PROCEEDING

2nd Banten International Conference on Health Advancement & Research
binar@poltekkesbanten.ac.id
https://binar.poltekkesbanten.ac.id/
Vol. 1 No. 2 (2026)

# Breaking the Thalassemia Chain: A Critical Analysis of Tasikmalaya Regional Government Policies

Dini Mariani[1], Novi Enis Rosuliana[2]*, Betty Suprapti[3]

[1,2]Department of Nursing, Poltekkes Kemenkes Tasikmalaya, Indonesia
[3]Department of Nursing, Bhakti Tunas Husada University, Indonesia
*Corresponding author: Novi Enis Rosuliana, Department of Nursing, Poltekkes Kemenkes Tasikmalaya, Indonesia, E-mail: ikhsanovi@gmail.com, Phone: +62 819-4494-2421*

## ABSTRACT

**Objective:** This study aims to analyse local government policies in breaking the chain of thalassemia disease. **Methods:** The research used a descriptive qualitative approach. The research subjects totalled 20 people, including the head of the Tasikmalaya City and Regency Health Office, the Head of the Office of the Ministry of Religion for the City and Regency of Tasikmalaya, the Head of the XII Regional Branch Office, and the Principal of a Senior High School. Research data collection using FGD (Focus Group Discussion) involves interview methods, directed group discussions, observation, and data analysis, including transcription and qualitative analysis using NVivo. **Results:** Data analysis obtained 25 codes, five categories and three themes, namely the first theme: Policy and Implementation to break the Thalassemia chain, the second theme: Challenges and obstacles faced in breaking the Thalassemia chain with the category of Challenges and barriers to policy implementation and the lack of supporting data on Thalassemia in related stakeholders, the third theme: Policy recommendations to break the Thalassemia chain in Tasikmalaya, including expectations in the implementation of policies and efforts related to future policies. **Conclusion:** The study emphasizes the significance of regional policy commitment in achieving zero thalassemia by implementing premarital screening and education, as well as addressing primary issues that arise, including data limitations, stigma, and financial constraints.

**Keywords: Child; Health; Thalassemia; Regional Government Policies**

## INTRODUCTION

Thalassemia is a congenital blood disorder characterized by premature destruction of red blood cells, resulting in chronic anemia and other clinical manifestations, including bone deformities, splenomegaly, and increased susceptibility to infection (Amelia et al., 2018). Globally, thalassemia remains an important public health problem. Epidemiological data indicate that thalassemia affects approximately 4.4% of every 10,000 live births, with β-thalassemia major being one of the most prevalent forms and associated with substantial morbidity and mortality, particularly among children (Kadhim et al., 2017). In Indonesia, approximately 3.8% of the population are thalassemia carriers, while reported cases increased from 4,896 in 2012 to 8,761 in 2018. Approximately 2,500 babies are estimated to be born with β-thalassemia major annually (Wahidiyat et al., 2022).

Thalassemia prevention includes primary, secondary, and tertiary prevention (Keputusan Menteri Kesehatan Republik Indonesia, 2018). Premarital screening and health education are important strategies for preventing the emergence of new cases. However, previous studies have shown that knowledge and awareness of thalassemia screening remain limited. Negative stigma, insufficient understanding of the hereditary nature of thalassemia, and limited interest in carrier screening continue to present challenges (Nor et al., 2022; Hossain et al., 2020; Rishmitha et al., 2022). Education regarding thalassemia and genetic inheritance therefore needs to be strengthened, particularly among adolescents and prospective couples.

The Indonesian government has established national guidelines for thalassemia management through the Decree of the Minister of Health of the Republic of Indonesia Number HK.01.07/MENKES/1/2018. However, the existing policy framework requires implementation at the provincial, city, and district levels. In Tasikmalaya, thalassemia control has involved collaboration between the Health Office, Indonesian Red Cross

(PMI), and hospitals, but there is no specific and integrated local government policy aimed at breaking the thalassemia chain. This situation indicates a policy gap that requires attention from local stakeholders.

The need for a local policy is further supported by the substantial economic burden associated with thalassemia treatment, particularly regular blood transfusions and iron chelation therapy (Rejeki et al., 2012; Shafie et al., 2021). Effective prevention through screening, education, and cross-sectoral collaboration may reduce the emergence of new cases and the long-term burden of disease. Previous research also emphasizes the importance of local government policies that are responsive to community needs and involve multiple stakeholders in their implementation (Wei et al., 2024).

Therefore, this study aims to analyze local government policies and develop policy recommendations for breaking the chain of thalassemia in Tasikmalaya, with a focus on health promotion, premarital counseling and screening, and the integration of thalassemia education within the educational sector.

## MATERIALS AND METHODS

### Research Design and Participants

This study used a descriptive qualitative research design based on the 4S framework, namely Structure, System, Staff, and Instruments, to explore local government policies and efforts to break the chain of thalassemia in Tasikmalaya. The study involved 20 informants representing relevant stakeholders, including the Heads of the Tasikmalaya City and Regency Health Offices, the Heads of the Ministry of Religious Affairs Offices of Tasikmalaya City and Regency, the Head of Regional Branch Office XII, the Principal and teachers of a Senior High School, health program holders, health analyst staff, P2PTM sub-coordinators, and representatives of the Indonesian Thalassemia Parents Association (POPTI).

### Data Sources and Data Collection

Data were collected through in-depth interviews, Focus Group Discussions (FGDs), observations, and documentation, supported by secondary data and relevant study documents. The interviews and FGDs were conducted with stakeholders involved in thalassemia prevention and policy implementation. The research instruments consisted of interview guides, FGD guidelines, and a screening intention instrument.

### Data Analysis

Qualitative data were analyzed inductively using NVivo 12. The analysis consisted of several stages: (1) collecting and transcribing interview and FGD data; (2) reading the transcripts comprehensively to understand participants' general and in-depth perspectives; (3) coding statements relevant to the research objectives; (4) grouping codes into categories; (5) developing descriptions and themes into qualitative narratives; and (6) formulating a local government policy concept for breaking the chain of thalassemia.

### Trustworthiness and Bias Control

The trustworthiness of the findings was supported through **data triangulation**, by comparing information obtained from FGDs, individual in-depth interviews, document analysis, and observations. Member checking was also conducted with selected informants to verify that the identified themes accurately represented their perspectives. The use of NVivo provided a systematic analytical process and supported an audit trail of the qualitative analysis.

### Ethics Approval and Informed Consent

This study received ethical approval from the Ethics Committee of FK Unram, with certificate number 167/UN18.F8/ETIK/2023. All participants received information regarding the objectives, procedures, benefits, and potential risks of the study before participation. Informed consent was obtained from all participants before data collection, with confidentiality and privacy maintained throughout the research process.

## RESULTS AND DISCUSSION

### Qualitative analysis results

The data was obtained from the results of the Focus Group Discussion (FGD) with participants from related stakeholders. Data analysis using inductive analysis using NVivo 12, obtained 25 codes, five categories, and three themes, namely: the first theme, Policy and Implementation to break the current thalassemia chain; the second theme, Challenges and obstacles faced in breaking the Thalassemia chain; and the third theme, Policy recommendations to break the Thalassemia chain in Tasikmalaya. The first theme consists of categories on current policy and policy implementation. The second theme consists of challenges and barriers to policy implementation and lack of supporting data. The third theme includes expectations in policy implementation and further policy-related efforts

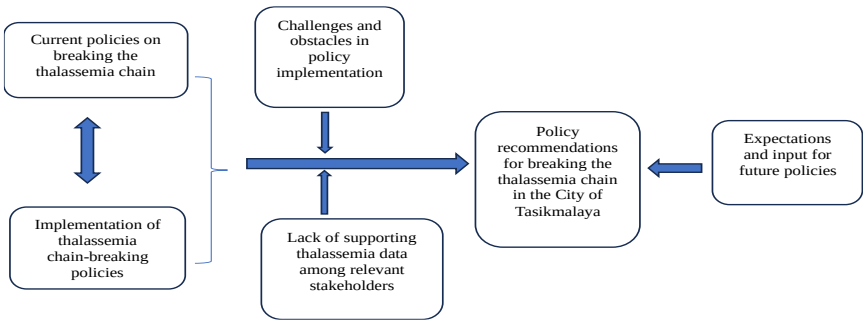



Figure 1. Mind Map Breaks the Thalassemia Chain in Tasikmalaya

**Table 1. Qualitative Analysis Results**

| Theme | Category | Code |
|---|---|---|
| I. Policy and Implementation breaking the current Thalassemia chain | 1. Current policies to break the thalassemia chain | There is a cross-sectoral cooperation program, but not yet for thalassemia<br>No specific policy yet<br>Support from the Health Office<br>Support from the Pediatrician Association<br>Screening is a current effort. |
| I. Policy and Implementation breaking the current Thalassemia chain | 2. Implementation of policies to break the thalassemia chain | Education and assurance for people with thalassemia<br>Education by Puskesmas<br>Special subjects on thalassemia do not exist in the new high school curriculum, which is related to the general subjects.<br>Implementation of screening to break the chain<br>Assistance for people with disabilities by health center counselors<br>Inclusive Programs for Cooperation Between Stakeholders |
| II. Challenges and obstacles faced in breaking the Thalassemia chain | 3. Challenges and barriers to policy implementation | The weight separates a positive marriage from a negative one<br>The card has not identified patient data.<br>The psychological effects of open screening at school age<br>Expensive screening prices and large quantities<br>The need for funds and blood donation is huge.<br>Readiness of the Social Security Administration Agency to fund thalassemia<br>Financing Challenges in Program Implementation<br>public sensitivity about disease openness |
| II. Challenges and obstacles faced in breaking the Thalassemia chain | 4. Lack of supporting data on Thalassemia among relevant stakeholders | There is no thalassemia data yet at the Ministry of Religious Affairs |
| III. Policy recommendations to break the Thalassemia chain in Tasikmalaya | 5. Expectations in policy implementation | Premarital guidance is an educational path to break the chain of thalassemia.<br>Early detection of newborn<br>Education is necessary to attend high school.<br>Support for the birth of the thalassemia chain-breaking policy<br>Joint movement with the Education Office<br>Be careful in implementing health programs.<br>Comprehensive policy<br>Policy needs from the center for regional control.<br>Encouraging the birth of Perwal or Regional Regulation to break the chain |

| | | |
|---|---|---|
| | | of Thalassemia<br>There needs to be a cross-sectoral cooperation agreement to follow up on the programme.<br>There is a need for a review of the potential of thalassemia. |
| III. Policy recommendations to break the Thalassemia chain in Tasikmalaya | 6. Further policy-related efforts | Need for standard policies from relevant stakeholders.<br>Need higher work<br>The need for pre-marital thalassemia screening<br>School Health Efforts at the elementary-high |

**Theme 1: Policy and implementation to break the current chain**

Based on the results of qualitative data analysis, three themes emerged: Policy and Implementation to Break the Current Thalassemia Chain, Challenges and Obstacles Faced in Breaking the Thalassemia Chain, and Policy Recommendations to Break the Thalassemia Chain in Tasikmalaya, comprising six categories and 21 codes.

Theme 1 Policy and Implementation to break the current chain with two categories, namely the policy of Efforts to break the current thalassemia chain, and the implementation of the policy to break the thalassemia chain. This research suggests that in Tasikmalaya, there is a need for a policy to be implemented by the Tasikmalaya city government, as the number of people with thalassemia is on the rise. However, to date, there has been no cross-sectoral cooperation, for example, between the Health Office, the Ministry of Religion, or with the high school; there is still no program that seeks to prevent the increase in people with thalassemia. Currently, there are no policies or regulations in the Law that regulate wedding preparations in terms of health (Munawaroh, 2019). A policy aims to address problems that arise, especially those related to the community's needs. Policies must be written in a formal and binding manner to regulate behaviour and serve as a guideline for action. The stages in policy making include: a) identifying problems and needs, b) analysing problems and needs, c) conveying information related to the policy plan, d) formulating the objectives of the policy, e) determining the selection of policy models, f) determining social indicators, g) building public support and legitimacy (Abdulah et al., 2022).

**Theme 2: Challenges and obstacles faced in breaking the chain of thalassemia**

Theme 2 comprises two categories: challenges and barriers to policy implementation, as well as a lack of supporting data on thalassemia among related stakeholders. Based on the results of the interviews, several challenges in breaking the thalassemia chain are due to the high cost of thalassemia screening that the community must bear. The study's results showed that effective health policies, tailored to local culture, in the form of thalassemia prevention programs with screening, were highly successful, with a success rate exceeding 95%. In addition, the screening program, which tests for genetic diseases, can save approximately $490 per case of thalassemia that is prevented. The importance of this research highlights the need for policymakers in Tasikmalaya to review the financing of health service programs (Kiani et al., 2024; Shafie et al., 2021).

The public's perception that still views thalassemia as a disgrace means it is less open to health workers. This perception also influences the psychology of students at school, particularly when known by their friends, which can lead to bullying acts. Additionally, the limited availability of funds and blood for transfusions is a related issue. Research journals also reinforce this condition (Rujito, 2019; Anemia & Langer, 2023). Other studies also show that if there is a family member who has thalassaemia, it will cause mental, social, physical, and financial suffering; besides that, repeated blood transfusions can also be the leading cause of death, morbidity conditions, and severe clinical conditions (Yousuf et al., 2022). In addition, perception and knowledge related to thalassemia pose a challenge that must be addressed, as increased public awareness will have an impact on attitudes and behaviors (Tursinawati & Fuad, 2018). Other research also shows that educational programs and policies should be tailored to the local culture of the community, by actively engaging the community and strengthening public communication about health, so that people's knowledge and understanding of Thalassemia can be improved (Dubey et al., 2024).

The second thematic finding, characterized by challenges in policy implementation and a distinct lack of supporting data among related stakeholders, represents a critical breakdown in Kingdon's framework, specifically in the Problem Stream. Our findings indicate a consensus among informants regarding the high cost of premarital screening and the lack of standardization across regional health facilities. This financial barrier directly hinders the development of solutions within the Policy Stream, as policymakers prioritize

cost-effective public health programs. Crucially, stakeholders like the Ministry of Religious Affairs (Kemenag) reported a 'lack of knowledge' about Thalassemia, hindering the integration of mandatory screening into premarital counselling. This lack of cohesive, standardized data and cross-sectoral awareness prevents the Problem Stream from reaching the required visibility and political gravity. Despite the presence of a solution (e.g., policy recommendation for a new local by-law), the absence of a politically charged and clearly defined problem (supported by local prevalence, screening coverage, and cost-effectiveness data, as pointed out by Reviewer 2) means the Policy Window remains closed. Therefore, a prerequisite for the successful implementation of the proposed local regulation is a dedicated governmental effort to establish a standardized, subsidized screening program and disseminate its quantitative data to secure the necessary political commitment (Politics Stream) for policy convergence.

**Theme 3: Policy recommendations to break the thalassemia chain in Tasikmalaya**

Theme 3 is the policy recommendations to break the thalassemia chain in Tasikmalaya. It includes expectations in policy implementation, where there are five codes, namely the existence of a premarital guidance program in the form of education related to thalassemia to break the thalassemia chain because based on informant data, it is stated that the premarital guidance program has been implemented, but has not included an education program related to thalassemia and there is no screening Thalassemia in the bride-to-be, because the Ministry of Religion does not know about thalassemia. In addition, the informant from the Health Office mentioned that the prevention program has been carried out by providing education; however, there has been no screening or early detection of thalassemia since birth due to the high cost of thalassemia screening. Meanwhile, information at school indicated that learning related to genetics and hereditary diseases has been included in the curriculum, but only at a general level. In addition, all informants from the research subjects expressed support for policies that could be implemented to break the thalassemia chain, as the condition is becoming increasingly prevalent.

Research also shows that the role of the Indonesian Thalassemia Parents Association is vital; however, in dealing with thalassemia patients, several related agencies must be involved in coordination and communication. Based on Regulation of the Minister of Health of the Republic of Indonesia No. 13 of 2022, it is evident that thalassemia is included in the Ministry of Health's work target for 2022-2024, as part of the 4th goal to achieve equitable health financing in promotive and preventive activities. Thalassemia, based on data from the Social Security Administration Agency, is one of 14 diseases that need screening services, including: 1. Congenital hypothyroidism, 2. Anaemia, 3. Tuberculosis, 4. Hepatitis 5. Diabetes Mellitus, 6. Hypertension, 7. Heart, 8. Stroke, 9. Chronic Obstructive Pulmonary Disease (COPD), 10. Thalassemia 11. Breast cancer 12. Cervical cancer, 13. Lung cancer and 14. Bowel cancer. In addition, thalassemia is included in a regulatory framework that supports screening, control of risk factors, and NCD surveillance, involving all relevant agencies (Menteri Kesehatan RI, 2022). So there is a need for awareness from policymakers in the regions to improve the system and immediately coordinate and cooperate in handling thalassemia patients in Tasikmalaya.

The final thematic finding highlights the strong support among stakeholders for the establishment of a regional regulation (Peraturan Daerah/Perda) on Thalassemia prevention. Based on the preceding MSF analysis (Theme 2), which found that the Policy Window remains closed due to a lack of data and structured planning, we propose a detailed, multi-sectoral implementation mechanism for the proposed Perda. This ensures the recommendation is not merely aspirational but politically feasible and academically rigorous, addressing the reviewer's concern regarding clarity of implementation.

**Proposed multi-sectoral implementation mechanism**

- Tasikmalaya Health Office (Dinas Kesehatan): Coordinator and Technical Lead. Responsible for developing standardized regional screening protocols (including the standardized cost and procedure), managing the central Thalassemia patient registry (data management), and ensuring the availability of diagnostic reagents and referral services across the region's primary healthcare facilities (Puskesmas).
- Ministry of Religious Affairs (Kemenag) Tasikmalaya: Primary Screening Gateway. Responsible for enforcing the requirement of a Thalassemia Carrier Status Certificate as a prerequisite for pre-marital counseling and registration. This integrates prevention directly into the marriage process, maximizing coverage.
- Education Sector (Dinas Pendidikan and Schools): Awareness and Education. Responsible for integrating basic Thalassemia information (inheritance, prevention) into the existing high school curriculum (e.g., Biology or Health Education) to target the most at-risk population cohort (adolescents/future parents).

**Funding mechanism**

- Regional Budget Allocation (APBD): The local government must allocate a dedicated APBD line item specifically for subsidized or free pre-marital Thalassemia screening for all prospective couples who cannot afford the standardized fee. This allocation should be prioritized annually.
- Integration with National Health Insurance (JKN/BPJS): Lobbying the central government/BPJS to classify pre-marital screening for Thalassemia as a preventive public health service eligible for coverage under the JKN scheme. This shifts the financial burden from individual or regional budgets to the central insurance system, thereby improving feasibility.
- Cross-Subsidy Mechanism: Implementing a nominal, mandatory administrative fee for marriage registration to be cross-subsidized into the screening fund, ensuring sustainability without relying entirely on direct government grants.

**Monitoring and evaluation**

- Policy Performance Indicators: Key indicators must be defined, focusing on: 1) Screening Coverage Rate (percentage of prospective couples screened per year) and 2) Thalassemia Incidence Rate (tracking the number of new major cases born).
- Annual Stakeholder Review: The Health Office must facilitate an annual Performance Review Meeting involving all key stakeholders (Health Office, Kemenag, Policy Makers, and POPTI/Thalassemia Patient Organization representatives) to evaluate the performance indicators, identify bottlenecks, and propose necessary budget or procedural adjustments.
- Public Reporting: The annual progress report on Thalassemia prevention must be submitted to the local legislative body (DPRD) and publicly disseminated to maintain political transparency (Politics Stream of the MSF).

## CONCLUSION

This study concludes that efforts to break the thalassemia chain in Tasikmalaya have been implemented through health education, screening, assistance, and cross-sectoral collaboration. However, these efforts have not yet been supported by a specific, integrated, and standardized local policy. The main challenges include the high cost of screening, limited financial resources and blood availability, stigma and concerns regarding disease disclosure, and inadequate supporting data among relevant stakeholders.

The findings indicate that strengthening regional policy is essential to support the prevention and early detection of thalassemia. The recommended policy directions include premarital thalassemia education and screening, early detection, integration of thalassemia education into schools, cross-sectoral collaboration, standardized policies among stakeholders, and the development of regional regulations (Perda/Perwal). These efforts are expected to strengthen local government commitment and contribute to breaking the chain of thalassemia in Tasikmalaya.

The study contributes to the development of evidence-based regional health policy by identifying stakeholder perspectives, implementation barriers, and feasible policy directions for thalassemia prevention. The findings may serve as a basis for strengthening coordinated preventive programs and developing integrated local policies aimed at achieving zero thalassemia.

## CONFLICT OF INTEREST (if any)

The authors declare that they have no financial or non-financial conflicts of interest related to this study.

## ACKNOWLEDGEMENTS (if needed)

Not applicable

## REFERENCES

Abdulah, Fitri, A. H., Sari, A. M., Gistituati, N., & Rusdinal. (2022). Tahapan pembuatan kebijakan publik sebagai landasan pengambil kebijaksanaan. *Jurnal Muara Pendidikan*, *7*(1), 148–155.

Amelia, R., Labellapansa, A., & Siswanto, A. (2018). Sistem pakar sebagai alat bantu untuk pendekatan diagnosis penyakit thalasemia pada anak menggunakan metode Dempster-Shafer. *IT Journal Research and Development*, *2*(2). https://doi.org/10.25299/itjrd.2018.vol2(2).1034

Anemia, M., & Langer, A. L. (2023). *Beta-thalassemia summary: Genetic counseling*.

Choed-Amphai, C., Kusontammarat, P., Chanthong, S., et al. (2025). Clinical course and management of hypertriglyceridemia thalassemia syndrome: A case-based systematic review. *World Journal of Clinical Pediatrics, 14*(2). https://doi.org/10.5409/wjcp.v14.i2.101543

Dewanti, W., Irawati, I., & Halimah, M. (2019). Implementasi kebijakan tata laksana thalasemia di Kabupaten Subang. *Natapraja, 7*(1), 139–152.

Dubey, A., Deb, R., & Devi, N. K. (2024). Assessment of knowledge, attitude and practice towards beta-thalassemia among Ahir community in Delhi and NCR. *International Journal of Anthropology, 39*(3–4), 273–283. https://doi.org/10.14673/IJA2024341128

El-Dash, H., & Adel, S. (2018). Cutaneous manifestations in Egyptian children with beta-thalassemia major: Relationship with serum ferritin, thyroid profile, and treatment modalities. *Pediatric Dermatology, 35*(5), 639–643. https://doi.org/10.1111/pde.13570

Ghassemi, F., Khamseh, M. E., Sadighnia, N., et al. (2024). Guideline for the diagnosis and management of growth and puberty disorders in patients with transfusion-dependent thalassemia. *International Journal of Endocrinology and Metabolism, 16*(1), 43–52.

Hossain, M. S., Hasan, M. M., Raheem, E., et al. (2020). Lack of knowledge and misperceptions about thalassaemia among college students in Bangladesh: A cross-sectional baseline study. *Orphanet Journal of Rare Diseases, 15*(1), 1–10. https://doi.org/10.1186/s13023-020-1323-y

Kadhim, K. A., Baldawi, K. H., & Lami, F. H. (2017). Prevalence, incidence, trend, and complications of thalassemia in Iraq. *Hemoglobin, 41*(3), 164–168. https://doi.org/10.1080/03630269.2017.1354877

Kattamis, A., Forni, G. L., Aydinok, Y., & Viprakasit, V. (2020). Changing patterns in the epidemiology of β-thalassemia. *European Journal of Haematology, 105*(6), 692–703. https://doi.org/10.1111/ejh.13512

Keputusan Menteri Kesehatan Republik Indonesia. (2018). *Keputusan Menteri Kesehatan Republik Indonesia*.

Kiani, A., Aliabadi, E. G., Kermani, B., Davarani, F. R., Rahmanian, V., & Daneshi, S. (2024). Assessing the success and effectiveness of the major β-thalassemia screening program in Southeast Iran: A case study of Jiroft District. *Journal of Health Sciences and Surveillance System, 12*(3), 319–326. https://doi.org/10.30476/jhsss.2023.97455.1707

Mettananda, S. (2020). Improving standards of care for children with thalassaemia in Sri Lanka. *Sri Lanka Journal of Child Health, 49*(1), 94. https://doi.org/10.4038/SLJCH.V49I1.8911

Menteri Kesehatan Republik Indonesia. (2022). *Peraturan Menteri Kesehatan Republik Indonesia Nomor 13 Tahun 2022 tentang perubahan atas Peraturan Menteri Kesehatan Nomor 21 Tahun 2020 tentang Rencana Strategis Kementerian Kesehatan Tahun 2020–2024*.

Munawaroh, L. (2019). Kesehatan tes sebagai syarat pra nikah (Studi UU pernikahan di Kuwait). *YUDISIA: Jurnal Pemikiran Hukum dan Hukum Islam, 10*(1). https://doi.org/10.21043/yudisia.v10i1.4684

Nor, M. A. M., Idris, N. S., Zulkifli, M. M., Abu Bakar, R., & Ahmad, I. (2022). Thalassemia screening: Low level of knowledge among unmarried youths in Kota Bharu, Kelantan, Malaysia. *Malaysian Family Physician, 17*(1), 57–65. https://doi.org/10.51866/oa.31

Olatunya, O. S., Babatola, A. O., Adeniyi, A. T., et al. (2021). Determinants of care-seeking practices for children with sickle cell disease in Ekiti, Southwest Nigeria. *Journal of Blood Medicine, 12*, 123–132. https://doi.org/10.2147/JBM.S294952

Palanisamy, B., Kosalram, K., & Chinnaiyan, S. (2024). Social networks and social support: Parents experiences in the management of thalassemia, a complex lifelong inherited blood disorder, in the indigenous context – A qualitative study. *Clinical Epidemiology and Global Health, 25*, 101491. https://doi.org/10.1016/j.cegh.2023.101491

Rejeki, D. S. S., Nurhayati, N., Supriyanto, S., & Kartikasari, E. (2012). Studi epidemiologi deskriptif talasemia. *Kesmas: National Public Health Journal, 7*(3), 139. https://doi.org/10.21109/kesmas.v7i3.61

Rishmitha, Badagabettu, S., M. V. A., Lakshmi, R. V., & C. U. J. (2022). Awareness on thalassemia and opinion of carrier screening among young women from selected undergraduate colleges of Udupi District. *Clinical Epidemiology and Global Health, 14*, 100978. https://doi.org/10.1016/j.cegh.2022.100978

Rujito, L. (2019). *Talasemia: Genetik dasar dan pengelolaan terkini*. UNSOED Press.

Saengnipanthkul, S., Sirikarn, P., Musikaboonleart, S., Tran, L. C., & Puwanant, M. (2025). Prevalence and associated factors of at risk of anemia among children under five in Northeast Thailand using noninvasive hemoglobin screening in a cross sectional study. *Scientific Reports, 15*(1), 1–12. https://doi.org/10.1038/s41598-025-05550-8

Shafie, A. A., Mohammed, N. S., See, K. F., Ibrahim, H. M., Wong, J. H. Y., & Chhabra, I. K. (2022). Efficiency and management factors: Finding the balance in thalassaemia care centres. *Health Economics Review, 12*(1), 1–13. https://doi.org/10.1186/s13561-021-00351-x

Shafie, A. A., Wong, J. H. Y., Ibrahim, H. M., Mohammed, N. S., & Chhabra, I. K. (2021). Economic burden in the management of transfusion-dependent thalassaemia patients in Malaysia from a societal perspective. *Orphanet Journal of Rare Diseases, 16*(1), 1–12. https://doi.org/10.1186/s13023-021-01791-8

Susanto, Z., Siswandari, W., & Rujito, L. (2020). Cd60 (GTG > GAG)/Hb Cagliari mutation was found in scanning of β-thalassemia alleles from patients of East Kalimantan, Indonesia. *Molecular Genetics and Metabolism Reports, 22*, 100550. https://doi.org/10.1016/j.ymgmr.2019.100550

Tursinawati, Y., & Fuad, W. (2018). Pengetahuan pengaruhi sikap dan tindakan mahasiswa terhadap program pencegahan thalassemia di Indonesia. *HIGEIA (Journal of Public Health Research and Development), 2*(4), 654–662. https://doi.org/10.15294/higeia.v2i4.25407

Wahidiyat, P. A., Sari, T. T., Rahmartani, L. D., et al. (2022). Thalassemia in Indonesia. *Hemoglobin, 46*(1), 39–44. https://doi.org/10.1080/03630269.2021.2023565

Wei, H. B., Liang, S., Wei, Y. J., et al. (2024). Quantitative evaluation of Guangxi thalassemia prevention and control policies based on PMC index model. *Modern Preventive Medicine, 51*(18), 3368–3373, 3392. https://doi.org/10.20043/j.cnki.MPM.202405199

Yousuf, R., Akter, S., Wasek, S. M., Sinha, S., Ahmad, R., & Haque, M. (2022). Thalassemia: A review of the challenges to the families and caregivers. *Cureus, 14*(12), 8–15. https://doi.org/10.7759/cureus.32491