



Meaning of Life for Autoimmune Survivors during the Pandemic

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Abstract: The Covid-19 pandemic has changed all aspects of life. This phenomenon has caused changes in various aspects of life. It not only affects physical health but also affects human psychological health. Vaccination development continues to be monitored by the government, but there are some people who cannot receive vaccination, such as those with autoimmune diseases. Autoimmune disease is an immune response that causes damage to the body's own tissue and disrupts the body's physiological functions. The coronavirus virus causes the immune system to start producing antibodies that attack the body's own tissue. On the other hand, the symptoms of the coronavirus that still exist, seen in patients who have recovered, also remain a threat to those who have already suffered from autoimmune diseases. The study participants consisted of two 23-year-old women who had had autoimmune diseases for 11 years and a 25-year-old woman who had had autoimmune diseases for 14 years. Data collection was done through interviews and observations. The results showed that the process of achieving meaning in life through sincerity, gratitude, commitment, religious assessment, and social assessment. In addition, the underlying aspects of achieving meaning in life were views on autoimmune diseases, experiences with autoimmune diseases, social support, stress coping, and religious values.

Keywords: meaning of life, autoimmune survivor, pandemic

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INTRODUCTION

The Covid-19 phenomenon is faced by all countries in the world. Global distribution data shows that there are 500,186,525 confirmed cases and 6,190,349 deaths, with a total of 11,294,502,059 vaccine doses administered (World Health Organization, 2022). Meanwhile, in Indonesia, the latest data as of April 16, 2022, stated that there were 6,050,811 positive cases, 155,863 deaths, 73,847 positive cases

(hospitalized), and 5,821,128 people declared recovered (Satgascovid, 2022). Yogyakarta Special Region, as one of the provinces in Indonesia, is also one of the areas affected by the Covid-19 pandemic, with the latest data showing 220,325 confirmed cases, 5,871 deaths, and 209,976 recoveries.

The government is giving serious attention to addressing the Covid-19 pandemic to reduce its impact. One of the ways is by implementing Large-Scale Social Restrictions (PSBB), Micro-scale

Community Activity Restrictions (PPKM Mikro), and Emergency PPKM (PPKM Darurat) (Ministry of Health, 2022). Additionally, the government is actively providing vaccines. The distribution of first-dose vaccinations has reached 92.8% (193.2 million doses), second-dose vaccinations have reached 72.7% (151.3 million doses), and booster or third-dose vaccinations have reached 7.6%. All of these efforts aim to reduce mobility or movements of the public, which is feared to be one of the causes of the high level of Covid-19 cases (Hartarto, 2022).

The development of vaccination is continuously carried out and monitored by the government, however, there are some people who cannot receive vaccination. One of them is people with autoimmune diseases, a condition where the body attacks its own tissues. The Corona virus causes the immune system to produce antibodies that attack. On the other hand, the remaining symptoms of the Corona virus, seen in patients who have recovered, also remain a threat to those who have autoimmune diseases. (Tükek, 2021). In addition, according to Assar et al. (2022), Covid-19 can disrupt immune tolerance, trigger immune responses, and produce pro-inflammatory cytokines. This is one of the risk factors that results in severity in patients with autoimmune diseases.

Autoimmune disease is an immune response that results in damage to the body's own tissues and disrupts physiological function (Khasanah, 2019). Autoimmune diseases can affect any part of the body with classical autoimmune signs of inflammation (Silvestre et al., 2017). Autoimmune is classified as a disease that has been increasing globally since the end of World War II. The autoimmune pandemic encompasses 80 diseases that have increased in both incidence and prevalence. At least 5,000 people in Indonesia are survivors or sufferers of autoimmune diseases. The exact number is unknown, and the number

of 5,000 is based on recorded survivors (Marisza, 2019).

Based on the results of research conducted by Wahyuni et al. (2016), the tendency of autoimmune diseases to occur is more commonly found in women than men, as is also the case with the results of this study where 75.8% of autoimmune disease patients treated were women, while men were 24.2%. Autoimmune diseases are chronic diseases. Chronic means that this disease will require long-term treatment, even when it reaches remission or a stable immune condition, it can still relapse. The duration and type of treatment will certainly vary even for the same autoimmune disease (Cardoba, 2017).

Being an autoimmune survivor in the midst of a pandemic is not an easy thing, because on the other hand access to medications during the pandemic is sometimes limited or difficult. Thus, treatment for autoimmune patients affected by Covid-19 cannot be optimal if their condition does not allow it. Prolonged Covid-19 will add to the burden for autoimmune survivors (Wahono, 2021). Someone who already has autoimmune disease is certainly not only vulnerable to their physical health but also to their psychological health. The conditions that occur during the pandemic have a significant effect on individuals with autoimmune diseases, as Covid-19 becomes a heavy stressor (Giacalone et al., 2020). This stressor causes autoimmune patients to experience pressure, leading to a decrease in their psychological health, which in turn impacts their physical health, as stress is a state of being under pressure, whether it be physically or psychologically (Ardani, 2007).

The stress condition can affect a person's immune system, especially in people with autoimmune diseases. This is particularly true during the Covid-19 pandemic, where people tend to be overly anxious, leading to the emergence of stress conditions. The low immunity of autoimmune patients due to the use of

immunosuppressants makes this group vulnerable to Covid-19. The inflammatory condition of Covid-19 triggers rapid immune dysregulation. However, to date, there is no exact data on the number or recurrence of autoimmune rheumatic patients related to SARS-CoV-2 infection. (Nurudhin et al., 2021).

The meaning of life is the things that are considered important, valuable, and provide a special value to someone, so they are worthy of being made a goal in life. If the meaning of life is found and fulfilled, it will make life feel meaningful and valuable. The meaning of life is actually present in life itself, and can be found in every situation, whether pleasant or unpleasant, happy or suffering (Frankl, 2003). The meaningfulness of life is a subjective feeling that everything that happens to the subject has a solid and meaningful basis, or in other words, the subject feels that they are right and correct (Erikson, 1995).

The meaning of life is something considered important and valuable that gives special value to an individual, making it worthy to be a goal in life. If the meaning of life is successfully found and fulfilled, it will make life feel meaningful and valuable. The meaning of life actually exists in life itself and can be found in every pleasant and unpleasant situation, happy and suffering conditions (Frankl, 2003). The meaning of life is a subjective feeling that everything that happens to the subject has a solid and meaningful basis, or in other words, the subject feels that they are right and appropriate (Erikson, 1995).

The meaning of life becomes a very important thing to study in order to provide an overview of the problems faced by autoimmune survivors in the midst of the Covid-19 pandemic. Autoimmune disease is a population of patients vulnerable to Covid-19 with a death rate of 14.5%, higher than the general population which has a lower death rate of around 5% (Nurudhin et al., 2021). Status and lifestyle will change when someone becomes an

autoimmune survivor, all movements will be limited when survivors want to do an activity.

Top of Form

Individuals with chronic and incurable diseases such as autoimmune diseases often feel isolated, worthless, unaccepted by their environment, low self-esteem, angry, disappointed, ashamed, emotional, more sensitive, and closed-minded, as well as other negative feelings (Nugraha et al., 2018). Some studies indicate that people tend to agree that meaning is very important in one's life (Gumilar & Uyun, 1996). Low meaning in life also correlates with tendencies towards neuroticism, anxiety, and anomie (O'Connor & Chamberlain, 1996).

It can be interpreted that being an autoimmune survivor will have an impact on life. Changes in lifestyle due to limitations will alter the view of the meaning, purpose, and significance of life. This happens because even before the pandemic, autoimmune survivors had to live with high health concerns, let alone during the pandemic they have to take extra care of their health to avoid contracting Covid-19. As Frankl (2017) stated, the meaning of life can change depending on how events in life are perceived and certain roles that influence them. Thus, being an autoimmune survivor in the midst of a pandemic certainly has different aspects in their meaning of life.

METHOD

The purpose of this research is to explore the experiences and meanings of meaning in life and the impact on autoimmune survivors during the pandemic. Therefore, the researcher believes that this research question can be answered through a qualitative method, which aims to explore and understand a specific phenomenon (Willig, 2008; Creswell, 2015). Qualitative research focuses on accentuating the exploration of individual or group meaning regarding social or human issues (Moustakas, 1994;

Willig, 2008; Creswell, 2015). The qualitative approach used in this study is phenomenology. The sampling type used to determine participants is maximum variation sampling, which involves selecting participants according to specific criteria and then selecting those who differ significantly based on those criteria. Qualitative informant characteristics present diverse perspectives from each individual to illustrate the complexity of the research topic (Herdiansyah, 2010). The criteria for this type of sampling include being a participant currently undergoing autoimmune treatment, experiencing moderate to severe autoimmune symptoms, receiving treatment during the Covid-19 pandemic, and two people will be selected as the research subjects. Observations in this study will focus on accurately observing, recording phenomena that arise, and weighing the relationships between aspects of the phenomenon, specifically autoimmune survivors during the Covid-19 pandemic. In-depth interviews will be conducted to obtain in-depth data. The type of interview used is a semi-structured interview based on a guideline interview. The data analysis in this phenomenological research is interpretive phenomenological analysis (AFI).

RESULT AND DISCUSSION

This research aims to explore the achievement of meaning in life and its underlying aspects among autoimmune survivors in the midst of the pandemic. The results of this study indicate that there are 5 aspects contained in the meaning of life for autoimmune survivors during the Covid-19 pandemic, namely views on autoimmune disease itself, experiences in living as an autoimmune sufferer, social support, stress coping, and belief in religious values. Furthermore, the analysis of the research findings related to the meaning of life and its underlying aspects will be discussed and reviewed based on relevant theories and research.

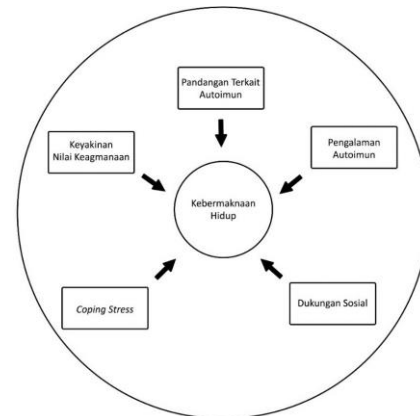


Figure 1. The Underlying Aspects of Achieving Meaning in Life

Achievement of Meaning in Life

This research found that significant life events can lead to the achievement of meaning in an individual's life. Achievement of meaning in life is defined as the interpretation and understanding of events or phenomena that occur in life due to one's perspective and values. Being an autoimmune survivor is perceived as a valuable experience and an acceptable difference, which is a main component in the process of achieving meaningful life. This is because autoimmune diseases are incurable and must be coped with for an uncertain period of time. Since becoming an autoimmune sufferer and undergoing treatment for a long time, various emotional and behavioral responses have been observed, including rejection experienced by autoimmune survivors. The rejection response experienced when in an unpleasant situation, according to autoimmune survivors in general, is physical discomfort and negative emotions that are experienced and felt by the sufferer (Suwastikaningrum, 2010). In addition, based on the results of a descriptive study conducted by Prasetyo & Kustanti (2017) on 8 lupus patients, it was found that patients generally have fears related to their illness. The high risk of death, deteriorating physical condition, and demands to adapt to their condition have a significant psychological impact on Odapus (People with Lupus). Moreover,

Odapus shows emotional symptoms such as feelings of fear, depression, sadness, lack of confidence, and guilt.

Living life as an autoimmune survivor in the midst of a pandemic is an extraordinary event. This makes the experience of being an autoimmune survivor in the pandemic an opportunity to develop a perspective for achieving meaning in life, as explained by Frankl (2003). Meaning in life actually exists in life itself, and can be found in every situation, whether pleasurable or painful, happy or suffering. Furthermore, in line with the previous explanation, Kawuri (2013) states that a significant event in one's life can change the meaning of life. This means that a person can be guided to find meaning in life through unexpected situations if they fully realize themselves, the situation, and the condition they are experiencing, and are able to use their potential to respond to situations and events positively.

Autoimmune survivors in the midst of the pandemic who have achieved meaning in life are based on gratitude that can make survivors accept their condition, making them more accepting of themselves by having life goals and being psychologically well. This is as explained by Daniella (2012) that an individual has a positive self-evaluation, able to act autonomously, master their environment, have life goals and meaning, as well as experiencing personality development, then the individual can be said to have psychological well-being.

Based on research findings, it is known that achieving meaning in life experienced by autoimmune survivors in the midst of a pandemic is an achievement that has positive values obtained through cognitive abilities to regulate emotions so that they can give meaning to their journey as autoimmune survivors in the midst of a pandemic. Lightsey and Boyraz (2011) proposed that achieving meaning in life and life satisfaction is done by individuals by making an effort that is built by

emotions influenced by the cognitive system. Thus, through contemplation and reflection, it can initiate the desire to live a meaningful life. Meaning here means being able to prioritize positive values in living life (Bastaman, 2007).

Based on the previous explanation, it can be concluded that being a long-time autoimmune sufferer is an extraordinary experience, as there are joys and sorrows that come with it. The process involved in being an autoimmune survivor, especially during a pandemic, limits everything that they can do, and they cannot live their lives like most people. Although there are limitations in living daily life during a pandemic, this does not hinder individuals from finding meaning in their lives. Achieving meaning in life is manifested in different ways for each individual.

Social Support

Autoimmune survivors in the midst of a pandemic cannot be separated from the support obtained through the social relationships built. Social support plays a primary role, which is obtained from family. The role of family is important as a place to express complaints during life as an autoimmune survivor in the midst of a pandemic. Verbal and non-verbal support provided by family, relatives, and friends become a source of encouragement and motivation to stay strong and persevere. The desire to fully recover is the main dream and motivation for autoimmune survivors in the midst of a pandemic, even though the possibility of recovery is very small. Considering that autoimmune diseases can only be controlled but not cured. This is in line with the explanation conveyed by Bastaman (1996) that the presence of positive relationships from certain parties will provide strong social support that motivates and strengthens individuals to rise up, thus having closeness, caring, and sincerity.

The social interaction as a form of support provided by autoimmune survivors during the pandemic is with their families

and closest friends. By engaging in these interactions, they can share their feelings, stories, engage in activities, and get encouragement, advice, and self-evaluation so that they can continue to fight as autoimmune survivors during the pandemic. This is in line with the view put forward by Hobfoll and Stokes (1988) that social support is defined as a psychological phenomenon in social interactions that occur between individuals in the form of assistance or attachment to perceived social relationships that include feelings of love, care, and willingness. This view is also supported by Lahey (2007) who defined social support as the role played by friends in providing advice, assistance, and some of them to tell personal feelings relatively. Consistent with this, a study conducted by Krause et al. (2007) found that social support relationships can change a person's sense of meaning in life, with negative interactions lowering a person's sense of meaning in life.

Social support from family and close friends also has an impact on the psychological health of autoimmune survivors during the pandemic. This is because seeing the enthusiasm and concern of family and close friends through informational support, appraisal support, instrumental support, and social support makes the individual feel valued and cared for even in a low point. Feeling valued and cared for becomes the cause of achieving meaning in life, which is to be grateful for what they have related to their family and close friends. These findings are in line with a study conducted by Dienillah and Chotidjah (2021) which shows that there is a significant influence between self-acceptance and gratitude. Social support has been proven to significantly moderate the relationship between self-acceptance and gratitude in patients with lupus.

Social support plays an important role in influencing the achievement of meaning in life for autoimmune survivors during the pandemic. This is because autoimmune survivors feel that they are

valuable, special, and have motivation and spirit to rise from their difficult condition and undergo treatment to control their autoimmune disease well. Attention, intimacy, attachment, and interpersonal relationships provide a foundation for achieving meaning in the lives of autoimmune survivors during the pandemic.

The Role of Coping Stress in Achieving Meaningful Life

During the process of undergoing treatment, autoimmune survivors in the midst of a pandemic experience stressors that lead to the emergence of negative emotions. The dominant negative emotions felt are sadness and despair, which autoimmune survivors express as feeling sad about being separated from their families due to their resistant treatment. This is in line with research conducted by Giacalone et al. (2020), which found that the condition during the pandemic has a significant impact on individuals with autoimmune diseases, as COVID-19 is a heavy stressor. This stressor causes individuals with autoimmune diseases to experience pressure, leading to a decrease in their psychological health, which in turn affects their physical health as stress is a state of pressure, both physically and psychologically (Ardani, 2007).

However, autoimmune survivors see the stress they experience as a step towards self-reflection and taking lessons from it. The achievement of meaning in life is felt by autoimmune survivors amidst the pandemic after being able to understand their existence and being able to maintain social life despite stressors and pressures. Autoimmune survivors in the midst of a pandemic realize that they cannot be immersed in a state of stress for too long, so they are able to overcome stressful situations. This is in line with Lazarus's (2000) concept that the meaning of life lies in the difference between stress and emotions. Someone who has good emotional regulation through appropriate

coping strategies will be able to find and realize changes in the meaning of their life. Research conducted by Krause (2007) found that coping with stress plays a role in restoring the meaning of life. This means that the ability of autoimmune survivors to cope with stress plays an important role in self-awareness in grounding the meaning of life changes.

Autoimmune survivors in the midst of the pandemic tend to use emotion-focused coping which functions to regulate emotions when under pressure. This choice is made because undergoing treatment during the pandemic requires good emotional regulation skills in daily life. This is supported by the statement by Jung et al. (2015) that systemic lupus erythematosus patients can find meaning in their suffering if they can find a coping style that can train themselves and think positively in enjoying daily life.

Belief in Religious Values

Autoimmune survivors in the midst of the pandemic cannot be separated from their respective beliefs in religion. Approaching God is a way to achieve meaning in life by being grateful for the blessings that God has given to autoimmune survivors. Even though they have shortcomings, autoimmune survivors are still grateful because they can still be active, interact with their social environment, which supports the search for meaning in life. Thus, autoimmune survivors have great hope in God for healing from their illness so that they can return to normal life and find meaning in life during their treatment. Autoimmune patients have to go through treatment throughout their lives because this disease cannot be completely cured and only goes into remission or temporary recovery (Oktaviani, 2016). As Crumbaugh (1971) said, the search for meaning in life is an important motivation in human life. This search ultimately positions humans as spiritual beings.

The meaning of life is closely related to a person's spirituality. Therefore, the instinct of spirituality that humans possess will drive their instinct to achieve and find a more meaningful life. Human spirituality involves belief in the religion they practice and the practice of the teachings of the religion they internalize, which can help them obtain and experience a more meaningful life (Japar, 2014). Mujib (2017) emphasizes that spirituality is not only about fulfilling one's needs, but also about enlightenment of the soul that can give a positive meaning to every event that happens in life, and constantly taking positive actions. Each individual has positive characteristics of spirituality with different levels of religion, beliefs, and life goals. These good qualities will make individuals closer to God, so they can find their purpose, wisdom, and the meaning of the:



Figure 2. Matrix of Achievement of Meaningful Life

CONCLUSION AND RECOMMENDATION

The achievement of meaningfulness in life is felt as an evaluative thing because it is the result of a reflection process that has been done on significant events in life, namely becoming an autoimmune survivor for a very long time. The changes felt related to lifestyle, carrying the status of an autoimmune survivor, and perspective will form certain values that can achieve meaningfulness in life. Finding meaning in life means finding positive meaning because there is a shift in meaning when becoming an autoimmune survivor and can

serve as a guide to continue life in the future. Among the achievements of meaningfulness in life that are felt include an increase in gratitude related to the condition experienced, the blessings given by God, and the support provided by family, the assessment of religiosity, namely getting closer to God, accepting all that is received by trying to accept the problems that exist, and changes in social assessment, namely being more selective in friendship.

The achievement of meaning in life is certainly based on certain aspects that underlie the perceived changes in meaning

in life. These aspects include the interpretation and appreciation of past experiences as well as the interpretation and appreciation of current situations. Among these aspects are views related to the autoimmune condition that has occurred and is currently happening, experiences with autoimmune conditions during the pandemic, social support that has contributed greatly during the treatment process, coping with stress that helps in achieving meaning in life, and the religious values that individuals hold which will drive human instincts to achieve and find a more meaningful life.

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