



Survival is not enough – Psychosocial problems and quality of life in CKD patients

Istvan Mucsi

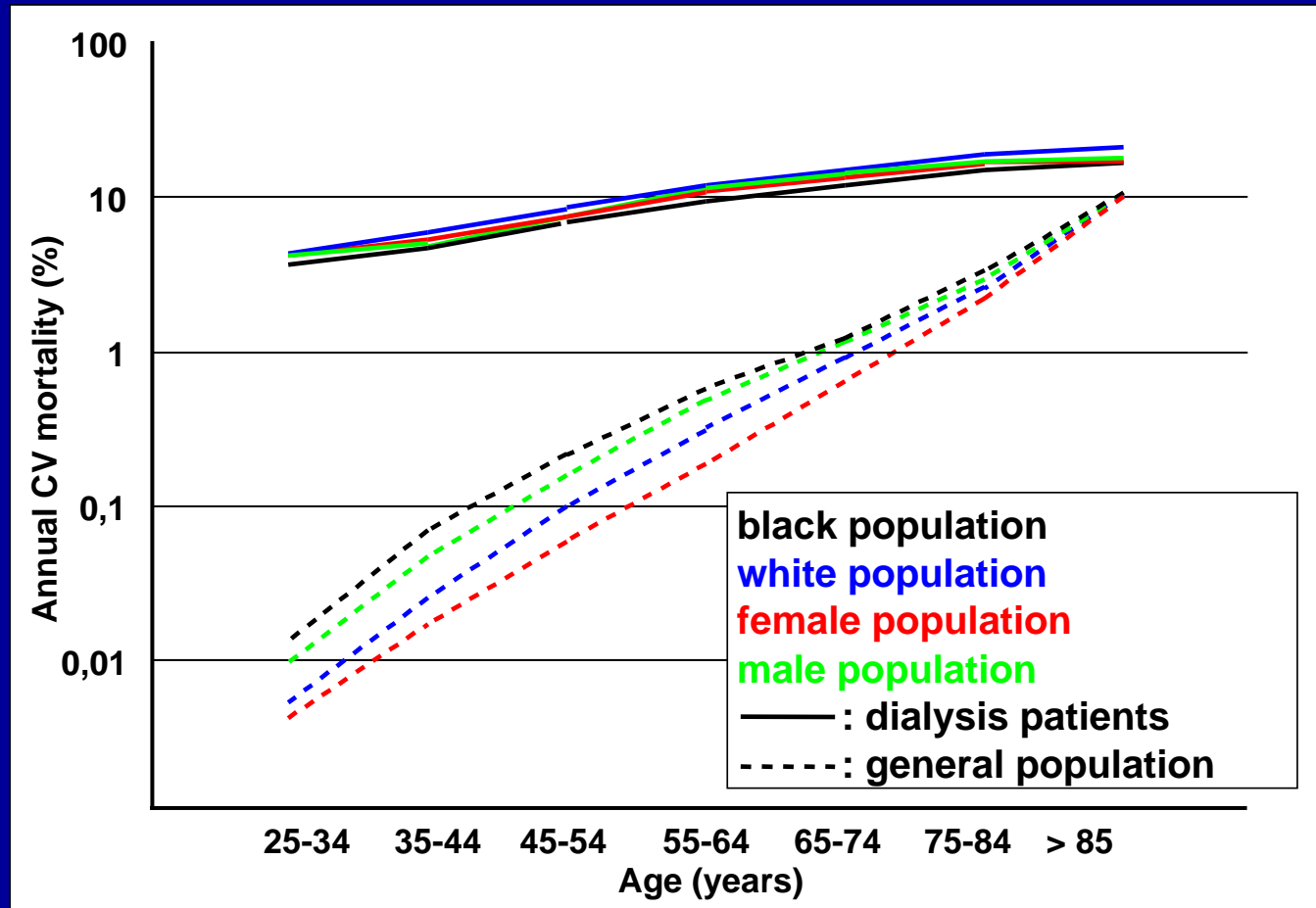
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- Psychosocial impact of a chronic, progressive, life threatening disease and its extremely intrusive treatment
- Crisis situations in the life cycle of the CKD patient
- Quality of life in CKD
- Selected psychosocial issues (aging, depression, social impact of CKD)
- What can be done?

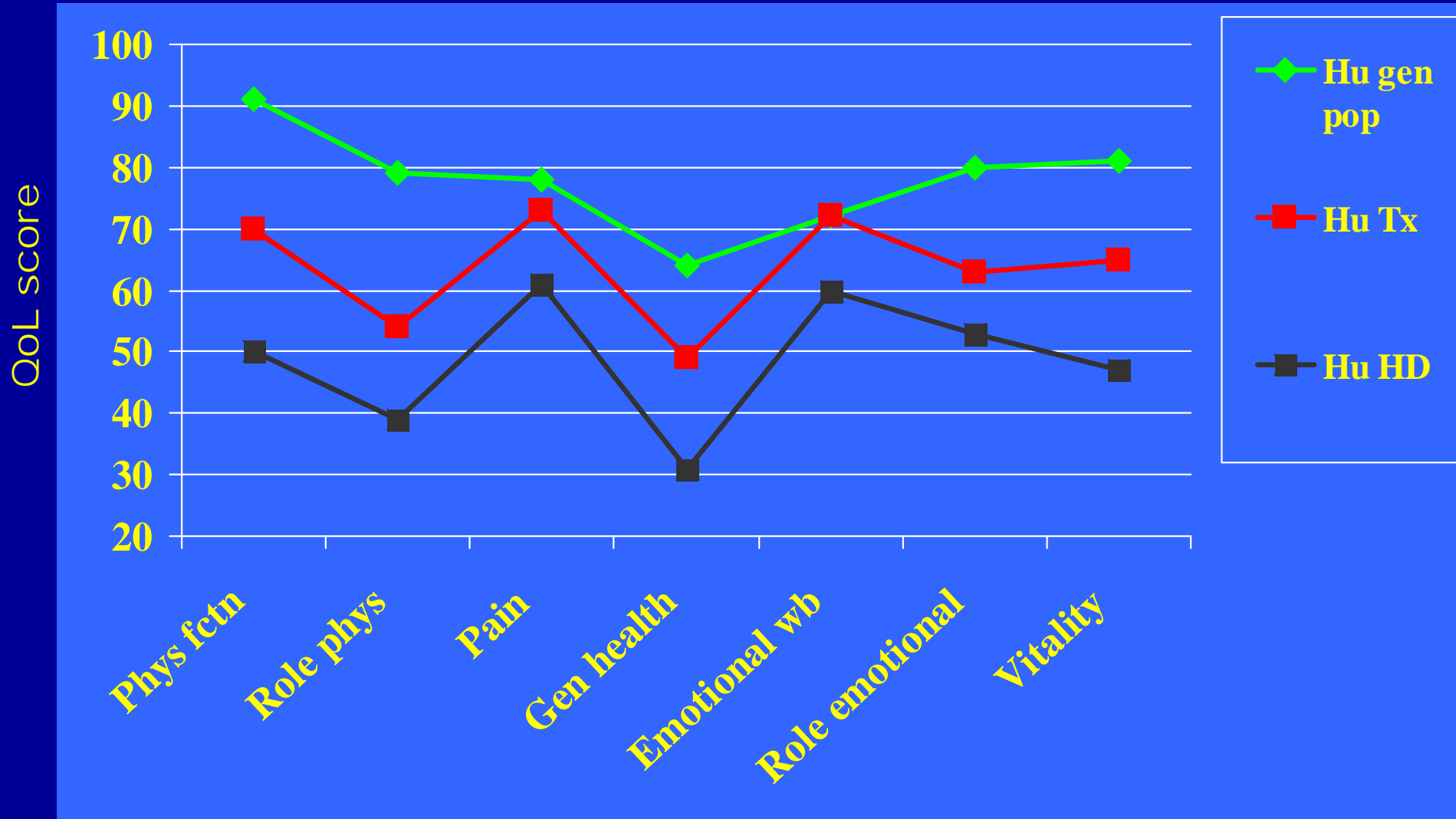
Chronic Kidney Disease:

a psycho-somatic disease with
significant renal involvement

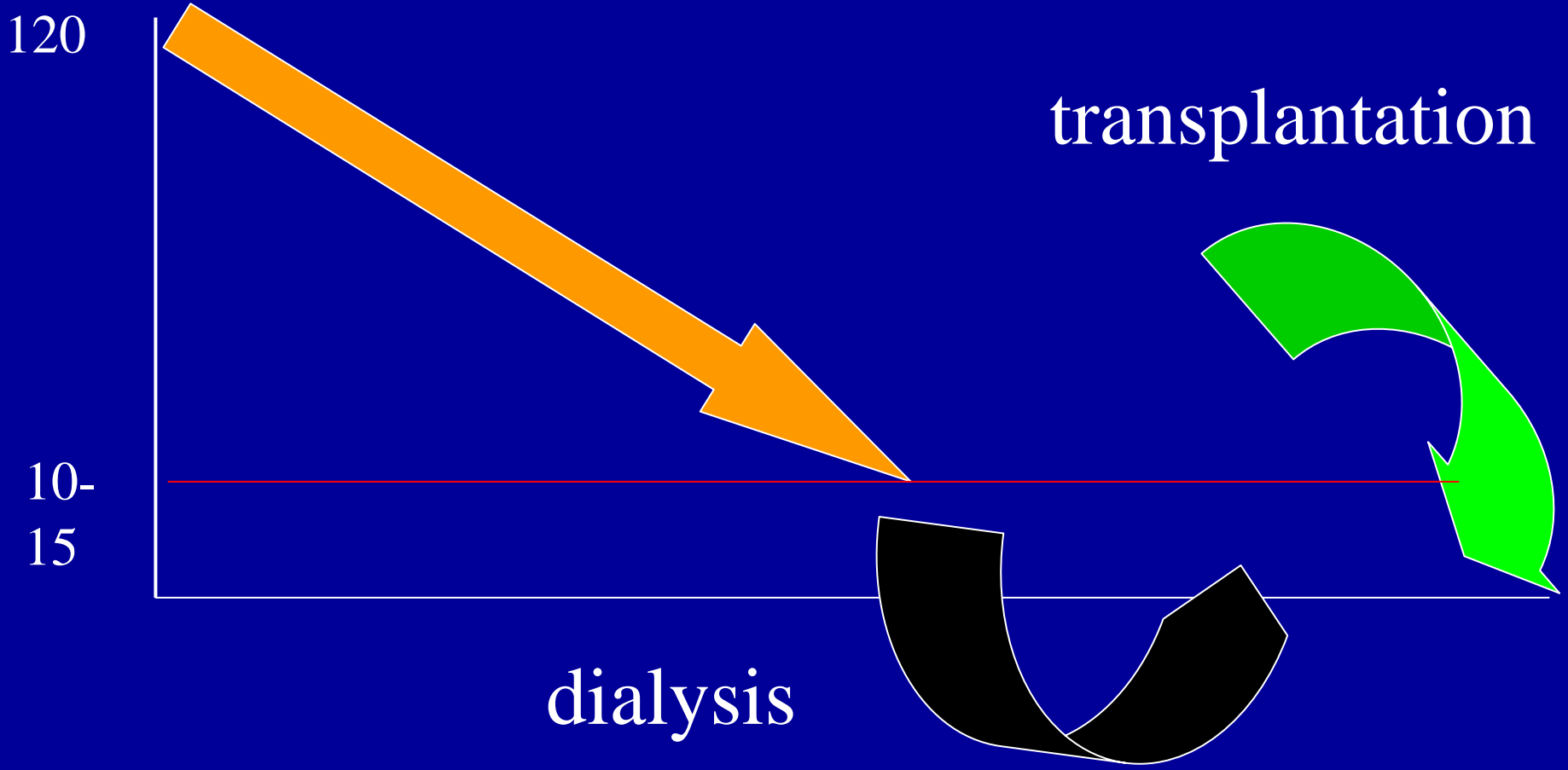
CV mortality in the general population and in dialysis patients



Quality of Life



GFR ml/min/1,73 m²



transplantation

dialysis

Potential times of crisis

- Diagnosis of renal disease
- Abrupt reductions in renal function - threat of dialysis
- Initiation of RRT - Modality selection
- Compliance with diet, fluid restrictions and dialysis

- Being on transplant waiting list
- Transplant surgery
- Rejections, graft failure- back to dialysis

Psychosocial challenges in chronic diseases

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

Psycho-social issues associated with CKD (Vourlekis BS et al,1997)

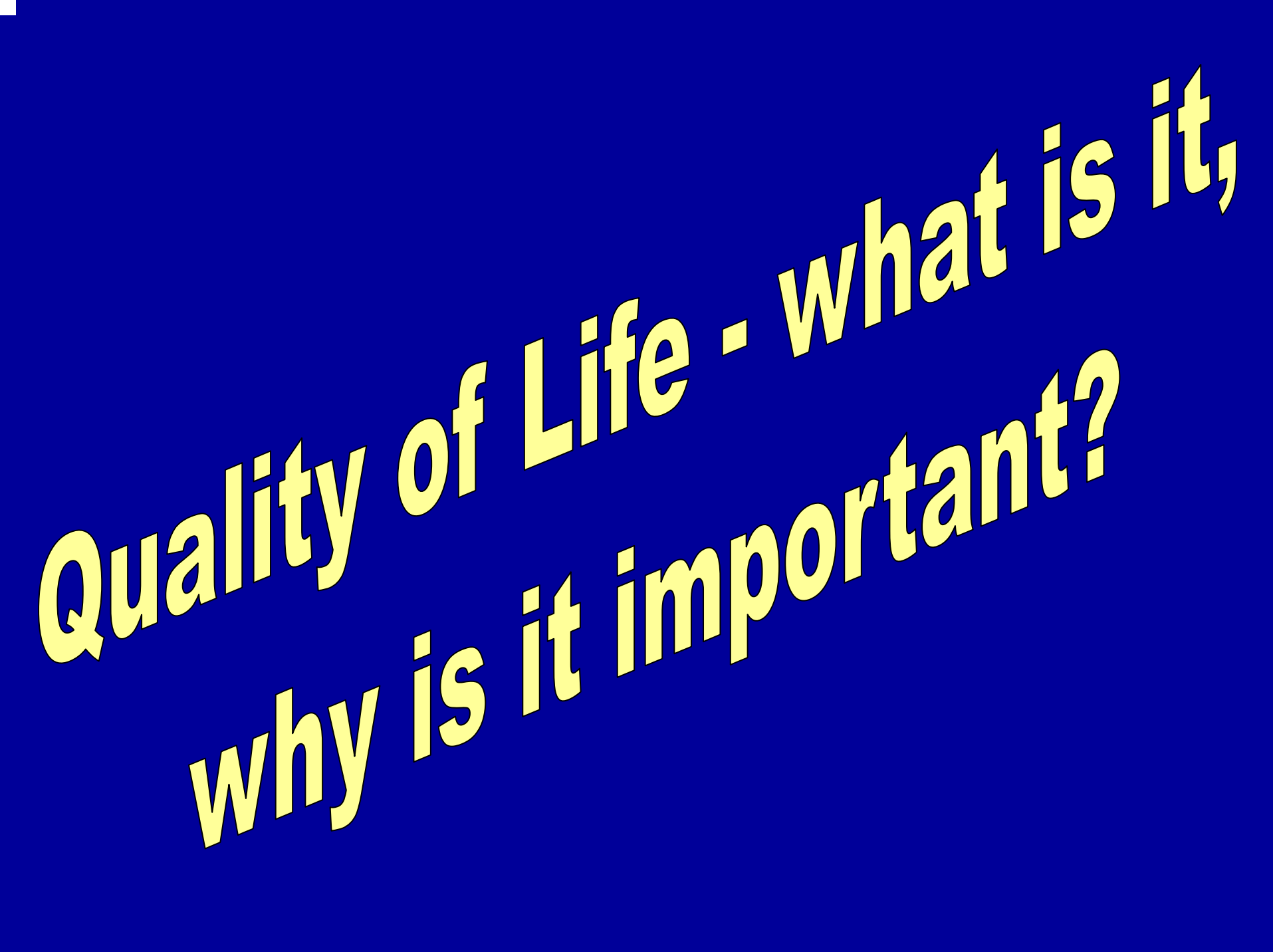
- Disease and treatment related problems
 - Uremic symptoms, complications, hospitalizations, dialysis access, timing of dialysis, modality, burn out, etc.....
- Financial difficulties, housing, transportation, recreation
 - Low income, social benefits, treatment related costs
- Family relations; coping of the family unit
- Social and cultural differences
 - traditional roles, religious beliefs, different health concepts, different attitudes to health care

Psycho-social issues associated with CKD (Vourlekis BS et al,1997) - 2

- Social relationships (peers, communities, health care workers)
- Emotional and behavioral problems (drug abuse, mood and personality disorders, sexuality, suicide)
- Education, vocational rehabilitation
- End of life issues

Transplantation – not a cure

- Recurrent crisis situations
 - listing, wait periode, surgery, intercurrent diseases, acute and chronic rejection, etc.
- Coping
- Immunosuppressive and other drugs
- Education, work
- Emotional problems



**Quality of Life - what is it,
why is it important?**

(Health Related) Quality of Life

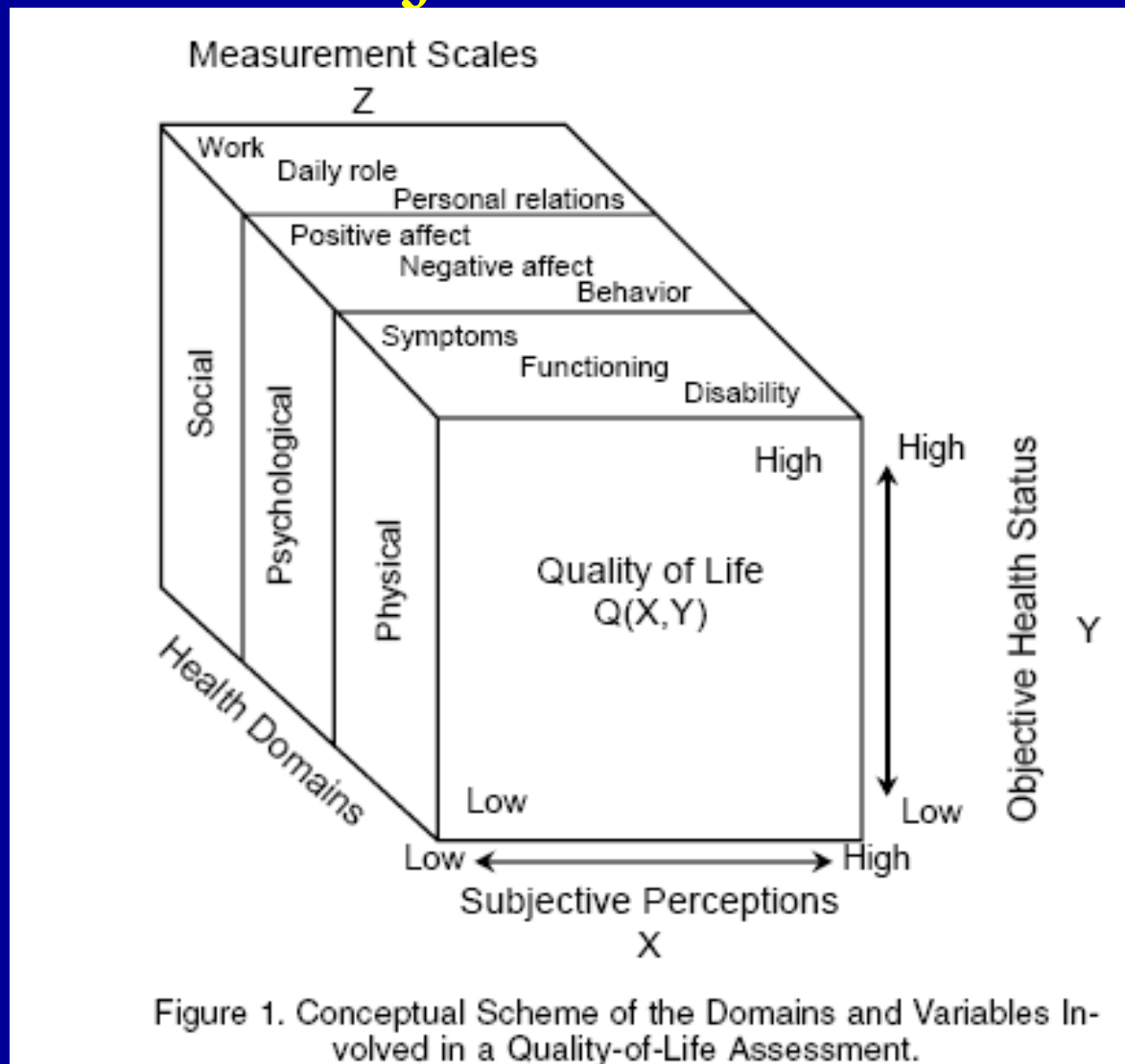
- Physical, psychological and social domain of health
- As influenced by a person`s beliefs, experiences and expectations.
- It is the **subjective** perception of ones own health and its effect on overall quality of life.
- In individuals with health problems HRQoL will be influenced by **disease** and **treatment** related factors (in adition to several others)

Health-related quality of life

HRQoL refers to a subset of quality of life endpoints related to the health of the patients.

<i>Physical/somatic</i>	<i>Psychological/mental</i>	<i>Social</i>
Functioning, stamina	Life satisfaction	Vocational rehabilitation
ADLs	Well-being	Recreation
Ability to work	Self esteem	Family and social relations
Pain, symptoms	Anxiety, stress, distress, depression	Sexuality

Subjective and objective elements of QoL



Types of QoL instruments

- Generic
 - Allows comparison of results with other populations patient groups population means etc. (e.g. SF-36)
- Specific
 - Additional information relevant to disease/condition and or intervention being studied.

QoL instruments used in CKD populations

- SF36
- Sickness Impact Profile
- Nottingham Health Profile
- Illness Intrusiveness Rating Scale
- KDQoL-SF
- RDQoL
- ESRD Symptom Checklist-Transplantation Module
- Kidney Transplant Questionnaire

KDQoL-SF36 questionnaire

(Hays et al., 1994)¹¹ - 79 items -

GENERAL DOMAINS

1. Physical functioning
2. Physical role
3. Pain
4. General health perceptions
5. Emotional role
6. Emotional well-being
7. Social function
8. Energy/fatigue

DISEASE SPECIF. DOMAINS

1. Symptoms/problems
2. Effects of kidney disease
3. Burden of kidney disease
4. Work status
5. Cognitive function
6. Quality of social interaction
7. Sexual function
8. Sleep
9. Social support
10. Dial./Tx staff encouragement
11. Patient satisfaction

Utilization of QoL data

- Evaluate quality, effectiveness of care (CQA/CQI)
- Improve clinical outcomes, facilitate rehabilitation
- Compare alternative treatments, cost effectiveness (QALY)
- Enhance patient satisfaction

**Factors associated
with QoL**

Factors – socio-demographic

- Age
- Gender
- Social status – education; work; financial status
- Beliefs/culture

Factors – clinical

- Underlying disease (DM, immune, etc)
- Comorbidity
- Renal function
- Anemia
- ESRD vintage
- Physical fitness
- Drug related
 - Cosmetic
 - Neurologic
 - Endocrine
 - Physical fctn
- Steroids
 - Bone
 - Psychological
 - Endocrine
 - sleep

Factors – Psychological/social

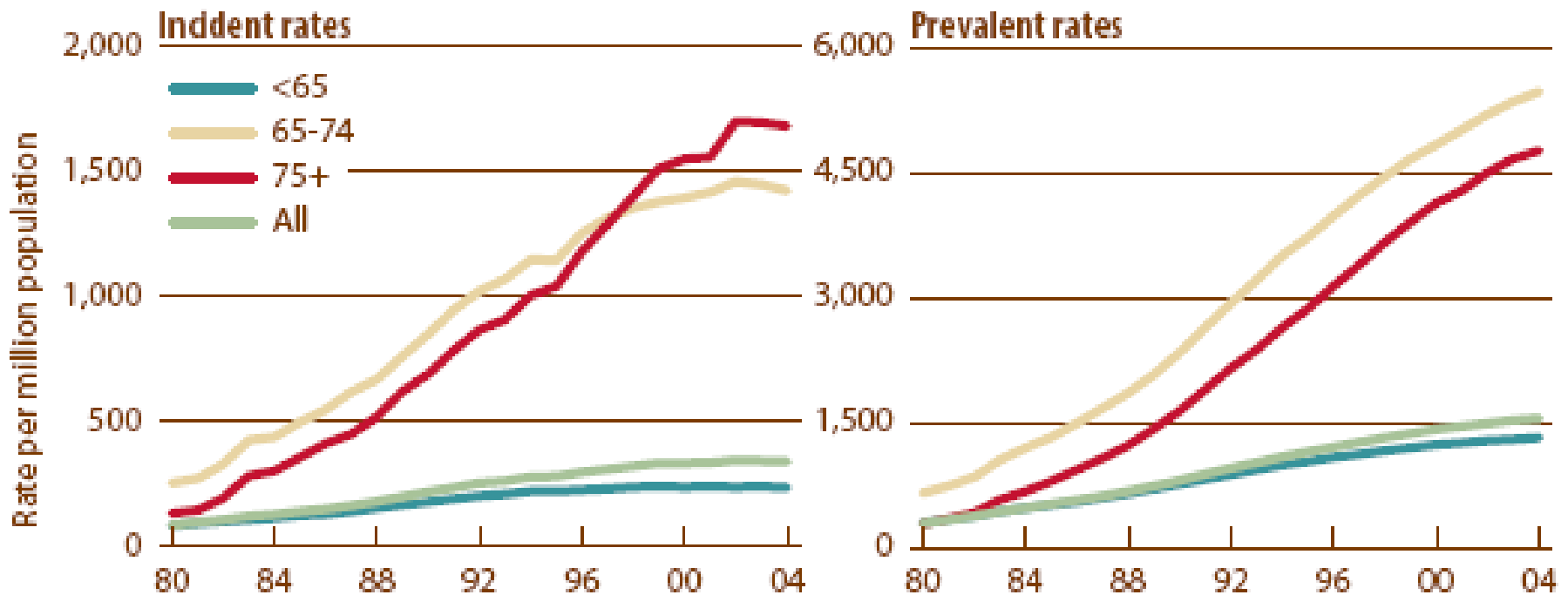
- Anxiety
- depression
- Distress
- Fear
- Control
- Grief
- Body image
- Personality –
premorbid
- Family relations
- Sexuality
- Pregnancy
- Social support
- Work
- Education

Agiling

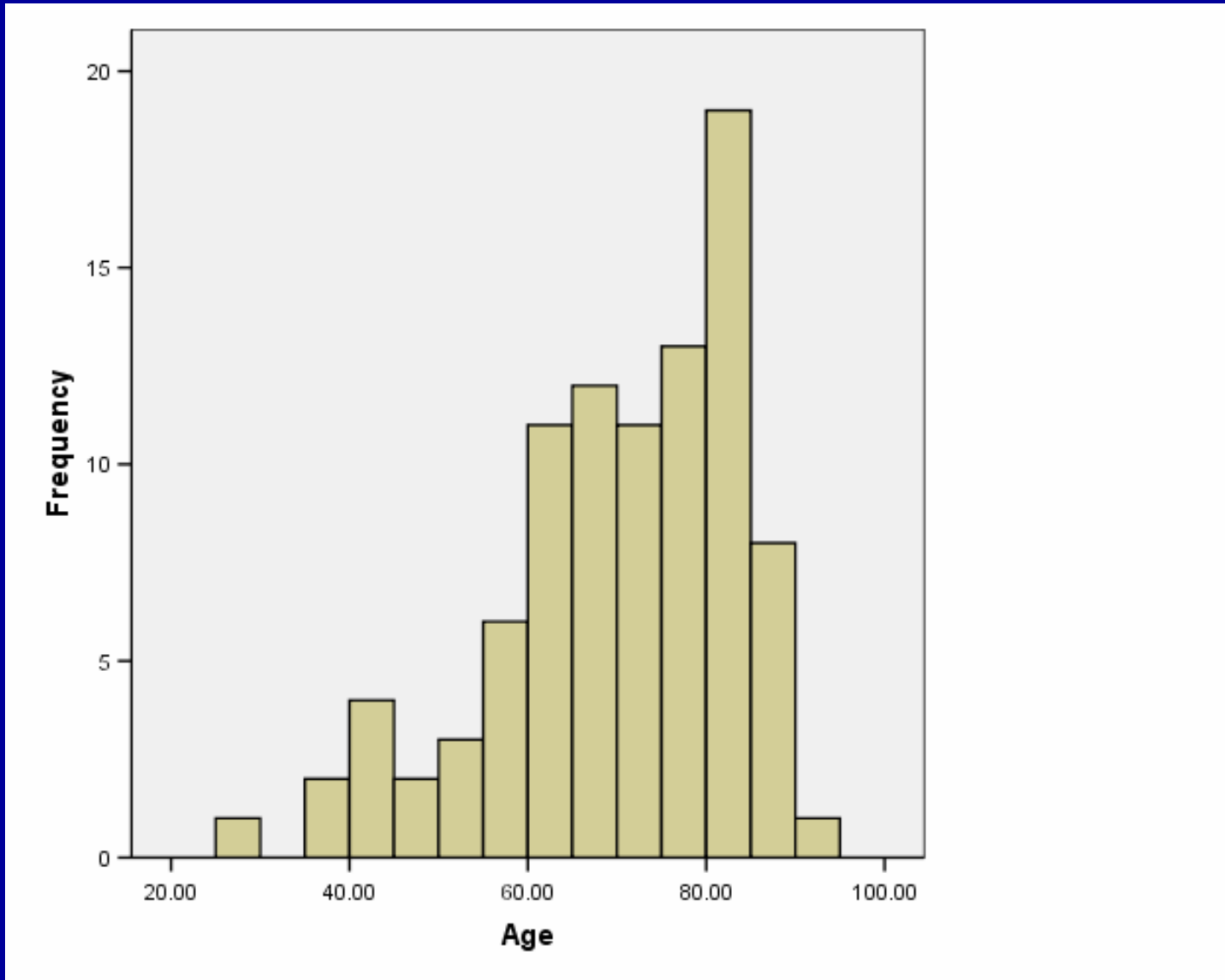
Age and CKD - 1

2.34

Incident & prevalent rates, by age incident & December 31 point prevalent ESRD patients

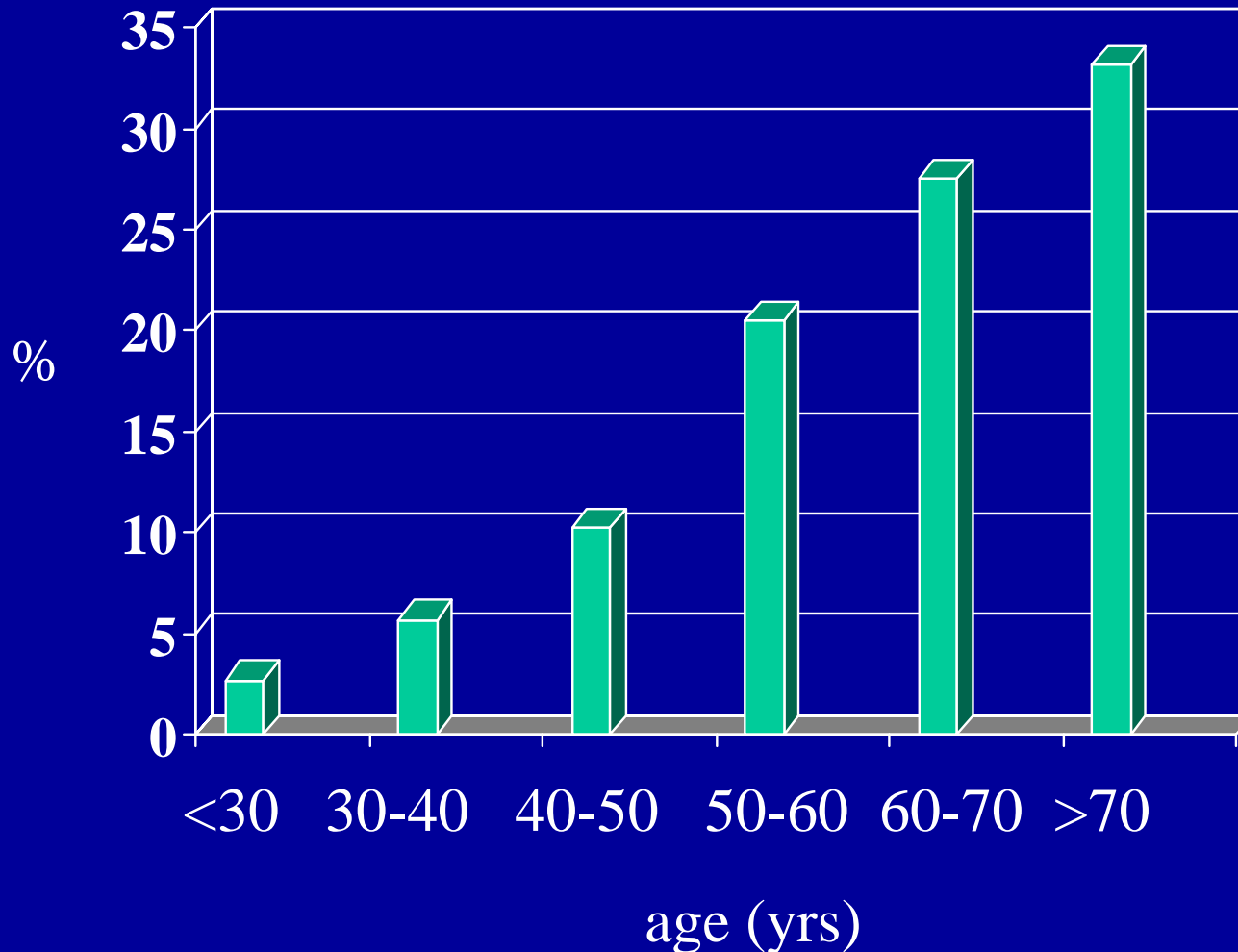


Age and CKD - 2



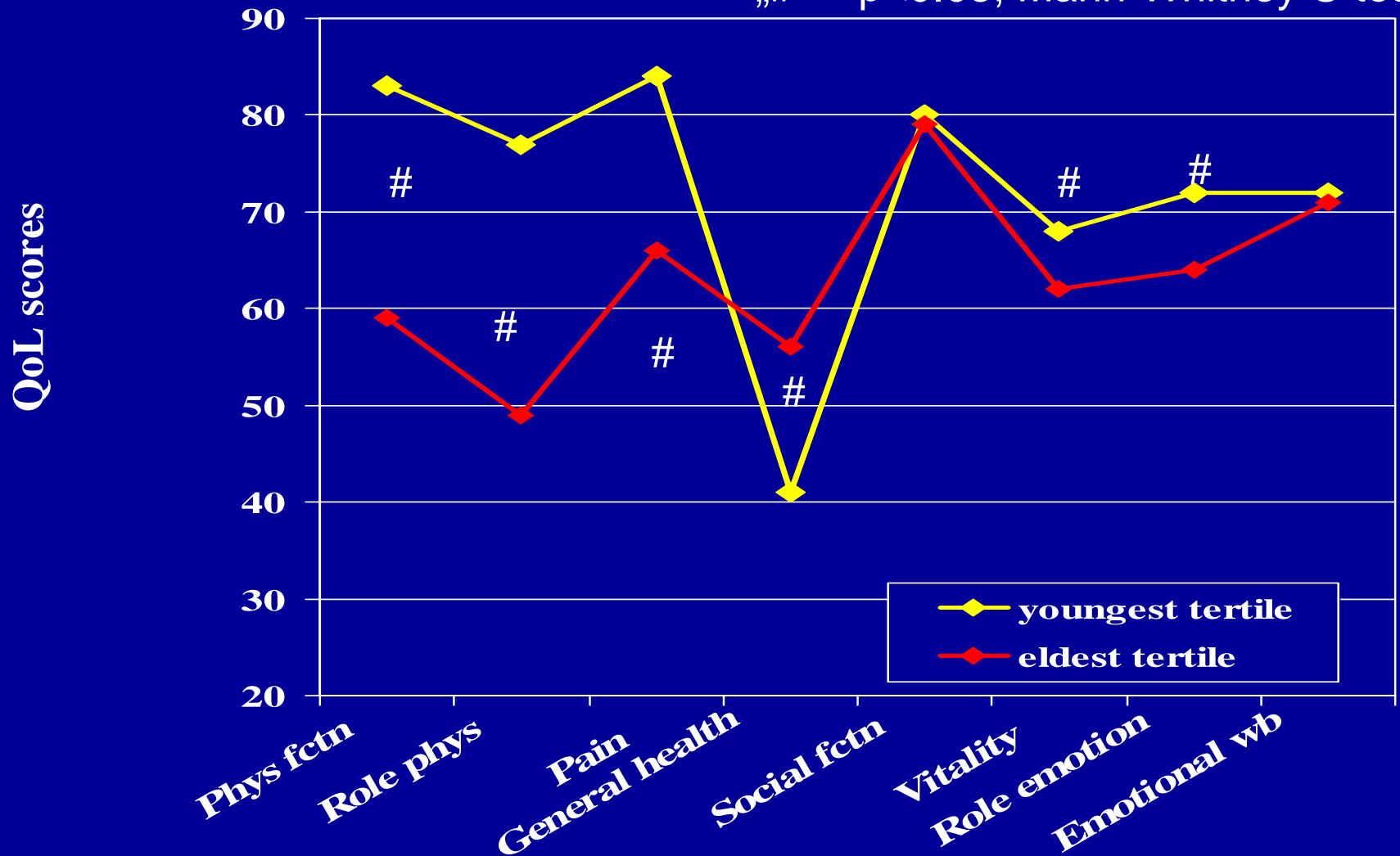
Pre-dialysis patients (CKD 3-5) – HRRH 2004

Age distribution of the Hungarian dialysis population



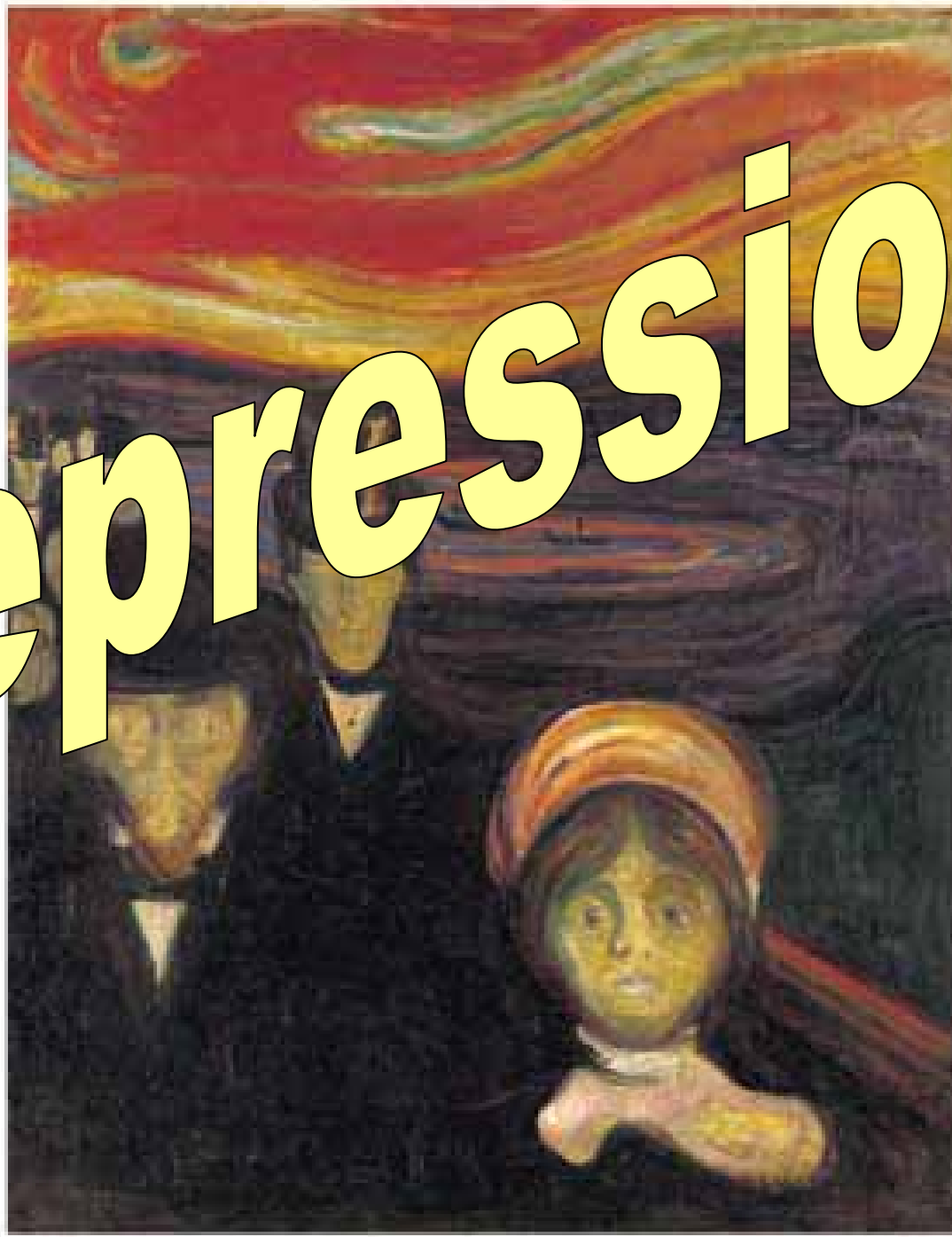
Age versus SF-36 scores in TX population

„#” = $p < 0.05$, Mann-Whitney U test



- **Mr. A.B. 84 male. DM, R AKA, CAD, AMI**
 - Started HD via AV fistula in 2004
 - Mild-moderate dementia at the start – progressed quickly on RRT
 - Now completely demented, bed ridden, lives in nursing home, dialysed via IJ line
- **Mr. S. K., 83 male. DM, osteoarthritis, TIAs, CAD, CHF, moderate-severe dementia**
 - Unable to sit thorough 4 hrs HD, unwilling to come for daily short HD
 - Ongoing MSK pain – requiring major pain meds
 - Repeated hospit. for intermittent confusion – now permanent
 - CCK survivor, unwilling to ccept „institutionalization”
- **Mrs. Z.A., 78 female. DM, HTN, PVD, CAD, AMI, TB, severe ROD – pain**
 - Constant, severe bone pain + pain from PVD, gangrene
 - Severe anorexia, malnutrition
 - Bed-ridden, intermittent confusion

Depression



Psychiatric disturbances in CKD patients

- Neuropsych. disturbances, cognitive problems
- Delirium
- Dementia
- Anxiety, PTSD?
- Sleep disorders
- **Depression - Subclinical depression**
- Suicide

Types of depression

- Major depression
- Minor – subclinical
- Chr depression –dysthymia

- Adjustment disorder – with depressed mood
- Depression often co-occurs with anxiety
- Depression and chr 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
- Decreased interest or pleasure ◇
- Psychomotor retardation or agitation
- Fatigue or loss of energy
- Diminished ability to think or concentrate
- Recurrent thoughts of death or suicide or suicide attempt

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

◇ One of these symptoms must be present

Depression in CKD

- The most frequent psychological problem (15-60%)
- Need to distinguish distress/depressed affect and „well-being” – positive affect
- Natural psychological reaction?
- Overlap between the symptoms of CKD and depression (fatigue, sleep, appetite).
- Prevalence in ESRD (Craven et al. 1987):
 - Depressive symptoms: 25-50 %
 - Major depression: 8-22 %

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 end-stage renal disease (ESRD)

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

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

Validated instruments? (Hedayati et al,2006)

Is one question enough?

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:

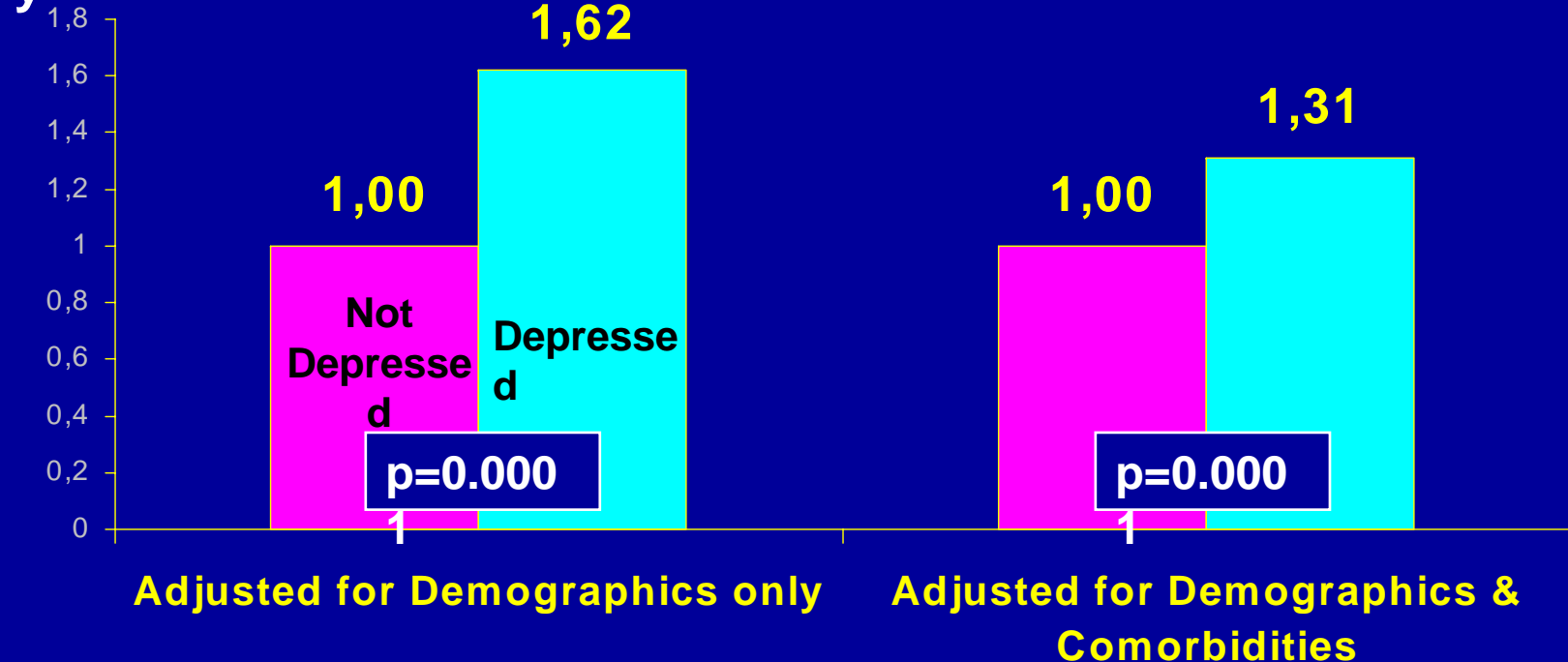
34.9% in patients with physician-diagnosed depr.

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

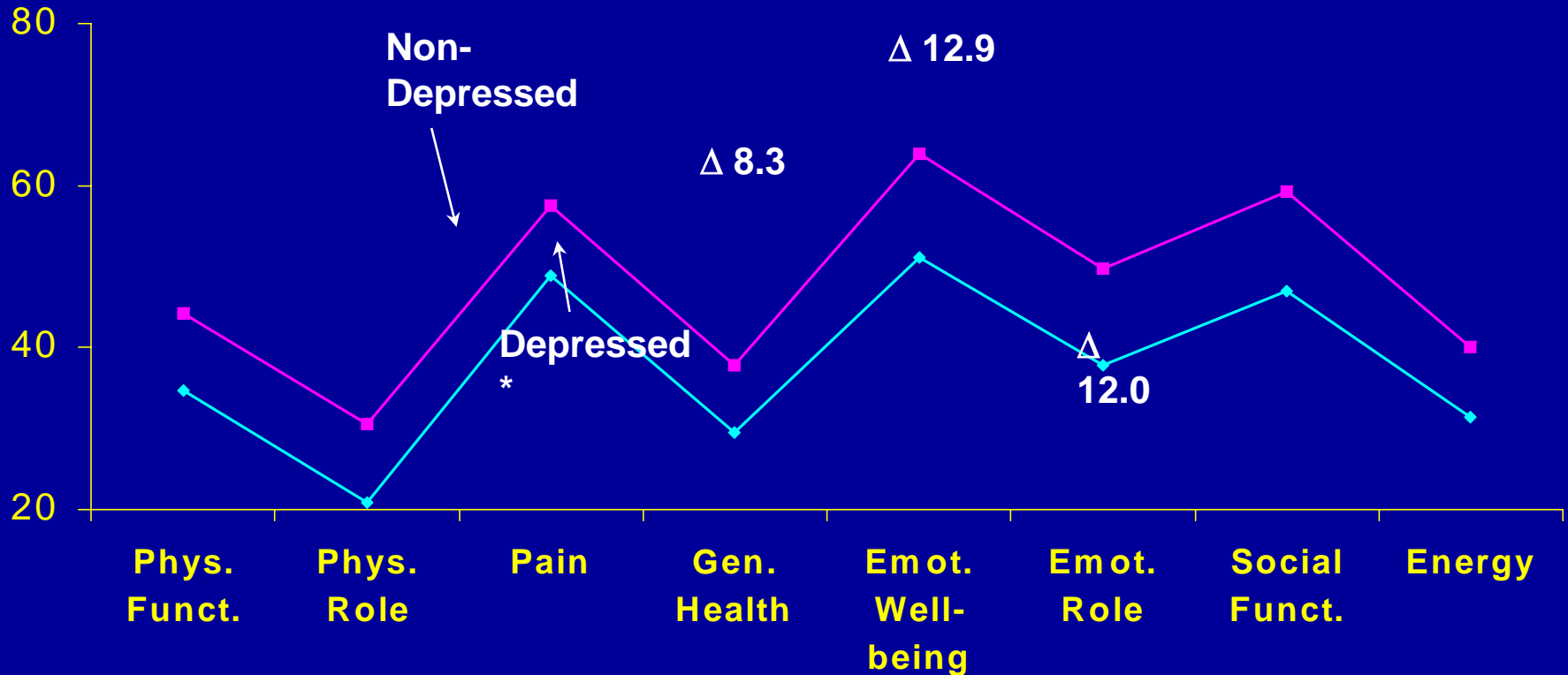
Depression was associated with female gender, lower educational status, unemployment status, some comorbid conditions

Depression and mortality in HD pts (DOPPS)

RR
Mortality



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

Data from our recent studies I.

Psychosocial survey in Hungary (3500 dialysis pts)

46 % reported symptoms of depression

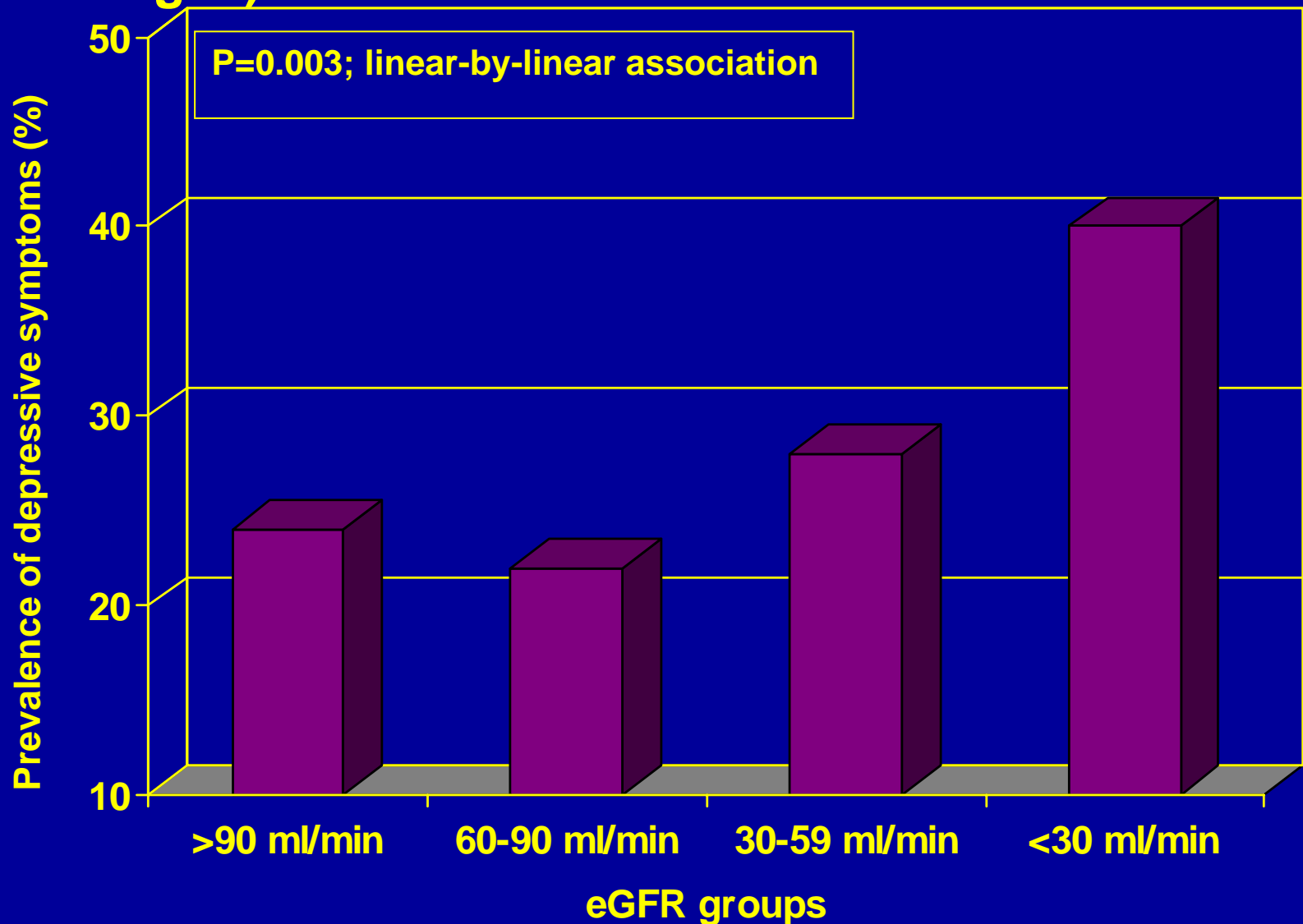
One third would like to get help

Depressive symptoms: women, low education, older age, bad financial situation

Data from our recent studies II.

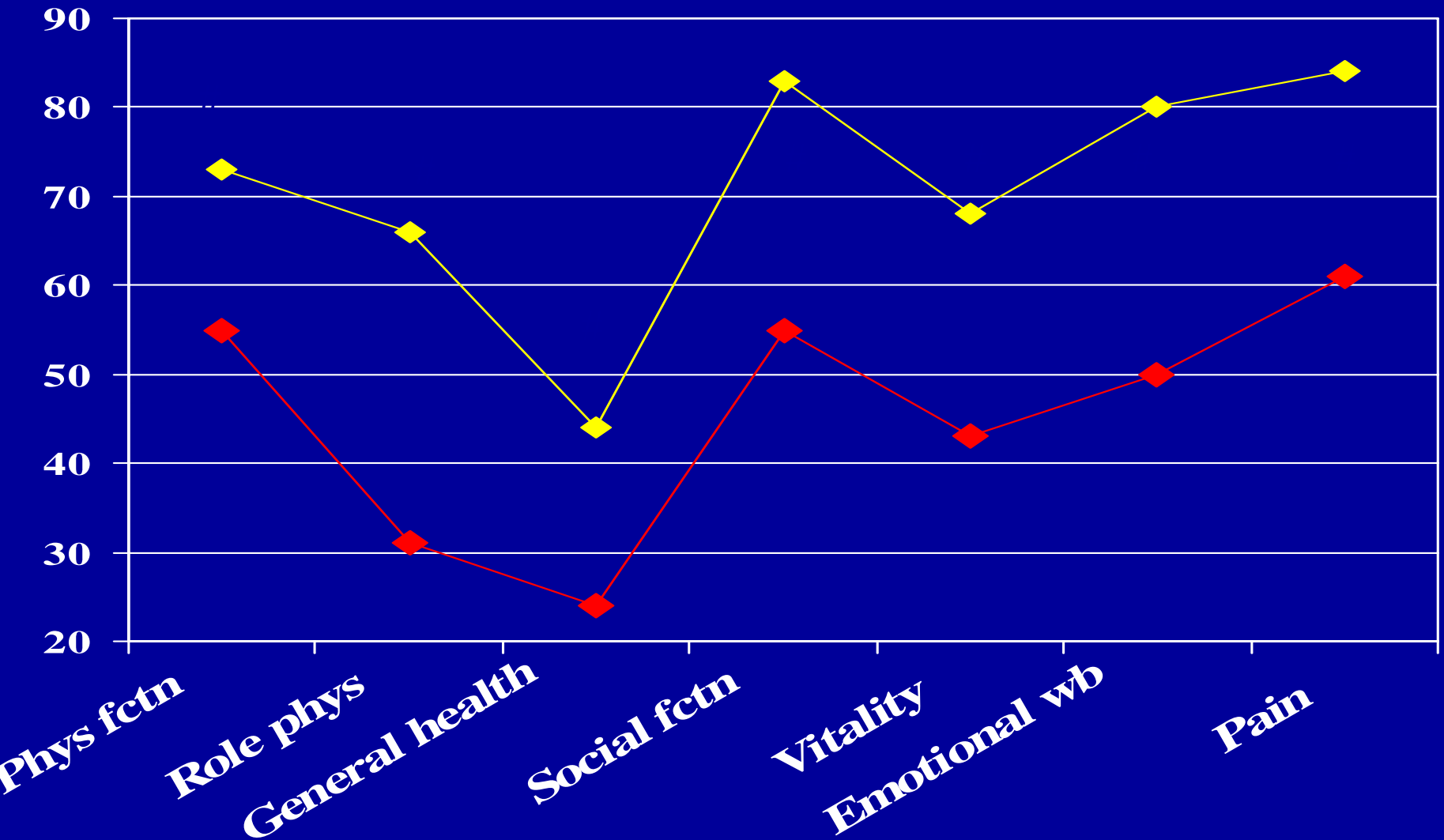
- Dialysis patients – 40-45%
- Transplant patients 24%
- Predialysis population – 44% (Humber River Hosp. data and Hungarian data)

Association between the prevalence of depressive symptoms and groups formed by eGFR (corresponding to chronic renal disease stages)

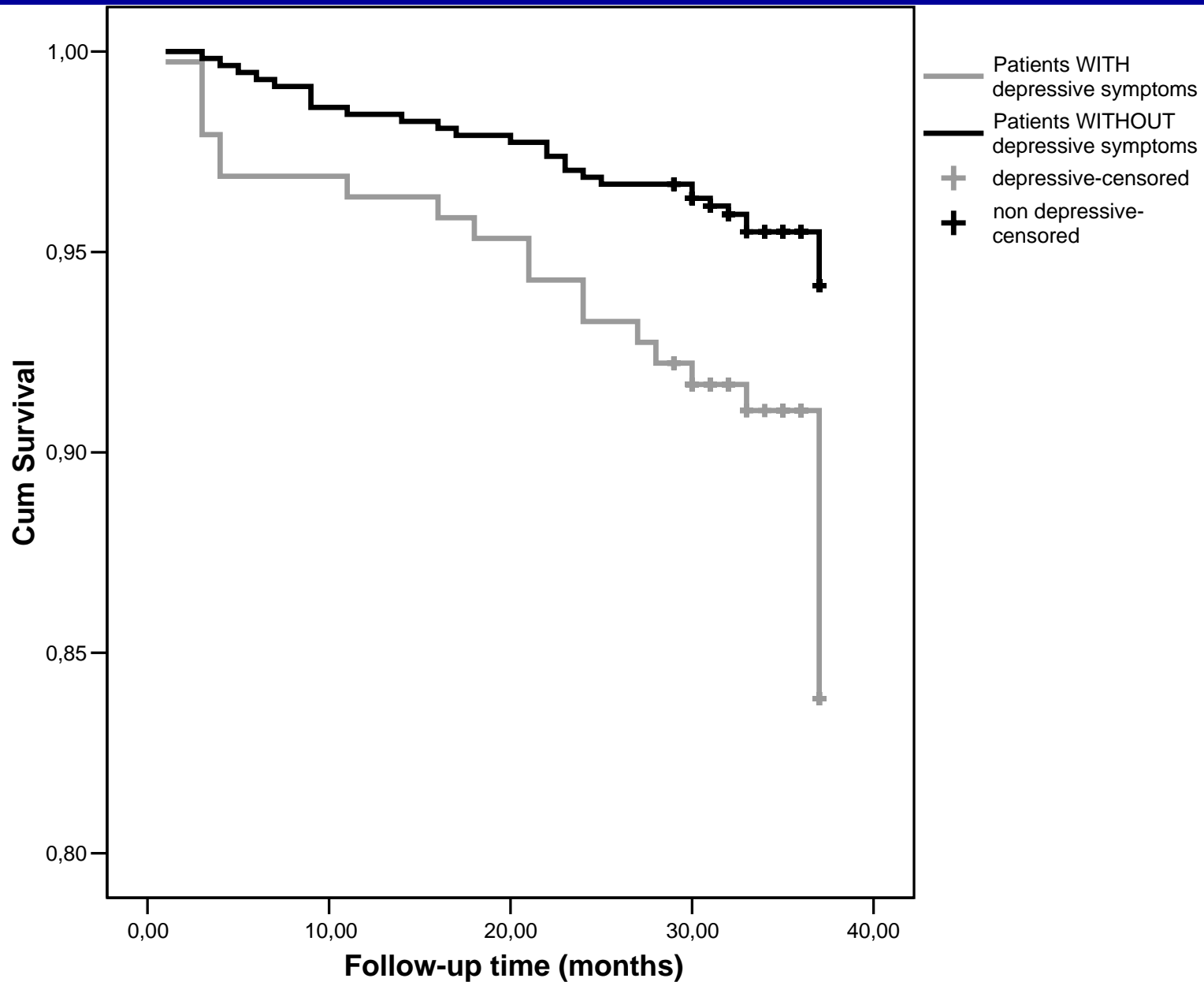


Depression and general HRQOL domains

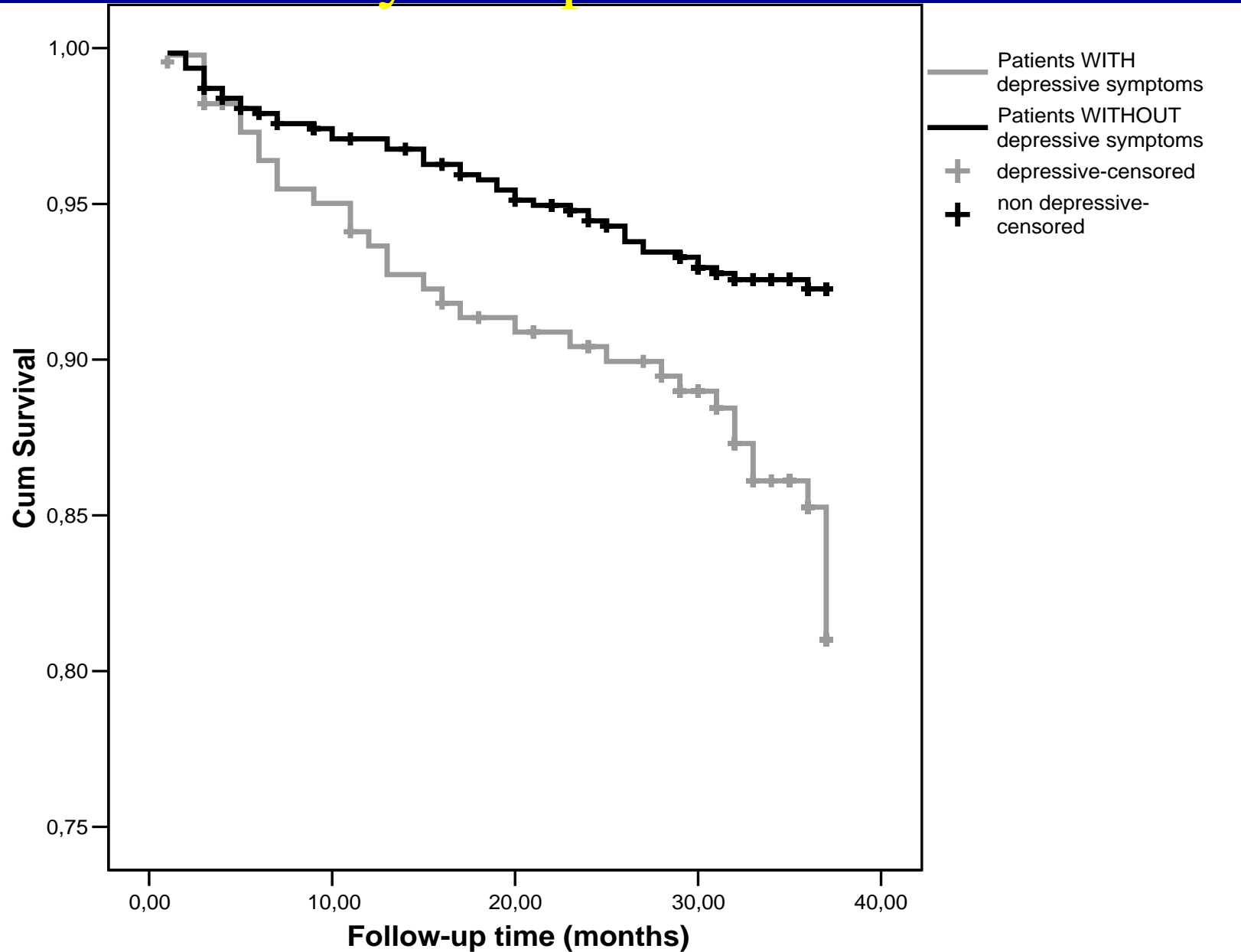
—◆— High risk for depression —◆— Low risk for depression



Return to dialysis - Kaplan-Meier curve



Mortality - Kaplan-Meier curve



Depression - Treatment considerations

- Only few studies – RCTs needed
- Pharmacotherapy
- Psychotherapy: individual, marital, group
- Flexible therapy options: during dialysis, over the phone?
- CBT, IPT, psychodynamic psychotherapy
- Crisis therapy?
- Other psychological and psychosocial interventions:
 - Behavioral interventions
 - Stress reduction
 - Communication skills



Treatment adherence

- Adherence is crucial (risk of rejection and death)
- Bi-directional association between adherence and QoL
- Prevalence of non-adherence is estimated about 20-50%
- Non-adherence may play a role in 1/3 or more of rejection episodes
- Medication related (dosing, side effects) and patient related (depression, anxiety, social factors, personality) both influence adherence

Vocational rehabilitation, education

- Vocational rehabilitation is insufficient world wide
- In Hungary cca 75% of the kidney transplanted patients and more than 90% of the dialysis patients are on disability benefit
- Work status is an important predictor of QoL
- In some studies appropriate level of education is reported for children and young adults after Tx
- In Hungary many children have problems with schooling – in part because of pathologies in the family unit



What can we do?

Chronic renal failure:

a psycho-somatic disease with
significant renal involvement

Paradoxes of modern nephrology (medicine)...

- Patient care is increasingly centred around **biological/molecular and technological issues** – at the same time the overall **psycho-social burden** of chronic diseases is increasing very rapidly
- Some of these problems are related to the disease, others to the therapies (this is especially true for nephrology/dialysis)
- Patients with chronic conditions would need strong **social support and solidarity** – in the era of global alienation, isolation, social-economical polarization
- Need for a holistic approach *vs* increasing financial pressure

A bio-psycho-social approach is needed...

- Psycho-social problems arising from chronic diseases affect both the patients and their social environment , as well
- Successful management of these problems will have an impact on the success of medical therapies

Treatment effectiveness and QoL

Age, gender
Social status
Social support
Depression
Comorbidity
Etc.

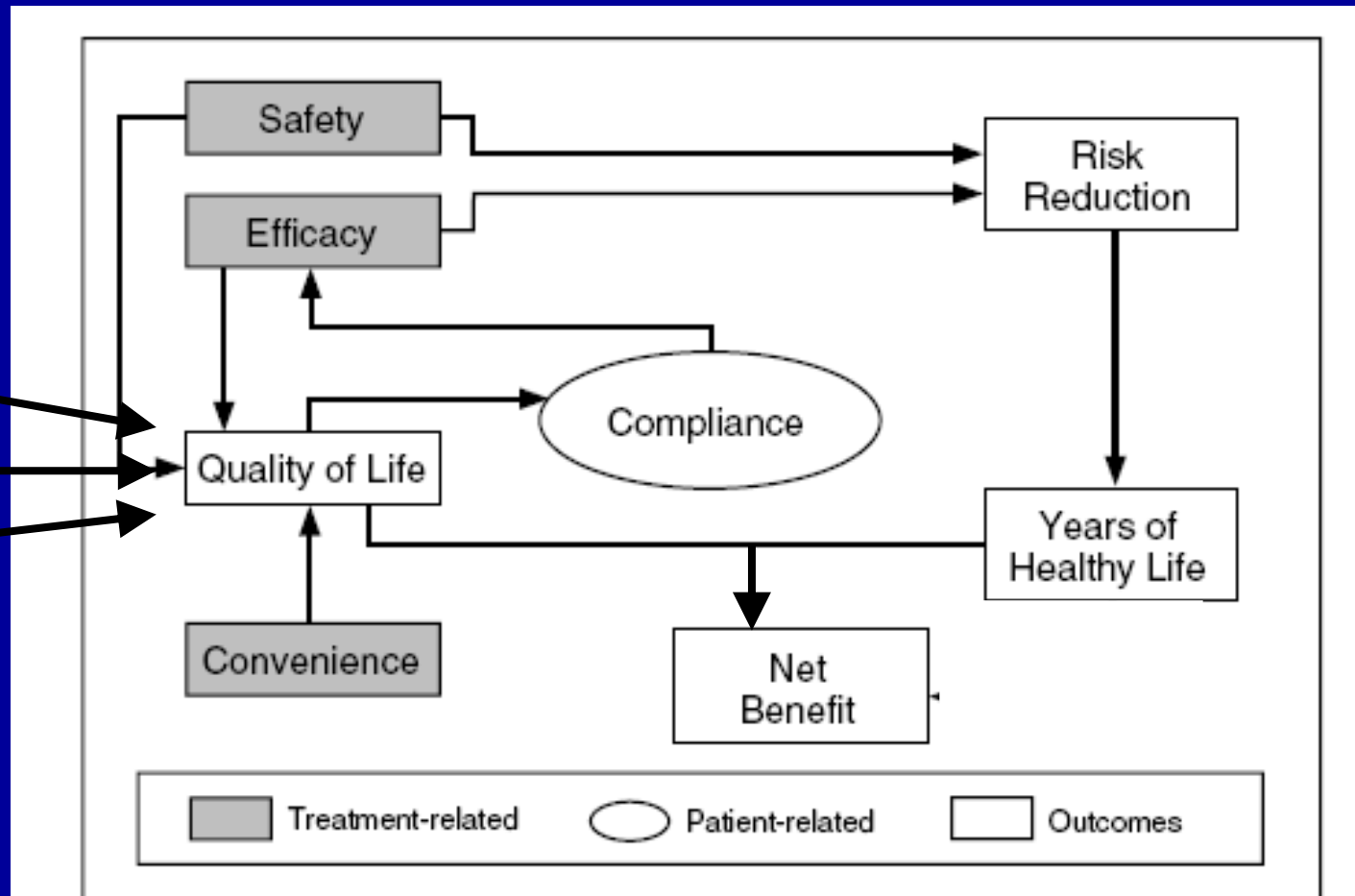


Figure 3. The Role of Quality of Life in Determining the Net Benefit of Therapy for a Chronic Disease.

What can be done?

- Complex rehabilitation program – multidisciplinary interventions
 - Should start from diagnosis of CKD - have to involve patient and significant others
 - „5 E“:
 - Encouragement
 - patient Education
 - Exercise
 - Education/Employment
 - Evaluation

Querfeld et al.: CRF vs DM pts, similar academic achievement and employment rate, however, lower rank jobs, more living alone or with parents

What can be done?

- Targeted interventions – identify high risk patients, modifiable factors
- Identify high risk situations (crisis intervention)
 - diagnosis
 - intercurrent illness
 - Rejection
 - Burn out (in patient, in family)

What can be done?

- Multidisciplinary team
- Complex psychosocial programs for patient and caregivers
- Regular monitoring of depression and QoL



Thank you for your attention!