"If it benefits someone, it will be good:" Perspectives on research participation from pregnant women living with HIV

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Abstract

Pregnant women living with HIV (PWLHIV) are becoming increasingly involved in HIV research; however, the ethical concerns regarding their decision-making in relation to research participation are not well-studied. This qualitative study aimed to understand the perspectives and lived research experiences of PWLHIV, with the goal of identifying important considerations to inform best practices. This study used semi-structured interviews (SSIs) of PWLHIV who participated in research studies in Eldoret, Kenya. All interviews were audio-recorded, transcribed, and translated. Qualitative analyses were performed, with line-by-line coding, constant comparison, axial coding, and triangulation to identify central concepts. Twelve PWLHIV participated**.** Overall, participants had positive experiences with HIV research. Most participants had difficulty distinguishing differences between the research process and enhanced clinical care. They reported a willingness to participate in future HIV research studies and indicated altruism as the primary motivator. Participants identified their preferences and experiences with recruitment, consenting, reimbursement, and enrolment of infants in HIV research. The largest barrier from participating in HIV research was identified as a concern that participation would lead to HIV disclosure. By understanding the lived experiences of PWLHIV who participate in HIV research, future researchers can design studies and consenting processes to optimize ethical research practices.

Keywords: pregnant women, ethical research, qualitative study, Kenya and HIV

Introduction

Despite progress against the HIV/AIDS epidemic globally, young women are still disproportionately affected by HIV, with a prevalence rate three times higher than their male counterparts (Karim & Baxter, 2019). Over 2 million women of childbearing age live with HIV in sub-Saharan Africa (Avert, 2020). Pregnant women living with HIV (PWLHIV) are often excluded from clinical trials of new HIV medications and interventions to minimize PWLHIV's risk of side effects or unintentional outcomes (Krubiner et al., 2016). However, this results in a paucity of data to guide clinical care of PWLHIV, which negatively impacts the practice of evidence-based medicine and health outcomes for this population. To optimize care of PWLHIV and their young children, these populations must be engaged at the inception of research studying new interventions, rather than first awaiting the results of trials involving non-pregnant populations. However, research teams may not feel prepared to manage the ethical considerations when engaging PWLHIV and their children in research studies.

Recently, a systemic review of ethical considerations revealed limited empirical data about PWLHIV's experiences in research. (Corneli et al., 2007; Sullivan et al., 2018). Thus, the purpose of this study was to qualitatively examine the perspectives of current and recently pregnant women living with HIV who had participated in research in Kenya. By understanding and addressing ethical concerns for research as identified by PWLHIV, researchers may become

more informed to design studies with appropriate ethical considerations for PWLHIV and generate the data needed for evidence-based clinical care for PWLHIV and their children.

Methods

Settings:

This study was set within the Academic Model Providing Access to Healthcare (AMPATH) program. AMPATH is a long-standing academic partnership between Moi University School of Medicine, Moi Teaching and Referral Hospital (MTRH), and a consortium of North American academic centers led by Indiana University. PWLHIV were recruited from AMPATH's maternal-child health clinic located at MTRH in Eldoret, Kenya. AMPATH is home to one of the world's largest HIV maternal and paediatric care programs, providing HIV-testing and care for approximately 80,000 pregnant women and 35,000 HIV-infected and HIV-exposed children (Indiana University School of Medicine, 2020). In addition to clinical care, AMPATH also provides the infrastructure for numerous research programs in all aspects of clinical and translational research, garnering over $180 million in awarded studies (AMPATH, 2021).

Study Design:

This qualitative, cross-sectional study utilized a questionnaire and semi-structured interviews (SSIs). The questionnaire was administered to collect demographic information and explore participant's prior research exposure. Qualitative SSIs were adopted to explore the individual experiences related to the study's objective while allowing both the interviewer and study participants to pursue ideas or responses to a greater depth of detail than would be allowed within a questionnaire (Gill, Stewart, Treasure, & Chadwick, 2008; Proctor et al., 2011). The interviewer was an experienced facilitator and received additional training by one of the authors with expertise in qualitative interviews (EM.)

Participants:

Participants for this study were recruited by convenience sampling. Inclusion criteria was as follows: (1) >18 years of age; (2) currently pregnant or <1 year since last pregnancy; (3) speak English or Kiswahili; (4) known to be living with HIV; (5) had previously been enrolled in a research study.

Two studies at AMPATH involving PWLHIV had recently been underway prior to recruitment for this study. While participation in these specific studies was not required for inclusion, all recruited individuals had participated in one of two longitudinal studies that involved PWLHIV recruited from MTRH's maternal-child health clinic. Both studies took place in Eldoret, Kenya through AMPATH. One of the studies was a nested case-control study that required additional lab collections to investigate PWLHIV's risk of developing gestational diabetes compared to non-HIV infected pregnant women, and two women from our study reported participating in this study. The other ten participants came from an epidemiological study focused on observing implementation of prevention of mother-to-child transmission of HIV services. analysing the effects of dolutegravir in PWLHIV (publication forthcoming). Both studies required written informed consent.

Data Collection:

A total of 12 SSIs were held between November 12, 2019, and March 12, 2020. Recruitment for the SSIs was abruptly discontinued due to the COVID-19 pandemic. The facilitator conducted SSIs in Kiswahili or English, the two national languages of Kenya. The interview guides were created by the authors, with questions informed by grounded theory, input from local healthcare providers, a Moi University faculty member from the Department of Sociology Psychology and Anthropology, a U.S.-based paediatric infectious disease researcher, and a systematic review of relevant literature (Raciti et al., 2021). Interview guides included questions related to perceptions of research, experiences with prior research participation, and discussed themes including community and cultural beliefs about HIV, experiences of stigma and discrimination associated with HIV, pregnancy, and potential interventions. Interview guides are available upon request.

The SSIs lasted between 30-90 minutes and were audiotaped. The recordings were transcribed verbatim and translated into English by a trained translator. The translated text was then verified by a separate bilingual (English-and Kiswahili- speaking) research assistant and deidentified. Written informed consent was obtained from study participants. Each participant received US$3 to cover travel expenses. This study was approved by the institutional review board of Indiana University School of Medicine in Indianapolis, Indiana, and by the institutional research and ethics committee of Moi University School of Medicine and MTRH in Eldoret, Kenya.

Data Analysis

The transcripts were analysed to arrive at a contextualized understanding of PWLHIV's perspectives on their participation in research. A priori codes were created and extracted from the interview guide and used as a starting point for data analysis. We then employed constant comparison, axial coding, and triangulation to identify central concepts (Corbin & Strauss, 2014). The initial stage of constant comparative analysis was done by two investigators (C.G.R and A.A.N). Line-by-line analysis was completed to elucidate the meanings and processes regarding the participants' perceptions of their previous participation, enrolment, and consent in research. The investigators coded lines individually using the qualitative analysis software Dedoose—a Web application for managing, analysing, and presenting qualitative and mixed-method research data ("Dedoose," 2020). The same two investigators independently extracted and compared themes to high degrees of agreement between the open codes and the themes extracted. Three investigators (C.G.R, A.A.N., and M.S.M.) performed axial coding—the process of relating categories to their subcategories and linking them together at the level of properties and dimensions—to organize themes into relevant relationships (Corbin & Strauss, 2014). Relevant themes and concepts were developed inductively from the data. Quotes are edited minimally for clarity and provided throughout the results to add descriptive detail and highlight major themes. Quotes are attributed to the research participant, using their age and occupation.

Results

Description of Study Population

Twelve individuals (mean age 38.5 years, range 26-51 years) participated in this study. Ten had a prior pregnancy before participating in research as a PWLHIV, and four of those had experienced a miscarriage or stillbirth during prior pregnancies. The majority (n=7) lived with the father of their child, while others lived alone or with a different family member. Just under half had jobs outside the home, and approximately 40% received education beyond primary school [Table 1].

Perspectives on Research versus Enhanced Clinical Care

Most were unable to identify specific differences between research and what they considered more attentive or enhanced clinical care. Participants noted that when engaging in research-related clinical care, the clinical providers would spend more time talking with them, answering their questions, and ensuring appropriate referrals for services. Participants uniformly expected that clinically relevant information regarding themselves or their baby would be disclosed to them during the course of research participation, including laboratory tests obtained for research. Some respondents viewed their research participation as attentive pregnancy care. One woman said, *"They told me that [they were] coming to see the baby and check how she is doing. So, I was not worried because it is helping since if the baby has any problem, they will discover it early."* (Participant 5, 40 years old). Despite low levels of understanding on distinguishing between research and usual care, many women noted receiving reimbursement for transportation during research, whereas they indicated having to pay money to go to the clinic. Only two women were able to distinguish research from enhanced clinical care, noting the key difference being that research is investigative, whereas clinical care involves intervention. Both of these women had received education beyond primary level. As one participant said, "You know when you come here, you are just given the drugs, but [during] research, they want to know how they can finish HIV." (Participant 6, 42 years old).

Perspectives on Motives Facilitating Participation

Participants expressed that the benefits of research outweigh the risks, with everyone stating a willingness to participate in research again if the opportunity arose. The most common response was altruistic in nature, with every woman describing a desire to help others in their community. The majority agreed to participate without additional personal gain. As one woman expressed, "so long as [it] benefits someone, it will be good." (Participant 7, 26 years old). The women identified their research participation as helping others through enhancing clinical treatment for all HIV patients and reducing the cultural stigma surrounding a positive HIV status.

Other motives for participation were accessible care, health education, reimbursement money, and social support. Participants noted that they had access to medical care through research, such

as medications and testing diagnostics, which they previously lacked. Furthermore, they noted that if the researchers could not provide the care needed within the study context, the participants would be referred by the researchers to seek care from a clinician. Many participants viewed the discussions on research-related medical topics provided by researchers, such as gestational diabetes and prevention of mother-to-child transmission of HIV, as teachings, and the teachings received during research were influential in their decision to participate. Participants had varying thoughts on whether reimbursement impacted their decision. Some participants viewed it as being very influential, while others report a willingness to participate without it. Primary reasons why reimbursement was desired were: 1) they would not have been able to get to the research facility, and 2) they could not have fed themselves or their family during their day of participation.

Perspectives on Concerns and Barriers to Participating

Confidentiality and privacy were identified as major concerns related to research participation. Several described the negative cultural sentiments towards HIV, explaining that if a neighbour learned of their involvement in an AMPATH-related study, many questions would arise about their status. Participants envisioned that community knowledge of their research participation would lead to status disclosure, resulting in discriminatory actions against their children and social stigmatization from the village. As one woman said, *"If you come to me [wearing an] AMPATH T-shirt, and I had never disclosed [my HIV status] to my friends, you know you will have come and disclosed me. If you disclose me to others, people will say, 'So and so has HIV.' People will point fingers at you. Others will discuss you. Others will find you somewhere, and they will insult you."* (Participant 8, 41 years old).

Three women stated that internalized stress related to their HIV diagnosis may also draw concerns for research participation. These women expressed concerns that the stress associated with becoming newly diagnosed with, or being reminded of their HIV status, may harm the fetus. Two of these three participants were diagnosed with HIV during their pregnancies, and one mentioned feeling uncomfortable because she was "*still young in that challenge*." (Participant 6, 42 years old). Additionally, another woman mentioned being more tired during pregnancy, hindering her desire to participate. Moreover, participants said that balancing family obligations with research commitments could be challenging, and if required to pick, they would choose family obligations. However, overall most women expressed no concerns regarding participating in research while pregnant. In fact, as previously noted, some preferred participating in research while pregnant because of the "care" provided. Descriptive quotes illustrating the different facilitators and barriers for research participation are noted in Table 2.

Perspective on Logistical Aspects of Research

Recruitment

Researcher Demographics: All participants preferred that the primary contact and recruiter was a known medical provider due to the sensitivity of their HIV status. If a stranger told them about the research, a few participants noted they would suspicious of how their HIV status became known. Furthermore, some participants stated that if their doctor told them about a research study, they would not refuse. . Participants also desired the initial recruiter to be Kenyan, but the research team to be of mixed nationalities. They believed having internationally collaborative research teams allowed for knowledge sharing and greater access to resources.

Location: As privacy was a significant concern, most women wished to be recruited while in the clinic or hospital rather than within their communities or villages. If researchers came to the villages, participants recommended first asking the chief for permission. Furthermore, participants felt strongly that all conversations regarding HIV-research needed to happen privately, citing concerns that community members may become aware of the individual's HIV status.

Consenting

Most participants lacked an understanding of the topic or nature of the research they participated in, with only three participants able to give a simple description of the study's objective. However, many women admitted being told the study information at enrolment that they had since forgotten. All participants expressed voluntarily enrolling. Most women remembered signing the form, while two individuals had no memory of signing a consent form to participate.

The participants expressed varying levels of understanding the purpose of the informed consent process. Some women gave no explanation. A few women thought it was conducted to explain the study before enrolling, and one participant thought it was for the government to track the number of people living with HIV.

When participating in longitudinal studies, the women thought it would be good to reconsent. As one woman said, *"It is like you started school, then you lacked fees [and left school], then you come back and stand on the door. When you come back, the teacher has the right to renew those things that you studied long ago."* (Participant 7, 26 years old).

Additionally, many women expressed a desire to bring the papers home and think about the study before consenting. There was one participant who preferred signing them in the clinic since the researchers would be present to answer her questions. Many preferred to read the forms themselves rather than being read to by a researcher, and they liked being offered the forms in Swahili or English.

Reimbursement:

Views regarding fair compensation for participation in research varied widely. Some women believed a flat rate was appropriate, whereas others thought that each person's compensation

should depend on the distance travelled. Others thought that reimbursement should be additionally based on the time commitment and number of visits required. One participant stated that researchers should pay as much as possible, whereas another thought the minimum amount would be best.

Subsequent enrolment of infant in research:

All participants were willing to enrol their unborn children and infants participating in research activities, although a few expressed hesitancies if injections or blood samples were needed. The majority (n=9) still expressed a desire to have their newborn participate. As one participant said, "when you take the baby's blood sample, it will help her because if she has a problem, you will find it out, and you will tell me so that we can help her early while she is still young." (Participant 5, 40 years old).

Additionally, most participants (n=8) noted that once the child was born, the decision to enrol the baby should be equally shared between the parents unless the mother is single. When the child is still in the womb, the participants thought the mother should be the key decision-maker.

Discussion

Participant engagement and involvement in intervention development and evaluation are critically important in improving health outcomes (Mkwanazi, Rochat, & Bland, 2017) for the target population. Our qualitative study observed that PWLHIV in Kenya view research participation as beneficial with generally positive experiences. Despite participants' awareness of research's benefit to the community, the majority could not differentiate its purpose from receiving more attentive clinical care. Most notably, many described their research participation as enhanced clinical care and expected to hear the results of the tests performed on them by the study. Altruism was also a leading motivator for participation. However, confidentiality was identified as a primary area of concern from participants living with HIV. This concern fuelled some women's desire to avoid contact with AMPATH staff members in public, for fear of unintentional disclosure of the women's HIV status. By gaining awareness of areas of concern, participant expectations, and addressing them in future research studies, future studies can optimize the ethical conduct of research, which may inform and improve patient care and outcomes.

Many participants viewed research as synonymous with enhanced clinical care. In fact, a number of women thought it was the researcher's obligation to provide medical attention and relay results back to them. These findings align with the therapeutic misconception recorded by other research studies in developing and developed countries (Georgetown, n.d.) Therapeutic misconception exists when participants believe that their individual health care is equally important to producing generalizable knowledge for medical advancements (Henderson et al., 2007). Historically, researchers differentiated research from enhanced clinical care by taking participants through the informed consent process (Kadam, 2017). The informed consent process is done to ensure participants understand the purpose of the study and their role in it, and the potential consequences of their participation (Kadam, 2017). Thus, by the very definition of informed voluntary consent, therapeutic misconception should not exist. Yet, given the reported

responses from this study, the current consent process might not effectively distinguish the intent or intended benefit of clinical research from enhanced clinical care.

Optimizing the informed consent process can be challenging for researchers to balance potential participants' rights to understand the risks and scope of research with the length and complexity required to achieve an adequate level of understanding. Common challenges encountered during the informed consent process are complex information, poor comprehension of consent forms, and patient competence (Kadam, 2017). National Bioethics Advisory Commission's states that participants' expectations must be understood by the researchers before they can participate in research. Formative research increases understanding of potential research participants' expectations and desires for research engagement (Georgetown, n.d.) and helps ensure ethical research design involving PWLHIV in cross-cultural settings. Researchers may also consider clarifying why their research study is different from standard clinical care within the informed consent form.

Fear of confidentiality breaches within research was a major barrier to participation. PWLHIV in low-and middle-income countries (LMICs) or other low-resourced settings experience multiple social risk factors, which prompts women to hide their HIV diagnosis. This is only exacerbated by the lack of education on HIV disclosure (Mkwanazi et al., 2017; Turan, Miller, Bukusi, Sande, & Cohen, 2008). Despite progress in reducing HIV-related stigma, many challenges remain, especially in low-resource settings (Smith et al., 2020). Congruent with recent literature, our participants described fears around participating in HIV-related studies because it could lead to HIV disclosure (Brittain et al., 2017; Smith et al., 2020). Our finding emphasizes the need for confidentiality, which is already a fundamental tenet of ethical research regulations. Participants gave specific examples, such as research teams having to visibly de-identify their association with AMPATH, as the community closely associates the organization with HIV care in western Kenya. There was also the issue of conducting home visits because it risks disclosure. Researchers must continue to remain cognisant of the critical role that HIV stigma may have on research participants within high HIV prevalence regions of the world (McHenry et al., 2017).

Equally important to ensuring confidentiality during the recruitment process is building a good rapport between the participants and research team. In line with recent literature, we found that our participants wanted their initial research contact to be Kenyan (Kochhar et al., 2017; Newington & Metcalfe, 2014) and preferred a healthcare worker who already knew them and their HIV status. This differs from how ethics boards typically want recruitment to be done (Fregonese, 2018). The contrasting views emphasize the need for community involvement to identify effectively responsible recruiting members (Fregonese, 2018). The participants' recruitment desires are likely a result of the stigma associated with being a PWLHIV.

Participants highlighted the importance of having internationally collaborative research teams, as they perceived them to have greater access to resources and new ideas. Collaboration and partnerships among high-income countries and LMICs can play a significant role in ensuring that research promotes global health and supports the appropriate health needs of each location it's serving (Mercer et al., 2018; Millar et al., 2020). The involvement of AMPATH likely influenced their desire for internationally collaborative teams in facilitating the research studies in which they participated. AMPATH's priority is to serve health needs through service,

education, and research, with reciprocity and mutual benefit among its partners (Mercer et al., 2018). This results in a policy for international collaboration of research projects performed within the partnership, which was likely noticed by the study participants and acknowledged as a positive quality of research.

Finally, our participants reported differing viewpoints on reimbursement. While researchers should reimburse travel costs and provide financial compensation for time to prevent overall costs on participants (Molyneux, Mulupi, Mbaabu, & Marsh, 2012), there is no universal consensus on what is acceptable. Researchers should work with local institutional review boards to determine appropriate amounts to minimize any chance of inducement (Mngadi, Singh, Mansoor, & Wassenaar, 2017).

Limitations

This study was limited by its small sample, which was a result of the COVID-19 pandemic. Despite multiple attempts, we could not re-engage and enroll new study participants safely within a reasonable timeframe. Thus, our findings are likely not representative of all PWLHIV. Furthermore, the current study relied on interviews, which can be subject to recall bias. Attempts were made to minimize the degree of recall bias by including participants who partook in a research study within the past year. However, despite the limited sample size, this study brings up important considerations in an area with limited knowledge.

Through mapping the contextual realities of participating in research as a PWLHIV, we learn more about the interplay between cultural context and research. While these results may not be generalizable to all PWLHIV participating in research, important insights were gained, including the perceived benefits of research for both the participant and the larger community. Future work investigating the perception of PWLHIV in the community who refused to participate in research could aid in our understanding of ethical considerations. However, the insights from this study can help guide future research involving PWLHIV to ensure voluntary and ethical participation.

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Declaration of Interests

The author(s) declared not potential conflicts of interest with respect to the research, authorship, and publication of this article.

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Table 1. Participant Characterisitics

Variable	n (%)
Caregiver's Age (in years)	
25-30	2 (17%)
31-35	1 (8%)
36-40	3 (25%)
41-45	5 (42%)
46-51	1 (8%)
Education Level	
Some primary	1 (8%)
Completed primary	6 (50%)
Completed Secondary	2 (17%)
University or additional training	3 (25%)
Occupation	
Homemaker	2 (17%)
Business owner	1 (8%)
Teacher	2 (17%)
Casual Worker	1 (8%)
Farmer	2 (17%)
Unemployed	4 (33%)
Married to Father of Child	
Yes	7 (58%)
No	5 (42%)
Number of Previous Pregnancies	
0	2 (17%)
1	2 (17%)
2	3 (25%)
3	2 (17%)
4	2 (17%)
5	0 (0%)
6	0 (0%)
7	1 (8%)
Learned of HIV Status during Pregnant	
Yes	2 (17%)
No	10 (83%)

N=12

Table 2: Facilitators and Barriers for Research Participation

Facilitators	**Illustrative quotes**
Altruism	*"What they told me is that it will help many other people. So I accepted"* (Participant 5, 40 years old, Housewife) *"Yes. So long as [it] benefits someone, it will be good"* (Participant 7, 26 years old, Unemployed) *"Because it will help many people."* (Participant 4, 41 years old, Teacher) *"You are told to love yourself and your neighbor."* (Participant 11, 26 years old, Housewife)
Clinical care	*"I saw that they were helping us a lot because at times you are worried like; "do I have diabetes? Or what do I have?" but when you get [research], you are helped. Someone tells you; "I can do this for you, we want to know your diabetes status, let us check if you have it or not" so at least you see they are helping you."* (Participant 1, 38 years old, Housewife) *"I will expect the results first. When they tell me the results that is the most important thing."* (Participant 8, 41 years old, Businesswoman) *"You know others could have thought that the baby is [HIV] positive, maybe they have not known that there is medicine [to prevent HIV] because there are others who go to the local clinics; they don't come to the main hospitals. So, some of them do not even get tested and when they come to the hospital, they get tested. They had never been tested before."* (Participant 4, 41 years old, Teacher) *"You know during pregnancy, there are so many problems that we do undergo. So, they came there, it was free, and you were not forced. It was voluntary and you could join if you wished. So, I saw on my own that there is no need for me to refuse because it is my health, and I should know how I am. I was tested and given a card which I went home with."* Participant 12, 32 years old, Housewife)

Teachings and lessons	*"You know one wants the knowledge, yes."* (Participant 9, 44 years old, Farmer)
	"Understanding things better that [otherwise] I could not have understood." (Participant 2, 41 years old, Businesswoman)
	"What will make me agree to participate is wanting to know more about that thing." (Participant 2, 41 years old, Businesswoman)
	"Wanting to know more about new emerging things." (Participant 3, 40 years old, Casual worker)
	"You will have gotten to learn something because even if you were in the house, you would have been there keeping quiet or outside there looking after the baby. But here at least you get something, you learn something and gain certain knowledge." (Participant 1, 38 years old, Housewife)
Reimbursement money	*"So, there are people who will participate because of the money and there are those that will participate without asking for the money."* (Participant 11, 26 years old, Housewife)
	"Yeah. Someone will say, "let me volunteer today. I will be given transport for coming and going back, I will be given lunch there". So even if I take this time, even if it is two hours, that is nothing to me." (Participant 9, 44 years old, Farmer)
	Yeah. It can make it easy. If you tell them that we will make some lunch, you will get lunch here and give you fare, one will make sure that they come. This is because most people come from far. (Participant 2, 41 years old, Businesswoman)
Social support	*"I was to lose hope and then I come here you tell me; "you are not alone, I have worked with many and you are not alone" so if I was losing hope, maybe you hear others have lost hope and they don't want drugs. So through research, you come and they tell you; "we have done this study, you are not alone" they don't tell you names but they tell you they have done it for long and there are many people in that problem. So at least they will give me hope to feel like; "Oh, I am not alone, we are many" and you will take life normal and just continue."* (Participant 12, 32 years old, Housewife)

Barriers	Illustrative quotes
Confidentiality/ privacy	*"They fear for privacy. If there will be no privacy, many of them fear coming out because their information may come out there and they don't want to be known."* (Participant 12, 32 years old, Housewife) *"Let us say now you come with something that shows AMPATH and then you come to my home, I will refuse (laughs). I will not accept."* (Participant 11, 26 years old, Housewife) *"What I am saying is that anything that will make me refuse is something that will expose me either my face or my name and where there is any risk. I will not accept that one."* (Participant 11, 26 years old, Housewife) *"They will start gossiping saying; "so and so is like this and that" it is not good. If the research reaches a level that will make people know your [HIV] status, I will not participate."* (Participant 9, 44 years old, Farmer) *"They must give it to the doctor who works here. They cannot give it anyhow. They must go through the doctor."* (Participant 3, 40 years old, Casual worker) *"Yes. It even brings problems to the children. When you find my [HIV] status is like that and because somebody knew my status and my children are negative, you will even find that my children will be discriminated from other children."* (Participant 11, 26 years old, Housewife) *"They will spread the gossip. They will talk of bad rumors in the village. You see that is our secret, which we finish it here, and no one knows."* (Participant 1, 38 years old, Housewife)
Being pregnant	*"I think stress is usually brought about by the pregnancy itself because when you are not pregnant, you don't get stressed, but when you are pregnant you get a lot of stress. I don't know why."* (Participant 11, 26 years old, Housewife) *"Yes. It was taking around three hours and you had to persevere because you want your wellbeing to be good. For example, we were being told never to eat anything from morning yet you are pregnant and then you had to give out the first blood sample, then stay there and again give out the second blood sample and then the third one and you are expectant. Normally an*

	expectant person would get hungry all the time, but you just had to persevere there so long as something has happened, you had to persevere." (Participant 8, 41 years old, Businesswoman) *"Maybe if she is tired or the distance that person is coming from."* (Participant 9, 44 years old, Farmer) *"You know when one is expectant, they don't want a lot of things. It is tiredness"* (Participant 10, 51 years old, Casual worker)
Balancing family obligations	*"It will depend. Now I have the baby. [If] I came from my house when I had not planned for such, you see that will be a barrier. You see like now I came when it was almost lunch time and then when I come here I get that research that will take three hours and I have the baby, I will not agree."* (Participant 11, 26 years old, Housewife) *"You know everything will stand. For example, my husband is someone who looks for casual jobs. He does construction work. So, when he goes to work, he will come back for lunch, and I will not be there and he will not know how to organize himself."* (Participant 9, 44 years old, Farmer)