

Research Summary

Social Support, Stress, and Life Satisfaction among Adults with Rare Diseases

The Adults with Rare Disorders Support project aims to improve psychological and social support for people with a variety of rare diseases and disorders. This multi-part project involves surveys and focus groups. We are reporting results from the 4th study, recently published in Health Psychology.

Background

Though there are nearly 7,000 different rare diseases, people with rare diseases share common challenges such as diagnostic delays and a lack of information, treatment options, and social support. These challenges may explain why adults with rare diseases report worse quality of life and life satisfaction than those with more common conditions. For the current study, we were specifically interested in how different types of social support influence life satisfaction for adults with rare diseases. We tested whether support was directly related to life satisfaction, or whether support related to life satisfaction by reducing the negative effect of stress on life satisfaction.

Methodology

We completed a large-scale survey of adults living in the U.S. diagnosed with any rare disease. 1203 participants were included in this study. Participants were asked to rate their levels of social support, stress, and overall satisfaction with life. Four different types of social support were measured: Companionship, emotional, informational, and tangible. Companionship support refers to having people to engage in leisure activities with and generates a sense of belonging, emotional includes feeling understood and validated by others, informational includes advice from others, and tangible is help with physical tasks of daily living.

Findings

Controlling for relevant demographic and disease factors, we found that only companionship support and emotional support positively predicted life satisfaction, with companionship support being the strongest predictor. Informational and tangible support did not predict life satisfaction. Stress was negatively related to life satisfaction, but none of the four types of social support buffered this negative relationship.

Conclusions

Both companionship and emotional support are important predictors of life satisfaction for individuals with rare diseases, regardless of how much stress they are experiencing. Finding ways to increase the amount of companionship and emotional support in the lives of adults with rare diseases is thus essential to improving their satisfaction with life. While informational and tangible support were unrelated to life satisfaction in the current study, they are likely important to other outcomes and thus deserve further study.

Next Steps

We are currently collecting data using surveys and interviews to better understand the impact of the COVID-19 pandemic on people with rare diseases, including access to healthcare and information, and psychosocial support. We are also preparing to publish findings from an analysis looking at which types of support are considered most important for adults with rare diseases, why, and how they can be given. The long-term goal of this project is to develop recommendations for providing psychological and social support to people with rare diseases.

Recommendations

- **Rare disease organizations should increase social support for people with rare diseases.** Our previous research has shown that support groups and conferences are effective in providing social support and reducing feelings of isolation, making them a great avenue for improving life satisfaction.
- **Rare disease organizations should make support groups and conferences more accessible.** There are many accessibility issues to these sources of support, such as distance, cost, and a lack of accommodations for the varied symptoms of rare diseases. Some organizations are taking steps to address some of these issues by providing more regional options, resting rooms, and using video conferencing.
- **Greater rare disease awareness efforts are needed at local, state, and national levels.** Emotional support, a key predictor of life satisfaction, refers to feeling understood and validated by others. Greater awareness of rare diseases could lead to more people having a better understanding of these diverse conditions, thus increasing the availability of emotional support

Acknowledgements

Most importantly, we thank the participants with rare diseases for their time, effort, and generosity in sharing their experiences. This research was funded in part by an Oregon State University College of Liberal Arts Research Award. We thank NORD and the Coordination of Rare Diseases at Sanford for assistance with recruitment. We thank NORD and its member organizations who consulted with the authors regarding this research.

Reference

Bryson, B., & Bogart, K.R. (2020). Social support, stress, and life satisfaction among adults with rare diseases. *Health Psychology*. Advance online publication.



Oregon State
University



Brooke Bryson,
Psychology PhD student,
Oregon State University



Dr. Kathleen Bogart,
Associate Professor
of Psychology, Oregon
State University