Psychonephrology: the patient with chronic kidney disease

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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 dyscomform, 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 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
GFR ml/min/1,73 m²

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 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
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 el 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, 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
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 Szefert, MD, Agnes Zsofia Kovacs, MD, Eszter Panna Vamos, MD, PhD, Rezso Zoller, MD, Andras Keszei, MD, PhD, and Istvan Mucsi, MD, PhD

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>
<th>Death Censored Graft Loss</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HR</td>
<td>95% CI</td>
</tr>
<tr>
<td>CES-D (for each 1-point increase)</td>
<td>1.02</td>
<td>1.00–1.04</td>
</tr>
<tr>
<td>Depression (presence)</td>
<td>1.66</td>
<td>1.12–2.47</td>
</tr>
</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.
QoL of depressed patients (DOPPS)*

*All Comparisons significant at the 0.0001 level
**A $\Delta$ 5 in QoL Scores is Clinically Meaningful

Adjusted for Demographics and Comorbidities

U 902 99 P
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.

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.
- Decrease cognitive functioning (memory)

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 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
“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

Operation related factors

Psycho-social factors

Illness intrusiveness

Control

Subjective well-being
Modifyable 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 “suprise” question to identify patients in needs
- Assess and provide support for caregivers (individual, couple, family or group therapy)
Figure 2. Psychosocial parameters: Spheres of influence.
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 (e.g. Balint group and other supportive programs)
- Multidisciplinary team
- Interdisciplinary collaborations
- Interprofessional education
- Research in psychosocial areas
Mihály (Michael) Bálint
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.

<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, DSM-III, MAACL</td>
<td>47%, 5%, 17%</td>
</tr>
<tr>
<td>Craven, Canada 1988</td>
<td>99 HD</td>
<td>DSM-III</td>
<td>8.1% major depr</td>
</tr>
<tr>
<td>Hinrichsen, USA 1989</td>
<td>124 HD</td>
<td>RDC</td>
<td>17.7% minor depr</td>
</tr>
<tr>
<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>
</tr>
<tr>
<td>Lopes, DOPSS I, multicenter 2002</td>
<td>5256 HD</td>
<td>Physician, „downhearted and blue“ – SF-36, „so down in the dumps“ – SF-36</td>
<td>17.7%, 21.5%, 19.5%</td>
</tr>
<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>
</tr>
<tr>
<td>Watnick, USA 2003</td>
<td>123 HD at start</td>
<td>BDI</td>
<td>44%</td>
</tr>
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</table>
# 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>
</tr>
</thead>
<tbody>
<tr>
<td>Einwohner, USA</td>
<td>2004</td>
<td>66 PD</td>
<td>ZDS</td>
<td>33%</td>
</tr>
<tr>
<td>Lopes, DOPSS II, multicenter</td>
<td>2004</td>
<td>9382 HD</td>
<td>CESD short (\geq 10)</td>
<td>43%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Physician</td>
<td>13,9%</td>
</tr>
<tr>
<td>Akman, Turkey</td>
<td>2004</td>
<td>27 Tx</td>
<td>BDI (\geq 11)</td>
<td>22,2%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>30 VL</td>
<td></td>
<td>40%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>31 HD</td>
<td></td>
<td>61,3%</td>
</tr>
<tr>
<td>Araplasan, Turkey</td>
<td>2004</td>
<td>40 Tx</td>
<td>SCID-I</td>
<td>50%</td>
</tr>
<tr>
<td>Wuerth, USA</td>
<td>2005</td>
<td>380 PD</td>
<td>BDI (\geq 11)</td>
<td>49%</td>
</tr>
<tr>
<td>Watnick, USA</td>
<td>2005</td>
<td>62 HD</td>
<td>BDI (\geq 16)</td>
<td>19% major depr</td>
</tr>
<tr>
<td>Tyrrell, France</td>
<td>2005</td>
<td>51 HD ((\geq 70) yrs)</td>
<td>MADRS</td>
<td>60%</td>
</tr>
<tr>
<td>Taskapan, Turkey</td>
<td>2005</td>
<td>40 HD</td>
<td>HDRS</td>
<td>35%</td>
</tr>
<tr>
<td>Kalender, Turkey</td>
<td>2005</td>
<td>68 HD</td>
<td>DSM-IV</td>
<td>24,1%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>47 CAPD</td>
<td>SCID-CV</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>26 predial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hedayati, USA</td>
<td>2005</td>
<td>1588 HD</td>
<td>ICD</td>
<td>14,7%</td>
</tr>
<tr>
<td>Wilson, Canada</td>
<td>2006</td>
<td>124 HD</td>
<td>BDI-II (\geq 14)</td>
<td>38,7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Nurse</td>
<td>41,9%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Nephrologist</td>
<td>24,2%</td>
</tr>
</tbody>
</table>
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