

Introduction

1 in 20 People with **hepatitis B** Are also infected with **hepatitis delta**.



- Hepatitis delta is a rare but serious form of hepatitis that can only infect people who also have hepatitis B.
- There is a lack of awareness and updated prevalence data leaves many undiagnosed.
- For diagnosed patients, there is only 1 minimally effective treatment.
- Most will develop serious liver disease or liver cancer within 10 years.
- It can be difficult to locate experienced doctors and find clinical trials.
- Before *Hepatitis Delta Connect*, no online resources for easy-to-understand information and support.

Research, effective treatments and true coinfection prevalence data are lacking.



Patient healthcare challenges and needs are poorly understood.

Methods

HEPATITIS DELTA | CONNECT



Hepatitis Delta Connect provides free online education, support and navigation to care to patients in some of the most remote regions of the world.

Qualitative data analysis of all 45 initial hepatitis delta patient inquiry emails received from 2016-2019 was done to better understand:

- Where patients are located
- Healthcare needs and challenges
- Emotional burden of the disease



Results

- Preliminary coding analysis revealed:
- Access to treatment and clinical trials are a top concern among patients
 - Many patients experience stress and uncertainty related to their disease and overall health
 - Patient consults are coming from high prevalence regions

Hepatitis D patient locations:

1. United States
2. Pakistan
3. Romania
4. Mongolia
5. Uzbekistan



Understanding Hepatitis Delta Patient Challenges, Healthcare Barriers and Needs Through Online Educational Support

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Thematic analysis revealed hepatitis delta patients face challenges to accessing effective care and treatment, and experience emotional stress related to the uncertainty of their diagnosis.

Major Themes:

Diagnosis, healthy lifestyle, finding a doctor, transmission, vaccination, treatment, medication access, clinical trials, alternative therapies, cure, liver damage/liver cancer, pregnancy, stigma, quality of life, barriers to care, symptoms, location

Patient quotes:

Finding a Doctor:

“We would like to know what physicians here in the U.S. are familiar with hep D because her GI doc here in (*information redacted*), has never seen hep D in his practice. My daughter is 26 years old and an adoptee.”

Treatment:

“I am contacting with you from Mongolia. My 5-year-old son is diagnosed with hepatitis B and Delta, which is active. Currently, there is no effective treatment for my son's disease. Therefore, I am searching the all ways to can treat my son.”

Quality of Life:

“Hello, I need help. I am from Mongolia. I just found out that I have hepatitis B and D together. My result is B virus under 20, but D virus is 4.88. Is there any treatment for me? How long can I live What should I do? Pls, help me! I'm so scared 🙏🙏🙏. Pls.”

Clinical trials:

“I have had hepatitis B for nearly 10 years and recently found out that I also have hepatitis D. I can't say I am feeling well. Isn't there any cure found for these? My doctor said that in Germany they created a medicine which is very expensive. And also that its price will hopefully reduce in a couple of years. And my last question how much at least I can live with these viruses do you think?”

Liver Cancer, Treatment, Alternative Therapies:

Early this year tests came back that I had cirrhosis & another hepatitis, hep D (delta), making me at high risk for liver cancer. This was all a shock. The treatment recommended was interferon. I'm not sure I want to go that route I don't like the side effects of interferon or the other antivirals & prefer alternatives (herbals). Also, I already have trouble with depression a side effect of interferon.

Conclusion

Data from preliminary analysis reveals the challenges hepatitis delta patients face after diagnosis. This information will help guide future public health programming and brings awareness to priority issues for patients living with hepatitis delta.

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