

Exploring the Meaning of Life in Individuals Suffering from Thalassemia

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INTRODUCTION

Individuals suffering from Thalassemia in the 2023 Global Thalassemia Review report are 56,000 individuals (Kurniawati & Monika, 2025). While in Southeast Asia, Indonesia ranked 3rd with a relatively high prevalence of around 3-10%, around 12,000 individuals (Kattamis et al., 2020; Soteriades et al., 2023). Sartika & Allenidekania (2020), revealed that individuals suffering from Thalassemia had to undergo blood transfusions to maintain hemoglobin levels above 10g/dL and transfusions caused iron buildup.

Iron buildup due to transfusions has side effects on organ function, heart failure, endocrine abnormalities, and growth hormone deficiencies and even complications and physical changes (Pasyar et al., 2020). Therefore, individuals suffering from Thalassemia should regularly take iron

chelation drugs to reduce the accumulation of iron amounts due to blood transfusions. Khan & Rauf (2024), states that, individuals suffering from Thalassemia disease struggle with the disease from birth or when it is first diagnosed. In order to live to adulthood, they must fight the disease for a lifetime with the help of medical care. However, this disease makes them weaker every day. This causes individuals suffering from Thalassemia to feel that life has no purpose and is full of uncertainty (Hertini et al., 2024).

The disease is incurable so it gives rise to uncertainty, pessimism, fear of death, despair, and helplessness (Surjoseto & Sofyanty, 2023; Wangi et al., 2023). They also have limited opportunities to engage in activities to achieve goals and develop themselves. This makes individuals stop taking medication and even blood transfusions, which further affect physical changes. Individuals feel low self-esteem, find it difficult to accept their shortcomings, feel unfair, blame the situation, and even feel guilty for having a chronic illness and burdening the elderly (Nur et al., 2021).

Individuals with chronic Thalassemia often find it difficult to connect with the outside world and live life independently. The disease is considered a threat to their life goals, physical functioning, and autonomy. The impact of illness requires them to change their life goals, which disrupts self-understanding and creates physical and psychological limitations. Chronic Thalassemia is a reminder of the limitations and obstacles in individual freedom, limiting daily routines and making it difficult to find one's identity in the midst of uncertainty. As a result, individuals often live without enthusiasm, and only follow the expectations of the environment, making it difficult to find the meaning of life (Andersen et al., 2021; Ferreira-Valente et al., 2021; Purc-Stephenson & Edwards, 2024).

The meaning of life can be understood as an individual condition to find the meaning of life in the suffering experienced, through important and valuable things so that they can accept themselves and the events experienced (Bastaman, 2007). The meaning of life is formed through 3 main dimensions. These dimensions are related to personal, social and values, in which there is a meaning of life, self-connectedness and directed activities (Bastaman, 2007). Individuals who live their lives as people with Thalassemia experience personal problems related to self-understanding, in taking attitudes to change for the better. This will be difficult, as individuals have to adjust to their illness. The social problems of individuals who suffer from Thalassemia disease are, being less able to socialize and only having enough relationships, because their activities are reduced, adjusting their capacity. This makes individuals who suffer from Thalassemia have to struggle to achieve their goals, they experience problems in terms of values. Although individuals are aware that they have Thalassemia, they do not have the self-discipline to take medication regularly or receive blood transfusions, as well as the focused activities necessary to reach their full potential (Latifah & Suwarti, 2022).

To support the phenomenon in this study, initial data collection was carried out. Preliminary study data was collected using the initial interview method with 4 participants suffering from Thalassemia from January to May 2025. The average participant was diagnosed with Thalassemia at the age of 4 years. The results of the interviews showed that all participants felt inferior and lacked confidence because they had Thalassemia which affected their appearance/physical state. In addition, they have fear and anxiety in the other person's view of themselves and their uncertain future. Related to other people's views makes them close themselves because they are afraid of being pitied and seen negative/different and this makes them have limited relationships. In doing blood transfusions and taking medication, 2 out of 4 participants have felt saturated/bored, in taking medication, individuals still do not consume regularly. With the support of their families and people who know they have Thalassemia; they can continue the routine to this day. Even before blood transfusions, individuals become more prone to weakness, dizziness, and less ability to manage their emotions.

Individuals who suffer from chronic diseases often feel pain or pain even though they have undergone various medical procedures and therapies that cause a sense of helplessness and anxiety about death or the future. From the psychological aspect, people with chronic diseases tend to close themselves off. Experiencing emotional changes, becoming angry more often as a form of compensation for the inability to deal with their sick condition. This disease can cause fatigue that negatively impacts adherence so this helplessness can affect treatment. Individuals who have support can increase their enthusiasm for therapy (Inayati et al., 2020; Kvarnström et al., 2021; Surjoseito & Sofyanty, 2023).

Individuals who suffer from chronic diseases in this case related to Thalassemia will have difficulty achieving the meaning of life. They are prone to emotional disturbances, anxiety, worry, and pessimistic attitudes (Pambuka et al., 2024). This starts from the individual's mindset, the view of himself who suffers from the disease and reinforces negative feelings, thus influencing them. Lack of self-acceptance of the disease and its uncertain course. Limited physical activity caused by illness and physical weakness and unstable emotional state before transfusion. All contribute to a decrease in physical activity and activities of daily life, role function in social and work or educational contexts, and decreased satisfaction (Van Wilder et al., 2021). Yun & Yun (2023), reveals that the burden of illness and the burden of non-disease (economic, social, personal) reinforce each other, increasing psychological suffering, dependence, and the danger of social isolation. The onset of unexpected and uncontrollable tiredness, discomfort, dizziness, paleness, and weakness that quickly makes them feel dependent and uncertain, so they feel unfairly treated.

The positive meaning of life can make individuals with chronic diseases, especially Thalassemia, able to accept that they have the disease in order to survive and continue living with the treatment that must be undergone, namely, blood transfusions and chelation therapy. Have positive emotions, because they can connect with other people or fellow sufferers and can share what they feel, do things according to their capacity (activity and balanced physical capacity) and be able to look for opportunities in them (Van Wilder et al., 2021). An optimistic outlook on the next life, the ability to adapt, and surrender to God as a form of transcendence accompanied by serenity, are all made possible by a positive meaning in life (Bahtiar et al., 2020). Individuals with chronic diseases, such as Thalassemia, are better able to achieve their goals, improve their daily functioning, and improve their physical and mental health through disease management, accepting the condition, and creating positive experiences (Rishworth et al., 2023). In addition, individuals with chronic illnesses who find meaning in their lives can reassess their priorities and self-worth, change their outlook on life, give purpose to their health condition, and feel that they can continue to grow as a human being and learn more about the world and themselves (Szcześniak et al., 2020).

Chronic diseases have a negative impact that interferes with daily functioning. Between 25% and 50% of individuals with chronic illness have a low quality of life, which includes low life goals, social, mental, emotional, and physical problems. Having a worse self-perception of their situation and lower levels of self-confidence and self-esteem, tend to shut themselves off and isolate themselves due to having poor self-concept and feeling different from other (healthy) individuals (Bravo et al., 2020). It has an impact on increased worry, depression, stress, reflection, negative, and unproductive thinking. This causes the quality of life to be worse by stopping taking medication or blood transfusions until suicide (Hasanah et al., 2025). Individuals suffering from Thalassemia will experience impairments in self-confidence that give them strength, hope, and purpose in life if they are unable to find meaning in life. This will make them more susceptible to feelings of hopelessness, loneliness, anxiety, fatigue, and sleep disorders (Purnama et al., 2021). Updegraff & Taylor (2000), reveals that individuals who are unable to find the meaning of life behind traumatic events can become confused, introverted, unhappy, and more susceptible to subsequent stressful states that interfere with routine activities and self-adjustment.

Indonesian people who have this genetic and non-communicable disease, that it, 1.5 per 1000 population (Himawan et al., 2022). Most of the Indonesian people do not know about Thalassemia. Individuals suffering from Thalassemia disease have a significant effect on physical, social, and emotional functioning (Yulia et al., 2025). This has an impact on the individual's appreciation of himself and the diseases he suffers from. This appreciation of life tends to be lower, and increasingly has negative impacts such as having no hope of survival (Nunes et al., 2025). The existence of this upheaval, in individuals suffering from Thalassemia disease, it is necessary to conduct research to explore the meaning of life that they have. This research was raised to look at the phenomenon that is still occurring in society, namely the lack of knowledge about Thalassemia disease and the psychological needs needed by sufferers, as well as the lack of research in Indonesia on the meaning of life in people with Thalassemia. Therefore, it is necessary to explore further the meaning of life that individuals suffering from Thalassemia have to help them live a good, positive, and hopeful life.

Study Aim

This study aims to explore the meaning of life in individuals suffering from Thalassemia.

METHODS

Design

This study uses qualitative research with an interpretive phenomenological analysis (IPA) design. This will be the methodology used in this study to obtain more detailed information using an interview approach (La Kahija, 2018). Understanding the life experiences of individuals who have directly experienced events is the objective of the interpretive phenomenological design. The interpretive phenomenological qualitative design in this study aims to explore the meaning of life in individuals suffering from Thalassemia, along with its factors.

The interviews were structured based on the dimensions and factors of the meaning of life by Bastaman (2007), as a guide for interviews that had been compiled in an interview guide. The dimensions of the meaning of life consist of personal dimensions, social dimensions, and value dimensions, which include the meaning of life, self-connection, and purposeful activities. The questions were open-ended, allowing participants to freely express their experiences in depth, and probing was also conducted. This study used an additional instrument, namely a mobile phone, as a medium for recording sound and documentation. In addition, writing instruments were used as a medium for recording important information from the participants' answers.

Table 1. Demographics of Research Participants

Characteristics	Description	N
Age at DPT	20 years	1
	6 years	1
	4 years	1
	Total	3
Current age	17 years	1
	19 years old	1
	34 years old	1
	Total	3
TD routine in 1 month	2x	1
	1x	2
	Total	3

Note: Age at DPT = Age of participants when first diagnosed with Thalassemia; TD = blood transfusion; N = number of participants.

Participants

Participants in this study were individuals suffering from Thalassemia aged between 15 to 35 years. An exclusive characteristic of this study was that participants had been diagnosed with Thalassemia since birth and underwent regular blood transfusions at least once a month. Data was collected from three participants who met these criteria. All research participants were first asked to fill out an informed consent form related to the research procedure.

The informed consent form contained a statement regarding the description of the research and the purpose of the participants' involvement in the research. After that, the participants chose the option to agree or disagree. The participants' demographic data are presented in Table 1.

Research Procedure

This study received ethical approval from the Research Ethics Committee of the Faculty of Psychology, Universitas Muhammadiyah Malang (Approval No.: E.6.m/334/KE-FPsi-UMM/VI/2025) to protect participants from ethical and moral violations. Participants were selected using a non-probability purposive sampling technique, with specific considerations for choosing individuals as data sources. Information regarding the study was provided, and participants indicated their voluntary agreement by completing an informed consent form.

Data were collected through semi-structured, in-person interviews lasting between 30 to 50 minutes. The data collection process via interview was exploratory in nature, and thus the originality of the data is contingent upon this specific procedural sequence. Participants were reminded of their right to withdraw from the study at any time without providing a reason. Upon concluding the interview, participants received a token of appreciation as an acknowledgment and expression of gratitude for their involvement in this research.

Data Analysis Techniques

The analysis began with the repeated reading of the interview transcripts to achieve a deeper understanding of their content and meaning. The analysis in IPA was conducted through an interpretative process grounded in the participant's own account as presented in the transcripts, employing an idiographic focus that attends to the uniqueness of each participant (La Kahija, 2018). After that, preliminary notes known as exploratory notes were made to analyze the transcripts submitted by participants. These exploratory notes were then processed into emerging themes. The emerging themes were combined into one larger topic (superordinate theme) and then focused in depth on all themes from all participants to identify patterns among their experiences (La Kahija, 2018).

According to Sugiyono (2024), internal validity credibility testing can be done in several ways. Researchers extend their observations by conducting interviews again with data sources they have already met or newly encountered. Researchers also conduct more careful and accurate observations in order to continuously discover new themes. Data triangulation needs to be done to check data from various sources and times. The next step is negative case analysis, where researchers look for evidence that contradicts or is inconsistent with the data that has been found. Finally, researchers conduct member checks to ensure that the data collected is consistent with what was conveyed by the participants, and use supporting reference materials to validate the data that has been found.

RESULTS AND DISCUSSION

Results

Background of Individuals Suffering from Thalassemia

An individual can suffer from Thalassemia after being medically diagnosed either as a child, adolescent or even as an adult. Being an individual suffering from Thalassemia always carries out

treatment every month or even every day, as a routine to support his life in terms of health. Every month I go to the hospital for a blood transfusion which previously had to be a blood test to check the hemoglobin level. Another routine that is carried out every day is to take medication and vitamins as support. In addition, the activities carried out by individuals suffering from Thalassemia disease are limited due to their physical condition which is easily tired. This makes them feel different from others. There are certain dimensions and factors that make them continue to live their lives. Each participant had a reason to be strong and had his own story as a Thalassemia sufferer.

All participants in this study almost have the same initial diagnosis of Thalassemia to the ability to continue living their lives to this day. Participant's "F" and "T" were diagnosed with Thalassemia as children, aged 4 and 6 years, while participant "A" was diagnosed with Thalassemia at age 20. The three participants had regular blood transfusions once a month or 2 times a month, which was done when the hemoglobin level was in the range of 7-9mg/dl. In addition to doing blood transfusions, they also consumed drugs and vitamins, participant A consumed regularly while participants F and T were still not routine. During the life they live, participants often feel that their physical capacity is limited so that the activities they carry out need to be paid more attention, although sometimes they force themselves to carry out activities and on the other hand still pay attention to their own capacity. Limited self-capacity and impact on the activities carried out often occur due to fatigue/weakness, dizziness, body pain and fever. They feel different from others and even inferior because of the routine they do, their capacity and their physical shape. It also often has an impact on feeling bored or tired of carrying out routines as an individual suffering from Thalassemia disease.

The Process of Forming the Meaning of Life in Individuals Suffering from Thalassemia

Thalassemia is a lifelong genetic disease, so it causes problems for sufferers, both due to the disease process itself and as a result of treatment both physically and psychologically. Therefore, individuals suffering from Thalassemia need to form and achieve the meaning of life because they realize that they are still able to face difficult situations and take a stance, develop their potential, to their goals and desires, in order to live a good life and not be easily discouraged. The following is the experience of each participant in the dimension of life meaning which refers to (Mariani & Rochimat, 2023; Buddhism & Astuti, 2025; Bastaman, 2007).

Personal Dimension

The personal dimension can be interpreted as the ability to realize and understand oneself so that one can take an attitude to change for the better. As an individual with Thalassemia disease, each participant can change a negative attitude to a positive attitude in undergoing treatment and illness in their life by making better decisions.

Views on Oneself as an Individual Suffering from Thalassemia

Each participant had a different view of himself as a person with Thalassemia. They feel inferior and different from other individuals (individuals who are normal/do not have Thalassemia). Participant A has felt traumatized because he experienced physical bullying.

"...There may be... Growth is also abnormal... Lots of bullies or sneers... it makes it traumatic... Ages 18-19... school time. Looking at myself sometimes I feel mentally down, sometimes I want to encourage... Humility often, all the time. See others busy... Going to work... departing this... We are at home..."
(A, p.17-p.32).

Likewise, other participants looked down on themselves and felt different from other individuals even though they did not have trauma.

"...It's normal... Sometimes I feel... Different from the others, can't be like the others... once a month must go to the hospital. Schools used to have most permits. Less sometimes... classified... shortest itself... from elementary school to now..." (F, p.25-p.34).

"...It's okay, I'm different from the others... Thoughts, then, now... It's different from the others. "Sometimes I feel less embarrassed when a friend of mine finds out that I have an illness and then has to take medication back and forth to the hospital as if I feel embarrassed like everyone else..." (T, p.45-p.50).

Treatment undergone as an Individual Suffering from Thalassemia

Each individual felt similar symptoms before undergoing treatment, as illustrated by the participants' complaints, such as 'dizziness, tiredness, body aches' (A), 'weakness, unwell' (F), 'dizziness, paleness, weakness, warmth, fever' (T). Individuals undergo routine treatment by going to the hospital for blood transfusions and taking medication daily, every 8 hours as well as taking vitamins. Blood transfusions performed by everyone are different according to hemoglobin levels below 10mg/dl and their routine, as well as different medications and vitamins consumed by everyone.

Participant A underwent both treatments regularly.

"...Transfusion 2 times a month... Early... Same in the middle of the month... Drugs are consumed... routine..." (A, p.9-p.16).

"...The range during the transfusion is at 7..." (A, p.73-p.74).

Participants F and T underwent regular blood transfusion treatment, but the drugs taken were irregular.

"...Once a month... sometimes not. Forget it, bored... lazy and when there is another activity..." (F, p.15-p.22).

"...Usually 7..." (F, p.83-p.84).

"...Once every 3 weeks... Next week... Drug consumption... Not routine... I didn't bring the medicine... Drink at home..." (T, p.27-p.40).

"...Sometimes 8... 9... 9,6... Just yesterday... Over a month ago... Hb is 7..." (T, p.125-p.128).

Feelings and Challenges of Undergoing Thalassemia Treatment

During the treatment, participant A was excited and felt that he had new hope because he would receive blood. However, when doing blood transfusions, there are challenges.

"...If you want to go to the hospital, there is a sense of enthusiasm. If possible, it's different with other children. If I want to have a transfusion tomorrow, I'm already excited. Already today, everyone is ready. Like I feel like there's a new hope... Enjoy... The challenge... Difficulty. Blood is not suitable... Bad Body... fever..." (A, p.35-p.44).

Meanwhile, participant F felt tired of undergoing treatment that had been carried out for 14 years. These feelings arise due to repetitive routines, long trips, and adjustments to college schedules.

"...I'm tired, I'm tired. The journey here to get there is a long way.... So, it's like I'm tired, I must go there every month... The challenge... If you have a

college schedule... Suddenly it changed... have to find an empty one... retreat..." (F, p.41-p.50).

On the other hand, T participants felt ordinary, more enthusiastic about fighting diseases, but fatigue was considered a challenge.

"...It's normal... I do that every day... Every week, every 3 weeks I do... So, it's normal... More enthusiasm... fight this disease and to heal... Hopefully it will heal... The challenge is like... Feeling tired... keep taking medication, keep transfusions..." (T, p.53-p.60).

Positive/Good Attitude as an Individuals Suffering from Thalassemia

Not all participants had a positive attitude as individuals suffering from Thalassemia. Some participants stated that the positive attitude they had taken was to continue to undergo treatment regularly and their enthusiasm also had other busyness.

"...Undergoing treatment, taking medication regularly, then enjoying it... Find a busy person to make us think positively... I'm in a pet home... birds and chickens..." (A, p.45-p.52).

"...Just keep your spirits up, keep your spirits up, Sis. "You can feel tired, you can feel tired..." (T, p.61-p.62).

Social Dimension

The social dimension can be interpreted as the existence of social support individuals are more able to direct themselves. This social support can be present through other trusted people or other people who are willing to provide help/support both physically and emotionally. The support is obtained by the participants through verbal and non-verbal expressions that they get and then form their feelings towards the support so that they know how to direct themselves more.

Perceptions or Social Support in Individuals Suffering from Thalassemia

Each participant gets a good outlook and social support. The views and social support obtained by participant A have experienced a difference for the better.

"...Unlike before, there are already differences... More like supporting... support..." (A, p.53-p.60).

Participant F received good views and social support from the surrounding environment, both college friends, the living environment, and parents.

"...Close friends... in lectures... Be Inspired... Because of the lightness... For example, sports are not strong enough to allow ... given encouragement..." (F, p.61-p.69).

Just like participant F, participant T received good views and social support from schoolmates, church friends and parents.

"...Some friends know I have a disease... School Friends... Friends of the Church... They are still eager to run... Encouragement..." (T, p.63-p.66).

Social Relationships of Individuals Suffering from Thalassemia

All participants had good social relationships with people around them who were 'quite good' (A), 'good' (F & T). Doing social relationships in general, such as playing, going out, group and church work or other activities around the residence.

Individual Feelings and Self-Direction in Social Support Received

Participant A felt overwhelmed, responded well and was able to direct himself to the social support obtained.

"...Overwhelmed... I used to be bullied... Now many are even supporting... Moved... Please. Responding to it is good... It's more social..." (A, p.61-p.64).

On the other hand, participant F felt enthusiastic but could not direct himself from the social support obtained.

"...How about it... That kind of enthusiasm..." (F, p.71-p.74).

Participant T was able to feel and direct himself to the social support he received, especially because he felt the difference before and after receiving support.

"...I feel more excited... From the previous ones... Before, I didn't know what to do... Why do you think the transfusion is still going on? Continue to take medication... Feeling so tired... If this is the spirit... more energized than ever... Thank you for them... Have given me support..." (T, p.71-p.74).

Dimensions of Values

The dimension of values is defined as the ability to seek and find meaning and purpose in life through directed activities. This is based on the interest that the participants have in the meaning and goals they have. All participants had different life goals and life goals. The goals that participant A has are inseparable from what he has now, namely his parents.

"...The purpose of life... To please the elderly..." (A, p.65-p.66).

Participant A has goals that are being lived now to achieve the desired goals.

"...Achieving goals... So... PGMI Teacher... PGSD..." (F, p.85-p.88).

On the other hand, participant T has a life goal to become a dancer as his or her goal and a desire to heal.

"...I want to get better... Have such a desire... If the goal... I want to... become a dancer..." (T, p.75-p.84).

The Meaning of Life

The meaning of life is an element of the dimension of values according to, which it can be interpreted as important values that are meaningful and aware of what is done. As a person with Thalassemia disease, you can feel happy and meaningful with the experiences created and the goals fulfilled through the activities that you direct.

Thalassemia Affects Life Goals

Participant A stated that the illness he suffered affected his life goals because of his limited time and health conditions.

"...Yes, if you think about it, it has a lot of influence... We are... may be bothered by the transfusion time... Cut the time... Maybe you are tired often or there are other complaints..." (A, p.67-p.70).

Meanwhile, participants F and T stated that their Thalassemia disease did not affect their life goals because their goals were pursued/achieved and balanced with blood transfusions to support the activities carried out.

"...No, no... How about that. to our destination... chased after it"

(F, p.89-p.92).

"...If I was... Nope... Because... Even though it is still moving... But what are we...? It is impossible not to continue the transfusion..." (T, p.85-p.86).

Important Things to Achieve Life Goals

Participants A and T stated that blood transfusions were important to achieve their goals as individuals suffering from Thalassemia.

"...The important thing is... healthy... transfusion. That's the most important thing. I try my best to find an empty schedule for the transfusion, no matter how busy I have to keep it to take care of her HB..." (A, p.71-p.72).

"Yes, it's routine... Stay routine... routine... transfusions, taking medication as well..." (T, p.87-p.88).

Meanwhile, participant F stated that the important thing to do to achieve the goals he had was to learn.

"...Learning... Learn... Look for materials that have not been taught in lectures..." (F, p.93-p.94).

The Meaning of Thalassemia for Individuals

Thalassemia disease that individuals have has its own meaning for them. Participants A and F interpreted Thalassemia as a state that must be lived with gratitude.

"...At that time... enlarged abdomen, small body. So, what about it... Pick up the book... 5 pieces in a bag... Not strong. Not even small water is strong... in the past. But now I have... normal... better... If you didn't know what disease it was... I don't know. Join the Foundation... Thalassemia... in Semarang. I only found out about the diagnosis from there. It's kind of down... As soon as I was invited again to his gathering, I became enthusiastic again... Rise again... And because of that, he's not alone. After that... Moving to Solo... be more enthusiastic, until now... That is why transfusions are enjoyable. The Meaning That Can Be Obtained... We are grateful... I've been here... Be grateful and walk..." (A, p.77-p.84).

"...It's different, that's from the others... Every month you have to go to the hospital... But yes, how do I go... Just be more grateful, Sis, there are still those below us..." (F, p.95-p.98).

Memorable Experience

The memorable experience that participants A and T had was during treatment and getting to know fellow patients with Thalassemia.

"...Undergoing treatment... a lot from the experience of other children, from the parents' side... So... exciting... transfusion that... In my mind, it was not a transfusion, but meeting a brother, playing. Brothers who are fighting together. But I don't know where it came from..." (A, p.85-p.86).

"...If it's from me... To meet peers who like me may have Thalassemia disease too, and then I can get to know them better... I can get to know more of his friends..." (T, p.95-p.98).

Things That Make Individuals Happy/Meaningful

Based on the interviews, participants A and F stated that the support from others they get, is meaningful or makes them valuable.

"...Yes, it was from the support of family friends and other relatives..."
(A, p.87-p.88).

"...Supporting the family is like friends..." (F, p.101-p.102).

Meanwhile, according to participant T, the thing that makes him happy and meaningful during routine blood transfusions and drug consumption is that there are better changes, physically visible.

"...If it's from me... Eee... In the past, his spleen was enlarged, continued to have regular transfusions, routinely took medication. Last month, I was told by the doctor that his spleen had been reduced... I feel a little relieved. it has shrunk no longer and its belly is not distended like that..." (T, p.99-p.100).

Self-Commitment

As a person with Thalassemia, of course, it is bound by blood transfusions and the consumption of drugs, vitamins. They have a commitment to carry out their routine with the motivations they have both from within and outside themselves. Although they are not yet fully committed to achieving goals and things that should be appreciated.

Achievement of Goals That Individuals Have

Participant T carries out various activities as a guide and a forum for self-development, to achieve their own goals with self-awareness and choice.

"...I took the exercises from school... extracurricular... Join the dance studio outside or stage outside... Enough to experience... achieving goals... There are also quite a lot of dancers outside the school..." (T, p.101-p.102).

Things that are Valued by Individuals

For participant F, something he appreciated while suffering from Thalassemia was to do a blood transfusion.

"...Appreciating... Sometimes if you don't have a transfusion... soft... Tired, dizzy..." (F, p.105-p.106).

Attitude Change as an Individual Commitment

Participants A and T had a change in attitude as a self-commitment in terms of the treatment carried out.

"...Further improve... I'm trying to get my medicine ordered... I used to be not... Ga, this, order... The spirit of taking medicine and transfusions..."
(A, p.95-p.96).

"...More... Just more enthusiasm, routine at the hospital transfusions, taking medicine... more enthusiasm for the school to achieve its goals..."
(T, p.107-p.108).

Meanwhile, participant F made a change in attitude as a self-commitment as a step to achieve goals.

"...Learning... Providing support to the family... Balanced with prayer..."
(F, p.107-p.108).

Motivation that Individuals Have to Achieve Goals

Participant A has external motivation, especially from the experience of his fellow Thalassemia friends.

"...I have 1 friend who is close to Thalassemia too... It gave me an experience... Transfusions are always together... Examined by an internal doctor and a Thalassemia doctor, it turned out that with the accumulation of iron there was fluid... and after the routine... Routinely munm the medicine, the fluid is gone. Nahh... Now it's even fresher. That's what makes me more enthusiastic about taking medicine and transfusions... very useful. That's what motivates me..." (A, p.96-p.98).

Participant F has both external motivation and internal motivation.

"...To achieve the goal, yes... The motivating thing... Family support... And then... I want to achieve that goal..." (F, p.109-p.110).

Meanwhile, T participants are motivated from within to achieve their goals with several choices they have.

"...If it's from me... He used to think of becoming a professional dancer... But... The burden is like that, have other options to be a professional dancer or not to become a Javanese writer... If you're a dancer in the studio, you might be able to... who is in the studio... Javanese writers are looking for further review, but it hasn't occurred to me that there are only 2 options..." (T, p.109-p.112).

The Meaning of Commitments and Goals That Individuals Have

Participant A interpreted positively that the medication consumed every day was not a burden for him because it was very useful.

"...If I... The meaning of the drug... like a daily snack..." (A, p.99-p.100).

Participant F still interpreted with a feeling of gratitude.

"...There is... grateful, more grateful..." (F, p.111-p.112).

The meaning of the commitment possessed by participant T is something that is done better, it will help him achieve his goals.

"...More... more excited... and strive to achieve... That was just yet... Javanese dancers or writers..." (T, p.113-p.114).

Directed Activities

As a person with Thalassemia disease, participants have targeted and deliberate activities to achieve their goals. This can be in the form of creativity, potential or talent in him, to the relationships he has. They do not fully understand or feel that they have outstanding potential/talents, but they have activities that are directed according to their abilities and desires. In this case, there are also challenges so that the meaning of life will be more achieved.

Self-Potential

Participant A has cooking potential.

"...It's more of a daily dish..." (A, p.103-p.104).

Meanwhile, the potential possessed by T participants is cooking and singing.

"...There is... Cook... Sing... Singing is usually sung in church for service, sometimes at school..." (T, p.115-p.116).

On the other hand, participant F felt that he had not found his talent/potential.

"...Still confused... Still confused as to how... still confused about talent... potential to the present..." (F, p.113-p.114).

Activities carried out by Individuals

The activity carried out from the potential that participant A has, namely cooking every day.

"...Yes, I cook every day for my father and mother..." (A, p.105-p.106).

Participant F carried out activities that were preferred in terms of the environment through on-campus activities.

"...Yes... on campus... There are activities... My Squirrel Is Following This... care about the environment, because it prefers to the environment, planting trees... Cleaning up garbage... in the community. Now I just got the material and later... developed into practice..." (F, p.115-p.122).

Activities carried out from the potential of T participants are serving in church and singing at school.

"...Rarely... dance more often. Singing is usually sung in church for service, sometimes in school..." (T, p.116-p.118).

Challenges of Developing Potential

Participant F felt that the challenges they had in their activities and developing potential came from the diseases they suffered, limited, and easily tired.

"...Sometimes... To get closer to the transfusion schedule there are still activities outside of that, such as... soft... It's not that good, it's not good... Sometimes it's restricting, but sometimes it's forced. You see... must... still strong..." (F, p.129-p.134).

Meaning of Potential

Participant F interprets the activity he does as something that can be useful to others.

"...Yes, it means... Can be... What a no. It can be meaningful to others around..." (F, p.135-p.136).

Factors Affecting the Achievement of Life Meaning in Individuals Suffering from Thalassemia

The factors of the meaning of life according to include creative values, experiential values, attitudinal values, and hopeful values. The meaning of life that individuals have comes from within themselves. The following are the factors that affect the meaning of an individual's life, namely.

Creative Values

Creative values can be realized by people with Thalassemia by making useful and valuable contributions in their lives, both for themselves and those around them. This is done by participants with commitment and a sense of responsibility, such as working, working, or creating something according to their duties and desires.

Contribution to the Surrounding Environment

Participant A contributes to the surrounding environment with residents and young people there. He received different treatment (given special treatment) than others because they knew that participant A had Thalassemia and should not be tired. On the other hand, participant A wants to be treated equally with others and can contribute to the maximum.

"...Young people... more privileged... I can't do anything... It's not even good... This is where you want to help, but you don't have to... Just sit down. that's not good... Invitation to the Reception... I went with them saying... more... Don't just go with it, the person is enough... If I don't follow sports, because I'm busy myself... A work of art sometimes comes along... a little bit of participation, but sometimes also told to sit down..." (A, p.109-p.114).

Contribute to the surrounding environment in youth activities such as receptions, community service and do not get different treatment or remain the same and equal to others.

"...Yes, there is, come along, if there is an activity, come along... Some people know it or not (Thalassemia), participating in (community service and reception) is not all the same (treatment)..." (F, p.137-p.148).

Creativity

The creativity that participant F once had, according to participant F, was participating in the Olympic competition in Senior High School.

"...I have been with KSM... The Madrasah Olympics were like that when I was in Senior High School... A Regency... The... KSM... doing the questions... This is for biology class, so the questions are about biology...." (F, p.149-p.152).

Commitments/Responsibilities

The commitment and responsibility possessed by participant F regarding the creativity they had in high school and participating in the Olympic competition was learning and transfusion.

"...Yes, he was chosen. Yes... Learn that... learn while transfusions as well..." (F, p.153-154).

Experiential Values

Many things have been experienced and obtained by participants who suffer from Thalassemia throughout their lives, this is an experience they have. The experience is in the form of love saying, truth and beauty that they receive and feel. Through these experiences they can understand, trust, and feel it to create a deeper meaning.

Experience Matters

A meaningful experience for participant A was to meet and get to know fellow people with Thalassemia because it added brotherhood.

"...In Thalassemia... There are... I joined for the first time... Please... For the first time, I joined and joined in... Please... Meet... The brother from Semarang joined that... Until now, I have even made friends from those who participated in the Kaliurang camp... Until now it is still a relationship... Rather, it adds more friends..." (A, p.115-p.118).

Meanwhile, according to the F and T participants, the meaningful experience they got was support from family and friends.

"...The most meaningful, yes... Family support, support, friends... that." (F, p.155-p.156).

"...More... What's up. They love me more, even though I am different from my family. Closer... more support each other..." (T, p.135-p.138).

Attitudinal Values

Attitude values are behaviors taken towards a certain situation that is being experienced, such as suffering or illness. Participants had been coexisting with Thalassemia for many years and had blood transfusions every month and took medications and vitamins. This if done regularly, good, and positive will give more meaning in their lives

Positive Attitude

Not all participants had a positive attitude as individuals suffering from Thalassemia. Some participants stated that the positive attitude they had taken was to continue to undergo treatment regularly and their enthusiasm also had other busyness.

"...Undergoing treatment, taking medication regularly, then enjoying it... Find a busy person to make us think positively... I'm in a pet home... birds and chickens..." (A, p.45-p.52).

"Just keep your spirits up, keep your spirits up, Sis. "You can feel tired, you can feel tired..." (T, p.61-p.62).

Hopeful Values

Patients with Thalassemia have hope and believe in good things that will happen in their lives, especially health conditions. Participants with Thalassemia have hope for a bright future.

Hope for the Future

All participants have hope for the future, especially in health, namely undergoing regular treatment and hoping to recover from the disease that Thalassemia has.

"...Health... Yes, I would like to. free from Thalassemia... Don't let it... It's nice to be back in the hospital. You have a brother, but... If you can stop... healed... Healthy no more transfusions... The hope is yes, the point is to be healthy first... That's the most important thing..." (A, p.123-p.128).

"...Yes... I want to maintain more lifestyle and diet, more regular transfusions, regularly take medicine. Her hope can be fulfilled... study more actively and pray more..." (F, p.165-p.168).

"...More... Routinely undergoing this routine continues... Even though we're different from each other, we're still excited..." (T, p.143-p.144).

Optimistic Outlooks and Confidence Individuals Have

Not all participants have an optimistic outlook and confidence in themselves.

"...Be more confident in yourself... undergo transfusions, take medication, and then... striving to achieve his goals... You can't... You can't be discouraged from doing that, transfusions and taking medication..." (T, p.147-p.148).

Discussion

Based on the results of the data analysis obtained, it was found that participants who suffered from Thalassemia disease had similarities and differences in the meaning of life they had. It was found that the initial diagnosis of Thalassemia was different, both in adolescence and in children. As time goes by, the more the participants grow and their knowledge increases, they become aware and accustomed to the routines carried out, such as hemoglobin checks, blood transfusions to the hospital to taking medication. The routines they live go hand in hand with their daily lives, such as socializing, studying, and pursuing their future. This is done according to one's capacity to carry out activities that are inseparable from fatigue, paleness, pain that may suddenly appear or other

physical discomforts, to feelings of being different from others and feelings of inferiority. Apart from that, the views and support of family, friends, and people around them are very influential on participants who suffer from Thalassemia. For this reason, the meaning of life that is individual, can be found and possessed by everyone who suffers from Thalassemia so that they can survive in all circumstances in their lives (Wati & Satwika, 2024). This is a reason for participants to explore the life journey and the meaning they give as individuals suffering from Thalassemia.

Living as a participant suffering from Thalassemia is certainly not easy. The effects of Thalassemia are very diverse, such as different routines from other people, limited activities, changes in physical shape, and having feelings of inferiority. This chronic disease is a hereditary disease or genetic condition due to abnormalities in red blood cells so that it requires a lifetime blood transfusion and cannot be completely cured (Paloma, 2023). In this study, there were diverse responses from each participant, regarding the Thalassemia disease they suffered. In research Van Hout et al. (2023), stated that the life of individuals with chronic diseases, the suffering is endless, their interactions are limited to feelings of isolation. This occurs because they are limited in sharing their personal experiences with others in a wider social environment or community, thereby hindering the formation of their identity. This study also found that the meaning of life for participants suffering from Thalassemia lies in acceptance, appreciation, support, purpose, and future hopes. These are important in guiding individual actions and are considered valuable. (Bastaman, 2007).

Individuals who suffer from Thalassemia have a meaning in life during their treatment and life. Doing blood transfusions and taking medication, getting support, having goals and hopes in life, are things that strengthen participants who suffer from Thalassemia in undergoing a routine that repeats every month. It is also dynamic and influenced by age factors, changes in circumstances, and health conditions that can lead to adjustments to life goals, and future expectations (Steptoe & Fancourt, 2020). They still have enthusiasm, gratitude, positive attitude, self-direction and have good social relationships. Even though he is in the middle of his routine, it is inseparable from the challenges faced such as fatigue and boredom to physical strength shortages. Individuals suffering from chronic illnesses often limit their physical activity to manage pain or endure greater discomfort in order to perform the activities they enjoy (Liddiard et al., 2024). Thalassemia disease quite affects their life goals, but they still make blood transfusions and drug consumption important things that must be done. In addition to having goals and wanting to achieve them, they still have their potential as an activity that is carried out daily and within a certain period. Likewise, the things that they think mean or make them happy, memorable experiences, motivation, and self-commitment that they have led them to achieve the meaning of life. In line with that, Bonino (2020), disclose that if therapy (routine) that focuses on activities and goals is in accordance with the individual's self-identity, then it can help overcome the difficulty of finding (or rediscovering) meaning in life, as one of the main challenges in adapting to chronic diseases. Thus, in the life process of participants suffering from Thalassemia have fulfilled the personal dimension, the social dimension, and the value dimension to achieve the meaning of life.

For the meaning of life to be formed, there are factors that affect it. Certain factors that support the meaning of life are shared by participants suffering from Thalassemia, but these factors are not the same for everyone. Factors the creative values that individuals suffering from Thalassemia do from their contribution to the surrounding environment and their creativity. Social contribution does not only affect health, but health conditions also affect social participation. This affects the well-being of individuals, because it provides a sense of belonging and intimacy, so that it can improve health (Klein et al., 2021). In line with that, Yusuf et al. (2025), active participation in society, whether through work, education, or social events, can increase an individual's sense of worth and meaning. Participants can contribute to the environment and create creativity amid the lives they live, although sometimes they receive different or special and limited treatment.

The experiences they gained, such as the support from others and the disease community activities they had participated in, meant a lot to them. In line with Kristianti et al. (2020), stating that one of the things that makes individuals feel meaningful with their condition and treatment that works in the long term is social support. Such support from family, friends, co-workers, spiritual advisors, medical experts, and community members can provide social support. Individuals who are members of the community can benefit from benefits such as a sense of not being alone and mutual respect. It affects health, where individuals have a position and social relationships within the community, satisfaction with the surrounding environment, and the community facilitates the dissemination of positive health information and services (Michalski et al., 2020). In addition, a positive attitude is obtained from good knowledge and possession, thus encouraging healthy behavior and more rational decision-making (Winarningsih et al., 2025). This study found that participants suffering from Thalassemia had a positive attitude to continue undergoing treatment because of their knowledge about the disease. This attitude value factor helps them to remain able to carry out the routine that must be lived.

Meanwhile, the hope for the future, especially in health as well as the optimistic outlook and confidence possessed by the participants, increasingly gave him strength. Individuals have a strong determination to live with hope for the future despite facing illness. As he helps and supports others in similar situations, he gains a sense of control over his own destiny and prepares himself for a bright future. He remains in control of his life and fate according to medical treatment (Moore, 2024). These are the factors that individuals who suffer from Thalassemia must shape/achieve the meaning of life.

In addition to the above dimensions and factors, other diversity was found in this study. Thalassemia cannot be cured, but by doing good post-transfusion care, there is still hope that they can survive amid their physical limitations (Saprudin & Sudirman, 2020). Participants suffering from Thalassemia wanted the same life as healthy/non-Thalassemia individuals. The desire to live a normal life without having to go to the hospital, school permits, take medication to do unlimited activities. This makes participants have a desire to be able to recover or be free from the Thalassemia disease they suffer. The results of this study found that each participant suffering from Thalassemia disease has diversity by having other factors to have and achieve the meaning of their own lives.

From this study, the three participants applied different dimensions and factors to shape and achieve the meaning of their lives. The participants have had meaning in their lives, and continue to live all the routines in their lives. Thus, this study has provided an exploration the meaning of life in individuals suffering from Thalassemia.

Implications

Based on the findings of the study, there are practical and theoretical implications related to the daily struggles of individuals suffering from Thalassemia. From a practical point of view, this study highlights the need for holistic treatment for Thalassemia, which focuses not only on the medical and blood transfusion aspects, but also on the psychological and spiritual well-being of the individual. These implications include the need for systematic psychosocial intervention and educational programs for families and surrounding communities to enhance emotional and instrumental support, as well as the formation of structured support groups that facilitate experiences, reduce social isolation, and strengthen collective identity. In addition, health workers need to be based on logotherapy or meaning-centered counseling to support individuals in the process of identifying meaning during suffering, overcoming negative emotions such as self-doubt and anxiety, and creating adaptive life goals. In terms of policy, this encourages the integration of psychological services into the field of Thalassemia in health facilities as well as the advocacy of inclusive policies in the areas of education and employment such as transfusion flexibility, physical

activity, and anti-stigma campaigns, so that individuals can actively participate in society without fear of being restricted.

Theoretically, this research enriches the fields of health psychology and positive psychology, especially in understanding the concept of the meaning of life related to chronic diseases that are inherited and last a lifetime. The results of this study validate and simultaneously expand the three-dimensional model Bastaman (2007), of personal, social, and value by showing that in individuals suffering from Thalassemia, the value dimension is formed through the experience of liminality (the "in-between" state) between the reality of drug dependence and the hope of recovery, while the social dimension serves as a space for ongoing identity negotiations. The study also highlights the importance of cultural factors, such as family values, spirituality, and social conventions in Indonesian society that influence the way individuals give meaning, where social support is obtained from religious organizations or groups of fellow sufferers in addition to interpersonal networks. In addition, the phenomenological-interpretive approach effectively uncovers subjective complexities that may be missed in quantitative approaches, such as the active role of individuals suffering from Thalassemia disease in transforming boundaries into opportunities for personal development and the instability dynamics between despair and new passion. As a result, this research not only offers a path to more empathetic and successful therapies, but it also sparks theoretical discussions for future research on the relationship between psychological resilience, meaning of life, and the sustainability of a dignified existence in the presence of chronic disease.

Limitations and Further Research

Based on the results of this study, researchers realized that there are still many shortcomings. Thus, for further development, the researcher suggested to expand the reach of participants with the same topic, using theory with dynamics in individuals suffering from Thalassemia disease with certain relationships, as well as quantitatively measuring the level of life worth of individuals suffering from Thalassemia disease in Indonesia. More than that, it can deepen the meaning of treatment/disease, experience and future for individuals suffering from Thalassemia in Indonesia.

CONCLUSION

Based on the studies that have been carried out in this study, it can be concluded that individuals who suffer from Thalassemia have different life meanings. With the life journey that comes with treatment, it is not easy for individuals suffering from Thalassemia to make sense of it and live their days. The novelty they get is the support from their family and people around them and their life goals are the reason for them to continue undergoing treatment and feel more meaningful. They want to live their lives much better according to the routine that must be done, so that they can achieve the goals and desires they have.

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AUTHOR CONTRIBUTIONS STATEMENT

All authors are directly involved in this research, starting from the process of preparing a research design, conducting research, to preparing a complete manuscript. All authors have also read and approved the final version of the manuscript.

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