

The Effects of Erythropoietic Protoporphyria on the Mental Health of Children in the United States

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ABSTRACT

The purpose of this study was to determine the mental health impact of Erythropoietic Protoporphyria on children eight to eighteen in the United States. Prior research demonstrates the physical side effects of EPP and the symptoms that result; however, there is a lack of research on how patients are impacted mentally. Data was collected through phenomenological semi-constructed interviews in which participants were prompted to respond to several questions regarding possible factors that may have impacted their mental health. Participants included seven EPP patients, male and female, ages nine through eighteen. Initial results generated five themes (Bullying, Frustration, Social Exclusion, Depressive Language, School Exclusion) which means that EPP patients are affected mentally by their disease. It can be concluded that there is an elevated negative mental health risk on EPP patients; however, this is limited to the small group of participants and cannot represent all EPP patients eight to eighteen in the United States. Future research should expand to more patients across the country in order to work towards improving the mental lives of EPP patients.

Introduction

Erythropoietic Protoporphyria is a genetically inherited rare disorder. Erythropoietic Protoporphyria is often shortened to its acronym, EPP. EPP falls under the broader category of porphyria, which includes eight different disorders that share one commonality, the buildup of porphyrins in the body. EPP is a cutaneous porphyria that affects about 1 in 74,300 individuals (American Porphyria Foundation [APF], n.d.). The cause of EPP is a mutation in the gene FECH. Because of the mutation in the FECH gene, the enzyme ferrochelatase, or FECH, is not produced enough. The low levels of the enzyme produce low levels of porphyrin which cause the symptoms of EPP (APF, n.d.). The major symptoms of the disease include itchy skin, swelling, burning, and redness immediately after or during sunlight exposure (APF, n.d.). Some patients experience gallstones that may obstruct the gallbladder, or they experience liver failure that may require a transplant (APF, n.d.).

Living with EPP impacts the overall lives of those with the disease. The activities EPP patients are allowed to participate in are limited due to the painful side effects of sun exposure. Simple activities such as going for an outdoor walk, bike riding, or going to the beach are often not possible for EPP patients. Even the simple task of walking from the car into a building must be taken with specific precautions in order to prevent sun exposure. Patients that are under the age of eighteen are mostly still in school. Going to school may provide challenges for EPP patients. EPP patients may not be able to participate in certain school activities such as outdoor recess, physical education class, or field trips. Even fire drills may cause issues on a day with a high UV index. These physical restrictions alter the daily lives of students with EPP. Previous research studies have failed to mention the mental health impacts that come along with having EPP and not being able to participate in daily tasks typical children are able to do. For example, in the article “Exonic Deletions as a Cause of Erythropoietic Protoporphyria,” the main discussion of EPP is focused on the mutation in the FECH gene and the

effects the mutation has on someone with EPP. There is no mention of how the patient's mental health is impacted. Yes, the EPP patients are taking the proper precautions to stay out of pain, but being unable to participate in various activities, especially at a younger age, may lead to an increased risk of mental illness.

Literature Review

Since the mental health of EPP patients has failed to be explored, there was no clear direction on where to begin research. So, to accommodate, predictions of possible factors that could impact the mental health of EPP patients were made using previous observations of EPP patients and later confirmed or rejected in the results of the research method. The first possible mental health factor explored was bullying. Bullying includes more than just physical altercations between two people. Bullying expands to any physical aggression, verbal aggression, relational aggression which includes social isolation, and cyber aggression (Andersen et al., 2015). Markus Kiefer et al. argues that bullying is a result of imbalanced powers between the bully and the victim (Kiefer et al., 2021). Due to the prevalence of bullying in schools, the consequences of bullying are extremely important to understand in order to prevent serious risks such as suicide (Andersen et al., 2015). Andersen et al. backs up his claims about suicide by referencing a review based on 37 studies that proves that a relationship between bullying and suicide risk and suicidal behaviors exists (Andersen et al., 2015). Both Kiefer et al. and Andersen et al. argue that there is an increased risk of mental disorders such as anxiety and depression. Andersen et al. discusses social anxiety, low self-esteem, loneliness and increased depression symptoms and how bullying is associated with these risks (Andersen et al., 2015). Leah Khan adds to the conversation by explaining how bullying rates increase as children get older and go from elementary school to middle school. Andersen et al.'s argument that age is a potential risk factor of bullying backs up Khan's claim. Results from cross-sectional and longitudinal studies have shown that high occurrences of bullying are seen at ages 15 to 17 (Andersen et al., 2015). Other than age, Khan describes how another key risk factor is having a disability or chronic medical condition (Khan, 2021). Children with EPP fall under this category of risk factors, putting them at higher risk of being bullied and therefore increasing their risk of depressive symptoms and mental illnesses.

The next predicted factor explored was social rejection. Social isolation, social exclusion, and social rejection all tie together and can be grouped together when discussing the mental health of EPP patients. Social exclusion is an indirect form of bullying and bullying has been previously correlated with increased depressive symptoms (Khan, 2021). Social rejection was discussed in various popular sources, and each argued that social rejection and isolation has long term effects on a person including depressive symptoms, trauma, and anxiety (Good Therapy, 2019). Graham Shannonhouse argues that despite the reason behind social isolation, whether it be due to bullying or not, the loneliness associated with social isolation can lead to long term damaging effects like the effects mentioned by Good Therapy such as depression and anxiety (Shannonhouse, 2021). Children with EPP are put at a higher risk of social isolation and rejection due to their physical inability to participate in various activities that could put them in danger of sunlight exposure. This higher risk of social rejection also puts them at a higher risk for the mental health risk factors that come with social rejection. This connection suggests how the physical limitations of EPP could affect a patient's mental health.

Due to the specific demographics of the participants in the research study, ages eight to eighteen and having EPP, research on children's mental health and the impact of having a disability on mental health were both explored to further the body of knowledge. Before the age of fourteen, about half of mental health conditions have begun (Darling et al., 2021). This means that prevention of mental illnesses is very important in the youth community. The events that occur in childhood could contribute to the development of mental health conditions that begin before the age of fourteen. About 10-17% of children and young adults ages four to seventeen qualify for the definition of a mental illness (Darling et al., 2021). Mental health conditions, when left alone or ignored

in childhood, could short-term affect children's performance in school and long-term lead to more serious and dangerous events such as suicide and low life quality as an adult (Darling et al., 2021). In response to Darling et al.'s concerns about ignored mental conditions in childhood, the National Institute of Mental Health offers warning signs that distinguish between typical childhood behavior and behavior that requires mental health evaluation. In teenagers, parents should watch for low energy, excessive alone time, self-harm, risky behavior, suicide thoughts, or lost interest in previously enjoyable activities (National Institute of Mental Health, n.d.). To connect these mental health risks back to children with EPP, Nicola Davies (n.d.) argues that there is an amplified mental impact on people with rare diseases. EPP, affecting only 1 in 74,300 individuals, classifies as a rare disease (APF, n.d.). Davies argues that many rare disease patients need psychological support in order to deal with the emotional toll put on them due to their rare disease. A disability is anything that involves difficulties in human functioning (Jung, 2021). Because EPP patients are unable to participate in typical human activities, the disease may also be classified as a disability. Morgan Stasell and Molly Bathje (2021) agree with Jung's claim and add that people who have disabilities struggle with accessibility. In relation to mental health, people with disabilities are vulnerable to depression due to their lack of independence (Jung, 2021). EPP patients, especially at a young age, need help doing simple daily activities which could create that lack of independence mentioned by Jung, suggesting a possible connection between EPP and increased risk of impacts on mental health.

Due to the prevalence of mental illness among children, the increased risk of depression in rare diseases, and the increased risk of mental illness in those who are bullied or socially rejected, EPP patients seem to have a higher risk of developing a mental condition. In previous EPP research, only the physical side effects of the disease were explained and studied. In this research, the mental impact of EPP will be explored in order to fill the lack of mental health research gap and to determine the relationship between children with EPP and mental health. This prompted the research question: How does having Erythropoietic Protoporphyrinemia impact the mental health of children eight to eighteen in the United States? My hypothesis is that having EPP is connected to an increased risk of mental illness. This research could bring awareness to the other effects of EPP besides the physical effects which could help improve the lives of children with EPP in the future.

Methodology

I used a phenomenological research method through semi-structured interview questions in order to explore the impact of Erythropoietic Protoporphyrinemia on the mental health of children ages eight to eighteen in the United States. Since I did not know and could only make predictions and assumptions regarding any variables that may affect mental health, I decided to use an exploratory approach to search for the impact of this rare disease on mental health. I was not looking for specific correlations, I was exploring the possible impacts the disease has mentally to determine if there is a negative mental health risk.

Through virtual interviews, I aimed to gather data on the experiences EPP patients have and how it impacted their emotions which could potentially impact their mental health. I used pre-determined interview questions that allowed for potential follow up questions. By using this method of data collection, I set myself up for analysis of my results through thematic analysis (Leedy, 2016). Asking questions in an interview style gave me the opportunity to code for themes I discovered during my conversations with patients. Identifying themes allowed me to come to conclusions on the risk of mental health impacts on EPP patients which fills the gap in the body of knowledge. By coding for mental health factors such as bullying, I had the ability to connect back to the body of knowledge and use my information from there to make conclusions.

Each of the subjects in my research study had to be between the ages of eight and eighteen of either gender and live in the United States. I chose to narrow down the age group to just focus on children so that I could study specific child-related mental health factors such as bullying and social rejection. Most importantly, the participants needed to have the disease since the focus of the research was the impact of having the disease

on a patient's mental health. Due to the rarity of this disease, I needed to broaden the location to more than just one region of the United States, but I kept it to one country because the education systems outside the country may be structured differently.

The data consisted of verbal responses that answered pre-determined interview questions (Appendix B). Participants responded to questions about their experiences in and out of school that could be affected by their disease. A lot of the questions asked if the patient had experienced various situations that may affect mental health and how they felt about those situations in order to compare responses between participants. My questions were each intended to guide the research and generate situations in which the EPP patients may have been impacted mentally. The eleven pre-determined questions could have been answered in a short response, but in order to gain the information needed to further analyze the responses, each participant was prompted to elaborate on their responses. They were prompted using generic questions such as:

1. How did that make you feel?
2. Can you describe an experience when you felt like this?

Instead of following a strict set of questions, the goal of this semi-structured interview method was to allow the participants to discuss their experiences and how they felt in a more open and relaxed environment. The tools used to conduct the interviews were the virtual software Zoom or FaceTime and the transcribing website Otter.ai. Zoom and FaceTime allowed participants to communicate with me in a more personalized way than a normal phone call or written questions. Since the questions being asked were highly personal and may bring up the emotions of participants, it was important to choose a method that allowed me to make the young participants feel comfortable through face-to-face exposure and conversation. Taking notes while the participant responds would have caused a distraction to me and the participant. To accommodate this possible issue, I used a transcriber, Otter.ai, to transcribe the interview into words as the interview was occurring (Appendix C). This allowed me to focus on my participants' responses rather than recording the information I thought could be useful in analysis.

Prior to the conduction of the interviews, the questions that were asked were approved by an IRB. Through a family connection, I reached out to a former member of the American Porphyrria Foundation. This former member was able to serve as a consultant. The consultant had the ability to contact various patients with EPP in the United States. I provided the consultant with my contact information so that interested participants could reach out to me and express their interest in participating. Once I secured my participants, I began interviewing. Each interview ranged in length from 10 to 30 minutes. Before conducting the interview, the participants were required to give consent verbally and have a parent or guardian do so as well. Participants were informed that they have the ability to not answer any question or to stop participating at any point in the interview. After the interviews were complete, it was time to move forward with the transcribed data and start analyzing the responses provided by each participant.

The analysis of my research related back to my question and the goal of my research. The goal was to find how mental health is impacted by the disease. By using thematic analysis, I was able to pull out key themes associated with mental health among the interviews in order to determine connections between EPP patient experiences and an increased risk of mental illness. The interpretation of these themes was done with reference to previously analyzed scholarly sources to see how the experiences and emotions found in the themes connect back to the impact on mental health. The most beneficial way to address my research question was to determine recurring experiences that EPP patients go through that could suggest a connection to an increased risk of negative mental health conditions. After all the interviews were complete, I began the coding process, and the themes were processed and analyzed as they will be described in the results section.

Results

In total, seven semi-structured interviews were conducted among participants ages nine to eighteen. The interviews were transcribed and then coded for recurring themes. The most prevalent themes were bullying, frustration, social exclusion, depressive language, and school exclusion. Each theme is defined in the Table 1 below.

Table 1. Definitions of Themes

Theme	Definition
Bullying	Participant expressed an experience where others had bullied or made fun of them at any point in their life due to their disease.
Frustration	Participant expressed anger, annoyance or frustration when discussing the difficulties of living with their disease.
Social Exclusion	Participant expressed feeling left out or excluded in social situations such as but not limited to spending time with friends or playing a sport.
Depressive Language	Participant used language that could suggest depressive feelings such as but not limited to “sad” or “upset”.
School Exclusion	Participant reported being excluded from school activities such as but not limited to recess, gym class, and field trips.

The prevalence of each theme throughout each participant’s interview is displayed in Table 2 as well as the ages of Participants A-G and significant quotes.

Table 2. Themes Present

Participant	Significant Quotes	Themes Present	Age
A	“It made me feel like I wasn’t good enough.” “That made me feel disappointed or not proud of myself.” “You just want to be normal.” “It will affect your social life.”	Social exclusion, depressive language, school exclusion, frustration	11
B	“I just want to rip them apart.” “I wanted to punch them.” “Makes me feel different than other kids.”	School exclusion, depressive language, social exclusion, bullying, frustration	9
C	“It’s just not fun.” “I’ve had to miss school a lot because of my disease.”	School exclusion, social exclusion, frustration	16
D	“It was really hard making friends.” “I was called a bunch of names.”	Social exclusion, school exclusion, frustration, bullying, depressive language	18

	<p>“It was a rough time.”</p> <p>“It’s a huge, for lack of better words, burden on your life.”</p> <p>“It’s a huge mental thing.”</p>		
E	<p>“It is an everyday thing.”</p> <p>“Most of the time when it’s mentally affecting it’s during an episode.”</p> <p>“We have to plan out our day based on EPP.”</p>	Depressive language, school exclusion, social exclusion	18
F	<p>“I didn’t want to admit that like I couldn’t do something I wanted to do.”</p> <p>“I was so excited. And then my mom was like, you cannot do that.”</p> <p>“Sometimes people look at me with disgust.”</p> <p>“I was so terrified.”</p>	Depressive language, school exclusion, frustration, social exclusion, bullying	16
G	<p>“My friends don’t really like do not do anything without me, like they don’t really do things that I’m not able to do.”</p>	School exclusion, frustration, bullying	16

The theme of bullying was found in four out of seven interviews. Participant B said, “I wanted to punch them,” when asked how they felt after being made fun of for having EPP. Participant D described a set of scenarios where they were called names by classmates, “I was called a bunch of names.” They went on to say, “It was a rough time.” Participant F described a situation where they were bullied by another child on a playground. They later remarked, “These kids used to think it was contagious. Like despite what I would tell them, they thought it was like fun to avoid me.” Participant G just noted being bullied once or twice in the past but could not remember any details.

The theme frustration was present in five out of seven interviews. When referencing anger, annoyance, or frustration, participants mainly were discussing the frustration they feel when others around them question the severity of their disease. Participant F described the questioning of their disease as, “So annoying.” Participant A described how the distrust of others around them made them also feel annoyed saying, “it makes me feel like these people don't trust me and think that I'm a liar and I'm not.” Participant D explained the frustration they felt based on people not understanding what an EPP patient must go through. They reported, “Um it gets frustrating at times when people are like, oh, yeah, I'm allergic to the sun too. I'm like, no, you're not.” Participant G also said that people often do not believe them or understand the restrictions and limitations of EPP patients. They answered, “Yes, people never really believe you at first. It's kind of weird that they never like are convinced that it's like a real serious thing.” Participant B felt frustration with the clothing they had to wear to stay safe from the sun saying, “I just want to rip them apart,” when asked how it feels to have to wear all the protective clothing.

The theme of social exclusion was reported in six out of seven interviews. Social exclusion ranged from being left out of activities with friends or not being able to play a sport or anything relating to being

excluded in a social environment. Participant A directly said, “It will affect your social life.” When asked how it felt to not be able to be with friends when they go outdoors, Participant A responded, “That made me feel disappointed or not proud of myself. Like I wasn’t good enough. And I wish I could be with them.” Participant B plainly said, “Mad, sad I can’t do it.” Participant C responded similarly saying it made them “very mad” when they could not do everything their friends were doing. Participant D shared the difficulties of friendship while living with EPP saying, “It was really hard making friends.” Both Participants D and F brought up feeling left out of outdoor birthday parties. Participants A, B, C, and D each brought up that they are unable to play outdoor sports and Participants A and C both said they wished they could do an outdoor sport.

The theme of depressive language occurred in five out of seven interviews. Depressive language referred to the way the participants described how they felt in situations they must go through. Participant D used language such as “burden” to describe life with EPP. They said, “It’s a huge, for lack of better words, burden on your life.” The youngest two participants, A and B both used the word “sad” often in describing their feelings. The older participants over age 16 used different phrases to express their emotions. Participant D simply said, “It was a rough time.” Participant F described feeling terrified of the sun, “I was so terrified.” Participant F said, “I felt hurt.” Although each participant used different words and phrases, five out of seven participants used a form of depressive language in their interviews.

The final theme was school exclusion, and it was found in all seven interviews. Participants A, B, C, and E mentioned the inability to go on school trips or participate in field day outdoor activities. When asked if they ever experienced being left out, Participant A described not being part of outdoor field day at school saying, “I basically couldn’t participate in any of it because I cannot be outdoors.” Similarly, Participant B said in reference to field day, “I have to go sit out for like an hour by myself.” Participants A, C, D, F, and G discussed special accommodations for gym class or recess in which they were not able to be with all the other students.

Discussion

Despite the constant variable of each participant living with the disease Erythropoietic Protoporphyrin, the results of the qualitative semi-structured interviews revealed vast differences in the experiences of each participant. The literature review discussed potential factors that may impact the mental health of EPP patients. A closer inspection of these factors within each interview suggests that not all participants experience the same lifestyle with their disease. Although the way each factor affected the lives of each participant, the results of the thematic analysis suggest a connection between having EPP and increased risk of mental illness.

It was determined that four out of seven participants fit into the theme of bullying. Despite three participants experiencing no forms of bullying in their life, the prevalence of the theme bullying was highlighted in the interviews with the other four participants. Participant D was bullied throughout their time in middle school because of their disease. They said, “I was bullied throughout my entire elementary and junior high because of this.” Participant D’s statement, along with the three other participants that experienced a form of bullying, allows it to be reasonable to assume that EPP may lead to an increased risk of bullying. Participant A’s experiences of living in a safe community with little bullying suggest that EPP does not guarantee being bullied, but it is still a risk based on the other four responses. These responses suggest an increased risk of bullying associated with having EPP. Based on conclusions by Kiefer et al. and Andersen et al., bullying has an increased risk of mental health conditions. Bullying is correlated with a high risk of suicide or suicidal thoughts and behaviors (Andersen et al., 2015). Being bullied also is linked to feelings of depression, sadness, low self-esteem, and loneliness (Kiefer et al., 2021). The connection between bullying and negative mental health implications, makes a convincing case that the bullying as a result of EPP is one of the causes of an increased risk of mental illness. The prevalence and consequences of bullying link EPP to an increased risk of mental illness.

Similar findings displayed the negative relationship between social exclusion and mental health. Social exclusion is often classified as a form of bullying, indicating that similar risks of depression symptoms may occur (Khan, 2021). The long-term effects of social exclusion include anxiety and depression (Shannonhouse, 2021). Six out of seven participants corresponded with the social exclusion theme. Although types of social exclusion ranged from missing out on birthday parties to having difficulties making friends, six of the seven participants experienced some form of social exclusion. As argued by Shannonhouse and Khan, social exclusion increases the risk of depression and anxiety, connecting living with EPP to an enhanced risk of mental illness. Of the six participants who felt socially excluded, at least three described feeling emotionally upset over it.

Continuing the discussion of being excluded, all seven participants experienced a theme of school exclusion and indicated so in their interviews. In contrast to social exclusion, school exclusion was specific to being left out in the school environment including gym class, recess, and field trips. Participants discussed the limitations of recess and gym class, claiming they often had to stay indoors while the other students were able to play outside. Similarly, field trips and outdoor activities were often not possible for EPP patients, and they had to sit out. These school related exclusions transferred into social exclusion experiences since participants could not be with their classmates or friends when sitting out. Social exclusion's link to depression and anxiety puts the mental health of EPP patients at risk especially when forced into social experiences in school where they are left out due to their disease.

Researchers such as Morgan Stasell and Molly Bathje (2021) and S. Jung (2021) discuss the difficulties of living with disabilities and the frustrations that may emerge. People with disabilities may struggle with depression as a result of their lack of independence (Jung, 2021). Participants may have felt a lack of independence in situations in school or where other people begin to question the severity of their disease. From these situations, frustration seemed to have emerged in five out of the seven participants. Compiling the data from each of the five who felt frustration, four of them felt that people did not understand the true severity of their disease and even encountered situations where they were dismissed or not believed after explaining their disease. Nicola Davies (n.d.) argues that having a rare disease leads to an amplified impact on mental health. The frustrations that emerged after other people did not comprehend the true nature and struggles of EPP suggest that living with a rare disease often leads to frustration and therefore an increased risk of mental illness.

The theme depressive language was a direct link from EPP patients' feelings to the impact on mental health. By reporting that situations caused by having EPP made participants feel "sad" or "hurt", there is a clear link to risk of depression. Words used by participants to describe plainly how they felt revealed a lot about their mental health currently. As previously discussed, themes such as social exclusion, bullying, and frustration can have immediate impacts or could affect mental health in the long run. In this theme, however, the participants have admitted their thoughts and emotions and the evidence can be used to connect to depressive feelings. As participants described feelings of fear or sadness, they revealed how living with EPP mentally impacts their lives currently. Although experiencing these emotions does not necessarily indicate the participant has depression, their lives were still impacted by EPP in a mental way that caused them to discuss and feel emotions relating to depression.

There are multiple limitations that impact this research and its results. To start, the interviews were not conducted to find out if the participants have an existing mental illness. The questions were designed for participants to describe how EPP affects their daily life and their feelings on their disease. These feelings had to be interpreted by a nonprofessional, which could affect the validity of the data presented. To challenge the limitation, there was no interpretation performed on the data that should have only been done by a professional, all the interpretation was based on connecting the collected data back to the literature review to suggest a risk of mental illness. The range of ages of each participant also affected responses, but not significantly enough to consider while discussing the results and the reasons behind them. Only having seven total participants also restricted the range of the results, but for a rare disease, seven participants proved to be more than anticipated and enough significant data was collected.

Each theme individually connects back to mental illness risks previously explored by researchers. By placing all the themes back together, the joint conclusion could be made that having EPP suggests a connection to an increased risk of mental illness in children ages eight to eighteen in the United States, therefore filling the mental health gap in the body of knowledge surrounding EPP.

Conclusion

The results of the phenomenological research study presented several themes that each suggest a connection to an increased risk of mental illness. The themes of bullying, social exclusion, school exclusion, depressive language, and frustration each connected back to an existing mental health risk factor. The elevated risk found based on the thematic analysis suggests that EPP increases the risk of mental illness. This suggestion carries over to future research opportunities. Further research into the mental health field could improve the quality of life for young EPP patients. EPP only affects about 1 in 74,300 individuals (American Porphyria Foundation [APF], n.d.). The rarity of the disease already limits the research previously done, not to mention the lack of mental health research. By exploring the negative mental health risks, new attention is brought upon EPP patients and the new mental health awareness could improve the lives of EPP patients mentally, highlighting the implications of this research. When EPP is discussed, often the severity of the disease, the symptoms, and the emerging medicine is all talked about. This research suggests a connection between living with EPP and elevated mental health risks, opening up the scholarly conversation to the mental health of patients. Future research could expand upon the mental health side of the disease. Official psychological testing could be performed to see if EPP is linked to a specific type of mental illness and what can be done to improve their lives. Other research could be to explore each theme found in the thematic analysis in order to limit the negative mental health impact risks. For example, further research could determine more specifically which school factors contributed to the abundance of the school exclusion theme. Future studies on school exclusion could improve the experiences of EPP patients in schools and prevent the next generation of EPP children from facing similar exclusion to that of the seven participants. Since only seven EPP patients were interviewed, the research could be expanded to more participants in order to expand the field of knowledge and determine more themes that could contribute to the overall conclusion that EPP is connected to an increased risk of mental illness.

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