Complex Rehabilitation, Hungarian Experience

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St. Margit Hospital, Budapest

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample (n = 3,563)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years (mean ± SD)</td>
<td>62 ± 14</td>
</tr>
<tr>
<td>Level of education (%)</td>
<td></td>
</tr>
<tr>
<td>≤ 8 y</td>
<td>43.5</td>
</tr>
<tr>
<td>8 – 12 y</td>
<td>45.4</td>
</tr>
<tr>
<td>&gt; 12 y</td>
<td>11.1</td>
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### Psychosocial characteristics

<table>
<thead>
<tr>
<th>Marital status (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Married or common-low</td>
<td>56.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Living status (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Alone</td>
<td>18.0</td>
</tr>
<tr>
<td>With family</td>
<td>79.2</td>
</tr>
<tr>
<td>In institution</td>
<td>2.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Self-reported financial situation (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>39.4</td>
</tr>
<tr>
<td>Fair</td>
<td>40.1</td>
</tr>
<tr>
<td>Poor</td>
<td>20.4</td>
</tr>
</tbody>
</table>
## Psychosocial characteristics

<table>
<thead>
<tr>
<th>Occupation</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time employed</td>
<td>2.8</td>
</tr>
<tr>
<td>Part-time employed</td>
<td>3.1</td>
</tr>
<tr>
<td>Homemaker</td>
<td>1.2</td>
</tr>
<tr>
<td>Retired</td>
<td>46.3</td>
</tr>
<tr>
<td>Disability pension</td>
<td>46.1</td>
</tr>
<tr>
<td>Unemployed</td>
<td>0.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Occupation &lt; 65 y (%)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time employed</td>
<td>5.0</td>
</tr>
<tr>
<td>Part-time employed</td>
<td>5.4</td>
</tr>
<tr>
<td>Homemaker</td>
<td>1.4</td>
</tr>
<tr>
<td>Retired</td>
<td>14.0</td>
</tr>
<tr>
<td>Disability pension</td>
<td>73.3</td>
</tr>
<tr>
<td>Unemployed</td>
<td>0.9</td>
</tr>
</tbody>
</table>
# Self-reported functional status

<table>
<thead>
<tr>
<th>Comorbidities (presence, %)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>30.2</td>
</tr>
<tr>
<td>Acute myocardial infarction</td>
<td>19.0</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>18.8</td>
</tr>
<tr>
<td>Limb amputation</td>
<td>8.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Limitations in everyday activities (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking without help</td>
<td>58.4</td>
</tr>
<tr>
<td>Climbing stairs</td>
<td>68.4</td>
</tr>
<tr>
<td>Bathing/clothing without help</td>
<td>43.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Functional impairments (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>44.1</td>
</tr>
<tr>
<td>Visual</td>
<td>43.8</td>
</tr>
<tr>
<td>Auditory</td>
<td>17.2</td>
</tr>
</tbody>
</table>
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.”
Specific aims of the rehabilitation

Patients have to build up a new life based on the remaining abilities and potentials

- Repair the previous capability as much as possible
- Restore earlier functions
- Restore earlier position in the family and in the community
- Maintain jobs
Rehabilitation interventions

• Medical care → prolong survival
  - adequate dialysis
  - treatment of comorbid diseases
  - good nutrition

• Physical activity interventions → prolong survival
  - aerobic or resistance training programs reduce disability
  - improving patients’ confidence to perform required tasks
  - empower behavioral and lifestyle changes
Rehabilitation interventions

- ESRD leads anxiety, depression and decreased QoL
- ESRD means
  - lifestyle restrictions
  - decreased independence
  - unemployment
  - financial problems
  - decreased ability to fulfill long-term life goals
- Great need for psychosocial support
  → prolong Survival and Quality of life
Psychosocial care

- Enhances coping skills
- Release stressful emotions
- Re-establish a balance in their life
How?

• Education
  - the well informed patient can self-manage his own disease
• Support by the family
• Support by dialysis personnel and social workers
The rehabilitation program

• Has to be individualized
• Optimally since the beginning of predialysis care until the patient’s death
Medical and physical rehabilitation – back to work

- 57 year old male, has CAD, DM and HTN
- ESRD, on PD
- Repeated coronary angioplasty, yet develops angina
- In June, 2015 open heart surgery: coronary artery bypass grafting with 4 grafts
- Successful operation, but suffered from dyspnoe, bilateral pleural effusion, pericardial effusion
- We provided enhanced PD and UF
He is also supported by a physical rehabilitation program → hopefully able to go back to work soon
Physical rehabilitation – gaining back independence

- 77 year old male, **living alone**
- DM and HTN, ESRD, on peritoneal dialysis since 2008
- In spite of meticulous foot care had gangrene on his leg
- In June, 2015 needed **below knee amputation** on his right leg
- He is supported by a **physical rehabilitation program** → hopefully will be able **to live independently**
Rehabilitation of elderly patients with ESRD

• Most of the time they have multimorbid conditions, → severe functional limitations
• Survival of elderly patients are related to their ability to **perform routine daily activities, such as self-care, walking, stair climbing, etc.**
PERITONEAL DIALYSIS TREATMENT IN A PATIENT WITH SEVERE MENTAL RETARDATION

• Hungarian Healthcare Law declares that „All patients have the rights for medical treatment without any discrimination”.
• Pisti, presently 32 years old,
  - was born with multiple developmental abnormalities
  - his mental age is about 5 years old
  - developed ESRD in 2003
  - lives in a long-term care facility
- He has small body size (130 cm, 29 kg)
- an even smaller abdominal space due to severe thoracic gibbosity
- excreting some urine by uretero-cutaneostoma
The 18-member staff of the long-term facility had been trained by us to perform CAPD.

These dedicated caregivers precisely make the bag exchanges, care for dietary restrictions, fluid balance, and are in charge of the daily medications.

Pisti has been living in his original environment, “complies with the CAPD”, being a “happy child”.
Occupational rehabilitation - Anita

Age of 15 (student in secondary school for health care)
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 43 years old, and has been living with RRT for 28 years.
EDUCATION AND LIFE STYLE CAMPS FOR PATIENTS AND THEIR RELATIVES IN DIÓSJENŐ
EDUCATION AND LIFE STYLE CAMPS FOR PATIENTS AND THEIR RELATIVES IN DIÓSJENŐ

- Voluntary registration
  The only „requirement”: **bring one of the relatives!**
- All the expenses are covered by our St Margit Hospital Kindey Foundation
- Education for one week duration, groups for
  - predialysis patients
  - CAPD pts
  - HD pts
- HD provided by Hemobil Kht. Organizaton on site, CAPD are performed in the pts’ rooms
- 2007-2014: **11 groups, 119 pts, 127 relatives participated**
MULTIDISCIPLINARY TEAM

NEPHROLOGISTS,
EDUCATIONAL NURSE,
DIETICIAN,
SOCIAL WORKER,
PSYCHOLOGIST,
REHABILITATION SPECIALIST,
TAI-CHI- AND PHYSIOTHERAPEUTIST,
CASE PRESENTATIONS BY PATIENTS
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
Kidney transplantation (living or cadaver donor Tx)
Major comorbidities
Assistance of social problems, rehabilitation, psychosocial issues
Legal rights of the patients
Alleviation handicap
MAIN RESULTS OF THE PREDIALYSIS PATIENTS

- 34 patients (19 males, 15 females) (accompanied by an immediate relative)
- Mean age 63.4±15 years
- eGFR 18.9±8 ml/min
- Charlson comorbidity index 3.5 (IQR 3)
- Follow up after the Educational Camp 28±17 months
Serum PO4 (mmol/l)

1.69±0.4
1.53±0.4

p=0.02

Proteinuria (mg/d)

1585 (IQR 1150)
1163 (IQR 1704)

p=0.04

Systolic blood pressure (mmHg)

134± 20
125± 17

p=0.01

Before Camp    After Camp
Rate of decline of eGFR in patients, who remained independent of dialysis (n=11)

Before the Camp
2.04 ml/min/year

After the Camp
0.85 ml/min/year
Transplantation activity of the patients who are alive (n=28)

Live donor Tx: 2 patients
Five of the relatives offered kidney donation
Wait-listed: 9 patients (32%)
Modality choice of the patients on RRT (n=16)

Hungarian registry data (2010):
wait-listed 10.7%, living related transplantation 8.5%, PD penetrance 12.8%.
MAIN RESULTS OF PD PATIENTS

• 25 patients (13 males, 12 females) (accompanied by an immediate relative)
• Age 56.4±18 years
• Controls: 46 PD patients followed on our PD Clinic, age 62.3±16 (p=0.15)
• Follow up between 2008-2013.
Transplanted patients in the groups

Patients with educational intervention
- 8 patients (32%)
- Live/cadaveric Tx: 3/5 (2 further donations were offered)
- Controls: 2 patients (4%)

p=0.003

Live/cadaveric Tx: 0/2
Transplantation and wait-listed status in the groups

Patients with educational intervention: 11 (44%)

Controls: 9 (20%)

p=0.029
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 and taking medications
- Importance of „psychoeducation”, self knowledge, psychological balance
- For the educators: not only teaching, but learning
Another way of psysico-psycho-social rehabilitation of patients with RRT

Two young patients on CAPD organized a Bike tour in 2012

There aim to prove:
patients on RRT may live healthy, active, high quality life

Around lake Balaton, 210 km, 4 days
6 pts, 4 nurses, 1 nephrologist, 16 friends
RenBike Tour 2013

- 26 patients, 130 participants
- Organized by a Hungarian nephrologist, Dr Károly Schneider, supported by several organizations
- Full financial support for the patients
- HD, CAPD treatments were organized in cities on the way
- Continuous medical control
- Everyone tolerated the activity well, without any complication
RenBike Tour 2014 and 2015

- 27 patients, 270 participants, 35 km around lake Velencei
- Later on bike tour around lake Balaton again, great success
- Three tours in 2015, increasing popularity