

The Intersection of Race on the Psychosocial Experiences of Adults with Fanconi Anemia

by  
Madeleine G. Limon

A THESIS

submitted to  
Oregon State University  
Honors College

in partial fulfillment of  
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degree of

Honors Baccalaureate of Science in BioHealth Sciences  
(Honors Scholar)

Presented August 26, 2024  
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## AN ABSTRACT OF THE THESIS OF

Madeleine G. Limon for the degree of Honors Baccalaureate of Science in BioHealth Sciences presented on August 26, 2024. Title: The Intersection of Race on the Psychosocial Experiences of Adults with Fanconi Anemia.

Abstract approved: \_\_\_\_\_

Kathleen Bogart

Fanconi Anemia (FA) is a genetic rare disease characterized by bone marrow failure and increased cancer predisposition. Although the adult FA population is growing due to medical advancements in bone marrow transplants, there has been little research on the psychosocial aspects of their lives as they enter adulthood. Additionally, the biomedical research that has been conducted on FA populations has primarily focused on White FA patients. This study was a two-part, mixed methods, participatory action research project that involved an advisory board made up of four to five individuals with FA. The second part of the study was qualitative interviews that focused on the psychosocial experiences of living with FA. For the purposes of this honors thesis, the experiences of participants of color will be centered as assessed in the qualitative study. Five overarching themes were found from the interviews using conventional qualitative analysis, such as “FA is All Encompassing” and Connection is Bittersweet. Some codes within these themes were more specific to the experience of adults of color with FA compared to White adults with FA, including Provider Fit and Discrimination. Our results show that the discrimination adults of color with FA experience because of their FA is amplified compared to the experiences of White adults of color with FA due to greater societal discrimination. There is room for improvement regarding the mental healthcare adults of color with FA receive. To improve these problems, focus should be placed on educating providers on the FA experience and expanding the FA community outside of Western countries.

Key Words: Fanconi Anemia, rare disease, race, psychosocial experiences, participatory research

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I understand that my project will become part of the permanent collection of Oregon State University, Honors College. My signature below authorizes release of my project to any reader upon request.

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Madeleine G. Limon, Author

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## **The Intersection of Race on the Psychosocial Experiences of Adults with Fanconi Anemia**

Fanconi Anemia (FA) is a rare, autosomal, recessive disease that is caused by mutations in the known 23 genes that encode for the DNA repair pathway (*What Is FA?*, n.d.). Disordered DNA affects every cell in the body and leads to individuals with FA having a high risk of bone marrow failure and an increased susceptibility to cancers, including squamous cell carcinoma in the head and neck regions, acute myeloid leukemia (AML), and anogenital cancers (*What Is FA?*, n.d.). FA also causes systemic issues, such as skeletal anomalies, kidney problems, developmental disabilities, and gastrointestinal difficulties (*What Is FA?*, n.d.). FA is found in all ethnic groups and affects males slightly more than females (*What Is FA?*, n.d.; Peake & Noguchi, 2022). Carrier frequency is higher in certain ethnicities, such as Ashkenazi Jews, sub-Saharan Blacks, and Spanish Gitanos (Tipping et al., 2001). FA was previously thought of to be a pediatric disease, but because of medical advancements allowing for allogeneic hematopoietic stem cell transplants to cure bone marrow failure, many with FA are able to live into adulthood for the first time (Peake & Noguchi, 2022).

### **Rare Diseases**

There are more than 7,000 rare diseases (RD), yet only 5% have effective treatment (National Institutes of Health, 2020). In the United States, a rare disease is defined as a disease that affects less than 200,000 people, with an estimated 25 million to 30 million Americans living with a rare disease (Genetic and Rare Diseases, n.d.). Research has found that individuals with RDs experience a lower quality of life compared to US norms (Bogart et al., 2022). According to the research (Bogart & Irvin, 2017), individuals living with RDs have unique challenges compared to individuals living with a common chronic disease. Such challenges include accessing medical information related to their RD, treatment, psychosocial support, and



copied with stigma and uncertainty. These surveyed participants had an average diagnostic odyssey of nine years (Bogart & Irvin, 2017). Many of the participants discussed the desire to meet other people with their RD, but how they were often not able to do so due to both the rarity of individuals with their RD in their physical locale, and due to a lack of community for psychosocial support (Bogart & Irvin, 2017). Bogart & Irvin (2017) also found that individuals with multiple RDs experienced a lower health-related quality of life when compared to individuals with one RD, which suggests an additive effect. Unsurprisingly, individuals with RDs who have higher incomes have a higher health-related quality of life across all domains (Bogart & Irvin, 2017). This is due to these individuals being more likely to be employed, have private insurance, and be able to travel far distances for specialized care. Bogart & Irvin (2017) concluded that rare disease health-related quality of life disparities are due to insufficient funding, lack of research, treatment, and psychosocial support directed towards individuals with RDs. They emphasize that there is nothing pathological about rare diseases that cause those with RDs to have a lower health-related quality of life compared to people with common chronic conditions. According to Bogart et al. (2022), many of the surveyed participants with RDs experienced significant diagnostic delay and difficulty in obtaining a diagnosis, with one third of participants waiting four or more years for a diagnosis and one fourth of participants seeing six or more doctors to receive a diagnosis. A quarter of participants paid \$3000 or more out of pocket for medical expenses, despite having health insurance (Bogart et al., 2022). Some participants reported experiencing insurance delays and denials, with approximately 14% reporting insurance denials to see specialists for their RD in general and 21% reporting insurance denials to see 'out of network' specialists. Bogart et al. (2022) also found that 14% of participants reported experiencing denials for procedures due to there not being a defined

‘standard of care’ for their RD. Participants were most satisfied with their specialist care and were more likely to report that the information on their RD they received from their specialist was sufficient when compared to the information on their RD they received from their general practitioner or primary care physician (Bogart et al., 2022), who likely do not know much about or are even aware of their RD. Overall, individuals with RDs are more satisfied with their healthcare providers when they experience a higher level of health-related quality of life and a lower level of RD related stigma (Bogart et al., 2022).

### **Fanconi Anemia and Psychosocial Experiences**

There is little known about the psychosocial experiences of individuals with RDs in general, and this holds true for individuals with FA. We have more research regarding the experiences of parents (Hamilton et al., 2013; Haude et al., 2017; Zierhut & Bartels, 2012), siblings (Hutson & Alter, 2007), and children with FA (Kearney et al., 2012).

Hamilton et al. (2013) investigated the decision-making process parents have to undergo when deciding whether or not for their child to undergo an allogeneic hematopoietic stem cell transplant. The researchers found that parents had a more difficult time making a decision when conflicting medical expert opinions were present, but that parents of a child with FA may rely on expert opinion to a great degree. On the other hand, some parents of a child with FA may prefer to leave the decision-making process up to healthcare providers, despite the promotion of shared decision-making, patient participation, and patient autonomy (Hamilton et al., 2013). The uncertainty present in the research regarding FA may not be extremely relevant to parent’s decision-making, but this may also be due to parents of a child with FA being unable to interpret and use the empirical evidence on FA to inform their decision (Hamilton et al., 2013). Overall,

Hamilton et al. (2013) found that emotional context strongly affects the decision regarding transplant.

One option parents of a child with FA have for increasing the likelihood of a successful allogeneic hematopoietic stem cell transplant is having a “savior sibling” who is unaffected by FA but is a human leukocyte antigen (HLA) match. HLA matching is done via preimplantation genetic diagnosis (PGD), which utilizes in vitro fertilization (IVF) (Haude et al., 2017). Haude et al. (2017) investigated the experiences of parents who had a child via PGD. They found that parents had varying levels of confidence and expectations throughout the PGD process, which was primarily affected by the degree of uncertainty versus hope the parents were experiencing at the time. Religion, the media, and bioethical concerns influenced decision-making to different degrees across the parents interviewed, with some discussing how these negatively affected them and others reporting that they had a neutral effect on their decision-making process (Haude et al., 2017). It was found that parents received social support from their partner, other FA families, family members, friends, and healthcare providers, with family and friends providing both emotional support and tangible support in the form of child care for the child with FA (Haude et al., 2017). All parents interviewed stated that overall, their relationship with their partner, children, and family either remained the same or grew stronger, and that they would change certain aspects of their experience, but that they had no regrets (Haude et al., 2017).

Zierhut & Bartels (2012) investigated the psychosocial experiences of parents regarding the time period between the child’s FA diagnosis and their child’s allogeneic hematopoietic stem cell transplant. Zierhut & Bartels (2012) emphasized that parents constantly think about FA, and felt like they were in a constant state of uncertainty and dread regarding disease recurrence. The main stressors parents experienced were related to their child’s FA and interactions with the

healthcare system, such as experiencing routine medical visits, monitoring their child's symptoms, unexplained medical terminology, and announcements of an individual with FA's death online. Positive thinking was the most common form of coping among the participants, and it was found that parents experienced stress relief after discussing FA and the implications of FA with their child (Zierhut & Bartels, 2012). Doctors played a crucial role in supporting the wellbeing of parents, and the FA community was perceived as supportive to some parents and stressful to other parents (Zierhut & Bartels, 2012).

Hutson & Alter (2007) investigated the experiences of siblings without FA of individuals with FA. The interviewed siblings reported trying to keep their own distress contained to avoid causing more worry or pain, feeling invisible, assuming a caretaker role to either parents or the sibling with FA, having their normal routine disrupted due to the healthcare needs of their affected sibling, worrying about the prognosis of their sibling, and experiencing despair (Hutson & Alter, 2007). Siblings worried about passing on FA to future children or developing it themselves (Hutson & Alter, 2007). For many of the interviewed siblings, the interview for the study was the first opportunity to discuss their feelings around FA and having a sibling with FA. It is unknown what the long term mental and emotional health consequences may be, but it is possible that a lack of communication between family members regarding the emotions around the FA experience could create feelings of anger and resentment towards the affected sibling (Hutson & Alter, 2007).

Kearney et al. (2012) investigated the psychosocial experiences of children with FA. Of the 22 participants, all were children at time of FA diagnosis, but six were adults at time of bone marrow transplant. They found that two thirds of referrals of FA patients to psychiatry were initiated an average of 25 days before transplant (Kearney et al., 2012). Of the participants

referred to psychiatry before transplant, mood and adjustment disorders were the most common diagnoses, and nonadherence to medical guidelines was present in half of the surveyed adult population after transplant (Kearney et al., 2012). Nonadherence may be associated with depression and PTSD, and may lead to poor health outcomes due to the risk of developing future cancers (Kerney et al, 2012). All of this implies an increased need for psychiatric services within the FA population.

Of these populations surveyed, only one research group (Haude) reported on and included racial diversity in their sample. No researchers asked questions about race/ethnicity related to the FA experience.

### **Race and Psychological Research**

Race and ethnicity are often used interchangeably, though they are two different concepts. Race is a “social construction and categorization of people based on perceived shared physical traits that result in the maintenance of a sociopolitical hierarchy” (American Psychological Association, 2023). Ethnicity is a “characterization of people based on having a shared culture related to common ancestry and shared history” (American Psychological Association, 2023). This paper focuses on race, even though ethnicity and nationality are mentioned in reference to race.

Despite race being a social construction, race nonetheless has direct effects upon individuals, communities, systems, and societies. Race impacts an individual of color’s access to healthcare resources, creating health disparities (Williams & Rucker, 2000). Black women are less likely than White women to be tested for osteoporosis (Dovidio et al., 2008). Healthcare providers have demonstrated implicit racial biases against Black people, such as stereotyping Black people as uncooperative patients and being less likely to prescribe medications to Black

people compared to White people (Dovidio et al., 2008). Healthcare providers who treat Black patients are less able to deliver high-quality care due to lacking needed resources (Chandra et al., 2024). In regards to psychological services, Black, Indigenous, People of Color (BIPOC) individuals have less access to mental health services and are less likely to receive necessary mental health care compared to White individuals (McGuire & Miranda, 2008).

In August 2017, the American Psychological Association (APA) released the current *Multicultural Guidelines: An Ecological Approach to Context, Identity, and Intersectionality* (American Psychological Association, 2017). This follows up on the previous version, which was released in 2002 (American Psychological Association, 2017). *Multicultural Guidelines* presents psychologists with ten overall guidelines, and asks psychologists to “engage in a fuller understanding of diversity and its considerations within practice, research... and to recognize the highly diverse nature of individuals and communities in their defining characteristics...” (American Psychological Association, 2017). *Multicultural Guidelines* also presents psychologists with a *Layered Ecological Model of the Multicultural Guidelines* that presents psychologists with the many ways they may interact with race regarding their research and practice in different systems, such as within communities, between individuals, and among larger societal contexts (American Psychological Association, 2017). The APA released in August 2019 their *Guidelines on Race and Ethnicity in Psychology: Promoting Responsiveness and Equity* (American Psychological Association, 2019). This follows up on the previous guidelines, which was released in 2003 (American Psychological Association, 2019). *Race and Ethnicity Guidelines* present more focused guidelines on race and ethnicity built upon the guidelines presented in *Multicultural Guidelines*. *Race and Ethnicity Guidelines* emphasizes building racial and ethnocultural responsiveness within psychologists, and specifically states that to be racially

and ethnoculturally responsive, one cannot only be aware, but also must use their position to address “racial and ethnocultural inequity in professional relationships, activities, institutions, and systems that are detrimentally affecting the health and well-being of people of color” (American Psychological Association, 2019). This call to action is affirmed by four specific guidelines aimed at psychological practice and five specific guidelines aimed at psychological research (American Psychological Association, 2019).

Despite these guidelines, we still see a lack of research that focuses on race, or includes people of color, especially BIPOC, within the research. We also still see a system within psychological sciences that upholds White voices and White research. The majority of psych research is done in WEIRD countries (Western, educated, industrialized, rich, democratic), which does not generalize to the majority of the human population, especially people of color (Henrich et al., 2010). The research that is done on BIPOC people is rare and often needs a White comparison group to get published (Buchanan et al., 2021). The majority of publications are edited by White people, which has led to few publications that spotlight race (Robert et al., 2020). Many of the articles that do highlight race are written by White people who did not include many participants of color within their research (Robert et al., 2020). All too frequently, the responsibility for research on communities/people of color is placed on psychologists of color and psychologists who already understand the gravity and need for researching race in psych; however, all psychologists should work to acknowledge their own positionality, biases, and awareness, regardless of whether or not they focus on researching race (Arshad & Chung, 2022).

Even without centering race, research on the mental wellbeing of individuals with FA remains elusive. At the time of writing, only one person had conducted research focused on the

mental health of adults with FA: the late Amy Frohnmayer, who herself had FA. Her research was found in an unpublished master's thesis (Frohnmayer, 2010) and a published conference abstract (Frohnmayer, 2016). While she did not ask questions specifically about race/ethnicity related to the FA experience, she did find psychosocial challenges across four domains: physical challenges, medical challenges, cognitive perceptual challenges, and social challenges (Frohnmayer, 2010). Frohnmayer (2010) found that individuals with FA use a combination of both problem-focused and emotion-focused coping strategies. Active Coping and Acceptance were the most commonly used coping strategies (Frohnmayer, 2010). Active, positive, problem-focused coping strategies were found to be positively associated with wellbeing, and passive, negative, emotion-focused strategies were found to be negatively associated with wellbeing (Frohnmayer, 2010). As illness severity increased, individuals with FA increasingly ceased attempts to cope (Frohnmayer, 2010). Frohnmayer (2010) also found that embracing FA comes with both positives and negatives, specifically that embracing FA can put their lives in perspective, but also that embracing FA can distance individuals from a normal lifestyle and put more focus upon the challenges inherent with FA. When Frohnmayer (2010) asked her participants about their future goals, participants talked about emotionally meaningful goals, such as wanting to "be happy, live life to the fullest, and leave a mark" as opposed to instrumental or knowledge-related goals, such as goals related to a career or money. Frohnmayer (2010) ends by saying that "individuals who have an impact on the care of these patients, including health care professionals and guardians, should help patients maintain confidence to pursue dreams, particularly in the context of rapidly improving medical prognoses."

Frohnmayer also did not collect demographic information about race/ethnicity in regards to both her interview participants and her survey participants. So while we can understand that



adults with FA do experience certain specific psychosocial challenges, her research and findings may not be generalizable to a population of color with FA.

### **Current Study**

The first part of this research project on the psychosocial experiences of adults with Fanconi Anemia was a quantitative survey. Of the 102 participants surveyed, 40 identified as White, 34 identified as African, Black, or Caribbean, 13 identified as Hispanic or Latino/a/x, six preferred not to answer, five identified as Asian, three identified as mixed race or multiple ethnic groups, one identified as Middle Eastern, and one identified as Indigenous. Overall, using published cut-off points, 32.4% of surveyed participants screened positive for anxiety, 25.5% participants screened positive for depression, and 50% screened positive for PTSD. Adults with FA had lower scores on all health-related quality of life and psychosocial factors, such as fatigue ( $M_{\text{pop. norm}} = 3.81, SD = 8.54$ ), pain ( $M_{\text{pop. norm}} = 7.85, SD = 7.96$ ), and social participation ( $M_{\text{pop. norm}} = -2.42, SD = 7.32$ ), compared to US population norms.

Participants had the option to opt in to be interviewed after they took the quantitative survey. From this pool of opted-in participants, we conducted semi-structured interviews with 18 participants with FA. Participants of color and participants of sexual and gender minorities were oversampled to be interviewed to ensure these underrepresented perspectives were captured. We aimed to explore adults with FA's mental health experiences, coping strategies, and involvement in the FA community and their intersection with race, sexuality, and gender. This undergraduate thesis will focus on how race intersects with mental health experiences, coping strategies, and involvement in the FA community.

## **Methods**

### **Overview**

This study was a two-part, mixed methods study. Both parts of the study were informed by our Lived Experience Advisory Board, a group of four to five people with FA. The first part of the study was a quantitative survey focused on the mental health of individuals with FA; however, I am focusing on the second part of our study, the qualitative interviews. Via conversations with our board members, we developed open-ended interview questions assessing psychosocial aspects of adulthood and FA. Participants were contacted from a prior quantitative survey on the psychosocial aspects of FA. We oversampled for people of color ( $n = 8$ ,  $Age = 31.5$ ) and sexual and gender minorities in our sample as they are often not represented in the research on FA. Participants of color were 56% Black, 33% Hispanic or Latinx, and 11% Indigenous. Participants of color were 44% female, 44% male, and 11% nonbinary; 67% were heterosexual and 33% were bisexual.

Interview topics included mental health experiences, engagement with the FA community, as well as high points, low points, and turning points from the life story interview (see Appendix) (Atkinson, 2009). Additionally, participants had the option of participating in Photovoice, an opportunity for participants to take photos that identify and represent their experiences (Wang & Burris, 1997; Hergenrather et al., 2009). The 30-60 minute interviews were conducted over Zoom in both English and Spanish. Participants were compensated for their time with a \$100 digital gift card. This study was approved by both the Oregon State University and University of Minnesota Institutional Review Boards (IRB-2022-1517).

### **Data Analysis**

All participants were assigned pseudonyms, either chosen by themselves or by the interviewers. The interviews were transcribed first by Zoom's auto-transcription software and manually checked by the interviewers. The interviews were coded using conventional qualitative

content analysis (Hsieh & Shannon, 2005), and general themes and specific codes were developed within the analysis. When coding disagreements arose, the interviewers and principal investigator discussed and came to a consensus. One interviewer/coder identifies as a White, heterosexual, able-bodied, cisgender woman. The other interviewer/coder identifies as an Asian, mixed race, queer, chronically ill, disabled, cisgender woman. The principal investigator identifies as a White, heterosexual, and cisgender woman with a rare disorder. The themes and codes, along with exemplar quotes that illustrated the themes and codes, were communicated to the Lived Experience Advisory Board and interviewees. We asked the Lived Experience Advisory Board and the interviewees if the communicated results matched their experience, if they wanted to add or change anything, and what aspect of the current research future research should focus on. Their feedback was incorporated into our final results.

## **Results**

Using conventional qualitative content analysis, five general themes were created: “FA is All Encompassing,” Mental Healthcare Systemic and Provider Barriers, Stigma and Trauma Take a Toll on Mental Health, “A Process of Accepting the Disease,” and Connection is Bittersweet. Each theme had five to eight specific codes. Some codes were more applicable to participants of color than White participants, such as Provider Fit, Discrimination, and FA Community can be Inaccessible. All of the following quotes are from participants of color.

### **Provider Fit**

The code Provider Fit fell under the theme Mental Healthcare Systemic and Provider Barriers. Interviewees explained their need for a provider with shared social identities, such as race, gender, and/or sexuality. They also talked about the trial and error in finding a mental health provider with a therapeutic style that works for them. Ashley, who lives in North America,

said, “So I think in the future I might look for someone that's a little bit older, and probably preferably [a racial] minority. But that's not, you know I wouldn't dismiss someone for not being, but it's just like a different level of understanding.” David, who lives in North America, stated that he, “... needed [a psychiatrist] who'd be open, who'd be open-minded. Who wouldn't discriminate [against] me based on my race.” Ronaldo noted, “[Because] in my culture, in the Nigerian culture. Well, it's not a common disease. ‘Cause you know FA, it's already sort of... From my culture it is this stigmatization especially. And that there's no standard default to people facing the same...”

### **Discrimination**

The code Discrimination was coded under the theme Stigma and Trauma Take a Toll on Mental Health. Interviewees discussed experiences of bullying and discrimination. Some individuals mentioned people thinking FA was contagious or that FA was a curse on their family. They stated how having additional minority social identities, such as race, gender, and sexuality, intensified stigma already experienced due to FA. John observed that, “Maybe a part about culture, people, you know, mostly here in Kenya. People have different cultural perspectives. So when they see me, and the way I look they see as if you know maybe it's [FA's] a curse, or something, or like sort from my ancestral lineage.” Daniel, who lives in North America, described a story of discrimination he encountered in a healthcare setting, “My spouse [and I] belong to different races... But the first [inaudible] we are referred to, at first they thought, because we went, the two of us. They thought... my spouse was the one who was supposed to be receiving the treatment. So at first the reception was a bit warm. But when they noted that I was the one to be supposed to receive the treatment I noticed the reception kind of changed. We

started having some cold treatment. Which, with my condition, I was not comfortable. and I just decided to forgo the process and seek another alternative.”

### **FA Community can be Inaccessible**

The code FA Community can be Inaccessible was coded under the theme Connection is Bittersweet. Interviewees discussed how the FA community can be inaccessible as the largest FA communities are located in WEIRD countries where the majority of people only speak English. Furthermore, there are not many queer people, people of color, or those in different stages of FA, such as individuals in remission. Ashley stated, “Yeah, it's just weird being a minority in white spaces in general, it's not really specific to FA. But like I have noticed little slight microaggression things at those meetings before... I don't want to call anything out or anything but yeah, it's a little bit different. That's just kinda being a minority in the U.S. though...” Both John and Ronaldo noted that they have not met anyone who has FA who lives physically within their respective countries. Ana, who lives in South America and speaks English as a second language, said, “That's why I learned English, because I wanted to know more about the disease. I wanted to know people with that disease, too.”

### **Discussion**

This research study explored the psychosocial experiences of adults with Fanconi Anemia, a rare disease that involves bone marrow failure and increased predisposition to cancer. This study adds to the small body of literature regarding both rare diseases and the psychosocial aspects of living with FA. This study also reveals valuable information regarding gaps within both the mental health care adults with FA receive and their overall care plan. Our participants’ stories and narratives support prior literature about the unique challenges the overall rare disease

community faces, such as Bogart & Irvin (2017), but also reveal challenges specific to the FA community and the people of color within the FA community.

One of the most pressing challenges our participants of color detailed was the desire for mental health providers with concurrent identities and overall lack of access to mental health providers of color. Previous research done by Eken et al. (2021) demonstrated that Black, Asian, mixed-race, and Hispanic people were more likely to report that it was important for their providers to share or understand their culture. Simultaneously, this same group also reported to be less able to frequently see providers who did share or understand their culture. Eken et al. (2021) also showed that people experiencing depressive symptoms were more likely to place importance on the need for providers to share or understand their culture, when compared to those without depressive symptoms or those experiencing anxiety. Moore et al. (2022) demonstrated that Black people indicated a preference for a mental health provider with the same racial identity. The participants within Moore et al.'s (2021) research indicated that racial concordance gave way to higher feelings of comfort, safety, relatability, and cultural understanding. Participants also expressed that mental health providers of a different race compensated for racial differences by showing cultural humility and increasing awareness of racial inequities. Cultural humility is defined as a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances present in a physician-patient relationship, and to developing mutually beneficial partnerships with patients and their communities (Tervalon & Murray-García, 1998).

Previous literature also shows that individuals with disabilities and chronically ill individuals also desire mental health providers with concurrent identities and/or mental health providers with an understanding of their disability or illness. According to Battalova et al.

(2020), mental health providers with disabilities recognized that their personal experiences with disability, despite being a different disability from their client's, still allowed them to build rapport and an emotional connection. When provider's disabilities were invisible, providers grappled with whether or not to disclose that they did experience disability. Mental health providers worried that discussing their own experiences with disability would de-emphasize the client's experiences and that the client would perceive them as more vulnerable and therefore less professional and more emotional. Battalova et. al (2020) also spotlights that while some clients with disabilities may view having a mental health provider with a disability as a positive, other clients with disabilities who do not interact with a disability community and/or professionals who have disabilities may see disability as a negative.

It is important to consider the intersection of identities, such as race and ability. Intersectionality is a constantly developing theoretical framework developed by Kimberlé Crenshaw and is rooted in Black feminism and critical race theory (Carbado et al., 2013). Intersectionality was developed to work with multiple identities, such as race, gender, and ability, within multiple academic disciplines and areas outside of academia, such as politics and law (Carbado et al., 2013). An example of intersectionality would be a Black woman experiencing both racism and sexism, as compared to a Black man only experiencing racism and a White woman only experiencing sexism.

Due to the trust and empathy needed to establish a productive rapport between a mental health provider and patient, it is important to emphasize concurrent identities and cultural competency. Because adults of color with FA exist at the intersection of being both of color and having a disability, they have a higher need for mental healthcare that is both racially and FA competent/specific. Adults of color with FA experience both racism and ableism, whereas a

White adult with FA would only experience ableism and an able-bodied adult of color would only experience racism. However, this also means that a provider with both of these abilities is less likely to exist. This means that if these individuals are able to access mental health services, they may have to settle for a mental health provider who is either racially specific or FA specific. This splitting of mental health needs does not serve the whole individual.

Our participants of color also discussed the FA community – another source of mental health support – being inaccessible in multiple ways, such as the largest FA communities being present in predominantly WEIRD countries, such as the United States, Canada, and the United Kingdom. Participants also talked about the FA communities being made up of predominantly White, cisgender, heterosexual, English-speaking, upper-middle-class men and women. Ashley’s experience being a racial minority and experiencing microaggressions within the FA community speaks to the FA community being relatively homogenous. Despite these inaccessibilities, participants emphasized that the FA community provides solidarity and resources that individuals with FA cannot access elsewhere.

The discrimination our participants of color discussed speaks to greater societal issues that affect the FA community as a whole, such as mental health services being inaccessible, culturally competent mental health services and providers not being accessible, and rare disease support organizations being concentrated in WEIRD countries. These issues do not just affect adults of color with FA, but every individual with a rare disease.

### **Limitations and Strengths**

The main limitation of this study involves how most interviewees had already engaged with the FA community. Their experiences may differ from others who have never heard of or used FA support resources. People who were not connected to FA-based communities were not



recruited, as recruitment was through FA centers of excellence, Fanconi Cancer Foundation, FA-based social media, and word of mouth from individuals in the FA community. All of these recruitment methods indicate some connection to the FA community. Therefore, there is still limited information on the mental health experiences of individuals who had not previously connected with FA community resources. We can speculate that individuals who are not connected with this community may experience even greater challenges in mental health support.

Despite an effort to recruit Spanish-speaking participants, only one participant of color spoke Spanish. Therefore, our results only generalize to English-speaking populations. The demographics of participants of color also skewed predominantly Black, African, or Caribbean, heterosexual, and cisgender. These results may not be generalizable to individuals of color who are not Black, heterosexual, and/or cisgender.

Despite the limitations, this study had many strengths. A participatory approach was taken to develop this study to ensure that the study reflected the experiences and needs of adults with FA. Our connections with the FA communities and a diverse advisory board allowed us to recruit a far more diverse group of participants than is conventional in RD research, including racial, ethnic, and sexual minorities.

### **Future Directions and Implications**

There are a few solutions that can be implemented to improve mental healthcare for adults of color with Fanconi Anemia. Looking at the results of this study, a multi-level approach will be most effective. Both mental and physical healthcare providers must be aware and educated on the clear need for FA-specific mental healthcare. Not only should they be aware and educated on the intricacies of the FA experience, but mental healthcare providers should also be advertising themselves as FA-competent mental healthcare providers so that they can be found

by the FA community. Efforts should be made to increase the representation of both BIPOC and disabled mental health providers overall. Finally, Fanconi Anemia organizations should work together to improve the funding and resources available in non-WEIRD countries so that FA communities within them can form.

Future research regarding the psychosocial experiences of adults with FA include emphasis on listening to and working with the voices of color within the FA community. Future studies should also research the psychosocial experiences of adults with FA using an intersectional lens to further understand how specific identities contribute to the adult FA experience. Ultimately, we aim to develop mental health guidelines for adults with FA and their healthcare team.

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## Appendix

### Interview Questions

1. How has your experience been living with FA? What does FA mean to you?
2. Can you tell me how other aspects of your identity (like gender, race, culture, age, religion/spirituality, sexuality) have affected your experience with FA?
3. [If the participant submitted Photovoice pictures.] I'd like to talk about the Photovoice pictures you sent. Let's talk about each one and what it means to you.
  1. Where was it taken? What was happening at the time? What did you hope would happen? How did you feel?
4. I'm going to switch gears to ask you about your mental health. These questions might bring up some tough topics. Please take your time and know that you can skip any questions that you would like or stop at any time. Have you experienced mental health symptoms or a diagnosis, like anxiety, depression, trauma, insomnia?
  1. If so, please tell me about what you think triggered them. If not, what do you think has kept you from experiencing this?
  2. Was there anything that helped? What are things you did to cope?
  3. Did you seek help from a mental health therapist and/or psychiatrist?
  4. During this time did you experience any challenges with access or accommodations in getting mental health support?
  5. What qualities did or do you look for in a mental health provider?
  6. Were you concerned about finding a therapist or other clinician who would understand or feel comfortable with you as a person with FA or with your other identities?



7. How comfortable and knowledgeable was or is your mental health provider with FA? Can you provide some examples of the ways that the person was particularly thoughtful (or not) in relation to your FA?
5. Have you connected with other people with FA? Why/why not? If so, tell us about your experience.
6. Have you engaged with the Fanconi Cancer Foundation (FCF)? Why/why not? If so, tell us about your experience.
7. These next questions will ask you about a low point and a high point in your time with FA. You may need to take a minute to think about that event and remember as much as you can about it. Please take as much time as you need. Here's the question: Thinking back over the entire time that you have had FA, please identify a scene or scenes that stand out as a low point in your life story. Tell me about the scene or scenes that come to mind, and provide as much detail as you can.
  1. What happened? Where did this happen? When did this happen? Who was involved? What were you thinking and feeling?
  2. What does this scene say about you or your life?
8. Now I'm going to ask you to do the opposite. Please think about a high point in your life related to FA. Please describe a scene that stands out as a high point in your life story.
  1. What happened? Where did this happen? When did this happen? Who was involved? What were you thinking and feeling?
  2. What does this scene say about you or your life?

9. In looking back over the entire time that you have had FA, it may be possible to identify certain key moments that stand out as turning points -- episodes that marked an important change in you or your life story.

1. If you cannot identify a key turning point that stands out clearly, please describe some event in your life wherein you went through an important change of some kind.
2. What happened? Where did this happen? When did this happen? Who was involved? What were you thinking and feeling?
3. What does this scene say about you or your life?

Is there anything else you would like to add about your experience with FA and mental health?

