

## SELF OPENNESS OF PLWHA: A LITERATURE ANALYSIS ON THE ROLE OF SOCIAL MEDIA IN BUILDING SOCIAL SUPPORT

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### ABSTRACT

*Stigma and discrimination against people living with HIV/AIDS (PLWHA) remain a major obstacle to achieving an optimal quality of life, especially in terms of self-disclosure and access to social support. In the midst of the rapid development of digital technology, social media has emerged as a potential online space that can be utilized by PLWHA to express their identity and build social support networks. This study aims to analyze the role of social media in supporting the self-disclosure of PLWHA and its contribution in forming a supportive online community. The method used is a literature review with a descriptive analysis approach that examines various academic studies from the last 5 years published from 2019 to 2024 through databases such as PubMed, JMIR, Springer, PMC and Google Scholar. The results show that social media provides a safe space for PLWHA to manage their identity narratives, increase self-confidence, and obtain validation and emotional support from online communities. However, the dilemma between the need for openness and the risk of stigma and invasion of privacy remains a significant challenge. This study recommends that future research emphasize qualitative exploration of PLHIV's direct experiences, as well as the development of inclusive and safe digital platform policies and designs to support the sustainability of empowering self-disclosure.*

**Keywords:** PLWHA, Self disclosure, Social Media, Social Support

## 1. INTRODUCTION

HIV/AIDS continues to be a complex global health problem. According to UNAIDS (2023), approximately 39 million people in the world are living with HIV with more than 1.3 million new infections each year. Although antiretroviral treatment has shown medical effectiveness, social and psychological barriers remain a major obstacle in HIV/AIDS prevention and treatment efforts. The social

stigma attached to people living with HIV/AIDS (PLWHA) is one of the barriers that often leads to discrimination in the social environment.

The phenomenon of stigma and discrimination in Indonesia based on data from the Ministry of Health of the Republic of Indonesia (2022), shows that although educational campaigns on HIV/AIDS have been actively carried out, negative attitudes and fear of PLWHA are still prevalent in society. This makes PLWHA feel isolated and reluctant to open up from their social environment. This situation hampers the recovery process as well as social support for their mental and physical well-being.

Amid the development of information technology, digital communication has changed dramatically with the development of social media as the main platform for social interaction. As reported by We Are Social and Hootsuite (2023), the number of active social media users globally has reached more than 4.9 billion. This indicates an increase in users compared to previous years. Social media serves as a means of sharing information, building community and social support. For PLWHA, social media is a means to share experiences, obtain information, build support networks that can reduce stigma and improve their quality of life (Dalimunthe, 2018).

PLWHA face challenges in their social life, namely the burden of lifelong health and stigma and discrimination in both physical and digital spaces. Initially, stigma was present in social interactions and has now reached the virtual world including social media. For PLWHA, social media has become a new space to express themselves and seek support. But on the other hand, it also creates a space between the need and risk of privacy. Not infrequently there is even the potential for public re-stigmatization.

Self-disclosure is the process of revealing one's self or identity to others. This openness is an important aspect in interpersonal communication and public communication including in the digital realm (Ritonga et al., 2024). Through this openness, a person can build relationships, expand social support, and obtain emotional validation. Self-disclosure for PLWHA on social media is a great potential to create relationships and social support while reducing psychological distress. However, self-disclosure or personal experiences also pose a great risk, such as exposure of their identity as PLWHA and potential rejection online (Ritonga et al., 2023).

Social media has become a place for PLWHA to form their own identities, both anonymously and openly. Social media such as Facebook, Youtube, Instagram, and community forums are places for PLWHA to share their experiences to strengthen each other (Ohorella et al., 2024). However, how PLWHA use social media and how they negotiate between the need to be open and the desire to maintain privacy is still an issue that requires further study.

In this situation, social media plays an important role in providing a platform for PLWHA to reveal their identity, share their stories, and seek support from the

community. Self-openness on social media can help PLWHA feel more accepted. Through social media in PLWHA communities, they can gain social support from the online communities they join in exchanging information, sharing experiences, and emotional support needed by PLWHA (Han, et al., 2018).

Participation in digital communities dedicated to PLWHA creates a virtual support system that offers more than just emotional comfort. These platforms facilitate the exchange of valuable information regarding treatment options, coping mechanisms, and lifestyle management, which can enhance health literacy and personal decision-making. Furthermore, such interactions help normalize the experience of living with HIV/AIDS, challenging dominant stigmatizing narratives and reducing the psychological burden associated with social isolation.

The presence of peer support through shared lived experiences allows PLWHA to draw strength from others who face similar challenges, fostering solidarity and emotional resilience. The supportive feedback, expressions of encouragement, and collective advocacy found in these online spaces can significantly contribute to mental well-being, while also promoting a more nuanced and humanized understanding of HIV/AIDS among broader audiences.

The effectiveness of these digital interactions depends on the extent to which online spaces are safe, inclusive, and moderated. Without appropriate safeguards, disclosure on social media can expose PLWHA to secondary stigma or breaches of privacy. Thus, while self-openness online offers numerous psychosocial benefits, it must be approached with awareness and supported by digital literacy, platform regulation, and peer-led moderation to ensure that these virtual communities remain supportive and empowering (Dalimunthe, 2018)

In essence, the role of social media in fostering openness and support among PLWHA is both significant and multifaceted. It not only facilitates personal expression and connection but also serves as a mechanism for building collective identity, resilience, and empowerment in the face of enduring social challenges (Han et al., 2018).

Although social media platforms provide many benefits, there is a discrepancy between what PLWHA expect and the reality. Many of them still feel anxious to share their life stories openly due to stigma. This situation makes it difficult to create an effective social support network. In addition, not all PLWHA have equal opportunities to access technology and social media, which may exacerbate inequities in support. These limitations underscore the need for a deeper understanding of how PLWHA utilize social media for the purposes of self-revelation and social support.

The problem that arises is how PLWHA utilize social media as a means of strategic self-disclosure, and in what context social media is effective in building social support. On the one hand, openness can trigger empathy, validation, and emotional support. On the other hand, digital space as a public space still has the potential to bring rejection, cyberstigma, and even harassment. This dilemma

poses a major challenge for PLWHA in deciding to share their identities and experiences online.

Although there have been many studies on the relationship between social media and mental health, as well as self-disclosure in general, studies that specifically address the role of social media in the process of self-disclosure of PLWHA and its contribution to the formation of positive social support are still relatively rare. Many previous studies have focused more on the technical aspects of social media usage without considering the social and emotional context experienced by PLWHA. Thus, this article aims to fill this gap by examining how PLWHA use social media to build social support through their self-disclosure.

The selection of this topic is based on the fact that social media has great potential as a space that supports the personal and social well-being of PLWHA. Academically, this study is expected to enrich the literature in the fields of communication, social psychology, and digital technology. From another perspective, this topic is important because it relates to issues of humanity, social justice, and the right to express oneself without discrimination. Personal experiences and academic backgrounds related to mental health and social support issues are of interest in this study. By looking at how social media can be an effective tool in creating communities, the author feels it is important to investigate further the role of social media in the context of People Living with HIV/AIDS (PLWHA). It is hoped that the results of this study can encourage the creation of safer, more supportive, and empowering online spaces for PLWHA.

Through this study, it is expected that there will be a meaningful contribution to communication theory as well as social support aimed at PLWHA. The findings of the study are expected to serve as a reference in the development of more efficient intervention programs, as well as provide policy recommendations that support the use of social media as a means to increase openness and social support for PLWHA. In this way, the research not only highlights the academic aspects, but also the real impact that can be felt by the PLWHA community.

## **2. RESEARCH METHOD**

The method used in this research is a literature review with a descriptive analysis approach. Creswell (2014) states that a literature review is a written description that summarizes the contents of scientific journals, books, and various other sources that explain the current and previous state of information by grouping them into certain topics or themes that aim to show gaps in further research. Through this process, researchers can identify patterns, certain trends, and research gaps in existing studies. Thus, literature review is important to strengthen the theoretical basis, help formulate objectives and methods and show the position of the research conducted. In this study, literature review was used by reviewing various scientific journals in the last five years between 2019 and 2024.

The literature search for this article included published journals such as PubMed, JMIR, PMC, Springer, and Google Scholar. The criteria included English and Indonesian articles with appropriate topics and context relevant to the openness of PLHIV and the role of social media and through a peer-review process. The search used the keywords “PLHIV stigma”, “PLHIV self-disclosure”, and “PLHIV social media”.

### 3. RESULT AND ANALYSIS

In the midst of the development of information technology, social media has emerged as an alternative space that allows for more open and supportive communication. Platforms such as Facebook, Twitter, Instagram, and various online forums offer a space for PLWHA not only to get information about their health but also to help them overcome their social problems. With social media, PLWHA can express themselves, share experiences, and build connections with individuals or communities who have similar experiences to strengthen social support. One study revealed that self-disclosure on social media has the potential to increase self-acceptance, strengthen social identity, and reduce psychological distress due to stigma (Naslund, et al., 2020). However, openness in digital spaces also carries risks, especially when the platform does not ensure safety and comfort for its users.

The openness of PLWHA on social media platforms is an important issue to discuss, given the huge impact that stigma has on society. The social environment serves as an important source of support for individuals, especially for PLWHA who often find it difficult to build self-confidence. Studies indicate that social support can improve the quality of life of PLWHA, but the negative stigma in society often makes them feel alienated. This suggests that although social support is very important, the barriers faced by PLWHA in obtaining such support are still a problem that needs to be addressed.

Research conducted by Panogiri, Luqman, & Hasfi (2023) states that the self-disclosure of PLWHA on social media, especially on the Youtube platform, is an anomaly because they close themselves. As for those who reveal their identity through effective communication, the threat of stigma and discrimination from society is still a significant threat and inhibiting factor. This shows that although social media offers a space to share, the fear of stigma is still a barrier for PLWHA to be open.

Furthermore, research conducted by Philpot, Murphy, Prestage, & Wells (2022) showed that out of 28 participants, 5 used social media to openly disclose their HIV status. The rest chose to remain private by not openly disclosing their identity on social media such as using the “close friends” feature on Instagram to share their experiences privately. This suggests that despite the desire to share, PLWHA are still afraid and worried about social stigma, so they prefer not to disclose their HIV

status on social media to avoid negative consequences and maintain their privacy (Harianto et al., 2023).

Sharing one's status as PLWHA through social media can help people form a stronger identity and reduce the mental burden caused by stigma. Studies show that social media-based approaches have been successful in increasing understanding and acceptance of HIV among adolescents (Dulli, et al., 2020). Social media is effective in supporting self-disclosure and strengthening social support among PLWHA, which can help reduce stigmatization and improve their mental health and treatment sustainability (Ibrahim, et. at., 2024). This suggests that social media not only serves as a platform to share information but as a tool to build awareness and reduce stigma in the community.

Social media has the potential to provide online social support activities that can help reduce feelings of isolation and stigma towards PLWHA. Social media makes frequent interpersonal communication easier, and builds a broader and more trusting social network among users, including PLWHA. In addition, social media can be an important source of information and emotional support, assisting PLWHA in managing stress and increasing their perception of social support. However, it is important to keep in mind that the use of social media can also potentially lead to negative experiences such as cyberbullying or transphobia, which must be managed properly for optimal benefits (Gerke, et al., 2020).

Moreover, social media serves not only as a communication tool but also as a dynamic space for sharing health-related information, including updates on HIV treatment, coping strategies, and self-care practices. These informational resources can empower PLWHA to make informed decisions, reduce uncertainty, and increase self-efficacy in managing their health conditions. Emotional support—manifested through expressions of empathy, encouragement, and shared lived experiences—also plays a critical role in helping individuals navigate the psychological challenges associated with chronic illness and social discrimination. In turn, such support contributes to heightened perceptions of being understood and valued, which are fundamental to one's mental well-being.

However, while the benefits are substantial, the use of social media is not without risk. Digital spaces are often unregulated and may expose PLWHA to harmful content such as cyberbullying, hate speech, or targeted discrimination—including transphobia and HIV-related stigma. These negative experiences can exacerbate psychological distress, hinder self-disclosure, and even deter users from seeking online support. Therefore, it is imperative that stakeholders—especially platform developers, mental health professionals, and community organizations—implement strategies to foster safe and inclusive environments. This includes developing content moderation systems, enhancing digital literacy among users, and promoting community guidelines that protect vulnerable populations.

While social media offers promising avenues for fostering social support and reducing stigma among PLWHA, maximizing its potential requires a deliberate effort to mitigate its risks. A balanced, well-managed approach can ensure that the digital realm becomes not only a source of connection and information but also a sanctuary of emotional resilience and empowerment for PLWHA in the face of ongoing societal challenges.

Social media such as Instagram and interactive platforms such as Tanya Marlo make it easy to disseminate informative and accessible information, which contributes to reducing stigma and discrimination against PLWHA. In addition, social media creates a platform for PLWHA to gain emotional and social support, and increases public awareness on the importance of understanding and acceptance for PLWHA. With its interactive and comprehensive features, social media facilitates the formation of social networks and assists PLWHA in understanding and dealing with their situation, while encouraging active involvement in HIV/AIDS prevention and treatment programs. Many PLWHA revealed that there are difficulties for them to open themselves in the social environment due to stigmatization, making it difficult for them to seek social support from both friends and close people such as family (Ayu, et al 2023).

In general, a person's actions are influenced by the individual's desire to perform or not perform certain actions. Before making a decision, individuals will think about the consequences of their actions. PLWHA will also evaluate and make judgments about the actions they take towards others, and whether or not these actions can have a negative impact on themselves. The level of openness of PLWHA in communication depends on the situation and the person being spoken to. If the interlocutor can create a comfortable and motivating atmosphere, PLWHA tend to be more open. However, if PLWHA are in an environment that has not been able to accept themselves, they will tend to close themselves. Likewise with the use of social media, PLWHA will feel more comfortable and open if the environment accepts their existence.

Erwansyah & Audilla (2021) found that in this digital era, social media and online communities have a significant role as a source of social support for PLWHA. These platforms support individuals in obtaining emotional support, exchanging information, and reducing the impact of stigma and discrimination they face in real-world social interactions. This suggests that social media can be an effective tool in building social support for PLWHA.

Overall, the results of the analysis demonstrate that social media platforms play a pivotal role in facilitating the self-disclosure of People Living with HIV/AIDS (PLWHA) through multiple mechanisms that are both empowering and psychologically beneficial. First, social media offers a flexible and customizable space that allows PLWHA to narrate and manage their personal experiences in ways that align with their comfort levels—either by selectively sharing with closed community groups or by making their stories public. This agency in storytelling

fosters a sense of autonomy and control, which is crucial for individuals navigating the complexities of health disclosure in a stigmatized context.

Second, the act of sharing one's lived experience through digital platforms not only enables PLWHA to articulate their identity but also functions as a form of affirmation. Through likes, comments, and expressions of empathy, individuals receive validation that strengthens their self-worth and confidence. In this way, self-disclosure via social media becomes a tool for reconstructing a positive self-image, often eroded by societal stigma and discrimination. Furthermore, digital engagement often fosters feelings of belonging, as individuals realize they are not alone in their journey—an experience that can be transformative in reshaping identity.

Third, the social support embedded in online interactions—manifested through positive feedback, expressions of solidarity, and reciprocal storytelling—significantly contributes to the psychological well-being of PLWHA. Emotional encouragement, informational exchange, and moral support found within virtual communities can reduce feelings of isolation, anxiety, and depression. These interactions mirror, and at times substitute, offline social support systems that may be limited or inaccessible due to stigma or geographic barriers.

Therefore, it becomes increasingly important to recognize social media not merely as a communication tool, but as a psychosocial intervention medium that can aid PLWHA in managing stigma, fostering resilience, and cultivating empowering social networks. Stakeholders—including healthcare professionals, NGOs, and public health communicators—are encouraged to harness the potential of these platforms to design digital strategies that amplify positive narratives, promote safe disclosure, and connect PLWHA to supportive communities. The integration of social media into psychosocial support frameworks represents a promising avenue for enhancing the overall quality of life for individuals living with HIV/AIDS in the digital age.

#### **4. CONCLUSION**

Social media platforms have a significant role in facilitating the self-disclosure of PLWHA as well as serving as a strategic tool to build social support networks amidst stigma and discrimination. PLWHA's self-disclosure through social media has been shown to provide a safer and more flexible environment for expressing identity, sharing experiences, and building mutually supportive emotional networks, both anonymously and openly. However, this process of openness is inseparable from the desire for support and the fear of online stigma, invasion of privacy, and possible rejection from society. A review of the literature in the last five years shows that social media not only acts as a communication tool, but also as a means of identity formation, self-validation, and improvement of mental well-being for PLWHA. Interaction in online communities has a positive impact on the



confidence and courage of PLWHA to be more open, although there are some who still choose a closed communication strategy considering the risks that may arise. Therefore, social media has great potential as a social and psychological intervention tool in supporting PLWHA, provided it is supported by adequate privacy protection policies and digital education. There is a need for collaboration between policy makers, digital platforms, and health practitioners to create online spaces that are inclusive, safe, and empower PLHIV to fight stigma and build strong and sustainable social support.

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