

## DAFTAR PUSTAKA

1. Capperlini, Farmakis, Porter. 2021 Guidelines for the Management of Transfusion Dependent Thalassemia (TDT). Thalassemia Internasional Federation; 2021. 228–247 p.
2. Kurniati M, Eksa D, Risnawati C. Thalassemia , Feritin Level , Chelation Therapy Adherence. *J Ilmu Kedokt Dan Kesehat*. 2020;7(April):433–42.
3. Betts M, Flight P, Paramore L, All E. Systematic literature review of the burden of disease and treatment for transfusion-dependent  $\beta$ -thalassemia. *J Clin Ther*. 2020;42(2):322–37.
4. De Sanctis V et al.  $\beta$ -thalassemia distribution in the old world: An ancient disease seen from a historical standpoint. *Mediterr J Hematol Infect Dis*. 2017;9:1–14.
5. Susanto ER, Syarif A, Muludi K, Perdani RRW, Wantoro A. Implementation of Fuzzy-based Model for Prediction of Thalassemia Diseases. *J Phys Conf Ser*. 2021;1751(1).
6. Kemenkes RI. Profil Kesehatan Indonesia. 2021. Kementrian Kesehatan Republik Indonesia. Diakses pada tanggal 4 Oktober 2022
7. Vichinsky E. Standards of Care Guidelines for Thalassemia [Internet]. 2012. 1–27 p. Available from: [www.thalassemia.com](http://www.thalassemia.com)
8. Porter J. Blood Transfusion Therapy in Thalassemia Major. *Int Conf Thalass Hemoglobinopathies*. 2011;6–7.
9. Putri, Oenzil, Efrida. Gambaran Status Gizi Anak Talasemia Beta Mayor di RSUP Dr. M. Djamil Padang. *J Kesehat Andalas*. 2015;4(3).
10. Jimmy B, Jose J. Patient Medication Adherence: Measures in Daily Practice. *Oman Med J*. 2011;3(26):155–9.
11. Marnis D, Indriati G, Nauli FA. Hubungan Tingkat Pengetahuan Ibu dengan Kualitas Hidup Anak Thalassemia. *J Perspekt*. 2021;4(4):519.
12. Punaglom N, Mangkarakeree N. Integrative Review for Factors Related to Family Functioning in the Family Living with the Children with Thalassemia. *Bangkok Med J*. 2020;16(2):242–9.
13. Nandeswari V, Indriansari A, Latifin K. Pengetahuan Orang Tua Merawat Anak Penderita Thalasemia. *J Keperawatan Fak Kedokt Univ Sriwij*. 2021;155–62.
14. Ghazanfari, Arab, Fourozi. Knowledge level and educational needs of thalassemic children's parents in Kerman. *Iran J Crit care Nurs* 3 [Internet]. 2010;3:99–103. Available from: <http://www.jccnursing.com/en/articles/7143>
15. Klassen. Understanding the Health Impact of Caregiving: A Qualitative Study of Immigrant Parents and Single Parents of Children With Cancer. *Int J Qual life Asp Treat care Rehabil*. 2011;21(9):1595–605.
16. Lee Y ling, Lin D tsamn, Tsai S feng. Disease knowledge and treatment adherence among patients with thalassemia major and their mothers in Taiwan. *J Clin Nurs*. 2009;18(4):529–38.
17. Maheen H, Malik F, Siddique B, Qidwai A. Assessing Parental Knowledge

- About Thalassemia in a Thalassemia Center of Karachi, Pakistan. *J Genet Couns.* 2015;24(6):945–51.
18. Menteri Kesehatan Republik Indonesia: Pedoman Nasional Pelayanan Kedokteran Tatalaksana Talasemia. Jakarta; 2018. Diakses pada tanggal 21 September 2022
  19. Grentina. Thalasemia [Internet]. Ikatan Dokter Anak Indonesia. 2016. Available from: <https://www.idai.or.id/artikel/seputar-kesehatan-anak/mengenal-thalasemia>
  20. Bahrman R, Kliegman R, Arvin A. Ilmu Kesehatan Anak Nelson. 15th ed. Wahab S (Trans. ., editor. Jakarta: EGC; 2012.
  21. WHO. The Global Burden of Disease Update [Internet]. World Health Organization. 2014. Available from: [www.who.int/healthinfo/global\\_burden\\_disease/](http://www.who.int/healthinfo/global_burden_disease/) .
  22. Rujito L. Talasemia Genetik Dasar dan Pengelolaan Terkini. Universitas Jendral Sudirman. Banyumas; 2021. 2013–2015 p.
  23. Victor HA, Paul. Hoffbrand's Essential Haematology. Seventh Ed. London: Wiley Blackwell; 2016.
  24. Mulyani M, Fahrudin A. Reaksi Psikososial Terhadap Penyakit Di Kalangan Anak Penderita Talasemia Mayor Di Kota Bandung. *Sosio Inf.* 2011;16(3):157–76.
  25. CDC. For Caregivers, Family, and Friends [Internet]. Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion. 2022. Available from: <https://www.cdc.gov/aging/caregiving/index.htm>
  26. Johns Hopkins Medicine. What Is A Caregivers? [Internet]. COMMUNITY HEALTH AT JOHNS HOPKINS BAYVIEW. 2022. Available from: <https://www.hopkinsmedicine.org/>
  27. Olagundoye O, Alugo M. Caregiving and Home Care. 2018; Available from: <http://dx.doi.org/10.5772/intechopen.72627>
  28. Triatmono MM, Rizky WV, Christopher E. Study protocol for a cross-sectional study on knowledge, attitude, and practice towards thalassemia among Indonesian youth AUTHORS. *BMJ Open.* 2021;11(12).
  29. CDC. Understanding Health Literacy [Internet]. Centers for Disease Control and Prevention. 2022. Available from: <https://www.cdc.gov/healthliteracy/learn/understanding.html>
  30. Rubin D. A Health Literacy Report : Analysis of 2016 BRFSS Health Literacy Data Office of the Associate Director. 2016
  31. Ann T, Dnp P, Barton AJ, Boyle DK, Loan LA, Dnsc JFS, et al. A concept analysis of health literacy. *Nurs J.* 2019;54(3):1–13.
  32. Sananreangsak S, Lapvongwatana P, Virutsetazin K, Vatanasomboon P, Gaylord N. Predictors of family management behavior for children with thalassemia. *Southeast Asian J Trop Med Public Health.* 2012;43(1):160–71.
  33. Rudd RE. The evolving concept of Health literacy : New directions for health literacy studies. *Soc Sci Med.* 2015;67(12).
  34. CDC. Understanding Literacy and Numeracy [Internet]. Centers for Disease Control and Prevention. 2022. Available from:

- <https://www.cdc.gov/healthliteracy/learn/UnderstandingLiteracy.html>
35. Aydinok Y. Psychosocial Implications of Thalassemia Major. *Pediatr Int.* 2005;47(1):84–9.
  36. Ghorbanpoor M, Mirzaie M, Mirhaghjou SN, Dkk. The Relationship Between Psychosocial Status and Adherence to Treatment Regimen in Adolescents With Thalassemia. *J Holist Nurs Midwifery.* 2020;30(2):78–85.
  37. Sabaté E. *Adherence to Long-Term Therapies: Evidence for Action.* Geneva; 2003.
  38. Lam WY, Fresco P. *Medication Adherence Measures : An Overview.* 2015;2015.
  39. Neiman AB, Ruppert T, Ho M, Garber L, Weidle PJ, Hong Y. CDC Grand Rounds : Improving Medication Adherence for Chronic Disease Management — Innovations and Opportunities. 2017;66(45):1248–51.
  40. Lailatushifah SNF. Kepatuhan Pasien yang Menderita Penyakit Kronis dalam Mengonsumsi Obat Harian. *J Psychol.* 2015;
  41. Morisky D, Munther P. New Medication Adherence Scale Versus Pharmacy Fill Rates in Senior with Hypertention. *Am J Manag Care.* 2009;15(1):59–66.
  42. Triwardhani ER, Reniarti L, Setiabudiawan B, Triwardhani ER, Reniarti L, Setiabudiawan B, et al. Hubungan Jenis dan Tingkat Kepatuhan Pengobatan Kelasi Besi Oral dengan Kadar Feritin Serum pada Penyandang Talasemia Beta Mayor Anak. *Sari Pediatr.* 2022;24(38):23–30.
  43. Wang VC, Mayer F, Ottawa F, Wippert P m. Translation Reliability and Test-Retest Reliability for Elite Athlete ' s Injury Translation Reliability and Test-Retest Reliability for Elite Athlete ' s Injury Risk Factor Questionnaire. *Sport & Exerc Res.* 2015;17:231–41.
  44. Muljono P. Penyusunan dan Pengembangan Instrumen Penelitian [Internet]. IPB;2002.Available from:<https://repository.ipb.ac.id/jspui/bitstream/123456789/34011/1/KPMpjm-makalah2-penyusunan>
  45. Yusup F. Uji Validitas dan Reliabilitas Instrumen Penelitian Kuantitatif. *J Tarb J Ilm Kependidikan.* 2018;7(1):17–23.
  46. Sugiyono. *Statistik untuk Penelitian.* Bandung: Alfabeta; 2014.
  47. Ghozali I. *Analisis Multivariat dengan Program IBM SPSS 23.* 8th ed. Semarang: Badan Penerbit Uviversitas Diponegoro; 2016.
  48. Notoatmodjo S. *Promosi Kesehatan dan Ilmu Perilaku.* Jakarta: Rineka Cipta; 2010.
  49. Ishfaq K. The Knowledge of Parents Having Thalassemia Child. *Isra Med J.* 2017;8(June 2016):79–83.
  50. Riyadi, Sukarmin. *Asuhan Keperawatan pada Anak.* Yogyakarta: Graha Ilmu; 2010.
  51. Lusiana R, Rahmawati F, Andhini D. Hubungan Pengetahuan dan Sikap Orang Tua dengan Kualitas Hidup Anak Penderita Talasemia. *Semin Nas Keperawatan.* 2018;4(1):128–34.
  52. Sugihartati. *Perkembangan Masyarakat Informasi dan Teori Sosial Kontemporer.* Jakarta: Kencana; 2014.
  53. Kalaman C, Ibrahim N, Shaker V. Parental Factors Associated with Cjild or

- Adolescent Medication Adherence: A Systematic Review. 2023;501(11):1–32.
54. Hijriani H. Pengaruh Psychoeducational Parenting terhadap Kecemasan Orang Tua yang Mempunyai Anak Pnyandang Talasemia Mayor. *J Keperawatan Silampari*. 2018;385–98.
  55. Setiawan D, Farihatun A, Nurmalasari A. Skrining Talasemia Beta Minor pada Pelajar SMK di Kecamatan Ciamis. 2020;5(3).
  56. Kurniawati D, Kristianingsih N, Sulistianingsih A. Hubungan Tingkat Pengetahuan Ibu Tentang Talasemia Dengan Kualitas Hidup Anak Talasemia. *J Ilm Kesehat [Internet]*. 2022;11(2):112–7. Available from: <https://ejournal.umpri.ac.id/index.php/JIK/article/download/1762/1004>