

Chapter 1 : Adherence to Pediatric Medical Regimens - Michael A. Rapoff - Google Books

This updated edition of Adherence to Pediatric Medical Regimens is an essential reference for anyone concerned with improving health outcomes in young people, especially clinicians, researchers, and graduate students in psychiatry as well as pediatric, clinical child, and health psychology.

Advanced Search Abstract Objective: To review empirical studies of psychological interventions for nonadherence to medical regimens for three chronic illnesses: For asthma, organizational strategies appear probably efficacious in promoting adherence, whereas educational and behavioral strategies appear promising. For JRA, behavioral strategies appear probably efficacious in improving adherence. For type 1 diabetes, multicomponent packages and operant learning procedures appear probably efficacious, whereas cognitive-behavioral strategies appear promising. These reports focus on identifying factors associated with nonadherence e. Many papers also describe intervention strategies to promote adherence, but few empirical studies address the actual implementation and evaluation of these strategies. This article will review available intervention studies targeting nonadherence to regimens for three pediatric chronic illnesses: These three illnesses were chosen because of their frequency of occurrence in children and adolescents, the range of adherent behaviors involved in the respective medical regimens, and the need to follow these regimens over an extended period of time. We summarize the prevalence of nonadherence, correlates of nonadherence, and possible intervention strategies, and we present an overview of the medical characteristics and treatments for these illnesses. The intervention studies for each illness will then be examined using a set of criteria developed by the American Psychological Association Task Force on Promotion and Dissemination of Psychological Procedures, headed by Diane Chambless Task Force, This definition not only delineates a range of adherent behaviors e. Nonadherence is also related to escalated health care utilization rates e. Correlates of Nonadherence Identified factors related to nonadherence to medical regimens can be placed into one of three categories: Regimen Characteristics Examples of regimen characteristics correlated with nonadherence include longer duration of the regimen, complexity of the medical regimen e. Inconsistent supervision by physicians and parents is also related to nonadherence in youths with chronic illnesses. Disease Characteristics Disease characteristics associated with nonadherence consist of asymptomatic periods, younger age at illness onset, and illness severity as perceived by the family. Premorbid behavioral and emotional problems e. These characteristics are based on correlational analyses or between-group differences in adherent versus nonadherent youths and families and, therefore, cannot be considered causative. Intervention Strategies Intervention strategies to improve adherence stem from clinical experience and research. These strategies can be grouped into one of three categories: Educational Strategies Educational strategies focus on providing verbal and written instructions to inform youths and their parents about the nature of the illness and its management. Instructions center on giving families factual information about the illness and the regimen requirements, explaining the importance of adherence, and advising families in advance about potential negative side effects of prescribed recommendations. Organizational Strategies Organizational strategies emphasize changing clinic and regimen characteristics as a means of promoting adherence. These strategies include, for example, simplifying regimens, increasing supervision by health care providers, improving clinic convenience e. Behavioral Strategies Behavioral strategies target specific adherent behaviors by incorporating visual reminders e. Encouraging parental support and dispensing incentives for adherence are also examples of behavioral strategies. Finally, clinical interventions directed toward modifying behavioral and emotional difficulties displayed by youths e. However, the confounding influence of economic status on biological predisposition in these groups is not clear Litonjua et al. Asthma is defined as a chronic inflammation disorder that causes airflow obstruction, which is often reversible either spontaneously or with treatment, and bronchial hyperresponsiveness National Institutes of Health, The first component of the definition entails the hallmark characteristics of asthma: The other two components of the definitionâ€”hyperresponsivity and airway inflammationâ€”are more recent defining characteristics. Inflammation produces further obstruction as the airway membranes swell and secrete excess mucus. Hyperresponsiveness and inflammation may occur in

response to a variety of environmental and internal stimuli, such as allergens e. Hyperresponsiveness seems to be attributable to the following factors: Inflammation in the airways also appears to be related to an interplay among inflammatory cells, mediators e. In general, both genetics the strongest identified factor and the environment are predisposing factors for the development of asthma Report, To achieve these goals, regimen requirements for asthma consist of medications, lifestyle changes emphasizing environmental control, and management of crisis National Institutes of Health, ; Young, Medications are prescribed to both manage and to prevent asthma attacks, whether these attacks are episodic, recurrent, or exercise-induced. The medications most often administered consist of bronchodilators, anti-inflammatory medicines, and steroids given on an intermittent or daily basis and are taken orally or inhaled. In terms of environmental control, youths and their families are instructed on how to reduce exposure to known triggers of asthma attacks, such as by avoiding animals, eliminating tobacco smoke and bedroom carpeting, and using air-conditioners and dehumidifiers. Immunotherapy allergy shots is also recommended if allergens are constant or can not be avoided, as with perennial indoor allergens. Management of a crisis or status asthmaticus usually requires administration of oxygen and varying combinations of medications, including injections of epinephrine or terbutaline, inhaled B-2 adrenergic agonists, theophylline IV, and methylprednisolone IV. Nonadherence usually involves failure to avoid allergens or irritants, underuse daily, or intermittent medications. In addition, appointments may be missed for scheduled allergy shots. The overall gender ratio for JRA is 2: Related medical complications that typically occur include ocular difficulties, abnormalities of growth and development, and infections Woo, JRA is divided into three basic types: It involves periodic fever spikes that appear over several days at a time, fatigue, minimal appetite, and anemia. The number of joints involved, and the severity of this involvement, varies widely among youths. Polyarticular onset JRA is characterized by the involvement of five or more joints, prolonged tiredness, minimal appetite, and low-grade fevers. In pauciarticular onset JRA, four or fewer joints are involved, with the knees and ankles the most common joints affected. However, spontaneous remission of pauciarticular JRA is rather standard. These goals are achieved through a combination of medications, physical therapy and occupational therapy, lifestyle changes e. Nonsteroidal anti-inflammatory drugs, such as ibuprofen, naproxen, and aspirin, are currently the medication of choice for managing and reducing inflammation, swelling, and pain. Prednisone, an anti-inflammatory drug, may also be given when nonsteroidal medications are not effective in controlling inflammation. Finally, antirheumatic medications, including gold hydroxychloroquine, sulfasalazine, and intravenous immunoglobulins, are prescribed for inflammation. Physical therapy and occupational therapy sessions are recommended to decrease pain, minimize deformity and disability, and retain function. Few reports exist on nonadherence rates in youths with JRA, either in terms of ingesting medication or exercising and wearing splints. Type 1 Diabetes Type 1 diabetes occurs in 1. Type 1 diabetes is characterized by an absence of insulin due to pancreatic failure Johnson, This insulin deficiency produces high blood glucose levels hyperglycemia , which cannot be used by cells for energy or fat and protein synthesis. As insulin levels fall, glycerol and free fatty acids are converted to ketones, which collect in the bloodstream along with glucose. Associated symptoms include extreme fatigue, weight loss with adequate consumption of food, and frequent urination polyuria and drinking polydipsia. In general, eradication of insulin-producing islet cells within the pancreas is an autoimmune process Eisenbarth, ; Johnson, Daily injections of exogenous insulin are required to treat the hyperglycemia. The duration of this period seems related to age at diagnosis in that the destruction of islet cells has occurred for a shorter time in older patients. Regimen requirements consist of multicomponents including medications, lifestyle changes, such as dietary adherence and exercise prescriptions, and management of crisis of insulin reactions. Subcutaneous injections of insulin are used to regulate blood glucose levels. Blood glucose levels should be monitored at least twice a day because of fluctuations over the course of a day. As such, monitoring typically occurs before all meals and bedtime using commonly available reagent strips and meters. Dietary guidelines are prescribed, including eating at least three meals and three snacks per day and avoiding or limiting sweets, whole milk, and fried or salty foods. Finally, regular aerobic activity is recommended so that glucose can be used for energy and to increase the efficiency of insulin receptors. Careful monitoring of blood glucose levels is mandatory due to the need for adjusting insulin doses based on the interaction among diet, exercise, illness,

and stress Johnson, Intervention Studies The studies in this review were selected following literature searches using Psych Lit and Medlines. Articles were included if they met the following criteria: Information from 8 articles on asthma, 4 on JRA, and 11 on diabetes was obtained that met these criteria. Outcome studies on asthma education programs were not included in this review because they were not designed to specifically target nonadherence and were not selective in recruiting children based on their level of adherence. In addition, studies that focused specifically on teaching regimen requirements e. The effectiveness of the interventions described in these studies was examined according to criteria proposed by the Chambless Task Force and modified by the Society of Pediatric Psychology Task Force SPP Spirito, To be considered a well-established treatment, an intervention must have been tested in at least two randomized group designs that showed superiority over a psychological placebo or alternative treatment with adequate statistical power about 30 per group. A large series of well-designed single-case experiments that compared the intervention to another treatment would also be acceptable. Further criteria for well-established treatments were that treatments must be manualized, samples must be adequately described, and effects must demonstrated by at least two independent research groups. Probably efficacious treatments require 1 two or more group intervention studies displaying superiority over a waiting list control group or 2 one study meeting criteria for a well-established intervention. A third category was added by the SPP Task Force, promising interventions, with the following criteria: Additional modifications to the Chambless criteria included 1 a specified treatment protocol could replace a manual, 2 the number for chronic illness groups could be smaller than 30, and 3 two multiple baseline designs by independent investigators would be evidence for a well-established treatment. Chambless Criteria Asthma Appendix I presents the sample characteristics, the diagnostic criteria, experimental design, assessment measures, treatment protocols, and outcomes of eight studies examining adherence to medical regimens for pediatric asthma. These eight studies are diverse in terms of methodology, including a single-subject design i. These studies have included a fairly equal number of males and females, with typically moderate or severe asthma, who are on daily medications to prevent asthma attacks. The age range of participants has been extreme i. For most studies the procedures followed to ensure participants were diagnosed with asthma were clear, but only one study da Costa et al. The studies used a variety of methods to assess medication adherence e. Unfortunately, the combinations of assessment methods and outcome variables in these studies were so divergent that any type of comparison is not possible. Educational, organizational, and behavioral strategies have been used alone and in combination in studies pertaining to adherence and pediatric asthma. One study relied exclusively on organizational strategies to affect adherence rates i. The studies by da Costa et al. The remaining two studies implemented a multicomponent treatment program consisting of educational, organizational, and behavioral strategies to increase adherence rates and optimize functioning in other areas. The educational component in these studies usually entailed verbal and written information given to parents and youths about asthma, asthma medications, management of asthma symptoms, and the importance of adherence. The study by LeBaron et al.

Chapter 2 : Pediatric Patients, Parents Overreport Adherence to ALL Medication Regimen - ONA

Adherence has been defined as "the extent to which a person's behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider."

Health and Psychosocial Consequences Inconsistencies in adherence can compromise the efficacy of medical treatments and the health and quality of life of patients with chronic conditions. Evidence-based Assessment To detect nonadherence and monitor efforts to improve adherence, there are a variety of measures of adherence that can be used. These include patient and parental reports, pill counts, pharmacy refills, observational methods, serum assays and electronic monitors. All of these measures have their relative strengths and weakness and no method is singularly adequate to assess adherence. Evidence-based reviews of measures have concluded that a minimum of two measures should be used for research purposes the continued development and validation of adherence measures that are more accurate and feasible for clinical purposes is in order. Culture, Diversity, Demographic and Developmental Factors Factors that predict poor adherence include the complexity of regimens, negative treatment side-effects, poor patient and family adjustment and coping, patient oppositional behaviors, and perceived barriers to adherence. Although members of minority groups have shown lower adherence to some medical regimens compared to other groups, some have argued that this type of comparison is too simplistic. One consistent developmental finding is that adolescents with chronic disease have poorer adherence than their younger counterparts, particularly when parents completely and prematurely discontinue their support and supervision of their adolescents. Evidence-based Interventions Two comprehensive meta-analyses have been published on the outcomes of adherence interventions for chronic pediatric diseases. Both of these reviews concluded that behavioral and multicomponent interventions are more effective than educational interventions alone. Also, the Graves et al. Effective interventions for improving adherence need to be disseminated into clinical settings. The efficacy of adherence interventions for chronically ill children: *Journal of Pediatric Psychology*, 35, Meta-analysis of psychological interventions to promote adherence to treatment in pediatric chronic health conditions. *Journal of Pediatric Psychology*, 33, Patterns of nonadherence to antiepileptic drug therapy in children with newly diagnosed epilepsy, *Journal of the American Medical Association*, , Adherence to pediatric medical regimens 2nd ed. Self-regulation predictors of medication adherence among ethnically different pediatric patients with renal transplants. *Journal of Pediatric Psychology*, 26, World Health Organization Adherence to long-term therapies:

Chapter 3 : Division 54 | Adherence to Pediatric Medical Regimens for Chronic Disease

Department of Pediatrics and The Center for the Promotion of Treatment Adherence and Self Management, Cincinnati Children's Hospital Medical Center, Cincinnati, OH by Michael A. Rapoff, New York, NY, Springer Publishing, , pp, Hardcover, \$ This is the second edition of a highly.

Received Feb 15; Accepted May This article has been cited by other articles in PMC. Abstract Poor adherence to medical regimens can compromise the efficacy of treatments for children and adolescents with juvenile rheumatoid arthritis JRA. The purpose of this review is to describe medical regimens for the treatment of JRA and the rates of adherence to these regimens. We also summarize and critically the few research studies aimed at improving adherence to regimens for JRA. Finally, we summarize strategies for enhancing adherence in clinical practice. Background Children and adolescents with juvenile rheumatoid arthritis JRA are often asked to adhere consistently and over a long period of time to a variety of medical regimens, most notably, medications and therapeutic exercises. We have chosen to use the term JRA because almost all of the studies in this area have been done with children meeting the American College of Rheumatology criteria for JRA [1]. Regimens for JRA may have delayed beneficial effects and in the short term may cause unwanted side-effects such as gastrointestinal irritation and pain. This constellation of factors associated with treatments for JRA i. This purpose of this review will be to 1 describe current regimens, define adherence, and review the prevalence of nonadherence to regimens for JRA; 2 summarize and critically evaluate research on improving adherence to regimens for JRA; and 3 review strategies for enhancing adherence in clinical practice. Medical regimens for JRA Pediatric rheumatic disease encompasses chronic multi-system disorders that involve acute and chronic tissue inflammation of the musculoskeletal system, blood vessels, and skin. JRA is the most common form of chronic arthritis and a major cause of both short and long-term disability. Patients are often required to adhere to complex medical regimens and cope with pain and psychosocial aspects of their disease. The etiology of JRA is not known but genetic and environmental factors likely are important. The laboratory tests are rarely definitive, the disease evolves over time and the treatment response is often not predictable. Even with good disease control, symptoms may fluctuate with other factors, such as intercurrent infection and weather changes. Synovitis is the hallmark of the disease and there are three basic subtypes, defined by the first 6 months of disease. These patients have high fever, characteristic rash and usually polyarticular arthritis, and may have organomegaly, serositis and risk for macrophage activation syndrome. Those children with polyarticular disease usually have symmetric, small joint involvement, particularly hands, wrists and hips. They often have low grade symptoms or signs such as fatigue and anemia and may be positive for rheumatoid factor, a marker for more aggressive disease. Children with pauciarticular oligoarticular disease are usually young, have predominantly large joint involvement and a high risk for uveitis, anterior chamber eye inflammation. The general approach to treatment is a stepwise approach, usually starting with non-steroidal anti-inflammatory agents and aggressively adding additional drugs depending on therapeutic response. Other aspects of treatment may need to address growth abnormalities including nutrition problems , vision, exercise needs-therapeutic and general, school and social function, and psychosocial and emotional health. Defining adherence "Adherence" is now the preferred term in the literature, replacing the term "compliance". The term adherence better reflects a more active role for patients in consenting to and following prescribed treatments [2 , 3]. This definition acknowledges that regimens for chronic conditions involve multiple behavioral components, with varying levels of adherence to each component, and that agreement to follow regimens has been secured from the patient. In pediatric rheumatology, agreement to follow prescribed regimens needs to be obtained from caretakers as well as patients. Another potentially useful distinction in the adherence literature is between inadvertent non-volitional and volitional or intentional nonadherence [5]. Inadvertent nonadherence may involve patients forgetting to take a medication dose or being away from home without access to medications. Whereas, volitional nonadherence may involve a reasoned and purposeful decision by patients to omit a medication dose, because they are asymptomatic, taking medications that interferes with their lifestyle, or are being

defiant. In the case of inadvertent nonadherence, one could help patients problem solve about how to keep track of medication doses such as using a pill reminder case and to have medications with them when away from home. In the case of volitional nonadherence, one would need to negotiate with patients and their families to obtain agreement on what they would be willing to do to treat their disease without compromising their quality of life. Two retrospective studies by Litt and her colleagues examined adherence to salicylate medications in the treatment of JRA. In three separate within-subject design studies involving five patients with JRA ages 3 to 14 years , who were suspected of having adherence problems by their pediatric rheumatologist, our research group assessed baseline adherence with salicylates and other medications, including naproxen, penicillamine, prednisone, and tolmetin sodium [8 - 10]. A "drug holiday" was defined as two or more consecutive days with no doses taken preceded and followed by at least one day with at least partial adherence. Patients with JRA are also asked to adhere to regimens other than medications, such as therapeutic exercise and wearing joint splints. Three studies have assessed parental and patient perceptions of adherence problems with these types of regimens as well as medications. In the first study [12], an adherence questionnaire was administered to 37 parents of children with JRA. The children were prescribed medications and range-of-motion exercises, splints, or both. Parents rated the degree of difficulty they have in motivating their children to adhere to the different types of regimens and noted any negative reactions their children had to the regimens. Parents reported more problems with prescribed exercises as compared with medications or splint wearing. In the second study [13], an adherence questionnaire was administered to 93 parents of children with JRA and to 41 of the children with JRA. Adherence was also reported to be lower for exercises as compared to medications. In the third study [14], fifty patients with juvenile idiopathic arthritis and their parents completed questionnaires asking them about adherence to medications, exercises, and splints. Specifically, they were asked about the frequency at which children followed the treatments, difficulties in following the treatments, any negative reactions to treatments, and the degree to which the treatments actually helped. Both parents and children rated adherence to medications as higher than adherence to exercises means of Compared to their children, parents rated them as having more difficulty doing exercises and as having more negative reactions to take medications and doing exercises. In the aggregate, these data suggest that the extent of adherence to treatments for JRA can vary widely across different samples and methods of assessing adherence but appears to be similar to what has been found with other chronic pediatric diseases [2]. The three survey studies would suggest that adherence to therapeutic exercises for JRA is more problematic than adherence to medications. What is not known is the optimal or minimal level of adherence necessary to produce acceptable disease and quality of life outcomes for patients. Clearly, there are some patients with JRA who may benefit from efforts to their enhance adherence. We now examine studies which have attempted to enhance adherence to regimens for JRA. Research on improving adherence to regimens for JRA Two studies by our group have examined the efficacy of parent-managed token reinforcement programs in altering adherence to regimens for JRA. These behavior modification programs involve awarding tokens points or poker chips to children for adhering to regimen components, taking away tokens for nonadherence, and allowing children to purchase special or routine privileges with tokens. The first study [8] focused on improving adherence to medications, splint wearing, and prone lying to prevent hip contractures for a 7-year-old female with severe systemic-onset JRA. A multiple-baseline-across-behaviors design was employed to evaluate the effects of the intervention on adherence. Although not formally assessed, the pediatric rheumatologist anecdotally noted concomitant improvements in function for this patient, such as greater hip extension. The second study [9] also tested the efficacy of a token system program in improving adherence to medications for a year-old male with polyarticular JRA. A withdrawal reversal , single-subject design was employed to evaluate the effects of the intervention on adherence and several clinical outcome parameters e. Though not as straightforward as the adherence results, there were improvements in clinical outcomes during the token system and follow-up phases e. Although the above-mentioned studies showed that token systems could be effective in improving adherence, they are labor-intensive for families and require well-trained personnel to implement and monitor. Therefore, our group reported on another study [10] that evaluated less complex behavioral strategies such as self-monitoring of adherence by children and parents and

positive verbal feedback by parents for adherence combined with educational strategies verbal and written information about medications for JRA, the importance of adherence, and strategies for improving adherence. A multiple baseline across subjects design was used to evaluate the efficacy of the intervention. Interestingly, the patient for whom the intervention was least effective was a year-old who had less parental supervision of her regimen and whose mother admitted she was nonadherent to medications prescribed to treat her arthritis. Unfortunately, clinical outcomes were not reported for these patients. The above-mentioned studies suggest that adherence can be improved by behavioral strategies alone or combined with educational strategies, a combination that has worked best for improving adherence to other chronic pediatric diseases [2]. However, these studies involved small sample sizes and did not generally assess clinical outcomes, such as active joint counts. These studies also involved patients who had been diagnosed with having JRA for varying lengths of time and for whom nonadherence was implicated as interfering with the effectiveness of treatments by their pediatric rheumatologist. The success of these interventions with limited numbers of patients who were persistently nonadherent led our group to test the possible benefits of intervening with newly diagnosed patients in order to prevent the anticipated drop in adherence over time which has been reported in the pediatric adherence literature [2]. We conducted a randomized controlled trial evaluating a clinic-based, nurse-administered educational and behavioral intervention to promote adherence to nonsteroidal medications among newly diagnosed patients with JRA [15]. Patients and parents in the experimental group were given verbal, written, and audiovisual information from a nurse about adherence improvement strategies, including prompting, monitoring, positive reinforcement, and discipline techniques [16]. Control group patients and parents were given verbal, written, and audiovisual information about JRA and treatments by the same nurse, but no specific information about adherence improvement strategies. The content of the phone calls centered on the information presented during the initial clinic visit. This electronic medication bottle cap records the date and time of each bottle opening. It can store openings and has an month battery life. The daily MEMS adherence score was the percent of prescribed doses taken within the recommended dosing interval, with a two- hour plus or minus forgiveness interval e. During these visits, the parents completed the Childhood Health Assessment Questionnaire CHAQ , which is designed to assess disease-related functional limitations over the past week in eight areas: For the week post-intervention follow-up, the experimental-group participants showed significantly better overall average adherence than the controls There were, however, no significant post-intervention group differences on disease activity and functional status measures. The lack of significant differences in disease-related outcomes may have been due to "floor effects" e. This floor effect may have prevented detection of improvements that could be unambiguously attributed to the experimental adherence intervention. A recent and unique randomized clinical trial focused on preventing osteoporosis in children with JRA by increasing calcium Ca intake [17]. Forty-nine children with JRA mean age 6 years and their parents were randomly assigned to a behavioral intervention BI group or an enhanced standard of care ESC group. Children and parents in the BI group met in separate groups for six sessions and received nutritional counseling on how to increase calcium intake and behavioral strategies praise coupled with use of a sticker chart to track progress for reaching targeted calcium intake levels. Children and parent in the ESC group were seen individually for 3 visits and received nutritional counseling only. Three-day food diaries were kept by parents at baseline and posttreatment and were analyzed for calcium intake. The above mentioned studies suggest that behavioral strategies combined with education is the most effective way to improve adherence to regimens for JRA and to prevent deterioration in adherence over time in newly diagnosed patients. The one dietary study also suggests that behavioral strategies are a necessary adjunct to nutritional education in improving calcium intake for patients with JRA. These findings are consistent with adherence intervention studies for other chronic pediatric diseases such as asthma, cystic fibrosis, and diabetes [2]. There are, however, too few adherence intervention studies and the ones which have been published involve small sample sizes, utilize less objective measures of adherence such as pill counts, and often fail to demonstrate that improvements in adherence produce improvements in disease and quality of life outcomes. Enhancing adherence in clinical practice By combining the results of pediatric rheumatology adherence intervention studies with a larger database in pediatric adherence research [2], strategies for enhancing

adherence can be recommended for clinical use. Studies that have been done suggest a three-tiered approach to minimize nonadherence: Primary prevention efforts would be most relevant for those patients who have not yet exhibited clinically significant nonadherence inconsistencies in following a particular regimen that may result in compromised health and well-being ; possibly those recently diagnosed or those who are able to sustain adequate adherence over time. Interventions at this level would involve educational e. Secondary prevention might be most applicable to those patients for whom clinically significant nonadherence has been identified early on in the disease course or has yet to compromise their health and well-being. Interventions at this level might include more frequent monitoring of regimen adherence by parents and patients, specific and consistent positive social reinforcement for adherence, and general discipline strategies e. Pediatric psychologists could train primary health care providers, particularly nurses, to implement primary and secondary level interventions. Tertiary prevention efforts would apply to patients with an ongoing pattern of clinically significant nonadherence.

Chapter 4 : Adherence to Pediatric Medical Regimens | Bookshare

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Kluwer Academic / Plenum Publishers New York, Boston, Dordrecht, London, Moscow.

Chapter 5 : Modi Lab | Center for Adherence and Self-Management

Adherence to medical regimens among children and adolescents with chronic medical conditions is another area in which clinicians have the opportunity to use behavioral principles in their interventions. Adherence to medical management is difficult for many children and families.

Chapter 6 : Improving adherence to medical regimens for juvenile rheumatoid arthritis

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