM. Kajian ini meneroka makna atau kehamilan berisiko tinggi, halangan untuk tidak mematuhi perkhidmatan rujukan dan persepsi perkhidmatan antenatal dan kelahiran berkualiti dalam kalangan wanita berisiko tinggi. Ini adalah kajian campuran di mana kajian kohort prospektif di hospital, kajian keratan rentas dan kajian fenomenologi diterapkan. Sebanyak 346 wanita hamil, 1000 bayi baru lahir dan 14 peserta berisiko tinggi telah terlibat. Kajian kuantitatif dilaksanakan di Koshi Hospital dan kajian kualitatif di daerah Morang di Nepal. Analisis regresi logistik berganda dan analisis tematik dilakukan. Prevalen kehamilan berisiko tinggi adalah 14.4%, SMM 6.6%, dan NNM 7.9%. Stratifikasi risiko dan SMM dikaitkan secara signifikan. Tahap pendidikan dikaitkan dengan SMM. Buta huruf, mengandung ramai, SMM, dan caesar dikaitkan dengan NNM. Sembilan tema muncul dalam kajian kualitatif: (i) pengetahuan dan pemahaman risiko, (ii) menormalkan dan tidak menerima risiko, (iii) pilihan kelahiran di rumah, (iv) kemerosotan autonomi dan ketergantungan kewangan wanita, (v) faktor bersyarat, (vi) faktor sosiobudaya, (vii) pendapat wanita dan faktor

perkhidmatan kesihatan yang memuaskan, (viii) harapan terhadap kemudahan dan kakitangan kesihatan, (ix) kekurangan cadangan untuk meningkatkan kualiti penjagaan. Wanita berisiko tinggi empat kali lebih tinggi kemungkinan mengalami SMM daripada wanita berisiko rendah. Tindak lanjut ANC secara rutin dapat mengenal pasti dan mencegah faktor berisiko tinggi pada kehamilan dan disyor untuk digunakan. Petugas kesihatan harus sedar bahawa persepsi risiko adalah subjektif. Walaupun risiko kehamilan atau kelahiran diberitahu, wanita mungkin tidak sepenuhnya yakin atau menafikan bahawa mereka berisiko. Fakor kepatuhan pada rujukan untuk kelahiran hospital dalam kalangan wanita hamil berisiko tinggi adalah kemiskinan. Mereka kurang mengetahui hak asas reproduktif mereka. Wanita menilai kualiti penjagaan dari segi tingkah laku interpersonal kakitangan, bekalan ubat percuma, pengalaman peribadi, atau pendapat saudara mereka.

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ABSTRACT

Early identification of pregnant women at risk of developing complications at birth, is fundamental to antenatal care (ANC) and an important strategy to prevent maternal death. The availability of services does not always increase their use. The quality of care should be monitored based on patients' perceptions. This study aims to determine the magnitude of risk stratification, severe maternal morbidity (SMM), and a neonatal near miss (NNM). It further explored association between risk stratification and SMM and the associated factors of SMM and NNM. This study explored the meaning of high-risk pregnancy, the barriers to non-adherence to referral services and the perceptions of good-quality antenatal and birthing services among women with high-risk factors. This was a concurrent mixed-method study where hospital-based prospective cohort study, a cross-sectional study and a phenomenological study was applied. A total of 346 pregnant women, 1000 newborns and 14 participants with high-risk factors were enrolled. The quantitative study was conducted at Koshi Hospital and qualitative study within Morang district in Nepal. Multiple logistic regression analyses and thematic analysis were performed. The prevalence of high-risk pregnancy was 14.4%, SMM 6.6%, and NNM 7.9%. Risk stratification and SMM were significantly associated. Maternal education was significantly associated with SMM. Illiteracy, multiparity, SMM, and caesarean section were associated with NNM. Nine themes emerged in the qualitative study: (i) knowledge and understanding of risk, (ii) normalizing and non-acceptance of risk, (iii) preference of

homebirth, (iv) women's diminished autonomy and financial dependence, (v) conditional factors, (vi) sociocultural factors, (vii) women's opinions and satisfactory factors of health services, (viii) expectations of the health facility and staff, (ix) a lack of suggestions to improve the quality of care. Women with high-risk factors were four times more likely to develop SMM conditions than low-risk women. Routine ANC follow-up could identify and prevent high-risk factors related complications in pregnancy and is recommended to be used. Healthcare providers should be aware that risk perception is a subjective matter. Although risk in pregnancy or childbirth is communicated, women may not be fully convinced or deny that they are at risk. Adherence to a referral for hospital birth among high-risk pregnant women was poor among the poorest segments. They lack knowledge of their basic reproductive rights. Women judge the quality of care in terms of staff interpersonal behavior, free drug supply, personal experiences, or based on their relative's recommendations.

CHAPTER 1 INTRODUCTION

In this introduction chapter, topics of interest are introduced with their background. In the background section, previous history of interest topics, their current situation, and possible gaps are introduced. The importance of the proposed research is included in the problem statement. This introduction chapter also includes research questions, study objectives, hypothesis, and operational definition. The end of the chapter includes the study's significance, which justifies why this research is needed.

1.1 Introduction

Maternal mortality remains a major public health issue worldwide, particularly in low resource countries which account for 85% of total maternal deaths (World Health Organization, 2014). Maternal mortality is extremely sensitive to standards of obstetric care (Rosenfield and Maine, 1985). The global maternal mortality ratio is 211 maternal deaths per 100,000 live births in 2017 (World Health Organization, 2019). The Sustainable Development Goal targets to reduce the global maternal mortality ratio (MMR) to less than 70 per 100,000 live births by 2030 (World Health Organization, 2019).

Globally, the MMR declined by 38% between 2000 and 2017; the greatest decrease during this period was in Southern Asia, with a nearly 60% reduction in MMR (World Health Organization, 2020). It is a widely studied public health problem worldwide (World Health Organization, 2014), but the existing research on maternal health represents only a fraction of the problem (Camargo *et al.*, 2011). About 40%–50% of maternal deaths are deemed preventable (Zuckerwise and Lipkind, 2017). The

maternal mortality ratio in Nepal was 239 per 100,000 live births (Ministry of Health Nepal *et al.*, 2017). Consistent with maternal mortality, severe maternal morbidity (SMM) rates are higher in low- and middle-income countries (Geller *et al.*, 2018) including Nepal.

Antenatal care (ANC) is an umbrella term used to describe the medical procedures and care performed during pregnancy (McDonagh, 1996). It is an entry point for a woman to the health care system for obstetric care, which could lower maternal deaths (Do *et al.*, 2017). The maternal and child care programs' central focus has been detecting pregnancies at risk and preventing the complications through antenatal screening (Prual *et al.*, 2000). The routine ANC consists of a number of scheduled visits aiming at detecting symptomless complications, monitor deviation of fetal growth, provide psychosocial support and provide health education to the pregnant women (Lindmark and Cnattingius, 1991). Antenatal care is concerned with adequate care of pregnant women (Yeoh *et al.*, 2016a). There should be continuous effort to improve ANC services.

Risk refers to the presence of any characteristic or factor that increases the probability of adverse consequences (World Health Organization, 1978). Risk is defined as a hazard, danger, or exposure to peril (World Health Organization, 1978). A high-risk pregnancy is any condition associated with a pregnancy where there is an actual or potential risk to the mother or fetus (Holness, 2018). In high-risk pregnancy, the maternal environment or past reproductive performance presents a significant risk to mother or fetus wellbeing (Jain *et al.*, 2014). Women classified as "high-risk" have a chance of adverse pregnancy outcome greater than the incidence of adverse outcome in the general population (Majoko *et al.*, 2005). Worldwide, 10–30% of pregnancies are estimated to be "at-risk" (Nesbitt Jr and Aubry, 1969; Blackburn, 1986; Mehta,

2013; Jaideep *et al.*, 2017). Women with risk factors for high-risk pregnancies have a one in four chance of developing complications compared to those with a low-risk pregnancies who have nearly one in ten (Lennox, 1984). The central focus of maternal and childcare programs has been the detection of at-risk pregnancies to prevent women from developing obstetric complications in childbirth (Groot *et al.*, 1993; Prual *et al.*, 2000). Risk assessment is a key component of ANC and has demonstrated benefits in improving maternal and perinatal outcomes (Dujardin *et al.*, 1995; Jordan and Murphy, 2009; Kolluru and Reddy, 2016). However, in Nepal, risk stratification is not practiced in routine ANC of four visits. Obstetric interventions are selectively applied to high-risk pregnancy to increase the likelihood of a favourable outcome (LeFevre *et al.*, 1989).

Risk scoring systems use risk factors during the antepartum, intrapartum, and neonatal periods separately or in combination, for risk stratification. Studies have suggested that to manage antepartum conditions, there should be an adequate period between identifying the risk factors and childbirth (Goodwin *et al.*, 1969; Majoko *et al.*, 2002; Burstyn, 2010). Obstetric complications may occur anytime during pregnancy, labour, birth, and puerperium, ranging from mild to severe, sometimes life-threatening. Therefore, the most accurate estimates of at-risk women can be made during late pregnancy periods (World Health Organization, 2010).

A risk-oriented approach using color codes (red, yellow, green, and white) was adopted in Malaysia in 1989 (Ravindran *et al.*, 2003; Yeoh *et al.*, 2016a). Using this approach, a woman's risk status is assessed throughout her ANC visits. The allocated color code may change at each visit. The color-coded function is used as a managerial tool to determine the appropriate care providers and the location of further ANC visits and childbirth. This approach is routinely practiced in Malaysia and is included in the

country's checklist guideline for mother and baby health care following color code system (Kementerian Kesihatan Malaysia, 2013).

1.1.1 Severe maternal morbidity

Maternal near-miss (MNM) and severe maternal morbidity (SMM) are strategic indicators of maternal health conditions (Souza *et al.*, 2008) which are used as an alternative strategy to reducing maternal mortality (Dias *et al.*, 2014; Norhayati *et al.*, 2016a). The World Health Organization (WHO) adopted and defined standard criteria of MNM and SMM in 2009 (Say *et al.*, 2009). The purpose of developing these uniform criteria was to provide common ground for comparisons across countries (Say *et al.*, 2009; Souza *et al.*, 2012). Evidence-based practice to treat MNM cases can help reduce preventable morbidity and mortality (Bakshi *et al.*, 2016). MNM is also used as an indicator to examine the standards of obstetric care and clinical practice (Say *et al.*, 2009; Madeiro *et al.*, 2015; Mekango *et al.*, 2017).

The MNM refers to "a woman who nearly died but survived a complication that occurred during pregnancy, childbirth or within 42 days of termination of pregnancy" (Say *et al.*, 2009). The WHO working group has recommended the use of the term MNM as it best reflects the severity of events (Say *et al.*, 2009) although "severe acute maternal morbidity" (SAMM) is also used for MNM (Say *et al.*, 2009). These near-misses share many characteristics with maternal deaths and can provide valuable information about obstetric care, allowing corrective action to mitigate the identified problems in the future (Tanimia *et al.*, 2016).

If observed across a wide spectrum, women's health starts from a healthy pregnancy and ranges to maternal death. SMM lies somewhere between these two spectra (Pacheco *et al.*, 2014). The criteria for SMM include a list of potentially life-

threatening conditions, namely, (i) hemorrhagic disorders, (ii) hypertensive disorders, (iii) other systemic disorders, and (iv) severe management indicators (Say *et al.*, 2009; World Health Organization, 2011). MNM cases can emerge if appropriate care and actions are not taken during the SMM stage (Say *et al.*, 2009). The terms "near-miss" and "severe maternal morbidity" are used interchangeably in the literature, but SMM reflects a less severe condition than MNM (Geller *et al.*, 2004b; Galvão *et al.*, 2014). SMM refers to "potentially life-threatening conditions during pregnancy, childbirth, or after the termination of pregnancy from which maternal near-miss cases would emerge" and is assessed based on the WHO criteria. While both "SMM" and "potentially life-threatening conditions" are used, the term SMM will be applied in this study.

The MNM is a multifactorial condition (Worke *et al.*, 2019). The risk factors for SMM are non-modifiable and modifiable; the non-modifiable risk factors can be prevented via provider- and system-level interventions, while for the modifiable risk factors, timely and proper treatment should be introduced to stop further aggravating medical conditions (Gray *et al.*, 2012). The most frequently studied SMM predictors are sociodemographic characteristics, previous obstetric conditions, and current obstetric conditions.

Research on the WHO near-miss approach has largely been limited to low- to middle-income countries, with very few studies in North America or Europe (England *et al.*, 2020) as the MNM rates are still higher in the former regions than in high-income countries (Chhabra, 2014; Geller *et al.*, 2018). The WHO uses clinical-, laboratory-, and management-based criteria to identify MNM (Giordano *et al.*, 2014). Many studies, especially those in low-income countries, have used a modified version of the WHO near-miss approach, mainly due to its limited applicability in low-income

settings, notably due to the laboratory- and management-based criteria (Tura *et al.*, 2019; England *et al.*, 2020). The adapted WHO criteria was recently suggested by the experts (Tura *et al.*, 2017) and one study had implemented the adapted "sub-Saharan African" MNM criteria in Ethiopia (Tura *et al.*, 2020). It is necessary to determine a relevant measurement of SMM (Nam & Park, 2020) and investigate the factors associated with SMM to improve maternal healthcare services (Galvão *et al.*, 2014). Studies on SMM determinants are not well-studied in Nepal, and this is, therefore, the first study to explore the determinants of SMM using the WHO criteria.

1.1.2 Neonatal near miss

The rate of paediatric mortality has long been considered an important indicator of social development, the level of economic prosperity, and healthcare quality. Globally, a 51% decline in neonatal mortality was recorded between 1990 and 2017; however, the decline in neonatal mortality has been slower than that of post-neonatal under-five mortality (Hug *et al.*, 2019). At the country level, annual neonatal mortality rates range from 0.9 to 44.2 deaths per 1,000 live births (Hug *et al.*, 2019).

South Asia had 25 neonatal deaths per 1,000 live births in 2018 (WHO, 2018), and is a hub of the highest number of neonatal deaths along with sub-Saharan Africa (Hug *et al.*, 2019); a child born in this region is 10 times more likely to die in the first month of life than a child born in a high-income country (WHO, 2018). The objective of Sustainable Development Goal 3 and that of the global Every Newborn Action Plan is to reduce neonatal mortality to 10 or less per 1,000 live births by 2030 (WHO and UNICEF, 2014).

The neonatal mortality rate in Nepal was 21 per 1,000 live births in 2016; of the total neonatal deaths, about four-fifths (79%) were early neonatal deaths; and 57% of all

births were health-facility births (Ministry of Health Nepal *et al.*, 2017). There are large variations in neonatal mortality within provinces, i.e. 15 vs 41 per 1,000 live births (Ministry of Health Nepal *et al.*, 2017). Nepal needs to reduce the rate of neonatal mortality by more than half in the next 10 years to achieve Sustainable Development Goal (target 3.2). Thus, accelerated efforts are needed to address interprovincial disparities concerning neonatal mortality rates. Neonatal near miss (NNM) is a novel concept that has recently emerged and is similar to MNM concept. It provides vital information required for an evaluation of the quality of care provided in the hospital and explores opportunities to improve healthcare providers' performance (WHO, 2004). Neonatal near-miss events occur three to six times more often than neonatal deaths (Nakimuli *et al.*, 2015a; Tekelab *et al.*, 2020). Thus, NNM evaluations can provide abundant evidence of neonatal deaths' causal pathways (Mathai, 2005).

The conceptualization of the term "NNM" in 2009, similar to "MNM," was proposed by Avenant (Pattinson, 2009). That same year, Pileggi *et al.* established pragmatic NNM criteria using the WHO Global Survey on Maternal and Perinatal Health (WHOGS) 2005 data (Pileggi *et al.*, 2010). The initial definition of pragmatic markers included very low birth weight (i.e., <1,500 g), <30 gestational weeks at birth, or an Appearance, Pulse, Grimace, Activity, and Respiration (Apgar) score of <7 at five minutes of life in neonates who went on to survive for seven days (Pileggi *et al.*, 2010).

Pileggi-Castro *et al.* re-evaluated the NNM definition using the WHOGS data and validated the revised definition using the WHO Multi-Country Survey on Maternal and Newborn Health data. The NNM refers to "an infant who nearly died but survived a severe complication that occurred during pregnancy, birth, or within seven days of extra-uterine life" (Pileggi-Castro *et al.*, 2014). The recommended pragmatic criteria

were birthweight of <1,750 g, <33 gestational weeks, or an Apgar score of <7 at five minutes of life in newborn infants who survived for seven days (Pileggi-Castro *et al.*, 2014).

Whereas for diagnostic accuracy, the management markers from this definition included the use of therapeutic intravenous antibiotics, nasal continuous positive airway pressure, intubation, phototherapy within the first 24 hours, cardiopulmonary resuscitation, vasoactive drugs, anticonvulsants, surfactant administration, blood products, steroids to treat refractory hypoglycemia, and surgery in early neonatal life (Pileggi-Castro *et al.*, 2014). The pragmatic criteria and management markers developed by Pileggi-Castro *et al.* were shown to have a sensitivity of 93% and specificity of 97% (Pileggi-Castro *et al.*, 2014).

There is no uniform definition of NNM to this date, although some NNM studies are available. Systematic reviews on NNM, conducted in 2015 and 2017, had recommended developing a standard definition for NNM (Santos *et al.*, 2015a; Surve *et al.*, 2017). The worldwide prevalence of NNM ranged from 39.2 to 131 per 1,000 live births in 2014 and 2018 (Silva *et al.*, 2014b; de Lima *et al.*, 2018). A population-based study conducted in Nepal applied community-appropriate NNM criteria adapted from Pileggi *et al.* (Pileggi *et al.*, 2010), and adjusted to the local context, demonstrated a prevalence of 22 per 1,000 live births (Rana *et al.*, 2018). NNM was shown to be caused by birth asphyxia (70%), very low birth weight (17%), neonatal sepsis (10%), and prematurity (3%) (Rana *et al.*, 2018).

1.1.3 Risk perceptions

Risk perception is defined as "a person's expectancy about the probability of an event" (Bayrampour *et al.*, 2013). It is a highly individualized concept and not solely based

on medical diagnoses (Heaman *et al.*, 2004). The way a woman perceives her risk can affect her healthcare decisions, motivations to seek antenatal care (Dujardin *et al.*, 1995), decisions about place of birth or choice about intensive medical interventions, adherence to medical recommendations and procedures, and other health behaviors (Jahn *et al.*, 1998; Kowalewski *et al.*, 2000; Bayrampour *et al.*, 2013; Lee, 2014). Risk perceptions or an individual's perceived susceptibility to a threat are a key component of many health behavior change theories (Ferrer and Klein, 2015).

The risk approach is one strategy to reduce maternal and perinatal mortality and morbidity (World Health Organization, 1978). Risk assessment is a process that started early in pregnancy. According to risk approach, previous or current obstetric risk factors and events are systematically examined, and risk factors that require close examination are identified for appropriate treatment (Blackburn, 1986; Kowalewski *et al.*, 2000). These women are then provided with timely referrals to places where the necessary expertise and equipment are available to prevent or minimize the anticipated adverse pregnancy outcome (Kowalewski *et al.*, 2000). To encourage health-facility births, risk screening should be followed by proper counselling of high-risk women (Aniebue and Aniebue, 2008).

Individual risk understanding is dependent on personal life philosophy, previous experience, history, and the sociocultural context (Carolan, 2009). Pregnant women understand the risk from the social approach, where the risk is influenced by the social, cultural, and political milieu in which they live (Slavin *et al.*, 2004; Carolan, 2009). High-risk pregnant women weigh up many factors and determine how they perceive the risks they face (Lee, 2014).

Risk perception mainly consists of two elements: i) a statistical assessment of how likely an event occurs and ii) a psychological component, which includes how women

feel about the risk (Alaszewski and Horlick-Jones, 2003; Lee, 2014). The statistical assessment can influence how healthcare providers present the risk, but people understand statistics at their level (Edwards *et al.*, 2002). The psychological component is affected by factors like life experience, coping strategies, and the context in which the risk occurs (Alaszewski and Horlick-Jones, 2003). Considerable differences exist between the proportion of pregnant women identified as "at-risk" and those who attend referral-level care in low-income countries (Dujardin *et al.*, 1995; Jahn *et al.*, 1998). In Nepal, only 32% of ANC attendees comply with the referral advice (Jahn *et al.*, 2000).

Pregnancy risk typically relies on scores derived from the risk-assessment tools scored by healthcare providers. These tools focus heavily on factors statistically associated with poor pregnancy outcomes and are typically skewed toward the biophysical domain (Gray, 2006). Mitigating high-risk conditions include adherence to early and frequent antenatal care, medical treatments, reduction of risk behaviors, and overall health (Brooten *et al.*, 2005). Evidence shows that expert-defined at-risk status had little influence on a woman's decision to seek hospital care (Kowalewski *et al.*, 2000). Births happen in the context of sociocultural norms (Bhattacharyya *et al.*, 2018). Pregnant women have different perceptions and interpretations of danger signs (Kowalewski *et al.*, 2000). Women made decisions based on their perceptions of whether their risk had increased or decreased, rather than on the actual numeric risk (Jordan and Murphy, 2009).

Researchers have indicated that risk perception in pregnancy is highly individualized, and it is not exclusively based on medical diagnoses (Heaman *et al.*, 2004; Lee *et al.*, 2014). This study aimed to explore the meaning of risk for high-risk pregnant women and how they perceive the risks they face.

1.1.4 Adherence

The WHO has defined the concept of compliance as the accomplishment of certain behaviors, such as taking prescribed medication, following a diet, executing lifestyle changes, and complying to the healthcare providers' recommendations (Sabaté and Sabaté, 2003). Thaddeus and Maine (Thaddeus and Maine, 1994) three delay model is the foundational model for studying delay in compliance. According to this model, non-adherence to a referral for childbirth in a birthing centre can be considered the first delay in decision making to seek care (Thaddeus and Maine, 1994). The referral process represents the handing over of care from a general practitioner to a specialist (Wåhlberg *et al.*, 2017). Referral during pregnancy is essential to ensure that women with high-risk pregnancies and complications access immediate and appropriate care (Jahn and De Brouwere, 2001). The adherence process requires both the patient and the healthcare providers' involvement and good communication among all involved parties.

Noncompliance with medical treatment is not unique to women with high-risk pregnancies (Donovan and Blake, 1992). Referral advice is given during pregnancy where these risk factors were not taken seriously as referral advice given during birth or when a complication occurred (Pembe *et al.*, 2008). Inconsistencies between risk appraisals made by pregnant women and healthcare providers have been noted as reasons for non-adherence (Gray, 2006). Pregnant women and their relatives may not accept a referral when they have seen other women with the same problem giving birth safely at home after being referred (Pembe *et al.*, 2008).

Facility-based birth assisted by a skilled birth attendant is a proven strategy to reduce maternal mortality (Campbell *et al.*, 2006). The facility-based birth coverage in Nepal is 63% (Ministry of Health, 2020), which is an increasing trend from 18% in 2006

(Ministry of Health and New Era and Macro International, 2006) to 57% in 2016 (Ministry of Health Nepal *et al.*, 2017), but is still not satisfactory progress. Women from poor and deprived communities are not utilizing the services that they should. The coverage of fourth ANC visit based on a national protocol for pregnant women, was about 56% (Ministry of Health, 2020).

Maternal and newborn morbidity and mortality are expected to decrease if referral during pregnancy is utilized appropriately (Gabrysch and Campbell, 2009). Many factors are involved in patients' noncompliance with facility-based birth, which is a major problem that prevents healthcare workers from achieving the desired outcomes of increasing the facility-based birth (Jin *et al.*, 2008), and failing to adhere to a referral can result in morbidity and mortality (Oosthuizen and Van Deventer, 2010). From the healthcare provider's perspective, noncompliance is an important issue because it significantly impacts the potential for increased disease progression and life-threatening consequences (World Health Organization, 2003). From the women's perspective, their perceptions of the quality of care at health facilities could influence their adherence to a referral (Pembe *et al.*, 2008).

Referral advice starts when a pregnant woman is identified as high-risk during the antenatal visits; the following decision-making process to adhere to this advice is a complex process intertwined by power dynamics at the household level (Pembe *et al.*, 2008). The purpose of the present study was to explore the barriers for non-adherence to referral hospitals in pregnant women with high-risk pregnancies.

1.1.5 Quality of care

The availability of maternal health services at a health facility does not always guarantee their access and use by women (Hulton *et al.*, 2000). Perceptions about poor-

quality health care (Andaleeb, 2001) and experiences can dissuade patients from using the available services (Hulton *et al.*, 2000; Andaleeb, 2001), and this is one of the factors in delaying seeking care (Thaddeus and Maine, 1994). There is growing evidence that the perceived quality of care services has a greater influence on patients' behavior (O'Connor *et al.*, 1994; Andaleeb, 2001), and the quality should be monitored based on clients perceptions (Bazant and Koenig, 2009). However, quality is not easy to define or measure (Hulton *et al.*, 2000).

The quality of care is viewed subjectively by individual patients (Larrabee and Bolden, 2001) and is repeatedly dismissed (Sofaer and Firminger, 2005). However, suppose a woman is unhappy with the quality of services and disrespectful treatment she receives. In that case, it does not matter how highly competent the clinical staff are; she may prefer home birth for future pregnancy with the support of traditional birth attendants (TBAs) (Hulton *et al.*, 2000). Assessing patients' perspectives of quality of care gives patients a voice to make services more responsive to their needs (Petersen, 1988; Duong *et al.*, 2004) and would lead to better outcomes (Hulton *et al.*, 2000; World Health Organization, 2000b).

Various frameworks of quality of care are available that can assess the quality of care from the users' perspective (Donabedian, 1988; Andaleeb, 2001), and several scales are used to evaluate patients' perceptions of care (Donabedian, 1988; Andaleeb, 2001). Data to be used in quality assessment can be obtained from diverse sources (Brook *et al.*, 1996).

The quality of ANC provided is often ritualistic and inevitably poor (Zanconato *et al.*, 2006). All women want the facility staff to provide "good" care. However, "good" care had multiple connotations (Bhattacharyya *et al.*, 2018). Clients were found to be willing to pay for private services and travel far if they perceived good quality of care

(Mrisho *et al.*, 2007). Healthcare professionals measure the quality of care in terms of process rather than outcome (Brook *et al.*, 1996), while patients measure it based on a combination of experiences, expectations, and perceptions (Dzomeku, 2011; Girma *et al.*, 2020). Women form their perceptions according to friends' and relatives' experiences, myths, and societal values (Dzomeku, 2011).

In low-income countries, the proportion of utilization of ANC services is higher than the utilization of health-facility birth (Mwaniki *et al.*, 2002; Dako-Gyeke *et al.*, 2013). One factor that hinder the acceptance of referral advice is the perceived quality of care at the hospitals (Kowalewski *et al.*, 2000; Pembe *et al.*, 2010b). Women will have their reasons for not receiving birthing services from the health facility, which need to be explored. The quality of care in maternity services has received inadequate attention (Hulton *et al.*, 2000). Despite this, it is considered a key component of the right to health and the route to equity and dignity for women and children (Tunçalp *et al.*, 2015). Quality of care can be measured from the provision of care provided from within the institution, and as experienced by users (Hulton *et al.*, 2000), the latter is explored in this study. This study attempts to explore women's perceptions of good-quality ANC and birthing services. Gaining an understanding of women's perceptions of the quality of care may improve public policies and result in better care for women.

1.1.6 Protection Motivation Theory

Ronald W. Rogers developed the protection motivation theory (PMT) in 1975 to understand the impact of fear appeals (Norman *et al.*, 2005). He then revised PMT in 1983 and added the concepts of reward and self-efficiency (Maddux and Rogers, 1983). According to Hebb, D.O. "fear is a state that motivates one to protect against danger or escape from a danger or harmful event" (Hebb, 1946). Fear is aroused as a

stimulus to a dangerous situation, which motivates a person to take protective actions, and it is related to both stimulus and response events (Rogers, 1975). Hovland *et al.* proposed that fear acts as a driving force that motivates trial and error behavior (Hovland *et al.*, 1953). In the PMT, a fear arousal is a crucial event that is mainly done through communication. Fear communication should be conducted in a way that evokes threat along with this fear arousal. According to the PMT, behavioural advice should always be included (Norman *et al.*, 2005).

The PMT shares a common concept—that the perceived threat motivates the individual toward taking protective actions to avoid the potential negative outcome—with three other theories: i) the health belief model, ii) the theory of reasoned action, and iii) subjective expected utility theory (Weinstein, 1993). These four theories also share a common idea of cost-benefit analysis. The individual weighs the costs of taking the precautionary action against the expected benefits of taking action (Weinstein, 1993).

There are three main stages in the new PMT model: i) sources of information, ii) cognitive mediating processes, and iii) coping modes. The information sources initiating any of the two cognitive mediating processes in the PMT are environmental or intrapersonal sources. Fear is aroused by convincing through verbal persuasion or observational learning, which are inputs from external environmental factors. People's personality traits or their prior threat experiences ignite intrapersonal threats. Exposure to information sources initiates two appraisal processes: threat or coping appraisal (Rogers, 1983). The maladaptive response is related to threat appraisal, whereas the adaptive response is linked to coping appraisal (Rogers, 1983). The threat appraisal pathway includes intrinsic rewards, extrinsic rewards, perceived severity, and vulnerability. The coping appraisal pathway consists of response efficacy, self-

efficacy, and response costs. Exposure to a threatening situation can lead to adaptive, maladaptive, or risky responses. The PMT outcome is the coping mode when the individual decides or intends to initiate, continue, or inhibit the applicable adaptive responses (Floyd *et al.*, 2000).

The PMT has been successfully applied to diverse topics, including areas beyond health-related issues (Floyd *et al.*, 2000). It can be applied to any threat for which there can be an effective recommended response that an individual can carry out (Floyd *et al.*, 2000). Thus, the current study applies the PMT to explain high-risk pregnant women's non-adherence to referral center births. Here, the desired outcome is the high-risk pregnant women's intended place of birth and the actual behavior of where they gave birth. While applying the PMT, complex social, cultural, and environmental factors must also be considered (Chambers *et al.*, 2016). In this study, the social and environmental factor was the "quality of care" experienced either by women or their close relatives that influenced their decisions.

1.2 Statement of the problem

The antenatal period is an entry point to the health care system for many women (Do *et al.*, 2017). Still, the content and scope of ANC programs are often ritualistic rather than evidence-based (Villar and Bergsjg, 1997). There is a growing consensus that ANC access is insufficient to alter the present maternal health conditions. Improving the quality of ANC services may be a key determinant to improving maternal and perinatal outcomes (Villar *et al.*, 2001). The new WHO guideline recommends eight contacts during a woman's pregnancy, starting from 12 weeks' gestation (World Health Organization). But, Nepal still follows recommended four ANC visits which are originally intended for women with low-risk pregnancies. The woman with high-

risk pregnancy does not fit into a blanket approach of four antenatal visits only. These women are lower in percentage, but they are the risk groups of women who had higher chances to develop complications during childbirth. Providing specialized care for every pregnant woman is not possible in low-income settings, so targeted interventions to high-risk pregnancy can save future complications and lives.

The rationale for providing ANC care is to screen predominantly healthy pregnant women to detect early signs of risk factors of development for abnormal conditions or diseases and to follow-up and provide effective and timely intervention to these at-risk women (Lumbiganon *et al.*, 2004). Use of high technology maternal and childcare is still unavailable in the low-income countries. Therefore, there is a need for a system that will identify women with high-risk pregnancies (Mufti and Mufti, 2008). Unfortunately, Nepal does not use any risk stratification approach so that women with higher risk gets required attention. Some women are at increased risk for complications even before they get pregnant and for some pregnancies, as pregnancies progress, it becomes high risk for a variety of reasons. A standard screening approach in a routine ANC care will decrease the chances of missing detecting high-risk pregnancies. In addition to this, in Nepal, there is insufficient evidence to reach a firm decision to reject study of ANC risk screening's effectiveness to detect high-risk pregnancy. Risk assessment tools look at-risk factors comprehensively, making it harder for risk factors to be overlooked. During routine ANC, the use of risk assessment tools will add value to prevent adverse effects in both mothers and their newborns. Evidence-based risk assessment is essential to providing optimal antenatal care (Jordan and Murphy, 2009).

Unlike maternal mortality, which is a distinct event, maternal morbidity is often more complex, resulting from many conditions of varying duration and severity (Adeoye *et al.*, 2015). Established obstetric risk factors with maternal complications can be

included in a screening tool to identify at-risk pregnancies during routine ANC check-ups. A risk factor is noteworthy even if it is not an effective predictor of the outcome of interest because it can be related indirectly with the outcome. Risk factors identification is often focused on secondary rather than primary prevention since many maternal complications can be treated but not prevented from occurring (Tsu, 1994). Study on identifying risk factors of SMM can reduce maternal mortality by ascertaining those factors that are modifiable by appropriate medical and public health interventions (Waterstone *et al.*, 2002; Goffman *et al.*, 2007).

In the global political health agenda, neonatal health still had insufficient visibility and attention. Neonatal health of infant will have a considerable long-term consequence in adulthood (Afrasiabi *et al.*, 2014). Countries from low- and middle-income are still struggling to reduce the neonatal mortality rates, and it is still one of the significant public health problems. NNM concept, although newly emerged, is globally relevant. There is still a gap in the knowledge and evidence in NNM, especially in low- and middle-income countries.

Women with high-risk pregnancies should be timely referred upon identification (Chard, 1991; Groot *et al.*, 1993; Majoko *et al.*, 2002; Davey *et al.*, 2015) and they must not just be referred but also be motivated to go to the referral centres with adequate services (Chard, 1991; Dujardin *et al.*, 1995; Majoko *et al.*, 2002; Davey *et al.*, 2015; De *et al.*, 2015b). Referral advice is not always followed due to various reasons which need to be explored e.g. women take referral advice more seriously during birthing than during pregnancy because of visible symptoms (Pembe *et al.*, 2008). Women's adherence to referrals for childbirth to the tertiary hospital due to their high-risk status during the antenatal period has received scant attention by researchers. In low-income countries, women attending antenatal clinics come only

once or twice and sometimes late in pregnancy (Zanconato *et al.*, 2006). The utilization of health-facility based deliveries is low mainly in low- and middle-income countries. Women's perceptions of the quality of care they receive from the health facility can be one reason for non-adherence.

1.3 Research questions

1. What is the prevalence of high-risk pregnancy in Morang district, Nepal?

2. What is the prevalence of severe maternal morbidity in Morang district, Nepal?

3. What is the association between risk stratification and severe maternal morbidity?

4. What are the associated factors for severe maternal morbidity?

5. What is the prevalence of neonatal near miss in Morang district, Nepal?

6. What are the associated factors for neonatal near miss?

7. How do the high-risk women perceive the meaning of having high-risk pregnancy?

8. What are the barriers to adhere to referral recommendations among high-risk pregnancy?

9. What are the perceptions of good-quality antenatal and delivery services among high-risk pregnancy?

1.4 General objective

To determine the prevalence of high-risk pregnancies, severe maternal morbidity and neonatal near miss, to identify the associated factors for severe maternal morbidity and neonatal near miss, and to explore the perception of risk, quality of care and reasons of non-adherence among high-risk women.

1.5 Specific objectives

Phase I (prospective cohort study)

1. To determine the prevalence of high-risk pregnancy in Morang district, Nepal.

2. To determine the prevalence of severe maternal morbidity in Morang district, Nepal.

3. To determine the association between risk stratification and severe maternal morbidity status.

4. To identify the associated factors for severe maternal morbidity.

Phase II (cross-sectional study)

5. To determine the prevalence of neonatal near miss in Morang district, Nepal.

6. To identify the associated factors for neonatal near miss.

Phase III (phenomenological study)

7. To explore the meaning of high-risk pregnancy among high-risk women.

8. To explore the barriers for non-adherence to referral among the high-risk women.

9. To explore the perception of good quality antenatal and delivery services among the high-risk women.

1.6 Operational definitions

Risk stratification refers to the four color codes based on the risk stratification approach, i.e., red, yellow, green, and white, used to assess the risk in Malaysia's antenatal women (Table 4) (Ministry of Health Malaysia, 2013). In this study, high-risk refers to red and yellow color codes, and low-risk refers to green and white color codes.

Severe maternal morbidity refers to "potentially life-threatening conditions during pregnancy, childbirth or after the termination of pregnancy from which maternal near miss cases would emerge." It includes haemorrhagic disorders, hypertensive disorders, other systemic disorders, and severe management indicators (Say *et al.*, 2009; Souza *et al.*, 2011). The identification of SMM were made based on WHO severe maternal morbidity criteria (Table 5). Presence of at least one of the criteria fulfils the inclusion criteria for severe maternal morbidity status.

Neonatal near miss refers to "an infant who nearly died but survived a severe complication that occurred during pregnancy, birth or within seven days of extra-uterine life" (Pileggi et al., 2014). The identification of NNM were made using both pragmatic and management criteria (Table 6). Presence of at least one of the criteria fulfils the inclusion criteria for NNM status.

Non-adherence refers to giving birth at the birthing centre or homebirth instead of referral hospital after referral advice made from the primary level of care.

Birthing centre refers to community-level health institution that provides basic emergency obstetric and neonatal care. The birthing centre provides seven basic services: administration of parenteral antibiotics; uterotonic drugs; parenteral anticonvulsants; manual removal of the placenta; removal of retained products; assisted vaginal birth; and basic neonatal resuscitation (Devkota *et al.*, 2011). The birthing centres are either a primary health care centre or a health post with basic emergency obstetric and neonatal care and have a skilled birth attendant who can assist normal births.

Referral hospital refers to hospitals with comprehensive emergency obstetric and neonatal care that provides caesarean section, blood transfusion and neonatal resuscitation in addition to the seven basic services (Devkota *et al.*, 2011).

1.7 Significance of the study

One of the purposes of routine ANC check-ups is identifying patients at-risks who might develop complications in their pregnancies with adverse outcomes. Numerous risk scoring systems are available and researched worldwide, but scant evidence were available from Nepal, including estimates of high-risk prevalence. There is no standard risk stratification guideline available in Nepal. Therefore, regular screening for high-risk status is not part of the routine ANC. The well-established simple checklist based color-coded risk stratification approach is used as a managerial tool in Malaysia to stratify risk among pregnant women. This color-coded risk stratification was chosen in this study because it can be applied at any time during pregnancy. Even uneducated women will understand color based coding. Additionally, it is easier to use, which does not include scoring and its summation. Malaysia has shown a successful history of reducing maternal morbidity. One of the credits goes to the implementation of the

color-coded risk stratification strategy. And lastly, this approach has the potential to be used beyond Malaysia.

Currently, maternal mortality ratio of Nepal is 239 per 100,000 live births (Ministry of Health Nepal *et al.*, 2017). The government of Nepal is aiming to reduce this indicator to 70 per 100,000 live births to meet the Sustainable Development Goal by 2030. Prevalence of SMM will be an effective measure for the hospital administration and the policy makers to understand its magnitude. Besides, SMM conditions not only puts the woman's life at-risks but also her fetus or neonates may suffer consequences of morbidity and mortality, therefore, its study will help in preventing a woman's progression along the continuum of severity (Geller *et al.*, 2018). In addition, studying maternal indicators like SMM is a new trend to understand factors that might aggravate maternal complications toward maternal deaths.

High-risk pregnancies if not timely managed with medical intervention, would develop maternal complications like SMM during labour. However, very few studies had explored the association between high-risk pregnancies and SMM. The majority of studies in the past had focused on exploring high-risk pregnancies to prevent adverse perinatal outcomes. So, this study had investigated associations of one of the less explored areas.

The child mortality rate has long been used as an important indicator of social development, economics, and healthcare quality to compare in between progress of countries. Globally, the decline in the neonatal mortality rate has been sluggish than under-five mortality rates. The Sustainable Development Goal 3 is to reduce neonatal mortality to at least 12 per 1000 live births by 2030. There is a large variation in neonatal mortality between provinces ranging from 15–41 per 1000 live births (Ministry of Health Nepal *et al.*, 2017). Statistics on neonates surviving the neonatal

period are not necessarily collected when assessing health care in pregnancy. It may give a false sense of complacency that everything is well. Study, including the near miss cases will have several advantages over studying only the neonatal mortality causes alone because these neonates have survived because of an effective intervention. A thorough investigation and study of factors involved in NNM cases can indicate areas that need better management to decrease neonatal deaths.

Research on identifying associated factors of SMM and NNM cases will reduce mortality by determining those factors that are modifiable by appropriate medical and public health interventions (Waterstone *et al.*, 2002; Goffman *et al.*, 2007). It will reduce the gap in knowledge in the field of maternal and child health. This study will strengthen the healthcare system and annual audit of these events to identify prevalence of life-threatening conditions at birth and during neonatal period, and thereby help develop an annual strategy for neonatal management in each setting.

Risk screening should be followed by the proper counselling of women among the high-risk category. The way woman perceives her risk can affect her health care use, motivations to seek ANC, decisions about place of birth, and adherence to medical recommendations. The success of ANC programmes based risk screening is the utilization of referral hospital by high-risk women (Dujardin *et al.*, 1995). Contradictory to this expectation, literature showed that women referred during routine ANC, 32% (Jahn *et al.*, 2000) to 43% (Prual *et al.*, 2000) women did not adhere to the referral advice. Researchers have indicated that–risks perception in pregnancy is highly individualized, and it is not exclusively based on medical diagnoses (Heaman *et al.*, 2004; Aniebue and Aniebue, 2008; Lee *et al.*, 2014). In addition, the general concept of pregnancy risk perceptions (Heaman *et al.*, 2004; Bayrampour *et al.*, 2012) has received scant attention. Little or no research on women's perceptions of