HHS Public Access

Author manuscript

J Clin Epidemiol. Author manuscript; available in PMC 2021 April 01.

Published in final edited form as:

J Clin Epidemiol. 2018 August ; 100: 32–43. doi:10.1016/j.jclinepi.2018.04.012.

Age, HIV status and research context determined attrition in a longitudinal cohort in Nigeria

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Abstract

Objective: We explored determinants of attrition a longitudinal cohort study in Nigeria.

Study Design and Setting: We enroled 1,020 women into a prospective study. Of these, 973 were eligible to return for follow-up. We investigated the determinants of attrition among eligible

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Author Contributions

EOD contributed to the study design, coordinated the study implementation and data collection, conducted the data analysis and drafted the manuscript. SNA contributed to the study design, interpretation of the results and drafting the manuscript. ORE, EMO, MKO facilitated the qualitative studies and contributed to writing the manuscript. RAO and YO contributed to study implementation. PDP supervised the data analysis and provided critical revisions to the manuscript. CAA had the idea for the study design, obtained funding, supervised all aspects of the study and provided critical revisions of the manuscript. All authors approved the final version of the manuscript.

Declaration of interests.

All authors declare that there are no competing interests.

women using a sequential mixed methods design. We used logistic regression models to compare the baseline characteristics of responders and non-responders. At the end of the parent study, we conducted 4 focus group discussions and 8 key informant interviews with non-responders

Results.—Of the 973 women included in the quantitative analysis, 26% were non-responders. From quantitative analysis, older women were less likely to drop out than younger women (reference: women ≤30 years; OR 0.46; 95%CI 0.30 – 0.70, p<0.001 women 31–44 years; and OR 0.31; 95%CI 0.17 – 0.56, p<0.001 women ≥45 years). HIV-positive women were also less likely to drop out of the study (OR 0.45; 95%CI 0.33 – 0.63, p<0.001). From qualitative analysis, contextual factors that influenced attrition were high cost of participation, therapeutic misconceptions, inaccurate expectations, spousal disapproval, unpleasant side effects, challenges in maintaining contact with participants and difficulties in locating the study clinic.

Conclusion: Several participant, research and environment related factors influence attrition. Retention strategies which address these barriers are important to minimize attrition.

Keywords

Retention; Attrition; Drop-out; Loss to follow-up; Withdrawal; Longitudinal studies

1. Introduction

Longitudinal studies are important for understanding relationships between risk factors and health outcomes, and can be used to determine causal relationships [1]. However, selective attrition in longitudinal studies, where individuals who continue to participate are systematically different from those who are lost to follow up, may pose significant threats to the internal and external validity of results [2–4]. High levels of attrition can reduce the statistical power of a study to detect a difference among groups or treatments and may lead to biased effect estimates, especially when the loss to follow up is non-random with respect to exposure and outcome [5, 6]. High levels of attrition may also lead to other practical concerns such as prolongation of research studies to recruit more participants and increased costs. Therefore, focused efforts at optimizing participants' retention are important in the design and conduct of studies to ensure that findings are valid and the study remains adequately powered.

Minimizing attrition in longitudinal studies can be very challenging and requires considerable effort and time during the design and implementation stages [7]. It is even more challenging for studies that require in-person visits to the study site. In a systematic review of studies that evaluated different retention methods to reduce loss to follow up, Booker et al reported that retention increased by an average of 18% when in person visit to study sites for follow-up was replaced with postal questionnaires[8]. In low and middle-income countries (LMIC), there are additional challenges to participants' retention in prospective studies. These include limited public health and research infrastructure, poor follow-up culture, poverty, low levels of education and high mobility. In these settings, attrition may vary from 5 – 30% in studies with tracking strategies, to 40–52% in studies without tracking strategies [9]. Although there is no absolute standard for acceptable attrition levels, bias becomes a major concern if attrition exceeds 20% [10].

Recently, several articles have investigated the predictors of participant attrition in longitudinal studies [11–18]. All of the studies that were conducted in LMIC focused on the attrition of patients in HIV care programs [11–13]. The experiences in such situations may differ from prospective research cohorts, particularly when participants are free of disease at baseline. As HIV care programs are relatively better funded than research studies in most LMIC, many HIV programs have investigated and implemented various interventions, such as home visits, peer support, task shifting, decentralization of services, and motivational counselling, to minimize attrition [19]. Furthermore, a strong motivation for adherence in HIV care programs that may not be present in several research settings, is the desire of HIV patients to reduce their high risk of morbidity and mortality associated with untreated HIV [20]. In contrast, most of the studies on participants attrition in high income countries (HIC) have focused on hard to reach populations such as ethnic minorities, children, and the elderly[14–16].

In this study, we use sequential mixed methods design to identify determinants of attrition in a longitudinal study in Nigeria, which required in-person study site visits for follow-up.

2. Methods

2.1 Study Design

This study on the determinants of attrition was conducted within a parent prospective study that evaluated host and viral factors associated with persistent high risk human papillomavirus (hrHPV) infection in Nigerian women. Details of the parent study have been previously described [21]. Briefly we recruited 1,020 women who were at least 18 years old and had a prior history of penetrative vaginal intercourse, from cervical cancer screening clinics in Abuja, Nigeria. We excluded women who could not commit to in-person follow-up visits, or had a history of cervical cancer or hysterectomy or were pregnant. We used structured questionnaires to collect information on demographic and lifestyle risk factors; performed a pelvic examination and collected biological specimens for HPV detection; and screened for cervical cancer using visual inspection with acetic acid/Lugol's Iodine. All participants were scheduled to return for follow-up visits 6 months after enrolment.

Within this parent study, we used sequential explanatory mixed methods design to evaluate the determinants of loss to follow-up. In this design, we collected and analysed quantitative data and followed up with analysis of qualitative data collected in focus group interviews and key informant interviews. Participant selection for the quantitative and qualitative data collection is described below.

2.2 Study Setting and Selection of Participants

Attrition was defined as attendance at the enrolment visit but failure to return for the scheduled follow up visit 6–9 months later, among women who were eligible to return for follow-up visits. Women who attended both the enrolment visit and the follow-up visits were defined as "responders" while women who attended only the enrolment visit were defined as "non-responders".

Of the 1,020 women enrolled in the parent study, 47 (5%) became ineligible to continue in the study (27 became pregnant, 4 had hysterectomies, and 16 relocated) leaving 973 women eligible to return for follow-up visits.

2.2.1 Quantitative Study—Of the remaining 973 women, 717 (74%) were responders while 256 (26%) were non-responders. These participants were included in the quantitative aspect of this study. Study flow diagram is provided in Figure 1. As part of the retention strategies in the study, we collected reasons for not returning for scheduled follow-up visits through phone calls. For non-responders that could not be reached by their primary phone numbers, we contacted members of their social network (spouses, relatives and friends). At the enrolment visit, all participants provided consent for study personnel to contact members of their social network for tracking purposes.

2.2.2 Qualitative Study—To provide contextual information on the determinants of loss to follow-up, we conducted four focus group discussions (FGD) and eight key informant interviews (KII) 6 months after the end of the parent study in March 2016. We were able to re-establish contact with some women who had been lost to follow-up during the parent study's duration.

We used simple random selection to identify 45 non-responders to participate in the FGDs. Of the 45 women approached, 40 agreed to participate in the FGDs but only 32 women turned up on the scheduled day and time. For the remaining 8 women, we conducted KIIs. Details of participant selection are provided in Figure 1. To prevent inadvertent HIV status disclosure, we stratified our population by HIV status and conducted two FGDs and four KIIs in each stratum.

Each FGD/KII was facilitated by a health research scientist, EMO and a physician, MKO who have both had training in qualitative research methods and together have over seven years' experience in conducting and analysing qualitative research. Each FGD session lasted between 30 and 40 minutes while each KII lasted for about 20 minutes. Each FGD/KII was conducted in English, audio-recorded and transcribed verbatim. The facilitators took supplementary reflective field notes which were reviewed by other members of the team within 48 hours. None of the participants had met any of the facilitators prior to the FGDs/KIIs. The FGD/KII interview guide was piloted among five women who were not part of the cohort. In brief, the interview guide was comprised of four sections: motivations to participate; barriers to study completion; perception of effects of non-completion and strategies to improve retention in future studies.

2.3 Retention Strategies

We applied the social cognitive theory [22] as a conceptual framework to design our retention strategies (Table 1). This theory postulates that behaviour is a function of aspects of the environment and of the person, all of which are in constant interaction. Using this framework, we identified strategies that would foster a conducive research environment and enhance the self-efficacy of participants and their motivation to comply with the study protocol. These strategies were evaluated and revised in an iterative process at monthly review meetings. We implemented a combination of different strategies (Table 1) as the

implementation of more than one retention strategy has been reported to be associated with better participant retention [23]. These strategies listed in Table 1 were implemented as preventive measures to minimize attrition levels in the study.

2.4 Statistical Analysis

2.4.1 Quantitative Analysis—The outcome variable for this analysis was response status: whether participants were responders or non-responders. We included 16 potential predictors grouped into 4 general categories: sociodemographic (6 predictors), lifestyle (2 predictors), reproductive and sexual health (6 predictors), and general health (2 predictors). The sociodemographic predictors were age, marital status, education, socioeconomic status, length of time in current residence and nature of dwelling (rural, semi urban or urban). To determine socioeconomic status (SES), we calculated the wealth index using principal component analysis (PCA) of data on household assets as described by Filmer and Pritchett [24]. Participants were categorized into low (lower 40%), middle (middle 40%) and high (top 20%) SES. Lifestyle predictors included smoking and alcohol use. Reproductive and sexual health predictors included lifetime number of sexual partners, sexual debut age, number of children, HIV status, HPV status at baseline and vaginal douching practice. General health predictors included presence of chronic ailments and self-rated health.

We used logistic regression models to evaluate association between potential predictors and non-response. All variables that were associated with non-response in age adjusted analysis at a p-value of <0.20 were included in a multivariable model. All analyses were performed in STATA 15 (Stata Corporation, College Station, Texas, USA).

2.4.2 Qualitative Analysis—We analysed the qualitative data using a content analysis approach and a combination of deductive and inductive methods to code transcripts and reflective field notes in an iterative process. We evaluated the coding frame for unidimensionality, mutual exclusiveness and exhaustiveness at a data review meeting. Recurrent themes were identified and classified into categories based on the ecological model[25]. This model consists of a series of nested layers that include participant factors at its core, researcher related factors and environmental factors, in its periphery, with interactions between the different layers. All analysis was conducted using ATLAS.ti version 7.5.10.

2.5 Ethics

Ethical approval to conduct this study was obtained from National Health Research Ethics Committee of Nigeria and the University of Maryland Institutional Research Board. We obtained written informed consent from all participants.

3. Results

3.1 Quantitative Study Results

Of the 973 women included in this study, 256 (26%) were non-responders (Figure 1). 89 (9%) of the 973 women included in this study required the use of other contacts to respond. Of the 256 non-responders, 33 (13%) withdrew, 111 (43%) were unreachable, 103 (40%)

missed their scheduled appointments despite multiple attempts at rescheduling and 9 (4%) did not provide any reasons.

Participant characteristics of responders and non-responders are presented in Table 2. Mean age (SD) of the 973 participants included in the quantitative study was 38 (8) years. Most participants were married (67%) and had completed more than six years of formal education (92%). Prevalence of smoking was very low (1%) and slightly more than half (53%) of the study population were HIV negative. Median lifetime number of sexual partners in this population was 3 (IQR: 1– 4). Most participants (78%) rated their general health as good.

Compared to women less than 30 years old, the OR for the likelihood of dropping out of our study for women aged 31 to 44 years was 0.46 (95% CI: 0.33 – 0.63, p <0.001) while that for women over 45 years of age was 0.31 (95% CI 0.17 – 0.56, p <0.001) (Table 3). HIV positive women were less likely to drop out of the study than HIV negative women (OR 0.45;95% CI 0.33 – 0.70, p <0.001). Other sociodemographic (education, socioeconomic status, nature of dwelling, length of time in current residence), lifestyle (marital status, smoking), reproductive (number of children), sexual (lifetime number of sexual partners, any human papillomavirus infection) and general health (presence of chronic ailments, self rated health) factors were not associated with dropping out of the study (Table 3).

3.2 Qualitative Study Results

The mean age (SD) was 38 (7) years for the FGD (32 participants) and 41 (6) years for the KII (8 participants). Most participants in the FGD (78%) and KII (87%) had more than 6 years of formal education. Slightly less than half of participants in the FGD (47%) were HIV positive while half of participants in the KII (50%) were HIV positive. Details of participant characteristics for the FGDs and KIIs are provided in Table 4.

3.2.1 Focus Group Discussions

High Cost of Participation: One of the commonly cited explanations for failure to return for follow-up visit was the prohibitive cost of transportation to the study clinic despite monetary incentives.

> *"… one of the things is transport issue, like I myself in particular, I may not* [cannot] *afford it. Even the money wey you give me the first time* [enrolment visit]*, e no reach* [not enough] *my transport"*

Other demands for time, such as commitments at the workplace, marketplace and school were cited for dropping out of the study.

> "It's just because I am too busy at my workplace"

Therapeutic misconception: Some participants equated participation in the study to their need for cervical cancer screening, which was provided as an added benefit for participation in the research study. Therefore, when they tested negative for cervical cancer and its precursor lesions at the enrolment visit, their attitudes towards continued participation was less favourable.

"But like me, they did it [cervical cancer screening] *the first time. They asked me to come after 6 months. I say to myself, there is no need"*

Inaccurate expectations: A few participants had inaccurate expectations about the research study that did not reflect the actual processes and outcomes described during the informed consent procedure. The commonest of these was related to the dissemination of research findings obtained from blood tests. While all participants received results for cervical cancer screening and were treated if necessary, they were informed during the informed consent process that other research results would not be immediately available.

"… And eh… there was another time they [study personnel] *took our blood samples they said they were taking it to the lab for test. So, I didn't hear anything in respect of that test since then ehn … that's why I didn't come back"*

Lack of understanding of risk of cervical cancer: Some participants had wrong notions about their personal risk of cervical cancer. They believed that they were not at risk of cervical cancer because they had been previously screened and have few sexual partners.

"I was told that I was supposed to come back again. After the first visit, I say there is no need. I believe I am not a single woman that ah…We [participant and sexual partner] *are just faithful to each other so I didn't see any reason for coming back again"*

Study Clinic Characteristics: Some participants believed that the urban location of the study clinic was a deterrent to study completion for participants who need to travel from rural environments.

'So, the people coming here from their lungu [villages] *it might not be that easy* [for them to return for follow-up visits]"

Some other participants opined that the location of the study clinic was not very visible and they had problems locating the study clinic.

"… I would love a more stable accommodation for you people [the research study]. *Because there is need for follow-up. You understand. That time, I came* [for follow-up visit], *I looked for those people* [study clinic staff] *that were here then* [enrolment visit] *… but I don't really know the location of the place that I want. Even when you tell them in National Hospital* [ask for directions at the hospital in which the study clinic is located], they *find it difficult to locate this particular building, this particular place. So, I think you need to improve on your publicity* [visibility].

3.2.2 Key Informant Interviews

Unpleasant side effects: Some non-responders opined that the pain and discomfort experienced during the speculum examination was an important determinant of attrition.

"I was afraid, I don't want the pain [associated with the speculum examination of the cervix] *again"*

> "Looking at the pain, it wasn't funny for me that day. So, I say… I don't want to believe that there is any problem…so let me just stay"

Spousal disapproval: An important normative influence on the decision to drop out of the study was spousal disapproval.

> *"...na my husband wey no agree say make I come back again* [return for follow-up visit]"

Difficulties in maintaining contact between study personnel and participants: Loss of contact between study personnel and research participants was an important barrier to returning for scheduled follow-up visits even when participants were aware they were required to return to the study clinic.

> "*Because that time when I do the first one* [enrolment visit], them [study personnel] *say make I go. Them* [study personnel] *give me date when I go come back do the second one* [follow-up visit]. *Na that time* [scheduled appointment period] *the phone come lost, I no know the time wey I go come back. Toh…[*after I found the phone] *you come call me* [for the KII].

4. Discussion

In this study, we used a multifaceted approach to investigate the determinants of attrition in a longitudinal study that required in-person follow-up visits to study clinics. From quantitative analysis, factors that increased the likelihood of attrition were younger age and HIV negative status. From qualitative analysis, we identified some participant related characteristics (high cost of participation, therapeutic misconceptions, inaccurate expectations, spousal dissaproval); research related characteristics (unpleasant side effects, and challenges in maintaining contact between study personnel and participants); and environmental factors (study clinic characteristics) that affected attrition.

Our findings of lower attrition among older women is similar to results from previous studies. In a prospective cohort study investigating sexual health among Australian women who have sex with women, attrition was associated with being less than 30 years of age at enrolment [26]. Similarly, in a nationally representative sample of women in a longitudinal study on women's health in Australia, older women were less likely to drop out of the study [27]. Younger persons are more likely to migrate from study areas for a plethora of reasons, including family formation, education and job opportunities. Among participants in a longitudinal cohort study on aging in the United States of America, attrition among younger participants was more likely to be attributable to mobility compared to attrition among older participants who were more likely to drop out for biological reasons such as mortality [28].

Some previous studies have shown that initiation of antiretroviral therapy (ART) among HIV positive women is associated with lower attrition rates in HIV care and treatment programs [29, 30]. In our study, most of the HIV positive participants were on ART and this may explain our finding of higher attrition levels among HIV negative women compared to HIV positive women. It is possible that HIV positive women who are on ART and otherwise

healthy are less likely to drop out of research studies, compared to HIV negative women, because the former may be better motivated to attend scheduled clinic visits and exhibit positive health seeking behaviours. The effect of the presence of comorbidities in research participants is likely to vary depending on the nature of the comorbidity and the research. Health disorders which limit the ability of patients to move or have a high risk of mortality within a short interval are likely to increase the chances of attrition [31]. While, chronic ailments which require routine clinic visits, such as HIV infection, are likely to foster positive health seeking behaviours with reduced chances of sudy drop out.

We did not find any strong associations between other sociodemographic (education, socioeconomic status, nature of dwelling, length of time in current residence), lifestyle (marital status, smoking) reproductive (number of children), general (presence of chronic ailments, self rated health) and sexual health (lifetime number of partners, any human papillomavirus (HPV) infection) factors with attrition. Previous studies have produced mixed results. Some studies show that attrition is higher among smokers [27], unmarried women [32], poorly educated individuals [33], and people with poor self-rated health [27] while other studies do not observe these relationships [26, 31, 33, 34]. As participation in longitudinal studies may be influenced by study attributes, local social and cultural factors and an interaction between various personal and contextual factors, the mixed results may reflect the varied study population and research protocols. For example, it has been suggested that more years of formal education, as a surrogate for English literacy, enables participants to have a better understanding of research protocols. Consequently participants with more years of formal education are less likely to drop out [27]. However, as our study personnel were culturally sensitive and able to communicate in local languages with participants who had low levels of literacy, level of education would be a poor surrogate for comprehension of research protocols masking any effects of education on attrition.

Our findings of high cost of participation as an important factor in attrition is similar to findings from previous research [35]. In a prospective randomised vaccine trial among healthy persons in Canada, it was observed that drawbacks to participation included time requirements and financial cost of participation. Even though we provided monetary incentive as a retention strategy, some participants reported that it wasn’t enough to cover their transportation cost. Our findings highlight the need to incorporate retention strategies that not only address the direct economic costs of participation but also the indirect costs of the time and effort taken to participate. Retention strategies that place an emphasis on the ethical principle of respect for persons may be better suited to addressing these indirect costs. These strategies may take the form of non-monetary incentives such as sufficient explanation during the informed consent process to ensure full disclosure and the right to self-determination; and providing participants with a sense of identification with the scientific community by providing project logo branded souvenirs to participants.

Higher levels of cognitive abilities in both fluid intelligence (reasoning, problem solving) and crystallized intelligence (comprehension, memory) have been linked to reduced levels of attrition [28, 31]. This is consistent with our findings in which therapeutic misconceptions and inaccurate expectations were important determinants of attrition. Despite provision of information on follow-up requirements and dissemination of research findings during the

informed consent procedure, some participants did not fully understand the need for them to return for follow-up. Most research on informed consent has been focused on participants understanding of autonomy, voluntariness, risks, benefits, and assessment of the readability of the informed consent document [36]. However, our study shows that comprehension of follow-up requirements and accurate expectations is particularly important for minimizing attrition levels in longitudinal studies. These may be addressed by more complex informed consent procedures that incorporate decision support, assessment of participants' understanding of follow-up requirements and expectations from the research.

Attrition due to negative experiences with research implementation has been described in previous studies [37, 38]. In a qualitative study on improving retention in clinical trials of cancer screening, prevention and treatment among minority women in the United States of America, it was observed that side effects from trial procedures and high participation burden were important barriers to continued participation in longitudinal studies [37]. The degree to which these factors affect studies would vary and be largely dependent of the nature of the research study. Research studies that collect highly sensitive and invasive personal information such as sexual behaviour, partner violence, substance abuse; or elicit painful memories may have higher attrition levels compared to other studies due to unpleasant experiences during the data collection. It is therefore important to consider retention strategies that are tailored to address the peculiar contextual factors that are relevant to any given study to minimize attrition.

We found that inability to contact participants was the commonest reason for attrition in our study. This finding is not unique to our study. In a longitudinal study of mothers of children with asthma, Zook *et. al.* [32], found that outdated contact information was the commonest reason for attrition accounting for 39% of all attrition. Although cell phones are commonly used, participants may lose their phones or change their phone numbers, may not answer if the incoming phone number is not recognized, or may be reluctant to use their phones for research study purposes if they have limited minutes. Errors in data entry may also result in inaccurate contact information for study participants. In a study evaluating the intensity and timing of contacts as part of a retention strategy, Senturia *et.al.*, reported that retention was positively correlated with number of phone contacts provided [39]. This finding emphasizes the need to collect as much locator information as possible and the need to test phone numbers while participants are at the clinic to minimize data collection errors.

Accessibility to research study sites as a product of site location and characteristics of the built environment has been identified as an important factor in participant retention in a previous research study conducted among researchers and research participants in the United States of America [40]. In that study, it was observed that sites that were easily accessible, physically attractive, clean, welcoming, and with comfortable waiting rooms encouraged continued research participation. It is therefore important to incorporate strategies that improve the overall experience of participating in research studies by improving the physical characteristics of research sites.

4.1 Strengths and Limitations

Our study has some strengths and limitations. We included a qualitative approach which enabled us to investigate research related and environment related factors in addition to participant level factors that influence attrition. There is limited information about these contextual factors especially in developing countries and our findings would be helpful in the implementation of future longitudinal studies. Table 5 provides some suggestions based on our findings, to minimize attrition in future studies with similar populations.

Our study was conducted among women in a prospective study on the host and viral factors associated with persistent high-risk HPV. Therefore, our findings may have limited generalizability to other populations. Despite this, we provide several retention strategies developed based on the social cognitive theory that can be adapted to suit other study populations.

We did not evaluate motivation for completion of study among participants who completed the study. To design effective retention strategies, it would be important to understand the reasons why participants complete longitudinal studies so that these motivational factors can be promoted in other studies to maximise retention.

5. Conclusion

This paper contributes to the understanding of barriers to retention, especially for longitudinal visits that require in-person follow-up visits in a developing country. We identify both participant related barriers and other contextual barriers that need to be addressed to optimise retention. We also provide several practical strategies that can be implemented to mitigate attrition. Our findings will be helpful to other researchers in the design and conduct of longitudinal studies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgement

We acknowledge the contribution of Chika Onyenakie, Ebimoboere Apreala, Joke Idowu, Dayo Satoye, Dorcas Jesse Bako, Jane Anichebe, Surraya Said Abdullahi, Clare Anyanwu, Thelma Ugorji, Gladys Omenuko, Temitope Filade, Patience Bamisaye, Miriam Anyogu and Nkiru Onwuka for their role in participant recruitment; Tolulope Gbolahan and Jesse James for their role in data management.

Funding

Research reported in this publication was supported by the UM-Capacity Development for Research in AIDS Associated Malignancy Grant (NIH/NCI 1D43CA153792-01) and African Collaborative Center for Microbiome and Genomics Research (NIH/NHGRI U54HG006947). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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What is New?

- Existing information on determinants of attrition in prospective cohort studies in low and middle-income countries is limited.
- We found that the likelihood of attrition was lower in older women compared to younger women less than 30 years old. HIV positive women were also less likely to be lost to follow-up than HIV positive women.
- We identified high cost of participation, therapeutic misconceptions, inaccurate expectations, spousal disapproval, unpleasant side effects, challenges in maintaining contact with participants and participant difficulties in locating the study clinic as important contextual barriers to study retention.
- Future studies in similar settings need to incorporate retention strategies that address the direct and indirect cost of research participation; provide more thorough and complex informed consent procedures to prevent participant misconceptions about requirements for follow-up; collect multiple contact information for participants and test participants' phone numbers while they are at the clinic to minimize attrition.

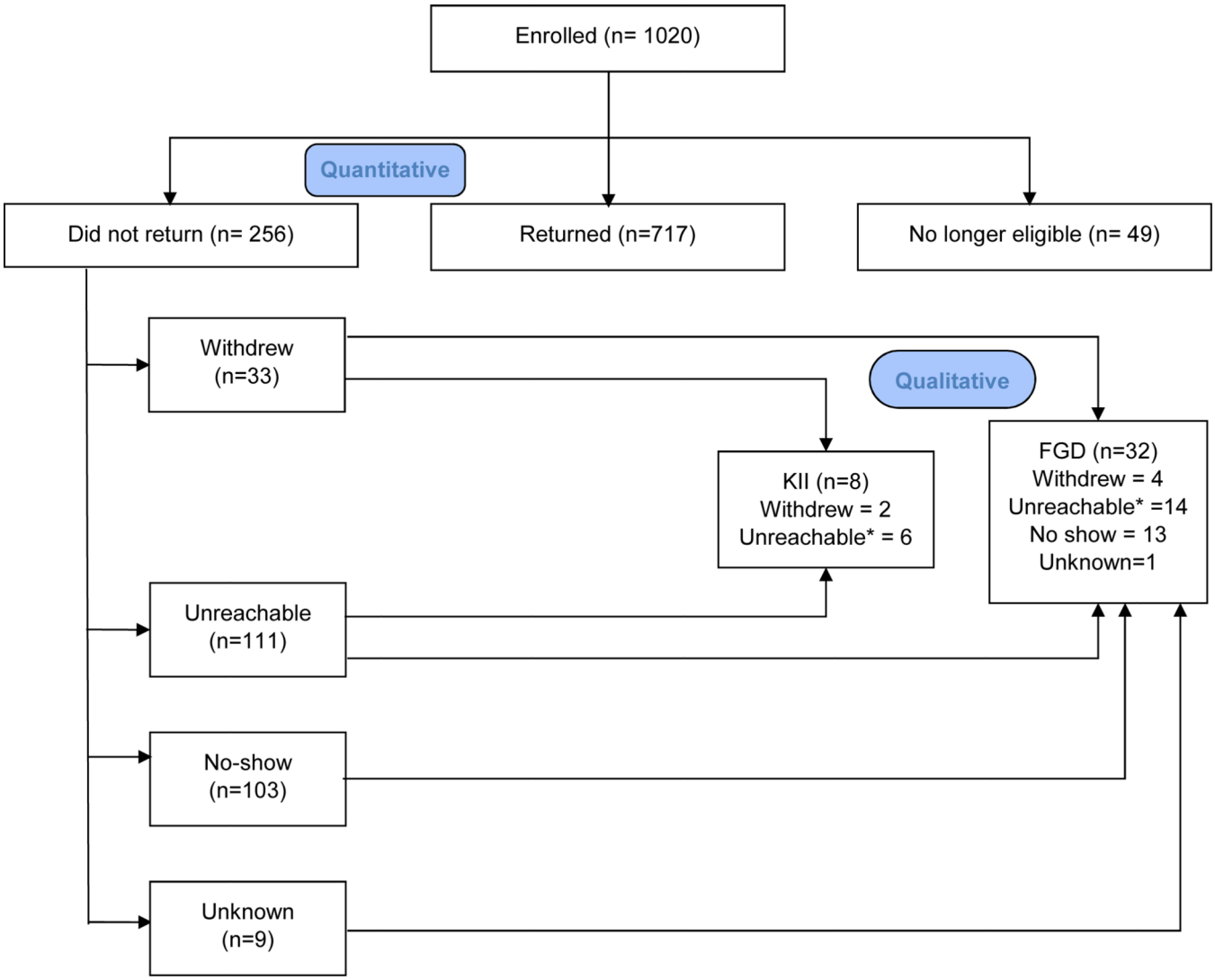

Figure 1: Participant flow chart

*These participants could not be contacted during the parent study but contact was reestabished at the time of the qualitative studies.

Table 1:

Retention Strategies

Staff/Visit Characteristics	Incentives	Participant contact	Participant Bonding	Community Engagement	Tracking system
Flexibilty in scheduling to include early morning and late evening appointments	Reimbursement of transportation costs	Phone calls and text messages to schedule appointments and reminder calls two days before appointment and morning of appointment	Use of study logos on questionnaires and all communication materials	Attendance at town hall meetings	Use of robust electronic scheduling and contact software
Engagement of culturally competent and sensitive staff with strong interpersonal skills	Benefits of participation – free see and treat cervical cancer screening	Phone calls for missed appointments up to ten attempts	Continuity of contact via text messages and emails in betweem study visits	Designing health promotion activities for the community e.g health alks encouraging physical activity	
Detailed study description to include the study requirements, follow-up demands and potential benefits/harms of the study	Benefits of particaption – free physical and breast examination	Use of scripts for phone calls	Availability of a platform for communication between participants and study personnel in between study visits for rapid resolution of queries	Presentation of research updates at regligous gatherings and other social events	
Training and retraining of study personnel to maintain appropriate atttitudes in researcher-participant interactions	Breast Self Awareness education	Record of outcome of all phone calls in call logs	If outcome of previous calls documented welfare concerns, schedule follow-up call to enquire about welfare	Engagement with local community leadership	
Mainitaing appropriate respect for study participants	Provision of informational brochures promoting healthy lifestyles	Multiple calls at different times/days up to ten attempts for unanswered calls.			
Research staff recognition for sites that maintain high retention rates	Altruisitc purposes: Discussion of the need for complete data to achieve study aims	Multiple contact phone numbers for each participant			

Table 2:

Baseline characteristics of study population by participation

Characteristics	Total = 973 N (%)	Responder = 717 N (%)	Non-responder = 256 N (%)
Sociodemographic factors			
Age, years (mean, SD)	38 (8)	38(8)	36 (8)
Marital status			
Married	645 (67)	472 (66)	173 (68)
Unmarried	320 (33)	239 (34)	81 (32)
Education			
≤6 years	109 (11)	84 (12)	25 (10)
7 – 12 years	256 (27)	178 (25)	78 (30)
>12 years	600 (62)	449 (63)	151 (60)
Socioeconomic status			
Low	382 (40)	276 (39)	106 (42)
Middle	385 (40)	288 (41)	97 (39)
High	189 (20)	141 (20)	48 (19)
Length of time in current residence, months (mean, SD)	33.2 (32)	32.8 (33)	34.0(27)
Nature of dwelling			
Urban	427 (44)	305 (43)	122 (48)
Semi urban	367 (38)	280 (39)	87 (35)
Rural	168 (18)	125 (18)	43 (17)
Lifestyle factors			
Smoking			
Never smoked	952 (99)	701 (99)	251 (99)
Ever smoked	13 (1)	10 (1)	3 (1)
Alcohol Consumption[*]			
No	835 (87)	612 (86)	223 (88)
Yes	125 (13)	96 (14)	29 (12)
Reproductive and sexual health factors			
Lifetime number of sexual partners (median, IQR)	3 (1 – 4)	3 (1 – 4)	3 (1–4)
Sexual debut age (median, IQR)	20 (18 – 22)	20 (18 – 22)	>20 (18 −23)
Number of children (median, IQR)	1 (0 – 3)	1 (0 – 3)	1 (0 – 2)
HIV status			
HIV negative	511 (53)	348 (49)	195 (64)
HIV positive	421 (44)	345 (48)	76 (30)
Any HPV status			
HPV negative	588 (62)	427 (61)	161 (63)
HPV positive	367 (38)	274 (39)	93 (37)
Vaginal douching			
No	347 (36)	251 (35)	96 (38)
Yes	619 (64)	461 (65)	158 (62)
General health			

Characteristics	Total = 973 N (%)	Responder = 717 N (%)	Non-responder = 256 N (%)
Presence of chronic ailments	230 (24)	179 (25)	51 (20)
Self-rated health			
Good health	752 (78)	559 (78)	193 (76)
Poor health	214 (22)	153 (22)	61 (24)

*Alcohol consumption within the three months preceding enrolment into the study

Table 3:

Association between participant characteristics and loss to follow-up

	Univariate model		*Multivariate Model*	
Characteristic	**Odds Ratio (95% CI)**	***p* value**	**Odds Ratio (95% CI)**	***p* value**
Age (years)		p_t = <0.001		
≤ 30	1.00		1.00	
31 – 44	0.53 (0.37 – 0.78)	<0.001	0.46 (0.30 – 0.70)	<0.001
>44	0.38 (0.23 – 0.63)	<0.001	0.31 (0.17 – 0.56)	<0.001
HIV status				
HIV negative	1.00		1.00	
HIV positive	0.47 (0.34 – 0.64)	<0.001	0.45 (0.33 – 0.63)	<0.001
Nature of dwelling		p_t = 0.27		
Urban	1.00		1.00	
Semi urban	0.78 (0.56 – 1.07)	0.12	0.86 (0.61 – 1.21)	0.44
Rural	0.86 (0.57 – 1.29)	0.47	0.92 (0.58 – 1.44)	0.26
Length of time in current residence (months)		p_t = 0.13		
≤ 25	1.00			
26– 60	1.07 (0.77 – 1.50)	0.69	1.05 (0.74 – 1.50)	0.79
>60	1.38 (0.92 – 2.07)	0.12	1.32 (0.86 – 2.04)	0.20
Number of children		p_t = 0.10		
None	1.00		1.00	
1 – 4	0.94 (0.70 – 1.26)	0.69	1.14 (0.81 – 1.61)	0.44
≥5	0.55(0.27 – 1.12)	0.10	0.60 (0.25 – 1.45)	0.26
Lifetime number of partners		p_t = 0.23		
1	1.00			
2 – 4	1.15 (0.81 – 1.62)	0.44		
≥ 5	0.83 (0.54 – 1.28)	0.41		
Marital status				
Married	1.00			
Unmarried	0.92 (0.68 – 1.26)	0.62		
Education		p_t = 0.73		
≤6 years	1.00			
7 – 12 years	1.47 (0.88 – 2.48)	0.15		
>12 years	1.13 (0.70 – 1.83)	0.62		
Socioeconomic status		p_t = 0.47		
Low	1.00			
Middle	0.87 (0.64 – 1.21)	0.42		
High	0.89 (0.60 – 1.32)	0.55		
Smoking				
Never smoked	1.00			
Ever smoked	0.84 (0.23 – 3.07)	0.79		

	Univariate model		*Multivariate Model*	
Characteristic	**Odds Ratio (95% CI)**	***p* value**	**Odds Ratio (95% CI)**	***p* value**
Any HPV status				
Negative	1.00			
Positive	0.84 (0.63 – 1.11)	0.22		
Chronic ailments				
Absent	1.00			
Present	0.90 (0.67 – 1.21)	0.49		
Self-rated health				
Good health	1.00			
Poor health	1.15 (0.82 – 1.62)	0.41		

Table 4:

Characteristics of Participants in the Focus Group Discussions and Key Informant Interviews

	FGD = 32 N (%)	KII = 8 N (%)
Age, years (mean, SD)	38 (7)	41 (6)
Education		
≤6 years	7 (22)	1 (12)
7 – 12 years	7 (22)	4 (50)
>12 years	18 (56)	3 (38)
Marital Status		
Married	22 (69)	5 (62)
Unmarried	10 (31)	3 (38)
Socioeconomic Status		
Low	13 (41)	3 (38)
Middle	16 (50)	2 (25)
High	3 (9)	3 (37)
HIV Status		
Negative	17 (53)	4 (50)
Positive	15 (47)	4 (50)
Number of children (median, IQR)	2 (0–3)	2 (1–4)
Lifetime number of sexual partners (median, IQR)	2 (1–4)	3 (1–4)

Table 5:

Strategies to minimize attrition based on study findings

Modifiable characteristics	Retention strategy
Participant related	
High cost of participation	• Monetary incentives to cover transportation costs. Need for flexibility as transportation costs may vary by participants • Non-monetary incentives that provide a sense of identification with the project. For example, project logo branded souvenirs • Provision of child care options, particularly for studies that recruit women of reproductive age
Misconceptions about follow-up requirements and benefits of participation	• Include pictorial illustrations of follow-up requirements to improve comprehension • Dedicate more time to explaining the follow-up requirements during the informed consent procedure • Ensure that informed consent procedures incorporate decision support, assessment of participants' understanding of follow up requirements and expectations from the research
Research related	
Side effects from study	• Principal investigators need to think through all risk and side effect possibilities • Minimize risks to the fullest extent possible. • Provide an accurate and fair description of the risks/discomforts and the anticipated benefits to the participants
Maintaining contact with participants	• Collect as much locator information as possible – multiple phone numbers of participants • Test phone numbers as they are collected to prevent data entry errors • Use of mhealth technology to maintain contact with participants
Environmental factors	
Study clinic characteristics	• Select study sites that are easily accessible • Ensure study clinics are physically attractive, clean, welcoming and with comfortable waiting rooms
Non-modifiable characteristics	
Young age	• Oversample from this demographic to account for potential attrition • Include strategies that allow participants to continue participation even when they relocate. These include the use of online questionnaires, self-collection and mailing of samples where feasible
HIV status	• As this may be an indicator of health seeking behaviour, researchers should consider strategies to improve the overall health seeking behaviour of participants • Recruit participants who are easy to follow and highly motivated to participate. For example, nurses in hospitals;