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# "They are Not 'Hidden', 'Unseen' or 'Hard-To-Reach'": Reflections on Recruiting Women who Have Sex with Women to Tailored Public Health Research in Tanzania

*Switbert R. Kamazima, Jackline V. Mbishi, Happiness P. Saronga & Saidah S. Bakar*

## ABSTRACT

Available literature suggests that women who have sex with women (WSW) are 'hidden', 'unseen', or 'hard-to-reach' because they operate underground, their size is unknown, and their daily lived experiences remain a mystery to outsiders including (public) health researchers. As a result, WSW are claimed unwilling to participate in medical/clinical or public health research. In this paper, we present our experience recruiting WSW to tailored public health research in Tanzania: the planned and unique nationwide integrated socio-behavioral and biological surveillance survey. We conducted a cross-sectional descriptive and retrospective qualitative formative study in Dar-es-Salaam Region, Tanzania, between January and February, 2021. Study population included community leaders; and WSW aged 18 years and above, who had lived in Dar-es-Salaam for six (6) months or more; had engaged in same-sex sex in the past year or were in same-sex relationship(s); had knowledge of WSW's lived experiences, and willing to participate in the study. Findings indicate that WSW in the study area are not 'hidden', 'unseen' or 'hard-to-reach' as researchers and other professionals claim.

**Keywords:** women's sexuality; 'hidden', 'unseen', or 'hard-to-reach' population; women who have sex with women; public health research; qualitative field research; Tanzania.

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# “They are Not ‘Hidden’, ‘Unseen’ or ‘Hard-To-Reach’”: Reflections on Recruiting Women who Have Sex with Women to Tailored Public Health Research in Tanzania

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## ABSTRACT

*Available literature suggests that women who have sex with women (WSW) are ‘hidden’, ‘unseen’, or ‘hard-to-reach’ because they operate underground, their size is unknown, and their daily lived-experiences remain a mystery to outsiders including (public) health researchers. As a result, WSW are claimed unwilling to participate in medical/clinical or public health research. In this paper, we present our experience recruiting WSW to tailored public health research in Tanzania: the planned and unique nationwide integrated socio-behavioral and biological surveillance survey. We conducted a cross-sectional descriptive and retrospective qualitative formative study in Dar-es-Salaam Region, Tanzania, between January and February, 2021. Study population included community leaders; and WSW aged 18 years and above, who had lived in Dar-es-Salaam for six (6) months or more; had engaged in same-sex sex in the past year or were in same-sex relationship(s); had knowledge of WSW’s lived experiences, and willing to participate in the study. Findings indicate that WSW in the study area are not ‘hidden’, ‘unseen’ or ‘hard-to-reach’ as researchers and other professionals claim. Similarly, we demonstrate that WSW’s recruitment to participate in (public health) research is not as tedious and tricky as previously presented. We validate that WSW exist in Tanzania and are willing to participate and support research with direct relevance to their livelihoods and their community’s wellbeing. They require WSW-friendly and sensitive approaches, as well as working with or through their trusted individuals, institutions, or organizations.*

**Keywords:** women’s sexuality; ‘hidden’, ‘unseen’, or ‘hard-to-reach’ population; women who have sex with women; public health research; qualitative field research; Tanzania.

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## I. INTRODUCTION

A review of available literature indicates that women who have sex with women (WSW) are a minority group; constituting a small proportion of a larger group of lesbians, gay, bisexual, transgender and intersex (LGBTI) that are wildly overestimated [1]. This perspective, suggests WSW are another ‘hidden’, ‘unseen’ or ‘hard-to-reach’ group like injecting drug users (IDUs), men who have sex with men (MSM), female sex workers (FSWs), and human and organ traffickers (TIP/O) whose actual sizes are unknown and tricky to estimate. In addition, these groups are known engaging in subversive behaviors and practices that lead to stigma, rejection, all forms of violence, discrimination, and criminalization from governments, societies, and communities around them [2,3]. In turn, this situation limits their willingness to participate in studies targeting them or the general population; thus, posing a

significant obstacle to recruitment [4-6] and underrepresentation in (health) research [7].

However, some researchers who have successfully conducted studies among minority groups observe that failure to recruit participants from diverse pools reflects not making enough effort to be inclusive. In other words, it justifies that participating in medical/clinical or public health research in the developed countries (the U. S. A. and Europe) is a matter of “who is invited to participate rather than who is willing to” [4], leading to underrepresentation of minority groups in medical/clinical trials and public health interventions [8]. In this paper, we present our experiences recruiting WSW to participate in the first and unique study (the formative qualitative, Phase I) among WSW in Tanzania’s largest and commercial city, Dar-es-Salaam. The main goal of this study was to generate data to inform the planned nationwide integrated biological and socio-behavioral survey (Phase II). We present and argue that recruitment of WSW for this study was not as difficult as we, the researchers, and colleagues at the Muhimbili University of Health and Allied Sciences (MUHAS) anticipated. We further point out some factors that could have contributed to this experience/scenario.

## II. STUDY AREA, METHODS AND PARTICIPANTS

We conducted a cross-sectional and retrospective qualitative formative study with WSW in three study districts of Dar-es-Salaam region: Temeke, Kinondoni, and Ilala. We purposely chose Dar-es-Salaam City because it is Tanzania’s largest and commercial city, harboring persons from different backgrounds and engaging in varied health behaviors and practices. Study population included community leaders; and WSW aged 18 years and above, who had lived in Dar-es-Salaam for six (6) months or more; had engaged in same-sex sex in the past year or were in same-sex relationship(s); had knowledge of WSW’s lived experiences, and willing to participate in the study.

The MUHAS Institutional Review Board (IRB) reviewed the study protocol and granted ethical

clearance. The Dar-es-Salaam Regional Administrative Secretary (RAS), the Ilala, Kinondoni, and Temeke District Administrative Secretaries (DAS), and the Street authorities granted permission to conduct the study in their respective areas. The process of interviewing neither had harm to nor re-traumatized the study participants. The average duration of IDIs and FGDs was one and half hours. However, as our participants had interest in this study, some IDIs and FGDs took longer time. The aim was to understand what it means to be a WSW in Tanzania to inform future female same-sex public health research targeting this group.

We selected and trained our research assistants (RAs) for three days on the study objectives and process, the vulnerability of WSW, ethical issues around this sensitive study, and proper interaction/interviewing procedures with the study participants. With permission from the participants, FGDs and IDIs were audio-recorded. In addition, the RAs took field notes and wrote full reports of observations on the same day. FGDs and IDIs were conducted in Kiswahili, a national language understood and spoken by almost everybody in the study area. We transcribed and translated data, followed by data analysis applying thematic approach where open systematic coding of data in the participants’ language and combining emerging emic concepts with preconceived theoretical constructs was used.

### 2.1 ‘Hidden’, ‘unseen’ and ‘hard - to - reach’ populations defined

Researchers use the term ‘hidden’ to refer to groups that have no defined boundaries, size and are tricky to sample [9]. ‘Unseen’ populations are claimed nonexistent, and if they do, are too small to impact the system in question or minority groups highly underrepresented in research [10-12]. Other researchers describe a population that is difficult to access as ‘hard-to-reach’ [13,14]. In this context, WSW may be defined ‘hidden’ because their size is unknown, their lived experiences are mysterious and work underground due to illegal status of their same-sex behaviors and practices; ‘unseen’ due to their survival tactics in communities where their overt

nature could put them at risk of greater harm (such as: discrimination, criminalization, stigma, violence, rejection and abuse); and ‘hard-to-reach’ due to the unjustified belief that WSW would be unwilling to engage (sharing their lived experiences) with outsiders, including (public health) researchers. It should be noted, however, that though the groups are outwardly distinct, the three terms are used interchangeably to denote vulnerable groups subjected to discrimination, rejection, and stigma [15] in referred contexts.

### 2.2 WSW as defined in this study project context

In this study project, we adopted and use an inclusive concept/term ‘women who have sex with women’ (WSW) [16] to refer to the targeted population, “Women who engage in sexual activities with other women, whether or not they identify themselves as lesbians, bisexual, pan-sexual, heterosexual, or discipline with sexual identification altogether” [17]. We preferred this definition because we focus on WSW’s behaviors and practices rather than labels attached to WSW’s behaviors and practices [18] and the public health implications of female same-sex relationships that develop from intimacy or sexual/physical attraction. As observed in previous studies, “Not all women who have sex with women are lesbians ... They might identify as straight, bi, span, queer, gay or curious ... They might be cis gendered, trans or non-binary [19,20]. Moreover, it is known that “Women who don’t identify as lesbians, bisexual, queer or even questioning often have had sexual relationships with other women” [21].

### 2.3 Female same-sex relationships and activities are illegal in Tanzania: the study context

The Tanzania Constitutions (Mainland and Zanzibar) do not recognize same-sex relationships. Thus, same-sex relationships/couples have no recognition on Tanzania Mainland (The Tanzania Penal Code of 1945 as revised by the *Sexual Offences Special Provisions Act, 1998*) and Zanzibar (The Zanzibar Penal Code of 1934, as amended in 2004). Same-sex behaviors and practices, therefore, are crimes punishable on conviction by life imprisonment [22,23].

Consequently, receiving death threats and persecutions is normal for LGBT individuals making it a matter of survival to keep their homosexuality hidden and rarely reported on [3,16,24]. Violence, rape, social exclusion (denial, rejection, stigma, and isolation), and discrimination characterize the daily life of individuals engaged in same-sex relationships in this country [3]. This situation has adverse effects to the WSW’s health, healthcare and livelihoods [3,24,25] triggering the horror of facing difficulties recruiting study participants from this group.

## III. STUDY TEAM STRENGTHS

The investigators on this study project are PhD/Master/First degree holders and members of the School of Public Health and Social Sciences (SPHSS) in the Behavioral Sciences, Epidemiology and Biostatistics, Community Health, and Environmental and Occupational Health Departments at MUHAS, vested with various interdisciplinary research skills and methods. The team has accumulated rich experience (from 1994 to date) studying issues and groups in this country whose behaviors and practices are socially regarded taboos, illegal, crimes and generally considered ‘un-African’: FSWs (sex work), IDUs (injecting drugs), human traffickers [trafficking in persons/organs (TIP/O)], homosexuality (male same-sex sex, MSM), borders, borderlands and borderlanders (border crossing practices), and now, WSW (female same-sex sex). A challenge we have always faced is proving to the study protocol reviewing bodies on the possibility of recruiting a ‘representative sample size’ of the group in question to participate in the study. So, we wished to have this justification from our formative research that recruiting WSW for a nationwide behavioral and biological surveillance survey (among WSW) is possible in Tanzania. Experience we have gained from previous research activities, facilitated navigating and negotiating rapport among our study populations.

### 3.1 Pre-study consultations

Upon receipt of research clearance from MUHAS IRB, we immediately started conducting initial

formal and informal consultations with colleagues at MUHAS and beyond. The aim was to solicit perceptions they had on our study and approach. On the one hand, most of our colleagues were pessimistic that we could succeed recruiting such women in the country. One fellow staff, for example, observed, *“I don’t think there is any Tanzanian woman or girl that would identify herself a lesbian or having sex with other women ... You should know, same-sex sex is illegal in this country ... Hence, if at all female same-sex behaviors exist, they are conducted underground and unnoticed by the outsiders ... However, try your luck and best wishes”* (Colleague 1\_MUHAS, 2021). Another colleague commented, *“You better go to Mara region where women marry women known as ‘Nyumba ntobu’... However, this traditional ritual is fading ... If you are lucky, you may find very few of them”* (Colleague 2\_MUHAS, 2021). The other colleague observed, *“Are you among those promoting homosexuality in this country? ... How different are those women [WSW] from heterosexual [women] to call for special attention from the public?”* (Colleague 3\_MUHAS, 2021).

On the other hand, colleagues who had conducted a behavioral and biological survey using respondent driven sampling (RDS) technique [26] among MSM in the country, had encouraging perspectives. One of them, for example, said, *“We have learnt from our study group [MSM] that there are many WSW in Dar-es-Salaam and other urban centers in this country ... All you need is to have a proper entry point that we shall link you to”* (Colleague 4\_MUHAS, 2021). Similarly, from our search on the internet, we found contacts of LGBTs group established in 2009 with a cause for other LGBTs in Tanzania – the LGBT Voice Tanzania: location, telephone numbers, and email, that we used to seek audience with the NGO’s officials and members.

### 3.2 Initial contacts with the targeted population

We held initial meetings with the Executive Director of the LGBT Voice Tanzania and our contact persons known living in same-sex unions or having sex with fellow women. At these meetings, we introduced the study protocol and

the expectations we had: learning from the WSW’s live-experience and their (health) needs to generate information needed for Phase II of the study project (the nationwide integrated biological and socio-behavioral survey). In turn, information generated from the survey would facilitate improving healthcare professionals’ ability to diagnose, treat, control, and prevent illnesses among WSW and the general public in Tanzania.

During the same meetings, the LGBT Voice Tanzania Director and the self-identifying WSW highlighted the ‘dos’ and ‘don’ts’ we must observe when interacting with members of this group. They assured us (the research team) that there were so many WSW of different backgrounds that we should be prepared to encounter and support throughout our study project (the two phases). In addition, they provided us with recommendations and solutions to potential challenges we were likely to face in this course. Our initial WSW contact person, for example, stressed, *“For you to succeed, you should work through and with us to reach these women ... Failure of which, you will end up in frustration”* (Informal interviews–MUHAS, 2021) 1).

### 3.3 Selection, characteristics and training of research assistants

Based on recommendations from our initial contacts with members of the targeted population, we selected nine (9) female research assistants (RAs) with a minimum education of a first degree in social sciences, good experience in conducting field research, and with good interviewing and probing skills. The RAs were among those we had worked with before on other studies [the baseline human trafficking study (in 2009-2010), the HIV behavioral and biological surveillance survey among FSWs in Dar-es-Salaam, 2010, and cross-border cooperation along the Tanzania-Uganda border (2002 and 2017/2018)]; have good experience managing field research logistical issues; and capable of working under minimum supervision. The RAs underwent a three days’ training on the objectives and procedures for this study. In addition, the RAs were sensitized on the vulnerability of WSW, exposed to the proper

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interaction and interviewing procedures/ethics with the study participants, and alerted on potential challenges they were likely to face in the field and possible mitigation and solutions.

### 3.4 (Always) expect the unexpected

With all the study logistics under control, we planned to start field work during the last week of March, 2020. However, by mid-March, Coronavirus 2019 disease (COVID-19) had been identified in the country on March 16. The government hastily closed learning institutions, banned activities and events that could result in crowding (sports, rallies, and cultural events like weddings) for the public health good [27-30]. Following the government order, the National Health Research Ethics Committee (TANHER Committee), the national overseer of health research activities in the country issued a directive banning all research activities (except lab-based and clinical trials) till further notice! Our team had to abide by this ban. However, the researchers remained digitally in touch with initial contacts. Most important, perhaps, is that the study funding tenure was one year, that is, September 2019 to August 2020! Anxiety of not meeting the study deadline grew among the research team members.

On June 16, 2020, the government announced recommencing of all activities that were suspended as part of the response to COVID-19 from Monday, June 29, 2020. Following the government's decision, the TANHER Committee called for the resumption of research activities in the country. Nevertheless, fear of being infected or spreading the coronavirus remained high among the researchers and members of the community. Our team, however, resumed activities in December. The research clearance application process at the Dar-es-Salaam regional level was completed in early January 2021, allowing the team to proceed to the district level. We started interacting with our study participants during the second week of January 2021.

Through our contact persons, recruitment of eligible study participants became somehow easier than the research team expected. By the

end of February, 2021, we had conducted six (two in each district) focus group discussions (FGDs) with WSW; 24 in-depth interviews (IDIs) with eight (8) key informants (KIs) (where each KI was interviewed at least three times). In addition, we conducted seven (7) IDIs with members of the community. As indicated earlier, all FGDs and IDIs were audio-recorded and the average time for each IDI and FGD was one and half hours. However, as our participants had interest in this study, some IDIs and FGDs took longer time. Detailed information on the WSW's existence and willingness to participate in future (public) health research is provided by Kamazima, *et al.*, [16] and Kamazima, *et al.*, [30] respectively. It suffices to note here that recognizing, respecting and considering WSW's life-norms and conditions in study researches' protocols, opens opportunities to maximize WSW's visibility by targeting recruiting approaches capturing women with differentiated characteristics and backgrounds to increase their willingness to participate in (public) health research.

### 3.5 What made participants' recruitment quick and successful?

We are contented, we were able to recruit, interact with adequate number of WSW, and generate information needed for this formative study on time due to a number of factors including: 1) the rich research knowledge, skills, and experience the investigators and RAs have facilitated building trust and acceptance among the initial contacts and the study participants at large. Being a MUHAS-based study (a trusted research institution and known conducting studies with vulnerable populations), was an added advantage to this study; and 2) working through and with persons and organizations trusted by the WSW community granted a wide range of opportunities to the research team's access to the study population and the women's willingness to participate in the study.

In addition, as the WSW we studied reported [30], the WSW were willing to participate and share their lived-experiences with the research team; recruit fellow WSW to the FGDs, and ready to participant in Phase II of the study due, but not

limited, to: 1) Phase I researchers approached the WSW with sensitivity, comprehensively explained the importance of participating in both phases of the study project, and clarified what participation in the study project entails; 2) the research team demonstrated love, trust, respect, and sympathy to the group irrespective of their behaviors and practices; 3) interactions with the research team enlightened the WSW on some female same-sex issues (female same-sex sex protective devices, female same-sex law-related matters, and female same-sex sex health-related problems) that they were unaware of [31]; 4) the study, both Phase I and II, promise relevant to the WSW's community around the country; 5) WSW recognized the study could uncover and facilitate addressing female same-sex health, reproductive health needs, and establish the group's size; and, 6) WSW believe having opportunity to access quality and equitable health and healthcare services they utterly need, could open more opportunities in that direction.

#### IV. CONCLUSION

Our study demonstrated that WSW are not a 'hidden', 'unseen' or 'hard-to-reach' group as many of the (public) health researchers and health professionals (may) think. WSW exist in this country and are willing to participate in research with direct relevance to their livelihoods and their community's wellbeing. They require WSW-friendly and sensitive approaches; working through and with their trusted individuals, groups, institutions, and organizations; and clear elucidations of what participation in a (public health) study or research entails. Researchers, therefore, ought to develop WSW-tailored research protocols' content, communication messages, and recruitment tactics to recognize, appreciate, and embrace the specific characteristics, backgrounds, and concerns of WSW in Tanzania.

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