

DAFTAR PUSTAKA

- Al Sawah, S., Daly, R. P., Foster, S. A., Naegeli, A. N., Benjamin, K., Doll, H., Bond, G., Moshkovich, O., & Alarcón, G. S. (2017). The caregiver burden in lupus: findings from UNVEIL, a national online lupus survey in the United States. *Lupus*, 26(1), 54–61. <https://doi.org/10.1177/0961203316651743>
- Alves, L. C. S., Monteiro, D. Q., Bento, S. R., Hayashi, V. D., Pelegri, L. N. C., & Vale, F. A. C. (2019). Burnout syndrome in informal caregivers of older adults with dementia: A systematic review. *Dementia & neuropsychologia*, 13(4), 415–421. <https://doi.org/10.1590/1980-57642018dn13-040008>
- Batran, R. R. M., El-Monem, H. H. A., & Ismail, S. S. (2022). The effect of instructional guidelines on caregivers to improve quality of life for their children with systemic lupus erythematosus. *Current Pediatric Research* (2022) Volume 26, Issue 8. DOI:10.35841/0971-9032.26.8.1559-1571.
- Bianchi, R., Schonfeld, I. S., & Laurent, E. (2015). Is it Time to Consider the "Burnout Syndrome" A Distinct Illness?. *Frontiers in public health*, 3, 158. <https://doi.org/10.3389/fpubh.2015.00158>
- Bevans, M., & Sternberg, E. M. (2012). Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA*, 307(4), 398–403. doi:10.1001/jama.2012.29
- Brandt, J., & Hagge, K., S. (2020). Education and social support: do migrants benefit as much as natives?. *Brandt and Hagge Comparative Migration Studies* 8:41 <https://doi.org/10.1186/s40878-020-00199-w>
- Broxson, J., & Feliciano, L. (2020). Understanding the Impacts of Caregiver Stress. *Professional case management*, 25(4), 213–219. <https://doi.org/10.1097/NCM.0000000000000414>
- Cahyani, I. (2023). Hubungan dukungan sosial dan tingkat stress dengan kejadian burnout pada family caregiver lansia di kelurahan ciapus bogor. <http://repository.upnvj.ac.id/id/eprint/25008>
- CDC (2023). Systemic Lupus Erythematosus (SLE). Online <https://www.cdc.gov/lupus/facts/detailed.html#sle>. Diakses pada tanggal 10 Januari 2024.
- Cohen S. (2004). Social relationships and health. *The American psychologist*, 59(8), 676–684. <https://doi.org/10.1037/0003-066X.59.8.676>

- Colvin, A. D., & Bullock, A. N. (2016). A review of the biopsychosocial aspects of caregiving for aging family members. *Journal of Family Social Work*, 19(5), 420–442. doi:10.1080/10522158.2016.1214657
- Danoff-Burg, S., & Friedberg, F. (2009). Unmet needs of patients with systemic lupus erythematosus. *Behavioral medicine (Washington, D.C.)*, 35(1), 5–13. <https://doi.org/10.3200/BMED.35.1.5-13>
- Del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., Ruzafa-Martínez, M., & Ramos-Morcillo, A. J. (2018). Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. *PloS one*, 13(1), e0189874. <https://doi.org/10.1371/journal.pone.0189874>
- Dewi, E. S., Putri, C. M. A., Desfryda, E. P., Dwinadella, S., Wahono, C. S., Sari, D. P., Handono, K., & Kalim, H. (2023). Optimalisasi Dukungan Sosial Bagi Pasien Lupus dan Keluarga Pasca Pandemi Covid-19 di Yayasan Kupu Parahita Indonesia. *International Journal of Community Service Learning*, 7(2), 199–207. <https://doi.org/10.23887/ijcs.v7i2.56434>
- Edú-Valsania, S., Laguía, A., & Moriano, J. A. (2022). Burnout: A Review of Theory and Measurement. *International journal of environmental research and public health*, 19(3), 1780. <https://doi.org/10.3390/ijerph19031780>
- Ferrell, B., Hanson, J., & Grant, M. (2013). An overview and evaluation of the oncology family caregiver project: improving quality of life and quality of care for oncology family caregivers. *Psycho-oncology*, 22(7), 1645–1652. <https://doi.org/10.1002/pon.3198>
- Fonseca, R., Bernardes, M., Terroso, G., de Sousa, M., & Figueiredo-Braga, M. (2014). Silent Burdens in Disease: Fatigue and Depression in SLE. *Autoimmune diseases*, 2014, 790724. <https://doi.org/10.1155/2014/790724>
- Gaspar, T., Raimundo, M., de Sousa, S. B., Barata, M., & Cabrita, T. (2023). Relationship between Burden, Quality of Life and Difficulties of Informal Primary Caregivers in the Context of the COVID-19 Pandemic: Analysis of the Contributions of Public Policies. *International journal of environmental research and public health*, 20(6), 5205. <https://doi.org/10.3390/ijerph20065205>
- Gérain, P., & Zech, E. (2019). Informal Caregiver Burnout? Development of a Theoretical Framework to Understand the Impact of Caregiving. *Frontiers in psychology*, 10, 1748. <https://doi.org/10.3389/fpsyg.2019.01748>
- Güven Baysal, Ş., & Çorabay, S. (2024). Caregiver Burden and Depression in Parents of Children with Chronic Diseases. *Turkish archives of*

pediatrics, 59(1), 70–77.
<https://doi.org/10.5152/TurkArchPediater.2024.23126>

Horn, J.E. Van, & Schaufeli, WB. (1998). The Dutch Educators Survey (MBI-NLES) Psychometric evaluations. Utrecht University: Department of Social and Organizational Psychology.

House, J. S. (1983). Work stress and social support. Addison-Wesley series on occupational stress.

Justiz Vaillant, A. A., Goyal, A., & Varacallo, M. (2023). Systemic Lupus Erythematosus. In *StatPearls*. StatPearls Publishing

Kartika, A. W. (2013). Studi Fenomenologi Pengalaman Keluarga Membangun Koping Dalam Merawat Anggota Keluarga Dengan Penyakit Kronis Di Kota Depok. <https://lib.ui.ac.id/detail?id=20349338&lokasi=lokal>

Keita Fakeye, M. B., Samuel, L. J., Drabo, E. F., Bandeen-Roche, K., & Wolff, J. L. (2023). Caregiving-Related Work Productivity Loss Among Employed Family and Other Unpaid Caregivers of Older Adults. *Value in health : the journal of the International Society for Pharmacoeconomics and Outcomes Research*, 26(5), 712–720. <https://doi.org/10.1016/j.jval.2022.06.014>

Kennedy, D. P., Friedman, E. M., Kirkegaard, A., Edgington, S., & Shih, R. (2024). Perceived loss of support to community caregivers during the COVID-19 pandemic in the United States. *Journal of community psychology*, 52(3), 475–497. <https://doi.org/10.1002/jcop.23107>

Khammissa, R. A. G., Nemutandani, S., Feller, G., Lemmer, J., & Feller, L. (2022). Burnout phenomenon: neurophysiological factors, clinical features, and aspects of management. *The Journal of international medical research*, 50(9), 3000605221106428. <https://doi.org/10.1177/03000605221106428>

Kikusui, T., Winslow, J. T., & Mori, Y. (2006). Social buffering: relief from stress and anxiety. *Philosophical transactions of the Royal Society of London. Series B, Biological sciences*, 361(1476), 2215–2228. <https://doi.org/10.1098/rstb.2006.1941>

Kilmer, G., Omura, J. D., Bouldin, E. D., Walker, J., Spears, K., Gore, J., Ali, A. R., & McGuire, L. C. (2024). Changes in Health Indicators Among Caregivers - United States, 2015-2016 to 2021-2022. *MMWR. Morbidity and mortality weekly report*, 73(34), 740–746. <https://doi.org/10.15585/mmwr.mm7334a2>

- Kim, M., Yeom, H. E., & Jung, M. S. (2022). Validation and psychometric properties of the multidimensional scale of perceived social support among Korean breast cancer survivors. *Asia-Pacific journal of oncology nursing*, 9(4), 229–235. <https://doi.org/10.1016/j.apjon.2022.01.004>
- Kneavel M. (2021). Relationship Between Gender, Stress, and Quality of Social Support. *Psychological reports*, 124(4), 1481–1501. <https://doi.org/10.1177/0033294120939844>
- Kort-Butler, L. A. (2017). *Social Support Theory. The Encyclopedia of Juvenile Delinquency and Justice*, 1–4. doi:10.1002/9781118524275.ej
- Lasebikan, V. O., & Ayinde, O. O. (2013). Family Burden in Caregivers of Schizophrenia Patients: Prevalence and Socio-demographic Correlates. *Indian journal of psychological medicine*, 35(1), 60–66. <https://doi.org/10.4103/0253-7176.112205>
- Lin, C. Y., Alimoradi, Z., Griffiths, M. D., & Pakpour, A. H. (2022). Psychometric properties of the Maslach Burnout Inventory for Medical Personnel (MBI-HSS-MP). *Heliyon*, 8(2), e08868. <https://doi.org/10.1016/j.heliyon.P.2022.e08868>
- Marchira, C. R., (2012). Pengaruh Intervensi Psikoedukasi Interaktif Singkat tentang Skizofrenia Terhadap Pengetahuan Caregiver, Keteraturan Kontrol, Ketaatan Pengobatan, dan Kekambuhan pada Penderita Gangguan Psikotik Fase Awal di Jogjakarta. Indonesia: Fakultas Kedokteran Universitas Gadjah Mada, Yogyakarta.
- Maslach, C., Schaufeli, W. B., & Leiter, M. P. (2001). Job Burnout. *Annual Review of Psychology*, 52(1), 397–422.
- Maslach, C., & Jackson, S. E. (1981). The measurement of experienced burnout. *Journal of Organizational Behavior*, 2(2), 99–113.
- Muninggar, P. U. A, Effendy, C., & Pangastuti, H. S. (2021). Description of Social Support for Family Caregiver in Treating Dementia Patients. *Jurnal Keperawatan Klinis dan Komunitas Vol 5 (1) Maret 2021*. <https://doi.org/10.22146/jkkk.84313>
- Nemcikova, M., Katreniakova, Z., & Nagyova, I. (2023). Social support, positive caregiving experience, and caregiver burden in informal caregivers of older adults with dementia. *Frontiers in public health*, 11, 1104250. <https://doi.org/10.3389/fpubh.2023.1104250>
- Nick, E. A., Cole, D. A., Cho, S. J., Smith, D. K., Carter, T. G., & Zelkowitz, R. L. (2018). The Online Social Support Scale: Measure development and

validation. *Psychological assessment*, 30(9), 1127–1143.
<https://doi.org/10.1037/pas0000558>

Nugroho, B., Y., S. (2019). Shift kerja, Beban Kerja, dan Burnout pada perawat rawat inap khusus RSUP Dr. Sardjito. Tesis Ilmu Kesehatan Masyarakat Universitas Gadjah Mada.

Oedekoven, M., Amin-Kotb, K., Gellert, P., Balke, K., Kuhlmei, A., & Schnitzer, S. (2019). Associations between informal caregivers' burden and educational level. *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry*, 32(1), 19–29. <https://doi.org/10.1024/1662-9647/a000199>

Otero, L. M. R. (2016). Burnout Syndrome in Family Caregivers of Dependents. *International Journal of Asian Social Science*, 6(1), 12–20. <https://doi.org/10.18488/journal.1/2016.6.1/1.1.12.20>

Ozbay, F., Johnson, D. C., Dimoulas, E., Morgan, C. A., Charney, D., & Southwick, S. (2007). Social support and resilience to stress: from neurobiology to clinical practice. *Psychiatry (Edmont (Pa. : Township))*, 4(5), 35–40.

Pacheco Barzallo, D., Schnyder, A., Zanini, C., & Gemperli, A. (2024). Gender Differences in Family Caregiving. Do female caregivers do more or undertake different tasks?. *BMC health services research*, 24(1), 730. <https://doi.org/10.1186/s12913-024-11191-w>

Parameshwar, D., Rusli, E., & Markam S., S. (2007). Gambaran burnout pada caregiver keluarga pasien stroke. <https://lib.ui.ac.id/detail.jsp?id=20341484>

Peters, E., Spanier, K., Radoschewski, F. M., & Bethge, M. (2018). Influence of social support among employees on mental health and work ability—a prospective cohort study in 2013–15. *European Journal of Public Health*.doi:10.1093/eurpub/cky067

Putera, A. M., Irwanto, I., Maramis, M. M., Prasetyo, R. V., Soemyarso, N. A., & Noer, M. S. (2020). Effect of Mental Health Problems on the Quality of Life in Children with Lupus Nephritis. *Neuropsychiatric disease and treatment*, 16, 1583–1593. <https://doi.org/10.2147/NDT.S250373>

Putra, A.C.M. & Muttaqin, D. (2020). Hubungan Antara Dukungan Sosial dengan Burnout Pada Perawat di Rumah Sakit X. *Psikostudia: Jurnal Psikologi*. Vol 9, No 2, Maret 2020, hlm. 82-87. <http://dx.doi.org/10.30872/psikostudia.v9i2.3901>

Profil Sahabat Cempluk, Komunitas yang Bawa Harapan Baru Bagi Pasien Lupus. (2024, Mei 24). Diakses Juni 27, 2024, dari kumparan: <https://kumparan.com/teman->

kumparan/22nkTvLswHo?utm_source=Desktop&utm_medium=copy-to-clipboard&shareID=1oNUWY17dZ5f

Riset Kesehatan Dasar (Riskesdas) (2018). Badan Penelitian dan Pengembangan Kesehatan Kementerian RI tahun 2018. http://www.depkes.go.id/resources/download/infoterkini/materi_rakorpop_2018/Hasil%20Riskesdas%202018.pdf – Diakses Desember 2023.

Robinso, S., & Weiss, J.A. (2020). Examining the relationship between social support and stress for parents of individuals with autism. *Research in Autism Spectrum Disorder*, 74. <https://doi.org/10.1016/j.rasd.2020.101557>

Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, 55(2), 309–319. doi:10.1093/geront/gnu177

Saefullah. 2012. *Psikologi Perkembangan dan Pendidikan*. Pustaka setia: Bandung.

Sarafino, E. P., & Smith, T. W. (2014). *Health psychology: Biopsychosocial interactions*. John Wiley & Sons.

Sarason, B. R., Shearin, E. N., Pierce, G. R., & Sarason, I. G. (1987). Interrelations of social support measures: Theoretical and practical implications. *Journal of Personality and Social Psychology*, 52(4), 813-832. <https://doi.org/10.1037/0022-3514.52.4.813>

Sastroasmoro, S., & Ismael, S. (Eds.). 2016. *Dasar-dasar Metodologi Penelitian Klinis*. Edisi ke-5. Jakarta: Sagung Seto

Shin, H., & Park, C. (2022). Social support and psychological well-being in younger and older adults: The mediating effects of basic psychological need satisfaction. *Frontiers in psychology*, 13, 1051968. <https://doi.org/10.3389/fpsyg.2022.1051968>

Szlenk-Czyczerska, E., Guzek, M., Bielska, D. E., Ławnik, A., Polański, P., & Kurpas, D. (2020). Needs, Aggravation, and Degree of Burnout in Informal Caregivers of Patients with Chronic Cardiovascular Disease. *International journal of environmental research and public health*, 17(17), 6427. <https://doi.org/10.3390/ijerph17176427>

Soerjono. S. (2004). *Sosiologi Keluarga*. Jakarta : PT Rineka Cipta.

Stahl, S. (2021). *Stahl's Essential Psychopharmacology* (5th ed.). Cambridge University Press. Retrieved from <https://www.perlego.com/book/4230556> (Original work published 2021)

- Stanley, M. & Beare, P.G. (2007). *Buku ajar keperawatan gerontik*. Edisi 2. Jakarta: Penerbit Buku Kedokteran EGC.
- Stanley, S., & Sebastine, A. J. (2023). Work-life balance, social support, and burnout: A quantitative study of social workers. *Journal of Social Work*, 23(6), 1135-1155. <https://doi.org/10.1177/14680173231197930>
- Stojan, G., & Petri, M. (2018). Epidemiology of systemic lupus erythematosus: an update. *Current opinion in rheumatology*, 30(2), 144–150. <https://doi.org/10.1097/BOR.0000000000000480>
- Sulistiani, W., & Kristiana, I. F. (2022). Validation of The Indonesian Version of The (MSPSS): A RASCH Model Approach. 21(1), 89–103.
- Tops, M., Boksem, M. A. S., Wijers, A. A., van Duinen, H., Den Boer, J. A., Meijman, T. F., & Korf, J. (2007). The Psychobiology of Burnout: Are There Two Different Syndromes? *Neuropsychobiology*, 55(3-4), 143–150. doi:10.1159/000106056
- Utset, T. O., Baskaran, A., Segal, B. M., Trupin, L., Ogale, S., Herberich, E., & Kalunian, K. (2015). Work disability, lost productivity and associated risk factors in patients diagnosed with systemic lupus erythematosus. *Lupus science & medicine*, 2(1), e000058. <https://doi.org/10.1136/lupus-2014-000058>
- Uzuner, S., Durcan, G., Sahin, S., Bahali, K., Barut, K., Kilicoglu, A. G., Adrovic, A., Bilgic, A., & Kasapcopur, O. (2021). Caregiver burden and related factors in caregivers of patients with childhood-onset systemic lupus erythematosus. *Clinical rheumatology*, 40(12), 5025–5032. <https://doi.org/10.1007/s10067-021-05867-5>
- van den Heuvel, E. T., de Witte, L. P., Schure, L. M., Sanderman, R., & Meyboom-de Jong, B. (2001). Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention. *Clinical rehabilitation*, 15(6), 669–677. <https://doi.org/10.1191/0269215501cr446oa>
- Vania, I. W., & Dewi, K. S. (2014). HUBUNGAN ANTARA DUKUNGAN SOSIAL DENGAN PSYCHOLOGICAL WELL-BEING CAREGIVER PENDERITA GANGGUAN SKIZOFRENIA. *Jurnal EMPATI*, 3(4), 266-278. <https://doi.org/10.14710/empati.2014.7580>
- Vater, M., Davis, A., & Jaser, S. (2024). Evaluation of health literacy and its association with medication adherence and quality of life in childhood-onset systemic lupus erythematosus. *Lupus*, 33(9), 1004–1011. <https://doi.org/10.1177/09612033241258189>

- Velando-Soriano, A., Ortega-Campos, E., Gómez-Urquiza, J. L., Ramírez-Baena, L., De La Fuente, E. I., & Cañadas-De La Fuente, G. A. (2020). Impact of social support in preventing burnout syndrome in nurses: A systematic review. *Japan journal of nursing science : JJNS*, 17(1), e12269. <https://doi.org/10.1111/jjns.12269>
- Velilla, L., Acosta-Baena, N., Allen, I., Lopera, F., & Kramer, J. (2022). Analysis of family stigma and socioeconomic factors impact among caregivers of patients with early- and late-onset Alzheimer's disease and frontotemporal dementia. *Scientific reports*, 12(1), 12663. <https://doi.org/10.1038/s41598-022-16400-2>
- Wickramasinghe, N. D., Dissanayake, D. S., & Abeywardena, G. S. (2018). Validity and reliability of the Maslach Burnout Inventory-Student Survey in Sri Lanka. *BMC psychology*, 6(1), 52. <https://doi.org/10.1186/s40359-018-0267-7>
- Wijaya, R., & Fun Fun, L. (2022). The Relationship between Burden of Care and Burnout in Family Caregivers of People with Dementia. *Humanitas (Jurnal Psikologi)*, 6(1), 49–62. <https://doi.org/10.28932/humanitas.v6i1.4501>
- Yulianti, Iskandarsyah A, Rafiyah I. (2018). Burnout Level Caregiver Clients Schizofrenia in Villages Kersamanah District Garut. *Jurnal Riset Hesti Medan*, Vol. 3, No. 1 Januari-Juni 2018. <https://doi.org/10.34008/jurhesti.v3i1.26>
- Zhang, M., Li, S., Han, D., Wu, Y., Zhao, J., Liao, H., Ma, Y., Yan, C., & Wang, J. (2023). Association of Job Characteristics and Burnout of Healthcare Workers in Different Positions in Rural China: A Cross-Sectional Study. *International journal of public health*, 68, 1605966. <https://doi.org/10.3389/ijph.2023.1605966>
- Zhong, Y., Wang, J., & Nicholas, S. (2020). Social support and depressive symptoms among family caregivers of older people with disabilities in four provinces of urban China: the mediating role of caregiver burden. *BMC geriatrics*, 20(1), 3. <https://doi.org/10.1186/s12877-019-1403-9>
- Zimet, G. D., Dahlem, N. W., Zimet, S. G., & Farley, G. K. (1988). The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment*, 52(1), 30–41. doi:10.1207/s15327752jpa5201_2