Psychonephrology

It’s OK to cry: the psycho-social impact of living with chronic kidney disease

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Outline

- To understand emotional and psychosocial impact of living with CKD
- Understand psychosocial barriers in patient education, self-management and modality choice;
- To discuss the opportunities of whole person care and collaborative care in CKD management;
- To consider ways of support to enhance self-management in patients with CKD.
- No conflict of interest in relation to this talk
Chronic renal failure,
End-stage renal disease:

“a „psycho-somatic” disease with significant renal involvement” (nephrologist);

“nephrology is not technical as before, it is now a specialty of relationships” (nephrologist);

“kidney disease is a mental disorder” (patients).
Chronic renal disease (CKD)
- Progressive
- Potentially life-threatening
- Dialysis started only in the 60s
- High co-morbidity, physical dyscomforth, pain
- Increased mortality
- End-stage renal disease (ESRD) – renal replacement therapies with intrusive treatment modalities
- High illness intrusiveness – both by disease and treatments
- Impaired quality of life
Renal replacement therapies

- Peritoneal dialysis
  - Continuous Ambulatory Peritoneal Dialysis (CAPD)
  - Continuous Cycler 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
My patient

- 36 y old jewish financial analyst
- Successful work
- Good marriage
- 3 children (8, 6, 4 years old)
- PKD
- Moderately severe depression

- “Failed trials of antidepressants”
- Sits in office and only cries
Other patients also cry…

- 54 y old successful businessman with PKD
- 65 y old patient from the dialysis unit
- 50 year old lawyer with impaired kidney function
- …
Psychosocial challenges in chronic diseases – the psychology of losses

- High psychosocial burden of disease
- Everyday adjustment to chronic disease – dynamic and always changing
- 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, quality of life vs longevity
New challenges in nephrology care...

- Older, sicker patients
- Living with CKD requires high level of self-care/self-management (SM) – with good self-efficacy etc;
- Modality choice is crucial and very stressful;
- Home dialysis modalities are extremely demanding examples of self-care;
New challenges in nephrology care

- Patient education is not enough, cultural understanding and emotional support is needed
- Barriers to SM have to be understood and addressed in nephrology care
- Facilitators of SM should be implemented in the system level
- Opportunities for collaborative relationship
Home Dialysis

- Home dialysis is a unique model of care/ self-care
- Self-care creates significant anxiety
- Patients on home dialysis function independently and are given significant responsibility when it comes to their care
- Challenges emerge when patients are hospitalized
- Conflict between paternalistic model and self-care
- Life worth living?
Barriers to Home Dialysis

- Fears and anxiety
- Non-compliance
- Lack of self-efficacy in performing the therapy
- Lack of confidence in self-cannulation
- Fear of burdening family members
- Fear of a catastrophic event.

Transplantation – not a cure

- Recurrent crisis situations (listing, wait period, surgery, intercurrent diseases, acute and chronic rejection, etc.)
- Coping
- Emotional problems
- Immunsuppressive and other drugs (adherence, side effects)
- Existential issues, life-death-survival
- Family, caregiver
- Adaptation to new roles, new lifestyle
- Rehabilitation, education, work
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 KESZEI, 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: $p = .004$

<table>
<thead>
<tr>
<th>Model 3</th>
<th>Mortality</th>
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<th>Death Censored Graft Loss</th>
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<tr>
<td></td>
<td>HR</td>
<td>95% CI</td>
<td>$p$</td>
<td>HR</td>
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<td></td>
<td>CES-D (for each 1-point increase)</td>
<td>1.02</td>
<td>1.00–1.04</td>
<td>.04</td>
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<tr>
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<td>Depression (presence)</td>
<td>1.66</td>
<td>1.12–2.47</td>
<td>.01</td>
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</tbody>
</table>

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.
Times of increased difficulties and crisis in patients with CKD

- Diagnosis of renal disease
- Threat of dialysis. Dialysis as death?/ “parking lot”
- 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.
CKD/ESRD as existential crisis

- Time of diagnosis or time of symptom onset?
- Why modality choice comes as a surprise?
- Denial as coping
- Dialysis seen as “death” or “parking lot”
- “not ready to die”
- “slow death”

- Goals/meaning of life
- Palliative care /techniques
- Dignity / “good death”
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
“Difficult patient”

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

Reframing: “Patient with difficulties”
Patient barriers to self-management/decision-making I.

- Socio-economical background;
- Culture, religion and language;
- Financial resources/competing interests;
- Knowledge, health literacy;
- Personality, relationship style (attachment/trust);
- Coping and resilience;
- Health beliefs, locus of control;
- Illness trajectory and illness experience (past and current);
Patient barriers to self-management/decision-making II.

- Mental health problems/disorders - Preexisting or new onset;
- Motivation to change;
- Health/death anxiety – dynamic;
- Shame, blame, guilt (symptoms, appearance, burden);
- Cognitive problems;
- Attitude/anxiety/experiences etc. of family members (same applies as for patients);
- Dynamic changes of the above
“The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies” (RL Morton et al, BMJ. 2010)

- Identified 593 citations
- 18 studies, 375 patients and 87 carers

Main themes identified for treatment choices:
- Confronting mortality (life/death, burden, limbo)
- Lack of choice (medical decision, resources)
- Gaining knowledge of options (peers, timing of information)
- Weighing alternatives (maintaining lifestyle, qol, family influences).
What can we do?

- Acknowledge existential suffering
- The power of the therapeutic relationship
- Therapeutic alliance – learning from psychotherapy
- Communications skills
- Understanding barriers in communication
- ?New? models of care:
  - Person-centered care
  - Whole person care
  - Narrative medicine
Helpful tools and strategies

- Stress-management skills;
- Communication skills;
- Cultural and religious aspects;
- Understanding “readiness to change”;
- Motivational interviewing and behavioral activation;
- Understading the impact of disease;
- Understanding the life story and the life goals of patients.
- Taking care of ourselves
Prochaska’s Stages of Change: Processes & Activities that Can Be Promoted at Each Stage of Change

Pre-contemplation
- Consciousness Raising: Public education using mass media, small groups.
- Dramatic Relief: Taking action to decrease anxiety and other negative emotions through role playing, grieving, testimonies, simulations, and other group activities.
- Environmental Re-evaluation: Learning how one’s actions affects one’s self/others through guided discussions w/family members, testimonies, story telling.

Contemplation
- Self-Reevaluation: re-evaluation of self-image through group activities:
  - values clarification exercises
  - contact and discussions w/role models
  - guided imagery (where people imagine themselves in the new situation [e.g., committed to abstinence])

Preparation
- Self- and Social Liberation: Belief that one can change and commit to change, and creating social conditions for change by:
  - Changing community norms to favor change
  - Drawing attention to those who have made commitments
  - Organizing events for public commitments

Action
- Using and fostering social support and caring relationships through peer groups
- Contingency management: Reinforcing positive steps towards desired behaviors (e.g., commitments), giving group praise and recognition
- Counter-conditioning: Learning to substitute healthy behaviors for problem behaviors (e.g., group activities, outlets).

Maintenance
- Continue positive reinforcement & social support through:
  - continuance of support groups
  - institutionalization (e.g., through local organizations) of rewards and recognition for keeping commitments.
- Stimulus Control: Removing triggers for unhealthy behaviors; Role-playing to substitute prompts for healthy behaviors.
- Maintain self-efficacy: Maintain confidence to resist temptations through regular discussions, accountability system.

Use of Mass Media, Motivational Interviewing techniques, and Other Methods

Skill Building, Social Support through Small Groups, and Other Methods
Dynamics of the stages
Self-management support

- Healthcare: education, developing models of collaborative care, establishing peer support opportunities

- Community: community centers, patient organizations, peer support outside of health care

- Other: internet, new technologies (iPad, phones etc)
Burnout, hope and hopelessness

- Future –oriented?

- Influenced by mental status, personality, cultural and religious factors, psychosocial factors (support)

- Existential questions, values, meaning

- Hopelessness might be more important than mood

- Predicts suicide, hastened death

- Assess with scale, interview

- Psychotherapeutic techniques useful
Psychosocial Predictors for shortened treatments

- HD and PD patients

- Individuals who shortened treatment were more likely to be depressed,

- to be bothered by the effects of kidney disease on their daily life, and

- to feel little or no control over their future health.

Improving quality of life of our patients

- Medical – modifyable factors?
- 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?
János Selye (1907 – 1982)
- the father of stress theory
Burn-out

“crisis in self-efficacy” (Maslach)
Typical for caring professionals (health care workers, teachers, caregiver, parents of children with chronic diseases, chronic patients)
Social support

- Emotional support
- Information exchange (providing info, opinions, feedback)
- Instrumental (providing practical-technical support)
Social support is the buffer of acute and chronic stress
“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?
Strategies to Enhance Care at Home

- Expectations and fears from the patients and care providers’ perspectives need to be discussed openly.
- Targeted attention
- “Supervision”
- Encouragement and support
Targeted attention, supervision, encouragement and support

Targeting isolation in home dialysis patients:
- Home visits during the first 6 months of therapy to monitor compliance in home dialysis patients.
- Follow up visits for those identified as having compliance problems.
- Involve a partner during the dialysis training as social support may reduce the patient’s experience of burden and improve compliance.

Targeted Attention

- Patients may need targeted attention from professional sources other than dialysis staff.
- This includes formal counseling or psychotherapy programs that address patients’ depression and/or anxiety.
- Psychotherapy /grouptherapy

What can we do to improve patient care and outcomes?

- Bio-psycho-social- (spiritual) model of care
- Systematic screening for emotional well-being psychological factors (mood, distress, anxiety, coping etc.) with scales
- New models of symptoms screening with interventions on different levels (multidisciplinary team)
- Find best dialysis modality for patients – takes time…. 
- Regular monitoring of distress,
- quality of life
- self-perceived health and patient satisfaction

- Use “suprise” question to identify patients in needs

- Assess and provide support for caregivers (individual, couple, family or grouptherapy)
What can we do?

- 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
Collaborative /integrated care models for chronic illness

- Integrating medical and mental health services, eg. in cancer care
- Focus is on supporting patient self-management
- Chronic Disease Self-Management Program (K Lorig at Stanford) – general coping skills and health behaviors (Better choices-Better health)
- Expert Patients Programme - UK
Psychonephrology Unit, UHN-TGH

- Psychotherapy for patients and families (individual and group therapy, couples)
- Anxiety, mood, sleep disorders
- Mental Health training for nurses
- Rounds regularly on psychonephrology topics
- Balint group for nurses to prevent burnout
- Communication training for fellows

- Implementing routine screening for distress
- New models of care/internet, telemedicine
“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
Compassion and Healing in Medicine and Society
On the Nature and Use of Attachment Solutions to Separation Challenges

GREGORY L. FRICCHIONE, M.D.
Thank you for your attention, time and support!

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       marta.novak@uhn.ca
DEPRESSION IN PATIENTS WITH CKD – is this a helpful concept?
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

- 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 – spiritual model
- Disease-related, comorbidities, pain, dyscomfort
- 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

OTHER MODELS MORE HELPFUL?
“What would you like me to know about you”?  
Do not interrupt/decrease disruptions  
Open-ended questions  
Time management/ continue next visit  
Ask patients to write about their illness  
Allow patients to discuss their concerns  
Look for a metaphor or key word
Narrative medicine cont.

- View noncompliance as a “blocked narrative”
- Record encounters (3 min)
- Be aware of your own body language
- Examine your assumptions and stereotypes ("prejudice", eg. tattoos)
- Ask patient: “what do you think is going on”? “How would others describe you?”
- “What is the one thing you have’nt asked or told me”? 
Types of support

- Structural – social network, connections
- Functional – purposes served by relationships (affection, information etc).

Sources of support: partner, family, parents, children, collegaues, social groups (neighbors, church, recreational activities) etc.

Via: personal contact, phone, email, chat etc.

Measurement: type (advising, social interaction, material aid, emotional support), direction, source, frequency.

Discrepancies, hoped for and perceived
Social support

- Social skills
- Emotional and social intelligence
- Empathy
- Trust
- Self – image
- Identity
- Attachment: bonding, making and keeping good relationships

Ability to ask and to provide help and support
RECEIVING AND GIVING
Benefits of social support

- Physical health
- Mental health
- Quality of life
- Behavior change
- Academic achievement
- Longer lifespan
- Fewer, less severe illnesses, lower risk of death
Staff-patient relationship

- Nature of relationship changing (paternalistic, MD as agent, shared decision making, informed 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
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.
Core elements of collaborative/integrated care (TEAMcare)

- Patient empowerment, education and support
- Case-managers collaborating with PCP and psychiatrist
- Identify vulnerable patients/patients at needs
- Enhance social support
- Use motivational interview
- Behavioral activation, problem solving
- Keep log
- Weekly case reviews
Core elements of SMS in chronic illness

- Understanding patient/person’s perspective
- Empowering patients through collaborative partnership
- Providing information and education
- Addressing emotional distress, anxiety, meaning
- Providing social support; Involving families; Peer support/groups
- Monitoring progress, feedback, motivation, support – in person, phone, internet
- Identify most vulnerable patients /young, old, single man, recent loss/stressful life events
<table>
<thead>
<tr>
<th>Year</th>
<th>Patients</th>
<th>Diagnostic tool</th>
<th>Prevalence of depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lowry, USA 1980</td>
<td>83 home HD</td>
<td>DSM-III</td>
<td>18%</td>
</tr>
<tr>
<td>Smith, USA 1985</td>
<td>60 HD</td>
<td>BDI</td>
<td>47%</td>
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<tr>
<td>Craven, Canada 1988</td>
<td>99 HD</td>
<td>DSM-III, MAACL</td>
<td>5%, 17%</td>
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<tr>
<td>Craven, Canada 1988</td>
<td>99 HD</td>
<td>DSM-III</td>
<td>8.1% major depr</td>
</tr>
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<td>Hinrichsen, USA 1989</td>
<td>124 HD</td>
<td>RDC</td>
<td>17.7% minor depr</td>
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<td>Kimmel, USA 1998</td>
<td>295 HD</td>
<td>BDI</td>
<td></td>
</tr>
<tr>
<td>Kim, Korea 2002</td>
<td>96 CAPD</td>
<td>CESD ≥ 16</td>
<td>75%</td>
</tr>
<tr>
<td>Walters, USA 2002</td>
<td>422 HD</td>
<td>DIS</td>
<td>45%</td>
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<tr>
<td>Lopes, DOPSS I, multicenter 2002</td>
<td>5256 HD</td>
<td>Physician, &quot;downhearted and blue&quot; – SF-36, &quot;so down in the dumps&quot; – SF-36</td>
<td>17.7%, 21.5%, 19.5%</td>
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<tr>
<td>Wuerth, USA 2003</td>
<td>380 CAPD</td>
<td>BDI ≥ 11, HDRS, DSM-IV</td>
<td>42%, (87% of this major depr)</td>
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<tr>
<td>Watnick, USA 2003</td>
<td>123 HD at start</td>
<td>BDI</td>
<td>44%</td>
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## Prevalence of depression in patients with ESRD II.

<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Patients</th>
<th>Diagnostic tool</th>
<th>Prevalence of depression</th>
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<tr>
<td>Einwohner, USA</td>
<td>2004</td>
<td>66 PD</td>
<td>ZDS</td>
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<td>Lopes, DOPSS II, multicenter</td>
<td>2004</td>
<td>9382 HD</td>
<td>CESD short ≥ 10</td>
<td>43%</td>
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<td>Physician</td>
<td>13,9%</td>
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<td>Akman, Turkey</td>
<td>2004</td>
<td>27 Tx</td>
<td>BDI ≥ 11</td>
<td>22,2%</td>
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<tr>
<td></td>
<td></td>
<td>30 VL</td>
<td></td>
<td>40%</td>
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<td>31 HD</td>
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<td>61,3%</td>
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<td>Araplasan, Turkey</td>
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<td>40 Tx</td>
<td>SCID-I</td>
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<td>2005</td>
<td>380 PD</td>
<td>BDI ≥ 11</td>
<td>49%</td>
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<td>Watnick, USA</td>
<td>2005</td>
<td>62 HD</td>
<td>BDI ≥ 16</td>
<td>19% major depr</td>
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<td>Tyrrell, France</td>
<td>2005</td>
<td>51 HD (≥ 70 yrs)</td>
<td>MADRS</td>
<td>60%</td>
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<td>Taskapan, Turkey</td>
<td>2005</td>
<td>40 HD</td>
<td>HDRS</td>
<td>35%</td>
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<td>Kalender, Turkey</td>
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<td>68 HD</td>
<td>DSM-IV</td>
<td>24,1%</td>
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<td></td>
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<td></td>
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<td>1588 HD</td>
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<td>Wilson, Canada</td>
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<td>BDI-II ≥ 14</td>
<td>38,7%</td>
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<td>Nurse</td>
<td>41,9%</td>
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<td>Nephrologist</td>
<td>24,2%</td>
</tr>
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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 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 and mortality in HD pts (DOPPS)

Adjusted for Demographics only

RR Mortality

Not Depressed

Depressed

p=0.000

1,00

1,62

Adjusted for Demographics & Comorbidities

1,00

1,31

p=0.000
QoL of depressed patients (DOPPS)*

*All Comparisons significant at the 0.0001 level

**A Δ 5 in QoL Scores is Clinically Meaningful

Adjusted for Demographics and Comorbidities
Depression in patients on maintenance dialysis

Depression is a predictor of:
- mortality
- hospitalization
- and withdrawal

in patients on dialysis

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
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 el al, AJKD 2008)
- Subclinical depression, minor depression chronic depression
- Suicide – withdrawal from dialysis
- Sleep disorders – mental health
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
Transplantation – not a cure

- Recurrent crisis situations (listing, wait period, 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
Maslach Burn-out Inventory (MBI)

- The MBI Surveys address three general scales:
  - *Emotional exhaustion* measures feelings of being emotionally overextended and exhausted by one's work
  - *Depersonalization* measures an unfeeling and impersonal response toward recipients of one's service, care treatment, or instruction
  - *Personal accomplishment* measures feelings of competence and successful achievement in one's work
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
Support interventions for caregivers of people with chronic kidney disease: a systematic review

How to prevent burn-out?

- Early recognition of symptoms (screening tools?)
- Work/life balance
- Stress management techniques
- Professional help (counsellors, life coaches, psychoterapists)
- Balint -groups
Mihály (Michael) Bálint
Bálint groups for GP-s
Balint-groups for home dialysis nurses

- 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
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
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 and noncompliance

- **Direct effects** - depression having adverse physiological manifestations.
- **Indirect effects** - behavioural phenomena mediating the relationship between depression and outcomes.

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 patient's attempts to be compliant with medical treatments.

- Depression is often accompanied by considerable social isolation and withdrawal from individuals who would be essential in providing support.

- Cognitive problems?

  DiMatteo et al., *Arch Intern Med*. 2000:160:2101-2107
Depression and Non-Compliance

- Recognizing that a patient might be depressed could help a health care professional manage his/her frustration around the patients 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.

DiMatteo et al., Arch Intern Med. 2000:160:2101-2107
Psychosocial Predictors

In studies of HD patients, depression, perception of illness, and perceived mental health are variables that have been suggested as important mechanisms contributing to patient non-compliance.