

WHIT lab Thesis Projects



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Introduction

Hello, and welcome!

WHIT is a research group that is mainly interested in the health of women and mothers globally. We are intentional about conducting research that advocates for equity and improved health among structurally marginalized communities. We are involved in advocacy work in global health; and previous members have gone on to work in academia, non-profit work, and other global health-related organizations.

We are a group of scholars with varying backgrounds, experiences, and identities; all of which contribute to making this an accommodative learning space, as well as aiming for representation and equity in the work we present. No prior experience is required to be a part of our research group: we are all enthusiastic to keep learning, open to new ways of doing so, and would like our work to amplify the health and advocacy efforts that partner communities are already involved in.

Whether you would like to be a part of us, or to talk to us about some of the work we have been involved in, we would be more than happy to hear from you. This document summarizes some of the thesis projects that current WHIT members have done (for either their undergraduate honors or graduate coursework), and it includes informal interviews with said members, so that you may get to know a bit about us as well.

We hope you enjoy reading about our work!

Investigating the Long-Term Impact of Apartheid on the Contemporary Fertility Rate of Black South African Women: A scoping Review

WHIT member: Arielle Desir

Thesis level: Undergraduate Honors Thesis (for May 2022 Graduation)

Thesis type: Scoping Review

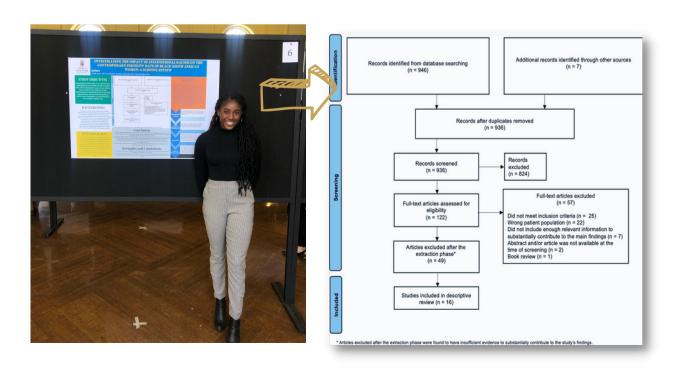
Advisors: Professor <u>Jennifer Pellowski</u> and Professor <u>David Rangel</u>

Abstract

Background: The South African fertility rate has steadily declined since the 1950s. Despite this decline among all population groups, Black South African women still have the highest fertility rate in the country. High fertility is associated with slower economic growth, an increase in environmental threats, and lower investment in human capital. The contemporary difference in fertility rates among women in South Africa is a consequence of historical socioeconomic and governmental disparities originating from colonization and apartheid. The purpose of this paper is to examine the existing literature on Black women's fertility rates and contraception use in South Africa, and to explore how lingering social determinants of apartheid contribute to the country's fertility rate.



Methods: This paper takes a historical methodological scoping review approach to evaluate past and contemporary forms of institutional racism such as housing discrimination, income inequality, and environmental racism, as well as their impact on fertility decisions among Black women in South Africa. The PRISMA-ScR checklist was used to guide the search methodology. A thematic analysis of included studies was conducted to explore key findings from the literature.





Results: The data from this study revealed a clear disparity between access to resources and fertility rates. Education, marriage/non-marriage, employment/the labor migration system, income, gender norms, and access to contraception were highlighted as key factors that influence fertility rates among all women. These factors had a more pronounced impact on Black South African women, as they have been historically disadvantaged and deprived of equal opportunity and resources due to apartheid and its legacy.

<u>Conclusion</u>: Given South Africa's history of racial inequality, evaluating the impact of social determinants on historically disadvantaged populations is critical when considering fertility and contraception options. Effective primary prevention methods must be identified and implemented in townships continuing to suffer from discriminatory policies that have a multigenerational and cyclical impact on Black people and their children. The only way to achieve primary prevention is to understand and resolve the historical events that have limited access to equitable resources for Black South African women.



Behind the scenes with Arielle:



What was the most enjoyable step in developing this thesis, Ari?

I would definitely have to say finishing the full text review of articles. After looking through the titles and abstracts, I used thematic coding to basically pull out information that is similar between readings —to help draw connections. Whether it was something that I wasn't expecting, or it in/validated a hypothesis I was expecting; it helped to see in real-time what the literature said, and how different literature sources spoke to each other.

How did you first reach out to your thesis advisors? Any advice?

Luckily, I was working with Jennie during the summer of my sophomore year - I had gotten a <u>SPRINT</u> award - after which she invited me into WHIT, which was an amazing opportunity. I learned (and continue to learn) so much from her and the WHIT ladies, and once I joined, Jennie took on the role of being a mentor for me. I always felt comfortable to approach her about public health questions, even outside of class, and she was always so kind and willing to make time to answer.

What advice do you have for someone who wants to do similar research or a thesis?

If you can, start making relationships with professors early, particularly those that have similar research interests. However, even if that is not the case, I would just say to do some research. A lot of professors at Brown have interest in research, mentoring students, expanding their knowledge, and learning new things. from students too. I would advice never to be afraid to broadcast your research interests to professors, or things you are thinking about.

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"I have to stand up on my own and do the best I can for my kids": An intersectionality perspective on the experiences of work (re-)entry among new mothers living with HIV in Cape Town, South Africa

WHIT member: Mamaswatsi Kopeka

Thesis level: Undergraduate Honors Thesis (for May 2022 Graduation)

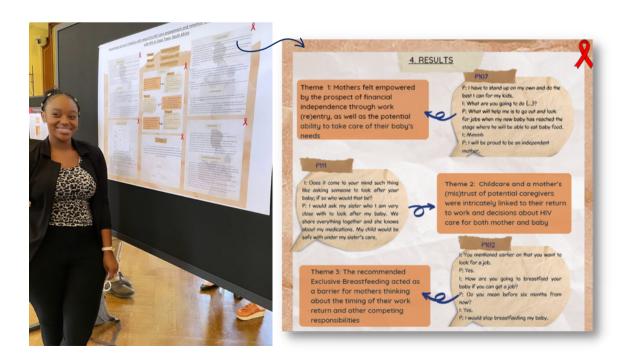
Thesis type: Secondary Qualitative Data Analysis

Advisors: Professor Jennifer Pellowski and Professor Barton Laws

Abstract

Background: Women in Sub-Saharan Africa are among the most vulnerable populations to HIV acquisition, and significant progress has been made in treatment options. For example, option B+, which requires that all pregnant women who test positive for HIV start on antiretroviral treatment, has been instrumental in reducing the risk of vertical transmission. In addition, South Africa recommends that mothers exclusively breastfeed for at least 6 months, to promote infant health. This recommendation, for mothers who are adherent to treatment, minimizes the risk of vertical transmission. However, almost half of WLHIV in South Africa disengage from care during postpartum. It is therefore important to discuss the return to (or looking for) work postpartum in relation to mothers' healthcare engagement, given that work is intricately linked to their socioeconomic status (and thus health outcomes) as well as their health-seeking ability.

Methods: As part of a larger study, women living with HIV in Cape Town, South Africa were recruited following the criteria: a) 18 years or older, b) at 32-35 weeks gestation (8 months), c) HIV positive, d) prescribed antiretroviral therapy (ART), and e) fluent in either English or isiXhosa. Semi-structured interviews were conducted with 26 women at 6-8 weeks postpartum. For this project, a secondary qualitative data analysis was conducted using NVivo, to investigate the mothers' experience with work (re-)entry and, subsequently, the implications for their treatment adherence as well as newborns' health.



Results: Three major themes were identified: a) Mothers felt empowered by the prospect of financial independence through work (re-)entry, as well as the potential ability to take care of their baby's needs; b) Childcare and a mother's worry about potential caregivers were intricately linked to their return to work and decisions about HIV care for the dyad, and c) The recommended exclusive breastfeeding acted as a barrier for mothers thinking about the timing of their work return and other competing responsibilities.

Discussion: Mothers must negotiate between a myriad of competing interests, such as their financial independence, baby's adequate childcare, and exclusive breastfeeding, and are, subsequently, often forced to make compromises. For many of the participants, their identity as women and mothers was intertwined, and a perception of their own personhood was tied to their independence and agency. Given this, the discussion about work is not merely about having money, but about identity, power, and agency –hence an intersectionality approach.

Conclusion: There is a dearth of knowledge on how Option B+ and exclusive breastfeeding recommendations translate into individuals' everyday lives. An important implication of this research is that health recommendations for HIV care need to account for individuals' socioeconomic needs and identities. As such, while exclusive breastfeeding is an important recommendation for a baby's health outcomes, it fails mothers living with HIV by disregarding the individual barriers they face.



Behind the scenes with Mamaswatsi:

What was most surprising in developing this thesis?

I guess for me, the amount of research that was already being done around returning to work, or starting work during postpartum was mindblowing! Especially, I would say, seeing these conversations center the non-traditional informal worker, or self-employed women -who are often left out of the discussion on work re-entry.

What do you wish you could have known beforehand?

To break it all into finy chunks that I could manage. Initially, this felt like such an overwhelming project because I had no idea where to start. But I worked with Dr Pellowski and the WHIT lab, broke all the tasks into small pieces and created a manageable timeline. Everyone helped to keep me accountable, and regularly checked in to see how the whole process was going- which helped significantly.

When do you think is the best time to start thinking about a thesis?

I don't think there is one best/perfect time to start thinking about it. I personally had not joined any lab until my junior spring, which is when I started thinking about my thesis topic. But I also know students who had long-term projects that developed into thesis ideas, and some who started reaching out to faculty in the summer before their senior year.

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"I can't do it all": Women's career trajectories during the COVID-19 pandemic

WHIT member: Kendall Stern

Thesis level: Undergraduate Honors Thesis (for May 2022 Graduation)

Thesis type: Primary Data, Mixed Methods Analysis

Advisors: Professor <u>Jennifer Pellowski</u> and Professor <u>Angela Bengtson</u>

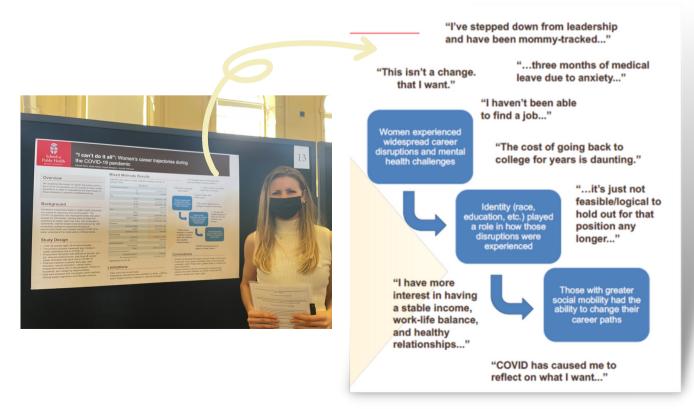
Abstract

Background: The COVID-19 pandemic has disproportionately disrupted careers for US women, causing them to leave the workforce at higher rates than men. The implication of these trends on women's future professional trajectories is not clear.

Objectives: To examine the impact of employment disruptions during the COVID-19 pandemic on US women's future career aspirations, and to characterize the lived impact of these stressors on women's professional lives.



Methods: We conducted an internet-based cross-sectional survey with embedded qualitative responses among US women focused on reproductive health and careers during COVID-19. n=93 participants were included. We used logistic regression to examine the relationship between employment disruption due to COVID-19 and changing career aspirations, as well as to explore factors associated with changing career aspirations. Qualitative responses were analyzed, using thematic analysis, to characterize the lived interaction between career disruptions and expectations for professional futures. Results were integrated using convergent mixed methods.



Results: 62.4% of participants reported experiencing an employment disruption due to COVID-19 (n=58). Women who experienced employment disruption had 3.08 (90% CI 1.48, 6.39) times the odds of changing their career aspirations compared to women who did not experience employment disruption. Factors associated with changing career aspirations were: being aged 40-49, White, unmarried, having a graduate degree, and being employed full-time prior to the pandemic. Qualitatively, women reported increased work-related stress during the pandemic and difficulty balancing their careers and personal lives. Financial stress and burnout were commonly cited as reasons for changing career aspirations.

Conclusion: Findings suggest that women with more means or flexibility (those who were older, more educated, unmarried, and/or White) had a greater ability to change their future career aspirations. These results point to a need for resources for individuals whose careers and mental health have been similarly impacted but who lack the means to change their career paths.

Behind the scenes with Kendall:



What was the most enjoyable step in developing your thesis?

This is such a difficult question because I enjoyed the entire process! But if I had to choose one step, I'd say bringing the data together for the mixed methods analysis. My thesis was a labor of love with a lot of intermediate steps, so it was extremely satisfying to fit all the pieces together in order to give voice to the everimportant experiences of the participants.

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What advice do you have for someone who, similar to you, wants to do their own data collection for their undergraduate thesis?

What did support look like for you during this process?

Support and mentorship during this project made it an incredibly enriching learning experience. One of the aspects that I appreciated the most about the mentorship I got was the ability to experiment in my analyses, make mistakes, and then redirect with their support. Dr. Pellowski and PhD candidate Alison Weber were critical in sharing their knowledge of qualitative and mixed-methods research. Dr. Bengtson was foundational in helping me develop an analytic plan for the quantitative data. Throughout the project, I was given an authentic research experience that allowed me to take ownership of the thesis while feeling supported by the insights of my mentors.

Start early! If you are like me and it's your first time collecting data, there will be a lot of learning—a.k.a. mistakes— involved. This is completely okay and it is actually what makes primary data collection and analysis such an enriching learning experience. One thing I loved about collecting my own data for this project was that while I knew what I wanted to study beforehand, I couldn't actually predict what kinds of data would be the most insightful in answering the big questions. I'm incredibly thankful that I had extra buffer time to further examine complex relationships and dive into mixed methods once I realized the nuance of the stories told.

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Understanding Experiences of Diet, Physical Activity, and Gestational Weight Gain Among Pregnant Women Living With HIV in South Africa - A Qualitative Analysis

WHIT member: Krystal Edwards

Thesis level: MPH Thesis (for May 2022 Graduation)
Thesis type: Secondary Data Qualitative Analysis

Advisors: Professor <u>Jennifer Pellowski</u> and Professor <u>Abigail Harrison</u>

Abstract

Background: South Africa has the largest prevalence of obesity in Sub-Saharan Africa, especially in women of childbearing age (18-44 years). Research has linked obesity during pregnancy to adverse outcomes such as stillbirth, cesarean delivery, and large gestational age. There is some evidence from South Africa to suggest that obese women tend to gain more weight during pregnancy than those with normal BMI, suggesting an even higher risk of adverse birth outcomes than normal weight women. Studies have shown that gestational weight gain in HIV-infected women is also associated with a high risk of high birthweight and spontaneous preterm delivery. This suggests that there is a need to integrate weight management interventions with routine care to support women at high risk of high BMI and gestational weight gain to promote healthy pregnancies.

Study Objectives: The objective of this study is to investigate the experiences of pregnant women living with HIV and obesity or other non-communicable diseases (NCDs) in regards to their diet, amount of physical activity, and gestational weight gain. To meet this objective, we propose a secondary qualitative data analysis with the following specific aims:

Aim 1: Explore personal experiences around day-to-day diet and physical activity in the context of pregnancy among women living with HIV (N=15).

Aim 2: Investigate experiences around clinical guidance related to pregnancy complications.



Methods: All 15 participants were recruited from the Gugulethu Midwife Obstetrics Unit (MOU). Inclusion criteria were i.) 18 years or older ii.) in the third trimester of pregnancy iii.) HIV-positive iv.) currently prescribed ART v.) diagnosed during current pregnancy with a complication indicative of an NCD (including pregnancy-associated obesity, hypertension, gestational diabetes, pre-eclampsia, cardiac disease, asthma, and anemia) vi.) speaks English or isiXhosa. Exclusion criteria were as follows: i.) self-reported participation in another ART adherence study and/or ii.) unable to understand the consent process. The interviews focused on experiences of women living with HIV and obesity or other NCDs within the healthcare setting, their experiences engaging in health behaviors including HIV treatment adherence, healthy eating and exercising during pregnancy, perceptions about weight gain during pregnancy, and plans for weight loss postpartum, as well as preparations for life with a newborn.

Results: The data from this study showed that there are multiple disconnections between clinic nurses and HIV-positive pregnant women that suffer from obesity and high blood pressure. The relationship the patients have with their nurses greatly contributes to their own health. Most of these women are not worried about their weight or are simply unaware of being obese. Clinic nurses also did not inform their patients of their excessive weight during routine checks. Another significant factor was the availability of healthy foods, which were imited for these patients either based upon location or socioeconomic status.

Behind the scenes with Krystal



What was the most enjoyable step in developing this thesis?

It has to be reading through the transcripts. Although I was not able to conduct the interviews myself, reading the transcripts made me feel as if I was there talking to the participants. Some participants shared real personal aspects of their life and those stories have stayed with me until today. I think that if I had the opportunity to interview the participants myself that would be my favorite part but because I did a secondary analysis, reading the transcripts was the next best thing.

What do you wish you could have known beforehand?

What advice do you have for someone who wants to do their MPH?

One thing I wish I would've known before doing my thesis was having in mind a topic that I really wanted to focus on for two years. I was very passionate about food insecurity but because I developed a love for maternal and child health, it took me a while to figure out a way to combine both. Luckily, I was pointed in the direction of Dr. Pellowski, who helped me figure out a way to put both of my passions together.

The advice that I have for someone who wants to do their MPH is to just do it. I don't think many people know the value that Public Health has not only towards their careers, but their everyday life as well. There are so many things that I have learned from being in the MPH program that have helped me tremendously. My advice is if an individual wants to be in the healthcare field, they should pursue an MPH.

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Identity of Motherhood: Analyzing the Lived Experiences of Postpartum Women Living with HIV In South Africa

WHIT member: Destry Jensen

Thesis level: MPH Thesis (for May 2022 Graduation)
Thesis type: Secondary Data Qualitative Analysis

Advisors: Professor <u>Jennifer Pellowski</u> and Professor <u>Abigail Harrison</u>

Abstract

Background: One in three pregnant women seeking antenatal care in public sector clinics in South Africa are living with HIV. 49% of women miss at least one HIV care appointment or drop out completely by six months postpartum. Rates of ART treatment dropout and nonadherence have been shown to increase after delivery and at later postpartum follow-ups. Motherhood has been found to be a motivation for treatment adherence during pregnancy, due largely to concern for one's child and the risk of vertical transmission of HIV. Yet, there has been little research on how the identity of motherhood influences HIV treatment adherence during the postpartum period. Motherhood can occupy a meaningful focus around the individual and social structure of identity, providing an advantageous point of analysis for HIV/AIDS.

Objectives: To address the current knowledge gaps, this study aims to provide an understanding of how the identity of motherhood impacts health behavior, and to investigate the social and cultural influences on such identity for postpartum women living with HIV in Cape Town, South Africa.

Methods: Qualitative data was collected in Gugulethu, South Africa, between March 2018 and May 2019. Thirty pregnant women living with HIV were interviewed during their eighth month of pregnancy and completed follow-up interviews at 6-8 weeks, 4-6 months, and 9-12 months postpartum (n=74 total postpartum interviews). Interview topics included personal perceptions of motherhood, HIV, motivation for and adherence to care, community and cultural attitudes, and female empowerment.



Results: The study findings address three themes: 1) perceptions of motherhood, 2) conceptualization of HIV, and 3) complexities of child health and feeding – and the relevance of the identity of motherhood in each theme. Participants expressed joy in their newfound role as mothers. Adherence to ART medication was motivated by a desire to live long, healthy lives in order to care for children. Women often reported little or no challenge taking medication while caring for their newborns, and often expressed acceptance of their HIV status. Participants often prioritized the health and wellbeing of their child above all else, which then caused heightened stress and fear of mother-to-child transmission of HIV when choosing a feeding option.

Conclusion: Participants in this study described a joy of motherhood, an acceptance of their HIV status, an adherence to treatment, and an ambient prioritization of their children's health and wellness that depicted their lived experiences; such findings add nuance to existing postpartum research and can be leveraged in future health interventions by considering the decisions, motivations, and perception of postpartum women living with HIV in South Africa.

Behind the scenes with Destry



How did you first reach out to your thesis advisors? Had you met any of them before?

The summer before I started my MPH at Brown, I knew I wanted to do my research on sexual and reproductive health in Sub-Saharan Africa because of past research I had been involved in. So I met with a student ambassador who gave me a short list of global health faculty in that area. After having great conversations with several professors, I felt that my personal research aspirations and passions aligned well with the ongoing and past projects of Dr. Pellowski, who kindly agreed to take me on as an advisee the first week of my Masters program.

What are you up to now, and any advice for any students who want to stay engaged in global health work?

I am currently living in Kigali, Rwanda working as a research fellow on emergency medicine. My advice for students who want to stay engaged in global health is to follow your passions and put yourself out there: apply to the job that seems like a reach or email that researcher because they led an inspiring project you read about – you never know where those inquiries or applications may lead!

What was the most enjoyable step in developing this thesis?

Discussing potential ideas with my advisors and colleagues. I learned so much in these conversations about the impact of global health research and the potential to focus on so many interesting and relevant topics.

Investigating The Efficacy of Doula Support in Decreasing Cesarean Section Rates for Birthing People in LMICs

WHIT member: Nancy Nkoudou

Thesis level: MSc Global Health (for May 2023 Graduation)

Thesis type: Systematic Review

Advisors: Professor Madina Agénor and Professor Jennifer Pellowski

Description of public health issue

There is worldwide debate within reproductive health regarding the appropriateness of cesarean section (CS) procedures without medical indication. Proponents for elective CS argue that the procedure "protects the woman from pelvic floor damage attributed to vaginal birth and avoids trauma and injury to both mother and fetus". Meanwhile, studies have demonstrated that CS procedures can result in adverse birth outcomes. —such as increased risk of death, admission to ICU, blood transfusion, and hysterectomy. Consequently, the World Health Organization (WHO) recommends a national CS rate between 10% and 15% in all countries. A longitudinal study conducted between 1990-2014 showed the global rate of CS is increasing worldwide—with the largest absolute increase occurring within Latin America, and Brazil being the country with the highest prevalence (55.6%). One solution to the increasing global prevalence of CS is the use of a labor support companion such as a doula. A 2017 Cochrane review analyzed the effects of labor companionship on birth outcomes in 13 high- and 13 middle-income countries. The major findings showed that continuous support may improve birth outcomes—namely by increasing spontaneous vaginal birth, shortening the duration of labor, and decreasing cesarean birth, among other outcomes.

Description of intervention

Throughout history and across cultures, birth companions have assisted in navigating the pregnancy, labor, and postpartum periods. However, the last century brought on many changes such that birth has become highly medicalized involving a slew of practices that limit - and some argue, dehumanize -birthing people in hospital settings. In response, there has been a surge in specially trained labor supporters, commonly known as doulas, that can provide continuous support throughout the perinatal period. Responding to this surge in trained labor supporters, the WHO released two guidelines recommending the use of a companion to accompany labor and childbirth to improve birth outcomes and feelings of satisfaction for the birthing person. Simultaneously, there is a growing body of literature supporting the use of doulas and other birthing companions in improving birth outcomes.

For the purposes of this review, a doula is defined as a non-medical birthing professional that provides emotional support, provision of information, physical support in the form of comfort measures and advocacy on behalf of the birthing person at any time during the perinatal period.

Behind the scenes with Nancy:

What has been the most enjoyable step in developing this thesis thus far, Nancy?

In April of this year, I was prompted to have a stakeholder meeting for a GPH course. In thinking about who would be best to interview, I thought back to my time last year in Brazil when I met Mairi Oliveira. At the time Mairi and I met, she was pregnant and open to getting some support through the rest of her pregnancy, birth, and postpartum.

Having worked with <u>Rede Postinho</u>, I was able to connect her to Monica B. who became her doula. Six months later I invited both of them on a zoom call to talk about their experience with one another, their experiences birthing in Brazil and their hopes for the reproductive health movement. This conversation was incredibly enlightening as it not only reinforced the importance of my own birth advocacy work but also challenged some beliefs and illuminated the importance of true informed consent throughout the peripartum period.

What advice do you have for someone who wants to do similar research or a thesis?

My passion for reproductive health advocacy stems from a desire to improve health outcomes for marginalized birthing people globally. A common word of advice I received from my mentors and would pass on is to be intentional about a specific public health question you're working towards, employ a spirit of scientific inquiry that is culturally relevant and evidence-based to address this question, and remain open to opportunities to learn from those who have the same interests.



Nancy and her first Doula baby (permission provided)

Understanding longitudinal perceptions of social support in pregnant and postpartum women living with HIV in Cape Town, South Africa

WHIT member: Enyonam Odoom

Thesis level: MPH Thesis (for May 2021 Graduation)
Thesis type: Secondary Data Qualitative Analysis

Advisors: Professor Jennifer Pellowski, Mary Kate Shapley-Quinn, and

Professor Margaret Waru Gichane

Abstract

Introduction: Women in South Africa remain disproportionately affected by HIV. Under the WHO's Option B+ strategy, all HIV-positive pregnant women are offered ART for the rest of their lives, irrespective of their CD4 count. At its most effective - Option B+ nearly eliminates mother-to-child transmission. Social support - defined as "support accessible to an individual through social ties to other individuals, groups, and the larger community"- plays an important role in physical and emotional well-being. It is provided by a network of family, friends, peers, romantic partners, and/or healthcare providers. This support is conceptually divided into four types: instrumental, emotional, appraisal, and informational. For pregnant and postpartum women with HIV, much less is understood about their experience with social support across the transition from pregnancy to postpartum. In this context, adherence to ART is doubly important since pregnant and postpartum women with HIV are not only protecting their own health but protecting their newborn child from HIV acquisition through vertical transmission as well.

Methods: The study was conducted in the Gugulethu Midwife Obstetrics Unit (MOU), Western Cape, South Africa. Data was collected as part of a larger longitudinal qualitative study conducted from 2018 through 2019. Participants in the study were interviewed during their final trimester of pregnancy; at 6-8 weeks, 4-6 months, and 9-12 months post-partum. A purposive sampling method was used, and eligibility criteria required that women were 1) HIV positive; 2) prescribed ART 3) 32-35 weeks pregnant; 4) 18 years old or older and 5) able to speak English or isiXhosa. Qualitative data analysis was done through a two-part process. First, interview transcripts from both time points were read to identify themes, and secondly, data analysis consisted of a longitudinal analysis focused on understanding expectations of social support and changes in social support over the course of the study as women transitioned from pregnancy to postpartum.

Results: Three major themes were identified: 1. Self-motivation to adhere; 2. Networks of support; and 3. Research as a source of support. Firstly, Pregnant women anticipated possible changes in support from their family and partners but were motivated to remain adherent regardless of the support. By looking to the future, many women made plans for supporting themselves and maintaining their adherence to ART postpartum. After giving birth, women followed through on plans regardless of the changes in support around them. Secondly, women have a complex network of support from different people in their lives and at different times during their pregnancy and post-partum journeys: "an elder person to guide" them, their partner, as well as their family members. Finally, the research project was also a source of support for the women, who felt it was "better sharing with a stranger".

Discussion: Partner support is of particular relevance to retention in PMTCT care. During pregnancy, many women in the study felt unable to rely on their partners for sustained, necessary instrumental support such as money for food and clothing for the new baby. Women planned for this anticipated change in support by looking for employment to become independent and support their families without their partner's help. The added stress of financial instability can lead to drops in adherence. Additionally, participants noted the need for emotional support from partners. Engaging partners in PMTCT to increase support and improve mothers' outcomes in sub-Saharan Africa has been previously researched, and there is still much room for improvement. One way to initiate partner participation is through HIV testing, which can facilitate their participation in services alongside their partner. Some mothers in the study noted that it was easy for them to remain adherent because their partner was also HIV positive and was a source of support due to this. However, testing and linkage services are not enough: male partners could also benefit from support groups and programs that are typically geared towards women, as well as more opportunities to engage in healthcare; doing so can improve mothers' retention in care.

Results: Case Study

Analysis of the interviews yielded three main qualitative themes relevant to partner, family, and community support.

Theme 1: Self-motivation to adhere

Women described high ART adherence throughout their pregnancy and postpartum, often independent of external support. Pregnant women anticipated possible changes in support from family and partners but were self-motivated to adhere. They made plans for maintaining their adherence to ART postpartum. After giving birth, women followed through on their plans regardless of the changes in support around them.

During Amogelang's pregnancy, she worried about her future after the baby was born. She perceived her partner to be supportive in some ways, but she felt she needed to be "self-dependent" without depending on anyone else - "neither my partner nor my parents" - in case his amount of support changed in the future. She felt that "somebody can be supportive now, but you do not know what will happen along the way, you are not sure when the person might change."

Amogelang reported remaining adherent throughout her pregnancy and continued to be adherent after giving birth; she discussed her motivation to adhere postpartum:

"Sometimes I work overtime and come back home after 23:00 but I know that I have to take my treatment before going to bed.... What motivates me is that I know my health comes first even though I have a child. I have to take care of myself and raise my baby because no one else will do that."

[PID 126, Timepoint 1]

Amogelang's partner did remain supportive
When their child was born, but the participant was
still excited about her self-sufficiency during her
final interview:

"What makes me proud is to be able to provide for everything that she needs that is within my power, even though there are times that I cannot afford everything that she needs. I become more proud when I can afford all the basic necessities like nappies and milk every month." [PID 126, Timepoint 4]

Results

Theme 2: Networks of support

Women in the study rarely discussed solely relying on one person as a source of support. Instead, they had a complex network of support from different people in their lives and at different times during their pregnancy and post-partum journeys.

"[My mother] helps me with the baby and sometimes I feel as if I am not a new mother, [my mother] help me a lot and look after him as well." [Sihle, age 22, T4] "[My partner] provides me with financial support. He came to visit us for the whole day [she was born], and he was holding her throughout the day. He is very supportive when it comes to my baby." [Elizabeth, age 34, 14]

Theme 3: Research as a source of support

During their interviews, women looked to research staff as a source of informational and emotional support, even though the study was observational, and interviewer did seek not to explicitly counsel the participants. Many women shared that they did not have friends or family that they talked to about things in their lives that caused stress or upset, particularly when that stress was compounded by their HIV status.

"For me it's just like counselling, it's everything. You are able to share your views. You have to say how you're feeling... You have a support system. That's very important." [Thabisa, age 27, T4] "Coming to attend my visits with you makes me feel free... it is a challenge to connect with other people around my community because they might not understand but here, I am able to share my life experiences." [Mpho, age 26, T4]

Conclusion

- Pregnant women planned for potential changes in social support over the course of their pregnancy and postpartum periods and followed through on their plans to remain adherent.
- Social support networks provide direct support with medication adherence, financial support that assisted with getting to and from the clinics, and tangible support that gave postpartum mothers the space to care for their health.
- Future PMTCT programs should utilize pregnant and postpartum women's networks of support to improve adherence to ART and focus on alleviating gaps in existing support structures.

Behind the scenes with Enyonam:

What was the most enjoyable step in developing your MPH thesis?

Definitely reading what participants had to say about their experience as pregnant and postpartum women in South Africa. Although this was not my lived experience, having them share their experience, and be open with what they have gone through was definitely the best part of my thesis.

What are you up to now, and any advice for any students who want to stay engaged in global health work?

So, I actually just came back from Rwanda about a month ago, where I completed my Caroline fellowship - shout out to Dr. Pellowski for mentoring me through the program. I am now working at <u>Kaiser Permanente</u>. For interested students, I would recommend any opportunity or fellowship in global health or contuing work that is global-health centered within the US, such as working with refugee communitues. You can still do a great amount of good in global health, wherever you are based.

How did you decide on doing your MPH, and why Brown?

During undergrad, I had an opportunity to do a CDC fellowship during the summer, and that exposed me to public health. Then I worked for two years doing research at a public health organization; and everyone I worked with had an MPH or a PhD in public Health, which told me that is what I needed to do the work that I was interested in. I chose Brown in particular because they value their graduate students, more than other programs do. I visited the campus on a random weekend, and because it is a small program, got to meet the faculty and talk to students, which really made me feel valued.

Mother knows best: grounding ethical research focused on pregnant and postpartum women living with HIV in maternal decision-making in the Option B+ era

WHIT member: Alison Weber, MPH

Thesis level: MPH Thesis (for May 2020 Graduation)

Thesis type: Scoping Review

Advisors: Professor <u>Jennifer Pellowski</u> and Professor <u>Abigail Harrison</u>

Abstract

Historically, maternal HIV research has focused on prevention of mother- to- child transmission and child outcomes, with little focus on the health outcomes of mothers. Over the course of the HIV epidemic, the approach to including pregnant women in research has shifted. The current landscape lends itself to reviewing the public health ethics of this research.

This systematic review aims to identify ethical barriers and considerations for including pregnant and postpartum women living with HIV in treatment adherence and retention research. We completed a systematic literature review following PRISMA guidelines with analysis using a relational ethics perspective.

The included studies (n = 7) identified ethical barriers related to (a) women research participants as individuals, (b) partner and family dynamics, (c) community perspectives on research design and conduct, and (d) policy and regulatory implications. These broader contextual factors will yield research responsive to, and respectful of, the needs of pregnant and postpartum women living with HIV.

While current regulatory and policy environments may be slow to change, actions can be taken now to foster enabling environments for research. We suggest that a relational approach to public health ethics can best support the needs of pregnant and postpartum women living with HIV; acknowledging this population as systematically disadvantaged and inseparable from their communities will best support the health of this population.

Published papers from Ali's thesis:

- Weber, A. Z., Pellowski, J. A., Brittain, K., Harrison, A., Phillips, T. K., Zerbe, A., Abrams, E. J., & Myer, L. (2020). "This is My Life We are Talking About": Adaptive Strategies for HIV Care Retention and Treatment Adherence Among Postpartum Women Living with HIV in Cape Town, South Africa. Maternal and Child Health Journal, 24(12), 1454-1463. https://doi.org/10.1007/s10995-020-02995-3
- Weber, A. Z., Harrison, A., & Pellowski, J. A. (2021). Systematic review of research focused on pregnant and postpartum women living with HIV: A relational ethics perspective. Bioethics, 35(8), 829-838. https://doi.org/10.1111/bioe.12917

Behind the scenes with Alison:



How did you first think of your thesis topic? Is this something you always wanted to do?

Why did you decide on an MPH?

That's such a great question! I came into my MPH knowing that I was interested in maternal health, so that's how I got connected with Dr. Pellowski. Although I wasn't explicitly interested in HIV work, she and I worked together to decide on my thesis topics. I came in with an interest in ethics, so that tied in nicely with the systematic review I worked on, and I was really excited to work on a strengths-based qualitative analysis of how women navigate their HIV care.

Coming into the MPH program in 2017 was a big career shift for me. Prior to that, worked in quality control/quality assurance for medical device manufacturers and pharmaceutical companies. It was a journey to figure out my next career move. Ultimately I realized that I either needed an MD or a PhD to do the work I was passionate about, and decided that an MD wasn't the right path for me. I came into the MPH program as a generalist to help me decide which area of public health I wanted to pursue in my PhD - and thank goodness I did! I initially thought I would want to focus on epidemiology but quickly realized after taking some courses that I loved the humanity and person-centred work in behavioral and social sciences.

What are you up to now? And in what ways has your MPH thesis contributed to your work afterward?

I'm in a PhD program now, still at Brown in the BSS department. My thesis work rolled right into many of the projects I'm working on now, where I continue to focus on maternal health.