

The Meaning of Life of People with HIV: a Phenomenological Study

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Abstract. People Living with HIV (PLHIV) have complex challenges in terms of health, social, psychological, and spiritual aspects. Therefore, the meaning of life becomes one of the critical aspects in helping PLHIV to confront every challenge from various aspects of life, so that the author becomes interested in researching the description of the meaning of life in people with HIV. This study aims to determine the meaning of life among PLHIV in Kupang City. The research method employed a qualitative method with a phenomenological approach. The sampling technique used in this study employed a purposive sampling method, involving a total of 3 participants. The data collection technique in this study involved semi-structured interviews, utilizing Descriptive Phenomenological Analysis techniques. The results showed that all participants in this study could find meaning in their lives, as seen from aspects such as self-understanding, the meaning of life, changing attitudes, self-bonding, directed activities, and social support.

Keywords: HIV, Life Meaning, People Living with HIV (PLHIV)

Abstrak. Orang yang hidup dengan HIV (ODHIV), mempunyai tantangan yang cukup kompleks baik dari segi kesehatan, sosial, psikologis, dan spiritual. Untuk itu, kebermaknaan hidup menjadi salah satu aspek penting dalam membantu ODHIV untuk menghadapi setiap tantangan dari berbagai segi kehidupan sehingga penulis menjadi tertarik untuk meneliti tentang gambaran makna hidup pada orang dengan HIV. Penelitian ini bertujuan untuk mengetahui makna hidup pada ODHIV di Kota Kupang. Metode penelitian yang digunakan yaitu metode kualitatif dengan pendekatan fenomenologi. Teknik pengambilan sampel dalam penelitian ini menggunakan metode *purposive sampling* dengan jumlah 3 partisipan. Teknik pengambilan data dalam penelitian ini yaitu wawancara semi-terstruktur dengan teknik analisis data fenomenologi deskriptif analisis. Hasil penelitian menunjukkan bahwa seluruh partisipan dalam penelitian ini dapat menemukan makna hidupnya dilihat dari aspek kebermaknaan hidup seperti pemahaman diri, makna hidup, perubahan sikap, keikatan diri, kegiatan terarah, dan dukungan sosial.

Kata kunci: HIV, Makna Hidup, Orang dengan HIV (ODHIV)

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Introduction

People living with HIV (PLHIV) have complex health, social, psychological, and spiritual challenges. Individuals who receive an HIV diagnosis can present many challenges, such as stress and emotional disturbances, because they feel burdened and not as expected as before (Rizal M, 2024). The burden of problems and unfavorable treatment from the social environment, such as stigma and discrimination against people living with HIV, can trigger them to tend to isolate themselves, blame themselves, and have difficulty in building relationships with others (Rizal M, 2024).

The various challenges certainly cause deep sadness for those who feel it. During these times, support and attention from those closest to them, such as family, friends, or partners are needed. When they are in such a situation, the support from their surroundings can provide a source of coping or a source of support for each individual, such as increasing self-confidence in order to deal with the trials they experience, as well as increasing hope and meaning in life (Tanjung, 2016). That is why the meaning of life is one of the essential aspects in helping PLHIV cope with various life challenges. Based on this, the author is interested in examining the description of the meaning of life in people living with HIV by looking at the various aspects that reinforce people living with HIV to survive.

Bastaman (2007) stated that the meaning of life is something that is considered very important and valuable and provides special value for a person, so it is worthy of being the purpose of life. The definition above is in accordance with that put forward by Wahyudi (2017), which says that the meaning of life is something that is unique in humans and is considered necessary, valuable, and worthy of being the purpose of human life, both in a pleasant and a sad situation.

Based on the above definition, it can be concluded that the meaning of life is a crucial aspect for individuals to use as a life goal, one that is derived from both positive and negative experiences. In the presence of the meaning of life, individuals can live their lives by the values or goals that have been set. It makes individuals feel worthy, considered important, valuable, and productive in doing things every day, both in difficult and pleasant conditions.

Bastaman (2007) explains that there are six aspects of meaningfulness in life, including self-insight, the meaning of life, changing attitudes, self-commitment, directed activities, and social support, self-awareness enables individuals to recognize their situation and strive to improve it for the better. The meaning of life, acquired from experience, serves as a goal that must be achieved. Attitude change enables individuals to shift from negative to positive attitudes, while self-attachment demonstrates a commitment to the meaning and purpose of life that has been discovered. Directed activity is an attempt made consciously by individuals to develop the potential or talents they possess. Lastly, social support from the closest people is an important factor in helping individuals cope with life's challenges. These six aspects interact with each other and contribute to the exploration and achievement of a person's meaningful life.

HIV (Human Immunodeficiency Virus) is a virus that compromises the human immune system by attacking and destroying CD4 cells, a crucial component of the body's defense mechanisms. WHO (2021) mentions several ways of HIV transmission, including HIV can be transmitted through the exchange of various fluids by infected individuals, such as blood, breast milk, semen, and vaginal fluids. In addition, HIV can also be transmitted from mother to child during pregnancy or childbirth. HIV infection has a significant impact on individuals from various aspects, including physical, psychological, and socioeconomic. Physically, PLHIV experiences a reduced immune system that makes them susceptible to various diseases, as well as early symptoms such as fever and rashes. Psychologically, HIV diagnosis often leads to severe emotional distress, with feelings of fear, guilt, and

depression due to the stigma and discrimination they receive. The socioeconomic impact is also evident, with PLHIV tending to withdraw from society and having difficulty finding employment, especially once their status is known (Sidi et al., 2023).

The meaning of life for people living with HIV (PLHIV) is certainly different from the meaning of life for people in general. This is because in their daily lives, they are required to be able to deal with quite complex problems due to the disease they suffer from. Problems encountered include physical health, psychological conditions, independence, social relationships, and the surrounding environment. This study will find out the meaning of life of people living with HIV by looking at aspects of the meaning of life according to Bastaman (2007). There are six aspects of the meaning of life that form the basis of this research: self-insight, the meaning of life, changing attitude, self-commitment, directed activities, and social support.

Method

The research method used in this study is qualitative. This research employs a descriptive phenomenological approach, in which the author aims to describe how participants give meaning to their experiences (Kahija, 2017). The selection of informants in this study was carried out using a purposive sampling method, which involves selecting samples based on specific criteria relevant to the research objectives. Informants in this study were people living with HIV and joined the *Jaringan Indonesia Positif* with the characteristics of 3 participants, consisting of 2 men and 1 woman, and were members of the *Jaringan Indonesia Positif NTT*.

The data collection technique used in this research is the interview technique. The interview structure used is a semi-structured interview, in which the researcher is given free rein to ask questions and has the freedom to set the flow and setting of the interview. The analysis technique used in this research is qualitative descriptive analysis. Through descriptive analysis, the author describes what has been obtained about the meaning of life of people with HIV in Kupang City.

According to Miles and Huberman (1984), activities in qualitative data analysis are carried out interactively and occur continuously until completion, encompassing data reduction, data presentation, and drawing conclusion.

Results

Data were collected from interviews and analyzed using a descriptive approach. Through descriptive analysis, the author describes what has been obtained about the meaning of life of people living with HIV in Kupang City. There are six aspects of the meaning of life that form the basis of this research: self-insight, the meaning of life, changing attitudes, self-commitment, directed activities, and social support. From these four indicators, it is evident that individuals possess good self-understanding, as evidenced by their awareness of their body condition, the process of self-acceptance, the existence of life goals, and the realization of their potential.

Table 1.

Participant Characteristics

Participant Initials	Age	Gender	Address
JM	32	Male	Oesapa
DR	25	Male	Fatului
ES	29	Female	Namosain

The interview results showed that all participants had a good awareness of their body condition because they received complete information about HIV, underwent routine treatment, and felt that they were used to HIV in their body. In addition to seeing good self-understanding, it is also necessary to know the process of individual self-acceptance after being diagnosed with HIV. Of course, when knowing the results of the diagnosis, there is rejection from the individual in accepting the fact that the individual is diagnosed with HIV. However, with the support of family, friends, community, and individuals themselves, they can help

others in self-acceptance. A good self-understanding can help individuals get direction for their life goals.

In this study, each individual already has a life goal, and the life goals of the participants include helping others, promoting self-acceptance, advocating for change to the government and society, being a better family member and friend, being productive, and staying healthy to take care of their family. To achieve these life goals, of course, requires the potential that the individual possesses. In this case, the potential possessed by individuals to achieve life goals includes having empathy, a good attitude, having good academic potential, having relationships with important people in several fields, being hardworking, and not depending on others.

Discussion

According to Marie Antoinette, people who have a good understanding of themselves are those who have a clear purpose in life, the right direction, a sense of responsibility, and a reason to live. They also have a strong self-identity and high social awareness (Kurniasih, Fitriyah, Hidayat, & Sunanto, 2020). This aligns with the author's findings that participants have a positive self-understanding, as evidenced by their awareness of a good body condition, a sense of purpose in life, the ability to accept themselves, and a sense of potential.

These findings are also in line with research conducted by Virgiani (2019) on the self-concept of people with positive HIV, where respondents have accepted what happened to them, are ready to face life in the future, and consider that life is a process of finding the meaning of life. Thus, in the aspect of self-understanding, the author concludes that individuals with HIV have good self-understanding, seen from awareness of their body condition, self-acceptance, life goals, and potential. Support from family, friends, and the community helps them in the process of self-acceptance after diagnosis. Individuals also have clear life goals, such as helping others, advocacy, and improving their family life.

The following aspect is the meaning of life, which encompasses four key indicators: the value of life, positive experiences, negative experiences, and the process of finding meaning in life. In this study, individuals found value in their lives after being diagnosed. The value of life, as discovered by the author through interviews with individuals, is a personal value that enables individuals to know themselves better, make peace with their past, accept reality, remain cheerful, and cultivate greater discipline. In addition, the author also identifies social values that emerge in individuals after diagnosis, including greater respect for others, becoming a more collectivist individual, being helpful to oneself and others, avoiding becoming a societal outcast, and helping friends in need.

The meaning of life can be gained through both positive and negative experiences that individuals encounter after diagnosis. The positive experiences found by the individuals themselves are positive feelings where individuals are still given life and health until now. In addition, there are also experiences of achievement, where individuals get jobs, job offers, become delegates out of town and abroad, and get counseling. While the negative experiences felt by individuals are shunned by all campus friends because of HIV diagnosis, rejected at a workplace because of their health status, difficulty in taking ARVs, and even being left by their own partners. With these experiences, individuals experience the process of finding the meaning of their respective lives. The meaning of life found through the experiences experienced by individuals is to focus on the needs of many people, enjoy life, and stay healthy for the family.

The results of this study are in line with the theory of Viktor E. Frankl (1962), who argues that the meaning of life includes everything that is considered valuable, important, and has special value for a person, so that it can be used as a life goal. In addition, Bastaman (2007) said that the meaning of life is also often interpreted as values or life lessons that contain goodness and benefits from various experiences, both happy and challenging (quoted from Widyawan, Fazrin, and Widyastuti, 2021). In this case, individuals can describe the essential values in their lives and the

process of finding meaning in their lives, drawing on both happy and challenging experiences.

The results of this study are also in line with research conducted by Widyawan, Fazrin, and Widyastuti (2021) on the Meaning of Life in HIV/AIDS-infected Commercial Sex Workers in Bandung City, which revealed the results of research with two respondents who could find the meaning of their respective lives where the first subject interpreted his life to establish a household relationship and raise his child while the second subject interpreted his life by being useful to the environment, especially his family. Thus, in the aspect of the meaning of life, the author concludes that the meaning of life for people with HIV is found through various experiences, both positive and negative. After being diagnosed, they begin to understand the value of life, such as knowing themselves, making peace with themselves, accepting the circumstances that have occurred, respecting others, and remaining helpful to others. Good experiences, such as getting a job and new opportunities, as well as bad experiences, like discrimination and rejection, are part of the process of finding the meaning of life. In the end, the meaning of life they find is to focus on the needs of many people, enjoy life, and maintain health for the sake of the family.

The third aspect is attitude change, which is reflected in three indicators: changes in attitude toward problem solving, changes in mindset, and changes in behavior. With these changes, individuals can change things that were previously negative to be more positive, especially in dealing with problems. In this study, 2 out of 3 participants had a change in attitude in dealing with problems, namely individuals felt happy when faced with problems and were calmer in making decisions and maintaining relationships that caused problems for the individual himself. With this change in attitude, individuals also change their mindset and behavior patterns. The changes in mindset felt by the individuals themselves are accepting and making peace with what has happened, thinking more about the future, thinking about the right time to take ARVs, and thinking about the

circumstances and conditions of friends. This study also found that individuals experienced changes in behavior after being diagnosed, including appreciating life more, maintaining a healthy diet, nurturing relationships, and engaging in positive activities.

According to Sarwono (2012), attitude change is a process in which a person changes their views on something due to new information, experience, or social influence. This is in line with what the author found in this study, that there are changes in attitude, changes in mindset, and changes in behavior in people with HIV after being diagnosed. In this regard, the author has not found research that aligns with the researcher's findings.

Thus, the author can conclude that changes in attitudes in individuals with HIV include changes in dealing with problems, mindset, and behavior. Individuals begin to transform negative aspects into more positive ones, such as approaching problems more calmly and maintaining healthy relationships. Their mindset also develops by accepting the situation, focusing more on the future, and paying attention to the health and conditions of others. Additionally, behavioral changes are observed in efforts to maintain a diet, appreciate life, and engage in meaningful activities. This shows that an HIV diagnosis encourages individuals to adapt and live life more positively.

The fourth aspect is self-attachment, the author identified two indicators: life commitment and individual efforts to change views/perceptions of themselves after diagnosis. In this aspect of self-attachment, it is evident that individuals are committed to their lives and strive to change their perceptions of themselves. The individual's commitment to the meaning of life and life goals after being diagnosed with HIV is to maintain themselves to become a better person, set goals every day, maintain an attitude of indifference to negative things, take regular ARVs, and maintain a better lifestyle. In the discovery of the meaning of life, there are also certainly individual efforts in changing views/perceptions about themselves. In this case, the efforts made by individuals in changing their views/perceptions about

themselves are efforts to always think positively, maintain commitment, set goals, compare themselves with others to encourage themselves to be better and participate in positive activities.

The results of this study align with research conducted by Febrianti & Huwae (2023) on both subjects who have a strong commitment to living a better life despite facing difficult conditions and a strong commitment to living life to provide the best for their families. Thus, the author can conclude that self-attachment in individuals with HIV is reflected in their commitment to living life better and changing perceptions of themselves. Individuals try to maintain the meaning of life by maintaining themselves to be a better person, not being affected by the negative views of others, and maintaining a healthy lifestyle, including ARV consumption. In addition, in an effort to change the view of themselves, individuals focus on a positive mindset, set goals, compare themselves with others, and are active in useful activities. This suggests that self-attachment enables individuals to find meaning and a clearer direction in life.

The fifth aspect is directed activities; the author identifies one indicator: efforts in developing self-potential. The efforts made by individuals in developing their potential are realizing good abilities in providing information to others, staying adapted by developing skills, finding the meaning of life through meaningful actions for others, utilizing their potential, learning to control themselves, controlling emotions, and stress to face life's challenges and learning from previous mistakes that have occurred. In this regard, the author has not found any parallel research. Thus, the author can conclude that, in this aspect, directed activities can help individuals develop the potential that exists within them and find meaning in life.

The last aspect is social support; the author identifies two indicators: the main source of support and the influence of social support. The main sources of support in this study include God, self, friends, and one's own family or partner. With the main source of support, of course, it influences social support. The effect of

social support found by the author in this research is that it can develop potential or something in PLHIV, can accept themselves, get motivation, direction, messages, and find principles to take care of themselves, children and help friends.

The results of this study are in line with the results of research conducted by Upe & Kusuma (2024) who said that the forms of social support received by PLHIV (People with HIV) include assistance from counselors, love and spiritual values from family, as well as acceptance and openness from friends, friends, and closest relatives who accept them as they are with all their shortcomings. Thus, the author can conclude that social support for individuals with HIV comes from God, friends, family, and partners. At the same time, the influence of social support on individuals is the development of potential, self-acceptance, and discovery of principles.

Conclusion

People living with HIV can find meaning in life through various aspects, including self-understanding, the meaning of life, attitude change, directed activities, and social support. Good self-understanding enables individuals to accept their condition, find purpose in life, and realize their full potential. The meaning of life is found through both good and bad experiences, which encourage PLHIV to stay focused on the positive aspects. PLHIV also experiences changes in attitude, mindset, and behavior that are more adaptive. Self-commitment is evident in their commitment to live a better life and transforming their self-perception. Additionally, PLHIV develops their potential through directed activities. Social support from family, friends, partners, and the community plays an essential role in helping PLHIV stay motivated and thrive. All these aspects demonstrate that, despite facing challenges, PLHIV can find meaning in life and live it more positively.

Suggestion

Holistic and sustainable support is essential to improve the quality of life of people with HIV (PLHIV). For PLHIV themselves, improving self-understanding and building good social relationships with family, friends, and community can provide invaluable support both physically and mentally. Leaders and workers in NGOs or other institutions are advised to provide empowerment programs that focus on improving the quality of life of PLHIV, as well as conduct education and advocacy to reduce stigma in the community. The community also has a significant role in creating an inclusive and supportive environment, so that PLHIV feel accepted without discrimination. On the other hand, families must provide strong emotional and psychological support so that PLHIV can accept themselves better and live a more positive life. Lastly, for researchers, it is essential to continue to explore the effectiveness of social and psychological support programs and identify factors that contribute to the meaningfulness of the life of PLHIV in various social and cultural contexts. All parties share a responsibility in creating an ecosystem that supports and empowers people with HIV, enabling them to lead better, more meaningful lives and be more accepted in society.

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