

Luaran Kesiapan Transisi Remaja Usia 15-17 Tahun dengan Lupus Eritematosus Sistemik pasca Modul Transisi Remaja di RSUPN Cipto Mangunkusumo = Transition Readiness as an Outcome for Adolescents Aged 15-17 Years with Systemic Lupus Erythematosus after the Adolescent Transition Module at Cipto Mangunkusumo General Hospital

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Abstrak

Latar belakang: Lupus eritematosus sistemik (LES) merupakan penyakit autoimun sistemik yang 10-20% kasusnya memiliki awitan sejak masa kanak. Kesintasan anak dengan LES di negara maju maupun berkembang jauh meningkat sejak beberapa dekade terakhir. Meskipun kesintasannya meningkat, tidak semua anak dan remaja LES dapat memasuki masa dewasa dengan baik. Layanan transisi remaja merupakan jembatan penghubung antara layanan kesehatan anak dan dewasa yang mulai banyak dikembangkan untuk remaja dengan kebutuhan medis khusus seperti LES.

Metode: Studi pre-eksperimental pada remaja LES berusia 15 tahun hingga 17 tahun 6 bulan dilakukan di RSUPNCM dalam kurun waktu antara Desember 2022 hingga Mei 2023. Dalam studi ini seluruh subyek diikutkan dalam modul transisi remaja yang kegiatannya dilakukan secara daring maupun luring. Kegiatan daring meliputi 3 kali pemaparan materi dan diskusi interaktif dengan tema LES, masa remaja, dan layanan kesehatan di klinik dewasa. Kegiatan luring dilakukan melalui bermain peran menyerupai suasana saat melakukan kunjungan mandiri di layanan kesehatan dewasa yang dilakukan pada akhir penelitian. Luaran modul transisi dinilai dengan membandingkan rerata skor TRAQ 6.0 Bahasa Indonesia sebelum dan sesudah mengikuti modul transisi.

Hasil: Terdapat 36 remaja LES yang mengikuti modul transisi, namun hanya 32 subyek yang mengikuti 75% kegiatan. Rerata skor TRAQ 6.0 Bahasa Indonesia sebelum mengikuti modul adalah 3,4 (0,6). Rerata tersebut meningkat menjadi 3,8 (0,6) setelah mengikuti modul ($p=0.001$). Tidak ada hubungan antara lama sakit, derajat aktivitas penyakit, dan kunjungan mandiri terhadap skor TRAQ 6.0 Bahasa Indonesia sebelum mengikuti modul transisi.

Simpulan: Modul transisi remaja terbukti dapat meningkatkan kesiapan transisi remaja dengan LES berusia 15-17 tahun.

.....Background: Systemic lupus erythematosus (SLE) is a systemic autoimmune disease in which 10-20% of cases have an onset in childhood. The survival of children with SLE in both developed and developing countries has increased greatly in the last few decades. Although survival has increased, not all children and adolescents with SLE can enter adulthood well. Adolescent transition services are a bridge between child and adult health services which have begun to be developed for adolescents with special medical needs such as SLE.

Methods: The pre-experimental study on LES adolescents aged 15 to 17 years 6 months was conducted at Cipto Mangunkusumo General Hospital from December 2022 to May 2023. In this study, all subjects were included in the adolescent transition module, whose activities were carried out both online and offline. Online activities include 3 presentations of material and interactive discussions on the themes of LES,

adolescence, and health services in adult clinics. Offline activities are carried out through role playing, resembling the atmosphere during independent visits to adult health services carried out at the end of the study. The main outcome of the transition module was assessed by comparing the average Indonesian TRAQ 6.0 score before and after participating in the transition module.

Results: There were 36 LES adolescents who took part in the transition module, but only 32 subjects took 75% of the activities. The average Indonesian TRAQ 6.0 score before taking the module was 3.4 (0.6). The mean increased to 3.8 (0.6) after participating in the module ($p=0.001$). There is no relationship between disease duration, degree of disease activity, and independent visits to the Indonesian TRAQ 6.0 score before joining the transition module.

Conclusion: The transition module has been proven to increasing transition readiness of adolescents aged 15 to 17 years with SLE.