Development and Validation of the Barriers Questionnaire – Juvenile Idiopathic Arthritis, Patient- and Parent-report Measures

By

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Abstract

Medication adherence among patients with Juvenile Idiopathic Arthritis (JIA) varies widely, suggesting some patients may not benefit fully from their medication regimens. Assessment of adherence barriers would assist clinicians and families in determining targets for adherence-promoting interventions. In this study the psychometric properties of the Barriers Questionnaire – JIA (BQ-JIA, patient- and parent-report measures) were tested. Thirty-five patients with JIA and their parents completed measures of adherence (self-report and pill count), barriers, and beliefs about medication taking. The 18-item barriers measures demonstrated variable internal consistency (Cronbach's $\alpha = 0.41$ and 0.72, patient and parent versions) and strong test-retest reliability over a brief period (median = 19 days). Concurrent, convergent, and divergent validity were supported through correlations with other study measures. Predictive and incremental validity were tentatively supported. Patient age moderated the relationship between parent-reported barriers and pill count adherence. The BQ-JIA measures showed promise as clinically useful measures of adherence barriers.

Keywords: juvenile idiopathic arthritis, medication adherence, barriers

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Due to multiple diagnostic systems for defining the different chronic arthritides with childhood onset, prevalence estimates for these diseases vary (Manners & Bower, 2002; Centers for Disease Control and Prevention, 2010) but tend to be small compared with the prevalence of other pediatric chronic illnesses, such as asthma (Newacheck & Taylor, 1992). However, chronic arthritis carries the risk of permanent physical disability. Currently available medical treatments have the potential to control arthritis symptoms adequately and decrease risk of disability, but poor adherence to prescribed medical regimens may limit these benefits. The Health Belief Model provides a well-researched theoretical framework for modeling relationships between different types of health beliefs and health behaviors (including regimen adherence). Adult studies show that perceived barriers to performing a health behavior represent the type of health belief most predictive of engaging in health behaviors (Abraham & Sheeran, 2005; Harrison, Mullen, & Green, 1992; Janz & Becker, 1984). Developing measures that could reliably elicit perceptions of barriers to medication adherence from pediatric patients with arthritis and their parents may assist clinicians in tailoring adherence-improvement interventions to target barriers specifically relevant to individual patients and their families.

After describing the classification systems, treatment components, and rates of adherence among pediatric patients with chronic arthritis, this author reviews the support for the relationship between barriers and health behaviors (including regimen adherence) as conceptualized in the Health Belief Model in adult and in pediatric studies. This author then presents the results of a pilot study conducted to develop and test the psychometric properties of a new clinical tool, the Barriers Questionnaire – Juvenile Idiopathic Arthritis (BQ-JIA).

Childhood Chronic Arthritides

Overview of classification systems and specific diseases. From the 1970s to the 1990s, physicians used two overlapping but distinct classification systems for determining specific pediatric arthritis diagnoses. These specific arthritides were differentiated on the basis of the number and types of joints affected by inflammation, organ systems affected in addition to the musculoskeletal system, and laboratory test results observed during the first six months of disease activity. The American College of Rheumatology's criteria for Juvenile Rheumatoid Arthritis (JRA) included arthritides with symptom onset before age 16 and minimum duration of six weeks. Systemic-onset, polyarticular, and pauciarticular (oligoarticular) were the three recognized onset types of JRA. Though the European League Against Rheumatism's criteria for Juvenile Chronic Arthritis (JCA) included the same age of symptom onset as JRA, the minimum duration of diseases classified under JCA was twelve weeks. Additionally, the criteria included Juvenile Ankylosing Spondylitis, Juvenile Psoriatic Arthritis, and the Inflammatory Bowel Diseases among the six subtypes of JCA, while the JRA criteria specifically excluded these diseases (Petty & Cassidy, 2010).

Since 1994, a third typology, developed by the International League of Associations for Rheumatology's Pediatric Standing Committee (Fink, 1995), has come into use, replacing the JRA and JCA systems. Juvenile Idiopathic Arthritis (JIA) remains a heterogeneous category encompassing arthritides of unknown origin with disease onset before age 16. Six onset subtypes (systemic JIA, rheumatoid factor positive polyarthritis, enthesitis-related arthritis, oligoarthritis, rheumatoid factor negative polyarthritis, and psoriatic arthritis) and one course subtype (extended oligoarthritis course) constitute the specific arthritides classified within JIA. Four of the subtypes identify homogenous disease entities, namely, systemic JIA, rheumatoid

factor positive polyarthritis, enthesitis-related arthritis, and oligoarthritis. Characteristic symptoms of systemic JIA include fever, rash, and serositis (inflammation of serous tissue) in addition to joint inflammation. These symptoms are believed to constitute a polygenic autoinflammatory syndrome (Prakken, Albani, & Martini, 2011). Approximately 10-20% of patients with JIA are diagnosed with systemic JIA (Petty et al., 2004). Rheumatoid factor (RF) positive polyarthritis is the only form of JIA characterized by the presence of rheumatoid factor. Patients with RF-positive polyarthritis experience inflammation in five or more joints. These commonly include joints in the hands, the wrists, the hips, the knees, the ankles, and the neck. About 5-10% of JIA patients are diagnosed with RF-positive polyarthritis (Petty et al., 2004). Enthesitis-related arthritis refers to an undifferentiated form of spondyloarthropathy. Clinical features of the spondyloarthropathies include back pain due to inflammation of the joints or ligaments of the spine (axial symptoms) and peripheral arthritis (Dougados & Baeten, 2011). The prevalence of enthesitis-related arthritis is not known (Petty et al., 2004). Oligoarthritis involves four or fewer active joints (usually larger joints) in the first six months. It tends to affect more females than males and to have an early onset (typically before age six). High concentrations of antinuclear antibodies (ANA) and a high risk of chronic iridocyclitis (inflammation of the eye's iris and ciliary body) are other characteristics of oligoarthritis (Prakken et al., 2011). The extended oligoarthritis course subtype represents a more severe form of oligoarthritis, as more joints become affected after the first six months; however, the other clinical features remain. Approximately 40-60% of JIA patients have oligoarthritis (Petty et al., 2004).

The subtypes identifying more heterogeneous disease groups are RF-negative polyarthritis (affecting 20-25% of JIA patients) and psoriatic arthritis (affecting 5% of JIA

patients; Petty et al., 2004). One form of RF-negative polyarthritis resembles oligoarthritis but with a greater number of active joints, while the other form lacks ANA expression. Psoriatic arthritis, which affects skin as well as joints, also has two forms: one resembles spondyloarthropathy and the other resembles ANA-positive oligoarthritis but affects smaller joints more often than larger ones (Prakken et al., 2011).

The JIA subtypes together represent the most common childhood rheumatic diseases, with prevalence estimates ranging between 0.07 and 4.01 per 1000 children and annual incidence estimates ranging from 0.008 to 0.226 per 1000 children (Manners & Bower, 2002). JIA is also a major source of short- and long-term disability (Rapoff, Belmont, Lindsley, & Olson, 2005). Over 20% of JIA patients suffer physical disability due to joint damage, and 10-70% of patients with JIA-related eye uveitis suffer visual impairment (Moorthy, Peterson, Hassett, & Lehman, 2010). Because no cure has been developed for these chronic diseases, the primary goals of medical treatment are to induce disease remission, manage pain, prevent joint deformities and preserve functionality, and treat systemic complications so that patients may experience normal growth and development (Petty & Cassidy; in Cassidy, Petty, Laxer, & Lindsley, 2010).

Treatment regimen components. JIA treatment regimens usually include medication and sometimes physical therapy or occupational therapy exercises and the use of joint supports. If needed, orthopedic surgery, nutritional support, and psychosocial support are also recommended. Because medications are the most commonly prescribed treatments, medication nonadherence may significantly reduce the efficacy of the overall treatment regimen. Treatment with medications occurs in a stepwise fashion in which nonsteroidal antiinflammatory drugs (NSAIDs) are initially prescribed and, if an adequate therapeutic response is not achieved, other types of medications are added (Rapoff & Lindsley, 2007).

NSAIDs are first-line medications used primarily for symptom relief. They alleviate pain, stiffness, and fever, and they reduce inflammation by inhibiting proinflammatory pathways. NSAIDs are generally safe for long-term use but may cause gastrointestinal discomfort. Specific NSAIDs commonly used to treat patients with JIA include acetylsalicylic acid (aspirin), tolmetin, naproxen, and ibuprofen, with the last two available as liquids or pills (Ilowite & Laxer, 2010). Other NSAIDs include piroxicam (Feldene), nabumetone (Relafen), and celecoxib (Celebrex). NSAIDs produce a significant response in approximately 25-33% of patients, many of whom have oligoarthritis (Haskes & Laxer, 2005).

Second-line medications include Disease-Modifying Antirheumatic Drugs (DMARDs), corticosteroids, and biological therapies that prevent or decelerate bone and cartilage damage. DMARDs are slow-acting medications that take effect after several weeks to months. Commonly prescribed DMARDs include methotrexate and sulfasalazine. Other disease-modifying drugs include hydroxychloroquine, oral gold, and D-penicillamine. In contrast, corticosteroids are fast-acting, potent, antiinflammatory drugs used to control severe systemic symptoms (e.g., fever, rash) or used as bridging medications until slower-acting medications take effect (Haskes & Laxer, 2005). Due to serious adverse effects of prolonged use, corticosteroids are typically used acutely or periodically at low dose. They may be taken orally, through intraarticular injection, or through eye drops (Ilowite & Laxer, 2010). Biological agents are recently developed medications and include tumor necrosis factor inhibitors – e.g., adalimumab (Humira) and etanercept (Enbrel) – and other classes of drugs. The tumor necrosis factor inhibitors are administered subcutaneously.

The number of medications, variety of administration routes (oral, injection, topical/eye drops), and variety of dosing schedules contribute to the complexity of JIA medication regimens.

Characteristics of the JIA medication regimens – their complexity, their delayed effects, their adverse side effects, and their chronic necessity – all represent impediments to adherence (Rapoff, 2010) that may limit patients' enjoyment of potential treatment benefits.

Adherence to JIA Medication Regimens

Adherence to medications by pediatric patients with chronic diseases generally averages 50-55% (Rapoff, 2010). Estimates obtained through a variety of adherence measures vary for patients with chronic arthritis, but they are also generally low. Litt and Cuskey (1981) found that 55% of patients with JRA were adherent according to salicylate serum levels. In other studies, 38-59% of patients have been classified as adherent according to pill counts or parental observations conducted at baseline prior to interventions (Rapoff, Lindsley, & Christophersen, 1984; Rapoff, Purviance, & Lindsley, 1988a; Rapoff, Purviance, & Lindsley, 1988b). Electronic monitoring has shown that the percentage of primary NSAID doses taken by patients in a control group decreased from 73% to 57% over a 52-week period (Rapoff et al., 2002). Another study using electronic monitors found that 52% of patients were fully adherent to a prescribed NSAID on more than 80% of days in a 28-day period (Rapoff, Belmont, Lindsley, & Olson, 2005). Patients responding to visual analog adherence scales gave mean ratings of 85% for their overall medication adherence, and parents gave mean ratings of 83% for their child's or adolescent's adherence (April, Ehrmann-Feldman, Platt, & Duffy, 2006). Similarly, parents reported their children's adherence at a mean of 90% (De Civita, Dobkin, Ehrmann-Feldman, Karp, & Duffy, 2005). These studies have shown that self-report measures tend to produce higher adherence estimates than more objective measures, a pattern observed across studies of pediatric patients with a wide range of chronic diseases (Rapoff, 2010). Because adherence measures vary in their metric properties, no gold standard currently exists. Thus, the use of multiple types of measures

is recommended in the assessment of adherence (Quittner, Espelage, Ievers-Landis, & Drotar, 2000).

The role of nonadherence among JIA patients is concerning in light of the consequences of uncontrolled JIA symptoms (e.g., joint pain and stiffness, joint deformity and loss of functionality, disability). These symptoms may in turn compromise quality of life and interfere with patients' school attendance (Rapoff, 2002). Feldman and colleagues (2007) reported that moderate parent-reported medication adherence levels predicted improvement in subsequent active joint counts among JIA patients. Improving adherence to JIA treatment regimens (especially medications) would also allow clinical decisions regarding treatment adjustments to be based more on actual treatment effectiveness and would thus maximize the cost-effectiveness of the treatments (Rapoff, 2010). Accurate assessment of potentially modifiable factors that could improve adherence would facilitate the targeting of these factors in adherence interventions and in the measurement of these interventions' effects. Among such factors, perceived barriers have demonstrated consistent correlations with health behaviors in the adult literature and have been investigated for their relationship with pediatric medical regimen adherence.

Model of Adherence and Perceived Barriers

A number of studies have described the associations between pediatric medical regimen nonadherence and patient and family, disease, and regimen characteristics (see Rapoff, 2010, for a comprehensive review). Some of these characteristics can be used to identify groups that may have more difficulty with adherence (e.g., adolescents, patients from families of lower socioeconomic status, patients prescribed more complex medical regimens). Other correlates may be causally related to nonadherence and amenable to modification (e.g., patient's and family

members' knowledge and beliefs about the patient's disease and prescribed treatment). Beliefs about treatment have not only represented potentially modifiable factors but also may represent stronger predictors of adherence than some patient demographic and regimen characteristics. A study conducted with chronically ill adults found that patient beliefs about medications – specifically, the degree to which beliefs about medication necessity were stronger than concerns about medications – were more predictive of adherence estimates based on patient self-report than were patient age, gender, educational experience, and the number of prescribed medications (Horne & Weinman, 1999).

A well-researched model of patients' health beliefs and their relationship with health behaviors (including adherence), the Health Belief Model was one of the earliest social cognitive theories constructed to explain differences in individuals' health behaviors. In the 1950s, social psychologists in the U.S. Public Health Service initially developed the Health Belief Model to understand factors contributing to the lack of participation in preventive health and disease detection programs (Strecher, Champion, & Rosenstock, 1997). The Health Belief Model's focus on potentially modifiable health beliefs allowed this model to provide a theoretical framework for designing health education interventions (Abraham & Sheeran, 2005). The four health beliefs originally composing the Health Belief Model were perceived susceptibility to and perceived seriousness of a health condition and perceived benefits of and barriers to the performance of specific health behaviors.

As a value-expectancy model, the Health Belief Model identified beliefs related to the individual's perception of personal vulnerability to a health problem, which influenced motivation (or state of readiness) to avoid illness or to improve one's health. This model also identified beliefs related to the individual's perception of the overall benefit of pursuing a

particular health behavior to address this vulnerability (Rosenstock, 1966/2005; Strecher et al., 1997). The perceived susceptibility and perceived seriousness components of the Health Belief Model composed the perception of personal vulnerability and provided the force propelling individuals toward taking action to address this vulnerability. The perceived benefits and perceived barriers of alternative health behaviors contributed to the selection of a specific course of action to undertake. Rosenstock (1966/2005) described perceived susceptibility as the individual's subjective evaluation of risk of contracting a condition. Perceived seriousness was the emotional arousal experienced by the individual when thinking of the health condition and the individual's beliefs about the difficulties resulting from the condition. He also defined perceived benefits of pursuing a specific health behavior as beliefs about the health behavior's availability and efficacy in reducing susceptibility or seriousness of the condition; perceived barriers were described as negative aspects of pursuing a health behavior (e.g., inconvenience, cost, discomfort). Later reformulations of the Health Belief Model included additional constructs such as cues to action (internal or external cues triggering engagement in health behaviors) and Bandura's concept of self-efficacy (Rosenstock, 2000).

A pediatric adaptation of the Health Belief Model, the Children's Health Belief Model (Bush & Iannotti, 1990), has been formulated to take into account the influence of parents' beliefs, as well as patients' beliefs, on patients' health behaviors. Previous studies have provided mixed evidence regarding the relationship between parents' health beliefs and patients' adherence to their medical regimens. Some studies demonstrated a significant relationship (e.g., Becker, Radius, Rosenstock, Drachman, Schuberth, & Teets, 1978; Drotar & Bonner, 2009) and other studies did not (e.g., Riekert, 2000). A possible explanation for this inconsistency could be that the studies finding nonsignificant relationships may have included more parents of older

patients, and thus the parents' health beliefs would not be expected to be strong predictors of adherence because of less direct involvement in supervising their adolescents' regimens (Quittner et al., 2000; Riekert, 2000). The lack of clarity regarding the relationships among patients' and parents' health beliefs and the patients' health behaviors and the likely influence of developmental changes on these relationships have highlighted the importance of obtaining information from multiple informants when possible.

Evidence from two quantitative reviews of studies of the four original Health Belief Model components demonstrated that the barriers construct was the strongest predictor of health behaviors (Abraham & Sheeran, 2005). Janz and Becker (1984) found that the relationship between barriers and health behaviors was significant in the predicted direction in 89% of all studies reviewed in which significance levels were presented for barriers. In 100% of prospective studies reviewed, barriers were significantly related to health behaviors in the predicted direction. Harrison and colleagues (1992) found in their meta-analysis that the weighted mean correlations between each of the four Health Belief Model components and health behaviors had magnitudes ranging from 0.08 to 0.21, with barriers having the strongest correlations with health behaviors. These meta-analyses suggested a consistent, modest relationship between barriers and health behaviors, though neither analysis provided a fail safe N estimate of the file drawer effect. However, because of the relationship between barriers and adherence reported in the adult Health Belief Model literature, a number of studies with pediatric samples have also examined the relationship between patients' or parents' perceived barriers and medical regimen adherence (e.g., Logan, Zelikovsky, Labay, & Spergel, 2003; Modi & Quittner, 2006; Simons & Blount, 2007; etc.). The majority of these studies reported significant, small-to-moderate relationships between perceived barriers and various measures of adherence.

The Health Belief Model was originally used to explain preventive health behaviors. The model has since been applied to explaining behaviors such as adherence to medical regimens (Becker, 1974). Within the context of an established health condition, the Health Belief Model components can be understood as acceptance of the condition (perceived susceptibility), health and social consequences of not engaging in treatment for the condition (perceived severity), perception of the prescribed treatment's efficacy (perceived benefits), and perception of impediments to treatment adherence (perceived barriers) (Rapoff, 2010). The expansion of the barriers construct from perceived negative aspects of the recommended health behaviors to the broader category of perceived impediments reflected both the lack of homogeneity in the operationalization of the Health Belief Model constructs noted in several reviews of the model (Harrison et al., 1992; Rosenstock, 1974) and also the overlap between the barriers construct and other Health Belief Model components as well as constructs from other social cognitive theories, such as Bandura's (1977) Social Cognitive Theory and Ajzen and Fishbein's (1977) Theory of Reasoned Action/Theory of Planned Behavior. For example, a common barrier to adherence, forgetting to take medications, reflects a lack of cues to action, while denial of a health condition reflects a low level of perceived susceptibility.

Pediatric Chronic Illness Measures of Barriers to Adherence

Given the consistent relationship between barriers and health behaviors and the absence of well-validated measures of medication adherence barriers designed to assess the experiences of JIA patients, the development of such measures may facilitate efforts to improve adherence and health outcomes of JIA patients. Two reviews – one conducted by the author of the first version of the Parents Barriers Questionnaire–Juvenile Idiopathic Arthritis and the other conducted by this author – of existing barriers measures that have been administered to other

pediatric samples provided the basis for developing the JIA barriers measures. These measures included both questionnaires and semi-structured interview protocols that assessed pediatric patients' and their parents' perception of barriers. Some of these were primarily measures of regimen adherence but included several items or a scale measuring barriers to adherence. These measures have been used to elicit reports from patients as young as eight years of age (Buchanan et al., 2012; Farley et al., 2008; Janicke, Storch, Novoa, Silverstein, & Samyn, 2007; Simon, Duncan, Janicke, & Wagner, 2012) and have been administered to families with patients having a variety of chronic conditions including asthma, cystic fibrosis, epilepsy, human immunodeficiency virus (HIV) infection, obstructive sleep apnea, organ transplant recipients and candidates, overweight or obesity, chronic pain, and sickle cell disease. Table 1 summarizes the characteristics and psychometric properties reported for the measures reviewed by this author, and this review was restricted to measures for which information about psychometric properties were reported.

The information gathered using these measures included qualitative descriptions of barriers experienced within a variety of recall periods ranging from the past week to the past year, number of barriers endorsed, ratings of the frequencies with which identified barriers were experienced (typically on Likert scales with descriptive anchors such as 1 = *never* and 5 = *almost always*), ratings of the level of difficulty caused by identified barriers, ratings of the level of agreement with statements reflecting barriers (typically on Likert scales with anchors such as 1 = *strongly disagree* and 5 = *strongly agree*), and ranking of the relative importance of the identified barriers.

Reliability and validity of barriers measures. Although some of the ways in which adherence barriers have been measured in both forced choice questionnaires and open-ended

interviews precluded testing certain psychometric properties, evidence of reliability has been reported for eleven of the seventeen measures reviewed (Table 1). Cronbach's α was reported as a measure of internal consistency for nine measures (Buchanan et al., 2012; Logan et al., 2003; Modi, Monahan, Daniels, & Glauser, 2010; Simon, Duncan, Janicke, & Wagner, 2012; Simons & Blount, 2007), with values ranging from 0.74-0.90. Test-retest reliability was reported for five measures (Logan et al, 2003; Simon et al., 2012; Simons, McCormick, Devine, & Blount, 2010). Values ranged from 0.62 to 0.88, and the intervals between administrations ranged from two weeks to eighteen months.

Evidence of validity was reported for fifteen measures. Support for the construct validity of eleven of these measures included the relationship between the barriers measure and one or more measures of adherence. Most of the barriers measures demonstrated significant relationships with adherence in the hypothesized direction. For a sample of organ transplant recipients, Simons and Blount (2007) reported higher mean scale scores on adolescent- and parent-report barriers measures for patients classified as nonadherent by their own report and parents' report, respectively, compared to adherent patients ($p < 0.05$). However, this relationship was not observed when adherence was measured by serum drug levels. Zelikovsky and colleagues (2008) reported moderate correlations between the number of barriers reported by adolescent renal transplant candidates and their reported number of missed medication doses ($r = 0.38$, $p = 0.004$) and number of doses taken late ($r = 0.47$, $p < 0.001$). Logan and colleagues (2003) reported a moderate negative correlation ($r = - 0.35$, $p < 0.01$) between their adolescent-report barriers measure (scale score) and health care providers' ratings of patient adherence to asthma maintenance medications. Fisak and colleagues (2012) reported that, in a sample of

caregivers of patients with sickle cell disease, caregiver-rated barriers were stronlgy negatively correlated with scores from a caregiver-report adherence measure (r = -0.56, p < 0.01).

In addition to participant- or provider-reported estimates of adherence, other studies have used a variety of other measures of adherence as criteria for assessing the validity of the barriers measures. Witherspoon and colleagues (2006) reported that caregiver-rated barriers (reverse scored) to their children's adherence to sickle cell disease treatment correlated strongly with adherence estimates derived from pharmacy refill records (r = 0.57, p < 0.01) as well as with caregiver-reported adherence estimates (r = 0.66, p < 0.01). In studies of pediatric patients with HIV (Buchanan et al., 2012; Farley et al., 2008; Marhefka, et al., 2006; Marhefka, et al., 2008), an increased number of barriers identified by caregivers of these patients was significantly related to subjective reports of nonadherence and tended to be associated with detectable viral load (p < 0.10). Modi and colleagues (2010) reported the barriers score (reverse scored) of their parent-report pediatric epilepsy management measure correlated with adherence measured by electronic monitor (r = 0.27, p < 0.01) as well as by parent-reported estimates (r = 0.35, p < 0.0001). Similarly, Simon and colleagues (2012) demonstrated that patient- and parent-reported barriers ratings were related to electronically monitored use of continuous positive airway pressure therapy (r = -0.44, p = 0.002). However, in a study of barriers reported by patients with asthma or cystic fibrosis and by their parents, Modi and Quittner (2006) did not find significant correlations between number of barriers reported by parents or patients and a variety of adherence measures (parent- or patient-reported, adherence estimated from daily phone diaries, pharmacy refill rates, or electronic monitor rates of adherence); correlations with these measures ranged from medium-sized correlations in the predicted (negative) direction to medium-sized correlations in the opposite (positive) direction.

Though concurrent validity was tested for nearly half of the reviewed measures, predictive validity was tested for only two. Simons and colleagues (2010) correlated scores from the Adolescent Medication Barriers Scale (AMBS) and the Parent Medication Barriers Scale (PMBS), administered to adolescent organ transplant recipients and their parents, with adherence estimates obtained 18 months later. Although total scale scores from the AMBS and PMBS did not predict adherence, specific barriers demonstrated significant correlations ($p < 0.05$) with adherence (and other clinical outcomes). Adolescent patients' scores on the AMBS Disease Frustration/Adolescent Issues subscale and on specific items within this subscale – "I sometimes just don't feel like taking the medicine," "I don't like what the medication does to my appearance," and "I am tired of taking medicine" – correlated significantly with reports of taking doses late at the 18-month follow up (*r*s = 0.32, 0.39, 0.33, and 0.37, respectively). Scores on the AMBS Disease Frustration/Adolescent Issues subscale and the items "I don't want to take the medicine at school," "I am tired of taking medicine," and "I am tired of living with a medical condition" also predicted unstable blood levels of the patients' immunosuppressant drugs at follow up (*r*s = 0.29, 0.28, 0.37, and 0.34, respectively). Parents' scores on the PMBS Regimen Adaptation/Cognitive Issues subscale and several of its items – "My child is forgetful and doesn't remember to take his/her medication every time," "My child is not very organized about when and how he/she takes his/her medication," and "I am not always there to remind my child to take his/her medication" – correlated significantly with reports of missed doses at follow up (*r*s = 0.33, 0.37, 0.25, and 0.26, respectively). Additionally, adolescents whose parents had endorsed the barrier, "My child believes the medicine has too many side effects," were more likely to be nonadherent, as indicated by having out-of-range drug levels (point-biserial correlation: $r_{pb} = 0.32$).

Barriers commonly endorsed by patients and parents. To examine the rates at which types of barriers were endorsed, this author reviewed 13 studies reporting 17 different measures (see Tables 2 and 3 for citations) in which patients or parents were asked to endorse, rate the level of difficulty caused by, rate the level of agreement with, or rate the frequency of relevant barriers from lists of specific barriers provided in the barriers measure. Studies in which respondents were asked to generate specific barriers in response to open-ended questions were excluded unless a list of commonly cited barriers was also provided. The members of the University of Kansas Medical Center (KUMC) Behavioral Pediatrics laboratory derived 16 categories that represented types of barriers from the items composing the measures of interest and then assigned each barrier item to one of the categories. From published data or data made available by the developers of the barriers measures, this author calculated the weighted mean percentages of patients and parents sampled who endorsed at least one barrier within each category of barriers.

The ten types of barriers most frequently endorsed by patients across disease groups were patient or parent forgetting, disagreement or communication problems with health care providers, psychosocial adjustment difficulties, interference between treatment and daily activities, difficulties incorporating treatment regimen into daily life, expected or experienced treatment side effects, desire to be or to appear to be normal, belief that treatment is not needed, regimen complexity, and miscellaneous barriers (e.g., difficulty with equipment related to medical treatment). The ten types of barriers most frequently endorsed by parents were patient or parent forgetting, difficulties incorporating treatment regimen into daily life, patients' dislike of medication taste, interference between treatment and daily activities, patients' oppositional behavior or problems with discipline, concerns and misconceptions about medications, expected

or experienced treatment side effects, treatment technique or administration difficulty, treatment or medication access difficulties, and miscellaneous barriers. Tables 2 and 3 provide, respectively, summaries by disease group of the weighted mean percentages of patients and parents who endorsed barriers in the 16 categories.

Collapsing across disease groups, it was found that the patient and parent lists of most commonly identified barriers overlapped (e.g., forgetting and interference between treatment and daily activities) but that the two groups also provided non-redundant perspectives (e.g., a greater percentage of patients than parents identified disagreement or communication problems with health care providers). Results from studies of patients sharing a particular diagnosis have reflected this relationship between patient- and parent-reported barriers as well. In a study of factors influencing adherence in a sample of pediatric patients with asthma, the correlation between scores from patient- and parent-rated barriers measures was found to be small but significant ($r = 0.28$, $p < 0.05$) (Branstetter, 2001). Other studies of pediatric patients with inflammatory bowel disease (Greenley, Stephens, Doughty, Raboin, & Kugathasan 2010), cystic fibrosis, asthma (Modi & Quittner, 2006), sickle cell disease (Modi, Crosby, Guilfoyle, Lemanek, Witherspoon, & Mitchell, 2009), and renal transplants (Zelikovsky, N., Dobson, T., & Norman, J., 2011) found that patients and their parents overlapped in their identification of commonly encountered barriers and also identified barriers unique to their perspectives (e.g., adolescents more frequently identified desire to be "normal" as a barrier, while parents more frequently identified difficulty incorporating certain treatments into their children's daily lives as a barrier). These findings that patient- and parent-reported barriers provide unique information underscore the need to assess both informants' perceptions systematically and to validate barriers measures for patients and parents independently.

Study Purpose and Hypotheses

Although the Child Adherence Report Questionnaire-Juvenile Idiopathic Arthritis (CARQ-JIA) (April et al., 2006) and Parent Adherence Report Questionnaire-Juvenile Idiopathic Arthritis (PARQ-JIA) (De Civita et al., 2005) contain items assessing barriers to adherence, test-retest reliability has only been reported for three of the four PARQ-JIA barriers items and no validity testing has been conducted on these items for either measure. Additionally, the CARQ-JIA and the PARQ-JIA's use of a yes/no or checklist response format for the barriers questions limits the amount of information elicited about the barriers. Thus, the purposes of the current study were to develop two scales of barriers to adherence, the Barriers Questionnaire-Juvenile Idiopathic Arthritis (BQ-JIA) and the Parents' Barriers Questionnaire-Juvenile Idiopathic Arthritis (PBQ-JIA), and to test their psychometric properties. After conducting a preliminary item analysis of the BQ-JIA and PBQ-JIA, this author tested whether these measures elicited reliable and valid reports of patient- and parent-perceived barriers that interfere with adherence to prescribed JIA medication regimens using a repeated measures study design. This author tested the following hypotheses from the thesis proposal:

Hypothesis 1: Reliability. The two barriers measures would demonstrate adequate internal consistency (i.e., Cronbach's $\alpha \geq 0.70$) and significant test-retest reliability over a two-week period. It was anticipated that, over this brief interval, the experience of adherence barriers would be found to be a stable phenomenon.

Hypothesis 2: Validity. The two barriers measures would demonstrate adequate concurrent, convergent, discriminant, and predictive validities through their relationships with measures of related constructs – estimates of medication adherence, reports of general difficulty experienced by the patient associated with medication taking, positive and negative outcome

expectancies of adhering to the medication regimens, and perceived illness severity and susceptibility to illness of the patient.

Hypothesis 3: Incremental validity. The two barriers measures would demonstrate incremental validity by improving hierarchical regression models' ability to account for variance in adherence when entered after patient demographic, disease, and regimen variables.

Hypothesis 4. Patients with JIA and their parents would provide related yet unique perspectives on barriers to adherence. The expectation was that the scores on the BQ-JIA and PBQ-JIA administered concurrently at Time 1 would correlate moderately (i.e., around $r = 0.50$). Also, the most commonly endorsed barriers identified by patients and parents were examined for overlapping and non-redundant information.

Hypothesis 5. The relative strengths of the relationships between patient- and parent-reported barriers and medication adherence estimated by pill count would vary with the patient's age. Specifically, the prediction was that parent-reported barriers (PBQ-JIA) would be better predictors of medication adherence than patient-reported barriers (BQ-JIA) for younger patients, and that patient-reported (BQ-JIA) scores would be better predictors of adherence for older patients.

In summary, the aim of the present study was to collect pilot data for refining and validating the BQ-JIA and the PBQ-JIA. These measures may be useful clinical tools for assessing perceived difficulties that may prevent medication adherence that patients with JIA and their families experience. Confirming the fourth and fifth hypotheses would lend support for the value of assessing patients' perceptions of adherence barriers as well as those of their parents when designing adherence-improvement interventions.

Method

Initial Measure Development

A medical student[1] reviewed four measures of barriers to medical regimen adherence (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; Modi et al., 2009; Modi & Quittner, 2006; Simons & Blount, 2007) and compiled a list of the items. These were written to elicit the perspective of parents. He then consulted the KUMC pediatric rheumatologist (who had over 38 years of experience in the field), the pediatric rheumatology clinic's nurse (who had over 20 years of experience), the clinic's occupational therapist (who had over 25 years of experience), and a Ph.D. pediatric psychologist (with over 32 years of experience in pediatric rheumatology), asking these experts to indicate independently the items from the list that described barriers to medication adherence that were relevant to patients with JIA and their families. Items that panel members independently and unanimously selected were retained, resulting in a thirteen-item barriers measure titled the Parents' Barriers Questionnaire – Juvenile Idiopathic Arthritis (PBQ-JIA). The medical student then asked eleven parents of patients with JIA to complete the PBQ-JIA by endorsing barriers experienced in the past month and to provide feedback regarding additional barriers experienced that were not reflected by the measure's items. The parents who were surveyed endorsed a mean of three barriers (range: 0 – 6). Individual items were endorsed by 0% – 64% of the parents. The two most commonly endorsed barriers were patient-reported bad taste of medication (64%) and the parent's forgetting to give the medications (45%), and two items that were not endorsed by any parents were parent confusion about number of pills of each kind of medication to give and parent's uncertainty about the patient's need for medication.

[1] Scott Matson participated in a month-long research experience (June 2010) as part of his training as a medical student at the University of Kansas Medical Center under the supervision of Dr. Carol Lindsley.

The members of the Behavioral Pediatrics laboratory made modifications to the PBQ-JIA. Two items were constructed to reflect parents' feedback on additional barriers experienced ("I did not fill or refill my child's medications because I could not afford it" and "It is hard to fit giving my child medications into the family's routine") and separated one of the original items ("We ran out of the medication or the pharmacy ran out") into two distinct items for greater clarity ("We ran out of medication" and "The pharmacy ran out of medication"). Five items proposed for inclusion in the measure based on this author's review of the barriers measures literature were reviewed by the original panel of experts to determine relevance to the JIA population. The experts were again asked to rate the potential items independently, though the pediatric rheumatologist and occupational therapist may have consulted with each other because of the close nature of their working relationship. These last five proposed additions to the PBQ-JIA represented barriers categories (see Tables 2 and 3) that the original items did not reflect, or they captured broader aspects of other, more specific items. The consulted experts unanimously selected two items ("My child does not like the medications' side effects" and "My child does not understand why he/she needs to take the medications when he/she is feeling well"). The number of items in the PBQ-JIA then stood at 18.

In addition to increasing the number of items, this author modified the questionnaire's response format. This author wrote new instructions to direct respondents to identify all barriers to medication adherence ever experienced and to report how frequently each barrier was experienced in the past seven days. The frequency ratings were made on a three-point Likert scale with qualitative anchors of 0 = *never*, 1 = *sometimes*, and 2 = *often*. These changes were intended to support comparisons of the relationship between total number of barriers and

medication adherence to the relationship between the frequency of experiencing barriers and medication adherence.

This author also rewrote the measure's items and instructions to address the patient's experience of barriers to his or her own medication adherence, creating a corresponding patient version of the PBQ-JIA called the Barriers Questionnaire – Juvenile Idiopathic Arthritis (BQ-JIA). See Appendix A for copies of the PBQ-JIA and BQ-JIA. The BQ-JIA has a Flesch Reading Ease level of 72.4 and a Flesch-Kincaid Grade Level of 7.0 (Flesch, 1948; Kincaid, Fishburne, Rogers, & Chissom, 1975), indicating that the measure requires at least a seventh-grade reading level. When the word "medication," a word with which young patients with chronic illnesses are likely to be more familiar than healthy peers, was removed, the Flesch Reading Ease level was 80.6 and the Flesch-Kincaid Grade Level was 5.8, indicating that a fifth-grade reading level may be sufficient for understanding the measure.

Participants

Participants in this study were recruited from among the patients treated in the clinic of the Pediatric Rheumatology Division at an academic medical center in a Midwestern city as well as several outreach clinics. Families meeting the following inclusion criteria were recruited for this study: (a) at least one of the children had received a JIA diagnosis from a pediatric rheumatologist according to established criteria (Fink, 1995); (b) the patient with JIA was between 11.00 and 18.99 years of age; (c) the patient was prescribed at least one medication to be taken at least once daily as part of treatment for JIA throughout the duration of their study participation; and (d) one of the patient's parents or caretakers also consented to participate in the study. Although barriers to adherence have been shown to affect younger patients with chronic illnesses as well as older children and adolescents, recruitment for this study targeted

patients in the 11-18 age range as a starting point, with the intention of investigating barriers in younger patients in future studies.

Exclusion criteria were as follows: (a) parent-reported developmental delays in the patient with JIA; (b) patient had a psychiatric diagnosis; (c) the family was non-English speaking; (d) the family did not have reliable access to a phone; or (e) the family was receiving services or interventions intended to improve medical regimen adherence. Because translated versions of most of the study measures were not available, and the phone interviewer primarily spoke English, families who did not speak English were not recruited. Also, one of the study's purposes was to establish the temporal stability of the two barriers measures over a period of two weeks, so patients whose adherence behaviors and barriers were being targeted for modification could not be recruited.

Measures

Background information about participating families and information regarding the patient's JIA diagnosis and treatment regimen were gathered from a Participant Demographics Form, a brief interview with the participating parent, and a review of the patient's medical chart. To determine the convergent validity of the BQ-JIA and the PBQ-JIA, this author measured related health beliefs and global estimates of medication-taking difficulty. To determine concurrent validity and predictive validity, this author measured medication adherence using two methods, self-reported estimates and pill counts, in accordance with the recommendation to use multiple assessments of adherence because no gold standard has been established (Drotar, Richard, Burgess, Levi, Nobile, Seti, & Walders, 2000).

Measures of demographic variables.

Participant Demographics Form *(Appendix B).* This form was used to collect information from parents about themselves and their children with JIA including the patient's gender, date of birth, age at time of JIA diagnosis, and ethnicity; parent's relationship to patient, age, marital status, occupation, and completed education level; number of siblings with and without chronic illness, household composition, and family income.

Hollingshead Index (HI) (Hollingshead, 1975), Revised Form (HRF) (Wasser, 1992) *(Appendix C).* From the socioeconomic information provided by parents, this author determined the HI of each family based on the completed education level and current occupation of each gainfully employed parent (Hollingshead, 1975). According to the HRF instructions (Wasser, 1992), education level was scored on a 4-point scale and occupation was scored on a 9-point scale that categorized the 450 occupational titles and codes from the 1970 US Census. This author calculated each family's HI as the sum of the individual, employed parents' HI scores, which were the sum of each person's education scale score weighted by 3 and occupation score weighted by 5.

Although the HI has been identified as the most frequently used index of socioeconomic status, Ensminger and Fothergill (2003) have recommended the examination of specific socioeconomic status-related variables individually as well as composite scores to determine which best predict other criterion measures. Both the HI ($r = 0.31$, $p = 0.07$) and the household annual income ($r = 0.31$, $p = 0.08$) were found to be predictors of pill count adherence at a trend level of significance, and they were therefore included in the hierarchical regression model used to test the incremental validity of the BQ-JIA.

Measures of medical regimen variables.

Parent interview *(Appendix D)***.** This author asked participating parents to give the name, dose amount, dosing frequency, and form (pill, liquid, or injection) of each medication prescribed for their children's JIA treatment. This author also asked parents to report any recent changes in the prescribed regimen.

Medical chart review. This author reviewed each participating patient's medical chart to confirm the patient's age at the time of diagnosis, specific JIA diagnosis, currently prescribed medications and dosing information, and current level of symptom severity (indicated by the active joint count, which is the number of joints with active inflammation). This author also recorded specific medication names and their form and class (NSAID, DMARD, corticosteroids, biological agents).

Medication Regimen Complexity Index (MRCI*) (*George, Phun, Bailey, Kong, & Stewart, 2004) *(Appendix E)***.** From the information gathered through the parent interview and the medical chart reviews, this author calculated the MRCI, a score summarizing regimen complexity that takes into account the dosage form (e.g., liquids, eye drops, injections), dosing frequency, and additional directions included in prescriptions for each medication. Time to calculate the MRCI for each regimen depended on level of complexity. George and colleagues (2004) demonstrated the MRCI's criterion validity by correlating its ranking of theoretical medication regimens with an expert panel's rankings. The authors also demonstrated high interrater and test-retest reliabilities for the MRCI total score and its individual section scores.

In their review of medication regimen factors' influence on treatment adherence, Ingersoll and Cohen (2008) found that medication regimen factors have typically been measured and analyzed individually, with dose frequency demonstrating an important relationship with

adherence. Few composite scores operationalizing "medication regimen complexity" have been used, but Ingersoll and Cohen recommended the incorporation of such indices in studies of adherence. Because the MRCI has not been used in many studies of adherence to pediatric chronic illness regimens, and one of these studies did not find a significant relationship between the MRCI and self-reported medication adherence (Dean, Wragg, Draper, & McDermott, 2011), this author measured and tested the relationships between adherence and the individual regimen-related variables (e.g., number of medications, highest and lowest dosing frequencies, forms of medications) as well as the MRCI scores. None of the individual variables were found to predict adherence at a trend level (all ps ≥ 0.23), though the MRCI scores did ($r = 0.27$, $p = 0.12$). The MRCI scores were thus entered as a predictor in the hierarchical regression model testing the BQ-JIA's incremental validity.

Measures of adherence and other validation criteria. Because of the different strengths and weaknesses of various adherence measures, no single measure is generally regarded as the gold standard. Instead, the recommendation has been to assess adherence using multiple methods of assessment, e.g., complementing a self-report measure with a more objective measure (Drotar et al., 2000; Quittner et al., 2000). In this study, we used pill counts as the more objective measure in addition to self-report measures to obtain patients' and parents' estimates of medication adherence. Pill count adherence rates were calculated as the total number of doses taken within the pill count interval divided by the total number of doses prescribed for all medications within a medication category (e.g., all NSAIDs prescribed for a patient). In analyses involving measures of adherence rates and barriers to adherence at Time 1, the self-report measures served as the adherence measures. In analyses involving measures of adherence at Time 2, the pill count adherence rates were used as the primary adherence measure

because of their less subjective nature and because fewer pill count adherence values were imputed compared to parent- and patient-reported adherence estimates. Though the patient- and parent-reported adherence estimates at Time 2 demonstrated moderate positive correlations with pill count estimates of adherence ($r = 0.371$, $p = 0.04$; $r = 0.456$, $p = 0.009$; respectively), secondary analyses were conducted using participant-reported adherence rates so that both the relationship between barriers and objectively measured adherence and the relationship between barriers and families' perceived adherence could be examined.

Pill Count. This author asked the parents to count the number of pills, to report the percentage of the volume of liquid medication remaining, or to report the number of syringes remaining for each medication. Because patients stored medications in multiple containers (e.g., the supply of naproxen was divided between a bottle stored at home and a bottle stored in the patient's book bag, or a week's supply of hydroxychloroquine was stored in a pill-reminder container at the beginning of each week), this author asked parents about all the containers used to store the patients' medications and prompted the parents to report the total number of pills (or the total volume or the number of syringes) for each medication to improve the accuracy of the adherence estimates (Rapoff, 2010). The first and second pill counts were scheduled approximately two weeks apart, though the actual interval ranged from 10 to 62 days with the median pill count interval equaling 14 days ($M(SD) = 16\ (8)$). Both pill counts were conducted over the phone with the participating parent, except in one case in which the pill count was conducted with the adolescent patient. Pill count adherence estimates were restricted to 0-100%, so that the effect of error due to medication dumping would be limited. Adherence estimates for each NSAID, DMARD, CS, and biological agent that was not prescribed p.r.n. were calculated. The weighted mean of these estimates served as the single estimate of overall medication

adherence by pill count, as pill count estimates of adherence did not appear to vary systematically by type of medication ($F(3, 71) = 0.441$, $p = 0.724$). Although pill counts do not confirm ingestion of medications and may overestimate adherence compared to blood assays (Rapoff, 2010), we chose to assess adherence through pill counts because of their feasibility, minimal invasiveness, and ability to provide adherence estimates for multiple medications.

***Child Adherence Report Questionnaire – Juvenile Idiopathic Arthritis (CARQ-JIA*) (*April et al., 2006) and Parent Adherence Report Questionnaire – Juvenile Idiopathic Arthritis (PARQ-JIA*) (*De Civita et al., 2005)** *(Appendix F).* The CARQ-JIA and the PARQ-JIA were developed to assess the patient's and parent's perceptions, respectively, of the distribution of treatment responsibilities among family members, the patient's ability to follow treatment recommendations, errors in taking medication, and the helpfulness of different regimen components. The PARQ-JIA included an additional item with a checklist of potentially problematic issues that could affect the patient's treatment. The two measures used a series of visual analog scales (VAS) to assess the patient's ability to follow each of three treatment recommendations – medications, prescribed exercises, and wearing splints – as they were relevant to the individual patient. The first item asked the respondent to rate the difficulty with which the patient followed each of the three treatment recommendations by drawing a line on the corresponding 100 mm VAS with endpoint anchors of *very easy* and *very hard*. The second item asked the respondent to rate the patient's frequency of following the three recommendations on the corresponding VAS with endpoint anchors of *never* and *always*. The third item asked the respondent to rate the frequency of the patient's negative reactions to the three treatment recommendations on the corresponding VAS with endpoint anchors of *never* and *always*. Child ability scores for taking medications, performing exercises, and wearing splints were the means

of the three VAS items corresponding to these different treatments calculated with first and third items reverse-scored.

De Civita et al. (2005) provided the following evidence for the reliability and validity of the PARQ-JIA's VAS items assessing the patient's ability to adhere to medication recommendations. The first and second VAS items demonstrated moderate concordance over time (intraclass correlation coefficient, ICC = 0.62 and ICC = 0.60, respectively). The third VAS item demonstrated poor concordance over time (ICC = 0.38). Moderate relationships with parent-reported global estimates of adherence ($r = 0.38$, $p = 0.033$) and adherence estimates calculated from parent-completed treatment adherence diaries (kappa = 0.40) provided evidence for the validity of the PARQ-JIA's child ability score for medications. From administering the CARQ-JIA to a sample of patients (age 9-18 years old) and administering the PARQ-JIA to their parents, April et al. (2006) found fair parent-patient agreement on estimates of adherence to medications (ICC = 0.32) and difficulty taking medications (ICC = 0.33), demonstrating that the CARQ-JIA can be used to elicit estimates of overall adherence to medication regimens from pediatric patients.

In the present study, two of the child ability-medication items from the CARQ-JIA were used to help establish the validity of the BQ-JIA. The general level of difficulty VAS item (designated $CARQ_1$) provided a criterion for establishing convergent validity of the BQ-JIA's scale score, and the frequency of following recommendations item ($CARQ_2$) provided a global estimate of medication adherence, which was used to test the concurrent and predictive validities of the barriers measure. We used the corresponding items from the PARQ-JIA (designated $PARQ_1$ and $PARQ_2$) to help establish the validity of the PBQ-JIA. To make the PARQ-JIA items consistent with the CARQ-JIA items, this author modified the original stems of the two

PARQ-JIA items so that the recall period would be the past week instead of the past three months. Shortening the recall period of the PARQ-JIA items to a one-week period was also intended to increase response accuracy (Rudd, 1993). Responses to each of the VAS items were recorded as the percentage of the scale length to the left of the line drawn by the respondent. The data collected from the present study's sample indicated that the test-retest reliability of the CARQ-JIA and the PARQ-JIA VAS items was supported; the test-retest correlation coefficients ranged from $r = 0.422$ to $r = 0.533$ (ps all < 0.05). This suggested that general difficulty with medication adherence as well as participant-reported adherence were somewhat stable through the duration of this study, which was consistent with the expectation that these constructs would be stable over a short time period in the absence of an intervention targeting adherence.

Beliefs About Medication Scale (BAMS) (Riekert, 2000; Riekert & Drotar, 2002) (Appendix G). The BAMS was a 59-item questionnaire designed to assess health beliefs that affect a patient's adherence to a chronic illness treatment regimen involving medication. Adolescent (ages 11-18 years old) and mother versions were developed to measure both patients' and parents' beliefs. The four BAMS subscales were Perceived Threat (PT, a combination of the respondent's perception of the patient's illness severity and susceptibility to illness), Positive Outcome Expectancy (POE, beliefs about the benefits of adhering to the prescribed medication regimen), Negative Outcome Expectancy (NOE, beliefs that present barriers to medical adherence and beliefs about negative consequences of engaging in adherence behaviors), and Intent to perform adherence-related behaviors in the next two weeks. To complete the measure, respondents would rate their level of agreement with health belief statements on a 7-point Likert scale having endpoint anchors of *strongly disagree* and *strongly agree* for items measuring the PT, POE, and NOE constructs or having endpoint anchors of *definitely not likely* and *definitely*

likely for items measuring Intent. The PT, POE, NOE, and Intent subscales have demonstrated acceptable internal consistency (Cronbach's α of 0.80, 0.87, 0.86, and 0.79, respectively) and test-retest reliability (0.72, 0.77, 0.75, and 0.71) for a sample of patients with asthma, HIV, or inflammatory bowel disease over a period of three weeks. The BAMS-Adolescent Version and its subscales have also demonstrated adequate validity, accounting for a significant portion of variance in medication adherence above and beyond that accounted for by demographic and illness variables (Riekert & Drotar, 2002). The BAMS-Mother Version subscales also demonstrated acceptable internal consistency (Cronbach's α values of 0.81 for PT, 0.76 for POE, and 0.77 for NOE) and test-retest reliability (0.89, 0.83, and 0.69, respectively), but the relationship between the subscale scores and adherence was nonsignificant (Riekert, 2000).

In the present study, patients and parents independently completed modified forms of the BAMS-Adolescent Version and BAMS-Mother Version that did not include the seven Intent items. These modified forms were designated BAMS-Patient and BAMS-Parent. Data from the present study's sample of patients with JIA and their parents indicated that all subscales of the BAMS demonstrated degrees of internal consistency comparable to those previously reported by Riekert and Drotar (BAMS-Patient subscales (Cronbach's α): PT (0.81), POE (0.86), and NOE (0.85); BAMS-Parent subscales: PT (0.87), POE (0.76), and NOE (0.80)). Correlations between the BAMS-Patient's three subscales and the BQ-JIA and between the BAMS-Parent's three subscales and the PBQ-JIA administered at Time 1 were used to test the convergent and discriminant validities of the BQ-JIA and PBQ-JIA, because the BAMS NOE subscale measured a construct related to barriers while the PT and POE subscales measured constructs related to but distinct from barriers. Measuring Intent to engage in adherence behaviors was not necessary because medication adherence was measured directly in this study.

Procedure

Recruitment. We obtained approval from the Institutional Review Board at the KUMC. The education coordinator of the KUMC pediatric rheumatology clinic and the occupational therapist assisted this author in identifying patient families who met the first three inclusion criteria and the next clinic appointments that these families had scheduled. The education coordinator and occupational therapist also assisted this author with recruiting families for the study. At the end of an eligible patient's clinic visit, the education coordinator or the occupational therapist (recruiter) confirmed that the patient met the other inclusion criteria and were not deemed ineligible due to exclusion criteria. The recruiter then provided a flier with a brief description of the study's purpose and procedures and sought the family's permission for this author to meet with them in person or contact them by phone to give more information about the study and to facilitate informed consent. Interested families were provided a packet that included consent and assent forms, four sets of questionnaires, and pre-stamped and addressed return envelopes.

Per informed consent procedures, this author reviewed the patient assent form and the parent consent form (which was used to obtain the parent's consent to participate as well as the medical records release authorization) with the family, answered any questions the family had, and provided the family with copies of the signed forms if the family chose to participate. Patients who were 18 years of age were provided an adult-participant consent form in place of the assent form. When this author was unable to be present at the pediatric rheumatology clinic and outreach clinics, consent was obtained by three-way conference call with the patient and participating parent, another researcher (who served as a witness), and this author. Families who

agreed to participate mailed signed consent and assent forms to the KUMC Behavioral Pediatrics laboratory using an envelope provided with the study materials.

Study procedure. When the patient assent and parent consent forms were signed in the clinic, a telephone interview with the parent was scheduled within the next 48 hours. When the consent procedure was conducted over the telephone, the interview followed the signing of the forms. During this interview, information about the parent's understanding of the patient's medication regimen and the first set of pill counts were obtained. After the first pill count, this author prompted both participants to complete the Time 1 questionnaires independently and to mail them to the laboratory in a second envelope given to them. The Time 1 questionnaires included the demographics form, the BQ-JIA and PBQ-JIA, two items from the CARQ-JIA and PARQ-JIA, and the modified versions of the BAMS (Patient and Parent forms). Completion of study measures at Time 1 was expected to take 25-35 minutes. The Time 2 pill count interview was scheduled with the parent approximately two weeks after the first.

Between Time 1 and Time 2, this author reviewed the patient's medical chart and consulted with the clinic nurse or occupational therapist when discrepancies arose between the parent's description of the medication regimen and the regimen recorded in the medical record. The clinic nurse or this author called the patient's parent to help clarify their understanding of the patient's prescribed regimen.

During the Time 2 phone interview, this author asked the parent about any changes in the prescribed regimen made during the intervening time and completed the second pill count with the parent. This author then prompted the participants to complete the second set of study measures and to mail them back to the laboratory using the provided envelope. The Time 2 questionnaires were the BQ-JIA and PBQ-JIA and the two items from the CARQ-JIA the

PARQ-JIA. Completion of the Time 2 questionnaires and the pill count was expected to take 10-15 minutes.

A family's participation was completed when this author had received the completed Time 1 and Time 2 questionnaires and had extracted the relevant information from the patient's medical charts. The Behavioral Pediatrics laboratory mailed a thank-you card to the family. This author calculated the HI based on information in the Demographics Form and the MRCI based on the review of the patient's chart and the parent interview.

Statistical Analyses

Data analyses were conducted using IBM SPSS version 18. All data were re-entered after data collection was complete, and discrepancies between the original dataset and the re-entered dataset were resolved to ensure correct data entry. Two-tailed tests of significance were conducted, and the level of significance was set at 0.05 for all analyses with the exception of analyses used to identify demographic, disease-related, and regimen-related predictors of adherence that were entered in a hierarchical regression model (level of significance was set at 0.20). After preliminary analyses of the data obtained through the different measures, a series of bivariate correlations, hierarchical regression, and polynomial regression analyses were conducted to refine the BQ-JIA and PBQ-JIA and to test the study's hypotheses.

Missing data.

This author attempted to minimize missing data by checking all measures when they were returned to the laboratory and contacting participants if data were missing and could reasonably be recovered. Roughly 45% of the originally missing data were recovered in this way. Of the 35 participating families, nine had missing responses that were not recovered. Two of these families did not return any Time 2 questionnaires, one did not return the patient's Time

2 questionnaires, and the remaining six families were missing responses to one or two questionnaire items from Time 1 or Time 2, but these responses could not be recovered. The unrecovered missing data were found on 30% of variables and, in total, accounted for 2.1% of all values in the dataset. Using SPSS procedures, this author found that Little's Missing Completely At Random test was significant ($\chi^2(1569) = 6.14$ E 26, $p < 0.001$). This indicated that the mechanism of missingness was not Missing Completely At Random. It was assumed that the data were Missing At Random – that is, that missingness was not related to the underlying values of the missing data but to other measured variables included in the analysis. The assumption of a Missing At Random mechanism was supported for missing values on the Time 2 questionnaires that were not returned: independent samples *t* tests comparing cases with missing values and cases without missing values on the Time 2 questionnaires indicated that these two groups did not differ significantly on the Time 1 questionnaires that were also administered at Time 2 (*p*s all > 0.05), suggesting that the missing values on Time 2 questionnaires likely did not differ significantly from the values collected from the other participants. The assumption of a Missing At Random mechanism for missing values on individual variables derived from Time 1 questionnaires could not be tested empirically, and it is acknowledged that a missing not at random mechanism could plausibly underlie the missing values on these variables (e.g., missing responses to the household annual income item of the demographics questionnaire could be related to the these families' unreported income level).

SPSS multiple imputation was used to estimate missing values in accordance with Tabachnick and Fidell's (1996) recommendations. Multiple imputation was selected for the purpose of obtaining more reliable parameter estimates from statistical analyses conducted on these imputed datasets compared with parameter estimates following traditional methods of

addressing missing data (e.g., deletion and single imputation) (Baraldi & Enders, 2010). Twenty imputations were conducted per the rule of thumb given by Graham and colleagues (2007). Variables for which values were imputed were originally missing 2.9% to 11.4% of values. Reported results of statistical analyses were pooled parameter estimates derived from SPSS multiple imputation procedures or from calculation of the mean of parameter estimates from each of the imputed datasets. However, descriptive statistics summarizing sample demographics were calculated on the original dataset with numbers of cases with missing values being reported separately.

Results

Study Sample

The CONSORT diagram (Figure 1) summarized screening, recruitment, and attrition. A total of 596 patients were pre-screened for study eligibility by clinic personnel's review of medical charts. The majority (487 patients, 81.7%) were deemed ineligible; of the 109 remaining, 31 (28.4%) were missed during their clinic visit(s), nine (8.3%) declined study participation due to lack of interest or time, seven (6.4%) were not recommended for study participation by the treating physician, and two families (1.8%) did not wish to participate because they were moving out-of-state. Of the 60 families who reported interest in the study and gave permission for this author to contact them with additional information, 46 (76.7%) families enrolled in the study; the other 14 families were lost to follow up (did not respond to calls regarding scheduling a time to review consent forms). Two of the enrolled families were later excluded from analyses because the diagnosis had been incorrectly recorded, and the patients had not been diagnosed with JIA. Of the 44 remaining families, nine (20.5%) did not complete Time 1 measures: eight of these were lost to follow-up (did not respond to three phone calls and a

mailed letter from the researchers), and one family discontinued participation due to acute worsening of the patient's symptoms and lack of time. Of the 35 families who completed the Time 1 measures, three (8.6%) did not complete the Time 2 measures: two of these were lost to follow-up (one returned the Time 2 parent-report questionnaires but not the patient-report questionnaires) and one family reported loss of interest in the study.

The 26 families who were eligible and were approached regarding the study but either did not consent to participate or did not complete the entire study were compared with the 32 families who completed the study. Patients in these two groups did not differ significantly with respect to whether families were recruited at KUMC or at an outreach clinic (recruited at KUMC: 35% of non-completers, 34% of completers; $\chi^2(1) < 0.001$, $p = 0.99$), proportion of female patients (92% of non-completers, 88% of completers; $\chi^2(1) = 0.36$, $p = 0.55$), age of patients at time of consent or recruitment (*M* (*SD*): 15.04 (2.01) years for non-completers, 14.93 (2.20) years for completers; $t(56) = -0.20$, $p = 0.84$), or JIA subtype ($\chi^2(5) = 2.71$, $p = 0.74$). Though information about medication adherence or disease severity was not available for non-completers, these findings suggested that the study sample was somewhat representative of the population of 11 through 18 year-old patients with JIA from whom they were recruited. See Table 4 for a summary of the characteristics of non-completers and completers.

Table 5 summarized the demographic and medical characteristics of the 35 families who completed at least the Time 1 measures. Roughly two thirds of participants were recruited through the pediatric rheumatology outreach clinics. The majority of patients were female (86%), Caucasian (71%), specifically diagnosed with RF-negative polyarthritis (51%), and had one or more joints actively affected by the disease (60%). Patients ranged in age from 11.2 years to 18.2 years at the beginning of the study (*M*(*SD*) = 15.0 (2.2) years). All patients' medical

regimens included at least one NSAID, 86% of patients were prescribed at least one DMARD, and a small minority were prescribed a corticosteroid (17%) or a biological agent (17%). The median number of medications prescribed to treat JIA symptoms was three. This did not include supplements that may have also been recommended. The majority of patients lived in two-parent households (83%), and 89% of adult participants were the patients' mothers. The parents participating in this study tended to be well-educated (i.e., achieved post-secondary education degrees), and over half reported annual household income of $50,000-$75,000 or $75,000-$100,000.

Mean participant-reported (at Times 1 and 2) and pill count (Time 2) adherence ranged from 0.78 to 0.84, suggesting that patients were generally adherent to their medication regimens. At Time 1, 71% of parents and 66% of patients reported at least an 80% adherence rate. At Time 2, 61% of parents and 72% of patients reported at least an 80% adherence rate. According to pill counts, 68% of patients took at least 80% of the prescribed doses of medications during the study period. Bivariate correlations among the three adherence measures taken at Time 2 suggested convergence across the subjective and objective measures of adherence. Patient- and parent-reported adherence rates demonstrated strong, positive correlations at both Time 1 ($r = 0.534$, $p = 0.001$) and Time 2 ($r = 0.518$, $p = 0.004$). Participant-reported adherence rates obtained at Time 2 demonstrated moderate, positive correlations with pill count weighted mean adherence rates ($r = 0.371$, $p = 0.04$ and $r = 0.456$, $p = 0.009$ for patient- and parent-reported rates, respectively).

Item Analysis

As part of refining the BQ-JIA and PBQ-JIA, this author identified individual items that might detract from the measures' utility. First, this author examined the distribution of

frequency responses to each item and found that the distributions of responses to over a third of the items in the BQ-JIA and over half of the items in the PBQ-JIA were significantly skewed. Second, this author found that two thirds of the items in the BQ-JIA and a third of items in the PBQ-JIA demonstrated low item-total correlations (i.e., $r < 0.25$). Third, this author found that over one third of BQ-JIA items and over two thirds of the PBQ-JIA items were highly correlated with other items ($r > 0.5$). Items that exhibited all three of the above characteristics (i.e., items 3, 5, and 12 on the BQ-JIA; item 15 on the PBQ-JIA) were considered for elimination, though decisions about eliminating items would be better informed by a study with a larger group of participants. The distributions of item responses obtained from a larger sample would more reliably reflect item response distributions in the population, and a larger sample size would also support an exploratory factor analysis to facilitate exploration of the structures of the measures. Though the determination of an adequate sample size for an exploratory factor analysis varies depending on the magnitude of communalities, number of factors, and number of indicators per factor, application of an EFA to the BQ-JIA or PBQ-JIA would likely require a sample size greater than 100, assuming the communalities would be moderately large given the measures' likely low indicator to factor ratio (MacCallum, Widaman, Zhang, & Hong, 1999). At this point, all items on both barriers measures were retained.

Testing Hypothesis 1: Prediction of Significant Internal Consistency and Test-retest Reliability of the BQ-JIA and PBQ-JIA

Tests of internal consistency were conducted on patients' and parents' ratings of barrier frequencies on the BQ-JIA and the PBQ-JIA at Time 1. Internal consistency was low for the BQ-JIA (Cronbach's $\alpha = 0.41$), suggesting the need for item reduction in a future, larger study. The PBQ-JIA, however, demonstrated adequate internal consistency (Cronbach's $\alpha = 0.72$).

The test-retest reliability of the two barriers measures was assessed by correlating Time 1 and Time 2 measure outputs – number of barriers ever encountered, number of barriers encountered in the past week, and barriers measure total score based on frequencies of barriers encountered in the past week. The BQ-JIA demonstrated adequate test-retest reliability (*r*s ranged from 0.55 to 0.56, all *p*s = 0.001), and the median test-retest interval was 19 days (*M*(*S.E.*) = 27 (3.4); range: 12-93 days). When test-retest reliability correlations were compared between patients whose test-retest interval was equal to or shorter than the median interval and patients whose test-retest interval was longer than the median interval, it was found that the correlations were not significant for the latter group (*r*s ranged from 0.40 to 0.46, all *p*s ≥ 0.09). This comparison indicated that test-retest reliability of the BQ-JIA was better supported (*r*s ranged from 0.62 to 0.67, all *p*s ≤ 0.004) over shorter intervals (i.e., 19 or fewer days). The PBQ-JIA demonstrated adequate test-retest reliability (*r*s ranged from 0.74 to 0.78, all *p*s < 0.001), and the median test-retest interval was 19 days (*M*(*S.E.*) = 27 (3.2); range: 11-88 days). The test-retest reliability of the PBQ-JIA was supported over the range of test-retest intervals.

Testing Hypothesis 2: Prediction of Adequate Concurrent, Convergent, Discriminant, and Predictive Validities

The concurrent, convergent, discriminant, and predictive validities of the BQ-JIA and the PBQ-JIA were determined by examining the relationships between each measure's output (Time 1) with the other measures completed by the same participant (patient or parent) at Time 1 and Time 2 as well as pill count adherence. Correlations among patient-report measures and correlations among parent-report measures were summarized in Tables 6 and 7, respectively. Table 8 provided a summary of mean patient- and parent-scores on study measures, as well as *t* tests and correlations comparing these sets of scores.

Concurrent validity.

Concurrent validity was determined through correlating the output from the BQ-JIA with the patient-reported adherence estimate ($CARQ_2$). The sum of the frequency scores for barriers experienced in the past week exhibited the strongest correlation with patient-reported adherence (r = -0.403, p = 0.02). Of the PBQ-JIA outputs, the number of parent-reported barriers experienced in the past week was most strongly correlated with parent-report adherence (r = -0.555, $p < 0.001$). The sum of frequency scores served as the BQ-JIA output variable in subsequent analyses of the measures' convergent and discriminant validity, and the number of barriers experienced in the past week served as the output variable for the PBQ-JIA. The moderate-to-strong, negative correlations between the barriers and adherence measures were consistent with the Health Belief Model's prediction of the relationships between the constructs they measure, lending support for the concurrent validity of the barriers measures.

Convergent validity and discriminant validity.

Convergent validity of the BQ-JIA and PBQ-JIA was assessed through correlating the barriers measures' output with the $CARQ_1$ and $PARQ_1$ items measuring general level of difficulty (Time 1) and the Negative Outcomes Expectancy (NOE) subscale scores from the BAMS measures. The BQ-JIA exhibited a moderate, positive correlation with the $CARQ_1$ (r = 0.466, p = 0.004) and a strong, positive correlation with the NOE subscale from the BAMS-Patient (r = 0.640, $p < 0.001$). Similarly, the PBQ-JIA correlated strongly and positively with both the $PARQ_1$ (r = 0.519, p = 0.001) and the NOE subscale from the BAMS-Parent (r = 0.491, p = 0.002). These moderate-to-strong, positive correlations between the barriers measures and previously established measures of related constructs supported the convergent validity of the barriers measures.

Divergent validity of the barriers measures was assessed through the comparison of correlations between the barriers scales' output variables and the Perceived Threat (PT) and the Positive Outcome Expectancy (POE) subscale scores with the correlation between the BQ-JIA and the NOE subscale scores. The correlation between the BQ-JIA and the patient-rated PT subscale score was not statistically significant ($r = 0.271$, $p = 0.12$), and the correlation with the POE subscale score was moderate and negative ($r = -0.481$, $p = 0.003$). The nonsignificant correlation with the PT subscale score supported the conceptualization of barriers to adherence as a distinct construct from the patients' perceived threat of unmanaged illness. The negative correlation between the BQ-JIA and the POE subscale score suggested that patients' perception of barriers was moderately but inversely related to their expectations regarding the benefits of medication taking. These findings supported the divergent validity of the BQ-JIA.

In contrast, the PBQ-JIA and PT subscale score from the BAMS-Parent measure were strongly and positively correlated ($r = 0.497$, $p = 0.002$), while the negative correlation between the PBQ-JIA and the POE subscale score was not significant ($r = -0.259$, $p = 0.13$). These results suggested that the barriers constructs measured by the PBQ-JIA and the BQ-JIA may differ.

Predictive validity.

To determine the predictive validity of the BQ-JIA and PBQ-JIA, the barriers measures' output variables (measured at Time 1) were correlated with pill count adherence and the corresponding participant-reported adherence estimates (measured at Time 2). The BQ-JIA total of frequency scores significantly correlated with pill count adherence estimates ($r = -0.372$, $p = 0.03$); however, the PBQ-JIA number of barriers encountered in the week before Time 1 was not significantly correlated with pill count adherence estimates ($r = -0.244$, $p = 0.16$). The BQ-

JIA correlated with the Time 2 $CARQ_2$ only at a trend level of significance (r = -0.335, p = 0.06), as did the PBQ-JIA and the Time 2 $PARQ_2$ (r = -0.331, p = 0.09). These results suggested that prediction of future adherence using the BQ-JIA was partially supported. However, the predictive validity of the PBQ-JIA was not supported, and incremental validity of the PBQ-JIA was not subsequently tested.

Testing Hypothesis 3: Prediction of Significant Incremental Validity

A hierarchical multiple regression analysis was used to evaluate the amount of variance in adherence that the BQ-JIA accounted for beyond that accounted for by demographic, disease, and medical regimen variables that demonstrated trend-level relationships ($p < 0.20$) with pill count adherence measured at Time 2. In the first step of the regression model, the patient's age at the time of study participation, the father's age, the family's annual income, and the combined HI score of the two parents were entered as the demographic variable predictors. No disease-related variables were correlated to adherence rates at a trend level. In the second step of the regression model, the MRCI was entered as the sole regimen-related predictor. The BQ-JIA total frequency of barriers encountered in the week prior to Time 1 variable was entered in the third step. The final model accounted for 39.1% of the variance in pill count adherence, and this represented a statistically significant amount of variance explained ($F(6, 28) = 3.013$, $p = 0.02$). The addition of the BQ-JIA to the model increased the portion of the variance in adherence rates accounted for by the model above that accounted for by the demographic and regimen-related predictors alone ($\Delta R^2 = 0.180$; $F(1, 28) = 8.316$, $p = 0.007$). Within the final model, the BQ-JIA was the only predictor that uniquely accounted for a significant portion of variance in adherence rates (β = -0.025, t = -2.855, p = 0.004). Table 9 summarized this model's parameter estimates. The significant, negative regression coefficient associated with the BQ-JIA predictor variable

and the significant increase in the variance in adherence rates accounted for by the full model compared to the model without the BQ-JIA as a predictor provided support for the incremental validity of the barriers measure.

Testing Hypothesis 4: Exploring the Relationship between Patient-reported and Parent-reported Barriers

To test the level of agreement between patients' and parents' reports of perceived barriers, the correlations for the following pairs of BQ-JIA and PBQ-JIA scores obtained at Time 1 were calculated: total number of barriers ever encountered ($r = 0.295$, $p = 0.08$), number of barriers encountered in the past week ($r = 0.459$, $p = 0.005$), and total scale score ($r = 0.554$, $p < 0.001$). The moderate-to-strong positive correlations between patients' and parents' perceptions of the number and frequency of barriers encountered in the previous week indicated greater patient-parent reliability in rating more recently experienced barriers to adherence. When the BQ-JIA and PBQ-JIA were administered at Time 2, patients' and parents' scores exhibited stronger correlations (rs ranged from 0.527 to 0.743, all ps ≤ 0.001).

The individual barriers were ranked by the percentages of respondents who indicated having experienced each barrier at any time in the past, and these rankings were compared between the groups of patients and parents to identify similar and unique barriers perceived by the different participants (see Table 10). No imputed values were included in this analysis. The majority of the barriers most frequently endorsed by patients were also frequently endorsed by parents, particularly barriers related to patient or parent forgetting, difficulty taking medication when away from home, and medication taste. Forty percent of patients endorsed resistance to injection medications, while only 20% of parents endorsed this item, suggesting either different interpretations of the item (e.g., patients may have been reporting an aversion to injection

medications whether they had been prescribed one or not, while parents may have been reporting on instances of active avoidance of prescribed injection medications) or that patients may have been more likely to recall past instances of injection avoidance. Altogether, these findings suggested that the BQ-JIA and the PBQ-JIA elicited fairly concordant perceptions of adherence barriers between patients and parents.

Testing Hypothesis 5: Predicted Opposite Effects of Patient Age on the Relationships between Patient-reported Barriers and Adherence and between Parent-reported Barriers and Adherence

To examine the effect of patients' age on the BQ-JIA and PBQ-JIA scores' abilities to predict adherence, interaction terms representing moderating effects of age on barriers scores in two multiple regression models of adherence were compared. In the first model, the patient-reported total frequency of barriers encountered in the past week (BQ-JIA at Time 1), patient age, and a term representing the interaction of the BQ-JIA variable and patient age were entered in the model as predictors of adherence measured by pill count. The second model included the parent-reported number of barriers encountered in the past week (PBQ-JIA at Time 1), patient age, and the interaction between the PBQ-JIA variable and patient age as predictors of adherence measured by pill count. The predictors were mean-centered to decrease the effects of multicollinearity. In the first model, the interaction term was not a significant, unique predictor of adherence ($\beta = 0.006$, $t = 1.33$, $p = 0.18$), indicating that patient age did not moderate the relationship between patient-reported barriers and medication adherence. Please see Table 11 for a summary of this model's regression coefficient estimates. In the second model, the interaction term was a significant, unique predictor of adherence ($\beta = 0.012$, $t = 2.24$, $p = 0.02$). Please see Table 12 for a summary of this model's regression coefficient estimates. The positive regression

coefficient for the interaction term indicated that as patient age increased, the negative relationship between parent-reported number of barriers and adherence assessed by pill count decreased in magnitude. In other words, the ability to predict adherence using parent-reported barriers weakened as the patient's age increased. The simple slopes illustrating this interaction between patient age and parent-reported barriers were plotted in Figure 2.

Discussion

This pilot study provided initial psychometric data for the BQ-JIA and the PBQ-JIA and preliminary support for their clinical utility as brief, self-report measures of barriers to medication taking. The low internal consistency of the BQ-JIA and the identification of three items exhibiting skewed response distributions, low item-total correlations, and high inter-item correlations suggested the need for further refinement of this measure. The PBQ-JIA demonstrated adequate internal consistency that was comparable to values reported for other barriers scales in the pediatric adherence literature, though future analyses of the measure's factor structure may reveal groups of items that represent more homogenous constructs within the barriers construct. Both the BQ-JIA and the PBQ-JIA demonstrated adequate test-retest reliability, and the results of this study provided support for their validity through the associations between the barriers measures and concurrent measures of adherence and measures of constructs posited in the Health Belief Model.

The specific output variables of the parent and patient barriers measures and their relationships to measures of adherence suggested the possibility that the barriers construct was measured differently in the group of patients compared to the group of parents. The slightly stronger relationships between the parent-reported number of barriers encountered in the past week and parents' ratings of their children's general levels of difficulty with medication as well

as overall medication adherence compared to the relationships between the other PBQ-JIA output variables and these other measures may indicate that parents' awareness of specific barriers but not necessarily the frequency at which barriers are encountered inform their perceptions of their children's adherence. Remarks that parents made when asked to record any barriers in addition to those listed in the PBQ-JIA indicated that several expected their older adolescents to take primary responsibility for taking medications, and this decrease in the parental role of monitoring medication adherence could conceivably relate to decreased awareness of how frequently patients struggle with adherence barriers as well as explain the nonsignificant relationship between parent-reported barriers and a more objective measure of adherence (pill count). The moderating effect of increasing patient age on a decrease in strength of the negative, predictive relationship between parent-reported barriers and adherence, as well as the support for the BQ-JIA's predictive validity and incremental validity, provided support for this interpretation.

The differing ways in which patient- and parent-reported barriers related to the constructs of perceived threat of illness condition and positive expectancies regarding medication taking also suggested differences in patients' and parents' conceptualizations of adherence barriers. The moderate, negative relationship between patients' perceptions of positive outcomes associated with medication taking and their reports of adherence barriers suggested either that a lack of perceived benefits represented a type of barrier to medication adherence or that barriers to adherence may diminish patients' perceptions of the benefits of medication taking, either of which could decrease motivation to be adherent. In contrast, parents' positive outcome expectancies appeared more independent of their perception of adherence barriers, which were more closely related to their perceptions of illness threat. It has been previously reported that

perceived threat and adherence were negatively related in adolescents with asthma (Riekert & Drotar, 2002), so perhaps the positive relationship between the PBQ-JIA measure and the PT subscale reflected a higher salience of illness severity and patient susceptibility in parents of nonadherent patients who encounter a number of barriers to adherence. These plausible differences in patients' and parents' perceptions of barriers as well as the differing ability of the barriers measures to predict adherence support the recommendation of assessing and including both perspectives when clinicians collaborate with families to design interventions to target specific adherence barriers.

Limitations

A major limitation of this study was the small sample size and attrition of eligible families at different stages of the study. Though efforts were made to recover missing data and to multiply impute missing values to retain statistical power, parameter estimates derived from a sample of 35 would need to be replicated in a larger study for greater assurance of their reliability. Also, the small sample size potentially limited the variability in responses to measures and in the range of sampled medication adherence rates compared to adherence rates in the population of patients with JIA.

Though multiple measures of adherence were employed in this study, including a more "objective" measure, participant-reported adherence rates may have overestimated actual adherence because of social desirability effects and problems with recall, and pill count estimates of adherence would not have distinguished between actual ingestion, misplacement, or dumping (Rapoff, 2010). Additionally, estimates of adherence may have been affected by the families' participation in a study explicitly focusing on medication adherence so that they were not representative of the patients' general adherence rates (i.e., reactivity effect). In a future study,

the use of a less obtrusive adherence measure, such as an electronic monitoring device, over a longer period of time may minimize the effects of reactivity and recall biases, though it would still be susceptible to medication dumping.

The poor internal consistency of the BQ-JIA represented another limitation of study results pertaining to this measure. Though this pilot study provided support for the validity of this measure, further refinement of the BQ-JIA and evidence of improved measurement reliability would be required before the validity of the measure can be more firmly established.

The patients' responses to the item on the BQ-JIA assessing for resistance to injections indicated that changing the stem of the item would promote more accurate reporting. Although 40% of patients endorsed this item, only 17% of the patients were prescribed a medication administered through injection during the study period. Changing the stem to indicate that only patients who are prescribed injection medications should respond to the item may assist respondents in consistently interpreting the item.

Future Directions

This pilot study has provided preliminary support for the reliability and validity of the BQ-JIA and PBQ-JIA as measures of patients' and parent's perceptions of recently encountered barriers to medication adherence. These measures would benefit from further refinement through exploratory factor analysis to determine factor structure as well as to identify items that do not contribute to the purpose of barriers measurement. Subsequent confirmatory factor analysis would provide additional support for the measures' factor structure. Given that roughly 100 adolescents with JIA who were prescribed at least one daily medication were seen over the course of one year through one major hospital's pediatric rheumatology clinic, it would be

beneficial to conduct a multisite study so that multivariate analyses like an exploratory factor analysis could be adequately powered.

After further measure development, the sensitivity of the BQ-JIA and the PBQ-JIA to changes in barriers and adherence could be tested within the context of an adherence improvement intervention study. Demonstration that these barriers measures can assist in the identification of specific, modifiable adherence barriers as well as in monitoring the effects of interventions targeting these barriers would lend support to the routine use of these measures in clinical settings.

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Table 1. Properties of Barriers Measures

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Asthma								
Logan, Zelikovsky, Labay, & Spergel (2003): Illness Manage-ment Survey (IMS)	Patient rates on Likert scale level of agreement with listed barriers (*strongly disagree*, *disagree*, *neutral*, *agree*, *strongly agree*)	27	Items reflected empirically supported barriers to adh among adolescents with chronic illness generated from literature review; items were intended to apply to range of chronic illnesses	Total scale score range: 27-135: higher score reflects greater perceived barriers; 5 subscales[b] (Cronbach's α; # items): disease/regimen/ medical systems (0.78; 7), cognitive difficulties (0.79; 7), lack of social support or self-efficacy (0.74; 6), denial/distrust (0.65; 5), peer/family issues (0.56; 4)	5-10 mins	N = 152 patients with asthma (11-18 yrs old)	Internal consistency: Cronbach's $\alpha = 0.87$; Test-retest reliability (4 weeks): $r = 0.88$	Concurrent validity: Scale score negatively correlated with health care provider rated adh to tx components; positively correlated with provider rated asthma severity, age, Adolescent Risk Taking Survey score, and patients' Perceptions of Asthma Med Scale score

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Modi & Quittner (2006): Barriers to Adherence Interview - Asthma: child and parent versions	Interviewee identifies barriers to txs (also can select from list of 25 common barriers), ranks barriers for each tx, and rates freq of each barrier on Likert scale (1 = *very rarely*, 2 = *once per month*, 3 = *twice per month*, 4 = *once per week*, 5 = *twice per week*, 6 = *more than twice per week*, 7 = *daily*)	8 specific txs listed; not all txs were applicable to all participants	List of 25 common barriers from the literature and expert review, including medical team	Number of barriers identified for each tx component, ranking of barriers' relative importance, self-reported freq of each barrier's occurrence	Depends on number of prescribed tx components; 15-20 mins if most components applied	N = 15 patients with asthma (10-13 yrs old), N = 36 parents of patients with asthma (6-13 yrs old)	Not reported	Concurrent validity: moderate negative correlations between number of barriers and adh to inhaled corticosteroids and pulmozyme for several adh measures, positive correlation between patient-reported adh and number of barriers for airway clearance and enzymes – all at trend level (not significant)

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Cystic Fibrosis								
Modi & Quittner (2006): Barriers to Adherence Interview - Cystic Fibrosis: child and parent versions	Interviewee identifies barriers to txs (also can select from list of 25 common barriers), ranks barriers for each tx, and rates freq of each barrier on Likert scale (1 = *very rarely*, 2 = *once per month*, 3 = *twice per month*, 4 = *once per week*, 5 = *twice per week*, 6 = *more than twice per week*, 7 = *daily*)	9 specific txs listed; not all txs were applicable to all participants	List of 25 common barriers derived from the literature and expert review, including medical team	Number of barriers identified for each tx component, ranking of barriers' relative importance, self-reported freq of each barrier's occurrence	Depends on number of prescribed tx components; 15-20 mins if most components applied	N = 19 patients with CF (10-13 yrs old), N = 37 parents of patients with CF (6 - 13 yrs old)	Not reported	Concurrent validity: moderate negative correlations between number of barriers and adh to inhaled corticosteroids and pulmozyme for several adh measures, positive correlation b/t patient-reported adh and number of barriers for airway clearance and enzymes – all at trend level

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Epilepsy								
Modi, Monahan, Daniels, & Glauser (2010): Pediatric Epilepsy Med Self-Management Questionnaire (PEMSQ)	For barriers scale, parent rates on Likert scale the freq of each listed barriers (1 = *never*, 2 = *seldom*, 3 = *sometimes*, 4 = *often*, 5 = *always*); other scales assess disease and tx knowledge, adh to meds, and beliefs about med efficacy	27 items in PEMSQ; 8 items in barriers scale	Original items generated based on expert advice from pediatric epileptologists and nurse practitioners as well as review of pediatric literature	Barriers scale score range: 8 - 40 (reverse scored: higher scores represented fewer barriers)	5-10 mins	N = 119 parents of patients with epilepsy (2-14 yrs old)	Barriers scale's internal consistency: Cronbach's $\alpha = 0.76$	Concurrent validity: positive correlations between barriers scale and MEMS cap adh and self-reported adh

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Human Immunodeficiency Virus (HIV) Infection								
Marhefka et al. (2006): 24-Hour Recall Interview (24RI)	Interviewee is asked to recount patient's activities from the previous day, including regimen-related events, and is asked to list "the things that made it difficult to follow the physician's medical recommend-ations during the previous day" and "the things that kept them from following the recommend-ations *exactly* during the previous day"	2 open-ended questions about adh barriers	Adaptation of 24RI used to assess diabetes regimen adh (Johnson, Kelly, Henretta, Cunningham, Tomer, & Silverstein, 1992)	Number descriptions of adh barriers experienced	Variable interview length; 3 phone interviews during a 2-week period (2 weekdays, 1 weekend day)	N = 51 caregivers of patients perinatally infected with HIV (2-12 yrs old)	Not reported for barriers items	Concurrent validity: report of 1+ barrier(s) were in agreement with measures of viral load (kappa) at a trend level ($p < 0.10$): 43% sensitivity, 79% specificity

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Marhefka, Koenig, Allison, Bachanas, Bulterys, Bettica, Tepper, & Abrams (2008): PACTG Pediatric Adherence Questionnaire Module 2	Interviewee is asked "When a dose of your child's med is missed, what are the reasons for the missed dose?" and is presented with 9 barriers from which to indicate all applicable responses		N/A	Number and type of barriers affecting adh to each prescribed med	Not reported	N = 127 adult caregivers of children with HIV (2-15 yrs old)	Not reported	Concurrent validity: identification of 0-1 barrier was associated with caregiver-reported adh; identification of 2+ barriers was associated with caregiver-reported nonadh

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Buchanan et al. (2012) †, Farley et al. (2008) ‡ : P1042S Child/ Adolescent Questionnaire; Parent/ Caregiver Questionnaire	Respondent rates freq with which different adh barriers occurred in the past month on a 4-point Likert scale (*Never or Rarely*, *Sometimes*, *Often*, *Mostly or Always*), and to indicate degree of responsibility for each of 4 tasks involved in med adh	29 items in total; 19 items related to adh barriers	Items selected from questionnaires already employed in PACTG and Adult AIDS Clinical Trials Group	†Number of barriers endorsed and frequency of barriers' occurrence in past month for all barriers and four types of barriers (Cronbach's α child report, Cronbach's α caregiver report): logistical barriers (0.84, 0.74), regimen barriers (0.80, N/A), child disclosure (N/A, N/A), and emotional barriers (N/A, N/A)	Not reported	N = 120 patients perinatally infected with HIV (8-19 yrs old) and their caregivers	†Internal consistency: Cronbach's α reported to be adequate for logistical and regimen barriers but not for other barrier types; interrater agreement: significant child-caregiver agreement (kappa) for barriers types but not for 63% of specific barriers	‡ Concurrent validity: absence of patient-reported adh barriers was associated with viral load measures at a trend level ($p < 0.10$); absence of caregiver-reported adh barriers was significantly associated with viral load measures

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Obstructive Sleep Apnea (OSA)								
Simon, Duncan, Janicke, & Wagner (2012): Adh Barriers to CPAP Questionnaire (ABCQ) – patient and parent versions	Respondent rates level of agreement with statements reflecting potential barriers encountered over the past 2 weeks using a 5-point Likert scale (range from *strongly disagree* to *strongly agree*)	31	Items were generated based on literature review and were reviewed by health and mental health professionals	Total scale score (range: 31-155)	10-15 minutes	N = 51 patients diagnosed with OSA (8-17 yrs old) and their caregivers	Internal consistency: Cronbach's $\alpha = 0.89$ and 0.90 for patient and parent versions, respectively; Test-retest reliability (2 weeks): $r = 0.81$ and 0.73 for patient and parent versions, respectively	Convergent validity: negative correlations with electronically measured adh rates and parents' ratings of health-care satisfaction; positive correlation with negative outcome expectancy

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Organ Transplant								
Simons & Blount (2007): Adolescent Med Barriers Scale (AMBS)	Patient rates level of agreement with listed barriers to medical regimen requirement using 5-point Likert scale (*Strongly Disagree*, *Disagree*, *Not Sure*, *Agree*, *Strongly Agree*)	17	Original items adapted from PEDS-TX Survey (Rodrigue, 2004), which was created by team of pediatric transplant physicians, clinical psychologists, and trainees specializing in pediatrics and transplantation	Total scale score (range: 17-85); 3 subscales (Cronbach's α; # items): disease frustration/adolescent issues (0.84; 8), ingestion issues (0.70; 5), regimen adaptation/cognitive (0.76; 4)	5-7 minutes	N = 69 adolescent solid organ transplant recipients (11-21 yrs old)	Internal consistency: Cronbach's α = 0.86; Test-retest reliability (18 months): r = 0.62 (Simons et al., 2010)	Concurrent validity: positive correlations between total scale score and patient-reported side effects and family conflict, negative correlations with patient-reported cohesion and expressiveness; AMBS scores differed between adh and nonadh groups

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Simons & Blount (2007): Parent Med Barriers Scale (PMBS)	Parent rates level of agreement with listed barriers to medical regimen requirement using 5-point Likert scale (*Strongly Disagree*, *Disagree*, *Not Sure*, *Agree*, *Strongly Agree*)	16	Original items adapted from PEDS-TX Survey (Rodrigue, 2004), which was created by team of pediatric transplant physicians, clinical psychologists, and trainees specializing in pediatrics and transplantation	Total scale score (range: 16- 80); 4 subscales (Cronbach's α; # items): disease frustration/adolescent issues (0.84; 7), regimen adaptation/cognitive (0.82; 5), ingestion issues (0.69; 3), parent reminder (1 item)	5-7 minutes	N = 77 parents of solid organ transplant recipients (11-21 yrs old)	Internal consistency: Cronbach's α = 0.87; Test-retest reliability (18 months): r = 0.68 (Simons et al. 2010)	Concurrent validity: positive correlations between total scale score and parent-reported side effects; PMBS scores differed between patient/parent-reported adherent and nonadh groups

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Zelikovsky & Schast, (2008), Zelikovsky, Schast, Palmer, & Meyers, (2008): Medical Adherence Measure (MAM)	Interviewee endorses barriers from choices presented in 7 of 8 modules (med, clinic attendance, nutrition/diet – no barriers question, dialysis, weight mgmt/exercise, urology-catheterization, cystic fibrosis-chest PT); other items in modules assess knowledge, adh behavior, and organizational system	1 barriers item for each of 7 modules	Listed choices for barriers from coded responses to early version of MAM which consisted completely of open-ended questions; respondents can generate responses in addition to ones listed	Number and types of barriers identified	Depends on number of modules that apply - range 10-30 mins for entire interview	N = 56 renal transplant candidates (11-18 yrs old) and their parents; only med module reported on	Not reported	Concurrent validity: number of barriers correlated positively with number of missed and late doses reported

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Overweight/Obesity								
Janicke, Storch, Novoa, Silverstein, & Samyn (2007): Pediatric Barriers to a Healthy Diet Scale	Respondent rates level of agreement with listed reasons why youth may or may not eat healthy foods as recommended by their physician using a 5-point Likert scale (ranging from *strongly agree* to *strongly disagree*)	17	Items developed from consultation with dietitians, pediatric psychologist, and child health psychology graduate students	Total Barriers score (range 17-85); 2 subscales (Cronbach's α; # items): Access factor (0.71, 8) and Desire factor (0.77, 9)	5 minutes	N = 171 overweight or obese youth (8-17 yrs old) and their caregivers	Internal consistency: Cronbach's α = 0.79	Convergent validity: positive correlations with depressive symptoms, and barriers to physical activity; negative correlation with measure of perceived social support

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Chronic Pain								
Simons, Logan, Chastain, & Cerullo (2010): [adh and barrier portion of] Adherence Telephone Interview Forms	Interviewee responded to the prompt, "Did anything make the recommendation difficult to complete?" following each prescribed tx not completed	1 item per relevant tx component	N/A	Qualitative descriptions of barriers that parents perceive; coded 4 categories: access problems, financial problems, competing time or schedule demands, negative attitudes or beliefs	5-7 minutes for adh and barrier portion, 30 minutes for entire interview	Parents of patients with chronic pain (10 - 17 yrs old); n = 23 identified barriers for medical tx, n = 20 for physical therapy, n = 22 for psychological tx	Measure reliability not reported; interrater agreement: kappa = 0.90	Not reported

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Sickle Cell Disease (SCD)								
Witherspoon & Drotar (2006): Barriers Interview	Semi-structured interview used to assess medical history, medication administration, barriers to adh, and amoxicillin tx adh	N/A	Developed by authors	Number of barriers	N/A	N = 30 caregivers of African American children with SCD (6-72 months old)	N/A	Concurrent validity: barriers total correlated positively with nonadh assessed by caregiver-report and pharmacy records
Modi, Crosby, Guilfoyle, Lemanek, Witherspoon, & Mitchell (2009): Disease Management and Barriers Interview - SCD – parent and patient versions	Interviewee describes adh behaviors, reports barriers (also list of 22 common barriers) and strategies to facilitate adh for each regimen component	60 items in interview (number of barriers items depends on number of relevant tx components)	List of 22 common barriers identified in the literature	Number of barriers identified or endorsed for each tx component	Depends on number of prescribed tx components; approximately 15-20 mins	N = 31 patients with sickle cell disease (13-18 yrs old) and N = 71 parents of patients with SCD (6-18 yrs old)	Interrespondent reliability: patients and parents reported similar number and freq of barriers for each tx component (except pain management)	Not reported

Author(s) (Year): Measure	Format	No. items	Item Origins	Measure Output	Time to complete	Participants studied	Reliability	Validity
Fisak, Belkin, von Lehe, & Bansal (2012): Barriers to Health Care Scale	Respondent rates how often each barrier has made it difficult to keep medical appointments, take med, or follow medical recommendations in the past 12 months using a 4-point Likert scale (*never or rarely, sometimes, often, almost always*)	16	Derived from the work of Soliday & Hoeskel (2001) and Witherspoon & Drotar (2006)	Total score (range: 16-64)	< 5 minutes	N = 78 caregivers of patients with SCD (5-17 yrs old)	Internal consistency: Cronbach's $\alpha = 0.87$	Concurrent validity: total score correlated positively with quality of life measure, hydroxyurea status, and pain crisis freq; correlated negatively with caregiver-reported adh

Notes: Abbreviations included adh = adherence, freq = frequency, ICC = intraclass correlation, med = medication, tx = treatment. Any information not available in published articles was requested and obtained from corresponding authors by email. Correlations and relationships listed were significant at $p < 0.05$ level unless otherwise noted

[a] Unpublished analysis conducted by author on original study's dataset

[b] Alternative factor structure of Illness Management Survey: Rhee et al. (2009) – Internal Consistency (Cronbach's $\alpha = 0.84$); Factor analysis retained 20 items and yielded 4 factors (α, # items) – Poor relationships with providers and negative perceptions about medical regimen (0.80, 9), Cognitive difficulty (0.76, 5), Social influence (0.64, 4), Denial (0.52, 2)

Table 2. Comparison across Chronic Illnesses of Weighted Mean Percentages of Patients Reporting Types of Barriers to Adherence

	All Disease Groups[b]	Asthma[c]	CF[d]	HIV[e]	IBD[f]	OSA[g]	SCD[h]	Transplant[i]
Patient or parent forgets								
Number of samples	8	1	1	1	1	1	1	2
Total N	481	14	18	120	79	53	71	126
Raw Mean % (range)[a]	51 (27-85)	64	56	41	85	38	27	47 (38-56)
Weighted Mean %	48							46
Disagreement or communication problems with HCP								
Number of samples	5	2	1	0	0	1	1	0
Total N	307	165	18			53	71	
Raw Mean % (range)[a]	17 (0-85)	43 (0-85)	6			17	3	
Weighted Mean %	46	78						
Psychosocial adjustment difficulties								
Number of samples	5	1	0	1	0	1	1	1
Total N	465	150		120		53	71	71
Raw Mean % (range)[a]	34 (0-85)	85		8		43	0	32
Weighted Mean %	39							
Treatment and daily activities interfere with each other								
Number of samples	6	1	0	1	1	1	0	2
Total N	530	152		120	79	53		126
Raw Mean % (range)[a]	32 (11-79)	79		20	34	11		14 (10-18)
Weighted Mean %	37							13
Incorporating treatment regimen into daily life								
Number of samples	9	2	1	1	1	1	1	2
Total N	631	164	18	120	79	53	71	126
Raw Mean % (range)[a]	34 (8-56)	41 (29-53)	56	24	43	47	8	18 (15-20)
Weighted Mean %	33	51						17

	All Disease Groups[b]	Asthma[c]	CF[d]	HIV[e]	IBD[f]	OSA[g]	SCD[h]	Transplant[i]
Expected or experienced treatment side effects								
Number of samples	9	2	1	1	1	1	1	2
Total N	631	164	18	120	79	53	71	126
Raw Mean % (range)[a]	18 (6-44)	44 (7-81)	6	18	6	28	7	14 (2-25)
Weighted Mean %	30	75						15
Patient desires to be or appear normal								
Number of samples	7	2	1	1	0	1	1	1
Total N	495	165	18	120		53	71	68
Raw Mean % (range)[a]	21 (8-35)	35 (7-62)	17	12		30	8	22
Weighted Mean %	30	58						
Believe treatment is not needed								
Number of samples	7	2	1	1	0	1	1	1
Total N	495	165	18	120		53	71	55
Raw Mean % (range)[a]	21 (8-35)	36 (0-72)	0	15		26	7	0
Weighted Mean %	30	65						
Regimen complexity								
Number of samples	6	2	1	1	0	0	1	1
Total N	446	166	18	120			71	71
Raw Mean % (range)[a]	17 (8-28)	28 (0-57)	11	9			8	27
Weighted Mean %	28	52						
Miscellaneous								
Number of samples	7	1	1	1	1	1	0	2
Total N	409	14	18	120	79	52		126
Raw Mean % (range)[a]	18 (0-42)	0	11	13	13	42		26 (15-36)
Weighted Mean %	20							25

	All Disease Groups[b]	Asthma[c]	CF[d]	HIV[e]	IBD[f]	OSA[g]	SCD[h]	Transplant[i]
Oppositional behavior or discipline issue								
Number of samples	6	1	1	1	1	1	0	1
Total N	339	14	18	120	79	53		55
Raw Mean % (range)[a]	20 (5-39)	21	39	20	11	25		5
Weighted Mean %	17							
Dislikes medication taste								
Number of samples	7	1	1	1	1	0	1	2
Total N	428	14	18	120	79		71	126
Raw Mean % (range)[a]	21 (6-33)	29	33	6	13		23	22 (16-28)
Weighted Mean %	17							23
Difficulties accessing medication/treatment								
Number of samples	6	1	1	1	0	1	1	1
Total N	347	14	18	120		53	71	71
Raw Mean % (range)[a]	13 (6-30)	7	6	21		9	6	30
Weighted Mean %	16							
Treatment technique or administration difficulty								
Number of samples	8	1	1	1	1	1	1	2
Total N	481	14	18	120	79	53	71	126
Raw Mean % (range)[a]	11 (7-22)	7	22	12	8	15	8	8 (2-14)
Weighted Mean %	10							9
Concerns and misconceptions about medications								
Number of samples	5	1	1	0	1	1	1	0
Total N	235	14	18		79	53	71	
Raw Mean % (range)[a]	8 (0-13)	0	6		10	13	11	
Weighted Mean %	10							

	All Disease Groups[b]	Asthma[c]	CF[d]	HIV[e]	IBD[f]	OSA[g]	SCD[h]	Transplant[i]
Treatment costs								
Number of samples	7	1	1	1	1	1	1	1
Total N	409	14	18	120	79	52	71	55
Raw Mean % (range)[a]	4 (0-23)	0	0	3	0	23	0	0
Weighted Mean %	4							

Note. For the study samples reviewed, the raw mean percentage (range listed) and mean percentage weighted by individual sample sizes (weighted mean %) of total N patients who endorsed at least one item within each adherence barrier category are listed within each disease group. CF = Cystic Fibrosis, HIV = Human Immunodeficiency Virus, IBD = Inflammatory Bowel Disease, OSA = Obstructive Sleep Apnea, SCD = Sickle Cell Disease.

[a]Or percentage of sample size N if only one study's data were available. [b]Total N and total weighted mean percentage given. [c]Logan, Zelikovksy, Labay, & Spergel (2003); Modi & Quittner (2006). [d]Modi & Quittner (2006). [e]Buchanan, Montepiedra, Sirois, Kammerer, Garvie, Storm, & Nichols (2012). [f]Gray, Denson, Baldassano, & Hommel (2012). [g]Simon, Duncan, Janicke, & Wagner (2012). [h]Modi, Crosby, Guilfoyle, Lemanek, Witherspoon, & Mitchell (2009). [i]Simons & Blount (2007); Zelikovsky, Schast, Palmer, & Meyers (2008).

Table 3. Comparison across Chronic Illnesses of Weighted Mean Percentages of Parents Reporting Types of Barriers to Adherence

	All Disease Groups[b]	Asthma[c]	Cystic Fibrosis[d]	Epilepsy[e]	HIV[f]	IBD[g]	OSA[h]	SCD[i]	Transplant[j]
Patient or parent forgets									
Number of samples	11	1	1	1	2	2	1	2	1
Total N	808	36	36	119	247	90	53	147	80
Raw Mean % (range)[a]	50 (24-91)	58	67	62	25 (17-33)	91 (88-94)	40	35 (33-38)	24
Weighted Mean %	44				25	89		35	
Incorporating treatment regimen into daily life									
Number of samples	11	1	1	1	2	2	1	2	1
Total N	808	36	36	119	247	90	53	147	80
Raw Mean % (range)[a]	36 (20-61)	22	61	20	23 (18-28)	61 (47-75)	43	28 (15-41)	33
Weighted Mean %	31				23	52		29	
Patient dislikes medication taste									1
Number of samples	7	1	1	1	1	1	0	1	80
Total N	536	36	36	119	120	74		71	21
Raw Mean % (range)[a]	29 (4-51)	36	42	51	4	11		35	
Weighted Mean %	27								
Treatment and daily activities interfere with each other									
Number of samples	6	0	0	1	1	2	1	0	1
Total N	461			119	120	90	52		80
Raw Mean % (range)[a]	26 (8-69)			18	10	69 (45-94)	8		21
Weighted Mean %	23					53			

	All Disease Groups[b]	Asthma[c]	Cystic Fibrosis[d]	Epilepsy[e]	HIV[f]	IBD[g]	OSA[h]	SCD[i]	Transplant[j]
Oppositional behavior or discipline issue									
Number of samples	8	1	1	1	2	2	1	0	0
Total N	580	36	36	119	247	90	52		
Raw Mean % (range)[a]	33 (8-78)	25	78	25	8 (5-12)	31 (18-44)	31		
Weighted Mean %	21				8	22			
Miscellaneous									
Number of samples	6	1	1	0	2	0	1	1	0
Total N	447	36	36		247		52	76	
Raw Mean % (range)[a]	19 (3-44)	3	3		14 (8-21)		44	44	
Weighted Mean %	19				15				
Concerns and misconceptions about medications									
Number of samples	6	1	1	0	0	1	1	2	0
Total N	288	36	36			16	53	147	
Raw Mean % (range)[a]	15 (6-23)	11	17			19	6	23 (8-38)	
Weighted Mean %	17							22	
Expected or experienced treatment side effects									
Number of samples	10	1	1	0	2	2	1	2	1
Total N	687	36	36		247	90	51	147	80
Raw Mean % (range)[a]	22 (5-34)	17	28		5 (1-8)	30 (16-44)	20	20 (14-25)	34
Weighted Mean %	16				4	21		20	

	All Disease Groups[b]	Asthma[c]	Cystic Fibrosis[d]	Epilepsy[e]	HIV[f]	IBD[g]	OSA[h]	SCD[i]	Transplant[j]
Treatment technique or administration difficulty									
Number of samples	9	1	1	1	1	2	1	1	1
Total N	605	36	36	119	120	90	53	71	80
Raw Mean % (range)[a]	18 (6-34)	14	31	19	6	34 (11-56)	9	21	10
Weighted Mean %	15					19			
Difficulties accessing medication/ treatment									
Number of samples	8	1	1	1	2	0	1	2	0
Total N	637	36	36	119	247		52	147	
Raw Mean % (range)[a]	13 (4-26)	11	8	26	10 (8-11)		4	21 (6-36)	
Weighted Mean %	15				10			21	
Psychosocial adjustment difficulties									
Number of samples	5	0	0	0	1	1	1	1	1
Total N	340				120	16	53	71	80
Raw Mean % (range)[a]	13 (3-31)				3	6	25	3	31
Weighted Mean %	13								
Patient desires to be or appear normal									
Number of samples	8	1	1	1	2	0	1	1	1
Total N	641	36	36	119	247		52	71	80
Raw Mean % (range)[a]	16 (5-36)	8	36	18	5 (2-8)		21	8	18
Weighted Mean %	12				5				
Regimen complexity									
Number of samples	6	1	1	0	1	1	0	1	1
Total N	359	36	36		120	16		71	80
Raw Mean % (range)[a]	17 (0-63)	0	3		3	63		13	21
Weighted Mean %	11								

	All Disease Groups[b]	Asthma[c]	Cystic Fibrosis[d]	Epilepsy[e]	HIV[f]	IBD[g]	OSA[h]	SCD[i]	Transplant[j]
Treatment costs									
Number of samples	8	1	1	0	1	2	1	2	0
Total N	482	36	36		120	90	53	147	
Raw Mean % (range)[a]	7 (0-25)	3	0		1	7 (1-13)	6	25 (7-43)	
Weighted Mean %	10					3		26	
Believe treatment is not needed									
Number of samples	7	1	1	0	1	2	1	1	0
Total N	406	36	36		120	90	53	71	
Raw Mean % (range)[a]	9 (2-14)	14	6		11	14 (13-15)	2	6	
Weighted Mean %	9					14			
Disagreement or communication problems with HCP									
Number of samples	5	1	1	0	0	0	1	2	0
Total N	272	36	36				53	147	
Raw Mean % (range)[a]	4 (2-8)	3	3				2	8 (1-14)	
Weighted Mean %	6							8	

Note. For the study samples reviewed, the raw mean percentage (range listed) and mean percentage weighted by individual sample sizes (weighted mean %) of total N parents who endorsed at least one item within each adherence barrier category are listed within each disease group. HIV = Human Immunodeficiency Virus, IBD = Inflammatory Bowel Disease, OSA = Obstructive Sleep Apnea, SCD = Sickle Cell Disease.

[a]Or percentage of sample size N if only one study's data were available. [b]Total N and total weighted mean percentage given. [c]Modi & Quittner (2006). [d]Modi & Quittner (2006). [e]Modi, Monahan, Daniels, & Glauser (2010). [f]Buchanan, Montepiedra, Sirois, Kammerer, Garvie, Storm, & Nichols (2012); Marhefka, Koenig, Allison, Bachanas, Bulterys, Bettica, Tepper, & Abrams (2008). [g]Hommel & Baldassano (2010); Ingerski, Baldassano, Denson, & Hommel (2010). [h]Simon, Duncan, Janicke, & Wagner (2012). [i]Fisak, Belkin, von Lehe, & Bansal (2011); Modi, Crosby, Guilfoyle, Lemanek, Witherspoon, & Mitchell (2009). [j]Simons & Blount (2007).

Table 4. Comparison of Study Completers and Non-completers

	Completed T2 (n = 32)	**Non-completers (n = 26)**	**Test (df)**	***p***
Recruitment Site: n (%)			$\chi^2(1) < 0.001$	0.99
KUMC	11 (34)	9 (35)		
Outreach Clinic	21 (66)	17 (65)		
Gender: n (%) female	28 (88)	24 (92)	χ^2 (1) = 0.36	0.55
Age: *M* (*SD*)	14.93 (2.20)	15.04 (2.01)	$t(56) = -0.20$	0.84
JIA diagnosis: n (%)			χ^2 (5) = 2.71	0.74
RF negative polyarthritis	16 (50)	14 (54)		
Spondyloarthropathy	5 (16)	3 (12)		
RF positive polyarthritis	4 (12)	2 (8)		
Oligoarthritis	3 (9)	3 (12)		
Enthesitis-related arthritis	3 (9)	1 (4)		
Systemic JIA	1 (3)	3 (12)		

Note. Abbreviations included JIA = Juvenile Idiopathic Arthritis, RF = rheumatoid factor.

Table 5. Study Sample Demographics and Medical Characteristics

	n (%)	*M* [*mdn*] *(SD)*	Range
Recruitment Site			
KUMC	12 (34)		
Outreach Clinic	23 (66)		
Patient's Gender (female)	30 (86)		
Patient's Age (years)		15.0 (2.2)	11.2-18.2
Patient's Age at Time of Diagnosis (years)		11.4 (4.6)	1.5-17.6
Patient's Ethnicity			
Biracial	6 (17)		
Caucasian	25 (71)		
Hispanic	2 (6)		
Middle Eastern	2 (6)		
Patient's Specific JIA Diagnosis			
RF negative polyarthritis	18 (51)		
Spondyloarthropathy	6 (17)		
RF positive polyarthritis	4 (11)		
Enthesitis-related arthritis	3 (9)		
Oligoarthritis	3 (9)		
Systemic JIA	1 (3)		
Number of Active Joints			
0	13 (37)		
1	8 (23)		
2	9 (26)		
3	1 (3)		
>5	3 (9)		
missing	1 (3)		
Number of Medications Prescribed for JIA		3.3 [3] (1.2)	1.0-6.0
Number of Patients Prescribed Type of Medication			
Nonsteroidal Anti-inflammatory Drug	35 (100)		
Disease Modifying Antirheumatic Drug	30 (86)		
Corticosteroid	6 (17)		
Biological Disease Modifying Drug	6 (17)		
MRCI[a]		12.9 (5.3)	5.5-28.5

	n (%)	*M* [*mdn*] *(SD)*	Range
Adult Participant's Relationship to Patient			
Mother	31 (89)		
Father	3 (9)		
Grandparent	1 (3)		
Parents' Age (years)			
Mother (or female caregiver)		41 (6)	29-52
Father (or male caregiver)		44 (7)	29-58
Patients Living in Two-Parent Household	29 (83)		
Parent Educational Achievement above HS diploma/GED			
Mother (or female caregiver)	29 (83)		
Father (or male caregiver)	25 (71)		
Annual Household Income			
< $25,000	2 (5.7)		
$25,000-$50,000	5 (14.3)		
$50,000-$75,000	9 (25.7)		
$75,000-$100,000	9 (25.7)		
> $100,000	7 (20.0)		
Did not disclose	3 (8.6)		
HI Score of Employed Parents			
Mother (or female caregiver) (n=13)		38 (11)	10-54
Father (or male caregiver) (n=20)		35 (13)	10-54
Household (n=20)		62 (24)	18-103

Note. Demographics of participating families and medical characteristics of patients who completed Time 1 measures. Abbreviations included GED = General Educational Development, HI = Hollingshead Index, HS = high school, JIA = Juvenile Idiopathic Arthritis, KUMC = University of Kansas Medical Center, MRCI = Medical Regimen Complexity Index, RF = rheumatoid factor.

[a]The MRCI is calculated from weighting the effects of different routes of medication administration, dosing frequencies, and special instructions for all medications (prescribed and OTC for JIA and other conditions) and supplements a child is taking regularly.

Table 6. Intercorrelations among Patient-Report Study Variables.

		1	2	3	4	5	6	7	8	9	10	11	12	13	14
1	T1 Number of barriers[a]	--													
2	T1 Number of barriers in past week[a]	.739**	--												
3	T1 Barriers frequency total[a]	.687**	.953**	--											
4	T1 How hard to take meds[b]	.270	.476**	.466**	--										
5	T1 How often took meds[c]	-.230	-.395*	-.403*	-.318	--									
6	Perceived Threat[d]	.277	.231	.271	.380*	-.138	--								
7	Positive Outcome Expectancy[d]	-.467**	-.464**	-.481**	-.363*	.190	-.163	--							
8	Negative Outcome Expectancy[d]	.545**	.576**	.640**	.410*	-.030	.485**	-.591**	--						
9	T2 Number of barriers[e]	.704**	.674**	.657**	.427*	-.283	.409*	-.281	.524**	--					
10	T2 Number of barriers in past week[e]	.461**	.544**	.517**	.495**	-.280	.223	-.211	.398*	.798**	--				
11	T2 Barriers frequency total[e]	.617**	.693**	.658**	.448**	-.397*	.150	-.255	.411*	.854**	.851**	--			
12	T2 How hard to take meds[f]	.433*	.616**	.531**	.462*	-.406*	.056	-.365*	.254	.576**	.577**	.646**	--		
13	T2 How often took meds[g]	-.180	-.350	-.335	-.373	.533**	.006	.249	-.016	-.285	-.375	-.368*	-.566**	--	
14	Adherence (pill count)	-.217	-.292	-.372*	-.324	.371*	.215	.100	-.002	-.402*	-.371*	-.470**	-.271	.371*	--

Note. Abbreviations included T1 = Time 1, T2 = Time 2.

[a]Variable derived from T1 Barriers Questionnaire-Juvenile Idiopathic Arthritis
[b]Time 1 Child Adherence Report Questionnaire item 1
[c]Time 1 Child Adherence Report Questionnaire item 2
[d]Subscale of Beliefs About Medications Scale – Patient questionnaire
[e]Variable derived from T2 Barriers Questionnaire-Juvenile Idiopathic Arthritis
[f]Time 2 Child Adherence Report Questionnaire item 1
[g]Time 2 Child Adherence Report Questionnaire item 2

* $p < 0.05$
** $p < 0.01$

Table 7. Intercorrelations among Parent-Report Study Variables.

		1	2	3	4	5	6	7	8	9	10	11	12	13	14
1	T1 Number of barriers[a]	--													
2	T1 Number of barriers in past week[a]	.691**	--												
3	T1 Barriers frequency total[a]	.658**	.971**	--											
4	T1 How hard to take meds[b]	.295	.519**	.464**	--										
5	T1 How often took meds[c]	-.265	-.555**	-.509**	-.710**	--									
6	Perceived Threat[d]	.437**	.497**	.503**	.284	-.229	--								
7	Positive Outcome Expectancy[d]	-.040	-.259	-.247	.029	.297	-.213	--							
8	Negative Outcome Expectancy[d]	.497**	.491**	.513**	.172	-.212	.652**	-.361*	--						
9	T2 Number of barriers[e]	.742**	.618**	.594**	.540**	-.458**	.348*	-.127	.332	--					
10	T2 Number of barriers in past week[e]	.504**	.770**	.702**	.583**	-.590**	.211	-.259	.321	.682**	--				
11	T2 Barriers frequency total[e]	.519**	.794**	.782**	.652**	-.578**	.254	-.136	.292	.713**	.880**	--			
12	T2 How hard to take meds[f]	.233	.487**	.477**	.530**	-.324	.134	.126	-.039	.479**	.475*	.565**	--		
13	T2 How often took meds[g]	-.136	-.331	-.290	-.601**	.422*	.013	-.162	.206	-.353*	-.411	-.479**	-.743**	--	
14	Adherence (pill count)	-.211	-.244	-.273	-.218	.090	-.038	-.109	.069	-.211	-.193	-.317	-.483**	.456**	--

Note. Abbreviations included T1 = Time 1, T2 = Time 2.

[a]Variable derived from T1 Barriers Questionnaire-Juvenile Idiopathic Arthritis
[b]Time 1 Child Adherence Report Questionnaire item 1
[c]Time 1 Child Adherence Report Questionnaire item 2
[d]Subscale of Beliefs About Medications Scale – Patient questionnaire
[e]Variable derived from T2 Barriers Questionnaire-Juvenile Idiopathic Arthritis
[f]Time 2 Child Adherence Report Questionnaire item 1
[g]Time 2 Child Adherence Report Questionnaire item 2

* $p < 0.05$
** $p < 0.01$

Table 8. Summary of Scores, Mean Comparisons, and Correlations between Patient and Parent Measures.

		Patients		Parents			
		Pooled *M* (S.E.)	Range	Pooled *M* (S.E.)	Range	*t*	*r*
1	T1 Number of barriers	5 (0.5)	0-11	4 (0.5)	0-13	-1.87	.295
2	T1 Number of barriers in past week	4 (0.5)	0-9	3 (0.4)	0-9	-2.65	.459**
3	T1 Barriers frequency total	5 (0.6)	0-12	4 (0.6)	0-13	-3.16	.554**
4	T1 How hard to take meds	0.23 (0.03)	0.00-0.68	0.21 (0.03)	0.00-0.81	-0.54	.177
5	T1 How often took meds	0.80 (0.04)	0.18-1.00	0.84 (0.03)	0.29-1.00	1.15	.534**
6	Perceived Threat	48 (2)	19-69	53 (2)	25-73	2.68	.665**
7	Positive Outcome Expectancy	110 (3)	83-136	91 (2)	58-115	-5.67	.131
8	Negative Outcome Expectancy	35 (2)	13-66	35 (2)	17-60	0.00	.599**
9	T2 Number of barriers	5 (0.4)	0-11	4 (0.4)	0-9	-2.64	.527**
10	T2 Number of barriers in past week	5 (0.6)	0-15	3 (0.5)	0-16	-3.68	.743**
11	T2 Barriers frequency total	6 (0.7)	0-17	4 (0.5)	0-12	-3.59	.617**
12	T2 How hard to take meds	0.21 (0.04)	0.00-0.96	0.23 (0.05)	0.00-0.85	0.36	.623**
13	T2 How often took meds	0.84 (0.03)	0.46-1.00	0.79 (0.04)	0.09-1.00	-1.15	.518**
14	Adherence (pill count)	*M* (S.E.): 0.83 (0.03), Range: 0.36-1.00					

Note. Abbreviations included T1 = Time 1, T2 = Time 2.

[a]Variable derived from T1 Barriers Questionnaire-Juvenile Idiopathic Arthritis
[b]Time 1 Child Adherence Report Questionnaire item 1
[c]Time 1 Child Adherence Report Questionnaire item 2
[d]Subscale of Beliefs About Medications Scale – Patient questionnaire
[e]Variable derived from T2 Barriers Questionnaire-Juvenile Idiopathic Arthritis
[f]Time 2 Child Adherence Report Questionnaire item 1
[g]Time 2 Child Adherence Report Questionnaire item 2

* $p < 0.05$
** $p < 0.01$

Table 9. Hierarchical Linear Regression Model of Adherence (Pill Count).

					β Step 1			β Step 2			β Step 3		
Step	**R^2**	**ΔR^2**	***F*(df$_1$,df$_2$)**	***p***	**β**	***t***	***p***	**β**	***t***	***p***	**β**	***t***	***p***
Step 1	0.191	--	--	--									
Patient age					0.022	1.423	0.155	0.020	1.235	0.217	0.026	1.801	0.072
Father age					0.003	0.547	0.584	0.002	0.394	0.693	0.001	0.329	0.742
Family income					0.045	1.129	0.259	0.042	1.060	0.290	0.058	1.627	0.104
HI					<0.001	0.115	0.908	<0.001	0.104	0.917	<0.001	-0.066	0.947
Constant					0.209	0.785	0.432	0.219	0.817	0.414	0.274	1.142	0.254
Step 2	0.211	0.021	*F*(1,29) = 0.751	0.393									
MRCI								0.005	0.858	0.391	0.003	0.570	0.569
Step 3	0.391	0.180	*F*(1,28) = 8.316	0.007									
BQ-JIA											-0.025	-2.855	0.004

Note. Abbreviations included BQ-JIA = Barriers Questionnaire-Juvenile Idiopathic Arthritis total frequency of barriers experienced in the week prior to Time 1, HI = Hollingshead Index, MRCI = Medical Regimen Complexity Index.

Table 10. Most Commonly Endorsed Barriers by Patients and Parents at Time 1

	Patients		**Parents**	
Rank	Barriers Item	n (%) Endorsed	Barriers Item	n (%) Endorsed
1	Patient forgets	26 (74)	Parent was not there to remind patient	26 (74)
2	Parent was not there to remind patient	21 (60)	Patient forgets	22 (63)
3	Hard to take medication when not at home	17 (49)	Hard to take medication when not at home	12 (34)
4	Medication taste	15 (43)	Medication side effects	11 (31)
5	Patient resists injections	14 (40)	Medication taste - and - Patient does not understand need for medications	10 (29)

Table 11. Multiple Regression Model Testing Moderating Effect of Patient Age on the Relationship between Patient-reported Barriers and Adherence (Pill Count).

Predictor	**β**	***t***	***p***
Patient age†	0.027	1.941	0.052
BQ-JIA†	-0.022	-2.400	0.016
Patient age† x BQ-JIA†	0.006	1.331	0.183
Constant	0.823	28.379	<0.001

Note. Abbreviations included BQ-JIA = Barriers Questionnaire-Juvenile Idiopathic Arthritis total frequency of barriers experienced in the week prior to Time 1.

†Predictor was mean-centered.

Table 12. Multiple Regression Model Testing Moderating Effect of Patient Age on the Relationship between Parent-reported Barriers on Adherence (Pill Count).

Predictor	**β**	***t***	***p***
Patient age†	0.023	1.630	0.725
PBQ-JIA†	-0.017	-1.425	0.154
Patient age† x PBQ-JIA†	0.012	2.240	0.025
Constant	0.821	28.095	<0.001

Note. Abbreviations included PBQ-JIA = Parent Barriers Questionnaire-Juvenile Idiopathic Arthritis number of barriers experienced in the week prior to Time 1.

†Predictor was mean-centered.

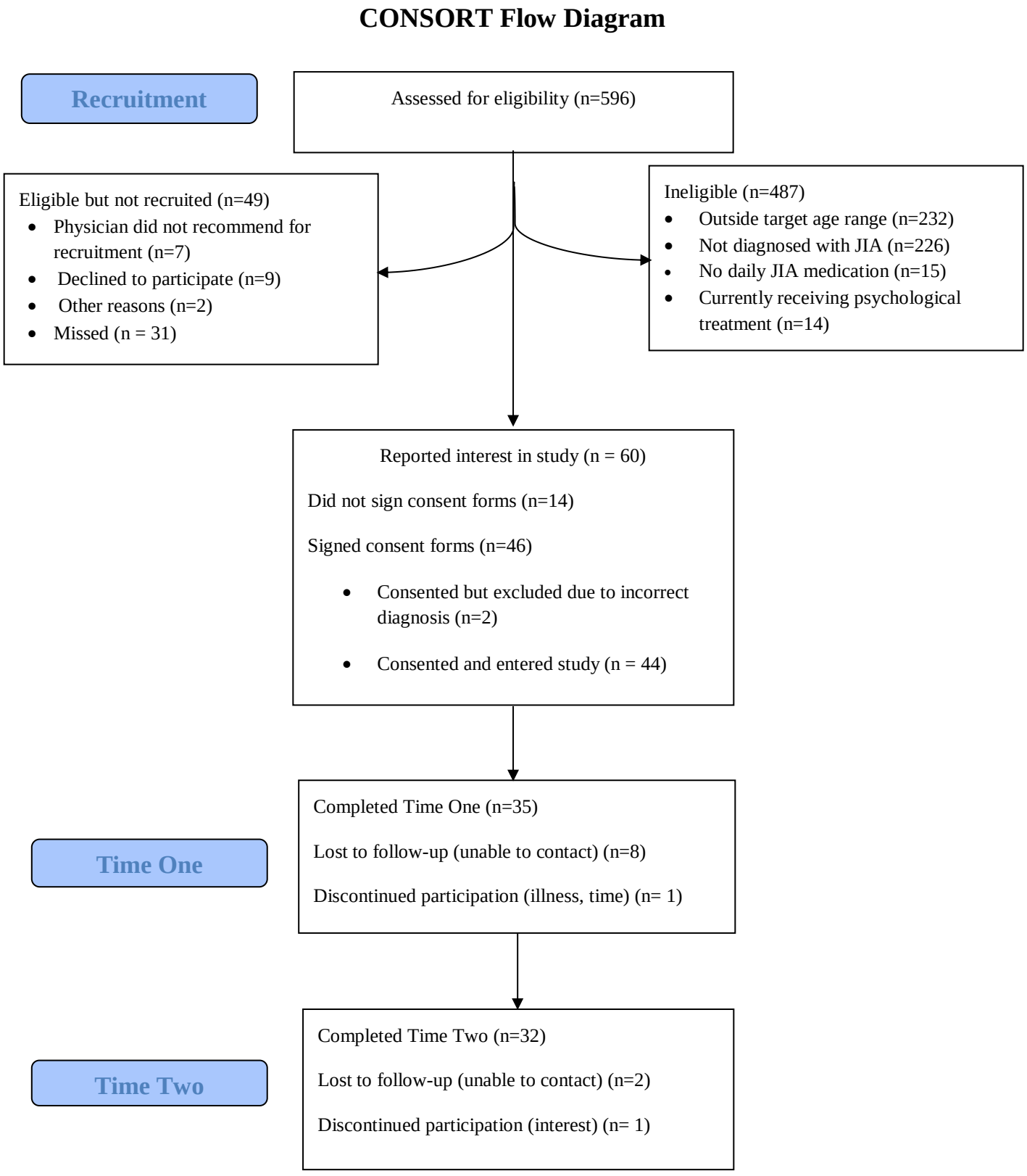

Figure 1. Consolidated Standards of Reporting Trials (CONSORT) diagram.

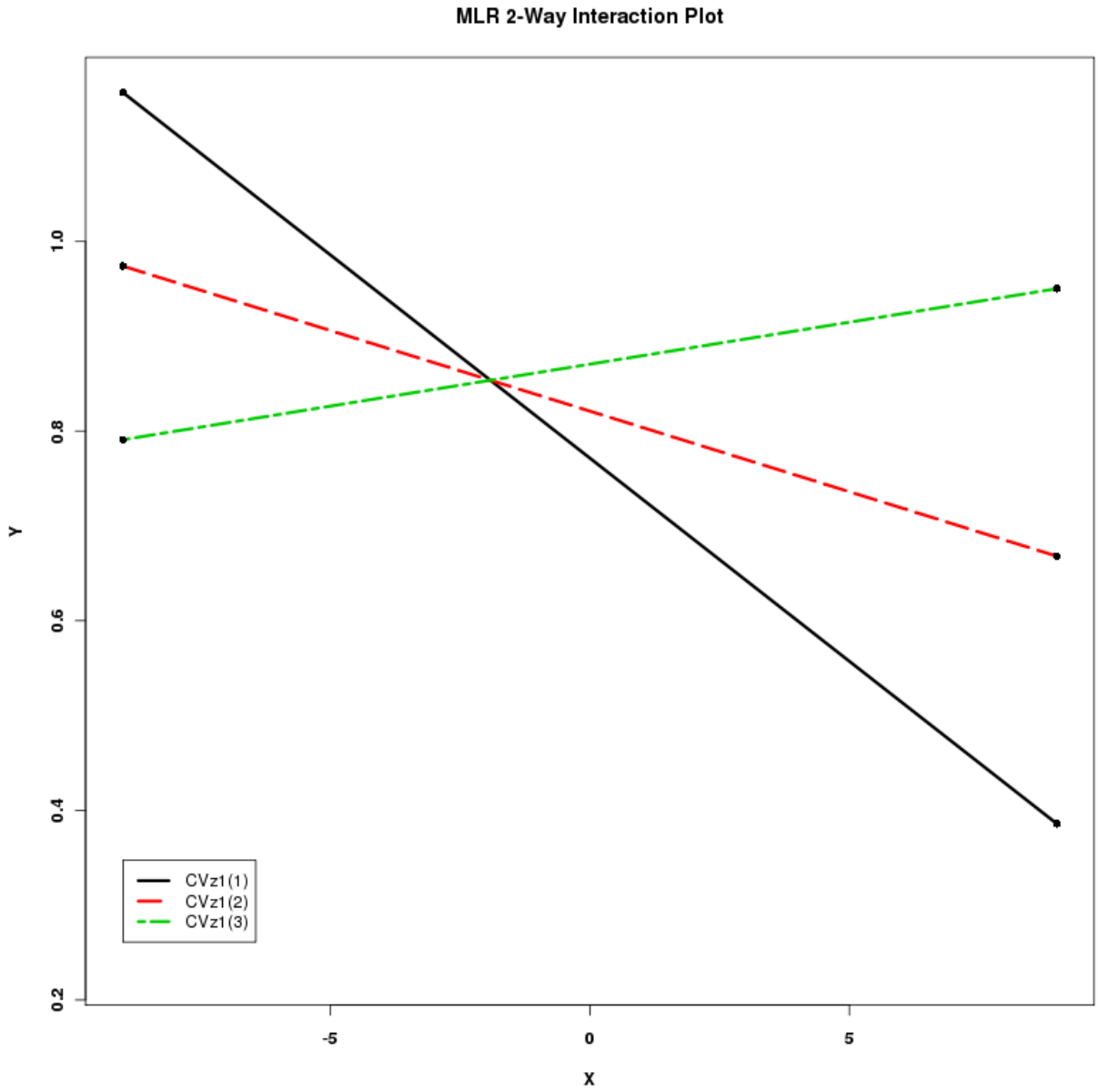

Figure 2. Patient age moderated the effect of parent-reported number of barriers experienced in the week prior to Time 1 on adherence measured by pill count (y-axis). Number of barriers (x-axis) was mean-centered, and simple slopes were plotted at patient ages 17.1 (*M* + 1 *SD*, green), 15.0 (*M*, red), and 12.8 (*M* – 1 *SD*, black) years. The interaction was plotted using the "Simple intercepts, simple slopes, and regions of significance in MLR 2-way interactions" online utility (Preacher, Curran, & Bauer; http://www.quantpsy.org/interact/mlr2.htm).

Appendix A

BQ – JIA[2]

Patients with arthritis or joint pain find it hard at times to be consistent in taking medications prescribed by their doctor. Below are some things (barriers) that make it hard for patients to be consistent in taking prescribed medications. Please look at the list of barriers and for each, tell us 1) if you have **ever** experienced this barrier (please circle "yes" or "no"), and, if so, 2) how often you experienced this in the **past seven days** (please circle one of the possible choices). Also, please write down any other barriers you have experienced that are not on the list.

Thank you very much for filling out this form.

		Have you **ever** experienced this?	How often did you experience this in the **past seven days**?
1.	I just forget when to take my medications	Yes / No	Never / sometimes / often
2.	It is too hard to take my medications when I am not at home	Yes / No	Never / sometimes / often
3.	I get confused about how many pills of each kind of medication to take	Yes / No	Never / sometimes / often
4.	I feel physically worse when I take the medications	Yes / No	Never / sometimes / often
5.	The pills are too hard for me to swallow	Yes / No	Never / sometimes / often
6.	My parent(s) is/are not always there to remind me to take my medications	Yes / No	Never / sometimes / often
7.	The medications taste bad	Yes / No	Never / sometimes / often
8.	I am not sure that I need the medications	Yes / No	Never / sometimes / often
9.	I started to feel better and did not need the medications anymore	Yes / No	Never / sometimes / often
10.	Several adults take care of me, and I am often in different places (daycare, school)	Yes / No	Never / sometimes / often
11.	I ran out of the medications	Yes / No	Never / sometimes / often
12.	The drug store ran out of the medications	Yes / No	Never / sometimes / often
13.	I try to avoid medications that involve injections	Yes / No	Never / sometimes / often
14.	Sometimes I just simply won't take the medications	Yes / No	Never / sometimes / often
15.	We did not refill my medications because we did not have enough money	Yes / No	Never / sometimes / often
16.	It is hard to fit taking medications into what I do every day	Yes / No	Never / sometimes / often
17.	I do not like the medications' side effects	Yes / No	Never / sometimes / often
18.	I do not understand why I need to take my medications when I am feeling well	Yes / No	Never / sometimes / often

Are there any other things that get in the way of taking medications that were not on this list? If yes, please write them down here.

[2] Matson, Rapoff, Lindsley, and Tsai (2011)

PBQ – JIA[3]

Parents of children with arthritis or joint pain find it difficult at times to help their children be consistent in taking medications prescribed by the doctor. Below are some things (barriers) that make it difficult to help children be consistent in taking prescribed medications. Please review the following list of barriers and for each, tell us 1) if you have **ever** encountered this barrier (please circle "yes" or "no"), and, if so, 2) how often you experienced this in the **past seven days** (please circle one of the possible choices). Also, please write down any other barriers you have experienced that are not on the list.

Thank you very much for filling out this form.

		Have you **ever** experienced this?	How often did you experience this in the **past seven days**?
1.	I just forget when to give my child medications	Yes / No	Never / sometimes / often
2.	It is too hard to give my child medications when we are not at home	Yes / No	Never / sometimes / often
3.	I get confused about how many pills of each kind to give to my child	Yes / No	Never / sometimes / often
4.	My child feels physically worse when he/she takes the pills	Yes / No	Never / sometimes / often
5.	The pills are too hard for my child to swallow	Yes / No	Never / sometimes / often
6.	I am not always there to remind my child to take medications	Yes / No	Never / sometimes / often
7.	My child says that the medication tastes bad	Yes / No	Never / sometimes / often
8.	I am not sure that my child needs medication	Yes / No	Never / sometimes / often
9.	My child started to feel better and did not need the medication anymore	Yes / No	Never / sometimes / often
10.	The child has multiple caregivers, and is often in different places (daycare, school, etc.)	Yes / No	Never / sometimes / often
11.	We ran out of medication	Yes / No	Never / sometimes / often
12.	The pharmacy ran out of medication	Yes / No	Never / sometimes / often
13.	My child resists medications that involve injections	Yes / No	Never / sometimes / often
14.	My child just simply refuses to take the medications	Yes / No	Never / sometimes / often
15.	I did not fill or refill my child's medications because I could not afford it	Yes / No	Never / sometimes / often
16.	It is hard to fit giving my child medications into the family's routine	Yes / No	Never / sometimes / often
17.	My child does not like the medications' side effects	Yes / No	Never / sometimes / often
18.	My child does not understand why he/she needs to take the medications when he/she is feeling well.	Yes / No	Never / sometimes / often

Are there any other things that get in the way of helping your child take medications that were not included in this list? If yes, please elaborate.

[3] Matson, Rapoff, Lindsley, and Tsai (2011)

Appendix B

Participant Demographics Form

Instructions: Please respond to the following questions by writing an "X" on the line next to the answer that best describes your family.

How are you related to the child who will be participating in this study?
_____ mother
_____ father
_____ grandparent
_____ other (please describe: _____)

With whom does the child live most of the time?
_____ mother
_____ father
_____ grandparent
_____ other (please describe: _____)

What is your current marital status?
_____ married
_____ single
_____ divorced

Please describe the occupations of both parents:
mother: _____ father: _____

What is the highest grade level completed by the child's **mother**?
_____ less than 7th grade
_____ junior high
_____ partial high school; what was the highest grade completed? _____
_____ high school graduate or GED
_____ some college or specialized training; how many years completed? _____
_____ college graduate; type of degree received? _____
_____ graduate/professional training; type of degree received? _____

What is the highest grade level completed by the child's **father**?
_____ less than 7th grade
_____ junior high
_____ partial high school; what was the highest grade completed? _____
_____ high school graduate or GED
_____ some college or specialized training; how many years completed? _____
_____ college graduate; type of degree received? _____
_____ graduate/professional training; type of degree received? _____

Gender of the child participating in the study:
_____ male
_____ female

Ethnicity of the child participating in the study:
_____ African American
_____ Asian American
_____ Caucasian
_____ Hispanic
_____ Other (please describe: _____)

Date of birth of the child participating in the study: _____

Age of child at time of diagnosis with Juvenile Idiopathic Arthritis: _____

Age of mother: _____ Age of father: _____

How many children are currently living in the household? _____
What are their ages? _____
How many are receiving treatment for chronic diseases? _____

Household income (yearly):
_____ less than $10,000
_____ $10,000 - $30,000
_____ $30,000 - $50,000
_____ $50,000 - $70,000
_____ $70,000 - $100,000
_____ more than $100,000

Appendix C

Hollingshead Revised Form (Wasser, 1992)

Hollingshead Index of Occupational Status Scale

(1) Farm Laborers/Menial Service Workers
(2) Unskilled Workers
(3) Machine Operators and Semiskilled Workers
(4) Smaller Business Owners, Skilled Manual Workers, Craftsmen, and Tenant Farmers
(5) Clerical and Sales Workers, Small Farm and Business Owners
(6) Technicians, Semiprofessionals, Small Business Owners
(7) Smaller Business Owners, Farm Owners, Managers, and Minor Professions
(8) Administrators, Lesser Professionals, Proprietors of Medium Sized Businesses
(9) Higher Executives, Proprietors of Large Businesses, and Major Professionals

Hollingshead Index Education Scale

(0) Less than High School (K-11)
(1) High School Degree or GED through partial college (12-15)
(2) Standard College Degree (16-17)
(3) Graduate Degree including Masters and Doctorate

Calculation

Parent #1	Scale Score	Factor Weight	Score x Weight
Occupation		X5	=
Education		X3	=
		Total score #1	=
Parent #2	Scale Score	Factor Weight	Score x Weight
Occupation		X5	=
Education		X3	=
		Total score #2	=
		Sum of Total Scores #1 & #2 (HI-R)	=

Appendix D

Parent Interview, Pill Count, and Medical Chart Review

Interview Questions

Time 1 Questions: Please list each of the medications currently prescribed for your child. For each medication, please tell me the prescribed dose (mg/mL, mg/pill, mL/syringe; AND how many mL, pills, or syringes per dosing time) and the prescribed dosing frequency (e.g., two times per day, once in two weeks). Also, please count the total number of pills (or the exact volume in mL or number of syringes) left of each medication. Have there been any changes to your child's prescribed medication regimen in the last three weeks, regarding type of medication, dosage, and/or dosing frequency? If so, what and when was this change made?

Time 2 Questions: We are going to review the medication(s) prescribed for your child that you listed previously. For each medication, please let me know if there have been any changes in dose or dosing frequency within the last two weeks, as well as the date on which these changes were made. Please tell me of any medications that your child's doctor stopped prescribing or has recently added. Also, please count the total number of pills (or the exact volume in mL or number of syringes) left of each medication.

Record from patient's medical chart: Currently prescribed medications along with their doses and dosing frequencies.

	Time 1: Date _____, Interviewer _____		Chart: Date_____, Reviewer_____	Time 2: Date _____, Interviewer _____		Chart: Date _____, Reviewer _____	Adherence Calculation:
#	Med Name, Dose, Dosing Frequency, and Form:	# of Pills (or Vol or syringes): (A)	Med Name/Class, Dose, Dosing Frequency, and Form:	Recent changes? (date; record new dose/freq)	# of Pills (or Vol or syringes): (B)	Med Name, Dose, Dosing Frequency, and Form:	[(A) – (B)] / (rx # pills)
1							
2							
3							
4							

	Time 1: Date _____, Interviewer _____		Chart: Date_____, Reviewer_____	Time 2: Date _____, Interviewer _____		Chart: Date_____, Reviewer_____	Adherence Calculation:
#	Med Name, Dose, Dosing Frequency, and Form:	# of Pills (or Vol or syringes): (A)	Med Name/Class, Dose, Dosing Frequency, and Form:	Recent changes? (date; record new dose/freq)	# of Pills (or Vol or syringes): (B)	Med Name, Dose, Dosing Frequency, and Form:	[(T1 # pills) – (T2 # pills)] / (rx # pills)
5							
6							
7							
8							
9							
10							

*Note: if there is a discrepancy between parent-reported and chart note recorded prescription information, verify with Judy Morris, R.N. what the currently prescribed medication regimen is and communicate this to the parent.

Additional information from medical charts

Patient age at time of JIA diagnosis: _____
Specific JIA diagnosis: _____
Current symptom severity (# of active joints): _____

Appendix E

Medication Regimen Complexity Index (MRCI)

George, Phun, Bailey, Kong, & Stewart (2004)

Total no. of medications (including prn/sos medications): _____

Instructions

1. MRCI applies only to prescribed medications. All entries are to be made only based on information on the label or drug chart (at the time of dispensing or discharge). No assumptions are to be made based on clinical judgment.
2. There are three sections in the scale. Complete each section before proceeding to the next. At the end, add the scores for the three sections to give the MRCI.
3. If the same medication (same brand and same dosage form) is present more than once in different strengths in a regimen (e.g., Marevan 5mg, 3mg, and 1mg mdu), it is still considered as one medication.
4. In cases where the dosage is optional, choose the dosing instruction with the smallest dose/frequency. (e.g., Ventolin MDI 1-2 puffs, 2-3 times daily will get weightings for 'metered dose inhalers', 'variable dose' and 'twice daily'; but not for 'multiple units at one time')
5. In certain cases the dosing frequency needs to be calculated (e.g., Ranitidine 1 mane and 1 nocte is 1 twice daily)
6. It is possible that with certain 'used as directed' instructions, the regimen will not get a score under dosing frequency (e.g., Prednisolone 5mg mdu)
7. If there is more than one dosing frequency direction, they should be scored for all the dosing frequency directions (e.g., Ventolin MDI 2 puffs bd and prn, will get scores for 'metered dose inhalers', 'multiple units at one time', 'twice daily' as well as 'prn')
8. Instances where two or more medications are mutually exclusive, they need to be scored twice or more as prn with the recommended dosing frequency (e.g., Ventolin MDI or Ventolin nebulizer twice daily will get scores for both 'metered dose inhalers' and 'nebuliser' under dosage forms, but needs to be scored two times for 'twice daily prn')
9. In cases where there is no matching option, choose the closest option (e.g., six times daily could be considered as 'q4h')

[A] Circle the weighting corresponding to each dosage form (ONCE ONLY) present in the regimen.

Dosage Forms		Weighting
ORAL	Capsules/Tablets	1
	Gargles/Mouthwashes	2
	Gums/Lozenges	2
	Liquids	2
	Powders/Granules	2
	Sublingual sprays/tabs	2
TOPICAL	Creams/Gels/Ointments	2
	Dressings	3
	Paints/Solutions	2
	Pastes	3
	Patches	2
	Sprays	1
EAR, EYE & NOSE	Ear drops/creams/ointments	3
	Eye drops	3
	Eye gels/ointments	3
	Nasal drops/cream/ointment	3
	Nasal spray	2
INHALATION	Accuhalers	3
	Aerolizers	3
	Metered dose inhalers (MDI)	4
	Nebuliser	5
	Oxygen/Concentrator	3
	Turbohalers	3
	Other DPIs (dry powder inhaler)	3
OTHERS	Dialysate	5
	Enemas	2
	Injections: Prefilled Ampoules/Vials	3 4
	Pessaries	3
	Patient controlled analgesia	2
	Suppositories	2
	Vaginal creams	2
	Total for Section A	

[B] For each medication in the regimen tick a box [√] corresponding to the dosing frequency. Then, add the no. of [√] in each category and multiply by the assigned weighting. In cases where there is no exact option, choose the best option.

Dosing Frequency	Medications														Total	Weighting	Weighting x No. of meds
Once daily																1	
Once daily prn																0.5	
Twice daily																2	
Twice daily prn																1	
Three times daily																3	
Three times daily prn																1.5	
Four times daily																4	
Four times daily prn																2	
q12h																2.5	
q12h prn																1.5	
q 8h																3.5	
q 8h prn																2	
q 6h																4.5	
q 6h prn																2.5	
q 4h																6.5	
q 4h prn																3.5	
q 2h																12.5	
q 2h prn																6.5	
prn/sos																0.5	
On alternate days or less frequently																2	
Oxygen prn																1	
Oxygen <15hrs																2	
Oxygen >15hrs																3	
															Total for Section C		

[C] Tick a box [√] corresponding to the additional directions, if present in the regimen. Then, add the no. of [√] in each category and multiply by the assigned weighting.

Additional Directions	Medications								Total	Weighting	Weighting x No. of meds
Break or crush tablet										1	
Dissolve tablet/powder										1	
Multiple units at one time (e.g., 2 tabs, 2 puffs)										1	
Variable dose (e.g., 1-2 caps, 2-3 puffs)										1	
Take/use at specified time/s (e.g., mane, nocte, 8 AM)										1	
Relation to food (e.g., pc, ac, with food)										1	
Take with specific fluid										1	
Take/use as directed										2	
Tapering/increasing dose										2	
Alternating dose (e.g., one mane & two nocte, one/two on alternate days)										2	
									Total for Section C		

Total for Section A	
Total for Section B	
Total for Section C	
Medication Regimen Complexity (sum)	

Appendix F

CARQ-JIA[4]

1. Place a vertical mark (|) on the line below where it best represents how hard you found it to take your medication(s) **in the past week:**

Very easy Very hard

2. Place a vertical mark (|) on the line below where it represents the best how often you took your medication(s) **in the past week:**

Never Always

[4] Adapted from De Civita, Dobkin, Ehrmann-Feldman, Karp, and Duffy (2005)'s Child Adherence Report Questionnaire – Juvenile Idiopathic Arthritis. The original item stems referred to medications, exercises, and splint wearing and were modified to refer only to medications for this measure.

PARQ-JIA[5]

1. Please place a single vertical mark (|) on the line below at the level which best describes your child's general level of difficulty in taking his/her medication(s) **in the past week:**

Very easy Very hard

2. Please place a single vertical mark (|) on the line below at the level which best describes how often your child followed treatment recommendations as prescribed (i.e., dosage, frequency) by the health care provider **in the past week:**

Never Always

[5] Adapted from De Civita, Dobkin, Ehrmann-Feldman, Karp, and Duffy (2005)'s Parent Adherence Report Questionnaire – Juvenile Idiopathic Arthritis. The original item stems referred to medications, exercises, and splint wearing and were modified to refer only to medications for this measure. Also, item stems were changed from "past three months" to "past week" to match child version's stem

Appendix G

Beliefs About Medication Scale – Patient Form[6]

Please rate how much you agree or disagree with each statement using the following rating scale:

(1) Disagree Completely	(2) Disagree Mostly	(3) Disagree a Little	(4) Neither Agree nor Disagree	(5) Agree a Little	(6) Agree Mostly	(7) Agree Completely

1. My friends think I should take my medicine the way the doctor says I should……. (1) (2) (3) (4) (5) (6) (7)
2. When I take my medicine the way the doctor says I should, I feel like I am doing something good for my health……. (1) (2) (3) (4) (5) (6) (7)
3. I do not think my illness is a serious illness…….... (1) (2) (3) (4) (5) (6) (7)
4. If I take my medicine the way the doctor says I should, it gets in the way of me living my life the way I want…….(1) (2) (3) (4) (5) (6) (7)
5. The side effects of my medicine are so bad that I do not want to take it……..…… (1) (2) (3) (4) (5) (6) (7)
6. My illness gets in the way of finishing my school work……..……..…… (1) (2) (3) (4) (5) (6) (7)
7. I worry about health problems I might have if I do not take my medicine the way I should……..…. (1) (2) (3) (4) (5) (6) (7)
8. I am sure that I can take my medicine the way the doctor says I should……..…. (1) (2) (3) (4) (5) (6) (7)
9. If I do not take my medicine the way I should, I will get sicker……...…. (1) (2) (3) (4) (5) (6) (7)
10. I worry that my illness may get in the way of me doing the things I want to do in the future…...…. (1) (2) (3) (4) (5) (6) (7)
11. If I take my medicine the way the doctor says I should, it makes me feel sicker……...…. (1) (2) (3) (4) (5) (6) (7)
12. As long as I feel well, my illness is not a problem……. (1) (2) (3) (4) (5) (6) (7)
13. It is often annoying for me to take my medicine the way the doctor says I should…….... (1) (2) (3) (4) (5) (6) (7)
14. Even if I got sicker, it would not change my life very much…… (1) (2) (3) (4) (5) (6) (7)
15. My family thinks I should take my medicine the way the doctor says I should……...…. (1) (2) (3) (4) (5) (6) (7)
16. It is embarrassing for me to take my medicine in front of people I do not know well……. (1) (2) (3) (4) (5) (6) (7)
17. It is stressful to take my medicine the way the doctor says I should……. (1) (2) (3) (4) (5) (6) (7)
18. I worry about getting sicker than I am right now……...…. (1) (2) (3) (4) (5) (6) (7)
19. My illness gets in the way of me having fun with my friends……..…. (1) (2) (3) (4) (5) (6) (7)
20. People in my life care if I take my medicine the way I should……. (1) (2) (3) (4) (5) (6) (7)
21. It takes too much time to take my medicine the way the doctor says I should……. (1) (2) (3) (4) (5) (6) (7)
22. I worry less about my health if I take my medicine the way I should……...…. (1) (2) (3) (4) (5) (6) (7)
23. My illness gets in the way of me doing things I want to do……..…. (1) (2) (3) (4) (5) (6) (7)
24. I am sure that I can take my medicine the way the doctor says I should even if there are other things I want to do..…….(1) (2) (3) (4) (5) (6) (7)
25. If I do not take my medicine the way I should, I could die……...…. (1) (2) (3) (4) (5) (6) (7)
26. I feel different from other children/teenagers because I have to take medicine……..…… (1) (2) (3) (4) (5) (6) (7)
27. It is easy for me to take my medicine the way the doctor says I should……..…… (1) (2) (3) (4) (5) (6) (7)
28. I feel pressure from my friends to skip taking my medicine……. (1) (2) (3) (4) (5) (6) (7)

[6] © Riekert & Drotar (2002)

Please rate how much <u>you</u> agree or disagree with each statement using the following rating scale:

(1) Disagree Completely	(2) Disagree Mostly	(3) Disagree a Little	(4) Neither Agree nor Disagree	(5) Agree a Little	(6) Agree Mostly	(7) Agree Completely

29. Other people with my illness get very sick even if they take their medicine the way the doctor says they should..……..…….(1) (2) (3) (4) (5) (6) (7)
30. I have a lot to gain from taking my medicine the way the doctor says I should…….(1) (2) (3) (4) (5) (6) (7)
31. Taking my medicine the way I should makes me miss out on doing fun things……....(1) (2) (3) (4) (5) (6) (7)
32. I am sure that I can take my medicine the way the doctor says I should even when my life is stressful..……...……..…….(1) (2) (3) (4) (5) (6) (7)
33. It upsets me to have to take medicine…….(1) (2) (3) (4) (5) (6) (7)
34. Even if people pressure me to skip a dose of my medicine, I will still take it……...…….(1) (2) (3) (4) (5) (6) (7)
35. If I take my medicine the way the doctor says I should, it will keep me from getting sicker…….(1) (2) (3) (4) (5) (6) (7)
36. I want to take my medicine the way the doctor says I should because it matters to people I care about..……...……..……...…….(1) (2) (3) (4) (5) (6) (7)
37. When I think about my illness I feel scared……...…….(1) (2) (3) (4) (5) (6) (7)
38. I do not feel better even when I take my medicine the way the doctor says I should…….(1) (2) (3) (4) (5) (6) (7)
39. My family helps me take my medicine the way the doctor says I should……...……....(1) (2) (3) (4) (5) (6) (7)
40. The good things that come from taking my medicine the way I should make the side effects worth it..……...……..……...…….(1) (2) (3) (4) (5) (6) (7)
41. If I take my medicine the way the doctor says I should, it helps keep me feeling well…..…….(1) (2) (3) (4) (5) (6) (7)
42. My illness gets in the way of me getting along with my family…….(1) (2) (3) (4) (5) (6) (7)
43. I miss a lot of school because of my illness……...…….(1) (2) (3) (4) (5) (6) (7)
44. Taking my medicine will keep me from having to go to the hospital…….(1) (2) (3) (4) (5) (6) (7)
45. Friends who are important to me care if I take my medicine…….(1) (2) (3) (4) (5) (6) (7)
46. I get out of doing things I do not want to do because I have to take medicine……..…….(1) (2) (3) (4) (5) (6) (7)
47. Taking my medicine the way the doctor says I should puts me in a bad mood……..……....(1) (2) (3) (4) (5) (6) (7)
48. My family knows if I take my medicine the way the doctor says I should……..……..…….(1) (2) (3) (4) (5) (6) (7)
49. When I take my medicine the way I should, I feel well enough to do things I enjoy…….……....(1) (2) (3) (4) (5) (6) (7)
50. I think I will become sicker than I am right now…….……..…….(1) (2) (3) (4) (5) (6) (7)
51. My friends help me take my medicine the way the doctor says I should……...…….(1) (2) (3) (4) (5) (6) (7)
52. If I take my medicine the way I should, I miss fewer days of school……...…….(1) (2) (3) (4) (5) (6) (7)

Beliefs About Medication Scale – Parent Form[7]

Please rate how much you agree or disagree with each statement using the following rating scale:

(1)	(2)	(3)	(4)	(5)	(6)	(7)
Disagree Completely	Disagree Mostly	Disagree a Little	Neither Agree nor Disagree	Agree a Little	Agree Mostly	Agree Completely

1. My friends think my child should take the medicine the way the doctor says he/she should…..……. (1) (2) (3) (4) (5) (6) (7)
2. If my child takes the medicine the way the doctor says he/she should, My child feels like he/she is doing something good for his/her health……...……. (1) (2) (3) (4) (5) (6) (7)
3. I do not think my child's illness is a serious illness…….... (1) (2) (3) (4) (5) (6) (7)
4. If my child takes the medicine the way the doctor says he/she should, it gets in the way of him/her living life the way he/she wants…..…….(1) (2) (3) (4) (5) (6) (7)
5. The side effects of the medicine are bad enough that I do not want my child to take them…….…… (1) (2) (3) (4) (5) (6) (7)
6. My child's illness gets in the way of his/her finishing school work…….…….. (1) (2) (3) (4) (5) (6) (7)
7. I worry about the health problems that my child might have if he/she does not take the medicine the way he/she should…….....…. (1) (2) (3) (4) (5) (6) (7)
8. I am sure that my child can take the medicine the way the doctor says he/she should……...…. (1) (2) (3) (4) (5) (6) (7)
9. If my child does not take the medicine the way he/she should, he/she will get sicker……..……..…. (1) (2) (3) (4) (5) (6) (7)
10. I worry that my child's illness may get in the way of him/her doing the things he/she wants to do in the future…….....…. (1) (2) (3) (4) (5) (6) (7)
11. If my child takes the medicine the way the doctor says he/she should, it makes him/her feel sicker... (1) (2) (3) (4) (5) (6) (7)
12. As long as my child feels well, his/her illness is not a problem……..……. (1) (2) (3) (4) (5) (6) (7)
13. It is often inconvenient for my child to take the medicine the way the doctor says he/she should….. (1) (2) (3) (4) (5) (6) (7)
14. Even if my child got sicker, it would not change his/her life very much……..……. (1) (2) (3) (4) (5) (6) (7)
15. My family thinks my child should take the medicine the way the doctor says he/she should……... (1) (2) (3) (4) (5) (6) (7)
16. It is embarrassing when my child has to take the medicine in front of people we do not know well… (1) (2) (3) (4) (5) (6) (7)
17. It is stressful to help my child to take the medicine the way the doctor says he/she should.…… (1) (2) (3) (4) (5) (6) (7)
18. I worry about my child becoming sicker than he/she is right now…….……..…. (1) (2) (3) (4) (5) (6) (7)
19. My child's illness gets in the way of him/her having fun with friends……...…..…. (1) (2) (3) (4) (5) (6) (7)
20. People in my life care if my child takes the medicine ……..…. (1) (2) (3) (4) (5) (6) (7)
21. It takes too much time for my child to take the medicine the way the doctors tell us he/she should… (1) (2) (3) (4) (5) (6) (7)
22. I worry less about my child's health if he/she takes the medicine the way he/she should……...…. (1) (2) (3) (4) (5) (6) (7)
23. My child's illness gets in the way of him/her doing things he/she wants to do……...…. (1) (2) (3) (4) (5) (6) (7)
24. I am sure that my child will be able to take the medicine the way the doctor says he/she should even if there are other things he/she wants to do..…….…….(1) (2) (3) (4) (5) (6) (7)
25. If my child does not take the medicine the way he/she should, he/she could die……..……...…. (1) (2) (3) (4) (5) (6) (7)
26. My child feels different from other children/teenagers because he/she has to take medicine…..…… (1) (2) (3) (4) (5) (6) (7)
27. It is easy for my child to take the medicine the way he/she should…….....…..…. (1) (2) (3) (4) (5) (6) (7)
28. I feel pressure from my friends to let my child skip doses of the medicine……..…. (1) (2) (3) (4) (5) (6) (7)

[7] Riekert & Drotar (2000)

Please rate how much <u>you</u> agree or disagree with each statement using the following rating scale:

(1) Disagree Completely	(2) Disagree Mostly	(3) Disagree a Little	(4) Neither Agree nor Disagree	(5) Agree a Little	(6) Agree Mostly	(7) Agree Completely

29. Other people with my child's illness get very sick even if they take their medicine the way the doctor says he/she should..…….(1) (2) (3) (4) (5) (6) (7)
30. My child has a lot to gain if he/she takes the medicine the way the doctor says he/she should…….(1) (2) (3) (4) (5) (6) (7)
31. I feel like having to take medicine the way he/she should makes my child miss out on doing fun things……...……....(1) (2) (3) (4) (5) (6) (7)
32. I am sure that my child will be able to take the medicine the way the doctor says he/she should even when his/her life is stressful..……...…….(1) (2) (3) (4) (5) (6) (7)
33. It upsets me that my child to have to take medicine……...…….(1) (2) (3) (4) (5) (6) (7)
34. Even if people pressure my child to skip a dose of the medicine, he/she will take it…….(1) (2) (3) (4) (5) (6) (7)
35. If my child takes the medicine the way he/she should, it will keep him/her from getting sicker……...(1) (2) (3) (4) (5) (6) (7)
36. I want my child to take the medicine the way the doctor says he/she should because it is important to people I care about..……...……...……. …….(1) (2) (3) (4) (5) (6) (7)
37. When I think about my child's illness I feel scared……...…….(1) (2) (3) (4) (5) (6) (7)
38. My child does not feel better even when he/she takes the medicine the way the doctor says he/she should…….…….(1) (2) (3) (4) (5) (6) (7)
39. My family provides me support to help my child take the medicine the way the doctor says he/she should……...……...…....(1) (2) (3) (4) (5) (6) (7)
40. The good things that come from my child taking medicine the way he/she should make the side effects worth it..……...……...……...……...…….(1) (2) (3) (4) (5) (6) (7)
41. If my child takes the medicine the way the doctor says he/she should, it helps keep him/her feeling well……..…….(1) (2) (3) (4) (5) (6) (7)
42. My child's illness gets in the way of my child getting along with the family…...…….(1) (2) (3) (4) (5) (6) (7)
43. My child misses a lot of school because of his/her illness…….…….(1) (2) (3) (4) (5) (6) (7)
44. Taking his/her medicine will keep my child from having to go to the hospital…….…….(1) (2) (3) (4) (5) (6) (7)
45. Friends who are important to me care if my child takes the medicine…….……...…….(1) (2) (3) (4) (5) (6) (7)
46. My child gets out of doing things he/she does not want to do because he/she has to take medicine….(1) (2) (3) (4) (5) (6) (7)
47. Taking his/her medicine the way the doctor says he/she should puts my child in a bad mood…….....(1) (2) (3) (4) (5) (6) (7)
48. My family notices if my child takes the medicine ……...……...…….(1) (2) (3) (4) (5) (6) (7)
49. When my child takes the medicine the way he/she should he/she feels well enough to do things he/she enjoys…….…….(1) (2) (3) (4) (5) (6) (7)
50. I think my child will become sicker than he/she is right now…….……...…….…….(1) (2) (3) (4) (5) (6) (7)
51. My friends help me help my child take his/her medicine the way the doctor says he/she should……..(1) (2) (3) (4) (5) (6) (7)
52. If my child takes the medicine the way he/she should, he/she misses fewer days of school……..(1) (2) (3) (4) (5) (6) (7)