

## DAFTAR PUSTAKA

- A.A.A Darman, R. Bahraen (2023). Hemofilia: Suatu Kelainan pada Faktor Pembekuan Darah. *JMH : Jurnal Medika Hutama*, 4 (2), 3299-3305.
- Abali O, Zülfikar OB, Karakoç Demirkaya S (2014). An examination of the symptoms of anxiety and parental attitude in children with hemophilia. *Turkey Journal Medic and Science*. 1087-90.
- Afrizal, Stevany, Polelah (2021). Peran Ganda Perempuan Dalam Peningkatan Perekonomian Keluarga. *Indonesian Journal of Sociology, Education, and Development* 3(1), 53–62.
- Agasani, Soedjatmiko, E. Windiastuti, (2019). Kualitas Hidup Anak dengan Hemofilia di Rumah Sakit Dr. Cipto Mangunkusumo. *Sari Pediatri*, 21 (2), 73-80.
- A. Jaelani, J. E. P. Utama (2023). Gambaran Kualitas Hidup Pada Penderita Hemofilia di Komunitas Himpunan Masyarakat Hemofilia Solo Raya. *Jurnal Kebidanan*, 15 (1) , 1-112.
- A. Torres Ortun O, R. Cuesta-Barriuso, J. N Ieto Munuera (2014). Parents of children with haemophilia at an early age: assessment of perceived stress and family functioning. *Haemophilia*, 1-7.
- Atoki, P.L., Gautam, R., & Atoki, A.M. (2024). The Relationships Between Gratitude and Resilience among Nigerian Married Couples. *International Journal of Religion*.
- B.A. Given, C.W. Given, And P. Sherwood k (2012). The Challenge Of Quality Cancer Care For Family Caregivers. *Seminars in Oncology Nursing*, 28 (4), 205-212.
- Beeton, K., Neal, D., Lee, C., & Watson, T. (2007). Parents of children with haemophilia : a transforming experience. *Haemophilia*, 13(5), 570-579. <https://doi.org/10.1111/j.1365-2516.2007.01494.x>
- BPJS Kesehatan (2022) Tentang penyakit dengan klaim bpjs kesehatan paling besar. Diakses Melalui : <https://indonesiabaik.id/infografis/penyakit-dengan-klaim-bpjs-kesehatan-paling-besar>.
- Brown (2017) The Royal Disease and The Royal Collapse: Political Effects of Hemophilia in the Royal Houses of Europe. *Honor Scholar Theses*. 63.
- Budiarty, Shanessa, Selvi Nafanti (2020). Menilai Kualitas Hidup Anak Penyandang Hemofilia. *Cermin Dunia Kedokteran*, 47(8). doi:10.55175/cdk.v47i8.784.

- C. C. Montecinos, S. P. Alenda, J. Casaña, J. J. Carrascol, L. L. Andersen, Rubén Lopez-Bueno, R.N. Cortés, S. Bonanad, F. Querol, J. Calatayud (2020). Effectiveness of progressive moderate-vigorous intensity elastic resistance training on quality of life and perceived functional abilities in people with hemophilia: Secondary analysis of a randomized controlled trial. *Europen Journal of Haematology*, 253–261. [DOI :10.1111/ejh.13900](https://doi.org/10.1111/ejh.13900).
- Connor, K., Davidson, J. (2003). Development of a New Resilience Scale: The Connor-Davidson Resilience Scale (CD-RISC). *Depression and Anxiety Research Article*.
- Dewi, Widiasvitri (2020) Resiliensi ibu dengan anak autisme. *Jurnal Psikologi Udayana*, 6 (1), 193-206.
- Driver, M. (2011). Coaching Positively: Lessons for Coaches from Positive Psychology. *Open University Press: McGraw-Hill Education*.
- Pargament, K. I., & Cummings, J. (2010). Anchored by faith: Religion as a resilience factor. In J. W. Reich, A. J. Zautra, & J. S. Hall (Eds.), Handbook of adult resilience (193–210). *The Guilford Press*.
- E. M. Ratnaningtyas, Ramli, Syafruddin, E. Saputra, D. Suliwati, B. T. A. Nugroho, Karimuddin, M. H. Aminy, N. Saputra, Khadir, A. S.Jahja (2022). Metode Penelitian Kualitatif. Aceh: Yayasan Penerbit Muhammad Zaini.
- Ergün S, Sülü E, Başbakkal Z. Supporting the need for home care by mothers of children with hemophilia. *Home Healthc Nurse* 2011;29:530-8.
- Fayed, N., Klassen, A. F., Dix, D., Klaaseen, R., Sung, L. (2011). Exploring Predictors of Optimism Among Parents of Children with Cancer. *Psycho Oncology Journal*, 411-418.
- Gatot, D (2014). Hemofilia: Tantangan dan Permasalahan di Indonesia. *Proceeding Book : Seminar Hemofilia*. 1- 4.
- Grothberg, E. (1995). A Guide to Promoting Resilience in Children: Strengthening the Human Spirit. *The International Resilience Project. Bernard van Leer Foundation*.
- Gupta, N., & Kumar, S. (2015). Significant Predictors for Resilience among a Sample of Undergraduate Students: Acceptance, Forgiveness and Gratitude. *Indian Journal of Health and Wellbeing*, 6, 188-191.
- F. Nashori, I. Saputro, (2021). Psikologi Resiliensi. Yogyakarta: Universitas Islam Indonesia
- Iranda, A (2021). Reseliensi Warga Desa Pendung Talang Genting Pasca Konflik Dengan Warga Desa Sleman Kabupaten Kerinci. *Al-Qalb: Jurnal Psikologi Islam*. 12 (1), 71-83. <https://doi.org/10.15548/alqalb.v12i1.1563>.
- Keputusan Menteri Kesehatan Republik Indonesia Nomor : HK.01.07/MENKES/243/2021 Tentang Pedoman Nasional Pelayanan

Kedokteran Tata Laksana Hemofilia. Diakses dari : <https://peraturan.bpk.go.id>.

- K. Fudyartanta (2012). Psikologi Perkembangan. Yogyakarta: Pustaka Pelajar.
- K. Khair S. Chaplin (2018). The impact on parents of having a child with haemophilia. *Haem: British Journal Of Haematology*. 3 (2), 4-14.
- K. Khair S. V. Mackensen (2017). Caregiver burden in haemophilia: results from a single UK centre. *Haem: British Journal Of Haematology*. 4 (1), 1-9.
- K. Ratajová, J. Blatný Iva, P. Šolcovál, Z Meierl, T Horňákovál, R Brnka l, P. Tavel (2020). Social support and resilience in persons with severe haemophilia: An interpretative phenomenological analysis. *Haemophilia*, 26 (3), e-74-e80. 1365-2516. <https://doi.org/10.1111/hae.13999>.
- Kumari, (2014). Conceptual Evolution of Resilience Capacity and Its Inclusion in PsyCap. Vol 19 Issue 3. *Journal of Humanities and Social Sciences*.
- Lawrenti, (2021). Hemofilia dan Perkembangan Terapinya. *CDK: Cermin Dunia Kedokteran*, 48 (9), 362-367.
- Little T, Strodl E, Brown S, Mooney T, (2016). Parenting a child with haemophilia while living in a non-metropolitan area. *J Haem Pract*, 3(1). DOI: 10.17225/jhp00066.
- Lutfatulatifah (2020). Dominasi Ibu Dalam Peran Pengasuhan Anak Dibenda Kerep Cirebon. *Equalita*, 2 (1), 67-73.
- Masten, A. S. (2018). Resilience theory and research on children and families: Past, present, and promise. *Journal of Family Theory & Review*, 10(1), 12–31. <https://doi.org/10.1111/jftr.12255>
- M. Beiranvand, M. K. Moghadam, R. Sabounchi, M. Delphan, A. Ghafuori, R. Keramati, Moghadam (2019). The effectiveness of positive thinking training on self efficacy and emotion regulation in men with hemophilia. *Trends in Medicine*, 19, 1-5.
- M. Franchini, P. M. Mannucci (2012). Past, present and future of hemophilia: a narrative review. *Orphanet Journal of Rare Diseases* 7(24), 1-8
- Mirchandani, K. (2021). The Relationship among Social Support, Self-Efficacy and Resilience. *The international Journal of Indian psychology*. 9 (3). DOI: 10.25215/0903.144.
- Marcinechovál ,D. Záhorcová L. Lohazerová K (2023). Self-forgiveness, Guilt, Shame, and Parental Stress among Parents of Children with Autism Spectrum Disorder. Springer. Doi: doi.org/10.1007/s12144-023-04476-6
- Monahan PE, Baker JR, Riskie B, Soucie JM. (2011) Physical functioning in boys with hemophilia in the U.S. *Am J Prev Med*. 1(4), 360-8

- Myrin-Westesson L, Baghaei F, Friberg F. The experience of being a female carrier of haemophilia and the mother of a haemophilic child. *Haemophilia* 2013;19:219-24
- Nahrussalwa (2018) Status Identitas Diri Pada Pria Dewasa Awal yang Mengidap Hemofilia. *Psikoborneo*, 6 (4), 613- 622.
- Ozbay F, Johnson DC, Dimoulas E, Morgan CA, Charney D, Southwick S. Social support and resilience to stress: from neurobiology to clinical practice. *Psychiatri*.
- Panchal, S., Mukherjee, S., & Kumar, U. (2016). Optimism in Relation to Well-being , Resilience, and Perceived Stress. *Procedia - Social and Behavioral Sciences*. 1541 – 1544.
- Pinquart M (2013). Do the parent-child relationship and parenting behaviors differ between families with a child with and without chronic illness? A meta-analysis. *J Pediatric Psychology* 38(7), 708-21. doi: 10.1093/jpepsy/jst020.
- Piel, M. h., Lietz, C. A., Geiger, J. M. (2016). Empathy as an Essential Foundation to Succesful Foster Parenting. *Springer Science New York*. DOI 10.1007/s10826-016-0529-z.
- Ramadhan, M. Dewi, R. Hafnidar, H. (2023) Pemaafan Dan Resiliensi Pada Mahasiswa Tingkat Akhir Di Universitas Malikussaleh. *INSIGHT: Jurnal Penelitian Psikologi*, 1(4). DOI: <http://doi.org/10.29103/uhjpm.v2i1.13420>
- Rayner, M., & Moore, S.M. (2007). Stress and Ameliorating Factors among Families with a Seriously Ill or Disabled Child. *Sensoria: A Journal of Mind, Brain and Culture*, 3, 86-93.
- Reivich, K. Shatte, A (2002). The Resilience Factor: 7 Keys to Finding Your Inner Strength and Overcoming Life's Hurdles. **New York: Broadway Books**.
- Rosenberg, A. R., Wolfee, J., Bradford, M. C., Shaffer, A. L., Curtis, J. R. (2014). Resilience and Psychosocial Outcomes in Parents of Children with Cancer. *Pediatr Blood Cancer Wiley Online Library*. DOI 10.1002/pbc.24854
- R. Stevens (1995). The History Of Haemophilia In The Royal Families Of Europe British Journal. *British Journal Of Haematology*, 25-32.
- Ruswahyuningsih, Afiatin (2015). Resiliensi pada Remaja Jawa. *Gadjah Mada Journal Of Psychology* 1 (2), 96-105.
- Sanayeh, M., Nourian, M., Tajalli, S., Khoshnavay Fomani, F., Heidari, A., & Nasiri, M. (2021). Resilience and Associated Factors in Mothers of Children with Congenital Heart Disease: A Cross-Sectional Study. *International Journal of Community Based Nursing and Midwifery*.
- S. Azwar (2019). Metode Penelitian Psikologi : Edisi II. Yogyakarta: Pustaka Pelajar.

- Shargi (2006). Depression in Mothers of Children with Thalassemia or Blood Malignancies: A Study From Iran. *Clinical Practice and Epidemiology in Mental Health*. doi:10.1186/1745-0179
- Southwick, S. M., Bonanno, G. A., Masten, A. S., Panter-Brick, C., & Yehuda, R. (2014). Resilience definitions, theory, and challenges: Interdisciplinary perspectives. *European Journal of Psychotraumatology*, 5. <https://doi.org/10.3402/ejpt.v5.25338>
- Stevens, R. (1999). The History Of Haemophilia In The Royal Families Of Europe. *British Journal of Haematology*, 105.
- Sugiyono. (2013). Metode Penelitian Kuantitatif, Kualitatif dan RdanD. Bandung: CV. Alfabeta
- Ungar, M. (2008). Resilience across cultures. *British Journal of Social Work*, 38(2), 218–235.
- Utami, C. T., Helmi, A. F. (2017). Self Efficacy dan Resiliensi: Sebuah Tinjauan Meta-Analisis. *Buletin Psikologi UGM*. 25 (1).
- Wagnild, G.M. Young, H.M. (1993). The Development and Evaluation of The Resilience Scale. *Journal of Nursing Measurement*. Springer Publication.
- Whiting, M., Nash, A.S., Kendall, S., Roberts, S.A. (2019). Enhancing Resilience and Self-Efficacy in the Parents of Children with Disabilities and Complex Health Needs. *Primary Health Care Research & Development*, 20 (33): 1-7.
- Yunus, M., & Chaudhary, P. (2023). The Role of Emotion Regulation in Stress Management: An Overview. *Journal of Clinical Research and Applied Medicine*.