

AWaRDS Study

Adults with **Rare Disorders** Support Study



Research Summary

Navigating the Unknown: A Content Analysis of the Unique Challenges Faced by Adults with Rare Diseases

Brooke Bryson, Kathleen Bogart, Makenzie Atwood, Kelly Fraser, Taylor Locke, Kiley Pugh, and Mohamed Zerrouk

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 second study, recently published in the *Journal of Health Psychology*.

Background

Currently, there are approximately 25-30 million Americans living with a rare disease (RD). Although there are about 7,000 different rare diseases, people with diverse rare disorders share similar challenges. Ours was the first study to look at similarities, as well as differences, in challenges unique to living with a RD across a variety of disorders.

Methodology

We completed the first large-scale survey of adults living in the U.S. diagnosed with any RD. 1157 participants were included in this study.

We analyzed responses to the question “What are the biggest challenges about living with your rare disorder?” We then created a list of categories (18) to capture these responses. On average, each participant mentioned approximately 4 challenges (Range: 1-28). Once the responses were separated into categories (e.g. symptoms, activity limitations, treatments, uncertainty) we counted how many times each category was mentioned.

Findings

Overall, participants mentioned **disease symptoms** most frequently as a challenge to living with their RD. For example, some participants said that “repetitive sinus and lung infections” and “constant pain that is fatiguing” were challenging for them. Participants also said **activity limitations** were challenging, such as performing daily activities like grocery shopping, laundry, and driving. Some mentioned physical barriers to these activities. For example, one participant said, “The store has a sloped entry, [which is] tricky to manage while opening door (poor balance)”. Those who reported challenges with **treatments**, the third most frequently mentioned challenge, said there were either no treatments available, negative side effects, or a general lack of treatment options. Sometimes this lack of treatment options led to “medical treatments [the individual] was not comfortable with...” Challenges related to **uncertainty**, the fourth most mentioned category, included “cycling between [being a] patient with active disease (relapse) and periods of remission” and worry that the individual’s disease will be inherited. For example, one participant said, “My disorder is genetic so I am worried for my children.” Challenges with **companionship support** were characterized by a lack of contact with others. Participants reported feelings of “unending isolation & loneliness that comes with [having a rare disease].”

Though less frequently mentioned, participants also reported challenges with **informational support** (“[Finding] a doctor who knows of the condition and actually manages it”), **doctor-patient communication** (“It took me years to get diagnosed because so few doctors even believed how much pain I was in and how sick I am”), **stigma** (“I hate pitying looks, weird advice, and always—the doubt of people who I thought knew my character”), **employment/academic issues** (“I am too sick to work, but too well to not work”), and a lack of public **awareness** about the various RDs (“I wish there were more awareness of myositis”).

Conclusions

People with RDs are currently facing many challenges that need to be addressed. Americans with RDs reported their greatest challenges were disease symptoms, activity limitations, treatments, uncertainty, and a lack of companionship support. These challenges may help explain why people with RDs have poorer quality of life than people with other chronic health conditions and lead to more targeted interventions.

Next steps

This study was one of many planned in the AWARDS project. We are now examining how different types of social support can best be given to people with RDs, using participants’ short-answer comments from the same survey to help achieve this goal. Focus groups are the next stage in the AWARDS project. Participants who indicated that they were interested in joining focus groups will be contacted in the next year.

Contact

Kathleen Bogart, PhD, Associate Professor,
Oregon State University, School of Psychological
Science 2950 SW Jefferson Way, Corvallis, OR
97331 Kathleen.bogart@oregonstate.edu

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Reference

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Oregon State
University



Brooke Bryson,
Psychology PhD student,
Oregon State University



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