

ABSTRAK

Latar belakang: Penyandang thalassemia usia remaja memiliki masalah ganda, tidak hanya menghadapi tugas-tugas perkembangannya tetapi juga harus menghadapi masalah-masalah akibat penyakitnya baik fisik maupun psikis.

Tujuan: Penelitian ini bertujuan untuk melihat efektivitas *self management* terintegrasi dalam meningkatkan kualitas hidup penyandang thalassemia usia remaja.

Metode: Jenis penelitian ini menggunakan metode *action research*, yang meliputi empat tahapan. Sampel dalam penelitian ini dipilih dengan sampel purposif sebanyak 60 penyandang thalassemia usia remaja. Waktu pelaksanaan intervensi *self management skills* dari bulan Juni 2018 sampai dengan bulan Agustus 2018. Data kualitatif dianalisis menggunakan enam langkah menurut Creswell yang meliputi; membuat transkripsi data, membaca keseluruhan data, membuat koding data, membuat kategori dan tema, membuat deskripsi data dan tema menjadi narasi kualitatif dan membuat suatu interpretasi penelitian kualitatif dari hasil temuan-temuan atau hasil-hasil. Data kuantitatif dianalisis dengan menggunakan uji Wilcoxon, *paired t-test*, Friedman dan *General linier model*.

Hasil: Didapatkan beberapa tema permasalahan penyandang thalassemia usia remaja antara lain; masalah fisik yang terdiri dari keterlambatan pertumbuhan dan perkembangan, mudah lelah dan nyeri. Masalah psikologis terdiri marah, khawatir dengan masa depan dan merasa berbeda. Masalah interaksi sosial terdiri dari adanya *bullying* dan masalah bermain. Tema kebutuhan *self management* penyandang thalassemia meliputi; kebutuhan informasi, kebutuhan dukungan masyarakat dan dukungan instansi layanan kesehatan & organisasi thalassemia. Secara statistik didapatkan hubungan yang signifikan antara nilai *self management skills* sebelum intervensi dengan *self management skills* sesudah intervensi dengan *p value* sebesar 0,013 dan didapatkan perbedaan nilai QoL pengukuran pertama, kedua dan ketiga ($PV < 0.001$).

Kesimpulan: pendekatan *self management* terintegrasi dapat meningkatkan *self management skills* dan kualitas hidup penyandang thalassemia usia remaja

Keywords: thalassemia, remaja, *self management* dan *quality of life*

ABSTRACT

Background: *Adolescents with thalassemia have a double problem not only in dealing with their developmental tasks but also must face difficulties due to their physical and psychological illnesses.*

Objective: *This study aims to look at the effectiveness of integrated self-management in improving the quality of life of adolescents with thalassemia in their teens.*

Method: *This type of research used the action research method, which included four stages. The sample in this study was selected with a purposive sample of 60 people with adolescent thalassemia. The time for the implementation of self-management skills interventions is from June 2018 to August 2018. Qualitative data were analyzed using six steps according to Creswell which include; data transcription, read entire data, data coding, create categories and themes, data descriptions and themes become qualitative narratives and make a qualitative research interpretation of the findings or results. Quantitative data were analyzed using the Wilcoxon test, paired t-test, Friedman and general linear model.*

Results: *Several themes of adolescent thalassemia problems found in adolescents include; physical problems consisting of delayed growth and development, fatigue and pain. Psychological issues include being angry, worried about the future and feeling different. Social interaction problems consist of bullying and playing problems. Themes of self-management needs found in adolescent thalassemia include; information needs, community support needs and support of health care agencies & thalassemia organizations. A significant relationship between self-management skills before intervention after the intervention was found with a p-value of 0.013 and the difference in the QoL values of the first, second and third measurements ($PV < 0.01$).*

Conclusion: *integrated self-management approach can improve self-management skills and quality of life of adolescent thalassemia*

Keywords: thalassemia, adolescents, self-management and quality of life