

BAB 5

KESIMPULAN DAN SARAN

5.1. Kesimpulan

Derajat disabilitas fungsi motorik kasar yaitu level GMFCS dan derajat stres pada orangtua mempunyai hubungan dengan rerata kualitas hidup anak CP. Setiap kenaikan level GMFCS akan menurunkan skor rerata kualitas hidup anak sebesar 4,725 poin, sedangkan setiap kenaikan derajat stres orangtua akan menurunkan skor rerata kualitas hidup .anak sebesar 5,461 poin. Faktor stress orangtua menjadi faktor yang bisa dimodifikasi untuk memperbaiki kualitas hidup anak CP.

5.2. Saran

Memperbaiki derajat stress orangtua dengan meningkatkan interaksi hubungan antara orangtua dan anak bisa menjadi salah satu faktor yang dapat dimodifikasi dengan jalan mengikutsertakan orangtua dalam grup support keluarga anak CP, dan memberikan intervensi berupa pendampingan psikolog kepada orangtua anak CP maupun diskusi rutin dengan keluarga anak CP. Intervensi dini bagi anak CP perlu dilakukan sedini mungkin dengan tujuan memperbaiki derajat fungsi motorik anak. Hasil penelitian ini bisa sebagai acuan untuk tata laksana anak CP agar mempunyai kualitas hidup yang lebih baik, yaitu memasukkan orangtua anak CP ke dalam grup support khusus anak *cerebral palsy* dan pendampingan maupun intervensi psikologis kepada orangtua anak CP.

DAFTAR PUSTAKA

- Abidin RR. (1995). The Parenting Stress Index. Lutz, FL: Psychological Assessment Resources.
- American Academy of Pediatrics. (2000). Clinical Practice Guideline: Early Detection of Developmental Dysplasia of the Hip. *Pediatrics*, Vol.105, pp 896 – 905.
- Amoghmath R., Gowda VK., Benakappa A. (2016). Comorbidities and Their Relationship to Subtype of Cerebral Palsy in a Tertiary Care Hospital in South India. *Indian J of Cerebral Palsy*, Vol.2. pp 90-93.
- Berker, N., Yalcin, S. (2017). *The HELP Guide Cerebral Palsy*.
- Boldingh E.J., Jacobs-van der Bruggen, M.A., Lankhorst G.J., Bouter L.M. (2004). Assessing pain in patients with severe cerebral palsy: development, reliability and validity of a pain assessment instrument for cerebral palsy. *Archives of Physical Medicine & Rehabilitation*. Vol 85; 758-66.
- Brevik H., Sorensen K., Tavi O. (2015). Evaluation of pain in children with communication difficulties: r-FLACC translated and validated in Nordic languages. *Scand J Pain*. Vol 9(1): 66-67.
- Butler G. (1993). Definition of Stress. *Occas pap R coll Gen Pract* (61):1-5.
- Centers for Disease Control and Prevention (CDC). (2018). Cerebral palsy. Available from <https://www.cdc.gov>
- Chalipat S., Malwade S.D., Karambelkar G.R., Agarkhedkar S.R. (2016). 'Assesment Of Quality of Life of Parents of Children with Cerebral Palsy'. *J.Evid.Based Med. Health.*, Vol.3. pp. 4673-677.
- Chih J.L., Chung Y.C., Chia L.C., Pei Y.S.C., I-Hsuan S., Ching Y.W. (2017). Longitudinal changes in health-related quality of life in preschool children with cerebral palsy of different levels of motor severity. *Reseach in Developmental Dissability*, (61):11-18.
- Colver, A., Fairhurst, C., Pharoah P.O.D. (2014). Cerebral palsy. *The Lancet*. Elsevier Ltd, 383(9924), pp. 1240–1249.
- Davis, E. Shelly A., Waters E., Davern M. (2010). 'Measuring the Quality of Life of Children with Cerebral Palsy: Comparing the Conceptual Differences and Psychometric Properties of Three Instruments', *Developmental Medicine and Child Neurology*, 52(2), pp. 174–180.
- Elkamil A.I., Anderson G.L., Vik T. (2011). Prevalence of hip dislocation among children with cerebral palsy in regions with and without a surveillance programme: across section study in Sweden and Norway. *BMC Musculoskelet Disord*; 12:284.
- Gharaborghe, S., N. Nurani S., Mohsen S., Hosseini., Sadegh S.M., Saadat S. (2015). 'Relationship between Quality of Life and Gross Motor Function in Children with Cerebral Palsy (Ages 4-12)', 37(2), pp. 48–53.
- Irwanto. (2010). Analisis Situasi Penyandang Disabilitas di Indonesia : Sebuah Deskreview. Jakarta.
- Jayanath S, Ong L.C., Marret M.J., Fauzi A.A. (2016). 'Parent-Reported Pain in Non-Verbal Children and Adolescents with Cerebral Palsy'. *Dev Med Child Neurology*, (4): 395-401.

- Kaswindiarti, E.D. (2016). Kualitas hidup pada anak dengan Congenital Rubella Syndrome. Tesis. Universitas Gadjah Mada.
- Kate himmelmann, A. and Elvrum .(2016). Bimanual Fine Motor Function BFMF Classifies Fine Motor Function in Children with Cerebral Palsy .
- Levine MS. (1980). Cerebral Palsy Diagnosis in Children over Age 1 Year: Standard Criteria. *Arch Phys Med Rehabil*, 61(9):385-9.
- Novak, I., McIntyre S., Morgan C., Campbell L., Dark L. (2013). 'A Systematic Review of Interventions for Children with Cerebral Palsy: State of the Evidence', *Developmental Medicine and Child Neurology*, 55(10), pp. 885–910.
- Parkes J., Caravale B., Marcelli M., Franco F., Colver, A. (2011). 'Parenting Stress and Children with Cerebral Palsy : a European Cross-Sectional Survey'. *Developmental Medicine and Child Neurology*, Vol 53: pp. 815-821.
- Power R. et.al. (2018). 'Health-Related Quality of Life of Children and Adolescents with Cerebral Palsy in Low-and Middle –Income Countries : a Systematic Reviews'. *Developmental Medicine & Child Neurology*. Pp 469-480.
- Preedy, V. R. and Ronald R. W. (2018). Handbook of Disease Burdens and Quality of Life Measure's. *Springer*, New York, NY.
- Puspitarini, Z. (2016). 'Faktor-faktor yang Berhubungan dengan Kualitas Hidup pada Anak Cerebral Palsy di Daerah Istimewa Yogyakarta'. Tesis.
- Radsel, A., Osredkar, D. and Neubauer, D. (2017). 'Health-Related Quality of Life in Children and Adolescents with Cerebral Palsy', *Zdravstveno Varstvo*, 56(1), pp. 1–10.
- Rapp, M., Eisemann N., Arnauld C., Ehlinger V., Fauconnier J., Marcelli M. (2016). 'Predictors of Parent-reported Quality of life of Adolescents with Cerebral Palsy: A Longitudinal Study', pp. 2016–2018.
- Renwick R., Schormans A.F., Zecovic B. (2003). 'Quality of life for children with developmental disabilities: a new conceptual framework'. *Journal on Developmental Disabilities*, Vol 10, No 1.
- Republik Indonesia. (2010). Peraturan Pemerintah Republik Indonesia Nomor 17 Tahun 2010 tentang Pengelolaan dan Penyelenggaraan Pendidikan. Sekretariat Negara. Jakarta.
- Ribeiro M.F.M., Sousa A.L.L., Luc Vandenberghe, Celmo C.P., (2014). 'Parental Stress in Mothers of Children and Adolescents with Cerebral Palsy. *Rev. Latino-Am. Enfermagem*, 22(3):440-7. Available form www.eerp.usp.br/rlae.
- Romeo D.M., Cion M., Distefano A., Battaglia L.R., Costanzo L. (2010). 'Quality of Life in Parents of Children with Cerebral palsy: is it influenced by the child's behavior?' *Neuropediatrics*.
- Sesmeliati, M. (2017). Perbedaan Kualitas Hidup Orangtua yang Memiliki Anak dengan Disability dan Non Disability di Wilayah Kerja Kelurahan Padang Sarai tahun 2017. Tesis. Universitas Andalas.
- Soetjningsih. (1995). Tumbuh Kembang Anak. EGC. Jakarta.
- Sikorova L., Buzgova R. (2016). Associations between the quality of life of

- children with chronic diseases, their parents quality of life and family coping strategies. *Central European Journal of Nursing and Midwifery*. Vol 7(4):534-541.
- Spore E. (2004). The Quality of Life of Primary Caregivers of Children with Chronic Condition. University of Illinois. Chicago. Thesis.
- Swaiman KF, Ashwal S, Ferriero DM., Schor NF., Finkel R.S. (2017). 'Swaiman's Pediatric Neurology: Principle and Practice'. Edinburgh: Elsevier.
- Tessier D.W., Heffner J.L., Newmeyer A. (2014). 'Factors Related to Psychosocial Quality of Life for Children with Cerebral Palsy'. *International Journal of Pediatrics*, Vol 2014. pp 1-6.
- Varni J.W et.al. (2006). The PedsQL in pediatric cerebral palsy : reliability, validity, and sensitivity of the Generic Core Scales and Cerebral Palsy Module. *Dev Med Child Neurol*. Jun;48(6):442-9.
- Vles, G.F., Hendriksen R.G.F., van Raak E.P.M., Soudant D., (2015). 'Quality of Life Children with Cerebral Palsy: a Cross-Sectional KIDSCREEN Study in the Southern part of the Netherlands'. *CNS & Neurological Disorders*, Vol 14.
- Koning W.M., Arnaud C., Dickinson H.O. (2007). 'Determinants of child parent agreement in Quality of Life Reports: a European Study of Children with Cerebral Palsy'. *Pediatrics*. Vol. 120, no. 4, pp.e804-e814.
- World Health Organization. (2004). 'The World Health Organization Quality of Life (WHOQOL-BREF)'. Diterjemahkan oleh: Ratna M., Satya J., Hartati K.R.S, Catolic University Atma Jaya, Jakarta.
- World Health Organization. (2019). WHOQOL: Measuring Quality of Life. Available from [http:// www.who.int](http://www.who.int).
- Yang X., Xiao N., Yan J. (2011). 'The PedsQL in pediatric cerebral palsy: reliability and validity of the Chinese version pediatric quality of life inventory 4.0 generic core scales and 3.0 cerebral palsy module'. *Qual Life Res*. Mar;20(2):243-52.
- Yilmaz H., Erkin G., Ali A. (2013). 'Quality of Life in Mothers of Children with Cerebral Palsy'. *ISRN Rehabilitation*. Vol 2013:1-5.
- Yudianta, Khoirunnisa N., Novitasari R.W. (2015). Assesment Nyeri. CDK. Vol 42, no 3, pp 214-234.