
The role of psychosocial factors in home dialysis care

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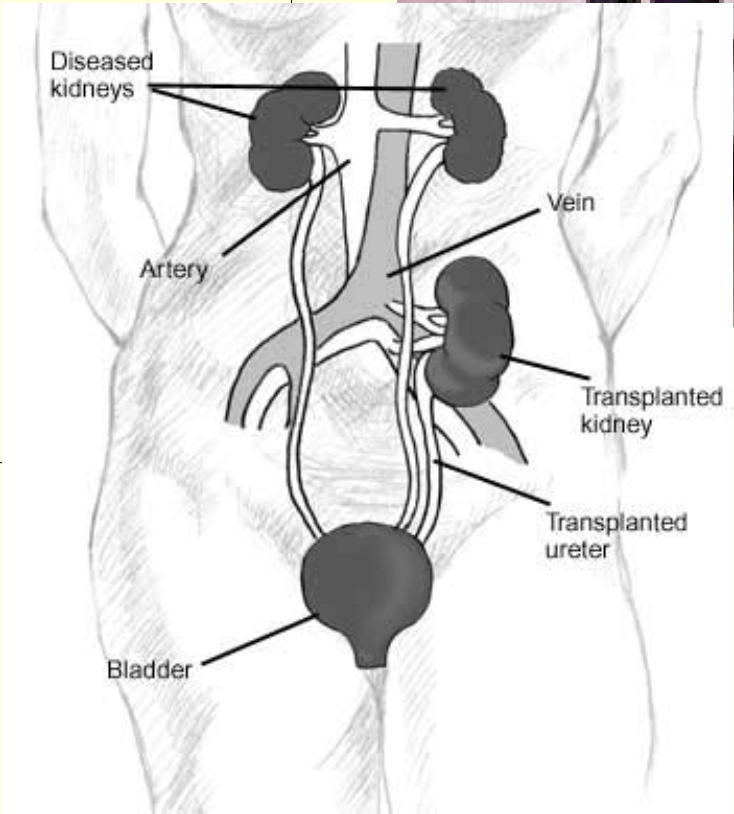
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- Psycho-social issues associated with CKD
 - Depression in patients with kidney diseases
 - Psychosocial factors in home dialysis
 - What can we do?

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 discomfort, pain
 - Increased mortality
 - End-stage renal disease (ESRD) –renal replacement therapies
 - Intrusive treatment modalities
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- 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?
- New modalities? New challenges

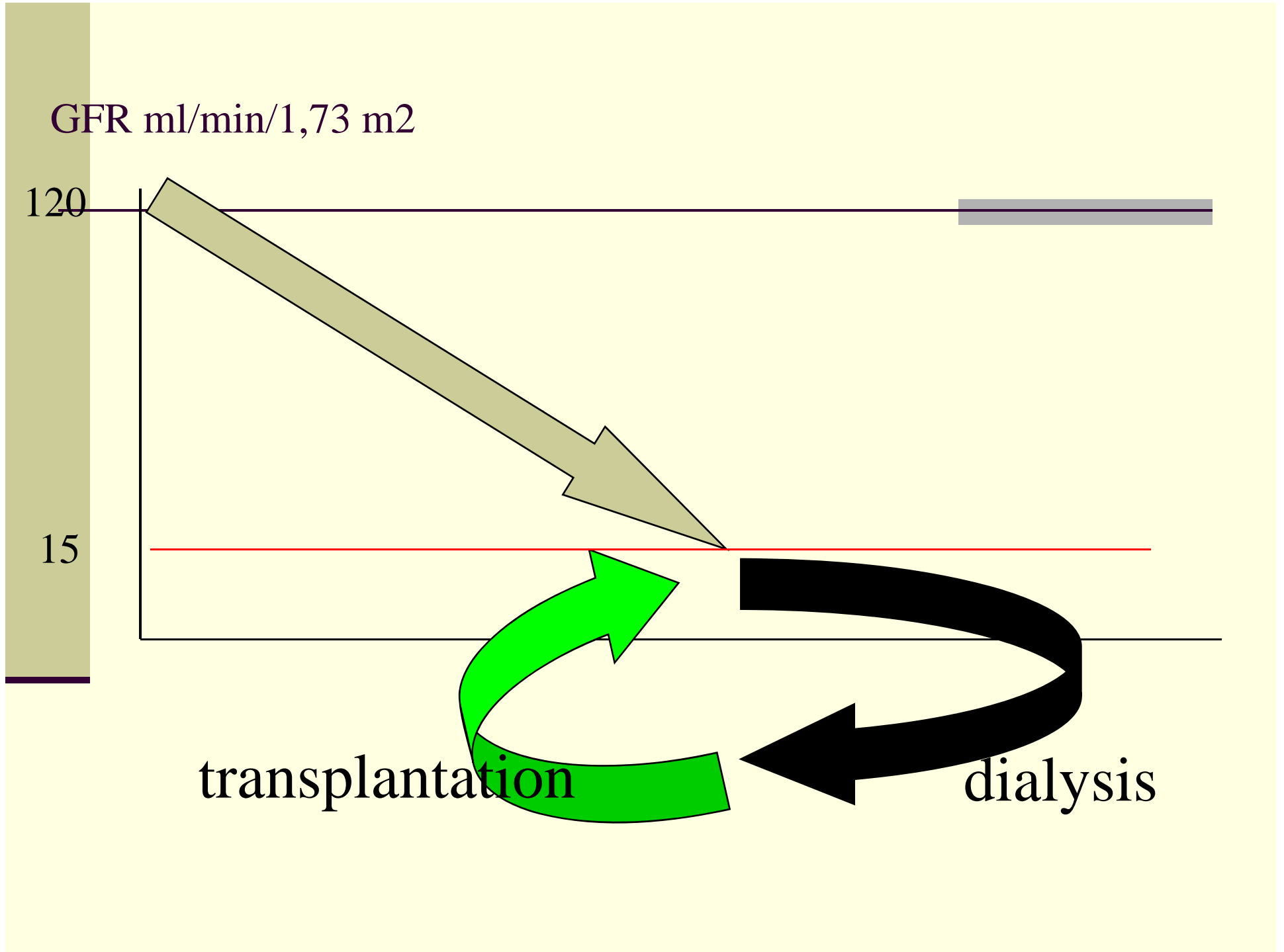
GFR ml/min/1,73 m²

120

15

transplantation

dialysis



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

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.

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

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?

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

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 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%

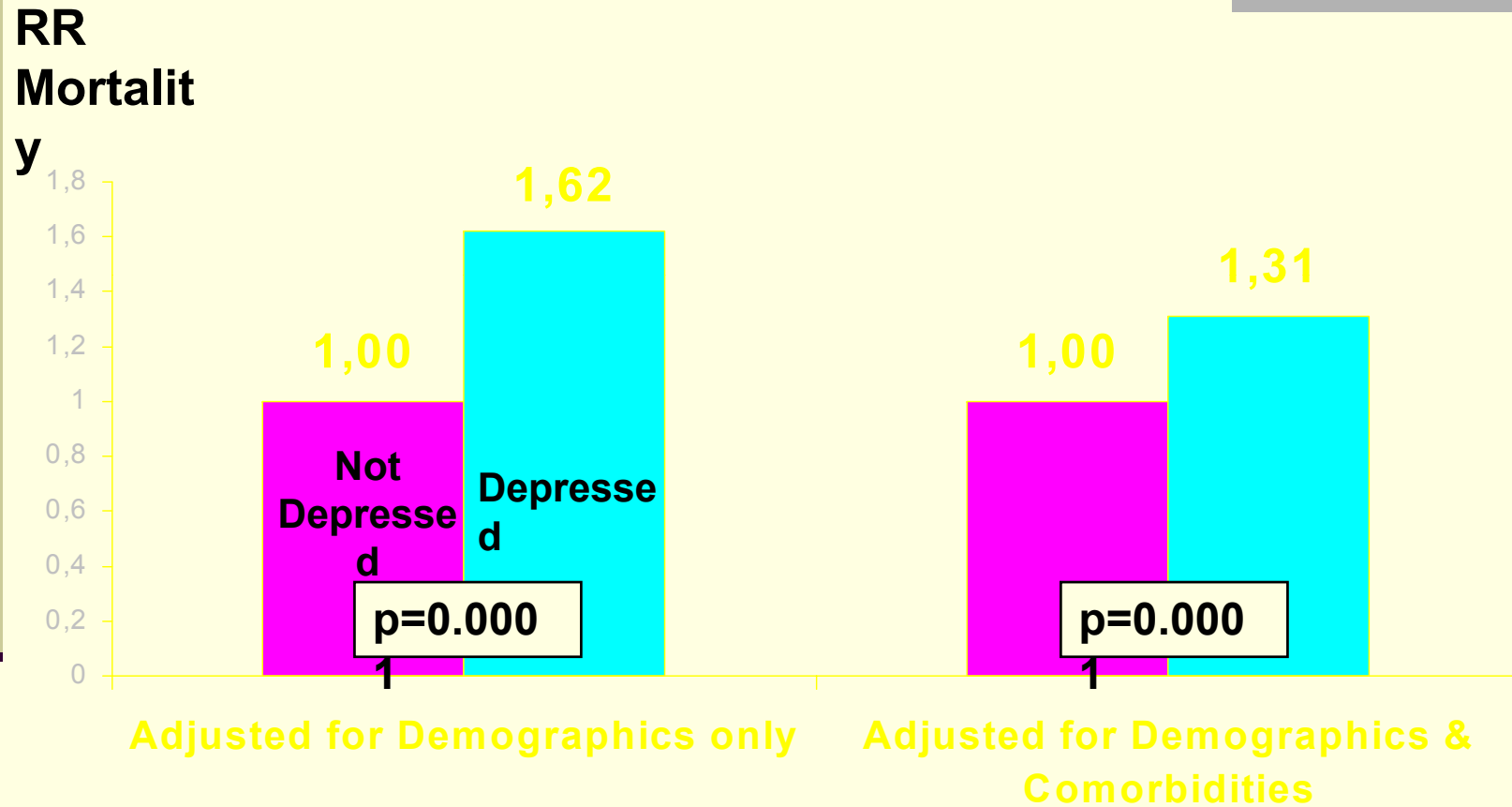
Antidepressant prescription was:

34.9% in patients with physician-diagnosed depr.

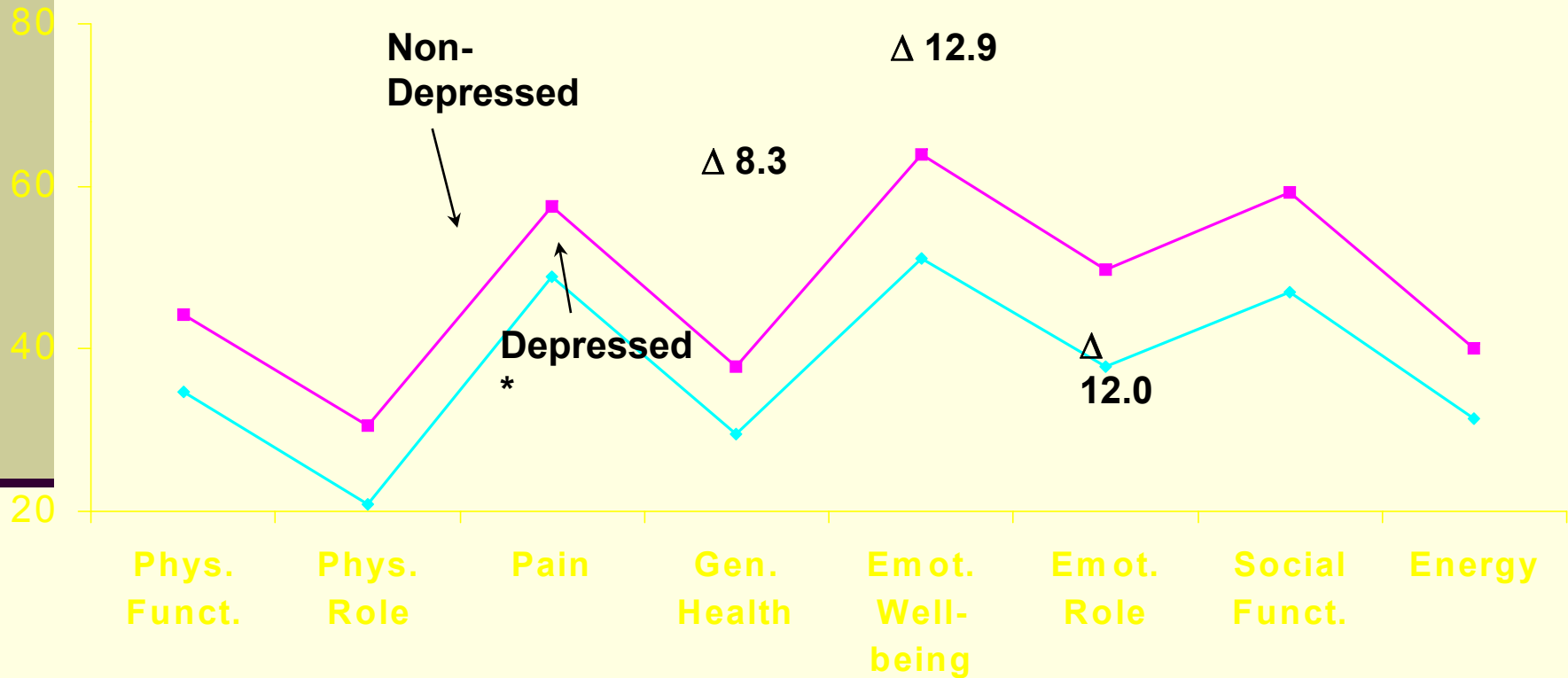
17.3% in patients diagnosed depr. based on CES-D

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

Depression and mortality in HD pts (DOPPS)



QoL of depressed patients (DOPPPS)*



*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

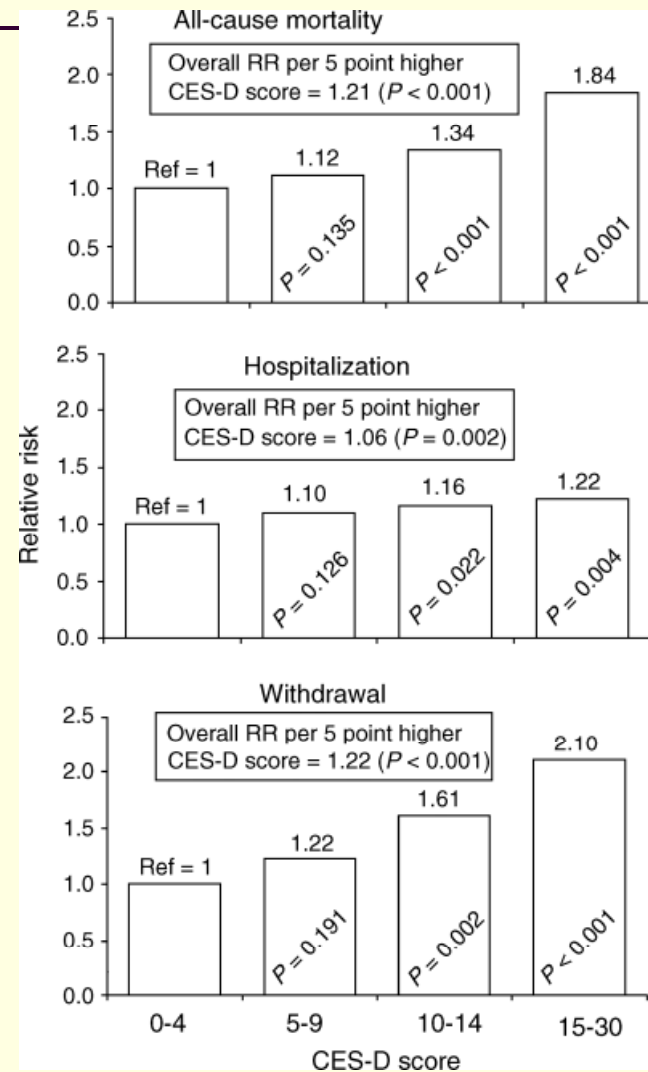
Depression is a predictor of:

mortality

hospitalization

and withdrawal

in patients on dialysis



Lopes et al.; Kidney International (2004)

Home Dialysis

- Home dialysis is a unique model of care.
- Patients doing home dialysis function independently and are given significant responsibility when it comes to their care.

Barriers to Home Dialysis

- Fears and anxiety.
- Non-compliance.
- Patient-perceived barriers were studied through a cross-sectional survey of prevalent hemodialysis patients at the University Health Network.

Cafazzo et al., *Clin J Am Soc Nephrol* . 2009;4:784-789.

Barriers to Home Dialysis

- Major barriers perceived by Conventional Hemodialysis patients were:
- lack of self-efficacy in performing the therapy
- lack of confidence in self-cannulation
- fear of burdening family members
- fear of a catastrophic event.

Cafazzo et al., *Clin J Am Soc Nephrol* . 2009;4:784-789.

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 patients partner during the patients dialysis training as social support may reduce the patient's experience of burden and improve compliance.

Bernadini et al., *Am J Kidney Disease*. 2000;35:1104-1110

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.
- One such program is a psychotherapy group for patients receiving dialysis that we are conducting at the University Health Network.

Baines et al., *Nephron*.2000;85:1-7.

Howard et al., *Nephrol News Issues*. 1999;13:31-34.

Group Psychotherapy Initiative

- Open to home dialysis patients.
- Currently, we have 8 participants, all being treated with Home Hemodialysis except one.
- Group members share their experiences, about home dialysis with each other.
- Support is provided.
- Discussions range from very technical aspects of patients dialysis to interpersonal problems and challenges patients receiving home dialysis face.

Home Dialysis

- Patients doing home dialysis function independently and are given significant responsibility when it comes to their care.
- A main goal of home dialysis is for patients to be effectively treated.
- Therefore, assessing the ability of patients to comply with treatment is an important part of an overall assessment on suitability to home dialysis.

Compliance In Patients Receiving Home Dialysis

- Peritoneal Dialysis-
- Based on home visit supply inventories, one study found that approximately 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 Receiving Home Dialysis

- An interesting multicenter study compared non-compliance with CAPD exchanges in US and Canadian patients.
- overall admitted rate of non-compliance-13%, 18% in the U.S. and 7% in Canada.

Blake et al., *American Journal of Kidney Disease*. 2000;35:506-514.

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.

Kimmel et al., *Kidney Int.* 1998;54:245-254.

Psychosocial Predictors

- Another study looked at a cohort of 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.

Kutner et al., *Nephrol Dial Transplant*. 2002;17:93-99.

Illness Intrusiveness

- Devins has shown that chronic illness and related therapies are widely experienced as intrusive in patients' lives, disrupting or interfering with valued activities and lifestyles.

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

Disease related factors

Control



Treatment related factors

Subjective well-being

Psycho-social factors

Lack of Control

- Individuals with a chronic disease who experience a diminished sense of control often seek alternative ways to re-establish control and a sense of self mastery.
- Non-compliance behaviours provide one readily available way for ESRD patients to deflect the perceived intrusion of kidney disease and dialysis into their daily lives.

Taylor et al., *J Soc Issues*. 1991;47:91-109.

Kutner et al., *Nephrol Dial Transplant*. 2002;17:93-99.

Lack of Control

- The tension between treatment related constraints and the individual's effort to maintain a sense of autonomy has been described as a “**compliance-independence tight rope**”.

Depression

- 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?

- Also research suggests the 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.

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

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

Why Might Depression Increase Non-Compliance?

- Depression can at times decrease cognitive functioning.
- This could affect a patient's ability to remember and follow through with treatment recommendations .

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

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

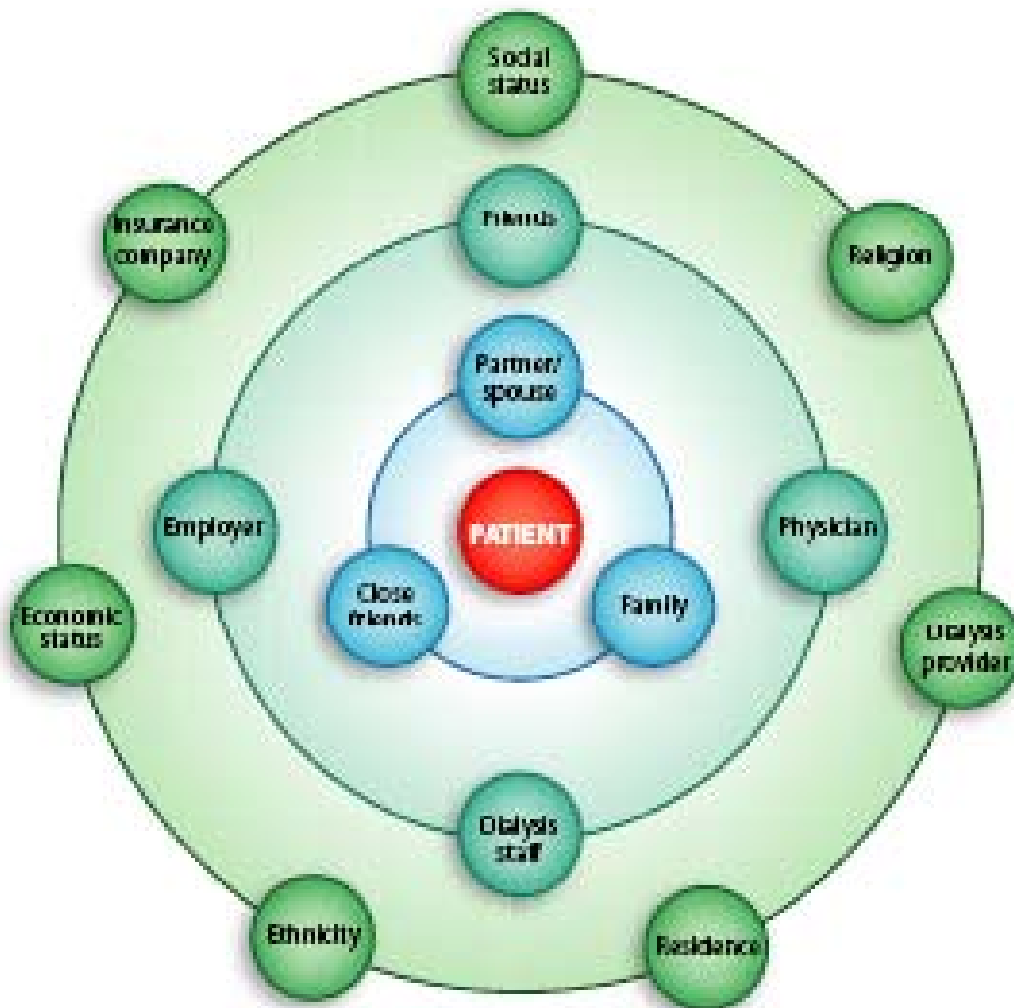


Figure 2. Psychosocial parameters: Spheres of influence.

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: 3043-3055, 2007

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
- Interventions on different levels
- Find best dialysis modality for patients
- Regular monitoring of distress, quality of life, self-perceived health and patient satisfaction
- Assess and provide support for caregivers (individual, family or grouptherapy)

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

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 lifesyle”, sun, exercise
- “5-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”

- Raise awareness of psychological and psychosocial factors in nephrology
- Learn lessons from psychooncology

Thank you
for your
attention!



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 ≥ 10	43%
			Physician	13,9%
Akman, Turkey	2004	27 Tx	BDI ≥ 11	22,2%
		30 VL		40%
		31 HD		61,3%
Araplasan, Turkey	2004	40 Tx	SCID-I	50%
Wuerth, USA	2005	380 PD	BDI ≥ 11	49%
Watnick, USA	2005	62 HD	BDI ≥ 16	19% major depr
Tyrrell, France	2005	51 HD (≥ 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 ≥ 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