

Women Who Have Sex with Women's Attitudes and Willingness to Participate in Future Female Same Sex Public Health Research: Opportunity for Disease Prevention and Control in Tanzania

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Received: 24 May 2021; Accepted: 10 June 2021

Citation: Kamazima SR, Saronga HP, Bakar SS et al. Women Who Have Sex with Women's Attitudes and Willingness to Participate in Future Female Same Sex Public Health Research: Opportunity for Disease Prevention and Control in Tanzania. Clin Immunol Res. 2021; 5(1): 1-7.

ABSTRACT

Recruitment of acceptable number of participants in a (public) health research with 'hard to reach'/'hidden' populations is an old global problem, mostly challenging public health researchers in resource limited countries like Tanzania. Violence, stigma, criminalization of behaviors practiced by these groups, and potential participants' suspicion toward the research and the researchers, further limit willingness to voluntarily participate. We conducted a cross-sectional descriptive and retrospective qualitative formative study with women who have sex with women in Dar-es-Salaam City region, Tanzania. The aim, among other objectives, was to understand women who have sex with women's attitudes and willingness to participate in future female same sex public health research targeting this group. Findings indicate that all women we studied expressed willingness to participate in future health research targeting issues around female same sex relationships in the Tanzania context; an opportunity for (public) health professionals to prevent and control diseases in the country. To attain this goal, we recommend tailoring research protocols' content, communication messages, and recruitment tactics to recognize, appreciate, and embrace the specific characteristics, backgrounds, and concerns of women who have sex with women in Tanzania.

Keywords

Women who have sex with women, Female same sex behaviors and practices, Health research participation, Research participants' recruitment, Qualitative research, Tanzania.

"Don't just hope for a cure — help us find one."
Alzheimer's Association. 2021.

Introduction

The recruitment of adequate number of individuals to participate in a (public) health research with 'hard to reach'/'hidden' populations or groups [female sex workers (FSWs), men who have sex with men (MSM), injecting drug users (IDUs), human and

organ traffickers, and women who have sex with women (WSW)] whose size is unknown, is an ongoing challenge for public health researchers in resource limited countries like Tanzania. Stigma, rejection, violence, discrimination, and criminalization of behaviors and practices that members of such groups engage in, limit their willingness to participate in studies targeting them or the general population. In addition, potential participants' suspicion toward the research and the researchers further restricts them from volunteering to participate in (public) health research.

On the one hand, researchers [1-6] have reported on reasons why individuals would volunteer participating in (health) research studies. The Research! America's [7] poll, for example, showed

that Americans would volunteer to participate in the medical/clinical trials based on the following: the reputation of the people or institution conducting the research and the opportunity to possibly improve their own health (89%); medical bills are covered if injury occurs as a result of the study (88%); the opportunity to improve the health of others (86%); physician's recommendation (80%); privacy and confidentiality issues adhered to (79%); and whether they would be paid to participate (77%).

The Alzheimer's Association noted, "By participating in clinical research, you can help to accelerate progress and provide valuable insight into potential treatments and methods of prevention" [8]. Khubchandani's study reported, unemployment, food insecurity, chronic illnesses, young age, being an older Black man with least education, and having previously participated in a trial were motivators for participating in clinical trials among racial, ethnic minorities [9]. The Piedmont Heart Institute (n.d.) concluded that some people volunteer participating in medical research because "[They] hope to get the most advanced treatment available. Others participate because they want to assist scientists in developing better ways to help people". The Seattle Cancer Care Alliance 2004-2021 (n.d.) concluded, "Some people participate in clinical trials because there are no standard treatments available for them or because the treatment they already tried didn't work". The Clinical Trials and Me reported some individuals participate in medical research because they know they will get paid [10].

Trauth, *et al.* [11] random digit dial telephone survey conducted with 489 persons in Southwestern Pennsylvania to examine public attitudes toward and support for medical research, reported that the public was divided into three main groups: those willing to participate, the undecided, and those not willing to participate. Determinants of willingness included, "having a relative or friend who has an illness; being middle aged (between 35-64 years old); prior experience with participation in a medical research study; having a favorable attitude toward the use of human subjects in medical research; and beliefs that diverse types of persons participate in clinical trials". Factors reported for being undecided about joining a clinical trial included, "having at least a college degree, having a favorable or neutral attitude toward the use of humans in medical research, and believing that the well-being of participants is the primary concern of researchers". Medical mistrust (doctors perceived less likely to comprehensively explain mode of participation and fear of being exposed to unnecessary risks) was the main factor for not willing to participate in clinical research.

In addition, the Research! America [7]' survey demonstrated that the American people were willing to share their health information so that "researchers can better understand diseases and develop new ways to prevent, treat and cure them (74%); health care providers can improve patient care (72%); public health officials can better track disease and disability (67%); and to advance medical research (73%)".

On the other hand, researchers have established (some) common barriers for participation in research studies, and the clinical/medical research in particular. Participants in the Research! America (2013)'s poll, for instance, reported that some individual are not willing to joining clinical research due to: "a lack of awareness (53%); a lack of trust (53%); concerns that it's too risky (51%); adverse health outcomes (44%); little or no monetary compensation (35%); privacy concerns (27%); and worries that it takes too much time (27%)". Bisbee observed the fear of side effects and unknown outcomes [12]; concern over compromised confidentiality and privacy; being a member of (ethnic) minority group; distrust toward healthcare professionals; and research potentially attributing to inequalities/misrepresentation in medical research, key factors that limit the willingness to participate in medical research. Jacewicz, stated that minority's suspicion toward medical research and researchers make them less inclined to participate in medical research [13]. Yates, *et al.*, highlighted the top five major challenges facing populations who are underrepresented in research as: low income; investigators bias; medical mistrust; limited medical and research literacy; and lack of transportation [14]. The University of Yorks research review revealed that "Fear about testing new treatments and possible side effects was the most common reason given by patients for not wanting to participate" in clinical research [15].

However, some researchers have observed and argued there is significant imbalance in the representation of minorities in clinical research [16] conducted in the developed part of the world. The analysis of participants in the U.S. Food and Drug Administration (FDA) (2018)'s Drug Trial Snapshots, for example, indicated that "The Whites make up 67% of the U.S. population, but are 83% of research participants. Black/African Americans make up 13.4% of the U.S. population, but only 5% of trial participants. Hispanic/Latinos represent 18.1% of the U.S. population, but less than 1% of trial participants" [14]. Similarly, the examination of 5,157 patients who participated in oncology trials in the U. S. revealed, 38% were women, 68% were White/European American, 15% were Asian American, 4% were Black/African American, 4% were Hispanic/Latino; 50% were 65 years and older, and only 38% were residing in the U.S. Even with attempts to regulate and include participants from more ethnic backgrounds in studies, 48% of the adult trials did not meet the target recruitment goal for including underrepresented populations [14].

The message here is that researchers claiming difficulties recruiting participants from minority groups argue, "People of color, especially African Americans, harbor suspicion toward medical research and are less inclined to participate in it. [Hence] A significant obstacle to recruitment" [13]. However, "Several researchers who have conducted clinical trials with diverse participant pools say some studies just aren't making enough of an effort to be inclusive. People of color are often happy to help with experiments [contending] racial suspicion may just be a convenient scapegoat for lily-white studies" [13]. In the view of such researchers, the U. S. and other similar countries have

segregated healthcare systems, where inclusion in clinical trials and or (public) research, “[Is] really not a question of who’s willing to participate. It’s who’s being asked” [13]. Kalloo observed that health-related disparities are an old global problem whose remedy depends on embracing diversity, equity, and inclusion (DEI) in health-related research [16].

Little, if any, is known about women who have sex with women’s (WSW) lived experiences [17], let alone their attitudes and willingness to participate in female same sex (public) health-related research in Tanzania. In fact, our proposed “Behavioral and biological surveillance survey among women who have sex with women in Tanzania” is a pioneer study project in this country aiming at breaking the continued silence regarding the ‘unseen and unheard’ WSW and their particular (health) vulnerabilities in this country. As a step to filling this gap, and meet our long-term target, we conducted a cross-sectional descriptive and retrospective qualitative formative study to inform Phase II of our project, a larger behavioral and biological surveillance survey among WSW in Tanzania. In this paper, therefore, we present WSW’s attitudes and willingness to participate in female same sex health-related studies in this country.

Materials and Methods

We conducted a cross-sectional descriptive and retrospective qualitative formative study with WSW in three study districts of Dar-es-Salaam City region: Ilala, Kinondoni, and Temeke. We purposely chose Dar-es-Salaam City region because it is Tanzania’s largest and commercial city, known harboring persons from different backgrounds and engaging in varied health behaviors and practices. Study population included 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); and had knowledge of WSW’s lived experiences and willing to participate in the study.

The Muhimbili University of Health and Allied Sciences (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. Only individuals aged 18 years or older, who could legally consent, participated in this study. 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, up to two hours. The aim was to understand, WSW’s willingness to participate in future female same sex public health research targeting this group.

We trained our research assistants (RAs) on the study objectives and procedures, the vulnerability of WSW, ethical issues around this sensitive study, and proper interaction/interviewing procedures with the study participants for three days. 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.

Results

One of the objectives of our formative study was to seek WSW’s and community members’ attitudes and willingness to participate in Phase II of this study project: a larger “behavioral and biological surveillance survey among women who have sex with women in Tanzania”. We asked our participants a question, “Would you be ready to participate in a larger survey on WSW in this country and why”? We further probed, “Would you be willing to invite your fellow WSW to participate in Phase II of this study project?”

One participant aged 46, never married, a mother of two children, a trans-man, has sex with men and started engaging in same sex at the age of 15, commented, “I appreciate your effort conducting this study that has enlightened me on some issues I wasn’t aware of; like female same sex protective devices. You have also enlightened me on same sex health-related problems. I assure you; I am ready to participate in the second phase of your study. If allowed, I shall recruit and encourage my colleagues to participate in your study. *Karibuni sana* [you are most welcome]” (IDI, G, 46 years, 2021).

Another participant, aged 26, never married, a trans-man and a university graduate, stated, First of all, I thank you for considering conducting a study on us [WSW]. "It shows the good intention you have for our group. I hope you will use the [study] findings to inform the public and the leaders that women practicing same sex exist in this country. The society should respect our rights. We are human beings like those considered perfect or straight. I suggest that phase two of the project should cover other regions where awareness of female same sex risks is lacking. You should cover Mwanza, Arusha, Dodoma, Mbeya, Tanga, Zanzibar. All regions because women who have sex with women exist even in rural areas. I assure you 100% participation in the second phase of your study. I shall be on the frontline recruiting participants you may need" (IDI, F, 26 years, 2021).

The other participant aged 35, divorced, a FSW and started engaging in same sex at the age of 19 reported, "First of all, I request you to use your study findings to inform the public that we [WSW] exist and we are like other Tanzanians. We need to be heard and respected as we respect the self-identifying straight citizens. Your findings should influence the government to solve the health challenges we face. I propose, the second phase of your study should include other regions on the mainland and even Zanzibar. Women in these regions are engaging in female same sex behaviors and practices unaware of their health consequences. I

promise to support you 100% in the second phase of your research. As I said, please remember recruiting women in other regions into the larger study" (IDI, B, 35 years, 2021).

Another participant aged 28, never married, a bottom, with O-level education and has five years practicing same sex, stated, "I think before going to the next phase, you should use this study findings to raise the public's awareness on the existence and rights of our group. We are human beings as well. We shouldn't be stigmatized or discriminated whenever we seek healthcare services at public health facilities. We need religious services like other members of the Church or Mosques. They [religious leaders] should respect our religious rights. As we have participated in phase one [of this study], you should involve us in the second phase. You will get 100% support from our group" (IDI, E, 28 years, 2021).

A participant aged 30, never married, a diploma in information technology (IT) holder, and who started feeling attracted to women at the age of 11, had this to say, "Sincerely, I am ready to participate in the second phase of this study. I will participate because I know your objective is to know how many we [WSW size] are in this country and our needs. You should create awareness among the public on our existence and rights. I know we [WSW] need attention like other key population groups: the sex workers, drug users or SMS [men who have sex with men]. Many people think female same sex is risk free. NO! Our same sex behaviors and practices could put us at risk of HIV and other sexually transmitted infections [STIs]. Disseminating your study findings to relevant authorities could guarantee us, the tomboys and transgender men in particular, access to equal and equitable health and healthcare services in this country" (IDI, C, 30 years, 2021).

Another participant aged 32, never married, a FSW, and a mother of one child, observed, "I am ready to participate in the second phase of your study. As you were able to reach me via your contact person, you should follow the same procedure to recruit your participants for a larger study" (IDI, H, 32 years, 2021). A participant aged 27, started engaging in same sex at the age of 11, divorced and has sex with men, reported, "I am ready to participate in the second phase of this study because I know findings will benefit our group [WSW]. I suggest, however, that you should include other regions outside Dar [Dar-es-Salaam], business places and all girls' boarding [secondary] schools where same sex feelings begin developing" (IDI, A, 27 years, 2021).

A participant in the FGD narrated, "I congratulate you for conducting this study. Through this study, I think, the public will have a good understanding of who we [WSW] are. You have enlightened us on the health problems associated with our sexual behaviors and practices [female same sex] and we now know where and when to seek healthcare" (FGD_1, 2021). Another participant in the same FGD said, "I am sure, all of us here agree to participate in the second phase of your study. You have proved to us that you trust and respect us irrespective of our lifestyles. That is why we were able to talk to you openly. We promise to cooperate 100% in the second phase of this project" (FGD_1, 2021).

A Religious Leader interviewed in Ubungo noted, "I am sure members of the community and the women [WSW] will be willing to participate in a larger study on this group [WSW]. However, you should also consider involving all key persons: household heads, religious leaders, government officials and traditional leaders in identifying and supporting these women" (IDI, I, 43 years, 2021). A Street Leader interviewed in Kinondoni stated, "I will be ready to give you support next time you are in this area. We need more information on these women [WSW] so that where possible, we can meet their needs. However, since these women [WSW] are in all parts of the country, you should consider reaching such women [WSW] in rural and urban parts of other regions" (IDI, K, 60, 2021). Another Street Leader interviewed explained, "In my view, these women must participate in the coming study because it aims at finding solutions to their [health] problems and needs: health, discrimination, stigmatization and violence. Their participation, therefore, will provide you with first-hand information you need to accomplish your mission" (IDI, L, 32 years, 2021).

Discussion

Two main reasons pushed us to investigate on our study participants' (the WSW) attitudes and willingness to participate in Phase II of our study project (a larger behavioral and biological national survey). First, we have accumulated rich experience (from 1994 to date) studying issues and groups in this country whose behaviors and practices are socially taboos, illegal, criminalized and generally considered 'un-African': FSWs (sex work), IDUs (injecting drugs), human traffickers (trafficking in persons/organs, TIP/O), homosexuality (MSM, and now, WSW), and borders, borderlands and borderlands (border crossing practices). 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.

Second, ostensibly, our attempt is the first systematic study on this group in Tanzania. As such, we had no benchmark of WSW's experience engaging in study research in the country. Our findings, however, indicated that some WSW engaging in sex work had been recruited, fully participated, and benefited from two behavioral and biological surveillance surveys conducted by the then Ministry of Health and Social Welfare (MoHSW) through the National AIDS Control Program (NACP) 2010 [18,19]. Other WSWs who inject drugs were reported participating in the methanol treatment clinics located at the Muhimbili National Hospital (MNH), Dar-es-Salaam and at several rehabilitation centers in the city. We are contented that reviewing these surveys and studies' proposals will add value to our Phase II study protocol.

Our study findings indicated that all WSW we studied expressed willingness to participate in future (public) health research targeting issues around female same sex relationships in the Tanzania context. Our study participants also confirmed their fellow WSW would be willing to participate, and they would facilitate recruiting them to join the study. This is a golden opportunity for (public)

health professionals to prevent and control diseases in Tanzania via (public) health interventions aiming at improving WSW's health and wellbeing.

WSW in Tanzania and elsewhere [17,20-24] are known engaging in risky behaviors and practices including: vagina sucking, wet-wet kissing, low healthcare services utilization, having sex with men and from high-risk populations, promiscuity, substance use and abuse, fingerling, low protective devices use, oral and anal sex, sex work, sharing sex toys and share features with IDUs and FSWs. Alarming, majority of the WSW in this country are unaware of health problems associated with female same sex behaviors and practices, and hold a myth that female same sex is risky-free [17,24]. WSW, therefore, have a likelihood of contracting HIV, syphilis and other STIs from (or transmitting to) high-risk and the general population. Impliedly, WSW is another at high-risk group [20] and a 'bridge population' forming a transmission bridge from the highest-risk groups (HRG) to the general population and vice versa. In addition, women are known facing almost all forms of violence from their intimate partners, the general public, and the law enforcement machinery, the police in particular, which is detrimental to their health and wellbeing (en.wikipedia.org (n.d.); [23]).

Unfortunately, WSW is a group in this country that has attracted limited (or no) attention from health personnel and the public health professionals, in particular. As a result, there is insubstantial understanding of WSW's socio-economic, health and reproductive health, and political needs that might be relatively different from the general population [25]. This finding, therefore, calls public health personnel to pay attention to WSW irrespective of their known sexual behaviors and practices. Public health researchers are interested in establishing the influence of determinants of populations' health. Their goal, therefore, is to understand the aetiology and apply knowledge generated as scientific evidence to propose (public) health strategies, interventions, and policies with the aim of improving the citizenry's (in this case, the WSW's) health and wellbeing, and possibly reduce health inequalities [26,27].

WSW we studied provided a wide range of reasons for their willingness to participate in Phase II of our study project including: 1) Phase I researchers approached them 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 them on some female same sex issues (female same sex protective devices, female same sex law-related matters, and female same sex health-related problems) that they were unaware of; 4) the study, both Phase I and II, promise relevant to the WSW's community around the country; 5) the study could uncover and facilitate addressing female same sex health, reproductive health needs, and establish the group's size; and, 6) they believe having opportunity to access quality and equitable health and healthcare services they utterly need, could open more opportunities in that direction.

This finding is reflected in other studies conducted on the underrepresentation of ethnic and minority groups in clinical/medical research in other parts of the (developed) world [1-6,28]. These studies concluded that among other reasons, "minority ethnic groups are willing to participate in research if the study has direct relevance to them and their community, and if they are approached with sensitivity and given clear explanations of what participation involves" [28].

Homosexuality in Tanzania is a social taboo, illegal and recognized 'un-African' culture. Female same-sex sexual acts (even in private and consensual), therefore, are criminal offences, punishable with life imprisonment. According to The Tanzania Penal Code of 1945 (as revised by the *Sexual Offences Special Provisions Act, 1998*) and The Zanzibar Penal Code of 1934 (as amended in 2004), same-sex relationships or couples have no recognition on Tanzania Mainland and Zanzibar respectively. The understanding of female same sex legal context in Tanzania, justifies our study participants' urge to use this study findings to raise awareness of the group's existence and their urgent health and healthcare needs for the improvement of their wellbeing [17,24]. Furthermore, this finding explains, in part, the paucity of public health research and literature available on this population group in the country.

Our study participants requested the researchers to be mindful and deliberately extend Phase II of the study to all parts of the country: rural and urban areas of all administrative regions in Tanzania Mainland and Zanzibar, and learning institution (mainly all girls 'O'-Level and 'A'-Level Secondary Schools and tertiary institutions). The entreaty follows their observation that many women with varied characteristics and backgrounds engage in female same sex behaviors and practices in all parts of Tanzania. However, the illegal nature of same sex relationship in the country pushes female same sex acts underground, making it difficult to establish their consequences to women's health and wellbeing [17,23].

Dearth of evidence is often alluded to as the reason for not devoting and investing in work targeted specifically at minority groups, in our case, the WSW. WSW are often marginalized in sexual health research, especially in countries where same sex is illegal and criminalized under Penal Codes like Tanzania. WSW (may) constitute a small, but significant group with specific healthcare needs [20]. "A lack of awareness among healthcare professionals about these [healthcare] needs may lead to ill-informed advice and missed opportunities for the prevention of illness" [25]. Hence, more visibility is needed. It is crucial that WSW talk about their lived experiences [29] and their health met and unmet needs [17,24]. Carvell, for example, showed that WSW prefer accessing sexual health services in community and voluntary settings that care for them regardless of their known sexual behaviors and practices [29]. WSW's attitude and willingness to participate in future (public) health research, in part, guarantees (public health) researchers' generation of quality inclusive national data to understand WSW better and paying attention to their feminine and female same sex-specific health and reproductive health needs.

Conclusion and Recommendations

Our study highlighted that WSW in this country are inclined participating in study research focusing on female same sex issues and problems. This finding, in turn, suggests opportunities exist to maximize WSW's participation by targeting recruiting approaches capturing women with differentiated characteristics and backgrounds. WSW are not a 'hidden', 'hard to reach' or 'unseen' group as many of the (public) health researchers may think. WSW are "willing to participate in research if the study has direct relevance to them and their community and if they are approached with sensitivity and given clear explanations of what participation involves" [26]. We recommend that the availability of comprehensive and informative data from multidisciplinary (public health) research among WSW in the country, like the planned Phase II of our study, is cardinal to achieve this long-term goal. This would involve tailoring research protocols' content, communication messages, and recruitment tactics to recognize, appreciate, and embrace the specific characteristics, backgrounds, and concerns of WSW in Tanzania.

Acknowledgements

Special acknowledgements go to our field research assistants for collecting quality data needed for this formative study and our study participants for their willingness to share their lived experiences. The authors acknowledge receiving financial support to conduct this study from the MUHAS Small Research Grants and comments on earlier versions of this paper from colleagues at MUHAS.

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