Introduction

Half of all patients taking maintenance medications for chronic disease, including those with rare genetic disorders, stop taking their medications as prescribed within one year of initiating therapy. Nonadherence is responsible for 10% of all medication-related preventable hospitalizations and illness, costing the U.S. health care system an estimated $100–300 billion annually. There are many reasons for nonadherence to medications. Copayments, the complexity of dosing regimens, and access to care affect adherence. Cochrane reviews of more than 70 randomized trials found no one simple intervention and relatively few complex interventions to be effective at improving long-term medication adherence and health outcomes.

Methods

A literature search revealed some commonalities or phenotypes that, adequately screened, could make it easier to identify corrective interventions. Our team developed an 18-question phenotype assessment tool that combines elements from evidence-based surveys, such as the Morisky Medication Adherence Scale and Oyekan’s Readiness Assessment Ruler, as well rare-disorder-specific questions. Once the phenotype(s) were identified on each patient, trained coaches and pharmacists implemented our evidence-based Accurate Adherence Accelerator intervention assessment tool. The tool includes phenotype-specific interventions such as collaborative care planning, self-management training, and medication therapy management. To measure the success of the intervention(s), we assigned 10 patients on orphan drugs in our pilot program using the simple random sampling method. Medication Possession Ratio (MPR) was measured for the 12 months before screening and intervention, and then again at the end of the 12-month intervention.

Results

Patients participated in the program for 12 months. We compared the baseline results with the MPR 12 months after the intervention. None of the patients in the program were admitted for an unplanned hospitalization. Adherence rates for the group increased by 11.6% collectively, with nine of the 10 patients showing an increase in MPR. All patients provided a 5 out of 5 ratings on the satisfaction survey.

Conclusion:

Based on the initial success of the intervention, we will continue to monitor our interventions and evaluate the tool with each new rare and complex therapy.