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Identifying Factors in Medication Non-Adherence in Teens Diagnosed with Juvenile Arthritis: A Pilot Study

Susan Viola Senzaki

*Northern California Consortium, Doctor of Nursing Practice Program, California State University, Fresno
and San José State University*

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IDENTIFYING FACTORS IN MEDICATION NON-
ADHERENCE IN TEENS DIAGNOSED WITH JUVENILE
ARTHRITIS: A PILOT STUDY

by

Susan Viola Senzaki

A doctoral project submitted in partial fulfillment of the requirements for the
degree of Doctorate of Nursing Practice for Northern California Consortium
California State University, Fresno and San Jose

APPROVED

For School of Nursing:

We, the undersigned, certify that the project of the following student meets the required standards of scholarship, format, and style of the university and the student's graduate degree program for the awarding of the doctoral degree.

Susan Viola Senzaki

Project Author

Ruth Rosenblum/TJ

Ruth Rosenblum (Chair) Northern California Consortium, San Jose

TJ

Terea Giannetta Valley Children's Hospital

Edsel

Edsel Arce Valley Children's Hospital

For the University Graduate Committee:

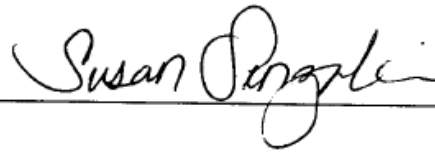
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I would like to thank my husband, Norm for his kindness, generosity, love and support. I could not be the person I am today without you. Thank you, always.

ABSTRACT

Purpose: The purpose of this study was to identify factors that correlate with medication non-adherence in teens diagnosed with juvenile arthritis.

Background: The impact of medication non-adherence often begins in childhood where children depend and learn from their care-givers how to manage their health. Children with chronic disorders are among those at risk for a higher medication non-adherence. Juvenile arthritis (JA) is a chronic childhood disorder where often medication non-adherence is an issue.

Methodology: This was a mixed-method qualitative and quantitative pilot study. Teens between the ages of 11 – 17 years, with juvenile arthritis were asked to volunteer in this study. Their medication adherence score were measured utilizing a Modified Medication Adherence Scale (MMAS). The second survey was to assess the patient's knowledge of their medication and was called the open-ended questionnaire. Fisher's exact test was used to determine if there was a statistical relationship between age, gender and ethnicity with their Modified Medication Adherence Score (MMAS). Knowledge comprehension of their medication's action was then compared to medication adherence scores.

Results: Results varied as some patients scored lower on their MMAS, but were knowledgeable about the action of their medication. The highest factor for all age groups, genders and ethnicity were forgetfulness. There were inherent limitations in this study as results were varied, subjective and skewed.

Conclusions: Based on this study, teens between the ages of 16-17 years of age scored higher in medication adherence. Gender and ethnicity were not shown to have a statistical relationship in their medication adherence scores. Forgetfulness was the common factor identified in medication non-adherence, while medication knowledge was not a factor in medication adherence scores.

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CHAPTER 1: INTRODUCTION

Background

The effect of medication non-adherence in this country is profound. A report from the World Health Organization (2011) found that in the United States an estimated one-thirds to two-thirds of the adult population do not take medication on a regular basis. This lack of medication adherence results in increased hospitalizations and disease processes that are preventable. A report from the World Health Organization, for the year 2010 in the United States, estimated the cost of medication non-adherence for adults and pediatrics to be over \$100 billion annually (Osterberg & Blashcke, 2003).

Medication adherence is an issue that touches patients of all races, ages, and social demographics (Rapoff, 2002). Children depend on their caregivers to obtain their medications for them, as well as to help them remember to take it consistently. Children tend to develop certain beliefs and views on medication and health care from their family. For every stage of child development, there is a common reason for children not adhering to their medication. In toddlers, this common reason is taste, which can be remedied by flavored syrups (Marla, Lussler & Bacar, 2011). In school-age children, forgetfulness is a common factor; calendars and journaling can help these children keep track of when to take their medications. Teens, who are at a risk-taking age, may take the chance of choosing alternative modes of medication or no medications at all (Gauthier & Cardot, 2012). These types of behaviors, if not corrected at a young age, may lead to future non-adherent adults.

Children diagnosed with juvenile arthritis (JA) experience joint inflammation and pain. If not treated, these children may have difficulty with gait and mobility, and some may need assistive devices in order to help with

movement. These children are prescribed medications over a long period of time, which often have undesirable side effects (SE) and prolonged therapeutic effects (Rapoff, 2002).

The first choice for treatment of JA is methotrexate (MTX). MTX is a chronic disease-modifying antirheumatic drug that has been shown to improve physiological and psychological effects of JA (Hahn & Kim, 2010). The most common recognized side effects of MTX are gastrointestinal, including nausea and vomiting (Klein et al., 2012). Mulligan et al. (2013) stated in their study that “a child who experiences nausea and vomiting, will develop anticipatory nausea (symptoms occurring before the medication is taken) and reluctance to take MTX may develop” (p.1). In an effort to decrease the side effects of MTX, injections of MTX can be given, but fear of injections and monthly monitoring of blood tests may decrease adherence to treatment (Mulligan et al., 2013).

Adherence to long-term treatment is a challenge for many patients with chronic diseases. In the last two decades, there has been an increase in studies on medication non-adherence in pediatrics with ADHD, asthma, diabetes, and JA (Hanghoj & Boisen, 2013; Marla et al., 2011). These studies showed that many factors contributed to medication non-adherence in patients, including finances, cultural beliefs, lack of insurance, lack of consistent health care, and forgetfulness from the patient or parent (Matsui, 2013). Research has begun on ways to increase pediatric adherence. This may include simplifying the medication routine, increasing adherence by electronic reminders, or even changing the way a medication tastes or is administered (Gardiner & Dvorkin, 2006).

The purpose of this study is to see if there is a relationship between age, gender, and ethnicity with medication adherence scores among teens diagnosed

with JA. This study also measures the correlation, if any, between patients' understanding of their medication and their medication adherence scores.

The survey I used to measure medication adherence was the Modified Morisky Medication Adherence Scale (MMAS). I chose this survey because it was easy for pediatric patients to read, complete, and understand. The questions were formulated to be answered in "yes" or "no" formats, and the final question uses a five-point Likert Scale to assess the amount of difficulty patients have remembering to take their medication. The MMAS measures factors such as patient forgetfulness, medication side effects, and convenience of medication regimen (Morisky & DiMatteo, 2011). Additionally, in order to assess participants' knowledge of their medication, I supplemented the MMAS survey with an open-ended questionnaire.

Theoretical Framework

Goal Attainment Theory

Imogene King's Theory of Goal Attainment is the metaparadigm theory that will provide the framework for this study. This theory takes into account the intrinsic and extrinsic factors that can help patients obtain particular healthcare goals. This theory also describes the nurse-client relationship in helping the patient achieve their optimal health goal (Alligood, 2014).

King's Theory of Goal Attainment can be summarized as a process of continuous and dynamic interaction between the nurse and the client. This interaction can happen through verbal or nonverbal communication; its purpose is to allow the nurse and patient to set common goals for the patient's care, based on their shared perception of the patient's situation (Alligood, 2014). This system emphasizes the importance of collaboration between the nurse and patient.

There are five key concepts comprising King's Theory of Goal Attainment: interaction, communication, transaction, role, and stress. The following is a summary of these five concepts.

- Interaction—the verbal and nonverbal behavior of two or more persons in mutual presence, directed towards some goal.
- Communication—the means by which human relations are developed and maintained. This includes intrapersonal, interpersonal, verbal, and nonverbal communication.
- Transaction—a process of interaction in which human beings communicate with the environment to achieve goals that are valued; goal-directed human behaviors.
- Role—a set of behaviors expected of a person occupying a position in a social system.
- Stress—a dynamic state whereby a human being interacts with the environment to maintain balance for growth, development, and performance, involving an exchange of energy and information between the person and the environment for regulation and control of stressors.
- Coping—a way of dealing with stress. (Alligood, 2014).

Parts of King's Goal Attainment Theory originated from her Interacting Systems Framework, describing the interactions and transactions between healthcare provider and patient. In King's Goal Attainment Theory, the nurse and patient mutually set goals and work to achieve them through a series of interactions and transactions. In this framework, both parties have a purpose; they perceive, judge, act and react upon each other. At the end of their communication, a goal will be set and with this the transactions are made. King believed that the

goal of nursing “is to help individuals maintain their health so they can function in their roles” (Alligood, 2014, p. 312).

These interactions between the nurse, client and outside stressors are the keys to medication compliance. It is the role of the nurse or care provider to educate and follow up on the patient’s home treatment. Among younger patients, the patient’s family is the primary factor in determining whether or not a child will comply with their home health routine. However, extrinsic factors such as health care accessibility, insurance, and financial stability also play a role in this situation.

King stated that nursing's focus is on the care of the patient, and its goal is the health care of patients and groups of patients (as cited in Alligood, 2014, p. 24). The goal of increasing medication adherence is achievable through patient education and simplifying a child’s medication routine. An important aspect of increasing medication adherence is increasing patient knowledge, not only for the patient but for the family.

The Teach Back Method

One way to increase patient knowledge of how to properly take their medication is through the teach-back method. The teach-back method is a way to educate patients by having the patients use their own words to restate what they had been taught by their healthcare providers. This method has been implemented in clinical and outpatient settings in over the last decade, as a tool in assessing how much of the healthcare information given by his or her provider the patient has retained (Xu, 2012).

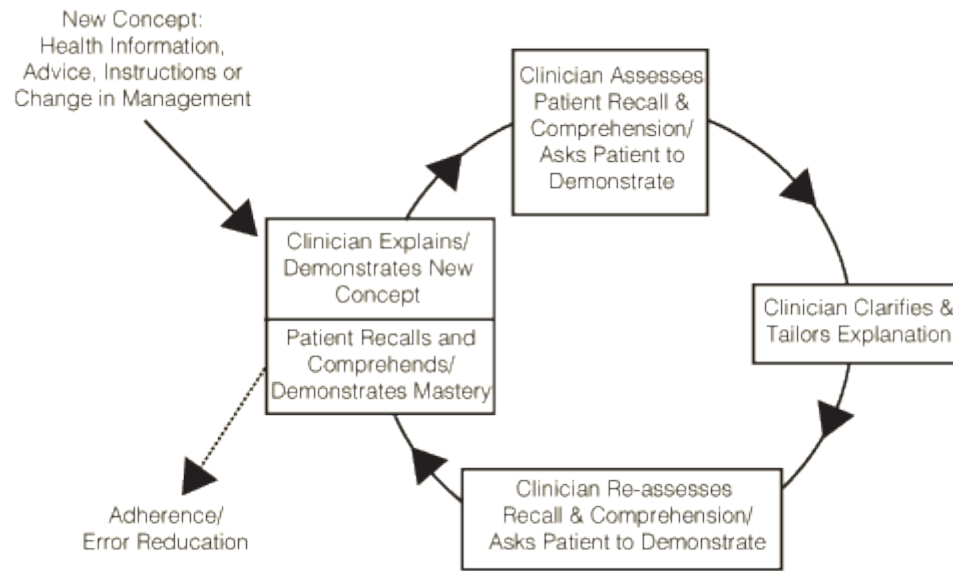


Figure 1. Teach Back Theory Model from Schillinger, D. et al (2003), p. 84

Orem’s Self-Care Deficit Theory

Orem’s general theory of nursing is based on three interrelated theories: the theory of self-care, the theory of self-care deficit, and the theory of nursing system (Cox & Taylor, 2005). In this framework, the theory self-care deficit specifies when nursing is needed. According to Orem, nursing is required when an individual is incapable or limited in his or her ability to provide continuous, effective self-care. Orem identifies five methods of helping individuals provide self-care: actively performing self-care tasks for the individual; guiding the individual; supporting the individual; providing an environment promoting personal development; and teaching the individual (as cited in Cox & Taylor, 2005). This reinforces the principle of the nurses helping patients by enabling patients care for themselves through patient education. Such care includes assessments on the part of the nurse as to how to simplify patients’ medication

routines in order to promote medication adherence. In this way, nurses can help guide patients towards independent self-care, in accordance with Orem's theory.

Unifying Theoretical Themes

King's Goal Attainment Theory and Orem's Self-Care Deficit Theory both focus on patients' ability to manage their own health care. They emphasize the role of healthcare providers in determining whether or not patients can effectively provide self-care, which includes adherence to their healthcare and medication routines. The unifying goal is patient knowledge and patient education. The ability to understand the importance of their medication and how to properly use it is a factor in whether or not a client will adhere to their medication. King's and Orem's theories unifying theme is patient's self-care through knowledge and goal setting.

CHAPTER 2: LITERATURE REVIEW

Juvenile arthritis is an autoimmune disease that affects nearly 250,000 children under the age of 16 each year (American Academy of Orthopedic Surgeons [AAOS], 2014). The physical side effects of JA include joint inflammation, joint contractures, and joint damage, pain, and growth abnormalities in children (AAOS, 2014; Bechtold & Simon, 2014). It is crucial to identify such conditions early on and implement appropriate treatment; poor management of juvenile arthritis in childhood and adolescence can lead to ineffective management in adulthood (Hanghoj & Boisen, 2013).

Definitions

Non-compliance has often been used to describe patients' refusal or inability to follow their medication or health regimens at home (Matsui, 2013). The term non-compliance has negative connotations, suggesting that patients do not want to follow, or comply, with their healthcare. Therefore, this term has been replaced with non-adherence in current healthcare writing (Delamer, 2006).

To date, measurement of patient medication adherence and use of interventions to improve adherence is not commonly practiced in routine clinical practice and acute care settings. For this reason, medication adherence has been called the "next frontier in quality improvement" and has become an important aspect of patient health care and initiatives (Heidenrich, 2004).

It should also be noted that the term juvenile arthritis (JA) is used throughout this study to refer interchangeably to juvenile rheumatoid arthritis and juvenile idiopathic arthritis.

Reasons for Medication Non-Adherence in Teens Diagnosed with JA

Adherence to long-term treatments is a challenge for many pediatric patients diagnosed with chronic diseases (Feldman et al., 2007). Medication adherence may be influenced by a number of factors intrinsic or extrinsic to the individual: these factors can include the individual's cultural upbringing, personal values and ideas (intrinsic); or may involve environmental, financial, and family dynamics, as well as external stressors that influence the patient's health care beliefs (Brown & Bussell, 2011). Families play an important role in medication adherence. Children are dependent on their guardians for following up on their medication, refilling prescriptions, and, in the case of younger children, administering medication.

Social demographics may play a part in treatment non-adherence. Studies of treatment adherence among patients diagnosed with JA reveal higher rates of adherence among patients from families with higher socioeconomic status (Rapoff et al., 2002). Economic factors influence whether or not a patient is able to adhere to such aspects of treatment as paying for medication, medical appointments and follow-ups, transportation to and from appointments, and health insurance (Rapoff et al., 2002). The families of children with chronic disorders may be burdened with economic issues. This may lead parents to omit their children's doses, split tablets to make them last longer, or delay refilling prescriptions (Matsui, 2013). An on-line community survey done by Laba, Brien and Jan (2012) found that out-of-pocket drug costs had a significant influence on whether or not patients continued with a medication. Other research, primarily from the United States, has shown that cost-related medication non-adherence is widespread (Law et al., 2012).

Patient-reported rates of cost-related underuse of medications ranged from 1.6% to 22% in survey studies (Kirking et al., 2006). Briesacher, Gurwitz, and Soumerai found that not having prescription drug coverage was a significant risk factor for cost-related medication underuse (2007). Lack of insurance for prescription medications was associated with a more than fourfold increase in the chance of non-adherence (Law et al., 2012). Patients' country of residence may also play a role in medication non-adherence. For example, patients in the United States have been found to be between two and three times more likely to report cost-related non-adherence than Canadian residents (Viswanthan, Golin, & Jones, 2012). Identifying factors contributing to cost-related medication non-adherence may facilitate the development of strategies to reduce cost-related burdens for patients.

However, cost-related factors are not the only predictors of non-adherence. Medication non-adherence may stem from factors that include the family's health beliefs, the side effects of the medications, and the frequency with which the medication must be administered (Briesacher, Gurwitz, & Soumerai, 2007).

Access to medication is another aspect that must be considered, and its relevance increases with each increase in the cost of treatment. Pelajo et al. assessed adherence to methotrexate among 76 children from two centers in two socioeconomically contrasting locations. The study showed poor adherence in 18% of patients. Among children in the Rio de Janeiro location, which had the lower average socioeconomic level, the difficulty of obtaining medication was the main cause of poor adherence. Among the children in Boston, which had the higher average socioeconomic level, the main cause of poor adherence was the child's refusal to take the medication (Pelajo et al., 2012).

Studies have shown higher adherence to medication in those environments with a better family structure and among patients with chronic diseases (Matsui, 2013; Rapoff, 2006 and Viswanthan et al., 2012). Families, or caregivers, whose child may be newly diagnosed with JA experience an increase in emotional stress which may contribute to decreased medication adherence. Mulligan et al. (2013) assessed the psychological stress and quality of life of 40 caregivers of JA patients. That study found caregivers who were female, single, and caring for patients with polyarticular JA to be most affected by stress and least likely to adhere to their child's medication regimen (Mulligan et al., 2013).

Not all caregivers can fully manage caring for children with chronic diseases, which often requires complex regimens of administering several medications a day and carrying out time-consuming non-drug treatments that require an organized schedule. In 2013, Mulligan et al. studied mothers' views of difficulties that children with JA experienced while taking MTX . They formulated a questionnaire for the mothers about the medication MTX, but the children themselves were not surveyed. This study found that the majority of mothers (68%) reported improved physical symptoms for their child while on MTX. More than half of the children taking MTX, reported nausea and vomiting before and after subcutaneous, as opposed to oral, administration of the medication. Feeling sick and anxiety over blood draws were the common complaints reported in this study (Mulligan et al., 2013).

There is additional risk of non-adherence in adolescents and young adults with JA. This population may have difficulties with self-management, particularly during the transition to adulthood. Lawson et al. (2011) administered a cross-sectional survey to teens between the ages of 13 and 20. This study found that the main reason for missing their medication was forgetfulness. Other barriers

reported from this sample: inability to fill prescriptions, schedule appointments, arrange transportation to and from appointments, ask questions, recognize relevant signs and symptoms, or manage healthcare-related finances and insurance. This resulted in a lowered prognosis for this age group, due to their lack of training in organizational and self-management skills related to their own healthcare (Lawson et al., 2011). This potential lack of self-management ability among teen patients and their caregivers may reduce teens' adherence to medical treatment (Claudio, Miotto, & Terreri, 2014).

Lawson et al. suggested potential solutions to these self-reported barriers to care among teens. These potential solutions included encouraging older adolescents to become pro-actively involved in their own health care, as well as patient education modified for children. They also suggested helping younger patients establish calendars for their medications and medical appointments (Lawson et al., 2011). Unless solutions can be found that will teach children and adolescents effective ways to manage their medications and medical treatment plan, we may be raising future adults who will continue to be non-adherent to their medications and plan of care.

The complexity of the therapeutic regimen also plays a factor in medication adherence in drug treatment. Claudio et al. (2014) revealed poorer adherence to medication when the regimen consisted of more than three daily drugs. There is also lower adherence to immunosuppressive medications and disease modifiers (Bugni et al., 2012).

Research has also pointed to common reasons for medication non-adherence particular to individual stages in children's development. For example, the main reason for medication non-adherence in toddlers tends to be taste; for school-aged children, the main reason tends to be forgetfulness. Meanwhile, teens,

who are at an age for risk-taking, may choose not to take their medications or follow through with medical treatment (Gardiner & Dvorkin, 2006).

The presence of unwanted side effects in drugs used in the treatment of JA—particularly NSAIDs, methotrexate, lefunomide, corticosteroids, biological drugs and immunosuppressive agents—also increases non-adherence. The presence of side effects may lead the patient to refuse the drug because of a fear of worsening his or her condition (Pelajo et al., 2012).

Lack of knowledge about the disease process is also an important factor that can lead to non-adherence. Patients and their families may be unfamiliar with their medications' delayed therapeutic effects or be confused by unwanted side effects. This can lead to patients refusing to take the drugs; it can also lead to patients stopping non-drug treatments, such as physiotherapy and the use of orthoses (Pelajo et al., 2012; Bugni et al., 2012, April, Ehrmann-Feldman, Platt, & Duffy, 2006).

Finally, the relationship between the patient and their healthcare provider also plays a part in medication adherence. Iwamoto et al. observed that lack of structure related to healthcare, difficulty in obtaining medication, and difficulty seeing the healthcare provider can be major psychological stressors for caregivers of JA patients (2008). Studies evaluating the main factors associated with satisfaction or dissatisfaction with healthcare services found a significant correlation between patient satisfaction with their healthcare team, and improved adherence to treatment and lower probability of switching providers (Costello, Wong, & Nunn, 2006).

In 2011, the American College of Preventative Medicine created the following summary of common factors in medication non-adherence among children with chronic diseases, including juvenile arthritis:

- Low literacy
- Forgetfulness
- Psychological stress or anxiety
- Lack of insight into illness
- Lack of belief in benefit of treatment
- Cultural incongruency
- Belief medication is not important or harmful
- Inconvenience of medication regimen
- Side effects or fear of side effects
- Cost of medication or co-payment
- Barriers to access to care or medication
- Inadequate follow-up
- Missed appointments

Studies of pediatric medication non-adherence often interview the parents of the children receiving medication versus the children themselves (Mulligan et al., 2013). In reviewing the literature, I have found few articles in which the children or teens with JA were, themselves, surveyed about their medications. Nor are there any studies on assessing a child's knowledge of their medication and its effects on their medication non-adherence. This study will look at whether there is a relationship between age, gender and ethnicity with medication non-adherence. This study will also see if there is a positive correlation between teen's knowledge of their medication and their medication adherence scores.

CHAPTER 3: METHODOLOGY

Project Survey Methods

The methodology for this pilot study used quantitative and qualitative methods, with correlational analysis. The quantitative methods used to determine if there was a statistical relationship between age, gender and ethnicity in relation to medication adherence (MMAS) scores was the Fisher's exact test. The qualitative portion looked at the subject's response in assessing knowledge of their medication in relation to their medication adherence score. The investigator administered the MMAS in order to measure medication adherence scores for the subjects tested. The second survey, administered with the MMAS, was the open-ended questionnaire. This measured knowledge of the patient's medication as well as alternative methods used to help their JA symptoms.

Setting

This study took place in a pediatric outpatient rheumatology clinic in the Central Valley between November, 2014 and January, 2015. Subjects were recruited on a voluntary basis. After their outpatient visit, subjects were asked if they would like to participate in this study.

Population Sample

Inclusive criteria for the subjects recruited for this study were: between the ages of 11–17 years, English-speaking, diagnosed with JA for a minimum of one year and only diagnosed with JA. The surveys were handed to 50 subjects, of whom 37 subjects volunteered to be part of the study. Out of the 37 subjects who completed the survey, 26 surveys were actually used. Eleven surveys were omitted due to parental involvement or incompleteness. Thorough explanation was done for

the patients and their parents and consents and assents were obtained. This was to ensure the subjects understood participation in the study was voluntary, and that their health providers would not see their results. After the children's assents, and parents' consent, explanations were done on the survey itself and time was given for the subjects to complete their survey and questionnaire with the investigators in the room. If the child was nervous or had questions about the survey, directions were provided to the child and questions were answered while the investigators were in the room.

During the administration of these MMAS surveys and open-ended questionnaires confidentiality was maintained. The names of the subjects were not written on the surveys itself. Data was summarized by subject numbers to ensure patient confidentiality. Patients and their families were instructed of this. IRB approval was obtained through the children's hospital site before the study began.

Instrumentation

Two surveys were administered for those participants who chose to consent to this study. The first survey was the MMAS survey, which is found in appendix D. The second survey asked patients open-ended questions such as knowledge of their medication, as well as what other activities they do to help with their JA symptoms. In addition, the open-ended questionnaire asks about participants' social demographics such as age, gender, ethnicity, and years diagnosed with JA.

Data Analysis

The survey tool used for this study was the Morisky Medication Adherence Scale (MMAS-8 Item). Questions 1–7 of the MMAS ask whether or not respondents ever forget to take medication, stop medication if side effects occurs, stopping medications when they don't experience symptoms from their JA, and

whether or not they feel inconvenienced by having to take their medication on a regular basis. These are “yes” or “no” questions. Question 8 of the MMAS asks participants to rate the difficulty of remembering to take one’s medication, based on a Likert scale from 0–4. The possible responses for Question 8 are: 4 = Never/Rarely forgetting to take one’s medication, 3 = Once in a while forgetting, 2 = Sometimes forgetting, 1 = Usually forgetting, and 0 = All the time forgetting to take medication.

The responses from 26 surveys were collected, coded, and given an adherence scale of 0–8. Low adherence were those scores <6, medium adherence are those scores from 6–7, and high adherence are those scores of 8. Specific coding instructions for the Morisky Medication Adherence Scale are clearly identified in the MMAS information sheet.

The results of the MMAS were calculated based on the percentage of yes and no questions for the first seven questions. The remaining question, which had five responses, was accounted for in the final calculations based on the percentages of each response. After medication adherence scores were calculated, Fisher’s exact test was used to determine if there was a statistical relationship between age, gender and ethnicity in relation to medication adherence scores. The remaining two questions were qualitative in nature as it was determined if knowledge of the subject’s medication affects medication adherence scores.

Precautions Taken to Minimize Risks

No names or identifying factors were included on the survey itself. Written consent by the participants, the patient and their parents was obtained, and none of the signed consent and assent forms could link the participant to the surveys. A small sticker was placed inside the file, or electronic tag, of the individuals who

were surveyed. This was to track those pediatric patients who had been asked to take part in this study.

Once the surveys were completed they were entered in a secured electronic file, only accessible to the primary investigator. Assents and consents were entered separately into a secured file at the rheumatology clinic. Data results were only interpreted by the primary investigator. All hard copies of the surveys, assents, and consents were shredded and disposed of properly once the study was complete.

CHAPTER 4: RESULTS

Reviewing all subjects (n=26) in their responses to their MMAS survey, the highest response was to Question 1. The questions asked, “How often do you forget to take your medication?” The percentage of subjects who answered “yes” to this question was 93%. This was the highest percentage measured based on all 8 questions from the MMAS. The second highest percentage of “yes” answers (83%) was to Question 5. This question asked participants, “Did they take their medications yesterday?” The lowest percentage of “yes” responses (19%) was to Question 3, which asked, “Have you ever cut back or stop, without telling your doctor, because you felt worse when you took it?” This question also indirectly measured the effects of side effects from their medications, suggesting that even if the subjects experiencing side effects would not discontinue their medications. The final question asked, “How often do you have difficulty remembering to take all your medications?” The response was based on a 5-point Likert Scale with subjects answering 15% to “Never,” 54% response to “Once in a while,” 23% answered “Sometimes,” 8% answered “Usually” and 0 subjects answered “All the time.” The majority of subjects (54%) responded that “Once in while” they would forget to take their medication. Similarly to Question 1, this question measures forgetfulness.

In measuring adherence using the MMAS, a score of = 8 is high adherence, a score of 6-7 = moderate adherence, and < 6 = low adherence. Of those tested, 1 subject scored high adherence, 8 subjects scored moderate adherence, and 17 subjects scored low adherence. The average MMAS adherence score was 4.75692. The median score was 4.75.

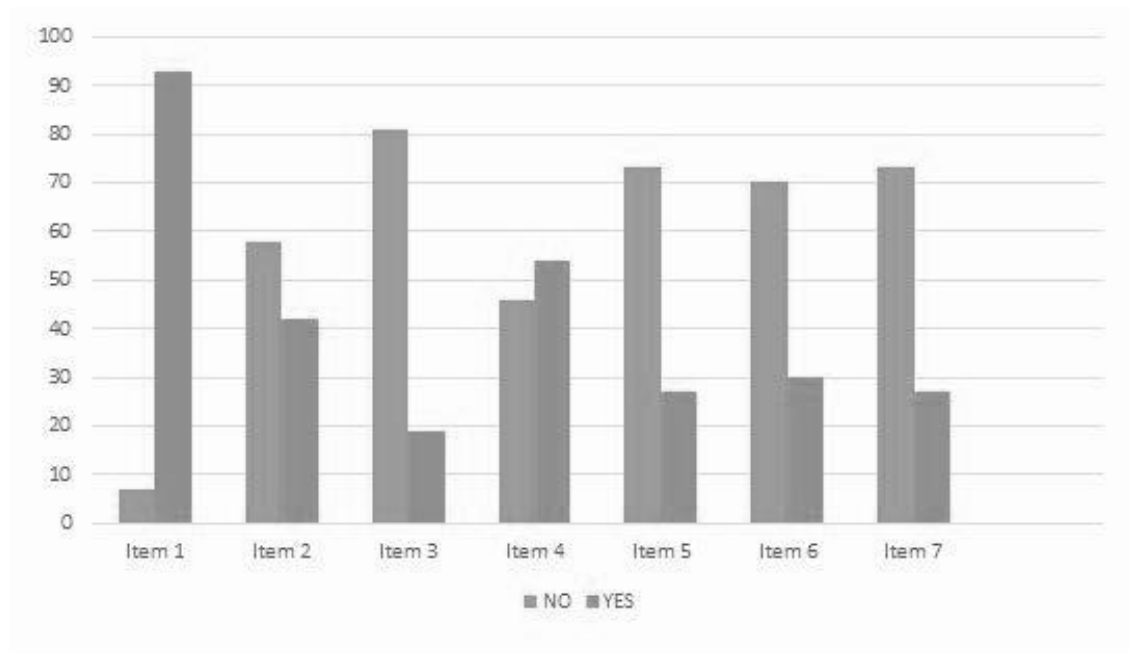


Figure 2. Responses to MMAS Survey Questions 1–7 (percent of participants)



Figure 3. Responses to MMAS Survey Questions 8 (percent of participants)

Statistical analysis used was Fisher’s exact test. It was used due to our small sample size; and, to determine if there were any statistical relationships between age, gender and ethnicity with medication adherence (MMAS) scores. In determining correlation between ethnicity and MMAS, based on Fishers exact test

($p \sim 1$) there was no statistical relationship. In determining correlation between gender and MMAS scores, based on Fishers exact test ($p = 0.336$), there was no significant statistical relationship. Therefore, based on this study, there was no statistical relationship with ethnicity and gender in relation to medication (MMAS) adherence scores.

In this study, there was a statistical relationship between the age of the subject and their adherence score. Older patients were more adherent than younger patients tested. The average age of the subject was 16.88 for a high adherence score. The average age for a moderate score was 14.76. The low adherence score's average age was 14.86. The probability of a child being older in age, over the age of 16, correlated with a higher adherence score. [Refer to table 3.]

In comparing the subject's knowledge of their medication to their MMAS score, the responses varied. The subject who scored a high adherence score (MMAS = 8) answered, "Actemera" as what her medication does. Therefore, this subject had low medication knowledge, but a high medication adherence score. Subjects who scored a moderate adherence score (MMAS = 6-7) had appropriate knowledge of their medication. Subject's responses to describing what their medication does to help their JA were: "Reduces inflammation and targets certain proteins in my body that don't respond properly." Another subject answered "It helps my joint to move better and not swell up." Those subjects who scored the lowest MMAS scores (MMAS <5) also had appropriate medication knowledge. Subjects who scored low medication adherence score (MMAS = 1 to 2) responses were: "Some medication helps stop the inflammation in my joints and also to help with the pain" and "Helps slow down the swelling." Therefore, based on this pilot study, we can conclude that a subject's knowledge of their medication does not correlate with higher medication adherence.

Table 1. MMAS Scores by Ethnicity: Number of Respondents with High, Medium, and Low Scores

| Ethnicity | High Score (8) | Med Score (6–7) | Low Score (<5) |
|-----------|----------------|-----------------|----------------|
| Hispanic | 3 | 3 | 3 |
| White | 2 | 3 | 2 |
| Other | 3 | 3 | 2 |

Fisher's exact test p-value: ~1

No significant relationship between ethnicity and MMAS scores.

Table 2. MMAS Scores by Gender: Number of Respondents with High, Medium, and Low Scores

| Gender | High Score (8) | Med Score (6–7) | Low Score (<5) |
|--------|----------------|-----------------|----------------|
| Female | 7 | 6 | 7 |
| Male | 1 | 3 | 0 |

Fisher's exact test p-value: 0.336

No significant relationship between gender and MMAS scores.

Table 3. MMAS Scores and Age

| Group | Df | SumSq | Mean Sq | Fvalue | Pr(>F) |
|------------|----|-----------------|----------------|----------------|---------|
| MMAS Group | 2 | 22.712 | 11.3562 | 3.7682 | 0.03996 |
| Residuals | 21 | 63.288 | 3.0137 | | |
| | | High MMAS Score | Med MMAS Score | Low MMAS Score | |
| Mean Age | | 16.88 | 14.78 | 14.86 | |

Statistically significant relationship between age and MMAS group.

CHAPTER 5: DISCUSSION

Adherence to recommended treatments is of great importance in JA and other chronic rheumatologic diseases. The effects of medication adherence are directly related to disease outcome, quality of life and prognosis (Pelajo, et al., 2012). Adherence to certain medications, such as methotrexate, is widely used in pediatric rheumatology. It is therefore important to differentiate lack of therapeutic efficacy of prescribed medications versus non-adherence to these medications.

In this pilot study, based on responses to the MMAS surveys, the majority of responses (93%) were “yes” to Question 1, “Do you sometimes forget to take your pills.” Based on the results of this pilot study, forgetfulness is the common reason for medication non-adherence. Forgetfulness is also a common thread, based on studies for medication non-adherence in school-age children (Feldman et al., 2007; Rapoff et al., 2002; Rapoff & Lindsley, 2006). In our study, results of medication non-adherence did not relate to gender, ethnicity, or years diagnosed with JA. However, there was a statistical relationship between age and adherence to prescribed medications. Older patients (age > 15 years) were more likely to be adherent than younger children (ages < 14 years). This may be due to growing autonomy or maturity.

Adherence rates to JA treatment vary widely, depending on the study, and on the method used to assess adherence. In general, more objective measures (such as electronic monitoring) show lower adherence rates of adherence than self-reports (Rapoff et al., 2002). Subjects tend to respond more favorably towards adherence when surveyed or questioned by researchers or their health care providers (April et al., 2006).

The results of this pilot study should be interpreted with several limitations in mind. First, surveys were conducted for subjects who regularly attended their

outpatient appointments. Therefore, survey participants may have been more likely to comply with their medications and treatment plan than average patients. Additionally, this study only surveyed older, English-speaking children, between the ages of 11–17. The sample size was also small (n=26) affecting the statistical significance of our results. Subjects surveyed were also asked after speaking with the physician, so there may have been a self-reported underestimation of medication non-adherence. Studies have shown that subjects tend to answer more favorably when research instrumentations of surveys or questionnaires are involved.

The manner in which surveys and questionnaires were collected also played a role in the answers of the participants. The investigators were in the room when the participants were completing the surveys. Parents, or care-providers, were also in the rooms with their child, which may have also influenced the subjects answered. Based on these limitations, subjects may have answered their responses more favorably towards adherence.

In the subjective portions of the open-ended questionnaires collected, knowledge of their medication varied. Those who filled out their open-ended questionnaires with understanding of what their medication, and who were older (over the age of 14 years of age) were most likely to have a higher MMAS score. However, knowledge of their medication did not correlate to a higher medication score, based on the results of the open-ended questionnaire. The subjects who had the highest medication adherence score (MMAS = 8) had low knowledge of their medication's action. Those subjects who scored low or moderate adherence scores (MMAS = 1-7) had appropriate knowledge of their medication's action.

The validity and reliability of the MMAS survey and the open-ended questionnaire were not tested. The MMAS survey had been previously researched

and tested with adult patients, but not with pediatric patients; therefore we cannot conclude the same results with children as we can with adults. The open-ended questionnaire had not been tested in any study. It was formulated specifically for this pilot study, in order to assess patient's knowledge of their medication. Therefore, we cannot assume the reliability of this open-ended questionnaire. Also, the timing of when the survey was administered also plays a role in the responses of the subjects surveyed. They were surveyed after meeting with their physician. Therefore, they may have received the response to the question asked on "what their medication does" after meeting with their health care provider.

Subjects speaking other languages, besides English, were not included in this study. Language barriers and low health literacy constitute additional obstacles to medication adherence that this study did not measure. The use of an interpreter and translation of the surveys in other languages would have influenced the results of this study. Results of this study may have varied, if we had included those patients for whom English was not the primary language spoken at home.

The limitations in this study can direct future studies in pediatric medication non-adherence. There has already been research in pediatric medication non-adherence among children with chronic disorders such as asthma, diabetes, cystic fibrosis, and epilepsy (Costello, Wong & Nunn, 2004; Gardiner & Dvorkin, 2006). Formation of an accepted medication adherence scale written for pediatrics is an area of future study.

Lack of knowledge of their medication is not the only barrier to teens adhering to their medication. There are other extraneous factors that influence a child's adherence to their medication, but first we need to develop a tool that measures a child's medication adherence. From there we can then begin to identify specific factors as to why certain pediatric patients do not adhere to their

medication. Once we can uncover the true reasons from the child or patients themselves, can we begin to identify the solutions.

Recommendations for Pediatric Medication Non-Adherence

One solution to increase medication adherence and understanding is the Teach Back Method. This method is an educational tool where the provider educates the patient on their medication. This method then requires the patient to state back, in their own words what they have learned from the provider's education. Essentially, "teaching back" what was taught to them. This tool has been studied and utilized in the past decade in clinics and acute settings, primarily with residents. Now, we see research and evidence that this method of patient education is successful in increasing patient knowledge of their health routine.

Possible solutions to increase medication adherence, specifically to JA, is *adherence-enhancement strategies*. Rapoff et al. (2002) suggested the following strategies for enhancing adherence: *cueing* (paring medication with an established behavior such as brushing one's teeth), *monitoring* (using a calendar to track when medication is taken) *positive reinforcement* (praising and rewarding with special tokens when medication is correctly taken) and *discipline* (using time-out for defiant refusals to take one's medication).

Other possible ways to increase medication adherence include simplifying the medication regimen (taking one pill per day, as opposed to four pills throughout the day), decreasing cost, clear explanation of how medication should be taken and why, consideration of patient needs and lifestyle with medication treatment, and follow-up on how their medication is working and if changes or further education needs to be done.

To date, measuring patient medication adherence and using interventions to improve adherence are uncommon practices in routine clinical care and acute care settings. For this reason, medication adherence has been called the “next frontier in quality improvement” and is an important aspect of patient health care and initiatives (Heidenrich, 2004). Therefore, it is imperative to continue to study the reasons for medication non-adherence. Once we find the reasons, can we then begin to identify and research solutions to remedy this preventable health care problem.

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APPENDICES

APPENDIX A: CONSENT FORM

Consent Form

Children's Hospital Central California
Informed Consent Form/Permission
For Participation in Research

Protocol Title: Obstacles in Medication Adherence in Children With
Juvenile Arthritis (JA).

Principal Investigator: Edsel Arce MD

Names of Sub-Investigators: Susan Senzaki RN, MSN, DNP (c) and Linda Miranda RN

Telephone number: (559)304-9345

Participant's Name: _____ **Date:** _____

What is the purpose of this research?

Your child is being seen at Children's Hospital of Central California in the Rheumatology Clinic. Your child is being asked to participate in a survey that is looking at barriers or obstacles in taking his or her medication. This survey is completely anonymous and voluntary. If your child chooses not to participate, that is their decision. We will not be upset if your child chooses not to participate.

Is there any risk to this research?

No, there is no risk. This research involves questions about taking medication, if they understand why they take it and how they take it. It also asks questions on what helps them other than their medication.

This research is based on questions on this survey and it poses no risk to your child. **Who will have access to the information on the surveys?**

This survey is completely anonymous. We do not ask for your child's name on the survey itself and the principal investigator looking at the survey and analyzing its data will be Susan Senzaki. After the surveys are taken, they will be placed in a folder in a locked file box. After the surveys are collected, the principal investigator will analyze the data and store the results on an electronic file with an encrypted password.

Will I be contacted after the surveys are collected?

No further contact will be done after the surveys are collected. We are also unable to share the results of the survey with the participants as no names will be asked on the individual surveys taken.

Benefits

The research that your child's participation in this survey will be enormous. Their responses will give us insight on what areas are needed to increase adherence to their medication routine. This includes if health care providers need to spend more time educating on the importance of what their medication does, side effects, and proper use of one's medication.

What are my rights as a participant?

Taking part in this study is voluntary. You may choose not to be in this study. If you decide not to be in this study, you will not be penalized and you will not lose any benefits to which you are entitled. Physicians and hospital personnel will still take care of you.

Who do I call if I have questions or problems?

For questions about this study or research, you can contact Susan Senzaki at (559) 304-9345.

APPENDIX B: CHILD CONSENT FORM

Child Consent Form

In order to help children with juvenile arthritis, it is important for them to take their medications. This means taking them correctly and regularly. The act of taking one's medication regularly and correctly is called adherence. However, we have found that it is difficult sometimes for children, and parents, to adhere to their medication routine.

This survey is to see what the obstacles in taking one's medication are.

This survey is to be done completely anonymous. We do not ask for your name on the survey, so your answers are completely anonymous. Your doctor will not see the responses to your survey, or will participating in this survey change your care in any way.

Your participation in this survey is greatly appreciated.

If you have any questions about this survey or our research please contact Susan Senzaki at (559) 304-9345.

Child's Name

Date

Printed Name of Witness

Date

Signature of Witness

I have been given a copy of all three (3) pages of this form.

I/We have reviewed the information and this research has been explained to me/us.

I/We have been able to ask questions and all of my/our research questions have been answered. I/We agree to take part in this study.

Printed Name of Legal Representative

Signature of Legal Representative

Date

Relationship to Participant: _____

INVESTIGATOR'S STATEMENT: I have fully explained this research study to the participants. In my judgment, and theirs, there was sufficient information regarding risks and benefits, to make informed decision. I will inform the participants in a timely manner any changes in the survey or research, if there is any.

Printed Name of Investigator

Signature of Investigator

APPENDIX C: MMAS SURVEY

©**Morisky Medication Adherence Scale (MMAS-8-Item)**. This is a generic adherence scale and the name of the health concern can be substituted in each question item.

You indicated that you are taking medication for your (identify health concern, such as “high blood pressure”). Individuals have identified several issues regarding their medication-taking behavior and we are interested in your experiences. There is no right or wrong answer. Please answer each question based on your personal experience with your [health concern] medication.

(Please check your response below)

| | No=1 | Yes=0 |
|---|------|-------|
| 1. Do you sometimes forget to take your pills? | | |
| 2. People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past two weeks, were there any days when you did not take your medicine? | | |
| 3. Have you ever cut back or stopped taking your medication without telling your doctor, because you felt worse when you took it? | | |
| 4. When you travel or to school, do you sometimes forget to bring along your medication? | | |
| 5. Did you take your medicine yesterday? | | |
| 6. When you feel like your is under control, do you sometimes stop taking your medicine? | | |
| 7. Taking medication is a real inconvenience for some people. Do you sometimes feel hassled by your medication routine? | | |

8. How often do you have difficulty remembering to take all your medications? (Please circle your response below)

- Never/Rarely.....4
- Once in a while.....3
- Sometimes.....2
- Usually.....1
- All the time.....0

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APPENDIX D: OPEN-ENDED QUESTIONNAIRE

Open-Ended Questionnaire

By answering this survey, you have given consent to participate in this study.

This survey is completely anonymous. Please do not include your name, or any other information that may identify you other than the items listed below.

How old are you? _____

Please Circle: Male or Female

Please circle your ethnicity:

White

Hispanic

Asian

African-American

Other

Years diagnosed with juvenile arthritis _____

1. Do you feel that your medication helps you with your pain? Yes or No

2. Do you understand what your arthritis medication does to help with your arthritis symptoms? Yes or No

3. What does your medication do to help with your juvenile arthritis? _____

4. Besides taking your medicine, what do you do that helps you with your juvenile arthritis?

Fill in your answer: _____