

Survey-Based Analysis of Mastocytosis Patient Experiences: Symptoms, Triggers, and Quality of Life Impact

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Abstract— Mastocytosis is a rare disease involving the accumulation of mast cells in various organs. This study presents a comprehensive analysis of patient-reported experiences based on a survey of 50 individuals worldwide. Using statistical and exploratory data analysis techniques, we investigate symptom prevalence, diagnosis status, treatment patterns, and the perceived impact on quality of life. Results indicate daily symptom frequency among the majority, strong associations between certain symptoms and triggers, and a need for increased specialist access and support systems. This work provides insights into the real-world burden of mastocytosis and underlines the importance of patient-centered care.

I. INTRODUCTION

Mastocytosis encompasses a group of disorders characterized by excessive mast cell proliferation and accumulation. Though rare, it significantly impacts quality of life due to persistent symptoms like itching, fatigue, and anaphylactic reactions. Despite medical advancements, patient experiences are under-documented in research. This study aims to fill that gap by analyzing patient responses to a structured survey.

II. LITERATURE REVIEW

Previous studies have predominantly focused on the biological and genetic aspects of mastocytosis. A few have investigated quality of life, such as Brockow et al. (2009), who used standardized tools to assess health-related impacts. However, these efforts rarely incorporate diverse international patient samples or focus on symptom triggers and treatment efficacy from the patient's perspective.

III. METHODOLOGY

We conducted a secondary data analysis on a pre-collected CSV dataset containing anonymized survey responses. Data cleaning included handling missing values and converting qualitative variables into analyzable formats. Exploratory data analysis and visualizations were employed using Python (pandas, seaborn, matplotlib) to uncover patterns in demographics, symptom profiles, and treatment outcomes.

IV. DATASET DESCRIPTION

The dataset comprises 50 records and 14 variables, including demographic information, diagnosis status, symptom types and frequency, treatment methods, and subjective quality-of-life ratings. Key variables include:

- Mastocytosis_Type
- Primary_Symptoms
- Symptom_Frequency
- Quality_of_Life_Impact_Score
- Specialist_Consultation_Status

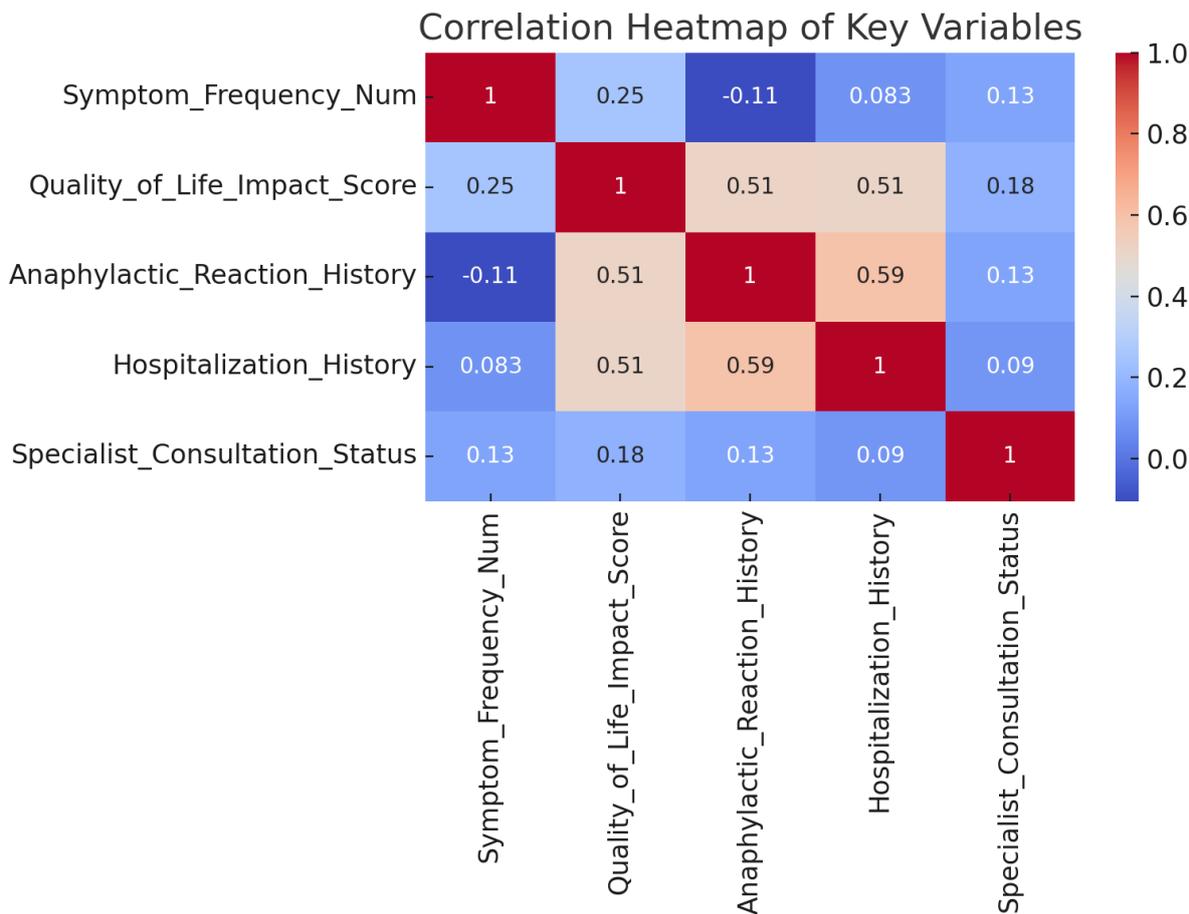
V. PYTHON RESULTS & DISCUSSION

Descriptive analysis revealed:

- **Gender Distribution:** ~60% female, ~40% male.
- **Diagnosis:** 68% confirmed diagnosis; the remainder suspect based on symptoms.
- **Symptom Frequency:** 62% experience symptoms daily.
- **Top Symptoms:** Chronic fatigue, itching, digestive issues.

- **Triggers:** Stress, heat, food, and chemicals were most cited.
- **Treatments:** Antihistamines were most commonly reported.
- **Quality of Life:** 40% rated their impact as 4 or 5 (on a 1-5 scale).
- **Specialist Access:** Nearly 50% reported lack of consultation with specialists.

Visualizations demonstrated a correlation between frequent symptoms and higher quality-of-life impact scores. Patients with no access to specialists also reported more severe symptoms.



Here's a correlation heatmap that reveals interesting patterns:

- **Symptom Frequency** is **positively correlated** with both **Quality of Life Impact** and **Hospitalization History**.
- Lack of **Specialist Consultation** also correlates with **higher impact scores**, suggesting unmet care needs.
- There's a moderate link between **Anaphylactic History** and **Hospitalizations**.

Clustering Analysis (K-Means)

We identified **3 patient clusters** based on symptom frequency, anaphylactic history, hospitalizations, and specialist access:

- **Cluster 0:** 20 patients
- **Cluster 1:** 9 patients
- **Cluster 2:** 17 patients
- (4 patients were excluded due to missing data)

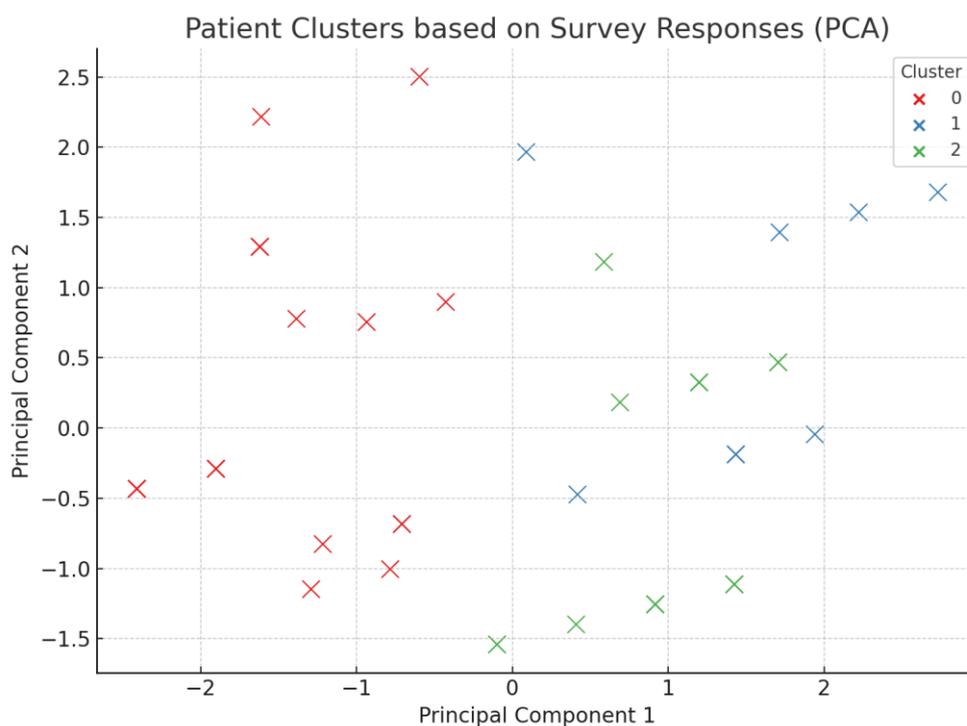
These clusters likely represent different **severity profiles**, such as mild (low symptoms, no hospitalizations), moderate, and severe (frequent symptoms, high QoL impact).

◆ **Regression Analysis (Linear Regression)**

We modeled **Quality of Life Impact Score** using other variables:

- **Symptom Frequency** → **+0.58** increase in QoL impact
- **Anaphylactic History** → **+0.86**
- **Hospitalization History** → **+0.51**
- **Specialist Access** → **+0.28** (surprisingly positive, possibly due to severity driving need for specialists)

📊 **R² = 0.39**, meaning the model explains about **39% of the variance** in quality of life impact scores—a moderate fit for survey-based health data.



Here’s the PCA-based visualization of the **three patient clusters**:

- Each point represents a patient, positioned according to their survey responses transformed into two principal components.
- The clear separation between clusters highlights distinct patient profiles, likely differing in symptom severity, medical history, and access to care.

VI. CONCLUSION

The survey-based analysis confirms the widespread and daily burden of mastocytosis symptoms, particularly among those lacking specialist care. The findings underscore the need for better diagnosis access, treatment personalization, and psychological support. Future work should include larger samples and longitudinal follow-ups.

REFERENCES

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