

---

# **Psychonephrology: the patient with chronic kidney disease**

Marta Novak, MD, PhD

Institute of Behavioral Sciences, Semmelweis University,  
Budapest, Hungary

Psychonephrology Unit, University Health Network,  
Department of Psychiatry, University of Toronto, Canada

- 
- Mental health issues associated with CKD
  - Depression and anxiety in patients with kidney diseases
  - Psychosocial factors, doctor-patient relationship, communication
  - What can we do? Modifyable factors
  - Lessons from our patients, lessons from psychooncology

---

What would be your first thoughts and feelings if your loved one would be diagnosed with renal disease?

---

What would be your first thoughts and feelings if you would be diagnosed with renal disease?

---

What would be your first thoughts and feelings if you would be diagnosed with hereditary renal disease (PKD)?

# Story of our patient

---

- 36 y old jewish financial analyst
- Married with supportive spouse
- 3 children under age 6
- Diagnosed with PKD
- Ref: difficulty coping
- Moderate depressive symptoms (sleep, motivation, guilt re: kids, anx about marriage, future)
- Emotional sensitivity
- Crying

# Chronic renal failure, End-stage renal disease

---

a „psycho-somatic” disease with  
significant renal involvement

# Chronic renal disease (CKD)

---

- Potentially life-threatening
  - Dialysis started only in the 60s
  - Progressive
  - High co-morbidity, physical dyscomfort, pain
  - Increased mortality
  - End-stage renal disease (ESRD) –renal replacement therapies with intrusive treatment modalities
- 
- High illness intrusiveness
  - Impaired quality of life



# Renal replacement therapies

---

- Peritoneal dialysis
  - Continuous Ambulatory Peritoneal Dilysis (CAPD)
  - Continous Cyler assisted Peritoneal Dialysis (CCPD)
- Hemodialysis
  - In center hemodialysis
  - Self-care hemodialysis
  - Home hemodialysis
  - Nocturnal hemodialysis (home or in-center)
  - Daily hemodialysis (home or in-center)
- Kidney or kidney – pancreas transplantation
- Graft failure- back to dialysis
- Choosing modalities – each different challenge
- New modalities? New challenges

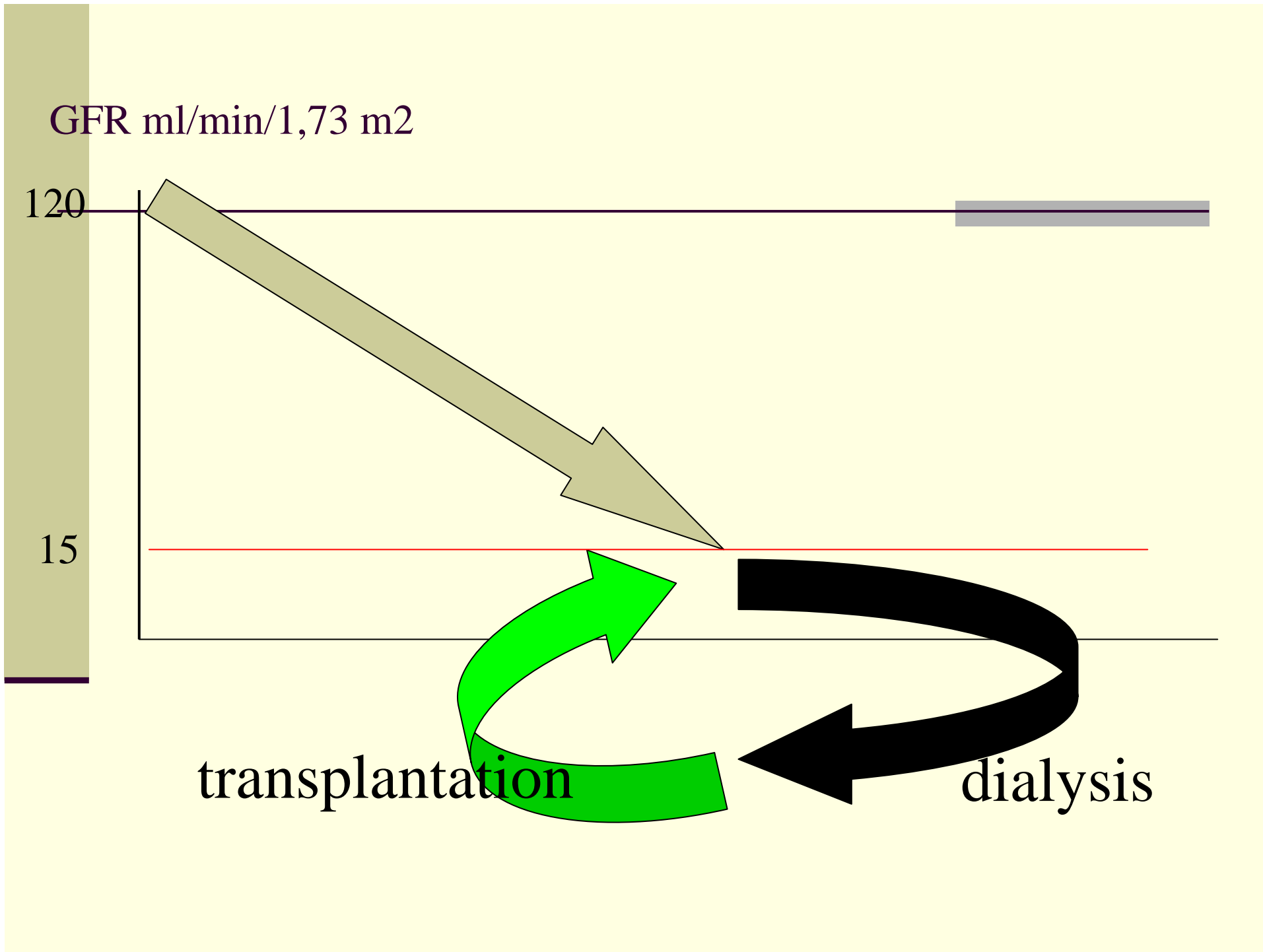
GFR ml/min/1,73 m<sup>2</sup>

120

15

transplantation

dialysis



# Psychosocial issues in CKD

(Vourlekis BS et al,1997)

---

1. Difficulties with everyday life and treatment
2. Technical and environmental issues (financial, transport, recreation)
3. Patient and family – approach to CKD
4. Cultural issues (society, ethnical, religious differences)
5. Social network (family, peers, caretakers)
6. Emotional, behavioral problems, psychiatric disorders
7. Work, job, study –vocational rehabilitation

---

# “IS THERE MORE TO LIVING THAN NOT DYING?”

A reflection on survival studies in dialysis”  
(JM Bargman, Seminars in Dialysis, 2007)

# Psychosocial challenges in chronic diseases

---

- high psychosocial burden of disease
- everyday adjustment to chronic disease
- existential - life-threatening disease: death always in the frontline
- coping with constant stressors- role of social support
- changes in social roles, intimate relationships, broken families
- loss of job, decreased income
- rehabilitation

# Home Dialysis

---

- Home dialysis is a unique model of care.
- Patients on home dialysis function independently and are given significant responsibility when it comes to their care.
- Conflict between paternalistic model and self-care
- Life worth living? Daily existential questions

# Transplantation – not a cure

---

- Recurrent crisis situations (listing, wait periode, surgery, intercurrent diseases, acute and chronic rejection, etc.)
- Coping
- Emotional problems
- Immunosuppressive and other drugs (adherence, side effects)
- Existential issues, life-death-survival
- Family, caregiver
- Adaptation to new roles, new lifestyle
- Rehabilitation, education, work

# Times of increased difficulties and crisis in patients with CKD

---

- Diagnosis of renal disease
- Threat of dialysis
- No linear progression
- Choosing modality - Initiation of dialysis
- Compliance with diet, fluid restrictions and dialysis  
Restricted lifestyle, freedom
- Being on transplant waiting list
- Transplant surgery
- Graft failure- back to dialysis
- ONGOING EXISTENTIAL ISSUES – Life/death –  
meaning of life, keeping alive etc.



# Psychological factors in CKD

---

- “Why me, why now”: anger, guilt, self-esteem
- Autonomy, freedom, fatalism, control, losses, grief
- Self-defence strategies, eg. denial
- Health belief system, locus of control
- Adaptation to illness and death: crisis, transition, acceptance, preparation
- Existential issues, meaning of life
- Role of spirituality, religion
- Social support, the biology of love
- The staff`s own approach to all these issues

# Life transitions – role transitions

---

- Biological (normal or illness-related):  
adolescence, pregnancy, aging,  
menopause/andropause, onset of chronic  
disease
- Social: marriage, divorce, death, school, job,  
child born, moving, immigration, retirement,  
“empty nest syndrome”
- CKD: the psychology of losses and changes

# Psychiatric disturbances in CKD

---

- Neuropsych. disturbances, cognitive problems
- Delirium
- Dementia
- Anxiety, PTSD (post-traumatic stress disorder)?
- **Depression - most common (BUT 40 % in 70 HD pts, anxiety 46 %, Cukor et al, AJKD 2008)**
- Subclinical depression, minor depression  
chronic depression
- Suicide – withdrawal from dialysis
- Sleep disorders – mental health

---

## DEPRESSION IN PATIENTS WITH CKD



# Depression in medically ill patients

---

- High prevalence in cancer, neurological disorders, cardiovascular disorders
- ? Related to the medical illness or medical therapies? Bidirectional link?
- Coping with medical illness
- Risk of suicide
- Compliance
- Predictor of relapse, outcome?

# DEPRESSION IN CKD

---

- Most common psychiatric/psychological problem (likely together with anxiety)
- Is it a „natural reaction?“
- Overlapping symptoms with renal disease: fatigue, sleep, appetite
- Prevalence (Craven et al. 1987):
  - Depressive symptoms: 25-50 %
  - Major depression 8-22 %

# Depression in CKD

---

- Prevalence varies between 10-60% (due to different screening tools and patient selection)
- Correlation between depression and patient compliance in dialysed population (Kimmel, 1998)
- An important predictor of quality of life in patients on dialysis (Walters, 2002)
- Independent predictor of mortality in patients on haemodialysis (Kimmel, 2000, Drayer 2006)

# Factors contributing to mood disorders in patients with renal disease

---

- Bio-psycho-social model
- Disease-related, comorbidities, pain, discomfort
- Treatment related? Medications?
- Biological: uremia, neurotransmitters, neurotoxins, inflammation?
- Psychological issues (loss): adaptation, role changes, life goals, loss, uncertainty, body image, intimacy
- Social: relationships, job, social roles, intimacy-sex
- Lifestyle issues: lack of exercise and light, altered sleep-wake schedule



# Diagnosing depression in patients with CKD

---

- Depressive symptoms
- Screening questionnaires (BDI, CESD)
- Structured clinical interviews (SCID, MINI)

Difficulties in renal patients: somatic symptoms  
(sleep, appetite, libido, fatigue)

Validated instruments? (Hedayati et al, 2006)

Is one question enough?

Who wants to get help?

# Depression in patients on maintenance dialysis in DOPPS

---

In the DOPPS (Dialysis Outcomes and Practice Patterns Study) study (20 000 dialysis pts, multicenter)

physician-diagnosed depression was 13.9%

CES-D based diagnosed was 43%

Antidepressant prescription was:

34.9% in patients with physician-diagnosed depr.

17.3% in patients diagnosed depr. based on CES-D

Depression was associated with female gender, lower educational status, unemployment status, some comorbid conditions

# Depression in patients on maintenance dialysis

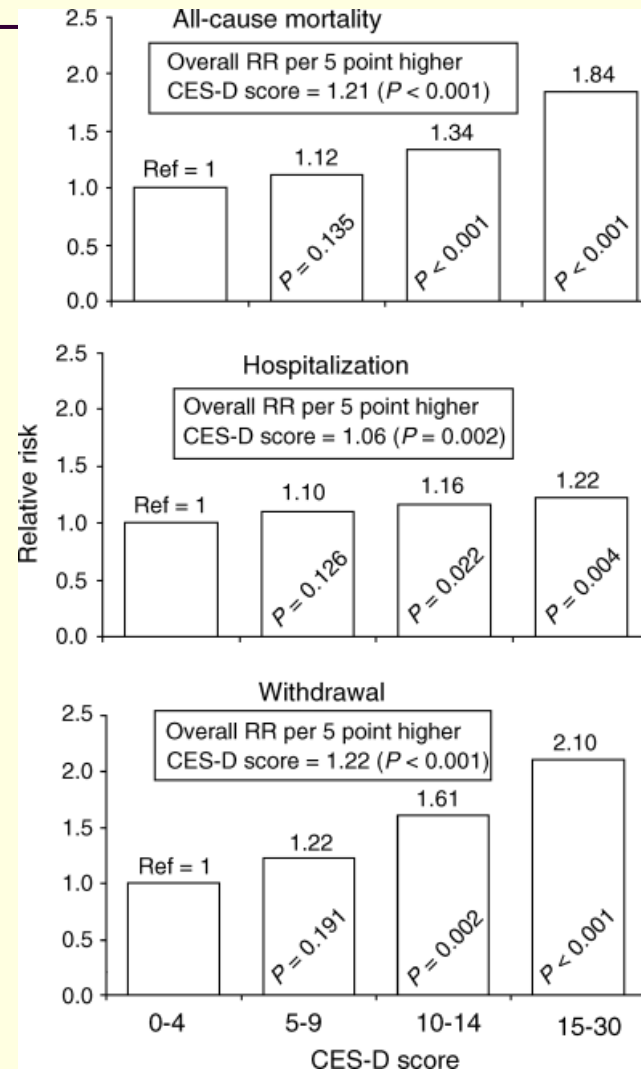
Depression is a predictor of:

mortality

hospitalization

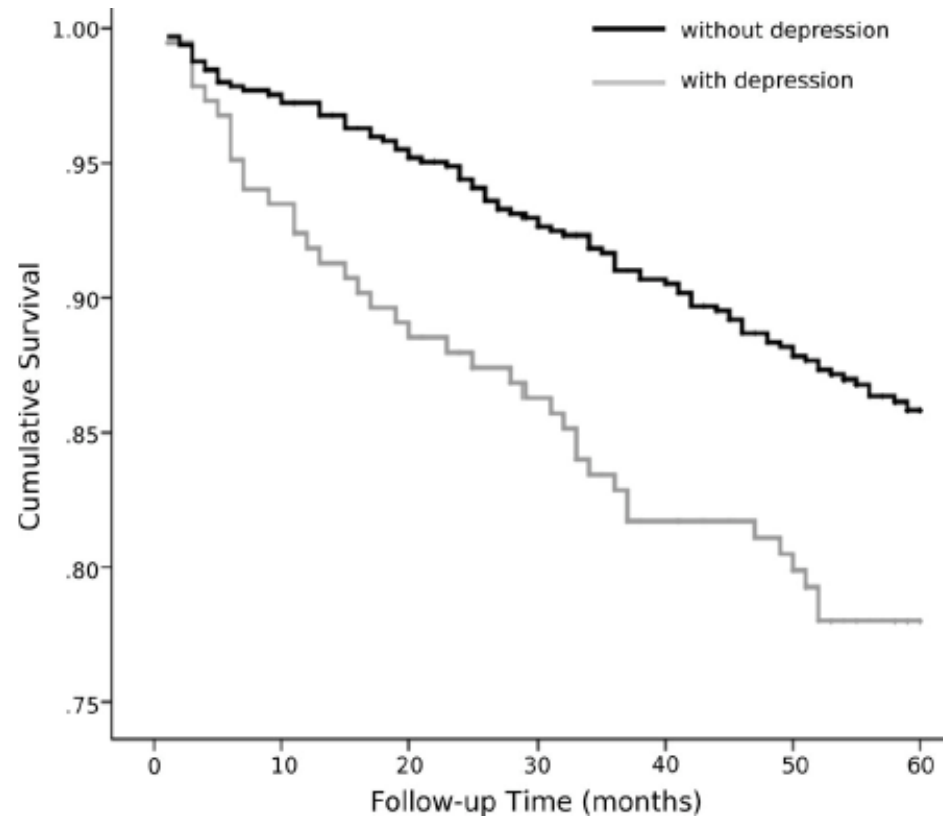
and withdrawal

in patients on dialysis



# Depressive Symptoms and Mortality in Patients After Kidney Transplantation: A Prospective Prevalent Cohort Study

MARTA NOVAK, MD, PhD, MIKLOS ZSOLT MOLNAR, MD, PhD, LILLA SZEIFERT, MD, AGNES ZSOFIA KOVACS, MD, ESZTER PANNA VAMOS, MD, PhD, REZSO ZOLLER, MD, ANDRAS KESZEL, MD, PhD, AND ISTVAN MUCSI, MD, PhD



Psychosomatic Medicine 72:000-000 (2010)

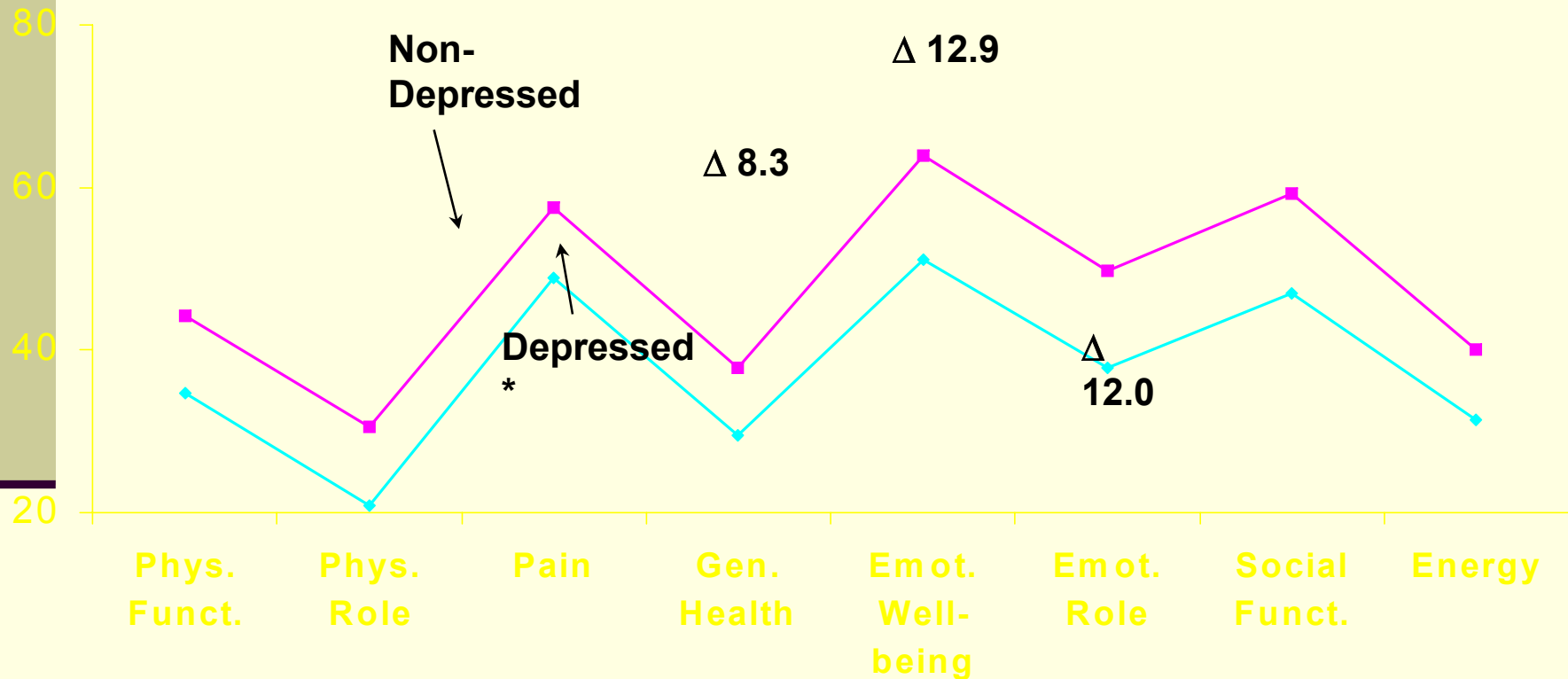
Figure 1. Kaplan-Meier survival plot: association between presence of depression and mortality, Log Rank:  $p = .004$

Model 3	Mortality			Death Censored Graft Loss		
	HR	95% CI	$p$	HR	95% CI	$p$
CES-D (for each 1-point increase)	1.02	1.00-1.04	.04	1.03	1.01-1.05	.01
Depression (presence)	1.66	1.12-2.47	.01	1.43	0.87-2.33	.15

Adjusted for: Model 1: age, gender; Model 2: Model 1 + number of self-reported comorbid conditions, total end-stage renal disease "vintage"; Model 3: Model 2 + estimated glomerular filtration rate, serum albumin, hemoglobin, serum C-reactive protein.

HR = hazard ratio; CI = confidence interval; CES-D = Center for Epidemiologic Studies-Depression.

# QoL of depressed patients (DOPPPS)\*



\*All Comparisons significant at the 0.0001 level

\*\*A  $\Delta$  5 in QoL Scores is Clinically Meaningful

Adjusted for Demographics and Comorbidities

# Compliance In Patients on PD

---

- Patients on Peritoneal Dialysis-
- Based on home visit supply inventories
- One-third of patients on continuous ambulatory PD (CAPD) and automated PD (APD) were noncompliant, as measured by performing fewer than 90% of prescribed exchanges.

# Compliance In Patients on CAPD

---

- multicenter study
- 656 CAPD at 14 centers in the United States and Canada. NC was defined as missing more than one exchange per week or more than two exchanges per month.
- overall admitted rate of non-compliance-13%, 18% in the U.S. and 7% in Canada.

# Depression and noncompliance

---

- Direct effects- depression having adverse physiological manifestations.
- Indirect effects- behavioural phenomena mediating the relationship between depression and outcomes.
- Non-compliance with treatment recommendations may be one of these behavioural mediators.

Wells KB. Psychosom Med. 1995;57:436438.



# Why Might Depression Increase Non-Compliance?

---

- Positive expectations and beliefs in the benefits and efficacy of treatment have been shown to be essential for patient adherence (DiMatteo et al., 1993).
- Depression often involved a degree of hopelessness.
- Compliance might be difficult for a patient who holds little optimism that any action will be worthwhile.

# Why Might Depression Increase Non-Compliance?

---

- importance of support from the family and social network in a patients attempts to be compliant with medical treatments.
- Depression is often accompanied by considerable social isolation and withdrawal from individuals who would essential in providing support.
- Decrease cognitiv functioning (memory)

DiMatteo et al., *Arch Intern Med.* 2000;160:2101-2107

DiMatteo MR. *JAMA.* 1994;271:79-83.

# Depression and Non-Compliance

---

- Recognizing that a patient might be depressed could help a health care professional manage his/her frustration around non-compliance and improve the physician/nurse-patient relationship.
- Screening for depression in patients beginning their treatment might prove to be a useful identifier of possible future non-compliance
- It might suggest closer monitoring and assistance to achieve adherence.

# “Difficult patient”

---

- Non-compliance
  - Anger
  - Mental health problems, substance abuse
  - Unacceptable behaviours towards staff or other patients (transference)
  - Strong emotional reactions (countertransference) from staff
- 
- “Patient with difficulties”

# Hope and hopelessness

---

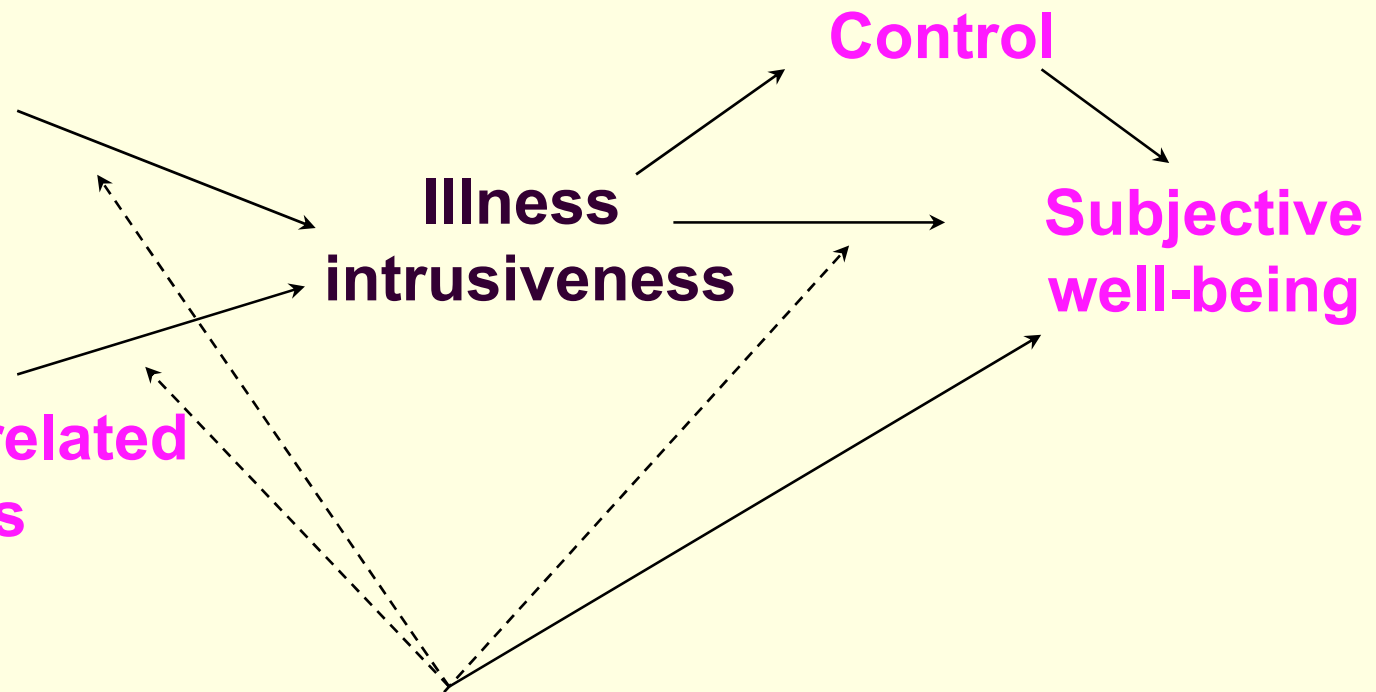
- Future
- Influenced by mental status, personality, cultural and religious factors, psychosocial factors (support)
- Existential
- Hopelessness might be more important than mood
- Predicts suicide, hastened death
- Assess with scale, interview
- Psychotherapeutic techniques useful

# Quality of life and illness intrusiveness (G. Devins, 1994)

**Disease related factors**

**Treatment related factors**

**Psycho-social factors**



# Modifiable factors?

---

- Medical?
- Symptoms: sleep, daytime functioning, fatigue, mood, anxiety, sex. Non – specific symptoms (somatization?), risk behaviors
- Death anxiety, existential issues
- Which symptoms affect the **quality of life** of the patient most?
- What areas of **functioning** can be improved?

# What can we do to improve patient care and outcomes? I.

---

- On the system level: organizing care, resources, guidelines (see cancer care)
- Educational needs
  - Patients
  - Caregivers, family
  - Staff
  - Society, media



# Doctor-patient relationship

---

- Nature of relationship changing (paternalistic, MD as agent, informed decision making, shared decision making, consumerism)
- Most important for patient satisfaction with treatment and compliance
- Bio -psycho-social - spiritual aspects of care
- “Doctor as medicine” – M Balint
- Empathy, understanding, reinforcement, support, hope
- “6 minute psychotherapy”

# Ill-ness versus dis-order

---

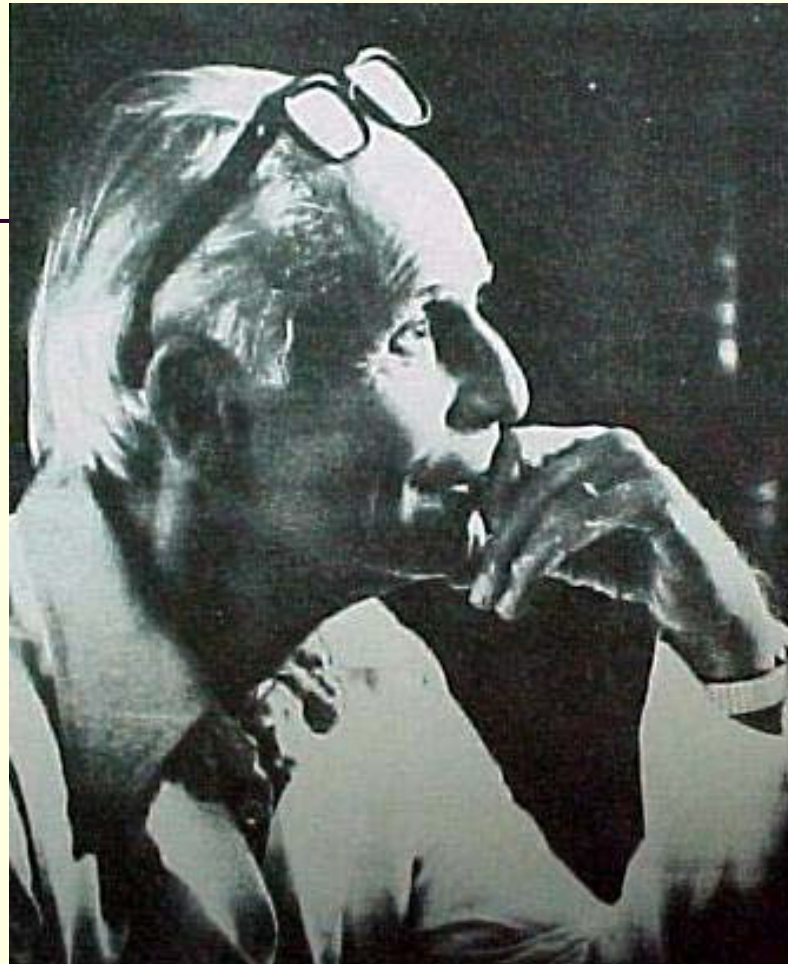
- Experience of patient with the illness in focus
- What does this illness mean to the patient and his/her family?
- Attention to motivation, values, desires, thoughts, feelings, experiences
- Understanding illness behavior, health beliefs, locus of control, ways of coping, resilience
- Dealing with emotions of staff

# “Tell me about yourself”

the patient story, developing a narrative

---

- Who is this patient?
- What does this patient want from the physician and medical team?
- How does this patient experience his or her illness?
- What are the pts ideas about the illness?
- What are the feelings about the illness?



**János Selye** (1907 – 1982)  
- the father of stress theory

# Positive psychology, protective factors and resilience

---

- the positive capacity of people to cope with stress and catastrophe.
- It also includes the ability to bounce back to homeostasis after a disruption.
- Having an adaptive system that uses exposure to stress to provide resistance to future negative events
- In this sense "resilience" corresponds to cumulative "protective factors" and is used in opposition to cumulative "risk factors".
- focus on individual capacity had evolved for a multilevel perspective.
- The focus in research also shifted from "protective factors" toward protective "processes"; trying to understand how different factors are involved

# What can we do to improve patient care and outcomes? II.

---

- Bio-psycho-social- (spiritual) model of care
- Screening for psychological factors (mood, distress, anxiety, coping etc.) with scales
- New models of screening
- Interventions on different levels  
(multidisciplinary team)
- Find best dialysis modality for patients

- 
- Regular monitoring of
    - distress,
    - quality of life
    - self-perceived health and patient satisfaction
  - Use “surprise” question to identify patients in needs
  - Assess and provide support for caregivers (individual, couple, family or grouptherapy)

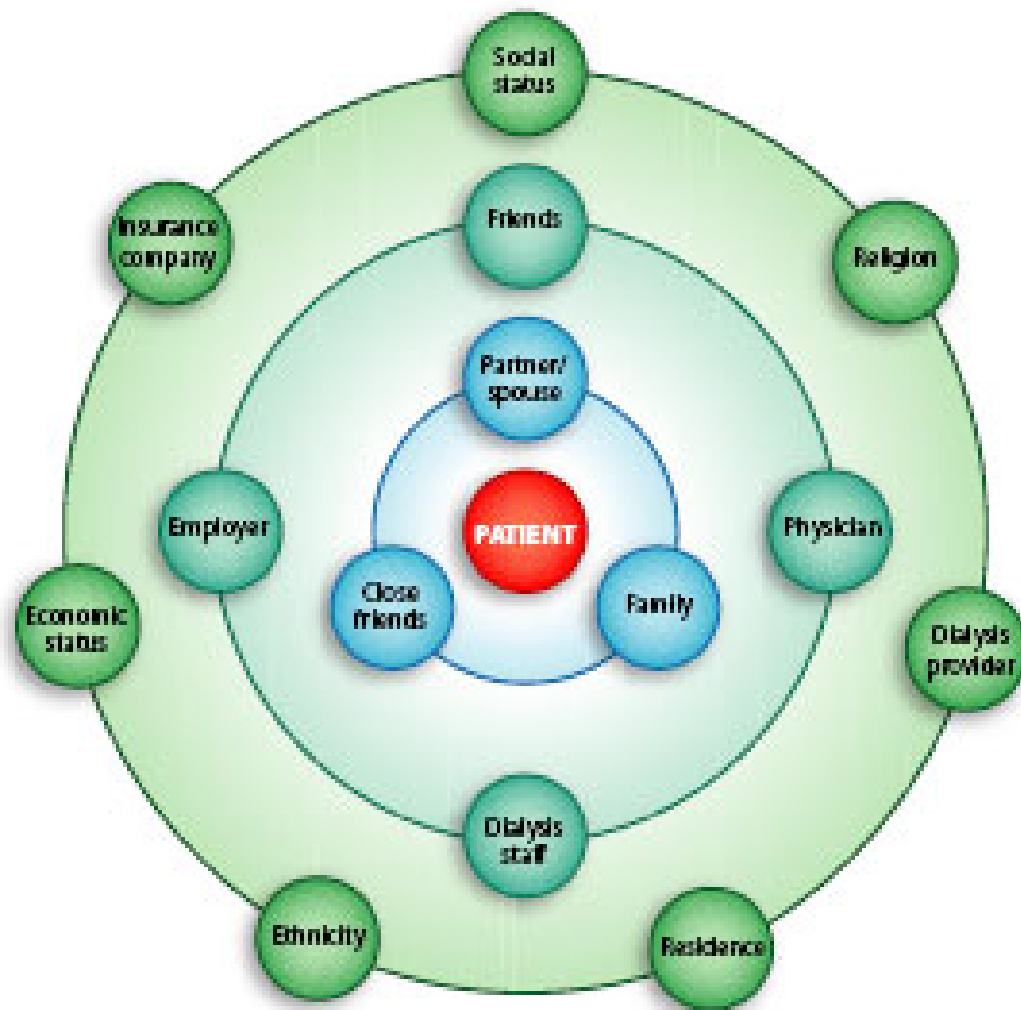


Figure 2. Psychosocial parameters: Spheres of influence.

Psychosocial Aspects of Chronic Disease: ESRD as a Paradigmatic Illness

Daniel Cukor,\* Scott D. Cohen,† Rolf A. Peterson,† and Paul L. Kimmel†

J Am Soc Nephrol 18: 3042-3055, 2007



# Enhancing couples, families

---

- Caregiver support essential, sometimes more challenges with coping than patient
- Burnout of caregivers
- Family issues, children
- Effective forms of couple therapies (cognitive, emotional focused, integrative)
- “Educational” sessions
- DVDs
- Attachment, communication, sex

# The story of my patient

---

- 36 y old jewish financial analyst
- Married with supportive spouse
- 3 children under age 6
- Diagnosed with PKD
- Ref: difficulty coping. Moderate depressive symptoms (sleep, motivation, guilt). Crying a lot.
- Intervention: crying.... after failed trials of ADs, supportive psychotherapy.
- Psychoeducation. Working around guilt, health anxiety.
- Sleep study, CPAP
- Feels stronger, more stable emotionally. Involve wife?

# What can we do to improve patient care and outcomes? III.

---

- Staff: address educational needs, group dynamics, conflicts and burnout (eg. Balint group and other supportive programs)
- Multidisciplinary team
- Interdisciplinary collaborations
- Interprofessional education
  
- Research in psychosocial areas



**Mihály (Michael) Bálint**  
(1896 Budapest, Hungary -1970 London, UK):  
Bálint groups for GP-s

# Balint-groups

---

- 6-12 member, regular meetings
- GPs, nurses, social workers etc.
- Internationally known, Balint societies
- Structure of the group (description of a case, questions, discussion, feedback, summary)
- New models, large groups, involvement of the whole interdisciplinary team

# What can we do to improve patient care and outcomes? IV.

---

- Education: technical, emotional, communication skills, lifeskills etc.
- Improve social support and other important functional measures of quality of life (eg. sleep)
- Counselling, psychotherapies (CBT, IPT, existential, supportive): individual, couple, family, group. Facilitate “normal lifestyle”, sun, exercise
- “6-minute psychotherapy”- active listening, empathy and support
- Address end-of-life issues, palliative care
- New forms of support and therapies: internet-based (chat, facebook, websites, groups), phone

# “Psychonephrology”

---

- “Medical psychiatry”: Different from traditional view of psychiatry
- Interdisciplinary collaboration
- Raise awareness of psychological and psychosocial factors in nephrology care
- Education: patients, caregivers, staff, public, media, decision makers
- Research and interventions to improve outcomes
- Learn lessons from psychooncology
- Learn lessons from our patients

---

■ Thank you  
for your attention,  
time and  
support!





# Types of depression

---

- Major depression
- Minor – subclinical
- Chronic depression –dysthymia
  
- Adjustment disorder – with depressed mood
- Depression often co-occurs with anxiety
- Depression and chronic stress

# Criteria for major depression\*

---

Five or more of the following symptoms during the same two week period representing a change from normal

- Depressed mood ◇
- Substantial weight loss or weight gain
- Insomnia or hypersomnia
- Feelings of worthlessness or inappropriate guilt
- Recurrent thoughts of death or suicide or suicide attempt
- Decreased interest or pleasure ◇
- Psychomotor retardation or agitation
- Fatigue or loss of energy
- Diminished ability to think or concentrate

\* From *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition

◇ One of these symptoms must be present

# Prevalence of depression in patients with ESRD I.

	Year	Patients	Diagnostic tool	Prevalence of depression
Lowry, USA	1980	83 home HD	DSM-III	18%
Smith, USA	1985	60 HD	BDI	47%
			DSM-III	5%
			MAACL	17%
Craven, Canada	1988	99 HD	DSM-III	8.1% major depr
Hinrichsen, USA	1989	124 HD	RDC	17.7% minor depr
Kimmel, USA	1998	295 HD	BDI	
Kim, Korea	2002	96 CAPD	CESD $\geq$ 16	75%
Walters, USA	2002	422 HD	DIS	45%
Lopes, DOPSS I , multicenter	2002	5256 HD	Physician	17.7%
			„downhearted and blue” – SF-36	21.5%
			„so down in the dumps” – SF-36	19.5%
Wuerth, USA	2003	380 CAPD	BDI $\geq$ 11	42%
			HDRS, DSM-IV	(87% of this major depr)
Watnick, USA	2003	123 HD at start	BDI	44%

## Prevalence of depression in patients with ESRD II.

	Year	Patients	Diagnostic tool	Prevalence of depression
Einwohner, USA	2004	66 PD	ZDS	33%
				6,5% major depr
Lopes, DOPSS II, multicenter	2004	9382 HD	CESD short $\geq 10$	43%
			Physician	13,9%
Akman, Turkey	2004	27 Tx	BDI $\geq 11$	22,2%
		30 VL		40%
		31 HD		61,3%
Araplasan, Turkey	2004	40 Tx	SCID-I	50%
Wuerth, USA	2005	380 PD	BDI $\geq 11$	49%
Watnick, USA	2005	62 HD	BDI $\geq 16$	19% major depr
Tyrrell, France	2005	51 HD ( $\geq 70$ yrs)	MADRS	60%
Taskapan, Turkey	2005	40 HD	HDRS	35%
Kalender, Turkey	2005	68 HD	DSM-IV	24,1%
		47 CAPD	SCID-CV	
		26 predial		
Hedayati, USA	2005	1588 HD	ICD	14,7%
Wilson, Canada	2006	124 HD	BDI-II $\geq 14$	38,7%
			Nurse	41,9%
			Nephrologist	24,2%

# Transplantation – not a cure

---

- Recurrent crisis situations (listing, wait periode, surgery, intercurrent diseases, acute and chronic rejection, etc.)
- Coping
- Emotional problems
- Immunosuppressive and other drugs (adherence, side effects)
- Existential issues, life-death-survival
- Family, caregiver
- Adaptation to new roles, new lifestyle
- Rehabilitation, education, work