Psychonephrology

Ágnes Haris MD, PhD, Kálmán Polner MD

St. Margit Hospital, Budapest

Well-being? Quality of life?

Male patient, born in 1970

1981. NS, steroid treatment

1989. kidney biopsy: MPGN – immunosuppression

1990-2009. attends pediatrician nephrologist irregularly

2009.July: St. Margit Hospital:
se-creat: 396umol/l, GFR 21ml/min

Has 5 children

Depressed, has poor compliance, refuses to get wait-listed for transplantation


BAKANCS
BAKANCS
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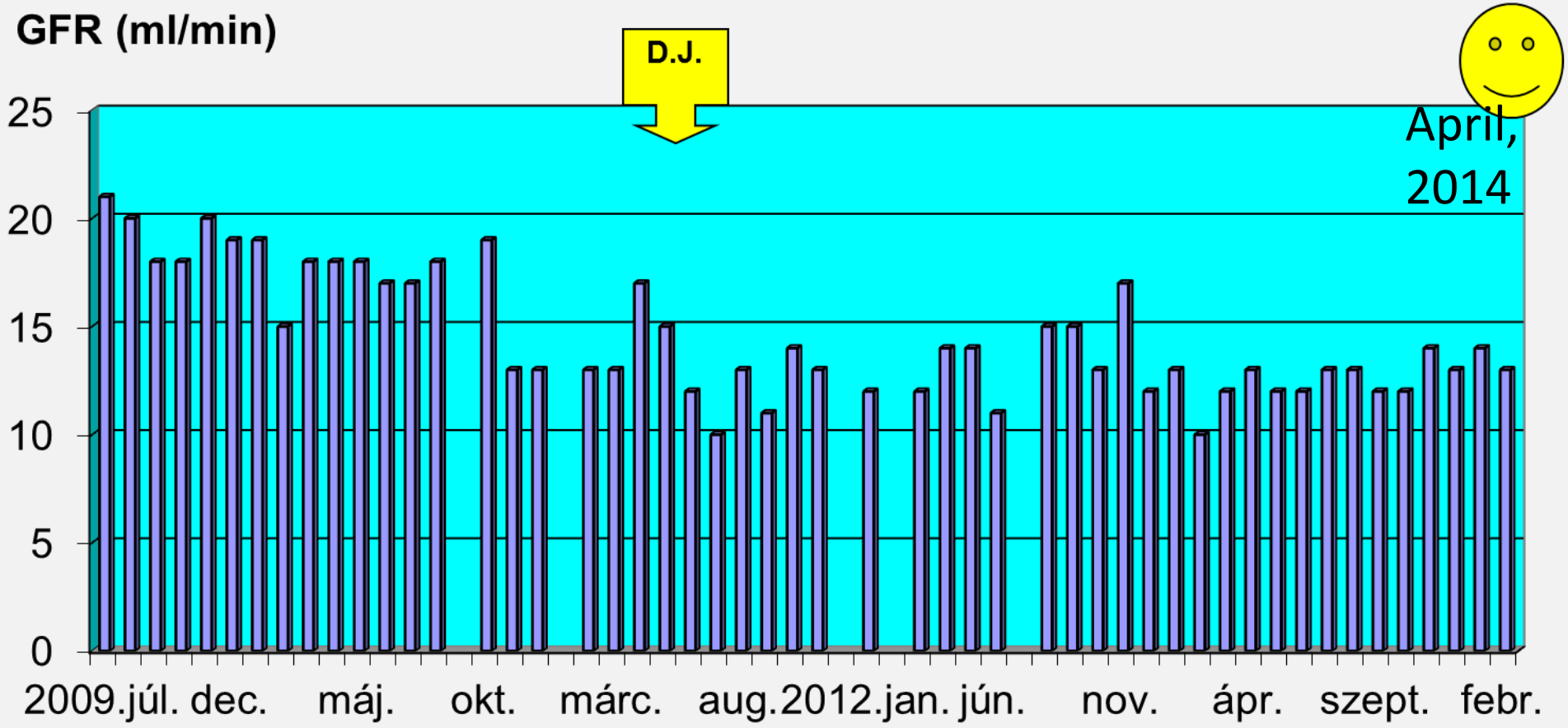
BAKANCS
BAKANCS
ILYEN VAGYOK MOST
INCLUSIVE
IBULEVE
IBULEVE
IBULEVE
IKEA 365+ ételvédő
and anti-inflammatory

GFR values between 2009–2014 (Educational Camp: July, 2011)



WHO definition of health

- The World Health Organization (WHO) defined human health in a broader sense in its 1948 constitution as "**a state of complete physical, mental and social well-being** and not merely the absence of disease or infirmity
- The main **determinants** of health include the **social and economic environment, the physical environment and the person's individual characteristics and behaviors**.

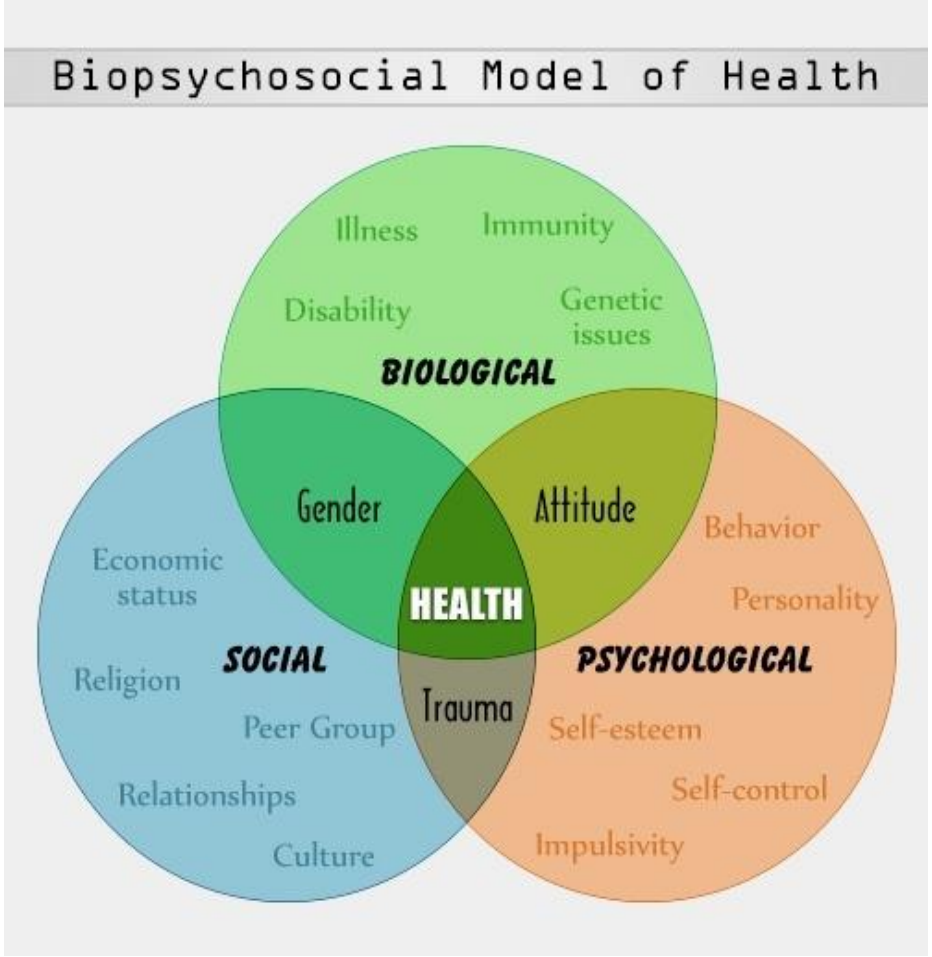
Quality of life - WHO definition

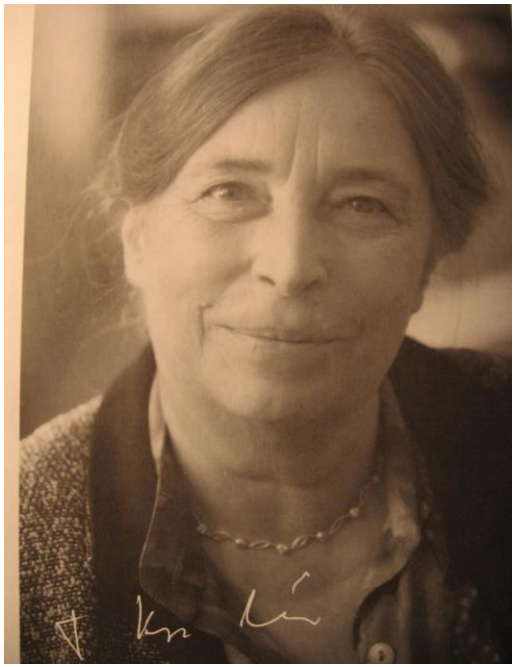
- “the individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals.”

Key factors that have been found to influence whether people are healthy or unhealthy include the following

- Income and social status
- Social support networks
- Education and literacy
- Employment/working conditions
- Social environments
- Physical environments
- Personal health practices and coping skills
- Healthy child development
- Biology and genetics
- Health care services
- Gender
- Culture

Bio-psycho-social model of health





Prof. Dr. Mária Kopp founder of Institute of Behavioral Sciences, Semmelweis University, Budapest

Psychonephrology

- Psychonephrology is an **appreciation of the psychological and social issues** that affect people living with the physical burden of kidney disease
- It puts emphasis on the patients as **whole a person, on his/her familial and psychosocial circumstances**, and aims complex care, **complex rehabilitation**, to achive imroved **coping** and **higher QoL** (Prof Dr Mária Kopp)

THE 2012 BUDAPEST DECLARATION OF THE IFKF

- „.....employ a holistic approach for the treatment of patients living with chronic kidney disease, recognizing **all their bio-psycho-socio-spiritual and somatic needs**."
- „.....focusing on the whole person and individual care to ensure better efficacy in the **prevention, treatment and rehabilitation**."

Signed and endorsed by:

- Laszlo Rosivall President of the 13th IFKF Annual Meeting
- John Feehally President of ISN
- Timur Erk President of IFKF

Chronic disease = physical, social, financial and emotional losses

- Physical problems related to the disease
- Perception of **altered body image**
- **Mental health problems**: stress, anxiety, depression, hopelessness, fears
- **Sexual** problems
- Conflicts of **dependency** and independency
- **Unrealistic expectations**
- Changes **in social roles** and **financial condition**
- **Divorse, social isolation**, loss of social support

Hungarian National, Cross-sectional Survey of Dialysis Patients (2006)

Polner et al. Clin Nephrol 2011.

Characteristic	Total sample (n = 3,563)
Age, years (mean ± SD)	62 ± 14
Level of education (%)	
≤ 8 y	43.5
8 – 12 y	45.4
> 12 y	11.1

Psychosocial characteristics

Hungarian National, Cross-sectional Survey of Dialysis Patients (2006)

Polner et al. Clin Nephrol 2011.

Marital status (%)	
Married or common-low	56.9
Living status (%)	
Alone	18.0
With family	79.2
In institution	2.8
Self-reported financial situation (%)	
Good	39.4
Fair	40.1
Poor	20.4

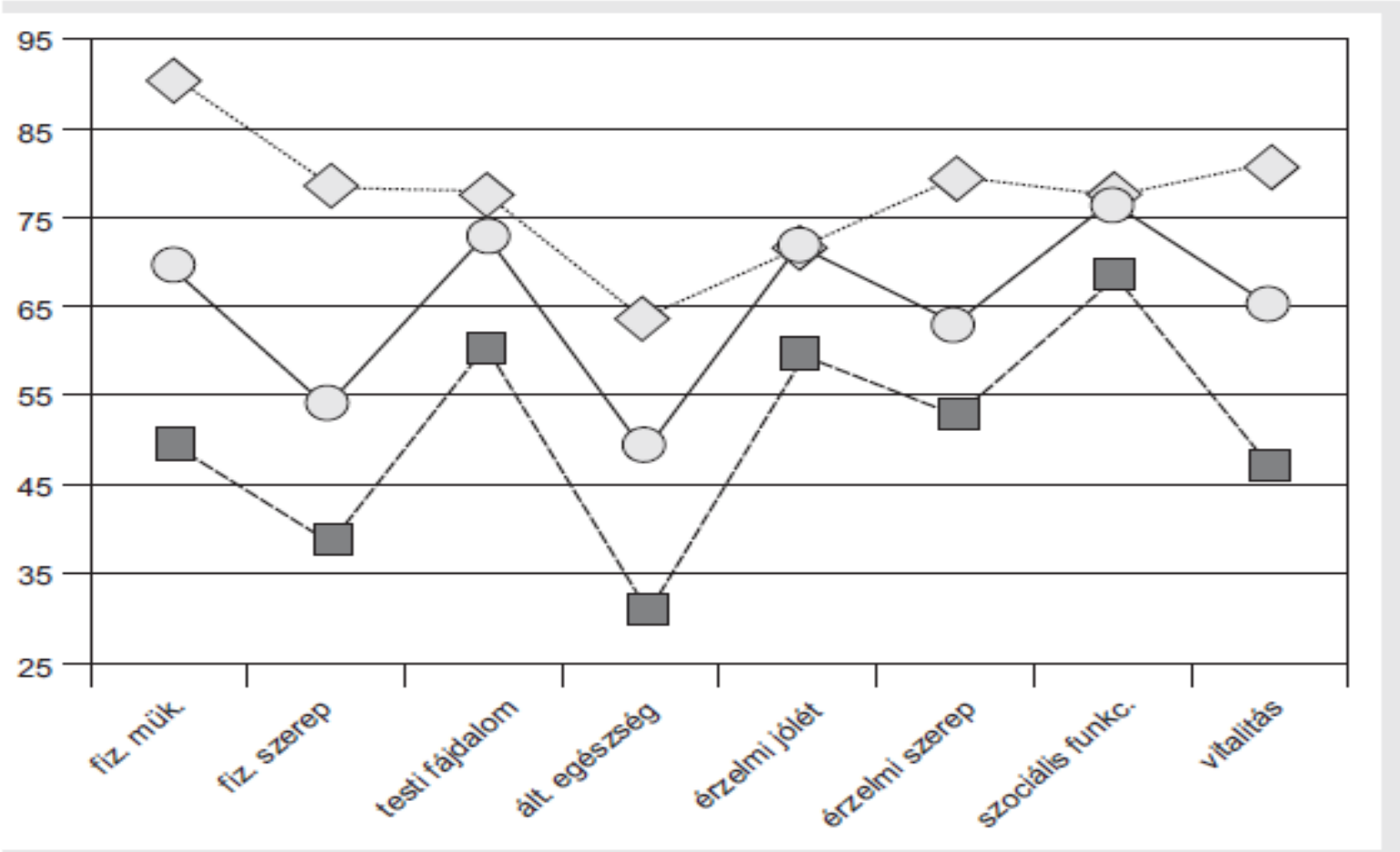
Psychosocial characteristics

Occupation (%)	
Full-time employed	2.8
Part-time employed	3.1
Homemaker	1.2
Retired	46.3
Disability pension	46.1
Unemployed	0.5
Occupation < 65 y (%)	
Full-time employed	5.0
Part-time employed	5.4
Homemaker	1.4
Retired	14.0
Disability pension	73.3
Unemployed	0.9

Self-reported functional status

Comorbidities (presence, %)	
Diabetes	30.2
Acute myocardial infarction	19.0
Cerebrovascular disease	18.8
Limb amputation	8.4
Limitations in everyday activities (%)	
Walking without help	58.4
Climbing stairs	68.4
Bathing/clothing without help	43.9
Functional impairments (%)	
Mobility	44.1
Visual	43.8
Auditory	17.2

QoL in dialyzed patients, transplanted patients and healty Hungarian subjects (SF-36)



1. ábra. Az ábrán dializált (n=300) (■) és vesetranszplantált (n=450)(●) betegek SF-36-tal mért életminőségét hasonlítjuk a magyar átlagpopuláción (19) (n=6963) (◆) kapott értékekhez (*Molnár M.Zs. és munkatársai* – nem közölt adatok)

How much do our patients know about their disease?

What kind of health literacy level they have?

Health literacy

Health literacy (HL) means the individuals capacity to **obtain, process and understand** health information and make **appropriate health decisions.**

Questionnaires

- **Chew questionnaire** tests patients' perceived confidence, independency and their difficulty in understanding health-related information. The higher the score the lower the HL.

- **Kidney Disease Knowledge Survey (KiKS**) evaluates patients' disease-specific knowledge about function of the kidney, treatment options, medications and symptoms of renal failure in 28 questions *(*Wright JA et al.* Am J Kidney Dis. 2011;57(3):387-395)

Demographic data of study participants (No = 101)	
Age (years)	62±17
Male/Female (%)	42/58
Serum creatinine (umol/l)	168 (IQR 154)
Followed on nephrology clinic (months)	52 (IQR 96)

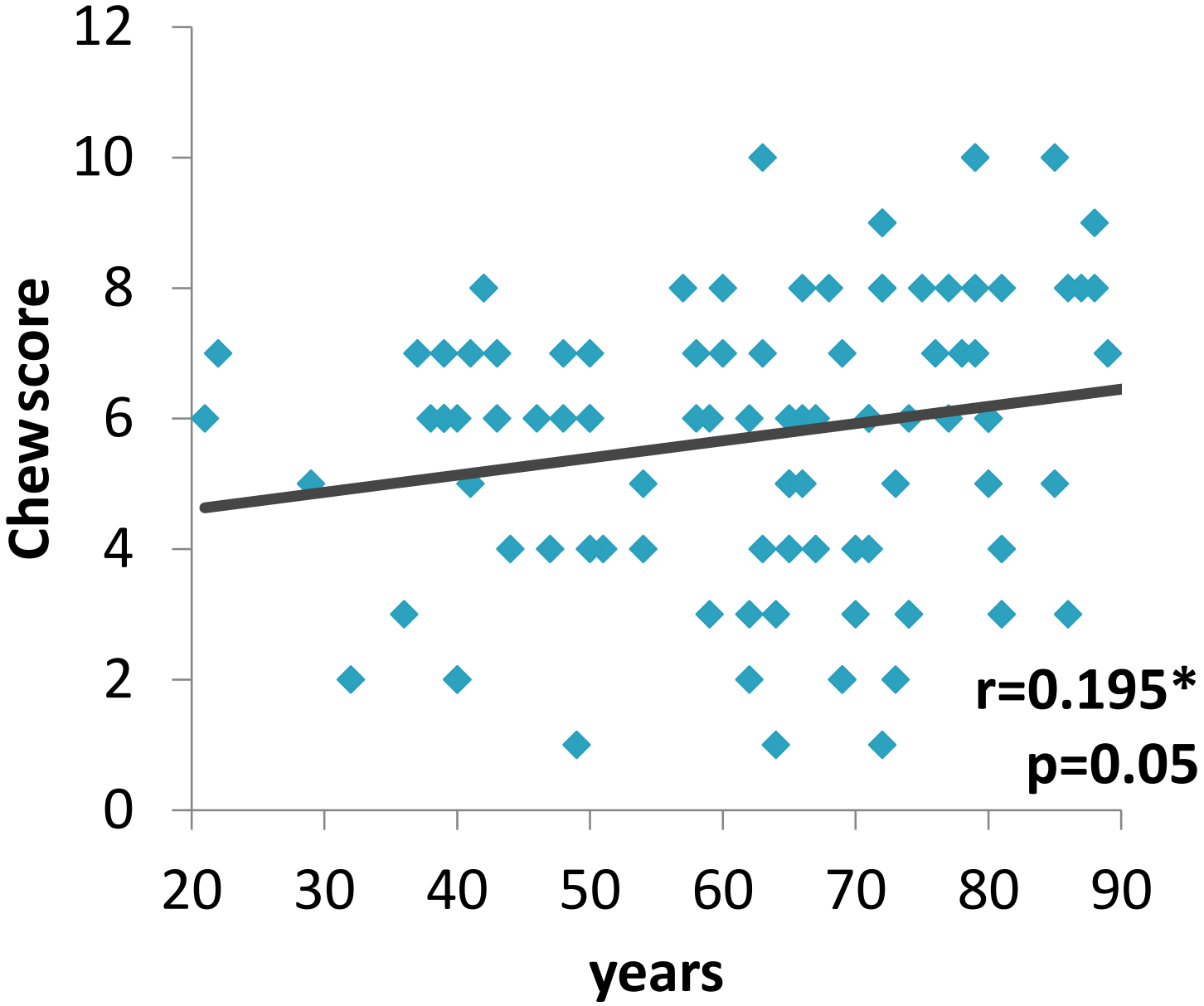
2017 October-2018 January: 112 patients were asked for participation. 11 patients refused it, referred to lack of time or being afraid of poor knowledge.

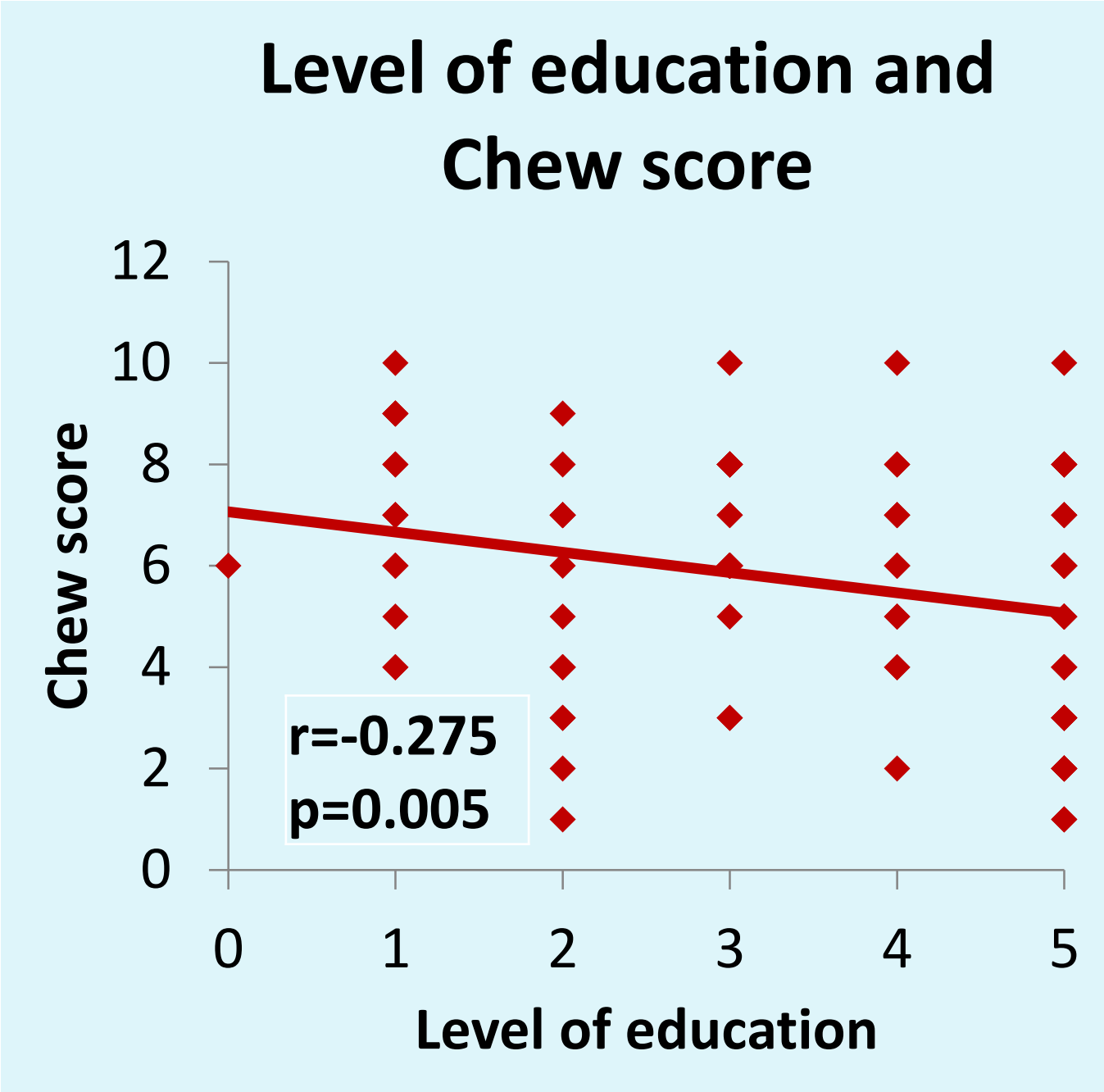
Chew scores				
CKD patients	5.7±2.2	Representative Hungarian sample*	4.25±2.5	p<0.001
CKD patients living alone	6.3±2.2	CKD patients living in family	5.4±2.1	p=0.03

**Papp-Zipernovszky et al* Hungarian Medical Journal, 157 (23): 905-915.

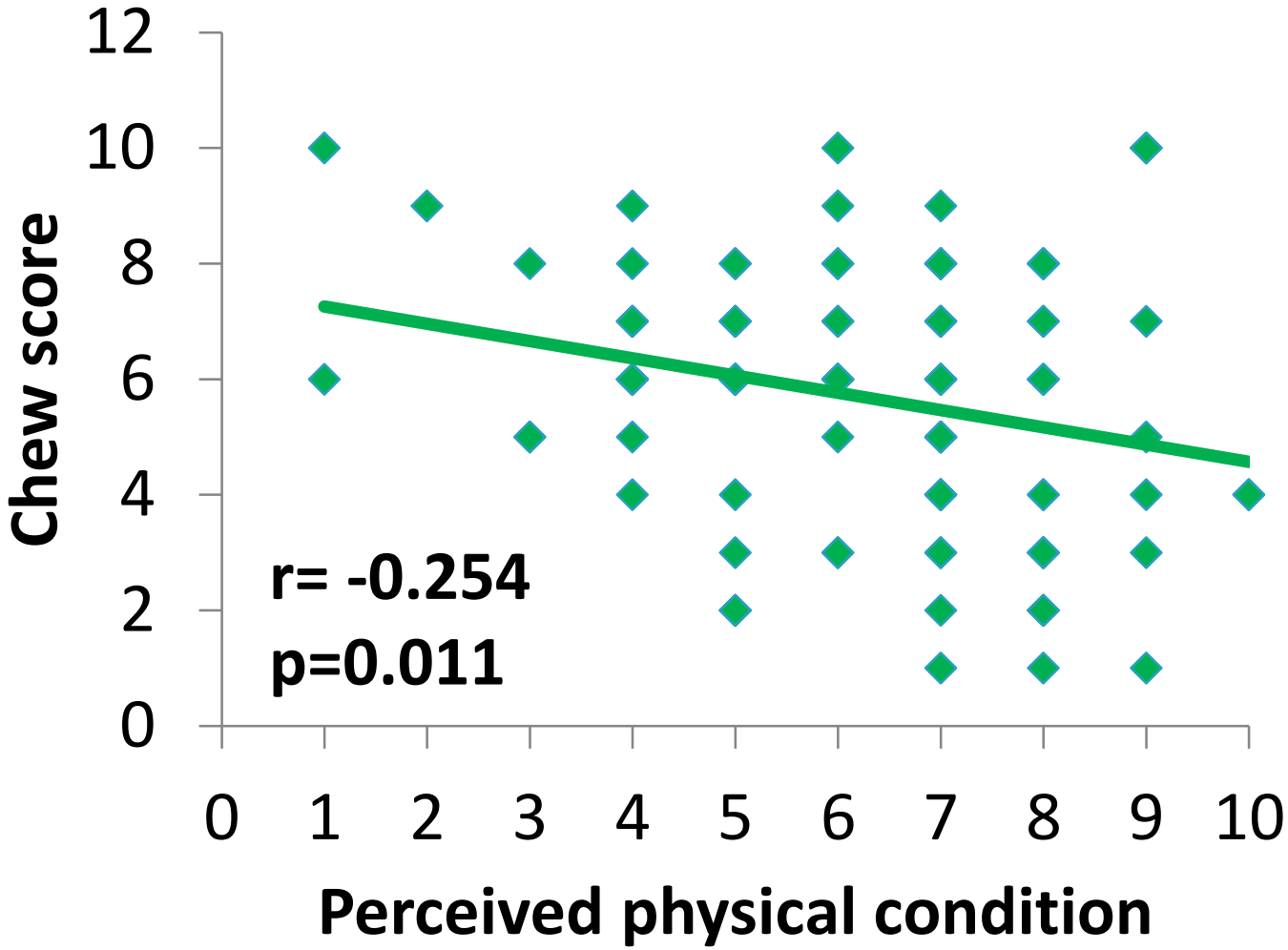
KiKS scores				
All patients	16.9±4.4 (60%± 16%)	Mean score in literature data*	66%±15 %	
Multidisclipli -nary educated patients	20.2±2.4 (n=13)	Patients with regular care (no MD education)	16.4±4.4 (n=88)	p= 0.004

Age and Chew score

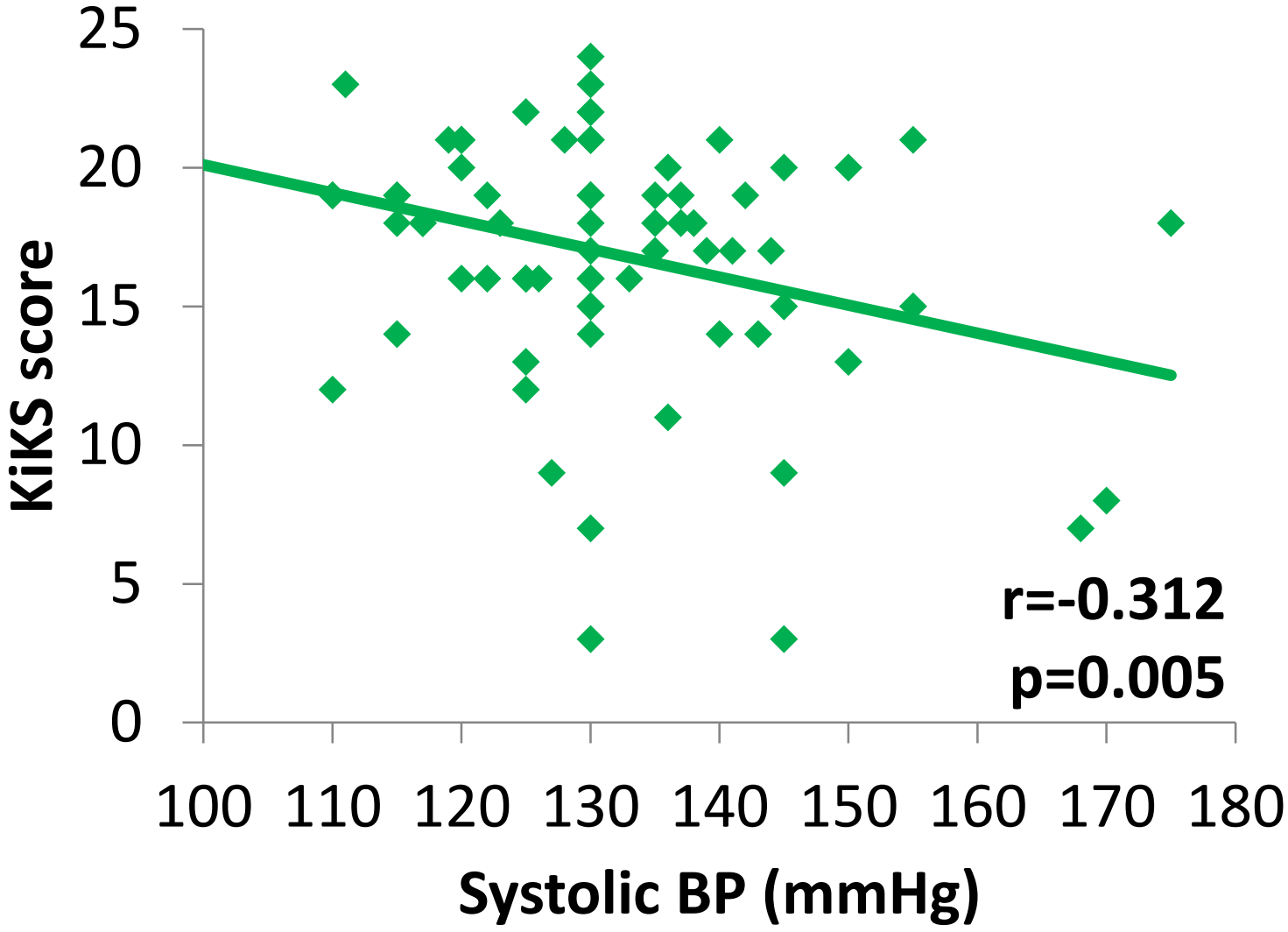


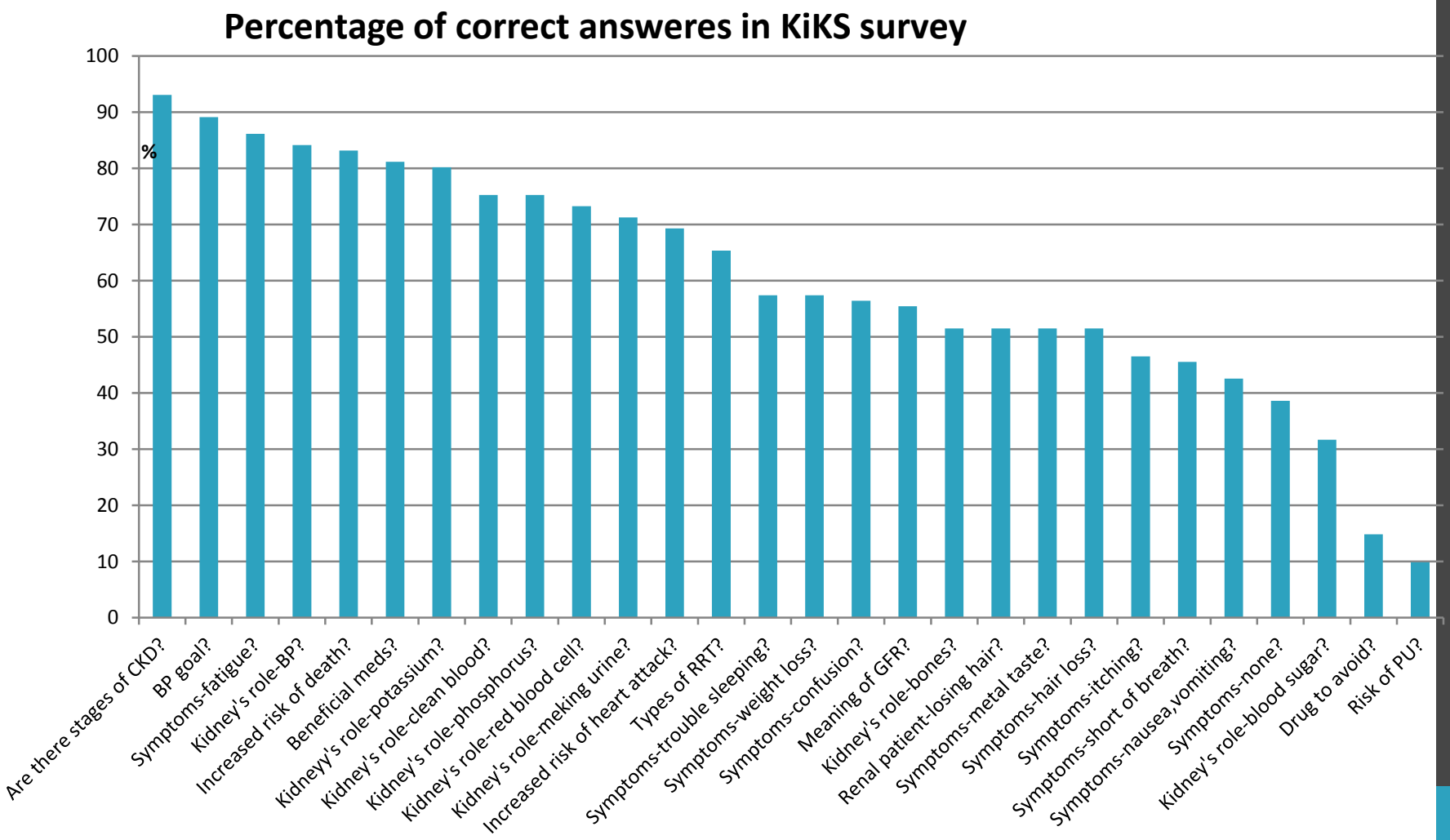

Level of education and Chew score
Chew score
12
10
8
6
4
2
0
0
1
2
3
4
5
Level of education
r=-0.275
p=0.005

Perceived physical condition and Chew score



Blood pressure and KiKS score




Percentage of correct answeres in KiKS survey
100
90
80
70
60
50
40
30
20
10
0
%
Are there stages of CKD?
BP goal?
Symptoms-fatigue?
Kidney's role-BP?
Increased risk of death?
Beneficial meds?
Kidneyy's role-potassium?
Kidney's role-clean blood?
Kidney's role-phosphorus?
Kidney's role-red blood cell?
Kidney's role-meking urine?
Increased risk of heart attack?
Types of RRT?
Symptoms-trouble sleeping?
Symptoms-weight loss?
Symptoms-confusion?
Meaning of GFR?
Kidney's role-bones?
Renal patient-losing hair?
Symptoms-metal taste?
Symptoms-hair loss?
Symptoms-itching?
Symptoms-short of breath?
Symptoms-nausea,vomiting?
Symptoms-none?
Kidney's role-blood sugar?
Drug to avoid?
Risk of PU?

HOW CAN WE HELP? – HOLISTIC CARE – REHABILITATION

Specific aims of the rehabilitation

Patients have to build up a new life based on the remaining abilities and potencials

- Repair the previous **capability** as much as possible
- Restore earlier **functions**
- Restore earlier **position in the family** and in the community
- Maintain **position in the society**

Holistic care - Complex Rehabilitation

Medical rehabilitation
(the most advanced medical treatment)

Educational rehabilitation

Social rehabilitation

Occupational rehabilitation
(help to return to work, or in everyday activities)

Rehabilitation needs to be started **as early as possible**, optimally during predialysis care

Education – to facilitate self-management

- Patients' active participation in their own care
- Manage illness related tasks
- Facilitate prevention of progression
- Taking ownership of health needs
- Developing knowlegde, skills and behaviors to manage the condition and follow treatment

Patients with CRF need high level of self-management

Per Ake Zillén: Daily to-do-list

	Patient	**Doctor**
Medication	Yes	Yes
Blood pressure	Yes	
Blood sugar	Yes	
Physical exercise	Yes	
Weight control	Yes	
No smoking	Yes	
Special diet	Yes	
Mental health	Yes	

Per Ake Zillén:
Self care and professional care

Hours/year	8760
Professional Care	10 hours/year
Self Care	8750 hours/year

....he also said:

- Health Care Providers need proper education
- Self Care Providers need proper education

Education – to facilitate shared decision making

- Patients' active participation in their own care
- Ability to negotiate treatment plans and decisions with care providers
- Health care providers – partnership, collaborative relationship

Social support

- **Social support** – the perception that an individual can receive affection, aid, and obligation
- **Socioeconomic issues** - jobs, financial difficulties
- Can be provided by family members, friends, colleagues in the workplace, and medical personnel, by communities

Psychosocial care

- **Emotional** support for both the patient and his family
- Release stressful emotions
- Re-establish a balance in their life
- Spiritual support
- Enchances coping skills

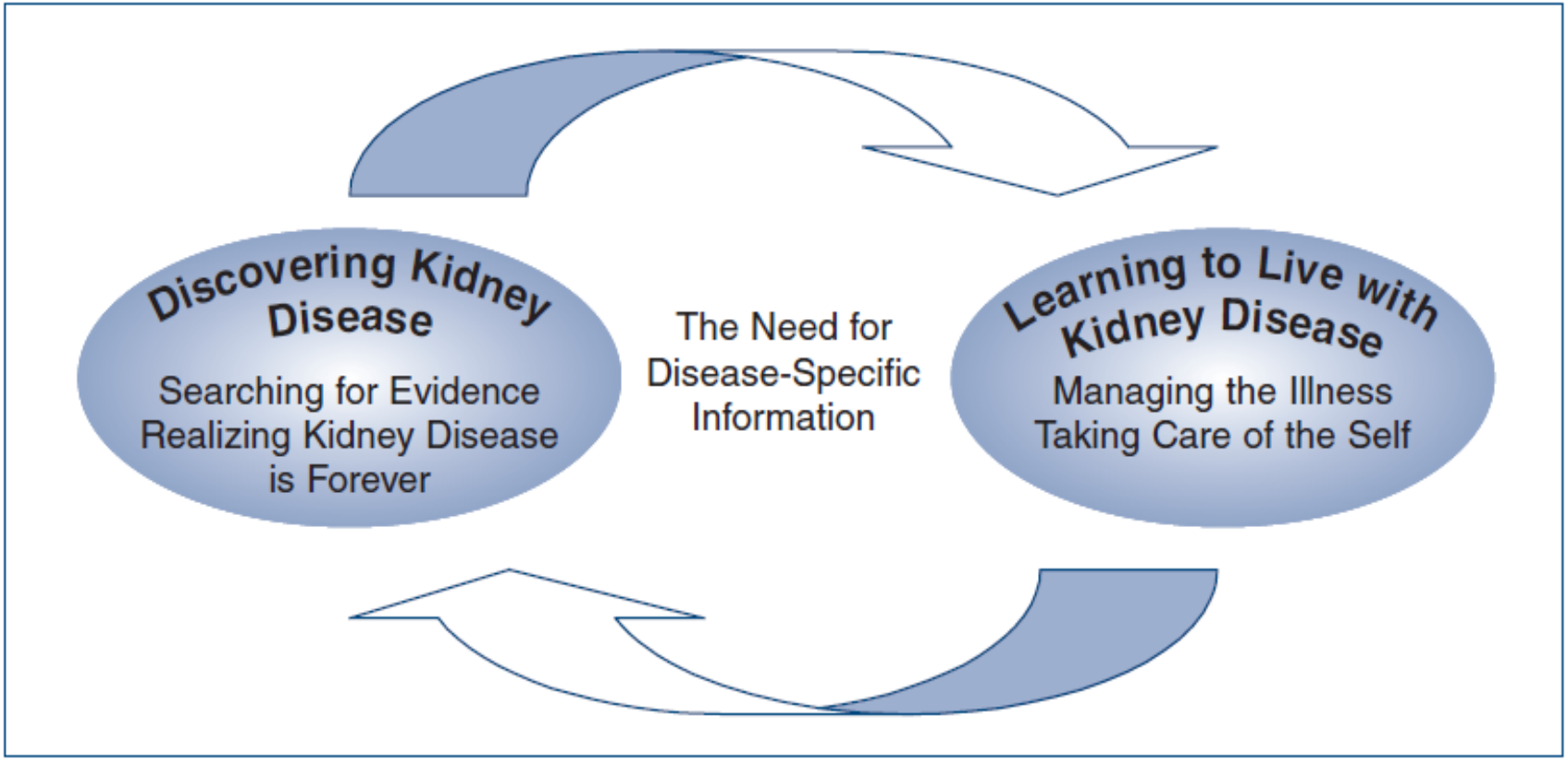
Maior aims of holistic care

- To increasing our patients' disease-specific knowledge, which may influence self-management behavior, which can decrease disease progression and improve long term outcome.
- To provide psychosocial care
- To develop coping strategies: decision making, problem-solving techniques

- All of these influence the ability of **coping** with the altered condition ⇒ **compliance** ⇒ **QoL**⇒ **survival**

Renegotiating Life with Chronic Kidney Disease

Constantini et al. Nephrol Nurs J 2008



Iterative process, moving back and force, and develop strategies to integrate the disease and its treatment into their lives

THANK YOU!