

Predictors of Successful Treatment Acquisition Among HPV Positive Women in Western

Kenya

by

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Thesis submitted in partial fulfillment of
the requirements for the degree of Master of Science
in the Duke Global Health Institute
in the Graduate School
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ABSTRACT

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Abstract

Background: While highly preventable cervical cancer remains a leading cause of cancer in women globally. Sub-Saharan Africa is disproportionately affected, and in Kenya specifically, over 4,800 new cervical cancer cases are diagnosed and over 2,000 deaths occur each year. While screening for human papillomavirus (HPV) is a more cost-effective screening strategy with the potential to increase screening uptake, there is substantial lost to follow-up (LTFU) for treatment following a positive HPV screen. This study aimed to identify the predictors of successful treatment acquisition and explore the barriers and facilitators to seeking treatment among HPV positive women.

Methods: This mixed-methods study was integrated into an ongoing cluster-randomized trial of implementation strategies in rural western Kenya. This study randomly selected 100 HPV positive women from the original study database and conducted a treatment acquisition behavior survey. The study sought a 50/50 ratio of women who were treated and LTFU, but obtained data from 61 treated women and 39 LTFU women. A subset of 10 women in each group were then selected for in-depth interviews. Analysis included descriptive statistics to compare treated and LTFU women's responses to the survey questionnaire. Interview transcripts were coded and analyzed through code-by-code comparisons of women who were treated and women who were LTFU.

Results: Cost of transportation and distance to the health facility were the most common challenges in seeking treatment among both treated and LTFU women. Among women who sought treatment, 67% (n=41) reported that their peers knew their HPV test result, whereas among LTFU women only 38% (n=15) reported that their peers knew their HPV test result (p=0.007). There was a significant difference in knowing their peers' HPV result between treated and LTFU women (p=0.03). Partner support was described by treated and LTFU women similarly, in that most women reported that they relied on their partners for transportation money, and that men not understanding the disease may prevent them from supporting their wives in seeking treatment. Additional barriers included fear of the treatment process, stigma within their community, logistical barriers, and lack of information on the disease and treatment. Facilitators to treatment seeking included peer encouragement, support and encouragement of their children, involving men in educational sessions, bringing facilities closer and providing transportation to the health facility.

Conclusions: Cost of transportation, distance to the treatment facility, support of partners and children, feelings of fear and stress, stigma within the community and logistical barriers were reported similarly across treated and LTFU groups. The greatest disparity between the two groups was a lack of social support among LTFU women. Given the potential impact of involving men and women in the community in

educational sessions, and promoting treatment seeking in groups, interventions that use these treatment facilitators are needed.

Dedication

I dedicate this thesis to the women of Migori County who were brave and kind enough to participate in this study, sharing their individual experiences in hopes of improving treatment access for all.

Contents

Abstract.....	iv
List of Tables	xi
List of Figures	xii
Acknowledgements	xiii
1. Introduction	1
1.1 Global disparities of cervical cancer in sub-Saharan Africa.....	1
1.2 HPV as the causal agent of cervical cancer	1
1.3 Simplification of screening strategies to improve uptake	2
1.4 Rationale and study aims	3
2. <i>Methods</i>	4
2.1 Setting.....	5
2.2 Participants	6
2.3 Procedures	7
2.4 Measures	8
2.4.1 Demographics	9
2.4.2 Alcohol and Drug Use	9
2.4.3 Mental Health.....	9
2.4.4 Physical, Sexual or Emotional Abuse	10
2.4.5 Peer Network Beliefs.....	10
2.4.6 Treatment Facilitators and Barriers	10

2.4.7 In-Depth Interview	11
2.5 Analysis.....	12
3. Results.....	13
3.1 Description of the sample.....	13
3.2 Trauma, alcohol and drug use, mental health, and abuse history	15
3.3 Previous treatment seeking experiences	18
3.4 Peer network beliefs and women in community’s thoughts on treatment.....	19
3.4.2 Social support.....	24
3.5 Partner support	25
3.5.2 Children’s support	28
3.6 Fear and stigma.....	28
3.7 Messaging, outreach and knowledge about HPV	30
3.8 Treatment barriers among treated women	32
3.8.2 Treatment barriers among LTFU women	36
3.9 Proposed treatment facilitators among treated and LTFU women	38
4. Discussion	40
4.1 Barriers to successful treatment acquisition	41
4.1.2 Facilitators to successful treatment acquisition.....	42
4.2 Implications for policy and practice	43
4.3 Implications for further research.....	44
4.4 Study strengths and limitations	44

5. Conclusion..... 45

Appendix A..... 46

Appendix B..... 53

List of Tables

Table 1: Sample demographics and characteristics.....	14
Table 2: Mental health symptoms and abuse history	16
Table 3: Peer network beliefs among women who sought treatment and LTFU women	20
Table 4: Treatment facilitators and barriers among women who sought treatment.....	33

List of Figures

Figure 1: Consort diagram of participant's recruitment and enrollment	7
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1. Introduction

1.1 Global disparities of cervical cancer in sub-Saharan Africa

Cervical cancer is a preventable disease, yet remains a leading cause of cancer in women worldwide. Each year over 520,000 women are diagnosed with cervical cancer, resulting in more than 260,000 deaths, or (740 women dying every day).[1, 2] Over 440,000 cases occur in less developed regions.[3] Sub-Saharan Africa carries a high burden of deaths with a mortality rate of 85%.[4] While cervical cancer is among the leading causes of cancer in women globally, it is the leading cause of cancer in women in sub-Saharan Africa and Kenya with breast cancer following close behind.[5, 6] In Kenya alone, there are over 4,800 new cervical cancer cases, and 2,000 deaths due to cervical cancer each year.[6] It is projected that in 2030 there will be nearly 140,000 new incident cases diagnosed in sub-Saharan Africa that year, a 90% increase in the region.[7] A lack of effective screening and treatment strategies is a leading cause of the high burden of cervical cancer deaths in low-income countries.[8]

1.2 HPV as the causal agent of cervical cancer

Nearly all cases of cervical cancer are caused by human-papillomavirus (HPV), and while most HPV infections resolve naturally, persistent infection can lead to precancerous lesions.[9] The HPV vaccine provides the potential for future reduction in the cervical cancer burden globally, however vaccine rollout in LMICs has been slow,

and women infected with oncogenic HPV prior to vaccination are still at risk of developing cervical cancer later in life.[10] It is therefore essential that secondary prevention methods of screening and treatment be implemented at the population level. For most women, persistent HPV infections and untreated precancerous lesions take over a decade to develop into cervical cancer, a process that is often asymptomatic, yet detectable through either cytology or HPV-based screening.[1, 2]

1.3 Simplification of screening strategies to improve uptake

The World Health Organization and the Kenya Ministry of Health recommend HPV screening as a feasible and cost-effective strategy for low-resource settings.[11-13] As far as cervical cancer screening and early detection in Kenya, cervical cytology (PAP) and visual inspection with acetic acid (VIA) are the most commonly recommended guidelines but are not generally available at the public primary health level.[14] However, in Kenya only 3.5% of all women aged 25-64 are screened every three years for cervical cancer as recommended.[6] Strategies to address the barriers to implementation of the WHO guidelines for screening and treatment are being tested in pilot programs and a few larger scale-up initiatives using self-collected HPV testing and visual inspection with acetic acid (VIA) as the primary tools for screening for precancerous lesions.[15, 16] Low-resource countries such as Kenya have had to adjust their screen and treat strategies and have moved toward cost-effective HPV testing,

followed by treatment with cryotherapy for HPV positive women.[9] While the screen and treat strategy is a vastly simplified screening protocol compared to that used in high-resourced countries, there remain significant barriers for follow-up visits. The convenience of self-testing has vastly improved screening uptake,[15, 17, 18] but necessary follow-up visits for cryotherapy increase the chance of loss to follow-up for treatment.[15, 19]

Few studies have been conducted to determine best methods for reducing loss to follow-up after a positive HPV screen.[20-23] One study in Tanzania is currently looking into whether or not SMS reminders will decrease loss to follow-up for treatment following a positive HPV screen.[24] Several scale-up initiatives in Guatemala, Nicaragua and Honduras are moving towards electronic records tracking of screen-positive women to improve treatment uptake.[15, 24]

1.4 Rationale and study aims

Despite simplifying screening in rural settings there are still significant barriers to treatment. Screening programs will remain ineffective at reducing the cervical cancer burden if follow-up and treatment are inefficient or inaccessible.[10] Although relatively low-cost, it is not feasible to supply and maintain functioning of cryotherapy equipment and ensure trained providers in each rural village health clinic.[19] While it is generally known that reducing the number of visits is helpful in reducing loss to follow up (screen

and treat strategy), little research has been conducted on strategies aimed at improving attendance at follow-up visits for women with positive screening results.[9] The increased sensitivity of HPV that leads to the improved cost-effectiveness of HPV-based strategies will be lost if only low numbers of women follow-up.[25]

Identifying predictors of seeking treatment for HPV positive women could improve our ability to provide better linkage to treatment strategies in the future. To address the evidence gap, this study aimed to identify factors that affected treatment seeking among screen-positive women who sought treatment and who were LTFU. Secondly, this study aimed to qualitatively explore the barriers and facilitators to treatment seeking behavior among HPV positive women. Barriers and facilitators investigated included social support, partner support, logistical barriers, education and awareness, and previous health seeking experiences. Findings from this study have the potential to influence future screen and treat strategies implemented at the population level in low-income countries.

2. Methods

This mixed-methods study was integrated into an ongoing cluster-randomized trial of implementation strategies for cervical cancer screening among women in rural western Kenya. In the parent study, women were offered screening for HPV using self-collected swabs in either community health campaigns or clinics. Women were offered

the choice of receiving their results via text message, phone calls, home visit, or clinic visit. Any woman who tested positive for HPV was referred to the County Hospital for treatment with cryotherapy, according to WHO guidelines. For the study described in this paper, we administered a treatment acquisition behavior survey among 100 HPV positive women. HPV positive participants in the parent study were stratified and then selected randomly to try to achieve 50 who had acquired treatment and 50 who were LTFU for treatment. We then followed up with in-depth interviews (IDIs) with 10 women in each group. Women were selected for IDIs based on their survey responses; ensuring interviews were conducted with women who shared diverse experiences in treatment seeking.

2.1 Setting

The study was conducted between August and November of 2017. The study took place in rural villages throughout Migori County, located within Nyanza Province in Western Kenya. The two most common languages spoken are Dholuo and Kiswahili. Census data from 2009 indicate the population of Migori County is 917,170 residents, with 51.6% male and 66.2% rural.[26] Migori County has a high dependency ratio, with 0-14 year-olds constituting 50% of the total population.[27] Only 15% of Migori County residents have completed secondary level education or above, with 65% of residents completing primary education only and 20% of residents with no formal education.[27]

2.2 Participants

In the main study, twelve communities were randomized to offer screening to women aged 25-65 in either government health facilities (control) or community-health campaigns (intervention). For this study, women who tested positive for HPV and who had not yet participated in other in-depth interviews for the study were randomly selected from the parent study database. We sought a 50/50 ratio of women who underwent treatment with cryotherapy, and women who were LTFU for treatment. We defined lost to follow-up as women who had initially engaged in care through screening and received their HPV test result and had not yet accessed treatment. We initially identified 132 eligible women (66 in each arm, respectively) to reach our target of 100 women for the survey, assuming we would not reach all women for interviews. 79 women from the list of 132 were reached and surveyed. An additional 80 additional women were identified (40 from each arm, respectively) to reach 100 women willing to participate. We did not stratify recruitment based on original study assignment. The survey was conducted with 37 women from the clinic arm and 63 women from the community-health campaign arm. See figure 1 for a breakdown of participant selection.

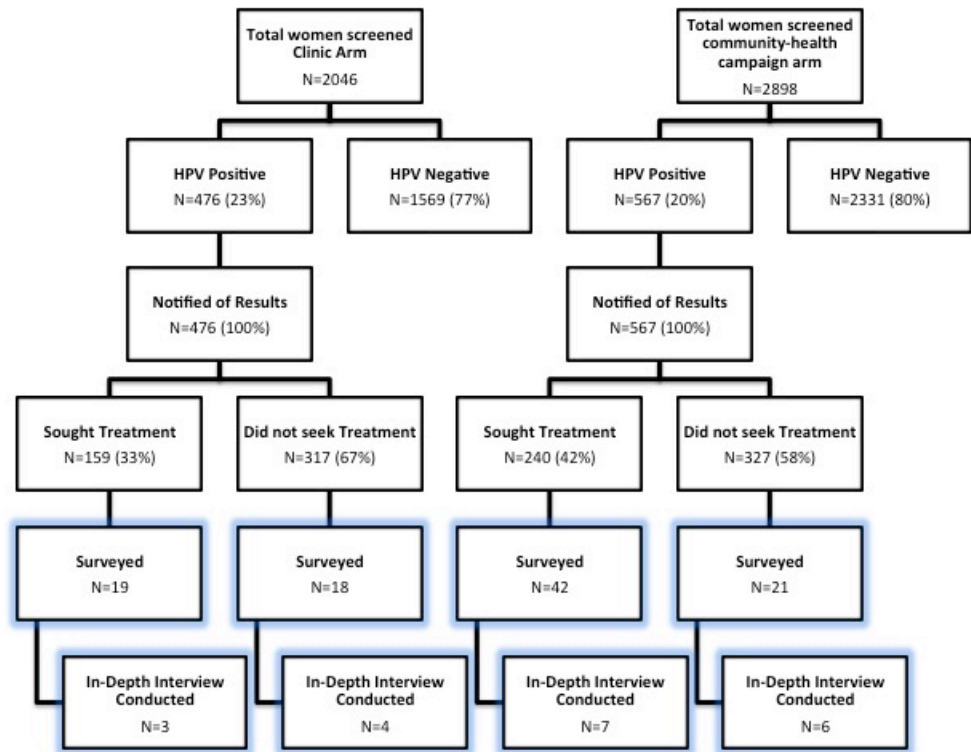


Figure 1: Consort diagram of participant’s recruitment and enrollment

2.3 Procedures

Survey Questionnaire: A Dholuo speaking female research assistant obtained oral consent from women interviewed by phone and written consent from women interviewed in person; surveys were conducted orally with research participants. Consent covered both the quantitative questionnaire and their possible participation in a follow-up IDI. Responses were recorded on tablets using Open Data Kit (ODK)

software.[28] The average length of time for the survey was 12 minutes and seven seconds, which included taking time to explain the questionnaire, obtain consent and conduct the survey. Participants were not offered compensation for completing the surveys and were reminded that they may be approached for a follow-up in-depth interview. See Appendix A for the treatment acquisition survey.

In-depth Interview: Participants for IDIs were selected based on their survey responses to ensure the most diverse responses possible. A Dholuo speaking female research assistant conducted oral in-depth interviews with research participants in person. Consent was reaffirmed. Interviews were conducted in a private space using a semi-structured interview guide (see Appendix B). Interviews were recorded, and handwritten notes were taken to assist with accurate transcription. The average length of time to complete the in-depth interview was 33 minutes.

The study received ethical approval from the Kenya Medical Research Institute (KEMRI) and Duke University. All women provided written or oral informed consent for participation in the survey and in-depth interviews.

2.4 Measures

Survey Questionnaire: The survey questionnaire consisted of 82 questions developed specifically for the study. Subsections of the questionnaire included demographic characteristics, alcohol and drug use, mental health, abuse history, peer

network beliefs, and treatment. The questionnaire was translated from English to Dholuo and all surveys were conducted in Dholuo. Referral systems were in place for women who reported alcohol and drug use, mental health or abuse history. The research assistants piloted the survey with one-another prior to implementing the tool with participants.

2.4.1 Demographics

Ten questions about demographic characteristics were asked, including age, relationship status, whether or not women earned their own income, occupation, religion, number of children, number of pregnancies, and education level.

2.4.2 Alcohol and Drug Use

Four questions on drinking habits and three questions on drug use were asked. Examples include how often a participant drinks alcoholic beverages, if drinking alcoholic beverages had impacted their ability to make decisions, whether or not they had tried recreational drugs, and whether or not the use of recreational drugs had impacted their ability to make decisions. Recreational drugs included cannabis (*bhang*), khat (*miraa*), cigarettes, cocaine, heroin, and ecstasy.

2.4.3 Mental Health

Five questions on mental health were asked; mental health related questions included how often a participant had felt down, depressed, or hopeless, whether they

had been diagnosed with depression, sought help for depression or wish they had sought help for their depression. This section was influenced by the PHQ-2, but questions were asked with slightly different wording after piloting the questionnaire with the study team.[29]

2.4.4 Physical, Sexual or Emotional Abuse

The abuse history sub-section included seven questions about physical, mental and emotional abuse by a partner at any time in the past. This section also assessed whether this abuse occurred in the past six months, as well as if they sought help for that abuse at any time.

2.4.5 Peer Network Beliefs

The peer network beliefs sub-section included twenty-one questions and assessed whether the participants partner, peers and/or family knew of their HPV status, and whether or not they felt embarrassed, ashamed, upset or angry if their partner, peers and/or family knew of their test result. This section also explored whether or not the participant knew of their peers HPV status and if they felt comfortable speaking about their HPV status with close friends and/or family.

2.4.6 Treatment Facilitators and Barriers

The treatment sub-section included seventeen questions about previous healthcare seeking experiences. This section specifically asked whether the participant

sought treatment. If the participant sought treatment for HPV following their diagnosis, they were asked why they sought treatment, what made them uncomfortable about treatment, whether or not they would have recommended seeking treatment to their peers, who accompanied the participant to treatment, and various questions related to partner support throughout the treatment process. Participants who sought treatment were also asked about transportation, distance to health clinic, and acquiring money for transport. Participants who did not seek treatment were asked whether they are planning to seek treatment and what had caused them to delay in seeking treatment.

2.4.7 In-Depth Interview

The semi-structured interview guide included 15 questions with the following subsections: demographic characteristics, thoughts and experiences regarding treatment seeking, treatment seeking challenges, and improving treatment uptake. The IDI guide was translated from English to Dholuo and all interviews were conducted in Dholuo. The first section explored the participants' individual experiences in seeking treatment for any illness in the past, as well as what thoughts the participant had when they first learned their HPV status, and what factors were most important when deciding whether or not to seek treatment. The second section explored factors that prevent women from seeking treatment, what role men played in seeking treatment, what travel to the treatment facility was like, and how current decision making may have been impacted

by past events or their current household dynamics. The third section asked for participant feedback about how treatment access, messaging, and outreach can be improved. The concluding section collected demographic information such as age, relationship status, occupation, and education level. The research assistants piloted the IDI with one-another prior to conducting the IDI with participants.

2.5 Analysis

Data from the treatment acquisition behavior survey were imported into SAS statistical software (version 9.4, Cary NC USA) for analysis. Descriptive statistics, including frequency tables and crosstabs for categorical variables and distributions for continuous variables were used to describe the demographic and other characteristics of the sample. Comparisons between treated and LTFU women were presented, including p-values for significant values or values trending towards significance. For continuous variables p-values were obtained using Wilcoxon test, and p-values for categorical variables were calculated with a Fishers Exact.

The IDIs were recorded, transcribed, and then translated from Dholuo to English. The codebook included both structural codes developed using the semi-structured interview guide, and inductive codes, developed by reviewing interview transcripts until saturation was reached. Saturation was reached when there were no new themes presenting themselves in the transcripts, which took place after reviewing 12 transcripts.

Data were analyzed with NVivo (version 11.4.0). An inter-coder agreement exercise was conducted with a researcher unaffiliated with the project with the intent of pointing out coding discrepancies and adjusting the original codebook. A meeting to discuss differences in coding, as well as make updates to the codebook took place after the inter-coder agreement was conducted. The first author using the modified codebook then coded all 20 interviews. The analysis process focused on developing code-by-code comparisons of women who were treated and women who were LTFU for treatment. Coded segments were reviewed for each code, separated by group (treated and LTFU), with data read closely to develop a thick description of the data comparing treated and LTFU groups.

3. Results

3.1 Description of the sample

The median age of the samples was 35 and 40, for LTFU women and treated women, respectively. There were no significant differences in any of the demographic characteristics comparing women who followed-up for treatment and those who were LTFU (see Table 1, below). In both groups, almost two thirds were married and one-third widowed/divorced. There is a trend toward lower education levels in the LTFU group, as well as a trend toward LTFU women being more likely to be the primary income earner for their household.

Table 1: Sample demographics and characteristics

Table 1: Sample demographics and characteristics			
Demographic Characteristics	Sought Treatment N= 61 N (%) or Median (IQR)	LTFU N= 39 N (%) or Median (IQR)	Exact P-Value
Age (years)	40 (32.0-43.0)	35 (30.0-40.0)	0.15
Relationship Status			
Married	37 (60%)	24 (61%)	
Relationship Living Separate	1 (2%)	0 (0%)	
Single	1 (2%)	1(3%)	
Widowed/Divorced	22 (36%)	14 (36%)	
Occupation Earning Income			0.68
Yes	25 (41%)	14 (36%)	
No	36 (59%)	25 (64%)	
Occupation Type (N=39)			0.38
Professional/Managerial	2 (8%)	0 (0%)	
Agriculture and Fishing	5 (20%)	3 (22%)	
Manual	4 (16%)	0 (0%)	
Sales and Services	13 (52%)	9 (64%)	
Other	1 (4%)	2 (14%)	
Primary Income Earner (N-39)			0.18
Yes	14 (56%)	11 (79%)	
No	11 (44%)	3 (21%)	
Religion			
Christian	61 (100%)	39 (100%)	
Have Children			0.68
Yes	58 (95%)	36 (92%)	
No	3 (5%)	3 (8%)	
Number of Children	4.5 (2.0-6.0)	4 (2.5-4.5)	0.20
Number of Pregnancies	6 (3.0-8.0)	5 (3.5-7.0)	0.84
Education Level			0.10
Primary	45 (74%)	34 (87%)	
Secondary	14 (23%)	4 (10%)	
Tertiary/College	2 (3%)	0 (0%)	
Other	0 (0%)	1 (3%)	

*IQR – Interquartile range

*LTFU – Lost to follow-up

3.2 Trauma, alcohol and drug use, mental health, and abuse history

In the survey, there were no significant differences between women who sought treatment and those who were LTFU in reported substance use, depression or intimate partner violence. Nearly all participants reported they never drink alcohol and had never tried recreational drugs.

Among women who sought treatment approximately 16% (n=10) reported feeling down, depressed or hopeless in the past two weeks, (3% almost every day, 5% most days, and 8% several days). None of these 10 women had been diagnosed with or sought help for depression. Among women who were LTFU for treatment approximately 31% (n=12) reported feeling down, depressed or hopeless in the past two weeks (18% almost every day, 5% most days, and 8% several days, $p=0.09$). Of these 12 women, 1 was diagnosed with depression, sought help for that depression and felt that seeking help was somewhat useful. Table 2 (below) presents data on intimate partner physical, sexual or emotional abuse history among treated and LTFU women. There were no significant differences between the groups regarding abuse history.

During the in-depth interviews women talked about previous life experiences that may have shaped current health consequences and health-related behavior. Treated

and LTFU women responded similarly and stated that when they were younger they engaged in sex recklessly (e.g., often, with many men and without protection) and were irresponsible. Women cited being diagnosed with diseases such as HIV and HPV as reasons for making changes in their behavior. Referencing HIV and HPV, a treated woman said, *“I’m not engaging into sex recklessly because those two diseases are sensitive to that.”* Some women reported they were no longer engaging in sex at all, some reported a new faithfulness to their partner, and others reported an overall sense of responsibility they now have as adults.

Most women had experienced a traumatic life event, although it was cited more often in the LTFU group. Traumatic life experiences included HIV diagnosis, death of a child, partner or close relative; or medical emergency. Several LTFU women cited a traumatic event as a reason for delaying seeking treatment for HPV. One LTFU woman referred to her inability to retrieve the phone number to make an appointment for treatment and said, *“I lost my son recently and we are kind of being in a mess, I will not be able to retrieve it.”*

Table 2: Mental health symptoms and abuse history

Table 2: Mental health symptoms and abuse history			
Mental Health and Abuse History	Sought Treatment N= 61 N (%)	LTFU N= 39 N (%)	Exact P-Value

Mental Health			
Down, depressed or hopeless in past 2 weeks			0.10
Almost everyday	2 (3%)	7 (18%)	
Most days	3 (5%)	2 (5%)	
Several days	5 (8%)	3 (8%)	
Never	51 (84%)	27 (69%)	0.39
Diagnosed with depression	0 (0%)	1 (3%)	
Yes	61 (100%)	38 (97%)	
No			
Sought help for depression	0 (0%)	1 (100%)	
Yes	0 (0%)	0 (0%)	
No			
Seeking help useful	0 (0%)	1 (100%)	
Somewhat			
Abuse History			0.79
Partner physical abuse	11 (18%)	6 (15%)	
Yes	50 (82%)	33 (85%)	
No			1.00
In past 6 months	3 (27%)	2 (33%)	
Yes	8 (73%)	4 (67%)	
No			1.00
Sexual abuse by anyone	3 (5%)	1 (3%)	
Yes	58 (95%)	38 (97%)	
No			
In past 6 months	3 (100%)	1 (100%)	
Yes	0 (0%)	0 (0%)	
No			0.78
Partner emotional abuse	9 (15%)	7 (18%)	
Yes	52 (85%)	32 (82%)	
No			0.31
In past 6 months	5 (56%)	6 (86%)	
Yes	4 (44%)	1 (14%)	
No			1.00
Sought treatment for any abuse in past	1 (2%)	0 (0%)	
Yes	60 (98%)	39 (100%)	
No			
*IQR – Interquartile range			
*LTFU – Lost to follow-up			

3.3 Previous treatment seeking experiences

In the survey among women who sought treatment 98% (n=60) reported they visited a health facility when sick (59% always, 20% very often, 3% somewhat often, 16% rarely; see table 4 below). In the IDIs nearly all treated and LTFU participants reported HIV treatment and testing being part of their previous treatment seeking experiences. Seeking treatment for malaria, ulcers, cholera, high blood pressure and typhoid were also mentioned frequently among participants. Treated women and LTFU women similarly reported being happy and satisfied with their previous healthcare experiences, and believed for the most part that the healthcare professionals did all they could to help them. Women were unsatisfied with the cost of drugs, lack of acceptance of the national health insurance, and long travel distance required to reach a health clinic. Regardless of the additional distance required to reach a hospital most participants sought treatment at a hospital, rather than a community health clinic or traditional healer, which are generally easier for participants to access. Among women who visited community health clinics, most were LTFU women who reported visiting these facilities due to the ease of walking on foot and not needing to pay for transport. For example, one LTFU woman said, *"I: Where did you get treated? P: At the dispensary health center which is affordable and closer because there was a hospital there that belongs to a particular white man*

which is very expensive leading to crowding at the dispensary.” Another LTFU women explained her preference in visiting a health dispensary: “I: Did face any challenge? P: I never observed any, it’s a short distance and fare is not required. You can go on foot even if you are sick.”

During the IDIs, women reported the main reason for not seeking treatment for illness in the past was lack of money for drugs or transport to the health facility. Procrastination and laziness were other common responses. Women stated that feeling pain or discomfort from illness symptoms was what drove them to seek treatment in the past. Most women mentioned being accompanied by someone in previous healthcare seeking experiences, typically a husband or close relative. Overall, very few women reported having been to Migori County Hospital, and those who had been there were mostly treated women who had been there infrequently.

3.4 Peer network beliefs and women in community’s thoughts on treatment

In the survey treated and LTFU women responded to a series of questions regarding feelings of shame, embarrassment and anger over their partner, peers and/or family knowing their HPV test result. Significant results included: Among women who sought treatment, 67% (n=41) reported that their peers knew their HPV test result, whereas among LTFU women only 38% (n=15) reported that their peers knew their HPV

test result ($p=0.007$). Among women who sought treatment, 61% ($n=37$) reported that their family knew their HPV test result, whereas among LTFU women only 38% ($n=15$) reported that their family knew their HPV test result ($p=0.04$). There were also significant differences in how treated and LTFU women felt about talking about their test results with close friends/family (see Table 3, below).

Among women who sought treatment, 82% ($n=50$) reported they knew peers who were tested for HPV and 90% ($n=45$) knew their peers' HPV status; whereas among women LTFU for treatment, 69% ($n=27$) reported they knew peers who were tested for HPV and 67% ($n=18$) knew their peers' HPV status. There was a significant difference between treated and LTFU women who knew their peer HPV test result ($p=0.027$).

Nearly all participants reported that the method by which they learned their peers' HPV status was through their peers telling them directly.

Table 3: Peer network beliefs among women who sought treatment and LTFU women

Peer Network Beliefs	Sought Treatment N= 61 N (%)	LTFU N= 39 N (%)	Exact P-Value

Does partner know HPV result			0.22
Yes	39 (64%)	20 (51%)	
No	22 (36%)	19 (49%)	
How did partner find out			
I told him	39 (100%)	20 (100%)	
Embarrassed partner knew result			
Yes	0 (0%)	0 (0%)	
No	39 (100%)	20 (100%)	
Ashamed partner knew results			1.00
Yes	1 (3%)	0 (0%)	
No	38 (97%)	20 (100%)	
Angry partner knew result			1.00
Yes	0 (0%)	0 (0%)	
No	39 (100%)	20 (100%)	
Do your peers know your HPV result			0.007
Yes	41 (67%)	15 (38%)	
No	20 (33%)	24 (62%)	
How did peers find out			1.00
I told them	40 (98%)	15 (100%)	
Other (they knew b/c participant was sick)	1 (2%)	0 (0%)	
Embarrassed peers knew result			0.47
Yes	40 (98%)	14 (93%)	
No			
Ashamed peers knew results			
Yes	41 (100%)	15 (100%)	
No			
Angry peers knew result			0.47
Yes	40 (98%)	14 (93%)	
No			
Does your family know HPV result			0.0404
Yes	37 (61%)	15 (38%)	
No	24 (39%)	24 (62%)	
How did your family find out			1.00
I told them	36 (97%)	15 (100%)	
Someone else told them	1 (3%)	0 (0%)	
Embarrassed family knew result			1.00
Yes	2 (5%)	0 (0%)	
No	35 (95%)	15 (100%)	

Ashamed family knew results	2 (5%)	0 (0%)	1.00
Yes	35 (95%)	15 (100%)	
No			
Angry family knew result	0 (0%)	0 (0%)	
Yes	37 (100%)	15 (100%)	
No			
Do you feel comfortable talking about result with close friends/family			.0123
Yes comfortable with everyone	36 (59%)	13 (33.3%)	
Comfortable with some people	18 (30%)	13 (33.3%)	
Not comfortable with anyone	7 (11%)	13 (33.3%)	
Did any peers get tested for HPV	50 (82%)	27 (69%)	0.17
Yes	11 (18%)	11 (28%)	
No	0 (0%)	1 (3%)	
Do not know			
Did you know your peers HPV status	45 (90%)	18 (67%)	0.027
Yes	5 (10%)	9 (33%)	
No			
How did you find out about peers HPV status	44 (98%)	17 (94%)	0.49
They told me	0 (0%)	1 (6%)	
Someone else told me	1 (2%)	0 (0%)	
Other (heard they were going to Migori for treatment)			
*IQR – Interquartile range			
*LTFU – Lost to follow-up			

In the IDIs nearly all treated women reported they knew friends and/or family who were diagnosed with HPV, and all those women also reported that those friends and/or family members sought treatment and shared their experience with them. These results were different in the LTFU group, where very few LTFU women knew friends and/or family members who were diagnosed with HPV, and therefore knew few people who had sought treatment. Nearly all treated women expressed their interest in sharing

their experience in a group setting to encourage other women to go for treatment, and nearly all LTFU women said they were interested in hearing from those who had been through the treatment process.

Treated women spoke about their friends' and/or families' experiences in seeking treatment in detail. When describing their friends' and families' experiences they knew the method of transportation they used, knew that they had a painless and simple procedure, that they had discharge post-treatment, and knew why they decided to seek treatment. Treated and LTFU women said the person they knew who had experienced screening and/or treatment was a close friend or a co-wife in a polygamous household, other relatives were not mentioned often. LTFU women were more vague in their responses about friends' and/or families' treatment seeking experiences or reasons for seeking treatment. Most knew only that they went to improve their health, and that they were happy with the experience.

Most treated women cited peer encouragement as a reason for seeking treatment and said that women organized to go to treatment together, and talked openly about taking control of their health and stopping the disease before it becomes deadly. A treated woman said, *"I used to share a lot with friend who encouraged me that we should use that opportunity productively. So we made a decision to participate and get treated."* Another treated woman said, *"We normally story in a group and during that period we encourage one*

another to seek treatment not to be a victim of risks associated with HPV.” There were several LTFU women who had been invited by other women to join them for treatment but did not have money for transport. *“Yes, we did encourage ourselves and made a promise that if possible will go for treatment as a group. But we allowed those of us who were ready to go. That is if you have transport ready.”* Overall treated and LTFU women provided different responses on individual experiences regarding peer encouragement.

3.4.2 Social support

During the IDI’s treated women talked about having social support at nearly three times the rate as LTFU women. Treated women more commonly said they have a trusted friend or family member that they can lean on for support. Social support was in many ways all-encompassing, women referred to having someone to talk to about their health, as well as someone to help with household chores and duties while away for treatment, and even had someone to attend treatment with. There were very few LTFU women who cited having someone to lean on for support, or that they had a trusted friend or family member that could help in the coordination of attending treatment. A LTFU woman referred to feeling alone in this endeavor saying, *“Yes, I have relatives and friend who are well off, but the haves never mixed well with the have not. They make promises which they never fulfill, so there is no need, we have to survive on our own.”*

3.5 Partner support

In the survey among women who sought treatment, 51% (n=31) reported their partner asked how he could support them in terms of seeking treatment, 16% (n=10) said he did not ask and 33% (n=20) did not have a partner. Among the 41 participants who had a partner, 78% (n=32) reported they personally asked their partner to be part of the treatment process. Among the 9 women who did not ask their partner to be a part of the treatment process, 56% (n=5) reported their partner would have helped them get treatment had they asked. Table 4 (below) presents the details pertaining to partner support among treated women.

During the IDIs women's comments on whether partners were supportive in encouraging and/or enabling women to seek treatment were conflicting, with some women reporting receiving support and others reporting a lack of support. When women talked about partners being supportive, it was usually in the context of providing money for transportation to the treatment facility. Some treated women said their husbands either encouraged them to seek treatment or accompanied them to the treatment facility.

"P: When I received the SMS that I tested positive I shared that with my husband and I could observe fear in him. I was brave to tell him that it's a normal disease like the others and it can be treated. So that compelled me to seek treatment as first as possible.

I: What else encouraged you to seek treatment?

P: I shared with my husband my treatment appointment date and he was very happy about that. The only challenge we had was lack of money to get me to Migori, so I explained to

him the challenge of missing treatment appointment, and he immediately promised to borrow that money from a friend. That was so gracious of him, I have to mention that..."

Most women felt that they must rely on their husbands for transportation funds, because women did not earn enough income to support that. Some women felt that if they told their husbands ahead of time, they would be able to help with household duties and childcare. One LTFU woman explained the conflicting support dynamics saying, *"It depends with an individual, some will only provide that money when you are almost dying. They get to their senses when their friends challenge them to be responsible. Others take it as their own responsibility and my husband I'm sure will support me."*

When women discussed lack of support from their partners, it was usually in the context of men being uninformed or misinformed about HPV. Due to their lack of knowledge of HPV, women felt that men were less inclined to encourage their partners to seek treatment and were less inclined to provide funds for transport to the treatment facility. Additionally, several women mentioned that if men knew they had to wait for sex for a while after treatment, they might not let their partner go to the treatment facility. Women also discussed the issue of men assuming women are going out to prostitute if they leave for extended periods of time. A treated woman said, *"You may share with him your test results, and because they are not that well informed about it, he will discourage you not to go for treatment because of ignorance making you believe that those are just rumors."* Additionally, women cited polygamy as a reason for a lack of partner support.

A LTFU woman recited her experience relying on her partner to provide transport costs saying, *“You can’t do that with a polygamous man, you have to have your own sources. He doesn’t care or he’s not aware of money issues affecting us. We are five of us, can you depends on a man like that? No. You have to have your own sources of income to support your family.”*

When women talked about decision-making in the household, most treated women said their husbands are the primary decision maker, while more LTFU women reported being the primary decision maker. Most women reported they talk about things as a family and they do not feel pressure from anyone in the household regarding decisions about their health.

All women provided recommendations on improving partner support for treatment seeking, and involving men in counseling with their wives and including men in conversations about cervical cancer were overwhelmingly encouraged. A LTFU woman said, *“We should love each other, that will enable us to bear each other’s burden, and if we can engage men they’ll understand that this disease does not come because of prostitution. So we should counsel couples together.”* Many women felt that if researchers and health professionals talked to men themselves about the risks of cervical cancer, men would be more receptive to the information than if it came from their wives.

3.5.2 Children's support

In the IDI's equal proportions of treated and LTFU women shared their HPV test result with their children, and had similar comments on the experience. Among women who shared their result with their children, most said their children were worried and stressed about their mother's positive HPV test result. Women reported that those emotions influenced their decision to seek treatment; because they wanted to reduce the worry and stress their children were feeling. LTFU women said it has been painful that they have not yet sought treatment because they want to be healthy enough to continue taking care of their children. A treated woman said:

"P: Yes, I shared with my first son and he was very worried and that stressed me a lot that he may be thinking that I might die.

I: Did that influence your decision to seek or not seek treatment?

P: Yes, that encouraged me to get treated to eliminate stress in them."

Women who did not share their result with their children cited not wanting to scare them, or children no longer living in the household as reasons for keeping their test result quiet. They did say that had they shared their result with their children, they would have been supportive by providing funds for transport or performing household duties for the day so their mother could attend treatment.

3.6 Fear and stigma

In the IDIs fear was mentioned in both groups; in most cases it was about a fear of dying after receiving their positive HPV diagnosis. Some women reported they feared

the treatment process, that it would be painful or lead to complications later. Several women said that counseling eliminated fear they had, that more information about the disease helped quell their worry about dying or seeking treatment. Women spoke about their close relatives, such as children and husbands being fearful after learning of their positive HPV result. Many women felt that fear was a normal reaction, and the only way to reduce fear was to provide more information about HPV. Treated women's reactions to their HPV test result typically included the word "*stressed*". LTFU women used much less emotional language about their HPV test result, usually citing their lack of financial capacity to reach the treatment facility. Women were stressed about the prospect of death, stressed because cancer cannot be treated, stressed because they are a single parent, and stressed because cancer is a dangerous and killer disease. Treated women reported stress even after receiving treatment because they did not have a follow up visit to confirm the HPV was gone.

Stigma within the community often came up when participants referenced concern that men and women in the community would mistake them as a prostitute for seeking treatment. A treated woman said, "*We are facing a lot of challenges in our families because at time our men think we are going out to prostitute, so some of us even if they test positive will not even think of going for treatment because of such.*" One participant explained that HPV is so new that nobody is talking about it.

In addressing stigma, treated women encouraged healthcare providers to keep health matters private, to make sure treatment is uniform across all patients, and to support and counsel women to access treatment. LTFU women were more open with their responses on addressing stigma and recommended bringing facilities and services closer to them to keep their status private. They recommended engaging couples together so that men understand this disease does not come from prostitution. Additionally, LTFU women felt that continued sharing of their treatment experiences would help eliminate stigma related to HPV in the community.

3.7 Messaging, outreach and knowledge about HPV

In the IDIs women generally agreed that the content of the messaging was clear and correct, but they felt going door to door would ensure the HPV test result and treatment instruction makes it to all women. Participants reported the use of SMS could have been scary for some women, and that some women experienced challenges with SMS or phone calls. There were mixed reports about whether the messaging content was scary; some women felt their previous HPV counseling prepared them for the messaging, while others felt it was normal to be scared and that additional counseling could potentially remedy the fear. Many women reported that even though they had some counseling on HPV during screening, when they got their positive HPV test result

they immediately assumed they had cancer. A treated woman reflected on receiving her result saying:

“I did receive my message at the clinic; yes some of us do like SMS and other do not because the SMS do scare them. In my opinion even me I don’t like receiving that result on my own, I will prefer to be with others while receiving it to know that I’m not the only one who is affected.”

Nearly all treated women reported understanding their test result and treatment explanation. This is likely because treated women had been through the treatment process and had better recall. Overall treated and LTFU women knew very little about the treatment process upon receipt of their positive HPV diagnosis. Women generally knew that treatment was free; that it was taking place at Migori County Hospital and that there was a number they needed to call to schedule the appointment. This was expected since during the education and counseling sessions prior to screening, there was limited instruction on the treatment process. Different from the treated group LTFU women reported losing the phone number to schedule an appointment, and said they received very little counseling on treatment, if any, as one participant said she received her test result without any counsel on treatment.

Women generally knew the risk involved with HPV, but some women struggled to understand the difference between having HPV versus cervical cancer. Women knew that cancer cannot be cured and if HPV is diagnosed early enough it can be treated, but that was the extent to their HPV knowledge. Most women openly stated they do not

have enough information on HPV and would like additional information and counseling. *“They only showed us picture on how the infection develops and spread. Then they began screening. Some of us were still not convinced to participate.”*

Women provided information on which sources they felt were the most reliable in receiving information about HPV and cervical cancer. Nearly all women reported wanting to hear from other treated women in the community in the form of women groups, to learn the benefits and risks involved in receiving treatment. Doctors, nurses and other healthcare professionals in the field were also reliable sources of information, and some women felt they were the only people who could provide accurate information. Many women reported not trusting community health leaders, saying they should not be too involved in their health, that community health leaders are not professionals in this field, that they are not well informed about HPV, and that they cannot keep secrets.

3.8 Treatment barriers among treated women

In the survey, women who sought treatment were asked in which ways treatment made them feel nervous or uncomfortable and of the 69 women who sought treatment 49% (n=30) reported there were none and 27% (n=17) reported they were worried about the cost of transportation to the health facility. Other responses included they thought treatment would be painful 15% (n=9), they were not sure the treatment

would work 3% (n=2), they were embarrassed to have a pelvic exam 2% (n=1), they feared people would learn they were HPV positive 2% (n=1), and feared community gossip about treatment 2% (n=1).

Nearly all treated participants reported that the trip to the treatment facility was long and that it was difficult to get money for the trip to the treatment facility. The most common form of transportation to the treatment facility among women who sought treatment was public transportation 92% (n=56), with motorbike being the only other recorded response 8% (n=5). Approximately 38% (n=23) of women reported getting their transportation fare from their partner, 26% (n=16) paid for it themselves, 18% (n=11) got it from another close relative, while other responses included getting fare from a friend (6%), and from their children (2%). Table 4 (below) presents details discussed in this section.

Table 4: Treatment facilitators and barriers among women who sought treatment

Sought Treatment (N=61) Facilitators and Barriers	N (%)
Frequency of health facility visit when sick	
Always	36 (59%)
Very Often	12 (20%)
Somewhat Often	2 (3%)
Rarely	10 (16%)
Never	1 (2%)
Reason sought treatment	
To prevent cervical cancer	31 (51%)

Health worker told me to	22 (36%)
Knew it would be good for me	4 (7%)
I had symptoms	2 (3%)
My partner encouraged me	2 (3%)
In which ways did treatment make you feel nervous or uncomfortable	
None	30 (49%)
Worried about cost of transportation	17 (27%)
Thought it would be painful	9 (15%)
I was not sure it would work	2 (3%)
Embarrassed of having a pelvic exam	1 (2%)
Fear people would learn I am HPV positive	1 (2%)
Other (fear b/c of how people were talking about treatment)	1 (2%)
Recommend seeking treatment to peers	
Yes	61 (100%)
Who accompanied to treatment	
Nobody	43 (71%)
Family member	7 (11%)
Partner	7 (11%)
Friend	4 (7%)
Why have someone accompany to treatment (N=18)	
Wanted emotional support	9 (50%)
Other	5 (28%)
They wanted to come	3 (17%)
I needed help getting home	1 (5%)
Has partner asked how he can support in terms of seeking treatment	
Yes	31 (51%)
No	10 (16%)
No Partner	20 (33%)
Did participant ask for partner to be part of treatment process (N=41)	
Yes	32 (78%)
No	9 (22%)
Would partner have helped get treatment if participant had asked (N=9)	
Yes	5 (56%)
No	4 (44%)
Method of transportation to get to treatment	
Motorbike	5 (8%)
Public transportation	56 (92%)
Was the trip from home to treatment facility long	
Yes	59 (97%)

No	2 (3%)
Was it difficult to get money for trip to treatment facility	
Yes	59 (97%)
No	2 (3%)
Where did participant get transportation fare from	
Partner	23 (38%)
Self	16 (26%)
Other close relative	11 (18%)
Other	6 (10%)
Friend	4 (6%)
Children	1 (2%)

In the IDIs, the biggest challenges faced by women who sought treatment were the cost of transport and distance to the treatment facility. Women were asked about the cost of the trip to Migori County Hospital and the time it took to get to the treatment facility from their home. Among treated and LTFU women the cost ranged between \$5-\$18 USD (500ksh-1800ksh) round-trip, and the trip duration one-way ranged between 1hour-6hours. One woman said, *“Yes, lack of money to get there. Money is everything and once you have it everything is possible, you get all the services you need.”* Another said, *“The only challenge we faced was money for transport. We didn’t even have the fare to get back home; we had to seek help from friends. She was not that happy with that but I had to encourage her.”* A small number reported hearing myths about HPV treatment, mainly that they may not be able to bear a child in the future. Negative influence of other people was limited among treated women, although a couple of participants mentioned that other women shared negative sentiments about treatment, discouraged others and stigmatized others not to seek treatment. Logistical challenges were also a problem, including a doctor’s strike that took place during the treatment window and electricity problems, which shut down the cryotherapy machines.

3.8.2 Treatment barriers among LTFU women

In the survey among women who were LTFU for treatment, 95% (n=37) reported they were still planning to seek treatment. Cost was the primary reason for delaying in seeking treatment with 62% (n=24) of women reporting this barrier. Approximately 5%

of women (n=2) cited travel distance and 5% (n=2) cited not knowing the treatment place as being barriers. The remaining 28% (n=11) cited other reasons such as logistical barriers, doctor and nurse strike, mechanical problems at treatment facility, fear of partner learning their HPV status, and losing the phone number needed to schedule the treatment appointment. Apart from the main reason for delaying in seeking treatment, additional barriers included not knowing the treatment location, being unsure they needed treatment, laziness, pregnancy, and being told treatment was over and no longer available.

In the IDIs, LTFU women regularly cited cost of transport and distance to the treatment facility as the primary barrier to seeking treatment, which was similar to the treated group. Treated and LTFU women agreed the trip to Migori Hospital is long and costly. Most women reported being comfortable taking public transportation and traveling long distances as long as they can afford it. Women reported that household duties would be put on hold for the day due to the long nature of the trip. Generally, women seemed comfortable with leaving household chores and duties for the day, because it was a necessary part of the process. Most women reported they had never been to Migori town, and among treated women the treatment visit was the first time they had visited Migori Hospital. Women expressed their concerns about the round-trip nature of the treatment process, as the roads were bumpy, causing some pain and discomfort after receiving treatment.

LTFU women frequently said they lacked information about treatment and needed more counseling, a difference from the treated group. One LTFU participant said, *“I didn’t have enough money for transport and anybody who could make things clear to me”*. Several LTFU women mentioned their partners acting as barriers to accessing treatment, one participant stated, *“Some are just afraid...we are scared of death, while others the information should not reach their men.”* Other barriers to treatment among LTFU women included losing the phone number to make an appointment, false beliefs that treatment would lead to wounds, and receiving negative information about treatment from others in the community.

3.9 Proposed treatment facilitators among treated and LTFU women

In the survey, when treated women were asked what their reason for seeking treatment following a positive HPV diagnosis was, 51% (n=31) reported it was to prevent cervical cancer and 36% (n=22) reported a health worker told them to. Other responses included they knew it would be good for them 7% (n=4), they had symptoms 3% (n=2), and their partner encouraged them to seek treatment 3% (n=2).

All treated participants said they would recommend treatment to their peers. Women were asked about bringing someone to accompany them during treatment and 71% (n=43) reported going alone, 11% (n=7) reported taking a family member, 11% (n=7) reported taking a partner and 7% (n=4) reported taking a friend. When asked why they had someone accompany them, of the 18 women who had someone accompany them, 9

reported they wanted emotional support, 3 reported the person wanted to come with them, 1 reported they needed help getting home, and 3 (n=5) reported other reasons including they were going to the treatment facility from the same area. Table 4 (below) presents the proposed treatment facilitators among treated women.

During the IDIs treated and LTFU women provided personal reasons for seeking treatment, or reasons for wanting to seek treatment. Most treated women cited influence of others as a reason for seeking treatment. Influence of others consisted of encouragement from peers, partners, neighbors, children, health professionals and co-wives in polygamous households. A treated woman referenced her child encouraging her to seek treatment saying, *"The 15 year old really encouraged me because he witness a teacher suffering from cervical cancer. He has been pleading with me to get treated."* Another treated woman said, *"What encouraged me were what my friend shared and the possibility that if the disease is detected early enough it can be treated, so I had to try my luck."* On the other hand, very few LTFU women were encouraged by friends' and/or relatives' to seek treatment, and instead reported wanting to be healthy as their reason for wanting to seek treatment, which was also mentioned among treated women.

All participants proposed facilitators to improving treatment seeking among HPV positive women. Providing money for transport, providing a vehicle to shuttle women to the hospital in groups, and bringing the health services closer to them were overwhelmingly the most recommended treatment facilitators. Women also

recommended providing food incentives to lower the cost involved and restore their energy after a long trip to Migori County Hospital. A LTFU participant stated:

“Maybe we are still challenged in terms of money for transport. By just welcoming you for counseling means we’ve accepted the message of health, but if I don’t want it, it’s simple, I’ll just give wrong contacts, not accepting your call, or blacklisting your contacts in my phone. I’m willing it’s only that I’m still challenge financially.”

Nearly all participants mentioned additional counseling either by health professionals or from women who underwent treatment, as proposed treatment facilitators. Treated women overwhelmingly volunteered to share their experience with their peers to encourage them to seek treatment, and LTFU women wanted to hear from treated women about their experiences.

“Engaging them in a group is more effective than dealing with individuals. I’m comfortable being with the others when I’m being engaged in this kind of issues. Being on your own is stressing a lot ... because we are always on our own after receiving that result, no nurse or doctor to talk to.”

Several women mentioned the necessity of including men in the counseling to galvanize support for seeking treatment. Both treated and LTFU women encouraged health professionals to go door to door to deliver results and encourage women to seek treatment.

4. Discussion

The study highlights that improving screening methods alone does not solve the issue of reducing loss to follow-up for treatment. To reduce the cervical cancer burden, improved screening and treatment interventions are needed. In the parent study, only 33% of women in the clinic arm and 42% of women in the community health campaign

arm sought treatment following their positive HPV diagnosis. The aim of this study was to understand the barriers and facilitators these women faced in seeking treatment.

4.1 Barriers to successful treatment acquisition

The study found that cost of transportation and distance to the treatment facility were the primary barriers to seeking treatment among all participants. This finding is consistent with that of several other studies that explored barriers to follow-up for treatment.[9, 22, 30, 31] In the survey 62% (n=24) of LTFU women reported cost as the primary barrier to seeking treatment. Cost of transport and distance to the health facility were barriers that did not differ between the two groups. Additional similarities in barriers between treated and LTFU women were logistical barriers, lack of partner support, facing stigma within the community and experiencing feelings of stress and fear; similar findings have been reported previously in other studies.[20, 22, 31]

Differences between the groups included a lack of knowledge of HPV and the treatment process among LTFU women, which was also found in a recent study conducted in Peru.[20] LTFU women were less afraid and concerned about their positive HPV test result compared to their treated counterpart and had a greater chance of being affected by a traumatic life event. LTFU women were also less likely to have visited a hospital in previous treatment seeking experiences and had never visited Migori County hospital where the treatment was taking place, a factor that could have influenced their decision to attend Migori County Hospital for treatment.

One of the most prominent differences between the two groups was the disparity in social support and peer networks. The survey found that treated women were significantly more likely to have known their peers HPV test result, and were more likely to talk with close friends and/or family about their test result. Treated women were significantly more likely to have shared their test result with their family and peers, and were also more likely to have shared the result with their partners. In the in-depth interviews nearly all treated women knew friends and/or family who were diagnosed with HPV and who shared their treatment experience with them; treated women were able to reference their peers treatment experiences in great detail. LTFU women rarely had someone to lean on for support, to share their test result or experiences with, and were rarely encouraged by others to seek treatment unlike the treated group. Social support appears to be a dominant disparity between the two groups of women, and should be taken into account when creating future strategies aimed at improving follow-up for treatment. This finding was similar to that in other studies, which found that lack of social support was a potential barrier to follow-up care.[23, 32]

4.1.2 Facilitators to successful treatment acquisition

Given cost of transport and distance to the health facility were the overwhelming challenges to treatment seeking, most proposed facilitators involved bringing services closer to the community or providing transport vehicles or vouchers. While most

women were aware of the risk of HPV, many felt that they could have benefitted from increased counseling on the disease and treatment, and that should be done in groups and with men included.

Treated women stressed the impact social support had on encouraging women to seek treatment. Many women discussed meeting in groups to discuss their health, and traveling in groups to the treatment facility. Treated women reported a desire to share their experiences with other women to encourage them to seek treatment, and LTFU women reported wanting to hear from treated women about their experiences. Lack of social support was a clear barrier among LTFU women, and a clear proposed facilitator to treatment among all women. Using social support as a facilitator for treatment seeking has been proposed in other studies in the past, supporting this finding.[9, 31]

While partner support did not differ between groups, most women felt that including partners in educational sessions about HPV would help garner support for treatment seeking and eliminate the misconceptions partners have about the disease. This finding was similar to other studies that showed women generally need approval or support from their partners to access health services.[9, 31]

4.2 Implications for policy and practice

Cervical cancer while preventable remains a significant burden among women in low-resource settings. In recent years steps have been taken to improve access to

screening, primarily through offering low-cost and convenient self-sampling for HPV testing. Identification of barriers and facilitators to treatment seeking among HPV-positive women has the potential to reduce the substantial loss to follow-up for treatment. The results from the survey and in-depth interviews with treated and LTFU women suggest that there are complex barriers to treatment seeking among women in rural western Kenya. Future studies should aim address logistical concerns, increase educational awareness among all community members, and use social support as a means to address women in groups and allow peer encouragement to drive health-seeking behavior.

4.3 Implications for further research

Little research has been conducted on perceived barriers and facilitators to follow-up treatment following a positive HPV screen, as this is a relatively new screening strategy in LMICs. Further research is needed to determine the relative contribution of the numerous factors examined in this study. Future instrument tools should look at the effect of social support, partner support and increased education and awareness on seeking treatment.

4.4 Study strengths and limitations

A strength of this study is that it sought and obtained qualitative data from an infrequently sampled group – rural women in East Africa, allowing them to use their own voices to tell their own stories in a way that could shape healthcare delivery plans.

Another strength is the use of mixed methods, including the use of the survey questionnaire to inform selection of women for in-depth interviews based on their survey responses.

A limitation of the study is that we only included women who were located in Migori County; therefore, generalization of the results is limited. Our results were similar to findings in other locations, so it is possible this information is generalizable to other low-resource settings.

5. Conclusion

This study has helped fill a gap in knowledge of barriers and facilitators to treatment seeking among HPV positive women in sub-Saharan Africa. Its findings underscore the importance of addressing logistical barriers like cost of transportation and distance to the health facility. Additionally, the study highlights the importance of addressing the potential benefits of engaging men and women in community settings to allow peer encouragement to assist in decreasing LTFU seen with a two visit screen and treat strategy. Treated women expressed their relief in being able to successfully access treatment, and LTFU women expressed eagerness to get to the treatment facility. There is a need to develop new interventions that are able to overcome the substantial barriers women in rural communities face when accessing treatment after a positive HPV screen. Existing knowledge on partner support, peer support networks, demand for increased

education and awareness, effect of stigma, and emotions of fear and stress should be consulted when developing new interventions.

Appendix A

Community-Based HPV Testing Treatment Acquisition Behavior – Survey

<p>Participant ID: _____</p> <p>Date: ____ / ____ / _____</p> <p style="text-align: center;">dd mm yyyy</p> <p>Interviewer: _____</p>
<p>Interviewer: “Thank you for taking the time to meet with me today. My name is _____ and I am going to ask you some sensitive questions. I am looking to obtain a better understanding of potential limitations to you seeking treatment, feel free not to answer if you are uncomfortable. I would like to tape record your answers during the interview if that is okay with you”.</p>

A. DEMOGRAPHIC CHARACTERISTICS

1. How old are you?	Age In Years: <input style="width: 30px; height: 20px; margin-right: 10px;" type="text"/> <input style="width: 30px; height: 20px;" type="text"/>
2. What is your current relationship status?	<ul style="list-style-type: none"> 1. Married 2. Living with a partner 3. In a relationship and living separate 4. Single, not in a relationship 5. Widowed/Divorced

3. Do you earn income outside the home?	1. Yes 2. No [If NO, skip to Q6]
4. Are you the main income earner in your household?	1. Yes 2. No
5. What is your occupation?	Agriculture and Fishing Sales and Services Housewife Manual Professional/Managerial Other (specify) _____
6. What is your religion?	Christian Muslim None Other (specify) _____
7. Have you had children?	Yes No [If NO, skip to Q10]
8. How many children do you have?	Number of Children: <input type="checkbox"/> <input type="checkbox"/>
9. How many times have you been pregnant?	Number of Pregnancies: <input type="checkbox"/> <input type="checkbox"/>
10. What is the highest level of education you have completed?	1. Primary 2. Secondary 3. Tertiary college 4. University 5. Other

B. ALCOHOL AND DRUG USE

11. How often do you have a drink containing alcohol?	1. Never [If NEVER, skip to Q15] 2. 2-4 times a month 3. 1-3 times a week 4. 4 or more times a week 5. Daily
12. Have you ever felt bad or guilty	1. Yes

about your drinking?	2. No
13. Have you ever felt the need to seek help for your drinking habits?	1. Yes 2. No
14. Has drinking alcohol ever impacted your ability to make decisions?	1. Yes 2. No 3. I don't know
15. Have you ever tried recreational drugs?	1. None [If NONE, skip to Q17] 2. Cannabis (Bhang) 3. Khat (Miraa) 4. Cigarettes/ tobacco 5. Cocaine / crack 6. Heroine 7. Ecstasy 5. Other, specify _____
15b. How often?	1. Once a month or less 2. 2-4 times a month 3. 1-3 times a week 4. 4 or more times a week 5. Daily
16. In the past 2 months, has your drug use impacted your ability to make decisions?	1. Yes 2. No 3. I don't know

C. MENTAL HEALTH

17. Over the past two weeks, how often have you felt down, depressed, or hopeless?	1. Never 2. Several days 3. Most days 4. Almost every day
18. Have you ever been diagnosed with depression?	1. Yes 2. No [If NO, skip to Q22]
19. Have you ever sought help for your depression?	1. Yes 2. No [If NO, skip to Q21]
20. How helpful was it to seek help for your depression?	1. Very 2. Somewhat 3. Not very beneficial

	4. Not beneficial at all
21. If you did not seek help, do you wish you did?	1. Yes 2. No

D. ABUSE HISTORY

22. Has a partner (husband, boyfriend) ever physically harmed you?	1. Yes 2. No [If NO, skip to Q24]
23. Has it happened in the past 6 months?	1. Yes 2. No
24. Has anyone ever forced you to have sex or do something sexual against your will?	1. Yes 2. No [If NO, skip to Q26]
25. Has this happened in the past 6 months?	1. Yes 2. No
26. Has a partner (husband, boyfriend) ever emotionally harmed you?	1. Yes 2. No [If NO, skip to Q28]
27. Has this happened in the past 6 months?	1. Yes 2. No
28. Have you sought treatment for any physical, sexual or emotional abuse?	1. Yes 2. No

E. PEER NETWORK BELIEFS

29. Did you receive your HPV result?	Yes No I don't know [if I DON'T KNOW or NO - End Survey]
30. Were you diagnosed with HPV?	Yes No [If NO, skip to Q47] I don't know [If I DON'T KNOW – End Survey]
31. Does your partner know you have HPV?	Yes No [If NO, skip to Q36]
32. How did your partner find out about your HPV status?	1. I told him 2. Saw a text message 3. Saw me with a health worker 4. Someone else told him

	5. Other
33. Were you embarrassed your partner knew of your HPV status?	1. Yes 2. No
34. Were you ashamed your partner knew of your HPV status?	1. Yes 2. No
35. Were you upset or angry your partner knew of your HPV status?	1. Yes 2. No
36. Do your peers know you have HPV?	1. Yes 2. No [If NO, skip to Q41]
37. How did your peers find out about your HPV status?	1. I told them 2. Saw a text message 3. Saw me with a health worker 4. Someone else told them 5. Other
38. Were embarrassed your peers knew of your HPV status?	1. Yes 2. No
39. Were you ashamed your peers knew of your HPV status?	1. Yes 2. No
40. Were you upset or angry your partner knew of your HPV status?	1. Yes 2. No
41. Does your family know you have HPV?	1. Yes 2. No [If NO, skip to Q46]
42. How did your family find out about your HPV status?	1. I told them 2. Saw a text message 3. Saw me with a health worker 4. Someone else told them 5. Other
43. Were you embarrassed your family knew of your HPV status?	1. Yes 2. No
44. Were you ashamed your family knew of your HPV status?	1. Yes 2. No
45. Were you upset or angry your family knew of your HPV status?	1. Yes 2. No
46. Is your HPV result something you feel comfortable speaking with close friends/family about?	1. Yes comfortable with everyone 2. Comfortable with some people 3. Not comfortable with anyone

47. Did any of your peers get tested for HPV?	<ol style="list-style-type: none"> 1. Yes 2. No [If NO or I DON'T KNOW, skip to Q50] 3. Don't Know
48. Did you know of your peers HPV status?	<ol style="list-style-type: none"> 1. Yes 2. No [If NO, skip to Q50]
49. How did you find out about your peers HPV status?	<ol style="list-style-type: none"> 1. They told me 2. I saw a text message 3. I saw them with a health worker 4. Someone else told me 5. Other <p>END SURVEY for those NOT diagnosed with HPV</p>

F. TREATMENT

50. If you are sick, how often do you go to a health facility?	<ol style="list-style-type: none"> 1. Always 2. Very Often 3. Somewhat Often 4. Rarely 5. Never 6. Don't Know
51. Did you seek treatment after your HPV diagnosis?	<ol style="list-style-type: none"> 1. Yes [If YES, answer through 62 then end survey] 2. No [If NO, skip to Q63]
52. Why did you seek treatment?	<ol style="list-style-type: none"> 1. A health worker told me to 2. I had symptoms 3. To prevent cervical cancer 4. I knew it would be good for me 5. My partner encouraged/told me to 6. My friends encouraged/told me to 7. My family encouraged/told me to 8. I don't know
53. Apart from the procedure, was there anything that made you feel uncomfortable or nervous about seeking treatment?	<ol style="list-style-type: none"> 1. Fear people would learn I am HPV positive 2. Embarrassed to have pelvic exam 3. I wasn't sure it would work

	<ul style="list-style-type: none"> 4. I thought it would be painful 5. Worried about cost of transportation 6. Worried about cost of treatment 7. No 8. Other, specify _____
54. Would you recommend seeking treatment to your peers who are HPV positive?	<ul style="list-style-type: none"> 1. Yes 2. No
55. Who accompanied you to your treatment?	<ul style="list-style-type: none"> 1. Friend 2. Partner 3. Family member 4. Nobody [If NOBODY, skip to Q57]
56. Why did you have someone go with you?	<ul style="list-style-type: none"> 1. I wanted the emotional support 2. I needed someone else help me get home after 3. They wanted to come 4. Other
57. Has your partner asked how he can support you in terms of seeking HPV treatment?	<ul style="list-style-type: none"> 1. Yes 2. No 3. No partner (If NO PARTNER, Skip to Q59)
58. Did you ask your partner to be a part of the HPV treatment?	<ul style="list-style-type: none"> 1. Yes [If YES, Skip to Q59] 2. No
58b. If no, would he have helped you get HPV treatment if you had asked?	<ul style="list-style-type: none"> 1. Yes 2. No 3. I don't know
59. What form of transportation did you use to get to your HPV treatment?	<ul style="list-style-type: none"> 1. Public transportation 2. Family member drove me 3. Friend drove me 4. Motorbike 5. Walked 6. Other, specify _____
60. Was the trip from your home to Migori for treatment long?	<ul style="list-style-type: none"> 1. Yes 2. No
61. Was it difficult to get money for	<ul style="list-style-type: none"> 1. Yes

your trip to Migori for treatment?	2. No
62. Where did you get money to travel to Migori?	1. Myself 2. My partner 3. My children 4. Friend 5. Another close relative 6. Other, specify _____ END survey for those who sought treatment
63. Are you planning on seeking treatment?	1. Yes 2. No
64. What has been the main reason you have delayed seeking treatment?	1. Cost 2. Travel/Distance 3. Fear 4. I did not know where to get treatment 5. I was not sure I needed treatment 5. People told me not to get treatment 6. Went to traditional healer 7. Other (specify) _____
65. Apart from the main reason, what were other reasons you delayed seeking treatment?	1. Cost 2. Travel/Distance 3. Fear 4. I did not know where to get treatment 5. I was not sure I needed treatment 5. People told me not to get treatment 6. Went to traditional healer 7. Other (specify) _____ [END SURVEY]

Appendix B

Treatment Acquisition Behavior In-Depth Interview Guide

A. THOUGHTS AND EXPERIENCES REGARDING TREATMENT SEEKING

1. What is your personal experience in seeking treatment for other illness/disease in the past? (Allow them to fully explain their experience, what the treatment was for, etc. before probing)

Probes:

- a. Where did you get treated?
 - b. What parts of seeking treatment were positive?
 - c. What parts were difficult?
 - d. Do you think the doctors and nurses did things to make accessing treatment easier? What did they do? What more could they have done?
 - e. How would you improve the experience?
 - f. Did you bring friends or family with you?
 - g. Have you been diagnosed with other illness/disease (mentioned above) in the past, but did not seek treatment?
 - h. What kinds of things made you seek or not seek treatment?
2. Do you have close relatives or friends that were diagnosed with HPV?
 3. Did those close relatives/friends who were diagnosed with HPV seek treatment and talk to you about it?

Probes:

- a. How did they get to the clinic of treatment?
 - b. Why do you think the believed treatment was important?
 - c. What did they say about the experience?
 - d. Were there things that influenced their decision or ability to get treatment?
 - e. Did you or others encourage/support them in their decision to seek treatment?
 - f. Did you think about going with them to the clinic?
 - g. If NO – Did they express why they did not seek treatment?
 - h. Did you or anyone else discourage them from seeking treatment?
4. What thoughts did you have when you found out you had a positive HPV test and that you needed treatment?

Probes:

- a. Did you understand what treatment is?
- b. Did you understand what the process is like?
- c. Did you know where to get treatment?

- d. Did you get enough counseling when you had your HPV testing done?
 - e. Were you fearful?
 - f. Did you hear from other people in the community what treatment was like?
5. What factors were most important in helping you make the decision to seek treatment?
- Probes:
- a. Of these factors, which would *most* influence your decision?

B. TREATMENT SEEKING CHALLENGES

6. What factors do you think would prevent you from getting treatment?
- Probes:
- a. Of these factors, which would *most* influence your decision?
7. Are there other factors that you or other women in the community face that would make it harder to seek treatment?
8. What is transportation to treatment facility like?
- Probes:
- a. What treatment facility did you attend / would you attend if you sought treatment?
 - b. Do you feel comfortable taking public transportation?
 - c. Do you feel comfortable traveling long distances?
 - d. Would you feel more comfortable if someone came with you for the trip?
 - e. How do you feel about traveling twice in one day (round trip) to the treatment facility and back?
 - f. How much does it cost to get to the treatment facility?
 - g. Do you worry about the money it costs to travel to a treatment facility?
 - h. Does it take a long time for you to get there and does the time away from home cause a problem?
9. What role do men play in seeking treatment? (Ask about their personal experience with their partner).
- Probes:
- a. In what ways could men be supportive?
 - b. Are there ways in which men prevent women from seeking treatment?
 - c. Are there ways in which we can encourage men to be more supportive or helpful in accessing treatment?
 - d. Do women typically rely on men to provide money for transportation?

- e. Are men willing to provide money for transportation?
- f. Are men willing to watch the children for the day while women go to seek treatment?
- g. Do men want to accompany women to treatment?

10. Do you have children?

Probes:

- a. How many? How old are they?
- b. Were you worried about their perceptions of your HPV diagnosis?
- c. Did that influence your decision to seek or not to seek treatment?
- d. Were your children, if old enough, willing to help with household duties for the day so that you could go to treatment?
- e. If old enough, did they or would they provide money for transportation for treatment?

11. Do you believe events in your past have shaped your ability to make decisions related to sexual behavior and health?

Probes:

- a. What were the events? Were they related to sexual trauma, alcohol/drug use, pregnancy complications, etc.?
- b. Why do you believe the event(s) impacts your ability to make health-related decisions?
- c. Have you healed from that event? Did you seek treatment to help you navigate through that event?
- d. Are you able to lean on anyone for help? Do you have a trusted friend/family member who can help?

12. Who is the primary decision maker in your household?

Probes:

- a. Do you feel comfortable making decisions regarding your health?
- b. Do you feel pressure from anyone in your household when making decisions regarding your health?
- c. If yes – who? What is that experience like?

C. IMPROVING TREATMENT ACQUISITION

13. What can be done to improve treatment access?

(If necessary – can bring up some ideas that have been used in other places, but let them answer completely first: Examples to bring up include: transportation vouchers, treatment “navigators”, mobile treatment units, SMS and phone reminders, involvement of community leaders, husbands/male partners, friendly health care providers.

Probes:

- a. In your opinion, which would be the most effective in improving access for women?

14. How do you think we can improve messaging and outreach for those who are HPV positive and need to seek treatment?

Probes:

- a. Are there ways in which the messaging seems scary?
- b. Are there ways in which messaging seems incorrect?
- c. Are there ways in which messaging is too complicated?
- d. Do you think there are ways to make treatment less stigmatizing?

15. What do you think is the best way to mobilize women to get treatment?

Probes:

- a. What do women know about HPV, the risk of HPV and treatment for HPV?
- b. What do you think about community meetings where women share their screening and treatment experiences?
- c. Who would you like to hear from about the screening and treatment process? (Healthcare workers, other women in the community, community leaders)
- d. What is the best way to approach women about HPV and Cervical Cancer?

D. DEMOGRAPHIC CHARACTERISTICS

1. How old are you?	Age In Years: <input type="text"/> <input type="text"/>
2. What is your current relationship status?	<ul style="list-style-type: none"> 1. Married 2. Living with a partner 3. In a relationship and living separate 4. Single, not in a relationship 5. Widowed/Divorced
3. What is your occupation?	<ul style="list-style-type: none"> 1. Agriculture and Fishing

	<ul style="list-style-type: none"> 2. Sales and Services 3. Housewife 4. Manual 5. Professional/Managerial 6. Other (specify) _____
<p>4. What is the highest level of education you have completed?</p>	<ul style="list-style-type: none"> 1. Primary 2. Secondary 3. Tertiary college 4. University 5. Other

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