

The Voices of Hypopara Survey: Journey of Patients Living with Hypoparathyroidism

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BACKGROUND

- Hypoparathyroidism (HP) is a rare disease that is characterized by insufficient levels of parathyroid hormone (PTH), resulting in hypocalcemia, hyperphosphatemia, and hypercalciuria¹
- Symptoms of HP include tingling, muscle cramps, fatigue/weakness, seizures, headaches, anxiety, and brain fog¹
- Some patients may suffer from “calcium crashes,” sudden or extreme drops in calcium levels that can cause confusion, memory loss, mood changes, muscle spasms, severe muscle cramps/tetany, numbness, burning and tingling, and/or seizures; a calcium crash can be severe enough to require an emergency room (ER) or urgent care visit to receive intravenous (IV) calcium infusion¹
- Standard of care (SoC) consists of calcium and active vitamin D supplementation; however, this can lead to severe long-term complications including calcium deposits in organs (e.g., kidney, brain, blood vessels, eye and other soft tissues)¹
- The HypoPARathyroidism Association (HPA) is a nonprofit organization dedicated to improving the lives of HP patients
- The HPA recently conducted the “Voices of Hypopara” survey to better characterize the patient journey and treatment-related burden in HP patients in the US

METHODS

- The online “Voices of Hypopara” survey was distributed to HPA members; the completed responses were collected between April 30 and May 8, 2020 and subsequently analyzed
- The survey consisted of 58 questions that focused on evaluating patients’ experiences including diagnosis, treatment, quality of care, and impact on daily living

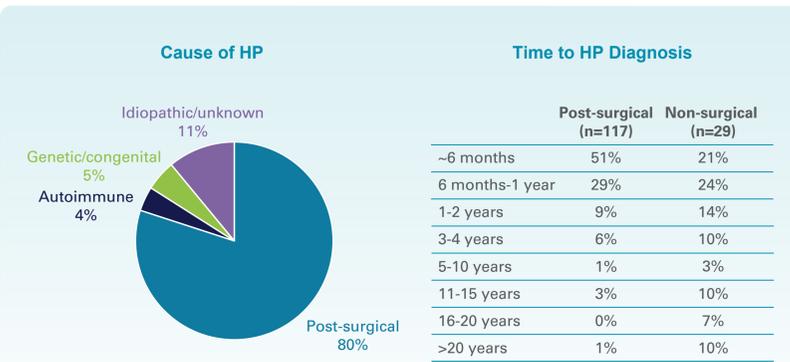
RESULTS

BASELINE DEMOGRAPHICS AND DISEASE CHARACTERISTICS

- The survey was completed by 146 HPA members (89% female; 92% white; mean age 51)
- The majority of participants (80%) were diagnosed with post-surgical HP (Figure 1)
- Diagnosis of HP was delayed more than 6 months in 55% of participants despite symptoms of chronic HP (Figure 1)
 - 80% of post-surgical HP patients were diagnosed within a year after surgery
 - Non-surgical HP patients took much longer to receive a diagnosis, with more than 30% taking >5 years
- 51% underwent >5 physician visits before obtaining a HP diagnosis
- Most participants reported they are currently taking SoC (calcium supplements in 91%; active vitamin D in 77%)
 - However, over half felt that this did not effectively address their HP symptoms
 - More than a quarter (27%) were extremely concerned about hypocalcemia despite supplementation
 - Many (69%) viewed SoC as moderately to extremely burdensome
- Other treatments may include phosphate binders, diuretics, PTH replacement, and/or investigational drugs
- Almost all participants (97%) had to adjust their regimens over the course of their disease, with 61% adjusting more than 5 times since diagnosis

RESULTS

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



IMPACT ON DAILY LIVING

- Participants were moderately to extremely concerned with the following HP symptoms:
 - Hypocalcemia/calcium crash (84%)
 - Fatigue (83%)
 - Brain fog (e.g., memory loss, difficulty thinking, slow or confused thinking) (82%)
 - Hyperphosphatemia (e.g., muscle weakness, spasms or pain; nausea) (73%)
- When asked about the challenges of living with HP (Figure 2), most patients (87%) cited minimizing the impact of HP on their quality of life, including:
 - Controlling daily symptoms (78%)
 - Handling physical activities (75%)
 - Maintaining psychological well being (68%)
 - Balancing social life and relationships with managing symptoms and complications (63%)
- The majority of patients (87%) also expressed concern with management of long-term complications
 - Of those, participants were extremely concerned with cardiovascular health (24%), kidney stones/function (21%), and organ calcification beyond the kidney (24%)

MANAGEMENT OF SEVERE HP SYMPTOMS

- More than two-thirds (69%) of participants reported a calcium crash in the past year; of these, 43% reported calcium crashes monthly or weekly and 4% experienced them daily
- Approximately 42% of participants said they visited an ER and/or urgent care facility in the past year to address their HP symptoms (Table 1)
 - 63% of participants who visited the ER and/or urgent care received IV calcium to manage their calcium crash; 26% of these participants received IV calcium 5 or more times in the past year
 - 56% of participants who visited the ER and/or urgent care believed that the staff did not know how to manage a calcium crash
 - Nearly 50% of participants who visited the ER and/or urgent care stated that their most recent experience (at the ER and/or urgent care) made them less likely to return in the future for treatment of the signs and symptoms related to their condition

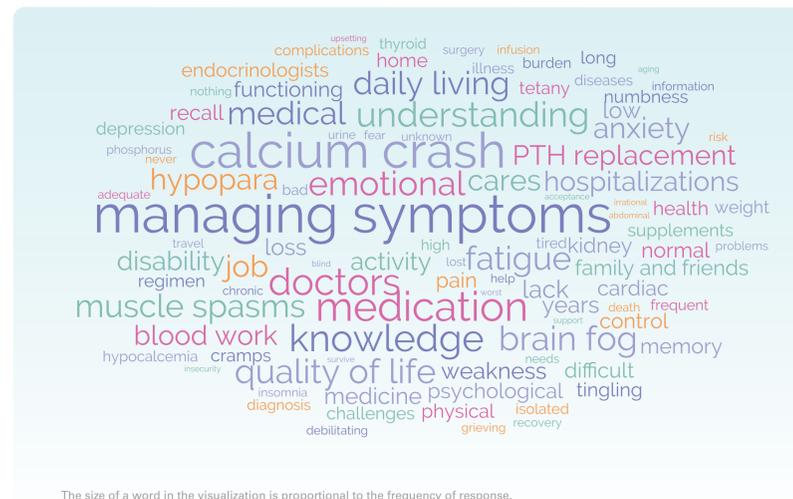
SELECT QUOTES ABOUT CHALLENGES OF LIVING WITH HP

“The fatigue, brain fog, and muscle complications have completely changed who I am and how I can function. I was forced to retire early due to frequent hospitalizations and physical issues. I have also not found a physician who understands the complications that occur even with calcium levels that are in a good range.

I have had to quit my job that I have loved. I have gained weight because I have no energy to do activities. I now have cardiac issues and my kidney function is worse. I am concerned daily about death from complications.

Because the symptoms aren’t easy to see I often feel like no one understands and feel very isolated.”

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



The size of a word in the visualization is proportional to the frequency of response.

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

Category, n (%)	Participants who visited the ER/Urgent care (n=62)
Number of visits to the ER/Urgent Care for HP symptoms in the last year	
Once	20 (32)
2-4 times	31 (50)
5-10 times	9 (15)
11-15 times	0
>15 times	2 (3)
I received IV calcium during my ER/Urgent Care visit in the past year	39 (63)
Once	12 (19)
2-4 times	17 (27)
5-10 times	8 (13)
11-15 times	0
>15 times	2 (3)

SELECT QUOTES ABOUT MANAGEMENT OF CALCIUM CRASHES

“My calcium level sits 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 told it’s anxiety, a possible TIA (transient ischemic attack), and sent through many many unnecessary tests. We can have major symptoms even while appearing slightly low.

Fortunately I’m well documented now at the ER I go to. And I know others with hypopara visit as well. Most doctors and nurses are caring and ask questions about my treatment. After a couple of years now, they often ask me what I need after labs are done. But I don’t dare go to another ER.

The staff was not knowledgeable about hypoparathyroidism and my situation. I had to educate doctors, PAs, and nurses. I had to explain what I needed (blood test for calcium and minerals, IV calcium, anxiety meds, and pain meds).

They make me feel that my condition is not THAT bad. I don’t like being accused of blowing my condition out of proportion.

I have no choice. I need the calcium IV or I can’t function. I have to go no matter what I think of the ER and the doctors. I need my calcium.”

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, especially those eventually diagnosed with non-surgical HP
 - 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 calcium crashes in the last year and almost half of all participants visited the ER or urgent care to address their HP symptoms; the majority of those that visited the ER or urgent care had to receive IV calcium
- 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

REFERENCES:
¹Mannstadt M, Bilezikian JP, Thakker RV, et al. Hypoparathyroidism. Nat Rev Dis Primers. 2017;3:17055.

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