

DAFTAR PUSTAKA

- Aji, D. N., Silman, C., Aryudi, C., Cynthia, *et al.*, 2009. Faktor–Faktor yang Berhubungan dengan Kualitas Hidup Pasien Thalassemia Mayor di Pusat Thalassemia Departemen Ilmu Kesehatan Anak RSCM. *Sari Pediatri*, 11(2), pp. 85-9.
- Andi, M., 2013. *Pengobatan dalam Islam*. Disertasi Magister. Makassar: UIN Alauddin Makassar, pp. 63-84.
- Ansari, S., Baghersalimi, A., Azarkeivan, A., dan Hassanzadeh, R. A., 2014. Quality of Life Patients with Talasemia Major. *Iranian Journal of Pediatric Hematology Oncology*, 4(2).
- Atmakusuma, D. dan Setyaningsih, I., 2009. Salah Satu Jenis Hemoglobinopati. In: *Dasar-Dasar Talasemia*. Jakarta: Interna Publishing, pp. 1380-1.
- Agung, L., 2012. *Hubungan Lama Sakit Terhadap Kualitas Hidup Anak Penderita Thalassemi Di RSUD DR. Moewardi*. [Internet]. Available from: <http://repository.usu.ac.id/handle/123456789/31252> [Accessed 28 Oktober 2020].
- Bakta, I. M., 2013. Anemia Hemolitik. In: *Hematologi Klinik Ringkas*. Jakarta: EGC, pp. 50-80.
- Bazi, A., Sargazi, A. O., Safa, A., dan Miri, M. E., 2017. Health-Related Quality of Life and Associated Factors Among Thalassemia Major Patients, Southeast of Iran. *Journal of Pediatric hematology/oncology*, 39(7), pp. 513-17.
- Brown, L. dan Seid, M., 2004. *The Healthy Families Program Health Status Assesment (Pedsql) Final Report*. CA: Managed Risk Medical Insurance Board.
- Bulan, S., 2009. Factor-Faktor Yang Berhubungan Dengan Kualitas Hidup Anak Thalassemia Beta Mayor. *Jurnal Universitas Diponegoro*.
- Capellini, M. D., Cohen, A., Porter, J., Taher A., *et al.*, 2014. Guidelines For The Management Of Transfusion Dependent Thalassemia. In: *Blood Transfusion*. 3th ed. Cyprus: Thalassemia International Federation (TIF), pp. 30-41.
- Catlin, A. J., 2003. Thalassemia : The Fact And The Controversies. *Pediatric Nursing*, 29(6), pp. 447-51.

- Departemen Agama Republik Indonesia, 2008. *Al-Qur'an dan Terjemahannya*. Bandung: Diponegoro.
- Dewoto, H. R. dan Wardhini, S. B. P., 2007. *Antianemia defisiensi dan eritropoietin. Farmakologi dan Terapi*. 5th ed. Jakarta: Balai Penerbit FKUI, pp. 794-03.
- Dewi, S., 2009. Karakteristik Thalasemia Yang Di Rawat Inap Di Rumah Sakit Umum Pusat H. Adam Malik Medan. *USU Repository*, pp. 10-12.
- Eiser, C., 1997. *Children's Quality Of Life Measures*. [internet]. Available from : , <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1717360/> [Accessed 26 Oktober 2020].
- Fung, A., Low, L., Ha, S., dan Lee, P., 2008. Psychological Vulnerability and Resilience in Children and Adolescents with Thalassaemia Major. *HK J Paediatr*, 13(4), pp. 239-52.
- Ganie, R. A., 2008. Distribusi Pembawa Sifat Thalassemia (α & β) dan Hemoglobin-E pada Penduduk Medan. *Kedokteran Nusantara*, pp. 41.
- Greer, J. P., 2003. Thalassemias and Related Blood Disorders. In: Borgagna, C. dan Galanello, R. eds. *Wintrobe's Clinical Hematology*. Philadelphia: Lippincott Williams & Wilkins, pp. 2647-47
- Ghorashi, Z. dan Ahari., 2007. Study Of Hemoglobin And Hematocrit Level In Thalassemia Major Patients Before And After Transfusion. *Pak Paed J*, 13(3), pp. 132-6.
- Hoffbrand, A. V. dan Moss, P. A. H., 2013. Talasemia. In: F. Sandra, eds. *Kapita Selekta Hematologi*. Jakarta: EGC, pp. 84-98.
- Hoffman, R., Benz, E., Shattil, S., Heslop, H., *et al.*, 2013. Basic Principle And Practice. In: *Hematology*. 6th ed. Philadelphia: Elseviers Saunders.
- Ikatan Dokter Anak Indonesia, 2015. *Penilaian Kualitas Hidup Anak : Aspek Penting Yang Sering Terlewatkan*. [internet]. Available from : <https://www.idai.or.id/artikel/seputar-kesehatan-anak/penilaian-kualitas-hidup-anak-aspek-penting-yang-sering-terlewatkan> [Accessed 25 Oktober 2020].
- Ismail, A., Campbell, M. J., Ibrahim, H. M., dan Jones, G. L., 2006. Health Related Quality Of Life In Malaysian Children With Thalassemia. *NCBI*, 4(39).

- Isworo, A., Setiowati, D., dan Taufik, A., 2012. Kadar Hemoglobin, Status gizi, Pola Konsumsi Makanan dan Kualitas Hidup Pasien Talasemia. *Jurnal Keperawatan Soedirman*, 7(3), pp. 183-9.
- Jafari, H., Lahsaeizadeh, S., Jafari, P., dan Karimi, M., 2008. Quality Of Life In Thalassemia Major: Reliability And Validity Of The Persian Version Of SF-36 Questionnaire. *J Postgrad Med*, 54, pp. 273-5.
- Jameson, J. L., Fauci, A. S., Kasper, D. L., Hauser, S. L., *et al.*, 2018. Disorders of Hemoglobin. In: Benz, E. eds. *Harrison's Principles of Internal Medicine*. 20th ed. Amerika: McGraw-Hill Education, pp. 631.
- Katyal, S., Khurana, A., dan Marwaha, R., 2006. Psychosocial Burden in Thalassemia. *The Indian Journal of Pediatrics*, 73(10), pp. 877-80.
- Karande, S. dan Kulkarni, M., 2005. Poor School Performance. *The Indian Journal of Pediatrics*, 72(11), pp. 961-7.
- Kemenkes RI, 2012. *Thalasaemia Bukan penyakit Menular*. Jakarta: Pusat Komunikasi Publik Sekjen Kemenkes RI.
- Kemenkes RI, 2018. *Thalassemia*. [Internet]. Available from : <https://www.persi.or.id/images/regulasi/kepmenkes/kmk12018.pdf> [Accessed 18 November 2019].
- Keohane, E., 2016. Thalassemias. In: E. Keohane, L. J. Smith dan J. M. Walenga, eds. *Rodak's Hematology Clinical Principles and Applications*. Canada: Elsevier, pp. 454-71.
- Khurana, A., Katyal, A., dan Marwaha, R. K., 2006. Psychosocial Burden In Thalassemia. *Indian Journal of Pediatrics*, 73(10), pp. 877-880.
- Lawrence, M. T., Stephen J. M., dan Maxine, A. P., 2004. Current Medical Diagnosis & Treatment. In: Damon, L. dan Andreadis. C. B., eds. *Blood Disorders*. USA: McGraw-Hill/Appleton & Lange, pp. 1.199-209.
- Lindstrom, B., 1995. Measuring And Improving Quality Of Life For Children. In: Social Paediatrics. *Oxford: Oxford University Press*, pp. 570-85.
- Liumbruno, G. M., Bernnardello, F., Lattanzio, A., dan Rossetti, G., 2011. Recommendations for the transfusion management of patients in the peri-operative period. III. The post-operative period. *NCBI*, 9(3), pp. 320-35.

- Loonen, H. J., Derkx, B. H. F., dan Otley, A. R., 2001. Measuring Health – Related Quality Of Life Of Pediatric Patients. *J Pediatr Gastroenterol Nutr*, 32, pp. 523-6.
- Marengo-Rowe dan Alain J., 2007. The Thalassemias And Related Disorders. *NCBI*, 20(1), pp. 27-31.
- Mariani, D., Rustina, Y., dan Nasution Y., 2014. Analisis Faktor yang Memengaruhi Kualitas Hidup Anak Talasemia Beta Mayor. *Jurnal Keperawatan Indonesia*, 17(1), pp. 1-10.
- Marnis, D., Indriati, G., dan Nauli, F.A., 2018. Hubungan Tingkat Pengetahuan Ibu Dengan Kualitas Hidup Anak Talasemia. *Jurnal keperawatan sriwijaya*, 5(2), pp. 31-42.
- Michael, J.G., 2009. *Gizi Kesehatan Masyarakat*. Jakarta : EGC, pp. 58-61.
- Nienhuis, A.W dan Nathan, D.G., 2012. Pathophysiology And Clinical Manifestations Of The β -Thalassemias. *Cod. Spring Harb. Perspect. Med*, 2(12), pp.a011726.
- Nikmah, M. dan Mauliza., 2018. 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*, 20(1), pp. 11-16.
- Notoatmojo, S., 2007. Pendidikan dan Perilaku Kesehatan. In: Notoatmojo, S., eds. *Kesehatan Masyarakat*. Jakarta: Rineke Cipta, pp. 142-9.
- Olivieri, N., 1999. The β Thalasemia. *The New England Journal of Medicine*, 341(1), pp. 99-109.
- Papanikolaou, G., Tzilianos, M., Christakis, J. I., Bogdanos, D., *et al.*, 2015. Hepcidin In Iron Overload Disorders. *Blood*, 105, pp. 4103–05.
- Purnomo, S., 2000. *Kapita Selekta – Ilmu Kedokteran Molekuler*. Jakarta: CV. Agung Seto, pp.17-30.
- Putra, A., Darussalam, D., dan Zanaria, T. M., 2017. Faktor-Faktor Yang Mempengaruhi Prestasi Sekolah Pada Pasien B-Thalassemia Mayor Di Rsud Dr Zainoel Abidin Banda Aceh. *Jurnal Ilmiah Mahasiswa Medisia*, 2(4), pp. 28-34.
- Pranajaya, R. dan Nurchairina., 2016. Faktor Yang Berhubungan Dengan Kualitas Hidup Anak Talasemia. *Jurnal Keperawatan*, 12(1), pp. 130-39.

- Rachmilewitz, E. A. dan Giardina, P. J., 2011. How I treat thalassemia. *Blood Journal*, 118(13), pp. 479-86.
- Regar, J., 2009. Aspek Genetik Talasemia. *Jurnal Biomedik*, 1(3), pp. 151-58.
- Rejeki, D. S. S., Nurhayati, N., Supriyanto dan Kartikasari, E., 2012. Studi Epidemiologi Deskriptif Talasemia. *Jurnal Kesehatan Masyarakat Nasional*, 7(3), pp. 139-44.
- Ribeil, J. A., Arlet, J. B., Dussiot, M., Moura, I. C., *et al.*, 2013 *Ineffective Erythropoiesis In Beta Thalassaemia*. [Internet]. Available from : pada <https://doi.org/10.1155/2013/394295> [Accessed 1 februari 2020].
- Rivella, S., 2009. Ineffective Erythropoiesis And Talasemias. *Curr. Opin. Hematol.*, 16, pp. 187-94.
- Rund, D. dan Rachmilewitz, E., 2005. Medical Progress β Thalassemia. *NEJM*, 353(1), pp. 1135-46.
- Rujito, L., 2019. *Buku Referensi Talasemia: Genetik dasar dan Pengelolaan Terkini*. Purwokerto: UNSOED Press.
- Said, Y. A. A., 2014. *Ujian dari Allah dan cara mengatasinya* [Internet]. Available from : https://d1.islamhouse.com/data/id/ih_articles/single3/id_Ujian_dari_Allah_dan_Cara_Mengatasinya.pdf [Accessed 1 februari 2020].
- Sawitri, H. dan Husna, C. A., 2018. Karakteristik Pasien Talasemia Mayor Di Blud Rsu Cut Meutia Aceh Utara Tahun 2018. *Jurnal Averrous*, 4(2).
- Syedifar, M., Dorkoosh, F. A., Hamidieh, A. A., Naderi, M, *et al.*, 2016. Health-Related Quality of life and Health Utility Values in Beta Thalassemia Major Patients Receiving Different Types of Iron Chelators in Iran. *International Journal of Hematology-Oncology and Steem Cell Research*, 10(4), pp. 224-31.
- Schrier dan Stanley, L., 2002. Pathophysiology Of Thalassemia. *Lippincott Williams & Wilkins, Inc*, 9(2), pp. 123-126.
- Sholikin, M., 2008. *Hadirkan Allah di hatimu*. Jakarta: Tiga Serangkai.
- Suryani, E., Wiharto, W., dan Wahyudiani., 2015. Identifikasi Anemia Talasemia Betha (β) Mayor Berdasarkan Morfologi Sel Darah Merah. *Scientific Journal of Informatics*, 2(1), pp. 15-28.

- Supartini, Y., Sulastri, T., dan Sianturi, Y., 2013. Kualitas Hidup Anak Yang Menderita Talasemia. *Jurnal keperawatan*, 1(1), pp. 1-11.
- Thavorncharoensap, M., Torcharus, K., Nuchprayoon, I., Riewpaiboon, A., *et al.*, 2010. Factors Affecting Health Related Quality Of Life In Thalassaemia. *Journal BMC Disord*, 10(1), pp. 1-10.
- Jauhari, I., 2011. Kesehatan dalam Pandangan Hukum Islam. *Kanun Jurnal Ilmu Hukum*, 55, pp. 33-57.
- Thein, S. L., 2005. *Pathophysiology of β Talasemia— A Guide to Molecular Therapies*. [Internet]. Available from : <https://doi.org/10.1182/asheducation-2005.1.31> [Accessed 1 Februari 2020].
- Varni, J. W., Skar, D., Seid, M., dan Burwinkle, T.S., 2002. Health Status Assessment Project. *Data Insight Report Children's Health Assessment Projects*, 10, pp. 1-11.
- Wahidiyat, I., 2003. Thalassemia dan Permasalahannya di Indonesia. *Sari Pediatri*, 5(1), pp. 2-3.
- Wijaya, L. J., Nancy, Y. M., dan Farida, H., 2018. Faktor-Faktor Yang Mempengaruhi Prestasi Belajar Pasien Talasemia Mayor Anak. *JKD*, 7(2), pp. 694-710.
- World Health Organization, 2008. *Global epidemiology of haemoglobin disorders and derived indicators*. [Internet]. Available from : <https://www.who.int/bulletin/volumes/86/6/06-036673/en/> [Accessed 25 Oktober 2020].
- World Health Organization, 2014. *The Global Burden Of Disease Update*. [Internet]. Available from : https://www.who.int/healthinfo/global_burden_disease/estimates/en/ [Accessed 26 Oktober 2020].
- World Health Organization, 2012. *Global Physical Activity Surveillance*. [Internet]. Available from : <https://www.who.int/ncds/surveillance/steps/GPAQ/en/> [Accessed 26 Oktober 2020].
- Yunanda, Y., 2008. Thalassemia. *USU e-Repository*, pp. 8-10.