





AGENTÚRA NA PODPORU VÝSKUMU A VÝVOJA

# Health literacy in dialysed patients

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# Доклад Я. Розенбергера XIV Общероссийская научнопрактическая конференция РДО

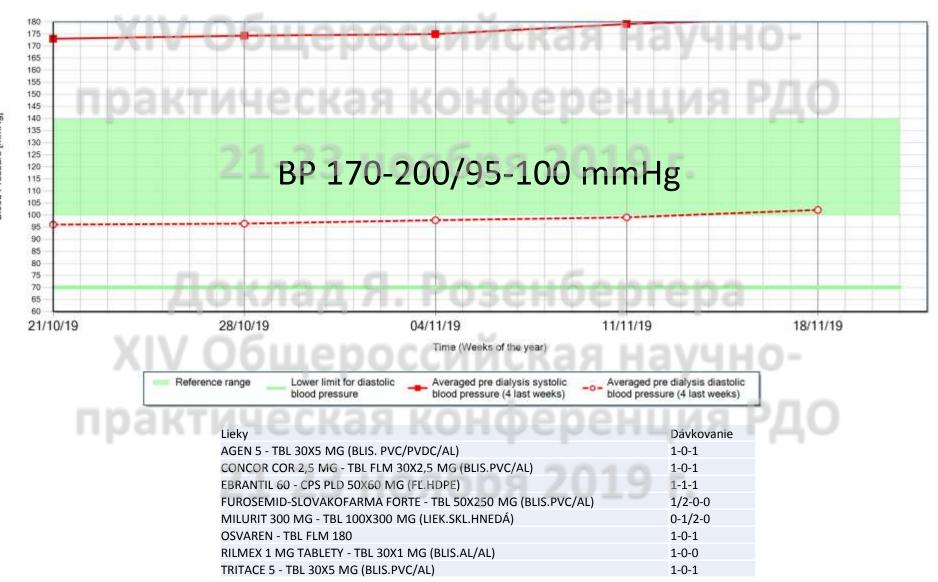
This work was supported by the Research and Development Support Agency under Contract No. APVV-16-0490.

### Доклад Я. Розенбергера XIV Общер Адентика ская научно-NA PODPORU VÝSKUMU A VÝVOJA Практическая конференция РДО 21-23 ноября 2019 г.

# 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



# 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

21 - 22.10.2019: 30 tablets

• Aha! How my colleague shouted at him!

практическа Health1-23 Literacy <u>Док</u>лад XIV Обще 21-23 ноября 2019 г.

# Доклад Я. Розенбергера **ХІ Общероссийская научно-**



# What is health literacy ргера

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

<u>From 17</u> 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.

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# **Definitions of health literacy**

WHO (19	98)
П	pa

"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 <u>sound health decisions</u> 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 509 2019 F.
- 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 conceptpa XIV Общероссийская научно-

- Improvement of clinical services
- Participation of communities on health improvement
- Planning of healthcare services
- Education in public health
- Development of health politics е нбергера XIV Общероссийская научнопрактическая конференция РДО 21-23 ноября 2019 г.

# Measuring health literacy epa XIV Общероссийская научно-

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: оклад Я. Розенбергера

•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 epa

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

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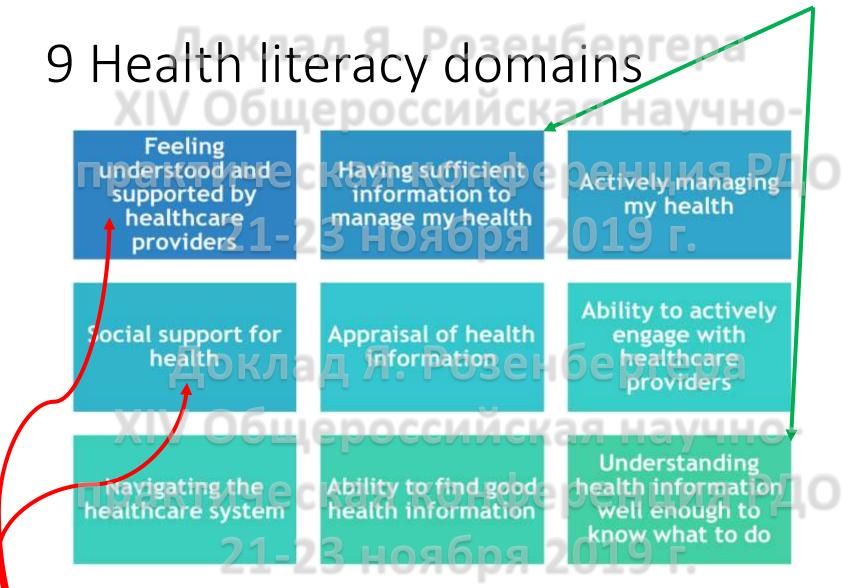
# Measuring health literacy Health literacy questionnaire (HLQ)

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- 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

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### We usually work on:



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 Recognize the importance and are able to take responsibility, they are not engaged in their healthcare and regard healthcare as something that engage in their own care and make their own is done to them.

responsibility for their own health. They proactively 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 Able to identify good information and reliable sources most health information and get confused when of information. They can resolve conflicting there is conflicting information. 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 Is proactive about their health and feels in control in 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.

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 Is an 'information explorer'. Actively uses a diverse dependent on others to offer information.

range of sources to find information and is up to date.

### 9. Understanding health information well enough to know what to do

<u>ктическая конф</u>

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	2. Having sufficient informatio n 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	7. Navigating the health system	8. Ability to find good health information	9. Understandin g health information well enough to know what
providers	,				care providers			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

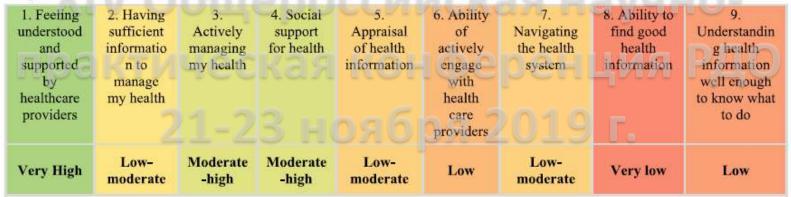
1. Feeling	2. Having		4. Social	JGG.MI	6. Ability	h na	8. Ability to	9.
understood	sufficient	Actively	support	Appraisal	of	Navigating	find good	Understandin
and	informatio	managing	for health	of health	actively	the health	health	g health
supported	n to	my health	<b>CKAR</b>	information	engage	system	information	information
by by	manage				with			well enough
healthcare	my health				healthcar			to know what
providers			22 m	og 6 k				to do
			20 N	UNUR	providers			
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).

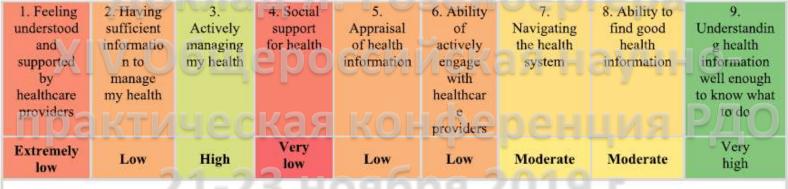
(Jean is likely to score very well on most health literacy screening tools because her reading and writing abilities are good. Her difficulties lie in other areas. Support for her could include building on her interesting in health (scale 3) and her ability to work with information and finding her way 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

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



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



-22 HOYODY 2013 I

# 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)

Health levels		Kent Nrow		w - oderate	Moderate	Modera High	te – High	R Pyery	high
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
1	2,87	2,62	2,40	3,01	CVV <sub>2,18</sub>	KC2,80	<b>HC</b> <sub>2,49</sub>	Ч <b>Н</b> Q, <sub>43</sub>	2,46
2	3,55	3,11	2,98	3,48		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	7 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

## XIV Общероссийская научно-

#### Area i

Environmental Research

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

Tranz Homenatora <sup>13,2,6,0</sup>, Peter Kolanik, <sup>14,0</sup>, Andrea Madatamere Gorberg, <sup>13,2,0</sup> Januare Rosenberger, <sup>13,2,3,4</sup>, Maria Majorenkova <sup>8</sup>, Daniel Klain <sup>9</sup>, Jitse P. vot. 17 (k<sup>-1,2,4</sup>) and <sup>3</sup>Space A. Beijnerold <sup>10</sup>0.

- <sup>1</sup> Department of Facility Psychology Faculty of Medicine, Pf-Marik University, Social UP (1997) Environ Westing procedure (Medica) (Mary et al.), and on generalizing the (AME) 2 process recording of the (AE).
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- <sup>3</sup> Department of Community & (Anapartonal Haulth, University Haultar) Contro Communes, University of Generatigns, Antonion Disamplean 1, 87(1):407 Generatigns, 70a Netherlands; Lo anjpervisit/humog.ul
- Observe Dimensity Social Health Josefuns, Paladay Versionity in Dimens, Versionities 22, Observe 27111, Contribution
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- PDC: Onlyses Services Handrids, Tradis (MP 1, 6811) Konnel, Norodke managemblymol com Institute of Mathematics, Encloy of Science, P. J. Saleck University, Sorena C, 68119 Konne, Versitian description/optic.id
- 4 Compositive downative independents for white the the

Bennoal D'Uniter 2019. Acceptal: 24/Uniter 2019. Published: 9.9 comber 2019

Alternative Network Alternative to dietary and fluid intuke recommendations (NetLFE) to its important factor for the effective instituent of dialyzed patients and must be backeted by his backly lipital (EE.) Therefore, we assessed whether low HL of dialy and partners is associated with they YLADFOR. We performed a realizative constant dealy in 20 states of the kine in the skin in + 452, sequence rate 70.71; mean up + 61.6 years; makes #1.71;). We present the association between some domains of HL and non-adherence diagh senses potentian, high senses phosphete: islative eccelectivation, and self-reported ScALEW) using poweral haven workets advanted for ope and product 44 mesons, we assessed the randomition by society meanic in tracipality. We found higher NATIVE space; pelotity with loss sufficient information for SACIN management if igh sensity prosphete lovel, odds onto (1961 8.77, 99% could not interval (23) 0.45-0.901 with a lower shifty to chickly manage their locality taill reported dat term-allowness CHE 0.74, 49% CL 8162-0.995, and those less able to activaly regage with handbeare providers (provhydrated) (NL 074/975 C) 0.07-0.96: Memoral SET modeled this scholene. Low HL affects the adherence of dialyzed patients. This shows a need to support patients with low HL and to main healthcare providers to work with three patients, taking into account ilwa 185. 

Keywoods had to be any dist advises of final set of a function dial and provide new other way





## 21-23 ноября 2019 г.

# 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.

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### практическая конференция РДО

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

## Доклад Я. Розенберг ХІV Общероссийская на практическая конференц ... the half of the 20<sup>th</sup> century – 23 ноября 2019





the end of the 20<sup>th</sup> century ...

### EDITORIAL

Доклад

### **Empowerment of Patient Preference in Dialysis Modality Selection**

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

To achieve a more rational modality distribution, there are 3 critically important strategies that nephrologists must embrace. At the healthcare-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 premote 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 empow 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

ября 2019 г.

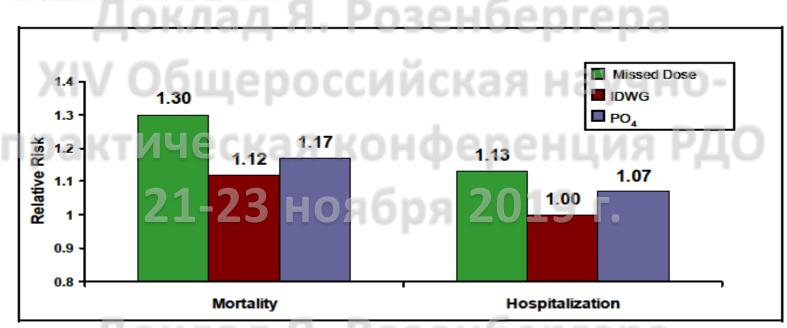
ered. This strategy should target both early referred patients with chronic kidney disease who have time to make informed decisions and those who present late and start on center-based HD. It is not enough for nephrologists to say that patient preference is most important; they must change their approach to dialysis modality decisions and make it so.

3 ноября 2019 г.

# Compliance and Adherence

- Compliance
- a patient's adherence to a recommended course of treatment
- Adherence 21-23 ноября 2019 г.
- 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
  - практическая конференция РДО
- Direct relationship to patient empowerment

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



### Figure 1: Noncompliance and Increased Risk of Mortality and Hospitalization

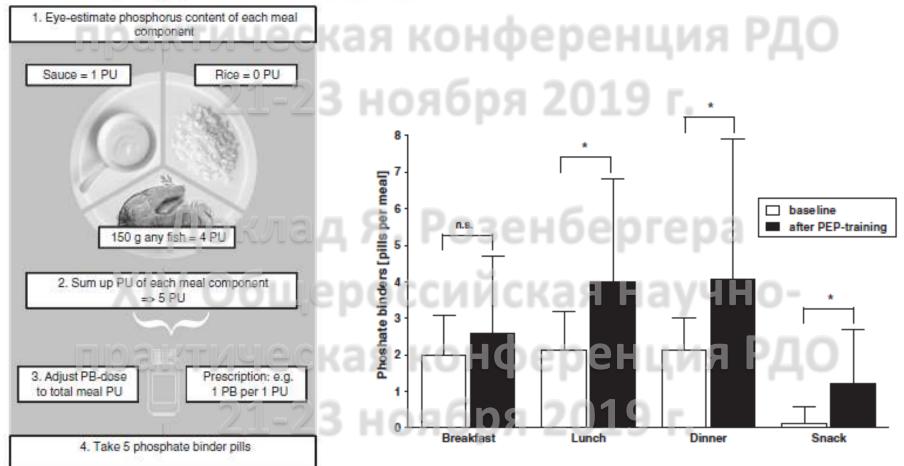
- Missed Dose means missing one or more dialysis sessions per month (vs. not missing)
- IDWG = Interdialytic Weight Gain

### PO<sub>4</sub> = 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.

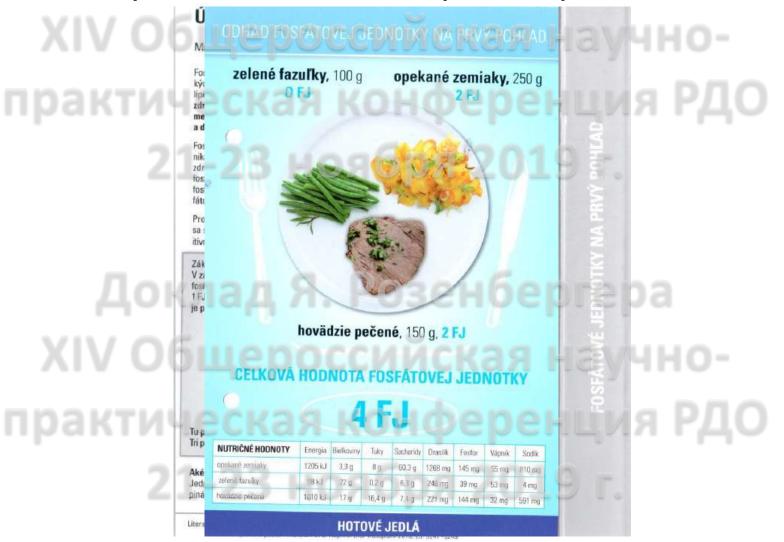
### Self-adjustment of phosphate binder dose to meal phosphorus content improves management of hyperphosphataemia in children with chronic kidney disease

Thurid Ahlenstiel<sup>1</sup>, Lars Pape<sup>1</sup>, Jochen H.H. Ehrich<sup>1</sup> and Martin K. Kuhlmann<sup>2</sup>



окладя. Розенб Just What Общероссийска Did the Doctor пра пическая консер Addressing Low **Order?** 21-23 ноябр Offealth Literacy in North Carolina August 2007 оклад Я. Розенбергера бщероссийская научно**ческая конференция РДО** 21-23 ноября 2019 г.

## Dietary tool for dialysed patients



### Dietary tool for dialysed patients ODHAD FOSFATOVEJ JEDNOTKY NA PRVÝ POHLAD XIV

opekané zemiaky, 250 g

zelené fazuľky, 100 g

научно-

практическая конференция РДО 2019 г. **Докла**д верг hovädzie pečené, 150 . 2 FJ XIV нау чно-ELKOVÁ HODNOTA FOSFÁTO нция РДО практи NUTRICNÉ HODNOTY Energia Biełkoviny Taky Sacharidy Drasilk Festor Vápnik Sodik opekané zemiaky 1205 kJ 3,3 g ßg 60.3 g 1268 mg 145 mg 55 mg 810 mg 17 g 16,4 g 7,4 g havadzie pedené 1010 kJ 144 mm **HOTOVÉ JEDLÁ** 

# Pills dosing individualisation



# Dosing individualisation: tablets or powder

zelené fazuľky, 100 g

0 FJ

21-23

21-2

практ







Г

hovädzie pečené, 150 g, 2 FJ

opekané zemiaky, 250 g

2 F.J.

### ПРАКТИЧЕС КСЕКОVÁ HODNOTA FOSFÁTOVEJ JEDNOTKY

NUTRIČNÉ HODNOTY	Energia	Bielkoviny	Toky	Sacharidy	Drasilk	Festor	Vápnik	Sodik
opekané zemiaky	1205 kJ	3,3 g	ßg	60,3 g	1268 mg	145 mg	55 mg	810 mg
zelené fazulky	98 kJ	72 g	0,2 g	6,3 g	248 mg.	39 mg	53 mg	4 mg
hovádzie pečené	1010 kJ	17 g	16,4 g	7.4 g	221 mg	144 mu	32.mg	591 mg

HOTOVÉ JEDLÁ

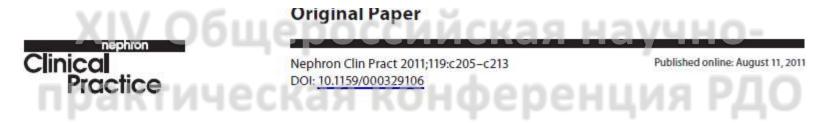
# Health literacy profiles of dialysed patients (N=542)

Health literacy Very low / Low C Low - C Moderate Moderate High / High

1100 Enc 201

Profile	Feeling	Having	Actively	Social	Appraisal of	Ability to	Navigating	Ability to	Understand
	understood	sufficient	managing	support	health	actively	the health-	find good	health
	and	information	my health	for	information	engage	care	health	information
	supported	to manage		health		with	system	information	well enough
	by health-	my health				health-			to know
	care	lокл	ал	Я. К	2036	care	ррге	ba	what to do
	providers				000	providers			
					<u> </u>				
1	2,87	2,62	2,40	3,01	2,18	KC2,80	<b>F</b> 2,49	<b>F</b> 2,43	2,46
2	3,55	3,11	2,98	3,48	2,42	3,83	3,07	3,28	3,35
3	0 G 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	2 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

# Beware: patient opinion matters!



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

Vari Wileman<sup>a</sup> Joseph Chilcot<sup>b</sup> Sam Norton<sup>a</sup> Lyndsay Hughes<sup>a</sup> David Wellsted<sup>a</sup> Ken Farrington<sup>c</sup>

<sup>a</sup>Centre for Lifespan and Chronic Illness Research and <sup>b</sup>School of Psychology, University of Hertfordshire, Hatfield, and <sup>c</sup>Renal Unit, Lister Hospital, Stevenage, UK

- 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

# Health literacy profiles of dialysed patients (N=542)

Health literacy Very low / Low C Low - C Moderate Moderate High / High

1100500 201

Profile	Feeling understood and supported by health- care	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	Navigating the health- care system	Ability to find good health information	Understand health information well enough to know what to do
	providers	цокл	ад	n. r	-03e	providers	spre	ра	
1	2,87	2,62	2,40	3,01	2,18	KC2,80	<b>F</b> 2,49	<b>F</b> 2,43	2,46
2	3,55	3,11	2,98	3,48	2,42	3,83	3,07	3,28	3,35
3	0 6 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

Доклад Я **ИV Общеросси** практическая Back to case report! Обш актическ

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

	teracy Very lo	bw Low	Low -			Moderate –	High	Very high	
evels		0.4	Mode	rate		High	4.0		
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
1	2,87	2,62	2,40	3,01	2,18	KG2,80	2,49	<b>F</b> 2,43	2,46
2	3,55	3,11	2,98	3,48	2,42	3,83	3,07	3,28	3,35
3	0 6 3 10	3 03	2 96	3 13	2 89	2 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

### Health Literacy Is:

# loклаinfo Thank you for your attention! оклад making decisions ficeling good about your health action together

Info