

DAFTAR PUSTAKA

- Ağaoğlu L. (2010). *Life in thalassemia*. *Türkiye Klinikleri*, 3 (1): 9–13. [Google Scholar]
- Aji, D. N., Silman, C. Aryudi, C. Cynthia. Centauri. Andalia, D. Astari, D. Pitaloka D., Wawolumaya,C. Sekartini, R. Amalia, P. (2009) Faktor– Faktor yang Berhubungan dengan Kualitas Hidup Pasien Thalassemia Mayor di Pusat Thalassemia Departemen Ilmu Kesehatan Anak RSCM. *Jurnal Sari Pediatri*, Vol. 11 (2), hal 85-89
- Ali, M., Muhyi, A. & Riastiti, D. (2021). Hubungan Usia, Kadar Hemoglobin Pretransfusi dan Lama Sakit terhadap Kualitas Hidup Anak Talasemia di Samarinda. *Jurnal Sains Kesehatan.*, Vol 3. No 4., 441-447
- Ali, S., Mumtaz, S., Shakir, H. A., Khan, M., Tahir, H. M., Mumtaz, S., Mughal, T. A., Hassan, A., Kazmi, S. A. R., Sadia, Irfan, M., & Khan, M. A. (2021). *Current status of beta-thalassemia and its treatment strategies*. *Molecular Genetics and Genomic Medicine*, 9(12), 1–14. <https://doi.org/10.1002/mgg3.1788>
- Andari, A. D. (2023). Perbedaan UMR, UMP, dan UMK Secara Lengkap. <https://umsu.ac.id/artikel/perbedaan-umr-ump-dan-umk-secara-lengkap/>
- Anemia, M., & Origia, R. (2021). *Beta-Thalassemia*.
- Anwar, K. & Waqar, S. (2018). *Psychopathological tendencies and quality of life among patients with thalassemia majör*. *Rawal Medical Journal*, 43 (1): 32–38. [Google Scholar]
- Angastiniotis, M., & Lobitz, S. (2019). *Thalassemias: An overview*. *International Journal of Neonatal Screening*, 5(1), 1–11. <https://doi.org/10.3390/ijns5010016>
- Arikunto, S. (2019). *Prosedur Penelitian*. Jakarta : Rineka Cipta.
- Armina & Pebriyanti, D. K. (2021). Hubungan Kepatuhan Transfusi Darah dan Kelasi Besi dengan Kualitas Hidup Anak Thalasemia. *Jurnal Akademika Baiturrahim Jambi (JABJ)* Vol 10, No 2, 306-312
- Artamia, I. P., Rakhmawati, W., & Shalahuddin, I. (2019). Gambaran Dukungan Keluarga Terhadap Pengobatan Remaja Penyandang Thalasemia. Holistik Jurnal Kesehatan, 13(3), 255–262.
- Azwar, S. (2011). *Sikap Manusia : Teori dan Pengukurannya*. Yogyakarta : Pustaka Pelajar.
- Baird, D. C., Batten, S. H., & K., S. S. (2022). *Alpha- and Beta-thalassemia: Rapid Evidence Review*. *America Family Physician*, 105(3), 272–280.
- Bajwa, H., & Basit, H. (2023). *Thalassemia*. *StatPearls* , 1–8.

- Borgna-Pignatti C, Marsella M. (2015). Iron Chelation in Thalassemia Major. *Clin Ther.* 2015 Dec 1;37(12):2866-77. doi: 10.1016/j.clinthera.2015.10.001. Epub 2015 Oct 27. PMID: 26519233
- Bozkurt G, Baysal E. *Thalassemia syndromes: Thalassemia prevention program in Cyprus and its results.* İstanbul: Ateş Press; 2019. [Google Scholar]
- BPS Kota Bandung. (2024). Upah Minimum Kota Bandung (Juta Rupiah). <https://bandungkota.bps.go.id>
- Bulan, S. (2009). *Faktor-Faktor yang Berhubungan dengan Kualitas Hidup Anak Thalassemia Beta Mayor.* Tesis. Universitas Diponegoro. Semarang.
- Cappellini, M. D., Cohen, A., Porter, J., Taher, A., & Viprakasit, V. (2014). *Guidelines for the Management of Transfusion Dependent Thalassaemia.* Nicosia (CY) : Thalassemia International Federation
- Ceylan S, Çetinkaya B, Karabudak S, et al. (2018). *Examining the factors affecting quality of life of children and adolescents with Beta-Thalassemia.* *Journal of Dr Behcet Uz Children s Hospital*, 8 (1): 15–22. [Google Scholar]
- Coacci et al. (2012). *Health Related Quality of Life in Middle Eastern Children with Beta- Thalassemia.* *BMC Blood Disorders.* 12 (6). 1-7
- Darvishi Khezri H, Emami Zeydi A, Sharifi H, Jalali H. (2016). *Vitamin C Supplementation in Patients with β-Thalassemia Major Beneficial or Detrimental? Hemoglobin.* 2016 Aug;40(4):293-4. [PubMed]
- Elzaree F, Shehata M, Wakell M, et al. (2018). *Adaptive functioning and psychosocial problems in children with beta thalassemia major.* Open Access Maced J Med Sci, 6 (12): 2337–2341. [PMC free article] [PubMed] [Google Scholar]
- Faraski, K., Rohima, W. & Putri, S. R. (2023). Hubungan Antara Tingkat Pendidikan Dan Pengetahuan Orangtua Dengan Kualitas Hidup Anak Talasemia Mayor Di Rsud Dr. M. Yunus Bengkulu. *Syntax Idea*, Vol. 5, No. 1, 1993-2011
- Farmakis, D., Eleftheriou, A., & Bain, B. (2022). *Management of Transfusion Dependent Thalassaemia (TDT) : A Short Guide 2nd Edition.* Cyprus : Thalassaemia International Federation
- Goldberg, E. K., Neogi, S., Lal, A., Higa, A., & Fung, E. (2022). *Nutritional Deficiencies Are Common in Patients with Transfusion-Dependent Thalassemia and Associated with Iron Overload.* *HHS Public Access*, 6(10), 674–681. <https://doi.org/10.12691/jfnr-6-10-9>
- Grift TC, Cohen-Kettenis T, Vries AC. (2018). *Body image and self-esteem in disorders of sex development: A European multicenter study.* *Health Psychol*, 37 (4): 334–343. [PubMed] [Google Scholar]
- Hoffbrand, A. V.& Moss, P. A. H. (2011). *Essential Haematology.* Oxford : A John Wiley & Sons, Ltd., Publication

- Hossain, M. J., Islam, M.W., Munni, U.R., Gulshan, R., Mukta, S.A., Miah, M.S., Sultana, S., Ferdous, J. & Islam, M.A. (2023). *Health-related quality of life among thalassemia patients in Bangladesh using the SF-36 questionnaire*
- Isworo, A., Setiowati, D., & Taufik, A. (2012). Kadar hemoglobin, status gizi, pola makanan dan kualitas hidup pasien thalasemia. *Jurnal Keperawatan Soedirman*, 7(3), 183–189.
- Jacob, D.E. & Sandjaya. (2018). Faktor Faktor Yang Mempengaruhi Kualitas Hidup Masyarakat Karubaga District Sub District Tolikara Propinsi Papua. *Jurnal Nasional Ilmu Kesehatan (JNIK) LP2M Unhas*, Vol 1 (1), 1-16
- Jalil T, Yousafzai YM, Rashid I, Ahmed S, Ali A, Fatima S, Ahmed J. (2019) Analisis Mutasi Beta Thalassemia Dengan Multiplex Arms-Pcr Di Khyber Pakhtunkhwa, Pakistan. *J Ayub Med Coll Abbottabad*. Jan-Mar 2019; 31 (1):98-103. [PubMed]
- Jariwala K, Mishra K, Ghosh K. (2019). *Comparative study of alloimmunization against red cell antigens in sickle cell disease & thalassaemia major patients on regular red cell transfusion*. Indian J Med Res. 2019 Jan;149(1):34-40. [PMC free article] [PubMed]
- Jorge RT, Brumini C, Jones A, et al. (2010). *Body image in patients with rheumatoid arthritis*. Mod Rheumatol, 20 (5): 491–5. [PubMed] [Google Scholar]
- Kemenkes RI. (2018). *Pedoman Nasional Pelayanan Kedokteran Tata Laksana Thalasemia*
- Kemenkes RI. (2019). Cegah Penderita Baru, Kemenkes Rumuskan Aturan Skrining Thalasemia. Retrieved from <http://www.p2ptm.kemkes.go.id/artikel-sehat/cegahpenderita-baru-kemenkes-rumuskan-aturan-skrining-thalasemia>
- Kemenkes RI. (2020). Thalassemia. Retrieved from <http://www.p2ptm.kemkes.go.id/informasi-p2ptm/thalassemia>
- Kemenkes RI. (2022). Penyakit Tidak Menular (PTM). https://yankes.kemkes.go.id/view_artikel/761/penyakit-tidak-menular-ptm
- Kemenkes RI. (2022). Talasemia Penyakit Keturunan, Hindari dengan Deteksi Dini. <https://sehatnegeriku.kemkes.go.id/baca/rilismedia/20220510/5739792/talasemia-penyakit-keturunan-hindari-dengan-deteksi-dini/>
- Khan, I. (2022). *Cooley Anemia*. StatPearls. NCBI.
- Kleanthous M. (2019). *Screening and prevention of thalassaemia in Cyprus. Hemoglobin*, 43 (6): 331. [Google Scholar]
- Knapp, M. L., Vangelisti, A. L. and Caughlin, J. P. (2014). *Interpersonal Communication and Human Relationships*. New Jersey: Pearson Education
- Kumar, G., Majumdar, A., & Pavithra, G. (2014). *Quality of life (QOL) and its associated factors using WHOQOL-BREF among elderly in Urban Puducherry, India*. Original Article, 8(1), 54-57.

- Mariani, D. (2011). Analisis Faktor Yang Mempengaruhi Kualitas Hidup Anak Thalasemia Beta Mayor Di RSU Kota Tasikmalaya Dan Ciamis. Tesis, sekolah pascasarjana. Depok : Universitas Indonesia
- Mariani, D., Rustina, Y. & Nasution, Y. (2014). Analisis Faktor Yang Memengaruhi Kualitas Hidup Anak Thalassemia Beta Mayor. *Jurnal Keperawatan Indonesia*, Vol. 17, No. 1, hal 1-10
- Moghaddam, A.A., Adineh, H.A., Zareban, I., Mohammadi, M. & Maghsoodlu, M. (2018). *The survival rate of patients with beta-thalassemia major and intermedia and its trends in recent years in Iran. Epidemiol Health.* 2018:40:e2018048. doi: 10.4178/epih.e2018048. [PubMed]
- Muhaimin, T. (2010). Mengukur Kualitas Hidup Anak. *Kesmas: National Public Health Journal*, 5(2), 51-55.
- Muriati, Santi, E., Damayanti, E. A. F. (2020). Dukungan Keluarga dengan Kualitas Hidup Anak Penderita Thalassemia di Ruang Anak. *Jurnal Nerspedia*, Vol 2 (1), 51-58.
- Nafisa, S., Sjakti, H. A., & Mulansari, N. A. (2020). Talasemia. In Kapita Selekta Kedokteran Edisi V Jilid I (pp. 157–160). *Media Aesculapius*.
- Nikmah, M. & Mauliza. (2018). Kualitas Hidup Penderita Talasemia berdasarkan Instrumen *Pediatric Quality of Life Inventory 4.0 Generic CoreScales* di Ruang Rawat Anak Rumah Sakit Umum Cut Meutia Aceh Utara. *Sari Pediatri*, Vol. 20, No. 1, Juni 2018
- Notoadmojo, Soekidjo. (2018). *Metodologi Penelitian Kesehatan*. Jakarta : Rineka Cipta.
- Origa R. (2017). β -Thalassemia. *Genet Med*, 19 (6): 609–19. [PubMed] [Google Scholar]
- Paloma, I. D. A. N. C. (2023). Talasemia: Sebuah Tinjauan Pustaka. *Biocity Journal of Pharmacy Bioscience and Clinical Community*, Vol 1(2): 89-100
- Pedoman Nasional Pelayanan Kedokteran *Tatalaksana Thalassemia*, (2018).
- Pollit & Beck . (2006). *Nursing research: Principles and methods* (Seven edition). Lippincott William & Wilkins.
- Potts & Mandleco. 2012. Pediatric Nursing; Caring for Children and Their Families. 3rd ed. Clifton Park. New York.
- Pranajaya, R. & Nurchairina .(2016). Faktor Yang Berhubungan Dengan Kualitas Hidup Anak Thalasemia. *Jurnal Keperawatan*, Volume XII, No. 1, 130-139
- Punriddum J, Sanasuttipun W, Sangperm P. (2018). *Factors related to body image of adolescents with thalassemia*. *J Nurs Sci*, 36 (1): 57–72. [Google Scholar]
- Purnamasari, I. & Supriyati, A. (2024), “Kualitas Hidup Anak Penderita Talasemia di RSUD Krt Setjonegoro Wonosobo Berdasarkan Instrumen *Pediatric Quality*

- Of Life Inventory 4.0 Generic Core Scales (PedsQL)"*, Jurnal Ilmiah Kesehatan, vol. 14, no. 1, pp. 70-77
- Rahayu, Y., Waluyo, E. M. J., & Supardi. (2016). Dukungan Keluarga dalam Kepatuhan Terapi pada Pasien Thalassemia di Rumah Sakit Umum Daerah Kabupaten Ciamis Tahun 2015. *Mutiara Medika*. Vol 16 (2) : 52-54
- Ruhmadi, E. & Budi, A. H. (2022). *Quality of Life Pada Pasien Terminal Illness*. Tasikmalaya : Perkumpulan Rumah Cemerlang Indonesia.
- Sarkar SK, Shah MS, Begum M, Yunus AM, Aziz MA, Kabir AL, Khan MR, Rahman F, Rahman A. (2019). *Red Cell Alloantibodies in Thalassaemia Patients Who Received Ten or More Units of Transfusion*. *Mymensingh Med J*. 2019 Apr;28(2):364-369. [PubMed]
- Sugiyono. (2018). *Metode Penelitian Kuantitatif, Kualitatif, dan R&D*. Bandung : Penerbit Alfabeta
- Suhana, Kusumajaya, H. & Nurvinanda, R. (2023) Faktor Faktor Yang Berhubungan Dengan Kejadian Thalassemia Beta Mayor Pada Anak. *Jurnal Penelitian Perawat Profesional*, Vol 5(4), 1713-1724
- Suhendro, Nainggolan, L., Chen, K., Pohan, H., : I., Setiati, S., Alwi, I., Sudoyo, A., Simadibrata, M., Setiyohadi, B., & Syam, A (2014). Buku Ajar Ilmu Penyakit Dalam Edisi VI. In Interna Publishing. *Interna Publinshing*.
- Suryoadji, K. A., & Alfian, I. M. (2021). Patofisiologi Gejala Penyakit Thalassemia Beta : A Narrative Review. *Khazanah: Jurnal Mahasiswa*, 13(2), 56–60.
- Suyono, E.P. (2021). Gambaran Kualitas Hidup Penderita Anak Thalassemia Beta Mayor Di Rumah Sakit Pmi Kota Bogor. Skripsi : Fakultas Ilmu Kesehatan: Universitas Siliwangi
- Taheri P, Nooryan K, Karimi Z, et al. (2020). *Effect of individual psychotherapy with a focus on self-efficacy on quality of life in patients with thalassemia major: A clinical trial*. *J Clinic Care Skill*, 1 (2): 49–54. [Google Scholar]
- Tarim, H.S. & Oz, F. (2022). *Thalassemia Major and Associated Psychosocial Problems: A Narrative Review*. *Iran J Public Health*. 51(1): 12–18. doi: 10.18502/ijph.v51i1.8287
- Thavorncharoensap, M., Torcharus, K., Nuchprayoon, I., Riewpaiboon, A., Indaratna, K., Ubol, B.O (2010). *Factors Affecting Health-Related Quality Of Life In Thai Children With Thalassemia*. *Bio Med Central Hematology*.
- Utami, T.A. & Anggraeni, L.D. (2018). Korelasi Penghasilan Orang Tua terhadap Kualitas Hidup Anak yang Mengalami Talasemia Mayor. *Faletehan Health Journal*, 10 (2), 148-158
- Varni, J.W. (2024). *Measurement Model for the Pediatric Quality of Life Inventory*. <https://www-pedsql-org>

- Vosper J, Evangel M, Porter JB, et al. (2018). *Psychological factors associated with episodic chelation adherence in Thalassemia*. *Hemoglobin*, 42(1): 30–36. [PubMed] [Google Scholar]
- Vullo, R., Modell, B., & Georganda, E. (2014) Apa itu Thalassemia? (Andrianto Gandhi, Penerjemah). Thalassemia International Federations.
- World Health Organization (WHO). (2018). *Palliative Care*. from <https://www.who.int/news-room/fact-sheets/detail/palliative-care>
- World Health Organization (WHO). (2019). *The Structure of the WHOQOL-100*. Retrieved from https://www.who.int/healthinfo/survey/who_qol-qualityoflife/en/index4.html
- World Health Organization (WHO). (2022). *Data and Statistics Prevalence Thalassemia in World Wide*.
- World Health Organization (WHO). (2023). *Noncommunicable diseases*. <https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases>
- Wulandari, R. D., Setijowati, E. D., & Widyaningsih, I. (2023). Pengenalan Thalassemia dan Konseling Genetik Pra-Nikah pada Mahasiswa. ABDI MOESTOPO: *Jurnal Pengabdian Pada Masyarakat*, 6(1), 19–28. <https://doi.org/10.32509/abdimoestopo.v6i1.2282>
- Yani, W., Andriani, R., Novhriyanti, D. (2023). Hubungan dukungan keluarga terhadap kualitas hidup anak penyintas thalassemia di Rumah Sakit Bhayangkara Setukpa Lemdikpol Kota Sukabumi. *Journal Of Public Health Innovation (JPHI)*. Vol. 4 No. 01
- Yayasan Thalassemia Indonesia. (2015). *Profile Thalassemia di Indonesia*.
- Zulfikar. (2016). *Tanda dan Gejala Thalassemia*. Jogjakarta: Nuha Medika.