"At Least You Don’t Have A REAL Disease": Understanding Rare Disease Relationships

Research Question: How does a diagnosis of a rare disease impact a person’s relationship with their family and friends?

What Challenges Occur in Rare Disease Relationships?

- Listening/Honesty
- Belief/Validation
- Social Support
- Practical Support
- Anticipating One’s Needs
- Realistic Expectations

Positive Identity

"The disease is who I am, and I’m proud of it."

Acceptance

"I can’t do anything about my disease, so I just laugh it off and go with it."

Negative Identity

"This disease has ruined my life."

Research Overview:

- We recruited 13 participants with rare diseases to join a private Facebook group.
- Participants were asked to complete 11 different activities in the group.
- We analyzed posts, discussions, comments, and photos posted by participants.
- During analysis, we searched for common challenges that were shared amongst participants.
- After analysis of posts and activities, we developed a code book that described main challenges participants faced in their lives and how it affected their relationship with others.

Next: Develop a prototype that eases the strains on these relationships.