



HUBUNGAN ANTARA DERAJAT STRES ORANGTUA DENGAN KUALITAS HIDUP ANAK CEREBRAL PALSY

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INTISARI

Latar belakang. Anak *Cerebral Palsy* (CP) mempunyai risiko mengalami berbagai macam masalah yaitu keterbatasan fisik, kesehatan, sosial dan emosional sehingga mempengaruhi kualitas hidup anak. Orangtua juga mengalami stress yang dapat mempengaruhi kualitas hidup anak.

Tujuan penelitian. Untuk mengetahui dan menganalisis kualitas hidup anak CP dan derajat stres orangtua dan faktor-faktor yang berhubungan dengan kualitas hidup anak CP.

Metode penelitian. Merupakan penelitian observasional dengan desain potong lintang. Subyek adalah semua anak CP di Yogyakarta yang masuk dalam grup Wahana Keluarga *Cerebral Palsy* (WKCP) dan pasien Rumah Sakit Akademik UGM dengan rentang usia 2-18 tahun. Anak CP yang sedang dalam perawatan di Rumah Sakit, orangtua tidak tinggal satu rumah dengan anak, atau tidak mengisi lengkap kuisioner dieksklusi. Orang tua mengisi Kuisioner PedsQLTM *Cerebral Palsy modul version 3.0* secara *proxy*, kuisioner WHOQOL-BREF dan *Parenting Stress Index* (PSI)

Hasil Penelitian. Total 98 subyek dengan 62 anak (63%) laki-laki, tipe spastik 86 anak (88%). Level *Gross Motor Function Classification System* (GMFCS) berturut-turut level I 18 anak (18%), level II 8 (8%), level III 25 (26%), level IV 13 (13%), dan level V 34 (35%). Level *Bimanual Fine Motor Function* (BFMF) berturut-turut level I 18 anak (18%), level II 27 (28%), level III 12 (12%), level IV 14 (14%), dan level V 27 (28%). Terdapat 36 anak (37%) memiliki lebih dari 2 komorbid, dan 54% anak mengalami nyeri. Rerata skor kualitas hidup anak CP yaitu $49,81 \pm 20,35$. Rerata skor kualitas hidup orangtua adalah $55,76 \pm 8,19$. Rerata skor total PSI orangtua adalah $94,92 \pm 17,02$ yang menunjukkan derajat stress yang berat. Orangtua yang mengalami stress berat sebanyak 63 (64%), dengan 94% mengalami disfungsi interaksi orangtua-anak. Analisis multivariate menunjukkan setiap kenaikan level GMFCS akan menurunkan skor rerata kualitas hidup anak sebesar 4,725 poin, sedangkan setiap kenaikan derajat stress orangtua akan menurunkan skor rerata kualitas hidup anak sebesar 5,461 poin.

Kesimpulan. Semakin berat derajat stress orangtua dan semakin berat level GMFCS akan menurunkan kualitas hidup anak CP.

Kata kunci : *cerebral palsy* – kualitas hidup anak CP- GMFCS-BFMF-*parenting stress index*-kualitas hidup orangtua.



RELATION BETWEEN PARENTAL STRESS AND QUALITY OF LIFE CHILDREN WITH CEREBRAL PALSY

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ABSTRACT

Background. Children with cerebral palsy (CP) have experiencing variety problems form physical health, social, and emotional thereby affecting their quality of life, and so does the parents.

Objective. To know and analized the quality of life CP children and parental stress, also factors related to their quality of life.

Methods. This study was an observational study with a cross sectional research design. Subyek were CP children in the Wahana Keluarga Cerebral Palsy parents group (WKCP) and UGM Academic Hospital since Januari 2019-August 2019 aged 2-18 years. Children who hospitalized, or parents didn't live in the same house with the child, or parents didn't complete fulfill the questionnaire were excluded. Parents filled out the PedsQLTM Cerebral Palsy module version 3.0 Questionnaire by proxy, WHOQOL-BREF and Parenting Stress Index (PSI) questionnaire.

Results. A total of 98 CP children were analyzed, 62 are boys (63%), with 86 spastic CP types (88%). Gross Motor Function Classification System (GMFCS) levels in CP children were level I respectively (18%), level II 8 (8%), level III 25 (26%), level IV 13 (13%), and level V 34 children (35%). Bimanual Fine Motor Function (BFMF) levels respectively; level I 18 (18%), level II 27 (28%), level III 12 (12%), level IV 14 (14%), and level V 27 (28%). A total of 36 children (37%) had more than 2 comorbidities and 54% had pain. The mean quality of life score for CP children was $49.81 \pm 20,35$ SD. The mean quality of life score of parents was 55.76 ± 8.19 . The mean total PSI score was $94.92 \pm 17,02$ which showed that the parents of CP children had severe degrees of stress. The parents of CP children who experienced severe stress were 63 (64%), with 94% in the domain of dysfunction in parent-child interaction. The results of multivariate analysis with showed the more severe levels of GMFCS and parental stress levels would reduce the average quality of life score of CP children by 4.725 points and 5.461 points, respectively.

Conclusions. The heavier degree of parental stress and the more severe level of GMFCS will reduce the quality of life CP children.

Keywords: cerebral palsy - quality of life of children CP-GMFCS-BFMF-parenting stress index-WHOQOL-BREF