The Voices of Hypoparathyroidism: Journey of Patients Living with Hypoparathyroidism

The Voices of Hypopara Survey: Journey of Patients

- The survey consisted of 58 questions that focused on evaluating patients’ experiences.
- The HypoPARAthyroidism Association (HPA) recently conducted the “Voices of Hypopara” survey to better understand the journey of patients with hypoparathyroidism.
- The online “Voices of Hypopara” survey was distributed to HPA members; the survey was dedicated to improving the lives of HP patients in the US.

IMPACT ON DAILY LIVING

- Participants were moderately to extremely concerned with the following HP symptoms:
  - Hypocalcemia/calcium crash (96%)
  - Fatigue (82%)
  - Brain fog (e.g., memory loss, difficulty thinking, slowed or confused thinking) (82%)
  - Hypersensitivity (e.g., muscle weakness, spasms or pain; nausea) (73%)
  - When asked about the challenges of living with HP (Figure 2), most patients (97%) cited minimizing the impact of HP on their quality of life, including:
    - Controlling daily symptoms (79%)
    - Balancing social life and friendships with managing symptoms and complications (63%)
    - The majority of patients (87%) also expressed concern about treatment-related complications.

BASELINE DEMOGRAPHICS AND DISEASE CHARACTERISTICS

- The survey was filled by 168 HP members (18% female; 56% white; mean age 51). The majority of participants (88%) were diagnosed with post-surgical HP (Figure 1).
- Diagnosis of HP was delayed more than 6 months in 56% of participants despite symptoms of chronic HP (Figure 1).
- 90% of post-surgical HP patients were diagnosed within a year after surgery. (Figure 1).
- Nearly all HP patients took more than 2 months longer to receive a diagnosis, with more than 35 taking 12 years.
- 51% underwent >5 physician visits before obtaining a HP diagnosis.
- Most patients reported they are currently taking SoC (calcium supplements in 81%; vitamin D in 73%).
- More than a quarter (27%) were extremely concerned about hypocalcemia despite supplementation.
- Many (83%) viewed SoC as moderately to extremely burdensome.
- Other treatments include phosphate binders, diuretics, PTH replacement, and/or investigational drugs.
- Almost all patients (97%) had to adjust their regimens over the course of their disease, with 67% adjusting more than 5 times since diagnosis.

RESULTS

- These findings underscore the limitations of current SoC and the urgent need for new treatment options.
- This survey conducted in 146 patients with HP demonstrates key gaps in HP management.
- Participants experienced delays in diagnosis, despite living with chronic HP symptoms, especially those eventually diagnosed with non-surgical HP.
- Despite treatment with SoC, more than two-thirds of patients experienced discomfort, and minimizing long-term complications of HP are important.
- The majority of patients (87%) also expressed concern about managing long-term complications.
- Of those, patients were extremely concerned with cardiovascular health (54%), kidney stone formation (31%), and organ calcification beyond the kidney (58%).

CONCLUSIONS

- This survey conducted in 146 patients with HP demonstrates key gaps in HP management.
- Participants experienced delays in diagnosis, despite living with chronic HP symptoms.
- Almost all participants were concerned with managing daily HP symptoms and minimizing long-term complications.
- Despite treatment with SoC, more than two-thirds of patients experienced discomfort, and minimizing long-term complications could have major implications even among patients who are considered to be living with HP in the future.

Figure 1: Delays in HP Diagnosis Despite Symptoms of Chronic HP

Figure 2: Word Cloud of Greatest Challenges Participants Face Living With HP

Table 1: ER and Urgent Care Visits to Manage HP Symptoms

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<thead>
<tr>
<th>Category</th>
<th>In the Prior 12 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of visits to the ER/Urgent Care for HP symptoms in the last year</td>
<td></td>
</tr>
<tr>
<td>- More than 10 visits</td>
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<tr>
<td>- 5-10 visits</td>
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SELECT QUOTES ABOUT MANAGEMENT OF CALCIUM CRASHES

"My calcium level site right at the low end of normal or right below - so that is looked over and ignored as the culprit of the symptoms. I have been lows for 10 years, a possible TIA (transient ischemic attack), and sent through many many unnecessary tests. I have to educate doctors, nurses, and myself. I have to explain what I need to live and what I need after labs are done but I can’t do that any other way, ER or urgent care to address their HP symptoms; the majority of those that visited the ER or urgent care felt their HP symptoms were not taken seriously.

These findings underscore the limitations of current SoC and the urgent need for greater disease and treatment understanding to best treat and support patients with HP."