Exploring Rare Disease Landscape Using Social Media Listening to Assess Patient Voices

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PCR112

Aim/Methodology (1)

Aim: Leverage **social media listening** as a powerful research method to provide real-world, **patient-focused insights** on Cushing's Syndrome (CS).
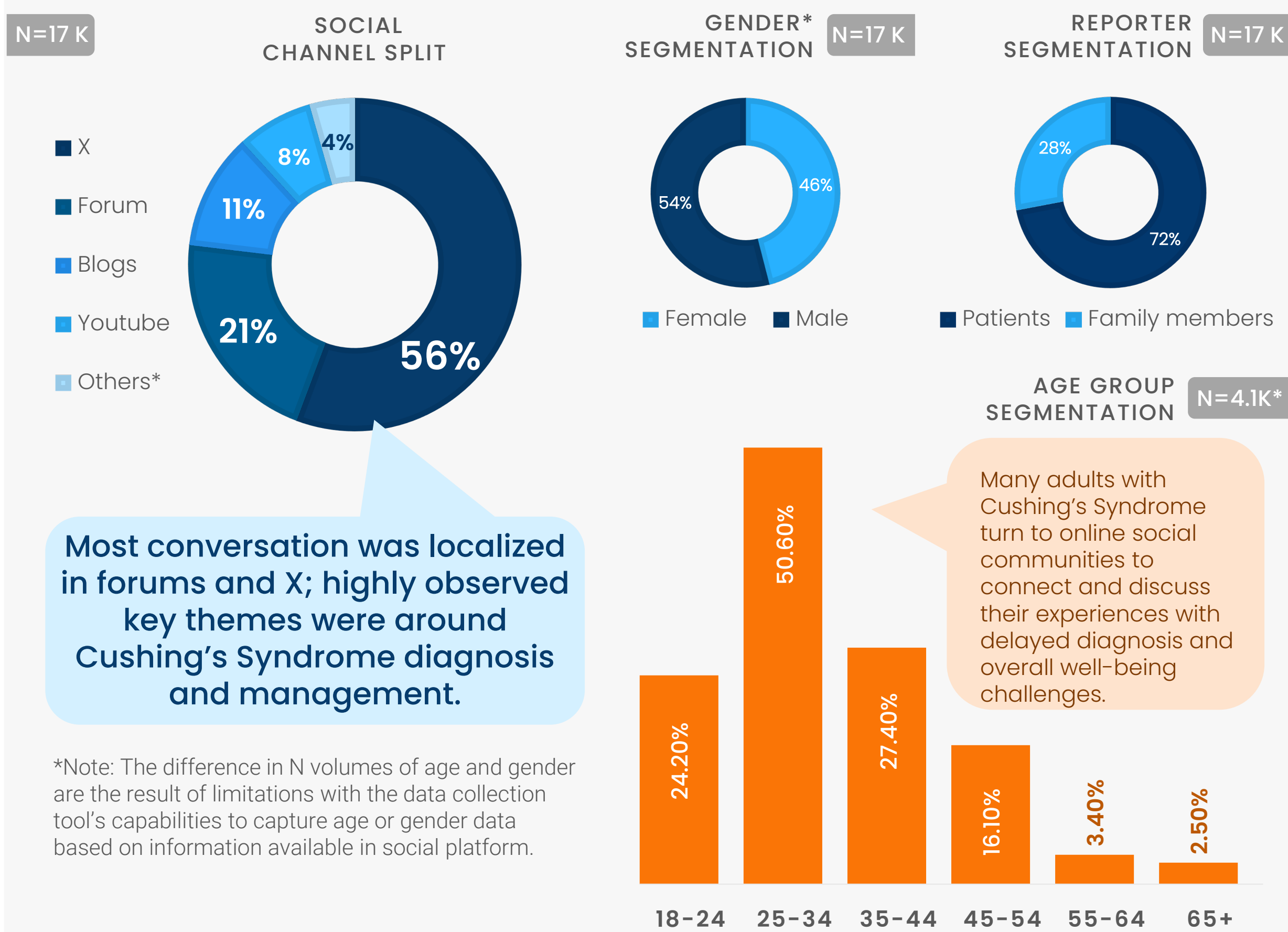
Why Cushing's syndrome?

Due to the disease **rarity and scarcity** of published patient data, Cushing's Syndrome (CS) is challenging to diagnose and often goes undetected, exacerbating a patient's health condition. Patient conversations on social media can be used to understand patient **grievances** in Cushing's, leading to improved patient health.
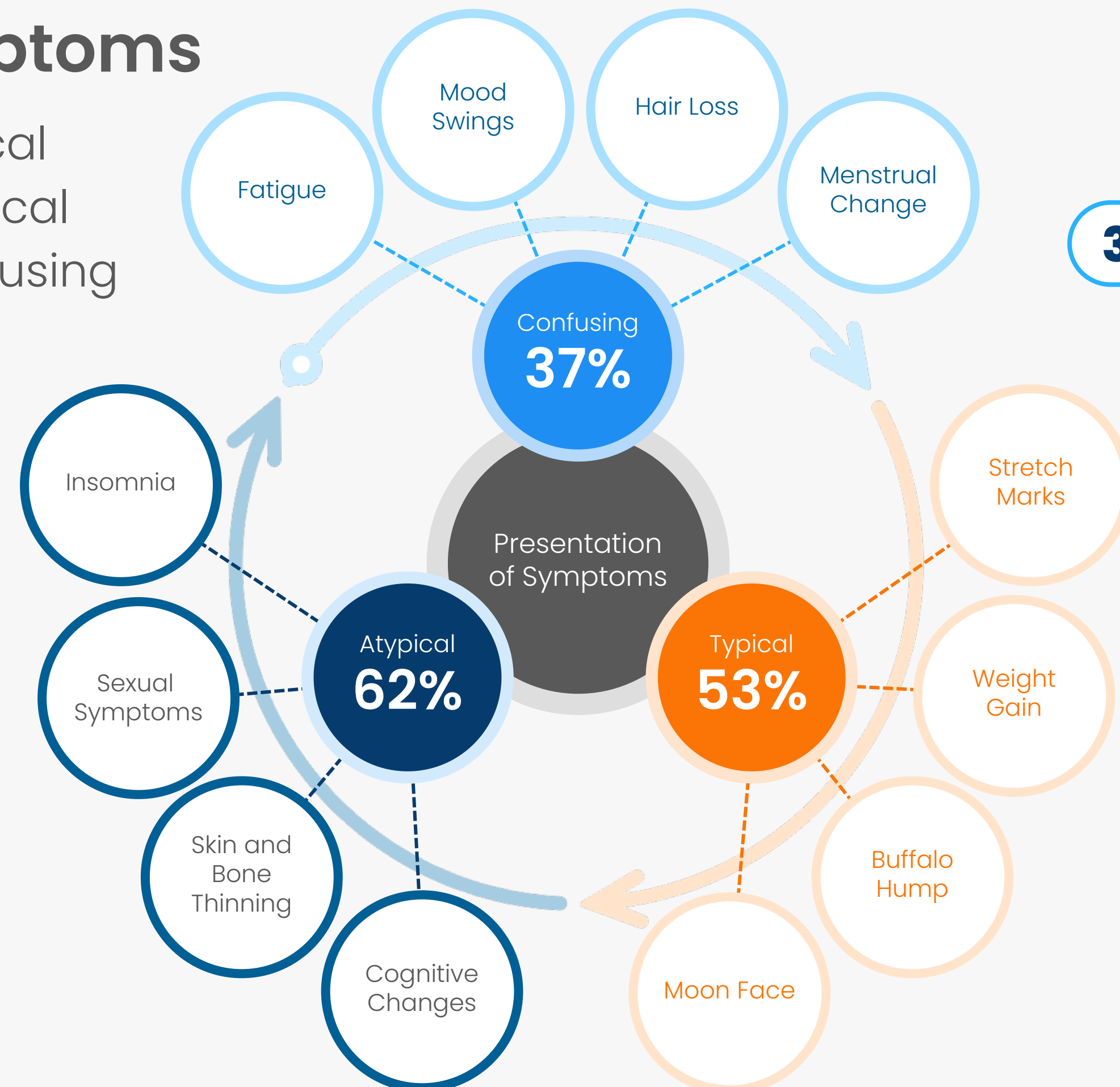
Methodology:

Data on **patient lexicon** for Cushing's syndrome was identified via research and a proprietary in-house tool. A conceptual model, guided by the **Cognitive Mediation Model,** was proposed to understand patient perspectives on social media. A Python web scraper complemented **manual** data collection, offering a comprehensive view of the data landscape.

Demographics (2)

N=17 K

SOCIAL CHANNEL SPLIT
- X 56%
- Forum 21%
- Blogs 11%
- Youtube 8%
- Others* 4%

GENDER* SEGMENTATION N=17 K
- Female 54%
- Male 46%

REPORTER SEGMENTATION N=17 K
- Patients 72%
- Family members 28%

AGE GROUP SEGMENTATION N=4.1K*
- 18-24: 24.20%
- 25-34: 50.60%
- 35-44: 27.40%
- 45-54: 16.10%
- 55-64: 3.40%
- 65+: 2.50%

Many adults with Cushing's Syndrome turn to online social communities to connect and discuss their experiences with delayed diagnosis and overall well-being challenges.

Most conversation was localized in forums and X; highly observed key themes were around Cushing's Syndrome diagnosis and management.

*Note: The difference in N volumes of age and gender are the result of limitations with the data collection tool's capabilities to capture age or gender data based on information available in social platform.

Symptoms (3)

- Typical
- Atypical
- Confusing

Presentation of Symptoms
- Confusing 37%
- Atypical 62%
- Typical 53%

Mood Swings, Hair Loss, Menstrual Change, Fatigue, Insomnia, Stretch Marks, Sexual Symptoms, Weight Gain, Skin and Bone Thinning, Buffalo Hump, Cognitive Changes, Moon Face
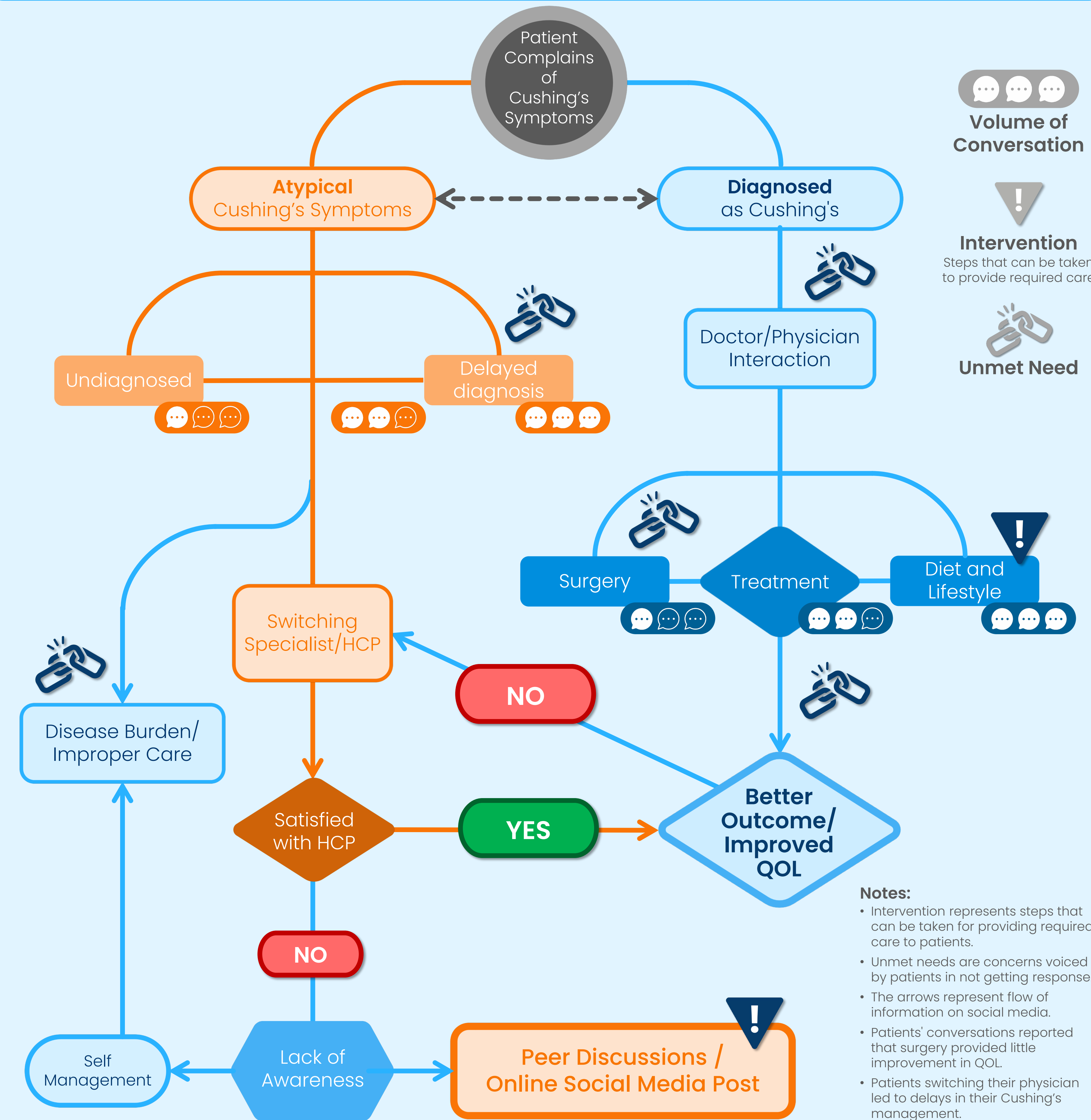
N=10K

PATIENT JOURNEY (Patient Journey)

Delayed identification and management of Cushing's syndrome drives patients to reach out to online forums

Patient Complains of Cushing's Symptoms

- Atypical Cushing's Symptoms ⟷ Diagnosed as Cushing's
  - Undiagnosed
  - Delayed diagnosis
  - Doctor/Physician Interaction
  - Switching Specialist/HCP
  - Surgery — Treatment — Diet and Lifestyle
  - Disease Burden/Improper Care
  - Satisfied with HCP → YES → Better Outcome/Improved QOL
  - NO
  - Self Management ← Lack of Awareness → Peer Discussions / Online Social Media Post
  - NO

Volume of Conversation

Intervention — Steps that can be taken to provide required care

Unmet Need

Notes:
- Intervention represents steps that can be taken for providing required care to patients.
- Unmet needs are concerns voiced by patients in not getting response.
- The arrows represent flow of information on social media.
- Patients' conversations reported that surgery provided little improvement in QOL.
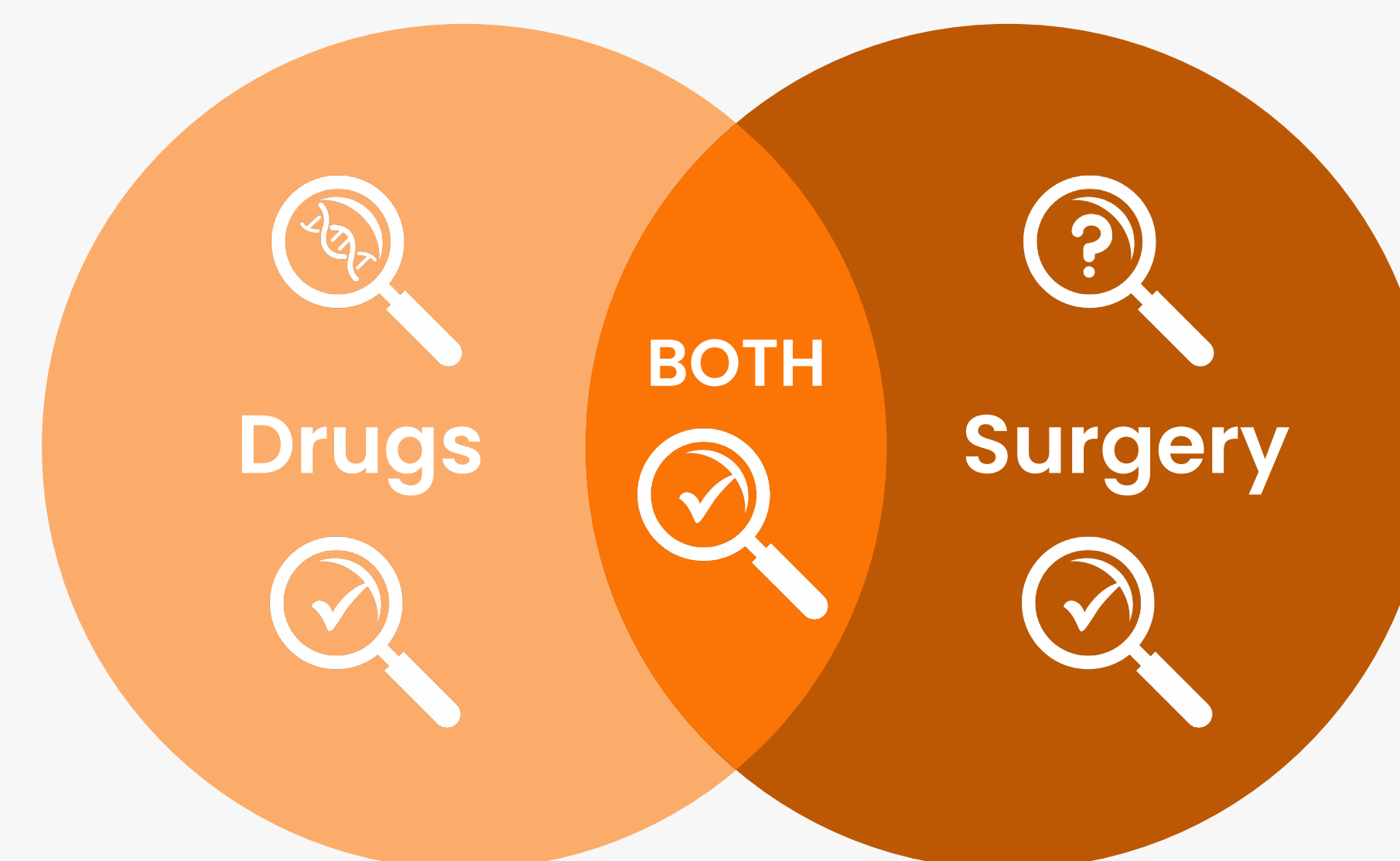- Patients switching their physician led to delays in their Cushing's management.

Patient segments (4)

Most suspected Cushing patients are treated with first line treatment, while definitive or predisposed Cushing's patients are treated with both surgery and drugs to manage the symptoms, but longer time and high cost of disease management creates distress amongst patients.

- **Suspected** Cushing's
- **Predisposed** Cushing's
- **Definitive** Cushing's

Drugs — BOTH — Surgery

N=5K

Patient Information Gaps (5)

- Diet & Lifestyle 0.2%
- Treatment Effectiveness 0.4%
- Disease Awareness 3.8%
- Treatment Options 5.6%
- Recovery Post Op 8.0%
- Diagnosis 23.7%
- Specialist 26.6%
- Symptoms 31.7%

N=13K

Recommendations (8)

- Integrating **patient-centric endpoints** in HEOR studies improves real-world data assessment, aiding **informed decision-making** by healthcare stakeholders.
- Partnering with advocacy groups and patient organizations improves education on **effective disease management**, enhancing **treatment adherence** and timely medical attention, thus reducing healthcare burden.
- Directing resources towards early diagnosis and access to local Cushing specialists **saves costs** by avoiding unnecessary procedures and enhances patient quality of life.
- Analyzing social conversations by region helps allocate resources effectively by **identifying geography** with high patient concentrations.

Patient Physician Interaction (7)

Awareness
Delayed diagnoses in many patients underscore the necessity for heightened awareness among healthcare professionals due to **insufficient information.**

Misdiagnosis
Patients frequently experience frustration due to the lack of **definitive tests** for Cushing's diagnosis, leading them to resort to self-diagnosis and potentially risking their health.

Doctor Availability
Frequent **appointment cancellations** suggest unavailability of doctors, resulting in delays in providing necessary care for patients.

Feeling Unheard
The prolonged uncertainty and dismissal by medical professionals can deeply impact patients, causing significant **emotional trauma** and affecting both their physical and mental well-being.
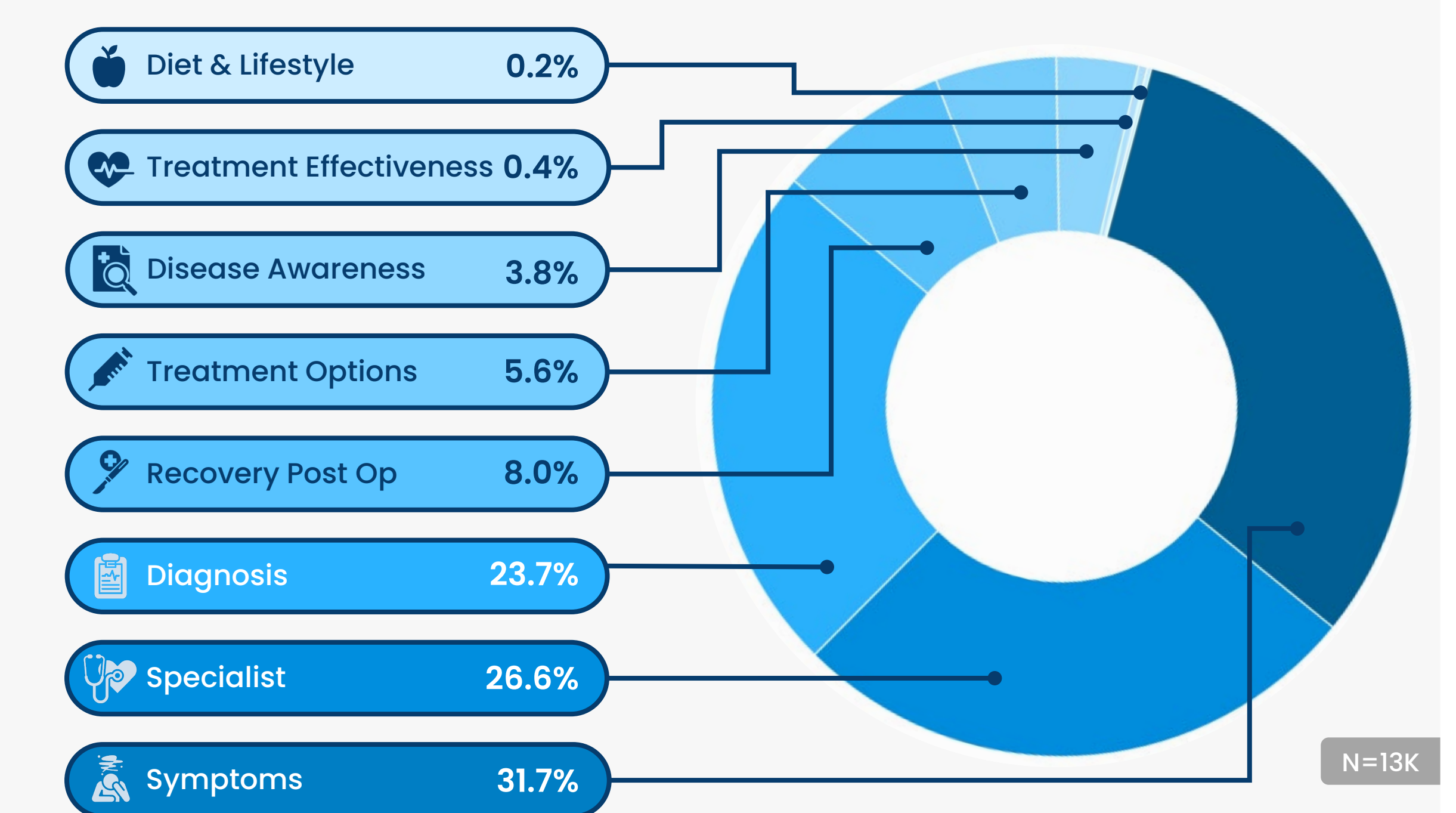
N=6.4K

Unmet Concerns (6)

Reduced quality of life, lack of support from HCPs and peers, delayed diagnosis, and misdiagnosis were some of the major patient concerns.

Quality of Life ~ 29%
Cushing's patients impacts patients' **physical abilities** and affects their day-to-day activities. For some, it was emotionally distressing which in turn also **impacted their work** and social life.

Ineffective HCP Communication ~ 25%
Low confidence in consultation, lack of face time, negligence and lack of empathy, not addressing specific patient queries, **delayed diagnosis** and **misdiagnosis** were some of the HCP related issues.

Emotional / Peer Support ~ 17%
As patients were affected emotionally, they looked for support from their family and relatives. Some patients felt isolated and sought **emotional support from peers online** in similar situations.

Delayed Diagnosis or Misdiagnosis ~ 15%
Patients discussed their experiences with **incorrect diagnosis,** that further led to delay in CS* diagnosis.

Caregiver Support ~ 14%
Patients sought information on caregiver **support groups** where they could exchange and discuss their experiences about living with Cushing's syndrome.

N=10K