

Peran pelayanan paliatif terhadap kualitas hidup, intensitas gejala, dan frekuensi kunjungan unit gawat darurat pada pasien anak dengan penyakit keganasan = Role of palliative care of children with malignancy focusing on quality of life, intensity of symptoms, and emergency unit admission

Pricilia Gunawan Halim, author

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Abstrak

Pendekatan integrasi antara terapi paliatif dan perawatan penyakit kronik dan atau mengancam jiwa telah banyak digunakan dalam beberapa tahun terakhir. Hingga saat ini, masih banyak yang beranggapan bahwa terapi paliatif hanya ditujukan untuk pasien dengan penyakit berat yang sudah berada di stadium terminal atau akhir hidupnya, namun pada kenyataannya banyak pasien mendapatkan manfaat dari terapi paliatif sedini mungkin. Penelitian ini merupakan uji klinis acak terkontrol yang bertujuan untuk mengetahui manfaat integrasi terapi paliatif pada pasien anak dengan penyakit keganasan. Pasien terdiri dari anak dengan penyakit keganasan usia 2-18 tahun yang dikonsulkan kepada tim paliatif. Pasien dibagi menjadi dua kelompok secara acak, yakni kelompok kontrol (30 anak) dan kelompok intervensi (30 anak). Intervensi berupa kunjungan rumah, komunikasi dua arah antara tenaga terlatih dengan pasien dan orang tua, dibagi menjadi 6 sesi (1 sesi setiap 2 minggu) yang berfokus pada edukasi penyelesaian masalah, manajemen gejala, perawatan diri sendiri, komunikasi, pembuatan keputusan dan pendampingan rencana perawatan lanjutan. Pasien diikuti dan dilakukan penilaian kualitas hidup dengan kuesioner Pediatric Quality of Life Initiative (PedsQLTM) modul kanker 3.0, intensitas gejala dinilai dengan Edmonton Symptoms Assesment Score (ESAS), frekuensi kunjungan unit gawat darurat (UGD) pasien anak dengan penyakit keganasan dicatat selama periode penelitian dan dibandingkan dengan sebelum penelitian. Kelompok intervensi memiliki kualitas hidup lebih tinggi bermakna (81,63) dibandingkan kelompok kontrol (62,39), $p < 0,001$. Ranah kualitas hidup yang paling meningkat secara signifikan adalah ranah nyeri, mual, kecemasan prosedur, kecemasan tata laksana, dan khawatir. Intervensi paliatif dapat menurunkan intensitas gangguan tidur ($p = 0,003$) dan anoreksia pada pasien ($p < 0,001$). Intervensi paliatif dapat menurunkan kunjungan UGD sebanyak 4,77 kali pada pasien anak dengan penyakit keganasan (OR 4,77, 95% IK 1,29-17,65; $p = 0,018$).

.....In these last few years, an integrated approach between palliative care and chronic and/or life-threatening conditions care have been widely used. Many people think that palliative care is only intended for those with end stage of disease or in the end of life period. In fact, many patients had benefit from early palliative integration. This study is aimed to know the role of palliative intervention in child with malignancy. A randomized controlled trial comparing patients who were given palliative care (a 3-month home visit) and those who were not (intervention vs control group) was conducted, each group containing 30 patients. Patients consisted of children with cancer aged 2-18 years old who were consulted to palliative team. A two-way communication between a trained health worker and patients with or without their parents were conducted as the intervention (report by proxy or self-report). Interventions were given in 6 sessions (1 session every 2 weeks) focusing on problems solving education, symptoms management, self-care, communication, decision making, and long-term care plan assistance. In the first and twelfth week of the intervention, all patients were assessed with the Pediatric Quality of Life Inventory (PedsQLTM)

questionnaire cancer module 3.0. Symptoms intensity were assessed by Edmonton Symptoms Assessment Score (ESAS). Emergency room admissions from the last 3 months were noted before patients were enrolled in the study. During the follow up period, ER admissions were recorded further. Data was analyzed using bivariate analysis, OR calculations were performed to see the effect of interventions on outcomes in this study. A significant difference of quality of life was found between the two groups with average total score in control group 62.39 and intervention group 81.63 ($p < 0.001$). Most significant increased domains were pain, nausea, procedural anxiety, treatment anxiety, and worry. Intensity of sleep disturbance ($p = 0.003$) and anorexia ($p < 0.001$) were decreased significantly in intervention group. Emergency room admissions were reduced by 4.7 times in intervention group (OR 4.77, 95% CI 1.29-17.65; $p = 0.018$).