

Mental Health Survey Results are Here

Managing and taking care of your mental health is important. While the Bleeding Disorders Foundation of North Carolina (BDFNC) is not a mental health organization, being able to successfully manage yours or your loved one's bleeding disorder requires that your mental health is also managed.

"[I have] anxiety about the future of myself and potentially children that I could pass it to. PTSD from emergency room visits with no advocacy."

In 2021, BDFNC began a *Mental Health Initiative* to better determine the mental health needs of the bleeding disorders community through a task force of interested community members and hemophilia treatment center (HTC) staff, a social media campaign, the start of the monthly *Community Conversations* support group meetings, a dedicated webpage to mental health on our website, programming that addresses mental health, and the administration of a mental health survey to assess the needs of those with a bleeding disorder in North Carolina.

The mental health survey was developed in partnership with the University of North Carolina Wilmington's (UNC-W) Department of Social Impact. With input from BDFNC, a survey was developed that would assess

"Basically when I'm having trouble with my bleeding disorder it makes the symptoms of my mental health more intensified."

connections to mental health conditions, the prevalence of those conditions, if there is a correlation between pain/hospital stays and mental health, and barriers to care. The criteria also looked at the demographics of who responded including bleeding disorder type, gender, age, non-white or white, and urban vs. rural. Additionally, open-ended questions were included that could be used to make some additional conclusions and help to direct further research.

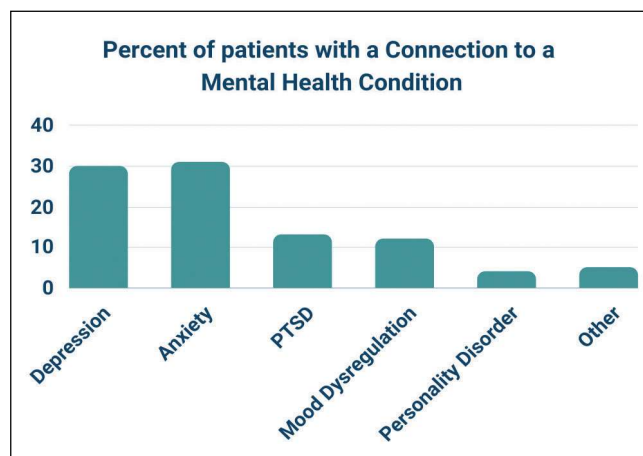
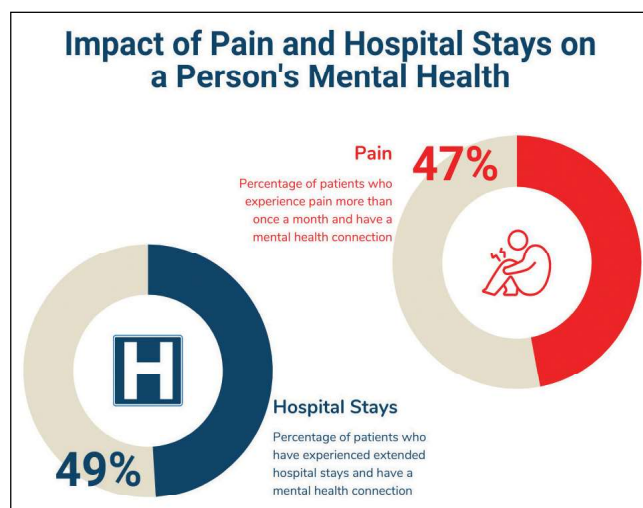
With the help of the HTCs, surveys were distributed to over 2,200 individuals with bleeding disorders across North Carolina through print and/or electronic means (email/social media) over four months, between November 1, 2021 and March 1, 2022. A total of **284 surveys** were completed, with the number completed electronically and mailed back split equally. The patients who completed the survey were diagnosed with hemophilia, von Willebrand disease, or a platelet disorder.

More than **1/3 of patients** with a bleeding disorder reported a connection to a mental health condition, meaning they were diagnosed with, had sought treatment for, or experienced symptoms of a mental health disorder. The mental health conditions that the survey looked at were **depression, anxiety, PTSD, mood dysregulation, personality disorder, or other.**

Depression and anxiety were the most common mental health conditions reported, with 18% of patients indicating that they have had a diagnosis of each disorder. However, even more people indicated that they had symptoms of depression and anxiety. Thirty percent of patients indicated they had symptoms of depression and 31% of patients indicated symptoms of anxiety. When looking at all of the diagnoses that were asked about, **29% of patients reported symptoms of a mental health condition but had not tried to receive any treatment.**

"As a parent, we have always a kind of fear in us for something to happen to our child that causes a bleeding problem. We are always worried about our child until he returns home from preschool."

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The survey found that the severity of a person's bleeding disorder does not have an impact on whether a person reports a mental health condition. However, **pain and hospital stays were significant influences on mental health. Forty-seven percent of patients**

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who experienced pain more than once a month had a personal connection to mental health. While patients who have had hospital visits were not more likely to report a mental health condition than those who have not had hospital visits, **49% of those who have had extended hospital stays** due to their bleeding disorder reported a mental health condition.

The responses were closely split between men and women. However **49% of women** reported a personal mental health condition while only **27% of men** reported a personal

“It can sometimes feel isolating, and causes a lot of anxiety for me as a mom.”

mental health condition.

Patients in urban counties are more likely to report mental health conditions than patients in suburban or rural counties. Due to the sample size, race was split into white and non-white.

White patients reported a mental health condition at the rate of 42% while 31% of non-white patients reported a mental health condition.

It is known that there are barriers in North Carolina to accessing mental health services. An alarming **70% of patients** with a mental health connection **reported a barrier** to mental

“[I] worry a lot about my own health to the point of extreme anxiety.”

health treatment. When asking survey participants about their barriers, **the most common barriers were cost (29%), hesitancy to seek treatment (27%), and time (21%).**

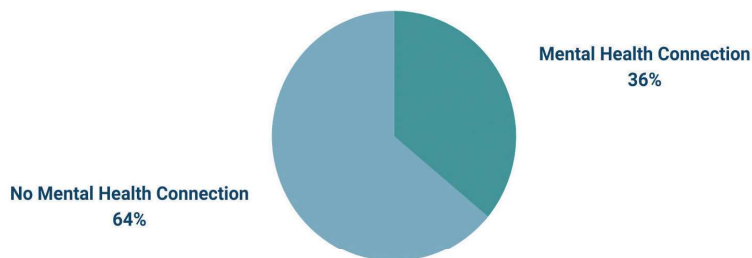
So what does this all mean? It is clear that BDFNC needs to continue its research into mental health in the bleeding disorders community and its commitment to providing resources and programming about mental health for those affected by bleeding disorders. BDFNC plans to continue collaborating with the HTC's to support the community. There will be continued emphasis on mental health at BDFNC events. BDFNC plans to continue to post on social media throughout the year to help normalize the conversation about mental health and contribute to ending the stigma. In addition, BDFNC hopes to translate the survey into Spanish in order to hear from the Spanish-speaking population, and the organization would like to continue its research into how mental health affects parents and caregivers of someone diagnosed with a bleeding disorder.

‘[I] spent three years in therapy/ group therapy following HIV diagnosis in 1984.’

ashamed of and are a reality for many living with a bleeding disorder. BDFNC continues to be here as a support for you and your family.

This survey was just the first step. Mental health conditions are nothing to be

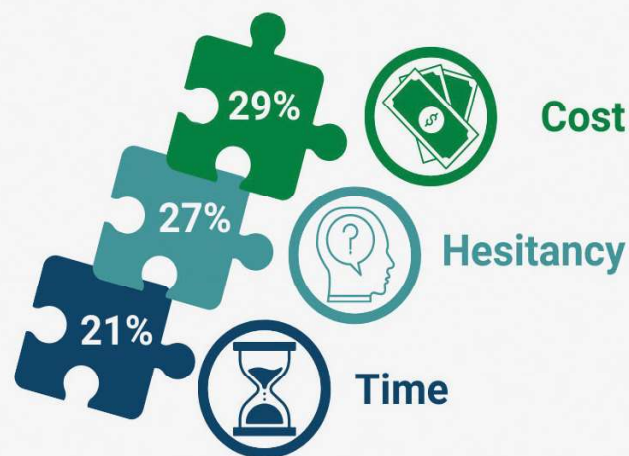
Percentage of Patients with a Bleeding Disorder Who Report a Connection to a Mental Health Condition



“It has been hard to find a therapist that knows how to help me with pain management.”

“I was completely healthy before my child was born. Being a dad, I always worried about my child growing up with factor 8 deficiency. Due to overthinking and continuous worrying, I got diagnosed with a moderate to severe anxiety and depression problem. I took medication and receive counseling from a mental health specialist. Now, I am doing fine.”

Barriers to Mental Health Treatment



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