Background/Purpose: Chronic health conditions (CHC) in adolescents is a critical issue with estimates of 12-18% affected and with 6.5% experiencing disability. Childhood rheumatic disease contributes to increasing morbidity and costs of medical care and decreased health related quality of life (HQRL). Studies in CHC have demonstrated that self-management interventions that augment medical treatments improve health outcomes and HRQL. Evidence of the effectiveness of self-management therapies in adolescents has been sparse. This purpose of this research is to evaluate an adult self-management program (SMP) for its effectiveness in adolescents with rheumatic disease.

Methods: 15 adolescents, ages 13-20, together with their parents, followed in the rheumatology clinic at the Children’s Hospital of Wisconsin (CHW) for greater than 3 months with a documented rheumatic disease were asked to participate. All were English speaking, and with no known cognitive delays. The program consists of 6 weekly sessions lasting 2 hours. To evaluate effectiveness of CDSMP, adolescents completed qualitative instruments including one time demographics, visual analog score of general health of adolescent by both parent and adolescent, general health symptoms (discouraged, worry, frustrated), self-management efficacy (SME), quantifying health service utilization, Peds QL Rheumatology and Peds QL Inventory teen reports. Data was collected at baseline, program completion and 3 months post program. Repeated measures analysis of variance with multiple comparisons corrections was used to identify changes from baseline.

Results: Demographics revealed that 60% were white, all were attending school, 60% came from a 2 parent household and 60% had the diagnosis of juvenile idiopathic arthritis, with the remainder either systemic lupus erythematosus or other defined rheumatic disease. Statically significant variables found an increase in hospital and emergency visits (p=0.029) at each measurement; and increase in SME (p=0.011) and communication, a subscale of SME (p=0.037) from baseline to 3 months post program. Urgent care doctor visits, hospitalizations and missed doctor visits showed no significant (NS) difference. General health symptoms, discouraged and frustrated, showed improvement (NS) from baseline to 3 months post program only; worried improved successively (NS). Peds QL Inventory subscales; physical health showed no difference; emotional social and school functioning, and psychosocial health all showed improvement from baseline to 3 months post program (NS). Peds QL Rheumatology subscales pain and hurt, daily activities, treatment, worry and communication had no improvement.

Conclusions: CDSMP effectiveness in adolescents with rheumatic disease showed significant improvement in self-management efficacy and communication related to SME. General health symptoms and Peds QL Inventory subscales documented improvement despite an apparent increase in HCP hospital and emergency visits. Future plans include development of an adolescent SMP to improve self-management skills and allow for evaluation of health care utilization, health behaviors and status, and HRQL.