



EXAMINING ANTICIPATED HEALTH CARE STIGMA AMONG ADULTS WITH RARE DISEASE: THE ROLE OF NUMBER OF RARE DISEASES AND SATISFACTION AND TRUST OF PHYSICIAN AS SOURCE OF INFORMATION

Chandra Char MPH, Veronica Irvin PhD MPH & Kathleen Bogart PhD



BACKGROUND

- There are approximately 25-30 million people (prevalence of 200,000) in the US who have a Rare Disease or disorder (RD).
- RDs affect approximately 1 in 10 individuals in the US.
- There are more than 7,000 different RDs.
- People with RD who experience anticipated stigma from health care providers (HCPs) are less likely to access health care.
- Although RDs may vary in etiology, symptoms and severity, many RDs are chronic, the struggle often comes from trying to find a diagnosis.
- Due to the uniqueness of RDs, many health care providers may not be knowledgeable about treatment options or be in a position to educate patients on their condition. This may impact patient's trust in their provider as a source of information.

STUDY AIMS

Determine the relationship between number of rare diseases and anticipated health care stigma (AHCS) for adults in the US with turn to physician for information, satisfied with physician as a source of information and trust physician as a source of information as moderators.

METHODS

This project analyzed data from the Adults with Rare Disorders Support (AWARDS) Study which surveyed 1218 US adults diagnosed with one or more RDs. The Chronic Illness Anticipated Stigma Scale (CIASS) was used to measure anticipated stigma using only the AHCS subscale. Data originally collected in 2017.

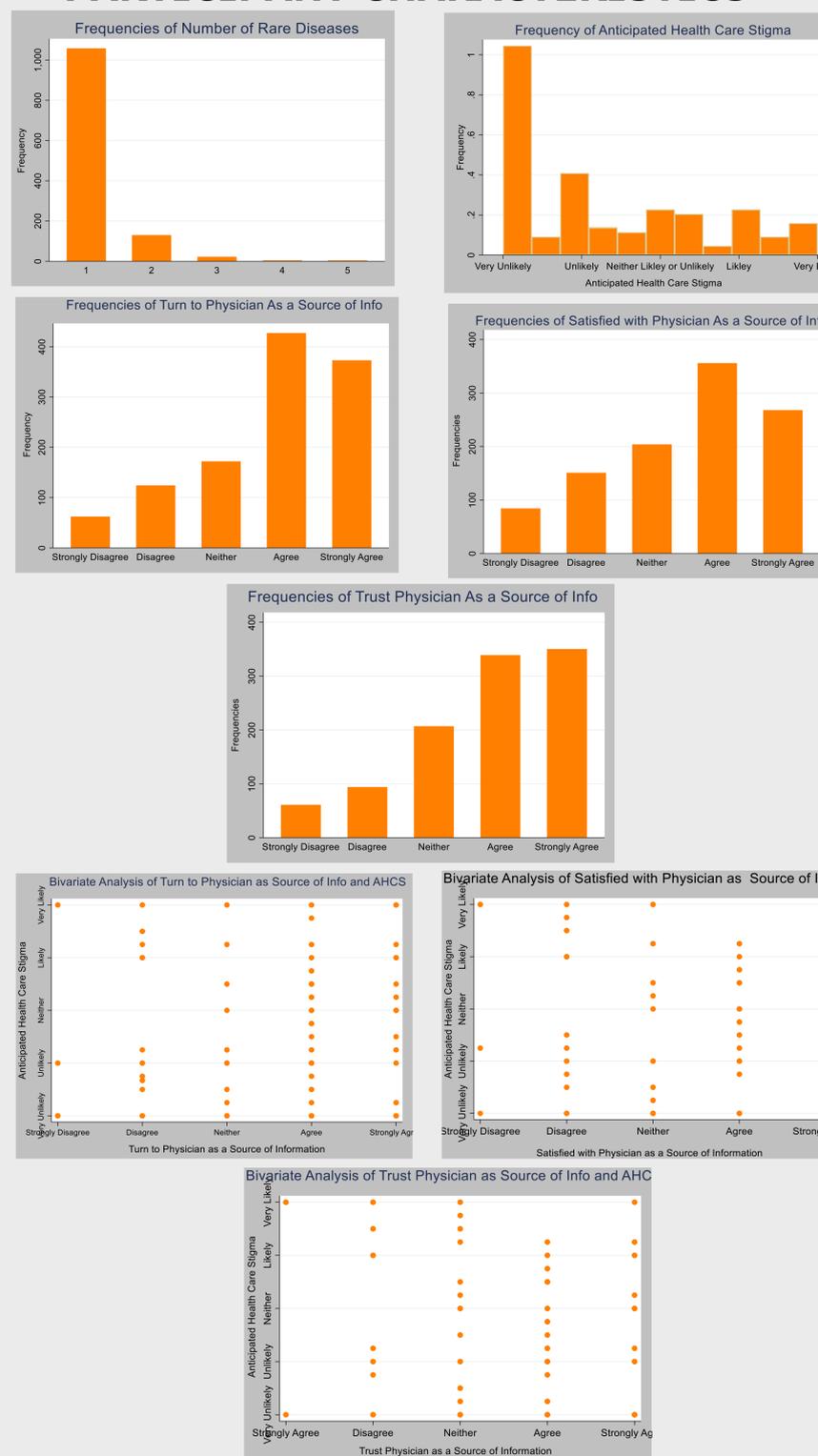
Gender: 77% of the participants were females. This is likely related to the fact that we recruited from Rare Disease organizations.

Race: Majority of the sample was white (94%).

Education: 29% of the population had a graduate degree or higher

Income: 32% of the population had an income of \$90,001 and above.

PARTICIPANT CHARACTERISTICS



RESULTS

Bivariate analysis was used for preliminary analysis of the relationship between number of RD and AHCS and moderators and AHCS. Results suggest that individuals with more than one RD experience more AHCS. AHCS was low for individuals that reported high satisfaction with information from a provider, high AHCS for individuals who do not use provider for information, and high AHCS for individuals with low trust in physician.

NEXT STEPS

This study requires further investigation. Proposed analysis plan includes:

- Multilinear Regression with backward stepwise elimination. Only significant interactions will remain in the final model to determine the role of these variables in the relationship between RD and AHCS.

CONCLUSION

- There is a significant relationship between number of RD and AHCS.
- We hypothesize that individuals with more than one RD will be less likely to turn to their health care provider for information regarding their RDs. Likewise, those with fewer RD may be more likely to turn to their physician for information regarding their RD.
- We hypothesize that those with more than one RD are less satisfied with the information provided by their physician. Similarly, individuals with fewer RD will be more satisfied with information provided by their physician.
- We hypothesize that individuals with more than one RD will have lower trust in their physicians.

DISCUSSION

- The results of this study help inform us of information seeking behaviors of individuals with Rare Diseases.
- This study also informs us of the role of trusting a physician plays in anticipated health care stigma for patients with rare diseases.

Acknowledgments: The authors would like to thank the Rare Disease Community and the Rare Disease Organizations that supported in data collection. As well as the Disabilities Network supporting disabilities scholarship on the OSU campus. The lead author would like to thank her parent's for their continual love and support during her doctoral education.