Improving adherence to maintenance therapy in children with asthma

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Learning aims

At the end of this presentation, you

• Can describe the importance of nondadherence in childhood asthma

• Can discuss the prevalence of nonadherence in childhood asthma

• Can begin to do something about nonadherence to maintenance therapy in childhood asthma
Overview

- Nonadherence: is it important?
- Measuring adherence in asthma
- Prevalence of poor adherence in asthma
- Determinants of poor adherence
- Treatment of poor adherence
Nonadherence: is it important?

• Poor adherence $\rightarrow$ poor outcomes in all chronic diseases

• Childhood asthma: poor adherence related to
  – Increased symptoms
  – Increased hospital admissions
  – Asthma deaths

Di Matteo, Med Care 2002;40:794-811
Ordonez, Arch Dis Child 1998;78:143-7
Robertson, Pediatr Pulmonol 1992;13:95-100

Milgrom, JACI 1996;98:1051-7
Nonadherence: is it important?

- 71 children with problematic severe asthma referred to national referral centre in UK
- Home visit:
  - 23% no medication at home, or med out-of-date

Bracken, Arch Dis Child 2009;94:780-4

Confirms clinical practice:

Most children referred for evaluation of problematic severe asthma have issues with adherence or inhalation technique

- 23% no medication at home, or med out-of-date

And their asthma can be well controlled once these issues have been taken care of

De Boeck, Pediatr Pulmonol 2009;44:743-8

The importance of nurse-led home visits in the assessment of children with problematic asthma

Bracken, Arch Dis Child 2009;94:780-4
Nonadherence: is it important?

- 2 studies comparing asthma management and follow-up in primary care and hospital-based paediatric asthma clinic
- Self-reported ICS adherence
  - Low in primary care
  - High in hospital care

Kuethe, Prim Care Respir J 2010;19:62-7
Klok, Acta Paediatr 2011;100:248-52
Nonadherence: is it important?

Kuethe, Prim Care Respir J 2010;19:62-7
Klok, Acta Paediatr 2011;100:248-52

Low ACQ = good control
Measuring adherence in asthma

- Parental report or self-report
- Interviewing child in non-confrontational way
- Pharmacy refill records
- Canister weight or device counters
- Electronic measurement
Parental/self report is unreliable

Canister weight and pharmacy refill rates overestimate true adherence

Electronic measurement necessary to assess adherence reliably

27 and 100 children 7-16 yrs with asthma 6-12 months adherence

Bender, Ann Allergy Asthma Immunol 2000;85:416-21
Jentzsch, Allergy 2009;64:1458-62
Measuring adherence in asthma

• Interviewing children in non-confrontational fashion (without parents present):
  – Reasonable assessment of adherence
  – 15% lower than measured adherence (Doser)
  – Better than computer-based questionnaire

• Doctor’s estimate of child’s adherence
  – Median estimate is accurate (70% vs 70.5%)
  – Correctly identifies only 12/21 “good adherence”

Talking to children about adherence is useful

More useful than talking to parents

Electronic measurement = gold standard

Bender, Pediatrics 2007;120:e471
Burgess, Respirology 2008;13:559-63
Electronic adherence measurements

- only counts doses
- does not account for “dumping”

- records date & time of actuation
- allows most accurate assessment of adherence
- accurate & valid

(Respir Med 2006;100:841-5)

Electronic Measurement of Medication Adherence in Pediatric Chronic Illness: A Review of Measures

Lisa M. Ingerski, PhD, Elizabeth A. Hente, BA, Avani C. Modi, PhD, and Kevin A. Hommel, PhD

J Pediatr 2011;159:528-34
Most people having been prescribed ICS do not pick up refill prescriptions after 3 months

Partly due to poor prescription of ICS by physicians (prescribed as 6-12 wk “course” for nonspecific cough or dyspnoea)


Days/year on which med was “taken”
(pharmacy refill rates)

Hasford, Allergy 2010;65:347-54
Prevalence of poor adherence

106 children (mean age 4.3 yrs) in GP with ICS prescription in past year

82 parents willing to provide information about current ICS use.

24 children still using ICS parents consented to electronic adherence measurement for 3 months

15 children (18%) used ICS daily, median adherence was 81% (range 34-97%)

9 children used ICS intermittently

29% of the children used ICS for non-specific respiratory symptoms

24 children received ICS for an isolated episode of wheezing or chronic cough

58 other children:
39 symptomfree, not been using ICS in the last 6 months
10 stopped ICS after giving consent
4 excluded (used devices incompatible with adherence loggers)
5 children only chronic cough.

24 children used ICS intermittently (advised by physician)

36% of the children used ICS intermittently

21 children used ICS intermittently

Don’t blame (only) the patient

Klok, ERS 2011
Long-term adherence to ICS is poor in children with asthma

Notoriously poor in adolescents and in inner-city children in USA

<table>
<thead>
<tr>
<th>Study</th>
<th>Participants</th>
<th>Device</th>
<th>Median adherence</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ferguson 1995</td>
<td>29 children 1-6 yrs</td>
<td>Chronolog</td>
<td>Median 63%</td>
<td></td>
</tr>
<tr>
<td>Jonasson 1999</td>
<td>163 children 7-16 yrs</td>
<td>Dose counter</td>
<td>Mean 77%</td>
<td></td>
</tr>
<tr>
<td>Burgess 2008</td>
<td>51 children 1.5-7 yrs (1 month)</td>
<td>Smartinhaler</td>
<td>Median 78.5%</td>
<td>Range 21-100%</td>
</tr>
<tr>
<td>Nikander 2011</td>
<td>115 kinderen 5-10 yrs (1.5 yrs)</td>
<td>Turbuhaler PIF measurement</td>
<td>Median 86% first 45 days, 59% last 45 days</td>
<td></td>
</tr>
</tbody>
</table>
Determinants of adherence

What is the most common cause of poor adherence?

a. Poor asthma knowledge
b. Low parental education
c. Mild asthma
d. Forgetting to take the medication
e. Parental perceptions of asthma & meds
Determinants of adherence

• Not important:
  – Severity of disease
  – Socio-economic status/education of parents
  – Asthma knowledge
  – Age of patient

• Important:
  – Illness & medication beliefs

Very few long-term studies

Very few studies looking at comprehensive range of possible determinants

– Socio-economic status/education of parents
– Asthma knowledge
– Age of patient

• Important:
  – Illness & medication beliefs

Ho, J Allergy Clin Immunol 2003;111:498-502
Weinstein, Ann Allergy Asthma Immunol 2011;106:283-91
Dean, Arch Dis Child 2010;95:717-23
Parents are concerned about safety of maintenance medication for their child’s asthma.

Medication beliefs are strong drivers of adherence and of asthma control.

- 77%: need > concern
- 13% concern > need

Conn, Pediatrics 2007;120:e521

Smith, Pediatrics 2008;122:760-9
The common sense model

Kaptein, Curr Opin Allergy Clin Immunol 2010;10:194-9
Zwolle Asthma Focus Group Study

Six focus groups
- Three from primary care (five randomly chosen practices)
- Three from our secondary care paediatric asthma clinic

Inclusion criteria
- Parents of children 2-12 years of age
- Doctor’s diagnosis of asthma
- Prescribed inhaled corticosteroids (ICS) last year

Standard focus group methodology
- Semi-structured interview by independent moderator
- Audiotaped and verbatim transcription
- Coded by two independent researchers

Klok, Acta Paediatr 2011;100:248-52
## Zwolle Asthma Focus Group Study

### Illness perceptions from parents in primary care

<table>
<thead>
<tr>
<th>Category</th>
<th>Perceptions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cause</strong></td>
<td>“My child has asthma; her airways are inflamed”</td>
</tr>
<tr>
<td><strong>Cure / control</strong></td>
<td>“Asthma is a chronic disease”</td>
</tr>
<tr>
<td></td>
<td>“I realise that my child will probably remain asthmatic for many more years”</td>
</tr>
<tr>
<td><strong>Consequence</strong></td>
<td>“Daily medicine keeps her airways quiet”</td>
</tr>
<tr>
<td><strong>Timeline</strong></td>
<td>“I know that asthma varies over time”</td>
</tr>
<tr>
<td></td>
<td>“When she has no asthma symptoms the airways may still be inflamed; therefore, she needs her daily medicine”</td>
</tr>
<tr>
<td><strong>Identity</strong></td>
<td>“She has asthma but can live a normal life”</td>
</tr>
</tbody>
</table>

### Medication perceptions from parents in primary care

- “It is poison”
- “We are afraid of long-term side effects”
- “I don’t like medicines altogether”
- “It doesn’t work as well when you use it on a daily basis”
- “I don’t believe in adding stuff to a body every day – that cannot be good”
Zwolle adherence study

- 150 children with asthma 2-12 yrs of age
- All followed up in secondary care asthma clinic
- All on maintenance therapy with ICS
- Follow-up for 1 year
- Adherence monitored electronically (Smartinhaler®, Smartdisk®)
- Comprehensive range of determinants of adherence assessed
Zwolle adherence study: first results

- 3 month adherence in 93 2-6 yr old children (representative sample from patients in clinic)

Median adherence 92%

72% of children used >80% of prescribed doses

Median adherence first month 93%, third month 90% (p=0.02)

Very high median adherence in this setting
Zwolle adherence study:

High adherence *can* be achieved

- Determinants significantly related to adherence:
  - good adherence $\rightarrow$ good asthma control
  - Answers to items on beliefs about medication questionnaire:
    - Without medicines, my child would be very ill
    - My child’s life would be impossible without his/her medicines
    - My child’s health depends on his/her medicines
  - Answers to treatment satisfaction questionnaire

93%: need $> \mathrm{concern}$

Klok et al, submitted
How to achieve good adherence

- Education alone → no effect on adherence
- Education + behavioral intervention improves adherence
  - Monitoring & goal setting
  - Problem solving self-management
  - Linking medicine taking to daily routines

A systematic review of interventions to enhance medication adherence in children and adolescents with chronic illness

Arch Dis Child 2010;95:717-23

Angela J Dean,1-3 Julie Walters,4 Anthony Hall4,5
Useful classification of nonadherence  (Rand 2004)

- **Erratic** nonadherence
  - Forgetting medication
  - Complexity of treatment
  - Chaotic lives or family routines

- **Unwitting** nonadherence
  - Do not understand rationale for treatment
  - Confuse maintenance with on demand treatment

- **Intelligent** nonadherence
  - Patients feel they know more about disease/med than doctor
  - Driven by illness beliefs and concerns about side effects

“You can’t alleviate fear by relaying facts”  (Søren Pedersen)
Treatment of nonadherence

Mauksch, Arch Intern Med 2008;168:1387-95
Doctors prescribe, parents decide

Child with asthma

Decide to consult physician

Coaching of parents by doctor / asthma nurse: listening, providing info, teaching self management, discussion of questions, concerns and beliefs

Seek support to make the right choices

Treatment at home decided by parents

Parents with own illness and medication beliefs

Directly observed treatment according to guidelines

Presents to A&E Dept

Treatment decided by doctor in hospital

Klok, Acta Paediatr 2011;100:248-52
Patient centered communication

- Adherence consistently associated to communication style
- Friendly, empathic communication with genuine interest in patient’s context → improved adherence
- Training doctors in communication → improved adherence

Med Care 2009;47:826-34

Physician Communication and Patient Adherence to Treatment
A Meta-Analysis

Kelly B. Haskard Zolnierzek, PhD,* and M. Robin DiMatteo, PhD†
Motivation enhancement

- Offering unsolicited advice is counterproductive
- First step = exploring patient’s reasons for the undesired behaviour (= poor adherence)
  - Illness and medication beliefs
  - Showing genuine interest
  - Looking for ambivalence cues
- Second step = assessing motivation
- Third step = asking permission to provide information
Shared decision making

Shared Treatment Decision Making Improves Adherence and Outcomes in Poorly Controlled Asthma

Sandra R. Wilson¹, Peg Strub², A. Sonia Buist³, Sarah B. Knowles¹, Philip W. Lavori⁴, Jodi Lapidus³, William M. Vollmer³, and the Better Outcomes of Asthma Treatment (BOAT) Study Group

¹Palo Alto Medical Foundation Research Institute, Palo Alto, California; ²The Permanente Medical Group, San Francisco, California; ³Oregon Health and Science University, Portland, Oregon; ⁴Stanford University School of Medicine, Stanford, California; and ⁵The Kaiser Permanente Center for Health Research, Portland, Oregon

• proof of principle study
• comparing regular (extensive care) to shared decision making

AJRCCM 2010;181:566-77
### Shared decision making

<table>
<thead>
<tr>
<th>Clinician decision making</th>
<th>Shared decision making</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establish rapport; explain follow-up</td>
<td>+ explain SDM approach</td>
</tr>
<tr>
<td>Assess asthma, triggers, medication use</td>
<td>+ identify patient goals and preferences</td>
</tr>
<tr>
<td>Provide information</td>
<td>Same</td>
</tr>
<tr>
<td>Analysis: discuss PFT results, assess level of control, address potential adherence problems</td>
<td>same</td>
</tr>
<tr>
<td>Prescription: Rx, written asthma plan, etc.</td>
<td>Negotiation: discuss treatment options &amp; relative merits bearing in mind patient goals &amp; preferences Agree on treatment</td>
</tr>
</tbody>
</table>

*AJRCCM 2010;181:566-77*
Shared decision making

- Higher refill adherence (67 vs 46%)
- Better asthma control (relative risk of total control 1.9, 95% CI 1.3-2.9)
- Trend towards better lung function
Conclusions

- High adherence to maintenance ICS in children with asthma *can* be achieved
- Requires comprehensive approach
  - Patient-centered communication style
  - Motivational interviewing
  - Shared decision making
- This can all be learned
- Best achieved by team effort
Further reading

S.C. Shea

S. Rollnick, W. Miller, C. Butler
The Zwolle approach

- Full work up by paediatric chest physician
- Diagnosis confirmed, treatment plan agreed with patient & parents
- Comprehensive asthma education by doctor & asthma nurse
- Entire team trained in patient centered communication
- Close follow-up:
  - Stress importance of daily ICS use
  - Address questions and concerns/beliefs
  - Actively identify and treat comorbidity
Laguna Miscanti (-8° C!)
San Pedro de Atacama, October 2011

¡Muchas gracias!