SPECIALISED MULTIDISCIPLINARY DAY CARE FOR PATIENTS WITH HUNTINGTON’S DISEASE, LIVING AT HOME

Marjoleine Pieper1,2,§, Jesseke de Man1, David Engelhard1 and Wilco Achterberg1,2

1. Huntington Centre Topaz, Nachtegaalaan 5, 2225 SX Katwijk, The Netherlands
2. Department of Public Health and Primary Care, Leiden University Medical Center, Post zone V0-P, PO Box 9600, 2300 RC Leiden, The Netherlands

Background
Independent living of patients with a chronic disease is preferred by most citizens. A chronic progressive disease, such as Huntington’s disease (HD) may threaten this independent living.

Aim
To assess whether a specialised, multidisciplinary day care program for patients with HD, is effective in preserving or improving self-efficacy and self-management skills, in order to maintain independent living and postpone admission. Baseline data are presented in this paper.

Methods
In a cohort study, patients with HD and their informal caregiver were interviewed.

Outcome measures

<table>
<thead>
<tr>
<th>Primary</th>
<th>Self-management</th>
<th>SMAS-30</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secondary</td>
<td>Self-efficacy</td>
<td>SES-NL</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>KATZ-ADL</td>
<td>EQ-5D</td>
</tr>
<tr>
<td>Functioning</td>
<td>Lawton-iADL, TUG, PPT</td>
<td></td>
</tr>
<tr>
<td>Satisfactory</td>
<td>VAS-scale</td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>Caregiver Burden</td>
<td>SRB-scale</td>
</tr>
<tr>
<td>Care Needs</td>
<td>CANE</td>
<td></td>
</tr>
</tbody>
</table>

Results
A total of 26 patients with HD (mean age: 51.7 years, range: 29-72, 9 males and 17 females), and 22 informal caregivers were interviewed.

Patients tend to classify themselves as self-manageable (SMAS-30: mean 71.1, SD=12.6), self-efficacible (SES-NL: mean 31.5, SD=5.4), pertain a relatively high level of functioning (KATZ: mean 6.7, SD=1.2) and quality of life (EQ-5D VAS: mean 70.4, SD=18.2), whereas informal caregivers observe several existing care needs (CANE: mean 9.0, SD=2.4) and experience themselves a moderate to severe care burden (SRB: 76% between score 50-80). Both patients and informal caregivers are satisfied with the specialised care program (patients; mean 8.6, SD=1.2, and informal caregivers; mean 7.9, SD=0.9).

Conclusion
Patients, as well as informal caregivers, appreciate the specialised care program. Future research will determine if this program is effective in preserving self-management abilities to maintain independent living and to postpone admission.

---

§ Corresponding author: Marjoleine Pieper (m.pieper@topaz.nl)
Huntington Centre Topaz Overduin - http://huntington.topaz.nl

in cooperation with LUMC