

Rational and Cultural Self-Disclosure through Social Media in People Living with HIV/AIDS

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Abstract: Stigma and discriminative treatment by community leads the People Living with HIV/AIDS or PLWHA to hide their HIV status. This research aimed to analyze rational and cultural self-disclosure through social media in People Living with HIV/AIDS. This qualitative research employed computer-mediated discourse analysis. This research joined Facebook group and collected data through online observation on site www.victoryplusaids.org, explored activity and network, including utilizing search, user list, statistics and tags facilities on March 20-25, 2017, and in-depth interview with the members related to conversation content, cause, advantage and disadvantage of self-disclosure in social media. Social media becomes a space for PLWHA for sharing feeling, perception, opinion through writing and photograph of their activities. Culture, self-confidence, wish of not burdening others, and need for protection became the matter of consideration for self-disclosure. PLWHA are no longer burdened with secret, obtain social support, and easy access to health service. However, from personal risk, relationship and professionalism aspect, they are isolated by their friend, declined by partner, and loss their job. Viewed from the content of site, other PLWHA and community can educate more and increase knowledge on HIV/AIDS, and respect the rights of PLWHA.

1 INTRODUCTION

People living with HIV/AIDS (PLWHA) are faced with difficult situation (Qiao et al., 2015). Hiding disease condition results in a very annoying inner sorrow due to the burden of securing secret, while revealing their HIV status also results in such problems as declination (Majumdar and Mazaleni, 2010; Chadoir et al., 2011; Rouleau, 2012).

One factors leading an individual to do self-disclosure is who the listener is to whom he/she will give information; so that he/she tend to share with the trustable one, close to him/her and he/she likes such as member family, friend and healthcare workers (Chadoir et al., 2010; Yonah et al., 2014; Devito, 2016; Bird and Voisin, 2013). Therefore, self-disclosure is important to be starting point for PLWHAs to express their thought and feeling, to improve the self-confidence, and to build relation with others, thereby finding out information about the disease, whether its symptom, transmission method, risk factor or treatment (Yadav, 2010; Stutterheim et al., 2016). As a part of society, PLWHAs are inseparable from media exposure that is context-

sensitive because every society has distinctive culture to interpret a variety of symbols in its life.

One of media activity forms is media literacy, a set of perspectives that we actively expose ourselves to the media to interpret the meaning of the messages we encounter. We build our perspectives from knowledge structures. To build our knowledge structures, we need tools and raw material. These tools are our skills. The raw material is information from the media and the real world. Active use means that we are aware of the messages and are consciously interacting with them (Potter, 2004; Luft, 1970). New media as those form that combine the three Cs: Computing and Information Technology (IT), Communication Network, digitized media and information content (Flew, 2014; Potter, 2016).

The application types of new media are varying including Twitter, Facebook, Instagram, Path, Line, and WhatsApp. Through social media, interpersonal communication is established, and socialization and information exchange can be done, as feeling can be shared, psychological expression can be revealed, and photo and video can be shared (Martens, 2010; Qualman, 2012). Understanding the content of media as a text gives us an ability of connecting culture to

life, enjoying, conceiving and appreciating it (Silverblatt, 1995; Rosenbaum et al., 2008; Jacquinet et al., 2008). So, being opened and participative will be useful to living along with PLWHAs. In this context, rationality plays an important part because the human's source of knowledge is mind or idea (Wawrzyniak et al., 2013; Baran, 2014; Thompson et al., 2015).

In some pages like www.spiritia.com, and www.victoryplusaids.org, PLWHAs become the main locus of media literacy activity, thereby can be connected to everyone including the newly known one and separated physically. The development of relation is analogized with onion explaining how people interact with each other by peeling their own information layers. Its dimension breadth is discussion topic, while its depth is which information layer can be revealed to other (Altman and Taylor, 1973; Littlejohn and Foss, 201; Griffin, 2011). PLWHAs' experience with performing self-disclosure through social media becomes the state of art of this research.

2 METHODS

This qualitative research employed a computer-mediated discourse analysis approach (Herring, 2001; Schiffrin et al., 2001; Phillips and Hardy 2002). The author joined the Facebook group and collected data through online observation on site www.victoryplusaids.org, exploring its activity and network, and utilizing search, user list, statistics and tags facilities from March 20-27, 2017, but focusing on the status content and conversation uploaded by 8 PLWHAs revealing their experience in detail, related to their HIV status, disease symptom, and risk factor through <https://www.facebook.com/Victory-PLUS-240409562760006/>.

They are 2 housewives (A1 and A2), a female sex worker (B), a high risk man (C), an IDU (injection drug user) (D), a gay (E), a transsexual (F), and a peer educator (G) recommended by the Chair Person of Victory Plus Peer Group, Yogyakarta Indonesia, corresponding to the objective of research. The author also interviewed the informant related to cause, advantage and disadvantage of their self-disclosure. This research has been approved by Ethical Committee of Social and Political Sciences Faculty of Sebelas Maret University.

3 RESULTS AND DISCUSSION

The result of investigation on self-disclosure status content of PLWHAs through [victoryplusaids.org](http://www.victoryplusaids.org) and <https://www.facebook.com/Victory-PLUS-240409562760006/> is divided into 3 categories: PLWHA's knowledge, attitude, and action related to their HIV status. PLWHAs' knowledge on HIV/AIDS is varying. A1 said that HIV/AIDS is an infectious, frightening, and life threatening disease. [A1, uploaded on March 20, 2017]. A2 stated that my physical health condition is impaired, and even clinical symptoms of other disease arises such as eating pattern, skin, visual impairment, fever, and limp [A2, uploaded on March 20, 2017].

Meanwhile B argued that I am really suffering from and in misery. I am so sad and cannot believe that I develop HIV [B, uploaded on March 21, 2017]. C and D wrote in their account as follows, on March 22, 2017, I am afraid of transmitting this disease to my wife and to die suddenly. In addition, I am sad for my neighbors treat me cynically and keep far away from me [C, uploaded on March 22, 2017]. I hate and regret my deed. [D, uploaded on March 22, 2017].

E and F said that they are submitted and shy, they said I am submitted because I am helpless and hopeless [E, uploaded on March 22, 2017]. As the one developing HIV/AIDS, of course, I feel shy but I do not know what I should do... [F, uploaded on March 22, 2017]. Meanwhile, G wrote, this disease really burdens me because I always think about it any time [G, uploaded on March 23, 2017].

Regarding the PLWHAs' attitude to their HIV status, A1, A2, and B suggest as follows. When I think about this disease, I am much stressed. [A1, uploaded on March 24, 2017]. Actually I want to escape from this physical and mental distress, and to live happily but, I have been infected HIV/AIDS, so I can do nothing. [A2, uploaded on March 24, 2017]. I hope my health is not getting worse, and I will be cured and healthy. [B, uploaded on March 24, 2017].

Because C, D, E, F and G want to escape from their physical and psychological distress, they state as follows. Where can I get Voluntary Counseling and Testing (VCT)? [C, D and E uploaded on March 24, 2017]. I went to VCT in Public Health Center (*Puskesmas*) of Wirobrajan Yogyakarta at 09.00 today [E, uploaded on March 24, 2017]. Where is mobile VCT located? Can I take HIV test when mobile VCT is conducted? Where can I access anti-retroviral? [C, D, E, F, and G, uploaded on March 25, 2017].

Through Facebook, PLWHAs get response from some receivers such as family, peer, peer group,

healthcare workers, HIV/AIDS activists, including the newly known one. The response from healthcare workers such as physicians, VCT counselors and nurses is suggested by A1, A2 and C in their account.

B gets support and attention from his/her coworkers, he/she wrote in his/her status as follows: Thank you my colleagues for your support, indeed although I am PLWHA, I should keep doing activities, working and being healthy [B, uploaded on March 25, 2017].

D and F obtaining support from their parents and brother/sister uploaded their photograph not reluctantly while writing: I feel secure and have life expectancy because my family always cares about me [D and F, uploaded on March 25, 2017]. E as peer educator and G participating actively in Prevention of Mother to Child Transmission (PMTCT) get response from Victory Plus Peer Group and PMTCT members. They uploaded photographs during conducting VCT mobile and HIV/AIDS socialization activities in Wirobrajan Yogyakarta.

Considering the result of interview, it can be found that the advantages of opening HIV status are, among others: no longer burdened with secret, can question and receive emotional support, and can access health treatment and take medication more easily. Some PLWHAs state that the disadvantages of opening HIV status are: avoided by friends, refused by partner and losing job, mixed feelings, ignoring others due to deathly disease, and assuming that any symptoms are related to HIV, afraid of assembling with others due to security, and the likely risk of experiencing physical and/or mental mistreatment. So, it is generally related to discrimination and negative stigma against PLWHA.

PLWHAs performing self-disclosure through social media take the advantages and the disadvantages into account, present and past experiences, and their personality. Cultural and personal factors affecting the PLWHAs to open their HIV status are self-confidence, not willing to burden others, needing protection from social pressure, self-denial as one way of solving problem, fatalism, and distrusting others or system. Asking for support actually makes an individual seems to be sick and weak, but he/she really needs it. External factors affecting the decision of self-disclosure are family, social support and VCT counselor, PMTCT Team and physician.

One of PLWHAs' inner distresses comes from fear and others' negative assessment when they disclose their disease condition. Self-disclosure through social media generates an expectation to be free from physical and mental distresses, due to

receiving information about disease, emotional support, and medication help. It affects PLWHAs' action to deal with distress by finding out, looking for support, telling about the condition encountered, taking medications and consuming drug accessed in pharmacy (yadav, 2010). Generally, the decision of self-disclosure is not made alone, but by asking for support first from the trustable ones who always care about, support, and treat them well like family, friend, Victory Plus peer support group, and healthcare workers.

Considering the content of status and conversation, it can be found that through self-disclosure, PLWHAs get advice from healthcare workers to keep taking medications, emotional support, and access to easy medication and treatment, and opportunity of expressing thinking and feeling (Wawrzyniak et al., 2013; Thompson et al., 2015). Self-disclosure makes PLWHAs getting correct information about HIV/AIDS thereby changing their misunderstanding on the transmission method, protecting partners and the beloved one, conducting PMTCT, and improving the consciousness of the importance of medication (Chaudoir et al., 2010; Yonah et al., 2014).

Thus, PLWHAs feel free from pressure, feel better and having future. Emotional support can help them receiving the condition they encounter, reduce fear and withdrawal from society. It means that it helps relieving psychological stress and potentially changing the life to the positive one (Qiao et al., 2015; Chaudoir et al., 2011; Lugalla et al., 2012). Family, friend, peer support group, and healthcare workers contribute to generating the PLWHAs' spirit to do some activities that can improve their life quality by taking medications, joining peer support group, and helping others. The participation of PLWHAs in Peer Support Group can reduce their fear, depression, loneliness and isolation, because environment support PLWHAs to express feeling. Sharing experience through social media makes PLWHA feeling not alone, better, and forgetting their sickness (Flew, 2014; Martens, 2010; Rosenbaum et al., 2008).

4 CONCLUSIONS

As social media users, PLWHAs conduct self-disclosure by disclosing their feeling, perception and opinion through writing, and sharing some photographs related to HIV status in their account. It becomes a source of social learning that we should remain to be alerted to HIV/AIDs.

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REFERENCES

- Altman, I., Taylor, D., 1973. *Social penetration: The development of interpersonal relationships*, Holt. New York.
- Baran, S. J., 2014. *Introduction to Mass Communication and Culture*, McGraw-Hill Education. London, 8th Edition.
- Bird, J. D. P., Voisin, D. R., 2013. You're an open target to be abused: A qualitative study of stigma and HIV self-disclosure among black men who have sex with men. *American Journal of Public Health*. 103(12): 2193-2199.
- Chaudoir, S. R., Fisher, J. D., Simoni, J. M., 2011. Understanding HIV disclosure: A review and application of the disclosure processes model. *Social Science & Medicine*. 72(10): 1618-1629.
- Chaudoir, S. R., Fisher, J. D., 2010. The disclosure processes model: Understanding disclosure decision-making and post-disclosure outcomes among people living with a concealable stigmatized identity. *Psychological Bulletin*. 2010; 136(2): 236-256.
- Devito, J. A., 2016. *The Interpersonal Communication Book*, Pearson. New York, 14th edition.
- Flew, T., 2014. *New Media*, Oxford University Press. Melbourne, Victoria, Australia, 4th edition.
- Griffin, E., 2011. *A first look at communication theory*, McGraw-Hill. New York, 8th edition.
- Herring, S. C., 2001. *Computer-mediated discourse*. In *Handbook of discourse analysis*, Blackwell Publisher. Oxford, UK, Schiffrin, D., Tannen, D and Hamilton, E.H. edition.
- Jacquinot-Delaunay, G., Carlsson, U., Tayie, Tornero, J. M. P., 2008. Empowerment through Media Education an Intercultural Approach. In *Empowerment Through Media Education an Intercultural Dialogue, Sweden: The International Clearinghouse on Children, Youth and Media Nordicom University of Gothenburg*. 19-33.
- Littlejohn, S. W., Foss, K. A., 2011. *Theories of Human Communication*, Waveland Press.Inc. Long Grove, Illinois, 10th edition.
- Luft, J., 1970. *Group processes; an introduction to group dynamics*, National Press Books. Palo Alto, California, 2nd edition.
- Lugalla, J., Yoder, S., Sigalla, H., Madihi, C., 2012. Social context of disclosing HIV test results in Tanzania. *Culture, health & sexuality*. 14(sup1), S53-S66.
- Majumdar, B., Mazaleni, N., 2010. The experiences of people living with HIV/AIDS and of their direct informal caregivers in a resource-poor setting. *Journal of the International AIDS Society*. 13(20): 2-9.
- Martens, H., 2010. Evaluating Media Literacy Education: Concepts, Theories and Future Directions. *Journal of Media Literacy Education*. 2 (1): 1-22.
- Phillips, N., Hardy, C., 2002 *Discourse Analysis Investigating Processes of Social Construction*, Sage Publication Inc. London.
- Potter, W. J., 2016. *Introduction to Media Literacy*, Sage Publication Inc. Thousand Oaks, California.
- Potter, W. J., 2004. *Theory of Media Literacy: A Cognitive Approach*, Sage Publication Inc. London.
- Qiao, S., Nie, J. B., Tucker, J., Rennie, S., Li, X. M., 2015. The role of social relationship in HIV healing and its implications in HIV cure in China. *Health Psychology and Behavioral Medicine*. 3(1): 115-127.
- Qualman, E., 2012. *Socialnomics: How Social Media Transforms the Way We Live and Do Business*, Wiley. United States, 2nd edition.
- Rosenbaum, J. E., Beentjes, J. W., Konig, R. P., 2008. Mapping Media Literacy Key Concepts and Future Directions. *Annals of the International Communication Association*. 32(1), 313-353.
- Rouleau, G., Côté, J., Cara, C., 2012. Disclosure experience in a convenience sample of quebec-born women living with HIV: A phenomenological study. *BMC Women's Health*. 12(37): 1-11.
- Schiffrin, D., Tannen, D., 2001. *Handbook of Discourse Analysis*, Blackwell Publisher Ltd. Oxford, UK, Hamilton EH. Edition.
- Silverblatt, A., 1995. *Media Literacy: Keys to Interpreting Media Messages*, Praeger. London.
- Stutterheim, S. E., Sicking, L., Baas, I., Brands, R., Roberts, H., van Brakel, W. H., Lechner, L., Kok, G., Bos, A. E. R., 2016. Disclosure of HIV status to health care providers in the Netherlands: A qualitative study. *Journal of the Association of Nurses in AIDS Care*. 27(4): 485-494.
- Thompson, J., Havenga, Y., Naude, S., 2015. The health literacy needs of women living with HIV/AIDS. *Health SA Gesondheid*. 20(1): 11-21.
- Wawrzyniak, A. J., Ownby, R. L., McCoy, K., Waldrop-Valverde, D., 2013. Health Literacy: Impact on the Health of HIV-Infected Individuals. *Current HIV/AIDS Reports*. 10(4): 295-304.
- Yadav, S., 2010. Perceived social support, hope, and quality of life of persons living with HIV/AIDS: A case study from Nepal. *Quality of Life Research*. 19(2) :157- 166.
- Yonah, G., Fredrick, F., Leyna, G., 2014. HIV serostatus disclosure among people living with HIV/AIDS in Mwanza, Tanzania. *AIDS Research and Therapy*. 11(5): 1-5.