# PORTRAITS OF ADHERENCE

## Patient-Centered Strategies in Cystic Fibrosis

# Webcast

JOHNS HOPKINS MEDICINE

JOHNS HOPKINS NURSING

Jointly Presented By the Johns Hopkins University School of Medicine and the Institute for Johns Hopkins Nursing.

Supported By an educational grant from Gilead Sciences, Inc.

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PORTRAITS OF ADHERENCE

Patient-Centered Strategies in Cystic Fibrosis


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BALTIMORE, MARYLAND

# LEARNING OBJECTIVES

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Integrate effective strategies to identify nonadherence in patients with CF into clinical practice.
- Create a comprehensive plan to address adherence barriers across the developmental spectrum including children, adolescents and adults.
- Incorporate adherence-improvement strategies into daily clinical practice, including using effective communication skills, engaging the multidisciplinary treatment team and making appropriate referrals.

# FULL DISCLOSURE POLICY AFFECTING CME ACTIVITIES

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

**The following relationships have been reported for this activity: PLANNERS**

| Name | Relationships |
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| Kristin Riekert, PhD | **Consultant:** Gilead Sciences, Inc. |

No other planners have indicated that they have any financial interest or relationships with a commercial entity.

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Patient-Centered Strategies in Cystic Fibrosis

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PORTRAITS OF ADHERENCE

Patient-Centered Strategies in Cystic Fibrosis


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PORTRAITS OF ADHERENCE

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# What is Adherence?

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# LEARNING OBJECTIVES

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Define the current state of adherence to CF therapies.
- Discuss the impact of adherence to CF therapies on health outcomes.

# ADHERENCE

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

## Definition (WHO 2001):

The extent to which a person's behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations.

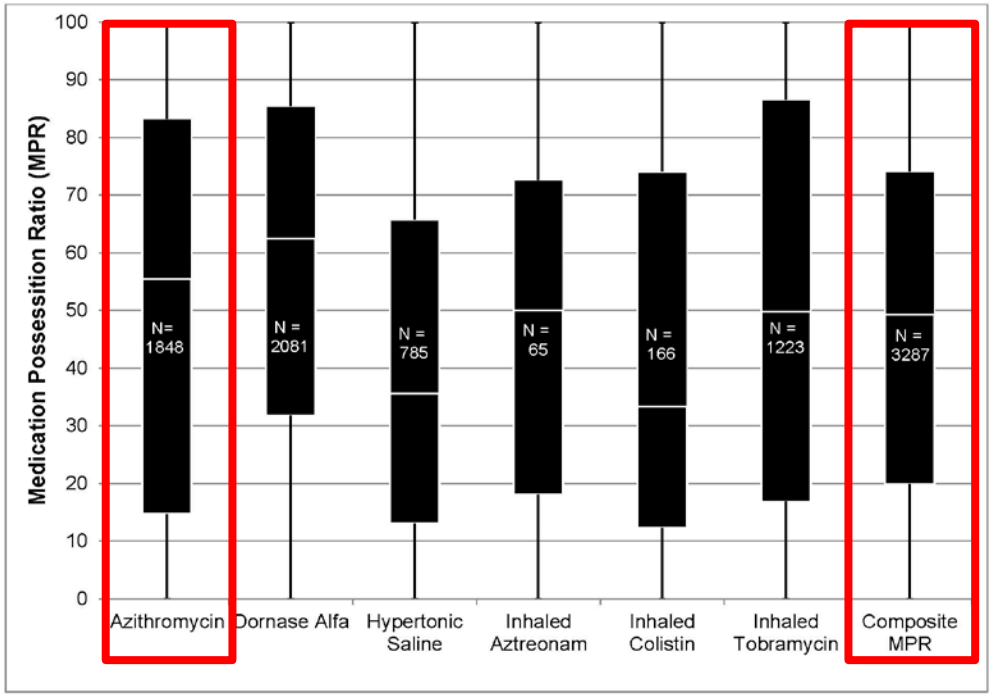
WHO 2003, Adherence to Long-Term Therapies: Evidence for action

# ADHERENCE IS IMPORTANT

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

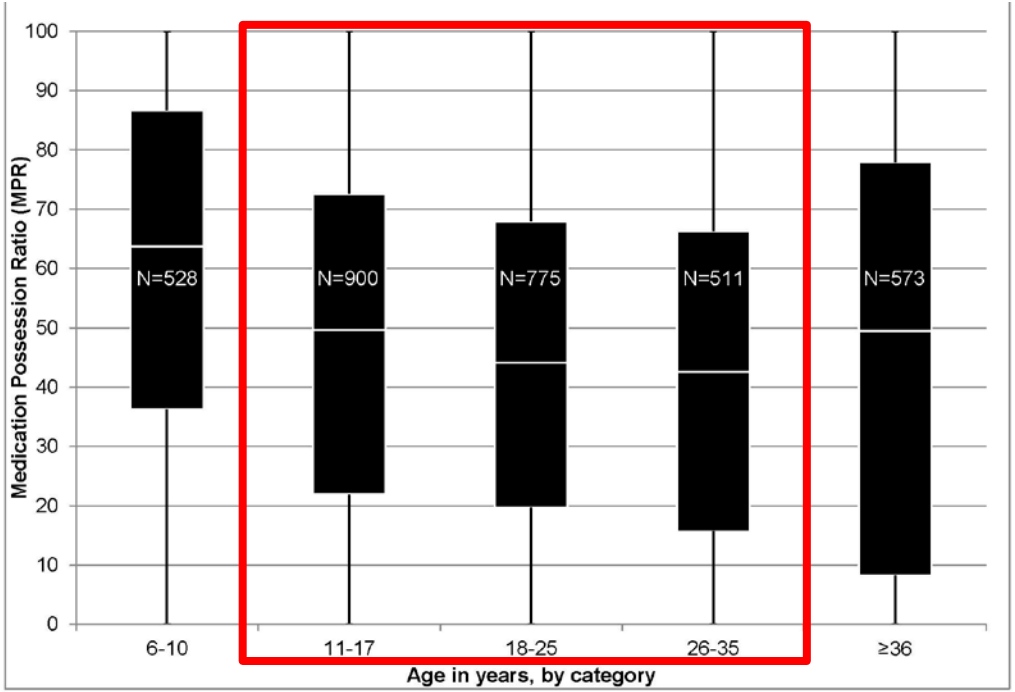
- Adherence is linked with better health outcomes
- Adherence to medications is associated with
  - Fewer pulmonary exacerbations
  - Higher lung function
  - Lower cost of hospital care
- Adherence becomes more important as therapies improve.

# ADHERENCE BY DRUG




Quittner AL, et al. *Chest.* 2014, 142-151.

# ADHERENCE BY AGE

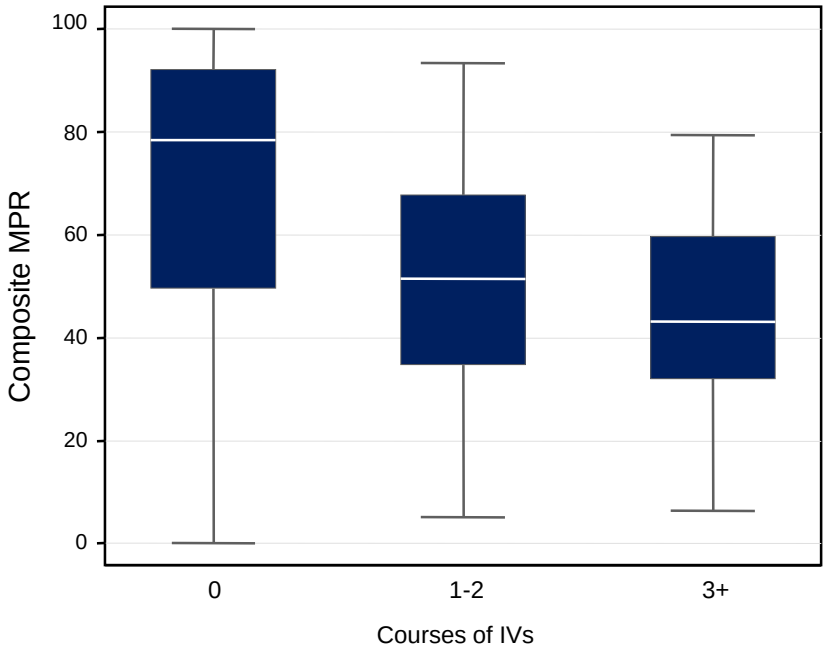



Quittner AL, et al. *Chest*. 2014, 142-151.

# IMPACT OF NONADHERENCE

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

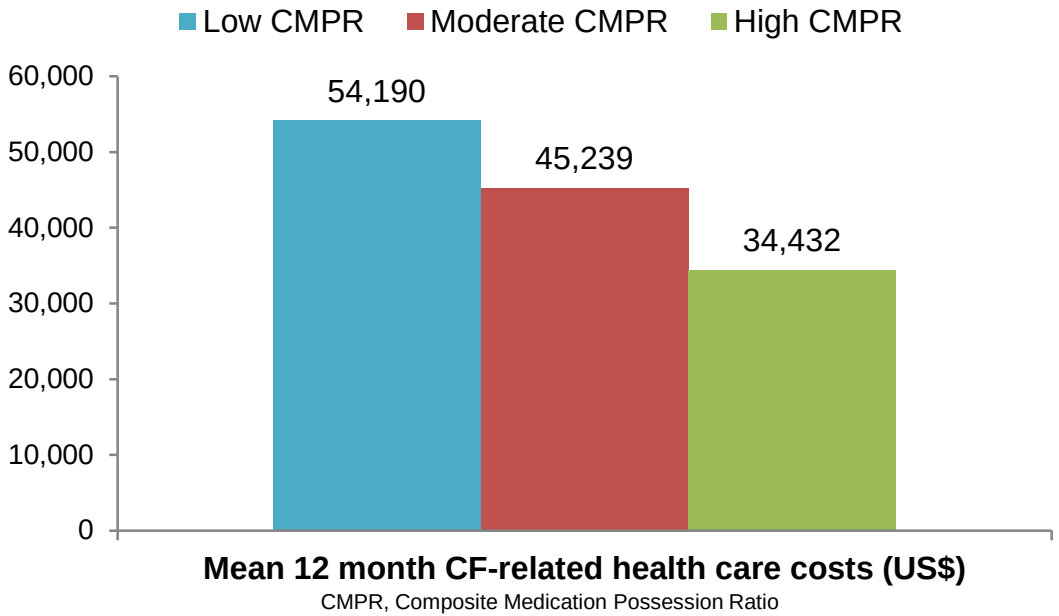
## Courses of IVs




Eakin MN, et al. *J Cyst Fibros.* 2011, 258-264.

# LOW ADHERENCE IS ASSOCIATED WITH HIGHER HEALTH CARE COSTS

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis




Quittner AL et al. *Chest.* 2014;146(1):142–151.

# CF FOUNDATION'S ADHERENCE STRATEGIC PLAN

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

## Partnerships for Sustaining Daily Care Program

# PATIENT AND PARENT QUOTES

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

"The constant self awareness that's needed to make good decisions to maintain one's health. The better you feel, the more you forget about taking care of yourself."

"You just have to stay to the treatment program at CF. You have no alternatives with CF; you have to just stick with the treatment plan."

"Finding a balance between living and doing all that is needed to do to be able to live."

"There is a lot of stress organizing treatment schedule; constant cleaning of equipment; time; money; balance of quality of life vs. quantity of treatments."

PORTRAITS OF ADHERENCE

Patient-Centered Strategies in Cystic Fibrosis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Kristin Riekert, PhD has indicated that she has no financial interests or relationships with a commercial entity whose products or services are relevant to the content of her presentation.

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# Conceptualizing Nonadherence

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# ADHERENCE TYPOLOGIES

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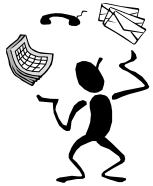
Patient-Centered Strategies in Cystic Fibrosis

## Unwitting

- Patient and provider mistakenly believe that the patient is adherent



## Erratic

- Patient understands and agrees with therapy but has difficulty consistently maintaining regimen

## “Rationalized”

- Patient deliberately alters or discontinues therapy

# THE RUBBER MNEMONIC

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

| | |
|---|---|
| **R**eview Regimen | • What does patient say they are taking? |
| **U**nderstanding | • What is patient's understanding of why, how & what they are taking? |
| **B**eliefs | • What does patient believe about the efficacy of their medications? Worries & concerns? Goals & values? |
| **B**arriers | • Any financial, personal, social, or organizational issues? |
| **E**ducate | • Clarify new regimen, correct misunderstandings, and answer questions |
| **R**epeat | • Ask patient to 'tell you back' what their regimen and understanding is. |

# REVIEW REGIMEN & UNDERSTANDING

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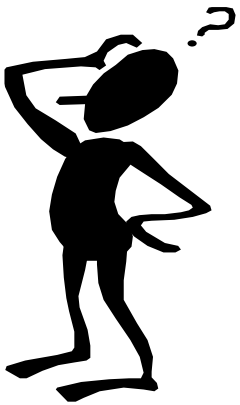
Patient-Centered Strategies in Cystic Fibrosis

## Unwitting Nonadherence



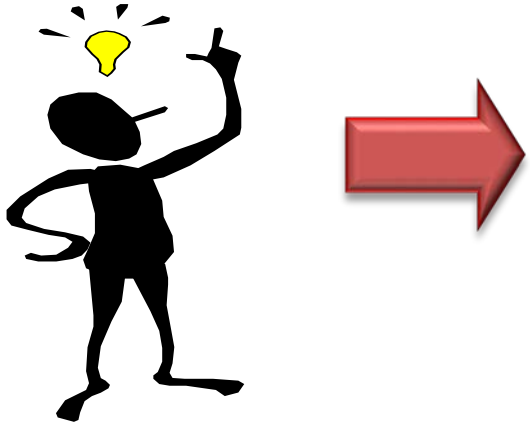
## RUBBER

- Provide & review written treatment plan
- Provide education
- Review device technique
- Ask patient to repeat dosing instructions (“Tell me back”)
- Get objective data on adherence levels

# BELIEFS

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

**“Rationalized” NonAdherence**



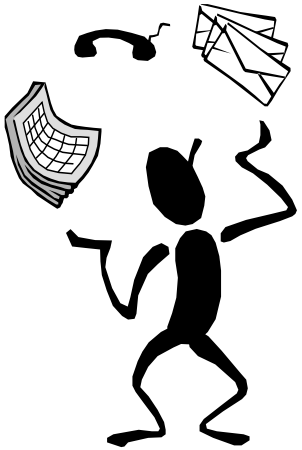
## RUBBER

- Identify beliefs and concerns about therapy
- Develop discrepancy between behavior and personal values and goals
  - Link therapy with these values and goals
- Personalized adherence and health feedback
- Use shared decision-making

# BARRIERS

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

## Erratic Adherence



## RUBBER

- Simplify & tailor regimen
- Behavioral strategies
- Reinforcement
- Encourage accessing social support
  - Including mental health support
- Link patient to resources

# EDUCATE & REPEAT

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

## RUBBER

- Elicit-Provide-Elicit
- “Tell me back” / “Teach back”
- Follow-up
  - Every clinic visit (You were going to try X, how did it go?)
  - Between visits (Was thinking of you, how is it going?)

PORTRAITS OF ADHERENCE

Patient-Centered Strategies in Cystic Fibrosis

# Why Adolescents Don't Adhere

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# PORTRAITS OF ADHERENCE

## Patient-Centered Strategies in Cystic Fibrosis


**GREGORY SAWICKI, MD, MPH**

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**BOSTON, MASSACHUSETTS**



Gregory Sawicki, MD, MPH has indicated that he has served as consultant to Gilead Sciences, Inc.

# LEARNING OBJECTIVES

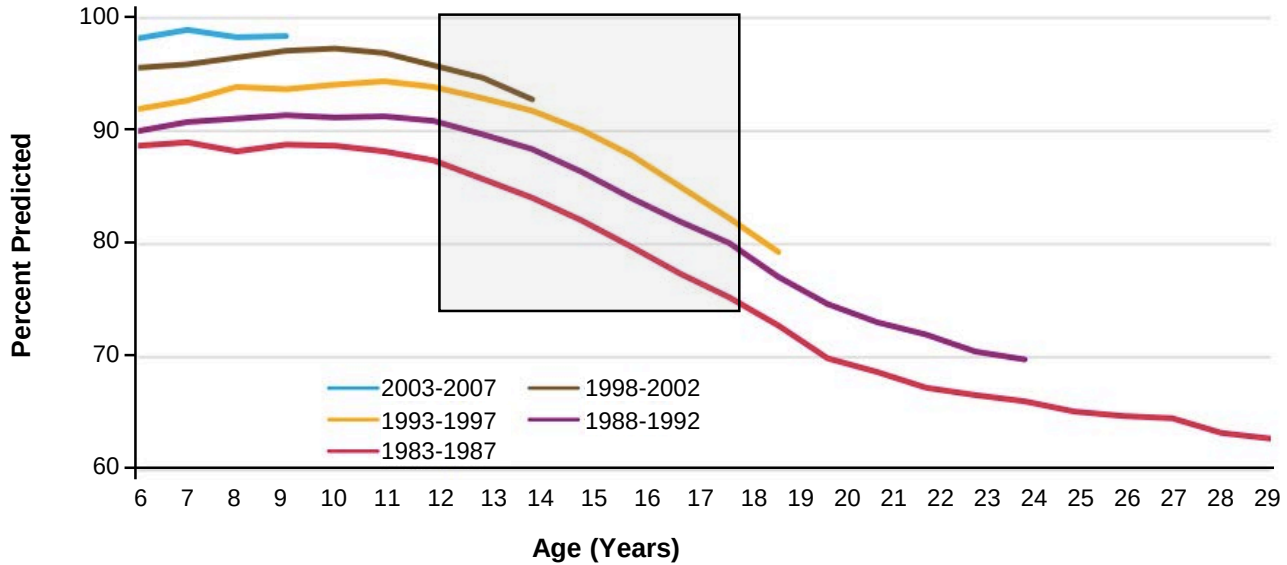
PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Identify the various types of barriers an adolescent with CF may experience.
- Recognize that each adolescent has individualized reasons for nonadherence.
- Describe ways to identify an adolescent's adherence barriers.

# ADOLESCENCE: A HIGH RISK PERIOD IN CF

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

## Median $FEV_1$ Percent Predicted vs. Age by Birth Cohort




CFF Patient Registry Data Report 2012

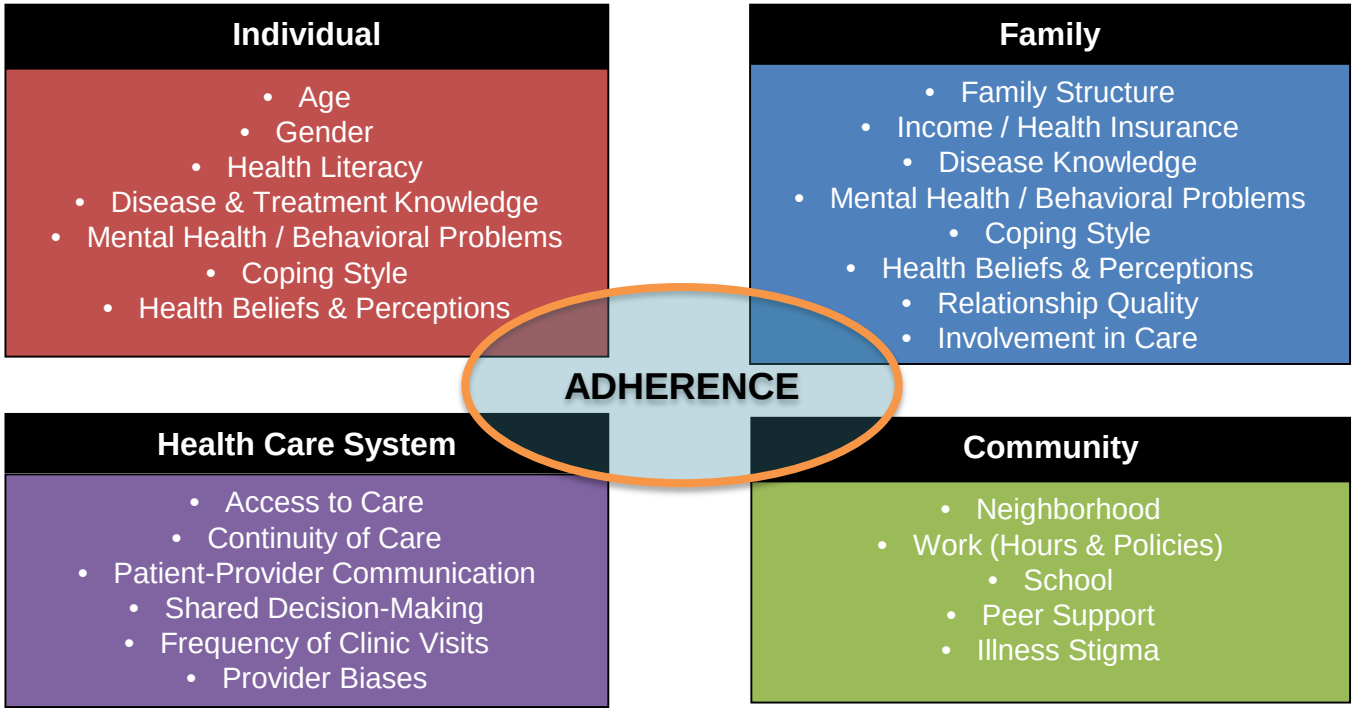
# COMMON ATTITUDES OF ADOLESCENTS WITH CF

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- CF is a problem their parents take care of
- CF is on the back burner
- Symptoms are a nuisance and are minimized
- Taking medication / completing treatments does not result in feeling better
  - May actually result in feeling worse!
- “When I skip my treatments I don’t feel sick”
- “If I am perfect with my meds I won’t or shouldn’t have problems”
- Anger at disease and caregivers

# WHAT IMPACTS ADHERENCE?

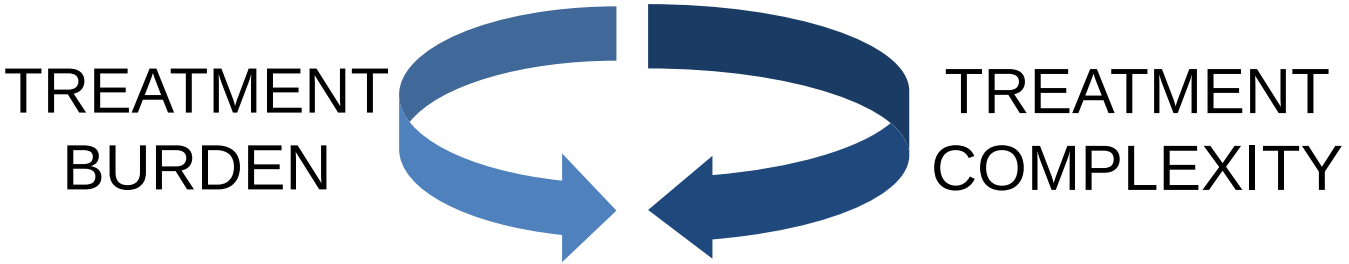
PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis




Adapted from Modi AC et al. *Pediatrics.* 2012;129(2)e473-485.

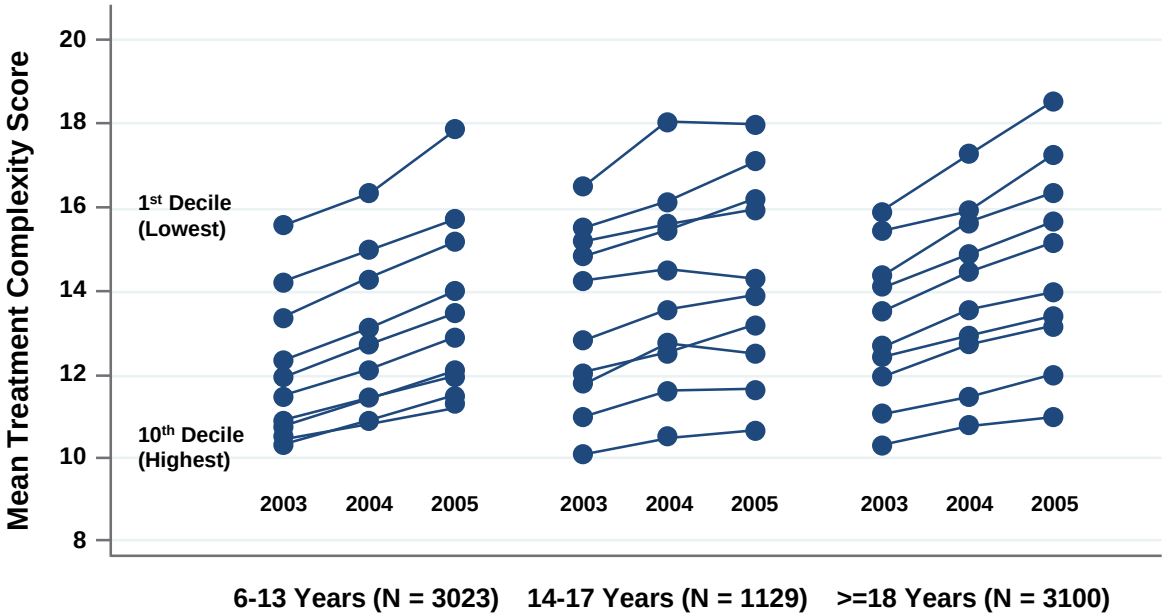
# CHALLENGE TO ADHERENCE #1: TREATMENT BURDEN AND COMPLEXITY

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis



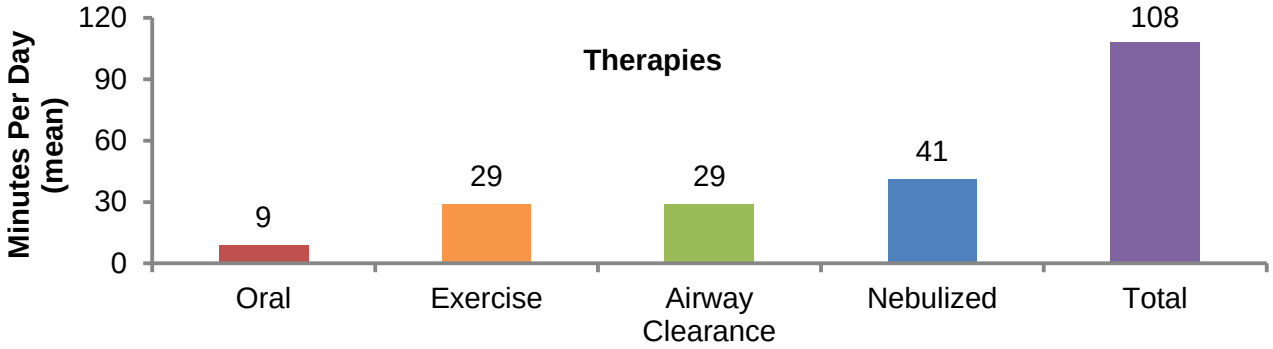
# TREATMENT COMPLEXITY IN CF HAS INCREASED

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis




Sawicki GS et al. *J Cyst Fibros*. 2013;12(5):461-467.

# HIGH TREATMENT BURDEN IN CF




| Medications | Median (Range) |
|---|---|
| # of Oral Medications | 3 (0-7) |
| # of Nebulized Medications | 2 (0-5) |
| # of Inhaled Medications (MDI) | 1 (0-4) |
| **# of Total Medications** | **7 (0-20)** |

Sawicki GS et al. *J Cyst Fibros.* 2009;8(2):91-96.

# CHALLENGE TO ADHERENCE #2: DEVELOPMENTAL ISSUES IN ADOLESCENCE

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Desire for greater independence
- Less parental supervision
- More erratic life style (sleep, schedules)
- Concerns increase over social acceptance, disclosure, physical appearance
- Experimentation and risk-taking
- Sense of invulnerability
- Lack of long-term goals

# BARRIERS TO ADHERENCE: ADOLESCENT PERSPECTIVES

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Immediate time pressures
  - Lack of time
  - Uncertain schedules
  - Forgetfulness – accidental or purposeful
- Awareness of disease trajectory
  - Recognizing the potential for futility in adhering to a therapeutic regimen
  - Avoiding therapies in favor of other activities due to a sense that life may be limited
- Competing priorities
  - Balancing time trade-offs
- Privacy concerns
  - Wanting to be “normal”; not wanting to seem different or disabled
- Lack of perceived consequences
  - Not seeing an impact on one's health from skipping treatments or medications

Sawicki GS, et al. *Pediatr Pulmonol* . 2015 Feb;50(2):127-36.

# FACILITATORS OF ADHERENCE: ADOLESCENT PERSPECTIVES

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Recognize the importance of therapies
  - Accepting responsibility for one's health and CF care
- Foster relationships with the CF Care Team
  - CF team should be creative in problem-solving with the adolescent and parent
- Empower adolescents
  - Enabling parents to cede control and entrust responsibility to adolescents
  - Allowing adolescents to experience the negative consequences to their health of nonadherence in order to increase the likelihood of future adherence to treatments
- Develop self-care skills through repeated practice
  - Gradually increasing responsibility given to the child for self-care
- Establish a structure
  - Having a daily routine, “making it a ritual”

Sawicki GS et al. *Pediatr Pulmonol*, 2015 Feb;50(2):127-36.

# SOME PLACES TO START

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Address Treatment Complexity
  - Explore ways to make therapies and interventions more practical
  - Identify ways to reduce treatment burden
- Design Interventions Tailored to Developmental Trajectories
  - Facilitate youth-derived goals for adherence behaviors that incorporate parents, peers, and multidisciplinary clinician input
  - Promote adult developmental milestones through early initiation and repeated practice of self-management skills

# PORTRAITS OF ADHERENCE

## Patient-Centered Strategies in Cystic Fibrosis

# HOW TO MEASURE ADHERENCE

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# LEARNING OBJECTIVES

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Describe challenges in measuring adherence to chronic therapies in CF.
- Identify strategies to measure adherence in CF.
- Characterize advantages and disadvantages of various measures of adherence in CF.

# WAYS TO MEASURE ADHERENCE

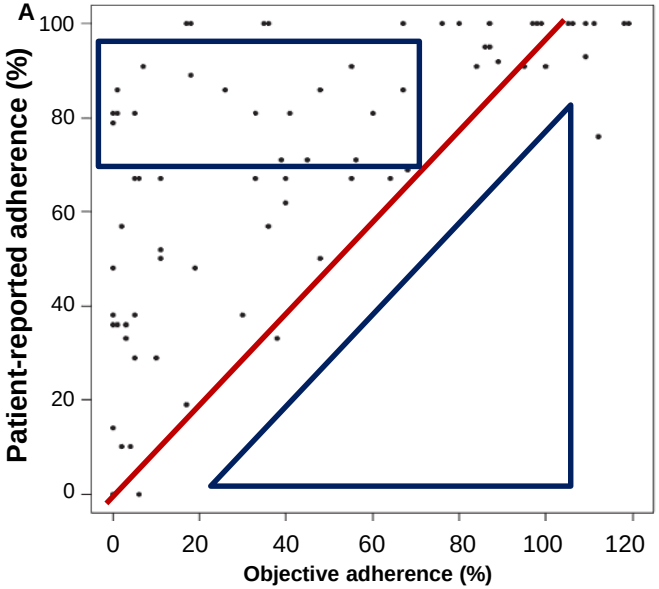
PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Self-report
  - Daily diaries
  - Questionnaires
  - Interviews
- Clinician-report
  - Questionnaires
- Pharmacy records
  - Medication Possession Ratio (MPR)
  - Proportion of Days Covered (PDC)
  - Number of refills
- Electronic monitors
  - MEMS caps
  - “Chipped” devices
  - MDI monitors

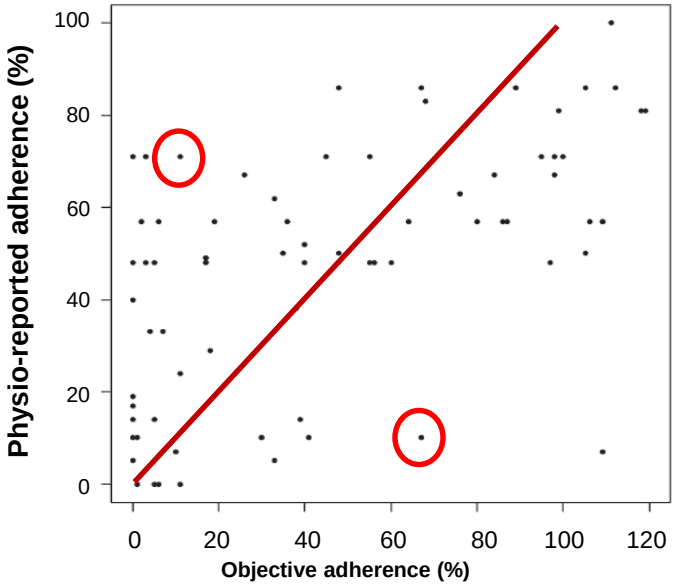
# CHALLENGES WITH SELF-REPORT AND CLINICIAN-REPORT

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

## PATIENT REPORT




## PROVIDER REPORT




Daniels T et al. *Chest.* 2011;140(2):425–432.

# ELECTRONIC MONITORING

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

## Advantages

- Continuous, long-term, real-time measure
- More objective than diaries or self-report
- Can identify a spectrum of issues
  - Underdosing
  - Delayed dosing
  - Drug “holidays”
  - “White-coat” adherence

## Disadvantages/Challenges

- Device malfunction
  - Recording events that did not occur
  - Fail to record events that did occur
  - Technology failure
- Cost
- Privacy concerns

# ELECTRONIC MONITORING: NEBULIZED THERAPIES

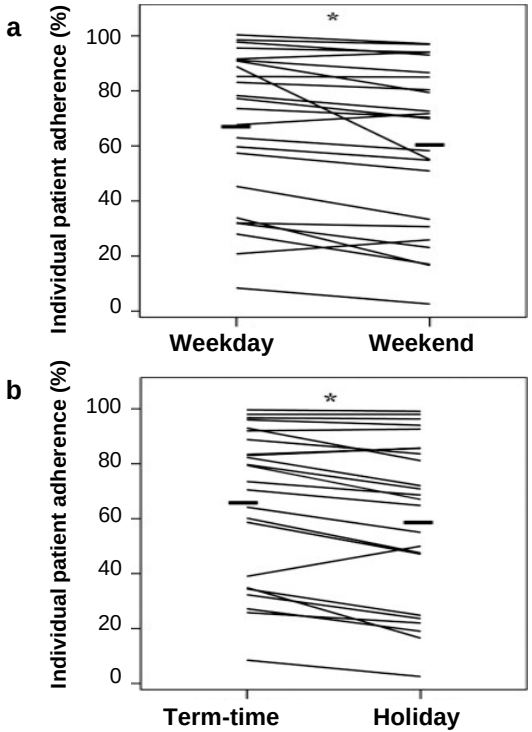


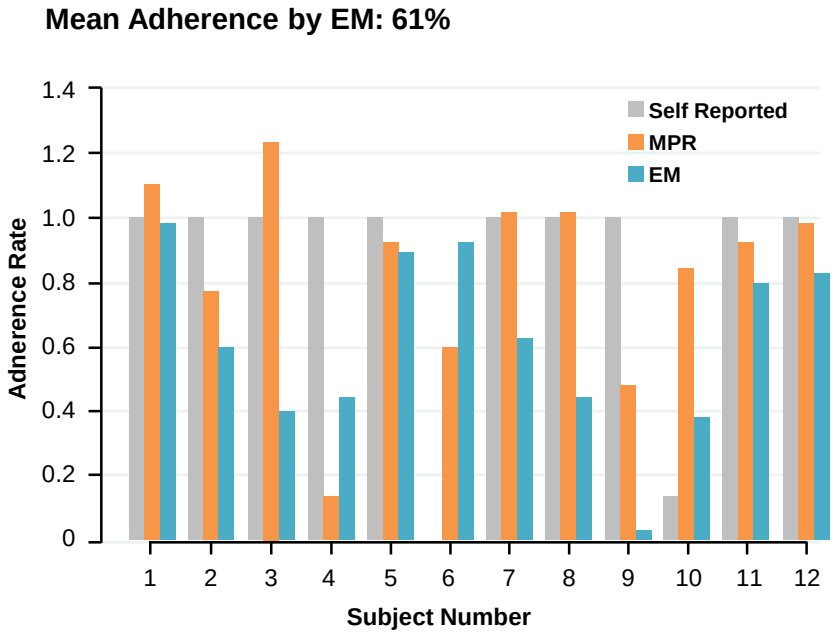

Fig. 1 Comparison of adherence to treatment for individual patients during a) weekdays and weekends and b) holidays and term-times. The horizontal thick bars represent mean adherence for the group (P = <0.001).

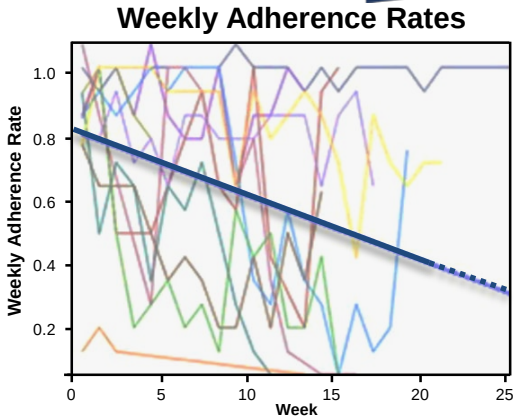
- Adherence in adolescents was higher on weekdays during school term-time

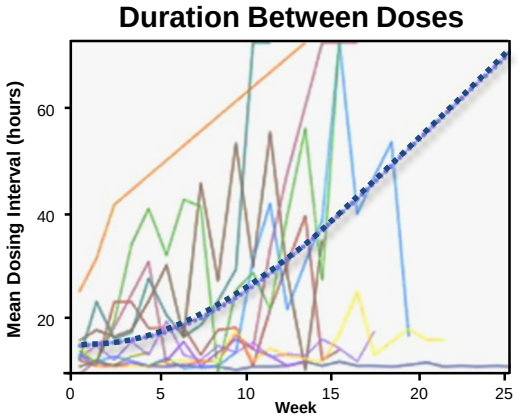
Ball R, et al. *Journal of Cystic Fibrosis*, Volume 12, Issue 5, 2013, 440 – 444.

# ELECTRONIC MONITORING: IVACAFTOR

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis




Siracusa CM, et al, *Journal of Cystic Fibrosis*. 2015-09-01, Volume 14, Issue 5, Pages 621-626.

# PHARMACY RECORDS

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

## Advantages

- Identify what medications an individual has obtained
  - As opposed to what is prescribed
- Allows for evaluation of adherence over a longer time period without need for individual input/recall

## Challenges

- Only measures dispensing of medication
- Not always clear exactly what has been prescribed
  - Dose/frequency
  - “Overfilling” of Rx
  - Lack of written treatment plans
- May not account for changing treatments over time
  - Alternating antibiotics
  - Hospitalizations

# WHAT IS THE DOMINANT TYPOLOGY?

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

1. Unwitting
2. Erratic
3. “Rationalized”

# TYPOLOGY

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

| Typology | Jamie |
|---|---|
| Unwitting | X |
| Erratic | XX |
| “Rationalized" | XXXXXXXX |

# HOW MIGHT YOU PROCEED?

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Develop an understanding of goals [“rationalized”--BELIEFS]
- Discuss concerns about therapy [“rationalized”--BARRIERS]
- Consider Problem-solving [erratic—BARRIERS]
- Education on how therapies work & why necessary [unwitting—Understanding & Educate]
- Shared-Decision Making [“rationalized”--BELIEFS]

# PORTRAITS OF ADHERENCE

## Patient-Centered Strategies in Cystic Fibrosis

# WHY CHILDREN DON'T ADHERE

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# PORTRAITS OF ADHERENCE

Patient-Centered Strategies in Cystic Fibrosis


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**PEDIATRIC PULMONARY CENTER**
**AMERICAN FAMILY CHILDREN'S HOSPITAL**
**MADISON, WISCONSIN**

# LEARNING OBJECTIVES

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Identify the various types of barriers children with CF may experience.
- Recognize that each child has individualized reasons for nonadherence.
- Describe ways to identify children's adherence barriers.

# FACTORS FOR NONADHERENCE: PRESCHOOL AND SCHOOL-AGE CHILDREN

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Limited time and continuity of provider-family interaction
- Unclear/conflicting recommendations
- Health literacy/education
- Child and family characteristics, structure, and function
- Caregiving environments
- Cost/food security

Winnick, S, et al. *Pediatrics*. 2005: 115(6): 718-724.

# FACTORS FOR NONADHERENCE: PRESCHOOL AND SCHOOL AGE CHILDREN

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Parental Stress/Depression
  - Parental anxiety and guilt associated with child feeding concerns and underweight can lead to:
    - Less structured meals and snacks/increased grazing
    - More intrusive feeding practices
    - Acceptance of mealtime disruptions/negative behaviors
- Culture and beliefs about food and diet
  - Necessity of nutritional interventions
- Child's age

Goodfellow, NA, et al. *BMC Pulm Med*. 2015: 15:43. Powers, SW, et al. *J Cystic Fibrosis*. 2005 (4): 175-182. Ward, C, et al.. *Arch Dis Child* . 2009: 94(5): 341-347.

# TYPES OF NUTRITION NONADHERENCE IN YOUNG CHILDREN WITH CF

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Food refusal
- Stalling
- Leaving the table
- Distraction
- Negotiating

- Fear of new food
- Mixed messages
- Autonomy and the power of “No”
- Attention seeking (reward)

Powers, SW, *JAMA Pediatr*. 2015: 169(5). Mitchell, MJ, et al. *J Dev Behav Pediatr.* 2004: 25(5): 335-346. Powers, SW, et al. *J Cystic Fibrosis*. 2005 (4): 175-182.

# IDENTIFICATION OF ADHERENCE BARRIERS IN PRESCHOOL AND SCHOOL-AGE CHILDREN

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- The “Interview” (“The Who, What, When, Where, and How?”)
  - Who is responsible for meals?
  - What’s eaten?
  - What happens when meal/snack is not eaten or food is refused?
  - What distractions are present both for child and parent (phone, tablet, TV, video game devices, siblings)?
  - When and where meals are taken?
  - How long are meals and snacks?
  - How are enzymes/vitamins/supplements given and how often are they missed? What happens when they are missed? Who’s responsible for administering them?

# THE INTERVIEW: PRESCHOOL/SCHOOL-AGE CHILD AND FAMILY

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Does child/caregiver have any concerns about meals/snacks?
- How do caregivers and child feel meal and snack time are going?
- What is the typical meal/snack schedule?
- How much and what does s/he eat at one time?
- Who decides what to eat and how much is enough?

# THE RUBBER MNEMONIC

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

**R:** Review Regimen: What does the child and family say they are doing?

**U:** Understanding: What is the child and family's understanding of why, how, and what they are doing for their nutrition care plan?

**B:** Beliefs: What does the child and family believe about the importance of nutrition? Worries and concerns? Family's goals and values?

**B:** Barriers: Are there any personal, financial, social or organization/system barriers? Food security? Do any goals and values conflict with religious or cultural beliefs?

**E:** Educate: Clarify the treatment plan, correct misunderstandings, and answer child's and family's questions

**R:** Repeat: Ask child and family to "tell you back" what their care plan and understanding is

# WHAT IS THE DOMINANT TYPOLOGY?

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

1. Unwitting
2. Erratic
3. “Rationalized”

# TYPOLOGY

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

| Typology | Collin |
|---|---|
| Unwitting | X |
| Erratic | XX |
| “Rationalized" | XXX |

# HOW MIGHT YOU PROCEED?

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Develop discrepancy [“rationalized” — BELIEFS]
  - What are the family’s goals?
- Discuss beliefs and concerns about nutrition [“rationalized” — BELIEFS]
- Education on nutritional behavior therapy & why necessary [unwitting — rewarding Collin’s eating behaviors with attention and toys]
  - Empathically provided with Elicit-Provide-Elicit
- Shared decision-making [“rationalized” — consistency with parenting — BELIEFS]
  - Plant seeds for future g-tube

PORTRAITS OF ADHERENCE

Patient-Centered Strategies in Cystic Fibrosis

# Why Adults Don't Adhere

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PORTRAITS OF ADHERENCE

Patient-Centered Strategies in Cystic Fibrosis


# KRISTIN RIEKERT, PHD

**CO-DIRECTOR, JOHNS HOPKINS ADHERENCE RESEARCH CENTER**

**DIRECTOR, CYSTIC FIBROSIS ADHERENCE PROGRAM**

**JOHNS HOPKINS SCHOOL OF MEDICINE**

**BALTIMORE, MARYLAND**


Kristin Riekert, PhD has indicated that she has no financial interests or relationships with a commercial entity whose products or services are relevant to the content of her presentation.

# LEARNING OBJECTIVES

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Identify the various types of barriers an adult with CF may experience.
- Recognize that each adult has individualized reasons for nonadherence.
- Describe ways to identify an adult's adherence barriers.

# QUALITATIVE INTERVIEWS (ADULTS N=25)

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

| BARRIERS | |
|---|---|
| 64% | •Treatment Burden |
| 60% | •Social Demands |
| 60% | •Work Demands |
| 60% | •Forgetting |
| 56% | •Absence of Perceived Health Benefit |
| 56% | •Fatigue |
| 36% | •Stigma/Embarrassment |

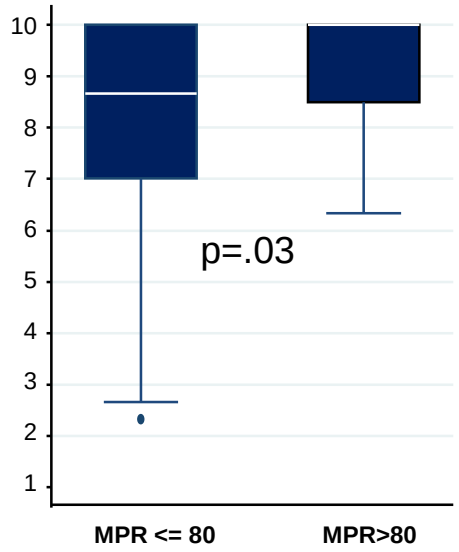
| FACILITATORS | |
|---|---|
| 76% | •Attending CF Clinic |
| 68% | •Support & Reminders |
| 68% | •Presence of Perceived Health Benefits |
| 48% | •Ease of Completion |
| 48% | •Habit / Routine |
| 44% | •Distractions & Rewards |
| 44% | •Guilt |

George M, et al. *Journal of Cystic Fibrosis*. 2010; 9:425-432.

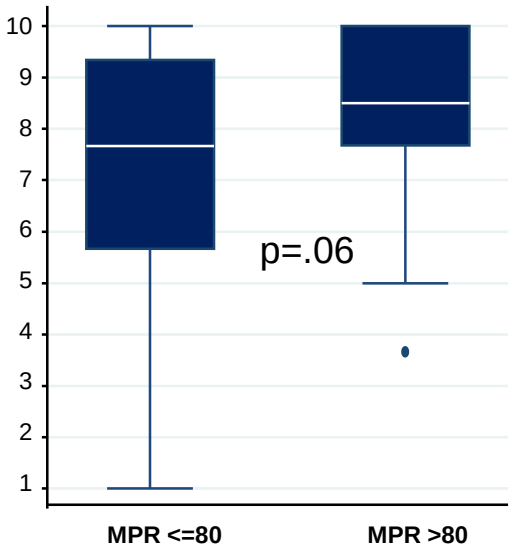
# HEALTH BELIEFS

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

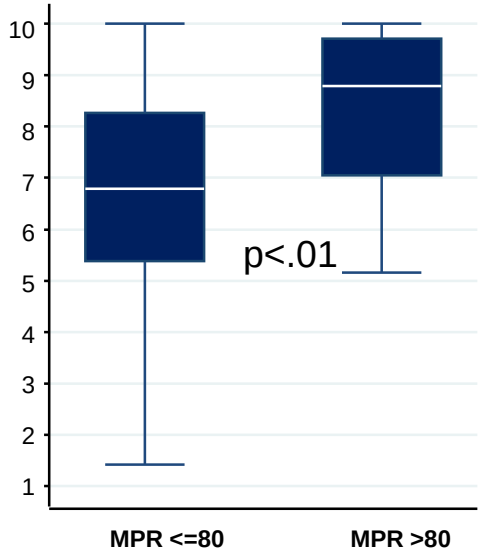
## IMPORTANCE




## MOTIVATION




## SELF-EFFICACY




Riekert KA. Presentation at: 26th North American Cystic Fibrosis Conference (NACFC); October 11-13, 2012; Orlando, FL.

# EMPLOYMENT

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Most adults will attain employment and independence from their parents.
- CF's impact on employment:
  - Career choice
  - Work part time or stop working (regimen burden and health)
  - Workplace discrimination
- Few do therapies at work
- Stressful balancing employment and CF care


Besier T, Goldbeck L. *Qual Life Res*. 2012 Dec;21(10):1829-35.

Higham L, et al. *J Genet Couns*. 2013 Jun;22(3):374-83.

Targett K, et al. *Occup Med (Lond)*. 2014 Mar;64(2):87-94.

Laborde-Castérot H, et al. *J Cyst Fibros*. 2012 Mar;11(2):137-43.

Demars N, et al. *Disabil Rehabil*. 2011;33(11):922-6.

# SOCIAL ASPECTS

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Young adults = No longer with parents; not yet with spouse
- Social functioning declines with age
- Life satisfaction is lower in adults
  - Even after controlling for lung function and mental health
- Desire for “normal”– get married, have children, be employed
- Unpredictable nature of CF makes it hard to plan

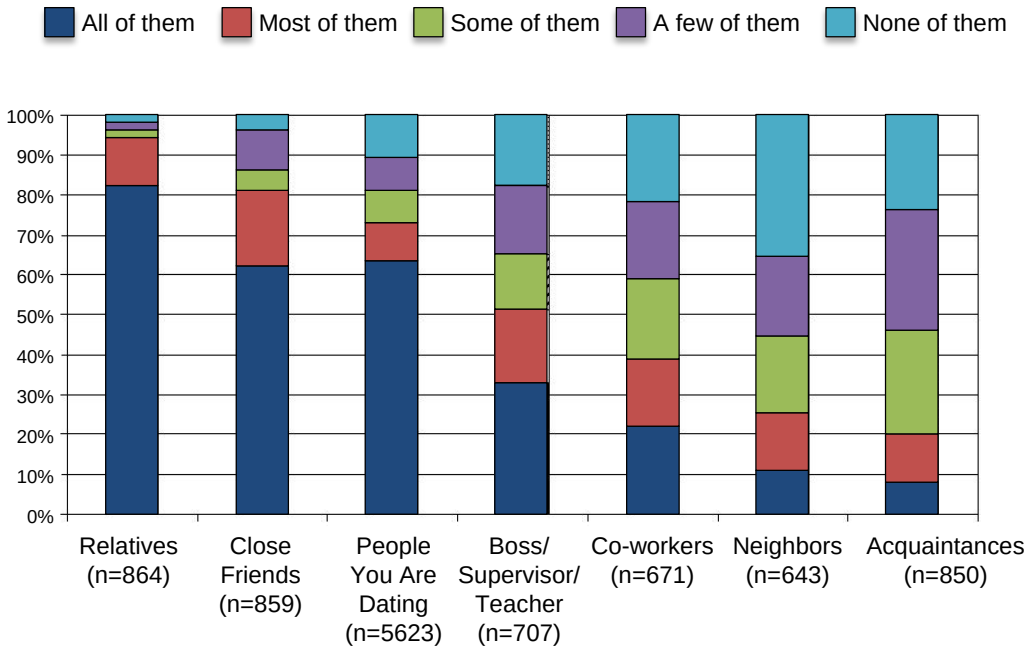
Besier T, Goldbeck L. *Qual Life Res*. 2012 Dec;21(10):1829-35. Higham L, et al. *J Genet Couns*. 2013 Jun;22(3):374-83. Dill EJ, et al. *Chest*. 2013 Sep;144(3):981-9.

# DISCLOSURE

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Comfort doing treatments in front of others
- Comfort discussing CF with others

- Higher Social Support
- Higher Self Efficacy



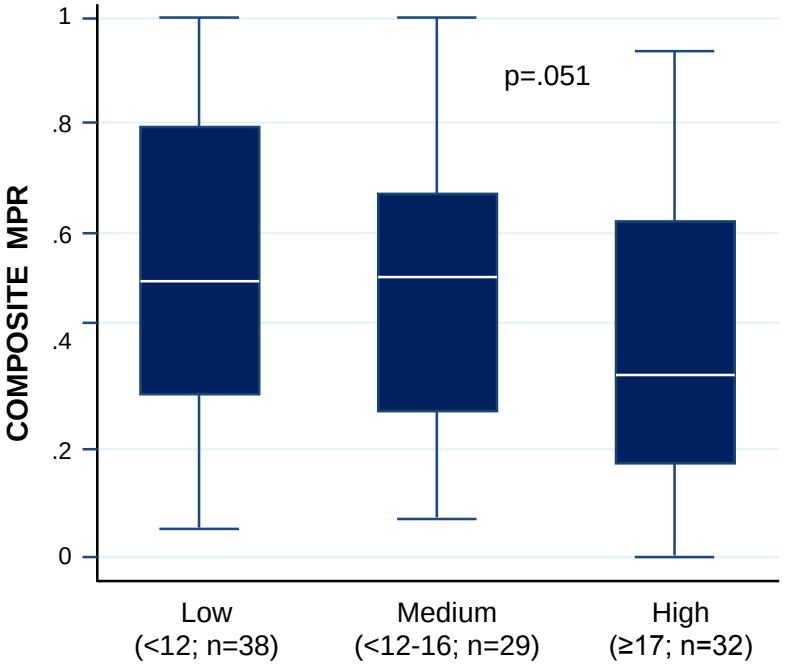


Modi AC, et al. *BMC Pulm Med*. 2010 Sep 10;10:46. doi: 10.1186/1471-2466-10-46.

Borschuk AP, et al. (2015) The Impact of CF on Relationships Throughout the Lifespan Symposium. NACFC Phoenix AZ

# FATALISM

Mean (SD) Age = 29 (11) years




Riekert KA, et al. Psychological Factors Associated with Respiratory Health Outcomes. May 1, 2012, A1095-A1095 (Poster presented at ATS conference 2012)

# WHAT IS THE DOMINANT TYPOLOGY?

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

1. Unwitting
2. Erratic
3. “Rationalized”

# TYPOLOGY

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

| Typology | Amy |
|---|---|
| Unwitting | X |
| Erratic | XX |
| “Rationalized" | XXXXXX |

# HOW MIGHT YOU PROCEED?

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Develop discrepancy [“rationalized” — BELIEFS]
  - What are Amy’s goals? How does adherence or nonadherence affect success?
- Discuss beliefs and concerns about therapy [“rationalized” — BELIEFS]
- Education on how therapies work & why necessary [unwitting — Understanding & Educate]
  - Empathically provided with Elicit-Provide-Elicit
- Shared decision-making [“rationalized” — BELIEFS]
- Screen for depression [erratic — BARRIERS]
- If willing to try therapy, problem-solving [erratic — BARRIERS]
  - To fit treatments into her day

# PORTRAITS OF ADHERENCE

## Patient-Centered Strategies in Cystic Fibrosis

# Engaging the Patient and Family

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# LEARNING OBJECTIVES

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

- Identify patient and family-centered communication skills.
- Recognize when additional support are needed beyond the capacity of the CF Care Team.
- Describe characteristics of difficult conversations about adherence.
- List three conversation tips that promote positive conversations between a patient/family and provider about adherence.

# DISCUSSION POINTS

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

1. What makes it difficult to have conversations about adherence with patients and their families?

# DISCUSSION POINTS

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

2. How do you promote a positive conversation about adherence with your patients and their families?

# DISCUSSION POINTS

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis

3. If more support is needed beyond what your Care Team can provide, what do you do?

# PORTRAITS OF ADHERENCE

## Patient-Centered Strategies in Cystic Fibrosis

# Questions and Answers

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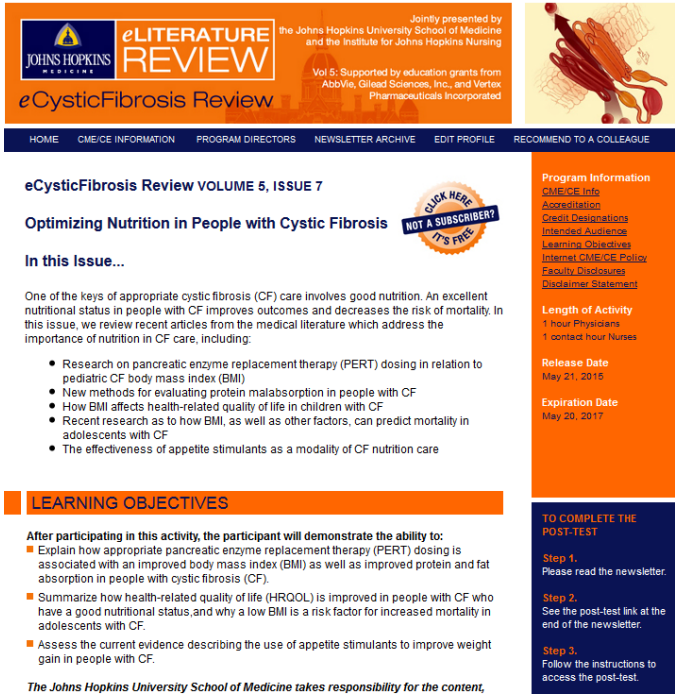
# ECYSTICFIBROSISREVIEW.ORG

PORTRAITS OF ADHERENCE
Patient-Centered Strategies in Cystic Fibrosis



JOHNS HOPKINS MEDICINE eLITERATURE REVIEW
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eCysticFibrosis Review VOLUME 5, ISSUE 7

Optimizing Nutrition in People with Cystic Fibrosis

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In this Issue...

One of the keys of appropriate cystic fibrosis (CF) care involves good nutrition. An excellent nutritional status in people with CF improves outcomes and decreases the risk of mortality. In this issue, we review recent articles from the medical literature which address the importance of nutrition in CF care, including:

- Research on pancreatic enzyme replacement therapy (PERT) dosing in relation to pediatric CF body mass index (BMI)
- New methods for evaluating protein malabsorption in people with CF
- How BMI affects health-related quality of life in children with CF
- Recent research as to how BMI, as well as other factors, can predict mortality in adolescents with CF
- The effectiveness of appetite stimulants as a modality of CF nutrition care

LEARNING OBJECTIVES

After participating in this activity, the participant will demonstrate the ability to:

- Explain how appropriate pancreatic enzyme replacement therapy (PERT) dosing is associated with an improved body mass index (BMI) as well as improved protein and fat absorption in people with cystic fibrosis (CF).
- Summarize how health-related quality of life (HRQOL) is improved in people with CF who have a good nutritional status,and why a low BMI is a risk factor for increased mortality in adolescents with CF.
- Assess the current evidence describing the use of appetite stimulants to improve weight gain in people with CF.

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PORTRAITS OF ADHERENCE
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