UNIVERSITY OF AMSTERDAM

Master's Thesis

"You give them a voice"

An ethnographic study on pregnancy care interactions among refugees and their healthcare providers in the Netherlands

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Abstract

In recent years, growing research has found that immigrant populations within the Netherlands, namely refugees, have unfavorable birth outcomes compared to Dutch citizens. As a result, there is a growing demand to understand both qualitative and quantitative factors that influence birth outcomes for refugee women. This thesis aims to describe how pregnancy care is experienced by the refugee women themselves, narrowing a major gap in the literature. To understand care interactions between Dutch healthcare providers and pregnant refugees, data was collected in nine semi-structured interviews with Dutch midwives, five semi-structured interviews with refugees, four observational days at midwifery practices, and one observational day at an asylum-seeking center. This thesis highlights the deep significance of communication and trust for pregnant refugees during care interactions. Further, the paper presents that when Dutch midwives cultivate environments with considerate communication and trust for refugees, the quality of pregnancy care is improved. Based on the findings which indicate an increased need for trust and communication in care interactions, it is recommended that the Dutch healthcare system implement support structures for both healthcare providers and pregnant refugees that foster empathetic care interactions to improve birth outcomes in the Netherlands.

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Lastly, thank you to all the women who participated in this study. I would specifically like to dedicate this work to refugee mothers who continue to fight for a better life for themselves and their children. Your strength is truly inspiring.

List of Abbreviations and Dutch Words

AZC: Asylum Seekers Center (Asielzoekerscentrum)

COA: Central organization of Asylum seekers (Centraal Orgaan Opvang Asielzoekers)

COL: Central reception location (Centrale ontvang locatie)

EU: The European Union

FGM: Female Genital Mutilation

GZA: Health Center for Asylum Seekers

IND: The Dutch Immigration and Naturalization Service

JGZ: The public health service for children ages 0-4 years old (Jeugdgezondheidszorg)

POL: Process reception location (Proces opvang locatie)

PVV: Partij voor de Vrijheid

UN: United Nations

UNHCR: United Nations High Commissioner for Refugees

Asielzoeker: Someone who seeks protection from another county

Eerstelijnszorg: First line care

Kraamzorg: Home care for mother and baby for the first eight days after delivery

Kraamverzorgster: Maternity care assistant that provides natal and postnatal care services

Statushouder: An asylum seeker with a Dutch residence permit

Tweedelijnszorg: Second line care

Tolk: Interpreter

Verloskundige: Midwife

1. Introduction

Since 2015 anti-immigration rhetoric has become increasingly popular in the Netherlands. Following the European refugee crisis, immigration has become a central point of contention in Dutch politics, and as a result, asylum seekers and refugees are continually scrutinized and marginalized. In a Dutch context, asylum seekers and refugees receive sub-optimal essential services such as healthcare, housing, and overall recognition as Dutch citizens. Among the already marginalized community of asylum seekers and refugees, there are especially vulnerable individuals and who are further at risk: pregnant women. Navigating pregnancy care as an asylum seeker or refugee draws up communication, trust, and quality of care issues.

Refugees are groups of people who have fled their home countries in fear of war, violence, and persecution (UNHCR, n.d.). An asylum seeker is an individual who has fled his/her country to seek protection from human rights violations while waiting for his/her request to be legally recognized as a 'refugee' and granted sanctuary in the foreign country they seek refuge in (Amnesty, n.d.). Healthcare systems and government policies combine asylum seekers and refugees into broad categories of 'migrants' and 'refugees.' Despite sharing similarities with migrants, asylum seekers often have divergent experiences, such as an increased rate of mental and physical health issues compared to those without a refugee background (Hanegem et al., 2011, p. 1010). In addition, asylum seekers and refugees encounter combinations of economic instability, language issues and social discrimination (Bollini et al., 2009, p. 452), making it difficult for refugees to navigate through the healthcare systems of their new countries. Within this specific population, pregnant asylum-seeking women often experience this culmination of health challenges more intensely. In addition to more mental and physical health issues, several studies indicate that pregnant refugees experience higher rates of late gestational booking, birth complications, and perinatal mortality (Hanegem et al., 2011, p. 1010). Adverse health outcomes experienced by pregnant refugees are opposed to the World Health Organization (WHO) definitions of healthcare (See Appendix 1. Figure 3)**.** Such challenges impact access, utilization, and quality of care and treatment that the WHO states that every human should have the right to experience in healthcare (Krasnik et al., 2002, p. 1207).

There are limited studies conducted in the Netherlands that highlight both positive and negative interactions with healthcare providers and pregnant refugees. However, studies

conducted within Europe that examine healthcare encounters with refugees and providers show a general dissatisfaction among refugees and the care they receive (Svenberg et al., 2011). For example, a study conducted in Sweden interviewed twenty Somali refugees who admitted to having a lack of desire to seek out healthcare because they felt that the Swedish healthcare system 'ignored immigrants' (Svenberg et al., 2011, p. 696). One of the main factors that led to Somali refugees' dissatisfaction with healthcare was a general lack of trust and feelings of rejection within the Swedish healthcare system (Svenberg et al., 2011, p. 698). Another study conducted in the United Kingdom observing difficulties with midwives' care and ethnic minorities (refugees, migrants, and asylum seekers) suggests that communication difficulties affect this population's quality of care. This study showed that while working with ethnic minority groups, the use of interpreters negatively influences communication as interpreters do not always understand medical terminology, thus not being fully equipped to effectively interpret information during care interactions. (Chitongo et al., 2021, p, 4). An Australian study further supports the claim that interpreters convolute care interactions (Mengesha et al., 2018). The Mengesha et al. (2018) study, observing healthcare professional's experiences working with interpreters and refugee women, exemplified how the use of male interpreters exacerbates a woman's discomfort discussing sexual health-related issues during care interactions (Mengesha et al., 2018, p. 199).

In this area of research, it is known that healthcare providers' interactions with refugees both *positively* and *negatively* influence healthcare experiences for refugees (Haith-Cooper & Bradshaw, 2013; Correa-Velez & Ryan, 2012). Qualitative research in other European countries has shown that implementing care models to adequately address the emotional, social, and psychological needs unique to refugees and asylum seekers, constructively changes care interactions. These care models ranged from 'women-centered care' to social models of care focused on a holistic approach (Owens et al., 2016; Haith-cooper & Bradshaw, 2013). These holistic approaches are defined as healthcare providers receiving specific training focusing on providing care to patients from various backgrounds and cultures. Once implemented, these care models had a positive impact on the continuity of care with an asylum seeker or refugee and the provider's own satisfaction with the patients (Johnsen et al., 2021). The strength of these care models was the use of cultural sensitivity to build connection and trust between pregnancy care providers and asylum seekers and refugees (Pangas et al., 2019, p. 40). The method encourages a

trustworthy connection between patient and provider, facilitating open conversations where women feel comfortable addressing issues with suboptimal pregnancy care (2019, p. 40).

As refugee women navigate a new healthcare system, we must be critical in how these healthcare systems can best support these women and their unborn children. The WHO has a framework outlining the eight standards for 'quality pregnancy care' (See Appendix 1. Figure 3). Considering that studies acknowledge how linguistic and cultural miscommunication add to negative pregnancy care experiences (Reitmanova & Gustafson 2008; Higginbottom et al., 2016), the core elements of this care model that I am most interested in for the context of pregnancy care for refugees in the Netherlands are: *communication with women and their families is effective and responsive to the woman's needs*, and *woman and family are provided emotional support* (Appendix 1. Figure 3).

In this thesis, I build on existing literature in the field to examine the following question: how do care interactions shape the pregnancy experience of refugees in the Netherlands? I address this question through the help of sub-questions: how does communication, particularly when mediated through an interpreter, influence care practices experienced by pregnant women and healthcare providers? And, how do healthcare providers' understandings of pregnant women's backgrounds shape how they care for pregnant refugees? I will use the next chapter to analyze how refugees are situated in the context of Dutch culture, politics, and healthcare.

1.1 Anti-Immigration Rhetoric

In the past ten years, Europe has seen an influx of migrants seeking asylum and to escape war, poor living conditions and political threats. At the end of 2016, 5.2 million refugees sought refuge in Europe (The UN Refugee Agency (UNHCR), n.d.). In 2020, the Netherlands alone received 13,697 asylum applicants, 23% of which were women (Asylum in Europe, n.d.). Many women seeking refuge in the Netherlands are of childbearing age and thus, it is not uncommon for these new asylum seekers to experience pregnancy care in their new host country.

Since 2015, the Netherlands has seen an increase in anti-immigration rhetoric fueled by the refugee crisis. Rhetoric focuses particularly on refugees from Islamic backgrounds, as

political parties like the 'Partij voor de Vrijheid'[1] (PVV) produce campaign material that explicitly promotes 'de-Islamizing' the Netherlands. The main driver of anti-immigrant attitudes is the perception of a threat, fueling fears that immigrants will have a negative impact on 'Dutch citizens'' way of life including the impression that it is an economic threat and creates a financial burden. Consequently, political parties such as the PVV have used the influx of refugees coming to the Netherlands to gain political stronghold in areas throughout the country, specifically in areas where AZCs are being built. As the anti-immigrant political dialogue percolates into mainstream Dutch culture, there has been an increase in discrimination towards refugees since 2015 (Tolsma et al., 2021; Di Saint Pierre et al., 2015). Consequently, communities where AZCs are built express their disapproval by 'hanging banners with anti-refugee slogans, such as 'Own people first'' (Tolsma et al., 2021, p. 2). The High Commissioners Office of the United Nations argues that this particular frame of mind from the Netherlands undoubtedly hinders Dutch societies' effort to act altruistically (Achiume, 2019). Dutch society is one that increasingly treats racial and ethnic minorities as eternally foreign (Achiume, 2019). The message often seems that to be 'Dutch' is to be white and of Western origin.

Cultural, political and societal views towards immigrants, especially refugees, affect a refugee's overall experience in their new host country. A recent survey conducted in the Netherlands among Afghani, Iranian and Somalian refugees revealed that it was not uncommon for this group to have a desire to return to their home country—despite the political upheaval, war, and unsafe environments (Di Saint Pierre et al., 2015). A desire to return home came from perceived discrimination, defined in this study as 'experiences of unfair treatment and a lack of acceptance due to one's ethnic origin' (2015, p. 1838). Further, discrimination was described as a 'strong stressor in immigrant's acculturation experience' (2015, p. 1841). Stress was seen as a direct result of 'unsuccessful structural integration' into Dutch society (2015, p. 1838). The authors in this study defined structural integration as: 'successful participation in the economic life of the host society; cultural integration, referring to the adoption of the host society values and customs; and social integration, involving participation in the social life of the host country' (2015, p.1838). Within this study, authors discovered that language proficiency in Dutch was integral to cultural integration as it is a way to connect with other Dutch citizens (2015, p. 1849).

[1] Translated into English: Party for the freedom

Therefore, it is important to question how political dialogue surrounding refugees in the Netherlands influences a refugees' ability to 'successfully integrate.'

As I will explain in the chapter about theoretical inspirations, Dutch migration politics are significant to this study as they shape care interactions between healthcare professionals and pregnant refugees and reflect political climates within the Netherlands. In addition to the investigation of communication and trust between healthcare providers and refugees, it is necessary to be mindful of political, social, and cultural dialogue currently occurring in the Netherlands. This may also influence care interactions.

1.2 EGALITE research

I conducted my master's research in collaboration with the EGALITE project comprised of several doctors from the Erasmus Medical Center in Rotterdam, the Netherlands. I notably spent most of my research time with doctor and Ph.D. candidate Julia Tankink from the EGALITE team.

EGALITE was set up because of the growing need to examine perinatal health in areas where studies have seen an increase in 'worse birth statistics' over the years within the Netherlands (Erasmus Project Proposal, 2020). Doctors characterize an 'unhealthy start to life' as issues with a woman's pregnancy, delivery of the baby and overall health concerns regarding the newborn child (Erasmus Project Proposal, 2020). An unhealthy start of life affects a child's lifelong health, school performance, and perpetuates a malicious cycle of social deprivation and poverty (Erasmus Project Proposal, 2020). As a result, in 2018, the Minister of Health in the Netherlands launched an action program called "Promising Start." Research has shown that approximately 14% of Dutch children do not have good starts at birth; areas concentrated with asylum-seeker and refugee populations are included in this demographic (Erasmus Project Proposal, 2020). In turn, the Erasmus Medical Center launched the EGALITE project in an effort to understand both the quantitative and qualitative happenings during a refugee's pregnancy and delivery of the child. This master's research is a small qualitative contribution, and the goal is to come to understand how the Dutch healthcare system can better support pregnant refugees.

1.3 Organization of Dutch maternity care for refugees

The Netherlands is one of few countries that approaches maternity care with a very distinguished division in care systems. Pregnancy care is divided into what is called 'Eerstelijnszorg' and 'Tweedelijnszorg.' The difference is that the midwife is ultimately responsible for the pregnancy, birth, and postpartum period in 'first line care.' In contrast, in 'second line care', the gynecologists assume responsibility (Appendix 2. Figure 4.). Appendix 2 outlines the nine different care paths that are available for pregnant women in the Netherlands. Most notably once a woman is placed in category 'Medium risk C,' the woman's care is overseen by a gynecologist in a hospital setting. Pertinent to this research study, many pregnant asylum seekers, and refugees with a residency permit (status holders) are recommended to enter the second line of care because midwives and gynecologists deem pregnancies under this population as 'risky.' Healthcare providers also consider asylum-seeking centers inappropriate for home births. If a woman is placed in 'second line care' the initial care process is supervised by a midwife. Following, she is directed to the hospital setting with gynecologists to support any complications during the pregnancy (Hanegem et al., 2011, p. 1010).

Upon arrival in the Netherlands, asylum seekers must conduct medical intake through the GZA (coa.nl, n.d.). It is prescribed but does not always happen that once the intake has taken place, asylum seekers are moved to a reception center in the Netherlands to prepare for the processing of their asylum application (coa.nl, n.d.). There is a 'pregnant attention officer' located at each COA center in the Netherlands (Ketenrichtlijn Geboortezorg Asielzoeksters, Juni 2020). Upon arrival, asylum seekers are given instructions and information on their access to obstetric care appointments. These information sessions are supported with material written in eight foreign languages, along with posters that have specific information regarding pregnancy care appointments at a COA center (Ketenrichtlijn Geboortezorg Asielzoeksters, Juni 2020). Asylum seekers have the right to use an interpreter during pregnancy consultations, the interpreter is provided by the COA and free of charge. This service is called 'Live Words' and is scheduled by midwives or hospital providers when needed. During the initial information meetings, a COA worker will also appoint a nurse to examine the child's health after they are born. All asylum seekers who are registered at the COA organization are entitled to these resources during their pregnancy care (Ketenrichtlijn Geboortezorg Asielzoeksters, Juni 2020):

a. GZA provides an obstetric care provider through a midwifery organization that works with the local COA center in a specific region in the Netherlands

b. All women are registered with ‘first line’ midwives unless there is an acute medical situation in which the midwife directs the woman to a gynecologist at a local hospital who will then provide the necessary obstetric care
c. Asylum seekers are given the ‘Structural ultrasound examination’ along with testing for any genetic disorders
d. Pregnancy check-ups for asylum seekers include:
    i. Pregnancy statement
    ii. Maternity care
    iii. Referral for an ultrasound
    iv. If necessary, an appointment with a gynecologist
    v. MRSA test [to look for methicillin-resistant Staphylococcus aureus, a type of bacteria resistant to antibiotics often found in hospitals] at week 34, along with blood tests for antibodies against chicken pox, rubella, HIV, Syphilis, and Hepatitis B

2. Theoretical Inspirations

This research uncovers different ways to ‘care.’ There are many definitions of the word *care.* However, the particular definition of relevance is ‘charge, supervision: responsibility for or attention to health, wellbeing, and safety’ (Merriam-Webster, n.d.). I am concerned with which factors present themselves to influence the care interactions and how healthcare providers adjust their care accordingly. This chapter will delve into how communication affects trust between the healthcare provider and the patient through a Patient-Centered Care (PCC) lens. I will also discuss theory on social citizenship, as refugees’ access to quality healthcare (as defined by the AAAQ framework) is violated when trust and communication are not maintained during care interactions.

The AAAQ framework created by the WHO (UNICEF, 2019) is a standard of care that every human being has a right to. The framework outlines ‘Availability, Accessibility, Acceptability and Quality’ as necessary aspects of a healthcare system (AAAQ, UNICEF, 2019). To achieve AAAQ for all, the WHO (2015), and growing literature (Lateef & Mhlongo, 2020) recommend that healthcare providers approach care using a PCC model. Under a PCC approach,

a patient is seen holistically with various interrelated needs to an individual's social, political, and cultural surroundings (WHO, Continuity and coordination of care, 2018, p. 8). PCC increases both the patient and provider's satisfaction during care interactions, and improves disease outcomes, general well-being, and addresses disparities particularly in a race, ethnicity, and socioeconomic status (Epstein et al., 2010). To address inequities and provide positive care outcomes, patients must possess support and resources to participate in their care (WHO, 2015, p, 7). Participation is a central element of the PCC model; however, participation cannot exist without trust, communication between patient and provider, and accessibility to care resources. In the following chapter, I will delve into the necessary components in achieving the AAAQ model of care through a PCC approach.

2.1 Trust in healthcare

Trust is a central component of a productive patient-provider relationship under the PCC model. As defined by the Brown et al. (2011) study examining important components to trust among 20 females with cervical cancer, trust in healthcare is the willingness to believe in the provider's benevolence. Brown et al. (2011) argue that trust is established in both macro (an umbrella of a healthcare network within a country) and micro (direct interaction among clients and individuals) levels of healthcare and healthcare providers. The micro-level, which I am most concerned with, involves immediate interaction with healthcare professionals. Therefore, prior to discussing trust in maternal healthcare, it is helpful to consider it in a conventional healthcare setting. Although there are many components to creating a trusting relationship, most notably in Brown et al.'s (2011) findings highlight how verbal language is a significant contributor to a trusting relationship. Findings also showed how non-verbal signals (e.g., touch, non-verbal behavior) were potent in the provider-patient relationships and equated to 'trusting' and 'caring' motives of care providers (Brown et al., 2011, p. 289). These findings are particularly significant for situations where language is not shared (healthcare interactions with non-native speakers) as it represents how trust can be built by healthcare providers through non-verbal methods.

Another study (Skirbekk et al., 2011) examined trust among provider-patient relationships in Norway, investigating and identifying conditions that facilitate trust in a provider-patient relationship. Trust 'mandates' were emphasized by the patients during

interviews, highlighted mandates include: the physician showing an early interest in the patient, the physician showing sensitivity to patient emotions, the physician giving the patient and the relationship time, establishing alliances against a common adversary, and instances of bracketing normal role behavior, e.g., through a shared sense of humor (Skirbekk et al., 2011, p. 1186). Notably, in the Skirbekk study, a 'trusting relationship' often requires healthcare providers to take risks, jumping into the unknown, often through spiritual and emotional connections with patients (2011, p. 1182) to initiate a relationship based on no prior connection.

Researchers (Skirbekk et al., 2011 and Plomp & Ballast 2010) suggest that patients seek trust due to vulnerability. Within healthcare, there are varying degrees of vulnerability; for example, pregnant refugees are at risk of being in a multi-layered state of vulnerability due to their lack of experience navigating a new healthcare system (Baarnhielm et al., 2014) along with their pregnancy. Sripad et al. (2018) examined trust in the maternity care setting in Kenya, arguing that the 'state of pregnancy' makes individuals dependent on health systems and healthcare providers in a unique way because of the intimate relationship between the mother's and baby's health and safety (2018). A 'state of dependency' among pregnant women is described as contingent on urgency, unpredictability, vulnerability, and intimacy (Sripad et al., 2018, p. 305).

Brown et al. and Sripad et al. agree that individuals have different abilities to trust based on how trust in healthcare is dependent on external sociocultural norms. For members of a specific social class, their trust may be embedded in negative perceptions of medical systems. Based on social, political, and cultural dialogue in the Dutch context as presented in chapter one, refugees may encounter barriers in trusting their healthcare providers, thus affecting their healthcare experiences. The way trust manifests in care interactions reflects how political contexts and social norms operate at collective levels, and therefore microscopically between midwife and refugee (Sripad et al., 2018, p. 306). Feeling unwelcomed, stereotyped and 'othered' affects the ability to cultivate trusting relationships between healthcare providers and their patients. Therefore, it is argued that research regarding trust in healthcare—especially maternal care—is needed in lower socio-economic settings. This thesis will show how pregnant refugees in the Netherlands fall under a specific category of social class, and as a result, trust needs to be examined

2.2 Communicative Justice

In Sripad's et al. study, researchers argue that communication is fundamental to building trust (2018, p. 5). Additionally, in a PCC approach, communication is essential as it facilitates the provider's response to a patient's 'needs, values, and preferences' (Martini, 2018, p. 187). For the purpose of this thesis, I examine communication with a specific focus on 'communicative justice' (Briggs, 2017) to focus on power imbalances in communication in the healthcare setting.

In Charles Brigg's 'Towards Communicative Justice in Health,' the anthropologist uses ethnographic observations to study a strange and deadly epidemic among 38 children of an indigenous community in the Venezuelan rainforest. Central to Briggs' ethnography is the anthropologist's argument that a critical part of care is the storytelling that occurs during the process of care (2017). He refers to care and storytelling as 'communicative justice' (2017) because communicative inequities during healthcare interactions can lead to injustices and violations of human rights within healthcare. Essential to the idea of storytelling during the care process is that beyond words, stories contain objects, bodies, and labor that become embodied during the narrative (2017, p. 287). Therefore, Briggs suggests that healthcare providers must provide a space where patients can convey their 'stories.' This thesis examines how storytelling occurs during care interactions between midwife and refugee as the content of these stories goes beyond obvious verbal interactions. Interestingly, Briggs positions care and storytelling as forms of labor that do not merely occur without affecting the other. Instead, care and storytelling co-produce one another (2017, p. 290). As I will discuss later in this thesis, many of the 'care' tactics midwives use are to engage in storytelling and narratives to understand their patients better. Healthcare providers must look to the stories of their patients not only in language but in fragments, gestures, and silences as well (2017, p. 290). As I will analyze in chapter four, during my observations, I, along with midwives, was challenged to understand the patient beyond what they were *saying*. Silence during a story did not just mean silence. A patient unable to look the midwife in the eye indicated more than just timidness. Every nuanced movement, pause, and signal was part of the communication between the midwife and the refugee, and ultimately this communication between the two *became* the care.

Regarding the focus on the population of pregnant refugees of this thesis, Briggs' indigenous participants and this thesis' pregnant refugees both share labeling that arguably puts these two populations in a vulnerable position that affects their ability to communicate with those

deemed more socially powerful. Briggs argues that when members of the indigenous community moved to higher levels of care, from community healers to doctors at the more urban hospital, the care had two effects (2017, p. 295). Firstly, a stacking of care and communication, where institutional hierarchies within the hospital setting excluded indigenous families from actively participating in the care process; secondly diminishing the space for the parents of the patients to participate in both the care and communication (2017, p. 295). Once indigenous persons engaged with higher levels of care, the less communicative ability they had. Doctors did not employ translators for the indigenous language and barely took time to explain the care of the sick children. By default, the parents of these sick children were rendered mute in the care process. Thus, the parent's form of labor in their children's care became signing medical papers in a language they did not understand (2017, p. 295). Briggs argues that this produced a relationship where doctors became the fabricators of knowledge. In contrast, parents became 'unreliable auxiliaries' (2017, p. 296) forced into spaces preconstructed with facts about their children's illness that were molded by healthcare providers (2017, p. 296). Briggs' communicative justice forces us to examine whether a patient's communicative labor is not only visible, but valued, and therefore a necessary lens to use while examining provider-patient interactions among refugees (2017, p. 296).

To examine social inequalities embedded in communication, I enlist the use of Critical Discourse Analysis (CDA). Teun van Dijk, a scholar in linguistics, discourse analysis, and CDA, defines CDA as examining how powerful speakers or groups enact or 'exhibit their power in discourse,' thus potentially leading to an abuse of power in discourse (1993, p. 259). Van Dijk argues that power, similar to social power, entails access to resources such as wealth, income, status, education, discourse and communication (1993, p. 255). In relation to this thesis, refugees do not have the same access to the Dutch language as their healthcare providers, which limits their freedom to participate in the discourse of their care interactions. Consequently, Van Dijk suggests that researchers observe power *abuse* during discourse interactions (1992, p. 255). A CDA lens is relevant to this research because a lack of access to clear communication during care interactions (i.e., not using interpreters or difficulty speaking Dutch or English) leads to ineffective communication between the patient and provider. Ineffective communication can lead to the provider having the power during the discourse, ultimately leading to power abuse.

Briggs' communicative justice coupled with CDA supports the claim that linguistic profiling converges with medical profiling—apparent while dealing with stereotypes of specific patient populations such as refugees in Western Europe (Briggs, 2017, p. 299). The presented literature enables us to see how communication and trust play a role in the pregnancy care interactions of refugees in the Netherlands, affecting refugees' ability to engage in care interactions. Communication and trust are intertwined in care interactions, and together, they can influence a refugees' human right to good and quality care.

2.3 Access to resources through social citizenship

CDA and theories on communication show how power imbalance during care interactions makes it challenging to access healthcare resources. Moreover, as stated in General comment No. 14 of the human rights declaration, under the AAAQ framework, *accessibility* to healthcare resources is a human right. However, accessibility to resources is convoluted for refugees who are not citizens in the judicial and political sense but can still access a country's resources through 'social citizenship' (Marshall, 1950). Social citizenship, coined by Thomas H. Marshall in 1949, involves the social inclusion that becomes attached to one's political and juridical rights as a citizen. Social citizenship can manifest in many ways like educational rights, public housing rights, and healthcare rights. Social and inclusive citizenship is shaped by our social interactions concerned with norms, practices, meanings, and identities formed by our access to social resources (Lister, 2007, p. 51). In healthcare studies, mainly centered around immigrants, citizenship is seen as a process by which 'a particular marginalized group, excluded from formal membership, finds an alternate route to belonging' (Varsanyi, 2006, p. 242). Groups of people whose citizenship status is newly granted or still pending, such as asylum seekers and refugees, often question their legitimate claim to a country's resources because they are excluded from (social) citizenship (Unnithan-Kumar & Khanna, 2014, p. 93). Feelings of disrespect while engaging in new healthcare settings and a lack of desire to pursue this form of social citizenship (Svenberg et al., 2011) influence their access to care, which, every human has a right to (AAAQ, UNICEF, 2019). As I will explore in this thesis, care interactions between a provider and patient become the crossroads in which a refugee feels like they have *access* into their new and adopted country and feel that they are worthy of receiving healthcare like every other citizen.

3. Methods

This thesis is based on an ethnographic study conducted between March and April 2021. Although a year into the pandemic, the COVID-19 outbreak slightly affected my ability to conduct certain methodologies. Following, I will describe which methods I used to collect this data and ethical challenges I had to overcome.

3.1 Data Collection

During my nine weeks of ethnographic fieldwork in the Netherlands I explored pregnancy care interactions among asylum seekers, status holders and their midwives. I began with an online meeting organized by the COA organization with several midwives whose practices work alongside asylum centers, as well as members from the EGALITE team. This meeting gave me insight into the various challenges the COA and participating midwifery practices encounter with pregnancy care, particularly which factors are affecting the continuity of care. During this meeting it became clear that communication between COA and participating midwifery practices needed improvement to support the continuity of care. Following, I began with observational days at midwifery practices across the country who care for asylum seekers and status holders. I also visited two asylum-seeking centers. I conducted four observational days: two at participating midwifery practices working alongside the COA, one day observing a midwife at the asylum-seeking center in (place)[2], and one day observing a doula at the asylum-seeking center in (place)[2]. Apart from two interviews that I organized alone, I conducted interviews and did observational days with my research partner, Julia Tankink. In total, I observed twelve pregnancy consultations with a variety of refugees and midwives. During these observational days I was able to connect with midwives willing to participate in interviews, as well as approach a few asylum seekers that considered participating in interviews with the help of participant information sheets in Arabic, English and Dari (spoken in Afghanistan, Iran and Pakistan).

I conducted nine in-depth, semi-structured interviews alongside Julia Tankink with midwives from eight different midwifery practices across the Netherlands[2]. In addition, I

[2] For the purpose of this thesis, the names of midwives, location of their practices and locations of asylum seekers centers will be kept anonymous

conducted three in-depth, semi-structured interviews with Syrian status holders. The foundation called “Stichting Nieuw Thuis” in Rotterdam brought me in contact with these status holders. The foundation supports new Syrian status holders that are trying to assimilate in the Netherlands as smoothly as possible. During two of the interviews with Syrian status holders, Fatima[3], friend and volunteer at Stichting Nieuw Thuis, acted as the translator. It is important to note that although it was beneficial to have a friend act as interpreter to easily build familiarity and rapport, interpreters influence the tone, structure and information filtered through the interview (Kosny et al., 2014, p. 844). Lastly, I conducted two in-depth, semi-structured interviews with asylum seekers. Collectively, the refugees came from Syria, Uganda and Somalia. Three were pregnant at the time of the interviews, while two had previously given birth as a status holder or asylum seeker in the Netherlands. Each refugee came from a different socioeconomic background, varying experiences of seeking asylum in the Netherlands, and came to the country pregnant or became pregnant soon after moving to the Netherlands. The duration of each interview was around one hour.

Table 1. *Overview of Refugee Participants*

	Age	*Children*	*Country of Origin*	*Refugee Status*
Hani	31	First child	Somalia	Asylum seeker
Miremba	30	Fourth child	Uganda	Asylum seeker
Amina	40	Fourth child	Syria	Status holder
Zara	35	Fourth child	Syria	Status holder
Bibi	43	Third child	Syria	Status holder

[3] Fatima (pseudonym)

3.2 Impact of COVID-19

Although a year into the COVID-19 pandemic, the lockdown in the Netherlands still affected my fieldwork period. Namely, nine out of the fourteen interviews were conducted online. In addition, there were moments when neither my research partner Julia nor I could be present during observational days. As a result, recruiting participants, namely refugees, were impacted because of the limited amount of observation days we were allowed to have.

Interestingly, online interviews via Zoom were more personal than I had originally expected (Archibald et al., 2019). Online interviews provided a conveniency, particularly for midwives who do not always have the time to host people for interviews. Zoom interviews allowed for my research partner and me to schedule multiple interviews per day with midwifery practices located across the country without the need to travel.

3.3 Representativeness of sample

This study involved a small sample of five refugees and nine midwives. My research partner and I found it difficult to recruit refugees – especially asylum seekers who were not approved for their residency permit yet. Although I approached several other refugees with different backgrounds, they were not interested in sharing their experiences and were perhaps intimidated by the scope of this research. Because this is such a small sample with only three status holders (all from the same country: Syria), and two asylum seekers, their experiences are unlikely to be representative of all pregnancy care experiences of refugees in the Netherlands. It is possible that for women with a residency status (i.e., status holders), their pregnancy experiences are not quite as comparable to asylum seekers because both groups of refugees have access to different resources. Moreover, the women come from different cultures, backgrounds and educations.

The nine midwives participating in this sample all had a Dutch background, except one. Accordingly, the midwife with a non-Dutch background had different views on working with

refugees than the midwives with a Dutch background. They were all similar age ranging from 29-38 and all had similar levels of education.

3.4 Ethics

There is a widely held opinion within the migrant research field that migrants and especially asylum seekers, are an extremely vulnerable population because this social group has little support, is of low socioeconomic status, and is at greater risk for health issues than the general population (Busetta et al., 2019, p. 2). Moreover, researchers often discuss the ethics of researching pregnant women because this raises issues of whether or not this population is at an increased risk of being harmed or wronged during the research (van der Zande et al., 2017, p. 658). Because this research is affiliated with the Erasmus Medical Center, Julia and I had to wait several weeks before our research proposal was accepted by the Medische Ethische Toestemming Committee[4] of the Erasmus medical center.

During my fieldwork period and throughout writing this thesis, I paid close attention to ethical considerations. I sent out participant information sheets (See Appendix 4) to the midwives and the refugees in their preferred language. I then gave each potential participant several days to think about participating before I reached out over WhatsApp or email to confirm their participation and receive oral consent. Before each interview, Julia and I read over our informed consent sheet (See Appendix 5) followed by a verbal consent from our participants. During the transcription and thesis writing process, I used pseudonyms instead of real names for both groups of participants. Because EGALITE is conducting their research over a three-and-a-half-year period, the project reached out to nine participating midwifery centers prior to me joining this study. Therefore, we had approval from midwives confirming their participation before we created the structure of my research. During the recruitment process, particularly with asylum seekers, I emphasized the fact that our interviews were not associated with COA or would have any negative repercussions on their asylum procedure. However, I cannot know for certain that women may have been skeptical and therefore unwilling to participate.

During the interviews, I emphasized that at any moment women could either skip a question or stop the interview if needed. During one of my interviews one of the asylum seekers

[4] Translated into English: Medical Ethics approval committee

became very emotional so I decided to stop the interview. Instead, I made her a cup of tea, and we had a conversation unrelated to this research. I was very cognizant of whether my questions were too probing, and I realize and acknowledge that for many refugees, their experiences of getting to a new country can be traumatic or questions can trigger traumas of the past. Therefore, I tried my best to read emotional cues from women and move on to a new question if I noticed that the question triggered intense emotions and made the decision to move on to a new question. I also acknowledge that during the research, three women were currently pregnant, and one woman was breastfeeding. Therefore, I wanted to be sensitive to the fact that these women are new mothers, and I did not want to take too much of their time or bother them with difficult interviews during a period in their life when they are preparing for a child.

3.5 Locating myself in the field

Conducting qualitative research is not complete without recognizing our positionality throughout the research process. Research presents a shared space where both the researcher and participant can influence the research process (Bourke, 2014, p. 1). I recognize that I have unintentional biases that may be present in this research. As a white, educated, Dutch female I am a member of the 'dominant culture in multiple categories' (Bourke, 2014, p. 2) in comparison to the participants of my research. During this research I tried my utmost best to be hyper aware that there is a perceived power imbalance between me and refugees. Block, Riggs, and Haslam suggest that when researching refugees, the researcher must not necessarily intend to reduce asylum seekers suffering or produce outcomes for this population because of the apparent power dynamic between researcher and participants (2013, p. 86). I must acknowledge that I hold a position of power as a Dutch citizen where I grew up with a western concept of healthcare and had access to its resources, persons and social groups. Refugees are often rendered with a lack of power because of their lack in citizenship status (Block et al., 2013). Because of this inherit power dynamic, I particularly had to be mindful when obtaining informed consent with the added layer of language barriers (my inability to speak languages other than Dutch and English, and refugee's inability to read in Dutch or English). Five of my participants are not originally from the Netherlands. Lastly, this research is shaped by the agenda of EGALITE to find gaps in the pregnancy care experience for refugees. There were moments during my research where I

questioned whether my presence as a researcher was doing more harm than good (Sanjari et al., 2017). For example, there were several occasions when midwives asked refugees if I was allowed to observe their consultations while I was already sitting in the observation room. During these moments I questioned whether gathering data—under the guise of doing so altruistically—was at the expense of participants (Sanjari et al., 2017). My goal during this research was not to alleviate issues with pregnancy care; however, this research provides an open platform for listening and allowing this group for their voices to be heard and ultimately help to improve their care.

3.6 Data analysis

I first began to analyze my data using open, descriptive coding to find recurring themes. Once I identified the core themes, I used focused coding to find topics that related to my initial findings. Because there is little known in this specific field of research, I approached this research with the intention of keeping my theoretical inspirations broad. During and after the data collection, I realized that communication was one of the central factors in influencing care interactions. My specific focus on communication, namely 'communicative justice' (Briggs, 2017), was useful while analyzing interviews and care interactions. Theories in communication proved useful when examining communication through an interpreter, as well as the effects of miscommunication between midwifery practices and COA. Moreover, communicative theories fueled my framework in trust, patient-centered care and social citizenship. I used CDA to examine power relations and inequality in language, particularly during interactions involving an interpreter and conversations between midwives and refugees (Blommaert & Bulcaen, 2000). CDA was useful in recognizing the way power (defined in this study as institutional power from the Dutch healthcare system) was reproduced during care interactions (Joergensen & Praestegaard, 2018, p. 3).

4. Chapter 4: Communicating, Interpreting, and 'hands and feet'

As outlined in the WHO's pregnancy care framework, respect, communication and support are cornerstones of good pregnancy care (WHO intrapartum care recommendations, 2018). For the

purpose of this thesis, I define communication as 'a process by which information is exchanged between individuals through a common system of symbols, signs, or behavior (Merriam-Webster, n.d.). In this first empirical chapter, I will show how language differences and an overall lack of understanding of the needs of asylum seekers and refugees makes it difficult to implement the AAAQ framework and the WHO's aspects of high-quality care.

In this chapter I will analyze communication between midwife and pregnant refugee through Briggs' communicative justice lens while using CDA. I will pay particular attention to the role of an interpreter and its ability to both hinder and enhance communication between patient and provider, and ultimately the WHO care model. In any relationship, communication takes precedence as one of the critical factors guaranteeing success, however different backgrounds and languages inhibit seamless communication between refugees and their midwives. During my observation days at midwifery clinics and several asylum-seeking centers in the Netherlands, along with semi-structured interviews, one thing became very clear: communication was always an issue. In this chapter, I aim to discuss how in addition to verbal communication being necessary for a pregnant refugee to feel at ease, the midwife's expression 'hands and feet[5] become just as necessary.

4.1 Talkin' through a tolk

A distinctive aspect to pregnancy care among asylum seekers and status holders in the Netherlands is the use of interpreters during consultations, medical work, and the birth of the baby. Unique to pregnancy care with refugees in the Netherlands is that not all refugees have equal access to interpreters during their care interactions. For example, asylum seekers who live in COA centers have access to free interpreters (provided by "Live Words") covered by the COA organization. In contrast, the healthcare system no longer pays the fee of using an interpretation service during care consultations for status holders. Throughout every interview with both midwives and refugees, use of the interpreter was always mentioned. However, interpreters do not always function as intended, 'they are practical' (Naomi[6], midwife) but not seamless when applied in real-life settings.

[5] Translated from Dutch 'handen en voeten'
[6] Pseudonym

> "Of course, you have no idea what they are saying to each other. So, if we say: 'I know that in the country you come from people are circumcised, I think it's a difficult question, maybe you think it's a difficult question, but I would like to ask if you are circumcised too?' Well, then, that interpreter starts talking to that lady and then there is only 'no,' something like that. And I think, "yes, but this wasn't all I said, was it?" So, I don't really know what the interpreter says to that lady, I don't really know what that lady tells the interpreter, and what part they share with me. I also sometimes feel that a piece of information is lost, and I think that this also depends on whether an interpreter feels somewhat comfortable with the situation." (*Naomi*) [7]

Naomi's quote supports previous research (Chitongo et al., 2021; Mengesha et al., 2018) examining the use of interpreter's influence in care interactions between providers and patients. Firstly, it is important in any healthcare interaction for the provider to gather all the information as no detail is deemed insignificant. As discovered in Chitongo et al. (2021) interpreters are not always equipped to relay medical information between the provider and patient. Lotte[8] (midwife) encountered this issue while working with an interpreter during one of her appointments with a refugee. During her care interaction Lotte suspected the refugee of suffering from a urinary tract infection (UTI) but the interpreter kept translating the UTI as a 'yeast infection.' A yeast infection would entail a different course of medical action. Accordingly, Lotte dismissed the interpreter and 'once again in their [Lotte and refugee's] best English'[9] explained what Lotte had initially meant. Moreover, when Naomi says 'that a piece of information is lost' she is also supporting Chitongo et al. (2021) findings that midwives are rarely certain if information has been communicated effectively while using an interpreter (p. 3). In addition to interpreters feeling comfortable relaying medical terminology, some interpreters do not share the same dialect with refugees therefore making it difficult to 'understand each other'[10] (Naomi).

[7] Original quote Naomi: Je hebt natuurlijk geen idee wat ze zeggen tegen elkaar, dus als wij zeggen van: 'ik weet dat in dat land van waar je vandaan komt dat mensen besneden zijn, ik vind het een lastige vraag, misschien vind jij het een lastige vraag, maar ik wil graag van jou weten of jij ook misschien besneden bent?' Nou dan begint die tolk tegen die mevrouw te praten en dan komt er alleen maar 'nee,' zoiets. En ik denk, 'ja maar dit was niet wat ik allemaal zei hè?' Dus ik weet niet zo goed wat die tolk tegen die mevrouw vertelt, ik weet niet zo goed wat die mevrouw tegen de tolk vertelt, en wat ik dan weer te horen krijgt. Ik heb ook wel eens het idee dat er een stukje informatie verloren gaat, en dat ligt dan denk ik ook wel eraan of een tolk zich enigszins comfortabel voelt met de situatie.

[8] Pseudonym

[9] Original quote Lotte: nog eens in beste Engels geprobeerd

[10] Original quote Lotte: elkaar ook beter te verstaan

The interpreter's influence during care interactions manifested in other ways, especially if there was a male interpreter:

> 'If there is a male interpreter, does she [Bibi] ask less questions to the doctor?' (*Sterre van Ede*)
>
> 'That's right, she [Bibi] has a lot of questions, but she doesn't dare [ask] because she's ashamed of culture and stuff, because she's not used to talking about that with men[11] (*Bibi, status holder, Syria: translated by Fatima*)'

During my field work period midwives discussed the extra time commitment needed prior to appointments to schedule interpreters in a specific dialect, language, or gender. Midwives tried to schedule female interpreters in advance as they recognized the importance of making refugees feel comfortable to discuss an array of maternal and sexual topics. However, there were times when midwives were not able to schedule female interpreters and forced to use a male. Bibi's quote above supports the Mengesha et al. (2018) study examining the experiences of healthcare professionals and refugee women. Like Mengesha et al. (2018), the presence of a male interpreter during Bibi's care interactions exacerbated her discomfort. Bibi mentioned that she doesn't 'dare'[12] to ask questions with a male interpreter or that she must first 'tell my husband and then my husband says to the interpreter.'[13] Bibi's experience of having a male interpreter forced her to avoid asking *any* questions to her doctor during her pregnancy. As a result, lack of communication and flow of information regarding her pregnancy mirrors Briggs' 'communicative justice' (2017). In addition, Bibi was forced into a care interaction where there was no option of using a female interpreter. Considering Bibi's hesitancy to share critical information with a male interpreter regarding her sexual well-being and pregnancy, this care interaction posits her healthcare provider as the one obtaining the power in this discourse interaction (Van Dijk, 1993). This results in a scenario where there is power *abuse* (Van Dijk, 1993, p. 259) during her care interaction as Bibi lacked control over her own narrative because she felt like she could not *share* her own narrative. Moreover, Bibi's experience supports the

[11] Original quote [Q]: Als er een mannelijk tolk is, vraagt ze ook minder vragen aan de dokter? Bibi: Ja klopt, ze heeft heel veel vragen maar ze durft niet, schamen door cultuur en zo, want ze is niet gewend zijn om met daar over met mannen te hebben.
[12] Original quote Bibi: durft niet
[13] Original quote Bibi: ga ik het tegen mijn man zeggen en dan zegt mijn man tegen de tolk zeggen

findings of Mengesha et al. (2018) that highlight in healthcare settings where interpreters are used for discussing sexual, reproductive and maternal care issues, there must be increased access to female interpreters (p. 203) as it makes it 'easier'[14] (Bibi) for refugees to discuss intimate health topics with their providers.

As Briggs discusses in 'Towards Communicative Justice in Health,' it is not uncommon to exclude patients from their care process (2017). Refusing to use an interpreter during care interactions creates a space in which healthcare providers not only hold power during discourse (Van Dijk, 1993) as it excludes the ability of a refugee to participate in conversation, it also inhibits a patient and provider relationship to form, which is an integral aspect to PCC (King & Hoppe, 2013, p. 384). As discussed earlier in this chapter an interpreter can facilitate participation for women during their pregnancy care process. However, there are times when healthcare providers do not create spaces for effective communication with refugees:

> 'Yes, I think that they [pregnant refugees] cannot always understand the language. And in the hospital the interpreter is not often used. You hear a lot [from the hospital]: 'Yeah I couldn't communicate with the woman very well,' but if you're pregnant, you have the right to really good communication. You just always need to call an interpreter, because maybe that woman will say the entire time yes, but can she still ask her own questions? Maybe she understands fairly well what I mean, but yeah, you must also discuss things like *feeling* and such. And that is really hard to do in a different language.'[15] (*Maud*[16]*, midwife)*

During this interview with Maud, she alluded to the fact that when women are referred to the second line of care, consultations take place in hospitals with doctors. During these consultations, many doctors do not have knowledge of a woman's background and have limited experiences working with pregnant refugees. Consequently, doctors and nurses are not familiar with calling an interpreter for care interactions. When Julia and I asked this midwife why that is the case, Maud responded with shrugged shoulders stating that 'many doctors and nurses simply do not care to take the time to call an interpreter.' Refusing to use an interpreter is in direct

[14] Original quote Bibi: Als het een vrouwelijke tolk is, dan is het makkelijker

[15] Original quote Maud: Ja, ik denk dat ze niet altijd de taal goed begrijpen. En in het ziekenhuis wordt de tolk vaak niet gebeld. Je hoort vaak: 'Ja ik kon niet goed met die mevrouw communiceren.' Maar als je zwanger bent, heb je het recht om echt goede informatie te krijgen. Je moet gewoon altijd een tolk bellen, want die mevrouw die zegt misschien de hele tijd "ja," maar kan ze ook haar vragen stellen? Misschien snapt ze ook redelijk wat ik bedoel, maar ja, je moet toch ook gewoon over dingen als gevoel enzo praten en dat is heel lastig in een andere taal.

[16] Pseudonym

violation of the AAAQ framework as the 'ability to communicate' (UNICEF, 2019) is obligatory for the right to good and quality care and excludes refugees from participating in their own care.

4.2 'You are of course as a midwife more than just the interpreter'[17]

> 'It's so strange to see the way a midwife looks at the phone while "speaking" to the refugee instead of looking *at* the refugee' (*Fieldnote, AZC)*

As mentioned, Briggs uncovers several manners in which violation of communication between a healthcare provider and a patient also inherently violates a patient's right to healthcare. During my fieldwork I found it interesting how not only the use of interpreters affected care interactions, but also how interpreters were digital added another complicated layer to pregnancy consultations. Forcing communication technology into care interactions (Ahlin, 2020), disrupts a patient's ability to communicate with their provider as interpreters influence the exchange of information. Tanja Ahlin, anthropologist and science and technology studies scholar conducted an ethnographic study looking at the way nurses from Kerala, India 'enacted care' (Ahlin, 2020, p. 70) through communication technologies (ICTs) with family members still living in India as a way of maintaining and fostering close relationships. For the purpose of this thesis, I implore the way Ahlin examines ICTs role in affecting the 'space' that they are presented in to help explain the presence of interpreters via a telephone and their influence on the overall pregnancy care interactions. Often, during my fieldwork observations a woman would walk in and be silent. Following, the midwife would ask a question about the pregnancy thus far, mostly in English. The woman would reply, hesitantly, with a simple 'yes,' or an attempt to say 'goed.'[18] The quiet and awkward mood of the room would only shift once the interpreter was present via the telephone. It was as if I could visibly see the relief from the woman once she was able to communicate with the midwife in her mother tongue.

I noticed a difficult scenario during my fieldwork when the technological use of an interpreter seemed to negatively affect the care experience:

> 'All of a sudden a certain beeping sound comes from the phone used to call the interpreter, indicating low battery. The asylum seeker has just begun to open up about her sexual trauma experiences from Afghanistan; as her head was down staring at her clasped

[17] Original quote Yara (midwife): je bent toch als verloskundige veel meer dan alleen een tolk
[18] Translated from Dutch: good

> hands, slowly uttering words to the interpreter via the telephone, the battery dies. The midwife swiftly says, 'I am sorry we will have to pick this up next time.' In my head I think, 'are you kidding me?' This terrified young woman is just beginning to open up, in what she thinks could be a safe space and this midwife brushes over the whole conversation as if it was no big deal just because the telephone died. I could not help but wonder if the midwife had paid a little more attention to the moment and consoled the woman, would the woman have appreciated it?' *(Field note, midwifery practice)*

This scene shows how the use of interpreters in pregnancy care for refugees is at times, a double-edged sword. Unlike other scenarios where the interpreter posed as the issue during consultations, the scene above demonstrates that the technological aspect of a telephonic interpreter service hinders the care experience. It is as though using an interpreter via the telephone presented an invisible, yet tangible barrier between the midwife and refugee that solidified pregnancy checkups as a sterile interaction. Arguably, this scene is in direct violation of Skirbekk et al. trust mandates where the physician is meant to show sensitivity to patient emotion (2011, p 1186), and breaches the WHO's intrapartum care recommendations (2018) to provide emotional support as well. In my observation there seems to be no empathy stemming from the midwife and almost no attempt to further understand this woman's past traumas. Shortly after the phone died the midwife quickly said, 'we will pick this up next time.' There was no effort to try and navigate the difficult conversation without an interpreter. In contrast, when discussing the topic of using interpreters during an interview with Yara,[19] a midwife, she stated that as 'a midwife you are so much more than just an interpreter'[20] when referring to a midwife's worth in pregnancy care. In my observation above, it was almost as if this midwife perceived her caring abilities to extend only as far as the use of an interpreter. However, she could have consoled this woman, tried using google translate (another method used by midwives), or referred this woman to a counselor. Although this thesis stresses the importance of good communication in care interactions with refugees, as seen in Brown et al. (2011), non-verbal communication is just as important in creating trust between a provider and a patient. In several interviews when midwives encountered roadblocks while verbally communicating, they resorted to using 'hands and feet' as a method to create connections. While other midwives, as seen in the scenario above, would not attempt to engage in other forms of 'communication.'

[19] Pseudonym
[20] Original quote Yara: je bent toch als verloskundige veel meer dan alleen een tolk.

Furthermore, this midwife neglected to understand this woman holistically as she did not create space for this woman to *story tell* – essentially rendering the refugees' past traumas as insignificant to her pregnancy care (Briggs, 2017).

The irony of using an interpreter is that although it offered information to be translated in a refugees' mother tongue, it did not directly equate to good and effective communication. As noted above, Naomi finds that 'information is lost' affecting her ability to gain a holistic view of her patients (essential when applying PCC). In Bibi's encounters with male interpreters, she was 'ashamed'[21] to discuss certain issues, therefore affecting her accessibility to receiving appropriate care (necessary when achieving the AAAQ framework). Lastly, as I witnessed in several observation days, the interpreter influenced a midwife's ability to create a space where communication could happen during care interactions, which, affected the *quality* of care for refugees in the Netherlands (UNICEF, 2019).

4.3 'They feel really relieved like, "oh we can finally talk to someone"'[22]

> '… as soon as they come to us, and call the interpreter, they feel really relieved like, 'oh we can finally talk with someone.' So, then everything really comes out. Which is also sometimes not obstetric related at all, but that they really feel a chance to ask all the questions they have, and then they ask us because they can finally communicate with someone. [23]*' (Roos[24], Midwife)*

In Roos' experience, the interpreter has the ability to create a safe space for women who do not have a social network around them in asylum-seeking centers to simply ask: 'how they are doing?' As portrayed in the quote above, there are times where, once a refugee encounters someone like a midwife who is caring for her and the baby with the use of an interpreter, the conversation would stray from pregnancy related topics. In this sense, an interpreter can facilitate a connection that extends beyond medical conversations. As discussed in Briggs' 'Towards Communicative Justice in Health,' once members of a lower socioeconomic status move to

[21] Original quote Bibi: schaamt
[22] Original quote Roos: dat ze echt een soort van opluchting hebben van, 'oh we kunnen eindelijk met iemand communiceren.'
[23] Original quote Roos: zodra dat ze dan bij ons komen, en bij de tolkentelefoon bellen, dat ze echt een soort van opluchting hebben van, "oh we kunnen eindelijk met iemand communiceren." Dus dan komt er echt van alles uit. Wat soms ook helemaal niet verloskundig gerelateerd is, maar dat ze echt even een kans voelen om alle vragen te stellen die ze hebben, en dan vragen ze het maar aan ons want ze kunnen eindelijk met iemand communiceren.
[24] Pseudonym

higher levels of care, they may, by default, be blocked from engaging in communication and participation during their care process (2017, p. 285). However, as portrayed in the quote above, an interpreter expanded a woman's ability to engage not only in her own pregnancy care, but other modes of care as well. For many women the sheer *ability* to have a conversation with someone felt comforting, even if these conversations were not pregnancy related. Allowing the communicative space to open for the woman and a midwife through an interpreter also allowed for trust mandates to form (Skirbekk et al., 2011). Midwives like Roos partook in conversations outside the realm of a woman's pregnancy. Therefore, the healthcare provider was able to cultivate a trusting relationship by staying attentive to the woman's emotions (Skirbekk et al., 2011) and by engaging in PCC care by focusing on things that are beyond the woman's immediate health conditions (Bauman et al., 2003).

Roos' experience in using interpreters to bridge relationships and form trust can be explained by previous studies (Skirbekk et al., 2011; Pomp & Ballast, 2010) suggesting that pregnant women and refugees seek trust due to their 'state of vulnerability' (Van der Zande et al., 2017, p. 658). Not only does Roos' experience of using an interpreter serve as the gateway to communicate with her refugee patients, but interpreters also help to allow Roos' relationships with refugee patients time to form, an important mandate of trust (Skirbekk et al., 2011, p. 1186). Midwives Britt[25] and Yara both agree that they consider their refugee patients to be more vulnerable than their 'regular' Dutch patients. Britt attributes this vulnerability to 'fewer economic possibilities,'[26] and 'gaps in their [refugees'] medical dossier.[27] While Yara credits 'difficulty 'speaking the Dutch language'[28] as attributing to a refugees' vulnerability. During my interview with Yara, she described that a lack of Dutch language skills makes a refugee vulnerable because they are often 'left out of discussions'[29] surrounding the provision of their care, further implicating their fundamental right to quality pregnancy care (AAAQ, UNICEF, 2019).

[25] Pseudonym
[26] Original quote Britt: weinig economische mogelijkheden
[27] Original quote Britt: medisch ook soms een vraagteken in hun dossier
[28] Original quote Yara: ls je de taal niet machtig bent, ben je super kwetsbaar als zwangere vrouw
[29] Original quote Yara: 'ja maar dat is helemaal niet met mij besproken,

4.4 'Care for status holders is actually a little bit more difficult?'[30]

As stated earlier, care for status holder and asylum seekers in the Netherlands differs greatly. Once asylum seekers are granted asylum, they are given a Dutch residency permit. Ironically, this does not entail that navigating the Dutch healthcare system becomes any easier. In fact, as discovered during my interviews, midwives and status holders both agree that 'being a status holder' is quite difficult when it comes to accessing pregnancy care.

> '…for status holders…I want to know them better and be able to ask questions'[31] (*Maud)*

Many midwives often found that status holders 'get lost in the system. 'Asylum seekers have the privilege of having COA organize their pregnancy care, but status holders do not. Status holders who do not have family or friends in the Netherlands are often left to navigate the Dutch healthcare system on their own—a difficult task if one does not speak the language well. For both midwives and status holders, the mere fact that midwifery practices or hospitals can no longer arrange a free interpreter for care interactions makes it incredibly difficult to effectively communicate with one another. As Maud mentions above, she wants to 'be able to ask questions' in order to 'know them better' because she can no longer schedule an interpreter for free. In several interview midwives explained instances when they resorted in using their own money or money from the midwifery practices to cover the cost of an interpreter in situations when they found it almost unbearable to communicate without one.

> '…her GP was Dutch, and she couldn't speak the language, and she didn't dare to ask. And she also has children who can speak it [Dutch] but she didn't dare to ask her children because she's ashamed of what happened to her [referring to the miscarriage]. But the third pregnancy goes better through the Arab GP in the hospital'[32](*Bibi: translated by Fatima)*

Bibi's experience as a status holder from Syria, elucidates the importance in providing refugees with the feeling that they have the *ability* to access pregnancy care in the Netherlands. Marshall's

[30] Original quote Julia Tanktink (JT)[Q]: Begrijp ik hieruit dat de zorg rondom statushouders eigenlijk moeilijker is?
[31] Original quote Maud: Ja, en voor statushouders… Ik wil ze beter herkennen en vragen kunnen stellen.
[32] Original quote Bibi: Omdat haar huisarts [was] Nederlandse en ze kon geen taal [kon] spreken, en ze durfde niet te vragen…en ze heeft ook kinderen die [het] kunnen het spreken maar ze durfde niet om haar kinderen te vragen omdat ze [zich] schaamt [over] wat [er] gebeurt met haar. Maar de derde zwangerschap gaat beter via de Arabische huisarts in het ziekenhuis.

'social citizenship' (1950) can make sense of the Bibi's hesitancy to engage in pregnancy care as she feels excluded from pregnancy care because she does not speak Dutch. During my interview with Bibi, she described feeling 'ashamed' and 'embarrassed' to seek out help from her doctor (the second line of pregnancy care) during a time when she believed to suffer from a miscarriage. Van Dijk's (1993) CDA can help to understand how Bibi' reluctance in seeking medical help from Dutch doctors results in a power abuse during discourse interactions. In Bibi's experience, her limited access to the Dutch language—a resource deemed powerful in Van Dijk's CDA (1993, p. 255)—meant that Bibi received zero care from Dutch healthcare professionals. It is in experiences like Bibi's where many midwives wish the Dutch government would take some 'responsibility'[33] (Tess[34], Midwife) in providing access to communication services for status holders.

Moreover, as a status holder, Bibi did not have access to a free interpreter during her interactions with a doctor. Additionally, Bibi suffered her miscarriage shortly after her arrival in the Netherlands, a time in which she barely spoke any Dutch (she prides herself on being able to converse in Dutch now). Bibi mentioned how she did not want to ask her children to come with her to the doctor even though they spoke better Dutch than her. It is not uncommon for refugees or immigrants to enlist the help of a friend or family member to translate during healthcare interactions (Woods et al., 2016). Although an immediate member of a refugees' community saves the cost of paying for an interpreter, studies find that this often presents challenges as it creates an environment of mistrust and a breach in the provider and patient confidentiality (Woods et al., 2016, p. 456). Moreover, midwives like Lotte occasionally experience situations where status holders bring their children to care interactions as interpreters. In one scenario, a status holder brought her son to a pregnancy checkup and despite Lotte's observation of how 'proud'[35] the son was to be able to speak in Dutch, Lotte noticed the status holder's hesitancy in sharing intimate health issues that she did not want to 'share'[36] (Lotte) with her son. This further supports the need for healthcare systems to provide interpretation services during care interactions for refugees (Chitongo et al., 2021).

[33] Translated from Dutch Tess: verantwoordelijk
[34] Pseudonym
[35] Translated from Dutch: Lotte: trots
[36] Original quote Lotte: als een vrouw bepaalde dingen eigenlijk niet wil delen eigenlijk met het mannelijke geslacht en dan ben je als zoon toch - moet je misschien dingen vertalen die je eigenlijk – die een moeder eigenlijk niet met hem wil delen.

Although status holders are given the freedom to navigate the Dutch healthcare system, Tess thinks that status holders are not fully supported while given that 'responsibility in the Netherlands.'[37] For the 'regular' Dutch citizen, midwives instruct women to schedule their own postpartum care or blood work (if needed to check for conditions during pregnancy). Technically speaking, midwives must instruct status holders to do the same. However, midwives such as Tess, Elin[38] and Maud take on the responsibility of arranging the postpartum caregiver and call the hospital to set up blood tests if one of their status holders needs to check for gestational diabetes. Because status holders are left to navigate the Dutch healthcare system without the help of COA, Tess, Elin and Maud agree that they need more support from the Dutch government to sufficiently support their status holders during pregnancy.

4.5 Conclusion

> '…I really think that whether you speak the language or not, doesn't mean that suddenly you're unimportant or that she [referring to a refugee] has no wishes'[39](*Yara)*

In this chapter I have shown the ways in which communication is the foundation to pregnancy care among refugees. It is crucial to the pregnancy care process for refugees, that despite the nuances of what an interpreter does, the interpreter allows refugees to become active 'participants' imperative while employing a PCC model. Without the *ability* to talk, the care process no longer becomes a collaboration between the refugee and midwife.

During my observations and interviews it became clear that interpreters both hindered and enhanced care interactions. It was a strange thing to witness two people speak through another person electronically. I observed some midwives pay more attention to the telephone while speaking to the refugee, while others made it a deliberate purpose in looking at the woman while speaking to the interpreter. Looking the woman directly in the face while using an interpreter was a means of holding some sort of emotional connection, even though some refugees did not understand what the midwife was saying until after the translation. Many

[37] Original quote Tess: …dat doe je zelf, dus je bent zelf verantwoordelijk. Nou, dat lukt niet…niet in Nederland.
[38] Pseudonym
[39] Original quote Yara: Kwalijk, ik vind dat echt heel kwalijk, dat ik echt denk van: of je de taal spreekt of niet spreekt, betekent niet dat ze opeens onbelangrijk is, of dat ze geen wensen heeft

midwives emphasized the importance of 'glimlachen' [40] during pregnancy appointments to personify the interaction with an electronic interpreter. If I have learned anything from the presence of an interpreter, and its significance in the care interaction, it is that communication extends far beyond that of verbal ability. Communication appears in those moments when a midwife makes a gesture to the woman's stomach to ask if the baby is moving enough, or in the moments when I caught the midwife and refugee smiling nervously, yet excited when talking about the delivery of the baby. But most of all, emotional communication occurred when I felt that the midwife tried her utmost best to make the refugee feel safe not only in the consultation room, but also in regard to her pregnancy, the health of the baby, and her new life in the Netherlands.

[40] Translated into English: smiling

5. The importance of background: 'Caring,' and 'Giving them a Voice'

This chapter will address my second sub-question by expanding on different techniques midwives used to build trust and partnerships with pregnant refugees. I explore how 'giving them a voice' (Tess) and 'asking them what they want' (Yara) not only customizes pregnancy care to individual refugees but also allows space for the midwife and the refugee to explore care *together.* As stated in this thesis' 'theoretical inspirations' chapter, PCC takes a particular focus on a patient's unique background (Lateef & Mhlongo, 2020). I uncovered several ways in which midwives used a refugees' background to build partnerships and, in addition, trust. Consequently, while midwives attempted to unpack how refugees were different from their general patient population, I discovered that refugees are often confronted with stigmatized experiences that affect their experiences during pregnancy. This ultimately led some refugees to feel 'othered' based on their background and feel that 'they [the Dutch system] don't care about us' (Miremba).

5.1 'You're on the same wavelength'[41]

> '…yes, for the rest, religion, I also notice a lot. That from religion there are certain things they do want to ask but they have something like: "the care giver doesn't have the same religious background, and won't understand me, or she is going to think I am strange…" At a certain moment you break the ice by talking on the same level, so to speak, like: "okay, from this religion I know what is accepted and what isn't, or that is accepted" and then I say: "oh there I can give my –also with specific medication, specific treatments, is that allowed, is that not allowed, do I need to pray, do I not need to pray, can I fast, should I not fast?" All those things. And if they notice that I know more things from a religious point of view, then the questions arise on their own. I notice that.' [42]*(Yara)*

[41] Original quote Yara: Je zit een beetje op hetzelfde golflengte

[42] Original quote Yara: ja voor de rest, religie, merk ik ook heel veel. Dat vanuit de religie dat bepaalde dingen ze wel willen vragen maar ze hebben zoiets van: 'de zorgverlener heeft niet dezelfde religieuze achtergrond, en dan gaat die mij niet begrijpen, of zij gaat mij misschien vreemd vinden'…op een gegeven moment - je breekt het ijs door op hetzelfde niveau te praten zeg maar, van oké, 'vanuit de religie weet ik ook dat dit wel toegestaan is of dat het niet toegestaan is' en ik zeg van: 'oh daar kan ik ook mijn— ook bepaalde medicatie, bepaalde behandeling, of mag dat dan wel, mag dat dan niet, moet ik wel bidden, moet ik dan niet bidden, mag ik vasten mag ik niet vasten.'

Considering a patient's possible trauma's, religious backgrounds and economic circumstances not only helps to provide quality care to individual patients, but also improve provider and patient satisfaction with care interactions (Lateef & Mhlongo, 2020, p. 24). Midwife Yara credits her 'multicultural upbringing'[43] and knowledge of different cultures, languages, and religions to build partnerships with refugees during care interactions. She adopted a PCC approach to her care as she paid particular attention to refugees' cultural background such as religion. During my interview with Yara, she mentioned that many religious refugees feel as though the caregiver won't understand the important role of religion in their lifestyle, therefore preventing refugees from asking questions. To gain her patient's trust, Yara would imagine herself in the position of the refugee and begin to 'talk on the same level' to address any questions regarding pregnancy care and religion.

Yara's experience echoes a study conducted in the United States among Muslim refugee women and their healthcare providers (Hasnain et al., 2011). The Hasnain et al. study (2011) helps to make sense of how contextual ignorance, namely religious ignorance stemming from healthcare professionals severely harms the quality of care (Hasnain et al., 2011). The Hasnain et al. study reveals how Yara's approach to understanding religion's influence, particularly women with a Muslim background, helps to form partnerships between the patient and provider and creates a trusting environment during care interactions (Hasnain et al., 2011, p. 79). As Yara said, 'If I give my advice from a religious point of view, that is the trust they would really like to have.'[44] Yara's forming of trust can be explained by Hasnain et al. (2011) findings that Muslim women often face barriers to care based on their religious beliefs, therefore seeking out health care professionals who try and understand their religious backgrounds (p. 80). Yara realized that approaching pregnancy care with a particular focus on the impact of religion to some refugees' lifestyle helped to establish long lasting relationships with some of her patients. When one of Yara's status holders became pregnant for the second time, she insisted on having Yara as her midwife again, despite having moved to a different city in the Netherlands. Moreover, Yara shows us that adopting a PCC approach (by viewing her patients holistically) to form trust also

Al die dingen dan als ze merken dat ik dan net iets meer weet qua religie dan komen de vragen vanzelf. Ik merk dat dat wel een puntje is

[43] Original quote Yara: multicultureel opgevoed

[44] Original quote Yara: Dus als ik zo met advies geven vanuit het religieuze oogpunt, dat is wel het vertrouwen wat ze graag wensen

supports Skirbekk et al. (2011) trust mandates by taking an early interest in her patient beyond medical inquiry (p. 1186). By not only understanding a refugees' medical, but personal background, Yara's interest allowed for her patients to feel trust therefore leading 'questions to arise on their own' (Yara) and develop long-lasting relationships with refugee patients.

5.2 'It is really personal care'[45]

> 'You give them a voice, that is actually what you are doing. Because that is actually what has always been taken away, or at least that's what it seems. You want to give that to them and also with the delivery [of the child]. Indeed, with someone with trauma to let them know that it doesn't have to be painful, you don't need pain, and it does not need to feel like a trauma. We can make appointments to discuss painkillers or epidurals, or appointments about internal examinations. We can make appointments. Nothing is necessary, everything is allowed. "What do you want then?" They are not used to that; they are not asked what they want'[46] (*Tess)*

In Tess' experience, the best way to form a partnership is collaborating with her refugee patients, a technique that Bauman, Fardy and Harris argue is essential while implementing PCC (2003, p. 253). Tess emphasized the need to 'give them a voice' by asking them 'what they want.' In Tess' experience in providing pregnancy care to refugees, she realized that this group of women are not usually confronted with questions as to what they 'need' and 'want' in their pregnancy. In Tess' opinion this is a result of their experience with pregnancy care from their country of origin or that refugees do not easily feel comfortable asking questions during care consultations. Tess' colleague, Elin, also supported this technique during care interactions. Elin stated that 'we don't just do things without telling them, you discuss with them.'[47] While 'discussing' a woman's needs, both Tess and Elin found themselves enquiring about a woman's past traumas and fears to provide 'personal care' (Tess). It is not uncommon for midwives to encounter refugee patients with past sexual traumas. Many refugees experience

[45] Original quote Tess: Dat het ook echt persoonlijke zorg is
[46] Original quote Tess: Je geeft ze graag een stem, dat is wat je doet eigenlijk. Want dat is wat ze eigenlijk altijd is afgenomen, of in ieder geval het gevoel hebben, dat ze dat niet is afgenomen, en dat wil je ze wel geven en ook met de bevalling. Inderdaad iemand met een trauma gewoon laten weten dat je geen pijn hoeft te hebben, en dat het niet als een trauma hoeft te voelen, we kunnen afspraken maken over pijnstilling, over ruggenprik, over eerst de ruggenprik, dan inwendig onderzoek, we kunnen daar afspraken over maken niks moet, alles mag. 'Wat wil jij dan?' Dat zijn ze niet gewend dat wordt niet gevraagd wat zij willen
[47] Original quote Elin: dat we niet zomaar dingen doen, dingen met hun bespreken,

sexual assault during their journey to asylum or come from countries where FGM is still practiced. Tess and Elin described that it is common during pregnancy care that interactions between the midwife and a refugee can trigger past sexual traumas. Instances where midwives must conduct vaginal exams, ultrasounds or even the delivery of the baby can trigger horrific memories and physical pain to refugees. Therefore, both Elin and Tess take the time to build relationships with their patient's by inquiring about background to 'focus on what that woman needs'[48] (Tess). During my interview with Elin and Tess, it became clear that when midwifes view a patient holistically, midwifes can assist a refugees' experience in birth by giving them the opportunity to experience a life-changing event in the way they would like to experience it.

> '… They are free here. But it is, I think, at least [for] us personally, it's good. [to know about a woman's background]. Because the better you know someone, the better care you can provide, in my opinion.'[49] (*Tess)*

Ultimately the goal of the midwife is to provide quality care for refugees. In the last three years in the Netherlands, there has been a growing demand for first line and second line pregnancy care to adopt a more holistic approach to care. I regard holistic care as a PCC approach, however, in response to the high perinatal mortality rate in the Netherlands, the Dutch Health Ministry regards holistic pregnancy care as a 'woman-centered care' (Rijnders et al., 2019). Countries in Europe with similar refugee statistics tend to adopt similar approaches. In Haith-Cooper and Bradshaw's study regarding woman-centered care among pregnant asylum seekers in the United Kingdom, researchers discovered that to reduce pregnancy and delivery risks, midwives must pay attention to a woman's 'psychosocial and cultural needs' (2013, p. 772). Arguably, despite dominant discourse that midwives fall short in providing well-rounded pregnancy care (Haith-Cooper & Bradshaw, 2013), midwives like Elin, Tess and Yara did their best to be cognizant of a woman's individual, social and cultural needs (2013).

Engaging in PCC, by asking women 'what they want' (Tess), midwives also create a space for non-hierarchal communication by dismantling the power imbalance between the healthcare provider and the patient to explore a refugees' needs. As seen in the Tess and Elin's

[48] Original quote Tess: maar we gaan echt toegespitst op die vrouw wat zij nodig heeft
[49] Original quote Tess: hier zijn ze vrij. Maar het is wel – denk ik, wi in ieder geval vinden het persoonlijk goed want hoe meer je iets van iemand weet, hoe beter je ook in mijn opinie zorg kan leveren

statements, they both create a space for storytelling, which, Briggs argues is vital in providing care (2017, p. 287). During my interview with Elin and Tess I was confronted with the beauty of a Dutch midwife asking a refugee what she wants in her birthing experience as this democratizes the care process for the refugee. Instead of seeing a midwife as a doctor that 'knows best' like many refugees do, the goal of a midwife is to break hierarchal barriers (Briggs, 2017) and provide tailored care while working *together.* The goal of not just 'doing care,' or 'doing a delivery,' is to show refugees that they are safe—something that is not easily felt. Especially due to their journey while seeking asylum or waiting for their asylum approval in the Netherlands. The care experience, interactions between a midwife and a patient, are moments when refugees have the ability to say what they want which is significant to asylum-seekers who are awaiting their acceptance into the country and have no say in their asylum process.

5.3 'They're afraid we will pass on information to the IND'[50]

In the previous two sections I outlined several ways in which midwives attempted to build partnerships and gain trust through a PCC approach by inquiring about their background. However, I also came across midwives who avoided asking about a patient's background. Instead, some midwives argued that it is rather difficult to achieve PCC while inquiring about a refugees' context because of barriers to trust and language:

> '…but we don't ask why they fled…Well, that—we don't want to be seen as the IND or COA. Women sometimes tell us things that they are afraid we will pass on to the IND for example. But that is absolutely not the case and we absolutely do not want to create that feeling.' (*Femke[51], Midwife)*

As chronicled by Femke, refugees experience trust differently during their care interactions because of their difficulty in trusting new people, institutions and healthcare systems. Researchers Kotovicz, Getzin and Vo conducted a study in the United States to identify the challenges of healthcare providers' ability to build trust with refugees because of their perceived mistrust in the United States' healthcare system (2018, p. 33). Refugees often face negative interactions with case managers, healthcare providers and government officials during their

[50] Original quote Femke: ze zijn bang dat wij die door zullen gaan spelen naar de IND
[51] Pseudonym

resettlement process and while navigating their asylum procedure. As a result, distrust often filters into their care interactions with healthcare providers even though many healthcare providers are a separate entity from governmental organizations, such as the COA (Kotovicz, Getzin & Vo, 2018, p. 31). In Femke's experience, asking 'questions' about a refugee's past or journey to the Netherlands mimics the IND asylum-seeking interview. The Sripad et al. (2018) study can help shed light on the way a patient's perception of a medical system is interwoven in their mistrust in a political system as a whole (p. 306). As discussed in chapter one, refugees feel as though they are unwelcomed in the Netherlands. This sense of 'mistrust' is often reflected during care interactions. In Femke's experience some refugees perceive that any person, system or institution affiliated with the Dutch government does not want refugees in the Netherlands. Therefore, midwives such as Femke sometimes encounter women who do not want to share *any* information on experiences such as sexual assault during their journey to asylum in fear that it will jeopardize their asylum procedure in the Netherlands. This, of course, is not Femke's intention. As a result, Femke would rather avoid asking 'too many' questions at the risk of mirroring the IND process—an interview notoriously known to cause great stress to refugees (Li et al., 2016, p. 82).

5.4 'Everybody is looking at me strange'

> 'In (place), first and foremost we are cohabiting. We are living in an ex-prison; it was a prison before and now it's AZC. So, the rooms are really tiny, and you have a small toilet by your room and a sink, and then it's like plywood that's like… and then you move out, it's covered and short, so it's very hot, and the window is just a quarter of this [motions to her window] and then it's in the middle of farms. Like here it's a farm of hens which are laying eggs, and here it's a farm of cows which are for dairy product, so in summer all the flies are many, and they come through that small window, and then you are fighting with flies all over the whole house. And with pregnancy, [it's] very hot, and there are really many mothers in that AZC so it's not good condition for them' (*Miremba, Asylum seeker, Uganda)*

Refugees in The Netherlands must face the perpetual experience of feeling like they do not belong (Pozzo & Nerghes, 2020, p. 844). It is as though the different religious beliefs, background and cultural differences begin to negatively affect a refugee. The materialization of feeling 'unworthy' in experiencing good healthcare like every other Dutch citizen occurs during interactions with the Dutch healthcare system. For pregnant women this occurs during their

interactions with midwives or when referred to the second line of care. It is not uncommon for refugees to feel as though they are rejected from their new healthcare system (Svenberg et al. 2011). During my interview with Miremba, she described her early months of pregnancy as 'very difficult' while living in a COA center. When Miremba described the living conditions in an AZC in Overloon, the Netherlands, it became clear that she felt disrespected by the COA. Living in an 'ex-prison' surrounded by 'flies' (Miremba), she felt as though 'no one cared.' As I discovered, Miremba is not the only refugee to experience such feelings while navigating healthcare services as an asylum seeker. In the Svenberg et al. (2011) study, researchers found that Somalian refugees were dissatisfied with their healthcare interactions due to a lack of respect from Swedish doctors (p. 694). Miremba pointed out that during her postpartum period she needed extra money for baby items such as diapers and wipes. Miremba received a mere thirteen euros worth of baby items from the COA and argued that these items were of such 'low quality' (Miremba). If it were up to her, she wished that she received the money directly so that she could buy quality baby care items because 'they [the COA] do not care' (Miremba).

Indeed, the feeling that my refugee participants experienced suboptimal care interactions seemed to resonate with every single woman.

> '…yeah inside [referring to the consultation room with the midwife] I feel comfortable, but when I am waiting there, I am not comfortable' (*Hani, Asylum seeker, Somalia)*

During my interview with Hani, she expressed her discomfort when travelling to a midwifery clinic in the Netherlands because she felt like an outsider. It is common for immigrants to feel this way during their acculturation process in the Netherlands (Di Saint Pierre et al., 2015). Hani expressed that I was one of the first Dutch people who took the time to have a conversation with her. She told me that she felt comfortable enough to speak with me because I 'smiled at her' (Hani) and complimented her 'dress' (Hani). During the interview Hani was grateful that I simply shared a cup of tea with her and asked her 'how are you doing?' Hani particularly felt 'othered'—a sense of isolation, apartness, disconnectedness and alienation (Udah, 2018, p. 390)—when she would go to her pregnancy checkups and sit in a waiting room with other Dutch women who would not 'even look at me' (Hani). During her pregnancy, Hani established feelings of fear and anxiety because she was 'scared' (Hani) for her newborn son to navigate a

life filled with uncertainty due to her pending asylum procedure in the Netherlands. Not only are stress and anxiety uncomfortable feelings for Hani to experience during pregnancy, but stress from the mother can also have detrimental effects for the baby's health (Brocco et al., 2019)**.** It is in refugees' experiences like Hani's where the Dutch healthcare system and COA fail to support their pregnant refugees by providing care that addresses their unique needs.

> '… There is –Nigerian women for example – we always say, yes, they have an enormous attitude about them, they are very –well they come across a bit bitchy now and then, let's say. Syrian women are very thankful, very calm, but can also ask a lot of questions, but are much calmer let's say. Syrian women, you can discuss anything with them. Yes, that is very stereotyped of course, but this is a bit of a distinction you can make.'[52] *(Femke)*

It comes as no shock that some refugees experience these feelings in the Netherlands. Hani's experience with the Dutch healthcare system seems to echo a previous study conducted in the Netherlands that found Somali refugees feeling 'disrespected' and not 'taken seriously' during their care interactions (Feldmann et al., 2006, p. 28). Studies like Feldmann et al. (2006) and Svenberg et al. (2011) show that when refugee patients feel this way, they are dissuaded from accessing healthcare, often travelling to countries like Germany which is positively regarded among refugees (Svenberg et al., 2011, p. 699). It certainly does not help that some healthcare professionals fall prey into generalizing populations and categorize some groups of refugees as 'bitchy' (Femke) or 'lazy' (Lotte). When healthcare providers fail to create a sense of belonging during care interactions, they simultaneously fail to establish social citizenship for refugees (Varsanyi, 2006). This further implicates not only a refugee's desire to seek out healthcare—therefore affecting whether a refugee receives care at all—however, it also implicates the AAAQ framework stating that 'social accessibility' must be present when providing good and quality care. Hani and Miremba's experiences of being 'othered' (Udah, 2018) and feeling 'disrespected' challenge the 'social accessibility' model in the AAAQ framework suggesting service providers respect and avoid stigmatization of persons (UNICEF, AAAQ framework, p. 1). Hani and Miremba's pregnancy experiences in the Netherlands show that despite receiving

[52] Original quote Tess: …Er zit wel in - Nigeriaanse vrouwen hebben bijvoorbeeld - zeggen wij altijd – ja, die hebben een enorme attitude over zich heen, die zijn veel – nou die komen een beetje bitchy over af en toe zeg maar, Syrische vrouwen zijn heel dankbaar, zijn heel rustig, maar kunnen daarin ook wel eisen stellen, maar zijn wel veel kalmer daarin zeg maar. Servische vrouwen kun je helemaal niet van opaan. Ja, dit is heel erg stereotyperend natuurlijk, maar dit is wel een beetje het onderscheid dat je kunt maken.

pregnancy care, a social citizenship resource, does not necessarily mean that it was *good* care that Dutch citizens do experience.

5.5 Conclusion

> 'No one really asks "how are you doing right now, and how does it feel to be here"'?[53] (*Britt*)

Throughout this chapter I have addressed my second sub question to show the importance of understanding refugees holistically in a midwives' approach to pregnancy care. I have focused on the way midwives adopted a PCC approach to form partnerships and trust with refugee women, often, simply by asking 'how are you doing?' (Britt). I have also addressed situations when midwives found it challenging to view a patient holistically because of barriers to trust and language. Moreover, I have shown how refugees become defined by their status of being a 'refugee' and struggle to access pregnancy care because of stigmatization that is imbedded during care interactions (Feldmann et al., 2006). I explored the tension between understanding a refugees' background in order to provide quality care, while at the same time exploring how an emphasis on differences in backgrounds can lead to moments of 'othering,' therefore potentially harming a refugees' pregnancy care interactions

6. Discussion and conclusion

The aim of this study was to explore care interactions between refugees and midwives in the Netherlands and its impact on the overall pregnancy care for the refugee. I use theories in communication and trust to serve as the foundation to connect patient-centered care and access to healthcare resources (through the lens of social citizenship). This allowed me to analyze how trust and communication are present in, and matter for pregnancy care interactions for refugees in the Netherlands. I draw on Critical Discourse Analysis to examine the way power imbalance in discourse and language affects what is being said during pregnancy consultations and how CDA influences the way midwives and refugees communicate. I specifically focused on the way

[53] Original quote Britt: niemand vraagt echt een keer van 'hoe gaat het nu met jou?' en 'hoe vind je het om hier te zijn?'

language and both verbal and non-verbal communication enrich or obstruct pregnancy care for refugees. In this final chapter, I discuss this study's limitations, practical recommendations and what this thesis can add to future research in the field of maternal care for refugees.

6.1 Main findings

As discussed in this thesis' analysis, care interactions heavily influence a refugee's overall experience with pregnancy in the Netherlands. My analysis supports existing literature as well as adding new content for future studies looking at qualitative experiences of pregnancy care among refugees in the Netherlands. I will now discuss several main findings from my research.

In my analysis it shows that the exchange of information (communication), non-verbal communication and communication through an interpreter were major factors influencing both the midwives and refugee's perceptions of pregnancy care. There were several elements in how interpreters influenced pregnancy care interactions. For example, because asylum seekers are under COA's jurisdiction, their access to a free interpreter is included in their care. Many midwives must schedule specific interpreters before appointments but often forget or neglect to do so. If this is the case, an interpreter is assigned at random. It is not uncommon that male interpreters are assigned to translate during pregnancy appointments. However, for asylum seekers with Muslim backgrounds, it can be difficult to talk to male interpreters about private health issues regarding the female body. Therefore, the 'presence' of a male interpreter influences a refugee's desirability to ask questions or speak about intimate issues. This creates a space where women may forego vital pregnancy information further implicating their access to care. Additionally, for status holders in the Netherlands there is no access to free interpreters during care interactions. As seen in my findings, some status holders must resort to using family members (raising ethical issues) or avoid seeking care at all because they are excluded from participating in their care due to languages barriers.

As I have brought to light, several midwives found it challenging to speak with interpreters. Some midwives discussed their experiences in giving detailed explanations to the interpreter, the interpreter would then (in the perspective of the midwife) give short explanations to the refugee, and the refugee would give one-word responses (Faire et al., 2020). Alternative forms of communication were especially necessary to compensate for poor communication while using inadequate interpreters. In instances when midwives recognized an interpreter's shortcomings,

midwives would partake in other forms of communication. Such as using Google Translate to increase engagement between patient and provider, as well as using 'hands and feet.' Therefore, uses of alternate communication such as gestures created a sense that midwives were talking *with* refugees and forming a care partnership, rather than talking *at* refugees that so often occurs in paternalistic styled care (Lateef & Mhlongo, 2020).

Lastly, in my analysis of a refugee's background, refugees discussed instances of feeling 'uncomfortable' during their care, which, resulted in lack of confidence that the 'Dutch system' has refugees' best interest. Unbeknownst to refugees themselves, midwives often generalized an entire population (Jonkers, et al., 2011). This finding reminds us that it is important to consider, as Sripad et al. (2018) argues, trust during care interactions is influenced by a patient's perception an entire 'country' or 'healthcare system.' On the receiving end of being 'othered,' refugees felt unworthy, ashamed and held the general opinion that 'they [Dutch system] do not care.' My findings support other studies that feeling 'unwelcomed' as a refugee led to a lack of trust with a refugees' provider (Svenberg at al., 2011; Feldmann et al., 2006). Distrust manifested in other ways, like Femke's experience of being seen as the IND therefore making it difficult to create a space where refugees feel safe to share information. As I will suggest later in this chapter, cultural competency training may be a solution to this issue. When refugees feel unwelcomed into the Netherlands, pregnancy care interactions are the entryway to feel accepted into Dutch society. Care interactions, formed by the work of midwives, have the ability to transform a refugee's pregnancy experience, and ultimately their new 'home' for better or for worse.

6.2 Study limitations

It is important to consider that this research thesis is a small contribution to the EGALITE study at large and therefore I must consider this study's limitations properly. Firstly, although I examined both the healthcare provider's influence in care interactions and the refugee's side, I obtained more data from midwives. My difficulty in recruiting more refugee women ultimately shows in my data (Correa-Velez & Ryan, 2012, p. 21). Moreover, the primary focus in this thesis was to examine the way communication affects pregnancy care for refugees. Two of my interviews with status holders required a translator which adds an 'extra layer of interpretation to

the data analysis' (Briscoe & Lavender, 2009, p. 22). It is possible that vital information was lost during these interviews, and it is suggested to use the original Arabic transcriptions from my interviews with status holders to examine any information lost (Gewalt et al., 2019). Despite limited funds for the EGALITE project, it is recommended that they explore the possibility of incorporating original transcripts to their data collection. I had a pleasant experience while using Fatima as an interpreter for the status holder participants, however Julia and I could have received a 'reduced rendition' (Dam & Schjoldager, 2017, p. 175). A reduced rendition occurs when an interpreter has difficulty remembering information or leaves out bits of information that they deem unimportant (Dam & Schjoldager, 2017, p. 175). As a result, we could have missed important data contributing to this research.

Secondly, throughout literature regarding healthcare experiences of refugees, asylum seekers, immigrants and status holders are often lumped together into one category: 'migrants' (Faire et al., 2020, p. 18). During this study, I too put asylum seekers and status holders into one category. It became clear during this research that the experiences of status holders in the Netherlands versus asylum seekers are not always directly comparable because of the different rules regarding their access to interpreters and associated with the COA. Furthermore, it became apparent that not all asylum seekers or status holders had one 'universal' experience. Their pregnancy experiences varied across backgrounds, language skills, support from social network and economic means. Therefore, it may be beneficial to focus on a specific category such as country of origin for asylum seekers or status holders (Oscarsson & Stevenson-Ågren, 2020). Taking this into consideration, it may be prudent to conduct separate studies examining the experiences of status holders in the Netherlands versus asylum seekers to gain a well-rounded, thorough analysis of pregnancy care for refugees.

Thirdly, all the midwives included in this study (besides one), were of Dutch origin. Midwives hold a unique skill set and knowledge base for working with women in all different backgrounds. However, acknowledging that even one interview with a midwife whose background was non-Dutch showed that her experience working with refugees was noticeably different than other midwifes. Therefore, it is suggested that future studies in this field of research should focus on recruiting midwives who speak several languages and have migration backgrounds to offer distinctive insight to providing care for refugees (Lepalla et al., 2020).

Lastly, as Monohar et al. argues, it is important to consider 'insider / outsider'

positionality when researching for cross-cultural and sensitive research (2017, p. 1). Throughout this research and thesis writing process I self-reflected on my positionality. However, it is inevitable that to some extent my own beliefs, values, and opinions have influenced the data analysis (Manohar et al., 2017, p. 2). This research involved sensitive topics and a more vulnerable population, therefore I tried to avoid any unethical situations. For EGALITE's future research I would recommend interviewers to have a list with supportive individuals or organizations that specialize in mental health in the event that interviews trigger traumas. By discontinuing my interview with Hani, I hoped to gain trust with my participant and show that I had her best interest at heart. However, I wish I could have done more to support her (Bradley, 1992, p. 437).

6.3 Methodological issues & implications

A blind spot in my methodology, namely during several interviews with status holders, was that because women could compare Dutch pregnancy care to their country of origin, Dutch pregnancy care was deemed to be particularly 'good.'

Recruiting refugees was by far the hardest aspect in conducting this research. It also shows in my data set as the proportion of midwives to refugees is unequally skewed. Seeing that EGALITE's research is associated with a well-known hospital in the Netherlands, and the project is rooted in the 2018 Minister of Health's initiative 'A promising start,' the methodology could be seen as intimidating to prospective participants. In our information sheets (See Appendix 4) the language and terminology used may have attributed to a lack of success in recruitment. For example, EGALITE was required to inform participants that as a medical study, EGALITE must keep a participant's information for 15 years. Although this data is stored in a safe and secure manner, this could have intimidated women from participating. Moreover, as I experienced during one of my interviews with a participant who started to get emotional, it is the researcher's responsibility to do 'no harm' (Block et al., 2013; Bloom, 2010) while working with refugees which is the reason why I discontinued the interview. As expressed by experiences from midwives, any type of interview can trigger stress and trauma for refugees who must go through intensive interviews in the IND process. Therefore, it is suggested that for future research in this field, researchers must reflect on their demeanor during interviews to avoid 'probing' questions and pay close attention to questions that may trigger traumas (Muraglia et al., 2020).

Lastly, it was necessary to recruit potential participants through someone that women trust. The only reason I was able to interview refugees was through the help of Stichting Nieuw Thuis in Rotterdam to find status holders, and through the help of a doula of two-asylum seekers. The foundation and the Doula took on the role of 'middleman' for my research partner and me. They could 'vouch' for us and convey to the women that we would not exploit their information, share their personal information anywhere, or generally do harm. It can be seen that in the eyes of refugees, my research partner and I are seen as the 'colonizer' and inadvertently influence their trust in our altruistic motives (Achiume, 2019; Tolsma et al., 2021). Moreover, this thesis shows that access to communication resources was confined to language (Blommaert et al., 2006, p. 42). To gain more well-rounded data, it would have been beneficial to include participant information sheets in several different languages to reach a wider audience of refugees, as we restricted ourselves to recruiting refugees who only spoke English, Arabic, or Dutch.

6.4 Practical implications for healthcare policy and practice

One of the significant implications for future healthcare policy change is midwives need to pay attention to the 'taken for granted aspects' of language (Briscoe & Lavender, 2009, p. 22). Meaning, as seen in this research, a woman can present as though she understands what is going on and shake her head yes, however, midwives need to make an effort in being responsive to non-verbal cues of refugee woman to create an encouraging 'care partnership' (Bauman et al., 2003). In order to address the lack of quality interpreting services, migrant and refugee Dutch health advisor Simone Goosen has initiated the campaign 'Language should not be an obstacle right? Interpreters return to healthcare, please.'[54] This initiative, part of the Johannes Wier Foundation for healthcare and human rights, is a practical solution for refugees (particularly status holders) who do not have access to free interpreters during pregnancy care interactions. The findings from this thesis support Simone Goosen's perspective that without proper interpreting services the human right to good care is violated (Goosen, n.d.)

This research underscores that experiences between asylum seekers and status holders differ considerably. As discussed in the findings chapters, asylum seekers have access to free

[54] Translate from Dutch: Taal mag toch geen obstakel zijn? Tolken terug in de zorg, alstublieft

interpreting services while status holders do not. As such, future studies, including EGALITE, should avoid lumping together ‘asylum seeker’ and ‘status holders’ because their access to healthcare resources are different. Subsequently, their experience during pregnancy is also different. Many factors influence a woman’s pregnancy; country of origin, economic means, asylum journey, language proficiency, the list can go on (van Loenen et al., 2017). Therefore, it is not enough to categorize pregnant refugees under one domain. It is suggested that researchers conduct multiple studies focusing on one factor such as ‘country of origin’ or ‘language’ proficiency to uncover the necessary pregnancy care needs.

Based on testimonials from midwives, it would benefit refugees and midwives to receive cultural competency training (Johnsen et al., 2021). Cultural competency training is needed so that healthcare providers can avoid stereotyping refugees and instead respect cultural and traditional practices (Faire et al., 2014, p. 19). The findings in this thesis and the Hasnain et al. (2011, p. 79) study underscore the importance of adopting a PCC approach to care for patient populations where it is difficult for healthcare professionals to provide culturally appropriate care. As such, midwives should continue implementing aspects of PCC to consider the social, emotional, and psychological needs of refugees (Owens et al., 2016, p. 129); however, there needs to be a deliberate effort in preventing the ‘othering’ during care interactions. This is also supported by the Svenberg et al. (2011) study recognizing Somali refugees’ feelings of ‘being unwelcomed’ (p. 699) into the Swedish healthcare system. Therefore, cultural competency training can help healthcare providers while caring for patients with different cultural, religious, and linguistic backgrounds.

Lastly, previous literature suggests that while providing pregnancy care for refugees, it may be beneficial to incorporate the use of a ‘befriender” (McCarthy & Haith-Cooper, 2013; WHO, 2020). The WHO suggests that when women have a ‘trusted companion’ during childbirth, their emotional and physical health outcomes improve (WHO, 2020**).** More specific literature in maternal care for refugees suggests that a **‘**befriender,’ who are asylum-seeking and refugee mothers themselves, receive training to provide support and guidance to other refugee patients. The benefits of implementing a system of befrienders are their proficiency in other refugees’ first languages, an understanding of a patient’s social and cultural background (an area where healthcare providers fall short) and an overall understanding of the difficulties refugee patients face while becoming a mother (McCarthy & Haith-Cooper, 2013). Implementing these changes

can lower the worrying perinatal statistics (EGALITE proposal, 2020) and positively impact a refugee's overall pregnancy experience.

6.5 Conclusion

If this research thesis has taught me anything, it is that every single woman deserves to feel supported and entitled to excellent, safe, and trustworthy pregnancy care regardless of their background. Effective communication is crucial in providing pregnancy care that follows the WHO's guidelines (See Appendix 1. Figure 3.). Although I had witnessed moments when good communication between a refugee and a midwife was achieved, I have also seen that it is challenging to achieve effective communication due to trust issues and language barriers in this field of care. Although layered with different complexities, I discovered that this type of pregnancy care is wonderful when both healthcare providers and refugees can form a partnership that focuses on tailored, holistic pregnancy care specific to the woman's needs. Several midwives in this study, like Tess, Elin and Yara, achieved beautiful care by asking women 'what they want,' 'what they need' by focusing on their patient's unique and individual backgrounds. In this thesis, I have shown that pregnancy care interactions between midwives and refugees are strongly influenced by communication, trust, and access to healthcare resources. My analysis focuses on how verbal and non-verbal communication, which includes and goes beyond an exchange of information, affects the overall experience of a pregnant refugee in the Netherlands. I primarily used Briggs' 'communicative justice' (2017) to analyze both noticeable and nuanced effects of communication during pregnancy consultations or surrounding the pregnancy care of a refugee. I have shown that external socio-political dialogue influences the ability of refugees and midwives to form a trusting partnership during pregnancy care. While a focus on PCC illuminated midwives' eagerness to use and positively understand a woman's context, a PCC lens also pointed to how a focus on 'difference in the background' can produce spaces of 'othering,' therefore harming a refugee's pregnancy experience.

Moreover, this thesis confronts the fact that despite refugees' lack of citizenship status in the Netherlands, this population of women still has a fundamental *human right* to quality pregnancy care. As one of the first research studies in the field to examine pregnancy care interactions for refugees, this thesis is a small stepping stone in providing insight into how the Netherlands can fix problems in pregnancy care for refugees. Too often are researchers,

stakeholders, and healthcare providers stuck with myopic perspectives and forget that many of these women have escaped wars, violence, and catastrophes to find safety for themselves and their families. I hope that this research study is the first of many to examine how the Dutch healthcare system can best support pregnant refugees to ultimately provide good and quality care for both women and their unborn children.

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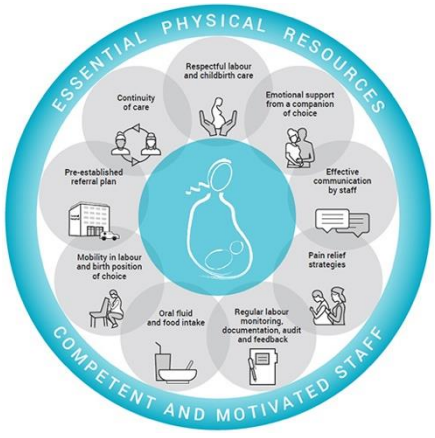
8. Appendix

Appendix 1. Figure 3



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Appendix 2. Figure 4

Tabel 1. Definities van de negen zorgpaden

Low risk A	gezonde nullipara
Low risk B	gezonde multipara
Low risk C	zwangere met aandachtspunten, bijvoorbeeld diabetes-screening
Low risk D	gezonde zwangere, eigen wens tweedelijnszorg
Medium risk A	Eerstelijnszorg met 1 à 2 consulten in de tweede lijn; bijv. bij fluxus post partum in de voorgeschiedenis
Medium risk B	Eerstelijnszorg met overname bij 36 wk door de tweede lijn; bijv. bij sectio in de voorgeschiedenis
Medium risk C	Tweedelijnszorg; bijv. bij pre-existente hypertensie
High risk A	Tweedelijnszorg door de perinatoloog; bijv. DCDA gemellizwangerschap
High risk B	Tweedelijnszorg door de perinatoloog; bijv. MCDA gemellizwangerschap

Jongmans, L. J. G., Verhoeven-Smeijers, C. J. M., Wijnen, H. A. A., & van Runnard Heimel, P. J. (2019). Definities van de negen zorgpaden. *Waar, en van wie ontvangt de zwangere haar zorg?*

Informatiebrief EGALITE onderzoek

Beste mevrouw,

Wij vragen u vriendelijk om mee te doen aan het EGALITE onderzoek van het Erasmus Medisch Centrum (Rotterdam). U besluit zelf of u wilt meedoen. Voordat u het besluit neemt, is het belangrijk om meer te weten over het onderzoek. Daarom krijgt u deze informatiebrief.

Wie zijn wij?
Julia Tankink is arts en onderzoeker. Sterre van Ede is student (medische antropologie). Samen met andere onderzoekers, artsen en verloskundigen werken wij aan het EGALITE onderzoek. U kunt ons altijd mailen of bellen over het onderzoek. U vindt onze contactgegevens onderaan deze brief.

Waarover gaat het onderzoek?
Uit eerder onderzoek blijkt dat zwangere vrouwen en hun baby's in asielzoekerscentra (AZC) vaker problemen hebben dan Nederlandse vrouwen. Het doel van EGALITE is om te leren hoe we de zorg voor zwangere vrouwen in AZC in Nederland beter kunnen maken. Als eerste willen we de situatie van zwangere vrouwen in AZC beter begrijpen. Daarom gaat dit onderzoek over de ervaringen en gevoelens van zwangere vrouwen die in een AZC wonen. We willen ook graag meer weten over de interacties tussen zorgverleners en zwangere asielzoeker vrouwen.

Wilt u meedoen?
U bent een zorgverlener voor zwangere asielzoeker vrouwen in een AZC. Daarom willen wij u vragen om mee te doen aan het EGALITE onderzoek. U doet alleen mee als u dat zelf wilt.

Als u meedoet aan het onderzoek willen wij graag met u praten in 1 of 2 gesprekken. In het gesprek stellen wij vragen over uw ervaringen met deze groep vrouwen en uw zorginteracties met hen. Wij vragen ook wat u vindt van de huidige zorg protocol voor zwangere vrouwen die in een AZC wonen in Nederland. Als u een vraag liever niet wilt beantwoorden, is dat geen probleem.

De gesprekken duren maximaal 1 uur. De tijd en de plaats (online mag ook) van het gesprek spreken we in overleg met u af. Er zullen twee onderzoekers bij het gesprek zijn.

Als u het goed vindt, zullen we het gesprek opnemen. Met deze geluidsopname kunnen we het gesprek later opschrijven.

Voordelen en nadelen van meedoen
U heeft zelf geen direct voordeel als u meedoet aan dit onderzoek. In de toekomst kan het onderzoek meehelpen om de zorg voor zwangere vrouwen (die asiel hebben gevraagd of gekregen) in Nederland beter maken. Het nadeel van deelname is dat het u tijd kost.

Uw keuze
Uw deelname aan dit onderzoek is helemaal vrijwillig. U bepaalt zelf of u wilt meedoen of niet. Als u niet wilt meedoen, heeft dat geen gevolgen voor u en uw baan als zorgverlener.

Als u mee wilt doen aan het onderzoek, kunt u later altijd kiezen om toch niet meer mee te doen. U hoeft nooit te vertellen waarom u niet meer wilt meedoen.

Uw gegevens
De opnames en geschreven gesprekken worden vertrouwelijk behandeld en op een veilige plek opgeslagen. Deze gegevens worden alleen gebruikt voor het EGALITE onderzoek. De onderzoekers mogen de resultaten van het onderzoek bekend maken, maar nooit uw naam of andere persoonlijke gegevens noemen. Uw identiteit blijft dus geheim.

De enige personen die uw gegevens kunnen zien zijn:
- de onderzoekers van het EGALITE team;
- de leden van de commissie in het ziekenhuis die het onderzoek heeft goedgekeurd;
- de bevoegde medewerkers van de Nederlandse Inspectie voor de Gezondheidszorg.

Van de Nederlandse wet moeten wij uw gegevens 15 jaar bewaren op een veilige plek. Als u het niet goed vindt dat wij uw gegevens 15 jaar bewaren, kunt u niet meedoen aan dit onderzoek.

Wij zullen snel contact met u opnemen. Als u dat wilt, zullen we alle informatie nog een keer goed uitleggen. Misschien heeft u nog vragen. Wij zullen uw vragen zo goed mogelijk beantwoorden. Als u alle informatie goed begrepen heeft, kunt u ons vertellen of u wel of niet wilt meedoen aan het onderzoek. Als u besluit dat u wel wilt meedoen, dan bespreken we met u hoe het verder gaat.

Bedankt voor het lezen van deze brief!

Met vriendelijke groet,

De onderzoekers van EGALITE
Julia Tankink | e-mail j.tankink@erasmusmc.nl | Tel.nr. 0614329842
Sterre van Ede | sterrevanede@hotmail.com | Tel. nr. 0682225561

Ook namens de andere onderzoekers van het EGALITE team:
Peggy van der Lans (gynaecoloog)

Dr. Hanneke de Graaf (verloskundige en directeur van het geboortecentrum in Rotterdam)
Prof. Dr. Arie Franx (professor in verloskunde)

Appendix 4. Information sheet: Refugees

Information sheet EGALITE research project

Dear Madam,

We kindly ask you to participate in the EGALITE study of the Erasmus Medical Center (Rotterdam). You may decide whether you would like to participate or not. Before making this decision, it is important to know more about the research. That is why you are receiving this information letter.

Who are we?
Julia Tankink is a doctor and researcher. Sterre van Ede is a student (medical anthropology). Together, we are working on the EGALITE study along with other researchers, doctors, and midwives. You can always e-mail or call us about this research. You can find our contact details at the bottom of this letter.

What is this research about?
Previous research shows that pregnant women and their babies who came to the Netherlands as refugees more often have problems than Dutch pregnant women. The goal of EGALITE is to learn how we can improve the care for pregnant refugees in the Netherlands. First, we want to better understand the situation of pregnant refugees in the Netherlands. That is why this research is focused on the experiences and feelings of pregnant women who came to the Netherlands as refugees. We would like to know what these women think of maternity care in the Netherlands.

Would you like to participate?
You are pregnant or you were pregnant while you were living in an asylum seekers' center, or while you just received a residence permit in the Netherlands. That is why we would like to ask you to participate in the EGALITE study. You may participate only if you would like to.

If you participate in the study, we would like to talk to you in 1 or 2 conversations. During the conversation(s) we will ask you questions about your pregnancy in the Netherlands. We will also ask what you think of the care for pregnant women in the Netherlands. If you prefer not to answer a question, that is no problem.

The conversations will last at maximum 1 hour. We will agree on the time and place of the meeting according to your preferences. There will be two researchers and an interpreter at the interview. If

you would like someone else to join the conversation (for example your husband), that is of course possible.

If you agree, we will record the conversation. With this sound recording we will write down the conversation later.

Advantages and disadvantages of participating
You yourself have no direct benefit if you participate in this study. In the future, this research can help improve care for pregnant women (who have applied for or received asylum) in the Netherlands. The disadvantage of participating is that it will take up some of your time.

Your decision
Your participation in this study is completely voluntary. You decide whether you want to participate or not. If you do not want to participate, this will not affect the care you will receive during your pregnancy.

If you want to participate in the study, you can always choose not to participate again later on. You never have to tell us why you want to stop participating.

Your data
The recordings and written conversations are treated confidentially and stored in a safe place. This data is only used for the EGALITE study. The researchers may disclose the results of the research but will never state your name or other personal information. We will do our very best to keep your identity secret.

The only people who can see your data are:
- The researchers of the EGALITE team;
- The members of the committee in the hospital that approved the study;
- The authorized employees of the Dutch Health Care Inspectorate.

Dutch law requires us to keep your data in a safe place for 15 years. If you do not agree with keeping your data for 15 years with us, then you will not be able to participate in this study.

We will contact you shortly. If you wish, we can explain all the information again. You may still have questions. We will answer your questions as best as we can. If you have understood all the information correctly, you can tell us whether or not you want to participate in this study. If you decide that you want to participate, we will discuss with you how to proceed.

Thank you for reading this information sheet!

Kind regards,

The researchers from EGALITE

Julia Tankink | e-mail j.tankink@erasmusmc.nl | Tel.nr. 0614329842
Sterre van Ede | sterrevanede@hotmail.com | Tel. nr. 0682225561

Also on behalf of the other researchers of the EGALITE team:
Peggy van der Lans
Dr. Hanneke de Graaf
Prof. Dr. Arie Franx

Appendix 5. Informed consent: Refugees

Informed consent procedure prior to participation EGALITE – qualitative study (oral)
1. After receiving the PIF, the reflection period and answering questions, the participant will indicate that she wishes to participant in the research.
2. Make an appointment for an IC procedure, Photovoice explanation session and/or interview.
3. During an appointment: ask for permission to make an audio recording of the conversation
4. Start recording
5. Read the participant information form
6. Check whether the intended participant still has questions; answer any outstanding questions
7. When all questions have been answered, read the text below

It is important that we are sure that you are participating in this study voluntarily. That is why I will now read this aloud so that you can agree to participate

Would you repeat with me every time you agree with what I have just said?

Today (date), I declare, (name), that I have understood the information about the EGALITE study.

(Let them repeat)

I had the opportunity to ask questions about the study. My questions have been sufficiently answered.

(Let them repeat)

I've had enough time to consider whether I want to participate.

(Let them repeat)

I understand that I have no obligation to participate in this study.

(Let them repeat)

I understand that I have the right to withdraw at any time without having to explain why.

(Let them repeat)

I agree to participate in this study.

(Let them repeat)

I give permission for the collection of my data by the persons as described in the information letter.

(Let them repeat)

I give permission to EGALITE to keep my data for 15 years after the end of this research.

(Let them repeat)

I give permission for the use of data (namely the photos that I have chosen and conversations that are conducted with me) for the purposes described in the information letter

(Let them repeat)

Now we can begin!

8. Stop recording, start new recording for the interview.