**Background, Objective and Methods**

**Objective**

- Study objective: To investigate the impact of Acute Intermittent Porphyria (AIP) on patients’ lives and to identify areas where improvements are needed.

**Methods**

- Data collection: Conducted telephone interviews with patients.
- Data analysis: Used qualitative coding techniques.

**Results**

- **Chronic disease symptoms between attacks**
  - Among 18 patients reported chronic symptoms:
    - 7 (37%) pain
    - 5 (26%) nausea
    - 4 (21%) weakness
    - 3 (16%) light sensitivity
    - 2 (11%) seizures
    - 2 (11%) fever
- **Acute pain**
  - During attacks:
    - Pain: 100%
    - Nausea: 73%
    - Vomiting: 51%
    - Seizures: 33%
    - Fatigue: 33%
- **Symptoms**
  - Most severe symptoms:
    - Pain
    - Nausea
    - Vomiting
- **Impact**
  - Pain affects basic activities of daily living, and mobility
  - Pain is a significant burden on patients’ lives and daily functioning
- **Analysis**
  - Interviews revealed that patients experience chronic symptoms during both attacks and between attacks.
  - Transcripts analyzed qualitatively suggest that these symptoms significantly impact patients’ lives.

**Conclusion**

- Acute Intermittent Porphyria (AIP) affects patients’ lives significantly.
- Chronic symptoms during both attacks and between attacks can have a significant impact on patients’ daily activities.
- Further research is needed to better understand the burden of AIP on patients’ lives.

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**Table 1. Participant demographics and clinical information**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Total (n=19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (Mean ± SD) range</td>
<td>39.8 ± 11.1 (24-61)</td>
</tr>
<tr>
<td>Gender</td>
<td>Female 15 (79%)</td>
</tr>
<tr>
<td>Male</td>
<td>4 (21%)</td>
</tr>
</tbody>
</table>

**Results**

- **Chronic AIP episode (n=18)**
  - Pain: 17/18 (94%) (52%%)
  - Nausea: 13/18 (73%) (42%%)
  - Vomiting: 11/18 (61%) (25%%)
  - Seizures: 5/18 (28%) (21%%)
  - Fatigue: 5/18 (28%) (11%%)
- **Symptoms**
  - Pain
  - Nausea
  - Vomiting
  - Seizures
  - Fatigue
- **Impact on daily life**
  - Pain affects daily activities and quality of life
  - Nausea and vomiting can lead to hospitalization
  - Seizures can be life-threatening
  - Fatigue can affect work and social activities

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**Reference**