REHABILITATION AND SOCIAL ASPECTS IN HOLISTIC APPROACH OF CKD PATIENTS

20TH BUDAPEST NEPHROLOGY SCHOOL
ÁGNES HARIS, KÁLMÁN POLNER
HOW MUCH TROUBLE A CHRONIC DISEASE CAN CAUSE TO A PATIENT?

• **53 years old female**, working as computer scientist, living with her husband and 2 children, in excellent financial situation
• Diagnosed with renal failure in 2010
• Started CAPD in 2 months
• Due to her poor condition, unable to work, got unemployed
“MAJOR DISASTER FOR THE PATIENT AND HER FAMILY”

- Several hospitalizations:
  - anemia, necessitates blood transfusion repeatedly,
  - high blood pressure complicated with neurological abnormality (aphasia),
  - MRSA infection, -CAPD peritonitis repeatedly,
  - having no appetite, weight loss, pleural effusion
- 2012. Had to transfer to HD
  - needs regular transportation because of weakness
  - severe protein-energy malnutrition, anorexic
- Her husband – earlier attentive, helpful - decides to divorce, children live separately,
- No financial income, extremely depressed, poor QoL
THE MOST IMPORTANT FACTORS FOR DIALYSIS PATIENTS

• Length of life and Quality of life

However,
• even advanced dialysis technic fails to improve outcome further nowadays

What else can we do for them?
THE 2012 BUDAPEST DECLARATION OF THE IFKF

• „.....employ a holistic approach for the treatment of patients living with chronic kidney disease, recognizing all their bio-psycho-socio-spiritual and somatic needs.”

• „.....focusing on the whole person and individual care to ensure better efficacy in the prevention, treatment and rehabilitation.”
HOLISTIC APPROACH TO OUR PATIENTS WITH KIDNEY DISEASES

• **Multidisciplinary care**
  The team: nephrologist, nurse educator, social worker, dietician, pharmacist, psychologist
  Medical care + education: Improving compliance, more effective dietary and lifestyle prescriptions, adherence to medications, optimal RRT modality selection

• **Physical activity**

• **Psychosocial care**
  - Patients and their family members/caregivers - psychosocial requirements

  ⇒

  • Decreasing burden of the disease
  Reducing progression – dialysis can be delayed

• **Morbidity and mortality ↓**  **Quality of life ↑**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample (n = 3,563)</th>
<th>Women (n = 1,696)</th>
<th>Men (n = 1,858)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years (mean ± SD)</td>
<td>62 ± 14</td>
<td>64 ± 14</td>
<td>60 ± 14</td>
<td>&lt; 0.001</td>
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<tr>
<td>Level of education (%)</td>
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<td>≤ 8 y</td>
<td>43.5</td>
<td>57.8</td>
<td>30.3</td>
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<td>8 – 12 y</td>
<td>45.4</td>
<td>34.8</td>
<td>55.0</td>
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<td>&gt; 12 y</td>
<td>11.1</td>
<td>7.3</td>
<td>14.6</td>
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<tr>
<td>Marital status (%)</td>
<td></td>
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<td>&lt; 0.001</td>
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<tr>
<td>Married or common-law</td>
<td>56.9</td>
<td>43.1</td>
<td>69.4</td>
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<tr>
<td>Living status (%)</td>
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<tr>
<td>Alone</td>
<td>18.0</td>
<td>24.3</td>
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<td>With family</td>
<td>79.2</td>
<td>72.4</td>
<td>85.3</td>
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<td>In institution</td>
<td>2.8</td>
<td>3.3</td>
<td>2.4</td>
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<td>Self-reported financial situation (%)</td>
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<td>Good</td>
<td>39.4</td>
<td>36.8</td>
<td>41.8</td>
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<tr>
<td>Fair</td>
<td>40.1</td>
<td>42.3</td>
<td>38.2</td>
<td></td>
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<tr>
<td>Poor</td>
<td>20.4</td>
<td>20.9</td>
<td>20.0</td>
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<tr>
<td>Occupation (%)</td>
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<td></td>
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<td>0.04</td>
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<tr>
<td>Full-time employed</td>
<td>2.8</td>
<td>1.5</td>
<td>3.9</td>
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<tr>
<td>Part-time employed</td>
<td>3.1</td>
<td>1.4</td>
<td>4.6</td>
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<tr>
<td>Homemaker</td>
<td>1.2</td>
<td>2.1</td>
<td>0.3</td>
<td></td>
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<tr>
<td>Retired</td>
<td>46.3</td>
<td>53.2</td>
<td>40.0</td>
<td></td>
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<tr>
<td>Disability pension</td>
<td>46.1</td>
<td>41.5</td>
<td>50.4</td>
<td></td>
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<tr>
<td>Unemployed</td>
<td>0.5</td>
<td>0.3</td>
<td>0.8</td>
<td></td>
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<tr>
<td>Occupation &lt; 65 y (%)</td>
<td></td>
<td></td>
<td></td>
<td>0.001</td>
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<tr>
<td>Full-time employed</td>
<td>5.0</td>
<td>3.1</td>
<td>6.3</td>
<td></td>
</tr>
<tr>
<td>Part-time employed</td>
<td>5.4</td>
<td>3.1</td>
<td>7.2</td>
<td></td>
</tr>
<tr>
<td>Homemaker</td>
<td>1.4</td>
<td>2.8</td>
<td>0.4</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>14.0</td>
<td>17.0</td>
<td>11.8</td>
<td></td>
</tr>
<tr>
<td>Disability pension</td>
<td>73.3</td>
<td>73.6</td>
<td>73.0</td>
<td></td>
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<tr>
<td>Unemployed</td>
<td>0.9</td>
<td>0.4</td>
<td>1.2</td>
<td></td>
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RESULTS FROM THE HUNGARIAN SURVEY OF PSYCHOSOCIAL CHARACTERISTIC AND SELF-REPORTED FUNCTIONAL STATUS

<table>
<thead>
<tr>
<th>Comorbidities (presence, %)</th>
<th>30.2</th>
<th>30.7</th>
<th>29.8</th>
<th>NS</th>
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</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Acute myocardial infarction</td>
<td>19.0</td>
<td>16.1</td>
<td>21.7</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>18.8</td>
<td>19.3</td>
<td>18.4</td>
<td>NS</td>
</tr>
<tr>
<td>Limb amputation</td>
<td>8.4</td>
<td>5.9</td>
<td>10.7</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Limitations in everyday activities (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking without help</td>
<td>58.4</td>
<td>65.3</td>
<td>52.1</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Climbing stairs</td>
<td>68.4</td>
<td>75.0</td>
<td>62.4</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Bathing/clothing without help</td>
<td>43.9</td>
<td>51.0</td>
<td>37.3</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Functional impairments (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td>44.1</td>
<td>48.7</td>
<td>39.9</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Visual</td>
<td>43.8</td>
<td>49.4</td>
<td>38.8</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Auditory</td>
<td>17.2</td>
<td>17.2</td>
<td>17.2</td>
<td>NS</td>
</tr>
<tr>
<td>Total time on dialysis, months</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>median (interquartiles range, IQR)</td>
<td>30 (46)</td>
<td>32 (50)</td>
<td>28 (42)</td>
<td>0.003</td>
</tr>
<tr>
<td>Transplantation waitlisting (%)</td>
<td>19.2</td>
<td>14.8</td>
<td>23.1</td>
<td>&lt; 0.001</td>
</tr>
</tbody>
</table>
EVALUATION OF THE HUNGARIAN SURVAY

- ESKD patients not only have renal insufficiency, but very often other organ impairments, which frequently lead serious disability or handicap.
- Their functional status is low; their ability to carry out daily activities, even self-maintaining is limited.
- They have more and more psychosocial problems, so
- They need help, help in holistic approach.
- They need complex rehabilitation.
The aim of the rehabilitation:
- repair the previous capability of the patients
- restore their earlier functions,
- their positions in the family, in their job and in the community.

The most important in this process is
- the assessment of the remained abilities and potentials,
- and help them to build up a new life.
The parts of the complex rehabilitation:

**Medical rehabilitation**
(medical treatment in the most advanced “up to date” level)

**Social rehabilitation**
(helping in social and financial problems)

**Occupational rehabilitation**
(help to return to work, or in everyday activities)

**Educational rehabilitation**
(teach the patients and their family to coping with their diseased life)

Rehabilitation needs to be started **as early as possible**, optimally during predialysis care.
MULTIDISCIPLINARY CARE OF PREDIALYSIS PATIENTS

- MDC educational-treatment sessions: ~1.5h per visit
- Standard care: 0.5h per visit with the same nephrologist, identical information sessions

<table>
<thead>
<tr>
<th>Table 1. Summary demographics at dialysis initiation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Entire cohort</td>
</tr>
<tr>
<td>---------------</td>
</tr>
<tr>
<td>N (%)</td>
</tr>
<tr>
<td>Clinic duration (months)</td>
</tr>
<tr>
<td>Age (years)</td>
</tr>
<tr>
<td>Female (%)</td>
</tr>
<tr>
<td>Diabetes (%)</td>
</tr>
</tbody>
</table>

CURTIS BM ET AL, NDT 2005
LABORATORY RESULTS AT START OF DIALYSIS, 6 AND 12 MONTHS LATER

<table>
<thead>
<tr>
<th></th>
<th>Standard nephrologist office care</th>
<th>Nephrologist and multi-disciplinary clinic</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney function at dialysis start</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Creatinine (µmol/l)</td>
<td>707 ± 188</td>
<td>650 ± 225</td>
<td>0.03</td>
</tr>
<tr>
<td>GFR(^a) (ml/min/m(^2))</td>
<td>7.0 ± 2.6</td>
<td>8.4 ± 3.8</td>
<td>0.001</td>
</tr>
<tr>
<td>Haemoglobin (g/l)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dialysis start</td>
<td>90 ± 14</td>
<td>102 ± 18</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>6 months</td>
<td>108 ± 15</td>
<td>116 ± 16</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>12 months</td>
<td>110 ± 17</td>
<td>120 ± 16</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Albumin (g/l)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dialysis start</td>
<td>34.8 ± 5.3</td>
<td>37.0 ± 5.4</td>
<td>0.002</td>
</tr>
<tr>
<td>6 months</td>
<td>36.5 ± 4.5</td>
<td>37.0 ± 4.7</td>
<td>0.4</td>
</tr>
<tr>
<td>12 months</td>
<td>36.9 ± 4.6</td>
<td>37.0 ± 4.2</td>
<td>0.9</td>
</tr>
<tr>
<td>Calcium (mmol/l)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dialysis start</td>
<td>2.16 ± 0.27</td>
<td>2.29 ± 0.21</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>6 months</td>
<td>2.33 ± 0.24</td>
<td>2.32 ± 0.22</td>
<td>0.9</td>
</tr>
<tr>
<td>12 months</td>
<td>2.28 ± 0.21</td>
<td>2.29 ± 0.17</td>
<td>0.6</td>
</tr>
<tr>
<td>Phosphate (mmol/l)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dialysis start</td>
<td>1.73 ± 0.55</td>
<td>1.73 ± 0.54</td>
<td>0.9</td>
</tr>
<tr>
<td>6 months</td>
<td>1.56 ± 0.51</td>
<td>1.61 ± 0.43</td>
<td>0.4</td>
</tr>
<tr>
<td>12 months</td>
<td>1.61 ± 0.47</td>
<td>1.59 ± 0.44</td>
<td>0.8</td>
</tr>
</tbody>
</table>
SURVIVAL AFTER STARTING CHRONIC DIALYSIS THERAPY

Fig. 1. Kaplan–Meier survival after starting chronic dialysis therapy. Comparison is made between patients seen prior to dialysis initiation in the multi-disciplinary clinic (MDC) vs standard nephrology care.
PREDICTORS OF SURVIVAL: AGE AND MODE OF EDUCATION (MDC)

Fig. 2. Risk of death according to multivariate Cox proportional hazards modelling. Comparator for race is Caucasian.
Option for voluntary registration for our renal patients
The only „requirement”: bring one relative!
All the expenses are covered by our St Margit Hospital Kindey Foundation
Education for one week duration
- for predialysis patients; for CAPD patients; for HD pts
Hemodialysis treatments are provided by Hemobil Kht. Organizaton on site, in the noon shift
CAPD treatments are performed in the patients’ rooms
EDUCATIONAL TOPICS

Basic function of the kidneys
Fluid and electrolyte balance
Normal and abnormal laboratory results
Importance of diet
Importance of drug treatments
Modality selection
Transportation of patients and treatment in the HD unit
Kidney transplantation (living or cadaver donor Tx)
Major comorbidities
Assistance of social problems, rehabilitation, psychosocial issues
Legal rights of the patients
Alleviation handicap
MULTIDISCIPLINARY TEAM

NEPHROLOGISTS, EDUCATIONAL NURSE, DIETICIAN, SOCIAL WORKER, PSYCHOLOGIST, CLINICAL PHARMACIST, REHABILITATION SPECIALIST, TAI-CHI- AND PHYSIOTHERAPEUTIST, CASE PRESENTATIONS BY PATIENTS
MAIN RESULTS OF OUR EDUCATIONAL AND LIFE STYLE CAMP (I.)

Choice of dialysis modality of our predialysis patients (N=34)

Patients intended to choose HD treatment: 17 (50%)
- 11 males, 6 females, mean age: 63.3 yrs
- HD started: 8 patients

Patients intended to choose PD treatment: 17 (50%)
- 9 males, 8 females, mean age: 57.9 yrs
- PD started: 8 patients
Renal transplantation of our PD patients 2008-2013 (n=71)

- 10/71 pts (14%)
- 9/10 participated in the camp and got multidisciplinary care in Diósjenő (p=0.03)
- 3/9 transplanted patients got living donation by a family member
MAIN RESULTS OF OUR EDUCATIONAL AND LIFE STYLE CAMP (III.) - COMPLIANCE

61 years old male
1989 Type II DM and HTN
1998 on insulin treatment, not on diet (neither his wife!)
2006 proteinuria
2007 se-creatinine: 143 umol/l
2009 get under nephrological care
   se-creat: 296 umol/l, GFR: 21ml/min
   refuses keeping diet, takes medications irregularly
2011 July.: se-creat: 546 umol/l, plan to operate fistula and start HD
2011 July: participates in our Education and Life Style Camp
After the multidisciplinary education he changes his opinion, accepts dietary restrictions, measures his BP, takes his meds regularly
His serum creatinine has decreased, and after two years he is still off dialysis.
Se-creatinine levels between Jan 2009-March 2013
EXPERIENCES OF THE EDUCATORS

- Patients were very enthusiastic
- By involving the relatives: more effective learning process, enhanced personal activity
- Patients accepted their diseases more easily, families fight together
- Self-directed, family assisted cooperation in diet, taking medications
- Importance of „psychoeducation“, self-knowledge, psychological balance
- For the educators: not only teaching, but also learning
„The most important recognition for me was, that my doctors and their team feel that it is their lives’ mission to improve and protect my-our lives’, to treat our diseases, and to fight for ameliorating our sufferings. I have felt much responsibility for myself, for protecting my own life. This experienced faith has given me incredible help to participate actively in forming my own fate, and also to enjoy the perfection of life.”
PATIENT EDUCATION: CAN IT MAXIMIZE THE SUCCESS OF THERAPY?
GOLPER T. NDT 2001

• Majority of patients have limited knowledge of their disease

• By educating them:
  - reducing their anxiety
  - better compliance
  - decreased the number of urgent start of dialysis
  - decreased the rate of hospitalization
  - more informed choice of modality selection
  - higher proportion of dialysed patients remains in employment
  (in US, educated/not educated:
   white-collar workers: 47% versus 48%
   blue-collar workers: 47% versus 24%)

• Education results cost savings!!!
WHY ARE PSYCHOSOCIAL FACTORS IMPORTANT?

• Significantly affect QoL by
  - patient’s perception of well-being
  - perception of burden of illness – patient’s assessment, how the disease interferes with his life in personal, social, familial, and occupational contexts
  - social support – the perception that an individual can receive affection, aid, and obligation - provided by family members, friends, colleagues in the workplace, and medical personnel
  - socioeconomic issues - jobs, financial difficulties

• All of these influence the presence or absence of coping with the altered condition ⇒ compliance ⇒ survival ⇒ QoL
Table 5. Predicting mortality from compliance indicators and psychosocial factors

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>Adjusted RR (95% C.I.)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Time compliance</td>
<td>0.76 (0.62, 0.91)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>% Attendance</td>
<td>0.87 (0.72, 1.05)</td>
<td>0.15</td>
</tr>
<tr>
<td>% Total time compliance</td>
<td>0.79 (0.66, 0.95)</td>
<td>0.01</td>
</tr>
<tr>
<td>Beck Depression Inventory</td>
<td>1.05 (0.87, 1.27)</td>
<td>0.59</td>
</tr>
<tr>
<td>Cognitive Depression Index</td>
<td>1.03 (0.85, 1.26)</td>
<td>0.73</td>
</tr>
<tr>
<td>Illness Effects Questionnaire</td>
<td>1.23 (1.00, 1.51)</td>
<td>0.05</td>
</tr>
<tr>
<td>Social Support (MSP)</td>
<td>0.80 (0.65, 0.98)</td>
<td>0.03</td>
</tr>
<tr>
<td>Satisfaction with Life Scale</td>
<td>0.83 (0.66, 1.04)</td>
<td>0.10</td>
</tr>
</tbody>
</table>

Abbreviations are: RR, Risk Ratio; C.I., Confidence Interval. All variables are standardized to a standard deviation of 1.0, so that the RR represents the expected change in mortality risk associated with a one standard deviation change in the risk factor. All relative risks are controlled for variations in patients’ age, severity coefficient, serum albumin concentration, and dialyzer type. Details are in the text.
Individualized rehabilitation programme

From the beginning of patient’s care until his death
Predialysis care
  secondary, tertiary prevention (compliance)
  education – modality selection – Tx!
Individualized schedule for dialysis
  (modality, dose, timing)
Assessment of the functional status
Individualized rehabilitation plan – teamwork
Continuous evaluation of the results – further
  assessments of the condition – modification of
  the programme
At age of 15 - Acute renal failure - HUS - needs RRT since that time (Tx x2, acute rejections).
Beside being a HD patient in Nephrocentrum Dialysis Unit, she applied for a job as a dialysis nurse. Since 1991, she has been working as a dialysis nurse, 7 hrs/day. Now she is 41 years old, and has been living with RRT for 26 years.
“Geriatric Nephrology is Coming of Age”
(Oreopoulos DG., Dimkovic N JASN 2003)

“...ESRD has become a geriatric illness....”, and “...nephrologists will be forced to practice mainly geriatric medicine as amateur geriatricians..”

- Octogenarians can be effectively treated by RRT

**Success of their care** depends not only on nephrological treatment, but early multidisciplinary medical care, adequate social support, good nutrition, appropriate physical activity, and rehabilitation promoting their ability for self-care
THE IMPORTANCE OF PHYSICAL TRAINING
Torkington M et al, Physiotherapy 2006

- 8 weeks training program
- 30 min „cycling” in the first 1-2 hrs of HD
- Significant improvement of walking distance
- Increased BMI
- Improved vitality
- Improved mental functions
Interdisciplinary geriatric rehabilitation

Li M et al. AJKD 2007.

- Special rehabilitation program for elderly patients with ESRD - initiated in 2002 in Toronto Rehabilitation Institute

- Major aims:
  - to improve functional condition
  - to support the patients’ ability for self-care
  - enable patients to provide self-care at home instead of being in nursing home
  - to decrease their needs for assistance by home care or institutional care
Rehabilitated patients’ population

Li M et al. AJKD 2007.

- 164 patients rehabilitated in 3 years
  - mean age: 74.5±7.8 years
  - Charlson score of their comorbidities was 7.9±2.4
  - 98% had severe limitations in mobility
  - 84% needed help for transfer between bed and chair

- Daily 2x30-60 minutes training sessions with physical and cognitive exercises
- Short daily dialysis sessions (6x2 hrs/wk) in the Satellite Dialysis Unit of the Institute
Results of the rehabilitation

- Median treatment time: 48.5 days
- Significant improvement in the functional condition
  - FIM scale score at admission: 76.4
    at discharge: 101.5

83% successful rehabilitation
- 69% of the patients was able to go home
International Federation of Kidney Foundations (IFKF)

13th IFKF Annual Meeting
22 – 25 August, 2012
BUDAPEST
Hungary

Presidents: Guillermo Garcia
László Rosivall
The 2012 Budapest Declaration of the IFKF

“.....develop and implement, as a priority, comprehensive programs for the screening, prevention, treatment and rehabilitation of individuals living with chronic kidney disease.”

“.....in a holistic manner, to achieve the best health outcomes, including rehabilitation and quality of life.”
Thank you for your attention!