

## Post-Traumatic Growth in Families with HIV/AIDS

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### Abstract

HIV is one of chronic diseases which can cause the emergence of traumatic event towards its sufferers. The traumatic event which can be faced strongly will lead individuals to positive change which is called as growth after trauma. The purpose of this research is to know the growth description after trauma on individuals with PLWHA status. This research used descriptive-qualitative method and data collection was done through semi-structured interview technique. The results obtained from the research is that there is positive change on both subjects which indicates the existence of post traumatic growth with PLWHA status. That change covers the improvement in term of individual's power, the correlation with other people, the rewards towards life, the identification of new possibility, and spiritual change.

**Keywords:** post traumatic growth, HIV/AIDS, PLWHA

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## *Post-Traumatic Growth pada Keluarga dengan HIV/AIDS*

### Abstrak

HIV merupakan salah satu penyakit kronis yang dapat menyebabkan timbulnya kejadian traumatis terhadap penderitanya. Peristiwa traumatik yang dapat dihadapi dengan kuat akan membawa individu pada perubahan positif yang disebut sebagai growth after trauma. Tujuan penelitian ini adalah untuk mengetahui gambaran pertumbuhan pasca trauma pada individu dengan status ODHA. Penelitian ini menggunakan metode deskriptif-kualitatif dan pengumpulan data dilakukan melalui teknik wawancara semi terstruktur. Hasil yang diperoleh dari penelitian adalah terdapat perubahan positif pada kedua subjek yang menunjukkan adanya post traumatic growth dengan status ODHA. Perubahan tersebut meliputi peningkatan dalam hal kekuatan individu, korelasi dengan orang lain, penghargaan terhadap kehidupan, identifikasi kemungkinan baru, dan perubahan spiritual.

**Kata Kunci:** post traumatic growth, HIV/AIDS, ODHA

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## Introduction

Health is a very important thing because it is related to the ability of survival and activities World Health Organization (WHO) (1947; Notosoedirdjo & Latipun, 2017) defined health as a state of prosperity, complete both in physical, mental and social well-being which merely limited by the absence of disease and weakness. It means that health must be seen in a state which is close to optimal physical, mental and social conditions (Notosoedirdjo & Latipun, 2017). However, not everyone has the optimal degree of health because of the various causes such as *Human Immunodeficiency Virus* (HIV). HIV is a virus that weakens immunity and defences the body against infection or cancer. If not immediately get HIV treatment will lead to become *Acquired Immunodeficiency Syndrome* (AIDS) that can develop for 2 – 15 years in individuals. AIDS is a condition where certain diseases or infections have evolved in a person's body due to weak immunity (WHO, 2019).

Based on data from WHO (*World Health Organization*) in 2018, there are about 37.9 million people have HIV/AIDS (PLWHA) with the number of deaths of 770,000 and about 1.7 million new infections (WHO, 2019). Indonesia places the third place with PLWHA and new infections in the Asia Pacific region. The cumulative amount of HIV infection until June 2018 amounted to 640,443 people with a majority age of 25 – 49 years. East Java occupies the second position with a total of 43,399 inhabitants of PLWHA (Kementrian Kesehatan Republik Indonesia, 2018). The invention of the case in Tulungagung from 2006 until March 2019 amounted to 2372 cases where 1604 PLWHA was at the age range of 25 – 40 years.

Infected by HIV is a traumatic and stressful experience which can cause negative effects on status of mental health (Brandt,

2009; Niu, et al., 2016). Psychological effects that may occur in individuals with HIV include depression, anxiety, PTSD and sleep disorders (Nadelcovych, et al., 2017; Jayarajan & Prabha, 2010). In addition, PLWHA must also face the social problems caused by their illness such as getting stigma and discrimination from the surrounding community (Dahlu, et al., 2015). Stigma and discrimination given to PLWHA reduces health-seeking behavior which is a barrier for PLWHA from getting treatment due to the fear of accepting their status as PLWHA (Kane, et al., 2019; Kiene, et al., 2017). Understanding others about HIV / AIDS also influences. Lack of other people's understanding of HIV/AIDS is causing PLWHA to be excluded from its environment. The situation brought significant adverse impacts for PLWHA, namely trauma, avoidance, no confidence, and so on (GWL, 2013).

Life-threatening illness or events can cause a person to become traumatized. This traumatic event causes a strong emotional response that provides negative consequences or positive consequences (Wei, dkk., 2017). The negative consequences of traumatic events are called *Post Traumatic Stress Disorders* (PTSD). The symptoms of someone who is experiencing PTSD is experiencing back or memory about traumatic events (flashbacks), avoiding things that remind them of traumatic, have more negative thoughts and feelings, continuously (National Center for PTSD, 2019). The positive consequences of traumatic events is called *Post Traumatic Growth* (PTG). The characteristics of a person who is experiencing PTG is increasing relations with others, enhancing the strength of the problem, identifying new possibilities, spiritual change in the positive direction, and increased

appreciation of life (Tedeschi & Calhoun, 2004<sup>b</sup>).

Post traumatic growth helps PLWHA to cope the symptoms of anxiety and depression. PTG is a positive emotional change that occurs after a traumatic event. PTG can also be experienced especially by PLWHA (Willie, et al., 2016). This is illustrated by the results of research showing that 59% of PLWHA experience PTG (Milam, 2004; in Willie, et al., 2016). Over the last few decades, many studies have focused on PTSD. However, research on PTG is still limited. Therefore, in this research researchers will discuss about PTG or post-traumatic growth in families with HIV/AIDS.

### **Post Traumatic Growth**

Post Traumatic Growth is a process experienced by individuals who cause positive changes to higher levels of adaptability and psychological function after individuals experience traumatic events (Tedeschi & Calhoun, 2004<sup>a</sup>).

Such traumatic experiences lead to a life crisis in individuals. Joseph et al., Ai et al., (In Hefferon & Boniwell, 2011) explains that post-traumatic growth can be experienced by individuals experiencing negative events that potentially caused high levels of distress such as, military warfare, bombing, loss of *significant others*, catastrophic diseases, natural disasters, drug dependence, HIV and so on.

Post-traumatic growth has five aspects, namely: 1) personal power, 2) the level of relationship with others. 3) increased in appreciation for life, 4) identification of new possibilities, as well as 5) positive spiritual changes (Tedeschi & Calhoun, 1996). First, personal power is a perceived change in individuals who have experienced trauma, individuals feel stronger, confident, open, empathy, creative, mature and have a

sense of humanity. Secondly, relationships with others, i.e. individuals have closer relationships with families, close friendships, improved relationships with known people like neighbors, are able to initiate good relationships. Thirdly, appreciation for life, i.e. increased existential consciousness, has a change in the Filsafah of life, began to ponder the issue of a deeper such as life goals. Fourth, identify new possibilities, namely the desire to change and improve the purpose of life, such as finding information to learn new things, and get a job or new skills. Fifth, positive spiritual change, that is, increased confidence in God, grateful, and actively participate in religious activities.

### **Methods**

#### ***Subjects***

The subject of research was married couple in the status of PLWHA. The first subject of the initial J was 73 years old with a male gender diagnosed with HIV in 2017. Subject of second initials DS aged 42 years old with female gender diagnosed with HIV in 2017.

#### ***Research Design***

This research used qualitative descriptive methods. According to Sugiyono (2008) Qualitative descriptive research is a method of research based on the philosophy of *post positivism* used in objective conditions. The use of this approach is to describe a variable that relates to a researched issue without noticing the relationship between variables. Qualitative descriptive methods of this study were used to get an overview and information about *post traumatic growth* on PLWHA.

#### ***Data Collection Method***

The data collection techniques used in this study were interviews. An interview is a method of data collection done by asking a number of questions to obtain in-depth information about a phenomenon (Hanurawan, 2012). This type of interview in

the study is a semi-structured interview that provides a broad opportunity for researchers to understand the subject. Semi-structured interviews selected due to more flexibility and natural *settings* (Herdiansyah, 2015).

## Result

### *Personal Strength*

The characteristics of individuals who experience increased post-traumatic personal power are feeling stronger, confident, open, empathy, creative, more alive, mature, and there is an increase in the sense of humanity, as well as humility. Based on the results of interviews that have been conducted by researchers, there can be known increased personal power. It is derived from the following interview results.

“ I used to drop so skinny, weighted only 28 kg, but thanks God now it's 49 kg.” (DS, 16-08-2019)

“Yes now it is often sick. If it used to be a little sick, but if until now never hurt at all because I drink ARV regularly.”(DS, 16-08-2019)

The subject statement above shows that there is an increase in the personal power of DS, DS feel stronger physically. Weight loss DS has experienced a increase of 21 kg from the previous 28 kg to 49 kg. In addition, the increase in personal power in DS is also depicted from the physical strength of her who is currently rarely sick.

DS also experienced an increase in its confidence with her status as PLWHA. DS is no longer considering what others are saying that insulted even DS will rebuke others who give the stigma of discrimination to her and her family directly. It is as revealed the following DS subject.

“If now I did this, if anyone says how does it feels?... People do not want to frankly me this way... But out there a lot of people who talking bad thing about me but I do not care anymore” (DS,16-08-2019)

“Unless there is a person immediately told me like this later I will be reprimanded. Like yesterday in the school where my son, it was someone who said if my son was contagious then his friends do not want to close him, I got to say to Ms. KPA and Mr. Doctor then they were given knowledge”. (DS, 16-08-2019)

Based on the explanation above, it can be noted that DS has increased personal power which is one of the important aspects in post-traumatic growth. In addition to DS, researchers also conducted interviews on the following J subjects.

“But I am confident and sincere anyway I can work hard and strong like a cane cutting, hoeing, I am just fine”. (J, 16-08-2019)

Statement J above shows that J has confidence in him that he is able to work hard and have the power to do a job after the status of PLWHA. In addition, J has also been able to cultivate an attitude of self-esteem after the status of PLWHA. J already does not care about the negative assumption and also the treatment given by others to himself with his status as PLWHA. This is after the expressed following J.

“Even if I was called haram, exiled, or someone told me I was cursed, it was up to the important thing I believe in myself”. (J, 16-08-2019)

“I am okay with what they say, I just ignore”. (J, 16-08-2019)

Additionally, J also has an increase in the strength of courage to be open in relation to the status of the PLWHA. Not shy and afraid to appear publicly as an individual with PLWHA because J has the belief that there are thousands of people who are the same as himself. This is in accordance with the following J presented.

“Yes I dare to open, even though people know yesterday I shot then I was shocked. That time I received the symbolic livestock from KPA. I don't fear Ms. KPA even though I entered the TV, which is important I'm healthy that's all”. (J, 16-08-2019)

“Active, the most active is me. Sometimes later with Ms. the KPA were invited to the campus because I am easy person”. (J, 16-08-2019)

“... I am not ashamed and afraid. According to my it is just usual thing just because thousands of people like me it's also a lot”. (J, 16-08-2019)

J also has increased the power of the self in the form of improved sense of humanity with a sense of concern to fellow sufferers people living with HIV. An increased sense of humanity in the form of a sense of caring shown J with the help of his cousin who also sufferers people living with hiv when other people around or the neighbors do not put my attention to the corpse of her cousin is. This is in accordance with the results of the interview J here.

“There are my cousin which is 10 km from here, he was very discriminated against, he be alone to cry because no

one cares, but I still care. Six months ago he died, no one village that matter, only I matter as I am sorry also at a glance I can't bear I think I like it how my fate so until his skin peeled off”. (J, 16-08-2019)

### ***Relations with Other People***

Individuals who have an increased relationship with other people post-trauma tend to have a closer relationship with the family, a relationship that is getting better with people who have known as neighbors, are able to initiate good relations and close friendships.

Based on the results of interviews with both subjects related to the relationship with other people after the status of PLWHA, it is known that there is increased closeness with the nucleus family and large family. The increase of closeness with extended family is described from the *support* given by the family to himself, his wife and also his son from who did not accept to be able to receive them after the status of PLWHA. Even the J family advises J to always take medication regularly. It is in accordance with the disclosed of DS and J following this.

“If the family is fine, can already receive the same I everything well”. (DS, 16-08-2019)

“I've been grateful siblings already know and are given support and help each other”. (J, 16-08-2019)

“... but my family already know all and instead give support to me to regularly take medication”. (J, 16-08-2019)

Aside from the family, there is also an increase in relations with others, namely neighbors who are in the DS environment.

Neighbors of DS who originally did the stigma of discrimination against them are now starting to receive DS that are status of PLWHA. They are already willing to receive drinks and food provided by J and DS. It is appropriate that said by DS as follows.

“There was a chance to eat here from KPA to eat here. Everybody does not want to, I give drink they do not want to. Although my brother used to be like that too, was not willing to drink. But now he's willing to drink”. (DS, 16-08-2019)

DS is also grateful because he feels that he has more friends post-status PLWHA. This is depicted in the following DS interview results.

“Thanks God now I am healthy, compared to the first point a lot of changes, better and more friends also now”. (DS, 16-08-2019)

In addition to DS, J also have an increase in relationships with other people after people living with hiv. Sometimes J are invited to the campus to do outreach about HIV/AIDS with the KPA. J is also active in meeting and gathering the KPA. This is in accordance with the statement J here.

“ Active, the most active is me. Sometimes later with Ms. KPA were invited to the campus because I am easy person”. (J, 16-08-2019)

### ***Appreciation of Life***

Individuals with an increased appreciation for life will increase awareness of the existential, changes in philosophy of life, began to ponder the issue more in-depth like, the purpose of life and understand what is important in life.

Here are the results of the interview to the second subject related to appreciation of life.

“The doctor was talking like this ‘this disease has no cure’. I had trauma as well because this disease has no cure. I'm also not sure that time, then that is important to drink the drug continues to be healthy”. (J, 16-08-2019)

“If I was always on medication, I'm not kidding about the issue of drugs so my immune awake”. (J, 16-08-2019)

Based on the interview results above, it can be seen from the appearance of self-confidence in J if it is important to do by himself after status of people living with hiv is a discipline in taking medicines to keep his health. The discipline applied by J is always consume drugs in the right time.

“There's good and there's hard because I think all that I have learnt the lesson, Javanese said, birds fly everywhere there is a food, no jobs here I run to go find a job, though my boss if I can work I sought-after told to work”. (J, 16-08-2019)

In addition, increased appreciation for life in J is also portrayed through changes in philosophy of life. A view that there is always wisdom in every incident that occurs in life. In addition, J has the belief that there is always a way to get a job for him.

### ***Identify New Possibilities***

Individuals with an increase in the identification of new possibilities will have a desire to modify life objectives, such as searching for information, learning new things, and getting new jobs or skills. The following are the results of a researcher

interview to two subjects relating to identifying new possibilities

“Participate in the training there for 6 months in a Rehabilitation Center HIV for sharing, given the insight, knowledge, and skills of sewing, computer and printing the year 2018 delivered by KPA”. (DS, 16-08-2019)

“Then I was sent the KPA to follow the training in the Rehabilitation Center Sukabumi for 6 months. I was given the knowledge about HIV/AIDS, money, and about the work”. (J, 16-08-2019)

Based on the interview quote above can be seen that DS and J learn new skills such as sewing, computer and printing through training for 6 months in a Rehabilitation Center of HIV. In addition, DS and J also gain new knowledge about HIV/AIDS itself. In addition to through training in the Rehabilitation Center of HIV/AIDS, DS also gain knowledge about HIV/AIDS itself of the results of information sharing when he joined in KDS. DS also increase insights about the disease through books taken in the hospital.

“Yes I join the KDS then sharing, and then I take a book in the hospital and then I read and then understand”. (DS, 16-08-2019)

In addition, a new increase in self-identification is described through the existence of J's desire to increase the insight he has on the way of transmission of HIV/AIDS so that he does not transmit the disease that he suffered to others. This is a matter of life, one of the purposes for which he has post-status PLWHA is to promise not to transmit the disease that he suffered to

others. This is in accordance with the following J statement.

“I have also promised myself to not to transmit this disease to others”. (J, 16-08-2019)

“My goal so these things including the usual thing, we who live we who bear the risks as this is also a bold promise and swear just did not want to pass then we need to know how it is transmitted”. (J, 16-08-2019)

The new increase in self-identification in J can also be seen from the following interview results.

“Javanese said, flying birds everywhere will find food, there is no job here I run there to find work, but my boss if I do not work he find me then told to work”. (J, 16-08-2019)

Based on the interview above, J has a belief that he is able to find and get a job even though in his village no one wants to accept it as a worker. However J does not despair and continues to seek new job opportunities outside his village.

### *Spiritual Changes*

The individual characteristics with positive spiritual changes after traumatic particular is the increased belief in God and the abundance. Based on the results of the interview the subject underwent a spiritual change after traumatic events as one aspect of post-trauma growth.

“This change now I am closer to God”. (J, 16-08-2019)

“If our age is not the define by us, he is now closer to God”. (J, 16-08-2019)

Based on the citation, it is known that the post-status of PLWHA, J is closer to Almighty God. The reason for the underlying spiritual change is the J's belief that human age problems no one knows.

### **Discussion**

A person's status as PLWHA (People with HIV / AIDS) will have an impact on their lives. HIV or AIDS can have an impact on a person's psychological situation such as depression, conflict, difficulties, helplessness, and feeling guilty. However, there is evidence that has been developed that shows positive changes that have arisen in PLWHA (Tedeschi & Calhoun, 2006). This positive change is referred to as post traumatic growth which will affect one's adaptation. Post-traumatic growth is an individual positive psychology experience in adapting to traumatic events. The traumatic events experienced by subject J and DS are diagnosed with HIV/AIDS. In the early diagnosis of HIV/AIDS, both subjects experienced stress and pressure caused by the disease itself and the stigma given by the community. Both subjects are not desperate and continue to make efforts to adapt to their new status as PLWHA.

Based on the analysis results The interview was known that both subjects fulfilled all four aspects of post-traumatic growth. This can be seen from an increase in personal power demonstrated by the physical health of both subjects that are improving, the emergence of confidence in both subjects post-status PLWHA, the belief in the subject that he was able to work, open his the status of PLWHA, as well as increasing sense of humanity.

The second aspect that appears on both subjects is the increased relationship with others. This is reflected by increasing closeness to the family and neighbors as well

as the two subjects that have more post-status friends of PLWHA. The increase in appreciating life is the third aspect that appears on both subjects. This is evident from the establishment of choosing what is important to do and the change in living philosophy. Research conducted by Mo, et al. (2013) explained that social support has a significant positive relationship with post traumatic growth, and can improve mental health.

The third aspect that found in both subjects is appreciation of life. This aspect is shown by the appearance of confidence and the change in philosophy in the subject. The subject is confident and tries to get a job with the status of PLWHA that they have. In addition, the subject assumed that in every event there must be a lesson that can be learned.

The fourth aspect that appears on both subjects is an increase in identifying new possibilities. This is demonstrated by the willingness of the subject to gain new skills, increasing insight, and never give up looking for new job opportunities. Positive spiritual changes also exist in the subject reflected in the increased closeness of the subject to God. Positive spiritual change is the fifth aspect of post-traumatic growth.

Based on this it can be noted that J and DS subjects experience post-traumatic organization after traumatic events. The findings are also supported by similar research results. Research conducted by Wan Shen-min and Lu Hong-Zhou (2019) showed that post-traumatic growth was also found in PLWHA as much as 59%-83%. Rzeszutek (2018) conducted a study that showed similar results that post-traumatic growth in PLWHA had a positive influence over time. In addition, the study of Amos (2015) resulted in findings suggesting that post-traumatic growth indeed existed among individuals living with HIV.

PLWHA who experience post traumatic growth have psychological conditions and good social relations such as optimism, resilience, coping, self efficacy, and social support (Rzeszutek & Gruszczyńska, 2018). Post traumatic growth helps minimize the negative effects due to HIV (depression, drug use, and PTSD symptoms). This statement is in line with the condition of the two subjects of this study, which is they have a belief that they can live healthy and can have good social relations so that they can adjust to their current situation. The researcher realizes that there are still limitations and deficiencies in this study. These limitations are mainly related to the number of interviewees, data, and time during the study. Resource persons in this study are limited because it involves only two subjects. In addition, the time spent during the study was still limited and the data used was not sufficiently explored in depth especially related to the post traumatic growth process in PLWHA.

### Conclusion

Based on the results of interviews on post-traumatic growth in PLWHA shows positive changes in both subjects. Subjects J and DS show indicators of the five aspects of post-traumatic growth, i.e. personal power, increased relations with others, identification of new possibilities, positive spiritual changes, and an increase in life awards. It indicates that the J and DS subjects experienced post traumatic growth post-status of PLWHA.

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