

UNIVERSITÀ DEGLI STUDI DI MILANO
Dipartimento di Scienze Sociali e Politiche
Graduate School in Social and Political Sciences (GSSPS)

**LANGUAGE, VIOLENCE AND STIGMA:
BARRIERS TO CARE FOR HIV-POSITIVE PREGNANT WOMEN IN THE
DOMINICAN REPUBLIC**

Doctoral programme in Political Studies (SPS/04)

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Academic year
2013/2014
XXVI cycle

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INTRODUCTION

The Regional Initiative for the Elimination of Mother-to-Child Transmission of HIV goal is to reduce the prevalence of HIV in the newborn population respectively to 2% by the year 2015. This Initiative is promoted by the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF). Governments from low and middle income countries have adopted and adapted the international directives of the Initiative to their national context in order to respond to international commitments, including the achievement of the Millennium Development Goals (MDGs) 5 and 6, related to maternal health and preventable diseases and infections, respectively.

Even though bio-medical innovations, mainly Anti Retroviral Drugs, and well-known best practices in public health implementation have made it feasible to prevent most of the Mother to Child transmission, approximately 2.5 million children worldwide are currently living with HIV and every day 1000 children are born with HIV (Marcos et al., 2012; UNAIDS, 2010).

In the Dominican Republic (DR), regardless a 98% coverage of antenatal services and institutional birth with skilled staff (MSP and UNICEF, 2011), there are lingering shortcomings that result in high maternal mortality and child mortality rates (150 per 100,000 and 36 per thousand, respectively) (UNICEF et al., 2013). If skilled attendance on birth is “the single most important factor in reducing maternal mortality” (WHO, 1999), how could anyone reconcile Dominican Republic’s quasi-universal skilled attendance with a maternal mortality rate that almost doubles the Latin American average? The answer to this paradox, according to UNDP, is the low quality and inequality of health care services (2010).

These systemic and institutional weaknesses also affect the Program for the Prevention of Mother to Child Transmission -PMTCT- where the current transmission rate has been estimated in 6% and the rate of full screening for HIV in pregnant women is only 19% (UNICEF, 2012). Consequently, the implementation of the PMTCT in Dominican Republic faces various challenges that range from the disempowerment and vulnerability of the target population (HIV positive pregnant women) to the weak incorporation of the initiative into mainstream prenatal care in order to avoid parallel programs (MSP and UNICEF, 2011).

Prevention of transmission from a HIV positive mother to her child requires the completion of a series of consecutive and necessary steps in a continuum of care, also known as the PMTCT cascade (Towle 2009, Marcos et al., 2012). One of the main problems identified in Low and Middle Income Countries (LMICs) is the poor retention and low adherence along this cascade. This phenomenon also called loss to follow-up (LFU) “has been recognized as a major hurdle by PMTCT programs in resource poor settings” (Panditrao et al., 2011). It affects 40% of women enrolled in India, up to 81% in Malawi, 84% in Cote d’Ivoire and more than 70% in South Africa and Zimbabwe (Panditrao et al., 2011; Manzi et al., 2005; Painter et al., 2004).

Given such high rates of non-adherence to the PMTCT Cascade, the effectiveness of these programs is eroded “not only because the objective of reducing pediatric HIV transmissions is compromised but also because of the missed opportunity to link HIV-infected women and their partners to further care and support activities”. (Panditrao et al., 2011). This programmatic failure is compounded by the lack of information and academic literature about the institutional or social mechanisms that trigger a higher or lower adherence level and the risk-factors that influence drop-out in PMTCT (Towle, 2009; Panditrao et al., 2011).

According to Horne “nonadherence is often a hidden problem: undisclosed by patients and unrecognised by prescribers” (2005). Notwithstanding massive advance in the evolution of health care services and in the presentation and design of medicine, adherence is still an unsolved problem and therefore the research question has been formulated to investigate:

Why are adherence and non-adherence triggered in the intended users of the Program for the reduction of mother to child transmission in the Dominican Republic?

In low and middle-income countries, where lack of appropriate data and information systems restrain longitudinal monitoring of patients and hinders systematic investigation, the study of adherence is often confined to epidemiological approaches, leaving the interaction between patient and the health system superficially addressed. Most of the existing literature focuses on the demand for HIV health services (patient behavior), ignoring supply (institutional arrangements and organizational culture). With regards to PMTCT, very few exploratory studies have discussed the social, economic and structural barriers and facilitators to full adherence in low and middle income countries (Towle, 2009; Painter et al., 2004; Castro and Farmer, 2005; Campbell, 2003; Parker, 2001; Trickett, 2005, 2004).

In order to analyze and unpack this phenomenon a Fuzzy Set Qualitative Comparative Analysis will be used to address the task of improving the understanding of PMTCT program, its mechanisms and the context in which adherence develops. Service level delivery will be analyzed using in depth interviews with 120 HIV positive women that attended the program. Their experiences with the program have been recorded, translated where necessary, and transcribed. All the data has been systematized, coded and analyzed with fuzzy set Qualitative Comparative Analysis looking at how different combinations of conditions concur to adherence and risk for them and for the baby.

Policy designers' opinions and practices have been studied during one year of participating in the National Technical Group for the Elimination of Mother to Child Transmission in the Dominican Republic that integrate members of the Ministry of Health and International Organization such as UNICEF and PAHO. This participation has endorsed the elaboration of a series of research questions and interest of the Ministry of Health opening up the access to the two main maternities in the country and partly their documents. Health care providers and practitioners' practices have been studied during two years of observations in maternities and this experience has been essential for creation of the interview questionnaire and in the interpretation of the fsQCA solutions.

This thesis is developed in five chapters. Chapter 1 presents the insertion of the study in the trend of analysis of Public Policies in LMICs and the state of the art in this academic field. The Chapter starts by describing current trends and challenges in the literature of health public policies in low and middle-income countries and develops by looking at the importance of adopting a locus at the front line service level to study the experience of non-traditional actors: the women involved in the program. Subsequently, the Chapter presents the factors found in literature that are related to the possible barriers faced by the women in the program from a psychological, social, economical and structural perspective. The chapter ends by presenting the most important and known definitions used to define different types of patient commitment to health programs.

The second Chapter presents the outcome, each single condition adopted for the model and their operationalization, the hypothesis and the data set. The third Chapter is divided in two parts. The first one presents the analysis with fuzzy set Qualitative Comparative Analysis starting with the results of the Analysis of Necessary Conditions for Positive and Negative Outcome and following with the Analysis of Sufficiency. The second part describes the result

of the episodes of violence's categorization that emerged during in depth interviews with the women interviewed. The Chapter ends by exploring the most relevant topics encountered during the analysis of the transcriptions related to the program and the mechanisms involved in adherence and non-adherence.

The last Chapter presents the discussion of the results and applied policy implication namely that the most significant determinants for adherence in the Dominican case are language and HIV Knowledge. Despite the numerous literature regarding education and female employment as strong determinants of adherence, the evidence collected does not support their status as necessary conditions. This final chapter ends by addressing the limitation of the current research and future possible development in the field of adherence to the PMTCT in LMICs.

1 LITERATURE AND STATE OF THE ART

1.1 Health Public Policy in Low and Middle Income Countries

In one of the few existing attempts to systematize theory and methodological issues relating to public health policies, Marin explains: “research in public health policies is complex not only for the implication to do research in this terrain but also for the complexity of this type of policies due to the multiple factors that influence them, its components and the actors that are involved” (2008). If it is true that many public health policies can be influenced by multiple factors, it is also true that the outcomes of such research deals with the most important aspect of human life, health. As such, these research merit special attention, once conclusions and recommendations are drawn.

More complex than doing research on public health policies, is doing so in low and middle-income countries (LMICs). Why? Because in these countries health policy analysis “is still in its infancy” (Gilson and Raphaely, 2008). Walt and Gilson clarify that even though such policy analysis is “an established research and academic discipline in the industrialized world,” in developing countries, the health care sector is traditionally “neglected” (Walt and Gilson, 1994), making health care policy research difficult. The scarce body of work, literature and methodological material that is produced by this negligence needs to be systematically addressed by researchers of health public policies.

As discussed in the following chapters, while it might seem straightforward to use the same frame of reference and research design as used in high-income countries, this can be highly problematic. Because context and culture strongly influence the interpretation of data -- especially if the researcher does not belong to the same cultural background -- applying

research frames developed in high income countries or in completely diverse context to other LMIC could result in dangerously skewed results.

Another important factor to consider is that social sciences, especially in impoverished-resources contexts, have been only marginally involved in the analysis of health programs. They have, instead, clashed with studies grounded in biomedical sciences that use completely different approaches and paradigms (Towle, 2009). In the context of the Program for the Prevention of Parents to Child Transmission (PPTCT), biomedical studies have focused on “knowledge, testing, drugs, individual decision-making and risk reduction” and in doing so, they have left out factors traditionally measured by social sciences, that are important influencers in the success or failure in adherence (ibidem) such as cultural, structural and ecological.

The criticism of previous approaches have been recently recognized in the biomedical investigation community, which has now formally accepted the importance of incorporating so-called “social determinants of health” into the analysis of public health programs. This acceptance was formalized in 2011 with the World Health Organization’s Rio Declaration. The Rio Declaration emphasized the importance of social science to medical science, specifying that “economic conditions have an important effect on health and disease and that such relations should be subject to scientific research” (Pelegri Filho, 2011) in order to design more effective interventions.

Despite the WHO’s formal commitment to change its health-research methods, there is still a very long road ahead before public policy analysis fully enters mainstream health studies literature, especially in LMICs. By referring to literature and methodological reviews conducted in this area, we come to understand the necessity of undertaking the analysis of

health programs from a public policy perspective including socio-cultural and structural conditions of the service.

A literature review about health policies in LMICs between 1994 and 2007 shows that in two of the most important databases, only 40% of all articles “demonstrate awareness of the wider field of policy analysis by referring to relevant concepts or theories” (Gilson and Raphaely, 2008) and they did so with limited success. Another article exploring methodological challenges relating to health-policy research in LMICs, emphasizes the nearly complete absence of guidance on how to conduct health policy analysis (Walt et al., 2008). More literature reviews reveal that public policy implementation studies -- conducted primarily in health and educational settings -- are only common in more affluent countries (Saetren, 2005). These findings accentuate the necessity to deepen our knowledge in this terrain by studying theoretical, methodological and practical issues related to these types of policies. Particular attention should be paid to contributing to the existing debate on theoretical and methodological issues.

Bearing in mind the theoretical and methodological challenges in LMIC health- related research, the following insights have been taken into consideration in developing the investigation hereby documented:

a) The necessity to critically incorporate existing frameworks of public policy contributing to existing theories (Walt et al., 2008)

b) The integration of theories from other social science fields to existing problems: such as evaluation-studies in the health sector in low and middle-income countries, and organizational studies;

c) The necessity to explicitly state paradigms and methodologies used, and interpretations made (Gilson and Raphaely, 2008);

d) The contribution to the betterment of the health program (object of the research) at the hospital and managerial level.

1.2 The Action-centered Research Framework

According to Barrett and Fudge, it is possible to examine the implementation process as a policy-action continuum that involves “interaction and negotiation, taking place over time, between those seeking to put policy into effect and those upon whom the action depends” (1981). Within this continuum, different stages of the policy process can be linked in different ways and changed directly and indirectly by different actors involved with the policy (Hill and Hupe, 2009). This dynamically challenges traditional views of the policy processes that consider static, sequential stages such as: Agenda Setting, Formulation, Implementation, and Evaluation (Lasswell, 1956).

According to these traditional views, the administrative level implements the policy, but has no discretion or room to adapt it. By way of contrast, in bottom-up approaches such as Barrett and Fudge, the policy process is analyzed from the perspective of the implementing actors. Specifically, bottom-up approaches take into account the different objectives pursued by actors involved in the implementation and the allocation of power. They thereby reveal that actors often adapt policies “deflect(ing) centrally-mandated programs toward their own ends” (Sabatier, 1986).

TABLE 2. *Comparison between top-down and bottom-up approaches*

	<i>Top-Down (Sabatier & Mazmanian)</i>	<i>Bottom-up (Hjern et al.)</i>
Initial Focus	(Central) Government decision, e.g., new pollution control law	Local implementation structure (network) involved in a policy area, e.g., pollution control
Identification of major actors in the process	From top down and from govt. out to private sector (although importance attached to causal theory also calls for accurate understanding of target group's incentive structure)	From bottom (govt. and private) up
Evaluative criteria	Focus on extent of attainment of formal objectives (carefully analyzed). May look at other politically significant criteria and unintended consequences, but these are optional.	Much less clear. Basically anything the analyst chooses which is somehow relevant to the policy issue or problem. Certainly does not require any careful analysis of official govt. decision(s).
Overall Focus	How does one steer system to achieve (top) policy-maker's intended policy results?	Strategic interaction among multiple actors in a policy network.

Figure 1: Sabatier, 1986

The framework used in this research focuses the analysis at the frontline-service level that is located at the hospitals in the Dominican Republic, home to the PMTCT Program. This framework's main purpose is to achieve the broader goals as defined in the program's strategy. In this sense, it focuses on ways to eliminate parent to child transmission of HIV and syphilis, and not on ways to follow the rigid guidelines that seek to impose the elimination of HIV and syphilis. This focus reflects the practical approach proposed by Barrett, who is mainly interested in the performance of a program rather than conformance to the guidelines which "compromise the means of achieving it" (Hjern, 1982).

Apart from focusing on actors and their capacity to exert power on, or over, their actions and personnel involved in policy implementation, it is important to focus attention on actions themselves. This lens, as exemplified by Barret and Fudge, demands the question

“why, in what circumstances, and with what assumptions are the various mode of action utilized?” (1981).

These questions allow us to systematically approach research design and methodology. To form a coherent research question, for example, it is important to look at the ways that protocols translate into actions in every day settings, such as hospitals. This reveals the inner-workings of the program: its development, its routine, and the criteria applied by medical professionals to adhere to it. These components are the program’s implementation structure, and have been described as: “the administrative entity that program implementers use to accomplish objectives within programs” (Hjern and Porter, 1981).

The discovery of the unit of analysis requires the constructions of a detailed system in which objectives, strategies and resources are analyzed in order to implement the program. It takes into special account procedures implemented to prevent and remedy drop out rates. It considers the way that institutions interact, systematically, in a stable and organized structure, within a given time-period. To identify the stream of implementation relative to a specific program, Hjern “starts by identifying the network of actors involved in service-delivery in one or more local areas, and asks them about their goals, strategies, activities, and contacts” (Sabatier, 1986).

This approach is coherent with the methodology used by Van Belle in the evaluations of a health program through Theory Driven Evaluation (TDE). Among other similarities, noteworthy is the shared importance given to perception of actors involved. Hjern et al. Emphasizes the importance of not beginning “with a governmental program but rather with actors' perceived problems and the strategies developed for dealing with them,” noting that these “are able to assess the relative importance of a variety of governmental programs vis-a-vis private organizations and market forces in solving those problems” (ibidem).

When assessing program implementation, Hjern et al also recommends giving the same importance to non-traditional actors as to traditional actors, in as much as other (traditional) actors recognize them as part of the network (ibidem). This also allows the recognition of different strategies followed by a variety of actors in the pursuit of their own goals and objectives, according to perceived importance. In the study of adherence, the attribution of importance is the product of interactions and perceptions of what is valuable and what is not. This, in turn, can be influenced by structural situations and priorities of workers involved.

The ability to recognize differences in goals, strategies, and objectives among different actors reveals implementation gaps. Implementation gaps are one of the steps that the TDE method analyzes as a possible consequence of non-implementation (Van Belle et al., 2010). According to TDE studies, different stakeholders have different “theories” regarding the program they are immersed in daily. Therefore, the success of the same program strictly depends on their perceptions of it.

As Weiss defines in his word theory, these perceptions -- “ a set of beliefs that underlie action” -- are also the “set of hypothesis upon which people build their program plans” (1998). Weiss’s theory focuses on the causal links that tie program inputs to expected program outputs. According to this approach, simultaneous program theories can affect program outputs in different ways, for example:

“sometimes the divergence in intentions that is papered over through vagueness operates at different levels of the hierarchy [...]. When goals are unclear or ambiguous, more than evaluation can be affected. Where there is little consensus on what a program is trying to do, the staff may be working on cross-purposes”

(ibidem).

As illustrated above, multiples theories may imply multiple (conflicting) goals that compete for scarce resources. Another issue that can affect program outputs is changing the conditions

under which a program operates. These include, but are not limited to, changes to the context, the budget, the practices, the clients, or the staff (*ibidem*). Changing conditions may mean that the program is no longer useful for its original purposes, and inherently change program goals.

Another important consideration is that some programs operate under vague, multiples directives, or unclear or outdated goals, making it necessary to modify the goals to understand how to make the program functional. In yet other circumstances, the program may be used as a structure to incorporate non-program related goals. In favor of these goals, program goals may be neglected.

Another danger to program outputs is when neither the intended users of the program have been consulted, nor their needs analyzed before program initiation. In this case, the program may not produce desired effects because it may not be reaching its target population in the right way. In this case, program implementation is rendered useless.

Studies in the sociology of organization describe the importance of organizing a program not only vertically but also horizontally in such a way that avoids the fragmentation of competencies. This necessitates the reconstruction and reorganization of original program parts to help make them horizontal. To illustrate, consider program A. Each part of program A is carried out for a specific set of people and has its own particular goals and resources. In order for the program to come together successfully -- instead of fragmenting -- all program pieces need to cooperate horizontally. Horizontal cooperation ensures that each part of the program does its job, and at the same time is aware of other program parts and recognizes the importance of cooperating (Butera, 1972). Program fragmentation, of course, can be due not only to lack of communication inside the healthcare clinic, but also inside the entire healthcare system. This can strongly affect the implementation of the program nationally, and prevent wider program proliferation (Frizelle et al., 2009).

Because there are several different problem-instigators during the implementation stage, various approaches must be used to understand how a particular portion of a program is operating. These methods are derived from a combination of actors, their resources, activities, outcomes, assumptions, goals, their positions and power, and their program visions (Wholey, 1987; Weiss, 1998). Together, they can be used to understand how a program is working and how it can be improved. Bottom-up approaches in the implementation literature put emphasis on interaction, context, and negotiation. This research implements the bottom-up approach because, as illustrated, these three elements are invaluable to understanding adherence.

1.3 Policy and Frontline Delivery

The analysis of frontline performances must consider several different factors that affect policy delivery and outcomes. One of them is, without doubt, power. Studies conducted in more-developed countries on implementation of public health policies have concentrated on how power is distributed, exerted, shaped, and limited in conjunction with how policy discourses are put into action by different actors involved in the policy. But the study of power involved in health policy implementation in LMICs has been given little or no attention. This, despite its central importance in the implementation of programs and for studies related to frontline service delivery (Erasmus & Gilson, 2008). Power is such a determining factor, that:

“the practice of power, for example, can generate misunderstanding among implementers, or misunderstanding between providers and patients; it underpins the ways in which implementers reformulate policies in implementation, with both negative and positive consequences for beneficiaries, or excludes beneficiary groups from decision-making”
(ibidem).

Since the PPTCT is strongly dependent on performance at the frontline service level, it is especially important to investigate how doctors and other implementation actors exert

power. On the one hand, it is important to consider resistance to change, infringements of rules, and the incapacity to manage centrally mandated policy enforcement. On the other hand, we must consider the capacities and opportunities generated by the adoption of national rules and international guidelines at the frontline service level.

Doctors and other medical practitioners play a crucial role and need to be considered closely since they “have widely been seen as exponents of different types of power” (Friedson, 1970) in medical settings. Especially important is the analysis of discretionary power exerted by those professionals directly involved with the delivery of services. This is particularly true in LMICs where doctors and other health care professionals have to face numerous challenges to respond to the pressures of their everyday environment (ibidem). Discretionary power is neither positive nor negative to program implementation, but should be analyzed in context to understand how it is exerted, and to what ends. As Lipsky warns, the use of discretionary power can signal that frontline workers are pursuing their own interests inside the program (Lipsky, 1980). It also can signal resistance to central control, in this case, the Dominican Ministry of Health.

According to Friedson, while the production and utilization of health knowledge is important, central control also limits and shapes the work of the healthcare professional:

“the foundation of medicine’s control over its work is thus clearly political in character, involving the aid of the state in establishing and maintaining the profession’s preeminence. [...]. Thus, it is by the interaction between formal agents or agencies of the occupation and officials of the state that the occupation’s control over its work is established and shaped”
(1970).

Tension is produced because historically doctors have enjoyed a great deal of power and autonomy, which pits the state and medical association against each other, in constant strife over the control of and organization of medical work.

Friedson explains this as a struggle over autonomy. According to Friedson, autonomy should be looked at through two different lenses: “autonomy from the influence or power of others, and autonomy to influence or exercise power over others” (ibidem). These two concepts shape our understanding of how guidelines can define the work of doctors at the frontline level, at the same time as they unveil the room to change guidelines once applied in the hospitals, or at the national level.

Also important is the identification of what sociologists have called technical autonomy. This has been described as “the possession of authority over a body of valued knowledge and skill, [which is] a lever by which the economically and politically powerful can be moved” (ibidem). At present, studies conducted by Friedson in United States indicate a change in the status of the medical profession, where doctors are becoming subordinate to the decisions of “equals” that establish standards of actions. This, in turn, signals a loss of autonomy on a personal level for medical professionals in the United States.

While, for this reason, Friedson’s studies may be applicable in the Dominican Republic, it must also be argued that the complete lack of consequences for medical negligence and other types of malpractice in Dominican Republic strongly limits the power of the system over different medical professions. Because the doctor still represents one of the most powerful and respected professions in the Dominican society, the establishment of medical standards, incentives, and consequences seems a very unlikely event in the near future.

Unfortunately the adoption international standards do not have the same effects in LMICs where the doctors still have a predominant position in the social system and high technical autonomy. This is no different in the Dominican context where medical doctors have a very important social position and a privileged status among all the professions. The same

Dominican health system encourages and perpetuates power in a predominant patriarchal frame of action where the same trainee doctors are trained in reproducing this type of violence against women's body and souls even if they are aware that this is completely wrong (Barinas, 2014). The same residents are in fact object of hazing and bullying by senior doctors. In a recent study about obstetric violence Barinas refers that all medical trainee interviewed had seen obstetric violence perpetuated against pregnant women and asked them to perpetuate the same type of violent practices:

“The resident told me: <<if you dare to suture her I will perform an episiotomy on, you can see how it is done...>>. He was giving me the opportunity to perform an episiotomy even if it was not at all necessary, and I said yes, because is by practicing that you learn, but it is not ok”
(Raquel, Medical Trainee, 23 years-old.

Translation of the author. In Barinas, 2014).

At the same time, it is possible to argue that the complete lack of consequences for medical negligence and other types of malpractice in Dominican Republic strongly limits the power of peers and the system over all the different medical professions and their actions. Therefore, the establishment of medical standards, incentives and consequences seems a very unlikely event in the near future.

Together with that of doctors, the relative autonomy of paramedical workers must also be taken into account. Paramedical workers are extremely important in the division of health labor and are directly controlled by physicians, both in their job and in their degree of autonomy, responsibility, authority, and prestige (Freidson, 1970). Inside and outside the hospitals, different professionals are in fact involved in the application of the program planning in different organizations and with different roles.

To identify which actors are directly involved in the implementation of the program we consider Towle's five interlocking policy parts:

“(1) increasing knowledge of general prevention, mother-to-child transmission risks and family planning through HIV/AIDS education initiatives; (2) voluntary counseling and testing (VCT) that targets pregnant women (or women of childbearing age) and their partners; (3) antiretroviral (ARV) interventions with HIV-positive women to substantially reduce the risk of transmission during pregnancy, birth and post-birth; (4) safe infant feeding practices that reduce or eliminate the risk of transmission through breastfeeding; and (5) follow-up with mother, child and family to monitor medical, nutritional and social needs and to provide linkages to care, support and treatment services”

(2009).

These steps have been adapted to the Dominican intervention-model, and are used in the definition of the outcome-condition for the analysis. Each one of these steps is extremely important to avoid the transmission of HIV to the child, and needs a strong commitment from both the mother and healthcare providers involved. Different factors can affect adherence of the program and the completion of all the steps.

Concerns with the relationship between service-level providers and intended users are an essential part of bottom-up approaches, especially in LMICs where more stress is placed on the provision, than on the quality, of service. A closer look at the profile of intended users of the program, in some cases incorrectly called beneficiaries, can clarify the context in which HIV positive women in the Dominican Republic receive medical attention while pregnant.

The interaction between the women and the health system can be analyzed with the lens of Hirschman’s theory. The lack of satisfaction of the patient can result in two behaviors while engaging with the health system: opt-out or complain (Hirshman, 1970). But what happen when patients are HIV positive pregnant women that come from the most disadvantaged background and impoverished part of the city? Which are the consequences for them and their babies? What happens when the violation of women rights and humiliations is the norm and the lack of consequences for negligence or obstetric violence (Barinas, 2014) disincentives

any form of protest or effective actions from the users of reproductive health services? Can this create a vicious circle in which violence keeps repeating everyday increasing the disempowerment and affecting the already more vulnerable sectors of the society: women and children?

1.4 Intended users of the PMTCT program and barriers to care

As well as considering the actors involved in the supply side of the initiative it is necessary to consider the intended users of the program, their level of empowerment and central role. Patient empowerment has been described as “a process of helping people to assert control over factors that affect their health” (Lau DH, 2002) and is not only a way of improving individual health care but also a commendable active policy with innumerable positive externalities for public health services: “finding out what matters to patients, making use of information technology to disseminate knowledge, establishing standards for disease management, and promotion of clinical research are likely to increase the benefit of the health care provided” (ibidem).

In low and middle income countries patients attending public hospitals may encounter different types of difficulties in following the cascade of actions dictated by the protocol Initiative during prepartum, intrapartum, and postpartum: “PPTCT interventions are often difficult for women and spouses to access as a result of sociocultural, structural and economic obstacles” (Towle, 2009). It is therefore very important to take into consideration the ecological, social, structural and economic factor that affect the implementation of the program called structural barriers but also the facilitators of the program (Parker et al., 2000). Compared to other health programs, the Initiative requires a strong and life-long commitment

by the patient and the willingness to face social stigma, discrimination and violence inside the hospital and in their community. In order for the Initiative to succeed it is necessary to consider that:

“comprehensive PPTCT requires that women are willing and able to engage in both outreach and clinical initiatives, a capacity made quite difficult in India due to socio-cultural disenfranchisement, behavioral expectations in a patrilocal society, economic restraints, poor medical infrastructure, marginalization in urban slums and rural regions, and stigma surrounding sex and HIV/AIDS”

(Towle, 2009).

If this is true for India, where Towle studied the PMTCT program, many similarities can be found in the barriers for women in the Dominican Republic. As a matter of fact women need to engage directly with the program, following a series of step that are sometimes difficult or impossible for them to be accomplished; the underlying theory of the program it is therefore to put a strong burden on women and their personal capacity to engage with the program. This implies various types of efforts in order to get to the hospital and above all a strong psychological responsibility.

Literature recognizes that in order to analyze barriers to a program, which is nothing more than a process (Corbin and Strauss, 2008), it is possible to divide them among Contextual Barriers and Individual Barriers and facilitators that improve the implementation of a program (Frizelle et al., 2009, Parker et al., 2000). Among the Contextual barriers, in the literature it is possible to identify the following : health care infrastructure and shortage of staff, healthcare workers' poor attitudes and interactions with intended users, poor quality of counseling and information, inadequate family-planning services and counseling, inadequate integration of services, poor referral links, lack of communication within the healthcare system, poverty and infrastructure, overlooking the needs of youth, cultural factors, social network barriers, stigma, gender related issues and male partner/husband support. While

among individual barriers: lack of awareness and knowledge, confusion and dilemmas around infant-feeding options, PPTCT practices that are perceived of as discriminatory, psychological barriers (Frizelle et al., 2009, (Towle, 2009; Parker et al., 2000).. These two types of barriers can also be seen as the supply side and demand side of the program.

As seen with studies related with health public policies in LMICs also PMTCT programs face the same challenges related to availability in literature of systematic studies that are able to address structural and supply side. In a comprehensive review of PMTCT studies related to community strategy to improve care and retention in the cascade, Marcos et al. identifies 430 articles related with PMTCT and HIV, of this only 107 included the words “PMTCT cascade”, “retention”, “loss to follow up”, “early infant diagnosis”; of this only 9 showed statistically significant results (2012).

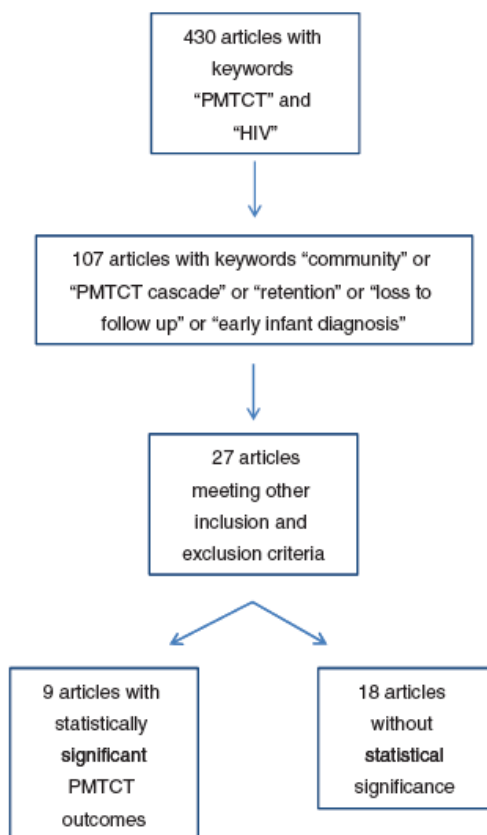


Figure 2: Schematic representation of the literature search and yield for articles discussing community strategies to address loss to follow-up along the PMTCT cascade. PMTCT, prevention of mother-to-child transmission of HIV (Marcos et al. 2012).

1.5 Compliance, Adherence and Concordance

Health-service literature identifies three main terms that deal with the level to which patients follow prescriptions provided by the doctors: compliance, adherence and concordance. These terms are sometimes used interchangeably but they describe three different concepts that encompass very different ideas regarding the relations that medical providers have with their patients.

By exploring the definitions of these three terms, it is possible to gain a deeper understanding of the level of involvement by the patient and by the doctor in any given

medical regime. Compliance has been described as “the extent to which the patient’s behavior matches the prescriber’s recommendations” (Horne et al., 2005). Adherence, in turn, is “the extent to which the patient’s behavior matches agreed recommendations from the prescriber” (Ibidem).

These two terms differ primarily in the attitude of the patient towards a program, but also in the field of scientific literature in which they have been used. Compliance is a term often associated with a passive role of a patient, in which he or she is coerced to take on a medical regime. The patient follows the doctor’s orders and does not have the possibility of negotiating his or her position. Therefore, “within this connotation, noncompliance may be interpreted as patient incompetence in being unable to follow the instructions, or worse, as deviant behavior” (Ibidem).

Adherence is a term that has been used in sociological and psychological literature to describe a situation in which the patient is free to decide whether to follow the doctor’s recommendations, or not. In the case the female patient is not compliant; blame should not fall on her. Because of this, the nature of the interaction between patient and health providers changes. Non-adherence is anticipated as a possibility in the treatment program.

Concordance has been described as:

“a new approach to the prescribing and taking of medicines. It is an agreement reached after negotiation between a patient and a health care professional that respects the beliefs and wishes of the patient in determining whether, when and how medicines are to be taken. Although reciprocal, this is an alliance in which the health care professionals recognize the primacy of the patient’s decisions about taking the recommended medications”

(Ibidem).

This approach changes treatment from the simple process of medicine taking to incorporating the understanding of the patient’s needs and beliefs to improve adherence.

In this analysis, the term selected to represent the outcome condition is adherence. Adherence has been selected over compliance and concordance for different reasons. First, adherence as a concept recognizes that the patient is able to decide whether or not to follow the doctor recommendations, and that the fact that this does not happen should not be a reason to blame the patient. It recognizes that different reasons can lead to compliance and noncompliance (Ibidem). Second, concordance as related to patient/doctor relationship is one of the determinants that can improve adherences, but this assumption needs to be further tested (Ibidem) quantitatively and qualitatively. Third, concordance requires a maturity of the system and of the institutional practices inside LMICs that is far yet to come and consequently is not a concept suitable or adapted to this type of context.

2 ARGUMENT

2.1 Introduction

To analyze adherence and non-adherence among HIV positive mothers, seven conditions were considered and adapted to Caribbean contexts and in particular to the Dominican context. Very few systematized studies investigate the relationship between barriers, facilitators, and adherence in HIV positive women in the Caribbean context (Panditraoa et al., 2011). Nor are there systematic and non qualitative studies that explore what motivates a HIV positive woman to complete program protocols towards the reduction of HIV transmission.

Due to the above-described scarcity, this chapter argues that it is only partially possible to reference existing literature in the field. Aggravating matters, the majority of existing literature has been developed in sub-Saharan Africa and India. While these are two regions with the highest percentage of mother to child HIV transmission in the world, their sociopolitical and cultural contexts vary greatly from the Caribbean. As a result, every condition that has been proved to directly affect adherence and risk in India and in Sub-Saharan countries must be analyzed minutely, taking into account that in the Dominican Republic these protocols may not produce desired results and may need to be redesigned using different mechanisms.

This does not mean that all conditions will apply to the Dominican context. Perhaps counter-intuitively, we will see in further chapters that other conditions –not previously considered in existing literature- will turn out to be important determinants of adherence in the country. In order to fully understand what motivates adherence, we must further examine specific contextual factors in the Dominican Republic, such as violence and language barriers.

These characteristics were derived through participant observation in public maternity hospitals in the country, the author's previous research on Dominican health centers, and literature on language barriers to healthcare in bilingual contexts.

The experiences of the women participating in the program were gathered using in-depth interviews. These interviews allowed the collection of sensitive PMCT-related data and also the women's life-stories, both inside and outside the program, specifically related to their HIV status. The interviews were transcribed and the conditions for the Qualitative Comparative Analysis –QCA- were chosen and calibrated for empirical examination with the fsQCA, kirq and Excel software. Beyond the expected QCA results, the interviews also shed light on struggles endured by HIV-positive pregnant women, such as frequent episodes of violence and conditions of extreme poverty. This qualitative data analysis uncovered more than 140 different episodes of violence --both inside and outside the hospital-- opening avenues for further investigation.

2.2 Conditions and operationalization

In order to analyze the phenomena of adherence through Fuzzy Set Qualitative Comparative Analysis (fsQCA) have been selected a series of conditions that are related and interconnected with the phenomena according to the literature and empirical knowledge. PMTCT literature has so far considered the following variables in the studies related to adherence in LMICs, (Towle, 2009; Cornman et al., 2007; Painter et al., 2004; Pfeiffer, 2004):

- 1) Age;
- 2) Education;
- 3) City and *barrio* in which intended users live;

- 4) Access to local health service providers;
- 5) Access to transportation public or private;
- 6) Family Size;
- 7) Employment status;
- 8) Income;
- 9) Distance from the center in which the program is administered;
- 10) Numbers of kids;
- 11) Marital status;
- 12) Number of current partners;
- 13) Awareness by the partner/s of her HIV condition.

Encouraged by the necessity to incorporate social science research, which criticizes the biomedical-delivery approach, and recognizing the importance of cultural and contextual understandings for effective programming and community-level impacts (Towle, 2009; Painter et al., 2004; Castro and Farmer, 2005; Campbell, 2003; Parker, 2001; Trickett, 2005, 2004), other conditions have been included in this research. Some of these conditions are derived from non-PMTCT general healthcare service literature, some from direct research in the Dominican context, and others from participant observation in Dominican Hospitals:

- 1) Understanding of HIV
- 2) Violence and stigma
- 3) Language
- 4) Significant other

We will start by first analyzing the outcome variable and then we will pass to describe the model and its set of associated conditions.

2.2.1 The outcome: Effective Risk

The outcome for this research, called “Effective Risk” for the mother and for the child, has been created specifically for research purposes. It is the product of the calculation of the encountered combinations of program steps that the mother could have followed during and after her pregnancy. Effective Risk has been calculated for each specific combination of steps found in the database, according to research showing how different steps in the program can lead to different risks for the mother and for the child. However, because skipping one or more steps in the program can lead to different risks and risk-levels, the measure is not cumulative.

The five most important steps in the so-called “Cascade of Intervention” (Ciaranello et al. 2011) or “program flow” have been considered in the systematization of outcomes. They are described in the table below. On the left-hand column, the name of each step in the program flow can be found. The right-hand column describes the step, and how it was operationalized for research purposes.

5 Step of the cascade of intervention	Description of the step
1. Gynecological and medical examination during pregnancy	The participant has had a minimum of two registered gynecological visits and has been taking the antiretroviral while pregnant. Women who are not aware of their situation at this point, or who discovered they were HIV positive while giving birth, should be excluded from the research population.
2. Attended birth	The participant has had cesarean or vaginal birth in the hospital according to protocol specifications and medical recommendations.
3. Referred to an integral attention service to continue treatment	The participant has been referred and continues to evaluate her status, even after giving birth. She continues with her antiretroviral regime when necessary.
4. Feeding selection and follow through	The participant has selected an infant-feeding option and she is able to follow through properly (either exclusive breastfeeding or exclusive replacement feeding) according to medical recommendations.
5. Child tested for HIV	The participant’s child has already done the ADN-PCR, or the test is scheduled.

Table 1: the 5 steps of the cascade of intervention and their description

These five steps have been chosen because they represent the five most important steps in the program flow. Data collection during research proved that they are easy for the participant to remember. Each of these steps requires the collaboration of both the patient and the healthcare provider. If either the women does not follow the corresponding protocols, or the hospital does not provide the corresponding services, adherence levels and effective risk are clearly influenced. The research's purpose is to investigate why women stop participating in the program once having begun, and not why they choose not to participate from the outset. Women who decided not to participate in the program are not considered in this research.

Each woman under study has been given a risk-level, calculated according to the combination of the steps that she has or has not followed during and after her pregnancy. For example, if she was able or allowed to follow all steps in the protocol, her risk level is low (only 2%). Chances are, neither will, her child seroconvert, nor will she develop health complications (Pan American Health Organization, 2010).

	A	B	C	D
	Very low risk (f.v. = 1)	Low risk (f.v. = 0.67)	High risk (f.v. = 0.33)	Very high risk (f.v. = 0)
	a)	a) b)	a) b) c) d) e) f) g) h) i)	a) b) c) d) e) f) g) h) i)
1. Gynecology and treatment	1	1 1	1 1 1 1 1 1 0 0 0	0 1 1 0 0 0 1 0 1
2. Attended birth	1	1 1	1 0 0 1 1 1 1 1 1	0 1 0 0 1 1 0 0 0
3. Referred and treatment	1	0 1	0 1 0 0 1 1 1 0 0	0 0 0 0 1 0 1 0 0
4. Feeding choice properly follow through with	1	1 1	1 1 1 0 0 0 1 1 1	0 0 1 1 0 0 0 1 0
5. HIV test to the child	1	1 0	0 1 1 1 0 1 1 1 0	1 0 0 1 1 1 0 0 1

Table 2: Operationalization of the Effective Risk Outcomes for the Mother and the Child According to Respective Combinations of Steps Found During Data Collection. 1 indicates the Patient's Participation and 0 Indicates Her Abstention for Each Step of the Program Flow.

How was Effective Risk calculated? The following section explains each combination of risk for the mother and the child.

2.2.1.1 Effective Risk very low, equal to fuzzy value 1

In the research population there was only one combination that had a fuzzy value equal to 1, equivalent to very low risk for the mother and the child. This combination indicates that the mother had both the opportunity and the capacity to follow each of the five main steps in the program, and signals full adherence to the recommendations of the healthcare provider. Because of this, risks of health complications, both for the mother and the child are extremely low. This combination is described in Column A, Table 2.

According to PAHO, women who follow all steps in the program properly only have a 2% chance of transmitting HIV to the child through transplacental transmission of HIV (2010). Even after taking necessary precautions, transplacental transmission can occur while the baby is still in the womb. Definitive preventative remedies have yet to be found.

2.2.1.2 Effective Risk low, equal to fuzzy value 0.67

The research population registered two combinations that can be categorized as low-risk (column B in table 2).

a) and b)

a)	b)
1. Gynecology and treatment	1. Gynecology and treatment
1. Attended birth	1. Attended birth
0. Referred and treatment	1. Referred and treatment
1. Feeding-choice follow through	1. Feeding-choice follow through
1. Child HIV tested	0. Child HIV tested

The risk for the mother of transmitting HIV to the child skipping the HIV test and therefore the follow-up visits, is the same as the previous combination just 2%. But since here it is considered the outcome Effective risk, which is the product of the combination of steps combined considering also other intervening factors, there is a possibility that the child would not seroconvert in the first six months and that the mother would take time to detect that the child has been infected during one of the previous steps followed. Therefore, compared to the previous combination there is a higher risk for the child of ending up with complications due to the birth, to the antiretroviral that the baby is taking, and not to get HIV diagnostic in time leading to many serious problem for the child.

The fact that many mothers do not follow up on treatment after pregnancy, has many different consequences for both mother and child. First, the mother runs the risk of her health deteriorating quickly and subsequently contracting AIDS, depending on her viral load and CD4 parameters. Contracting AIDS, in turn, weakens the mother, affecting her ability to take care of her child. Second, a mother who does not continue with treatment may run a higher risk of transmitting the virus to her baby, in the eventuality of accidentally breastfeed her child.

Even so, the fact that the woman has followed all other steps properly lowers the risk for both the baby and herself. For example, the child in this combination eats regularly according to the feeding procedure recommended by healthcare providers. Therefore, the risk of infection from breastfeeding is extremely low. In this combination, the fact that the child continues treatment will make it easy to detect complications in the mother, should they arise and vice versa.

2.2.1.3 Effective Risk high, equal to fuzzy value 0.33

a)

a)
1. Gynecology and treatment
1. Attended birth
0. Referred and treatment
1. Feeding choice follow through
0. Child HIV-tested

In this combination, because both the mother and her child do not continue with treatment, complications may not be detected in time. The mother will probably not discover complications in her child’s health before the child has serious or irremediable health problems. The risks of not following through with these program-steps are, therefore, high.

b) and c)

b)	c)
1. Gynecology and treatment	1. Gynecology and treatment
0. Attended birth	0. Attended birth
0. Referred and treatment	1. Referred and treatment
1. Feeding-choice follow through	1. Feeding-choice follow through
1. HIV test to the child	1. HIV test to the child

One of the more sensitive steps during which HIV can be transmitted to the child is during delivery. The fact that the women in the cases above were able to follow an antiretroviral regime reduces the risk of complications during vaginal delivery. Nonetheless, both of these combinations represent high risk for the patient and her baby.

Another factor, which mitigates risk, is that the women continued treatment after giving birth, according to program requirements. Because the patient is able to adhere to all program steps except “giving birth according to doctor recommendation,” she faces a low risk of her child contracting the virus. Other program steps protect the child, and if, as stipulated, the child takes anti-retrovirals for forty-five days after birth, the development of the virus should be prevented. The fact that the woman who has followed all previous treatment steps should have a low viral charge, also indicates a very small chance of transmitting HIV to her baby, even during an unattended vaginal birth.

d), e) and f)

d)	e)	f)
1. Gynecology and treatment 1. Attended birth 0. Referred and treatment 0. Feeding-choice follow through 1. Child HIV tested	1. Gynecology and treatment 1. Attended birth 1. Referred and treatment 0. Feeding-choice follow through 0. Child HIV test	1. Gynecology and treatment 1. Attended birth 1. Referred and treatment 0. Feeding-choice follow through 1. Child HIV test to the child

In these cases, the fact that the mother does not follow the doctor-prescribed feeding regimen means that her risk level has been calculated as between 25% to 48% (Wiktor et al. 1997). Luckily, only few mothers in this research directly breastfed their babies without continuing with treatment. The majority of those who scored 0 were in fact not properly nourishing their babies in accordance to their healthcare provider’s directions regarding age-appropriate foods. The fact that these mothers did not follow through with treatment, and that their babies did not

eat properly, increase both of their health risks. Moreover, because the mothers in some cases have not scheduled the AND-PCR test for their children can increase the risk of not detecting in time the non sero-conversion of their newborn.

g), h) and i)

g)	h)	i)
0.Gynecology and treatment 1. Attended birth 1. Referred and treatment 1. Feeding-choice follow through 1. Child HIV tested	0.Gynecology and treatment 1. Attended birth 0. Referred and treatment 1. Feeding- choice follow through 1. Child HIV tested	0.Gynecology and treatment 1. Attended birth 0. Referred and treatment 1. Feeding-choice follow through 0. Child HIV tested

Antiretroviral treatment is one of the most effective measures in preventing vertical transmission (Chinkonde et al., 2009). Skipping this step is a serious health danger for the mother and for the child, increasing risks of complications during delivery and of intrapartum transmission. In this case, the fact that the mothers were able to follow the majority of all other program steps mitigates possible health complications during pregnancy.

2.2.1.4 Effective Risk high, equal to fuzzy value 0

a), b), c), d), e), f), g), h) and i).

a)	b)	c)
0.Gynecology and treatment 0. Attended birth 0. Referred and treatment 0. Feeding-choice follow through 1. Child HIV tested	1.Gynecology and treatment 1. Attended birth 0. Referred and treatment 0. Feeding-choice follow through 0. Child HIV tested	1.Gynecology and treatment 0. Attended birth 0. Referred and treatment 1.Feeding-choice follow through 0. Child HIV tested

d)	e)	f)
0.Gynecology and treatment 0. Attended birth 0. Referred and treatment 1. Feeding-choice follow through 1. Child HIV tested	0.Gynecology and treatment 1. Attended birth 1. Referred and treatment 0. Feeding-choice follow through 1. Child HIV tested	0.Gynecology and treatment 1. Attended birth 0. Referred and treatment 0.Feeding-choice follow through 1. Child HIV tested
g)	h)	i)
1.Gynecology and treatment 0. Attended birth 1. Referred and treatment 0. Feeding-choice follow through 0. Child HIV tested	0.Gynecology and treatment 0. Attended birth 0. Referred and treatment 1. Feeding-choice follow through 0. Child HIV tested	1.Gynecology and treatment 0. Attended birth 0. Referred and treatment 0.Feeding-choice follow through 1. Child HIV tested

The combinations of risks identified in this category describes a mother who does not follow, or did not have access to, the most critical steps in the program flow, and who did not take mitigating steps to reduce risks. Take, for example, the case H: a mother who does not adhere to the gynecological and antiretroviral treatments, and who is not able to access a physician-attended birth. The viral load of this woman will most likely be high, due to the fact that she did not take antiretrovirals during her pregnancy. Because her CD4 is dangerously low, she is fragile and exposed to numerous complications and infections. If, in this state of health, she does not receive proper care during labor and delivery, chances are that her baby will contract the virus, and her own health will be compromised, possibly without remedy.

The program protocols hereby researched were designed as a series of complementary steps that are able to mitigate risks even if one or a few of them are skipped. But in the combinations described in this section, the mother not only skips the most important step, but also the other steps that might have lowered risks for her and the baby. The combinations of above-describe steps are, therefore, extremely dangerous for the mother and for the child. The Repercussions will most likely be both serious and permanent.

2.2.2 The model with 7 conditions

The conditions that have been chosen for analysis stem from theories, empirical knowledge derived from observation and the transcription of the interviews, and previous research done by the author in the Dominican context. These variables most likely explain why a woman is able to complete all steps in the program flow. Inside the parenthesis is the code used in the analysis with fsQCA and kirq. The selected conditions are:

- a. Understanding of HIV
- b. Violence
- c. Education
- d. Economic autonomy
- e. The significant other's knowledge
- f. Cost
- g. Spanish spoken.

2.2.2.1 Understanding of HIV and the program (und)

The knowledge that a patient has over her condition has been described as a crucial element in adherence to the program. Many studies reveal “unintentional non-adherence arises from the poor cognitive outcomes [...], particularly poor understanding and recall of information presented in the consultation” (Horne at al., 2005). According to the Health Belief Model, understanding a condition is directly linked to the patient's understanding of the condition's effects on her health:

“individuals will generally not attempt to treat or prevent a condition unless they perceive themselves vulnerable or susceptible to the disease or its consequences or actually have the disease, and believe that treatment will be beneficial or effective in preventing or reducing the susceptibility and/or severity of disease”

(Singh et al., 2010).

It follows that if a person understands the source of the risk, and acknowledges its vulnerability, she takes action. On the contrary the denial will result in non-adherence. As has been well established, healthy protective behavior is derived from perceived susceptibility to the disease and mediated by available and highly effective treatment (Aiken et al. in Baum et al., 2012). If the patient perceives herself at risk and recognizes that she has a highly effective treatment available, her adherence to the program improves. In other words, “perceived susceptibility to disease is an important early force in the adoption of health protective behavior” (Ibidem).

In this case, indispensable to assumption of the susceptibility, in turn, is knowledge of both the HIV virus and of the program. If the woman does not understand how the virus is transmitted and what the program can do for her, how she can follow the healthcare provider’s recommendations?

This has been operationalized using six factors necessary to comprehend HIV, that are explained during HIV pretest-counseling for all pregnant women in maternity hospitals in Dominican Republic. All of them combined result in a proxy of the knowledge of how HIV works and can be transmitted. These six factors are also commonly used in HIV surveys around the world to test for knowledge in the area (Carey et al., 1996). They are:

1. Transmission by mosquito bites
2. Drinking from the same glass
3. Transmission by kissing
4. Mother to child transmission
5. Transmission through breastfeeding
6. Sexual transmission

To conceptualize this condition, four fuzzy values were developed:

1 = Predominantly aware. The participant has knowledge of at least five out of six HIV transmission factors;

0.67 = Aware. The participant has knowledge of four out of six HIV transmission factors;

0.33 = Slightly aware. The participant has knowledge of three out of six HIV transmission factors;

0 = Not aware. The participant has knowledge of less than three out of six HIV transmission factors.

The zero value was also attributed to women who were in denial. This, because denial overrides acquired knowledge gained regarding HIV status, when dealing with a variable strictly related with perception (Wringe et al., 2009).

2.2.2.2 Violence (vio)

The possibility to incorporate a gender-sensitive, multi-sectorial approach is extremely important since HIV positive women can be exposed to different social hurdles, and psychological and physical violence, including: social exclusion, discrimination, and femicide. To understand the magnitude of the problem, it is necessary to understand that the Caribbean region is home to the third-highest rate of HIV infections on the planet. It is also one of the regions that registers one of the highest rates of pregnancy in adolescents, with high rates of incest (Sutherland, 2014). In some regions of the Dominican Republic, rates of pregnancy in adolescents can be higher than 40% (Barinas, 2012). This increases the probability of contracting different sexually transmittable disease at younger ages.

Moreover, according to León in *Violencia contra la Mujer y VIH/SIDA*, the fear of producing a violent reaction in a male partner can provoke aversion to getting tested for HIV

(2006). Notwithstanding the fear of a violent reaction, or of discovery of their HIV status, women are tested more often than men. This is especially due to pregnancy. Women partners are, thus, usually the first to discover an infection which may affect the dynamic of the couple dramatically. Not only this, but the world is witnessing a feminization of the epidemic.

Fear of a violent reaction is well founded. Femicide is the most tragic, but not the only form, of violence that a woman may suffer due to her lower social condition and absence (in many cases) of negotiating power. Since the beginning of 2012, more than ninety-eight women were victims of femicide in Dominican Republic.

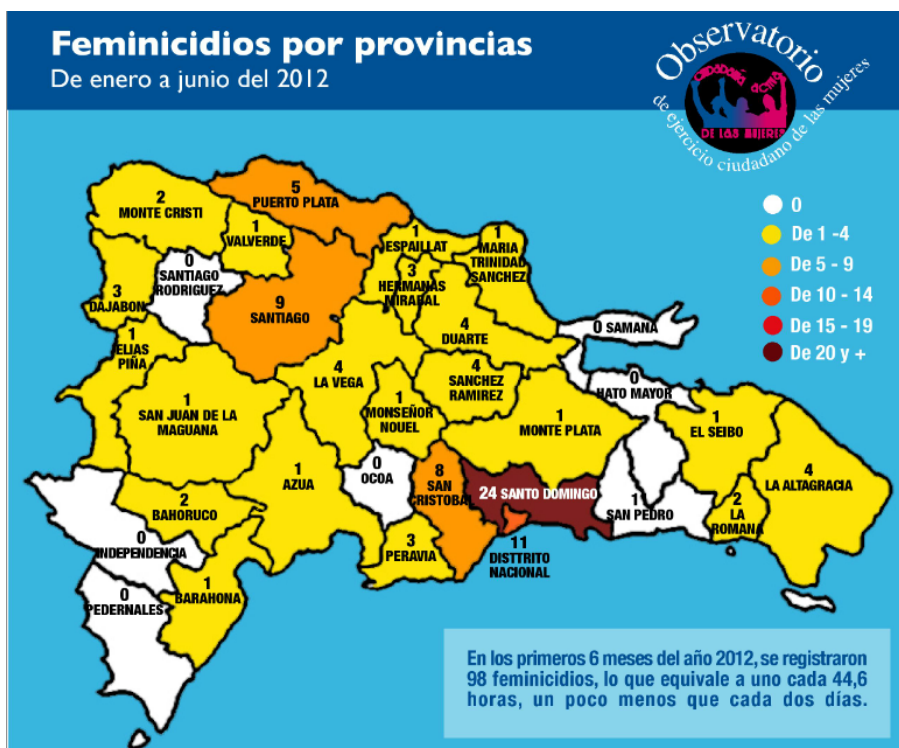


Figure 2: Femicide per province in Dominican Republic (Source: Observatorio Ciudadanía Activa de las Mujeres according to the data of the Procuraduría General de la República, 2012).

The results of one of the few studies that has been conducted in Dominican Republic regarding the relationship between violence and HIV (conducted by ONUSIDA, UNICEF, UNFPA and Planned Parenthood) reveal how a seropositive woman has a higher chance of

been left by her husband than a woman who is HIV negative (Betances, 2007). Moreover, a woman who announces her status is likely to suffer from discrimination and abandonment by her family, and social exclusion in her community (ibidem). But abandonment is not the only violent consequence provoked by a woman's disclosure of her HIV status.

A study conducted in the United States reports that more than 45% of women infected with HIV suffer from physical violence as a direct consequences of disclosure of their status (Gielen et al., 2000). Betances in the Dominican Republic reports that 80% of women were afraid to reveal their condition and 60% of women reported cases of violence directly related to disclosing their HIV status to their partners (2007). These are the reasons why it is necessary to adopt a gender-sensitive approach to the disclosure of HIV, and a gender sensitive approach in the program in general.

It is also necessary to consider that the Dominican Republic recently approved the law No. 135-11, which orders the compulsory revelation of a person's HIV positive status to his or her sexual partners. The infringement of this law through the non-revelation can be punished with from two to five years of prison. Behind the law's approval lies the hope that the disclosure of an HIV status will allow the couple to take the necessary precautions to avoid the spread of the infection to the other partner. This, in turn, relies on logic that the infection can be stopped if the partner is informed, and therefore the general number of infections can be reduced. In the context of violent repercussions discussed above, the harm principle becomes more important than the right of life and self-preservation. Mill's wrote:

“the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number, is self protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others”

(1991).

Unfortunately, no studies have proved this logic is effective. As O'Grady reports:

“recently, it has been recognize more widely in the public health community that the assumption that a greater degree of disclosure of HIV-positive status by individual to their sex partners would result in decreased sexual transmission if HIV may be incorrect. In fact, the effectiveness of disclosure of HIV status as an HIV prevention measure is not known (Pinkerton and Galletly, 2007). Consequently, disclosure of HIV status to sex partners may not be an important public health focus for preventing the spread of the epidemic”

(2009).

Important to this discussion is that HIV as an infection is still stigmatized as a “different” infection, not only in communities, but also in the medical sphere. One of the women interviewed in the study of Betances declares: “my husband told all the people in the *barrio*¹ that I got SIDA, continuously. He does that so that I’ll feel bad and when he dies, no one will marry me anymore” (2007; Author’s translation).

The necessity to consider a gender-sensitive approach to this initiative also comes from the demographic and social positioning of HIV positive women in the Dominican Republic. During the study conducted by Betances, 60% of the HIV positive women interviewed reported only having started primary school. This suggests that HIV is a disease strongly related to the opportunities and the economic income that a woman has access to. It follows that an HIV positive woman may also live in more vulnerable community environments and work in lower-paid, dangerous and degrading jobs. The need to adopt a gender-sensitive approach to the program cannot disregard the conditions in which women are raised, socialized and treated, all of which shape her conceptions of herself. Women and their children have to be protected and assisted once they discover their seropositive condition so

¹ Neighborhood. Usually in Dominican Republic the word *barrio* is associated with an impoverished and marginalized part of a city.

that they can receive adequate support and avoid retaliation once the condition is known. If this is achieved, the experiences of other HIV positive women can be avoided:

“I got together with a man but he only kicked me. He kept threatening me with a *machete*. If I didn’t want to have sex, he kicked me, he forced me, and after that he kept me locked inside the house to punish me. He used to go to the capital and left me alone locked in the house without anything, without food or money for the kids and for me...”

(Betances, 2007; Author’s translation).

According to UNAIDS “violence is both a cause and a consequence of HIV and AIDS” (UNAIDS, 2004). Violent reactions to divulgence of HIV status directly affect the outcome of the program. Important to consider is that many program participants suffer violence both inside and outside the hospital, although precise estimates at the national level are not available.

This research documented a number of violent episodes both inside and outside the hospitals, even if in many cases the women themselves did not interpret these as violations of their rights. This is especially true with regards to obstetric violence. In those cases, for example, where the woman was sterilized without consent, but she did not know if this sterilization was right or wrong, legal or illegal, the action was not categorized as directly affecting program adherence. But in those cases where the woman recognized that behaviors of healthcare providers or practitioners was wrong or illegal, the action *was* categorized as violence, and directly affecting her adherence.

This condition was operationalized as follows:

1 = The participant does not consider herself as a survivor of violence or is not able to identify episodes of violence or rights violations inside and outside the hospital, on her own;

0 = The participant considers herself a survivor of violence and/or is able to identify episodes of violence or right violations inside and outside the hospital on her own.

2.2.2.3 Education (edu)

Education is a primary factor in facilitating the access to reproductive healthcare services. Literature supporting this is vast (Mumtaz and Salway, 2005; Santow, 1995; Jejeebhoy, 1995; Castro, 1995). In low and middle income countries women education has been associated with an appreciation for antenatal and reproductive health services even if in some studies and depending to the context this was not the most important factor encountered (Mumtaz and Salway, 2005). On the contrary literature directly related with loss to follow up in PMTCT programs in LMIC is very scarce and there are only a few studies that analyze the relationship between the characteristics of the women and her adherence (Panditrao et al., 2011). It is important to highlight that less educated and economically deprived women who live in impoverished countries look for services in public or free hospitals where the services are in the majority of cases of low quality and the service slow and cumbersome (Panditrao et al. 2011).

More difficult to establish is the cut-off point in which women with lower education have a disadvantage compared to more educated women, when it comes to access to sexual and reproductive healthcare. In a 31-country study, Ahmed et al. shows how having a complete primary education compared to not having an education or an incomplete primary education leads to completely different outcomes in the attendance and access to health services (2010). Therefore, primary education has been used in many studies as a proxy for literacy and might vary between 5 and 7 years of education.

This variable has been operationalized as follows:

1 = the woman has completed at least her primary education (seven years);

0 = the woman has not completed primary education, or she does not have any education.

2.2.2.4 Economic autonomy (job)

There is little doubt that women are harder pressed than men to maintain both their sexual and reproductive health, particularly in low and middle income countries (Santow, 1995; Caldwell, 1986). Among the determining variables that shape this disadvantage are: education, socio-economic status, number of kids, age, distance from the clinic equipped to provide sexual and reproductive health services, religion, type of job, medical history, and autonomy (Mumtaz & Salway, 2005; Santow, 1995; Jejeebhoy, 1995). Autonomy, in particular, is important to consider, as it is the variable used to explain a woman's social status as relates to gender inequalities relative to health.

Some studies argue that autonomy is a determining variable in the maintenance of a woman's sexual and reproductive health only when considered in tandem with other factors (Sathar & Kazi, 1997). Others consider a woman's autonomy is as important as education level achieved (Cleland et al., 1996). Yet while we can irrefutably measure the positive affects of higher education levels on a woman and her children's health, it is not possible to do the same when studying connections between autonomy and sexual and reproductive health (Bhathiaa & Cleland, 1995; Castro, 1995). It is, for example, easy to associate a woman's education with her tendency to seek medical care upon the recognition of symptoms indicating dangers to her personal health, and/or during pregnancy. In many low and middle income countries, education is also associated with lower fertility rates, tendency to marry later in life, and the use of contraceptives (Castro, 1995). Yet other studies prove that physical autonomy, and above all, a woman's capacity to move about independently and unaccompanied, is not always directly related to her sexual and reproductive health (Sathar & Kazi, 1997; Fikree et al., 2001; Mumtaz & Salway, 2005). These conflicting studies necessitate the precise

definition of a woman's autonomy as relates to her sexual and reproductive health. To do so, we must explore the definition of autonomy and understand that autonomy can take many different forms.

A ballpark explanation of autonomy as relates to the health sector is simply the idea that a subject has control over her own life (Mumtaz & Salway, 2005). Jejeebhoy (1995) is more detailed in his definition. She defines autonomy as a combination of multiple, interrelated capacities that usually include -- but are not limited to -- the power of decision making, social and economic autonomy, and physical and emotional autonomy. In this context, physical autonomy can be interpreted as the kind of autonomy that connects the woman to the world outside her house and her community. In many studies, physical autonomy is empirically measured as a woman's capacity to access transportation, whether accompanied or unaccompanied. Physical autonomy can also be analyzed as the freedom of mobility and travel, without the consent of another person (Bhatiaa & Cleland, 1994). These varying examples reveal autonomy not only to be a multidimensional concept (Mason, 1987), but also as dependent on the context in which it is being studied, and the ways it has been operationalized.

Along with autonomy, we must also define the idea of sexual and reproductive health, a main component of which is maternal health. This thesis adopts the definitions espoused by the Cairo Conference on Population and Development (UN, 1994). According to the conference definition, sexual and reproductive health is the condition whereby a person develops the capacity to reproduce and regulate her fertility, during prenatal and postpartum pregnancy. It is also indicates a couple's ability to freely conduct relationships, and to have sexual relations without unwanted births and diseases.

The Cairo conference marks the formal recognition of a woman's rights to her own sexuality, in such a way that she may access quality health services, including family planning, birth control, and safe births. The international magazine, *Reproductive Health*, proposes another interesting and detailed definition for sexual and reproductive health:

“Reproductive health is defined as a state of physical, mental, and social well-being in all matters relating to the reproductive system, at all stages of life. Good reproductive health implies that people are able to have a satisfying and safe sex life, the capability to reproduce and the freedom to decide if, when, and how often to do so. Men and women should be informed about and have access to safe, effective, affordable, and acceptable methods of family-planning of their choice, and the right to appropriate health-care services that enable women to safely go through pregnancy and childbirth”.

(*Reproductive Health*, 2012).

The recognition of the right to sexual and reproductive healthcare-services highlights the need to implement sexual education programs for women, to reduce healthcare-access inequalities, and to eliminate barriers that prevent women from living full and satisfactory sexual and reproductive lives. Autonomy, or lack thereof, is a factor that may well influence a woman's sexual and reproductive health. Researchers have already connected differing forms of autonomy with sexual and reproductive health using qualitative, quantitative, and mixed research methods. For example, in western contexts, a woman's limited physical autonomy, as relates to finances and decision making in the home, has been empirically connected to barriers to improving sexual and reproductive health. In this way, autonomy is directly related with self-determination, and a woman's ability to make personal decisions.

Brené Brown (2010) warns western cultures against confusing autonomy with self-sufficiency, or the idea of always doing things on one's own. Brown notes that western cultures associate personal success with not depending on anyone. This, she calls the myth of being “self-sufficient”. Self-esteem and personal worth tend to be inextricably tied to the

ability to “never ask anyone for help, but always be ready to give it”. Dangerously, this western definition of autonomy is not always beneficial to women, especially in those contexts where interdependence is a fundamental factor for social recognition and overall wellbeing.

What dominantly emerges from studies linking autonomy and sexual and reproductive health is a direct relationship between a woman’s lack of physical autonomy and her poor sexual and reproductive health (Cleland, Kamal, & Sloggett, 1996). Globally, many women find it impossible to escape physical, psychological and social isolation, and as a result they are not able to access basic services, like schools and healthcare centers. The denial of freedom of mobility is ingrained socially, in community and religious norms. In many cases, it cohabits with an unfriendly environment towards the woman. Leaving the house turns into a necessary evil, full of hostility or harassment.

Clearly, lack of freedom of mobility affects access to the services that ensure a woman’s well being. These services vary according to stage of life, community environment, social positioning, work, and resources, etc. A woman’s freedom of mobility (or lack thereof) is not static. It is dynamic and changes along with factors and circumstances. Many studies suggest a direct relationship between more autonomy and less healthcare-access barriers for women, as compared to women with less autonomy (Bloom et al. 2001; Bhatia & Cleland, 1994). One strong constraint to autonomy are the social conditions that women confront in their every day environment, and high rates of sexual and verbal assault in busses and on the streets.

Limited physical autonomy, imposed by social norms and self-isolation motivated by frequency of assaults is much more prevalent than commonly thought, even in countries that have adopted drastic measures, such as segregating public transportation to reduce such occurrences. Among those countries that have adopted similar measures are: Japan, Egypt,

India, Iran, Taiwan, Brazil, Mexico, Indonesia, the Philippines, Malaysia, and Dubai. Today, physical assault is such a common phenomenon that Amnesty International has demanded that attention be paid to recent attacks and acts of aggression against female journalists and photographers who work on the streets (Amnesty International, 2013).

Because of these attacks, collective hostility, social norms and systems of oppression, women's public space has been drastically reduced, limiting physical autonomy. Public space, personal mobility, and physical autonomy are, in turn, fundamentally important factors to consider when implementing healthcare programs that target women in low and middle-income countries. In 1993, Bhatia y Cleland conducted a survey spanning southern India to investigate women's behavior as related to access to prenatal healthcare. The authors broke down the significance of autonomy into four components and developed four questions dealing with: a woman's economic and financial decision-making power, mobility, ability to communicate sensitive topics with her spouse, and workload related to household maintenance. Participating women answered questions directly. Along with these variables, researchers collected other important determinants for sexual and reproductive wellbeing such as: education level, personal hygiene, economic status, religion, whether or not they were giving birth for the first time, number of kids, and motivation for attending healthcare centers.

Determining factors in the use of maternal healthcare services were found to be education, place of residence, and personal hygiene. Autonomy and economic status did not turn out to be statistically significant. Religion was found to be an important factor for Muslim and Hindu women. Contrary to popular thought, according to the survey, Muslim women access pre and postpartum care much more frequently than Hindu women. All of this together allows us to infer that autonomy can be both a determining or a non determining factor when it comes to use of prenatal of postpartum healthcare.

In order to operationalize autonomy one of the most direct measures has been used as proxy for this condition: access to paid job. This variable has been operationalized as follows:

1 = the woman has a job at the time of the interview;

0 = the woman does not have a job at the time of the interview.

2.2.2.5 The “significant other’s” knowledge (Sig)

Another important factor associated with commitment to the program is the partner’s awareness of the woman’s HIV condition. Women whose partners are aware of their conditions seem to be three times as likely to stay in the program, compared to women whose partners are not informed of her sero status (Kebaabetswe, 2007). While this may be the case, literature from a Dominican study illustrates how the woman’s disclosure of her condition to her partner might lead to violence and rejection (Betances, 2007). In the Dominican context, therefore, the notion of “partner knowledge” has been changed to “significant other” knowledge as suggested by Lie and Biswalo (1996). This takes into account that within the Dominican context, both extended and close family members are part of a support system in the case of economic, social and health crises. This is not a new concept, and applies directly to HIV positive women. Lie and Biswalo illustrate how the importance of sharing the information with a “significant other,” who may be relied on a confidant (usually a mother or a sister) indicated positive consequences on the medical regime of the patient:

“It was very rare for the HIV-infected individuals or AIDS patients to choose someone outside the family when deciding on a confidant. But among the family members chosen, 90% were close family as compared to extended family. The family plays a critical role in the lives of most Tanzanians, emotionally as well as materially. Belonging within the family is of utmost importance for the AIDS patient in a very profound sense of the meaning of the term ‘belonging’. The fear of rejection is a fear that most patients have to overcome. Choosing a close family member, preferably of one’s own gender and of one’s own generation, seems to be a way of

ensuring empathy, but in the context of soliciting support in the process of securing continued belonging in the family”

(Lie and Biswalo, 1996).

This condition variable has been operationalized as follows:

1 = the women could identify at least a “significant other” on which to rely when in need;

0 = the women could not identify a “significant other” on which to rely when in need.

2.2.2.6 Cost (cos)

There is an important body of literature addressing the importance of service accessibility, place of residence and cost of transportation in women’s sexual and reproductive health care (Thaddeus and Maine, 1994; Mekonnen, 2002; Say and Raine, 2007; Gabryisch and Campbell, 2009). The transport between community and health facility usually imposes an unaffordable expense on time, money and opportunity cost on women seeking health care (Gabryisch and Campbell, 2009; Marcos et al., 2012), especially on rural settings characterized by extreme long distances (Zachariah et al., 2006; Bwirire et al.; 2008).

The PMTCT studies mostly carried out in rural settings of Africa, India and Bangladesh (continental-size territories) highlight the “inability to afford transport costs related to the long distances to the hospital” (Bwirire et al., 2008) as one of the factors influencing loss of follow-up and lack of adherence to the cascade of PMTCT (Zachariah et al., 2006) This concern about transportation costs and long distance as a disincentive and obstacle to adequate sexual and reproductive health care has led to a series of policy recommendations aimed at making health services accessible and affordable to poor women (Koblinsky et al., 2000, Rahman et al., 2007). The rule of thumb for policy-making has been coined by Rahman et al.,

“the effect-modifying role of service accessibility has a major policy implication: to reduce the inequality in care-seeking between rich and poor, empowered and non-empowered, services need to be made available and accessible” (Ibidem).

The implication for PMTCT programs has been to decentralize PMTCT and ART services, expanding the network of health facilities and placing them closer to the communities where the intended users live. (Green, 1998; Zacariah et al., 2006, Bwirire et al., 2008). However this rationale does not take into account the role of stigma-avoidance in the service provider decisions made by women living with HIV. As Marcos et al. point out,

“access to healthcare services is further compounded by stigma, which makes it especially difficult for women to seek and receive the care they need for themselves and their babies. Often women face the added burden of travelling to areas where they will not be recognized so that they may anonymously use prevention of vertical transmission services”.

(2012).

The obvious consequence of that prevalence of stigmatization is that women are reluctant to disclose their HIV positive status and they may prefer to go to ANC clinics where they are not known or change to another clinic where their HIV status is unknown. (Msellati, 2009). This is especially relevant in the urban-settings of *popular barrios* in Santo Domingo where most of the women included in the population studied live. As it will be seen in the following chapters, most of them decide to receive PMTCT services in facilities different than the ones located in their immediate environment. Conversely, in order to guarantee anonymity and avoid public shame, family exclusion and partner violence (Karamagi et al 2006, Msellati, 2009) they decide to use more remote facilities, even if it implies a higher transport cost. Therefore, cost needs to be included in order to be tested in for the analysis.

This variable was constructed using the main forms of public transportation in the Dominican Republic and their costs, from home to hospital, and back. The most popular form of public transportation in the country used is the so-called “carrito público.” This is a normal

five-seat car that sits seven people: three in the front and four in the back. Each carrito has specific routes, and the standard fair is 25RD\$ (0.49 euros). Considering that the interviewee's average income was 700RD\$ per fifteen days, the transportation costs involved in reaching the hospital at least twice a month can be extremely taxing on her tight budget. For example, the average cost per woman per round trip was 140RD\$, or 20% of her average, 15 days income.

The minimum roundtrip cost that a program participant incurs in Santo Domingo is 50RD\$. This is equal to two carritos: one to arrive at the health center, and one to return to her house. The scale of expenses used in this research is calculated starting from 50RD\$, and considering 140RD\$ as the average cost.

The cost variable, has been operationalized as follows:

1 = the woman spends no more than 50RD\$ to travel between her health center and her home (“2 carritos”);

0,67 = the woman spends between 51RD\$ and 150RD\$ to travel between her health center and her home (“4 carritos”);

0,33 = the woman spends between 151RD\$ and 200RD\$ to travel between her health center and her home (More than “4 carritos” and a “motor”)

0 = the woman spends more than 201RD\$ to travel between her health center and her home (“Guagua” or taxi for long distance travel).

2.2.2.7 Spanish spoken (spa)

Dominican Republic shares the island of La Hispaniola with its neighbor Haiti. Given the significant and widening socio-economic gap between both countries², there is an important migration flow from Haiti –the poorest country in the Americas- towards the relatively richer Dominican Republic. Historically the migration pattern was directed towards the rural areas, specially the sugar cane plantations. As Silie points out, this traditional migration was

“formed by rural workers, concentrated in sugar cane industry and other minor agriculture activities. This pattern led the Haitian migrants to concentrate in sugar cane enclaves with little visibility for the urban sectors in the hosting country. Furthermore it was a mostly male labor force with seldom women that played a secondary role in terms of domestic work in the migrant households”.

(2013; Author’s Translation).

However, with the decline of the Dominican Sugar Industry in the mid 80’s and the subsequent restructuration and diversification of the Dominican Economy along with Haiti’s sustained economic crisis and socio-political instability, a new migration pattern arose, increasingly urban, with more regional diversity and a moderate growing participation of women and children. (Silie, Segura & Dore 2002, Silie 2003, UNDP 2005 & 2010). In 2002, according to OM-FLACSO Survey of Haitian Migrants, women represented 22% of the Haitian migrants, a percentage that has been increasing over time and in 2012, according to the National Survey of Migrants they comprise 34.6%.

This steady feminization of the Haitian migration (Silie 2003, Landry 2013) has direct effects on the health system and the sexual and reproductive health of both the migrant and the general population. According to Health Ministry reports (2008), 18% of all births in the

² Some indicators of this gap, as reported by UNDP (2010), are: DR Human Development Index is 77 spots higher than Haiti’s, Life Expectancy is 15.7% higher, Literacy rate is 30% higher, and the Haitian GDP per capita PPA is just 17% of the Dominican GDP.

public health system are from Haitian mothers, but in the border region with Haiti, Santo Domingo, the capital city, and Santiago, the second city, this percentage is over 25%.

Most Haitian migrants (92%) lack any kind of health insurance. Consequently, public health centers are the most common health service available for them. According to ENI 2012, 66% of the Haitian migrants who had health problems on the last 12 months attended public hospitals, and in the case of women this percentage climbs to 72%. Almost half of the migrants received free medical services.

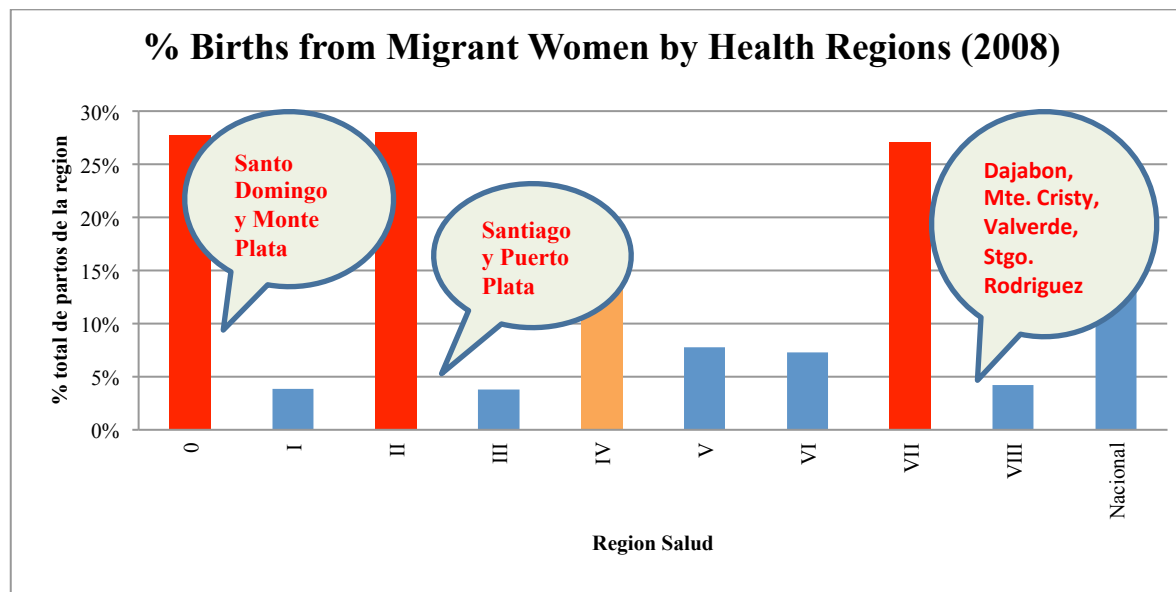


Diagram 1: Elaborated by Mercedes (2010) with official data from Health Ministry.

Literature shows that in bi-lingual or multilingual settings, language operates as one of the most important barriers for health care of migrant populations, especially when a rather numerous group of migrants has limited proficiency of the local language (Ku & Waidman, 2003; Ku & Flores, 2005; Saha & Fernandez, 2007)

As Flores (2006) states, “language barriers can have deleterious effects. Patients who face such barriers are less likely than others to have a usual source of medical care; they

receive preventive services at reduced rates; and they have an increased risk of non-adherence to medication”. There is also higher risk compromising the quality of care through misdiagnosis, medical errors, less effective patient-provider communication, poorer follow-up/adherence and possible conflicts with patient privacy rights and informed consent (Ku & Flores, 2005; Schenker, 2007; Regenstein, 2008).

According to ONE (2012), 82% of Haitian Migrants speak Kreyol at home and only 35.7% spoke Spanish ”well or very well”. More than a quarter (26%) spoke little or no Spanish and more than a third (38.1%) spoke it with difficulties. Hence, almost two thirds (64%) had Limited Spanish Proficiency –LSP-. There is also a significant gender gap in Spanish Proficiency, where the percentage of Haitian women that spoke little or no Spanish is 35.6% while on men is 20.9%. Haitian women with LSP represent 69% of the Haitian female migrant population.

As Dohan and Levintova (2007) reminds us, “language barriers actually obstruct two channels of communication –linguistic and cultural- and the latter may be the more important”. Translating words may be relatively simple, but unpacking their cultural meaning could be more challenging.

In order to overcome these barriers a mix of language services could be applied by health centers. The most common options are (Regenstein 2008):

- 1) Interpreter: a professional who translates a spoken message into a second language
- 2) Dual-role staff: A clinical or non-clinical staff member with proficiency in more than one language who is asked to interpret for patients with limited language proficiency.
- 3) Bilingual provider: Health care provider with proficiency in more than one language

- 4) Ad-hoc interpreters: untrained person (family member, friend) or a bilingual non-clinical staff who has not been properly trained in medical interpretation or lacks medical fluency.

In the PMCT program there are no formal interpreters. Most of the communication occurs without translation or is translated by ad-hoc interpreters (mainly relatives and friends) or by dual-role staff, namely the consejeras pares) who are fluent in Kreyol but have not been trained in medical interpretation. There are a few bilingual providers but clearly insufficient. Most of the patient-provider communication is distorted by what Ku & Flores (2005) in the US context call “poorly trained, inexperienced or inappropriate interpreters”. The use of untrained medical interpreters can sometimes do more harm than good by misinterpreting or omitting information³.

This lack of adequate language interpretation services constitutes an important patient safety concern, infringes patient privacy, and undermines the necessary informed consent (Ku & Flores, 2005, Schenker et al., 2007, Flores, 2005; Flores, 2006), all of which are parameters of paramount importance in sexual and reproductive health.

There are significant Risk Factors associated with LSP population: a) they experience disproportionately high rates of infectious diseases, chronic diseases and infant mortality (Office of Minority Health, 2007); b) the quality of care is affected, including worse interpersonal care and lower patient satisfaction (Ngo-Metzer et al., 2007), less access to preventive health services (Woloshin et al., 1997), and less access to documentation and appropriate information (Schenker et al., 2005), c) the patient’s participation and engagement

³ One study in the US revealed that ad-hoc interpreters omitted or misinterpreted up to half of the physicians questions (Ebden et al., 1998).

in care is diminished, including follow-up compliance and adherence to medical instructions (Ku & Waidmann, 2003; Andrulis, et al., 2003).

The women that were able to conduct interviews in Spanish have been categorized as fluent in Spanish. A 1 was attributed to them. Others have been attributed with a zero 0.

1 = The woman speaks Spanish

0 = The woman does not speak Spanish.

ADHERENCE TABLE FOR FUZZY ANALYSIS

Outcome & Condition	Value	Description of value attribution
Effective Risk (o)	1	Very low risk for the woman and her baby; perfect adherence
	0,67	Low risk for the woman and her baby; good adherence
	0,33	High risk for the woman and her baby; low adherence
	0	Very high risk for the woman and her baby; lack of adherence/no adherence
Understanding of HIV (und)	1	Predominantly aware. The participant has knowledge of at least five out of six HIV transmission factors.
	0,67	Aware. The participant has knowledge of four out of six HIV transmission factors.
	0,33	Slightly aware. The participant has knowledge of three out of six HIV transmission factors.
	0	Not aware. The participant has knowledge of less than 4 out of 6 HIV transmission factors.
Violence (vio)	1	The participant does not consider herself a survivor of violence or is not able to identify episodes of violence or right violations inside our outside the hospital on her own.
	0	The participant considers herself a survivor of violence and/or is able to identify and recognize episodes of violence or right violations inside or outside the hospital on her own.
Education (edu)	1	The woman has completed at least primary education (7 years of school).
	0	The woman has not completed primary education or she does not have any education.
Economic autonomy (job)	1	The woman had a job at the time of the interview.
	0	The woman did not have a job at the time of the interview.
The "significant other's" knowledge (sig)	1	The woman could identify at least one "significant other" on which to rely when in need.
	0	The woman could not identify at least one "significant other" on which to rely when in need
Cost (cos)	1	The woman spends no more than 50RD\$ to travel between the health care center and her home. ("2 carritos")
	0,67	The woman spends between 51RD\$ and 100RD\$ to travel between the health care center and her home. ("4 carritos")
	0,33	The woman spends between 101RD\$ and 150RD\$ travel between the health care center and her home.
	0	The woman spends more than 201RD\$ to a travel between the health care center and her home. ("Guagua"- autobus or taxis for long distances)
Spanish spoken (spa)	1	The woman speaks Spanish
	0	The woman does not speak Spanish

2.3 Hypothesis

The hypothesis has been formulated as follows:

If a woman is fluent in the main language of the program, has a high understanding of her HIV condition and does not live in extreme poverty, she will be able to lower her effective risk for her and for her child.

2.4 Dataset

obs	o	und	vio	edu	job	pov	sig	cos	spa
1	1	0.67	1	1	1	1	1	0.67	1
2	0.33	1	1	1	0	0	1	0.67	1
4	0.67	1	1	0	1	1	0	0.67	1
6	0.67	1	1	0	0	0	1	0	1
10	0.33	0	1	0	0	1	1	0.67	0
11	1	1	0	0	1	0	0	0.67	1
12	0.33	1	1	1	0	1	1	0.67	1
13	1	1	1	0	0	1	1	0.67	1
14	0.67	1	0	0	0	0	1	1	1
16	0.67	1	1	1	0	1	1	0.33	0
17	0.33	0	1	0	0	1	1	1	0
19	0.67	0.67	1	1	0	1	0	0.67	0
20	1	0.67	1	0	1	1	1	0.67	1
21	0.33	1	0	1	0	0	1	1	0
22	0.33	1	1	0	0	1	0	1	1
23	0.67	1	1	0	0	1	0	1	1
24	0	0	0	0	0	0	0	0.67	0
25	0.33	1	1	1	0	0	1	0.67	1
26	0.67	1	1	1	0	1	1	0.67	1
27	0.67	1	1	1	0	0	0	0.67	1
28	0.67	1	1	0	0	1	0	0.67	1
29	0	0.33	0	0	0	1	1	0.67	0
30	0	1	1	0	0	0	0	0.67	1
32	0.33	1	1	1	0	0	1	0.67	1
33	0.33	0	1	0	0	1	0	1	0

35	1	1	1	0	1	1	1	0.67	0
37	0.67	0.67	0	1	0	0	0	1	0
38	1	1	1	1	0	1	1	0.67	1
46	0.67	0.33	1	0	1	1	1	0	1
47	0.67	0.33	1	1	0	1	1	0.33	1
48	1	1	1	1	1	1	1	0.67	1
49	0.33	1	1	1	0	0	1	0.67	1
50	1	1	0	1	1	1	1	0	1
52	1	1	1	1	0	1	1	0.67	1
53	0.33	0.67	0	1	1	1	0	1	1
54	0.67	1	0	1	0	1	1	0.33	1
57	1	1	1	1	0	1	1	0.67	1
58	0.67	1	0	0	0	1	0	0.67	1
59	1	1	1	1	1	1	1	0.67	1
60	1	1	1	1	1	1	1	0.67	1
61	0.67	0.67	1	0	0	0	1	0.33	1
63	0	1	1	1	0	1	1	0.33	1
65	0.67	1	1	1	1	1	0	1	1
70	0.33	1	0	0	0	0	1	0.67	1
71	1	1	0	1	0	1	1	0.67	1
72	1	1	1	1	0	1	0	0.33	1
73	0.33	1	0	1	1	1	0	0.67	1
74	0.67	1	0	1	1	1	1	0.33	1
75	0.67	1	1	0	0	1	1	0	1
76	0.67	0.67	1	0	0	1	1	1	1
77	1	1	1	1	0	1	1	0.67	1
78	0.67	0.67	1	1	0	1	0	0.33	1
79	1	1	1	1	0	1	1	1	1
80	1	1	1	1	0	1	1	0.67	1
81	0.33	1	0	1	1	1	0	0.67	1
82	0.67	0.67	1	1	0	1	1	1	1
84	1	1	1	1	0	1	1	0.67	1
85	1	1	1	0	0	1	1	0.67	1
86	0.67	1	1	1	1	1	0	0.33	1
88	1	1	1	1	0	1	1	0.67	1
93	1	1	1	1	1	1	1	1	1
94	1	1	1	0	1	1	1	1	1
95	0.67	1	1	1	0	1	1	1	1
97	1	1	1	1	1	1	1	1	1

98	0.33	0.67	0	0	1	1	1	0	1
100	1	1	1	1	0	1	0	0.67	1
101	0	0	1	0	0	1	0	1	0
102	0.67	0	1	1	0	0	0	0.67	1
103	0.33	0	1	0	0	1	0	0.67	0
104	0.33	0.33	0	1	0	0	0	0.67	0
106	0.33	0	0	0	1	1	0	0.67	1
107	0	0.67	1	0	0	0	0	1	1
108	0	0	1	1	0	1	1	0.67	1
109	0.67	0	1	0	0	0	0	0.67	1
110	0.67	1	1	0	1	1	0	0.67	1
111	0.33	1	1	1	0	1	1	0.67	0
112	0.33	1	1	1	0	1	1	0.67	1
113	1	1	1	1	0	1	1	0.67	1
114	0	1	1	1	0	0	1	0.33	0
115	1	0.33	1	0	0	1	0	0.33	1
116	0.67	0.67	0	0	0	1	0	1	0
118	0	1	0	0	0	1	1	0.67	1
119	1	0.33	1	0	1	1	1	1	1
120	0	0	1	0	1	1	0	1	0

3 ANALYSIS

3.1 Fuzzy Set Qualitative Comparative Analysis

This chapter presents two levels of analysis: the Fuzzy Set Qualitative-Comparative Analysis and Qualitative Analysis of transcribed interviews. These two levels are inherently related and were used to triangulate all information in the data collection process through a mixed method analysis. Using a mixed method allowed for the triangulation of data in such a way that conclusions drawn could be validated through the interaction of these two analysis levels.

The chapter is divided into two parts, accordingly: Fuzzy Set Qualitative-Comparative Analysis and Qualitative Analysis. In the first part, Fuzzy Set Qualitative-Comparative Analysis, the dataset was analyzed using both Positive and Negative Outcome analysis. In the second part, the transcribed interviews are analyzed using narrative research that triangulates the results of FSQCA.

3.2 Analysis of Necessity

3.2.1 Analysis of Necessity with Positive Outcome

A condition is said to be necessary for the outcome “if it is always present when the outcome occurs” (Rihoux and Ragin, 2009). It follows that for a condition 'X' to be necessary, it must be present when the outcome 'Y' is present. In other words, “Y is a subset of X”. The first step in the data analysis was to conduct an Analysis of Necessity for the outcome variable, “Effective Risk”. The Analysis of Necessary Conditions describes the Consistency and Coverage for each of the seven conditions in our database. From this first output it became clear

that 'Understanding of HIV (und)' and of the virus is *almost* a necessary condition as relates to low risk levels and high adherence program steps.

Analysis of Necessary Conditions

Outcome variable: o

Conditions tested:

	Consistency	Coverage
und	0.890308	0.707782
~und	0.186303	0.507376
vio	0.813117	0.656719
~vio	0.186883	0.483000
edu	0.625653	0.673750
~edu	0.374347	0.537500
job	0.341846	0.736250
~job	0.658154	0.567000
sig	0.690075	0.673019
~sig	0.309925	0.516774
cos	0.742117	0.683535
~cos	0.449410	0.833214
spa	0.884117	0.682090
~spa	0.115883	0.352353

The other condition that appears to be extremely important in reducing the effective risk for the child and for the mother is the condition 'Spanish spoken (spa).' This is logical, as explanations of how to navigate the program and its parts are given mainly in Spanish. All other conditions register values well below the 0.88 consistency. In some cases, a value's negation had a stronger consistency than the value itself. This is true, for example, with the condition 'Job.'

3.2.2 Analysis of Necessity with Negative outcome

This part analyzes all seven conditions, and their necessity for negative outcomes. In the analysis of the negative outcome, Coverage is not analyzed, only Consistency.

Through this analysis, we immediately note that only the condition 'Cost' -- the condition that describes the cost of transportation from the program participant's home to the healthcare

center -- has a consistency of over 0.86. This indicates that low transportation costs is *almost* a necessary condition (guidelines stipulate that 0.90 indicates a necessary condition) for the *absence* of the outcome. This counterintuitive result stems from the fact that program participants tend to access healthcare centers that give high quality service, according to recommendations. The fact that these are, in any case, located at a distance from their homes, allows them to avoid stigma and discrimination. 'Cost' is not, therefore, a barrier in the Dominican context. Unfortunately, the results of the analysis do not permit us to draw more conclusions about other conditions presented, and their necessity.

Analysis of Necessary Conditions

Outcome variable: ~o

Conditions tested:

	Consistency	Coverage
und	0.710616	0.353122
~und	0.411947	0.701264
vio	0.679975	0.343281
~vio	0.320025	0.517000
edu	0.484680	0.326250
~edu	0.515320	0.462500
pov	0.659548	0.327846
~pov	0.340452	0.578947
job	0.195915	0.263750
~job	0.804085	0.433000
sig	0.536366	0.326981
~sig	0.463634	0.483226
cos	0.856082	0.492872
~cos	0.450325	0.521879
spa	0.659239	0.317910
~spa	0.340761	0.647647

3.3 Analysis of Sufficiency for Positive Outcome

This part of the chapter presents those combinations of solutions derived from the Positive Outcome Analysis, that allow us to analyze the set of determinants of the program according to the voice of the participants who were able to complete the program with a very low risk of infecting their children. The first part of this subchapter analyzes data, starting with

the analysis of Necessary Conditions and the Truth Table Analysis with Complex Solution, Parsimonious Solution and Intermediate Solutions.

This part also describes steps used during the analysis, and reasons for adopting certain conditions and not others. Using these steps, the researcher was able to solve contradictions and improve understanding of the process of adherence and risk for the woman and for the child.

3.3.1 Resolving Contradictions

In a first attempt to analyze the database, the following Complex Solution was observed, using all seven conditions in the analysis: (und, vio, edu, job, sig, cos, spa). In this first part, no assumptions and no methods to deal with logical reminders are used:

```

Algorithm: Quine-McCluskey
True: 1

--- COMPLEX SOLUTION ---
frequency cutoff: 1.000000
consistency cutoff: 0.798206


```

	raw coverage	unique coverage	consistency
und*vio*~job*sig*spa	0.348230	0.045270	0.739523
und*edu*~job*sig*spa	0.289998	0.012962	0.713809
und*vio*sig*cos*spa	0.381118	0.090540	0.879464
und*~vio*~edu*~job*~sig*cos	0.025924	0.025924	1.000000
und*edu*~job*~sig*cos*~spa	0.032308	0.032308	1.000000
und*vio*edu*~sig*~cos*spa	0.051654	0.026117	1.000000
und*~vio*edu*sig*~cos*spa	0.051654	0.032308	1.000000
~und*vio*~edu*job*sig*spa	0.032308	0.019539	1.000000
vio*edu*~job*~sig*cos*spa	0.051654	0.026117	1.000000
und*~edu*job*~sig*cos*spa	0.038886	0.038886	1.000000
und*vio*~edu*job*sig*cos	0.051654	0.012962	1.000000
~und*vio*~edu*~job*~sig*~cos*spa	0.019346	0.019346	1.000000
solution coverage:	0.768814		
solution consistency:	0.856281		

This second output of fsQCA software revealed that the solution consistency for this model is in generally high: at 0.85 with solution coverage of 0.76. This indicates that 0.76 of the cases are included in the twelve configurations presented. Importantly, the first two configurations presented have consistencies of 0.74 and 0.71 respectively. These are comparatively low values, with respect to the others configurations. Rubinson reporting Ragin affirms that “consistency measures the strength of subset relationships and enables researchers to assess the degree to which cases sharing a particular combination of conditions also exhibit the same outcome” (2013). In other words, consistency reports the proportion of cases that exhibit the outcome (Rubinson, 2013). A consistency score lower than 0.75 implies substantial inconsistency (Ragin, 2008). It is necessary, therefore, to solve the contradictions implied in the first two configurations by returning to the original data.

In order to analyze each of these configurations in more detail, it is necessary to complement fsQCA with kirq. This last software allows the direct association between case and configuration in order to clear up the contradictions in the first analysis. 'Table 1' presents all configurations and the value for each condition (column und, vio, edu, job, sig, cos, spa), the number of cases for each configuration (column N), the consistency for each configuration (column Consist), whether or not the configuration is sufficient for the outcome (column Outcome), and which cases are consistent (column ObsConsist) or inconsistent (column ObsInconsist).

	und	vio	edu	job	Sig	cos	spa	N	Consist	Outcome	ObsConsist	ObsInconsist
1	True	True	True	True	True	True	True	6	1.00	True	1;48;59;60;93;97	-
2	True	True	True	True	True	True	False	0	n/a	Rem	-	-
3	True	True	True	True	True	False	True	0	n/a	Rem	-	-
4	True	True	True	True	True	False	False	0	n/a	Rem	-	-
5	True	True	True	True	False	True	True	1	0.75	False	-	65
6	True	True	True	True	False	True	False	0	n/a	Rem	-	-
7	True	True	True	True	False	False	True	1	1.00	True	86	-
8	True	True	True	True	False	False	False	0	n/a	Rem	-	-
9	True	True	True	False	True	True	True	18	0.80	Con	26;38;52;57;77;79;80;82;84;88;113	2;12;25;32;49;95;112
10	True	True	True	False	True	True	False	1	0.50	False	-	111
11	True	True	True	False	True	False	True	1	0.89	True	-	63
12	True	True	True	False	True	False	False	2	0.60	Con	16	114
13	True	True	True	False	False	True	True	2	1.00	True	27;100	-
14	True	True	True	False	False	True	False	1	1.00	True	19	-
15	True	True	True	False	False	False	True	2	1.00	True	72;78	-
16	True	True	True	False	False	False	False	0	n/a	Rem	-	-
17	True	True	False	True	True	True	True	2	1.00	True	20;94	-
18	True	True	False	True	True	True	False	1	1.00	True	35	-
19	True	True	False	True	True	False	True	0	n/a	Rem	-	-
20	True	True	False	True	True	False	False	0	n/a	Rem	-	-
21	True	True	False	True	False	True	True	2	1.00	True	4;110	-
22	True	True	False	True	False	True	False	0	n/a	Rem	-	-
23	True	True	False	True	False	False	True	0	n/a	Rem	-	-
24	True	True	False	True	False	False	False	0	n/a	Rem	-	-
25	True	True	False	False	True	True	True	3	1.00	True	13;76;85	-
26	True	True	False	False	True	True	False	0	n/a	Rem	-	-
27	True	True	False	False	True	False	True	3	0.80	Con	61	6;75
28	True	True	False	False	True	False	False	0	n/a	Rem	-	-
29	True	True	False	False	False	True	True	5	0.46	False	28	22;23;30;107

30	True	True	False	False	False	True	False	0	n/a	Rem	-	-
31	True	True	False	False	False	False	True	0	n/a	Rem	-	-
32	True	True	False	False	False	False	False	0	n/a	Rem	-	-
33	True	False	True	True	True	True	True	0	n/a	Rem	-	-
34	True	False	True	True	True	True	False	0	n/a	Rem	-	-
35	True	False	True	True	True	False	True	2	1.00	True	50;74	-
36	True	False	True	True	True	False	False	0	n/a	Rem	-	-
37	True	False	True	True	False	True	True	3	0.49	False	-	53;73;81
38	True	False	True	True	False	True	False	0	n/a	Rem	-	-
39	True	False	True	True	False	False	True	0	n/a	Rem	-	-
40	True	False	True	True	False	False	False	0	n/a	Rem	-	-
41	True	False	True	False	True	True	True	1	1.00	True	71	-
42	True	False	True	False	True	True	False	1	0.33	False	-	21
43	True	False	True	False	True	False	True	1	1.00	True	54	-
44	True	False	True	False	True	False	False	0	n/a	Rem	-	-
45	True	False	True	False	False	True	True	0	n/a	Rem	-	-
46	True	False	True	False	False	True	False	1	1.00	True	37	-
47	True	False	True	False	False	False	True	0	n/a	Rem	-	-
48	True	False	True	False	False	False	False	0	n/a	Rem	-	-
49	True	False	False	True	True	True	True	0	n/a	Rem	-	-
50	True	False	False	True	True	True	False	0	n/a	Rem	-	-
51	True	False	False	True	True	False	True	1	0.49	False	-	98
52	True	False	False	True	True	False	False	0	n/a	Rem	-	-
53	True	False	False	True	False	True	True	1	1.00	True	11	-
54	True	False	False	True	False	True	False	0	n/a	Rem	-	-
55	True	False	False	True	False	False	True	0	n/a	Rem	-	-
56	True	False	False	True	False	False	False	0	n/a	Rem	-	-
57	True	False	False	False	True	True	True	3	0.43	False	-	14;70;118

58	True	False	False	False	True	True	False	0	n/a	Rem	-	-
59	True	False	False	False	True	False	True	0	n/a	Rem	-	-
60	True	False	False	False	True	False	False	0	n/a	Rem	-	-
61	True	False	False	False	False	True	True	1	1.00	True	58	-
62	True	False	False	False	False	True	False	1	1.00	True	116	-
63	True	False	False	False	False	False	True	0	n/a	Rem	-	-
64	True	False	False	False	False	False	False	0	n/a	Rem	-	-
65	False	True	True	True	True	True	True	0	n/a	Rem	-	-
66	False	True	True	True	True	True	False	0	n/a	Rem	-	-
67	False	True	True	True	True	False	True	0	n/a	Rem	-	-
68	False	True	True	True	True	False	False	0	n/a	Rem	-	-
69	False	True	True	True	False	True	True	0	n/a	Rem	-	-
70	False	True	True	True	False	True	False	0	n/a	Rem	-	-
71	False	True	True	True	False	False	True	0	n/a	Rem	-	-
72	False	True	True	True	False	False	False	0	n/a	Rem	-	-
73	False	True	True	False	True	True	True	1	0.50	False	-	108
74	False	True	True	False	True	True	False	0	n/a	Rem	-	-
75	False	True	True	False	True	False	True	1	0.67	False	47	-
76	False	True	True	False	True	False	False	0	n/a	Rem	-	-
77	False	True	True	False	False	True	True	1	1.00	True	102	-
78	False	True	True	False	False	True	False	0	n/a	Rem	-	-
79	False	True	True	False	False	False	True	0	n/a	Rem	-	-
80	False	True	True	False	False	False	False	0	n/a	Rem	-	-
81	False	True	False	True	True	True	True	1	1.00	True	119	-
82	False	True	False	True	True	True	False	0	n/a	Rem	-	-
83	False	True	False	True	True	False	True	1	1.00	True	46	-
84	False	True	False	True	True	False	False	0	n/a	Rem	-	-
85	False	True	False	True	False	True	True	0	n/a	Rem	-	-

86	False	True	False	True	False	True	False	1	0.00	False	-	120	
87	False	True	False	True	False	False	True	0	n/a	Rem	-	-	
88	False	True	False	True	False	False	False	0	n/a	Rem	-	-	
89	False	True	False	False	True	True	True	0	n/a	Rem	-	-	
90	False	True	False	False	True	True	False	2	0.40	False	-	10;17	
91	False	True	False	False	True	False	True	0	n/a	Rem	-	-	
92	False	True	False	False	True	False	False	0	n/a	Rem	-	-	
93	False	True	False	False	False	True	True	1	0.75	False	109	-	
94	False	True	False	False	False	True	False	3	0.25	False	-	33;101;103	
95	False	True	False	False	False	False	True	1	1.00	True	115	-	
96	False	True	False	False	False	False	False	0	n/a	Rem	-	-	
97	False	False	True	True	True	True	True	0	n/a	Rem	-	-	
98	False	False	True	True	True	True	False	0	n/a	Rem	-	-	
99	False	False	True	True	True	False	True	0	n/a	Rem	-	-	
100	False	False	True	True	True	False	False	0	n/a	Rem	-	-	
101	False	False	True	True	False	True	True	0	n/a	Rem	-	-	
102	False	False	True	True	False	True	False	0	n/a	Rem	-	-	
103	False	False	True	True	False	False	True	0	n/a	Rem	-	-	
104	False	False	True	True	False	False	False	0	n/a	Rem	-	-	
105	False	False	True	False	True	True	True	0	n/a	Rem	-	-	
106	False	False	True	False	True	True	False	0	n/a	Rem	-	-	
107	False	False	True	False	True	False	True	0	n/a	Rem	-	-	
108	False	False	True	False	True	False	False	0	n/a	Rem	-	-	
109	False	False	True	False	False	True	True	0	n/a	Rem	-	-	
110	False	False	True	False	False	True	False	1	0.66	False	-	104	
111	False	False	True	False	False	False	True	0	n/a	Rem	-	-	
112	False	False	True	False	False	False	False	0	n/a	Rem	-	-	
113	False	False	False	True	True	True	True	0	n/a	Rem	-	-	
114	False	False	False	True	True	True	False	0	n/a	Rem	-	-	

115	False	False	False	True	True	False	True	0	n/a	Rem	-	-
116	False	False	False	True	True	False	False	0	n/a	Rem	-	-
117	False	False	False	True	False	True	True	1	0.49	False	-	106
118	False	False	False	True	False	True	False	0	n/a	Rem	-	-
119	False	False	False	True	False	False	True	0	n/a	Rem	-	-
120	False	False	False	True	False	False	False	0	n/a	Rem	-	-
121	False	False	False	False	True	True	True	0	n/a	Rem	-	-
122	False	False	False	False	True	True	False	1	0.00	False	-	29
123	False	False	False	False	True	False	True	0	n/a	Rem	-	-
124	False	False	False	False	True	False	False	0	n/a	Rem	-	-
125	False	False	False	False	False	True	True	0	n/a	Rem	-	-
126	False	False	False	False	False	True	False	1	0.33	False	-	24
127	False	False	False	False	False	False	True	0	n/a	Rem	-	-
128	False	False	False	False	False	False	False	0	n/a	Rem	-	-

Table 3: Output kirq with Consistency Threshold 0.80, Proportion Threshold 0.80, und, vio, edu, job, sig, cos, spa as Conditions, All Configurations and Respective Observations.

	und	vio	edu	job	Sig	cos	spa	N	Consist	Outcome	ObsConsist	ObsInconsist
9	True	True	True	False	True	True	True	18	0.80	Con	26;38;52;57;77;79;80;82;84;88;113	2;12;25;32;49;95;112
12	True	True	True	False	True	False	False	2	0.60	Con	16	114
27	True	True	False	False	True	False	True	3	0.80	Con	61	6;75

Table 4: Output kirq Filtered with Excel to Show Only Contradictions with Consistency Threshold 0.80, Proportion Threshold 0.80, und, vio, edu, job, sig, cos, spa as Conditions, Contradictory Configurations and Respective Observations.

Before analyzing the process of minimization, the contradictions present in the Truth Table must be solved. To find configurations with contradictions, the kirq file was exported to Excel and a filter produced by kirq was applied to the output. With the filter applied to the column 'Outcome,' three contradictory configurations and their respective cases were identified. These are shown in Table 2.

How were the contradictions solved? According to Rubinson, “there are three ways of doing so: by modifying the data set, by changing the parameters of the analysis, and by manually coding the Outcome column.” The contradictory configuration '9' was the first set analyzed. Of its eighteen cases, seven (observation 2; 12; 25; 32; 49; 95; 112) produced different outcomes. These seven observations register the following values for each condition:

obs	o	und	vio	edu	job	sig	cos	spa
2*	0,33	1	1	1	0	1	0,67	1
12*	0,33	1	1	1	0	1	0,67	1
25*	0,33	1	1	1	0	1	0,67	1
26	0,67	1	1	1	0	1	0,67	1
32*	0,33	1	1	1	0	1	0,67	1
38	1	1	1	1	0	1	0,67	1
49*	0,33	1	1	1	0	1	0,67	1
52	1	1	1	1	0	1	0,67	1
57	1	1	1	1	0	1	0,67	1
77	1	1	1	1	0	1	0,67	1
79	1	1	1	1	0	1	1	1
80	1	1	1	1	0	1	0,67	1
82	0,67	0,67	1	1	0	1	1	1
84	1	1	1	1	0	1	0,67	1
88	1	1	1	1	0	1	0,67	1
95*	0,67	1	1	1	0	1	1	1
112*	0,33	1	1	1	0	1	0,67	1
113	1	1	1	1	0	1	0,67	1

Table 5: Observation for Contradictory Configuration 9 with Respective Values

Returning to the transcribed interviews, the researcher uncovered an interesting pattern. While social connections and economic possibilities varied among all of the women, none of the interviewees had a job. Some of them did not have access to any type of economic help,

while some depended on their partners, their parents, or others for support. The condition, 'Job,' although a proxy in many high income countries for access to service -- as it relates to a woman's autonomy literature -- seems to count less in middle and low income countries. This is also described by Mumtaz y Salway (2009).

At this point, we must ask a very important question: what do different sociologies about women's autonomy contribute to understanding access to sexual and reproductive healthcare services? At the time of their interviews, the majority of interviewees were not working a paid job outside of the house. This can be attributed to two things. Some were postponing re-entering the job market, and therefore were not currently salaried. Some were housekeepers.

Western literature based on studies in developed countries maintains that economic autonomy -- one of the main predictors of which is a paid job outside the home -- is positively correlated to access to sexual and reproductive health services (Cleland, Kamal, & Sloggett, 1996; Bloom et al. 2001; Kim J, et al., 2002). These investigations, when developed in LMIC, lead to important policy implications. For example, in order to improve access to sexual and reproductive health services for women, it would be necessary to increase their access to the job market, thereby lessening their dependence on husbands or fathers. Although this is a very tempting theory -- and completely plausible in many western countries and in some LMICs -- in other, more 'traditional' societies, social connections and social capital are far more important in accessing sexual and reproductive health services than direct access to an income from a job.

In this research, the condition 'Job' has therefore been substituted with the condition "access to income". This, in turn, describes extreme poverty (pov). Not having a job in the Dominican context does not mean that the woman is economically deprived and socially excluded. On the contrary, many program participants counted on someone economically, usually a partner or a close family member. The condition was constructed using information

based on interviews that indicated whether or not the woman had access to income from close family members or her partner, allowing her to access basic commodities such as shelter and food. If the woman declared that she did not have access to food, or if she testified to not having access to other forms of income, she was attributed a 0. If she had access to food and shelter, if she worked, or if someone else was providing for her basic economics needs, she has been attributed a 1.

obs	o	und	vio	edu	pov	job	sig	cos	spa
2	0,33	1	1	1	0	0	1	0,67	1
12*	0,33	1	1	1	1	0	1	0,67	1
25	0,33	1	1	1	0	0	1	0,67	1
26	0,67	1	1	1	1	0	1	0,67	1
32	0,33	1	1	1	0	0	1	0,67	1
38	1	1	1	1	1	0	1	0,67	1
49	0,33	1	1	1	0	0	1	0,67	1
52	1	1	1	1	1	0	1	0,67	1
57	1	1	1	1	1	0	1	0,67	1
77	1	1	1	1	1	0	1	0,67	1
79	1	1	1	1	1	0	1	1	1
80	1	1	1	1	1	0	1	0,67	1
82	0,67	0,67	1	1	1	0	1	1	1
84	1	1	1	1	1	0	1	0,67	1
88	1	1	1	1	1	0	1	0,67	1
95	0,67	1	1	1	1	0	1	1	1
112*	0,33	1	1	1	1	0	1	0,67	1
113	1	1	1	1	1	0	1	0,67	1

Table 6: Configuration #9 with the Addition of “pov” as Condition

As observed in Table 4, access to income (pov) discriminates to a greater extent than the condition 'job.' Using this condition, the majority of contradictions were successfully eliminated. This being the case, the researcher ran the analysis again, substituting the new condition 'pov' for 'job.' First, the researcher ran the data for the analysis of necessity, with all eight conditions, even though the values for the other conditions did not change:

Analysis of Necessary Conditions

Outcome variable: o

Conditions tested:

	Consistency	Coverage
und	0.890308	0.707782
~und	0.186303	0.507376
vio	0.813117	0.656719
~vio	0.186883	0.483000
edu	0.625653	0.673750
~edu	0.374347	0.537500
pov	0.845231	0.672154
~pov	0.154769	0.421053
job	0.341846	0.736250
~job	0.658154	0.567000
sig	0.690075	0.673019
~sig	0.309925	0.516774
cos	0.742117	0.683535
~cos	0.449410	0.833214
spa	0.884117	0.682090
~spa	0.115883	0.352353

In this analysis, poverty scored among the highest in both Consistency and Coverage, indicating that it is a plausible condition to should be considered for the analysis. Since 'access to income' discriminated more than the condition 'job,' the data was run again to determine if contradictions were present, even after inserting the new condition. The new kirq outcome is reported in Table 5. Table 6 reports three new contradictory rows: number 5, 21 and 27. As follows, it was again necessary to begin where the number of cases was the higher, and thus more difficult to solve: contradictory row 21. Table 7 describes the five observations that fall under contradictory row 21, with the values of their conditions. Reviewing each transcribed interview, it was not possible to identify an additional condition or reason for which -- especially Observation 22 -- presented a different outcome compared to other observations. The consistency to for observation 22 was only 0.77. Because the proportion threshold was established at 0.80, and because this configuration only scores 0.60, it has been set as a reminder.⁴

⁴ “[...] the researcher can always manually recode a contradictory row. It may be that, for one reason or another, a contradiction cannot be eliminated empirically. The researcher may be unable to collect additional data. Or there

This decision represents a more conservative approach than the approach suggested by Rubinson, who affirms that for large-N, individual-level studies, it is acceptable to lower the proportion threshold to 50% in order not to produce contradictions filters. Quo Rubinson: “this is particularly useful for large-N, individual-level studies and other instances in which one expects a fair amount of inconsistency within the vector spaces corners” (2013).

Table 8 shows the contradictory configuration #5, and the values of its conditions. After reviewing interview transcripts, and considering the fact that the values of the outcome registered a consistency of 0.88, and also that the presence of one significant, alone, cannot drastically affect the risk described in the outcome, this configuration has been established as sufficient for the outcome. It has been included in the process of minimization.

Contradictory row #27 is the last of the contradictory configurations. The values for each observation pertaining to this configuration are shown in Table 9. This case registered a consistency of 0.80. Considering the distribution of values -- as in the aforementioned table -- there are enough elements to affirm that this configuration is sufficient for the outcome.

may be random variation among the observations. In such circumstances, if the researcher has a strong theoretical and/or empirical basis for classifying a particular combination of causal conditions as consistent or inconsistent, he or she should do so” (Rubinson, 2013).

	und	vio	edu	pov	sig	cos	spa	N	Consist	Outcome	ObsConsist	ObsInconsist
1	True	True	True	True	True	True	True	20	0.91	True	1;26;38;48;52;57;59;60;77;79;80;82;84;88;93;97;113	12;95;112
2	True	True	True	True	True	True	False	1	0.66	False	-	111
3	True	True	True	True	True	False	True	1	0.89	True	-	63
4	True	True	True	True	True	False	False	1	1.00	True	16	-
5	True	True	True	True	False	True	True	2	0.88	Con	100	65
6	True	True	True	True	False	True	False	1	1.00	True	19	-
7	True	True	True	True	False	False	True	3	1.00	True	72;78;86	-
8	True	True	True	True	False	False	False	0	n/a	Rem	-	-
9	True	True	True	False	True	True	True	4	0.49	False	-	2;25;32;49
10	True	True	True	False	True	True	False	0	n/a	Rem	-	-
11	True	True	True	False	True	False	True	0	n/a	Rem	-	-
12	True	True	True	False	True	False	False	1	0.00	False	-	114
13	True	True	True	False	False	True	True	1	1.00	True	27	-
14	True	True	True	False	False	True	False	0	n/a	Rem	-	-
15	True	True	True	False	False	False	True	0	n/a	Rem	-	-
16	True	True	True	False	False	False	False	0	n/a	Rem	-	-
17	True	True	False	True	True	True	True	5	1.00	True	13;20;76;85;94	-
18	True	True	False	True	True	True	False	1	1.00	True	35	-
19	True	True	False	True	True	False	True	1	0.86	True	-	75
20	True	True	False	True	True	False	False	0	n/a	Rem	-	-
21	True	True	False	True	False	True	True	5	0.77	Con	4;28;110	22;23
22	True	True	False	True	False	True	False	0	n/a	Rem	-	-
23	True	True	False	True	False	False	True	0	n/a	Rem	-	-
24	True	True	False	True	False	False	False	0	n/a	Rem	-	-
25	True	True	False	False	True	True	True	0	n/a	Rem	-	-
26	True	True	False	False	True	True	False	0	n/a	Rem	-	-
27	True	True	False	False	True	False	True	2	0.80	Con	61	6
28	True	True	False	False	True	False	False	0	n/a	Rem	-	-
29	True	True	False	False	False	True	True	2	0.00	False	-	30;107

30	True	True	False	False	False	True	False	0	n/a	Rem	-	-	
31	True	True	False	False	False	False	True	0	n/a	Rem	-	-	
32	True	True	False	False	False	False	False	0	n/a	Rem	-	-	
33	True	False	True	True	True	True	True	1	1.00	True	71	-	
34	True	False	True	True	True	True	False	0	n/a	Rem	-	-	
35	True	False	True	True	True	False	True	3	1.00	True	50;54;74	-	
36	True	False	True	True	True	False	False	0	n/a	Rem	-	-	
37	True	False	True	True	False	True	True	3	0.49	False	-	53;73;81	
38	True	False	True	True	False	True	False	0	n/a	Rem	-	-	
39	True	False	True	True	False	False	True	0	n/a	Rem	-	-	
40	True	False	True	True	False	False	False	0	n/a	Rem	-	-	
41	True	False	True	False	True	True	True	0	n/a	Rem	-	-	
42	True	False	True	False	True	True	False	1	0.33	False	-	21	
43	True	False	True	False	True	False	True	0	n/a	Rem	-	-	
44	True	False	True	False	True	False	False	0	n/a	Rem	-	-	
45	True	False	True	False	False	True	True	0	n/a	Rem	-	-	
46	True	False	True	False	False	True	False	1	1.00	True	37	-	
47	True	False	True	False	False	False	True	0	n/a	Rem	-	-	
48	True	False	True	False	False	False	False	0	n/a	Rem	-	-	
49	True	False	False	True	True	True	True	1	0.00	False	-	118	
50	True	False	False	True	True	True	False	0	n/a	Rem	-	-	
51	True	False	False	True	True	False	True	1	0.33	False	-	98	
52	True	False	False	True	True	False	False	0	n/a	Rem	-	-	
53	True	False	False	True	False	True	True	1	1.00	True	58	-	
54	True	False	False	True	False	True	False	1	1.00	True	116	-	
55	True	False	False	True	False	False	True	0	n/a	Rem	-	-	
56	True	False	False	True	False	False	False	0	n/a	Rem	-	-	
57	True	False	False	False	True	True	True	2	0.60	False	-	14;70	
58	True	False	False	False	True	True	False	0	n/a	Rem	-	-	

59	True	False	False	False	True	False	True	0	n/a	Rem	-	-
60	True	False	False	False	True	False	False	0	n/a	Rem	-	-
61	True	False	False	False	False	True	True	1	1.00	True	11	-
62	True	False	False	False	False	True	False	0	n/a	Rem	-	-
63	True	False	False	False	False	False	True	0	n/a	Rem	-	-
64	True	False	False	False	False	False	False	0	n/a	Rem	-	-
65	False	True	True	True	True	True	True	1	0.60	False	-	108
66	False	True	True	True	True	True	False	0	n/a	Rem	-	-
67	False	True	True	True	True	False	True	1	0.75	False	47	-
68	False	True	True	True	True	False	False	0	n/a	Rem	-	-
69	False	True	True	True	False	True	True	0	n/a	Rem	-	-
70	False	True	True	True	False	True	False	0	n/a	Rem	-	-
71	False	True	True	True	False	False	True	0	n/a	Rem	-	-
72	False	True	True	True	False	False	False	0	n/a	Rem	-	-
73	False	True	True	False	True	True	True	0	n/a	Rem	-	-
74	False	True	True	False	True	True	False	0	n/a	Rem	-	-
75	False	True	True	False	True	False	True	0	n/a	Rem	-	-
76	False	True	True	False	True	False	False	0	n/a	Rem	-	-
77	False	True	True	False	False	True	True	1	1.00	True	102	-
78	False	True	True	False	False	True	False	0	n/a	Rem	-	-
79	False	True	True	False	False	False	True	0	n/a	Rem	-	-
80	False	True	True	False	False	False	False	0	n/a	Rem	-	-
81	False	True	False	True	True	True	True	1	1.00	True	119	-
82	False	True	False	True	True	True	False	2	0.40	False	-	10;17
83	False	True	False	True	True	False	True	1	1.00	True	46	-
84	False	True	False	True	True	False	False	0	n/a	Rem	-	-
85	False	True	False	True	False	True	True	0	n/a	Rem	-	-
86	False	True	False	True	False	True	False	4	0.18	False	-	33;101;103;120
87	False	True	False	True	False	False	True	1	1.00	True	115	-

88	False	True	False	True	False	False	False	0	n/a	Rem	-	-
89	False	True	False	False	True	True	True	0	n/a	Rem	-	-
90	False	True	False	False	True	True	False	0	n/a	Rem	-	-
91	False	True	False	False	True	False	True	0	n/a	Rem	-	-
92	False	True	False	False	True	False	False	0	n/a	Rem	-	-
93	False	True	False	False	False	True	True	1	0.67	False	109	-
94	False	True	False	False	False	True	False	0	n/a	Rem	-	-
95	False	True	False	False	False	False	True	0	n/a	Rem	-	-
96	False	True	False	False	False	False	False	0	n/a	Rem	-	-
97	False	False	True	True	True	True	True	0	n/a	Rem	-	-
98	False	False	True	True	True	True	False	0	n/a	Rem	-	-
99	False	False	True	True	True	False	True	0	n/a	Rem	-	-
100	False	False	True	True	True	False	False	0	n/a	Rem	-	-
101	False	False	True	True	False	True	True	0	n/a	Rem	-	-
102	False	False	True	True	False	True	False	0	n/a	Rem	-	-
103	False	False	True	True	False	False	True	0	n/a	Rem	-	-
104	False	False	True	True	False	False	False	0	n/a	Rem	-	-
105	False	False	True	False	True	True	True	0	n/a	Rem	-	-
106	False	False	True	False	True	True	False	0	n/a	Rem	-	-
107	False	False	True	False	True	False	True	0	n/a	Rem	-	-
108	False	False	True	False	True	False	False	0	n/a	Rem	-	-
109	False	False	True	False	False	True	True	0	n/a	Rem	-	-
110	False	False	True	False	False	True	False	1	0.66	False	-	104
111	False	False	True	False	False	False	True	0	n/a	Rem	-	-
112	False	False	True	False	False	False	False	0	n/a	Rem	-	-
113	False	False	False	True	True	True	True	0	n/a	Rem	-	-
114	False	False	False	True	True	True	False	1	0.00	False	-	29
115	False	False	False	True	True	False	True	0	n/a	Rem	-	-

116	False	False	False	True	True	False	False	0	n/a	Rem	-	-
117	False	False	False	True	False	True	True	1	0.49	False	-	106
118	False	False	False	True	False	True	False	0	n/a	Rem	-	-
119	False	False	False	True	False	False	True	0	n/a	Rem	-	-
120	False	False	False	True	False	False	False	0	n/a	Rem	-	-
121	False	False	False	False	True	True	True	0	n/a	Rem	-	-
122	False	False	False	False	True	True	False	0	n/a	Rem	-	-
123	False	False	False	False	True	False	True	0	n/a	Rem	-	-
124	False	False	False	False	True	False	False	0	n/a	Rem	-	-
125	False	False	False	False	False	True	True	0	n/a	Rem	-	-
126	False	False	False	False	False	True	False	1	0.00	False	-	24
127	False	False	False	False	False	False	True	0	n/a	Rem	-	-
128	False	False	False	False	False	False	False	0	n/a	Rem	-	-

Table 7: Output kirq with Consistency Threshold 0.80, Proportion Threshold 0.80, und, vio, edu, pov, sig, cos, spa as Conditions, All Configurations and Respective Observations.

	und	vio	Edu	pov	sig	cos	spa	N	Consist	Outcome	ObsConsist	ObsInconsistent
5	True	True	True	True	False	True	True	2	0.88	Con	100	65
21	True	True	False	True	False	True	True	5	0.77	Con	4;28;110	22;23
27	True	True	False	False	True	False	True	2	0.80	Con	61	6

Table 8: Output kirq Filtered with Excel to Show Only Contradictions with Consistency Threshold 0.80, Proportion Threshold 0.80, und, vio, edu, pov, sig, cos, spa as Conditions, Contradictory Configurations and Respective Observations.

obs	O	und	vio	edu	pov	sig	cos	spa
4	0.67	1	1	0	1	0	0.67	1
22*	0.33	1	1	0	1	0	1	1
23*	0.67	1	1	0	1	0	1	1
28	0.67	1	1	0	1	0	0.67	1

110	0.67	1	1	0	1	0	0.67	1
-----	------	---	---	---	---	---	------	---

Table 9: Observations for Contradictory Configuration 21 with Respective Values.

obs	O	und	vio	edu	pov	Sig	cos	spa
65	0.67	1	1	1	1	0	1	1
100	1	1	1	1	1	0	0.67	1

Table 10: Observations for Contradictory Configuration 5 with Respective Values.

obs	O	und	vio	edu	pov	Sig	cos	spa
6	0.67	1	1	0	0	1	0	1
61	0.67	0.67	1	0	0	1	0.33	1

Table 11: Observations for Contradictory Configuration 27 with Respective Values.

3.3.2 Enhanced Standard Analysis

Traditional approaches to fsQCA use standard analysis as a procedure to minimize truth table rows and create three types of solutions (conservative, most parsimonious, and intermediate). These approaches process lines of the truth table that have not been empirically observed (logical reminders). Traditional approaches tend to use intermediate solutions as preferable to complex and parsimonious since they:

“have several advantageous properties: they strike a balance between parsimony and complexity; they are the results of supplementing the empirical information at hand with a controlled dose of theory-guided assumption; and they handle logical reminders in a conscious yet practical manner”

(Schneider and Wagemann, 2013).

However, in *Set-Theoretic Methods for the Social Sciences*, Schneider and Wagemann advocate that parsimony is always preferable. They propose an alternative remedy to deal with logical reminders, the so-called, Enhanced Standard Analysis (ESA). ESA is a strategy for avoiding unattainable assumptions. It does so by barring untenable assumptions from the minimizations process, replacing parsimony with theoretical soundness (ibidem).

As previously discussed, the ability of a program participant to understand both her condition as seropositive pregnant women, and the risks associated with this (und), and her ability to speak and understand Spanish (spa), thus facilitating theoretical and substantive knowledge of the topic, is vital. The ability to speak Spanish facilitates the communication and comprehension that lead to higher adherence to the program, which are necessary conditions for the outcome effective risk (o). In order to apply ESA, it is therefore

necessary to eliminate all logical reminders rows in the truth table, where und and spa are equal to 0. This avoids unattainable assumptions.

From a point of view centered on application, the solutions presented below are the results of ESA with the database presented in Chapter 2. They are the result of three assumptions derived from three directional expectations: spa, pov, und. All logical reminders rows in the truth table, where und and spa were absent (0), were barred from the logical minimization process. This has been done by imposing 0 to the column 'outcome' in fsQCA software in the truth table. All other rows remaining were either imposed 1 (where their consistency was > to 0.80) or 0, if inferior. Logical reminders where und and spa were present were deleted to be included in the logical minimization process:

```
Assumptions:
spa (present)
pov (present)
und (present)
```

	raw coverage	unique coverage	consistency
spa~cos*pov~edu*vio	0.077191	0.032115	0.858065
spa*sig*pov~edu*vio	0.135616	0.032114	0.876250
spa*sig*pov*edu*und	0.406462	0.304314	0.851642
cos~sig*pov~edu~vio*und	0.025924	0.025924	1.000000
cos~sig~pov*edu~vio*und	0.019346	0.019346	1.000000
spa*cos~sig~pov*edu*vio	0.025924	0.025924	1.000000
spa~cos*sig~edu*vio*und	0.064423	0.025924	0.834587
cos*sig*pov~edu*vio*und	0.090540	0.012962	1.000000
cos~sig*pov*edu*vio*und	0.058038	0.058038	0.900901
~cos*sig*pov*edu*vio*und	0.121493	0.019346	0.903597
~spa*cos~sig~pov~edu~vio~und	0.000000	0.000000	0.000000
solution coverage: 0.761656			
solution consistency: 0.868137			

Firstly, and viewed broadly, we observe that for the solutions derived from fsQCA software, the consistency is high (0.87). This implies that “the degree to which empirical evidence is consistent with the set theoretic relations in question” (Ragin, 2006a book Set relations in social research), is high. For a large-N individual study like this one, this is

especially true. Another indicator important in the analysis of the solution is the solution Coverage. Coverage, which “assesses the empirical relevance of a consistent subset” (Ragin, 2006a), is 0.76. This indicates that only 0.24 cases are *not* encompassed in the solutions presented in the ESA solutions. Each of these solutions will be discussed in the following subchapters.

3.3.2.1 spa*sig*pov*edu*und

The first solution discussed encompasses the majority of cases (40%). It describes women who speak fluent Spanish, have a significant other in their lives that support them emotionally, have access to an income and are therefore are not in extreme poverty, who have completed their primary education, and who understand their condition and how HIV is transmitted. The solution covers most of the conditions selected for the analysis, indicating that one path to adherence is the presence of all considered conditions apart from the condition 'cost' and 'violence.'

This should come as no surprise. Logical, even from the outset of the research is that women who count on the most facilitators strongly reduce their effective risk of passing the virus to their baby. They also, in general, live healthier and longer lives. These women can be categorized as those who face less challenges during pregnancy, since they are able to exactly understand their conditions and take advantage of all opportunities in the program, such as: free distribution of artificial milk, free C-sections, free psychological counseling, and free gynecological visits.

In the home, these women also count on a strong support network and rely on at least one person when in need. The majority of women interviewed with this configuration rely on a close-knit family that supports them, emotionally. In other cases, they have known

about their conditions long enough that have explained the nature of HIV, and dangers of infection, to their families. In this way, these women have complete control over their condition and have sufficiently high self-esteem to respond assertively to attacks from outsiders and/or to protect themselves and their loved ones. This, many times through hiding their conditions and selectively choosing with whom to share their story.

Analysis of interviews reveals that the majority of these women know of their rights and are able to describe the program steps. All of these elements combined indicate a group of women with all the conditions in their favor to follow the program. This, in turn, points to the fact that their wellbeing is dependent on a series of strong social determinants. A successful program participant seems to be a woman who has sufficient social connections to rely on in times of economic and psychological distress, and who has developed sufficient social capital to be able to follow all program steps, even without a job. Some women in the group had already been through the program in the past, or had been aware of their HIV condition for more than two years.

This solution also includes those privileged women who had primary connections inside participating hospitals with doctors or nurses. Some of them judged the treatment to be high in quality, and did not have any complaints about the system. This solution, and the stories of these women, prove that all necessary resources to adhere to high standards and achieve program objectives are in place: training, capacity, expertise, spaces, and supplies.

The consistency for this solution is 0.85, which is high enough to consider it a valuable path to adherence and low risk for program participants and their children. It also has a 0.30 unique coverage, which represents a unique contribution, with respect to the others. Which are the other solutions that illuminate other possible paths toward adherence?

3.3.2.2 spa*sig*pov*~edu*vio and cos*sig*pov*~edu*vio*und

The next set of solutions presented are very similar. The solution a) spa*sig*pov*~edu*vio has coverage of 0.13 and a consistency of 0.87. Solution b) cos*sig*pov*~edu*vio*und has a coverage of 0.09 and a consistency of 1.0. Women that are encompassed in solution a), are women who speak fluent Spanish, can rely on at least one significant person, do not live in extreme poverty, and have not suffered any form of violence. Women that are encompassed in solution b) pay low transportation costs, can rely on at least one significant other, do not live in extreme poverty, have not suffered violence that they can relate to the program, and thoroughly understand their condition. Common to these two sets are education levels: none of the women had completed their primary schooling.

As Betances shows in her study, 16% of HIV positive women in her sample were illiterate (2008). This is a common pattern for women who live in poorer parts of the city, and, in many cases, do not have access to any form of structured education. A direct implication for these solutions is that the program must improve efforts in counseling and explaining concepts in simple and straightforward ways. On the one hand, it becomes clear the state must also increase coverage of primary schools in impoverished parts of the city.

Fortunately, the group of women in question here -- similar to the previous configuration -- count on a social system that prevents program-desertion and decreases effective risk for program participants and their children. Especially important is the fact that they count on someone to help them understand medical procedures and treatments needed, and who help them follow program steps, usually by accompanying them to doctor's appointments.

3.3.2.3 ~cos*sig*pov*edu*vio*und

The third solution presented is extremely interesting because it directly contradicts what the Dominican Ministry of Health does to improve the adherence. That is, maximize the number of centers closer to poorer communities. This solution registers a coverage of 0.12 and a very high consistency, 0.90.

It includes women who have a significant other on which to rely, are not in extreme poverty, have at least completed their primary education, have not suffered violence, thoroughly understand their condition, and who pay *high transportation costs*, compared to their available income. Education has always been identified as one of the facilitators that allow women to access sexual and reproductive health services. In keeping with this, this analysis reveals that if the woman understands her condition, either through counseling in the healthcare center or through lived experience, education can be a relatively important factor, even it is not a necessary condition.

This result thus affirms studies run in traditional societies in LMICs in Southeast Asia, conducted by LMICs scholars such as Bhatiaa and Cleland in South India (1993) and Mumtaz and Salway in Pakistan, (2005, 2009). For these studies, education and personal hygiene were far better social predictors to access sexual, maternal, and reproductive services, than autonomy and economic status. Similar to the above-mentioned studies, the majority of women in this solution set did not have access to a paid job, but do not live in extreme poverty. Instead, someone else takes care of their most important needs, such as food, shelter and health. Like in the Southeast Asian context, these results necessitate the beginning of a discussion about autonomy in Central America and the Caribbean.

What happens to HIV positive women who do not necessarily have access to a paid job outside the house, but who complete all program? As discussed, these are women who are extremely privilege with regards to all the other conditions. They had the privilege of an education, and are well connected and respected inside their families. Most likely, they are matriarchs and take care of the household organization. They are familiar with the different steps of the program and are able to navigate its bureaucracy in order to take care of their babies and of themselves.

They are, therefore, women who have accepted their conditions, have sufficient means to nourish themselves and take their antiretroviral. They are privileged women who do not need to work because of their extended relatives. Instead, they take care of housekeeping, look after the kids, and cook etc.. These are women who are sufficiently supported and who have the money for transportation to and from hospitals. They have all other economic and social support they need.

Their family connections and social standing allow them to spend an important amount of money on their health, even without a direct source of income. Compared to the previous solutions, this solution-set differs in the sense that a fair amount of women included spend a high amount of money on transportation. Clear becomes: if family and community systems are sufficiently stable, a program participant should be able to follow all program steps with high adherence levels, even if transportation costs are high.

Interesting to note is that according to western literature, high transportation costs should work *against* adherence, increasing risk both for the women and their babies. However, as previously discussed, this interpretation should be partially discarded as 80% (sixty-six of over eighty-two) of all women interviewed were afraid to disclose their condition to a close family member. All women reported having suffered some form of

stigma due to their condition. Consequently, they tend to access treatment as far away from their home communities as possible, thereby avoiding stigma and discrimination.

Moving Integral Attention Services (medical units where HIV treatments are administered) closer to impoverished communities in an attempt to improve adherence, without breaking the strong stigma against people living with HIV, is, therefore, not likely to be effective. This type of measure reveals the lack of empirical foundations used in policy development in the Caribbean context, and is economically irrelevant. Instead, high transportation costs ensure privacy for women, and in general do not stop them from receiving treatment. Other conditions in this set that help women continue with treatment and decrease risk for them and their babies are community and family connections.

3.3.2.4 spa*~cos*pov*~edu*vio

This solution has coverage of 0.07 and a consistency of 0.85. It describes women who speak Spanish, incur high transportation costs, do not live in extreme poverty, have not completed primary school, and have not suffered violence that they can relate to the program. This alternative path for the outcome is further evidence to the fact that cost is not a necessary factor in reducing the risk, and reducing cost does not necessarily lower risk.

The women in this category, as compared to the others, face more barriers but are still able to complete all program steps. In the analysis for negated outcomes, we will further understand some of the patterns that lead women *not to complete* the protocol, thus increasing the risk for them and for the baby.

3.3.2.5 cos*~sig*pov*edu*vio*und

This solution presents a 0.05 coverage and a high consistency of 0.90. Women in this configuration incur low transportation costs, are not extremely poor, have primary educations, have not suffered violence that they can relate to the program, and thoroughly understand their condition and its implications. They cannot, however, trust anyone enough to disclose their condition.

In this situation, the counseling center, which is essential in its provision of psychological support, becomes the only safe place for women to describe and share their situations. Other forms of support occasionally given to women, paid for directly by peer counselors or psychologists are: asking for police intervention and protection, support while she and her child moves out of her house, techniques to negotiate for condom usage, and payment of food and travel expenses etc.

Although these women live very difficult lives, they understand the importance of following treatment protocols and understand obstacles associated with this including: dangerous situations, violence, discrimination, and lack of family-acceptance. In this context, where taking antiviral can be fatal if family or partners find out, the healthcare center and especially the counseling center, are a pivotal places. What distinguishes these women from women who do not follow through with the program, is their ability to understand their condition, how the virus is transmitted, and the program steps. They understand that if they continue treatment, they will not pass away. They understand that treatment allows them to live long and healthy lives. If, however, they were not to comprehend their condition, nor understand the consequences of not following program steps, they might well quit the program, and surrender to obstacles.

3.3.2.6 $\text{cos}^*\sim\text{sig}^*\text{pov}^*\sim\text{edu}^*\sim\text{vio}^*\text{und}$ and $\text{cos}^*\sim\text{sig}^*\sim\text{pov}^*\text{edu}^*\sim\text{vio}^*\text{und}$

Due to the extremely low coverage, these solutions should not be used to draw conclusions about future program participants. They are presented for the sake of completeness. $\text{cos}^*\sim\text{sig}^*\text{pov}^*\sim\text{edu}^*\sim\text{vio}^*\text{und}$ is the first solution presented. It has a coverage of 0.02 and a consistency of 1.0. The second solution presented has the configuration: $\text{cos}^*\sim\text{sig}^*\sim\text{pov}^*\text{edu}^*\sim\text{vio}^*\text{und}$. It has a coverage of 0.025 and a consistency of 1.0. These two configurations include women who suffered from the worst conditions possible, as compared to others with the same levels of low risk.

The first solution describes women who incur low transportation costs, cannot trust anyone to disclose their conditions, do not live in extreme poverty, and have had limited access to education, and have not completed primary schooling. They have also been victims of violence (inside or outside the hospital) directly linked to the program and their seropositive condition. The second solution describes women that incur low transportation costs, cannot trust a significant, live in extreme poverty, and have finished their primary education. They are also victims of violence and they thoroughly understand their condition.

Both of these configurations describe women who, on the one hand, were able to find a safe space in the hospital, especially during counseling with peer counselors, doctors and psychologists, and who, on the other hand could have been victims of violence inside the hospital. These are women who cannot rely on a close family, and whose partners or ex-partners perpetrate different forms of violence against them due to their conditions. The majority of these women have suffered violence consistently in their lives, since they were little girls. This is pertinent because various studies show that incidence of HIV in women

who are survivors of violence is three times higher, as compared to women who have not suffered any type of violence in their lives (Betances, 2008, Amraf, 2005).

Strong stigma associated with HIV positive women can lead to different kinds of abusing behavior and violence, from verbal abuse to death. During this research, two pregnant women attending the hospital in which the investigation was taking place, lost their lives while pregnant. These two configurations represent the most extreme cases in which it was still possible to observe a low effective risk for the woman and the child. The configurations may well have resulted in different outcomes, and a most probable a drop-out, in accordance timing and the type and the intensity of violence.

Unfortunately, in the majority of cases, the Dominican system is not able to respond to women who have reported major issues, both inside and outside the hospitals. The maternity hospitals are not prepared to navigate, detect, or take actions against episodes of violence, both perpetrated by partners or family members, and /or inside the hospital itself.

Clear is that once the situation becomes difficult for program participants, few cases show positive outcomes. The fact that no paths belonging to non-Spanish speaking women are presented is a red flag, indicating a strong deficiency in the system. It is not capable of responding to current challenges related to ethnicity and seems, in fact, to discriminate according to ethnicity. The remainder of this chapter uses specific examples to analyze different types and mechanisms of discrimination in the program.

This makes it essential to examine what happens when the outcome is negated. In other words, what configurations lead to women not completing all program steps?

3.4 Analysis of Sufficiency for Negative Outcome

Herewith the results of the Negative Outcome analysis are presented. With this methodological step are analyzes observations that lead to non-adherence to the protocol, and therefore high risks of HIV infection for the mother and child. Looking at negative outcomes better illuminates factors that allows women to finish all protocols and reduce risks for them and for their babies. Due to the assymetric nature of QCA

3.4.1 Complex Solution

As seen in the fsQCA matrix below, the complex solution can be interpreted in its entirety, however an important limitation must be highlighted. The consistency of this complex solution is almost 0.90, but the coverage is low, only 0.57. This might imply that the conditions selected for the presence of the outcome are not sufficient to cover the variety of the population for the absence of the outcome.

In fact, when analyzing cases for which the outcome is absent, we find that the solutions do not explain 0.43 of the cases. This indicates the necessity to develop other conditions that impede the success of the program; sufficient paths cannot be found using conditions in this research. Clearly, the factors facilitating program adherence, and those impeding access, are different. This is due to the fact that “causality is not assumed to be symmetrical—rather, causal asymmetry is assumed, meaning that the presence and the absence of the outcome, respectively, may require different explanations” (Rihoux and Ragin, 2008). For future development in this field, it is therefore necessary to work on other conditions that cause non-adherence.

```

--- COMPLEX SOLUTION ---
frequency cutoff: 1.000000
consistency cutoff: 0.000000

```

	raw coverage	unique coverage	consistency
~und*~vio*~pov*~sig*cos*~spa	0.051687	0.051687	1.000000
~und*vio*~edu*pov*cos*~spa	0.144847	0.103374	0.876404
~und*~edu*pov*sig*cos*~spa	0.062210	0.020737	0.858974
und*~edu*~pov*~sig*cos*spa	0.041473	0.041473	0.666667
und*~vio*~edu*pov*sig*spa	0.051687	0.051687	1.000000
und*vio*pov*sig*cos*~spa	0.030950	0.030950	0.598802
~und*~vio*~edu*pov*~sig*cos*spa	0.020737	0.020737	1.000000
und*vio*edu*~pov*sig*~cos*~spa	0.020737	0.020737	1.000000
und*vio*edu*pov*sig*cos*spa	0.062210	0.062210	1.000000
und*~vio*edu*~pov*sig*cos*spa	0.082946	0.082946	1.000000
~und*vio*edu*pov*sig*cos*spa	0.041164	0.041164	0.801205
solution coverage:	0.569174		
solution consistency:	0.887548		

3.4.1.1 ~und*vio*~edu*pov*cos*~spa

By examining individual solutions, we find that the most interesting of the complex solutions is the second, with a 0.87 of consistency and a coverage of 0.145. This set describes cases where non-completion of the protocol is found in women who do not properly understand HIV, had not suffered violence, have a low level of education, do not live in poverty, do not speak Spanish, and who incur low transportation costs. These factors, combined, can lead to the absence of the outcome.

3.4.1.2 und*vio*edu*~pov*sig*cos*spa

The other solution worth examining is the penultimate, which has a coverage of 0.08 and a consistency of 1.0. In this case, poverty is the factor that seems to have a negative effect on the outcome. This seems quite plausible, since in order to take antiretrovirals, the woman must have sufficient access to food for example. Case in point:

some program participants testified that they were not able to take medicine because they did not have access to sufficient food during pregnancy.

3.4.2 Parsimonious Solution

The parsimonious solution shows a very low consistency, of only 0.77. It is therefore difficult to make inferences about this series of solutions. As Ragin notes, “with observed consistency scores below 0.75, it becomes increasingly difficult on substantive grounds to maintain that a subset relation exists, even a very rough one” (Ragin, 2006a).

This can be seen in the table below:

```

--- PARSIMONIOUS SOLUTION ---
frequency cutoff: 1.000000
consistency cutoff: 0.000000

```

	raw coverage	unique coverage	consistenc
und*~edu*~pov*~sig	0.051687	0.051687	0.625468
~vio*~edu*pov*sig	0.082637	0.061900	0.890000
vio*edu*~pov*sig	0.113897	0.103683	0.736000
~und*~spa	0.247911	0.061900	0.858521
~vio*edu*pov*~sig	0.062210	0.051996	0.670000
~und*pov*~sig*cos	0.164964	0.020737	0.889816
~und*edu*pov*cos	0.071804	0.041164	0.875472
vio*sig*cos*~spa	0.082637	0.030950	0.727520
solution coverage:	0.640669		
solution consistency:	0.766951		

A cursory observation of the fifth solution reveals how women who do not complete all program protocols also do not speak Spanish, and understand very little about their condition as seropositive women. This solution is the most interesting one, because of its very high consistency, and coverage of 0.17. Additionally, this solution covers only 0.27 of cases, which indicates the necessity to further investigate which other conditions can explain the absence of the outcome.

3.5 Qualitative analysis

In this part of the chapter are analyzed the finding from the transcriptions of the interviews analyzing the different experiences that the women of the program have had. The purpose of this analysis is to shed light on some of the factors that are influencing adherence inside the program and to have a better understanding of the dynamics inside the hospitals and its staff. The population for the research is descriptively analyzed in the first part looking at the most important characteristics of these women such as age, education, working conditions etc. In the second part we are going to look more in depth at the episodes of violence and how it is possible to classify them. In the third part we are going to analyze women that have had a very positive experience in the program with women that had the opposite.

3.5.1 At a glance description of the women interviewed

The total population of HIV positive women interviewed is 119. A first categorization use was to ask which was the main language spoke in the house. This allowed the researcher to identify that 60 women speak mainly in their house in Spanish and 59 speak mainly in their house in Creole. This is a very important distinction to make since in many cases to ask which was their nationality has been misleading and source of mistakes in different studies conducted in the field. This has also lead many women to avoid the interviews and to give personal information for fears of been identified as Haitian or of Haitian origins after their declaration in the interview. The study has been in fact conducted during a national sentence (n. 168 of 2013) that directly affected the populations of Haitian origin living in Dominican Republic trough a denationalization process and,

indirectly, also the responses of this study. In any case, at any moment should this categorization been interpreted as a proxy of nationality.

Briefly describing the population it is possible to affirm that the mean age for the population is 27 years old and their average number of years spent in school is 7.5, while the average number of kids per women is of 2.27.

Of these women only 31% reported a remunerated job at the time of the interview with an average personal month income of RD\$6,318.00 among those who were working. The general average personal income per month is very low and has been calculated in RD\$1,432.00. The women who earned the most is working for RD\$20,000.00 per month having two jobs.

85 of them reported the presence of a partner in their life although not always he was the biological father of the last child. The average time to get from their house to the hospital where the birth for cesarean section or vaginal birth was performed, and in the majority of cases the main steps of the program, is of 57 minutes with an average cost for one day for both ways of RD\$135,00. If we consider that 69% of women does not have a personal source of income it is ease to notice the dependence from other sources to get their basics expenses covered. In the majority of cases (67%) is the actual or previous partner that provides the women with money to cover basic expenses such as the money for the transportation to and from the hospital.

The other source of income are family members (mothers in particular) and neighbors, which cover a very critical role in the life of HIV positive women interviewed sometimes helping and in other cases undermining the antiretroviral regime, the security of the women and their psychological wellbeing through acute discrimination.

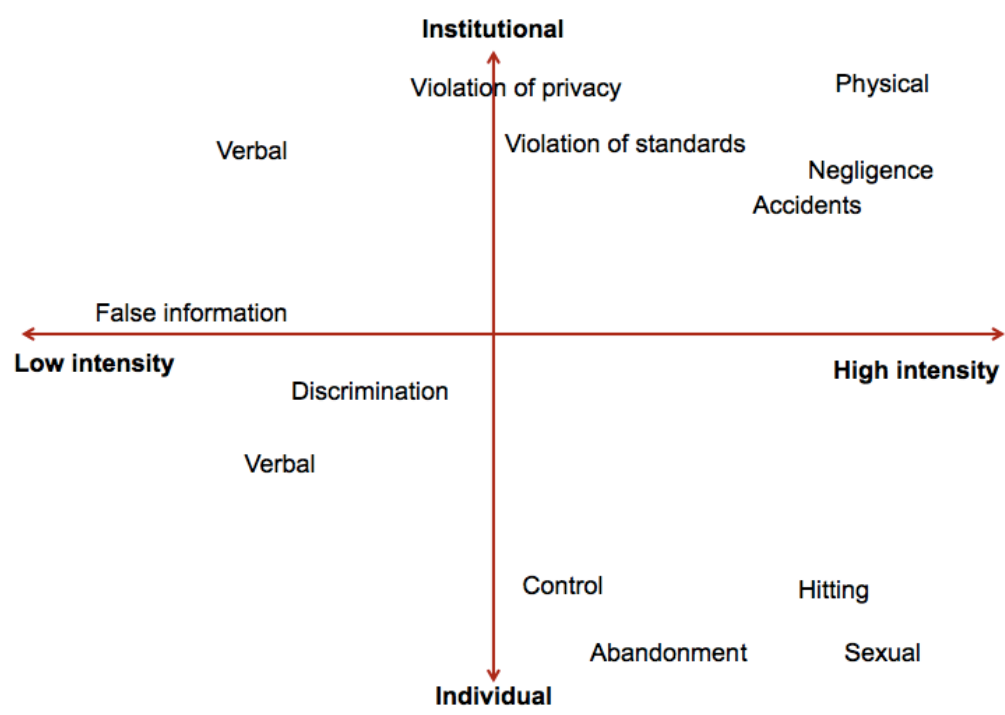
57% of women HIV positive that have taken part in the program thought that a mosquito could be responsible for the transmission of HIV. 41% of the women reported that it is possible to pass the virus kissing in the mouth his partners and in different interviews women reported that they were not kissing the kids in the cheek either. 9 women reported that they were not aware that the virus could be transmitted from mother to child during pregnancy. The average number of years the women has been aware of her condition living with HIV is 2,4 years. From this first description of the women interviewed is it possible to notice how the population that took part in the program it is extremely poor and with a very reduced economic autonomy. The average education is low and their understanding and knowledge of their condition modest.

3.5.2 The continuum of violence in the women exposed to the PMTCT

In order to analyze and systematize the different forms of violence suffered by women in the program, a Cartesian Plane categorizing violence type and intensity was constructed. To understand the Cartesian Plane, first we must ask: “what is violence?”. The definition stemming from the analysis is that violence is an identifiable behavior that has adverse consequences for a specific person. This behavior can differ, and its consequences are of varying intensities low (in the case of shouting) or high (in cases of physical damages).

As follows, the x-axis of the following Cartesian Plane orders intensity. The y-axis describes the nature of the violence. Intensity is classify using a range from 'high to low,' while the nature of the violence is measured on a range of 'private to public.' These categories were developed in accordance with episodes of violence directly experienced by

the women in the program, and not through violence witnessed or experienced by other women.



Graph 1: Visual Position in the Cartesian Axes of the Different Types of Violence and Rights Violations, According to Intensity and Systemic-Positioning.

Different expressions of violence were categorized and placed in one of the four above-displayed quadrants. Major forms of violence that are physically damaging to the women are positioned in the right-hand quadrants. Lesser forms of violence are found in the left-hand quadrants. Private violence, usually perpetuated by a partner or by conservative family members, are located in the bottom quadrants, while violence perpetrated in institutionalized setting are located in the upper quadrants. The higher the position in the y-axis, the more institutionalized the violence. This graphic representation allows us to immediately differentiate between forms of violence that the interviewed

women suffered, and to grade these episodes in terms of their health, and psychological and physical risks for program participants.

Data analysis identified two prevalent forms of violence:

- Institutional violence
- Individual / private violence

Institutional violence was classified as it took place inside the premises of maternity hospitals, private clinics, and ambulatories related to the PMTCT Program between 2012-2014. Individual violence was classified as it took place in the private lives of program participants, starting at their birth.

In-depth interviews revealed a total of 140 episodes of violence suffered by the interviewees. Eighty-nine of these were categorized as 'Institutional' and fifty-one of these were categorized as 'Individual' in nature. Each woman may have been subject to more than one episode of violence at the hands of different healthcare professionals, and in different moments in the program. Each single episode of violence has been reported no more than once, in one single category. In the diagram below, the findings of the research are presented visually, in a tree-diagram:

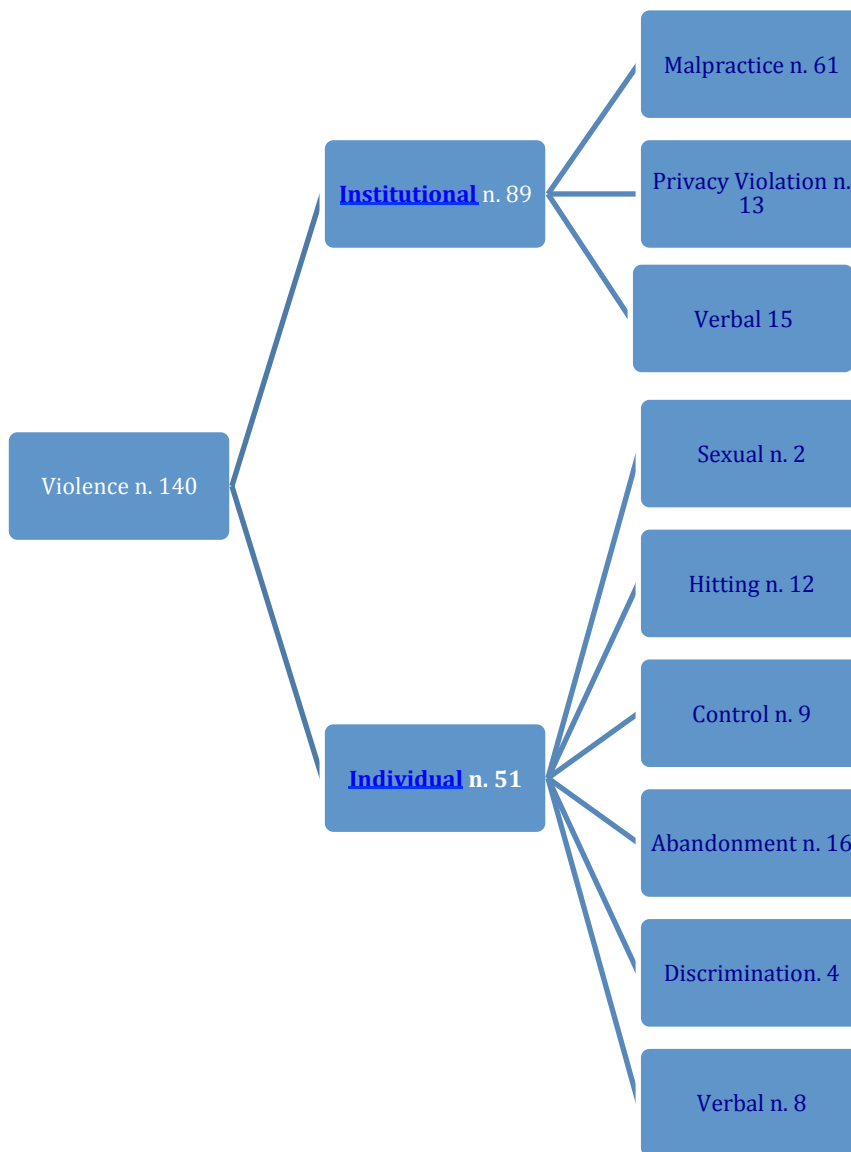


Diagram 2: Forms of Violence as Divided into Two Main Categories and Nine Subcategories, with Respective Numbers of Episodes Reported for Each Category

The tree-diagram describes the different categories of violence identified in the research. The number of episodes associated with each category is found next to each category. Institutional violence has been divided into three subcategories according to intensity:

Malpractice

Privacy violation

Verbal violence

Individual violence has been divided into six subcategories according to intensity:

Sexual

Hitting

Control

Abandonment

Discrimination

Verbal Violence

To the right of each category in the diagram is the number of corresponding violent episodes, as reported in the interviews. As is readily clear, 'Malpractice' -- defined as an act damaging to the patient, whether committed through negligence, by accident, or purposefully -- was the most prevalent violence experienced. Program participants reported sixty-one episodes of malpractice. For the category of 'Individual Violence,' abandonment was most commonly experienced by the women interviewed.

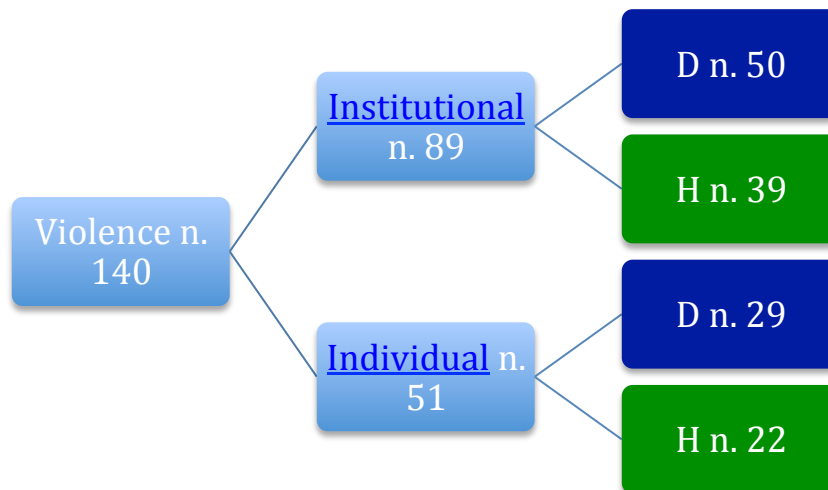


Diagram 3: Graphic Representation of the Main Categories of Violence and Their Distribution Among Spanish-Speaking and Creole-Speaking Women.

The second tree-diagram describes the forms of violence according to the language-demographic who experienced it. Spanish-speaking women, identified with the color blue, have suffered fifty episodes of 'Institutional Violence,' while Creole-speaking women have suffered thirty-nine. Fifty-one women, of whom twenty-nine are Spanish-speaking, and twenty-two are Creole-speaking, reported having experienced 'Individual Violence'. It may be reasonable to conclude that Creole-speaking women are more afraid to report episodes of violence experienced inside hospitals, as compared to Spanish-speaking women. This would explain why the gap between Creole-speaking women who reported violence and Spanish-speaking women who reported violence is largest in the 'Institutional' category.

Finally, actors responsible for perpetrating violence were analyzed. According to interviews, doctors committed the majority of violent acts. Twenty-eight violent episodes were attributed to them. Nurses were the second-most common perpetrators, having committed nine acts of violence. Stretcher-bearers committed three acts, residents two acts, and finally, peer counselors committed one act of violence. A special category was added to identify violence in which responsibility is shared among various healthcare providers, including administration. Interview-analysis registered forty-six episodes in this category. These episodes have been identified as 'Systemic Violence.'

Interviews revealed that perpetrators of 'Individual violence' were mainly program participants' partners, whether current or previous. Forty-six episodes of individual violence, perpetrated by partners, were reported. The majority of these episodes represent just one in a long string of violent acts associated with relationships and the home, suffered by the women interviewed.

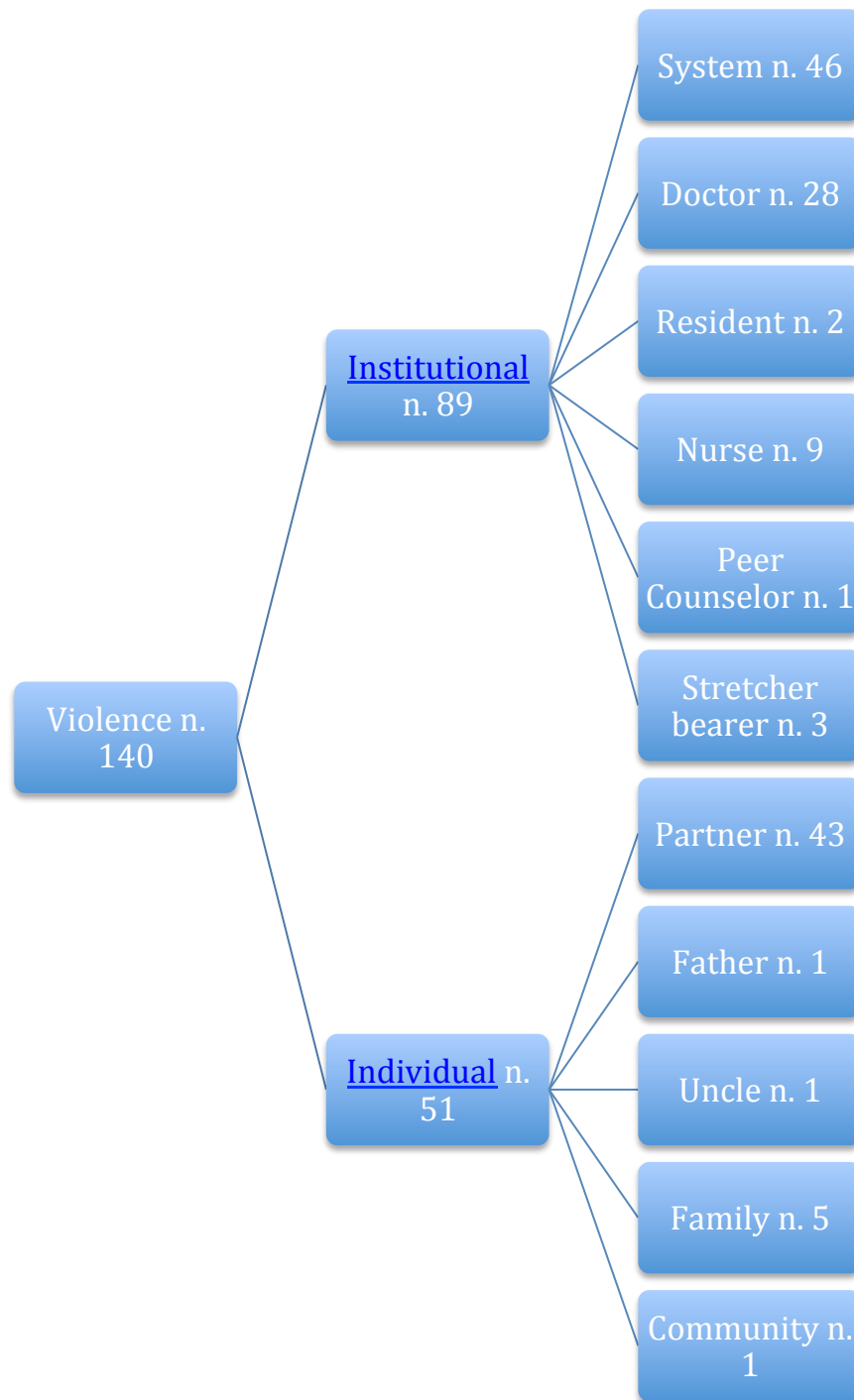


Diagram 4: Graphic Representation of Perpetrators of Violence Against Women in the PMTCT Program.

3.5.3 Institutional Violence

As previously described, Institutional Violence was divided into three main categories (Malpractice, Privacy Violation and Verbal Violence) and into nine subcategories (Physical Violence, Negligence, Accidents and Violations of Standards, False Information, Inadequate Disclosure, Disclosure to Third Parties, Numbing and Defamation, Racial Slurs, and Shouting) . This is represented in the following tree-diagram:

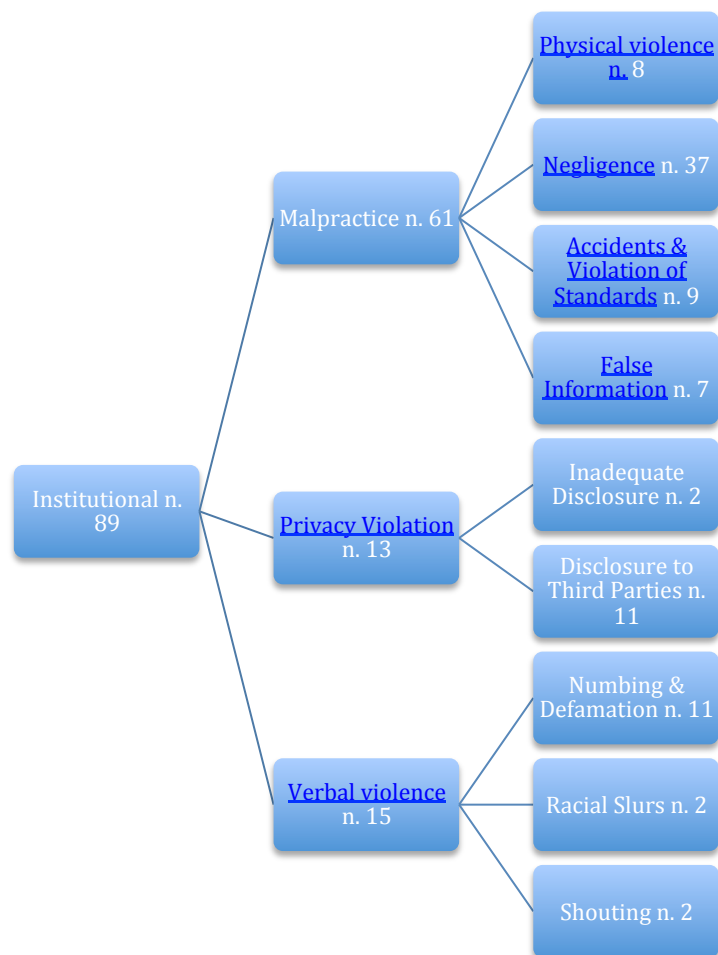


Diagram 5: Graphic Representation of Institutional Violence, Its Main Categories and Subcategories, with Absolute Frequencies.

In the pages that follow, each subcategory and its frequency of occurrence are explained. Categories are represented methodologically, from more intense (Physical) to

less intense (Shouting). They have been determined considering the practitioner's level of involvement.

3.5.3.1 Malpractice

In order to identify an episode as Physical Violence, the women must have suffered a violation to her body, and the healthcare practitioner must have willingly committed it. Forced sterilization falls into this category. Negligence is, in a way, the opposite of Physical Violence, but it is not less harmful. It simply indicates that the healthcare practitioner has not taken or performed an action as stipulated by the PMTCT protocol, and he or she has done this voluntarily. A doctor who does not perform a C-section at the right time falls into this category.

Episodes categorized as 'Accidents' are defined as legitimate procedures that nevertheless extensively damaged the patient's health. A C-section saturation that opens up is an example of this.

A Violation of Standards implies that that the healthcare provider does not know of, or ignores, the importance of a critical very measure. The failure to use gloves while aiding in the birth of a program participant's baby, is an example of this.

	Willingness present	Willingness absent
Action	Physical violence (Paragraph 3.3.1.1)	Accident (Paragraph 3.3.1.3)
Failure to Act	Negligence (Paragraph 3.3.1.2)	Violation of standards (Paragraph 3.3.1.3)

Table 12: Table Describing the Typology Used to Describe Malpractice and How Each Episode has been Categorized.

3.5.3.1.1 Physical Violence

The following tree-diagram describes the violent episodes in the category of 'Physical Violence' suffered by program participants. The lighter blue-beginnings of the tree diagram represent the type of violence, and its perpetrators. In the leafs on the far right of the tree diagram, each participant is represented by a case number. Darker blue and green are used to rapidly distinguish between acts of violence committed against Spanish and Creole-speaking women. Although throughout the research Spanish-speaking women reported the majority of violent episodes, in the case of intense physical violence, Creole speaking women outnumbered Spanish-speakers with a ratio of 7:1.

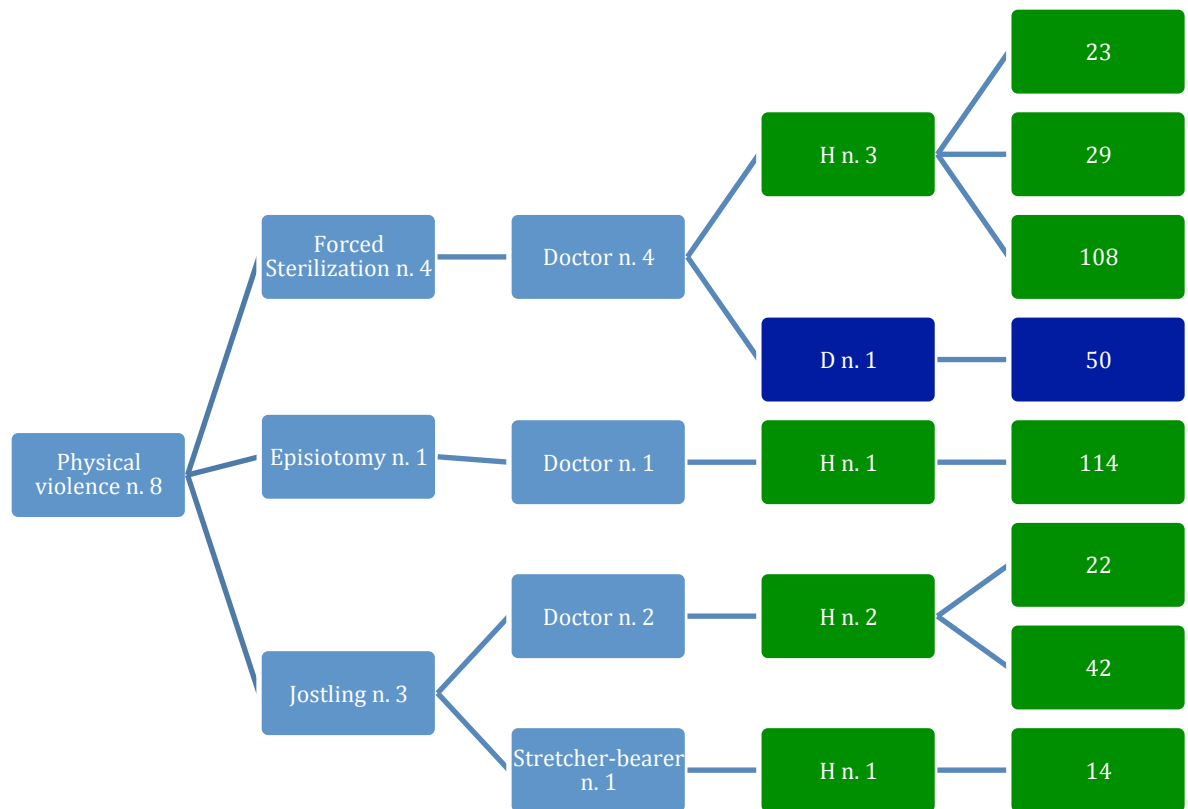


Diagram 6: Tree-diagram of the Different Types of Physical Violence Reported by Women in the Sample

3.5.3.1.2 Negligence, Service Denial, and Deferment

The following diagram shows all episodes in which service has been denied or deferred, provoking problems for program participants during pregnancy or labor. All of these episodes share a common factor: a doctor denied service. In two different cases, the woman was left in the hospital for eight and fifteen days respectively, waiting for a doctor to perform the cesarean. Program participants also reported that many doctors are afraid of them, or afraid of HIV, and do not want to touch or visit them. Other interviews documented cases in which a woman in labor was sent home, even if already dilating. When she returned to the hospital, it was too late to perform the cesarean. This presents an alternative scenario to the widespread conviction that many program participants do not respect appointments for surgery, and arrive, too-dilated to give birth by C-section.

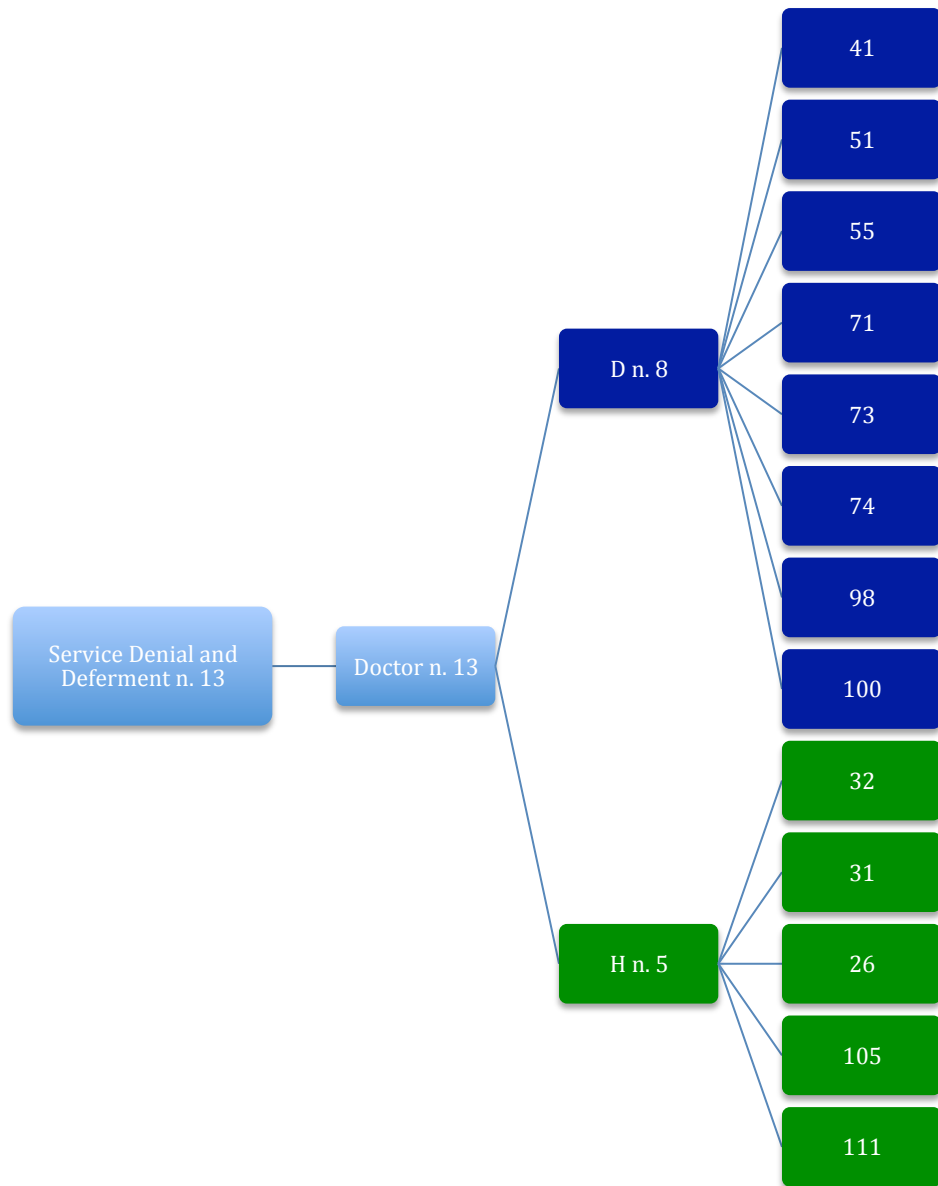


Diagram 7: Tree-diagram of the Different Episodes of Services, Denied and Deferred, as Reported by Women During Interviews.

3.5.3.1.3 Lack of Follow Up and Information

This tree-diagram reports all episodes in which a woman was not referred, either after and before giving birth. The subcategory, "Not Referred for Antiretroviral After Birth," does not include cases in which the woman was referred but did not attend a

Servicio de Atención Integral (SAI), through which she could have continued with antiretroviral treatment.

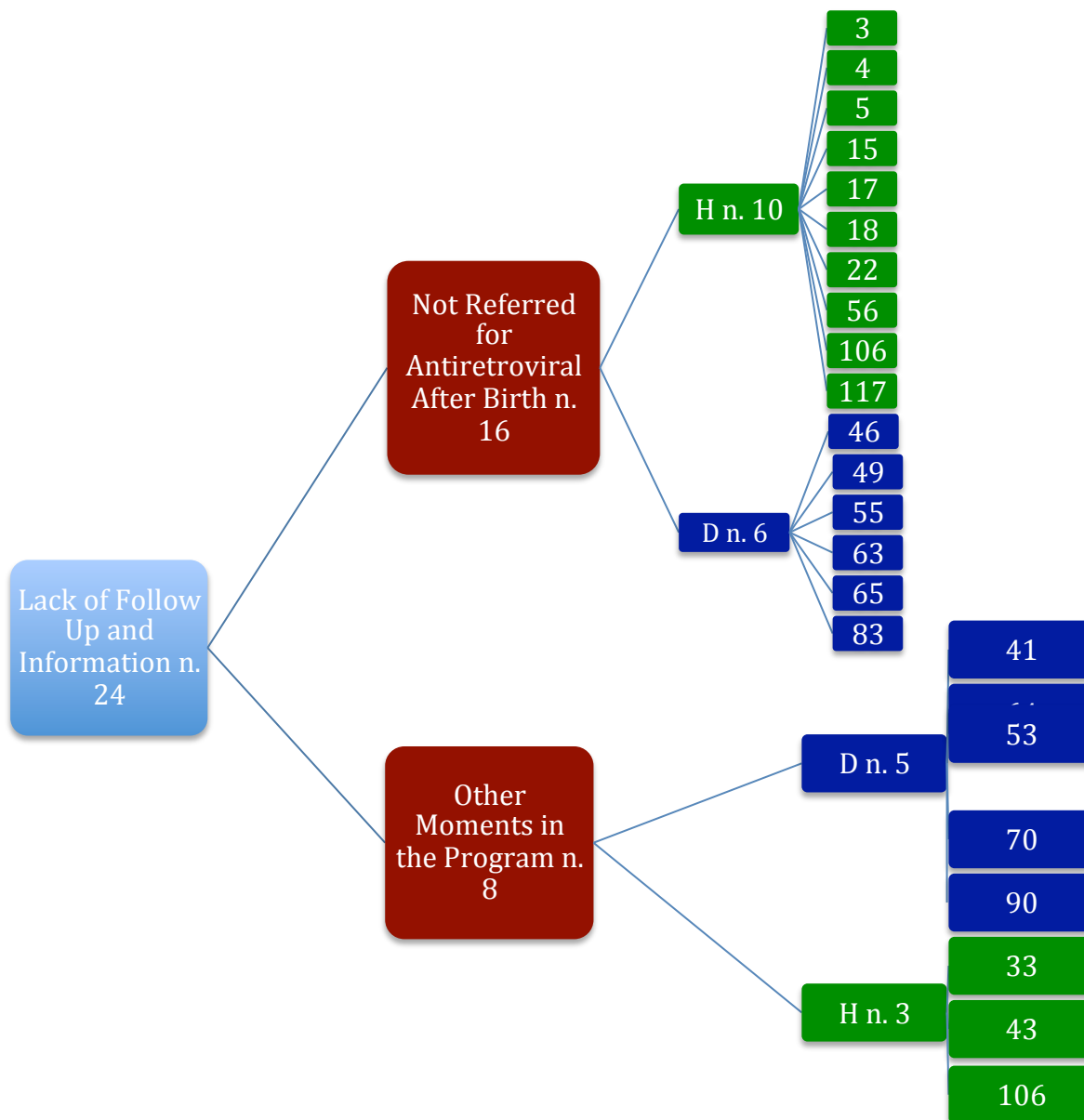


Diagram 8: Tree-diagram of the 24 Episodes of Lack of Follow Up and Information, Divided by Moment In Which the Episode Occurred.

3.5.3.1.4 Accidents and Violation of Standards

The following tree-diagram describes accidents reported by women and violations of basic standards of healthcare. These include: failure to use of gloves while a nurse is

performing an injection, or during the birth, or failure to clean a bed that was stained with another patient's blood.

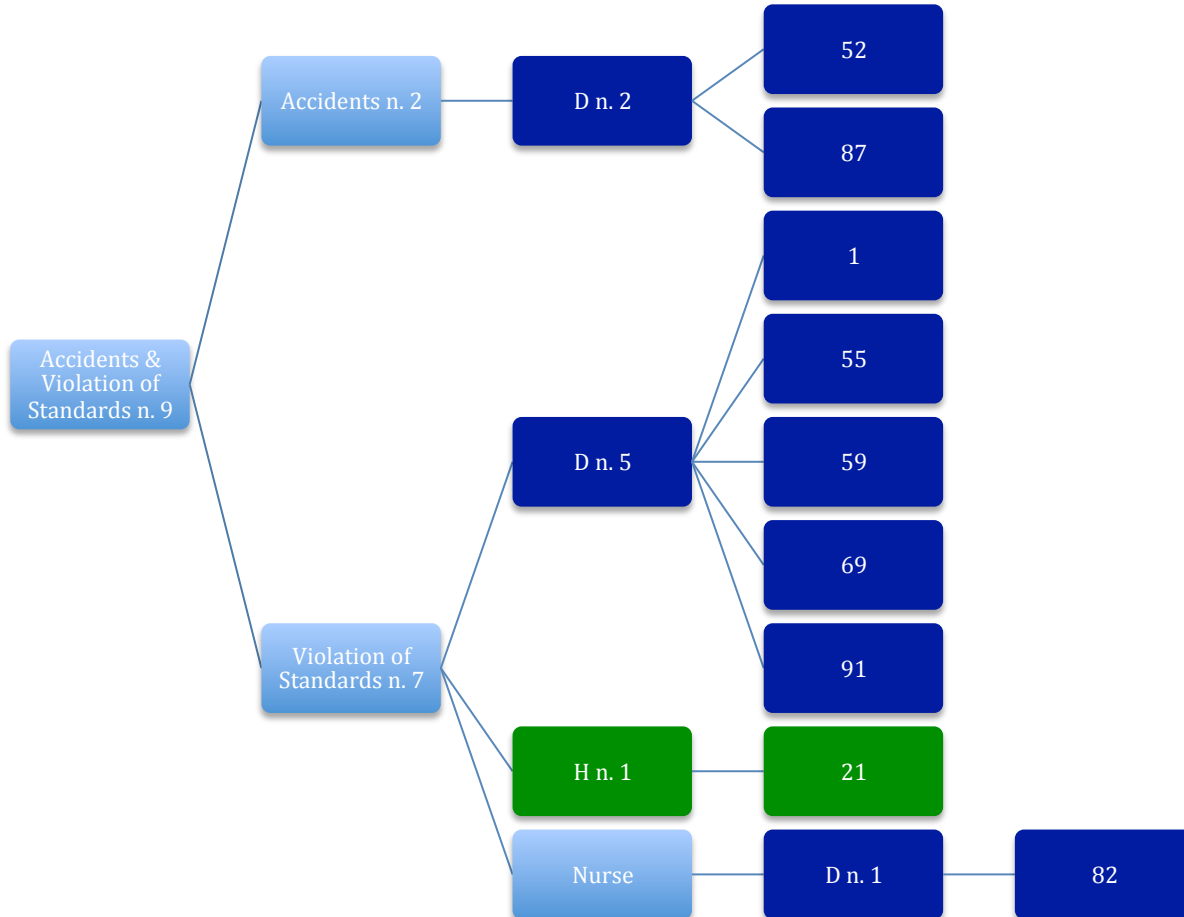


Diagram 9: Tree-diagram of Episodes Categorized as Accidents and Violation of Standards, Reported During Interviews.

3.5.3.1.5 False Information

This category reports the episodes in which women have received either incorrect information, or information that is potentially harmful to her personal or her child's wellbeing. Prohibiting the mother from kissing her baby in the face, hands and body falls into this category, as does demanding payment for a cesarean surgery. This type of

information can prevent the woman from connecting with her own child, and transmits false information on how the virus can be transmitted.

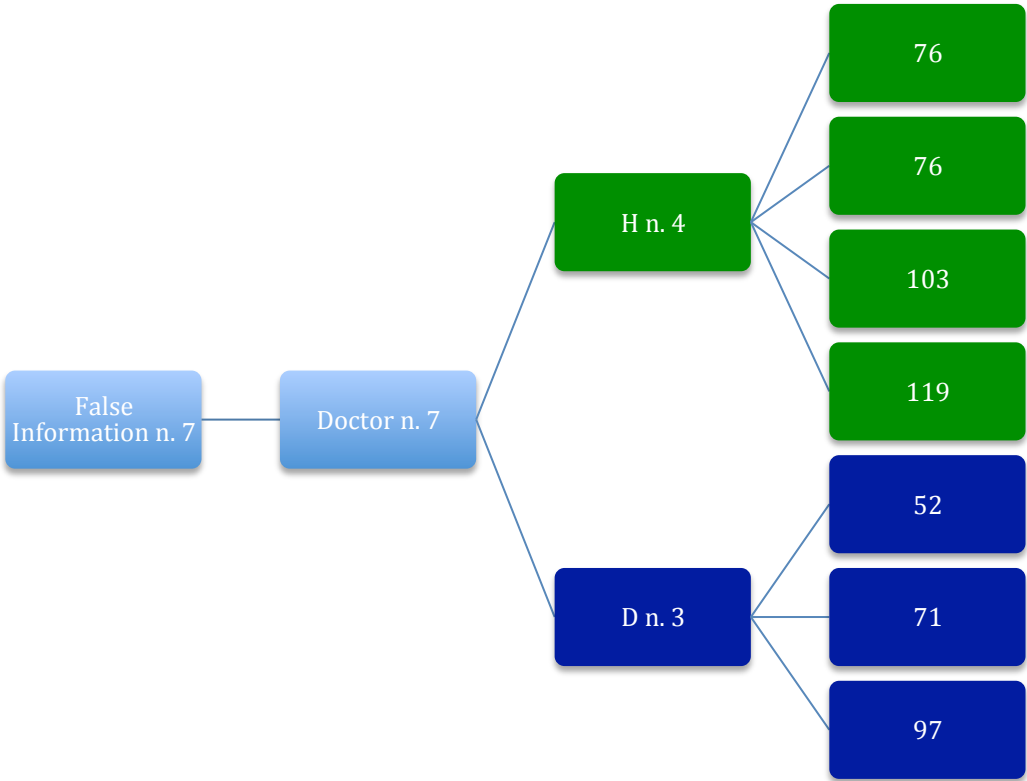


Diagram 10: Tree-diagram Representing Episodes Involving the Transmission of False Information, Directly Affecting a Woman or Her Baby's Personal Health

3.5.3.1.6 *Verbal Violence*

'Verbal Violence' is strictly related to the hostile environment in which the women find themselves, especially directly before and after giving birth. Various types of violence -- from slurs with racial connotations, especially against Creole-speaking women, to shouting and insults while giving birth -- fall in this category. It is possible that more

Spanish-speaking women perceive this violence, since many Creole-speakers would not understand derogatory language. This hypothesis is concurs with a report by the Dominican NGO, Profamilia, about obstetric violence in public hospitals in the Dominican Republic.

Many acts of violence directed towards Creole-speaking program participants were reported, however this research only takes into account those episodes directly reported by the patients, and not by other women who may have witnessed episodes while interned.

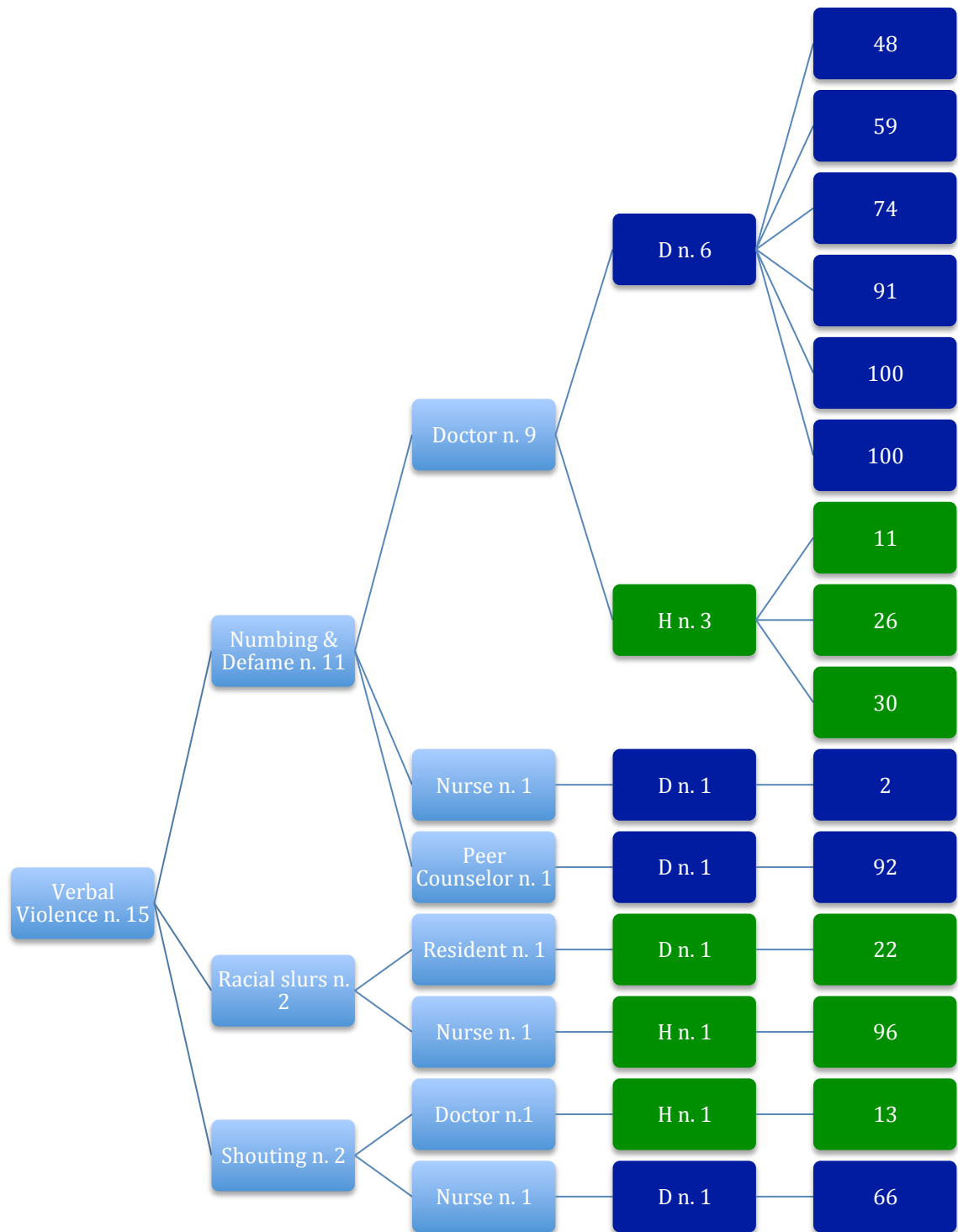


Diagram 11: Different Categories of Violence and Their Subcategories According to Perpetrators and the Language Spoken by Program Participants.

3.5.4 Individual Violence

Why is it important to analyze Individual forms of violence in addition to Institutional Violence? It is important because the women in the program typically come from disempowered home environments where, as shown in the tree-diagram below, violence is part of their everyday lives. The institutional response to the program participant's condition, and healthcare system as a whole, should not contribute to greater levels of disempowerment and disenfranchisement. A setting that should help protect women cannot be the stage for yet more forms of violence, that in addition to being inherently vicious, can further undermine the program participants' self-esteem and also their confidence in public healthcare.

As previously-discussed, the category "Individual Violence," reports episodes of violence that a woman relates to her personal life. The women's partners, current or past, are the most common perpetrators of this type of violence. It is not possible to identify a clear pattern between Creole-speaking and Spanish-speaking women.

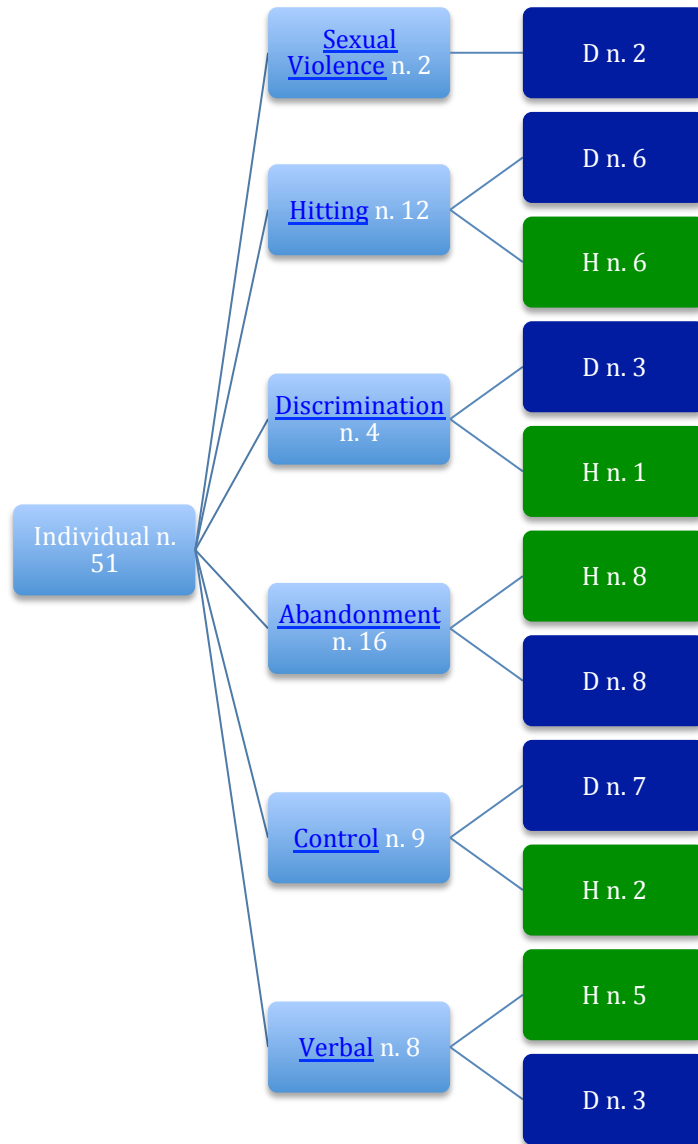


Diagram 12: Individual Violence by Episode, According to Its Subcategory and the Main Language Spoken the Interviewee.

The subcategory, 'Abandonment,' is defined as when a program participant's partner leaves her, due to the disclosure of the participant's HIV status and/or her pregnancy. 'Hitting' and 'Abandonment' were the most frequent forms of Individual Violence reported by the women interviewed.

3.5.5 Behind and beyond hospital closed doors

Upon examining the program participants' testimonies, we uncover a diverse range of experiences and life-histories. These span from stories of women who received quality medical care to women that were treated poorly; from women that have decent social support networks, to women that live in a marginalized and undignified conditions. As discussed previously in this chapter, it is not uncommon to find that the women interviewed suffered violence or a violation of their rights, both inside and outside the hospital.

Yet behind this commonality hide experiences, diverse in their variety of professionals involved, ethics employed, treatments and procedures used, and standards of quality upheld. This leads us to question: if it is true that so many women have suffered violence, what factor leads a program participant to have a *positive experience* inside the hospital?

Firstly, we must recognize that the majority of the women interviewed were not able to recognize violence against their bodies. The most striking example of this is that of all the women that have been sterilized without consent, none of them filed any type of complaint, whether written or verbal. From this, we may deduce that at the time of the procedure, these women did not understand it as a form of malpractice and negligence, and therefore did not protest. Instead, they accepted the procedure with resignation and fatalism:

“Interviewer (I): at the moment are you using any type of birth control?”

E23: No. Because they told me that they had prepared me (sterilized). When they were doing the C-section I heard that one of them say: “prepare her”. And I said no, because I just have one daughter, and I asked them not to prepare me. I said that, but I don’t know if they prepared me or not, but I think that they prepared me.

I: How do you know that they prepared you?

E23: Because I heard them while they were talking, and when one of them said 'prepare her.' They asked me how many children I had, and I told them that I just had one, and that they should not prepare me. But they prepared me anyways.

I: But after they told you that they had prepared you, did you confirm if they had prepared you, or you are just assuming that?

E23: I think they prepared me because I have not gotten pregnant since then, and I was not using birth control. I just have this daughter and if it were God's will, I wish I could have another child.

I: But what did you do in that moment (of the C-section)?

P: I, myself? I didn't do anything. I couldn't do anything. They'd already done it.”

(Participant E23, personal interviews).

The same woman, when asked about her overall experience in the program, declared it to be 'good.' This is just one of many examples uncovered by the interviews that show how women in the program blindly accepted medical decisions, and did not protest when a medical procedure was carried out against their own wills and bodies. The excerpt of the above-cited interview also exemplifies the fact that doctors feel it completely within their rights to perform an illegal procedure, without obtaining consent from program participants. Not only are these procedures met with little resistance, but as a result, the doctors' autonomy is never criticized, nor questioned.

Secondly, we must examine the concept of discretion, as it relates to treatment. Although many of the women interviewed suffered discrimination, humiliation and rights violations, others did access first-class treatment. What makes these women different? The main thing to notice is that the hospital can potentially count with all the necessary equipment, staff and training to perform a very high quality service. This is so much the case that one of the women interviewed affirmed, without having been asked:

“E48: So for now I don't have any complaints about the program, thank God. Imagine, I'm so satisfied that even if I had a private insurance,

I'd come here to give birth, because they treat me well here. I like the Maternity⁵".

(Participant E48, personal interviews).

The first thing to note about this interview is that the interviewee was referred directly to the researcher in order to ensure that she was interviewed. It must be underscored that one of the peer counselors involved in the program explicitly asked some program participants to give positive feedback, while interviewed. This clearly modified some of their answers. Once this was discovered by the researcher, measures were applied to help avoid this type of influence. But, in the case of the interview cited above, one of the first things interviewee reported-- even before a question was asked of her-- was that she did not have any complaints about the program. She was clearly anticipating questions that had been asked to other program participants.

Even so, we must not discard the idea that this woman did receive such high quality treatment that even if she had had private insurance, she would have decided to continue treatment in the public "Maternity." Why? Usually, under no circumstances would the Dominican middleclass go to a public hospital to give birth, especially considering that Dominican Republic is one of the countries with highest maternal mortality rates in the world⁶. This is true, unless they can count on a close relationship with a family member or a friend inside the public hospital:

"I: Ok. Good. So can you talk to me a bit about the first time you came in the hospital?

E48: the same thing, everything went fine, I was well received by the program, and, like the other time, Dr. Mendez was my doctor. Apart from being a doctor, she was my friend and that was the advantage".

(Participant E48, personal interviews).

⁵ It's the name of the hospital where she was attended.

⁶ The estimated maternal mortality ratio in the Dominican Republic is 100 per 100,000 live births (World Bank, 2013).

The interviews documented an ample variety of behaviors exhibited by doctors, in relation to the management of patients. The fact that these changed according to personal connections inside the hospital points a finger at the use of public resources for personal purposes. The benefits of having a close relationship inside a hospitals can span from receiving the best possible care from the best doctors, to having a private room in an overcrowded hospital, to accessing a C-sections without waiting for weeks. Even if the program is supposedly 'public and free for all the women,' -- in accordance with a rights-based policy approach -- this is clearly only true to a limited extent. The fact that some interviewees reported quality treatment, while others suffered violence, is an indication that should sanctions for negligence and malpractice be implemented, it is well within the system's capacity to improve treatment for all.

In another interview, participant E74 declared that she waited in the hospital for *fourteen days* before she was admitted in surgery for her C-section. Only once the woman was able to contact her sister, who knew someone inside the hospital, was she properly attended to.

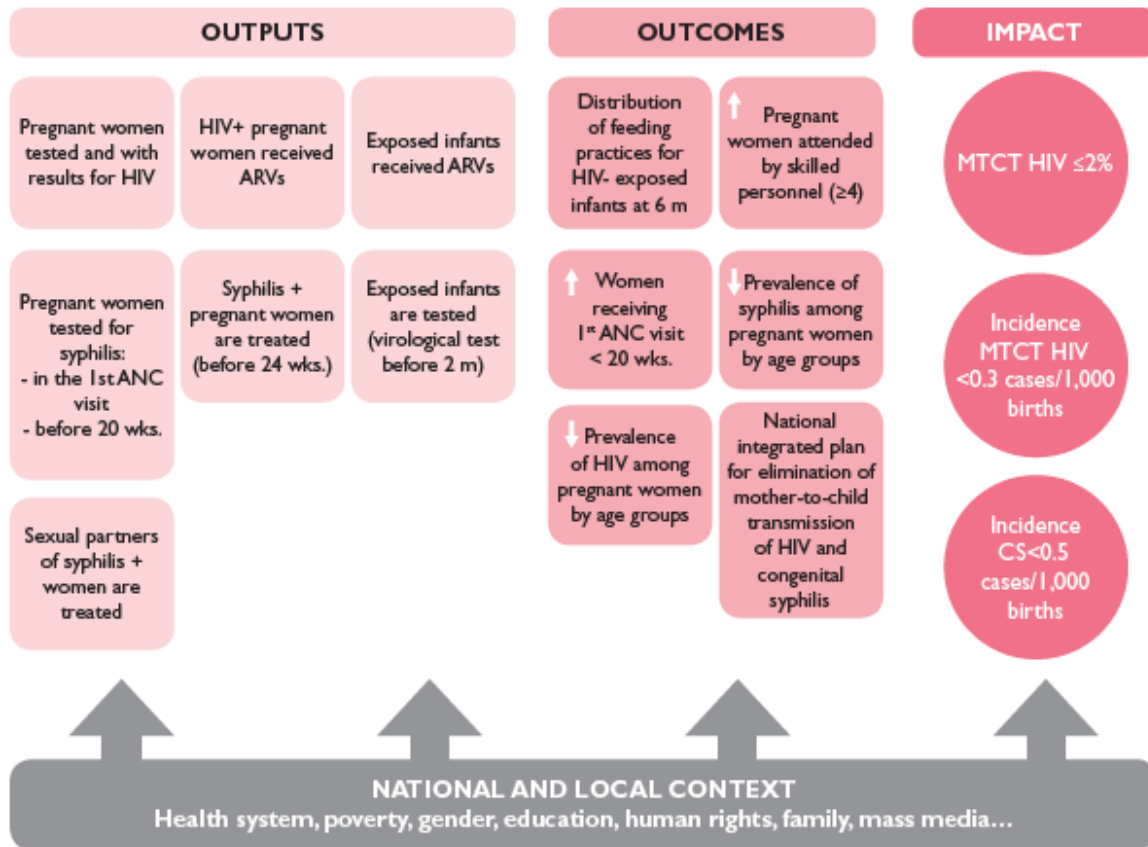
The consequences of malpractice are both very common, and can be devastating. During the first years of this research, a doctor poorly calculated the doses of antiretroviral treatment to a newborn. The mistake killed the newborn instantly. The same doctor had already miscalculated doses for other kids, without sanctions. Four years have passed since the incident, and the same doctor remains in the same hospital attending the newborn babies of HIV-positive mothers. She has yet to receive any sanction for her actions.

Thirdly, in order to understand different treatment-experiences, it is necessary to examine structural factors and to question how international and national guidelines and initiatives frame the discourse around the PMTCT. An analysis of program-participant data

reveals that 28.4% of women (twenty-five of over eighty-eight who answered this question), were not informed that they could continue treatment after giving birth. Of the sixty-two women that were informed of this option, twenty-nine were not in treatment at the time of the interview (46%).

These figures can be explained in several ways, each of which are embedded in the everyday life of the program, at all levels: from national discourses of the policy-design experts, to the actions of service providers, at the service level. First and foremost, at the national level, the strong emphasis is on the child. This much is readily clear when we read various documents related to the Regional and National Initiative for the Elimination of the Mother to Child Transmission. As seen in 'Picture 1,' all of the initiative's impact-indicators and are centered on the child:

1. Reducing mother-to-child transmission of HIV to 2% or less,
 2. Reducing the incidence of pediatric HIV cases to 0.3 or less per 1,000 live births,
- and
3. Reducing the incidence of congenital syphilis to 0.5 cases or less per 1,000 births by 2015.



Picture 1: Alonso González M. Regional Initiative for the Elimination of Mother-to-Child Transmission of HIV and Congenital Syphilis in Latin America and the Caribbean: Regional Monitoring Strategy. Washington, DC: Pan American Health Organization; 2010.

Because the program is designed around the child and his/her wellbeing, it fails to emphasize national guidelines that would encourage the healthcare providers to urge program participants to continue treatment after birth. This is a classic example of “playing for the test” at the national level, as the Dominican Republic will be evaluated based on indicators centered on the child, and not the mother. It should not be surprising, therefore, that of the same women who were informed of their option to continue treatment, only seven did not bring or schedule their children for the his/her HIV test. We can deduce the

following: the mother is more than willing to come back to the hospital, even after birth, but only if enough emphasis is placed on the importance of all program-steps.

On a structural level, it is evident that a completely different emphasis is placed on the program participant before she gives birth, than after giving birth. Before she gives birth, it is strongly recommended that she takes her medicine, that she eat properly, and that she not have unprotected sex etc. After she gives birth, the emphasis passes from her to the child. The mother should not breastfeed, and she should access the free powdered milk from the program. She has to bring the baby for checkups, and she should test her child with an AND-PCR. Whether or not she, herself, follows up with treatment, is not enforced. Neither is whether or not she continues to check in regularly, nor if she continues to protect herself from other contagious diseases.

This is also due to the way the program is designed in the Dominican medical system. While the woman is pregnant, she receives both antiretroviral treatment and gynecological checkups with a gynecologist in the maternity hospital. She does not have to take the drugs in another center. After she gives birth, she has to do her checkups and pick up her drugs in a so-called 'Integral Attention Service' (Servicio de Atención Integral, SAI). These are centers that should provide 360° attention (medical and psychological) to HIV-positive patients. Unfortunately, in many cases the program participant must decide whether to spend the money she has available for transportation to go to the SAI to checkup on herself, or to go to the maternity to checkup on her baby. As previously described, the program participants cannot continue treatment in the same maternity where they were first treated, and where her baby will continue to be treated. This is true even though in theory, there are no structural limitations that prevent the mother from being treated in the Maternity until her baby is six months old, and seroconverts. Perversely, as stands, the

mother tends to prioritize her baby's health over her own. The results are extremely dangerous, and include the risk of developing resistance to antiretroviral. If the program is successful, in the near future we could see HIV-free babies, with very sick or even deceased mothers. Allowing the mother to treat her baby and herself in the same medical facility -- whether in SAI or Maternities-- could improve the mother's adherence to program protocols, and prevent this type of situation.

Fourthly, adherence to the program as a concept must be reframed in order to incorporate the fact that quitting the program can be a form of protest, and a way to protect a seropositive women and her children. Currently, even though rights violations are common, program participants continue to , at least in theory, adhere to the program. If the program is not reframed, this will continue to result in program failures that hide serious-- and hard to detect-- systemic problems.

Hard to detect because of the patriarchal and vertical relationship between a doctor and his/her patient, that strongly limits the possibility of the patient speaking out against rights violations. Absence of red flags is a strong indicator of disempowerment of the women in the program, who accept violent situations characterized by lack of quality services, and by passivity. And if this is not recognized, quitting the program will continue to be seen as a sign of the program participant's lack of responsibility, both by the participants themselves, and by all of the actors involved in the program:

“Frankly, people with HIV die because they want to, well not exactly because they want to, because sometimes they don’t have the possibility...”

(Participant E48, personal interviews).

When a woman drops out of the program, fault is typically placed on her. No consideration is given to the strong impediments (economical, social, psychological) or to

institutional viciousness (malpractice, negligence and false information) that contextualize her story and experience.

4 DISCUSSION AND POLICY IMPLICATIONS

4.1 Main findings

Studies on the determinants of adherence in programs for the Prevention of Mother to Child Transmission usually concentrate on demographic, medical and epidemiological aspects of the patient. In doing so, they neglect social, economic, and structural conditions. This research has focused on the latter. Existing literature developed in the African continent and in India identifies a series of determinants that are only partially applicable to the Caribbean and Central American context. Among the conditions *not identified* in previous investigations of PMTCT, or that have different effects on adherence in the Dominican context, it is possible to highlight five that are especially relevant: a) language barriers, b) understanding of HIV, c) education, d) violence, and e) transportation cost. For the first two of the above-mentioned determinants, there is enough evidence to consider them necessary conditions for adherence to PMTCT. In the case of the last three, the evidence is either not conclusive or ambiguous.

We will start the discussion by addressing language barriers in the Dominican PMTCT program. No previous study in LMIC-contexts has addressed language barriers as a factor related to adherence. In the Dominican context, with an important ethno-linguistic minority, the ability to understand doctors' recommendations and program protocols -- explained exclusively in Spanish -- during pre- and post-counseling, directly effects a participant's ability to finish the program successfully. As such, data analysis revealed a consistency parameter of 0.88, proving language to be a necessary condition for the successful completion of the program cascade, thus reducing risks for the mother and the child.

So far the program has only minimally addressed language barriers. It has done so by hiring *one* female Creole-speaking staff per hospital. Unfortunately this person generally has neither medical translation training nor skills that would allow her to culturally mediate between patients and other medical staff. Incrementing the number of personnel who speak Creole and who are able to communicate with patient, especially in emergency situations, is a necessary step, but it is not sufficient. In a Haitian-phobic society such as the Dominican Republic, HIV positive women of Haitian origin face double discrimination that needs to be comprehensively addressed to successfully improve service quality.

Secondly, the QCA analysis proved that ‘Understanding of HIV’, with a consistency parameter of 0.89, was the most important condition in the population studied, thus resulting a necessary condition for finishing all the steps of the PMTCT protocol. This has several implications that are inextricably related to literature in PMTCT. The majority of the women who enter into the program are first timers. When the psychologist informs a program participant of her HIV positive status, it is likely to be the first time that she has heard about her condition. During this first session with the psychologist, it is therefore extremely important to ensure not only that the woman understands her condition, but also that the program steps are well and easily explained. Pre and post counseling are not mere requirements to be filled. They must be carried out in private sessions with healthcare providers, with sensitivity and care. Guaranteeing that this step is properly completed ensures that program participants are well aware of the risk and possibilities of the program, and what is expected from them. This reduces their fears about the program, and about their children's future lives. If this knowledge about the HIV condition and the PMTCT protocol and personal requirements is not properly transmitted, the rate of success will be seriously compromised.

The third important factor is education of the mother. Based on our results, with a consistency parameter of 0.63, it has only marginal effects on adherence. Although many studies prove education to have “consistently strong effects” on the use of antenatal services (Castro, 1995; Gabrysch and Campbell, 2009; Ahmed et al 2010), the current research only found this to be true in some configurations. This suggests that, in terms of adherence, education is a factor that influences the outcome only in association with other conditions, such as understanding of HIV, speaking Spanish, and the support of a significant other. In the context of this study it is not, independently, a necessary condition.

The fourth condition to be discussed is transportation costs to and from the main healthcare center where the program is delivered. With a consistency parameter of 0.74, ‘cost’ alone is not a necessary condition in completing all program steps. On the contrary, program participants affirmed being scared of disclosing their status to family members, and in the community where they live. To maintain their privacy, they access healthcare centers sufficiently far away from their homes to overcome stigma and maintain their HIV status a secret. Although for some women cost is an important factor in program adherence, for others, high costs are necessary in order to access treatment without facing stigma and violence against them and their children.

This finding should help the Ministry of Health reconsider their proposal of building new SAI (Integral Attention Services) closer to marginalized communities. Plans to build SAI closer to impoverished communities in the Dominican Republic are based on the findings of African studies in this area. Unfortunately, this analysis makes clear that patients in the Dominican Republic typically access treatments in SAI far enough away from their home communities so that they do not have to disclose their status to family members or acquaintances. Stigma against HIV positive women is still very strong. It is so

internalized in Dominican society that not even the healthcare system is immune to it. Fear of touching, operating on, or even sitting close to an HIV positive woman are just a few of the everyday discriminations that HIV positive patients face in hospitals and were revealed in the qualitative analysis. At the same time, no coordinated actions are being taken to improve the wellbeing of patients at the community level, and thereby reduce stigma.

Additionally, women who attend the program in public hospitals are often extremely vulnerable and economically poor. However, in terms of adherence there is a substantial difference between poverty, unemployment and extreme poverty. All women analyzed were poor. The sub-set of women in extreme poverty was operationalized as those not being able to cover their basic needs of food and shelter, either via gainful employment or via social networks and safety nets. Female employment has been constructed in reproductive health literature as a proxy for economic autonomy and is thought to be closely associated with better access to service (Jejeebhoy, 1995). However, the empirical data about being employed showed a low consistency parameter of 0.65. An important group of women were able to complete all the steps without having a gainful job, while others could not do it despite being employed.

The empirical analysis showed that extreme poverty's consistency was 0.85, which is much higher than job. Even though it would not qualify as a necessary condition to complete the cascade of the program, it suggests that 'access to living wage' is a very important enabling condition. Not having access to basic food needs strongly impairs a program participant's ability to finish the program. It is important to remember that the ARVs have many side-effects when taken with an empty stomach. In this respect, the women who finished the program were women, that being employed or not, had sufficient social networks to allow them to access basic necessities, especially food. This finding

should help refocus program efforts towards vulnerable groups, so that through the program or other social programs (such as cash-transfers, social security or community-based interventions) their basic needs are met. The program should put in place active mechanisms for adequate responses to women in strong physical and psychological distress, as quite obvious when one person has not eaten in a few days.

A final condition to be discussed is violence. Violence has been analyzed at length in this thesis, and is one of the more controversial conditions. Although more than 140 direct episodes of violence and violation of human rights were identified through this research, only some of them resulted in the patient abandoning the program. Seldom could program participants directly identify violence and violations of their rights, even when it directly affected their ability to live. Chapter 4 explains two prevalent forms of violence suffered by interviewees: categorized as Institutional and Individual. Each of these two categories was divided into subcategories to shed light on different manifestations of violence, their perpetrators, and their absolute frequencies.

Doctors and other medical staff inside hospital premises have perpetuated the most frequent forms of violence, as classified in the category 'malpractice'. This type of episode unveils dynamics of disempowerment and the practice of discretionary treatment inside Dominican hospitals. This patriarchal system commonly violates the bodies, the privacy and the dignity of patients. The woman is perceived as a passive human being, over whose body, the doctor has complete control. The reported episodes of forced sterilization without consent or, indeed, explanations offered, exemplify this: doctors in the Dominican system frequently impose their wills on disfranchised patients. Although Dominican program participants were more prone to report episodes of violence as compared to women of Haitian origins, women of Haitian origins reported more intense episodes of violence, with

a ratio of 7:1. In this sense, the research exposes a serious failure to implement a right-based approach in the program, and insists on the need to work honoring to the will and informed consent of the patient, and not of the medical staff and their misguided perceptions about HIV positive women.

These data on violence highlights the need to reconstruct the concept of adherence in its entirety. Program drop-out rates, or what Hirshman would refer as ‘exit’ (1970), cannot be perceived as a sole responsibility of the participant, nor as an irresponsible individual decision, which is the predominant perception, both in literature, and in the healthcare system. For example, when epidemiological research only considers demographic conditions of program participants to follow up the cascade, the underlying assumption is that personal variables are sufficient to understand adherence.

On the contrary, non-adherence is often the consequence of a healthcare system not prepared to offer services to the most fragile populations in the Dominican Republic. Both sides of the coin -- individual choices (demand-side) and program downfalls (supply- side) -- interact to determine adherence patterns. Drop out can, therefore, be reinterpreted as the only way for some of the patients to avoid humiliation, stigma, and violence inside the hospital, and in home-communities. Adherence is a process in which structural conditions, usually ignored in systematic analyses, language barriers, violence, stigma and understanding of HIV interact with other more traditionally studied factors to shape outcome.

Literature about PMTCT, as far as this investigation’s comprehensive review, has barely touched on this. Only Gabrysh and Campbell, in their review of determinants of delivery service use, allege that studies that ignore the supply side of services, tend to “blame the victim” (2009). Consequently, to consider only demand-side factors without

taking into account the socioeconomic contexts in which the program and its patients are immersed is a sterile exercise that may well lead to erroneous policy recommendations. The greater difficulties involved in operationalizing supply-side conditions, as compared to demand side conditions, should not deter research regarding adherence and its related facilitators and barriers.

Unfortunately, this means that both the system and goals of the Dominican initiative need to be restructured. The strong emphasis on avoiding transmission of the virus to the child -- at the expense of ignoring the mother's health -- undermines the possibility of integrated treatment for the mother and her newborn. This has strong repercussions for program implementation and the actions and treatments recommended by healthcare professionals. If the system does not ensure the health of the mother and the father, in a few years we could see an influx of HIV-free orphans.

As discussed throughout this thesis, there is a gap in the PMTCT literature that fails to unpack the social, economic, institutional and structural conditions that enable or deter patient adherence to the program. With the combination of QCA and qualitative analysis it has been shown that in the case of the Dominican Republic, language barriers to the Haitian migrants and their descendants, systemic institutional violence, and cultural stigma strongly affect adherence to the cascade of the program.

These conclusions represent a mere first step in the analysis of determinants of adherence in the Dominican Republic's PMTCT. They should be complemented with further studies in this area, and in the Caribbean Region, that ensure better comprehension of program mechanisms and their implementation, inside hospitals and in the communities.

4.2 Limitations and wide open premises for further research

The research presents several limitations that can be addressed in the future as part of a coordinated effort for the improvement of PMTCT between the Ministry of Health and researchers working in this field. Firstly, the model presented in the research with seven conditions explains only positive outcomes for the analysis. Therefore, we were able to respond systematically only to the first part of the research question related to the trigger mechanisms of adherence through fsQCA, while non adherence has been only assessed through qualitative relevancies. This means that further research is needed to tackle conditions strictly related to women who drop out of the program. To do so, researchers must coordinate with hospital staff to immediately detect when a program participant misses a check-up or an important program step.

Mutual trust must be built to allow open access to administrative records. In many occasions, the women who drop out were impossible to contact because they gave a wrong number or a wrong address. This makes it extremely difficult contact or even detect those women. Moreover, both the contact itself, and an establishment of trust between participant and researcher is extremely costly, both in terms of time and energy. Although multiple efforts have been made and different techniques have been used to contact dropouts, the rate of responses to phone calls and meetings for interviews was extremely low. Due to the extremely precarious conditions suffered by women in the program, risk factors for dropouts are a wide-open field of investigation.

Another important limiting factor is the (non)availability of national data. Program data is still collected in paper format and entered in the system as stock data. This implies that no inferences can be made about the population of HIV positive women, nor

longitudinal data gathered regarding steps taken in the program. Important efforts must be made to start collecting data with software available in the hospitals, and improve the monitoring of indicators of compliance to program steps. Such program software are already available, and should be synchronized between hospitals to ensure they do not duplicate women data. As stands, there is no systematic process connecting a mother's data to her child's, and therefore it is not possible to study different ways that a mother can follow the program according to its effectiveness.

Adherence to PMTCT programs is a new and open field of investigation for researchers in LMICs, and especially in Central and South America, where very scarce, predominantly qualitative -- and not robust -- literature is available. It is therefore important to make efforts for improving the Dominican program and to adapt existing literature framework to this topic.

Another open field of investigation is the involvement of the male partner into the PMTCT program. Because the woman, in many cases, is the first of the couple to discover her HIV positive status, she is more exposed to violence and abandonment. It is important, therefore, to investigate the impact of the involvement of the male partner in the successful completion of program steps. This would not only decrease the mother's risk, but also the possibility of re-infection for both partners. Studies show that a male-partners participation can improve adherence up to three times more effectively, as compared to women whose partners are not involved (Faraquhar et al., 2004).

Thanks to the insight of 120 in-depth interviews, we can affirm that the foundations are in place to research adherence to PMTCT within a wider, longitudinal and multi-country study. This investigation of PMTCT patients in LMICs would open the way for comparisons of different institutional configurations and different mechanisms of

adherence and non-adherence. Analyses should be always complemented by examining adherence from the supply-side, and analyzing procedure, processes, and structures inside hospitals and maternities wards. To continue addressing adherence as women's problem would be naïve and not effective in elucidating the problem present and their embedded practices.

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6 ANNEXES

6.1 Methodology, method and technique

Methodology is here referred as the discourse about the method (Marradi, 2007) and it can also be seen as the strategy that we use to acquire knowledge (Hay, 2006 b). Been the research always a specific policy problem, the construction of theory will be a continuous deductive process that starts from experience and builds up deductively to then arrive at “a general theory of wider acceptability” (Della Porta & Keating, 2008). Östlin explicitly refers to the necessity to use approaches that are gender sensitive since non-gender sensitive approaches to the study of health public policies can happen to not fully catch the complexity of the program in place. From a practical point of view, it is extremely important to consider gender because, as Östlin noticed:

“health promotion policies that take women's and men's differential biological and social vulnerability to health risks and the unequal power relationships between the sexes into account are more likely to be successful and effective compared to policies that are not concerned with such differences”

(Östlin et al., 2007).

In order to talk about the gender sensitive methodological foundations of the Approach it is necessary to commit the investigations developed in this sector to five main criteria derived from feminist literature in social sciences research and especially the criteria by Harding (1987) and Wylie et al. (2012):

- 1) Relevance of the research for the women
- 2) Women’s experience
- 3) Horizontality
- 4) Reflexivity

5) Methodological provisionism

We are going to describe these five criteria one by one because it is truly important to understand these starting points in order to develop further methodological considerations. The first criterion is the relevance of the research for the women. This implies that the research needs to be practically useful to improve the condition of the women and/or to advance the political agenda for the women.

A clarification here has to be made in the distinction of gender sensitive research and feminist research. There seems to be not practical differences between feminist research and gender sensitive research in health public policies. Different field of studies tend to use one of the other or both interchangeably. Even so in health public policy action research there seems to be a general agreement on using the term gender sensitive. Other interpretation in other fields tend to identify gender sensitive research as a less politically involved than feminism in the sense that gender sensitive research in general does not make political claims while feminist research does so.

The second important criterion is to consider the importance of women's experience especially of those women of which the experience is unknown or invisible. The third one is related to the status of the researcher and the necessity to be at the same level with the study participants. This implies that the participants of the research have to be empowered at the end of the research and not exploited and/or that the result of the study need to be inclusive and useful to that same population object of the study. This characteristic of gender sensitive theories is also compatible to the new direction of the World Conference on Social Determinants of Health in which one of the guiding principle for applied research in public health policy should be the necessity to work towards closing the gap among different types of inequalities in gender, race, social and economic condition.

The fourth criterion implies that the researcher needs “to collocate her/him-self” respect to the research is developing. This implies the necessity to declare its values, position on the topic, origins, ethnicity and the effect that these characteristics can have on the research he/she is conducting. She or he needs to therefore have a reflexive approach. The last criterion is what can be called the “methodological provisionalism” and it deals with the necessity for the researcher of, in a way, keeping the protocol of investigation open in order to be able to make the necessary adjustment during the research to better investigate the issues (Wylie et al, 2012). These criteria, recalled by public health policy literature according to the denomination of gender sensitive theories to women’s health, do not contemplate a specific method to which refer or adhere.

The possibility to incorporate a gender sensitive multi-sectorial approach is extremely important since HIV positive women can be exposed to different social hurdle, psychological and physical violence, among which social exclusion, discrimination and femicide. In order to understand the magnitude of the problem is necessary to understand that the Caribbean is the third region in the world with the highest rate of HIV infections of the planet and one of the regions with the highest rates of pregnancy in adolescent. In some regions of the Dominican Republic pregnancy in adolescents can be higher than 35%, which also increase the probability of getting different sexually transmittable disease at younger age than any other country.

The method that has been used in the current research recognizes the complexity of the topic and the necessity to integrate different levels of analysis and contextual and individual factors affecting adherence. In our applied research, contextual and individual factors affecting women adherence have been divided in two types of analysis: one is related to the demand side (patient) and the other to the supply side (health care services). It

is therefore necessary to integrate both analytical levels in order to understand these two essential aspects of the research since both have a direct influence on why women in the program can have different level of adherence in the PMTCT.

Qualitative Comparative Analysis (QCA) has been selected as a method that suited the necessity of the question that has been asked so to identify the mechanisms that are leading the women to different types of adherence, since:

“According to realistic evaluation, political programmes can trigger a range of mechanisms of change. The specific mechanisms triggered will depend on the programme context. As a result, a political programme can lead to a variety of outcomes in different contexts”
(Befani et al, 2007).

QCA recognize the possibility of different paths to the same outcome that involves a specific concept of causation called multiple conjunctural causation. This helps to recognize and embrace the complexity of today’s health public programs in LMICs and apart from allowing a certain level of generalization, it allows not to forget those that are outliers cases since these can be very useful in understanding the program and the underlying mechanism involved (Rihoux and Ragin, 2009). Especially relevant for our specific research was also the necessity to consider a rather scarce body of public policy literature on this topic and therefore the method had to embrace the possibility of a constant feedback between data and literature:

“the choice of the variables (conditions and outcomes) for the analysis must be theoretically informed. In this sense, there is a deductive aspect to QCA; however, QCA techniques can also be used more inductively, gaining insights from case knowledge in order to identify the key “ingredients” to be considered”
(Rihoux, 2003, 2006; Rihoux and Lobe, 2009 in Rihoux and Ragin, 2009).

This is especially important in a context in which we have a very small body of literature and therefore the necessity to negotiate and adapt conditions to a specific context

and emerging data. Since this is not only a problem of this program but as seen a general trend in health public policies in LMICs it is extremely important to be able to recognize this pattern and have a method capable of giving an answer to this challenge.

After choosing a method that was appropriate for the context and able to satisfy the research question, it was important to look at the collection of the data. The collection of data has been made through in depth interviews and ensuring to collect some more direct information of the participant in the research. This technique has been chosen to better catch underlying mechanism and also because it was the more appropriate to treat delicate issues in women lives. As a matter of fact the initial technique chosen for the study was semi-structured interview but unfortunately this technique was not working. It is extremely important to be ready to change the instrument chosen and also to sharpen the questions through few in depth interviews as a trial. Using semi-structured interviews was not allowing the possibility to create an empathic dialogue essential to investigate delicate aspects of women life such as the discovery of her HIV status, violence, abandonment from the partner, livelihood means.

The possibility to use in-depth interview left the door open for new insight that comes from data and the capacity to modify the QCA conditions used in the analysis as soon as the interviews were transcribed and analyzed. Which are therefore the differences between an approach that does not take into consideration gender in health public policies in LMICs and gender sensitive approaches? Im and Meleis propose a practical comparison for applied research in public health policies considering gender, voice, nature of experience, perspective and context.

Table 2. Components of Gender-Sensitive and Insensitive Theories		
Major components	Gender-sensitive theories	Gender-insensitive theories
Gender	Gender as a basic feature and a central agenda	Gender as one of multiple mediating factors
Voice	Women's own voices and experiences	Theorists' interests
Nature of experience	Diversities and complexities of women's experiences	Universal women's experiences
Perspective	Theorists' reflections on underlying androcentric and ethnocentric assumptions	Theorists' objective stances
Context	Sociopolitical contexts and constraints of women's experiences	Objective sociopolitical, influence-free theory.
Guidelines for action	Empowerment and guidelines for raising consciousness and actions	Description, interpretation, and understanding

Figure 3: differences between Gender-sensitive and Insensitive Theories

One of the first things to notice that is extremely relevant for the approach that we are presenting is the Nature of experience and the Context. These two major components are extremely relevant to conduct research in LMICs:

“Based on her international experience with women’s health, Barroso (1994) strongly emphasized that the development of a sound theoretical framework for women’s health should be one that takes into account not only gender hierarchies but also diversities and complexities of women’s experience from different kinds of hierarchies of countries, classes, and ethnicities. Gender-sensitive theories incorporate diversities and complexities in women’s experiences, while gender-insensitive theories assume an objective stance in women’s experiences and reduce women’s health and illness experiences to a disease or health problem”
(Barroso in Im and Meleis, 2001).

As a researcher in LMICs it is necessary to be aware of the difference of experiences of women attending public hospitals, public services or following a public program related to their health. Vulnerable population such as migrants, drug users, adolescents etc. even if attending the same program may have very different opinions about

it and extremely different necessities. Among the most important conditions that affect adherence in the program is the origin of the patient. Haitian population, with which the Dominicans share the Hispaniola Island, has a higher HIV prevalence (2.1% according to the World Bank compared to 0.7% of the general Dominican population) and also a higher risk of not completing all the steps of the program. During a previous personal explorative study in one of the hospitals has been shown how HIV positive Creole speaking women have a significant difference in finishing the program, child death and in the type of antiretroviral treatment that they follow leading to different outcomes respect to Dominican women in the same conditions. Therefore it is important to consider how the program is responding to these different groups of intended user of the program in order to offer a better service and therefore avoid non-adherence.

Adapting the research to the different conditions of the women involved in the program implies also to be aware of the difference of the intended users following the program paying particular attention to gender differences and other contingent participant characteristics. For instance, especially in impoverished countries where access to health care is unequal among different women it is important to analyze which are the factors that create disparities. A huge part of literature related on maternal health service use in impoverished countries considers:

“women’s use of antenatal and family planning services are determined by not only the physical availability of such services, but also by a set of gendered norms and values that shape women’s access to education, ability to travel, financial and social resources and decision-making authority in key aspects of their lives”

(Mumtaz et al., 2010).

Moreover, it is also extremely relevant for the research in health policies in LMICs the context in which the health program in embedded. This is important not only for the

general economic and social and political structure in which the program operates, but also in order to take into consideration social movements, community based organization, current demands (Im and Meleis, 2001) and more importantly, solutions to the problem. Impressive insights, data, non published studies can come from associations that are supporting the PMTCT in the hospitals, from hospital volunteers and from associations that work in defending the rights of people living with HIV.

PMTCT guidelines worldwide recognize the need to center attention on the inequalities of the system and to identify possible marginalized subject through an in depth understanding of the conditions in which the program takes place. This is impossible without the involvement of the researcher in a systematic fieldwork and with the interaction of health care practitioners and intended users.

Improvement needs in Analysis of PP in LMICs	Insights from Gender Sensitive Methodology
a) necessity to critically incorporate existing framework of public policy contributing to existing theories (Walt et al., 2008);	1) Relevance of the research for the women
b) integration of theories from other social science fields to existing problems such as evaluation studies in the health sector in low and middle income countries and organizational studies;	2) Women's experience
c) make explicit the paradigm, the methodology used and the interpretation made (Gilson and Raphaely, 2008);	3) Horizontality and Methodological <i>provisionalism</i>
d) contribute to the betterment of the program object of the research at the hospital and managerial level.	4) Reflexivity and Providing guidelines for action

Table 1: review of the literature improvement needs in Analysis of Public Health Policy in LMICs and Insights from Gender Sensitive Methodology

6.2 Survey

Survey about the experience of the PMTCT user

Thank you very much for taking the time to answer this questionnaire! For us it is very important your opinion as a user of the program. It is very important to inform you that at no time your name will be associated with the answers you will give or to your identity (your name, identity card, etc.). This implies that the questionnaire is completely anonymous. You can stop at anytime to answer the questions, or to skip some of them.

The information you provide will be used for a doctoral thesis about the Program for the Reduction of Mother to Child Transmission of HIV in the Dominican Republic.

The research has been approved by the Dominican National Council on Bioethics in Health (CONABIOS) that guarantees that there are no physical or psychological risks associated to in taking part in this research.

Thank you very much for your cooperation!

1. Can you talk to me about how your pregnancy went?

(Opening question - get to know the emotions, how she felt, when she discovered the sex of the baby and other questions to break the ice with the participant).

2. When and how you found out to be HIV positive?

(Find out the following: In what year? If with this pregnancy or during a previous pregnancy, where she took the test?)

How the people who work in the hospital treat you when they told you that you were HIV positive? What did they say?

How did you feel? (very sensitive question, find out if there is acceptance of the diagnosis and how she feels now).

3. Can you describe your experience with the PMTCT?

ANTEPARTUM: Did you take drugs while you were pregnant? Where you got them? Do you remember the names of the medications? How many times a day do you take them?

How many follow-up visits have you had? How the doctor treat you during the visits while you were pregnant? Were you checking only in here or also in other centers? Where? When you received the results of your HIV test?

3.2. DURING LABOR: Where did you give birth? Vaginal or Caesarean? Can you tell me a little bit about how the labor went? Did you enter through the emergency or you had an appointment? What did the doctors say when they saw you? And the nurses? You said something to them about your condition? Did you come alone to the hospital or someone came with you? Are you taking birth control now? What kind? Did you decide the type of birth control or someone else choose for you?

3.3. AFTER DELIVERY: You gave ARV to your son / daughter? (As prescribed? Are you following up the treatment for your baby? Where? What does your son/daughter eat every day? (Find out if you they are just giving formula or breastmilk also).

4. Now, are you taking any type of drugs? (What medications are you taking? Every how many hours? Do you have any side effects? Check if she is eating properly.

5. Is your daughter or son already registered? Are you declared?

6. Was your pregnancy planned?

7. Why you did not follow up in the program? (question that has been added for women who exited the program)

8. If I give you \$ 100,000.00 RD to improve the program what would you do with this

money? How can we improve the program?

9. If these actions are initiated, would you come back to the program in the future?

10. Do you have a job? Do you have access to some money without someone to control

how are you spending it (eg your partner, your friend, your mother?)?

11. Do you have a spouse, a partner or are you dating anyone at the moment? Who helps

you with your every day problems? Can you talk a bit about him or her?

11.1. Does he/they know that you are HIV positive?

11.2. Does he/she supports you when you are in need? How?

12. Have you had the opportunity to have some sort of sex education? Where did you get

the information that you know about sex?

13. One last question, if you drink from this bottle and then I drink from it there is a chance

than I can get infected with HIV? And if a mosquito bites you and then me? During sex?

Breastfeeding your child? Kissing your partner? And if you are pregnant can you pass the

virus to your kid?

B) Closed questions (do them after finishing the interview with open questions and find out

if they this information has already been collected).

14. Place where the user is being interviewed: _____

15. In what year were you born?

16. What languages do you speak with the people living in your house?

17. Were you able to attend school? How many years have you studied?

18. In which city do you live?

19. In which sector or neighborhood?

20. With how many people do people do you live at home?

21. How many children do you have?

22. Are you receiving medicalcare at other health centers, clinics or other hospitals?

23. Do you work?

23.1. YES: what kind of work do you do?

23.1.1. How many days a week do you work?

23.1.2. How much do you earn in a day?

23.2. NO: go to question 24.

How long does it takes for you to get the hospital from your home?

25. How did you arrived? Motoconcho, bus, on foot, with a car?

26. Which is the cost to get from your house to the hospital?

27. What are the health services [clinics, primary care unit (UNAPS)], you know near your home? Make a list

28. Do you use some of these?

29. In conclusion, you know some other woman who has been in the program to reduce vertical transmission? Could you put me in touch with her for an interview?

(Thank you for your participation).