

ORIGINAL ARTICLE

Factors Associated with non-participation in a Research: Observations from community engagement experiences in a home based VCT randomized controlled trial in Monze

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ABSTRACT

Participation in research is crucial for success of research. It has been widely argued to be an important factor in interpreting research and implementation of the findings. In this study, factors associated with non-participation in the home based RCT VCT study in rural communities in Monze were explored.

Methodology: Qualitative approaches using ethnographic methods that included observation and contextualization were employed. Triangulation was achieved using observation, in-depth interviews and focus group discussion (FGDs). Purposive sampling was used to select participants for the 8 FGDs (stratified by sex) in which each FGD consisted of 6-12 respondents. In-depth interviews were conducted with 20 key informants that were aged between 25-50 years. Data collected was transcribed replacing all identifiers with coded labels. Thematic content analysis employing iterative approaches and word processing guided the analysis. In addition for the in-depth interviews, systematic textual analysis was used to highlight quotes that support or refute identified themes.

Results: Overall there were 20 in-depth interviews, 4 observations per village were conducted and 8 focus group discussions. Majority of the respondents from the FGDs were male (56.3%) aged between 25-49 years. Superstition and mistrust of the research assistants was

cited consistently as a key reason for non-participation in the home based VCT RCT baseline survey by majority (97.8%) of the respondents. Many of the respondents described fears about the drawing of blood to test for HIV. Most of the key informants (15/20) cited mistrust to be the main reason of non-participation. The other factors that were identified included lack of understanding the study and benefits of participating, failure to respect culture and tradition, fear of violence by an intimate partner following HIV testing and disclosure of results, poor timing and prior negative engagements with the community.

Conclusion: The findings of this study show that mistrust, superstition and lack of understanding of the study benefits were core factors associated with non-participation in health research. This may underscore the need for setting specific and appropriate community engagement processes.

INTRODUCTION

Recent years have seen an increase in HIV/AIDS research to respond to the numerous challenges associated with the pandemic such as low uptake of VCT. More community based research is required to provide solutions to the numerous challenges posed by the HIV/AIDS pandemic on the communities. It is imperative that the communities in countries that are heavily affected participate in research. It has also been widely argued that participation is an important factor of improving health outcomes, including health research outcomes². Further, community

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participation in research is crucial to the success of any study. Low and non-participation have numerous consequences. Both have been associated with sampling bias, delays in completion of the study as well as increased costs¹.

Research efforts have dramatically increased the level of knowledge regarding motives to participate in research. However, understanding the reasons for non-participation has been missing in most empirical studies¹. It is critical to understand factors associated with non-participation to increase participation in future studies. So far, many attempts have been made to identify ways of increasing participation in both experimental and observational studies³. Conversely not much research has focused on factors associated with non-participation.

The reasons for non-participation may be variable and vary from place to place. Therefore it is important to recognize the value of identifying the possible barriers to participation prior to inception of a community based study. It has also been observed over time that strategies that are highly effective for a particular group of people may be ineffective to the other. Engaging the community at all stages of the research process may help understand the key factors of non-participation in a study.

METHODOLOGY

Qualitative approaches using ethnographic methods that included observation and contextualization were employed. Triangulation was achieved using observation, in-depth interviews and focus group discussion (FGDs). Purposive sampling was used to select participants for the 8 FGDs (stratified by sex) in which each FGD consisted of 6-12 respondents. **These** FGDs were conducted in Tonga the local language in the study area. The overall sample for focus group discussion was n=71. Of the 71 respondents, 31 were female and 40 were male. To ensure anonymity no names or initials were used.

In-depth interviews were conducted with 20 key informants that were aged between 25-50 years. These interviews were all conducted in Tonga and they lasted between 45 to 60 minutes. The key informants were drawn from four villages in chiefdoms Mwanza and Chona. They comprised of 7 females and 13 males

respondents. In each of the four villages five key informants were identified using the snowball method. The key informants included the village headmen, village committee secretaries, Traditional birth attendants, wives to the headmen, home based care providers and neighborhood health committee members. Overall there were more male (58.2%) respondents than female (41.8%). Data collected was transcribed replacing all identifiers with coded labels. Thematic content analysis employing iterative approaches and word processing guided the analysis. In addition for the in-depth interviews, systematic textual analysis was used to highlight quotes that support or refute identified themes.

Results and discussion

Overall there were 20 in-depth interviews, 4 observations per village were conducted and 8 focus group discussions. Majority of the respondents from the FGDs were male (56.3%) aged between 25-49 years.

Superstition and mistrust of the research assistants was cited consistently as a key reason for non-participation in the home based VCT RCT baseline survey by majority (97.8%) of the respondents. Superstition can hinder participation in a study. Therefore, it is very important to have a plan to deal with superstition and rumours about the study⁴. In this study, lack of trust was generated by genuine concerns that surrounded drawing of the participants' blood. Many respondents feared that their blood would be used for other purposes other than testing for HIV. Most of the study participants had fears of "Satanism". Fear of 'Satanism' is genuine fear that has been reported elsewhere in Zambia⁵. Equally, fear of 'Satanism' was wide spread in this study area. The fear of 'Satanism' is genuine and it has been reported in the past in an HIV testing study in Lusaka, Zambia where 97.8% of the respondents had some superstition; chiefly Satanism. The key reason for the superstition was that, the survey involved drawing of blood. Many of the respondent in this study suspected that their blood would be used for 'satanic' purposes. This finding was in consistent with other research findings that many people interpret the act of drawing blood for medical purposes; often regarded as "satanic"⁵.

A key informant said,

"...We heard they wanted to draw our blood to test. Some people told us they are satanic, they take small amounts of blood but using magic they can take more and sell....I can't trust a stranger with my blood..... remember these days people use blood for satanic purposes...."

The persistent myths, misconceptions and superstition were an important barrier to participating in the survey. From these findings it can be further urged that fears of 'Satanism' were also linked to lack of trust of strangers. Majority of the respondents had fears that researchers drew a lot more blood through magic. This myth regarding researchers collecting blood to sell is also reported in other studies⁶. The myths that researchers sell blood undeniable lead to low participation and in some cases refusal to participate in the study. The respondents strongly associated people who drew blood even for medical purposes to be linked to 'Satanism'. In all the discussions, Satanism was closely linked to acts of Satanism. A key informant said,

"...Ah! We thought that those drawing blood are 'satanic'. That was the main point. There is nothing else. What made people refuse to participate is that they didn't trust those people...."

Several persistent myths and misconceptions have surrounded previous studies^{5, 6}. These myths and misconceptions were that "researchers collect blood to sell", "researchers infect women with HIV", "women are being used as guinea-pigs", "researchers pay the women to use the trial products" and "the act" as well as the person drawing the blood being referred to as "satanic". Mistrust of the researchers was also reportedly prominent among the respondents in both studies. The other similarity is that these studies were conducted in 'research naïve' communities⁶. This may be one of the main reasons why myths, misconceptions and superstition were very high.

Suspicions were an important indicator of lack of trust in this study. Since trust is the reason of participation, it can be suggested that superstitions were also some of the key barriers to participation. These findings are similar to those of Zachary⁵ where mistrust of doctors and research scientists was reported over and over again as a barrier for research participation by community members. Although the study by Zachary⁵ was conducted in an

urban setting, the findings do not vary with these from those from this study where many respondents associated the drawing of blood for HIV testing to be used in rituals. This extent of fear shows that in these communities extensive community engagement is essential to provide information relating to a study. Information provided during the community engagement process is likely to lessen the fears that potential participants may have. The above findings may also suggest that community engagement is vital in biomedical studies especially if drawing of blood is required.

Many of the respondents described fears about the drawing of blood to test for HIV. Most of the key informants (15/20) cited mistrust to be the main reason of non-participation. Trust is very important for meaningful participation to ensue. Similar findings were reported by Masiye⁷ who cited trust as reason why participants enrolled in a study. It is unlikely that communities will accept to participate in a study if they lack trust in the study or the researchers. The findings from this study are also similar to those of Zachary⁵ where mistrust of doctors and research scientists was reported over and over again as a barrier for research participation by community members. Questions on trust can't be disregarded in a study. Some respondents reported that they refused to participate in the home based VCT RCT baseline survey because they questioned the trustworthiness of the study. This thought is expressed in the following narrative,

"...People are not scared of VCT; but are only questioning the trustworthiness of the program. How would we be looked for and get tested by the people from the other side of the river (meaning people from outside his community) while we have clinic...why weren't the clinic staff working with those people who were coming to our village? It was going to be easy if we saw one of them (clinic staff)..."

According to this respondent, the misunderstandings and unanswered questions that lead to mistrust can be overcome by including local clinic staff in the study.

The other factors that were identified included lack of understanding the study and benefits of participating. Informing the community on the potential study benefits is essential. Understanding the study benefits is likely to enhance participation. A male respondent from one of the focus group discussions said,

“....for us to take part we need to be educated on the benefits of testing.. For us in the villages to learn the goodness of testing. The greatest thing is learning. I say so because AIDS is harvesting every day...people are delaying testing and starting treatment...”

This finding shows that being 'educated on the benefits of testing' was the greatest need of many people in this study area. Understanding the benefits of testing was linked to participation in HIV activities including studies on VCT. According to the above citation, learning the 'benefits of testing' perhaps would result in behaviour change. This would help prevent the infections that were thought to be occurring daily and leading to numerous deaths. The demand for HIV/AIDS services would also increase. Consequently, this would decrease the delays in seeking treatment and deaths due to AIDS related causes. This thought is logical because adequate education on benefits of testing would motivate people to accept VCT and other intervention that enhance VCT uptake. VCT is an entry point for most HIV related services including ART. Early diagnosis and ART is crucial in the care of people living with HIV and those suffering from AIDS.

The types of study benefits were also an important reason the community chose to participate or not. Some (54.9%) of the respondents did not view knowledge of one's HIV status as a key benefit for participating in a study. Regarding the types of benefits for participating, the respondents preferred material benefits such as receiving a bicycle. Most of the respondents were concerned about personal benefits. For instance one key informant said,

“...what are you giving for participation? I mean when I know my status then what will change? Give me and my family a bicycle....”

This type of reasoning was common in Moomba village only and was linked strongly to refusal to participate in the home based RCT VCT baseline survey. It is shown in the following narrative,

“....we were told to refuse to participate in that program...”

If the above thinking is true, it could be said that some people did not participate because the key stakeholders did not perceive any personal benefits from the survey. Consequently they discouraged other community

members from participating in the study. It is possible to think that some people did not participate because of the failure to perceive the study benefits during the home based VCT baseline survey. This was shown in the following narrative,

“....there must be something coming at the end of it all.... but you keep coming like that... you come and 'fish' (meaning looking for people to participate) then you leave; that is difficult. Even when you would want to fish using a fishing hock you still have to put a worm (meaning an enticement) in front of the hock so that you can catch some fish....”

Failure of participants to identify benefits in a study was cited as a deterrent from participation by some of the respondents. One respondent from the focus group discussions said,

“...if we see that what we are doing has no profit to us, we stop...”

Failure to respect culture and tradition was another factor that was closely linked to non-participation in the home based RCT VCT baseline survey. Respect for culture and tradition is very important in all community based studies. Whilst it is important to improve the women's awareness to making independent decisions when participating in a study, it is equally important to acknowledge that culture and customs of a community must be respected. Majority (65.7%) of the female respondents preferred seeking permission from their spouses before participating in a study. During the home based VCT RCT baseline survey, many female respondents reported declining to participate because they felt that it wasn't in order to be interviewed in the absence of their husband. Failure to respect culture and tradition could result in non-participation as shown in the following citation,

“.....I refused to take part in that discussion when those people came last year....I asked them, you want to give me questions when my husband is not there? When I'm alone? They (research assistants) said yes, then I said me no, when my husband is not there! No! My husband stops me.....”

These findings show that women were more likely to accept to participate in a study if their husbands were present and consented. Respect for culture and tradition

whilst improving the women's awareness and decision making related to participating in research must be emphasized in all community based studies. This delicate balance must be maintained if participation is to be enhanced.

Partners were an important factor in HIV testing and participation in HIV/AIDS or VCT studies. The refusal to test for HIV by some male partners was an important barrier to participation that was reported consistently. Many women cited failure to participate or to test for HIV because of their partners' lack of willingness to test for HIV. Some women reported difficulties in getting consent from their spouses to test for HIV. One of the respondents in a women's focus group discussion group said,

".....the men are difficult, they refuse to test when we are pregnant pregnancy is a scary, it is a risk. They still refuse....now if my husband refuses to test whilst I'm pregnant, to say I test when I'm just ok because there is a program; it is not possible....."

The non acceptance of the male partners to test for HIV and failure to consent to their partners' participation in a study is an important barrier. This is a very significant barrier in areas where women depend on their male partners to test or participate in an HIV study. Findings in this study also revealed that women who considered going ahead with the test also reported facing a multitude of challenges such as difficulties in negotiating for safer sex and accusations of infidelity. This consequently led to the non perception of benefits of testing and knowing one's status. This is shown in the following narrative,

"..... As a woman there is no reason I would be taking part in the program for testing because tomorrow my husband will say I'm refusing to have sex with him because I tested, or if my result negative I request to use condoms he will say just because you are 'clean" you have refused to have sex with me or There is another man you are in love with....this can destroy my marriage.."

The above citations may also suggested that married women whose husbands refused their wives to test for HIV during antenatal period were not likely to undergo VCT or participate in an HIV study that requires testing. It is therefore not surprising that some of these women could not attempt to participate in the home based VCT

trial. They did not see the usefulness of testing if their partners did not permit them. This is shown in the following citation,

"..During antenatal my husband does not agree for me to test. Now you think he can just agree if I said let us take part and test? I can't even waste my time to take part...how do I get and of what use will my results be?"

Some of the female respondents opted to continue with their marriage without knowing the results. This is a crucial decision for those implementing HIV services. Nonetheless, many married women in this study said they would rather continue with their 'peaceful' marriages rather than stir up trouble by testing. One of the female respondents said,

"I still want to be married....so if he says no it is no, I can't force and test....I want to continue with my peaceful marriage..."

Fear of violence by intimate partner was also reported to be an important barrier to participation in a VCT study. Most (57.9%) of the female respondents reported fear of violence by their intimate partners following HIV testing and disclosure of test results as reason for their non-participation in the home base VCT baseline survey. This is shown in this citation,

"...if a husband says no, but you go ahead with the HIV test, he can beat you....."

According to this respondent, a woman who tests against their partner's will or consent, risks some form of violence. In this respondent's view, women are likely to experience physical violence. This suggested relationship between intimate partner violence and HIV testing may be said to be the cause of non-participation in the home base VCT RCT trial baseline survey for some of the women in this study area. Women who experienced any forms violence from their partners were less likely to participate in studies that involve testing for HIV if their partners never consented. Apart from physical violence, female respondents also reported other forms of violence such as psychological violence. Verbal abuse was also frequently cited.

"...at times he will use bad words if you insist on saying I want to take part and testing. It is worse when you try to

use condoms to protect yourself ...he can use bad words such as; you are a prostitute! (uli mu mwuule!)...

Other female respondents reported fear of being divorced following disclosure of test results. This is shown in the following narrative,

".....when the woman tests.... the man says you have HIV, let us divorce...so I fear to test in the first place...what can I do, I still want to be married....."

Fear of divorce was uncommon among the male respondents. Only one male respondent cited fear of divorce. He said,

"....what we fear is divorce. Now you must tell the women that there is no divorcing if your partner is found with HIV..."

This is genuine fear as some studies have reported some form of violence following a positive HIV test result. Fear of intimate partner violence and divorce are important obstacles to women participating in an HIV study. The desire to remain married appeared to make women tolerant of partner violence. Violence from an intimate partner has been reported in previous studies to be the cause of fear to test for HIV and disclose of HIV results⁸. In their study they associated intimate partner violence with rural residence, multiple partners and low education of male partners. Similar findings were also significant in this study; the demographic characteristics show low education (only 10% of the respondents had attained secondary school education) of participants in a rural community and most of the respondents being in polygamous marriages. This thought is further supported by the following citations,

"....Men here have multiple partners.... you may try to stop a man, but he can't stop....the problem is he can't allow you (referring to herself) to test for HIV....he would refuse....."

"....no one can stop a man from having an extra marital relationship...."

There was a sense of despair among some female respondents who reported lack of control with regards to their partners' sexual behaviors. This unregulated freedom to have as many partners as a man wished was a depressing

factor to many women. It was also mentioned that men with multiple partners did not allow their women to test. Conversely some male respondents reported to have tested before with their extra-marital partners. This provided a sense relief as the men never had worries of HIV thereafter. This is shown in this narrative,

"...I secretly went and tested with 'musimbi wamusokwe' (my girlfriend but literally meaning a woman I met with in the bush)... This gave me relief as I had no fears of HIV anymore....i don't have to use condoms..."

Other male respondents openly declined use of condoms despite having multiple partners. One male respondent said,

"tu jumbo (small gumboots but meaning condoms) are for those who know they are walking in the thorns and not us. I trust all my women...."

This implies that this respondent trust all his women and perceives no risk of contracting HIV. However some female respondents counteracted such trust. They mentioned that it was not always possible to stay faithful when one was in a polygamous relationship. This lack of faithfulness was attributed to lack of attention, care and long duration of being denied sex. Majority of the married female respondent said having an HIV test was still difficult although they knew that their partners had extra marital partners. Other women reported that in spite of having multiple extra marital relationships, some men refused HIV testing as well as protected sex. This is shown in this quotation,

"....my husband refused that we participate in last year's program of testing for HIV.....to use condoms he doesn't want even though I know that 'so' and 'so' are his girlfriends. Every time I say we test, he refuses. If I insist telling him that we test, he can just beat me....."

Violation of the fundamental human rights of women has contributed to the public health problems related to reproductive health of women such as women failing to negotiate for and have safer sex. Partners' refusal to participate in biomedical research is an important barrier to participating for most women in rural settings. In situations where women tested without their partners' consent, the benefits of testing for HIV such as having protected sex were not realized. In this study, some

women complained that testing for HIV and knowing ones' status did not change their sexual life and therefore they didn't see the need to participate in the home based VCT randomized controlled trial baseline survey. This is shown in the following narrative,

".....even if I were to take part and be tested, how can I protect myself? If I go and bring condoms, I will be told it is "buhule bwako" (it is because of your prostitution). He will say I want to use condoms because I have "musankwa wa musyokwe" (a 'boy friend')

Some of the female respondents reported difficulties in practicing protected sex safely following an HIV test. Verbal abuse and accusation were consistently cited as deterrent to undergoing an HIV test for some women as well as using condoms. According to these respondents, there was no advantage to their testing as they failed to negotiate for and have protected sex. Similar findings were reported in Uganda⁸. Their study revealed that men reacted violently when their women tested for HIV, disclosed their HIV test result or requested to use condoms. In the same study, it was also mentioned that men perceived testing for HIV and requesting to use condoms as evidence of "prostitution" and therefore "AIDS" in the women. The male respondents justified their having multiple partners and violence. Some of the male respondents accused women of driving them into to this act. This is shown in the following narrative,

".....at times our wives cause us to be careless..."

Poor timing on the part of the research assistants was also identified as a reason for refusal to participate. Some of the respondents (47.2%) reported that the research assistants followed them to their field to request them to respond to their questionnaire and they felt this was inappropriate. The community did not appreciate being stopped working in their fields to respond to the interviewers. Some of respondents stated that it was wrong for research assistant to follow them at their field. This is shown in the following quotation,

".....What happened last year, making someone knock off from the field was bad, that thing is bad...it should not happen."

The above quote also indicates lack of patience. This may be attributed to lack of experience in data collection on the

part of research assistants. It may also be due to over confidence in cases where the research assistant may have participated in many surveys. However, it is important to train research assistants to exercise patience whilst following their working schedule. This can be achieved by making appointments and having call backs so that respondents can also prepare themselves for the interview.

It is of great importance to know if the research team members had prior engagements with the community. Although difficulty, care must be taken to unearth the types of engagement, whether there were any problems with the community. Previous negative experiences between a research assistant and a particular community can affect a new study because the community may still have some resentment. This came to light in the following narration,

"....who is M in this program, we know her, she used to work for a fertilizer support program and we don't like her here because she didn't give us fertilizer that was due to us...seeing her here infuriated most of us as we were reminded of the past...personally I came face to face with her and chased her with her team from my home...I refused to participate in their program..."*

According to this respondent, refusal to participate was due to the past negative experience with one of the research assistants. This calls for careful selection and orientation of the research assistant. Making them understand the need to declare past engagement would be helpful so that they are not sent to areas where the community has issues with them. Failure to do so would negatively affect participation in a study in the aggrieved community.

CONCLUSION

The findings from this study suggest that factors such as mistrust, superstition about the study, failure to respect culture and tradition, lack of understanding of the study and study benefits, fear of violence as well as inadequate community engagement process might be core factors associated with non-participation in a study. Superstition and fear is more marked when a study requires collection of blood specimen for testing. This then underscores the need for setting specific and appropriate community engagement processes as input, process and outcome of biomedical research.

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