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Interpretation of HRQoL in Children with Thalassemia Major and Healthy Children From an Islamic Perspective

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Abstract

Thalassaemia has been proclaimed a global health challenge by the World Health Organization (WHO) due to its presence in many areas of the world. Challenges faced by children with thalassaemia include physical, psychological, social and academic difficulties that affect their Health-Related Quality of Life (HRQoL). However, the HRQoL from Islamic perspective is not only seen from physical, social, and psychological aspects, but also spiritual and moral aspects. The present study aimed to explore the Islamic view of the differences in Health-Related Quality of Life (HRQoL) between children with thalassaemia major and healthy children. This study uses a library research method, which is a comprehensive review of the literature sources. The findings indicate that the conditions experienced by children with major thalassemia and healthy children can be understood as part of Allah's divine decree, which contains wisdom and meaning. Islam emphasizes that a person's value before Allah is not determined by physical, psychological, or social perfection, but rather by their piety and deeds. Accordingly, this study is expected to contribute to healthcare professionals, educators, and parents or caregivers by encouraging them to consider not only children's physical and psychological conditions but also their spiritual well-being and sense of meaning in life.

Keywords Health-Related Quality of Life (HRQoL); Islamic Perspective; Thalassemia Major.

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INTRODUCTION

Thalassaemia is classified as a global health problem by the World Health Organization (WHO) because of its high prevalence in many regions of the world especially Mediterranean, Middle East, and Southeast Asia (Tuo et al., 2024). According to the World Bank, approximately 7% of the world's population are carriers of the thalassaemia gene (Kattamis et al., 2020). Indonesia is one of the countries in the "thalassemia belt", an area with a high prevalence of thalassaemia gene carriers (Kemenkes, 2018). Epidemiological studies in Indonesia show that the prevalence of thalassaemia carriers is 3% to 10% of the total population (Kemenkes, 2018). Data from the Indonesian Thalassaemia Foundation and the Parents Association of Thalassaemia Patients (YTI-POPTI) has shown a continuous rise in cases of thalassaemia in Indonesia. In 2018, there were around 9,000 cases, and by June 2021, the number of cases reached 10,973 (Handayani et al., 2022). The upward trend indicates that

thalassaemia is not only an individual problem but it is a major public health problem that needs considerable healthcare resources and policy attention.

Thalassaemia is a hereditary blood disorder, which is caused by a defect in the production of haemoglobin. The red blood cells are weak and easily destroyed. This condition causes chronic anaemia and life-threatening complications (CDC, 2024; Kattamis et al., 2020). The gene responsible for beta-thalassemia is the beta-globin (HBB) gene, which is crucial for haemoglobin synthesis (Saad et al., 2023) and is found in approximately 1.5% of the global population. Thalassaemia is classified into three types based on its clinical severity: thalassaemia minor (carrier state), thalassaemia intermedia, and thalassaemia major requiring continuous blood transfusions (Sinlapamongkolkul & Surapolchai, 2020). Among these types, thalassemia major is considered the most severe form. Patients typically experience severe anemia from early childhood and require lifelong blood transfusions accompanied by iron chelation therapy (Sanchez-Villalobos et al., 2022) Iron chelation therapy is essential to remove excess iron and prevent complications resulting from repeated transfusions (Lerksaipheng et al., 2024) Nevertheless, repeated transfusions can lead to iron overload, which may cause severe complications such as heart failure, diabetes mellitus, hypothyroidism, and other endocrine disorders that significantly affect children's physical functioning (Hakeem et al., 2018).

The impact of thalassaemia is more complex among children of less than 18 years of age as they are still in a critical phase of physical, cognitive and psychosocial development. According to Havighurst's developmental task theory, children are expected to achieve several developmental milestones, including acquiring physical skills, developing a positive self-concept, adjusting to peers, and establishing appropriate social roles (Jannah, 2015). However, the chronic nature of thalassemia may hinder children from fulfilling these developmental tasks. Consequently, the physical, psychological, social, and academic challenges experienced by children with thalassemia can significantly affect their Health-Related Quality of Life (HRQoL) (Biswas et al., 2023).

From an Islamic perspective, the concept of quality of life extends beyond material and psychological well-being to include spiritual and moral dimensions. This perspective is reflected in the Qur'an, where Allah states:

وَمَا خَلَقْتُ ٱلْجِنَّ وَٱلْإِنسَ إِلَّا لِيَعْبُدُونِ

"And I did not create the jinn and mankind except to worship Me." (QS. Adz-Dzariyat (51) :56).

In addition, the Prophet Muhammad stated:

إِنَّمَا بُعِثْتُ لِأُتَمِّمَ صَالِحَ الْأَخْلَاقِ

"I was sent only to perfect noble character." (HR. Al-Bukhori).

Abul A'la et al. (2026) in their study entitled "Hidup Sehat dalam Perspektif Islam: Integrasi Nilai Spiritual dalam Pendekatan Kesehatan Masyarakat" examined health from a holistic perspective encompassing physical, mental, and spiritual dimensions. However, the study did not specifically address children living with chronic illnesses, particularly those with major thalassemia. Similarly, Anyta Widianti et al. (2025) examined Qur'anic perspectives on health and explored how the teachings of the Qur'an can provide guidance for maintaining physical and mental health. Burhanuddin Ridlwan (2018), in his study entitled "Kualitas Hidup dalam Perspektif Ajaran Qur'an" discussed the essence of understanding quality of life, the nature of Qur'anic understanding, and the conceptualization of quality of life from the perspective of Qur'anic teachings. However, these studies did not specifically examine children living with chronic illnesses. Therefore, previous studies have not specifically addressed the interpretation of Health-Related Quality of Life (HRQoL) among children with major thalassemia and healthy children from an Islamic perspective. This gap highlights the need for a more specific and integrative examination of HRQoL that considers not only physical, psychological, and social dimensions but also spiritual well-being and the meaning of life within an Islamic framework.

More concerningly, the phenomenon observed indicates that a considerable number of otherwise healthy children engage in harmful behaviors, such as drug use, cyberbullying, online gaming addiction, and other negative activities (Karimulloh et al., 2024). Meanwhile, children with thalassemia major struggle with their illness in their efforts to survive and maintain their health. Therefore, this article aims to explore the Islamic perspective on the differences in Health-Related Quality of Life (HRQoL) between children with thalassemia major and healthy children.

METHOD

This study employed a qualitative approach using a literature review method. The study was conducted by collecting, reviewing, and analyzing relevant research findings from various sources to provide a comprehensive understanding of the topic under investigation (Zed, 2008). The research process began with the identification and collection of relevant literature from

academic journals, classical Islamic texts (*turāth*), books, and other related sources. These sources were obtained through Google Scholar and national and international journal databases and portals (Rukin, 2019). Following the literature analysis, the findings were described and interpreted in the context of health-related conditions among children with major thalassemia and healthy children from an Islamic perspective. Conclusions were subsequently drawn based on the analyzed and synthesized findings (Rukin, 2019).

RESULTS AND DISCUSSION

1. Health-Related Quality of Life (HRQoL) from an Islamic Perspective

Health-Related Quality of Life (HRQoL) is a comprehensive measurement of an individual's physical, psychological, and social functioning used to assess the impact of chronic diseases, identify health inequalities in society, and provide guidance for health policy planning and patient management (Chen et al., 2015) According to Hays & Reeve (2008), HRQoL describes how well individuals perform their daily functions and how they perceive their physical, mental, and social well-being in relation to health. HRQoL consists of four dimensions: physical functioning, emotional functioning, social functioning, and school functioning.

The first dimension of HRQoL is physical functioning which indicates the health condition and ability to perform daily activities. This dimension also includes physical complaints, such as pain and reduced energy that may affect daily life (Varni et al., 2001) In Islam, health is considered one of the greatest blessings bestowed by Allah SWT to human beings, yet its value is not always fully recognised. The Prophet Muhammad (peace be upon him) said:

نِعْمَتَانِ مَغْبُونٌ فِيهِمَا كَثِيرٌ مِنَ النَّاسِ ، الصِّحَّةُ وَالْفَرَاغُ

"Two blessings which many people waste: health and free time." (HR. Al-Bukhari).

This hadith means that people generally do not utilise the blessings of health and free time for useful work. If a person is physically healthy, he can carry out daily activities more optimally, including worshipping Allah SWT and fulfilling his social roles and responsibilities. Thus, maintaining health is not only an effort to avoid illness but also gratitude for the blessings of Allah and responsibility to the body that is entrusted by Him (Aufa et al., 2024). This is emphasized by the Prophet Muhammad in his saying:

إِنَّ لِبَدَنِكَ عَلَيْكَ حَقًّا

“Indeed, your body has a right over you.” (HR. Bukhari and Muslim).

The second dimension is emotional functioning, which refers to a person’s feelings and psychological state, such as fear, anger, sadness, sleep disturbances, and worries about the future (Varni et al., 2001). This function reflects the degree to which individuals can control their emotions and adapt to psychological pressure and life challenges. In the Islamic view, emotions are a human nature that must be well-managed to stay in balance and avoid excess and thus preserve inner peace (Oviensy et al., 2024). One of the major ways in Islamic teachings to cope with negative emotions and achieve inner peace is through remembrance of Allah SWT. As the Qur’an puts it:

اَلَّذِيْنَ اٰمَنُوْا وَتَطْمَىِٕنُّ قُلُوْبُهُمْ بِذِكْرِ اللّٰهِۗ اَلَا بِذِكْرِ اللّٰهِ تَطْمَىِٕنُّ الْقُلُوْبُۗ

“Those who believe and whose hearts find tranquility in the remembrance of Allah. Indeed, in the remembrance of Allah do hearts find tranquility.” (QS. Ar-Ra’d (13): 28).

This verse explains that by increasing remembrance (dhikr) and drawing closer to Allah, individuals can alleviate negative feelings and find true peace and spiritual fulfillment (Roslan & Zainuri, 2023). Furthermore, Allah SWT emphasizes the importance of following His guidance as a means for humans to attain peace of heart:

قُلْنَا اهْبِطُوْا مِنْهَا جَمِيْعًاۚ فَاِمَّا يَأْتِيَنَّكُمْ مِّنِّيْ هُدًى فَمَنْ تَبِعَ هُدَايَ فَلَا خَوْفٌ عَلَيْهِمْ وَلَا هُمْ يَحْزَنُوْنَ

“We said, ‘Go down from it, all of you. But when guidance comes to you from Me, whoever follows My guidance will have no fear, nor will they grieve.’”(QS. Al-Baqarah (2): 38).

This verse emphasizes that Allah’s guidance is the primary source through which humans can be freed from worry, sadness, and other negative emotions ((Rahmansyah et al., 2023). By following His guidance, individuals will experience peace and security not only spiritually but also in their daily lives.

The third dimension is social functioning, which relates to an individual’s ability to interact and participate within their social environment (Varni et al., 2001). From an Islamic

perspective, humans are created as social beings who naturally need to establish relationships with others (Nurhuda et al., 2023). This is explained in the Qur'an:

يٰٓاَيُّهَا النَّاسُ اِنَّا خَلَقْنٰكُمْ مِّنْ ذَكَرٍ وَّاُنْثٰى وَجَعَلْنٰكُمْ شُعُوْبًا وَّقَبَاۤىِٕلَ لِتَعَارَفُوْاۚ اِنَّ اَكْرَمَكُمْ عِنْدَ اللّٰهِ اَتْقٰىكُمْۗ اِنَّ اللّٰهَ عَلِيْمٌ خَبِيْرٌ

"O mankind, indeed We created you from a male and a female and made you into nations and tribes so that you may know one another. Indeed, the most honorable of you in the sight of Allah is the most righteous among you. Indeed, Allah is All-Knowing, All-Aware." (QS. Al-Hujurat (49): 13).

This verse explains that the differences among humans are part of Allah's will, intended to strengthen social relationships and foster mutual understanding and respect (Nurhuda et al., 2023). Thus, social life is part of human nature, as humans are created to live together and complement one another. Islam also emphasizes that good social relationships should not only be based on human needs but must also be grounded in values of goodness and piety. Allah SWT says:

وَتَعَاوَنُوْا عَلَى الْبِرِّ وَالتَّقْوٰىۖ وَلَا تَعَاوَنُوْا عَلَى الْاِثْمِ وَالْعُدْوَانِۚ وَاتَّقُوا اللّٰهَۗ اِنَّ اللّٰهَ شَدِيْدُ الْعِقَابِ

"And cooperate in righteousness and piety, but do not cooperate in sin and aggression. And fear Allah; indeed, Allah is severe in punishment." (QS. Al-Ma'idah (5): 2).

This verse emphasizes the importance of building social relationships based on goodness and piety. Helping one another in the path of Allah is seen as a means to achieve righteousness and strengthen solidarity among individuals (Saputra, 2022).

The final dimension is school functioning, which relates to an individual's ability to perform activities and roles within the school environment (Varni et al., 2001). In Islam, seeking knowledge holds a very high position and is considered an obligation for every Muslim. The Prophet Muhammad said:

طَلَبُ الْعِلْمِ فَرِيضَةٌ عَلَى كُلِّ مُسْلِمٍ

"Seeking knowledge is an obligation upon every Muslim." (HR. Ibn Majah)

This hadith emphasizes that every Muslim has the obligation to seek knowledge, as knowledge is a fundamental necessity in human life both in this world and the hereafter (Repi

et al., 2024). Islam also views seeking knowledge as a noble act of worship with great value in the sight of Allah. The Prophet Muhammad also said:

مَنْ خَرَجَ فِى طَلَبُ الْعِلْمِ فَهُوَ فِى سَبِيْلِ اللهِ حَتَّى يَرْجِعَ

"Whoever sets out in search of knowledge is in the path of Allah until he returns." (HR. Tirmidzi).

These hadiths affirm that seeking knowledge is an act of obedience to Allah and a form of worship that contains elements of struggle (jihad). The process of acquiring knowledge requires patience, perseverance, and sincerity in facing various challenges (Darani, 2021). Allah SWT also promises elevated ranks for those who believe and possess knowledge:

يَرْفَعِ اللهُ الَّذِيْنَ اٰمَنُوْا مِنْكُمْۙ وَالَّذِيْنَ اُوْتُوا الْعِلْمَ دَرَجٰتٍۗ

"Allah will raise those who have believed among you and those who were given knowledge by degrees." (QS. Al-Mujadilah (58): 11).

Based on the explanation above, it can be concluded that the concept of Health-Related Quality of Life (HRQoL) from an Islamic perspective does not merely assess well-being from physical, emotional, social, and school aspects but emphasizes the relationship between physical and spiritual health as a form of obedience to Allah SWT. Health-related quality of life (HRQoL) in Islam is not only the absence of disease but also how well individuals fulfil their roles as servants of Allah responsibly. The real quality of life in health is when a person can balance the physical, mental, social and spiritual health based on faith and piety to Allah SWT.

2. Interpreting Health-Related Quality of Life (HRQoL) Among Children with Major Thalassemia and Healthy Children in Indonesia from an Islamic Perspective

Children are defined as individuals under the age of 18 years, including those still in the womb (Kemenkes, 2014). Healthy children can be identified through good conditions across several aspects, including physical, psychological, and social well-being (Dewi, 2022). According to the Kemenkes (2014), characteristics of healthy children include balanced growth and nutritional status, age-appropriate motor, cognitive, and affective development, cheerful

and active behavior, the ability to adapt to the environment, stable mental conditions, and freedom from physical illness.

In Islam, children's health includes two important dimensions. The first is physical health (as-shihah), which refers to a healthy body free from illness. The second is spiritual health (afiat), which has a broader meaning referring to perfect health (al-shihah al-tammah), encompassing not only a healthy body but also a strong and stable soul (Budiyanto, 2020). Thus, a healthy child from an Islamic perspective is one who is not only physically healthy but also possesses strong mental and spiritual qualities. However, not all children are born or grow up with the same health conditions, for example children with major thalassemia.

Thalassemia is a genetic blood disorder characterized by a reduction or absence of globin chain production in hemoglobin, which interferes with the normal formation of red blood cells (Sanchez-Villalobos et al., 2022). Clinically, children with major thalassemia generally have hemoglobin (Hb) levels below 7 g/dL with Hb F <90%, which leads to bone marrow expansion, splenomegaly, bone deformities, and growth delays (Sanchez-Villalobos et al., 2022)). In its management, children with major thalassemia require lifelong regular blood transfusions. However, repeated transfusions carry the risk of iron overload in various organs, which without proper treatment can lead to complications and increase mortality risk among thalassemia patients (Hussain et al., 2018).

In Islam, illness is not viewed solely as something negative but as a test that can elevate a person's level of faith in Allah SWT (Nawwir, 2020). Allah SWT says:

كُلُّ نَفْسٍ ذَاۤىِٕقَةُ الْمَوْتِۗ وَنَبْلُوْكُمْ بِالشَّرِّ وَالْخَيْرِ فِتْنَةً ۗوَاِلَيْنَا تُرْجَعُوْنَ

"Every soul will taste death. And We test you with evil and with good as trial; and to Us you will be returned." (QS. Al-Anbiya (21): 35).

This verse emphasizes that human life is a series of tests, both good and bad, designed to test faith and patience. Thus, the illness experienced by children with major thalassemia can be understood as part of such a test.

In facing these trials, children with thalassemia and their families are encouraged to practice patience, effort (ikhtiar), and reliance on Allah (tawakkal) (Sarianti & Rini, 2023). Seeking treatment is a form of effort strongly encouraged in Islam. The Prophet Muhammad said:

إِنَّ اللَّهَ لَمْ يُنْزِلْ دَاءً إِلَّا أَنْزَلَ لَهُ شِفَاءً، عَلِمَهُ مَنْ عَلِمَهُ وَجَهِلَهُ مَنْ جَهِلَهُ

"Allah has not sent down a disease except that He has also sent down its cure." (HR. Ahmad).

The hadith emphasizes that every disease sent down by Allah has a remedy, thereby encouraging individuals to seek medical treatment as an expression of obedience to and faith in Allah SWT (Hakim et al., 2023). For children with major thalassemia, treatments such as regular blood transfusions and iron chelation therapy represent concrete forms of ikhtiyar (active effort) to maintain health and prolong life expectancy. Families play a crucial role in ensuring adherence to transfusion schedules, meeting children's nutritional and rest needs, providing emotional and spiritual support, and creating an environment free from stigma associated with the child's health condition. Parents should also help children gradually understand their health condition in accordance with their age and developmental level, thereby fostering their autonomy, self-acceptance, and ability to adapt to the illness they experience. These responsibilities are consistent with the parental obligation to uphold the trust (amanah) entrusted to them and to provide children with the best possible protection, care, and upbringing (Gamal & Aslati, 2026).

On the other hand, healthcare and educational institutions have a responsibility to create supportive environments that promote the well-being, continuity of care, and development of children with major thalassemia. Healthcare institutions should implement patient- and family-centered care that addresses not only the child's medical condition but also their psychological, social, and spiritual well-being. Educational institutions should provide flexibility regarding attendance and academic activities for children who undergo regular blood transfusions, offer appropriate learning support when children require medical treatment or hospitalization, and prevent discrimination and stigma within the school environment.

Based on the foregoing discussion, it can be concluded that the interpretation of Health-Related Quality of Life (HRQoL) among children with major thalassemia and healthy children in Indonesia can be understood as a form of diversity that constitutes part of sunnatullah (the divine order established by Allah) and as a test containing inherent wisdom. In Islam, every child, regardless of differences in physical, psychological, or social conditions, has equal value in the sight of Allah SWT, because a person's worth is not determined by their condition but by their level of piety. This understanding has important practical implications: children with major thalassemia should not be viewed solely as patients, but as individuals who have the right to grow, learn, interact with others, receive care and affection, engage in spiritual life, and

develop their potential to the fullest. Therefore, improving HRQoL requires a holistic and collaborative approach involving children, families, healthcare professionals, educational institutions, and the wider community. Such an approach enables the Islamic principles of sabr (patience), ikhtiyar (active effort), and tawakkul (reliance on Allah) to move beyond religious concepts and be translated into concrete actions, including comprehensive healthcare services, sustained family support, inclusive education, and a social environment free from stigma. Thus, the Islamic perspective contributes not only to how illness is understood and interpreted, but also to the development of concrete support systems aimed at improving the quality of life and preserving the dignity of children with major thalassemia.

CONCLUSIONS

The interpretation of Health-Related Quality of Life (HRQoL) among children with major thalassemia and healthy children in Indonesia indicates that the differences between them constitute part of Allah's divine decree and contain inherent wisdom. Islam emphasizes that a person's worth in the sight of Allah is not determined by physical, psychological, or social perfection, but rather by their piety and deeds. Accordingly, children with major thalassemia who consistently demonstrate patience and gratitude hold equal dignity and worth, and may even attain greater honor in the sight of Allah SWT. These findings contribute to broadening the conceptualization of HRQoL beyond a mere indicator of health status by incorporating spiritual well-being, meaning in life, and social responsibility. The findings may also provide valuable information for healthcare services to identify children's needs more comprehensively, including their medical, psychological, and spiritual needs.

Accordingly, the primary contribution of the Islamic perspective in this study lies in emphasizing that improving the quality of life of children with major thalassemia is a multidimensional responsibility that extends beyond the success of medical treatment. This perspective encourages the development of more holistic and integrated services involving healthcare professionals, psychologists, families, schools, and religious services, enabling children with major thalassemia not only to achieve better medical outcomes but also to grow, learn, interact with others, and lead meaningful lives in accordance with their potential.

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