

Impact of Mental Health Stigma on Outcomes in Pheochromocytoma

Elise Hachfeld

Secondary Division | Chapter #11021 | Apple Valley High School | Minnesota



Abstract

Background

- Pheochromocytomas and paragangliomas are rare neuroendocrine tumors (NETs).
- Up to 50% are diagnosed at autopsy, and 25-64% are discovered incidentally.^{[6][18]}
- Differential diagnosis includes anxiety disorder, the most common mental illness.^[20]
- Stigma toward people with serious mental illness increases mortality rates.^[7]
- Experience with psychiatric patients decreases stigma.^[12]

Purpose

- Does mental health stigma impact the accurate diagnosis of pheochromocytoma?
- Explore the relationship between diagnostic interval and patient experience.
- Investigate mental health stigma as a potential cause of diagnostic delay.
- Identify possible solutions to decrease the mortality rate and improve outcomes.

Study Design

- Patients recruited in online forums completed a short questionnaire.
- Questions included measures of symptom severity, quality of life, and satisfaction.
- Statistical analysis in RStudio and SPSS revealed relationships between survey items.

Findings

- Even after diagnosis, patients experience a significantly decreased quality of life.
- Mental health stigma contributes to the misdiagnosis of pheochromocytoma.
- Experience treating psychiatric patients benefits rare disease patients as well.
- Clinicians should consider excluding NETs as a cause of refractory anxiety, hypertension, or cardiovascular disease.

Methods

Target Population

- Adults (18+ years old) diagnosed with pheochromocytoma or paraganglioma.

Data Collection

- Snowball sampling aided in reaching a limited target population.
- Patients agreed to an informed consent form before entering the questionnaire.
- **Online Questionnaire** (cost-effective, increases participation, ensures anonymity)
 - Demographics: Identify sampling bias and potential disparities in care.
 - Likert Scales: Assess satisfaction with and opinion of healthcare providers.
 - HRQOL-14^[5]: Quantify health outcomes.
 - Free Response: Further understand the patient experience.

Data Analysis

- Statistical analyses performed with RStudio and SPSS provided interpretable data.
- Tests included crosstabulation, bivariate correlation, and linear regression.
- Likert Scale internal consistency confirmed with Cronbach's Alpha ($\alpha = .752$.)
- After stop word removal, word frequency sorting discerned common responses.
- HRQOL-14 responses compared to Behavioral Risk Factor Surveillance System data.
- Quotes, scatter plots, bar graphs, and tables visualize the data.

Potential Biases

- Respondents likely have more social connections and increased internet activity.
- The sample has low demographic diversity and may not represent the whole population.

Results

What do you wish healthcare providers knew about your condition?

"It's not some benign, easy to treat condition. It's debilitating."

"I wish they would know what it is!"

"Listen to your patients, they live with it."

"Not every sufferer has all the main symptoms."

Describe your path to diagnosis.

"Change in mental status, requiring psychiatric help."

"Dismissed as treatment resistant anxiety for many years even though I had [a] previous pheo."

"I was fit and healthy otherwise, so no one suspected anything was wrong. [...] Cardiologist dismissed me as an anxious timewaster."

Describe any symptoms you experienced.

"Insomnia, irritability, anxiety without cause. I was dismissed as a drug seeker."

"They are debilitating. I've lost my independence. Doctors thought I was making things up."

Interpretation

- The most common misdiagnoses were anxiety (50%), followed by primary hypertension (42%), migraine headache (39%), depression (35%), and panic disorder (23%).
- Symptoms are most commonly "very severe," and increased symptom severity is associated with misdiagnosis of depression (Figure 1.)
- Older patients perceived clinicians to be less knowledgeable about their condition (Figure 2.)
- A long and convoluted path to diagnosis is a burden on both the patient and the healthcare system and can be remedied partially by better communication.

Conclusion

Discussion

- People with pheochromocytoma have a significantly lower quality of life than the overall United States population (Figure 3.)
- Mental health stigma affects people living with mental illness **and** rare disease patients. Patients reported feeling dismissed despite suffering debilitating symptoms.
- Further research is necessary to investigate clinician perspectives on this topic.

Significance

- Even with exceptional medical care, some people may not be diagnosed until death.
- Pheochromocytomas may be more prevalent than currently recognized because most people who die of heart disease or stroke are not autopsied.
- The relationship between physical and mental illness often remains unrecognized.
- Severe symptoms can cause depression, masking the primary cause of illness.
- Clinicians can reduce the mortality rate of pheochromocytoma patients by increasing their experience with psychiatric patients.



George Floyd Mural in Minneapolis, Minnesota | Chad Davis
Diagnosed with Paraganglioma upon autopsy^[1]



President Dwight D. Eisenhower | Smithsonian
Diagnosed with Pheochromocytoma upon autopsy^[14]

Figures

Figure 1: Symptom Severity vs. Misdiagnosed with Depression

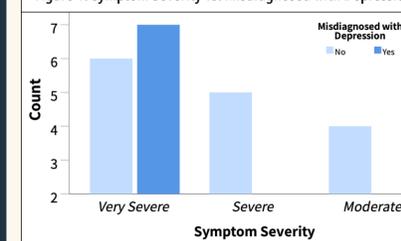


Figure 2: Perceived Knowledgeability vs. Respondent Age
 $r(24) = .40, p < 0.05$

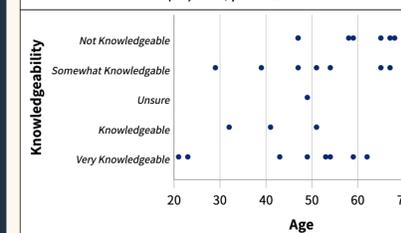


Figure 3: Quality of Life for Respondents vs US Population



Acknowledgements

- Emma Laskey
- Pheo Para Alliance
- Helen Anderson
- Pheo Para Project

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