THE DECISION-MAKING PROCESS IN REFERRAL OF RISK PREGNANCIES IN THE INTERIOR OF SURINAME

BARRIERS AND EXPERIENCES

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Decision- making process in referral of risk pregnancies in the interior of Suriname. Barriers and experiences

A thesis submitted in partial fulfillment of the requirement for the degree of Master of International Health

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Declaration: Where other people's work has been used (either from a printed source, internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements. The thesis *Decision-making process in referral of risk pregnancies in the interior of Suriname. Barriers and experiences* is my own work.

Signature:.....

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For Manu and Luca

" May your choices reflect your hopes, not your fears"

Nelson Mandela

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ABBREVIATIONS

ANC	Antenatal care
BEmONC	Basic Emergency Obstetric and Neonatal Care
BOG	Bureau Openbare Gezondheidszorg/ Bureau of Public Health
CEmONC	Comprehensive Emergency Obstetric and Neonatal Care
CMWO	Commissie Mensgebonden Wetenschappelijk Onderzoek/ Ethical Board
FGD	Focus Group Discussion
HCA	Health Care Assistant
IDI	In-Depth Interview
KIT	Koninklijk Instituut voor de Tropen/ Royal Tropical Institute
IMPAC	Integrated Management of Pregnancy and Childbirth
MM	Medical Mission Primary Health Care Suriname
MMR	Maternal Mortality Ratio
MoH	Ministry of Health
OPD	Outdoor Patient Department
PHC	Primary Health Care
RGD	Regionale Gezondheidsdienst /Regional health Services
TBA	Traditional Birth Attendant
UNICEF	United Nations Children's Fund
VU	Vrije Universiteit/Free University
WHO	World Health Organization

DEFINTITION OF TERMS

Autonomy	A woman's capacity to make life-affecting choices. (1)
Empowerment	Empowerment is defined as: "*a process by which those who have been denied the ability to make choices acquire such an ability*".(2)
Female respondent	In this study defined as a woman who experienced a risk pregnancy in the last year.
Grand Multiparity	In this study defined as ≥7 live births and stillbirths ≥20 weeks of gestation in history.
Maternal Mortality	Defined as the death of a woman while pregnant or within 42 days of termination of pregnancy or irrespective of the duration and site of pregnancy, from any cause related to, or aggravated by the pregnancy or its management but not from accidental or incidental causes.(3)
Maternal Mortality Ratio	Defined as the number of maternal mortality per 100.000 live birth.(4)
Neonatal mortality	Defined as the death of a live born baby within the first full 28 days of life.(3)
Risk pregnancy	A risk pregnancy in this study is defined as a pregnancy which faces a higher risk on poor maternal or neonatal birth outcomes. Examples are teenage pregnancy, grand multiparity in history or pregnancy complicated by diabetes, hypertension or anemia. Adapted from(5).
Teenage pregnancy	Defined as a pregnancy in a girl between 10 and 19 years of age.(3)

ABSTRACT

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Title: *The decision-making process in referral of risk pregnancies in the interior of Suriname. Barriers and experiences*

Problem Statement: Maternal death is in the majority of cases preventable by quality care around birth. Referral of risk pregnancies is a strategy to support appropriate care around birth. This strategy relies on women, who experience a risk pregnancy, to be compliant to referral and give birth at such facilities. However, in the context of MM, non-compliance to referral is often seen. This non-compliance could lead to complex deliveries in an environment not capable of managing those deliveries and death of mother or child is seen. The decision-making process in referral is complex and not well studied. Therefore factors of influence on this process remain unknown. The aim of this study is to determine factors of influence on the decision-making process in referral of risk pregnancy in the interior of Suriname to suggest interventions that contribute to improved referral policies and practices.

Methods: This study consisted of a review of literature and a qualitative study incorporating in-depth interviews and focus group discussions. Participants (n= 64) included women who experienced a risk pregnancy in the last year, health care providers and community members. The study area included three villages in the interior of Suriname.

Results: The decision-making process in referral of risk pregnancies was influenced by many factors. Most mentioned factors were lack of autonomy of the pregnant women, lack of money and lack of housing availability. Underlying causes as poverty and low education were seen. Furthermore poor health care providers' attitude was seen which influenced access to care. Finally, delay in receiving a health care insurance led to inadequate care around birth for half of the women in this study.

Conclusion and recommendations: Women with a risk pregnancy face many barriers within current referral system of MM. Without interventions addressing these barriers, adequate care around birth will not be guaranteed. Priority should be placed in solving delay in receiving a healthcare insurance and exploring the possibility of maternity waiting homes as they improve access to care. Furthermore the lack of autonomy for women and underlying causes like poverty and gender inequality should be acknowledged and policies should incorporate interventions addressing those causes.

Key words: Referral system, Decision-making process, Three delay model, Maternal Health, Access to care.

Word count: 12486

INTRODUCTION

As a child I already knew I wanted to become a tropical doctor. I would have never guessed however that, in 2013, I would end up in the lush and green amazon forests of the country of Suriname. Different tribes live here, scattered over the large interior. As a tropical doctor working in primary health care in this area I lived among them and became acquainted with their way of living, their language and some of their cultural practices.

A major public health issue worldwide is the death of women during pregnancy or childbirth. Addressing this subject, a lot has been written on the importance of quality care around birth. As quality care is so important, women with a higher risk on complications during birth are electively referred from the interior of Suriname to receive this quality care in the hospital in Paramaribo as the health clinic in the interior lacks skills and equipment to provide for this care. However, non-compliance to referral is a problem often seen in the interior.

My own experiences with non-compliance were the start off point of this thesis. I have witnessed complicated deliveries leading to poor maternal and neonatal outcomes that could have been prevented. The reasons why women are non-compliant to referral have never been the focus of research while it is extremely important to know which factors are of influence on this decision-making process.

During my medical study, there was a focus on numbers, telling the student how many, how often, how long. But the **why** behind the numbers are not often the focus. My aim with this research is to get the story behind the numbers. Which factors are of influence on the decisions made within referral of pregnant women? And if known, what can we do to improve outcome of pregnancy and childbirth for mothers and their babies?

CHAPTER 1: BACKGROUND

1.1 SURINAME

The republic of Suriname is situated on the north east coast of South America and is bordered by Guyana to the west, French Guiana to the east and Brazil to the south. It covers 163.820 km^2 and is home to around 558,368 people.(6) With over 94% of Suriname covered by amazon rainforest,(7) most of the people live in a thin strip of coastal area in the north of the country where the capital Paramaribo is also situated. The amazon rainforest is considered the interior of the country and is the least densely populated area. Suriname has a multi-ethnic population with the four major ethnic groups being Hindustani (27,4%), Maroon (21,7%) Creole (15,7%) and Javanese (13,7%).(6) As Hindustani, Creole and Javanese people live mainly in the urban area of Suriname, the interior is mostly inhabited by Maroon and Amerindian tribes and home to approximately 50.000 people. Maroons are descendants of African slaves who ran away from the Surinamese plantations in the 17th century and established tribal communities in the rainforest.(8) Today, most community members are hunters and subsistence farmers but tourism and gold mining has also become a source of income. Annex 1 shows the living area of different maroon and Amerindian tribes. Amerindians are native inhabitants of the amazon rainforest who lived as nomads in different tribes like the Wajana and Trio tribe. In the early 1960s they came in contact with missionaries who convinced them to live in villages.(9)

Suriname is a country rich in language. While the official language in Suriname is Dutch, the language spoken by the majority of Surinamese people is Sranangtongo which means "*Surinamese tongue*". The communities in the interior mainly speak tribal languages like Saramaccaans or Trio.

1.2 HEALTH SYSTEM OF SURINAME

The Ministry of Health (MoH) is responsible for the overall management of the health system. The Bureau of Public Health (BOG), a core institution of the MoH, has a wide range of responsibilities such as surveillance, environmental inspection and the management of public health programs.

COVERAGE OF HEALTH SERVICES

In Suriname primary health care (PHC) is provided through governmental and non-governmental health care providers namely Regional Health Services (RGD) and Medical Mission Primary Health Care Suriname (MM). Furthermore numerous private practitioners provide PHC services in the capital of Paramaribo. There are six hospitals in Suriname, five of which are located in Paramaribo and one which is located in Nieuw Nickerie. In the interior of Suriname, MM is the only available health care service provider. The health workforce in Suriname is unequally distributed with the availability of 0.8 physician per 1000 people in the urban area compared to 0.2 physician per 1000 people in the interior.(10)

COSTS OF HEALTHCARE

The total expenditure on healthcare of the republic of Suriname is estimated around 5.4% of the gross domestic product.(11)Exact data on expenditure are scarce as the latest National Health Accounts dates back to 2006. In that report the main sources of funding of healthcare were the Ministry of finance (37,5%) private firms (34,1%) and out-of-pocket payment (20%).(12)

In 2014, the *Basic Health Care Insurance Act* came into effect. The goals was to achieve health insurance coverage for children <16 years of age and elderly >60 years of age.(13) Furthermore it became mandatory for all people to be covered by a healthcare insurance but this law was only enforced after 2016. At this moment, there are several private insurance companies in Suriname, the State Health Foundation which covers all governmental personnel and currently also people that are insured under the *basic health care insurance act*. Although a healthcare insurance is mandatory, many people lack sufficient income to pay the fees. Those people can apply for a healthcare insurance through the Ministry of Social Affairs.(13)

HEALTH PACKAGES

In 2016, Suriname was hit by an economic crisis and suffered from one of the highest inflation worldwide which had its impact on the healthcare system as funding was not guaranteed.(14) The private companies and the state health foundation cover most curative care services including most pharmaceuticals. However, since the economic crisis, amendments have been made and less pharmaceuticals are covered. For pregnant women antenatal care (ANC) including laboratorium and radiological examinations is covered by all the insurance companies, as is giving birth with a skilled birth attendant.(15)

1.3 MEDICAL MISSION PRIMARY HEALTH CARE SURINAME

MM is a non-governmental health organization that is responsible for the delivery of PHC to the communities in the interior of Suriname. MM has 50 health clinics scattered over the interior (figure 1).

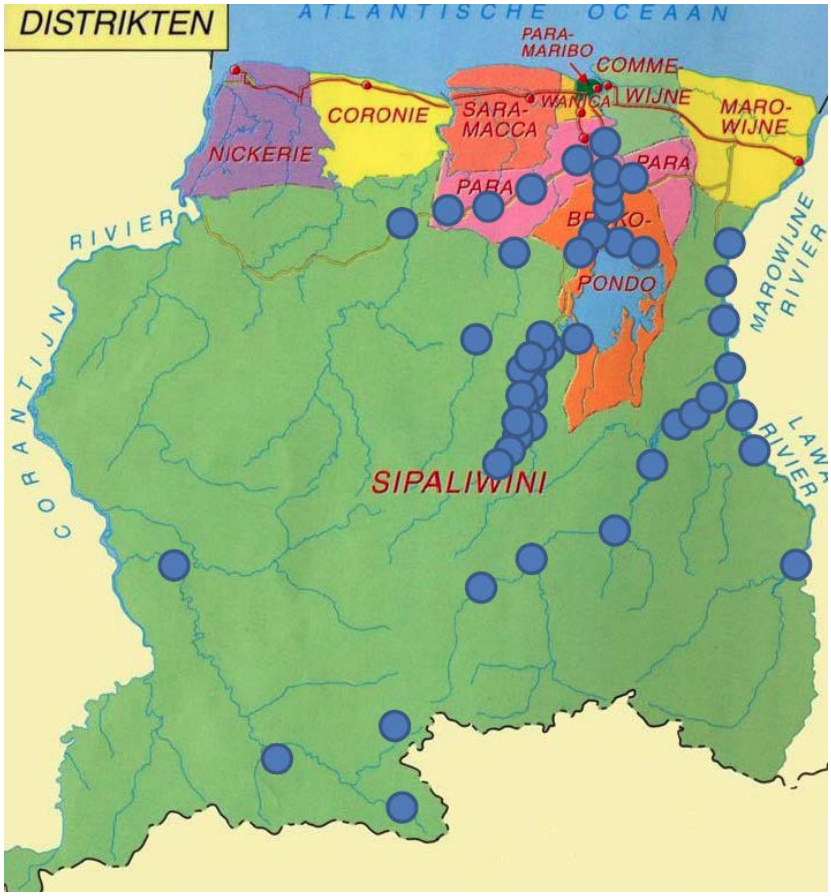

Figure 1. MM clinics in Suriname. Adapted from (16).

Most of the clinics are only accessible by boat or plane when travelling from Paramaribo. Travelling to the city can take up to several days or even weeks during the rainy season when landing strips are often closed for planes. The health clinics are staffed by approximately 110 health care assistants (HCAs) distributed over the different locations and supervised by eight medical doctors. The HCA cadre is the backbone of the health services MM provides and the first point of contact with patients. Services provided are, among others, mother and child care, emergency care and outreach. More complex pathology is referred to medical specialists in Paramaribo. The referral process of MM is briefly explained in box 1.

The recent years, MM service provision has suffered from instable governmental funding.(17,18) As a healthcare insurance became mandatory, MM should receive reimbursement of provided care through the health insurance companies. However, as most people in the interior remain uninsured, MM works on a loss while providing free at the point of care services to the communities in the interior. While people are eligible

for a healthcare insurance provided by the Ministry of Social Affairs, this institute is only located in Paramaribo and therefore not easily accessible for the communities of the interior.

THE REFERRAL PROCESS AT MM

Process

The local health clinic is the first point of care for the communities in the interior. The clients are examined and if complex pathology seems present, clients are referred for specialized care in Paramaribo. This care includes laboratorial or radiology exams or referral to a medical specialist. Clients are referred from the interior with a referral note and, if compliant, travel to the coordination center of MM in Paramaribo. There, at the outer patient department (OPD), they receive a consultation with one of the medical doctors working for MM and are further referred to specialized care.

Cost

Clients who have insufficient financial means are eligible for a healthcare insurance provided by the Ministry of Social Affairs. This insurance will cover all direct healthcare costs. Indirect costs associated with referral are costs for transport, housing, food and child care and should be paid by the client.

Duration

The time spent in the city depends on the indication of referral and is usually between several days to several months.

Box 1. The referral process at MM

1.4 PROBLEM STATEMENT

Every year around 300.000 women worldwide die of causes related to childbirth or pregnancy.(19) Most of those maternal death are preventable by quality care around the time of birth.(20–23) Maternal death is considered one of the greatest inequities of the 21st century as 99% of these deaths occur in developing countries and affect mostly poor and vulnerable communities.(24,25) In Suriname, a Maternal Mortality Ratio (MMR) of 154 per 100.000 live births (26) was seen in 2015 which leaves Suriname to be among the poorest performing countries of the Latin-American and Caribbean region (4,19) and maternal death to be a leading public health issue.(26) Within the country disparity in care during pregnancy and childbirth is seen where, in 2010, 68% of pregnant women in urban areas received four antenatal care (ANC) visits compared to 58% of the pregnant women living in the interior. Furthermore, 95% of births in urban areas was attended by skilled birth attendants in comparison to 77% of the births in the interior that were managed by skilled birth attendants, namely the HCAs working for MM.(27)

To decrease maternal mortality, the World Health Organization (WHO) advocated that all deliveries should take place in a facility with skilled birth attendants and basic emergency obstetric and neonatal care (BEmONC) services.(28–31) In the interior of Suriname, the WHO recommendation of BEmONC services in all facilities attending deliveries is unfortunately not met. The availability of those services at the health clinics of MM is shown in Table 1. Whenever a complicated delivery occurs, the woman in labor will be emergency referred to the hospitals in Paramaribo. However, as MM operates in extreme remote areas, this emergency transportation could take hours to days and leads to significant delay in adequate care for mother and baby.

Table 1.
The availability of services of BEmONC and CEmONC at MM. Adapted from (32).

Services	BEmONC	CEmONC	Availability at MM
1. Parenteral administration of antibiotics	X		Yes
2. Parenteral administration of anticonvulsants	X		Yes
3. Parenteral administration of oxytocin	X		Yes
4. Assisted vaginal delivery	X		No
5. Manual removal of placenta	X		No (only if a doctor is at the clinic)
6. Perform removal of retained products of conception	X		No
7. Perform neonatal resuscitation with bag and mask	X		Yes
8. Perform Caesarean Section		X	No
9. Provide blood transfusion		X	No

A functioning referral system is essential in improving maternal health outcomes.(28,33–36) While women with low-risk pregnancies are allowed to deliver in the health clinics of MM, those with a profile that indicates a higher risk to maternal or neonatal complications are referred to hospitals in Paramaribo providing comprehensive emergency obstetric and neonatal care (CEmONC) services. This referral protocol of so called *risk pregnancies* is supported by evidence that shows poorer neonatal and maternal outcomes of pregnancies complicated with diabetes (37), hypertension (38), severe anaemia (39), grand multiparity (40) and young age of the mother (41,42). Since delay to appropriate care in emergency referral is high, the referral protocol of MM is quite strict and 50% of all pregnancies are referred. Referral rates worldwide vary between 14 and 52% and are very context specific.(43–45)

The success of a referral systems depends on pregnant women to visit ANC services, to be compliant with referral advice and to have access to referral hospitals.(25) In the interior of Suriname however, non-compliance to referral is a frequently encountered problem. Since data on non-compliance are never investigated, the true magnitude of this problem remains unknown. Non-compliance could lead to complex deliveries in an environment not capable of managing those deliveries and sometimes maternal or neonatal death as a most severe consequence of non-compliance is seen.

The decision-making process in pregnancy is multifactorial and influenced by factors at supply- and demand side (46–48). Non-compliance to referral is an outcome of this decision-making process and understanding the reasons behind the decisions made by all actors involved in the referral of risk pregnancies is of great importance to improve maternal and neonatal health outcomes.

1.5 JUSTIFICATION

The importance of a functioning referral system on maternal health outcomes is already acknowledged in several studies.(25,34,49,50) However, a referral system is complex as it incorporates access to facilities, transportation, the perceptions of risks by pregnant women and health care providers and health seeking behavior. Within this complex process some components have been extensively studied while others have not. A component like health seeking behavior of pregnant women is well studied and factors of influence are women's knowledge, experiences and social and economic conditions.(24,46,51–57)

Low compliance to referral is a tendency known around the world(44,45), nonetheless the decision-making process in compliance with referral is not well studied. Baral et al. (58) suggested in 2010 already that the decision-making process in referral should be the subject of extensive research. Pembe (44) furthermore stated that more qualitative research is necessary to reveal perceptions and experiences of pregnant women on their referral. To fully grasp the decision-making process within referral the perceptions of all actors involved including health care providers and the community

should be studied in each contextual circumstance.(49,59,60) When the factors of influence on this process are known, recommendations could be formulated to different policymakers to improve referral policies and practices. Therefore, the main objective of this study is to determine factors that influence the decision-making process in referral of risk pregnancy in the interior of Suriname.

1.6 SPECIFIC OBJECTIVES

- Explore individual factors that influence the decision-making process in referral of women with a risk pregnancy
- Explore environmental factors that influence the decision-making process in referral of women with a risk pregnancy
- Explore factors related to the health system that influence the decision-making process in referral of women with a risk pregnancy
- Based on the results, make recommendations for interventions addressing the referral system and lead to improvement of maternal and neonatal health outcomes.

CHAPTER 2: METHODOLOGY

2.1 STUDY DESIGN AND POPULATION

This study consisted of two parts. First, an extensive literature review was conducted before, during and after the fieldwork including scientific published and *grey* literature perceived from PubMed, PLOS, Science direct and Google scholar. The search strategy used is shown in Annex 2. This literature review was used as a foundation for the study. The focus was on identification of areas to explore and results were used while developing a conceptual framework. Furthermore, during and after the fieldwork the literature review was used to look at best practices from similar settings to address issues identified.
Second, fieldwork was conducted with the use of qualitative research methods. The fieldwork consisted of face-to-face in-depth interviews (IDIs) with women who experienced a risk pregnancy and HCAs, in addition to focus group discussions (FGDs) with community members. Table 2 shows the distribution of IDI and FGD. IDIs and FGDs were chosen as they are reliable methods to obtain insight in perception, experiences and beliefs about certain themes. IDIs created the possibility to follow the flow of reasoning of the participant and the freedom to explore some themes more profoundly. In the FGD participatory methods were used. Furthermore three key informants, being two doctors and a HCA with extensive experience in emergency referral were interviewed.

Table 2.
Distribution of IDI and FGD.

Participants	Inclusion criteria	IDI	FGD
1. Women who experienced a risk pregnancy in the past year	*Age: >14 years*	15	
2. HCA	*No specific*	10	
3. Community members	*Age: 25-45* *Having children*		6 (36)
4. Key informants	*Experience with the subject*	3	

2.2 STUDY AREA

The study took place in two villages in the interior of Suriname (figure 2) namely Brownsweg and Ladoani. Due to costs and time limitations it was not possible to visit the third village of Kwamalasamutu and therefore interviews with participants from that village took place at the coordination centre of MM in Paramaribo. The villages were selected based on their population size and number of pregnant and referred women each year. The total number of pregnant women from the three villages in 2017 was 176 women of which approximately 50% were indicated as having a risk pregnancy. In this study approximately 20% of those women were included.

Figure 2. Study area (16)

Brownsweg

Brownsweg is the largest maroon village of the interior, accessible by road and within a two hour driving range of Paramaribo. The clinic in Brownsweg is the biggest MM clinic and is staffed with a medical doctor and nine HCAs. Furthermore there is permanent ambulance transport available in case of emergencies. Specifics of the study area are shown in table 3.

Table 3.
Specifics of study area.(61)

Study area specifics	Brownsweg	Ladoani	Kwamalasamutu
Population (persons)	4104	2600	1320
Ethnicity	Maroon	Maroon	Amerindian
Distance to Paramaribo	110 km	240 km	430 km
Accessibility from Paramaribo	Road	Boat	Plane/boat
Number of pregnant women 2017	123	23	30

Ladoani

The MM clinic of Ladoani lies on the banks of the upper-Suriname river and is only accessible by boat. It will take approximately 5-8 hours to reach the city of Paramaribo. The clinic is staffed with a medical doctor and five HCAs.

Kwamalasamutu

Kwamalasamutu is the biggest of Amerindian villages and home to a trio tribe community. It is one of the most remote villages of Suriname. If weather allows, a plane travels there from Paramaribo, once every week. By boat it will take around 2-3 weeks to reach Paramaribo. The MM clinic in the village is staffed with three HCAs.

2.3 SAMPLING AND RECRUITMENT

Purposeful sampling was used for women who experienced a risk pregnancy (**female respondents**), key informants and community members as this study was looking for participants with specific characteristics. Convenient sampling was used for HCAs. In Brownsweg convenient sampling was used together with snowballing for the FGD.

RECRUITMENT OF FEMALE RESPONDENTS

Fifteen female respondents were selected for this research by screening the administration of pregnant women in 2017 from the three different villages. The management of pregnancy at MM is explained in detail in annex 3. To fully explore the trajectory from MM to specialised care and all delays that occur, this study therefore included women with a risk pregnancy that have been electively referred. It was the aim of this study to include equal numbers of compliant and non-compliant women to get insight in possible differences in factors of influence on the decision-making process. However, non-compliant female respondents (n= 4) were often reluctant on participating in the study which resulted in more compliant female respondents (n= 11) that participated. Female respondents were notified about the study by HCAs of the local clinics. An information letter (Annex 4) was provided and explained by the main researcher to the HCAs who distributed this letter to possible participants. As women

may have not been aware of having had a risk pregnancy, the focus of the information letter was on decision-making within their pregnancy rather than on the risk. Four women who experienced a risk pregnancy from Kwamalasamutu were approached at the coordination center in Paramaribo concerning this study.

RECRUITMENT OF HCAS

Participating HCAs were selected based on their availability at the moment of research and were approached by telephone or in person by the main researcher. HCAs from eight different clinics in the interior participated including Brownsweg, Ladoani and Kwamalasamutu.

RECRUITMENT OF COMMUNITY MEMBERS

Local leaders were approached concerning the study after which they performed the recruitment of community members for the FGD in Ladoani. They were informed in advance about the selection criteria. In Brownsweg recruitment was performed by the translator and main researcher due to a miscommunication around the date of the FGD. Recruitment was performed by walking through Brownsweg and informing people about the study. The recruitment of community members from Kwamalasamutu was performed via the HCA and the local leaders. Community members that were currently in Paramaribo were approached and through snowballing enough community members agreed to participate in the FGD.

Finally three key informants were recruited. They were selected based on their roles in the referral process of women with a risk pregnancy. As they all have experience with the process they could provide insight which would improve validity.

2.4 DATA COLLECTION AND PROCESSING

The study was conducted between 6th of January 2018 and 16th of February 2018 and consisted of IDIs (n= 28) and six FGD with a total number of participants of 36. Topic guides (Annex 5-8) were developed and were based on the conceptual framework as shown in figure 3. In line with the iterative process of this type of study, pilot testing led to minor adaptation of the topic guides. Two vignettes were developed and used in the study to be able to discuss sensitive issues without a focus on the participant itself. The vignettes are shown in box 2.

VIGNET 1

Lily is a 15-year old girl. She is six month pregnant and lives in Kwamalasamutu. It is her first pregnancy. She comes for check-up at the clinic frequently. The HCA refers her to the hospital in the city. She has no family or place to stay in the city.

VIGNET 2

Anoenziata is a 40-year old mother of seven from Ladoani. She is pregnant with her 8st child. All her pregnancies went well and she delivered with the traditional birth attendant. In this pregnancy she went for regular check-ups at the clinic. The HCA advised her to go to the hospital to deliver but she wants to deliver at home with the traditional birth attendant.

Box 2: Vignettes

IDIs and FGDs were conducted in four different languages namely Dutch, Sranangtongo, Saramaccaans and Trio. Although the main researcher has a fair understanding of Sranangtongo and Saramaccaans, a translator was used for Sranangtongo, Saramaccaans and Trio to assure detailed understanding. The translator used for Sranangtongo and Saramaccaans was a Maroon woman from the interior with no affiliation with MM. The trio translator was, due to lack of other translators, a HCA from Kwamalasamutu. The FGD with male community members from Kwamalasamutu was translated by her husband who has no employment with MM.

Interviews took place in MM clinics of Brownsweg and Ladoani. FGDs took place at different locations around the villages. Interviews and FGDs in Paramaribo took place at the education department of MM. All interviews were, with permission, tape recorded and were transcribed using Express Scribe Transcription software. Transcripts were coded in Excel according to the themes of the conceptual framework and codes were added if necessary. No coding software was used. Analysis took place with regular discussions with supervisors. As data processing and analysis was performed by the main investigator, no double coding was initiated.

2.5 CONCEPTUAL FRAMEWORK

The conceptual framework used in this study is a fusion of two acknowledged models. The first model important in maternal health is *the three delay model* by Thaddeus and Maine which is used in explaining factors contributing to delay in receiving appropriate care and leading to maternal death.(62) The phases of delay used by the model constitute of phase 1: *deciding to seek care*, phase 2: *identifying and reaching the health facility* and phase 3: *receiving adequate and appropriate care*. The original model was only used for emergency obstetric care. In 2009 Gabrysch (33) adapted the model and included preventive care including referral. However, the factors of influence on delay remained unchanged while factors influencing delay in receiving adequate preventive care could differ from those in case of an emergency. Since the decision-making process is the main focus of this study, factors of influence on delay were taken from a second

model. This *health field model* was developed by Lalonde (63) and has a focus on decision-making regarding your health. The model divides influential factors into four major groups namely individual, environmental, biological and health systems. Of those four determinants, three were used in the adapted model. The fourth group, being biological factors like genetic inheritance, was left out as this will not likely contribute to the decision-making process. Individual factors that are known to have an impact on decision-making are knowledge and attitudes, experiences and autonomy.(64–66) Environmental factors influencing decision-making are socio-cultural determinants such as cultural norms, physical factors such as distance to facility and socio-economical as financial dependence.(50,67–69) The perceived quality of a health facility, its accessibility and availability of care could also be of influence.(51,53) The conceptual framework is showed in figure 3.

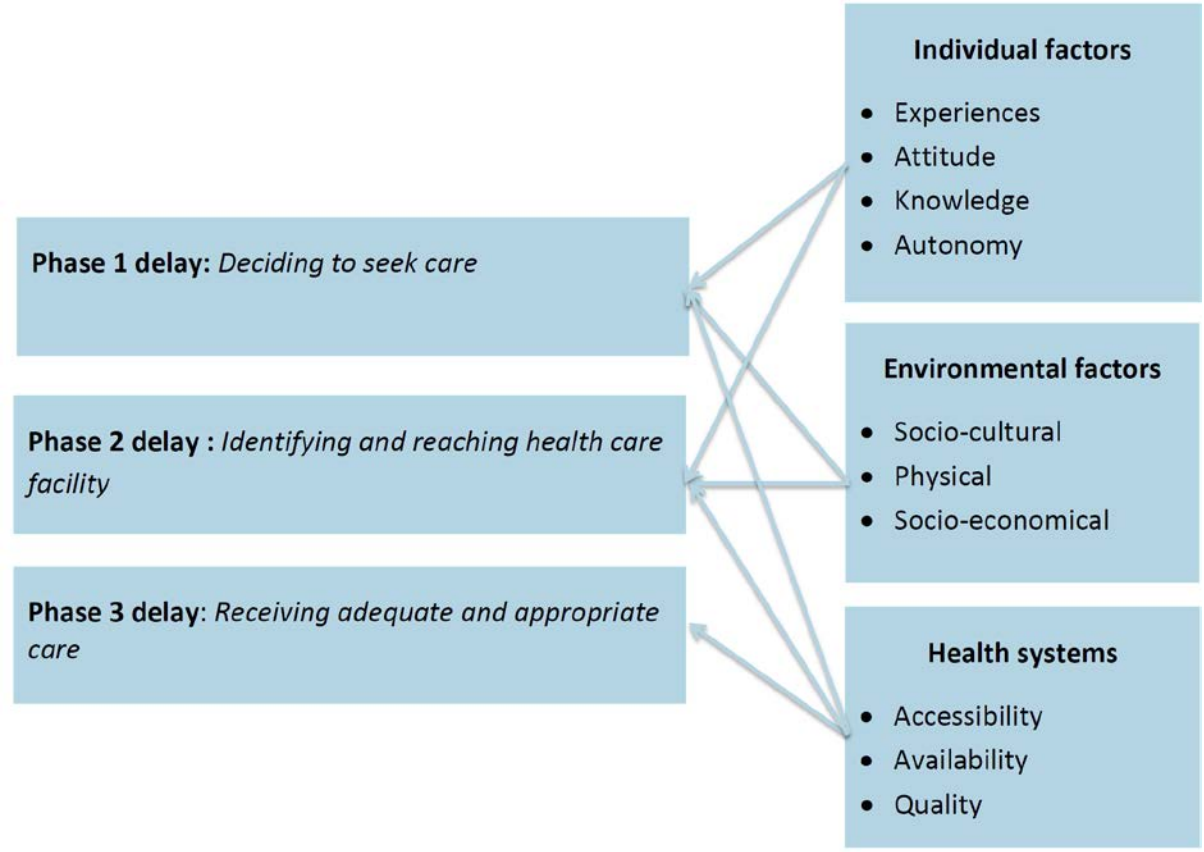

Figure 3. Conceptual framework.(33,63)

2.6 QUALITY ASSURANCE

Several mechanisms were in place for quality assurance. First of all, topic lists and vignettes were discussed with supervisors and peers and adapted were needed. The number of interviews held was dependent on saturation of themes. Interviews were conducted until saturation emerged. Data collection and analysis was performed by the same person with a translator to assist where needed. As there was limited experience with qualitative research, two experienced qualitative researchers gave advise prior to the interviews and during coding and analysis. To optimize validity, pilot testing of the interview, which resulted in some minor adjustments, was performed with a colleague. Furthermore triangulation, by interviewing three key informants was performed. Finally, the results of the interviews were discussed with the participants as member checking.

2.7 ETHICAL CONSIDERATIONS AND INFORMED CONSENT

Ethical approval from the Koninklijk Instituut voor de Tropen (KIT) ethical committee (Annex 9) and from the Surinamese Commissie Mensgebonden Wetenschappelijk Onderzoek (CMWO) (Annex 10) was obtained. Informed consent (Annex 11-13) was given in writing or verbally on record. If the participant was a minor both informed assent by the minor and informed consent by parents or caretakers was obtained (Annex 14).

2.8 DISSEMINATION OF RESULTS

The results of the study are shared with participants and their communities as well as with the MM and MoH. Recommendations are formulated and shared with MM and MoH.

CHAPTER 3: RESULTS

This chapter will start with a description of the participants and their characteristics. Secondly the findings of the study will be presented and sometimes complemented by findings from the literature review. Female respondents in this study shared their experiences, decisions and sometimes their delay within the chronology of their pregnancy. To keep results in that order and be consistent with the conceptual framework, results will be presented according to the different phases of delay.

Despite the heterogeneous aspect of the participants, results were noteworthy in their homogeneity. However, if findings differed from Maroon to Amerindian participants, results are mentioned separately.

PARTICIPANTS

A total of 64 people participated in this study. Fifteen female respondents, including three teenagers, were interviewed. Within the female respondents, four women were Amerindian while 11 women were from Maroon communities. Risk pregnancies included in this study were, teenager, anemia, hypertension, blood loss, multiparity, previous caesarean section and having twins. Furthermore ten HCAs contributed to this study and a total of 36 community members. Community members were included in six FGDs, two for each village with separate groups for men and women. While it was the aim to include only persons between 25-45 years of age, some of the participants were older. Since men and women from Kwamalasamutu were scarce to find in Paramaribo, the choice to include a wider age range was made. The male FGD included men between 27-63 years of age while the female FGD included females between 40-58 years of age. Furthermore, two doctors from clinics with high numbers of pregnant women and one HCA who is now responsible for the coordination of emergency referrals at MM were included as key informants in this study. The characteristics of the study participants are shown in table 4.

Female respondents were between 14 and 40 years old with a mean of 24.4 years. Most women were married in the traditional setting. Interestingly in the characteristics of the participants is that just one of the female respondents and two community members finished secondary school. Furthermore 13/15 female respondents had their first child while being a teenager with an average age of 17.5 years old. In total, female respondents, had between one and eight children with an average of 3.3. The number of children from HCAs and community members varied between 1 to 20 with an average of 4.8 and 4.9 respectively. As polygamy is present in the interior of Suriname, the number of wives was asked but several men refused to answer. Income was asked during interviews but is not mentioned in the table as none of the female respondents had a regular income and neither did their husband except one. Out of all 36 community members, only three men stated having some income as they worked as gold miners. Two female community members had an income as they worked as cleaning ladies.

Table 4.
Characteristics of participants.

Characteristic	Specifics	Number of female respondents	Number of HCAs	Number of community members
Age (years)	<20	5	-	-
	20-29	6	1	6
	30-39	3	3	14
	40-49	1	3	9
	>50		3	6
	Mean (range)	24.3 (14-40)	42.8 (25- 58)	38.9 (24-63)
Sex	Men	-	4	18
	Woman	15	6	18
Education	None	2	-	-
	Uncompleted Primary school	4	-	20
	Completed Primary school	8	-	14
	Completed Secondary school	1	10	2
Number of children	1	5	2	4
	2-4	4	3	16
	>5	6	5	16
	Mean (range)	3.3 (1-7)	4.8 (1-8)	4.9 (1-20)
Marital status*	Married	13	8	
	Unmarried	2	2	
Age at first pregnancy? (years)	≤19	13	-	6
	>20	2		3
	Unknown	2		27
	Mean (range)	17.5 (14-27)		

*Note: * marital status was based on the traditional concept of marriage as seen in tribal communities. It is not a marriage recognized by Surinamese law*

3.1 PHASE 1 DELAY: DECIDING TO SEEK CARE

Decision making is not limited to one event but is a process that occurs several times during pregnancy. Within this study, with its focus on the decision-making process in referral of risk pregnancy, several other decision-making processes were identified that had a potential influence on decisions concerning referral namely: deciding to get pregnant and deciding to visit ANC. Furthermore the health seeking behavior of women non-compliant to referral in case of an acute event was explored. The three identified processes are briefly mentioned within this first delay as they are important for the complete overview.

Important to state and further discussed within the discussion chapter is the fact that this study placed the decision to comply to referral by female respondents under the first phase delay. The decisions of the HCA regarding referral were defined as a third phase delay and will be discussed in that section.

3.1.1 DECISION-MAKING PROCESS REGARDING FAMILY PLANNING

11/15 female respondents stated that their last pregnancy was unwanted. Within the decision-making process regarding family planning four contributing factors were identified namely knowledge, autonomy, cultural norms and accessibility of the health clinic.

KNOWLEDGE

10/15 women expressed having no knowledge on how to prevent pregnancy. Others knew how to prevent pregnancy but had no say in the decision of getting pregnant.

I don't exactly know when I could get pregnant but I don't have a say in it anyway

(Female respondent, 40 years old)

AUTONOMY IN DECISION-MAKING

Autonomy can be defined as a woman's capacity to make life-affecting choices (1). Most female respondents shared the fact that they were not in control of family planning. Some stated men not allowing contraceptive use, some stated men were in control of when sex should take place. Four female respondents said their man wanted to have more children. Men confirmed their disapproval of contraceptives in the FGD. They also stated control over a women is important.

If she gets pregnant, she is under your control cause you are the father of her baby.

(Male community member, 25 years old)

CULTURAL NORMS

Cultural norms and practices were seen to play a part in reproductive health of maroon women in the interior of Suriname. Although some maroon communities adapted the Christian religion, they kept their ancestor's rituals. This in contrast to Amerindian communities, who converted to Christianity and left all cultural practices. The ritual of importance for this study and mentioned by every maroon participant is the ritual of *Kojo* and *Pangi* described in box 3.

KOJO AND PANGI RITUAL

After a girl in Maroon culture starts menstruating, she is ready for adulthood. Her mother celebrates this event by giving her a *kojo. Kojo* is a piece of cloth used as a skirt. After receiving her *kojo* it is upon her mother to decide when the ritual of *pangi* should take place. A *Pangi* is a similar piece of cloth which is presented to the girl in a ritual. This ritual reflects the transition of that girl into adulthood. After she receives her *pangi* she is looked upon as adult. The ritual of *pangi* is performed for every Maroon girl in the interior of Suriname.

Box 3. *Kojo* and *Pangi* ritual

The ritual was frequently mentioned in the study within the context of teenage pregnancy. Most women stated that if a girl gets *pangi* she is an adult. Therefore family planning is her decision. Men however stated it should more be seen as a ritual into adult life.

If a girl gets pangi then that means she should learn adult life, like cooking, from her mother. It does not directly mean she should get a husband.

(Male community member, 27 years old)

Several participants stated mothers delaying the ritual of *pangi un*til after the girl finishes school. Getting pregnant before receiving *pangi* is considered a disgrace so if mothers notice girls being sexual active they will give them their *pangi* quickly to prevent this disgrace. When discussing teenage pregnancy, it became clear that, however very prevalent, teenage pregnancy was not accepted within the culture as stated by the majority of participants. Both men and women stated teenagers who get pregnant cannot make their own decisions as they lose that right by becoming pregnant and parents should decide for them.

ACCESSIBILITY MM

Several female respondents drew an image of teenagers not feeling free on asking contraceptives at the clinic which was confirmed by most HCAs and community members. Teenagers are afraid contraceptives will be denied by the HCA or their privacy will not be respected. This lack of accessibility to family planning has an impact on the ability of the patient to prevent their pregnancy and therefore their attitude towards a pregnancy.

3.1.2 DECISION-MAKING PROCESS IN ATTENDING ANC

While half of the female respondents interviewed expressed the importance of visiting ANC, the decision to visit the clinic is made late. 12/15 women stated never to visit the clinic before three months of pregnancy and the average first visit to ANC found in this study was at 16 weeks pregnancy. Factors of influence were experiences, attitude of female respondents towards their pregnancy and cultural norm. 11/15 female respondents shared negative attitude towards their pregnancy as they stated their last pregnancy being unwanted. Furthermore female respondents said it was the cultural norm to wait until the pregnancy is starting to show. This statement was confirmed by community members. However, they also mentioned pregnant women being afraid something will happen to their child if people know they are pregnant.

If you are pregnant, you have a great secret. A child is so important. You should tell nobody that you are pregnant because people could speak evil about this baby and this will harm the baby.

(Male community member, 33 years old)

All HCAs confirmed female respondents usually seek ANC late in their pregnancy as women want to conceal their pregnancy out of shame or fear. Three female respondents confirmed delaying their first ANC visit out of fear of the reaction of the HCA. 3/4 Amerindian female respondents gave fear of being referred to the city as a reason for coming late to ANC. The decision of attending ANC is usually made by the patient themselves. However, some female respondents, especially teenagers, are brought to the clinic by their mothers or other family members. As ANC is free of charge and most villages have a MM clinic, money or transport availability did not influence the decision on visiting ANC.

Although female respondents in this study were aware of the importance of ANC, the cultural norm was waiting until the pregnancy is visible. The practice of coming late to ANC was already described by Roberts in 2015.(70) Literature is mixed on whether or not knowledge increased preventive healthcare seeking. Several articles found knowledge increased health seeking behavior in case of a complication but not in preventive care.(33,55,56) Perhaps in preventive healthcare seeking other factors like social norms are of more influence. In this study only three female respondents came

for ANC in the first trimester. The attitude of female respondents towards their pregnancy was negative in the majority of cases in this study. In literature, negative attitude towards a pregnancy was associated with later initiation of ANC.(71,72) In this study no comparison between female respondents with negative attitude and female respondents with positive attitude towards their pregnancy and their initiation of ANC was made.

3.1.3 DECISION-MAKING PROCESS REGARDING REFERRAL

The decision-making process regarding referral was extensively discussed in this study. It is found to be influenced by several individual, environmental and health system factors.

3.1.3.1 INDIVIDUAL FACTORS

KNOWLEDGE, ATTITUDES AND EXPERIENCES

All female respondents knew why they were referred to the city. Community members were also able to mention referral indications. A couple of men within the FGD shared their experience with referral. The HCA of the clinic had send for them to explain why their wives needed to deliver in the city.

If you hear from the doctor that if she delivers here and she loses blood she will die directly, then you are obliged to send her to the city

(Male community member, 25 years old)

Despite female respondents having knowledge on the risks, some HCAs shared examples of lack of awareness, despite information been provided.

All those deliveries here were fine and now I have to go to the city? I will not go, it will be fine

(HCA)

Three female respondents shared positive attitude towards referral as their experiences with referral of their previous pregnancies were good. 10/15 female respondents experienced negative attitude towards their referral. Underlying cause of this negative attitude were barriers they faced with referral like housing availability or financial difficulties. HCAs confirmed most pregnant women being negative towards referral to the city. One HCA stated fear of a caesarean section being the cause of this negative attitude towards referral which was confirmed by several female respondents and community members.

They fear a caesarean section because they say if you have a scar it is difficult to function as a whole anymore.
(HCA)

The fear of receiving a caesarean section has been previously described in literature and is said to be socio-culturally influenced.(29,73)

AUTONOMY IN DECISION-MAKING

The decision of being compliant in case of referral is usually made by the patient, husband and/or mother of the patient. 3/15 female respondents claimed to have made the decision themselves. All others stated mother, husband or family members of mother should make that decision as they are dependent on them.

I believe there is a delay in referral because women cannot decide by themselves.

(Key informant)

HCAs also stated the traditional authority of the villages having a great impact on that decision. If women refuse to be referred, they usually contact them for help. As so many people are involved in the decision-making process delay is very likely to occur. Many men do not work in their own villages and women have to wait for their return to be able to decide.

When they are referred I ask them: when do you want to go? Then they tell me ok nurse, my husband is not here. I will send him a message. Maybe he arrives in a week.
(HCA)

Lack of autonomy as a barrier in access to care is often described in literature. The ability of women to make decisions is an important determinant of their access and use of maternal healthcare services.(29,33,55) In this study 12/15 woman stated having no decision-making power. They shared stories of mothers, husbands or traditional authority deciding for them. This lack of autonomy led to delay in decision-making as they waited for their husband to return home or families to come together and decide. Interesting was the fact that the decision to visit ANC was mostly made by women themselves which shows that women could make decisions themselves but not decisions involving money or travelling.

3.1.3.2 ENVIRONMENTAL FACTORS

HOUSEHOLD COMPOSITION

One patient expressed having no child care as a reason of being non-compliant to referral. Several female respondents, HCAs and community members addressed this issue as a barrier.

If you go to the city your other children are neglected, nobody watches over them. They just walk around. I know so many women that refuse to go because they will not leave their children alone.

(Female community member, 36 years old)

Household composition is not often described as factor of influence on decision-making in literature.(24) In the context of MM however, without adequate care for other children the choice of non-compliance is understandable however a challenge to tackle with regard to interventions.

HOUSING AVAILABILITY

All study participants addressed housing availability as a barrier to compliance to referral. Some female respondents stayed with family in the city but 7/15 female respondents said to have no housing options available in the city, therefore they travelled back and forth to the hospital in Paramaribo or where forced to rent a place in the city. As most literature describes emergency referral, housing availability is not seen as an issue as women are directly admitted to the hospital. In elective referral however, availability of a place to stay is one of the most mentioned constraints in compliance to referral. Other countries with remote areas like Suriname have adapted maternity waiting homes as an intervention to improve facility-based deliveries.(74) Suggestions for a maternity waiting home were made by several community members in this study which hopefully is a reflection of the opinion of the rest of the community.

MONEY

All female respondents stated having no financial means. Nobody was able to pay for their own transportation or living expenses in the city. They were all dependent on husbands, mothers or other family members.

I delivered at home. I had to go to the city soon but did not find money yet.
(Female respondent, 35 years old)

Money as a barrier in compliance to referral is previously described in literature.(34,44,45,75) Community members agreed that money restricted the ability to be compliant to referral. Two male community members stated that MM should be responsible and pay for the referral of female respondents, despite the availability of

money within the family. The search for money caused delay in referral as two female respondents waited over two months for sufficient financial means to travel to the city while two other female respondents were non-compliant to referral due to financial difficulties.

*Some people do not have a choice. They stay here ("*the interior"*) till they die. If you have no money…..*

(Female respondent, 35 years old)

COMMUNITY SUPPORT

The traditional authority within the community has a lot of influence on the decision-making process. If women are non-compliant to referral, the HCAs will involve the traditional authority as they support the referral system of MM. However, the community never supplies financial support to women with a referral indication. This is regarded as the responsibility of the family and not the community as shared within the FGDs.

3.1.3.3 HEALTH SYSTEM

PERCEIVED QUALITY OF CARE

The perceived quality of care in the hospital was good by most female respondents and no negative experiences were shared. In the review of literature perception of care has been found to be of great importance in the decision to seek care.(29,53,76) Several positive experiences of female respondents with hospital care worked as enablers in compliance to referral and show the importance of positive perception and experiences on health seeking behavior.

ACCESSIBILITY

The HCAs at the clinics in the interior speak the local language. In the hospital however, the nurses and doctors only speak Dutch and some Sranangtongo. Most female respondents stated language to be a barrier in compliance to referral which HCAs confirmed.

Some people refuse to go to the hospital because they have nobody who could help them communicate ("with the doctors")

(HCA)

3.1.4 CARE SEEKING IN CASE OF AN ACUTE EVENT

The decision on seeking care when a complication occurs was not often seen in this study as most women interviewed were compliant to referral and had no complications occurring while being at home or in the city. Of the four female respondents non-compliant to referral however, three were finally emergency referred during or shortly after delivery of which two referrals were due to poor neonatal outcomes. Delay in seeking care occurred as one Amerindian female respondent stated going to the forest to deliver instead of the MM clinic which led to significant delay in receiving care.

I stayed home for almost 17 hours. I went with my grandma to the forest to deliver. The delivery was difficult. The baby was born weak. When the baby was born it had a bad breathing.

(Female respondent, 15 years old)

HCAs shared their concerns of non-compliance to referral of women with risk pregnancy. They realized their obligation to provide care but feelings of incapacity to manage the complexity of some cases were shared. In the interviews, HCAs gave many examples of complex deliveries in cases of non-compliant women, which showed the magnitude of the problem and the impact of the cases on the HCAs. Several HCAs stated being unable to forget the case as families and communities often blame the HCA for the death of a mother or child.

The father said: no, she should deliver here because she has no identification card. I don't want to pay for the hospital. When she came, one hand ("of the baby")*was born, I called directly to MM, it was such a problem. The plane came to get the woman. She got an caesarean section but the baby was already dead.*
(HCA)

One woman came to the clinic to deliver. She stayed home for hours. Then she came and started bleeding. The baby was stillborn. On the way to the airstrip she died.
(HCA)

They told me it was my fault. But I had warned her about this. She had to go see the medical specialist but did not go. Before the women passed away she started bleeding profoundly. I have seen it. It was a ruptured uterus. There was nothing we could do.
(HCA)

ATTITUDE OF HCA

One patient stated that she experienced negative attitude of a HCA due to her decision of non-compliance. HCAs stated that if female respondents were non-compliant to referral they will not seek care at the clinic anymore because they are afraid of what the HCA will say.

Some of us say: you had your referral letter. Don't come for checkups anymore. You should leave
(HCA)

SUMMARY OF PHASE 1 DELAY

Delay occurs in different processes of deciding to seek care. The decision on visiting ANC is usually made by the woman itself but almost always late as cultural norms prevent ANC visits in the first trimester. Fear and shame also play a role in delay. The decision on compliance to referral is influenced by many factors but most prominent are autonomy, lack of money and housing availability. When non- compliant to referral, delay in seeking care at MM by the pregnant women is seen and could be influenced by poor attitude of HCAs towards those women. Most women in this study experienced an unwanted pregnancy which was the consequence of lack of knowledge, lack of autonomy or access to family planning.

3.2 PHASE 2 DELAY: IDENTIFYING AND REACHING THE HEALTH FACILITY

In this study, the delay to two different health facilities were studied namely the MM clinics and the hospital in Paramaribo.

3.2.1 IDENTIFYING AND REACHING THE MM CLINIC

Since there are 50 clinics in the interior of Suriname most villages have a clinic nearby. As this study was performed in villages with a clinic, barriers in reaching the facility of MM were not mentioned by female respondents.

3.2.2 IDENTIFYING AND REACHING THE HOSPITAL

When the decision is made to be compliant to referral, transport to the city is by plane (Kwamalasamutu), boat and bus (Ladoani) or bus (Brownsweg). The transport itself was only seen as a barrier by participants from Kwamalasamutu as planes only land in good weather and delay therefore occurs in the rainy season. Boat and bus transport from Ladoani and Brownsweg is daily. In 2012 the road to the south was paved which improved transport time to the city greatly. Many female respondents stated not the transport but the costs of transport being a barrier in reaching the hospital. HCAs and key informants discussed delay in transport to be an important factor in emergency referral, more than elective referral.

Transport within the city was named as a barrier several times. It was stated that people do not know the way in the city and that they cannot afford transportation in the city. This was problematic as female respondents did not attend ANC at the hospital due to lack of money.

Girls can't get to their checkups because they don't have money for the buses or taxis. So they stay at home.

(Female community member, 42 years old, Kwamalasamutu)

CULTURAL PRACTICES

Cultural practices were seen to cause a delay in reaching appropriate care as they need to be performed before travelling to the city. They did not influence the decision to go (first delay) but the timing of transport to the city and therefore are the most important factor influencing second phase delay. Cultural practices during pregnancy are very common among Maroon women. 9/11 maroon female respondents performed a ritual named "*potu'* in which the family will cook herbs with water to drink to prevent poor or prolonged labor. All maroon HCAs have shared experiences of delay in referral of women with a risk pregnancy due to cultural practices.

Nurse , I am going to do this and this or I cannot go. If I go my baby will die.

(HCA)

Most HCAs say they refer sooner as they predict this delay to occur. However, risk is not always predictive and some referrals are not planned beforehand. In these cases delay due to cultural practices can lead to maternal death.

We informed the doctor and would send the woman to the city but she had to finish her rituals. Potu, she had to go to camp. At night the woman was brought in pale and out of breath. We did not have a telephone so we waited till morning to ask for a plane. When the plane arrived, the woman died.

(HCA)

The Amerindian respondents all stated having no traditions during pregnancy anymore as they converted to Christianity in the last decades.

With our ancestors there were rituals to drive away the evil spirits but now, with the coming of the Holy Spirit, we left everything

(Male community member, 45 years old, Kwamalasamutu)

Cultural practices were the only factor of influence on the decision-making process that differed from Maroon to Amerindian participant. This factor however, was not of influence on the decision-making itself but caused delay in referral. In review of literature this delay is not often recognized as literature is more focused on cultural norms like birth with a traditional birth attendant (TBA) as a preference to facility birth.(33,77,78) Despite the presence of TBAs in the interior of Suriname, this preference has not been found in this study.

SUMMARY OF PHASE 2 DELAY

Identifying and reaching MM is not considered problematic by most participants. Delay is mostly seen due to cultural practices that need to be performed before travelling to the city. In this study performing cultural practices was considered a phase 2 delay as the decision to comply to referral was already made. Furthermore transportation within the city is a barrier to adequate care as financial constraints exist.

3.3 PHASE 3 DELAY: RECEIVING APPROPRIATE HEALTH CARE

3.3.1 RECEIVING APPROPRIATE CARE IN MM CLINICS

QUALITY AND ACCESSIBILITY

When discussing the quality of care at MM most comments made by female respondents were concerning the poor attitude of the HCAs. Only 3/15 female respondents stated experiencing positive HCA attitude. Six female respondents said they feared the HCA and therefore experienced a barrier in accessibility of MM. They were afraid to be scolded at because they were pregnant at a young age, came late to their first ANC visit or did not comply to referral. 6/10 HCAs admitted getting angry with pregnant women at some time during ANC. Also community members commented on poor attitude of some HCAs and confirmed that poor attitude is a barrier in access to the MM clinic as women fear the HCA.

The first visit was not good. They were not friendly to me because I came late.

(Female respondent, 18 years old)

AVAILABILITY

Availability of HCAs was general good. Three female respondents experienced medication being out of stock while visiting the policlinics. The main discussion within this theme was the availability of equipment to perform a caesarean section in the interior of Suriname. Some female respondents, HCAs and community members suggested having a hospital in the interior to provide quality care in the interior. Furthermore, several participants suggested the availability of a maternity waiting home in the city and a boat from MM for transportation purposes. The availability of HCAs did not seem to influence compliance to referral in this study.

DECISION-MAKING PROCESS OF THE HCA ON REFERRAL

As this study explores the decision-making process within the referral of risk pregnancy, the decisions made by the HCA are also of great importance as the HCA should recognize risk which should lead, without delay, to the decision of referral. In this study all HCAs correctly named all indications of referral. Furthermore all female respondents confirmed that they experienced a risk pregnancy and were aware they were referred to the city due to that risk pregnancy. They could name the risk and 11/15 female respondents could name complications that could occur.

When referred we tell them why it is important to go. For example grand multiparity: At your delivery there is a chance that you will bleed a lot because your uterus is weaker and if you bleed a lot you could die. (HCA)

Knowledge and skills of the healthcare provider are important in effective referral as previous studies have shown delay in referral to occur as health care providers fail to detect complications or have a poor perception of risk.(44,60) In this study however, the knowledge and recognition of referral indications by HCAs was accurate and their sharing of that information with the patient showed they provided quality health care.

3.3.2 RECEIVING APPROPRIATE CARE HOSPITAL

ACCESSIBILITY

Access to care in the hospital was a huge problem for female respondents. A healthcare insurance is mandatory to receive hospital care. This insurance will be provided by the government if you can proof financial difficulties. However, obtaining this card was problematic for all female respondents interviewed. Of the 11 female respondents compliant to referral, five women finally gave birth without a healthcare insurance. They delivered their babies at the emergency room of the hospital where some had to pay out of pocket for the delivery. The other six female respondents travelled to the city and waited between two weeks and seven months for their healthcare insurance.

*I stayed home ("*in Paramaribo"*) the whole day. They had given me medication from Ladoani clinic and I took it. On the day of the delivery I went to the hospital and they let me pay.*

(Female respondent, 31 years old)

Without a healthcare insurance, check-up at the gynecologist was not performed. HCAs and community members confirmed this to be a huge issue. Some community members also paid for their wives delivery in the city out of pocket.

Social affairs does not have medically educated people there so they say: you can wait three more weeks with your belly because next insurance month starts then and then. Then you have a delay for this woman in getting tests or visiting the gynecologist

(Key informant)

LANGUAGE BARRIERS

Language was experienced as being a barrier in receiving adequate health care with 8/11 female respondents. Female respondents searched for translators to accompany them to the hospital. Translation during delivery is however difficult as most translators are male and unrelated and therefore not allowed to be present. One of the Amerindian HCAs explained that in the hospital caesarean sections are quickly performed on Amerindian women as they scream during delivery and are unable to communicate the problem. Gynecologist often interpret this screaming as an alarm symptom while screaming during delivery is imbedded in Trio culture and more a cultural practice than a sign of severe pain.

A girl of 15 years old that speaks only trio should deliver by herself (without understanding the health care staff and without family). *That is difficult for us.*

(Female community member, 42, Kwamalasamutu)

AFFORDABILITY

Money caused delay in receiving quality care as women were unable to visit hospital checkups due to financial restrictions and the inability to afford transport in the city. Worrisome were the comments within the Amerindian FGD where all men participants stated knowing examples of women with a risk pregnancy that were referred and ended up prostituting themselves to obtain money for survival in the city. These events made the traditional authority of the Amerindian villages disapprove referral to the city.

If they start prostitute themselves, some don't return to Kwamalasamutu anymore. We don't know where they went. That is a big problem for us. We don't want that.

(Male community member, 50, Kwamalasamutu)

SUMMARY OF PHASE 3 DELAY

The biggest barrier in receiving quality care is the availability of a healthcare insurance. The protocol of elective referral of MM is developed to optimize quality care for women with a risk pregnancy. However, in the current situation several of the referred women are not receiving any care due to delay in obtaining their healthcare insurance. Second constraint is language as it is seen as a barrier between patient and doctor and therefore likely influences quality of care. Important is the access to care of female respondents non-compliant to referral as this study shows negative attitude of HCAs towards this patient group. Fear of this negative attitude leads to delay in care seeking by female respondents.

Despite the heterogeneity among the participants, the main common factors they share might be of particular importance in this study namely living in remote villages in the interior in tribal communities. They have their own languages and people live of the land directly and hunt instead of participate in a money-driven economy. This raises the same barriers for all pregnant women in the decision-making process: lack of decision-making power, insufficient financial means, lack of housing availability and a language barrier. Lack of income made female respondents eligible for receiving a healthcare insurance but delay was experienced.

CHAPTER 4: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

In this chapter, the most important factors of influence on the decision-making process within referral of women with a risk pregnancy will be further discussed and a bigger picture will be framed. Furthermore justification and contextualization of interpretations is given, strengths and weaknesses of the study will be mentioned and the conceptual framework will be discussed. Finally a conclusion is made and recommendations for interventions or further research are given.

4.1 FRAMING THE BIGGER PICTURE

How can this study into the decision-making process of women with a risk pregnancy in the interior of Suriname lead to improved outcome for mother and child in that interior? First of all research was needed to understand the factors that influence decision-making within referral of risk pregnancy. Secondly, recognition should lead to appropriate interventions that address those barriers to care. So what is the bigger picture behind the results of this study?

The decision-making process of women was mainly influenced by money, housing availability (environmental) and autonomy (individual). All factors found in this study are shown in figure 4.

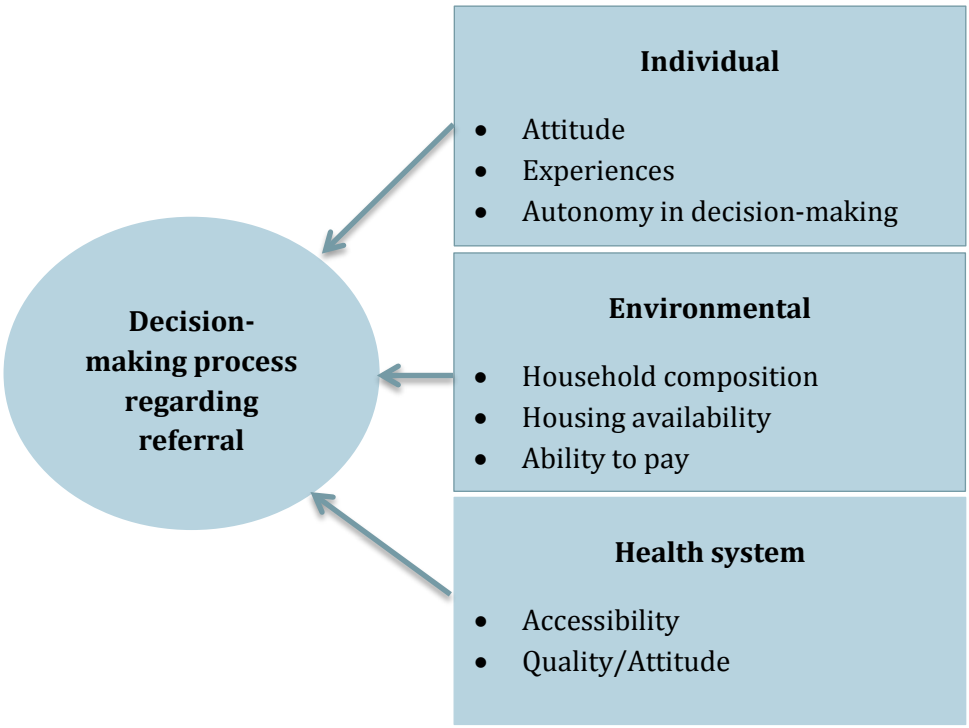

Figure 4: Factors of influence in the decision-making process regarding referral.

DECISION-MAKING AUTONOMY

Lack of autonomy in decision making was evident in this study and led to delay in seeking and receiving adequate care. Despite the focus on decision around referral, the lack of autonomy within family planning was apparent in this study. Without decision-making power safe motherhood, defined as being a woman's ability to have a safe and healthy pregnancy and delivery at the time she wants, will not be fulfilled in the interior of Suriname. With lack of autonomy comes the need to empower women. Empowerment is a multidimensional concept defined as the expansion in women's ability to make choices in a context where this ability was previously denied to them.(2) This concept throughout literature has a broad variation of definitions and a wide range of indicators that measure empowerment.(79) In 2012 Some stated that the empowerment of women is vital to the reduction of maternal mortality.(46) Empowerment of women should lead to women making their own decisions concerning their own health. Although most studies have a focus on the impact of empowerment of women on their reproductive health, Samari (80) studied the effect of reproduction on empowerment and showed that giving birth empowered women greatly. In this study this impact has not been studied. Furthermore, the magnitude of the influence of low autonomy on maternal health outcomes in this study remain unclear, as it was qualitative in nature, and should be subject of further study.

The ability to decision-making power on family planning is extremely important in improving outcome for mother and child.(81) The United Nations Children's Fund (UNICEF) showed in 2010 a high unmet need for contraceptives in the interior of Suriname were the highest unmet need was seen in the age group between 15-19 years.(27) WHO stated in their *global strategy for women's, children's and adolescents health 2016-2030* that if there was no unmet need for contraceptives and all pregnant women received care at the standards recommended by WHO, MMR would decrease with 67%. Furthermore WHO estimated that a 10% reduction in marriage before the age of 18 could contribute to a 70% reduction in MMR.

MONEY

None of the female respondents in this study had an income and all were dependent on extended family or husbands. A study about poverty in Suriname revealed 75% of people in the interior receive an income of less than 3 US dollar per day.(82) The decision to comply to referral was mostly based on the availability of money. Poverty-related barriers are previously described as having a major impact on the decision-making process regarding childbirth.(83) A recent study in Suriname showed that maternal death in Suriname is associated with poverty in 69% of the cases.(26) Health outcomes are worse among women that are the poorest, the least educated and those that live in the most remote areas.(81,84) MM target population includes those women. Results of this study included stories of pregnant women deciding to prostitute themselves to survive in the city, waiting for their baby, in absence of money. These

circumstances are unacceptable and marginalize these women even further. The need to sell or borrow to pay for health care is previously described by Kruk et al in 2009.(85) One intervention successful in increasing access to care is conditional cash transfers.(86) Cash transfer experiments furthermore have shown greater economic independence of women which is associated with greater decision-making autonomy.(87) However, in this qualitative study, it did not become clear whether the availability of money would increase the ability of the woman to make her own choices. Further research in that area is needed.

Autonomy and money seemed linked in this study as women were dependent on others for money and therefore could not decide themselves. Two great barriers restrict a woman's ability to translate demand into effective utilization of maternal health care, namely gender inequality and poverty. Without addressing those two root causes no sustainable reduction of MMR can be achieved.(88) Interventions addressing these structural causes are however complex. WHO's global strategy concerning maternal, adolescent and child health recognizes the critical role of eradication of poverty. As interventions addressing poverty need strong leadership, sufficient finances and a multisector approach, efforts from all policymakers are required.

HOUSING AVAILABILITY

As referral in this study was elective in nature, the availability of housing was a major constraint in complying to referral. Several community members suggested patient waiting homes as an intervention as they had experienced the benefits in neighboring countries like Guyana and Brazil. Results on the effect of those homes on facility births are mixed and the success of the home is mostly influenced by community acceptance.(89) As the community is however positive about its use, it has the potential of becoming an effective intervention enabling better access to care for women with a risk pregnancy.

HEALTH INSURANCE

In this study, the most important health system barrier found to receive adequate hospital care was lack of healthcare insurance. This should be top priority as the management of risk pregnancy and its referral at MM is based on the accessibility of adequate care for referred patients. If women who experience a risk pregnancy lack access to appropriate care they could wisely be not referred but monitored in the care of MM. Also lack of money and subsequently transport barriers to the hospital influences the access to care for pregnant women which could be addressed by conditional cash transfers.

HEALTH CARE PROVIDERS' ATTITUDE

HCAs made an honest contribution to this study as they shared the existence of negative attitude towards women non- compliant to referral. Although understandable, as women's decision-making could put HCAs in a difficult position, any person has the right to healthcare in any circumstance. Bossyns in 2004 already stated: "*Referral decisions are not just a matter of technical or organizational considerations, they also involve emotions on supply and demand side".*(90) This study showed female respondents having fear of the HCA which caused a barrier and a delay in receiving quality health care. The health care providers' negative attitude is previously described (65,68,69,91) and the current strategy of WHO focuses on respectful care with dignity and good communication(92) It should also be the aim of MM to achieve respectful, women centered, quality care for pregnant women.

THE ROLE OF EDUCATION

Education is a factor not explicitly included in the framework of this study. It is however considered an important underlying cause of lack of knowledge and lack of autonomy. In this study only one female respondent finished secondary school. Previous studies have shown educational level to be associated with decision-making power and higher education has shown to be correlated with better maternal health outcomes.(93) Correlations between education, poverty, gender inequity and decision-making are known, however the magnitude of the association remains unknown.(84) Maternal health is therefore intricately tied to the social and economic status of women. As decision-making and educational level are linked, education should be included in frameworks for further research. The WHO global strategy concerning maternal, adolescent and child health include support for completion of higher levels of education for boys and girls.

THE ROLE OF THE COMMUNITY

Community involvement plays a key role in the improvement of maternal health.(81) Communities in this study were actively involved in the decision-making process. Community involvement has been shown in other studies to enhance obstetric health outcomes and speed-up the decision-making process.(49) In overcoming barriers to care however, the communities showed no responsibility as this was considered a matter for the family. For implementation of effective interventions that are based on community involvement, a sense of responsibility of that community in improving maternal health should first be made apparent.

4.2 STRENGHTS AND LIMITATIONS OF THE STUDY

This is the first study that is undertaken in the interior of Suriname addressing this topic. The context of MM is quite unique to the world. MM serves extremely remote areas. Where most distance to facilities in other studies are around 5-25 km, distance to the MM clinics are relatively short. However, distance to the referral facility in the context of this study could be well over two weeks of travel. Although neighboring countries have a somewhat similar context, Brazil, Guyana and French-Guyana do have roads to remote areas. Suriname has not and is dependent on boat travel. No studies addressing the decision-making process of pregnant women have been found in the neighboring countries.

A strength of this study is its inclusion of women who experienced a risk pregnancy, health care professionals and community members which gave the opportunity to explore the issue from both supply and demand side. Limitation of this study was its restriction to particular geographical areas. Therefore it should not be considered representative for the barriers faced by women in the whole interior of Suriname, although it might be expected they suffer similar issues. Furthermore Amerindian participants were scarce and where all interviewed in the city. Therefore the opinions of people that did not come to the city were missed and could have influenced results. Women who experienced a risk pregnancy and were non-compliant to referral where less eager to participate in the research which is a limitation of this research.

This study was performed in four different languages and translators had to be used. In the case of trio the only available female translator was a HCA which could have influenced the answering of certain questions. Beck et al. stated that the quality of the translations are influenced by the translator's cultural experience, knowledge and qualifications. Furthermore the issue is not if the translator makes her mark on the research but whether this is acknowledged or not.(94)

4.3 DISCUSSION OF THE FRAMEWORK

As the results show, the decision-making process during pregnancy is complex with different factors intermingling. In order to fully grasp this complex process, a complex framework was created. The framework helped to order and structure events during this study. However as so many events and factors intermingled, the complexity of the framework increased. Education should be added as an individual factor as it has its influence on the decision-making process.

In other studies concerning delay, referral is usually considered a second delay.(33,95) This study put emphasis on the decision-making regarding compliance to referral as a first delay as a woman should decide on compliance before facing transport barriers, identify a hospital (phase 2), or face delay in receiving appropriate care (phase 3). The interpretation given to delay in this framework was slightly different than that of the original framework by Thaddeus and Maine and not for the simple fact that Thaddeus and Maine created their framework to be used in emergency obstetric care. The phases of delay in this framework were used to visualize the importance of time as time in decision-making is a crucial component. In this study the differences between phases of delay were shown to be of less importance than might have been the case for emergency referral. After working with the framework throughout the study, the decision-making process was placed at the core of the study whilst not completely reflected in the framework. However, the framework fit the purpose and could be used for studies concerning similar objectives.

4.4 CONCLUSIONS

This was, to my knowledge, the first study addressing the decision-making process within the referral of risk pregnancy in the interior of Suriname. The factors of influence on this process where explored within the context of MM so that specific interventions could be proposed to improve maternal and child health outcomes. Results revealed the influence of many factors, some already known through studies concerning health seeking behavior, others more context-specific. As this study involved actors on supply- and demand side, barriers mentioned seem valid as they were mentioned by all actors involved. Women living in the interior face several barriers in accessing and receiving adequate care. Results of the study showed female respondents to be low educated and in lack of regular income. Furthermore female respondents did have knowledge on risk in pregnancy but this knowledge did not seem to influence the decision-making process. Attitude towards pregnancy was found negative in the majority of cases but the importance of ANC was acknowledged and this negative attitude did not restrict women from deciding to seek care. Past experiences with hospital care served as enabling factors for compliance to referral. The most important individual factor influencing the decision-making process and causing delay in referral was lack of autonomy experienced by the female respondents. Furthermore environmental factors seem to have the biggest impact on the decision to be compliant to referral as lack of money and lack of housing were most mentioned barriers. Underlying those barriers are structural causes like poverty, low education and gender inequality. Those three factors are strongly associated with each other as women that lack decision-making power are more prone to poverty and are mostly less educated. Furthermore poverty is a risk factor for teenage pregnancy, which was frequently observed in this study.

Health system factors did have an influence on the decision-making process within referral. First of all poor attitude of HCAs acted as a barrier to seeking care by female respondents. The quality of the hospital care was perceived good but a language barrier was often present and could have influenced this quality. Accessibility of the hospital was the biggest barrier as women faced severe delay in obtaining a healthcare insurance and therefore in receiving adequate care for their risk pregnancy. This delay should be a priority for MM to acknowledge and interventions should be placed. Affordability was an issue as cost of living in the city and transport cost raised a barrier in receiving adequate care as women did not reach care and stayed home.

The importance of women to be able to make informed choices about their health and seek and receive health care services they need, is demonstrated by better health outcomes for women and child. Hopefully this study serves as a starting point for the implementation of interventions addressing barriers that women in the interior face in receiving adequate care.

4.5 RECOMMENDATIONS

INTERNAL RECOMMENDATIONS MEDICAL MISSION

1. Install a mediating person between the patient and Social Affairs to end the delay in receiving a healthcare insurance. Information about patients can be send to social affairs or social affairs can send someone to the interior.
2. Explore the possibility for a maternity waiting home in Paramaribo as it reduces a barrier in receiving adequate care.
3. The management of referral of risk pregnancies should be revised as there is no continuum of care in the current situation. Till barriers are addressed and overcome, continuum of care should be the responsibility of MM.
4. Provide training to all HCAs in positive patient-centered, non-judgmental healthcare provision, including care for adolescents.

EXTERNAL RECOMMENDATIONS MEDICAL MISSION

5. Discuss the results of this study with communities and address the role of communities in improving maternal health. According to WHO strategic plan create understanding and support in reducing pregnancy before the age of 20. Actively support positive change to social norms like the ritual of *pangi* and attitudes that impede progress.
6. When designing a program addressing maternal health, incorporate and address inequalities in women's education, economic status and decision-making power.

FURTHER RESEARCH AT MM OR MOH

7. Perform a mixed-methods study addressing family planning and teenage pregnancy as this study has shown existing barriers in access to family planning. Mixed-methods would be preferred as it can show the magnitude of the problem and the experiences of men and women in need of family planning.
8. Further research on the magnitude of poverty, gender inequality and women's empowerment should be performed to visualize their impact on health seeking behavior.

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This research is about all women living in the interior of Suriname. I would like to thank them for sharing their experiences and barriers which made the core of this research. Also the community members and healthcare assistants made such great contributions to this research.

Gre, you supported this whole process beginning till end. Not only by your presence but also with comments, thoughts and ideas. Thank you for flying all over the world to enable me to follow this path in life.

To my parents. I can imagine your faces when I would have told you I wanted to finish my Master International Health while being a doctor in Suriname and a mother of two boys under 3. I feel sad that I can't share this experience with you anymore. You are missed every day!

To my sister. Thanks for being there for me and for just always being my big sis!

To Laurens, thank you for your unconditional support, for always speaking your mind and for challenging me to become the person I want to be. Thanks for being the greatest father in the world to Manu and Luca and for all the love you give us every day.

ANNEXES

ANNEX 1: LIVING AREA OF MAROON AND AMERINDIAN TRIBAL COMMUNITIES

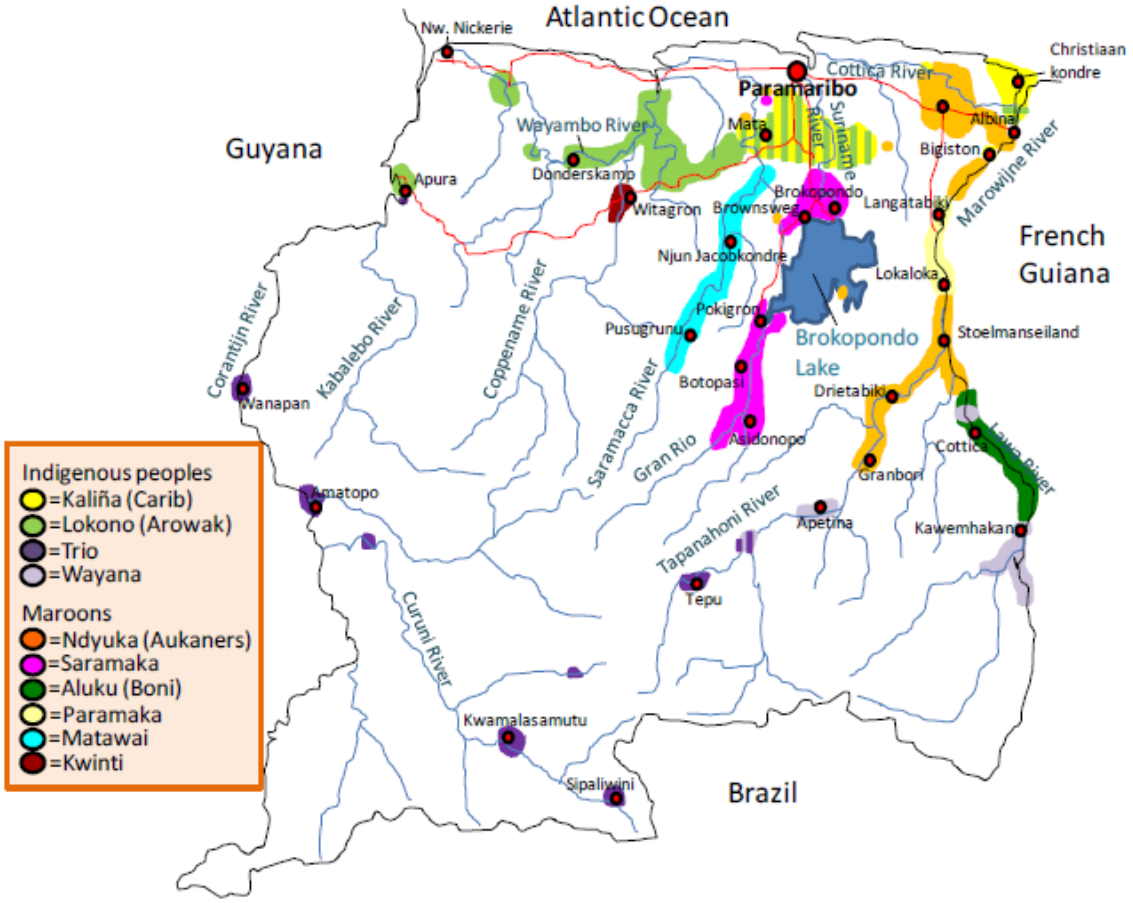

Figure 5. Map of living area of Maroon and Amerindian tribes (8)

ANNEX 2: SEARCH STRATEGY OF LITERATURE STUDY

The search included scientific published and *grey* literature. Policies of Suriname were gathered at Ministry of Health, PAHO, UNFPA, UNICEF and Medical Mission. Websites of world bank, the United Nations and WHO were searched for relevant material.
Online databases used were *PubMed, Medline, Google scholar.* Search terms used were *referral, maternal mortality, three phases of delay, decision- making delay, first phase delay, second phase delay, third phase delay, stillbirth, maternal complications, Thaddeus and Maine, referral delay* , *Suriname, LAC, risk pregnancy, anaemia in pregnancy, adolescent pregnancy*, *ecological model, socio-ecological model, Lalonde, autonomy, knowledge, barriers* and combinations of those. Literature found has been used throughout the document. Additional relevant studies were obtained by examining the references of each selected publication. Literature from 1995 to present was used and language limitation was English and Dutch.

ANNEX 3: MANAGEMENT OF RISK PREGNANCY AT MM

MM follows the WHO protocol *Integrated management of pregnancy and childbirth* (5). This protocol has clear guidelines on referral to CEmONC care of a pregnant woman.

Referral indications according to protocol:

1. Severe anaemia (Hb <5,0 mmol/l)
2. Caesarean section in history
3. Hypertension in pregnancy
4. Adolescent pregnancy (age < 17)
5. Grande Multiparity
6. Diabetes Gravidarum
7. Primi gravida with short stature (<150 cm) and no engagement of foetal head at 37 weeks gestation.
8. Multiple pregnancy (twins)

Process of referral of risk pregnancy

At MM antenatal care is managed by the HCA. If a woman is pregnant she receives an ANC file the first time she comes to visit. All files of pregnant women are screened by medical doctors as they visit the clinics. As soon as a risk (e.g. age <17) or complication (e.g. hypertension) occurs within a pregnancy and is acknowledged by the HCA the women will be referred according to protocol. The medical doctor is responsible for the final referral decision. Women receive their referral advice by HCAs in the interior. Women will travel to the city with their ANC file and a referral note stating the indication for referral. They need to travel to the OPD at MM coordination center in Paramaribo. This travel is taking place at their own expenses. Only women living in the Amerindian communities in the south of Suriname are transported by MM as there are few possibilities for them to travel to the city. All other women should find their own transport and financial means. At the OPD, the women receive a consultation with a medical doctor and are further referred to specialized care in the hospital. As a result of this system all women compliant to referral present themselves at the OPD in Paramaribo and are registered as compliant to referral. Women non-compliant to referral stay in the village and are therefore still under the care of MM. Figure 6 shows a flowchart of management of pregnancy at MM.

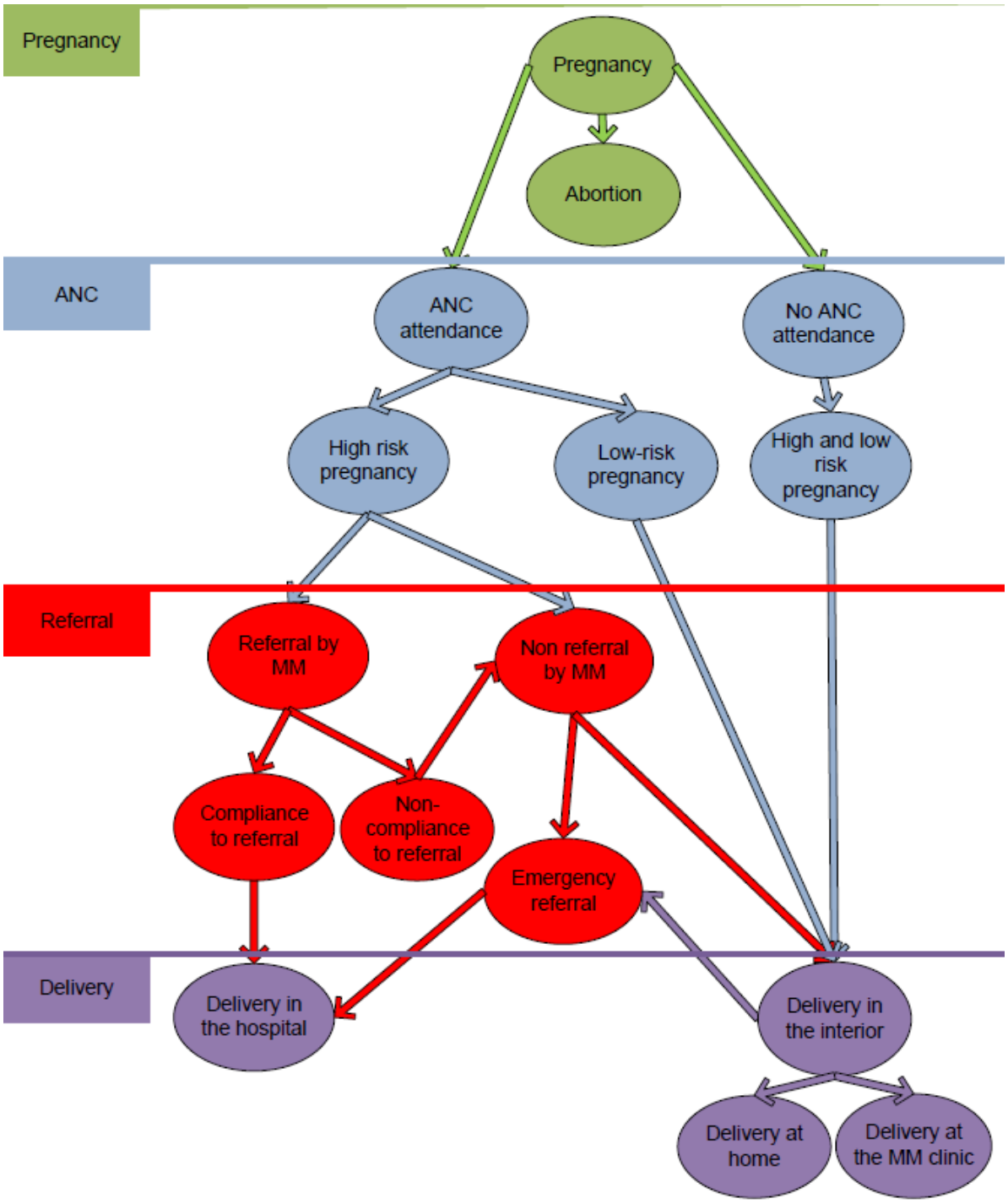

Figure 6. Flowchart of the management of pregnancy at MM

Onderzoek naar beslissingen tijdens zwangerschappen in het binnenland van Suriname

Mijn naam is Rosanne Peuscher. Wellicht heeft u mij eerder gezien want ik ben al 4 jaar werkzaam als dokter bij Medische Zending PHC Suriname. Ik ben ook onderzoeker. In samenwerking met KIT Amsterdam doe ik namens MZ onderzoek en vraag daarbij om uw hulp. Het onderzoek heeft als doel meer kennis op te doen over verschillende typen zwangerschappen en welke beslissingen er in de zwangerschap gemaakt worden.

Als zwangere kunt u ervoor kiezen naar de polikliniek te gaan voor controle. Ook zou u kunnen kiezen om dit niet te doen. Indien er problemen zijn met u zwangerschap wordt u soms naar het ziekenhuis in Paramaribo gestuurd. Sommige vrouwen blijven echter in het dorp. Ik wil graag weten waarom u bepaalde keuzes maakt en welke zaken hier allemaal van invloed op zijn. Daarom willen ik graag met u praten. U hoeft niets te vertellen wat u niet wilt. Alles wat u vertelt blijft geheim. Ik wil met dit onderzoek erachter proberen te komen welke zaken allemaal een rol spelen in de beslissingen die u neemt tijdens u zwangerschap. Hierdoor hoop ik dat we bij MZ straks nog beter voor u kunnen zorgen.

U kunt altijd zeggen dat u niet meer mee wilt doen, ook als u eerst ja hebt gezegd.

Als u erover denkt om mee te willen doen aan ons onderzoek, wil ik u vragen om met mij contact op te nemen. Dan zal ik eerst nog meer over het onderzoek uitleggen en mag u altijd beslissen of u wel of niet mee wilt doen aan het onderzoek.

U mag ook andere zwangere vrouwen vragen of zij misschien willen helpen. Ik ben opzoek naar tieners die zwanger zijn of zwangere vrouwen die problemen hebben tijdens hun zwangerschap.

Contact opnemen kan door u aan te melden bij de polikliniek en te melden dat u met mijn onderzoek mee wilt doen. Indien u niet bij de polikliniek wilt melden kunt u mij bellen op +597-7591654

Dank u voor het lezen van deze brief en bedankt voor uw hulp.

Met vriendelijke groet,

Mevr. Rosanne Peuscher, onderzoeker en dokter

Mede namens dr. Bianca Jubitana, dokter en hoofd afdeling MESO MZ

ANNEX 5: TOPIC GUIDE WOMEN WITH A RISK PREGNANCY IN HISTORY

Code: time start: time end:
Age: Village: Number of living children:

Marital status: Insurance: financial aid/income:

Education level:

Risk pregnancy:

Referral compliance: yes/no

Children DOB	Delivery (normal/complicated)	Where	By who	Comments
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				

Vignet 1

What do you think about the case of Lily?
If you were here mother or sister, what would you advise her?
Which factors are important in the decision of Lily?
Do you know of similar cases in your community? Can you give me an example?

Vignet 2

What do you think about the case of Anoenziata?
If you were here mother or sister, what would you advise her?
Which factors are important in the decision of Anoenziata?
Do you know of similar cases in your community? Can you give me an example?

UNDERSTANDING RISK PREGNANCY

How did you experience your pregnancy?
Were you referred for your delivery?
Do you know why you were referred for your delivery?
What did you think were the risks of your pregnancy?
What did you think about the referral of your pregnancy?
Which advice was given to you by the HCA?
What did the HCA mean with this advice?

DECISION MAKING PROCESS

Why did you go or not go to the hospital?
Who made the decision to adhere/not adhere to referral? Can you explain a bit further?
Which factors influenced this decision?
When were you referred en when did you decided to go? Was there a delay in going? Why did you have a delay?
Which traditions exist around pregnancy or childbirth? Can you elaborate on that?
Which influence do the traditions have on your decision to go/not go to the city?
Has your family influence on the decisions that you make concerning your pregnancy and the referral? Can you give an example? What about your friends? Church?
Who pays for the transportation to the city?
What happened with you other children when you went to the city/ Who would look after your other children if you would have gone to the city?

PERSPECTIVES ON THE HEALTH CLINIC

Did you go to ANC services?
When did you decided to go to the ANC services?
Who decided that you should go to the ANC services?
How often did you go to the ANC services?
Did you visit a traditional birth attendant during your pregnancy?
Did the HCA inform you that you needed to have to deliver in the hospital?
What did they tell you?
Did you discuss your ideas whether to go or not? Why? Why not?

PERSPECTIVES ON THE HOSPITAL (IF COMPLIANT TO REFERRAL)

Did you know where to go in the city?
Did you have a place to stay in the city?
What did you know about the hospital care in the city?
Did you have difficulties with going to the hospital for the delivery? Can you tell me more about it?
What where your expectations about the hospital?
What were your experiences with the hospital? Can you tell me more about it?
What were your experiences with getting an insurance card?
What would you do if you have another pregnancy? Would you make the same decisions?

Is there more you would like to tell me about this topic?
What are the most important subjects we discussed?

ANNEX 6: TOPIC GUIDE IN-DEPTH INTERVIEW HCA

Code:	time start:	time end:
Age:	village:	
Marital status:	M/F	children:

EXPERIENCE AND UNDERSTANDING OF RISK PREGNANCIES

What is your experience with referral of risk pregnancies?
Which risk pregnancies are referred to the city?
Why are they referred to the city?
Are they always referred to the city?
Can you give me examples of cases where the referral did not take place?
Which factors were of influence on that?
In your opinion, Is there a delay in referral? What are factors of influence to that delay? In your opinion, what is good about the referral system?
In your opinion, what can be improved in the current referral system? Why do you believe this needs to be improved?

HEALTH FACILITY

Are you aware of barriers that women face while going to ANC services?
What is, in your opinion, the attitude of pregnant women towards referral of risk pregnancy? Can you give me examples?
What is, in your opinion, the influence of family? Of peers? Of friends? Of the church? Of traditions? Can you elaborate on that?
What is your experience with the compliance to referral by pregnant women?
Which barriers are faced with referral?
Do you discuss those barriers with the patient?
Which questions do the pregnant women ask about the referral
Which information do you provide about the referral
What is the attitude of the community towards referral of risk pregnancies?
From your experience what is the perception of pregnant women on going to the hospital to deliver?
Which factors influence their perceptions on going to the hospital?

Is there more you would like to tell me about this topic?
What are the most important subjects we discussed?

ANNEX 7: TOPIC GUIDE FOCUS GROUP DISCUSSION MEN

time start: time end:

village: participants (number and age)

OBJECTIVE: To explore the decision-making process of women with risk pregnancies and factors of influence on this process in order to make recommendations for interventions to improve maternal and neonatal health.

VIGNET 1

If you were Lily's husband/father. What would you advise her to do?
Why would you advise this?
Which factors are of influence on this advice?

VIGNET 2

If you were Anoenziata's husband/father. What would you advise her to do?
Why would you advise this?
Which factors are of influence on this advice?

UNDERSTANDING RISK PREGNANCY

Do you know why some women go to the city to deliver and some stay here? Can you elaborate on that?

Which influence do the traditions have on decisions of people to go to the city or stay here, in your opinion?
What is the influence of family on decision making by a pregnant women?
Can you give an example? What about friends? Church?
Who pays for the transportation to the city?
Does the community provide transportation for pregnant women to the city?
What happened with you other children when you went to the city/ Who would look after your other children if you would have gone to the city?

PERSPECTIVES ON THE HEALTH FACILITY

What do you think about the ANC services at the health clinic?
Do women visit a traditional birth attendant ?
What do you think about the quality of care?
What is your opinion on ANC services at MM?
Which barriers do you believe exist in access to care

PERSPECTIVES ON THE HOSPITAL

What are your perspectives on the hospital?
Do women know where to go? Do women have a place to stay?
Does the community has influence on the decision to go to the city? Can you elaborate on that?

Is there anything we missed that you would like to talk about?
What is the most important point we discussed?
Thank you all for your participation. We are done

ANNEX 8: TOPIC GUIDE FOCUS GROUP DISCUSSION WOMEN

time start: time end:

village: participants (number and age)

OBJECTIVE: To explore the decision-making process of women with risk pregnancies around referral for delivery, and factors of influence on this process in order to make recommendations for interventions within this referral system to improve maternal and neonatal health.

VIGNET 1

If you were Lily, what would you do? Or if you where her mother or aunt?
Who has influence over your decision?
Which factors are of importance in this decision?

VIGNET 2

If you were Anoenziata's mother/sister. What would you advise her to do?
Why would you advise this?
Which factors are of influence on this advice?
UNDERSTANDING RISK PREGNANCY
Do you know why some women go to the city to deliver and some stay here? Can you elaborate on that?

DECISION MAKING PROCESS

Which traditions exist around pregnancy or childbirth? Can you elaborate on that?
Which influence do the traditions have on decisions of people to go to the city or stay here, in your opinion?
What is the influence of family on decision making by a pregnant women?
Can you give an example? What about friends? Church?
Who pays for the transportation to the city?
Does the community provide transportation for pregnant women to the city?
What happened with you other children when you went to the city/ Who would look after your other children if you would have gone to the city?

PERSPECTIVES ON THE HEALTH FACILITY

What do you think about the ANC services at the health clinic?
Do women visit a traditional birth attendant ?
What do you think about the quality of care?
What is your opinion on ANC services at MM?
Which barriers do you believe exist in access to care?

PERSPECTIVES ON THE HOSPITAL

What are your perspectives on the hospital?
Do women know where to go. Do women have a place to stay?
Does the community has influence on the decision to go to the city? Can you elaborate on that?

Is there anything we missed that you would like to talk about?
What is the most important point we discussed?
Thank you all for your participation. We are done

ANNEX 9: ETHICAL APPROVAL KIT

KIT | Health

Contact Meta Willems
Telephone +31 (0)20 568 8514
m.willems@kit.nl

KIT Health | P.O. Box 95001, 1090 HA Amsterdam, The Netherlands
BY E-MAIL:
Rosanne Peuscher, Student KIT
rosannepeuscher@hotmail.com>

Amsterdam, 30 October, 2017

Subject Decision Research Ethics Committee related to S-84

Dear Ms Rosanne Peuscher,

The Research Ethics of the Royal Tropical Institute (REC) has reviewed your application for ethical clearance for "The decision making process in risk pregnancies in the interior of Suriname. Barriers and believes (S-85) " research proposal, that was re-submitted on October 18, 2017.

The Committee has reviewed the revised protocol and has taken note of your amendments and clarifications and is pleased to see that you have addressed our concerns and questions to our full statisfaction.

The Committee is of the opinion that the proposal meets the required ethical standards for research and herewith grants you ethical approval to implement the study as planned in the afore mentioned protocol.

Kind regards,

L. Blok,
Co-Chair Research Ethics Committee, KIT

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KVK 33185213
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ABN AMRO USD NL46 ABNA 0570 1267 38

Royal Tropical Institute

ANNEX 10: ETHICAL APPROVAL CMWO SURINAME (DUTCH)

Ministerie van Volksgezondheid
in
Suriname

Directie en Centrale Administratie

Paramaribo, 8 januari 2018

No.: VG30-17

Onderwerp: Decision- making process in risk pregnancies in the interior of Suriname

Aan: mevr. Rosanne Peuscher,
Master of International Health Student
Kit (Royal Tropical Institute) Health Education/ Vrije Universiteit Amsterdam

Beste mevrouw Peuscher,

Middels deze deel ik u mede dat het Ministerie van Volksgezondheid u toestemming verleent voor het uitvoeren van bovengenoemd onderzoek. Dit onder de volgende voorwaarden:

1. U zult de verzamelde gegevens met de grootst mogelijke discretie behandelen.
2. Het verzameld materiaal zal alleen voor dit onderzoek gebruikt worden.
3. Het ministerie zal na afronding van het onderzoek en voor publicatie van enig resultaat, een rapport van u ontvangen.

Ik wens u veel succes met de uitvoering van dit onderzoek.

Met vriendelijke groeten,

Mevr. E. Moore-Tilon, M.Ed

Onderdirecteur Volksgezondheid

cc. Dr. S. Vreden, CMWO voorzitter

ANNEX 11: INFORMED CONSENT HCAS (DUTCH)

Introductie
Mijn naam is Rosanne Peuscher en ik ben een van de artsen die werkzaam zijn bij Medische Zending. Ik ben momenteel bezig met een onderzoek naar besluitvorming binnen risicozwangerschappen. U krijgt dit formulier om u uitleg te geven over het onderzoek en omdat ik hoop dat u zou willen meedoen aan het onderzoek. U beslist zelf of u mee wilt doen aan het onderzoek. Dit is vrijwillig en niet verplicht.

Doel van het onderzoek
Een risico zwangerschap is een zwangerschap zoals een tienerzwangerschap, of een zwangerschap gecompliceerd door een hoge bloeddruk of suikerziekte. Omdat deze zwangerschappen vaak meer risico's met zich meebrengen op problemen voor moeder en kind worden deze zwangerschappen verwezen naar de stad. Dit onderzoek gaat over de besluitvorming van zwangere vrouwen rondom deze verwijzing. We willen er middels dit onderzoek achter komen welke factoren een rol spelen bij de beslissingen die gemaakt worden. Dit is voor ons belangrijk om te weten omdat we daar dan voortaan beter mee om zouden kunnen gaan.

Soort onderzoek
Bij dit onderzoek zouden we u graag willen laten deelnemen aan een diepte interview. Dit zal ongeveer één uur in beslag nemen.

Selectie deelnemers
U bent uitgenodigd voor deze studie omdat u te maken heeft gehad met de zorg voor zwangere vrouwen en met name risico zwangerschappen

Vrijwillige deelname
Voorop staat dat uw deelname geheel vrijwillig moet zijn. U mag zelf kiezen of u wel of niet deel wil nemen en ook mag u altijd later besluiten of u wil deelnemen of niet.

Procedure
We zullen u vragen over uw ervaringen met risicozwangerschappen en verwijzingen naar
de stad.

Tijdsduur
De individuele interviews zullen ongeveer een uur in beslag nemen. De totale tijdspanne van het afnemen van alle interviews zal twee weken bestrijken

Risico's
Het praten over deze onderwerpen kan gevoelig liggen. U kunt bijvoorbeeld vertellen over nare ervaringen welke u meegemaakt heeft of moeilijke situaties met het verwijzen van patiënten. Dit kan bij u emoties oproepen aan de ervaring.

Voordelen
Er zijn geen directe voordelen voor u tijdens het onderzoek. We hopen echter wel dat mede door uw informatie er een leidraad of aanbevelingen kan worden geschreven en verspreid zodat de zorg en verwijzing van zwangere vrouwen verbeterd kan worden.

Onkostenvergoeding
Behalve onkostenvergoeding als reiskosten of drinken zullen er geen andere kosten vergoed worden.

Vertrouwelijk
Uw informatie zal vertrouwelijk worden behandeld. De verzamelde informatie zal zes maanden bewaard blijven, daarna wordt deze vernietigd.

Delen van de resultaten
De resultaten van het onderzoek zullen we in een rapport en/of artikel uitbrengen. Daarnaast zullen we aanbevelingen doen voor verbetering van het verwijsbeleid binnen medische zending. Voordat dit gedaan wordt willen we graag uw mening hierover horen en daarom zullen we u vragen of u met ons wilt meedenken over het uit te voeren beleid.

Recht om te weigeren of terug te trekken
U mag ten aller tijden stoppen als u betrokken bent in dit onderzoek, zonder opgave van reden.

Contact
Het onderzoeksvoorstel is gezien en goedgekeurd door de ethische commissie van het KIT. Deze commissie zorgt ervoor dat deelnemers aan deze studie worden beschermd tegen schade welke veroorzaakt zou kunnen worden door dit onderzoek. Mocht u daar meer vragen of details over willen weten, kunt u contact opnemen met Koninklijk Instituut voor de Tropen in Amsterdam

Toestemmingsverklaring
Ik heb de bovenstaande tekst gelezen en heb de kans gekregen om vragen te stellen over dit onderzoek en daarop antwoorden gekregen welke voldeden aan de vraag.
Ik verklaar dat ik vrijwillig deelneem aan dit onderzoek.

Datum
Naam Handtekening

ANNEX 12: INFORMED CONSENT WOMEN WHO EXPERIENCED A RISK PREGNANCY (DUTCH)

Introductie

Mijn naam is Rosanne Peuscher en ik ben een van de artsen die werkzaam zijn bij Medische Zending. Ik ben momenteel bezig met een onderzoek naar besluitvorming tijdens de zwangerschap. U krijgt dit formulier om u uitleg te geven over het onderzoek en omdat ik hoop dat u zou willen meedoen aan het onderzoek. U beslist zelf of u mee wilt doen aan het onderzoek. Dit is vrijwillig en niet verplicht.

Doel van het onderzoek

Er bestaan verschillende redenen waarvoor u tijdens uw zwangerschap soms naar het ziekenhuis in Paramaribo wordt gestuurd. Sommige vrouwen gaan naar Paramaribo en sommige gaan niet. Met dit onderzoek wil ik graag weten waarom u bepaalde keuzes maakt en welke zaken hier allemaal van invloed op zijn. Dit is voor ons belangrijk om te weten omdat we daar dan voortaan beter mee om zouden kunnen gaan.

Soort onderzoek

Bij dit onderzoek zouden we u graag willen laten deelnemen aan een diepte interview. Dit zal ongeveer één uur in beslag nemen.

Waarom willen we dat u meedoet?

U bent zwanger geweest in de afgelopen twee jaar. We willen graag weten welke beslissingen u maakte tijdens deze zwangerschap en waarom.

Deelname is vrijwillig: Moet ik meedoen?

U hoeft niet mee te doen aan het onderzoek. Het is vrijwillig. Indien u niet mee doet is dat ook geen probleem

Het onderzoek: wat gaan we doen?

Ik wil graag met u praten over uw laatste zwangerschap. Ik wil graag weten wat u weet over zwangerschap en bevalling. Verder wil ik graag weten wat u ervaringen zijn en gevoelens en ideeën over de ontvangen zorg. Ook zou ik graag willen weten wat u gaat doen als u naar de stad moet om te bevallen. Het totale interview duurt ongeveer een uur.

Nadelen: Het afnemen van het interview kan nare herinneringen boven brengen.

Voordelen: Er zijn geen directe voordelen aan meedoen, alleen hopelijk leiden de antwoorden op het interview naar veranderingen in beleid

<u>Geheimhouding: wordt het interview gedeeld met anderen?</u>

Alle informatie uit dit interview wordt alleen gebruikt voor het onderzoek. Het wordt **niet** met andere gedeeld. Het interview wordt gecodeerd en daardoor staat nergens je naam vermeld. Alleen de onderzoeker weet welke code bij welke naam hoort, verder niemand. Het hele interview zal vertrouwelijk worden afgenomen. De verzamelde informatie zal zes maanden bewaard blijven, daarna wordt deze vernietigd.

Delen van de bevindingen van het onderzoek:

Als het onderzoek klaar is zullen de resultaten met jouw ouders en jou gedeeld worden. Vertrouwelijke informatie blijft altijd vertrouwelijk. Resultaten van het onderzoek worden gedeeld binnen MZ en in de vorm van een scriptie of een artikel voor een medisch tijdschrift.

Recht om weigeren of stoppen? Kan ik ook niet meedoen met het onderzoek? Kan ik ook stoppen met het interview?

Je hoeft niet mee te doen met het onderzoek. Het is geheel vrijwillig. Indien je tijdens het interview niet meer mee wilt doen mag je dit ook altijd zeggen. Niemand verplicht je om mee te doen.

Contact

Het onderzoeksvoorstel is gezien en goedgekeurd door de ethische commissie van het KIT. Deze commissie zorgt ervoor dat deelnemers aan deze studie worden beschermd tegen schade welke veroorzaakt zou kunnen worden door dit onderzoek. Mocht u daar meer vragen of details over willen weten, kunt u contact opnemen met Koninklijk Instituut voor de Tropen in Amsterdam

Toestemmingsverklaring

Ik heb de bovenstaande tekst gelezen en heb de kans gekregen om vragen te stellen over dit onderzoek en daarop antwoorden gekregen welke voldeden aan de vraag.

Ik verklaar dat ik vrijwillig deelneem aan dit onderzoek.

Datum

Naam Handtekening

ANNEX 13: INFORMED CONSENT PARTICIPANTS OF FGD (DUTCH)

Introductie
Mijn naam is Rosanne Peuscher en ik ben een van de artsen die werkzaam zijn bij Medische Zending. Ik ben momenteel bezig met een onderzoek naar besluitvorming bij zwangere vrouwen. U krijgt dit formulier om u uitleg te geven over het onderzoek en omdat ik hoop dat u zou willen meedoen aan het onderzoek. U beslist zelf of u mee wilt doen aan het onderzoek. Dit is vrijwillig en niet verplicht.

Doel van het onderzoek
Er bestaan verschillende redenen waarvoor u tijdens uw zwangerschap soms naar het ziekenhuis in Paramaribo wordt gestuurd. Sommige vrouwen gaan naar Paramaribo en sommige gaan niet. Met dit onderzoek wil ik graag weten waarom u bepaalde keuzes maakt en welke zaken hier allemaal van invloed op zijn. Dit is voor ons belangrijk om te weten omdat we daar dan voortaan beter mee om zouden kunnen gaan.

Soort onderzoek
Bij dit onderzoek zouden we u graag willen laten deelnemen aan een focus groep discussie. Dit is een discussie waarbij we meerdere thema's zullen behandelen in een groep van ca 8 anderen.

Selectie deelnemers
U bent uitgenodigd voor deze studie omdat we uw mening willen weten betreffende besluitvorming binnen zwangerschap

Vrijwillige deelname
Voorop staat dat uw deelname geheel vrijwillig moet zijn. U mag zelf kiezen of u wel of niet deel wil nemen en ook mag u altijd later besluiten of u wil deelnemen of niet.

Procedure
We zullen u vragen over uw ervaringen met risicozwangerschappen en verwijzingen naar de stad.

Tijdsduur
De focusgroep zal ongeveer 1,5 uur duren.

Risico's
Het praten over deze onderwerpen kan gevoelig liggen. U kunt bijvoorbeeld vertellen over nare ervaringen welke u meegemaakt heeft of moeilijke situaties met het verwijzen van patiënten. Dit kan bij u emoties oproepen aan de ervaring.

Voordelen
Er zijn geen directe voordelen voor u tijdens het onderzoek. We hopen echter wel dat mede door uw informatie er een leidraad of aanbevelingen kan worden geschreven en verspreid zodat de zorg en verwijzing van zwangere vrouwen verbeterd kan worden.

Onkostenvergoeding
Behalve onkostenvergoeding als reiskosten of drinken zullen er geen andere kosten vergoed worden.

Vertrouwelijk
Uw informatie zal vertrouwelijk worden behandeld. De verzamelde informatie zal zes maanden bewaard blijven, daarna wordt deze vernietigd. Aan alle respondenten zal gevraagd worden om de informatie voortkomend uit de discussie groep niet te delen. Vanwege het feit dat u met 7 andere mensen in een discussie groep zit kan privacy echter niet worden gegarandeerd. U hoeft persoonlijke informatie niet de delen binnen deze groep! U kunt uw mening, of veronderstellingen met ons delen.

Delen van de resultaten
De resultaten van het onderzoek zullen we in een rapport en/of artikel uitbrengen. Daarnaast zullen we aanbevelingen doen voor verbetering van het verwijsbeleid binnen medische zending. Voordat dit gedaan wordt willen we graag uw mening hierover horen en daarom zullen we u vragen of u met ons wilt meedenken over het uit te voeren beleid.

Recht om te weigeren of terug te trekken
U mag ten aller tijden stoppen als u betrokken bent in dit onderzoek, zonder opgave van reden.

Contact
Het onderzoeksvoorstel is gezien en goedgekeurd door de ethische commissie van het KIT. Deze commissie zorgt ervoor dat deelnemers aan deze studie worden beschermd tegen schade welke veroorzaakt zou kunnen worden door dit onderzoek. Mocht u daar meer vragen of details over willen weten, kunt u contact opnemen met Koninklijk Instituut voor de Tropen in Amsterdam

Toestemmingsverklaring
Ik heb de bovenstaande tekst gelezen en heb de kans gekregen om vragen te stellen over dit onderzoek en daarop antwoorden gekregen welke voldeden aan de vraag.
Ik verklaar dat ik vrijwillig deelneem aan dit onderzoek.
Datum
Naam Handtekening

ANNEX 14: INFORMED ASSENT MINOR (DUTCH)

Deze informed assent is bedoeld voor meisjes onder de leeftijd van 18 jaar welke het afgelopen jaar zwanger zijn geweest

Onderzoeker: drs. R. Peuscher, arts *Medische Zending Primary Health Care Suriname*

Onderzoek: ***Factoren van invloed op besluitvorming van zwangere vrouwen***

Introductie onderzoek

Mijn naam is Rosanne Peuscher en ik ben een van de artsen die werkzaam zijn bij Medische Zending. Ik ben momenteel bezig met een onderzoek naar besluitvorming van vrouwen tijdens hun zwangerschap. U krijgt dit formulier om u uitleg te geven over het onderzoek en omdat ik hoop dat u zou willen meedoen aan het onderzoek. U beslist zelf of u mee wilt doen aan het onderzoek. Dit is vrijwillig en niet verplicht. We zullen ook toestemming vragen bij uw ouders/verzorgers over uw deelname aan dit onderzoek. Vanwege de wet moeten we voor onderzoek ook altijd toestemming van uw ouders vragen zolang u nog geen 18 jaar bent. U mag dit onderzoek altijd even bespreken met vrienden of uw ouders. U hoeft niet direct te beslissen. Indien er woorden of zinnen onduidelijk zijn kunt u altijd uitleg vragen.

Doel van het onderzoek: Een risico zwangerschap is een zwangerschap zoals een tienerzwangerschap. Omdat tieners nog niet volgroeid zijn kan de zwangerschap of de bevalling soms moeilijk verlopen en daarom verwijzen we alle tienerzwangerschappen naar de stad. Dit onderzoek gaat over de besluitvorming van zwangere vrouwen rondom deze verwijzing. We willen er middels dit onderzoek achter komen welke factoren een rol spelen bij de beslissingen die gemaakt worden. Dit is voor ons belangrijk om te weten omdat we daar dan voortaan beter mee om zouden kunnen gaan.

Waarom willen we dat u meedoet?

U bent zwanger geweest als tiener. We willen graag weten welke beslissingen u maakte tijdens deze zwangerschap en waarom.

Deelname is vrijwillig: Moet ik meedoen?

U hoeft niet mee te doen aan het onderzoek. Het is vrijwillig. Indien u niet mee doet is dat ook geen probleem.

Het onderzoek: wat gaan we doen?

Ik wil graag met u praten over uw laatste zwangerschap. Ik wil graag weten wat u weet over zwangerschap en bevalling. Verder wil ik graag weten wat u ervaringen zijn en gevoelens en ideeën over de ontvangen zorg. Ook zou ik graag willen weten welke

beslissingen u tijdens uw zwangerschap heeft gemaakt.. Het totale interview duurt ongeveer een uur.

Nadelen: Het afnemen van het interview kan nare herinneringen boven brengen.

Voordelen: Er zijn geen directe voordelen aan meedoen, alleen hopelijk leiden de antwoorden op het interview naar veranderingen in beleid.

Geheimhouding: wordt het interview gedeeld met anderen?

Alle informatie uit dit interview wordt alleen gebruikt voor het onderzoek. Het wordt **niet** met andere gedeeld. Het interview wordt gecodeerd en daardoor staat nergens je naam vermeld. Alleen de onderzoeker weet welke code bij welke naam hoort, verder niemand. Het hele interview zal vertrouwelijk worden afgenomen. De verzamelde informatie zal zes maanden bewaard blijven, daarna wordt deze vernietigd.

Delen van de bevindingen van het onderzoek:

Als het onderzoek klaar is zullen de resultaten met jouw ouders en jou gedeeld worden. Vertrouwelijke informatie blijft altijd vertrouwelijk. Resultaten van het onderzoek worden gedeeld binnen MZ en in de vorm van een scriptie of een artikel voor een medisch tijdschrift.

Recht om weigeren of stoppen? Kan ik ook niet meedoen met het onderzoek? Kan ik ook stoppen met het interview?

Je hoeft niet mee te doen met het onderzoek. Het is geheel vrijwillig. Indien je tijdens het interview niet meer mee wilt doen mag je dit ook altijd zeggen. Niemand verplicht je om mee te doen.

Contact voor extra vragen

Voor vragen over het onderzoek kun je altijd contact op nemen met de polikliniek of rechtstreeks met de onderzoeker: R. Peuscher

(tel 7591654)

Als je ervoor kiest om mee te doen met het onderzoek geef ik je een kopie van dit papier om bij je te houden. Je kunt je ouders er altijd naar laten kijken indien je wilt.

Heb je begrepen waarom we dit onderzoek doen en wat voor soort onderzoek we doen?
Heb je nog vragen over het onderzoek?

PART 2: CERTIFICATE OF ASSENT

Ik heb begrepen dat het onderzoek bestaat uit het afnemen van interviews. In de interviews wordt gekeken naar tienerzwangerschappen en alle factoren welke van invloed zijn op de keuzes welke gemaakt worden tijdens de zwangerschap. Voor dit onderzoek doe ik eenmalig mee aan een interview welke ongeveer 1 uur duurt.

Ik heb deze informatie gelezen (of deze informatie is me voorgelezen). De onderzoeker heeft al mijn vragen beantwoord en ik weet dat ik altijd nog vragen mag stellen tijdens het onderzoek.

Ik ga akkoord met deelname aan het onderzoek

of

Ik wil niet mee doen met het onderzoek en heb daarvoor niet getekend voor akkoord.

Paraaf kind _____.

<u>Alleen als het kind akkoord gaat:</u>

Naam kind: _____

Handtekening van kind: _____

Datum:_____

Ik ben getuige geweest van het lezen van dit formulier aan of door het kind en het kind heeft de mogelijkheid gehad om vragen te stellen. Ik bevestig dat het kind vrijwillig meedoet met het onderzoek

Naam getuige_____ of duimafdruk deelnemer

Handtekening getuige _____

Datum _____

Ik ben getuige geweest van het lezen van dit formulier aan of door het kind en het kind heeft de mogelijkheid gehad om vragen te stellen. Ik bevestig dat het kind vrijwillig meedoet met het onderzoek

R. Peuscher_____

Handtekening van onderzoeker_____

Datum_____

INFORMED CONSENT OUDERS/VERZORGERS

Introductie

Mijn naam is Rosanne Peuscher en ik ben een van de artsen die werkzaam zijn bij Medische Zending. Ik ben momenteel bezig met een onderzoek naar besluitvorming bij zwangere vrouwen. U krijgt dit formulier om u uitleg te geven over het onderzoek en omdat ik hoop dat u zou willen meedoen aan het onderzoek. U beslist zelf of u mee wilt doen aan het onderzoek. Dit is vrijwillig en niet verplicht.

Doel van het onderzoek

Een risico zwangerschap is een zwangerschap zoals een tienerzwangerschap. Omdat tieners nog niet volgroeid zijn kan de zwangerschap of de bevalling soms moeilijk verlopen en daarom verwijzen we alle tienerzwangerschappen naar de stad. Dit onderzoek gaat over de besluitvorming van zwangere vrouwen rondom deze verwijzing. We willen er middels dit onderzoek achter komen welke factoren een rol spelen bij de beslissingen die gemaakt worden. Dit is voor ons belangrijk om te weten omdat we daar dan voortaan beter mee om zouden kunnen gaan.

Soort onderzoek

Bij dit onderzoek zouden we uw dochter graag willen laten deelnemen aan een diepte interview. Dit zal ongeveer één uur in beslag nemen.

Selectie deelnemers

Uw dochter is uitgenodigd om mee te doen aan het onderzoek omdat zij een tienerzwangerschap heeft gehad.

Vrijwillige deelname

Voorop staat dat deelname van uw dochter geheel vrijwillig moet zijn. Uw dochter mag zelf kiezen of ze wel of niet deel wil nemen en ook mag ze altijd later besluiten of u wil deelnemen of niet.

Procedure

We zullen uw dochter vragen over haar ervaringen met risicozwangerschappen en verwijzingen naar de stad.

Tijdsduur

Het interview zal ongeveer een uur duren. Er worden meerdere interviews per dag afgenomen.

Risico's

Het praten over deze onderwerpen kan gevoelig liggen. Uw dochter kan bijvoorbeeld vertellen over nare ervaringen welke zij meegemaakt heeft en kan emoties oproepen aan de ervaring.

Voordelen

Er zijn geen directe voordelen voor u tijdens het onderzoek. We hopen echter wel dat mede door uw informatie er een leidraad of aanbevelingen kan worden geschreven en verspreid zodat de zorg en verwijzing van zwangere vrouwen verbeterd kan worden.

Onkostenvergoeding

Behalve onkostenvergoeding als reiskosten of drinken zullen er geen andere kosten vergoed worden.

Vertrouwelijk

Uw informatie zal vertrouwelijk worden behandeld. De verzamelde informatie zal zes maanden bewaard blijven, daarna wordt deze vernietigd.

Delen van de resultaten

De resultaten van het onderzoek zullen we in een rapport en/of artikel uitbrengen. De resultaten zullen met u gedeeld worden voordat ze naar voren worden gebracht in een rapport.

Recht om te weigeren of terug te trekken

U mag ten aller tijden stoppen als u betrokken bent in dit onderzoek, zonder opgave van reden.

Contact

Het onderzoeksvoorstel is gezien en goedgekeurd door de ethische commissie van het KIT. Deze commissie zorgt ervoor dat deelnemers aan deze studie worden beschermd tegen schade welke veroorzaakt zou kunnen worden door dit onderzoek. Mocht u daar meer vragen of details over willen weten, kunt u contact opnemen met Koninklijk Instituut voor de Tropen in Amsterdam

Toestemmingsverklaring

Ik heb de bovenstaande tekst gelezen en heb de kans gekregen om vragen te stellen over dit onderzoek en daarop antwoorden gekregen welke voldeden aan de vraag.

Ik verklaar dat mijn dochter mag deelnemen aan dit onderzoek.

Datum

Naam Handtekening