**Part I: Preliminary Information**

**Title:**The role of Ethiopian midwives in the prevention of mother-to-child-transmission of HIV:

            A human rights framework

**Abstract:**

Respecting patients’ rights is challenging in the treatment of highly stigmatized diseases such as HIV/AIDS. In sub-Saharan African countries, prenatal care is often the first point of contact with the health system. Policymakers have therefore used HIV-testing of pregnant women during prenatal care and prevention of mother-to-child transmission (PMTCT) services as the entree to HIV care. With the expansion of PMTCT programs, many countries have dramatically increased the numbers of midwives. Little is known about how midwives view the women they serve or their role in providing PMTCT services. Filling this knowledge gap is crucial as provider attitudes towards women with HIV affects the uptake of PMTCT interventions and respect for patient's’ rights for women receiving care.  This study explores the structural and contextual factors that influence the integration of patients’ rights into PMTCT services through an examination of Ethiopian midwives’ perceptions of mothers with HIV and PMTCT counseling processes.

**Personal Statement**:

I grew up with one ambition: to save the world. On my eighth birthday my parents’ gift to me was to sponsor Anna, a girl my age, from Bolivia on my behalf. When I turned twelve and began receiving an allowance, I was to pay for half the sponsorship. Every two months over the next ten years, my family sent $32 dollars through the organization to go towards her clothes, food, and school. I would tear open Anna’s letters in excitement, devouring each word that she wrote about her life in Bolivia. I was overjoyed to hear that my money helped her afford school uniforms, access to programs, the ability to play on a sports team, and daily meals. At the time, it seemed that lessening the disparities between my family and Anna was as easy as giving a donation, but as we grew together into our teenage years, I recognized dissonance while reading Anna’s letters. It was no longer enough to know that Anna had more resources as a result of charitable donations; I wanted to know why she didn’t have access to those resources in the first place. My intellectual journey thus far has led me to recognize and embrace the complexity of both the causes and consequences of disparities.

I came to Elon a few years later bursting with questions. What is the most sustainable model of humanitarian aid? How can philanthropic organizations work with communities to develop authentic partnerships focused on capacity building to address their own challenges?  My courses radically altered my understanding of the poor and strategies designed to eradicate poverty.  Unbeknownst to me, I had subconsciously accepted the American ideology of social mobility through my correspondence with Anna attributing Anna’s success in school and at home to her individual efforts to work hard and my donations. I ignored the very policies, norms, and practices that kept her family in poverty. Over several semesters, I was familiarized with the models of inequity, and realized that issues such as gender inequality, discrimination, interpersonal networks, and policy create interlocking systems of oppressions that make it difficult for organizations to address the various components that keep people in poverty.

Armed with this new knowledge, I joined Periclean Scholars, a program committed to engaging in culturally relevant dialogue to assist partnerships in Zambia through community run development programs focused on long-term success. I have had many thought provoking discussions with my cohort.  For example, do we have any right to go into a village and suggest they change their way of life in order to attain a “good outcome?” I wrestle with the effectiveness and ethics of our interventions.  There are no simple answers.

My passions lie in evaluating how both individual and systemic conditions can oppress or support groups of people. I seek to begin at the micro level, making connections with people and understanding their day-to-day experiences. From there, I want to progress to the macro level, examining the history and broader political and cultural forces behind social injustice.  Ultimately I want to better understand how to develop and implement culturally competent, sustainable programs that partner with historically disadvantaged communities to address structural inequalities that hinder social equity. I have learned that I cannot save the world. However, I do now believe that armed with research, community partnerships, and grit I can work to change systems of inequality.

**Part II: Project Description**

**Focus:**

Prior to the advent of antiretroviral treatment (ART), 30% of pregnant women with HIV transmitted the virus to their infants during pregnancy, delivery, and/or breastfeeding (DeCock et al, 2000cite).  However, ART offered during pregnancy, labor, and to the infant reduced the risk of transmission to less than 2% in high resource countries (Cooper et al., 2002).  The ability to reduce mother-to-child transmission of HIV comes with a number of challenges and implications for human rights (Vernooij & Hardon, 2013).  The proposed project explores the attitudes of midwives towards pregnant women with HIV and views of prevention of mother-to-child transmission (PMTCT) counseling through a human rights framework.  Countries worldwide have developed PMTCT protocols to identify pregnant women with HIV in order to prevent vertical transmission and offer treatment and follow-up care to women and their infants.  However, research in sub-Saharan Africa has raised concern that provider-initiated efforts designed to encourage HIV testing of pregnant women may be coercive, thus violating human rights of pregnant women (e.g., Turan, Miller, Baukusi, Sande & Cohen, 2008).  It has also been found that provider stigma and discrimination can reduce participation in PMTCT programs at each stage of the testing and care PMTCT cascade (Rakgoasi, 2005).

In recent years, the importance of respecting patients’ rights has been emphasized in global and national policies (Cohen & Ezer, 2013; Whyte, 2009). A human rights framework for patient care refers to both the theoretical and practical applications of general human rights principles, including self-determination, autonomy, equal access to goods and services, and fair treatment to the interactions between patients and providers (Cohen & Ezer, 2013). The approach focuses on ethical care for the most marginalized and vulnerable groups, and is preeminently important for the care of HIV-positive mothers and babies in the prevention of mother to child transmission (PMTCT) of HIV (Joint United Nations Programme on HIV/AIDS, 2014; Raisler & Cohn, 2005).

PMTCT programs are at the forefront of the battle against the HIV epidemic, especially in low-income countries like Ethiopia. They are the most effective interventions in combating new HIV infections as they test pregnant women for the disease, and if a woman is found to have HIV, explore ART options, and connect them with ongoing care (Ladner, Besson, Rodrigues, Saba, & Audureau, 2015; World Health Organization, 2013). Ethiopia has an adult HIV prevalence of 2%, which includes 80,000 HIV-positive pregnant mothers, and women in general comprise 59% of those living with HIV in the country (Federal Democratic Republic of Ethiopia Ministry of Health, 2010).  Fourteen thousand infants are born with HIV each year and the Ministry of Health has identified strategies designed to improve the effectiveness of PMTCT interventions. Health officials have written policy detailing the best practices for PMTCT programs as outlined by WHO and the UN, and invested resources in training healthcare providers and expanding programs (Federal HIV/AIDS Prevention and Control Office, 2007). Despite a marked increase in the number of facilities offering programs, only 8.2% of Ethiopian mothers with HIV received PMTCT services (Federal Democratic Republic of Ethiopia Ministry of Health, 2010).

Reasons for the low uptake of PMTCT services despite increased availability in Ethiopia are unclear. Some reasons include weaknesses within the healthcare system, and limited financial and human resources (Raisler & Cohn, 2005). However, research in other countries has found that healthcare providers fail to accurately implement the opt-out PMTCT policies.  Opt-out policies require that pregnant women be informed that they will be tested for HIV unless they explicitly refuse (Angotti, Donne, & Gaydosh, 2011). According to the WHO/UNAIDS guidelines, “Patients must receive adequate information on which to base a personal and voluntary decision whether or not to consent to the test, and be given an explicit opportunity to decline a recommendation of HIV testing and counseling without coercion” (WHO, 2007, p. 33).

However, a study in Malawi revealed that healthcare workers indicated to pregnant women that HIV testing was compulsory, rather than voluntary (Angotti, Dionne, & Gaydosh, 2011).  Researchers in Uganda also found that healthcare workers made HIV testing compulsory, did not fill out healthcare forms with the women’s consent, and offered inadequate counseling (Vernooij & Hardon, 2013).  They justified their actions based on their professional belief that the healthcare worker knows best and that the health of the baby is most important, illustrating the power dynamic that exists between midwife and client, a dynamic grounded in the income and education gap between the two (Bowser & Hill, 2010).  It is important to examine underlying structural and contextual factors that interfere with or support the provision of human rights-based care with an eye towards how these factors play out in service delivery.

Midwives in Ethiopia

Across sub-Saharan Africa midwives play an increasing role in healthcare systems because they can be quickly trained, are less expensive than physicians, and often work in facilities close to where women live (World Health Organization, 2013).   Midwives play a critical role in implementing PMTCT programs yet studies have shown that pregnant women with HIV are at risk for poor health outcomes due to provider prejudice and stigma (Mbonu et al., 2009). Some pregnant women avoid PMTCT programs and prenatal care altogether due to fear of unwanted disclosure of their HIV status by clinic providers (Thorsen, Sundby, & Martinson, 2008). Midwives play an especially important role in the provision of sexual and reproductive services in Ethiopia since abortion laws were liberalized in 2005 allowing midwives to offer abortion care (Holcombe et al., 2015).  Therefore, understanding their perceptions of PMTCT counseling and attitudes towards pregnant women with HIV are particularly important especially in light of the high HIV prevalence among Ethiopian women of childbearing age.

Research in Ethiopia related to the effectiveness of PMTCT programs has mostly focused on the patients themselves – how their own knowledge about HIV, perceptions of stigma in the healthcare facilities, and willingness to seek help has influenced their access of services (Gourlay, Birdthistle, Mburu, Iorpenda, & Wringe, 2013; Merdekios & Adedimeji, 2011; Workagegn, Kiros, & Abebe, 2015). The extant literature has not examined the Ethiopian midwives’ perceptions of women with HIV and PMTCT, which is vital to understanding their delivery of quality care centered on human rights.

Human rights are an important aspect of effective patient care and are a particularly salient issue in PMTCT.  It is necessary to understand midwives’ views of PMTCT counseling and attitudes towards women with HIV as these views can influence the quality of care provided.  Previous research in Ethiopia has explored the maternal perceptions of PMTCT services and adherence to PMTCT protocols, as well as perceived barriers to accessing services (Asefa & Mitike, 2014; Gourlay et al., 2013; Merdekios & Adedimeji, 2011; Workagegn et al., 2015). Research in multiple countries in sub-Saharan Africa has found that healthcare providers’ views shape the care provided to pregnant women with HIV, in some cases deviating from best practice care and violating human rights (e.g. Uganda, Malawi).  Current literature does not address provider views and quality of care in Ethiopia, a country with a focused role for midwives, high rates of maternal HIV infection and low uptake of PMTCT services.

Through interviews and direct observation of 25 Ethiopian midwives, the following specific research questions will be addressed.

What are midwives’:

* perceptions of their role in PMTCT counseling?
* attitudes towards pregnant women living with HIV?
* views on patients’ rights with regards to HIV testing and PMTCT services, in particular?

What individual and organizational factors influence the integration of patients’ rights into PMTCT service delivery?

**Proposed experiences**:

This project will be based on interviews with practicing and student Ethiopian midwives who deliver PMTCT counseling. Experiences center on data collection/analysis, conference attendance, and publications.

Summer 2016: Complete Human Services Practicum. Continue to research Ethiopian PMTCT practices/policies and regularly communicate with our California contacts. Attend the 13th Annual Qualitative Research Summer Intensive at UNC.

Fall 2016: Visit Drs. Burrowes and Holcombe in California to discuss survey questions and interview procedures in person. Develop interview questions. Complete my Elon College Fellows research proposal. Apply for SURE 2017.

Winter 2017: Complete final draft of my interview questions and finalize travel itinerary.

Spring 2017: Study abroad in Copenhagen.

Summer 2017: If funded, participate in SURE.  Travel to Ethiopia for data collection. Following SURE, begin data analysis.

Fall 2017: Complete data analysis and participate in data analysis workshop at UNC. Submit abstract to the International AIDS Conference.

Winter 2018: Complete manuscripts for the *Journal of Midwifery and Women’s Health* and *BMC Pregnancy and Childcare*.  Write a report and prepare videoconference presentation to the Debre Markos University.

Spring 2018: Attend the International AIDS Conference in Amsterdam, and present report to Debre Markos University.

**Proposed products:**

Formal Abstracts/Presentations: SURE, Elon College Fellows Proposal, SURF, IAS, video presentation to Debre Markos University.

Peer Reviewed Manuscripts: Findings on the role that stigma and power dynamics plays into the quality of PMTCT care offered by midwives will be submitted for publication to *Journal of Midwifery and Women’s Health*. Analysis of these influences within the human rights framework will be submitted for publication to *BMC Pregnancy and Childcare*.

**Part III:  Feasibility**

**Feasibility statement**:

This project is feasible for many reasons including access and mentor expertise,  as well as my own qualifications and passion. First, access to this difficult-to-find study population has been granted due to connections of my mentor has with Dr. Burrowes and Dr. Holcombe. They are professors of global health at Touro University in California, as well as researchers in Ethiopia who are currently researching disrespectful/abusive care during childbirth in facilities (DACF). DACF is a widespread and multifaceted problem that s a contributing factor to the high maternal mortality rates in Ethiopia.  Drs. Burrowes and Holcombe are partnering with the midwifery program at Debre Markos University, a large state-run university in the rural highlands and the Headquarters of Ethiopian Midwives Association in a longitudinal study designed to strengthen the link between communities and formalized healthcare systems that offer prenatal care, as well as reduce the incidence of DACF.  Their current project does not include a specific focus on mothers living with HIV and they expressed great excitement about my project.

Further, Debre Markos University has participated in a student global health-training program with Touro University for seven years and is accustomed to hosting and supporting U.S. students. It is because of our connection to these two researchers, that I have access to research infrastructure. Both have told me that I will be able to interview practicing and student midwives at the Debre Markos University, as well as conduct interviews at the Headquarters of Ethiopian Midwives Association. Since the midwives at Debre Markos University and the Headquarters speak proficient English, I will not have difficulty interacting with them, but in order to not miss the complexities underlying the topic, I will be working in Amharic and then analyzing the translated transcript. The translator will transcribe the interview, which will then be translated back into English for data analysis. Dr. Burrowes and Holcombe have recommended good local interviewers at Debre Markos, as well as translators who can assist with transcription (S. Burrowes, personal communication, 03/12/16). I would be conducting my own research while also being incorporated into their ongoing research and training projects. As published researchers in the field of patient rights in Ethiopia, they have shown enthusiasm for my project.

Second, the experience and knowledge of my mentor, Dr. Fair, also contributes to the feasibility of the project.  Dr. Fair has a wealth of knowledge on the effects of HIV-related stigma as she has worked in the field of HIV/AIDS treatment and prevention for many years. She has studied both individuals living with HIV as well as healthcare providers who work in the field.  She previously mentored another successful Lumen Prize applicant, Lauren Taylor (‘10), who studied attitudes of nurses and midwives towards women with HIV in South Africa.

Third, my own experiences and future plans place me in a good position to carry out the proposed project, I have had practice building relationships with communities through my community development course in India. My study abroad there allowed me to practice the skills I need to establish rapport with individuals from diverse backgrounds. Taking workshops through the Qualitative Research Intensive at UNC related to cross-cultural competency will give me more insight into building relationships with the midwives who come from a culture different from my own.

Attending the 13th Annual Qualitative Research Summer Intensive this summer and participating SURE next summer, will deepen my knowledge regarding qualitative data collection and analysis. The courses I’ve taken as a College Fellow, have given me some familiarity with conducting research, but attending the intensive workshops will help me learn how to further develop my research question, collect data appropriately, and analyze themes in the data.

Finally, I have a strong belief in the importance of this question, the intersections of HIV, patient care, and human rights issues is fascinating and also has the potential to improve the lives of women and their babies. This is a serious healthcare problem that has received limited attention in n Ethiopia yet is associated with increased morbidity and mortality for women and children. The products of my work will be valuable to key stakeholders in this issue – health facilities, health provider training programs, midwives, women, and their children. I have a desire to conduct research that will benefit the communities with whom I work.

**Budget:**

* **Interviewee Incentives**
  + Culturally Appropriate Gift – Flash Drive and Snacks $100.00
* **Conferences**
  + IAC $200.00
    - Flight Raleigh to Amsterdam        $1,700.00
    - Hotel/Food Expenses        $1,000.00
  + Poster   $90.00

Total            $2,990.00

* **Professional Development**
  + **California Trip to Visit Touro University** 
    - Flight RDU to San Francisco $500.00
    - Hotel $750.00
  + **Research Workshops**
    - Summer Course Fee $500.00
    - Fall Course Fee $250.00
    - Hotel/Food Expenses $400.00

Total            $2,380.00

* **Ethiopia**
  + Flight Raleigh to Addis Abba, Ethiopia        $1,600.00
  + Hotel/Food        $1,500.00
  + Local Phone $100.00
  + Monthly Airtime and Internet Fees $30.00
  + Translation/Transcription Costs ($6.00 per page) $600.00
  + Digital Audio Recorders ($200 per one) $400.00
  + Drop Box Subscription   $200.00

Total          $4,430.00

* **Tuition** 
  + Tuition              $5,100.00

Grand Total   $15,000.00

**Timeline:**

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|  | **Proposed Experiences** | **Proposed Product(s)** |
| **Summer 2016** | Human Services Practicum  Research on PMTCT Practices and Policies  13th Annual Qualitative Research Summer Intensive  Monthly phone call with California contacts | PMTCT Literature Review |
| **Fall 2016** | LUM 498- 2 Credits  Visit Dr. Burrowes and Dr. Holcombe in California for Fall Break  Develop Interview Questions | Submit Application for SURE  Elon College Fellows Research Proposal |
| **Winter 2017** | Interview Question Development  Apply for IRB Approval | Final Draft of Interview Questions  Receive IRB Approval |
| **Spring 2017** | Semester abroad in Copenhagen, Denmark | Opportunity to examine gender perspectives in Human Rights and diverse approaches to international policy |
| **Summer 2017** | SURE (if accepted)  Travel to Ethiopia | Data Analysis |
| **Fall 2017** | LUM 498- 2 credits  Odum Institute Data Analysis Workshop | Completed Data Analysis  Submit Abstract to International AIDS Conference |
| **Winter 2018** | LUM 498- 2 credits | Draft manuscripts for *BMC Pregnancy and Childbirth* and *Journal of Midwifery and Women’s Health* |
| **Spring 2018** | LUM 498- 2 credits  Attend IAC in Amsterdam, Netherlands July 22-28 | SURF Presentation  Poster Presentation (if accepted) at IAS  Video Conference Findings with Debre Markos University  Complete manuscripts for *BMC Pregnancy and Childbirth* and  *Journal of Midwifery and Women’s Health* |

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