

From Drawings to Puppet Shows: Creating a Collective Space for HIV-Positive Women

Learning from Feminist-Participatory Action Research

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Abstract - Women with HIV are the real knower of their life, however, women living with HIV are highly stigmatized in Indonesia. As researchers we are, therefore, conscious of the sensitive nature of our research. The article explores the use of creative and visual methods to create a space with HIV-positive mothers through Feminist-Participatory Action Research (FPAR). FPAR was conducted in 2017 with a group of 18 women with HIV in Palembang, South Sumatera, Indonesia over four months. The combination of methods used included informal interviews and group discussions, with the use of creative and visual methods. Those HIV-positive women are referred to as co-researchers. Creating space, participation, and action are an integral part of FPAR. Some FPAR principles are learned during the research process in applying creative and visual methods. First, building trust is an on-going process even after the end of the fieldwork. The positionality as insider and outsider are interchangeable and may contribute to build up trust and rapport to get involved in this study. Secondly, giving a friendly and safe environment may contribute to enhance their privilege and creativity to create collective and individual actions- including drawings, mind-mapping, role-playing, puppet shows, and creating new lyrics of the famous traditional song (such as “Cuk Ma Ilang”). Thirdly, we learn to honour the voice of HIV-positive women through partnership and a variety of creative representation from their expressed aspirations. By engaging creative and visual methods as principles of FPAR, their aspiration through their actions can travel visually, viscerally, and verbally to influence individuals and group of health workers, non-governmental organization, and HIV policy makers.

Keywords: a space, women living with HIV, feminism, Participatory-Action Research, aspiration, visual methods, partnerships

INTRODUCTION

Women with HIV in Indonesia reported being negatively labelled, stereotyped, and receiving denigrating and discriminatory treatment when accessing HIV treatment such as PMTCT services, compared to men living with HIV (1-6). In this study, the women were all aware of stigmatisation, fears, and prejudices present in healthcare services and they often had to deal with harassment and derogatory comments and treatment.

Some women also depended on their husband's decision and support for their own health. The patriarchal structure and male dominance over women, according to Noone and Stephens (7), has reinforced men's masculine identity as “virtuous users of health care services” (p. 711) and gender inequalities may contribute to a lack of women's access to Prevention of Mother-to-Child of HIV transmission (PMTCT) services. This gendered morality can result in a localised phenomenon - the stigmatisation of Women Living with HIV (WLWH) – and only recognises individual responsibility and is “away from broader structural conditions”, such as gender norms and the status of women in a patriarchy (8).

Hence, the bias of health systems, lack of privacy, and persistent victim-blaming attitudes may contribute to institutionalised discrimination for women to share their voices and aspiration to better PMTCT services. This research endeavoured to create a safe space for HIV-positive mothers to be involved in the process of making a commitment to participate in research activity, breaking the silence of their voices and sharing their lived experiences, sharing knowledge on an issue or problem, building interpersonal relationships, and raising political awareness in order to create solutions together. This paper elaborates on the relevance of Feminist- Participatory Action Research or FPAR and visual methods in our study and the impact it had on the richness of the data collected.

METHODS

Methodology: Feminist Participatory Action Research

Lykes and Coquillon (9), Lykes and HershBerg (10), and Reid and Frisby (11) explicitly introduced the terms Feminist-infused Participatory Action Research or FPAR. There are three main dimensions of social transformation, according to Lykes and HershBerg that allow the necessary place and space to reposition gender, race, and class, to bring about indigenous knowledge and wisdom, and “deploy intersectionality” as an analytical tool for social transformation (p. 331). In addition, Reid and Frisby articulated six dimensions of FPAR as further guidelines to help the novice feminist participatory action researcher: 1) centring gender and women’s diverse experiences while challenging forms of patriarchy; 2) accounting for intersectionality; 3) honouring voice and difference through the participatory research

process; 4) exploring new forms of representation; 5) developing a critical reflection or reflexive dialogue between the researcher and participants; and 6) honouring many forms of action. In women’s health, Poncic et al. (12) added that creating a space to share women’s individual and collective voices, and experiences of their health, in all stages of FPAR, can contribute to improving the quality of women’s health. They added that cultivating relationships or shared collective power and strategies is essential in every FPAR study to best utilise everyone’s knowledge to address the complex nature of women’s health issues.

Applying FPAR in our research, we argue for the centrality of a woman’s position as a subaltern, as a woman, a mother, and an HIV-positive individual. This is followed by co-constructing knowledge and engaging in the co-learning process through women’s shared experiences, thoughts, and aspirations. Furthermore, even the often-silenced voices are enabled to develop a collective voice to raise their critical consciousness, and to reflect and find solutions to their problems, leading to individual and collective actions (10, 12, 13).

Method: Participatory visual methods

Participatory visual methods were used during series of Focus Group Discussions and interviews. Participatory visual methods are considered modes of inquiry, production, and representation in the co-creation of knowledge. Participants and communities are engaged to create evidence about their own health and well-being, as well as modes of dissemination in relation to knowledge translation and mobilisation (14). These methods allowed for participants to express their thoughts (i.e., feelings, aspirations, ideas, desires,

experiences) through visual representations through visual representations such as collages of HIV vulnerability factors among women and puppet shows adapting traditional songs to promote improving the availability of antenatal HIV tests. Such visual outcomes were used as key empirical evidence and data to be analysed and were powerful tools to assist the presentation of women’s ideas to other groups in the study and create space for them to expand on additional visual presentations that could be both empowering and reflective (14-17).

Table 1: Creative audio-visual outputs produced by 18 HIV-positive mothers

Participants	Output	Title and theme
Group Sehati A	Modified lyrics of “Cuk Ma Ilano”	Compulsory antenatal HIV tests
Group Sehati B	Puppet show for a role play	Comprehensive PMTCT services
Individuals	Drawings	Being resilient and resourceful HIV-positive women

The research began with a series of FGDs with two groups of HIV-positive women. Of the 18 HIV-positive women in this study, 11 decided to form two groups named “Sehati A” (five members) and “Sehati B” (six members). “*Sehati*” can loosely translate as “in solidarity or in one hearth we are together”. I had five FGDs with each group. Members of each group worked together, starting with brainstorming the barriers of accessing PMTCT services, followed by developing strategies to enable women to access the services, choosing a creative medium to present their message, matching their message with the creative medium platform, practising their performance, having it digitally recorded, and disseminating their performance to their group of choice. We will explore three examples out of over 30 creative and visual outcomes of our participants, HIV- positive

women, collectively or individually. The creative outcomes produced by the participants are summarised in Table 1.

Creative and visual Action 1: Modified lyrics of “Cuk Ma Ilang”- Compulsory antenatal HIV tests

The first group of HIV-positive women, Sehati A, decided to modify the original lyrics of a Palembangse folksong, *Cuk Ma Ilang*, in order to deliver their *Cuk Ma Ilang* is originally a traditional Palembangse folksong. The song contains four sentences in each verse and the lyrics in the second verse will be the answer to questions in the first verse. Every second verse starts with a similar chorus: “*Cuk Ma ilang; Mak ilang jaga batu; Dimano kucing belang* (Where your ginger cat is); *Disitu rumah aku* (That’s where my house is).” This folksong is sung widely by all ages and can be understood as a sung poem about love, romance, friendships and old wisdom. The tones of this aspiration of better PMTCT services. The lyrics produced, tell a story of women’s strength, resilience, courage, and aspirations and needs for compulsory HIV testing for pregnant women. The song’s theme was inspired by the experiences of two members of Sehati A whose children were HIV-positive. One of these women had a stillborn baby and believed it was due to her then undiagnosed HIV status. Song can be emotional or melancholic or cheerful and up-beat. I began the participatory process with Sehati A by providing the group with paper and coloured pens. Once the group agreed on using *Cuk Ma Ilang* to capture and impart their message, one group member volunteered to download the original version of *Cuk Ma Ilang* from her mobile phone and share it with the rest of the group members. Together they brainstormed the key messages to be captured in

the song for the right lyrics to match up with the tune of *Cuk Ma Ilang*, which took them about an hour to complete. Then the group practised the song twice and video-recorded it. The practice was done in a soundproof secure room in a public university. We recalled watching the practice and how members were supportive of each other. They reminded each other to be calm and

confident. For their final performance, the group then came up with another option, which was to use puppet figures. We watched the puppet show and then reflected the messages of the song. The following Figure 1 cycle, presents the participatory process of collectively creating a creative outcome of modified lyrics.

'S' cycle of creative participatory of creating lyrics

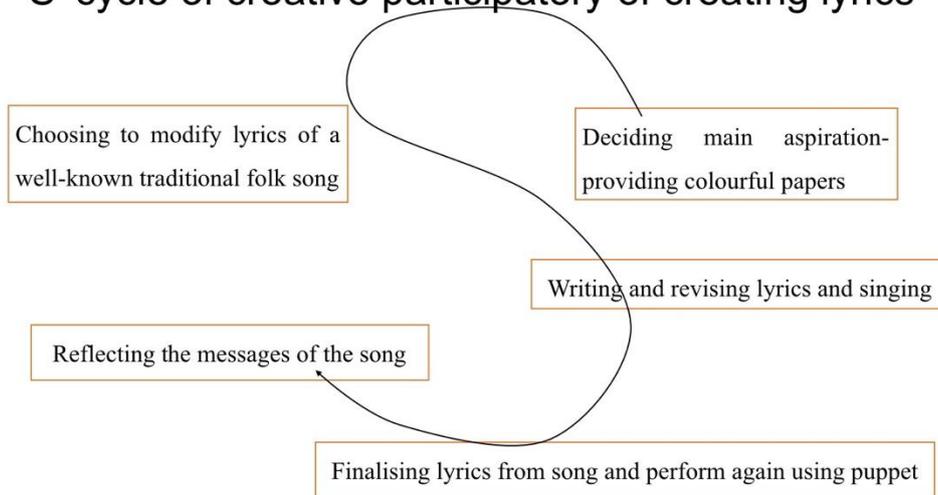


Figure 1: Process of creative participatory of creating modified lyrics of *Cuk Ma Ilang*

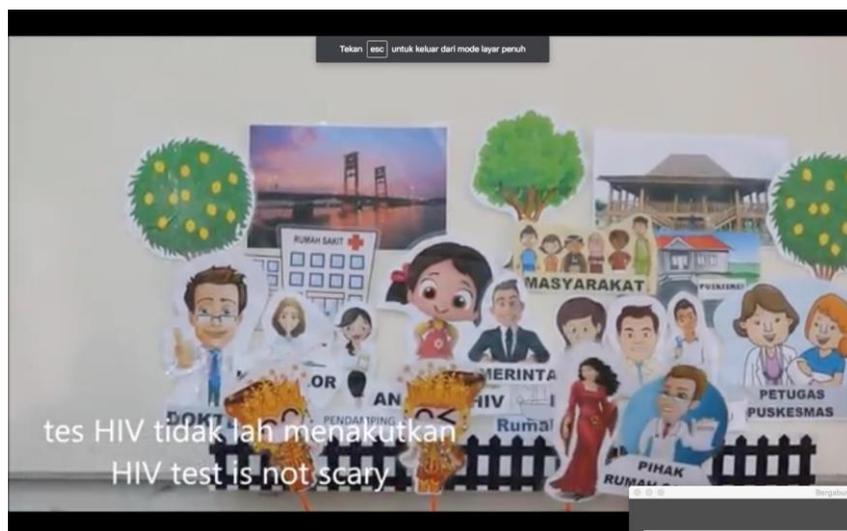


Figure 2: Visual outcome: Puppets used for creating a video of an adaptation of a traditional Indonesian song *Cuk Ma Ilang*

Note: Reprinted from Sehati A's *Creative Outcomes*, by Sehati A, 2017, Palembang, Indonesia. Copyright (2017) by Sehati A. Reprinted with permission. Link for the

modified lyrics of *Cuk Ma Ilang*: <https://www.youtube.com/watch?v=APKaNT7SYQ8>

Creative and visual Action 2: Puppet show for a role play for a need of comprehensive PMTCT services

The second group of HIV positive women, Sehati B, made a drama by first developing the storylines, then working out a role play. Drama or role playing as a research technique, has been used to represent and study interpersonal behaviour such as the thoughts and feelings of individuals and groups (18). The story in this study was inspired by the experiences of the two group

members who had accessed PMTCT services in *puskesmas* in the early stages of their pregnancies, and delivered their babies in hospital. After rehearsing their role play, they recorded it and reviewed as a group. They included five short story segments (scenes) in their role play, before deciding to have their final output as a puppet show. Each scene or story segment was rehearsed and reviewed separately from other segments. This process is depicted in Figure 3 and the puppet shows in Figure 4.

'S' cycle of creative participatory of role play

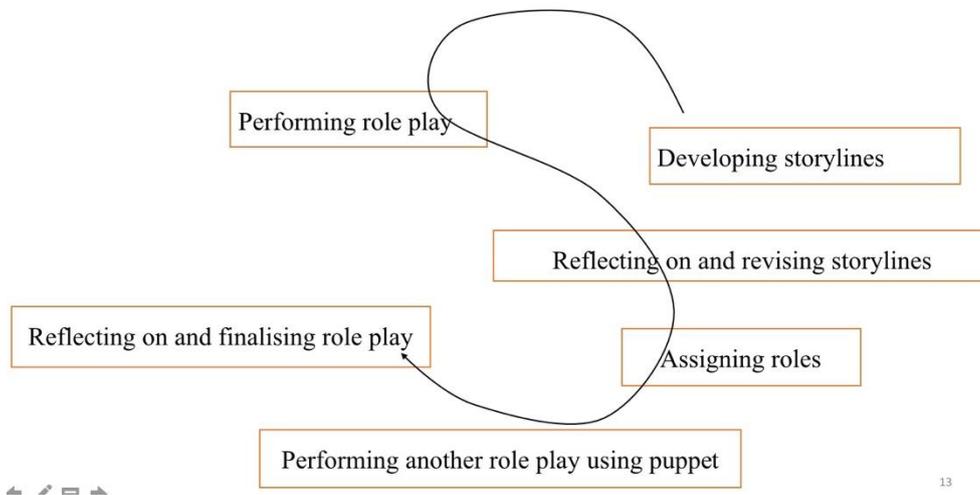


Figure 3: Process of creative participatory of role play



Figure 4: Puppet show for role play with a group of HIV-positive women

Note: Reprinted from Sehati B's *Creative Outcomes*, by Sehati B, 2017, Palembang, Indonesia. Copyright (2017) by Sehati B. Reprinted with permission.

women), other women in this figure, nurse and hospital administrative staff.

Note. English translations: *dokter* (doctor), *suami* (husband), *ibu hamil* (+) HIV (HIV- positive pregnant

Creative and Visual Action 3: Drawings to inspire other HIV-positive women for being resilient and resourceful HIV-positive women

Another component of the research process included “go-along” interviews with seven HIV-positive women who were not comfortable being involved in FGDs. Meeting individually with them created the opportunities to observe hospital treatment for HIV-positive pregnant women and HIV-positive women with their HIV-positive children who were taking prophylaxis treatment. Three of the women were able to see me several

times and produced a poem, drawings, and mind-mappings. The remaining four women, due to various commitments, were able to have only one interview session each. In addition, the first author had the opportunity to meet four of our participants’ husbands during the interviews and had informal discussions with them. For instance, Mona drawings with her family to express the importance of seeking Anti-retroviral therapy to survive for her family (Figure 4) and to disclose her HIV status to her second husband (an HIV-negative man) before their marriage (Figure 5) then later her husband supported Mona to access PMTCT services.



Figure 5: Zee’s drawing of a mother goose and her goslings

Note. Zee’s picture that depicted a mother goose feeding her three goslings. In Mona’s imagination, the drawing reflected Zee’s dreams to have her

mother (Mona) looking after and feeding three children.



Figure 6: Mona’s poster: I am HIV positive

Note. Mona (HIV-positive mother) believed it was very important for her to disclose her HIV status to second husband.

She expressed her feelings in poster form with the words “I am HIV positive”

DISCUSSION

Creating space, participation, and action are an integral part of FPAR. Three primary principles of FPAR are learned during the research process in applying creative and visual methods. They are 1) cultivating trust with marginalised women; 2) centering women within a safe physical environment to communicate with the marginalised women; and 3) honouring the voice of HIV-positive women through partnership and a variety of creative representations from their expressed aspirations. We will discuss each in turn.

First Principle: Cultivating trust with marginalised women

FPAR emphasises building trust as the first important stage in the research, and not data collection (see 19, 20). Feminist researchers have argued that the culture of oppression may not fully capture women’s lived experiences in society (11, 21-23). The present study confirms that building trust is the first step in conducting research with marginalised women. Our findings demonstrate that building trust contributes to the honest expression or authenticity of our participants’ voices, particularly on the range of silent experiences related to discriminatory treatment in health settings and taboo topics in everyday women’s lives. Fully capturing women’s lived experiences within society shifted over the time of the research both before and after gaining the

women’s trust. For example, the WLWH in this study wanted to present themselves as good women and probably worried about our judgements, even when we said we did not judge them. Surprisingly, after gaining their trust, some participants were open to discussing their private lives with the researcher; for example, the experiences of being a sex worker, a female IDU, and the second wife of their current husband were all discussed, even though they are taboo topics for Indonesian women. One participant said, “finally, I met someone to share my story that I kept secret for ages; I hope other women will learn from my story” (Mona,2017).

Second Principle: Centering women within a safe physical environment to communicate with the marginalised women

Women’s diverse lived experiences in their daily lives cannot be excluded from patriarchal values and their structured subordinated position (Reid, 2008; Coghlan & Brydon-Miller, 2014). Our participants had internalised stigmatisations from seeing themselves as being responsible for being infected with HIV by their husband. Therefore, HIV-positive women may not have found it easy to speak about their lived experiences and aspirations to me as a researcher, whom they had only recently met. At the same time, being HIV-positive women and users of HIV care, they perceived themselves as the real knowers of their problems. One HIV-positive mother confidently revised the researcher’s understanding related to some issues in this research by saying “*bukan cak itu bu, tapi cak ini*” (it was not correct, let me explain to you, madam, FGD).

FPAR researchers have emphasised that women with less privileged positions in society or marginalised groups need “a safe space for all

voices to be heard” and “mutual respect for diversity, caring, and compassion and egalitarian understanding of power” is critical [e.g. Ponice, Reid (12)]. The current study shows that a researcher needs to ask participants about a safe place to talk. We always asked participants to decide on the location for our interview or FGDs. We became aware of the importance of this question when two participants withdrew from the study due to concerns about their privacy, as they had not disclosed their positive HIV status to their husbands. Surprisingly, groups of HIV-positive women were happy to meet in open areas for FGDs, such as in a public park, and had strategies to protect their privacy by using the coded term “B20” for HIV. For specific activities and privacy, we offered them a discussion in a closed room, for example, when they were developing their puppet shows. Others preferred to meet me in a house, office, or hospital.

The place of meeting should be based on women’s choice to protect them as participants who are negatively stigmatised in their communities. Within their chosen safe, physical, and supportive environments, we learned how the women exercised a sense of freedom of expression and we recognised their privilege as the real experts of their problems and solutions. They were able to share their vulnerability and the challenges of HIV transmission, as well as their hopes for better solutions to enhance access to PMTCT services, regardless of their social status, religious, or cultural circumstances.

Third Principle: Honouring the voice of HIV-positive women through partnership and a variety of creative representations from their expressed aspirations

The third step of the FPAR journey was honouring the participants’s forms of action, by accepting a variety of creative representations (using visual outcomes) expressing their aspirations, based on the participants’ choices. Action, according to Gordon (2001/2006 cited in Reid & Frisby, 2008), is “an integral part of reflective knowledge, and can be conceptualized as speaking or attempting to speak in order to perform validation of every unique lived experience to gain the better understanding of women’s issues and solutions (p. 101). Borrowing Reid and Frisby’s (2008) work on honouring many forms of action, this practice became powerful in the formulation of women’s critical consciousness, producing diverse creative actions and providing a space for them as real knowers of their problems and the main problem solvers. Our study suggests three main steps in relation to this 3th principle of FPAR: 1) cultivating partnership, 2) providing individual and collective space, and 3) using participatory visual methods.

The first strategy for honouring their voices, was to cultivate a partnership with them as marginalised women. According to Ponice et al. (2010), cultivating relationships or shared collective power and strategies are the best ways to utilise every woman’s knowledge to address the complex barriers and provide the best solutions to women’s health issues. For example, when creating the modified lyrics to *Cuk Ma Ilang*, our participants said “madam, can you make the lyrics for us?” They may have thought that the researcher had that capability due to the first author’s higher education, but she was aware of the drawbacks of being an outsider. The first author suggested we have lunch first and then modify the lyrics together, to increase teamwork

during group discussions (Najmah, fieldnotes, April 2017).

The second strategy for honouring the voices, was to provide a collective space for the women, individually or collectively, using a range of media for them to express their aspirations based on their methods of choice with other participants, or in their own space with their family. Many forms of actions among the HIV-positive women, collectively or individually, demonstrated the creativity of women's heads, hearts and bodies, and became a medium within a communicative space and safe physical environment to express their aspirations to other groups in the study (24). Of course, the first author's supervisor regularly reminded her, "Najmah, remember, participants' choice of action was a priority in this research to express their words, not your preferences (Sari Andajani, personal communication, April 2017). She reminded me not to misuse the first author's power as the researcher, to control participants to fit with her preferences.

Participatory visual methods, the third strategy, provided a space for a variety of creative representations of their aspirations. The HIV-positive women added pictures from magazines, connected pictures and images by writing storylines, created song lyrics and expressed their aspirations through visual role play, puppet shows, and drawings. The visual outcomes were used as key empirical evidence and data, but more importantly, became powerful tools to assist in the presentation of their ideas to other groups in the study (see Aldridge, 2015; Fraser & al Sayah, 2011; Leavy, 2015; Mitchell & Sommer, 2016).

This study has identified that the obstacles of structural inequality that situated the participants

as a marginalised group, were minimised by empowering them deliver their aspirations through audio-visual outputs to groups such as health workers, NGO workers and policymakers. We delivered the majority of visual outcomes from HIV-positive women, health workers and NGO workers to the final group of our research, the HIV stakeholders. This created an empowering and reflective discussion and later initiated changes, providing evidence of the value of FPAR.

CONCLUSION

HIV-positive women are the real knowers of their lived reality, problems, and the solutions that could enable them to access PMTCT services. Through our journey as a novice feminist participatory action researcher, we extended the principles of FPAR into three main points: 1) cultivating trust with WLWH, 2) providing a safe physical environment to communicate with WLWH, and 3) honouring their voices through partnership and a variety of creative representation from their action (such as puppet shows, drama, and drawing). The research methodology used in this study, FPAR created an active opportunity for WLWH to feel empowered to understand, analyse, and express their feelings about their personal situations, the stigma attached to HIV, and the gendered relations in their marriages. FPAR made it possible for my participants to take action to overcome barriers and access PMTCT services to improve both their own and their children's health outcomes, and inspire other Indonesian and HIV-positive women to access these services and influence policy makers to listen their voices.(3,394 words).

Declaration

Ethics Approval

The Auckland University of Technology Ethics Committee (AUTEK) on 7 March 2017 (Reference No. 17/22).

The Research Ethics Committee of the Faculty of Medicine, of Sriwijaya University (Reference No.39/keprsmhfkunsri/2017) on 15 March 2017

Consent to publish

None declared

Availability of data and materials

None declared

Conflict of Interest

The authors declare that they have no competing interests

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