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Meghan McGrady disclosed owning stock in Medtronic all relevant financial relationships have been mitigated.

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Better Questions, Better Answers: Assessing Medication Adherence in Pediatric Primary Care

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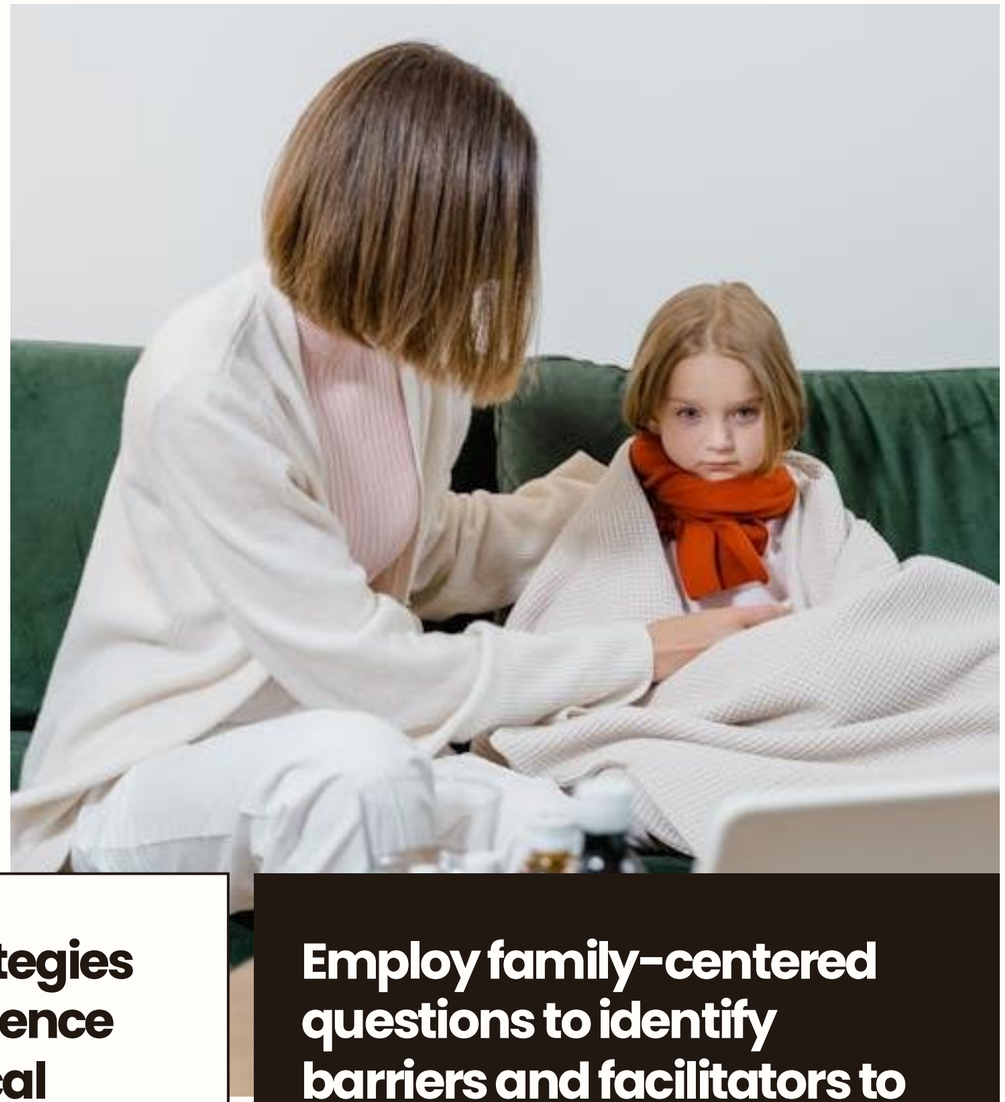
Learning Objectives



Recognize the importance of rigorous medication adherence assessment.

Apply practical strategies to implement adherence assessment in clinical practice.

Employ family-centered questions to identify barriers and facilitators to guide intervention delivery.

Pre-Seminar Survey

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Case Example

Your Patient

Imagine one of your recent or upcoming patients who is taking a medication as part of their treatment regimen
Who are they? What are their supports/resources?

Their Regimen

What is their medication regimen?
What medication(s) do they take?
Times a day? Days a week? Duration?

How Do You Typically Ask?

How do you currently assess medication adherence?

Medication Adherence is Complex

ACCESS

*Afford Prescription
*Refill on Time
*Pick up Medication

IMPLEMENT

*Understand dosage & timing
*Follow directions
*Remember

MANAGE SIDE EFFECTS

*Manage reactions
*Monitor symptoms
*Discuss with provider

Barriers to Adherence

*Depression
*Forgetting
*Cognitive Impairment
*Lack of motivation
*Lack of knowledge
*Beliefs

*Social stigma
*Lack of social support

*Limited health literacy
*Financial strain
*Housing instability
*Lack of transportation

*Medication cost
*Health insurance
*Patient-provider communication

Modi et al. *Pediatrics.* 2012.

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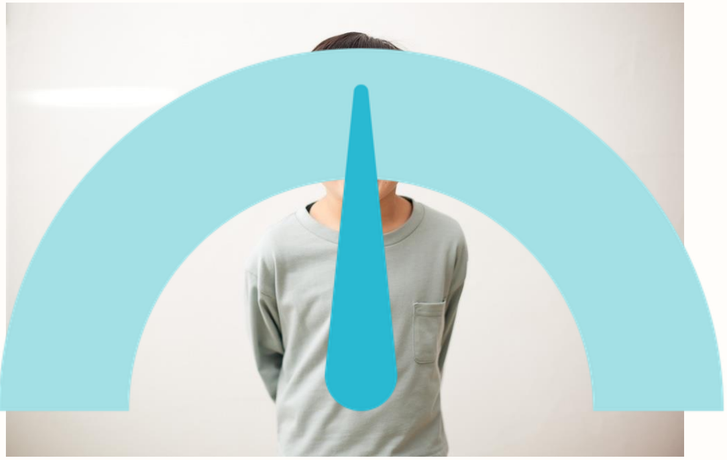

Up to 50% of children and adolescents miss doses

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Adherence Assessment is a Standard of Care

Oncology

"Adherence should be assessed and routinely monitored throughout treatment"

Sickle Cell Disease

"Monitoring percent fetal hemoglobin at least once per year...to monitor for medication effect and adherence."

Asthma

"All healthcare providers should be encouraged to assess asthma control, adherence and inhaler technique at every visit."

Jacob et al. *JAMA Netw Open.* 2025.
Pai & McGrady. *Pediatr Blood & Cancer.* 2015.
GINA Initiative for Asthma, 2025

How Do I Identify Non-Adherence?

Findings are Mixed

PATIENT

*Older age
*Minoritized race
*Hispanic ethnicity

FAMILY

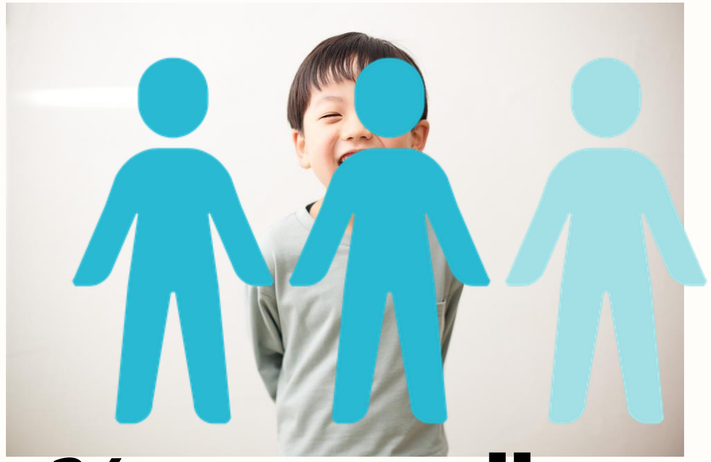
*Lower educational attainment
*Lower income
*Lower health literacy

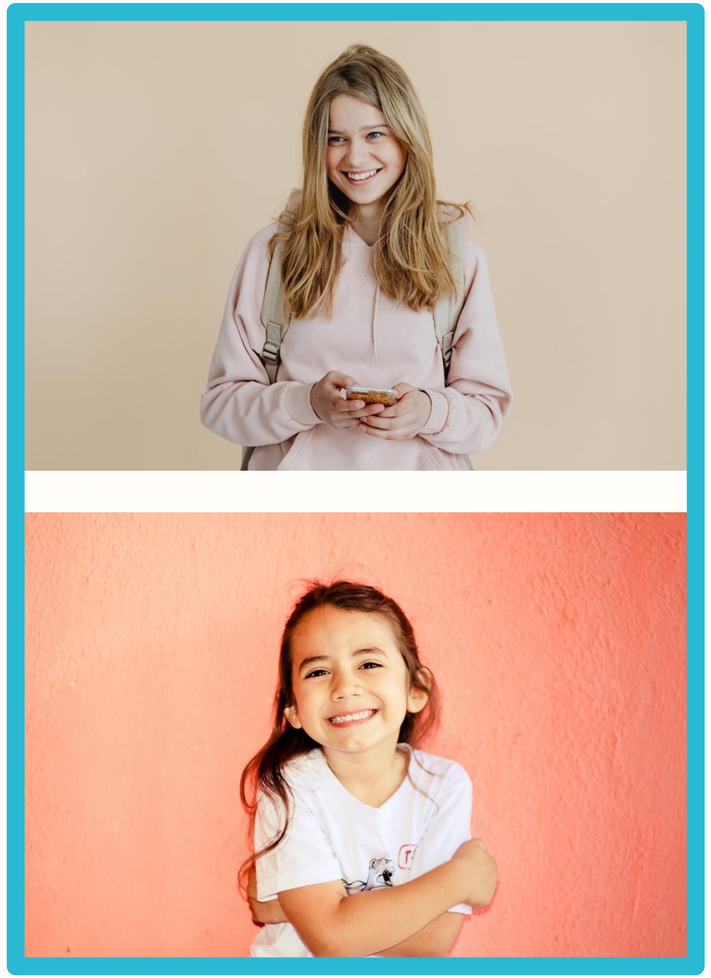
REGIMEN

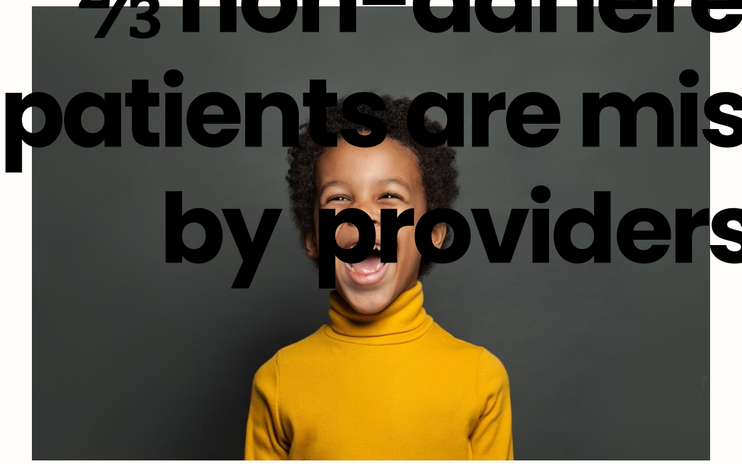
*More medications
*Longer duration
*More complex regimens

Drotar & Bonner. J Dev Behav Pediatr. 2009; Gray et al. Pediatr Pulm. 2018.
Killian et al. Pediatr Transplan. 2018.; McGrady & Pai. J Adolesc Young Adult Oncol. 2019.

Provider Perception is Inaccurate





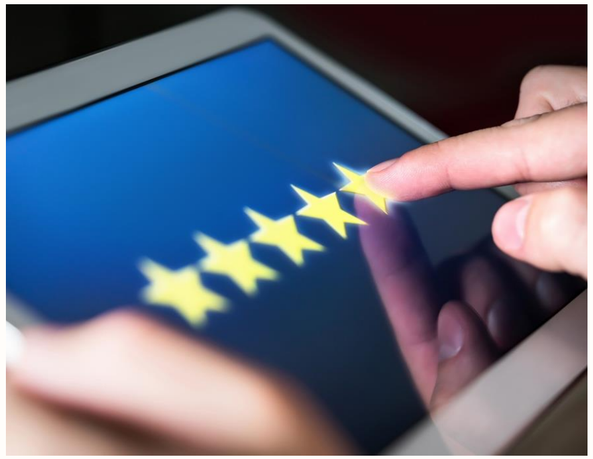


⅔ non-adherent patients are missed by providers

Finney et al. *Child Health Care.* 1993.
Rapoff. Adherence to P*ediatr Med Regimens.* 2011.

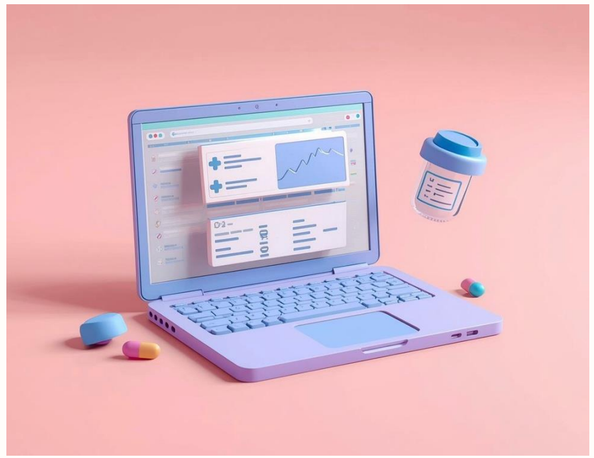
How Do I Identify Non-Adherence?

*Evidence-based methods



SELF-REPORT

PILL COUNT



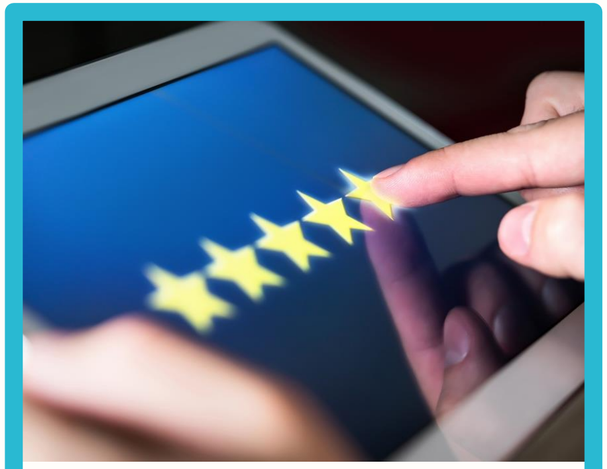
PHARMACY REFILL

ELECTRONIC MONITOR

*No one method is best for all situations/patients

How Do I Identify Non-Adherence?

*Select most appropriate strategy



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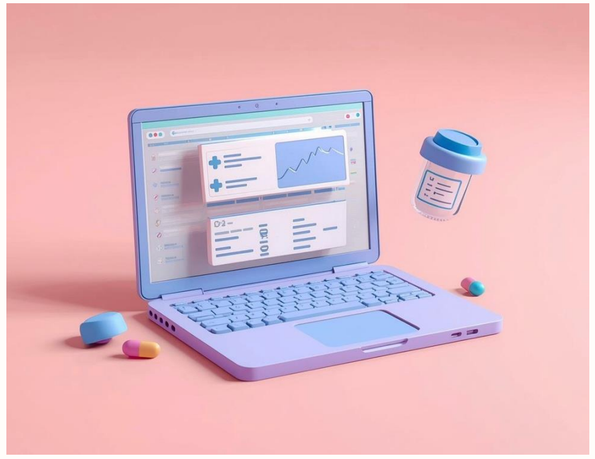

PHARMACY REFILL

ELECTRONIC MONITOR

*Follow best practice guidelines

Quittner et al. J Pediatr Psychol. 2018.
McGrady et al. Ann Intern Med. 2018.

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Using Self-Report

COMMON QUESTIONS

"You didn't miss any doses of your [MED] this week, did you?"

"You're still taking your [MED] as prescribed, aren't you?"

How Accurate is Self-Report?

Self-report is about 9% higher than electronic adherence monitoring data

***58%- "Over-Reporters"**
***39%- "Under-Reporters"**
***3%- "Perfect" Reporters**

McGrady et al. Unpublished data.
Monnette et al. Pharmacoeconomics. 2018.

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What Impacts the Accuracy of Self-Report?

Overestimation

Social Desirability Bias

Upward Bias

Memory Errors

Recall Bias

Measurement Flaws

Interviewer Bias

Insensitive Measure Bias

Sinnappah et al. Br J Clin Pharmacol. 2023.

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"I want to understand what it's like for you to take your medication each day. We know that most people miss doses once in a while. How many times did you miss taking your [MED] in the last week?"

Lead with Curiosity & Empathy

Creates Safe Space & Time

Addresses Upward Bias

"And half of, half of the doctors... [it's] like, they hadn't talked to a person in six years or something....And...I just dreaded it."

"[she would] come in the door right away and she's like 'oh, um, here are your lab results and everything.' Ya know. 'Did you take your medicine?' 'Yeah.' 'Okay, bye!'"

McGrady et al. Unpublished data.
Sinnappah et al. Br J Clin Pharmacol. 2023.
Stirratt et al. Transl Behav Med. 2015.

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"I want to understand what it's like for you to take your medication each day.

We know that most people miss doses once in a while.

How many times did you miss taking your [MED] in the last week?"

Normalize Non-Adherence

Creates a Safe Space

Addresses Upward Bias

"I didn't feel comfortable enough to like, open up and tell them about, ya know, my problems or whatever"

McGrady et al. Unpublished data.
Sinnappah et al. Br J Clin Pharmacol. 2023.
Stirratt et al. Transl Behav Med. 2015.

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"I want to understand what it's like for you to take your medication each day. We know that most people miss doses once in a while. How many times did you miss taking your [MED] in the last week?"

Ask for a Number

- Addresses Social Desirability
- Addresses Interviewer Bias

"I am treated well if I adhere to my HIV medication"

Ondenge at al. *Sex Transm Infect.* 2017.
Sinnappah et al. Br J Clin Pharmacol. 2023.
Stirratt et al. Transl Behav Med. 2015.

“I want to understand what it’s like for you to take your medication each day. We know that most people miss doses once in a while. How many times did you miss taking your [MED] in the last week?”

Set a Concrete Timeline

Addresses Insensitive Measure Bias

“So today is Tuesday. I know you guys were at a soccer tournament last weekend. Thinking back to last Tuesday before you left…”

Sinnappah et al. Br J Clin Pharmacol. 2023.
Stirratt et al. Transl Behav Med. 2015.

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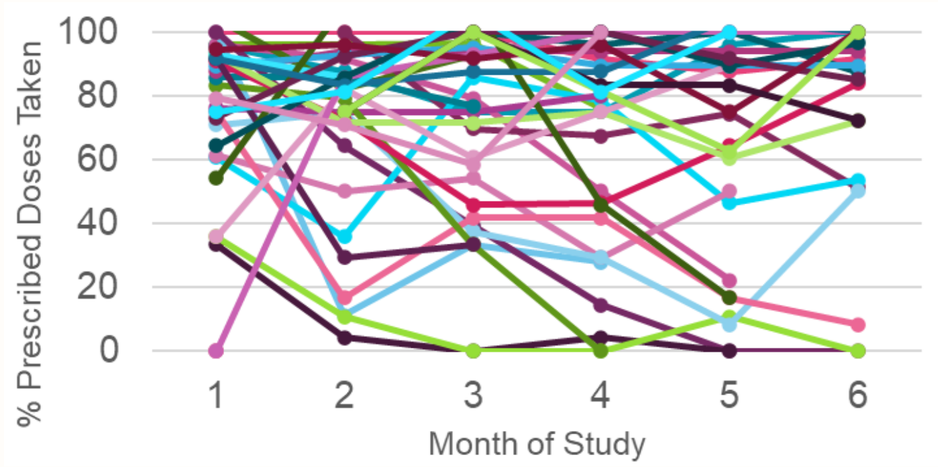
"I want to understand what it's like for you to take your medication each day. We know that most people miss doses once in a while. How many times did you miss taking your [MED] in the last week?"

Ask Frequently

Monthly adherence changes for ALL adolescents and young adults



McGrady et al. *Pediatr Blood Cancer.* 2023.

Assessing Adherence

LEAD with CURIOSITY

EMPATHIZE

NORMALIZE

ASK CLEAR QUESTIONS

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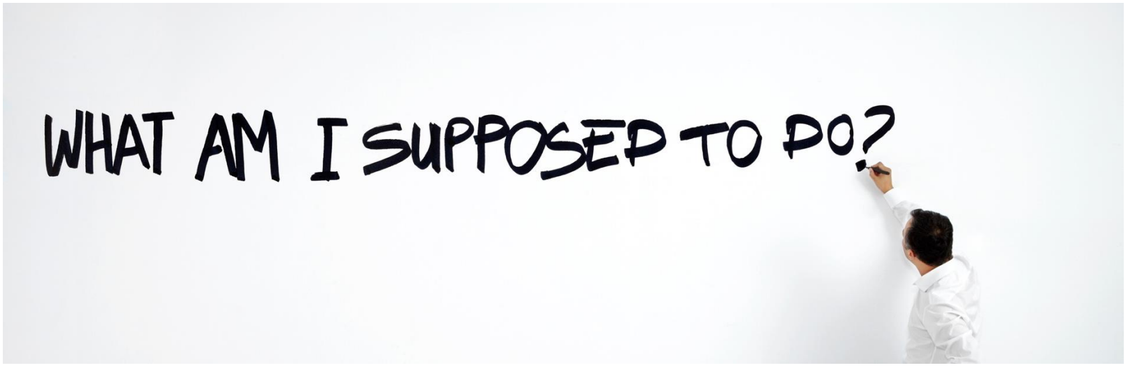
My Patient is Missing Doses? Now What?

Continue to be:
***Curious**
***Empathetic**

Ask questions to understand what their "barriers" are



Barriers to Adherence

*Depression
*Forgetting
*Cognitive Impairment
*Lack of motivation
*Lack of knowledge
*Beliefs

*Social stigma
*Lack of social support

We Need to Identify Barriers Before Providing an Intervention

*Limited health literacy
*Financial strain
*Housing instability
*Lack of transportation

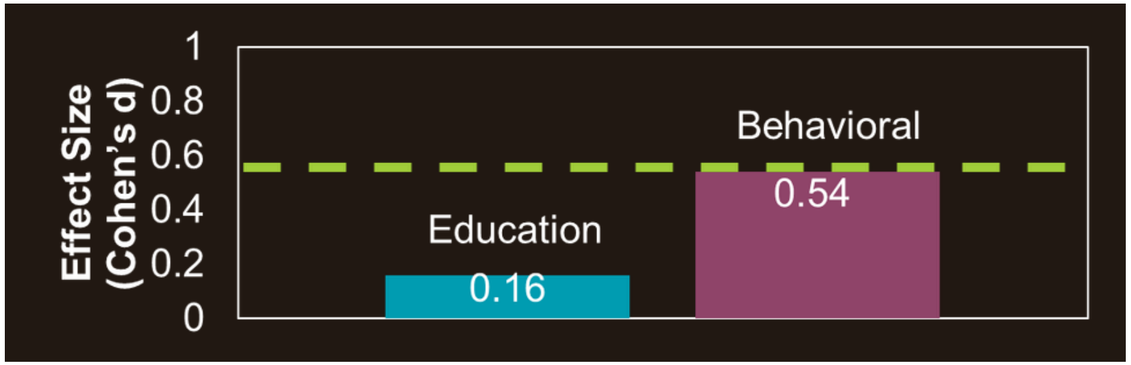
*Medication cost
*Health insurance
*Patient-provider communication

Modi et al. *Pediatrics.* 2012.

What Patients are Saying

I don’t want to take my medications anymore Disease Burnout	**I don’t like shots**	**I think my child is taking too much medicine** Health Beliefs	**I take it when I can or when I remember** Lack of Organization
I don’t feel good after taking it Side Effects	**I don’t like the taste** Dislikes Med Attributes	**There was a death in our family** Family Stress	**We can’t afford the medication** Lack of Access
I ‘m worried I might have to stop what I’m doing Fear of Side Effects	**I just don’t remember** Forgetting	**I play basketball & take care of my brothers & sisters** Gets in Way of Activities	**It’s hard to get to the pharmacy** Lack of Access

Education Alone is Not Sufficient



"It's just more of an annoyance because they're like 'make sure to take your pills.' I'm like 'I know…I know what to do. You don't need to say it."

"[Nurse] always threatens me that, ya know, I'm gonna relapse. It doesn't work. It kind of makes me mad."

Kahana et al. *J Pediatr Psychol.* 2008.
McGrady et al. Unpublished data.
Schellhaas & Ramsey, 2024

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“There are a lot of things that can get in the way of taking your medication as prescribed. I want to understand what’s going on so we can make it easier for you. What has made it hard for you?”

Normalize Challenges

Addresses Social Desirability

Understand their Routine

*Tell me about what it looks like when you take your medication.

*What happens when it’s time to take your medication?

Case Example: Diago

- 6 y.o. M with severe, difficult-to-treat, asthma
- Spanish/English speaking family
- Multiple admissions in the past year
- Multiple outpatient appointments that were not attended
- Medication reconciliation shows infrequent pickups

Case Example: Diago

- What open-ended questions can you ask the family?

HOW TO SHOW UP

*Non-judgmental & Curious
*Empathetic
*Normalize & Validate

WHAT TO ASK

*Ask about a specific behavior
*Ask for a number (not yes/no)
*Include a clear timeline

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Case Example: Diago

Case Example: Diago

- Managing your child's asthma care can be overwhelming. I know you all have had difficulty coming to your appointments, and Diago has been pretty sick this year. Can you help me understand what has been getting in the way of coming to these appointments?

- If you think about this last week, what medications did Diago get and when?

Case Example: Diago

- Dad believes that his son gets sick when he comes to the hospital
- Diago afraid of the hospital after multiple admissions
- Dad does not think he needs to take the medications
- Mom not sure, she had asthma as a child and her mom

BARRIER 1
Health Beliefs

BARRIER 2
Forgetting

BARRIER 3
Family Stressors

Case Example: Anna

- 14 y.o. F with type 1 diabetes (T1D)
- Wears an insulin pump and uses a CGM
- Her pump data shows she is entering carbohydrates for meals
- At today's routine endocrinology visit her HbA1c went up to 8.7% from 7.5% in March

Case Example: Anna

- What open-ended questions can you ask the family?

HOW TO SHOW UP

*Non-judgmental & Curious
*Empathetic
*Ready to Normalize & Validate

WHAT TO ASK

*Ask about a specific behavior
*Ask for a number (not yes/no)
*Include a clear timeline

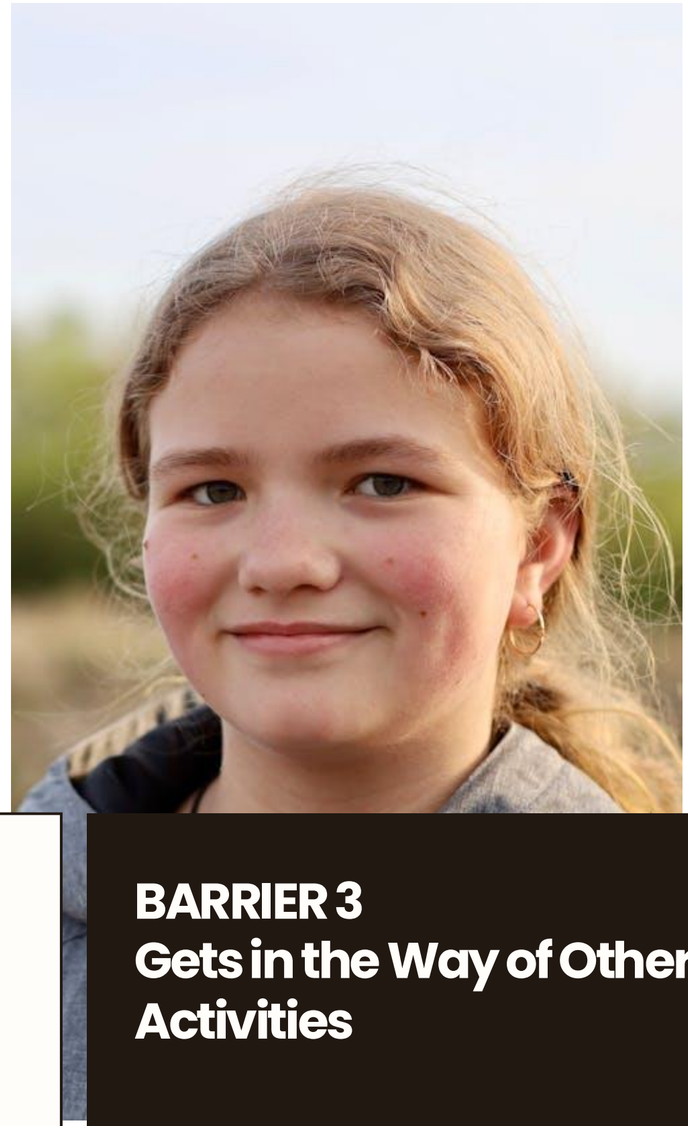
Case Example: Anna

Case Example: Anna

- I know there are a lot of things you have to do to take care of your diabetes. Can you tell me what your routine is around giving yourself insulin?
- When have you worn your insulin pump / CGM over the last week?
- Has anything changed since the last time I saw you in your self-management routine?

Case Example: Anna

- Hannah recently started soccer again
- She is taking her insulin pump off before soccer practice due to fear of blood glucose going low



BARRIER 1
Fear of Hypoglycemia

BARRIER 2
Forgetting

BARRIER 3
Gets in the Way of Other Activities

- Parents are busy with younger siblings

Key Takeaways

- Adherence is best assessed with multiple data points
- Working collaboratively with the patient and family is key for buy in
- Ask open ended questions
- It is an ongoing conversation, and it will not be fixed in one visit
- Assess own biases or opinions before going into the room

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Up Next

From Barriers to Behavior Change: Delivering Tailored Adherence Support

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Thank You So Much

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