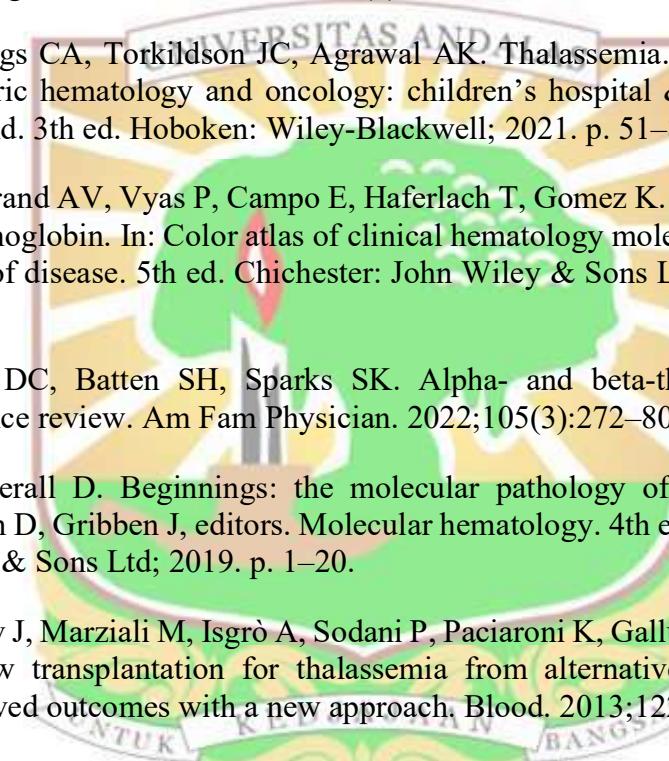


DAFTAR PUSTAKA

1. Kattamis A, Forni GL, Aydinok Y, Viprakasit V. Changing patterns in the epidemiology of β -thalassemia. *Eur J Haematol.* 2020;105(6):1–12.
2. Kementerian Kesehatan Republik Indonesia. Pedoman penanggulangan talasemia. Jakarta; 2022.
3. Rujito L. Talasemia: genetik dasar dan pengelolaan terkini. Purwokerto: Universitas Jenderal Soedirman; 2019. 74–9 p.
4. World Health Organization. Guideline on haemoglobin cutoffs to define anaemia in individuals and populations. Geneva; 2024.
5. Marcdante KJ, Kliegman RM, Jenson HB, Behrman RE. Nelson ilmu kesehatan anak esensial. 6th ed. IDAI, editor. Singapore: Elsevier; 2018. 599–613 p.
6. Yani W, Andriani R, Novhriyanti D. Hubungan dukungan keluarga terhadap kualitas hidup anak penyintas thalassemia di rumah sakit bhayangkara setukpa lemdikpol kota sukabumi. *JPHI.* 2023;4(01):68–76.
7. Purbasari D, Alfi Lail N. Kepatuhan konsumsi terapi kelasi besi dengan kualitas hidup anak pada penderita thalasemia mayor di rsud majalengka. *Mejora.* 2024;2(1):17–24.
8. Lindström B, Henriksson B. The essence of existence on the quality of life of children in the nordic countries. *Scand J of Soc Welf.* 1996;5(2):117.
9. Sarafino EP, Smith TW. Health psychology : biopsychosocial interactions. 10th ed. New Jersey: John & Wiley Sons Ltd; 2014. 328–55 p.
10. Katimenta KY, Nugrahini A, Araya W, Rusana E. Hubungan dukungan keluarga dengan kualitas hidup anak thalassemia. *J Born.* 2022;2(2):6–11.
11. Rahayu Y, Waluyo EMJ, Supardi. Dukungan keluarga dalam kepatuhan terapi pada pasien thalassemia di rumah sakit umum daerah kabupaten ciamis tahun 2015. *MMJKK.* 2016;16(2):52–6.
12. Gaya ML, Rini EA, Izzah AZ. Hubungan kadar ferritin serum dengan fungsi tiroid pada anak dengan thalassemia beta mayor. *Sari Pediatri.* 2023;25(1):27–31.
13. Putri DM, Oenzil F, Efrida E. Gambaran status gizi anak talasemia β mayor di rsup dr. m. djamil padang. *JKA.* 2015;4(3):804–7.
14. Yeni H, Yani FF, Izzah AZ, Lubis G. Relationship between serum ferritin and zinc levels in patients with major thalassemia. *Paediatr Indones.* 2019;59(3):144–9.

- 
15. Ayudhia S, Rini EA. Gangguan endokrin pada pasien thalassemia β mayor di rsup m djamil padang. *Hum Care J.* 2020;5(2):554–9.
 16. Windiastuti E, Nency YM, Mulatsih S, Sudarmanto B, Ugrasena IDG. Buku ajar hematologi onkologi anak. Jakarta: Badan Penerbit IDAI; 2018. 60–103 p.
 17. Bain BJ, Rees DC. α , β , δ and γ thalassaemias and related conditions. In: Haemoglobinopathy diagnosis. 3th ed. Hoboken: John Wiley & Sons Ltd; 2020. p. 85–184.
 18. Wahidiyat PA, Sari TT, Rahmartani LD, Setianingsih I, Iskandar SD, Pratanata AM, et al. An insight into indonesian current thalassaemia care and challenges. *ISBT Sci Ser.* 2020;15(3):334–41.
 19. Hastings CA, Torkildson JC, Agrawal AK. Thalassemia. In: Handbook of pediatric hematology and oncology: children's hospital & research center oakland. 3th ed. Hoboken: Wiley-Blackwell; 2021. p. 51–8.
 20. Hoffbrand AV, Vyas P, Campo E, Haferlach T, Gomez K. Genetic disorders of hemoglobin. In: Color atlas of clinical hematology molecular and cellular basis of disease. 5th ed. Chichester: John Wiley & Sons Ltd; 2019. p. 106–21.
 21. Baird DC, Batten SH, Sparks SK. Alpha- and beta-thalassemia: rapid evidence review. *Am Fam Physician.* 2022;105(3):272–80.
 22. Weatherall D. Beginnings: the molecular pathology of hemoglobin. In: Provan D, Gribben J, editors. Molecular hematology. 4th ed. Hoboken: John Wiley & Sons Ltd; 2019. p. 1–20.
 23. Gaziev J, Marziali M, Isgrò A, Sodani P, Paciaroni K, Gallucci C, et al. Bone marrow transplantation for thalassemia from alternative related donors: improved outcomes with a new approach. *Blood.* 2013;122(15):2751–6.
 24. Khan I, Shaikh H. Beta thalassemia mayor (cooley anemia). Treasure Island: StatPearls Publishing; 2023. 11 p.
 25. Needs T, Gonzalez-Mosquera LF, Lynch DT. Beta thalassemia. Treasure Island: StatPearls Publishing; 2023. 11 p.
 26. Vitrano A, Calvaruso G, Lai E, Colletta G, Quota A, Gerardi C, et al. The era of comparable life expectancy between thalassaemia major and intermedia: is it time to revisit the major-intermedia dichotomy. *Br J Haematol.* 2017;176(1):124.
 27. Kurniasari A. Dampak kekerasan pada kepribadian anak. *Sosio Informa.* 2019;50(1):15–24.

28. Mooi-Reci I, Wooden M. Jobless parents, unhealthy children? how past exposure to parental joblessness influences children's future health. *SSM Popul Health.* 2022;19:101–44.
29. Anisawati LD, Rosyidah I, Nur T. Dukungan orang tua dengan kualitas hidup anak penderita thalasemia (ruang poli anak rsud dr. soeroto ngawi). *JK.* 2018;16(1):54–61.
30. Varni JW, Limbers CA. The pediatric quality of life inventory: measuring pediatric health-related quality of life from the perspective of children and their parents. *Pediatr Clin North Am.* 2009;56(4):843–63.
31. Shafie AA, Chhabra IK, Wong JHY, Mohammed NS, Ibrahim HM, Alias H. Health-related quality of life among children with transfusion-dependent thalassemia: a cross-sectional study in malaysia. *Health Qual Life Outcomes.* 2020;18(1):141.
32. Kementerian Kesehatan Republik Indonesia. Pedoman pengendalian penyakit thalassemia di fasilitas kesehatan tingkat pertama. Jakarta; 2017.
33. Handayani R. Metodologi penelitian sosial budaya. Bantul: Trussmedia Grafika; 2020. 69–84 p.
34. Sugiyono. Metode penelitian kuantitatif, kualitatif, dan r&d. 1st ed. Bandung: Alfabeta; 2019. 217–22 p.
35. Azwar S. Sikap manusia teori dan pengukurannya. 3rd ed. Yogyakarta: Pustaka Pelajar; 2022. 113–35 p.
36. Mariani D, Rustina Y, Nasution Y. Analisis faktor yang memengaruhi kualitas hidup anak thalassemia beta mayor. *JKI.* 2014;17(1):1–10.
37. Varni JW, Burwinkle TM, Seid M, Skarr D. The pedsql 4.0 as a pediatric population health measure: feasibility, reliability, and validity. *Ambul Pediatr.* 2003;3(6):329–41.
38. Varni JW, Seid M, Rode CA. The pedsql: measurement model for the pediatric quality of life inventory. *Med Care.* 1999;37(2):126–39.
39. Varni JW, Burwinkle TM, Seid M. The pedsql as a pediatric patient-reported outcome: reliability and validity of the pedsql measurement model in 25,000 children. *Expert Rev Pharmacoecon Outcomes Res.* 2005;5(6):705–19.
40. Varni JW, Seid M, Kurtin PS. Pediatric health-related quality of life measurement technology : a guide for health care decision makers. *JCOM.* 1999;6(4):33–9.
41. Bulan S. Faktor-faktor yang berhubungan dengan kualitas hidup anak thalassemia beta mayor [thesis]. Universitas Diponegoro; 2009.

42. Varni JW, Seid M, Kurtin PS. The pedsql 4.0: reliability and validity of the pediatric quality of life inventory version 4.0 generic core scales in healthy and patient populations. *Med Care*. 2001;39(8):800–12.
43. Aulianah H, Asse. Faktor-faktor yang berhubungan dengan kualitas hidup anak thalasemia beta mayor. *J Aisyiyah Medika*. 2024;9(1):151–66.
44. Putranto KA, Salimo H, Riza M. Perbedaan kualitas hidup pada remaja talasemia mayor dengan gizi kurang dan gizi baik menggunakan instrumen pedsql. *Sari Pediatri*. 2021;23(3):171–7.
45. Kamil J, Gunantara T, Suryani YD. Analisis faktor-faktor yang memengaruhi kualitas hidup penderita talasemia anak di rsud al-ihsan kabupaten bandung tahun 2019. *Jurnal Integrasi Kesehatan & Sains*. 2020;2(2):140–4.
46. Utami TA, Anggraeni LD. Korelasi penghasilan orang tua terhadap kualitas hidup anak yang mengalami talasemia mayor. *FHJ*. 2023;10(2):148–58.
47. Utami W, Murfiantono EN. Hubungan dukungan keluarga dengan performa sekolah anak penderita talasemia di rsud dr.soedirman kebumen. In: Prosiding 19th Urecol : Seri MIPA dan Kesehatan. 2024. p. 409–15.
48. Widadi SY, Ramdani HT, Nurafita H. Kualitas hidup anak penderita thalassemia mayor usia 6-18 tahun di poliklinik thalassemia rsud dr. slamet. Prepotif : *Jurnal Kesehatan Masyarakat*. 2023;7(1):226–36.
49. Amelia SR, Utami A, Roslita R. Hubungan dukungan keluarga terhadap kualitas hidup anak dengan talasemia. *JKA*. 2022;6(1).
50. Astarani K, Yuli F.W L, Sutik, Taviyanda D, Richard SD. The correlation between family support with the quality of life of school-age children with thalassemia. *BNR*. 2024;5(3):484–94.
51. Adly RK, Mohamed AAER, Abuelela IS, Mohammed MD. Family management and its relation to health-related quality of life among thalassemic children. *MNSJ*. 2023;14(1):49–58.
52. Rima UN, Siska S. Hubungan dukungan keluarga orangtua dengan kepatuhan orangtua anak penderita thalasemia usia 2-5 tahun untuk menjalani transfusi darah di rs bhayangkara setukpa lemdikpol kota sukabumi. *Lentera*. 2018;3(1):51–62.
53. Artamia IP, Rakhmawati W, Shalahuddin I. Gambaran dukungan keluarga terhadap pengobatan remaja penyandang Thalassemia. *HJK*. 2019;13(3):255–62.
54. Winandar A, Gunawan G, Darimi M, Anam S. Faktor-faktor yang berhubungan dengan peningkatan kualitas hidup anak thalasemia di rumah

- sakit umum daerah dr. zainoel abidin tahun 2024. Mimbar Integritas Jurnal Pengabdian. 2025;4(1):338–52.
55. Nikmah M, Mauliza M. Kualitas hidup penderita talasemia berdasarkan instrumen pediatric quality of life inventory 4.0 generic core scales di ruang rawat anak rumah sakit umum cut meutia aceh utara. Sari Pediatri. 2018;20(1):11–6.
 56. Tobaiqi MA, Aljohani AH, Alharbi FS, Alshenqiti UM, Alahmadi NM, Abdelrahman MA, et al. Assessing the quality of life of parents of children with thalassemia: a cross-sectional study in medina city, saudi arabia. Cureus. 2024;16(10):716–53.
 57. Hossain MS, Mahbub MH, Petrou M, Telfer P, Al-Mosabbir A. The parental perspective of thalassaemia in bangladesh: lack of knowledge, regret, and barriers. Orphanet J Rare Dis. 2021;16(1):315.
 58. Azzahra NA, Amalia L, Andriyani S. Hubungan antara dukungan keluarga dengan quality of life pada anak thalasemia mayor. JGK. 2025;18(1):1–14.

