



Participatory Action Research to Co-Design Internet-Based HIV Prevention with Young Men Who Have Sex with Men in HIV Prevention in Bali, Indonesia

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Abstract

BACKGROUND: There is increasing awareness of the need to develop innovative and relevant methodologies to best capture the voices of young men who have sex with men (YMSM), which will inform HIV prevention.

AIM: This article discusses the process of researching with YMSM in Bali, the solution to methodological gaps in research for internet-based HIV prevention.

METHODS: This research endorsed the Habermas Communicative Action Theory which was then translated to participatory action research (PAR) methodology. Nine YMSM aged 18–24 years old participated in this research through multiple research activities for four months. Data collection included structured group meetings, group workshops, informal participant observations, and after-hour conversations over afternoon tea and shared meals. Participants used a range of visual and digital media to share their collective ideas and different trial strategies.

RESULTS: Our findings confirm the unique contribution of Habermas' theory and PAR research methodology

CONCLUSION: We argue for the opportunity for PAR to strengthen the roles of YMSM in HIV prevention.

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Introduction

Young men who have sex with men (YMSM) are at high risk of HIV infection due to low testing rate, low-risk perception for HIV infection, and lack of condom use during anal sex [1]. The 2015 integrated biological and behavioral survey reported a 20% HIV prevalence among YMSM, higher than other MSM groups and key affected populations such as female sex workers and injection drug users [2]. Furthermore, YMSMs are highly stigmatized, socially condemned, and discriminated resulting in not only poor access to health and social services and vulnerability to violence [1]. Cultural and social discrimination against homosexuality and homophobic attitudes in the community further increase their vulnerability for HIV infection. Social discrimination may compel YMSMs to conceal their sexuality and or secretly engage in often unprotected sex [1].

Internet-based HIV prevention for YMSMs is a relatively new approach being explored in Indonesia. While the internet is a daily necessity for YMSM, it

has rarely been used to seek HIV-related information and services [3]. In Indonesia, Nugroho, Erasmus [4] revealed that the internet could promote retention in HIV treatment and viral load suppression among MSM. Another research in Malaysia supported smartphone-based apps to promote HIV testing, treatment, and relevant services to YMSM [5]. A study in China, in 2017, confirmed the benefit of the internet for sexual health promotion and reaching hidden YMSM who were experiencing sexual minority stress [6].

Various internet based-HIV services have also been developed, such as a web-based Adam's Love service in Thailand that combines online outreach promoting Pre-exposure Prophylaxis or PrEP and HIV services. Users can book HIV services and counseling using this app. There has been a growing research interest in the use of the internet to promote HIV self-testing kits [7], yet this approach is a novelty in many developing nations, including Indonesia.

The internet can provide information on HIV, health, and free applications for education and advocacy [8], [9]. The internet can be a valuable tool

for promoting HIV prevention by increasing HIV testing uptake, enhancing antiretroviral adherence, and improving viral suppression. The internet offers limitless potential for improving access to prevention to HIV for key affected populations. The Internet shows effective and fast tract initiatives to accelerate early treatment and treatment coverage for HIV, noted by the Joint United Nations Programme on HIV/AIDS [10], [11].

Given the considerable stigmatization against homosexuality and HIV in Indonesia, undertaking HIV research with YMSMs is challenging [12]. In addition, methodological challenges exist when researching vulnerable communities such as YMSM, which may negatively affect the participants. YMSM is a highly invisible population, recruitment can be challenging and time-consuming [13], [14].

The participatory methodology is crucial in constructing a communicative space that enhances meaningful participation in research [15]. The Habermas Theory of Communicative Action argues for the pivot of communicative space in bridging gaps between the real-life experiences and social, cultural, life world of those who are particularly marginalized, with the often rigidity, bureaucratic, and top-down system world [16].

This article discusses insights gained from conducting participatory action research (PAR) in creating space for YMSM to develop ideas for internet-based HIV prevention. How Habermas theory and PAR enhance the participation of YMSM in Bali to work on an Internet-based HIV prevention program. Result of this study is presented elsewhere [17].

Study Setting

This research was conducted in Denpasar City, Bali Province, a popular tourist destination with a population of 4.336.000 in 2019 [18] and ranked sixth in the number of new HIV/AIDS cases out of 34 provinces in Indonesia [19]. Most YMSM in Bali are familiar with internet use, particularly for social media and communication. For this research, we partnered with gaya dewata foundation (GDF) to establish a recruitment strategy. GDF is the first organization in Bali to offer HIV prevention services to MSM and one of the few community-based organizations that provide HIV education to YMSM.

Methods and Analysis

This study aims to create space for YMSM to produce knowledge on how to develop ideas on utilizing the internet for HIV prevention.

Study design

Building a communicative space.

Habermas' Communicative Action theory underpins the epistemological approach in this research. This Habermas theory and PAR both advocate creating a safe communicative space where individuals can discuss their concerns freely, without fear of being judged or ignored because of their views - and which facilitates inter-group collaboration to reach an agreement. Further, PAR offers a systematic approach to the production of collective social action [20] through empowerment and active participation of the YMSM throughout the research process, execution, data collection methods, and research evaluation (Cahill *et al.*, 2015).

The communicative space is the key to providing a psychological and physical space where YMSM can share their knowledge and experiences. Participants discussed, investigated, and explored the value of the internet as means of HIV prevention in Bali. In this space, they shared knowledge on HIV prevention, and then developed internet-based HIV prevention.

Sharing an epistemological solidarity with the Habermas theory, PAR also seeks to build meaningful participation, ownership, and collaboration among research participants [15]. This methodology provides a space for research participants to collectively identify social problems, conceptualize, plan and implement proposed internet-based HIV prevention strategies [21]. In action research, the researcher acts as a facilitator who works collaboratively with participants to involve participants in each research process [22], facilitating an empowering environment where participants are central to the research process. Participants are "co-researchers" in PAR.

Driven by the concept of communicative space, we aimed to involve greater participation of YMSM in this study. Communicative space refers to a conceptual and physical discursive space (de Souza, 2009), which invites people to actively engage in open discussions and arguments to reach an understanding (Kemmis *et al.*, 2014). The physical aspect of communicative space is the space and time intentionally provided to participants ensuring safety, accessibility, comfort and timeliness in the study (Bevan, 2013). A key element of communicative space is to enable participants to enter the research space as equals to share their concerns, choose the research methods familiar to them, and reach an agreement on an action (Kemmis *et al.*, 2014).

Building a communicative space for the researcher is one of the first steps in acting together. The leading researcher and participants can understand each other and their respective roles in this research. We also aim to build a safe space for the research members to express their ideas and perceptions on

HIV prevention practices, sexual practices, and the barriers to HIV prevention. In our research, the process generally begins with establishing relationships, negotiating agreed roles and responsibilities. Essential to PAR is the democratic, equitable, liberating and life-enhancing process of building research. This approach vastly differs from traditional qualitative research, which views participants as a source of information but instead seeks to form a collaborative partnership with individuals with social, cultural, and economic power. In this research, the participants contributed to shaping the data collection methods.

Throughout the data collection process, participants were invited to collectively reflect and discuss different or similar experiences, attitudes, beliefs, and knowledge, to inform ideas, designs, and implementation of internet-based HIV prevention. Participants were appreciated as experts and they led the discussion forums, meeting agendas, and organization of the meetings.

Participant recruitment

Initially, the recruitment included using the GDF Facebook page and printed fliers distributed by the GDF outreach workers to their network. However, this effort only yielded two comments on Facebook and failed to recruit participants. From consultation with the foundation director, we subsequently modified the recruitment strategies by asking GDF volunteers to help distribute information about the study. As a result of the latter strategy, 14 potential participants expressed their interest. They were then invited to a series of introductory meetings to ask questions and clarification. Finally, nine YMSM consented to their participation in this research.

PAR process

We provide the characteristic of the participants in Table 1. Participants were 21–24 years old. Only two participants were of ethnic Balinese, and the other seven participants migrated to Bali from different Indonesian provinces. Those who migrated to Bali had lived or

worked in Bali for 6 months to 6 years. Six participants completed high school, one completed a diploma 2, and two were current undergraduate students. Nine group meetings were conducted, including group discussions, group presentation, planning, and production of the HIV prevention plan (i.e., using a visual or digital platform). A closed community Facebook page was developed for the research team to share ideas outside the formal face-to-face meetings. Meetings were audio-recorded, narratives were transcribed verbatim and thematically analyzed.

This study followed the phases of PAR, which include a cyclic process of (1) building a research team where the research design and team were introduced and a group agreement created, (2) sharing concerns, (3) planning, (4) action and (5) reflections and share. One action cycle has been completed as shown in Figure 1 below.

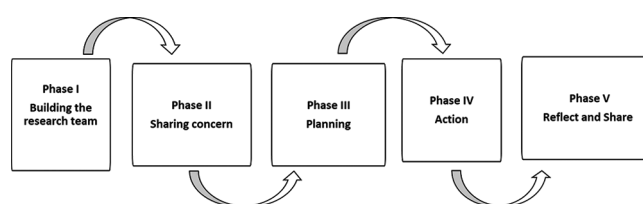


Figure 1: The PAR Process with YMSM

The aims, activities, tools, and outcomes of every phase of the PAR are presented in Table 2 below.

Ethics approval was granted by the Auckland University of Technology of Ethics Committee (AUTEC) on October 29, 2014 [AUTEC Reference number 14/320].

Phase I building the research team

Following this process, nine group activities were conducted (Table 2). Two introductory meetings were conducted to explain the research concept and build rapport among members of the research team. Although few participants have previously been involved with research; however, PAR approach and process were novel to them. It was essential to have safe, informal, comfortable, and easy to reach meeting venues. The choosing of the meeting spaces was pivotal in creating a sense of safety, comfort,

Table 1: Participant demographic profile

Pseudonym	Age (years)	Education	Ethnicity	Employment	Length of residing in Bali (approx. years)
Reza	24	Final year at university	Balinese	Freelancer	most of his live
Adi	23	Second year at university	Non-Balinese	No Job	2 years
Andi	24	High School	Balinese	Casual perfume salesman; having a small laundry business, part-time dancer	5 year
Doni	21	High School	Non-Balinese	A drag queen	All his life
Komang	24	High School	Balinese	Master ceremony for product promotion and bar, casual work as a drag queen	All his life
Toni	22	High School	Non-Balinese	Outreach staff in an NGO, Part-time dancer	1 year
Frangki	24	Diploma	Non-Bali	Staff in a private holiday villa company	5 year
Made	24	High School	Non-Bali	An owner of a creative dance company. Casual staff in a restoran	3 years
Budi	22	High School	Non-Bali	Volunteer of a Ngo-based HIV	3 years

Table 2: Aims, activities, tools, and outcome of each phase of the PAR

Phase	Aims	Activities	Tools	Outcome
Phase I:	To build the research team	Introduce the research design, introduction of the participants, and seek agreement Discuss the aim of the study and expectations and invite participants to ask questions Review and reflect on Session II, share knowledge on the participants' experience of using the internet for HIV prevention, list of internet channels, and ideas to develop internet for HIV prevention	<ul style="list-style-type: none"> Participant Information Sheet. Consent form PAR handbook YouTube video Visual tools Mind-map Laptop Mobile phones Visual tools (i.e. mind-map) Digital recorder 	14 potential participants attended and 9 of them consented to participate Data on the experience of the participants on access to HIV prevention and how they use the internet
Phase II:	To sharing concern	Discus experience of HIV prevention and their strategy to HIV prevention		Group agreement Games
Phase III:	To develop ideas	Brainstorm the model, the prevention, storyboard, plan and re-plan	<ul style="list-style-type: none"> An IPAD, Computer, Flip Chart, Marker Spidol 	Ice-breaker activities A draft of Kita Banger's model of Internet based-HIV prevention
Phase IV	To create action	video making	<ul style="list-style-type: none"> An IPAD, Computer, Flip Chart, Marker Spidol 	A draft of video education for MSM
		video making	<ul style="list-style-type: none"> An IPAD, Computer, Flip Chart, Marker. Spidol 	A draft of video education for MSM
Phase V	To reflect and Share the result	Group reflection on the research process and lesson learned Present and share the video artifact with a youth-based NGO Present and share the video artifact with Ngo in Bali	<ul style="list-style-type: none"> Metaplan, Flip chart, Spidol marker. Computer, LCD Computer, LCD 	Data on lessons learned Data on what people said on the video education Data on what people said on the video education

belonging, and building teamwork [22]. Initially, I offered the research team to use meeting space in one HIV-based organization. However, the rest objected to this option, which the venue was quite far from where most of the participants lived. Instead, participants suggested meetings at the rental place of one of the participants, which was relatively within the close distance to participants' homes. They liked this place as a comfortable hang-out space. Involving participants in the decision-making from the get-go was crucial in building a sense of research ownership.

Phase II

The YMSM learn the concept of the participatory approach as research methods

Following the first team-building meeting, another meeting was conducted to build participants' research skills and strengthen team collaboration. Budi (pseudonym) was recruited as the research facilitator, assisting with the research process. During the introductory sessions were conducted with Budi and the participants. They worked together to create some games and ice breakers to better group engagement. During a session explaining PAR, the first author provided a handbook about PAR and used videos from YouTube that demonstrate the participatory process.

Phase III: Understanding the issues

As noted in Table 2, following the first meetings on team building, participants were asked to investigate

how YMSM utilizes the internet in daily lives, what HIV prevention information was available, and what experiences they had in accessing HIV prevention facilities. Participants raised concerns on the quality of HIV prevention delivered by outreach workers, which mainly focuses on achieving the program target rather than providing psychosocial support.

YMSM faces a structural barrier in utilizing HIV prevention services due to societal stigma and discrimination against homosexuality. The participants revealed that many YMSM lacks the knowledge that condoms can be used for HIV prevention. They perceived condoms as only a birth control method. At the same time, there has been a strong rejection against condoms by religious leaders [23].

One of the participants, Andi, explained how the lack of condom use among YMSM stemmed from social norms that associate condoms with heterosexual married couples and prevent unwanted pregnancies. Another use of condoms outside this heterosexual normativity is considered *jorok* (filthy, dirty):

Since we were little, we were indoctrinated by the principles of Pancasila, our national principles. We are taught not to have sex before marriage and that something related to sex is *jorok*. Even when we learned about reproduction in school, we would think that it was *jorok*. Condom is also perceived (as) only for family planning and heterosexual couple (s). Therefore, because we are gay, it is ok not to use condoms.

Participants agreed on the importance of using mobile phones for HIV prevention. Access to the internet is widely available and can easily be accessed through

personal mobile phones. The internet is a central part of Indonesians' daily lives, and people use online apps for personal, social, and commercial purposes. However, the participants very rarely used the Internet to look for HIV prevention information. Participants explained that useful HIV prevention information mainly was written in English, and language barriers prevented them from accessing that information. The Figure 2 depicts views on how to different types of online media for HIV prevention.

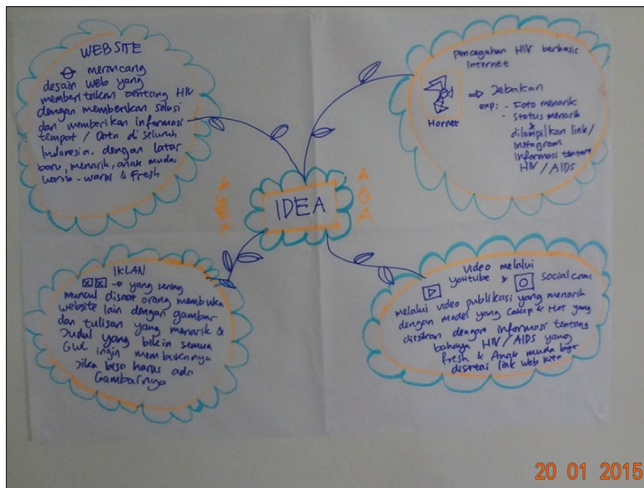


Figure 2: Different type of online media for HIV prevention.

Phase IV: Creating action and collaboration: The “so-us” model

During this study, the participants worked together to produce two videos to raise awareness on condom use among YMSM. They wanted to post the videos online and used them as health promotion sources to increase condom use. The participants used a storyboard technique to aid the participatory video-making process (Lukas *et al.*, 2012). Together, the participants decided on a timeline, target audience, themes, contents, design, and distribution strategies. There was also some valuable discussion on the appropriate language use in the video. For example, one participant suggested focusing on sexual fidelity as a theme for the video. However, the rest rejected this idea, as it was a loaded and inappropriate message for YMSM.

The “So-Us” then informed the themes and storyline of the two videos that raised awareness on condom use to protect themselves and their partners from HIV. A video entitled “Condom Cetai” (spectacular condom) was produced. In this video, Mr. P, a character, was reluctant to use condoms although worried about getting HIV. A helpful friend of Mr. P then introduces him to various enjoyable condoms and lubricants that increase sexual pleasure and protection from HIV infection. The second video, titled “It’s Real Love,” yielded the power of love as a motivation for condom use. This second video depicted a non-monogamous relationship among young gay men and used humor in

conversations between two characters on the benefits of condom use. The Figure 3 depicts the image of the video created by participants.

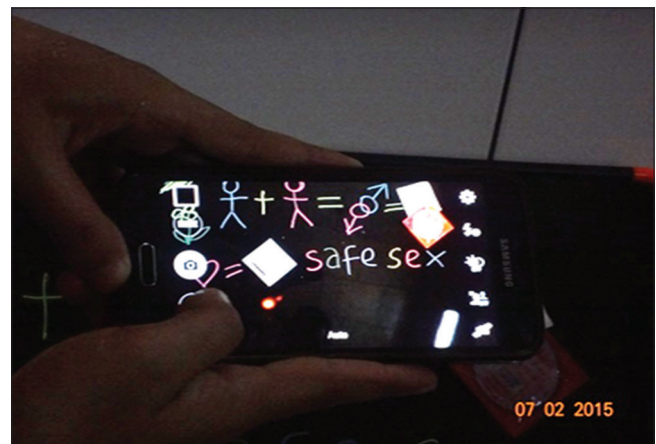


Figure 3: The image of video created by the participants using mobile phone

Participants’ insights, experiences, and practices on HIV protection and Internet use then informed the development of an internet-based HIV intervention platform, the so-called “Kita Bange!” (So-US) model. More findings on the “So Us” have been published elsewhere [17] (Figure 4).

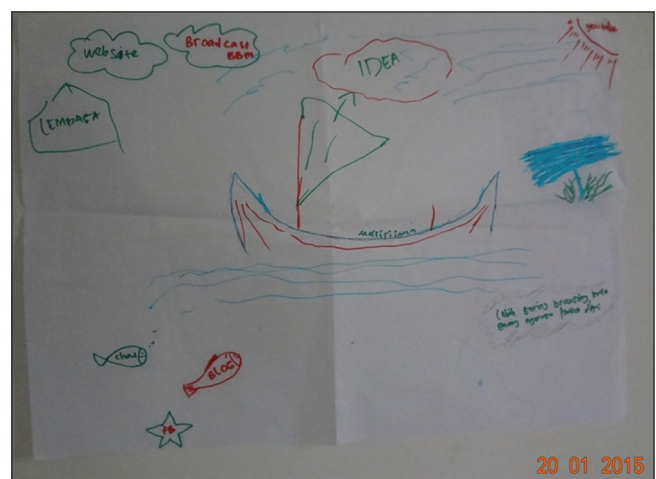


Figure 4: The So-Us imaginary for HIV Prevention

Phase V: Reflection and dissemination

As noted in Table 2, one final meeting was conducted to reflect and discuss participants’ insights and lessons from the research process. Following this meeting, the participants then presented their videos to two HIV-based foundations, GDF and Kita Sayang Remaja (Kisara). The latter was a youth-based organization working on youth sexuality and reproductive health in schools and young people empowerment. This dissemination meeting provided a significant opportunity for the participants to share their concerns, ideas, and opinions openly.

We screened the two videos to around fifteen members of Kisara and staff at GDF. At Kisara, the

co-researchers publicly discussed the social reality of pre-marital sex among youth and the sensitive topic of men who have sex with men. In addition, at GDF, the potential use of participatory video drama when engaging with clients and as a tool for developing HIV prevention messages was discussed.

Discussion

Methodological implications

Our research differs from conservative public health research, limiting the participants' ability to shape the research. The study participants were involved in the meeting venues' decision-making process, using creative audio-digital and visual tools to express their views and opinions better. Therefore, the information, insights, and internet-based HIV prevention tools produced were appropriate and well-reflected the realities, language, interpersonal relationships, feelings, communication, and real needs of YMSM (read: Life world). Three primary implications of the communicative action and PAR are creating a comfortable space through venue selection, a space for YMSM to voice their opinions and teamwork and collaboration in action.

Our findings confirm the unique contribution of Habermas' theory and PAR research methodology, on the following. First, Habermas' construction and explanation of the communicative action, life world, and system world carried out throughout the research, had enhanced participants' confidence, ownership, and group belonging in this research. Second, participants' reflections and participation in the research processes during the face-to-face meetings and Facebook pages drove for creative empowerment and innovative problem-solving skills presenting a practical solution in creating an internet-based strategy, namely "So Us" or "Kita Banget [17].

First, creating a comfortable space was one strategy to improve data collection. We were aware of the structural barriers to stigma and discrimination among people in same-sex relationships in Indonesia. Furthermore, the sensitive nature of sex life and sexuality necessitates a relaxed environment to facilitate participants in discussing their experiences and developing ideas for internet-based HIV prevention.

Creating space for YMSM was achieved in this collaborative approach, facilitating greater engagement from the participants. This study provided space for participants to discuss the best way to share their thoughts and concerns about HIV prevention intervention in Bali and ideas on internet-based HIV prevention. Participants suggested information-sharing strategies familiar to them through these discussions, such as

discussion, presentation, role play, and producing video. The importance of creative and communicative space in promoting participation and equal opportunity to share their experience and ideas. This has been confirmed are previous studies on adolescent and youth health and reproductive health [24], [25].

Second, communicative action and PAR are about collaboration in expressing concern and voices and flexibility where the people negotiate action during the research process. The space is comfortable through venue selection, as a space for YMSM to voice their opinions and teamwork and collaboration in action. PAR is a meta-methodology, hub, or container of various methods that orchestrate the overall research process in a distinctive way (Greenwood and Levin, 2005). In our study, participants were involved in the research planning, conducting the research as participants, creating the action, and evaluating the research process-methods on how to best answer the research questions were also negotiated collectively with participants. Various research methods were utilized, such as presentations, games, discussions, sketching, and videos. Likewise, during data analysis, the first author also involved participants in generating the main findings. In this research, PAR provided a systematic cyclic process of the research, where participants participated in the decision-making process, implementation, evaluation, and alteration of the plan, as necessary to yield expected actions. For example, participants brainstormed their ideas, discussed, and explored possible themes, choice of language, storylines for the videos. Participants worked on several plans and storyboards and edited the video to reflect the "So-Us" model best. The research teamwork did not end at the data collection stage but continued planning, production, execution, and implementation of their strategies.

Third, communicative action as a theoretical concept strengthened the use of PAR (Kemmis *et al.*, 2014). The PAR gave insight into how knowledge can be produced to improve data quality, demonstrated by the participants' contribution to developing methods used in this study. PAR provided opportunities for participants to co-design the "So-Us" Internet-based HIV prevention for YMSM. Using PAR provided an insight on the need to shift the role of YMSM in HIV prevention from being clients to being collaborators. The transformative role of YMSM is pivotal to strengthening their position in HIV prevention in Bali to ensure the HIV program and policymakers hear the voices of YMSM. Merely providing communicative space in research with vulnerable communities is insufficient for dialogues to take place. Further support is instrumental to participants' involvement in democratic decision-making, social action, or assisting in making changes to current HIV prevention initiatives. Capacity building for YMSM in the research process was central and active support from LGBT communities, in the research areas,

was supportive to the voices and actions of YMSM participants.

Another element to consider was to encourage the participants to take ownership and build a sense of belonging and teamwork to the research. In this research, participants shared the same interest in HIV prevention in YMSM, concerns over inadequate HIV prevention resources, and the aspiration to make an action and deliberation of Internet-based HIV prevention tool.

During the early stages of the research, participants were given opportunities to understand the research approach, steps, and skills needed. Meetings were conducted to build participants' confidence in the research process and their involvement in the data collection plan. Confidence in the research process and research partnership was central to the success of the PAR [26].

In building the research confidence, it was important for the participants to discuss and sync their perceptions, and understanding of the specific research topic should also be examined to facilitate better engagement in the research process [27]. In this study, it was of utmost importance to keep the participants on track with the topic discussed, keep them motivated, and maintain punctuality. There were several instances where participants did not arrive punctually according to the agreed meeting schedule because they were occupied with other commitments.

Conclusion

This paper provides insights on the use of PAR in developing an internet-based HIV prevention for and with YMSM in a context where the discussion on sex is taboo; homosexuality and YMSM are stigmatized, limiting the space for YMSM concerns to be heard.

Using communicative action has broadened our thinking on the difference between YMSM's perception of the HIV prevention system as a mechanic, systematic, and goal-oriented. At the same time, YMSM emphasizes the meaning of life, relationships, language, caring, and empathy.

In this research, participants were encouraged to express their ideas on the HIV prevention initiatives by providing a comfortable space. In this research, participants became experts, leaders, and peer educators within their teams. Our findings confirm literature on the appropriate use of participatory research with marginalized populations such as sex workers and YMSM [28], [29]. This study proposed a strategy for meaningful participation of YMSM in HIV prevention initiatives, which shifted their role from being the program's object to being involved in the program's

planning, implementation, and evaluation. Further empowerment for YMSM is recommended through expanding the space for community members to foster meaningful participation in the HIV prevention program.

Author Contribution

DL designed the study, conducted data collection and analysis, wrote the first draft of the manuscript and edited the manuscript. CC and SA assisted with the study design, data analysis, provided feedback, and edited the manuscript.

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