

FLORIDA INTERNATIONAL UNIVERSITY

Miami, Florida

PSYCHOSOCIAL AND STRUCTURAL BARRIERS TO SEEKING, REACHING,  
AND RECEIVING CARE FOR OBSTETRIC EMERGENCIES AND PERIPARTUM  
CARDIOMYOPATHY AMONG PREGNANT AND EARLY POST-PARTUM  
WOMEN IN HAITI

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by

Cassandra Rene

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To: Dean Tomás R. Guilarte  
Robert Stempel College of Public Health and Social Work

This dissertation, written by Cassandra Rene, and entitled Psychosocial and Structural Barriers to Seeking, Reaching, and Receiving Care for Obstetric Emergencies and Peripartum Cardiomyopathy Among Pregnant and Early Post-Partum Women in Haiti, having been approved in respect to style and intellectual content, is referred to you for judgment.

We have read this dissertation and recommend that it be approved.

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Patria Rojas

---

Purnima Madhivanan

---

Florence George

---

Jessy G. Dévieux, Major Professor

Date of Defense: June 12, 2020

The dissertation of Cassandra Rene is approved.

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Dean Tomás R. Guilarte  
Robert Stempel College of Public Health and Social Work

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Andrés G. Gil  
Vice President for Research and Economic Development  
and Dean of the University Graduate School

Florida International University, 2020

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## DEDICATION

This dissertation is dedicated to all my loved ones:

My grandparents, Joseph Guillaume and Marie Carissa Momplaisir Guillaume.

My parents, Fanie Guillaume, Dominique René, and Louis Nemorin.

All of my aunts and uncle.

Sony Jean and Marie Marthe Rene Jean.

My cousins.

My best of friends, Geraldine, Mitzy, Sasha, and Paulin who have been my source of encouragement throughout this journey. My newest of friends, P.O.P. for holding it down.

But above all, my Lord and Savior.

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ABSTRACT OF THE DISSERTATION  
PSYCHOSOCIAL AND STRUCTURAL BARRIERS TO SEEKING, REACHING,  
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by

Cassandra Rene

Florida International University, 2020

Miami, Florida

Professor Jessy G. Dévieux, Major Professor

Peripartum Cardiomyopathy (PPCM), a form of heart failure in pregnant and early postpartum women, has been shown to have a higher incidence in Haiti compared to the U.S. PPCM can often go unnoticed or misdiagnosed because the signs/symptoms are similar to that of regular pregnancy and may have negative outcomes for women if left untreated. This exploratory study 1) utilized a questionnaire to assess the knowledge, attitudes, and practices (KAP) of health professionals (n=128) regarding obstetric emergencies and PPCM in Haiti, 2) assessed the psychosocial and structural barriers to seeking, reaching, and receiving care for obstetric emergencies and PPCM among 6 focus groups of HIV+ and HIV- pregnant and early postpartum women and 3) translate and adapt the Fett self-test based on four focus groups with physicians and nurses/midwives, and 16 cognitive interviews with Community Advisory Board (CAB) members.

In Aim I of the study we found that when assessing knowledge, the nurse/nursing student group had almost 1.5 times more odds (AOR = 1.46, 95% CI: 1.38, 1.55) of scoring

higher, and the midwife/midwifery student group had about 2 times more (AOR = 1.98, 95% CI: 1.87, 2.10) odds of scoring higher in knowledge compared to the physician/resident group. In Aim II we found that factors such as 1) knowledge of obstetric emergency signs or symptoms, 2) awareness of eclampsia, 3) transportation, 4) country's insecurity, 5) negative treatment by medical providers, 6) good interpersonal relationship with medical providers, and 7) perception of women regarding traditional and medical maternal care played a significant role in women seeking, reaching, or receiving care. In Aim III of the study, we developed a final adaptation of the Fett instrument that accounted for cues associated with the reality of our target population and simple enough to be administered by a lower level personnel.

The findings from this study can be used to 1) improve training among health providers regarding obstetrical emergencies and PPCM, 2) increase awareness of PPCM among women and develop initiatives that will help bring services to women and 3) implement a Haitian Creole assessment tool to help better facilitate screenings of PPCM.

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## ABBREVIATIONS AND ACRONYMS

ANOVA	Analysis of Variance
AOR	Adjusted Odds Ratio
CAB	Community Advisory Board
CDC	Centers for Disease Control and Prevention
CI	Confidence Interval
EMR	Electronic Medical Records
FIC	Fogarty International Center
GHESKIO	Groupe Haitien d'Etude du Sarcome de Kaposi et des Infections Opportunistes
HIV	Human Immunodeficiency Virus
HUEH	L'Hôpital de l'Université d'État d'Haïti
INSFSF	l'Institut National Supérieur De Formation de Sages-Femmes
JHPIEGO	Johns Hopkins Program for International Education in Gynecology and Obstetrics
KAP	Knowledge, Attitudes, and Practices
NIH	National Institutes of Health
OR	Odds Ratio
PPCM	Peripartum Cardiomyopathy
SHOG	Société Haïtienne d'Obstétrique et de Gynécologie
WHO	World Health Organization

## INTRODUCTION

Developing countries account for 99% of all maternal deaths worldwide, with 830 women dying daily due to pregnancy- or childbirth-related complications (World Health Organization., 2018). Most of these deaths are preventable, however they occur in resource-limited settings that lack access to care (Alkema et al., 2016). Previous studies have stressed the importance of identifying barriers to receiving appropriate maternal health care to prevent maternal deaths (Gabrysch & Campbell, 2009; Thaddeus & Maine, 1994). Peripartum Cardiomyopathy (PPCM) is a disease of the heart which manifests in pregnant women during their last month of pregnancy and up to 6 months postpartum. It causes the muscle to have difficulty contracting and effectively pump and circulate blood throughout the body (Demakis & Rahimtoola, 1971; Medline Plus,2020). As a result, this strain may cause the heart to become weaker and lead to heart failure. With a limited understanding of the disease, research has not confirmed the specific reasons why pregnant women develop PPCM (Hilfiker-Kleiner & Sliwa, 2014). However, PPCM has been shown to have a higher prevalence among women of African descent.

Structural barriers in the Haitian health system, such as cost, distance, and location, limit the diagnostic and reporting of heart failure and PPCM during pregnancy and the early post-partum period; similarly, limited economic resources contribute to women's delays in seeking appropriate medical care (Pierre et al., 2010). Often, women living in rural areas will die at home and their deaths will go unreported or authorities must rely on verbal autopsies to determine a cause of death (Barnes-Josiah, Myntti, & Augustin, 1998; Dowell et al., 1993; Lewis, 2003). Consequently, there is a strong likelihood that heart

failure and PPCM are vastly underreported among pregnant and early post-partum women in Haiti (Boyd et al., 2017).

## **Background**

Haiti has one of the highest maternal mortality rates in the Caribbean, with 359 deaths per 100,000 live births, compared to the average mortality rate of 68 deaths per 100,000 live births in the region. These rates are partly due to delays in seeking medical assistance in obstetric emergencies, reaching an appropriate obstetric facility, and receiving adequate care at the obstetric facility (Barnes-Josiah et al., 1998). One of the medical contributors to this high maternal mortality rate in Haiti is heart failure and peripartum cardiomyopathy. Haiti's prevalence exceeds even that of sub-Saharan Africa (SSA; Fett, 2005; Fett & Markham, 2015; Malebranche, Tabou Moyo, Morisset, Raphael, & Wilentz, 2016), contributing to a maternal mortality rate that is the highest in the Western Hemisphere (Fett, 2015; Streeter, 2017; World Health Organization., 2015). In Haiti, the incidence of PPCM is approximately one case per 300 live births, compared to one case per 3,000 to 4,000 live births in the United States (The World Bank., 2015). This incidence is responsible for approximately 47.1 maternal deaths per 100,000 live births in Haiti, in contrast to 0.62 maternal deaths per 100,000 live births in the United States (Fett, 2005).

Cardiomyopathy shares many of the same signs and symptoms that will naturally present themselves in pregnant women (Fett, 2011). Therefore, pregnant women may develop cardiomyopathy and attribute their signs and symptoms to the pregnancy. Though the pathogenesis of PPCM is still not well understood, studies have identified areas that provide a better understanding of the disease, such as: 1) awareness of PPCM is important

to aid in early diagnosis, 2) PPCM has a higher incidence and presents more severely among those of African heritage, 3) hypertension during pregnancy increases the risk for PPCM, and 4) PPCM may have a genetic predisposition. Studies with HIV positive patients, have also shown that among this population, HIV associated cardiomyopathy is known to occur frequently (Mwita et al., 2017). Nonetheless, there are areas that necessitate further exploration to determine what initiates PPCM and why women of African heritage experience higher incidence levels and more severe PPCM (Fett, 2014).

James Fett developed and validated a self-test tool to help pregnant and postpartum women distinguish the early signs and symptoms of heart failure from normal term pregnancy signs and symptoms (Fett, 2011). However, this tool was only validated among a sample of women in the United States.

### **Theoretical Framework**

This study was guided by the Three Delays Model (Figure 1) developed by Thaddeus and Maine (Thaddeus & Maine, 1994). This model was developed to understand and address maternal mortality and gaps in care in low resource settings; the model hypothesizes that maternal mortality is primarily related to delays in women seeking care, delays in reaching a service facility, and delays in receiving appropriate care once signed in or admitted as a patient. The first delay addresses knowledge and ability to ascertain emergency signs in informing the decision to seek care. The second delay assesses economic and structural factors that causes a delay in reaching a medical facility. Lastly, the third delay examines factors such as quality of care at the facility, the number of trained staff, and the accessibility of appropriate supplies and equipment to provide effective care.

The delays from the individual level to the facility level impede prompt treatment and care, thereby increasing the risk of pregnancy related emergencies leading to death.

### **Statement of the Problem**

Maternal mortality among low- and middle- income countries remains a public health issue. In Latin America and the Caribbean, Haiti has the highest rate of maternal mortality (The World Factbook., 2020; World Health Organization., 2018). With obstetrical emergencies and PPCM contributing to these high rates in Haiti, studies examining the factors that contribute to these negative outcomes are needed to fill the existing gap in the literature. This study explored these various factors by assessing the knowledge of medical providers about PPCM and the psychosocial and structural barriers that women face in accessing to care for PPCM. In addition, this study developed a tool that will contribute to assessing PPCM among this vulnerable population.

### **Significance of the Study**

This study is important for several principal reasons: First, there are no studies in the extant literature that explore Haitian providers and auxiliary personnel's awareness of PPCM and how it is managed with their patients. It will also be the first study that utilizes the Three Delays Model to specifically examine PPCM emergencies in Haiti. The study also utilized providers and community members to translate, adapt, and refine a previously validated PPCM self-assessment tool. The findings from this study will inform future preventative and clinical interventions to aid in addressing PPCM in Haiti

## **Current Study**

The overall objective of this study was guided by the Three Delays Model to determine the psychosocial and structural barriers that contribute to delays in seeking (recognizing), reaching, and receiving care for obstetric emergencies and PPCM in Haiti among HIV-positive and HIV-negative pregnant and early post-partum women. We sought to assess the knowledge attitudes, and practices of health professionals regarding peripartum cardiomyopathy. We also aimed to inform the translation and adaptation of the Fett self-assessment test designed to differentiate heart failure from the signs and symptoms of normal pregnancy to improve early detection and outcomes in pregnant women with PPCM (Fett, 2011). This study lays the groundwork for future preventive and clinical intervention studies involving HIV-positive and HIV-negative pregnant and post-partum women in Haiti and globally.

## **Research Aims**

**Aim 1:** Assess the knowledge, attitudes, and practices (KAP) of health professionals and auxiliary personnel (n=128) regarding obstetric emergencies and PPCM in Haiti and approaches to addressing these conditions in pregnant and early post-partum women.

*Hypothesis 1: Health providers and auxiliary personnel will report limited training in heart failure and lack of equipment and resources to aid in the diagnosis of heart failure at their health facilities.*

*Hypothesis 2: Health providers will report higher knowledge of the signs and symptoms of heart failure and peripartum cardiomyopathy compared to auxiliary personnel.*

**Aim 2:** Assess the psychosocial and structural barriers to seeking, reaching, and receiving care for obstetric emergencies and PPCM among 6 focus groups of HIV-positive (N=3) and HIV-negative (N=3) pregnant and early post-partum women, as guided by the Three Delays Model.

**Aim 3:** Translate and adapt the Fett self-test based on a total of four focus groups, two with physicians (N=15) and two with nurses and midwives (N=14) and refine the measure based on cognitive interviews with 16 members of a Community Advisory Board (CAB) that included women of childbearing age.



## FIGURES

Figure 1. Three Delays Model



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## MANUSCRIPT 1

### Knowledge, Attitude and Practices Among Health Professionals Regarding Heart Failure and Peripartum Cardiomyopathy in Haiti: A Cross-Sectional Study.

#### Abstract

**Background:** Peripartum cardiomyopathy (PPCM) is a pregnancy-related form of heart failure that is confirmed by signs of diminished heart functioning as a result of conducting an echocardiogram test. Due to the similarity of the condition's signs and symptoms to that of regular pregnancy signs and symptoms, health professionals play a significant role in the early detection and diagnosis of patients with suspected cases of PPCM. **Objective:** The aim of this study was to assess the knowledge, attitudes, and practices of health professionals in Haiti regarding Heart Failure and Peripartum Cardiomyopathy. **Methods:** A cross-sectional study was conducted among 128 providers from various health centers in Port-Au-Prince, Haiti. An adapted questionnaire was self-administered among participants to obtain demographic characteristics, knowledge, attitudes, and practices information. **Results:** Study participants consisted of physicians and residents (19.5%), nurses and nursing students (45.3%), and midwives and midwifery students (35.1%). Physicians and residents mean score showed higher overall knowledge, attitudes, and practices compared to nurses and nursing students and midwives and midwifery students, however it was not statistically significant ( $p = 0.59$ ). When assessing knowledge, the nurse and nursing student group had almost 1.5 times more odds (AOR = 1.46, 95% CI: 1.38, 1.55) of scoring higher, and the midwife or midwifery student group had about 2 times more (AOR = 1.98, 95% CI: 1.87, 2.10) odds of scoring higher in knowledge compared to

the physician or resident group. **Conclusion:** Though the majority of respondents had good practices, there is a need to improve attitudes and increase knowledge of obstetric emergencies and PPCM among health professionals in Haiti.

## **Introduction**

Primary health care is essential to providing comprehensive medical experiences for patients, where the fundamental premise is to address physical, mental, and social health needs (Starfield, 2012; World Health Organization, 2019). The World Health Organization (WHO) has defined the concept of primary health care based on three components, one of which is to utilize promotive, protective, preventive, curative, rehabilitative, and palliative care to meet the health needs of individuals and families (World Health Organization, 2019). Therefore, health care providers play an important role in serving as a first line of defense in patient--centered care (Gage et al., 2017). They are well positioned to identify any looming health concerns that may arise during the lifespan of individuals and communities (Gage et al., 2017). However, in order to do so, providers require a particular level of education and training to help them identify and manage different health concerns among patients.

In Haiti, there are only 23 medical doctors per 100,000 Haitian residents (The World Factbook., 2020). There are currently three medical schools in Haiti, however because of the socioeconomic burdens of the country and the fragile healthcare system many of the graduates leave to practice in other countries and those who study abroad do not normally return back to Haiti (Reed, 2010; "Université d'État d'Haïti," ; "Université Notre Dame d'Haïti,"). Due to the small number of physicians who can address the needs of the population, certain medical obligations are often attended to

by mid-level medical personnel, such as nurses and midwives. Haiti is estimated to have approximately 1,400 qualified nurses; the majority of the nurses work in the capital city, Port-Au-Prince (Clark et al., 2015; Garfield & Berryman, 2012). With the recent emphasis on task-shifting, there has been an increase in the number of trained midwives in the country (Floyd & Brunk, 2016; Gallagher, Eagle, Sarkar, Cassiani, & Lori, 2019).

Only 5.4% of expenditures in Haiti are invested in the health of the population and due to the economic situation of the population, pregnant women's access to healthcare is often affected (Jacobs, Judd, & Bhutta, 2016; The World Factbook., 2020). When assessing maternal health in Haiti, the country falls below average for prenatal visits in comparison to the rest of Latin America and the Caribbean. Haiti also has the highest maternal mortality ratio in the Western hemisphere and the 22nd highest in comparison to the rest of the world, at 480 deaths per 100,000 live births (The World Factbook., 2020; World Health Organization., 2018). A contributor to the steep maternal deaths in Haiti is the issue of peripartum cardiomyopathy (PPCM; Fett, Christie, & Murphy, 2006; Kwan et al., 2016; Lewis, 2003; Malebranche, Tabou Moyo, Morisset, Raphael, & Wilentz, 2016). It is a form of heart failure that is potentially life-threatening to pregnant and postpartum women if not properly diagnosed and treated (Demakis & Rahimtoola, 1971; Fett, 2016; Hilfiker-Kleiner & Sliwa, 2014).

Consequently, healthcare professionals play a key role in diagnosing PPCM among women. Providers will search for specific signs during a physical examination such as orthopnea, dyspnea, unexplained coughing, swelling of the lower extremities, excessive weight gain during the last month of pregnancy and palpitations (Fett, 2011).

Performing an echocardiogram can help detect the cardiomyopathy by showing the diminished functioning of the heart (Demakis & Rahimtoola, 1971). To help reduce maternal mortality due to obstetric emergencies, specifically PPCM, providers must have an understanding of the heart condition and have known protocols in place to allow for timely diagnosis. The literature lacks research on health care professionals knowledge, attitudes, and practices (KAP) with regard to peripartum cardiomyopathy in Haiti. Therefore, it is necessary to conduct this study to gain a preliminary understanding of where gaps in knowledge exist and how attitudes and practices may contribute to treatment, if and when the condition is identified and diagnosed.

## **Methods**

### *Participants*

Between April 2019 and August 2019, 128 health care providers and auxiliary personnel were recruited from the Haitian Group for the Study of Kaposi Sarcoma and Opportunistic Infections (GHESKIO), L'Hôpital de l'Université d'État d'Haïti (HUEH), l'Institut National Supérieur De Formation de Sages-Femmes (INSFSF), and Société Haïtienne d'Obstétrique et de Gynécologie (SHOG) in Port-Au-Prince, Haiti to participate in a self-administered survey. The exploratory survey was to assess the knowledge, attitudes, and practices of health care providers and auxiliary personnel who had some experience working with pregnant and/or postpartum women. The head physician, charge nurse, or coordinator were contacted at the respective facilities. They were informed of the study and we requested permission to recruit their physicians, nurses, and midwives to participate in the study.

After receiving permission from the institutions, the study consent forms were disseminated to potential participants for their review. The consent forms outlined the purpose of the study and individual rights as a voluntary study participant. Written informed consent was obtained from all individuals who agreed to participate in the study. The surveys were then provided to each participant to complete and upon completion they were provided with a small incentive for their participation.

The questionnaire responses were then entered into a GHESKIO database by trained data entry personnel, and quality control (QC) was conducted to ensure the accuracy of the data entered into the database.

#### *Ethics Statement*

The study was approved by the GHESKIO Ethics Committee, Cornell University Institutional Review Board (IRB) and the Florida International University (FIU) IRB. Study participants were at least 18 years old and written informed consent was obtained.

#### *Measures*

The study questionnaire was adapted based on the JHPIEGO guidelines for assessment of skilled providers after training in maternal and newborn healthcare (JHPIEGO, 2004). JHPIEGO is a non-profit health organization founded by Johns Hopkins University. The instrument was translated from English to Haitian Creole, then pretested among individuals similar to our target population. To assess knowledge, attitudes and practices regarding obstetrical care and PPCM, we analyzed the data based on demographic characteristics, participants' knowledge (6 questions), attitudes (11 questions), and practices (3 questions).



### *Data Management and Analysis*

The responses from the surveys were collected on printed hard copies. It was then entered into a database designed by the GHESKIO informatics department and quality control was conducted. For analysis, the data were exported and statistical analyses were conducted using Statistical Package for the Social Sciences (SPSS v 24) and SAS software (v 9.4).

Knowledge was assessed by a total of 6 question items that were each assigned a point for each correct response. Participants could select multiple responses for the question, “A woman who has PPCM can present with which of the following signs or symptoms?” and were assigned one point for each sign/symptom that they selected. For the question, “A woman can present with the signs and symptoms of peripartum cardiomyopathy during what period?” they were assigned a point for selecting the response that encompassed both “during the last month of pregnancy and within 6 months postpartum.” However, if they selected only “during the last month of pregnancy” or “within 6 months postpartum” then they were assigned half a point for having partial knowledge of the timeframe. The knowledge section was scored out of a total of 11 potential correct responses.

In assessing attitudes, respondents were asked 11 questions (11 total points), such as “When women don’t seek care from a health facility during an obstetric emergency, it’s because the facility is too expensive,” and “The lack of knowledge to recognize the signs and symptoms of peripartum cardiomyopathy has a negative impact on obstetrical emergency care in Haiti.” Each respondent could answer with either “agree,” “disagree,” or “don’t know.” If they selected “disagree” then they were assigned one

point; they were assigned zero points if they chose “agree” or “don’t know.” Therefore, the higher the score, the more positive the attitude of the respondent.

There were 3 questions (3 total points) to assess practices; respondents could select either “yes” or “no” as a response. For example, one of the questions was, “Do you educate pregnant women on the danger signs during pregnancy?” If participants chose “yes” then they were assigned one point, but if they chose “no,” then they were assigned zero points.

Participants were also asked about their attitudes towards preventative practices and training regarding obstetric emergencies and PPCM. One of the questions was “If they offered a 2-day seminar on peripartum cardiomyopathy, I would...” Participants were given the option to choose one of the following responses: 1) be very happy to participate even if it were during my time off/vacation time, 2) participate only if it counted as a regular work day, 3) participate only if my facility stresses it, or 4) not be either happy or unhappy. We used these questions to examine if there were particular preventative practices or trainings participants would be accepting of if they were later implemented. These responses were not calculated into the attitudes scores.

Descriptive analyses were used to summarize participant characteristics. Continuous variables were expressed as means (*SD*), and frequencies (%) were calculated for categorical variables. Kruskal-Wallis tests were used to study the differences in means among the health care profession groups. Multivariate multiple regression analyses with mixed linear models were conducted. Scores for Knowledge, Attitude, and Practice were used as the outcome variables, and the model accounted for age, sex, years of medical experience, years working with pregnant women, years

working with postpartum women, ever received education in the obstetrical domain during health training, ever received education on heart conditions or PPCM during health training, number of maternal deaths registered at the center last year, number of obstetrical emergencies managed as a health professional last month, number of cases managed related to a heart condition last month, number of cases managed related to postpartum cardiomyopathy last month, and the type of health professional.

KAP score variables were dichotomized using median splits and Chi square analysis was conducted to find differences in proportions. Multiple multivariate logistic regression analysis were conducted accounting for the previously mentioned variables. In addition to this, using the above-mentioned variables, hierarchical cluster analysis was conducted to explore how participants were grouped using Ward's minimum variance method, where the distance between two clusters is the ANOVA sum of squares between the two clusters summed over all the variables. Ward's approach also does well in separating clusters if there is noise between clusters. Hierarchical clustering treats each unique observation as a unique cluster. In the next steps, this method: (1) identified the two similar or close clusters, and (2) merged the two most similar clusters. This process was repeated until all the similar clusters were merged together. Using this clustering technique, similar data from participants were grouped together such that the members in the same group were more similar to each other than the members in the other groups.

## **Results**

### *Demographics*

Of the 170 questionnaires that were distributed, we obtained 128 surveys that were sufficiently filled out and could be analyzed. The majority of respondents were nurses and nursing students (45.3%), then midwives and midwifery students (35.1%), and physicians and residents (19.5%). Most respondents were female (85%) with males accounting for only 15% of the responses. Over half the respondents fell between the ages of 25 and 35 (55.9%). Half of the respondents had less than six years of medical experience (Table 1).

Among the physicians and residents, 91.7% reported that they received education on heart conditions during their medical training, and 95% received education specifically on PPCM. Of the nurse and nursing student respondents, 61.5% had received education on heart conditions, while fewer than 40% received education on PPCM. Over 80% of the midwife and midwifery students reported receiving education on heart conditions during training; less than 80% of them had received education on PPCM (Table 2).

### *Knowledge*

Eleven items were used to assess postpartum obstetrical care and PPCM knowledge. The majority of respondents knew that a mother should have a postpartum visit 6 hours, 6 days, and 6 weeks postpartum and any time she has danger signs (86.2%). Likewise, 89% of respondents knew that specific information should be collected from women pertaining to problems during pregnancy, during and after

childbirth, and any current problem. Moreover, 78.1% of the respondents knew that a history should be collected for both the mother and baby.

Roughly half of the respondents knew that orthopnea (56.4%), dyspnea (48.9%), swelling of lower extremities (52.6%), and palpitations (54.9%) were signs/symptoms of PPCM. However, unexplained cough (13.5%) and excessive weight gain during the last month of pregnancy (15.8%) were underreported as signs/symptoms. Only 23.9% of respondents knew that the signs and symptoms of peripartum cardiomyopathy could appear among women during both the last month of pregnancy and within six months of giving birth (Table 3).

### *Attitudes*

Regarding the attitudes of healthcare professionals and students towards why women do not seek care from a health facility during an obstetric emergency, 30.2% stated it was because the facility was too expensive, less than half stated it was too difficult to reach the facility, 36.2% stated it was due to the negative treatment from the healthcare center employees, and over 70% reported it was because the women don't recognize that they are presenting with signs/symptoms of an obstetric emergency. There were 81.4% who agreed that women do not seek care for PPCM because they are not knowledgeable about the signs and symptoms. The majority of the healthcare professionals and students, stated that some of the negative outcomes of obstetrical care, that resulted from treatment by providers in Haiti, were due to lack of qualified health personnel who are knowledgeable of the signs and symptoms of PPCM (91.7%); they also noted that the lack of diagnostic equipment limits the capacity to carry out an effective PPCM diagnosis (90.7%; Table 4). Many of the statements that

providers agreed with were associated with barriers to access and resources resulting from the social and economic conditions of the country.

The majority of respondents (92.8%) reported that providing material to study independently about obstetrical emergencies would be helpful in decreasing maternal mortality. Similarly, 90.5% agreed that hanging posters that describe the signs and symptoms of PPCM would be useful in reducing maternal mortality. They also agreed that a one-time seminar would be useful (65.4%) and an annual seminar/training in obstetrical emergencies (92.9%) would also be useful in reducing maternal mortality. Over 90% of participants would be open to attending a 2-day seminar on PPCM, even if it took place during their time off/vacation time (Table 5).

### *Practices*

Most of the healthcare professionals reported that they educate pregnant women on the danger signs and symptoms that may occur during their pregnancy (98.4%) and after they give birth (96.0%). However, just over half of the respondents educate women during their pregnancy about the signs and symptoms of PPCM (57.9%; Table 6).

### *Knowledge, Attitude, and Practices*

The overall mean score of knowledge, attitudes, and practices among physicians and residents concerning postpartum care and PPCM was higher when compared to the other professionals (Figure 1). However, the Kruskal-Wallis test showed no statistically significant difference among the three professional groups (Table 7). The median split among provider's knowledge, attitudes, and practices scores also showed no statistical difference among the groups (Table 8).

Mixed linear models (Table 9) show that in general, knowledge, attitude, and practice scores were lower among nurse and nursing student, and midwife and midwifery student groups as compared to the physician and resident group. Adjusted beta coefficients from this analysis indicate that the midwife and midwifery student group was less likely to score higher in knowledge and practice domains, however, in the attitude domain, they were more likely to score higher compared to the nurse and nursing student group. Results from bootstrapped logistic regression analysis (Table 10) suggests that those who are nurses and nursing students had almost 1.5 times higher odds (AOR = 1.46, 95% CI: 1.38, 1.55) of scoring higher, and the midwife and midwifery student group had about 2 times more (AOR = 1.98, 95% CI: 1.87, 2.10) odds of scoring higher in knowledge compared to the physician or resident group. The adjusted odds ratio for nurses and nursing students was 0.26 with a 95% confidence interval of [0.24, 0.28] and 0.43 with a confidence interval of [0.41, 0.46] for midwives and midwifery students. This suggests that the nurse and nursing student group had 0.26 times less odds, and midwives and midwifery students had 0.43 less odds of scoring higher in the attitudes domain when compared to the physician and resident group. This trend was similar for practice domain where nurse and nursing student group had about 0.50 times less odds (AOR = 0.53, 95% CI: 0.49, 0.56), and midwife and midwife student group had 0.32 times less odds (AOR = 0.32, 95% CI: 0.30, 0.34) of scoring higher when compared to the physician and resident group.

Table 11 summarizes the cluster means and their characteristics. Clusters 3 and 4 were the bigger groups as compared to Clusters 2, 1, or 5. Cluster 1 had the most years of medical experience and the highest number of years working with pregnant women

and postpartum women. This Cluster was comprised of mostly 40% midwife/midwifery student, and 40% nurse/nursing student. Cluster 3, the largest cluster, had the youngest participants with the least amount of medical experience, but had the highest reporting that they had received education on PPCM (78%) in comparison to the other clusters. Though there was a 17-year difference in experience between Cluster 1 and Cluster 3 with working with pregnant women, the mean knowledge was roughly the same between the two clusters.

## **Discussion**

Half of respondents were able to recognize most of the signs and symptoms of peripartum cardiomyopathy, but very few knew that women can develop it during the last month of pregnancy and within 6 months postpartum. The study findings also showed that respondents expressed that factors such as the lack of personnel who are knowledgeable about PPCM and the lack of diagnostic equipment has a negative impact on obstetric emergencies in Haiti. Nonetheless, a high percentage of respondents showed a strong willingness to learn about peripartum cardiomyopathy. Almost all of participants reported providing education to pregnant women about the danger signs during pregnancy (98.4%) and after delivery (96.0%), however only about half of participants reported providing women education on the signs and symptoms of PPCM. The low percentage of participants providing education to pregnant women about the signs and symptoms of PPCM may be due to providers own limited knowledge in the condition.

A strength of our study is that we were able to obtain the perspective of healthcare providers at different stages in their medical education and training. It helped to furnish



a perspective as to the necessity of providing enhanced peripartum education during healthcare providers' medical schooling. The healthcare providers had good knowledge of postpartum care, which is essential as it demonstrates that they are aware of which particular time point is appropriate for them to provide sensitive evaluation of the women's health and that they have had an opportunity to screen for PPCM. Approximately half of healthcare professionals were able to identify at least four of the six signs and symptoms of PPCM. Therefore, since PPCM has to be confirmed by an echocardiogram, an exam that must be ordered by a physician, it is important that healthcare professionals are knowledgeable about recognizing potential PPCM cases (Marangou et al., 2019; Vedanthan, Choi, Baber, Narula, & Fuster, 2014).

Since the nurse and nursing student group and midwife and midwifery groups had 1.98 and 1.49 (respectively) times increased odds to score higher in the area of knowledge as compared to physician and resident groups, it shows that nurses and midwives play a pivotal role in noticing an obstetric emergency or PPCM. However, with findings in the attitudes and practices area being fairly similar across the professional groups when compared to physician and residents, all 3 groups should be targeted in trying to increase positive attitudes and in implementing future changes to better their practices. Since there were no statistically significant differences between the groups across the three domains, we cannot be sure which provider is the most prepared and better positioned to identify an emerging obstetrical emergency and peripartum cardiomyopathy. Therefore, it's important that all of the groups are well educated and trained in this particular area. In our cluster analysis, we found that though Cluster 1 had more years of experience in working with pregnant and postpartum

women, less than half had education on Peripartum Cardiomyopathy. Therefore, providing education and trainings in Peripartum Cardiomyopathy may be necessary among providers regardless of their years of experience (Ameh & van den Broek, 2015; Pattinson et al., 2019; Pattinson et al., 2018). Consequently, we found that providers were willing to learn more about obstetric emergencies and peripartum cardiomyopathy to further gain an understanding of the impact that it has on maternal health in Haiti. Their enthusiasm could allow for increased sensitization of this health condition among many providers and health facilities in Haiti. Facilities in countries like Nigeria have recommended trainings as knowledge and skills in emergency obstetric care were lower than average and studies in Zimbabwe (Crofts et al., 2015) have shown that an increase in trainings had improved clinical outcomes (Okonofua et al., 2019).

The enthusiasm shown by providers for additional training would allow for more passive initiatives such as displaying preventative health materials, for example posters, that will not only help the women become knowledgeable about PPCM, but may also educate other people in the community. With some low income countries experiencing literacy as a determinant of health outcomes, the use of visual aids is often more effective to increase awareness about health concerns (Gilder et al., 2019; Kilfoyle, Vitko, O'Connor, & Bailey, 2016).

Much of the providers' attitudes were based on structural issues that limited the capacity to effectively diagnose PPCM due to the lack of diagnostic equipment and qualified professionals. A majority of the healthcare professionals agreed that women often do not seek care from a medical facility because they do not recognize that they are exhibiting the signs/symptoms of an obstetric emergency, such as PPCM. Due to

the reality of the limited resources that the people of Haiti often experience with medical care, pregnant women may simply seek the aid of traditional midwives in the community if they sense something may be atypical with their health (Dev et al., 2019). Often times, these individuals have not received medical training, therefore they may lack the awareness to identify cases of PPCM and prompt pregnant or postpartum women to seek assistance from a medical facility. Thus, there should be an effort to equip these traditional midwives with the knowledge and tools to serve as a sort of liaison between the community and healthcare facilities. Studies have shown the necessity of training traditional community workers in countries like Haiti with significantly high maternal mortality (Dynes et al., 2013; Floyd & Brunk, 2016; Hosler, Abrams, & Godsay, 2018).

### **Limitations**

There were several limitations that may have influenced the present study. The questionnaires were self-administered and completed on the respondents' own time, thus there was no way to verify if respondents sought out assistance for any of the responses. We did not observe the providers in the clinical settings, therefore we had to rely on self-reporting by the respondents for an assessment of their practices. The sampling size is not large enough to generalize the findings, however there are findings that may inform future representative studies. Our study was subject to information bias due to the missing data from our questionnaires. Social desirability bias may have also influenced the attitudes and practices responses as respondent may have chosen to report more desirable responses. However, we attempted to limit this form of bias by

keeping identifiable information, such as respondents' names, separate from the questionnaire.

## **Conclusion**

The findings from the study accentuate the need to increase knowledge of PPCM among healthcare professionals and students. However, the knowledge of postpartum clinical care protocols was good among the respondents. An annual training or seminar is recommended to increase knowledge, as well as for healthcare professionals to stay abreast of obstetric emergencies and PPCM occurrences in Haiti. Our study also suggests there are social barriers in Haiti that need to be addressed to increase the positive attitude of providers toward obstetrical care in the country.

## **Funding Statement**

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## TABLES AND FIGURES

**Table 1.** Demographic characteristics of healthcare providers.

	n	%
<b>Healthcare Profession</b>		
Physician & Resident	25	19.5
Nurses & Nursing Student	58	45.3
Midwives & Midwifery Students	45	35.1
<b>Age</b>		
< 25 years	7	5.9
25 - 35 years	66	55.9
≥ 36 years	45	38.1
<b>Sex</b>		
Male	19	15
Female	108	85
<b>Years of Medical Experience</b>		
< 6 years	58	50
6 - 10 years	28	24.1
11 - 20 years	16	13.8
21 years ≤	14	12.1

**Table 2.** Medical education on heart conditions and peripartum cardiomyopathy.

	Yes		No	
	n	%	n	%
<b>Have you ever received education on heart conditions during your medical training?</b>				
Physician & residents	22	91.7	2	8.3
Nurses & nursing students	32	61.5	20	38.5
Midwives & midwifery students	34	82.9	7	17.1
<b>Have you ever received education on peripartum cardiomyopathy during your medical training?</b>				
Physician & residents	19	95.0	1	5.0
Nurses & nursing students	14	36.8	24	63.2
Midwives & midwifery students	26	76.5	8	23.5

**Table 3.** Knowledge about postpartum care and peripartum cardiomyopathy.

	n	%
After childbirth, the mother should have a postpartum visit with a skilled provider...		
Once, at 3 weeks postpartum	10	8.6
Once, at 6 weeks postpartum	5	4.3
Three times: at 6 hours, 6 days, and 6 weeks postpartum and any time she has danger signs	100	86.2
Don't know	1	0.9
During the postpartum visit to the clinic, obtain a history for the...		
baby only	1	1
mother only	2	1.9
mother and baby	82	78.1
mother, her support person, and the baby	19	18.1
Don't know	1	1
During each postpartum visit, specific information should be obtained from the woman about...		
Problems during pregnancy, during and after childbirth, and any present problems	113	89
Present problems only	12	9.4
Only those problems directly related to childbirth	0	0.0
Don't know	2	1.6
When there is an obstetric emergency, tell the woman and her family or support person		
As much as possible about the management of the emergency	53	65.4
As little as possible about the management of the emergency	14	17.2
What the provider thinks she/they should be told	13	16.0
Nothing at all	0	0.0
Don't know	1	1.2
A woman who has peripartum cardiomyopathy can present with which of the following signs or symptoms? *		
Orthopnea	75	56.4
Dyspnea	65	48.9
Unexplained cough	18	13.5
Swelling of the lower extremities	70	52.6
Excessive weight gain during last month of pregnancy	21	15.8
Palpitations	73	54.9
Don't know	4	3
A woman can present with the signs and symptoms of peripartum cardiomyopathy during what period?		
During the last month of pregnancy	59	52.2
Within 6 months postpartum	13	11.5
During the last month of pregnancy & within 6 months postpartum	26	23.9
Don't know	15	13.3

\*Participants could select more than one option. N is based on the number of participants who selected the response as an option.

<b>Table 4. Attitudes towards obstetrical emergencies and peripartum cardiomyopathy.</b>		
	<b>n</b>	<b>%</b>
<b>When women don't seek care from a health facility during an obstetric emergency, it's because the facility is too expensive.</b>		
Don't agree	73	56.6
Agree	39	30.2
Don't Know	17	13.2
<b>When women don't seek care from a health facility during an obstetric emergency, it's because it's too difficult to reach the facility.</b>		
Don't agree	56	43.3
Agree	60	46.5
Don't Know	13	10.1
<b>When women don't seek care from a health facility during an obstetric emergency, it's because the employees don't treat them with respect.</b>		
Don't agree	70	55.1
Agree	46	36.2
Don't Know	11	8.7
<b>When women don't seek care from a health facility during an obstetric emergency, it's because they don't recognize that they are presenting with signs/symptoms of an obstetric emergency.</b>		
Don't agree	25	19.4
Agree	93	72.1
Don't Know	11	8.5
<b>When women don't seek care from a health facility when they present with signs/symptoms of peripartum cardiomyopathy, it's because they aren't knowledgeable of the signs/symptoms.</b>		
Don't agree	17	13.2
Agree	105	81.4
Don't Know	7	5.4
<b>The lack of knowledge to recognize an emergency has a negative impact on obstetrical emergency care in Haiti.</b>		
Don't agree	6	4.7
Agree	122	95.3
Don't Know	0	0
<b>The lack of competence in providing appropriate emergency care has a negative impact on obstetrical emergency care in Haiti.</b>		
Don't agree	7	5.4
Agree	118	91.5
Don't Know	4	3.1
<b>The lack of knowledge to recognize the signs and symptoms of peripartum cardiomyopathy has a negative impact on obstetrical emergency care in Haiti.</b>		
Don't agree	8	6.2
Agree	119	92.2
Don't Know	2	1.6
<b>The lack of qualified health personnel who are knowledgeable of the signs and symptoms of peripartum cardiomyopathy has a negative impact on obstetrical emergency care in Haiti.</b>		
Don't agree	3	2.3
Agree	122	91.7
Don't Know	3	2.3
<b>The lack of diagnostic equipment has a negative impact on obstetrical emergency care in Haiti.</b>		
Don't agree	2	1.6
Agree	125	97.7
Don't Know	1	0.8
<b>The lack of diagnostic equipment limits the capacity to carry out an effective peripartum cardiomyopathy diagnosis in Haiti.</b>		
Don't agree	8	6.2
Agree	117	90.7

Don't Know

4

3.1

**Table 5.** Attitudes towards preventative practices and training regarding obstetrical emergencies and PPCM.

	n	%
Providing reading material to study independently in the obstetrical emergency domain is useful in decreasing maternal mortality in my environment.		
Yes	116	92.8
No	9	7.2
Hanging posters in the facility that describes the signs and symptoms of peripartum cardiomyopathy is useful in diminishing maternal mortality in my environment.		
Yes	114	90.5
No	12	9.5
A one-time seminar to teach and practice competence in obstetrical emergency is useful in diminishing maternal mortality in my environment.		
Yes	83	65.4
No	44	34.6
An annual seminar and training that certifies you in obstetrical emergencies, is useful in diminishing maternal mortality in my environment.		
Yes	117	92.9
No	9	7.1
If they offered a 2 day seminar on peripartum cardiomyopathy, I would...		
...be very happy to participate even if it were during my time off/vacation time.	116	91.3
...participate only if it counted as a regular work day.	8	6.3
...participate only if my facility stresses it.	1	0.8
...not be neither happy or unhappy.	2	1.6

**Table 6.** Practices towards pregnancy education.

	n	%
Do you educate pregnant women on the danger signs during pregnancy?		
Yes	126	98.4
No	2	1.6
Do you educate pregnant women on the danger signs after delivery?		
Yes	121	96.0
No	5	4.0
Do you provide pregnant women education on the signs and symptoms of peripartum cardiomyopathy during the pregnancy?		
Yes	70	57.9
No	50	41.3



**Table 7.** Kruskal-Wallis test for differences in mean scores among health professional groups.

Score	Physician or Resident	Nurse or Nursing student	Midwife or Midwife student	<i>p</i> -value
Knowledge, Mean ( <i>SD</i> )	5.64 (3.22)	5.27 (2.42)	5.16 (1.98)	0.979
Attitudes, Mean ( <i>SD</i> )	2.04 (1.56)	2.14 (1.70)	1.98 (1.75)	0.818
Practices, Mean ( <i>SD</i> )	2.60 (0.58)	2.40 (0.79)	2.36 (0.65)	0.281
Total, Mean ( <i>SD</i> )	10.28 (3.28)	9.80 (3.41)	9.49 (2.70)	0.592

**Table 8.** Provider type by knowledge, attitude, and practice scores dichotomized by median split, *n* (%).

Score	Physician or Resident	Nurse or Nursing student	Midwife or Midwife student	<i>p</i> -value
Knowledge				0.434
< 5	14 (56%)	26 (44.8%)	18 (40%)	
≥ 5	11 (44%)	32 (55.2%)	27 (60%)	
Attitude				0.973
< 2	11 (44%)	27 (46.6%)	21 (46.7%)	
≥ 2	14 (56%)	31 (53.4%)	24 (53.3%)	
Practice				0.183
< 3	9 (36%)	26 (44.8%)	26 (57.8%)	
≥ 3	16 (64%)	32 (55.2%)	19 (42.2%)	
Total				0.770
< 10	10 (40%)	26 (44.8%)	22 (48.9%)	
≥ 10	15 (60%)	32 (55.2%)	23 (51.1%)	

<b>Table 9.</b> Adjusted beta coefficients for knowledge, attitude, and practice scores.		
	Adjusted Beta Coefficients (95% CI)	1000 Bootstrapped Samples Beta Coefficients (95% CI)
<b><i>Knowledge</i></b>		
Physician or Resident	Ref.	
Nurse or Nursing student	-0.4125 (-2.2365, 1.4115)	<b>-0.3775 (-0.4447, -0.3103)</b>
Midwife or Midwife student	-0.6544 (-2.4501, 1.1414)	<b>-0.6501 (-0.7163, -0.5840)</b>
<b><i>Attitude</i></b>		
Physician or Resident	Ref.	
Nurse or Nursing student	-0.8336 (-2.0397, 0.3724)	<b>-0.8217 (-0.8663, -0.7771)</b>
Midwife or Midwife student	-0.5755 (-1.7629, 0.6118)	<b>-0.5639 (-0.6078, -0.5200)</b>
<b><i>Practice</i></b>		
Physician or Resident	Ref.	
Nurse or Nursing student	-0.2403 (-0.7491, 0.2685)	<b>-0.2393 (-0.2581, -0.2206)</b>
Midwife or Midwife student	-0.2309 (-0.7318, 0.2701)	<b>-0.2326 (-0.2511, -0.2141)</b>

<b>Table 10.</b> Adjusted odds ratios for dichotomized knowledge, attitude, and practice scores.		
	Adjusted Odds Ratio (95% CI)	1000 Bootstrapped Samples AOR (95% CI)
<b><i>Knowledge</i></b>		
Physician or Resident	Ref.	
Nurse or Nursing student	1.405 (0.327, 6.037)	<b>1.458 (1.376, 1.546)</b>
Midwife or Midwife student	1.983 (0.461, 8.531)	<b>1.980 (1.867, 2.099)</b>
<b><i>Attitude</i></b>		
Physician or Resident	Ref.	
Nurse or Nursing student	0.251 (0.049, 1.277)	<b>0.260 (0.243, 0.277)</b>
Midwife or Midwife student	0.417 (0.085, 2.046)	<b>0.431 (0.405, 0.460)</b>

<i>Practice</i>		
Physician or Resident	Ref.	
Nurse or Nursing student	0.529 (0.101, 2.775)	<b>0.527 (0.493, 0.564)</b>
Midwife or Midwife student	0.320 (0.063, 1.624)	<b>0.320 (0.300, 0.341)</b>

**Table 11.** Cluster means and characteristic proportions.

Characteristic	Cluster, Mean or <i>n</i> (%)				
	1	2	3	4	5
Frequency	11	21	52	43	6
Age (years)	48.79	32.45	27.45	37.21	33.63
How many years of medical experience do you have? (year)	3.78	1.76	1.22	2.18	1.93
How many years have you been working with pregnant women? (years)	20.91	6.62	3.37	7.60	5.23
How many years have you been working with postpartum women? (years)	21.45	6.88	3.38	7.25	4.69
Have you ever received education in the obstetrical domain during your health training? (yes)	10 (90.9%)	14 (73.7%)	48 (96%)	38 (92.7%)	1 (50%)
Have you ever received education on heart conditions?	7 (63.6%)	11 (61.1%)	43 (87.8%)	27 (67.5%)	2 (100%)
Have you ever received education on PPCM during your health training?	4 (44.4%)	6 (40%)	32 (78%)	19 (63.3%)	0%
During the last month, how many maternal deaths have be registered to you center?	2.50	3.75	2.29	2.73	0
During the last month, how many obstetrical emergencies have managed as a health professional?	6.33	4.00	3.33	11.44	.00
During the last month, how many cases have you managed as a health professional that were related to a heart condition?	0.33		2.77	1.74	.00
During the last month, how many cases have you managed as a health professional that were related to PPCM?	1.00	.00	1.03	.53	.00
Knowledge Total	5.86	4.59	5.87	5.11	1.08
Attitude Total	2.36	2.09	1.83	2.51	0.33
Practice Total	2.36	2.47	2.60	2.40	0.17
Health professional type					
Physician or Resident	2 (20%)	2 (9.5%)	11 (21.6%)	10 (23.8%)	0%
Nurse or Nursing student	4 (40%)	12 (57.1%)	23 (45.1%)	16 (38.1%)	3 (75%)
Midwife or Midwife student	4 (40%)	7 (33.3%)	17 (33.3%)	16 (38.1%)	1 (25%)

Note: Due to missing data, total may not equal to 100% or total frequency for individual column

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## MANUSCRIPT 2

### Psychosocial and Structural Barriers to Seeking, Reaching, and Receiving Care for Obstetric Emergencies and Peripartum Cardiomyopathy Among Pregnant and Early Postpartum Women in Haiti.

#### Abstract

**Background:** In Haiti, pregnant and early postpartum women face barriers in access to health care for obstetric emergencies and peripartum cardiomyopathy (PPCM). Using the Three Delays Model, our aim was to assess the barriers that delay Haitian women from seeking, reaching, and receiving care. **Methods:** Six focus group discussions were conducted with a total of 39 participants. Three groups were conducted with 21 pregnant and postpartum women living with HIV, and the other three with 18 HIV sero-negative pregnant and postpartum women. **Results:** We identified several factors that may contribute to a delay in access to care. These factors were then grouped into 3 main categories: 1) recognizing and seeking care for an obstetric emergency and PPCM, 2) structural and social barriers to reaching care, and 3) receiving care at medical facilities. **Conclusion:** Though women were willing to seek care when they notice problematic pregnancy-related signs or symptoms, factors such as the country's insecurity due to violent political protests contributed to a delay in reaching care. Therefore, there should be an emphasis placed on interventions that will further educate women on PPCM and how to recognize when they maybe suffering from signs or symptoms related to PPCM. Also, protocols should be set in place to help bring medical services to the women's community when factors such as political unrest prevent

women from getting to care. Related to third delay, the relationship between providers and patients may have either a negative or positive effect on a woman's experience at a medical facility and influence her overall outlook on medicine and willingness to trust the facility. Training should be implemented in facilities to help improve interpersonal relationships with providers and hence increase the quality of care patients receive.

## **Introduction**

In low income countries, the lifetime risk of maternal death is 1 in 45, in contrast to 1 in 5,400 among high income countries (UNICEF, 2019). In 2017, roughly 295,000 women died during pregnancy, childbirth, and early postpartum worldwide (World Health Organization., 2019). Though preventable, 94% of these deaths occurred in low-middle income countries (Alkema et al., 2016; World Health Organization., 2019). Some of these factors are attributed to the fact that women in resource-poor countries are likely to have more pregnancies than women from developed countries (Van Otterloo & Connelly, 2016). Subsequently, this presents more opportunities for women to be susceptible to complications that may develop during pregnancy. Previous studies stress the importance of getting to care early to allow for immediate diagnosis and treatment (Oladapo et al., 2016; Shah et al., 2009).

Haiti has the highest maternal mortality rates in the Caribbean with 359 deaths per 100,000 live births, compared to the average mortality rate of 68 deaths per 100,000 live births in the region (The World Factbook, 2020). The incidence of 1 case of PPCM per 300 to 400 live births in Haiti is responsible for approximately 47.1 maternal deaths per 100,000 live births in Haiti, in contrast to 0.62 maternal deaths per 100,000 live births in the United States (Fett, 2005). These rates are partly due to the three delays



in seeking medical assistance during an obstetric emergency, reaching an appropriate facility, and receiving adequate care at the facility. The Three Delays model theorizes that maternal mortality is not simply due to a women's lack of economic resources, but also because of interconnected factors (Thaddeus & Maine, 1994). The first delay is the woman's ability to recognize a health concern and decide to seek medical care. The second delay pertains to structural barriers such as availability and cost of transportation and distance to health facilities to obtain care. The third delay relates to structural issues at the facility that may prevent the woman from receiving adequate care.

Obstetric emergencies such as heart failure and peripartum cardiomyopathy (PPCM) contribute to the high maternal mortality rate in the country. Peripartum cardiomyopathy is a form of heart failure that may occur during the last month of pregnancy or up to 5-6 months postpartum. Some of the signs and symptoms of PPCM are identical to that of a normal pregnancy and, as the disease manifests, it can often go undiagnosed (Billson & Vollmer, 2014; Dennis, 2015; Fett, 2015; Fett, 2014). Women may experience signs or symptoms such as shortness of breath, edema, and excessive weight gain during the last month of pregnancy (Fett, 2011). This form of heart failure causes difficulty in the heart being able to effectively pump blood throughout the body, therefore, if left untreated, it may lead to death (Fett, 2016; Fett & Markham, 2015; Fett & McNamara, 2016).

A critical study utilizing The Three Delays Model to examine maternal mortality in Haiti found that, to address the challenges women face, the focus should be on improving quality and dependability of care at the country's medical facilities (Barnes-

Josiah, Myntti, & Augustin, 1998). Among the studies conducted in Haiti regarding PPCM, there were no qualitative studies in the literature that included the perspective of Haitian women. It is therefore important to better understand the broad context of factors that delay pregnant and postpartum women from accessing care through their own personal accounts. Our study examined the experiences and opinions of pregnant and early post-partum Haitian women on access to care for obstetric emergencies and PPCM.

## **Methods**

The study was conducted in Port-Au-Prince, Haiti between June 2019 and July 2019. We employed a qualitative study design with six focus group discussions. After a comprehensive review of the literature, a focus group guide was developed and adapted based on questions from the JHPIEGO Monitoring Birth Preparedness and Complication Readiness manual (JHPIEGO, 2004). JHPIEGO is an international, nonprofit affiliate health organization of the Johns Hopkins University, whose goal is to enhance the health of women and families in low- and middle-income countries. The intent of the manual was to help contribute to the broad effort to improve maternal and child health outcomes internationally.

We coordinated with the head nurses from both the HIV-positive and HIV-negative maternal health clinics at the GHESKIO Health Center to recruit participants into our study. We screened each participant to ensure they met the eligibility criteria: 1)  $\geq 18$  years, 2) pregnant or within 6 months postpartum, 3) living with HIV or HIV seronegative, and undergo informed consent process. If eligible, participants were invited to a scheduled focus group discussion. Prior to their participation in the focus group,

informed consent was obtained and a copy of the consent form in Haitian Creole was provided to them for their reference. Upon completion of the focus group, participants were provided with a meal, a beverage, a phone card, and transportation money for their participation in the study.

The qualitative study focused on engaging the participants in a discussion that would help them openly express narratives of their experiences and knowledge of obstetric emergency signs or symptoms, awareness of eclampsia, transportation, the country's insecurity, negative treatment by medical providers, good interpersonal relationship with medical providers, and the perception of women regarding traditional and medical maternal care. There were a total of 6 focus groups (3 HIV + and 3 HIV-) consisting of 6 – 8 women who were pregnant or within 6 months postpartum; they were conducted from June 2019 to July 2019 over a span of 3 weeks. All focus groups were facilitated by two female researchers trained in qualitative methodology and fluent in Haitian Creole. One of the facilitators led the discussion among the group while the other noted any major points that emerged during the session. After each focus group, the facilitators discussed observations and thoughts gathered from the respective group. If the facilitators found anything from a discussion they thought might be significant, they deliberated on how to further explore that particular topic with the subsequent focus groups.

### **Ethics Statement**

The study was approved by the GHESKIO Ethics Committee, Cornell University Institutional Review Board (IRB), and the Florida International University (FIU) IRB. Study participants were at least 18 years old and written informed consent was

obtained. The consent forms were in Haitian Creole and were explained in depth to each of the women to ensure they understood before agreeing to participate.

### **Data Analysis**

The audio-recorded focus groups were transcribed in Haitian Creole, the language spoken by participants, by two individuals who were fluent in Creole. The 6 transcripts were then entered into the qualitative data analysis software NVivo (Version 12) for coding. We utilized a deductive coding method to code our data. The most comprehensive of the 6 transcripts was selected for review and coded individually by 3 researchers. Upon completing this initial coding, the researchers held a meeting to review and discuss the main codes that emerged from the document. A codebook was developed with the main codes and subcodes, along with a description of each code. The initial codes were developed based on the three delays: 1) recognizing an obstetric emergency and seeking care, 2) reaching care, and 3) receiving care. We then selected and adapted the first level of subcodes based on the established factors that are associated with each of the three delays in the literature: 1) knowledge of obstetric emergency signs, 2) knowledge of heart failure signs/symptoms, 3) family input, 4) community support, 5) country's insecurity, 6) transportation, 7) distance to medical facility, 8) lack of private transportation, 9) private transportation money, 10) lack of public transportation, 11) public transportation money, 12) health/medical cost, 13) negative treatment from providers/staff, 14) good interpersonal relationship with medical providers, 15) and lack of medical equipment/supply.

After completing the coding of the first document, we held another meeting was held to discuss our selected codes and if any other themes that emerged. From that

meeting, we added the following codes to the codebook: 1) preventative beliefs, 2) pregnancy, 3) obstetric emergency, 4) eclampsia, 5) family planning, 6) pregnancy dreams, 7) prenatal care, 8) postnatal care, 9) loss of pregnancy, 10) traditional care, 11) medical care, 12) vaginal steaming [a natural remedy where a woman sits over a bucket filled with boiled water containing leaves and herbs to cleanse and tighten the vagina], and 13) massage the abdomen. After finalizing the codebook, the remaining focus group transcripts were individually coded line-by-line by the 3 researchers. The individually coded transcripts were then reviewed and compared for themes. The transcripts were then summarized into 6 final documents, incorporating the coding by the 3 researchers.

The pregnant and postpartum women's perception of traditional and medical maternal care, and the Three Delays Model guided the analysis of themes. This model highlights the factors that often cause women to delay accessing maternal care; it has been utilized in various studies assessing maternal and child health issues worldwide. Therefore, the Three Delays Model is appropriate for guiding our assessment of how the psychosocial and structural barriers women experience affect their access to care during obstetric emergencies. Narratives from the focus groups were selected and are quoted within this paper to support the concepts being presented.

## **Results**

### *Participant Demographics*

A total of 6 focus groups were conducted with 39 participants (6 to 8 per group) of childbearing age. Of the 6 focus groups, three were conducted with pregnant and

postpartum women living with HIV and another other three groups were comprised of HIV sero-negative pregnant and postpartum women (Table 1).

### *Delay 1: Recognizing and Seeking Care for an Obstetric Emergency and PPCM*

In this delay, we noticed that, based on the codes of knowledge of obstetric emergency signs, eclampsia, preventative beliefs, and obstetric emergencies, there were narratives that presented two major themes: 1) knowledge of obstetric emergency signs and symptoms and 2) awareness of eclampsia. The participants had a high level of awareness of the problematic signs and symptoms that could occur during and after pregnancy. There were a few women who shared their experiences with having palpitations, difficulty breathing, and swollen extremities. It also seemed that the women living with HIV were even more adamant about seeking care from a medical facility if they felt that their symptoms were too painful to manage at home. Though women stated that they were unaware of PPCM, in the discussions they mentioned experiences that paralleled some of the common signs and symptoms of PPCM.

#### *Knowledge of Obstetric Emergency Signs or Symptoms*

Participants understood the value of going to seek care when they realized their breathing and heart rate were abnormal. However, it seemed that the women made the decision to seek care only when those symptoms were worsening. Some of the HIV positive women seemed to be firm in the belief that going to a hospital was necessary once they felt they were experiencing abnormal symptoms.

“...once, I had a medical crisis. But it was my chest. I couldn't breathe, I couldn't stand. I didn't know how to even hold myself; they rushed me to the Doctors Without Borders Hospital at 3 o'clock in the morning.” [HIV Negative, Focus Group 2, Participant 2]

“...after going to bed, I felt the side of my waist hurting me. I couldn’t breathe; this pain started during my current pregnancy. The pain increased so much that I couldn’t inhale. I was suffering to the point that I couldn’t sit down so they took me to the Doctors Without Borders Hospital” [HIV Negative, Focus Group 2, Participant 2]

“If I feel like I am unable to breathe and my heartbeat is faster than normal, I will go see a doctor.” [HIV Positive, Focus Group 2, Participant 1]

Some women reported noticing certain changes to their bodies that seemed alarming and made the decision to go discuss those concerns with a medical provider. “Sometimes when we tell them [the health provider] that, they say it is normal and it's not a problem for the foot to be swollen. There are times they say it's because of too much fat. Once, they sent me to do a test because my feet were very swollen. The moment Dr. B. saw my feet, he rubbed alcohol on them and since then I haven’t had the problem...” [HIV Positive, Focus Group 1, Participant 3]

### *Awareness of Eclampsia*

The women often noted the importance of managing their stress and avoiding any situations that may upset them because it could affect their blood pressure and put them at risk for developing eclampsia. Also, some of the women discussed situations where their partner was responsible for putting them in a stress-induced situation. “Yes, just like I just said if you are stressed when you are pregnant, that can have an effect on your heart and cause you problems” [HIV Negative, Focus Group 2, Participant 1]

“You could be pregnant and the stress could kill you...if the person whom you’re pregnant by isn’t taking care of you well, you have to manage your stress. If you don’t manage it, it won’t turn out well for you.” [HIV Positive, Focus Group 3, Participant 1 ]

“Well, they say...the pregnant woman, if she gets upset and have to complain a lot, she can easily develop eclampsia.” [HIV Positive, Focus Group 3 , Participant 4]

“Eclampsia is having to talk a lot and get upset. For instance, if your husband is arguing with you don’t respond, just concentrate. Also, they say if you have physical contact [sex] you can develop eclampsia.” [HIV Negative, Focus Group 4 , Participant 4]

“When a partner is arguing with you often, little by little, this will cause you to get upset. If you don’t let it get to you then you can handle it, even if you give it any importance.” [HIV Positive, Focus Group 3, Participant 5]

“Yes, someone can develop it several times. One time, I had been really upset, I even fought with a lady. I didn’t even know her but she told me that I was pregnant by her husband.” [HIV Positive, Focus Group 3, Participant 5]

“Well, I don’t know what would cause a woman to develop eclampsia, but this is what I know. It is when the person’s blood pressure increases to a certain level they can no longer tolerate and after that they’ll have an eclampsia episode. The doctor may see that they would be unable to give birth to the baby, therefore they’ll do a c-section” [HIV Positive, Focus Group 2, Participant 1]

“What I understand about this eclampsia problem is that, when the person is pregnant their blood pressure may start to go up and down when they get to the phase where they have to give birth and their blood pressure gets up to a certain level where they have



an eclampsia episode or develop eclampsia. They have a chance of passing away or of losing the baby.” [HIV Positive, Focus Group 2, Participant 8 ]

### *Delay 2: Structural and Social Barriers to Reaching Medical Care*

As we evaluated the narratives from this delay we realized that the codes of transportation and country’s insecurity best described the personal accounts that the women shared about their experiences in getting to care. Most women stated that they would face no challenges in finding transportation to the nearest medical facility, even if it meant them having to walk. However, though participants were willing to get to care, a significant factor in the delay to reaching a medical facility was the issue of the country’s level of insecurity. Political protest was a common theme that women mentioned as a barrier to reaching care.

#### *Transportation*

Some participants stated that if an emergency were to arise and they did not have someone at home or in their neighborhood to drive them to a local health facility, getting to the location would not be a barrier because access to transportation is largely available in their area. Although some women had to travel to multiple locations to receive care, they did not deem it difficult to find another car to take them to a secondary location.

“...I started labor at 10 o'clock in the morning. I had no one in the house with me and my husband was not there. I have two children, they were not there. I have a brother who lives next door to me, he wasn't there. I have neighbors, but I don't even talk to them. But I got up and called a taxi to take me to the General Hospital. When I arrived, they told me there weren't any nurses to help me. So, I just caught another public car

and went to Delmas, to the Delmas hospital”. [HIV Negative, Focus Group 1, Participant 4]

Participants pointed out situations in which a woman may not have access to any form of transportation. However, because of the area in which she resides, there are instances where they can call for an ambulance to pick them up. However, more than likely the ambulance may never actually arrive and the woman may not make it to the hospital.

“What can prevent a pregnant woman [from getting help during an emergency] is the means of transportation, depending on the area where she lives. If during the time she’s in labor she cannot find a car to go to the hospital she may try to call the ambulance that never comes. In that case, what can happen is that the woman does not make it to the hospital; she may give birth in the street or any accident or misfortune can happen to her. That’s what I think.” [HIV Positive, Focus Group 2, Participant 4]

#### *Country’s Insecurity*

During political protests in Haiti, women are faced with potential threats to their safety when leaving their homes to run errands related to their health care. They often have to go on foot because as the level of violence increases during the protests, there are fewer public cars available to help women get to their destination. However, some women did not see this as a barrier because they were determined to reach their health facility.

“Well, regarding what people say that the hospital is too far, I think it’s a lack of determination. Because if you have the motivation, you’ll go anyways... I needed to bring my test results to the clinic, but when I was supposed to come, because of the

country's insecurity, I went back home. I was scared to walk down to bring the test results...Today I just got up and decided to come here. I didn't hesitate or stop to think if the road was long nor when I would arrive. I came from Delmas 18, I went down the main street until I arrived here because I didn't want to have to call to say that I didn't have money to take public transportation to bring the test results. They had asked me to bring them and it was my responsibility that I had not brought the results yet. I think that as long as you have the determination, as long as GOD gives you a little bit of strength and you are not feeling too bad, you can get here somehow." [HIV Negative, Focus Group 3, Participant 5]

"Yes, because the other day there was a shooting in this area, there was no public transport, everyone came by foot." [HIV Negative, Focus Group 2, Participant 4]

"I haven't talked to the doctor yet because every time I have planned to come to the hospital, even without an appointment, the protests start and I can't go out." [HIV Positive, Focus Group 1, Participant 4]

"Yes, what can make a pregnant woman not come to the clinic is if there are protests in the streets and it is dangerous., Then the person may not be able to come" [HIV Positive, Focus Group 1, Participant 6]

"I wouldn't come because I'm afraid of the tension in the streets" [HIV Positive, Focus Group 1, Participant 2]

"Like the other day, I left the area called "Three Hands" near the airport but I went to catch a public transport by foot quite far to get here because the streets were dangerous." [HIV Positive, Focus Group 1, Participant 2]

“...If you can’t find public transport, it’s not a problem. The person can walk, but if there is shooting in the streets, I won't go" [HIV Positive, Focus Group 3, Participant 2]

### *Delay 3: Receiving Care at Health Facilities*

Themes from discussions about receiving care were often related negative treatment from providers/staff and good interpersonal relationships with medical providers. The women reported having good experiences with the providers and staff at their current maternal health facility, GHESKIO. However, their personal accounts with other medical centers and that of other women they know have been negative. They emphasized that at other health facilities, patients may be mistreated by the nurse and often overlooked by the physicians.

### *Negative Treatment by Medical Providers*

The negative treatment and experiences with medical personnel outside of GHESKIO was mentioned during the focus groups. The women noted how discouraging it can be to spend an entire day at the facility and not receive any care. However, when patients feel that the medical personnel are welcoming and keep them informed as they wait to be seen, it has a positive effect on their overall experience. It also has an effect on their outlook on medicine and making the decision to get care for their maternal needs at the health facility.

“Well, I see that here they are very patient and kind because there are places where the nurses have a bad attitude and act negatively towards you. They’ll talk to you rudely. Like they will leave you sitting around. But here, even when you’re sitting and they haven’t called you, if there is a problem, they’ll come to tell you what the problem is.

Or if you decided to talk to them, they'll tell you to wait a moment. They'll call you, talk to you respectfully. But there are places where they'll talk to you badly, and before you know, you'll see that a lot of time has passed and they haven't called you" [HIV Negative, Focus Group 2, Participant 2]

"Well, it may happen that a woman goes to a hospital or clinic and they are being mistreated and spoken to harshly. If she needed some information, she may end up saying she will no longer seek services at that facility again. Or she may choose not to speak to the nurse again ... " [HIV Negative, Focus Group 2, Participant 2]

#### *Good Interpersonal Relationship with Medical Providers*

Within facilities where women feel they have a good relationship with some of the personnel, they are willing to walk a far distance to ensure they make their medical appointments. They believe that their good relationship with the provider will allow them to ask for financial assistance to help them pay for a public car to get back home. This established relationship with their provider served as a motivator to ensure that they would find the means to reach the facility and make their appointment.

"When I walk to the hospital, if I feel I can't go back home walking again, I ask the nurse to give me 10 or 25 gourdes to pay for the public transport" [HIV Positive, Focus Group 3, Participant 2]

"Because of my relationships with the doctors and nurses, that's what encourages me to continue to come to the doctor. They encourage me to give birth in a hospital; I feel welcome and when at times I feel discouraged, they boost my morale." [HIV Positive, Focus Group 2 Participant 8]

“Our relationship is always good; when I have an appointment, the clinic always calls me before the date of the appointment. I always remember the date of the appointment, I never miss my appointments. When I go to the clinic, they always have a conversation with me and I always receive my medication. I am not negligent regarding the time they ask me to take my medicine; I always take it, I never miss a day.” [HIV Positive, Focus Group 1, Participant 4]

### *Perception of Women Regarding Traditional and Medical Maternal Care*

Women’s perspective on traditional care at home and medical care from a health establishment has an effect on how they manage their prenatal and postnatal care. These themes emerged from the codes prenatal care, traditional care, medical care, vaginal steaming, and massage the abdomen. Participants highlighted their experiences with traditional and medical maternal health practices.

#### *Traditional Care*

Women discussed the importance of carrying out certain practices like vaginal steaming and massaging the abdomen when they delivered at home. These practices are important to the women because it ensures that whatever residual blood was left inside the woman’s reproductive tract after child birth has been cleansed to prevent her from experiencing any pain.

“The blood that’s inside ...if she doesn’t get some medicine for it the blood won’t properly circulate. But she lives in Kafou. When I went to Kafou, I asked if they did do the vaginal steaming for her and they told me no. Even though her mother had sent herbal leaves for her. So, I took all of the leaves and a pot, I boiled the leaves. I had her sit on the bucket and I placed a covering over her head. I also gave her the [traditional]

medicine while I was there and her painful suffering came to an end.” [HIV Negative, Focus Group 1, Participant 2]

“No, if the person gives birth at home she has to do a vaginal steaming to melt the blood, to prevent the person from having severe pain and to keep the blood from forming a clot inside of her. But if the person gave birth under the care of a doctor, they have to prescribe her pills to control the pain.” [HIV Positive, Group 1, Participant 3]

“And they tell you that too, when you’re at home you find people to support you. Meaning, when you’re done bathing, when you’re in pain, you can find someone to hold you. When you’re in the hospital, they tell you to walk on your own, they send you to go on a walk. As long as the baby’s head isn’t out they don’t pay you any attention. It’s when the baby comes out, they will pay you any attention. It’s either the doctor is playing around or chatting, and it’s when the child... When I was at the hospital, I saw a baby that was born while the mother was on the small gurney while the doctors were chatting, they were just there joking around and the baby fell out on its head. The woman kept saying the baby is coming but in the time it took for the doctor to run over and take him, the mother lost the baby. That’s when I said, I’m not going to deliver in a hospital; I would rather just have the baby at home. If the bush doctor sees that I really cannot deliver and I’m in my last month of pregnancy and I don’t feel well, I will go to the hospital but if I just started having contractions, I’m not going to the hospital.” [HIV Negative, Focus Group 2, Participant 4]

### *Medical Care*

The women had mixed feelings about medical care. Some participants, particularly those from the HIV positive group, noted that it was important to immediately start

seeing a doctor once they discovered that they were pregnant. Also, the fear of giving birth at home was something that was expressed by some of the participants. But there were women who witnessed serious incidents that made them afraid to give birth in a hospital. The women reported that knowing that the doctor would be performing a vaginal exam, that they deemed intrusive, was a deterrent in getting medical care.

“Yes, this can demotivate you. Because when you arrive, they do a vaginal exam, digging their hands inside you and make you go through a lot of tribulations while you are in pain. For example, after I gave birth to the baby and I pushed him on my own, the doctor put his hand inside of me, so he can press my abdomen. He said he’s doing this to make things go quickly for me, but I had already pushed the baby out.” [HIV Positive, Group 2, Participant 4]

“Some women say that the doctors don’t take good care of them. They’ll leave them and they’ll only look over when the baby’s head appears. And there are some people who say that sometimes you’ll push the baby and the moment they see the head they cut you.” [HIV Negative, Focus Group 3, Participant 3]

“Well, the person can have the vaginal steaming if they gave birth at home with a traditional midwife. But if you deliver with a doctor, you can’t use this method, it won’t be good for you.” [HIV Negative, Focus Group 1, Participant 3]

“I thought I would return to the hospital, but I began to think that maybe I would see the same nurse that didn’t massage my abdomen the way she should have. I said to myself that going back to seek care at the hospital might mean they would put their hands inside of me to see if there was not some residual blood that was still inside of me.” [HIV Negative, Focus Group 1, Participant 2]



“Well, once you’re pregnant it is an obligation to seek care from a doctor..” [HIV Negative, Focus Group 3, Participant 1]

“They sometimes tell us that when we’re in pain, going into labor, don’t give birth at home because there are some dangerous risks with it.” [HIV Positive, Focus Group 1, Participant ]

“Yes, sometimes they’ll make you have a c-section for more money.” [HIV Negative, Focus Group 3, Participant 1]

“Well, I’m scared to give birth at home. I gave birth in the hospital.” [HIV Negative, Focus Group 3, Participant 4]

## **Discussion**

Women living with HIV are often excluded from PPCM studies, therefore it was important that we seek out the perspectives of this population to determine if there were any nuances within their experiences that varied from that of HIV sero-negative women (Mandal, Dattaray, Dutta, Sarkar, & Sinha, 2013; Sliwa et al., 2011). Though crucial differences did not arise, we noticed that the women living with HIV placed considerable emphasis on going to seek care if they exhibited any questionable signs or symptoms affecting their health. It is possible that since women living with HIV receive care from a specialty clinic that educates and supports them in maintaining adherence to their antiretroviral (ART) treatment, these women may be more attuned to the vulnerability of their bodies and are more proactive about seeking medical care.

### *Delay 1*

During the discussions, when asked about their awareness of preeclampsia, both the HIV -positive and the HIV sero-negative participants were able to point out several

signs of the disease and actions to help prevent it. Therefore, if educated on PPCM, as they have been with preeclampsia, the women may take the necessary measures to seek care or discuss those signs/symptoms with their providers. Though they reported that they had never heard of PPCM, the participants made references to experiencing signs such as shortness of breath when lying down, swollen ankles, and palpitations. These references were consistent with a study in Ethiopia that assessed the knowledge of obstetric dangers signs (Bililign & Mulatu, 2017; Chang et al., 2017; Guha et al., 2018). Previous studies in low- and middle-income countries have mentioned that in some places a woman's decision to seek care was contingent upon their partner or family member having the final say (Nabieva & Souares, 2019; Sumankuuro, Mahama, Crockett, Wang, & Young, 2019; Wallace et al., 2018). A study in 2018 conducted in Timor-Leste found that husbands were a factor in the decision to seek care. However, in our study the women did not verbalize that as a concern. In fact, some of the participants noted that regardless of who may have been in the house with them, if they felt they needed to seek care, they would take public transportation to do so.

### *Delay 2*

Though the women mentioned they were able to find public transportation, especially later in the evening, this situation may not be the case in the rural areas of Haiti. The political unrest in Haiti contributing to insecurity can often cripple the country's public transportation system (Price & Bohara, 2013). However, though it is often unsafe for pregnant and postpartum women to travel to a medical facility during political protests, there are some women who discussed going on foot to seek care because attending their appointment was important.

### *Delay 3*

These patients were individuals who were receiving services from GHESKIO, therefore their perception of care is relatively positive, in contrast to women who seek medical services at other facilities. However, there were some participants who had obtained care from other health centers who explained the differences between receiving services at GHESKIO compared to other facilities. A systematic review assessing attitudes and behaviors of maternal health care providers in Africa and Asia and the Pacific found that verbal abuse from providers was the most highly reported negative behavior observed by patients and providers (Mannava, Durrant, Fisher, Chersich, & Luchters, 2015). Also, studies often mention that medical cost is often noted as an obstacle in low- and middle-income countries, however, most of the women reported that regardless of their situation they would always find a way to pay to be seen by a provider. In other countries, however, a multi-country analysis found that low capacity to pay out-of-pocket health costs served as a key barrier in accessing care and contributing to catastrophic health expenditures (Xu et al., 2003).

### *Limitations*

Our study had a few limitations. This was a qualitative study with a small sample size; therefore, the findings cannot be generalized to the rest of the country. Also, Port-au-Prince, being the capital of Haiti, is not representative of other cities and rural areas in the country. GHESKIO is a unique, well-resourced site and all medical care is provided free of charge to patients. Therefore, our participants receive better specialized care and services in contrast to other medical facilities in Haiti.

## **Conclusion**

The accounts shared by the women in our study suggest they are willing to be proactive in seeking care as long as they are knowledgeable about danger signs. They are sometimes faced with the barrier of transportation because of chronic political unrest in the country, but if they make the decision to get to care, the women seem to have a determination to reach the medical facility. The experiences that women have at a medical establishment has a significant effect on their motivation to return to that establishment for ongoing care.

### *Delay 1 and Delay 2*

The study provides insight that, just as women are knowledgeable about preeclampsia, they should also be informed about PPCM to help increase their awareness about signs and symptoms that need to be monitored during their pregnancy and postpartum period. Participants had a positive outlook about getting to care, as long as some form of transportation was available. However, if their safety was at risk due to the country's insecurity and violent political protests, then it would be difficult for them to make the decision to seek or reach care. Therefore, ongoing political unrest that may pose a threat to the community's safety and may limit the availability of transportation. There should be initiatives in place to help bring services to pregnant and postpartum women in case they face complications that could endanger their lives if care is not received.

### *Delay 3*

Though this was not mentioned by most of the women, it was pointed out by a few women that they have been turned away before and had to seek care elsewhere because

there were no nurses on staff during the evening. This situation should be further explored in future studies. Training should be in place throughout facilities to help increase positive interpersonal relationships between providers and patients. Along with training, there should be metrics and protocols implemented to monitor patient satisfaction to ensure that the women have a positive experience during their time at the facility. If women feel that they are being cared for and treated with respect, they are more likely to seek care.

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## TABLES AND FIGURES

<b>Table 1. Description of Focus Group Participants</b>			
<b>Focus Group</b>	<b>HIV Status</b>	<b>Age Range (yrs)</b>	<b>Number of Participants</b>
Group 1	Negative	25 - 41	6
Group 2	Positive	26 - 42	8
Group 3	Positive	22 - 37	7
Group 4	Negative	19 - 34	6
Group 5	Negative	24 - 32	6
Group 6	Positive	23 - 43	6
<b>Total</b>			<b>39</b>

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## MANUSCRIPT 3

### Translation and Adaptation to Haitian Creole of the Fett Peripartum Cardiomyopathy (PPCM) Self-Test

#### Abstract

**Background:** Peripartum Cardiomyopathy (PPCM) is considered rare in the United States, however the literature notes that the disease has a higher prevalence in developing countries such as Haiti. Dr. James D. Fett, a U.S. cardiologist, developed and validated a self-assessment measure for PPCM in the United States to aid women to easily differentiate the signs and symptoms of heart failure from those related to a normal pregnancy. Although this instrument was validated, it lacks the adaptation necessary to account for the language, culture, and education of the Haitian population. **Objective:** The aim of this study was to translate and culturally adapt the Fett PPCM self-assessment measure for use among a Haitian Creole speaking population. **Methods:** A preliminary Haitian Creole direct translation was developed from the original English Fett self-test. A total of four focus groups with medical professionals and 16 cognitive interviews with members of a community advisory board (CAB) were conducted to refine the preliminary Haitian Creole translation and adaptation. **Results:** The adaptation focused on incorporating cues that would be tangible and connected to the reality of the Haitian population while maintaining the intended meaning of the original Fett measure. **Conclusion:** The final adaptation provides an instrument suitable for administration by auxiliary health providers and community health workers to help patients assess and quantify the severity of signs and symptoms that might be indicative of heart failure.

## **Introduction**

Peripartum Cardiomyopathy (PPCM), a form of heart failure that manifests among pregnant and early postpartum women, has a prevalence of one case per 300 to 400 live births in Haiti (Fett, Christie, Carraway, & Murphy, 2005). With this disease, the heart chambers become enlarged, thereby weakening the muscle and making it difficult to effectively pump blood (Demakis & Rahimtoola, 1971; Medline Plus, 2020). The common signs and symptoms of PPCM are often similar to those attributed to a normal pregnancy, therefore the condition is often unnoticed or misdiagnosed. Though the pathophysiology of PPCM is not well understood, there are certain risk factors that the literature suggests contribute to the development of the disease, such as being of African descent, older maternal age, having multiple pregnancies, and poor nourishment (Fett, 2014) (Fett et al., 2006). Unfortunately, PPCM is a global health concern with few studies that provide population-based research to explain how PPCM affects communities across the world. However, a few studies have stressed the strong association between African ancestry and PPCM. Black women have a higher relative risk of PPCM compared to their white counterparts, with a study showing a 15.7-fold higher incidence of PPCM among African American women than non-African Americans (Gentry et al., 2010). With access to health care being a significant factor preventing care, African American women appear to have a poorer prognosis compared to women of other races (Bauersachs, 2017; Gentry et al., 2010; Irizarry et al., 2017). Therefore, the literature recommends that early recognition and diagnosis of PPCM is key to increasing the chance of survival and recovery (Fett, 2013, 2016; Fett, Fristoe, & Welsh, 2010).

As a result of these recommendations, U.S. cardiologist, Dr. James Fett developed and validated a self-test instrument to aid women to distinguish the signs and symptoms of PPCM from that of a normal pregnancy. Dr. Fett identified the six common signs and symptoms of PPCM as: 1) orthopnea, 2) dyspnea, 3) unexplained cough, 4) swelling, 5) excessive weight gain during last month of pregnancy, and 6) palpitations; each of these were quantified with a simple scale of 0, 1, and 2 to facilitate self-scoring (Fett, 2011). In the study, the instrument was tested retrospectively among a sample of 47 mothers who were previously diagnosed with PPCM and a control group of 10 non-PPCM mothers. Based on the results, it was recommended that patients with a score greater than 4 should have their providers conduct a blood B-type natriuretic peptide test and an echocardiogram to aid in diagnosis (Fett, 2011). The Fett self-test is readily available and easy to understand; however, when accounting for patients whose primary language is not English, a simple direct translation may obscure the test's meaning (Control, 2016).

Translating health screening tools is essential for expanding access to resources and alleviate health disparities cross-culturally. However, direct translations of screening instruments are insufficient to ensure patient understanding. Previous models of translation merely focused on direct and forward translations from the original to the target language (Control, 2016). However, the literature demonstrates that the lack of adaptation does not allow for patients or evaluators to apply the measure in the local context, while ensuring the original meaning of the instrument is accurate.

In this study, we aimed to adapt the previously validated Fett PPCM self-test for use among a Haitian Creole speaking population. The translation and adaptation of health screening instruments reflect an intricate process that necessitates a systematic approach.

Studies have shown that end-users' opinions of translated health screening tools are often not sought (Control, 2016). Therefore, this study sought the perspective of both health professionals and community advisory board members to culturally adapt the Fett PPCM measure through the use of focus groups and cognitive interviews.

## **Methods**

### *Study Design*

Data collection took place between May 2019 and July 2019. A qualitative approach was most appropriate for the scope of this study, employing focus groups and cognitive interviews. Each of the systematic steps employed in this process was used to inform the next to preserve the integrity of the adaptations. To begin the study, we conducted a direct translation of the Fett PPCM Self-Test from English to Haitian Creole while making minor adaptations to account for cultural nuances. The original Fett version was translated by two Haitian Creole speakers who were fluent in both languages and verified by a third translator to ensure the most accurate direct translation. A qualitative approach was then employed through the use of focus groups and cognitive interviews. We began the study by conducting a total of four focus groups (n=29) with medical providers in Haiti (Table 1). Two of the focus groups consisted of nurses and midwives, while the other two comprised of obstetricians, primary care physicians, and pediatricians. We began the series of focus groups with the nurses and midwives. As they represent the supporting staff who engage with the Creole speaking patients more frequently, we believed that it was best to conduct the first assessment of the translation and adaptation with them.

The measure was further refined based on feedback gathered after each subsequent focus group, resulting in a 6-item, culturally adapted screening instrument that would be

administered by an auxiliary health care professional or community health care worker. The cognitive interviews were then conducted with the adapted screening tool among 16 Community Advisory Board (CAB) members (Table 2). Upon completion of the focus group or cognitive interview, each participant was offered refreshments equivalent to approximately 175 Haitian gourdes (~ \$2.50 U.S.), for their participation in the study.

### *Recruitment*

Study participants were recruited from the Groupe Haitien d'Etudes du Sarcome de Kaposi et des Infections Opportunistes (GHESKIO) center in Port Au Prince, Haiti. The physicians and nurses from various departments within the center were contacted and invited to participate in the study focus groups. We also worked with the Director of the GHESKIO Community Advisory Board (CAB) to recruit participants for the cognitive interviews. The GHESKIO CAB includes members from all socio-demographic levels and opinion leaders from all sectors of the population. It was established in 1998 as a link between GHESKIO and the local community; its members regularly serve as advisers on research protocols. Informed consent was obtained from participants who expressed an interest in participating in the study.

### *Initial Direct Translation*

In the direct translation of the measure we added a three-sentence set of instructions for the personnel administering it to be read to the patient. It stated, “I will ask you questions about some signs and symptoms that pregnant and postpartum women usually have. For each question, tell me to what extent you have felt these things during pregnancy or in the first 6 months after giving birth. If you have never experienced

them, tell me; also, if you have any of these symptoms, tell me to what extent you feel them.”

It was translated into Haitian Creole as follows:

“Mwen pral poze w kèk kesyon sou kèk siy ak sentòm moun ansent ak moun ki fèk fin akouche konn genyen. Pou chak kesyon, di m jiska ki pwen ou konn santi bagay sa yo pandan ou ansent oubyen nan 6 premye mwa ou finn akouche. Si w pa janm fè eksperyans sa yo, di m ; tankou tou si ou konn santi kèk nan sentòm sa yo, di m jiska ki pwen ou konn santi yo.”

### *Focus Groups*

Focus groups help with capturing a great deal of information and encourage conversations among participants allowing facilitators to gauge the perspective of multiple people ("An evaluation toolkit for e-library developments").

With the use of the original Fett self-test and initial direct translation, four focus groups were conducted with health professionals to gather their perspective and to begin refining and adapting the initial translation (Table 3). The feedback from health care professionals helped to validate each instrument item. The focus groups were facilitated by two professionals fluent in Haitian Creole. One facilitator led the group discussion with the use of a flip chart, while the second facilitator noted significant comments and suggestions that emerged during the session. Each participant was provided with a physical copy of the original English Fett self-test as a reference, while the initial translations were presented on the flip chart and used to guide the focus groups. While participants had a good understanding of English, some were significantly more fluent than others. Therefore, if any confusion arose regarding the terminology during the focus

group, participants were able to talk through it amongst themselves with very limited intervention from the facilitators. Upon completion of each focus group session, the facilitators would review each of the instrument items with the group and ask for a final consensus on the best adaptation based on the suggestions discussed. The facilitators would then move forward with the changes only if the majority of the participants agreed. The final adaptations made by the end of each focus group was based on the sole guideline that it retained the context of the original measure and was simple enough for the target audience to grasp.

### *Cognitive Interviews*

Following the adaptations gathered from the feedback of healthcare providers during the focus groups, the cognitive interviewing process allowed for a form of pre-testing among community board members whose sociodemographic characteristics were similar to that of the target population (Collins, 2003). We worked with the Director of the GHESKIO Community Advisory Board to recruit CAB members who interact with the community; participants included women of child-bearing age who could relate to the context of the self-test instrument; participants included women of child-bearing age who could relate to the context of the self-test instrument. During the cognitive interviews, individuals were able to help with rephrasing and identifying problematic questions or statements; the process gives them the opportunity to restate questions in their own words to ensure they understood the question as intended (García, 2011). It is essential that changes made to the assessment tool accurately measure symptoms in the same manner as the original instrument.



## **Results**

### *Focus Groups*

The primary concern among the providers related to the responses that required patients to count or measure. A large proportion of the target population have little to no education, therefore providers stressed that any questions involving interpretation of large numbers or unknown concepts would make it difficult for the target population to grasp, potentially resulting in inaccurate responses.

The first item of the instrument assessing orthopnea had an option describing the need to elevate the head 45 degrees or more. This response option assumes that the patient has the ability to measure what 45 degrees means. Therefore, providers agreed to use the number of pillows as an equivalent concept. The number of pillows mentioned was no more than three, which is simple enough that patients could differentiate it with ease. Providers discussed the importance of emphasizing the “need” in this first item, so that patients understood that though they may not have necessarily carried out this action, they felt a need to do so in order to relieve their difficulty breathing when lying flat. For example, patients may feel a need to use three pillows to alleviate their difficulty breathing, however, they may not have had three pillows to do so.

The second item assessing dyspnea, includes climbing 8 or more steps. Providers noted that many patients may not normally walk up a flight of stairs, therefore patients may be unable to conceptualize what is comparable to climbing 8 steps. Thus, providers agreed to use a small incline as an equivalence, as they are more commonplace in the city and the patients were more likely to encounter them. However, they also agreed that it was important to still include climbing stairs, but to remove “8 steps”.

The third item asked if the patient had unexplained coughing; however, providers suggested that based on their experience with patients, they would more often than not respond to this question with a “yes.” Thus, it was key to follow up the question by asking: “when do you experience the coughing?” Based on their reply, interviewers or providers could determine which of the three response options was most appropriate (Table 3).

The fourth item, swelling in the extremities, was considered challenging because patients might find it difficult to determine the specific location of swelling in their lower extremities; the options included: 1) None, b) below the knee, and c) above and below the knee. However, when directly translated into Haitian Creole, providers found it difficult to understand and thought it would likely cause confusion. It was suggested that the question specify “nan pye” (literally: in the foot) for below the knee and “tout janm nan” (literally: the entire leg) for above and below the knee. Providers thought it would be important to have the individual administering the instrument have the patient point to the specific area of their leg that was swollen. The provider would then select the appropriate response based on where on the leg the patient had indicated.

The fifth item assesses excessive weight gain during the last month of pregnancy. The options were: a) under 2 pounds per week, b) 2 to 4 pounds per week, and c) over 4 pounds per week. However, providers also found this question to be problematic. Access to resources like a scale and forming the habit of regularly weighing themselves is not commonplace among the population in Haiti. Therefore, providers believed that though patients’ responses may be inaccurate, asking them this question was still important to evaluate their perspective of their weight gain during the pregnancy. Providers decided to adapt the response choice to state, “a) ou santi w fè yon ti gwosi, b) ou santi w fè yon bon

gwosi, and c) ou santi w gwosi anpli anpli” (Table 3). The literal translations of the adaptations were: “a) you feel you have gained a little bit of weight, b) you feel you have gained a good amount of weight, c) you feel you have gained “a lot, a lot of weight” (Table 3). However, the personnel administering the questionnaire would either follow up with the patient’s provider or access their documented weight on the electronic medical record (EMR) to note the proper response on the questionnaire.

The last item of the instrument assesses palpitations (sensation of irregular heartbeats). Providers suggested removing the word “irregular” in the Haitian Creole translation because patients would not be familiar with the term; however, they would be familiar with “palpitation” and “heartbeat.” Therefore, it would be important to include certain probes to aid patients in describing their perception of irregular heartbeats, for instance, the use of a familiar onomatopoeia such as “bidip bidip” to describe to patients the sensation of rapid heartbeat. Providers also discussed accounting for the phrases that patients often use to describe the sensations they often feel in relation to their heartbeat (Table 3).

We observed that the nurses and midwives were highly focused on basing their proposed adaptations on the realities and personal accounts their patients had shared with them. In contrast, although the doctors were sympathetic to their patients’ experiences, their concern was also to ensure that the integrity of the measure’s clinical value was preserved. Since the four focus groups occurred in an alternating pattern of: nurses/midwives, physicians, nurses/midwives, and physicians, we were able to build on the changes from each type of provider and safeguard the original intent of the test.

### *Cognitive Interviews*

During the cognitive interviews, the CAB participants reported that the instructions section was specific and direct enough to convey the purpose of the questionnaire. They also noted that all the questions were comprehensive and clear enough for patients to understand. However, to ensure consistency with Item No. 4, about the location of swelling, they recommended adding a diagram as a visual aid that specifically defines what constitutes as the “janm” and “pye,” as described previously under Item 4. There was no significant feedback obtained from the CAB participants aside from the suggestion of utilizing a visual aid for Item 4.

### **Discussion**

The findings from the study suggest that a direct translation of the Fett Self-Test measure was inappropriate for a primarily Haitian Creole speaking population. Various studies on the cultural adaptation of health instruments have stressed a similar perspective regarding the inappropriateness of relying solely on direct translations (Beaton, Bombardier, Guillemin, & Ferraz, 2000; Chaves, Reis, Pagano, & Torres, 2017; Control, 2016; Madi & Badr, 2019; Marc et al., 2014; Martinez, Ainsworth, & Elder, 2008). The processes described by these studies were similar to the current study as they included an initial forward and back-translation of their respective instrument by individuals fluent in the native language. This translation was then followed by a review by another individual or a panel to help assure the validity of the translation and adaptation. The Haitian Creole PHQ-9 study on the reliability and validity of the instrument for instance, followed this approach and tested the tool among a sample of 1,080 participants in Haiti (Marc et al., 2014). It was found to be a valid measure for use in assessing depression among

participants. Another study conducted among a Lebanese speaking population, translated and adapted the Adolescent Pediatric Pain Tool (APPT) following the schema of forward and back-translations, expert panel, pre-testing and cognitive interviewing (Madi & Badr, 2019). Their process yielded an effective tool that is both culturally sensitive and reliable.

Though we gathered the focus groups based on profession, it is important to note that integrating each focus groups with doctors, nurses, and midwives may also have been beneficial. It would have allowed the focus group discussions to have a wider set of perspectives and stimulate conversations that may not have emerged by keeping participants grouped based on profession. However, “power structure” could be a concern when blending the focus groups; nurses and midwives may feel less expressive or intimidated to voice their opinions with physicians present (Benner, 2007; Siedlecki & Hixson, 2015; Vagharseyyedin, 2016).

To account for the low literacy rate of the target population, tailoring the self-test measure into an interviewer-administered instrument was most appropriate for the population. Therefore, the adapted measure included an instruction section followed by the six common signs and symptoms of PPCM in questionnaire form. The instrument provides short probes for each of the items to account for the variation in patient responses. The most challenging obstacle of the adaptation process was ensuring that the original meaning of the self-test was not lost throughout the focus group and cognitive interview adaptations.

### *Limitations*

This study had several limitations. Pregnant and postpartum women were not utilized to evaluate the Haitian Creole adaptation of the instrument. This decision was purposefully taken for ethical reasons, to avoid alarming the women about potential

problems without having the infrastructure and linkage in place to provide follow-up care if the women were to present with the signs and symptoms of PPCM. The participants in this study were all recruited from one site; therefore, the reach and perspectives were limited to those who were associated with GHESKIO. Providers and community members outside of GHESKIO may not have the same level of formal training, therefore their interpretations of the instrument's items may be different from the interpretations of GHESKIO staff. A supplemental document, that provides a brief description and objective of each question could be used in conjunction with the measure to ensure that interviewers or providers understand what each question is assessing.

### **Conclusion**

The strength of this study is that it provides an instrument for a primarily Haitian Creole speaking population to help understand the signs and symptoms of PPCM during late pregnancy and the early postpartum period. It was adapted based on feedback from medical professionals and individuals who closely identify with the community. Though some of the instrument's components were easily translated with minor adaptations, several benefited from a multi-stage adaptation and refinement process. This study has resulted in a Haitian Creole version of the Fett Self-Test instrument, which can be administered by auxiliary health care personnel and community health care workers to assess the need for further evaluation for PPCM among patients. The availability of this measure will allow for use in clinical as well as non-clinical settings and potentially in future preventative studies on peripartum cardiomyopathy in Haitian Creole communities. It is recommended that further research be conducted to validate the adapted instrument.

## TABLES AND FIGURES

Group	No. of Participants	Sex	Specialties
1	7	7 Female, 0 Male	5 Nurses, 2 Midwife/Nurses
2	8	3 Female, 5 Male	2 OB/GYN, 6 Primary Care Physicians
3	7	7 Female, 0 Male	5 Nurses, 2 Midwife/Nurses
4	7	4 Female, 3 Male	1 OB/GYN, 5 Primary Care Physicians, 1 Pediatrician

Participant No.	Gender	Number of Years Working at the Center in the Area of Maternal Health
1	Female	9
2	Female	6
3	Female	9
4	Female	9
5	Female	9
6	Female	9
7	Female	12
8	Female	9
9	Female	9
10	Female	2
11	Female	¼
12	Female	8
13	Male	1
14	Male	5
15	Female	9
16	Male	9

Original Feth Version	Initial Haitian Creole Direct Translation	Final Adaptation Haitian Creole	Final Adaptation English Translation
<b>Orthopnea (difficulty breathing when lying flat):</b>	<b>Difikilte pou respire lè w kouche plat (Orthopnée):</b>	<b>Ou konn gen pwoblem pou w pran souf lè w kouche tèt ba?</b>	<b>Do you have problems breathing when laying down with your head low?</b>
(a) None	(a) Okenn difikilte	Si non, chwazi opsyon a.	If no, choose Option A.
(b) Need to elevate head	(b) Bezwen pou leve tèt mwen tou piti	Si wi, mande l «konbyen zòrye ou ta bezwen mete anba tèt ou pou w santi w alez?» Epi chwazi repons la.	If yes, ask them “how many pillows would you need to put underneath your head to feel comfortable?”
(c) Need to elevate 45 degrees or more	(c) Bezwen pou leve tèt mwen 45 degre oswa pi wo	(a) Pa konn gen okenn pwoblem pou ou pran souf lè w kouche tèt ba.	Choose the response.
		(b) Bezwen pou ou mete yon lòt zòrye.	(a) Don't have any problem breathing when laying down with my head low.
		(c) Bezwen pou ou mete plis ke 2 zòrye.	(b) Need to add an additional pillow.
			(c) Need to add more than 2 pillows.
<b>Dyspnea (shortness of breath on exertion):</b>	<b>Souf kout lè w fè efò (Dyspnée):</b>	<b>Ou konn santi souf kout oubyen souf anlè lè w fè efo (santi w bouke)?</b>	<b>Do you feel shortness of breath or labored breathing on exertion (feeling tired)?</b>
(a) None	(a) Pa ditou	Si non, chwazi opsyon a.	If no, choose Option A.

(b) Climbing 8 or more steps	(b) Lè w monte 8 mach eskalye oswa plis	Si wi, mande l «nan ki moman?» Site opsyon b ak c, epi chawzi pi bon repons la.	If yes, ask them “in which instance?” State Option B and C, and choose the best response.
(c) Walking on level	(c) Lè w mache sou menm nivo a	(a) Pa konn gen okenn pwoblem souf kout oswa souf anlè oswa m pa konn bouke lè m fè efo.  (b) Lè w monte nenpòt ti mon oswa mach eskalye.  (c) Lè w mache nòmalmman.	(a) Don’t have any shortness of breath, labored breathing, or tiredness on exertion issues.  (b) When you walk up any small incline or stairs.  (c) When you walk normally.
<b>Unexplained cough:</b>	<b>Tous san rezon:</b>	<b>Wap touse?</b>	<b>Are you coughing?</b>
(a) None	(a) Pa ditou	Si non, chwazi opsyon a. Si wi, mande l «kilè ou konn ap touse? oswa “nan ki moman ou konn ap touse?» Site opsyon b ak c, epi chawzi pi bon repons la.	If no, choose Option A. If yes, ask them “when do you cough?” or “in which instance?” State Option B and C, and choose the best response.
(b) At night	(b) Lan nwit sèlman	(a) Non. M pap touse.  (b) Lannwit sèlman.  (c) Lajounen tankou lannwit.	(a) No. I’m not coughing.  (b) Only at night.  (c) Day and night.
(c) Day and night	(c) Lajounen tankou lannwit		
<b>Swelling (pitting edema) lower extremities:</b>	<b>Pye ak janm enfle (enflamasyon)</b>	<b>Ou konn gen pye ak janm anfle?</b>	<b>Do you sometimes have swollen legs and thighs?</b>
(a) None	(a) Pa ditou	Si non, chwazi opsyon a. Si wi, mande patisipan pou li montre w kote ki anfle. Epi chawzi pi bon repons la.	If no, choose Option A. If yes, ask the patient to show you where is swollen. Choose the best response.
(b) Below knee	(b) Anba jenou	(a) Pa konn gen pye ak janm anfle.  (b) Nan pye.  (c) Tout janm nan.	(a) Don’t have swollen legs and thighs.  (b) In the leg.  (c) The entire thigh and leg.
(c) Above and below knee	(c) Anwo ak anba jenou		
<b>Excessive weight gain during last month of pregnancy:</b>	<b>Gwosi twòp pandan dènye mwa gwoès la:</b>	<b>Ou santi w gwosi twòp pandan dènye mwa gwoès la?</b>	<b>Do you feel like you have gained too much weight during the last month of the pregnancy?</b>
(a) Under 2 pounds per week	(a) Mwens pase 2 liv pa semèn	Site tout chwa yo, epi chawzi pi bon repons la. Verifye pwa pasyan an avèk medsen oswa enfimyè.	State all of the options and choose the best response. Verify the patient’s weight with the doctor or nurse.
(b) 2 to 4 pounds per week	(b) Ant 2 a 4 liv pa semèn	(a) Ou santi w fè yon ti gwosi.  (b) Ou santi w fè yon bon gwosi.  (c) Ou santi w gwosi anpli anpli.	(a) You feel you have gained a little bit of weight.  (b) You feel you have gained a good amount of weight.  (c) You feel you have gained a lot, a lot of weight.
(c) Over 4 pounds per week	(c) Plis pase 4 liv pa semèn		
<b>Palpitations (sensation of irregular heart beats):</b>	<b>Sansasyon batman kè iregilye (Palpitasyon):</b>	<b>Ou konn santi sansasyon batman kè (kè w ap bat fò oswa kè w ap pile)?</b>	<b>Do you feel the sensation of your heart beating forcefully (your heart is beating rapidly or your heart is pounding)?</b>
(a) None	(a) Okenn	Si non, chwazi opsyon a. Si wi, mande l « kilè ou konn gen sansasyon sa ? » Epi chawzi pi bon repons la.	If no, choose Option A. If yes, ask them “when do you have that sensation”? Choose the best response.
(b) When lying down at night	(b) Lè w kouche lan nwit sèlman	(a) Pa konn santi sa.	



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(c) Day and night, any position	(c) Lajounen tankou lannwit, nan nenpòt ki pozisyon	(b) Lè w kouche lannwit sèlman.	(a) Don't feel that.
		(c) Lajounen tankou lannwit, nan nenpòt ki pozisyon.	(b) Only when you lay down at night.
			(c) Day and night, in any position.

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## **Conclusion**

### **Summary of the Study**

This formative study utilized qualitative and quantitative methodologies to collect data from a sample of health professionals, pregnant and postpartum women, and community advisory board members in Port-Au-Prince, Haiti. The goal of this dissertation was to use the Three Delays Model to examine the factors that delay Haitian women in seeking maternal health related care for obstetric emergencies and PPCM. We also assessed the knowledge, attitudes, and practices of health professionals regarding obstetric emergencies and PPCM. Lastly, the Fett Self-Test instrument for Peripartum Cardiomyopathy was translated and adapted into Haitian Creole.

The pregnant and postpartum women who participated in our study were of childbearing age and were either living with HIV or HIV sero-negative. During the focus groups we found that the key factors that contributed to a delay were: 1) knowledge of obstetric emergency signs or symptoms, 2) transportation, 3) country's insecurity (political unrest), and 4) negative treatment by medical providers. The women also shared experiences and practices that contributed in their split perspectives on modern versus traditional medicine.

In assessing providers, we found that though the overall mean knowledge, attitudes, and practices of physicians and residents was slightly higher than that of the nurse/nursing students and the midwife/midwifery students, it was not statistically significant. However, in employing multivariate logistic regression analysis the nurse and nursing student group had almost 1.5 times more odds (AOR = 1.46, 95% CI: 1.38, 1.55) of scoring higher, and the midwife or midwifery student group had about 2 times more (AOR = 1.98, 95% CI:

1.87, 2.10) odds of scoring higher in knowledge compared to the physician or resident group. Despite some participants having more years of experience working with pregnant and postpartum women, we found that this fact did not have a significant effect on their knowledge, attitudes, and practices.

Based on the focus groups conducted to adapt the Fett tool, providers suggested that including onomatopoeias to describe certain sensations would be essential in helping patients better articulate the sensations that they are experiencing. They found that it was particularly important to restrict the use of numbers in the tool because our target population's level of education would be limited. During the cognitive interviews, CAB members noted that adding a visual aid as a reference to help distinguish the difference between janm (thigh and leg) and pye (leg) for the "swelling in the lower extremities" assessment would be helpful.

### **Strengths and Limitations**

The strength of our study is that it utilized physicians, nurses, and midwives who are in different points in their careers to assess their knowledge, attitudes, and practices regarding PPCM. However, a limitation of this component of the study was that the sample size was not large enough to generalize the findings. Also, the providers' questionnaires were self-administered and completed on the respondent's own time, therefore there was no way to confirm if some respondents did not seek assistance.

Our focus group discussions with the women sought to better understand the psychosocial and structural barriers that contributed to a delay in pregnant and postpartum women seeking, reaching, and receiving care. Women who were living with HIV were often excluded from PPCM studies, however this one sought to include this particular

population so that we could gather their thoughts and perspectives regarding PPCM to determine if their experiences were any different from that of women who were HIV seronegative. A limitation in this study was that the dynamic of a focus group may have hindered the participants from being able to disclose more sensitive experiences.

This study provides a tool for the Haitian Creole speaking population of women and providers to better understand the signs and symptoms of PPCM. This instrument was adapted based on the opinions of Haitian health professionals and individuals who closely identify with the target population. However, a limitation of the translated Fet instrument is that pregnant and postpartum women were not used to evaluate the final adaptation. However, this was intentionally done to avoid alarming the women about the issue without first establishing the medical infrastructure and linkage to properly diagnose and treat women who may develop PPCM.

### **Future Extensions**

The study aimed to provide a better understanding of how PPCM is perceived among providers and women in Haiti. With there being limited studies examining the psychosocial and structural aspects of PPCM in the current literature, this study helps to fill this gap. It is important to facilitate trainings among providers about obstetrical emergencies and PPCM to allow them to be better prepared to identify and treat women who may present with the signs and symptoms, thereby contributing to the decrease of maternal mortality cases in Haiti. Also, this study provides a measure that can be administered by lower level personnel which may further expand the potential for medical professionals to screen for PPCM among their patients. The findings from the focus groups with the pregnant and postpartum women illustrates how several factors may cause women

to delay seeking necessary care for an obstetric emergency and peripartum cardiomyopathy, therefore it is important to use the learnings from this study to develop and implement initiatives that can help mitigate some of these barriers. Future studies should be conducted to further expand on our findings.



## Appendix I

### Aim I Questionnaire Questions - English

DEMOGRAPHIC CHARACTERISTICS	
Question	Response Choices
What is your gender?	Male Female
What is your date of birth?	_ _ / _ _ / _ _ _ _
How old are you?	_ _ _ _
Please tell me on what level can you speak, read, write Kreyol. (Speak) (0=No Proficiency, 5= Native Proficiency)	1   2   3   4   5
Please tell me on what level can you speak, read, write Kreyol. (Read) (0=No Proficiency, 5= Native Proficiency)	1   2   3   4   5
Please tell me on what level can you speak, read, write Kreyol. (Write) (0=No Proficiency, 5= Native Proficiency)	1   2   3   4   5
What type of health professional are you?	Doctor  Nurse  Midwife  Resident  Social Work  Other: _____
What is your specialty?	OB/GYN  Pediatrics  Midwife  Nursing Care  Nursing Care/Midwife Care  Social Work  Other: _____
What clinic do you work in?	_____

How many years of medical experience do you have? (year)	_ _
Years of Medical Experience	_ _
What is your principal job?	Supervising the clinic Professor/Educator/Instructor Advisor Research Other:
How many years have you been working with pregnant women? (years)	_ _
How many years have you been working with postpartum women? (years)	_ _
How many hours per week do you spend providing obstetric care?	< 5 hours 5-10 hours 11-20 hours 21 hours > 21 hours
Have you ever received education in the obstetrical domain during your health training?	Yes No
Have you ever received education on heart conditions or PPCM during your health training? (Heart Conditions)	Yes No
Have you ever received education on heart conditions or PPCM during your health training? (PPCM)	Yes No
During the last month, how many maternal deaths have be registered to you center?	_ _
How many maternal deaths cases have you witnessed as a health professional in the last year?	_ _
During the last month, how many obstetrical emergencies have managed as a health professional?	_ _
During the last month, how many cases have you managed as a health professional that were related to a heart condition?	_ _
During the last month, how many cases have you managed as a health professional that were related to peripartum cardiomyopathy?	_ _

**KNOWLEDGE**

<p>Focused antenatal care includes which of the following actions?</p>	<p>Checking the baby's position at 28 weeks</p> <p>Checking the woman's blood pressure at every visit</p> <p>Assessing ankle edema at 36 weeks</p> <p>Counseling the woman about danger signs only at the last visit</p> <p>Don't Know</p>
<p>When there is an obstetric emergency, tell the woman and her family or support person</p>	<p>As much as possible about the management of the emergency</p> <p>As little as possible about the management of the emergency</p> <p>What the provider thinks she/they should be told</p> <p>Nothing at all</p> <p>Don't Know</p>
<p>During the postpartum visit to the clinic, obtain a history for the...</p>	<p>Baby only</p> <p>Mother only</p> <p>Mother and baby</p> <p>Mother, her support person, and the baby</p> <p>Don't Know</p>
<p>After childbirth, the mother should have a postpartum visit with a skilled provider...</p>	<p>Once, at 3 weeks postpartum</p> <p>Once, at 6 weeks postpartum</p> <p>Three times: at 6 hours, 6 days, and 6 weeks postpartum and any time she has danger signs</p>

	<p>Only if they present with any danger signs</p> <p>Don't Know</p>
<p>During each postpartum visit, specific information should be obtained from the woman about:</p>	<p>Problems during pregnancy, during and after childbirth, and any present problems</p> <p>Present problems only</p> <p>Only those problems directly related to childbirth</p> <p>Don't Know</p>
<p>At each postpartum visit, the mother should be counseled to seek care if she has which of the following danger signs</p>	<p>Temperature 37 degrees C, or slight breast engorgement</p> <p>Edema of hands and face, severe abdominal pain, or sore, cracked nipples</p> <p>Severe headache, foul-smelling lochia, or calf tenderness</p>
<p>Each postpartum examination should include:</p>	<p>Measurement of blood pressure and temperature, and assessment of conjunctiva, breasts, abdomen, perineum, and legs</p> <p>Observation of breastfeeding</p> <p>Information about contraception, safer sex, and counseling and testing for HIV</p> <p>Don't Know</p>
<p>A woman who has peripartum cardiomyopathy can present with which of the following signs or symptoms?</p>	<p>Orthopnea</p> <p>Dyspnea</p> <p>Unexplained cough</p> <p>Swelling of the lower extremities</p> <p>Excessive weight gain during last month of pregnancy</p>

	Palpitations Don't Know
A woman can present with the signs and symptoms of peripartum cardiomyopathy during what period?	During the last month of pregnancy  Within 6 months postpartum  Don't Know
<b>ATTITUDE</b>	
A woman should plan ahead of time where she will give birth to her baby.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
A woman should plan ahead of time how she will get to the place where she will give birth.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
When women do not go to a health facility to give birth, it is mainly because it is too expensive.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
When women do not go to a health facility during an obstetric emergency, it is mainly the facility is too expensive.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
When women do not go to a health facility to give birth, it is mainly because it is too difficult to get there.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
When women do not go to a health facility during an obstetric emergency, it is mainly because it is too difficult to get there.	Strongly Disagree Disagree Agree Strongly Agree Don't Know

When women do not go to a health facility to give birth, it is mainly because the staff there do not treat women respectfully.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
When women do not go to a health facility during an obstetric emergency,, it is mainly because the staff there do not treat women respectfully.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
When women do not go to a health facility during an obstetric emergency, it is mainly because they don't recognize that they are experiencing a sign/symptom of an obstetric emergency.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
When women do not go to a health facility during when they present with a sign/symptom of peripartum cardiomyopathy, it's because they are not knowledgeable of the signs/symptoms of PPCM.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
If the woman trusts the provider and feels that they care about the outcome of the pregnancy, she will be more likely to return for scheduled antenatal care visits.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
If the woman trusts the provider and feels that they care about the outcome of the pregnancy, she will be more likely to return immediately if a danger sign appears.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
If the woman trusts the provider and feels that they care about the outcome of the pregnancy, she will be more likely to comply with recommended treatment.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
When offering HIV testing services to a pregnant woman, the provider should counsel the woman and let her decide whether to be tested.	Strongly Disagree Disagree Agree Strongly Agree Don't Know

Counseling the woman about danger signs only at the last visit, ask the husband's permission.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
Counseling the woman about danger signs only at the last visit, perform the test without informing the woman	Strongly Disagree Disagree Agree Strongly Agree Don't Know
Counseling the woman about danger signs only at the last visit, tell the woman she must have the test for her baby's benefit.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
The lack of knowledge to recognize an obstetric emergency, has a negative impact on obstetric care at the hospital.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
The lack of knowledge to recognize an obstetric emergency, has a negative impact on obstetric care in Haiti.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
The lack of knowledge to recognize the signs/symptoms of PPCM, has a negative impact on obstetric care at the hospital.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
The lack of knowledge to recognize the signs/symptoms of PPCM, has a negative impact on obstetric care in Haiti.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
The lack of knowledge to recognize the signs/symptoms of PPCM, has a negative impact on obstetric care at the hospital.	Strongly Disagree Disagree Agree Strongly Agree Don't Know

<p>The lack of knowledge to recognize the signs/symptoms of PPCM, has a negative impact on obstetric care in Haiti.</p>	<p>Strongly Disagree Disagree Agree Strongly Agree Don't Know</p>
<p>The lack of competency to provide appropriate emergency care, has a negative impact on obstetric care at the hospital.</p>	<p>Strongly Disagree Disagree Agree Strongly Agree Don't Know</p>
<p>The lack of competency to provide appropriate emergency care, has a negative impact on obstetric care in Haiti.</p>	<p>Strongly Disagree Disagree Agree Strongly Agree Don't Know</p>
<p>The lack of health professionals has a negative impact on emergency obstetric care at the hospital.</p>	<p>Strongly Disagree Disagree Agree Strongly Agree Don't Know</p>
<p>The lack of health professionals has a negative impact on emergency obstetric care in Haiti.</p>	<p>Strongly Disagree Disagree Agree Strongly Agree Don't Know</p>
<p>The lack of qualified health professionals, knowledgeable about the signs/symptoms has a negative impact on obstetric care at the hospital.</p>	<p>Strongly Disagree Disagree Agree Strongly Agree Don't Know</p>
<p>The lack of qualified health professionals, knowledgeable about the signs/symptoms has a negative impact on obstetric care in Haiti.</p>	<p>Strongly Disagree Disagree Agree Strongly Agree Don't Know</p>
<p>The lack of diagnostic equipment, has a negative impact on emergency obstetric care at the hospital.</p>	<p>Strongly Disagree Disagree Agree Strongly Agree Don't Know</p>



The lack of diagnostic equipment, has a negative impact on emergency obstetric care in Haiti.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
The lack of diagnostic equipment, limits the capacity for an effective diagnosis of peripartum cardiomyopathy at the hospital.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
The lack of diagnostic equipment, limits the capacity for an effective diagnosis of peripartum cardiomyopathy in Haiti.	Strongly Disagree Disagree Agree Strongly Agree Don't Know
<b>PRACTICE</b>	
Do you educate pregnant women on how to practice personal hygiene, rest, and exercise during pregnancy?	Yes No
Do you educate pregnant women on diet and nutrition during pregnancy ?	Yes No
Do you educate pregnant women on the danger signs during pregnancy?	Yes No
Do you educate pregnant women on the danger signs after delivery?	Yes No
Do you provide pregnant women education on the signs and symptoms of peripartum cardiomyopathy during the pregnancy?	Yes No
When advising a pregnant woman about a birth plan, health professional should inform them that if they don't have any risk factors they can give birth at home with a midwife (traditional birth attendant).	Strongly Disagree Disagree Agree Strongly Agree Don't Know
Providing material in the domain of emergency obstetrics, to study independently, helps in diminishing maternal mortality in my environment.	Yes No
Invited guest speakers who lecture on emergency obstetrics, helps in diminishing maternal mortality in my environment.	Yes No
Hanging posters in the medical establishment that describes the emergency procedures, helps in	Yes No

diminishing maternal mortality in my environment.	
Hanging posters in the medical establishment that describes the signs/symptoms of PPCM, helps in diminishing maternal mortality in my environment.	Yes No
A one-time seminar teaching and practicing competency in emergency obstetrics, helps in diminishing maternal mortality in my environment.	Yes No
An annual seminar and certification training emergency obstetrics, helps in diminishing maternal mortality in my environment.	Yes No
If they offered a 2 day seminar on obstetrical emergencies, I would...	<p>“...be very happy to participate even if it were during my time off/vacation time.”</p> <p>“...participate only if it counted as a regular work day.”</p> <p>“... participate only if my facility stresses it.”</p> <p>“...not be neither happy or unhappy.”</p>
If they offered a 2 day seminar on peripartum cardiomyopathy, I would...	<p>“...be very happy to participate even if it were during my time off/vacation time.”</p> <p>“...participate only if it counted as a regular work day.”</p> <p>“... participate only if my facility stresses it.”</p> <p>“...not be neither happy or unhappy.”</p>

## Appendix II

### PPCM: Discussion Guide for Focus Groups with Pregnant and Postpartum Women

**Note to Facilitators:** Before the discussion group begins, make sure you fill out the demographic information form for each participant]

**1.Explain the purpose of the talk:** Before we begin, I would like to thank you for taking the time to talk with us today. We invited you and other women like you to participate in this discussion group so we can learn more about the barriers to seeking, reaching, and receiving medical care for heart problems and peripartum cardiomyopathy. Before we begin, I will ask you to sign this form that explains everything I just told you and that you have consented to participate in this discussion group. **[Instructions:** Ask each volunteer to sign the consent form, If she has not yet signed.]

#### **2.Some Ground Rules for this discussion group:**

(a) I want to assure you that **everything we say in this group will be kept secret**. This means that no one, not even the staff working in the clinic, will know what we said. We also ask you to respect others who are here and to not repeat outside of this group what people said here. We will give each of you a number and, when we invite someone to speak, call you by the number. Before you speak too, we ask that you identify yourself by your number and not by your real name. When all the discussion groups are over, we will write a report where the information we gather from everyone involved in these group discussions will be summarized together. Your name will not appear in this report. Participation in this discussion group will not make you lose any of the benefits you receive here or from other organizations you receive care from.

(b) The second ground rule is **everyone participates in the discussions** and should feel free to give their opinions on the issues that we will discuss. Everyone is free to say what they think or believe about any question. There is no “right” or “wrong” answer to any question.

(c) **We will turn off all cell phones** so we can focus. We will spend about 1 hour together. Do you have any questions? Do you agree to respect these ground rules? "

**3.Permission to record the conversation:** To make sure we do not forget anything that will be discussed in this conversation, we will record all the talks. When the report is written, all audio recordings will be destroyed. Do you have any questions?"

**INSTRUCTIONS:** Before starting the group discussion, give each participant a number and make sure they understand to identify themselves with the number when speaking.

#### **1.Getting to know each other**

[Say] “To begin we would like each person to take turn and say the number they are going to use during this conversation.” [Wait for each person to say their number and verify that they remembered correctly]

[Say] “As an introduction, would each person say how many times they have been pregnant in their lives?”

## **2. Information about health care experiences during pregnancy or early postpartum**

“Now, I would like you to tell us about your experiences with your pregnancy care, beginning with when you started coming to the GHESKIO center until today.” [Wait for responses’]

*[Areas for probing: Find out how long they have been followed at the GHESKIO pregnancy clinic. Find out from participants why they chose to come to the GHESKIO centers for their pre-natal or postpartum follow-up care. Find out if nurses, doctors, midwives, or any health care professionals have discussed with them the signs and symptoms they should be aware of during pregnancy. Also find out if they are told about health problems that can occur late in pregnancy or a few months after a woman gives birth and that could endanger women’s lives]*

“Would you share what you have heard about preeclampsia?” [Wait for responses’]

*[Areas for probing: Find out what they have heard and from whom (e.g., doctor, nurse, midwife, people in the community); elicit their personal experiences with preeclampsia; the signs and symptoms of preeclampsia; what they know about the prevention and treatment for the condition, etc...]*

“Would you share what you have heard about Peripartum Cardiomyopathy (PPCM)?” [Wait for responses’]

*[Areas for probing: Find out what they have heard and from whom (e.g., doctor, nurse, midwife, people in the community); their personal experiences with PPCM; the signs and symptoms of the condition; what they know about the prevention and treatment for the condition, etc...]*

## **3. Health Problems or Emergencies During Pregnancy or Early Postpartum**

“Tell us about some health problems or emergencies that may occur during pregnancy or a few months after a woman gives birth? [Wait for responses].

*[Areas for probing: Find out what signs and symptoms they perceive as problematic; who they call upon or where they go; their experiences while seeking care; use the signs and symptoms mentioned by the women to find out the level of severity that motivates them to seek care (e.g. : difficulty breathing when lying down, shortness of breath when exerting,*

*unreasonable cough, swollen feet and legs, excessive swelling during the last months of pregnancy, and throbbing sensations); explore what can prevent a women from seeking care, even if she would want to go to a doctor or a hospital]*

Questions to elicit barriers to seeking care: “Some women might give the following reasons for not seeking care; would you tell us to what extent they apply to your experience?”:

- The hospital is too far away
- I do not have a private car or access to public transportation
- I have no gas or money to pay the transportation fee
- I have no money to pay for the doctor
- I must wait for my partner or family member to make the final decision.

#### **4. Other barriers to accessing, seeking, and receiving care during pregnancy and the postpartum period;**

“Tell us about how conditions of insecurity in the country affect the ability of pregnant or postpartum women to seek care if they are not feeling well?” [Wait for responses’]

**[Areas for probing:** *Elicit specific examples of times that protests in the streets or hearing gun shots in their neighborhood have prevented them or women they know from seeking care; find out what they do when transport may be unavailable to go to the area where GHESKIO is located, etc]*

“Now, would you share how you feel about your relationships with doctors, nurses, or midwives who provide care for pregnant and postpartum women here?” [Wait for responses’]

**[Areas for probing:** *Find out if they feel free to explain what they feel when they have a health problem; find out how well they feel the doctors, nurses, and midwives explain everything they need to know or respond to the questions they ask in a way they can understand; elicit examples of instances that illustrate both positive and negative experiences they might have had at their current clinic or others where they’ve sought or received pregnancy-related services; find out their perceptions about how well they think the doctors, nurses, and midwives who provide services to them do everything in their power to help them when we are not feeling well?]*

“Would you share with us how other women in your family or community help you or counsel you during pregnancy or after childbirth?” [Wait for responses’]

**[Areas for probing:** *Find out what types of tips or advice do they receive in their family during pregnancy or in the postpartum period; explore their use of traditional practices when they or women they know deliver at home versus go to the hospital and their perceptions of the effectiveness of these practices]*

## **5.Perceptions of maternal death and recommendations for improving health care**

“In your opinion, why do you think there are women in the community who die during pregnancy or after childbirth?” [Wait for responses’]

*[Areas for probing: Find out if any of the participants have had a personal experience in this area with someone they know dying during pregnancy, childbirth, or postpartum; listen empathically when these experiences are reported, especially if the experience discussed appears to have been a traumatic one for the women reporting them; explore what they think is the best way to educate women about the signs and symptoms that should be monitored during pregnancy or in the postpartum period that could endanger a woman’s life?]*

## **6. Conclusion of the discussion:**

Thank the women for taking the time to talk with you and for contributing to the discussion. Ask them if they have any other questions or if they would like to add anything else. Ask the women how they felt during this discussion group. Give all the reassurance that would be necessary at this time, should any participant be upset by any aspect of the group discussion.

## Appendix IV

### PPCM: Focus Group Discussion Guide with Health Professionals for Adaptation of Fett's Self-Test for Creole-Speaking Pregnant and Postpartum Women

**Note to Facilitators:** Before the discussion group begins, make sure each participant fills out the demographic information form]

**1.Explain the purpose of the talk:** Before we begin, I would like to thank you for taking the time to talk with us today. We invited you and other health professionals like you to participate in these discussion groups so we can gather your opinions on how best to adapt the initial translations made from English to Creole of a test designed to evaluate the signs and symptoms of peripartum cardiomyopathy (PPCM). You, as a member of the GHESKIO Centers health professional staff who works primarily with patients who speak and understand Creole, are in a unique position to give us feedback on the adaptations of the instructions, the language and words to use for each of the 6 questions of the test to insure that the majority of the patient population will understand them readily. Our aim is to adapt the questionnaire to the context and reality of the Haitian population while maintaining the intended meaning and clinical integrity of the measure.

As some of you may know, PPCM is a heart problem that pregnant women may develop during the last months of pregnancy or up to 6 months after delivery; many pregnant Haitian women develop heart problems. Dr. Fett, an American cardiologist who specializes in heart failure has developed a 6-item questionnaire that can be used to help recognize the signs and symptoms pregnant women may have that may indicate problems in the future. However, the questionnaire was developed in English. That is why we seek to refine the translation and adaptation of this test for a population that primarily speaks and understands Creole.

We know that not all of you participating in these focus groups have the same medical experience and you may speak Creole differently. This means that each person may have their own opinion on the translations and adaptations that will be required to make the measure appropriate for use with our target population. There are no good or bad answers; we would like for you to give your own opinions and say what you think about the translations both from the patient's perspective and from a health provider perspective. We aim to have a final translation and adaptation that is easily understood by the patients and at the same time retains the intended meaning of the question.

Before we begin, I will ask you to sign this form that explains everything I just told you and that you have consented to participate in this discussion group. **[Instructions:** Ask each volunteer to sign the consent form, If s/he has not yet signed.]

**2.Some Ground Rules for this discussion group:**

(a) I want to assure you that **everything we say in this group will be kept secret**. This means that no one, not even the staff working in the clinic, will know what we said. We also ask you to respect others who are here and to not repeat outside of this group what people said here. We will give each of you a number and, when we invite someone to speak, we will call you by the number. Before you speak too, we ask that you identify yourself by your number and not by your real name. When all the discussion groups are over, we will write a report where the information we gather from everyone involved in these group discussions will be summarized together. Your name will not appear in this report. Participation in this discussion group will not make you lose any of the benefits you receive here.

(b) The second ground rule is **everyone participates in the discussions** and should feel free to give their opinions on the issues that we will discuss. Everyone is free to say what they think or believe about any question. There is no “right” or “wrong” answer to any question.

(c) **We will turn off all cell phones** so we can focus. We will spend about 1 hour together. Do you have any questions? Do you agree to respect these ground rules? "

**3. Permission to record the discussions:** To make sure we do not forget anything that will be discussed here, we will record all the discussions. When the report is written, all audio recordings will be destroyed. Do you have any questions?"

**INSTRUCTIONS:** Before starting the group discussion, give each participant a number and make sure they remember to identify themselves with the number when speaking.

### **1. Getting to know each other**

[Say] “By way of introduction, we would like each person to take turn and say the number they are going to use during this group discussion and say how long they have been practicing as a health provider and the age groups they’ve been providing care to (e.g., children, teens, or adults).” [Wait for each person to say their number and introduce themselves]

### **2. Adaptations of the Initial Creole Translation**

#### **Questionnaire to Assess Signs and Symptoms of PPCM**

**[Note to Facilitators:** One facilitator will pass around copies of the English version and the first Creole translation of the Fett’s test to each of the participants to follow along during the group discussion; the same facilitator will take notes during the focus group discussion. The second facilitator will lead the discussion group and, using a flip chart, will write the suggested changes in wording to the initial Creole translation of the questionnaire, including the instructions to future potential patients and interviewers administering the test].



**[Note to Facilitators:** For each section of the following sections of the test, lead the discussion and note suggested changes that participants make to improve clarity of the Creole translation of the Instructions section as well as each of the 6 questions in the test. Allow opinions and suggestions to be discussed until a consensus emerges on how best to adapt the translation to the Haitian context].

**“Instructions:** I will ask you some questions about the signs and symptoms of pregnant women and women who had just given birth usually have. For each question, tell me how much you feel during pregnancy or in the first 6 months after giving birth. If you have never experienced these, tell me; like if you experience any of these symptoms, tell me to what extent you experience them.”

1. Difficulty breathing when lying flat (Orthopnea):
  - (a) None
  - (b) Need to elevate head
  - (c) Need to elevate 45 degrees or more”
2. Shortness of breath on exertion (Dyspnea):
  - (a) None
  - (b) Climbing 8 or more steps
  - (c) Walking on level”
3. Unexplained cough:
  - (a) None
  - (b) At night
  - (c) Day and night”
4. Swelling lower extremities (Pitting edema):
  - (a) None
  - (b) Below knee
  - (c) Above and below knee”
5. Excessive weight gain during last month of pregnancy:
  - (a) Under 2 pounds per week
  - (b) 2 to 4 pounds per week
  - (c) Over 4 pounds per week”
  
6. Sensation of irregular heartbeats (Palpitations):
  - (a) None
  - (b) When lying down at night
  - (c) Day and night, any position

### **3. Conclusion of the Focus Group Discussion**

Thank participants for their active participation in the adaptation process of the Fett’s PPCM test. Ask participants if they have any questions they would like to ask or some final comments they want to make. When you have finished answering the questions, thank them again for taking the time to participate in this discussion group and their contributions to the discussion. Offer refreshments prepared for participants.

## Appendix V

### COGNITIVE INTERVIEW GUIDE FOR THE ADMINISTRATION OF THE TRANSLATED AND ADAPATED VERSION OF THE FETT'S SELF-TEST

#### 1. Explain the objective of the interview:

Before we begin, I would like to thank you for agreeing to answer some questions that I will ask you about the translated and adapted version of a test for assessing the signs and symptoms of cardiomyopathy peripartum (PPCM). Today I invited you to participate in this interview so we can determine if the translations and adaptations that we did are accurate and can be easily understood. You, as a member of the GHESKIO Community Advisory Board (CAB) and someone who works and advocates primarily with patients who speak and understand Creole, are in a unique position to give us feedback on the language and words the majority of the population will understand readily.

PPCM is a heart problem that pregnant women may develop during the last months of pregnancy or up to 6 months after delivery; many pregnant Haitian women develop heart problems. Dr. Fett, an American cardiologist who specializes in heart failure has developed a 6-item questionnaire that can be used to help recognize the signs and symptoms pregnant women may have that may indicate problems in the future. However, the questionnaire was developed in English. That is why we seek to refine the translation and adaptation of this test for a population that primarily speaks and understands Creole.

We know that not all CAB members who will be participating in these interviews have the same medical experience and may speak Creole differently. This means that each person may have their own opinion on the translation and adaptation that we will discuss. There are no good or bad answers; we would like for you to give your own opinions and say what you think about the translations both from the patient's perspective. We aim to have a final translation that is easily understood by the patients and at the same time retains the intended meaning of the question.

We would like to know which expressions or words you think most of the patients who come to GHESKIO will understand. We will ask you what you think of the translation and adaptation of each question in the questionnaire with that in mind.

#### 2. Ground Rules for the Interview

- (1) I want to assure you that **everything we say in the interview will remain confidential**. This means that no one will know what you said. We will assign you a number and, when I ask you a question, I'll use that number, not your real name. When all the interviews are completed, we will write a report where the information we gather will be summarized. Your name will not appear in this report. Your participation in this will not deprive you of any advantages or rights you have.

(2) We would like you to **feel free to give your opinions** on the translations and adaptations we will discuss.

(3) We ask you to **turn off your cell phone** so we can focus. We will spend less than 1 hour together. Do you have any questions? Do you agree to respect the rules of the interview?

### **3. Permission to record the interview:**

To ensure that we do not forget anything of what will be discussed today, I will record the conversation. Once we have written and finished the report, we will destroy all audio recordings. Do you have any questions about that?

#### **Fett's Test to Evaluate Signs and Symptoms of PPCM**

**[Note to Interviewer:** Before starting, ask each participant to say their number and say how many years they have been a CAB member and advocating for patients of any age, including pregnant women]

#### **1. Refine instructions for the instrument**

**[Note to Interviewer:** Pass a copy of the translated and adapted test to the participant to follow along while one of you go through each section of the questionnaire]

**(a) Read the Creole translated and adapted instructions as they appear on the copy distributed to the participant:**

**“Instructions:** I will ask you some questions about the signs and symptoms that pregnant women and women who have just given birth may have. For each question, tell me to what extent you have felt these during pregnancy or in the first 6 months after giving birth. If you have never experienced these, tell me; similarly, if you have experienced any of these symptoms, tell me to what extent you have experienced them.”

**Ask participant:** “What do you think of the instructions that I just read to you? Do you have any suggestions for making them clearer?” **[Take brief notes on participant's suggestions for improving the instructions or making them clearer]**

#### **2. Refine the Creole translated and adapted questions and answers as they appear on the copy distributed to the participant.**

Read to the participant each of the 6 questions of the test that have been translated into Creole and adapted, then after each question, ask the participant what s/he understands of what the question asks and her opinion on how each item can be changed to improve

understanding by the targeted population. As in the previous section of the test, take brief notes on the suggested changes. This process is followed for each of the following questions to arrive at a consensus formulation that most agree will be understood by the pregnant and postpartum women patients.

1. **Do you have problems breathing when laying down with your head low?** [If no, choose Option A. If yes, ask them “how many pillows would you need to put underneath your head to feel comfortable?” Read Options B and C, and choose the option that best fits the patient’s response]
  - (a) Don’t have any problem breathing when laying down with my head low.
  - (b) Need to add one additional pillow.
  - (c) Need to add more than 2 pillows.
  
2. **Do you feel shortness of breath or labored breathing on exertion (feeling tired)?** [If no, choose Option A. If yes, ask them “in which instance?” Read Options B and C and choose the option that best fits the patient’s response]
  - (a) Don’t have any shortness of breath, labored breathing, or tiredness when you make any efforts.
  - (b) When you walk up any small incline or stairs.
  - (c) When you walk normally.
  
3. **Are you coughing?** [If no, choose Option A. If yes, ask them “when do you cough?” or “in which instance?” Read Options B and C, and choose the option that best fits the patient’s response.]
  - (a) No. I’m not coughing.
  - (b) Only at night.
  - (c) Day and night.
  
4. **Do you sometimes have swollen legs and thighs?** [If no, choose Option A. If yes, ask the patient to show you where it is swollen. Read Options B and C, and choose the option that best fits the patient’s response]
  - (a) Don’t have swollen legs and thighs.
  - (b) In the leg.
  - (c) The entire thigh and leg.
  - (d)
  
5. **Do you feel like you have gained too much weight during the last month of the pregnancy?** [Read all of the options and choose the best response. Verify the patient's weight with the doctor or nurse]
  - (a) You feel you have gained a little bit of weight
  - (b) You feel you have gained a good amount of weight.

(c) You feel you have gained a lot, a lot of weight

6. **Do you feel the sensation of your heart beating forcefully (your heart is beating rapidly or your heart is pounding)?** (If no, choose Option A. If yes, ask them “when do you have that sensation”? Read Options B and C, and choose the option that best fits the patient’s response.]
- (a) Don’t feel that.
  - (b) Only when you lay down at night.
  - (c) Day and night, in any position.

**Conclusion**

Ask the participant if she has any questions or some final comments she wants to make. When you have finished answering the questions, thank the participant for taking the time to talk with you and for her contributions to the discussion.

Offer the refreshments prepared.

## VITA

### CASSANDRA RENE

2009 – 2013	Bachelor of Science Family, Youth and Community Sciences University of Florida, Gainesville, FL
2014 – 2016	Master of Public Health University of Miami, Miami, FL
2016 - Present	Doctoral Candidate Public Health, Health Promotion and Disease Prevention Florida International University, Miami, FL
2016 – 2018	Graduate Assistant, Florida International University, Public Health, Health Promotion and
2016 – 2017	Disease Prevention, Miami, FL Graduate Minority Opportunities Program Fellow, Florida International University
2018 – 2019	Global Health Equity Scholar Fogarty International Center National Institutes of Health
2019 - 2020	Dissertation Year Fellowship Florida International University, Miami, FL
2020	C.V. Starr Scholarship Recipient Florida International University, Miami, FL

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