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Behind the screen of stigma: A qualitative case study of digital vulnerability and resistance of the HIV/AIDS community in Indonesia

✉ **Argyo Demartoto**
Department of Sociology
Universitas Sebelas Maret
Surakarta, Indonesia

Bhisma Murti
Department of Public Health
Universitas Sebelas Maret
Surakarta, Indonesia

Sri Hilmi Pujihartati
Department of Sociology
Universitas Sebelas Maret
Surakarta, Indonesia

Novel Adryan Purnomo
Department of Sociology
Universitas Gadjah Mada
Yogyakarta, Indonesia

Abstract (English)

Contemporary digital landscape in a network society offers both potential and risks for marginalized communities such as the HIV/AIDS survivor and supporting communities in Indonesia. Digital platforms can facilitate peer support and information dissemination but also become an arena for reproducing digital stigma. This study aims to critically analyze the dynamics of digital stigma management, including the phenomenon of digital vulnerability and the HIV/AIDS community's resistance against stigma on social media screens. The study adopts Goffman's dramaturgy and stigma management framework elaborated with Crenshaw's intersectionality framework and Castells' network society. The study was carried out using a qualitative research method based on case studies focusing on three regions of Solo Raya, Indonesia: Surakarta, Sukoharjo, and Boyolali. Data collection was carried out through in-depth interviews with 12 HIV/AIDS survivors and Focus Group Discussions with healthcare workers from Dr. Oen Surakarta Hospital, representatives of local Community Health Centers, the Regional AIDS Commission (KPAD), Peer Support Groups (KDS), AIDS Care Residents (WPA), and Non-Governmental Organizations (NGOs) addressing HIV/AIDS prevention and control issues in Solo Raya. The study found that privacy vulnerabilities stem from negligence in socio-technical practices, where network programs instead expose backstage data, such as HIV status leaks through contact crowdsourcing applications (GetContact). Digital stigma is further exacerbated by intersectional layered stigmas created by sexual orientation, morality issues, disinformation on social media, and biased content moderation. Resistance efforts made by the HIV/AIDS community are dramaturgical in nature, ranging from withdrawal to innovation in an anonymous counseling platform (konselinghiv.com), which builds counter-power and an alternative digital private sphere as a safe network. This research contributes to a paradigm shift from system security to socio-technical safety in digital health interventions and media criticism studies.

Keywords: digital vulnerability, social media, HIV/AIDS, social media dramaturgy, socio-technical vulnerability, media criticism.

1. Introduction

The social media landscape raises ambivalence for marginalized communities such as People Living with HIV (PLHIV) and People Living with HIV/AIDS (PLWHA), as well as peer supporters within the HIV/AIDS community. On the one hand, digital platforms promise new spaces, potentially enabling the articulation of peer support, facilitating the dissemination of health information, and fostering communal solidarity that transcends spatial-temporal boundaries (Taylor et al., 2023). Theoretically, digital spaces provide previously unimaginable arenas

for empowerment and connectivity. These spaces promise a participatory utopia where geographically or socially isolated individuals can discover understanding, share experiences, and access critical knowledge about health and treatment without the physical barriers that have traditionally limited them (Ede et al., 2025; Fortuna et al., 2019; Frey & Kerkemeyer, 2022; Keogh et al., 2024; Töpfer & Brabänder, 2021).

On the other hand, the digital arena has become a field for stigma reproduction and amplification, discrimination, and surveillance practices. Within Castells' network society framework, the fundamental power producing stigma is shaped through social networks (Castells, 2013). These phenomena shape a new reality called digital stigma, a new challenge emerging in the social media landscape for marginalized and stigmatized groups (Fuady et al., 2025; Khurshid et al., 2023). Digital stigma is a significant contemporary challenge not only for the HIV/AIDS community but also for other marginalized and stigmatized groups seeking support online. The digitalization of stigma is not simply the transfer of stigma from the offline to the online world, but also an algorithmic process through which hatred can be disseminated at unprecedented speed and scale. This is often legitimized by the anonymity facilitated by social media platforms (Dickel & Schrape, 2017; Gramigna, 2024).

The Manifestation and Markings of HIV Stigma in Indonesia and Stigma Index 2.0 study confirms that the persistence of stigma at all levels is increasingly complex due to digital mediation (Friedland et al., 2020; Sudastri et al., 2025). The stigma occurring is not monolithic but manifests in various forms, including internal stigma, as explained through Crenshaw's intersectionality framework (Crenshaw, 1997). Layered stigma gives rise to shame, self-blame, perceived stigma attempting to anticipate rejection, and actual stigma (Haryanti & Wartini, 2019; Khurshid et al., 2023). This complexity arises because digital media accelerates the interaction between various forms of stigma. For example, hate comments on one social media account can drastically increase the perceptions of many people, then reinforcing the stigma itself (Wijaya, 2025). The consequences of this stigma extend significantly to mental health, inhibiting the disclosure of status, and complicating family and community dynamics for HIV/AIDS survivors (Ibrahim et al., 2019; Sidi et al., 2023). This condition even leads to a decreased quality of life, an increased risk of depression, and poorer adherence to treatment (Wardojo et al., 2022).

This complexity is exacerbated by issues of privacy, confidentiality, and data security within digital platforms. Network architectures generate power, making digital platforms no longer neutral technologies. While these platforms offer anonymity and peer support, they also carry a high risk of data breaches and confidentiality breaches. For the HIV/AIDS community, digital vulnerability poses a real threat. Fear of inadvertent disclosure of status, doxing, or the use of personal data for discriminatory purposes by irresponsible parties are significant barriers. These concerns limit the involvement and the effectiveness of digital interventions. A paradoxical situation arises where features designed to foster connectivity, such as location sharing, photo tagging, and visible friendship networks, become potential avenues for privacy violations for this community (Hlatshwako et al., 2025).

Several previous studies have predominantly focused on macro-level analysis of HIV/AIDS information systems or big data (Oktavianus et al., 2021; Tromp et al., 2016). This paradigm ignores the lived experience of people living with HIV/AIDS (PLWHA) as a fundamental dimension influencing this phenomenon. Therefore, this study was conducted by prioritizing a perspective based on the lived experience of people living with HIV in depth regarding the dynamics of social media use and digital stigma management. To dissect the phenomenon

complexity, the study adopted the stigma management and social dramaturgy framework proposed by Erving Goffman (Goffman, 1963). Goffman defines stigma as a discrediting social relationship. Stigmatized individuals, referred to as *spoiled identities*, are constantly engaged in *impression management* through maintaining public (*frontstage*) and private (*backstage*) spheres. Furthermore, the modern social media context, in the form of the digital social media landscape, adds to the condition complexity. Therefore, this study aims to critically analyze the dynamics of digital stigma management within the HIV/AIDS community, particularly the phenomenon of *backstage collapse* and their technology-based resistance strategies. This research was carried out using a case study approach to gain in-depth data on the HIV/AIDS community in Surakarta, Sukoharjo, and Boyolali. This research seeks to provide a contextual understanding of how the HIV/AIDS community negotiates their identity within the risky architecture of social media. This research focus is crucial for transcending generalizations and developing interventions rooted in the lived experiences of marginalized communities, particularly the HIV/AIDS community.

2. Methodology

This research was carried out using a qualitative research method with a multiple case study approach to gain an in-depth understanding of the dynamics of digital stigma management and the PLWHA's resistance strategies (Yin, 2009). This approach was selected because of its ability to explore the complexity of phenomena in the context of real-life (*lived experience*) experienced by HIV/AIDS survivors. In addition, a qualitative approach is important considering the measurement gap in the literature examining similar phenomena in the Indonesian context. The main unit of analysis in this study is the experience of HIV/AIDS survivors in Surakarta, Sukoharjo and Boyolali in managing their stigmatized identities in the digital realm. *Case boundaries* were determined by deciding the research period, namely April-July 2025; spatially in the Solo Raya area which includes Surakarta (urban), Sukoharjo (sub-urban) and Boyolali (sub-urban) with relatively high internet penetration but thick social norms related to HIV/AIDS.

The study employed a dual-recrutment strategy to ensure analytical depth and representativeness across different stakeholder perspectives. First, for the in-depth interviews focusing on lived experiences, we recruited 12 HIV/AIDS survivors (PLHIV) residing in Surakarta, Sukoharjo, and Boyolali. The sample size was determined based on the principle of 'information power' (Malterud et al., 2016) and data saturation, where recruitment ceased after the twelfth participant as no new thematic codes emerged, indicating sufficient depth to draw robust conclusions.

To support the intersectional analysis of stigma, we ensured a specific demographic breakdown among the 12 key informants. The sample consisted of 7 men and 5 women. To distinguish between different layers of stigma related to sexual orientation and gender norms, the male group was further categorized into 4 Men who have Sex with Men (MSM) and 3 heterosexual men, while the female group consisted of 5 women (including housewives and private workers). The participants ranged in age from 23 to 48 years. This proportional distribution allows for a comprehensive examination of how digital stigma operates differently across gender and sexual orientation lines.

Table 1: Sociodemographic information of interview respondents

No.	Pseudonym	Gender	Category/ Risk Group	Residency
1	Informant K	Male	MSM	Solo Raya
2	Informant T	Male	Heterosexual	Solo Raya
3	Informant G	Male	MSM	Solo Raya
4	Informant P	Male	MSM	Solo Raya
5	Informant S	Female	Private Worker	Solo Raya
6	Informant F	Female	Housewife	Solo Raya
7	Informant M	Male	MSM	Solo Raya
8	Informant W	Female	Private Worker	Solo Raya
9	Informant R	Female	Private Worker	Solo Raya
10	Informant C	Male	Heterosexual	Solo Raya
11	Informant U	Female	Housewife	Solo Raya
12	Informant I	Male	Heterosexual	Solo Raya

Source: Research data analysis

Second, to capture structural and systemic perspectives and ensure robust data triangulation, we conducted two separate Focus Group Discussion (FGD) sessions involving a total of 15 stakeholders. We intentionally distributed participants into two distinct groups to foster open discussion among peers with similar roles. The first FGD session involved 8 participants representing formal institutions, including healthcare providers from Dr. Oen Hospital and Community Health Centers (Puskesmas), as well as officials from the Regional AIDS Commission (KPAD). The second FGD session involved 7 participants from community-based organizations, specifically Peer Support Groups (KDS), AIDS Care Residents (WPA), and NGOs. This separation of methods into in-depth interviews for survivors and FGDs for institutional stakeholders ensures that the analysis captures both the micro-level of individual vulnerability and the meso-level of socio-technical support systems.

Table 2: Sociodemographic information of respondents

Session	Initial	Affiliation	Role/Description
FGD 1	Informant IF	Puskesmas Boyolali I	Healthcare Worker/Inovator konselinghiv.com
	Informant TW	Dr. Oen Hospital	Healthcare Provider (Formal Institution)
	Informant W	KPAD	Officials from Regional AIDS Commission
FGD 2	Informant H	NGO Spekham	Representative/Field Advocate
	Informant B	Surakarta KDS	Peer Support Group Member
	Informant A	NGO Mitra Alam	Program Coordinator for Key Populations
	Informant Hn	City's WPA	AIDS Care Residents (WPA) Member
	Informant X	NGO Mitra Alam	Counselor/Content Creator Advocate

Source: Research data analysis

To facilitate focused interaction, we utilized a semi-structured FGD guide comprising three core questions: (1) How do stakeholders perceive the socio-technical risks (such as data privacy) in current HIV/AIDS services? (2) What forms of digital stigma and disinformation have been observed in the community? (3) How effective are the existing institutional and community-based resistance strategies in countering these digital threats?

To recruit participants, we employed a multi-stage sampling strategy designed to access this hard-to-reach population. Initially, we used purposive sampling to select key informants via Peer Support Groups (PSGs) and partner NGOs, ensuring participants met specific inclusion criteria: being HIV-positive, residing in the study area, and actively using social media. Subsequently, we utilized snowball sampling to access larger-to-reach individuals, particularly within the MSM community and those not formally affiliated with support groups, relying on trusted referrals to overcome barriers of trust and anonymity (Creswell & Poth, 2016). Ethical clearance for this study was formally granted by the Health Research Ethics Committee of the Faculty of Medicine, Universitas Sebelas Maret (Review Number: 118/UN27.06/KEPK/2025). Given the involvement of vulnerable populations (PLHIV/PLWHA) and the sensitive nature of the data, the research protocol strictly adhered to the Declaration of Helsinki. All participants provided written informed consent after being fully briefed on the study's voluntary nature, absolute anonymity, and their right to withdraw at any time without consequence. Data collection was conducted through in-depth semi-structured interviews and focus group discussions (FGDs) with stakeholders such as healthcare workers at Dr. Oen Surakarta Hospital, NGOs, peer support groups (PSGs), and AIDS-caring citizens (WPA). The data were then analyzed using reflective thematic analysis (Braun & Clarke, 2006). This process included familiarizing the data through interview and FGD transcripts; generating initial codes; searching for themes; reviewing themes; defining and naming themes, and then writing a report. This analysis is aimed at identifying themes that operate at different levels, including individual, interpersonal, and HIV/AIDS community levels. The data were then tested for validity through data source and method triangulations.

3. Results

In-depth interviews with 12 (twelve) HIV/AIDS survivors and focus group discussions (FGDs) with stakeholders including healthcare workers, NGOs, peer support groups (PSGs), and AIDS-Caring Citizens (Indonesian: *Warga Peduli AIDS* or WPA) revealed three key interrelated findings. They are: *first,* the privacy paradox, where the collapse of the private sphere is caused by socio-technical negligence; *second,* the phenomenon of layered stigma, disinformation, and biased content moderation faced by HIV/AIDS survivors on social media; and *third*, the spectrum of dramaturgical resistance presented through individual coping strategies and digital innovation.

3.1. Privacy Paradox: The Collapse of the Private Sphere Due to Socio-Technical Negligence

The most significant and repeatedly emphasized finding in the FGDs was the fundamental privacy vulnerability stemming not from formal digital systems like the HIV/AIDS Information System (SIHA), but from informal socio-technical practices. The leakage of HIV status through contact *crowdsourcing apps* like GetContact reinforces this phenomenon. This leakage was identified as a direct consequence of negligence in naming contacts by healthcare workers and HIV/AIDS survivors. This negligence often occurs because the users are not aware of the platform's architecture.

> *"This also happened in Boyolali. This data leak did not result from the system, but it resulted from the use of the Getcontact platform... several clients from our community complained that their Getcontact test was marked positive, for example, person A was positive, person B was positive... What we might not have thought before was, 'How can we know someone just from their contacts?'... This is perhaps part of the risk that we are all unaware of... often we are just forced to do it and given training to operate it without being aware of the potential risks existing." (Informant H, NGO Spekham, FGD).*

This finding was confirmed by another informant, a member of the peer support group, explaining how this careless naming practice differed from internal community protocols. The community itself had developed safe naming strategies, such as avoiding the use of codes indicating a person's HIV status.

> *"Many of my peers also sometimes ask me, 'What do you call me in your contacts, Brother?' To be honest, we and our peer support friends, we do name Beni (pseudonym) KD as his last name, for example. KD means Klien Dukungan (Supported Client). So we... naming him (them) KD indicates the friends we support. We do not use the words AIDS, PLWHA, or HIV... It is expected that perhaps our fellow officers, the officers themselves, will name them more wisely... The important thing is not to name him Beni PLWHA because B20 has also been the code understandable. So, this largely results from there indirectly, Prof." (Informant B, Surakarta KDS, FGD)*

This oversight is compounded by the fact that not everyone understands how the technology works or how to work around it using some specific features of the application.

> *"We have to be careful, indeed. Although the Getcontact platform can be turned off via the web, not everyone is tech-literate; it definitely cannot be turned off. In my case, I had turned off my number... And I have also told my fellow Field Assistants (Indonesian: Pendamping Lapangan or PL) not to name KDs carelessly because the current generation is more literate." (Informant A, NGO Mitra Alam, FGD)*

To HIV/AIDS survivors, this phenomenon generates deep anxiety and insecurity. They feel that the privacy they have so carefully guarded could be compromised by factors beyond their control.

> *"It feels like being stripped naked, Prof. We have worked so hard to keep the secret, and then it is revealed just because someone jokingly named our contact 'PLWHA'. It immediately makes us feel down. I do not know whom I should be angry with. In the end, I become even more closed off." (Informant K, Survivor, In-Depth Interview)*

> *"I lost contact with some old friends because of that [GetContact]. I do not know whether they saw my name tag or what happened, but they suddenly moved away. It made me even more isolated. We need a support system, after all." (Informant T, a Survivor, In-Depth Interview)*

> *"I do not dare install GetContact. I am scared. It happened to one of my friends once, and his name was tagged strangely, like 'So and So' with HIV.' The person who gave the name was probably a healthcare worker or someone else. Since then, I've been paranoid about giving my phone number to new people, especially in healthcare settings." (Informant G, a MSM, In-Depth Interview)*

> *"To be honest, I am paranoid now. Every time a new number comes in, I check it on GetContact. Not to stalk him, but to see what my name is on his phone. I am so afraid someone will call me 'Si P PLHIV (P with PLHIV)'. It feels like I am living under constant threat." (Informant P, a Survivor, In-Depth Interview)*

> *"We trust healthcare workers and our companions. They are the ones who should keep our secrets. But if they are careless enough to name contacts, who else are we supposed to trust? It feels betrayed, Prof. We just want to live a normal life." (Informant S, a Survivor, In-Depth Interview)*

This phenomenon illustrates the collapse of private domain. which is not caused by physical proximity but rather by the technological architecture aggregating private data (Goffman, 1959). Labels such as PLWHA and B20, which should be administrative tools in *the backstage* of services, are instead exposed to the *frontstage* domain of social networks, thus causing deep anxiety.

3.2. Layered Stigma, Disinformation, and Biased Content Moderation

Beyond the threat of data breaches, the digital sphere has become a primary arena for the amplification of layered stigma. A, a program coordinator for key populations, explained how stigma against HIV is often

inseparable from stigma against gender identity and sexual orientation, such as men who have sex with men (MSM), transgender women, or other gender identities, which is further exacerbated by social media framing.

> *"Online stigma and discrimination. Key populations are often the targets of hate speech, bullying, or discrimination on social media. Negative comments can impact mental health... Now, many news stories have narratives or framings that, when they include LGBT people, are like, wow. Like the last one in Bogor, even though it was not a sex party, it was just an event, but the framing was that it was a sex party." (Informant A, NGO Mitra Alam, FGD)*

Survivors experienced this digital assault firsthand, describing various forms of verbal and psychological attacks in digital spaces. These attacks ranged from public insults on public platforms to discrimination on more private apps. The threats even can be terror, endangering their privacy and security in the real world.

> *"I once posted on Facebook about the importance of HIV testing, Prof. I was just trying to raise awareness about health. The comments were, oh my God... 'Dirty disease,' 'punishment,' 'the one often changing sex partners'. ' They did not even know who I was or what my status was. I was just educating people. I immediately deleted the post; I could not take it mentally." (Informant F, a PLHIV, In-depth Interview)*
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> *"On dating apps, it is even more brutal. As soon as we find out or suspect we are 'positive,' we are immediately blocked. Or we even get nasty messages like, 'Luckily we have not met, you are dirty.' It is social media, too, Professor. It feels like we are trash, with no right to find a partner or friends." (Informant M, MSM, In-Depth Interview)*
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> *"I tried to be honest on dating apps, writing 'U=U' (Undetectable = Untransmittable). I hoped someone would understand. But instead, I was cursed. I was called a 'fraudster,' 'looking for prey.' After all, we are human, and we want a partner. In the end, we either lie or do not play at all." (Informant W, a Survivor, In-Depth Interview)*
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> *"What I fear most is if someone knows me in real life and then posts my status on Twitter or Instagram. I once had a friend (a fellow PLHIV) who was threatened like that by her ex. They wanted to share her ID card photo, and they said, 'Watch out, I will reveal your shame.' That is no longer insults, but terror. That is why many of us have deactivated our social media accounts." (Informant R, a woman, In-Depth Interview)*

This stigma stems not only from the public but also from the closest social circles. Informant H (WPA) described a case where rejection stemmed from a family who felt their self-esteem was being destroyed by a member who was an HIV/AIDS survivor. This led to discrimination in their neighborhood.

> *"In a middle-class family seeming to have always held their prestige in high regard... after the incident, the family's self-esteem collapsed and fell. That is what ultimately shook the PLWHA. Actually, the community has been welcoming... Well, it turns out that our homework is the situation in his family, Prof." (Informant Hn, a member of City's WPA, FGD)*

Pressure from family and the environment is the main reason for PLHIV and PLWHA to strictly hide their status in the digital sphere.

> *"At home, I pretended to be healthy. I hid my ARV medication under the mattress. My family knew, but they were in denial. They considered me a disgrace. When I assembled with my family, I was not allowed to share eating utensils. Even though I knew it was not contagious, explaining it to my own family was harder than explaining it to others." (Informant C, a Heterosexual, In-Depth Interview)*

> *"On social media, I can be someone else. But at home? It is hard. My mother once said, 'Do not post anything, or people will find out and embarrass the family.' So the stigma is not only from outsiders, but also from within the home itself. That is what hurts the most." (Informant U, a Survivor, In-Depth Interview)*

However, this vulnerability is exploited by the rise of health disinformation. Platforms like TikTok have been identified as a major source of hoaxes threatening ARV adherence, thus undermining the goals of HIV/AIDS prevention and control.

> *"Lack of relevant and safe content. Information available on social media is sometimes not-inclusive (exclusive), inaccurate, or even misleading. For example, many people still believe that HIV treatment requires herbs. Especially on the platform TikTok, so many sellers sell a lot of herbal medicines, even though we currently only use ARVs for HIV treatment. But so many other things are popping up on those platforms... So, people falling for the hoax might buy those medicines and stop consuming ARVs." (Informant A, NGO Mitra Alam, FGD)*

> *"I was tempted to stop taking ARVs. There were a lot of people selling 'herbal remedies' on TikTok, claiming they could 'completely cure' me. The videos were convincing, and there were lots of testimonials. Luckily, I asked my counselor first, otherwise... I would have stopped taking my medication. Why don't those platforms filter out people selling things like that?" (Informant I, a Survivor, In-Depth Interview)*

> *"One of my friends died, Professor. He stopped taking ARVs because he believed in 'herbal remedies' advertised on Facebook. He said he was 'tired of taking medication for life.' I tried to remind him, but he believed the ads. I am so sad. Hoaxes really kill." (Informant K, a Survivor, In-Depth Interview)*

This problem is exacerbated by biased content moderation. Social media platforms fail to filter herbal disinformation and instead actively censor accurate HIV educational content, especially that coming from key communities (Hamid & Abubakar, 2024; M. Syam et al., 2025).

> *"Social media algorithms sometimes censor contents discussing sexuality, gender identity, or drug use, even if it is intended to be educational or advocating. Information about HIV/AIDS or sexual health can be downvoted or restricted in its reach, or even taken down." (Informant A, NGO Mitra Alam, FGD)*
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> *"Strangely enough, those selling fake herbal remedies are perfectly safe. But when I tried to share my experience taking ARVs on my Instagram Story, using the 'HIV' sticker, my story was taken down. They said it violated community guidelines. It is confusing. The right thing is not allowed, but the wrong thing is allowed." (Informant M, an Activist, In-Depth Interview)*
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> *"The algorithm is really strange. I posted about 'The Spirit of PLWHA Warriors' using a red ribbon, and it was shadow-banned, limiting its reach. But accounts that openly insult and spread hoaxes have their videos viewed by millions. It feels unfair. We, who want to educate, are being silenced." (Informant P, a Survivor, In-Depth Interview)*

3.3. The Dramaturgical Spectrum of Resistance: From Individual Coping to Digital Innovation

Facing a digital landscape that poses risks to PLHIV, PLWHA and their support communities have developed various resistance strategies, including individual coping, creating a safe *backstage, and conducting cyber campaigns*. Individual coping is the most fundamental strategy employed by HIV/AIDS survivors on social media through defensive information management, including hiding their status and using anonymity (Meanley et al., 2019).

> *"I rarely post or make strange comments on social media. I am just afraid someone will find out my status and spread it. I would rather stay quiet or use a fake account if I want to search for information about HIV." (Informant P, MSM, Surakarta, In-depth Interview)*
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> *"I have two Instagram accounts. One 'real' account is for family and work friends, filled with casual photos. The other is an 'alter' account, using a pseudonym. That is where I started following HIV education accounts, asking questions in DMs, or just looking for friends who are in the same boat. This is how I survive and prevent myself from being stressed." (Informant G, MSM, In-Depth Interview)*
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> *"The alter account is like my 'breathing space.' On my real account, I have to put on a 'healthy,' 'happy' mask. But on my alter account, I can be myself. I can complain, I can cry, I can ask about side effects of medication without being judged. Without that account, I might have gone crazy." (Informant K, a Survivor, In-Depth Interview)*

The next strategy is to create a safe *backstage*. This form of proactive resistance is the most prominent one through the creation of an alternative *backstage*. The example we got is the creation of the counselinghiv.com platform, an initiative of healthcare workers at the Boyolali I Community Health Center (Indonesian: *Puskesmas Boyolali I*). This platform is explicitly designed to combat fear of formal services and guarantee absolute anonymity.

> *"There is an innovation in our place, there is a website accessible throughout Indonesia called konselinghiv.com... you can have private, confidential counseling. There is no such thing because we do not ask for names, addresses, and so on when counseling... Most of them are afraid to come to healthcare services... through this website we can help many people access the nearest service center, so they are not afraid... 'Where should I access PrEP drugs?' then PEP drugs..." (Informant IF, a Healthcare Worker of Puskesmas Boyolali 1, FGD)*

This initiative has evidently been effective in reaching individuals who are hesitant or afraid to access offline services and providing them with a safe space to acquire initial information about HIV/AIDS.

> *"I have used [konselinghiv.com]. I was hesitant at first, but because it guaranteed anonymity, I felt brave enough to share. It was incredibly helpful. It felt liberating to be able to ask questions without having to show my face or ID. If I had been told to go directly to the community health center, I probably would not have gotten tested." (Informant W, Private Worker, In-Depth Interview)*

> *"When I first suspected [I was infected], I did not dare go anywhere. I was embarrassed to go to the community health center, afraid of meeting my neighbors. Finally, I found an anonymous counseling website. I chatted with the counselor until 2 a.m. She was the one finally convincing me to get tested. If that service did not exist, I might still be living in fear and never seeking treatment." (Informant U, a Survivor, In-Depth Interview)*

Cyber campaigns are also a resistance strategy employed by PLHIV, PLWHA, and support communities in virtual spaces. They conduct campaigns and outreach not only through conventional means but also through efforts to produce counter-content to counter disinformation and stigma.

> *"We indeed focus more on the community. So I ask my friends to be more active, more massive on social media by making videos like the one I mentioned. What was it made of? To provide information correctly, not incorrectly, and especially so that there are no false news or hoaxes. That is an example of what is called a cyber-campaign related to the availability of PrEP services now accessible in Surakarta. In addition, there is also an e-flyer... about how HIV is transmitted..." (Informant A, NGO Mitra Alam, FGD)*

This strategy also requires continuous adaptation to the digital landscape as emphasized by other NGO representatives regarding the need for increased digital capacity.

> *"Willy nilly, we are entering the digital world... our friends [young survivors]... maybe we need to continue, AI is important for our service fellow counselors and for us... Secondly, learn to be a content creator. Willy nilly, like it or not... this one is still an image or flyer. Now it is in video format." (Informant X, NGO Mitra Alam, FGD)*

HIV/AIDS survivors, although many people prefer creating anonymous accounts, are participating in this campaign as a form of personal resistance.

> *"Even though I do not dare show my status, I always help repost educational content made by NGOs. At least, that is my way of contributing. I share it on my second account. This is to prevent the spread of hoaxes. We have to fight using accurate information." (Informant M, a Survivor, In-Depth Interview)*

> *"At first, I was afraid [of reposting HIV content]. But after a while, I realized that if we all stay silent, hoaxes and stigma will win. Finally, I mustered up the courage to at least like or share it with my close friends on Instagram. "Just a little bit, the important thing is that we do not stay silent. This is our fight too." (Informant K, a Survivor, In-Depth Interview)*

Overall, the findings of in-depth interviews and focus group discussions revealed a constant dramaturgical resistance made by people living with HIV (PLHIV), people living with HIV/AIDS (PLWHA), and support groups. On the one hand, digital technology produces socio-technical negligence and biased algorithms, creating *backstage collapse* and amplifying stigma. However, on the other hand, HIV/AIDS communities and survivors are engaging in resistance by building counter-digital infrastructure such as konselinghiv.com and conducting *cyber campaigns* to seize control over the invasion of their private sphere.

4. Discussion

The results of study indicate that the dynamics occurring in the social media landscape are fundamentally a crisis of identity management, best understood through Goffman's dramaturgical framework. While the digital era introduces the complexities of a network society, the core experience of PLHIV, PLWHA, and support communities in Solo Raya represents a transformation of how "spoiled identities" must be navigated on a precarious digital stage. The discussion focuses on three aspects of theoretical implications digital: stigma management, vulnerability in the digital space, and resistance among HIV/AIDS survivors in response to this phenomenon (Contissa et al., 2013).

4.1. The Collapse of the Backstage as a New Vulnerability for HIV/AIDS Survivors in the Digital Space

Goffman's dramaturgical framework emphasizes the vital separation between *frontstage* and *backstage* domains and the loyalty of the "performance team" (Goffman, 1963). The findings related to the leak of someone's HIV status through the GetContact application present not just a technical glitch, but a sociological failure of this

performance team. In the traditional context, healthcare workers and NGOs act as the survivor's performance team, cooperating to safeguard the secret of their HIV status. However, our findings reveal a socio-technical negligence where this team fails to adapt to the digital architecture. The practice of naming contacts carelessly serves as a breach of dramaturgical loyalty (Aceros et al., 2019). When a companion saves a number as "Budi HIV", they are unknowingly feeding a data-mining algorithm that forcibly drags a *backstage* secret onto the public *frontstage*. This confirms that in a network society, the walls between private and public are porous; a single error in social practice (naming a contact) can trigger a systemic collapse of privacy (Leith & Farrell, 2021). Consequently, the vulnerability is not merely about system security (encryption or passwords) but about socio-technical safety, the capacity of the human ecosystem to understand how their social behaviors interact with platform architectures (Sangaroonsilp et al., 2022). This collapse creates a state of digital panopticism, forcing survivors into exhausting hypervigilance. They feel betrayed not by the virus, but by the very people supposed to protect their narrative (Gray et al., 2024). This risk becomes increasingly complex for groups facing layered stigma, such as MSM and sex workers (Crenshaw, 1997). This finding challenges the current focus of digital health interventions, suggesting that training for healthcare workers must shift from technical operation to *digital ethics and privacy literacy* to restore the integrity of the performance team.

Socio-technical vulnerabilities specifically destroy the physical boundaries that should protect us. As interview data shows, even the family space has become an arena of fierce struggle where pople must hide their identities, medications, and various symbols of health status in order to face daily stigma and maintain a healthy appearance. Digital data leaks threaten to destroy these fragile internal relational boundaries instantly. This shows that digital stigma management cannot be separated from physical survival, where failures in digital network architecture inevitably determine the level of discrimination experienced even within the closest social circles. The study confirms that stigma in the digital sphere is not monolithic but layered and intersectional. Drawing on Crenshaw (1997), we found that the digital medium acts as an accelerator for multiple burdens. For an HIV-positive individual who is also MSM or a transgender woman, the digital attack is not singular; it attacks their morality, their health status, and their gender identity simultaneously. However, a critical theoretical insight from this study is that the digital frontstage is not neutral terrain but it is a rigged theater. The findings on health disinformation and content moderation reveal a structural imbalance. Social media algorithms, driven by the logic of engagement (Castells, 2013), effectively prioritize sensationalist hoaxes (herbal cures) while systematically silencing the educational narratives of the HIV community through shadow-banning.

The manifestation of intersectional stigma is particularly harmful when it occurs in private digital spaces such as dating apps. Victims who attempt to negotiate their identity through transparent disclosure, such as stating their undetectable status, are often confronted with labels that further stigmatize them. This situation creates a new dilemma for victims between honesty, which invites digital harassment, and secrecy, which maintains the psychological burden on survivors. In this situation, digital architecture actually reinforces social rejection and makes efforts to produce virtual support a long, traumatic endeavor in a manipulated, algorithmic theater. In dramaturgical terms, the stage lighting is manipulated. It shines brightly on stigmatizing disinformation while leaving valid health information in the dark (Nave, 2025). This creates a distorted reality where the spoiled identity of the survivor is magnified, and their attempts to present a normalized self are algorithmically

suppressed. This structural discreditation explains why internal stigma remains high; survivors are not just fighting public opinion, they are fighting an invisible code that profits from their marginalization.

The consequences of this algorithmically manipulated theater go beyond emotional distress; they directly threaten public health. Driven by the viral logic of networked society, health misinformation about herbal medicines spreads unchecked on platforms such as TikTok, Instagram, X, and Facebook. Our findings indicate that this algorithmic bias actively misleads survivors and even causes some of them to discontinue life-saving antiretroviral therapy. In Castells, this condition demonstrates the power of networks that are capable of navigating collective public health issues (Castells, 2013). These networks form in tandem with platforms' failure to moderate hoaxes, thereby transforming the digital space into a direct enemy of medical intervention.

4.2. Digital Stigma Management: Resistance Efforts by the HIV/AIDS Community

Faced with a collapsed backstage and a rigged frontstage, the HIV/AIDS community in Solo Raya does not merely withdraw; they actively engage in dramaturgical repair. This resistance manifests in a spectrum from individual coping to collective infrastructure building. At the individual level, the widespread use of *alter* (anonymous) accounts represents a tactical audience segmentation. Survivors consciously construct a sanitized *frontstage* (real account) for family and work, while maintaining a hidden backstage (alter account) for peer support. This digital dualism is not deception; it is a survival mechanism to maintain psychological well-being in a hostile environment (Liu et al., 2024). It allows them to access the benefits of connectivity without paying the price of exposure. Beyond mere audience segmentation, these anonymous accounts serve as vital emotional infrastructure. Interview data shows that survivors view these anonymous profiles as breathing space where they can safely remove the heavy mask of appearing healthy in public. Within this hidden network, they can express their sadness, discuss treatment, and seek solidarity without the threat of disruptive moral judgment. This demonstrates that in a highly stigmatized society, anonymity is not a tool for deception, but rather a fundamental requirement for psychological survival and profound dramaturgical healing.

In addition to establishing protective boundaries, resistance is also carried out through proactive cyber campaigns. Despite fears of exposure, survivors and peer support groups utilize these alternative accounts to spread alternative narratives, such as promoting the concept of "undetectable equals untransmittable" and combating herbal hoaxes. This collective action is a direct effort to counter manipulated algorithmic theater. By systematically liking, sharing, and reposting verified educational content, this community is engaged in resistance and attempting to reclaim narrative power that is systematically denied by social media algorithms.

This study also found forms of collective resistance through the konselinghiv.com platform, which represents a collective takeover of communication power (Castells, 2013). We argue that this innovation is an attempt to construct a completely new, Counter-Backstage. Recognizing that commercial platforms like WhatsApp or GetContact are structurally unsafe, the community built their own digital architecture designed specifically to guarantee anonymity. This is a socio-technical rejection of the dominant platform logic. By stripping away the requirement for personal data, this platform restores the information control that Goffman deemed essential for stigmatized individuals. It allows survivors to seek help without the performance anxiety of the public gaze. This confirms that resistance in the digital age is not just about speaking out (cyber campaigns), but also about

building in for creating safe, alternative infrastructures that fix the dramaturgical failures of the mainstream web (Fuady et al., 2025).

The success of the Counter Backstage program developed through konselinghiv.com proves that socio-technical security directly improves clinical outcomes. By guaranteeing absolute anonymity, this platform effectively eliminates the dramatic anxiety that typically prevents vulnerable populations from accessing offline health facilities. The platform functions as a secure digital bridge, successfully directing previously hard-to-reach individuals toward critical physical services such as testing and preventive medication. This demonstrates that future HIV/AIDS interventions must prioritize the creation of secure, community-driven digital architecture as the primary foundation for effective health communication in networked societies.

5. Conclusions

This study analyzes the dynamics of digital stigma management and resistance strategies of the HIV/AIDS community in Solo Raya through the lens of Goffman's dramaturgy. Key findings emphasize that the digital landscape serves as an ambivalent arena that not only offers potential support but also generates significant privacy vulnerabilities and stigma amplification. This has profound implications for mental health, behavioral patterns, disclosure, treatment adherence, and ultimately, the primary goal of HIV/AIDS prevention and management. The study identifies the collapse of the HIV/AIDS survivors' private sphere (*backstage collapse)* in the virtual space stemming from socio-technical negligence, such as data leaks due to unsafe contact names by certain individuals through the GetContact application. Vulnerability is exacerbated by layered, intersectional stigmas stemming from values, morality, religion, and gender, as well as health disinformation in the digital sphere. In response to this attack, PLHIV, PLWHA, and support communities developed a spectrum of dramaturgical re-systems. These efforts range from individual coping strategies to collective innovation to build an anonymous counseling platform, konselinghiv.com. This innovation represents an effort to build a safe alternative *backstage and represents counter-power* in the contestation of network society. This platform is a form of peer support having evidently built resilience for HIV/AIDS survivors.

The research findings emphasize that *backstage collapse* is not a technical failure, but rather a failure of *socio-technical safety practices* stemming from negligence on the part of digital platform users. The data leak via GetContact represents a dramatic failure of *performance teams* that should have maintained backstage confidentiality. This failure stems from a failure to understand how network programs destructively connect private data to public networks. This creates a new form of horizontal social surveillance, or digital panopticism forcing HIV/AIDS survivors into a state of psychologically exhausting vigilance. The stigma amplified on social media is perpetuated through biased platform algorithms. Algorithms fail to moderate dangerous disinformation, such as hoaxes about herbal remedies, but instead censor educational content from communities, silencing the voices of vulnerable groups.

The spectrum of resistance found in this study is also *socio-technical* in nature and represents the struggle to seize *communication power*. Innovations such as the production of the konselinghiv.com platform are not merely tools but also innovations designed to respond to the dramaturgical failures of formal and informal systems. This

platform creates a controlled and secure alternative digital *backstage* where absolute anonymity is a primary requirement for rebuilding trust. At the individual level, the practice of audience segmentation through alter accounts becomes a tactic for maintaining psychological health and evolves into a collective strategy for conducting *cyber campaigns*. This represents an effort to reclaim the narrative in the digital public space, previously dominated by hoaxes, hate speech, and attacks against HIV/AIDS groups.

Theoretically, this research elaborates the concept of *backstage collapse* in a socio-digital context and elaborates Goffman's theory to analyze contemporary digital practices in new interaction media. The research also shows how Crenshaw's intersectionality framework, viewing the plurality of digital stigma and the reality of Castells' network society, explains the amplification of stigma and resistance as part of practices in digital media. Practically, the research findings have implications for encouraging a paradigm shift from *system security to cybersecurity* toward *socio-technical safety*. This requires multi-level and multi-stakeholder interventions. Ethics and digital literacy training is needed for health workers and companions interacting directly with HIV/AIDS survivors. Digital literacy training is also needed for PLHIV, PLWHA, and support communities to maintain their resilience efforts. Community empowerment is necessary to realize stigma reduction, including the involvement of all subjects, such as the survivors' closest families. Future research can be oriented toward developing and validating digital stigma measurement instruments that are adaptive to the socio-cultural context in Indonesia to address methodological gaps and the global goal of *zero discrimination*. Furthermore, further studies on platforms such as konselinghiv.com can be conducted to further elaborate on the platform's efforts to represent resistance against internal stigma and even increase treatment adherence and broader HIV/AIDS prevention and response efforts.

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Conflict of interest
The authors declare no conflict of interest.

Ethical statement
This study was conducted in accordance with the Health Research Ethics Committee of the Faculty of Medicine, Universitas Sebelas Maret ethical standards and approved by Review Number: 118/UN27.06/KEPK/2025.

Declaration of AI usage
No generative AI tools were used in the preparation of this manuscript.

Data availability
The data supporting the findings of this study are available upon request.

Author contributions

	Argyo Demartoto	Bhisma Murti	Sri Hilmi Pujihartati	Novel Adryan Purnomo
Conceptualization	X	X		X
Data curation	X			
Formal analysis	X	X	X	X
Funding acquisition	X			
Investigation	X	X	X	X
Methodology	X		X	
Project administration				X
Resources	X	X		X
Software				X
Supervision	X			
Validation	X	X	X	
Visualization				X
Writing - original draft	X	X	X	X
Writing - review & editing	X	X	X	X

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