**Objective**
- Describe the management of myotonic dystrophy (DM) patients compared with matched controls (MCs) in the five years post-diagnosis.

**Background**
- Myotonic dystrophy types 1 and 2 are rare, dominantly inherited, multisystem diseases that cause progressive muscle weakness and myotonia, along with variable cardiological, gastrointestinal, and neurological manifestations.1–8
- Long-term data on patients with myotonic dystrophy are limited.
- There are currently no approved therapies for myotonic dystrophy.9

**Design/Methods**
- We used PharMetrics deidentified U.S. claims (Jan 2010—Mar 2021) to retrospectively evaluate care for:
  - 1 DM patient
  - 2.2 DM claims
  - 3 non-DM MCs

**Results**
- We identified 892 myotonic dystrophy patients and 2,676 MCs. Both cohorts: mean age 41 years (standard deviation 18) and 55% female.
- In the five years following diagnosis, patients with myotonic dystrophy had higher utilization of medical and prescription services.
- Healthcare across all locations of care annual mean:
  - Costs: $25,000
  - Services: 100
  - Days of care: 21.8

- Compared with controls, persons with myotonic dystrophy had more comorbid conditions based on both International Classification of Diseases, ninth/tenth revisions (ICD-9/-10) claims and AHRQ categories:
  - Mean unique diagnoses and AHRQ categories:
    - Mean # of prescriptions: $203 vs $35
    - Mean days with prescription fills: 0.51 vs 0.12

**Conclusions**
- Healthcare utilization was significantly higher in myotonic dystrophy patients five years post-diagnosis versus controls.
- Utilization likely reflects multi-specialty care in managing myotonic dystrophy.
- The data reflect the multi-system disease burden and financial consequences on myotonic dystrophy patients and their families and provide insight into management that may reduce morbidity and mortality.
- Since there are no approved therapies for myotonic dystrophy, the increased use likely reflects the manifestations of its diseases.
- The numerous non-specific comorbidity categories identified suggest that presentation of myotonic dystrophy varies across patients, and management and diagnosis vary across clinicians.

**References**

**Table**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Cost Difference</th>
<th>Days of Care Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cataracts</td>
<td>$203 vs $35</td>
<td>0.51 vs 0.12</td>
</tr>
<tr>
<td>Cardiac dysrhythmias</td>
<td>$474 vs $88</td>
<td>1.39 vs 0.29</td>
</tr>
<tr>
<td>Other gastrointestinal disorders</td>
<td>$330 vs $39</td>
<td>1.52 vs 0.24</td>
</tr>
<tr>
<td>Other nervous system disorders</td>
<td>$3,386 vs $49</td>
<td>12.07 vs 0.30</td>
</tr>
</tbody>
</table>

Cost difference significant at ≤0.01.

**Figure**

- **Prescriptions:**
  - Mean prescription cost: $15,000
  - Mean # of prescriptions: 12.4
  - Mean days with prescription fills: 0.52

- **Costs Services Days of care**
  - DM patients: $21,728, 15.1, 20
  - Non-DM MCs: $253, 0.12, 0.51

**Figure (continued)**

- **Cataracts:**
  - 38.2% vs 26.6%
  - $203 vs $35
  - 0.51 vs 0.12

- **Cardiac dysrhythmias:**
  - 54.7% vs 17.2%
  - $474 vs $88
  - 1.39 vs 0.29

- **Other gastrointestinal disorders:**
  - 56.3% vs 26.6%
  - $330 vs $39
  - 1.52 vs 0.24

- **Other nervous system disorders:**
  - 100.0% vs 29.4%
  - $3,386 vs $49
  - 12.07 vs 0.30

- **Other connective tissue disease:**
  - 75.0% vs 50.1%
  - $3,386 vs $49
  - 12.07 vs 0.30

- **Other disorders:**
  - 38.2% vs 12.1%
  - $3,386 vs $49
  - 12.07 vs 0.30

- **Other tissue disease:**
  - 35.8% vs 12.1%
  - $3,386 vs $49
  - 12.07 vs 0.30

- **Other system disorders:**
  - 75.0% vs 50.1%
  - $3,386 vs $49
  - 12.07 vs 0.30

- **Other substance:**
  - 1.81 vs 0.88
  - 10.7 vs 5

- **Other nervous system disorders:**
  - 54.7% vs 17.2%
  - $474 vs $88
  - 1.39 vs 0.29

- **Other tissue disease:**
  - 75.0% vs 50.1%
  - $3,386 vs $49
  - 12.07 vs 0.30

- **Other system disorders:**
  - 75.0% vs 50.1%
  - $3,386 vs $49
  - 12.07 vs 0.30

- **Other substance:**
  - 1.81 vs 0.88
  - 10.7 vs 5