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## 1 INTRODUCTION

Cushing's Syndrome (persistent elevated cortisol) causes many non-specific physical, metabolic, and neuropsychological morbidities. Long-term QoL issues are under-represented in literature and minimally understood by doctors. **The scope of damage a patient will face is directly related to:**

- **time to diagnosis**
- **experience of the doctors and surgeon**
- **the support, referrals, follow up, and education received after surgery**

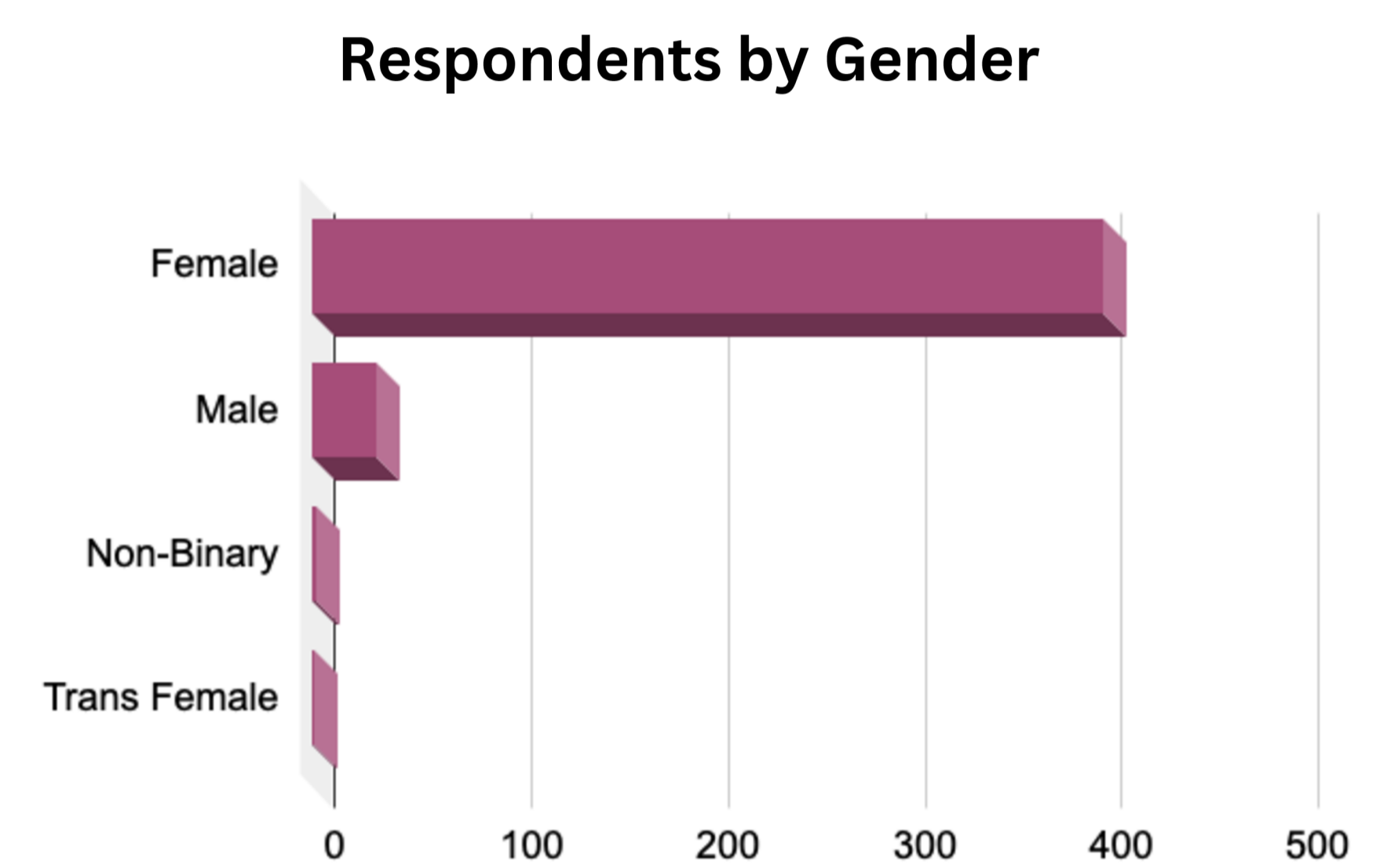
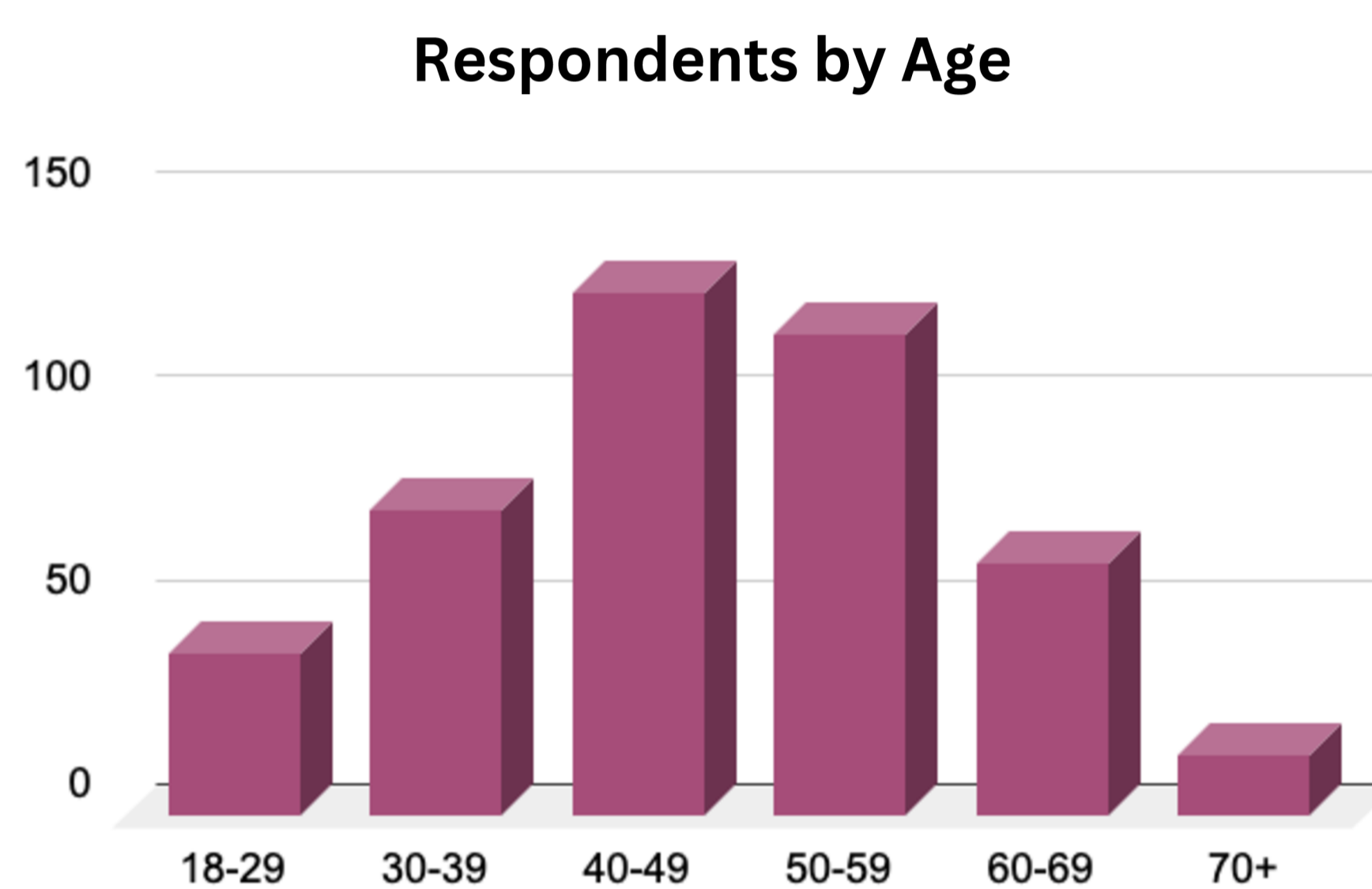
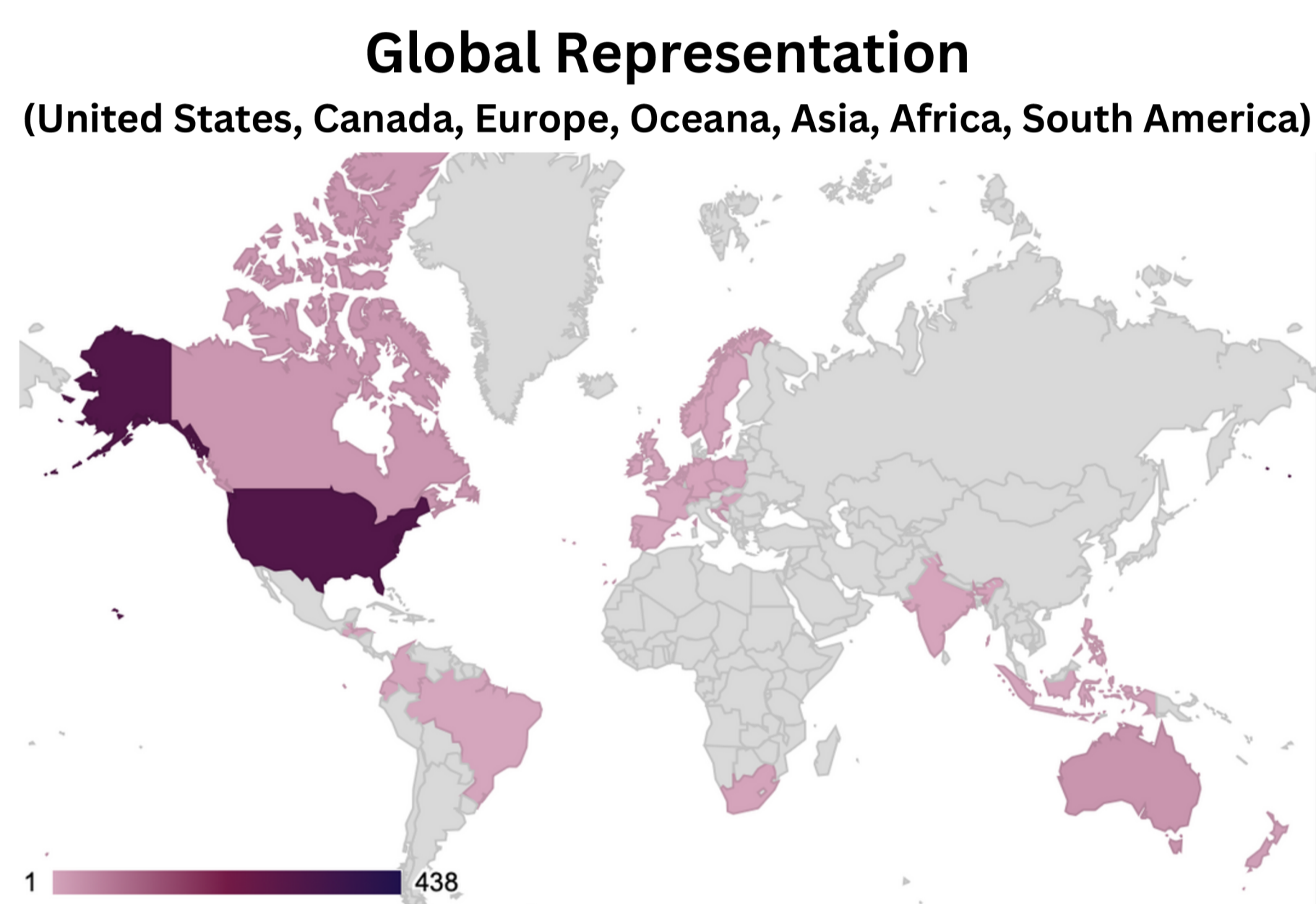
## 2 METHODOLOGY

In 2023, a committee of patient advocates built a quality of life survey with over 150 questions using examples from two previous patient-created studies done by CSRF in 2020 and 2022. This survey was translated into Spanish and French, then shared amongst multiple global support communities via email and social media. SurveyMonkey was used for layout and response collection.

## 3 DIAGNOSTIC ODYSSEY & RESULTS

The survey received 438 responses from 38 countries. Though the majority of respondents were from the United States, the unprecedented collaborative efforts of international patient organizations was reflected in the volume of responses and added depth to the data.

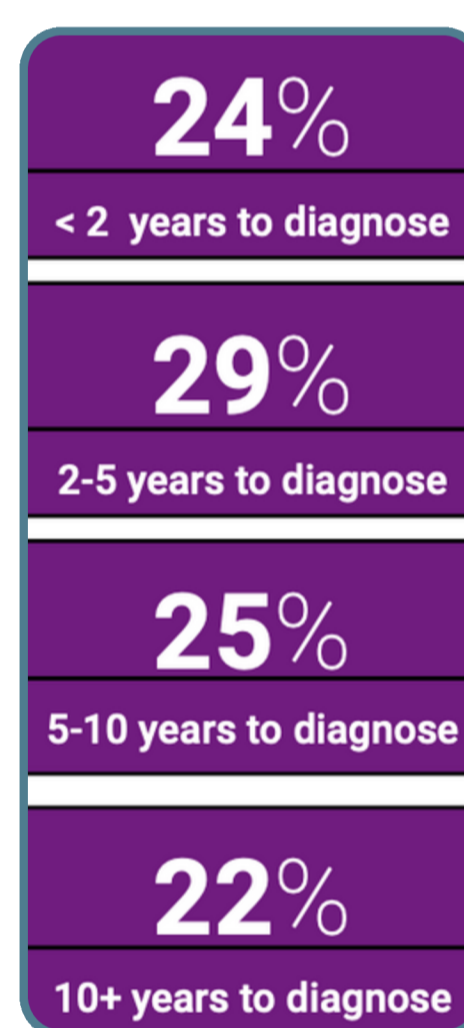
### DEMOGRAPHICS & PROFILES



### BY THE NUMBERS

#### Delay in diagnosis equates to worse long-term prognosis –

It took more than 10 years for a full quarter of respondents to get an accurate diagnosis.



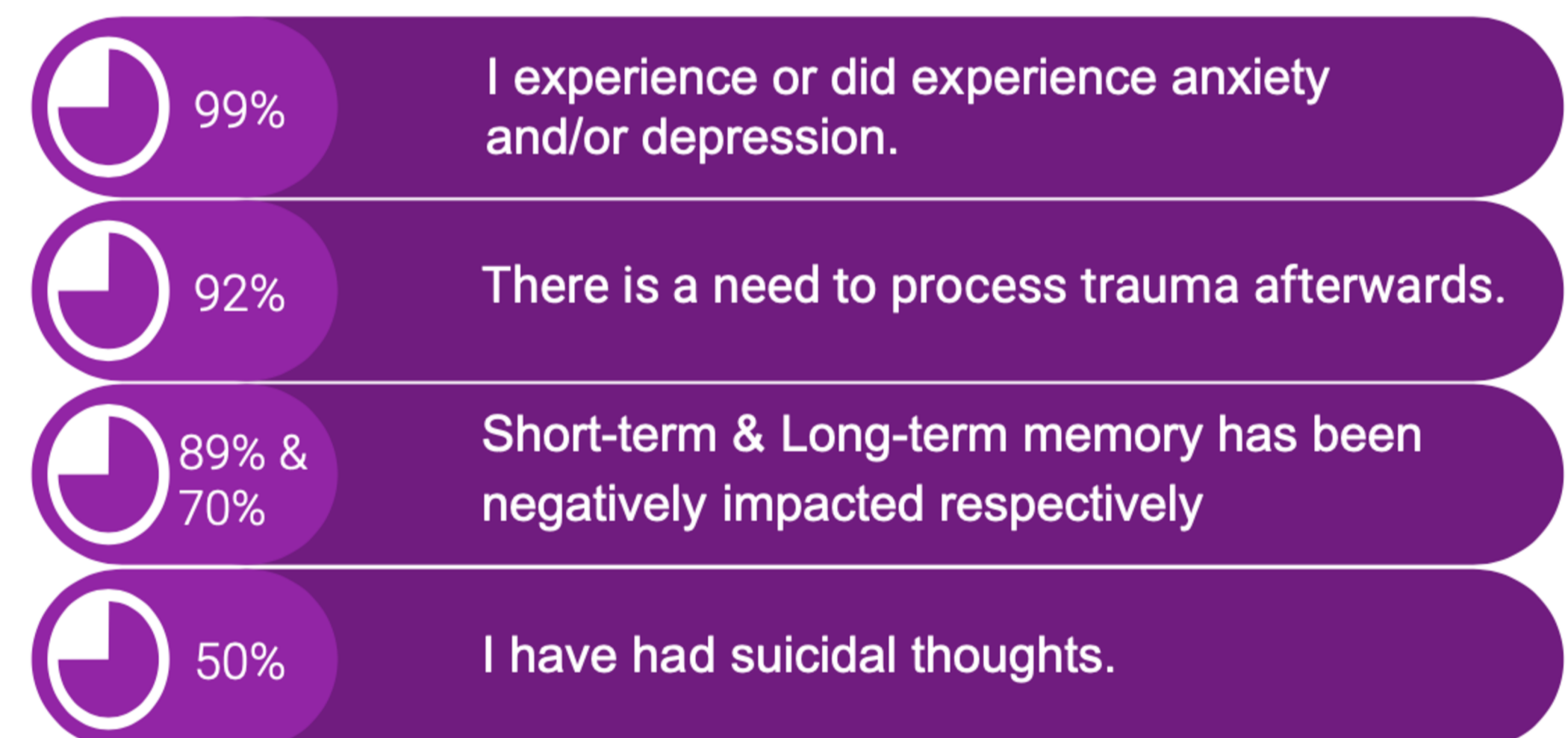
#### Cushing's is overwhelming –

Over 90% of respondents said they were negatively impacted by the complexity of symptoms and that it is almost impossible to fully understand the diagnosis in the beginning.



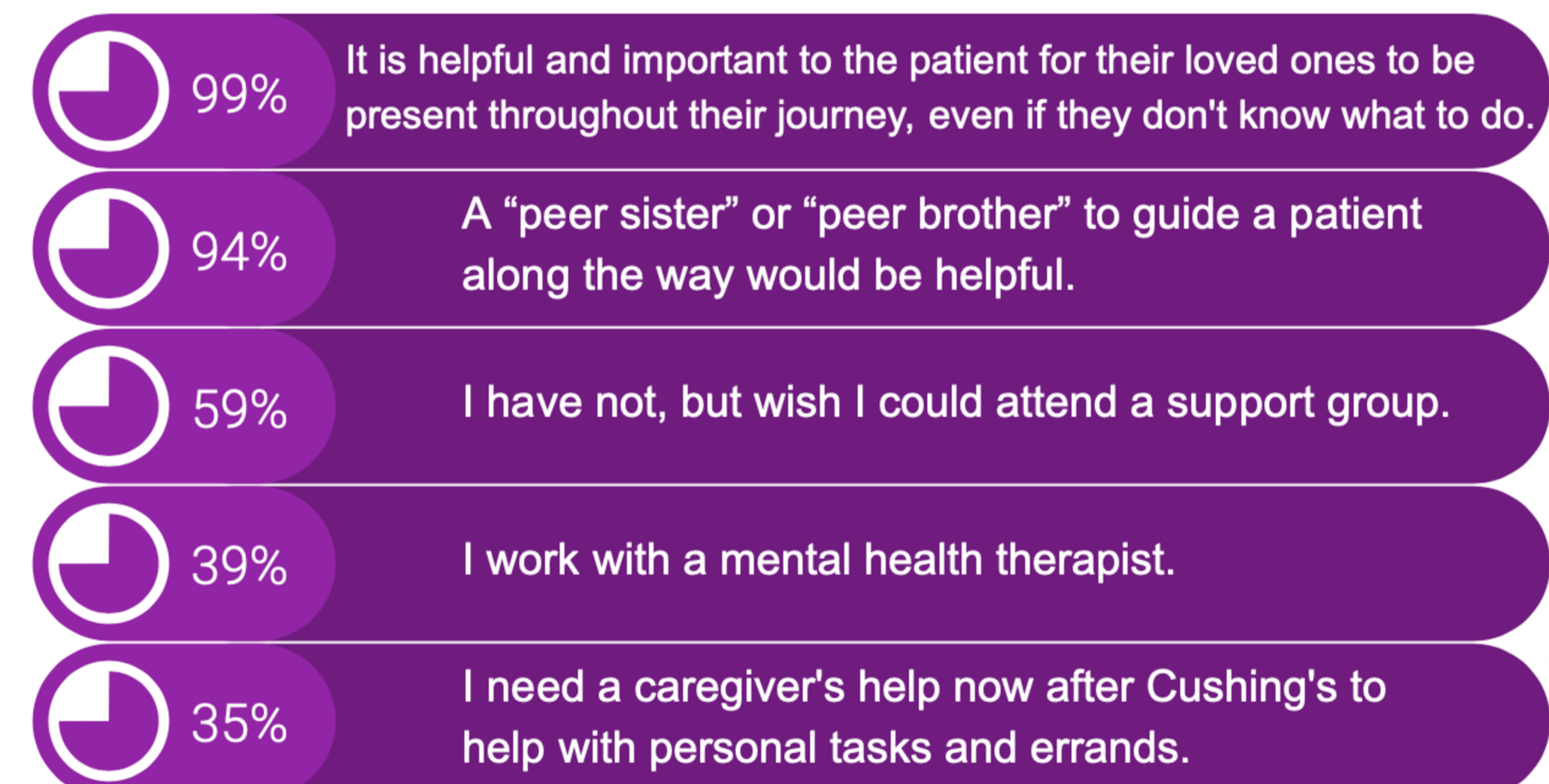
#### Mental health support is vital –

It was nearly unanimous that mental health support should be part of a patient treatment package (99.3%) and that therapy can be helpful even when a patient has good coping skills (95.7%); a need to process trauma after Cushing's was expressed by 92% of participants.



#### Peer support can be priceless –

98% agree that it is beneficial to share experiences with other patients, and 94% said that a "peer sister" or "peer brother" to guide a patient along the way would be helpful.



**The devastating reality** – Almost three quarters of patients reported that grief has been constantly present throughout the journey and they were not prepared for what life was like after surgery, and concern is nearly unanimous about life-shortening cardiovascular damage and changes to the brain.

## 4 CONCLUSION

We must ignore "rare" bias and consider these people in their worlds, as Dr. Harvey Cushing compelled us all to do. Treat all patients as if they were your spouse, sibling, or friend telling you how they suffer. Know that you are not even hearing the entire story. Patients need and deserve validation, treatment, and referrals. Partnering with a patient advocacy organization can provide crucial missing pieces to the puzzle of better care for rare.

SCAN FOR DATA FROM OUR 2020-2024 QOL STUDIES



## 5 NEXT STEPS

- **CSRF is building a global Cushing's Patient Registry to professionalize our studies. Join us!**
- **Identify health inequities and work together to eradicate them.**
- **Collaborate/partner on projects that can be used by everyone, everywhere.**
- **Encourage and help establish more global support and advocacy groups.**