

Factors associated with non-participation in a health study:
Observations from community engagement experiences in a home-based VCT randomized controlled trial in Monze.

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Dedication

This thesis is dedicated with love to my children (Mwiinga, Luciz and Muntanga) who gave me practical and emotional support throughout my study period.

I also dedicate this thesis to my late parents; Litaba Syanzila and Vivian Muthano Syanzila for the good parental guidance.

Declaration

I declare that the dissertation herewith submitted for the degree in Masters In Public Health (MPH) at the University Of Zambia has not previously been submitted by me for a degree at any other university or institution of higher education.

Signed: ----- Date: -----

Maureen Syanzila (Student)

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Abstract

Participation in research is crucial to the success of any study and it has been widely argued to be an important factor in conducting research and implementation of the findings. Non-participation has numerous consequences such as sampling bias, delays in completion of the study as well as increased costs (Williams *et al.*, 2007). For this reason factors associated with non-participation in a health study were explored in selected communities in Monze district.

Methodology

Qualitative approaches using ethnographic methods that included observation and contextualization were employed. Triangulation was achieved using observation, in-depth interviews and focus group discussions (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 key informants. Snowball sampling was used to select the 20 key informants. Data collected was transcribed replacing all identifiers with coded labels. Thematic content analysis employing iterative approaches and word processing guided the analysis. In addition, systematic textual analysis was used to highlight quotes that supported or refuted identified themes.

Results

Overall there were 20 in-depth interviews 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 from an intimate partner following HIV testing and disclosure of results, poor timing and prior negative engagements with the community.

Conclusion

The findings from this study suggested 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 were more marked when a study required collection of blood for testing. This then underscored the need for setting specific and appropriate community engagement processes as input, process and outcome of health research.

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List of Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
AVAC	AIDS Vaccine Advocacy Coalition
CDC	Center for Disease Control and prevention
CHW	Community Health Worker
CSO	Central Statistical Office
GHAP	Global HIV Program
HIV	Human Immune Deficiency Virus
MOH	Ministry of Health
NAC	Zambia National HIV/AIDS/STI/TB Council
UNAIDS	Joint United Nations Program on HIV/AIDS
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

Definition of key terms

Community is a term used to describe interactions among people in relation to a geographic location, with similar values, systems and cultural characteristics (Tindana *et al.* 2007).

“From a participatory research perspective ‘community’ ultimately can be defined in terms of those whose participation is necessary for the implementation of research and whose well being is likely to be affected by the conduct of the research” (CDC 1998).

Community engagement refers to “activities in which communities work collaboratively with the research team in decision making, problem solving and research implementation” (Global Campaign for Microbicide 2004).

Home based HIV counseling and testing is testing and/ or delivery of HIV test results at home rather than in clinics (Bateganya *et al.* 2007)

CHAPTER 1

1.0 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 (Meda, 2013). In the last decade, traditional community-based health research methods have been challenged due to limited community participation (O'Fallon, *et al.*, 2000). In order for community-based health research to be successful, it is imperative that the communities in countries that are heavily affected participate. Low and non-participation in a study has been reported to result in sampling bias, delays in completion of the study and increased costs (Williams *et al.*, 2007). On the other hand, it has been widely argued that participation is an important factor to improving health outcomes, including health research outcomes (Padarath *et al.*, 2006).

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 studies (Williams *et al.*, 2007). It is critical to understand factors associated with non-participation in a study to increase participation in future studies. So far, many attempts have been made to identify ways of increasing participation in both experimental and observational studies (Smeeth *et al.*, 2001). 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. It has also been observed that strategies that are highly effective for a particular group of people may be ineffective to the other (Home-based VCT RCT baseline survey initial report, 2009).

Understanding the factors of non-participation has been reported to enhance participation in research (Williams *et al.*, 2007). Engaging the community at all stages of the research process may be helpful in understanding the key factors of non-participation in a study.

1.1 Community engagement.

Understanding the social environment and behaviors is essential when considering increasing participation and requires engaging the communities under study. In epidemiological, health and social research, the process of community engagement is very critical (Sapienza *et al.*, 2007; Marsh *et al.*, 2008). It is particularly important prior to starting a new community intervention. This process provides the researchers information on the social environment as well as behaviors in the study environment; it also ensures community satisfaction and reduces misconceptions about the study (Morin *et al.*, 2003). Further it enhances the rate of enrollment, retention and stakeholder participation (O'Fallon and Dearry, 2002). Conversely it reduces refusal rate and attrition (Watson, 2005). For this reason, there is a growing realization that engaging the communities in health studies would greatly improve their participation.

Community engagement has been reported to significantly enhance participation in studies (Morin *et al.*, 2003). Participation in a study is very important. Merzel and D'Afflitti (2003) have shown that participation is valuable in a study because behaviour change is an absolute responsibility of the people in a community. Behaviour change is important in reducing incidence of illness within a population. Long-term health improvement is achieved and maintained when communities participate fully in health programs including research.

The process of community engagement has been reported to strengthen community participation in research (Dickert & Sugarman, 2005; Kenyon and Gordon, 2009). It is helpful in building trust and avoiding misinformation. It also allows interested parties to convey their views and/or concerns about a study (Sapienza *et al.*, 2007). This enhances transparency and accountability to the study population. Further, community engagement safeguards and empowers the study participants. For this reason, it has been recognized as an ethical requirement in studies involving humans. In fact, it is an obligatory requirement particularly if the study is conducted in the community (Council for International organizations of Medical Sciences, 2002). Dickert and Sugarman (2005)

proposed the following as the four ethical goals of community engagement; enhanced protection for subjects and communities, enhanced benefits to study participants or the study community and legitimacy through allowing the interested parties to express their views or concerns. Community engagement also ensures shared responsibility among the interested parties. Further this process is helpful in identifying the real stakeholders, conducting community sensitization and providing feedback to the study team.

It is crucial to engage communities prior to commencing a community intervention in order to have a good understanding of the community. It is also important during the study implementation phase as well as when disseminating the study findings to reduce misinformation and myths. When well conducted, community engagement has numerous benefits. According to Dickert & Sugarman (2005), it is beneficial because of the mutual relationship that exists subsequently. It leads to protection, respect and empowerment of the participants. It is also valuable in establishing, building trust and partnerships between the community and the research team.

Trust and partnerships are essential in community-based studies as they enhance participation. Community engagement also leads to increased transparency and accountability of the research to the community (Ramjee *et al.*, 2008; Slevin *et al.*, 2009). The other benefit of community engagement is that it builds a sense of community ownership of the study (Quinn, 2004; Dickert & Sugarman, 2005). In addition, it also helps in reducing misconceptions regarding a study. Moreover Community engagement has been reported to increase the rate of enrollment, retention and stakeholder participation. Conversely it reduces the refusal and attrition rates (Watson, 2005). Community engagement has also been found to decrease the stigma and discrimination associated with HIV/AIDS (The International AIDS Conference, 2008). HIV/AIDS was reported to be one of the highly stigmatized communicable diseases (UNAIDS, 2005) making it difficult for some individuals to participate in HIV/AIDS research.

1.1 The importance of community engagement in health research such as HIV/VCT studies

In health research engaging communities is crucial. Community engagement helps communities build a sense of ownership of a health program including research. The process of community engagement is far more helpful when conducting studies to respond to the numerous health problems such as low uptake of VCT (Mutale *et al.*, 2010). Historically, VCT has predominantly been provided in clinical sites. As shown by various studies, acceptability of clinic based VCT services has been challenging because of the following reasons; difficulties in getting to the testing site (Bateganya *et al.*, 2010; Obare *et al.*, 2009); understaffed health facilities, long queues and long waiting hours (Zachary *et al.*, 2005). These outlined factors have contributed to the low uptake of VCT in many places. In response to low VCT uptake, it has been theorized that providing VCT in other settings such as homes would enhance acceptability of HIV testing (Bateganya *et al.*, 2007).

Various studies have shown that home-based VCT has been found to overcome some of the challenges of HIV testing such as the difficulty in accessing the test and cost of obtaining an HIV test (Bateganya *et al.*, 2007; Lugada *et al.*, 2010). Lugada *et al.*, (2010) associated home-based HIV testing with higher uptake and increased identification of HIV-infected persons than clinic-based provision. Mutale *et al.*, (2010) related home-based HIV testing with very high uptake among the young people and groups with low educational attainment. This was further thought to significantly reduce inequalities in accessing VCT services. More community-based studies are required to provide more answers to the challenges in provision of health services such as VCT.

Community-based studies may be good sources of research data. Nonetheless, it is important to ensure adequate community engagement when conducting studies in the community to promote participation and retention. Participation is critical to the success of a community-based study. Misunderstandings and misconceptions can adversely affect participation. Adequate community engagement is vital in reducing misconceptions about the nature of a study (Morin *et al.*, 2003). It also helps in averting the

misunderstandings. Failure to ensure adequate community engagement would result in multiple challenges.

1.3 Challenges of community engagement

A community-based study or trial's success depends on adequate community engagement. In community-based trials, community engagement may help address the challenges of participant recruitment, participation as well as retention. On the other hand, inadequate community engagement can also negatively influence the future studies. Community-based studies can be challenging for multiple reasons that may include the following; fear and mistrust, perceived power differentials, cultural barriers, and difficulties in effectively communicating the benefits of participation (Dancy *et al.*, 2004 in Trinh-Shevrin *et al.*, 2007).

Therefore, the process of community engagement requires a variety of stakeholders. It is also likely that the community representatives such as the traditional leaders may not represent the community as is desired (Marsh *et al.*, 2008). The community engagement process may be helpful in identifying community members and stakeholders that have legitimate and relevant interests (Dickert & Sugarman 2005). Importantly, selection of the stakeholders must be done with the help of the communities.

In many developing countries community engagement may be challenging because of divergent reasons. At times this process may be dominated by political or other local agendas (Slevin *et al.*, 2009) rather than the interests of the community. This may cause dissatisfaction on the part of the community and study participants. In a number of developing countries, trials have been suspended or stopped due to inadequate community engagement (Slevin *et al.*, 2009). There are varied lessons to be learned from Cambodia, Cameroon, Ghana, Nigeria, and Thailand where studies to test the safety and effectiveness of using tenofovir disoproxil fumarate as an oral pre-exposure prophylaxis (PrEP) to prevent HIV transmission were discontinued (Tindana *et al.*, 2007; UNAIDS and AVAC, 2007; Slevin *et al.*, 2009). Clinical trials were started in 2004 in the five countries named above. In four of these countries except Ghana, the studies were

prematurely closed. Lack of meaningful community engagement of the local communities and civil society was reported to be the cause of closure of four of the clinical trials. The governments of Cambodia and Cameroon closed the clinical trial due to miscommunication and media reports (Slevin *et al.*, 2009).

The process of community engagement provides the study communities the necessary information about a study, before, during the study and when the results of the study have been disseminated. In Mazabuka District, Zambia some important lessons can be learnt on community engagement and dissemination of study results. Following the dissemination of the Microbicide trial results in Mazabuka, Zambia, many non-participants including a traditional ruler received the results with mixed feelings and bitterness. Chief Mwanachingwala of Mazabuka District was quoted to have been asking for the arrest of researchers and in another unpleasant incident a man was reported to have divorced his wife over failed Microbicide clinical trials (Robinson *et al.*, 2010). This called for intensive community engagement even after the study was over.

1.4 Thesis focus

This thesis has been undertaken with the view to attempt to discuss the factors associated with non-participation in a health study by examining the events that preceded the Home-based VCT Randomized controlled Trial (RCT) baseline survey in Monze District between 2009 and 2010. In so doing a conceptual framework derived from literature review and the precede-proceed model was employed.

1.5 The conceptual framework

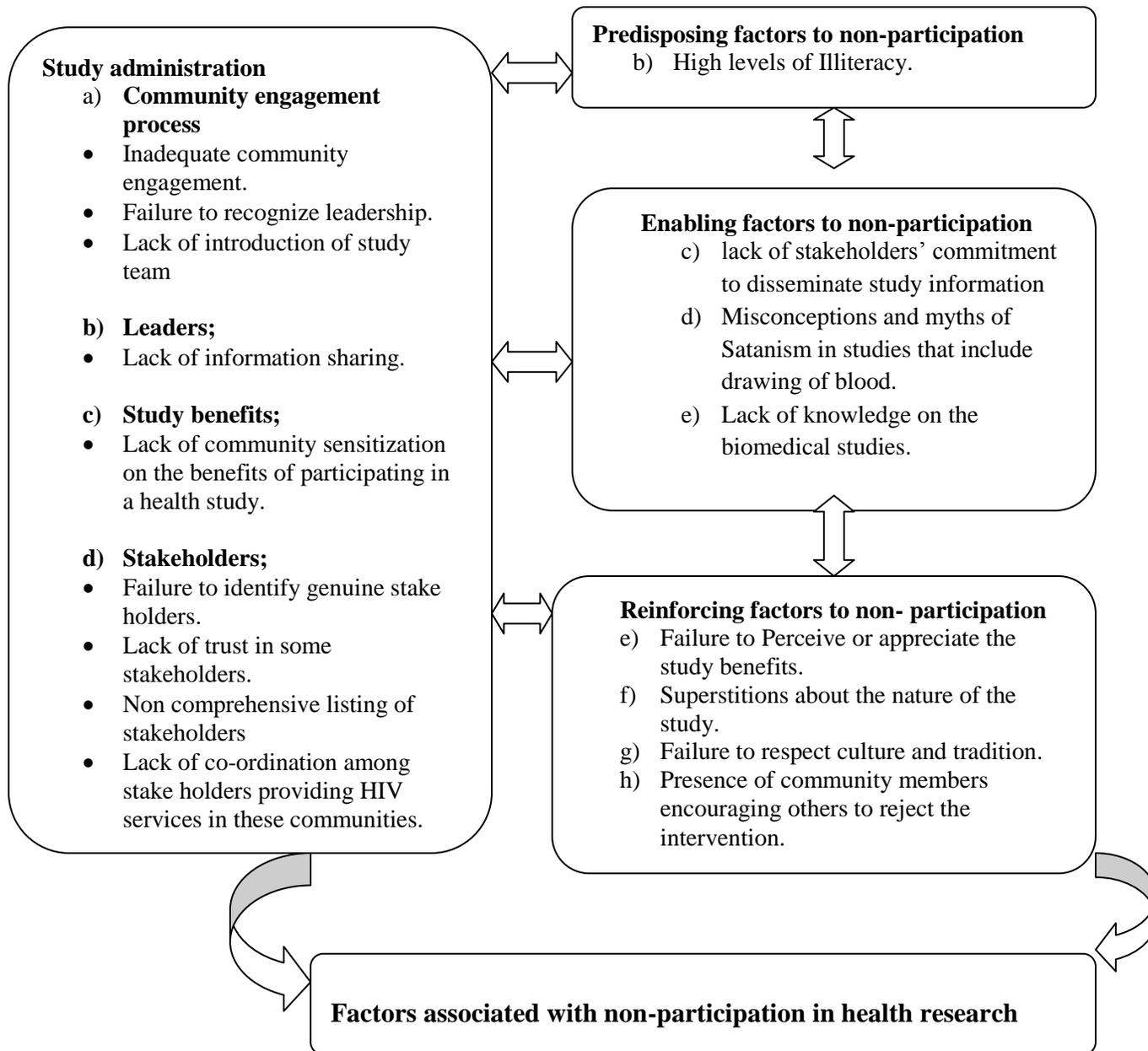
In order to ensure guided collection, analysis and interpretation of data for health research Boerma (2005) recommends that conceptual frameworks be used. The conceptual frameworks are a useful guide to ensure coherence in research. Literature review, phases four and five of the precede-proceed model (Green and Krueger, 1999) were used to identify factors associated with non-participation in a health study. The features of this model that were critical were the identification of predisposing, enabling and reinforcing factors to behaviour in this case, non-participation in a study.

The framework brings out the set of factors that the researchers must be mindful of when conducting a health study in a community. In this study, the precede-proceed model was used to understand factors that would predispose, enable and reinforce non-participation in a health study. This framework demonstrates how factors such as high levels of illiteracy and inadequate community engagement process can lead to non-participation in a study. The enabling factors to non-participation in this study included lack of stakeholders' commitment to disseminate study information, already existing misconceptions of studies that are related to drawing of blood and lack of knowledge on health studies among the study population. The reinforcing factors included; failure to perceive or appreciate the study benefits, superstitions about the nature of the study, Research Assistants failing to respect culture and traditions and presence of community members encouraging others to reject the intervention.

Factors related to the study administration include; inadequate community engagement process, inadequate community sensitization on the benefits of participating in a health study and failure to identify genuine stakeholders resulting from non-comprehensive listing of existing stakeholders. What is clear from literature is that taking into consideration the above factors may enhance participation in a health study. This means planning to engage the community fully prior to a study may help in identification of factors that lead to non-participation in a study. This consequently provides for planning for adequate community engagement process tailored to a specific community.

Even though this model does not take into account all possible complex interactions during the community engagement process in health studies, it is a useful tool in understanding the association between factors that may influence non-participation.

Figure 1 community engagement conceptual framework: factors associated with non-participation in health research



CHAPTER 2

JUSTIFICATION

While a lot of attention has been paid to solving health problems in the past decades, most of the interventions used have been ineffective as they have not been culturally tailored to the study communities (Gehlert and Coleman, 2010). Likewise, there has been inadequate community engagement in most of these studies (UNAIDS and AVAC, 2007). This has led to multiple challenges such as; miscommunication and negative media reports (Slevin *et al.*, 2009; Robinson *et al.*, 2010); fear, mistrust, cultural barriers as well as closure of some trials in a number of countries (Tindana *et al.*, 2007; UNAIDS and AVAC, 2007; Slevin *et al.*, 2009). According to Marsh *et al.*, (2008), there is also relatively little published experience of community engagement in practice in health studies.

During the home-based VCT RCT baseline survey in Monze District, communities from four villages refused to participate. Nevertheless the villages with the lowest coverage at baseline survey were excluded from the trial. Even so, it was important to understand their reasons for non-participation. The lessons learnt from this study are critical for future community-based health studies. Focusing on reasons for non-participation in community-based research would be helpful when trying to increase participation. Non-participation or low participation leads to delays in completion of the study, increased costs, sampling bias (Williams *et al.*, 2007) as well as reduced statistical power. Hence conducting this study was necessary.

CHAPTER 3

RESEARCH OBJECTIVES

3.1 General objective

To explore factors that are associated with non-participation in a health study.

3.2 Specific objectives

3.2.1 To determine the key stakeholders in communities.

3.2.2 To establish the requirements for entry to a community during a community-based study.

3.2.3 To establish factors associated with non-participation in a study.

CHAPTER 4

RESEARCH DESIGN AND METHODS

4.1 study Location (site) and population

The study was carried out in Chief Mwanza and Chief Chona areas in Monze District in Zambia. Monze is a rural District, in the Southern province of Zambia. The District covers an area of 6, 875 square Kilometers. Its population was approximately 190,000 inhabitants in 2010 (Monze District Health Office report, 2009). The main economic activity is substance farming and small scale businesses. The study area had three primary schools and one community school. Each of the two Chiefdoms is serviced by a clinic. The selection of the study sites was influenced by the fact that the home- based VCT RCT baseline survey took place in these villages.

The study targeted individuals that were living in the listed villages at the time of the home-based VCT RCT baseline survey. Key informants that were either male or female such as village headmen ward councilors, community health workers and community-based agents were included in the study.

The inclusion criteria were that respondents:

- Be 18 years and older.
- Must have lived in the selected village for more than one year.
- Accepted to participate in the study.

The exclusion criteria were respondents that didn't meet the above criteria.

4.2 study design

The research was an explorative study. Qualitative approaches using ethnographic methods that included observation and contextualization were employed. From a qualitative approach the participants brought out their own perspectives regarding non-participation in a study. The qualitative approach also allowed for probing of responses.

4.3 sample description

The study comprised of 8 focus group discussions with a sample n= 6-12 (overall n= 71) and 20 in-depth interviews with key informants. The key informants included the local leadership such as the village headmen and their committee members, community health workers, and other community-based agents. They were selected using purposive and snowball sampling.

Selections of study participants

The study focused on qualitative insights that were obtained through focus group discussions of community members and in-depth interviews of key informants in all the four villages included in the study. The focus group discussion participants were selected using purposive sampling to include heads of households and persons that were above 18 years. Key informants were identified using purposive and snowball sampling until saturation was reached in each of the four villages. The villages were selected purposively in order to obtain documentary evidence of the cause of lack of participation in the home-based VCT RCT baseline survey in four villages in Mwanza and Chona areas.

4.5 Data collection and analysis

Qualitative approaches using ethnographic methods that included observation and contextualization were employed. Triangulation was achieved using observations, field notes, in-depth interviews and FGDs. Participants were stratified by sex. FGDs were conducted with participants of the same socio-economic status, background, and sex in order to facilitate free discussion. The interviews and group discussions were conducted in Tonga, the local language and were audio taped for transcription following the informants' consent. Data collected was transcribed replacing all identifiers with coded labels. Thematic content analysis employing iterative approaches and word processing guided the analysis. In addition, systematic textual analysis was used to highlight quotes that support or refute identified themes.

The study tools were pre-tested to ensure consistence of questions and quality of data that was generated; to draw out flaws in the data collection tools, such as ambiguity as well as to ensure the tools generated the desired responses. The data collected using the tools was reviewed to ensure that the tool generated meaningful data. The Research Assistants were also trained prior to data collection to enable them collect quality data. Probes were used to encourage the respondents to elaborate their answers.

4.6 Ethical consideration

Permission: Approval to conduct this study was obtained from the University of Zambia (UNZA) Health Research Ethics Committee. Written permission was obtained from the Monze District Medical Office. Verbal permission from Chiefs Mwanza and Chona to conduct the study in their villages was obtained. Verbal permission was also obtained from

the village headmen in the relevant villages to ensure the headmen had full knowledge of the study. This also ensured the Research Assistants were permitted to enter the villages for data collection.

Consent: Consent was sought from the study participants at the beginning of each interview and focus group discussion. Permission to record the discussions was also obtained from the participants. It was explained to the study participants that they had the freedom to terminate their participation if they so wished without facing any penalties and that there was no physical harm or risks to their lives that were associated with participating in this study (Appendix 7).

Confidentiality and privacy: The records were allocated numbers to identify the data with the respondents. The computer was protected with a password that prevented unauthorized access to data files. The data that was generated was kept as confidential. Only the researcher had access to the transcribed data files. Anonymity was achieved by not mentioning names of respondents or names of the villages where the respondents were drawn from.

4.7 Pre-test

Data collection tools were pre-tested in a non-study site to establish validity. The activity was important to ensure consistence of questions, quality of data that was generated and also to understand the data collection tool. The villages where pre-testing was done had similar characteristics to those of the study site.

CHAPTER FIVE

Research results

5.1 Demographic characteristics of the respondents

Eight Focus group discussions (FGDs) were conducted by the Investigator as the moderator assisted by a note taker. These FGDs were conducted in Tonga, the local language in the study area. The overall sample for FGDs was n=71. To ensure anonymity no names or initials were used. Each FGD consisted of 6 to 12 respondents. The FGD participants were stratified by sex and included community members that were aged 18 years and above. Of the 71 respondents, 31 were female and 40 were male.

Twenty in-depth interviews were conducted with key informants. These interviews were all conducted in Tonga and they lasted between 45 to 60 minutes. The key informants were drawn from 4 villages in Chiefdoms Mwanza and Chona. In each of the Chiefdoms, 2 villages were selected using purposive sampling to include only the villages with low baseline coverage during the home-based VCT RCT baseline survey or the villages whose communities refused to participate.

In each of the four villages five key informants were identified using the snowball sampling method that began with identification of the village headman. The key informants comprised of 7 females and 13 males. Most of the key respondents were aged between 25 and 49 years. They included the village headmen, village committee secretaries, traditional birth attendants, wives to the headmen, home-based care providers, CHWs and neighborhood health committee members. Overall there were more male (58.2%) respondents than female (41.8%).

There were only Christian denominations present in this area. Of the 91 respondents 37.4% were Salvationists, 31.9% were Catholics, 28.6% were seventh day Adventists and 2.2% were from other churches. Majority (62%) of the respondents attained primary education only while 10% attained senior secondary education. The majority (96%) of respondents were married and 32% of them were in polygamous marriages.

There were no substantive variations in the remarks of in-depth interview respondents and focus group discussants. The findings from this study demonstrated that adequate or well thought community engagement activities could enhance participation in health studies.

Participation in any study is cardinal to prevent sampling bias and encountering high costs of conducting the study. To achieve full participation, there must be adequate and specific community engagement processes that are suitable for the study community. It is important to fully engage the community throughout the research period and after dissemination of the study results. However, researchers must appreciate the significance of recognizing the differences in community dynamics if there is to be a meaningful community engagement process.

Monze home-based VCT RCT baseline survey initial report (2009) provided evidence that even when communities were proximal, enormous differences existed in how they reacted to the same study. In this study, communities that refused to participate in the home-based VCT RCT baseline survey or had low coverage were found to be proximal to communities that attained high baseline coverage. Non-participation in the study was influenced by a variety of factors such as; lack of understanding of the study, study benefits, mistrust, superstition, fear of strangers, failure to respect culture, male partners declining to consent to test for HIV or participate in HIV studies, fear of violence by an intimate partner, poor timing and negative prior engagement with the community.

From the numerous responses, themes to help understand what led to non-participation were identified. These are the common themes that were identified;

1. Entry to a community
2. The key stakeholders in the community.
3. Reasons for non-participation in the home-based VCT RCT baseline survey.

5.2 Discussion of the research findings

5.2.1 Entry to the community

Gaining entry to the community is among the first important steps taken when conducting a community-based health study. It provides knowledge on the existing community structures. It also helps in identification of relevant community leaders. During this stage of the study, great care must be taken not to disturb the existing community structures. This helps the researchers gain co-operation of the host communities.

Regarding entry to a community, the responses from the participants were similar. Many respondents mentioned the headman and his committee as the first people to meet in a village when conducting a study. A key informant said,

“Before you start...you first see the headman. After that we the village committee members and our community must have a meeting before you people start your program so that we explain to the people that there is something new coming...we explain to them what it is they are to expect. Those who wish to participate, let them agree, those who don't want let them refuse...”

These findings suggested that community working groups could strengthen the community engagement process. In this study, the village committees with the headmen were cardinal in explaining to the community that there was “something new” meaning a study in their community. These findings are similar with those of Ramjee *et al.*, (2010) who reported community working groups to be useful in conveying correct messages to the community, thereby dispelling myths and misconceptions.

The above finding seemed to imply that a systematic community engagement process was important to enhance participation. In the above citation, the respondent seemed to suggest that this ought to be done before the researchers enter a particular community. The respondent also seemed to suggest that following the researchers gaining of permission from the traditional leaders to conduct a study, it was important that the community met to discuss the study. The rationale of this meeting was to provide the community with the necessary information about the study. This meeting would provide the community an opportunity to understand the fundamental elements of the study such as informed consent, the prospective study benefits and risks to the potential participants. The initial meeting was expected to include information on who was eligible to participate, explanations on the recruitment

process and the study objectives. Knowing the study objectives would enable people to make decisions to participate in a study or not. This would consequently enhance participant autonomy. This thought was also shown in the following narrative,

“....at the first meeting, we would like to be told about the program, so that we know what to expect...we can decide to participate or not...otherwise it will be difficult for you....”

The above citation showed that participation in a study was also influenced by understanding the research process. Participation is important if solving health problems requires only the community. These findings could also suggest that for a study to have a positive impact, the study community should fully participate. They must feel ownership of the research process so as to give out accurate information and suggestions of best ways they can improve their own health. More recently, researchers have called for a renewed focus on an ecological approach that recognizes that individuals are surrounded by multiple factors that may shape behaviors and participation in interventions that maintain health (Israel, 2000 in O’Fallon, 2000). Therefore, it is very important that researchers and the community representatives identified existing community structures, beliefs and behaviors that would influence participation negatively or positively.

Notably, identification of legitimate community leadership was fundamental and could be achieved during the preliminary community meetings. These findings; regardless of age, residence or whether the respondent was from the focus group discussions or an in-depth interview was key. Acknowledgment of the traditional leaders was perceived very essential in a community-based study. Importantly, it was reported that to minimize challenges associated with the entry into a community it was important to recognize the authority of the village headmen. Moreover failure to recognize traditional leadership was said to lead to non-participation by almost all respondents. One of the key informants said,

““If you pass through the headman, there would be no problems. It can be easy when he introduces you to us.... if you fail to respect him...you will fail to carry out your program here. No one will listen to you. We don’t know you here....”

Introduction of the researchers to the community prior to the initiation of the study was very vital. This seemed to enhance co-operation between the host community and the researchers. The findings above also showed that failure to ensure the research team was introduced by the community leader who was a village headman in this study, led to difficulties when

conducting a community-based study. Significantly, trust in the village headman was the motive for participation for most of the respondents. Therefore, it was not surprising that in the villages where the people lacked trust of their headmen, the Research Assistants experienced and reported more difficulties than in the other villages. The findings of this study also revealed that in villages where the headmen were not trusted, refusal to participate in the Monze home-based VCT RCT baseline survey was reported by most of the respondents.

The findings further suggested that there must be a diverse combination of stakeholders in the community engagement process to supplement the efforts of a traditional leader. Furthermore the findings suggested that the process of community engagement must incorporate efforts of the informal leaders. This thinking is outlined in the following narrative,

“...This is how we want you to come to our village; you go to the headman first for permission. When you find the headman, ask him where you can find the person who works at the health centre (CHW)...ask him, can these people agree to participate in this? (meaning the study) at least there must be one person that we know in your program....”

Acceptability of communities to participate was linked to the participation of locals such as the CHWs. In this study, most of the key informants mentioned that it was important to include the CHWs in any community-based health study. This thought was reasonable considering that CHWs are well known in their catchment areas and they are already providing some health services. This thought seemed to suggest that the CHWs were trusted by their communities. It was easy to think that CHWs were also well respected in their communities and their exclusion from the study could be received with mixed feelings by their community.

Inclusion of the informal leaders in the community engagement process was also reported to be useful in learning and understanding the nature of the study communities; in terms of what they were able to accept and reject. This seemed to be exceptionally necessary when offering a new health invention or service to a community where little was known about the community and how they would react. Therefore, engaging well respected and trusted community volunteers as significant partners seemed to be very helpful in overcoming hostilities to the study.

5.2.2 *The key stakeholders in the villages*

Community-based health studies require the full support of the host communities. Identifying and working with key stakeholders is very useful in a community-based study. Strategic participation of major stakeholders from mixed backgrounds and understanding about the community is vital in the development, implementation and dissemination of study results (Pinto, *et al.*, 2008). This ensures that the study has social and cultural relevancy. The community engagement process provides clues to the researchers on the cultural, social issues important in their study communities and the relevant stakeholders. For this reason, the key informants were asked who the most important stakeholders were in the community engagement process. The majority of the key informants perceived traditional leaders, CHWs, the local community radio station (radio Chikuni), the Chikuni parish home-based care unit and other informal leaders that were respected in the community as the key stakeholders in the community engagement process. Particularly, the traditional leaders were frequently cited as key informants. It should be noted that acknowledging and respecting the traditional leaders was of great value to the study, the potential participants and the host communities. The study also revealed that participation of traditional leaders in the community engagement process was thought to influence participation positively. Further, the findings showed that the participation of traditional leaders created some reassurance for potential participants that the study was good and probably that there would be no exploitation. This thought was supported by the following narrative,

“...Each village headman has a committee; the first time you come here, please don’t forget them so that your job is clear to all.....when our traditional leaders participate, we know that the program is good and clear...our headmen can even help you explain some of these things. It is also good when .our leaders have been recognized too...”

This quotation suggested that the traditional leaders were very important in the community engagement process. Most of the traditional leaders were held in high esteem by their communities and their recognition by the researchers was valued. Their participation in a study was thought to signify clarity of the study. Consistently, clarity and understanding study objectives were among the reported key reason of participation. It is important to ensure that every thing possible was done to enhance clarity and understanding of the study objectives during the community engagement process to enhance participation. The quotation above was supported by the following citation,

“...it is easy to participate in something you understand very well. Most often when the program is clear many people participate...”

To achieve full participation and enhance retention in a study, the study findings revealed that it was cardinal to consider the traditional leaders as equal partners in the community engagement process. However, it was also important to ensure that other village committee members were included to complement the efforts of the traditional leaders. This point was illustrated in the following citation,

“...the headman must not be alone...we need more people as you know “munwe omwe tu pwai njina” (one finger cannot crush lice...A Tonga saying meaning one person can't perform a task efficiently and there is need to work with others).

The respondents acknowledged the important role multiple stakeholders played in a health study. The above citation showed that combined efforts were recognized as vital. This finding was consistent with the findings of Ramjee *et al.*, (2010) who reported the significance of involving a wide range of community leaders when setting up community-based research. While most of the research participants indicated trust of the local leader as a motivator to participation, there was an apparent distrust in some of the headmen. It was therefore not surprising that in villages where traditional leaders were not trusted or appreciated, their subjects refused to participate even after their leaders had addressed them. This thought was supported by the following extract,

“...when I talked to them about that program they didn't trust me. They accused me of selling them (community members) to the 'strangers' (researchers) who were coming to this village asking questions.....”

The narrative above showed how trust in the traditional leader during the community engagement process was paramount. Inclusion of other village committee members in the engagement process seemed to ease mistrust. The above extract illustrated that participation in a study was founded undeniably on trust. This finding seemed to agree with results of the study conducted by Pinto, *et al.*, (2008) that showed that Community-based studies ought to be founded on trust and commitment that culminated in meaningful social support and improved health status. In this study, some respondents thought if the village committee members were also included in the initial community engagement process they would also

benefit from the accurate or 'first hand information'. This thought was supported by the following excerpts,

"...some headmen are not trusted ...include other village committee members in your first meetings, at least we will have first hand information.... so that we can hear the truth..."

"...you must know that it is not all who show up or speaks well people who can represent us...I think if we choose these people to represent us; it would help us and you...."

This excerpt seemed to suggest a lack of trust in some community leaders. It was probable that the opinions of some of the community leaders were not all appreciated. The excerpt above also may have suggested that this community preferred to choose their representatives. Based on these findings, it was therefore, possible to recommend that the process of community engagement included a wide range of stakeholders that were chosen with the help of their communities. This would be helpful in identifying people that could truly represent the community. Further, it was found that some community-based agents and local clinic staff were also considered as significant partners in the community engagement process. Most of the village committee members felt that other than the formal traditional leaders, community health workers (CHWs), neighborhood health committee members as well as local clinic staff, there were other important stakeholders in health related studies. For instance, one of the Village committee members said,

".....If you want to do anything here, the people you must first pass through are the Chief, senior headman, the other village leaders, community health workers, neighborhood health committee members, businessmen as well as the local clinic staff...."

This respondent implied that if any organization was to offer any service in the villages, they had to acknowledge the traditional leaders first. Apart from the traditional leaders, the local health centre staff and CHWs, the businessmen were other important people in his village and they had to be included in the community engagement process. The above response seemed to suggest that the community members wanted to have a wide range of community representatives apart from the village headmen and the Chiefs. This would ensure that non-formal leaders were included in the community engagement process. While there was evidence of wanting the headmen to be included unanimously in the community engagement process, other respondents strongly suggested inclusion of other stakeholders such as businessmen. Similarly, in some villages, the non formal leaders were reported to be more

influential than the traditional leaders. These often determined the course of action for the majority of the community members. In one of the villages, it was noted that a businessman was remarkably influential. He was more authoritative than his village headman. In all the four villages, CHWs were well respected, mostly because of the health services they provided in the communities. It was clear that they were not to be overlooked. These findings may also imply that communities in this study site were comfortable with being represented by less formal community representatives, provided they are trustworthy.

Regarding community sensitization, most of the respondents felt it was the responsibility of the village headmen to call his subjects so that they could be sensitized on the study. A male respondent from a focus group discussion said,

“.....The village headman has the authority of calling all his subjects so that people may get sensitized. If there are any questions they would ask.....”

This finding suggested that the village headmen still played a significant role in sensitizing their community as well as providing responses to some queries that the community members would have about the study. By this statement, the respondent seemed to imply that following the initial community engagement process the village headmen were required to explain to their subjects the purpose of the new study that would take place in their area. This would allow people to ask questions and receive clarifications where necessary. Therefore, this process would help in clarifying any queries the community would have prior to the commencement of the study. However, this called for provision of adequate study information to the traditional leaders. The study findings also revealed that in the villages where the headmen never called meetings to discuss the home-based VCT RCT baseline survey, most of the community members refused to participate.

Based on the above findings, it could be suggested that for a community-based study to be successful a variety of stakeholders were required. This would provide essential knowledge and experiences about the study population. The study results also showed that apart from the traditional leaders and the other reputable community members, the local community radio station was considered another key stakeholder in a community-based study. In this study, the local community radio was reported to be a reputable source of information. Many respondents perceived the community radio station (radio Chikuni) to be a major source of information on the subject of HIV/AIDS and VCT in this area. A key informant said,

“You can use radio Chikuni to inform us about HIV/AIDS and VCT programs. They have programs for HIV/AIDS.many people listen to these programs and we follow them well.....”

It was likely that messages provided by the local radio station (radio Chikuni) on subjects such as HIV/AIDS or even VCT were well received and considered as valid by the community. Most of the respondents considered the local radio station to be a reputable source of HIV information. Respondents from focus group discussions and in-depth interviews shared similar sentiments that Chikuni community radio station was a trusted source of information. This confirmed that the local radio station was a good source of information in this area.

Engaging already existing stakeholders such as radio stations in the community engagement process would help overcome some of the barriers to participation such as mistrust, superstitions and miscommunication. A male respondent from one of the focus group discussion groups said,

“Radio Chikuni is important. Many of us listen to it. If you tell us you are coming through the radio, many people will hear it. Even if the program is new we will be ready for you without confusion. You know, that radio station is for the church and there is no Satanism there, so people won't be afraid”.

Radio Chikuni was thought to be an important stakeholder in providing the communities with the necessary information because it had a very wide coverage. It should be noted that even if the community had marked superstition of ‘Satanism’, the radio was considered an unmatched outstanding source of health and research information. It can be suggested that in these communities, the community radio station was an important stakeholder in breaking the myths and misconceptions the community would have about the health studies especially myths of ‘Satanism’.

Chikuni parish home-based care unit was also perceived as another important key stakeholder in the provision of VCT and HIV/AIDS related services in this area. One of the key informants said,

“...Here, you must work with the Chikuni Home-based Care. I say so because they are the ones that provide that kind of service (VCT). Every month there is a day they come to Kayola

(an outreach post) *to test and teach us. Here people know that VCT.....it is 'Mrs. N* and her team'... They don't run away....we are used to her program...*”

By this statement, the respondent may have implied that for any HIV/AIDS study or even a new organization providing HIV/AIDS and VCT services to be accepted in this area (Hachizangwa and Hamachenje villages in Chief Chona Chiefdom) they had to work in partnership with Chikuni parish home-based care (HBC) unit. Its long standing existence in this area made it a very strong stakeholder when providing HIV/AIDS interventions, particularly VCT services or research. It was well known, trusted and well established in this area. This implied that comprehensive listing of organizations in a particular area was vital before planning on whom to include in the community engagement process. Listing of the existing stakeholders required the help of the local leaders, local clinic staff and the community volunteers providing health services. It was also easy, therefore, to recommend that organizations that were already present in a particular study site be integrated in the community engagement process. This was because they had great experience that would provide important insights and had gained trust over the years through the long standing relationships with the host communities. This would lead to a rich understanding of the nature of the study community. The organizations that had worked in an area over a considerable period of time would have valuable lessons that would be very helpful in the community engagement process.

Characteristics of an ideal stakeholder

The respondents were requested to mention some of the characteristics of what they considered an ideal stakeholder in the community engagement process. Respondents' opinions were similar as most of them preferred a mature person, of good character and record, able to read and write in English, able to understand complex information and one that would maintain confidentiality (“sicaamba”).

Fundamentally, entry to the study community and identification of the key stakeholders in the communities were some of the key administrative issues when conducting a study that couldn't be disregarded. From the findings above, adequate community engagement process, recognizing local leadership, introduction of study team, information sharing, adequate community sensitization on the benefits of participating in the health study, identification of genuine stake holders, trust in the stakeholders, comprehensive listing of stakeholders and co-

ordination among key stake holders in these communities were imperative for the success of a community-based study.

5.2.3 Reasons for non-participation in the home-based VCT RCT baseline survey

Multiple factors may lead to non-participation in a study. Understanding the factors underlying refusal to participate in a study is critical. The results of this study revealed some key factors that were thought to be linked to non-participation in the home-based VCT RCT baseline survey in Monze were; Lack of understanding of the study, study benefits, mistrust, superstition, fear of strangers, failure to respect culture, male partners declining to consent to test for HIV or participate in HIV studies, fear of violence from an intimate partner, poor timing and negative Prior engagement with the community.

Lack of understanding of the study

It was found that majority of the respondents did not understand the home-based VCT RCT baseline survey. This was one of the outstanding reasons for non-participation. In this study, 71.4% of the respondents cited lack of understanding of the study as one of the reasons for not participating in the home-based VCT RCT baseline survey. This was shown in the following excerpt

“.....we didn't understand that program well...”

This appeared to be in accordance with the findings of Mfutso-Bengo *et al.*, (2008) who reported ignorance about research as one of the factors associated with non-participation. People usually participated in activities they understood well. For that reason, it was not surprising that those who did not understand the research process did not participate. One respondent from the focus group discussion said,

“This ‘thing’ (research) is new in this area; therefore many of us did not understand why we were being followed in our homes that time...we feared that we were going to be forced to test...we also did not really know the machines they were using that looked like a phone ...many people did not know those machinesand where they were taking that information...”

Few health studies, particularly community-based studies have been conducted in the villages in Monze District. In Njola Mwanza and Chona villages, the respondents said it was “new” being followed in their homes by researchers. Sixty-three percent (63%) of the FGDs

participants reported that they did not understand the explanation they received about the home-based VCT RCT baseline survey. From the above citation, the key misconception was that the participants would be “*forced to test*”. This greatly contributed to non-participation. The above citation also revealed that the community had fears of the data collection tools. They feared and had misconceptions regarding the personal digital assistants (PDAs) that were used to collect baseline information. This finding was not different from that of Ramjee *et al.*, (2010) who reported fears of the data collection tools by respondents that the GPS [Global Positioning System] machines were perceived to put “*people and their families in danger*”. It was therefore, important that using simple language, the Research Assistants always explained the instruments used to collect data so as not to cause unnecessary anxiety.

Most of the respondents also linked refusal to participate in the home-based VCT RCT baseline survey to their low education levels. The educational levels of majority of the respondents were very low. Only 10% of the respondents attained senior secondary education. Similarly, some of the respondents perceived low education as a major contributing factor to difficulties in understanding the research process as shown in the following citation from an in-depth interview,

“.....In the villages we are difficult, we delay in understanding issues. We are not very educated so it is not easy for us to understand.....”

The respondent perceived low or lack of education to cause failure in understanding and comprehending new concepts in their domain. The respondent viewed education as key to understanding and embracing new concepts. This finding seemed to suggest that planning for basic research education be a component of the community engagement process. This could be helpful in providing the community with general information of a study. This would be especially helpful when providing information to communities in areas where no study had been carried out before. However, immense care needed to be taken to ensure the information package was in accordance with the educational levels of majority of the community members. There was also need to make the information package attractive to the potential study participants.

Lack of interest in learning new concepts and HIV/AIDS related issues could pose some challenges during the community engagement process. One of the respondents said people in his village distanced themselves from learning, especially HIV related issues. He said,

“.....concerning Education, mostly, in this village we strive to distance ourselves..... We are told; let us learn about HIV, you hear people saying; ah!! If we insist talking about HIV, others stand up and walk away.....”

By this statement the respondent was implying that people in this village were apathetic when discussing HIV/AIDS issues. He attributed the apathy to lack of interest in learning. The above citation also showed that HIV/AIDS was still a highly stigmatized condition in this respondent's village. This finding was similar to the report of UNAIDS (2005) that AIDS was a highly stigmatized condition. Further, previous studies showed that stigma was an important barrier to participation in a study (Padarath *et al.*, 2006). Therefore, it was not surprising that some people in the study area refused to participate in the home-based VCT RCT baseline-survey because of its link to HIV/AIDS.

According to Padarath *et al.*, (2006), stigma could be at the level of an individual, household or community. In the above citation, the respondent seemed to suggest stigma at community level to be one of the key barriers to participation in the home-based VCT RCT baseline survey. When stigma was at the level of the community it was difficult for community members to fully participate in a study that ultimately led to knowing their HIV status. It is important to appreciate that stigma was not only an important barrier to participation in an HIV/AIDS study but could consequently lead to delays in testing and initiation of antiretroviral treatment (ART). Fear of being stigmatized could also compromise adherence to treatment for those who needed ART.

It was also possible that due to the low levels of education, the people in this study area did not understand the purpose of the home-based VCT RCT baseline survey. If this reasoning was correct, the communities would have participated in the study if they had understood the purpose of the home-based VCT RCT baseline survey. The findings also suggested that had the study been on another subject matter other than HIV/AIDS many more community members would have participated. This was also revealed in another respondent's sentiments. He said,

“.....The problem is this, people never come when invited to learn about AIDS... unless you include AIDS while talking about other things. If you directly invite people to talk about AIDS messages, people will not agree..... People fear what they put in their minds when they are thinking of testing”

Discussing HIV/AIDS in this village was problematic because people were not very enthusiastic. It was found that HIV/AIDS messages could only be accepted when included in other messages. It would never be a main message as people would not attend that particular meeting. This citation suggested that strengthening HIV/AIDS health education in this study area would create demand for HIV/AIDS related services and consequently increase participation in HIV/AIDS/VCT studies. The most striking reason for non-participation in the above citation was the fear of testing for HIV. The study findings further showed that fear of testing was an important barrier to participating in the HIV/AIDS and VCT activities in these villages. It was therefore, not surprising that people in these study areas refused to participate in the home-based VCT RCT baseline survey because of fear of positive test results. If this thought was valid then it is important to strengthen the messages on HIV/AIDS, especially, the benefits of testing and positive living.

Lack of understanding of the study benefits

The study results showed that informing the community the potential study benefits was essential. Knowing and understanding the study benefits was likely to enhance participation. This was supported by the following citation,

“.....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 revealed that being ‘educated on the benefits of testing’ was one of the greatest needs 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. The respondent seemed to suggest that knowing the benefits of testing would help prevent the infections that were thought to be occurring daily and leading to numerous deaths. Consequently, the demand for HIV/AIDS services would also increase. Therefore, the delays in seeking treatment and deaths due to AIDS-related causes would decrease. This thought was 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 (Alemie and Balcha 2012). Early diagnosis and ART is crucial in the care of people living with HIV and those suffering from AIDS.

Study benefits

The types of study benefits were also an important reason the community chose to participate in a study. 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, the respondents preferred material benefits such as receiving a bicycle. Most (60%) of the respondents seemed more 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.... I will 'campaign' for you. If you came the next day; all the people here will agree to take part in what you are doing...they will even test for HIV....."

From the above citation, this key informant suggested that he had the capacity to encourage people in his village to participate in the survey. Similarly he also had capacity to discourage them. Unfortunately, he was only concerned with what he was going to obtain from the study. Even though coercion is unethical, it was important to appreciate that some community members could coerce others not to participate if they did not perceive personal gain. This type of reasoning and behavior was common in Moomba village only. This was shown in the following narrative,

"....we were told to refuse to participate in that program..."

If the above thinking is correct, 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. Therefore, it is possible to think that some people did not participate because of the failure to perceive the study benefits during the home-based RCT 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...”

The other respondents expressed concerns of the researchers exploiting the community. They felt that the researchers received more gain than the study community. This thought was interrelated with feeling vulnerable and used. This is shown in this narrative,

“.....we know that they are paying those people who came here a lot of money because of our answers...”

This finding was not divergent to those of Schulz-Baldes *et al.*, (2007) who stated that researchers' benefits usually outweighed the participant and community benefits. Hewison and Haines (2006) also reported research to be considered a “morally suspect activity conducted in pursuit of researchers' private interests”. Similarly, these thoughts were also cited by a female respondent from an FGD, who said,

“...How else can you explain their persistent coming to our village? Then when they come to us they say ‘test’ that is your benefit...what benefit is this when I can go to the clinic on my own?”

From the citation above, the respondent seemed to suggest the researchers' main motivation in conducting research was their gain from the study than the benefits or needs of the study participants. The study findings also revealed that some respondents felt their pressing health needs were neglected and the researchers were more concerned with their study. This was shown in the following narrative,

“...here in Nkaaba A village, our problem is that drinking water is poor...livestock and people drink from the same source.....now that you people are only coming for HIV/AIDS....that is all you want from us.. What about our problems?”

This finding was in accordance with the findings of Pinto *et al.*, (2008) who showed that the researchers' assessment and knowledge of the needs of their study community was important. Therefore, there was great need for the researchers to develop close relations with the study communities. This could be helpful in the identification of the communities' felt needs. Moreover, it is imperative that studies have a component of social responsibility to their study communities. This would provide the researchers an opportunity for collaborating and networking with other stakeholder. Failure to ensure that the critical needs are met leaves the community feeling vulnerable and used.

Mistrust

Winning over the communities' trust is a big positive step in a study (Pinto *et al.*, 2008). Mistrust was another important issue that surrounded non-participation in the home-based VCT RCT baseline survey. When the key informants were asked why they did not participate in the study, many (15/20) cited lack of trust to be the cause of non-participation. This was shown in the following narrative,

".....We ran away from our homes to hide in the bush because we did not trust the program..."

By this statement the respondent was implying that the community members fled their homes because of lack of trust. Trust was very important for meaningful participation to ensue. Similar findings were reported by Masiye *et al.*, (2008) who cited trust as the reason why participants enrolled in a study. It was unlikely that communities would accept to participate in a study if they lacked trust in the study or the researchers. The finding was similar to that of Zachary *et al.*, (2005) 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. In this 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 was 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 out side 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 could be overcome by including local clinic staff in the study. In his opinion, this respondent suggested that trust in a study would be enhanced if the local clinic staff were part of a study. He seemed to think it was difficult for people in his village to believe that researchers who were strangers would be so concerned about their health. According to the narrative above, the local clinic staff also played an important role in ensuring a trusting relationship between the researchers and the study community was achieved. Poor or lack of communication among stakeholders seemed to contribute greatly to the questioning of the trustworthiness of the study. This thought was supported by the following citation,

“...we asked the nurse at the clinic if she knew this program. She did not know them now because of that we felt that those people were not to be trusted....”

From the above citation, health workers at Njola Mwanza and Nampeyo rural health centers that provide health services to the two Chiefdoms did not know about the home-based VCT RCT baseline survey that was being conducted in their catchment area. The brief lack of communication between the District Health Office and the health centers impacted negatively on the study as the communities thought the study wasn't genuine. It was also found that the Research Assistants did not pay a courtesy call at the health centre. This would have helped verify whether the health centers had been reliably informed and oriented about the research process. This was shown in the following citation from a health worker,

“I did not know anything about that study until the community representative asked me. Then 2 senior staff from the District Health Office visited the health centre to explain the study. But this was after the research team had experienced great difficulties in the villages. Most of the people were running away from them...”

Poor communication between the researchers, District Health Office and the health centers in the study areas at the time of the home-based VCT RCT baseline survey appeared to have led to immense mistrust of the study by the concerned communities. This thought was supported by the following citation from a community-based agent, who said,

“We have people who govern us in our village and these were not respected at that time Firstly I requested for a document/letter from the headman or the local clinic, they (Research Assistants) didn't have it. Secondly, I inquired as to whether they had passed through the clinic, they didn't, and thereafter I had to refuse to accept anything from them...”

The results from this study also indicated that refusal to participate in the survey was also due to misunderstanding the study. For many of the respondents, trust and understanding the study was one of the most important reasons for participating. These findings were similar to those of Williams *et al.*, (2007) where people refused to participate in a study because they misunderstood the nature of the study. In this study, lack of trust often worsened by misunderstanding seemed to be a significant barrier to participation. It was therefore, important that an adequate community engagement process precede a community-based study to ensure the community understood the study.

Negative media reports on the Microbicide Development Program (MDP) that was conducted in Mazabuka, a District near Monze may have compounded the problem of misinterpretation of research in this study area. Following the negative media reports and non-reputable information, many respondents said they found it difficult to trust researchers. This seemed to consequently result in the non-participation. One key informant said,

“...I heard about something like that in Mazabuka.... there were stories of how a program (referring to MDP) infected women with HIV...here it was difficult for people to take part after learning such things. They can't trust anyone...If you can find a way the people can trust you, it can help you...otherwise it will be hard for you....”

These findings reaffirmed the results of Ramjee *et al.*, (2010) who reported that some of the common myths and misconceptions that surrounded their study were that "researchers infect women with HIV". This citation also seemed to be in agreement with the findings of Pinto, *et al.*, (2008) who reported that trust was important when conducting a study in the community. Nonetheless, the respondent suggested the involvement of people who are trusted by the communities to be one way to reduce mistrust.

Superstition

Superstition was an important barrier to participation in this study. Superstition 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' was indisputable fear that had been reported elsewhere in Zambia (Zachary *et al.*, 2005). Equally, fear of 'Satanism' was wide spread in this study area. The fear of 'Satanism' was real and it had been reported in the past in a HIV testing study in Lusaka, Zambia. In that study 97.8% of the respondents had some superstition, Chiefly Satanism. The key reason for the superstition was that, the survey involved drawing of blood (Zachary *et al.*, 2005). Similarly, many of the respondent in this study suspected that their blood would be used for 'satanic' purposes. This finding was consistent with the findings of Zachary *et al.*, (2005) where many people interpreted the act of drawing blood for medical purposes; often regarded as "satanic". 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 home-based VCT RCT baseline survey. From these findings it could 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 was also reported by Ramjee *et al.*, (2010). The myths that researchers sold blood undeniable may have led 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’. This finding was not different to the findings of Zachary *et al.*, (2005) who reported that drawing of blood for medical purposes was linked to Satanism. In this study, all the discussions closely linked collecting blood for HIV testing to acts of Satanism. A key informant said,

“... 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...”

The above findings were like those of Ramjee *et al.*, (2010) and Zachary *et al.*, (2005) who reported several persistent myths and misconceptions surrounding their studies. 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 found between the study by Ramjee *et al.*, (2010) and this study was that both studies were conducted in 'research naïve' communities. This may be one of the main reasons why myths, misconceptions and superstition were very high.

Superstition was an important indicator of lack of trust in this study. Since trust was the reason of participation, it could be suggested that superstition was also one of the important barriers to participation. These findings were not different to those of Zachary *et al.*, (2005) where mistrust of doctors and research scientists led to superstition. In their study, Zachary *et al.*, (2005) reported superstition as a barrier for participation in research. Although the study by Zachary *et al.*, (2005) was conducted in an urban setting, the findings do not vary with these. Many respondents associated the drawing of blood for HIV testing to be used in rituals.

This extent of fear showed that in these communities extensive community engagement was essential to provide information relating to a study. The findings in this study also suggested that information provided during the community engagement process was likely to lessen the fears that potential participants had. The findings in this study further suggested that community engagement was vital in health studies especially if drawing of blood was required.

This study revealed varied reactions to fears of ‘Satanism’ by the communities. The common reactions ranged from violent behavior to fleeing their homes. Some community members fled their homes to live in makeshift homes in the bush to avoid being interviewed. This was expressed in the following narrative,

“.....People ran away from them (researchers) to hide in the bush. We had places where we could go and stay....because we thought that they were satanic agents. Others were also hiding in their houses... At times we would see the vehicle approaching, and then we would leave home....”

From the above citation, community members did not only flee their homes during the home-based VCT RCT baseline survey, they also hid in their houses to avoid the interviewers. This behaviour was prominent in Hachizangwa and Hamachenje villages while in Moomba village violence was exhibited. It was quoted,

“...here we did not understand why we were followed in our homes. People were confused as to where these people came from. We did not understand... People thought they were Satanists....they (community) wanted to beat them (Research Assistants) but they were lucky they used another way to go back....”

The community members did not understand the study methodology which included home visitation. It seemed they were also not prepared for the study. Inadequate preparation of the community could result in misconceptions and superstition of ‘Satanism’. Failure to prepare the community for a study as well as failure to recognize the community structures and norms was likely to endanger the research team as shown in the quotation above. This was also supported by the citation below,

“...Those people were not supposed to be beaten, only that they were asking people to answer questions even when people did not fully understand the purpose of their program...”

From the above citation, it can be suggested that the research teams need to be introduced to the communities by the headmen. According to the citation above this would ensure their safety. This was deduced from the following quote;

“....it is better to begin with the headman, then he introduces the group to us...it will be easy for you to go about our village....”

In Nkaaba village, one of the study sites, the interviewers were reported to have been ignored. Some respondents indicated that they left the interviewers waiting for them for hours. This was expressed in the following narrative,

“...Many people never spoke to those people. They ran away..... Like you have come, I would tell you that I'm coming. I just leave you sitting here alone. There is nothing you can do, when you see I'm not returning you will just leave....”

In areas where few or no studies have been conducted before, it was important to ensure an adequate community engagement process preceded a study to prepare the communities. Inadequate community engagement would leave a lot of unanswered questions for the community. In Moomba village, some community members wondered why their villages were chosen as a study site. This thought was expressed in the following narrative,

“...What caused that to happen like that; is because it is something that we are not used to. To say the truth we have never seen this thing happening in our villages; for people in vehicles to follow us. Why us? People ran away from them; reason being that they were thought to be satanic. They were suspected to want people's blood. We thought in town they were now known; now they were coming to the villages because we don't know much...”

Fear to participate in the Home-based VCT RCT baseline survey was significantly associated with fears of ‘Satanism’ and feelings of vulnerability. Vulnerability was linked to lack of knowledge of selection of the study sites. It seemed the respondents did not know why their community was selected as a study site. It was therefore, not surprising that some community members in this village felt that they were in danger. The high levels of suspicion whilst feeling vulnerable could be the reason for their violent reaction. Therefore, these findings may suggest the importance of engaging the community prior to research. This may eliminate the thoughts of vulnerability because the community would perceive themselves as equal partners.

The respondents also associated the color of the vehicles used during the home-based VCT RCT baseline survey with ‘Satanism’. A respondent from a focus group discussion said, *“We were afraid of the black pajero that was going round our villages.....black color represents darkness and blindness. It represents death too. Now when you see strange people in black vehicles with dark (tinted) windows moving around the villages saying they want to bring a program for testing blood, people feared, we cant take part in such a program....we fear Satanism....”*

This respondent associated black color with darkness, blindness and death. She also attributed non-participation to the fears the people had pertaining to the type of vehicles used and also the nature of the specimen (blood) that was required in the study. Most importantly, the act of collecting and testing blood was consistently associated with ‘Satanism’ in every discussion. Therefore, it was not surprising that in the four villages where these myths, misconceptions and superstition were prominent, there was low and in some cases non-participation in the home-based VCT RCT baseline survey. Although the respondents couldn’t give details about ‘Satanism’, almost all of them referred to it as a key reason for declining to participate. From these unchanging findings, it can be argued that fear of ‘Satanism’ was indisputable in these communities and it must be recognized as one of the important barrier to participating in a HIV/AIDS/VCT studies and other studies especially those that required drawing blood.

Fear of strangers

Fear of strangers interconnected with the superstition of ‘Satanism’ was also another significant reason why some people did not participate. This can be shown by the following quote;

“.....Now won’t someone be scared the face you have never seen, saying they want you....we asked ourselves how come this one wants me, if you check around you, satanism in the world has increased.”

Other respondents suggested that trust would be enhanced by engaging a local person in the study. A key informant who is a village neighborhood health committee member said, *“.....Just find a way you would get this person who is known by the community, whom you would train. He must be well known by the people. This person can help collect the needed information.....”*

Using a local person that communities were familiar with to collect data was frequently cited as a way to overcome the fear of strangers, mistrust and fear for ‘Satanism’. Most of the key informants suggested that local people be included in all community-based studies. One of the cardinal issues raised was that this person must be chosen by the community. This thought was expressed in the following narrative,

“....When you reach the village at least there must be at least one person that we know working with you. It is better when we choose this person as a village. He has to be someone we trust....”

This person had to be trusted by his community or he/she had to be a person with a traceable track record.

Failure to respect culture and tradition

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 husbands. 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 said yes, then I said me no, when my husband is not there! No! My husband stops me.....”

These findings showed that women were more likely to accept to participate in a study if their husbands were present and consented. Similarly, Ramjee *et al.*, (2010) emphasized respect for culture and tradition whilst improving the women’s awareness and decision making related to participating in research. This delicate balance must be maintained if participation is to be enhanced.

Male partners declining to consent to test for HIV or participate in HIV studies

Partners were an important factor in HIV testing and participation in HIV/AIDS/VCT studies. The refusal to test for HIV by some men in this study area was an important barrier to

participation that was reported by most female respondents 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 frightening, 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 above finding seemed to imply that non-acceptance of the male partners to test for HIV and failure to consent to their partners' participation in a study, was an important and recognized barrier to participation. This was a very significant barrier in areas where women depended on their male partners to test. 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 is 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 could destroy my marriage.."

The above citations may also have suggested that married women whose husbands refused to test for HIV during antenatal period were not likely to undergo VCT or participate in an HIV study that required testing. It was therefore, not surprising that some of the women could not attempt to participate in the home-based VCT RCT baseline survey. 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 my results and of what use will they be?"

Some of the female respondents opted to continue with their marriage without knowing their HIV 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 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

Fear of violence by an intimate partner was also reported to be an important barrier to participation in a home-based VCT RCT baseline survey. 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-based VCT RCT 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 tested against her partner’s will risked some form of violence. In this respondent’s view, women were likely to experience physical violence. This may also be another important cause of non-participation in the home-based VCT RCT baseline survey for some of the women in this study area. Women who experienced any forms of violence from their partners were less likely to participate in studies that involved testing for HIV if their partners never consented. Apart from physical violence, female respondents also reported other forms of violence such as emotional and verbal abuse were also frequently cited.

“....at times he will use bad words if you insist on saying I want to take part and test. 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 mvhuule!)...”

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

“.....when a woman tests and has a positive result.... 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 being divorced was uncommon among the male respondents. Only one male respondent cited fear of divorce. He said,

“....we fear being divorced.... tell the women that there is no divorcing if your partner is found with HIV...”

Fear of intimate partner violence and divorce were important obstacles to women participating in the home-based VCT RCT baseline survey. The desire to remain married appeared to make women tolerant of partner violence. Karamagi *et al.*, (2006) reported intimate partner violence to be the cause of fear to test for HIV and disclose of HIV results. 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 showed low education (only 10% of the respondents had attained secondary school education), rural communities and most of the respondents were 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 of 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 any more....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 on thorns (who have partners who are not honorable) and not me. I trust all my women....”

This implied that this respondent trusted all his women and perceived 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 respondents 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 to test for HIV. It was also difficult for the women to negotiate for protected sex. This was supported by the following 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 end up beating 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 having safer sex. Partners’ refusal to participate in health research was 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 RCT 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 to the clinic and bring condoms, I will be told it is “buvhuule bwako” (it is because of your prostitution). He will say I want to use condoms because I have “musankwa wa musyokwe” (a ‘boy friend’).

From the quotations above, some of the female respondents reported difficulties in practicing protected sex safely following an HIV test. Verbal abuse and accusation were consistently cited as deterrents to undergoing an HIV test for some women as well as using condoms. According to these respondents, there was no advantage of testing for HIV as they failed to negotiate for and have protected sex. Similar findings were reported in Uganda by Karamagi *et al.*, (2006). 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 having multiple partners and violence against their spouse. Some of the male respondents accused women of driving them into to this act. This was shown in the following narrative,

“.....our wives cause us to be careless. At times you are sleeping; you may want to do that which is supposed to be done (sexual intercourse). Then she refuses. You beat her...if she doesn't change.... you to go outside to find another woman who is more willing to give you what you want.....”

On the contrary, some of the female respondents did not view partner violence as abuse. A respondent from one of the FGDs said,

“It is only love that can make your husband beat you when you make a mistake. If he does not love he will not care...”

Therefore, partner violence wasn't reported in most cases. Consequently it perpetuated the human rights violation of some women in this study area. Partner violence was problematic especially in communities where sexual coercion was not regarded as a problem. It was also problematic when women and their partners perceived it as a sign of love (Jewkes *et al.*, 2002). This made some women accept this form of abuse and fail to attain their right to health and health service. Many (82%) of the female respondents said even when their partners had extramarital affairs they couldn't participate in a VCT study or even test for HIV. They also couldn't negotiate for safer sex either in spite of knowledge of their partners' various sexual partners. These findings also showed that although 10 of the 13 male key informants had extra marital partners, majority of them stated that they did not use condoms consistently. One of the key informants said,

“....after some time in a relationship we usually put condoms aside. You can't feel anything...that is a plastic...”

In this study, 10 male key informants were hesitant to allow their partners to test for HIV as well, mainly because they feared the result would be positive.

Poor timing

Poor timing on the part of the Research Assistants was also identified as a reason for refusal to participate. Some (47.2%) of the respondents reported that the Research Assistants followed them to their field and requested them to respond to their questionnaire. They felt

this was inappropriate. Some of respondents stated that it was wrong for Research Assistants to follow them at their field. This was shown in the following quotation,

“.....What happened last year was bad... making someone leave the field to answer questions was bad...it should not happen again.”

The above quote also indicated lack of patience by Research Assistants. This could be attributed to lack of experience in data collection. It may also be due to over confidence in cases where the Research Assistant may have participated in many surveys. Nonetheless, it is important to train Research Assistants to exercise patience whilst following their working schedule.

Prior engagement with the community

It is of great importance to know whether the research team members had prior engagements with the study community. Although difficult, 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 could affect a new study. 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. Therefore prior negative engagements with the community may be a barrier to participation.

Chapter 6

Conclusion, policy implication and recommendation

6.1 Conclusion

What can be concluded from this study is that in selected communities in Mwanza and Chona chiefdoms, Monze, non-participation in research could be linked to misunderstanding the study and its benefits, mistrust, superstitions, failure to respect culture and tradition, fear of violence by an intimate partner as well as poor timing. A similar study by Mfutso-Bengo *et al.*, (2008) also highlighted comparable findings that included failure to follow traditional customs, lack of study benefits, superstition, poor informed consent procedures, ignorance of health research, fear of strangers, lack of cultural sensitivity, poor timing and previous bad research experience as reasons why people do not participate in health research.

This study has notable significances and limitations. Among the significant findings, this study seemed to re-affirm that adequate community engagement was vital in health research especially if blood withdrawal was requisite. The results of this study also showed that lack of commitment among key stakeholders led to various misconceptions and myths that were among the prominent barriers to participation in a study. There seemed to be a very close link between mistrust and superstition. Superstition and mistrust appeared to be the most important barriers to participation in a study.

This study had some limitations. It was conducted in communities that refused to take part or had low coverage during the home-based VCT RCT baseline survey. The results thus do not reflect the thoughts of other communities in the District outside these Chiefdoms. Despite this limitation, the findings may indicate areas for further exploration thereby contributing to the understanding of factors that lead to non-participation in health research.

6.2 Implications for policy

The findings presented and discussed in this thesis raise numerous policies. The results of this study may suggest that adequate and well thought out community engagement process may enhance participation. Community engagement in a community-based study is crucial in reducing refusal rates, misconception, misinformation, superstitions as well as mistrust. There is need to ensure specific and appropriate community engagement processes are included in community-based studies as an input, process and outcome of health research.

6.3 Recommendations

Based on the findings of the study, it appears that community engagement is very important in health research, to avoid non-participation. Causes of non-participation are various, and it takes adequate community engagement to understand these factors. In light of the above policy implication it is important to consider the following recommendations:

Community engagement process

Identification of stakeholders: setting community-based health studies requires identification of local stakeholders. With the help of the concerned communities, legitimate stakeholders could be identified. Local clinic staff and community-based agents have been consistently reported to be significant stakeholders. Through the District Health Office, there is need to ensure the local clinic staffs have full knowledge of the study from the onset to enable them respond to queries adequately. Engage local stakeholders such as the community radio or other organizations that are providing similar services to what is being investigated is equally necessary.

Community engagement process ought to be an important component of community-based research so that community participation is enhanced. This may also help minimize misinformation and misconceptions that may arise because of the study.

Misconceptions, misinformation and superstition: It is necessary to have plans to address misconceptions, misinformation and superstition through village meetings. It is also important to include the local clinic staff in these meetings.

Male partner involvement: There must be deliberate attempts to involve male partners to support the recruitment and participation of women.

Permission ought to be sought from the village headman. This should be done at two levels. When engaging the traditional leaders and entering the village to collect data. Seeking permission from individual village headmen is obligatory.

Research

- It is important to have a local person (such as a community health worker, lay counselor etc) that was well respected by the community to work with the research team.
- It is also important to explain the purpose of the study to the study communities and how the results may influence their care. There is need to orient the Research Assistants on cultural issues in the study.
- Before the inception of the study discussing prior engagement with the community is required to avoid challenges during data collection.
- The research team should avoid using dark or even 'black' tinted vehicles in communities as black color could easily be associated with "Satanism". White colored vehicles are more acceptable in the villages.

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APENDIX 1

IN-DEPTH INTERVIEW SCHEDULE GUIDE (Key informants)

THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE
DEPARTMENT OF COMMUNITY MEDICINE

TOPIC: Factors associated with non-participation in a health study: Observations from community engagement experiences in a home-based VCT randomized controlled trial in Monze.

DATE.....
TIME INTERVIEW STARTS.....
TIME INTERVIEW ENDS.....
PLACE OF INTERVIEW.....
NAME OF INTERVIEWER.....

INSTRUCTIONS FOR THE INTERVIEWERS

1. Introduce yourself to the respondent and explain the purpose the interview.
2. Do not write the respondent’s name on the interview schedule to ensure anonymity
3. Obtain written consent from the respondents before the interview
4. Probe for responses to ensure completeness of question has been fully answered
5. All information provided by respondent should be kept in strict confidence.
6. Allow respondents to ask questions.

Questionnaire Number.....

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SECTION A

1. General information

- a) Tell me about where you live? (Probe how many people live with respondent, the sleeping spaces/rooms. Probe whether it is just nuclear family members or extended family).

2. Stakeholders

- a) In this community which people must be seen first before starting a new program?
- b) Who else must be consulted? (Probe why?)

3. participation in a study

- a) In your opinion, what prevents participation in a study?
- b) Tell me about the home-based VCT trial baseline survey, what prevented some people from participating?
- c) How can we increase participation in a study?
- d) Tell me what do you think encourages people to participate? (Probe the responses)

4. Administrative and policy assessment

- a) Tell me how can organizations working in your area to providing HIV/AIDS and VCT services work together?

THANK YOU

APENDIX 2

FOCUS GROUP DISCUSSION GUIDE

Village name..... Moderator.....
Chiefdom..... Note-taker.....
Number of participants..... Transcriber.....
Date
Start End.....

1. Stakeholders and VCT trial

- a) In this village are there any arranged HIV/AIDS and VCT activities?
- b) Have you participated in these activities?
- c) Have you heard about the home-based VCT trial that will be carried out in Mwanza and Nampeyo villages?
- d) What would you say about this trial?

2. Stakeholders and entry to the community

- a) In this village, which people must be consulted first in this community when planning to start a new program?
- b) What else must be done before starting a new program?

3. Participation in a study

- a) What would deter people from participating in a study?
- b) What would influence participation in a study?
- c) What do think can be done to encourage participation in HIV/AIDS and VCT activities?

4. Administrative and policy assessment:

- a) What would you suggest to improve these HIV/AIDS and VCT studies in your community?

THANK YOU VERY MUCH

APPENDIX 3

PARTICIPANT OBSERVATION CHECKLIST

CATEGORY	NOTES
1. BIO-DATA a) AGE b) GENDER	
2. VERBAL BEHAVIOUR & GESTURES (who initiates interaction, tone of voice)	
3. PERSONNAL SPACE (how close people sit together)	
4. PEOPLE WHO STAND OUT IN THE GROUP DISCUSSION	

Source: Mack, N., Woodsong C., Mac Queen K.M., Guest G. and Namey E. (2005)

APPENDIX 4

INFORMATION SHEET

TOPIC: Factors associated with non-participation in a health study: Observations from community engagement experiences in a home-based VCT randomized controlled trial in Monze.

INTRODUCTION

I am Maureen Syanzila, a master of public health student in the department of community medicine at the University of Zambia. I would like to request for your participation in my research study.

PURPOSE OF THE STUDY

The purpose of the study is to gain an in-depth understanding of the community's perception on what affects community engagement and non-participation in a health study. This will ultimately improve the uptake of HIV testing.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. This means that you are free to decline to participate in the study without any consequences. You are free to discontinue the discussion during the interviews should you wish so without facing any penalties.

RISKS AND DISCOMFORTS

The study does not involve any obvious risks to you. However, I acknowledge that discussing HIV/AIDS and testing is a very sensitive issue. In our discussion we will not require you to disclose your HIV status to us.

BENEFITS

There are no monetary benefits for participating in this study. However, there will be transport refunds to assist you travel back to homes. You will contribute to information that will go a long way in assisting the home-based VCT trial and Government policies to consider community opinions during policy formulation. The time you will spend in discussing the issue is of great value.

CONFIDENTIALITY

Personal information you will entrust me with will not be disclosed to third parties unless there is a legal requirement to do so. This will be done only after you have consented. Your identity will be kept anonymous. For the purpose of identification a number will be allocated to you instead of your name.

INFORMATION AND CLARIFICATION

For any clarifications over the research study, direct your questions to:

<p>MAUREEN SYANZILA UNIVERSITY OF ZAMBIA SCHOOL OF MEDICINE DEPARTMENT OF COMMUNITY MEDICINE P.O. BOX 50110 LUSAKA CELL # 0955 9155883</p>	<p>THE CHAIRPERSON RESEARCH ETHICS COMMITTEE UNIVERSITY OF ZAMBIA P.O. BOX 50110 LUSAKA. ZAMBIA TEL # 01 256067</p>
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APPENDIX 5
CONSENT FORM

I agree that the study and its purpose have been explained to me. The risks and benefits have been explained to me. I agree to have my responses recorded for the purpose of the research. I understand that I can withdraw from the study whenever I wish to without being restricted. My participation in this study is voluntary.

I -----(NAMES) agree to take part in the study.

Signed / Thumbprint -----Date: -----(Participant)

Signed: -----Date: ----- (Witness)

Signed: -----Date: -----(Researcher)

APPENDIX 6

TRANSLATED IN-DEPTH INTERVIEW SCHEDULE GUIDE (Key informants)

THE UNIVERSITY OF ZAMBIA.
SCHOOL OF MEDICINE
DEPARTMENT OF COMMUNITY MEDICINE

MUTWE: kulanga-linga zyiletelezya kutatambula kutola lubazu mubuvwuntauzyi bwa zyanseba. Mububoni buzwa mimkwasyi mukwibelesya mukusola kuti bantu kabalyaaba kulaigwa alimwi akupimwa mumanda (home-based VCT) mucilikiti ca Monze.

Mwezi.....
Ciindi mubandi wakubya niwatalika:.....
Ciindi mubandi wakubya niwamana:.....
Mbusena bwakubuziyila:.....
Zina lyako yebo sikubuzya:.....

MALAILILE AYA NGA BANTU BALA MULIMO WAKUBUZYA-BUZYA.

1. Kosanguna kulipandulula kumuntu ngoyanda kubuzya-buzya alimwi komwambila amuzezo uli kunze akumubuzya oku.
2. Utalembi zina lya muntu ngobuzya awo mpolembela twaambo ntwakupa kutegwa kabe kaziye.
3. Asangune kuli zuminina kumulomo sikubuziyigwa kotana mubuzya mibuzyo.
4. Bwiinguzi boonse ubulembe mumasena apegwa.
5. Makani oonse akwambila sikubuziyigwa ayelede kuyobolwa mumaseseke.
6. Komuzumizya muntu ngoli kubuzya wamanizya kumubuzya kuti awalo akubuzye.

NAMBALA YA MUBUZYO.....

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CIBEELA CITANZI (SECTION A)

BUBE BWA BUUMI

1. Twaambo twaambo twabuyela

- a) Kamundambila kujatikizya nkomukkala? (mubuzyisye sikwingula kutegwa ambe busena na zyuli ndobona mbolibede kukomena.komubuzya kuti hena mba mukwasyi walo na kuli balelwa)

2. Bajisi nguzu

- a) Mbantu nzi beledde kusanguna kubonwa ccililanwa lipya kalitana talika?
b) sena kuli bambi na? (buzya)

2. Kutola lubazu

- a) Mukuyeya kwakao, ncinzi cisinkilizya bantu kutoola lubazu mukuvutanuzya.
b) ndambile oko kuvuntazya kwakulaigwa a kumpiminwa a munzi, cinzi cakapa kuti Bantu bakakilwe kutoola lubazu?
c) ino inga twa cita buti ikuti Bantu batoole lubazu mukuvuntazya?
d) ndambile echo ncoyeya ikuti inga ca pa ikuti Bantu batoole lubazu? (buzya)

4. Kuseba bwendelezi amilazyo

- a) Kondaambila imbungano zibeleka mulimo wakazunda mbozi konzya kubelekela antoomwe?

TWALUMBA KAPATI

APPENDIX 7

TRANSLATED FOCUS GROUP DISCUSSION GUIDE

MALAILILE AMUSALO WABULANGIZI BWA MUKABUNGA

Zina Iya Munzi na BBUKU.....	Weendelezya.....
Mwami.....	Mulembi watwaambo.....
Mwelwe wabantu batola lubazu.....	Usandulula.....
Buzuba.....	
Ciindi ncmwatalika.....	Masimpilo.....

MAKAMU AANDEENE ALIMWI AKUSOLA KUKULWAIZYA KULYAABA KULAIGWA AKU PIMWA KAZUNDA (STAKEHOLDERS AND VCT TRAIL)

1. Makamu nzi aadeene abeleka milimo ya kazunda mubusena buno?
2. Hena mwakasangana mukutola lubabazu mumaccililanwa ya kazunda?
3. Hena mulazyi makani asolwa akubuziyigwa kwakulyaaba akupimwa kazunda mu manda kuminzi lili ku Njola-Mwanza alimwi aku Nampeyo?
4. Hena mubwene buti mulimo na kusola oku?

1. Mbunga zila nsana nzyomubeleka limwi alimwi atwaambo tupati-pati

- a) Mumunzi uno mbani belede kusanguna kubuziyigwa ciindi kwatalikwa ccililanwa pya.
- b) Nchinzi ciyandika kucitwa ciimbi akutalika ccililanwa pya?

2. Kutola lubazu

- a) Ncinzi cipa kuti bantu batakulwaile mumunzi wanu kutola lubazu mubuvwunatuzyi bwa kazunda alimwi sikalileke?
- b) Ncinzi cipa kuti Bantu bakulwaile kutola lubazu?
- c) ncinzi cinga ca citwa ikuti Bantu bakulwaile kutola lubazu mubuvuntauzi bwasilalileke?

3. Bwendelezi amilazyo

- a) ncinzi nco yeeyela ikuti inga casumpula buvuntauzi bwasilalileka?

TWALUMBA KAPATI

APPENDIX 8

BUPANDULUZI BWABUVWUNTAUZYI

MUTWE: kulanga-langa zyiletelezya kutatambula kutola lubazu mubuvwuntauzyi bwa zyanseba. Mububoni buzwa mimkwasyi mukwibelesya mukusola kuti bantu kabalyaaba kulaigwa alimwi akupimwa mumanda (home-based VCT) mucilikiti ca monze.

KUTALIKA

Mebo ndime Maureen Syanzila sicikolo utola lwiiyo lusumpukide mucibela camisamu (a master of public health student in the department of community medicine) acikolo cisumpukide ca University of Zambia. Ndimulomba kuti mutole lubazu mubuvwuntauzyi bwangu.

MUZEZO WABUVWUNTAUZYI OOBU

Muzezo wabuvwuntauzyi oobu ngwa kuzyibisya bantu mbobalanganya ciletela buyumu-yumu mumikwasyi kuswangana akutola lubazu mukuvwuntauzya kazunda (HIV). Mulimo ooyu kakunyina akuzumbauzya uyakusumpula mweelwe wabantu bapimwa kazunda.

KULISANGA KUTOLA LUBAZU

Kutola lubazu mubuvwuntauzyi oobu nkwakulyaaba na kuliandila. Nkokuti eeci caamba kuti mulangulukile kukaka na kuzumina kutola lubazu kakunyina buyumu – yumu mbomunga mwajana. Mulangulukile kuleke akati kulasa na kubandika ciindi nomubuziyigwa kuti na mwalombozya mbubo cakunga inga timwapegwa cisubulo.

ZILIJAZYO A KULIBILIKA KULIKO

Buvwuntauzyi tabujisi zilizazyo kuli ndinwe. Nokuba boobu ndamucenjezya kuti notulya musalo wakazunda alimwi abulwazi kwasikalileke alimwi akupimwa, ootu ntwaambo twakunso na maseseke. Mumusalo wesu tatuyandi kuti mutwambile mpomwendela kumakani akazunda.

BUBOTU

Kunyina mali avwolwa kutola lubazu mubuvwuntauzyi oobu. Bubotu buliko mbwa kuti lubazu ndomuyakutola kwiinda mukupa twaambo muyakugwasyabkulyaaba kulaigwa akupimwa mumaanda. Kwalo kusolwa alimwi ciyakupa kuti balanganya maccillilanwa. Ciindi ncomuya kulipa kulasa kaambo aaka tulacipa bulemu na cililemekedwe kapati.

MASESEKE

Twaambo twenu ntomuyakundipa kunyina muntu watatu weelede kuzyiba ccita kuti kwaba mulawo uzumizya kucita boobu alimwi eeci cikonzya buyo kucitika kuti mwazumina nobeni. Twaambo ntumwaamba tuyakusiswa. Kutegwa twaambo twenu tutakazimini, muyakupegwa nambala yatwaambo ntaomwapa kutali kulemba zyina lyanu.

KUTI KAMUYANDA MAKANI MANJI AMBWENI AKUSALALILWA KWIINDA WAWA

Kuti kamuyanda kusalalilwa kubuvwuntauzyi oobu ambweni kuli mpomwatasalalilwa na mwanyenaala, ayanda mujisi mibuzyo, amwitumine kubabantu batobela.

<p>MAUREEN SYANZILA UNIVERSITY OF ZAMBIA SCHOOL OF MEDICINE DEPARTMENT OF COMMUNITY MEDICINE P.O. BOX 50110 LUSAKA CELL # 0955 9155883</p>	<p>THE CHAIRPERSON RESEARCH ETHICS COMMITTEE UNIVERSITY OF ZAMBIA P.O. BOX 50110 LUSAKA. ZAMBIA TEL # 01 256067</p>
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CIZUMINANO

Ndazumina kuti buvwuntauzyi a muzezo zyasandululwa kuli ndime. Ntende a bubotu zyasandululwa kuli ndime. Ndazumizya kuti imubandi oyu inga walembwa mumunchini kuti ukabelesegwe mubuvwuntauzyi oobu. Ndazumina na ndazyiba kuit ndakonzya kuleka mu buvwuntauzyi oobu kufwumbwa buyo ndayanda kakunyina kugutayikwa nokuba kukasyigwa. Luubazu ndwetola mubuvwuntauzyi oobu ndwakulyaaba.

Mebo ndime..... (Mazyina) ndazumina kutola lubazu mubuvwuntauzyi oobu.

Busimbo/calanganda.....Buzuba.....

Kabomboni.....Buzuba.....

Sikuvwuntauzya.....Buzuba.....