Journal of Infrastructure, Policy and Development 2024, 8(13), 9507.
https://doi.org/10.24294/jipd9507

Article

The role of female community AIDs activists in supporting people with HIV/AIDS through confidentiality and trust

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CITATION

Yuliati N, Pawito P, Wijaya M, Utari P. (2024). The role of female community AIDs activists in supporting people with HIV/AIDS through confidentiality and trust. Journal of Infrastructure, Policy and Development. 8(13): 9507. https://doi.org/10.24294/jipd9507

ARTICLE INFO

Received: 8 October 2024
Accepted: 17 October 2024
Available online: 13 November 2024

Abstract: An important element in dealing with HIV/AIDS is to disclose of its status to others. One of the problems faced by HIV/AIDS sufferers in disclosing their status is finding people they can trust, who can keep information about their HIV/AIDS status and not divulge it to other parties without their permission. Not many people can accept them without prejudice and stigma. This article discusses the communication efforts carried out by female AIDS activists in the community as co-owners who receive information from people with HIV/AIDS and subsequently become confidants and assist them in medical and psychological and social aspects. This study used a qualitative method. Data was collected through in-depth interviews with 9 Community AIDS activist women from 7 regions. The results of the study reveal the process of housewives transforming into community AIDS activists, how they get personal information about the status of HIV/AIDS and eventually become co-owners of information who eventually become confidants, have responsibilities and help people with HIV/AIDS in health, psychological and social aspects.

Keywords: disclosure; private information; people with HIV/AIDS

1. Introduction

HIV/AIDS sufferers are often ostracized by society, friends and even their own families. They actually need psychological and social support. One of the important elements in HIV/AIDS case is the issue of disclosing HIV/AIDS positive status to others. People with HIV/AIDS have great pressure when they decide to disclose their status. Disclosure itself can be an additional trauma so to avoid stigma (Greene et al., 2003), withdraw and keep it a secret (Smith and Hipper, 2010). Thus, disclosure of HIV/AIDS is a social and psychological problem that will continue to occur, as revealed in several studies including how the process of disclosure by HIV/AIDS sufferers to a group of men (Gaskins et al., 2012), and how and to whom to open up (Latzoo, 2013; Miller and Rubin, 2007)The main problem for HIV/AIDS is the secretive nature of the disease. Previous studies have stated that it is not easy to disclose the status of HIV/AIDS to even the closest ones, such as spouses (Xiao et al., 2015), mothers to their children (Tenzek et al., 2013), or families (Ngula & Miller, 2010). Even though sharing with others about the condition of HIV/AIDS is very meaningful because they can release feelings of depression, but at the same time it is also full of challenges because of the possibility of getting unpleasant and unexpected reactions when revealing their AIDS disease (Latzoo, 2013).

There are various advantages for People with HIV/AIDS to share their status with others because by disclosing themselves to certain selected targets (people) they can gain access to social support, as well as get help such as getting access to treatment. People who disclose their status can also get more appropriate medical care. People who have not notified medical staff about their HIV/AIDS status can complicate the medical management of other illnesses. Disclosing about HIV/AIDS status has the potential to reduce the stigma associated with HIV and AIDS. Beyond this primary support need, People with HIV/AIDS may also want to talk about the disease or plans for the future, and disclosure is needed to gain support for this. Therefore, by having other people to share with, the infected person can build a social support system. Social support improves the quality of life of HIV/AIDS sufferer (Yadav, 2010).

HIV/AIDS remains a complex global health issue, especially in developing countries, including Indonesia where cultural and religious norms greatly influence public perceptions of HIV/AIDS, People with HIV/AIDS often face social rejection which worsens their access to medical care and social support. Amid these challenges, women community AIDS activists played a significant role. They are not only drivers of social change in educating citizens, but also guardians of trust who protect the privacy of People with HIV/AIDS. In an environment where HIV status is still considered taboo, these women activists act as protectors of sensitive information, ensuring that the identities and health status of People with HIV/AIDS are not shared without permission. More than that, they also provide essential emotional, legal and social support for People with HIV/AIDS who are often marginalized by society. The role of women community AIDS activists in assisting People with HIV/AIDS becomes very crucial. In the Indonesian context, female AIDS activists often emerge from housewives who not only play domestic roles but also act as agents of social change. This transformation creates interesting dynamics regarding their role in managing sensitive information about HIV status and how they protect the privacy of People with HIV/AIDS.

Considering the social and psychological complexity involved, this research aims to (1) Describe the social setting related to AIDS which is the background for interactions between women activists and the community in managing the personal information of People with HIV/AIDS; (2) Analyze the transformation process from housewives to AIDS activists; (3) Identifying activists’ experiences as co-owners of AIDS information, and (4) Exploring various forms of support provided by activists to People with HIV/AIDS and their impact on the holistic welfare of People with HIV/AIDS.

Using the CPM theoretical framework, this research highlights the importance of privacy management in improving the quality of life of People with HIV/AIDS, while emphasizing the unique challenges faced by women activists in carrying out their roles. With an approach that combines CPM theory and socio-cultural studies, this article aims to provide deeper insight into the role of women community AIDS activists in assisting People with HIV/AIDS.

Most private information research in the health sector is investigated by disclosing parties such as research on factors influencing patient disclosure to physicians in birth control clinics (Lewis et al., 2011), concealing eating disorders (Tenzek et al., 2013), condom use by women (Hernandez, 2018) and disclosure of health personally identifiable information for enhanced pain treatment (Ahmadi et al., 2019; Robinson, 2019). In the context of AIDS, self-disclosure of AIDS sufferers as authorized owners was investigated such as factors leading to self-disclosure of a positive HIV diagnosis (Miller & Rubin, 2007) self-disclosure of HIV seropositivity (Ngula and Miller, 2010), HIV disclosure for rural African American Men (Gaskins et al., 2012) and managing and controlling HIV/AIDS talk among Ghanaians living with HIV/AIDS (Latzoo, 2013). Meanwhile, research on HIV-infected people or people with AIDS that examines the co-owner and confidant side as the party who shares personal information is still very rare. There is a significant gap in the literature on how women activists, particularly in developing countries like Indonesia, manage personal information regarding their HIV/AIDS status. This research, which is based on Communication Privacy Management (CPM) theory, provides a strong framework for understanding the dynamics of disclosure. It may also serve as a theoretical model that can be applied to a variety of other community contexts facing privacy and health issues.

2. Theoretical Framework

2.1. Disclosure and private information in communication privacy management

Communication Privacy Management (CPM) is a perspective on the dialectic of tug-of-war between being private or being part of the public. Humans are social creatures with a need to connect with other people. CPM is a theory applied to understanding how people manage dialectical tensions regarding privacy and disclosure (Petronio, 2004). While one needs to be open, there is also a need to protect oneself (Petronio and Martin, 1982), individuals protect their personal information because they do not want to be hurt. Vulnerability is a problem for everyone so that someone takes care of the resources (information) they have (Petronio and Kovach, 1997).

Disclosure is done with consideration and intentional where individuals must take into account the results of the disclosure of personal information before they disclose it (Petronio and Martin, 1982). The concept of disclosure can be traced to Sidney Jourard in the 1970s where disclosure is narrated as “the act of making yourself manifest, showing yourself so others can perceive you” with the main focus being on opening up to others. Jourard assumes that disclosure is a healthy private key. Jourad’s work is continued by Altman and Taylor, they argue that disclosure occurs reciprocally in two dimensions: first; depth, namely the level of intimacy of disclosure, and second; breadth, namely the number of topics discussed. Through this process people develop significant relationships with each other (Berger, Roloff, & Petronio, 2016) because always when individuals want to open up there is also a constant desire to protect themselves.

While in the initial studies the researcher argued that self-disclosure had a positive connotation, further research stated that disclosure may not always end with positive results. As research began to illustrate that disclosure can be both positive and negative, it became clear that a new way of conceptualizing disclosure was needed. One way for researchers to expand the notion of disclosure is seen in a theoretical perspective called Communication Privacy Management. Petronio’s theory of privacy management communication builds on Altman's dialectical conception of privacy as a process of opening and closing boundaries for others. CPM theory argues that when people disclose personal information, they rely on a rule-based boundary system as a basis for decisions to manage accessibility levels (Petronio, 2008). As for what is disclosed or hidden is personal information. Therefore, there is a need for rules that allow one to consider how decisions are made whether to disclose or hide personal information (Petronio, 2008). When some personal information is shared with others, other people may become co-owners of the personal information. Information can be shared in family, group, and organizational settings. Because co-ownership entails the responsibility to protect personal information, individuals must negotiate a number of rules that govern the disclosure and concealment of shared information and must commit to mutual holding and coordinating these rules (Petronio and Kovach, 1997).

CPM from Sandra Petronio provides a full view of the principles and processes that explain the communicative decision systems that people make when they decide and manage to disclose or protect their personal information. CPM theory provides a way to unravel the complex issues of privacy management (Petronio, 2008). Petronio assumes the theory of Communication Privacy as a map of how one navigates privacy. There is privacy restriction that include information that we have but other people don't know about. Privacy boundaries can range from thin filters to thick, impenetrable barriers that protect deep and dark secrets. But every time someone shares some of that information with others, he or she will reshape the boundaries of privacy (Griffin, 1991).

CPM is an important theory that elaborates the dialectical process in interpersonal relationships, where Petronio's research has crossed the context of interpersonal communication, family, and health, and will continue to use various medical problems to describe how people manage their personal information (Littlejohn and Foss, 2009). The use of the CPM approach helps direct researchers to track and describe individuals in sharing private information in various contexts such as family (Afifi, 2003; Docan-Morgan, 2011; Hammonds, 2015; Kam et al., 2019, work place (Allen et al., 2007; Charoensap-Kelly et al., 2020; Helens-Hart, 2017; McBride et al., 2020) public health such as sexual history (Nichols, 2012), pain treatment (Robinson, 2019), relationships such as hurtful experiences (Pederson and McLaren, 2016).

2.2. Co-ownership and confidant

CPM theory recognizes that individuals believe they have personal information and have the right to control that information (Petronio and Child, 2020). There are 2 levels related to CPM which identify the information, first owner or original owner and second is the co-owner or 'authorized co-owner' which indicates the legitimacy of access to information (Berger, Roloff and Petronio, 2016). CPM argues that because disclosure is a communicative process, the act of disclosure connects people within the boundaries of privacy to be collective. In other words, telling someone personal information (usually considered self-disclosure) makes the confidant a co-owner, pulls them into the boundaries of information privacy, and they also become responsible for the information. Thus, personal information becomes collective because two or more people are expected to be responsible for the information (Petronio, 2002), They also agree to create a “privacy spanner”, a term which refers to individuals who bring out shared personal information in order to relate it to others (Petronio et al., 2004)

The Co-owner context in CPM is based on the assumptions that every individual has the right to his personal information and has a desire to control his personal information. The owner of personal information becomes the original owner of the information. Individuals will disclose their personal information to a trusted person or confidant, where the confidant will become a co-owner who co-owning of the personal information. The owner and co-owner negotiate the rules for managing the personal information. Co-owner will have a ‘guardianship role’ to the original owner and assist in psychological, social and health or medical/health access (Petronio, 2002)

When other is notified of or discover someone’s personal information, he or she become co-owner of that information. As co-owner, the person tends to feel responsible for the information and as co-owner of the information he or she must protect the information. Co-owner of personal information need to negotiate mutually agreed rules. For the sake of harmony, the original owner and the co-owner must be congruent. Co-owner should negotiate to create mutual privacy boundaries (Petronio, 2010). Once a person is allowed to know someone else’s personal information, that person becomes a co-owner and confidant (Petronio, 2010). So, one of the important issues in CPM is the role of the confidant. So, someone who receives personal information becomes an insider where the nature of the coordination process depends on how the recipient treats the experience. Thus, judgment in making a wise decision to disclose personal or confidential information depends on finding the right confidant. They are discreet, secretive, non-judgmental and able to offer new insights into their secrets (Kelly, 1999). Since the recipient of the secret becomes one of the owners of the secret after the secret is disclosed, the reactions of confidants also play an important role in the disclosure calculus. Generally, individuals are more likely to reveal secrets if they feel safe from criticism, judgment, or accusations. Factors such as secret owners feel safe in their relationship with their trusted people and believe that the trusted person will accept disclosure or reciprocate with their own disclosure will affect someone’s disclosure (Berger, Roloff and Romo, 2016).

3. Method

To uncover the phenomenon, this study uses a constructivist-interpretive paradigm with a case study research method. Qualitative research examines things in their natural environment seeking to understand, or interpret phenomena based on the meanings people give to them. Conventionally, qualitative methodologies tend to be associated with the researcher’s desire to examine meaning, context, and a holistic approach to phenomena (Chang, 2009). They state that humans are active beings and beings who think when building interactions with each other. The case study approach is used where an exploration is bounded by time and place, and it is the case being studied—a program, an event, an activity, or an individual (Yin, 2009).

The research was conducted in Bandung City, West Java which includes. Seven Districts in Bandung City, namely Bojongloa Kidul, Sumur Bandung, Cicendo, Babakan Ciparay, Sukajadi, Taman Sari dan Andir. The subjects or participants in this study were women’s AIDS Community activists in the City of Bandung.

Determination of the sample in qualitative research has its own criteria. Qualitative research uses a theoretical sampling strategy, in which the research locus, respondents, or cases are selected based on theoretical considerations such as whether they fit the phenomenon being studied, whether they have certain characteristics that make them unique and suitable for the research being conducted (Creswell and Creswell, 2018). Therefore, a small sample can be accepted in interpretive research as long as it is in accordance with the nature and purpose of the study, as stated by (Bhattacherjee, 2012).

This study used a qualitative method. The data collection technique used was the depth interview. This data collection refers to Cresswell that multiple sources can be used in case study research including interviews (Creswell and Creswell, 2018). Data was collected in 2 periods; March–April 2019 and November–December 2020. Each interview was conducted for 60–120 minutes. Interviews were conducted with 9 Community AIDS activists spread over 7 areas in Bandung City and recorded with their permission. The recording was then made into the form of a transcript.

The determination of informants was carried out purposively based on the researcher's consideration that they had adequate information about the problem under study and were willing to reveal their experiences. Determination of the sample in qualitative research has its own criteria where the participants in this study are women activists who interact with and have accompanied HIV-infected people and People with AIDS. Activists interviewed were women activist who become member of the Warga Peduli AIDS (WPA) movement or local residents concerned about AIDS aged over 35 years with a duration of involvement in community activities of more than 5 years. The process of getting access to participants is not direct, the researcher gets data from "Komisi Penanggulangan AIDS" or the City AIDS Management Commission Bandung City which has data related to the AIDS community. After receiving data and contacts from the AIDS Prevention Commission Bandung City, the researcher made contact and managed to gain access to women community AIDS activists in Bandung City.

This research uses qualitative methods because it focuses on the process of female community AIDS activists in constructing their experiences as activists and their interactions with PLWHA which would be difficult to quantify. Qualitative methods will explore data from perpetrators in their natural settings.

The subjects or informants in this research were female community AIDS activists in Bandung City, West Java, Indonesia. Subject selection was carried out with the following considerations and criteria and detail can be found in **Table 1**:

1) Participants are women community AIDS activists who know information about the status of People with HIV/AIDS in their environment.
2) Participants are women community AIDS activists who are trusted people of People with HIV/AIDS in their environment.
3) Participants are women community AIDS activists who accompany People with HIV/AIDS and communicate with them.

As a case study, this research uses the following case study data analysis flow:

1) In the initial stage, the researcher thoroughly describes the experiences experienced by the research subjects. The interviews conducted were recorded and then transcribed.

2) The interview transcripts are then sorted and inventoried, which statements are relevant, important and appropriate to the topic.
3) Group the statements into meaningful themes or units.
4) Describe the essence by building a comprehensive description of the meaning and experience of the research subject.
5) Research report, where the researcher reports the results of his research. The phenomenon under study is described so that it can be understood by others.

Table 1. Participants.

Participant	Age	Education	Sub-district.
Di	44 years old	Senior High School	Bojongloa Kidul
Hh	43 years old	Senior High School	Bandung Wetan
Yu	50 years old	Associate's Degree	Sumur Bandung
Wn	45 years old	Associate's Degree	Sumur Bandung
Hn	61 years old	Senior High School	Sumur Bandung
Wi	38 years old	Senior High School	Andir
Nu	54 years old	Senior High School	Cicendo
Ne	49 years old	Senior High School	Sukajadi
Yl	46 years old	Senior High School	Babakan Ciparay

The researcher chooses WPA area based on the area that represents the city and industrial areas. The researcher initially established a relationship with the AIDS Prevention Commission (KPA) Bandung City. This was done to obtain a unified, holistic analysis related to the social and economic context of the area which is the domain of women's AIDS activists in the community. Determination of the research location is determined purposively in order to get a representation of the criteria for urban and industrial area.

To validate the research data, the researcher used a triangulation flow as described by Stake by using multiple perceptions to clarify meaning, verifying the repeatability of an interpretation.

4. Results

4.1. Social setting of local residents concerned about AIDS in Bandung, Indonesia

Bandung City is the capital city of West Java Province. West Java itself is in the 3rd position of the province with the highest number of AIDS cases in Indonesia, while Bandung City is the city with the most AIDS cases in West Java. Bandung is one of the 10 most populous cities in Indonesia, with an area of 16,767 hectares. With a population of around 2.5 million people in 2018 (1.26 million men and 1.24 million women) and its population density can cause various social problems, both physical, psychological, economic and health (BPS, 2023). The case of HIV/AIDS in Bandung City was first discovered based on a report from a hospital in 1991 (KPA, 2010) and was already in the AIDS phase. HIV/AIDS cases in the city of Bandung from 1991 to June 2010 found 2100 cases, 111 people died and is the highest case in West Java. The participants in this study are in 7 Districts that represent cities and industry area in Bandung City, Indonesia.

In general, AIDS cases in Bandung are related to drugs and prostitution. The use of shared needles and unsafe sex have contributed greatly to the increasing spread of AIDS. Coupled with the poor economic condition of the community and low education, people do not have adequate knowledge about AIDS, as well as limited access to information. Not to mention talking about AIDS and the aspects that accompany it such as sex is still considered a sensitive and even taboo subject. The results of interviews with participants stated that the community's rejection of AIDS sufferers was still high. People with AIDS accept various forms of discriminatory treatment, while the issue of AIDS is still difficult to convey. Residents even feel afraid to hear the word AIDS. However, they do not feel the need to know and check themselves. Various problems related to AIDS which were summarized from the interviews were due to (1) shame; (2) fear of being ostracized; (3) stigmatized; (4) associated with moral issues such as sinners, deviance, as expressed by the following participants:

> *"The drugs here are terrible. We see how they use it; we know how they transact. Around 2014 there was HIV-infected people who was abandoned. According to the family he will die soon. (Yu)."*
>
> Indifference and fear:
>
> *"One family, all died. First his father, second his mother, lastly his son. There were two families here who all died. When the child died, I bathed, because other people didn't want to. I became a companion even though he has families. I just helping because no one cared, so I and other WPA activists intervened (Hh)."*

When he was being treated, I was confused about what to do because in the end I had to tell his sister. No one from his family knew. At first, he didn't want to tell his sister because if his sister found out he had AIDS, he was afraid that his sister's husband would divorce her. But in the end, he told his sister. I then called his sister, then finally I explained that HIV is not transmitted like watching TV. Then, we talked about bacteria and it's contagious (Di).

Residents sometimes find it difficult to accept HIV/AIDS sufferer. Even religious leader says let them die it's because of the disease, because of their action. AIDS is a 'dirty disease', the affected are prostitutes or homosexuals. So, people think people with AIDS are bad people. It was due to lack of information about AIDS (Nu).

AIDS phenomenon in Indonesia has been marginalized since the beginning through moral issues, stigma, labeling, and stereotypes. For example, the stigma associated with groups such as men who have sex with men and injecting drug users persists, even though today most of the world's HIV infections originate from heterosexual transmission and this fact is still ignored by many persons. One of the spread of AIDS is through the HIV virus which is transmitted through sexual intercourse. There are still many people—including Indonesia—who cannot talk about sexual matters openly and honestly and as a result, HIV/AIDS becomes difficult to discuss and thus difficult to control. The history of the cycle of the existence and perception of AIDS in Indonesia starting with homosexuals and female sex workers has made AIDS cases marginalized through moral issues, stigma, labeling, and stereotypes. AIDS cannot only be seen and cannot be treated as just a disease because of the different views of society about it.

4.2. Communicating awareness of AIDS in the community: From housewives to activist

WPA or residents concerned about AIDS is the first form of community action to respond to AIDS in Indonesia. The majority of WPA members are housewives who after joining WPA and received various trainings they become AIDS activists in the smallest community groups, namely at the Urban village level and are the initiators of mobilizing information and actions about AIDS, and some of them accompany HIV-infected people and people with AIDS. The participants are activists who become co-owners where HIV/AIDS sufferers share information about their status to them. This openness of HIV-infected people and people with AIDS were initiated by WPA activists. They work in their community to identify, approach and interact with HIV-infected people or people with AIDS, see **Table 2**.

Table 2. Trainings were followed by the participants.

Health and HIV/AIDS Training	Human Rights and Gender Training
1. Basic HIV Information training.	1. Basic HIV Information training.
2. TB and HIV training.	2. SOGI (sexual orientation gender identity) training.
3. PPIA (prevention of HIV transmission from mother to child) training.	3. SOGIE (sexual orientation gender identity and expression) training.
4. Open status people with HIV/AIDS training.	

Furthermore, several participants provided assistance to People with HIV/AIDS in their area. This was done because HIV/AIDS suffers experience various problems both from themselves and from their environment. There is indifference among people with AIDS and HIV-infected people where there are still many of them who do not care about themselves. Also, there is still a strong stigma against people with HIV/AIDS because there are still many people around who do not understand. As a result, the community loses empathy for HIV-infected people and people with AIDS.

WPA activist women are housewives who initially engaged in Pemberdayaan Kesejahteraan Keluarga (PKK) or Family Welfare Movement. The Family Welfare Movement is a ‘movement’ in the sense that it does not have a registered membership like an organization usually does. The Family Welfare Movement is a community development movement that grew up among women themselves (Setiadi et al., 2024). This movement aims to improve family welfare by providing various health, sanitation and nutrition counseling to improve living standards. The role of the wife and mother in Indonesian society has an important and very prominent role. The PKK is in the environment of the participants and is already known to them as stated by the participants:

Individuals can discover new paths through challenging life experiences. For instance, a housewife who initially had little interest in the outside world and focused solely on household matters eventually transformed her social role through community involvement (Ahmadi and Adzhani, 2019). Once she began socializing with her neighbors and participating in community activities such as the Integrated Health Post

(Posyandu) and the Family Welfare Program (PKK), her role evolved. One informant, Di explains despite not having a medical background, her interest in the health sector had been evident since childhood. Although she lacked the opportunity to pursue a formal education in medicine or midwifery, her dedication to community health remained strong. Her personal experiences and active involvement in health-related activities made her a recognized activist in her community, particularly in assisting neighbors who were financially constrained in accessing healthcare services.

> *Wi, meanwhile, her involvement in youth organizations such as Karang Taruna opened opportunities for training and knowledge enhancement on issues like HIV/AIDS and reproductive health. Then, she joined an NGO focusing on issues like sexually transmitted infections (STIs) and HIV, particularly due to her residence near a prostitution area. Through these activities, she became a vital source of information for female sex workers, providing much-needed education and support.*

WPA or Local Residents Concerned about AIDS Movement is the first form of community action and participation to respond to AIDS in Indonesia where a group of women in Indonesia have pioneered community-based organizations that approach HIV/AIDS in their neighborhoods. Becoming activist is an active process in participants' interactions with their social environment where they reconstruct their understanding of HIV/AIDS.

> *Involvement in Women's Community AIDS Activist groups transforms participants' perspectives on HIV/AIDS. Initially, their emotions may range from fear and suspicion to compassion, motivating them to engage in efforts to combat the epidemic. However, through training and interaction with affected individuals, they acquire a nuanced understanding of the disease. By acquiring knowledge grounded in facts rather than prejudice, these activists can make informed observations about their environment and design strategies to address the complexities of HIV/AIDS. As a result, they build new values around co-owning private information and willingly assume the role of confidant. This evolution from an emotionally driven approach to a rational, informed stance exemplifies the dynamic nature of community activism in the context of HIV/AIDS.*

4.3. Co-owning private information about HIV/AIDS in the community

Getting people-infected HIV or people with AIDS to open up takes a lot of effort. They have various reasons for not wanting to open up, as stated by the participants. Disclosure consists of at least two individuals in a social interaction, each of which involves the feelings, beliefs, attitudes, values, and expectations of the people involved. Furthermore, the behavior of the two people is influenced by physical, social, psychological, and relational contexts. Building trust and ensuring confidentiality are crucial when working with individuals affected by HIV/AIDS, particularly in densely populated communities. Women's community AIDS activists often play a vital role in bridging the gap between those affected and the healthcare system. This process requires patience, empathy, and the ability to gain the trust of individuals who may be hesitant to disclose their status. In some instances, the activist's role extends to involving family members to ensure that individuals receive the necessary support. One participant, Hn, shared an experience involving a male relative who was initially reluctant to seek help due to stigma and fear. By discreetly approaching the man's wife and providing support, the activist was able to facilitate the man's eventual openness about his HIV-positive status.

Furthermore, activists often find themselves in challenging situations where they must navigate complex family dynamics and limited resources. For example, one activist *named Ne* had to support a friend suffering from prolonged illness, later identified as HIV-positive, and subsequently had to inform the family about her condition. In another case, an activist Wn had to reassure the family of an HIV-positive individual about transmission risks, reflecting the importance of providing accurate information to mitigate fear and misconceptions.

The journey to gaining the trust of individuals living with HIV/AIDS is often fraught with challenges. The participants in this study demonstrated that their extensive experience in interacting with various groups within their communities enabled them to access and support individuals living with HIV/AIDS more effectively. As activists, they have garnered the community's trust, which not only empowers them but also serves as a catalyst for encouraging others to open up about their status. This highlights the indispensable role of community activists in managing the social dynamics of HIV/AIDS within their environments.

> *Community AIDS activists often serve as critical links between individuals living with HIV/AIDS and the support systems they need. For instance, Yl, a community AIDS activist, was notified of an HIV case in her area involving a woman named S, who was homeless and isolated. According to Jones community health workers play a crucial role in identifying and supporting individuals affected by HIV/AIDS, especially in cases where social stigma and economic challenges exacerbate their vulnerability. In Yl's case, it was decided to inform S's family. Initially, S's sister was in disbelief and overwhelmed by fear, especially because she was pregnant. This reaction is not uncommon, as (Moghadam et al., 2018) explain that family members often experience shock and fear due to misconceptions about HIV transmission. Yl provided the necessary support and information, reassuring the family that HIV is not easily transmitted through casual contact. Gradually, S's sister accepted the situation, though logistical challenges remained, as her small living space made it difficult to accommodate S. This scenario highlights the complex social and economic factors that often accompany HIV cases, requiring tailored interventions and empathy from community activists.*

Disclosure of HIV status is a complex and sensitive process that requires careful navigation. Many individuals living with HIV/AIDS face immense fear of stigma and rejection, which can hinder them from seeking help. The activists' established presence in the community allows them to bridge the gap between those affected and the broader support network. Through their extensive experience and interaction with residents, activist like Yl has developed the skills and relationships necessary to facilitate access to various groups, including those who are often marginalized and excluded due to their HIV status.

The relationship between HIV/AIDS activists and the community they serve is a delicate balance of trust, support, and advocacy. By fostering open communication and providing accurate information about HIV transmission, these activists can reduce fear and promote acceptance among families and communities. The work of Yl and others like her is a testament to the importance of grassroots efforts in combating the stigma surrounding HIV/AIDS. The collective efforts of activists, informed by both personal experience and community dynamics, are essential in creating a more inclusive environment for individuals affected by HIV/AIDS.

4.4. Role of confidant in community

In interacting with the community, participants have awareness and actively identify their environment so that they know the social situation around them. The participants realized what constituted social problems in their environment, namely poverty, the threat of drugs, and the influence of prostitution that took place around them which became fertile grounds for the spread of HIV/AIDS. While antipathy, prejudice and negative stigma, neglect and fear of people with HIV/AIDS are still very high. This knowledge makes participants participate in building a social role and be active in providing knowledge about HIV/AIDS and become confidants.

Community AIDS activists face multifaceted challenges in their roles, particularly as confidants to individuals living with HIV/AIDS. In many cases, they are not only dealing with the physical and emotional struggles of the affected individuals but also confronting societal stigma and discrimination. One activist, Yu, exemplifies deep commitment as a confidant. Despite the scarcity of resources, she provided shelter for an individual with HIV who had no home. The social services could only offer temporary solutions, and the individual was reluctant to be placed with an NGO. Through her personal care and efforts, Yu nursed the individual back to health, raising funds to cover the costs as most HIV/AIDS patients in her community come from impoverished backgrounds. This level of dedication highlights the critical role community activists play in bridging gaps where formal healthcare systems fall short. (Smith and Niedermyer, 2009)underscore that grassroots efforts are pivotal in mitigating the impact of social determinants on health outcomes for people living with HIV/AIDS.

> *Activists often face personal challenges, especially at the beginning of their involvement. Yu shared how stressful and overwhelming it was initially, grappling with the complexities of care and the emotional toll of supporting those who had been abandoned by society. This sentiment was echoed by other participants, like Di, who admitted feeling confused and unprepared despite having some theoretical knowledge about HIV/AIDS.* (Earnshaw & Chaudoir, 2009) *point out that community health workers often experience high levels of stress due to the demands of their roles and the emotional weight of caring for individuals in dire situations. Participant Yl mentioned the despair and resignation commonly found among people living with HIV/AIDS, many of whom believe that a diagnosis equates to a death sentence. In one case, Yl accompanied an individual whose government health insurance was inactive due to non-payment, resulting in a lack of access to medical care. By navigating bureaucratic hurdles and accompanying the individual to the hospital, Yl played*

> *a crucial role in ensuring that they received the necessary medical attention.*

The experiences of these activists also reveal instances of extreme neglect and discrimination. For example, in 2014, Yu was called upon to assist a person in the AIDS stage who had been abandoned in the market. With no health insurance or identification, this individual was in a critical state, requiring urgent intervention. Yu coordinated with local authorities and healthcare providers to ensure the person received emergency care, illustrating the complexities and urgency activists often face in their work. Parker et al discuss how people with HIV/AIDS are often ostracized and denied basic services, making the role of community activists indispensable. This dedication to confronting societal barriers aligns with the transformative journey of activists who initially may have been driven by fear or curiosity but, through their experiences and training, develop a more rational understanding of HIV/AIDS.

Each case faced by the informant in this research is closely related to information management and the role as a confidant is at the core of the informant's actions as a volunteer accompanying HIV/Aids sufferers. The motivations, challenges, and cases faced by each individual demonstrate how they must navigate patient privacy rules, including when to disclose or protect patient personal information. Their cases show that the boundaries of privacy are blurred due to urgent medical or social needs, but informants must still ensure that sensitive information about HIV/AIDS sufferer is managed responsibly and with empathy.

The activities carried out by the participants as confidants when accompanying people infected HIV- AIDS began by helping patients with access to health facilities because most of them came from the poor. In addition, people infected HIV/AIDS did not know hospital procedures when they needed treatment. Participants helped people infected HIV/AIDS in taking care of administration so that in the end they get health services for free because it is covered by the government. If there were people infected HIV/AIDS who are sick, the participants voluntarily accompany them for treatment and even accompany them because sometimes there was no family who wanted to accompany them or because participants were asked by the people infected HIV/AIDS's family. Thus, participants become guardians for HIV/AIDS patients who represent patients and their families if there was a hospital requiring approval for medical action to be taken.

> *One participant explained that there were HIV/AIDS positive patients who lacked confidence when talking to doctors, so they were less open to doctors or nurses. Another participant said that sometimes people with HIV forget or get tired of taking pills so she has to remind them. Patients also sometimes couldn't take medicine to the hospital because they cannot leave their jobs. For this reason, it was the participants who took the medicine for her/him. People infected HIV/AIDS sometimes do not know how to explain the difficulties they face to doctors or nurses. Some sufferers even complain to participants that doctors or nurses think they are lazy and feel they are not being treated properly. These various conditions make people infected HIV/AIDS dependent on participants. Patients feel more comfortable when accompanied by participants. People infected HIV/AIDS also believe in participants so that there is a good relationship between the two.*

5. Discussion

Referring to Petronio’s line of thought, individuals basically believe that they have the right to own and regulate access to their personal information (Petronio, 2008). Petronio also assumes that other people are also important in the process of disclosing personal information (Petronio, 2010). For this reason, disclosure is not only about oneself, it also involves other people, so that to fully understand the depth and breadth of disclosure, do not limit the process only to yourself, but expand it between individuals, namely between the discloser and the recipient of the disclosure. Petronio’s assumption underlies this research which elaborates on the experience or involvement of female community AIDS activists in the process of disclosing HIV/AIDS information. The focus of this research is the involvement of women community AIDS activists. In the context of disclosure, they are the recipients of the disclosure.

The research findings describe stigma as the thing that People with HIV/AIDS fear most, as stated by the female community AIDS activists who accompany them. The female community AIDS activists in this research saw the fact that People with HIV/AIDS in the environment where they lived felt fear and confusion. Based on interviews with all participants, it can be concluded that the difficult situation faced by People with HIV/AIDS originates from the root of the stigma attached to HIV/AIDS sufferers, namely:

1) Misperceptions about HIV/AIDS

All participants in this study lived in poor neighborhoods. Minimal knowledge gives rise to wrong perceptions about AIDS which leads to stigma. Community AIDS women activists reported that many of the People with HIV/AIDS they accompany still think that if they get HIV they will immediately die. HIV/AIDS is seen as a deadly disease and there is no cure. This bad stigma stems from the fact that many people still do not have adequate information about Aids. Residents still believe that Aids is easily contagious and deadly. People still don’t know how Aids is transmitted. According to residents’ estimates, Aids is transmitted through direct contact, such as TB which can be transmitted through the air. This fear makes ordinary people not understand, thereby triggering stigma towards AIDS sufferers. Negative perceptions are reflected in the answers of female community AIDS activist participants who recorded residents’ responses to HIV/AIDS, namely, “AIDS is a cursed disease” “AIDS is a dirty disease” “HIV-AIDS is the result of their bad actions”, “Just leave them alone”, “Dead”, “The sufferer is not worthy of help”, “Disgusting”, “Trash”, “Sinner”.

2) Group bias.

Women community AIDS activists reported that residents considered people with HIV/AIDS to be people who had deviant behavior. The majority of cases faced by female community AIDS activist participants living in the Sumur Bandung area were injecting drug users, and groups with tattoos, while other participants faced cases of women or men who contracted HIV due to sexual intercourse. Another participant found cases of female sex workers infected with HIV. It was also discovered by female community AIDS activist participants that cases of housewives were infected by their husbands who had had sexual relations with other women. A very small profile of homosexual People with HIV/AIDS was found in this study. The profile of HIV/AIDS sufferers in this study has changed from homosexual to hetero but the label that HIV/AIDS sufferers are deviant sex offenders is still strongly attached. This finding further strengthens previous studies in many countries, one of which is China, where the main source of stigma related to HIV/AIDS is still associated with sexual deviation among the general public in China. Chinese society generally thinks that only immoral behavior causes someone to contract HIV/AIDS, even though in China many people contract HIV/AIDS through drug abuse and selling blood (Guo, 2016). This stigma comes from a negative image that is deeply rooted in people's beliefs about this disease. Residents assume that AIDS is the result of behavior that goes against social norms and morals, such as prostitution and homosexuality. Currently, most of the HIV infections in the world originate from heterosexual transmission and this fact is still ignored by many people (Greene et al., 2003). Isolation, insecurity, and fear about the future and the impact on personal and family relationships.

Other findings from this study indicate the transmission routes of HIV/AIDS as in **Figure 1**:

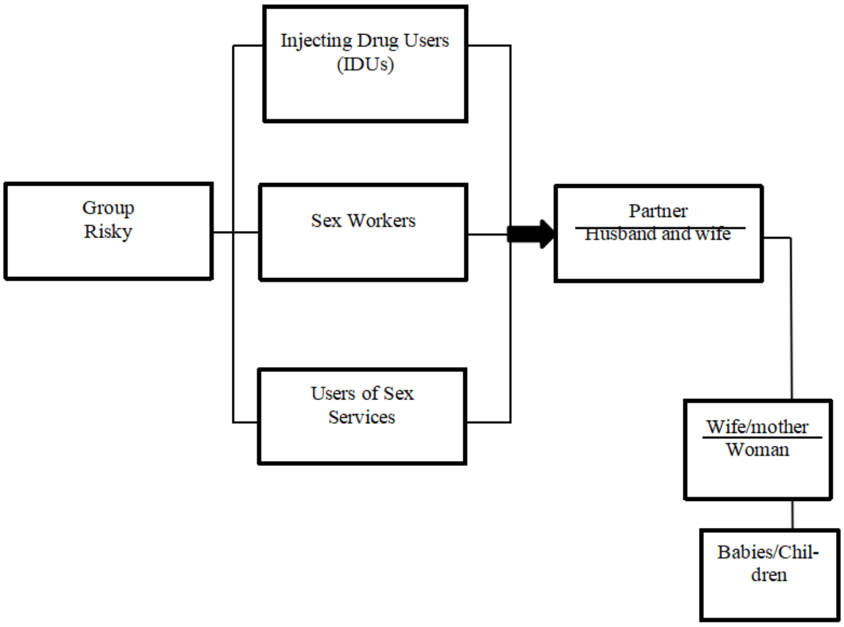

Figure 1. Chart of the HIV/AIDS transmission route.

The fact that HIV is a life-threatening and incurable disease makes disclosing the status of People with HIV/AIDS an emotionally difficult task. The cases faced by women community AIDS activists when receiving disclosures illustrate this. One participant reported that she had encountered People with HIV/AIDS who revealed her status to her in a hysterical state. There were also participants who received status disclosure when People with HIV/AIDS were sick, helpless and afraid to tell their family about their illness. This finding is in line with the results of the following research, namely romero et al. emphasize that stigma and discrimination are significant barriers to the disclosure of HIV status (Romero et al., 2006), contributing to a reluctance to access healthcare and support services. According to (Earnshaw and Chaudoir, 2009), stigma associated with HIV/AIDS significantly hampers the support and care provided to individuals living with the disease, often leading to isolation and inadequate healthcare. Parker et all discuss how people with HIV/AIDS are often ostracized and denied basic services, making the role of community activists indispensable.

The very challenging conditions faced by female community AIDS activist participants illustrate how they face this difficult situation. Nevertheless, all female community AIDS activist participants stated that all disclosures were voluntary. This means that there is no coercion. The following is **Table 3** of disclosure of HIV/AIDS status received by participants in matrix form as follows:

Table 3. Matrix of disclosures received by women community AIDS activists.

Nature of Disclosure	Layer of disclosure	Recipient of Disclosure
• Voluntary. • Managed. • Selective and Limited. • It's inevitable.	• Medical • Nuclear family • Interpersonal	• Health workers • Nuclear family • Women's Activists

The first disclosures received by female community AIDS activists were voluntary. The participants said that People with HIV/AIDS made the choice to tell them without any coercion. Disclosure is done with full awareness. Second, disclosure is also 'managed', People with HIV/AIDS carefully consider who they will disclose their status to. Women community AIDS activists were chosen as recipients of information on the status of People with HIV/AIDS because they can help them get treatment, are reliable, and will defend them. Third, female community AIDS activists stated that People with HIV/AIDS reveal their status very selectively. Based on participants' reports, People with HIV/AIDS tend to limit themselves in disclosing their status to a small circle, namely the family. Relational ties are important for People with HIV/AIDS in disclosing their status. Finally, the nature of disclosure found in this research is that disclosure is inevitable. The situation that emerged was that women community AIDS activists discovered that People with HIV/AIDS were already seriously ill, and had even entered the AIDS phase. People with HIV/AIDS have no choice but to reveal their status to female activists so that female AIDS activists in the community can help them by taking them to health services. This aligns with the findings of (Miller and Rubin, 2007), who emphasize the importance of community activists in combating stigma and enhancing access to health services for vulnerable groups. This intervention reflects the importance of a nuanced and empathetic approach, as noted by (Laschober et al., 2019), who highlight the need for community activists to employ culturally sensitive strategies when addressing HIV/AIDS-related stigma. Meanwhile (Romero et al., 2006) emphasizes that community activists are pivotal in creating safe spaces for People with HIV/AIDS, fostering a sense of acceptance and support.

The findings of this research also raise a layer of disclosure, namely the medical layer, where People with HIV/AIDS first find out that they are HIV positive. This layer is doctors or health workers in health services. The next layer is disclosure in the dimension of intimacy. The family exists in this dimension of intimacy. The female AIDS activist community stated that People with HIV/AIDS want their families to know their status. Meanwhile, female community AIDS activists are in the interpersonal disclosure layer. This layer is trusted individuals. They are not health workers and nor are they families of People with HIV/AIDS. Individual profiles in this layer refer to people around PLWHA who are believed to be able to retain information, and female AIDS community activists meet these criteria.

An interesting finding from this research is that women community AIDS activists are housewives who initially became health cadres and eventually transformed into community AIDS activists. Becoming an AIDS activist in a community in Indonesia is an empowerment process by fostering social intelligent-social responsibility. Empowerment relies on various concepts such as broadening the horizon of possibilities, from what people imagine about themselves and their abilities which expands the choices and opportunities of people who enable individuals to make choices to improve their lives. Empowerment is a combination of increased awareness and participation so that individuals not only understand their society and their current place in it, but that they make efforts to modify social relationships (Sulaiman and Ahmadi, 2020).

The role of wives and mother in Indonesian society have an important and very prominent role. This identity as wife and mother seemed to be attached to the participants when they were active outside the home. The informants have awareness and actively identify their environment so that they understand the social situation around them. The participants were aware of the social problems in their environment, namely poverty, the threat of drugs, and the influence of prostitution that took place around them which became fertile ground for the spread of AIDS. Meanwhile, attitudes of antipathy, prejudice and negative stigma, neglect and fear of people with People with HIV/AIDS are still very high. This understanding made them want to build a social role where they finally decided to become community AIDS activists who were active in providing knowledge about AIDS and becoming companions for People with HIV/AIDS.

The participants as people who are trusted by People with HIV/AIDS play a very crucial role in accompanying people with HIV/AIDS in this research. The support behavior provided by participants was varied, starting from non-media administrative aspects, health-related assistance to moral and emotional support. These forms of support can be divided into the following categories:

1) Administrative assistance such as helping People with HIV/AIDS apply for free health insurance, identity cards or family cards. People with HIV/AIDS in the participant environment are poor ones who don’t even have personal documents. In marginalized communities such as those faced by the participants, the assistance provided by the participants was very significant in reducing administrative barriers which were obstacles for People with HIV/AIDS getting adequate health services.
2) Help monitor medication taking. Taking ARVs is not an easy thing for People with HIV/AIDS. At the start, there is a feeling of discomfort due to the effects of ARVs felt by People with HIV/AIDS such as nausea, dizziness and even causing rashes. Taking ARVs for a long period of time also causes boredom. Therefore, the participants as activists monitor People with HIV/AIDS to regularly take medication. When People with HIV/AIDS are bored, participants motivate them with an empathetic approach. Supervision of medication taking is not only a

technical task but also has emotional and social dimensions.

3) Assistance in the treatment aspect: This support shows the importance of a holistic approach in assisting People with HIV/AIDS patients, considering that their general health must be maintained. People with HIV/AIDS not only receive attention to aspects of HIV or AIDS, but also health in general. Participants help People with HIV/AIDS gain access to health services, so that People with HIV/AIDS's health complaints can be handled appropriately.
4) Financial assistance: Regarding financial assistance or donations for People with HIV/AIDS. People with HIV/AIDS often avoid getting help because they are afraid, they will have to reveal their status. This kind of support given by participants shows that female community AIDS activist are important figures who can be relied on when People with HIV/AIDS A experience economic difficulties. People with HIV/AIDS come from marginalized groups who are poor, so they don't even have the money to go to the hospital. Participants were often willing to provide assistance to them.
5) Emotional support: All participants in this study revealed that in the end People with HIV/AIDS opened up because they needed other people to share the pressure they felt. People with HIV/AIDS usually need other people because they want to confide a lot, especially regarding the illness they suffer from, especially in the beginning after finding out they are infected with HIV. Furthermore, the participants provided psychological support because this disease has an impact on the mental condition of the sufferer.

The multifaceted role of women community AIDS activists in this research is supported by Smith et al, who argue that the trust that activists gain in their communities can be a source of empowerment for People with HIV/AIDS (Smith and Niedermyer, 2009). According to Greene et al, community-based interventions have proven effective in increasing HIV awareness, reducing stigma, and improving the quality of life of people living with HIV/AIDS (Greene et al., 2003)

This article illustrates the stress faced by several informants. Based on investigations in the field, it can be explained that at the beginning of their role as companion for People with HIV/AIDS, the participants experienced stress because they were shocked by the complexity of the problems faced by People with HIV/AIDS, and also because they were not health workers, so at the beginning their knowledge about AIDS was still inadequate. However, as time goes by, the informants become increasingly trained in dealing with People with HIV/AIDS along with a better understanding of AIDS. When visualized, the reduction in stress can be seen in the following **Figure 2**:

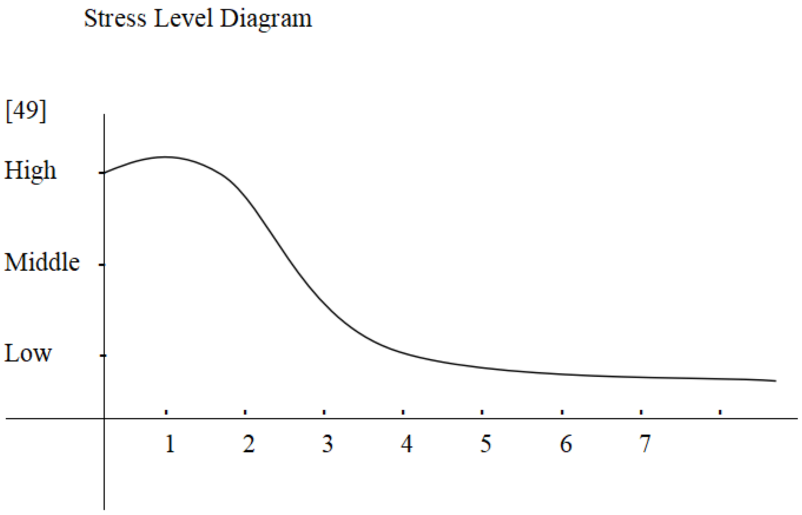

Figure 2. Stress Level Diagram.

In the Communication Privacy Management (CPM) theory developed by Sandra Petronio, the concept of a confidant is very relevant in the context of HIV/AIDS, especially in terms of managing personal information about HIV status. A confidant is an individual who is entrusted with knowing sensitive personal information, and in CPM theory, this is closely related to the privacy rules and shared responsibilities that arise after information is shared. In CPM theory, individuals who manage personal information, such as PLWHA, often choose confidants based on emotional considerations, trust, and level of closeness. This selection is not a random process, but rather is based on the expectation that the person will comply with the agreed privacy rules. In the context of HIV/AIDS, choosing a trusted person becomes a critical decision. People with HIV/AIDS need to consider whether their trusted person can keep their status confidential and provide emotional support without judgment. Additionally, confidants must understand the sensitivity of the information provided and not disseminate it without permission.

Information is a central part of all developing relationships. People seek information about other people and give information about ourselves. An important aspect of relational communication therefore involves the exchange of personal information. In relationship deciding how much information to share with others is a constant tension so the act of disclosure has been considered a communication skill (Ahmadi et al., 2023; Derlega et al., 1993; Greene et al., 2003; Littlejohn and Foss, 2009). In CPM, Petronio points out that disclosing information to someone can result in co-ownership of the information. The consequences of disclosure such as abandonment, isolation, or loss of trust make co-owners to keep the secret about HIV positive status secret.

Our study gives insight on the role of confidant to handling difficulties among HIV/AIDS related to medical and non-medical aspect. Confidants play a role in companionship activities for HIV-infected people or people with AIDS, especially because they do not have access to health facilities. Participants as activists have access to various accesses, both health and non-health. Our results also reveal how confidants used particular strategies in helping HIV/AIDS patients in their community and showing the benefit of knowing the environment gives confidants able to manage communication with community members and to approach people with AIDS and HIV-infected people. As (Berger, Roloff and Romo, 2016) states that feeling secure in their relationship with their confidant and as though the confidant would accept the disclosure or reciprocate with their own disclosure, further influences people's disclosure.

One of the characteristics of confidants as shown in the study of (Smith & Hipper, 2010) where confidants are close people of AIDS sufferers will prevent their loved ones who suffer from AIDS from telling others or keep it a secret to avoid detrimental actions associated with stigmatization. While the confidants in this study are AIDS activists who are outsiders and not the family of people-infected HIV or people with AIDS. The results of this study show the characteristics of this AIDS care community movement where this movement is bottom-up, informal, and non-biomedical. Our results also reveal that as confidants, women AIDS community activists feel emotional exhaustion, and still get prejudice from members of their community. However, most confidants even though they are not medical experts, they have several advantages, namely the experience of interacting with their community so that they are close and trusted. They are also health activists in their environment so they have access to relevant authorities such as hospitals, health centers, midwives and doctors.

Previous studies may have discussed the role of community support for People with HIV/AIDS, but few have specifically focused on the role of women as activists or volunteers. In fact, women often have a unique position in providing emotional and social support in society. This research can fill the gap in understanding how female community AIDS activists manage issues of confidentiality and trust in supporting People with HIV/AIDS. Furthermore, this research can fill the gap by focusing on community-based approaches taken by women activists. This research can explore how informal support from these women activists makes an important contribution to the well-being of People with HIV/AIDS and helps them face social challenges such as stigma and discrimination. This research thus fills the gap by providing a special focus on the role of women community AIDS activists in managing confidentiality and trust, which is an important but under-researched aspect in studies of support for People with HIV/AIDS. By exploring gender aspects, confidentiality management strategies, and community-based approaches, this research offers new perspectives that are relevant for understanding support for People with HIV/AIDS, especially in communities with high levels of stigma.

6. Conclusion

Many AIDS interventions are top-down, without paying attention to the relational relationships built between activists and People with HIV/AIDS. This research could provide a new insight based on trust and privacy, where emotional support and personalization of information are key elements in successful interventions. This will be the basis for a humanistic approach in supporting HIV/AIDS. Women community AIDS activists often serve as informal educators in the community. Understanding how they manage privacy information and support People with HIV/AIDS can help in designing more targeted education programs, where People with HIV/AIDS feel safe and supported in the process of disclosing information related to their health status.

This research appears to focus on one specific group. It would be interesting to see comparative research involving other groups of mentors, both men and women from different organizations, to understand the differences or similarities in managing HIV/AIDS information privacy.

Research on women community AIDS activists can expand understanding of the support provided to People with HIV/AIDS by combining health, social, and emotional aspects. This can help in formulating better policies and more effective intervention programs. This research could produce practical guidance for female AIDS activists on how to manage sensitive personal information, such as HIV status, so that the privacy of People with HIV/AIDS remains protected. It is also relevant for organizations or institutions working in public health in general, and in particular in the field of People with HIV/AIDS, as a basis for formulating appropriate policies and procedures in the management of sensitive information. The results of this research can be used to strengthen existing policies and protocols in assisting People with HIV/AIDS, by emphasizing the importance of privacy and managing sensitive information. The next crucial element is the competency aspect of AIDS activists, so it is necessary to review training programs for female cadres in confidentiality and trust management. This research could explore effective strategies to strengthen their skills in supporting People with HIV/AIDS. This research appears to focus on one specific group. It would be interesting to see comparative research involving other groups of mentors, both men and women from different organizations, to understand the differences or similarities in managing HIV/AIDS information privacy.

Author contributions: Conceptualization, NY, PP, MW and PU; methodology, NY; software, NY and PP; validation, NY, MW and PU; formal analysis, NY; investigation, NY; resources, NY; data curation, PP; writing—original draft preparation, NY; writing—review and editing, NY, PP, MW and PU; visualization, NY; supervision, MW and PU; project administration, NY; funding acquisition, NY. All authors have read and agreed to the published version of the manuscript.

Conflict of interest: The authors declare no conflict of interest.

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