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Real Life Impact of Cushing's Syndrome: A Shared Global Story

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Introduction

Cushing's Syndrome creates short- and long-term challenges to physical and mental health. Clinical and surgical outcome statistics have improved over time, but patients continue to report diagnosis delays, confusion about treatments, and the feeling of being “dropped” once cortisol is normalized. White matter is damaged by persistent high cortisol, and a return to eucortisol often unmasks new or worsened autoimmune, neuropsychological, physical, and other conditions.

Hypothesis

Patients have been sharing best practices and supporting each other through patient networks for decades on topics that are misunderstood, dismissed, and under-treated in the clinical setting. Improvements to care will come faster if this kind of patient-created data is made widely available, and advocacy groups must establish an acceptable method to accomplish this.

Methodology

A committee of patients reviewed the design and content of two large Quality of Life surveys conducted in recent years, then built a new survey for a larger international patient cohort. SurveyMonkey was used for layout and response collection. Spanish and French translations were done with DeepL then cleaned up by native speakers. The survey was then promoted within global patient advocacy organizations and on social media. The survey comprised over 150 questions and received 438 responses from 38 countries. nearly unanimous about life-shortening cardiovascular damage and changes to the brain.

Results

Respondents answered questions about their daily lives including physical, emotional, mental and social well-being. Examples:

- 75% of respondents are still trying to determine their “new normal”.
- Over 80% report memory problems that did not exist before.
- Almost 90% took much longer than six weeks to return to work in any capacity.
- A third of male patients and a fifth of female patients report that their marriage or long-term relationship ended because of Cushing's.
- Almost half of respondents felt that their medical team was unable to support them beyond cortisol issues.
- More than 50% who answered this survey have experienced suicidal thoughts due to the overwhelming nature of Cushing's.

Conclusion

Dr. Harvey Cushing, namesake of the disease, identified the most underrated element of the patient experience when he made his famous statement:

“A physician is obligated to consider more than a diseased organ, more than even the whole man—he must view the man in his world.”

The man in his world. The results of our study paint a picture of the ongoing burden of hypercortisolism that often starts seven or more years before an official diagnosis is made and continues indefinitely. Patients can help fast-track the identification of areas where more work needs to be done. It is therefore incumbent on a group of well-organized advocates to develop a structure that translates the patient voice into datasets that are useable by all doctors, researchers, and stakeholders in the Cushing's community.

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