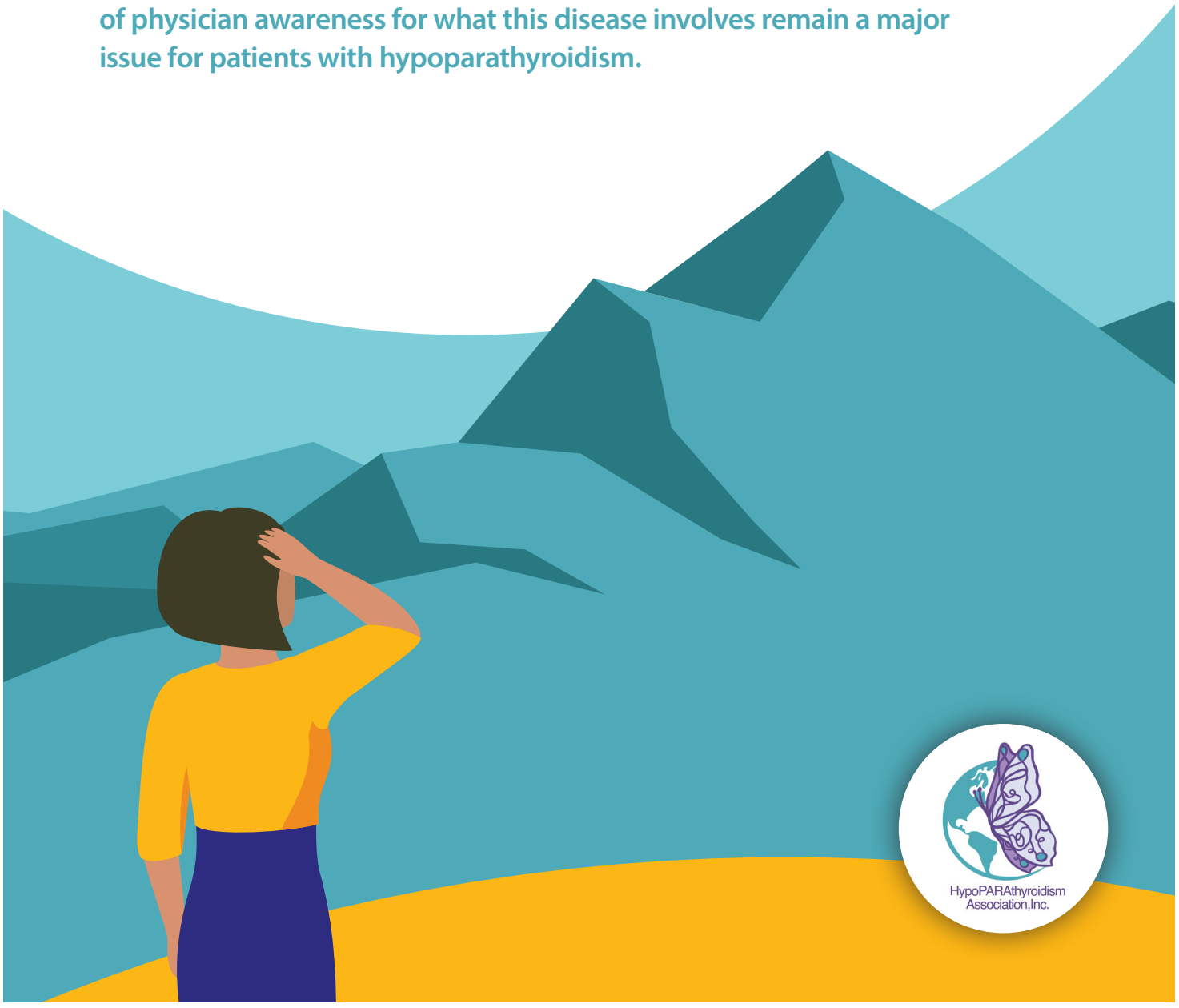
VOICES OF HYPOPARA v2.0 SURVEY RESULTS

Real-World Journey

The unmet needs of people living with hypoparathyroidism in the United States.

The HypoPARAthyroidism Association (HPA) conducted a survey, Voices of HypoPARA v2.0, focused on evaluating patients' experiences with diagnosis, treatment, and quality of life.

As the survey shows, lack of effective treatment options and lack of physician awareness for what this disease involves remain a major issue for patients with hypoparathyroidism.



VOICES OF HYPOPARA v2.0 SURVEY RESULTS

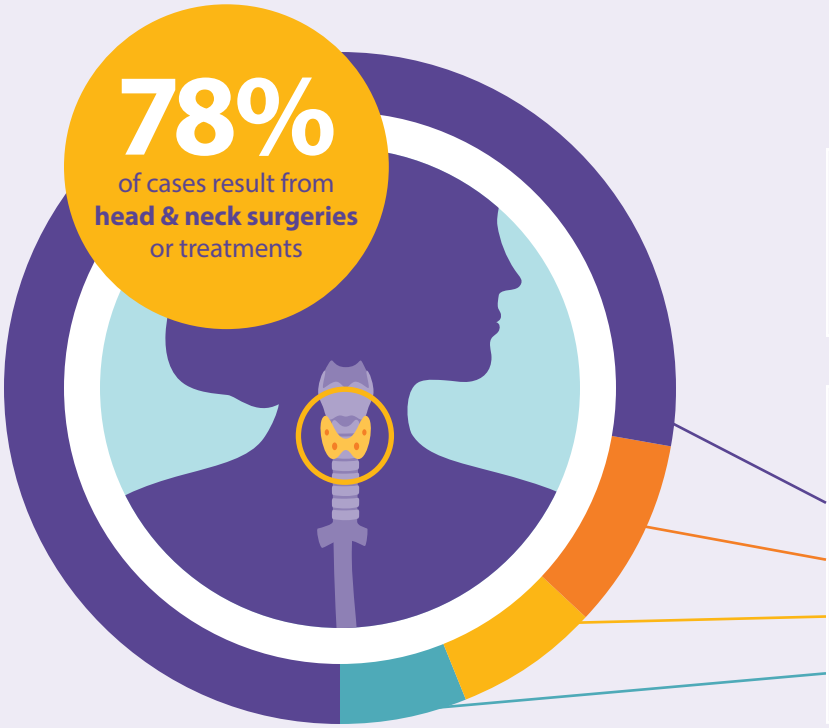
What is Hypoparathyroidism?

A rare disease associated with significant morbidity, poor quality of life, and increased healthcare utilization.[1]

Hypoparathyroidism is a rare endocrine disease resulting from the absence or deficiency of parathyroid hormone (PTH) in the body. It can be linked to several multiorgan manifestations, including cardiovascular, respiratory, and renal complications.[2] Most cases (78%) result from head and neck surgeries or treatments – for example, thyroid cancer surgery.[3]

Patients with hypoparathyroidism are at risk for many complications, from the disease itself and from adverse effects of conventional treatment regimens with oral calcium and active vitamin D.[2]

In addition, hypoparathyroidism is associated with a major financial burden due to increased healthcare use. Individuals with chronic hypoparathyroidism have significant symptoms and comorbidity resulting in increased healthcare costs and use healthcare resources with increased numbers of outpatient and emergency room visits.[1]



Hypoparathyroidism affects about 77,000 – 115,000 people in the United States.[3]

Causes of Hypopara[3]

78% Postsurgical

9% Other Causes

7% Genetic

6% Idiopathic

1 Evaluation and Management of Hypoparathyroidism Summary Statement and Guidelines from the Second International Workshop - Khan - 2022 - Journal of Bone and Mineral Research - Wiley Online Library.
2 Mannstadt M, Bilezikian JP, Thakker RV, et al. Hypoparathyroidism. Nat Rev Dis Primers. 2017;3:17055. doi:10.1038/nrdp.2017.55
3 Clarke BL, Brown EM, Collins MT, et al. Epidemiology and diagnosis of hypoparathyroidism. J Clin Endocrinol Metab. 2016;101(6):2284-2299. doi:10.1210 jc.2015-390

VOICES OF HYPOPARA v2.0 SURVEY RESULTS

#BeTheChange

It's time to realize how profoundly debilitating hypoparathyroidism is.

Survey after survey, including results from Voices of HypoPARA v2.0 shared here, shows patients again and again expressing an urgent need for more well-informed care, more thoughtful and regular quality-of-life evaluations, and access to new and promising medicines that have been proven safe and effective in clinical trials.

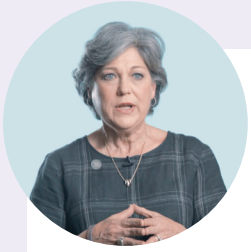
Despite industry progress and medical education initiatives, hypoparathyroidism today remains the only hormone deficiency for which a hormone replacement therapy is still not broadly available in the United States. As a rare disease, hypoparathyroidism is frequently treated by physicians who do not fully understand it. Gaining – and then losing – promising treatment options these past years has been gut-wrenching for patients here and around the world.

There's no reason for us to suffer any longer.

Be The Change

HypoPARAthyroidism Association

RESEARCH • DIAGNOSIS • TREATMENT



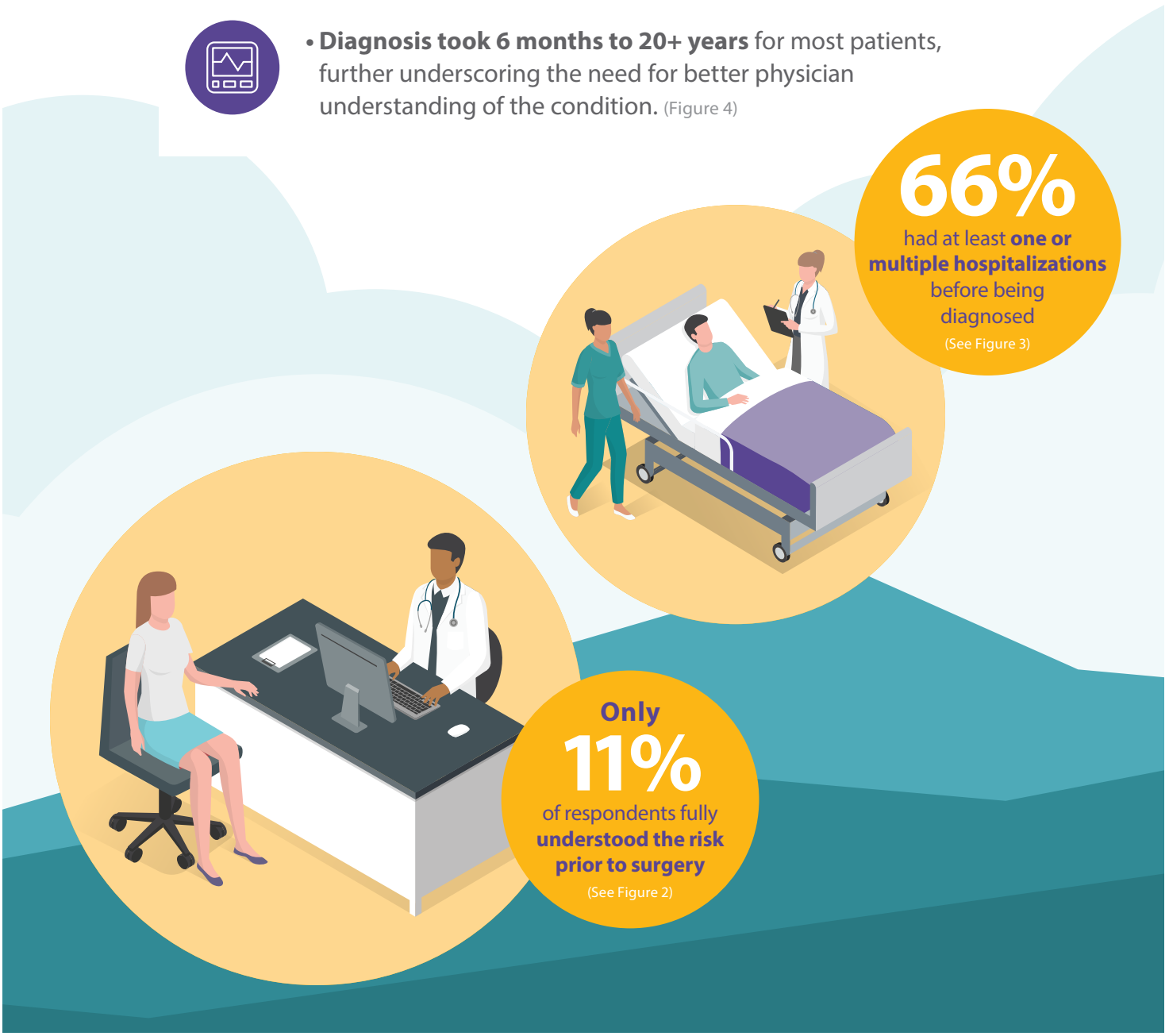
"Either I'm going to suffer the consequences of being hypopara to the point of the **damaging effect of the calcium** going too low or I'm going to suffer the consequences of my kidneys failing because of the calcium that I'm taking that's saving me."

— Paula Voisin, hypopara patient

Diagnosis

Unmet Needs Surrounding Patient Journey

- 87% responded they were **diagnosed post-surgically**, the most common cause of hypoparathyroidism. (Figure 1)
- Only 11% of these respondents fully understood the risk prior to surgery. (Figure 2)
- Before being diagnosed, 66% had at least **one or multiple hospitalizations**. (Figure 3)
- **Diagnosis took 6 months to 20+ years** for most patients, further underscoring the need for better physician understanding of the condition. (Figure 4)



Treatment

Current Care Challenges

- Only 10% of respondents are happy with their treatment option, pointing to **a large unmet medical need.** (Figure 7)
  - Long-term administration of conventional therapy (active vitamin D and high dose oral calcium) has the **potential to damage organs over time.**[4]
- Many patients responded they could better manage their condition with **access to more knowledgeable healthcare professionals/specialists**, more effective medication options, and screening tools. (Figure 9)
- 63% had their serum calcium level checked due to symptoms of hyper/hypo calcemia. (Figure 10)
  - Half (50%) preferred the ability to check their serum calcium levels at home. (Figure 9)
- Almost half (44%) stated that **where they live affects their ability to get appropriate care.** (Figure 11)
  - The majority (80%) of respondents currently live in in either rural or suburban areas. (Figure 12)

Only

10%

of respondents said they were happy with their treatment option, **pointing to a large unmet medical need.**

(See Figure 7)

4 Brandi ML, Bilezikian JP, Shoback D, et al. Management of hypoparathyroidism: summary statement and guidelines. J Clin Endocrinol Metab. 2016;101(6):2273-2283. doi:10.1210/jc.2015-3907

Quality of Life

Lifestyle & Well-Being: Patients Are More Than Their Lab Values

- Only 25% strongly agree their physician fully understands hypoparathyroidism and its **impacts on their life.** (Figure 7)
- 49% say their condition has **negatively impacted their job** status. (Figure 8)
- 71% **do not have their quality of life (QoL) assessed** regularly by a physician. (Figure 5)
  - 41% of respondents have never had a QoL assessment. (Figure 5)

Patient Values, Needs and Concerns

Only
25%
strongly agree their **physician fully understands** their condition.
(See Figure 7)

"**A newly approved treatment option for hypoparathyroidism would mean everything to me and the community.** Currently, there are not many options available except the standard of care, that does not adequately treat our symptoms and give us a good quality of life."

— Mirranda McVay, hypopara patient

"My main challenge when it comes to living with hypopara is just not having enough spoons to do anything.* I used to be a very active person, and so not being able to go out and see people and talk to people, **the isolation is probably the worst part for me.**"

— Medb Juniper Rose Hestia, hypopara patient

"**My biggest issue—and it scares me to death—is the brain fog.** I have calcification on my brain. I have issues with my feet. My kidneys are calcifying and I'm down to 35% of kidney function."

— Deb Murphy, hypopara patient

* The "spoon theory" is a metaphor that people living with chronic illnesses, or disabilities, often rely on to describe the amount of energy — mental and physical — they have for basic, everyday tasks.
For more information: What The 'Spoon Theory' Means for People Living With Chronic Illnesses, Disabilities | The Swaddle. TheSwaddle.com, accessed 16 February 2024.

VOICES OF HYPOPARA v2.0

Reference Charts

While the majority (87%) of respondents said their hypoparathyroidism diagnosis resulted from post-surgical causes, half of them (50%) said their surgeon did not inform them at all that hypoparathyroidism was a potential side-effect of surgery.

Meanwhile, only 11% of post-surgically diagnosed respondents fully understood the risk of their surgery, indicating that physicians and surgeons are not thoroughly educating patients about possible outcomes.

Figure 1

When you were diagnosed, what was identified as the cause of your hypoparathyroidism?

- **87%** Postsurgical
- **7%** Idiopathic/unknown
- **6%** Genetic/congenital
- **1%** Autoimmune

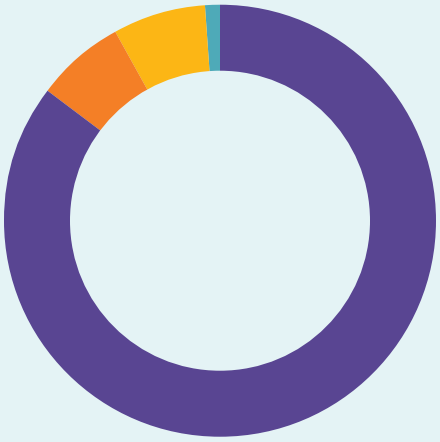
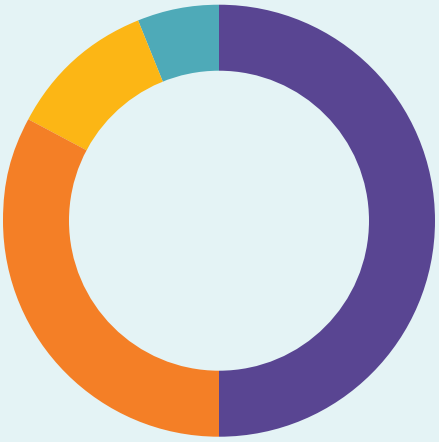


Figure 2

Did your surgeon inform you that hypoparathyroidism was a potential side-effect of your surgery?

- **50%** No
- **33%** Yes, but didn't clearly understand what hypoparathyroidism meant
- **11%** Yes, and I understood the information
- **6%** I don't know



"We need more physician education and better communication from surgeons. I had no idea this disease could be the outcome from my surgery."

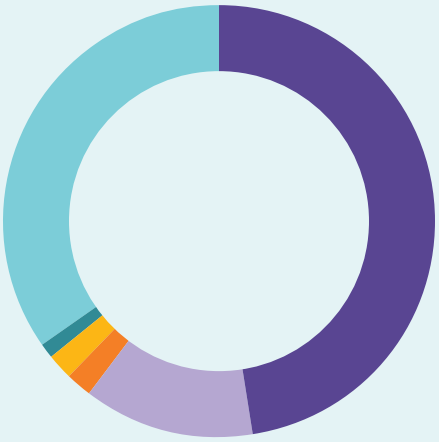
— Survey respondent

More than half (66%) of respondents had at least one or multiple hospitalizations before getting diagnosed with hypoparathyroidism. Many respondents felt as though their symptoms and concerns were not taken seriously due to lack of physician knowledge about this disease.

Figure 3

Please estimate how many emergency room visits and/or hospitalizations you had while experiencing symptoms of hypoparathyroidism before you were diagnosed with chronic hypoparathyroidism.

- **48%** 1-5 visits
- **13%** 6-10 visits
- **2%** >30 visits
- **2%** 21-30 visits
- **1%** 11-20 visits
- **35%** I did not visit an emergency room and was never hospitalized



"I would like physicians to know how scary the experience of being diagnosed was and how awful it felt when people told me it wasn't a big deal."

— Survey respondent

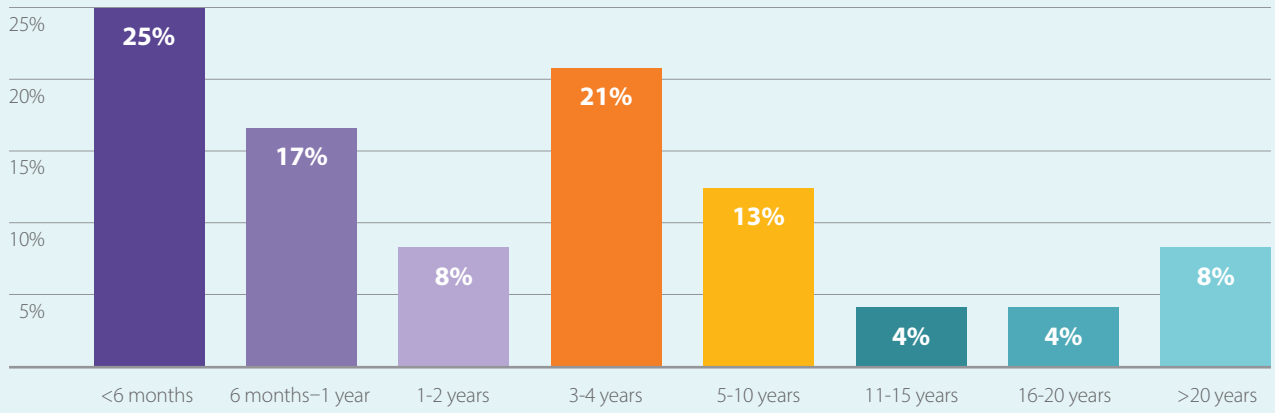
"I would love physicians to just understand the disease more so they can better explain it to me. It's very frustrating and anxiety-inducing constantly ending up in the hospital."

— Survey respondent

Diagnosis took 6 months to 20+ years for most patients, further underscoring the need for better understanding of the condition among healthcare professionals.

Figure 4

Please estimate how many emergency room visits and/or hospitalizations you had while experiencing symptoms of hypoparathyroidism before you were diagnosed with chronic hypoparathyroidism.



"I was never told that I had hypopara. I didn't feel well after my thyroid surgery, but I thought it was because I had no thyroid. 20 years after my surgery, I went to get my medical records at the hospital and saw hypoparathyroidism written at the bottom - and wondered *what is that?* I never heard the word before that."

— Survey respondent

"I actually have idiopathic hypoparathyroidism. I've had it my entire life, but it was only diagnosed in late 2017."

*— Medb Juniper Rose Hestia, hypopara patient**

* This quote was captured during patient/caregiver interviews at the 2023 HypoPARAthyroidism Association Annual Conference.

Most respondents (71%) do not have their quality-of-life assessment checked regularly by a physician, and of those that do, only 8% are assessed with a validated tool. Furthermore, 41% of respondents have never had a quality-of-life assessment by a physician.

Figure 5

How often does your physician conduct a quality-of-life (overall well-being) assessment in relation to your hypoparathyroidism?

- **41%** My physician has never conducted a quality-of-life assessment
- **21%** Every visit
- **16%** Rarely
- **14%** Some visits
- **9%** Most visits

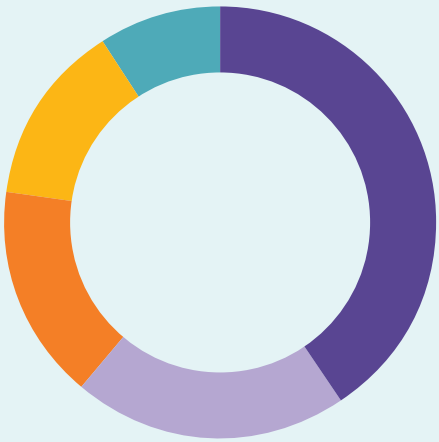
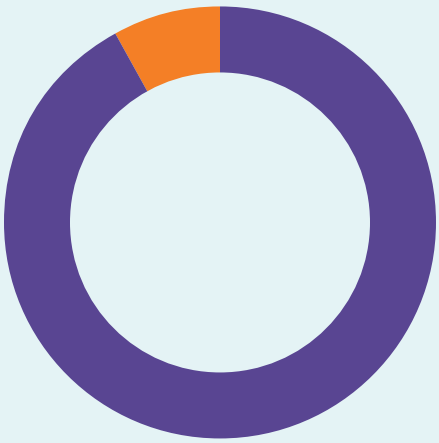


Figure 6

How does your physician conduct a quality-of-life assessment in relation to your hypoparathyroidism?

- **92%** Informally
- **8%** With a quality-of-life assessment tool



"Even when labs are 'normal', I still have symptoms. My quality of life has been drastically declined by this condition, even on my best lab day. That lack of stability makes it difficult to live a normal life of any kind."

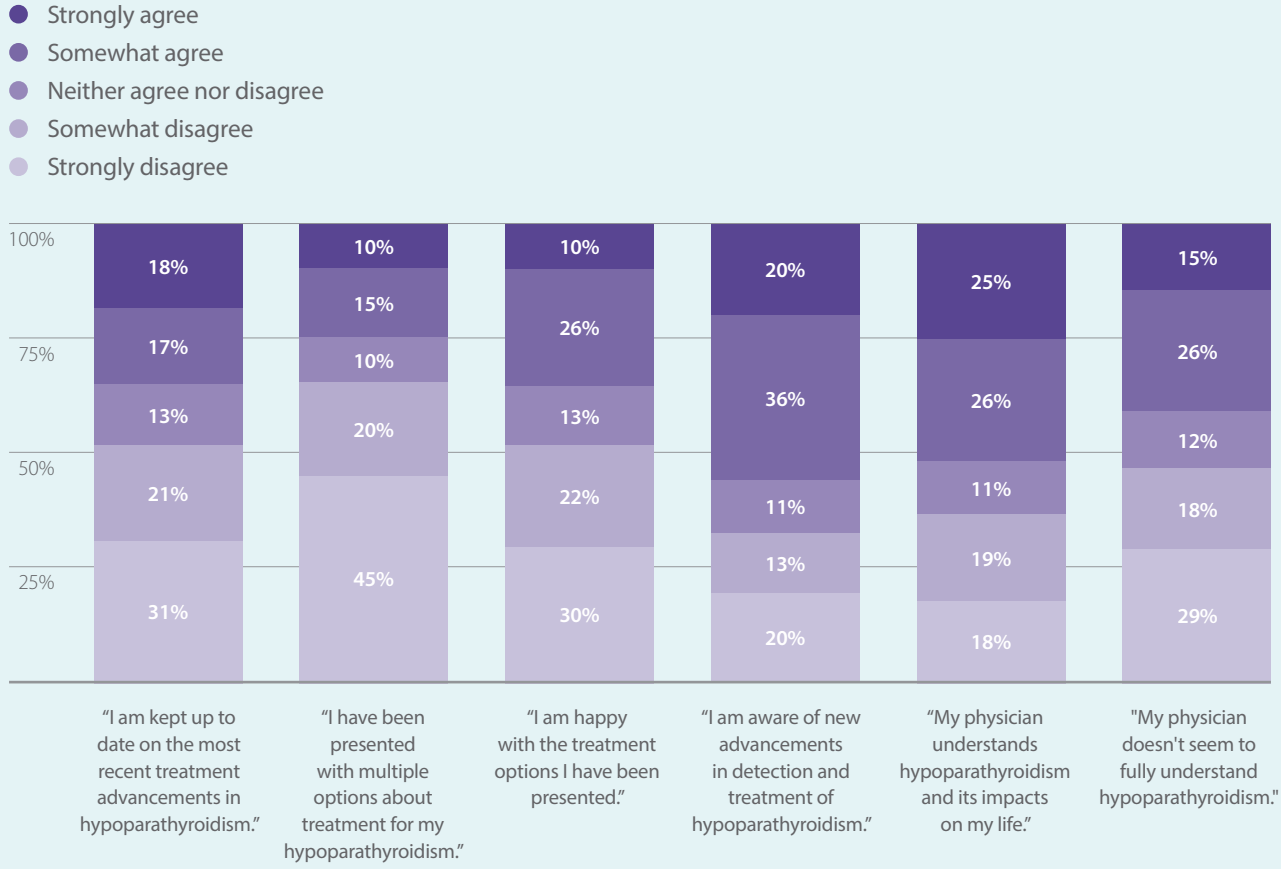
— Survey respondent

Only 25% of respondents strongly agree that their physician fully understands hypoparathyroidism, underscoring the need for more knowledgeable physicians.

Only 10% of respondents said they were happy with their treatment options, pointing to a large unmet need for more effective treatments.

Figure 7

How much do you agree with the following statements about your hypoparathyroidism care?



"To even have a doctor knowledgeable of this condition is rare."

— Survey respondent

"No one really understands what it's like taking 40-50 pills a day and hoping for no side effects."

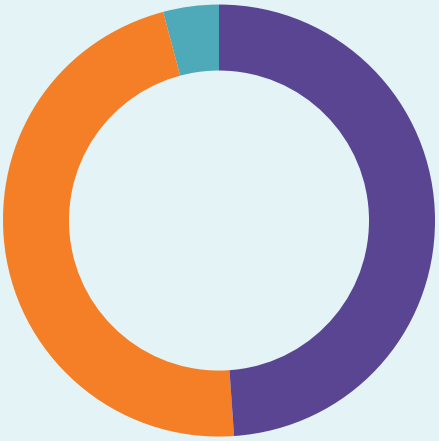
— Survey respondent

Almost half (49%) of respondents believe that their hypoparathyroidism has negatively impacted their level of employment.

Figure 8

How has hypoparathyroidism impacted your employment status?

- **49%** Negatively impacted my level of employment
- **47%** No impact to my employment
- **4%** Positively impacted my level of employment



"Jobs are demanding, but this disorder is a lot like taking care of a newborn baby. It has to be taken care of, and it has to be put first."

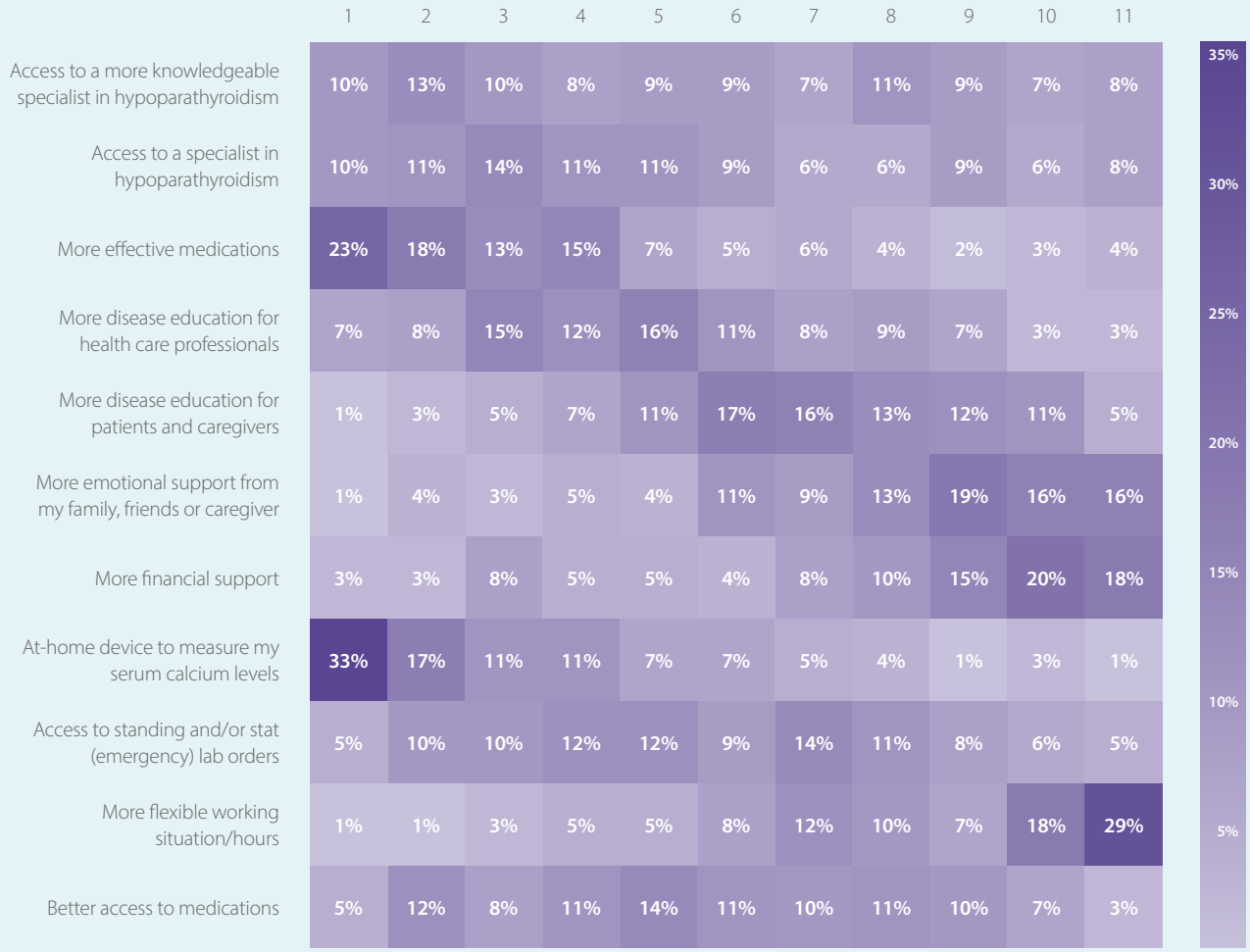
*— Andrea Ligler, hypopara patient**

* This quote was captured during patient/caregiver interviews at the 2023 HypoPARAthyroidism Association Annual Conference.

Many patients feel like they could better manage their hypoparathyroidism if they had more knowledgeable specialists, access to specialists, more effective medication options and an at-home device to check serum calcium levels.

Figure 9

Which of the following would make it easier for you to manage your hypoparathyroidism? Please rank these options by rearranging the options up or down on the screen to your preferred order.



"The change in serum calcium is just as symptomatic as having low calcium, and it is really hard to manage without a monitoring device."

— Survey respondent

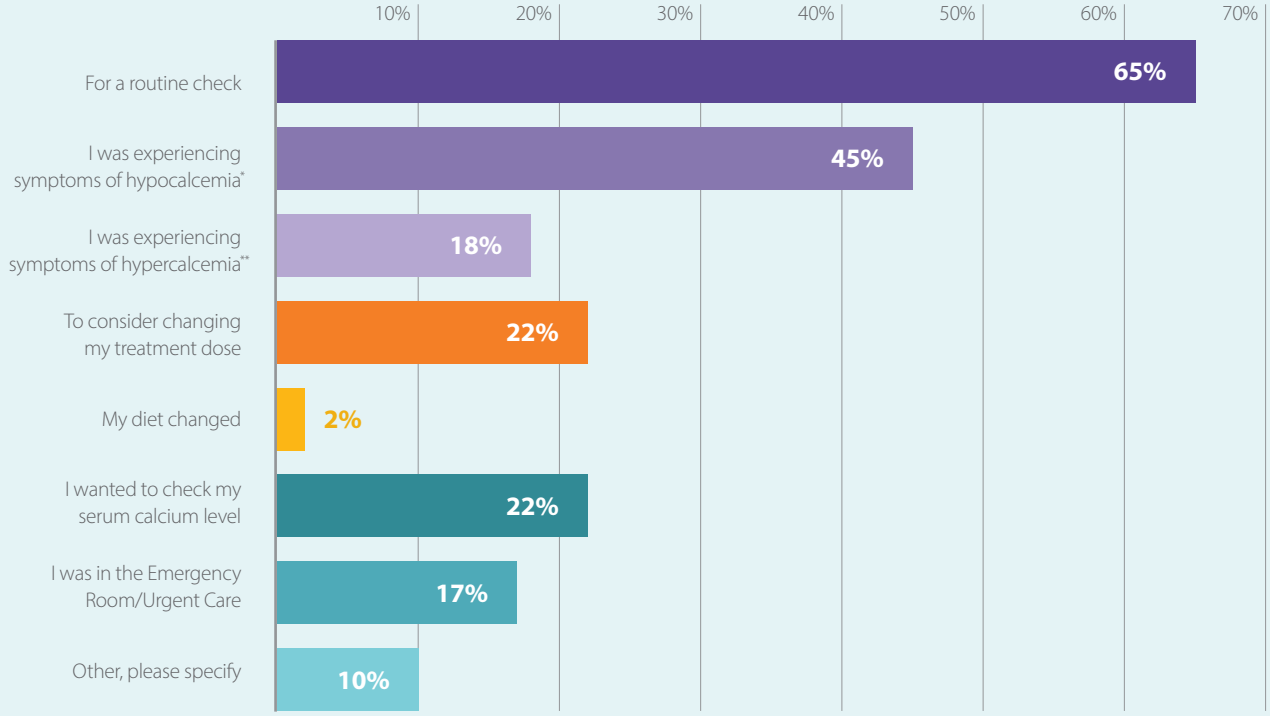
"I wish doctors spent as much time as I do researching new prescriptions and new trials, conferences, etc. I feel that I am informing my doctor in a lot of areas vs the other way around!"

— Survey respondent

More than half (63%) of respondents had their serum calcium level checked due to symptoms of hyper/hypo calcemia, and when asked to rank options of what would make it easier to manage their hypoparathyroidism, half (50%) preferred the ability to check their serum calcium levels at home. (see Figure 9)

Figure 10

During the past year, which of the following reasons caused you to have your serum calcium level checked at a physician's office or at a lab? Please select all that apply.



"The most challenging part of having hypoparathyroidism is tetany. For me it can be my chest and my neck or my arms. I know that when I'm in a lot of pain... but it's hard to predict when that will happen."

*— John Killean, hypopara patient****

* Symptoms of hypocalcemia include confusion, memory loss, mood changes, muscle spasms, severe muscle cramps/tetany, numbness, burning and tingling, seizure

** Symptoms of hypercalcemia include more frequent urination, constipation, nausea, vomiting, abdominal pain, weakness, poor memory

*** This quote was captured during patient/caregiver interviews at the 2023 HypoPARAthyroidism Association Annual Conference.

Almost half (44%) of respondents stated that where they live affects their ability to get care for their hypoparathyroidism, with the majority (80%) of respondents currently living in either rural or suburban areas.

Figure 11

Does where you live affect your ability to get care for your hypoparathyroidism?

- **56%** No
- **44%** Yes

Figure 12

What best describes where you live?

- **51%** Suburban
- **29%** Rural
- **20%** Urban

"The challenge is I have to travel out of state to get with the specialist that I need for my rare condition."

*— Sissy Paul, hypopara patient**

"We are completely medically underserved [in our area], and we only have one endocrinologist. And Miss Sissy has to travel hours upon hours to find proper care."

— Caregiver to Sissy Paul (hypopara patient)*

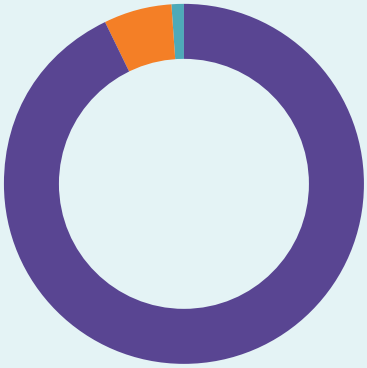
* This quote was captured during patient/caregiver interviews at the 2023 HypoPARAthyroidism Association Annual Conference.

Demographics of Survey Respondents

Gender

How do you describe yourself?

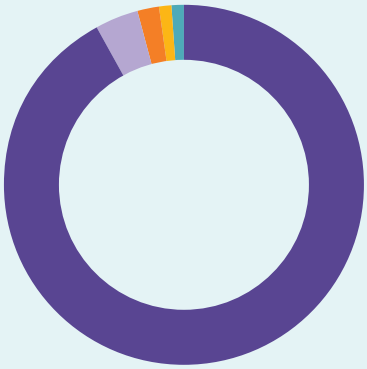
- **92%** Female
- **6%** Male
- **1%** Prefer not to say



Race

Choose one or more races that you consider yourself to be:

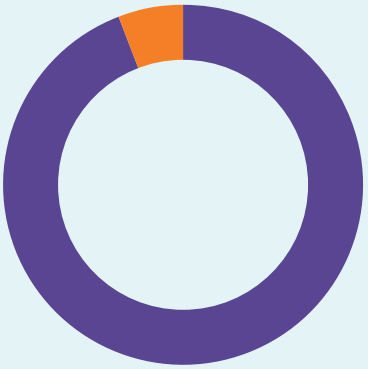
- **93%** White or Caucasian
- **4%** Other
- **2%** Black or African American
- **1%** Asian
- **1%** Prefer not to say



Ethnicity

Are you of Spanish, Hispanic, or Latino origin?

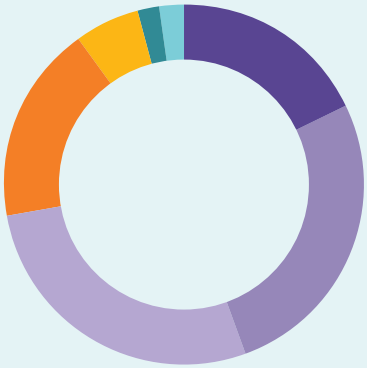
- **94%** No
- **6%** Yes



Age

How old are you?

- **18%** 65+ years old
- **27%** 55-64 years old
- **28%** 45-54 years old
- **18%** 35-44 years old
- **6%** 25-34 years old
- **2%** 18-24 years old
- **2%** Under 18



About HPA

The HypoPARAthyroidism Association is dedicated to improving the lives of people impacted by hypoparathyroidism (hypoPARA) through education, support, research, and advocacy. With over 5,000 members, we strive to be a reliable, dedicated, accessible, inclusive, and empowering resource for hypoPARA patients and families.

The Voices of HypoPARA v2.0 survey was conducted to highlight the experiences of patients in the US who are living with hypoPARA. The survey consisted of questions that focused on evaluating patients' experiences from diagnosis, to treatment and care, and quality of life. The survey was distributed to HPA members between October 27 and November 30, 2023. A total of 227 qualified responses were analyzed.

HypoPARAthyroidism Association,Inc.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