SHARED DECISION – MAKING IN CHILDREN

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DECLARATION OF INTERESTS (I)

My participation in "ARIA Masterclass: From Guidelines to Real-life" is fully supported by EUFOREA.

I have no other conflict of interests related to this presentation.

DECLARATION OF INTERESTS (II)

- 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- 100% of the population suffer from daily sneezing… (previous pilot research by Jean Bousquet, unpublished)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 [ʌtʃiu:] means THANK YOU!

DICTIONARY CREATED ON THE FLIGHT TO BRUSSELS

What is it?

It is balance of power in decission making "swing" between the physician and patient: paternalism with no patient's participation in one side and full authonomy with no physian's participation in the other

When it start?

In 2001 US Institute of Medicine endorsed Shared decission 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 visite

Is it still important?

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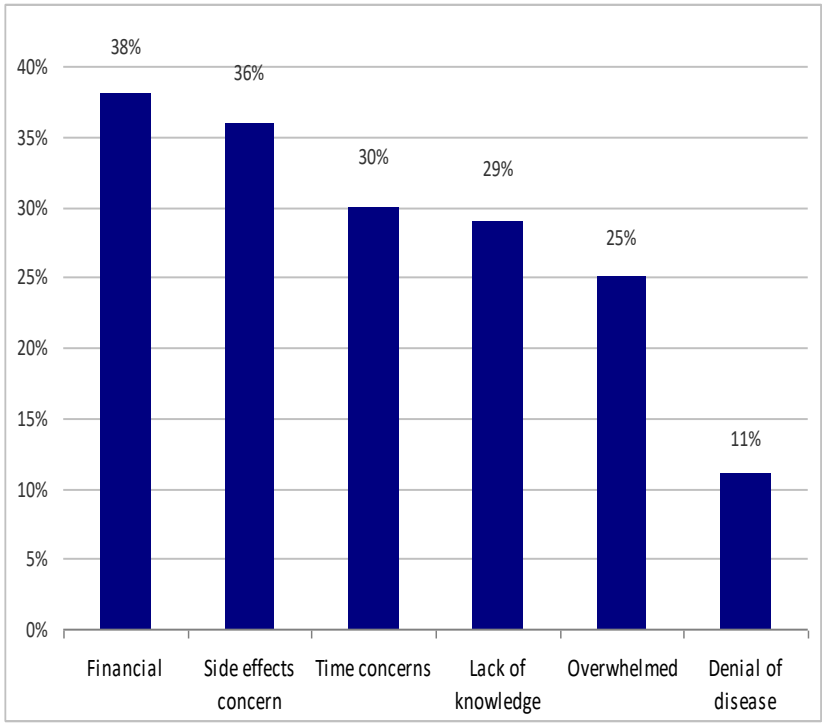
WHAT DO PATIENTS WANT FROM THEIR ASTHMA CARE DOCTOR?

Rubin B, Zhao W, Winders TA
Paediatric Respir Rev 2018; 27: 86–89.

What do you want most from your doctor?

Access	Convenient location and office hours, more time per visit
Authenticity	Eye contact, empathy, attitude and competence in work
Shared decision making	Partnership, more listening and interaction from physician
Patient-friendly education	Support services, prescription assistance

What are the most common barriers for the care?



Asthma & Allergy Network: survey of 1000 parents of asthmatic children

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SHARED DECISION MAKING IN SCHOOL AGE CHILDREN WITH ASTHMA

Butz AM, Walker JM, Pulsifer M, et al.
Pediatric Nurs 2007; 33 (2): 111–16.

INSTRUMENTS:

- **VISUAL AIDS**
- **TURN-TAKING**
- **ELICTING ATTENTION / REQUESTING HELP** Complex of methods for the increasement 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 confidental and accurat 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

SHARED DECISION MAKING IN SCHOOL AGE CHILDREN WITH ASTHMA

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Pediatric Nurs 2007; 33 (2): 111–16.

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**

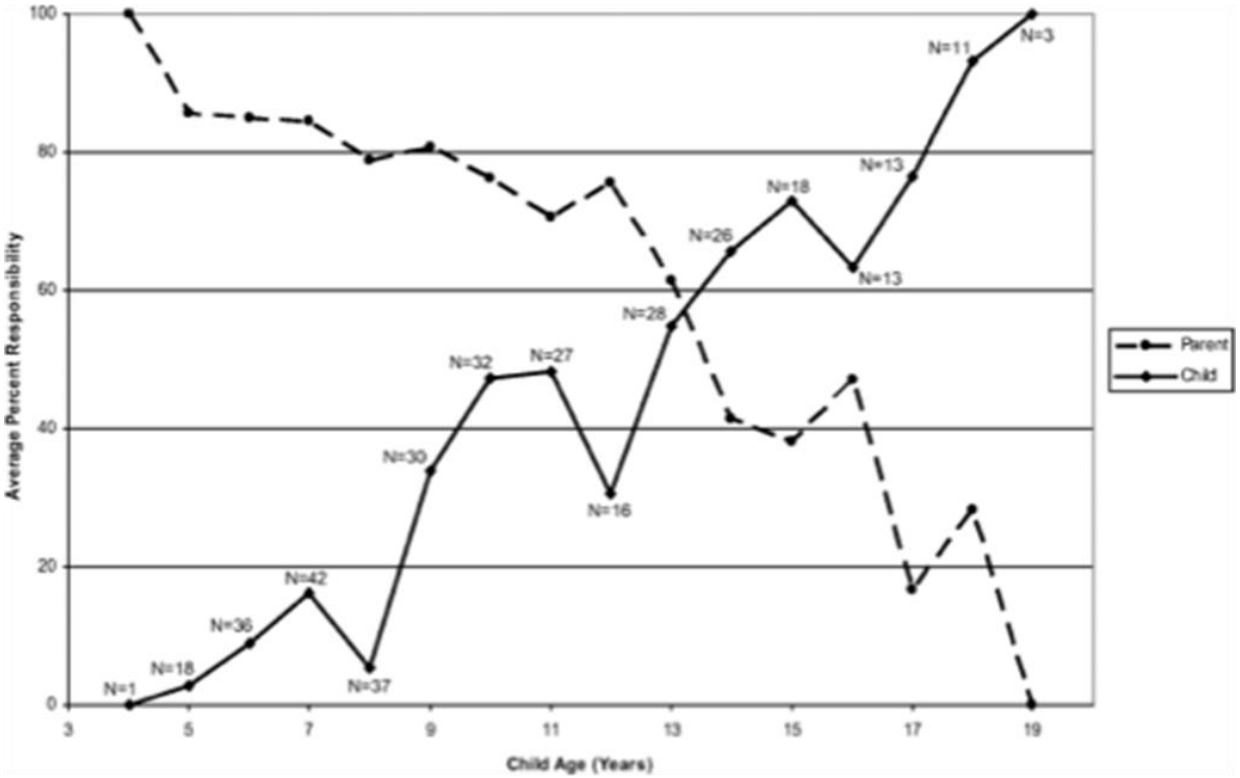
SHARED DECISSION-MAKING: TIME TO ACT

PATERNALISM *or* DIDACTIC DECISION MAKING	SHARED DECISION-MAKING
Establish: contact with the patient, provide information about importance of follow-up	+ **Explain:** SDM approach with key message, that **there are always multiple options**
Assess: asthma clinical signts, triggers, medications	+ **Identify:** patient's goals and preferences
Provide: information	Same
Analyse: spirometry results, level of control, potential adherence problems	Same
Act: prepare preferably written asthma plan	**+ Negotiate:** discuss treatment options **seeking consessus (contract) with the patient**

Brand P, XIX VIPPACS, 2014

AGE SPECIFIC ISSUES:
AGE OF CHILDREN AND TAKING DAILY MEDICINES ON THEIR OWN

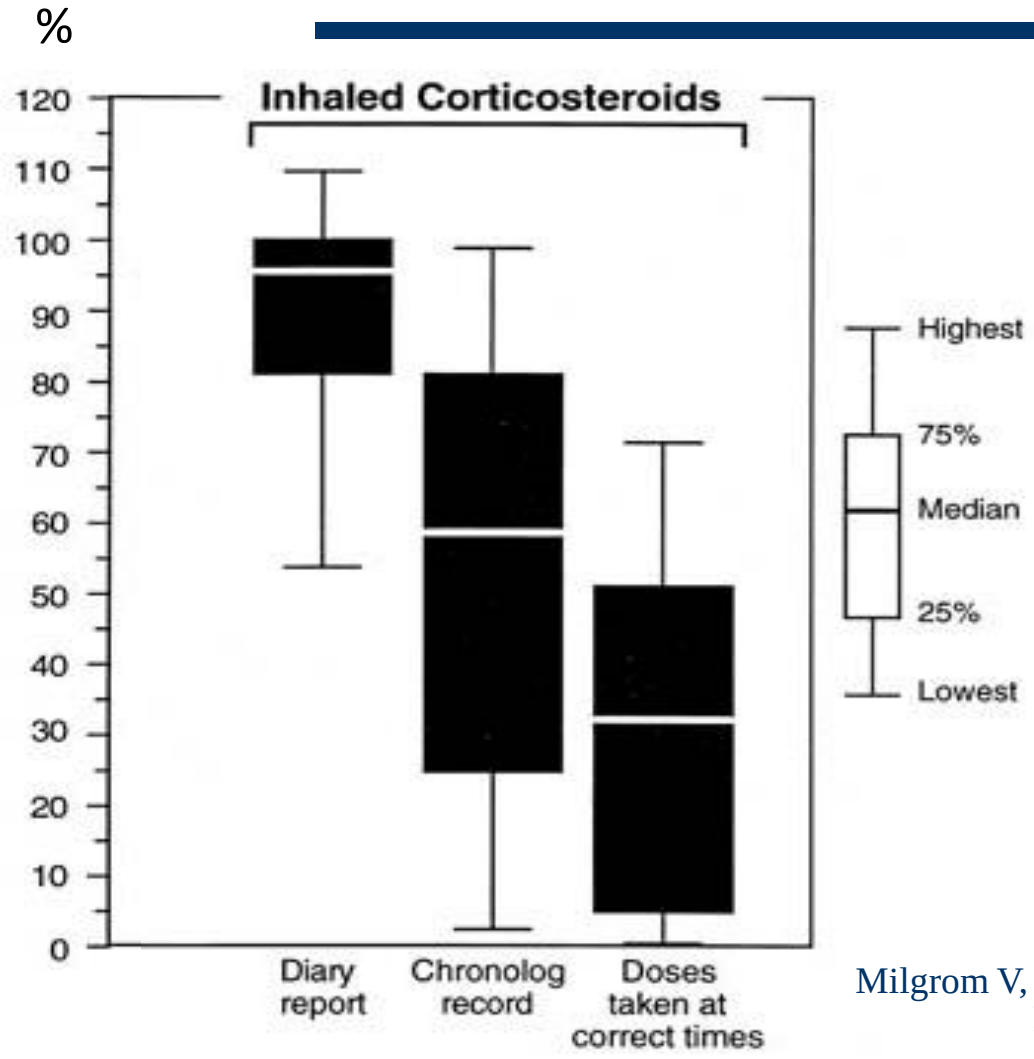
Transition to self-care: child's "weight" in decission making on daily treatment is depending on age



Valiulis A, 2018

Orell-Valente JK, Pediatrics 2008; 122: 1186-92

AGE SPECIFIC ISSUES:
TO TELL YOU TRUTH



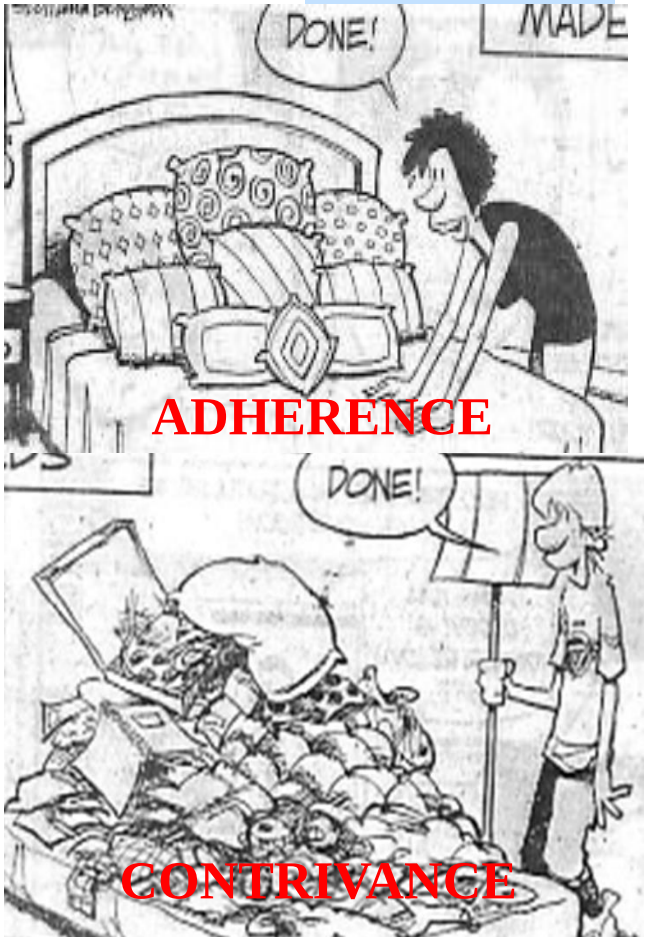
Diary cards
95.4%

Electronic counter
58.4%

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



Rubin B, 2014

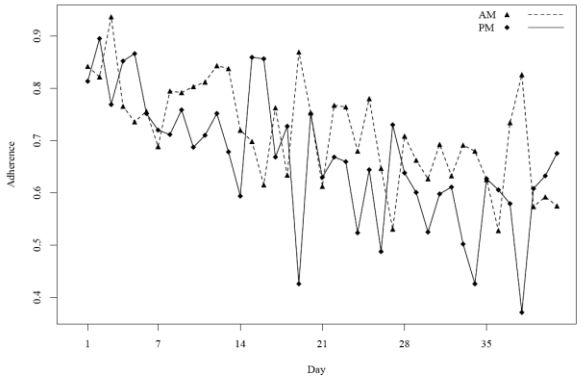
Valiulis A, 2018

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 treatme*
- *Intelligent nonadherence*

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

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

Valiulis A, 2018

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

Bulletin World Health Organization 2018 ; 96 (8): 520-21
A human rights approach to mental health and people with dissabilities
Fleck F; DOI: http://dx.doi.org/10.2471/BLT.18.030818

- **To develop human rights-based approach to CNDs**
- **The principle of confinement is used too often to manage the patient with chronic disease**


Dainius Puras

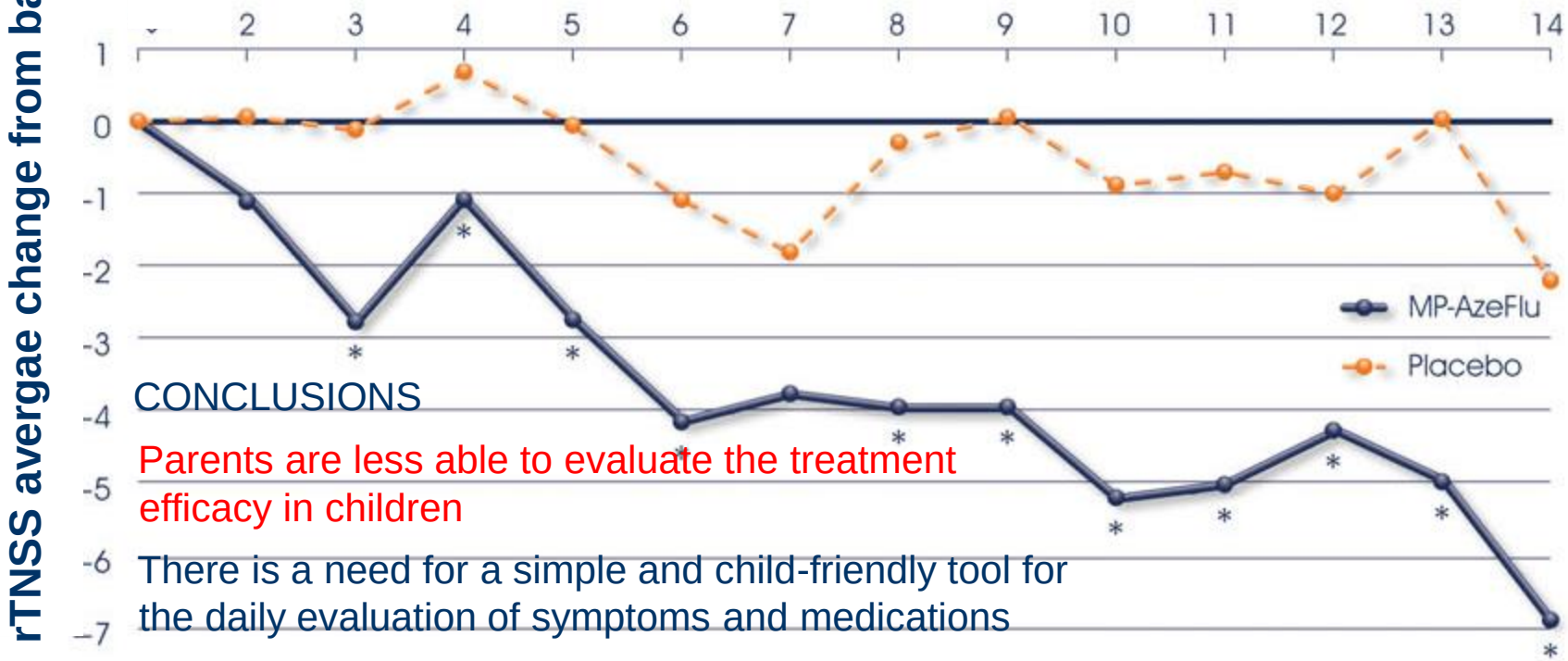
Dainius Puras is the United Nations Special rapporteur on the right of everyone to enjoyment of the highest attainable standard of physical and mental health. He has held senior posts at the Centre of Child Psychiatry and Social Paediatrics at Vilnius University since 1986, including as head since since 2012. He has held senior posts at the Child Development Center at Vilnius University Children's Hospital since 1993. From 2007–2011, Puras was a Member of the United Nations Committee on the Rights of the Child. He is active in civil

- **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.
Pediatr Allergy Immunol 2016; 27: 126-33.

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



CONCLUSIONS

Parents are less able to evaluate the treatment efficacy in children

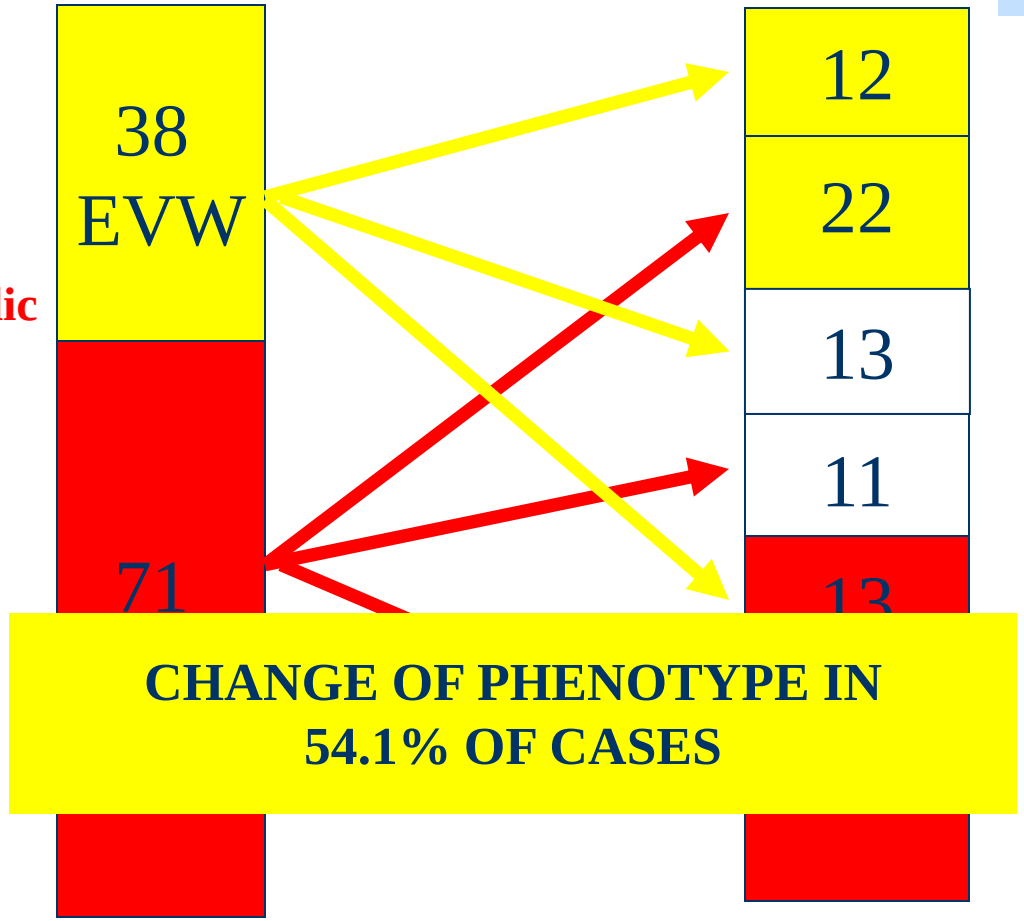
There is a need for a simple and child-friendly tool for the daily evaluation of symptoms and medications

Valiulis A, 2018

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**



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
Commu-nication	Worry	Daily Activities	Family Relationships

General Questio-nnaire

Asthma Control Test

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*

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

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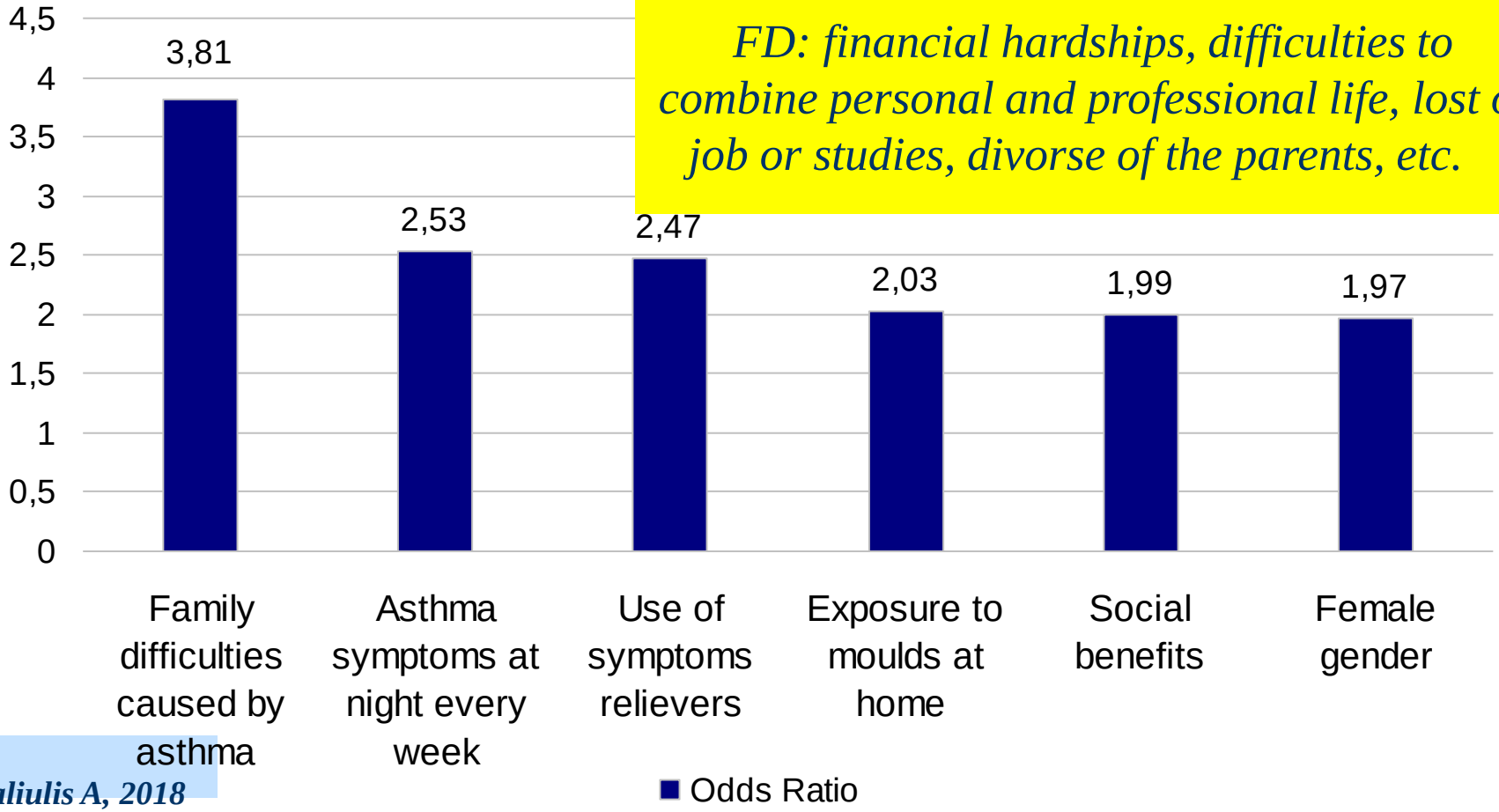
N = 382; Wald-chi^2 = 35.24; p<0.001; Hosmer-Lemeshow test chi^2 = 7.715; df = 8; p = 0.462; correctly classified 65.4%; Nagelkerke R^2 = 0.340.

MAJOR DETERMINANT OF QUALITY OF LIFE OF THE FAMILY OF ASTHMATIC CHILD IS NOT ASTHMA-RELATED

Taminskiene 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.



DO PATIENTS OF SUBSPECIALIST PHYSICIANS BENEFIT FROM WRITTEN ASTHMA PLANS?

Sheares BJ, Mellins RB, Dimango E, at al.
Am J Respir Crit Care Med 2015; 191: 1374-83.

- **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 Decission Making to Guided Self Management in adults and at least in some groups of children**

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 poticians 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)

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 decission-making transforming to Guided self management
- *Post hoc* Result: Declaration as plan of action and networking

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

JUST FEW BECAUSE...

"I do **not** think I'm God. God-like, yes, but not God."

- 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 spead, if comp 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 embeding our patient to live with new God

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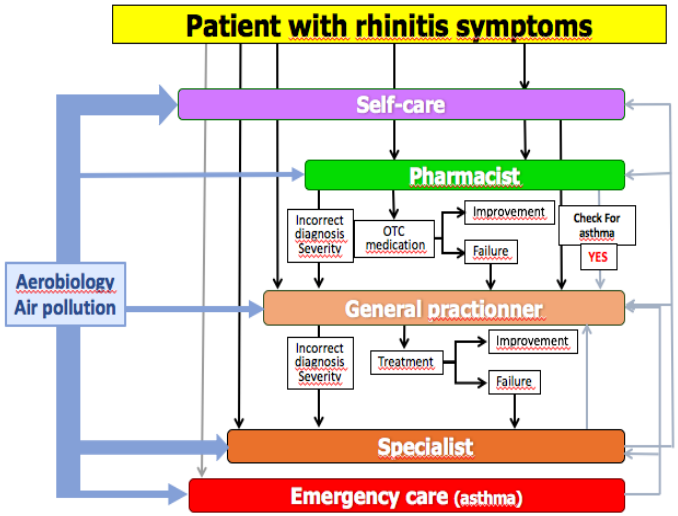
INTEGRATED CARE PATHWAYS AS PREREQUISITION FOR MERGE mHEALTH AND SDM

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



Bousquet J, 2018

Valiulis A, 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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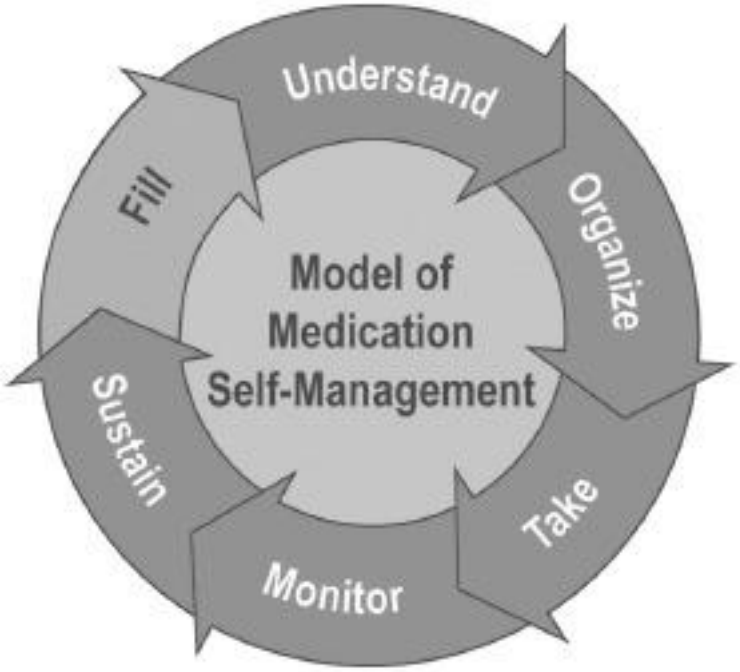
EU VILNIUS SUMMIT:
EVOLUTION OF SHARED DECISSION MAKING TO GUIDED SELF MANAGEMENT

Autonomy ← **Shared Decision Making (Mutuality)** → Paternalism

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



Bailey SC. J Health Commun

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

A Valiulis, J Bousquet, A Vaiyg, U Suprun, D Sergeenko, S Cebotari, D Borelli, S Pietikainen, J Banys, I Agache, NE Billo, A Bush, I Chkhaidze, L Dubey, WJ Fokkens, J Grigg, T Haahtela, K Julge, O Katilov, N Khaltaev, M Odemyr, S Palkonen, R Savli, A Utkus, V Vilc, A Bedbrook, M Bewick, J Chorostowska-Wynimko, E Danila, A Hadjipanayis, R Karseladze, V Kvedariene, E Lesinskas, L Münter, B Samolinski, S Sargsyan, B Sitkauskiene, D Somekh, L Vaideliene,
T Alasevicius, A Valiulis, PW Hellings