

The Society for Clinical Child and Adolescent Psychology (SCCAP): Initiative for Dissemination of Evidence-based Treatments for Childhood and Adolescent Mental Health Problems

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Workshop

Enhancing Adherence to Pediatric Medical Regimens: Primary and Secondary Approaches

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Objectives

1. Describe evidence-based interventions to prevent medical adherence problems.
2. Describe evidence-based interventions intended to treat medical adherence problems.
3. Identify ways to deliver effective interventions via technology (web-based, phone apps).
4. Apply adherence theories to case studies.

Part 1 of 2

Adherence Definitions

“The extent to which a person’s behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice.”

Haynes et al. (1979). *Compliance in health care*. Baltimore: The Johns Hopkins University Press.

“The extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.”

World Health Organization (2003). *Adherence to long-term therapies: Evidence for action*. Geneva, Switzerland.

Medical Adherence Caveats

- Providers need to be adherent to recommended clinical care guidelines and prescribe efficacious treatments.
- Avoid “blame and shame” approach.
- Encourage active role for patients and families in health care.
- Nonadherence may be rational & adaptive.

Types of Medication Nonadherence

- Not filling prescription
- Not (or delaying) refilling prescription
- Omitting doses
- Drug holidays (no doses for several consecutive days)
- “Toothbrush Effect” or “White-coat” Adherence (increased adherence around clinic visits)
- Overdosing or taking extra “make-up” doses

Adherence to Inhaled Steroids in the treatment of Asthma

- M = 69% (65% classified as nonadherent, <80%) by electronic monitoring (Berg et al., 2007)
- M = 44% by canister weight (Celano et al., 1998)
- Underuse recorded on M = 55% of days by electronic monitoring (Coutts et al., 1992)
- M = 48% by electronic monitoring (McQuaid et al., 2003)
- M = 51% by electronic monitoring (McQuaid et al., 2005)
- M = 46% by electronic monitoring (Walders et al., 2005)
- M = 77% @ 3-month f/u to M = 49% @ 27-month f/u by dose counting (Jónasson et al., 2000)

Adherence to Prednisone in the treatment of Cancer

- 52% had subtherapeutic levels by serum assay (Festa et al., 1992)
- 42% had subtherapeutic levels by urine assay (Lansky et al., 1983)
- 33% had subtherapeutic levels by urine assay (Smith et al., 1979)
- 19% nonadherent (any missed dose in preceding month) @ 2-weeks, 40% @ 20-weeks, & 35% @ 50-weeks by patient and parent report (corroborated by serum assay) (Tebbi et al., 1986)

Adherence to Gluten-free Diet for Celiac Disease

- 28% classified as nonadherent by pediatric gastroenterologist (Anson et al., 1990)
- 46% classified as “occasional nonadherence” and 15% as “frequent nonadherence” by dietician interview (Bazzigaluppi et al., 2006)
- 40% had “poor adherence” by serum anti-bodies and clinical exam (Demir et al., 2005)
- 17% nonadherent by serum nitric oxide levels @ 1-yr f/u (Ertekin et al., 2005)
- 54% had “occasional lapses” by “clinical evaluation” (patient and parent interview plus serum anti-bodies) (Hartman et al., 2004)
- 29% nonadherent by serum anti-bodies (Kolaček et al., 2004)

Adherence to Antiretroviral Medications in the treatment of HIV/AIDS

- 44% of caregiver-youth dyads reported missing doses in the past week (Dolezal et al., 2003)
- M = 80.9% during 1st 3 months & M = 78.5% during last 3 months by electronic monitoring (Martin et al., 2007)
- 40% of caregivers & 56% of patients reported missed doses in the past month (Mellins et al., 2004)
- 43% of caregivers reported a missed dose in the previous week (Reddington et al., 2000)
- 30% of caregivers or patients reported missing some or all doses in the past 3 days (Van Dyke et al., 2002)
- 16% of caregivers or patients reported missing some doses in the past 3 days (Williams et al., 2006)

Adherence to NSAIDs in the treatment of JRA

- Baseline M = 86%; 3-mos f/u M = 92%; 6-mos f/u M = 90%; 9-mos f/u M = 92%; 12-mos f/u M = 89% by parent report over past 3 months (Feldman et al., 2007)
- 3% nonadherent (<60% of doses) by pill counts (Giannini et al., 1990)
- M = 95% by pill counts (Kvien & Reimers, 1983)
- 45% nonadherent by serum salicylate assay (Litt & Cuskey, 1981)
- 45% nonadherent by serum salicylate assay (Litt et al., 1982)
- Median levels showed partial or no adherence on 21% of 28 days; 48% nonadherent(<80% of doses) by electronic monitoring (Rapoff et al., 2005)

Adherence to Immunosuppressive Medications Post-renal Transplantation

- 43% nonadherent by pill counts (Beck et al., 1980)
- 21% nonadherent (<80% doses) by electronic monitoring (Blowey et al., 1997)
- 50% nonadherent by patient report plus serum assay (Ettenger et al., 1991)
- 16% nonadherent by patient report plus serum assay (Feinstein et al., 2005)
- M = 80% by electronic monitoring (Gerson et al., 2004)
- 14% nonadherent (missing medication ≥ 3 times a month) by patient report (Penkower et al., 2003)

Consequences of Nonadherence

- Compromises the efficacy of effective treatments
- Physicians unaware of nonadherence may order more invasive, risky, and costly procedures and may prescribe more potent meds with greater side-effects (Rapoff, 2010)
- Poorer health outcomes and more days with functional limitations and school or work absences; reduced quality of life
- 71% of nonadherent patients experienced rejection & had partial or total loss of allograft function (Ettenger et al., 1991)
- Nonadherence associated with higher viral loads in HIV/AIDS (Martin et al., 2007; Reddington et al., 2000)
- Cost of nonadherence in U.S. estimated at \$100 billion per year (Berg et al., 1993)

Adherence Enhancement Strategies

- Educational (about disease, treatments, and importance of adherence)
- Organizational (delivering health care in a way that facilitates adherence)
- Behavioral (cognitive and behavior change strategies to enhance adherence)

The What of Education (Content)

- The Disease (causes, course & prognosis)
- Treatments (what to do and why)
- Negative Side Effects (how to minimize)
- Adherence (importance and improvement strategies)

The How of Education (Strategies)

- As an ongoing process
- Effective verbal communication (avoid jargon, stress instructions, repeat info., encourage questions)
- Written & other media
- Modeling and behavioral rehearsal

Organizational Strategies

- Increase access to health care
- Consumer-friendly clinical settings
- Increase provider supervision
- Simplify regimens
- Minimize negative side effects

Behavioral Strategies

- Increased parental monitoring & supervision
- Prompting adherence
- Adherence incentives
- Discipline strategies
- Contracting
- Self-management strategies (goal setting, self-monitoring, self-administered consequences, problem-solving, & cognitive reframing)

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			<p>1</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>2</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>3</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>4</p> <p><u>Naproxen</u> ___ am ___ pm</p>
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<p>19</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>20</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>21</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>22</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>23</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>24</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>25</p> <p><u>Naproxen</u> ___ am ___ pm</p>
<p>26</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>27</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>28</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>29</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>30</p> <p><u>Naproxen</u> ___ am ___ pm</p>	<p>31</p> <p><u>Naproxen</u> ___ am ___ pm</p>	

Adherence-related thoughts about treatments and diseases that can have positive or negative consequences

THOUGHT	POSSIBLE POSITIVE CONSEQUENCES	POSSIBLE NEGATIVE CONSEQUENCES
“I take my medicine depending on how I feel; sometimes more, sometimes less.”	Useful guide for PRN (as needed) medications, if the person can appropriately match with symptoms.	Failure to achieve therapeutic drug level for continuous regimens.
“This medicine is causing harm or making me feel worse.”	Could avoid potentially serious side-effects.	Premature discontinuation of effective treatment (especially when side-effects are not serious, temporary, and can be minimized).
“This medicine (treatment) is not helping.”	Discuss with provider and treatment is modified or other treatments are added.	Premature discontinuation of effective treatment, (especially if insufficient time has elapsed to judge efficacy)
“I don’t really have this disease.”	If true, then avoids unnecessary treatments with possible negative side-effects.	If false, heightens the potential for decreased quantity and quality of life.
“My disease is not that bad.”	If true, then unnecessary treatments are avoided.	If false, heightens the potential for decreased quantity and quality of life.

Helpful Thoughts Worksheet

Directions: Try to notice when your thoughts are unhelpful. Write down any unhelpful thoughts you have on the left side of this page. Then try to change the “unhelpful thoughts” to “helpful thoughts”. Write the “helpful thought” on the right side of the page.

Unhelpful Thought	Helpful Thought
“My child often refuses to take his medication. Why do I even try?”	“My child does not like taking medication. I know that medication is important to his health. By using time-out to discipline my child, I will be helping him to be healthier.”

	In the past week, did this interfere with your child taking medications?	YES	NO
1.	I just forget to give my child medications		
2.	It is too hard to give my child medications when we are not at home		
3.	I get confused about how many pills or how much liquid of each kind to give to my child		
4.	My child feels physically worse when taking the medications		
5.	The pills are too hard for my child to swallow		
6.	I am not always there to remind my child to take medications		
7.	My child says that the medication tastes bad		
8.	I am not sure that my child needs medication		
9.	My child started to feel better and did not need the medication anymore		
10.	My child has multiple caregivers, and is often in different places (daycare, school, etc.)		
11.	We ran out of the medication		
12.	The pharmacy ran out of medication		
13.	My child resists medications that involve injections		
14.	My child just simply refuses to take the medications		
15.	I did not fill or refill my child's prescription because I could not afford them		

Review of Intervention Handouts

- CF Treatment Plan
- Written instructions for using an inhaler
- Pill swallowing protocol
- Regimen Monitoring Form
- Token System: “The Exchange Program”
- Negotiating and Contracting
- Essential Elements of CD-ROM or Web-based Programs

(Please follow along with the PDF Handouts provided)

Part 2 of 2

Meta-Analysis I (Kahana, Drotar, & Frazier, 2008)

N = 70 adherence-promotion studies

Weighted (by sample size) mean d across all adherence outcomes was in the “small” range:

$d = .34$ (95% confidence interval (CI) = 0.30 – 0.38)

However, there was significant heterogeneity across adherence outcomes. Therefore, the authors examined potential moderators of d .

Meta-Analysis I (Kahana, Drotar, & Frazier, 2008)

Moderators of Adherence Outcome d

Types of Interventions

- Behavioral: $d = .54$ (medium), 95% CI = 0.34-0.73
- Multicomponent: $d = .51$ (medium), 95% CI = 0.45-0.57
- Psychosocial: $d = .44$ (small to medium), 95% CI = 0.23-0.65
- Educational: $d = .16$ (small), 95% CI = 0.10-0.22
- Technology based: $d = .08$ (NS), 95% CI = -0.09-0.25

Meta-Analysis II (Graves et al., 2010)

- N = 71 studies (group and single subject designs)
- Mean effect size (weighted by sample size) for group designs: $d = 0.58$ (“medium” range), 95% CI = 0.51-0.65
- Moderators of effect size: Higher effect size for studies using a wait-list control design (mean $d = 1.09$) vs. an alternative treatment design (mean $d = 0.43$)
- Mean effect size (weighted by sample size) for single-subject designs: $d = 1.53$ (“large” range), 95% CI – 1.07-1.98). No moderators of effect size as homogeneous.

Meta-Analysis II (Graves et al., 2010): Health Outcomes

- 31 studies reported health outcomes: direct (e.g., A1C) indirect (disease activity), healthcare utilization, or subjective (quality of life = QOL).
- Mean $d = .40$ (small to medium),
95% CI = 0.31 – 0.50
- d higher for A1C, PFT, disease activity, & healthcare utilization vs. BMI & QOL

Prevention Model

- Primary: focus on patients not yet exhibiting “clinically significant nonadherence (CSN)” (“inconsistencies in following a particular regimen that may result in compromised health & well-being”; Rapoff, 2000)
- Secondary: focus on patients for whom CSN has been identified early on in disease course or has yet to compromise health & well-being
- Tertiary: focus on patients with ongoing pattern of CSN

Primary Prevention

- *Adherence enhancement strategies*: educational (e.g., about medical regimens & their importance), organizational (e.g., simplifying regimens), & behavioral (e.g., monitoring of adherence by providers or parents)
- *Implemented by*: primary health care providers (nurses, physicians)

Secondary Prevention

- *Adherence enhancement strategies*: more frequent monitoring of adherence by patients & parents, positive social reinforcement, & general discipline strategies (e.g., time-out for younger children)
- *Implemented by*: primary health care providers (nurses, physicians)

Tertiary Prevention

- *Adherence enhancement strategies*: token systems, written contracts, self-management training (e.g., problem-solving to anticipate & manage adherence barriers) & possibly psychotherapy
- *Implemented by*: pediatric psychologists & social workers

e-Health Interventions

Definition

“e-health interventions are applications of technology that seek to either improve a client’s understanding of health information or use technology as a surrogate for the clinician in treatment delivery.”

Modes of Delivery

- Programs designed to be Web-based (77% of US population has access to the internet)
- CD-ROM (internet access unnecessary)
- Organization websites (e.g., Juvenile Arthritis Alliance on Arthritis Foundation website)
- Computer games (e.g., STARBRIGHT Foundation)
- Personal Digital Assistants (PDAs)
- i-Phone applications (deliver content or prompts to engage in healthy behaviors; e.g., PTSD Coach by VA)
- Telehealth (deserving of it's own talk)

Comprehensiveness

- Some programs are self-sufficient, needing very little contact with clinicians or researchers, except for prompts to enter data or complete modules
- Some are more limited adjuncts to contacts with clinicians to provide additional reminders or information (e.g., email contact between clinic visits)

Advantages of e-health interventions

- Can be highly structured and standardized, enhancing treatment fidelity
- Can also be tailored to specific barriers/concerns
- Cost-effective and accessible: parents miss less work, children less school; reduced travel and visits
- Parents and children (especially children) are techno savvy
- Can add engaging elements such as audio, video, animations, music, and interactivity to make programs more attractive and increase use
- Data entry and completion of program modules can be monitored online in real time and generate prompts

Meta-Analysis of e-health interventions

- Cushing & Steele (2010)
- N=33 studies that targeted impact of programs on a pediatric disease (e.g., asthma), adherence to medications, or deleterious health behaviors (e.g., smoking)
- 13 studies (39%) used educational interventions and 20 studies (61%) used behavioral interventions
- Used Cohen's d for calculating effect sizes (.20 to .49 "small", .50 to .79 "medium"; and .80 and above as "large")
- Weighted (by sample size) mean effect size for all interventions was small ($d = .12$, 95% CI = .07 to .17); for behavioral interventions ($d = .35$, 95% CI = .23 to .48) while educational interventions were not significantly different from zero

Conclusions from the Meta-analysis (Cushing & Steele, 2010)

- Education not effective as it targets knowledge not changes in health behavior
- Knowledge alone is not sufficient to produce behavior change
- Effectiveness of behavioral interventions mirrors that of face-to-face delivered interventions
- Make sure there is evidence for the efficacy of face-to-face delivered interventions before making them e-health interventions

Systematic Review (Stinson et al., 2009)

- Reviewed internet-based self-management programs for youth w/ health conditions (asthma, pain, encopresis, traumatic brain injury, and obesity)
- Defined self-management as “the individual’s ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic illness” (Barlow et al., 2002)
- N= 9 studies (8 RCTs and 1 quasi-randomized trial)
- 7 of 9 studies demonstrated significant improvements in health outcomes compared to controls
- 4 studies on asthma found significant decreases in health care utilization

Conclusions from Systematic Review (Stinson et al., 2009)

- Adherence to internet interventions is problematic: mean dropout rate = 14% (range = 0 to 28%) comparable to 20% rate found in CBT studies w/ chronically ill children (Karlson & Rapoff, 2009)
- Need higher quality studies w/ larger samples
- Develop consensus on steps to take in developing and testing internet interventions to ensure usability and feasibility
- Greater uniformity across assessment intervals and longer ones to evaluate long-term effects
- Elucidate the mechanism of action of interventions

Barriers, Legal, and Ethical Issues

- Some families may not be so techno savvy
- Low SES families may not have computers or access to internet at home
- Programs are expensive to develop, implement, and maintain
- Quality control is critical with content reviewed by informed professionals
- Requires input of many professionals: physicians, psychologists, computer and web programmers, web designers and graphic artists, database developers, and health informatics

Barriers, Legal, and Ethical Issues (continued)

- HIPPA compliance
- Encryption of email and other type of online information
- Protecting privacy and confidentiality
- The lack of professional monitoring of patient or family chat rooms, twitter, facebook, and email contacts (need at least a disclaimer that information obtained in these ways should be discussed with clinician)
- Lack of personal contact with clinicians and unexpected negative outcomes from interventions

Recommendations for Future Research and Clinical Practice

- e-health interventions in pediatrics are promising and need to be adapted from validated face-to-face interventions
- Needs consensus on steps for developing and testing interventions:
 - Identify problem
 - Ascertain effectiveness of established treatments
 - Operationalize treatment completely
 - Consider legal and ethical issues
 - Transform treatment elements using engaging internet components
 - Personalize, tailor as much as possible
 - Construct the program and do initial focus group to get feedback
 - Finalize and do the initial pilot study (Ritterband et al., 2003b)

Recommendations for Future Research and Clinical Practice (continued)

- Evaluate interventions vs. treatment as usual then go to attention placebo comparisons
- Use multiple outcomes, quantitative (e.g., adherence to medications) and qualitative (e.g., user ratings of acceptability and feasibility of interventions)
- Measure outcomes over longer time intervals
- Measure adherence to e-health interventions
- Facilitate collaboration across multiple sites
- Start to incorporate well-validated e-health interventions into routine clinical practice as an adjunct to good clinical care

“Adherence-Strong”

- NIH-funded RCT, wait-list controlled trial of a web-based program for parents of children 2 to 7 years with juvenile arthritis (JA)
- PI: Michael Rapoff; Co-Investigator: Carol Lindsley; RA: Catrina Lootens; Study Coordinator: Suzie Wright
- Teaches parents strategies for enhancing adherence to prescribed medications for JA over a four week period
- Electronic and parent-rated adherence measures as well as quality of life
- [Adherence-strong](#)

Case Studies: Theory-based Analyses

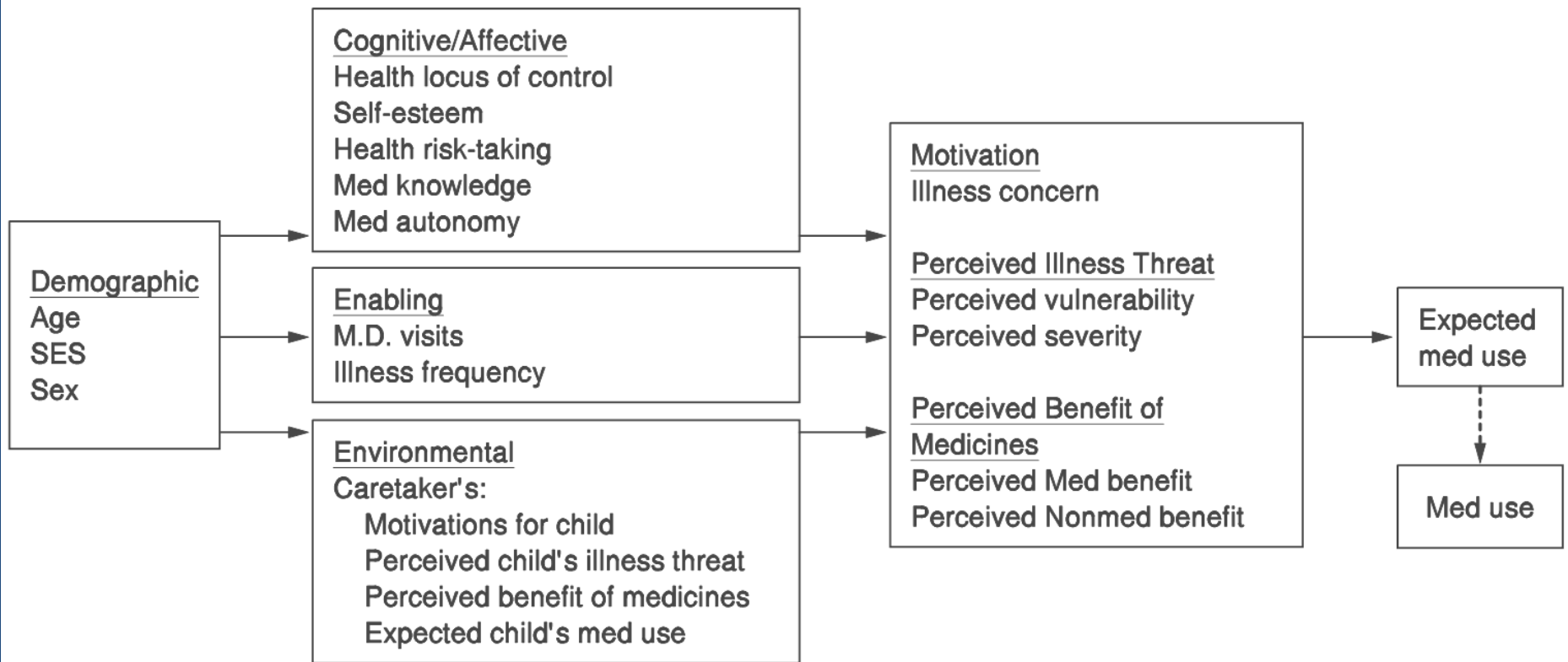
Rapoff (2010)

Children's Health Belief Model (CHBM)

MODIFYING FACTORS

READINESS FACTORS

BEHAVIOR FACTORS



An 8 year old boy who has moderately persistent asthma requires daily inhaled anti-inflammatory medication and an inhaled bronchodilator medication as needed. The boy has also been asked to monitor his peak flow levels once per day and after he takes his bronchodilator medication. His parents have been asked not to smoke in the house and to take steps to minimize his exposure to other allergens in the home, such as dust and pet dander.

Implications from the CHBM

Perceived susceptibility and severity:

- The clinician could assess whether the patient and his parents have accepted his condition and have a realistic view of the severity of his asthma.
- If they have an unrealistic view of severity, the clinician could review peak flow records and encourage the patient and parents to more closely monitor his symptoms in order to gain a more realistic perspective about severity.
- Information about severity should be balanced with positive information and encouragement that conveys a sense of optimism about the patient's and parents' ability to control his disease with increased monitoring and better adherence to prescribed regimens.

Perceived Benefits:

- The clinician could assess how confident the patient and parents are that the prescribed regimen is beneficial, especially in terms of quality of life benefits.
- If confidence is low, the clinician could review potential benefits of the prescribed regimen, such as increased participation in social and recreational activities.
- Clinicians should be alert to the possibility that prescribed treatments may not be beneficial for particular patients, in spite of optimal adherence. In these instances, the patient and parents should be encouraged to communicate this information to the physician and ask for modifications/additions to increase regimen efficacy.

Perceived Barriers:

- The clinician could interview the patient and parents to identify logistic barriers that prevent them from fully adhering to the regimen. For example, taking inhaled bronchodilator medications “as needed” requires the patient or parents to make judgments about “need”. They may need assistance in how to monitor symptoms and decide when bronchodilator medications are required.
- The parents may also perceive multiple barriers to reducing their son’s exposure to indoor allergens, such as finding the time to remove dust and pet dander on a regular basis and going outside to smoke during the winter. A good general question to ask of patients and parents would be: “What gets in the way or prevents you from doing.....?” The answer to this question should lead to practical recommendations from clinicians (e.g., smoke in the garage during the winter).

Cues to Action:

- The clinician could assess for the presence of reliable internal and external cues to prompt adherence.
- If the patient is relatively asymptomatic, there may not be consistent internal cues (such as dyspnea) to prompt adherence behaviors. Therefore, external prompts may be required, such as having the patient set his watch alarm for times when medications are to be taken or encouraging the parents to monitor and prompt adherence behaviors.

Applied Behavior Analysis/Operant Conditioning

		EFFECT ON BEHAVIOR	
		Increase (strengthen)	Decrease (weaken)
OPERATION	Add	Positive reinforcement (payoff, reward, positive consequences)	Positive punishment (scold, hurt, spank)
	Subtract	Negative reinforcement (relief, escape)	Extinction or negative punishment (loss, penalty, fine, response cost)

ABA Rule-Governed Behavior

- Behavior analysts are also giving increased attention to the unique role of verbal antecedents in the control of human behavior; so-called, rule-governed behavior. Rules are ubiquitous and can take many forms, such as instructions, laws, maxims, proverbs, advice, grammar, and scientific propositions. They are valuable because people can learn them more quickly without having directly experienced (or without ever experiencing) the consequences implied or specified by the rule. Parents count on rules, such as “look both ways before crossing the street”, to keep their children out of harms’ way.
- Whether rules are followed or not depends on the following factors: (1) a generalized history of reinforcement for following rules (or punishment for failing to follow rules); (2) immediate local consequences for following rules (often in the form of social approval or disapproval); (3) contact with the contingencies described in a rule (e.g., taking medications and experiencing symptom relief); and (4) automatic or self-given consequences (e.g., positive or negative feelings and thoughts).

- A 14-year-old male was diagnosed with polyarticular JRA two years ago. His disease has been under poor control as evidenced by multiple active joints, extended joint stiffness in the morning, severe limitations in daily activities, and moderate to severe joint pain reported by the patient. His regimen consists of an oral anti-inflammatory medication (Naproxen) two times a day, range of motion exercises once per day, and wearing joint splints on his wrists at night. The referring rheumatologist suspected that nonadherence to this regimen contributed significantly to the patient's poor disease control. The patient lived with both parents, who worked outside the home, and an older sister.

Implications from ABA

- Focusing on the complexity of the regimen (response costs), the clinician might discuss with the patient's physician and occupational therapist ways to simplify the regimen. For example, the patient may be able to switch to another anti-inflammatory medication that is taken once per day rather than twice and reduce the number of range-of-motion exercises.
- The clinician might need to help the patient and parents find specific and reliable cues or prompts for adherence on days when his disease symptoms are not as severe. For example, the patient may be asked to monitor and record adherence tasks as he completes them using a calendar chart posted in a prominent place or use a daily pill box.

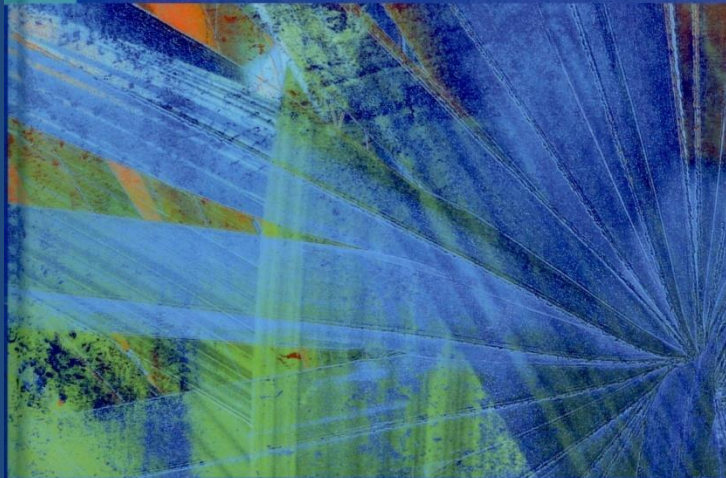
- The clinician may need to provide advice about how to reduce aversive consequences of adhering to the regimen. For example, anti-inflammatory drugs often cause gastric irritation and pain. The patient could be reminded to take medications with foods and along with his parents, to consult with his physician about the use of antacid medications to reduce gastric irritation and pain.
- Positive consequences for adherence may occur for this patient when he is symptomatic and adherence results in relief of disease symptoms, such as pain. During relatively asymptomatic periods, positive consequences may need to be specifically programmed to reinforce adherence behaviors. For example, the patient could be exposed to a token system program, whereby he earns points for adhering to regimens tasks and exchanges points for routine and special activities. The token system might also need to include point fines for nonadherence.

- Taking a rule-governed perspective, the patient may operate on unrealistic or unhelpful rules about his disease and regimen. For example, he may think he needs to be vigilant about following his regimen only when he is symptomatic. The clinician would need to help him challenge the utility of this rule and to formulate more helpful rules to advance his health status (e.g., “I need to take my medications, do my exercises, and wear my splints at night, even when I feel ok, in order to control my arthritis and to prevent flare-ups.”).

ISSUES IN CLINICAL CHILD PSYCHOLOGY

Michael A. Rapoff

Adherence to Pediatric Medical Regimens



Second Edition

 Springer

For more information, please go to the main website and browse for more videos on this topic or check out our additional resources.

Additional Resources

Online resources:

1. Society of Pediatric Psychology Adherence to Pediatric Medical Regimens Fact Sheet: <http://www.apadivisions.org/division-54/evidence-based/medical-regimens.aspx>
2. Society of Clinical Child and Adolescent Psychology website: <http://effectivechildtherapy.com>

Books:

1. Rapoff, M.A. (2000). Facilitating adherence to medical regimens for pediatric rheumatic diseases: Primary, secondary, and tertiary prevention. In D. Drotar (Ed.) *Promoting adherence to medical treatment in childhood chronic illness: Concepts, methods, and interventions* (pp.329-345). Mahwah, N.J.: Lawrence Erlbaum Associates.
2. Rapoff, M.A. (2010). *Adherence to pediatric medical regimens* (2nd ed.). New York: Springer.

Peer-reviewed Journal Articles:

1. Celano, M., Geller, R.J., Phillips, K.M., & Ziman, R. (1998). Treatment adherence among low-income children with asthma. *Journal of Pediatric Psychology*, 23, 345-349.
2. Cushing, C.C. & Steele, R.G. (2010). A meta-analytic review of eHealth interventions for pediatric health promoting and maintaining behaviors. *Journal of Pediatric Psychology*, 35, 937-949.
3. Drotar, D., Greenely, R., Hoff, A., Johnson, C., Lewandowski, A., Moore, M., Spilsbury, J., Witherspoon, D., & Zebracki, K. (2006). Summary of issues and challenges in the use of new technologies in clinical care and with children and adolescents with chronic illness. *Children's Health Care*, 35, 91-102.
4. Graves, M.M., Roberts, M.C., Rapoff, M.A., & Boyer, A. (2010). The efficacy of adherence interventions for chronically ill children: A meta-analytic review. *Journal of Pediatric Psychology*, 35, 368-382.
5. Kahana, S., Drotar, D., & Frazier, T. (2008). Meta-analysis of psychological interventions to promote adherence to treatment in pediatric chronic health conditions. *Journal of Pediatric Psychology*, 33, 590-611.
6. Rapoff, M.A., Belmont, J.M., Lindsley, C.B., & Olson, N.Y. (2005). Electronically monitored adherence to medications by newly diagnosed patients with juvenile rheumatoid arthritis. *Arthritis Care & Research*, 53, 905-910.
7. Stinson, J., Wilson, R., Gill, N., Yamada, J., & Holt, J. (2009). A systematic review of internet-based self-management interventions for youth with health conditions. *Journal of Pediatric Psychology*, 34, 495-510.

