

# CONGENITAL SYPHILIS PREVENTION IN COLOMBIA

MULTIPLE ONTOLOGIES, SILENCES, ABSENCES AND COLLATERAL  
REALITES

Submitted by

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To the University of Exeter

as a thesis for the degree of Doctor of Philosophy in Anthropology

February 2024

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## DEDICATION

In loving memory of my dad, José Saúl. To my mom, Ana Maria. Thanks for teaching me to persevere and follow my dreams.

## ACKNOWLEDGEMENTS

I would like to express my deepest appreciation to my Supervisors, Professor Mike Michael and Dr Hannah Farrimond, for their valuable insights, patience and collaboration throughout this experience. I am also extremely grateful to Colfuturo, the Ministry of Science and Technology of Colombia (MinCiencias) and the University of Exeter for their scholarships. I could not have undertaken this journey without the guidance of Luisa Consuelo Rubiano, who invited me to research on Congenital Syphilis while we were working at CIDEIM.

I am also grateful to the study participants for their time and for sharing their experiences with me. Many thanks to the Secretary of Health of Quibdó, Dirección Territorial de Salud de Caldas, Corporación Sagrada Familia in Manizales, and Traditional Midwives Association in Chocó (ASOREDIPARCHOCÓ). I would like to acknowledge my classmates and staff from the Department of Philosophy, Sociology and Anthropology, Egenis and the Welcome Centre for Cultures and Environments of Health, who inspired me.

Words cannot express my gratitude to my family and friends for their help and support, even during the darkest times. Special thanks to Ana Maria Jaramillo de Estrada, Rodrigo Estrada, Santiago Estrada, Carlos Felipe Estrada, Clara Ramirez, Liliana Arango, Juan José Estrada, Tomás Estrada, Lucia Estrada, Isabel Estrada, Maria Helena Estrada, Julian Ortiz, Lizzie Müller, Violeta Henao, Ana Jaramillo, Clodomir Santana, Beatriz Arellano, Sima Farokhnejad, Dunia Urrego, Barend van Maanen and Yûnis Abakay.

## ABSTRACT

Why is that a preventable disease is not being prevented, or at least, not being prevented as expected? That is the case for Congenital Syphilis (CS), the transmission of Syphilis from mother-to-child in Colombia. Despite several efforts made by public health authorities through the implementation of Clinical Practice Guidelines (CPG) in 2014, there has not been a significant reduction in the incidence of CS in Colombia, which has become more acute during the COVID-19 pandemic.

In this study, I argue that not acknowledging other ontologies (realities) besides those from science and “experts” is one of the main problems for CS prevention. In Quibdó, Manizales and Riosucio (Colombia), where this study is conducted, several ontologies are enacted in a bundle of practices that not only clash, contradict and cooperate, but also make CS appear and disappear at certain moments, places, and for some people.

To address these issues, data was collected using online methods such as document analysis, interviews, Online Asynchronous Focus Groups (OAFG) and diaries with mobile phones or WhatsApp (January – August 2021) with healthcare workers and administrators, traditional midwives, pregnant women or recent mothers and their partners (Indigenous, Afrodescendants, migrants, Internal Displaced people).

Through the multimodal and apparently fragmented-discontinuous data, I uncovered silence, absence and discontinuity practices related to diverse care assemblages, stigmas and taboos. Those practices challenge the assumption that more knowledge and awareness regarding the CPG, and individual and behavioural measures, would be effective for CS prevention.

It is argued that CS prevention as a matter of care requires the integration of diverse caring assemblages (that incorporate biomedicine, traditional medicine, midwives, religion, curanderismo and online resources) in order to address taboos and stigmas, as well as silence and absence practices. This suggests the need for the local, regional, national and international coordination of practices in order to stop configuring the neglect of CS.

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## AUTHOR'S DECLARATION

The material contained within this thesis is original work conducted by the author. The following communications and publications are based on empirical data collected as part of this research project but not from the thesis.

### Peer-Reviewed Publications

Estrada-Jaramillo, A., Michael, M. and Farrimond, H. (2022) 'Absence, multiplicity and the boundaries of research? Reflections on online asynchronous focus groups', *Qualitative Research*. doi: 10.1177/14687941221110169

### Conferences

Estrada – Jaramillo, A. 2024a. "Congenital Syphilis prevention in Colombia: Multiple Trajectories and Temporalities" Society for Latin American Studies Conference. University of Amsterdam July 1 – 3rd.

\_\_\_\_\_. 2024b. Poster "Congenital Syphilis prevention in Western Colombia". Understanding Life in a Changing Planet. Egenis Conference. University of Exeter April 17 - 19th.

\_\_\_\_\_. 2023. "Online Research Methods: Situating and negotiating ethical principles in sensitive topics research ". Research Ethics Conference. University of Bath July 6 - 7<sup>th</sup>.

\_\_\_\_\_. 2021. "Situational ethics in pandemics: issues with using online messaging apps in the context of sensitive topics in Colombia ". Research Ethics Conference. University of Exeter June 25<sup>th</sup>.

## ABBREVIATIONS

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>ANT</b>	Actor Network Theory
<b>ASOREDIPARCHOCO</b>	Traditional Midwives Association of Chocó
<b>CIDEIM</b>	International Centre for Training and Biomedical Research
<b>CLIA</b>	Chemiluminescence Immunoassays
<b>CPG</b>	Clinical Practice Guidelines
<b>CPR</b>	Cardiopulmonary Resuscitation
<b>CS</b>	Congenital Syphilis
<b>DANE</b>	National Administrative Department of Statistics
<b>ELN</b>	National Liberation Army
<b>EPS</b>	Healthcare service administrators
<b>FARC</b>	Revolutionary Armed Forces of Colombia
<b>FOSYGA</b>	Solidarity and Guarantee Fund
<b>FTA - ABS</b>	Fluorescent Treponemal Antibody Absorption
<b>GS</b>	Gestational Syphilis
<b>HIC</b>	High Income Countries
<b>HIV</b>	Human Immunodeficiency Virus
<b>INS</b>	National Institute of Health - Colombia
<b>IPS</b>	Healthcare service provider
<b>LMIC</b>	Low Middle-Income Countries
<b>MHA - TP</b>	Microhemagglutination Assay for Antibodies
<b>MTCT</b>	Mother to Child Transmission
<b>NGO</b>	Non-Governmental Organisation
<b>NTT</b>	Nontreponemal Test
<b>OAFG</b>	Online Asynchronous Focus Groups
<b>PAHO</b>	Pan American Health Organisation
<b>RPR</b>	Rapid Plasma Reagin
<b>STD</b>	Sexually Transmitted Disease
<b>STS</b>	Science and Technology Studies
<b>TP - EIA</b>	Treponema Pallidum Enzyme Immunoassay
<b>TP -PA</b>	Treponema Pallidum Particle Agglutination Assay
<b>TPA</b>	Treponema Pallidum Antibodies
<b>TPHA</b>	Treponema Pallidum Hemagglutination Assay
<b>TT</b>	Treponemal Test
<b>UK</b>	United Kingdom
<b>US</b>	United States of America
<b>VDRL</b>	Venereal Disease Research Laboratory
<b>WHO</b>	World Health Organisation

## CHAPTER 1 INTRODUCTION

Diseases, illnesses, and ailments appear and disappear. They gain more attention or become more relevant during specific periods and for certain people, according to some knowledges and expertise, in certain places, and to some experiences.

This research is about a disease that has been around for a long time. A disease that appears and disappears, with consistent discontinuity and fragmentation: syphilis.

I will not discuss the origin of the disease or its physical signs, which were, for many years, also signs of stigma; nor am I going to emphasise the increase in syphilis cases worldwide – although some discussion of this inevitably present in this research. Rather, I am going to discuss the prevention of mother-to-child transmission (MTCT) – namely, congenital syphilis (CS) – in two regions of western Colombia during the COVID-19 pandemic. There are a number of reasons for this focus.

Syphilis is a sexually transmitted disease (STD) caused by the *Treponema pallidum* bacteria. If a pregnant woman is diagnosed with syphilis, this is “gestational syphilis” (GS). The disease can then be transmitted to her baby, unless she and her sexual contact(s) receive adequate treatment. Therefore, CS is considered a preventable disease, as MTCT can be avoided.

However, CS is one of the “neglected” diseases – or diseases of poverty – as classified by the World Health Organization. The United Nations (UN) Millennium Development Goals 2000–2015 establish a commitment to eliminate CS, which in practice means a rate of no more than 0.5 cases per 1,000 newborns (Delmiro *et al.*, 2019). Furthermore, the United Nations Sustainable Development Goals established the improvement of maternal and child health as primary goals implicating elimination of CS as part of that goal. While CS has been eradicated in several countries – including Cuba, Belarus, Moldova, Antigua and Barbuda, Bermuda, Malaysia, Thailand, Anguilla, Cayman Islands, Montserrat, St. Christopher, and Nevis (Chen, 2019) – it remains a public health concern in other countries in Latin

America and the Caribbean (Pan American Health Organization, 2014). Colombia has not reduced congenital syphilis incidence (2016–2019), and in some regions there is a high incidence and prevalence, specifically: Chocó, Arauca, Guainía, Atlántico, and Amazonas (Instituto Nacional de Salud, 2021).

In 2013, clinical practice guidelines (CPGs) for the prevention of MTCT of syphilis were developed by the National University of Colombia, with the collaboration of experts (paediatricians, obstetricians, gynaecologists, dermatologists, infectiologists, among other medical specialities), the Ministry of Health, and the United Nations Population Fund (UNFPA) (Ministerio de Salud y Protección Social, 2014a). The guidelines recommend the best processes and procedures according to available scientific evidence and made several changes to the procedures previously in place. Among these changes were the definitions of GS and CS; the establishment of a new algorithm for diagnosis; the use of treponemal rapid tests, same-day diagnoses, and treatment; and the provision of treatment for a pregnant woman's partner or sexual contact without the need for a test.

It was expected that the implementation of the guidelines would contribute to a reduction in MTCT. However, the results have not met expectations. Moreover, during the COVID-19 pandemic, rates actually increased, passing from a CS incidence of 1.9 cases per 1,000 newborns in 2019 to 2.8 in 2020 and 3.1 in 2021 (Instituto Nacional de Salud, 2021).

Therefore, one of the main aims of the present research is to question why a preventable disease is not being prevented. Why is CS not being prevented in these regions of Colombia? Or, at least, why is its rate of incidence not declining as expected?

Now, it might seem that this case study is less timely, important, and 'cutting-edge' than studies of COVID-19, non-transmissible diseases (e.g., diabetes), or even malaria. Furthermore, this study does not deal with innovative biomedical interventions or the most recent approaches to disease prevention and control. However, a lot of what is vital for disease prevention and primary care in relation to those diseases is also a focus of the present research. As such, I suggest that this research is important because its contributions go beyond the 'niche' of CS

prevention in Colombia. To explain, I will set out how this research project was conceived.

A few years ago, I was working as a research assistant at the International Centre for Training and Biomedical Research (CIDEIM) in Colombia. There was a project dedicated to identifying hotspots of dengue transmission through entomological, epidemiological, and social variables in three cities in Colombia and designing a web system that could inform interventions. In 2016, collaborating with the CIDEIM syphilis team and the Secretary of Health in Cali (Colombia) on a project analysing the implementation of the CS CPGs, I conducted fieldwork in two primary care settings.

As a qualitative researcher, I identified the barriers to and facilitators of the implementation of the CPGs. Although there were financial, administrative, social, and political difficulties (within and beyond the CPGs), the correct implementation of the guidelines was considered the main way of contributing to CS prevention.

Those experiences showed me how much disease-prevention work rests on assumptions of a lack of knowledge and information on the part of publics, by demands for individual responsibility to accomplish the prevention measures, and the prioritisation of scientific knowledge and disregard of all other types of knowledge and expertise. Moreover, in the case of CS, administrative difficulties in the health care system and failures in sex education seemed to be particular impediments in the prevention process.

This research then explores prevention practices regarding CS in two regions of Colombia (one of which has been constantly marginalised) as a way to illuminate and contribute to the reduction of CS in Colombia.

Furthermore, the importance of this research goes beyond a contribution to the reduction of CS in Colombia. Academic discussions in public health, the sociology of health, and science and technology studies (STS) are also addressed by this case study. I will refer to some of these here and further develop these discussions in the second chapter.

Over the last few decades, some public health practitioners have established a separation between individual and collective interventions of health and the public and private spheres, emphasising “patient choice” (Petersen and Lupton, 2000). According to this perspective, prevention campaigns are directed at individuals who are able to make choices about their health, particularly in their private space. The campaigns assume that patients are effectively equal in terms of their needs and access to healthcare services, regardless of any social inequalities. They assume that subjects will know what they want and need, once the information has been provided. Accordingly, public health campaigns are directed at lifestyles because it is assumed that individuals can change their behaviour in light of new, relevant information. These assumptions become problematic when one considers individuals from different backgrounds in multicultural settings.

Scholars of medical sociology have provided critical insights into the biomedicalisation of disease, evidence-based medicine, risk, and stigma. Researchers have highlighted how institutional, political, and social aspects define a disease and how it is treated (Petersen and Lupton, 2000; Timmermans and Epstein, 2010). However, an emphasis on biomedicine and its institutional dominance as analytical tools is not always adequate in contexts of diverse healing knowledge and practices.

By comparison, some researchers in medical anthropology have highlighted the importance of incorporating diverse approaches and contexts into discussions of health and illness and questioned some of the assumptions associated with a focus on science and biomedicine. For instance, some have launched discussions about medical pluralism, where diverse healing practices are combined to investigate the tensions and negotiations between global and local knowledge and expertise surrounding healing practices (Hsu, 2017; Trnka, 2021).

Similarly some scholars STS have shown the importance of incorporating the perspectives of the marginalised into consideration of the diagnosis and treatment of disease. Doing so facilitates an engagement with different kinds of medical objectification, commodification, and standardisation (Timmermans and Almeling, 2009). Furthermore, by seeing care as central to healing practices, STS scholars

show it to be contextual, situated, and emergent (Schillmeier, 2014). Thus, to consider care is to be attentive to both the particularities of daily activities, in contrast to standards and general principles, and to the ways in which these local practices mediate standards and general principles (Tronto, 1993; Barnes, 2013; Schillmeier, 2014).

Some scholars, including those working on sex, gender, and technology in STS, have highlighted how the social relations of sex, gender, and race shape specific experiences, usually reflecting the ways in which people are marginalised (Crenshaw, 1991; Fishman *et al.*, 2017). For my research participants, alongside sex, race, and ethnicity, other categories that did not necessarily define their identities also become part of their experiences of pregnancy and giving birth, ultimately affecting how they were cared for. For example, whether it was their first pregnancy, their migration status, their mobility in the territories, the territory itself (more or less distant from the capital; urban, rural, or isolated rural), the type of health insurance they held, where they were obligated to look for healthcare, the care practices they used, when they discovered they were pregnant, whether their pregnancy was during the first months of the pandemic lockdown: all of these elements defined the individual's particular experience.

Therefore, situatedness and context are important to any consideration of disease prevention, particularly in relation to the empirical sites studied in this research. Given this, I now introduce some of the specificities of the relevant regions in western Colombia.

#### [A Sketch of the context](#)

Colombia covers 1,141,748 square kilometres, divided into five natural regions (Caribbean, Pacific, Orinoco, Amazon, and Andean) and 32 *departamentos* (i.e., states or counties), each of which has limited autonomy in terms of its finances, management, and policies. According to the 2018 census, there are 48,258,494 inhabitants of Colombia, of whom 1,905,617 identify as indigenous; 4,671,160 as Black -Afro-descendants – Raizal – Palenquero; and 2,649 as *Rrom* (Romani; DANE, 2019a).

Although Spanish is the official language, more than 65 indigenous languages – including two Creole languages, Portuguese and Romani – are also spoken in Colombia. The 1991 Constitution acknowledges Colombia as a multicultural and ethnically plural nation.



*Figure 1*

Colombian Departments

**Map 1.** Colombian Departments. Adapted from “<https://www.colombiaenmapas.gov.co/>” by Ortiz, J (2024). <https://www.colombiaenmapas.gov.co> Retrieved February 20, 2024.

Quibdó and Lloró are municipalities in the region of Chocó. This is a region characterised by high biodiversity, whose economy is based heavily on platinum and gold mining using traditional and non-traditional methods and which produces some crops and a wood industry. It is also one of the poorest regions in Colombia, with



73% of its population not meeting their *necesidades básicas satisfechas* (according to the “Bare Necessities Index”; DANE, 2020). Many of its inhabitants have limited access to public services (education, health, sanitation, etc.). Just 75.8% of homes in the region have access to electricity, 27.8% water, 20.4% sewage connections, and 13.2% internet access (DANE, 2019a). Regarding health care access, Chocó has 96,5% of its population affiliates, of which 9,8% belong to the contributory regime and 89,9% to the subsidiary regime (DANE, 2020).

Most of Chocó's population self-identify as Afro-descendant, but there are also indigenous groups – namely, the Emberá, Tule, Cuna, and Wuanan people. In January 2021, there were also 799 migrants from Venezuela (Romero, 2021).

Quibdó frequently receives displaced people due to armed conflict in other municipalities of Chocó. Since the signing of the 2016 peace agreement with *FARC* (the Revolutionary Armed Forces of Colombia), Chocó has been dealing with a conflict between *ELN* (the National Liberation Army) and the *Urabeños* (the Gulf Cartel) for the control of territories for drug trafficking, human trafficking, and mining. Some of these conflicts have spilled into Quibdó. Some gangs related to the Gulf Cartel have established *barreras invisibles* (mobility restrictions)<sup>1</sup> and engaged in extortion against small shops and businesses (Dickinson, 2022).

As Quibdó is the capital of the department, many people have to travel there for health care. There is only one secondary care hospital in Chocó, and this is located in Quibdó. Furthermore, it is not uncommon for patients and pregnant women from other municipalities, such as Lloró, to travel to Quibdó for health services.

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<sup>1</sup> These restrictions prevent people from being in or travelling through a neighbourhood that is not their own if they do not have a permit from the gang leader who “owns” that territory.

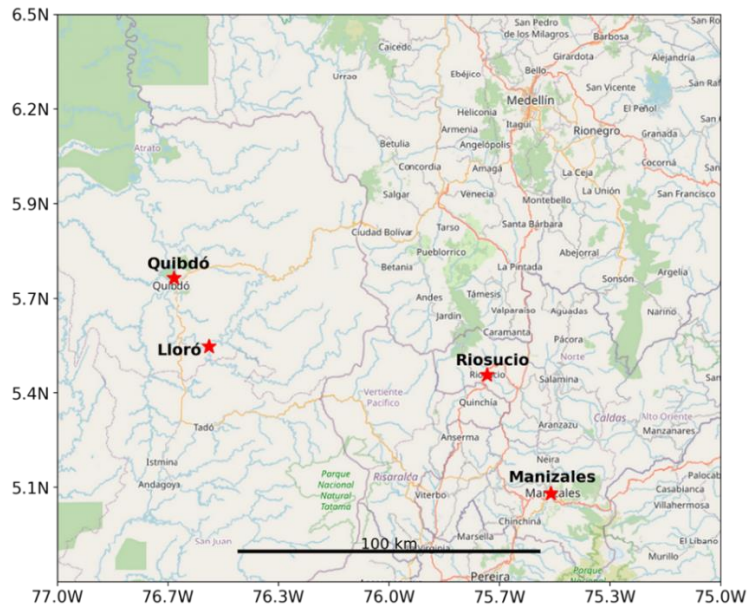


Figure 2

Map of Quibdó and Lloró (Chocó) and Manizales and Riosucio (Caldas). Adapted from “Cartopy: A cartographic python library with a Matplotlib interface”, by Arellano (2022). Chocó is more rural than Caldas and its populations more dispersed.

In contrast, Manizales and Riosucio are municipalities in the region of Caldas. Coffee production is the department's main economic activity, followed by the growing of other crops and mining. Most of its population self-identifies as “without ethnic affiliation”. This category was introduced in the last census (2018) to distinguish between Indigenous people, Black people, and Afro-descendants. However, other categories are used in everyday interactions to indicate racial and ethnic distinctions, such as *mestizo* (mix of white and Indigenous), *mulato* (mix of white and Black), and *blanco* (white).

Of the 395,818 inhabitants of Manizales, 4,036 identify as indigenous, 4,811 as Black or Afro-descendant, and 382,941 as without ethnic affiliation (DANE, 2019b). In Riosucio, there are 48,012 inhabitants, 36,346 of whom identify as indigenous (Emberá Chamí), 242 as Black or Afro-descendant, and 11,196 as without ethnic affiliation. In Manizales, 5.77% of the population does not meet the baseline defined by the Bare Necessities Index, while the figure in Riosucio is 5.76% (DANE, 2019). Overall, there is better access to public services than in other country regions. Electricity is present in 99% of households, water services in 92.1%, and sewage

connections in 83.6%. Some 57.6% of households have internet access, which is close to the national average of 56.5% (DANE, 2020).

In terms of health services, 94.1% of the population is affiliated with the health system, with 56.4% belonging to the contributory scheme and 43.4% to the subsidiary scheme (DANE, 2020).

Several universities in Manizales offer bachelor's degrees in health sciences, and two also offer degrees in medicine.

Although these two regions have clear differences (see Figure 2 above for their geography), both are dealing with high rates of CS and struggling to prevent the spread of infection. Such problems with prevention are more acute in Chocó, as shown in Tables 1 and 2 below.

**Table 1. Gestational syphilis prevalence 2016–2021**

Territory	2016	2017	2018	2019	2020	2021
<b>Caldas</b>	8	9.3	9.9	13.9	16.2	18.5
<b>Chocó</b>	18.8	14.4	13.1	10.3	20.7	32.5
<b>Colombia</b>	6.6	7.9	8.8	11.1	14.1	16.2

*Figure 3*

Gestational syphilis prevalence between 2016 and 2021, by territory. Prevalence rate (per 1,000 newborns and stillbirths). Adapted from reports by the Instituto Nacional de Salud (2016; 2017; 2018; 2019; 2020; 2021).

**Table 2. Congenital syphilis (CS) incidence 2016–2021**

Territory	2016	2017	2018	2019	2020	2021
<b>Caldas</b>	1.14	2.5	1.17	0.96	2.1	2.8
<b>Chocó</b>	6.92	5.37	5.77	0.94	5.2	6.7
<b>Colombia</b>	1.11	1.41	1.51	1.9	2.8	3.1

*Figure 4*

CS incidence between 2016 and 2021, by territory. Incidence \* (1,000 newborns and stillbirths). Adapted from reports by the Instituto Nacional de Salud (2016; 2017; 2018; 2019; 2020; 2021).

An examination of these regions allows us to see how race and ethnicity, as well as rural and urban localities and related inequalities, play a role in the configuration of CS prevention.

Race and ethnicity have been at the core of broader discussions of CS and syphilis. Several analyses have found that Black and Indigenous people have a higher prevalence of syphilis – both gestational and congenital (Cruz *et al.*, 2013; Korenromp *et al.*, 2018; Thomas *et al.*, 1999; Parker *et al.*, 2012; Hogben & Leichliter, 2008). In this context, it is important to note that Indigenous and Afro-descendants tend to be located in the poorest and most rural areas, with the least access to public and health services in Colombia. As Wade (2014) argues, instead of being identified as “risk factors” for CS, race and ethnicity should be viewed as “technologies of belonging” – that is, systems of classification with different meanings and implications that are constantly changing.

As previously mentioned, race and ethnicity are also correlated with access to healthcare services. Thus, it is valuable to look more closely at the characteristics of the Colombian healthcare system to grasp its characteristics and the challenges for the implementation of the CS-prevention clinical guidelines.

#### Colombian healthcare system

Colombia has two types of health insurance: *régimen contributivo* (RC; contributory insurance) for those with payment capacity (mainly people with a formal job contract) and *régimen subsidiado* (RS; subsidised insurance), for those who do not have payment capacity. The RS is funded by the fiscal resources of the government and cross-subsidies from contributory insurance. Some people also acquire *medicina prepagada* (private insurance) to complement the health services that they receive under the RC scheme and to ensure that they receive prompt treatment.

Each municipality applies the survey SISBEN (System for the Identification and Classification of Potential Beneficiaries of Social Programmes), in which those with fewer points become part of the subsidiary regime (RS) and do not have to pay fees for most services (Levels 1 and 2). This category is called *población pobre no asegurada* [not insurance poor population (PPNA)]. It also includes people who are in transition or waiting to have a SISBEN survey, migrants (internally displaced by

armed conflict, international migrants from Venezuela, etc.), and those who are considered victims of the internal conflict (Victims Law 1448 of 2011).

Seven percent of the population does not belong to the RS or RC (DANE, 2020) because they do not have a formal contract under the RC scheme or meet the criteria for the RS. This group must acquire health services by their own means.<sup>2</sup>

The money from taxes and the contributions of RC members is collected by *Fondo de Solidaridad y Garantía*<sup>3</sup> (FOSYGA; the Security and Guarantee Fund), which then distributes the resources to the various entities in charge of the administration of the resources. The *Entidad Promotora de Salud* (EPS; healthcare service administrator) is the entity in charge of the administration and payment of healthcare services. Most EPSs operate in specific regions of the country, with only a small proportion (those with the highest number of patients) operating in the majority of regions. This represents a challenge for patients who have migrated or who have high mobility in the territory.

The EPSs have patients from the RS and RC schemes and establish contracts with *instituciones prestadoras de servicios de salud* (IPSS; healthcare services providers), hospitals, clinics, and laboratories that provide services to the patients. Among those providers are *empresas sociales del estado* (ESEs; state social enterprises), which also cover those healthcare providers that belong to the state but have full autonomy. The ESEs usually provide services for subsidized insurance members.

Some resources from FOSYGA go to the EPSs for services delivered to members of the contributory and subsidised schemes. Others go to municipalities or regions for services for the PPNA and complementary services under the RS. Each EPS receives a fixed payment (*unidad de pago por capitación* [UPC]) for each member

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<sup>2</sup> Either borrowing money from family members or neighbours, looking for “cheaper” healthcare services, or following recommendations from traditional medicine.

<sup>3</sup> Created from Law 100 of 1993 and regulated by Decree 1283 of 1996 to ensure compensation for people under different healthcare insurance schemes (private and public).

regardless of their health status. Some EPSs have many older affiliates, some of whom have high-cost diseases and are reliant on the subsidised scheme.

In Colombia, it is not uncommon for an individual to pass from contributory to subsidised health insurance, or vice versa, or from one EPS to another. This is due to the number of people in informal jobs or with precarious job contracts that can last fewer than six months, as well as residential mobility between villages and cities and the closing down<sup>4</sup> of an EPS, whose beneficiaries then have to be transferred to a replacement.

The FOSYGA and EPS are usually able to identify who belongs to the subsidised scheme and who belongs to the contributory scheme. However, it can take up to 15 days for this information to be accessed by healthcare providers. Due to precarious employment, women frequently move in and out of the subsidised scheme, which means that it often takes time to establish whether a woman can receive attention in a healthcare centre.

The Colombian government has implemented several measures to provide migrants from Venezuela with healthcare services. Those with a special residence permit (PEP) or a temporary protection permit (PPT) can be affiliates of the RC – or the RS, if they do not have payment capacity (Ministerio de Salud y Protección Social Colombia, 2018).

Although healthcare coverage has improved during recent decades (World Bank, 2019), the healthcare system continues to have difficulties with resources, infrastructure, capacity, healthcare workers, and management, particularly in rural areas (Guerrero *et al.*, 2011). It is common for EPSs to delay payments to IPS for health services, and there have been cases of poor management of resources and even corruption (Bernal and Barbosa, 2015).

There are several persistent inequalities in the healthcare system. For instance, as shown by Viafara-Lopez *et al.* (2021), structural inequality is highly related to race

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<sup>4</sup> Some EPS are closed down by the Ministry of Health due to financial difficulties, corruption or an inadequate provision of health services.

and ethnicity in Colombia. As most Indigenous and Afro-descendant people live in the poorest regions in the more-dispersed territories, there remains an element of inequality, despite the strategy of universal healthcare coverage that was implemented to overcome historical inequality (Viafara-Lopez, Palacios-Quejada and Banguera-Obregon, 2021).

Those inequalities are especially prevalent in the context of prenatal care and maternal mortality. A comparison between Chocó and Caldas reveals a maternal mortality rate of more than 100 per 100,000 births in Chocó in 2014, 2019, and 2020. In Caldas, the rate was 30–50 per 100,000 births in 2014 and 2019, increasing to 70–100 in 2020 (DANE, 2021).

In the following section, I will provide an account of how prenatal care is organised and provided and detail some of the limitations encountered during the COVID-19 pandemic.

#### Prenatal care

In Colombia, the CPGs (Ministerio de Salud y Protección Social, 2014a) state that every pregnant woman should ideally start prenatal care before the tenth week of her pregnancy. Antenatal control is performed by a physician or a trained nurse if the pregnancy is not considered risky. When the pregnancy is considered risky, the obstetrician is in charge of performing the antenatal control during weeks 28–30 and 34–36.

Pregnant women are typically expected attend at least 10 antenatal controls before labour if it is her first pregnancy – and seven appointments if it is not. The first prenatal care appointment should last 30 minutes and other appointments 20 minutes. If a pregnant woman begins her prenatal care late (especially after week 26), the appointment should be 40 minutes in duration, during which time all the activities that should have been conducted in previous appointments should be completed.

In addition to the medical record, a *carné prenatal* [prenatal card] should be filled out at the beginning of the prenatal care and at each appointment. Relevant information includes the woman's body mass index, blood pressure, uterine height, test

screening results (HIV, malaria, syphilis, toxoplasmosis, rubella, hepatitis B, group B Streptococcus, blood glucose, haemoglobin), and treatment related to any positive diagnosis or abnormality in the results.

During prenatal care sessions, pregnant women should be monitored regarding their nutrition, mental health, risk of domestic violence, and level of family support. They should also receive information, advice, and referrals for any other services needed.

However, the previous recommendations for prenatal care have not always been followed in Chocó and Caldas, especially during the COVID-19 pandemic. During that time, lockdowns, mobility restrictions, social distancing, fear of attending healthcare settings, and healthcare staff shortages led to a reduction in prenatal care sessions and attendance (Rojas-Botero, Saavedra and Valencia, 2021).

In Colombia, the lockdown started on 25 March 2020 and lasted until 31 August, though some restrictions were lifted earlier to allow for the provision of goods and some services. In the healthcare domain, only emergency services were available during the lockdown. GP and prenatal care appointments were only conducted online during the first two months of lockdown, unless the pregnancy was classified as high-risk. Face-to-face appointments for pregnant women restarted after two months, while appointments and services for the rest of the population remained online.

It is important to highlight that the Colombian healthcare system configures particular ways to access healthcare services and facilitates the combining of multiple care practices beyond biomedicine.

The following section will provide a more detailed introduction to the reality of syphilis in order to clarify the challenges of its treatment and prevention in the Colombian context.

#### [Syphilis – gestational and congenital](#)

The clinical manifestations of syphilis are not always clear. In fact, syphilis has long been called a “silent disease”, as it can go unnoticed for years. Four stages of the



disease have been identified – primary, secondary, latent, and tertiary – each of which has diverse manifestations.

During the primary and secondary stages, painless sores appear on the penis, vagina, anus, rectum, lips, and/or mouth. In the second stage, there is a reddish-brown rash on the palms of the hands and feet, fever, swollen lymph nodes, a sore throat, patchy hair loss, fatigue, weight loss, and muscle aches. During the latent syphilis stage, no symptoms or signs are visible; hence, the disease can go unnoticed for years. In the tertiary stage, syphilis can affect organ systems (the heart, blood vessels) and lead to death. The tertiary stage can happen as long as 10–30 years after the initial infection. Syphilis can also spread to the brain and nervous system (neurosyphilis), the eye (ocular syphilis), and the ear (otosyphilis).

CS appears in babies under two years as an enlarged liver and/or spleen; fever; failure to gain weight; irritability - irritation; and cracking of the skin around the mouth, genitals, and anus; bone abnormalities; and watery fluid from the nose. In older infants, CS symptoms include Hutchinson teeth (peg-shaped and notched teeth), blindness, decreased hearing or deafness, joint swelling, deformity of the nose with a flattened nasal bridge (saddle nose), and clouding of the cornea (the covering of the eyeball).

Due to the difficulties with identifying the clinical signs, syphilis diagnoses have relied heavily on testing. There are treponemal and non-treponemal tests that differ in terms of their costs and the infrastructure and training that they require. Among the non-treponemal tests are rapid plasma reagin (RPR) and venereal disease research laboratory (VDRL), while the treponemal tests include treponema pallidum particle agglutination assay (TP-PA), fluorescent treponemal antibody absorption (FTA-ABS), and others. All of these tests are used according to diagnostic criteria – whether they are used for screening, case confirmation, or treatment follow-up. The main difference between treponemal and non-treponemal tests is that treponemal antibodies can appear earlier than non-treponemal antibodies and remain detectable for life even after successful treatment.

Testing also presents several challenges for syphilis diagnosis. For example, there is a risk of false-negative results. This happens when an RPR test is performed during the first or late stages of syphilis, when there are no antibodies fighting the infection. False positives can also occur in people with tuberculosis, Rickettsia diseases, endocarditis, HIV, malaria, or lupus. False positives can also arise for people who have recently been vaccinated – with the smallpox and COVID-19 vaccines, for example (Centers for Disease Control and Prevention, 2021).

Penicillin is the recommended treatment for syphilis at all stages. One dose is required during the primary, secondary, or early stages of latent syphilis and more than one dose for later stages. All babies born to a mother with GS also receive penicillin.

However, syphilis treatment with penicillin also includes challenges of potential allergic reactions and periodic drug shortages. The WHO note that 41% of countries saw penicillin shortages between 2015 and 2016, and 5% in 2019 (<https://www.who.int/teams/global-hiv-hepatitis-and-stis-programmes/stis/treatment/shortages-of-penicillin>). This tendency has continued into 2023 and 2024, with an imbalance between demand and supplies of penicillin that will have implications for future shortages (Seghers *et al.*, 2024).

CS elimination has been a goal for more than a decade. In an effort to reduce CS prevalence worldwide, the WHO has published several recommendations as a way to provide standards based on evidence. In 2013, Colombia decided to update the 2000 guidelines to introduce contextual particularities. I will now turn to the process by which the clinical guidelines were adapted for the Colombian context, explaining what the guidelines entail and detailing some of their challenges.

#### Clinical practice guidelines

Following the implementation of the clinical guidelines for the management of GS and the prevention of CS in 2000, there was a considerable increase in the number of cases in Colombia. As a result, it was considered necessary to update the clinical guidelines.

Following the Appraisal of Guidelines for Research and Evaluation (AGREE) by a group of experts and postdoctoral researchers at the Universidad Nacional de Colombia, evidence from studies around the world was gathered and curated. The AGREE framework is used to indicate the quality of clinical practice. Following an assessment of the evidence, the key points for GS management and CS prevention were established. As stated in the CPGs, most of the studies and evidence did not meet the criteria to be considered “high” (Ministerio de Salud y Protección Social, 2014a).

However, information regarding patients’ preferences for syphilis treatment was not included, as indicated in the CPG. This absence of information “reflects shame and stigma. No information is available because there are no groups, organisations, or patients’ representatives, as there are for other diseases such as HIV/AIDS and cancer” (Ministerio de Salud y Protección Social, 2014:26, my translation).

A number of workshops and discussions were then held with healthcare practitioners from multiple specialties, as well as nurses, experts from the UN Population Fund, and a patients’ representative. Efforts were made to include healthcare practitioners from other regions outside the main cities (Bogotá, Medellín, and Cali), but most participants were associated with urban settings. To address the difficulties and particularities of healthcare service provision in rural areas, broader participation from other regions and practitioners working in rural isolated areas is fundamental.

Following the expert panels and discussions about the evidence, two main recommendations were established. These were the need for rapid tests (treponemal) at the point of care and same-day treatment with benzathine penicillin 2,400,000 IU (Ministerio de Salud y Protección Social, 2014a). Several indicators were also established: syphilis diagnosis before 20 weeks of pregnancy, the percentage of pregnant women diagnosed during the first prenatal care appointment, the percentage of pregnant women to receive adequate treatment, and the percentage of pregnant women with a positive diagnosis whose sexual contacts have also received adequate treatment.

The CPGs also state that they should be updated in the next three years – or before that time, if more adequate evidence becomes available. However, this has not been

done. Although many healthcare practitioners remain up-to-date with the latest debates and evidence on syphilis treatment and CS prevention, there been no formal update of the clinical guidelines in Colombia.

In addition to advocating the use of rapid tests and the provision of same-day treatment at a point of care, the CPGs establish various other recommendations for GS management and CS prevention, including the following:

- Include a full medical record of all pregnant women who attend prenatal care, including information about their history of sexually transmitted infections (STIs), their risk factors, their previous treatment, and treatment of their sexual contacts.
- Do not give a penicillin-allergy test to pregnant women with positive syphilis diagnoses. Instead, it is suggested to provide more information in the medical record regarding potential hypersensitivity to penicillin and other medications.
- When a pregnant woman with a positive syphilis diagnosis has received her first dose of treatment, she should have a non-treponemal test (VDRL or RPR), reported in dilutions. The result of the non-treponemal test can then be evaluated at the following prenatal care appointment.
- Pregnant women with positive syphilis diagnoses and histories of allergy to penicillin (or other allergic reactions) should receive oral desensitisation for penicillin.
- The same treponemal rapid test should be taken during every trimester, during labour, post-partum, post-abortion, and during the first consultation after labour if it was at home.
- This should be followed up with a non-treponemal test (VDRL or RPR) for pregnant women with positive syphilis diagnoses during every trimester, during labour, post-partum, post-abortion, and during the first consultation after labour if it was at home.
- Sexual health consultations should be conducted with pregnant women and their sexual contacts, with an emphasis on STIs.

- The sexual contacts of pregnant women should be notified by the healthcare service provider after an initial contact has been made by the woman and in line with what she considers the best course of action.
- Do not run syphilis tests on pregnant women's sexual contacts.
- Deliver three doses of benzathine penicillin to pregnant women's sexual contacts (one dose per week).
- Deliver three doses of benzathine penicillin to pregnant women with a reinfection of GS.
- Provide tests to newborns of mothers with GS diagnoses. The treatment for the baby consists of two doses of penicillin G-crystalline or one dose of benzathine penicillin if the mother received adequate treatment.
- Follow-up babies with a CS diagnosis with a non-treponemal test (VDRL or RPR) every 3 months until 12 months.

However, the implementation of the CPGs poses several challenges. The Secretary of Health of Cali and CIDEIM conducted research to identify the barriers to (and facilitators of) implementation of the CPGs in 2016. I will now share some of the lessons learned from that research, in which I participated as a research assistant.

#### [Research on CPG barriers and facilitators](#)

The aforementioned research consisted of a comparison of two prenatal care settings, one of which had implemented the CPGs, including rapid testing at the point of care. The research team analysed the process measures from the clinical charts of women seen in 2015 and compared this with information collected during three months in 2016 (Potes, Rubiano, Ramirez, Tunubala, *et al.*, 2017).

As a qualitative researcher, I conducted interviews with pregnant women, healthcare practitioners, and administrators to identify the barriers to and facilitators of the implementation of the CPGs and, consequently, the prevention of MTCT of syphilis.

Through the fieldwork, it became clear that the implementation of the CPGs was being made difficult by several administrative and legal restrictions, some of which have since been discussed elsewhere (Potes, Rubiano, Ramirez, Tunubala, *et al.*, 2017).

At the time, Decree 412 of 2000 by the Ministry of Health was still in place, mandating the procedures for the prevention and control of diseases considered a public-health concern (HIV and syphilis, for example). Since the new procedures identified in the CPGs were not aligned with the decree, the CPGs were considered to be essentially suggestions, making their implementation more difficult.

Furthermore, healthcare service providers did not have updated codes with which to charge for the services indicated by the CPGs, nor did the guidelines reduce the number of steps needed for authorisation (e.g., tests, diagnosis, treatment), which led to patients being obliged to attend several sites across the city. In addition, primary care settings were not authorised to administer penicillin, including during consultations.

Most EPSs do not provide rapid syphilis tests, due to the restrictions in their existing contracts, nor do they provide treatment to pregnant women's contacts, particularly those who did not belong to the same EPS.

Healthcare service provision is also challenging because it is not centralised. This means that pregnant women must attend different sites across the city for authorisations, appointments, tests, and treatments, as EPS requirements usually include numerous documents and extensive bureaucracy. That leads to delayed services and missed opportunities for adequate antenatal control and disease prevention and control.

Many pregnant women do not know their rights or from whom they can seek help to access healthcare services, which is crucial when migrating to other villages, cities, or neighbourhoods. (This is common, given the level of mobility in this population.) This situation is then more pronounced for rural, Afro-descendant, and Indigenous women; the poorest populations; and migrant<sup>5</sup> women.

At the time the fieldwork was being conducted, physicians were not permitted to prescribe penicillin to pregnant women with syphilis diagnoses outside of an

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<sup>5</sup> By the time the study was conducted (2016) there were not a lot of pregnant women from Venezuela looking for health care services in Cali. However, this situation changed. During the last six years the number of migrants from Venezuela in Colombia has increased considerably.

appointment, due to administrative restrictions. In some cases, a woman had to wait several weeks for an appointment with a physician for prenatal care.

In addition to the administrative restrictions, there was also mistrust and reduced acceptance regarding certain aspects of the CPGs. Many bacteriologists, lab technicians, and other healthcare practitioners did not trust the rapid syphilis test or the rapid HIV/syphilis duo test, being concerned about false-positive and false-negative results. Several healthcare workers and administrators also cited a lack of knowledge of the CPGs as the main barrier to their implementation. This was also identified by Garces *et al.* (2017) in their study in Cali.

In addition, the pregnant women who were interviewed were initially willing to take the syphilis tests. However, this had often changed by the second and third trimesters of pregnancy: at that stage, for most of the women, it was not clear why they had to take the same tests every trimester. Moreover, they expressed that healthcare workers did not provide clear and sufficient information regarding the tests, procedures, and so on.

It was several years before the legal and administrative changes needed for the implementation of the CPGs were made. At the beginning of 2019, Decree 412 of 2000 was replaced by Decree 3280 of 2018, indicating how to provide perinatal care more in line with the CPGs. The updated codes for service charges were implemented in 2016 through the *clasificación única de procedimientos de salud*, (CUPS); the [Unified Health Procedure Classification], which determines fees for the services detailed in the CPGs.

This study thus revealed that, even if the barriers to the implementation of the CPGs were lifted, several obstacles regarding individual responsibilities and deficit models would remain impediments to CS prevention.

In the “deficit model”, a lack of information is assumed to be the main cause of any barriers or impediments to the implementation or acceptance of certain behaviours or technologies (Irwin and Michael, 2003). In CS prevention, these “deficits” concern healthcare workers and administrators’ knowledge of the CPGs and pregnant

women's knowledge and acceptance of activities that can prevent CS during pregnancy.

However, these deficit models are not the solely responsible for the failures of CS prevention in Colombia. I turn now to the main aims and questions addressed by this thesis and introduce the topics covered in each chapter.

#### Thesis outline

In light of the discussions briefly presented above and considering the characteristics of the regions I want to examine, this thesis poses the following research questions:

- 1) How do different care practices in two regions of Colombia currently enact congenital syphilis prevention?**
- 2) What would change if we were to provide good care for the prevention of congenital syphilis in Colombia?**

In summary, this research aims to contribute to the body of knowledge on providing good care during pregnancy and labour and preventing CS by utilising more than scientific and expert knowledge. The following chapters present the theoretical, methodological, and analytical discussions around the main themes of this case study. They are structured as follows.

The second chapter addresses the main theoretical and conceptual approaches that shape this thesis. Drawing on post actor-network theory, I discuss ontological politics (Mol, 1999; Law, 2015) and care practices understood as situated, emergent, and non-standardised. Given the importance of situatedness, I also provide a glimpse of the diverse ontologies – or multiple worlds (Viveiros De Castro, 2004; Blaser, 2009) – that configure what is visible, legitimate, and acknowledged in primary care settings (public spaces) and the private sphere.

In the third chapter, I address the methodology, the ethical issues, and my positionality as a researcher. This research project had to adapt to the changing conditions of the COVID-19 pandemic. As a result, online methodologies were used as an alternative to ethnography in a hospital during prenatal care appointments, as initially envisioned. Methods also included document analysis, online asynchronous



focus groups (OAFGs), interviews, and diaries kept via mobile phones and WhatsApp. This chapter provides the rationale for my methodological decisions and presents pertinent reflections on the assumed opposition between online and offline research. This discussion makes a case for the use of online methodologies (particularly online focus groups) and, more broadly, for the advantages of hybrid online and offline research. Furthermore, given that the use in research of messaging apps – particularly WhatsApp – raises various ethical issues, this chapter also presents advocates for a more flexible and situated ethical approach.

Ontological multiplicity, fragmentation and discontinuity lie at the core of the fourth chapter. Here, I explain how syphilis and CS appear and disappear in pregnant women's experiences and for healthcare workers and administrators. I indicate how and when CS becomes a matter of care (Puig de la Bellacasa, 2011; Puig de la Bellacasa, 2012) and how the experience of discontinuity and fragmentation further complicates disease prevention. This contrasts with the usual approaches to disease, which tend toward the linear, continuous, and sequential.

The fifth chapter explores the mix of care practices. This mix can include biomedicine, traditional medicine, traditional midwives, religion, and some online resources used by pregnant women and new mothers during pregnancy, birth, and the first months of their babies' lives. In the context of disease prevention, it is highly important to acknowledge the various ontologies and practices that can emerge besides those of biomedicine. In addition to the evidence-based medicine that underpins the CPGs as the principal tool for prevention of MTCT, there are other assemblages of knowledge, practices, expertise, and trust. This chapter traces some of the diverse care assemblages and thus further complicates the traditional assumption of the deficit model that underpins the primary solution for disease prevention. This is intended to challenge the guiding idea of this model – namely, that the provision of more information to healthcare workers (regarding the CPGs) and to pregnant women (regarding the importance of prenatal care and STIs) is sufficient to provide good care. Rather than empty vessels, as which deficit models usually portray, it is argued that participants are already engaging with diverse combinations of knowledge, experiences, and expertise.

The sixth chapter explores taboos and stigmatisation practices. Building on some of the analyses presented in previous chapters, I concentrate on sex taboos and stigmas and territorial stigmas. I describe how silences, absences, and emotions enact taboos and stigmas. In this process, I also examine the interplay between taboo and stigma as individual and collective practices.

In the final chapter, Chapter 7, I summarise the key findings of the research and discuss the limitations and potentialities of this investigation. I highlight the methodological possibilities for future research, with a particular focus on online methodologies. As one of the main aims of the research is to identify how to provide good care, I aim to make policy and practical recommendations at the local, regional, and national levels.

The following chapter presents the findings on my literature review, with an account of the relevant literature dealing with CS prevention, ontological politics, care practices, taboos, and stigmas.

## CHAPTER 2 LITERATURE REVIEW

Congenital syphilis (CS) is syphilis transmitted from mother to child during pregnancy. CS is considered a preventable disease (Arnesen, Serruya and Durán, 2015), but it is still a major public health concern in Colombia and in other countries in Latin America and the Caribbean (PAHO, 2021) and Asia (Wu *et al.*, 2016), as well as in some states of the United States (Chan *et al.*, 2021). Recently, it has become a concern in the UK, where there has been an increase in rates (<https://www.gov.uk/government/news/gonorrhoea-and-syphilis-at-record-levels-in-2022>).

In 2014, the Ministry of Health of Colombia, in consultation with United Nations Populations Fund (UNPF), implemented clinical practice guidelines (CPG) for the prevention of CS. However, although the CPG incorporate the best available evidence, including the advice of local experts, Colombia is yet to achieve a reduction in CS, with rates rising from 0.94 cases of congenital syphilis per 1,000 new-borns in 1998 to 4.7 per 1,000 new-borns in 2019 (Instituto Nacional de Salud, 2019). Rates are particularly high in Western regions.

Colombia has relied on prevention measures such as the implementation of evidence-based medicine (EBM), standardisation through CPG, the identification of at-risk groups, and the assumption of a lack of knowledge and information among the public. Health authorities attribute this increase in CS to a lack of knowledge of the CPG among healthcare workers, deficiencies in prenatal care (starting late, not having tests and treatments on time, not having the minimum amount of prenatal care appointments), and the non-treatment of the pregnant women's partners (Instituto Nacional de Salud, 2018).

Why can a preventable disease not be prevented (or prevented as expected)? With this question, we see the emergence of a research gap. Moreover, since efforts to prevent CS seem to have been “effective” in some areas of Colombia, why are some regions having more difficulty with prevention than others?

Initially, when I started my PhD in 2019, I considered drawing primarily on the literature on care and carelessness, in particular the work of Annemarie Mol regarding the “logic of care” (Mol, 2008), as the principal aim of the research was to understand how good care can be achieved.

However, other aspects became more salient after conducting online fieldwork in Colombia. The data led me in other directions and toward other possibilities. In addition to the literature on multiple ontologies, discussions of silences, absences, discontinuities, and assemblages also became recurrent and more “relevant”. This literature review examines those changes. One aspect remained constant throughout the process: the aim of contributing to CS prevention in Colombia by engaging with more than “expert” and “scientific” ontologies.

In the following sections, I draw primarily on literature from science and technology studies (STS) and the sociology and anthropology of health to illuminate what has been consistently silenced, absent, and disregarded.

The first four sections highlight the tensions between public health approaches and CS-prevention efforts, contrasting those with experiences of HIV prevention. Since the CPG are a focal point for CS prevention in Colombia, there is a discussion of the challenges for the implementation of those worldwide and the CPG for CS prevention in Colombia. The legal, administrative, and financial difficulties for the implementation of clinical guidelines, along with the claim regarding more provision of information and education (i.e., the deficit model) to healthcare practitioners and patients are explored.

A discussion of ontological politics and care is at the core of the fifth and sixth sections. Ranging from material semiotics, particularly the work of John Law (Law,

2019), Annemarie Mol (1999; 2002), and Puig de la Bellacasa (2011; 2012), these are the concepts that shaped the core of the research.

The following sections deal with the main topics, discussions, and concepts of the thesis chapters. The seventh and eighth sections deal with practices, silencing, and absence practices where syphilis, gestational, and CS are enacted as multiple. In those sections, an indication of what is considered practice and why it is relevant for the study of disease prevention is given.

The ninth section discusses care practices, in particular how CS is prevented in particular localities. Care assemblages are discussed vis-à-vis the traditional accounts of medical pluralism (coexistence of different medical traditions; Cant, 2020: 31) and medioscapes (globally dispersed health landscapes; Hörbst and Wolf, 2014).

In the 10<sup>th</sup> and 11<sup>th</sup> sections, I discuss the aspects of risk, race, and ethnicity that constitute contextual characteristics for the enactment of disease prevention and CS prevention in Colombia.

Finally, the last section presents the conclusions of the chapter and offers an outline of the following chapter, which deals with the methods.

### Public health tensions

In public health, there can be tension regarding how public health concerns are tackled. On the one hand, one perspective looks to biomedical methods, emphasising educational models and behavioural changes that involve a focus on individuals (as criticised by Petersen & Lupton, 2000; Mol, 2008). On the other hand, some prefer to engage with the wider social determinants of health, focusing on the collective actions of communities and institutions (Van den Broucke, 2021).

The development of CPG supported by EBM is a biomedical approach to preventing CS. Such approaches tend to involve communities and institutions and prioritise particular types of evidence and practices (clinical trials and meta-analysis). Even without considering how CPG is to be integrated into primary care settings and into

interactions with communities and institutions, CPG can be subject to several criticisms.

The CPG for the prevention of CS were established on the basis of EBM to standardise procedures, ignoring multicultural factors, local adaptations, and diverse knowledge. EBM is considered a source of “objective” information that brings knowledge acquired from population studies into the treatment of individuals, but it has also been used for management purposes to measure performance and financial indicators (Hafferty and Light, 1995 in Timmermans & Almeling, 2009).

However, there are disagreements concerning the use of EBM in clinical settings. Lambert (Lambert, 2006) establishes criticisms of EBM: failure to acknowledge patients’ views, production of “cookbook” guidelines, exclusion of clinical autonomy and criteria, bias toward individualised interventions, non-recognition of community-based and more complex interventions due difficulties with implementation and evaluation, and the complexity of translating the evidence from clinical trials to individual patients (Lambert, 2006). Furthermore, the possibility of applying EBM outside of the contexts (well-funded and well-equipped) in which it was generated has been contested (Geltzer, 2009).

Meta-analysis, systematic reviews, and randomised clinical trials are considered the best evidence (Slater, 2010), but doctors and scientists sometimes disagree on the best way to conduct a study in terms of the “scientific” and “ethical” components of its design (Richards, 1988, 1991 in Will, 2009). Evidence depends on the studies available. Not everything is studied (this depends on the pharmaceutical and healthcare industry), and not every study is published. Moreover, the use of averages makes it challenging to translate the recommendations from studies to individual patients (Darlenski *et al.*, 2010).

Evidence is considered “objective” without the intervention and negotiation of “social” factors. In fact, what makes EBM a trustworthy source is its “ability to guide health care decisions making by appealing to the ‘the evidence’ as the bottom line (...) it proposes to rationalise this complex social process” (Kirmayer, 2012:252). However, what constitutes evidence is mediated by cultural assumptions and economic and

political interests. Furthermore, most studies are conducted with populations whose characteristics are not relevant to other specific cultural groups (Kirmayer, 2012; Karnik, 2001; Epstein, 2010).

Epidemiology in particular has contributed to EBM, CPG, and healthcare practices. This relies heavily on statistical methods that allow practitioners to calculate risk factors, model epidemics and, more recently, contribute to the design of protocols and CPG following the development of EBM.

The role of epidemiology is to provide information that informs policy through monitoring and suggests how conditions at the local and national levels can be improved (Amsterdamska, 2005; Law & Moser, 2010).

The analysis provided by epidemiological models creates contexts and interactions (Law and Moser, 2010) that establish in which ways recommendations are followed. There is a vast difference between policy in theory and practice, as highlighted by Singleton and Michael, who show that GPs have ambiguous associations and ambivalent discourses over smear tests in England (Singleton and Michael, 1993).

The implementation of epidemiological recommendations has resulted in a “patchwork” (Law and Moser, 2010), with local adaptations that differ from the suggestions. In other words, the recommendations made by epidemiologists and experts for the prevention of mother-to-child syphilis transmission are not always followed as expected.

Scholars working on public health and health promotion have proposed other approaches to incorporate the broader social aspects that play a role in the configuration and prevention of disease (Van den Broucke, 2021; Makoge & Maat, 2023; Harvey et al., 2022). Some of these approaches have also been promoted by the World Health Organization and other multilateral agencies and are reflected in their policies, projects, and interventions. Among them are the social determinants of health (SDH) and salutogenesis.

The World Health Organization commissioned Michael Marmot to write a report on SDH after he published a book on this concept in 1999. SDH are the nonmedical

factors (social and economic) that influence people's health (World Health Organization, 2008). Although they include several dimensions (education, social inclusion, and access to health services), a considerable body of work has focused on the influence of income, wealth, and education on health outcomes (Bravenan and Gottlieb, 2014).

In addition, salutogenesis – or the salutogenic model of health (Antonovsky, 1996; Mittelmark and Bauer, 2022; Makoge & Maat, 2023) – has been considered a complementary approach to the focus on SDH, used to identify strengths and factors that can support health interventions. According to this perspective, this involves the sense of coherence and confidence that one has in internal and external environments in which things will manifest as expected (Antonovsky, 1996). Psychosocial factors help to navigate “movement on the health ease/dis-ease continuum” (Mittelmark and Bauer, 2022:11). The salutogenesis approach has been considered particularly valuable in contexts with resource scarcity, such as “developing” countries.<sup>6</sup> Instead of looking at how people prevent and cure diseases, this model focuses on how people maintain and procure health. Therefore, health and disease are not oppositional but rather on a continuum.

Latin America scholars belonging to social medicine and critical epidemiology traditions have articulated several criticisms of SDH approaches, highlighting their “pathogenic” perspective of diseases (emphasising the biological aspects), exclusion of social contexts and inequality, narrow perspectives of behavioural change, emphasis on individual agency, and assumption of direct causal links with certain variables (sex, race, ethnicity, income). Although salutogenesis acknowledges the active role of people and the relevance of collective interventions, it has also been criticised for not paying sufficient attention to inequality and the configuration of health and disease (Westbrook & Harvey, 2022; Breilh, 2021; Waitzkin et al., 2001).

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<sup>6</sup> Several interventions and programmes have applied salutogenesis to overcome SDH, acknowledge the positive characteristics and conditions of communities, and promote specific types of “agency” and resourcefulness among people.



Latin American social medicine, or “collective health”, as it is also called, is a movement consolidated in the 1970s that differs in respect of its approach to public health. Among the key differences are its consideration of health and illness in a dialectic rather than dichotomous way and the attention paid to social elements in the configuration of diseases. Furthermore, instead of a focus on individuals and linear causation in its analysis, social medicine does not consider collectives as the sum of individuals but rather as full entities set into historical contexts of diseases, leading to multicausal explanations beyond biological and individual accounts (Breilh, 2021; Waitzkin et al., 2001; Harvey et al., 2022). Social medicine and critical epidemiology have also incorporated other voices and perspectives beyond the scientific. As in Canada, where Indigenous perspectives have been incorporated into public health (Tremblay and Martin, 2023), Latin American social medicine has also referred to Indigenous perspectives (Harvey, Piñones-Rivera and Holmes, 2022). However, those approaches and narratives are not predominant within the field.

Through my fieldwork, it became evident to me that healthcare workers and administrators had different considerations when integrating knowledge and practices from outside of biomedicine, thinking about how intercultural healthcare services can be provided and whether the CPG are adequate for CS prevention. Some healthcare workers and administrators are relatively committed to the principles of social medicine, especially those individuals closer to the public health schools of the Universidad de Antioquia and Universidad del Valle (public universities in Medellin and Cali). The persecution of healthcare practitioners who were applying the principles of social medicine led to a weaker incorporation of these approaches in Colombia, compared to countries such as Ecuador and Argentina (Waitzkin *et al.*, 2001).

Differences between contexts in terms of the implementation of public health approaches and the integration of other knowledge are also relevant to understanding how diseases might be prevented in those contexts. The following section describes in greater detail how CS prevention has developed worldwide, particularly in Colombia.

## Congenital syphilis prevention

There is little literature evaluating public health interventions for CS prevention around the world (Plotzker, Murphy and Stoltey, 2018). Unlike HIV/AIDS and malaria interventions, CS prevention has not received much attention.

Most CS prevention studies have focused on characterising risk factors (at-risk groups and biomedical interventions), particularly in low- and middle-income countries (LMIC).

In South America, Brazil has produced a considerable body of research on CS prevention. Studies show that, in certain regions (particularly in the northeast), Indigenous and Black women have less access to prenatal care and greater syphilis and CS prevalence (Cardoso *et al.*, 2023). There is also an indication of several barriers in terms of CS diagnosis and treatment, including delays in test results, mainly from a lack of rapid tests; longer waiting times for appointments; and a lack of knowledge among healthcare workers regarding the guidelines (Bruneli, Gonçalves and Filho, 2020), as well as a fragmentation of systems and the absence of accurate data (Brito *et al.*, 2023).

In high-income countries (HIC) such as the United States and Australia (Freyne, Nourse and Walls, 2023), a significant increase in syphilis and gestational syphilis cases has turned medical attention toward syphilis, with a growing number of studies in certain states. In 2020, the Centers for Disease Control and Prevention (CDC) described regional differences in CS cases (Plotzker *et al.*, 2022). Some studies have focused on vulnerable groups (homeless people and drug addicts; Plotzker *et al.*, 2022), reflecting the need to detect and treat cases outside of traditional prenatal care settings. Other studies have indicated structural barriers in prenatal care – both overall and for CS prevention. These include the limited guidance on clinical management, difficulties with the health infrastructure, and inadequate support for patients' social conditions (Chan *et al.*, 2021).

Although there are many similarities between the different incidences of syphilis (gestational and CS cases in HIC and LMIC countries), there are several controversies over what is clinically effective according to context and local

particularities, such as diagnostic algorithms (e.g., the use of treponemal tests), universal treatment provision during the third trimester, and partner notification (Freyne, Nourse and Walls, 2023). Differences in diagnosis and treatment arise due to variations in syphilis prevalence, level of access to laboratory facilities, and cost-effectiveness (Freyne, Nourse and Walls, 2023).

Many of these dynamics can be found in the Colombian context. The literature on CS prevention in Colombia focuses mainly on characterising the at-risk groups and identifying necessary biomedical interventions (Becerra-Arias *et al.*, 2022; Castrillon *et al.*, 2013; Cruz *et al.*, 2013; Cruz, 2012). Several conclusions have been established from those studies, highlighting the higher prevalence of CS in certain regions (notably the Pacific region); the impact of a low socioeconomic level, subsidised health insurance, and a low educational level; and Afro-descendants being more likely to have CS. Recent migration has revealed Venezuelan migrants as another group with considerable syphilis-CS prevalence, as well as higher rates of other infectious diseases (e.g., HIV, hepatitis B, tuberculosis, Chickenpox; Ibáñez, Rozo and Urbina, 2021; Acosta-Reyes *et al.*, 2022).

Studies have also highlighted difficulties accessing healthcare services (Ibáñez, Rozo and Urbina, 2021; Acosta-Reyes *et al.*, 2022), a lack of adequate prenatal care (Castrillon *et al.*, 2013), syphilis screening failures, and inadequate treatment (Potes *et al.*, 2017; Castrillon *et al.*, 2013). Some have indicated a possible link between violence–migration and higher rates of syphilis and CS in some regions (Becerra-Arias *et al.*, 2022).

Common to all these studies is the observation that prevalence of syphilis and CS reflects health inequality, with prevalence being greater in regions with limited access to resources and larger numbers of Indigenous people and Afro-descendants, migrants, and internally displaced people (IDP).

HIV/AIDS prevention evokes a different scenario. Although, since the late 1980s, a combination of biomedical, behavioural, and structural approaches has been prioritised (Parkhurst, 2014), the majority of the research and interventions has entailed both biomedical and behavioural approaches (Parkhurst, 2014). Of the two,

biomedical interventions have been shown to be more successful (Mannell, Cornish and Russell, 2014).

It is not only more challenging to show behavioural–structural outcomes using indicators that consider only certain variables, it is also true that structural and behavioural approaches do not embrace complexity, diversity, Indigenous knowledge, or inequality (Mannell, Cornish and Russell, 2014). This task is not easy to accomplish due to the characteristics of the organisations that work on these matters (i.e., there is a constant need to demonstrate results and effects) and the type of methods and theoretical approaches that are incorporated. As highlighted by Ashworth *et al.* (2021) when discussing the necessity of developing methods to promote community engagement and behavioural–social change during epidemics, a clash between epidemiologists and social scientists on the grounds of their respective epistemological principles further complicates effective collaboration.

Several tensions are evident from work on HIV/AIDS prevention and intervention in the domain of behavioural and structural matters. These include a greater emphasis on individuals rather than communities or collectives; a greater tendency to scale up and disseminate strategies, rather than seeking to fit them to contextual or group characteristics; and the consideration of risks vs. environmental – barriers and facilitators (Campbell and Cornish, 2010; Parkhurst, 2014; Kaufman *et al.*, 2014).

Let us take a moment to consider what Campbell and Cornish (Campbell and Cornish, 2010) refer to as the “four-generation approaches to HIV/AIDS prevention” and to reveal how some of these tensions emerge. In the first generation, strategies are intended to promote HIV awareness. The underlying rationale for these strategies is that individuals engage in risky behaviours either due to ignorance (Aggleton *et al.*, 1994) or because of their perception of risks, costs, and benefits (Rosenstock, Strecher and Becker, 1994). It is assumed that the rational individual will then decide, following the provision of this information, what is best for them. This disregards the complexity of the practices, relationships, and negotiations that individuals establish in their contexts and within their communities. In the second generation (Campbell and Cornish, 2010), peer education is promoted to empower “at-risk” groups. These interventions are especially directed toward marginalised and

“hard to reach” groups. Aiming to translate information into action, the idea that peer groups offer education suppose they relate closely to the specificities of these groups regarding needs, expectations, language and trust. The problem here is that dialogues do not proceed two-ways, especially since other contextual dynamics are also needed to enable behavioural changes (Campbell and Cornish, 2010). In this regard, the example exposed by Campbell (Campbell, 2003) referring to an intervention in Africa illuminates how contexts and communities are important for successful interventions. According to Campbell (2003), in the Summertown Project, legacies from the apartheid in South Africa, as well as poverty, mistrust and miscommunication, configure a failure for HIV prevention.

Community mobilisation is at the core of the third generation. It is assumed that behavioural change is fuelled by communities who support individuals, peer norms, and spaces for critical dialogue and empowerment (Campbell and Cornish, 2010). However, contexts can enhance or limit changes in terms of prevention. This is one of the reasons for the fourth-generation approach. The fourth generation focuses on mobilising political will and community changes that support local, national, and international actions. It acknowledges local diversity and empowerment. These approaches consider context to be particularly relevant because their material, symbolic, and relational aspects fuel the changes necessary for disease prevention (Campbell and Cornish, 2010).

In this regard, political will”, defined as “the commitment of actors to undertake actions to achieve a set of objectives and to sustain the costs of those actions over time” (Mhazo and Maponga, 2022:1), has received considerable attention as a principal ingredient for successful programmes and policies that support prevention. Although awareness is frequently highlighted as a condition for political will (Lezine and Reed, 2007; Mhazo and Maponga, 2022), there is also an indication that power struggles and differences in group interests also play a significant role (Baum *et al.*, 2022; Mhazo and Maponga, 2022; Mtuy *et al.*, 2020).

The latest recommendations from the Pan American Health Organization (PAHO) regarding mother-to-child transmission of HIV and syphilis are directed toward a fourth-generation approach. The Framework for the Elimination of Mother-to-Child

Transmission of HIV, Syphilis, Hepatitis B, and Chagas (Pan American Health Organization, 2017) emphasises the need for direct links with other policies and international agreements (i.e., sustainable development goals, global strategy to women's), human rights, and community engagement. Nonetheless, at the time of my online fieldwork, the Secretaries of Health had only just started to envision the incorporation of this strategy into their plans and activities.

Of the few studies looking at potential interventions in Colombia, some are focused on the implementation of CPG as a central strategy for CS prevention. Garcés *et al.* (2017) found confusion and a lack of knowledge and awareness of CS and CPG among healthcare workers.

It is believed that improvements in healthcare workers' knowledge and awareness can contribute significantly to CS reduction. Another study (Potes, Rubiano, Ramirez, Tunubala, *et al.*, 2017) looked at the implementation of a point of care (same-day treatment) during prenatal care in Cali. It concludes that the diffusion of CPG has been insufficient to control CS due to several barriers to their implementation. It also highlights a lack of knowledge of the CPG on the part of healthcare workers and the failure of health insurance companies to provide rapid tests. Similarly to what others have highlighted in Brazil, CS reflects the reduced "effectiveness of the primary care strategy" (Cardoso *et al.*, 2023:11012). Let us now consider research on the challenges for the implementation of clinical guidelines, including those designed to tackle other diseases.

#### Clinical guidelines

Most studies of clinical guidelines have focused on the challenges of their implementation (Ahmedov *et al.*, 2013; Hobbs and Erhardt, 2002; Chandler *et al.*, 2008; Wharton-Smith *et al.*, 2019). Few studies (Song *et al.*, 2021) have described the difficulties related to design, including the adaptation, adoption, or development from scratch of a guideline that takes into consideration contextual characteristics. In their study, Song *et al.* (2021) highlight certain limitations regarding the quality of the sources for the clinical guidelines, as mentioned in the CPG for CS in Colombia (Ministerio de Salud y Protección Social, 2013b), and barriers to implementation such as a lack of resources and skills. It has been common for experts to make the

decisions while designing guidelines and reflecting on the particularities of their settings. However, this approach is contested by Wang et al. (Wang *et al.*, 2023), who suggest that the design process should also include patients, managers, and clinical personnel.

Although the implementation of clinical guidelines varies according to context, disease or condition targeted, and whether implementation is in primary or secondary care (Wharton-Smith *et al.*, 2019), various similarities have been found regarding the associated challenges.

Several studies have emphasised the disconnection between the clinical guidelines and real practice (Wang *et al.*, 2023; Chandler *et al.*, 2008; Wharton-Smith *et al.*, 2019). For instance, difficulties have been highlighted regarding the diagnosis algorithm for malaria (Chandler *et al.*, 2008), dengue (Wharton-Smith *et al.*, 2019), and GS and CS (Salas-Romero *et al.*, 2023), as well as a lack of time (Hobbs and Erhardt, 2002), resource constraints (Hobbs and Erhardt, 2002; Ahmedov *et al.*, 2013; Wharton-Smith *et al.*, 2019), lack of structural and administrative support (Hobbs and Erhardt, 2002; Ahmedov *et al.*, 2013; Wang *et al.*, 2023), increased administrative burden (Ahmedov *et al.*, 2013), and difficulties with state and federal regulations (Wang *et al.*, 2023).

Following the identification of these barriers, studies have recommended simplifying the guidelines and promoting their availability more widely (Hobbs and Erhardt, 2002), incorporating them into healthcare practitioners' workflows (Wang *et al.*, 2023), increasing training (Hobbs and Erhardt, 2002; Wang *et al.*, 2023; Wharton-Smith *et al.*, 2019), providing personal and financial incentives to practitioners (Hobbs and Erhardt, 2002; Ahmedov *et al.*, 2013), and increasing technical support – including with electronic medical records and digital tools (Wang *et al.*, 2023).

It is thought that providing more education to patients and health practitioners will increase acceptance and implementation of the clinical guidelines (Hobbs and Erhardt, 2002; Wang *et al.*, 2023; Wharton-Smith *et al.*, 2019; Ahmedov *et al.*, 2013; Chandler *et al.*, 2008). However, as stated by Wharton-Smith *et al.* (2019), “knowledge and availability of guidelines is a necessary, but not sufficient condition

... As studies of many other conditions and settings, from the UK to Tanzania, have found, knowledge of guidelines in theory does not always reflect clinical practice” (p.8).

In Colombia, some studies on the implementation of the clinical guidelines for GS and CS have found barriers such as a lack of knowledge of the guidelines, including confusion regarding the diagnosis algorithm (Garcés *et al.*, 2017; Potes *et al.*, 2017; Salas-Romero *et al.*, 2023); deficiencies in the use of rapid tests, due to either lack of availability or inadequate training (Garcés *et al.*, 2017; Salas-Romero *et al.*, 2023);<sup>7</sup> and a lack of training in the CPG (Garcés *et al.*, 2017), particularly among nurses in charge of prenatal care (Salas-Romero *et al.*, 2023). They have also highlighted difficulties with the provision of treatment to pregnant women due to the risk of allergic reaction and to their partners (Garcés *et al.*, 2017; Salas-Romero *et al.*, 2023). Barriers to the implementation of the CPG have been identified in Cali (Garcés *et al.*, 2017; Potes *et al.*, 2017), Bolivar (Salas-Romero *et al.*, 2023), and Chocó and Meta (Gaitán-Duarte, 2023).

Some of these difficulties are administrative barriers caused by the contracts with insurance companies (EPS; Potes *et al.*, 2017), As an EPS will not provide treatment to contacts who do not belong to the same EPS. Other barriers include the management of potential allergic reactions in a primary care setting, the accessibility of rapid tests, and the conditions required to ensure their quality (adequate temperature, storage, and use).

Researchers in Colombia have also found difficulties with the GS and CS case reports (Salas-Romero *et al.*, 2023; Garcés *et al.*, 2017; Gaitán-Duarte, 2023), leading to recommendations that the information collected on cases be used to help improve health policy and interventions, as was also indicated by Ahmedov *et al.* (2013) in their study on Uzbekistan. Scholars including Gaitán-Duarte (2023), Song *et al.* (2021), and Ahmedov *et al.* (2013) have all identified a need to update the guidelines and references.

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<sup>7</sup> This difficulty has been also identified in other studies in Pakistan and Brasil (Salas-Romero *et al.*, 2023).



Several lessons have been learned from the studies previously discussed on the implementation of clinical guidelines in Colombia and elsewhere.

The appropriate implementation of clinical guidelines requires more than a solution to the problem of resource scarcity. Even if sufficient resources are available, other factors and conditions are necessary for their implementation. In addition to challenges in clinical practice, other factors (e.g., legal, administrative, and financial) are also relevant. One cannot deny that clinical practice, as standard (even if contextualised according to the particularities of certain settings), includes gaps between what is stated in the guidelines and what is accomplished in practice (Ahmedov *et al.*, 2013; Potes *et al.*, 2017; Salas-Romero *et al.*, 2023).

Although the need for more training and education for healthcare practitioners and patients to improve the implementation of and adherence to clinical guidelines is constantly highlighted, this is also insufficient. As stated by Wharton-Smith *et al.* (2019), “Attributing treatment delays to public ignorance and poor practice in primary care is perhaps a universal claim of hospital physicians, and medical officers reports of patient and GP practice” (p.8). The wide range of challenges and barriers to CGP implementation cannot be solved by more information provision alone.

However, even if those barriers to the implementation of the CPG are overcome, many aspects remain to be considered. Relying heavily on the CPG to prevent CS is problematic not only because of standardised implementation (controversies, workarounds) but also because this standardisation excludes marginalised others – namely, the bodies, subjectivities, and ontologies (realities) which are the focus of this thesis.

The lack of information as a problem and the provision of more information as a solution (deficit model) are constantly recalled in discussion of disease prevention, the discussion about new technologies, and behavioural change. Let us look more closely at these discussions of deficit models.

#### Deficit models

A deficit model addresses a lack of information or deficiency in terms of literacy or understanding (Irwin and Michael, 2003). According to this approach, people are not

able to engage with science (the CPG, in this case) because they do not properly understand it or because they are ignorant of it. Therefore, more and better information is needed for people to engage with science adequately.

Several authors, mainly from STS, have indicated the disadvantages of a deficit model approach (Rip, 2006; Wynne, 2007).

Irwin and Michael (2003) and Wynne (2003) have shown that more information does not necessarily lead to a particular course of action. In the present case, one implication is that the CPG will not necessarily be followed. The CPG is one of many types of knowledge that is applicable and available. Different types contribute different perspectives, which can be more integrative, addressing complex issues that people must deal with daily (Elliott and Williams, 2008). Moreover, even if all social actors agree with the guidelines, the question remains as to whether they can be implemented in a primary care setting. There is more involved than simply techno-scientific matters.

This deficit model implies that people agree with – and behave according to – a particular perspective (scientific perspective) which is considered the most accurate. This neglects the different ontologies (realities) and practices in favour of the expertise and knowledge of scientists.

From a literacy perspective, then, experts (scientists) are responsible for participating in debates about science and technology and making decisions. If people do not know about science, they cannot make decisions on the basis of it. This implies that only those who know the CPG can and must perform them in prenatal care settings.

In the literature, the debate on “public understanding of science” (PUS) reveals that there is more than literacy at stake: the role of trust in relation to expertise is central.

Who is considered an expert depends on what is considered science, who is within or outside of that boundary (Star, 2010), and who is permitted to speak (i.e., to be a legitimate spokesperson) and to decide. Scientific knowledge depends not only on discoveries but also on processes in which communities with similar ways of seeing

phenomena exchange ideas until they recognise the knowledge as verified and adequate (Fleck, 1979; Arksey, 1994; Evans and Collins 2002 in Russell & Kelly, 2011). That is why laypeople can be considered experts without being acknowledged as legitimate for decision-making (Collins and Evans, 2002). Publics cannot question what counts as expert knowledge because the cultural framework of science is privileged (Wynne, 1996; Wynne, 2003).

Similarly, considerations of trust have also received attention. The core of the debate is less literacy and expertise than public trust. For some (Collins and Evans, 2002), distrust in science is due to competing expert versions. For others (Wynne, 1996; Michael, 1992), publics have a reflexive dependency and ambivalence regarding experts and science. That ambivalence is mediated by trust, in which understandings of science and its institutions have to do with social identity (social processes of identification and differentiation; Michael, 1992; Epstein, 2010; Epstein & Timmermans, 2021).

On the one hand, science is scrutinised by the public in terms of either the principles of the institution of science (science in general) or the interests of specific practitioners (science in particular) (Michael, 1992). On the other hand, publics are critical of scientific institutions' official aversion to uncertainty and the lack of agency afforded by those institutions to publics (Wynne, 2006).

Valuable insights have emerged from what has been referred to as the "ethnographic turn in the public understanding of science" (Irwin and Michael, 2003). Among these insights are the legitimacy of public concerns, the acknowledgement of local expertise, the limitation of technical knowledge when applied to new settings, the need for openness to self-critical and reflexive discussions of science, and the value of two-way communication. On this basis, Irwin and Michael (2003) propose the concept of ethno-epistemic assemblages as a way to elucidate the local ontologies that emerge across coalitions of actors engaged in controversies over science and technology. Ethno-epistemic assemblages are "[...] locally situated, have more or less well-delineated identities (though drawing on global flows of knowledge and culture) and are, crucially, involved in the 'establishment' of knowledge and the production of knowledge claims" (Irwin and Michael, 2003:85).

Other studies (Wynne, 2007; Wynne, 2006) show that publics have non-unitary experience of and attitudes toward science. Instead, people have different perspectives, since there are multiple “publics”. Despite the consideration of multiplicity, trust, and expertise and the inclusion of other publics (policymakers, industries, citizens) to enrich the PUS debate (Einsiedel, 2007), the public deficit model remains highly resilient (Cortassa, 2016).

Cortassa (2016) proposes two reasons for the persistence of the public deficit model. First, it explains the gap between science and society, establishing a direct link between cause and consequence, which is apparently easier to address institutionally. Second, it is based on epistemic asymmetry – namely, the idea that science has more objective and privileged access to knowledge than the public.

There are several reasons for challenging the deficit model. First, more information does not translate into acceptance or behaviour change, as shown by several examples in the literature (Rose 1985 in Davison et al., 1991). In their study, Davidson et al. (1991) refer to the prevention paradox, indicating that health measures for preventing diseases represent much at the population level but very little on the individual level.

Second, deficit models presuppose that people are “empty vessels” that can be filled with information, disregarding the possibility of multiple interpretations – even those able to contest that information. However, those “vessels” are not empty; they are already configured and filled with different traditions and epistemologies. In other words, the interpretations of the messages and practices from biomedicine regarding prevention measures are diverse. Multiple messages and understandings are connected, and prevention information is shared and mediated, especially in multicultural contexts.

Third, in most of these discussions, the main issue is not whether laypeople know but whether they trust (Wynne, 1992). Trust is a pre-requisite for information to be believed and assimilated. Fourth, the publics, – in this case study, healthcare workers, women, and their partners – do not have a unitary experience of or uniform

attitudes toward science. Instead, they have different perspectives since the publics are internally multiple (Wynne, 2007; Wynne, 2006).

Even if healthcare workers and administrators agree on which measures are better for CS prevention, other ways of caring for pregnant women during pregnancy and delivery remain unaddressed. Here, I argue we are dealing with an ontological problem (i.e., what realities exist), not an epistemological one (i.e., how we know reality). As several authors dealing with ontological politics have indicated, there are disputes over what is visible, what is legitimate, and what exists (Viveiros de Castro, 2004; De la Cadena & Blaser, 2018; Mol, 1999; Law & Lien, 2013). This is also the case with CS prevention in Colombia. Let us now consider more deeply what ontological politics can bring to our understanding of CS prevention in Colombia.

#### Ontological politics

“Ontological politics” refers to scholarly works in which authors are concerned with struggles over the definition of reality, particularly over ontologies. An example of ontological politics is what has been called the “ontological turn”. The ontological turn is a set of diverse approaches from STS, anthropology, and sociology that question such dualisms as the nature–social divide – that is, the idea of knowledge as a perspective that aims for universalism. It opens up the possibility to “imagine” or consider other possibilities by questioning the idea of nature or society as destiny; it considers that things can be otherwise (Law, 2019; Michael, 2017; Brives, 2013).

Several authors in anthropology and STS have incorporated the principles of the ontological turn into their work. These include scholars from actor-network theory (ANT; Mol, 2002; Thompson, 2002) and feminist material semiotics (Haraway, 1997; Haraway, 2007), postcolonial scholars (Verran, 2018), and some working in Latin America (Viveiros de Castro, 2004; De la Cadena & Blaser, 2018; Descola, 2012; Escobar, 2020).

There are differences among them, but I will not focus on these. Instead, in this study, I will draw on the set of tools and sensibilities provided by “material semiotics” to configure the research’s interests and questions and to highlight what is absent.

Some scholars working on ontologies engage with what has been called “material semiotics”, including post-ANT, feminist material semiotics, and postcolonial STS (Michael, 2017; Law, 2019). In material semiotics, there is a bracketing of social structures or fundamental social mechanisms; on the contrary, the emphasis is on practices. Instead of focusing simply on people or groups, the analysis is oriented towards heterogeneous interactions. It also considers humans and non-humans in similar terms (both can act), which opens up possibilities for empirical questions – for instance, about how realities can be enacted in particular ways.

Several critics have commented on these approaches. Some have considered ontology to be another word for “culture”, another way to show variation (Candea, 2010; Carrithers, 2010). Others have stated that it is apolitical because it takes a narrow view of inequality and historical processes of domination (Bessire and Bond, 2014). For instance, it does not explain how differences come to matter or why some are not considered by researchers (e.g., gender, class, race; Bessire and Bond, 2014). It has also been argued that it focuses more on the future, on how things could be, limiting discussions of the present (Bessire and Bond, 2014).

I will now consider some of these criticisms in light of the present study, developing an ontological approach to CS prevention. Let me start with a consideration of ontology as culture.

Although ontology and culture deal with differences, the latter is usually associated with people and supposed “cultural packages, coherent inside and different from what is elsewhere” (Strathern 2002 in Henare et al 2006). In contrast, the consideration of ontologies as multiple, situated, and particular leads to the recognition of “as many ontologies as there are things to think through” (Henare et al., 2006:27). It is important to consider human and non-human interactions because, although things “travel” across “cultures”, it is the situated configuration of relational practices that enacts and expresses differences. This also allows for fluidity and even contradictory practices surrounding belonging and identity. Against a traditional account of culture, where there is an expectation that is only Indigenous people practising traditional medicine or ‘externally’ engaging with biomedicine, the

consideration of diverse ontologies allows us to show how Indigenous people diversely and heterogeneously enact healing practices (as I will show in Chapter 5).

Regarding the claim that ontological approaches are apolitical, it is worth noting that approaches incorporating historical perspectives do not necessarily provide a better account of reality. Historical accounts can be filled with reductionist, Eurocentric, and partialised accounts. On the other hand, several authors who incorporate ontological approaches deal with politics (Mol, 1999; De la Cadena & Blaser, 2018; Law, 2019; Law & Joks, 2019). In ontological politics, there is constant consideration of the “struggles between different versions of reality” (Law, 2009:2). Here, there is a concern with not only which things can be otherwise (practices are contingent and specific), but also that some might be good or do not fail to engage with difference (Law and Joks, 2019; Verran, 2018; Jerak-Zuiderent, 2015).

Several scholars in STS have highlighted the importance of treating natural facts and social concerns as interrelated, acknowledging their ethical and political effects. For instance, we note the account of Bruno Latour (Latour, 2004) that scientific and technological objects (matters of fact) also involve diverse social and political interests (matters of concern), which can be further treated as matters of care (Puig de la Bellacasa, 2011; De la Cadena & Blaser, 2018).

Although matters of concern (Latour, 2004) imply worrying about an issue and trying to de-objectify matters of fact, they do not necessarily address neglected things. As an example, the effort made by the Ministry of Health to promote diverse healing practices through intercultural health does not necessarily imply that certain activities (e.g., legal and administrative) are employed to incorporate them during prenatal care. Matters of care (Puig de la Bellacasa, 2011), by comparison, is committed to engaging with neglected experiences, divergence, and conflict, encompassing diverse and oppositional standpoints (Puig de la Bellacasa, 2011).

In what follows, I discuss how care is understood and how matters of care and caring are relevant to the consideration of CS prevention.

## Care

Since the 1970s and 1980s, more attention has been given to care, especially to practices that were usually disregarded as unimportant. Feminist and STS scholars have debated what “care” means as a vital affective state, an ethical obligation, and a practical labour (Puig de la Bellacasa, 2012).

Care has been defined as an activity with a disposition that implicates an emotional response towards someone in need (Tronto, 1993). Tronto defines it as “everything that we do to maintain, continue and repair ‘our world’ so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all that we seek to interweave in a complex, life-sustaining web” (Tronto, 1993:103).

It has also been considered a non-rational emotional activity performed in a private space by someone without agency, almost powerless. However, several authors have stated that care is a practice that involves others’ understanding and their situations (Tronto, 1993; Mol, 2008; Schillmeier, 2017; Puig de la Bellacasa, 2012). In that sense, care is particular and implies more than an intention; it involves judgements (Tronto, 1993). However, when judgements are being made about that practice, carelessness can be manifested. That is to say, there is always conflict in caring practices because there is not always a match between caregivers and care receivers’ needs and the assumption of a lack of agency by care receivers. These conflicts confound what is needed (Tronto, 1993). Unlike Tronto (1993), some authors have questioned the difference between caregivers and care receivers (Mol, 2008; Mol et al., 2010), arguing that care as a practice is distributed among humans and non-humans.

Several authors have highlighted the association of care with affection and positive feelings as problematic, as it does not allow observers to be critical about care (Murphy, 2015; Schrader, 2015; Martin et al., 2015). Instead, there is a need to acknowledge power relationships, who receives attention, what is excluded, and the possibilities for care that can be changed (Martin, Myers and Viseu, 2015; Puig de la Bellacasa, 2011). Furthermore, when care is associated with compassion in the provision of governance and management in healthcare settings, as shown by Singleton and Mee (2017), it can be challenging and risky and it can become unjust



for some (Martin, Myers and Viseu, 2015). In a study conducted in the United Kingdom, Singleton and Mee (2017) discuss the tensions and potential harms highlighted in a report on the need for compassion as a key ingredient of healthcare, noting the constant tensions between policy and healthcare practice.

A different perspective on care as affection and positive feelings focuses on “care” as being troubled, worried, and unsettled (Murphy, 2015). In that sense, Schrader (2015) establishes a difference between “caring for” and “caring about”. While “caring for” is goal-oriented (teleological) and looks to improve the situation, “caring about” implies starting to care, and is not directed to a specific need or action (Schrader, 2015). The discussion about care as teleological is essential because it is at the core of the definition of care. Care is contextual, situated, and emergent (Schillmeier, 2013; 2014; 2017; Mol, 2008; Mol & Hardon, 2020). It is linked to specific configurations of time (Schrader, 2015), and it is impossible to determine what is needed in advance (Martin, Myers and Viseu, 2015; Puig de la Bellacasa, 2012; Puig de la Bellacasa, 2011). In this light, one can be attentive to care in terms of particularities and daily activities, but not to standards and general principles (Barnes, 2013; Schillmeier, 2014).

The situatedness of care (Schillmeier, 2017) involves more than concern about time. The negotiation entailed in care is about now and the future as becoming, but also about places. Interactions in various contexts create diverse possibilities of care (Barnes, 2013) and carelessness, which is why it is crucial to consider “post-placed care” (Ivanova, 2020). Ivanova (2020) refers to the material and immaterial elements of caring in an assemblage of the digital, affective, and sensory. Through the concept of “placed care”, various layers of place are considered (private and public, virtual and non-virtual), as well as how interdependencies and responsibilities are distributed among places, people, and devices (Oudshoorn, 2012).

Similarly, Annemarie Mol (2008) proposes the logic of care, which she envisages as a relational practice distributed among human and non-humans. For Mol, the logic<sup>8</sup> of care is a view from somewhere (situated knowledge), in which care is negotiated

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<sup>8</sup> For Mol, logic is not a coherent set of practices. Instead, the practices are unexpected, creative, and local (Mol, 2008).

among different types of actants, is relational, and can be achieved collectively. This logic recognises that subjects cannot always decide the best choice. Subjects have problems with their bodies, and what they need is more important than what they know or want. Accordingly, knowledges, technologies, and needs are negotiable because the definitions of “normal” are questioned. In this logic, care practices are adaptable and directed to different subpopulations, as they are sensitive to how categories (race, ethnicity, class, risk) inform identities and shape practices. The logic of choice, on the other hand, considers people “citizens” or “customers” who make choices to control their bodies through their lifestyles and behavioural changes, informed by objective knowledge and technologies that are not up for discussion.

Contrary to the logic of choice, the logic of care assumes that fragility and unpredictability are parts of life (Mol, 2008). However, the logic of choice – the logic of care (Mol, 2008) has received several criticisms. It has been stated that Mol does not provide a clear definition of “care”, and it is not possible to see how those logics enact diseases in multicultural settings and where healthcare settings operate under resource constraints (Bowlby, 2010; Will, 2017; Spink, 2015; Stilgoe, 2008; Beckmann, 2013).

Other authors suggest that the logic of choice and the logic of care cooperate and clash in healthcare settings, but studies have only described how these logics apply in each context and none (to date) has focused on disease prevention (Nørskov, 2019; Winthereik & Langstrup, 2010; Spink, 2015; Beckmann, 2013). Even though the context described by Beckmann (2013) regarding HIV/AIDS in Tanzania is similar to that of my research, there are several significant differences between HIV/AIDS and syphilis. For example, much greater attention and investment worldwide is afforded to HIV prevention. In addition, in this study, the focus is on how patients negotiate their choices over treatment while being responsible in ways that clash with healthcare workers’ expectations. In contrast, with CS, there is also a reliance on responsibility of healthcare workers and administrators through the implementation of the CPG. Moreover, different illnesses require different care practices (Schillmeier, 2017).

Usually, in healthcare, there is assumed to be a dichotomy between care and cure. Activities for healing (surgeries, pills, injections) can differ from those for caring (basic activities and palliative care). However, research has shown that there is no such division. Care and cure are interrelated activities – cure involves care (Mol and Hardon 2020).

On the basis of the concern for CS prevention and in light of the discussion about care, it is important to address why prevention is fundamental and how it relates to care. As indicated previously, not only is it valuable to conceptualise care as relational, situated, and contextual and to show that it “[...] involves material engagement in labours to sustain interdependent worlds, labours that are often associated with exploitation and domination” (Puig de la Bellacasa, 2012:198). Moreover, in care, “there are various ‘goods’ at stake simultaneously, as usually there are; caring involves mediating between these. And if things change, if they go better or worse, new adaptations are needed, again and again” (Mol and Hardon, 2020:12).

Care, as understood by Puig de la Bellacasa (2011), involves an interest in neglected things and the commitment to do something. Therefore, care is at the core of this thesis, as one of the aims of this thesis is to contribute to how to provide “good care” during prenatal care, labour, and the first months of a baby’s life, while preventing CS.

It is worth noting that I had envisaged my work primarily drawing on Mol (2008). However, though I make use of her contributions on both care and multiple ontologies (Mol, 2002), these are not the only theoretical approaches that are applied. Other concerns regarding practices are also important, especially in terms of how caring and carelessness are enacted in several practices. Caring then involves practices, and practices are at the core of caring during prenatal care, labour, and the first months of a baby’s life. While I was doing online fieldwork, the need to focus on practices became very evident. Silences, absences, healing, and stigmatisation practices were also salient. In the following section, I will describe some of the theoretical discussions around practices and the elements relevant to the analysis presented in the following chapters.

## Practices

Several authors have been interested in practices, especially as ways of explaining social order and change. Under the umbrella of “practice theory”, a considerable variety of authors are grouped – from Anthony Giddens (Giddens, 1984) and Pierre Bourdieu (Bourdieu, 1980) to Schatzki (2002) and Shove et al. (2012). Although there are differences between these authors in terms of what they believe constitutes a practice and which analytic focus is appropriate, one of the main differences between the latter authors and Giddens and Bourdieu is the importance they attribute to materials. For the latter, individuals and materials are key to practice.

In this thesis, practice is an organised form of activities that involve materials, competences, and meanings (Shove, 2017; Blue et al., 2016; Blue & Spurling, 2017). It implies the integration of “materials (objects, consumer goods and infrastructure), competence (including understandings of the situation, practical know-how), meanings (including embodied understandings of the social significance of the practice and past experiences of participation)” (Shove et al., 2012a:42).

As connections between these three elements are made, sustained, or broken, practices emerge, shift, or disappear (Shove, Pantzar and Watson, 2012a). Practices are then seen as practice-as-entity (as a “thing” with a history and trajectory) and practice-as-performance (practices exist through their enactment and reproduction; Shove et al 2012). That difference allows us to identify not only the components of practice but also their configuration and the relationships and dynamics among those elements and other practices.

Two main observations follow from adherence to these considerations. First, practices are not in isolation; they establish relations in a “nexus of connections” (Nicolini 2012 in Welch, 2017) with other elements and practices. Second, the description of practices identifies how they hang together in the present and how they matter for future interactions. It is precisely at this point that some critics have emphasised the inability of theories of practice to trace change (Shove, Pantzar and Watson, 2012a).

There are similarities and differences between this approach and the one taken by some scholars in STS (Pickering, 1993; Latour, 2000). The similarities include an acknowledgement of materials and their role in practices. Shove, Latour, and other scholars from post-ANT do not share the traditional consideration of individuals or humans found in classical sociological approaches. Nonetheless, they differ in how they focus their attention. While Latour (Latour, 1983) follows actants, Shove (Shove, Pantzar and Watson, 2012a) follows the elements of the practice. In that sense, the latter is interested in decentring individuals as actors and in contexts of social interaction and intersubjectivity.

Amongst the criticisms aimed at the theory of practice are that individuals are usually neglected and accounts of large-scale phenomena are absent, with the focus instead on local phenomena (Shove, Pantzar and Watson, 2012a).

Let us consider the case of CS prevention for a moment to weigh those criticisms. This research deals with CS prevention in some localities in Colombia, but that does not imply that this is a “small” phenomenon. CS prevention is a bundle of practices configured in various socio-historical situations that not only entails the integration of particular elements of CS but also incorporates relationships with other practices (identity, inequality, healing, among others). Furthermore, a focus on individuals alone (e.g., pregnant women) would not provide a better account of CS prevention. Materials are also included: medical records, rapid syphilis tests, diagnosis algorithms,<sup>9</sup> and penicillin, among others (more in Chapter 4, “Ontological Discontinuities”). It is precisely due to the limitations of an individualistic approach that theories of practice are better suited to illuminate ideas around CS prevention.

In contrast, health and disease prevention are usually approached from behavioural perspectives, in which “behaviour” is “the expression of an individual’s values and attitudes” (Blue & Spurling, 2017:4), with limited participation by others (Luque et al., 2016; Southerton and Welch 2015; Welch 2017). Considering only individual attitudes and values disregards the multiple relations, cooperation, infrastructures,

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<sup>9</sup> Diagnosis algorithms indicate the step-by-step process of making a diagnosis according to a combination of symptoms, signs, or test results. These diagnosis algorithms help to standardise clinical practice and are a vital component of the CPG, supported by EBM.

and materials that are also needed for an individual to perform an activity or establish new routines.

Moreover, behavioural–individualistic approaches do not consider “collateral realities” (Law, 2009). Collateral realities are “[...] realities that get done incidentally. They are realities that get done, for the most part, unintentionally” (Law, 2009:1). These realities are usually enacted during struggles between ontologies. The relevance of collateral realities lies in the fact that, although these practices usually go unnoticed, they nevertheless help to coordinate other practices. In the assemblages of relations, realities (including collateral) configure patterns and juxtapositions of practices (Law, 2009). A focus on collateral realities can reveal practices related to CS prevention, allowing them to be noticed and contested.

Other studies (Duncan *et al.*, 2022; Flacks, 2018; Rhodes *et al.*, 2024) have taken a collateral reality approach to illuminate alcohol policy in Australia, international drug law reform, and care practices during the first days of the COVID-19 pandemic in hospitals in Colombia. Each of these studies uncovers politics, gaps, and tensions surrounding gender (Duncan *et al.*, 2022), childhood and children’s agency (Flacks, 2018), and “exhausting care” (Rhodes *et al.*, 2024). Unlike in the other studies in Rhodes *et al.* (2024), materials are a part of the configuration of care and collateral realities. However, none of the studies cited above explores collateral realities in disease prevention.

In the following sections, I will discuss the collateral realities that help to coordinate CS prevention in Colombia. Those practices are discussed further in the following chapters. For now, let us take a closer look at some theoretical differences.

#### Silence – absence and discontinuity practices

This section discusses silences, absences, and discontinuities. I touch on various traditions from sociology, anthropology, and STS, including diverse approaches (phenomenology, cognitivism, social constructivism, postmodernism, postcolonialism, and decoloniality). Although from different backgrounds and contrasting traditions, these concepts and theories show what is neglected. This is relevant to CS prevention, as the following chapters will show.

I will start with the discussion around discontinuities and fragmentation and then discuss absences and silences.

While I was doing the online fieldwork, and during the initial stages of the analysis, many indications of fragmentation appeared. I noticed how migrants from Venezuela navigated prenatal care and healthcare service provision according to the limitations imposed by their migratory status (either documented or undocumented), which municipalities they were attending for healthcare, and whether they had subsidiary or contributory health insurance.

Some studies have indicated fragmentation in care in terms of either institutional and healthcare service provision (Gamboa et al., 2023; Cebul et al., 2010) or diagnosis and treatment of disease across different medical specialties, as in the case of neurofibromatosis (Carrieri *et al.*, 2016).

Cebul et al. (2010) show how institutional and healthcare service provision in the United States is fragmented between distinct and competing entities with contrasting obligations, objectives, and capabilities, in a mix of public and private health insurance. These “fragmented organisational structures” (p.93) lead to inefficient information flows and disrupted relationships between those who intervene in health services. Similarly, Gamboa et al. (2023) show how the fragmentation of healthcare for breast cancer in Colombia leads to adverse health outcomes (lower survival rates), higher costs, inefficient use of resources, and lower patient satisfaction. In their study, Gamboa et al. (2023) measured healthcare fragmentation across regions in Colombia, finding Chocó to be the region with the highest level of fragmentation and Caldas with the second highest.

Both studies (Cebul *et al.*, 2010; Gamboa *et al.*, 2023) show the relevance of information flow and information systems for adequate healthcare service provision. Although information flow regarding healthcare access and medical records is paramount for CS prevention (e.g., to ensure treatment efficiency), other aspects cannot be explained by the fragmentation of care (i.e., the practices that enact CS as neglected).

Furthermore, one might note what John Law says regarding fragmentation: it is not that multiplicity implies reality is fragmented, but rather that “[...] different realities overlap and interfere with one another. Their relations, partially coordinated, are complex and messy” (Law, 2004:61). In CS prevention (as I will discuss in the following chapters), the multiplicity of ontologies, temporalities, and trajectories enact practices differently from the teleological, goal-oriented, and coordinated activities that are usually expected in disease prevention.

On a different note, from a structural perspective, one could consider the social structure of denial (Zerubavel, 2010) or the administration of harm when certain elements are neglected (Broom *et al.*, 2023) as examples of how systems and collectives engage in absences and silences. Zerubavel (2010) highlights that collectives seek consensus over what things should be ignored and what attracts attention, engaging in collaborative denial – or, as he calls it, a “conspiracy of silence” (Zerubavel, 2010). Moreover, he indicates that “Separating the ‘relevant’ from the ‘irrelevant’, after all, is for the most part a “sociomental” act performed by members of particular social communities who are socialised to focus on, and thereby notice, certain things while systematically disregarding others” (Zerubavel, 2010:34).

By contrast, Broom *et al.* (2023) argue that what is neglected emerges from structural factors that determine priorities, with the choice of options that cause harm to some and benefit the few. In research on antimicrobial resistance (AMR), Broom *et al.* (2021) consider that systems cause more harm than individuals do, but this is hidden, by design, under the concept of “unintended consequences”, which means that certain phenomena – such as AMR – are ignored.

Both Zerubavel (Zerubavel, 2010) and Broom (Broom *et al.*, 2023) agree that collective action brings attention to an “agenda” and to a certain set of priorities.

However, priorities are not only established through agreements on where to focus our attention. They are also established on the basis of certain temporalities. Scott (Scott, 2022) suggests that societies arrange time by projecting themselves forward and backward, recognising what is relevant and coordinating their actions



accordingly. With this focus on temporality, some authors refer to “slow violence” (Nixon, 2011) or “slow death” (Berlant, 2007), indicating that when consequences are less obvious in the short- or mid-term, no great consideration may be afforded to them because of the lack of immediate impact. These consequences may, over time, be especially noteworthy for the economically poor, racialised minorities, and future generations (Nixon, 2011).

One can therefore argue that a bundle of practices also “hold” each other together across temporalities, as some authors have suggested: “[...] practices can hold each other together in bundles (in various configurations in various socio-historical situations), they can become mutually dependent on each other, and they can break apart in ways that are important for their routine reproduction. At specific moments in time and space, such bundling depends on the exclusion of other practices or of other configurations” (Blue et al., 2016:45).

However, we must acknowledge that multiple ontologies involve multiple temporalities. Those temporalities are not necessarily linear, that is, move forward. However, disease prevention, particularly CS prevention, assumes a linear temporality (teleological), a projection to the future – anticipating possible outcomes and acting accordingly. However, that is not necessarily the case with practices that involve other ontologies. For instance, the practice of *omb ligada* (a practice of cutting the umbilical cord) is customary among Afro-descendants, with the placenta put into the soil and “planted” in the territory so that the newborn will not forget their past, their ancestors, or the territory. In this practice, there is no linear temporality.

Responding to typical accounts of modernity (universalism, linear temporality), postcolonial and decolonial authors have made various critiques. Postcolonial critics (e.g., Edward Said, Homi Bhaba, Gayatri Spivak) have discussed modernity and questioned several of its assumptions. For instance, in her essay, “Can the subaltern speak?”, Spivak (2010) problematises notions of identity, culture, and representation in which Eurocentric ideations homogenise humanity in a dynamic of domination in which the subaltern is absent, has no history, and cannot speak.

Other authors, such as Anibal Quijano (2007) and Maria Lugones (2010), have also criticised the coloniality of knowledge and the relationship between the colonised and the coloniser. Lugones (2010), for example, proposes re-readings of gender, race, and sexuality, as the organisation of these homogenous, separable categories by the colonial/modern system – for instance, “woman” and “Black” – in fact erases colonised women: “their intersection show us the absence of black women rather than their presence” (Bhambra, 2014).

Similarly, Anibal Quijano (Quijano, 2007) identifies another way of absencing the Other, emphasising how the coloniality of power is associated with the coloniality of knowledge, linking modernity and rationality. Knowledge, then, is not an intersubjective relationship but an individuated production in which the “Other” is absent and there is no social totality.

Various other authors have critiqued the social sciences and academic knowledge (Bhambra, 2014; Bhambra and Santos, 2017;<sup>10</sup> Bhakuni and Abimbola, 2021).

Gurminder Bhambra (Bhambra and Santos, 2017) calls for a critique of sociology regarding its traditional accounts of “modernity” and the “global”, claiming that there is little discussion of structures, processes, and movements that do not correspond to Europe but that are nevertheless crucial. Bhambra (Bhambra, 2014) also calls for the recognition of cultural and epistemic diversity to rethink sociological “categories and concepts in light of newly understood alternative formations of the global and the social movements that bring them about” (Bhambra and Santos, 2017:3).

Other authors have also engaged in critiques of sociology. Among them, Wayne Brekhus (Brekhus, 1998) indicates that more attention has been paid to the “political salient” and “ontological uncommon”, disregarding other phenomena and leaving them “taken-for-granted”.

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<sup>10</sup> Recent allegations of inappropriate behaviour by Boaventura de Sousa Santos have led some intellectuals and activists to stop engaging with and citing his work. Even if it is not possible to separate an author from their ideas, on this occasion, I continue to engage with his work for several reasons. First, his work is the result of collaborations with communities, organisations, intellectuals, and activists in several localities (Colombia, Brazil, Portugal, Argentina, and Chile). Second, it is precisely one of my arguments that we should not disregard or silence something that could contribute to dialogue and build bridges, even if its contribution is contradictory and conflictual.

To facilitate epistemic and cultural diversity, Bakhuni and Abimbola (Bhakuni and Abimbola, 2021) refer to epistemic injustice in academic global health, highlighting assumptions regarding a “credibility deficit” and “interpretive marginalisation”. While in a “credibility deficit”, knowers are considered less credible, in “interpretive marginalisation”, their sensemaking process is not considered at all. Furthermore, “[...] with interpretive marginalisation, dominant social and epistemic groups who do not give sufficient attention to the possibility that their interpretive tools or conceptual and knowledge frames are imperfect (especially regarding their experiences of marginalised groups), negatively affect the knowledge-related freedoms of such marginalised groups” (Bhakuni and Abimbola, 2021:1466). An example of interpretive marginalisation is how the literature on global health prioritises universal conceptions of “respectful maternal care principles” over notions of good care (Bhakuni and Abimbola, 2021).

On a different note, some authors have confronted scientific knowledge (including the social sciences) by bringing in other perspectives: non-scientific, popular, and vernacular knowledge (Santos, 2011; Viveiros de Castro, 2004; Escobar, 2020).

Boaventura de Sousa Santos refers to the sociology of absences, indicating that what does not exist is actively produced as non-existent when considered unintelligible, disregarded, and disposable (Santos, 2006; Santos, 2011). He brings attention to how certain knowledges are marginalised, suppressed, and silenced, particularly within sociology, which has a heritage of positivism. In its place, he proposes an “ecology of knowledges” (Santos, 2011), in which there is an openness to dialogue with a pragmatic conception of knowledge, the acknowledgement of other temporalities (in addition to the linear), the acceptance of difference beyond the establishment of hierarchies, the articulation of different scales (local, national, and global), and the valorisation of alternative production systems.

Boaventura de Sousa Santos (Santos, 2011; Santos, 2006) emphasises that our traditional scientific accounts (including those from sociology) leave aside other realities (e.g., non-Western) and practices that do not correspond to what is usually considered “scientific”, valid, and “rigorous”. That discreditation of knowledge also discredits the groups whose practices are based on that “alternative” knowledges.

He then proposes the “sociology of emergences” (Santos, 2006), which involves not only other practices and knowledges but also what is still not-yet (or, what is becoming). Instead of considering the idea of determination, he advocates for an idea of care which places emphasis on relationships between humans and non-humans, past and future.

This consideration of alternatives and connections between different knowledges and practices is shared by Arturo Escobar (Escobar, 2020). Escobar refers to the “pluriversal” (the connection between the human, natural, and spiritual worlds), describing the existence of multiple worlds that enrich the possible alternatives for the future.

Some resemblances can be found between Boaventura de Sousa Santos, Arturo Escobar, and some authors in STS (e.g., standpoint theory), despite their differences, in terms of their respective ontological and epistemological accounts.

Standpoint theory (Haraway, 1988; Harding, 1993) implies thinking from the margins, from marginalised experiences, to transform knowledge, practices, and socio-material configurations. Producing standpoints means that there is not only a commitment to care for some issues, rather than others, without providing a normative vision; it also indicates an attempt to add something to the world (Puig de la Bellacasa, 2011). It is precisely in its focus on neglected things (Puig de la Bellacasa, 2011) that care plays an important role in this thesis. One of the aims of this thesis is to consider multiple ontologies, diverse temporalities, and practices that are usually disregarded and neglected.

John Law has discussed how absence is enacted in presence. This enactment is necessary for the constitution of an absence (Law, 2004). Law differentiates between “manifest absence”, as something that is absent but acknowledged as relevant, and “absence as otherness”, as something enacted as irrelevant, impossible, or repressed. He then proposes a “method assemblage” (Law, 2004) that allows the bundling of relationships between presence, manifest absence, and otherness to be made present. In his words, “[...] it is the crafting, bundling or gathering of relations in three parts: (a) whatever is in-here or present (for instance a representation or an

object); (b) whatever is absent but also manifest (it can be seen, is described, is manifestly relevant to presence); and (c) whatever is absent but is other because, while necessary to presence, it is also hidden, repressed or uninteresting” (Law, 2004:144).

I have incorporated these provoking insights from method assemblage into my own research methods, alongside some ideas from postcolonial and decolonial authors to make visible and heard some of the absences and silences enacted while seeking to prevent CS in Colombia. The mix of diverse traditions is intended to build the bridges and dialogue necessary for disease prevention. Following what Catherine Walsh (Walsh, 2007) says about interculturality, I attend not only to what has been marginalised, what has been rendered subaltern and negated, but also to dialogic connections, potential encounters, and coordination between multiple ontologies. Silence and absences are enacted, with multiple ontologies becoming part of CS prevention. As the following chapters will suggest, what seems discontinuous and fragmented in CS prevention is the coordination of silencing and absenting practices.

In the following section, I will focus on care practices involved in pregnancy, labour, and babies’ first months. Some of these have not been considered in CS prevention, but have rather been silenced. Nevertheless, they are used and combined in complementary or even “contradictory” ways.

### Care practices

During pregnancy, labour, and the first months of a baby’s life, pregnant women and new mothers use diverse care practices from biomedicine, traditional medicine, traditional midwives, religion, and online resources. In what follows, I engage with concepts and approaches from anthropology and the sociology of health to provide insights that could clarify not only the care practices themselves but also the multiple ontologies involved in CS prevention.

Traditionally, a medical system is considered a set of theories of affliction – “[...] a rational, conceptual scheme or myth that provides a plausible explanation for the patient’s symptoms and provides a ritual or procedure for resolving them” (Nestler,

2000). In these systems, patients and healers have specific roles and perform symbolic actions and rituals that are expected to be effective and to allow recovery (Frank 1973 in Kirmayer, 2004). In the literature, in references to medical systems (Leslie, 1980; Hsu, 2017), the implication is that there is a division of labour that provides training for health practitioners, maintains facilities, and supervises populations in terms of their health (Leslie, 1980). Usually, medical systema refers to biomedicine (“Western” medicine), with its processes of national and international standardisation and its positivist and naturalistic approach to health and disease.

During the 1970s and 1980s, several authors criticised the overemphasis of medical systems on biomedicine and the perspectives of medical professionals. Leslie (Leslie, 1980), looking at the different traditions of health practitioners in South Asia, found a pluralism among those practitioners, with hybrid and complementary elements being frequent. The concept of “medical pluralism” developed from his work, describing “[...] the coexistence of different medical traditions and practices grounded in divergent epistemological positions and based on distinctive worldviews” (Cant, 2020: 31).

Arthur Kleinman (Kleinman, 1978) provides an example of medical pluralism in his description of the three sectors of health systems: the popular, the folk, and the professional sector. The popular sector is non-professional; part of the popular culture; and includes home remedies, diet, and exercise. The folk sector is non-professional and made up of specialists in traditional medicine. The professional sector is biomedicine, supported by the state and bureaucratic relationships and procedures. Kleinman (1978) emphasises that the popular sector is the most important because “[...] decisions are made here about both the initial and continuing use of treatments, regardless of the sector from which they originate. It provides the points of entrance into, exit from, and interaction between the different sectors” (Klienman 1980 in Stevenson et al., 2003).

Other authors emphasise that, in medical pluralism, there is not only coexistence and borrowing between traditions (Hill *et al.*, 2022; Cant, 2020), but also the establishment of boundaries and dynamics of mutual exclusion, as shown by Eves and Kelly-Hanku in their study of medical pluralism in Pentecostalism in Papua New

Guinea (Eves and Kelly-Hanku, 2020). This is also highlighted in a literature review on complementary medicine (CM) by Wiese, Oster, and Pincombe (2010), where three conceptual models were identified: incorporation, integration, and pluralism. The first model involves the selective incorporation of some elements of CM. In the second model (integration), there is collaboration between CM and biomedicine according to the patient's needs. In the third model (pluralism), patient autonomy is emphasised, with the level of integration dependent on the patient as a consumer.

However, the theory of medical pluralism has been criticised for its emphasis on the practitioner's perspective (Penkala-Kaweka and Rajtar, 2016), its privileging of biomedical and Western worldviews (Cant, 2020), its perspective of biomedicine as monolithic (Hsu, 2017), its emphasis on individual and micro-sociological aspects (Hsu 2017), and its problematic idea of the possibility of choosing between traditions (Hsu 2017; Capelli, 2011).

It is claimed that medical pluralism does not acknowledge power and authority hierarchies between traditions, such as the authority of biomedicine over other complementary traditions (Lambert, 2012; Stevenson et al., 2003). Furthermore, some scholars (Uibu and Koppel, 2021) have indicated that the use of system-level terminology such as "biomedicine" and "complementary medicine" as exclusive categories promotes polarisation between traditions and does not correspond with the flexibility of individual health choices.

Nevertheless, medical pluralism is still considered an appropriate perspective to explain healthcare (Penkala-Kaweka and Rajtar, 2016; Hsu, 2017).

Discussions of medical pluralism consider medical diversity, in which mixtures and intersections of therapeutic practices are considered beyond medical systems as separate worlds (Hansen, Berntsen and Salamonsen, 2020). Medical pluralism continues showing the reasons behind patient choice. On one hand, through healthcare utilisation approaches in which consumption of healthcare services are the main reason (i.e., availability, financial constraints). On the other hand, social, psychological and cognitive factors are the core reason for choice (Chowdhuri, Kundu and Meyur, 2022).

Some studies have highlighted that medical pluralism is more common among patients with fewer treatment options, such as patients with chronic diseases, including cancer (Hansen, Berntsen and Salamonsen, 2020). Uibu and Koppel (2021) stress that internet forums where people can share experiences and views have also contributed to a growing diversity of healthcare cultures. Other authors state that not only does the health system affect an individual's choices, but individual choices can affect the health system. "This creates a dynamic situation where condition, contexts, needs and choice of health-seeking actions vary" (Hansen, Berntsen and Salamonsen, 2020;341).

An increase in flexibility, movement, and mutual borrowing among systems in therapeutic pathways has led to consideration of other approaches, including the concept of "landscapes". Since the 1990s, the concept of "landscapes" has become more relevant because it draws on "spaces" (a relevant concern in globalisation) and focuses on connections and interdependencies, as opposed to the clearly bounded, demarcated dynamics that medical systems and medical pluralism might imply.

Several concepts have emerged to describe the dynamics between health and space. One crucial example is therapeutic landscapes (Gesler, 1992), as the "[...] healing process works itself out in places (or situations, locals, settings and milieus)" (Tomalin et al., 2019:57). This refers to more-than-human spaces and also includes social and symbolic dimensions. Another example is medical landscapes (Hsu 2008), as "rather than invoking a clearly bounded culture concept with a culturally adept healer in its centre, the notion of medical landscapes implies social processes, relatedness, and movement between foregrounds and backgrounds, and across boundaries" (Hsu 2017, p11). Similarly, medioscapes (Hörbst and Wolf, 2014) are relevant in that they refer to globally dispersed landscapes (not confined to nation states), emphasising the linkages (biological and social) between places, sites, people, and traditions at the local and global levels and the interdependencies among health institutions.

Nonetheless, some issues arise when considering landscapes as a concept. For instance, the division between foreground and background denotes the perspective of an observer (an "outsider"), rather than someone who is involved. Although,



considering a “landscape”, it might seem that the researcher could be more aware of their positionality, the consideration of a background as a “hidden” place, already established and composed, limits the possibility of acknowledging interconnections between foreground and background.

In recent decades, the concept of “assemblages” (diagnostic and therapeutic assemblages, for example) has been applied to health and illness, without anchoring these to specific sites, as landscapes do. For instance, diagnostic assemblage (Locock *et al.*, 2016) refers to the temporal and spatial diversity of the diagnostic moment in which individuals connect and reorder signs and events that are negotiated, assessed, dismissed, and contested. On the other hand, therapeutic assemblages (Trnka, 2021) focus on the interrelations between the social and material (humans and non-humans) that influence the body, health practices, and health outcomes. Furthermore, assemblages of care (Trnka, 2021) are multi-sited, online, and “real” life places in which care and therapeutic elements are enacted.

The concept of assemblage – or “agencement”, a more accurate translation from Deleuze and Guattari (Buchanan, 2021) – involves such notions as disposing, arranging, combining, and ordering. It is, to reiterate, a “relational nexus of bodies, materials, affects and signs which are gathered into an ongoing process of 'arranging'” (Brown & Reavey, 2019:135).

In the context of CS prevention, “assemblages of care” (Trnka, 2021) are a better descriptor. They indicate how diverse elements inter-relate and enact care, enabling the analysis of multiple becomings, flexibility, and connections among elements, even if these are sometimes contradictory. In this study, diverse care practices are enacted, drawing on elements of biomedicine, traditional medicine, curanderismo, traditional midwifery, religion, and online healing care (a more detailed account of this is provided in Chapter 5).

Several distinctions are important to make when considering assemblages. First, assemblages are accomplished temporarily (Andrews and Duff, 2019); they are not fixed. Second, they do not require a particular kind of relationship in advance (Brown and Reavey, 2019). Instead, their interactions enact a particular reality (Law 2011 in

Michael, 2017). Third, in care assemblages, what "constitutes 'care' and 'health' are properties that are entirely relative to the assemblage itself" (Brown & Reavey, 2019:135). Fifth, they take into account formal and informal relations (Duff and Hill, 2022) and, one can add, institutional and non-institutional relationships.

Care assemblages involve several considerations of risk – a discussion that I will approach in the following section.

### Risk

The concept of risk is now omnipresent in medical and sociological studies. It is paramount in disease prevention, particularly in prenatal care, while measurements, calculations, and predictions categorise certain people as "at-risk". In the context of CS, Indigenous people, Afro-descendants, migrants, people of the lower socioeconomic strata, and rural inhabitants are considered at-risk.

Although "risk" refers to specific practices and measurements, it is notable that not all healing practices enact risk. In what follows, I will discuss some accounts of risk.

Risk is defined according to objective and subjective perspectives. An objectivistic approach to risk implies its quantification through statistical techniques to rationalise management and decision-making. This approach is similar to "risk society" (Beck, 1992) in which uncertainties and contingencies that are human-manufactured require individuals to make the right decisions (Woodman, Threadgold and Possamai-Inesedy, 2015).

In contrast, subjectivistic approaches (Lane, 2015; Zinn, 2009) consider risk to be found in different sites, practices, and discourses, while the distinction between "self" and "other" is at the core of the process of constructing risk (Lupton 1999 in Zinn, 2009).

However, the dichotomisation of objective/subjective and rational/irrational regarding risk can be mapped onto the expert–lay debate, in which only one perspective is privileged (typically the scientific one; Ridgeon et al. 1992 in Zinn, 2009). Yet expert knowledge has weaknesses and lay knowledge has strengths, as both refer to certain types of knowledge and rationality (Wynne, 1992, Wynne, 2003, Wynne,

2007). Publics bring broader concerns to definitions and evaluations of risk than experts' models do. Experts' models assume predictability (ideas about control, standardisation, and agency) that are not seen as possible from the public's perspective, with the latter tending to entail more flexible and adaptive models (Wynne, 1996).

Pregnancy is usually seen as uncertain, or risky – mainly because women's bodies are considered inferior to those of men and vulnerable (Lane, 2015; Scamell & Alaszewski, 2012; Ross, 2015; Lupton, 2012). In highly medicalised contexts, the surveillance of women's bodies through statistics, technological interventions, and hospitalisation is indicative of women's objectification in the process of looking for care in medical settings (Ross, 2015, Lupton, 2012). In multicultural settings, the objects of risk are more diffuse and diverse (Lane, 2015) because biomedicine interacts with other ontologies and healing practices, as we see in Colombia. For instance, although risk is not quantified as in biomedicine, traditional medicine advocates certain food prohibitions, the avoidance of certain places, and non-discussion of certain topics, as these are dangerous for the mother and the baby.

Through biomedicalisation (Clarke et al., 2000 in Fosket, 2004), risk is diagnosed, along with diseases and conditions such as pregnancy and childbirth. Predictive models, standardisation, and categories create groups for whom risk is higher or specific risky events are more likely to occur (Fosket, 2004). For a risk to be managed, it is necessary to select, make differences, and establish variations between the "high" and "low" risk categories (Heyman, Alaszewski and Brown, 2012). In many countries, besides bodies, historical, cultural, social, and geographical barriers play a role as risk factors (Lane, 2015).

In Colombia, pregnant women are classified as high-risk or low-risk according to medical and psychosocial conditions. During the first prenatal care appointment, the nurse fills out a form which poses questions about whether the woman lives in a rural or urban area, her socioeconomic status, her employment status, the support she has from her partner and family, and her risk of domestic violence. Taken together, these questions identify the pregnant woman's current level of risk.

The categorisation of “low risk” has been related to normality. However, “normal” is difficult to define, as discussed by Scamell and Alaszewski (2012), in their study of midwives in the United Kingdom, and by Schillmeier (2017), in his studies of disability, which note that ill bodies diverge from what is “normal” or “normative” – that is, they contest what is included in and excluded from biomedical practices.

Although classification as “at-risk” or “high risk” might have negative implications in terms of discrimination, it might also facilitate access to certain health facilities and interventions (Fosket, 2004). When disease and risk are combined, this creates a new category of “patients in waiting”, patients categorised as “at-risk” even though they do not feel ill (Skolbekken, Østerlie and Forsmo, 2012). Risk factors might be environmental (something done to a person), lifestyle-related (what a person does and/or does not do), or embodied (within the person’s body; Kavanagh and Broom, 1998). Embodied risks show that threats are not only in the present but also in the future, a constant threat for an individual. In the case of CS prevention, race and ethnicity are seen as embodied risks because of the way that they are enacted during prenatal care (more on this in the next section).

Science, medicine, governments, and other organisations establish measures for the governance of pregnant women’s bodies. Risk is measured, monitored, and intervened in, particularly for pregnant women. For governments, childbirth as a risk is an important principle to manage at the individual, family, and workforce levels (Lane, 2015). The measurement of pregnancy and childbirth establishes a sense of citizenship and of a “good mother” (Lane, 2015, Scamell and Alaszewski, 2012, Skolbekken, Østerlie and Forsmo, 2012). Specifically, “good mothers” are those who look for assistance, attend prenatal care, follow all the recommendations, and do not question what they have been told (Williamson *et al.*, 2012). Pregnant women are then responsible if something goes wrong because the concept of risk is linked with what Douglas (1990 in Scamell and Alaszewski, 2012) calls “blame culture”. Misfortune is no longer seen through the eyes of religion and sin, but rather assumed to be a product of human agency (i.e., the pregnant woman’s own fault).

In this context, it is important to recall that the responses of pregnant women and their partners to risk depend on the individuals’ judgements of an institution’s

trustworthiness and relevance and the roles of the various related agents, as Wynne has proposed (Wynne, 1996). This means that any analysis of how CS risk is established must engage with particular aspects of Colombian culture, not least concerning race, ethnicity, and gender. I will discuss these aspects in the following section.

### Race and ethnicity

There are several ongoing discussions regarding race and ethnicity in biomedicine and the social sciences. In the latter, race is usually referred to as a difference in physical appearance with a biological basis, while ethnicity is a self-identification by a group in terms of language, religion, and origins (Bradby, 2012; Wade, 2010).

Some scholars emphasise that race and ethnicity are systems of classification, taking different meanings over time (Wade, 2014; Lee, 2007), reminding us of the “[...] struggle over the meaning [...] as socially constructed or biologically real” (Lee, 2007 p. 125).

Amade M'charek (M'charek, 2013), on the other hand, argues that race and ethnicity are relational objects; they are not given but are configurations of relationships between differences. The multiplicity of race and ethnicity and how these are enacted differently in time and space can be acknowledged in the process of examining race and ethnicity in healthcare practices, in the configuration of risky groups, and indeed in the constitution of the Colombian nation.

However, ethno-racial categories appear in clinical and epidemiological research as “culture”, ignoring the different ways in which those categories are lived, practised, and contested, particularly in contexts of intermixing cultures and hybrid identities (Kirmayer, 2012; Karnik, 2001). However, caution must be taken when epidemiological and demographic data are used to inform certain practices related to disease. Categories and subjectivities are also produced, and these might imply specific “moral regimes” that identify which “reproductive bodies are worthy of protection” (Brunson & Suh, 2020; Will, 2009). Such categories allow us to trace the process of inclusion–exclusion, the articulation of people and things in order to comply with particular standards, how actants interact differently in different settings,

and how those standards are contextualised (Bowker & Leigh Star, 2000; Timmermans & Almeling, 2009; Smart et al., 2008).

Race and ethnicity contribute to shaping understandings of disease (how it is explained and what treatment is to follow), clinical decisions, and healthcare service provision. In Colombia, race and ethnicity are closely related to the nation's constitution in a story of continuing inclusion–exclusion. Political action has been taken to acknowledge Otherness, collective rights, and private life (particularly in relation to sex and gender relations) (Wade, 2013). Although race is a contested category, many actants acknowledge multiple racial identities: “[...] ‘internal’ (how we think about ourselves), ‘expressed’ (what we say we are), and ‘observed’ (what others assume based on our appearance)” (Harris and Sim, 2002 in Campbell & Troyer, 2007:751).

During colonisation in Latin America, caste (not race) was the primary system of categorisation. In Colombia, social categories were assigned to people to reflect their “origin” and the kind of behaviour and legal rights available to them (Leal, 2010). The categories included *mestizo*, which was the result of the mixing of Spanish and Indigenous groups; *mulato*, the mix of Spaniards and Africans; and *zambo*, the mix of Africans and Indigenous people. Compared to the other groups, *mestizos* had better access to connections and resources and more legal rights.

When the Colombian nation was established, the idea of *mestizaje* allowed for the common ideal of the nation. *Mestizaje* refers to the encounters between different races in the constitution of the Colombian nation. Although European, Indigenous, and Black people are acknowledged as parts of those encounters, *mestizos*, the category from which *mestizaje* comes, only recognise European and Indigenous backgrounds (Ng'weno, 2007, Cunin, 2004, Leal, 2010). With *mestizaje*, everybody becomes “citizens” in an ideal of equality that erases the differences once portrayed by the caste system. Although this ideal is still present today (Restrepo, Schwartz and Cárdenas, 2014), the problem remains that some groups have been excluded (from national history, nation building, equity). In this story, Black people were considered foreigners who “arrived” and thus did not have the same rights as others (Ng'weno, 2007; Leal, 2010, Hooker, 2005).

During the 1990s, multiculturalism highlighted the difference between how Indigenous and Black people were treated in the constitution. While Indigenous people were recognised as ethnic groups with special rights, Black people were only acknowledged as Afro-descendants under exceptional circumstances and were given different rights to Indigenous people. In this case, while race was treated as evident, ethnicity had to be proven. Afro-descendants must prove their ethnicity, unlike Indigenous people, who demonstrate their ethnicity through their language, communal territory, and traditions (Ng'weno, 2007).

In the literature on collective rights and everyday narratives, there is more emphasis on the political mobilisation of Indigenous and Afro-descendant people than on racial discrimination (Hooker, 2005). Although laws against discrimination have been implemented (i.e., Law 1482 of 2011), race and racism are still present. As stated by Wade, race is and is not a problem. For some people, race is commented on indirectly, through silence or humour (Wade, 2013). Stereotypes and racialised concepts of Indigenous and Black people (Afro-descendants) are still present, such as the image of Black people as good dancers, hypersexual, and promiscuous (Wade, 2010). These stereotypes and racialised notions can affect clinical decisions and healthcare service provision (Geary and Bukusi, 2014; Plotzker, Murphy and Stoltey, 2018; Cardoso *et al.*, 2023).

Race and ethnicity have become pathologised in epidemiological, genetic, and clinical research, with racial categories considered risky (Lee, 2007; Kaufman, 2008; Wade, 2014; Saldaña-Tejeda & Wade, 2018). It is also assumed that race and ethnicity are underlying causes of disease, denying the SDH that – although acknowledged among healthcare workers and researchers – have not been subject to appropriate intervention (Cogburn, 2019). For instance, several papers have indicated that Black and Indigenous people have a higher prevalence of syphilis (gestational and CS) – both in Colombia (Cruz *et al.*, 2013; Korenromp *et al.*, 2018) and worldwide (Cardoso *et al.*, 2023).

Racism has an empirical reality (Bradby, 2012), expressed in societies that reinforce racial inequality (Cogburn, 2019). Many studies show disparities in healthcare

service provision (Ganle, 2016; Kaufman, 2008) and discriminatory behaviour (Ganle, 2016, Uzogara, 2019; Taquette & Meirelles, 2013).

Race, class, and gender have been studied independently. However, there has been more interest lately (mainly in the domain of feminist theory) in understanding how those experiences intersect or are articulated in everyday lives – for example, how people identify differences and sameness, mobilise, and make alliances and enemies (Wade, 2010; Wade et al., 2008).

*Mestizaje* is still acknowledged in Colombia. It is intertwined with gender relations regarding notions of reproduction, genealogy, family, and parenthood (Wade, 2013). *Mestizaje* is a way to control discourses of citizenship and of inclusion and exclusion (Wade, 2013). Furthermore – and in line with the focus of this research – race, ethnicity, and *mestizaje* entail practices of silence, absence, and discontinuity.

There are several reasons why race and ethnicity are relevant to this research. First, many studies have indicated that ethnic and racial groups have a higher prevalence of syphilis and CS in Colombia and worldwide. This has led to those groups being considered “at-risk” (usually without reference to historical and structural inequality), contributing to their stigmatisation and, in Colombia, their territorial stigmatisation. Second, in an attempt to include Indigenous and Afro-descendant groups in the “multicultural” and “pluriethnic” nation, Colombia has made efforts to institute intercultural approaches to health that partially account for those differences but which, from a biomedical perspective, continue marginalising the experiences and knowledge of these groups.

#### Final remarks

In this chapter, I have reviewed the literature from the sociology and anthropology of health and illness, public health, and STS that sheds light on CS-prevention efforts in Colombia. In the following chapters, I will focus on the concepts and approaches that inform my analysis.



My starting point was to argue that disease prevention should not be based on behaviouralist, dichotomous, or reductionist approaches that do not take into account diversity. Relying mainly on biomedical interventions in which the CPG for the prevention of mother-to-child syphilis plays a main role cannot account for the diversity of the contexts, knowledge, and expertise of diverse localities. Furthermore, the assumption of a lack of awareness reinforces deficit models in which only information (and a particular kind of information) is considered relevant. Efforts are being made via the EMTCT Plus (Pan American Health Organization, 2017) strategy to prevent the mother-to-child transmission of several diseases (a fourth-generation intervention, according to Campbell and Cornish 2010), and a mix of other interventions are in evidence in Colombia for the prevention of CS. This is valuable because there is a multiplicity of “publics” (even among healthcare practitioners and administrators). There are also differences between public health traditions, which has created tensions when applying the suggestions of multilateral organisations (the WHO, PAHO) and the Ministry of Health (e.g., encouraging the use of EBM). Moreover, there are differences between clinical and tacit knowledge.

To acknowledge multiple ontologies, I advocate for material semiotics (Mol, 2002; Thompson, 2005; Verran, 2018; Law, 2004), where practices between humans and non-humans enact multiple ontologies. In a multicultural context, and particularly when seeking to prevent CS, several ontologies come into conflict. Some of these conflicts result from a failure to acknowledge and incorporate diverse ontologies. Given these concerns about the excluded, silenced, and disregarded, I also bring attention to matters of care (Puig de la Bellacasa, 2011), which is fundamental to CS prevention beyond matters of fact (Latour, 2004) and technoscientific matters.

By “care”, I refer to relational, contextual, and situated practices (Mol, 2008) that engage with interdependent worlds in constant negotiations. Care involves engagement with various “goods”, mediating between them, with an openness for constant adaptations (Mol and Hardon, 2020). I highlight that care is situated (Schillmeier, 2017) and, unlike certain ideals of positive feelings, involves not only caring but also doing something about it (Puig de la Bellacasa, 2011). I also highlight that the distinction made by Mol (Mol, 2008) between the logic of choice and the

logic of care illuminates some conflictual and contested practices regarding public health and CS prevention. The logic of care acknowledges care practices accomplished by humans and non-humans in which it is not always possible to decide what is best or to define “normal” because knowledge, technologies, and needs are negotiated. However, I do not focus my attention only on the logic of care (Mol, 2008), as other practices and ontologies are also involved beyond the boundaries of biomedicine and biomedical settings.

Drawing from multiple theoretical possibilities, I consider “practices” to be an organised form of activities that involve materials, competences, and meanings (Shove, 2017; Blue et al., 2016; Blue & Spurling, 2017). With the integration of materials, competence, and infrastructure (Shove et al, 2012), we can identify differences in terms of what is neglected, the diverse dynamics among elements, and other practices. Thus, CS prevention can be considered beyond individualistic and behavioural approaches, where materials and infrastructure are also relevant. For instance, in Chapter 4, “Ontological Discontinuities”, there is an indication of how certain practices silence syphilis during diagnosis, treatment, and surveillance. Moreover, a consideration of practice reveals how to enact CS prevention beyond its isolation, in the interconnection with other practices (a bundle of practices) with other diseases (e.g., HIV, hepatitis B, chagas).

In the context of practices, I also focus on collateral realities (Law, 2009), which are produced unintentionally but help to coordinate other practices. In the following chapters, collateral realities are central because they help to elucidate the CS-prevention practices that usually go unnoticed. Some of the collateral realities in CS prevention yield silence, absences, discontinuity practices, care assemblages, taboos, and stigmas that interfere with and further complicate CS prevention.

To approach those practices, I reviewed the literature on fragmentation. Although some practices seem fragmented (either by administrative or healthcare service provision), I agree with Law (Law, 2004) in his claim that reality is not fragmented but rather a “mess” of different realities, overlapping and interfering with one another.

Rather than fragmentation, there is consistent coordination (or lack of) regarding silences, absences, and discontinuity practices. Not only do multiple ontologies clash, contradict, and cooperate (Mol, 2002) when enacting those practices, they also entail diverse temporalities, interests, and attention that marginalise or disregard certain practices.

Despite the differences between their respective theoretical, methodological, and epistemological accounts, I relate postcolonial and decolonial approaches (e.g., Spivak, 2010; Santos, 2006; Santos, 2011; Escobar, 2020) with standpoint theory and matters of care (Haraway, 1988; Puig de la Bellacasa, 2012; Puig de la Bellacasa, 2011) and method assemblage (Law, 2004) from STS to uncover and emphasise the presence of what at times seems absent, silenced, and/or discontinuous.

I refer to Boaventura de Sousa on the “sociology of emergences” (Santos, 2006) to include other knowledge and practices ignored by traditional accounts (including some from sociology). In line with John Law, one can then consider a “method assemblage” (Law, 2004) that allows to make present the bundling of relations between presence, manifest absence, and otherness. These considerations also contribute to the methods employed in this research.

The mix of diverse traditions that I bring to these discussions has the purpose of creating the bridges and dialogues necessary for disease prevention. In line with what Catherine Walsh (Walsh, 2007) says about interculturality, this focuses attention not only on what has been marginalised and become subaltern and negated, but also on dialogic connections.

It is precisely while exploring care practices during pregnancy and labour that one can find assemblages of care (Trnka, 2021), given the multi-sited, online, and “real” life places in which care and therapeutic elements are enacted. The combination of diverse healing practices – including biomedicine, traditional medicine, *curanderismo*, traditional midwives, religion, and online resources – includes more than complementary traditions and biomedicine, as is typically indicated by “medical pluralism” (Hsu, 2017).

Something similar happens while considering certain experiences and bodies “at-risk”. There are mismatches between what are considered “objective” and “subjective” perceptions of risk (Lane, 2015; Zinn, 2009): for instance, pregnant women do not consider living in isolated rural areas as placing them at-risk; rather, they associate risk with having a “medical condition” (e.g., high blood pressure). While these considerations attract more attention to these groups in terms of their need for healthcare service provision, they also encourage discrimination and stigma, particularly for Indigenous people and Afro-descendants in the Pacific region of Colombia.

In the next chapter, “Methods”, I will present the research design and the data collection and analysis along with a reflection on the use of digital methods (in particular, online asynchronous focus groups). I also highlight the importance of situational ethics in online research and hardly reach populations. In addition, I discuss some of the limitations of this study.

## CHAPTER 3 METHODS

This research project had to adapt to the changing conditions of the COVID-19 pandemic, moving away from ethnography in hospitals and primary care settings (as initially envisioned) and into online methodologies. In this chapter, I discuss the methods, research design and strategy, and data-collection methods employed, as well as the limitations of the study. In the following sections, several reflections on online methodologies and their ethical implications are presented, along with details of the study's design, development, and analysis.

This chapter presents three main lessons and an account of how the methods were envisioned and conducted. First, I discuss the flexibility needed to adapt to rapidly changing circumstances. Second, I identify the opportunities that online methodologies (particularly online asynchronous focus groups [OAFG]) can provide for research (including hybrid online–offline research) and I reflect on our assumptions about focus group methods (Estrada-Jaramillo, Michael and Farrimond, 2022). Third, I consider how a more flexible approach to research ethics necessitates continual reflection on research ethics during the research process and facilitates a more connected approach with a changing landscape, as was the case during the pandemic in Colombia. The specific characteristics of the contexts and localities (urban and rural settings with dispersed hard-to-reach populations) also play a main role.

In the first section, I will present the research questions, the study design, and the data-collection process, explaining the rationale behind my choices and how I adapted to the new context and the participants' circumstances during the pandemic. Data analysis is the topic of the second section, where I focus on how silence, absences, and fragmentation played a vital role in the research results and in the analysis. In the third section, I will discuss my reflections on the methods and their ethical implications for online research, explaining why I advocate for a situational ethics perspective. I also highlight the limitations of the study.

Having discussed the chapter's themes and structure, I now turn to the first section, where I present the research questions, study design, and data-collection methods.

### Study design and data collection

This research is the first of its type to focus on CS prevention in Colombia, paying particular attention to the practices and acknowledging different ontologies and more-than-expert perspectives. I chose qualitative methods to uncover the practices within multiple ontologies of CS prevention. Such methodologies are able to highlight multiple, diverse, contradictory practices and identities (Blaikie, 2009; Creswell, 2013; Creswell, 2014).

In particular, “assemblage” – as a theory, as analysis, and technique (Law, 2004) was a fundamental aspect of the research. This allowed me to explore the relational nexus of bodies and materials (Brown and Reavey, 2019), heterogeneity, and emergence (Marcus and Saka, 2006), as well as the non-linear and the diffuse (Campbell and Cornish, 2021). Contrary to Euro–American methodological considerations that draw on the notion of the assemblage, in line with the metaphor of the rhizome (Deleuze and Guattari, 1987), any part of the assemblage can connect with any other part (Michael, 2017).

In what follows, I will provide a brief “natural history” of the project. As will become clear, not only did the methods change in response to the COVID-19 pandemic restrictions, the research approach, focus, and analysis also changed considerably.

### The project’s changing landscape

Before the COVID-19 pandemic, this research was planned as a standard ethnographic study (including interviews and observations) of prenatal care sessions in Cali, Colombia. After the declaration of the coronavirus pandemic by the World Health Organization in March 2020, the Colombian government imposed several restrictive measures to prepare for and cope with the impact of the pandemic to protect against the collapse of the healthcare system. The Ministry of Health established recommendations for healthcare workers carrying out prenatal care sessions, including virtual assistance during pregnancy, the self-isolation of pregnant women with symptoms, and the avoidance of caesarean sections and ultrasounds (Ministerio de Salud y Protección Social, 2020b). Pregnant women and

recent mothers were at the time considered high-risk for COVID-19. Local health authorities could determine whether the prenatal care sessions could be conducted in health care centres, some of the sessions were conducted online or by telephone. The partners and relatives of pregnant women and recent mothers were not permitted to attend prenatal care appointments, tests, or during the birth.

In Colombia, the lockdown started on 25 March and lasted until 31 August 2020, though some restrictions were lifted earlier to allow for the provision of goods and some services. In the healthcare domain, only emergency services were available during the lockdown. GP and prenatal care appointments were conducted online during the first two months of lockdown, unless the woman was classified as high-risk. Face-to-face appointments for pregnant women restarted after two months; but for the rest of the population, appointments and services remained online.

The circumstances of the pandemic changed as the months passed, but restrictions on social interaction, the wearing of face masks, and at-home quarantine remained throughout 2021 in Colombia. The University of Exeter did not allow researchers to conduct research activities involving face-to-face encounters until the end of 2021. Therefore, I decided to amend my choice of methods and opt for internet-mediated methodologies: document analysis, semi-structured interviews, online asynchronous focus groups (OAFGs), and diaries. I also changed the planned site of the study due to the difficulties faced by the healthcare system and healthcare workers – in Cali, Colombia, were dealing with both COVID-19 and a dengue virus epidemic.

I selected two regions in Colombia to conduct the study: Chocó and Caldas. The regions are distinct in terms of CS incidence, healthcare access and provision, public service infrastructure, social and economic inequality, and ethnic composition. These differences provided points of contrast for the analysis of CS prevention. Compared with Caldas, Chocó has historically seen higher incidences of CS (Instituto Nacional de Salud, 2019; 2020), more social and economic inequality, and a higher proportion of Afro-descendant and indigenous populations.

Based on the findings from the literature review, the fieldwork experience, and the iterative data-analysis process, the following research questions were posed:

- 1) How do different care practices in two regions of Colombia currently enact congenital syphilis prevention?**
- 2) What would change if we were to provide good care for the prevention of congenital syphilis in Colombia?**

In the following section, I will provide the rationale for the selection of online methods, given the particularities of the pandemic and the characteristics of the participants and study sites. But first, let me provide an important disclaimer: I will refer to “traditional” considerations with regard to methods (sample size, sample selection, triangulation, etc.) to clarify what happened during the research process and decision-making. However, I will also refer to “messiness” (Law, 2004) and to the non-linear, “subjective”, and less-traditional accounts of methods. This is because it is my intention to not only enrich the exploration of disease prevention, particularly CS prevention, but also facilitate connections between diverse knowledges and epistemological traditions.

#### Methods selection

The present project involved qualitative, multimethod research. A multimethod approach (Creswell *et al.*, 2003) combining diverse methods was selected to explore diverse data types and the different experiences of participants, authorities, and institutions. In this case, the multimethod approach, more than secure triangulation and internal validity (Creswell, 2013), allowed for the exploration of practices and interactions without the need to offer closure, showing the multiplicity, fluidity, and emergence of realities (Law, 2004; Oosterhoff *et al.*, 2021; see below).

My selection for the document analysis was motivated by the need to address images, conceptions, interactions, and practices (Freeman & Maybin, 2011, May, 2011; Creswell, 2014) central to the enactment of CS and the responses to it. Documents also have the capacity to facilitate organisational routines (Dupret, 2019), categorise, and order people, practices, and objects, thereby creating potential chaos and opportunities (Bowker and Leigh Star, 2000). As James Ferguson (1994) and Arturo Escobar (1995) explain, documents – particularly those



from institutions and organisations – allow us to unveil professional knowledge, power relations, planning and implementation practices.

However, one significant disadvantage of these documentary data was that they become less “stable” over time. As Kotamkaju explains, “while digital technology provides opportunities for new forms of research, it should be borne in mind that it lends itself to the creation, modification, destruction, and replacement of information with very little effort and very little cost” (Kotamraju, 1999:467). It is thus vital to consider the contextual elements during the interpretation and analysis of documents (May, 2011). Therefore, semi-structured interviews, OAFG, and diaries were also conducted. These provided contextual and contrasting information, and they were combined with the method assemblage.

I also chose semi-structured interviews because they are one of the most widely used techniques for gathering qualitative data – particularly data on experiences (Hermanowicz, 2002). This is a particularly useful option when participants cannot be “directly observed”, as it can provide historical information and allow the researcher to pursue diverse areas of inquiry (Creswell, 2014). For instance, it allowed comparisons of between before and after the implementation of the CPG and before and during the COVID-19 pandemic.

The nature of semi-structured interviews allows flexibility for exploring topics, as follow-up questions can be developed and put to the interviewee. This allows the researcher to obtain clarification regarding specific issues. Among the disadvantages, however, are that it is not possible to apprehend the “natural” field setting, the presence of the researcher might induce a certain bias in the responses, and some people might feel intimidated and have difficulties articulating their views in an interview setting (Creswell, 2014).

The focus group methodology was chosen for its collaborative dimension, which reveals how ideas appear and are challenged in group interactions (Lobe & Morgan, 2021). Several studies have shown the potential of this method for dealing with sensitive topics and including underrepresented groups (Gordon et al., 2021; Williams et al., 2012; Liamputtong, 2015; Kitzinger, 1994; Reisner et al., 2018).

Furthermore, the possibility of understanding practices and interactions from the participants' perspective – and according to their language – is one reason for focus groups' ubiquity in healthcare research (Flynn et al., 2018; Williams et al., 2012; Reisner et al., 2018; Ranieri et al., 2019; Smithson, 2008).

Online focus groups also have various advantages, including limiting the difficulties of recruitment and reducing costs, while accommodating participants from geographically dispersed areas, and facilitating confidentiality and anonymity (Woodyatt et al., 2016; MacNamara et al., 2021). Regarding their disadvantages, however, some have indicated that participant engagement and contributions might result in fewer and shorter messages, thus lessening the richness of the resulting data (Abrams et al., 2015; Zwaanswijk & Van Dulmen, 2014; Woodyatt et al., 2016; Brüggén & Willems, 2009; Nicholas et al., 2010). However, others (MacNamara et al., 2021; Gordon et al., 2021; Tates et al., 2009) have emphasised their potential to accommodate discussion of sensitive topics. When dealing with taboos and stigmas, there is a strong tendency among study participants towards social compliance, lessened participation, and silence, all of which create several challenges for researchers. This was particularly beneficial for the current study, which concerns several taboo and stigmatised topics, such as STDs and sex during pregnancy. As Kitzinger (1994) indicated in a study about HIV/AIDS, knowing 'too much' about some topics can be seen as problematic, as participants might consider themselves to be associated with the negative connotations of those topics.

Several studies have shown that a key advantage of using diaries in research is that they provide access to personal experiences, such as those of patients and pregnant women. This is particularly beneficial when participants might be reluctant to answer a telephone call or make a video call because of privacy concerns (Ahlin & Li, 2019; Williamson et al., 2012; Day & Thatcher, 2009). During the lockdown, some people struggled to find privacy at home and were unable to discuss certain sensitive issues in front of others. In this study, the diaries allowed participants to share their experiences, while protecting their privacy. Some participants may have felt more comfortable sharing their experiences in this format than during an albeit supportive interview. As stated by (Plumer, 1983 in Alaszewski, 2011), "The diary is the

document of life par excellence, chronicling as it does the immediately contemporaneous flow of public and private events that are significant to the diarist” (Alaszewski, 2011:16). However, it is also well known that diaries have several drawbacks. For example, the diarist can lose interest in the project; literacy levels and language barriers can be an obstacle; and the data can be unfocused, not relating directly to the research project, which can detract from the analysis. It might also be necessary to provide time-consuming training and support to participants to create the diaries (Snowden, 2015; Alaszewski, 2011).

Given the various methods used, one might ask whether this research project could be labelled a digital ethnography. Why refer to internet-mediated methodologies instead of digital ethnography? Recent studies have discussed the diverse ways in which digital research can be conducted (Lupton, 2014; Pink et al., 2016; De Seta, 2020; Androutsopoulos, 2008; Bluteau, 2021). Indeed, several characteristics from both ethnography and digital ethnography are present in this research project, especially if one refers to the definition of ethnography as “iterative–inductive research (that evolves in design through the study), drawing on a family of methods [...] that acknowledges the role of the theory as well as the researcher’s role and that views humans as part object/part subject” (O’Reilly, 2005 in Pink et al., 2016:2).

Classical approaches to ethnography problematise not being “there” in the “field” (Paoli & D’Auria, 2021), as was the case with this research. However, several authors (Lupton, 2014; Pink et al., 2016; Bluteau, 2021; De Seta, 2020) have contested that stance in light of the opportunities offered by digital research. Pink (2016) proposes several ways in which a researcher can be “there” – from face-to-face (physically present); remotely present; virtually, as in a “third place”; or imaginatively. She also establishes the concept of “ethnographic place” (Pink et al., 2016) as the interconnection of people, places, and objects that are grouped for the research aims. Similarly, Lupton (2014) argues that the participant observer need not be at a specific, well-defined field site.

Having considered these arguments, I would say that, in my research, I was present as the researcher in multiple forms (remotely, virtually, and imaginatively) and in a number of places – through mobile calls, WhatsApp chats, TikTok videos, YouTube

videos, and apps. The ethnographic place was a collection of research participants, places (Manizales, Quibdó, Lloró, Riosucio, Cali, Buenaventura, Exeter), multimodal data (songs, emojis, stickers, links), mobile phones, WhatsApp messages, webpages, apps, social media platforms, and elsewhere on the internet.

However, it remains unclear whether this research can be considered a digital ethnography, especially given the importance granted to observation or, as others have indicated, the prevalence of sight (Stoller, 1989; Rice, 2003). While working with the Songhay in Niger, Stoller (1989) found that the community considered taste, smell, and hearing to be more relevant than sight, as is usually the case in Western societies. Visual observation is foundational in ethnography (digital and otherwise) and in knowledge production.

My participant observation in this research was limited. The research participants and I were navigating the online–offline boundaries where, instead of seeing, we heard, read, felt, and imagined – and where I composed this “ethnographic place”. Nonetheless, I did not fully “witness” the research participants’ practices. Despite the criticisms established above about the foundational principle in ethnography (Fine, 1993), I am unable to provide a definitive statement as to whether this research is digital ethnography.

Moreover, given the possibilities of assemblage as a theory, a technique, and as analysis (Law, 2004), one might consider this research close to other recent ethnographies known as “assemblage ethnography” (Wahlberg, 2022; Ghoddousi and Page, 2020), which are more interested in “connections between levels and forms of social process and action, and exploring how those processes work in different sites-local, national and global” (Wahlberg, 2022:13).

However, what the pandemic has thrown into relief is that virtuality is now a central part of many societies and that data can take many forms. This suggests that there needs to be an ongoing discussion about what it means to do ethnography (Estrada-Jaramillo, Michael and Farrimond, 2022).

## Data collection

Ethics approval from the University of Exeter Committee was granted in November 2020, with the code 202021-018. The project also received approval from the Secretaries of Health of Quibdó (Chocó) and Caldas, *Corporación Sagrada Familia* (NGO) and *ASOREDIPARCHOCÓ* (Association of Traditional Midwives of Chocó). Obtaining approval from the latter involved an extended negotiation because, in this region, there is resistance to research due to complaints of “intellectual extractivism” (Grosfoguel, 2016). In other words, there is often no sense of tangible benefits of research conducted in the region after researchers have finished their projects. A more detailed discussion of these ethical issues and procedures is presented in the third section of this chapter.

For the interviews, OAFG, and diaries, I used a snowball sampling strategy and, when possible, maximum variation sampling (Creswell, 2013). This allowed me to access more of the complexity, variation, and contextual elements. For the document analysis, criterion sampling (Creswell, 2013) was employed for the documents most relevant to CS prevention, some of which were suggested by research participants.

Participants were recruited through the Secretaries of Health, an association of traditional midwives in Chocó (*ASOREDIPARCHÓ*), *Corporación Sagrada Familia* (NGO in Manizales), acquaintances from previous jobs, and referrals from participants. All potential participants received an information sheet about the research project, complemented by an infographic for pregnant women and recent mothers and an informed consent form.

All of the queries from potential participants were answered. Those who decided to participate (in interviews or OAFGs or by completing diaries) signed the informed consent. The healthcare workers and administrators sent the completed consent form by email or over WhatsApp; while the pregnant women, recent mothers, their partners, and traditional midwives replied to each question as a WhatsApp text or audio message.

I conducted the online fieldwork between January and August 2021. This included 47 interviews, 3 OAFGs, 3 diaries, and the analysis of 7 documents.

**Table 3 Human Participants**

<b>Region</b>	<b>Participant Type</b>	<b>Age Range</b>	<b>Notes</b>
National level	Researcher	35–54	Interview on Skype without video. Female epidemiologist researcher in congenital syphilis.
Chocó	Healthcare worker	35–54	Interview via mobile phone. Female Afro-descendant bacteriologist.
Chocó	Healthcare worker	18–34	Interview via mobile phone. Female nurse prenatal care.
Chocó	Healthcare worker	35–54	Interview via mobile phone. Female Afro-descendant bacteriologist.
Caldas	Recent mother	18–34	Interview via WhatsApp. Indigenous healthcare worker on maternity leave. Preconception counselling, two children, contributory healthcare.
Caldas	Healthcare worker	55–64	Interview via mobile phone. Male paediatrician.
National level	Healthcare administrator	35–54	Interview via mobile phone. Female public health practitioner.
Chocó	Recent mother	18–34	Interview via mobile phone. Afro-descendant. First-time mother. Professional on maternity leave, contributory healthcare.
Caldas	Recent mother	18–34	Interview via mobile phone. Indigenous, first-time mother. Independent sales job.
Chocó	Healthcare worker	18–34	Interview via mobile phone. Female epidemiologist.
Caldas	Recent mother	18–34	Interview via mobile phone and OAFG. Mixed background, three children, informal worker, subsidised healthcare, no support from partner.

National level	Researcher	35–54	Interview via mobile phone. Female medical specialist. Researcher on syphilis. Participant in the development of the CPG.
Caldas	Recent mother	18–34	Interview via mobile phone. Two children, unemployed, subsidised healthcare, supported by partner.
Caldas	Traditional midwife	35–54	Interview via mobile phone. Indigenous traditional midwife.
Caldas	Pregnant woman	18–34	Interview via mobile phone. First-time mother. Mixed background, administrative job, contributory healthcare, no support from partner.
Caldas	Pregnant woman	18–34	Interview via mobile phone and OAFG. Mixed background, first-time mother. Administrative job, contributory healthcare, support from partner.
Caldas	Pregnant woman	18–34	Interview via mobile phone and OAFG. Preconception counselling, first-time mother, mixed background, administrative job, on leave, contributory healthcare, support from partner.
National level	Healthcare administrator	55–64	Interview via mobile phone. Nurse, specialist in STI prevention.
Caldas	Recent mother	18–34	Interview via mobile phone and OAFG. Indigenous, first-time mother, informal worker, contributory healthcare, support from partner.
Caldas	Partner	18–34	Interview via mobile phone. Male, first-time parent, professional, contributory healthcare, attends preconception counselling and prenatal care appointments.
National level	Midwife	35–54	Interview via mobile phone. Female midwife trained in the US.

Caldas	Pregnant woman	18–34	Interview via mobile phone. Second pregnancy, 27 weeks, subsidiary healthcare, support from partner.
Caldas	Pregnant woman	18–34	Interview via mobile phone. First pregnancy, 30 weeks, contributory healthcare, housewife, changed healthcare service provider during pregnancy, support from partner.
Caldas	Pregnant woman	18–34	Interview via mobile phone. First-time mother, subsidiary healthcare, support from partner.
Caldas	Pregnant woman	18–34	Interview via mobile phone and OAFG. First-time mother, undocumented migrant from Venezuela, unemployed, support from partner.
Chocó	Pregnant woman	18–34	Interview via mobile phone. Second pregnancy, 13 weeks, lawyer with a job contract, contributory healthcare, support from partner.
Caldas	Partner	18–34	Interview via mobile phone. Male, documented migrant from Venezuela, casual jobs.
Caldas	Pregnant woman	18–34	Interview via mobile phone, OAFG, and diary. Mixed background, five children, unemployed, subsidiary healthcare, internally displaced person, support from partner.
Caldas	Healthcare worker	35–54	Interview via mobile phone. Male, sexologist.
Caldas	Pregnant woman	18–34	Interview via mobile phone. Three children, 34 weeks, contributory healthcare, housewife, support from partner.
Chocó	Pregnant woman	18–34	Interview via mobile phone. First pregnancy, positive congenital syphilis diagnosis, unemployed, subsidiary healthcare.



Chocó	Pregnant woman	18–34	Interview via mobile phone. First pregnancy, subsidiary healthcare, problems with healthcare service provider from different municipality.
Caldas	Partner	18–34	Interview via mobile phone. Male, three children, contributory healthcare, technician.
Caldas	Recent mother	18–34	Interview via mobile phone. First-time mother, housewife, contributory healthcare, problems with healthcare service provider due to change of subsidised healthcare provider.
Caldas	Recent mother	18–34	Interview via mobile phone and OAFG. Two children, mixed background, employed, contributory healthcare.
Chocó	Pregnant woman	18–34	Interview via mobile phone and OAFG. Afro-descendant, two previous pregnancy losses, 34 weeks pregnant, subsidiary healthcare, support from partner.
Caldas	Healthcare worker	35–54	Interview via mobile phone. Female perinatologist.
Caldas	Healthcare administrator	35–54	Interview via mobile phone. Female, nurse staff from Secretary of Health.
Chocó	Traditional midwife	35–54	Interview via mobile phone. Female nurse and traditional midwife. Afro-descendant.
Caldas	Healthcare administrator	18–34	Interview via mobile phone. Male sexologist.
Chocó	Pregnant woman	18–34	Interview via mobile phone. One child, contributory healthcare, problems with healthcare service provider due to recent job contract, support from partner.
Chocó	Traditional midwife	More than 65	Interview via mobile phone. Female, Afro-descendant.

Chocó	Traditional midwife	35–54	Interview via mobile phone. Female, Afro-descendant.
Caldas	Healthcare administrator	35–54	Interview via mobile phone. Female nurse in charge of collective intervention plans for disease prevention.
Caldas	Healthcare worker	35–54	Interview via mobile phone. Female nurse in charge of prenatal care.
Caldas	Healthcare worker	18–34	Interview via mobile phone. Female junior doctor in charge of prenatal care.
Chocó	Healthcare administrator	35–54	Interview via mobile phone. Female professional working at the Secretary of Health.
Caldas	Pregnant woman	18–34	Diary. Another child in addition to the baby, housewife, subsidiary healthcare, support from partner.
Caldas	Pregnant woman	18–34	Diary. Two children, casual jobs, subsidiary healthcare, support from partner.
Caldas	Recent mother	18–34	OAFG. First-time mother, housewife, contributory healthcare, support from partner.
Chocó	Recent mother	18–34	OAFG. Afro-descendant, one child, unemployed, subsidiary healthcare.
Caldas	Recent mother	18–34	OAFG. First-time mother, undocumented migrant from Venezuela, unemployed, support from partner.
Caldas	Recent mother	18–34	OAFG. One child, mixed background, subsidiary healthcare, housewife, support from partner.
Chocó	Recent mother	18–34	OAFG. Afro-descendant, three children, subsidiary healthcare, support from partner.
Chocó	Recent mother	18–34	OAFG. Afro-descendant, two children, subsidiary healthcare.

Chocó	Recent mother	18–34	OAFG. Afro-descendant, first-time mother, contributory healthcare, maternity leave.
Chocó	Recent mother	18–34	OAFG. Afro-descendant, first-time mother, subsidiary healthcare, support from partner.
Chocó	Pregnant woman	18–34	OAFG. Afro-descendant, first-time mother, subsidiary healthcare, no support from partner.
Chocó	Recent mother	18–34	OAFG. Afro-descendant, sales job, contributory healthcare, support from partner.

*Figure 5*

**Table 4 Documentary sources**

<b>Institution /Author</b>	<b>Source type</b>	<b>Description</b>	<b>Access</b>
Ministry of Health	Secondary	Clinical practice guidelines for the prevention of mother-to-child syphilis transmission, 2013	Webpage
Ministry of Health	Secondary	Clinical practice guideline for pregnancy, birth complications, 2013	Webpage
	Secondary	Law 1751 of 2015 in Health. Includes intercultural health, 2015	Webpage
Ministry of Health	Secondary	Preconception Counselling Protocol, 2014	Webpage
ASOREDIPARCHOCÓ Traditional Midwives Association of Chocó	Secondary	Traditional midwifery systematisation of experiences, 2021	Unpublished internal document from the Association

			of Traditional Midwives of Chocó
National Institute of Health	Secondary	Gestational and congenital syphilis incidence and prevalence report, 2020	Webpage
National Institute of Health	Secondary	Gestational and congenital syphilis incidence and prevalence report, 2021	Webpage

Figure 6

I now turn to the data-collection and -analysis methods.

#### Documents

Documents were retrieved from the internet based on the following criteria: published from 2014 to 2022; related to CS, GS, syphilis, prenatal care, or giving birth; and focused on – or with implications for – Colombia. Some of these documents were selected after initial referral by researchers, healthcare workers or administrators, or traditional midwives.

The documents selected for the analysis were the Clinical practice guidelines for gestational and congenital syphilis (CPG) (Ministerio de Salud y Protección Social, 2013a), the Clinical practice guideline for pregnancy and birth complications (Ministerio de Salud y Protección Social, 2013b), Law 1751 in Health (Intercultural Health Law) (Ley 1751 de 2015, 2015), *Protocolo de Atención Preconcepcional* [Preconception Counselling Protocol] (Ministerio de Salud y Protección Social, 2014), *Sistematización de experiencias de parteras ASOREDIPARCHOCÓ* [Systematisation of experiences] (ASOREDIPARCHOCÓ, 2021), and reports from National Institute of Health regarding CS and GS prevalence during 2020 and 2021 (Instituto Nacional de Salud, 2020; Instituto Nacional de Salud, 2021).

#### Interviews

I conducted 47 interviews between January and August 2021 over Skype (1), WhatsApp (1), and mobile phone (45). I interviewed 9 healthcare workers, 10

healthcare administrators, 2 researchers, 27 pregnant women or recent mothers, and 2 partners.

The interviewees ranged between 19 and 70 years old (with the eldest being an Afro-descendant traditional midwife). Thirty self-identified as “mestizo” (mixed background), 14 were Afro-descendants, and three were Indigenous. Five of the interviewees were men: one was a gynaecologist, two were healthcare administrators, and two were male partners (one of whom was an international migrant from Venezuela).

I asked all the interviewees questions about pregnancy, prenatal care, motherhood, and CS prevention but focused more on healthcare service access and provision when interviewing healthcare workers and administrators. A £3 voucher was given to pregnant women, recent mothers, partners, and traditional midwives in return for the participation.

The interviews were conducted in Spanish, and the audio was recorded digitally with the agreement of the interviewees. I then transcribed the recordings, combining verbatim transcription with my notation on the participants’ nonverbal expressions (Halcomb & Davidson, 2006). I paid particular attention to pauses, interruptions, silences, changes in tone of voice, background sounds, laughter, word repetitions, and hesitations, and I indicated those in the transcriptions in the style and conventions of conversational analysis (Oliver et al., 2005).

#### Online asynchronous focus groups (OAFGs)

After receiving information about the OAFGs, 19 pregnant women or recent mothers decided to participate. They sent their informed consent through WhatsApp, replying to each question with a text or audio message.

I provided dedicated SIM cards and mobile top-ups for participants to use during the duration of the OAFG (3 days). A £5 voucher was offered as compensation for their participation, and they were each given the option of keeping the dedicated SIM card after the completion of the sessions. The dynamic was explained to the participants and each person was assigned a pseudonym (i.e., “Participant #”). WhatsApp groups were created the day before the OAFGs began, with up to seven participants

in each group. Three OAFGs were conducted between April and July 2021. A more detailed account of and reflection on the OAFGs can be found in (Estrada-Jaramillo, Michael, and Farrimond, 2022).

The participants in Focus Group 1 were women aged between 24 and 38 years, living in Manizales and Riosucio. Five self-identified as “mestizas”, one of whom was an internally displaced person (IDP) due to armed conflict and another was Indigenous. In the second focus group, there were seven participants, all living in Manizales, Quibdó, or Lloró and aged between 20 and 28 years. Five of these participants self-identified as “mestizas”, two of whom were undocumented migrants from Venezuela and two were Afro-descendants. Focus Group 3 included women from Quibdó and Lloró, all of whom were Afro-descendants.

Participants were encouraged to share their thoughts, feelings, and opinions through text and voice messages, memes, pictures, songs, and links and to comment on each other’s comments, even those shared hours or days previously. The topics for discussion included issues related to pregnancy, birth, and motherhood; sex during pregnancy; and support from healthcare workers, partners, and relatives.

After the OAFGs were completed, I transcribed the contents, including all text and audio messages (with contextual information as background sounds); information about the times when the messages were sent; songs; images; stickers; TikTok videos; and emojis.

#### Diaries

After receiving an infographic of the project and the information sheet, three pregnant women agreed to participate by writing diaries. They provided their informed consent to participate. The women were aged 27–34 years, self-identified as *mestizas*, were living in Manizales, and they completed their journals between March and August 2021. Two of the women used WhatsApp. The third woman completed a handwritten diary but sent pictures of her diary over WhatsApp.

I encouraged the women to share their thoughts, feelings, and opinions about their experiences during pregnancy and to use text, images, songs, videos, and so on. On one specified day each week of the three-month period, I reminded the

participants to journal. I also provided mobile top-ups for each week in which they were participating.

The participants collectively wrote 15,131 characters: 6,422 words, 2,918 words, and 5,791 words. They also shared a video, two pictures, seven drawings, and various emojis. I completed a verbatim transcription of the messages, including textual descriptions of the images and videos.

#### Fieldnotes and WhatsApp messages

While conducting the fieldwork, I took notes in the form of questions, descriptions, and reflections on the research process. I also took notes on the WhatsApp messages, emails, and telephone calls to gather contextual information, even though these communications were not technically included among the methods. For instance, one participant revealed her positive gestational syphilis diagnosis after an interview, and this helped me to approach that interview from a different perspective. Other participants messaged me before, during, and after the OAFGs. Some of these messages emphasised their experiences as a continuous online–offline interaction, leading me to reflect on the focus group methods. Moreover, while there was a formal and institutional approach with the healthcare workers and administrators, most of my interactions with the participants (including potential participants) were via WhatsApp. Their responses – or lack of responses – also gave me valuable insights for the analysis.

#### Data analysis

Assemblage, particularly method assemblage (Law, 2004), was an important concept and methodological approach in this study. Assemblage is a “relational nexus of bodies, materials, affects and signs which are gathered into an ongoing process of arranging” (Brown and Reavey, 2019:135).

Assemblage, as a theory and an analytical tool, was well suited to this research because the work was focused on interactional processes (Brown and Reavey, 2019), allowing us to consider relationships between stability and transformation (Duff, 2023) – and as a rhizome (following the metaphor of Deleuze and Guattari), any part of the assemblage can connect with any other part (Michael, 2017). The

rhizome links non-linear, diffuse, everyday actions and agencies in the process of social change (Campbell and Cornish, 2021).

This research dealt with multiple materials (human and non-human), multiple ontologies, and multimodal data sometimes enacted as “data fragments”. The data and analysis were constantly moving between multiple trajectories, “layers”, or “dimensions” (international, national, regional, and local). Moreover, method assemblage, as Law (2004) states, has “widened the notion of ‘method’ to include not only what is present in the form of texts and their production, but also their hinterlands and hidden supports” (p.144). Certain parts are emphasised, while others are left to be accounted for, or “othered”.

The flexibility of method assemblage allowed me to explore, combine, and recombine fragments, ideas, traditions, and even methods. When reflecting on the OAFGs, I occasionally used elements of discourse analysis (Van Dijk, 2003; Wodak and Weiss, 2003), thematic analysis (Nowell *et al.*, 2017; Naeem *et al.*, 2023; Braun and Clarke, 2006), and argumentative interaction (Kitzinger, 1994). (More detail in later paragraphs).

For the discourse analysis, I identified key arguments, metaphors, and emotive language; deciphered relevant meanings; and attempted to access what was “behind” the words. When analysing the documents, I used rhetorical analysis (Van Dijk, 2003) to identify the audience, purpose, context, intentions, and possible connections with other documents. And as Gill and Whedbee (2000) advocate, I constantly interrogated the documents for omitted information.

I moved between inductive and deductive strategies in a constant iterative process that was much messier than this methodological section could detail. Although some methods include specific theoretical approaches, the central theoretical perspective of this research was one of material semiotics and Post-ANT, which raised several challenges for the analysis because materials are granted agency.

In the following paragraphs, I will detail the analytical process. It is important to keep in mind that, in reality, this was far from continuous and linear. In this text, I grouped



the analytical activities by stage for the sake of comprehension, but in practice, some of these stages were co-occurrent.

#### Stage 1:

Before starting the online fieldwork, I read a selection of documents, including the Clinical Practice Guideline for gestational and congenital syphilis (CPG) (Ministerio de Salud y Protección Social, 2013a), the Clinical Practice Guideline for pregnancy and birth complications (Ministerio de Salud y Protección Social, 2013b), *Protocolo de Atención Preconcepcional* [Preconception Counselling Protocol] (Ministerio de Salud y Protección Social, 2014), and the reports from the National Institute of Health regarding CS and GS prevalence during 2020 and 2021 (Instituto Nacional de Salud, 2020; Instituto Nacional de Salud, 2021).

I identified the themes, actants, processes, and interactions. I then used some of these elements to develop the interview questions, especially those put to healthcare workers and administrators. These questions concerned prenatal care and CS-prevention challenges, administrative barriers, healthcare service provision, intercultural health, and interactions with traditional midwives.

#### Stage 2:

I familiarised myself with the data by reading (documents and transcripts), listening (interviews, voice messages, songs), viewing (emojis, stickers), and navigating (webpages, links). This familiarisation with the data occurred before, during, and after the transcription of the interviews, OAFGs, and diaries. I took notes in the form of questions to ask the data, comments about potential patterns, and observations of aspects that caught my attention.

#### Stage 3:

I identified the initial categories and themes, focusing on the interviews and OAFGs. I used an Excel sheet to record the categories and themes associated with the health agencies, healthcare workers, healthcare administrators, and pregnant women and

recent mothers. I also included initial descriptions and extracts from the interviews and OAFGs (see Figure 3).

CATEGORY	Health care workers	Pregnant women	Traditional Midwives	Secretaries of Health	Health Agencies
SILENCE	Epidemiological silence. There is not enough report cases in most places. Also staff from Secretaries of Health delete cases or changes the municipality of occurrence.			Epidemiological silence. There is not enough report cases in most places. INS remove cases and other Secretaries remove cases. Report cases as foreign cases even if the patient has been more than three months in the country. Problems with case definition. Some people prefer to do the treatment particular so it does not appear in the medical record	National Health Institute: Epidemiological Silence. Municipalities do not report or misreport cases
	Silence about pregnancy in Quibdo and Lloro. "Trama - trama". Do not tell the date of birth or much information regarding pregnancy and special characteristics of newborns.	Silence about pregnancy in Quibdo and Lloro. "Trama". Do not tell the date of birth or much information regarding pregnancy. It will lead to birth complications	Silence about pregnancy in Quibdo and Lloro. "Trama". Do not tell the date of birth or much information regarding pregnancy. It will lead to birth complications		
	Sex during pregnancy. Few questions and conversations, pregnant women laughing nervously. Taboo	Sex during pregnancy. Few words, few questions. Fear, discomfort. Something accepted because of their partners. Enjoyed during first months of pregnancy. More emphasis on baby's health	Emphasis on pregnant women's wellbeing. It is not encourage during last weeks of pregnancy and during "dieta" (after giving birth)	Sex during pregnancy. Few questions and conversations, pregnant women laughing nervously. Taboo	
	Syphilis signs - if not pain the do not ask. Certain body parts silenced. When healthcare workers do not touch pregnant women, do not look at them during the prenatal care or the appointment.	Doctors are more into filling forms - writing or looking into the computer than paying attention to me and my baby	Syphilis is a disease of western medicine. I do not treat syphilis, I refer to the hospital.		
	Talking about diagnosis with partners - contacts	Talking about diagnosis with partners - contacts. There is much things hide - it's a matter of trust			
BODY	Body parts touch - seen: belly, hands - feet (alarming signs pregnancy). Belly (baby stimulation). Body parts not seen: anus, genitalia, mouth.	Body parts touch - seen: belly. Body parts not touch -seen: anus, genitalia, breast. Sometimes not seen - touch during prenatal care	Barely seen while Indigenous is giving birth and midwife is Afro (genitalia). I touch, see belly, genitalia, legs, feet, hands		
	If doesn't hurt or discomfort there are no	If doesn't hurt or discomfort there are no questions - consultation. When I was diagnosed I look at my body and especially to his body if there were lesions or			

Figure 7

Table 5 Initial Categories and Themes

#### Stage 4:

I selected the themes and subthemes and established connections through mind maps. The rationale behind the selection concerned not only repetition of the themes (Naeem *et al.*, 2023) but also theoretical connections with aspects of the initial research questions. I included provocative themes that had metaphorical richness. For instance, silence was a recurring theme, including “epidemiological silence” (see Figure 4). I also include a theme titled “miscellaneous”, which included categories and sub-themes that had no “clear” connection to other aspects or which seemed “less relevant” than others. Unlike in traditional thematic analysis (especially with

grounded theory), I was not looking for consensus, as proposed by McGaw and Vance (2023). It was important to explore the “controversies”, negotiations, and contradictions that occur when attempting to prevent CS. Twelve themes were particularly salient, and I decided to incorporate these into the three findings chapters: care practices, ontological fragmentation, and taboo and stigma. The themes were silence, fragmentation and discontinuity, the body, syphilis, sex practices, pandemics, risk and danger, gender, care, sex education, taboo and stigma, and pregnancy.

**Mind Map 1. *Tiempo* (Time) – Themes and Subthemes**

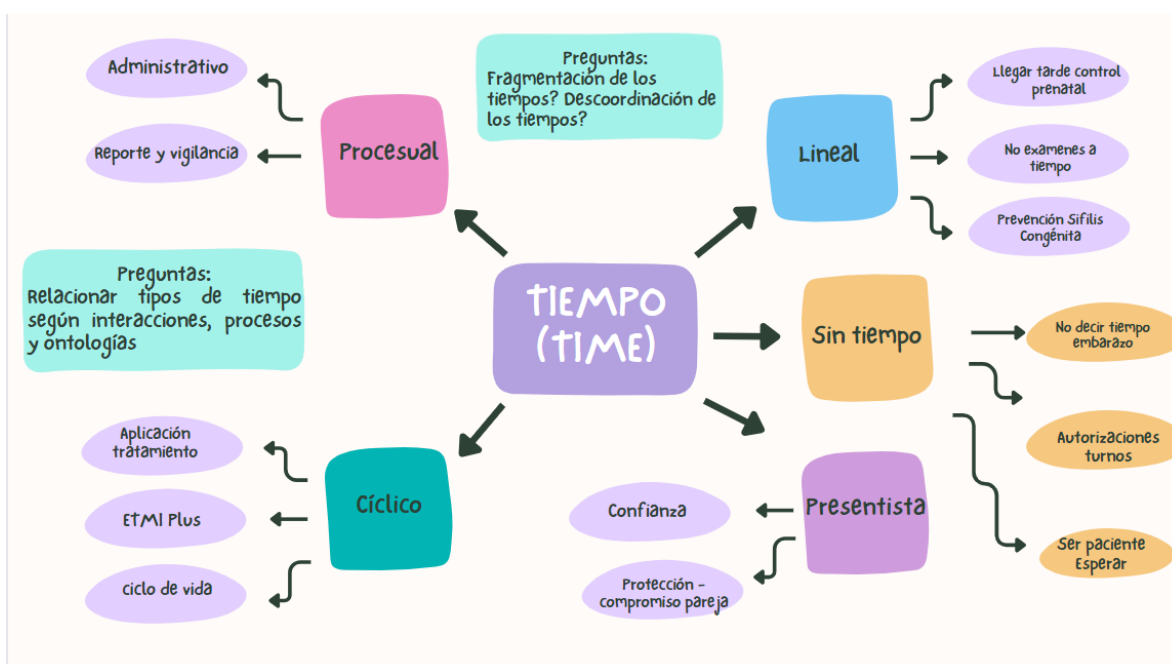


Figure 8

Mind Map 1 Tiempo Themes and Subthemes

Stage 5:

I decided the focus of the findings chapters as follows: ontological fragmentation, care practices, and taboo and stigmas. I then conducted more specific analysis of these themes when writing the chapters. As explained by Braun and Clarke (2006), analysis involves a constant moving back and forth, even while writing. For each chapter, I looked again through the references and introduced new concepts and

ideas to create “dialogue” with the data. For instance, rereading Mol (2002;1999) and Law (2004) helped me to focus more on the discontinuities and trajectories that arise when seeking to prevent CS, rather than focusing on ontological fragmentation.

#### Stage 6:

I focused on the outcomes of the OAFGs, reflecting on the characteristics of the data and on its themes and patterns. I then wrote an article about the data characteristics, fragmentation, and participants’ engagement, experiences (online and offline, and private and public); silences; and discontinuities. Given the challenges of asynchronicity and fragmentation, I followed the idea of argumentative interaction (Kitzinger, 1994) to make sense of the data. I found argumentative interaction regarding risk, labour, being *primeriza* [a first-time mother], sickness or illness during pregnancy, weight (diets, losing or gaining weight), and adequate care and treatment for pregnant women and babies. I also identified differences between the three OAFGs in terms of the interactions and the categories covered in the discussions. For instance, in OAFG 3 – where all participants were Afro-descendant – there were no conversations about “risk”.

#### Stage 7:

I conducted a more detailed analysis for Chapter 4, “Ontological discontinuities”, initially titled, “Ontological fragmentation”. I explored the documents and interviews, searching for themes of fragmentation, silence, absences, and multiple ontologies. After completing an initial draft of the chapter, I began to analyse certain types of silences (“falling silent”, “making silent”, and “choosing silence”), looking at the types of interaction, their meanings, and the agencies involved in those. Also, since practices became relevant, I also looked at certain activities in order to reveal the silences and absences in terms of materials, competences, and meanings (see Figures 5, 6, and 7).

## Mind Map 2. Section A “Materials”

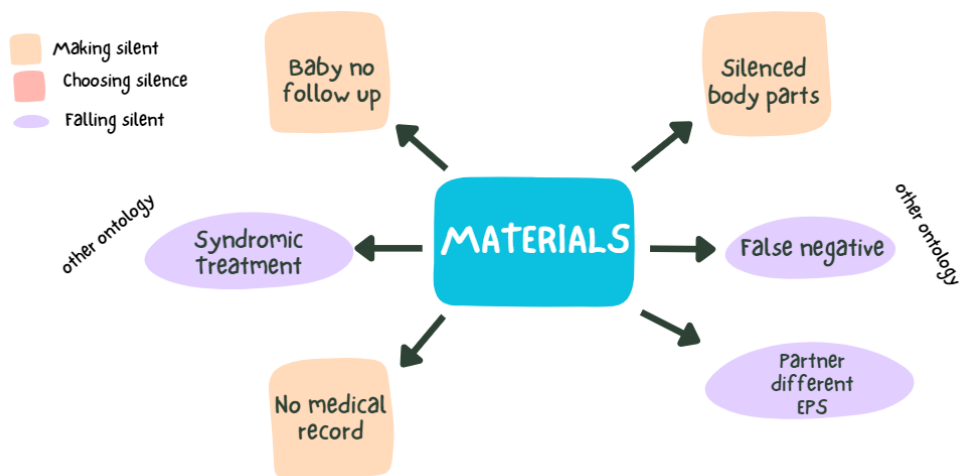


Figure 9

Mind Map 2 Section A Materials

## Mind Map 2. Section B “Competences”

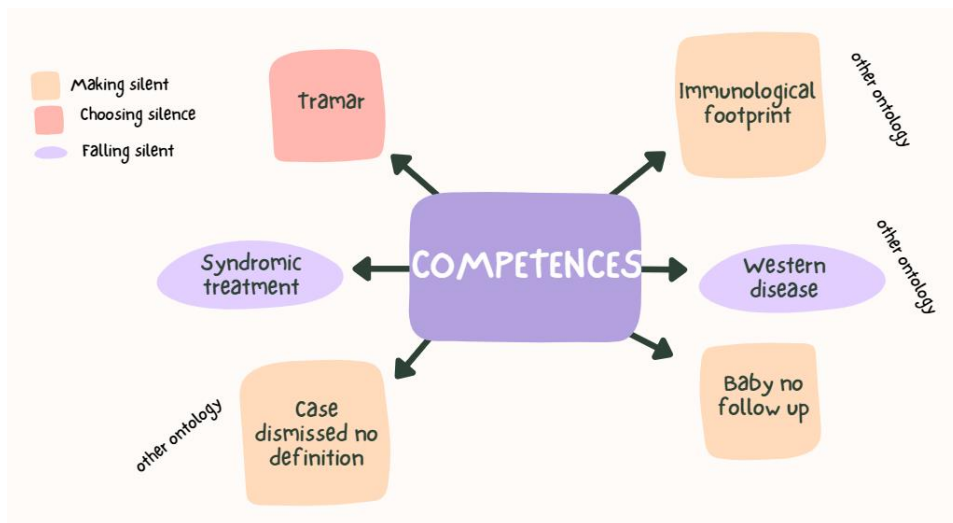


Figure 10

Mind Map 2 Section B Competences

## Mind Map 2. Section C “Meanings”

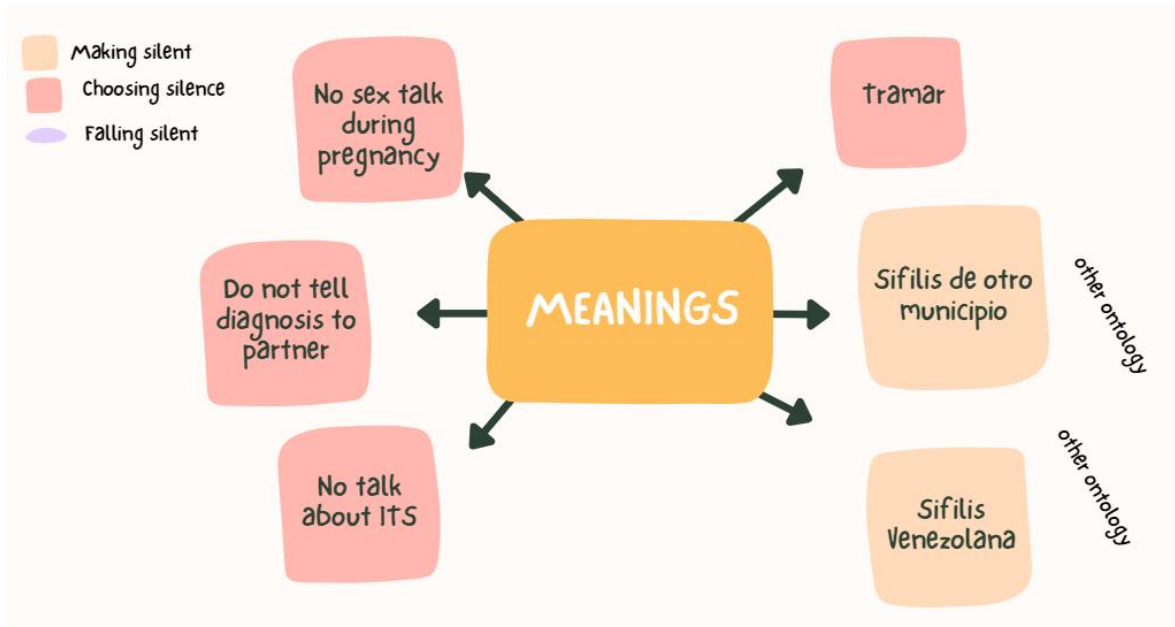


Figure 11

### Mind Map 2 Section C: Meanings

Stage 8:

For Chapter 5, “Care assemblages”, I analysed the texts of the interviews and OAFGs, diaries, other documents, links, videos, songs, and webpages and became a user of an app called “BabyCentre”, which some of the pregnant women had used and recommended. My analyses focused on silences, metaphors, and themes.

Stage 9:

For the sixth chapter, “Taboos and stigmas”, I focused on silences, negative valuations, metaphors, and related themes. In the second draft of the chapter, I paid particular attention to absences, manifest absences, and othering (Law, 2004). I also explored the different ways in which territorial stigma was enacted.

The previous sections have described the processes of data collection and analysis, and the following section presents my reflections on the methods and research ethics.

#### Reflections on the limitations of the study, methods, and research ethics

The circumstances of the COVID-19 pandemic imposed several limitations on the study, mainly regarding access. Most healthcare workers and administrators were burdened with new responsibilities related to the pandemic, in addition to those that they would normally have. For instance, staff from the Secretaries of Health who usually worked in the areas of maternal health or STDs were also assigned to COVID-19-related activities. This was particularly challenging in Chocó, where I was unable to interview GPs or medical specialists and only able to talk to a nurse working in prenatal care. Chocó has a tradition of distrusting institutions and researchers, particularly those from other regions. This is due to allegations of intellectual extractivism (Grosfoguel, 2016). “Intellectual extractivism” is defined as a hierarchical, non-horizontal relationship in which the researcher does not consider participants’ views and needs during the investigation, gathering data without ensuring that the resulting research will benefit the participants. The inclusion of contrasting experiences from healthcare workers in Chocó might have illuminated other elements of the practices involved in CS prevention.

In addition, I was unable to interview staff from the Ministry of Health or the National Institute of Health, despite several attempts to make contact. Insights from members of these institutions might have provided other elements for the analyses of national, regional, and local practices and of silence and absence practices, especially those related to administrative, legal, and managerial aspects of the healthcare system, syphilis diagnosis, treatment, and surveillance. This might also have shed light on the contrasting regulations and practices in traditional medicine and for *parteras* in CS prevention.

Although I interviewed traditional midwives in both regions, I was only able to interview one indigenous midwife in Riosucio. This lack of access to Indigenous traditional midwives in Chocó was due to barriers of language, face-to-face rapport, and mobile phone access. Having more insights from Indigenous traditional

midwives might also have yielded data about other materials, competences, and meanings in care practices and assemblages.

Only two partners were interviewed in the study. Some of the pregnant women and recent mothers did not have a partner at all or had a difficult relationship with their partner, and in other cases, a lack of time availability made interviews impossible. Partners are usually considered “absent” in prenatal care and CS prevention, as expressed by several healthcare workers. They are not usually screened for syphilis (unless they are part of an at-risk group), and it is challenging for them to receive treatment. However, partners play an important role in CS prevention – for instance, in stopping the transmission and potential reinfection of women with gestational syphilis. Insights into other gendered practices are not fully addressed in this research, including pleasure and sex practices, condom use, negotiations with partners and sexual contacts, infidelity and open relationships, and bisexuality. There are also fundamental concerns regarding sex education, sex practices, prenatal care, and syphilis diagnosis and treatment.

On a similar note, regarding access, several measures were taken to facilitate participation – for instance, providing top-ups and SIM cards to participants and allowing pregnant women and recent mothers to contribute at their own pace to the OAFGs. Nonetheless, some women were unable to participate, despite an increase in the number of mobile phone users and internet and mobile coverage during the pandemic (DANE, 2020). Some people (including pregnant women) were unable to access those services due to lack of coverage or access to a mobile phone or smartphone. It is also important to note that people in Colombia and other Latin American countries frequently share devices with their relatives and neighbours, as indicated by Hill *et al.* (2022), who conducted research in Ecuador and Argentina during the pandemic. This prevented some people participating in the OAFGs because sharing a smartphone would have compromised their anonymity and confidentiality.

Another limitation of the study concerned the chosen online methodologies (mobile calls and OAFGs via WhatsApp, rather than via video calls or face-to-face), which meant the absence of some non-verbal clues that could have added greater diversity



to the interpretations and analyses. However, as stated before, those absences also contributed to how this research and analysis were configured.

Due to its theoretical and methodological nature as a qualitative study with a material semiotics approach, this study could not be unproblematically generalised to other regions or contexts in Colombia or elsewhere. Nonetheless, some of the elements and practices described in this thesis might serve as starting points or reference points for further research in, for instance, other regions of Colombia and countries where CS is a major public health concern.

#### Reflections on methods

Several assumptions underpin the accepted “gold standard” for offline research methods. There are assumptions about who counts as a research participant, signs and expressions of participation and engagement, the avoidance of silence, the “authority” of the researcher to navigate and “guide” what is relevant and supposed to happen in a research encounter, and the priority of textual data.

Taking the example of an OAFG conducted via WhatsApp, it appears that several of these assumptions can be contested. As a result, we as researchers need to reflect and incorporate other practices, styles, and considerations into our research. In the OAFGs, the participants were able to contribute at their own pace, leading to various delays in their interactions. Non-verbal clues might have indicated that there was no clear engagement, long silences were frequent, and the participants had more autonomy in deciding when – and in response to what – they wished to participate. At times, it might have seemed that the OAFG was “out of control”, since other topics less “relevant” were being discussed, with some questions producing few responses and more prolonged silences.

However, as the participants in such activities are constantly navigating between online and offline and public and private interactions, their participation and engagement are directed beyond the OAFG, and we, as researchers, should look for ways to capture them for the OAFG. Furthermore, we should not be afraid of silence, as this allows us to grasp more about practices, interactions, and ontologies.

We must remember that silence is part of any interaction (Smithson, 2008). Silence is a valuable source of data, a practice in itself, and an analytical tool.

In online research, non-textual data can also provide valuable insights. Songs, videos, stickers, memes, and emojis also hint at experiences, practices, and identities. Emojis were used by participants to express their emotions and to indicate agreement, disagreement, and support. The selection of emojis also gave clues about the participants and their identities. For instance, participants who self-identified as Afro-descendants chose 👍, from a selection of diverse emojis, while those participants who self-identified as “mixed background” used either the former or 🙌. Further analysis of race and ethnicity would be beyond the scope of the present research, but this is noted here as an example of how non-textual data can also provide avenues for analysis. As Mason (2002) states:

“...the idea that observations and interviews become data when they are transformed into text is a very influential one in the social sciences. This probably has the effect of over-emphasizing the inherent credibility of documentary and particularly textual data, and under-playing that of visual and other non-text-based forms of data” (Mason, 2002:106).

#### Reflection on ethics

The use of online methodologies always requires careful attention to confidentiality and security, and this became more acute during the pandemic and when dealing with sensitive topics such as congenital syphilis prevention in Colombia. Here, I argue for a situational ethics approach (Warrell and Jacobsen, 2014; Halford, 2017; Snee, 2013) that allows for flexibility to navigate the constantly changing landscapes of online research – in this case, in the context of messaging apps.

The present research relied heavily on the use of WhatsApp to reach out to vulnerable populations who might otherwise have been unable to participate in research. I also used WhatsApp to conduct interviews, online asynchronous focus groups and diaries with a diverse group of participants (health care workers, health care administrators, pregnant women, partners, and relatives).

While preparing my application for the ethics approval, I carefully analysed the relevant security and confidentiality measures. Syphilis is a sexually transmitted disease, and there is a lot of stigma associated with the topic. The research would be eliciting sensitive information about sex, intimacy, relationships, race, discrimination, sexual behaviours, and sexually transmitted diseases (Reisner et al., 2018; Bonda et al., 2002; Stangl et al., 2019). To comply with confidentiality and the need for participants' safety, I employed the following measures. First, I contacted pregnant women via referrals from the Secretaries of Health and health care workers by sending invitation letters. The Secretaries did not reveal any information regarding the women's diagnoses or treatment. I provided a security word for each participant to confirm before the interview began. I asked for permission to record the interviews, and I kept all the resulting files in password-protected documents, uploaded to the University One Drive. I maintained different files for contact details, interviews, OAFG documents, and diaries. Most importantly, I deleted the WhatsApp messages as soon as I had produced the transcriptions.

The Online Asynchronous Focus Groups (OAFGs and diaries (both the WhatsApp and handwritten files) required more attention to security and anonymity principles. I provided pay-as-you-go SIM cards for the OAFG participants and topped-up these cards with data. The focus group participants were asked to use this new number for the focus groups. They did not upload a profile picture or name to their WhatsApp profile, and they were assigned a pseudonym for use during the sessions. Various rules were established for the duration of the focus group, namely: participants deleted their messages as soon as possible after they had sent them; they did not take screenshots from the chat; they did not share pictures of themselves, their families, or their babies; they did not share the information discussed in the group with anyone else; and they did not back-up their WhatsApp account. Participants could leave the WhatsApp group and/or ask for help or comfort at any time. They were also reassured that they could participate at their own pace. Every experience and message would be received with respect and compassion from me, as the researcher, and from the other participants.

Similar measures were taken for the WhatsApp diaries, although these participants did not receive a dedicated SIM card for participation.

As with any research project, and particularly one involving digital methods, not everything went as expected. In what follows, I will focus on two main aspects that show how important it is to be continually adapting and negotiating research ethics: the dedicated SIM card for the OAFG and the introduction of WhatsApp's new terms and conditions.

Most of the OAFG participants did not use the dedicated SIM card to participate. In some cases, it was difficult for them to access the card because the mobile service providers did not cover the participants' territories. In most cases, the participants were reluctant to use the other SIM cards because their devices did not permit dual SIM usage and they needed their normal SIM cards to keep in touch with their employer and family. With the exception of this element, the other conditions and rules for participation in the OAFG were maintained.

I received ethics approval in November 2020 and started the online fieldwork at the end of January 2021, just as new WhatsApp terms and conditions were published. Those measures did not affect all countries equally, owing to differences in national regulations. For instance, they did not affect users in the UK or Europe due to the General Data Protection Regulation (GDPR) in those regions. Although Colombian Law 1581 of 2012 for Data Protection was inspired by the GDPR, it is less restrictive.

WhatsApp's terms and conditions changed several times between January and 15 May 2021. The new conditions referred to sharing information with Facebook's companies and with businesses that use their services. This information included mobile numbers; IP addresses; locations; other contacts' numbers; transactions and payments through the app; and the frequency, time, and duration of interactions between users (businesses included). Since January 2021, many Latin American users have migrated to other messaging apps, such as Telegram or Signal, which have different system architectures and security settings. However, at the time of my fieldwork, only Telegram had been assessed for use by our institutional ethics committee.

In Colombia, many people download messaging apps other than WhatsApp – such as Telegram and Signal – but few people actively use them. Instead, most people, including the research participants, use WhatsApp. Only a tiny proportion of the participants were users of Telegram. The others explained that, with WhatsApp, there was better video call quality and messages were received more quickly. Many had insufficient space on their devices for another app. Most importantly, mobile service providers do not include Telegram or Signal in their top-ups or mobile billing plans. Only in June 2021 did one mobile provider begin to cover Telegram.

I did not conduct interviews or focus groups through Telegram or Signal. However, I considered it essential to take a situational ethics approach to my online fieldwork, particularly when using messaging apps. Messaging apps – especially those that are free and popular with users – change their configurations and terms and conditions according to the market, regulations, and national and international constraints.

Situational ethics allows a research methodology to be adapted, while ethical principles are followed – for example, permitting new apps to be trialled in a constantly changing research landscape. Advocacy for situational ethics does not imply that there is no need for advisory ethics committee guidance before fieldwork. However, it does mean – in this case – that situational ethics (related to context and circumstances) were considered not only before the ethics approval process but also during every stage of the research, including the fieldwork (Weis, 2019; Munteanu et al., 2015).

It permits constant reflection on and adaptation to the unexpected. This should be taken into account during ethics committee approval decisions. As Preston-Shoot and others note: “greater attention needs to be given to how researchers behave after project approval and to how the ethical demands of research in-between, the translation of principles into a project, and then research in practice respond to the unfolding relational complexities” (Preston-Shoot et al., 2008:169).

While approaching potential participants and during their participation, I realised that many were less “literate” regarding issues of personal data protection and safe use

of messaging apps. Some of the participants did not care about these issues, and many did not know about the technical issues. I explained to participants how to set up the features and the reasons behind the requirements, instructions, and rules for the research, particularly the focus groups and diaries.

For instance, some OAFG participants were not "caring" or were indifferent to the questions of anonymity, data protection, and the use of WhatsApp – even after the changes to the app's terms and conditions.

Several authors have highlighted the mismatch between the formal regulation of ethics committees and participant concerns (Hammersley, 2009; Hammersley and Traianou, 2015; Truman, 2003). This was also the case in this research, specifically in relation to privacy, confidentiality, and the management of sensitive information.

Regarding the latter, the ethics committee considers race, ethnicity, sexual orientation, and STI diagnosis to be sensitive information. Such information must be handled with care. However, some of the participants did not consider details of their race and ethnicity to be sensitive information. Rather, they were open about this, as it gave them a sense of belonging, pride, and empowerment.

Similarly, there was a mismatch regarding the committee's and the participants' views of weeks of pregnancy as sensitive information. It is common among Afro-descendants in the Pacific region of Colombia not to share information about the weeks of pregnancy or expected date of birth, as it is believed that this can lead to *trama*. *Trama* (*tramar*, or *tramada*), refers to the difficulties during labour due to the hips of the woman closing and become increasingly narrow. The baby goes up until the point of suffocating the mother and producing their death. Since it is uncertain who is able to perform *trama*, information about the weeks of pregnancy and due date are not shared with some relatives, neighbours, or healthcare workers. On the other hand, STI diagnoses can be shared with healthcare workers, but they are more difficult to share with partners and relatives. This is an example of the differences that can arise in definitions of "sensitive information" and "privacy", with variation in opinions regarding who should access certain information.

However, something that is highly relevant for most participants but not necessarily pivotal for ethics committees is the “impact” or benefits of the research. For many participants in this study, it was important that the results and benefits of the research be shared with the relevant communities. In Chocó in particular, there is increasing mistrust of researchers and research institutions due to the use of “intellectual extractivist” practices that treat participants as informants (Grosfoguel, 2016).

The previous examples show that mismatches can arise between what participants and ethics committees consider to be the main issues. This has also been observed in previous studies (Lees and Enria, 2020), where participants have challenged Western notions of research ethics.

Several studies (Ellis, 2020; Ellis et al., 2013; Dencik & Cable, 2017) have shown that people relate in diverse ways to the techno-securitisation of everyday life when using online technologies, including attitudes of indifference or compliance that draw into question our assumptions regarding participants’ concerns and decisions.

Should we, as researchers, provide information, “training”, and support for participants asked to use apps? It might be necessary, under certain circumstances, to provide advice on these matters. However, it might not be desirable for all research participants, in other research projects since there might be different circumstances and contextual differences.

Reflecting on these situations, I wondered if, in the future, we should include paid messaging apps with more security settings that are less likely to change their terms and conditions. However, the most popular apps are perhaps most appropriate for research because they are already used daily by potential participants. The free apps are often attractive because they are free and allow users to connect with others. In addition, they are easy to use and internet-enabled.

The tensions between principles of protection and autonomy in online research can put researchers in a difficult position because researchers must consider the potential risks, explain them to participants, and take the necessary precautions to avoid or mitigate them. However, those risks are not always evident, and

researchers may have little control over the context of their research. Furthermore, infringing participants' autonomy leads to paternalistic approaches that deny agency to participants, which is particularly detrimental for those who are usually marginalised and for whom research can be emancipatory.

Given the mismatches between what is expected by ethics committees and by research participants, as well as the continual negotiations over ethical principles and the associated power dynamics, situational ethics and inclusive dialogue are the approaches most likely to benefit participants.

To conclude, I want to emphasise the need for situational ethics and a focus on context and circumstances from the beginning of the ethics approval process and throughout the fieldwork, at every stage of research, enabling rapid adaptation in response to changes in the research landscape.

#### Final remarks

In this chapter, I have specified the project's aims, the research questions, the research design and methodology (including adaptations made in response to the COVID-19 pandemic), and the theoretical and methodological approaches applied. I have shared the rationale behind the selection of methods, in which the COVID-19 pandemic and the specificities of the research participants played key roles.

I highlighted how method assemblage (Law, 2004) was fundamental as both a theoretical approach and a method. This method allowed for the flexibility to explore absences, silences, discontinuities, and multiple ontologies. It also allowed the flexibility to combine different methodological traditions (discourse analysis and thematic analysis) to be combined without the constraints usually associated with them. Moreover, it allowed me to explore and question the Euro-American assumption of a single reality and the illusion of a method that could account for everything, without absences.

The literature on focus groups often highlights the limitations of the online format, citing issues of engagement, quality of contributions, and the absence of non-verbal communication. However, it has also been argued that online and face-to-face interactions simply produce different types of data, and the challenges faced in



online focus groups cannot be straightforwardly compared with those of face-to-face sessions. Online focus groups offer new possibilities for research practice, especially when dealing with sensitive topics and hard-to-reach and geographically dispersed populations.

This research is the result of adaptations to continually changing conditions, especially in relation to the use of online methods. I advocate for a situational ethics approach to research. In this chapter, I have provided several examples of mismatches between what participants and ethics committees consider to be the main issues (privacy, sensitive information, and anonymity). Several notions of research ethics were challenged by the participants in this study, which triggered reflections and discussions about what research entails, researchers' assumptions about participants, and the ongoing negotiations required in the field.

Finally, throughout this chapter, I have emphasised how silence and absences become paramount while data-collection and -analysis processes are configured as the focal point of this research. This is the result of constant inductive and deductive analytical processes and the alternation between local-territorial, regional, national, and international "layers" or "scales". The following chapter provides a more detailed account of the silences, discontinuities, and absences in the data, reflecting on their role in CS prevention.

## CHAPTER 4 ONTOLOGICAL DISCONTINUITIES

Practices of silences, absences, and temporalities

Congenital syphilis (CS) prevention has relied heavily on the implementation of clinical practice guidelines (CPGs) that involve certain procedures, trajectories, and temporalities – and for which certain people are responsible and expected to coordinate activities in a cohesive and not fragmented healthcare system (more in Chapter 1 or 2). However, that is not the case while preventing CS.

The main argument of this chapter is that the prevention of mother-to-child transmission of CS requires a bundle of practices, including some that occur before, alongside, and beyond prenatal care. To achieve prevention, there are several essential considerations. First, it is vital to look at diverse ontologies as multiple realities (Mol, 2002) and practices. Practice is understood as organised activities that involve materials, competences, and meanings (Shove, 2017; Blue and Spurling, 2017; Blue *et al.*, 2016).

Second, human and material agencies interact while preventing CS, in which diverse temporalities, resistance, and accommodations evident in the practices that make up the collateral realities – realities that are not contested and which are considered “common sense reality” (Law, 2011:174). Third, absences, silences, and discontinuity practices are enacted as collateral realities during efforts to prevent CS. Sometimes those collateral realities occur because other practices take precedence – preventing other diseases (COVID-19, HIV), for example, or guaranteeing the wellbeing of the mother and baby.

In the following six sections, I explain practices surrounding the prevention and manifestation of syphilis during pregnancy in two sites in western Colombia. In the first section, the diverse ontologies of syphilis are highlighted to show how different practices (materials, competences, and meanings; see Shove, 2017) intervene in its enactment. In the second section, I describe the interrelated practices of silence and absence beyond the implementation of the CPGs for the prevention of CS, proposing a broader perspective for prevention efforts. The third section is dedicated to the tensions between the expected linear (continuous) temporality of CS prevention and the multiple discontinuous and “fragmented” temporalities that are also enacted

during syphilis- and CS-prevention work. The fourth section explores the discussions regarding silences, absences, and discontinuities in the context of agency and other relevant concepts from the literature. Some differences between silence, absences, and discontinuities are presented in the fifth section. The final section makes some general remarks and explains the connection with the chapter which follows, on care assemblages. But first, let us consider the diverse ontologies of syphilis.

### Diverse ontologies

In her book *The Body Multiple* (Mol, 2002), Annemarie Mol explains how atherosclerosis can be more than one, showing the diverse practices that medicine enacts in its diagnosis and treatment. She further clarifies that this does not indicate a perspectivalism (multiple perspectives) or a continuous fragmentation. Instead, she proposes the following:

“... objects come into being – and disappear – with the practices in which they are manipulated (...) since the object of manipulation tends to differ from one practice to another, reality multiplies (...) Thus, far from necessarily falling into fragments, multiple objects tend to hang together somehow” (Mol, 2002 p.5).

Something similar happens with syphilis, gestational syphilis (GS; syphilis during pregnancy), and CS, particularly in the localities in which this study was conducted.

At the laboratories where syphilis is researched and diagnosed, *Treponema pallidum* is enacted in a blood sample, a sore or placenta, inoculated in rabbits for research purposes, or “visible” in one of multiple tests: the non-treponemal test (rapid plasma reagin [RPR]; venereal disease research laboratory [VDRL]) or treponemal test (*Treponema pallidum* particle agglutination assay [TP-PA]; fluorescent treponemal antibody absorption [FTA-ABS]; micro hemagglutination assay for antibodies to *T. pallidum* [MHA-TP]; *Treponema pallidum* hemagglutination assay [TPHA]; *T. pallidum* enzyme immunoassay [TP-EIA]; Chemiluminescence immunoassays [CLIA]). All of these tests are used depending on certain specificities: costs, infrastructure, and competences. Their application also depends on diagnostic

criteria – namely, whether they are used for screening, case confirmation, or treatment follow-up.

When rapid syphilis tests are used, syphilis is enacted as a possibility, requiring another test for its confirmation. Sometimes, *T. pallidum* is enacted as part of a duo test which tests for HIV and syphilis simultaneously. While using a rapid test for syphilis or a duo HIV–syphilis test, syphilis is enacted sometimes beyond the laboratory (during a prenatal care appointment in a primary care setting), run by a nurse or a trained healthcare worker.

At the hospital or healthcare centre, if syphilis is diagnosed in a child of 14 years old or younger, the patient has to be cared for as a sexual victim, with other procedures put in place.

Syphilis is also enacted through clinical criteria (i.e., signs of syphilis in the body) or lab tests. It can also be classified according to its manifestations and timing (primary, secondary, latent, tertiary, neurosyphilis). However, during prenatal care, for treatment purposes, the disease is usually considered to be of unknown duration (more on this in the section on diagnosing syphilis).

According to the CPGs, when a pregnant woman receives a positive diagnosis, she is responsible for informing her sexual contact(s), who should receive treatment immediately, without confirmation of a diagnosis.

While a pregnant woman is receiving treatment, her follow-up test results might indicate reinfection or the possibility of an immunological footprint. When the body reacts to a pathogen (immune response) that it has previously interacted with, there is a more rapid and efficient immune response upon subsequent exposure to the antigen.

There is no standard definition of a “CS case” around the world, with CS appearing in diverse forms in Colombia and elsewhere. Moreover, despite the introduction of the CPGs in Colombia in 2014, some healthcare workers have not yet incorporated the contents into their case definitions.

Therefore, when cases do not correspond to the current case definition, sometimes syphilis disappears from the epidemiological surveillance reports collected by the healthcare providers and consolidated by INS *Instituto Nacional de Salud* [Colombia's National Institute of Health]. For instance, CS can be established by epidemiological nexus if the baby or stillborn child of a mother with GS did not receive adequate treatment, regardless of the result of the test run on the baby. In this case, syphilis is presumed due to the baby's contact with the mother. No tests or clinical signs on the baby are required.

Appropriate treatment is defined as at least one dose of benzathine penicillin 30 days before giving birth. If any of these conditions are not met, the case may be excluded from the data. This is especially common if the GS diagnosis of the mother is unclear when produced by a VDRL or RPR, instead of a rapid syphilis test.

GS and CS are sometimes categorised as *sífilis Venezolana* [Venezuelan syphilis], when the pregnant woman or her baby are migrants from Venezuela, or as *sífilis de otro municipio* [syphilis from another municipality] when the mother or her baby have been living for more than six months in a municipality other than the one reporting the case.

Before presenting a more detailed discussion of the multiple ontologies and their temporalities, I will focus on how practices enact ontological multiplicity and collateral realities (Law, 2009). First, let me clarify these concepts.

In this research, "practice" refers to an organised form of activities that include materials, competences, and meanings (Shove, 2017; Blue *et al.*, 2016; Blue and Spurling, 2017). It involves the integration of "materials (objects, consumer goods and infrastructure), competence (including understandings of the situation, practical know-how), meanings (including embodied understandings of the social significance of the practice and past experiences of participation)" (Shove, Pantzar and Watson, 2012:42). Practices are not grasped in isolation; they establish relations in a "nexus of connections" (Nicolini 2012 in Welch, 2017) with other elements and practices.

CS prevention is a bundle of practices configured in various socio-historical situations that entails the integration of particular elements of CS and incorporates relationships with other practices (identity, inequality, healing, among others). Further, focusing on individuals (e.g., pregnant women) will not provide a better account of CS prevention. Materials – medical records, rapid syphilis tests, diagnosis algorithms, and penicillin, among other things – are involved (more on this in the following sections).

In what follows, I will detail some of the bundles of practices, particularly those that enact absences, silences, and discontinuity practices into CS prevention.

#### Silence and absence practices

Syphilis- and CS-prevention practices are not linear or straightforward (more on this in the following section). Although disease prevention can look like a coordinated process, with specific timeframes involved, particularly in the case of CS prevention, for which there are CPGs, it is not. There are multiple related and interlinked practices. CS prevention entails activities that go beyond pregnancy and prenatal care and that are more related to the general population. Let us consider those practices for pregnant women.

In Colombia, activities to screen and treat for syphilis beyond prenatal care are only carried out occasionally, focusing on high-risk populations (sex workers, drug addicts, and the homeless) and patients with clinical signs of the disease, while they are attending GP or specialist doctors' appointments.

There are bundles of activities related to contraceptive methods, planning for pregnancy, and care practices for pregnancy (in diverse healthcare systems or assemblages and at the individual–family–communitarian level). These include prenatal care, administrative and financial activities related to healthcare service provision. There are also activities related to the implementation of protocols (guidelines, laws), the collection of data (medical records and the use of software to share the information), test diagnostics (lab tests and rapid tests), the administration of treatment, case reporting and epidemiological surveillance, public health indicators, and goals for disease reduction.

As established by Welch (2017), disentangling the practices in the CS analytical process is complicated. Therefore, in the following sections, I approach particular aspects of these practices to explore CS prevention in the two sites of study in western Colombia.

In this section, I will focus on silence and absence practices, particularly how certain activities configure absences and discontinuities in the process of bringing together diverse practices of CS prevention. I will touch on discontinuity practices later in the section on diverse temporalities.

Although I group these silence and absence practices into distinct practices, this does not mean they are not interrelated. But first, let us pay attention to how syphilis has been researched and the implications for CS prevention.

#### Researching syphilis

The bacteria that cause syphilis *Treponema pallidum* can be seen only at certain moments through specific activities (at the lab, in test results). Until recently (2018), *Treponema pallidum* did not grow *in vitro*, and its study in rabbits was the best option for experimental investigation (Avila-Nieto *et al.*, 2023). It is considered a problematic bacterium for research due to its structure and composition, as explained by one researcher:

“Rabbits are the closest animal model for research. To research rabbits is expensive, and it has more ethical implications than in mice (...) *Treponema* has an unstable membrane, so it gets damaged with some procedures. This is one of the biggest difficulties at the laboratory (...) You have a patient with syphilis, you have to isolate the bacteria – so, for instance, you have to obtain a smear from a chancre and inject it into the rabbit, then wait 20 days [and] kill the rabbit to see if the *Treponema* grew or not, and then isolate the DNA... Well, it is complicated, expensive, difficult”. (Interview 12, Researcher)

According to several studies, there are numerous *T. pallidum* strains circulating globally (Leader *et al.*, 2003; Cameron, 2018). Some studies even suggest frequent exchange through international transmission (Beale *et al.*, 2021). Although there have been advancements in the use of *in vitro* and bioinformatics techniques (Avila-Nieto *et al.*, 2023), several gaps in the knowledge are encountered regarding *T. pallidum* remain. For instance, two of the three subfamilies of proteins are the most

studied, with several disagreements regarding their respective functions (Avila-Nieto *et al.*, 2023). Further, since a considerable number of the strains used for research come from laboratories in the United States (Nichols strain) and "... most TPA genomes published to date originate from USA, Western Europe and China... our understanding of the true breadth of diversity of TPA is incomplete" (Beale *et al.*, 2021:1549).

In addition to the difficulties entailed in *T. pallidum* research and associated with the costs of the experiments, there is also insufficient prioritisation of the work, with more attention and resources being dedicated to diseases such as HIV, leaving this disease "neglected" (Klausner, 2013).

For example, in the United States, the budget dedicated to the National Institute of Health for HIV and AIDS research increased consistently from 2021 to 2024 (<https://www.hiv.gov/federal-response/funding/budget>), including an increase of \$100 million (3.1%) between 2022 to 2023 (<https://oar.nih.gov/sites/default/files/OAR-PJ-FY2025-Publication-FINAL-508.pdf>). According to UNAIDS, in 2022, the contributions to their Joint Programme were US\$ 224.3 million (<https://open.unaids.org/top-contributors>).

The budget allocated for syphilis research, in contrast, has been decreasing in the United States, despite to the considerable increase in cases. There was a 40% reduction in the budget between 2003 and 2018 ([https://www.ncsddc.org/wp-content/uploads/2018/08/Syphilis-over-time-vs-Federal-funding\\_NCSD.pdf](https://www.ncsddc.org/wp-content/uploads/2018/08/Syphilis-over-time-vs-Federal-funding_NCSD.pdf)) and for STDs (including syphilis) in 2022 and 2023 budget (<https://www.ncsddc.org/biden-budget-fails-address-std-crisis/>).

Similarly, there are more institutions, organisations, research groups, and networks dedicated to HIV and AIDS than to syphilis. For example, there is UNAIDS, the organisation founded by the United Nations and other allies to fight HIV and AIDS; the International AIDS Society, which has 13,000 members worldwide; the Global Network of People Living with HIV; the HIV/AIDS Clinical Trials Networks; and the HIV Partnership Groups.



Moreover, a brief search of the internet, including some scholarly databases, reveals differences in the results and resources available online. Google Scholar produces 4,010,000 results for “HIV”, but just 1,160,000 for “syphilis”. In Semantic Scholar, there are 676,000 results for HIV and 70,100 for syphilis. Google produces 1,600,000,000 results for “HIV” and 85,000,000 for “syphilis”.

During an interview, one healthcare administrator described syphilis as the “Cinderella” of diseases:

“...to me, syphilis is like the Cinderella of all the diseases. I don’t know why but we can see that other diseases have a lot more resources. I have spoken about it but there was no echo... Penicillin is cheap and there are so few exams for its diagnosis, but no. I don’t know why”. (Interview 18, Healthcare administrator)

In addition, there is very little literature evaluating the public health interventions for CS prevention worldwide (Plotzker, Murphy and Stoltey, 2018). Unlike HIV/AIDS and malaria interventions, CS prevention has received little attention. Most CS-prevention studies focus on characterising the risk factors and at-risk groups and biomedical interventions, particularly in low- and middle-income countries (LMICs).

Although there are many similarities between incidences of syphilis (GS and CS) in HIC and LMIC countries, several controversies have emerged over what is deemed clinically effective in different contexts and in relation to local particularities. Such conflicts have concerned diagnostic algorithms (including the use of treponemal tests), universal treatment provision during the third trimester, and partner notification (Freyne, Nourse and Walls, 2023). The distinction between HICs and LMICs is emphasised in the literature and in the epidemiological profile of the disease, leading to an assumption in HICs that syphilis cases are particularly prevalent among men who have sex with men. In contrast, in LMICs, the disease is more widely found in the heterosexual population (Cameron, 2018). As a result, differences have been established in terms of diagnosis and treatment according to syphilis prevalence, level of access to laboratory facilities, and cost-effectiveness (Freyne, Nourse and Walls, 2023).

In syphilis research, several silence and absence practices are enacted: a limited knowledge of *Treponema pallidum* regarding its diversity and the function of its proteins, the intense research into certain strains (the Nichols strain) at the expense of others, and the constraints of using rabbits or *in vitro*, with further difficulties around incorporating that knowledge into the development of a vaccine.

Materials, competences, and meanings all play a role here. It is not only that the bacteria has a difficult structure and composition that impedes research. It is also that more resources and competences have been focused on either other diseases or certain aspects of *Treponema pallidum* (i.e. the Nichols strain). The distinctions between HICs and LMICs have shaped how syphilis is researched and how it is approached regarding diagnosis, treatment, and surveillance.

In the following section, I will continue with silence and absence practices in the context of pregnancy and prenatal care.

#### Pregnancy – prenatal care

Pregnancy is associated with many silence practices. Some of the women in this study were unwilling to reveal their pregnancies or talk about them (especially women from Chocó). In some cases, it was not the woman herself who acknowledged her pregnancy but someone else. During the interviews, some pregnant women explained that they had been told by someone else that they might be pregnant (with some being informed during their second trimester) and that they had then confirmed their pregnancy with a home pregnancy test.

A woman may be unaware of her pregnancy and thus need to be informed by someone else because she is not intending to get pregnant, is using contraception, or has a medical condition related to infertility (as was the case for Participant 8). During the pandemic, some women had problems accessing contraception, leading to unexpected pregnancies. That was the case for four of the participants, as well as many other women in Colombia (Profamilia, 2021). Some of these interviewees only realised that they were pregnant during their second trimester. According to the healthcare workers – and the terms of the CPGs – these women started their prenatal care “late”.

Some participants actively choose not to talk much about their pregnancies, especially during the first months. This is because they have concerns about things going wrong and thus losing their babies. In Quibdó and Lloró (Chocó), it is common for pregnant women not to reveal publicly how many weeks of pregnancy they have nor their due date. It is believed that revealing this information might lead to a woman being *tramada*. *Tramar* is a practice in which some activities done by the pregnant woman or someone she knows make giving birth more difficult. In some cases, it is believed that someone might deliberately cause harm to the woman or her baby. Sometimes, the lack of trust regarding this issue among some health care workers might lead to differences in the estimations of the number of weeks of pregnancy. Instead, some women might refer to the trimester of pregnancy, rather than the months or weeks. As indicated by a traditional midwife,

“ ... the thing about *tramas*, it is only about the months. You don't ask how many months pregnant they are. Just ask for the trimester. You can say, 'Which trimester are you in? Are you in the first or the second?' Then she will tell you, 'I am in X trimester'. That way, they can tell you”. (Interview 39, Traditional midwife)

Even after the baby is born, if the mother or her family notice a salient characteristic in the baby (for instance, unusual eye movements, such as the eye moving side-to-side, up and down, or round in a circular motion), they might not inform healthcare workers, as this characteristic is considered a gift and, if they comment on it, the baby will attract *ojo* [the evil eye]

“... when the baby is born, sometimes they have signs that can be warning signs, but many mothers do not talk about them because they think it will allow someone to make *ojo* or because they think it is a virtue.... They don't tell anybody – not even the family will talk about it. They think that, when you talk about a virtue, the baby dies”. (Interview 10, Healthcare worker)

*Mal de ojo* or *ojo* [the evil eye] happens when someone causes harm to another person (especially babies and children) by looking at them in a hostile manner, usually motivated by envy. Symptoms in babies are believed to include fever, vomiting, loss of appetite, diarrhoea, rashes, and crying. A bracelet is usually worn on the baby's wrist to protect them from *ojo*.

During pregnancy and prenatal care, some body parts are silenced. While body parts such as the belly, hands, and feet become more visible, others are ignored. It is not customary for women – and especially pregnant women – to look at their genitalia to identify changes, “symptoms”, or “difficulties”. The vagina and the anus are not assumed to reveal “warning signs”, unlike the hands and feet (which show signs of preeclampsia). The vagina becomes relevant when there is bleeding or out of the “ordinary” discharge. Further, some women are not accustomed to seeing the penis or pelvic area of their partner. As stated by one participant who had GS:

“... I didn’t have any of the symptoms, and my partner didn’t have the symptoms... I distrusted him, so I said, “Let me take a look over you. I saw something”... I mean, you become fearful of everything that looks suspicious”. (Interview 35, Pregnant woman)

Several meanings are often attributed to body parts. According to Catholicism and most Christian evangelical, masturbation is a sin. Directing one’s attention to the genitalia could lead to the act of self-pleasure, which does not correspond with the view of sex as an act intended solely for conception.

In the first stages of syphilis (primary and secondary), the materiality of syphilis becomes apparent in the form of painless sores on the penis, in the vagina, in the anus or rectum, on the lips, or in the mouth. The sores are not always visible; there are no practices usually directed to looking at their own or other people’s body parts, especially if they are related to their genitalia or anus and rectum (as mentioned by some pregnant women or recent mothers during the interviews). However, even if a sore is present, this is not necessarily a matter of concern, especially if there is no pain associated. Pain is an indication that something is not right; it is a sign to pursue a consultation.

Pain is a particular concern for pregnant women, they can feel more pain-related experiences. During the online asynchronous focus groups, the participants described back pain, headaches, pain in the ankles, and abdominal pain. This pain may also be a warning sign of risk to the baby. This was expressed by one of the participants:

“If I bleed, have lower pain or pain that doesn’t stop, or contractions for more than four minutes, or unbearable headaches or earaches or blurry vision ... or if I don’t feel the baby”. (Interview 24, Pregnant woman)

During the pandemic, social distancing and the use of face masks reduced the length of the prenatal care appointments. Sometimes, the healthcare workers did not touch the pregnant women or look for signs, and sores on lips were not visible due to masking.

Several of the participants (pregnant women and recent mothers) mentioned that the healthcare workers had filled in the forms and medical records on the computer or by hand during the pandemic. This made it more difficult for the healthcare workers to identify possible signs of syphilis, at least during the early stages. Prenatal care appointments already involved numerous forms (medical records, authorisations for exams, referrals for other medical specialities). But during the pandemic, less time and attention were given to examining the patient, asking questions, and looking for potential signs. The considerable amount of information that has to be recorded – and occasional failures in the system, such as poor internet connection and software breakdowns – can mean that even less time and attention is given to “looking at” and assessing the patient.

With the introduction of the CPGs, the prioritisation of laboratory syphilis diagnoses over clinical diagnoses (i.e., the identification of symptoms consistent with syphilis) might limit the skills and competences required for syphilis diagnoses during prenatal care.

It can be difficult for pregnant women to understand and acknowledge when they are experiencing syphilis-related symptoms. Like the painless sores, other symptoms might be confused with other ailments during the second stage of the disease. These ambiguous symptoms include rashes, fever, swollen lymph nodes, sore throat, patchy hair loss, headaches, weight loss, muscle aches, and fatigue. According to *curanderismo* and *parteria*, some of those symptoms can be treated separately: a ginger infusion or gargling with baking soda, lemon, and garlic for a sore throat; aloe vera for hair loss; and eucalyptus and rue herb in a lotion for muscle aches.

Similarly, in biomedicine, some of those symptoms might be treated separately. In fact, the World Health Organization (WHO) promotes the syndromic management of STIs, particularly in places where there are no laboratories or rapid tests available for diagnoses. They suggest applying an algorithm (flowchart) to identify the possible cause of the STI symptom and the preferred treatment (World Health Organization, 2005). However, according to some healthcare workers, administrators, and researchers, this process can complicate STD prevention – and CS prevention in particular. Syndromic management can increase the potential for antimicrobial resistance (which is especially acute for some STDs, including gonorrhoea and mycoplasma genitalium). This can also make it more difficult to identify active syphilis cases in the general population because, in Colombia, syphilis is reported only when seen in pregnant women and their babies (GS and CS).

During prenatal care, little information is provided regarding STDs. According to some of the study participants, healthcare workers briefly indicate the tests that they are going to run during prenatal care appointments. These tests are usually portrayed as “routine”.

“I have toxoplasmosis tests every month. The glycaemia test I had three times because the first one was abnormal. The second time was ok, but the last time it was abnormal again. So, they sent me additional tests and a referral for a specialist ... They also sent me for routine tests, for the thyroid and everything”. (Interview 22, Pregnant woman)

The other participants said that they had heard something about STDs but had not paid attention. However, they said that it would be a concern for them if a positive result appeared. They would find it difficult to receive a diagnosis regarding their own health or that of their babies, and they would struggle to have a conversation with their partners.

Most participants said that they did not generally discuss sex-related topics or talk about STDs with their partners. Some of the healthcare workers said that, even when a pregnant woman received treatment for GS, she did not always pass this

information onto her partner because she often did not know what to say, how to explain the result, or how to discuss the implications of it for the relationship.

The silences during sex talk are frequent. Sex talk is not common in families, rather mention are indications or warnings in terms of “protecting against pregnancy”.

“... my mom is very conservative she doesn't talk about those topics with us. I mean, we realised that sex is something that each of us does, but it is something personal”. (Interview 22, Pregnant woman)

“My mom always told us how we should protect and take care of ourselves, how to prevent a pregnancy at an early age and [prevent] unwanted pregnancy”. (Interview 24, Pregnant woman)

Sex talk is rare in school, except for some sessions where the emphasis is on using condoms and having monogamous relationships to reduce the risk of STDs. This does not mean, however that there is no sex talk at all. When it occurs, sex talk is secretive and made silent. However, when it is between friends and peers, sex talk can be about pleasure, personal experiences, and performance. One of the participants said:

“At home? No, we never talked about those things [about sex] or at school. We didn't have a teacher to talk to about it, no ...”

“{how did you learn} Well, to be honest, having sex with your boyfriend [was how you learned about sex] but we didn't talk about it... We talked with our friends and shared our experiences and things like that”. (Interview 36, Pregnant woman)

However, during pregnancy, sex talk becomes even less frequent. Healthcare workers do not usually raise the topic unless in response to a question from a pregnant woman or her partner. But women do not usually ask, nor do their partners. If questions regarding sex during pregnancy arise, they are typically related to the risk of harming to the baby (i.e., whether penetration can affect the baby), pain during intercourse, or vaginal infections.

*Cursos psicoprofilácticos* [psychoprophylaxis training], a breathing method for use during labour, is taught to pregnant women, delivered alongside information about physical changes during pregnancy and how to take care of the baby during the first months. During these courses, sex during pregnancy is talked about and encouraged for the woman's wellbeing. It is, however, contraindicated if an STD, an infection, bleeding, or another related health issue is found. Traditional midwives also recommend sex during pregnancy but not during *dieta* (40 days after giving birth).

During the pandemic, few of these courses were provided, leaving pregnant women to ask more experienced people (relatives, friends, healthcare workers) for advice or to consult the internet for answers. Information and advice regarding sex during pregnancy were not always available. For instance, one of the web pages used by the participants (<https://winny.com.co/>)<sup>11</sup> focuses on physical and psychological changes during pregnancy, the baby's development, and possible complications.

While talking about sex, there is an emphasis on penetrative vaginal sex. During the interviews with the pregnant women and healthcare workers and a workshop for healthcare workers, there were several indications of that emphasis. Other sexual practices – such as oral or anal sex, activities integrating sex toys, and “rubbing” of the genitalia – are not included. In addition, there was an emphasis on heterosexual sex practices among most of the participants (the pregnant women, healthcare workers, and administrators). A small proportion of the healthcare workers and administrators, particularly those working on the reporting of STDs or with sexual health services, did not limit themselves to accounts of heterosexual and penetrative sex.

In the case of a positive STD or syphilis result during pregnancy, condoms and information about sex during pregnancy are provided, but these topics are not otherwise necessarily discussed with pregnant women during prenatal care.

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<sup>11</sup> This nappy brand offers information and advice on pregnancy, giving birth, and the babies' first months, as well as offering the brand's own products and a community space for mothers to share their worries.



The traditional midwives in Chocó consider syphilis to be a “Western disease”. They think of syphilis as something to be treated by doctors at the hospital. If they know a pregnant woman has a positive diagnosis, they will suggest that she receive treatment at the hospital. However, they would not help her give birth (more on this in the next chapter, “Care Assemblages”). It is not clear how the signs of syphilis are identified by *parteras* if there has not been a formal diagnosis and if the requirements for referral to the hospital have not been met.

Some of the materials may also be “silenced” or absent, as is the case with discussions of certain body parts and sexual practices unrelated to penetrative sex during prenatal care appointments. Let us now turn to practices of silence and absence related to syphilis diagnosis.

#### Diagnosing syphilis

First, let us assume that there are tests available for diagnosing syphilis (either rapid tests or another form). There can be difficulties with diagnosing syphilis, including a risk of false-positive results during the early or late stages, when there is no presence of antibodies. A false-negative result is also a possibility if other diseases are present (e.g., tuberculosis, HIV, malaria) or if patients have been recently vaccinated against another disease (e.g. COVID-19).

Syphilis diagnosis is further complicated by its clinical manifestations not always being clear. Syphilis has been called a “silent disease” because it can go unnoticed for years. During prenatal care of women with syphilis, the disease is considered to be of “unknown” duration because it is difficult to establish its current stage (Ministerio de Salud y Protección Social, 2013a).

Therefore, medical records are crucial for diagnosing and documenting syphilis and its progression. The medical record facilitates assessment of the risks of a false-negative or false-positive result, a syphilis reinfection, and/or the patient being allergic to penicillin, as well as consideration of whether appropriate and adequate treatment has been provided (after follow-up monitoring).

Incomplete, unclear, or unavailable medical records can increase the absences and silences surrounding syphilis. Pregnant women, usually being seen by numerous

physicians and specialists, can move between diverse healthcare providers in different levels of care (primary, secondary, tertiary) – even across municipalities, cities, and *departamentos*. Medical records can be a patchy collection of handwritten, printed, and/or electronic information that does not necessarily reflect the patient “history” during pregnancy, labour, and the baby's first months.

The pregnant woman may not bring her own medical records to an appointment. For example, a woman may go to a different health service provider or require another level of care. In such cases, a healthcare worker or administrator would print the woman's medical record or make notes on the most relevant information (e.g., her primary health conditions, test results, treatment, and reasons for referral to another healthcare provider). However, this is not always the case, as explained by a healthcare worker in this study:

“... These institutions buy their own software, so each patient comes with a printed medical record from each hospital that she has attended. Usually, these patients have their prenatal care at the first level. They rarely end up at the third level for syphilis. Sometimes it is because of something else – like early birth, preeclampsia... Even in hospitals with the same software, we cannot see the medical records from another hospital”. (Interview 37, Healthcare worker)

Although electronic medical records are used in many healthcare centres and hospitals, access to information can be an issue. Not all healthcare providers use the same software for medical records and test results. This prevents sharing of information across platforms. In addition, even when healthcare providers do use the same software, administrative permissions may prevent information sharing. Moreover, the integration and continuity of medical records is hindered when different materials are used for the records (e.g., handwritten notes, data recorded using software, documents printed from software).

In some cases, it is expected that the pregnant woman will “integrate” all of these materials herself and provide an account of the process, summarising her experiences when attending her prenatal care appointments. As explained by one pregnant woman, “... the GP nagged me because I didn't have the medical records, I didn't have the test results, and because I didn't know what they had done to me” (Interview 23, Pregnant woman).

Due to this movement between doctors and health centres, there is a lack of trust in what is stated on the medical records. For instance, one healthcare worker said that “most of these patients are from a low socio-economic and low socio-cultural level. They are bad informants. Sometimes they don’t even understand they have syphilis” (Interview 37, Healthcare worker).

This type of fragmentation and discontinuity of medical records is not exclusive to prenatal care or to syphilis diagnosis and treatment. However, medical records are nevertheless pivotal to diagnosing, treating, and monitoring syphilis and preventing CS.

The practices related to syphilis diagnosis depend heavily on the use of tests, due to the difficulty of identifying clinical signs at certain stages of the disease. Therefore, absences in the necessary conditions (particularly materials) for obtaining syphilis diagnosis, failure to integrate information through medical records, and gaps in the competences of healthcare workers can all “silence” syphilis.

The following section will discuss the silences and absences that emerge during treatment.

#### Treating syphilis

When syphilis is diagnosed in a pregnant woman (GS), her partner – and her sexual contacts more generally – should also receive treatment. However, if the partner belongs to a different EPS (healthcare administrator), they might not receive treatment unless they go to their own EPS to take a test and receive a positive result. Not all EPSs will include a partner’s or sexual contact’s treatment as part of the treatment of the pregnant woman. As mentioned by one of the healthcare administrators, it is not possible to buy the treatment over the counter, and many people would rather not have a syphilis diagnosis on their medical record due to the associated stigma.

The location of the treatment can also be a problem. The CPGs indicate that, penicillin should be provided on the same day and at the point of care. However, it is common to oblige pregnant women to go to the emergency room for treatment.

There are several reasons for this. Penicillin is not available at all healthcare centres, as some do not have permission to administrate it. This is partially because some centres lack the equipment needed for cardiopulmonary resuscitation (CPR) (defibrillators, oxygen, airway management equipment etc.) in the event of an allergic reaction.

In an emergency room, the provision of penicillin as a treatment for syphilis can be low priority, as it does not necessitate immediate medical attention. The treatment of a pregnant woman is also seen as less urgent if there is a risk of an adverse reaction and she needs to be desensitised. Although anaphylaxis in pregnancy is considered rare (1–3 cases per 100,000 maternities; Garcia *et al.*, 2021), it can be fatal. Desensitisation is suggested for pregnant women with a positive syphilis diagnosis and penicillin allergy. This consists of the administration of a low dose of penicillin, provided every 15 minutes until the therapeutic dose is achieved, continuing if there are no complications. This process can take up to three or four hours.

At the emergency room, it is common for pregnant women with “pregnancy warning signs” to be obliged to wait, despite their being members of a “prioritised population”. In Colombia, there are two ways to establish who is prioritised for medical care: first are those who need urgent attention, as identified by triage, and second are the prioritised populations (children under five years, pregnant women, and adults over 65 years).

The current CPGs suggest that a comprehensive medical record be taken and the patient interviewed to identify indicators of adverse-reaction risk, even if the patient has not been referred for penicillin. Although the probability of finding a patient with an adverse reaction to penicillin is low, healthcare workers prefer not to give treatment when there are no necessary conditions. Many are particularly concerned about this because medical malpractice and negligence claims have increased considerably during the last decade.

If a different treponemal test is used during the follow-up (e.g., VDRL followed by RPR, or vice versa), it can be difficult to identify whether the treatment has been

effective, the pregnant woman needs more doses, or she has been reinfected, owing to the differences in the techniques and results. In such cases, it can be difficult to establish a difference. It can also be difficult to establish whether the result is a reinfection (a “new” syphilis) or a *huella inmunológica* [immunological footprint]. For instance, the result of a VDRL may indicate reactivity after treatment, but this does not necessarily mean that the treatment has been ineffective. In short, antibodies can show reactivity, so this is not necessarily an active infection. This is challenging, as mentioned by several healthcare workers during the interviews:

“Something that is frequent and difficult for everybody is the interpretation of the serology when they are doing a follow-up. I think people get stuck. They are not clear that the only alteration is if it increases, right? Or if, after 6 or 12 months, it doesn't decrease the two dilutions or four times. So, they take the serology every month and it doesn't decrease and they give more treatment. So, a pregnant woman might get three times the three doses in one pregnancy because they are assuming the treatment is ineffective because the serology isn't decreasing”. (Interview 37, Healthcare worker)

Key points here concern practices that enact absences, particularly regarding materials and competences. Regarding materials, the women's affiliations with different healthcare providers makes it difficult to administer treatment to the women's partners and sexual contacts. In addition, the need to administer penicillin in an emergency room and to desensitise the patient to avoid an adverse reaction to the medication also play a role. Furthermore, regarding competences, there are uncertainties around the administration of the treatment and the determination of its efficacy, which also configure absence practices and silencing syphilis.

In the following section, I will discuss the surveillance of syphilis.

### Syphilis surveillance

The surveillance of GS and CS is important at the patient and population levels. There are several interlinked practices involved in the counting, measuring, and comparing of numbers of cases, incidences, and prevalences.

In each healthcare facility (from primary to tertiary level of care), healthcare workers must report the numbers of gestational and congenital cases. Most *departamentos*

[counties] of Colombia report on both GS and CS cases. However, some consistently report no or only very few cases. *Silencio epidemiológico* [epidemiological silence] is the term commonly used to refer to such an absence of reports. This term is frequently used by healthcare administrators and workers, especially those working closely on epidemiological surveillance. It can also be found in documents from the INS in Colombia (Instituto Nacional de Salud, 2016). *Silencio epidemiológico* [epidemiological silence] also describes the practice by *departamentos* of sending case reports to the INS late or making amendments to previous case notifications.

Some of the interviewee healthcare workers suspected that GS and CS cases were being silenced, pointing out that some *departamentos* currently reporting low numbers should actually have very similar numbers to other high-reporting counties because they share similar characteristics (high mobility, highly dispersed rural populations, difficulties with healthcare access, etc.). This is particularly true for *departamentos* in Amazonia and at the border with other countries. Moreover, some of the interviewee healthcare administrators indicated that the high numbers of cases in their own *departamentos* were because they were so effective in epidemiological surveillance. As one administrator said, “*El que busca encuentra*” (“One who searches, finds”; Interview 18, Healthcare administrator).

Following the introduction of the CPGs in 2014, there was a change in the GS and CS case algorithm (the case definition). As noted earlier, there is no universal definition of a syphilis case. Each country establishes its own case definition, according to its own particularities (incidence, prevalence, high-risk population), as shown by Petty-Saphon *et al.* (2019), who noted the challenges for epidemiological surveillance produced by applying the EU definition to Ireland.

A key trait of the new case definition is the order in which the testing for syphilis is to be performed. At the regional and national levels, if the case reports do not correspond to the case definition, those cases are not included and do not count towards the incidence rates. Each year, a percentage of syphilis cases are dismissed due to not fulfilling the case definition. In 2020, 24.5% of cases in Chocó and 19% of those in Caldas did not fulfil the case definition (Instituto Nacional de Salud, 2020). However, other *departamentos* show even higher proportion of non-eligible cases,

with 45.8% in Córdoba, 30.8% in Cauca, and 27% in Bolivar (Instituto Nacional de Salud, 2020). It is not a surprise, then, that healthcare administrators manifest a tendency to “finish with syphilis from the desk” (Interview 7, Healthcare administrator). This refers to how health authorities from the INS seek to reduce the number of GS and CS cases by using an administrative measure that does not reflect the clinical and epidemiological “reality”.

There is a close relationship between a GS and CS case, as the latter is a consequence of the former. A CS case report is expected to come with a GS case report from the mother. However, as explained by some healthcare administrators, this is not always the case. This is partially because CS cases can be reported months after giving birth. Some of the healthcare administrators alleged that there was insufficient monitoring of babies after birth, given that CS can manifest as much as a year after the baby is born.

Another practice in which absences and silences are enacted occurs in the reporting of GS and CS cases. The report form draws a distinction between the *municipio de procedencia* (city of origin), the *municipio de residencia* (city of residence), and the *municipio de ocurrencia* (city in which the report is made). The *municipio de residencia* is considered the primary city for the case report. In a country such as Colombia, where there is high mobility between municipalities and *departamentos*, it is possible for a pregnant woman to have moved to her current city from elsewhere (indeed, this was the case for 4 of the 27 pregnant women and recent mothers in this study). If a pregnant woman has lived for more than three months in a city or municipality, the GS and CS case then belongs to her current city or municipality. Therefore, on some occasions, the Secretaries of Health acknowledge GS and CS cases “too late”, with a different municipality having filed the report.

In those situations, there seems to be a lack of active engagement with the follow-up, including monitoring and CS prevention at the level of epidemiological surveillance. As commented by a healthcare administrator,

“... the Institute [National Institute of Health], they compile data from all over the country and they said, ‘Hey! You have a maternal death, an undocumented migrant’. And I said, ‘What? But where?’ ‘It was in X [municipality].’ So, they started

to look closely. The girl had only been in “X” for two months, and before that, she was in another municipality. So, the report was for [name of other municipality]”. (Interview 7, Healthcare administrator)

On some occasions, cases attributed to one municipality can be attributed elsewhere after an analysis of the case. This is a “relief” for the healthcare administrative staff because it means the case does not count towards the statistics affecting their metrics. A lack of system integration, miscommunication, and silence thus lead to the emergence of cases for which no one responsible.

Something similar happens with what has been characterised as *sífilis Venezolana* [Venezuelan syphilis]. During the interviews, some healthcare administrators referred to GS and CS cases from women from Venezuela as “syphilis from Venezuela”. Associated with this categorisation was the idea that these cases were difficult to prevent: there was nothing that could be done about them:

“The year before last year (...) 30% of gestational syphilis cases occurred among women without healthcare insurance. 90% of those were undocumented migrants from Venezuela. So, that is difficult (...) There are people who don’t have insurance because they don’t have a job, right? But they also don’t have money to pay”. (Interview 7, Healthcare administrator)

Besides the administrative difficulties in providing healthcare services to these women, some emphasised issues surrounding sexual and reproductive rights, sex education, configuring some stigmatisation practices (see Chapter 6, “Taboos and Stigmas”):

“STDs are more common among them [Venezuelan migrants], a lot more common. HIV, hepatitis, syphilis, everything – and the morbidity (...) I think there is a lot to do regarding sexual and reproductive rights among Venezuelans. It is not just family planning, condoms, education about STDs (...) I think it should be a goal for the government because those issues cost a lot of resources in our healthcare system”. (Interview 37, Healthcare worker)



In the last couple of years, there has been mass migration of more than 3 million people from Venezuela to other countries in South America. For many Venezuelans, Colombia is a route by which to access other countries in the north or the south of America, and for some it is a place to settle permanently. Although the Colombian government, other international agencies, and NGOs have all made efforts to provide these migrants with access to healthcare services, the resources are limited, particularly if those migrants are undocumented. Pregnant women from Venezuela have difficulties accessing prenatal care (usually starting “late”), and many of the women who are moving from one place to another, not staying in any particular city or municipality, encounter difficulties in accessing resources. Larger cities – and cities in which more Venezuelans have chosen to stay – tend to dedicate more resources for their care.

The categorisation of certain GS and CS cases as *sífilis Venezolana* [Venezuelan syphilis] means that these are considered “foreign” and not the direct responsibility of the health secretaries. In short, they are not regarded an indicator of “poor” performance on the part of the local health systems.

However, while a pregnant Venezuelan woman with GS is considered to be a case of *sífilis Venezolana*, it is unclear whether her baby with CS is also categorised in the same way. As stated by a healthcare administrator,

“... we have to worry about those pregnant women who raise our indicators. If they [the pregnant women] have been living here for a year, that syphilis is Colombian. That syphilis did not come from Venezuela: that syphilis was contracted here. Even if it came with her husband, that syphilis was contracted here”. (Interview 38, Healthcare administrator)

Furthermore, according to Colombian law, all babies born in Colombian territory are Colombian and entitled to receive medical attention. However, it can be difficult to follow-up babies after birth to establish whether they have CS, and other priorities in terms of epidemiological surveillance (maternal deaths, COVID-19 cases) are considered more urgent.

As noted in previous sections, in the context of syphilis surveillance, there are issues of healthcare competence and meanings that are fundamental of absences and silencing practices. Categorisations, definitions, standards, and procedures can cause certain syphilis cases to become “absent”, as well as silencing the difficulties of migrants associated with high mobility, a lack of resources, and stigmatisation in a healthcare system that do not accommodate to people’s circumstances.

Let us now turn to the trajectories and temporalities that constitute discontinuity practices.

#### Temporalities, trajectories, and discontinuities

Disease prevention – particularly the prevention of CS – is usually assumed to have a linear trajectory (teleological), comprising goal-oriented activities and processes that aim for control (i.e., the reduction of CS). However, I argue that there is no single temporality. Multiple practices enact multiple ontologies and these implicate multiple temporalities.

I will begin by discussing the temporality usually acknowledged in the CPGs referred to by healthcare workers and enacted in the process of providing prenatal care.

If a woman gets pregnant, ideally, she should start prenatal care during the first trimester, by 10 weeks of pregnancy (Ministerio de Salud y Protección Social, 2013). During the first prenatal care appointment, a complete medical record, including a measure of pregnancy-related risks and psychosocial risks, should be taken. Syphilis screening should also be done.

According to the CPG (Ministerio de Salud y Protección Social y Fondo de Población de las Naciones Unidas, 2014), a rapid syphilis test should be used for the screening, and if positive, the first dose of penicillin should be provided at the point of care, assuming there is no history of allergic reaction to penicillin. Alongside this, a treponemal test (VDRL or RPR) should be taken to establish the reactivity and verify the effectiveness of treatment during the subsequent months.

In every trimester of pregnancy and at delivery, a syphilis test must be done to identify the presence of syphilis, whether the treatment has been effective, or if there

has reinfection that needs further treatment. A reinfection occurs when, after receiving adequate treatment, a woman who is currently pregnant or within 40 days of giving birth presents with lesions in her genitalia or on her skin or her VDRL/RPR test results increases four times or by two dilutions. A reinfection is also indicated if, after six months from the initial test and after receiving adequate treatment, a woman's test results do not decrease four times or by two dilutions (Ministerio de Salud y Protección Social, 2013a).

All babies born to a mother with GS receive penicillin and are monitored every 3, 6, 9, and 12 months to check for late manifestations of the disease (Ministerio de Salud y Protección Social y Fondo de Población de las Naciones Unidas, 2014).

Two key points can be identified in the previous observations. First, there is a sense of continuity and linearity in the activities conducted during prenatal care. Second, the necessity of meeting specific times in order to carry out the activities related to disease prevention. Even practices and activities before or beyond the prevention trajectory (i.e., prenatal care) should be connected and integrated. For instance, women are expected to attend *consulta preconcepcional* [preconception counselling] one year before getting pregnant to plan for their pregnancy. Here, the performance of times and activities implicate certain standards and expectations, as well as the coordination of activities. However, this does not necessarily happen, and there are constant "disruptions" of the timeline.

Specific trajectories also presuppose a system. They imply closely interconnected instances or parts that cooperate synchronically and diachronically. In the CPGs, for instance, the diagnostic algorithm assumes a linear trajectory in which several steps are followed according to a reduced number of options. However, other temporalities are also enacted while preventing CS. There are some temporalities which are "closer" to temporalities of prevention. For instance, we see this in how the disease is considered and how it is prevented in terms of either cycles or "events". Syphilis is "seen" through the lens of disease stages, sometimes even "latent" (unnoticed for months or years) and only screened for and treated during certain moments of prenatal care or among high-risk populations. Particularly for CS prevention, women

are screened and treated during pregnancy or before giving birth but not necessarily before or after pregnancy.

The idea of “on time” prevention implies that individual trajectories might be coordinated with other activities. For example, this is evident in the notion of starting prenatal care “on time” (i.e., before 12 weeks of pregnancy), the running of a syphilis screening before week 12, and the receipt of treatment for GS as soon as possible or 30 days before giving birth.

The trajectories and temporalities of these practices are oriented towards a goal: they are future-oriented. However, other activities point to different temporalities and trajectory.

Some temporalities entail a period of waiting. For instance, temporality is “slowed” when a pregnant woman waits for authorisation to access certain health services or to receive the results of lab tests before the next prenatal care appointment (this can be a month or more). Something similar happens when Afro-descendant pregnant women are asked about their due date or the stage of their pregnancy. To avoid a *trama* [complications arising due to the envy of a third-party], some women choose not to share their due date or details of the week of their pregnancy. This is also a “waiting time” because there is no clear indication of when the event will happen. This also arises when going to the emergency room. The classification made by triage protocol determines when someone will receive medical attention, and it can be unclear when exactly that will happen.

The temporality in the emergency room reminds us of the difference regarding “urgency”. An urgent act in prenatal care – such as the provision of penicillin to a pregnant woman with a positive syphilis result – is not necessarily urgent in the emergency room. The protocol for triage in the emergency room indicates the conditions that should be prioritised and identifies high-risk patients who require immediate medical attention (Ministerio de Salud y Protección Social, 2016). The provision of penicillin to a pregnant woman for syphilis treatment is not on the first level of the triage scale. This is then further deprioritised if the pregnant woman needs desensitisation due to a potential allergic reaction.

Traditional medicine and traditional midwives practice other temporalities, sometimes more focused on the past and on tradition, sometimes more focused on the present (more on this in the next chapter, on care assemblages). These practices involve a principle of equilibrium to maintain health that and entail constant interaction between diverse sources and elements. This differs from the avoidance of risk (particularly calculated risk), which is embedded in disease prevention. One additional difference can be found here.

Since the equilibrium is not directed towards a particular ailment or disease in traditional medicine, practices differ from those typically found in biomedicine. Avoiding or protecting against a risk associated with one disease might generate a greater risk or danger of another disease. For instance, by avoiding the risk of COVID-19, some pregnant women did not attend hospitals and healthcare facilities or were not monitored as expected, leading to an increase in pregnancy-related complications and maternal deaths.

Further, during the pandemic, the difference between the “newness” of COVID-19 and the “oldness” of syphilis was emphasised – as stated by one of the participants, “syphilis has been around for a while” (Interview 18, Healthcare administrator), while COVID-19 is comparatively unknown. COVID-19 was more “urgent”, massively affecting populations worldwide. However, it not only “urgency” and “newness” that play a role here. In addition, practices related to the prevention, diagnosis, and treatment of syphilis (GS and CS) do not always “catch our attention” or only do so at specific times, when it might be “too late”.

The preceding examples reveal the significance of temporalities for disease prevention. Consideration of the multiple temporalities reveals that multiple ontologies are enacted in the prevention of CS and that sometimes these clash, bringing about discontinuities, absences, and silences. Further, we can glimpse how behavioural-change approaches cannot fully grasp what disease prevention entails in actuality, as they often assume only certain types of temporality. As indicated by Shove (2017), practice has a complex history and trajectory, and something can be “missed” when other temporalities and trajectories are not taken into account.

In the next section, I will introduce some further concepts to continue the discussion on silence, absence, and discontinuities.

#### Discussions over silence – absences and discontinuities

So far, we have seen the interrelationship between practice elements and the configuration of silence practices, some of which suggest a “falling silent”, others a “choosing silence”, and others a “making silent” (each suggestive of diverse configurations of agency). Let me clarify further.

One might consider “making silent” an imposed activity, occurring when some body parts are “silenced”, when there are no medical records or records are incomplete, and when there is no clear difference between immunological footprints. This also occurs when there is no follow-up of babies after they are born, when *sífilis Venezolana* [Venezuelan syphilis is recorded], and where cases are dismissed because they do not fit perfectly with the case definition or they belong to a different municipality. Moreover, when other diseases are more prioritised and when there is “epidemiological silence” in all these cases, silence has been imposed.

On the other hand, false-negative syphilis results, syphilis being defined as a “Western disease”, the partner of a woman with GS belonging to a different EPS, the immunological footprint being unclear, when there is a syndromic treatment, and syphilis not being evident in certain stages are all practices that “fall silent” (a passive activity).

In other cases, there is an actively “chosen silence” – when avoiding *tramar* (see Chapter 6, “Taboos and Stigma”), not discussing sex during pregnancy or STDs, and being unwilling to share a positive syphilis diagnosis with a partner.

However, there are several points to consider before we can provide clear definitions of these types of silences. First, there are questions of agency – namely, relational agency between humans and non-humans (more on this in the following section). Second, we have to consider the interrelationships between materials,

competences, and meanings (Shove, 2017), looking at how they clash, interfere, and interact in each practice of silence.

One might consider that silence or absence practices are particularly common in relation to materials, given the examples of false positives, partners with different EPSs, syphilis not being visible in certain stages, lack of complete medical records, or failure to provide treatment on time. In contrast, one might consider that silences are frequently associated with competences, arising when acknowledging an immunological footprint, “silencing” certain body parts, comparing test results to identify the effectiveness of treatment while comparing how many dilutions they have increased or decreased. An emphasis on identifying the change in the dilutions with several examples was indicated during two workshops (one regional and one at the national level) where healthcare workers participated.

Alternatively, a mixture of materials and competences that make enact silence, as in the case of “epidemiological silence”.

The discussion of agency and temporalities is relevant in disease prevention because, in the context of the latter, there is usually reference to responsibility and intentionality. Discussing how materials, multiple ontologies, and temporalities interact to complicate prevention will illuminate the issues and affect how care is manifested (which materials, temporalities, connections, and disconnections are included).

In what follows, I will engage in a discussion of agency and show how, by paying attention to different types of agency, different types of interactions affect prevention practices and collateral realities such as silence, absences, and discontinuities.

### Agency

One might wonder what kind of agency is enacted in silence and absence practices. The discussion of agency is theoretically relevant to and important for disease prevention. “Agency” (broadly speaking, the capacity to act) is linked to who has the

capacity to act but also who might be responsible for change (Hainz, Bossert and Strech, 2016; Kenney and Müller, 2017; Lupton, 2012).

In disease prevention, agency appears regularly in both implicit and explicit forms. Most of the time, individuals are assumed to have a certain type of agency (intentional, without many constraints) and expected to follow certain courses of action (lifestyles), avoiding certain risks, engaging in certain behaviours, and seeking to be healthy and avoid contracting diseases. In this respect, one can point to the ideal citizen, who makes their own choices and changes following a lifestyle, as noted by Mol (2008) and Campbell and Cornish (2021).

I will now provide three examples from the study that illustrate the relevance of human and non-human agency, as well as the complex and heterogeneous attributive agency that interact in CS-prevention efforts, especially while considering different trajectories and temporalities. Although I will not provide a full account of these types of agency, it is worth noting that they are relevant to CS prevention and will need further analysis in future work. Nevertheless, it is possible to explore diverse types of agency or, rather, the coordination (or miscoordination) of agency during CS prevention.

In the first example, a pregnant woman is tested for syphilis during prenatal care and before giving birth. If positive, she is “responsible” (has agency) for receiving treatment and for communicating her result to her partner and/or sexual contacts, so that they can also receive treatment. The partner or sexual contacts are then “responsible” (have agency) for communicating the information to their own sexual contacts, so that they, too, can receive treatment.

This form of attributive agency (Thompson, 2005) is complex, particularly in the case of partners and sexual contacts. On the one hand, partners/sexual contacts are considered “passive”, while pregnant women are tested and receive treatment for syphilis. On the other hand, they are considered “active”, being responsible for the contagion and/or reinfection of women with syphilis. Some of the interviewees (namely, healthcare workers and pregnant women, particularly in Chocó) considered men “responsible” for infection because they assumed that men would have more



sexual partners than women would. For instance, in Chocó, several interviewees referred to men as *hombre canal* (an expression literally translated as “canal men”; Interview 4, Healthcare worker). Some interviewees attributed to men the capacity to “bring” and “spread” syphilis from “outside” to “inside”, to pregnant women and into the home.

Although equally men and women can infect their partners/sexual contacts, an emphasis on the role of men in this regard shows the tensions regarding responsibility for syphilis treatment and CS prevention in prenatal care and primary care settings.

Given this example, it is important to acknowledge that agency cannot be associated solely with either pregnant women or men. To prevent an infectious disease such as syphilis, diagnosis and treatment involves several agencies in a complex network of interactions (sexual contacts).

Another form of attributive agency can be found with pregnant women. Pregnant women are sometimes considered “passive” while receiving a diagnosis, following recommendations for treatment, and having a “good pregnancy”. The pregnant interviewees in this study complained about healthcare workers, relatives, and even neighbours telling them what to do, imposing restrictions, and providing unsolicited advice. However, pregnant women are typically considered active in any poor outcomes, particularly if the baby contracts CS, or if they are deemed to be not a “good mother”, as was the case for several of the interviewees. Sometimes, pregnant women “reclaim” their agency by stating that, even if people are providing advice and imposing restrictions, the final decisions ultimately depends on them: it depends on their “instinct”, as reported by several participants in online asynchronous focus group 1.

Similarly, traditional midwives also encounter attributive agency. They are sometimes active (especially for the WHO, UNICEF, and some healthcare workers) when looking after pregnant women's wellbeing, monitoring the development of the baby, repositioning the baby when it is not well positioned, and seeking assistance from healthcare facilities in the event of complications. However, they are also

considered passive – by themselves, but also by some healthcare workers and administrators in terms of helping during the births of women who are high risk and/or who have diagnoses of HIV or syphilis.

In the third example, one can see what Michel Callon and John Law refer to as “hybrid collectives” – “... an emergent effect created by the interaction of the heterogeneous parts that make it up” (Callon and Law, 1997:98).

In this case, GS and CS prevention can be complicated by difficulties with medical records. Medical records have attributive agency while interacting with healthcare workers and pregnant women. Let us explore this through the experiences of one participant.

A pregnant woman (Interview 31) attended a prenatal care appointment, where a healthcare worker<sup>1</sup> filled in her medical record. A couple of weeks later, she went to a different healthcare centre, where a healthcare worker<sup>2</sup> continued filling in her medical record. However, there were no previous records present at this second appointment, as the software at that centre was different to the one in the first centre. The healthcare worker<sup>2</sup> “nagged” the woman because the woman did not know what tests had been performed previously, nor did she know her diagnosis or whether she had received treatment.

The pregnant woman was expected to have in her possession the information missing from her medical record. The healthcare worker<sup>2</sup> wrote an “abstract” of the most important points in preparation for the pregnant woman’s visit to hospital. However, a healthcare worker<sup>3</sup> at the hospital did not trust the “abstract” written by healthcare worker<sup>2</sup> as it looked incomplete. The pregnant woman was about to give birth and the healthcare workers needed to know whether she had received treatment for syphilis. A current positive diagnosis is only an “immunological footprint”. But without a clear medical record, diagnosis, treatment, and prevention are more complicated.

The previous examples illustrate the need for a deeper analysis of the intricacies of the materials, competences, and meanings; the multiple forms of agency; and the discontinuities in trajectories and temporalities.

Let us move now to some differences in silence and absence practices.

#### Differences between silences, absences, and discontinuities

So far, I have emphasised the presence of silence practices during pregnancy, prenatal care, syphilis diagnosis and treatment, and epidemiological surveillance. I have also indicated that, more than knowledge and know-how intervene in those bundles of practices, as well as the relevance of some materialities and meanings in deciphering how CS is to be prevented. Moreover, I have suggested that making silent, choosing silence, and falling silent show how diverse combinations of materials, power relations, and agency intervene around CS prevention.

I have also highlighted that, not only do silence practices make certain other practices and ontologies less salient, they also allow those bundles of practices to be connected and disconnected, occasionally increasing the sense of discontinuity and fragmentation. If CS prevention is a process of interrelated activities, it may “fail” or not “progress” due to some of these practices of silence and absence.

However, one might wonder about the difference between silence and absences practices and be tempted to consider silence and discontinuity practices as absences. However, in “silence”, there is an absence of words, sounds, and signs, whereas in an “absence”, there is an absence of continuity in a trajectory or temporality, or a lack of steps toward a goal. Additionally, one might draw on the difference established by John Law (2004) between “manifest absence” (recognised as relevant) and “otherness” (absent and seen as irrelevant, impossible, or repressed).

Yet, while emphasising silence besides absence practices, a consideration of certain types of agency can be brought into the discussion. For example, one can point to agency – which is infused with intentionality – employed to stay silent or to make something or someone else silent. However, a problem arises while considering the “silencing” of body parts. These materialities are silenced either by the pregnant

women or healthcare workers, by a lack of attention or a fixation of attention on other body parts. Here, body parts do not have the capacity to “speak” but semiotically have the capacity to “express” or “indicate” a sign of syphilis, if such a sign can be recognised and acknowledged.

The difference between silence and absence practices is, thus, that the former is related to not talking, not saying, not allowing expression. Although this might be indicative only of human practices (including the exercise of intentionality), practices related to the enactment of the disease are also involved. As such, while sometimes the disease is absent (either as a manifest absence or an otherness; Law, 2004), at other times it is silent (either falling silent or being made silent).

Discontinuity practices comprise another form of absence. As indicated previously, they entail absences in trajectory, temporality, or stage. Here, the emphasis on timelines, trajectories, and stages is necessary not only because these constitute important elements of CS prevention, but also to indicate that diverse temporalities, trajectories, and stages contribute to the ontological multiplicity that further complicates the ideal of prevention and control. Moreover, those discontinuities “mis-coordinate”, “interrupt”, and “clash”, while attributive agencies (human and non-human) interact.

To provide a better account of these issues (temporalities, trajectories, agency), the following chapters will explore care assemblages and taboos and stigmas.

#### Final remarks

In this chapter, I have made several interconnected points regarding disease prevention, particularly CS prevention.

First, CS prevention entails a bundle of practices before and beyond prenatal care, determining how syphilis is researched, diagnosed, treated, and surveilled by multiple ontologies that involve multiple trajectories and temporalities. Examples of trajectories and temporalities are different stages of the disease, disease signs that can go unnoticed for years, epidemiological silence, and cases that do not comply with the case definition, just to name a few. Silence and absence practices are enacted during pregnancy, prenatal care, labour, and the first months of babies'

lives. Such practices include silenced body parts, silences around the details of a pregnancy, and the non-provision of treatment to pregnant women's sexual contacts.

Unlike in prevention of anaemia and atherosclerosis (Mol, 1999; Mol, 2002), in CS prevention, the continuity of practices is constantly disrupted, "elongated", suspended, and "altered" – in part because of multiple absences and discontinuities, and the impact of these on how trajectories and temporalities are enacted. For instance, a false positive result, the use of different tests for diagnosis, and the administration of penicillin in the emergency room all clash with the specific temporality needed for the prevention of CS during prenatal care.

Second, lack of competences (know-how) are not the main cause of this miscoordination of practices, as might be supposed if the focus were on the effective implementation of the CPGs. Rather, there is also a discoordination of materials and meanings at particular moments, leading to the emergence of trajectories of discontinuities, absences, and silences. The lack of integration in the healthcare system regarding information sharing (e.g. medical records), the absence of timely provision of authorisations for healthcare services, and the failure to provide services to affiliates who do not belong to the same EPSs all lead to silences, absences, and discontinuities.

Third, consideration of the practices in disease prevention (particularly CS prevention) reveals the limitations of the deficit models, which privilege the provision of more information as a solution for high incidence of CS. This is indicative of how behavioural-change approaches fail to grasp what disease prevention entails, since they tend to assume certain types of ontology and temporality. As indicated by Shove (2017), when practice is considered as an entity, it has a history and trajectory. That practice can "miss" something when it does not consider other temporalities or trajectories, which are sometimes more salient or urgent (such as the prevention practices employed during the COVID-19 pandemic).

Fourth, several accounts of human agency have been drawn from the literature to inform the data analysis. Healthcare workers and pregnant women are usually the active agents responsible for – and intentionally looking to comply with – the goals

aligned to the CPGs for the prevention of CS. However, several types of agency are in evidence here. Material and human agency interact while enacting CS prevention, occasionally in ways that are not necessarily intentional. Discontinuity in practice can arise due to “negative agency” (Ferrero, 2022). For other activities, alternative priorities are pivotal at certain times, leading to inaction (negative agency). In all this, the distribution of agency between humans and materials produces collateral realities that are central to CS prevention.

Fifth, there is the matter of ontological unity. The collateral reality (assumption) that syphilis and CS can be prevented in the same ways disregards the differences evident at the international and national levels. The differences between strains of *Treponema pallidum* bacteria have not been fully explored. For example, there are gaps in knowledge of the bacteria, differences in diagnosis and treatment (the reverse algorithm in LMICs and the traditional algorithm in HICs), and the surveillance of GS and CS during prenatal care.

Sixth, another collateral reality involves the linear temporality assumed by the CPGs in which syphilis diagnosis and treatment must be accomplished at specific times, regardless of the circumstances that surround the healthcare provision (e.g., availability of tests and treatment, the care practices with which women engage to find out about their pregnancies and start their prenatal care).

Seventh, another collateral reality consists of the healthcare system as integrated. It is assumed that all activities, procedures, and steps lead to CS prevention in a linear, goal-oriented fashion. However, constant disruptions and “delays” occur, for instance, for pregnant women who are migrating between municipalities or changing between types of health insurance.

Most of the ontologies discussed in this chapter relate to biomedicine, but it is possible to identify the negotiations, clashes, and cooperations that emerge during a bundle of practices (pregnancy, prenatal care, giving birth, disease prevention, health inequalities).

In summary, CS prevention and other practices during pregnancy and labour involve care and diverse material engagements in a relational, situated, and contextual way. They occur in interdependent worlds (Puig de la Bellacasa, 2012), in which constant adaptations are needed (Mol and Hardon, 2020).

However, one cannot provide a clearer account of CS prevention without referring to ontologies, silence, absence, and discontinuity practices and their multiplicity without incorporating other knowledges, other temporalities (not only linear), and scales (local, national, and global), as proposed by Boaventura de Santos Sousa (Santos, 2011). Therefore, other knowledges, ontologies, and experiences – besides those from biomedicine – need to be discussed, and we turn to these in the following chapter, on care assemblages.

## CHAPTER 5 CARE ASSEMBLAGES

In the previous chapter, “Ontological Discontinuities”, I showed how multiple ontologies (i.e. realities) are enacted while preventing CS, which indicated a bundle of interrelated practices that configure disease prevention while sometimes enacting collateral realities such as silence, absences, and discontinuities.

In this chapter, I provide an account of other ontologies, knowledge, and temporalities that are also enacted by pregnant women and recent mothers looking for care.

This chapter deals with care assemblages that are understood as “a relational nexus of bodies, materials, affects and signs which are gathered into an ongoing process of ‘arranging’” (Brown & Reavey, 2019:135).

In the next six sections, I highlight the main argument from this chapter. Diverse care practices (biomedicine, traditional medicine and *pateria*,<sup>12</sup> *curanderismo*, religion, and online) are constantly negotiated by pregnant women - recent mothers, healthcare workers, *parteras*, relatives, and neighbours. These negotiations, in which trust and expertise are emergent, enact particular care assemblages that relate to historical, traditional, and regional configurations. As we shall see, while configuring care assemblages, the discoordination and clashes among care practices sometimes enact syphilis and CS as absent or silent.

In what follows, this chapter looks at how most CS prevention has been approached through the principles and practices of biomedicine. It also shows how pregnant women – recent mothers and healthcare workers engage with other care assemblages from traditional medicine, traditional midwives, *curanderismo*, religion, and some online resources during pregnancy, giving birth, and during the first months of their babies’ lives in complementary or even “contradictory” ways.

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<sup>12</sup> *Parteria* refers to traditional midwifery, while the traditional midwife is the *partera*.



Therefore, this chapter develops a broader comprehension of disease prevention by considering diverse care assemblages enacted by pregnant women - recent mothers, healthcare care workers and administrators, traditional midwives, and other research participants. In addition, the chapter explores how trust - authority and expertise are constantly negotiated during prenatal care appointments, pregnancy, giving birth, and the first months of babies' lives. Based on these analyses, the assumption that CS prevention is best supported by providing more information, particularly according to biomedical ontologies and principles, is clearly insufficient.

In the first section, I raise some theoretical discussions that emphasise the reasons why referring to care assemblage is better than healing practices, medical systems, or medical pluralism. I then document the principles, characteristics, and practices of the diverse care practices in the regions under study, which include biomedicine, traditional medicine, *parteria*, *curanderismo*, religion, and online resources. In the third section, I explain how these practices enact care assemblages by researching participants in these regions and exploring relevant differences. Regional differences are at the core of the fourth section, where I also indicate how the participants of the study negotiate trust - authority and expertise in relation to these diverse care practices. In the fifth section, I indicate how these multiple care practices enact syphilis and CS. In the last section, I provide final remarks and establish a connection with the following chapter on taboos and stigmas.

By way of initial illustration, let us consider the experience of one of the participants. Participant 8, a woman in her middle 30s living in Quibdó, went to the hospital because she was bleeding and had recently found out about her pregnancy. She was concerned and asked for an urgent appointment at the hospital: "I told her [the GP] what happened to me, and basically she sent me to look on the Internet" (Interview 8, Recent Mother).

From that day, Participant 8 started to look online for other resources and information. It was her first pregnancy, and she had not taken a psycho-prophylaxis course. During such courses, recommendations throughout the pregnancy, giving birth, and the baby's first months are provided. However, most of these courses were

not provided during the pandemic; only a couple of EPS (healthcare service administrators) continued offering them.

While looking for information, she found an app and used it during the rest of the pregnancy: “It is an app called BabyCenter. It is great. It shows the contractions, and everything is for free. It shows the development of the baby month by month. It is really good. (Interview 8, Recent Mother)

After that consultation at the hospital, Participant 8 was told that she could have preeclampsia. She consulted a *partera* [traditional midwife]:

“I told her about my bleeding and that in a test, they said I had a predisposition to preeclampsia. She told me to drink this, and I did it (laughing), and it worked. I don't know what it was I drank, but it worked. (Interview 8, Recent Mother)

Participant 8 also asked some relatives and neighbours about her symptoms and doubts during pregnancy and the first months of her baby's life. It was suggested to her that she drink water with lemon and sleep on her left side. During the interview, she constantly referred to being grateful to God for not having complications while praying for everything to go well. For instance, she was grateful to God when she changed to another EPS, and there were no complications or delays with the service provision. Moreover, she thanked God while taking tests for sexually transmitted diseases (STDs) because of a possible positive result. She had never taken these tests before and was insecure about her past partners or the possibility of her current partner having other sexual contacts. As she stated, “One never knows” (Interview 8, Recent Mother).

This experience, not untypical amongst the other research participants, exemplifies how pregnant women attend to different care assemblages with a combination of biomedicine, traditional medicine - midwives, *curanderismo*, religion, and online care practices (including web pages, videos, testimonies, and apps). According to the literature, one may relate these experiences as complementary therapies, “a non-mainstream practice that is used together with conventional medicine and

'alternative' medicine as a non-mainstream practice used in place of it" (Ng et al., 2022:2), or even as medical pluralism, the mix of different medical traditions with diverse epistemological considerations in complementary and contradictory ways (Leslie, 1980).

However, there are more than medical systems and partial connections happening here. I now turn to theoretical discussions to emphasise why the experiences of pregnant women looking for care are shaped through care assemblages and, thus, why it is valuable to provide an "assemblage" analysis of disease prevention, especially CS prevention.

#### Care assemblages: theoretical discussions

Care assemblages provide a better account of care practices compared to medical landscapes (Hsu, 2012) or mediascapes (Hörbst and Wolf, 2014), even though they share similarities, as shown in Chapter 2, "Literature Review", for several reasons.

First, by considering care assemblages, one is not only focused on a patient-centred perspective but also combines materials, competences, meanings, and practices of care while caring for pregnant women and their babies.

Second, care assemblages can contribute to the understanding of human and non-human interactions, even the enactment of multiple ontologies, while providing care or preventing diseases. In the case of CS prevention, the assemblage of multiple care practices enacts silences and absences that also complicate CS prevention.

Even if boundaries are more clearly defined between care practices (e.g. biomedicine, traditional medicine, and *parteria*) for syphilis and CS, CS prevention entails practices during pregnancy, childbirth, and the first months of babies in which those boundaries constantly fluctuate. Moreover, care assemblage allows for attending to the combinations, interactions, and negotiations among care practices. For instance, how preeclampsia, hypertension, *trama*, pain, and syphilis are cared for is more intricate than the consideration of medical pluralism and medical landscapes with their backgrounds and foreground dynamics.

Susanna Trnka (2021) showed that one can understand the care assemblage from an analytic perspective, in which

“care and other elements of the therapeutic come to be understood as neither anchored to a single site nor constituted through the inter-relation of home and clinic but defined via a shifting, dynamic, and multi-directional assemblage of multiple places, people, and resources”.(p.1)

Therefore, assemblage, particularly care assemblage, allows us to consider interactions and relations, as well as the nexus of practices beyond the constraints of systems with their clear boundaries, institutional configurations, and coordination that medical systems and medical pluralism implicate.

In the following sections, I describe rhizomes (i.e. elements of assemblages) according to the experiences of pregnant women-recent mothers, healthcare workers, administrators, and traditional midwives. Although describing them makes them look like an arborescence (i.e. tree-like) following Deleuze and Guattari (1987), one should not disregard that any part of the assemblage can connect with any other as well as some of these parts could also configure linear relations.

### Care Practices

In the context of this research, pregnant women used biomedicine (i.e. “Western medicine”) as the main element in their care assemblage. The interview data revealed that traditional medicine was more used among women in Quibdó, Lloró, and Riosucio. *Curanderismo* was also practised in these contexts and by some women in Manizales. Most participants practised some elements of religion as care assemblage (predominantly Catholic in Riosucio and Manizales and Christian Evangelical in Quibdó). Many participants from Manizales and some from Quibdó also use the “online” care assemblage.

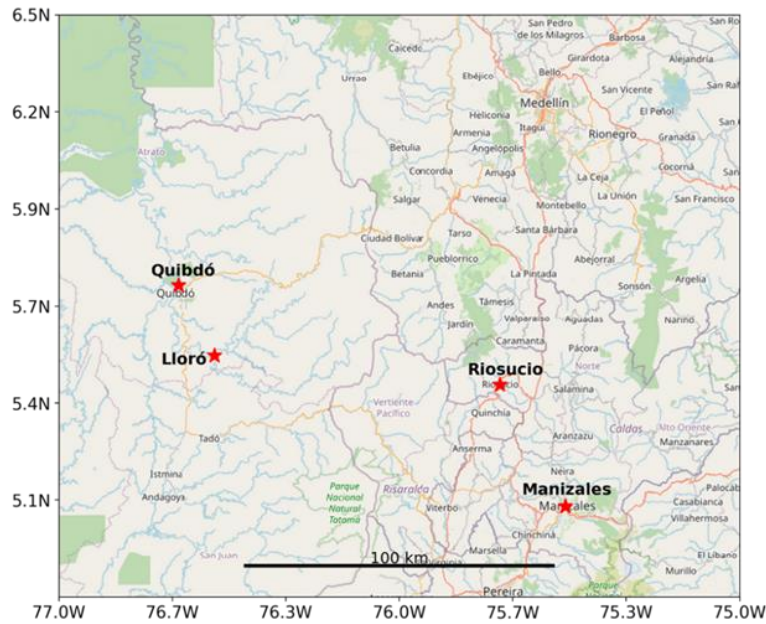


Figure 12

Map 3 Study Sites

Quibdó and Lloró (Chocó) and Manizales and Riosucio (Caldas). Adapted from “Cartopy: a cartographic python library with a Matplotlib interface” by (Arellano, B 2022).

Practices from biomedicine are pivotal because they are offered by the Colombian healthcare system (legally mandatory). Moreover, biomedicine is supported by the principle of science and evidence, which does not recognise and integrate other knowledges and practices.

These care practices share common principles and practices. For instance, all consider that pregnant women should have good nutrition and a balanced diet. Hence, they acknowledge the connection between mother and child. These principles mean that everything that happens to the mother also happens to her baby. Also common is the view that certain behaviours should be avoided to maintain health-equilibrium.

Nonetheless, several differences exist among these care practices that must be acknowledged and considered when exploring how CS is prevented. Let us consider each bundle of practices and its principles and characteristics.

## Biomedicine

In biomedicine, the aetiology of a disease is usually a single cause, which is explained as a malfunction of the body. The body is seen as a conglomerate of parts that have been dissected and separated to produce specialised knowledge. This fragmentation also happens in the relationship between mind and body as separate entities. Moreover, the treatment is usually conducted at the individual, not at the group or communitarian level. Patients are seen as passive, although some cooperation is expected (Wade and Halligan, 2004).

During prenatal care, some parts of the body are more relevant. These parts are where healthcare practitioners will look for signs of abnormalities: the hands and feet for changes in colour or inflammation, as well as measuring the belly to have a sense of the baby's development. Healthcare practitioners also assess blood pressure, blood, and urine that provide key data to consider abnormalities or if a treatment has been successful. Other important data are collected through ultrasound, where the baby is monitored and measured. In biomedicine, sight constitutes a predominant way to collect information.

In comparison, in *parteria* [traditional midwifery], sight is likewise important to determine the state of equilibrium of a pregnant woman. However, hearing, touching, and talking are also important. Listening to a pregnant woman's body and what the pregnant woman says and feels is as important as using the senses to grasp its state.

Moreover, with the development of epidemiology and evidence-based medicine, control measures and anticipation are created to avoid or treat disease, as is the case for risk and “at-risk” categories. Several implications regarding pregnancy follow this perspective. Pregnancy is seen as uncertain (i.e. risky) mainly because women's bodies are considered inferior and vulnerable (Lane, 2015; Scamell and Alaszewski, 2012; Ross, 2015; Lupton, 2012). The argument here is that women's bodies are objects of surveillance through statistics, technological interventions, and hospitalisation (Ross, 2015, Lupton, 2012).

During prenatal care, women are tested, measured, and monitored to be classified as high, low, or at-risk according to standardised measures that indicate who should receive more attention or a more intense intervention. Besides the biological risk of pregnancy (e.g. hypertension, diabetes, hypothyroidism, preeclampsia, age, and previous complications during pregnancy), there is also a classification of risk according to what healthcare workers call “sociocultural aspects”, such as living in an isolated rural area with difficulties accessing health services, not having support from a partner or relatives, experiencing domestic violence, or being a displaced person due to an internal conflict or international migration. These risks are established during the first prenatal care appointment and indicate what special measures should be taken to treat or attend to pregnant women.

Another type of classification is used during prenatal care appointments and while attending pregnant women: race and ethnicity also appear as classificatory categories that enact how care is accomplished. For instance, Afro women are regarded as sexualised subjects more susceptible to having STDs, Indigenous women are viewed as not adherent to treatment, and migrants do not have adequate prenatal care.

For instance, in referring to STD cases, a perinatologist (i.e. a maternal-fetal medicine specialist) I interviewed worked in Manizales and said,

“It can happen in Afro, in Indigenous cultures, or even in the Afros [where] the man travels a lot. Let's say from a rural area to a city or a harbour to work, and there he will have unsafe sexual activity, and he will take all of that to his house”. (Interview 37)

On the other hand, a GP in charge of prenatal care in Riosucio indicated,

"I work with a difficult population here because they are Indigenous and have different beliefs. They do many traditional things with beverages, a lot of stuff, showers, and other things. So, sometimes, they withdraw from the diagnosis, the echography necessary for adequate prenatal care. Then, it is more complicated". (Interview 46)

However, these conceptions are not held by all the healthcare workers I interviewed. Some considered that being Indigenous, Black, or an Afro-descendant did not

implicate a higher risk for syphilis and/or CS just because these populations usually have more difficulties accessing healthcare services and treatments, so they are more prone to those diseases. As one interviewee indicated,

"Indigenous and Afro are the people with the highest lack of access to health services in the Colombian context. It can be because of administrative access or because it is difficult due to distance since they live in dispersed rural areas where transportation is expensive. That represents the biggest barrier to access to complete prenatal care (...) Secondly, it is a cultural aspect since the system [healthcare system] is not adapted to the vulnerability conditions; there is no prenatal care adapted to the idiosyncrasy of Afro culture where *partera* is an essential part of maternity in the culture (...) It is still difficult for an Indigenous woman from its culture to access healthcare services and be cared for by Western medicine that does not understand her perceptions and does not communicate adequately with her". (Interview 1, Physician and Researcher)

In 2015, Law 1751 established interculturality as one of the main principles for healthcare provision. It considers interculturality as the respect of differences and the integration of those differences (i.e., knowledges, practices, and traditional and alternative means) into healthcare. It also created the SISPI (the Indigenous Intercultural Health System run by Indigenous people) to support a certain level of autonomy in their territories: *resguardos* [Indigenous reservations]. They can make decisions regarding healthcare service administration, provision, and delivery with traditional medicine and *parteria* alongside biomedicine. In contrast, in the case of Black and Afro-descendants, health services are mandated to them (Law 1751, 2015). They are not autonomous regarding healthcare services provision/administration, while the inclusion of traditional medicine-parteria in their territories is not fully acknowledged within the healthcare system, unlike what happens with the Indigenous in their territories.

Culture (i.e. ethnic categories, traditions, and practices) sometimes appears in prenatal care settings as a consideration for how to provide care and treatment, as in an *Enfoque diferencial* [differential approach]. "*Enfoque diferencial*" in health indicates a differential treatment and healthcare provision to individuals and communities that have certain vulnerabilities regarding age, ethnic group, disability, gender, and sexual orientation or as victims of internal conflict (Ministerio de Salud



y Protección Social, 2020a). However, even if there are efforts to account for differences, they are usually portrayed as mattering in terms of malfunction or the propensity for the disease, something that should be changed or accommodated, as shown by some of the previous interview fragments. Biomedicine regards these practices as problematic in various ways, as concretely expressed by some of the healthcare workers and administrators I interviewed.

This viewpoint differs from other care practices where “culture” includes differences that matter, which are pivotal and part of the tradition that provides care (as in traditional medicine). In other cases, “culture” does not contribute to the malfunction. Instead, it is the loss of equilibrium regarding those differences that may exacerbate the disease, as discussed below.

Pregnant women who follow advice from a *partera*, their mother, other pregnant women, *curanderismo*, or traditional medicine were not well regarded by the majority of interviewee healthcare workers. These alternatives to biomedicine are considered antagonistic visions that can be threatening and lead to an ineffective diagnosis, follow-up, and treatment. Therefore, the pregnant women and recent mothers I interviewed did not mention using other sources or following advice different from that of their healthcare workers during the prenatal care appointments.

The constant fragility of women and their babies during pregnancy is an idea related to several other biomedical ideas regarding pregnancy. For instance, there is the idea that the woman's immune system is constantly in the process of rejection as if having a war with the foetus (Cadili, 2008) or that the placenta is a site that is a source of bacteria<sup>13</sup> (Gunter, 2018).

The idea of constant fragility is especially present, particularly during childbirth, so a considerable number of measures are taken to deal with potential complications. For instance, there is an anticipation of the need for a caesarean procedure, extreme

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<sup>13</sup> The placenta is present in several practices in *partería* and has a completely different meaning, as shown in the next section.

disinfection measures, not allowing other people (including *parteras*) to be present during childbirth, and providing medication for pain and accelerating contractions.

Since many of the participants could not attend psycho-prophylaxis courses, they lacked information about how giving birth would unfold, what they should do, and what to expect. In psycho-prophylaxis courses, physical, psychological, and behavioural techniques and strategies prepare pregnant women for the stages and changes during pregnancy and birth. They include the acceptance of pregnancy, common beliefs about pregnancy, giving birth, and the first months of the baby's life while working on specific body muscles, breathing, and relaxation to reduce pain during childbirth.

Some of these doubts were more acute due to COVID-19. During the pandemic, being alone while preparing for and giving birth was mandatory to reduce the risk of contagion, which made the women feel more anxious and disconnected from their families and communities. This nervousness was exacerbated by the tradition of receiving a newborn with family and friends present, particularly in Chocó.

Most participants (i.e. recent mothers) complained about how they were treated at the hospital while giving birth. They referred to being screamed at, told off, neglected, treated with impatience, forced to hold uncomfortable positions at length, and cut (i.e. an episiotomy). One of the participants referred to being severely affected by the episiotomy and facing the possibility of having another surgery to repair her perianal region because of the effects on her bowel movements.

Some women referred to being spoken to aggressively while giving birth or even being told not to complain, to deal with the pain, or to wait, as explained by a woman who was receiving anaesthesia to have a caesarean section.

"Well, what happens is that they tell you off because they are impatient. I told the doctor it hurts because an injection in the spine hurts, especially when you have a big belly. You had to bend, squeezing the baby, and the anaesthesia was ineffective. It was the worst. The doctor was really upset, telling me off, saying, "Bend your head." But doctor, I can't if I bend more, I squeeze my belly, and my belly was huge. "But do not move; stay still", [the doctor said]". (Interview 11, Recent Mother)

These childbirth practices contrast with those associated with *parteria*. Let us now turn to traditional medicine and *parteria*, where care and health are enacted differently from what we have seen in biomedicine.

#### Traditional medicine and *parteria*

In traditional medicine, the origin of disease lies beyond biological malfunction. It is an imbalance following the principle of hot and cold found in the body, as well as at the communitarian and social levels. In this case, envy, bad behaviour (such as not following the recommendation during pregnancy or *dieta* [40 days after birth]), and spirits can also cause disease. Thus, other people can contribute to the disease but also help heal it or become an obstacle to curing it (Gomez *et al.*, 2015). Unlike biomedicine, in traditional medicine, the body is not comprised of parts; it is an interrelated entity that connects with other bodies and spirits, even with the territory to which a woman is attached.

The role played by the territory is notable since it is where the relations with other entities are held, where specific threats can be established, and where traditional doctors and midwives can find the plants and the elements that allow them to re-establish balance. In this context, it is unsurprising that after pregnant women give birth, the placenta is given to the mother so it can be planted in the soil. In this way, the baby is rooted in the territory and will not forget its ancestors and traditions.

Several care practices from traditional medicine differ from those of biomedicine. Alcohol, roots, plants, and other symbols are provided in beverages, showers, steams, incense, and amulets to treat and prevent diseases. These practices sometimes include rituals (e.g. snake poisoning). Several ways exist to cure the poison of a snake, such as using the same snake to cure it, drinking a beverage with alcohol and plants, or performing a ritual in the same place where the incident occurred that symbolises the snake's death (the latter two occur when the snake is not present). One of the steps for this treatment is for the traditional doctor (i.e., the *curandero*) to blow on the crown of the head and temples (Gomez *et al.*, 2015). From a biomedical perspective, this act should not be performed due to its implicated risk, particularly during the COVID-19 pandemic.

The interconnection between entities is also seen in the recommendations for those who work in the forest. The day before going to work, they should not have sex since, in the case of having been bitten by a snake, the plants to cure them do not work. Under these circumstances, the person they have sex with must take a shower. Then, that water can then be used to complement the treatment of the bitten person.

During pregnancy, several specific recommendations must be followed to have a good birth and a balanced baby. The recommendations of the traditional midwives and recent mothers I interviewed are as follows. Pregnant women should not pass near stairways, sit with their legs crossed, sit where many people pass, get drenched by the rain, or go outside their houses at night. Moreover, they should avoid particular foods or limit their intake (e.g. cheese for being *graso* [fat] and yam for being *liso* [smooth]). Pregnancy is considered “hot”, so certain things should be avoided so as not to alter the equilibrium. One of the most important recommendations is to practice silence during pregnancy. Not following this recommendation can cause diseases or complicate further treatment. In terms of pregnancy, it implies not revealing the weeks of pregnancy or the estimated date for giving birth. If these measures are not followed, then the pregnant woman is *tramada*.

*Tramar*, or to be *tramada*, refers to the difficulties arising while giving birth, in which the hips of the woman close and become increasingly more narrow. The baby goes up until the point of suffocating the mother and producing their death. It is commonly understood that *tramar* is usually caused by another woman who envies the woman's pregnancy. Since it is not clear who can *tramar* – it can be a neighbour, friend, or acquaintance – much secrecy surrounds information about pregnancy and its details, even among healthcare workers.

Nonetheless, a pregnant woman can *tramar* herself. For instance, if she does not follow the precautions suggested above, she may also have a complicated birth.

During pregnancy, women are encouraged by *parteras* [traditional midwives] to attend prenatal care at the hospital or healthcare centre. Although they can provide advice and treatment during pregnancy and attend to the birth of a baby, they do not

in cases where the pregnant woman does not attend prenatal care. *Parteras* do not attend the birth if the woman has not attended a prenatal care appointment or has hypertension, diabetes, or preeclampsia.

During the interviews I conducted, some *parteras* said they would not attend someone's birth if the pregnant woman had HIV, syphilis, or another untreated STD. However, this approach was not always the case. For instance, one provided treatment for a particular STD before delivery:

“No, not for that disease [syphilis]. For venereal [gonorrhoea], for *gallito* [papillomavirus], yes, but for that one [syphilis], no”. (Interview 42, Traditional Midwife)

Pregnant interviewees in Chocó mentioned looking for *parteras* when they had doubts about the baby's health, if something concerned them (e.g. discharge and spotting blood), or if the baby was positioned in an uncomfortable position. Even if they were not going to have a birth assisted by a *partera*, they consulted with them for advice or a second opinion.

In some cases, the *partera* would tell the pregnant woman to go to the hospital since what she had was beyond the realm of the *partera's* intervention:

“It is important for us as *parteras* to look at the prenatal report because we can see her diagnosis. We do not attend to women with AIDS. We do not attend women with high or low blood pressure, or diabetic women, or when there are pregnancy alarm signs or when there is blood bleeding. It is important to go to the doctor, make a referral, take the pregnant woman to the doctor”. (Interview 43, Traditional Midwife)

During a consultation, a *partera* listens to the baby bump, takes the blood pressure, looks for signs of an unbalanced state, massages the pregnant woman, and, if needed, conducts specific procedures to accommodate the baby. While biomedicine has emphasised and developed ways to “look” at the baby to assess if its development is adequate and is in good health, traditional midwives use hearing and touching. During the final weeks of pregnancy, the *partera* gives the pregnant woman some beverages and ointments to prepare the body for easy delivery to *abrir las carnes* [open the body or the vaginal canal] and also to relax. In this respect, *parteras*

establish a difference between *abrir las carnes* that they practise and what is practised at the hospital, namely, *cortar* [to cut] and *usar el cuchillo* [use of the knife] (Interview 42, Traditional Midwife).

If the *partera* attends the birth, others may be present, such as the pregnant woman's mother and other female relatives, but only occasionally the partner. The *partera* asks the pregnant woman which position she wants to take. Some women prefer giving birth in a squat position, while others prefer going on all fours with hands and knees. The *partera* then provides massages and beverages to make the pregnant woman feel comfortable. Traditional music, chants, and prayers are present while attending the birth.

After giving birth, women are advised to follow specific food recommendations (mainly meat, chicken, and some fish). They should not carry heavy weights, not go outside of the house frequently – particularly not at night, and not have sex during the *dieta* [40 days after giving birth].

Besides the ritual performed with the placenta, there is another practice, *ombligar* [umbilical cord care], which is full of meaning in *partería*. Through several practices, the care provided to the umbilical cord unites the newborn with the territory and the newborn's identity.

Although *parteras* play an essential role during pregnancy and childbirth in some regions of Colombia, they are not integrated into the healthcare system. However, since 2017, they have been recognised as cultural heritage. Moreover, since 2020, Law 350 indicates the incorporation of measures to preserve this traditional knowledge and its practices. Primarily, the Ministry of Culture has implemented measures in this regard, with Law 350 in 2020 and Law 2244 in 2022 on “humanised childbirth”. Indeed, more measures to integrate *parteras* into the healthcare system involving the Ministry of Health and healthcare providers are expected.

Traditional medicine and *partería* share similar practices and principles with *curanderismo*, to which I now turn.

### *Curanderismo*

*Curanderismo* (Garzón Chirivi, 2015) is a mix of practices from Africa, Europe, and America practised mainly by peasants and people in the cities (especially the working class or migrants from rural areas). These practices and related behavioural recommendations are mediated by older women (i.e. grandmothers, mothers, or older neighbours) through the use of beverages and plants that provide care for pregnant women. Traditional midwives also use some of these beverages. In the case of *curanderismo*, the cumulative experiences of older or more experienced women suggest interventions appropriate to the circumstances.

Some of these suggestions are boiling an armadillo shell and drinking it with chocolate, drinking ginger infusions, fennel infusions, or water with lemon, as commented in the first online asynchronous focus group (OAFG 1), or using an amulet for the baby to avoid the evil eye (Interview 8, Pregnant Woman).

In rural areas, people cultivate plants to treat different ailments. In bigger villages and cities, small stores sell the roots and plants needed for these treatments. In these places, the vendors indicate which plants are recommended and how they should be taken, applied, and inhaled. However, other symbols, including religious ones (e.g. amulets, holy water, and saints' figures), are also used for treatment and prevention purposes in conjunction with plants and other compounds.

Although the influence of *curanderismo* seems limited regarding pregnancy and giving birth, it is still used, especially when women consider there is a problem with themselves or their babies. At least half of pregnant women or recent mothers who participated in the study referred to using *curanderismo* practices alongside biomedicine and other care practices (e.g. religion and traditional medicine). *Curanderismo* was more common among participants from Quibdó, Lloró, and Riosucio. Several participants in Manizales indicated its use, particularly after having difficulties during pregnancy or after giving birth.

Family members, neighbours, and friends tend to suggest what would be best if they observe something that may affect the pregnant woman or the baby. Most of these suggestions refer to *curanderismo* and the experience of previous mothers (other

family members or neighbours) who have experienced something similar. However, even though the research participants considered most of these suggestions helpful, they considered that it was their choice of whether to follow the suggestions.

During the interviews and the OAFG, pregnant women and recent mothers referred to the fact that it was suggested to them to drink ginger or mint infusions if they had nausea during the pregnancy, drink lemon to regulate blood pressure, and receive fennel infusions while breastfeeding their babies to stimulate breast milk production. However, even if suggested by older or more experienced women, the research participants considered their personal experiences to also be pertinent in the process. They decided what to do and whether to try some of the suggestions and continue following them. As indicated by one of the recent mothers who drank fennel infusions,

"Listen to your instinct, what your heart tells you as a mother. One accepts advice because sometimes you need them, but sometimes, you have to ignore them. For example, I followed the suggestions that my mother-in-law gave me because she knows. She works with babies and has experience as a mom". (Participant 1, OAFG1)

In this case, a recent mother (Participant 1, OAFG1) accommodated her practice according to her and her mother-in-law's experience, including some elements from *curanderismo*. Although it was not the case for this participant, others (i.e. pregnant women and recent mothers) incorporated practices from *curanderismo* and religion.

### Religion

For most research participants, religion was present and intervened in every part of their pregnancy, giving birth, and the first months of their babies' lives.

Although accounts of praying or thanking God were found in the interviews and the OAFG with pregnant women and recent mothers, the details and content were particularly noteworthy in the diaries written by the pregnant women. In almost every entry, all three participants referred to God (i.e. either being grateful for something that occurred during their pregnancy or asking for health and well-being for themselves and their babies). For instance, religion was present in the entries for Diary 1:



"My diary today: Tuesday, March 16th. Well, I feel anxious and happy because the 18<sup>th</sup>, I have my second ultrasound. I feel a lot of emotions because I'm going to know if it's a baby boy or a baby girl. I am the happiest mother on earth, and I am grateful to God because the baby's moves are stronger, and my belly is getting bigger. I am in love with feeling a new life inside of me". (Diary 1, Pregnant Woman)

Pregnancy and childbirth are considered fragile and unexpected moments during which anything can happen. Pregnant women ask God for comfort and protection. God will intervene while they become pregnant (especially if they want to have a baby) if they have been diagnosed with a disease that may put the baby's health at risk – a disease of the baby or malformation, but especially while giving birth.

A research participant from Manizales in her late 20s indicated that she struggled to become pregnant. During one of the prenatal care appointments, some of the baby's measurements indicated the baby might have a problem (i.e. a congenital malformation), so she prayed to God and promised her baby's name would be taken from the angel Gabriel (who has the power to announce God's will):

"We are believers. My mom and my mother-in-law told me not to worry; they told me to appeal to God. God is going to help you (. . .) My baby's name is Gabriel, and he has that name because of the archangel because that is what we offer to God in this case. We told him to help us, and we offered our baby. If she is a girl, it is going to be Gabriela, and if it is a boy Gabriel". (Interview 17, Recent Mother)

Prayers to God also appeared when this participant had a problem while giving birth and had complications with her episiotomy. She, with her partner and close relatives (i.e. mother and mother-in-law), referred to God. As indicated by her partner,

"I prayed. I said, "Please, God, protect my family. Please don't let anything wrong happen to them. God, please. They are all I have". (Interview 20 Partner)

From these experiences, it is possible to highlight that they followed the recommendations of diverse care practices; however, they acknowledged that it was God's will in the end. In one of the OAFGs, several participants shared songs related to their experiences with pregnancy in which God and religious meanings were pivotal:

"Thanks, my Lord, for giving me strength when I did not have  
For taking care of my loved ones  
For everything you have given to me

Thanks, my Lord, for always listening to my prayers  
To forgive my mistakes  
Thanks for all the blessings.  
Thanks my Lord." (Song "Thanks my Lord" by Yahaira Plasencia; Participant 8, OAFG2)

In traditional medicine and *partería* in Colombia, many influences are from Catholicism, as portrayed in the literature (Laza Vasquez & Ruiz De Cardenas, 2010; Suárez-Baquero & Champion, 2021; Suárez-Baquero & Champion, 2022). This influence was also evidenced among the traditional midwives I interviewed. God and religious symbols were also brought into the prevention and treatment for the imbalance in the form of prayers, holy water, saints' figures, and songs. *Parteras* pray to several saints (i.e. San Antonio, Santa Eduviges, and Santa Elena) and virgins (i.e. Virgen del Carmen and Virgen de los Dolores). However, the main saint they prayed to was San Ramon Nonato (the saint of midwives and newborns).

Even the *parteras* acknowledged how vital God is in their practice. They said they are "*asistentes del milagro de la vida*" [miracle-of-life assistants] (Interview 43, Afro-descendant Traditional Midwife). As demonstrated in other studies (Laza Vasquez & Ruiz De Cardenas, 2010; Suárez-Baquero & Champion, 2022), traditional midwives "believe that, through their hands, God is taking care of pregnant women and children" (Suárez-Baquero & Champion, 2021:538). Moreover, the *parteras* encourage pregnant women to pray and believe that God will help during childbirth.

#### Online care

Pregnant women also went to the Internet (i.e. web pages, YouTube, TikTok, and apps) to look for information and advice if they had concerns that were not satisfactorily covered in the practices or suggestions provided by other care practices. For instance, a diaper brand offered workshops and information on its web pages for pregnant women. For some women in Manizales, it was an option to acquire more information and understand their pregnancies concerning what was "normal" versus what might be a concern.

Regarding apps, BabyCentre was the most used among pregnant women. In this app, information regarding the changes during pregnancy, the baby's development,

and recommendations regarding diet are provided. Suggestions and updates constantly appear according to the time of pregnancy.

A mix of biomedical, traditional healing, and personal experiences from other pregnant women are combined in this “online care assemblage”. It is also worth noting that healthcare workers (i.e. administrators and some traditional midwives) also made use of this care assemblage. Hence, they could suggest certain web pages and videos to pregnant women-recent mothers and their partners. Particularly during the pandemic, online resources were pivotal because of the inability to access psycho-prophylaxis courses or have sufficient time in appointments to discuss certain doubts in a more detailed manner.

One of the participants, whose baby was four months old, indicated that she used an app during pregnancy and still used it to know what is “normal” or expected in her baby's development.

"I used, and I still use BabyCentre (...);It shows general information about your baby every month: how much it should measure, how much it should weigh. The gynaecologist will tell you this in this period, the thing the perinatologist will tell you during the ultrasound. It even shows you the images of how your baby should look like compared to an echography (...) It gives you much advice in terms of what to eat, all the things you see on the courses [psycho-prophylactic courses], but you can find it there". (Interview 17, Pregnant Woman)

However, not all the online resources confirmed or resonated with information derived through biomedicine. As Participant 1 of the OAFG 1 said, she watched a video on TikTok in which a “nurse” suggested that birthing in a standing position was more beneficial. The participant then recalled her own experience confronting what she was going through:

*“Y yo toda la inducción de parto acostada [And I was laid down throughout the labour induction].* (Participant 1, OAFG 1)

There are further differences in terms of online resources. For instance, it is different when a pregnant woman looks at a particular online resource, such as a YouTube channel run by a gynaecologist she knows (i.e. Interview 24, Recent Mother) or a

message on WhatsApp, than when looking at the Internet via search engines. In the latter case, the configuration of the algorithms (i.e. keywords, IP addresses, regional differences, the language used for the search, the type of searching engine used, and search history) configures particular possibilities for access to those resources. This disparity implies that two pregnant women in the same municipality may not find the same online resources at the top of the search results while looking for the same information. These differences in the results made by search engines have been discussed in the literature (Roy & Ayalon, 2020; Baker & Potts, 2013; Nikolov et al., 2018) quantifying biases). Some studies have even highlighted biases regarding certain groups (Noble, 2018; Al-Abbas et al., 2020).

Although none of the research participants referred to this issue while searching for information online, the differences between searching and accessing information online while doing fieldwork in Colombia and analysing data in the UK were clear.

Most participants admitted to using many online resources during the pandemic due to the lack of information and the limited interaction with healthcare workers, practitioners from other care practices, and other mothers dealing with similar situations. However, as some pregnant women also acknowledged, sometimes going online to look for information could be challenging, particularly when investigating symptoms, as one participant declared, "*Todo es cáncer*" [everything is cancer] (Interview 30, Pregnant Woman). Online, things can rapidly seem more severe or risky.

Moreover, healthcare workers and administrators also conveyed the use of online resources. For instance, one GP suggested a pregnant woman (Interview 8, Recent Mother) look for information online regarding her pregnancy, while a gynaecologist suggested looking at her videos on YouTube (Interview 30, Recent Mother). Furthermore, during the pandemic, the interactions through WhatsApp and emails for pregnant women and recent mothers provided information and the fulfilment of administrative procedures.

In sum, pregnant women and recent mothers' experiences with online resources were sources of information that complied with biomedicine (amplifying certain

doubts) while promoting “self-monitoring”. Other studies, such as the one conducted on apps’ period tracking (Ford, De Togni and Miller, 2021), have indicated certain levels of patient “autonomy”.

So far, this section has focused on care practices. The following section discusses how elements from diverse care practices configure care assemblages.

#### Care assemblages: enactment

Women attend prenatal care with physicians and nurses, where tests, ultrasounds, heart rate, weight, and blood pressure are measured. It is also usual for Indigenous and Afro-pregnant women to attend consultations with traditional midwives where relevant practices are enacted, questions addressed, and appropriate procedures conducted during pregnancy indicated. Traditional midwives attend births if the pregnancy is not considered high-risk. During the pandemic, traditional midwives were more frequently consulted. Some pregnant women were afraid of going to hospitals, or it was difficult for them to find transportation to get there. Sometimes, when they wanted to clarify something regarding their pregnancy and a healthcare worker was unavailable, they turned to traditional midwives.

Although differences existed among the Indigenous and Afro-traditional midwives who attended to pregnant women in Riusucio and Quibdó, they all referred to principles of *parto humanizado* [humanisation of childbirth], the integration of families and communities during pregnancy and birth, and the physical and emotional equilibrium of pregnant women.

It is important to highlight that pregnant women could not have psychoprophylaxis courses during the pandemic, during which they normally received recommendations concerning pregnancy, breastfeeding, and their babies’ first months. Such courses were offered only in limited numbers, and most *primeriza* [first-time mothers] felt they were not cared for much because of this situation. Thus, “online care practices” were a way to overcome difficulties with access to information and treatment, as well as when looking for another opinion, particularly among pregnant women and recent mothers.

In cases of considerable concern regarding the pregnancy or the baby's health, most women looked to religion. For Catholic and Christian/Evangelical pregnant women, God was the source of hope and calm during difficult news regarding the baby's health or when possible complications were identified. Moreover, religion was also considered a source for reinstating health through faith and prayers.

For instance, a participant found that her baby might have a problem with its development during one of her prenatal care appointments. She sought help from religion, as was the case for a recent mother (Interview 17).

Pregnancy was experienced somewhat differently for those women who had already given birth since they knew what to expect and how to deal with situations that arose. Nevertheless, they also felt some uncertainties because these *primerizas* [first-time mothers] considered each pregnancy unique with particular challenges. They even considered some pregnancies or childbirths more difficult than others.

When not undergoing a first pregnancy, the women had a stronger sense of autonomy. They knew uncertain situations and other women's experiences. Although experienced women kept asking questions to others about what they should do, there was a greater sense of embodied experience that allowed them to gauge what was at stake and judge what was valuable advice. These strengths further enabled them to negotiate different perspectives on the situation despite their attachment to different care practices and the tensions among them. As indicated by a recent mother on what kind of advice one should follow,

“Listen to your instinct, what your heart tells you as a mother. One accepts advice because sometimes you need them, but sometimes you have to ignore them. For example, I followed the suggestions that my mother-in-law gave me because she knows she works with babies and has experience as a mom. [And who did you ignore?] Ladies that gave opinions without you asking for them”. (Participant 1, OAFG 1)

Pregnant women felt that they received much advice and many recommendations even when they did not ask for them. Ultimately, after receiving advice and engaging with diverse care practices, these pregnant women decided what was more beneficial for them and their babies. This autonomy was more prevalent among

those who were not *primerizas* [first-time mothers]. Nine of the 11 interviewed participants who are not *primerizas* mentioned it, such as Participant 1 of the OAFG1.

At the beginning of this chapter, I provided the example of the experience of a recent mother (Interview 8) from Quibdó who engaged with diverse care practices from biomedicine to *partería*, *curanderismo*, religion, and online resources (including app BabyCentre).

Now, I want to provide another way to trace the enactment of a care assemblage using the experience of a recent mother, *primeriza* [first-time mother], from Manizales (Interview 17).

This woman in her late 20s attended a preconception appointment to have a check-up one year before becoming pregnant. Since she was struggling to become pregnant, she prayed to God and the Virgin Mary and read the Bible. When she became pregnant, she started prenatal care at the healthcare centre and followed the recommendations made by the physician, the nurse, and the nutritionist in charge of prenatal care. Among those recommendations were to take iron and folic acid while following a balanced diet.

Following the diet was particularly difficult for her since she had morning sickness and vomited during most of her pregnancy. She did not see improvements after following the prescribed recommendations, so she decided to drink a beverage made with an armadillo and chocolate, as suggested by an older relative.

A potential congenital malformation was spotted during one of the ultrasounds, so she visited two perinatologists to have different opinions on an amniocentesis test.<sup>14</sup> She also looked at the BabyCentre app, which explained ultrasound measures, what to expect, and the potential risks of an amniocentesis test. She and her partner decided not to have the test and prayed to God for their baby's condition – for the baby's health and well-being.

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<sup>14</sup> This test is performed during pregnancy to confirm genetic or congenital conditions by taking a sample of amniotic fluid. The procedure implies some risk for the baby.

In summary, the experience of this *primeriza* [first-time mother] showed how diverse care practices are accommodated, adapted, and constantly negotiated in configuring a particular care assemblage.

After overviewing diverse care practices that intervene during pregnancy and delivery, I now indicate regional differences concerning the combination of these care assemblages.

### Regional differences

Pregnant women and recent mothers in this study used biomedicine as their primary care practice. Traditional medicine and *partería* were used more amongst women in Quibdó, Lloró, and Riosucio (five participants in the OAFG and six from the interviews). *Curanderismo* was also practised in these contexts and by some women in Manizales (11 participants in the OAFG and 20 from the interviews). Most participants practised religion (Catholic in Riosucio and Manizales, and Christian Evangelical in Quibdó, comprising nine participants in the OAFG and 22 from the interviews). A considerable proportion of participants from Manizales and some from Quibdó also used “online” care assemblages (11 participants in the OAFG and 25 from the interviews). Most of what they considered, followed, and practised was biomedicine.

*Partería* [traditional midwifery] was mainly practised in Lloró and Quibdó. Most of the participants in that region consulted with *parteras*; however, only one wanted a *partera* to attend the birth. Although all of them were afraid of having the baby at the hospital (due to COVID-19, possible complications, having a caesarean procedure, and being alone during the delivery), they also acknowledged that their high-risk pregnancy implicated having the baby at the hospital or feeling more safe and secure in case something went wrong.

Riosucio has an EPS (health care service administrator) run by Indigenous communities that incorporates biomedicine, traditional medicine, and *partería* into its healthcare services. Although I had the opportunity to talk to three pregnant women of Riosucio, none had their babies with *parteras* since all had high-risk pregnancies.



In Manizales, none of the pregnant women consulted *parteras*, and all would have or had their babies at the hospital (some of them had a caesarean procedure).

Most participants in both regions mentioned receiving advice from older women (i.e. grandmothers, mothers, neighbours, and friends) regarding their pregnancy, delivery, or first months of their babies' lives in the form of beverages, showers, and amulets. Some women followed *curanderismo* in both regions, although differences in their characteristics differed from region to region. For instance, the amulet for *mal de ojo* [evil eye] was used more in Riosucio, Quibdó, and Lloró.

In both regions, the influence of religion is considerable, mainly in the form of Catholicism. However, in Quibdó and Manizales, Christian Evangelic churches have also become relevant. In this study, I do not focus much on the differences between these two religious practices since it is beyond the scope of my research. Instead, I focus more on the aspects they share.

Concerning the use of online resources, women in Manizales and Riosucio used them more. However, participants in Quibdó and Lloró also mentioned them. These regional differences regarding care practices – and care assemblages – are due to several practices, which I discuss below.

Before 1993, access to healthcare services was limited for most of the population, especially those with no payment capacity, and particularly for those in rural, isolated regions such as those in Chocó. Thus, the people have relied on traditional medicine, *parteria*, and *curanderismo* practices to care for themselves, their families, and their communities. However, in 1993, Law 100 established the principle of universal health coverage and the configuration of the healthcare system (with subsidised and contributory regimes). Alongside increased health coverage, special projects, and programmes for vulnerable populations (i.e. Indigenous, Afro-descendants, and internally displaced people) were also enacted. Although some policies were set up to recognise other health practices (e.g. traditional medicine and *parteria*) like “*Enfoque diferencial*” (Ministerio de Salud y Protección Social, 2020a), legal, economic, and political constraints from the government, multilateral organisations, NGOs, and educational institutions have operated to support the healthcare system

that recognises biomedicine as the main care practice. Moreover, until recently, in the discourse about the configuration of the Colombian nation, Indigenous and Afro-descendant traditions were portrayed as problematic and preventing the progress and development of the country (Rojas & Castillo, 2005; González, 2014). For instance, constant references to traditional medicine and *partería* practices as causes of maternal and newborn deaths have been common (Laza Vasquez, 2012).

It is then unsurprising that in Manizales, biomedicine practices had more influence than in the other study sites, which may be due to the population's characteristics (i.e. fewer Indigenous and Afro-descendants) and the influence of at least four universities that offer health-related programmes, two concerning medicine at the undergraduate and postgraduate levels.

From these regional differences, it was possible to identify differences regarding trust and expertise since they are important elements as care practices are negotiated. Let us now turn to a brief discussion regarding trust and expertise.

In terms of expertise, as indicated in Chapter 2, "Literature Review", who is considered an expert depends on what is considered science and who is within or outside of that boundary (Star, 2010). Even if laypeople are considered experts, they are not necessarily acknowledged as legitimate for decision-making (Collins and Evans, 2002). Moreover, they cannot question what counts as an expert since the cultural framework of science is privileged (Wynne, 1996; Wynne, 2003).

However, something different happens regarding expertise in the case of the aforementioned care practices, especially in the enactment of care assemblages. There are similarities to what Epstein and Timmermans (2021) referred to as the "blurring of boundaries between 'expert' and 'lay' voices" (Epstein & Timmermans, 2021:244). They indicated a proliferation of sources and a diversification of cultural authority, which are understood as the "probability that particular definitions of reality and judgements of meanings and value will prevail as valid and true" (Starr, 1982:13 in Epstein and Timmermans, 2021:23). According to them, this proliferation and diversification accounts not only for medicine but also for complementary and alternative medicine (CAM) and online resources (including nonmedical actors).

Most of these nonmedical actors refer to wellness (i.e. “healthism”) rather than to health.

Therefore, these other definitions and configurations of expertise implicate additional considerations about trust and authority. For Epstein and Timmermans (2021), trust differs from cultural authority since trust varies according to gender and race and implies different concerns ranging from the effectiveness of a treatment to perceptions of the medical profession and how resources are allocated. For them, cultural authority is an antecedent of social authority (e.g. the authority of physicians). Epstein and Timmermans (2021) also considered that cultural authority could be present in objects.

“[It] may be instantiated in devices, encoded in algorithms, and embedded in nosology . . . the rise of evidence-based medicine, which invests cultural authority somewhat less in the practitioner and more in systematised knowledge, diagnostic classification schemas, and transnational consensus- making institutions”. (Epstein and Timmermans, 2021:243)

In contrast, Giddens (1991) did not acknowledge objects as part of trust relations and considered that trust in the representative system (e.g. physicians) allowed trust in the health system. For him, trust is negotiated between individuals, especially when there is partial understanding. Even in the case of risk (where partial understanding can be magnified), what is at risk also influences trust (Meyer *et al.*, 2008). Giddens (1991) argued that trust is a constant negotiation since societies are more dependent on expert systems. Nevertheless, he acknowledged that expert systems could not “anticipate the future” (Giddens, 1991:144).

Several elements from these discussions concerning trust and authority are important to recall when discussing how they are enacted in care practices within care assemblages. First, the data from this research do not allow us to conclude that cultural authority is a condition for social authority (following Epstein and Timmermans’ terms) or that trust in the representative of the system leads to trust in the system, as Giddens (1991) suggested. The data suggest that trust and authority were constantly negotiated between pregnant women/recent mothers and

healthcare workers. However, it was also negotiated between pregnant women/recent mothers and traditional midwives/practitioners from other care practices (e.g. *curanderismo* and online care). Furthermore, trust and authority were negotiated between the “representatives” or “experts” of these care practices.

For instance, for the *parteras*, this negotiation includes the stethoscope for blood pressure measuring, the use of chemical products (e.g. sodium hypochlorite and alcohol) for disinfection,<sup>15</sup> as well as the referral of pregnant women to the hospital for prenatal care appointments when they are high risk or have complications during childbirth. As indicated by the four traditional midwives I interviewed (one Indigenous and four Afro-descendant). In these examples, *parteras* incorporated materials and practices from biomedicine combined with traditional medicine, religion, and traditional midwifery practices, a sign of the complexity and fluidity of trust and authority.

Second, unlike Giddens (1991), one should not consider trust as primarily directed toward a healthcare system. Instead, as Epstein and Timmermans (2021) indicated, authority goes beyond the healthcare system and medicine to include other care practices. According to the traditional midwives I interviewed, they suggested practices related to religion (i.e. holy water and prayer), as well as certain plants (also used by *curanderismo*), while incentivising pregnant women to attend prenatal care appointments at the hospital.

Third, although Giddens (1991) and Epstein and Timmermans (2021) did not provide much detail on the characteristics of those who trust (in medicine and healthcare systems or their representatives), it was a prominent element in the data from this research. Previous experiences with care practices differed among participants, with some regional differences. For instance, pregnant women from Lloró and Quibdó (Chocó) had a close relationship with traditional midwives. On many occasions, *parteras* have helped pregnant women and served as leaders in their communities (Suárez-Baquero and Champion, 2021). Moreover, they have also mediated in conflicts (Laza Vasquez and Ruiz De Cardenas, 2010) and, according to the

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<sup>15</sup> Other studies on traditional midwives have also indicated some of these measures (e.g. Suárez-Baquero and Champion, 2021).

testimonies of some healthcare administrators, have participated in health promotion campaigns, particularly those for malaria in Chocó.

One may consider that what happens regarding care assemblages is a sort of “situational trust”. It is a mix of institutional and experiential trust that was prominent during the pandemic but also refers to past experiences, traditions, and legal and administrative considerations. Let me explain further.

If we consider the experiences of pregnant women and recent mothers during their pregnancies and while giving birth, they constantly accommodate practices and negotiate what physicians, nurses, traditional midwives, family, neighbours, apps, and other online resources have suggested. They may follow or accommodate recommendations according to previous experiences (either personal experiences or from people they know). This factor was more prominent during the pandemic because COVID-19 constituted a threat, and hospitals and healthcare workers were sometimes less trustworthy, particularly in Chocó. As indicated by a pregnant woman, “They [physicians, nurses] let us die at the hospital” (Interview 26, Pregnant Woman).

Most participants suggested it was also difficult to trust what the GPs or nurses said during an appointment. These practitioners were usually more focused on filling in forms, typing on a computer, or writing on paper rather than paying attention to the pregnant woman. This issue was exacerbated because some practitioners avoided close contact with pregnant women. As described by one of the participants,

“When I was 27 weeks pregnant, I went to prenatal care, and the doctor didn't look at me; she asked me how I felt during that month. She didn't use the ultrasound to hear the baby's heart, and in the prenatal care record noted the cardiac rhythm. That concerned me. Thank God everything went well. And I wondered how she wrote on the prenatal care record without listening to it.” (Participant 19, OAFG 2)

It was not uncommon to ask for advice beyond biomedicine and accommodate that advice and related practices into what each pregnant woman or recent mother considered was most pertinent at the time.

Notably, even if most pregnant women had more trust in biomedicine for childbirth, that trust was also the subject of doubts and contradictions, especially for recent

mothers who recalled their childbirth experiences and recounted what went wrong for them.

In sum, it was possible to establish regional differences regarding what kind of care practices were more prominent at each study site and how those differences referred to historical, traditional, and administrative dynamics. For instance, the prominence of *partería* and religion in Chocó is based on the community's interrelated practices and traditions. Moreover, *parteras* have played an essential role there beyond pregnancy and giving birth, mainly due to difficulties with access to healthcare facilities and services (i.e. biomedicine) in that region.

Furthermore, some regional differences could be due to how trust in authority and expertise have been situational and emergent, particularly during the pandemic. Not only have difficulties in accessing and performing certain practices been relevant here (due to the lockdown restrictions and the social distancing), but the unknown and unexpected have configured dangers and mistrust surrounding biomedicine and hospitals.

Let us take a look now at how care practices enact syphilis and CS.

#### [How care practices enact syphilis and congenital syphilis](#)

This section overviews how diverse care practices enact syphilis and CS. I mainly focus on biomedicine because it has traditionally accounted for syphilis diagnosis and treatment, and a higher proportion of my data relates to it. Further investigation is needed to clarify the specificities regarding other care assemblages.

According to biomedicine, a bacterium causes syphilis. When detected during prenatal care and treated effectively, the transmission of syphilis from mother to child (i.e. CS) can be prevented. Hence, CS is a preventable disease. However, according to the interviewees (i.e., healthcare workers, administrators, and staff from the Secretaries of Health), two main reasons exist for CS in Colombia. First, CS is caused by sociocultural aspects of the population. Common references to practices or behaviours from “vulnerable” or stigmatised groups (following social categories that refer to race, ethnicity, and migration status) are highlighted as causes of the disease. Included are promiscuity, a low knowledge of STDs and prevention

measures, a late start of prenatal care and attending all required appointments, and a low adherence to treatment.

Second, CS results from failures and difficulties in the healthcare system in terms of access to healthcare services, timely diagnosis and treatment, and administrative barriers, as indicated by some healthcare workers and administrators. For instance, a healthcare administrator indicated that “congenital syphilis is a failure in the health system” during the interview (Interview 29, Healthcare Administrator).

By contrast, bacteria do not “exist” in traditional medicine and *partería*. For them, syphilis and CS are “Western” diseases. Although traditional midwives can identify some signs of STDs, and some of them provide beverages to alleviate some symptoms, they usually refer pregnant women to the health centre or hospital to receive treatment. They do not treat STDs, particularly syphilis; it does not comprise part of what they do. As indicated by an Indigenous traditional midwife,

“It is not the same to treat a normal person with syphilis or HIV than to treat a pregnant woman with syphilis or HIV. It is not the same, right? So (. . .). that is with Western medicine. I do not engage in that matter”. (Interview 14, Indigenous Traditional Midwife)

The case of CS is different from other diseases with an “equivalent” in the knowledge and practices of traditional medicine and *partería*. For example, the *mal de los siete días* [the evil of the seven days] occurs after cutting the belly button of the newborn, with the baby having sucking difficulties, neck rigidity, and spasms, which according to biomedicine, corresponds to neonatal tetanus. The Ministry of Health and Health Secretaries made an effort to train *parteras* and health promoters to follow certain measures while doing the *ombligada* [cutting the baby’s belly button] (Delgado *et al.*, 2006). Following recommendations of nurses and physicians, traditional midwives have engaged in practices of biomedicine by taking more precautions, such as using chemical disinfectants, hand sanitation, and being aware of possible warning signs of *mal de los siete días* [the evil of the seven days].

However, in the case of syphilis and CS, traditional midwives have not accommodated their practices toward caring for syphilis. They refuse to attend to pregnant women with a positive syphilis result.

Something similar happens with religion. For the Roman Catholic Church, STDs reflect inappropriate behaviour. For decades, the Catholic Church has been against the use of condoms as a prevention measure since it is considered that condoms are not effective for STD prevention. Instead, condoms reflect selfish pleasure, lack of self-control, and responsibility avoidance. It has been considered that “natural” birth control, marital fidelity, and abstinence are the best prevention measures since they promote the reproductive purpose of sex (Benagiano *et al.*, 2011).

However, in 2010, Pope Benedict XVI said that in some cases, condoms may help, for instance, when some individuals are infected and their partners do not allow them to continue with their sex lives. Condoms then can protect the uninfected partner.

Similarly, in Evangelical churches, “physical sickness had a significant spiritual component (. . .) sinful lives caused emotional pain” (Wentzell, 2017:339). This pain manifests in the body.

For Catholics and Evangelicals, God is the “ultimate arbiter of health” (Wentzell, 2017), with the implication that believers must facilitate “God’s assistance” (Wentzell, 2017). For Evangelicals, this belief requires them to adapt most of their behaviours to follow specific principles.

Indeed, biomedicine and religion (Catholicism and Evangelical beliefs) are compatible in Latin America (Wentzell, 2017). However, as shown in several studies (Seffner *et al.*, 2011; Murray *et al.*, 2011), churches are not monolithic, so plenty of negotiations have focused on how to approach disease and its prevention. For instance, most pregnant women-recent mothers who participated in the research acknowledged that they had engaged in sexual activity from a young age (between 13 and 16 years old) with successive boyfriends, even those who were Catholic or Evangelical Christians. Two participants indicated they had several boyfriends simultaneously. One of them assured me she changed her behaviour after getting pregnant: “I have to respect my baby. I have to be a good mother for my baby” (Interview 23, Recent Mother).



For two participants, the Evangelical church made them change how they conducted their relationships with their partners and how they had sex. For four participants, it was “growing up” and becoming adults that made them change (some changed because they became mothers). Nevertheless, even after having sex before marriage (which is not allowed by their religion), pregnant women and recent mothers who believe in God and practice Catholicism or Christianity pray to God and follow religious practices as a way to maintain their health and the health of their babies.

Concerning online care practices, providing a general indication of how they portray STDs is challenging. These indications are comprised of diverse sources and expertise (e.g. biomedicine, traditional medicine, and mothers’ experiences). Moreover, each search (considering the Internet and apps) and message (through social media or messaging apps) is an interconnection of relations via mediated networks (from contacts through algorithms). Hence, the “observer”, “user”, or, in this case, a woman, configures these online resources by adding more pieces to the care assemblages she feels are necessary. However, according to the participants, the topic of STDs appears at certain moments in their searches and online resources, as well as when adding these words into a search engine or looking at some of the online resources they referred to. Overall, more information, advice, and references are offered regarding pregnancy and giving birth than concerning sex during pregnancy and STDs. I had this experience navigating the two most used web pages by the participants<sup>16</sup> and the app BabyCentre.

So far, I have emphasised how biomedicine care practices have been a primary nexus for syphilis and CS enactment. Even though other care practices are implicated during pregnancy and while giving birth, the discoordination of and clashes between care practices at times render syphilis and CS absent and silent.

In the previous chapter, “Ontological Discontinuities”, I showed how diverse biomedical practices enact syphilis and CS as silent and absent. In this chapter, I

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<sup>16</sup> The webpages are <https://www.pequenin.com.co/> and <https://embarazadas.winnny.com.co/>

add another layer by indicating how other care practices that configure diverse care assemblages also contribute to the silences and absences of syphilis and CS.

#### Final remarks

This chapter reviewed the practices and interactions that configure care practices and related assemblages during prenatal care while giving birth and during the babies' first months to illuminate CS prevention.

Research data have indicated that concepts such as medical systems (Kleinman, 1978), medical pluralism (Leslie, 1980), therapeutic landscapes (Gesler, 1992), and medioscapes (Hörbst and Wolf, 2014) are an insufficient account of the multiple experiences, practices, and trajectories in which pregnant women and recent mothers, as well as healthcare workers, traditional midwives, families, and neighbours, engage with. They engage with diverse care practices in complementary and contradictory ways while configuring multiple care assemblages.

The enactment of care assemblages relates to regional differences, historical and traditional configurations, and considerations over expertise and trust-authority that are constantly negotiated. Instead of considering trust-authority as institutional or systemic, as usually depicted in the literature (Giddens, 1991; Epstein & Timmermans, 2021), I have shown that trust and expertise are “situated” and enacted according to the multiplicity of experiences, trajectories, and uncertainties that pregnancy, childbirth, and the first months of babies implicate, especially during the COVID-19 pandemic.

One of the findings derived from the analysis of care practices is that syphilis and CS have been enacted mainly from biomedicine. A collateral reality (Law, 2011; 2009) is enacted here while considering ontological unity, in which syphilis and CS are one, as diseases that can be prevented from biomedicine regardless of contextual differences. In contrast, the enactment of syphilis as a “Western” disease reminds us of the multiplicity of ontologies that require the necessity of acknowledging them, providing the conditions for dialogues, and establishing bridges and cooperations.

The lack of coordination and accommodation with other care practices (i.e. *parteria* and religion) complicates CS prevention since syphilis and CS are sometimes enacted as absent and neglected. Nevertheless, more research is needed to clarify the multiple ways in which syphilis and CS are enacted related to other care practices (besides biomedicine), particularly concerning online care practices.

Several forms of silencing, absencing, and stigmatising practices have appeared throughout this chapter. They have instantiated in how some care practices enact syphilis and CS (i.e. “Western” disease, *Sífilis Venezolana*) and in how certain people are considered as the “cause” of CS (e.g. Indigenous and Afro-descendants), as some healthcare workers mentioned during the interviews. Precisely, taboo and stigmatisation practices are at the core of the next chapter.

## CHAPTER 6 TABOOS AND STIGMAS

The previous chapter, “Care assemblages”, showed that the enactment of care assemblages not only enacts silence and absences but also taboo and stigmatisation practices. Those practices can be found in relation to some of the enactments of syphilis and congenital syphilis (CS; e.g., the notion of Venezuelan syphilis) and in how certain people are considered the “cause” of CS, as some healthcare workers mentioned during interviews. These are effectively taboos and stigmatising practices and lie at the core of this chapter.

Two main arguments are developed here. First, both stigmas and taboos are enacted in STD- and CS-prevention efforts during pregnancy, prenatal care, and childbirth. To challenge the portrayal in the literature of taboos and stigmas as separate phenomena (with taboos attributed mainly to “primitive” cultures), I argue that both are enacted and, even, sometimes, linked. When people follow taboos and avoid things that are “forbidden”, they do so to avoid the stigma of an unfavourable social valuation – for example, avoiding sex during pregnancy or treating a positive STD diagnosis as taboo. I emphasise that, while multiple ontologies (Mol, 1999) are enacted during CS prevention, absence relations enact taboos and stigmas in the form of otherness (absent but enacted as impossible or repressed) and othering (manifest absence recognised as relevant; see Law, 2004).

The second argument I will make is that the territory itself (understood more than as the backdrop of interactions and rather as the “form and effect of particular social relations” (Storey, 2001:27)) also mediates stigmas, particularly in the Pacific region in Colombia and around CS prevention in a low-to-middle-income country. These stigmas have historical and structural configurations that further complicate health inequalities and CS prevention.

Through seven sections, I will explain how taboos and stigmas are enacted in pregnancy, prenatal care, and labour in ways that add complexity to the prevention of STDs and CS. In the first section, I examine the theoretical discussion over taboos and stigma – highly debated and politically charged concepts. In particular, I look at

how the literature has tended to present taboos and stigma as non-overlapping phenomena occurring in “primitive” and “non-primitive” cultures, respectively.

The second section takes a closer look at taboos and stigma enactment by drawing on the study findings. I highlight how restrictions are imposed upon pregnant women during pregnancy and in the first months of their baby’s life, placing them under constant surveillance and subjecting them to judgements of their success as a “good mother”.

In the third section, I analyse the taboos and stigmas concerning sex, in particular during pregnancy. I note the tensions and negotiations over sex and sex talk. On the one hand, sex is seen as promoting the well-being of women and babies, but at the same time, it is considered as a risk and potential danger, with negative judgements made of those who engage in it.

The meanings of silence, absence, and emotions are discussed in the fourth section. I focus on how othering can be a way of managing danger and give five examples from the data. In the fifth section, I consider how the participants responded to taboos and stigmas. I offer several examples of this and discuss how the practice of “humanised childbirth” can integrate and potentially destigmatise *parteras* [traditional midwives] and *parteria* [traditional midwifery].

The integration of sex practices into STD prevention is discussed in the sixth section, highlighting that education and individual behavioural changes are not sufficient for STD and CS prevention. Finally, in the seventh section, I provide the chapter’s final remarks, identifying a number of points that will be elaborated upon in the following chapter.

#### Taboos and stigmas – theoretical discussions

In Chapter 3, “Methods”, and Chapter 4, “Ontological Discontinuities”, it was observed that stereotypes, prejudice, negative valuations, silence, blame, laughter, and shame were in evidence during the interviews and online asynchronous focus groups (OAFGs). These elements suggested that taboo and stigma were

entrenched in discussions of sex during pregnancy, babies' well-being, childbirth due dates, STDs and CS prevention (Estrada-Jaramillo et al., 2022). I will now discuss taboos and stigma. These two highly debated and politically charged concepts are important to consider because they pose several challenges to efforts to prevent CS (and STDs more broadly). Let us begin with the concept of taboo.

### Taboo

Taboos are defined as the “culturally prescribed avoidance of a thing or activity” (Price, 2020:92). They promise the reduction of disorder and protect the consensus over how the world is organised (Douglas, 1966). Several authors – including James Frazer, Sigmund Freud, Radcliffe-Brown, Emile Durkheim, Claude Lévi-Strauss, Victor Turner, and Roy Rappaport – have approached the notion of taboos by highlighting the ambiguities of sacred and profane entities and activities and their function in societies and in how social relations are organised. Although the taboo's universality has been implied in the literature, there is an emphasis on “primitive” cultures in the research, establishing a difference between Western and non-Western cultures and highlighting how, in “primitive” cultures, a lack of differentiation between the sacred and the profane requires the use of taboos to regulate social groups (Price, 2020; Glowczewski, 2019).

Recent research has shown that taboos remain a relevant group regulator in societies, including Western ones. Taboos impose moral and social prohibitions regarding both sacred and secular matters, as indicated by research on linguistic taboos (Miller, 2022; Pizarro, 2018; Alan, 2018), taboos in health (Lunkenheimer et al., 2021; Jackson and Hallam, 2021), and taboos in marketing (Sabri, Manceau and Pras, 2010). For example, linguistic taboos might concern sex (Pizarro, 2018a), menstruation (Gatambuki, Ochieng and Wangeci, 2018), perinatal diet (Lunkenheimer *et al.*, 2021), and breastfeeding. In marketing, suicide can be a taboo, along with nudity in Muslim countries (Sabri, Manceau and Pras, 2010).

Moreover, research has identified several similarities between concepts of taboo and risk (Douglas, 1966). Both are morally and politically charged concepts that indicate dangers to be avoided and behaviours to be followed accordingly. Both also establish differences between “them and us” to promote a group identity. A

complicating factor is that understanding of risk has become a type of expert knowledge involving technical calculations.

Several conclusions have been derived from more recent research on taboo. First, taboos are found in societies with diverse characteristics. They are found in both Western and non-Western groups and include prohibitions on food, language, activities, and so on. Second, the definitions of taboos fluctuate; they are not fixed. Practices considered taboo can cease to be identified as such, and previously accepted practices may become taboo. Examples include changes of social attitudes toward abortion in some countries of Latin America (including Colombia), same-sex marriage, and gay rights.

Third, taboos are context-dependent. As shown by research into linguistic taboos (Gatambuki, Ochieng and Wangeci, 2018; Alan, 2018; Cestero, 2018), definitions and responses depend on the conversational circumstances, interlocutors, and other contextual characteristics (e.g., type of interaction, the strength of the taboo, its consequences). People negotiate with taboos and their consequences, with some attracting greater sanctions than others: “the degree of harm can fall anywhere on a scale from a breach of etiquette to real fatality” (Alan, 2018:V).

Studies of linguistic taboos in discussions of sex reveal differences in terms of gender, educational level, and age (Cestero, 2018; Pizarro, 2018a). Euphemisms (indirect wording, substitutions), dysphemism (negative and derogatory connotations), and orthophemism (straight talk) constitute a repertoire from which interlocutors choose (Cestero, 2018). The prohibitions established by language taboos are more closely related to meanings and conceptualisations than to specific words (Pizarro, 2018a). That is why taboo words can sometimes appear during conversations without the loss of their taboo label.

Taboos and stigma are connected because they are both ways exercising control over how the world is organised. Taboos establish a difference between “us and them” and they evoke a moral prescription that can be socially marked and thus be linked to a stigma. Taboos are still present—absent in this research – as linguistic

taboos (e.g., sex talk) and in the avoidance of certain places, food, and sex during pregnancy.

Let us now turn to stigma to discuss how taboo and stigma are connected and why they matter in this research.

### Stigma

Historically, the term “stigma” was used to describe the mark or tattoo on the skin of slaves, people with criminal records, and people deemed “morally inadequate”. It is a mark that highlights difference between “us and them” and which appeared initially in the context of colonialism (Tyler, 2020).

The definition of stigma has since evolved, developed substantially in the work of Erving Goffman (1963). Today, it is still considered a mark that categorises its bearer, marking out difference between “them and us” and socially devaluing them due to that difference – a difference identified as a moral distinction, a consideration of what is “good”, “desirable”, and “expected” and what is not.

Stigma and stigmatisation (practices that attribute stigma and thus categorise someone) have been extensively researched in the social sciences and health research. In this body of literature, several revisions and criticisms have been established, mainly of Goffman’s perspective.

Goffman (1963) considers stigma a relationship that emerges in social settings in which those who are “stigmatised” learn how to manage the stigmatisation and its effects in an effort to develop their identities according to the parameters of normality. Although Goffman states that stigma is historically specific and functions as a form of social control, he does not place much emphasis on this matter (Tyler and Slater, 2018). In contrast, several authors have highlighted stigma as an expression of relationships that involve power struggles, inequality, and structural configurations with historical contexts (Tyler, 2020; Tyler and Slater, 2018; Link and Phelan, 2014; Falk, 2010). Many authors emphasise the structural and historical aspects of stigma and how these can replicate and reinforce power struggles and inequality. They show that stigma can be a way to establish a difference between “them and us”; to emphasise certain identity characteristics in order to devalue



others; and to exercise control, exploit, exclude, and amplify inequality (Link and Phelan, 2014; Stangl et al., 2019).

Other authors (Turan et al., 2019; Bowleg, 2021) highlight how diverse social identities (i.e., belonging to diverse social groups) and being identified with specific categories configure different stigmas and the particular experiences associated with them. Moreover, race, gender, ethnicity, class, age, and sexual orientation can all amplify or reduce the inequalities, power struggles, and social devaluation that groups and individuals deal with, including in healthcare access (Sangaramoorthy, Jamison and Dyer, 2017; Mak *et al.*, 2006). For example, some studies have explored how already stigmatised people with HIV diagnoses deal with additional stigmas (Luoma *et al.*, 2023; Karver Sanchez *et al.*, 2022) – study subjects have included women of a certain age (40 – 60 years) and Afro-Americans (Sangaramoorthy, Jamison and Dyer, 2017).

The stigma associated with syphilis dates back several centuries (Whitty, 1999); and today, it tends to have negative connotations as a sexually transmitted disease, being considered “avoidable”. It is thought to be a consequence of objectionable behaviour. The stigma associated with syphilis has not remained the same over the years, and other practices have altered its constitution. In this regard, it shares considerable similarities with other STD stigmas, particularly HIV (including mother to child transmission; Bonda et al., 2002; Pan American Health Organization, 2014; Rahangdale et al., 2010).

Sex workers, promiscuous people, migrants, poor people, and minorities continue to be stigmatised as more likely to have syphilis. With the introduction of penicillin as an effective treatment for syphilis in the 1940s, another negative connotation of the disease became more prominent: its controllability. As shown by Ribeiro *et al.* (2022), certain diseases are associated with prejudices and the people who have those diseases are considered deviant. Many are then rejected, punished for their failure to avoid the disease.

In health research, health-related stigma is defined as “a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation

that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem” (Turan *et al.*, 2019:2).

There is a considerable body of literature on health-related stigma, particularly HIV, showing how it impacts health-seeking behaviour (Clair, Daniel and Lamont, 2016; Turan *et al.*, 2019), engagement with care (Clair, Daniel and Lamont, 2016), and treatment adherence (Geary and Bukusi, 2014; Stangl *et al.*, 2019; Scorgie *et al.*, 2021). Research has also shown that health-related stigma complicates disease prevention (Roelen *et al.*, 2020). Attempts have been made to develop models to address the stigma of diseases such as COVID-19 (Logie and Turan, 2020). The lessons learned from examinations of HIV stigma include that there is a need to go beyond individualistic approaches (Parker and Aggleton, 2003; Stangl *et al.*, 2019), that stigma reproduces and increases social inequalities (Parker and Aggleton 2003, Roelen *et al.*, 2020), and that knowledge about a disease is not necessarily a solution to stigma against those who have it (Mak *et al.*, 2006).

Following the emergence of the HIV/AIDS epidemic, the syphilis stigma did not disappear, but it underwent several changes. Initially, HIV/AIDS was considered a “gay cancer”, the consequence of a ‘deviant behaviour’, and a death sentence, but there have since been a number of developments. While the stigma still exists, it has changed. Today, the disease is no longer seen as something that only affects gay men. It can happen to anyone. Furthermore, with the development of new treatments, the life span of people living with HIV and AIDS has increased considerably. Thus, in certain contexts, the stigma associated with HIV and AIDS has decreased (Clair, Daniel and Lamont, 2016). Research has been done and interventions have been developed to tackle these stigmas, and a considerable number of people and groups have advocated for HIV- and AIDS-related matters has also made a difference. However, the opposite seems to have happened in relation to syphilis, especially congenital syphilis.

Stigma can be applied not only to groups of people but also to spaces. Territorial stigma, or spatial stigma, is “the negative representations of particular localities” (Halliday, Brennan, Bamba, and Popay, 2021:1). As shown by several authors

(Wacquant, Slater, and Pereira, 2014; Wacquant, 2007), historical and structural processes bring about territorial stigmas in localities usually characterised by social exclusion and inequality. It is through territorial stigmas that "...struggles to establish claims over the environment" (Wacquant, Slater and Pereira, 2014:1272) appear. Although territory has not been a focus of research into intersectional approaches and intersectional stigma, it is particularly relevant to health-related stigmas (including syphilis stigma) in Colombia. Regions in the country with a higher prevalence and incidence of syphilis and CS are those with a larger populations of Indigenous, Afro-descendant, and migrant people and individuals from a lower socioeconomic strata.

Let us not forget that territory is more than merely the backdrop of interactions. Rather, "it is also itself a form and effect of particular social relations bound into the intersections of power, space and society" (Storey, 2001:27). In territories, the boundaries and differences that distinguish "them" from "us" and reflect inequalities and identity valuations are performed (more on this in the following paragraphs).

It is vital to acknowledge that stigmas are associated with historical processes and that these processes determine the form of the stigma and how it will unfold (given that stigma is not fixed). Farrimond (2021), writing on how stigma emerges and changes over time, proposes a notion of *lineage*, with one stigma originating in previous stigmas. Stigma as *variation* explains the changes over time and in content, and stigma as *strength* acknowledges that it can be amplified or weakened. When one considers stigma as *lineage*, it is clear how concepts of other STDs have contributed to syphilis stigma. The stigma associated with HIV and mother-to-child transmission of STDs also configure practices of stigmatisation (Turan et al., 2019; Mak et al., 2006; Clair et al., 2016; Stangl et al., 2019).

These stigmas might prevent pregnant women and partners from seeking and adhering to treatment, compromising their own health and that of their babies. Moreover, every missed opportunity for receiving treatment increases the possibility of further transmission, which further complicates CS prevention. Some authors have highlighted the importance of tackling stigma to reduce inequalities and control pandemics (Roelen *et al.*, 2020). Furthermore, health-related stigma is still

necessary since how expert knowledge and its credibility address stigma makes a difference regarding how to destigmatise certain populations and diseases (Clair, Daniel and Lamont, 2016).

I will draw on these previous discussions to explain how stigma and stigmatisation processes are enacted in the context of prenatal care, birth, and congenital-syphilis prevention. Special attention will be paid to the historical configurations and intersections that affect the enactment of stigma and stigmatisation.

### Taboo and stigma enacted

#### Taboo findings

In the online interviews and online asynchronous focus groups (OAFGs) in this study, there were indications of taboos. Although nonverbal communication was lost due to the absence of video recordings, there were still a considerable number of indications (linguistic and otherwise). These included the use of euphemism, dysphemism, and orthophemism during the conversations; extended silences; laughter due to shame or fear; and practices intended to “repair” or compensate for what has been said or done. Silence and absences surrounding sex talk took various forms, including pauses, hesitations, unanswered questions, and laughter (more on this in the following section). For example, during the OAFGs with pregnant women and recent mothers, the questions about sex received the lowest number of responses in all three groups. Only two participants in each group said something about this topic (Estrada-Jaramillo *et al.*, 2022). (More on this article can be found in Chapter 3 “Methods”.)

Linguistic taboos appeared during the discussions of sex practices, related body parts and fluids, sexual activities, sex during pregnancy, and/or the postpartum period (More on this in the following section.).

Another taboo enacted during CS prevention, pregnancy, labour, and postpartum is the death taboo (specifically in relation to infant and maternal mortality). Pregnancy, labour, and the first months of life are considered hazardous experiences for mothers

and their babies. It is believed that there are numerous things that might go wrong. In response, a number of restrictions are put into place.

Food taboos are often imposed – such as prohibitions on eating particular foods during pregnancy (certain types of fish, cheeses) and postpartum food restrictions (garlic, cauliflower) since might affect the baby. It is believed that the properties of particular foods can affect the well-being of the mother and therefore that of the baby. The mother is expected to adopt this behaviour; otherwise, there might be consequences for her baby (sanction).

There are also linguistic taboos regarding pregnancy. It is common for women not to reveal their pregnancies before the second trimester. It is widely thought that this can prevent something from going wrong. Furthermore, it is customary among Afro-descendants not to reveal the approximate due date of the baby, as it is believed that revealing this information could lead to *trama*. *Trama* is a practice in which a neighbour, relative, or acquaintance create difficulties for a woman during her labour, potentially leading to her death or that of the baby.

In addition, it is common among Afro-descendants not to reveal any “special” or “particular” characteristic of a baby or a child. For this reason, a “warning sign” (e.g., rapid eye movement) might not be commented on by the GP. It is considered that as soon as a “special attribute” is revealed, it will be lost or the baby may die.

“... my mom says that I had a *virtud* [virtue]. If someone acknowledged my virtue when I was little, for example, if an eye moves to a side or even physical alterations ... So, they [mothers] cannot tell anyone or take [their babies] to the doctor. They just wait. No-one can say anything about what is happening with the baby because it is a *virtud* and when you tell people about the *virtud*, the baby dies”. (Interview 10, Healthcare worker)

Pregnant women are subject to numerous restrictions, beyond those mentioned above. There are restrictions on their bodies, activities, and space. Pregnant women are not supposed to put pressure on their bellies, or wear clothes that reveal their bellies. They are not supposed to make strenuous efforts (using their strength to lift heavy weight) or to walk under stairs. It is thought dangerous for pregnant women

to go outside at night or to a cemetery. Rather, they are expected to stay at home as much as possible.

Linguistic taboos are also noted in the context of babies' deaths: specifically, one cannot use the word "baby" when discussing this topic. For instance, *mortinato* [stillborn], *nacido vivo* [live birth], and *no nacido* [unborn] are all ways of referring to babies in epidemiological surveillance, describing instances in which something has gone wrong. This language allows reference to congenital syphilis without direct reference to the deaths of babies, providing euphemisms as replacements.

Alongside infant mortality and maternal mortality, there are also other taboo practices. As mentioned before, fears around *tramar* are inspired by the desire to avoid infant and maternal mortality. Given the fear that delivery complications could arise due to *tramar*, women do not openly share information about their stage of pregnancy or due date. During pregnancy and the postpartum period, there are also food taboos (diet restrictions). In these cases, concerns include the mother's well-being, plus the possibility of future pregnancies and complications during delivery.

In these aforementioned practices, absences and silences are enacted as otherness (Law, 2004); they are enacted as repressed relations. Taboos, then, are not only a way to accomplish "social regulation" (as is usually argued in the literature), they are also a way to make certain ontologies more salient and meaningful.

#### Stigma findings

In the interviews and documents analysed for this study, as well as in the broader literature (Castrillon *et al.*, 2013; Cruz *et al.*, 2013; Korenromp *et al.*, 2018; PAHO, 2021; Valderrama, J., F. Zacarias, 2004), there are frequent references to certain groups that are stigmatized as those more likely to have syphilis (gestational and congenital). The affected individuals are more likely to be Indigenous, Afro-descendant, or international migrants – particularly from Venezuela (more on this in Chapter 4) and certain regions such as the Pacific region of Colombia.

Congenital syphilis is considered a preventable disease, something that can be controlled. It is also considered a disease of poverty, a neglected disease. These categorisations contribute to the stigmatisation of the poor, the distinctions between the “Global North” and the “Global South” and between the “developed” and “undeveloped” worlds. A considerable number of the countries in which CS is a public health problem are in the Global South, and these categorisations reinforce the idea of CS as controllable, as an outcome of an individual’s choices, and thus as a situation that can be changed. The WHO launched a certification of countries in which CS has been eradicated.<sup>17</sup> Despite its good intentions, this had the negative effect of intensifying prejudice against those countries yet to receive that certification.

Furthermore, negative valuations of certain places were evident in the data from the interviews and OAFGs. Certain places were considered problematic in terms of STDs, CS, and sexual practices compromising babies’ health. There were several references to rural areas, mining areas and the Pacific Coast. Numerous practices contribute to this stigmatisation.

In this regard, it is important to note some of the particularities of the Pacific region – and especially Chocó. Some Afro-descendants established their territory in this region after escaping from slavery, sharing the territory with indigenous people who had also survived subjugation by the Spaniards and *mestizos* [mix of Spaniards with Indigenous or Black origins]. From colonial times, the jungle, climate (high humidity and heavy rain throughout the year), difficulties with access routes and connectivity, and presence of tropical diseases (particularly Yellow Fever and malaria) have left Chocó an isolated and dangerous territory. During the internal armed conflict, those territories also experienced intense disputes between *paramilitares*<sup>18</sup> and guerrillas and, more recently, between guerrillas and drug cartels. The region has lately become a significant route for the smuggling of drugs and other commodities and the migration of undocumented people on their way to North America.

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<sup>17</sup><https://www.paho.org/en/news/14-5-2021-dominica-celebrates-elimination-mother-child-transmission-hiv-and-syphilis>

<sup>18</sup> Armed groups financed by civilians acted against guerrillas with nexus with some members of the Colombian Army. In this region, *paramilitares* (paramilitary groups) fight against ELN guerrillas (National Liberation Army).

Chocó is one of the poorest regions in Colombia (DANE, 2020), with limited investment in infrastructure and social spending, as well as difficulties accessing public services, including healthcare. Chocó is also known for its considerable mining industry dedicated to the extraction of gold, platinum, and other minerals, several potential ecosystem services due to the biodiversity of the region. The narrative of Chocó as a dangerous, undeveloped, and isolated region is still common in Colombia and frequently heard in daily conversations, on the news, and across social media.<sup>19</sup>

Against this backdrop, the epidemiological surveillance reports by the Secretaries of Health and the National Institute of Health show higher incidence and prevalence of CS and other STDs in the Pacific region than elsewhere. The highest rates of gestational and congenital syphilis are found in Chocó, Buenaventura, and Valle (Instituto Nacional de Salud, 2020; Instituto Nacional de Salud, 2019).

A considerable body of research on syphilis and CS has been conducted in this region (Garcés *et al.*, 2017; Cruz, 2012; Cruz *et al.*, 2010; Hopkins and Florez, 1977; Maloney, Ramirez, Levin, and Blattner, 1989), emphasising the sense of a link between the region and the presence of STDs and CS. In addition, the region has the largest black and Afro-descendant population in the country – a population that is commonly portrayed as “hypersexual” (Wade, Urrea, and Viveros, 2008; Viveros, 2002; Wade, 2013). This region also has one of the largest Indigenous populations in the country, including the most prominent indigenous organisation, *Consejo Regional Indígena del Cauca* [Regional Indigenous Council], which actively participates in the development of public policy and the organisation of national strikes.

The previous paragraphs show how the stigmatisation of such territories contributes to the stigmatisation of those who live in or come from those territories. The territory thus becomes a site in which several stigmas intersect. The people affected by these stigmas – Afro-descendant, Indigenous, migrant, rural, and mine-working people –

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<sup>19</sup>As exemplified here <https://www.elespectador.com/opinion/columnistas/francisco-leal-buitrago/choco-y-su-acumulacion-de-problemas-column/>



are also frequently suspected of being at particular risk of syphilis and congenital syphilis.

The next section shows how taboos and stigmas surrounding sex are enacted, providing a glimpse of how they can make STD and CS prevention more challenging.

#### Sex taboo and stigma – findings

During the interviews and OAFGs, it became clear that sex talk was avoided by some healthcare workers and most parents, teachers, pregnant women, and their partners. It seemed that many found it uncomfortable to talk about these subjects, especially if there was limited trust or if discussions were occurring in public spaces.

As indicated by the pregnant women and recent mothers (in the interviews and OAFGs), conversations about sex and sex education are usually avoided by parents at home, especially if the parents consider their children too young for a committed relationship or parenthood. The participants noted some variations in this, though. They noted that conversations with male children often emphasised the need for *cuidarse* [taking care, being careful]. *Cuidarse* refers to not getting a woman pregnant. For instance, one participant said, “it is different talking [about sex] with a boy than with a girl because the boy has to use a condom to avoid catching a disease or getting a girl pregnant” (Interview 25, Pregnant woman). In the case of a girl, the participant stated, *cuidarse* refers not simply to avoiding pregnancy but to not having sex at all. Parents are concerned with unwanted pregnancies, especially when they consider it the wrong time for their daughter to have a baby.

Although some mothers urged their daughters to *cuidarse*, most participants said that their parents had not talked to them about sex or contraception. They also indicated that these topics were rarely discussed in class and are even actively avoided in school. There are often disagreements among parents regarding how much their children should be taught about these topics. During the interviews, several participants indicated that some parents were against teaching children about sex and sexuality at school and had even moved their children to different schools for that reason:

“...at the school where one of my kids studies, there was a mom who took her daughter out because they [teachers] started to talk about her private parts and how she should take care of them”. (Interview 28, Pregnant woman)

Most participants remembered having conversations about sex and sex education in some of their classes – for instance, talking about the reproductive system in a biology class or attending a workshop on preventing pregnancy and STDs. They suggested that teachers, students, and others who had to talk about the topic were uncomfortable and felt *pena* (shame, embarrassment). As indicated by a participant:

“I remember in eighth or ninth grade, I don’t know, there was a sex education class, and I remember there was a lot of taboo talking about that. I mean, the teacher was afraid of talking about it”. (Interview 17, Pregnant woman)

Shame, embarrassment, and fear are the core emotions identifying something as taboo and stigmatised (Cestero, 2018; Glowczewski, 2019a; Miller, 2022b). These emotions are integral to the manifestation of the taboo and they ensure its continuation, establishing the difference between “them” and “us”.

Restrictions on sex during pregnancy (sex and sex talk), lack of discussion of STDs, and non-disclosure of a syphilis diagnosis, especially to partners, are “silence practices” that pregnant women engage in. They chose not to talk, not to reveal information, or to avoid certain topics. As noted above, sex is a highly sensitive topic. It is taboo, especially for pregnant women and recent mothers, who are expected to behave in certain ways and to avoid association with certain stigmas.

During the interviews and OAFGs, the pregnant women and recent mothers frequently chose not to refer directly to sex. Instead, they used the word *eso* [“that” or “it”]. For example, one pregnant woman said:

“I felt shame talking about that really, and I didn’t communicate about it. At school, they taught sex education and we talked with female friends, but there was only that”. (Interview 25: Pregnant woman)

This use of *eso* [that or it] not only reflects a language taboo (Miller, 2022a), it is also a practice of avoidance and a way of avoiding being seen as *promiscua* (promiscuous), a *puta* (whore), a *callejera* (wanderer),<sup>20</sup> a “bad mother”-categorisations intended to stigmatise certain people, places, and behaviour. When referring to *eso* (sex), the participants frequently laughed, took pauses in the conversation (silences), hesitated before speaking, and were reluctant to provide details:

“...in my time, sex education was not too open. I remember once a classmate had to make a presentation about condoms, and he used a carrot to explain how to put it on [laughter]. Everything was a joke, and we didn’t talk much about the topic”. (Interview 17, Pregnant woman)

Alongside laughter, silences, and hesitations, there was also fear. Fear often manifests itself in avoidance – such as avoidance of talking about sex or of asking questions to reassure oneself about a concern. However, the pregnant women and recent mothers had also dealt with their fears by talking about sex with their children and younger relatives. Many participants expressed that they did not want their children and young relatives to experience what they had suffered due to the restrictions on sex talk and education. Thus, they had started talking to their younger relatives (brothers, sisters, cousins) and to their older children to help them avoid those difficulties:

“I’ve been thinking a lot about it. My partner and I have thought a lot and I will talk openly. I will say he [her child] has to be careful [...] I see myself in the future talking openly and saying he has to use condoms and he has to have a moderate sex life”. (Interview 24, Pregnant woman)

During the conversations, several silences and absences reflected the taboos and stigma around this topic, limiting the provision and receipt of information and the integration of that information into practice. As highlighted above, there is a taboo surrounding sex and sex talk. This topic is not usually widely discussed and information is often not disclosed. This is not only a matter of trust (i.e., the need to identify trustworthy people to talk to), it is also considered problematic to take a

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<sup>20</sup> As opposed to a “*niña o mujer de casa*” (good woman or woman who stays at home).

matter from the private sphere and introduce it into the public sphere (e.g., during a prenatal care appointment).

In discussions of CS prevention, assumptions tend to be made about heteronormative sex (heterosexual penetrative sex) and about sex being primarily for the purposes of reproduction. This was reflected in this study in frequent remarks by the pregnant women and recent mothers about vaginal penetration as the main sexual practice and about their reluctance – or that of their partners – to engage in penetrative sex, especially during the later months of pregnancy. In addition, as indicated by a healthcare administrator:

“...we have to teach people how to use condoms and dental dams, explain what happens with lubricants, what happens with oral sex and anal sex, and what happens with sex toys. We have to talk about it because there are many options and there are risks associated with those things. But we don't [talk about it] and we should”. (Interview 18, Healthcare administrator)

There is a considerable emphasis by healthcare workers on pregnant women, while often not acknowledging men and women before, immediately after, and beyond prenatal care. This limits the discussion of condom-related practices in the advice that they provide, as well as discouraging condom provision. Healthcare workers often assume similar values regarding pleasure, desire, sexuality, gender roles, and relationships when attempting to get more people to use condoms for STD prevention. Approaching STD prevention through the lens of sexual and reproductive rights encourages the acknowledgement of diverse sexual practices and options (from autonomy to individuals to diverse sexual identities), it also involves negotiations and various consequences for specific groups: Indigenous, Afro-descendants, migrant, and rural populations, who have diverse religious beliefs and are involved in different care assemblages.

In the regions under study, religious practices from Catholicism and other forms of Christianity exert a considerable influence. This leads to continual tensions in discussions of sex, unwanted pregnancy, and STD prevention.

The Ministry of Health, following the guidelines of the WHO and the Pan American Health Organisation (PAHO), have established a policy on sexual and reproductive rights that protects the individual's right to make informed choices about their sexuality and reproduction. The policy has to be implemented in the healthcare system by healthcare workers and administrators to reduce the stigma associated with sex and STDs, as stated by a healthcare administrator:

“...talk about human rights and sexual and reproductive rights – and start working with the idea of sexual and reproductive rights. Thinking about them as applying human rights to the domain of sexuality and sexual health. Why might this change things? Because, that way, everybody is involved as a guarantor of human rights: controlling entities, academia, healthcare services providers, and administrators [...] There are a lot of things that can be done. At least, that removes the possibility of people talking about what they think is sexuality according to their ethical perspective, which can be respected but make things more difficult to work with so many variables. It establishes a minimum level of sexual and reproductive rights”. (Interview 29, Healthcare administrator)

It is not easy to protect sexual and reproductive rights. Many religious groups, primarily the Christian Evangelical groups, argue that such measures promote promiscuity and “bad” behaviour. In 2016, the Ministry of Education created a booklet in alliance with the UNPF to educate people about gender and sexual diversity and to reduce discrimination in schools. However, several organisations, churches, and even representatives from the Congress opposed the initiative ([https://elpais.com/internacional/2016/08/10/colombia/1470835286\\_954924.html#?prm=copy\\_link](https://elpais.com/internacional/2016/08/10/colombia/1470835286_954924.html#?prm=copy_link)), alleging that the booklet encouraged a lack of morality, promoted promiscuity, and ideología *de género* (gender ideology). *Ideología de género* is a recurrent narrative in Colombia and other countries in Latin America among those who consider acknowledgement of sexual and gender identities and the associated rights to be an imposition that threatens Christian values and corrupts society.

This type of stigmatisation was also heard during the interviews when some participants (mainly pregnant women and new mothers) recounted their experiences with sex talk and sex education at home and school:

“My family is too religious. For my dad, me starting contraceptive methods at 15 [years old] meant I wanted to go whoring. Although I started my sexual life at 13”. (Interview 34, Pregnant woman)

As observed in this testimony, a woman's attempt to make decisions about her own sexual life – something that the policy states she has a right to do – may be constrained by her family and by the values and traditions that they support. This is not a surprise, Crawford (1994a) explains, because, in the 19<sup>th</sup> century,

“...the family assumed more of the burden of social control in the containment of a proliferating series of deviances. In this way, health became the umbrella under which a number of moral and disciplinary projects were initiated, a social objective for which the family acted as an agent of surveillance, normalisation and control” (p.1351).

Healthcare workers and administrators, particularly those working with populations from diverse backgrounds, acknowledge the difficulties of implementing a sexual and reproductive policy. Cultural differences are intertwined with questions of what is considered a right; views of how much autonomy an individual should have in decision-making; and opinions of sex, pleasure, family planning, pregnancy, and labour. Several remarks were made by healthcare workers and administrators during the interviews on these topics:

“You cannot get directly to an indigenous woman – because of her context. The social and cultural organisation does not allow women's leadership. It is through the shaman or the traditional doctor”. (Interview 1, Researcher)

These situations were a reminder of something that is particularly unwelcome with regard to sex and sex talk: namely, talking in the public sphere and/or with untrusted people. The participants said that they usually trust their friends more than their parents or teachers. However, this changed when they became pregnant: then, in addition to their friends, they trusted some healthcare workers. When looking for information and for answers to their questions, they also trusted the Internet.

There are several things to consider here. First, the discussion of sex in public is not necessarily evidence that this topic is not avoided. Rather, it can be treated as an

exception. In fact, one way of dealing with language taboos is categorised in the literature as orthophemism (straight talk; Pizarro, 2018b). Second, the focus on heterosexual penetrative sex goes hand-in-hand with the assumption that sex is only for reproductive purposes. The participants also referenced this in comments about prenatal care and the *cursos psicoprofilácticos* [psycho-prophylactic course]. Third, laughter and expressions of shame were evidence of “othering” – that is, they characterised attempts to avoid association with situations or people considered inappropriate or deviant, establishing some distance from them and thus reinforcing the taboo (avoidance). Various other stigmatisation practices were also present here. People who do not adhere to the taboo were categorised and treated as *promiscuo* [promiscuous] or as *puta* [whore] and associated with sex work or *libertinaje* (debauchery). This was explained by a researcher:

“That huge barrier of believing that giving sex education equates to prostitution is complicated. With HPV, HIV, hepatitis B, and syphilis, it is the same. If it is assumed that vaccination, prevention, or any public health measure in sexual and reproductive health means promiscuity, prostitution, or debauchery, well, that does not contribute to better public health”. (Interview 1, Researcher)

As explained by this researcher, many activities and practices are problematic for people because of associated stigmas and negative judgements and this hinders disease-prevention efforts. These types of social devaluations and stigmatisation practices also affect pregnant women and recent mothers, for whom a categorisation as a “good mother” (or “bad mother”) are linked to not having sex (Kenney and Müller, 2017; Thompson, 2005).

Previously, I mentioned that pregnant women and recent mothers are subjected to restrictions on sex and sexual practices. During the interviews and OAFGs, the participants were less likely to talk about sex during pregnancy. The healthcare workers and administrators said that pregnant women and their partners did not usually ask about or comment on these issues. It seems that sex was a practice that corresponded to their previous “role status” as a woman, but not their role as a mother-to-be. As indicated by a participant:

“I was sexually active, but not anymore because I owe respect to my partner and, above all, to my son”. (Interview 34: Pregnant woman)

Other participants referred to their discomfort – or that of their partners – with talking about sex or having sex during pregnancy:

“Well, in the end, you feel very tired and the belly is uncomfortable. So, in the end, it is not nice”. (Interview 5, Pregnant woman)

“...but when the belly was bigger, we were scared. I didn't. Honestly, I refused a lot because the belly was too big, so it wasn't that comfortable. So, those last months, no, we didn't have it”. (Interview 17, Pregnant woman)

Here, the reference to the belly is not only “physical” but also symbolic. The belly is not only where the baby is, it is also the “place” where doctors, nurses, traditional midwives, relatives, neighbours, and other community members focus their attention. The belly is constantly scrutinised and monitored; it is under surveillance.

There were several indications of this. There are various restrictions on the activities of pregnant women that are intended to protect the belly. The belly is measured during prenatal care appointments, and others comment on how big or small it is compared to what is expected. There are tests performed in this area (echography, amniocentesis). In addition, the massages that traditional midwives perform and the procedures to correct the position of the baby all involve the belly. If a pregnancy is categorised as high risk, the belly becomes a site for greater vigilance. Pregnancy is seen as uncertain or risky, mainly because women's bodies have been considered inferior and vulnerable (Lane, 2015; Lupton, 2012; Ross, 2015; Scamell and Alaszewski, 2012).

Interestingly, sex during pregnancy is often recommended and even encouraged by healthcare workers, traditional midwives, some relatives, and neighbours because it is considered helpful, facilitating an easier delivery with fewer complications. (This was noted during two of the OAFGs.) However, despite these recommendations,



pregnant women do not usually have sex during the last trimester, as reported by most of the participants.

Here, I found evidence of ambivalence and negotiations around sex during pregnancy. Even though healthcare workers promoted it, sex did not appear in conversations during prenatal care, medical appointments (with specialists or in the emergency room), or messages about preventing STDs. If conversations about sex did occur, they were during psycho-prophylactic courses (one session), in response to questions from pregnant women or their partners, or with women who had positive STD diagnoses.

This taboo in relation to sex continued after the birth. Healthcare workers, traditional midwives, and relatives all agree that sex postpartum is a “risk” (in biomedical terms) or a danger (according to traditional midwives), particularly for the new mother. Biomedicine and traditional medicine agree that women need to recover from labour and to dedicate their time, energy, and resources to the newborn.

Furthermore, biomedicine and traditional medicine agree that women should not get pregnant again during the postpartum period or the first months of the new baby’s life. As such, this avoidance is indicative of a “good mother” who is focused on taking care of her new baby.

Given the taboo regarding sex, particularly during pregnancy and the postpartum period, it is unsurprising that there are stigmatisation practices associated with STDs. Being diagnosed with an STD during prenatal care means that one is likely to be considered promiscuous, a *puta* [whore], amoral, irresponsible, and a “bad mother”. Unlike most other diseases, STDs elicit judgements and assumptions about a failure to attain expected standards of behaviours. STDs are sometimes considered avoidable consequences of controllable behaviours or situations (Mak *et al.*, 2006).

In the case of syphilis and CS, taboos and stigmas are not only guide how pregnant women, healthcare workers, and administrators accommodate and negotiate their practices, they also show how communitarian, social, and institutional practices;

constraints; and dynamics constitute and perpetuate inequalities and asymmetries, for instance in terms of social regulations. CS is considered a preventable disease, thus having a baby with CS suggests a lack of control and the unmet expectation of taboo avoidance. Moreover, the view of CS as a preventable disease and as part of the group of “neglected diseases” or a “disease of poverty”<sup>21</sup> can contribute to the paradox of stigmatisation practices: namely, bringing attention and resources to prevent and treat CS implies that healthcare workers and administrators are not currently doing enough. When CS is intertwined with poverty, this then contributes to a narrative of a lack of initiative, helplessness, and bad behaviour – all of which are usually portrayed as a reflection of poverty (Tyler, 2020b).

This section has explored the taboos and stigmas associated with sex and argued that these are subject to constant negotiation. Direct mentions of sex in public conversations do not indicate the nonexistence of this taboo. In addition, it has been shown that the influence of religion has shaped these taboos and stigmas, making STD and CS prevention more challenging. The next part of this chapter will show that silences and absences are not only expressions of taboo and stigma – they also enact them.

#### [Silence, absence, emotions: taboos and stigmas](#)

In Chapter 4, “Ontological Discontinuities”, I showed how researching, diagnosing, treating, and surveilling syphilis can enact practices of silence, absence, and discontinuity, thus making CS prevention more challenging.

In this section, I focus on two forms of silence, absences, and emotions: first, expressions of and responses to taboos and stigmas, and second, practices that enact taboos and stigmas. As Shove et al. (2012) indicate, practice can be an entity (silence as a “thing” with a history and trajectory) and a performance (the existence of the practice through its performance).

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<sup>21</sup> It is considered that certain diseases such as tuberculosis, malaria, and Leishmaniasis are more common among low-income populations, indicating a nexus between poverty and its prevalence. The WHO have special programs and research for its prevention and control.

Helene Joffé (1999), in an examination of social representations of HIV, shows that people externalise threats by othering. If we can say that “others” (not “me” or “us”) are more vulnerable to a threat, this becomes a way to manage the danger of that threat. This involves negotiations over identities, since “individuals protect their identities by holding representations which link potential crises to ‘the other’ in terms of their own group identity positionings. This not only results in a widespread sense of invulnerability to the risk, but also contributes to a sense of spoiled identity in those group members who are linked with the threat in the dominant representations” (Joffé, 1999:VII).

In what follows, I will refer to five examples from the data that show how othering is accomplished. Let us consider these more closely.

In the first example, the traditional midwives in my sample considered syphilis a “Western disease” and refused to attend to a pregnant woman during delivery if she had not received treatment for the condition (see Chapters 4 and 5). This is one way of avoiding the taboo of infant death. In addition, this might prevent an association forming between STDs and the traditional midwife and midwifery (both traditional labour and STDs are highly stigmatised, as noted above).

On numerous occasions, the traditional midwives whom I interviewed indicated that they did not treat syphilis. They said that they might treat other STDs (gonorrhoea, *gallito* [human papillomavirus]) but not syphilis or HIV, which are scrutinised and monitored by health authorities in a different way. Referring to syphilis as a “Western disease” is a way of othering and establishing a difference between what a traditional midwife does and a negative consequence over which the traditional midwife has little influence – and thus, for which midwifery cannot be held responsible.

The second example of othering concerns how pregnant women’s body parts are silenced by healthcare workers, pregnant women, and even relatives (see Chapter 4). It is not only that certain body parts receive more attention – such as the belly (where the baby is) and the hands and feet (as indicators of possible complications and risk) – it is that other parts are silenced. The vagina (if it is not bleeding or experiencing discharge), the anus, and the mouth are silenced. During the

pandemic, the use of face masks made the mouth invisible; and the time limitations on appointments (due to social distancing measures and the absence of personnel) made healthcare workers occasionally pay more attention to filling out forms than to their patients. These practices that make certain body parts silent are in accordance with taboo avoidance (particularly sex taboos). They also reinforce stigmatisation.

In the third example of othering, CS is silenced through the removal of cases from epidemiological surveillance reports, as well as by enacting *silencio epidemiológico* [epidemiological silence] and the categorisation of certain cases as *Sífilis Venezolana* [Venezuelan syphilis].

In Colombia, Secretaries of Health monitor the incidence and prevalence of gestational and congenital syphilis. This is not only a matter of epidemiological surveillance and public health concern, but also the enactment of achieved goals (for their reduction) and of performance indicators at the national level that are referenced against global indicators (established by World Health Organization).

Case dismissal occurs when syphilis “disappears” from the epidemiological surveillance reports collected by healthcare providers and consolidated by the INS (National Institute of Health) because those cases do not correspond to the current case definition. On the other hand, *Silencio epidemiológico* [epidemiological silence] is a commonly used term referring to the absence of case reports. This term is frequently used by healthcare administrators and workers, especially those working on epidemiological surveillance. *Sífilis Venezolana* [Venezuelan syphilis] is the name given to the disease when identified among migrants from Venezuela. This categorisation implies that the cases are “foreign” and thus not the responsibility of the health secretaries.

Not reporting cases (epidemiological silence), the dismissal of cases, and the concept of *Sífilis Venezolana* are thus ways to avoid the stigmatisation of hospitals and Secretaries of Health and their staff, showing that the latter are successful in their work. With syphilis considered a “preventable” disease, when it is not prevented, blame may be attributed.

When a larger number of cases appears in a particular hospital, that hospital will be subject to more verification, greater surveillance, and more extensive monitoring, compromising its reputation as a good healthcare service provider and limiting the possibility of future contracts with EPS (i.e., the entities paying for healthcare services).

The staff of the Secretaries of Health are monitored by the National Institute of Health, the Ministry of Health, and other multilateral organisations (WHO, PAHO). Many Secretaries of Health receive resources for CS-prevention activities and the reduction of maternal and newborn mortality – and if their indicators are poor, this can compromise their future access to disease-prevention resources.

During an interview, one healthcare administrator recounted an anecdote regarding a colleague who had been reporting CS cases to the National Institute of Health. Her colleague was happy because the National Institute of Health had removed one of their CS cases and attributed it to another municipality:

“...Look, this is great! That [CS case] was here, but she [the pregnant woman] came from X [another municipality]. She was here only for two months, so the case was attributed there, not here”. (Interview 7, Healthcare administrator)

Several healthcare workers made allegations about the responsibility of the healthcare system for the CS cases. For instance, one participant who works for the Secretary of Health indicated that “congenital syphilis, it is due to a problem with the healthcare system” (Interview 29, Healthcare worker). These statements were supplemented by complaints about unsuccessful measures:

“Gestational and congenital syphilis are our priority. We have implemented many interventions, but there is a social and cultural aspect that does not help much [...]. There is not adequate integration for us to improve those indicators”. (Interview 47, Healthcare administrator)

Silence practices are a way of avoidance and a way of dealing with stigmatisation and the inefficacy of the healthcare system and/or healthcare workers and administrators.

The fourth example of othering are the practices of choosing silence, employed by Afro-descendant and Indigenous pregnant women. Choosing not to reveal the stage of pregnancy or the due date is a way to avoid both a *trama* and the infant-death taboo. This practice is also common among migrants and other women, who do not reveal much information about their pregnancies during the first months. This is noted in the literature showing that women are often reluctant to talk about their pregnancies during first months as a way to “prevent” potential complications (Ross, 2015).

In a previous section, I commented on sex taboos and stigmas. I want to emphasise in this fifth example that, during the interviews and OAFGs, the pregnant women and recent mothers frequently did not refer directly to sex. Instead, they used the word *eso* [that or it].

Alongside laughter, silences, and hesitations, there was also embarrassment and fear. Talking or asking questions about sex, especially when there was a concern, caused fear and embarrassment among several participants. The presence of laughter and fear, therefore, suggested the enactment of taboos and stigmas.

Eduardo Viveiros de Castro (2012) emphasises the important role of fear and laughter in enacting alterity. In his work with Indigenous people from Amazonia, he notes that the participants could laugh at the same things that caused them fear:

“This is a form of fear that, far from demanding the exclusion or disappearance of the other in order for the peace of self-identity to be recuperated, necessarily implies the inclusion or incorporation of the other or *by* the other (*by* also in the sense of “through”), as a form of perpetuation of the becoming-other...” (Viveiros De Castro, 2012:29).

In a similar way, when a pregnant woman talks about sex during pregnancy, indicating that her partner enjoys it, and she is laughing, she is negotiating the language taboo around sex talk and differentiating herself from her partner. She differentiates herself, as a pregnant woman, from her partner and what he wants and enjoys. In establishing those differences, she creates distance from her potential stigmatisation.

Additional silences and absences also contributed to the practices surrounding pregnancy, prenatal care, birth, and postnatal care. However, there is insufficient data to clarify these. For instance, we might ask how desire, pleasure, and sexual practices are configured in different groups and how eroticism is practised among diverse groups, especially among Indigenous people.

Unfortunately, the present research gathered insufficient evidence from partners and sexual contacts (I only interviewed two). More data about their practices and the diverse configurations of masculinities and femininities is needed to go beyond the assumptions made in STD prevention, with its predominant narrative of heteronormativity.

This section has discussed silences, absences, and emotions as expressions and enactments of taboos and stigmas. In the next section, I will present some of the different ways of responding to taboos and stigma.

#### [Responding to taboo and stigma](#)

In this section, I focus on how taboo and stigma practices are avoided, negotiated, and resisted through multiple ontologies (realities). Let us recall, first, two main points regarding multiple ontologies (Mol, 1999, 2002) and othering (Law, 2004). First, as indicated in previous chapters (especially Chapter 4), in CS prevention, a bundle of practices enacts multiple ontologies. Second, the presence of certain realities implicates the absence of others, as Law and Singleton (2005) showed in their research on alcoholic liver disease: “Objects become ontologically complex, multiple and (in some cases) mutually exclusive... they are other to other” (Law and Singleton, 2005:8). In the immediate context, othering can facilitate ways of avoiding, negotiating, and resisting stigmas and taboos. I draw on four examples from the data to clarify these points.

As mentioned in previous sections, the infant-death taboo (and practices for its avoidance) is manifested in a bundle of practices that occur during pregnancy, prenatal care, labour, and the baby’s first months.

Babies’ multiple ontologies are one of the areas in which those avoidances are enacted. Sometimes babies are not “babies”; instead, they are foetuses that are

measured, observed, and monitored to compare with standards to determine whether there is “foetal viability”. In Colombia, until February 2022, the law established three justifications for a legal abortion: the pregnancy was a result of rape, the mother’s life was in danger as a result of the pregnancy, or the baby had a medical condition that meant it was not viable. In February 2022, new legislation allowed abortion during the first 24 weeks of a pregnancy, regardless of condition. At the time of my fieldwork, this law was not yet in place and women could not have abortions. One participant in the study had considered an abortion but chose not to proceed after seeing the baby during an echography and encountering several barriers to a safe abortion.

The diagnosis of congenital syphilis and the clinical practice guidelines (CPG) make no reference to a “baby”. The text of the CPG indicates that there is *fruto de la gestación*<sup>22</sup> [result of conception], and it establishes a nexus between the mother and the “outcome”. According to the diagnosis algorithm, if a woman has gestational syphilis and does not have “appropriate” treatment (at least one dose of benzathine penicillin), the *fruto de la gestación* also has CS, regardless of clinical signs.

In the context of epidemiological surveillance, *mortinato* [stillborn] and *nacido vivo* [newborn] are two terms that are similarly accounted for in terms of the prevalence of CS. The numbers of stillborn and newborn babies are added to establish the proportion of CS cases and the prevalence in each region and in the country as a whole. Babies then become numbers, aggregates of data that are counted to obtain a measure of CS prevalence and the accomplishment of goals and indicators. Following guidelines from the WHO and PAHO, the National Institute of Health and the Secretaries of Health develop programmes and activities to reduce the incidence of CS. These indicators are also used as measures of the performance of the Secretaries of Health and their staff.

For more than a decade, Colombia has maintained the goal of reducing the prevalence of CS to 0.5 per 1,000 newborns. This goal is used as a measurement

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<sup>22</sup> This concept is similar to that of an embryo, but it emphasises the “product” or result of conception. *Fruto* also refers to “fruit” as the product of a tree or plant.



at both the regional and the national levels – as a public health indicator and as a measure of the efficiency of the Secretaries of Health.

As shown, monitoring, diagnosis, and surveillance practices enact multiple ontologies surrounding “babies” that allow healthcare workers and administrators to respond and negotiate the infant-death taboo and several other stigmas. It might seem that this avoidance is essentially a language taboo (Miller, 2022; Glowczewski, 2019), intended to avoid the word “baby”. However, this focus on other aspects of the “baby” is a “depersonalisation” practice that establishes a distance between the “object” (baby) and the “subject” (the healthcare administrator) and spreads responsibility for CS and infant death beyond any one individual. This is particularly important for healthcare workers and administrators because, despite their engagement, it is not always possible to protect and support the life of the baby.

In the second example of how othering can facilitate the avoiding, negotiating, and resisting of stigmas and taboos, something similar happens, as *parteras* respond to stigmatisation practices through *parto humanizado* [the humanisation of childbirth]. Some healthcare workers and administrators fear that traditional midwives can create complications during pregnancy and labour. There are frequent allegations of unhygienic practices, inappropriate attendance of a birth, and late referrals of pregnant women to hospital. As indicated by one GP who attends births:

“...births at home are frequent, which increases the risk of neonatal sepsis because that is not an adequate environment for delivery” (Interview 46, GP)

In some cases, traditional midwives are blamed for maternal and infant deaths. Furthermore, it can be difficult to work with them or integrate them into certain procedures because they are not acknowledged by the healthcare system or the Ministry of Health (unless they belong to an Indigenous health service provider). They are not allowed to attend maternity wards or hospitals for “hygiene reasons”. As explained by a healthcare worker:

“They [traditional midwives] give beverages and we don’t know what they are made of and they affect women and their babies”. (Interview 44, Healthcare worker)

The tension between science and non-science (traditional knowledge) emerges frequently. Here is one example of the contrasting perspectives regarding the diverse knowledge and experiences of traditional midwives and healthcare workers:

“Those ladies [traditional midwives] have plenty of experience. They have been doing that for many years – and even if it is not what one has been taught in the operating room or labour ward, they can be trained to attend to emergencies like bleeding or something like that. They might know something because deliveries are frequent, and so far, I haven’t seen complications during labour, no. So, they might know something. They might have some knowledge and experience that is very valuable”. (Interview 46, GP)

The healthcare workers and administrators in Chocó and Riosucio were more supportive of traditional midwives because, in their context, there is a long history of traditional medicine and midwifery. In Manizales, in contrast, the influence of traditional medicine and traditional midwives is less strong and there are frequent allegations of bad birthing practices, with traditional midwives considered responsible for delivery complications.

Traditional midwives respond to those allegations by emphasising *parto humanizado* [the humanisation of childbirth], the value of tradition, and the help that they provide to their communities.

*Parto humanizado* [the humanisation of childbirth] is a “movement” or approach that questions the excessive bio-medicalisation of birth and the lack of autonomy women have over their bodies – not least during labour (Curtin *et al.*, 2020). Although, initially, the movement focused on those women who were unlikely to experience complications during childbirth, it has since been extended to all women, regardless of their pathway to labour (Curtin *et al.*, 2020). Traditional midwives advocate for the principle that women must make decisions about their own bodies and that they have a right to feel comfortable and to express themselves and, if possible, to avoid caesarean procedures. Traditional midwives argue that their knowledge is relevant – it is part of their culture and who they are. They even highlight that most GPs and nurses in Chocó were themselves delivered by a *partera* [traditional midwife]

“...they think we are invading their space, that traditional midwifery is something that has gone and it is not going to happen again, that now there is only them, just

because they are doctors. But they forget, I can assure you that a *partera* delivered 90% of the doctors. So, they forget where they come from, who they are, who helped them, who helped their mom so that they could be here today". (Interview 43, Traditional midwife)

Moreover, *parteras* argue that they provide care to people and places that are frequently left unattended or disregarded by healthcare workers.

"We go where they don't go, we go wherever someone needs us". (Interview 42, Traditional midwife)

Interestingly, during the COVID-19 pandemic, many participants saw hospitals as "dangerous" and were "fearful" of them, seeing them as places to avoid. Fears of contagion and death and of being left to die were common among the participants. In Chocó, it is common for women to prefer to have their babies at home or with a traditional midwife, as opposed to going to a hospital where "they left you to die" (Interview 26, Pregnant woman).

In addition, during the first months of the pandemic, it was difficult to access hospitals or health centres (due to the lockdowns, lack of transportation, and economic restrictions). In that context, *parteras* played a vital role in caring for women during pregnancy and labour.

As noted previously, several practices, multiple ontologies, and various narratives manifest the response to stigmas in terms of "them" and "us" (traditional midwives vs healthcare workers). However, we have also seen how, among some healthcare workers, there was interest in collaborating with traditional midwives. Traditional midwives were also open to collaborating, dialoguing, and learning more to provide better care. They considered more communication with healthcare workers vital for the benefit of women and babies. As one traditional midwife stated:

"they think we are competing with their work, that we are going to take their work away from them, but our work complements theirs". (Interview 14, Traditional midwife)

Traditional midwives are aware that women employ various care practices during pregnancy and after giving birth, but this is not an issue for them – unlike some healthcare workers and administrators. *Salud intercultural* (intercultural health) is popular with traditional midwives, who are particularly appreciative of the regulations that promote an intercultural approach to health (Law 1715 of 2015). Although *salud intercultural* is acknowledged by healthcare workers and administrators as a regulation that should be followed, a lack of clarity in how to proceed – and the difficulty of achieving *salud intercultural* – means that it is primarily a “paper exercise”:

“I am realistic; I think it only exists on paper (...). In every workshop, they talk about interculturality. I have listened to that since I graduated from University, but it is not practised”. (Interview 10, Healthcare worker)

Although Law 1715 of 2015 promotes an intercultural approach to health, the conditions needed for its implementation (and adaptation) in multicultural contexts are not yet in evidence. First, there is a need for the destigmatisation (Clair, Daniel and Lamont, 2016) of traditional midwives and biomedicine, clearing the way for open dialogue and collaboration. Some movement in this direction is already evident, with some healthcare workers and administrators acknowledging the role of traditional midwives and traditional medicine, especially during the pandemic. However, there is still much more to do.

The third example of how othering can facilitate the avoiding, negotiating, and resisting of stigmas and taboos concerns the sexual and reproductive rights policy regarding STD prevention, sex education, unwanted pregnancies, and choices around sexuality and its exercise. The use of condoms is promoted by healthcare workers during STD-prevention campaigns – and during prenatal care, if a pregnant woman tests positive for an STD – but it is primarily seen as a contraceptive method. In this study, the healthcare workers and women (pregnant women and recent mothers) indicated that their use of condoms was limited for several reasons.

First, some women said that they used condoms only if they have an infection or if they *se están cuidando* [follow a contraceptive method] and do not want to get pregnant. However, most participants said they did not use condoms because they were in a monogamous relationship and they trusted their partners. For these women, using a condom sends a clear indication that either they do not trust their partner or they are promiscuous and their partners should be suspicious of them (an indication of promiscuity)(Campbell, 1997a). Furthermore, most of the pregnant women said that their partners – or they themselves – did not like condoms because sex did not feel the same when using them. However, many pregnant women considered it important to use condoms, even with their partners, although they said that it was not always possible to do so. As stated by one of the interviewees:

“Condom use even with your partner. They are *machistas* (sexist men). They say it does not feel good, that it is not the same with the condom, but women have to stand up and say, ‘no more’”. (Interview 34, Pregnant woman)

For some pregnant women, there is a paradox regarding trust and STD testing during prenatal care and labour. On the one hand, they know that all pregnant women have to be tested, which removes the stigma for a woman of having those tests. On the other hand, they are concerned about receiving a positive result and see the testing itself as drawing their trustworthiness into question. In that case, trust is contested.

Pregnant women usually attribute a positive result to their partner. As some stated, “they can be in a relationship with you, but you never know” (Interview 32: Pregnant woman). Since CS prevention is highly focused on women, advocating for men to take more responsibility is a way of responding to the stigma and taboo.

The healthcare workers, administrators, and women who participated in the study emphasised that men have considerable responsibility for gestational and congenital syphilis.

It is not known how many women experience syphilis reinfection during pregnancy. However, there is a strong narrative that men are responsible for these reinfections.

It is commonly believed that men do not seek out treatment and that many have multiple sexual partners outside of their formal relationships. During the interviews and OAFGs, men were portrayed as *hombre canal* [men-canal], refusing treatment, being unwilling to collaborate, and being promiscuous or hypersexual and irresponsible.

The concept of the *hombre canal* [men canal] indicates that men are more present in the public space, are more mobile (going to other municipalities or to other cities to work), and migrate more often. In that sense, men are associated with practices of channelling from the outside to the inside, from the public to the private space, from outdoors to home. Since women have usually been restricted from accessing the public sphere, and even stigmatised for engaging in practices associated with the public sphere, men are considered the conduit between the outside (diseases) and the inside (home), as explained in the literature (Campbell, 1997; Ministerio de Salud y Protección Social y Fondo de Población de las Naciones Unidas, 2011; Mueses, Tello and Galindo, 2017). An indication of this stance can be found in the following segment from an interview:

” ...if we talk bacteriologically, that is the exchange of microorganisms. Men are a canal that passes from here to there”. (Interview 4, Healthcare worker)

Men, particularly in Chocó, are considered promiscuous and hypersexual. This notion can be found in the literature (Viveros, 2003; Viveros, 2002; Wade *et al.*, 2008) and was heard from participants in that region:

“Men in Chocó do not like to have only one woman. They do it [seek out another woman] when they are not satisfied with what they have at home or if they just want another woman”. (Interview 31, Pregnant woman)

Many of the healthcare workers felt that men did not cooperate with treatment or CS prevention. They often abandoned the pregnant women, choosing not to take responsibility for the pregnancies, to receive treatment, or to let other sexual contacts know about their diagnosis. Some healthcare workers and administrators (especially those dedicated to STD prevention) also noted the particular risks for men who have sex with other men (MSM). Although in countries such as the United States, MSM

are considered a high-risk population in terms of syphilis, few studies have been conducted on this population in Colombia (Mueses, Tello, and Galindo, 2017; Ministerio de Salud y Protección Social y Fondo de Población de las Naciones Unidas, 2011). Some of the healthcare workers and administrators indicated during the interviews that this was an issue that needed to be tackled.

Some healthcare workers and researchers have proposed screening the general population, particularly men, for syphilis to reduce its transmission, rather than focusing on examinations of pregnant women. Men could be screened in emergency rooms, when playing sports, or when meeting with friends. Some have also proposed that incarcerated men be screened in prison.

“I know of some cases where, when they tried to find the partner of a positive syphilis case, he was in jail. There is nothing you can do. You can’t go there to provide treatment, and people come and go... they pass on diseases”. (Interview 7, Healthcare worker)

As we can see, men are not only considered the “channel” for syphilis and thus responsible for pregnant women’s reinfection, they are then absent from prenatal care, psycho-prophylactic courses, and syphilis treatment. That being said, it is important to note that I was only able to interview two men (one partner of a recent mother and one partner of a pregnant migrant woman). Therefore, no contrasting insights can be provided here.

In this section, I have discussed various ways in which taboos and stigmas are contested and negotiated during efforts to prevent STDs, particularly congenital syphilis. In the following section, I discuss the implications of integrating discussion of sex practices into STD prevention.

#### [Implications of integrating sex practices into STD prevention](#)

During the interviews and OAFGs, I questioned the participants about how STDs – and CS in particular – can be prevented. For the healthcare workers and administrators, CS prevention was about implementing clinical practice guidelines, facilitating healthcare access, and providing treatment to partners. They also agreed

with the pregnant women and recent mothers that STD prevention should also include more information and sex education.

“Well, besides education to prevent it, I also think we need to strengthen the collective intervention plan<sup>23</sup> and provide more information about syphilis because people do not know much about the disease”. (Interview 10, Healthcare worker)

However, although sex education and information were identified as the main ingredients for STD prevention, this relationship is not considered straightforward. First, there are no consistent programmes or activities dedicated to sex education, except those given at specific moments during medical appointments (e.g., education on birth control, prenatal care, STD diagnoses). Even during prenatal care appointments, other priorities – such as filling out forms; looking for warning signs; and checking blood pressure, weight, and babies’ development – are considered more pressing.

Second, sex education cannot be the sole responsibility of healthcare workers or traditional midwives. It should also be the responsibility of educational institutions, families, and communities. Nonetheless, the taboos and stigmas around sex (especially sex during pregnancy) create restrictions that complicate this. The influence of religion, particularly Catholicism and Evangelical Christianity, shapes how certain conversations, practices, and people are perceived and also how and what can be done to provide sex education and develop activities that promote STD prevention.

It has been considered that providing more information leads to behavioural changes for disease prevention (Garcés *et al.*, 2017; Esacove, 2013). However, this type of deficit model is problematic in two ways. First, it does not acknowledge the taboos and stigmas and the silence and absence practices that the information must address. Second, the focus on behavioural change disregards the fact that a number of practices must be integrated and coordinated. As discussed in previous chapters,

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<sup>23</sup> *Planes de Intervenciones Colectivas* [collective intervention plan] are plans and activities to prevent the diseases or public health concerns that are prioritised in each region.



CS prevention entails practices before and beyond prenatal care, childbirth, and the first months of the babies' lives. Those practices involve healthcare workers and administrators, women, and their partners. They also require communities, relatives, neighbours, traditional midwives, and priests – as well as, more broadly, materials, competences, and meanings (Shove, 2017) associated with diverse care assemblages.

Health and disease prevention are usually approached from behavioural perspectives in which “behaviour” is “the expression of an individual’s values and attitudes” (Blue and Spurling, 2017:4), with limited participation from others (Luque *et al.*, 2016; Welch, 2017). When only individual attitudes and values are considered, this disregards the multiple relationships, cooperation, infrastructure, and materials that are also needed for an individual to perform an activity or establish a new routine.

Let us consider, as an example to clarify this further, the use of condoms as a preventative measure. Currently, condoms are provided to pregnant women with a positive STD diagnosis, high-risk populations (homeless people, sex workers, etc.), and men during family planning appointments. However, the provision of condoms and information on how to use them does not necessarily lead to more people using condoms to prevent STDs, given the influence of other aspects of social life, such as identities and ideologies (Campbell, 1997; Valdiserri, Holtgrave and Kalichman, 2020).

Several silence and absence practices bound up with taboos and stigmas can limit the provision and receipt of information and the integration of that information into practice (e.g. taboos associated with sex and sex during pregnancy).

As highlighted in the previous sections, there are taboos associated with sex and sex talk. This topic are not usually widely discussed, as there are concerns about trust (i.e., identifying trustworthy people to talk about it) and privacy (i.e., sharing private information in the public sphere).

Moreover, there is stigma associated with using condoms in a “committed relationship”, including associations of promiscuity, lack of trust, and question marks over the partners’ commitment to and engagement in the relationship. In addition, using condoms to prevent unwanted pregnancies is considered unnecessary when other contraceptive methods are being used.

CS-prevention efforts in prenatal care appointments and psycho-prophylactic courses often include assumptions about heteronormative sex (heterosexual penetrative sex) and about sex being primarily for reproductive purposes. Silenced body parts such as the vagina (in contexts other than penetration), the anus, and the mouth are not mentioned in relation to sex practices or in the narratives surrounding STD prevention, particularly in the context of syphilis prevention. Moreover, CS-prevention efforts emphasise pregnant women during prenatal care and do not focus on men and women before, immediately after, or beyond prenatal care. This also limits the incorporation of condom-related practices.

The interviews with healthcare workers and administrators revealed certain assumptions and similar values regarding pleasure, desire, sexuality, gender roles, and relationships as “universals”, along with a goal of more people using condoms for STD prevention. Although approaching STD prevention through the lens of sexual and reproductive rights acknowledges diverse sexual practices and options (autonomy, diverse sexual identities, etc.), it also suggests that certain groups – such as Indigenous, Afro-descendant, migrant, and rural populations – have to negotiate and adapt to those practices, as they have diverse religious beliefs and are involved in different care assemblages (as discussed in Chapter 5).

Furthermore, as one healthcare administrator emphasised, the ways in which people relate, establish relationships, and engage in sexual contact have changed considerably during the last two decades – with the introduction of dating apps, a tendency towards less committed relationships, and earlier initiation of sexual activity:

“Sexuality is more open [today]... it has fewer steps, so to speak. I mean, now, I open an app and I get a sexual partner for the same day. I don’t need to follow the

same steps that you used to do 30, 40 years ago, as an example". (Interview 40, Healthcare administrator)

This statement contrasts the "ideal" (i.e., monogamous and committed relationships) with the reality of multiple partners and early sexual contact, highlighting that this change has occurred over recent decades. Paradoxically, other healthcare workers and pregnant women indicated that monogamous committed relationships were a valuable means of STD prevention. This clashes with the emphasis on condom use, as the "committed relationship" serves as a "protective factor", leading to the non-use of condoms. The pregnant women frequently referred to not using condoms because they were in a serious relationship or only using them when they were not *cuidando* (using other contraceptive methods).

One healthcare worker said:

"I think we have to provide them [pregnant women] with tools, encouraging the use of condoms, encouraging stable partners, monogamy... I think there is more freedom now, and that is not bad, but promiscuity is related to disease". (Interview 37, Healthcare worker)

The assumption of monogamous relationships also impacts syphilis treatment. When a pregnant woman is diagnosed with gestational syphilis, treatment should also be provided to her partner and any other sexual contacts. However, several EPS (healthcare service providers) only provide treatment for partners.

Information about prevention practices should ideally address the reality that many people are not in monogamous relationships and that condoms are not only used to avoid pregnancy. However, this is challenging, as the provision of sex education has been stigmatised by certain groups because it is perceived to promote promiscuity. As explained by a researcher:

"That huge barrier that equates sex education with prostitution is too complicated. With HPV [human papillomavirus], HIV, hepatitis B, syphilis, it is the same thing. If communities believe that vaccination or disease prevention or public health

measures for sexual and reproductive health support prostitution and promiscuity, that does not contribute to public health”. (Interview 1, Researcher)

The researcher quoted above explained that several STDs are seen similarly in terms of the actions required for their prevention and the barriers and challenges to the implementation of these actions. HIV, syphilis, and hepatitis B are STDs that can also be transmitted from mother to child. However, there are differences between them. Hepatitis B differs from HIV and syphilis in that it has a shorter incubation period and can be detected earlier. There are vaccines available for hepatitis B, and most mother-to-child transmission occurs labour. In Colombia, GS and CS have higher rates of incidence and prevalence than hepatitis B.

In contrast, syphilis and HIV can both go unnoticed for years, without being detected during prenatal care or in high-risk groups. However, more attention is directed to HIV than to syphilis. This includes more resources in terms of research, prevention campaigns, special programmes, and advocacy. The research participants more readily recognised HIV as a risk. Three of the 27 pregnant women and recent mothers interviewed mentioned having a relative with HIV, and most could identify the symptoms and complications of the disease. For all of the interviewees, HIV was more frightening than syphilis. One of the participants said:

“I was looking for information about HIV, and it is like a slow death, right? So to speak. I was also looking at syphilis and that is like a sore, like a rash. I don’t know. Both are scary. All diseases make me feel scared”. (Interview 35, Pregnant woman)

Thus far, this section has shown that efforts to prevent STDs and CS are hindered by several difficulties, particularly in relation to certain sex practices. The taboos and stigmas associated with sex have a significant impact on the provision of sex education and information related to disease prevention. Furthermore, there is an excessive focus on individual behavioural approaches (based on deficit models) and a failure to engage with the intricacies of what is required regarding sex education before and beyond prenatal care appointments.

## Final remarks

This chapter has focused on taboo and stigma, clarifying their manifestations and their connections with historical and contextual processes of othering, inequality, and discrimination, showing how they influence the practices of congenital-syphilis prevention.

Drawing on contemporary discussions over taboo, it was possible to identify the language taboos and taboos surrounding sex and death (infant and maternal mortality). I showed that taboos emerge during efforts to prevent CS and that the traditional distinction found in the literature between taboo and stigma in “primitive” and “non-primitive” societies, respectively, cannot be supported. In fact, it was possible to establish links between taboo and stigma. When people follow taboos (prohibitions), they are seeking to avoid the associated social devaluation (stigmatisation) – for example, the stigma accompanying sex during pregnancy or a positive STD diagnosis.

Furthermore, sex taboos and stigmas are enacted during CS prevention in the form of assumptions (collateral reality) about heterosexual vaginal penetrative sex in monogamous relationships that are altered or suspended during pregnancy.

Several examples are presented in the chapter to show how pregnant women experience and enact intersections of stigma, given the historical and structural configurations of those stigmas. A relevant finding from this study is that, not only do race, ethnicity, and gender influence how stigmatisation is manifested, territorial stigma (in terms of relationships, rather than spatial configurations) also affects health inequalities and stigmatisation. The consideration of the Pacific region in Colombia (particularly Chocó) and the lack of capacity to control a preventable disease in a low- to middle-income country such as Colombia are stigmatisation practices that further complicate the coordination necessary for the prevention of CS.

The chapter has also shown that silence and emotions are not only expressions of taboo and stigma, they also enact them. In several instances, silences and laughter

played an important role in “othering” (Law, 2004), allowing the participant to navigate dangers, risks, and potential negative judgements.

I have also suggested that several connections between syphilis and HIV/AIDS highlight another collateral reality. Stigmas surrounding syphilis and HIV are rooted in an assumption that these diseases can be avoided. Thus, the collateral reality of CS implies that, if CS is not prevented, this failure is not due to biomedical interventions; on the contrary, it can be explained by “sociocultural” aspects such as the characteristics of the population (race, ethnicity, socioeconomic level, region, country), a lack of knowledge about the CPG, or how the healthcare system works.

## CHAPTER 7 CONCLUSIONS

This chapter provides the final remarks in five sections to indicate the main findings and contributions, reflections on the study, recommendations derived from the thesis' findings, and areas for further research.

In the first section, I offer an account of the study's main findings. Here, several arguments against deficit models and behavioural approaches for disease prevention are provided. I elucidate how diverse collateral realities (Law, 2009) configure CS prevention in particular ways.

The second section indicates the reflections on the study regarding access and the data's characteristics. It also highlights that what initially could be considered a limitation (i.e. being unable to conduct face-to-face focus groups or interviews) enabled fruitful possibilities related to novel methodologies.

How the study relates to the literature is at the core of the third section. I particularly emphasise the contributions of the study regarding empirical (participants' diversity), theoretical (care assemblages and taboos and stigmas) and methodological (OAFG) aspects. For instance, I mention care assemblages (in which trust and expertise are emergent) and possibilities for OAFG at the intersections of online and offline interactions.

In the fourth section, I provide an account of recommendations at the international, national, regional, and local levels, which emphasise the necessity of coordination at the international and national levels. The last section pinpoints areas for further research. I highlight theoretical and methodological avenues. I also indicate other potential research projects following upcoming changes within the Colombian healthcare system, the introduction of the ETMI Plus strategy,<sup>24</sup> and several implications for CS prevention regarding antimicrobial resistance.

Let us now turn to the study's findings.

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<sup>24</sup> The ETMI Plus strategy or EMTCT Plus (in English) is a framework for the elimination of mother-to-child transmission of HIV, syphilis, hepatitis B, and Chagas established by the Pan American Health Organisation (PAHO, 2017).

### Findings of the study

This thesis initially started with the intention to delve into why a preventable disease such as CS cannot be prevented or at least prevented as expected in two regions of Colombia. After the literature review and the initial data analysis, two research questions were stated:

- 3) How do different care practices in two regions of Colombia currently enact congenital syphilis prevention?**
- 4) What would change if we were to provide good care for the prevention of congenital syphilis in Colombia?**

In Colombia, most efforts at CS prevention have relied heavily on implementing the CPG (Ministerio de Salud y Protección Social, 2013b). However, the incidence of CS has not been reduced. Notably, it became more prevalent during the COVID-19 pandemic (Instituto Nacional de Salud, 2020; Instituto Nacional de Salud, 2021). The Ministry of Health, the National Institute of Health, as well as other public health authorities in Colombia have considered three leading causes for CS prevalence: inappropriate prenatal care (beginning after the 12th week of pregnancy), the lack of knowledge regarding the CPG, and its correct implementation and the lack of treatment of pregnant women's partners. Alongside other studies conducted in the country, there has been an association of syphilis and CS with race, ethnicity, low economic and educational levels, and certain regions (Becerra-Arias *et al.*, 2022; Korenromp *et al.*, 2018; Cruz *et al.*, 2013; Cruz, 2012).

During the interviews conducted for this study, there were indications of the necessity for further knowledge provision to improve CS prevention—for instance, more knowledge of the CPG, more knowledge about syphilis, and more sex education. Moreover, individual behavioural activities for CS prevention were also expected and encouraged. Pregnant women were expected to start prenatal care “on time”, attend all appointments, and follow treatment and recommendations. Healthcare workers were expected to follow the guidelines (i.e. the CPG) and contribute to reducing CS rates.



The findings suggested that a high reliance on providing knowledge regarding the CPG (i.e. the deficit model as it is sometimes called [Cortassa, 2016]) and individual behavioural actions did not necessarily contribute to CS prevention in the study sites for several reasons.

CS prevention entails several struggles over ontologies (i.e. realities). Besides biomedicine, other care practices and care assemblages are enacted during prenatal care (e.g. traditional medicine, *curanderismo*, religion, and online resources). Syphilis and CS' multiple ontologies are also enacted, including multiple temporalities and trajectories.

Particularly in CS prevention, collateral realities (Law, 2009) are paramount since practices related to CS prevention can be noticed and contested. Collateral realities are “realities that get done incidentally. They are realities that get done, for the most part, unintentionally” (Law, 2009:1). The relevance of collateral realities lies in that, though these practices usually go unnoticed, they help coordinate other practices. These “background practices” (Michael, 2017) or assumptions allow things to hold together, yet not without discontinuities, contradictions, and apparent fragmentation. In collateral realities, a particular reality is assumed that silences other realities. In this study, collateral realities, such as silence, absences and discontinuity practices, are enacted while preventing CS.

One of the main collateral realities or assumptions is ontological unity. Biomedicine, healthcare workers, administrators, and public health authorities tend to configure syphilis and CS as one and assume that both can be prevented the same way, regardless of contextual differences. Furthermore, international differences in *Treponema pallidum* bacteria have not been fully explored, for example, how syphilis is researched (with some omissions regarding the knowledge about the bacteria), the differences regarding the diagnosis and treatment (i.e. the reverse algorithm in low- and middle-income countries and the traditional algorithm in high-income countries), and how the surveillance of gestational and congenital syphilis is accomplished during prenatal care.

Similarly, CPG practices are supported by the assumption (i.e. collateral reality) of a linear temporality in which syphilis diagnosis and treatment must be accomplished

at specific times, regardless of the circumstances that surround healthcare services provision or the availability of tests and treatment and care practices in which women engage while finding out about their pregnancies and starting their prenatal care. Furthermore, there are multiple care practices in which pregnant women, relatives, and healthcare workers engage, so their care assemblages are beyond what biomedicine and CPG implicate.

Another collateral reality is the assumption that the healthcare system is integrated, and all the activities, procedures, and steps lead to CS prevention in a linear, goal-oriented fashion. However, constant disruptions and delays occur (e.g. for international migrants who move from different municipalities, especially those who are undocumented). An integrated healthcare system supposes no administrative barriers and borders.

Paradoxically, although the baseline assumption is that the healthcare system is integrated, a collateral reality we see in practice in this thesis is that the administrative borders and limitations for healthcare service provision are configured more as disruptions, interruptions, and even divisions. Administrative borders between countries, municipalities, and the EPS (i.e. the healthcare service administrator) constantly disrupt the trajectories and temporality of CS prevention.

It is important to highlight that a bundle of interrelated practices that go before and beyond prenatal care are necessary to enact CS prevention. Hence, the coordination of activities regarding materials, competencies, and meanings (Shove, Pantzar and Watson, 2012b) is implicated.

One cannot only consider the practices enacted by biomedicine. In the regions under study, pregnant women, recent mothers, and some healthcare workers engaged with diverse practices configured of care assemblages of biomedicine, traditional medicine *parteria* [traditional midwifery], religion, *curanderismo*, and online resources. Multiple ontologies or realities (Mol, 2002) are also enacted during pregnancy, childbirth, and the babies' first months, which leads to contradictions, negotiations, and even cooperation between materials, competencies, and practices while enacting silences and absences that further complicate CS prevention. In this regard, the enactment of syphilis as a "Western" disease reminds us of the

multiplicity of ontologies and the necessity of acknowledging them, providing the conditions for dialogues, and establishing bridges and cooperations.

The assumption of ontological unity (a collateral reality) also tends to enact the prevention of diseases in isolation, one disease at a time, without considering the links and connections with other diseases. Although this research focused on CS prevention, it has been clear from the beginning that practices and ontologies enacting other diseases, mainly HIV-AIDS, COVID-19, and hepatitis B, along with preeclampsia, hypertension, and diabetes, also relate to CS prevention in cooperative and conflictive ways. For instance, the COVID-19 pandemic necessitated the mobilisation of considerable resources, attention, and care, which led to neglecting CS prevention and other diseases. On the other hand, although HIV-AIDS received more attention and resources compared to syphilis and especially CS, their co-occurrence (i.e. coinfection cases) resulted in the possibility of making it more challenging to care for patients with HIV-AIDS.

Precisely, one of the links between syphilis and HIV-AIDS highlights another collateral reality. The stigma concerning syphilis and HIV assumes that these diseases can be avoided. Moreover, the collateral reality enacted in CS implies that if CS is not prevented, the failure does not relate to biomedical interventions. On the contrary, “sociocultural” aspects such as the characteristics of the population (e.g. race, ethnicity, socioeconomic level, region, and country) or the lack of knowledge about the CPG and how the healthcare system works are valid explanations.

Three other interrelated collateral realities are enacted here. First, disease prevention (i.e. CS prevention) depends on the assumption of human agency, particularly pregnant women. Thus, pregnant women are deemed “responsible” for CS prevention, to be “good mothers” (following the recommendations of diverse care practitioners) and even responsible for the integration of diverse trajectories and activities (including information as with medical records) during prenatal care. This collateral reality denies that materials also interact, affect, or, more broadly, have agency. Second, little research exists on practices that link taboos and stigmas or show that taboos are only practised in certain contexts, especially where sacred practices are implicated, such as I found here.

I argue that while participants follow taboo restrictions, they are also motivated to avoid the stigmatisation related to an unfavourable social valuation, particularly regarding sex during pregnancy or a positive STD diagnosis. Sex taboos and stigmas are enacted during CS prevention under the assumption (a collateral reality) of heterosexual vaginal penetrative sex in monogamous relationships that are altered or suspended during pregnancy.

Taboos must be tackled and contested since they allow silences, absences, and avoidance practices that nurture stigmatisation practices and make CS prevention even more challenging.

As discussed in the chapter on taboos and stigmas, pregnant women/recent mothers enact several intersections of stigma that have historical and structural configurations. Not only do race, ethnicity, and gender enact stigmas, but the territory (territorial stigma) also does, as well as health inequalities. The Pacific Region as a territory (more than a space or the backdrop of interactions) and considering Colombia as a low- to middle-income country that cannot prevent a preventable disease are other configurations of territorial stigma. Here is the third interrelated collateral reality. These stigmas uncover that materials also interact and are an important part of disease prevention, while historical inequalities and the coordination and cooperation of individuals and collectives, institutions, and communities (more than those who are attributed by scientific expertise) are necessary for CS prevention.

Therefore, as I argued in this thesis, more information is insufficient for CS prevention since trust and expertise are emergent, particularly during uncertain times like the pandemic.

Chapter 5 discussed care practices negotiated by pregnant women/recent mothers, healthcare workers, *parteras*, relatives, and neighbours. Trust and expertise emerge during these negotiations and are enacted by particular care assemblages related to historical, traditional, and regional configurations.

Therefore, providing more knowledge and information does not guarantee disease prevention. Other studies (Rosenstock, Strecher and Becker, 1994; Irwin and

Michael, 2003) have indicated that deficit models are insufficient for behavioural change because of several populations with diverse characteristics and different levels of expertise and engagement with diverse levels of trust. I also add that the necessary practices for disease prevention, particularly CS prevention, implicate multiple ontologies, trajectories, and temporalities. They include the coordination and cooperation of diverse materials, with competencies and meanings that exceed what information and behavioural change entail. Similarly, they also exceed the focus on individuals responsible for prevention and bad outcomes, as has been the case in prenatal care while dealing with CS, with an overemphasis on the responsibility and agency of pregnant women/recent mothers and healthcare workers.

As one can appreciate, one of the greatest difficulties with providing more information and focusing on behavioural change as ways for CS prevention is that only certain ontologies, trajectories, and temporalities are acknowledged, mainly those from biomedicine. It is fundamental to acknowledge and dialogue with care practices that implicate other ontologies, trajectories, and temporalities while coordinating and cooperating with prevention practices that account for multiplicity. These include engaging with relevant humans and non-humans and relinquishing the idea of total control over diseases.

Following the second research question regarding the necessary changes to provide good care for the prevention of CS in Colombia, several points can be highlighted in this thesis.

CS prevention requires the coordination of several practices at the international, national, regional, and local levels. These practices go before and beyond prenatal care and implicate multiple ontologies (besides biomedicine) and more than the trajectories and temporalities expected in implementing the CPG.

Dialogues and coordination among representatives from different care practices, including those from religion, are fundamental to accomplishing better coordination of practices during prenatal care and for sex education and the necessary changes to deal with stigmatisation and taboo practices.

For instance, the dialogue with traditional medicine and *parteras* would help to provide better prenatal care and limit the clashes constantly encountered due to the ambivalent inclusion of traditional medicine and *parteras* in health regulations (i.e. intercultural health) that are excluded from the healthcare system.

Several inequalities are present during prenatal care and labour in the regions under study, and those should also be addressed with coordinated efforts from the government, NGOs, community organisations, and representatives from care practices and communities.

In the section dedicated to practical and policy recommendations, I provide a more detailed account of what CS prevention and the provision of good care during prenatal care imply.

This summary points to the general empirical findings of the thesis and the key frameworks used to analyse these findings. I discuss the contributions of the study in another section. This research has several limitations, which I discuss now.

#### [Reflections on the study](#)

Due to the theoretical and methodological approach, a qualitative study with a material semiotics approach, this study cannot be unproblematically generalised to other regions or contexts in Colombia or elsewhere. Nonetheless, some elements and practices described in this thesis can offer a relevant reference point for further research.

The circumstances posed by the COVID-19 pandemic posed several limitations of the study, mainly regarding access. I started the PhD in October 2019. At the beginning of the pandemic (March 2020), I conceived of conducting an ethnographic study in several hospitals and primary healthcare sites. After making considerable adjustments to the research project and acquiring ethical approval, I conducted online fieldwork in Colombia from January 2021 until August 2021, where face-to-face and social interaction restrictions were still in place.

Most healthcare workers and administrators were burdened with activities related to the pandemic beyond their general responsibilities. For instance, staff from the

Secretaries of Health who usually worked on maternal health or STDs were also dedicated to COVID-19-related activities. It was particularly challenging in Chocó, where I could not interview GPs and medical specialists. I only had the chance to talk to a nurse who worked in prenatal care. Contrasting experiences from healthcare workers of Chocó could have helped illuminate other elements of the bundle of practices that implicate CS prevention. Despite several attempts, I could not interview staff from the Ministry of Health or the National Institute of Health. The insights from members of these institutions might also have helped to provide other elements for the analysis of the national, regional, and local practices and the configuration of silence and absence practices, especially those related to administrative, legal, and managerial aspects of the healthcare system, syphilis diagnosis, treatment, and surveillance. Moreover, other indications of the contrasting regulations and practices for including traditional medicine and *parteras* in CS prevention might have become apparent.

Although I interviewed traditional midwives in both regions, I only interviewed one Indigenous midwife in Riosucio. I could not access Indigenous traditional midwives in Chocó due to difficulties using mobile phones, their fluency in Spanish (I do not speak Embera), and especially because they needed more face-to-face interactions to create rapport and a willingness to participate in the research. More insights from traditional Indigenous midwives in the future would yield data about other materials, competencies, and meanings in care practices and assemblages.

Only two partners were interviewed in the study, as I focused on the mothers engaged in prenatal care in the first instance. Some pregnant women/recent mothers either did not have a partner, had a difficult relationship with one, or could not schedule an interview due to time availability. Partners are often considered “absent” in prenatal care and CS prevention, as manifested by several healthcare workers. They are not usually screened for syphilis (unless they are part of an at-risk group), and it is challenging for them to receive treatment. However, partners play an important role in CS prevention, for instance, in stopping the transmission and the potential reinfection with syphilis of a woman who has gestational syphilis. Insights into other practices that engage gender differences were not fully addressed in this

research.<sup>25</sup> However, they are also fundamental regarding sex education, sex practices, prenatal care, and syphilis diagnosis and treatment. Therefore, future research focusing on this group would be highly valuable.

During the interviews with healthcare workers and administrators, there were indications of the necessity to address prevention with men who have sex with men (MSM) and consider sex practices beyond heteronormativity. As indicated in Chapter 6, there is an overemphasis on prevention practices related to heterosexual penetrative sex, which silences other practices that also limit CS prevention. More research is needed regarding these issues, especially since they are highly taboo and stigmatised.

It is also relevant to highlight that during fieldwork, I did not directly observe most of the practices discussed in this thesis due to needing to conduct the fieldwork primarily online. However, it is important to clarify two main points. First, I refer to practices, particularly from a performative consideration. Second, as John Law (2004) reminded us, practices do not implicate a performer; rather, they are “assemblages”, a mix of discourses, objects, and technologies brought together to perform a particular reality. Hence, if there is no need for a performer, then there is arguably no need for a “direct” observer. Therefore, what could be considered a limitation of the study according to traditional epistemological accounts becomes a possibility for exploring multiple ontologies.

Finally, although several limitations are acknowledged, it does not implicate that there are no valuable findings from the study. As John Law indicated, in every method, something is absent since “what is being made present always depends on what is also being made absent” (Law, 2004:83) . Making clear the limitations, difficulties, and messiness of the research also opened up the discussion about its theoretical and methodological aspects.

The following section specifies how the thesis relates to previous research and the study’s empirical, theoretical, and methodological contributions.

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<sup>25</sup> For instance, pleasure and sex practices, condom use, negotiations with partners and sexual contacts, infidelity/open relations, and bisexuality.



### Contributions of the study

This research is unique in the Colombian context. Most research on disease prevention in Colombia has approached population samplings in certain regions (through quantitative methods) or specific groups or communities (using qualitative methods). Moreover, some research has focused on healthcare workers, administrators, patients, and the general public. However, this thesis has considered healthcare workers' and administrators' practices and experiences while including a diverse range of participants, including Indigenous, Afro-descendants, international migrants, and internally displaced people. The multiplicity of the participants and their practices, including some shared by several groups (e.g. traditional midwifery by Indigenous and Afro-descendants), provided relevant insights into CS prevention and healthcare provision. Regarding the latter, the study indicates several difficulties and barriers that the healthcare system and how resources for healthcare provision are administrated implicate difficulties for overall healthcare access and disease prevention, not only for CS.

Research conducted on syphilis and CS in Colombia has focused mainly on biomedical research and has included the characteristics of the most at-risk population. There has also been a tendency worldwide to approach syphilis and CS prevention from the social determinants of health (SDHs). Authors from social medicine and critical epidemiology in Latin America (Breilh, 2021; Waitzkin *et al.*, 2001; Harvey, Piñones-Rivera and Holmes, 2022) have criticised the SDHs by highlighting their “pathogenic” perspective on diseases (emphasising more biological aspects) that do not include social contexts and inequalities and narrow the perspective of behavioural change by emphasising individual agency and considering certain variables (e.g. sex, race, ethnicity, and income) in terms of direct links for causation.

From the data of this research, it is also important to highlight other experiences relevant as potential determinants of health, like immigration status, type of health insurance, healthcare services provision, and mobility in the territory (national and international). These should also be considered in the SDH analysis. Such

“determinants” (following these terms) further complicate health inequalities and disease prevention.

Another consideration is related to the “fragmentation” of healthcare services due to differences, which lead to accommodations<sup>26</sup> of resources and administrative and managerial decisions, as indicated by several studies (Gamboa *et al.*, 2023; Cebul *et al.*, 2010). There are differences, for instance, regarding the type of health insurance (public or private), how healthcare services administrators establish their contracts with hospitals for healthcare service provision, authorisations needed, being in a city or a rural, isolated village, access restrictions to healthcare services due to transportation, financial hardship, and immigration status (with or without documents).

Nevertheless, more than the “fragmentation” of healthcare services provision, this research study showed that multiple ontologies, temporalities, and trajectories can lead to the coordination and miscoordination of practices necessary for CS prevention. Moreover, I identified that multiple ontologies clash, contradict, and cooperate in enacting those practices while entailing diverse temporalities, interests, and attention that marginalise or disregard other practices. In this respect, the present research echoes the efforts made by social medicine and critical epidemiology scholars to incorporate other voices and perspectives beyond scientific ones. For instance, there are parallels here with incorporating Indigenous perspectives into public health in Canada (Tremblay and Martin, 2023), in which Indigenous practices and meanings are also considered (Harvey, Piñones-Rivera and Holmes, 2022).

Furthermore, in contrast to some authors in public health and the sociology of health approaches (particularly from Salutogenesis-Antonovsky, 1996) in which individuals are mainly “responsible” for their health and make the necessary accommodations or changes for its maintenance, this thesis insists that materials are also important in the practices that facilitate disease prevention. In this regard, materials and interactions between humans and non-humans are also relevant: the constant and

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<sup>26</sup> These can include more authorizations to acquire a health service, delays and waiting lists, constant trips to other cities or municipalities for some healthcare services, or even denied access to certain services due to unfulfilled administrative criteria.

crucial negotiations and accommodations between humans and non-humans demonstrate that information and behavioural interventions alone are insufficient for disease prevention practices.

Combining STS approaches (i.e. ontological politics and collateral realities) with medical sociology and anthropology led to relevant insights into multiple ontologies, care assemblages, and taboos and stigma, which constitute other important contributions of the study.

By now, the reader may identify several similarities with Annemarie Mol's work (Mol, 1999; Mol, 2002). In both studies, multiple ontologies were enacted (i.e. multiple atherosclerosis and glycaemia were enacted in the laboratory, at the doctor's appointment, and during surgery). Some of these practices occurred in medical settings (mainly hospitals), where biomedicine (biomedical knowledge and expertise) was enacted.

However, other differences were salient when comparing Mol's research on anaemia and atherosclerosis (Mol, 1999; Mol, 2002) and this study. First, these studies comprise different diseases: anaemia, atherosclerosis, and CS. Each disease configures a particular set of practices, especially if we focus on an infectious disease which is sexually transmitted, such as syphilis. Moreover, CS implicates the potential or actual manifestation of syphilis in a baby, which sometimes is held as absent, as an outcome in a trajectory of disease prevention. The practices I referred to in this work also implicated other differences since they are not only comprised of biomedicine, as discussed in Chapter 5, but dedicated to care assemblages. Other healing practices are also implicated.

Mol (Mol, 2002) showed that in atherosclerosis, the patient's experience and clinical judgement usually indicate the need for an operation, while in anaemia (Mol, 1999) and syphilis, tests usually indicate subsequent treatment steps.

Finally, Mol showed the continuity of practices, indicating how materials and texts circulate between practitioners, which allows practices to "hang together" (Mol, 2002:5). On the contrary, in CS prevention, continuity is constantly disrupted,

“elongated”, suspended, and “altered”, partly because multiple trajectories and temporalities are also enacted.

Considering care assemblages as a concept (Trnka, 2021) allowed for exploring several practices and dialogue concerning the anthropology and sociology of health and illness. Regarding some approaches in medical sociology, as stated by Law (2004), there has been an emphasis on patient perspectives to overcome the privileging of biomedicine. On the contrary, as indicated in this thesis, the notion of care assemblages implicates a bundle of practices in constant negotiation that yield diverse reconfigurations. Hence, patients (i.e. humans) and biomedicine (i.e. scientific knowledge) are not the only elements relevant to comprehending disease prevention. Based on this thesis, we can conclude that humans and non-humans configure care assemblages in a constant interaction that entails materials, competencies, and meanings.

Regarding perspectives on the anthropology of health, care assemblages imply a different perspective from medical pluralism. Even though care assemblages share similarities with more recent considerations on medical pluralism (Uibu and Koppel, 2021; Hansen, Berntsen and Salamonsen, 2020; Sundararajan *et al.*, 2020) and with medical-therapeutic landscapes (Brown and Reavey, 2019; Tomalin, Sadgrove and Summers, 2019), several differences make care assemblages a more suitable approach to comprehensive CS prevention.

Care assemblages acknowledge the flexibility of care practices without the boundaries and restrictions of medical systems, which allows for appreciating the emergence of care practices and traditions such as those online.

When considering medical systems or traditions, not all diseases or illnesses exist, are acknowledged, or treated by them, which sometimes leads to practices of silence and absences that make it more difficult to prevent disease. Focusing on practices, particularly care assemblages, allows for identifying and comprehending the multiplicity of ontologies within and among diseases. In the case of CS prevention, practices are related to wellbeing, illnesses, and diseases during pregnancy, childbirth, and the babies' first months.

This focus is paramount since, unlike medical pluralism/diversity and medical landscapes, care assemblages recognise the multiple ontologies of a disease, the interactions between humans and non-humans, the coordination and miscoordination of practices and how materials, competencies, and meanings in practice are constantly reconfigured and enacted.

Following that consideration, care assemblages go beyond the individual/collective divide, either by a patient- or system-centred approach, as medical pluralism sometimes portrays.

This thesis revealed the constant negotiations of practices and diverse “hierarchies” between traditions, as well as the importance of trust in those practices. This trust is partial, emerges at various time points, and depends on the expertise of practitioners, not just institutions. This emergent trust was particularly the case in my study because of the need to negotiate CS preventive care online during the COVID-19 pandemic, which raised new and complex issues relating to trust that were not as acute prior to this emergent complex social setting. Furthermore, “online assemblage” suggests that care practices are constantly mixed in sometimes “contradictory” forms. For instance, participants in my study combined scientific knowledge from YouTube videos with tacit knowledge derived from previous mothers in WhatsApp groups or online forums, while traditional knowledge was presented on web pages. Again, the complexity of these care assemblages needs to be further investigated if CS prevention in prenatal care is to deal with the realities and collateral realities of people’s everyday lives.

I want to highlight two further discussions relevant to this literature. First, as I argued throughout this thesis, taboos have traditionally received less attention in contemporary health studies than health stigmas. Classic studies on taboos have tended to emphasise their presence in “primitive” or non-Western societies (Douglas, 1966). Taboos have also received more attention in linguistic studies (Cestero, 2018; Gatambuki, Ochieng and Wangeci, 2018). As discussed in Chapter 6, I suggested strong links exist between taboos and stigmas that emerge while prenatal care is enacted. People are motivated to follow taboos (i.e. social prohibitions) while they

also avoid the social devaluation (i.e. stigmatisation) that accompanies sex during pregnancy or a positive STD diagnosis.

Furthermore, while considering intersectional stigma (Turan *et al.*, 2019), other experiences and practices are relevant when considering health inequalities and stigmatisation. In particular, I argued that territorial stigma is important in complex locations for prevention, as is being an LMIC, which adds other ingredients to stigmatisation practices.

Regarding methods, I made several contributions to the methodological literature. In particular, the COVID-19 situation required developing critical reflections on the feasibility and meaning of online focus groups and, particularly, OAFGs. As I argued in my methods chapter, this work has provided new possibilities for research practice, particularly related to sensitive topics and difficult-to-reach and geographically dispersed populations. Most of the literature on focus groups has assumed that face-to-face focus groups are the “gold standard” and has highlighted the problems with online focus groups, especially regarding participant engagement, the quantity and quality of participant contribution, and limitations on interactions and the absence of non-verbal communication (Abrams *et al.*, 2015; Brügger and Willems, 2009; Nicholas *et al.*, 2010). However, as discussed elsewhere (Estrada-Jaramillo, Michael and Farrimond, 2022), the present research showed that underpinning these reservations is the view that online focus groups are just adaptations of face-to-face focus groups. However, I argued that the data in both types of interactions is different while sharing particular challenges. In the OAFGs for this thesis, for instance, I identified silence, continuity, and the contribution of other topics beyond the research and questioned what might be considered participant engagement, useful data, and the boundaries of the research event. Thus, researchers should become more sensitive to these differences and reflect on the research process while developing other means to explore these boundaries and possibilities from multiple data types.

The following section highlights policy recommendations for disease prevention, especially CS prevention, at the international, national, regional, and local levels.

### Practical and policy recommendations

Several recommendations can be given based on the present study. As mentioned in the previous sections, CS prevention requires the coordination of several practices at the international, national, regional, and local levels. Therefore, I offer recommendations according to those different levels.

#### *International and national levels*

Several dialogues and agreements between the WHO, the PAHO, and member countries, including Colombia, are needed:

- More dialogue with traditional medicine and *parteras* is necessary to coordinate the practices required for CS prevention. This ongoing conversation implicates an effort at the international level, particularly from the WHO. Even though it supports projects in Colombia to strengthen *parteras'* labour, it does not include them in some reports and recommendations. Such is the case of the “The State of the World’s Midwifery Report” of 2021 (United Nations Population Fund, 2021) that indicates “although they [*pateras*] attend a significant proportion of births in some countries and can play a role in community engagement and support, many are not formally educated, trained or regulated” (p3). More support from international multilateral organisations such as the WHO could also incentivise the coordination of activities at the national and regional levels in Colombia from the Ministry of Health and the Secretaries of Health. This research showed several ambivalent accounts for including traditional *parteras* and *partería*. While they are considered heritage needing protection and a vital part of “intercultural health”, they are not included in the CPG, prenatal care activities, and the healthcare system.
- National and international efforts must seek to improve the quality of rapid tests, including those for the diagnosis of concurrent diseases (i.e. HIV, syphilis, and hepatitis B), as well as new technologies for the improvement of current confirmatory tests for syphilis that decrease potential false positive and false negative results, as well as specialised laboratory equipment and high costs. Alongside developments for diagnosis, it is important to direct

efforts toward penicillin availability to avoid potential shortage. In the long term, Colombia and other countries in Latin America and the Caribbean can make efforts to develop the necessary infrastructure for the production of rapid tests, confirmatory tests, and treatment (i.e. penicillin) to meet their needs. For instance, national and international agencies can incentivise these developments with funding from the Ministry of Science and Technology in Colombia.

- Since syphilis treatment and CS prevention can contribute to antimicrobial resistance, it is important to make a joint effort worldwide to address this issue alongside efforts for CS prevention. Investing more in *Treponema pallidum* research would be relevant, particularly regarding the gaps other than the well-known strain (Nicholls). This research can lead to the development of alternative treatment in case of potential resistance to penicillin and the development of a syphilis vaccine.
- Syphilis should also be included in case reports besides GS and CS, which would allow for identifying syphilis in the general population to provide more directed strategies for its prevention beyond prenatal care.
- The industry should be incentivised with the production of male and female condoms and dental dams (i.e. oral condoms) to facilitate their availability and reduce their costs.
- Several prevention practices can be conducted and accommodated to prevent STDs in Colombia and worldwide. It is important to address STD prevention overall rather than the focus on one disease at a time (i.e. HIV/AIDS).

#### *National and regional levels*

- Following the international landscape regarding the increase of syphilis cases, antimicrobial resistance and the reforms to the healthcare system in Colombia,<sup>27</sup> it is necessary to update the CPG. Moreover, since the ETMI Plus strategy proposed by the PAHO is going to be implemented in Colombia, it is

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<sup>27</sup> Until now (February 2024), Bill 339 of 2023 is still being discussed in Congress for its approval. Some significant changes refer to the functioning of the EPS (healthcare administrator), how resources are allocated and administrative measures, particularly for rural, isolated areas.



relevant to review that legal, administrative, and financial resources respond to its requirements and that the current CPG laws and decrees related to prenatal care and mother-to-child transmission (e.g. HIV, syphilis, Chagas, and hepatitis B) are in tune.

- Reforms to the healthcare system in Colombia should account for what is needed for the CPG, particularly CS prevention, without ignoring intercultural health principles and practices.
- Negotiations and accommodations with other care practices should also include representatives of relevant religions since these also afford relevant care practices regarding sex education, STD prevention, and prenatal care.
- The necessary coordination of practices for CS prevention also concerns the healthcare system. The inclusion of traditional medicine and *parteras* plays an important role here, along with informational, administrative, and managerial measures necessary to adapt to the high mobility of the Colombian population (among municipalities and *departamentos*) and between healthcare types of insurance (i.e. subsidiary and contributive).
- Regarding the high mobility of the population, it is essential to consider how migrants (internally displaced from the armed conflict and international migrants) are also integrated into the healthcare system related to prenatal care in general and for CS and other prenatally transmitted diseases specifically. Further, we need to pay more attention to how legal, administrative, and financial barriers are negotiated, particularly by pregnant women during prenatal care, which needs to be better accommodated.
- The Ministry of Health should enforce the EPS (i.e. the healthcare service administrator) to include contracts that provide syphilis treatment to pregnant women and their sexual contacts, even if they do not belong to the same EPS.
- Since the provision of penicillin in a primary care setting due to potential adverse reactions is a concern, more clarity on how to proceed in these cases and the necessary training, equipment, and administrative/legal measures should be implemented.
- The fragmentation of healthcare service provision was identified as a difficulty in the present study, as elsewhere (Gamboa *et al.*, 2023; Potes *et al.*, 2017).

It is fundamental to reduce this fragmentation, including the number of authorisations and times for service provision, particularly regarding syphilis diagnosis and treatment.

#### *National and local levels*

- Adequate infrastructure with administrative and financial resources should be implemented to provide same-day syphilis treatment at the point of care. Better communication between healthcare practitioners, administrators, and lab staff should also be included. It is a common practice in the regions under study for pregnant women to receive all lab test results for the next prenatal care appointment. Pregnant women should start syphilis treatment as soon as the results are available.
- Syphilis screening and treatment must be promoted beyond prenatal care and high-risk populations. Screening and treatment of the general population must include men and women while attending to the emergency room and extramural activities.
- More information is needed to clarify syphilis reinfection in the general population, particularly among pregnant women. This information will lead to a better comprehension of the phenomena (i.e. syphilis cases and potential antimicrobial resistance) and identify better-directed prevention strategies.
- Alongside the improvement and availability of rapid tests, it is important to review the necessity of the recommendations made by the WHO for the syndromic management of sexually transmitted infections.
- The integration and interoperability of information systems must allow access to the data of medical records, lab results, health insurance affiliation, and epidemiologic surveillance in a timely manner from primary to third-level health services while limiting the barriers currently present between municipalities, regions, and healthcare insurances. It is important to address system integration and accountability difficulties, particularly in places with resource scarcity, including difficulties with internet access and electricity. The use of tablets or mobile phone apps that can store information and upload it when connected to WiFi can help in this regard.

- It is imperative to provide sex education in tune with cultural differences that address silence, shame, and stigmas around sex and STDs. This education should focus on contraceptive methods, STD prevention, sexuality, sexual and reproductive rights, bodies, pleasure and desire, and the use of condoms and sex toys. This education should be offered to students at schools and healthcare practitioners. It also can be delivered in workshops and talks at fairs, carnivals, and other extramural activities. Artists, community associations, and NGOs can also collaborate in this regard.
- Following the previous recommendation, more research on sex education must be conducted concerning sexual and reproductive rights that consider cultural differences (e.g. Indigenous and Afro-descendant) and that deal with sexual practices beyond heterosexuality for the prevention of CS and other STDs.
- More information and advice should be provided during prenatal care and psycho-prophylaxis courses about sex during pregnancy, contraceptive methods, safe sex, the use of condoms (i.e. female, masculine, and oral dams), and sex toys.
- Contextual characteristics in some areas of Colombia should be clarified where few to no CS cases constitute *silencio epidemiológico* [epidemiological silence]. Relevant information about these situations can help better accommodate syphilis case management and CS prevention overall.

*Practical recommendations during a pandemic*

- Following the experiences of many women in Colombia (including some research participants), the availability and access to contraceptive methods should also be a priority during a pandemic.
- Although considerable resources must be dedicated to mitigating a pandemic, it is important to continue providing services, monitoring, and surveillance of prenatal care and pregnant women. Lack of adequate healthcare service provision, as well as fear of attending hospitals, increases maternal mortality and CS cases.
- Information and communication technologies can help to provide information, guidance, and advice to pregnant women, particularly first-time mothers.

These technologies can also help to complete administrative tasks regarding service authorisations, test results, and medical records.

Overall, the healthcare system must have better coordination of activities for syphilis and CS diagnosis, treatment, and surveillance.

The following section indicates several avenues for future research.

#### Future research

Possible areas for further research can be divided into two types: those related to disease prevention and CS and those related to my theoretical and methodological contributions. Regarding the latter, I would be keen to further explore the “care assemblages” framework, notably the “online assemblage”, which implicates constant negotiations of trust and expertise. This research is vital as increasingly more people engage with information offline and online for disease prevention, derive treatments, and identify and implement practices that make care assemblages more complex and multidirectional than ever. In this study, I suggested preliminary ways in which trust, expertise, and care assemblages could intersect. Therefore, future research could examine these across a range of case studies.

In Colombia, Law 350 of 2020 establishes traditional midwifery as a part of Colombia’s heritage and identifies the need to promote actions to protect and preserve traditional knowledge. This law is echoed by Law 2244 in 2022, which promotes humanised childbirth. These laws can implicate more dialogue between biomedicine and traditional medicine/*parteras*, as well as the coordination of practices for disease prevention, particularly those related to pregnancy/childbirth and CS. This potential for integrating diverse knowledge and practices seems like a particularly fruitful field of further research.

Another related avenue for further research is the methodological possibilities of OAFGs, including online/offline interactions, as well as the examination of hybrid methods (online/offline). Such a methodological development might be more sensitive to the fluidity and mobility of practices and interactions. Similarly, it would

be relevant to explore the possibilities of multimodal data (e.g. emojis, stickers, songs, links, voice messages, and links) beyond a linguistic analysis, for instance, how race and ethnicity are enacted in the hybridity of offline and online interactions, and how those interactions configure particularities for practices during prenatal care and CS prevention. Again, the thesis explored these new possibilities in this context, so further research in other case studies would solidify and expand their potential.

While considering future research on disease prevention, especially CS prevention, it is relevant to focus on more than heteronormative sex practices, as well as on how gender enactments also configure particular ways for STDs and CS prevention. More research is needed in this regard.

Furthermore, disseminating the research is important, particularly since one of the ultimate aims is to provide good care regarding prenatal care and CS prevention. Developing research using participatory research principles that incorporate art (e.g. music, performance, animation, and paintings) created by artists and stakeholders to express and disseminate the research results would be relevant. Therefore, research dissemination products would not rely heavily on text, which is usually conceived from a one-way perspective (i.e. the researcher's). Incorporating art in participatory contexts can introduce multivocality, diverse languages, mediators, and materials to blur boundaries and distinctions among stakeholders' expertise. Furthermore, these art objects could open up the dialogue about intellectual extractivist allegations (Grosfoguel, 2016), due to which some communities are reluctant to participate in research.

Furthermore, regarding future research on disease prevention, CS prevention in particular, several measures about to be implemented in Colombia will change several elements discussed in this thesis, which implies ongoing adaptations at the local and national levels. First, the current government, led by Gustavo Petro, is seeking approval to reform the healthcare system. Especially relevant for CS prevention are changes in the EPS (i.e. the healthcare services administrator) regarding how the resources are administered and the prioritisation of healthcare services provision in rural areas, particularly those more isolated. Second, the institution and implementation of the ETMI Plus strategy (Pan American Health

Organization, 2017) aims to stop the transmission of mother-to-child HIV, syphilis, hepatitis B, and Chagas. This focus incorporates similar principles to those of the CPG for CS. However, it acknowledges that disease prevention of these diseases implicates practices that go beyond prenatal care to encompass full life cycles. It would be relevant to research differences in implementing this strategy across the regions in Colombia, as well as how prevention and care practices regarding certain diseases (e.g. HIV) might clash and “interfere” or coordinate with others.

At the international and national levels, it would not be possible to elucidate CS prevention without addressing its connections to antimicrobial resistance. Having more *Treponema pallidum* resistant to penicillin, which is the recommended treatment for syphilis (particularly for CS prevention according to the CPG), will further complicate its prevention. Furthermore, with more high-income countries such as the United States or Australia, new updates to the CPG could appear and point to other practices and accommodations. Along those lines, developing a syphilis vaccine would have major implications for CS prevention. Several scientists have indicated the necessity of adapting the syphilis vaccine in the context of dynamics present in HIV; for instance, the effectiveness of the syphilis vaccine can be affected in cases of coinfection (HIV/syphilis; Avila-Nieto *et al.*, 2023; Cameron, 2018).

Another avenue for further study is how syphilis and CS prevention are integrated into pandemic preparedness plans within two scenarios: (1) when the pandemic is caused by a pathogen (respiratory or vector-borne) and (2) sexual transmission of the pathogen. After the COVID-19 pandemic, it has been evident that other diseases cannot be disregarded while directing much of the resources and attention to the pandemic.

Ultimately, future research into disease prevention should focus more on practices rather than on behavioural changes to provide more knowledge about ways to prevent diseases. This research should acknowledge more than scientific and expert ontologies, temporalities, and trajectories, which is highly important in multicultural contexts, as in this study, and in other contexts where controversies over scientific

knowledge (particularly over emergent diseases) and diverse enactments of trust also play an essential role.

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## APPENDIX (Ethical Approval 2020)

### COLLEGE OF SOCIAL SCIENCES AND INTERNATIONAL STUDIES

All staff and students within SSIS should use this form; those in Egenis, the Institute for Arab and Islamic Studies, Law, Politics, the Strategy & Security Institute, and Sociology, Philosophy, Anthropology should return it to [ssis-ethics@exeter.ac.uk](mailto:ssis-ethics@exeter.ac.uk). Staff and students in the Graduate School of Education should use [ssis-gseethics@exeter.ac.uk](mailto:ssis-gseethics@exeter.ac.uk).

**Before completing this form please read the Guidance document**

which can be found at <http://intranet.exeter.ac.uk/socialsciences/ethics/>

Applicant details		
Name	Ana Lucia Estrada Jaramillo	
Department	Sociology, Philosophy and Anthropology	
UoE email address	Ae399@exeter.ac.uk	
Duration for which permission is required		
Please check the meeting dates and decision information online before completing this form; your start date should be at least one month after the Committee meeting date at which your application will be considered. You should request approval for the entire period of your research activity. Students should use the anticipated date of completion of their course as the end date of their work. Please note that <u>retrospective ethical approval will never be given.</u>		
Start date:16/11/2020	End date:22/09/2023	Date submitted:31/10/2020
Students only		
All students must discuss (face to face or via email) their research intentions with their supervisor/tutor prior to submitting an application for ethical approval. <b>Your application <u>must</u> be approved by your first or second supervisor (or dissertation supervisor/tutor) prior to submission and you <u>MUST</u> submit evidence of their approval with your application, e.g. a copy of an email stating their approval.</b>		
Student number	620028015	

Programme of study	<b>Doctor of Philosophy (PhD)</b> If you selected 'other' from the list above please name your programme here
Name of Supervisor(s) or Dissertation Tutor	<b>Mike Michael</b>
Have you attended any ethics training that is available to students?	Yes, I have taken part in ethics training at the University of Exeter EG the Research Integrity Ethics and Governance: <a href="http://as.exeter.ac.uk/rdp/postgraduateresearchers">http://as.exeter.ac.uk/rdp/postgraduateresearchers</a> OR Ethics training received on Masters courses. If yes, please specify and give the date of the training: <b>Research Integrity Ethics and Governance</b> 25/10/2019

### **Certification for all submissions**

**I hereby certify that I will abide by the details given in this application and that I undertake in my research to respect the dignity and privacy of those participating in this research.**

I confirm that if my research should change significantly I will seek advice, request approval of an amendment or complete a new ethics proposal. Any document translations used have been provided by a competent person with no significant changes to the original meaning.

**Ana Lucia Estrada Jaramillo**

Double click this box to confirm certification ☒

**☒ I confirm that if I travel outside the UK to conduct research I will:**

- (a) Obtain [International Travel Insurance](#) from the University of Exeter.
- (b) Monitor Travel Advice from [Worldaware](#) and the [Foreign & Commonwealth Office \(FCO\)](#) and (c) Complete an [International Travel Risk Assessment](#)

*Submission of this ethics proposal form confirms your acceptance of the above.*

## TITLE OF YOUR PROJECT

*The Logics of Care in Congenital Syphilis in Western Colombia*

## ETHICAL REVIEW BY AN EXTERNAL COMMITTEE

No, my research is not funded by, or doesn't use data from, either the NHS or Ministry of Defence.

If you selected yes from the list above you should apply for ethics approval from the appropriate organisation (the NHS Health Research Authority or the Ministry of Defence Research Ethics Committee). You do not need to complete this form, but you must inform the [Ethics Secretary](#) of your project and your submission to an external committee.

## MENTAL CAPACITY ACT 2005

No, my project does not involve participants aged 16 or over who are unable to give informed consent (e.g. people with learning disabilities)

If you selected yes from the list above you should apply for ethics approval from the NHS Health Research Authority. You do not need to complete this form, but you must inform the [Ethics Secretary](#) of your project and your submission to an external committee.

## SYNOPSIS OF THE RESEARCH PROJECT

*Maximum of 750 words.*

Syphilis is a Sexually Transmitted Disease caused by the Treponema Pallidum bacteria. Congenital syphilis is considered as a preventable disease since the transmission from mother to child can be avoided if the treatment is provided to the pregnant women and her sexual contacts, a caesarean procedure is accomplished, and the child is not breastfeeding.

From 2014 the Colombian Government started to develop Clinical Practice Guidelines (CPG) to prevent mother-to-child syphilis transmission. These guidelines instituted several changes to the procedures that had been previously in place.

According to the Ministry of Health, the Guidelines would contribute to a reduction in mother-to-child syphilis transmission. However, the results have not met these expectations. Colombia has passed from 0.94 cases of congenital syphilis per 1000 new-borns in 1998 to 1.93 per 1000 new-borns in 2017 (Instituto Nacional de Salud, 2018)<sup>28</sup>.

The National Institute of Health (INS) has highlighted in the last reports that the deficiencies, while providing prenatal care as well as the limited amount of partners that receive treatment, are among the reasons for the lack of control of congenital syphilis in Colombia.

Therefore it is important to know what happens during the implementation of the CPG while providing prenatal care in healthcare centres.

After the declaration of the Coronavirus pandemic, the Ministry of Health has started a raft of recommendations in order for healthcare workers to conduct the prenatal care sessions including virtual assistance during pregnancy, virtual prenatal care sessions, self-isolation of pregnant women with symptoms, avoidance of caesarean sections and ultrasounds (Ministerio de Salud y Protección Social, 2020)<sup>29</sup>. There are no clear indications of how and under which circumstances routine screenings (for syphilis) will be conducted during prenatal care sessions.

According to the National Department of Statistics in Colombia (DANE), only 52.7% of households have Internet access and 72% have mobile phones. These percentages are uneven in most regions and particularly in rural areas, where the problem is also electricity (DANE, 2019)<sup>30</sup>.

There are many controversies surrounding the prevention of CS at prenatal care settings in a multicultural contexts, like those in Western Colombia (Valle del Cauca, Caldas and Chocó). Among these controversies are the definition of the CS case, the use of a Rapid Syphilis Test, the management of false positive results, the provision of same-day treatment, the use of penicillin in a primary care setting, the disclosure of the diagnosis to pregnant women and their partners, the allowing of access to the primary care setting, and the provision of adequate sex education.

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<sup>28</sup> Instituto Nacional de Salud (2018) Sífilis Gestacional y Congénita 2018, Protocolo de Vigilancia en Salud Pública.

<sup>29</sup> Ministerio de Salud y Protección social, R. de C. (2020) Lineamientos provisionales para la atención en salud de las gestantes, recién nacidos y para la lactancia materna, en el contexto de la pandemia de COVID-19 en Colombia

<sup>30</sup> DANE (2019) Boletín Técnico Indicadores básicos de tenencia y uso de Tecnologías.

These controversies may indicate that more information over the CPG is not enough for actors to follow them, since the CPG requires local adaptations as well as an acknowledgment of different ontologies (realities) in a multicultural primary care setting.

In the regions under study, afro - descendants, indigenous, rural migrants, poor, displaced people and international migrants look for health care services. The CPG as the standard for best practice during prenatal care do not recognize the knowledge and experiences of pregnant women and their communities, nor the knowledge and experiences from other health care workers (for example physicians, nurses, health administrators) in charge of prenatal care at the local level.

Following the current circumstances, it is good to ask how the Clinical Practice Guidelines will be adapted according to the current situation of the pandemic and the lockdown restrictions. How will prenatal care be conducted under limited Internet and mobile phone access? How will ICT play a role while providing care for pregnant women and congenital syphilis prevention and control? In areas where midwives provide assistance during birth, how will the prenatal care be conducted? Ultimately, how will Coronavirus impact congenital syphilis prevention and control?

How then can good care be provided during prenatal care in Western Colombia, while preventing the occurrence of Congenital Syphilis? What is good care and how can it be provided, acknowledging different ontologies?

This research intends to make a contribution as to how to provide good care in a prenatal care setting while acknowledging more than 'expert' and 'scientific' ontologies.

### **Research Questions**

What is good care and how can this be achieved during prenatal care for the prevention of Congenital Syphilis according to the ontologies of different actants in two sites of study in Western Colombia?

Research question 1a: How are the logic of choice and the logic of care enacted during prenatal care in two sites of study in Western Colombia?

Research question 1b: What are the tools and practices that actants use in this context during virtual prenatal care sessions?

Research question 1c: How is risk embodied while preventing Congenital Syphilis in the two sites of study?

## INTERNATIONAL RESEARCH

This research will be conducted in Colombia following the Colombian regulations (Colombian Constitution, Colombian law for Data Protection 1581 from 2012), and the GDPR. Since the Colombian law for Data Protection was made following the GDPR, the indications made under the GDPR will be followed.

The regions for the research will be Caldas and Chocó. These regions have shown many cases of Congenital Syphilis and have multicultural populations. According to the Secretaries of Health of those regions, there is no need to obtain Ethics Approval from the Secretaries of Health under study. It is enough for them to have approval from the Ethics Committee of the University.

The following sections require an assessment of possible ethical consideration in your research project. If particular sections do not seem relevant to your project please indicate this and clarify why.

## RESEARCH METHODS

This research will involve document analysis as well as Internet-mediated methodologies.

1. **Document analysis.** Scientific articles, grey literature, reports and prevention campaigns produce by healthcare workers, healthcare administrators and public health authorities since 2014 will be analysed. The analysis will indicate how prenatal care sessions have been adapted to the current pandemic and how congenital syphilis is prevented. The documents will be accessed on the web as well as obtained through the Health Secretaries.
2. **Pregnant women´s diaries.** At least three pregnant women will share their thoughts and feelings during the process of pregnancy, prenatal care and the birth of their child through diaries. They will be encouraged to share images, audio voice messages, links and messages on WhatsApp that they consider essential to understanding their experiences. For those who do not have access to a mobile phone or prefer to do the diary handwritten for personal or security reasons, there will be the possibility of

completing the diary and sending it to the researcher. Special security measures will be taken to maintain anonymity and privacy. Please read the sections devoted to Assessment of Possible Harm and Data Protection and Storage.

Procedure: I will transcribe handwritten diaries. The diaries will be kept securely for the duration of the research and destroyed afterwards, unless the participants want them back.

- 3. Semi-structured interviews with health workers, health care administrators and scientists.** No less than 10 health care administrators and 20 health care workers will be interviewed online through Skype for Business, WhatsApp or mobile phones. Only if the participants agree, will the interviews be recorded for analysis; otherwise, notes will be taken during the interview. The conversation will take 40 minutes at most. In these interviews, participants will be asked how congenital syphilis has been prevented before and during the Coronavirus Pandemic, as well as what it means for them to perform good care and how the prevention can be improved.

Procedure: If agreed by the participants, the interviews will be recorded, and I will make transcriptions.

- 4. Semi-structured interviews with pregnant women and their sexual contacts.** A minimum of 20 pregnant women will be interviewed online through WhatsApp or mobile phones. The interviews will be recorded only with the agreement of the interviewees; otherwise, notes will be taken during the interview. They will be asked about their experiences and thoughts on their pregnancy (related to congenital syphilis prevention), prenatal care and what good care means for them. It is fundamental for this research to know what should be done differently during prenatal care and how it should be improved.

Procedure: If agreed by the participants, the interviews will be recorded, and I will make transcriptions.

- 5. Focus groups with pregnant women and their sexual contacts.** At least three asynchronous focus groups will be conducted through WhatsApp for Business (two with pregnant women and one with their partners) to identify similarities and differences between their experiences, allowing participants to express their thoughts without social compliance.



These focus groups will each be held for three days with participation from four to six participants.

### **Characteristics of the Sample**

The Secretary of Health<sup>31</sup> and the Coordinators of prenatal care programs will send letters of recruitment, information sheets and informed consents to potential participants. Those potential participants will contact me. Snowball sampling, as well as maximum variation sampling, will be considered in order to ensure variation among participants. Those potential participants will share the recruitment letter to their partners, relatives, pregnant women or health care professionals.

**All the participants will be above 18 years.**

#### *Inclusion criteria Health Care administrators*

- Administrative staff from the Ministry of Health, the Secretaries of Health, EPS<sup>32</sup> and IPS<sup>33</sup> at the local and national level.

#### *Inclusion criteria Health Care workers - Scientists*

- Health care workers who work in prenatal care, help attend births or attend to new-borns in the public and private health care providers.
- Scientists and/or researchers - consultants whose work focus on syphilis, gestational – congenital syphilis and/or prenatal care.

#### *Inclusion criteria Pregnant women – women who have given birth*

- Pregnant women (**above 18 years**) with a minimum of eight weeks of pregnancy or that have given birth during the last four months. Giving birth as well as the first weeks of new-borns are crucial moments for congenital syphilis prevention; however, these women will be not contacted during

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<sup>31</sup> The Secretaries of Health are responsible for the execution of public health policies and the improvement of health in the regions and municipalities. It is not fully autonomous because it has to follow the guidelines from the Ministry of Health.

<sup>32</sup> EPS (Entidad Promotora de Salud) is the entity in charge of the administration and payment for the health care services.

<sup>33</sup> The EPS have contracts with IPS (Health Care services Institution's Providers) hospitals, clinics, laboratories.

the first weeks after giving birth because those are stressful and difficult moments for the mothers.

- Women (pregnant or having given birth in the previous four months) that live or have prenatal care in the region under study.
- Women that are not planning to make a voluntary interruption of pregnancy under the circumstances stated by the Colombian Law. Besides the psychological stress and discomfort, the research focuses on analysing prenatal care.
- Women whose pregnancy is not the result of sexual assault. It would be stressful and painful for a woman to take part in this research under these circumstances.

*Inclusion criteria sexual contacts – partners of pregnant women*

- Men/women partners – sexual contacts (**above 18 years**) of a pregnant woman or a woman who has given birth during the last four months that meet the inclusion criteria mentioned above.

*Inclusion criteria relatives of pregnant women*

- Relatives **over 18 years** of a pregnant woman or a woman who has given birth during the last four months that meet the inclusion criteria mentioned before.
- Relatives (**over 18 years**) who have accompanied and supported the pregnant women during the pregnancy, prenatal care and/or while giving birth.

In the section of the voluntary nature of participation, there is more information clarifying the recruitment.

**Expected Outputs**

- Thesis.
- Conference – seminars and presentations.
- Journal articles.

- The socialisation of findings with e.g. MinCiencias, Secretaries of Health, health care practitioners, pregnant women and their partners.

### **Discussion of sensitive topics**

This research involves a Sexually Transmitted Disease, therefore it is likely that during the interviews, focus groups or diaries, participants talk about sex, intimacy, relationships, pregnancy, their health and the health of their new-borns. **Conversations over other STD and HIV might appear due to the reference of some participants, however, I would not go deep into that information since it is beyond the focus of this research. I would refer participants to people in charge of prenatal care if during the interviews some participants need to discuss further with an expert in order to obtain assistance.**

Please refer to the section on Assessment of Possible Harm to see how I intend to minimise potential harm to participants.

## **PARTICIPANTS**

I will interview at least 10 health administrators and 20 health care workers – researchers who work in Colombia. I would not offer any incentive to these participants.

I will interview 10 partners – sexual contacts/relatives of the pregnant women and 20 pregnant women or women who have given birth during the last four months. I will provide a £3 voucher to each participant as an incentive.

To those women who participate in the WhatsApp diary, I will give a £5 voucher as an incentive, as well as £5 to top up their mobile phones. If the woman who participates writes the diary by hand, I will give the £5 voucher incentive and provide the payment for them to send the diary through a certified courier.

I will give a £5 voucher to each participant in the focus group as an incentive. Each participant of the focus group will be provided with a Pay as you Go Sim

card to use WhatsApp for Business to comply with pseudonymisation and security reasons. They can keep the Sim Card after the focus group finishes.

## THE VOLUNTARY NATURE OF PARTICIPATION

The participants will be recruited through either the information provided by the Secretaries of Health or some participants' referral. I will provide a recruitment letter for the Secretaries to send to pregnant women or those who have given birth, as well as to health workers and administrators. Pregnant women will also send the recruitment letter to their relatives and partners.

I am not going to ask to the Secretaries of Health information over pregnant women's diagnosis. This will be information that might appear while doing the interviews, focus groups or diaries.

I would specify to participants that even though I sent the invitation through the Secretary of Health, I am not related to the Secretary, and their participation in the study does not affect in any way the provision of health care services. They will be able to **withdraw from the research at any time until November 2022**, and that would not have consequences for them or their health care services since their participation is voluntary.

The information from the interviews, diaries and focus groups will be pseudoanonymised and confidentially will be secured.

I will obtain informed consents from the participants (electronic consent from health care workers and administrators) and oral consent from pregnant women, partners and relatives. **I will reconfirm consent whenever an interview or focus group commences or re-commences. I will record their consent through a voice or text message.** Please see those consents as well as the script for oral consent in the attachments.

I will always use my University email account for sending emails and a mobile number dedicated only to this research to secure confidentiality and to distinguish my academic life from my personal life.

## SPECIAL ARRANGEMENTS

There are no special arrangements since there will not be participants with special needs.

## THE INFORMED NATURE OF PARTICIPATION

A recruitment letter will be send alongside with an information sheet and informed consent. Those documents will be sent through email, WhatsApp, or text messages to potential participants clarifying the purpose of the research and emphasizing the voluntary nature of participation. At any stage of the interviews, focus groups or diaries, the participants can ask questions that I would answer. They can **withdraw from the research at any point until November 2022**, and that would not have consequences for them or their health care services. If they withdraw from the research, all their information will be deleted. Please find attached the recruitment letter, the information sheet, the scripts for obtain verbal consent, and consent forms for each type of participant in Spanish as well as in English.

## ASSESSMENT OF POSSIBLE HARM

### **Interviews with health care workers, health care administrators and researchers**

There is a risk of potential identification of individuals after using an alias; therefore, any identifying details will also be removed. Special attention will be paid to not disclose information to other participants that might identify any participants and affect their professional reputation. While sharing the results from the research all the information will be pseudoanonymized to secure confidentiality.

It will be made clear from the beginning that they can avoid answering any question they do not feel comfortable with. It will also be possible to stop the interview and **withdraw from the research at any time until November 2022** without consequences for them. **If a participant experiences distress during the interview, I will stop the interview and comfort him/her. I will finish the interview by talking about pleasant topics so the participant do not remain focused on distress.**

### **Interviews with pregnant women or women who gave birth during the last four months**

Confidentiality will be secure for all the participants. While sharing the results from the research, all the data will be pseudoanonymized. Each participant will have a code word prior to the interview that will be used to verify the identity of the caller.

Some participants may find it stressful talking about pregnancy, giving birth, sex, relationships, and health conditions. Therefore, it will be made clear from the beginning that they can avoid answering any question they do not feel comfortable with. It will also be possible to stop the interview and **withdraw from the research at any until November 2022** time without consequences for them. If a participant experiences distress during the interview, **I will stop the interview and comfort her. I will finish the interview by talking about pleasant topics so the participant do not remain focused on distress. I will refer participants to prenatal care providers in case a stressful topic or questions appear in order for them to obtain assistance and advice.**

During the lockdown of the Coronavirus pandemic, some women are not comfortable discussing specific topics at home. Those women would have the chance of taking the interview by text messages or audio messages at their own pace. They will be advised to delete the messages after sending them as well as to not back up their WhatsApp accounts for the duration of the research.

#### **Interviews with sexual contacts – partners and relatives**

Confidentiality will be secure for all the participants. While sharing the results from the research, all the data will be pseudoanonymized. Each participant will have a code word prior to the interview that will be used to verify the identity of the caller.

Some participants may find it stressful talking about pregnancy, giving birth, sex, relationships, and health conditions. Therefore, it would be clear from the beginning that they can avoid answering any question they do not feel comfortable with. It will also be possible to stop the interview and **withdraw from the research at any time until November 2022** without consequences for them. **If a participant experiences distress during the interview, I will stop the interview and comfort him/her. I will finish the interview by talking about pleasant topics so the participant do not remain focused on distress. I will refer participants to health care providers in case a stressful topic or questions appear in order for them to obtain assistance and advice.** During the lockdown of the Coronavirus pandemic, some participants are not comfortable discussing specific topics at home. Those participants would have the chance of taking the interview by text messages or audio messages at their own pace. They will be advised to delete the messages after sending them as well as to not back up their WhatsApp accounts for the duration of the research.

### **Pregnant women's diaries**

All the information will be pseudoanonymised since all women will be given an alias and any potential identification of individuals will be removed.

Women who keep their diaries through WhatsApp will be advised to delete the messages after sending them as well as to not back up their WhatsApp accounts for the duration of the research. Those who handwrite their diaries will be encouraged to keep these in a secure space and send them through a certified courier with an alias in which the sender's address will be the post office. I will use a post office box to receive the diaries instead of my home address. Special data protection measures will be taken for the diaries. Please refer to the Data Protection and Storage section.

All the participants will be reminded that they may stop writing the diary at any point and **withdraw from the research if they want to until November 2022** without any consequences for them. If that is the case, all the electronic and paper material will be destroyed.

**Writing a diary might trigger emotions in the participants; I will check on participants how the process of writing the diary is going to identify distress. If distress happens, they be referred to prenatal care providers in order for pregnant women to have advice and assistance.**

### **Focus groups participants**

All focus group participants will be provided with a Pay as you Go Sim card to use WhatsApp for Business to preserve confidentiality. They will have an alias instead of their name and be told not to use a picture of themselves as a profile picture. Each participant will have a code word prior to the focus group that will be used to verify the identity of the participant. They will be reminded not to share information as their real name, personal information or information from the focus groups with anyone as well as to delete the messages after staying for the duration of the focus group (3 days). Participants will be advised not back up their WhatsApp accounts for the duration of the research. At the beginning of the focus group, all participants will be informed of its purpose, how it works, as well as reminders for the respect of other participants. Information not related to the aim of the focus group is not allowed to be shared and participants will be reminded to do so. They can **withdraw from the focus group at any time and from the research until November 2022** without consequences for themselves or their partners in terms of health care services.

**If participants feel stress or discomfort during the focus groups, the researcher will contact these participants through private messages to calm them down and if necessary, refer them to health care providers in order to have advice and assistance.**

Confidentiality will be secured for all the participants. Any information shared from the research will be pseudoanonymized as well as any identifying detail will be removed.

**If needed, some participants will be referred to well-being services as well as help lines for health care services provision rights such as Supersalud. Supersalud is the governmental institution dedicated to health care rights affiliated to the Ministry of Health in Colombia.**

- **Well-being helpline 106 or 123**
- **Health care rights [www.supersalud.gov.co](http://www.supersalud.gov.co) Help Line: 018000 513 700**

#### **Possible risk for the researcher**

A Sim card dedicated only for this research will be used by the researcher to make phone calls and use WhatsApp for Business. The Sim card will no longer be used at the end of fieldwork. The University email address will be provided for further contact in case participants need or want to stay in touch. I will use a post office box to receive the diaries instead of my home address.

The use of the University email account, the Sim card dedicated for the research, as well as the post office box allow to distinguish between my personal and my work as a researcher.

**Some issues that participants might want to discuss are beyond the scope of this research and my expertise. If needed, I will refer participants to the health care and prenatal care providers in order for participants to obtain advice and orientation.**

**Some information retrieved by the interviews, focus groups and/or diaries might trigger emotional discomfort. If that is the case, I will look for counselling with well – being services at the University.**



## DATA PROTECTION AND STORAGE

### Personal Data

This research intends to make a contribution as to how to provide good care in a prenatal care setting while preventing Congenital Syphilis. The **following personal and sensitive data will be collected to understand how the different experiences and perspectives have created practices over prenatal care that can be improved in order to prevent Congenital Syphilis.**

**Health care workers and administrators:** name, mobile number, profession, position, time in position, information about their experiences while providing prenatal care and preventing Congenital Syphilis.

**Pregnant women:** name, mobile number, age, week of pregnancy, number of pregnancies, result for syphilis test, syphilis treatment, race, ethnicity, type of health insurance. Information about their experiences during prenatal care and how can be improved for the prevention of Congenital Syphilis. Information over the result of syphilis test and treatment will be collected only if the participant mention while conducting the research techniques.

**Partners – sexual contacts or relatives of pregnant women:** name, mobile number, age, result for syphilis test, syphilis treatment, race, ethnicity, type of health insurance. Information about their experiences and support during prenatal care and how can be improved for the prevention of Congenital Syphilis. Information over the result of syphilis test and treatment will be collected only if the participant mention while conducting the research techniques.

Clarification over the type of data, the reasons for obtain the information, the pseudonomysation, the retention period, and the withdraw from the research will be stated on the Information Sheets, Scripts and Informed Consents.

### Contact Details and Personal information

The Secretary of Health and the Coordinators of prenatal care programs will send a recruitment letter to potential participants and they will contact me. **Although it is important for this research to know if a pregnant woman has or had a positive Syphilis result, I wold not ask the Coordinators of prenatal care programs for this information. Instead, I will allow each participant to share this information with me if that emerges while doing the interviews.**

Other potential participants will be referred by some participants that will receive the recruitment letter, the information sheet and consent form. As soon as I receive the information from potential participants, I will create the **alias of those potential participants in a protect file with a password that I will upload into**

**the University One Drive into a separate folder to other research data.** The received email, text or WhatsApp message will be delete immediately after writing the information on the secure file.

The contact details from the participants as well as the protect file with the **alias will be kept securely for the duration of the research and then destroyed.** The contact details from the non-participants will be deleted immediately after their refusing to take part in the research, those who withdraw from the research included.

### **Interviews**

Each participant will have an **alias** instead of their real name. Only those interviews in which the interviewees agree to be recorded will be transcribed by me and the files uploaded to the One drive. As soon the transcription files are in the One Drive, the recordings will be deleted.

If the interviewees do not agree to be recorded, notes during the interview will be taken in a notebook which will be stored in a cash box with a key that I keep securely at home. After the transcription of these notes is uploaded onto the One drive, the notebook will be destroyed.

Contact details will be kept securely for five years and then destroyed. The transcriptions and notes from the interviews will be deleted after the research have finished. All the electronic files will have a password for access the information. If a participant do not want to be part of the research anymore, data from the interview will be deleted.

### **Diaries**

Each participant will have an **alias** instead of their real name. For the diaries through WhatsApp, participants will be advised to delete the messages after sending them as well as not back up their WhatsApp accounts for the duration of the research. As soon as I receive the messages, I will collect them into a Word file secure with a password and uploaded into the One Drive. As soon as the messages are in the electronic file, I will delete the messages from the chat.

For the handwritten diaries, the participants will be advised to keep their diaries in a safe place until they can send it through a certified courier. **The sender's name will be an alias, and the sender's address will be the address from the post office.** I will use a post office box to receive the diaries instead of my home address.

As soon as I get the diaries, I will keep them in a cash box with a key that I keep securely at home. After transcribing the files into a Word file with a password, and uploading the data to the One Drive for Business, I will destroy the diaries. The electronic records with the information from the diaries (from WhatsApp and handwritten) will be destroyed after finishing the research. The information provided by a participant that withdraw from the research will be destroyed.

### **Focus Groups**

Each participant will have an **alias** instead of their real name. While the duration of the focus group, the messages on the WhatsApp group will be put into a Word file with a password that will be uploaded to the One drive. After uploading the word file all the messages of the focus group will be deleted. The participants will be advised to delete the messages as well as not back up their WhatsApp accounts for the duration of the research. The WhatsApp group will be deleted as well. After finishing the research, all the files with the focus groups information will be deleted. If a participant want to withdraw from the research, his/her information will be deleted.

### **Documents - files provided by the Secretaries of Health**

The files provided by the Secretaries of Health (reports, statistics) that are not publicly available will be **pseudoanonymized** if they contain personal or identifying information. Then, the files will have a password and will be uploaded to the One Drive for Business. Those files will be saved on the One drive and kept for further research.

All the devices used by the researcher will have a password encrypted.

## **DECLARATION OF INTERESTS**

My PhD is funded by the Ministry of Science, Technology and Innovation of Colombia (MinCiencias). **Even though the Ministry will provide resources to conduct this research, it does not mean personal and confidential information will be shared with the Ministry or the Health Secretaries.**

**Although the Secretary of Health will provide initial information and referral, I do not work with the Secretary. I will make a presentation of the**

**results to MinCiencias and the Secretary of Health but will not disclose personal and confidential information with them.** The Ministry and the Secretary of Health are two of many stakeholders with whom I would share the findings of my research.

**There will be a clarifying note about my funding, my relationship with the Secretary, and the objectives of this research on the information sheet.**

## **USER ENGAGEMENT AND FEEDBACK**

Due to the difficulties of reaching the participants, the review of oral transcripts from participants is not considered. However, transcriptions from the interviews or their messages on the focus group will be provided under the participant's request. Focus group's participants will have access only to their messages.

The key findings from the research will be shared to the Secretaries of Health, health care workers and administrators as well as other participants once the research has ended respecting confidentiality and anonymity principles. The information will be pseudoanonymized as well as any identifying detail will be removed.

## **INFORMATION SHEET**

Please find attached the information sheets for each type of participant (health care administrators and workers, pregnant women, partners and relatives), and research technique (interviews, focus groups, diaries). The information sheets are written in Spanish and English.

## **CONSENT FORM**

Most of the participants belong to ethnic groups (indigenous and Afro-Colombian) who have no trust in signing documents. Moreover, since scams are common in Colombia (there were 138 crime reports daily in 2019)<sup>34</sup>, there are a lot of people who do not trust signing documents or providing personal information by phone. This is the reason why verbal informed consent will be

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<sup>34</sup> According to the General Prosecutor's Office of Colombia (Fiscalía General de la Nación) <https://www.eltiempo.com/justicia/delitos/denuncias-por-estafa-en-colombia-411020>.

obtained for pregnant women, their partners and relatives. **I will record their consent through a voice message or text message.** Please find attached the script for verbal consent in Spanish and English according to each type of research technique (interviews, focus groups, and diaries).

Electronic informed consent will be obtained from health care workers, health care administrators and researchers. An electronic file with the information sheet with a button of “Agree” will be sent to participants to obtain consent. Please find attached this consent forms in Spanish and English.

## **SUBMISSION PROCEDURE**

Staff and students should follow the procedure below.

**Post Graduate Taught Students (Graduate School of Education):** Please submit your completed application to your first supervisor.

**All other students** should discuss their application with their supervisor(s) / dissertation tutor / tutor and gain their approval prior to submission. Students should submit evidence of approval with their application, e.g. a copy of the supervisors email approval.

**All staff** should submit their application to the appropriate email address below.

This application form and examples of your consent form, information sheet and translations of any documents which are not written in English should be submitted by email to the SSIS Ethics Secretary via one of the following email addresses:

[ssis-ethics@exeter.ac.uk](mailto:ssis-ethics@exeter.ac.uk) This email should be used by staff and students in Egenis, the Institute for Arab and Islamic Studies, Law, Politics, the Strategy & Security Institute, and Sociology, Philosophy, Anthropology.

[ssis-gseethics@exeter.ac.uk](mailto:ssis-gseethics@exeter.ac.uk) This email should be used by staff and students in the Graduate School of Education.

Please note that applicants will be required to submit a new application if ethics approval has not been granted within 1 year of first submission.