Autosomal Polycystic Kidney Disease – Costs and Resource Utilisation in the Nordic Countries

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Background

• Autosomal dominant polycystic kidney disease (ADPKD) is a rare systemic disorder characterised by the development of renal cysts. ADPKD is nonetheless the most common of all the hereditary cystic kidney diseases and is the fourth leading cause of renal failure. [1,2]
• The prevalence in the EU is estimated to be less than 4 in 10,000. [3]
• The objective of this study was to advance the knowledge of the economic burden of ADPKD by estimating the annual costs associated with ADPKD by disease severity, as well as to describe resource utilisation in the 12-month period around dialysis initiation and transplant procedure, respectively.

Methods

• Patients from nine nephrology clinics across Denmark, Finland, Norway and Sweden were enrolled between April 2014 and December 2014.
• Eligible patients were those diagnosed with ADPKD at least 12 months before enrolment. Enrolment of subjects was stratified by four mutually exclusive strata using a hierarchical approach:
  1. Dialysis
  2. Transplant
  3. Chronic Kidney Disease (CKD) stage 4–5
  4. CKD stage 1–3
• Upon receipt of informed consent, retrospective data were collected from each patient’s medical chart (past 12 months) and via self-administered questionnaires. (Figure 1)
• Annual costs related to ADPKD were assessed from a societal perspective. Resources used were quantified for each patient and costs derived as a function of local price-lists and other public data on costs of healthcare services.
• Costs were analysed in terms of direct medical costs, direct non-medical costs (nursing home care) and indirect costs (informal care and productivity loss).
• In addition to annual costs, resource utilisation during the 12 months around dialysis initiation and transplant surgery, respectively, was assessed using medical chart data. (Figure 1)

Results

• A total of 266 patients were contacted, 343 (91%) of whom provided consent to participate in the study. Nearly 50% of the included patients were Danish.
• Dialysis and transplant patients tended to be older than patients in earlier stages of the disease, and a majority of patients had a record of at least one comorbidity. (Table 1)
• Employment rates were lowest among dialysis patients; only 18% of those aged < 65 years were employed. The overall work productivity loss ranged between 9% in CKD stage 1–3 to 42% in dialysis patients. (Table 1)
• Average total annual costs amounted to €9,919 in CKD stage 1–3, €16,761 in CKD stage 4–5, €74,015 in dialysis patients and €31,496 in transplant recipients (p<0.0001). (Figure 2)
• Productivity loss was a major driver of costs across all stages of disease, reaching 72% of total costs in CKD stage 1–3. Direct medical costs were substantial among dialysis patients, with maintenance dialysis alone accounting for 58% of total costs.

Table 1. Patient characteristics

<table>
<thead>
<tr>
<th>CKD 1–3 (n=61)</th>
<th>CKD 4–5 (n=55)</th>
<th>Dialysis (n=63)</th>
<th>Transplant (n=63)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex, females</td>
<td>38 (62)</td>
<td>29 (54)</td>
<td>33 (52)</td>
</tr>
<tr>
<td>Age (mean ± SD)</td>
<td>53 ± 13</td>
<td>57 ± 12</td>
<td>64 ± 10</td>
</tr>
<tr>
<td>BMI, kg/m²</td>
<td>30 (16)</td>
<td>11 (20)</td>
<td>15 (25)</td>
</tr>
<tr>
<td>Currently employed</td>
<td>40 (65)</td>
<td>27 (49)</td>
<td>13 (21)</td>
</tr>
<tr>
<td>Currently employed, ≤65 years</td>
<td>40 (65)</td>
<td>26 (47)</td>
<td>11 (18)</td>
</tr>
<tr>
<td>Work impairment (%) (mean ± SD)</td>
<td>9 ± 15</td>
<td>23 ± 19</td>
<td>42 ± 33</td>
</tr>
<tr>
<td>Comorbidities (≥1)</td>
<td>43 (67)</td>
<td>44 (80)</td>
<td>61 (100)</td>
</tr>
<tr>
<td>Age at dialysis initiation (mean ± SD)</td>
<td>-</td>
<td>-</td>
<td>59 ± 10</td>
</tr>
<tr>
<td>Age at kidney transplant (mean ± SD)</td>
<td>-</td>
<td>-</td>
<td>50 ± 11*</td>
</tr>
</tbody>
</table>

Data are presented as n (%); P value calculated with x² test unless otherwise specified. *Nunval-Whitney test; BS: body mass index; ¶n = 5; ¥n = 41

Figure 1. Cross-sectional study design

• Among patients < 65 years of age, average annual work productivity loss ranged from €3,339 in CKD stage 1–3 to €19,598 in dialysis patients.
• Resource utilisation was substantially higher in the 12-month period around dialysis initiation and transplant surgery compared with the most recent 12 months. (Table 2)

Conclusions

• ADPKD is associated with substantial economic burden in all levels of disease.
• Costs associated with ADPKD increase substantially as the patient progresses to dialysis. Interventions that can slow the progression of the disease have the potential to lead to substantial reductions in costs and patient burden.

References