Background & Significance: Hepatitis Delta Virus (HDV)

- Hepatitis: viral infection of the liver causing inflammation, damage/scarring, and cancer risk
- Transmission: perinatal, sexual, blood borne
- Multiple types: hepatitis A, B, & C more well known
- Variable clinical presentation: acute, chronic, asymptomatic vs. symptomatic
- Symptoms: fever, nausea, vomiting, abdominal pain, “jaundice”, dark colored urine and/or abnormally colored stool
- Large mortality burden: worldwide mortality from viral hepatitis is 1.34 mil/year – comparable to HIV/AIDS and tuberculosis
- Lack of Awareness: 95% of those with chronic hepatitis B and/or C are unaware of their disease

Hepatitis Delta Virus (HDV): A public health threat

Rare: 5% of those chronically infected with hepatitis B are co-infected with HDV

~15 – 20 million cases worldwide

*Public heath threat because:
- Rare: 5% of those chronically infected with hepatitis B are co-infected with HDV
- Blood borne: Hepatitis B is transmitted through blood
- Permanent: can remain chronic for decades
- The majority of HDV patients are not aware of their infection
- Lack of awareness remains endemic to many developing countries and has increased incidence in developed countries

Table 1: Codebook Excerpt

<table>
<thead>
<tr>
<th>Code</th>
<th>Definition</th>
<th>When to use</th>
</tr>
</thead>
<tbody>
<tr>
<td>D1</td>
<td>Use when individual is asked about hepatitis B and adolescents are asked if they have been vaccinated</td>
<td>Do not use when individual is asking about care, prevention (vaccination), transmission.</td>
</tr>
<tr>
<td>T1</td>
<td>Use when questions asked about disease for after exposure or risks of transmission; e.g. previous hepatitis, blood exposure, needle-stick, mother to child, blood transfusion</td>
<td>Do not use when vaccine is mentioned, when and if results are blood.</td>
</tr>
</tbody>
</table>

Results:

4 Unifying Themes:

- Sample characteristics: 65 queries (60-66) met study inclusion criteria
- Queries were from 17 countries (n=17), including the United States

<table>
<thead>
<tr>
<th>Country</th>
<th>Query Frequency</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Romania</td>
<td>11</td>
<td>16.9</td>
</tr>
<tr>
<td>Pakistan</td>
<td>10</td>
<td>15.4</td>
</tr>
<tr>
<td>United States</td>
<td>9</td>
<td>13.8</td>
</tr>
<tr>
<td>Mongolia</td>
<td>4</td>
<td>6.2</td>
</tr>
<tr>
<td>Uzbekistan</td>
<td>3</td>
<td>4.6</td>
</tr>
</tbody>
</table>

Table 2: Top 3 Countries in Frequency of Queries

1. Disease Knowledge & Prevention
2. Disease Symptoms & Outcomes
3. Treatment Modalities & Access
4. Barriers & Quality of Life

Discussion: What did we learn?

- Relatively few HDV-related queries were received, which may reflect the rareness of the disease, a lack of awareness of disease status in hepatitis patients, and less knowledge of available resources in hepatitis patients, caregivers, and the general public
- HDV is very rare, not much is known about the disease and what a diagnosis with this condition means
- Most queries came from individuals living in Romania and Pakistan respectively, which may be due to the fact that HDV is endemic to both these regions and occurs at a higher incidence
- HDV patients and their caregivers may need more information about: (1) availability of clinical trials (2) medication access (3) diagnostic test interpretation and (4) treatment modalities
- A large majority of queries were related to the process of finding and registering for clinical trials, suggesting more advanced knowledge of disease
- Our sample may not be as representative of the true HDV-affected population
- Those who reached out to the Hepatitis B Foundation may have greater English language capabilities, access to resources (e.g. – working internet access), and disease awareness
- Efforts should be made to make educational resources more widely accessible

Next Steps: Where do we go from here?

- Literature review for existing HDV-related patient education materials
- Development of frequently asked questions (FAQ) in brochure or pamphlet form
- Piloting of FAQ with Hepatitis B Foundation staff and patients and feedback
- Dissemination of patient education materials by the Hepatitis B Foundation

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