SHARED DECISION – MAKING IN CHILDREN

ARUNAS VALIULIS
European Academy of Paediatrics (EAP/UEMS-SP)
European Forum for Research and Education in Allergy & Airway Diseases
Vilnius University Medical Faculty Institute of Clinical Medicine
Lithuanian Academy of Sciences Mother and Child Commission, Chairman
Global Alliance Against Chronic Respiratory Diseases, Planning Committee Member
Allergic Rhinitis and its Impact on Asthma, Chairman of ARIA-Lithuania
Clinic of Children’s Diseases of Vilnius Clinical Hospital, CEO
Lithuanian Paediatric Respiratory Society, President
Antakalnio Str. 57, Vilnius LT-10207, LITHUANIA
El. paštas: arunas.valiulis@mf.vu.lt
http://www.eapaediatrics.eu
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I have no other conflict of interests related to this presentation.
Lithuania is the World’s capital of allergic rhinitis

100% of the population suffer from daily sneezing… (previous pilot research by Jean Bousquet, unpublished)

Lithuanian AČIŪ [ʌtʃiː] means THANK YOU!

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What is it?
It is balance of power in decision making “swing” between the physician and patient: paternalism with no patient’s participation in one side and full autonomy with no physician’s participation in the other.

When it start?
In 2001 US Institute of Medicine endorsed Shared decision model (SDM) and recommend to use it in clinical settings (Berwick, 2002).

Why we need it?
Child’s contribution during “traditional” medical visit is rather limited at an estimated 10% of the visit.

Is it still important?
WHAT DO PATIENTS WANT FROM THEIR ASTHMA CARE DOCTOR?
Rubin B, Zhao W, Winders TA
Paediatric Respir Rev 2018; 27: 86–89.

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What do you want most from your doctor?

<table>
<thead>
<tr>
<th>Access</th>
<th>Convenient location and office hours, more time per visit</th>
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<tbody>
<tr>
<td>Authenticity</td>
<td>Eye contact, empathy, attitude and competence in work</td>
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<tr>
<td>Shared decision making</td>
<td>Partnership, more listening and interaction from physician</td>
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<tr>
<td>Patient-friendly education</td>
<td>Support services, prescription assistance</td>
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What are the most common barriers for the care?

- Financial: 38%
- Side effects concern: 36%
- Time concerns: 30%
- Lack of knowledge: 29%
- Overwhelmed: 25%
- Denial of disease: 11%

Asthma & Allergy Network: survey of 1000 parents of asthmatic children
SHARED DECISION MAKING IN SCHOOL AGE CHILDREN WITH ASTHMA


INSTRUMENTS:

• VISUAL AIDS
• TURN-TAKING
• ELICITING ATTENTION / REQUESTING HELP Complex of methods for the increase of initiativeness of the patient
• ROLE MODELLING Role-playing is a positive force in shaping the performance of school age children and has been used in several behavioral programs for the reducing fears of medical treatment
• TEACHING PARENTS HOW TO DELIVER INFORMATION Due to necessity of confidential and accurate disclose of the information to the child, parents may need a demonstration or modeling of how to integrate the information into the child’s self-concept and adaptation to the condition
• CLARIFYING COMMUNICATION At the end of the medical encounter, school age children should be asked to rephrase their understanding of the recommendations of physician in their own words
PRE-INTERVENTIONAL PREPARATION:

- Assessing the child’s competence at different ages and abilities can be achieved by asking the child to count up to 100 or spell simple words (usually SDM applicable for children as young as 8 years of age).
- Once the child’s competency level is assessed, the child can be provided with the opportunity to ask questions about treatment, i.e., why he or she needs to avoid triggers, why medications need to be taken.
- Use of prompts such as an allergy coloring book or card devices that include picture identification for triggers, symptoms, and medications can be used to start an allergy dialogue.
- For children with frequent episodes of exacerbation, a more in-depth approach may be needed such as having children draw pictures to illustrate how they feel or use metaphors or puppets to demonstrate body functioning and symptoms.
## PATERNALISM or DIDACTIC DECISION MAKING vs. SHARED DECISION-MAKING

<table>
<thead>
<tr>
<th>PATERNALISM or DIDACTIC DECISION MAKING</th>
<th>SHARED DECISION-MAKING</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Establish:</strong> contact with the patient, provide information about importance of follow-up</td>
<td>+ <strong>Explain:</strong> SDM approach with key message, that <strong>there are always multiple options</strong></td>
</tr>
<tr>
<td><strong>Assess:</strong> asthma clinical signs, triggers, medications</td>
<td>+ <strong>Identify:</strong> patient’s goals and preferences</td>
</tr>
<tr>
<td><strong>Provide:</strong> information</td>
<td>Same</td>
</tr>
<tr>
<td><strong>Analyse:</strong> spirometry results, level of control, potential adherence problems</td>
<td>Same</td>
</tr>
<tr>
<td><strong>Act:</strong> prepare preferably written asthma plan</td>
<td>+ <strong>Negotiate:</strong> discuss treatment options seeking consensus (contract) with the patient</td>
</tr>
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</table>
AGE SPECIFIC ISSUES: AGE OF CHILDREN AND TAKING DAILY MEDICINES ON THEIR OWN

Transition to self-care: child’s “weight” in decision making on daily treatment is depending on age

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Orell-Valente JK, Pediatrics 2008; 122: 1186-92
AGE SPECIFIC ISSUES:
TO TELL YOU TRUTH

Diary cards
95.4%

Electronic counter
58.4%

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Milgrom V, et al. JACI 2006; 98: 1051-57
Rubin B, XX VIPPACS, 2015
AGE SPECIFIC ISSUES: WHAT WE ARE SPEAKING ABOUT?

- **Compliance**: Do as I say
- **Adherence**: Do what is right
- **Contrivance**: I do what I want, when I want, and how I want it
LET’S TALK ABOUT ADHERENCE
ONLY: PHILOSOPHY OF NONADHERENCE

- **Erratic nonadherence**
  - Forgetting medication
  - Too big complexity of treatment
  - Chaotic live or family routine

- **Unwitting nonadherence**
  - Do not understand rationality of treatment
  - Confuse maintenance / on demand treatment

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

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Adherence is lower in the evening and declines over time

Kim et al. JACI 2005

Curr Opin Allergy 2010; 10: 194-99
Brand P, XIX VIPPACS, 2014
WHY WE NEED TO RECONSIDER SDM AND MOVE TOWARD BIGGER AUTHONOMY OF THE PATIENT?

• Practical aspects:
  A. Adherence to the treatment of CRDs is much more lower when we are expected before (5 vs 30 perc.)
  B. Teaching programmes focussing on increasement of adherence are ineffective or at least effect is short lasting

• Ethical aspects:
  A. Recommendations & guidelines sometimes evidence based are denied by other evidences; big dosis of speculations is in each evidence based medical conclusion
  B. Mechanical equality between the patient and physician not means ballance of power in decission making

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To develop human rights-based approach to CNDs

The principle of confinement is used too often to manage the patient with chronic disease

Confinement not necessarily means physical isolation, it could be psychosocial, emotional or other type of active or passive bordering or just lack of understanding

It is based on misconception that there is no connection between medicine and human rights
EFFICACY OF MP-AzeFlu IN CHILDREN WITH SEASONAL ALLERGIC RHINITIS: IMPORTANCE OF PAEDIATRIC SYMPTOM ASSESSMENT
Berger W, Meltzer EO, Amar N, (...) Bousquet J.

NASAL SYMPTOMS - rTNSS QUESTIONNAIRE
( rTNSS, <10%, ≥10 % - ≤90%, >90% CHILDREN GROUPS)

CONCLUSIONS
Parents are less able to evaluate the treatment efficacy in children
There is a need for a simple and child-friendly tool for the daily evaluation of symptoms and medications

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ERS GUIDELINES 2014: HOW STABLE ARE PHENOTYPES?

Schultz A et al. The transient value of classifying preschool wheeze into episodic viral and multiple trigger wheeze. Acta Paed • 2010; 99: 56-60

- One year follow-up
- 2-6 yr asthmatic children with episodic viral wheeze or multiple trigger wheeze
- ICS treatment
- ERS classification preschool wheezing

CHANGE OF PHENOTYPE IN 54.1% OF CASES

Valiulis A, 2018
QoL OF 527 CHILDREN WITH BRONCHIAL ASTHMA AND THEIR PARENTS
Taminskiene V, Alasevicius T, (...) Valiulis A.
European Journal of Pediatrics, 2018 in press

PedsQL Family Impact Module

- Physical Functioning
- Emotional Functioning
- Social Functioning
- Cognitive Functioning
- Communication
- Worry
- Daily Activities
- Family Relationships

General Questionnaire
Asthma Control Test

Valiulis A, 2018
### ASSOCIATION OF LOWER PedsQL FAMILY IMPACT MODULE SCORES WITH POSSIBLE RISK FACTORS

Taminskiene V, Alasevicius T, (...) Valiulis A.  
European Journal of Pediatrics, 2018 in press

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>OR (95%CI)</th>
<th>p</th>
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<tbody>
<tr>
<td><strong>Woke up at night because of asthma during the last 12 months</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Every week</td>
<td>2.53 (1.34-4.75)</td>
<td>0.004</td>
</tr>
<tr>
<td>&lt; 1 time per week</td>
<td>1.99 (1.15-3.43)</td>
<td>0.014</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1.97 (1.27-3.05)</td>
<td>0.002</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td></td>
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<tr>
<td><strong>Use of symptom relievers (almost) every day during the last month</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2.47 (1.57-3.87)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td></td>
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<tr>
<td><strong>Family difficulties caused by the child's disease</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3.81 (2.45-5.93)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td></td>
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<tr>
<td><strong>Social benefits as the main source of income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.99 (1.05-3.80)</td>
<td>0.035</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td></td>
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<tr>
<td><strong>Moulds at home</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2.03 (1.29-3.19)</td>
<td>0.002</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
<td></td>
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</tbody>
</table>

N = 382; Wald-$\chi^2$ = 35.24; p<0.001; Hosmer-Lemeshow test $\chi^2$ = 7.715; df = 8; p = 0.462; correctly classified 65.4%; Nagelkerke $R^2 = 0.340$. 

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MAJOR DETERMINANT OF QUALITY OF LIFE OF THE FAMILY OF ASTHMATIC CHILD IS NOT ASTHMA-RELATED
Taminskie V, Alasevicius T, (…) Valiulis A.
European Journal of Pediatrics, 2018 in press

FD: financial hardships, difficulties to combine personal and professional life, lost of job or studies, divorse of the parents, etc.
• 407 patients with persistent asthma cared by either pulmonologists or allergists were divided into routine medical care alone and with an additional written asthma action plan. Asthma symptom frequency, number of emergency visits, and asthma quality of life were compared after 12-months follow-up
• Surprisingly, both groups showed equally significant reduction in asthma symptom frequency, nocturnal symptoms, β agonist use, number of emergency visits as well as increase of asthma quality-of-life scores
HOW HUMAN RIGHTS-BASED APPROACH CAN BE INTRODUCED FOR THE MANAGEMENT OF CRDs?

- We need to move for the power balance in SDM equality to the side of bigger autonomy of weaker (it means - patient) side of the “swing”
- We need to recognize “silent resistance” of our patients against any chronic treatment (not necessarily against overtreatment)
- We need to re-evaluate benefits and limitations of chronic treatment especially concerning possibility to modify natural course of CRDs
- It should be established stepwise approach to the evolution from Shared Decision Making to Guided Self Management in adults and at least in some groups of children

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FIRST ATTEMPT TO PUSH THEORY TO DAILY PRACTICE: EU Vilnius Summit on CRDs

- It was the second conference for opinion leaders in respiratory medicine and health politicians under the auspices of EUFOREA organized in Seimas (Parliament) of Lithuania on March 2018. The first one was organised in the European Parliament in March 2017.
- Vilnius Declaration (VD) on Chronic Respiratory Diseases as a road map of control of CRDs using ICPs and mobile technologies was discussed and approved during this summit.
- European Commission was directly involved as well as acting Ministers of Health from CEE region, European Parliament members became co-authors of Vilnius Declaration.
- EU Vilnius Summit “twinning” with other important meetings on biological and environmental interactions through mHealth including World Health Assembly (May 2018) and the High Level United Nations meeting on CNDs (Sept 2018).

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EDUCATIONAL AND POLITICAL TARGETS OF VILNIUS EU SUMMIT ON CRDs

- Goal: Multisectoral care pathways
- “Special guest”: Air pollution
- Method: mHealth including interoperability and transborder operations
- Way of Management: Shared decision-making transforming to Guided self management
- Post hoc Result: Declaration as plan of action and networking

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WHY IT IS SO IMPORTANT TO MERGE mHEALTH AND SHARED DECISION-MAKING MODEL?

JUST FEW BECAUSE...

• Because we simply lost competition with IT technologies; internet, but not a doctor is God for the patient today

• Because IT technologies are developed with much more higher speed, if compare to the development of our understanding of the disease

• Because we have no power to control internet, but we can empowering patient to use it for the control of the disease, it means that we simply need embedding our patient to live with new God

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INTEGRATED CARE PATHWAYS AS PREREQUISITION FOR MERGE mHEALTH AND SDM

- CRD multi-morbidity demands incorporation of self-management and aerobiology
  - Precise medicine
  - Endotype-driven treatment
- ICPs characterised by:
  - Multidisciplinary team
  - Quality/coordination of care

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Bousquet J, 2018
EU VILNIUS SUMMIT: EVOLUTION FROM eHEALTH TO mHEALTH

- eHealth use information and communication technology for health services during last decades
- mHealth characterised by:
  - Mobile technologies and applications
  - Integration of mobile health
  - Continued growth over cellular networks
- mHealth has the potential to:
  - Better understand and improve adherence
  - Enable shared decision making
  - Improve self-management

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EU VILNIUS SUMMIT: EVOLUTION OF SHARED DECISION MAKING TO GUIDED SELF MANAGEMENT

- Indocrination of human rights approach for bigger patient’s autonomy and more effective self-management
- Focus on early life interventions and personalized medicine
- Start Mobile Shared Decision Making (mSDM) = Guided Self Management

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LESSONS FROM HISTORY
KEEP AMBITIOUS BIG ENOUGH TO CHANGE THE WORLD...

Helsinki Declaration 1975 (Helsingin päätösasiakirja) is the final act of the Conference on Security and Co-operation in Europe in Helsinki on August 1, 1975

Vilnius Declaration 2018 is the final document of the 2nd EU Summit on Chronic Respiratory Diseases in Vilnius on March 23, 2018

Helmut Schmidt, Chancellor of Federal Republic of Germany (West Germany), Erich Honecker, Chairman of the State Council of the German Democratic Republic (East Germany), Gerald Ford, President of USA and Bruno Kreisky, Chancellor of Austria, among the leaders of 35 countries in Finlandia Hall, Helsinki, Finland

Prof. Peter Hellings, President Elect of EAACI, Chairman of EUFOREA, Vytenis Andriukaitis, European Commissioner for Health and Food Safety, Antanas Vinkus, Member of Lithuanian Seimas, Prof. Arunas Valiulis, Chairman of Organizing Committee of EU Vilnius Summit, Prof. Jean Bousquet, Chairman of Scientific Committee of EU Vilnius Summit, Chairman of MASK MACVIA ARIA, in Seimas (Parliament) Hall, Lithuania
Vilnius Declaration on Chronic Respiratory Diseases

Multisectoral care pathways embedding guided self-management, mHealth and air pollution in chronic respiratory diseases
