

# Raising Public Awareness on HIV/AIDS Issues: How Do Social Media Play a Role?

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## ABSTRACT

Social media is the most effective communication media for sharing information in industrial revolution 4.0 era. Almost everyone has a smart phone, connected to the internet that can be used to access social media easily anywhere and anytime. However, this research analyzes the issue of HIV/AIDS on social media. It is expected that the issue of HIV/AIDS on social media can help preventing and reducing the infection of HIV/AIDS in reality. This research uses descriptive qualitative research methods. The study was conducted by taking visual data and literal data of popular social media accounts such as Facebook and Twitter. The research results show that there are five classification of posts on social media both Facebook and Twitter. On Twitter, they are: government posts (59 posts), news agencies (220 posts), netizen posts (347 posts), netizen share news (81 posts), and others (113 posts). On Facebook, they are: government posts (0 post), news agencies (0 post), netizen posts (0 post), netizen share news (4 post), and others (0 post). From this result, Twitter is more effective to share information related to HIV/AIDS.

**Keywords:** *HIV/AIDS, issues, social media*

## 1. INTRODUCTION

AIDS become the monster for human living. UNICEF in 2010 predicted that almost 700 teenagers (10-19 years old) get infected of HIV every day, or one person for every two minutes. Today HIV/AIDS is a major health emergency around the world, giving acute problems, affecting many aspects, causing millions of deaths and still moving. Based on UNAIDS data at 2018, there are 37.9 million people globally were living with HIV. And, there are only 23.3 million people who were accessing antiretroviral therapy. The data also shows that there are 770 000 people died from AIDS. The sufferers are not only adults (36.2 million), but also the children under 15 years old (1.7 million). AIDS-related mortality has declined by 33% since 2010 becomes good news for people.

AIDS stands for Acquired immunodeficiency syndrome. It is a set of symptoms and infections that are life threatening and result from damage to the human immune system. It is caused by the human immunodeficiency virus (HIV) (Liang and Wang, 2011). The world still cannot find the effective medicine to cure HIV/AIDS disease. The only way to reduce the mortality is by using Highly active antiretroviral therapy (HAART). It is very effective in suppressing viral replication and has led to a significant reduction in the mortality rate of the disease, an increase in the life expectancy of HIV/AIDS patients, and an improvement in quality of life of these patients. However, according to Park,

et. al. (2009), HAART does not offer a complete solution to the problem.

HIV and AIDS is often mentioned together by writing HIV/AIDS. But, in facts, those are different. HIV is for viruses and AIDS is for the disease. People who live with HIV is not always as AIDS sufferers. But those who get AIDS in their life is absolutely initiated by getting HIV viruses. A positive HIV test does not mean that a person has AIDS. A diagnosis of AIDS is made further.

Unfortunately, not all people living HIV knows that they are infected the disease. Around 79% of all people living with HIV knew their HIV status, and the rest about 8.1 million people did not know that they were living with HIV. This phenomenon makes the treatment getting blurred. Those who got HIV and knew that they live with HIV/AIDS will get the treatment from the government or the health services. But those who do not know that they live with HIV/AIDS will live peacefully without considering the danger of their diseases. In Indonesia itself, there are 36.9 million sufferers and 25% of them do not know that they get HIV/AIDS in their body (Kompas.com, December 1 2018).

The limited information of HIV and AIDS for people makes the prevention getting harder. Besides, the stigma of AIDS sufferers from surroundings give impacts on the treatment. People still believe that AIDS is a curse. They cannot be safe in their life and they will end in death. Those

stigmas should be decreased as well as the socialization and sharing information is urgently needed. Dealing HIV treatment has challenge into two classification: those who HIV-infected and HIV-uninfected. It is beneficial to be known because of several factors. Avoiding negative stigma becomes the major reason that ODHA still have “a chance” to live. People just avoid the viruses and disease without avoiding the sufferers.

According to Richman (2011), for HIV uninfected people, the development an HIV vaccine is imperative if a truly substantial reduction in epidemic transmission is to be achieved. For HIV infected people, the two challenges are the provision of effective treatment for those without access, which is a major operational and economic challenge, and the development of approaches to cure the latent reservoir for those on treatment, which is a major scientific challenge.

The offering information about HIV/AIDS is basically consists of information related to what and how HIV/AIDS, how it is transmitted and how to avoid virus transmission. As a basic, it deals with: what is HIV/AIDS? How is HIV spread? How can the people reduce risk of getting HIV? What is the treatment for HIV? What are the symptoms of HIV/AIDS? How is AIDS diagnosed? (Cited from AIDSinfoU.S. Department of Health and Human Services).in addition, sharing information is not only about the prevention, but also the stigma. According to the Basic Health Research (Riskesdas) 2018, 65.2 percent of Indonesians have a poor and limited understanding of HIV/AIDS. Misunderstanding or lack of knowledge about HIV/AIDS has contributed to public fear, stigma, and discrimination. People must understand that HIV/AIDS can be prevented and managed so that people living with HIV can live as healthily as normal people.

Sharing information in conventional way is done through the mass media, but it requires expensive costs. However, now days, the power of social media can make the socialization effective and affordable. Some countries still use the conventional ways for HIV/AIDS socialization. As research carried out by Nwaolikpe (2018), some countries in Africa still use mass media and education in schools for socialization about HIV/AIDS. Surely, this method is quite expensive, because the cost of broadcasting in mass media and supplying the socialization in school curriculum need high expenses.

The 4.0 industrial revolution is digital era. It makes people can access internet through smart phone everywhere. According to Mpofo and Salawu (2014), The use of the internet and its applications for health information purposes is on the rise with studies showing the internet as one of the most widely used resource for health information. They add the emerging social media such as online forums, message boards and health related social networking sites have received immense attention from health information seekers. Almost the internet users have social media account and they can access it every day. According to Elkin (2008) approximately one third of online health information seekers

have used social media resources and this number is expected to grow as more and more people seek information and help from their peer. However, the use of social media for HIV/AIDS socialization is effective and affordable. Everyone can share everything related to HIV/AIDS through social media without having to pay because the social media, like Facebook and twitter is free to access.

Siagian (2015), in his research, said that the use of social media as a communication medium is very effective because of the feedback. Surely, the information receiver can give feedback to the information sender. This feedback will increase participation, usually by participating in sharing the information to others. That is why the social media users can be effectively as agent or communicator related to HIV/AIDS.

Ratnamulyani & Maksudi (2018) said that social media was quite effective among young people because almost all young people had utilized social media. This fact supports the importance of HIV/AIDS socialization among young people, because this age groups have high possibilities to be infected HIV/AIDS, like having free sex and drug abuse.

According to Cahyono (2016), social media is an online media, with its users can easily participate, share, and create contents including blogs, social networks, wikis, forums and the virtual world. Social media positively can give several impacts as follows: the people can interact with others easily without seeing distance and time as barriers, expand relations, express themselves easily, share information quickly, and need cheaper expenses. However, social media also gives negatives impacts: create the distances among people because they just focus on their own smart phone and vice versa, decrease the intensity of face to face communication, make people addict to the internet, create conflicts, raise privacy problems, and tend to get bad influence from others.

Mulawarman&Nurfitri (2017) defined social media as a communication tool used by users in social processes. The academics and researchers concern highly on some social media features, like selfie, cyberwar, online shopping, personalize self, and sharing habit. Human behavior that is increasingly inseparable from cyberspace needs serious attention.

Khairuni (2016) said that generally social media is defined as online media that support social interaction. Social media uses Web-based technology that changes communication into interactive dialogue. Some popular social media today include: Blogs, Twitter, Facebook and Wikipedia.

Data from the Ministry of Health (2014) shows that most HIV/AIDS sufferers are in the age of 20-29 years (32.9%) and 30-39 year (28.5%). This group is the biggest internet users. Besides, this age group also have high technology information ability. Therefore, utilizing social media to socialize HIV/AIDS will be effective for them.

In Indonesia, there are numerous popular social media with great users. The picture below will show the popular social media in Indonesia.

Platform Social Terpopuler di Indonesia

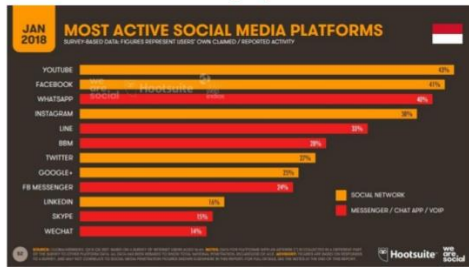


Figure 1 Most Active Social Media Platforms per January 2018. (Cited from Indonesia Political Digital Landscape - Augusts 2018)

From the picture above, the yellow indicates the social network and the orange indicates the chat app. The researchers focus on Facebook and Twitter as selected social media to be analyzed. According to Simas, et.al. (2017), Facebook is a social sharing site that connects individuals with friends, families and acquaintances. It allows sharing of written content, images and videos. People in one's network can engage by liking (and, more recently, expressing a variety of other pre-supplied emotions or 'reactions') and commenting upon posts, as well as by sharing those posts on their own timeline, thus extending the reach of a post. Similar to Facebook, Twitter is a micro-blogging site for short messages or tweets. Each tweet contains a maximum of 140 characters and pictures can be linked to them. Like other social media, Twitter can be used to stay in contact with a network of friends. However, it is also frequently used as a platform for sharing and receiving news and promoting business. Discussions on Twitter are organized around themes and common interests and not necessarily friendship connections.

2. METHOD

This research uses descriptive qualitative research methods. The study was conducted by taking visual data and literal data of popular social media accounts such as Facebook and Twitter. In the first stage, the researchers observe the issues of HIV/AIDS on Facebook and Twitter through its search engine. The results of searching activities are in the form of images, videos or posts and comments from Facebook and Twitter users admitted as research data. The data were gathered on April 1-August 31 2019. the data were classified into five categories: Government posts, news, netizen/users' posts, Netizen news sharing, others (NGO, academician, schools, support groups). the posts are limited into Indonesian citizens and posts in Bahasa Indonesia. The data were counted by using tally in the table.

Observations were made to identify themes and issues posted or discussed by Facebook and Twitter media users about HIV/AIDS. Then, posts and conversations were analyzed to find out the trends and theme intensively discussed by Facebook and Twitter users. The researchers also identify the information and prevention of HIV/AIDS discussed by the social media users.

3. FINDINGS AND DISCUSSIONS

3.1. Findings

Seeing the trends of sharing HIV/AIDS information on social media indicates that people have utilized social media. After analyzing the data, the research results are classified into five category of posts both on Facebook and Twitter. Those are: government posts (posts from the government. Ministries, department, agencies through Indonesia), news (posts from online news media), netizen posts (the users' post), netizen sharing news (user behavior in sharing news), and others (posts from non-government organization, support group, schools, academicians, non-profit organization). the results are presented below:

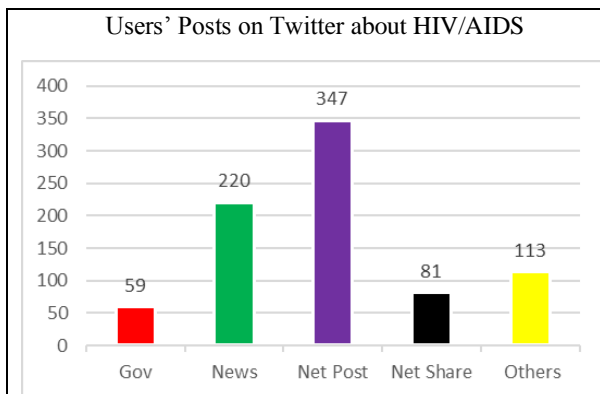


Figure 2 Users' Posts on Twitter

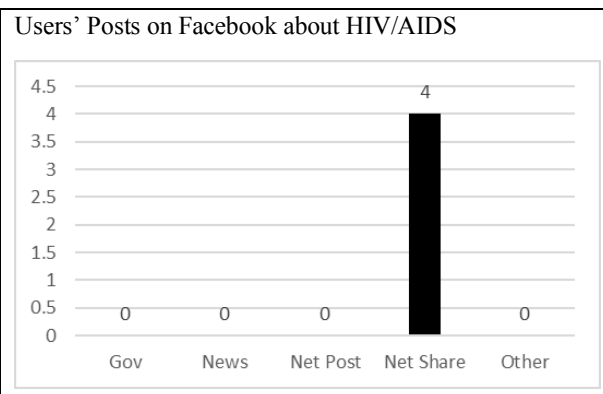


Figure 3 Users' Posts on Facebook

The picture above shows the traffic of posts from April 1 until the researchers do not want to compare its effectiveness in August 31 2019. It implies that Twitter is more crowded than sharing information related to HIV/AIDS issues. The Facebook. Twitter raises many posts, re tweet, as well as researchers bring it together as media to share information. comments from its users. While Facebook is more silent. But

**3.2. Discussion**

**HIV/AIDS on Twitter**

Twitter seems effective in sharing information. It can be seen from the traffic among users discussing about HIV/AIDS. The traffic above is classified into five types posts:

**3.3. Government Posts**

Government plays important role in bring information related to everything because the citizen will trust more the post from the government. As seen in the data, in 5 months Period, the government posts around 59 tweets. It is not only the ministries or state government, but also the local departments, office department is province or region. Here is the example:



**Figure 4** Kemenristekdikti account shares HIV/AIDS information



**Figure 5** Humas Dinkes Lampung shares activities related to HIV/AIDS

The picture above implies that governments care much in sharing information related to HIV/AIDS. Kemenristekdikti conducts a seminar related to HIV/AIDS prevention. While the right picture shows that Lampung Health Office also care to HIV/AIDS prevention by share information related to prevention and limit HIV virus transmission. Government has to be a leading changing in sharing information. They tend to believe that formal posts on social media by the government is trustful.

**3.4. News**

There are many online news agencies that posts information related to HIV/AIDS issues. The second trusted media to share information is through news agencies. The big news agencies like Kompas, Tempo, JawaPos, etc will give them

qualified paper based on research or studies. The information shared is also based on journalism data around Indonesia. Based on the findings, news plays good posts by 220 posts in five months. The pictures below are the examples.



**Figure 6** Jawa Post releases a news about two kids were infected HIV/AIDS



**Figure 7** Kompas releases a news related to HIV/AIDS in Lamongan

The left picture is news from Jawa Post about the kid's transmission of viruses from their mother. Jawa Posts have changed their platform into digital media since the worldwide expansion of online news. They cannot keep on paper form of media to widen the people readability. On the left side, Kompas also do the same. It issues about the HIV/AIDS sufferers in Lamongan East Java.

### 3.5. Netizen Posts

Netizen posts become the greatest post in twitter with 347 posts in five months. It includes the original posts and the re

tweet from other users' posts. Netizen posts are taken from common users' tweets. Those are individuals who concern much on sharing information related to HIV/AIDS issues.

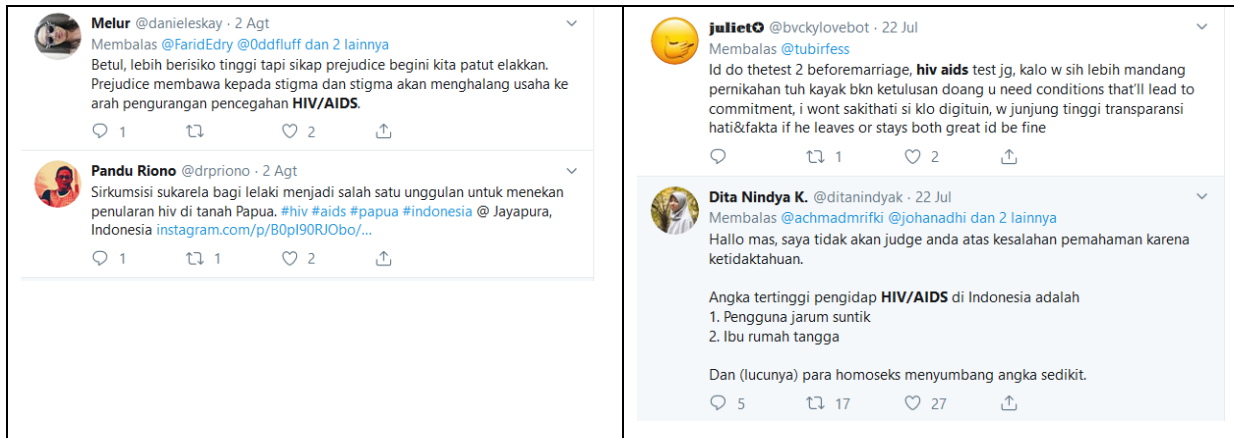


Figure 8 Netizen Posts related to HIV/AIDS

Twitter users are more active than other social media users. It can be seen from the traffic posts and re tweets from the users for five months. This is beneficial for the prevention of HIV/AIDS. They are dynamic. They share information and get feed backs from other users. Besides, other users can re tweet the original posts to expand for other users. Twitter seems dynamic in expanding the news.

### 3.6. Netizen Share

Despite posting their opinions related to HIV/AIDS, the Twitter users also share news related to HIV/AIDS information. The number is also high with 81 posts.



Figure 9 Twitter users share news from online news portal

It is like pyramid in communication sharing. News agency issued the news on Twitter broadly and the users can broaden its scope by sharing its news. It is more effective because not all the users follow the account of those news agencies.

### 3.7. Others

In Twitter, there are many support groups for sharing information related to HIV/AIDS diseases. Those are the non-organizational governments, academicians, schools, even

non-profit organizations. They play important roles in handling HIV/IDS issues, like sharing the test schedules, conducting HIV tests, giving personal counseling to the sufferers, and making event to support them. The number of these parties are greatly increased. The posts also reach 113 tweets in five months. It indicates that those parties have high motivation to handle the issues of HIV/AIDS.

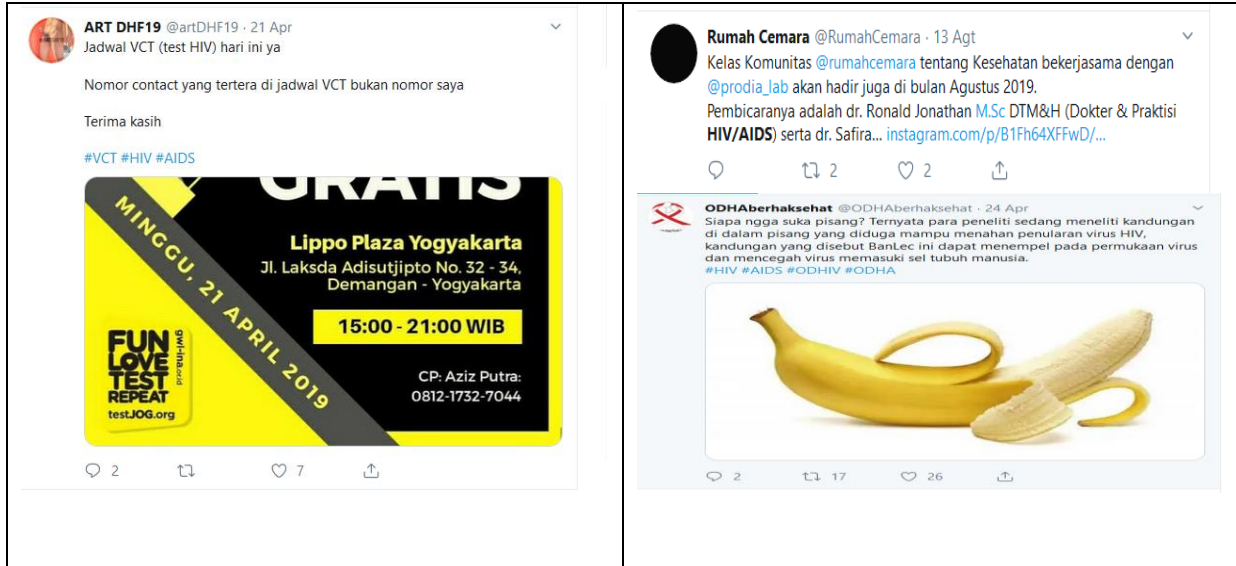


Figure 10 Support Group for HIV/AIDS sufferers

The left picture is support group in Yogyakarta. They issue a schedule for HIV test or VCT test complete with the date and the place. It is beneficial for common people who want to check their health related to HIV/AIDS prevention. On the top right side, RumahCemara as non-profit HIV/AIDS support on Twitter issues the seminar related to HIV/AIDS collaborated with Prodia Lab. While the bottom right side is also support group for HIV/AIDS in Indonesia. This support group is actively posting many tweets on Twitter, including the tips for ODHA, the news, the events, and other information of HIV/AIDS.

**HIV/AIDS Issues on Facebook**

Unlike Twitter, Facebook is more silent in sharing information related to HIV/AIDS. The researchers count that there are only four posts along 5 months period. It includes 4 posts from news sharing. Here are the examples:

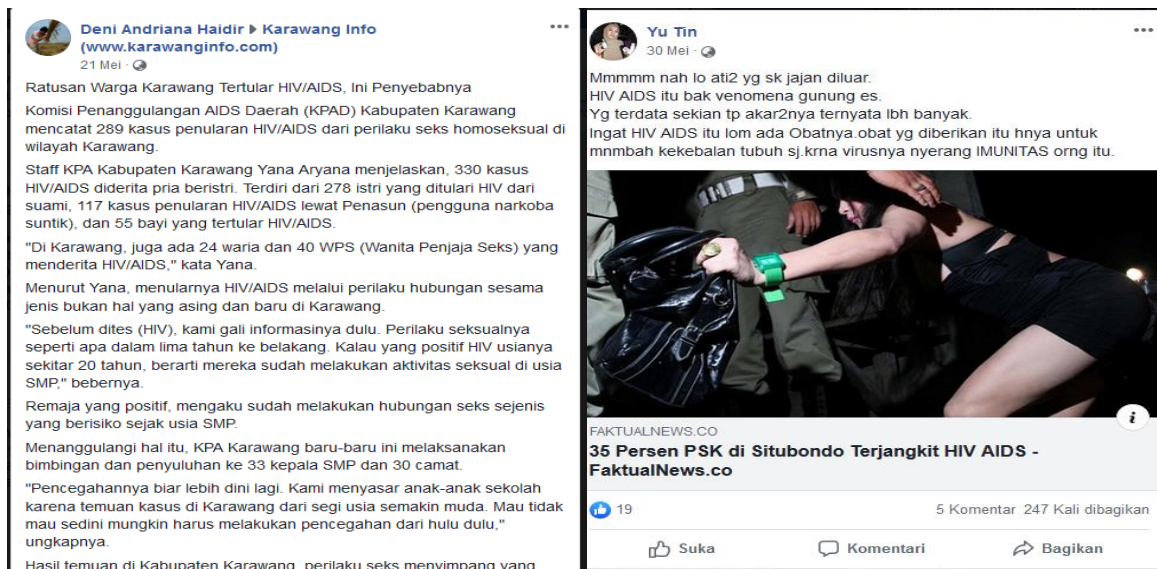


Figure 11 Facebook News Sharing of HIV/AIDS

Except these four posts mentioned in the data, there are no other posts that raise the issue of HIV/AIDS. This shows that the issue of HIV/AIDS is still limited to be discussed by Facebook users, unlike political or election issues that get more attention from Facebook users. This phenomenon

also shows that the issue of HIV/AIDS has not been effectively informed through social media Facebook.

However, there is a community group concerned to HIV/AIDS on Facebook with 8,727 members. As written

on group description, this group is for all people who care about HIV/AIDS. The group aims to be a place for mutual support, a place to share experiences, knowledge and developments related to HIV/AIDS. This group is also a place to share all activities related to HIV/AIDS in Indonesia.

This group cannot be analyzed further because it is a closed group. Member registration is needed to access all the activities and issues discussed inside the group. This closed group indicates that not all social media users can read directly the issues discussed by group members. The admin locked the group in order to focus the information for limited group member.

The closed group makes it less effective to share information for all people related to HIV/AIDS, both for

the sufferers and to other parties who have knowledge of HIV/AIDS issues. The common users and non-member social media users cannot access the information. However, it needs to create an open group of HIV/AIDS support and care that can be accessed freely by many people.

The results are actually beyond the expectations. As mentioned above, Facebook is the biggest social media in Indonesia with huge members. Twitter is in third place below Instagram. But Twitter seems positively take action in sharing information of HIV/AIDS. It is not only the faults why Twitter is more popular than Facebook in sharing information. It leads its features. Based on Social Media report 2019, here are the differences of posts between Twitter and Facebook:

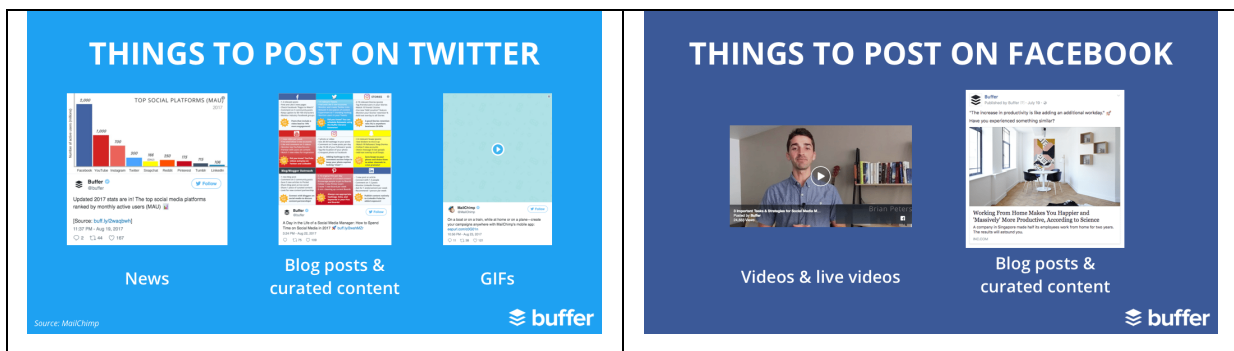


Figure 12 Social Media Features between Twitter and Facebook

From this picture, it is clear that Twitter is easy to share news and information. Hash-tag features on twitter also play. It makes the people can see what the popular items discussed worldwide. In Facebook, the people need to register and create profiles to catch the information. Besides, they have to be listed as friends. The main feature of Facebook is giving people to stay connected with friends, relatives and family. It is more exclusive and the account holder can limit with whom they will share the information.

Unlike Facebook, Twitter is “wider” in the sense of viewers. The users can interact with other through message called tweets which as limited to 140 characters only. The registered users can post tweets and those who are unregistered can just read the posts. The main feature of twitter is giving the information worldwide without any barriers. On Facebook, our posts will only be viewed to people as listed as our friends. But twitter can reach wider. Therefore, Twitter is much more effective in sharing information.

#### 4. CONCLUSION

After analyzing the data, there are five classification of social media posts related to HIV/AIDS issues: On Twitter, they are: government posts (59 posts), news agencies (220 posts), netizen posts (347 posts), netizen share news (81 posts), and others (113 posts). On Facebook, they are: government posts (0 post), news agencies (0 post), netizen posts (0 post), netizen share news (4 post), and others (0

post). From this result, Twitter is more effective to share information related to HIV/AIDS. Seeing from the result, Twitter users seem more active than Facebook users in sharing information related to HIV/AIDS issues.

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