Navigating the Unknown: Mental Health with Rare Disorders

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What are rare diseases?

One in ten Americans has a RARE DISEASE.

There are more Americans who live with a RARE DISEASE than ALL of those who have either HIV, Heart Disease or Stroke.

Only 5% of RARE DISEASES have treatments.

Rare disease universals

- Psychosocial commonalities across different disease pathways
- **Need for specialized support**
  - Average diagnostic delay of 7-9 years (Bogart & Irvin, 2017)
  - 2/3 of people with RD feel they do not get sufficient informational, social, and psychological support through the healthcare system (Limb et al., 2010)
- **Stigma**
  - Isolation
  - Lack of public awareness
    - "Burden" of explaining condition to others

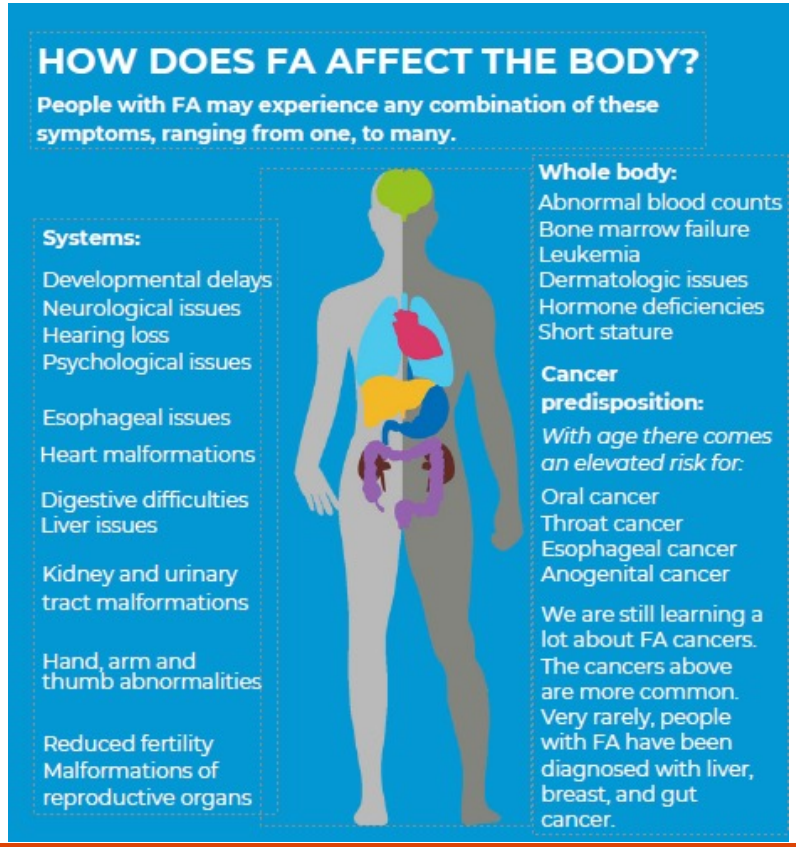
Rare disease health-related quality of life

- Survey of 1,128 adults and caregivers living in the US with any type of RD
  - 344 different RDs
- Adults and children with RDs had lower health-related quality of life and greater anxiety, depression, and stigma on all scales compared to population norms and common chronic disease norms

MINNESOTA
RARE DISEASE ADVISORY COUNCIL

Bogart, K. R., Hemmesch, A. R., Barnes, E., Blissenbach, T., Beisang, A., Engel, P., & the Chloe Barnes Advisory Council on Rare Diseases. (2022). Healthcare access, satisfaction, and health-related quality of life among children and adults with rare diseases. *Orphanet Journal of Rare Diseases. 17*(196) 1-18

Mental health in the first generation of adults with Fanconi Anemia



- 2 stage project
  - Survey of 102 adults with FA
  - In-depth interviews with 18 adults with FA
    - Photovoice

Lived Experience Advisory Board

Sean Breininger

Jasmine Bennetsen

Anna Chou

Dexter Sherrell

Mental health outcomes

- 50% screened positive for PTSD
- 33% screened positive for anxiety
- 25% screened positive for depression

Factors associated with anxiety, depression, and PTSD

Risk factors:

- Stigma
- Fatigue
- Concern with death and dying

Potential protective factors:

- Disability self-efficacy
- Post-traumatic growth

“FA is all-encompassing”

- “FA is a ticking time bomb”
- FA affects goals
- “Professional patient”

Theme 2: Stigma and trauma take a toll on mental health

- Healthcare trauma
- Isolation
- Discrimination
- Body image and gender norms

Theme 3: Connection is bittersweet

Connecting with FAmily

Giving back to FAmily

Grief

Theme 4: “A process of acceptance”

I’m a fighter

Appreciate the current moment

Uniqueness

Acceptance

What did we do with our findings?

- Published in scientific journals
- Created recommendations for supporting the mental health of adults with FA

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How can we understand and support mental health in adults with Bloom syndrome?

- Engage advisors with Bloom syndrome
- Conduct in-depth interviews
- Survey to assess frequency of mental health issues
  - Possibly via registry

Let’s chat!

- What resonated with you?
- What next steps would you like to see?

Thanks!

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Newsletter

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