Health literacy in dialysed patients

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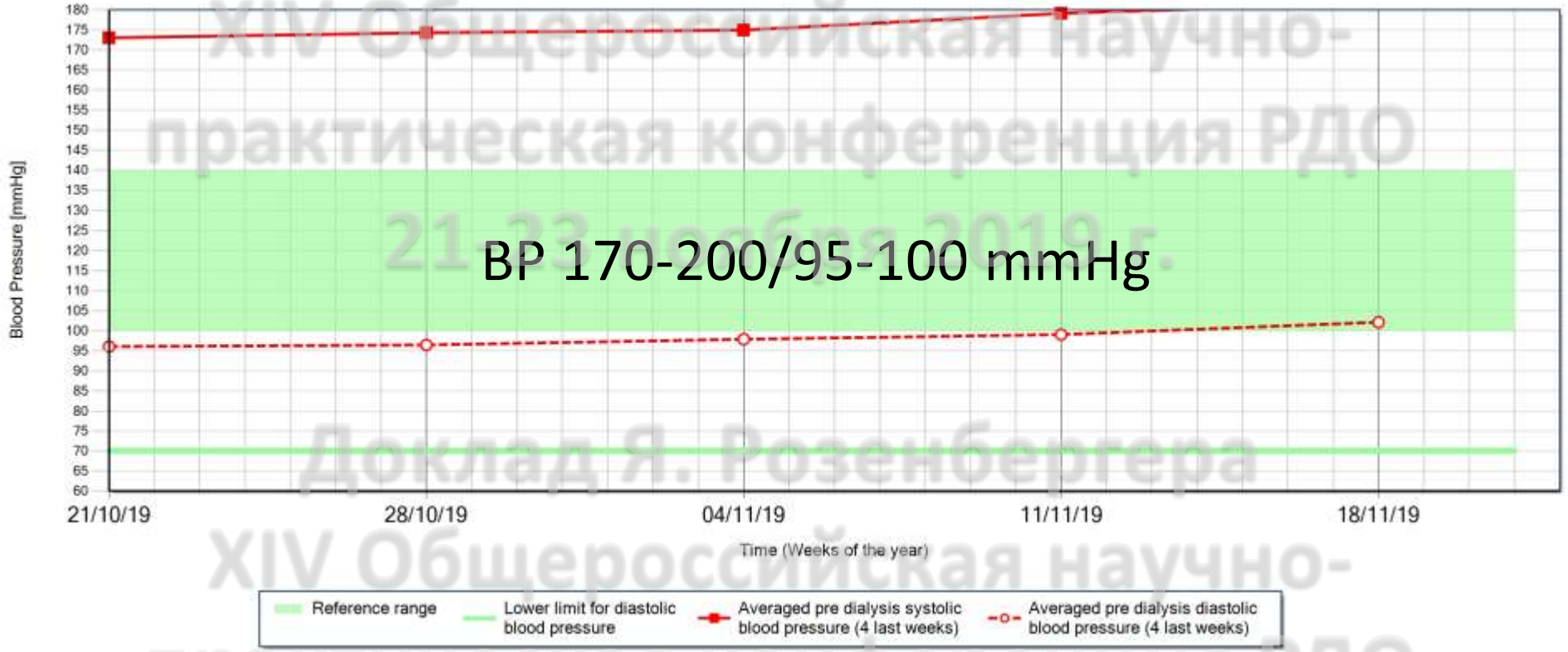
Let’s start with a case report!

- 16 years old boy
- poor socio-economic background
- rapid progressive IgA GN
- acute dialysis in 4/2018
- (partial) remmision after immunosuppression
- last dose in 8/2018; then … not coming
- deterioration in 12/2018
- chronic hemodialysis since 5/2019

Case report: resistant? hypertension



Lieky	Dávkovanie
AGEN 5 - TBL 30X5 MG (BLIS. PVC/PVDC/AL)	1-0-1
CONCOR COR 2,5 MG - TBL FLM 30X2,5 MG (BLIS.PVC/AL)	1-0-1
EBRANTIL 60 - CPS PLD 50X60 MG (FĽ.HDPE)	1-1-1
FUROSEMID-SLOVAKOFARMA FORTE - TBL 50X250 MG (BLIS.PVC/AL)	1/2-0-0
MILURIT 300 MG - TBL 100X300 MG (LIEK.SKL.HNEDÁ)	0-1/2-0
OSVAREN - TBL FLM 180	1-0-1
RILMEX 1 MG TABLETY - TBL 30X1 MG (BLIS.AL/AL)	1-0-0
TRITACE 5 - TBL 30X5 MG (BLIS.PVC/AL)	1-0-1

Case report: resistant? hypertension

What should I do?

- Ask the patient: do you take your drugs? YES!
- Let's check drug prescription …
- e.g. ramipril: 20.5. 2019: 30 tablets
  20.10.2019: 30 tablets
- Aha! How my colleague shouted at him!

Health Literacy

What is health literacy

Health literacy is a term introduced in the 1970s and contemporarily gains increasing importance in public health and healthcare.

From 17 explicit definitions of HL, only defs by the American Medical Association, the Institute of Medicine and WHO are cited most frequently in the eligible literature.

Definitions of health literacy

WHO (1998)	"The cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health
American Medical Association's(1999)	"The constellation of skills, including the ability to perform basic reading and numeral tasks required to function in the healthcare environment"
Nutbeam (1999)	"The personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health"
Institute of Medicine (2004)	"The individuals' capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions"
Kickbusch, 2001	"Health literacy is the ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, the healthcare system, the market place and the political arena"

Patients with low health literacy may have difficulties with…

- Locating providers and services
- Filling out health forms
- Sharing medical history with provider
- Seeking preventive health care
- Managing chronic health conditions
- Understanding directions on medication
- Understanding and acting on health-related news and information
- … and many more

Potential of the HL concept

- Improvement of clinical services
- Participation of communities on health improvement
- Planning of healthcare services
- Education in public health
- Development of health politics

Measuring health literacy

The existing tools to measure health literacy vary in their approach and design, as well as in terms of their purpose

Some tools have been developed for **screening**, and serve to divide people into categories with low or high levels of health literacy.

They are often used in clinical settings, these tools are necessarily **short**, **quick** and **easy to use**.

For example:

- **REALM** - Rapid Estimate of Adult Literacy in Medicine
- **TOFHLA** - The Test of Functional Health Literacy
- **NVS** - The Newest Vital Sign (NVS)

But, numerous studies showed methodological weaknesses including inadequate consideration of possible confounders

Measuring health literacy

Other tools aim at measuring a **broader concept of health literacy**, with a view to provide an **in-depth assessment** of the dimensions of health literacy, or to explore its relationships with social determinants, health behavior, health status or healthy service use such as:

- **NAAL** - National Assessment of Adult Literacy survey
- **CHC** - the Critical Health Competence Test
- **HeLMS** – the Health Literacy Management Scale
- **HLQ** - the Health Literacy Questionnaire

Measuring health literacy
Health literacy questionnaire (HLQ)

- HLQ is a critical advancement in health literacy measurement
- a multi-dimensional tool that has been designed to provide practitioners, organizations and governments with data on HL
- describes the HL strengths and limitations of individuals
- 9 domains capturing the complexity of HL
- Enables to create profiles of HL – groups of patients with similar HL across 9 domains

We usually work on:

9 Health literacy domains

Do you remember the boy from case report? His poor socio-economic background? And my colleague shouting at him?

Low level of the domain	High level of the domain
1. Feeling understood and supported by healthcare providers	
People who are low on this domain are unable to engage with doctors and other healthcare providers. They don't have a regular healthcare provider and/or have difficulty trusting healthcare providers as a source of information and/or advice.	Has an established relationship with at least one healthcare provider who knows them well and who they trust to provide useful advice and information and to assist them to understand information and make decisions about their health.
2. Having sufficient information to manage my health	
Feels that there are many gaps in their knowledge and that they don't have the information they need to live with and manage their health concerns.	Feels confident that they have all the information that they need to live with and manage their condition and to make decisions.
3. Actively managing my health	
People with low levels don't see their health as their responsibility, they are not engaged in their healthcare and regard healthcare as something that is done to them.	Recognize the importance and are able to take responsibility for their own health. They proactively engage in their own care and make their own decisions about their health. They make health a priority.
4. Social support for health	
Completely alone and unsupported for health	A person's social system provides them with all the support they want or need for health.
5. Appraisal of health information	
No matter how hard they try, they cannot understand most health information and get confused when there is conflicting information.	Able to identify good information and reliable sources of information. They can resolve conflicting information by themselves or with help from others.

Low level of the domain	High level of the domain
6. Ability to actively engage with healthcare providers	
Are passive in their approach to healthcare, inactive i.e., they do not proactively seek or clarify information and advice and/or service options. They accept information without question. Unable to ask questions to get information or to clarify what they do not understand.	Is proactive about their health and feels in control in relationships with healthcare providers. Is able to seek advice from additional healthcare providers when necessary. They keep going until they get what they want. Empowered.
7. Navigating the healthcare system	
Unable to advocate on their own behalf and unable to find someone who can help them use the healthcare system to address their health needs. Do not look beyond obvious resources and have a limited understanding of what is available and what they are entitled to.	Able to find out about services and supports so they get all their needs met. Able to advocate on their own behalf at the system and service level.
8. Ability to find good health information	
Cannot access health information when required. Is dependent on others to offer information.	Is an 'information explorer'. Actively uses a diverse range of sources to find information and is up to date.
9. Understanding health information well enough to know what to do	
Has problems understanding any written health information or instructions about treatments or medications. Unable to read or write well enough to complete medical forms	Is able to understand all written information (including numerical information) in relation to their health and able to write appropriately on forms where required.

Profile of health literacy

Vignette 1. Doesn't really understand what to do, but would trust the doctor

1. Feeling understood and supported by healthcare providers	2. Having sufficient information to manage my health	3. Actively managing my health	4. Social support for health	5. Appraisal of health information	6. Ability of actively engage with health care providers	7. Navigating the health system	8. Ability to find good health information	9. Understanding health information well enough to know what to do
Very High	**Low-moderate**	**Moderate-high**	**Moderate-high**	**Low-moderate**	**Low**	**Low-moderate**	**Very low**	**Low**

Giovanni is a 73 year old Italian man whose wife died 3 years ago. He now lives alone. Giovanni has type 2 diabetes and arthritis, and was recently diagnosed with heart failure. Although he trusts everything the doctor tells him and tries to follow instructions (scale 1), he gets very confused about how to manage all his new heart failure medications, and his fluid restriction (scales 2 and 9). He never feels certain that he is actually doing the right thing. He doesn't feel right about asking questions of the doctor (scale 6) because he was brought up to never question what a doctor says. He doesn't really look for information elsewhere either (scale 8). His daughter helps when she can (scale 4), but she doesn't always have the knowledge to explain things to him. The doctor referred him to a lifestyle education program at the community health center, but a lot of the information seemed very complicated, and because it doesn't come from his doctor, Giovanni doesn't try to take it all in.

(Giovanni is likely to score poorly on a health literacy screening test due to his poor reading and writing (scale 9) but this is partly compensated by his good relationship with his doctor. Health literacy interventions could focus on strengthening his social support further (scale 4) and building trust in the advice of social care services (scales 6) and provision of information endorsed by his doctor.)

Profile of health literacy

Vignette 2. Reasonable capacity and confidence, but only moderate engagement and support

1. Feeling understood and supported by healthcare providers	2. Having sufficient information to manage my health	3. Actively managing my health	4. Social support for health	5. Appraisal of health information	6. Ability of actively engage with healthcare providers	7. Navigating the health system	8. Ability to find good health information	9. Understanding health information well enough to know what to do
Extremely low	**Low**	**High**	**Very low**	**Low**	**Low**	**Moderate**	**Moderate**	Very high

Jean is a 73 year old woman with osteoarthritis and type 1 diabetes who is receiving some cleaning services from the council. She has been with the same doctor for ten years and trusts his advice. Recently, however, her doctor has partially retired and now she often needs to see doctors in the practice that she doesn't really know. Sometimes she thinks they are telling her different things. She isn't always honest with the doctors as she knows she isn't doing all the things that they recommend. Recently one of the doctors really told her off and now she feels scared about going unless she can see her old doctor (scale 1). She has a reasonable amount of knowledge of medical terms and can read and understand information that she receives (scale 9)– it's just that most information that she receives is not as practical as she is looking for (scale 2). Her main concern is how her osteoarthritis impacts her mobility. She knows that if she lost some weight, it would help but she has never been able to achieve that despite trying many diets that she has come across. She doesn't like talking to people about her problems because she feels they are tired of hearing about them and often judge her because she is overweight (scale 4).

(Jean is likely to score very well on most health literacy screening tools because her reading and writing abilities are good. Her difficulties lie in other areas. Support for her could include building on her interesting in health (scale 3) and her ability to work with information and finding her way around the system (scales 2, 7, 8), setting up consistency of messages across her practitioners (scale 1) and building her support networks (scale 4).)

Profile of health literacy

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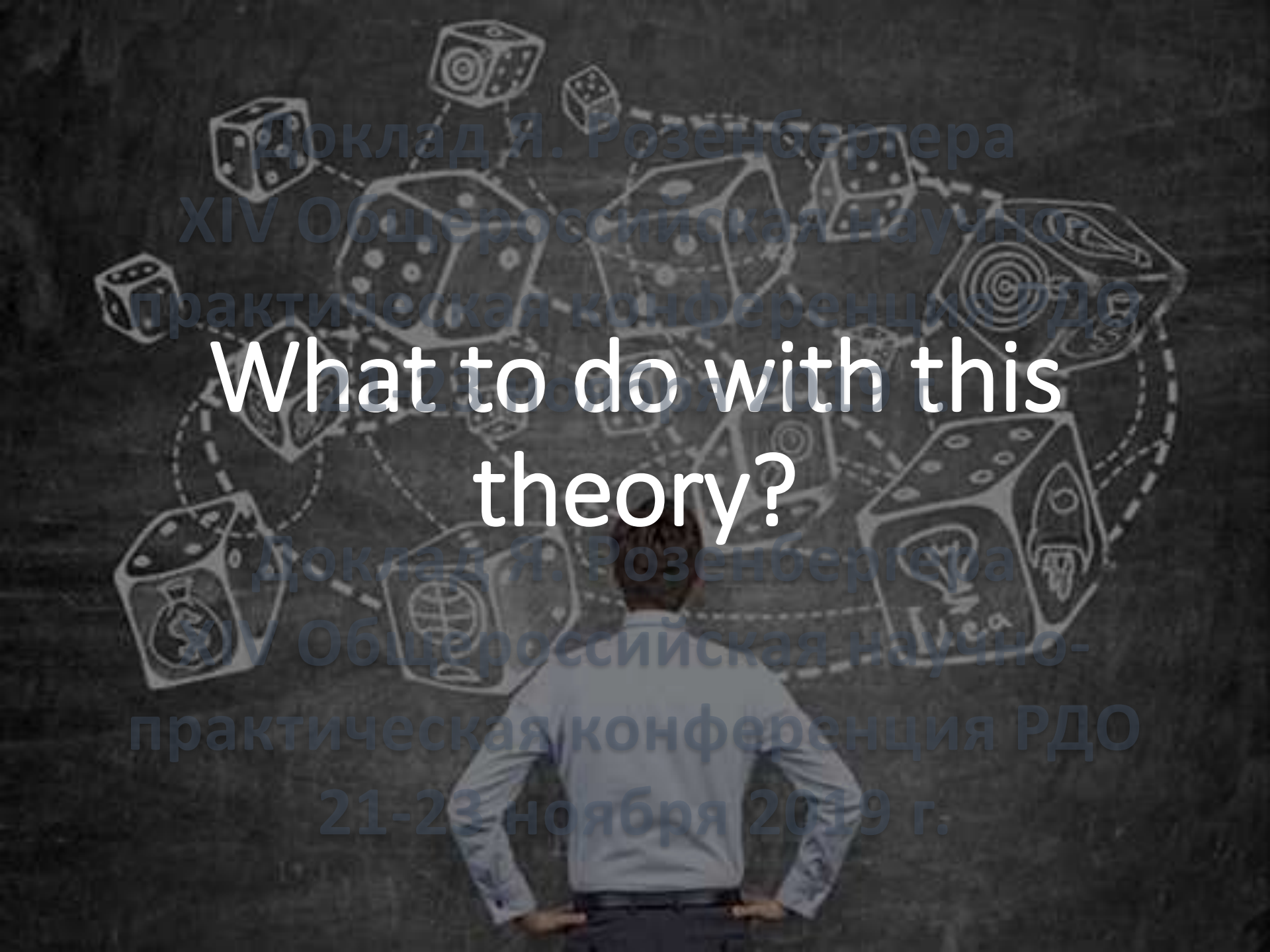
Low health literacy in dialysed patients

- Prevalence of LH: 25% (Taylor et al., 2018)
- Strong association of LHL with socio-economic factors - age, education, ethnicity (Paasche-Orlow, Wolf, 2007)
- Worse health outcomes, more complications, increased mortality (Devraj, Gordon, 2009; Taylor et al., 2017, Cavanaugh et al., 2015)
- Worse access to transplantation (Grubbs et al., 2009; Kazley et al., 2015)
- Missed and shortened dialysis sessions, more hospitalisations connected with dialysis (Green et al., 2013; Tohme et al., 2017)



What to do with this theory?

Health literacy profiles of dialysed patients (N=542)

Profile	Feeling understood and supported by health-care providers	Having sufficient information to manage my health	Actively managing my health	Social support for health	Appraisal of health information	Ability to actively engage with health-care providers	Navigating the health-care system	Ability to find good health information	Understand health information well enough to know what to do
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2	3,55	3,11	2,98	3,48	2,42	3,83	3,07	3,28	3,35
3	3,10	3,03	2,96	3,13	2,89	4,09	3,94	4,00	4,02
4	2,91	2,82	2,92	2,90	2,90	3,36	3,22	3,33	3,41
5	3,76	3,69	3,51	3,73	3,46	4,43	4,27	4,36	4,31
6	3,95	3,97	3,87	3,96	2,47	4,97	4,95	4,86	4,66

Our latest research on the topic of health literacy and adherence

Is Health Literacy of Dialyzed Patients Related to Their Adherence to Dietary and Fluid Intake Recommendations?

Patient Empowerment

this concept entails a re-distribution of power between patients and physicians.

Empowered patients attempt to take charge of their own health and their interactions with health care professionals.

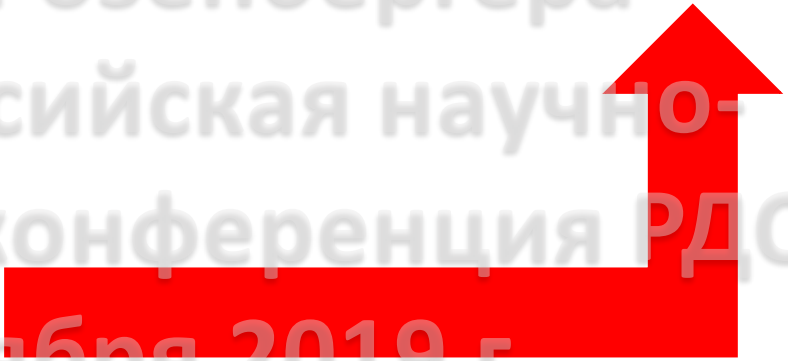
different levels (micro, meso, and macro) and patients have different ideas about what it means to `take charge' and `be empowered'.

Some empirical evidence suggests that active patient participation in health care is associated with better patient outcomes.

Roberts KJ. Patient empowerment in the United States: a critical commentary. Health Expectations, 1999

... the half of the 20th century

the end of the 20th century ...



EDITORIAL

Empowerment of Patient Preference in Dialysis Modality Selection

American Journal of Kidney Diseases, Vol 43, No 5 (May), 2004: pp 930-932

David C. Mendelssohn, MD, FRCPC
Head, Division of Nephrology
Medical Director of Dialysis
Humber River Regional Hospital
Weston, Ontario
Associate Professor of Medicine
University of Toronto
Toronto, Ontario
Canada

To achieve a more rational modality distribution, there are 3 critically important strategies that nephrologists must embrace. At the health-care-system level, we need to develop and implement strategies that will lead to earlier referral of patients with chronic kidney disease to nephrologists.[26] In parallel, we need to explore new models of chronic kidney disease care to enable the potentially large number of patients with this condition to access the expertise of a limited pool of nephrologists. Second, home dialysis (especially daily home HD) will require nephrologists to advocate locally, nationally, and internationally for appropriate funding models, infrastructure, and other system enhancements in order to develop and promote these modalities as options for all suitable patients. Finally, at the patient level, nephrologists must ensure that patients are provided with detailed education about modality options and that true patient choice is empowered. This strategy should target both early referred patients with chronic kidney disease who have time to make informed decisions and those who present late and start on center-based HD. It is not enough for nephrologists to say that patient preference is most important; they must change their approach to dialysis modality decisions and make it so.

Compliance and Adherence

- Compliance
- a patient's adherence to a recommended course of treatment

- Adherence
- the obedience of the patient to the medical advice

- Factors contributing to adherence in CKD patients:
- age, gender, health beliefs, social support, personality, locus of control, self-efficacy, depression

- Direct relationship to patient empowerment

Kidney International, Vol. 64 (2003), pp. 254–262

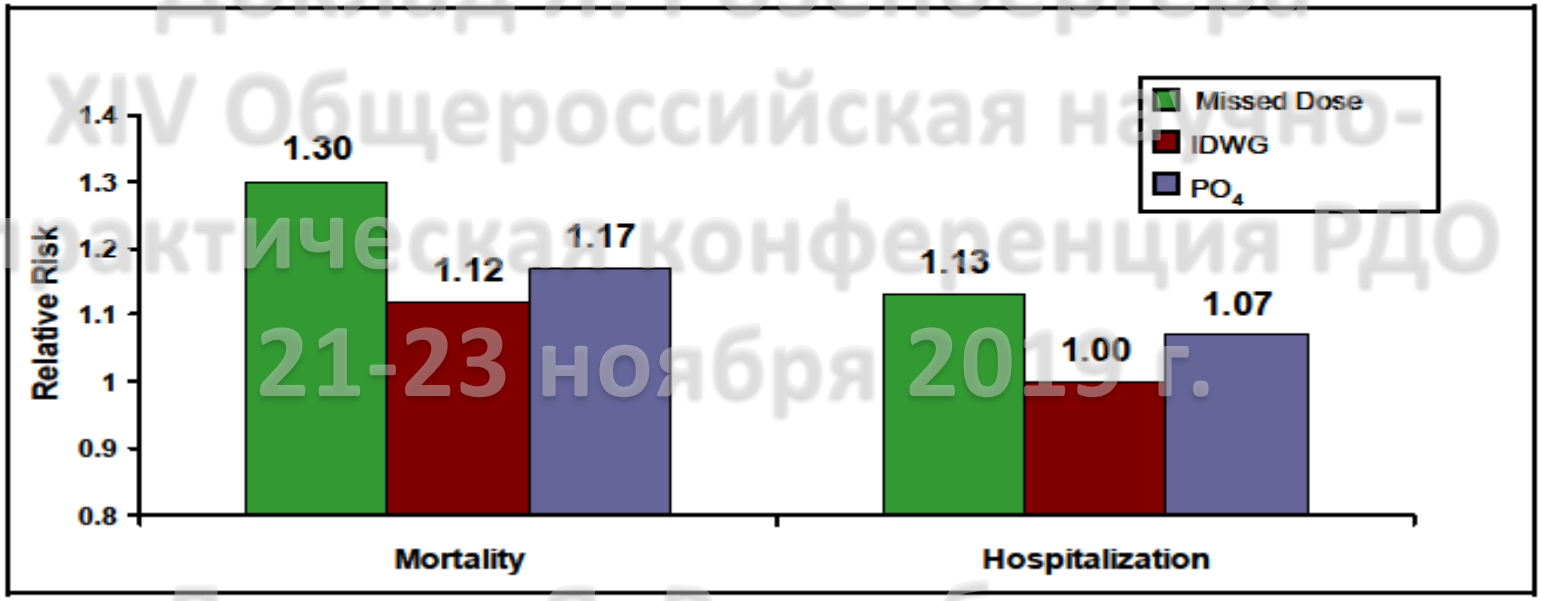


Figure 1: Noncompliance and Increased Risk of Mortality and Hospitalization

- Missed Dose means missing one or more dialysis sessions per month (vs. not missing)
- IDWG = Interdialytic Weight Gain
- PO_4 = Phosphate levels > 7.5 mg/dL

All relative risk data significant at $p = 0.05$ except IDWG for hospitalization. A relative risk above 1.0 suggests an increased risk of mortality or hospitalization.

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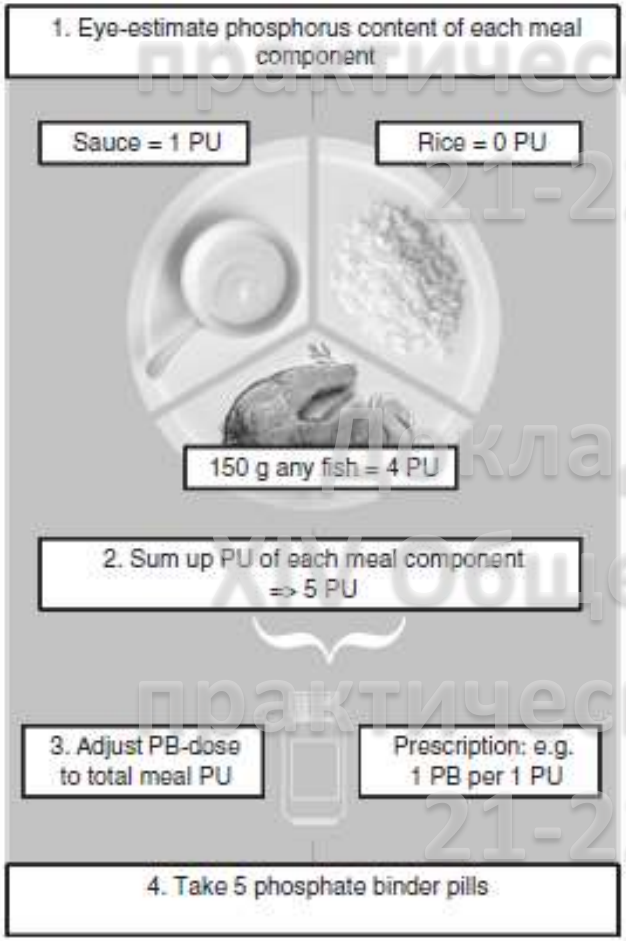
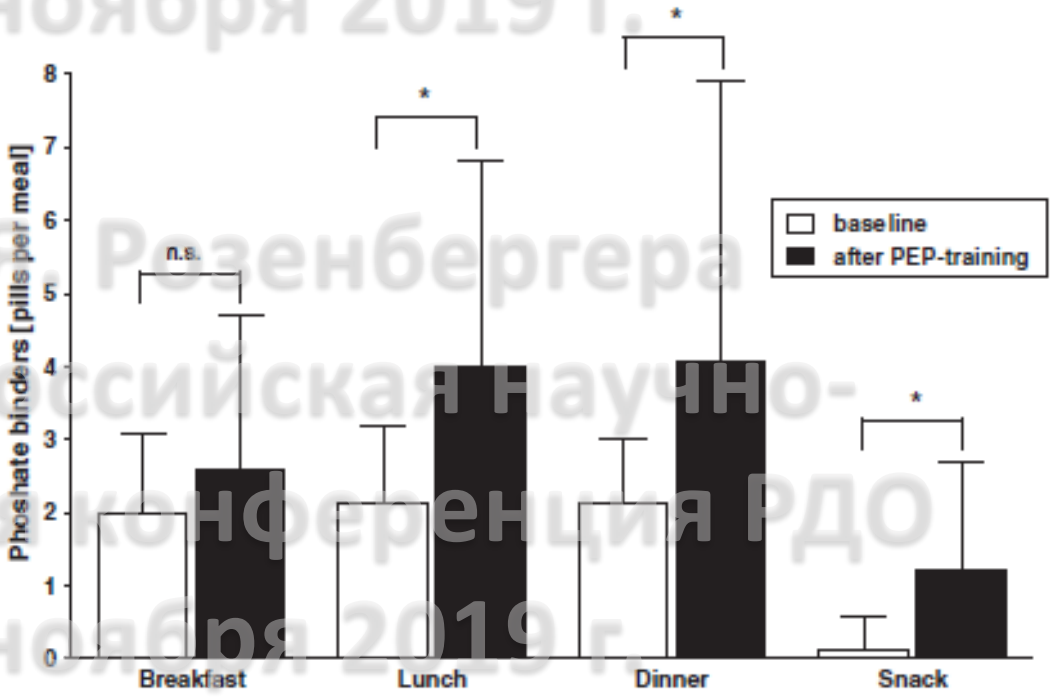
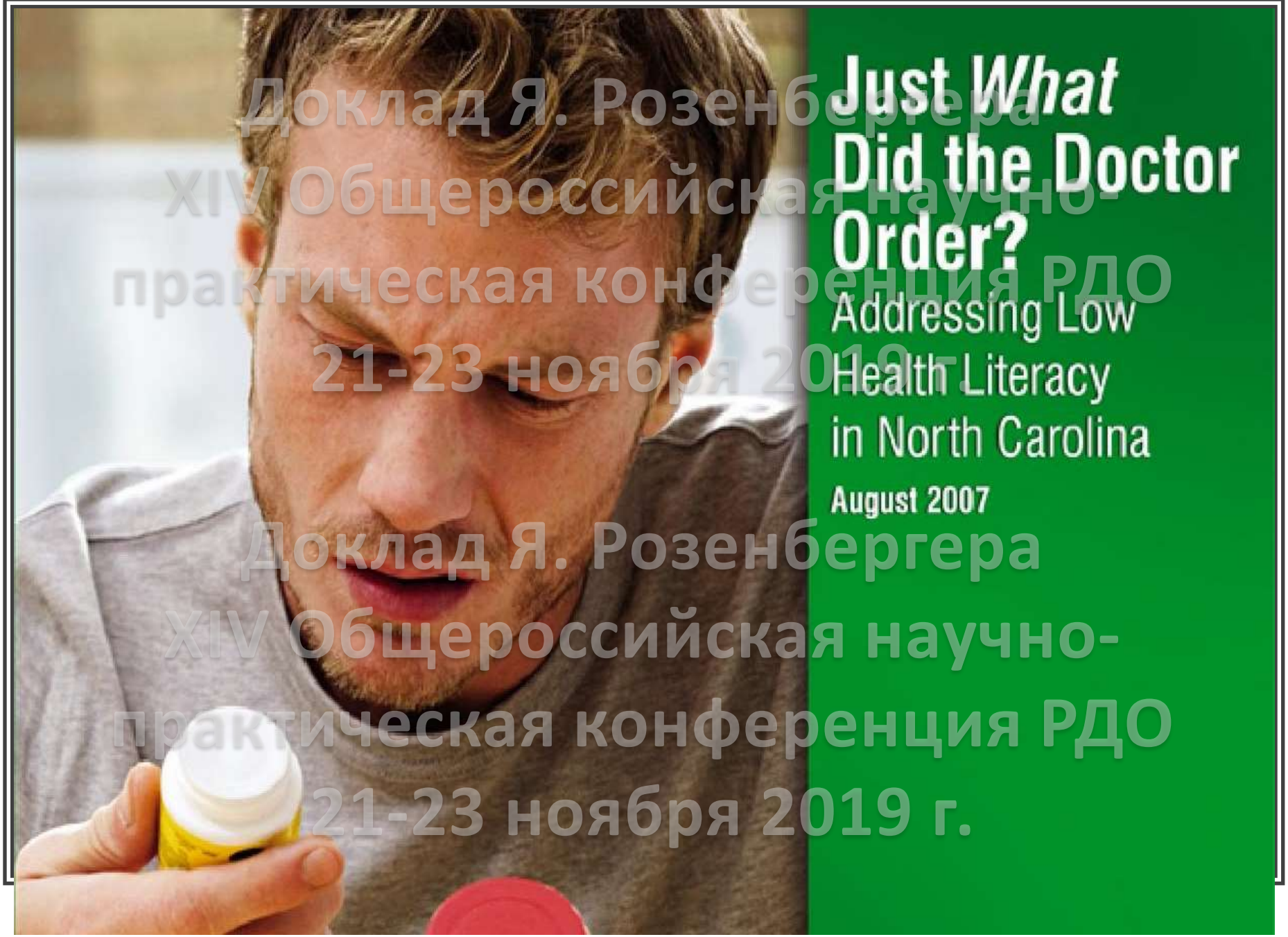
Nephrol Dial Transplant (2010) 25: 3241–3249
doi: 10.1093/ndt/gfq161
Advance Access publication 22 March 2010

Self-adjustment of phosphate binder dose to meal phosphorus content improves management of hyperphosphataemia in children with chronic kidney disease

Thurid Ahlenstiel[1], Lars Pape[1], Jochen H.H. Ehrich[1] and Martin K. Kuhlmann[2]







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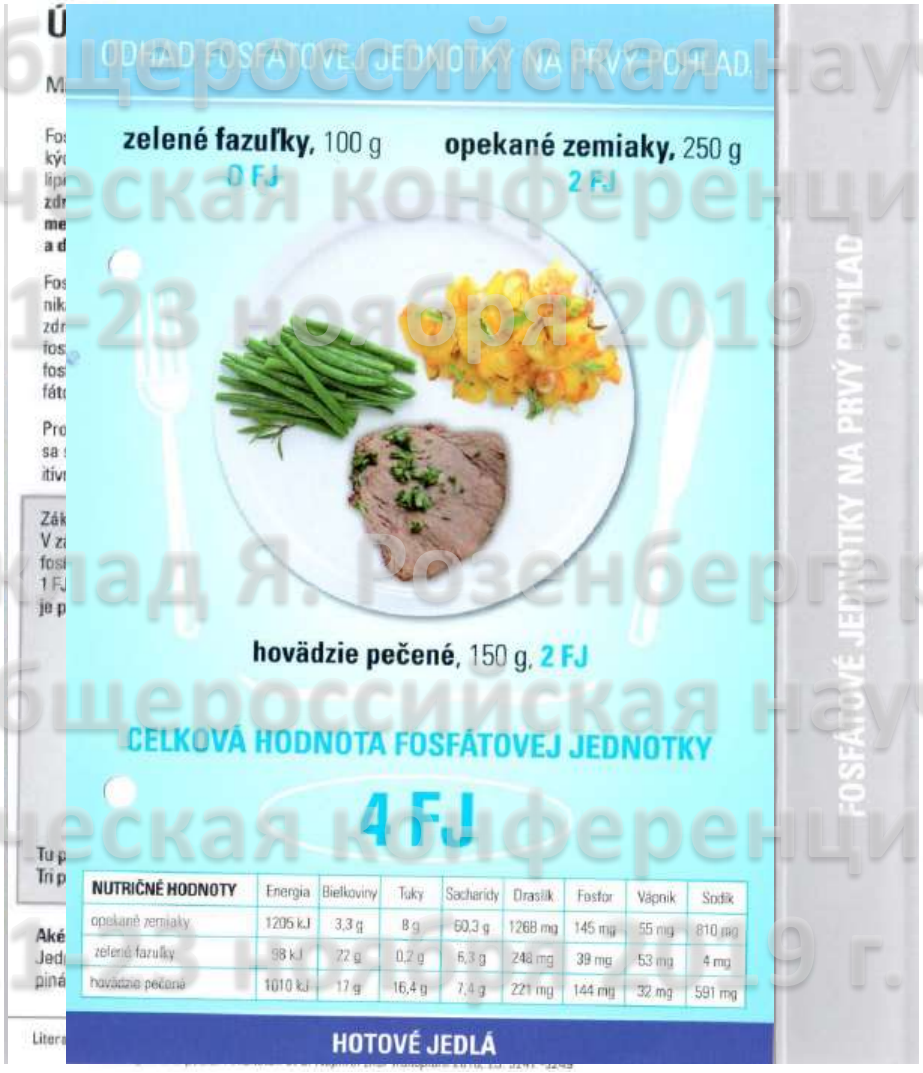
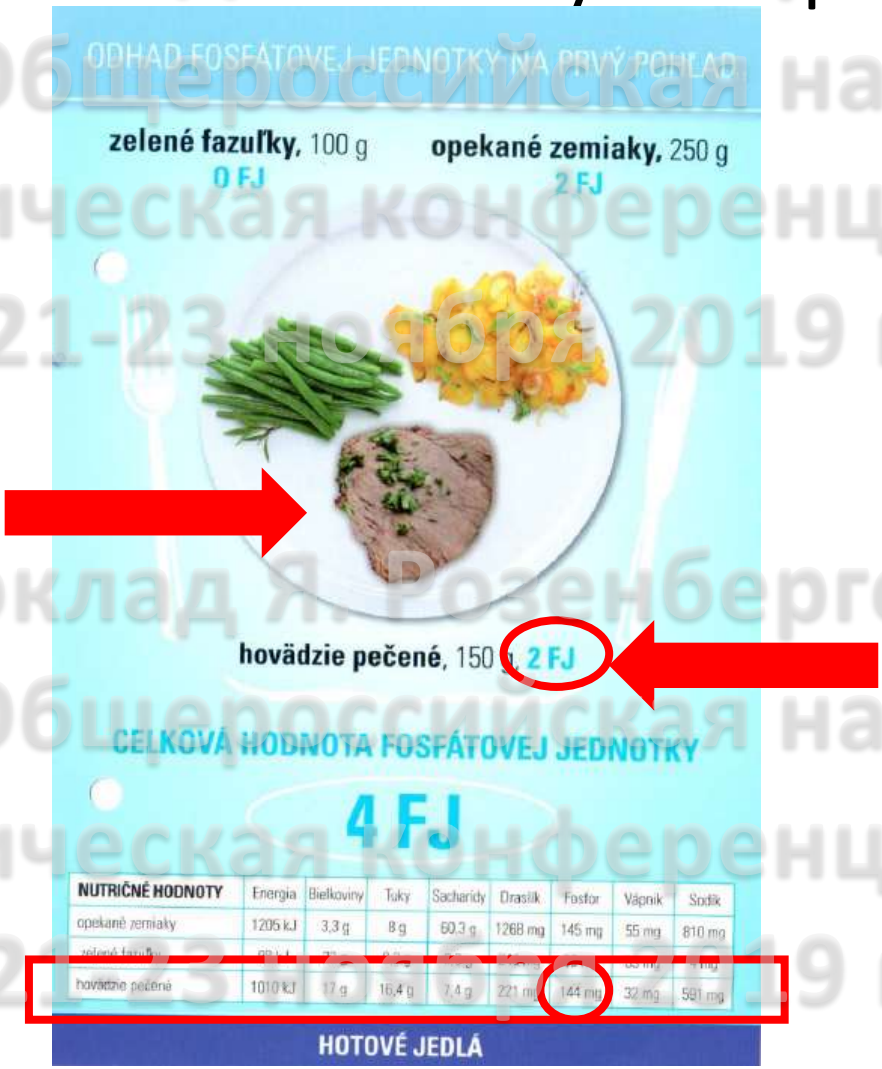
Dietary tool for dialysed patients



Dietary tool for dialysed patients



Pills dosing individualisation

1 PU **0,5-2 pills**

=

Dosing individualisation: tablets or powder

NUTRIČNÉ HODNOTY	Energia	Bielkoviny	Tuky	Sacharidy	Draslík	Fosfor	Vápnik	Sodík
opekané zemiaky	1205 kJ	3,3 g	8 g	60,3 g	1268 mg	145 mg	55 mg	810 mg
zelené fazuľky	98 kJ	22 g	0,2 g	6,3 g	248 mg	39 mg	53 mg	4 mg
hovädzie pečené	1010 kJ	17 g	16,4 g	7,4 g	221 mg	144 mg	32 mg	591 mg

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Beware: patient opinion matters!

Original Paper

nephron Clinical Practice

Nephron Clin Pract 2011;119:c205–c213
DOI: 10.1159/000329106

Published online: August 11, 2011

Choosing Not to Take Phosphate Binders: The Role of Dialysis Patients' Medication Beliefs

Vari Wileman[a] Joseph Chilcot[b] Sam Norton[a] Lyndsay Hughes[a]
David Wellsted[a] Ken Farrington[c]

[a]Centre for Lifespan and Chronic Illness Research and [b]School of Psychology, University of Hertfordshire, Hatfield, and [c]Renal Unit, Lister Hospital, Stevenage, UK

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- 14.5% patients announced that they **actively** refused the use of P binders
- doubts about the need of P binders were correlated to nonadherence
- patients with doubts about the need of P binders had higher serum P

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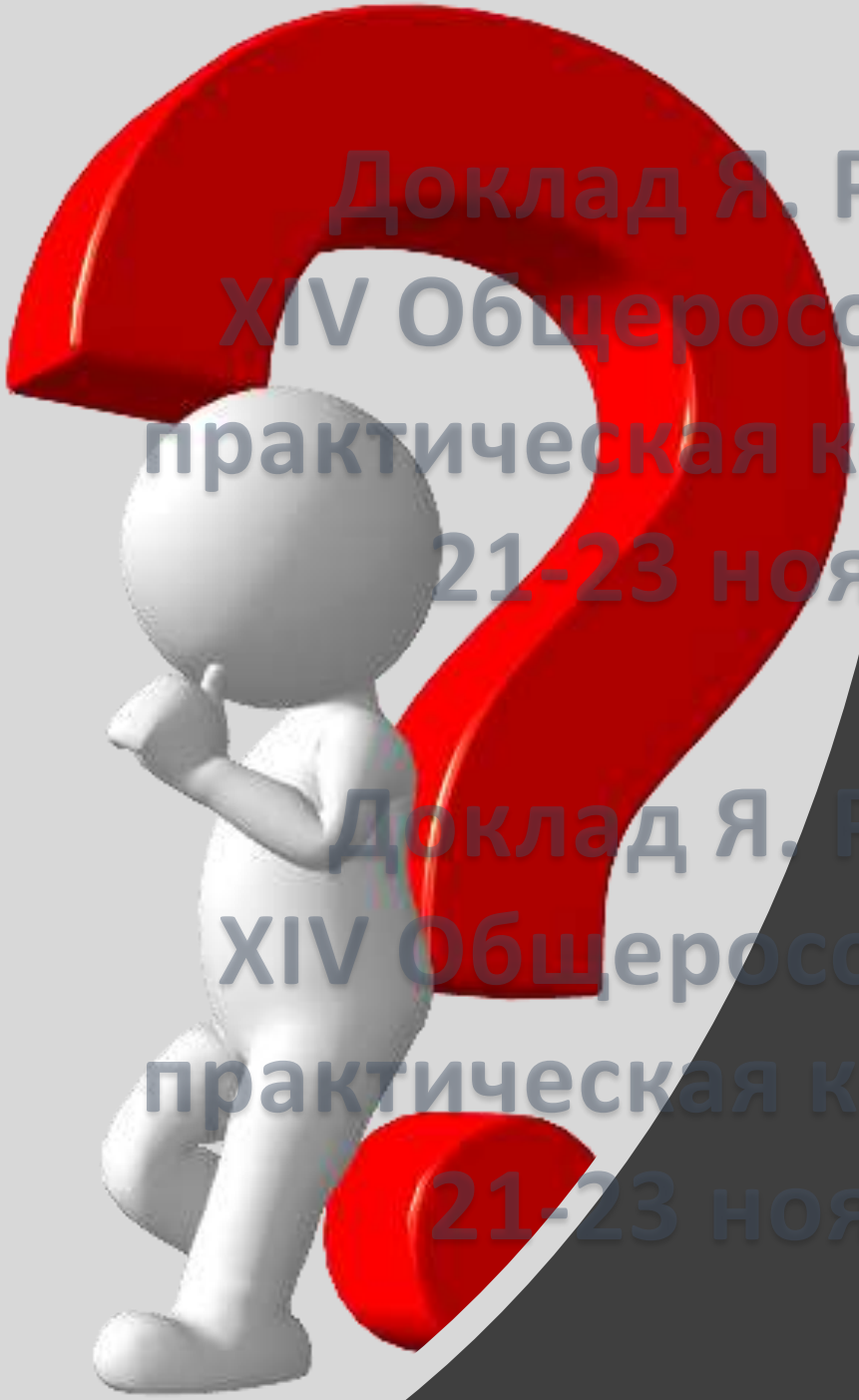

Back to case report!

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Boy has likely health literacy profile 4 …
… tough work ahead …
… and shouting won't help …

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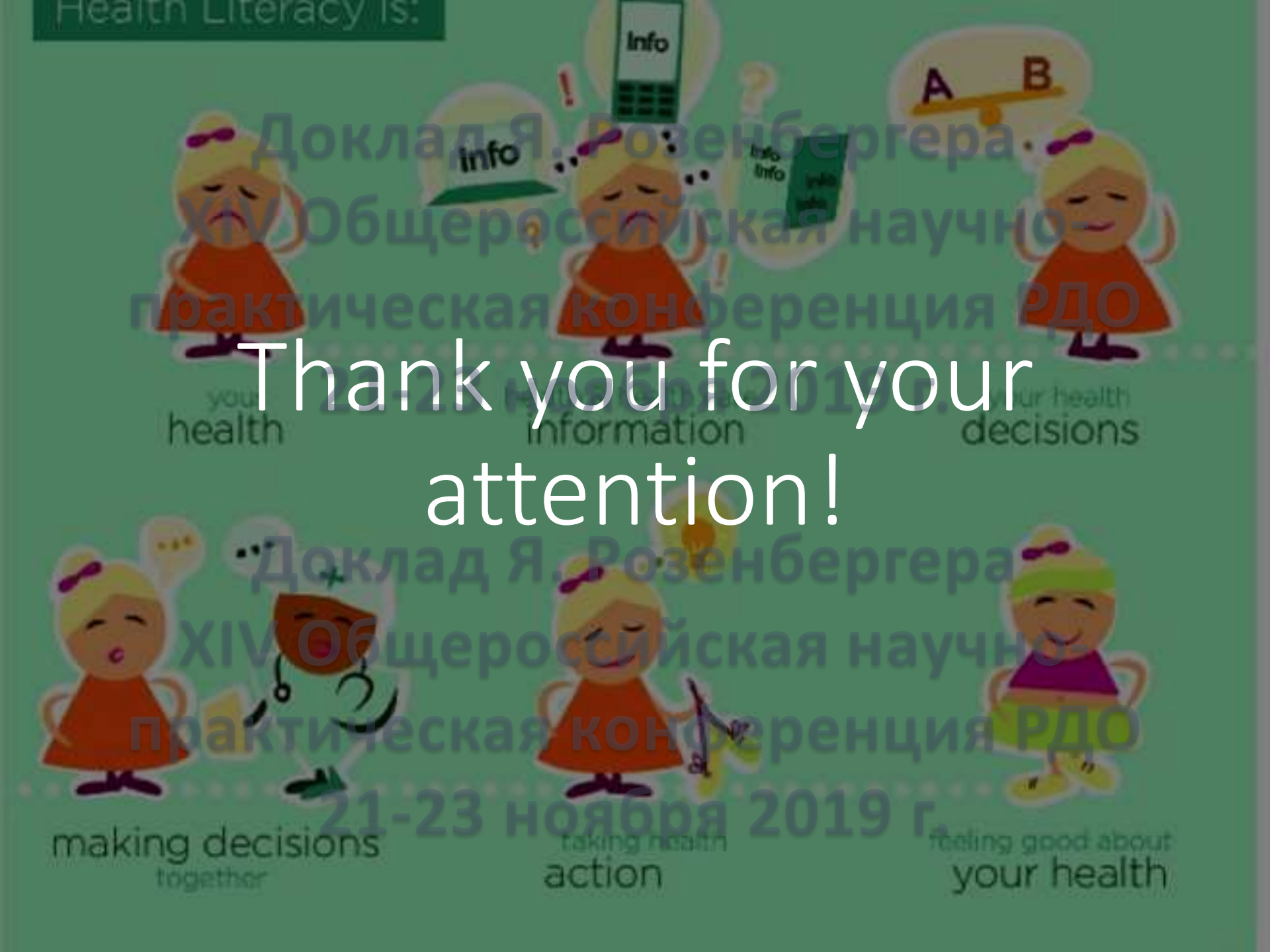

Thank you for your attention!